



**Children in Russia's Institutions: Human Rights and Opportunities for Reform**

Findings and Recormnendations ofa UNICEF Sponsored Fact-finding

Mission to the Russian Federation 20th October through 6th November 1998

February 6, 1999

by:

Mental Disability Rights International

1156 15th St. NW, Suite 1001

Washington, DC 20005

202-296-6550

[MDRI@erols.com](mailto:MDRI@erols.com)

Copyright 1999

Mental Disability Rights International

Copies of this report are available for $10.00 from:

Mental Disability Rights International 1156 15th St. NW Suite 1001

Washington, DC 20005

Telephone: 202-296-0800

Fax: 202-728-3053

E-mail: [MDRI@mdri.org](mailto:MDRI@mdri.org)

The full text of this report has been published in Russian. Copies of the Russian edition may be obtained by contacting MDRI.

Also available from MDRI:

HUMAN RIGHTS & MENTAL HEALTH: URUGUAY (1995) ($10.00) HUMAN RIGHTS & MENTAL HEALTH: HUNGARY (1997) ($20.00) HUMAN RIGHTS & MENTAL HEALTH: MEXICO (2000) ($20.00)

See also:

Eric Rosenthal, Elizabeth Bauer, Mary F. Hayden and Andrea Holley, *Implementing the Right to Community Integration for Children with Disabilities in Russia: A Human Rights Framework for International Action,* 4 HEALTH AND HUMAN RIGHTS 83{1999).

**Mental Disability Rights International**

Mental Disability Rights International (MDRI) is an advocacy organization dedicated to the international recognition and enforcement of the rights of people with mental disabilities. MDRI documents human rights abuses, suppo1ts the development of mental disability advocacy abroad, assists advocates seeking legal and service system reforms, and promotes international oversight of the rights of people with mental disabilities in the United States and abroad. Drawing on the skills and experience of attorneys, mental health professionals, system users and their families, MDRI is forging a new alliance to challenge the discrimination and abuse of people with mental disabilities worldwide.

MDRI has assisted mental disability rights advocates in Argentina, Mexico, Uruguay, Armenia, Azerbaijan, the Czech Republic, Hungaiy, Lithuania, Poland, Romania, Russia, Slovakia, Slovenia, and Ukraine. MDRI has published three other repo1ts on human rights in mental health systems, *Human Rights and Mental Health: Uruguay* (1995), *Human Rights and Mental Health: Hunga,y* (1997) and *Human Rights and Mental Health: Mexico* (2000). Additional information about MDRI and our publications is available on our website at [*www.mdri.org.*](http://www.mdri.org/)

**Authors**

**Eric Rosenthal,** JD. Eric Rosenthal is the founder and Executive Director of Mental Disability Rights International (MDRI), Washington, DC.

**Elizabeth W. Bauer,** MA. Elizabeth Bauer is Executive Director of the Michigan Protection and Advocacy Service and former President of the National Association of Protection and Advocacy Systems.

**Mary F. Hayden,** Ph.D. is Research Director, Research and Training Center on Community Living, University of Minnesota.

**Andrea Holley,** former program associate at MDRI.

TABLE OF CONTENTS

Ack110,vledgrnents . , ............ , ........................ , i

Executive Sun1mary ............................................... , iii

1. Introduction 1
   1. [Objectives I](#_TOC_250023)
   2. [Methods 2](#_TOC_250022)
   3. [Limitations and implications for systemic human rights reforms 3](#_TOC_250021)
   4. [Legal and policy framework 4](#_TOC_250020)
   5. [Economic and social context 7](#_TOC_250019)
2. Obset"Vatio11s .............................................., 10
   1. [Defectology and disability 0](#_TOC_250018)
   2. System structure and services 12
   3. [Entrance to and conditions in the institutions 15](#_TOC_250017)
   4. [Behavior programs 8](#_TOC_250016)
   5. [Medical care and treatment 9](#_TOC_250015)
   6. [Neglect in institutions 20](#_TOC_250014)
   7. [Rights and patient choice 22](#_TOC_250013)
   8. [Institutionalization of non-disabled children 23](#_TOC_250012)
   9. [Access to institutions and oversight 23](#_TOC_250011)
3. [Human Rights Obligations and Strategic Recommendations 25](#_TOC_250010)
   1. [Right to community integration 25](#_TOC_250009)
   2. [Right to family and community support 28](#_TOC_250008)
   3. [Right to highest attainable standard of health and development 32](#_TOC_250007)
   4. [Right to education 36](#_TOC_250006)
   5. [Protections against inhuman and degrading treatment 37](#_TOC_250005)
   6. [Child's right to exercise choice 40](#_TOC_250004)
   7. [Citizen participation in national planning 41](#_TOC_250003)
   8. [Public education 43](#_TOC_250002)
4. First Steps: Recommendations fol' Low-cost Immediate Action ......... ,., 44
5. Inte1·national Cooperation .................... , .... , 47
   1. [Recommendations to international donors 47](#_TOC_250001)
   2. [Proposed pilot programs for UNICEF 52](#_TOC_250000)

Conclusion: The Road to Refol'm ........................................, 54

**Appendix A: Community Integration Models** ,,,, **55**

-

Acknowledgments

The staff and project team of Mental Disability Rights International (MDRI) is indebted to many people in Russia who gave generously of their time to provide observations and insights about the conditions in children's institutions. Family members, service providers, members of the medical and educational professions, government officials, and staff of non-governmental and international organizations were instrumental in our investigation.

We would like to thank all people at UNICEF/Russia who made our mission successful and productive. Dr. Olga Remenets of the International Child Development Centre deserves our most sincere gratitude for arranging visits, confronting logistical problems on our behalf, and accompanying the team into institutions. Without Dr. Remenets, our mission would not have been possible. Our interpreter Lengvard Khitrov was also essential to our work. Ekaterina Staravoytova assisted us with logistics and we will not forget her helpfulness and efficiency. We would like to thank Dr. Ezio Murzi above all for giving us the opportunity to conduct this investigation and contribute our suggestions for change in Russia's child care institutions.

We would also like to thank the many Russian government officials who made our visit possible. Elena Kupriyanova of the Ministry of Labor and Social Development was essential to our access to institutions and our meetings with officials in the regions of Kaliningrad, Saratov, and Moscow. We express our great appreciation for all her work and her accommodation of our needs. We would also like to thank the regional and local officials of the ministries of education and labor and social welfare for their gracious welcome and cooperation. We appreciated the opportunity to discuss the operation of children's institutions at length and in detail.

The MDRI project team would like to thank the directors and staff of the institutions visited for their time and openness. We found the great majority of staff we met at the institutions to be caring and concerned and willing to assist us in our work in order to improve conditions for the children. In many cases, these individuals have made great personal sacrifices for the children, working long hours for little pay. We acknowledge the difficult circumstances in these institutions in Russia and appreciate the dedication of the staff.

MDRI would like to thank the members of non-governmental organizations (NGOs) in Russia who provided us with critical background about the lives of people with mental disabilities and their families in Russia in and out of institutions. We would particularly like to thank Sergei and Marina Koloskov of the Down Syndrome Association. The courage and dedication of the members of the Down Syndrome Association who offered us hospitality and assistance was an inspiration to the entire MDRI team. Finally, we would like to thank Dr. James Conroy, Director of the Center for Outcome Analysis, and Karin Raye, Director ofMDRI's Women's Rights Advocacy Initiative, for reviewing and commenting on this report.

This project was funded primarily by UNICEF/Russia. Core funding to MDRI from the Open Society Institute (OSI) and the Public Welfare Foundation covered part of the costs of on-site research as well as the operating costs necessary to write this report.

### *Mental Disability Rights International* • iii

Executive Summary

The Russian Federation has inherited from the Soviet Union an extensive institutional system of services and education for children that unnecessarily and improperly segregates them from society. The vast majority of children we observed within Russia's institutions and special schools could live, grow, develop, receive an education, and maintain family ties in a more integrated community environment. This is true for children with disabilities and children without disabilities who are orphaned or who come from troubled families. The health, education, and social services necessary to permit children to remain in the community with their own family or with substitute families are lacking. The **MDRI** team interviewed numerous parents of children with disabilities who are desperately trying to keep their children at home but find it difficult to do so in the absence of adequate government support. The great majority of children in Russia's institutions are "social orphans," many of whom have been placed in institutions by parents as a result of the lack of economic resources and other needed social support. Both real and social orphans could live with their own family or a substitute family if adequate educational services and support were available.

Russia's recent economic hardship has contributed greatly to problems facing children with disabilities and their families. With fewer resources available to them in the community, more and more parents are forced to place children in institutions. Institutional budgets, already stretched thin, are forced to cover the costs of serving an increased number of children. Children in institutions and in the community are increasingly at risk of impoverishment and neglect.

The near exclusive reliance on institutional care for children who require support contributes to the disabilities of children. Research in child development and the experience of other countries around the world has demonstrated that children experience developmental delays and potentially irreversible psychological damage by growing up in a congregate environment. This is particularly true in the earliest stages of child development (birth to age four), in which the child learns to make psychological attachment to parents (or substitute parents). Even in a well staffed institution, a child rarely gets the amount of attention he or she would receive from his or her own parents. Consequently, institutionalization precludes the kind of individual attachments that eve1y child needs. In Russia, the MDRI team observed many caring staff doing everything they could to spread their attention to meet the needs of all the children under their care. Resources are inadequate to meet the needs of all children. The situation is particularly serious for children with disabilities who need the most care. Overworked staff are not able to meet their needs. Many children are left to spend long hours, days, or years in a crib without the attention or stimulation needed to grow and develop. The damage caused in their early years will likely stay with them forever. These children are effectively denied the opportunity to lead the full life of which they are capable.

Older children also suffer from unnecessary and improper institutionalization. Many older children are placed in institutions "temporarily" for a host of stated reasons - to give them an evaluation diagnosis, to provide "corrective services," or to give parents the time to get over a difficult period. Children labeled as "disabled" are placed in segregated classrooms in institutions or in the community, where they receive an inadequate or second-class education. Lacking contact with the mainstream, children fail to develop the social skills necessary to thrive in the community.

*iv• Children in Russirt's Institutions: Human Rights and O,1i,portunities for Reform*

Frequently, children temporarily placed in an institution lose contact with family or friends in the community. The loss of these social ties makes return to the community more and more difficult over time. Once family ties are severed, a child may lose hope of ever returning to the community. Children with mental disabilities are often consigned to a lifetime in an institution.

MDRI's major recommendation is that the Russian Federation should commit itself to a policy of community integration. To implement this new policy, appropriate authorities must create a network of community-based services and support systems to permit children to live, grow, and receive an education in the community. This system will end the unnecessary break-up of families and will help prevent mental disabilities that are caused by children's institutionalization. Educational systems must also be reformed to permit integration of children with mental disabilities within mainstream schools and classes. Ultimately, every child should grow up with a family and no child should ever have to be placed in an institution.

The International Convention on the Rights of the Child (CRC) embodies the principle that all children - regardless of disability - have value as human beings. The CRC establishes that the opportunity to grow up with a family in the community is a fundamental right of all children. The CRC specifies that health, education and social services be provided - to the extent of available resources - to ensure enforcement of these rights. The CRC requires laws to be reformed to protect all children against discrimination in society. These laws should also assure children access to needed social services and education in the community. Human rights oversight mechanisms (including ombudsmen) should be established to protect children against neglect and abuse and to ensure the enforcement of basic human rights for children remaining in institutional care. Oversight mechanisms must also be established to ensure enforcement of the rights of children receiving community-based services.

The Russian Federation must commit itself to a new policy of promoting the maximum possible community integration and family support for all children, particularly children with disabilities. As the United Nations has called for in the "Standard Rules on Equalization of Opportunities for Persons with Disabilities," national planning is needed to ensure enforcement of human rights and full opportunity to participate in public life in the community. Planning on the regional and local levels is needed to develop programs to bring about long-term reform. People with disabilities and their families should be invited to work with government authorities at all levels to develop effective reform plans and programs.

While the Russian Federation is going through a difficult time of transition at present with hardships shared by much of the population, the humanitarian concern of children in institutions are urgent. A delay in the development of community-based alternatives creates increased human and financial costs. As institutional placements rise and more families break-up, children face rising levels of mental disability. Public exposes of abuses in institutions will increasingly pressure government authorities and international donors to invest in improving institutions. These new investments may increase the incentives for financially-strapped parents to place children in institutions. While emergency efforts may be needed to ensure sufficient food, heath, clothing,

## *Mental Disability Rights lnternatio11al* • 1'

sanitation, and medical care in institutions, the bulk of assistance should go to children and families in the community. The Russian Federation should avoid the path taken by countries such as Romania, where international exposure of abuses in orphanages was followed by new investments in institutions - and an almost fifty percent rise in the total population of institutionalized children. The challenge to community integration will be even greater and more difficult if Russia follows this path. Russian authorities should respond to the current crisis by creating community services to meet the needs of children in their own home and conununity. As soon as possible, the entry door to institutions should be closed - and all new admissions should be terminated.

International assistance at this time is critical. Programs targeted to support families with children at-risk ofinstitutionalization can prevent unnecessary break-up of families. These programs should be linked to advocacy training programs to empower family members to take part in reform efforts at the national level and through their local and regional authorities tlll'oughout Russia. International funding can lead the way to reform by supporting model programs that demonstrate the effectiveness of community integration. Russian models for community integration for children in out-of-home care do exist. These programs should be expanded to serve children with mental disabilities, and these models should be replicated throughout the Russian Federation.

Chapters III through V of this report provide detailed reconunendations to the Russian government, local authorities, and the international donor community about steps they can take to bring about rights enforcement and service system reform. The following is a summary of the major objectives of reform:

1. Right to Community Integration

Policies and programs at all levels of government should reflect a broad commitment to community integration for children. The CRC requires a policy of commitment to promote community integration wherever possible. These policies should be reflected in local or national laws and practices. Full enforcement of the right to community integration will require, over time, the creation of a full network of community-based service and support systems for children with disabilities.

1. Right to Family and Community Support

Social services systems in the community should be established to make it possible to keep children with their families wherever possible. Where out of home placement is necessary, a substitute or "foster" family should be made available.

1. Right to the Highest Attainable Standard of Health and Development

Health and development of children in institutional care can only be maximized through the creation of community alternatives to institutions and outplacement programs. Emergency programs

###### *vi• Children in Russia's Institutions: Human Rights and Op\_portunities for Reform*

to protect the health of children in institutions may be needed. Model community programs are needed to demonstrate the effectiveness of community integration of children with disabilities. More habilitation professionals should be trained and employed to service children with disabilities; these professionals should work for community authorities and not for institutions so that programs can be adapted to serve children in the community as needed.

#### Right to Education

All children, regardless of disability, shall receive a free and appropriate education in the most integrated/least restrictive setting suitable to the individual's abilities. Special programs shall be created in mainstream classrooms to ensure that children with mental disabilities can maximize their individual potential in a setting that promotes community integration.

#### Protection Against Inhuman and Degrading Treatment

Russian authorities must establish enforceable legal rights, meeting internationally accepted human rights standards, to protect all children from inhuman and degrading treatment institutions; human rights oversight and enforcement mechanisms (including, but not limited to ombudsmen) are needed to ensure enforcement of these rights.

#### Child's Right to Exercise Choice

All children in institutions - including children with disabilities - have the right to express and exercise choice about basic decisions that affect their rights. Services should be flexible enough to be shaped to meet the individual needs and expressed wishes of the child where possible.

#### Citizen Participation and National Planning

National, regional, and local planning committees should be established to develop and implement community integration policies. These committees should include people with disabilities, family members, and representatives of other concerned citizens groups.

#### B. Public Education

Public awareness campaigns are needed to promote understanding of the rights and potential for community integration of children with mental and physical disabilities. People with disabilities and their families should be actively involved in designing and implementing these efforts. These public awareness campaigns should be directed to people with disabilities, professionals, educators, family members, and to the general public.

1. **Introduction**
   1. Objectives

This report was sponsored by UNICEF/Moscow to identify major human rights issues and reform needs in Russia's system of institutions for children.1 The report focuses especially on the needs of children with mental disabilities2 and other children in out-of-home care. Children in out­ of-home care, particularly children with disabilities, are particularly vulnerable to discrimination, neglect, and abuse in any society. Regular oversight, advocacy, and professional exchange is needed to ensure rights enforcement as well as appropriate reform of health, education, and social service systems.

This report is intended to facilitate international exchange and collaboration to promote rights and service system reform for children in Russia's institutions. The major challenges Russia faces in enforcing children's rights and modernizing service systems are strikingly similar to those faced in other countries - East and West.3 Throughout the world, institution-based services have been reformed through legal changes, social service system development, and non-governmental advocacy by professionals, people with disabilities, and their family members. The development of

'This report will refer broadly to "services for children" to include all services for children with mental disabilities, orphans, and children in institutions, orphanages, special schools or other out-of-home care. The term also includes the services, education, and support available to children with disabilities living with their parents.

2This report refers to children with mental disabilities to refer broadly to children with mental illness or with a developmental disability (such as mental retardation or cerebral palsy). A disability, as defined by the United Nations may encompass one of"a great number of different functional limitations occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental

illness." *Standard Rules on the Equalization of Opportunities for Persons with Disabilities,* G.A. Res.96, UN GAOR, 48th Sess. (1993). Human rights protection against discrimination on the basis of disability or mental health apply to people with disabilities as well as people improperly labeled as such.

3Thomas Hammarberg, vice-chair of the UN Committee on the Rights of the Child, has noted that a "widespread problem is the tendency to invest in large institutions, to where some children are brought, instead of developing local programs for home like environments."

Thomas Hammarberg, *The Rights of Disabled Children: the UN Convention on the Rights of the Child,* HUMAN RIGHTS AND DISABLED PERSONS: ESSAYS AND RELEVANT HUMAN Rimrrs

INSTRUMENTS 147, 151 (Theresia Degener and Yolan Koster-Dreese, eds. 1995). Mental Disability Rights International has documented the improper segregation of children and adults with mental disabilities in Hungary and Uruguay. *See* MENTAL DISABILITY RIGHTS INTERNATIONAL, HUMAN RIGHTS AND MENTAL HEALTH: HUNGARY (1997), and MENTAL DISABILITY RIGHT INTERNATIONAL, HUMAN RIGHTS AND MENTAL HEALTH: URUGUAY (1995).

community-based services and support systems for natural and foster families has brought about tremendous gains in improving the health and quality of life for children once placed in closed institutions. These programs have demonstrated that every child can benefit from life in the community. The principle that every child has a right to a family and that government policies should promote community integration to the extent possible has been widely accepted around the world and is a central principle protected by the International Convention on the Rights of the Child (CRC).

Countries like the Russian Federation striving to enforce the rights of the child under the CRC can learn from the experience of the reform movements in other countries - both positive and negative. As this report describes, the Russian Federation has as much to gain from avoiding the mistakes of other countries as from emulating successful programs. By drawing on experiences of reformers in other countries, Russians will develop an approach to reform that will be effective in their own country. Throughout the Russian Federation, the MDRI/UNICEF team encountered government administrators, service providers, educators, and parent activists who are deeply committed to reform. These individuals have already initiated impressive new reform projects - often without any external recognition or support. We hope that this report will stimulate a process of public discussion about children's rights, community integration, and service system modernization. Ultimately, this process will broaden, support and strengthen the work of the many Russians we encountered who are committed to reform.

Complex transformation of the Russian Federation's system of education and social services cannot be expected to take place immediately but will require a sustained effort on the part of government and non-governmental advocates. Until a broad consensus for change is established, and adequate funds for national reform are committed, small "pilot" programs can lead the way to change. By demonstrating the need for reform to protect the rights of children with disabilities in Russia, we hope that this report will help raise international financial and technical support.

As a result of the economic crisis now taking place in the Russian Federation, many people in Russian society have experienced great hardship, and financial resources are inherently limited for new reform projects. This report demonstrates that the first steps toward reform can begin at little cost. This report includes low-cost recommendations for first steps at every institution we visited. Long-term change will require Russian leadership and a governmental commitment to reform to ensure that pilot programs are supported and replicated and that effective planning for reform takes place on local, regional, and national levels.

#### Methods

This report was researched and written by Mental Disability Rights International (MDRI), a non-governmental advocacy organization dedicated to the international recognition and enforcement of the rights of people with mental disabilities. With support from UNICEF, MDRI brought a team of experts to Russia for three weeks. We visited four regions of the Russian Federation: Kaliningrad, Saratov, Moscow and St. Petersburg. The interdisciplinary team, comprised of Eric Rosenthal, JD, Mary Hayden Ph.D, Elizabeth Bauer MA, and Andrea Holley, brings expertise

in the domains of international law and disability legislation, systems analysis and community integration for individuals with disabilities, and residential and educational services for people with disabilities.

The MDRI team viewed a total of fourteen facilities in the four regions of the Russian Federation that we visited. We visited several types of institutions: *internals* (residential facilities also serving as boarding schools for some children) administered by the Ministry of Education; *internals* administered by the Ministry of Labor and Social Development; *dam rebyonka,* or baby houses, administered by the Ministry of Health, regional diagnostic centers, a regional rehabilitation center, a psychiatric hospital, and a psycho-neurological hospital. In addition to these site visits, the team met with policy makers and local authorities, directors of centers, hospitals, and schools, medical and educational professionals, legal and non-governmental advocates. Team members met with and interviewed numerous parents and children in the community and in the institutions.

Two members of the MDRI team, Eric Rosenthal and Elizabeth Bauer, visited Moscow in May 1998. We visited one *internal,* met with family advocacy organizations, human rights groups, and other NGO's, and we participated in a forum at the Russian Ministry of Education on education for children with mental disabilities. We have drawn some of our observations from this visit.

* 1. Limitations and implications for systemic human rights reforms

This report makes general observations about the system of services for children that we observed, though there is clearly a great deal of variation throughout Russia. This report synthesizes observations about what we obse1ved in four regions to raise basic issues about reform needs. Russia is a large country, however, with enormously varying economic, social, and political conditions. Education and social services are administered by regional and local authorities who have almost complete discretion to establish their own policies and programs without intervention from the federal authorities. Even within the regions we visited, the MDRI/UNICEF team found significant differences among the institutions based on the particular approach of the directors and

staff.

With a note of caution, we believe the findings of this report are relevant throughout Russia. Due to limitations of time, we did not gain as much understanding ofa complex system of services as we would have liked. We did not visit parts of Russia where economic hardship is the most extreme and where starvation is repo1ted to be present in the population-at-large. All site visits were organized through Russian government authorities, who - despite great openness, honesty, and candor - generally wished to show us the best facilities. For the most part, we were shown the institutions with the least disabled or non-disabled children . With a few limited exceptions, we did not have an opportunity to visit the institutions that house the most disabled children. Within the range of institutions we visited, children with more severe disabilities generally live in the worse conditions. The *internal* that we visited independently in May 1998 had children with more severe disabilities and conditions were worse than anything we were shown on our official tour in

November 1998.

All our visits were planned in advance, and staff had an opportunity to clean up buildings and dress children in their best clothes. In one institution, we obse1ved fresh paint on walls. While we were generally given free access to the institutions we visited, the limitations of time did not permit us to visit eve1y room or meet with every child in every institution. Thus, it is possible that we were not shown to rooms that contained the worst conditions. Egregious abuses could easily have been kept from our view.

This report is not a substitute for the systematic oversight needed to ensure the protection of basic human rights within institutions. In a number of cases, we can only identify issues about basic rights and health care that require further investigation. Despite these limitations, the issues we identify have major implications for the rights of children with disabilities throughout the Russian Federation. If our observations and recommendations hold true for the "best" institutions in Russia, they are certainly relevant to the "worst" facilities. More broadly speaking, MDRI's experience in facilities around the world suggests that the differences between the best and worst institutions for children are less significant than the difference between life in the institution itself and life in the community. As Gunnar Dybwad, a leading activist in Europe and the United States, has concluded, "four decades of work to improve the living conditions of children with disabilities has taught us one major lesson: there is no such thing as a good institution."4

International human rights law obliges the Russian Federation take immediate steps to end egregious abuses within institutions. But the International Convention of the Rights of the Child (CRC) also protects the right of every child to grow up in a family and in the community to the extent possible. As described in this report, children who grow up in congregate settings are more likely than other children to suffer from developmental delays and potentially irreversible psychological deficits. In the long-term, no amount of money invested in institutions can substitute for new social and educational policies that promote community integration and support of the family. This report identifies immediate actions the Russian Federation must take to protect the rights of children within institutions. It is our larger goal, however, to promote long-term policies that will ensure that the children in institutions today will have a hope for tomorrow ofliving within a family and living the fullest possible life in the community.

* 1. Legal and policy framework

This report relies primarily on the CRC as the framework for assessing Russia's institutions and system of services for children. As a country that has ratified the CRC, Russia is under an international legal obligation to enforce basic children's rights. The CRC is also a useful tool to promote international cooperation on reform. The CRC, like other widely accepted human rights instruments, provides a universal standard of assessment that permits fair and objective analysis of

laws, policies, and treatment practices that are not specific to any one national or cultural approach.*5*

4Keynote speech at K97 International Conference Human Rights for Persons with Developmental Disabilities, September 1997, Prague, Czech Republic.

5Robert Drinan, CRY OF TilE OPPRESSED 158-161 (1987).

As a United Nations agency mandated to promote the concerns of children, UNICEF can play a special role in promoting international cooperation to advance the principles embodied in the CRC.6 The CRC entitles UNICEF specifically to report on the implementation of the convention. 7

1. Commitment to international cooperation and access to institutions

The preamble of the CRC emphases "the importance of international co-operation for improving the living conditions of children in every country..."," and the convention makes numerous references to the importance of international technical cooperation to promote its enforcement.9 The commitment to promote international cooperation applies to *all* State Parties

to the CRC, including donor countries and countries in.need of assistance to ensure full enforcement of rights under the convention.10 To protect the rights of children with disabilities, the CRC creates

an obligation to "promote, in the spirit of international cooperation, the exchange of appropriate information," including "access to information concerning methods ofrehabilitation, education, and vocational services, with the aim of enabling States Practices to improve their capabilities and skills and to widen their experience in these areas."11

Russia's openness in permitting the MDRI/UNICEF team to gain access to children's

institutions and to study Russian treatment practices for children with disabilities has been and continues to be critical to establishing collaborative programs to promote children's rights under the

CRC.12 Russia has generally not been as open with other NGO's.13 We hope to demonstrate with

*6See* Daniel O'Donnell, *The Convention on the Rights of the Child: A challenge for UNICEF, in* UNITED NATIONS BULLETIN OF HUMAN RIGHTS, ill 91/2 UNITED NATIONS BULLETIN OF HUMAN RIGHTS: THE RIGHTS OF THE CHILD 25 (1992).

7"The specialized agencies, the United Nations Children's Fund [UNICEF], and other United Nations organs shall be entitled to be represented at the consideration of the implementation of such provisions of the present Convention as fall within the scope of their mandate." CRC, a1ticle 45(a).

'International Convention on the Rights of the Child (entered into force 2 September 1990) ("CRC"), *preamble.*

9CRC, article 23(4) (cooperation relating to children with disabilities); article 24(4) (cooperation on health), and article 28(3) (cooperation in education).

10 Philip Alston, *The Legal Framework of the Convention 011 the Rights of the Child, in*

UNITED NATIONS BULLETIN OF HUMAN RIGHTS, *supra* note 5, at 25.

11CRC, article 23(4).

12While many Russian government officials were very helpful and many institutions were opened to the MDRI/UNICEF team, we experienced some difficulties in obtaining access to institutions, particularly institutions for children with mental disabilities. These are described

this report that Russia will benefit from increased openness through greater and more effective international cooperation and assistance.

2, Application of intemational UN standards on human rights

The CRC recognizes that everyone, including children, are protected by the full range of international human rights established by the Universal Declaration of Human Rights and the International Covenants on Human Rights (the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR)).14 Article 2 of the CRC protects against "discrimination of any kind," including discrimination on the basis of disability. Thus, children with disabilities are protected by the same rights as all other individuals under international law.

The application of the broad human rights principles established by the CRC and other conventions can be greatly aided through reference to specialized international instruments adopted by the United Nations General Assembly that establish internationally accepted minimum standards of care for children and adults with disabilities. These UN standards are not binding (as are international conventions), but they are an authoritative guide to the application of the principles established in international human rights conventions. 15 The key international standards are the *Standard Rules on the Equalization ofOpportu11itiesfor Persons with Disabilities* ("StRE "),16 the *Principles for the Protection of Persons with Mental Illness* (the "MI Principles"), 17 the *Declaration on the Rights of Mentally Retarded Persons,*18 and the *Declaration on the Rights of Disabled*

further in Chapter III, Section I.

13Both international and domestic international human rights organizations have experienced difficulties in gaining access to Russia's institutions for children. Human Rights Watch, ABANDONED TO THE STATE: CRUELTY AND NEGLECT IN RUSSIAN ORPHANAGES 6 (1998).

14CRC, *preamble.*

*15See* Eric Rosenthal and Leonard S. Rubenstein, *Jntemational Human Rights Advocacy under the "Principles for the Protection of Persons with Mental Illness,"* 16 INIBRNATIONAL JOURNAL OF LAW & PSYCHIATRY 257 (1993) (describing the use of UN human rights standards as a guide to the interpretation and application of binding international conventions).

16StRE, *supra* note 5.

*17Principlesfor the Protection of Persons with Mental Illness and for the J111prove111ent of Mental Health Care,* G.A. Res. 119, UN GAOR 46th Sess. No.49, Annex, at 188-92, U.N. Doc. A/46/49 (1991).

18G.A. Res. 2856, U.N. GAOR, 26th Sess., Supp. No. 29, at 99, U.N. Doc.A/8429 (1971).

*Mental Disability Rights International* 111 *7*

*Persons.*19 As described below, these international UN standards and the CRC have major implications for the structure and provision of services for children with disabilities.

* 1. Economic and social context

1. **Children's l'ights in a time of cl'isis**

The concerns of children in Russia's institutions must be understood in context of recent economic difficulties as Russia makes the difficult transition to a market economy. As a result of this transition, far fewer resources are available for social services and the social safety net has been significantly cut back. The transition has had a negative impact on the public health of the population as a whole. Children in Russia's institutions, entirely dependent on government resources, have been particularly vulnerable to these cutbacks.

The Russian population has experienced a decrease in the life expectancy from 1970 to 1997 (69 to 65.)20 Increases in violence and the use of alcohol and drugs may explain part of this decrease in life expectancy and the corresponding increase in the crude death rate (9 to 14 per 1000.)21 Many of these factors, stemming from the breakdown of the former Soviet health system, contribute to the problem of institutionalized children in various ways. Families are unable to care for children due to their own ill health or inability to support the costs of child rearing. Behaviors and diseases that lead to childhood disabilities are on the rise.

Children in institutions represent only a small fraction of the children or adults suffering from the economic crisis. In addition to the 400,000 to 600,000 children in institutions, the Ministry of Interior estimates that there are 1,000,000 to 4,000,000 children living in the streets of Russia.22 There are also a large number of children in the criminal system, including prisons, jails, and other forms of juvenile detention.23 Adequate food is reported to be lacking for children in criminal detention. The salaries of staff at criminal and non-criminal institutions have been greatly reduced by inflation, and even this low salary is frequently not paid until months after it is due. Indeed, much of the population of Russia must live with greatly reduced and late payment of wages. Starvation

19G.A. Res. 3447, U.N. GAOR, 30th Sess. Supp. No.34, at 92 U.N. Doc. A/10,034 (1975).

2°UNICEF, STATE OF THE WORLD'S CHILDREN ( 1999).

21Ibid.Tuberculosis and an increase in the prevalence ofHIV-AIDS also contribute to the deterioration of the public's health.

22 Boris Altshuler et al, RUSSIAN NGOs ALTERNATIVE REPORT TO THE COMMITTEE ON TI-IERIGIITSOF1HECHILD(l998) at 10.

23 With juvenile detention and other correctional facilities taken into consideration, there are an estimated two million children living in institutions in Russia. Bill Powell with Yana Dlugy, *R11ssia's G11/agsfor Children,* NEWSWEEK, December 21, 1998, at 25.

and malnutrition are reportedly concerns for sections of the Russian population in some areas, as well as in the Russian army.24 Reports of Red Cross Winter food distributions were printed in local newspapers during our mission.

Russia's economic difficulties helps explain how conditions have come to be as poor as they are for children and staff in Russian institutions - but *economic difficulties do not excuse the government of Russia of its responsibility for rights enforce111ent.* "Civil and political rights," such as the right to life, the right to protection against inhuman and degrading treatment, and the protection against arbitrary detention, must be immediately and fully enforced. 25 As a matter of international law, these rights are not derogated (limited) by difficult economic conditions.26 The CRC, which protects both "civil and political rights," as well as "economic and social rights," requires States Parties to "unde1iake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention."27 With regard to economic and social protections under the CRC, "States Parties shall undertake such measures to the *111axi111um extent of available resources....* "28 Bringing out the full outcomes promised in the CRC may be take time due to economic limitations, but Russia must commit itself as a matter oflaw and policy to allocating available resources to work towards the goals set forth in the CRC.29

24Russian Red Cross Society Central Committee, EMERGENCY APPEAL - BELARUS, MOLDOVA, RUSSIAN FEDERATION, UKRAINE: WINTER EMERGENCY 1998-1999 (1998).

25The CRC states uncategorically that "[ nJo child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment." CRC, article 37(a).

26Certain rights protected by the CRC, such as the protections against inhuman and degrading treatment, are equivalent to those protected by the International Covenant on Civil and Political Rights (ICCPR). Rights protected by the ICCPR may be limited only under conditions ofa "public emergency which treatments the life of the nation." ICCPR, article 4(1). Lack of financial resources alone do not constitute such a public emergency. United Nations Economic and Social Council, Commission on Human Rights, STUDY OF1l!E IMPLICATIONS FOR HUMAN RIGHTS OF RECENT DEVELOPMENTS CONCERNING SITUATIONS KNOWN AS STATES OF SIEGE OR

EMERGENCY, U.N. Doc. E/EN.4/1982/15 (prepared by N. Questiaux).

27CRC, article 4.

###### *"Id.*

29Thomas Hammarberg of the Committee on the Rights of the Child describes this as "obligations of *conduct* that than result; the emphasis is on what efforts the State party makes in promoting the implementation of the Convention." Hammarberg, *supra* note 3, at 152.

Describing the phrase "to the maximum extent of their available resources," Hammar berg adds that this "is not an escape clause for the less resourced countries; it asks all State parties to give priority within their means to the implementation of the Convention." *Id.* at 154.

***Mental Disability Rights International*** • ***9*** Given the increased pressures on Russia's social system, more and not less attention is

needed on population who are particularly vulnerable to neglect and abuse at a time when resources are scarce. Russia's economic difficulties increase the urgency of international assistance and support for children's rights in Russia at this time of crisis.30

1. Impacts on children with disabilities

The economic crisis has had a major, negative impact on the rights of children with disabilities and on conditions of all children in the Russia's institutions. As government resources have declined, local governments in some areas have severely cut funding to facilities such as *internals.* Families have also experienced great economic hardships, particularly if they have a child with a disability. MDRI team interviewed numerous parents of children with disabilities desperately struggling to keep their children at home - despite inadequate government support and sometimes contrary to professional advice. Parents barely able to make ends meet before the crisis are under greater pressure today, and many more of them have been forced to place their children in institutions. Most of the institutions we visited in November 1998 repmt an increase in the number of children brought to institutions for care over the course of the last year. State institutions for children are thus experiencing increased pressure from two sides at once: they have fewer and fewer resources to serve more and more children.

Staff at *internals* report to the MDRI team that "troubled families" frequently place their children in the institution because the family cannot afford to provide adequate food. Children can be taken away from "troubled families" because of suspected alcoholism or abuse. We also heard reports from professionals that children are taken away from families by the authorities because of the parents failure to provide for their basic needs - such as the food and clothing that are increasingly hard to afford.

The economic difficulties faced by families has resulted in an increase in the number of so­ called "social orphans" - children who have living parents who are abandoned to an institution. Often, placement in an institution is considered temporary until parents are able to get over a difficult period of economic difficulty. As economic difficulties continue, and as social contacts between children and the outside world weaken over time, family ties break down. Placement in an institution - even for a non-disabled, healthy child - can also lead to developmental delays and potentially irreversible psychological deficits. This is particularly true when children are placed in institutions under the age of four. Thus, institutional placement becomes a self-fulfilling destiny for children. As they acquire disabilities in the institution, it becomes increasingly difficult for them ever to have the hope of returning to their family, home, or community. Many children who are or become disabled face the prospect of a life-long institutionalization.

30The CRC call for international support, particularly "where needed" to ensure enforcement of economic and social provisions of the convention. CRC, article 4.

1. Observations

This section lays the foundation for our findings by describing the discipline of defectology in Russia and its role in the history of disability. Both the medical and educational aspects of defectology are pertinent to our discussion, as they relate to the historical segregation and exclusion of people with disabilities from society and the notion of "correction." The following sections describe the structure of the current system of services. The sections also describe alternative services available outside of institutions at the present time, which may be the basis for future programs and planning. The final sections discuss conditions in the institutions and the impact on the children living there.

* 1. Defectology and disability

In Russia, the discipline ofdefectology has existed since the l930's. In 1929, the Institute of Defectology was established and brought together scientists of all descriptions to discuss the issues surrounding education of children with developmental delays. L.S. Vygotsky , a developmental psychologist, was one of the initial founders of the Institute and his writings were very influential during that period.31 The role of Vygotsky and his colleagues was limited for ideological reasons in the Soviet period. During that period, educational philosophy insisted on a State where as many children as possible could be brought up to standards that were predicated on "normal" development.32 This tradition still prevails today in Russia and much of Central and Eastern Europe."

The philosophy of the Russian teams always focuses on 'correcting' the child to make her or him "normal," rather than assisting with her or his functional limitation in adapting to the environment or adapting the environment to make it accessible to the child with a disability. Professionals frequently reported to MDRI that it is best for a child with any form of deficiency to be separated from normal children and, in many cases, separated from their families. They say that other children would mock the child with a disability and that the child with a disability has absolutely no chance of 'catching up' to the others without intense, specialized instruction outside of a normal school. Thus, instead of making schools accessible to children with disabilities, the child is excluded from school until he or she can be "corrected." In practice, some children will never conform to an inflexible "norm" and will remain in separate, segregated schools her or his entire

"Nikolai N. Malofeev, *Special Education in Russia: Historical Aspects,* 31 JOURNAL OF LEARNING DISABILITIES 2, 182 (1998).

*"Id.*

*33See* Mary Ann Burke, UNICEF International Child Development Centre, *Child Institutionalization and Child Protection in Central and Eastem Europe,* 52 ECONOMIC POLICY SERIES i (1995).

life.34

By maintaining children with disabilities in separate, segregated facilities, Soviet society existed as if there were no people with disabilities. They were invisible. For many years, official data collection on disability was prohibited; thus, even today, it is difficult to measure the prevalence of disability. In a paper presented by Korkunov and Nigayev in 1994, the following statistics collected by the Ministry of Education were given:35

|  |  |
| --- | --- |
| Category | % general population |
| Delay in development | 2.4 |
| Speech defect | 2.3 |
| Mental defect | 2.35 |
| Hearing defect | 1.2 |
| Sight defect | .03 |
| Defect in movement | .10 |
| Other | 1.4 |
| TOTAL | 8.7 |

In light of these statistics, a few points should be made. The total disability prevalence of 8.7% in Russia seems comparable to estimates of disability found in many countries; however, in the course of our visits, we were often given statistics in a particular region which seemed to indicate a much lower prevalence of disability (often in the range of 1.5 to 2% of the population.) These reports could

34Defectology's focus on "correcting" children and meeting pre-established "norms" stems from an attachment to the medical model of disability. The paradigm shift in disability is part of a larger international discussion of the concept of disability. "Impairment" is a concrete, physical limitation of an individual due to a somatic condition. "Handicap" is the term used to describe the loss of opportunities or limitations in society due to an impairment. "Disability" summarizes a great number of different functional limitations occurring in any population in any country of the world. The Russian defectology system emphasizes impairment and handicap, not disability. When professionals focus on disability, concepts of accommodation and flexibility emerge. When they do not focus on disability, a perpetual need to cure and correct the impairment persists.

* 35Vladimir Korkunov et al., *Special Education in Russia: Hist01y, Reality, and Prospects,*

3 I JOURNAL OF LEARNING DISABILITIES 2, 189 (I 998).

be related to several sources of bias: under-reporting in general, exclusive reliance on official records of disabled children, and inconsistent definitions of terms and diagnoses.

The difficulty of establishing distinct and consistent definitions of ce1iain disabilities hinders national planning, international cooperation, and attempts to institute reform. The terminology used to describe children with intellectual disabilities in Russia is different from the terms now used internationally in the disability field. In Russia, debil, imbecile, and idiot are the standard terms used to describe children with mild, moderate, and severe mental disabilities, respectively. The term "debil" is so broad however, that it would include a child with less than average intelligence as well as a child with average intelligence and a learning or speech disability. This arbitrary terminology indicates a severe problem in the realm of evaluation and diagnosis. In certain cases, the MDRI investigators were informed that a physician looks at a child and performs a perfuncto1y examination to arrive at the conclusion that the child is disabled. This approach creates a bias towards classifying any child with a speech defect or other visible impairment as disabled and in need of special education or institutionalization.

In certain cases, it is not only severity of disability which predicts placement in a boarding school or other institution, but socio-economic status, as well. On many occasions, directors told the team that a particular child who appeared to have no functional lilllitations was placed in the *intemat* due to a "troubled" family life. All of these practices reflect a reliance on non-standardized and professionally questionable methods. Using the internationally accepted definition of disability, a consequence of impairment in terms of functional limitation and activity by the individual, we conclude that many of the children currently residing in *intemats* do not fit the internationally accepted definition.36

For a child deemed "disabled,"using these arbitrary and scientifically questionable parameters, Medical-Pedagogical Comlllissions emphasize to family members that they could never provide the care and education that the child requires to succeed. This statement becomes a self­ fulfilling prophecy. By failing to provide supports or services in the community, governments leave families without the resources needed to care for their child on their own. Thus, parents are forced to turn to institutional care. In many cases, the families place their children in specialized schools and institutions without fully understanding their child's condition or the choices available to them. All too often, parents are blamed for abandoning their children when, with some assistance, they would have gone to great lengths to keep them at home.

* 1. System strnctul'e and services

In Russia, the federal system and the regional systems of care operate separately. The federal level of each ministry serves in a consultative role and cannot dictate policy directly to regions. Regions finance their own institutions and set their own policies. Se1vices for children in institutions are divided among three ministries: health, education, and labor and social protection. The Minist1y

36*See* discussion and definition adopted by the UN General Assembly as part of the StRE in note 2, *supra.*

of Health is charged with care of new born to four-year-old children in what are called *dom rebyonkas,* or baby houses. In these baby houses, children have a range of conditions and abilities. In many cases, babies have been abandoned to the baby house due to the unstable situation of the family or child's physical deformity. We learned that many babies arrive at the baby house by virtue of the fact that they come from a large family, where there simply is no means to support another child. At age four, a team evaluates a child to determine whether she/he should be placed in an institution run by the Ministry of Education or the Ministry of Labor and Social Development.37

The difference between the two types of institutions can be simplified by the perception that children are either "educable" or "uneducable." Children considered "educable" are generally placed in facilities under the Ministry of Education, and children who are "uneducable" are under the Ministry of Labor and Social Development. We were also told that staff often try to hold children in the baby houses to prevent them from being placed in another institution where they fear care is inferior and that the child will suffer. These stories also exemplified the personal care and attachments of staff to children in these residential institutions.

Personal attitudes of directors and staff play a large role in determining children's activities, programs, and level of staff interaction. In some cases, we could not discern the difference between the children in Ministry of Education *internals* and the children in Ministry of Labor and Social Development *intemats.*38 In many cases, there was no apparent difference between children who had the benefit of staff interaction and children who were left **in** bed, almost untouched. For children who reach the age of eighteen in a Ministry of Labor and Social Development *intemat,* it is virtually assured that they will go on to live in an institution for adults with disabilities. Services for children with disabilities under the care of the Federal Ministry of Labor and Social Development are currently under the authority of the Department of Veterans and Elders - which may reflect an expectation that children in these programs will remain in institutions for the long-term.39

In the institutions we visited under the Ministry of Education, many children are given a basic education. Certain children are given vocational training, and all children are given 'life preparation'

training. 4°Children living in these *internals* are either full-time residents or five day residents, who

37In a few cases, children are adopted from baby houses, often by foreigners.

38Namely, the *internal* in the village ofBazarno-Karabulaksky. The team debated whether this *internal* was under the Ministry of Education or the Ministry of Labor and Social Development since children there are educated in a variety of ways: basic education, vocational, and recreational. We were informed by Elena Kupriyanova that the *internal* is under the Ministry of Labor and Social Development.

39Meeting with Elena Kupriyanova, Mr. Petrukhin, and Ms. Kuznetsova of the Ministry of Labor and Social Development, Moscow, 21 October 1998.

4°Life preparation indicates skills such as food preparation, housekeeping, shopping, and certain basic banking and job skills.

go home on week-ends. It is important to note that children who enter Ministry of Education *internals* do not only come from baby houses. Many children are evaluated by professionals for the first time when they arrive at school at age four or at age seven. Children who are placed in Ministry of Education *intemafs* at this level often have families who are told by professionals that it is best for their children to reside at the *internal* the majority of the time, but they maintain contact through weekend and summer visits. The team was informed that in many instances transportation and an uneven distribution of se1vices for children with disabilities was a clear contributing factor to the out of home placement of these children. At the age of eighteen, children from these *internals* may return to their families in the community, but those with little contact are more likely to go on to live in an adult institution under the Ministry of Labor and Social Development.

Children who are placed in the Ministry of Labor and Social Development *intemats* at the age of four face a different situation. Generally speaking, these children are deemed "uneducable." We did see *intemats* where self-care skills and various activities of daily living were being taught, but we also saw rooms where certain children never left their beds. The staff in these institutions are called "cleaners," and it is clear that children are being cared for, but only in the sense of custodial care. In the Minist1y of Labor and Social Development facilities we visited, there was little or no systematic effort to habilitate, rehabilitate, or educate the children.

Ironically, the best programs we observed in the community are run by the Minist1y of Labor and Social Development. The team visited two alternative services - a community based rehabilitation center for children with disabilities and a community refuge center/shelter. Both are - which are both experimental projects under the Minist1y of Labor and Social Development of the Saratov region. The first center provides a variety of rehabilitation services to children on a daily basis. They also provide information on disabilities and related services in the region and legal advice. Fainily members appear to be heavily involved in the center's activities, and one parent is a member of the board of directors, as well as the President of the parents' association. The center sponsors joint sports activities with other children in the community and is involved in the wider league of International Special Olympics. The community refuge center/shelter is a temporary residential facility which runs both a hotline for children and families in crisis and a foster care program. This center seems to address primarily the issues of social orphans and prevention of that phenomenon. They screen, select, and train families to care for children who come from very difficult circumstances or "troubled families." The center also does some community outreach and identifies families at risk within the community. Both of these centers seemed open to new ideas and information, as well as being effective service delivery sites..

A number of Russian government officials emphasized that many families do keep their children at home and that there is a *'de facto'* integration of children with disabilities in many communities. 41 The team was unable to measure or document the actual number of children with disabilities in mainstream schools. We received many reports to the contra1y from educators and

41Interview with Mr. Shilov, Head of the Department of Rehabilitation and Special Education of the Ministry of General and Professional Education of Russia, Moscow, 21 October 1998,

professionals. In part, this situation is a product of the over-definition of "disability." Children termed "disabled" and attending mainstream Russian schools may not meet the internationally accepted definition of disability.42 Our interviews with parents associated with the Down Syndrome Association in Moscow corroborated the latter viewpoint. Many children with disabilities are cared for in the home, but these children receive almost no public support other than the disability pension from the government, which is inadequate to support the needs of a child with a disability. Through their own family network and information dissemination campaigns, the Association has encouraged and aided several families in caring for their child at home in the community.

* 1. Entrance to and conditions in the institutions

In the Russian system, there are many pathways into the institutional setting and very few out. For certain children who are born with visible and obvious impairments, physicians usually make an immediate decision to recommend placement in a baby house to the parents. Some families return home with their child, only to abandon them later at an institution - after the realities of home care become overwhelming or unaffordable. Other children are referred to Medical-Pedagogical Commissions by physicians at polyclinics later in their development, between the ages of zero and four. Still other children are referred to the Medical-Pedagogical Commissions by teachers when they reach school at age four or at age seven. These referrals are based on a variety of factors, yet they seem to be strongly correlated with deficiencies in speech or some other deviance from the norm in the traditional disciplines of reading, writing, and arithmetic. These deficiencies need not correspond with functional disabilities that would inhibit mainstream education and community integration.

The Medical-Pedagogical Commission is the gatekeeper of the realm - determining much of a child's future through his or her diagnosis and institutional referral. Each region has one regional commission and a certain number of local commissions. For example, the Saratov region has seven local commissions. Each commission consists of a psychologist, a psychiatrist, a speech therapist *(logoped),* a special educator *(defectologue),* an audiologist, an ophthalmologist, and usually a neurologist or other specialist, such as an orthopedist or pediatrician.

The Medical-Pedagogical Commission's task is to evaluate a child, determine her or his diagnosis, and then prescribe a special educational program to "correct" deficiencies. This may or may not mean placement in a specialized boarding school. The MDRI/UNICEF team discussed procedures and methods used by these commissions with professionals in Kaliningrad, Saratov, and Moscow. We found it impossible to identify a common set of criteria or tests used by all commissions. Interviews and a review of health records are usually included in the analysis. Some commission members report the use of standardized tests, such as the Wechsler exam for intelligence quotient. Commission members also report the use of other specialized examinations by the various specialists on the Commission. In some cases, the administration and interpretation of these exams appear to left entirely to the discretion of a pa1iicular expert. The evaluation process varies in length

"Disability refers to reduced function and activity of a person, based on the International classification of Impairments, Disabilities, and Handicaps.

from one day (or less) to the course of two months or more, depending on whom we asked. In Kaliningrad, we were told that the Commission often travels to schools, institutions, and even homes to evaluate children. Yet, in other regions, it seemed more common for the child to be brought to

. a center for evaluation.

The MDRI/UNICEF team received mixed reports about parental compliance with the Medical-Pedagogical Commission. We were told that certain parents hide their children from the Medical-Pedagogical Commission. Other parents reportedly defy the decision of the Commission after allowing their child to be tested. In Kaliningrad, the head of the Conunission claimed that no parent kept a child with a disability at home to educate her or him and that very few parents defied the Commission. 43 In Saratov, however, the head of the Commission claimed that approximately fifty percent of children with cognitive disabilities are kept at home by parents receiving disability pensions and that disagreements between parents and the Commission are arbitrated by an independent Conflict Commission.44

While there appears to be varying levels of agreement with Medical-Pedagogical Commissions on the part of parents, professionals who make up these commissions clearly believe that they know what is best for these children and that state facilities can meet these children's special needs far better than their parents. In a sense, they are realistic, acknowledging the parents' need to work outside the home and their lack of time available to devote to a child with special needs. In another sense, there is a clear imbalance of information and power. Parents do not fully understand their child's needs and lack the training to address them; therefore, the Medical­ Pedagogical Commission single-handedly decides a child's fate in many cases. Parents are frequently said to have "abandoned" their children when, in fact, they were never offered the supportive services necessary to keep them at home.45

For children deemed so disabled that they need to be placed in a residential institution, the options are narrowly defined. Living conditions in residential institutions under the authority of the Ministry of Education and Ministry of Labor and Social Development more or less comparable. Most *intemats* house between I50 and 200 children in the age range of 5 to 18 years old. The larger *internals* we visited in Moscow had 500 to 600 residents. Boys and girls have separate sleeping quarters with bedrooms containing eight to twenty beds each. Children are generally divided according to their diagnosis or level of ability. In some *internals,* however, we observed a family­ style living arrangement where children of mixed ages lived in one section of the *internal* as a

43Meeting at Kaliningrad Rehabilitation Center, Kaliningrad, 22 October 1998. "Interview in van with the head of the Saratov Regional Medical-Pedagogical

Commission, Saratov region, 27 October 1998.

45Many professionals as well as family members we interviewed have never been exposed to the supportive services that have proven effective in permitting children with mental disabilities to live a full life in the community. Appendix A of this report provides a brief description of these services.

"family." The furnishings of the *internals* vary from one site to the next, but they generally have some decorations, sufficient bedding and linens, and recreation rooms. In almost every internat we visited, there is a lack of personal space and a place to keep personal belongings.

Certain *internals* have kitchen areas or other facilities where children learn and practice certain skills of daily living. Ahnost all the *intemats* visited possess music rooms and theaters, workshops of all descriptions, and classrooms. Institutions were clean during our visits and they appear to be relatively well kept, considering the financial situation. Staff reported that children eat regularly and do not face shortages of essential nutrients. Meals are always planned and eaten together as a group.

Financial constraints exist at all facilities. We were told at one *internal* that they receive 3 rubles per day per child for medications and 21 rubles per day per child for food. We were also told that children with disabilities and orphans receive a pension from the state in the amount of 400 rubles per month. If the parents are involved with the child in any way, the parents receive the stipend. If not, 300 mbles goes to the institution each month, and the other I 00 rubles goes to the child in a special account. Special allowances for clothes and equipment were cut after the recent economic crisis. Salaries are 200 rubles a month for cleaners and 450 rubles a month for physicians; however, salaries have not been paid on time (or at all) for the past six months. The director also informed us that most staff worked double shifts in order to make enough money to survive and that she was lacking in specialists and trained staff.46 The majority of the directors claimed that their facilities are in desperate need of construction and repairs, but the municipalities either could not or would not give them the money to do the necessary work. Foreign donations enable many institutions to survive, particularly in Kaliningrad which receives extensive assistance from German donors. Even in these regions, however, staff complain that foreign visitors come and offer help only to disappear when it comes time to deliver.

While financial constraints are real, questions of money and resources do not eclipse all other considerations. Many factors affect children's lives, including a pervasive discrimination against children deemed "uneducable." Children who are considered to be "educable' are more likely to: (1) receive special education services; (2) be taught vocational skills; (3) be engaged in meaningful activities; (4) receive physical and speech therapy, and (5) be involved in community recreational activities that include non-disabled children. Children who were labeled as "uneducable" receive fewer services, therapies, supports in the institution, and opportunities to interact with "non­ disabled" children. For example, there were two sisters who live in two different *intemats* in the Moscow region. One was visiting the other one during vacation. They indicated that they wanted to live together, but we were told that would not happen because one was "educable" and the other was "uneducable." Since the two groups are housed in different institutions, they would have to remain apart.

#### Behavior programs

46Interview at *Internal* #28, Moscow, 30 October 1998.

We found a great shortage of behavior programs in all institutions for children with mental disabilities. This is particularly serious for children with severe mental disabilities, who are placed in "lying down" rooms - where they may remain permanently without any form of activities or other programs. 47 According to officials at the Federal officials, an estimated twenty percent of children with mental disabilities under Ministiy of Labor authority never leave their beds.

Rhythmic motion or "rocking" is common in the lying down rooms where children are deprived of any form of human contact or stimulation. We observed a number of cases of children with self-abusive behavior, hitting themselves or gouging their own eyes or scars. In some cases, we observed children in full upper-body restraints (strait jackets). Staff explained that these children are self-abusive. When we asked what kind of programs are available for such children, we were in some cases that physical restraints are the only response they know of 48 Thus, these children are permanently restrained. We questioned staff in a number of facilities who said that they were not familiar with the behavior modification programs that have proven effective in other countries in reducing many self-abusive behaviors. Staff did not seem to understand that self-injurious behavior and self-stimulation is frequently the result of living in an environment lacking in appropriate stimulation. Moreover, there is a cormnon lack of awareness that the self-injurious behavior may be due to the presence of certain syndromes and disease and, as a result, the child needed to be evaluated. For example, children with mental disabilities who hit their heads may do so in an attempt to alleviate pain from an ear infection or a toothache. More skilled professionals are needed in institutions for disabled children to assist in responding to these behavior problems.

We were told by some institution directors and staff that the *internal* system is not able to care for children with behavioral problems, such as physical aggression towards others. Children with this type of behavioral problem are reportedly placed in a psychiatric setting. The MDRI!UNICEF team toured two psychiatric facilities. In a few cases, we observed outward signs suggesting that children may be over medicated (e.g. lack of energy, shuffling walk). The major limitation of the psychiatric hospital programs is the lack of a social work staff to assist children in re-integrating into the community. In the absence of a network of community-based services, there is little the psychiatric hospital staff can do to assist a child who is ready to leave the hospital.



Staff responses to behavioral problems varied on a number of occasions when children became agitated by our presence. In one case in the Moscow psychiatric hospital, staff talked very

47"Lying down" room is the term the team used to describe the areas in certain institutions where children are kept in bed all day. Many of these children do not receive physical therapy, rehabilitation, habilitation, or other activities that might get them out of bed. These children are in the worst situation and experience the most difficult living conditions.

48In other cases, ward staff said that children received special drug treatment and in *intemat* number #I I we were told by ward staff that self-abusive children are placed in "special facilities" for children with behavior problems. We were never able to identify these other facilities and we have not cleared up this question. The directors of this institution contradicted staff and told us that self-abusive children are treated at the institution.

*I*

*Mental Disability Rights International* • *19*

quietly to an agitated child and gently redirected him to another area of the room. The staff person continued to talk to him. He quieted down and hugged the staff person. However, we later observed a child in an *intemat* in Moscow who was visibly upset and standing in the hall. A staff person was obviously angry with the child. While she yelled at the child and pulled her by the arm, the child cowered. The staff person placed the girl in a classroom and left her there without turning on the lights. In a few circumstances, we observed similar inappropriate staff responses to outbursts of this kind.

* 1. Medical care and treatment

Many children are delayed in physical stature and do not meet minimally acceptable milestones for development. In a number of institutions for children with disabilities, the team observed children who appear to be four to five years of age, who are recorded to be eight to ten years old. We witnessed other children barely able to sit up or crawl - or just learning to do so - whose are reportedly in the age range of four to eight. We did not have the opportunity to perform a thorough analysis of these development delays. Nor did we document the nutrition available to children in the institutions. Our observations suggest, however, that many children are underdeveloped because they are undernourished. This is a very serious threat to the health of children that requires futther documentation and - if true - an immediate response.

The lack of nurturing and attention by staff is a pervasive threat to the proper development of children perceived by staff to be the most disabled. In most cases, the number of staff available does not permit more attention. The MDRI/UNICEF team observed a large number of children with Down syndrome in the *internals* under the Ministry of Labor and Social Development, particularly in the rooms where children remain in bed all day. There appears to be an automatic assumption by professional and direct care workers that children with Down syndrome are severely handicapped and are "uneducable." As a result, many of these children are placed in the "lying down" rooms without proper assessments or evaluations. The children stay in their beds all day and, as a result, become more developmentally and physically delayed due to the lack of stimulation and education, rather than the presence of Down syndrome. This phenomenon reinforces our theory that physical appearance plays a key role in diagnosis and treatment of children with disabilities.

Basic lack of medications threatens the health of children - and this may be the only reason why these children do not remain at home. This is particularly true for children who are institutionalized because they have a chronic medical (somatic) condition. MDRI observed a large number of children who are institutionalized because they have asthma, mild to severe cases of cerebral palsy, or seizures. It appears that the lack of appropriate medications (i.e. asthma medications and inhalers, the full range of seizure medications and medications for spasms ) is the primary barrier to these children being successfully treated in the community or at home with family. In some cases, institution staff report that they do not have the full range of medications to control seizures or the symptoms of cerebral palsy. Staff explain that when they run out of the most appropriate type of medication, they are forced to substitute another type of medication. Switching between different types of medications can exacerbate the seizures or spasms. Lack of medications and the lack of access to the entire range of particular types of medications appear to result in

unnecessary institutionalization and poor medical care.

The daily *per die111* that the institutions receive to purchase medications is insufficient. If the *per die111* is increased however, it is unclear whether or not the staff could get access to needed medications. The MORI/UNICEF team received mixed reports regarding the availability of medications in Russia. Some staff report that it is difficult to get medications but others state that, if they were to have the money, they could buy what they need. Staff from institutions in St. Petersburg report that they need to vaccinate the children, but do not have the money to buy vaccinations.

We observed numerous practices on the part of staff who clean and feed children that create serious health risks for children. We observed staff cleaning children covered with urine and feces going from child to child without washing hands. These practices create serious risks of spreading infectious diseases. We also observed staff feeding children in recumbent positions, creating a risk of aspiration pneumonia. These staff did not appear to be trained in proper hygiene or feeding techniques. Given the low number of staff available to serve large numbers of children in lying down rooms, it is highly likely that practices of "bottle propping" and other unsupervised feeding for children with disabilities create an increased risk of death by aspiration.

* 1. Neglect in institutions

In all three types of institutions (Health, Education, and Ministry of Labor and Social Development), the team witnessed practices which constitute neglect. Despite the fact that staff and directors demonstrate great concern about the children, conditions are poor. In one of the baby houses visited in Kaliningrad, the team observed five and six children sitting together in linoleum­ lined cribs. Staff appear deeply concerned about the well-being of children in their care, and they monitor and change the children periodically. Despite this, the limited size of the staff makes it impossible to provide children with the attention they need. As a result, this children sit alone with little human interaction. In the adjoining room, there were eight children in a row of cribs with different disabilities and medical complications. The staff acknowledged a lack of proper medications, appropriate technology, and staff to care properly for these children. We were informed that this facility is one of the best in the region. If these conditions exist in one of the best facilities, we infer that conditions elsewhere are worse.

I

Many of the institutions had lower staff-to-child ratios, with one untrained staff(some times *j*

called a "cleaner") to care for twenty or more children. With the large number of children who are

*I*

not toilet-trained, these staff members could not possibly do more than clean children and the surroundings. Lack of social stimulation or inter-personal contact poses the greatest danger for children's development and emotional health. This is inevitable in the institutions with the staff ratios we observed. The dangers of isolation and neglect are particularly great for children with mental disabilities in institutions, where the complicated care of some children leaves others with almost no attention.

Children believed to be uneducable and labeled as 'imbecile' can be placed indefinitely in

bed in lying down rooms indefinitely. In these locations, staffing may be lower than in other parts of the same facility, and it is clearly difficult for children to receive the minimal clothing, clean sheets, and food that they need. The rooms where these children live are often filled with a strong odor from urine. Although physical therapists and massage therapists provide some services, the children spend the majority of their time in bed and not engaged in any type of activity.

Many of the children in lying down rooms have some muscle atrophy. In some extreme cases, limbs are locked into physically contorted ("pretzel") positions. Although we observed the children receiving physical and massage therapy, the institutions are understaffed and cannot provide adequate physical therapy services to all the children who need them. The large number of deformed children evidence this. Staff do not have the time to reposition children regularly to avoid muscle atrophy and other problems. Several children whose bodies were twisted at the trunk were only able to see from one direction. In some cases, we observed that staff did not even move children's beds so that they could look out into their enviromnent. These children spend their days staring at a wall or the ceiling. As a result, they fall further and further behind in both physical and mental development.

In the Bazarno-Karabulaksky *intemat,* children were dressed in uniforms and appeared to have no choice of clothing. The bedrooms consist often to sixteen beds each, and when asked, staff informed us that children keep their belongings and toiletries in communal closets down the hall. Many doors are locked and children are unable to roam freely within the *internal.* Certain children are chosen to participate in workshop activities and vocational education, yet other children are prohibited from such pursuits. The team remarked on the appearance of the same ten children in each vocational classroom, as if they had moved from one room to the next as we approached. Discrimination within the institution operates with regard to access to education and activities. Staff give attention and guidance freely to certain children, yet other children do not receive the same level of involvement or interaction.

In *Jntemat* #28 under the Ministry of Labor and Social Development in Moscow, the team was informed that this facility was also one of the best of its kind. The director informed us that foreign donations, particularly Dutch and British, provide much of the equipment used in the facility. She mentioned that she was severely under-staffed, however, and that many employees worked double shifts on a regular basis. In addition, she stated that she was forced to choose which specialists to keep on staff because she could only afford three (e.g. a psychiatrist as opposed to a neurologist or pediatrician). In *Internal* #28, the team observed a "lying down" room with fifteen children. We were informed that none of the children leave their beds. Even with the specialized equipment and facilities (e.g. whirlpool and gymnasium) available, this institution does not provide rehabilitative services to certain children. The perception that these children are hopeless determines their treatment - or lack thereof

* 1. Rights and patient choice

There is a broad failure to apply internationally accepted rights standards in residential

###### *22* • *Children in Russia's Institutions: Human Rights and Oe.portunities for Reform*

settings.49 For example, international human rights standards place strict controls on the use of physical restraints. We observed children tied to wheelchairs with sheets and other children restrained in bed with homemade strait-jackets. Without proper control or regulation, these measures constitute inhuman and degrading treatment, as prohibited by international human rights law.50

The environment of most institutions appears to be regimented and does not lend itself to children developing or exercising their capacity for individual choice. Under the United Nations Rules for the Protection of Juveniles:

[T]he physical envirolllllent should be in keeping with the rehabilitative aim of residential treatment, with due regard to the need for the juvenile for privacy, sensory stimuli, opportunities for association with peers and participation in sports physical exercise and leisure-time activities "51

The right to privacy does not exist in theory or in practice in any of the institutions we visited.52 Due to the placement of eight to twenty children in any one bedroom and the communal recreation areas, a child does not have time nor space to her or himself Many children are left in bed all day, without stimulation, and they do no receive any meaningful education. Decisions regarding a child's abilities set the limits of their education, and many children are not allowed the opportunity to develop to their maximum potential.

The institutional system limits children's freedom of choice and opportunities for community interaction. Children cannot choose their clothing, their food, or their schedules in the majority of institutions we visited. Certain *intemats* facilitate friendships outside of the institution through children's attendance at general schools, but this arrangement is the exception and not the rule. The

structure of the institutions impinges on both children's freedom of movement and freedom of

expression, as well. Activities are scheduled throughout the day, dictating that children be in a I

certain place at a certain time. Children are corrected when they speak without having been

*I*

*49See* Chapter I, Section D for analysis of applicable international standards. In addition to *I*

the broad rights protected under the CRC, the most detailed set of internationally accepted

standards of the rights of people with mental disabilities in institutions are the United Nations "Rules for the Protection of Juveniles Deprived of their Liberty" and the "Principles for the

Protection of Persons with Mental Illness"(the MI Principles). The MI Principles principles apply *I*

both to children and adults. *I*

*I*

*'0See* discussion in Chapter III, section E, below. The United Nation's "Principles for the Protection of Persons with Mental Illness" (MI Principles) set detailed standards on the abuse of physical restraints and does not permit them unless they are the only means necessary to prevent "imminent harm." MI Principles, principle 11(11).

51Rules for Juveniles, section D(32).

52These rights also protected in the MI Principles, principle 13(l)(b).

addressed or asked a question first. At certain moments, the team felt as if children were responding with phrases they had been instructed to use. In most cases, the team could not determine if children had the freedom to express any religious beliefs or the right to pursue marriage and a family.

In certain cases, children retain their right to a family while living in an institution and the right to have personal belongings. Many children supposedly go home on the weekends and spend summers with their families, so they maintain family contact. Notably, the children who had family relationships were also the children who most often own personal items. Certain *intemats* allow children to keep small toys and other donated items. In one *intertnat,* there was a small store where children or families could purchase items for money or for points earned through good behavior. The items at this store had been donated through international charities, raising questions about whether these items had been intended for sale.

* 1. Institutionalization of non-disabled children

In every institution visited, the team saw numerous children who appeared to have no intellectual disability. In certain cases, directors explained that children with no disability come to the *intemat* due to a "troubled" family background or the fact that they have no parents at all. Institutions classify children in this situation as "disabled" in order to allow them to reside in such a 'specialized' institution. Directors of these institutions pointed out that these children are able to get a broad array of services that they could not get at home. In some cases, institution directors agreed that the same services could be provided to children in their own home if transportation were freely available or if service systems were de-centralized. In other cases, directors insisted that it would be dangerous to leave children with disabled, alcoholic or otherwise "unfit" parents. In most cases, service providers said that support services for these parents were not available or were inadequate and that no serious effort had been made to keep children with these families.

The creation of support services in the community and preventive measures designed to keep families together can reduce this unnecessary institutionalization - and the terrible cost of social isolation that comes with it. The expansion of the existing foster care system can assist in keeping children in difficult circumstances out of institutions. For instances where residential placement is inevitable, children with no disability have a right to an appropriate education and services, which they will be must less likely to receive by being labeled as disabled and placed in a "correctional" school.

* 1. Access to institutions and oversight

The MORI/UNICEF team greatly appreciated the access we were given to institutions in Moscow, Kaliningrad, and Saratov. According to reports from other non-governmental advocates, however, access poses a problem throughout the country for many non-governmental organizations. In the course of MDRI's mission, the team faced some difficulties with access to the institutions. We had a particularly hard time gaining access to facilities for children with the most serious mental disabilities.

##### *24• Children in Russia's Institutions: Human Rights and Opportunities for Reform*

In Moscow, where we asked to see the largest facilities, the MDRI/UNICEF team was granted permission to visit *Internal* # I I and *Internal* # I *5* in Moscow. We visited *Internal* #11 that afternoon. By the following morning, the Moscow authorities revoked permission to visit *Intemat* # 15. Numerous calls were made on our behalf by UNICEF, other Russian NGOs, and Ms. Elena Kupriyanova of the Ministry of Labor and Social Development. Permission was not granted and the team never visited *Internal* #15. The fact that UNICEF and officials within the Russian federal ministry are unable to obtain access to certain institutions under Moscow regional authorities exemplifies the "closed" nature of these facilities.

In Saratov and Kaliningrad, when we asked to see institutions for children with the most severe disabilities, we were informed that institutions we requested to see were too far away to visit. Authorities in both Saratov and Kaliningrad were entirely open with us, but we had unfortunately not prepared our schedule to meet these extra travel requirements. The problem of gaining access to these facilities, however, demonstrates one of the dangers of placing children with disabilities in a remote location. Even when official rules permit access, limits on access may be very real for children's family and friends, for whom the cost and time of travel could be a barrier for regular visits. Barriers to access will not be completely removed until children are moved back to their own communities.

Because children in institutions are inherently "out of public view," systems of oversight must exist to protect the rights of the children residing there. Children in general, and particularly children with mental disabilities, may not be able to speak out about their own abuses. Thus, pro­ active efforts are needed to assure certain basic minimum standards of care. The team was informed that a system of oversight does exist in the regions, but this system relates to appropriate expenditure of funds and proper staffing. We were informed that official standards of care and human rights do

not exist, at the federal or regional level. Without standards, oversight is impossible. Creation of

standards and monitoring of institutional conditions through unannounced visits, thorough I

inspections, and periodic review of children's treatment and legal status are essential.

*!*

*I*

# *I*

*1*

*I*

1. Human Rights Obligations and Strategic Recommendations

The following is a summary of MDRI's findings and analysis of Russia's obligations to reform under the CRC. The Russian Federation can enforce these rights only through a program of progressive development that will require sustained commitment and funding over time. **In** this section, we identify the major human rights objectives needed to bring the Russian Federation into conformity with international human rights law, In addition, we include strategic recommendations to assist Russia in developing appropriate policies and programs to bring about service system reform and rights enforcement.

* 1. Right to community integration

The Russian system of services for children reflects the Soviet-era preference for institution­ based rather than community-based care. Community-based services and support systems are inadequate to permit children with mental disabilities to remain with their own family, and mechanisms to provide and support substitute family placement are inadequate. Substitute family programs (including foster care, supported foster care, or adoption) are extremely limited and cannot meet the needs of the many orphaned children or children given up by their parents. As a rule, institutional placement is used instead of family support and counseling programs to assist in keeping together families of children from "troubled homes," (i.e. children of single mothers, parents experiencing economic difficulties, parents with a desirability, parents with a substance abuse problem, etc.). As a result, some 400,000 to 600,000 children are unnecessarily placed in closed segregated institutions.

International human rights law recognizes a right to community integration that applies to children with and without disabilities. For all children, the right to community integration is reflected in the extensive protections that exist for families and the preference of family verses institutional placement. For children with mental or physical disabilities, Article 23 of the CRC requires that services "facilitate a child's active participation in the community."53 The CRC recognizes that special services must be made available to make it possible for children with disabilities to live in the community. Thus, the CRC requires countries "to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities *in a manner conducive to the child's achieving the jilllest possible social integration and individual development* "54 The right

to community integration for people with disabilities is a core principle of other United Nations human rights declarations, as well, including the Standard Rules on the Equalization of

53States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self reliance and facilitate a child's active participation in the community. CRC, article 23(1).

54CRC, article 23(3)(emphasis added).

Opportunities for Persons with Disabilities,55 the **MI** Principles, 56 the Declaration on the Rights of Mentally Retarded Persons. 57

Russia's system of orphanages and segregated special schools isolate children from the community. Despite the great efforts of many conuuitted, professional, and well-meaning staff, placement in an orphanage rather than an integrated, family-like environment hinders a child's social integration. Without close relatives with whom to form attachments, placement in institutions frequently delays or inhibits children's individual development. Government authorities and professionals must adopt a commitment to community integration wherever possible. Major changes are needed in policy and practice on the part of authorities at all levels to re-structure the service system to create the network of services needed to permit the fullest possible social integration.

Human Rights Objectives:

**Objective A: Policies and programs at all levels of government should reflect a broad commitment to community integration over institutional care for children. The CRC requil'es a policy of commitment to promote community integration wherever possible. These policies should be reflected in local or national laws and practices. Full enforcement of the l'ight to community integration will require, over time, the creation of a full network of community-based service**

""Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinaty structures of education, health, employment, and social services." UN Disabled Persons Unit, *I11trod11ction: Pwpose and content of the Standard Rules 011 the Equalization of Opportunities for Persons with Disabilities,* section 26, THE STANDARD RULES (I 994). The preamble of the Standard Rules states that "intensified efforts are needed to achieve the full and equal enjoyment of human rights and participation in society by persons with disabilities." StRE, *preamble.* This includes rehabilitation programs "based on the actual individual needs of persons with disabilities and on the principles of full pa1iicipation and equality All rehabilitation services

should be available in the local community where the person with disabilities lives. However, in some instances, in order to attain a certain training objective, special time-limited rehabilitation courses may be organized, where appropriate, in residential form." *Id.* Rule 3.

I

56"Every person with a mental illness shall have the right to live and work, as far as *I*

possible, in the community." Ml Principles, principle 3. Where treatment is necessary, "[e)very *i*

*I*

patient shall have the right to be treated in the least restrictive environment and with the least restrictive or intrusive treatment appropriate to the patient's health needs and the need to protect the physical safety of others." *Id.,* principle 9(1).

57The Declaration states that, "[w]henver possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life." A person should be placed in an institutions only ifit "becomes necessary." Declaration on the Rights of Mentally Retarded Persons, section 4.

### *Mental Disability Rights I11ternatio11al o 27*

and support systems for children with disabilities.

**Strategic Recommendations:**

* + 1. **Available resources should be re-allocated to permit the creation of community-based services and support systems for children with disabilities** - The CRC recognizes that the creation of the community se1vices needed to maximize social integration is "subject to available resources."" While overall resources are limited, the Russian Federation can re­ allocate available funds to promote community alternatives to institutions wherever possible. National and regional planning will be needed to re-allocate cost to bring about the development and implementation community integration policies (see recommendation E).
    2. **Russian authorities should work toward a moratorium on new admissions** - Russian authorities should place the highest priority on preventing new placements in institutions. To make it possible for children with disabilities to remain in the community, they will have to develop a full range of community services and support programs. As it is easiest to start small, new services should be targeted to meet the needs of children most at-risk of placement in an institution. The break-up of bonds with parents, extended family, and the community is a critical experience that may lead to long-term damage. Placement in an institution that is intended to be temporary may lead to breakdown of family and community ties, and this may ultimately lead to long-term institutionalization. An approach of this kind can prevent certain developmental delays and psychological disabilities, and will reduce the amount of future resources needed for institutional care.
    3. **Institutions should not be closed and their budgets should not be reduced until appropriate and safe alternative services are created** - The Russian Federation should not make the mistake made by many Western countries in prematurely closing institutions or cutting budgets for social services. The development of effective community-based alternatives to institutions (described further in this report) are needed before institutional beds can be reduced or institutions closed. Russian institutions are already short of the funds they need to provide appropriate care to children currently residing within them; their budgets must not be reduced until children can be safely moved to the community. Community integration will be less expensive for some children in the long run, but governments should not expect cost savings during the time of transition to institutional care. New investments will be needed over time to create a complete system of community

alternatives.

* + 1. **Russian authorities should initiate immediate, low-cost measures to prnmote integration** - Local and regional authorities can make important, short-term improvements in community integration with little or no new investment. In many respects, leadership and commitment to the rights and community integration of children with disabilities is more important than financial resources. Oppo1iunities to integrate children into the community

58CRC, article 23(2).

can begin immediately at little or no cost in every locale of the Russian Federation. In some cases, the MDRI team observed mainstream schools side-by-side with segregated facilities for children with disabilities. Opening the doors between mainstream and segregated facilities may cost nothing. Local authorities can tap existing "natural supports," such as family members, children in mainstream care, and volunteer contributions on the part of the community to expand resources currently available to them. Part IV of this report identifies low-cost programs to begin conununity integration in every institution visited by the MDRI team. Local governments and institutions can use these programs as models to begin immediate efforts at community integration in their area.

* 1. Right to family and community support

The CRC enshrines respect for the child's family "as the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children..."59 Thus, the family "should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community."60

Social service programs in Russia are constructed to remove the child from the family that is considered "troubled." As a result, family support and counseling programs are extremely limited. In the Russian system, any child with or without a disability or health problems may be placed in an institution because of the troubles of his or her parent. A child may be institutionalized because ofa parent's disability or because his because his or her parent simply lacks the economic resources to take proper care of the child. Frequently, the children of single mothers experiencing financial difficulties are placed in institutions. Institutional placement because of a parent's problems with alcohol or substance abuse are also common.

Throughout MDRI's visit to Russia, service providers explained that the institution was the only service available to children from troubled families. While the CRC does permit children to be taken away from abusive parents, it recognizes that the primary responsibility for the child should be with the parents. Where necessary, the CRC requires that the state provide "appropriate assistance to parents and legal guardians in the performance of their child rearing responsibilities....."61 Family support and counseling programs must be developed and expanded to prevent ullllecessary institutionalization of children.

Objective B: Social services systems in the community should be established to make it possible to keep children with their family wherever possible. Where out of home placement is necessary, a substitute or "foster" family should be made

59CRC, *preamble.* Significant protections for the family are included in articles 2, 8, 9, 16, 18, 27, and elsewhere in the CRC.

*'0Id*

61CRC, article 18(2).

## *Mental Disability Rights I11ternatio11al* • *29*

**available.**

The priorities of Russian social service systems in responding to the needs of children from troubled families should be changed, so that every effort is made to keep children at home. In order to make this possible, local and regional authorities must create new family support programs. Support, counseling, and respite care should be provided to "troubled families" with a child at-risk of institutionalization. Substitute family and adoption programs should be created for orphans and children unable to remain with their parents.

**Strategic 1·econ11nendations:**

* + 1. **Adequate benefits should be made available** to children with disabilities and their families in the community - Russia currently provides a disability pension benefit to families of children with disabilities. Families consistently report that this benefit does not come close to covering the cost of a child with a disability living in the community. Without a full range ofcornmunity services, the burden on families seeking to keep a disabled child at home is enormous. Often one family member has to stay home with the child and one full parents' income is lost. When schools do not accept children with disabilities, parents do not benefit from the daily respite afforded to most parents. The CRC requires that pension (or "social insurance") programs be appropriate for the special needs of all children.62 Cash payments to parents of children with disabilities have proven to be one of the most low-cost and effective ways of preventing unnecessary institutionalization and should serve as the cornerstone of Russia's connnunity-based support program.
    2. **End incentives to institutionalize children** - The Disability Pension should only be available for children who remain at home. At present, when a child is placed in an institution, the disability pension is paid directly to the facility. This creates a financial incentive on the part of the institution to keep children with disabilities.
    3. **Local and regional autho1·ities should create family support programs** - With appropriate support, counseling and education, many families in Russia will be willing and able to keep disabled children at home. While the CRC does require that alternatives be created to protect children from neglect and abuse by their own parents or other care-givers,63 the vast majority of children from "troubled families" can safely remain at home if parents receive appropriate supports. This includes children from homes where there is only one parent, a parent with a disability, a parent with a history of alcoholism or substance abuse. Russian authorities should study and adapt models for family support that have proven effective in other countries. Professional education programs for psychologists and social workers should train students to implement these models. Continuing education programs should exposed

62CRC, article 26(l)and 26(2).

*63/d.* article 8(1). Human rights oversight programs must ensure the protection of children in all community programs. See recommendation E-5.

experienced professionals to new ways of supporting family members.

The CRC requires "appropriate assistance to parents and legal guardians in the performance of their child-raising responsibilities."64 The CRC also requires child-care services for children of working parents, as well as material assistance and support.65 Enforcement of the right to education (described further below) will also assist parents keeping disabled children at home, as this will free up parents during the working day.

* + 1. **Russian authorities should make substitute family programs** (**e.g. foster care) available to all children at-risk of institutionalization** - When a child does not have a family, or when parents cannot take care of a child, institutions are used far more often than substitute family arrangements, such as foster care. When no possibility of family unification is possible, or if parents are deceased, adoption should be an option. The MDRI team did identify one very impressive foster care program in the city of Saratov, demonstrating that the foster care model can be effective in Russia. Unfortunately, this form of substitute family program is not made available to the vast majority of children in Russia's institutions. Service providers in all three areas we visited reported that foster care was not available for children with disabilities and that adoption is extremely difficult to obtain. The CRC requires that "alternative care" be available for children not able to remain with their parents. This care may include foster placement foster care or adoption.66

Substitute family arrangements should be made available to all children before resorting to institutional placement, which should only be used "ifnecessary."67 Models of community services that have been developed demonstrate almost all children, even those with the most severe disabilities, can be served safely and effectively in the community.

* + 1. **Parents and people with disabilities should be actively involved in the development and implementation of new community prngrams** - In many countries, parents and people with disabilities have provided key leadership in the development of innovative new programs. As a practical matter, these individuals are most familiar with the needs of service system users and they know what programs will be effective. The United Nations has recognized that people with disabilities and other concerned non-governmental organizations need to paiiicipate in program planning, development, and implementation.68

64/d article 18(2).

*65/d* arts. 18(3), 27(3).

*66/d* article 20(3).

68Persons with disabilities and their families should be able to participate in the design and organization of rehabilitation services concerning themselves." StRE, rule 3(3). *See also*

*Mental Disability Rights International* • *31*

* + 1. **Leaders among service system professionals should be exposed to community-based service models and trained to implement them** - Many service system professionals are not familiar with the existence of habilitation teclmiqnes, family supports, or the range of community-based service programs that could permit the community integration of children with even the most severe mental disabilities. Leaders in the field should be exposed to models that have been created in other countries so that they will truly believe that these techniques work. These leaders should then be trained to implement these services and to develop appropriate curricula for training within Russia. Training in programs needed for community services should be a standard part of training curricula for all professionals serving children with disabilities.
    2. **Service practitioners should be provided with in-service education** to permit them to incorporate new skills and practices into their work needed to provide services to children in the community. Curricula should be adapted to provide short five to ten day seminars for service professionals.
    3. **Techniques of "functional assessment" should be introduced** to policy-makers, program administrators, and to members of Medico-Pedagogical Commissions who currently diagnose children. University training programs should establish short curricula so that professionals can learn the essential of functional assessment and can design and implement programs based on this approach. The functional assessment approach will identify a child's skills and abilities and will permit the provision of services that maximize the use of those skills as a valued member of society. Instead of the medical model approach used by defectology, which aims to "cure" or "correct" inadequacies of the child, the functional approach identifies and provides whatever additional supports are needed to ensure community integration. Training programs will also expose professionals to both developmental and support models. Through this in service training, professionals will be able to move from the medical model through the developmental model to a system of

supports.

* + 1. **Public education, outreach, and prevention programs should be established** - Public education is needed to provide information about available services in the community. Anonymous information hotlines can provide people with disabilities and family members with the support and information they need. Educational prevention projects within maternal/child health care clinics and programs can help avoid certain health problems and can ensure early intervention for others.
  1. Right to highest attainable standard of health and development

Rule 4(7) ("persons with disabilities using [personal assistance programs] have a decisive influence on the way in which programs are delivered"); rule 14( I) "[s]tates should involve organizations of persons with disabilities in all decision-making relating to plans and programmes concerning persons with disabilities or affecting their economic and social status."

The CRC requires States to "ensure to the maximum extent possible the survival and

development of the child."69 In addition, children have a right "to the enjoyment of the highest attainable standard ofhealth...."70 MDRI's findings in Russia's institutions suggest that placement

in an institution in Russia creates serious health risks, particularly for young children. We observed many caring staff members working hard to provide care to children. Yet staffing is simply not high enough to provide each child with the individual attention required for optimal growth and development. In some of the institutions we visited, there was no more than one staff person for fifteen children in a room at any one time. Children thus remain much of the day in a crib or bed without any stimulation. The situation is particularly serious for children with severe disabilities, where the demands on staff are even greater. Staff are not trained to provide the habilitation programs to teach these children basic self-care skills. We observed numerous children self­ stimulating through rocking or through self-abuse. Due to shortages of staff and lack of specially trained professionals, behavior modification programs to respond to such behavior problems are largely absent. We also observed large numbers of children with deformities that could have been avoided through regular exercise, re-positioning, and physical therapy. In many institutions where trained staff do provide physical therapy they are ove1whelmed by the large numbers of children in need and cannot provide adequate assistance to all children.

Reform effo1is to improve health conditions in Russian institutions should be informed by international experience. While higher staff ratios and more trained staff will ameliorate some conditions, international experience strongly indicates that protection of the health and maximization of individual social and psychological development will require community integration. Children - particularly infants and toddlers - who spend their first years in congregate facilities rather than home-like environments will be more likely to experience developmental delays and psychological deficits even in well staffed, well equipped, and well funded institutions.71 Through adoption, foster care or return to parents, many cognitive deficits acquired during early child institutionalization are reversible, but some social, behavioral and emotional may not be.72 Children who grow up in congregate facilities are exposed to higher rates of avoidable health risks than those who grow up

*69ld.* art 6(2).

*701d.* art 24.

71 Studies from Romanian orphanages demonstrate that, where social stimulation is limited, developmental deficits can be profound. Even in well staffed institutions, deficits in cognitive development and verbal skills can be significant. Deborah A. Frank, Perri E. Klass, Felton Earls, and Leon Eisenberg, *Infants and Young Children in 01phanages: One View from Pediatrics and Child Psychiafly,* 95 PEDIATRJCS 569, 572 (1996); Sandra Kaler and BJ. Freeman, Analysis of Environmental Depravation: Cognitive and Social Development in Romanian Orphans, 35 J. CHJLD PSYCHOLOGY & PSYCHIATRY 769 (1994).

I

I

72Frank, et. al., *supra* note 70, at 574.

###### *Mental Disability Rights International o 33*

in a home-like setting. This includes higher rates of risk of infectious illness73 and malnutrition." A major increase in resources for institutions and higher levels of staff may reduce many of these dangers, research suggests that higher rates of risk for institutionalized children cannot be entirely eliminated. 75 Given the reality that major new investments in institutions are unlikely in Russia at

73The major health risks associated with placement of children in a congregate setting are respiratory and gastrointestinal infections, as well as malnutrition. International studies show a higher rate of infectious morbidity for children in congregate settings as compared to children who remain in their own homes:

The three factors most consistently linked to infectious disease transmission in group care have been young ages of the children, institutional versus family day care, and hours spent in the institutional setting. The increased risk of infection in young children in out of home care, compared with own family care, seems to attain statistical significance when there are more than three children in a child care setting.

Frank, *et al, supra* note 32, at 570. In places where Hepatitis B and Tuberculosis are a problem in the general population, such as Russia, it can be expected that there will be an even greater danger for children in orphanages:

Even "[v]accine-preventable diseases...persist as threats in the orphanage setting. Even with meticulous compliance with the recommended immunization schedule, infants may remain vulnerable until the series is completed (e.g. Pe1tussis) or until the immunologic capacity to respond to the vaccine develops (e.g., measles and pneumococcus)." *Id.*

Unlike day-care programs, orphanages cannot keep out children who are "ill and infectious but not sick enough to require hospitalization."

*Id.* at 571 (citations omitted).

Even when food supplies are adequate, there is still a risk of malnutrition:

[M]ost investigators suggest that growth failure historically noted in institutionalized infants and young children did not necessarily reflect insufficient quantity and quality of available food, but too few care givers to assure that the available food was fed to those too young to feed themselves. Medical accounts of large institutions for infants describe universal bottle propping (with or without purees ii1 the bottle) Bottle propping in

infants and unsupervised feeding in toddlers, in addition to depriving the child of critical interpersonal interactions with a care giver, entail an unacceptable risk of fatal aspiration, which historically was frequently noted at postmortem examinations of institutionalized infants.

*Id.* at 571 (citations omitted).

75A literature review concludes:

From a developmental perspective, infants and young children are uniqnely vulnerable to the medical and psychosocial risks intrinsic to institutional care. Some of these risks are theoretically subject to intelligent amelioration, but others cannot be reduced to tolerable levels even with massive expenditure. The literature does suggest that with extraordinary funding to support a I :3 trained staff-to-child ratio, to purchase, prepare, and offer sufficient food and to provide developmentally stimulating materials in a context of social

this time, MDRI recommends that the primary emphasis of reform efforts should be directed to community integration.

**Objective C: Health and development of children now in institutional care can only be maximized through the creation of community alternatives to institutions and outplacement programs. Emergency programs to protect the health of children in institutions may be needed. Model community programs are needed to demonstrate the effectiveness of community integration of children with disabilities. More habilitation professionals should be trained and employed to service children with disabilities; these professionals should work for community authorities and not for institutions so that programs can be adapted to serve children in the community as needed.**

**Strategic Recommendations:**

* + 1. **Community re-integration programs should be created for children now in institutions**
       - Community integration is necessaiy for all children to obtain the highest attainable standard of health and individual development. The right to community integration and support for the family under the CRC does not terminate upon placement in an institution. Even when bonds have been broken with families, children currently residing in institutions can benefit from substitute family programs that reintegrate them into society. Supported foster-care programs have proven particularly effective, particularly for children with disabilities (supported foster care programs are described further in Appendix A).
    2. **Model programs should be established** to demonstrate the potential for community re­ integration of children with disabilities now residing in institutions. Many professionals and service providers in Russia believe that children with disabilities residing in Russia's institutions cannot be effectively reintegrated into the community. Model programs are needed to demonstrate how such programs would operate. These programs should adapt techniques developed in other countries to provide the education, habilitation, financial support, and family counseling, and other follow-up services needed for the difficult progress of community re-integration. Funding should be provided to study and disseminate information about the operation of model programs so that they can be appropriately adapted to the Russian context, evaluated, improved, and replicated on a national scale. Programs should used to train service system professionals in the design and implementation of community programs. Non-governmental organizations made up of people with disabilities and family members should be actively involved in the design, implementation, and evaluation of these model programs.

###### *Id.*

interaction, growth failure and severe developmental retardation among institutionalized infants might be avoided.

* + 1. **Childl'en with sevel'e mental disabilities must be included in model programs** - Model programs must ensure the inclusion of children with severe mental disabilities. Without the inclusion of children with disabilities, model programs will not accurately reflect the real challenges and full range of services needed to create effective community integration for the current population in Russia's institutions. Model programs that start with non-disabled children may be misleading, because they may result in an underestimate of the cost of community integration. Programs demonstrating that children with severe mental disabilities can be integrated into the community are most useful to the development of new policies and a new political consensus for reform because they prove that children with less severe or no disabilities can be so integrated.
    2. **Model programs should be fully integrated and should pl'ovide for the full continuum of cal'e** - Children with disabilities require a full continuum of care in the community, including habilitation, health care, respite care, and education. Care-givers will require training, counseling and financial support. Model programs that are too small and provide only one pa1t of the continuum of care may not be fully effective in permitting children with mental disabilities to be integrated into the community.
    3. **Pl'ofessional training and suppol't** - More professionals should be trained and suppo1ted to provide habilitation to children with disabilities - in or out of institutions. Programs should be community-based and tailored to the living circumstances of children most in need.

Within institutions, MDRI found a great shortage of staff with expertise in habilitation for children with mental disabilities, including speech therapy, training in self-care skills, education, physical therapy. MDRI identified a number of highly qualified individuals in each area we visited, but their numbers were not adequate to meet the needs of all children in institutions. Additional training and support is needed for new staff. These staff should not be funded or employed through institutions but should work for local community authorities. In this way, they can adapt service programs to the needs of children in the community (or in the institution). Over time, as more and more children are served in the community, they can shift the locus of their activities from institutions to the community.

* + 1. **Emel'gency assistance should be provided** to ensure adequate food, heating, clothing, hygiene, and medical care to children in institutions. The national government should establish a simple assessment tool to be implemented at the regional and local level to identify areas in need of emergency assistance.
    2. Minimum standards oftl'eatment and quality assurance prngmms must be established
       - Each institution we visited reported almost complete discretion to make decisions about the type of care they would provide. To the extent that oversight exists, it appears to be limited to monitoring the use of funds to prevent corruptions. Neither national or regional government authorities establish enforceable minimum standards of care. These standards are essential to ensure that basic medical care and minimum levels of habilitation are

provided in each institution. In order to make these minimum standards effective, central authorities must create a quality assurance system based on regular inspections. Legal enforcement mechanisms must be created to ensure compliance with minimum standards. The involvement of people with disabilities and family members in establishing, monitoring, and enforcing human rights is essential.

* 1. Right to education

The CRC guarantees all children a right to education, including a primaty education "available free to all" and secondary education "accessible to every child."76 States shall "ensure that the disabled child has effective access to and receives education...in a manner conducive to the child's achieving the fullest possible social integration and individual development...."77 The purpose of education - for children with and without disabilities - is preparation "of the child for a responsible life in a free society...."78 The StRE specify that "[g]eneral educational authorities are responsible for the education of persons with disabilities in integrated settings."79

As a practical matter, children with disabilities are excluded from mainstream schools in Russia. The Ministry of Education reports that children with disabilities are served in regular schools, but the children they identify as "disabled" are likely children slightly below the mean in intelligence.'0 These children would not be recognized as suffering from the major functional limitations that define the term in international standards. Children with severe mental disabilities are deemed "uneducable" and receive no education at all. Children with mild mental disabilities are usually denied an education in the community. The only education available to these children is in the residential setting of the *intemat.* The very isolation and segregation of the *intemat* system undermines the core purpose of an education - to promote social integration and to maximize individual development.

Objective D: All children, regardless of disability, shall receive a free and appropriate education in the most integmted/least restl'ictive setting suitable to the individual's abilities. Special programs shall be created in mainstream classrooms to ensure that children with mental disabilities can maximize their individual potential in a setting that promotes community integmtion.

I

76CRC, article 28(1).

*77ld.* article 23(3).

*I*

*78ld.,* article 29(l)(d). *I*

79StRE, Rule 6(1).

' Ministry of Education officials report that they support new legislation to promote increased opportunities for integrated education of children with mental and physical disabilities. They have drafted new legislation for this purpose but it has not yet been adopted.

0

Strategic Recommendations:

* + 1. **Right to free, appropriate, integrated education** - All children should have a legally enforceable right to a free and appropriate education in the least restrictive setting.
    2. **Special programs should be established to ensure appropriate cmTicula and accessible classrooms** - Special programs should be established within mainstream schools to ensure that education for children with mental disabilities is appropriate and tailored to the individual needs of the child. Integrated education for children with mental disabilities will require some re-training for teachers in mainstream schools. Teachers aides may also be necessary in some classrooms. Schools should also provide related services, such as speech pathology, physical therapy, and mental health services that enable a child to benefit from an education. These services should be adapted to the individual needs of the child. Local authorities should ensure that classrooms and transportation to and from school are available and accessible to children with disabilities.
    3. **Local authorities should c1·eate model integrated classrooms** - Educators and professionals throughout Russia do not believe that children with severe mental disabilities can benefit from any education, let alone an education in an integrated setting. Model programs dedicated to providing appropriate education for children with severe mental disabilities will demonstrate the value of a mainstream education for all children. Successfol model programs will help build the political constituency to promote policy changes on a national level. Model curricula from other countries can be imported form other countries and adapted to Russia. The effectiveness of these programs in Russia should be documented so that models can be improved and replicated throughout Russia.
    4. **Children in institutions should be integrated into mainstream schools in their neighborhoods** - Community placement of children now living in institutions will take time, but local authorities can make begin immediately to integrate children from institutions into mainstream schools. This approach to reform is quick and low-cost, and it will provide children's with significant opportunities for individual growth. Education can be the first step toward children establishing contacts in society at-large. Children will develop social skills from these contacts that will greatly assist in their community integration.
    5. **Russian educators should be trained** and exposed to Western models of community integration and educational techniques for teaching children with mental disabilities. Over time, this training should be incorporated into all teacher training and certification programs throughout Russia.
  1. Protections against inhuman and degrading treatment

Unlike decisions about the structure of service systems, protections against inhuman and degrading treatment in institutions are not subject to resource limitations. The CRC states uncategorically that "[n]o child shall be subjected to torture or other cruel, inhuman or degrading

treatment or punishment."81 This includes children in institutions.82 The CRC requires countries to take "all appropriate measures...to protect children from all forms of sexual exploitation and **abuse."83**

International human rights authorities have held that the law on inhuman and degrading treatment applies to conditions in institutions, such as the improper use of seclusion or physical restraints.84 Where practices, such as the use of seclusion or restraints, cause great pain or mental anguish, they may constitute inhuman or degrading treatment even if they were not intended to do so. Thus, the placement of a child in physical restraints for the administrative convenience of ward staff is prohibited by human rights law - regardless of levels of staffing or resources available to institutional authorities. The great mental anguish and feeling of abandonment caused by placement in a crib without any form of personal attention other than feeding or toileting for days or months may constitute inhuman and degrading treatment. We believe that the practice in certain institutions ofleaving disabled children in cribs without attention causes suffering as serious as any recognized as illegal under international human rights law.

MDRI identified a number of examples of inhuman and degrading treatment involving the misuse of physical restraints during our visit to institutions. In many cases, we identified children with disabilities who were reportedly left for hours or days in physical restraints (strait jackets that prevent the movement of arms). In practice, these children may live their whole lives in restraints. The United Nations "Principles for the Protection of Persons with Mental Illness" (MI Principles) provides detailed minimum guidelines for the treatment of people in institutions, and these can be used as a guide to the requirements of human rights protections against inhuman and degrading treatment.85 The MI Principles restrict the use of physical restraints, for example, to occasions when they are "the only means available to prevent immediate or imminent harm to the patient or others."86 Physical restraints cannot be considered the "only means" available to prevent harm, even when children engage in self-abusive behavior. Behavior modification programs can be used to prevent

most dangerous activity on the part of children with disabilities.

81CRC, article 37(a).

""Every child deprived of liberty shall be treated with humanity and respect for the inherent dignity of the human person, and in a manner which takes into account the needs of persons of his or her age." *Id,* article 37(c).

*83Id,* article 33. j

84Rosenthal & Rubenstein, *supra* note 14, at 273 (reviewing decisions of the European I

Commission and Court of Human Rights on inhuman and degrading treatment).

*85/d* at 270.

86MI Principles, principle 11(11).

Objective E: Russian authorities must establish enforceable legal rights, meeting internationally accepted human rights standards, to protect all childl'en from inhuman and degrading treatment institutions; human rights ovel'sight and enforcement mechanism (including, but not limited to ombudsmen) are needed to ensure enforcement of these rights.

**Strategic recommendations:**

* + 1. **Establishment of enforceable legal rights for children in institutions** - a detailed bill of rights for children in institutions is needed. This bill of rights should at least meet the minimum requirements of international human rights standards, such as the MI Principles. The rights of children in institutions should be legally enforceable and their violation should carry appropriate punishments.
    2. **Creation of confidential complaint procedures** - Children in institutions must have the opportunity to file complaints in a manner that is confidential and will guarantee their safety from retaliation by institutional authorities. The creation of an independent authority, such as an ombudsman, would greatly enhance the effectiveness of the complaint procedure.
    3. **Creation of human l'ights oversight and enforcement mechanisms** - Children in institutions may not be able to speak out about abuses against them, so oversight and enforcement mechanisms must be established to ensure pro-active efforts to document treatment practices and living conditions in institutions. One oversight mechanism is the children's rights ombudsman. In addition to ombudsmen, independent advocacy services with enforcement powers would also be valuable. Oversight and enforcement mechanisms should be independent of institutions, but they should have a guaranteed right of unannounced access to all children living in institutions, all places within institutions, and all medical or administrative records. Oversight bodies should publish regular reports of their findings, and they should have the authority to initiate legal action against institutions that do not terminate illegal practices.
    4. **Creation of human rights committees** - Human rights cormnittees made up of staff, children in institutions, lay advocates, family members, and other members of the community can provide a valuable mechanism for promoting human rights oversight. Human rights committees visit institutions and speak to children informally on a routine basis. Human rights committees are flexible structures that assure that members of the local cormnunity are aware of conditions and treatment practice in the community. Human rights committees should not be created in *lieu* of more formalize human rights oversight and enforcement

mechanisms.

* + 1. **Pl'otections against abuses in the community** - Human rights oversight and enforcement mechanisms must protect against abuses in the community, as well as in institutions. Abuse, including sexual abuse, by parents, as well as foster parents or other care givers is an unfortunate reality in any society. Foster parents and other community care givers should

receive appropriate training and evaluation before they can participate in a community program. Standards for coll1lllunity care should be established and programs should be regularly monitored and evaluated. Education should be available to children about taking appropriate precautions against sexual and other forms of abuse. Information should be available to children and the public about child protective services. Where neglect abuse is documented, an independent judicial authority must make a determination that alternative placement of a child is in the child's best interest. When children are removed from their homes, alternative community placements should be made available.

* 1. Child's right to exercise choice

While the CRC protects the over-arching principle of the "best interest" of the child, the

convention also protects the right of "the child who is capable of forming his or her own views the right to express those views in all matters affecting the child, the views of the child being given due

I

weight in accordance with the age and maturity of the child."87

I

This right - as with all other rights

in the CRC - applies equally to children with disabilities. It cannot be assumed that a child with mental disability is not "capable" of forming his or her own views. Even if a child is considered to be mentally retarded, any decision to restrict or deny his or her rights "must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and the right to appeal to higher authorities."88 Thus, it should be assumed that all children with disabilities retain their right to free exercise of choice provided to their peers, unless a determination is made that he or she is specifically unable to make that choice.

Objective F: All children in institutions - including children with disabilities - have the right to express and exercise choice about basic decisions that affect their rights. Services should be flexible enough to be shaped to meet the individual needs and expressed wishes of the child where possible.

**Strategic recommendation:**

* + 1. **Notice of rights** - Children should be appropriately informed about their rights and about alternatives options available to them in all activities from the most mundane to the most serious. Special programs must be established to ensure that matters of choice are presented to children in a way that is understandable to them; these programs should be individualized to meet the needs of all children, including children with mental disabilities. Augmented and facilitated coll1lllunication formats should be employed as needed.
    2. **Self-advocacy training** - All children, including children with disabilities, can be taught

*I*

skills that will assist them in participating effectively in decisions that affect them. This is i

87CRC, article 12(1).

"Declaration on the Rights of Mentally Retarded Persons, sec. 7.

called self-advocacy.89 Children with disabilities in Russia should be trained in self­ advocacy. Russians with disabilities can be trained as "trainers" so that they will have the skills to train their peers in self-advocacy skills.

* + 1. **Responsive social service programs** - Social service programs should be adapted to reflect children's preferences and choices. This may include, for example, individualized preferences for food, decoration of personal living space, or decisions about the use ofleisure time. Major life decisions, such as a residential decisions, should also take into account a child's preference.
  1. Citizen participation in national planning

Reforming laws to protect children in institutions and in the community, creating a system of community-based services, and re-allocating existing resources to maximize community integration is a complex process that requires careful planning. The United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities (StRE) calls on states to "initiate and plan adequate policies for persons with disabilities at the national level, and stimulate and support action at regional and local levels."90 The process of planning should be as open and public as possible. The StRE call on states to "involve organizations of persons with disabilities in all decision-making relating to plans and programs concerning persons with disabilities or affecting their economic or social status."91 In addition to people with disabilities, the StRE call on states to facilitate the participation of "local communities" in program developrnent,92 as well "non­ governmental organizations and other interested bodies."93

Throughout the world, non-governmental organizations made up of people with disabilities and family members of people with disabilities have been key leaders· and activists in the reform process. People closest to the day-to-day challenges of people with disabilities are most familiar with issues that need to be address and with solutions that would be most effective in addressing them. To ensure effective citizen participation, local, regional, and national governments should establish citizen advisory boards made up of or including consumers (people with disabilities and family members). The United Nations has adopted guidelines, endorsed by the UN General Assembly, on the development of citizen advisory boards which "strongly urge government to

89Self-advocacy by people with disabilities has proven effective in many countries around the world. *See* NEW VOICES: SELF-ADVOCACY BY PEOPLE WITH DISABILITIES (Gunnar Dybwad

and Hank Bersani, Jr. eds., 1996) (describing experiences with self-advocacy around the world).

90StRE, Rule 14(1).

*91/d.* rule 14(2).

*92/d.* rule 14(5).

93*Id.* rule I6(2).

establish an organizational framework - or strengthen the existing one - as a permanent structure."94

Objective G: National, regional, and local planning committees should be established to develop and implement community integration policies. These committees should include people with disabilities, family members, and representatives of other concerned citizens groups.

**Strntegic recommendations:**

* + 1. **National, regional, and local governments should sponsor the establishment of independent advisory committees or "disability councils" to begin planning service system reform** - Disability councils should be supported and recognized by governments, but they should be independent and self-governing. They should include a majority of non­ governmental members. Numerous models for disability councils have been established around the world, including countries of Central and Eastern Europe (such as Hungary and the Czech Republic) that can serve as models for Russia.
    2. **People with disabilities and community members should be included in planning and implementation of reform progrnms** - National planning for reform of Russia's service system for children should be as open as possible, and the government should ensure that all interested parties, including people with disabilities, family members, and other interested non-governmental organizations are part of this process.
    3. **The Russian government and international funders should support advocacy training for people with disabilities, family activists, and NGO's** - Effective citizen participation in reform efforts by and for people with disabilities will require advocacy training. Frequently, consumers lack exposure to models of services other than what they have experienced, and they are unaware of the effective reform programs that have been created in other parts of the world. Without experience in policy advocacy and program development, many consumers may lack skills necessary for full participation. Advocacy

94UN Centre for Social Development and Humanitarian Affairs, GUIDELINES FOR THE ESTABLISHMENT AND DEVELOPMENT OF NATIONAL COORDINATING COMMITTEES ON DISABILITY

AND SIMILAR BODIES 12 (1991), *endorsed in Implementation of the World Programme of Action*

*I*

*concerning Disabled Persons and the United Nations Decade of Disabled Persons,* G.A. Res. 46/96, December 16, 1991. The World Federation for Mental Health, an international non­

governmental organization dedicated to the promotion of mental health joined the call for all I

countries to create national coordinating committees "to reform laws and mental health systems

to ensure full enforcement of the rights of people with mental disabilities." *Proclamation, World Mental Health Day: Human Rights and Mental Health* (October 10, 1998) (proclamation accompanied by detailed action steps for governments and non-governmental organizations to take to promote citizen participation in human rights and reform efforts).

training models have been effectively implemented in Central and Eastern Europe.95

* 1. Public education

There is widespread stigma against people with mental disabilities in Russian society. The MDRI team found nothing to suggest that stigma against children with mental disabilities is any greater in Russia than it is in most other countries of the world. There are no special cultural reasons in Russia that would necessitate placement in an institution for children with disabilities. Without a tradition of programs that integrate children with mental disabilities into the community, however, there is a widespread lack of understanding about the potential for children with mental disabilities to be integrated into society. Medical professionals, disability experts, and educators also lack exposure to the potential of people with mental disabilities to benefit from an education or from an opportunity to live and work in the community. Misinformed by experts, many parents have similarly come to believe that their children with mental disabilities must be segregated from society. The CRC specifies that countries should make its protections widely known to both children and adults\_%

The StRE calls on States to "take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution."97 The StRE contain extensive guidelines to States concerning public awareness-raising through distribution ofup-to-date information on available programs98 and public information campaigns "conveying the message that persons with disabilities are citizens with the same rights and obligations as others, thus justifying measures to remove all obstacles to full participation."99 In addition, "States should initiate and promote programs aimed at raising the level of awareness of persons with disabilities concerning their rights and potential. Increased self-reliance and empowerment will assist persons with disabilities to take advantage of the opportnnities available to them."100

Objective H: Public awareness campaigns are needed to promote understanding of the rights and potential for community integration of children with mental and physical disabilities. People with disabilities and their families should be actively

95With support from UNICEF, the Open Society Institute, and USAID, experts from MDRI have conducted advocacy training programs in Armenia, the Czech Republic, Hungary, Poland, and - to a limited extent - in Russia.

96CRC, article 42.

97StRE, rnle I. *981d,* rnle I ( 1). *99/d,* rule 1(2).

*mold.,* rule 1(7).

involved in designing and implementing these efforts. Public awareness campaigns shonld be directed to people with disabilities, professionals, educators, family members, and to the general public,

**Strategic Recommendations:**

* + 1. **Mass media should be used** to convey positive images of people with disabilities. These programs should inform the public about the rights of people with disabilities, about their hist01y of discrimination, and about their potential for full conmrnnity integration.
    2. **Training for stakeholder communities,** including people with disabilities, family member, and staff is needed to dispel mis-information about the limitations of people with disabilities. These informational trainings should also include information about world-wide trends toward community integration and about the lessons of reform and rights movements in others countries. Providing stakeholders with information about the potential for community integration will empower them to become active change agents.

1. First Steps: Recommendations for Low-cost Immediate Action

For each site we visited, the MDRI team has identified a low-cost, pragmatic community integration program that local authorities can implement on their own initiative. These programs build on existing resources and demonstrate how existing funds can be redirected to provide participatory and inclusive services for institutionalized children. The sites which are the focus of our proposed pilot projects are excluded from this list.

**Boarding School #12, Kaliningrad** - site of proposed pilot project detailed further below.

**Zelenogradsk Orphanage, Kaliningrad** - This orphanage is directed by a man with impressive vision and creativity. The institution is set up such that the children live in "families" of eight to ten children of mixed ages. (In certain cases, blood siblings are residents and live together in the same family.) The facility already has children living there who attend the general school in town, and children from the town currently attend the primary school located adjacent to the *internal.* We suggest the establishment of a fully integrated school at this institution. The primaiy school integration exists already, and we believe that a continuation of the integration of these particular students through the secondary level would demonstrate the positive outcomes ofinclusive education for all children. As many children from this school continue on to university or obtain jobs in the same manner as general school children, this will show the community that the effects of inclusive education on "normal" children are not harmful and can even be beneficial.



**Sovietsk Children's House, Kaliningracl** - The doctor who rnns this institution is a woman of vision and caring who appears to be open to developing innovative new programs. Many children living in this facility have moderate to severe handicaps. We would suggest two possibilities: the introduction of rehabilitation techniques, such as "Small Steps" published by the Down Syndrome Association in Moscow, into this institution with supportive training for staff, and the concept of

volunteer specialists (national or international) who could evaluate these children's surgical needs and possibly treat them. In many cases, the team had difficulty in determining if it was a lack of physical therapy and rehabilitation which caused children problems or a more profound somatic condition which might require surgery.

**Kaliningrad Regional Rehabilitation Center, Kaliningrad** - This center serves as both the base of the regional Medical-Pedagogical Commission and as a diagnostic treatment center for children with special needs. We believe that the professionals working here have exposure to certain outside techniques in the field of disability and would be receptive to training and materials on functional assessment and other alternative means of evaluation. We suggest an on-site training in these methodologies for the professionals of this center using the expertise of medical and educational professionals from the United States and Europe.

**Bazarno-Karabulaksky District *Internat,* Saratov** - This institution is the home of 170 children with various levels of cognitive disability. The facility is in a rural area, and for this reason we would suggest establishing a cooperative farm for the children to work. According to the director, they have many children who are interested in gardening and livestock. Additionally, certain former residents of this *internal* now live and work in the community, and the majority of them do farm work of some sort. A farm supervised by personnel of the *internal,* yet managed by former residents and staffed with current residents could be very successful and instrumental in meeting the alimenta1y needs of the *internal.* The director of the institution stated that the three greatest needs of the institution are: computers, a tractor, and a combine.

**Balakova Orphanage, Saratov** - This *internal* had many children living there who return home to their families on weekends and live in the institution for reasons of transport. We envision a program where transport could be facilitated for these children to and from their homes on a daily basis. Perhaps a contract could be arranged with a local transport authority since almost none of the children seemed to need special accommodation to ride in a bus or car. Another service which this *internal* may be capable of providing is respite care. Respite care is a service that permits families to bring their children on a short-term, temporary basis to be cared for while they get a break to pursue personal business or simply rest.

**Balakova Children's House #4, Saratov** - This institution was full of children who were ve1y mature and well spoken. Several older girls showed us around the *internal* and explained their activities and interests. A supported employment or apprenticeship project at this school seems possible. The town, as well as the region, is commercially well developed and relationships with potential employers could be established by the Mayor's Office or the ministry - since both seemed very supportive of community integration for children **in** the institutions.

**Saratov Refuge Center/Shelter** - site of proposed pilot project - see details below.

**Saratov Diagnostic Center, Saratov** - In this facility, we observed the use of Wechsler l.Q. tests and other traditional forms of evaluation. The center also has some residential facilities and special classes. We would introduce testing methods which incorporate non-verbal methodologies and train

staff in innovative learning models for children which accommodate different modes of learning: aural, visual, tactile. These materials and training would be available on-site with the assistance of an outside expert and the translation of various manuals to be kept there.

**Regional Rehabilitation Center, Saratov** - The center focuses more on chldren with physical disabilities than mental disabilities, but they are extremely innovative and very conscious of parental input and support. We would support a program there which they have already designed and discussed with local officials. They would like to create a park in the city of Saratov, which has both handicap accessible playgrounds and activities such as horseback riding to bring children with disabilities and non-disabled children together for sports and recreation. This group already has some experience in this domain, and they report positive results in terms of integration.

**Psycho-Neurological Hospital #18, Moscow** - This hospital treats children with neurological defects as well as 01thopedic needs. Children who come there are often kept for extended periods, and the director informed us that mothers of these children stay in hostels on site and are trained in the care and rehabilitation of their children. We would propose a project where mothers who receive such training are encouraged (even paid) to train other parents in their communities to care for their children with special needs in the same way.

**Psychiatric Hospital #6, Moscow** - At this facility, we observed children who had very little cognitive dysfunction and were mainly suffering from mental illnesses. In one section of this hospital, there was a computer room. We would suggest practical training on these computers for the residents of this hospital. Rather than only allowing them to play games on these computers, the staff should look into instructing these children in practical skills such as word processing and programming. The software could be easily purchased and installed, and this sort of training could lead to these children obtaining productive employment in the community in the future. Computer games could then function as a means of introduction to the community and a reward for learning real work applications.

***lllternat* #28, Moscow** - This institution is well-funded relative to most *internals* we saw. The director of this *internal* expressed her wish that one day she could see some of her "graduates" living in the community in supported group houses and working in the community. We support her idea and would mention that certain "graduates" are already employed in and around the *internal.* She described how certain staff could be shifted and re-trained to work in smaller settings, such as group houses. However, she did not seem to think that they had staff available (or trained) to serve as job coaches for supported employment outside the institution. We propose supporting such training.

*I*

*Intemat* #11, Moscow - This large *intemat* was in much worse condition than #28. Nonetheless, the director here told us that she would like to see a garden created for the children. She also described

a few cases of volunteers coming to the institution in the past. We formulated a program whereby ii

volunteers, especially elderly retired people, could come to the *internal* and help the children realize this thought ofa communal garden. It would allow the children to be outdoors, and it would provide an opportunity for interaction with people from the community. Additionally, the *internal* has one very modern playground, which the director admitted could be used to bring other children in to play

*Mental Disability Rights International* 111 *47*

with the children at the *intemat* and promote integration.

1. International Cooperation

International cooperation and suppo1i is urgently needed to respond to the humanitarian concerns of the 400,000 to 600,000 children in Russia's institutions - and a larger number of children now living with their families who are at-risk of being placed in institutions because their parents lack the resources and support necessary to keep them at home. As economic hardships increase pressure on the families of children with disabilities, there is a great risk that many new children will be placed in institutions. Emergency foreign assistance programs can prevent the break-up of the family by targeting assistance to the families of children most at-risk of institutionalization.

Improperly directed foreign assistance may unintentionally strengthen the current outmoded and segregated system of services and may delay the process of reform. Investments in orphanages - as well as programs that supp01i living conditions in institutions without supporting families in the community - may create increased incentives for financially strapped parents to place children in institutions. Thus, new investments in orphanages may increase the total population in orphanages, contributing to disability among children and increasing the total cost of reform.

A well planned and focused response to the current crisis facing Russia's children can have a major, long-term impact if funds are used to promote structural reforms in the service system for children. International donors are strongly encouraged to concentrate their efforts to support advocacy for service system reform to bring about community integration of children, particularly children with disabilities. Programs should assist Russian national, regional, and local authorities to implement the strategic recommendations described in Chapter III of this report. International programs should also support non-governmental advocacy for rights enforcement and service system reform. Advocacy training, combined with professional development and exchange programs, will have an impact on the rights of children well after the immediate crisis. International support for a media and public education campaign can promote Russian support for community integration, raise the public profile of Russian reformers, and ensure a national impact for new investments in reform.

* 1. Recommendations to international donors

The following principles should guide the development of programs to assist children in Russia's institutions. While each of the proposed program areas is valuable alone, these projects are mutually reinforcing. Each type of project proposed will have a greater chance of success if it is linked with a larger, more ambitious campaign for reform. MDRI strongly encourages international donors to cooperate among themselves - and with Russian counterpa1is - to develop a reform package that ensures funding for each of the following components:

* + 1. Model programs linked with advocacy for systemic reform

The international community should promote rights enforcement of children by assisting Russia in making the transition from an institution-based to a community-based service and

###### *480 Children in Russia's Institutions: Human Rights and Ol!,porttmities for Reform*

education system. Investments in education and social programs for children should encourage the adoption of internationally recognized "best practices." Investments in programs that bring about incremental improvements in the current system will eventually have to be replaced, raising the total cost and slowing down the process of reform.

One way to promote social service reform is to support the development of model community-based service programs. Model programs will demonstrate that people with mental disabilities can be safely and effectively integrated into the community. Model programs can also be used to train service system professionals in the development of community-based services (see description of proposed UNICEF models #1 and #3 below). In order to have an impact on a service system as a whole, model programs must be linked with support for advocacy. This should include funding for advocacy training. In addition, donors should provide funds to document, evaluate, and disseminate information about the operation of each model program. The success stories of local activists should be included in a public education campaign (see recommendations in section V-A-8 below). A high profile conference (or series of annual conferences) on this issue in Russia can also be used to disseminate information about model programs and encourage national replication of these models.

Model programs must ensure a full range of community services to permit children with mental disabilities to live in the community. Funders must commit or identify sustainable sources offimds, preferably from local authorities. Without fully integrated seivices and sustained funding, children with mental disabilities may be unnecessarily returned to an institution. This can be disillusioning for participants and operators of otherwise impressive model programs. These negative experience will undermine the effectiveness of model programs.'°' A fully funded program, with local government investment and participation, in contrast, will help build long-term support for policies of community integration.

Wherever possible, effective and innovative Russian models should be used and replicated. Support for cooperation among neighboring countries could be extremely valuable."" In some cases, models from other Central and Eastern European countries can be used (OSI has supported the establishment ofa number of impressive model programs in other countries). Support for local models, however, should not be used in place of the creation of best practices. Where local models do not constitute internationally recognized best practices, international support can be used to help with the improvement of local models (see proposed UNICEF project model #3).

1. Rule of law and human rights enforcement *I*

'°'The need for a full continuum of care should not be used an argument against smaller *!*

integration efforts. As described in Chapter IV, significant steps toward coll1lllunity integration can be made in most locations with little or no additional funding.

'"'This is paiticularly true for Kaliningrad, which is physically separated from the rest of Russia. There are excellent advocacy resources in Poland and Lithuania, for example.

*Men/{I/ Dis{lbi/itv Rights Internation{I/ e, 49*

Russia should receive assistance in reforming its laws to protect the rights of children in institutions. In addition to protecting rights within institutions, law reform should be used to promote community integration and to protect against discrimination in the community. Law reform projects should be linked with programs to create human rights enforcement mechanisms. As with other model programs, internationally recognized best practices should be used. Special training should be provided to ensure the involvement of lay advocates in human rights enforcement programs. Training for lawyers, judges, and other human rights enforcement personnel will be needed.

1. Rights-based advocacy and citizen participation

Advocacy by people with disabilities, families of children with disabilities, and progressive service system professionals, have been critical to reform efforts around the world. In Russia, there are a number of impressive activists dedicated to the rights of people with mental disabilities. Advocacy organizations exist, but they function at a basic level and are in great need of development. In the Russian Federation, as in many other countries of the world, these organizations have not received the kind ofinternational suppmt or recognition that has been made available to other human rights organizations. Due to the discrimination they face throughout society, and the lack of government support for their financial needs, people with mental disabilities and families often live at the margins of society in great economic hardship. The development of effective advocacy in Russia, therefore, will require suppo1t for the development of basic infrastructure for these groups, including membership outreach. The development of new membership and the creation of new chapters outside of major cities is particularly important. Suppmt for the translation and dissemination of educational materials for parents will greatly aid in the expansion of the parent network. Consumer or family controlled "drop-in" centers can be a valuable way to help build a sense of community and ensure that a safe space is available for networking and meetings.

International programs can also support the creation of structures to ensure democratic citizen participation in public policy development and program implementation (e.g. citizen adviso1y boards, disability councils, etc.). Models for these programs exist in Central and Eastern Europe. With support from OSI, MORI has worked with activists in Hungary who have created a Psychiatric Disability Advisory Council in Hungary.

1. Advocacy training

Advocacy training for people with disabilities, family members, and progressive service professionals can greatly assist disability rights organizations and can make a major difference in the ability of activists to participate in policy-making and new program implementation. Activists are often unfamiliar with models of community integration that have proven effective in other countries. Advocacy groups can benefit greatly by studying the experience of activists in other countries. Programs that use a "non-formal education" model have proven particularly effective in training adult activists because these program maximizes the involvement of participants in the learning process. This approach draws on the knowledge that activists already have and helps them organize this information and develop advocacy strategies. By building on the knowledge of the activists

###### *50• Children in Russia's Institutions: Human Rig/its and Opportunities for Reform*

about their own service system, the non-formal education approach is easily adaptable to foreign contexts. With support from the Open Society Institute and UNICEF, Mental Disability Rights International (MDRI) has successfully adapted advocacy training curricula developed in Western Countries for use in Central and Eastern Europe and the former Soviet Union.

Government officials and participants in new human rights oversight and enforcement mechanisms can also benefit from advocacy training programs. For people involved in a specialized area of policy development or program implementation, it is extremely important to be exposed to the broad goal of community integration as well as the operation of service systems and human rights enforcement programs. Government officials involved in program development and planning can benefit greatly from meeting with counterparts involved in similar work in other countries.

1. Professional development

Funds for the development of model programs should be linked with professional development and training. Short-term practical training should be emphasized at the outset. In the long-run, it will also be necessa1y to develop university programs to train professionals and educators in the full range of se1vices required for community integration.

Many professionals who have only been exposed to the current system of services will not believe that community integration is cost-effective, possible in a country like Russia, or desirable for people with severe mental disabilities. MDRI has found that short (ten to fifteen day) study tours abroad to expose professionals to models of community integration can be extremely effective in changing attitudes and gaining support for community integration. While exchange programs are relatively expensive, they can be used to train a small cadre of leaders in the major professional groups. Professionals trained abroad can then raise support from a much wider number of their peers at home. Reform leaders should be trained to serve as trainers and should receive support to disseminate the knowledge and skills they obtain abroad. Universities training service system professionals and educators should receive assistance to build these training programs into their standard curricula.

1. Emergency assistance to families and children most at-risk

This report identifies a number of practices that create direct health risks for children in institutions and in the community. International programs can make a particularly important contribution to preventing the health and development risks associated with family-breakup and institutional placement. Funding for these programs should be directed to community-based structures at the local level. Family advocacy organizations can be a particularly valuable partner in these projects. Family members are uniquely positioned to identify the needs of children and other family members, and they can help identify children most at risk. Programs to assist these children and their families will help family organizations strengthen mutual support networks.

*I*

Funding for protection of children's health in institutions should optimally be directed to pay for service programs that will not reinforce segregated systems of services. Service professionals

###### *Mental Disability Rights International ta 51*

who are based outside of institutions, for example, can assist children in these facilities when needed. They should also be in a position to provide equivalent services to children residing in their own families. International funders should not provide assistance to programs that might require parents to give up their children to an institution.

While humanitarian assistance programs may be developed to meet emergency needs, they can also be used to support sustainable projects that will enhance reform. Wherever possible, assistance programs should be linked with model community-based service programs that meet the standards described in Section V-A-1 of this report.

1. Ensure participation of people with disabilities and family organizations in all programs

As described in Chapter III of this report, people with disabilities and family members should be actively involved in public policy advocacy, program development and implementation, and human rights enforcement efforts. In societies that place a great value on professional training and experience, the introduction of non-professional participants may meet opposition or resistance. Once people with disabilities and family members are introduced into jobs and perform effectively, resistance to their participation will diminish greatly or disappear. International funders can play a key role in ensuring that people with disabilities and family members are included in all programs affecting their rights. People with disabilities and their families should make up at least half of all participants in all advocacy programs, human rights enforcement projects, and public policy advisory boards.

As international donors design and implement new programs, they should consult with Russian professional groups and non-governmental organizations, including organizations made up of people with disabilities or their family members. If Russian advisory boards on disability matters are established, at least half of their members should be people with disabilities or family members.

1. Public education

A public education campaign through the mass media is needed to change attitudes about people with disabilities and to raise public support for reform. The great majority of the Russian public has not been exposed to the community integration of people with disabilities. Most people do not know that a person with a severe disability can lead safe, productive, and meaningful life in the community. Popular support for reform will be difficult until the public knows about the potential for reform. It can be helpful to publicize the commonalities between Russia and other countries. The campaign should emphasize the fact that many other countries once had orphanages, like Russia, but most of these facilities have been closed down and children - even children with disabilities - are now raised in the community. The campaign can be used to publicize the efforts of local reformers and the success of local model of community integration.

The public education program should particularly target young parents who do not know about the possibility for keeping their disabled children at home. Young parents should be made

aware of the choices available to them, including the existence of parent support groups and advocacy organizations.

* 1. Proposed pilot programs for UNICEF

MDRI proposes that UNICEF support the following three model programs. These programs build upon positive models that have already been established within Russia. They will demonstrate the value and efficacy of key components to a community-based service system for children with mental disabilities: parental family support, supported foster care for children who cannot remain with their own families, integrated education, and parent advocacy. The program will also provide practical opportunities for professional development.

UNICEF should also provide funds to monitor, evaluate, and disseminate information about the operation of these model programs. Each model program can develop a training manual for its participants. These training manuals can be published and distributed to other practitioners in the field of disability in Russia. These manuals should include checklists for monitoring and evaluation.

Model #1: Professional development, parent advocacy, and family support

This project will combine professional development, parent advocacy training, and the development of model family support programs. The program will begin with an exchange project for professionals and parent advocates based in Moscow and/or St. Petersburg. For any change to be made in institutional care in Russia, professional education must be updated and refocused to emphasize the provision of community supports. Professionals and parents must also gain the experience of working together and learning from one another. This program will train leaders among professionals and parent groups who will have the knowledge and skills to develop community based services in Russia.103 This program will also train these professionals and parents as trainers, so that they can pass their new skills on to their counterparts throughout Russia.

Once the initial training is complete, a model family support program will be established. This model program will provide an oppo1iunity to continue the training of professionals in the new skills they have learned. Professionals will be assigned to work with a family or families who have a child with a mental disability. They will assist this family in understanding their child's disability and ways of coping with it, while gaining a knowledge of the daily reality of having a child with a disability. The families will receive the support services they need (see description of family support in model #3). Families will have access to information directly through the teaching center, as well.

*I*

*I*

*I*

""Professionals will include representatives of the major specialty areas providing 1/

services for children with mental disabilities: special educators, psychologists, speech therapists, and physicians. Physicians have major leadership roles in the Russian system of services. As such, physicians are well placed to influence the practices of their peers, as well as other professionals.

This project can be based at a university pedagogical institute or at a free-standing center. If this program is to be based at a university, it is essential that this program have full institutional support. During our visits to Moscow and St. Petersburg, we identified educators interested in establishing a program of this kind.

Exchanges of Russian parent activists and professionals with counterparts from Europe and the United States should continue to assist in the replication of model in other locations. Professional and parent leaders should visit model community-based services in other countries. These exchanges can range in length from ten days to six months (depending, in part, on the availability of funds). Study tours abroad will combine theory and practice in the field of rehabilitation, special education, and advocacy. Russian professionals will be exposed to alternatives to institution-based care, they will learn the theoretical frameworks behind these alternatives, and they will study the way other countries have moved from institution-based to community care. Once a small cadre of leaders have been exposed to models abroad, the number of professionals and parents involved in the project can be expanded through workshops, seminars, and conferences within Russia. It will be important to bring outside experts into Russia during the next few years to help professionals train their counterparts and to establish the credibility for new ideas and practices.

Model #2:. Integrnted classroom in Kaliningrad

The second project we propose for UNICEF funding is an integrated classroom demonstration model at Boarding School #12 in Kaliningrad. The boarding school in Kaliningrad is adjacent to a mainstream school, and the problem of transporting the children is eliminated. The project will start with one class or group of children of the same age level. Students in this class will study both academic disciplines and vocational activities together. Educators may have to alter certain methodologies of instruction, encouraging group work and peer tutoring as opposed to a purely didactic lecture style of instruction. UNICEF utilizes the 'Child to Child' methodology in promoting health education and other programs throughout the world. This approach can be used in Russia along with a parallel program of peer tutoring and paired classrooms. This project will provide a framework for meaningful interaction between groups of children and establish the basis for further community integration with the natural support of friendships formed in school.

The instructors involved in this project will need special training. The opportunity to visit integrated classrooms in other countries will be extremely valuable. Study tours for educators in this program could be combines with participants in model program# I, described above. The instructors will also study educational evaluation techniques so that they can closely monitor the children's skill acquisition and go beyond the normative standards currently enforced in most of the Russian Federation. Qualitative measurements of the children's experience will demand equal attention. At periodic intervals in the project, instructors will conduct interviews and group discussions with the children to document their feelings about the classroom activities, their learning experience, and their relationships with their peers.

Model #3: Supported foster care program

The third pilot project we propose for UNICEF funding is the development of a supported foster care program in Saratov. This program will build on a model foster care program already in place in Saratov for children without disabilities. This project will extend the current program to ensure that children with mental disabilities can receive its services. Training of professionals working in this program will be coordinated with the model professional education programs, described in project #I, above.

The center already has a well-defined screening and selection procedure for families, as well as a training curriculum and procedural regulations for trial visits and family placements. Professionals will be trained to provide supportive services to foster parents. There will also be special training for families who care for the children with disabilities. In many cases, the family who receives a child with special needs is one who is already acquainted with the child through a formalized care giver relationship (e.g. a staff person at an institution), an extended family relationship, or neighbor. Nonetheless, screening and training of families is essential, in addition to oversight to ensure the proper care and rights protection of all children involved in the program.

As one component of the monitoring mechanism, parents and children will be required to visit to the center for counseling and medical check-ups. Home visits by the director and staff of the center (announced and unannounced) will also be used. The demonstration of the project's success will be the growth and development of the child, her or his level of achievement in acquiring new skills, and the establishment of relationships in the community with family and friends.

The foster families will need financial support and access to appropriate services, as well as training. Local authorities should be encouraged to contribute necessary funds for this project and to ensure the program's long-term sustainability.

Conclusion: The Road to Reform

Throughout the world, disability activists have found that the most successful periods change takes place when bold, new initiatives are adopted that generate public interest and excitement about community integration and reform. New policies by governments, model programs, vocal citizen's advocacy groups, and public information campaigns all feed on one another for support. The best new programs are often adopted in the worst of times. Despite the tremendous hardships now experienced throughout Russian society, the urgency of the humanitarian concerns facing children in institutions provides be a unique opportunity to gain public support for change. We encourage the Russian government, non-governmental organizations, and international donors to work together at this critical moment. The greater the collective investment in reform, the greater the opportunity for success. The children of Russia, including children with disabilities, deserve no less.

*I*

I

*i*

I

Appendix A: Community Integration Models

Community integration for a person with disabilities entails more than just presence in the community; true integration requires the protection of rights and promotion of personal interests, oppo1tunities for maximum individuals, social and psychological development, and full community participation.1°' The full array of service and supports systems may be needed to permit a child with a mental disability to be fully integrated into the community. This appendix describes key elements of social service programs that have been used successfully to support children in the community.

Community-based services and support systems include:

family supports and assistance; habilitation programs for the child;

appropriate education in mainstream schools;

housing in the community for themselves and their care-givers; accessible medical services;

legal protection and advocacy services;

support for self-advocacy (by people with disabilities) and parent advocacy.

These community-based services provide natural opportunities for a person's growth and development and inherently facilitate individual rights protection for persons with disabilities in society.

Family supports and housing

To provide community-based care for children, one must begin with aiding the family or other care-givers. In general, the goals of a family support program include: (I) addressing the needs of individual and family to enable them to maximize their potential and enrich their lives; (2) maintaining the disabled individual within their natural home by relieving at least some of the financial burdens and emotional stresses experienced by family members; (3) preventing costly out­ of-home residential placements; and (4) preserving the development of relationships between the individual and his/her fellow neighbors. 105 Typical components of a family support program are the following:

**Respite Care:** This service provides a temporary residential service for a child when a family is in crisis, experiencing stress, or needs a vacation.

**Family Aides:** Individuals are provided in homes to care for a child for a few hours or a day at a time. This service is similar to respite care, but takes place in

10'Pam Walker, COMING HOME: FROM DEINSTITUTIONALIZATIONTO SUPPORTING PEOPLE IN THEIR OWN HOMES IN REGION VI, NEW HAMPSHIRE 7 (1993).

ios/d. at 3.

the family's home.

**Homemaker Services:** Individuals come to the family home and assist with household duties or daily tasks, such that family members are free to care for their child.

**Transportation:** This service assists families in transporting themselves or memberto school, recreational activities, medical visits, and other with the use of specially-designed, adapted vehicles.

a family facilities

**Family education and training:** Programs may be offered to assist individuals or family members in dealing with a child or educating a child at home.'°'

Family education and training holds the key to a child's development. These services may be integrated with other forms of therapy for a child and with other forms of therapy for the family. A critical component of family support involves contact with other families through self-help organizations.107 For example, a "Family Support Advisory Council," could be established to assist in program planning, implementation, and evaluation. This could include a Parent-to Parent program, which facilitates information sharing and the development of supportive relationships among families through regular meetings and telephone networks. Social services systems should provide families with a family liaison to assist in obtaining services for their child, as well as recreational links. These programs provide a fornm for families and children to connect in an informal and integrated setting.108 Together, these programs allow families to keep children with mental disabilities at home and provide the care they require.

**Integrated and inclusive education**

For children from institutions to enter the community, they must also attend standard schools. Emphasis on academics in education must shift to a focus on functional skills. Adapted curricula, which teach skills necessary to negotiate and succeed in a specific environment, serve the needs of children with disabilities. Categories of skill acquisition generally include: motor skills (grasping, walking, reaching), communication skills (symbols, signs, sounds), and social skills (initiating

*I*I

106Valerie J. Bradley, DEINSTITUTIONALIZATION OF DEVELOPMENTALLY DISABLED PERSONS: A CONCEPTUAL ANALYSIS AND GUIDE 99 (1978).

107Frank J. Floyd et al, FAMILIES COPING WITH MENTAL RETARDATION: ASSESSMENT AND I

I

•

THERAPY IN MANuAL OF DIAGNOSIS AND PROFESSIONAL PRACTICE IN MENTAL RETARDATION

279, 277-288 (John W. Jacobson and James A. Mulick, eds., 1996) .

108Walker, *supra* note I02, at 4.

interactions, responding to interactions, and continuing interactions.)109 In other cases, instruction centers on remediation, maintenance, and acquisition of skills in an adapted setting."0 In either case, classrooms need to have a structure which is inclusive, an accommodating curriculum, flexible and integrated supports, and a focus on cooperation between both home and school and among peers.

Inclusive regular public education requires certain elements to succeed. In Italy, four elements emerge as critical to success: (!) support teams for the classroom teachers comprised of special education teachers, physicians, psychologists, social workers, nurse, speech and physical therapists; (2) sharing of responsibility by parents, teachers, medical personnel, and community, forging an effective coalition to create an alternative to the traditional medical model for children with disabilities; (3) educating the public, using various media and public meetings; and (4) the presence of charismatic leaders early on, such as Dr. Franco Basaglia and Dr. Adriano Milani Comparetti. Two decades ago, the Organization for Economic Co-operation and Development (OECD) cited Italy as the most advanced country in its policy to include all children with disabilities in regular public schools. The OECD publication describes how support teachers work with class teachers to run the class by teaching in small groups and never isolating the child with a disability. An emphasis on interpersonal interaction, friendship , and peer support facilitate mainstream education in Italy.'"

109Alan C. Repp et al, COGNITIVE AND VOCATIONAL INTERVENTIONS FOR SCHOOL-AGE CHILDREN AND ADOLESCENTS WITH MENTAL RETARDATION IN MANuAL OF DIAGNOSIS AND PROFESSIONAL PRACTICE IN MENTAL RETARDATION 267, 265-276 (John W. Jacobson and James

W. Mulick eds., 1996).

*" Jd* at 271.

*0*

'"Carol Berrigan and Dennis Taylor, EVERYONE BELONGS: SCHOOL INCLUSION AND

SOCIAL RELATIONSHIPS IN ITALY ( 1997).

