

Quando l'orrore diventa quotidiano

<http://www.superando.it/content/view/2645/112/>

Le disastrose condizioni in cui versano le persone con disabilità intellettiva in Serbia sono state denunciate in un rapporto dell'MDRI (Mental Disability Right International). Un orrore quotidiano sul quale sono già stati prodotti documenti analoghi riferiti al Kosovo, alla Romania, alla Russia, alla Turchia, all'Ungheria e, oltreoceano, all'Argentina, al Messico, al Peru e all'Uruguay



Edvard Munch, L'urlo, 1893

Bambini con diverse disabilità legati strettamente a fetide brande, che non hanno mai potuto abbandonare dalla loro nascita. Un ragazzo di sei anni che ha provato a tagliarsi un orecchio mentre era legato ad una sedia. Un'adolescente che ha tentato di togliersi gli occhi, mentre lo staff dell'ospedale psichiatrico stava lì a guardare senza fare nulla.

Vere e proprie **scene di orrore quotidiano** catalogate in un rapporto diffuso nei giorni scorsi dall'[MDRI](#) (Mental Disability Rights International), un gruppo per i diritti umani con sede negli Stati Uniti che ha denunciato **il sistematico abuso sui pazienti con disabilità intellettiva** negli ospedali psichiatrici e negli istituti della **Serbia**.

Il ministro serbo della Salute **Tomica Milosavljevic** ha dichiarato di non aver letto il rapporto, ma ha ammesso che **l'assistenza psichiatrica ha continuato a languire** nel suo Paese, mentre quest'ultimo lottava per risollevarsi dalle varie guerre civili succedutesi negli anni Novanta. Egli ha però sottolineato che il documento non sembra tenere nella dovuta considerazione **i progressi fatti in Serbia dal 2000 in poi** per migliorare le condizioni degli ospedali psichiatrici. «Non voglio dire - ha precisato Milosavljevic - che tutto sia ideale, ma non penso che i problemi illustrati nel rapporto illustrino la situazione reale».

E del resto quanto denunciato non può essere verificato indipendentemente, poiché ad esempio l'«**Associated Press**», la rete internazionale di agenzie di stampa, non ha ricevuto l'autorizzazione a visitare gli istituti di cui si parla.

Sembra che il pessimo trattamento riservato alle persone con problemi psichici si sia manifestato in tutta la sua chiarezza dopo che l'autocrate presidente **Slobodan Milosevic** venne rovesciato nel 2000 a seguito di una rivolta popolare. Infatti, durante gli undici anni di "regno" di Milosevic, **gli**

standard delle cure sanitarie sono letteralmente crollati, con i finanziamenti governativi dirottati principalmente verso le spese di guerra in Croazia, Bosnia e Kosovo.

Anche oggi, per altro, il rapporto dell'MDRI attribuisce gli abusi e le negligenze alle **limitatezze di organico** e agli **scarsi finanziamenti** ricevuti dagli ospedali. E questo potrebbe rappresentare un passo indietro per la regione dei Balcani nel suo tentativo di entrare nell'Unione Europea.

Dal canto suo il ministro serbo degli Affari sociali **Rasim Ljajic** non ha discusso quanto riportato negli allegati del rapporto, ammettendo egli stesso che «quando visito questi posti **non riesco a dormire per tre giorni**». Ljajic ha ordinato inoltre che uno degli istituti citati nel rapporto smetta di accettare altri bambini, in quanto vi si trovano già più di cinquecento pazienti «severamente ritardati» (sic!).

Pur riconoscendone i meriti, Ljajic ha però bollato il documento come «malevolo», in quanto «non porterebbe alla soluzione del problema». Lo stesso semplice titolo del rapporto - *Tormento non Trattamento* - suggerisce, secondo il ministro, che qualcuno voglia intenzionalmente torturare i pazienti e questo «è assolutamente falso e inaccettabile».



Risale ai tempi di Slobodan Milosevic l'epoca in cui crollarono in Serbia gli standard delle cure sanitarie. A difesa del lavoro svolto dall'MDRI, **Eric Rosenthal**, che ne è direttore esecutivo, ha dichiarato che l'intenzione non era quella di accusare qualcuno di comportamenti sbagliati, ma esclusivamente **di evidenziare determinati problemi**. «Il nostro è un messaggio di speranza sul fatto che il governo serbo possa immediatamente apportare dei cambiamenti che modifichino questa situazione inaccettabile».

Altri esponenti del gruppo hanno poi dichiarato di voler inviare il rapporto all'Unione Europea, alle Nazioni Unite e ad altre organizzazioni, affermando anche che le condizioni degli ospedali psichiatrici serbi sono state certamente migliorate grazie ai contributi di donatori stranieri, ma che **resta ancora molto da fare** «per risolvere i seri problemi di diritti umani per **18.000 pazienti**».

«Mangiano, vanno al bagno e muoiono in queste brande», ha raccontato **Laurie Ahern**, ispettore dell'MDRI, illustrando un grafico sui pazienti e sulle condizioni degli istituti serbi. «Legare una persona e lasciarla in un letto per tutta la vita equivale a torturarla», ha aggiunto Eric Rosenthal. «Ho guardato in una branda e ho visto un bimbo che sembrava avere sette o otto anni - ha dichiarato un altro ispettore - ma l'infermiera mi ha detto **che ne aveva ventuno** e che era nell'istituto da undici. Le ho chiesto da quanto non scendesse dal letto e lei mi ha risposto: mai, mai in undici anni».

Laurie Ahern ha aggiunto che il ragazzo - **con sindrome di down e problemi di comunicazione** - riceve regolarmente visite dalla madre. «Quando la madre va a trovarlo, nei suoi occhi ci sono le lacrime perché vorrebbe riportare il figlio a casa con sé, ma non ha i mezzi per farsene carico». Il rapporto ha registrato con chiarezza come molti dei bambini tentino incessantemente **di farsi del male da soli**, comportamenti di fronte ai quali è comunemente accettato **l'uso di restrizioni fisiche**. L'MDRI auspica infine che alcuni degli istituti della Serbia possano essere chiusi quanto prima e che i loro pazienti possano essere supportati nell'accesso all'istruzione, al lavoro, ad avere un alloggio decente e sicuro e a vivere insieme a parenti e amici.

Un'annotazione conclusiva, ma non certo consolante. Sembra proprio che la Serbia non sia la sola a violare in questo modo i diritti delle persone con disabilità intellettive. L'MDRI, infatti, ha già realizzato documenti analoghi sulle situazioni in **Kosovo, Romania, Russia, Turchia, Ungheria** e, oltreoceano, in **Argentina, Messico, Peru** e **Uruguay**.

(Giuliano Giovinzio)

mdri

Mental Disability Rights International

Torment not Treatment:

**Serbia's Segregation and Abuse of
Children and Adults with Disabilities**



NOT FOR RELEASE

Embargoed until November 14, 2007

Torment not Treatment:

Serbia's Segregation and Abuse of Children and Adults with Disabilities

A report by Mental Disability Rights International

NOT FOR RELEASE
Embargoed until November 14, 2007

Primary authors:

Laurie Ahern, Associate Director, MDRI
Eric Rosenthal, JD, Executive Director, MDRI

Co-authors/research team

Elizabeth Bauer, MA, Michigan State Board of Education
James Conroy, Ph.D., Center for Outcome Analysis
Karen Green McGowan, RN, specialist in treatment of people with disabilities
Spomenka Grujicic, Helsinki Committee for Human Rights in Serbia
Ljiljana Palibrk, Helsinki Committee for Human Rights in Serbia
Dragana Ciric Milovanovic, human rights consultant, Belgrade, Serbia
Dea Pallaska O'Shaughnessy, MDRI Director of European Programs
Dr. Eva Szeli, Ph.D., JD, adjunct professor, New York Law School

Expert reviewer:

Clarence Sundram, JD, President of MDRI and Special Master, US District Court,
District of Columbia

To contact the authors:

Laurie Ahern: 202.361.1402 (cell phone US and Serbia) Lahern@mdri.org
Eric Rosenthal: 202.361.9195 (cell phone US and Serbia) Erosenthal@mdri.org

For copies of the report, photos, video or to arrange interviews:
MDRI, Washington DC – Adrienne Jones: 202.296.0800

**This report was funded by the Open Society Institute, the Ford Foundation,
the Morton and Jane Blaustein Foundation, and other supporters of MDRI.**

Cover photo: Marc Schneider

ADVANCE COPY – NOT FOR RELEASE BEFORE NOVEMBER 14, 2007

Torment Not Treatment: Serbia's Segregation and Abuse of Children and Adults with Disabilities

Copies of this report are available from:

Mental Disability Rights International
1156 15th Street NW, Suite 1001
Washington, DC 20005
Telephone: 202.296.0800
E-mail: mdri@mdri.org
Website: www.mdri.org

This report is available in English and Serbian

All human beings are born free and equal in dignity and rights...

Universal Declaration of Human Rights, article 1

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others....and their full inclusion and participation in the community...

Convention on the Rights of Persons with Disabilities,
opened for signature March 30, 2007, article 19

No one shall be subjected to torture or to inhuman or degrading treatment or punishment.

European Convention on Human Rights, article 3

For the purposes of this Convention, the term torture means any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted...*for any reason based on discrimination of any kind*, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.

UN Convention against Torture and Other Cruel,
Inhuman or Degrading Treatment or Punishment,
article 1(1) (emphasis added)

State Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

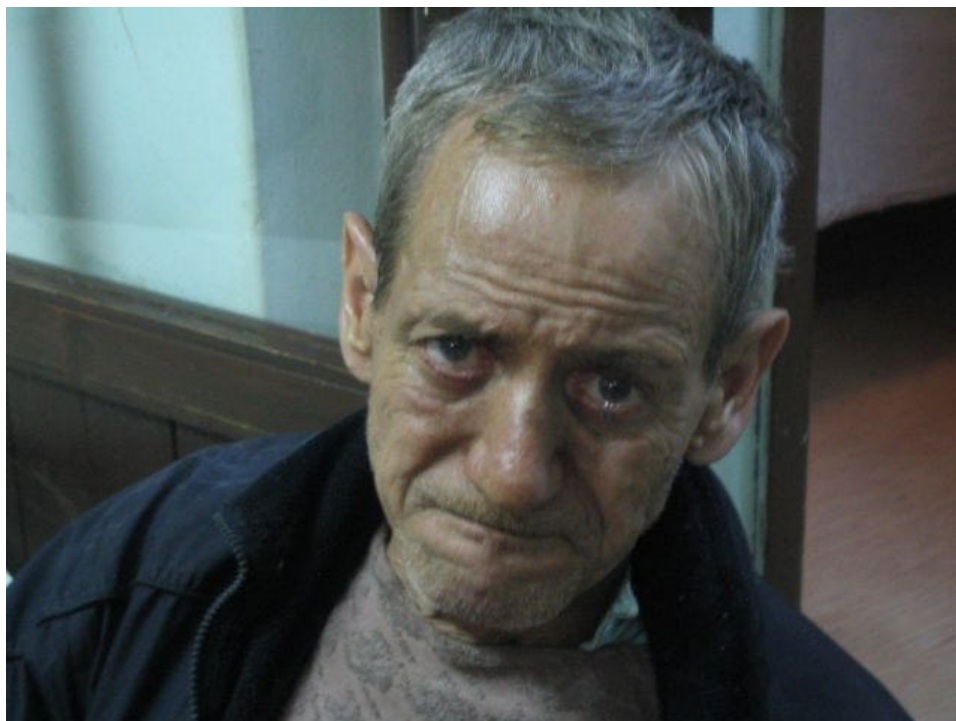
Convention on the Rights of the Child, article 23(1).



1. MDRI investigators found this young child with Down's Syndrome, in Subotica Children's Institution, restrained to prevent "self abuse" – a product of mind-numbing boredom and lack of human contact. Photo MDRI 2006



2. Children and young adults labeled "immobile" spend years lying in cribs in Stamnica, never getting out. Photo MDRI 2006



**3. This man began crying as he told investigators he had been living in Curug for 7 years.
Photo MDRI 2006**



4. Residents at Curug Institution, wearing winter coats and hats indoors, huddle by a radiator to try and keep warm. Photo MDRI 2006



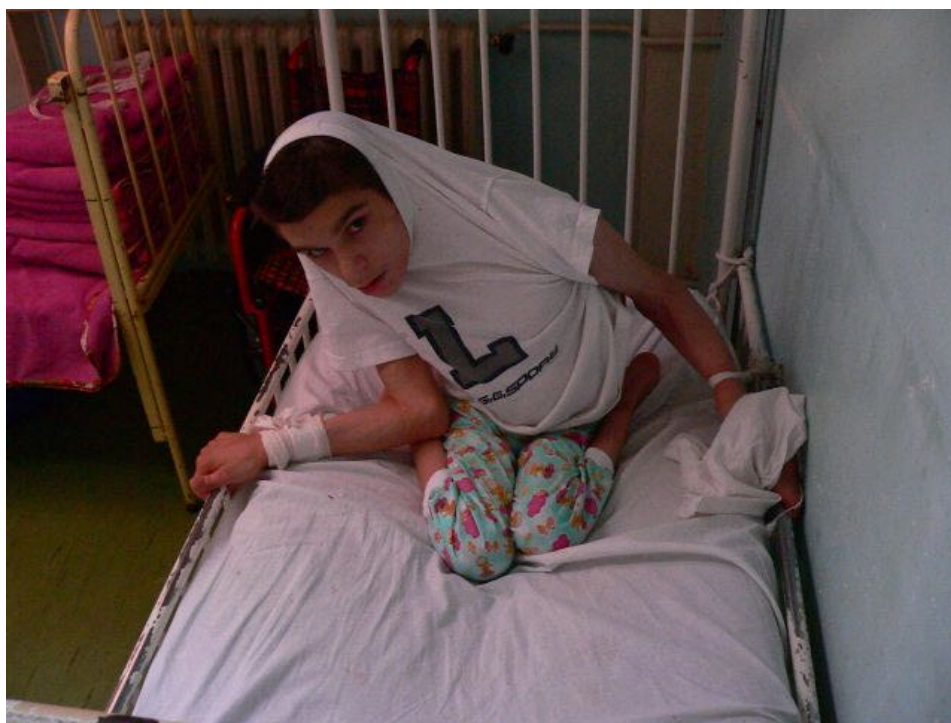
**5. Rows and rows of neglected children alone in cribs at Kulina.
Photo Marc Schneider 2007**



6. MDRI investigators found this 7 year old girl, with untreated hydrocephalus, in Kulina. Staff reported that medical treatment was withheld at her birth because doctors advised against it because “she will die anyway.” Photo Marc Schneider 2007



7. Boys and men with developmental disabilities are kept in a barren and bleak room all day in Kulina. Photo Marc Schneider 2007



8. Teenage boy, arms tightly bound to bed at Kulina. Photo Marc Schneider 2007



**9. Young girl tied into bed during the daytime at Kulina.
Photo Marc Schneider 2007**



10. An emaciated and dehydrated little girl, suffering from life-threatening diarrhea, tied into a crib at Kulina. Photo Marc Schneider 2007

Mental Disability Rights International

Mental Disability Rights International (MDRI) is an advocacy organization dedicated to the human rights and full participation in society of people with mental disabilities worldwide. MDRI documents human rights abuses, supports the development of mental disability rights advocacy, and promotes international awareness and oversight of the rights of people with mental disabilities. MDRI advises governments and non-governmental organizations to plan strategies to bring about effective rights enforcement and service system reform. Drawing on the skills and experience of attorneys, mental health professionals, 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 offices in Kosovo and Ireland. MDRI has investigated human rights conditions and assisted mental disability rights advocates in Argentina, Armenia, Azerbaijan, Bulgaria, the Czech Republic, Estonia, Hungary, Kosovo, Lithuania, Macedonia, Mexico, Paraguay, Poland, Peru, Romania, Russia, Serbia, Slovakia, Slovenia, Ukraine, and Uruguay. MDRI has published the following reports: *Ruined Lives: Segregation from Society in Argentina's Psychiatric Asylums* (2007); *Hidden Suffering: Romania's Segregation and Abuse of Infants and Children with Disabilities* (2006); *Behind Closed Doors: Human Rights Abuses in the Psychiatric Facilities, Orphanages and Rehabilitation Centers of Turkey* (2005); *Human Rights & Mental Health: Peru* (2004); *Not on the Agenda: Human Rights of People with Mental Disabilities in Kosovo* (2002); *Human Rights & Mental Health: Mexico* (2000); *Children in Russia's Institutions: Human Rights and Opportunities for Reform* (2000); *Human Rights & Mental Health: Hungary* (1997); *Human Rights & Mental Health: Uruguay* (1995).

MDRI founder and Executive Director, Eric Rosenthal, is vice president of the United States International Council on Disability, the US affiliate of Rehabilitation International and Disabled Persons International. Rosenthal has served as a consultant to the World Health Organization (WHO), UNICEF, the United Nations Special *Rapporteur* on Disability, and the US National Council on Disability (NCD). On behalf of NCD, Rosenthal co-authored *Foreign Policy & Disability* (2003), documenting discrimination against people with disabilities in US foreign assistance programs. Rosenthal is an advisor in the Public Interest Law Scholars program and is an adjunct professor at Georgetown University Law Center.

Laurie Ahern, MDRI's Associate Director, worked for 10 years as a newspaper editor and is an award-winning investigative reporter. She is the former co-founder and co-director of the federally-funded National Empowerment Center (NEC) and former vice president of the US National Association of Rights Protection and Advocacy (NARPA). She has written and lectured extensively on psychiatric recovery and self-determination, and she is an officer of the International Network for Treatment Alternatives for Recovery (INTAR). Her manual on psychiatric recovery has been translated into seven languages.

MDRI Staff

Eric Rosenthal, JD, Executive Director
Laurie Ahern, Associate Director
Alison Hillman de Velasquez, JD, Director, Americas Program
Adrienne Jones, Office Manager
James L.F. Howell, Development Director
Dea Pallaska O'Shaughnessy, Coordinator, Eastern European Programs
Zamira Hyseni, Program Director, Kosovo

Board of Directors

Clarence Sundram, JD, Board President
Special Master United States District Court

Elizabeth Bauer, MA, Secretary
Michigan State Board of Education

Holly Burkhalter
International Justice Mission

Judi Chamberlin
National Empowerment Center

Leah Harris
National Association for Rights Protection and Advocacy

Paul Steven Miller, JD
University of Washington School of Law

Leonard Rubenstein, JD, Treasurer
Physicians for Human Rights

Robert Schiffer
The Justice Project

Cathy Ficker Terrill, MA
Ray Graham Association for People with Disabilities

Patricia M Wald, JD
US Court of Appeals, ret.

Alicia Ely Yamin, JD, MPH
Harvard Law School

Table of Contents

Acknowledgments	i
Executive Summary	iii
Conclusion and Recommendations	ix
Goals and Methods	x
I. Abuses in Institutions	1
A. Physical restraints and seclusion	1
B. Degrading, dangerous conditions and lack of medical care	5
C. Dangers of neglect on children	8
D. Lack of habilitation and rehabilitation	10
E. Dangerous and life threatening physical conditions	12
II. Structure of Services	14
A. Improper Segregation from Society	14
B. The Promise of Reform	16
C. Implementation of the reform program	18
III. Violations of International Human Rights Conventions	20
A. Segregation from society as unlawful discrimination	21
B. Threats to health and life	22
C. Torture, inhuman & degrading treatment	23
1. Inhuman and degrading treatment	23
2. Torture	25
D. Arbitrary detention	26
1. Lack of any independent review or oversight	27
2. Inadequate protections in the guardianship process	27
3. Lack of due process protections against psychiatric commitment	28
Appendix A – Model Programs	31
Endnotes	52

ADVANCE COPY - NOT FOR RELEASE BEFORE NOVEMBER 14, 2007

Acknowledgments

Mental Disability Rights International (MDRI) is indebted to many people in Serbia who generously gave their time to provide information and insights with regard to the human rights concerns of people with disabilities in Serbia. People who assisted MDRI investigators included people with disabilities and their families – some who spent years in institutions and some who still reside there, advocates from non-governmental organizations (NGOs), institutional staff and government officials.

We are particularly grateful to the staff of *People in Need* and *Big/Little* (see Appendix A) for providing us with extensive background on the human rights situation of people with disabilities in Serbia in addition to translation services, transportation and other logistics.

In the United States, we appreciate the work of Lazarina Todorova for video and photographic editing. Thanks to Brian Cooper for his meticulous copy editing.

Adrienne Jones provided invaluable assistance with everything from design and layout to moral support. Alison Hillman de Velasquez reviewed and proof-read the entire report. Veronica and Peter Doherty's support at every step of this project has also been much appreciated.

We would like to thank the Open Society Institute, the Morton and Jane Blaustein Foundation, the Ford Foundation and numerous other foundation and individual donors to MDRI for funding this project. This work would not have been possible without their support.

ADVANCE COPY - NOT FOR RELEASE BEFORE NOVEMBER 14, 2007

Executive Summary

Torment not Treatment: Serbia's Segregation and Abuse of Children and Adults with Disabilities is the product of an investigation spanning four years, by Mental Disability Rights International (MDRI), into the human rights abuses perpetrated against institutionalized children and adults in Serbia. From July 2003 to August 2007, MDRI has documented a broad array of human rights violations against people with disabilities, segregated from society and forced to live out their lives in institutions (all observations in this report are from December 2006 through August 2007 except as noted). Filthy conditions, contagious diseases, lack of medical care and rehabilitation, and a failure to provide oversight renders placement in a Serbian institution life-threatening. MDRI investigators found children and adults with disabilities tied to beds or never allowed to leave a crib – some for *years* at a time. Inhumane and degrading treatment in Serbian institutions – in violation of article 3 of the European Convention on Human Rights (ECHR) – is widespread. Children and adults with disabilities tied down and restrained over a lifetime are being subjected to extremely dangerous and painful “treatment” that is tantamount to torture.

Serbia lacks adequate laws to protect people with disabilities from arbitrary detention in psychiatric hospitals or social care facilities. Despite an improved new guardianship law, people with mental disabilities can still have all their rights stripped away without adequate due process of law or right to counsel. As a practical matter, many people in institutions are detained for life with no legal process or judicial oversight. For more than 11,000 people detained in Serbia's institutions under the Ministry of Labor and Social Policy (MLSP), and for more than 6,200 in psychiatric institutions under the Ministry of Health, these practices violate the right to “liberty and security of person” under article 5 of the ECHR.

Children with disabilities placed in institutions are likely to spend their entire lives incarcerated. Adults with psychiatric disabilities, placed in institutions by family members, are also at risk of spending years, and in some cases their whole adult lives in institutions. There are virtually no supports or services in the community for people with disabilities nor are there supports for families wanting to keep their children born with disabilities with them. Despite a stated policy of ending new detentions, children continue to be separated from parents and placed in institutions because of a lack of support in the community. Authorities have reported to MDRI that physicians still encourage parents to institutionalize children with disabilities at birth.

Since 2000, the government of Serbia, with the support of international donors, rebuilt many of its old institutions. As international support for reform recedes, Serbia is left with a segregated service system and few resources for reform.

The government of Serbia deserves credit for enormous candor in admitting to poor treatment practices in institutions and for recognizing that most people detained in institutions should be properly cared for in the community. As part of a stated commitment to protect human rights and seek integration into Europe, Serbia established a new social welfare policy in December 2006, committing the government to serving people with disabilities in the least restrictive environment suitable to their conditions. The Ministry of Health has adopted a similar policy for

the reform of the mental health system. In April 2006, Serbia adopted a progressive new “Law on the Prevention of Discrimination Against Persons with Disabilities.”¹ Serbia’s new constitution also bans discrimination based on mental or physical disability.

Despite these important government commitments, actual treatment of people with disabilities violates Serbia’s own law and policy on a large scale. The service system discriminates against people with disabilities by taking away peoples’ rights without due process and segregating them from society. Serbian law calls for people with disabilities to have an opportunity to live in the community, but the creation of community support systems is left to local governments without the funding necessary to implement these programs. At the same time, funds continue to be used to build and expand institutions at Veliki Papovac and Kovin. When the new buildings are complete at the Kovin psychiatric institution, for example, the capacity of the facility will increase from about 600 to 850 patients.. While the MLSP has promised to create new 130 community placements for some 500 individuals, these programs will not meet the needs of thousands of children and adults who remain abandoned in overcrowded institutions. Even if current reform plans are fully implemented, the vast majority of people with disabilities now detained in institutions have no hope for returning to the community. **The government of Serbia has no plan or program to end the improper detention of thousands of people with disabilities – or to end the abusive treatment within its institutions.**

There is no solution to the situation at Kulina except to close the institution.

– government official, MLSP

The MLSP recognizes that the most abusive institutions, such as Kulina, should be closed. In July 2007, MLSP officials reported to MDRI that they have a plan to reduce the population of Kulina by 20% by moving children to “better institutions.” Even if fully implemented, this plan will leave the great majority of children and adults at Kulina languishing at the facility.

While the children transferred may experience some improvement in physical condition, they will still remain in inappropriate congregate care settings. In August 2007, staff at Kulina were unaware of *any* plan to reduce the population at the institution. “An institutional reform plan has existed for years,” reports the chief nurse, “but such promises had been made for years without being fulfilled.”

The state does nothing. Parents get no support. And there is no interest in adopting children even with the mildest of disabilities or Roma children. Most parents would like to keep their children at home. – doctor, Subotica children’s institution

As the European Union (EU) readies to continue talks on a Stabilization and Association Agreement (SAA) - the gateway to EU candidacy for accession consideration – MDRI urges the EU to insist that Serbia must first protect the basic human rights of its most vulnerable citizens.

Summary of findings

MDRI observed the following conditions in institutions:

- ❖ **Babies, children and adults with disabilities are confined to institutions for a lifetime, in conditions that are dangerous and life-threatening, and that inflict both mental and physical suffering.** – Babies with disabilities spend most waking hours lying in cribs, with little or no human contact. Children and adults who are labeled “immobile” are also doomed to an existence of confinement in metal cribs and beds where they may be left to eat and defecate.

There were rows of metal cribs filled with teenagers and young adults. Labeled immobile or bedridden, many of them were kept naked from the waist down on plastic mattresses, covered only with a sheet to facilitate staff clean-up of bladder and bowel incontinence. Staff reported they also eat in the cribs and spend all of their time in the cribs. They never get out. – MDRI investigator, Stamnica Institution

Teenagers and young adults confined to cribs in Stamnica Institution were labeled with “blindness, deafness, Cerebral Palsy, Hydrocephaly and mental retardation.” The lights were off and it was dark in the room in the middle of the day. The smell of urine and feces was overpowering and there was one staff person in the room for about 25 people. There was no stimulus of any kind – no music, conversation, television or radio – only darkness and silence.

I looked into the crib and saw a child who looked to be 7 or 8 years old. The nurse told me he was 21 and had been at the institution for eleven years. I asked her how often he was taken out of the crib and she said “never, he has never been out of the crib in 11 years. – MDRI investigator, Stamnica Institution

In the Subotica Institution for babies and small children under the age of 7, babies with disabilities lie in cribs where an insufficient number of caregivers can do little but feed and change the children, with no time for playing, rocking or holding. We observed bottles propped rather than hand fed and babies get virtually no human contact.

We have long recognized that placing any child in a setting with little human interaction is inherently dangerous. The children we observed in Serbia who are emaciated and immobile may have adequate nutrients offered to them. But in my clinical experience, emotionally abandoned children may stop eating or simply lose the will to live. The research literature backs this up. – Karen Green McGowan, RN, expert on children with complex disabilities

- ❖ **The use of restraints and seclusion on both children and adults** – There are no enforceable laws or regulations regulating the use of physical restraints in Serbia, and there is no oversight to prevent the abuse of this potentially torturous practice. As a

result, individuals may be left in restraints for days, weeks – or *years*. In severely understaffed institutions, restraint is used for the convenience of staff who cannot provide adequate individual attention or treatment to people detained in institutions. On two different visits to the Kulina Children's Institution in July and August 2007, MDRI found dozens of children tied to beds, chairs and cribs, some in 4-point restraints (i.e., legs and arms tied to the four corners of the cribs and beds). We also found extensive use of restraints in the adult facility of Kragujevac, where many residents were tied to beds. In another institution for adults in Curug, MDRI found tiny rooms where people are kept in seclusion with just a cot and a bucket on the floor for a toilet.

In the geriatric ward at Kovin, I observed a room filled with about 30 elders, many of them tied to chairs. It was July and one of the hottest days of the year and all were wearing heavy striped pajamas. There was no air conditioning. Old men and women struggled to pull off their clothes, but they could not do so because of the restraints. One woman pulled so hard, her chair tipped over and she hit her head on the ground. Her robe came off to reveal open sores on her buttocks (perhaps from sitting tied to the chair). A nearby man tried to help her stand up, but he too was restrained and could not reach her. The woman lay motionless on the floor for close to ten minutes before staff noticed her and placed her back in the chair. She screamed as they forced her to sit in the chair despite her open sores. - MDRI investigator, Kovin psychiatric hospital.

- ❖ **Restraints are used instead of treatment or care for self abuse --** Children who grow up in congregate care without love and attention often become self-abusive. In its mildest form, self stimulation may include rhythmic motions or rocking behavior. Over time, children or adults may be driven to more extreme behavior, including head banging or repeated acts of hitting or biting themselves. Left without attention, the practice can become self-mutilating, including children who gouge out their own eyes. MDRI observers witnessed the full range of such practices in Kulina and Stamnica. None of the institutions we visited had any specialized staff or behavior programs designed to assist children with problems of self-abuse. The commonly accepted “treatment” for self-abuse is the use of physical restraints. This practice actually exacerbates the underlying psychological damage to the person, resulting in continued self-abuse and even more physical restraint. Additionally, prolonged use of restraint can lead to muscle atrophy, life-threatening deformities, and even organ failure.

At Kulina, staff reported that a 6 year old boy with Spina Bifida was very aggressive towards himself and tried to rip off his own ear. We observed this boy tied to a chair. At Stamnica, a teenage girl, permanently confined to a crib, was observed attempting to gouge her eyes out while staff stood by and did nothing. We observed many children at the institution biting and chewing their own fingers. – MDRI investigator

- ❖ **Lack of rehabilitation and medical care –** There is a broad lack of rehabilitation, physical therapy and medical care for children and adults with disabilities detained in

Serbian institutions. Left to languish for years in a state of total inactivity, children or adults who do not become self-abusive become more disabled in other ways. Without activity, movement or physical therapy, children and adults labeled “immobile” can suffer from contorted and atrophied limbs and spines, dislocated bones and breathing problems. Children who receive little or no human contact and are emotionally abandoned can develop “failure to thrive” and are at increased risk of death.

MDRI investigators found a 3 year old boy who had recently been permanently placed in Subotica institution by his parents after he contracted Hepatitis B & C. The doctor at the facility stated he was not adjusting well and “he does not want to eat – he is having a difficult time.” Staff pointed out another 3 year old child with Down’s Syndrome who also refused to eat.

50 % of the children and adults have hepatitis – nurse, Kulina children’s institution

Investigators found residents in different institutions in dire need of medical attention. At Curug, a psychiatric social care facility, a man was kept in an isolation room – which lacked heat and had only a tin bucket as a toilet – because of his Tuberculosis, yet he was not receiving any treatment. Many people had no teeth due to lack of dental care. Infants and babies diagnosed with Hydrocephalus lay motionless in cribs, with heads swelled so large they were unable to move. Staff at Subotica institution wondered out loud “why doctors had not drained it” – often a life-saving procedure for children with such conditions.

When MDRI investigators asked staff at Kulina why a 7 year old girl, with an enormous head from Hydrocephalus, was not getting medical treatment that could save her life, a doctor stated:

When this girl was born, the doctor advised the parents not to bother with the surgery she needed since she would die anyway. But she is still alive. – doctor, Kulina

- ❖ **Inhuman, degrading and life threatening physical conditions of facilities people with disabilities are forced to endure** – During the winter, MDRI investigators found institutions with little or no heat, with patients huddling around radiators trying to keep warm. Many wore hats and coats indoors. The director of Curug Institution told MDRI that the facility was infested with rats and mice and the walls of the building were covered with asbestos. Lack of bathrooms and plumbing forced patients to defecate in buckets which they keep under their beds – causing a stifling smell in the room. MDRI found windows that would not open and faulty electrical wiring.

We have three buildings with 204 clients, many of whom are immobile. With the electric wiring I worry about a fire. At night we only have one nurse and one security guard on duty for three buildings. – director of institution, Curug

ADVANCE COPY - NOT FOR RELEASE BEFORE NOVEMBER 14, 2007

Conclusion and Recommendations

The new Constitution of the Republic of Serbia identifies integration into Europe as one of the main goals of the nation. This Constitution also guarantees the protection of human rights and bans discrimination on the basis of mental and physical disability. These are all worthy goals. It is to Serbia's credit that the country's mental health and social policies call for a transformation of its social service and mental health systems to integrate people with mental disabilities into the community. Model community-based programs have been created, providing valuable information about how these new policies can be implemented throughout Serbia (see Appendix A for examples of these programs).

Serbia's new policies of community integration are consistent with the requirements of international human rights law. With the recent adoption of the new Convention on the Rights of People with Disabilities, the United Nations and the international community recognizes that the unnecessary segregation of people with disabilities from society constitutes unlawful discrimination and violates their fundamental human rights. Established international human rights conventions, such as the European Convention on Human Rights, the Convention on the Rights of the Child, and the UN Convention Against Torture, provide essential protections to some of the most vulnerable people in any society: institutionalized children and adults with disabilities.

While Serbia's constitutional commitment to human rights protection is laudable, the policies and programs that the government of Serbia has put in place do not begin to address the serious human rights problems that exist for some 18,000 people detained in the country's psychiatric facilities and social care institutions. These individuals are arbitrarily detained in violation of article 5 of the ECHR. Within these facilities, inhuman and degrading treatment in violation of ECHR article 3 is widespread. Some children and adults with disabilities literally never leave their beds or cribs, and some are tied down for a lifetime. The most extreme human rights violations are tantamount to torture.

Immediate action is needed to end the country's most serious and life-threatening human rights violations. Serbia's laws on psychiatric detention and guardianship must be brought into conformity with international law, and resources must be provided to people with disabilities to provide the support and legal representation they need to protect their rights. While Serbia has created valuable model programs that demonstrate the potential for community integration, they are no substitute for programs that will bring an end to the human rights violations to which thousands of children and adults are now subject. A stated commitment to community integration does not constitute a plan for responding to these problems. Serbia must immediately allocate the resources necessary to implement its new anti-discrimination law, end abuses in institutions, and fulfill its stated goals of community integration. International donors that contributed so generously to rebuild Serbia's institutions should now shift their priorities to provide an equivalent level of support for the creation of community-based programs.

Children and adults with disabilities in Serbia have the right to live the most integrated and self-determined life in the community. People with disabilities cannot be denied access to education,

employment, decent and safe housing, friends and family based on their disability. Human rights protection for *all* people in a society is the hallmark of a truly civil society.

Goals and Methods

From December 2006 through August 2007, MDRI examined conditions in seven institutions under the authority of the Ministry of Labor and Social Policy (MLSP) and two psychiatric hospitals under the Ministry of Health (MoH). This report refers collectively to these as “institutions” and refers to them by their location, as indicated in parentheses below:

- Kulina Institution for Children and Youth with Developmental Disabilities (Dom za decu i omladinu ometenu u razvoju Kulina)
- Institution for children and youth "Kolevka" in Subotica (Dom za decu i omladinu "Kolevka" u Subotici)
- Special institution for children and youth "Dr Nikola Sumenkovic" in Stannica (Specijalni zavod za decu i omladinu "Dr Nikola Sumenkovic" u Stannici)
- Special institution "Gvozden Jovancicevic" in Veliki Popovac (Specijalna ustanova "Gvozden Jovancicevic" u Velikom Popovcu)
- Special institution for people with developmental disabilities Veternik (Specijalna ustanova za lica ometena u razvoju Veternik)
- Institution for mentally ill people Curug (Dom za dusevno obolela lica Curug)
- Institution for adults "Male pcelice" in Kragujevac (Zavod za zbrinjavanje odraslih "Male pcelice" u Kragujevcu)

The institutions we visited under the Ministry of Health are the Special Neuro-Psychiatric Hospitals (Specijalna neuro-psihijatrijska bolnica) at Vrsac and Kovin.

Torment not Treatment assesses Serbia’s enforcement of international human rights law pertaining to children and who reside or receive treatment in children’s facilities or adult institutions operated by the Ministry of Health or Ministry of Labor.

The goal of this report is to provide the information necessary for a full public understanding and debate about matters of fundamental importance to thousands of Serbian individuals with disabilities and their families. It is our hope that this assessment will assist the Serbian government and citizens in promoting the promised reforms to bring practices into conformity with international human rights law. MDRI has published similar reports on human rights conditions in Hungary, Mexico, Peru, Russia, Turkey, Uruguay, Argentina, Romania and the United Nations administration of Kosovo. In each report, we use international human rights law to provide a fair and consistent standard of assessment.

This report is not intended to place blame on institution staff or mental health professionals as a group. Many members of institutional staff we encountered work under the most difficult of circumstances and could not continue to work except out of their professional dedication and

care for the individuals they serve. MDRI would like to thank the many public officials, professionals, and staff who contributed their time and insights to our work.

At every institution we visited, we attempted to be as thorough as we could in understanding the human rights situation of people living or receiving treatment at the facility. We asked to visit all parts of the institutions. We interviewed institutional authorities, staff, and patients. During each site visit, MDRI teams brought a video camera to record observations. To the extent that we could, we took photographs in each institution. It is our experience that photo and video documentation is tremendously helpful in corroborating our observations and helping the public to understand the reality of life in an institution. We are sensitive to the concerns of individuals depicted in photographs, for whom placement in an institution may constitute a massive violation of their privacy and their ability to make choices about their lives. We generally find that people within institutions are amenable or eager to have their photographs taken.

This report is not a comprehensive study of the many institutions for children and adults in Serbia. Our report raises broad human rights concerns based on visits to a small portion of Serbia's institutions. There are inevitably differences in the mental health and social service systems in different regions and within the sites that we visited. There are no doubt valuable programs – as well as serious abuses – that we were not able to include in our report. In recent years, numerous model programs have been established to provide support to people with disabilities in the community. It is our hope that this report will support the national replication of these programs to ensure that everyone with a disability has an opportunity for a full life in the community.

We have made every effort to provide as accurate and comprehensive analysis of the major human rights issues as we were able to understand them. The observations and conclusions reached in this report represent the position of the authors and of MDRI alone. If any reader identifies errors or omissions in the report, we encourage you to contact MDRI at mdri@mdri.org. We intend to publish updates of this report, as well as corrections, on our Internet web site at www.MDRI.org.

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

I. Abuses in Institutions

MLSP officials informed MDRI that, in December 2006, there were at least 11,350 people in institutions under their authority (including 2,300 children). The actual number of institutionalized individuals with mental disabilities in Serbia is likely much higher, and official statistics are inconsistent.² There are 17 institutions for people with disabilities and 5 residential institutions for children out of a total of 78 institutions under the authority of the Ministry of Labor and Social Policy (MLSP). Individuals with mental disabilities who happen to reside in one of these institutions may not be in the total number tracked by the MLSP. Also, this figure does not include thousands of individuals detained in psychiatric hospitals under the authority of the Ministry of Health (MoH). According to the MoH, there are 46 inpatient psychiatric facilities with more than 6,200 beds.³ Additionally, in the two psychiatric facilities visited by MDRI, investigators found people with physical and developmental disabilities.

During our 2006-07 visits, the population of the institutions we visited under the MLSP totals over 3,300 people. The two psychiatric institutions we visited house 1,500 adults in Vrsac and Kovin. To the extent that the nine institutions visited by MDRI are indicative of all such facilities in Serbia, MDRI concludes that placement in such institutions puts children and adults at risk for serious human rights violations including inhuman and degrading treatment and torture.

Most people placed in these facilities will spend their entire lives segregated from the community. The environment is unsuitable for habilitation or rehabilitation, and most patients become more disabled as they languish in inactivity. This is true irrespective of the amount of funds that have been spent to rebuild the physical structures. Some of the worst abuses we observed were in buildings recently rebuilt with foreign assistance. The geriatric ward of the Kovin psychiatric hospital, for example, was recently rebuilt with the assistance of Norwegian funds. In this ward, we observed people sitting around a room in inactivity, tied down to benches and wheelchairs, some with skin raw from the bedsores they developed from inactivity.

People who are immobile in bed rarely get out. We feed them in bed...they die in their bed. – ward staff, Kovin psychiatric hospital

A. Physical restraints and seclusion

There is no protocol on restraints – no limit of time. – psychiatrist, Vrsac Institution

The use of physical restraints and seclusion are among the greatest limitations on individual liberty which any person may be subjected. Particularly dangerous and painful is the prolonged use of these methods to control institutionalized people. The Council of Europe recognizes that “persons with mental disorder should have the right to be cared for in the least restrictive environment and with the ***least restrictive or intrusive treatment available***, taking into account their health needs and the need to protect the safety of others.”⁴ Thus, “[s]eclusion or restraint should only be used...to prevent imminent harm to the person concerned or others and in proportion to the risks entailed.”⁵ It must only be used “under medical supervision” and should

be “regularly monitored.” The “reasons for, and duration of, such measures should be recorded in the person’s medical records....” The United Nations has established similar standards, making it clear that restraints or seclusion “*shall not be prolonged* beyond the period which is strictly necessary” to protect against “imminent harm.”⁶

MDRI investigators observed children and adults tied to beds, chairs, or benches and those labeled “immobile” permanently confined to cribs and beds at both psychiatric facilities and institutions for people with intellectual disabilities. The problem was particularly serious at Stannica and Kulina, where dozens of children were left in permanent restraints and cribs. We also observed extensive use of restraints among adults in Kragujevac, Kovin and Vrsac institutions.

1. Lack of standards, oversight, or protections

None of the institutions we visited reported having any written policy or procedure to guide the use of restraints or to prevent potentially dangerous abuses of this practice. No limitations existed on the times people could be held in restraints. There is no required oversight over the use of restraints and no requirement that restraints be marked in a medical record. Some institutions reported that they did record the use of restraints, but ward staff were never able to produce such records. Other institutions, such as Vrsac, report that it is their practice to require a physician to order restraints. Even this limited control is not a written policy, however, and can be neither monitored or enforced. MDRI’s observations in institutions under the MLSP are consistent with the findings of the Serbian Helsinki Committee in psychiatric facilities throughout the country.⁷

2. Inappropriate response to neglect and self-abuse

Kulina Children’s Institution is located 3 hours drive from Belgrade, at the top of a narrow, mountainous road, barely accessible in winter months. 580 babies, children and adults live in this remote facility, which is woefully understaffed. According to the director, all have developmental disabilities or “mental disabilities” and some have physical disabilities as well. Nurses told MDRI that 250 children and adults “cannot leave their beds and are totally immobile” and another 250 who are mobile are not toilet trained.

In the absence of any standards, some children and adults are subject to a life-time of restraints. Ward staff at most institutions report that everyone is taken out of restraints now and then. As the chief nurse explained at Kulina, staff are overwhelmed and have no choice but to continue to tie down the same “difficult” patients over and over again.

MDRI investigators found that many children and adults permanently restrained at Kulina were referred to as “auto-aggressive” or self-injuring. The problem of self-abuse is reportedly a problem with 40% of all of those living in Kulina and occurs at an even higher rate with children. Self-abuse is a well known phenomenon which occurs when there is a lack of human contact or stimulation. Loving attention is the best way to prevent self-abusive behaviors, but once this practice develops specialized treatment is necessary.⁸ Without such treatment, self-

abuse “may cause permanent and disabling tissue damage and may sometimes be life-threatening. For example, severe head banging or hitting may lead to cuts, bleeding, infection, retinal detachment, and blindness.”⁹

I walked into one room after another, a ward for children 4 to 7 years old. It was the middle of the day and children were confined to their cribs. There was no staff in any of the rooms, no toys, no music – nothing. One boy with Downs Syndrome was hitting his head over and over against the metal crib. Another was tied to the crib in 4 point restraint and still another, with a deep gash on his ear, had his arms tied to the side of the crib – MDRI investigator

MDRI found several children tied into chairs. In one room, devoid of any staff and filled with toddlers all in cribs, a lone child sat crying, tied to a chair in the corner. In still another room, two small boys were tied at their wrists and waists into chairs. One of them had bandages over his ears. According to staff, he had tried to rip his own ears off. Experts in the field of disability agree that hitting, scratching and biting oneself is a reaction to mind-numbing boredom and lack of age appropriate stimulation and human contact.

Self-abuse is created and exacerbated among children who receive no love and attention and who are abandoned in beds or cribs. Psychological experts agree that they crave some form of stimulus, so they would rather feel pain than feel nothing. – Karen Green McGowan, RN, expert on children with complex developmental disabilities

Some staff are acutely aware that boredom and lack of human contact is the cause of self-abuse but feel they have no alternative to restraints due to the lack of staff. One nurse described a child’s transformation when he was taken out of the institution by some charity workers:

The charity group took some of the mobile children to the seaside and I accompanied them. One child was very aggressive and was on four medications. He only needed one medication at the seaside. It was if he were two different children. He was not being aggressive because he had something to spend his energy on. If we had more staff working with these kids, there would be less aggression. – chief nurse, Kulina

3. Administrative convenience and lack of staff

MDRI also found many adults in restraints. In most cases, the use of physical restraints for adults was the result of a lack of staff to provide attention to people in need.

In the ward for men with intellectual disabilities who were not “immobile,” men sat in an empty room with only some benches or wandered up and down the halls. The smell of feces was overpowering and there were only two staff per shift. One young man sat on the floor with his hands bound because “he tried to escape through a window.”

In another building, a man was tied into a wheelchair at the waist, wrists and feet. Upstairs, on a floor with no staff in attendance, an emaciated young man, who nurses said had broken his own nose while punching his face, was tied into a bed at the legs, arms and waist. And he was all alone in the completely empty room.

In the Institution for Care of Adults in Kragujevac, which houses 943 people with intellectual, psychiatric and physical disabilities, MDRI found restraints tied to many beds.

As we walked through one room with about 6 women in bed (during the day) a 24 year old woman, who had a restraint tied to her bed and who overheard us talking about the restraints, screamed out to us and said “yes, yes they tie us!” – MDRI investigator

When MDRI investigators queried the staff on the use and duration of restraints, the “defectologist” on the ward explained that only the psychiatrist decides when and how long a person can be restrained. However, when we reminded her that the director of the institution had told MDRI that there was no staff psychiatrist at the institution, she offered this explanation:

Some of them are suicidal, so they ask staff to restrain them. Patients decide how long they want to be in restraints. – defectologist, institution in Kragujevac

At Vrsac Neuropsychiatric Institution, staff showed MDRI leather restraints that they routinely use at the 900 person facility – restraints, they said, that were donated to them by an international humanitarian charity.

We use chemical and physical restraints. The (leather) restraints are fixed on the bed and then we restrain their arms and legs. Sometimes we use a sheet with a hole in it for the head to restrain people. There is no policy. Each patient is different. You can’t have one rule for everyone. – nurse, Vrsac

In the geriatric ward at Kovin Neuropsychiatric Institution, investigators found 4 residents tied to chairs and wheelchairs. One woman, naked from the waist up, had fallen out of the chair onto the floor, with her arm still bound to the chair. Staff stood by and did nothing while another resident attempted to untie the woman.

In addition to the highly abusive use of restraints, “immobile” children and adults are subjected to permanent and ongoing seclusion by virtue of the fact that they never leave their beds or cribs. MDRI found many people, unable to move without assistance, in beds and cribs during the middle of the day. In one building at Kulina which housed 97 adults, the second and third floors were mainly dedicated to this population. With only two to three staff during the day and one at night for the entire building, it is impossible for staff to do more than feed people and dispense medication. **As a result, people labeled “immobile” are virtual prisoners in their beds and cribs.**

250 children and adults are totally immobile and cannot leave their beds or cribs. - doctor, Kulina

In Stamnica, MDRI found several darkened rooms where rows of cribs were filled with teenagers and young adults with “Cerebral Palsy, Hydrocephaly, Microcephaly, and blindness with mental retardation.” Despite the fact that it was during the day, lights were off and there was no stimulus of any kind – no music, toys or television – and no staff in attendance. And the rooms were eerily quiet – not a sound coming from those confined to the cribs. Although they looked the size of 5 or 6 year olds, their ages ranged from 10 to 30, their growth stunted due to years confined to cribs.

They can’t move and they spend all of their time in the cribs.

- head nurse, Stamnica

The nurse pointed to the young man in the crib and said, “he has never been out of the crib in 11 years.” – MDRI investigator

The Institution for Children in Subotica houses children ages birth to 7 years, both with and without disabilities. This facility was among the cleanest and best staffed of all we visited in Serbia. Babies and children had stuffed animals and toys in their cribs and rooms were well lit. Diapers and pajamas were clean and there was no stench of urine and feces permeating the building. But despite this, MDRI observed children biting their hands and rocking back and forth and staff had restrained several of the children, by wrapping sheets or blankets around their torsos and arms, to prevent further self-injury.

Children rarely go out or leave their cribs. They come directly from the hospital. This is the best staffed facility in Serbia. The ratio seems good, but we don’t have enough workers. The biggest thing these children miss is social activity. – doctor, Subotica institution

We have no time to play with or hold children – nurse, Subotica institution

B. Degrading, dangerous conditions and lack of medical care

Conditions are really bad. We have up to 27 beds in one room.

- chief nurse, Kovin psychiatric institution

MDRI investigators found children and adults with disabilities, confined to Serbian institutions, in grave and life-threatening conditions due to dangerous physical conditions and lack of medical care. The Council of Europe requires that “[f]acilities designed for the placement of persons with mental disorder should provide each such person...with an environment and living conditions as close as possible to those of persons of similar age, gender, and culture in the community.”¹⁰ They should “receive treatment and care provided by adequately qualified staff and based on an appropriate individually prescribed treatment plan.”¹¹ The United Nations has established that “[e]very patient shall be protected from harm, including unjustified medication,

abuse by other patients or staff or others or acts causing mental distress or physical discomfort.”¹²

Staffing levels are so low that basic medical care and rehabilitation, individual attention, and oversight is lacking. Most children we observed in institutions spent their day with no purposeful or meaningful activity – laying in cribs, sitting on benches, or milling in hallways. In December 2006, the MLSP publicly admitted to these sweeping problems within the institutions under its authority:

The facilities are in poor condition, the staff structure prescribed by the norms is inadequate, and care-takers are insufficiently trained for the application of contemporary work methods.¹³

While many buildings have been rehabilitated or rebuilt in recent years, unhygienic conditions and filth are common. In Kulina, 50% of those residing there have Hepatitis B – a blood-borne form of the disease which can be passed to an uninfected person through blood, saliva and other bodily fluids. Staff reported it was the “lack of vaccines” that led to the spread of the disease throughout the institution. They also reported severe problems with scabies, chicken pox (for which a vaccine is available) and often life-threatening salmonella.

MDRI found many emaciated and dehydrated children lying in cribs. In one room, four very gaunt children, who looked to be toddlers but were much older, were tied into cribs and were receiving intravenous fluids for dehydration. According to nurses, they were suffering from “diarrhea.” However, staff did not know why they had not been transferred to a hospital.

The children in the cribs I saw were emaciated and dehydrated, with little or no subcutaneous fat. With no ability to give any of them individual attention, they are all at risk. – Karen Green McGowan, RN, observation at Kulina

One of the most gut-wrenching sights we observed were children with untreated Hydrocephalus – an abnormal buildup of cerebral spinal fluid in the skull. Hydrocephalus left untreated causes swelling of the brain and skull and has a death rate of 50% - 60%.¹⁴

MDRI found a 7 year old girl moaning in her crib and unable to move, her head swelled to the size of a basketball.

When this girl was born, the doctor advised the parents not to bother with the surgery she needed since she would die anyway. But she is still alive. – doctor, Kulina

MDRI also observed numerous people in several institutions with open cuts and sores, eye infections and the vast majority had missing and/or rotted teeth. Directors at several institutions said it was very difficult to find medical staff willing to work in the institutions :

It is a big problem providing health care. Some doctors don't want to treat people with disabilities. It is difficult to find medical and dental staff willing to treat patients. – doctor, Subotica

In Curug , MDRI found two, tiny locked isolation rooms with no heat and buckets used for toilets. A woman was in one of the rooms because she needed “medical isolation” and a man was confined to the other room “because we think he has Tuberculosis.” However, neither was receiving any medical treatment.

One of the most consistent problems reported by institutions is the discrimination faced by people with psychiatric or intellectual disabilities in the general health care system. Based on the reports received by MDRI, the responsibility for the problem seems to be shared by local governments, hospitals, and social care facilities. A physician at Curug said that he had a difficult time getting authorization from regional authorities to send patients to a hospital for somatic health care. In addition, “there’s a terrible stigma in the health system,” said the doctor, because “hospitals don’t want to take our patients.” The doctor described a recent case in which a patient died of cancer in the institution. The cancer had never been diagnosed – despite major symptoms of motor limitations:

I must not say it, but unofficially it is true. It never occurred to the staff to send the patient to a regular doctor. This is not just a problem here, it is a problem everywhere. They don't recognize the somatic problems...if someone is a psychiatric patient it is over for them.

MDRI received similar reports from staff at the Vrsac and Kovin psychiatric institutions.

We have to sign a piece of paper stating the diagnosis. If we write down schizophrenia, they won't get good care. There is an assumption that schizophrenics are dangerous. If we write down “depression,” they are better cared for. We are already short of staff, but we have to send one of our own to the hospital just to make sure they get treatment. -- acting director, Vrsac

At Kragujevac, the director reported that the lack of medical care was a problem because of a shortage of medical staff at the facility. For hospital care, the director of Kragujevac said that they have to send the patient back to the region they come from, and the delay in getting authorization can be a problem. Sometimes, local authorities simply do not respond to their requests for the transfer. The director at Kargujevac also noted that there is also no dentist on staff. Many long-term patients have no teeth, limiting the range of food that they can eat and creating other serious health risks.¹⁵ MDRI observed chronic patients missing teeth at every institution we visited.

C. Dangers of neglect on children

The lack of stimulation and care is particularly dangerous for children. Raising children in a congregate environment without a parent or parent-like figure can result in irreversible psychological damage, including reactive attachment disorder.¹⁶ Basic human needs are the same for children with and without disabilities. It is well documented in the research literature that all humans – especially babies and children – need human contact to not only thrive, but to survive. Dr. Dana Johnson, a world renowned expert and researcher on the effects of institutionalization on babies and children stated in a 2006 BBC interview:

I think putting a child in a long-term institution is an act of abuse...The conclusions are that nothing replaces family...Children in institutional care have deteriorations in many things that we want to see children improve in during the earliest years of their life...Their cognitive abilities are lower, their growth is terrible and their brain development is abnormal as well...A few days in an institution should be as long as children are asked to endure.

The following is an analysis of the damage – both physical and psychological – caused by lack of medical care and rehabilitation, lack of staff and staff training, the long term use of restraints and seclusion and isolation of children in institutions. Firsthand observations by Karen Green McGowan, RN, an expert on the needs of children with complex physical, intellectual and medical disabilities.

On 8/30/07, I visited a facility for children and adults with developmental disabilities in Kulina, Serbia with MDRI investigators.

The Kulina facility is located in a very rural part of the country. Due to the extreme drought in this part of Serbia, water was being trucked into the facility, which serves about 560 individuals, the majority of whom we visited that day. The facility is not air-conditioned, and the heat had been oppressive in the past few months. Many of the children I saw appeared to be mildly to moderately dehydrated.

One unique characteristic of the population is that fully one-third is Down's Syndrome, including children as young as 3 years of age. Although this is a frequent cause of mental retardation, it is rare to see more than 5-10 percent of an adult population in congregate care in the West today. When these youngsters are raised in a loving family, most of these individuals can become fully independent for the majority of their adult life. IQ scores from those raised in institutional facilities will fall 40 or 50 points below their home-raised counterparts, not to mention the difference in social skills. When any child is deprived of the attention of loving caretakers, the IQ is invariably affected.

In the first unit we visited, there were about 25-30 youngsters. Two children were restrained in poorly fitting wheelchairs. The staff told us that these youngsters would engage in "self-aggression" if they were released. The first of these two was a very pretty 7-year-old who was very thin. She had the vacant eyes of a child who has never been nurtured and eventually disengages from human interaction. She did not respond in anyway to my attempts to engage her. When I released her arms and legs from the restraints, she merely tried to hit herself in the face. When I asked how often someone might take this child into their laps and cuddle her, I was told that there was no staff in the facility with time for anything but basic care. While I was working with this little girl, a 3 year old toddler with Down's Syndrome scooted over on hands and knees and crawled into my lap, where she proceeded to wrap her arms and legs around me and cuddle for dear life.

Another stunning feature of the children was that many were very thin with little body fat. The first little girl was not more than 10 Kilograms (22 pounds), which is significantly below the weight expectation for a child her age.

In that same day room, about 8-10 children, mostly those with Down's Syndrome, were sitting on a mat on the floor with nothing to do. Another little girl with auto-aggression was tied in a wheelchair such that her arms and legs were immobilized. The seat of the chair was too deep and the front edge of the seat came nearly to her ankles. She sits this way day after day with few opportunities to move or exercise her limbs. There were welts and her arms where the restraints had restricted the circulation to her extremities. We found this phenomenon on a number of other individuals.

Staff wanted to know what techniques they could use to prevent auto-aggression, which is a problem throughout the facility. The term *auto-aggression* is used to describe self-injurious behaviors, such as chewing on hands and head-banging among others. Children, normal or those with developmental disabilities, cannot thrive without a warm and nurturing home. We have learned from long, hard experience that babies and young children who grow up without nurturing often die or they eventually engage in the only behavior that seems to get them any attention, namely "auto-aggression."

On another unit in the same building was a group of children lying in their cribs with arms restrained and tied to the bars on either side. Some had waist restraints, and a few more had legs restrained. One little boy had a pancake chest, which results from gravity flattening the rib cage because so much time is spent lying on the back. His hips looked dislocated, which is common when children are not helped to stand at a normal developmental stage. This is because the hip sockets do not develop without weight bearing. This boy is a little bag of bones and is probably older than he appears.

We saw two children with untreated Hydrocephalus. This is a condition where spinal fluid cannot escape from the brain. Because it has nowhere to go, the fluid seeps into any available space in the brain, causing it to become very large. This condition is almost never seen in the US because a draining device called a shunt which is put in within a few days of birth. One little boy, whose age was difficult to determine, had pressure sores all over his head. This is a direct reflection of lack of care, and by his appearance, of lack of adequate nutrition as well.

I made it my habit to ask about body weights, and many of the children at this facility are grossly underweight, at less than the 5th percentile of what you would expect of a normal child of the same age. Many of the children had disuse atrophy of the arms and legs. Most of them were apathetic as well. There is not sufficient staff in this facility to provide any level of attention. For that matter, there are not enough staff to even provide minimal custodial care.

The staff told me that there was few staff in any area of the institution. One building housing 97 people on three floors has 6 staff on the day shift to feed, bathe and change more than 32 persons per floor. On the night shift, there is only one person for the entire building. The most physically handicapped and "immobile" individuals reside on the third floor, where the only route to the lower levels is by the stairs because there is no elevator.

This facility is desperately in need of many more staff, as well as more adequate physical facilities. If a fire ever happens in the building mentioned above, no one will escape, particularly those on the second and third floor. Staff believes that only 10% of the persons can be moved to less restrictive settings

If the societal disincentives could be handled, most of the children in the Kulina facility could be readily placed into specialized foster care. In the meantime, this facility cannot even provide any decent level of custodial care. So, we are left to watch children with mild disabilities being shaped by their lack of care and nurturing into persons with more profound disabilities.

D. Lack of habilitation and rehabilitation

Smoking is their major activity. - staff on ward for chronic patients, Vrsac

There was little in the way of activity, let alone meaningful rehabilitation or habilitation in most all of the institutions visited by MDRI. Children and adults labeled "immobile" or "severe" were excluded from the few activities that did exist. Such attitudes and discrimination combined with the lack of staff, make it impossible for institutionalized people with disabilities to preserve or enhance their daily living skills.

The United Nations has recognized that people detained in institutions have a right to rehabilitation or habilitation services “directed toward preserving and enhancing personal autonomy”¹⁷ The Council of Europe has specified that “[v]ocational rehabilitation measures to promote the integration of those persons in the community should also be provided.”¹⁸ According to the United Nations Convention on the Rights of People with Disabilities (CRPD), governments must ensure that they:

...take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life... Article 26 CRPD

The Serbian MLSP has recognized its own failure to provide meaningful programs or rehabilitation. Indeed, it has admitted to the core problems that make any form of rehabilitation difficult or impossible. The Ministry recognizes that the majority of people in institutions do not need to be there at all, but are simply unable to obtain services and supports in the community.¹⁹ Such individuals face unnecessary “social isolation” by virtue of being in a facility at all. Once in these facilities, people many are placed in institutions “with no adequate programs to address their needs.” For example:

young persons with disabilities could be placed in institutions for the elderly; children and youth with cognitive disabilities are excluded from the educational system and placed in institutions for persons with mental health issues, although, with proper support, their needs could be better fulfilled in their natural environment....²⁰

Particularly dangerous was the lack of therapy for children and those confined to cribs and beds. Much of the self-abuse and “failure to thrive” can be attributed to the lack of activities and human contact. Without any physical therapy or movement, children with disabilities forced to live in cribs develop life-threatening and painful conditions. Dislocated hips, atrophied muscles and respiratory problems are common and cause further disability and death.

At the adult institution in Kragujevac, MDRI toured buildings known as “pavilions” where people were lying in their beds or wandering the halls in the middle of the day. Bathroom fixtures were broken, rooms smelled of feces and urine. Huddled near radiators, people wore coats and sweaters indoors due to lack of heat. Yet on the same campus, staff gave MDRI a tour of the “workshop” building – a brand new facility with computers, a library and art room which were completely empty of patients and looked completely unused. We were told that people were not allowed to take books from the library and bring them to their rooms for fear they might damage them.

The defectologist decides who is able to participate and who is capable.

– defectologist, Kragujevac

At Curug Institution, the director reported to MDRI that he tried to provide some occupational therapy to patients but “unfortunately, only 30 out of 204 clients are able to participate mainly due to lack of staff.”

I can't even find a dentist or a psychologist who will work here, not even as a consultant. We have no therapy, no group therapy and no trained staff. Tranquilizers and neuroleptics are the only therapy we have. - director, Curug

Veliki Popovac social care facility houses 290 adults with intellectual disabilities and according to the director, 100 of the more “severe” clients cannot be included in any activities or therapy due to lack of staff. MDRI found this population confined to small empty rooms where they spend 12 hours a day. Each room held 20 or so people, with one staff person. One man, who staff reported self-injures, was found sitting on the floor with a large open gash to the head. MDRI investigators observed a women languishing in the barren room and pulling out her hair.

Several institutions MDRI visited described “work therapy” as part of the rehabilitative process. Residents clean bathrooms, mop floors and do laundry in return for an occasional reward such as cigarettes or coffee. At Kovin Neuropsychiatric Hospital, MDRI also observed staff yelling at some residents to clean and sweep floors as we were touring the facility.

The lack of staff is the major limiting factor in the inability to provide care:

We have so few staff] we cannot even talk to the patients. If you could get to a patient on time, you could stop patients from getting worse. You could give less medications. – ward staff, Kovin

E. Dangerous and life threatening physical conditions

The conditions which institutionalized human beings are forced to endure in some Serbian facilities are not only humiliating and degrading, but dangerous or life-threatening. Lack of staff is the most pervasive problem. At Kovin, staff report that patients get more medications as staff are cut back because of the lack of attention people receive. With recent cuts:

We are left to do the basics, drawing blood, giving medications, and feeding them. At lunch, some patients don't have the energy to eat. We could assist them before, but now we can't. We don't even have forks or knives. We have to cut the food for them. – ward staff, Kovin

At Kulina, the director lamented about the shortage of water due to lack of rain and snow in the mountains and his fear of a fire:

I am in great panic because of the lack of water. Sometimes there is no water in the fire hydrants. God forbid we have a fire here.

With over 250 “immobile” children and adults at the facility – many confined in multi-story and inaccessible buildings with little or no staff, residents would be in grave danger if a fire were to occur.

At Curug, staff was also concerned about fire due to faulty electrical wiring. In the evenings, 204 residents – many who are immobile – are confined to three buildings with only two staff on the entire premises, making an evacuation impossible.

Lack of heat during winter months is particularly life-threatening to elderly, sick and bedridden people. At Curug, residents were wearing winter coats, hats and sweaters indoors when MDRI visited the facility in December.

The heating system is just one main pipe and some radiators are totally cold. – director, Curug

Rats and mice in bedrooms are a “big problem” according to the director, as is the asbestos coating on the walls. Lack of staff forces bedridden patients and those who cannot walk without assistance to urinate and defecate in metal buckets which are kept under their beds.

The deplorable conditions for the 60 people living at the oligophrenic ward at Vrsac Neuropsychiatric Institution were unfortunately not unique to that facility alone. Dark halls, feces and urine on walls and floors, horrendous smells, filthy bathrooms lacking soap or towels, showers and toilets with no doors or curtains were observed by MDRI on several different wards of various facilities. Additionally, rooms crammed with rusted metal beds, peeling paint, mold and mildew on walls were common place.

...we remain under the strong impression that life in the oligophrenic ward is simply not worthy of a human being. – Serbian Helsinki Committee report:
People on the Margins of Society

At Kovin, as in other facilities, both women and men were found with heads shaven. In one unit, people were all dressed the same – in long-sleeved striped pajamas – despite the 38 C. (100 F) plus temperature inside the building in July.

They all looked the same. They had nothing in the way of any personal items. It was difficult to tell men from women. Their individuality and humanity had been stripped away. – MDRI investigator

Staff reported that 128 people died at Kovin in 2006 – fully 26% of the residents. When a person dies at a psychiatric institution, there is no requirement of an independent death investigation. The doctor at the institution determines the cause of death and can call for an investigation or an autopsy at his or her discretion. A physician at the Curug psychiatric social care home reported the same practice.

MDRI visited the institution at Veternik in 2003 and again in 2006. It was established in 1972 with a capacity of 590 beds, initially for children. But, due to overcrowding throughout the institutional network of care in Serbia and the “unsolved problem of caring for adults with disabilities,” there is nowhere to transfer children when they reach the age of majority. During MDRI’s first visit, this institution housed 596 residents, up to the age of 50, with labels ranging from mild to severe mental retardation. Most of the residents receive benzodiazepines, in addition to any other medications they may be prescribed.

We need to sedate them to sleep and so they don’t detract from activities or destroy things in the environment. Keeping children asleep is a problem. If one starts to ‘howl,’ then they all awaken. – staff, Veternik

In 2003, physical conditions at the facility range from good – a new building funded by a private German donor for 18 young adult residents who live largely independently – to horrendous – a separate, fenced-in, locked area for 160 adults labeled “severely retarded.” In this area, residents were monitored in clusters throughout the common areas by staff members assigned to maintain order and behavioral control. Many of these residents were partially clothed and self-abusing from lack of activity or stimulation, in an environment that was barren, foul-smelling, and infested with flies. When MDRI returned in 2006, the director refused to let us see the locked area or answer most of our questions and eventually asked us to leave.

There is also a danger of sexual exploitation at institutions. In some institutions, such as Vrsac, some men and women live in mixed wards. We observed many men and women in bed together. Ward staff report that they make no effort to determine whether or not sex is consensual.

The man who has cigarettes has girlfriends-- ward staff, Vrsac psychiatric institution

In the mental retardation ward of Vrsac, no birth control is provided to patients. Ward staff reported to MDRI that “people with mental retardation cannot get pregnant.” This statement, obviously untrue, suggests that unwanted pregnancies are going unreported or the long-term patients on the ward have been sterilized.

II. Structure of Services

A. Improper Segregation from Society

The mental health and social services systems of Serbia have been built and operate to segregate people with mental disabilities from society at large. The structure of social services in Serbia has been accurately recognized by the MLSP itself as sorely inadequate. Indeed, the government recognizes that many of its citizens with disabilities are improperly placed in institutions:

Due to a high level of centralization, limited funds...and consequent insufficient interest in the social welfare system, community-based services are not developed in line with citizens’ needs. This has resulted in a predilection for residential

accommodation, ***even when it is not essential***...and an inadequate fulfillment of needs for a great number of beneficiaries. Namely, a centralized approach in planning residential capacities and financing [benefits], alongside insufficient resources at the local level has created a bungling network of institutions that ***does not respond to the real needs of the beneficiaries and does not provide adequate services.***²¹

The Ministry of Health recognizes similar limitation in the psychiatric system:

Large psychiatric hospitals represent asylums for chronic psychiatric and mentally retarded patients. The majority of these patients remain institutionalized for years, most of all for social reasons. The hospitals are overcrowded, in bad economic conditions, lacking in staff, and treatment often does not follow the principles of modern psychiatry.²²

As a result of Serbia's institution-based structure of services, placement in an institution usually means life-time detention. As described by the directors of institutions visited by MDRI:

Clients usually spend their entire lives here. – director, Veliki Popovac

Children who come here will stay here for the rest of their lives. – director, Kulina

Children with disabilities come directly from the hospital to the orphanage. Doctors encourage this. There is no interest in adopting children even with the mildest disability. Children without disabilities will go to foster families or will be adopted. Children with disabilities are left behind. – doctor, Subotica
Institution for babies

As a result of lifetime placements, according to the MLSP, “institutions which were originally meant for children with disabilities gradually became institutions for the accommodation of adults as well. These institutions are characterized by a large number of beneficiaries (from 300 to 650), children and adults aged from 4 to 50, even older....”²³

Within psychiatric institutions, unlike institutions under the authority of the MLSP, there are some people who come for treatment and return to the community. Both of the psychiatric facilities we visited, the Vrsac and Kovin psychiatric facilities, also had chronic wards where people remain for very long stays or for life. MDRI investigators interviewed staff at both these institutions who explained that many people are detained in these facilities not for the severity of their illness, but rather, because they had no family or place to go.

They stay here forever. Their families put them here and then forget them. - director, Kovin

At least 200 patients could go home if they had a home to go to. – head nurse, Vrsac

The MLSP admits that the reason for institutionalization is “usually as a result of the lack of other community-based services (day care centres, small group homes, etc.)”²⁴

Institutionalization results in “isolation of many beneficiaries whose needs would be better fulfilled through other types of services.”²⁵

The open acceptance of improper institutionalization leaves staff and clients powerless to challenge the *status quo*. MDRI investigators met two women in Stamnica, who had physical disabilities and used wheelchairs, Both had lived their entire lives in institutions. One of them stated:

I have grown up in this institution. And yes, I would live in the town, in a home, if there was such a place for me.

Investigators also found a 15 year old girl who had been in Stamnica for “2 to 3 years” after her parents decided to put her in an institution because, according to the nurses, the parents said she might become a prostitute like her sister. “They put her in here for her own protection. She has no disability.” Despite the fact that she can read and write, she does not go to school – a decision, according to staff, made by the Center for Social Work (CSW) when she was institutionalized. Staff also reported that CSW social workers have only come to visit and evaluate her situation twice over the 2-3 year period.

Many of the children and young adults living in institutions have families. These families have relinquished their children to custodial care primarily due to the lack of financial resources and/or support alternatives. Advancing parental age, economic hardship, lack of experience and training in addressing everyday challenges, and co-occurring physical disabilities are often cited as reasons for families admitting their children to these institutions. MLSP officials explained in December 2006 that – despite official policy to the contrary – doctors, Centers for Social Work, and Categorization Commissions often recommend that families give up their children with disabilities, suggesting that they will be “better cared-for by the experts.” This professional advice sometimes emphasizes that parents should “focus on their healthy children” or “try again” when children are born with a disability. This approach reflects a system which has historically labeled and segregated people identified with a disability, particularly when that disability is intellectual, developmental, or psychiatric in nature.

B. The Promise of Reform

The structure of services now found in Serbia is common throughout Central and Eastern Europe and is built on an outmoded perception that people with mental disabilities must be segregated from society. The tragedy of modern Serbia is that the current system of large institutions with impersonal wards holding dozens of people in a room is *not* leftover from a bygone era. After international sanctions were lifted in 2000, the government of Serbia and international donors invested considerable sums to rebuild the old institutions along the old model. When MDRI investigators first visited Serbia in 2003 and 2004, many of the institutions we visited were under construction. To this day, plaques on the walls of institutions still indicate which foreign donor helped with the rebuilding process. Despite dramatic improvements in physical conditions,

treatment practices and opportunities for meaningful life activities have changed little for people with mental disabilities since MDRI's first visits.

Many international donors have now switched their priorities and are generally supporting a new shift to community-based services. MLSP authorities reported in December 2006, however, that the overall amount of foreign support for mental health and disability services has greatly declined. Having rebuilt a segregated model of services, foreign donors are not making an equivalent new effort to help Serbia bring its service system into line with modern trends in community-based care. To Serbia's credit, the major new investments in community-based housing for people with mental disabilities is now coming from its own National Investment Fund. This is a one-time influx of resources generated by the privatization of state properties.

Serbia's current "Social Welfare Development Strategy," adopted by the government of Serbia on December 1, 2005²⁶ was developed in collaboration with the World Bank and the Government of Norway.²⁷ The stated goals of the new strategy are "poverty reduction" as well as "the development of a more efficient social welfare system which will protect human rights and fulfill the existing needs of citizens."²⁸ This includes a commitment to "providing services in a least restrictive environment" as well as "harmonization of the national legal system with ratified international documents and the contemporary theory and practice of social work."²⁹ An explicit goal of the strategy is to further the inclusion of Serbia into the "European integration process."³⁰

The MoH has adopted a national reform plan similar to the one adopted by the MLSP, the "National Mental Health Policy and Action Plan."³¹ According to the plan, "[m]ental health reform should promote local community services, which are non-discriminatory, easily accessible and the work of which (both therapeutic and preventative) is evidence based."³²

The Social Welfare Development Strategy is part of a broader legal commitment to non-discrimination and inclusion of people with disabilities in society. In April 2006, Serbia adopted a progressive new "Law on the Prevention of Discrimination Against Persons with Disabilities."³³ In addition to banning disability-based discrimination, the law obliges governments to provide services for people with disabilities to promote "independence in their everyday life as well as exercising their rights."³⁴

There are enormous obstacles to implementation of Serbia's anti-discrimination law and social policy. One of the main obstacles to reform, according to the MLSP, is that "social welfare institutions and services are centralized, bureaucratized, inflexible, paternalistic, inefficient and not cost effective."³⁵ The new approach to reform entails a shift toward a "market-oriented society...an efficient system of social transfers...."³⁶ The main thrust of reform is to decentralize the social welfare system, provide for greater local control, and correspondingly shift the burden of finance to local governments.³⁷

The Social Welfare Plan establishes a number of important objectives for reform regarding individuals with mental disabilities:

- "transformation of residential institutions..."

- “development of alternative forms of social care which support life in the community, day care centres for persons with specific needs, at-home social care and assistance...”
- “development of foster care and adoption”
- “protection of children from abuse and neglect”
- “development of professional standards, procedures, protocols, and norms.”³⁸

In recent years, important groundwork has been done that demonstrates Serbia’s potential for reform. Model inclusive programs have been established (some of these programs are described further in the appendix to this report). Foster care programs have been created that include a limited number of children with disabilities. The government of Serbia and international funders have supported a pilot “deinstitutionalization” project that has demonstrated that people with mental disabilities can “leave the institutions where they were confined and begin living fruitful lives in the wider world.”³⁹

Serbia’s recognition of the goal of community integration for all people with disabilities is a valuable first step. This new goal is consistent with the requirements of international human rights law and the promise of integration into society now enshrined in the new UN Convention on the Rights of People with Disabilities (CRPD). If implemented, this new policy would radically shift the direction of social services which, over the last decade, has solidified and perpetuated an outmoded system of segregation.

It is unrealistic to close institutions...-- MLSP official, December 2006,

The language of Serbia’s reform plan, however, is sufficiently vague to avoid a real commitment to address the country’s most serious human rights problems facing children or adults with disabilities. If fully implemented, there may be some downsizing of institutions and part of one facility will be closed. When pressed, however, officials at the MLSP made clear that a commitment to “transformation” of institutions does not mean a commitment to closure of institutions or to integrate individuals into the community who are now improperly segregated from society. **When it comes to individuals with disabilities, the Serbian government’s plans for implementation of reform falls well short of the stated national goal of bringing about compliance with international human rights standards.** Strikingly, the proposed programs fail to address the rights or needs of the people who are most vulnerable to abuse: children and adults with mental disabilities who are now detained in institutions.

C. Implementation of the reform program

First we have to persuade the decision-makers at the local level. We can have a very good strategy as a matter of policy, but if we cannot persuade decision-makers in the relevant environment, we can’t achieve much.

- official in charge of disability services, MLSP

With resources from the National Investment Fund, the government of Serbia has promised to purchase 130 new apartments. According to MLSP authorities in December 2006, these homes will be purchased over the next two years, and they will serve up to 500 individuals with

disabilities. The supported housing program will be supplemented by the creation of 100 new “day centers” to support children with disabilities living in their own homes. These day programs would integrate children with and without disabilities. MLSP officials stated in December 2006 that they would institute a moratorium on new commitments “within weeks” of our meeting. In 2007, the Ministry promised to create its first program to license and accredit programs serving people with disabilities.

Serbia’s proposed new programs are all excellent ideas and should be fully supported. This program, however, does not respond to the massive human rights problem in the country’s institutions. If proposed programs were directed solely to people now detained in institutions, the community integration of 500 individuals out of more than 11,000 would leave behind thousands of improperly institutionalized individuals. In practice, however, the new placements for 500 people are not likely to help many people placed in institutions or people with major disabilities. Current facilities are now overwhelmed, and there is a long backlog of individuals on waiting lists to get into institutions. As they create new community placements, MLSP officials said that they would give priority to children and adults “most at-risk of institutionalization.” These individuals have “pretty high abilities” as they are already functioning in the community. The Ministry stated that it would have a preference for less disabled individuals who are capable of being employed in “simple jobs” in the community.

The proposed moratorium on new admissions is an excellent idea, but when MDRI visited in July and August 2007, it had not yet been implemented. On the day MDRI visited Kulina in July 2007, a child was admitted. According to authorities at Kulina, there was no claim that the child needed institutional services. An economically-strapped single mother had two children: one had a disability and the other was sick. Instead of helping the mother to keep both children at home, the MLSP approved the institutionalization of the child with the disability. The MLSP official explained that “we have a shortage of community support services, so it makes it difficult to implement the moratorium.”

It is impossible to deinstitutionalize without services at the local level. Children with special needs don’t have to be institutionalized but people here have no idea that all children have the same rights. – official, MLSP

While proposed programs over the next 2-3 years are inadequate, the government claims that it will fully implement its reform goals by 2015. In practice, MLSP officials are aware of major obstacles to the implementation of their proposed programs. With the shift toward decentralized authority, the Ministry can no longer impose decisions at the local level. Both local governments and institutional directors and staff have been resistant to the ideas in the national reform plan. Additional financing from local governments is required. Where local governments can apply for funds from the Ministry, “we must still get the municipalities to establish people with disabilities as a priority over other local concerns.”

UNICEF is reported to be supporting community-based “local action plans” in 20 municipalities, and the MLSP is trying to convince other international donors to provide funding and incentives to gain support for new programs at the local level. After years of international donors

supporting building projects for institutions, MLSP officials expressed frustration about the decline in international funding that might provide an opportunity to implement the new reform program.

When MDRI visited institutions, we encountered considerable resistance regarding proposed reforms at the local level. At Veliki Popovac, new buildings are still being built. At the Curug facility, authorities are seeking additional funds to expand the facility. Given the long waiting lists at these facilities, authorities reported feeling the pressure to increase the size of their institutions.

MLSP officials stated that the closure of institutions in the short term is unrealistic. Funds are not available to increase staff at institutions. The MLSP promised that 1 million Euros would be invested to improve “working conditions” and to train existing staff. “At this moment, we see no other possibilities” to improve conditions for people detained in institutions.

Official policy with regard to the Kulina institution reveals the limitations of a policy of candor without a corresponding program of action. MLSP officials admit that the Kulina facility is so abusive there is no way of solving the problems except to close it down. According to Ministry officials in Belgrade, the plan is to reduce the population of Kulina by 20% once community-based services are established in the coming years. As of the summer of 2007, the director of Kulina and the chief nurse indicated that they were unaware of this plan. The chief nurse did indicate that she was aware of an institutional transformation plan. This plan, however, has been on the books for years and has never been implemented.

Authorities in the mental health system reported a parallel set of problems in implementing mental health system reform. At the Kovin psychiatric institution, two new buildings are being built. Staff reported that the capacity of the facility will go up from 600 to 850 beds when the new buildings are complete. The National Mental Health Policy calls for the creation of community-based services. The director of Kovin psychiatric institution reported, however, that there was not yet any funding for the creation of community programs. Under the plan, the psychiatric institutions will be responsible for creating the community programs. At present, Kovin has funds to build two new buildings at the institution. But “[t]he National Plan does not say when we will get the new funds” for community programs. The director of Kovin reported that his most urgent need is for new staff at the facility, as well as a new ambulance. If new funds become available, improving staffing in the facility will be the first priority.

III. Violations of International Human Rights Conventions

The position of inferiority and powerlessness which is typical of patients confined in psychiatric hospitals calls for increased vigilance in reviewing whether the Convention has been complied with.

-Herczegfalvy v. Austria, European Court of Human Rights, para. 82, 15 EHRR 437 (1993).

Serbia's new Constitution, adopted November 2006, establishes that "[g]enerally accepted rules of international law and ratified international treaties shall be an integral part of the legal system in the Republic of Serbia and applied directly."⁴⁰ Under article 1 of the Constitution, the government is:

based on the rule of law and social justice, principles of civil democracy, human and minority rights and freedoms, and commitment to European principles and values.

The Constitution prohibits "[a]ll direct or indirect discrimination based on any grounds" including "mental or physical disability...."⁴¹ The government of Serbia has ratified the European Convention on Human Rights (ECHR), the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic and Social Rights (ICESCR), the Convention on the Rights of the Child (CRC), and the UN Convention Against Torture (CAT)

A. Segregation from society as unlawful discrimination

Throughout the world it is well documented that people with mental disabilities can live dignified lives in the community with full rights of citizenship when programs and supports are available to them and their families. The government of Serbia has freely admitted that the majority of people detained in institutions are improperly committed and would benefit from community care. Serbia's failure to provide support services in the community leaves people with mental disabilities improperly segregated from society. This constitutes a form of unlawful discrimination under the International Covenant on Economic, Social, and Cultural Rights (ICESCR).⁴² The lack of community-based services violates the right to live, work, and receive treatment in the community as recognized by the UN's Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules)⁴³ and other international disability rights norms.

The obligation to protect children against improper segregation is particularly strong. Article 23(3) of the UN Convention on the Rights of the Child promises that children with disabilities have the right to "education, training, health care services, rehabilitation services...in a manner ***conducive to the child's achieving the fullest possible social integration*** and individual development...." Even if its current form plans were fully implemented in the coming years, the government of Serbia is failing to take action that would meet its human rights obligations to the great majority of children with disabilities now placed in the country's institutions.

Article 19 of the new United Nations Convention on the Rights of People with Disabilities (CRPD) recognizes "the equal right of all persons with disabilities to live in the community, with choices equal to others....and their full inclusion and participation in the community..." While the CRPD has not yet entered into force (or been ratified by Serbia), the convention represents a growing worldwide recognition that it is inherently discriminatory to segregate people with disabilities from society who are otherwise capable of living in the community. The MLSP has

declared the CRPD one of the “keys with which we in Serbia are going to unlock the field of equal opportunities for all.”⁴⁴

The United Nations General Assembly has recognized that all people with mental disabilities have “the right to be treated and cared for, as far as possible, in the community in which he or she lives.”⁴⁵ Given the abusive and dangerous conditions MDRI has observed in institutions, there is great urgency for Serbia to begin planning for the full community integration of people with mental disabilities.

The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) clearly states in the CPT standards:

...CPT has found...patients whose mental state no longer required them to be detained in a psychiatric establishment nevertheless remained in such establishments, due to lack of adequate care/accommodation in the outside community. For persons to remain deprived of their liberty as a result of the absence of appropriate external facilities is a highly questionable state of affairs.⁴⁶

The process of detaining a person in an institution in Serbia lacks the legal protections required by international human rights law. As described in part D, below, procedures for declaring a person incompetent and placing him or her under guardianship are particularly flawed. These limitations have been summarized in a report by the Mental Disability Advocacy Center that concludes:

Adults under plenary guardianship are subject to significant, arbitrary, and automatic deprivations of their human rights. These include deprivation of their right to property, to a family life, to marry, to vote, to associate freely, to access courts, and to make a will. Even if not specifically deprived of certain rights, a lack of procedural capacity ensures the inability to enforce them.⁴⁷

B. Threats to health and life

The failure to provide health care in Serbian institutions puts the lives of individuals at risk. Article 12 of the ICESCR establishes “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”⁴⁸ Where health care is inadequate, it puts individuals at life-threatening risks, in violation of article 2 of the ECHR protecting the right to life. The right to health entails a right to “the underlying determinants of health,” including safe living conditions and adequate care for people detained in institutions.⁴⁹

The lack of medical staff at institutions and the failure of institutions to transfer patients to hospitals for somatic health care can be life-threatening. The lack of dental care and oral hygiene is also dangerous. Decay and loss of teeth can create discomfort (in addition to toothaches, loss of teeth may lead to decreased saliva production, muscle spasms, and chronic headaches) and other serious health risks. People who lose their teeth and lack replacements

must eventually limit themselves to soft foods, which may lead to malnutrition and a general decline in health.⁵⁰

It has come to be widely recognized that long-term isolation from societies contributes leads to increased dependency on an institution, results in a decline in social functioning for any person – even for people who could once care for themselves.⁵¹ The damage to health of long-term institutionalization has been documented in many countries.⁵² The threat to the physical and mental health to children is particularly great. Young children raised in congregate facilities experience potentially irreversible psychological deficits as well as developmental delays. This is true even if institutions are well funded, well maintained, and well staffed.⁵³ The concept of progressive realization under the ICESCR recognizes that resources are not limitless, and governments cannot be expected to do more than to make the best of available resources. However, certain elements of the right to health are immediate, including the obligation to guarantee protections against discrimination.⁵⁴ Services systems that improperly segregate people from society constitute one such form of discrimination that violate the right to health.⁵⁵

The failure to provide physical therapy or rehabilitation to individuals with disabilities may result in their remaining in cribs for years at a time. Staffing is so low at Serbian institutions that children or adults left in cribs and beds often get no physical activity or exercise. Many labeled “immobile” never leave their cribs. The lack of any form of activity results in muscle atrophy and puts people at risk of bedsores that is dangerous and life threatening.⁵⁶ Unless a bedridden person shifts body position to reduce pressure “the local pressure continues and skin ulcers develop.”⁵⁷ To avoid bedsores, staff would have to check each person regularly to ensure that they do not remain in the same position for more than two hours, and they would have to make sure that bedridden individuals are kept clean.⁵⁸ Given the lack of staff in Serbian institutions, such attention is impossible. In addition to violating the right to health of individuals left in cribs, the lack of care causes suffering that violations the article 3 prohibition that “[n]o one shall be subjected to torture or to inhuman or degrading treatment or punishment.”⁵⁹

C. Torture, inhuman & degrading treatment

1. Inhuman and degrading treatment

The European Court of Human Rights and other human rights oversight bodies have come to accept that dangerous or degrading conditions of detention in a psychiatric facility or other institution violate article 3 of the ECHR’s guarantee that “[n]o one shall be subjected to torture or to inhuman or degrading treatment or punishment.” The involuntary isolation of children and adults in the grim wards of institutions where they have little or no activity or stimulation and are cut off from society for years at a time, must be considered a violation of ECHR article 3.

Governments are under an immediate obligation to bring to an end any violation of article 3 – be it torture or inhuman or degrading treatment. Article 3 protections are considered so important that they can never be limited (they are “non-derogable”) even in times of national emergency.⁶⁰

The lack of financial resources does not excuse these human rights violations. In its recent summary of international human rights law, the World Health Organization has stated that:

The lack of financial or professional resources is not an excuse for inhuman and degrading treatment. Governments are required to provide adequate funding for basic needs and to protect the user against suffering that can be caused by a lack of food, inadequate clothing, improper staffing at an institution, lack of facilities for basic hygiene, or inadequate provision of an environment that is respectful of individual dignity.⁶¹

The widespread misuse of physical restraints we observed in Serbian institutions – without laws or regulations limiting the time or manner of the practice and without monitoring and oversight to prevent against abuse – is a serious form of inhuman and degrading treatment.⁶² The use of physical restraints can be extremely painful and can cause great emotional suffering. The dangers of physical restraints include a risk of “serious injury or death, retraumatization of people who have a history of trauma, and loss of dignity and other psychological harm.”⁶³ In September 2005, the Council of Europe adopted a recommendation restricting physical restraints and seclusion to cases where it was necessary “to prevent imminent harm...and in proportion to the risks entailed.”⁶⁴ In addition the requirement that all cases of restraint be recorded in the person’s medical records, the “person subject to seclusion or restraint should be regularly monitored.”⁶⁵ The United Nations has specified that the use of physical restraints must not be used except “in accordance with official approved procedures” and “only when it is the only means available to prevent immediate or imminent harm to the patient or others...” Even then, such treatment “shall not be prolonged beyond the period which is strictly necessary for that purpose.”⁶⁶ A person restrained must be kept under “human conditions” and must be under the “care and close and regular supervision of qualified members of the staff.” The United Nations also specified that special oversight requirements must be created to monitor any potential for abuse. Thus, “[a]ll instances of physical restraint or involuntary seclusion, the reasons for them and their nature and extent shall be recorded in the patient’s medical record.” In addition, a “personal representative, if any and if relevant, shall be given prompt notice of any physical restraint or involuntary seclusion of the patient.”

A limitation on the application of article 3 in the medical or social context is the European Court’s doctrine of “medical necessity.”⁶⁷ Where physical restraints are necessary medical treatment, the Court has ruled that their use does not violate the ECHR. The “Court must nevertheless satisfy itself that the medical necessity has been convincingly shown to exist”⁶⁸ using the standards of “psychiatric principles generally accepted at the time.”⁶⁹

In recent years, it has been demonstrated that physical restraints are not a therapeutic necessity – and most restraints can be avoided through increased staff and staff attention, appropriate staff training, and oversight programs to monitor and enforce clear standards.⁷⁰ Indeed, it is increasingly accepted that anything but short-term use of restraints constitutes a “treatment failure” that can and should be avoided through appropriate care.⁷¹ Based on these findings, one research team concluded:

It is difficult to imagine that the use of restraint and seclusion will ever again be viewed as common, necessary mental health interventions. The outrage resulting from the deaths associated with these practices has resulted in critical scrutiny of the practices themselves and of the culture within which they are considered “normal.” We have a substantial understanding of the physical and psychological danger inherent in restraint and seclusion, the false assumptions surrounding the use of these interventions, and the arbitrary manner in which they are often used.⁷²

Developments in standards of psychiatric practice have resulted in increasingly strict legal protections against the use of physical restraints. The international standards on the use of physical restraints adopted by the Council of Europe in 2004 and the United Nations in 1991 clearly indicate the practices in Serbia do not comply with internationally accepted psychiatric standards.

While the UN Convention on the Rights of Persons with Disabilities (CRPD) has not yet entered into force at this writing, the principles it entails represent the evolving standards for medical care and rehabilitation pertaining to people with disabilities. The core principle of the CRPD is that people with disabilities should be guaranteed “[r]espect for inherent dignity, individual autonomy, including the freedom to make one’s own choices.”⁷³ Rehabilitation and habilitation programs shall be designed “to attain and maintain maximum independence, full physical, mental, social, and vocational ability, and full inclusion and participation in all aspects of life.”⁷⁴ All health care services must be designed “to minimize and prevent further disabilities.”⁷⁵ Perhaps most important, the CRPD represents the new understanding that “the existence of a disability shall in no case justify a deprivation of liberty.”⁷⁶ Thus, physical restraints are not a form of treatment but are a temporary measure to be used as a last resort to protect against imminent harm. Restraints cannot be considered a form of medical necessity beyond what has been accepted by United Nations and Council of Europe Standards.

2. Torture

MDRI investigators observed the egregious practice of keeping children and adults with disabilities in a state of permanent, lifetime restraints. While some staff observed that people may be temporarily released from restraints for cleaning or other reasons, they also commented that certain individuals considered “difficult” by the staff are continually tied up again and again. While the short-term use of physical restraints can be extremely painful, the prospect of facing a lifetime largely tied down to a bed is a horrific practice causing mental and physical suffering that no person could be expected to endure without severe psychological damage. Having one’s arms and legs tied to the corners of a bed removes all control of the most basic of bodily functions, including the inability to feed oneself or the elimination of bodily waste. The long-term use of restraints is a serious threat to the physical health and the life of the individual. The World Health Organization (WHO) has singled out “long-term bodily restraint” as “a cruel treatment often leading to muscular atrophy and skeletal deformity.”⁷⁷

The European Court of Human Rights has stated that the distinction between inhuman and degrading treatment and torture – all prohibited by article 3 of the ECHR – “derives principally from a difference in the intensity of the suffering inflicted.”⁷⁸ In determining whether a practice violates article 3 of the ECHR, the court examines “all the circumstances of the case, such as the duration of the treatment, its physical or mental effects, and in some case the sex, age and state of health of the victim, etc.”⁷⁹ Thus, in addition to the “duration” of the treatment, the health, vulnerability, and powerlessness of the victim are all critical factors in determining the impact of a particular practice. The exact same mistreatment may not constitute torture on a strong healthy individual may be obvious torture if applied to “an elderly sick man.”⁸⁰ The Court has stated that “the assessment of whether the treatment or punishment concerned is incompatible with the standards of Article 3 has, in the case of mentally ill person, to take into consideration their vulnerability and their inability, in some cases, to complain coherently or at all about how they are being affected by any particular treatment.”⁸¹

The UN Convention Against Torture specifically prohibits the use of extreme pain for the purpose of “coercion” or “discrimination.”⁸² The adoption of the UN Convention on the Rights of People with Disabilities underscores the fact the international community no longer tolerates discrimination on the basis of disability – nor does it tolerate the deprivation of liberty on the basis of disability. The deprivation of liberty entailed by the long-term use of physical restraints unrestricted by legal protections is extreme and total and would not be tolerated on individuals without disabilities. Relegating a child or adult with a disability to a lifetime of being tied down is torture and should not be tolerated in any society and is deserving of the highest level of international recrimination.

D. Arbitrary detention

One of the most important among a broad array of rights that should be protected in any mental health law is the protection against arbitrary detention in an institution. The European Court of Human Rights has ruled that every detention in a psychiatric facility be reviewed by an independent judicial authority.⁸³ This includes the right to participate in a hearing, in person or through a representative. The procedures for implementing this right have been set forth by the Council of Europe in Recommendation (2004)10. These standards specify that involuntary treatment may only be ordered for “therapeutic purposes”⁸⁴ and where “the person’s condition represents a significant risk of serious harm to his or her health or to other persons.”⁸⁵ People subject to psychiatric detention have a right “to be heard in person or through a personal advocate” at the hearing.⁸⁶ The standards provide that “[w]here the person cannot act for him or herself, the person should have the right to a lawyer and, according to national law, to free legal aid.”⁸⁷ Individuals also have the right to appeal a commitment decision and to review the legality of such commitment at “reasonable intervals.”⁸⁸

Serbia has recently adopted a new law on guardianship, and it is in the process of revising its law on psychiatric commitment. As described below, Serbia’s guardianship law lacks some of the critical protections required by international standards. Even with this new law, authorities at social care facilities report that there has traditionally been no independent judicial review of commitments. Serbia’s laws on psychiatric detention are similarly flawed. The lack of

independent review with appropriate due process protections renders placement in a social care facility a violation of the right to liberty and security of the person under article 5 of the ECHR. This detention process also violates article 14(b) of the CRPD, providing that “the existence of a disability shall in no case justify deprivation of liberty.”

The CRPD provides even more important protections for people subject to guardianship. Instead of depriving individuals of legal capacity, article 12(3) requires them to receive “the support they may require in exercising their legal rights.” No such support is available for people whose legal capacity is called into question – or arbitrarily stripped away – in Serbian institutions.

As a practical matter, the limited protections that exist under Serbian laws are circumvented by the fact that the service system is overwhelmed. In the absence of community-based services, authorities report that they have no choice but to admit people who have no need for institutionalization – except that they have no place else to go.

People are dropped off here by family members who do not want them. There is nothing we can do. We have to take them or they would be living on the streets.

-- Acting Director, Vrsac psychiatric institution

1. Lack of any independent review or oversight

Authorities at some of the institutions we visited, such as Kulina, report that that majority of people detained in the facility have not been ordered there by a court and are not under any form of guardianship. These findings are consistent with those the Mental Disability Advocacy Center (MDAC) based on interviews conducted in 2004-5.⁸⁹ Historically, placement has usually been made at the request of a family member and is approved by authorities at the facility. While new procedures for formal guardianship have been instigated, authorities at Kulina stated that there is no process for reviewing the detention status of individuals already placed in the facility. Once a person is placed at an institution, all major decisions in that person’s life – including decisions about major medical care – can be made by institutional authorities. In theory, a Center for Social Affairs must approve such decisions. As a practical matter, institutions are acting as “guardians” for their residents.

Under European⁹⁰ and United Nations standards, persons may not be deprived of their ability to make choices about themselves – including a decision to be detained in a social care facility – except “after a fair hearing by an independent and impartial tribunal established by domestic law.”⁹¹ The European Court of Human Rights has ruled that independent judicial oversight of all commitments is needed – even for non-protesting patients in social care facilities.⁹² As part of such a review, article 5(1) of the ECHR affords a person subject to commitment with a right to counsel to challenge detention.

2. Inadequate protections in the guardianship process

Serbia has recently adopted new guardianship legislation (though guardianship is still governed by multiple laws, including the Family Act⁹³ and the Non-Litigious Procedures Act⁹⁴). Some

institutions, such as Kragujevac, report that they are retroactively submitting long-term detainees to a guardianship review. Yet the new guardianship laws have serious shortcomings that undermine their due process protections.

The right to legal representation is limited by the fact that court-appointed counsel is under no obligation to represent the views of the person subject to commitment.⁹⁵ The “right to be heard in person” at the hearing, required by European standards,⁹⁶ can be arbitrarily denied where a court determines that such participation is not possible due to the mental or physical condition of the person subject to review.⁹⁷ There is no truly independent professional opinion available to the court because, under Serbian law, this function is served by a guardianship authority (known as Center for Social Affairs and under the authority of local government) which has conflicting roles in the guardianship process.⁹⁸ The guardianship authority can serve as the expert body to the court and as a court-appointed guardian during the review process (a guardian *ad litem*).⁹⁹ Once the court determines that a person shall be submitted to guardianship, the guardianship agency appoints the guardian, monitors actions of the guardian, and is responsible for seeking restoration of legal capacity where guardianship is no longer needed.

3. Lack of due process protections against psychiatric commitment

When patients are agitated, we don't inform them of their rights. When they are calm, we sometimes tell them. - Acting director, Vrsac

The Serbian Helsinki Committee has studied the law and practice of psychiatric commitment in Serbia and has concluded that:

The procedure for patient placement in hospital is not specific and clear, nor does it conform to relevant international norms. The judicial procedure regarding the involuntary placement of patients as well as current judicial practice in general give rise to arbitrary decisions and violations of the right to a fair trial.

Serbia's Health Protection Act and Non-Litigious Procedures Act govern voluntary and involuntary admission to psychiatric hospitals.¹⁰⁰

a. Overly broad standard of commitment

International law permits a person to be detained involuntarily if he or she presents a “serious likelihood of immediate or imminent harm to that person or other persons.”¹⁰¹ Involuntary detention for treatment is permitted for a person “whose judgment is impaired” when the failure to provide that treatment is likely to lead to a “serious deterioration in his or her condition.”¹⁰² Involuntary commitment is permitted for treatment only when treatment is not available in a less restrictive environment.¹⁰³ When the CRPD enters into force, grounds for psychiatric commitment may be much further restricted.¹⁰⁴

Serbian law permits a person to be involuntarily detention based on much broader grounds. Initial commitment is possible based simply on a threat to “property.”¹⁰⁵ Under the Law on Non-

Litigious Procedures, a court may keep a person detained “if the nature of the illness such that the person’s freedom of movement or of communication with the outside world must be restricted.”¹⁰⁶ This standard is extremely vague, not providing the court with any guidance as to when these basic rights must be restricted. The law clearly does not limit psychiatric detention to the exigent circumstances required by international law.

Placement in a medical facility may also take place when a court decides a person is not capable of “thinking rationally” and then decides “to completely or partially deprive that person of the capacity provide for him/herself...”¹⁰⁷ Involuntary detention is permitted for three months in order to assess a person’s “mental condition.”¹⁰⁸ Under European Standards, psychiatric commitment is only permissible for therapeutic purposes and not for evaluation.¹⁰⁹

b. Lack of oversight or independent review

There are many chronic patients who have been here for years...there is no procedure for reviewing their commitment. - acting director, Vrsac

A court is required to be notified about any psychiatric commitment within 48 hours following the date of institutionalization. After up to three months of detention for purposes of evaluation, the court can then order psychiatric commitment for one year.¹¹⁰ The health institution must submit “periodic reports” on the detainees “medical condition” but does not specify when such reports must be submitted or what they are supposed to be reporting.

While a court is required to review each psychiatric commitment, the law does not provide the due process protections to ensure the detainees right to independent review. While the court must obtain the expert opinion of “two relevant specialists,” they may be staff members at the institution where the person is detained. The person subject to detention has no right to participate in the hearing. He or she does not have a true right to counsel to represent his or her views at the hearing. A new law has created a “Protector of the Rights of Patients” at each psychiatric institution, and this person is supposed to help individuals subject to involuntary commitment. In practice, authorities at Vrsac and Kovin both report that the “Protector” or “legal representative” of the patient is not required to represent the views of the patient or even to speak with the patient. At Vrsac, the Protector “makes her own judgment based on discussions with the staff.” At Kovin, the chief nurse informed MDRI that the legal representative “must agree with the doctor.”

At Kovin and Vrsac, MDRI found that any court review at all is usually avoided by authorities by signing in most patients as voluntary. The Helsinki Committee for Human Rights in Serbia has conducted a thorough study of the procedures for detention in psychiatric facilities. As they describe the process at Kovin:

Admission procedure [entails] the following steps: the staff obtains a consent for placement in a psychiatric institution (voluntary consent) by having a patient sign a “statement of voluntary consent for accommodation and treatment;” “statements” are always signed in the presence of two citizens who are not hospital employees, have not brought a patient to the hospital and are

not the persons who had applied for the patient's hospitalization. As a rule, these citizens-witnesses are the hospital's former employees living in the vicinity and are called in whenever necessary."¹¹¹

As described above, the European Court of Human Rights has ruled that voluntary admissions procedures cannot be used to skirt the protections of the Convention. Even in cases of supposed voluntary admission, European human rights law requires independent review of every commitment.

Appendix A – Model Programs



Autism Society of Serbia

11 000 Belgrade * St.Gundulicev venac 40* Phone/Fax: ++381 11 3391051*
Transfer account: **5443-07060181**

The President of the main board of the Society: VESNA PETROVIC, ++381 63 820 55 55
E-mail: AUTISMPR@EUNET.YU

The Secretary of the main board of the Society: NATALIJA LAZIC, ++381 64 184 55 26

When a small group of parents and professionals founded the Autism Society in 1977, there was almost no knowledge of autism in Serbia. Over the last 28 years, the Society has developed into a strong, acknowledged, voluntary organization and achieved many important goals concerning both the status of autistic persons and their families, and in general awareness and comprehension of the problem among parents, professionals and society in whole. Due to the efforts of the Society, the rights of people with autism for specialized education, health care and social security are lawfully regulated and protected.

The Main Board and the Assembly of the Society consists of parents from whole Serbia. One section of the Society is also the Expert group, advisory body, which performs all the activities also on voluntary basis. The Society has its sections in Kragujevac, Niš, Novi Sad, Cacak, Požarevac, Kovacica, Jagodina, Kosovska Mitrovica which perform program activities in local communities.

The Society initiated the establishing of the following institutions:

- With Elementary School “Anton Skala” in Belgrade: two elementary education classes and school class for extended education of autistic individuals (for 20 pupils)
- With Elementary School “ Dušan Dugalic” in Belgrade: three elementary education classes (for 12 pupils)
- With Elementary School in Kovacica: one elementary education class (for 6 pupils)
- With Elementary School “Mara Mandic” in Pancevo: one elementary education class (for 6 pupils)
- Daily Center for children and adolescents with autism “Olga Hadži- Antonovic”, St.Kornelija Stankovica 13, Belgrade (capacity 30 persons)
- Daily Center for children with autism, St.Diljska 12, Belgrade (capacity 35 children)
- Stationary center for people with autism, St.Autoput bb, Bežanijska kosa, Zemun (capacity 47 persons)
- Daily Center for preschool and school children in Kragujevac (capacity 12 pupils)
- Daily Center in Jagodina (capacity 6 children)
- Daily Center in Niš (capacity 6 children)

- Daily Center in Novi Sad (capacity 18 children)
- Daily Center in Požarevac (capacity 6 children)

The Society actively participates in the functioning of these institutions, especially the one for permanent residence, focusing on the realization of lawfully guaranteed rights of autistic persons, as well as on constant improvement of conditions and treatments in these institutions, supervising their proper functioning.

One of the important [activities](#) of the Society is organizing round-tables, seminars and workshops on subjects related to autism for parents and professionals. During the past fifteen years, several cycles of seminars were organized around the country, one especially significant and well-attended was held by Rita Jordan and Glanys Jones, experts for autism from The Birmingham University, Great Britain. Representatives of the Society attended international seminars (Barcelona, Budapest) and visited major institutions for autism (San Diego, Paris)

The Society has successfully realized several projects with help and support of Save the Children organization, I.O.C.C organization and Government.

The main commitment and aim of the [Society](#) is to look after the interests in the broadest sense of individuals with autism and their families, to improve the quality of life of autistic persons by promoting understanding, acceptance and full community inclusion.

To achieve these aims, the [Society](#) is directed to:

- create conditions which will enable an early identification of autism and hence to an early start of treatment
 - determine the exact number of persons with autism in Serbia
 - to include children with autism in regular education system
 - stimulate activities which are aimed at creating education, guidance and care facilities
 - setting up new classes for children with autism within existing schools for learning difficulties
 - the foundation of communities and protected workshops for adolescents and adults
- create regional sections of the Society which will lead to the improvement in the field of diagnosis, increasing awareness of the problem and a general improvement in treatment of people with autism and their families
- the foundation of new regional work shops and permanent residential institutions
- improve current programs and treatments in institutions dealing with autism maintain cooperation with similar associations and humanitarian organizations from abroad
- join international societies for autism
 - encourage colleges of higher education to include the field of autism into their educational programs
 - improve current law regulations concerning autistic persons and their families, especially in the field of health and social protection
 - constantly provide information, promote publications, organize courses, conferences and seminars

The Society is one of the main sources of information on autism. The Society's [Information Centre](#) runs a library consisting of books, publications, tapes and other material. It has also published several brochures and other material on autism.

A new important section of the Society is The Service for helping persons with autism and their families. The Society actively seeks for donations aiming at improving the quality of life for autistic persons both at home and in institutions. It also organizes group summer and winter-holidays partly supported by donators. The Society maintains [contacts](#) with other humanitarian organizations at home and abroad.

CARITAS SERBIA AND MONTENEGRO

Caritas Serbia and Montenegro is a member of the international confederation [Caritas Internationalis](#) with headquarters in Rome. As an institution of the Bishop Confederation, Caritas Serbia and Montenegro has been present in the social-humanitarian field for about 15 years. Mental Health Program in Serbia and Montenegro has developed as a response to the needs of one of the most vulnerable groups in the society: psychiatric patients.

Situation in the beginning of year 2000

During nineties, among the most endangered institutions were definitely psychiatric hospitals. Drastic decrease of resources and staff, difficult social situation brought psychiatric hospitals into difficult state of isolation and turned them into real madhouses. Before the Caritas' intervention, most of the patients in those hospitals lived in degrading conditions without any human dignity. The lack of food, beds, mattresses, bed-clothes, clothes, shoes, hygienic material and medication, lead to the lack of human concern and humanity. There were no Mental Health Centers, or health protection that would be alternatives to hospitalization, which was a practice in treatment of these cases. Caritas professional advisors for psychiatry together with coordinators of local offices began evaluation of the situation in psychiatric hospitals in Serbia.

1. Mental Health Program (2001/02)

Caritas Serbia and Montenegro, as local partner, agreed with the suggested action plan and begins the joint work on solving the key problems:

- Decrease of institutionalized patients through promotion of modern psychiatric service
- Transformation of hospitals into structures exclusively for acute patients or attempt for deinstitutionalization in coordination with time and state resources
- Radical change in approaching the patients: Humanization of madhouses
- Motivation of the employed, training and support of the newly-employed

The first material aiming sensitizing was produced «*Život napolju*» (*Life Outside*). Pilot Project was implemented in Mladenovac – inclusion of children from special classes into mainstream classes.

2. Mental Health Program (2003/04)

Thanks to democratic changes, initiatives undertaken by Caritas, World Health Organization and Stability Pact, sensitizing of society happened with regards to the problems of tolerance and mental health, which resulted with the creation of National Committee on Mental Health within the Ministry of Health, chaired by prof. dr Dušica Lecic-Toševski.

Support for institutional reform was provided through seminars and workshops which were facilitated by dr Paolo Sera in 16 Serbian towns. Directors of the biggest psychiatric hospitals have visited centers in Italy twice, the support was provided for the new law on the rights of the patients with mental disabilities, as well as for the psychiatric system reform. Anti-stigma campaigns were carried on, opened competitions were organized for the posters on the subjects of sensitizing in schools, which culminated with the event «*Ujedinjene boje duše*» (*United Colors of Soul*) where psychiatric patients participated as well. The second movie named “*Hocu kuci*” (*I Want to Go Home*) was produced.

Besides humanization of psychiatric hospitals and improvement of living conditions for patients and promotion of modern psychiatry service, program included activities for sensitizing and promotion of *community based* approach, support of deinstitutionalization process and inclusion of the patients in their social and/or family environment.

3. Mental Health Program (2005/06)

The most important practical outcome of our work was implementation of pilot project: opening of the first Center for Protection of Mental Health, in Niš, in municipality Medijana on October 2, 2005. Center is opened within the frames of Psychiatric Hospital Gornja Toponica in Niš, in cooperation with the Ministry of Health, Stability Pact and Caritas. Center represents an important pilot project which would bring about opening of other similar centers in other towns of Srbija (as it is foreseen in the National Strategy for Protection of Mental Health in Community adopted in January 2007).

In 2005, on TV channel Studio B 13 programs named «*Tolerancija*» (*Tolerance*) were aired.

In June 2006, together with NGO UCODEP, four medical technicians from Mental Health Center in Niš, finished training in Italian Mental Health Centers.

Today

Mental Health Program continues reviewing future required steps needed in the health system, society in order for the work done until now to show the way to a safe future. Major areas of work remain the same as the ones in the previous years:

- Training of the staff in Mental Health Centers which will be opened;
- Monitoring of pilot project Mental Health Center in Niš and its expansion;
- Sensitizing of civil society.

Seminar February 16, 2007

In the Center for Protection of Mental Health «Medijana», Caritas Serbia and Montenegro has organized the seminar «Role of mental health professionals in protection of mental health in the community» together with Specialized Psychiatric Hospital Gornja Toponica and Caritas Italy, while it was sponsored by Ministry of Health, National Committee on Mental Health and World Health Organization. Beside the presentations by the professionals, in seminar were exchanged experiences in the

ADVANCE COPY - NOT FOR RELEASE BEFORE NOVEMBER 14, 2007

field of mental health practices in first place. Ten local and international experts presented in front of about 120 participants.

"Child's Heart"

"Child's Heart" is a humanitarian, non-governmental and non-profit organization which assists people with developmental disabilities since 2001, through implementation of integrative, psycho-social and educational programs. Assistance is based in education of their parents, as well as volunteers who with their work want to contribute to their more qualitative life.

Mission of the organization is to provide professional support to people with developmental disabilities in territory of Serbia and Monte Negro.

Vision of the organization is to eliminate prejudices and integration of these persons into society.

Eight teams function within organization:

- Team for development of programs "School of Life" and "School of Living skills"
- Team for writing and implementing projects
- Team for carrying on daily activities
- Team for logistical and technical support
- Team for cooperation with local sector
- Team for cooperation with media
- Team for education of volunteers and parents
- Team for creation and implementation of development programs with small children

Team that I work in is the **team for development of programs "School of Life" and "School of Living Skills"** where I work as assistant to the coordinator of program. **"School of Life"** stands for a program in which people with developmental disabilities separate from their parents or get out from institutions for a period of seven days, take care of their personal hygiene by themselves, as well as of the hygiene of the environment where they live, they participate in workshops, assist in cooking meals and learn the rules of life in group. Program **"School of Living Skills"** stands for a training program for people with developmental disabilities for independent life through learning of basic living skills, as well as theoretical and practical training of assistants for support of people with developmental disabilities during their independent life. The aim of the program is to provide these people the needed support for independent life, in accordance with their needs, wishes and abilities. My job description includes creation of documentation, monitoring and evaluation of achievements, writing reports about participants, as well as direct work with people with developmental disabilities during seven days long "School of Life" and "School of Living Skills."

Helsinki Committee for Human Rights in Serbia (HCHRS)

Helsinki Committee for Human Rights in Serbia (HCHRS) was established in September 1994. Although the constitutional and legal human rights guarantees in Serbia are in accordance with the internationally accepted standards, the actual state of human rights has been more than disturbing.

Therefore, the Helsinki Committee for Human Rights in Serbia appears as a professional organisation working on the promotion of the idea of the rule of law and protection of human rights.

The Helsinki Committee for Human Rights in Serbia is a full member of the International Helsinki Federation for Human Rights (IHF) seated in Vienna, Austria (www.ihf-hr.org). IHF has consultative status with the United Nations and the Council of Europe.

The IHF is a unique community of human rights NGOs in 37 countries of the OSCE, working together internationally to insist on compliance with human rights standards. Our network of Helsinki committees is dedicated to monitoring all forms of human rights abuse in the OSCE region, mobilising international pressure for local change and supporting the role of civil society in protecting human rights. The IHF's website offers access to news about human rights, press releases and IHF statements, and is also the gateway to all Helsinki Committees and cooperating organisations.

Projects

Among many others Helsinki Committee implements the following projects:

- Legal Aid to Victims of Human Rights Violations
- Return of Refugees ("I want to go home" project)
- National Minorities
- Confidence Building Measures between Albanians and Serbs
- Facing the Truth

Helsinki Charter

Helsinki Committee publishes a monthly magazine in 3000 copies which covers all the issues we work on. It has become a valuable way of communication with different with different groups of population from refugees to minorities and individuals facing legal and other problems.

Reports

HCHRS sensitises domestic public about human rights issues through press releases, reports,

round tables, etc. These human rights issues include minority rights, refugees, free expression, discrimination on all levels, individual human rights, independence of judicial system, conscience objection, etc. The committee has so far produced near hundred reports on the topics.

Helsinki Files and other books

The Committee has published many books about freedom of speech, civic and student protests, Serbian-Albanian dialogue, Kosovo crisis and the legal system of FRY. HCHRS publications include special editions such as Helsinki Files, Chronicles and Testimonies.

Contact

Call us or write to us by e-mail, by postal mail, by fax, or phone (Voice). Your comments and suggestions are welcome and highly appreciated.

Feel free to contact our [webmaster](#) at for issues concerning the HCHRS website.

Our Postal Address is:

Helsinki Committee for Human Rights in Serbia
Rige od Fere 20
11000 Belgrade
Serbia

Call us by phone (voice):

(+381 11) 30 32 408
(+381 11) 26 39 437

E-mail us at biserkos@eunet.yu

People in Need Serbia



People in Need is an international non-profit non-governmental organization established in 1996 and based in the Czech Republic. PIN runs projects both at home, in the Czech Republic and abroad. Since its establishment, PIN has been active in 33 countries. In 2007 PIN is one of the largest NGOs in the new EU member states working in relief and development. PIN is an active partner in Alliance 2015, the Czech Forum for Development Cooperation (FoRS), the European Union Monitoring Center (EUMC), EUROSTEP and Concord. PIN is also implementing partner of the Czech Government, ECHO, Europe Aid, UNHCR, UNICEF, WFP, IOM and many others as well as being registered USAID as an international voluntary organization.

In Serbia PIN has been active in the social services field since 2001, focusing in particular on people with learning disabilities and working towards their inclusion in society. PIN's activities principally concern the introduction of new and alternative social care methods with an overall goal of contributing to a general change in social services. All PIN's activities are in compliance the strategic reforms in social care system of Ministry of Labor, Employment and Social Policy of Republic of Serbia (MoLESP) and therefore PIN's input in this area has been highly valued by MoLESP.

From 2001 – 2004 PIN was mainly providing humanitarian aid to institutions for people with mental disabilities. From 2004 PIN has focused on development programs and has implemented several projects.

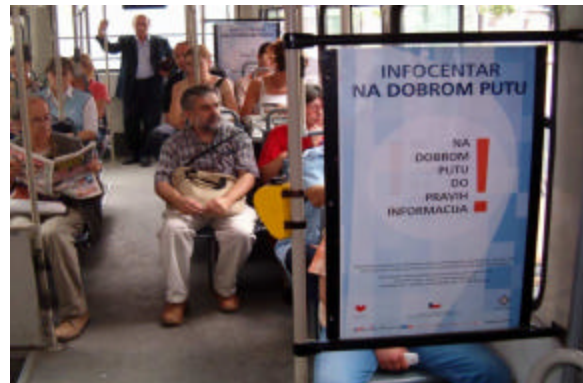
May 2004 – Dec 2006 (finished): *“Supporting Transformation of Institutions and Initiating Changes in the System of Care for the Mentally Disabled in the Republic of Serbia”*, supported by The Ministry of Social Affairs Czech Republic.

The aim of the project was to introduce alternative methods of social care in selected institutions and to initiate changes in the system of the social care in Serbia in general. The project consisted of three parts:

1. training of specialists and employees of residential facilities and organizing educational fellowships for Serbian employees in the Czech Republic in an effort to present new models of work with people with disabilities. Employees of 7 institutions participated in this program.



2. information and consultation centre in Belgrade – the main goals were to raise the general public's awareness towards the situation of people with learning disabilities, to network organizations working in this field, provide information for professionals about modern and alternative methods in social work and support parents of children with disabilities through personal or phone consultations.



3. Sheltered living facilities – 4 houses were bought and renovated in Petrovac na Mlavi and Jabuka which are now being used by (9 Petrovac + 4 Jabuka) people with disabilities and serve as a model of alternative care for people with mental disabilities in Serbia. PIN has continued providing monitoring and evaluation of services in those facilities.



May 2004 – Dec 2006 (finished): *“Support of social inclusion of pre-school age children from socially and culturally disadvantaged environment – Sumadija region”,* supported by The Ministry of Labour and Social Affairs Czech Republic.

The aim of the project is to enable successful inclusion of socially disadvantaged or handicapped children into 5 ordinary kindergartens in Kragujevac. Pre-schools teachers are trained about integration, various kinds of disabilities and social problems and can gain a deeper understanding of those issues during their internships in the kindergartens in the Czech Republic, where integrative education is being offered. Interactive workshops regarding integration are being offered to the parents.



Jan – Dec 2007 (ongoing): *“Education for children with disabilities within a residential institution with a view to their subsequent integration into society in Stamnica institution”,* supported by The Ministry of Foreign Affairs Czech Republic, CIDA.

The project focuses on building cooperation among local social and educational system stakeholders, building the specific capacities of those working in the Stamnica residential facility, designing and implementing an educational program for children within Stamnica and raising public awareness regarding the issues faced by people with disabilities.

Creative and Educational Center for People with Special Needs

KEC MNRO – Creative and Educational Center for People with Special needs is non-governmental non-profit organization, which derived from a several year's long experience in creation and implementation of workshops for people with special needs in Belgrade. KEC MNRO has been established by people of good will, who want to improve the quality of work and education for people with special needs, as well as parents of children with special needs, acknowledged professional, not only from the field of defectology, psychology, pedagogy, but as well as from different fields of medicine, educational staff, artists and theologians.

KEC MNRO believes that all citizens have a talent and strength which they can use in order to contribute to the well being of their narrow and wider community. Therefore the mission of KEC MNRO is to provide support and to develop programs for people with special needs, in order for them, together with their families, to be able to live fulfilling lives.

The goal of KEC MNRO programs is to strengthen self-confidence, increase of the level of independence, communication abilities, awareness of personal value of each user, as well as their wish to be a part of the society they live in.

Objectives and duties of KEC MNRO are:

- Implementation of projects related to the education, creative development and counseling of people with special needs, people with disabilities, children, youth, refugees, displaced persons and members of the socially endangered environments;
- Engagement in implementation of their basic citizen and human rights, with highlight on achievement of communication among the mentioned population, as well as in relation to the same social community with the aim of successful integration.

Information about the work of KEC MNRO so far:

- Providing of humanitarian assistance to the families of people with special needs;
- Organizing of functions on religious and state holidays;
- Distributing gift on New Year, Easter and Christmas;
- Organizing visits to the White Palace on religious holidays with the support of Her Royal Highnesses Crown Princes Katherine Foundation;
- Providing school and teaching material;
- Organizing selling exhibitions of the work-pieces made by people with special needs;
- Working engagement of people with special needs in McDonald's restaurants, with the support of ministry of Labour, Employment and Social Policy;
- Implementation of workshop "Creative educational workshops for people with special needs and their families" in 10 locations in towns, in Societies for Aid for People with Special Needs in five Belgrade central municipalities and in primary schools for children with special needs in

cooperation with Belgrade Municipal Association of Societies for Aid for People with Special Needs, with the support of Her Royal Highnesses Crown Princes Katherine Foundation;

- Organizing seminars, tribunes and cooperation with professionals from abroad in cooperation with the State Association of Societies for Aid for People with Special Needs;
- Implementing the project "Preventive-corrective exercises for people with special needs" in pool, Sport Center Vracar and Tašmajdan;
- Implementing the project "Creative educational center for people with special needs" during 5 years in continuity with 15 regular users, with the support of The American Joint Distribution Committee, through SJSCG, Ministry of Labour and Social Policy and Social Innovation Fund.
- KEC MNRO implements its activities each day from 9 am -3 pm in MZ "Starina Novak," Str. 27 Marta 71 a, Belgrade.

President of KEC MNRO
Margareta Kecman
Mobile 064/1965806

Address: Preševska br. 124 ? 11000 Beograd, Srbija ? Tel/fax: 011/ 38 08 395, 241 51 07
E-mail: kecmnro@eunet.yu ? www.kecmnro.org.yu
Account number: 275 2230785081 106 52 Societe Generale Yugoslav bank

Dear Dragana,

I apologize for not sending the required information earlier, but until September 14, I need to submit two projects for funding, which mean further survival for us.

Information about us are in the attachment, although there are changes, because besides being engaged in working in McDonalds' restaurants and Parking Service, our users are also engaged in working in private businesses. Until now, we have total of 50 persons engaged in working and two employed.

We recommend that the law on professional rehabilitation and employment of people with disabilities is passed as soon as possible. This law would:

- regulate the right of people with disabilities for professional rehabilitation;
- regulate the issues concerning the employment. It is especially important to pass the law which will enable people with disabilities, who receive care from someone else and will help to receive compensation for their working engagement, or which will enable them to establish an employment with monetary compensation, but with the right that after the conclusion of their employment have the right to receive care and assistance from someone else. (Models about this issue exist in neighboring countries).
- Regulate the issues and stimulations for employers who employ people with disabilities

In order to enforce the abovementioned provisions of law, new types of programs should be establish: professional rehabilitation of people with disabilities who have more than 30% working capacity, program of social inclusion or working engagement of people with disabilities who have 30% and less working capacity, program of employment for people with disabilities, than vocational training in working place and program of motivation.

ADVANCE COPY - NOT FOR RELEASE BEFORE NOVEMBER 14, 2007

I hope that we will have further opportunities to exchange experiences and ideas in order to improve the situation of people with disabilities.

Kind greetings from Greta

Organization “Otvoreni krug” (*Open Circle*) from Pancevo

Association of citizens “Otvoreni krug” is an organization of professionals established in 2002 with the aim of providing professional assistance to people from marginalized groups. In order to achieve its goals, association in particular:

1. promotes health, social and psychological protection;
2. provides psycho-social and medical assistance/support to abovementioned individuals and their families in need;
3. promotes modern methods of work which include medication, hygiene-dietetic regimes, physical therapy, psychological help and re-socialization;
4. through assistance, protection and support improves the quality of life of the abovementioned individuals and their families in general;
5. through the rehabilitation program in the community it contributes to the increase of the societies sensibility for the respective individuals and their integration in the broader social environment;

In the past five years we have implemented a large number of projects in the field of protection of people with special needs, Roma, refugees.

The most important projects that we would mention are:

1. Training of the teachers and professors for acceptance of children with special needs in regular schools – program accredited by the Ministry of Health
2. Health and psycho-social support for Roma refugees from Kosovo – Project implemented in five towns in Vojvodina: Pancevo, Vršac, Beocin, Apatin and Sombor, in partnership with Novi Sad Humanitarian Centre (NSHC) from Novi Sad
3. Integration of children with special needs in social community – Save the Children project implemented in all bigger towns of Vojvodina
4. Training of the volunteers for carrying out the program of hipotherapy for children and youth with special needs – project financed by Municipal Assembly of Pancevo
5. Hipotherapy for children and youth with special needs – project is currently being implemented and is being financed by the Ministry for Social Affairs of Republic of Serbia
6. Vocational engagement of people with special needs over 18 years of age, and youth with autism from territory of municipality of Pancevo – Project of the Ministry for Social Affairs of Republic of Serbia
7. Media promotion of the rights of these people through continual existence of the program “I mi smo tu” (*We are here, too*), which has been aired for six years on Radio Pancevo every Wednesday from 5-6 pm alive on frequency 92,1.

Several clips and the documentary "Na krilima Pegaza" (*On the Wings of Pegasus*) were produced and were aired in all major TV channels as well as in most local TV channels.

Members of the organization are: doctors, defectologists, psychologists, psychotherapists, physiotherapists, nutritionists, lawyers, economists, journalists, producers, cameramen, editors, sound designers, organizers, instructors of therapeutic riding, and a large number of volunteers. Besides from the projects, the organization is financed from the donations as well, like: NIS Rafinerija nafte (NIS Oil Refinery), HIP Petrohemija (HIP Petrochemistry), PIK Tamis, etc.

In Pancevo
September 8, 2007

Jovanovic Dobrila, graduated defectologist
President of the organization "Otvoreni krug"

Initiative for Inclusion “VelikiMali”

Initiative VelikiMali started developing programmes for children with disabilities in 1999, but was officially registered on 12th April 2000.

Organization *VelikiMali* provides direct support to children with disabilities, and in the same time influences conditions for quality work with children within official institutions.

All VelikiMali activities are directed at **protection and promotion of rights of children with disabilities** in accordance with **United Nations Convention on the Right of the Child**. The aim of our programmes is forming strong local support services and setting conditions for complete inclusion of people with disabilities in the everyday life of the local communities, and thus realisation of their rights.

Our working methodology is based on *holistic approach* to the needs and rights of a family, *individualised approach* to every service user, *fieldwork* and principle of *complete inclusion* into the life of the local community.

Direct service users of NGO VelikiMali are children with various types and extent of disabilities (autism, cerebral palsy, intellectual disability, vision impairment etc), aged between 3 and 15. Secondary services users are young people, aged 15 to 18 as well as they families.

Throughout our work, we also work with and influence children of wider population, general public, professionals working with children (pedagogues, psychologists, special educators, teachers, social workers etc), and public authorities.

We put strong emphasis on programmes and activities supporting **education of children with disabilities**. In cooperation with Pre-school Institution “Decja radost” in Pancevo, in 2000, we started a programme of **including children with disabilities in regular kindergartens with personal assistance**. So far, more than 40 children passed through this programme, and majority of them is included independently into the mainstream kindergarten group or continued education by attending regular primary schools. In 2005, NGO VelikiMali started with realisation of **first inclusive kindergarten** in the municipality of Pancevo. The aims of this project are: ensuring quality education of every child and ensuring that these types of programmes become part of the Pre-school Institution strategy, which will be supported by the local authorities. We also provide support to children with disabilities attending **mainstream primary schools**, throughout creating individual educational programmes, providing consultation with teacher, pedagogues and psychologists in the schools. We are now supporting about 20 children in **mainstream primary schools** in Pancevo.

In the course of developing educational programmes for children with disabilities, we held about 25 **seminars** for professionals working with children (teachers, pedagogues, psychologists, special educators etc) about characteristics of working with children with disabilities, about personal assistance, inclusive educational system etc

In 2007, VelikiMali started a project named “Specijalized fostery for children with disabilities”. Centre for social work in the municipality of Pancevo has a program of foster families, but the percentage of children with disabilities is very low. From about 60 foster families, 1-2 children have some developmental disabilities. Team responsible for abandoned children expressed their need for further support in developing this program. By implementing this project, we

expect, besides starting foster families for children with disabilities, to provide support to children at risk of institutionalization. In addition, we will continue influencing changes in practice and policy in official institutions.

In the same time as working with children, their families and professionals, we constantly have been organising **public awareness campaigns** and **advocacy activities**, with the aim of promoting rights of children with disabilities and making them more “visible” in the local community. The most important public awareness campaigns are “Different – so what?!” aimed at alleviating prejudices and forming approving public attitude towards children with disabilities, as well as “Quality Education for Everyone”. **Legal service** has been working within the organisation since 2003 in order to support parents and strengthen them for advocating for their children’s rights.

In order to exchange experience in the field of inclusive education and strengthen the influence of the civil society organizations in Serbia, VelikiMali started one, and became a member of several national networks.

- **Network for promoting rights of children with disabilities in Serbia** – national network of NGOs and professionals in Serbia, which are promoting rights of children with disabilities (and other children from marginalised groups) to education and life within the family – developing local services, preventing institutionalisation of children and also building local cooperation and advocating for children’s rights. Within this network, in 2005 we started implementing capacity building seminars for the organisations and institutions in about 15 municipalities in Serbia. The network is coordinated by VelikiMali;
- **Coalition against Discrimination** – national coalition initiated and coordinated by Centre for Advanced Legal studies from Belgrade; the Coalition gathers nine NGOs, which work on advocating for bringing *Equal Treatment Act* in domestic legislation and on informing public about discriminatory practice. In 2005, we started activities within this Coalition. So far, we have been participating in creation of *the Act against discrimination of people with disabilities* (adopted in March 2006), *Proposal of Equal Treatment Act*, and we also contributed to the report “Discrimination in Serbia”, that was published in 2006.
- **Inclusive education - from practice to policy-** Local Inclusive Teams and the Network for Inclusive Education (teachers and educators in kindergartens) in 10 towns in Serbia, which are formed to promote and advocate for implementing inclusive education for children from marginalised groups, coordinated by Fond for Open Society
- **FENS** – Federation of Non-governmental organisations; national network advocating for the adopting of the Civil Society Organizations Law

We also participated in creating of the *Proposal of Act on volunteering*, and changes of *the Act on basics of education*.

In order to have the complete insight into the needs and problems of children with disabilities and their families, and in order to promote their rights more effectively, NGO VelikiMali constantly works on **researching and publishing activities**.

Publications:

- **Legal Guide for Parents of Children with Disabilities** within areas of law, education, health and social protection, 2002 and revised edition 2004 (currently we work on the third edition of the Legal Guide);
- **Be a Volunteer!** – the principles of volunteering, volunteering in VelikiMali, 2003;
- **Comics book “Kitchen – VelikiMali Special Friend”** – promotional comics book, 2003;
- **AntiDefect** – holistic approach to children with disabilities, individual support programmes, inclusion throughout fieldwork by the organisation VelikiMali, 2004;
- **Against Discrimination** – interactive guide through the children’s rights; 2006;

Researches:

- Researching attitudes of primary school and kindergarten teachers towards including children with disabilities in mainstream educational institutions “Different among Peer”, 2002;
- Researching number and type of difficulties in learning that children of lower grades (1st, 2nd, 3rd, 4th) are having in Primary schools; 2004
- Researching attitudes of general public, professionals, and Associations of people with disabilities towards respecting/violating rights of children with disabilities in practice; 2005
- Analysing programmes of major political parties in Serbia and researching their attitudes towards rights of children, education and the Convention on the Right of the Child, 2006;

In 2006, organisation VelikiMali was awarded **special jury’s prize** by the Handicap International **for good practice of community-based services for people with disabilities in South East Europe**.

Down's Syndrome Aid Society

Down's Syndrome Aid Society Serbia implements the project “Deinstitutionalization of people with intellectual disabilities and accommodation in community-based supported living.” Project began in 2004 with the financial support of Open Society Mental Health Initiative, Fund for an Open Society Serbia and Fund for Social Innovations. Project receives professional support from Association for Promoting Inclusion from Zagreb.

In five apartments in Belgrade live 23 persons with intellectual disabilities. They have all moved out from the institution for social care, Sremcica.

In December 2006, Open Society Mental Health Initiative and Ministry for Labor and Social Affairs of Serbia signed a Memorandum of Understanding, in order to replicate the pilot-project, establishment of community-based supported living and other support services in entire country. Non-governmental organization Serbia Association for Promotion of Inclusion was established in 2007, with the goal of promoting social inclusion of people with intellectual disabilities.

Serbia Association for Promotion of Inclusion, together with other non-governmental organizations, and in partnership with Ministry of Labour and Social Policy of Serbia and Mental Health Initiative, work on development of the national program for deinstitutionalization. This project, named “Initiative: Community for All – Serbia,” is a part of governments strategy for reform of social care. Project will make it possible for people with developmental disabilities to live in community with professional support.

Serbia Association for Promotion of Inclusion is expecting a strong support from the Ministry of Labour and Social Policy for all the initiatives from the non-governmental sector, which promote and implement programs that are in accordance with strategic plan for protection of people with disabilities, particularly of people with intellectual disabilities.

Endnotes

- ¹ Ministry of Labour, Employment, and Social Policy, THREE KEYS FOR EQUAL OPPORTUNITIES 92-118 (2007) (publication in English and Serbian with the full text of the International Convention on the Rights of Persons with Disabilities, Strategy for Improving the Position of Persons with Disabilities in the Republic of Serbia and Law on Prevention of Discrimination Against Persons with Disabilities) (herein after Three Keys for Equal Opportunities).
- ² The Social Welfare Development Strategy report states that there are 5,574 people in 17 residential institutions “for persons with cognitive disabilities, mental health issues, and persons with physical disabilities” as well as 7,800 people in homes for elders. This alone adds up to more than 13,000 people – not counting 4,900 children in “institutions and foster families.” Ministry of Labour, Employment, and Social Policy, THE SOCIAL WELFARE DEVELOPMENT STRATEGY 11 (2005) (hereinafter the “Social Welfare Development Strategy”).
- ³ National Committee for Mental Health, Ministry of Health, *National Mental Health Action Plan* 7, July 2006.
- ⁴ Council of Europe, Committee of Ministers, Recommendation (2004)10 of the Committee of Ministers to member states concerning the protection of the human rights and dignity of persons with mental disorder,” article 8, *adopted* 22 September 2004.
- ⁵ *Id.* article 27(1).
- ⁶ *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care*, G.A. Res. 46/199, 46 U.N. GAOR, Supp. No.49, Annex at 188-192, U.N. Doc. A/46/49 (1991) (the “MI Principles”).
- ⁷ Helsinki Committee for Human Rights in Serbia, PEOPLE ON THE MARGINS OF SOCIETY: HUMAN RIGHTS IN PSYCHIATRIC INSTITUTIONS IN SERBIA 10 (September 2006 – March 2007), Helsinki Files #25 (2007).
- ⁸ Gregory L. Hanna, *Stereotypic Movement Disorder and Disorder of Infancy, Childhood, or Adolescence*, in COMPREHENSIVE TEXTBOOK OF PSYCHIATRY/VI 2359, 2364 (Harold I. Kaplan & Benjamin J. Sadock, eds., 1995).
- ⁹ *Id.* at 2360.
- ¹⁰ Council of Europe, Rec. (2004) 10, article 9(1).
- ¹¹ *Id.* article 12(1).
- ¹² MI Principles, principle 8(1).
- ¹³ Social Welfare Development Strategy at 11.
- ¹⁴ Hydrocephalus, Medline Plus Medical Encyclopedia at <http://www.nlm.nih.gov/medlineplus/ency/article/001571.htm>
- ¹⁵ Carolyn Jarvis, PHYSICAL EXAMINATION AND HEALTH ASSESSMENT 405 (1992) (describing the overall threat to health by a lack of oral hygiene).
- ¹⁶ Fred Volkmar, *Reactive Attachment Disorder of Infancy or Early Childhood*, in COMPREHENSIVE TEXTBOOK OF PSYCHIATRY/VI 2354 (Harold I. Kaplan & Benjamin J. Sadock, eds., 1995).
- ¹⁷ MI Principles, principle 9(4).
- ¹⁸ Council of Europe Rec. (2004)10, article 9(1).
- ¹⁹ Social Welfare Development Strategy at 11.
- ²⁰ *Id.*
- ²¹ *Id.*
- ²² National Committee for Mental Health, *supra* note 3, at 8.
- ²³ Social Welfare Development Strategy at 11.
- ²⁴ *Id.*
- ²⁵ *Id.*
- ²⁶ *Id.*
- ²⁷ *Id.* at 5.
- ²⁸ *Id.*
- ²⁹ *Id.*
- ³⁰ *Id.* at 7.
- ³¹ National Committee for Mental Health, Ministry of Health, *National Mental Health Action Plan*, July 2006.
- ³² *Id.* at 9.
- ³³ Ministry of Labour, Three keys for Equal Opportunities, *supra* note 1, at 92-118.
- ³⁴ *Id.* Article 32,
- ³⁵ Ministry of Labour, Social Welfare Development Strategy, *supra* note 2, at 8.
- ³⁶ *Id.* at 9.
- ³⁷ *Id.* at 13.

³⁸ *Id.* at 9.

³⁹ Judith Klein and Dragan Lukic, *Out of the Asylum*, The Guardian, March 1, 2007.

⁴⁰ Constitution of the Republic of Serbia, article 16(2).

⁴¹ *Id.* article 21.

⁴² General Comment No. 5 (1994) on Persons with Disabilities, Rreport on the Tenth and Eleventh Sessions, U.N. ESCOR 1995, Supp. No. 2 at 112, para. 15, U.N. Doc. E/1005/22-E/C.12/1994/20 (1995).

⁴³ United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities, U.N. G.A. Res. 48/96, U.N. GAOR, Annex (1993).

⁴⁴ Ministry of Labour, Employment, and Social Policy, THREE KEYS FOR EQUAL OPPORTUNITIES 7 (2007).

⁴⁵ Principles for the Protection of Persons with Mental Illness, principle 7(1).

⁴⁶ Committee for the Prevention of Torture, CPT STANDARDS (2006), Inf/E (2002) 1 – Rev. 2006.

⁴⁷ Mental Disability Advocacy Center GUARDIANSHIP AND HUMAN RIGHTS IN SERBIA: ANALYSIS OF GUARDIANSHIP LAW AND POLICY 6 (2006).

⁴⁸ ICESCR, article 12.

⁴⁹ Eric Rosenthal and Clarence J. Sundram, “International Human Rights in Mental Health Legislation,” 21 NEW YORK LAW SCHOOL JOURNAL OF INTERNATIONAL AND COMPARATIVE LAW 469,

⁵⁰ Carolyn Jarvis, *supra* note 15, at 405.

⁵¹ World Health Organization, TREATMENT OF MENTAL DISORDERS: A REVIEW OF EFFECTIVENESS 19 (Norman Sartorius, Giovanni de Girolamo, Gavin Andres, G. Allen German, and Leon Eisenberg, eds., 1993).

⁵² *See, e.g.* J. Tsantis *et. al.* *The Leros PIKPA Asylum, Deinstitutionalization and Rehabilitation Project*, 167 BRITISH JOURNAL OF PSYCHIATRY 10 (1995).

⁵³ Deborah A. Frank, Perri E. Klass, Felton Earls & Leon Eisenberg, *Infants and Young Children in Orphanages: One View from Pediatrics and Child Psychiatry* 92 PEDIATRICS 569, 572 (1996); Sandra Kaler & BJ Freeman, Analysis of Environmental Deprivation: Cognitive and Social Development in Romanian Orphans 35 JOURNAL OF CHILD PSYCHOLOGY AND PSYCHIATRY 769 (1994).

⁵⁴ Committee on Economic, Social, and Cultural Rights, International Covenant on Economic, Social and Cultural Rights, General Comment No. 14, U.N. Doc. E/C.12/2000/4 22nd Sess., art. 12 (2000), para. 30.

⁵⁵ Committee on Economic, Social, and Cultural Rights, International Covenant on Economic, Social and Cultural Rights, General Comment No. 5, U.N. Doc. E/1193/22/ 11th Sess., para. 3 (1994).

⁵⁶ Bedsores pose a serious danger to anyone confined to a bed or a wheelchair. People in physical restraints are at particular risk of bedsores. Lillian Sholtis Brunner & Doris Smith Suddarth, THE LIPPINCOTT MANUAL OF NURSING PRACTICE 66 (1982).

⁵⁷ Joseph Agris and Melvin Spira, *Pressure Ulcers: Prevention and Treatment*, in CLINICAL SYMPOSIA ANNUAL 2, 6 (1979).

⁵⁸ *Id.* at 6-7.

⁵⁹ ECHR, article 3. *Tanko v. Finland*, Application 23634/94 (1994), *unreported* (in which the European Commission on Human Rights noted that “...a lack of proper medical care in a case where someone is suffering from a serious illness could in certain circumstances amount to treatment contrary to article 3.”), *as cited in* Keir Starmer, EUROPEAN HUMAN RIGHTS LAW 407 (1999).

⁶⁰ Article 3 of the ECHR provides the same protections as article 7 of the International Covenant on Civil and Political Rights (ICCPR). The UN Human Rights Committee, has stated that, even in situations of public emergency, “no justification or extenuating circumstances may be invoked to excuse a violation of Article 7 for any reasons....” General Comment 20(44), para. 3, in United Nations Office of the High Commissioner on Human Rights, MANUAL ON HUMAN RIGHTS REPORTING (1997) ZHR/PUB 91/1 (REV.1).

⁶¹ World Health Organization, WHO RESOURCE BOOK ON MENTAL HEALTH, HUMAN RIGHTS, AND LEGISLATION 11 (2005) [hereinafter RESOURCE BOOK ON MENTAL HEALTH].

⁶² *See* Rosenthal & Sundram, *supra* note 49 at 512 (examining the use of physical restraints as a form of inhuman and degrading treatment).

⁶³ K. Huckshorn, *Re-designing state mental health policy to prevent the use of seclusion and restraint*. 33 ADMINISTRATION & POLICY IN MENTAL HEALTH. 482 (2006); Alisa B Busch and Miles F Shore, *Seclusion and Restraint: A review of recent literature*, 8 HARVARD REVIEW OF PSYCHIATRY 261 (2000).

⁶⁴ Council of Europe, Rec. (2004)10, *supra* note 4, article 27.

⁶⁵ *Id.* article 27(3)(i).

⁶⁶ MI Principles, Principle 11(11).

⁶⁷ *Herczegfalvy v. Austria*, para. 4, App. No. 10533/83, E. Ct. H.R., Sept. 24 1992 (“[m]easures taken out of therapeutic necessity cannot be regarded as inhuman and degrading treatment”).

⁶⁸ *Id.* para. 82.

⁶⁹ *Id.* at para. 83.

⁷⁰ Gregory M. Smith, *et. al. Special Section on Seclusion & Restraint: Pennsylvania State Hospital System’s Seclusion & Restraint Reduction Program*, 56 PSYCHIATRIC SERVICES 1115 (2005); US Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, ENDING HARM FROM RESTRAINT AND SECLUSION: THE EVOLVING EFFORTS (August 2005). Busch and Shore, *supra* note 63 at 265.

⁷¹ Smith, *supra* note 70, at 1116.

⁷² US Department of Health and Human Services, *supra* note 70. at 21.

⁷³ CRPD, article 3(a).

⁷⁴ *Id.*, article 26(1).

⁷⁵ *Id.*, article 25(b).

⁷⁶ *Id.*, article 14(1)(b).

⁷⁷ WHO, Review of Effectiveness, *supra* note 51 at 349, 365.

⁷⁸ *Ireland v. United Kingdom*, para. 167, App. No. 5310/71, Judgment Ser. A., No. 25, Jan. 18, 1978.

⁷⁹ *Selmouni v. France*, Para. 104, App. No. 25803/984, Judgment E. Ct. H.R., 29 E.H.R.R. 403, July 28, 1999.

⁸⁰ *Ireland v. United Kingdom*, separate opinion of Judge Zeika. “As an example I can refer to the case of an elderly sick man who is exposed to a harsh treatment – after being given several blows and beaten to the floor, he is dragged and kicked on the floor for several hours. I would say without hesitation that the poor man has been tortured. If such treatment is applied on a wrestler or even on a young athlete, I would hesitate a lot to describe it as inhuman and degrading treatment and I might regard it as a mere rough handling.”

⁸¹ *Keenan v. United Kingdom*, para. 112, App. No. 27229/95, Judgment, E. Ct. H.R. Apr. 3, 2001.

⁸² UN Convention Against Torture, article 1.

⁸³ *Winterwerp v. Netherlands*, ECt.HR 6301/72, judgment October 24, 1979. *See* Rosenthal & Sundam, *supra* note 62, at 527 (summarizing international legal protections against arbitrary detention of people with mental disabilities).

⁸⁴ Council of Europe, Council of Ministers, Recommendation (2004)10, article 17(1)(iii).

⁸⁵ *Id.*, article 18(ii).

⁸⁶ *Id.* article 25(1)(ii).

⁸⁷ *Id.* article 25(3).

⁸⁸ *Id.* article 25(1).

⁸⁹ MDAC, *supra* note 47, at 17.

⁹⁰ Council of Europe, Committee of Ministers Recommendation No. R(99) 4 “Principles Concerning the Legal Protection of Incapable Adults,” principle 11.

⁹¹ MI Principles, Principle 1(6).

⁹² *H.L. v. United Kingdom*, ECHR, 45508/99, judgment October 5, 20004.

⁹³ Family Act, Official Gazette RS No. 18/05, articles 126-150, July 1, 2005.

⁹⁴ Non-Contestant Procedure Act, Official Gazette RS, No. 25/82, 48/88, 46/95, articles 31-44.

⁹⁵ *Id.* article 6.

⁹⁶ Council of Europe, Rec. R(99)4, Principle 13.

⁹⁷ Non-Contestant Procedure Act, article 36, paras 1-2.

⁹⁸ *See* discussion in MDAC, *supra* note 47, at 25.

⁹⁹ *Id.*

¹⁰⁰ Health Protection Act, Official Gazette, No. 107/05.

¹⁰¹ MI Principles, Principle 16(1)(a).

¹⁰² *Id.* Principle 16(1)(b).

¹⁰³ *Id.*

¹⁰⁴ Article 12 of the CRPD recognizes that everyone has the right to legal capacity, as well as the right to assistance in asserting that right. This raises question as to whether a person may be institutionalized involuntarily for the purposes of treatment.

¹⁰⁵ Law on Health Care, Official Gazette 107/05, article 44, *as cited in* Serbian Helsinki Committee, *supra* note 7, at 100.

¹⁰⁶ Law on Non-Litigious Proceedings, article 45 (1).

¹⁰⁷ *Id.* article 31(1).

¹⁰⁸ *Id.* article 38(3).

¹⁰⁹ Council of Europe, Rec. (2004)10, article 17(1)(iii).

¹¹⁰ Law on Non-Litigious Proceedings, article 51(1)..

¹¹¹ Helsinki Committee, *supra* note 7, at 32.