

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

#### **Primary authors:**

Laurie Ahern, Associate Director, <a href="mailto:lahern@mdri.org">lahern@mdri.org</a>
Eric Rosenthal, JD, Executive Director, <a href="mailto:erosenthal@mdri.org">erosenthal@mdri.org</a>
Dragana Ciric Milanovic, Director, Serbia office, <a href="mailto:dciric@mdri.org">dciric@mdri.org</a>

#### **Co-authors/research team**

Elizabeth Bauer, MA, MDRI Board James Conroy, Ph.D., Center for Outcome Analysis Karen Green McGowan, RN, specialist in treatment of people with disabilities Dea Pallaska O'Shaughnessy, MDRI Director of European Programs

Full text of this report with photographs available at: www.MDRI.org

#### **Executive Summary**

- 1. 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 lifethreatening. 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 in Serbia's institutions are systematically tormented by being subjected to dangerous and painful "treatment" conditions that are tantamount to torture.
- 2. 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, the majority of 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.

- 3. 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.
- 4. Since the mid-1990s, 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 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."
- 5. For people with disabilities, actual practice violates Serbia's own law and policy on a large scale. The service system discriminates against people with disabilities by stripping away peoples' rights without due process and segregating them from society. 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, the population 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 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

- 6. 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.
- 7. 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

8. 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:**

9. 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 of their life 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

10. 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

11. 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

**12.** 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 abuse. 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. **The long-term use of restraints frequently results in severe levels of pain that constitutes torture**.

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.

13. 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

14. 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

- 15. 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.
- 16. 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

17. **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.

### **Conclusion and Recommendations**

18. Immediate action is needed to end the country's most serious and life-threatening human rights violations. 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 stated goals of community integration. Within institutions, adequate staffing and medical care are essential to end inhuman and degrading treatment and torture. The long-term use of restraints or detention in cribs must be outlawed, and laws should ensure accountability and criminal prosecution for authorities who perpetrate torture. Independent monitoring and oversight should be established to protect against further abuses in institutions.