Hidden Suffering:
Romania’s Segregation and Abuse of Infants and Children with Disabilities

MDRI found this emaciated teenager in an adult psychiatric institution.

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Hidden Suffering:
Romania’s Segregation and Abuse of Infants and Children with Disabilities

A report by
MENTAL DISABILITY RIGHTS INTERNATIONAL

Primary Authors:
Laurie Ahern, Associate Director
Eric Rosenthal, JD, Executive Director, MDRI

Research Team & Co-Authors:
Elizabeth Bauer, MA, Michigan State Board of Education
Robert Levy, JD, Adjunct Professor of Law, Columbia University
Karen Green McGowan, RN, MDRI Advisory Board, expert on complex developmental disabilities
Dr. Robert Okin, MD, Chief of Psychiatry, San Francisco General Hospital

Expert reviewer:
Clarence Sundram, JD, President of MDRI & Special Master,
US District Court, District of Columbia

Contacts in Washington, DC:
Eric Rosenthal   Tel: 202-296-6550, Cell: 202-361-9195, erosenthal@mdri.org
Laurie Ahern     Tel: 202-296-6573, Cell: 202-361-1402, lahern@mdri.org

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Mental Disability Rights International (MDRI) is an advocacy organization dedicated to the human rights and full participation in society of people with mental disabilities worldwide. MDRI documents human rights abuses, supports the development of mental disability rights advocacy, and promotes international awareness and oversight of the rights of people with mental disabilities. MDRI advises governments and non-governmental organizations to plan strategies to bring about effective rights enforcement and service system reform. Drawing on the skills and experience of attorneys, mental health professionals, 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 Prishtina, Kosovo and Istanbul, Turkey. 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: 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 (1993), 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-director of the federally-funded National Empowerment Center. 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 Velásquez, JD, Director, Americas Advocacy Initiative
Dea Pallaska O’Shaughnessy, Coordinator, Eastern European Initiative
Sehnaz Layikel, MDRI representative in Turkey
Zamira Hyseni, Program Associate, Initiative for Inclusion, Kosovo
Isuf Halimi, Program Assistant, Initiative for Inclusion, Kosovo
Myrvete Bajrami, Peer Support Project Coordinator, Initiative for Inclusion, Kosovo
Samia Khan, Development Manager
Adrienne Jones, Office Manager

MDRI Board of Directors

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

Elizabeth Bauer, MA
Michigan State Board of Education

Robert Bernstein, Ph.D.
Bazelon Center for Mental Health Law

Judi Chamberlin
National Empowerment Center

Robert Dinerstein, JD
Washington College of Law, American University

Robert Goldman, JD
Washington College of Law, American University

Leah Harris
National Association for Rights, Protection & Advocacy

Paul Steven Miller, JD
University of Washington School of Law

Leonard Rubenstein, JD
Physicians for Human Rights

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

Patricia Wald, JD
US Court of Appeals, ret.

Alicia Ely Yamin, JD, MPH
Physicians for Human Rights
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Executive Summary

*Hidden Suffering: Romania’s Segregation and Abuse of Infants and Children with Disabilities* is the product of an 18-month investigation by Mental Disability Rights International (MDRI) into the human rights abuses of children with disabilities in Romania. This report documents a broad range of atrocious conditions for children with disabilities inside Romania’s institutions. While Romania has reduced its orphanage population and created foster care placements for many children, the reforms have left behind children with disabilities. This report documents serious human rights violations against children with disabilities in an institution for babies and in adult facilities. As the European Union (EU) readies to announce a date for Romania to join the EU, we urge the EU to insist on immediate action by the government of Romania to end these abuses.

This report finds:

- Children are detained in adult facilities in conditions that are dangerous and life-threatening; some children are kept in permanent restraints (pp 7-12).

  *I have visited institutions in twenty countries around the world. What I witnessed in Braila was the most disturbing horror I have ever seen. These children were close to death.* – MDRI investigator

  Children were tied to cribs, wrapped head to toe in sheets used as full-body restraints, with open wounds and bed sores all over their bodies, malnourished, and near death. We found teenagers so emaciated that they looked like they were 3 or 4 years old. Their spindly arms and legs were twisted into contorted positions from disuse and atrophy. Their eyes were deeply sunken into their skulls, and they stared blankly at us when we entered the room. Ribs and other bones stuck out from their skin, which seemed to sag from their bodies without any extra flesh.

- Romania’s new law 272 that bans placement of babies in institutions does not protect children with “severe disabilities;” despite this law, MDRI found babies with and without disabilities detained in institutions (pp 2-6).

  *I have worked here for twenty years and my heart has turned to stone. I thought it would be better after the revolution, but it is not.* – Nurse in institution for babies

  In February 2006, MDRI found 65 infants – with and without disabilities – in an institution for children in the city of Timisoara. Staffing is so low that the children never leave their cribs. These children are becoming psychologically and developmentally disabled as a result of this placement. Staff informed MDRI investigators that some children, with little or no disability could easily be adopted, but they are stuck in the facility only because they lack identity papers.
Off the public record, it is impossible to say how many more facilities of this kind exist in Romania.

_We do our best, but it is impossible for us to stop the spread of lice and contagious diseases….I give an injection and a baby cries and I have to keep going. There are too many. They become disabled from being here._
– Nurse, hospital for babies in Timisoara

- Children with disabilities are hidden away in adult and medical institutions (pp 7-13); according to UNICEF statistics in 2005, thousands of babies have no identity papers; officially, they do not exist (pp 2-6).

_The medical staffs still encourage the abandonment of children with disabilities._
– Sub-secretary, National Authority of Protection of Children’s Rights

- As part of Romania’s reform, many children with disabilities have merely been moved from large to small institutions. While these facilities are newer and cleaner, they are still inappropriate for children and will contribute to increased disability. Extensive Romanian and international funding has gone into building new institutions, draining scarce resources from the process of creating foster care and other services necessary for the community integration of children with disabilities. According to UNICEF, nearly 200 new “small” institutions have been opened in recent years (pp 13-20);

_As a result of the investigation by the Center for Legal Resources (CLR) and MDRI, and support from UNICEF, the lives of the children detained in Brailas psychiatric facility have been saved from impending death. They have been transferred to two new facilities. While some may be transferred to foster care, the authorities informed MDRI that many of the children will spend their entire lives in institutions._

- Thousands of children with disabilities face life-time segregation from society in extremely abusive and barren institutions (pp 21-24).

_Staff agreed to unwrap several of the children. One girl, who looked to be about 4 or 5 years old, was actually 17 and weighed no more than 25 pounds (about 10 kilos). As the staff removed the restraint, her skin came off with the sheet, leaving a raw open wound beneath it. Another boy looked to be the size of a baby, but was 7 years old. He too, when unwrapped, was wasting away, his legs covered with sores and his fingers chewed and swollen._
– MDRI investigator

- No true, national commitment or planning for community integration of children with disabilities detained in adult facilities and a pervasive lack of information by the government regarding the nature and scope of the problem (pp 23-28).
Our planning process is like a man who wakes up every morning and says he is going to paint his house. But somehow, he keeps talking and the house never gets painted. -- Report to the Intersectorial Committee for Coordination on Mental Health by a representative of the National Authority on Persons with Handicap, February 2006

While the child protection authorities admit that there remain more than 30,000 children in Romania’s institutions, children outside the child protection system are off the public record. Ministry of Health and Child Protection authorities told MDRI that they do not know how many more facilities with conditions like those we found in Braila there might be in the psychiatric system. While health authorities admit that at least 700 infants have never left maternity wards of hospitals, they deny the existence of any other infants in institutions.

Violations of International Human Rights Conventions

The conditions documented in this report constitute violations of the European Convention on Human Rights (ECHR) and the Convention on the Rights of the Child (CRC). The abusive conditions and lack of care constitute “inhuman and degrading treatment” under article 3 of the ECHR. The absence of adequate nutrition, the dangerous use of physical restraints, the lack of hygiene and the exposure to communicable diseases threaten the right to life under article 2 of the ECHR.

As the psychiatric literature reveals, it is not just physical deprivation that can lead to loss of life. Emotional abandonment – resulting in “failure to thrive” – causes both emotional and physical damage to children at a critical time in their development. Even children who receive adequate food in clean institutions become disabled; some children are so emotionally neglected they will not eat – they may become malnourished and die. While some developmental delays can be reversed, the psychological impact of institutionalization may plague a child for a lifetime. Thus, Romania’s newer, cleaner, and smaller institutions constitute a threat to children’s right to life and protection from inhuman and degrading treatment under articles 2 and 3 of the ECHR. Reforms that leave an entire class of children with disabilities behind are thus discriminatory under article 14 of the ECHR.

Law 272, which bans institutionalization of all children under the age of two, allows children with so-called “severe” disabilities to be institutionalized. As applied, the law is discriminatory. The authorities use the law to write off a broad class of children with disabilities who are capable of living in the community.

By leaving children with disabilities behind in “smaller” institutions, Romania’s reform violates a broad array of rights under the UN Convention on the Rights of the Child (CRC). Under the Convention, children “should grow up in a family environment…” to ensure their “full development.” The CRC defines a “child” as “every human being below the age of eighteen years…” Thus, the CRC’s protections apply to all children – including children with so-called “severe disabilities.”
recognizes the right of “a mentally or physically disabled child [to] enjoy a full and
decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child’s active participation in the community.”5 To make this possible, governments must provide the “education, training, health care services, rehabilitation services, preparation for employment… in a manner conducive to the child’s achieving the fullest possible social integration and individual development.…”6 Romania’s community service system, which fails to provide support for “severely disabled” children, does not protect their rights under the CRC. Placement in a small institution is not the “fullest possible” social integration for children with severe disabilities.

The lack of human rights monitoring and oversight in Romania’s institutions and community programs violates CRC article 3(3), which requires governments to “ensure that institutions, services, and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities…” Romania’s failure to register children, provide them with an identity, and acknowledge their existence within institutions violates CRC article 7(1) specifying that “[t]he child shall be registered immediately after birth and shall have the right from birth to a name… and, as far as possible, the right to know and be cared for by his or her parents.”

Conclusions and Recommendations

As Romania prepares to join the European Union, the EU has stated that “care and living conditions of the mentally ill in specialized institutions continue to cause great concern.”7 This report documents the need for urgent attention to protect children in the mental health system. We urge the Romanian government and international funders not to waste additional funding – and precious time in the lives of children – on new forms of institutional care. Small institutions, group homes, and so-called “family-like” settings are no substitute for real families. To avoid future institutionalization for children with disabilities, Romania must dedicate itself to creating true community services for people with disabilities.

While expressing concerns about psychiatric facilities, the EU has concluded that Romania has met its EU accession requirements with regard to children. This is based on the following findings:

New legislation on children’s rights and adoption entered into force in January 2005. This legislation brings Romania in line with the UN Convention on the Rights of the Child and the European Convention on Human Rights and completes the reform of child protection.8

This report disputes these findings and documents serious violations of both human rights conventions. When Romania joins the European Union – in 2007 or in 2008 – these human rights violations become not only the responsibility of the Romanian government – but also of the EU. MDRI calls on the EU to recognize and take a responsible stand against these human rights abuses. EU “structural funding” provided to new member States should be linked to clear and verifiable outcomes on the part of the
Romanian government -- to create community services and end the pervasive human rights abuses against Europe’s newest and most vulnerable citizens.
Preface: Goals and Methods of this Report

*Hidden Suffering: Romania’s Segregation and Abuse of Infants and Children with Disabilities* describes the findings of an 18-month investigation in Romania by Mental Disability Rights International (MDRI) on the human rights of people with mental disabilities (this is a broad term that includes people with a diagnosis of mental illness and people with an intellectual disability such as mental retardation). This work is the product of visits to Romania in February, June and December 2005 and February 2006. Our visits to adult facilities were conducted jointly with the Center for Legal Resources (CLR). MDRI conducted all site visits to children’s institutions and interviews with child protections authorities on our own.

*Hidden Suffering* assesses Romania’s enforcement of international human rights law pertaining to children who reside or receive treatment in children’s facilities, or adult institutions operated by the Ministry of Health or Ministry of Labor. By referring to children in “adult facilities,” we are expressing particular concern about children in institutions outside the authority of the official child protection system.

The goal of this report is to provide the information necessary for a full public understanding and debate about matters of fundamental importance to millions of Romanian individuals with disabilities and their families. It is our hope that this assessment will assist the Romanian government and citizens in promoting the 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, 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 difficult circumstances and would 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.

A number of our sources took risks in speaking out about abuses they observed. Staff expressed fears that they could be punished for talking to us or allowing us to take photographs. To protect them, we have not used the names of our sources in this report. We have provided as much identifying information as we can to explain the perspective and basis for which a source provides information.

At every institution we visited, we attempted to be as thorough as we could in understanding the human rights situation of people living or receiving treatment at the facility. We asked to visit all parts of the institutions. We interviewed institutional authorities, staff, and patients. During each site visit, MDRI teams brought a video camera to record observations. To the extent that we could, we took photographs in each institution. It is our experience that photo and video documentation is tremendously
helpful in corroborating our observations and helping the public to understand the reality of life in an institution. We 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 hundreds of institutions for children and adults in Romania. Our report raises broad human rights concerns based on visits to a small portion of Romania’s institutions. Romania is a large country, and there are inevitably differences in the mental health and social service systems in different regions and within the sites that we visited. There are no doubt valuable programs – as well as serious abuses – that we were not able to include in our report. 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 website at www.MDRI.org.

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

Romania inherited an extensive system of segregated services for children and adults with mental disabilities from the former Ceaușescu regime. Since 1989, there has been extensive international attention and assistance to bring an end to the problem of Romania’s orphanages. Over the last decade, model community-based programs have been established in Romania, demonstrating that children and adults with mental disabilities can live in the community. Romania has created an extensive “maternal assistance program” to provide substitute family (foster) placement for many children once left in orphanages. A family support program has also been created to assist families of children with disabilities.

As of 2006, however, the Romanian National Authority on Child Protection statistics state that there remain more than 31,000 children in institutions under their authority. In addition, 9,000 babies are abandoned each year – a rate of abandonment that has not changed over thirty years. At least 700 abandoned children have never left the maternity wards of hospitals. Most maternity wards do not allow new mothers to stay with their infants while they are in the hospital. Authorities at the National Authority for Children’s Rights told MDRI in 2006 that doctors still encourage parents to give up a child when a baby with a disability is born. UNICEF concludes from a recent study of child abandonment that “[t]he acceptance and perpetuation of such situations constitutes not only a violation of the law, but also an acute lack of understanding of the child’s developmental needs.”

Once a child is abandoned, government action further increases the likelihood that the child will be institutionalized. According to UNICEF, “two-thirds of the children abandoned in maternity wards are transferred at least once to pediatric/recovery wards before any protection measures are taken.” Of the total number of abandoned babies, 64% in maternity wards and 30% in pediatric hospitals have no name or identity papers. Without identity papers, children cannot receive community services – or even receive basic medical care.

MDRI is concerned that the actual number of institutionalized children may be much higher than officially recognized. Our investigation has found children detained outside the child protection system – in psychiatric facilities, institutions for adults with disabilities, and other hospitals. A complex division of responsibilities for these facilities – divided up between the Ministry of Health, the Ministry of Labor, Social Solidarity and Family, as well as local governments – means that no one authority makes policies or can be held accountable for conditions in these institutions. The National

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* MDRI has found that the array of services described by authorities do not always exist in practice. In theory, according to UNICEF, the following services are available: “Children with disabilities receive a state allowance that is twice as high as that for children with no disabilities. In certain circumstances, children with severe disabilities may benefit from a personal assistant employed by the local administration authorities. The child’s parents or legal guardian may choose between receiving compensation equal to the net salary of a beginner state unit social worker or a personal assistant. Furthermore, any person supporting, supervising, or raising a disabled child may benefit from sick-leave to look after the child.” UNICEF, CHILD CARE SYSTEM REFORM IN ROMANIA 19 (2004).
Authority for Persons with Handicap (NAPH) reports to the Ministry of Labor about the facilities under its authority, but here is no system in place for holding anyone accountable for the implementation of standards within this system. In February 2006, the Ministry of Health reported to the Prime Minister’s office that they could not plan for service system reform because they do not know the number of people in psychiatric facilities, why they are there, or what their needs are.\(^\text{17}\)

Out of public view, MDRI has found serious human rights violations in these facilities. Our findings are corroborated in reports published by the Center for Legal Resources and Amnesty International. MDRI is particularly concerned about the abandoned infants and young children who are at an extremely vulnerable time of development and will bear scars from this treatment over a lifetime.

As Romania prepares for accession into the European Union, the EU has stated that “care and living conditions of the mentally ill in specialized institutions continue to cause great concern.”\(^\text{18}\) This report documents the need for urgent attention to children in the mental health system. Thousands of children with mental disabilities face the prospect of a life-time segregated from society in abusive facilities – due largely to the lack of community based services. Our concerns for children, however, are broader than this. We are concerned that many of the stated reforms in Romania – for which the EU has given much credit to Romania – do not protect the basic human rights of children with disabilities. In its 2005 Comprehensive Monitoring Report to Romania, the EU stated:

New legislation on children’ rights and adoption entered into force in January 2005. This legislation brings Romania in line with the UN Convention on the Rights of the Child and the European Convention on Human Rights and completes the reform of child protection.\(^\text{19}\)

This report disputes these EU conclusions as a matter of law and practice. Romania’s new Law 272 bans the placement of infants in institutions but explicitly permits the continued segregation of children with severe disabilities from society. In practice, the lack of community based services and supports for children with disabilities means that almost any child with a disability can be abandoned to an institution. Much of the reform in Romania merely transferred children with disabilities from large to small institutions. According to UNICEF, hundreds of new institutions for up to 50 children have been built. In a three and a half year period, the number of new institutions increased from 123 in December 2000, to 330 in June 2003.\(^\text{20}\) MDRI’s findings indicate that these institutions are still dangerous places, leaving children abandoned and segregated from society.

I. Hidden Babies: Infants in Institutions

In January 2005, Romania’s Law 272, providing for the protection and promotion of the rights of the child, entered into force. Included in this law was the ban of the placement of children two years old and younger in residential institutions.
The placement of the child who has not yet reached the age of 2 years old may only be decided with the extended or substitute family, and it is forbidden to place him or her in a residential service. – Article 60, paragraph 1

However, this law does not extend protection to babies with disabilities.

As an exception to the provision stipulated under paragraph (1), the placement in a residential service of the child who has not yet reached the age of 2 years old may only occur in the case in which the child has a severe disability and is dependent on specialized residential care services. – Article 60, paragraph 2

In each of the site visits described below, MDRI investigators have found a disparate pattern of children and babies being labeled with “severe disabilities.” The phrase apparently can be used whenever it is administratively convenient, and it is often applied to children with little or no disability.

A. Visit to an institution for newborns in Timisoara

In the city of Timisoara, MDRI investigators asked the local child protection authorities about the placement of newborn children with disabilities. At first, they denied the existence of institutions outside their authority. When we asked about infants with severe disabilities, however, they informed us that there might be children in an institution under local health authorities. They did not know how many such children there were, however, or what forms of treatment they received. They were unable to arrange a visit to the facility.

MDRI investigators then visited a ward for newborns in a general hospital. When investigators asked about abandoned babies, nurses said that there was an institution for them several blocks away. At this facility, staff told investigators that the institution housed 62 children from newborn to age two. Investigators counted 65 babies at the facility. The youngest was a three-week old infant. Despite being referred to as the Sectia De Recuperare Nutritional a, or a nutritional recuperation center, staff informed us that most infants abandoned in this facility were not placed there for nutritional reasons.

MDRI learned that most of the babies were permanently abandoned and had resided there since birth. According to the nurse, reasons for abandonment included “abuse, brain injury, heart disease, poverty and premature birth.” None of the children, the nurse reported, had a “severe disability,” other than the disabilities they acquired from being institutionalized.

Some children are here because their parents do not have enough heating fuel. When it gets cold, we have more babies. – Staff, Timisoara baby institution
The facility’s entire staff consisted of one nurse and three caregivers. Each staff member works a twelve hour shift. According to the nurse on duty, there was no specialized medical care available at the institution and they were only able to treat simple ailments such as a cold. During MDRI’s visit, the caregivers were feverishly involved in feeding and changing the babies. Overwhelmed with this task, staff said they could do little else. Under the circumstances, the facility was strikingly clean. Without more staff, however, the children live for years without leaving their cribs. Of 65 children, investigators observed only two children out of their cribs sitting in doughnut-shaped walkers located near the changing station, where staff could keep an eye on them as they changed diapers.

After a while, they just stop crying. – Nurse, Timisoara baby institution

Children who do not receive attention when they cry learn to stop crying. During MDRI’s visit, there was an eerie silence about the facility. Only one baby on the ground floor was crying – staff informed investigators that this child had been placed in the institution the day before. While about one-third of the babies were sleeping, two-thirds were awake but there were no sounds of cooing or babbling, normal developmental sounds of babies that age.

We do our best, but it is impossible for us to stop the spread of lice and contagious diseases...I give an injection and a baby cries and I have to keep going. There are too many. They get disabled from being here. – Nurse, Timisoara baby institution

The facility was organized with the youngest children on the first floor and the older children on the second floor. Walking through the facility, investigators witnessed how the children abandoned in the facility for longer periods had become more disabled the longer they had been in the institution. The older children in the facility, aged 1 to 2 years, were able to sit up in their cribs, but there was no talking or other sounds as would be developmentally appropriate. As investigators entered the rooms with slightly older children, the children were rocking back and forth, with little or no reaction to investigators’ presence in the room. By age two, some of the children were banging their heads. Others were making the rhythmic sounds from dislocated jaws common in children left lying down for extended periods with no opportunity to leave their cribs.

Many of the babies had no identity papers and therefore “do not exist” according to the state, said the nurse, remarking, “Many are Roma.” Staff informed MDRI investigators that some children with little or no disability could easily be adopted, but they are stuck in the facility only because they lack identity papers.

I have worked here for twenty years and my heart has turned to stone. I thought it would be better after the revolution, but it is not. – Nurse, Timisoara baby institution
MDRI was extremely impressed by the staff’s dedication and caring for the children at this facility, despite the impossible job they had of attending to so many children.

B. Findings of other studies

While placement in an institution is dangerous at any age, the risks are particularly great for infants:

Well into the modern era, placement of an infant in an orphanage was tantamount to a death sentence. Mortality rates within foundling homes exceeded 90% during the first year of life into the early 20th century in major European and American cities. Significant improvement was not seen until the 1940’s when mortality rates dropped to 10%...Recent experience reinforces how dangerous orphanage care for infants continues to be even in countries with extensive resources.21

Care France is one organization that has investigated the institutionalization and abandonment of newborns and children in Romania. Their most recent report was based on visits to twelve different facilities in October 2005. The report expressed concern that maternity wards were slowly becoming orphanages and quoted one doctor in a maternity ward as saying that babies there “never leave their cribs.” Additionally, they found “deplorable conditions” in many of the orphanages they visited. This included plumbing that did not function, “boys and girls indistinguishable”; children “crammed in tiny rooms,” and in winter, “not enough heat.” They found some children “reduced to the state of animals.” Care France concludes [MDRI’s translation from the French]:

In the first two years of their lives, abandoned children have no other option than to vegetate in hospitals, which are transformed into orphanages without either the means or the competence [to care for them].

The Care France report also expressed concern about the conditions of children placed in maternal assistance programs “which often function without training or oversight.” In addition, “children are separated at the age of two years to create a place for another baby, and moved to orphanages.” While the EU accession process has created pressure on the Romanian government to reform its service system, they also observe that it creates a corresponding pressure to hide the flaws in the system:

The majority of Romanian leaders, both in Bucharest and in the provinces, are perfectly aware of the senselessness of this situation and are desirous of taking measures to remedy the situation. But none of them dare publicly express their opinion for fear of reprisals from Brussels, which would threaten the process of Romania’s accession to the European Union. – Care France 2005 report

C. Pressures to institutionalize
It is a tragedy for a family when a disabled child is born, because there is nowhere to go for help. – Mother of a child with a disability, Braila

Regarding children with disabilities, we find solutions for them, but not as good as with normal children. Usually they find a family for disabled children, but if they have a mental disability and cannot be placed, they are put in a residential facility….Doctors will decide, depending on how disabled, what will happen and make recommendations. The paralyzed, low IQ and very disabled will be placed in these institutions. – Sub-Secretary of State, National Authority of Protection of Children’s Rights

Officials from the National Authority for Protection of Children’s Rights informed MDRI that Law 272 is intended to ensure that infants are placed in foster or family care settings. But existing programs may not be able to provide for children with “severe disabilities,” especially mental disabilities, so many of these children end up in institutions.

As a practical matter, it is MDRI’s observation that children are classified as “severely disabled” if their needs are greater than the maternal assistance program can provide. Child protection authorities in Timisoara explained that the children are placed in institutions if their needs are “too complex” for the system to handle – no matter how simple these problems may actually be.

The existence of a category of disabled children who may legally be detained in an institution leaves any child at risk of such placement. As described by authorities and family members in Braila, the lack of community services for children with disabilities may be caused by fears on the part of potential maternal assistants about caring for a disabled child. Such fears are apparently not countered by educational programs to teach maternal assistants how to care for these children. In addition, national child protection authorities report to MDRI that this may be due to stigma among parents who do not want to admit to having a child with a disability.

Despite resistance from some parents or maternal assistants, there is evidence that many parents would welcome increased support to allow them to keep disabled children at home. According to statistics from the National Authority for the Protection of Children’s Rights (NAPCR) free phone line, NAPCR received 13,188 calls between November 2001 and June 2005. Of these calls, 42% of the callers requested support in order not to abandon their child, and 20% of the callers were interested in adopting a child.22

Yet pressures to institutionalize children continue to come from the system itself. Some medical and local authorities are resistant to creating the kind of services required to support children with disabilities in the community. National child protection authorities told MDRI that, in some cases, a lack of trained foster parents and interruptions in payments to the foster parents contribute to the problem. For example,
they explained, local authorities unilaterally decided not to implement community support programs for children. The Sub-secretary of State at the National Authority for Children’s Rights told MDRI in February 2006:

*The medical staffs still encourage the abandonment of children with disabilities. Children younger than two cannot be placed in group homes, only with maternal assistants. But children 0-2 years with severe or medium disabilities go to residential centers…and sometimes babies with minor handicaps can be in residential services due to the lack of maternal assistants.* – Sub-secretary, National Authority of Protection of Children’s Rights

II. Dangerous Conditions of Children in Adult Institutions

In February 2006, Romania’s national health authorities flatly denied the existence of children in adult facilities. The State Secretary for Medical Assistance, the chief authority on mental health at the Ministry of Health, vehemently denied the existence of any infants or children under age two in health care institutions – apart from the 700 officially acknowledged children in maternity wards – stating that this was prohibited by law 272. In a limited survey of adult facilities since February 2005, MDRI found children in five institutions outside the child protection system (in addition to the health care facility for infants described above). The following represents a small sample of what exists in countless institutions across Romania.

A. The horrors of Braila: June 2005

*This is like the middle ages. We are ashamed at what is happening here.*

– Psychiatrist on the children’s neuropsychiatric ward, St. Pantelimon Psychiatric Institution

In June 2005, a team of MDRI investigators, along with the Center for Legal Resources (CLR), a Romanian non-governmental organization that monitors psychiatric institutions, documented the abusive conditions of 46 children at the St. Pantelimon adult psychiatric facility in Braila. Several months prior to MDRI’s visit, CLR filed a written complaint with the national child protection agency but received no response.

*I have visited institutions in twenty countries around the world. What I witnessed in Braila was the most disturbing horror I have ever seen. These children were close to death.* – MDRI investigator

MDRI investigators found children between the ages of 7 to 17 in this facility.

*The children were so emaciated many of them looked like they were 3 or 4 years old. Their spindly arms and legs were twisted into contorted positions from disuse and atrophy. Their eyes were deeply sunken into their skulls, and they stared blankly at us when we entered the room. Ribs and other bones stuck out*
from their skin, which seemed to sag from their bodies without any extra flesh. Some children were missing patches of hair, others were bald. – MDRI investigator

A large portion of the children investigators observed were self-abusive.

They were biting down hard on their fingers and forearms, leaving bloody patches or stubs for fingers. One child sat stabbing himself in the eyes during our entire visit. Another ingested a long rope, spat it out, and ingested it again over and over. We observed one child who sat with his entire hand up to his wrist shoved into his mouth. Many of the children sat rhythmically rocking back and forth in their cribs. – MDRI investigator

According to one MDRI investigator, a nurse who is an expert in children with disabilities:

Self-abuse is created and exacerbated among children who receive no love and attention and who are left abandoned to beds or cribs with no attention. Psychological experts agree that they crave some form of stimulus, so they cause themselves pain just to feel something. – Karen Green McGowan, RN – expert on children with disabilities

MDRI investigators interviewed staff who revealed that many of the children never leave their beds or cribs. Those few who were dressed and sitting in chairs never go outside or have any form of activity. We interviewed staff who were completely unaware of any of the common behavioral treatments for self-abuse. They did not know that stimulus, attention or activity would help alleviate the self-abuse.

Instead of giving these children attention, staff tied them down. In the first room investigators visited, children sat staring into space or nearly immobile around a barren table. There were torn strips of cloth on their small chairs. As MDRI investigators waited to get into the room, we wondered whether the staff were cleaning up for the visit. When we asked the staff, they confirmed that these strips of cloth are used to tie the children to chairs.

In the next room, where children were detained in cribs, almost all the children were still restrained. In addition to having their arms and legs tied to the bars of their cribs, some children were wrapped head to toe in bed sheets. When MDRI investigators lifted sheets, we found many children left sitting in their own urine and feces. The stench of human excrement was overpowering.

Some children were tied so tightly in bed sheets investigators could not remove them. As one investigator related,

Staff agreed to unwrap several of the children. One girl, whose name was Adinana, looked to be about four or five years old, but was actually seventeen
and weighed no more than 25 pounds (about 10 kilos). As the staff removed the restraint, her skin came off with the sheet, leaving a raw open wound beneath it. Another boy looked to be the size of a baby, but was seven years old. He too, when unwrapped, was wasting away, his legs covered with sores and his fingers chewed and swollen. – MDRI investigator

Many of the children’s arms and legs were atrophied and twisted into pretzel-like shapes from disuse. Twelve year old Costel, who appeared to be no more than six, lay in a crib with his legs and feet tied up over his head.

After MDRI and CLR brought the dire situation of these children to government attention, the children were moved to two smaller institutions for children. With a grant from UNICEF, CLR brought in Karen Green McGowan, an expert in the treatment of children with complex intellectual disabilities and one of the top clinical nurses from the United States. In addition to her assessment, she developed a habilitation plan for each child. In McGowan’s opinion, none of these children needed to be in an institution for medical reasons. Indeed, each of them need to be outside an institution in a home-like setting with a family who could give them love and attention.

When MDRI returned to Romania in December 2005, all of these children had been moved to two, much improved institutions with considerably more staff attention. In this short time, they had gained a significant amount of weight. Their lives have clearly been saved by this intervention. Yet all of these children remained in institutions. Karen Green McGowan’s recommendations for each child had not even been translated into Romanian. Detailed findings from our follow-up investigation are described in section II of this report.

MDRI’s investigation into the conditions of children in Braila demonstrates the dangers that children face when placed in an adult psychiatric facility – particularly at a young age. Without any official recognition or statistics of the problem of children in psychiatric or other adult institutions, however, it is impossible to say how many other children are living in similar situations today.

B. How many other Brailas?

We don’t really know if there are any more Braila’s. – Sub-Secretary of State, National Authority of Protection of Children’s Rights

Documenting the exact number of institutionalized children with disabilities is nearly impossible because of the massive disarray in the adult disability services system. This system is divided among multiple ministries at the national and local levels (see section IV of this report).

It is the informal policy of the [Romanian] government not to count the number of children with disabilities in institutions. – UNICEF expert, Bucharest

† McGowan is a member of MDRI’s Board of Advisors and is a co-author of this report.
There is also no way to know exactly how many children with disabilities are born in Romania each year. Children with disabilities are not counted in government statistics unless they obtain an official disability certificate from the County Commission for Child Protection. Most often this occurs when a child reaches school age in order to qualify for special schools and services. Consequently, children with disabilities, under the age of 6 or 7 years, are rarely counted. And the many abandoned children, who lack a birth certificate, are also missing from the official disability statistics as they are legally “non-existent.”

1. **Podriga Psychiatric Hospital**

MDRI visited this facility in February 2005 and found 80 residents, with both psychiatric and intellectual disabilities living in this 60-bed adult institution. Although the head nurse described the institution as a place for people with “severe psychiatric illnesses,” there is no independent review showing that detainees were either dangerous or in need of in-patient psychiatric treatment. The director of the hospital is a dermatologist, and a psychiatrist visits once a week.

*Approximately 30 of the 80 residents came from orphanages. It is difficult to find placements for orphans once they turn 18, so the orphanages send children to the psychiatric hospitals by the age of 16.*

-- Director of Podriga

Gabrielle is one of many orphans at Podriga who will likely spend her life alone and isolated, locked away and forgotten behind the walls of yet another institution. MDRI investigators found her in a room with two other women, rocking back and forth. Now 26 years old, Gabrielle had been sent to the adult psychiatric facility from an orphanage at the age of 16. Staff said she had been raped as a child by her father and she was placed in an orphanage to protect her from the abuse. When investigators found her, her arms were lacerated and bruised – a result of self-abuse according to the staff. She receives no counseling or treatment other than medication, and staff report that no one has ever talked to her about her abusive past. Diagnosed with “schizophrenia and mental retardation” staff said “she does not talk.” However, Gabrielle was eager to converse with MDRI investigators.

*We never talk about home, everyone misses home – and for those who came from orphanages, what does home mean to them?* – Head nurse

At the time of MDRI’s visit, the dormitory-style bedrooms at Podriga were extremely cold and many people had no coats or shoes. Some people in slippers and pajamas were shivering in the cold. The temperature at the time was 5 degrees centigrade.

In one room, MDRI investigators found 17 men and women sharing 8 narrow beds pressed end-to-end in a tiny room. They wore old, ragged shirts and pants, and in
some cases with no underwear (despite protests by CLR, whose investigators found these people naked months before). The beds were crammed together. There were no sheets and they shared 5 pillows among them. Investigators were told that the youngest in this room was 20 years old, but he appeared to be much younger. As investigators watched, one resident repeatedly punched another in the face. Staff present did nothing to stop this.

When investigators asked about the safety of detaining men and women in the same room, staff reported that women are given monthly shots of the contraceptive Depo-Provera. The women are told these are vitamins.

Residents spend their day in inactivity, huddled together on benches or sitting in beds. Staff report that except for walking to the dining hall for meals – which is located in a separate building – no one ever goes outside. Everyone in this facility is cut off from the outside world. The head nurse stated that those with guardians might get a visit every couple months, others receive visitors once every “year or two or three – or not at all.”

*We expect that most of the residents will be institutionalized for the rest of their lives.* – Director and head nurse

The director and the head nurse complained that, because many of the residents have no identification papers, they do not qualify for the medical services they need and that Prodriga cannot provide. According to the director, one man who needs a hernia operation will not receive it because he has no identification papers and no pension. He told MDRI he was powerless to help and has no plan to deal with the problem.

2. Sasca Mica Rehabilitation Center

Sasca Mica is a large facility – billed as a rehabilitation center rather than a psychiatric hospital – with some 360 residents living in several buildings on 11 acres, which includes a farm. Relative to other facilities that MDRI visited, this institution was well-staffed, clean and warm, offered activities for the residents and had an abundance of food. However, for the children with mental and physical disabilities living there, it was one of the more horrendous scenes investigators encountered.

In a second-floor room, in one of the buildings on this sprawling campus, investigators found approximately 30 teenagers crammed into cribs, with a few sitting around the room on chairs. Most appeared to have both mental and physical disabilities; staff described them as mostly non-verbal. Many in the cribs had severely atrophied arms and legs – one boy’s legs were turned completely backward.

*I took the covers off one child who was blind. She was not wearing any pants and she was covered in urine. A staff person told me that the children were between 14 and 16 years old but they looked like little kids. These children never get out of the cribs – staff said they urinate and*
defecate in the cribs and the staff is supposed to change the sheets. They even eat in their cribs. – MDRI investigator

In another room, MDRI investigators found a young man chained to his bed with a padlock. A nurse reported to investigators that he was “violent” and “dangerous” and therefore he remained chained every day – all day and night – except for mealtimes. However, he appeared very calm and was smiling at MDRI investigators during our entire visit. Investigators also observed deep wounds around his wrists from the chains.

3. Siret Psychiatric Facility

The Siret orphanage, located on the northern border of Romania, was once one of the largest institutions for children in Romania. When it was closed down, many of the children were transferred to other institutions. MDRI visited a children’s facility in Siret, which is now referred to as an “external ward” of the Siret Adult Psychiatric Hospital. There were 166 residents of this facility, most of whom were teenagers or young adults in their twenties, with some in their thirties.

We were told that they all came from orphanages and many did not seem to be disabled at all. – MDRI investigator

Some of the residents worked outside the facility in the town. One girl told investigators she works at the homes of the staff members while another young man reported “doing some cooking” in the town.

The physical conditions of the facility were dangerously deficient and the residents complained of the cold and lack of heat. There were no sheets or blankets on the beds, and in one room for girls, there were more residents than beds. There was no hot water and the bathrooms smelled of feces and there was no toilet paper or soap. MDRI investigators observed many of the young people missing teeth and of special concern – residents appeared to be afraid of the staff. MDRI found one young teen tied to a chair. Staff confirmed that this boy was tied to the same chair every day. In another part of the room, another boy or young man was left tied to a wheelchair.

4. Voila Psychiatric Hospital

Voila is located deep in the countryside, isolated from the village by miles of winding, hilly roads. The hospital has 430 beds for adults – although there were 460 patients the day we visited – and staff admitted that “we don’t know exactly how many patients there are.” The hospital also has a 100 bed “sanitorium” for children along with a 35 bed unit for children in “severe states.” Children range in age from 1 year to 18 years old and there were 110 children living there when investigators arrived. Children attend a “special school” on the grounds of the hospital and are not in any way integrated with other children in the community. A few who have families in distant locales are allowed to go home on the weekends. However, staff reported many of the children come from orphanages.
The children’s section of the Voila institution is clean, and staff appear to relate well to the children. While the older children can go out of the facility during the day, the younger children never leave the facility and are extremely isolated. Some of the children are transferred temporarily from orphanages to Voila for psychiatric care. Staff told us that this abrupt change in the children’s life can be disturbing and can lead to worsened psychiatric conditions and behavioral difficulties.

III. Dead End Reform: Dangers of “Smaller” Institutions

The experience of the children from Braila demonstrates the limits and dangers of reform in Romania’s child protection system that shifts children with disabilities from large to small institutions. Physical conditions may be improved, but children are denied the essential qualities of close psychological attachment and social integration that they need for their full and safe development. The obstacles to community integration faced by these children also demonstrate some of the inadequacies of Romania’s current community-based services for children.

A. Institutionalized for life – Braila: December 2005

After MDRI and CLR brought the situation of the Braila children to the government’s attention in the summer of 2005, the children detained in the adult psychiatric facility were moved to two other congregate care facilities. The more disabled children were placed in a large converted home (that also houses another institution for children). The children deemed less disabled were moved to an institution that also serves as a day center for other children with disabilities.

MDRI visited the children of Braila in December 2005. The material conditions and staffing were much improved in both new facilities. Children appeared to have gained weight and most physical restraints had been removed. Despite expert recommendations, however, none of the children were moved to family settings. We were told that some of the children would be moved to six-bed group homes, while others would be placed in a new facility that would soon be constructed.

*In my personal view, it is necessary to have a residential program for these children….The county has no rehabilitation services now for children like these.* -- Director of the institutions for the more disabled children of Braila.

*The plan is to keep them here until they are 18 years old. Then they will be transferred to an adult facility.* – Staff at institution for the less disabled children of Braila

Ironically, investigators observed a much warmer atmosphere in the institution for the more disabled children, and caregivers who were more actively engaged with the children. These children had gained a significant amount of weight and were clearly...
responsive. Yet despite this positive attention, staff told investigators that most of these children spend almost the entire day in their cribs. While the increased staff contact had clearly resulted in a decline in self-abuse, the new staff had no specific training to assist these children. Indeed, investigators observed one child still kept in restraints with his hands tied inside his sleeves so he cannot use his hands. Staff reported that the child was permanently restrained because he bites his fingers. The child observed by the investigators in June 2005 rhythmically ingesting and regurgitating a string, still sat in bed for over an hour engaged in this same practice. Staff were unaware of the activities and behavior programs recommended by UNICEF/MDRI that could help combat problems of self-abuse.

While cleaner and much improved over the adult psychiatric hospital, it is difficult or impossible to provide the habilitation and treatment these children need in the confines of the environment investigators observed. There is no contact with the outside world, with adults other than staff, or non-disabled children. There is not even a bathroom. As a result, children cannot be trained or supported to use regular toileting skills. All children in the facility, up to age 17, use diapers.

At the facility for children who were considered less disabled, the limitations in care were even more disturbing. The rooms were clean, but there were no decorations (investigators were told that they only decorate for Christmas). The few toys available were up on a shelf – out of reach of the children. Despite having much lower levels of disability, the great majority of these children also remained in cribs or beds during the entire day.

Staff said that there are no programs to help children who are self-abusive. Investigators observed one child who had just bitten her hand, and the wound was open and bleeding. Up and down her arms, there were scars. Investigators observed other children biting their fingers and banging their heads against the sides of their beds or the walls.

While there is much more staff at this facility than at the psychiatric institution, the limited staff made it impossible to engage most children. Staff informed investigators that there is two staff for every nine children on each shift. These staff are responsible for both the children’s care and for cleaning the facility. There is only one educator for the whole institution.

_I can’t work with all the children because I am overwhelmed._

_Educator at Braila facility for less disabled_

During investigators’ visit, the only children involved in any programs were two non-residential children in the day treatment program. In the physical therapy room, one child was attempting to exercise on an adult-sized bicycle and could not reach the pedals.

Investigators observed that staff did not appear to engage with the children. Some merely watched over children in cribs. Many of these children clearly craved human
attention. At one point, MDRI investigators observed a staff member dragging a child down the hallway by his arm.

I held out my hand to one boy, who grabbed it and hoisted himself out of his bed. While his legs lacked the strength to walk on his own, he was eager to use his arms for support and demonstrated to me that he could walk. Yet there was nowhere to go in this cramped room filled with cribs. He laughed with delight as we walked in a circle around the room five or six times. But when I had to go, he had no choice but to slump back into his bed in inactivity. – MDRI investigator

MDRI investigators asked staff at both new institutions in Braila why the children were not moved directly into foster families. Their responses revealed a great deal about the limitations of current community-based services and about perceptions of children with disabilities among people supposedly charged with their community integration. When investigators asked whether there are any examples in Romania of foster care or substitute family program for children like the more disabled ones from the Braila psychiatric facility, the director said:

No. [Children with severe disabilities are not placed in foster care]…with severe disabilities. With small disability, yes. Just in the last year some [foster care programs] have been set up, but these are only for children with minor disabilities. – Director, Braila facility for more disabled

When investigators asked Braila’s director to explain the level of disability that could be accommodated in current foster care programs, he explained:

…[O]nly children who can go to mainstream school. More disabled kids cannot go to school and cannot be in foster care programs. No maternal assistant has ever applied to take care of kids with this kind of disability. For the next ten years, transitional services will be necessary. But still no maternal assistants will apply to take such kids. – Director, Braila facility for more disabled

…[T]here is nowhere to go [for children with disabilities]. There is a center in Arad for kids with severe disabilities. This is the only good center for kids with a mental disability. But this is very far from here. Parents have to go to Arad to get consultation and training. There is nothing here. -- Mother of a child with a disability, and representative of Trebuie, an NGO made up of parents

The recent experience of the Braila children illustrates how terminology and labels are used inconsistently and for the administrative convenience of staff. When investigators visited the children at the psychiatric facility in June 2005, they were all described as “severely” disabled. When the children had to be split into two institutions,
they were divided into two categories of “more” and “less” disabled. Yet at both facilities children were referred to as “severely disabled.” At the facility for the “less disabled” staff informed MDRI that all the children “have an IQ between 5 and 10. The maximum IQ here is 15.” This diagnosis – which would place these children among the smallest minority of the most profoundly disabled – is obviously incorrect and demonstrates a lack of knowledge of diagnostic categories. Yet more importantly, this devaluation of the children accompanies an expectation that the children have no ability for habilitation. Such attitudes also communicate hopelessness and undermine the ability of the staff to help the children with what skills they might develop.

The expectation of staff at Braila contrasts starkly with the assessment by Karen Green McGowan. Her assessment, performed on all of the children from the Braila psychiatric facility in August 2005, found numerous potential strengths among these children. The assessment found that the children were most in need of attention, food, a chance to walk and move rather than constant confinement to cribs. Perhaps most of all, these children need human contact and stimulation. The expert recommended that all of the children need, and would thrive, in a home-like environment.

A group of Romanian advocacy groups, led by CLR, has dedicated great efforts to bring attention and assistance to the children of Braila. As a result of their efforts, authorities have recently promised to assist some of the children in finding homes with families through Romania’s maternal assistance program.

B. False Integration

Romania’s reform has shifted children throughout the country from larger institutions to smaller institutions. While some children are moved out of orphanages and into “maternal assistance programs” in a family, the children left behind are likely to be children with disabilities.

MDRI met with the executive director of the local child protection authority in Timisoara in February 2006 and one of her associates. They described that there were once a number of large orphanages in the area of Timisoara, including a very abusive facility called Lugos, as well as Recas and Gavosdia. These facilities were in the process of being downsized or closed as children were moved back to their natural families, extended families, or into maternal assistance programs. In theory, the maternal assistance program is supposed to help children with disabilities. We were told that “rehabilitation, parent education, a day center, and respite care” are available. There is also special training for children in the maternal assistance network to assist caretakers for children with disabilities.

In practice, however, child protection authorities explained that children with “severe disabilities” remain in institutions. These institutions, however, are “small” facilities, usually with fewer than 50 children. Investigators were told that considerable funds were used to rehabilitate a building in the center of Timisoara so that children
could be integrated into the community. The Timisoara child protection authorities invited MDRI investigators to visit this new institution.

Upon our visit, we found an institution housing 25 children. According to the child protection authorities, all of the children in this facility have mental or physical disabilities. When investigators asked why these children are in the facility rather than in foster families, child protection authorities responded that the children have “severe disabilities.” While they said that it is possible to place some infants with disabilities with foster families, these children (aged 6 to 16) are no longer infants so they are “too old” to be placed in foster families. In their experience, they said, foster families will not take children with disabilities who are no longer infants. When asked to define what constitutes a “severe disability” that would prevent community integration, the authorities stated that the children in the facility are either physically paralyzed, cannot eat, or are not toilet trained. Some need “specialized complex services” not available in the community. While it is up to doctors as part of a special commission to evaluate each child, the child will be placed in an institution if community services are not available to meet his or her needs.

When investigators visited the institution in late afternoon, we found that the facility was indeed new and clean. But the situation was otherwise very different from what we were told by the child protection authorities. While the building is technically in the center of the city, it is located within a walled compound with a number of different hospital buildings on the campus. Children had no actual contact with the community. Children were younger than reported by the child protection officials (the age range 3 to 14 rather than 6 to 16), making it hard to understand how they could be “too old” for placement in foster families. The children were also far less disabled than officially reported. Staff told us that some but not all the children have “severe” disabilities. Many of the children had been institutionalized their entire lives. According to staff, however, some have little or no disability except what has been caused by lifelong institutionalization. Many of the children interacted with us during our visit, some effusively hugging us and calling us mommy or daddy. Some children came up to investigators, greeted us, and asked us questions. Others waved to us from the windows. Some children, staff said, have only mobility impairments. Investigators observed one boy using a wheelchair. Despite their physical disabilities, staff said none of the children were “paralyzed.”

The most striking fact of life in the facility was that many of the children sat motionless on the floor. One toddler was lying on the floor sitting on a beanbag chair. In the day room on the ground floor, 14 or 15 children were sitting on the floor in near total inactivity. As in some of the worst facilities, toys in this room were all on a shelf, out of reach of the children.

‡ The inability to distinguish between a stranger and a family member is a common symptom of attachment disorder, one of the most common and potentially damaging impacts of growing up in a congregate setting. Attachment disorder is common among children adopted from orphanages and, while it can be serious, it not a reason why children should remain institutionalized.
In one room, two children, aged 14 at 15, were sitting in child seats. These children were playing with toy dolls, but they seemed unable to move out of their seats. The seats were inappropriate for them and did not provide the kind of support they needed to engage in their game or with each other. In another room, six children were playing with toys. No children were actively involved in educational activities. One girl asked the investigators to use a pen and she drew a picture of two people (she was overjoyed about being allowed to keep the pen as there did not appear to be any other pens or markers to draw with). The weather was sunny and pleasant, but not one of the children was outside playing.

Staff report that there are one part time and two full time physical therapists and two psychologists on staff. Staff report that self-abuse is a big problem among the children. Despite the existence of psychologists, however, ward staff said that there were no programs to respond to the problems of self-abuse. There is also no program to teach toilet training skills.

The reasons these children were not integrated into the community – according to the chief of the child protection authority – included a lack of toileting skills. Yet there was no effort to teach this skill to children. As at Brailia, the diminished expectations of staff for the children could easily be self-fulfilling. While this newly refurbished building appeared cleaner than the larger, older facilities, as it ages the new institution may also decay and look like the older buildings. But most important, the critical needs of these children are not being met. There are no consistent care-givers in their lives. They are growing up without a family and without people with whom they can form emotional attachment. Their lives are ordered by the rhythms of the institution.

In institutional settings – whether 200 children or 25 children – children are completely segregated from the community and denied any semblance of a normal, socially integrated life. Group activities are established for the convenience of the staff rather than the choices and needs of the children. Meals, bedtimes, wake-up times, bath times and other activities of daily living are scheduled to accommodate staffing regimes and not the individual choices or needs of the specific children. The children in the small institution in the center of Timisoara will likely become more developmentally delayed over time.

The gaps for people with disabilities in community programs in Timisoara are striking, given the fact that the city is fortunate to be served by Pentru Voi, a highly regarded, internationally funded non-governmental organization (NGO). Pentru Voi provides some the best community programs for adults with mental disabilities in the country. Investigators had the opportunity to visit a Roma family in the community with two children with disabilities, one of whom participates in Pentru Voi’s day programs. The mother and father were present, along with three of four daughters and a son. There was also a small child in a crib being cared for by the mother. The father works outside the home, while the mother takes care of the baby and the two children with disabilities.
One daughter, age 23, has a developmental disability and was not allowed to go to school because of her disability. She was diagnosed with “encephalopathy and a provocative personality” and was given an IQ of 35 (a very severe disability) by the Commission for Persons with Disabilities, according to paperwork her mother showed investigators.

_She said to me in English, “My name is E” and that her favorite television show was “Tom and Jerry” – a cartoon._ - MDRI investigator

E’s command of English and her interaction with investigators made it clear that the assessment of an extremely low IQ (which would be a severe disability) was inaccurate. Her mother said that her daughter is very fortunate to be able to hold a job and participate in activities operated by Pentru Voi.

E’s brother, aged 20, is not so lucky. He is not toilet trained and exhibited aggressive behaviors that were controlled during investigators’ visit by his father. The son stayed, for the most part, on the bed in the room pulling covers over his head and body. Pentru Voi has offered day services to this boy, but he is unable to take advantage of them because he has no assistance in getting to the program. His mother, engaged in helping her other daughter with a disability, cannot get him up and dressed in time to ride with his sister. Because of her son’s disability, the mother receives cash payments from the government to serve as his personal assistant. Yet the family reports that the payment is not nearly enough to cover expenses. While a social worker from Pentru Voi visits the family regularly, the city of Timisoara has no program to help the family take advantage of a rich opportunity being offered by an internationally funded NGO. As a result, he is isolated and remains at home all day in total inactivity.

C. Harmful effects of “smaller” institutions

As described above, in recent years the reform of Romania’s child protection system has included the establishment of 200 new institutions with 50 children or less. As site visits to the facility in Timisoara demonstrate, smaller institutions may retain many or all of the harmful characteristics of larger facilities.

There is a parallel process that explains the apparent decline in numbers of large adult facilities. At a meeting of the Intersectorial Committee for Coordination in Mental Health in February 2006, this process of re-classifying patients into smaller institutions – without actually moving them --- was confirmed by a representative of the National Authority for Persons with Handicap (NAPH). He justified the value of the practice and defended the importance of smaller administrative units, even if the same number of patients shared a building. At least, he said, the smaller facilities would have two directors rather than one, and this would facilitate more effective administration.

Throughout Romania, children have been shuffled from one institution to another. While smaller institutions may appear to be an improvement, they do not provide the family-like environment that a child needs and deserves. Twenty, thirty or fifty children
living together in a congregate setting will be denied the close emotional ties that are established in a true family setting.

Over the last 50 years, researchers have documented the damaging consequences of placing children in institutions. When infants are placed in institutions, there is a significant risk of death from diarrhea and other contagious diseases. While dangers are particularly great during infancy, children placed at an older age are also vulnerable. These dangers include cognitive problems, severe emotional and behavioral disorders, a syndrome that mimics autism, sensory integration issues, speech and language delays, serious medical problems, and deficiencies in physical growth. While it is hard to document, children in institutions in any country are likely at a higher risk of physical and sexual abuse than other children. Clinicians working in US institutions in the 1960s observed a high rate of death among newly placed infants. Children born with a disability, who need specialized care, are even more at risk when placed in an institution.

Children placed in institutions under the age of four are particularly vulnerable to psychological impairments. While children adopted from institutions may recover from many of the developmental delays caused by institutionalization, the psychological damage caused by institutionalization is likely to last a lifetime.

The harmful emotional effects of growing up in an institution are linked with the child’s need for close emotional attachments to a consistent care-giver. Thus, placement in a small institution may cause the same psychological damage as placement in a large facility. Even placement in a group home can be similarly detrimental if staffing is not consistent and emotional bonds cannot be maintained over time. One researcher reviewing the research literature concludes:

> Current studies do add an exclamation point to the concept that nothing replaces a family or at least a consistent, devoted caregiver in promoting normal development in early childhood. Though institutionalization of children…is clearly a tragedy, it is happening at a time when neuroscientists are devoting considerable attention to how early life experiences effect brain development….The knowledge forthcoming may…assist in the effort to permanently end institutional care for infants and young children worldwide.

Recently, the Bucharest Early Intervention Project (BEIP), a five year research investigation on the effects of institutionalization on children two years and under, released some of its findings. Dr. Dana Johnson, an expert on institutionalized children and adoption and a consultant to the project was quoted in a February 2006 BBC interview:

> I think putting a child in a long-term institution is an act of abuse…The conclusions [from the Bucharest Early Intervention Project] 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.– Dr. Dana Johnson

IV: Prospects for a Lifetime: Adult Institutions

A. Frightening prospects for the future

Teodora is my 24 year-old daughter. If I get sick, there is no help for my daughter. My daughter would get no protection. She might be placed in a 120 bed facility or a psychiatric hospital….She would lose all the abilities she has gained in the last 20 years. I’ve taught her to feed herself and use the toilet. She dresses herself. She would lose all this in an institution. – Representative of parents NGO, Braila

My son was troublesome, so they kicked him out of school. So I had to keep him at home. Only children with minor disabilities can go to school. This organization [Pentru Voi], was the answer to my prayers. From total isolation, my son now has a place to go and never wants to be at home….But when I get too old to take care of him]…there is nothing but the sanitarium. – Father of a child with disability, Timisoara

There are a few group homes in Romania run by NGO’s with international support, but our children are too disabled for them. – Mother of a child with a disability, Timisoara

Thousands of children with disabilities live in the community with their parents. These children are clearly much better off than children who grow up in institutions. Yet they, and their parents, live in fear for the day when the parents will no longer be able to take care of them. Until the government creates a broad array of community-based services for adults with disabilities, children with disabilities, even those at home with families, face the prospect of a lifetime in an institution.

B. Young Adults in Institutions

After growing up in an institution, children with mental disabilities may be transferred to adult facilities. The Prahova Center for Recovery and Rehabilitation for Persons with Handicap is one example of an adult institution, visited by MDRI in December 2005, that demonstrates the inhumane and degrading treatment facing children and adults detain in long-term adult institutions. We found several young adults with disabilities in this facility. Staff did not seem to know how long they had lived at the facility other than to say “a long time.” The human rights violations we observed in this facility were serious for patients of all ages.
MDRI investigators visited this facility on a bitterly cold and snowy day in December 2005. Investigators were asked to wait outside the locked iron gate of the institution as the guard secured permission from the director, as the visit was unannounced.

*As we entered the grounds, the staff dragged patients from one building into another for group showers. The female staff stripped the men naked as they waited in line, shivering. Staff piled the filthy clothing into a big pile. We could smell the stench of feces when they opened the door. – MDRI investigator*

According to staff, 260 patients reside at this institution and “most” have been there twenty to thirty years. As investigators walked the grounds, “security guards” were very hostile and pushed and grabbed several MDRI investigators as they attempted to make their way to what was referred to as the “agitated” ward. As investigators entered this unit, there was an overpowering smell of feces mixed with ammonia and the floors were streaked with feces – an obvious attempt to mop the floors before MDRI investigators were let in.

There were 74 people living in this unit, according to staff. Investigators were shown the “isolation room” where 13 beds were crammed together filled with men of all ages. Glass from the windows had all been broken. Snow and an icy wind blew through the barred, open windows into the room as the patients shivered under paper-thin blankets. There was a wood stove in the room but no fire was burning and a bucket on the floor served as a toilet. Staff stated that most of the men stayed in the room all of the time and are put there if they “try to escape” the facility. The door is locked at night. None of the men had any shoes and they complained that they are taken away “to keep them from going outside.” Staff referred to one young man, who was 27 years old and had been in the isolation room for six years, as “the monkey” because he continually climbed the bars on the windows, in an effort to escape. Staff did not know how long he had been in the institution. Another man, who said he was 52 years old and had been on the unit for 13 years and had been put in the room several weeks earlier, sobbed as he begged MDRI investigators to help him get out of the facility.

Across the hall, MDRI found a small room with eight men and only four beds. Several of the men had physical disabilities and were unable to get out of their beds without assistance. Two young men with cerebral palsy, who appeared to be in their twenties shared a single bed, one head at each end, with their twisted and atrophied legs meeting in the middle.

*He grabbed my hand so hard I thought it would break. He made some noises and looked at me, but he could not speak. But he kept pointing to the sheet. I lifted it up and saw what it was he wanted me to see – the two men were covered in blood and feces – MDRI investigator*
The man in the next bed, who was paralyzed himself but had no mental disability, told investigators that they are never taken out of their beds, even at mealtime. He also stated that he had spent his entire life in institutions.

Given the horrendous living conditions at Prahova, MDRI investigators were particularly concerned that children with disabilities living there would have faced a high risk of illness and death. However, before we were able to obtain any additional information on the ages and deaths of former patients, the director of the facility had us involuntarily escorted out of the institution.

C. No national priority for reform

*I cannot say that this is a national priority.* – Advisor to the Prime Minister of Romania, at a meeting of the Intersectorial Committee for Coordination on Mental Health

In February 2006, at a meeting with MDRI, the State Secretary for Medical Assistance (the chief Ministry of Health official in charge of mental health, hereafter referred to as the “State Secretary”) said:

*It is not clear how many patients there are with disability in psychiatric hospitals. We do not know why or on which basis people are kept in different institutions. There are people with disabilities and without disabilities in institutions…patients’ rights are not well known, even by the doctors…All institutions are over-crowded. We have many people with social needs who were transferred from orphanages and placement centers.* – State Secretary

The report of the Council of Europe Commissioner for Human Rights says “Looking ahead to 2007, it is proposed to undertake a full review of mental health services, to develop outpatient psychiatric services in every county, to draw up an action plan to implement mental health policies, and to involve the local authorities in the operation of the institutions.”

The Ministry of Health made a similar promise to conduct a full review of mental health services on May 19, 2004 – in a plan that included timetables for reform. Those deadlines have since come and gone. The Ministry of Health has recently promised that there are $3 million Euros allocated to community mental health day programs throughout the country. The so-called new community programs, however, are not new and they are not in the community. The State Secretary explained to MDRI that the plan is to re-name 51 medical laboratories that provide outpatient services in hospitals to “mental health centers.”

When MDRI interviewed the State Secretary, investigators asked him whether there were any plans to help any patients now living in institutions to return to the community. The official said that there are none. Other than day programs to be established at the mental health laboratories, which will only serve people already living
with family in the community, the State Secretary confirmed that there are no plans and
no funding to create any new community-based services for people now living in
institutions. If a person does not have a relative in the community ready to take him in,
the State Secretary confirmed that the patient will not be able to leave a psychiatric
institution.

As Ministry of Health authorities described to MDRI, plans to decentralize
institutions will create serious dangers to people in these programs. So-called “external
wards” of psychiatric facilities now under Ministry of Health authorities are to be turned
over to local control. But there will be no corresponding shift in funding for these
programs. Thus, local governments will inherit new patients without necessarily having
any additional budget to care for them.

Reform of the service system for people with mental and physical disabilities is
complicated by the arbitrary division of authority between Ministries and between
national and local governments for the hundreds of institutions where people with
disabilities are detained. A recent example demonstrates this problem. In 2005, MDRI learned that the
government of Romania requested a major loan from the World Bank to reform the
system of institutions for thousands of people with disabilities in Romania. The partner
for this loan is the National Authority for People with Disabilities, under the authority of
the Ministry of Labor, that is responsible for operation and oversight of hundreds of
psychiatric institutions in Romania. The Ministry of Health, which also operates
hundreds of institutions, is entirely left out of the planning process. As of February 2006,
the Ministry of Health was unaware of plans for this World Bank loan.

On February 28, 2006, MDRI attended a meeting between the Intersectorial
Committee for Coordination in Mental Health and a senior advisor to the Prime Minister.
The Ministry of Health submitted a memorandum setting forth a broad range of activities
it proposed to undertake in the coming months. Despite the array of activities, the memo
lacked details and did not constitute even the beginnings of a plan for reforming the
service system. The State Secretary said that the government lacks data on the number of
patients in the system, the types of service they are now receiving, or their needs. The
Ministry of Health announced that it would create a National Mental Health Center to
study the problem. When the Prime Minister’s advisor asked how long it would take to
develop a plan for reform, the State Secretary said: “this will take a lot of time.” In
response to the Ministry of Health report, the advisor to the Prime Minister of Romania
expressed frustration with the pace of reforms. The advisor stated:

It is easy to say you need money. But I do not have any document that
says what you need. Tell me we have 100 hospitals with 100 toilets. We
need 100 new toilets with seats. Until I can go to the government with

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specific needs, I cannot ask for money. I cannot say that this is a national priority.

The State Secretary said at this meeting:

_I don’t know how much money I need to run the Romanian mental health system._

The representative of the National Authority for Persons with Handicap described the reform process:

_Our planning process is like a man who wakes up every morning and says he is going to paint his house. But somehow, he keeps talking and the house never gets painted._

While the government of Romania has stated its commitment to reform of the adult mental health system, there is little action to match these words. Ironically, there are numerous plans for reform created by international experts. The problem is not a lack of plans – but the lack of a political will to implement real change.

V. Legal Protections and Human Rights Oversight

In 2004, the Center for Legal Resources and Amnesty International documented that more than 100 people died of exposure in the Poiane Mare psychiatric facility in 2003, and seventeen people died in the facility in February 2004. To date, no one has been held accountable, and the Romanian government still insists that people died of natural causes or “deficiencies of an administrative nature.” These so-called “administrative deficiencies” included “lack of heating in the patients’ rooms, hypocaloric food, insufficient and unqualified staff for the care of psychiatric patients, lack of good medicines, extremely reduced possibilities of pre-clinical investigation…. etc.” At the February 28, 2006 meeting of the Intersectorial Committee, the advisor to the Prime Minister questioned the Ministry of Health’s actions to prevent human rights abuses. The Prime Minister’s advisor stated:

_People in psychiatric hospitals are in chains, not fed, mistreated…I have been reading about this for years – tell me what you are going to do about it? …those people are treated like animals. When there is a violation of human rights, the problem must be solved immediately._

The State Secretary of the Ministry of Health responded:

_That was true, but no longer. There is no more maltreatment or torture._

While admitting that they do not know about conditions in the system, Ministry of Health officials deny the existence of the problems they are facing. Government
officials’ promises of reform are not credible until they admit to the reality before them – tremendous human rights abuses are still taking place in the mental health system.

A. No human rights monitoring system

*To date, I have not ever received any complaint about what is going on in the mental health system. There is no mechanism in place to bring complaints to me.* – State Secretary, Ministry of Health

While the children of Braila have been removed from the immediate dangers of the psychiatric facility where they were so neglected and abused, the government of Romania has not taken the precautions necessary to prevent such abuse in the future. Abuses in institutions – or in community programs – are foreseeable until independent human rights oversight and advocacy systems are established. Both the United Nations and the Council of Europe\(^3^7\) have established detailed standards for human rights monitoring of institutions. Recommendation (2004)\(^1^0\) of the Council of Europe specifies that a mechanism should be “organizationally independent from the authorities or bodies monitored.”\(^3^8\)

There is no independent mechanism to monitor human rights in institutions, and there are no plans to create such a system. The Ministry of Health says that new staff is being hired to inform authorities about what is happening in the mental health system. The staff hired for this purpose will also be responsible for informing patients of their rights. When investigators interviewed the State Secretary, he clarified that this new staff will work for the Ministry and answer to the health authorities. This new personnel will have no obligation to take complaints or represent the views of patients.

Within the child protection system, according to UNICEF staff in Bucharest, there is a similar lack of human rights oversight and monitoring both within institutions and in community programs such as the maternal assistance network. The National Authority for Children’s Rights does have a small staff to monitor the implementation of community programs, but these individuals are not trained as human rights investigators and have no ability to act independently of the agency that employs them.

B. Lack of legal protections

On July 11, 2002, the government adopted Law 487, establishing a sweeping array of rights.\(^3^9\) The Law defines “a person with a mental disability” broadly enough to include children and adults with intellectual or psychiatric disabilities.\(^4^0\) A “patient” is any person with a mental disability receiving care in a medical facility.\(^4^1\) Thus, in theory, this Law would protect children or adults with mental disabilities detained in the country’s mental health system or in other health care institutions.

For almost four years, the Ministry of Health did not issue regulations (known in Romania as “Norms”) that would allow Law 487 to be implemented. On April 10, 2006,
While the Norms establish some valuable protections for children and adults with mental disabilities, they do not resolve some of the gaps in Law 487. As identified by an expert team of mental health law experts in an EU “Twinning Light” study, Law 487 has “serious shortcomings” and does not provide adequate protections against arbitrary detention as required by article 5 of the ECHR. In February 2006, when Ministry of Health authorities promised to promulgate regulations to implement Law 487, they said that they would not seek any amendments to Law 487 to respond to the limitations identified by the EU expert.

Law 487 establishes no protection against the misuse of physical restraints or seclusion, as required by the ECHR. One of the major abuses MDRI observed at Braila and other facilities was the highly abusive practice of leaving children in permanent physical restraints. Under the Norms, procedural protections are established to prevent against the abuse of physical restraints, and there is a ban on the use of restraints for more than four hours. While this ban is valuable, there is no independent mechanism to monitor or enforce these protections. The courts of Romania may yet have to resolve whether these provisions of the Norms are truly binding, given the lack of an underlying legal protection.

The most serious limitation of Law 487, however, is not remedied by the Norms. Law 487 allows a broad array of public authorities to request psychiatric detention, including representatives of “local public administration services…the police, gendarmerie…or the fire brigade.” The decision to involuntarily admit a patient may be made by a “competent psychiatrist.” The Norms do not limit who may request involuntary admission, they merely require that a physician or psychiatrist requesting admission not be the same person who makes the final determination as to whether the person should be detained. This does not meet the standards established by the European Court of Human Rights in Winterwerp v. The Netherlands and subsequent cases upholding the right to an independent judicial review of any psychiatric commitment.

While a person has the right to challenge his or her detention under Law 487, the Law does not provide adequate protections against “non-protesting” patients as required by the recent decision of the European Court in H.L. vs. United Kingdom.

When MDRI met with Ministry of Health authorities in February 2006 and asked about the implementation of the new Norms, they said that there were no plans or resources to review the commitments of thousands of individuals now detained in Romania’s institutions.

C. Failure to implement the right to treatment and rehabilitation

While Law 487 is weak on the civil liberties of patients, it provides a strong legal obligation to create community-based services for children or adults with mental disabilities. The promises contained in the Law, however, are far from the realities of the
mental health system. Primarily, the Law recognizes the rights of people with mental disabilities to community care (Section 2, article 25). Everyone in a psychiatric facility has a right to an “individualized therapeutic program” (article 28) with the aim of “the protection and enhancement of personal autonomy” (article 27). The Law provides that people have a right not to be detained except for treatment (Chapter V, art. 40). It also states that no one will be admitted to a psychiatric hospital unless it has “adequate conditions” (article 46).

Law 487 creates a legal obligation on the part of the government to reform and improve its mental health system and create a system of community-based services for children or adults with mental disabilities. Yet four years after the Law’s adoption, the government has not taken concrete steps to implement the Law. MDRI’s investigations into conditions in mental health facilities illustrate how these institutions are essentially custodial facilities where children and adults are detained in almost total inactivity. In a place where people spend their days crowded into rooms—laying in cribs or beds or sitting on benches staring at the walls—no meaningful rehabilitation takes place. At present, institutions are far from having the staff necessary to implement the current Law.

Given the lack of an immediate plan or funding for community-based services, any short term implementation of Romania’s mental health Law is highly unlikely. If the government decides to change course after years of neglect and take action now to provide appropriate services for children and adults with mental disabilities, the Norms provide a valuable set of guidelines to facilitate this new commitment.
Endnotes

1 See endnotes 25 to 30 and accompanying text.
4 Id. art. 1 of the CRC defines "the child" as including "every human being below the age of eighteen years..." Thus, all the rights of the child include children with the most severe disabilities.
5 Id. art. 23(1) (emphasis added).
6 Id. art. 23(3) (emphasis added).
10 MDRI visited the programs of Pentru Voi in Timisoara, which provide exemplary community-based services for adults with mental disabilities. See http://www.pentruvoi.ro/index_en.htm.
12 MDRI interview with State Secretary, Ministry of Health (Feb. 27, 2006). Some sources have indicated that the number of abandoned babies in maternity wards is much higher.
13 UNICEF, supra note 11. at 9.
14 Id. at 11.
15 Id. at 10.
16 Id. at 106.
17 Statement by the State Secretary of the Ministry of Health at the meeting of the Inter-Ministerial Committee on Mental Health, February 28, 2006. MDRI representatives attended this meeting.
18 Follow-up Report, supra note 7, para. 47.
19 European Commission, supra note 8, at 17.
20 UNICEF, supra note 11. at 47.
21 Johnson, supra note 2, at 14.
22 National Authority for the Protection of Children’s Rights, Ministry of Labor, Educational Campaign on Family Advisory Issues and Child Rights: Fact Sheet (no date; provided to MDRI in February 2006).
23 Even if it were an accurate IQ score, its utility would be limited. According to Karen McGowan Green, MDRI advisory board member and disability expert hired by UNICEF to do individual assessment plans on the Braila children, “An IQ score is meaningless. I have several friends who have PhD’s who cannot communicate in traditional ways due to a disability. IQ measurements and labeling children says more about our inability to understand them than it does about their abilities.”
24 The family reported that the cash payment from the government is barely enough to cover the out-of-pocket costs for their son’s psychotropic medications. According to government officials interviewed by MDRI, those medications are supposed to be provided free of charge.
25 Charles H. Zeanah et al., Designing research to study the effects of institutionalization on brain and behavioral development: The Bucharest Early Intervention Project, 15 DEVELOPMENT AND PSYCHOPATHOLOGY 885, 886 (2003) (reviewing five decades of research literature on the damaging effects

26 Johnson, *supra* note 2, at 114.

27 *Id.* at 146.


29 Johnson, *supra* note 2, at 147.


31 Johnson, *supra* note 2 at 117.


33 *Id.*; Johnson, *supra* note 2, at 152.

34 *Id.* at 156.


36 Romanian Ministry of Justice, Directorate of International Law, “Note on the criminal proceedings in the cases concerning the deaths of some ill persons at the Psychiatric Hospital of Poiana Mare” (2005).


38 *Id.* art. 36(2)(ii).


40 *Id.*, Chapter I, art. 5(a).

41 *Id.*, Chapter I, art. 5(c).


44 *Id.* at 13.

45 Art. 21(6).

46 Law #487, *supra* note 39, Chapter V, Section 2, art. 47(1).

47 *Id.*, art.45.


50 *Id.* at 5 (describing the protections for non-protesting patients under the ECHR) and 14 (describing the limitations of Romania’s law in this area).