Abstract

Human rights organizations have documented a widespread pattern of abuse in Russia's orphanages and institutions for children with disabilities. Community integration is critical to attack the underlying causes of discrimination and abuse of children in institutions. While there is an immediate need to protect children in institutions, investment in improving orphanages may inadvertently strengthen an outmoded system of segregated services, delaying long-term reform. This article describes a response to abuses in institutions based on the internationally recognized right to community integration for all children, including children with mental and physical disabilities. While tailored to Russia, the framework for action described here applies to many countries in which children and adults with disabilities are similarly segregated from society in closed institutions.

Les organisations des droits de la personne ont documenté l'abus fréquent des droits de la personne dans les orphelinats et dans les établissements pour enfants handicapés en Russie. L'intégration de ces enfants dans la communauté joue un rôle primordial dans la lutte contre les causes fondamentales de la discrimination et des abus perpétrés à leur égard dans ces institutions. Bien qu'il soit urgent de protéger les enfants au sein de ces institutions, il arrive que les fonds investis pour l'amélioration des orphelinats servent parfois malheureusement au renforcement de systèmes surannés basés sur la ségrégation, retardant ainsi l'application de réformes à long terme. Cet article propose une réponse aux abus dans les établissements qui se fonde sur le droit reconnu sur le plan international à l'intégration dans la communauté de tous les enfants, y compris ceux qui souffrent de handicaps physiques et mentaux. Bien qu'il soit adapté particulièrement à la Russie, le type d'action qui est décrit ici peut s'appliquer à de nombreux pays où les enfants et les adultes handicapés sont ainsi séparés de la société et placés dans des institutions.

Las organizaciones de derechos humanos han documentado un extenso patrón de abusos en orfanatos e instituciones para menores discapacitados en Rusia. La integración a la comunidad es fundamental para combatir las causas principales de la discriminación y de los abusos a menores internados en instituciones. Si bien existe la necesidad urgente de proteger a estos menores, la inversión para mejorar los orfanatos puede acarrear efectos negativos imprevistos al fortalecer un anticuado sistema de servicios segregados, postergando asi una reforma de fondo. Este artículo describe una respuesta a dichos abusos en instituciones basada en el derecho reconocido internacionalmente a la integración en la comunidad para todos los niños y niñas, incluyendo aquellos menores con discapacidades mentales o físicas. Si bien ha sido elaborado para el caso de Rusia, el marco para la acción aquí descrito, tambien puede ser aplicado a muchos otros países en los cuales tanto menores como adultos discapacitados son segregados de la sociedad a través de instituciones de encierro.

Implementing the Right to Community Integration for Children with Disabilities in Russia: A Human Rights Framework for International Action

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Over the last year, Russian activists have documented serious and pervasive human rights abuses in Russia's orphanages, boarding schools, psychiatric hospitals, and other specialized facilities for children with disabilities (collectively referred to here as "institutions"). According to reports from Russian nongovernmental organizations (NGOs), there are 400,000 to 600,000 children in Russian institutions.[1] This number is rapidly expanding as economic and social hardships pressure more parents to give up their children to institutions. According to some estimates, more than 100,000 children have been "abandoned" by their parents each year since 1996—almost double the annual rate in 1992.[2] Russian authorities report that the number of children officially registered as "left without parental care" has gone up almost 90% over the past five years.[3]

As reports filter through to the West, pressure for international action is growing. In October 1998, the U.S. House Appropriations Committee directed the U.S. Agency for International Development (USAID) to use $3 million to assist Russian and Ukranian orphanages—a major portion of the $28 million allocated for Russia in 1999.[4] In December 1998,

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Human Rights Watch issued a report on Russian orphanages, attracting additional international attention to abuses in institutions.[5]

In the autumn of 1998, UNICEF/Russia asked Mental Disability Rights International (MDRI) to assess the conditions in Russian orphanages and develop a strategy to promote the rights of institutionalized children under the Convention on the Rights of the Child (CRC).[6] This article draws heavily on the findings of the fact-finding mission conducted by MDRI at institutions in the Moscow, St. Petersburg, Kaliningrad, and Saratov regions from October 20 to November 6, 1998.[7] MDRI found that children with physical and mental disabilities experience the most serious abuses within Russia's orphanages.[8] In the absence of community-based services and support systems, children with disabilities are at risk of spending a lifetime in an institution.[9] The MDRI report to UNICEF proposes an innovative new strategy to the Russian authorities and to the international community to promote a fundamental restructuring of Russia's system of services for children. A full range of community-based services and support systems for families would need to be created to permit children with mental disabilities to be integrated into the community and to prevent unnecessary new placements in institutions.

This article describes the right to community integration as it is recognized for children under the CRC and is increasingly recognized for all people with disabilities under human rights resolutions adopted by the UN General Assembly and the Council of Europe. The article also describes experience in the West and in Central and Eastern Europe demonstrating that community integration is critical to attack the underlying causes of discrimination and abuse of children in institutions. Drawing on the findings of successful community integration efforts around the world, this article presents a framework for the planning and implementation of programs that the Russian government and the international community will need in order to enforce the right to community integration. While tailored to Russia, the framework for action to enforce the right to community integration applies to many other countries in which people with disabilities have been traditionally segregated from society in closed in-

stitutions—especially other countries within Central and Eastern Europe, whose social service systems have many commonalities.[10]

The Right to Community Integration

International human rights law requires states to promote community integration for all children—with and without disabilities. In the CRC, the right to community integration for all children is reflected in the extensive protections that exist for families and the obligation on States parties to provide the support necessary to ensure that children can remain with their family.[11] The Preamble of the CRC recognizes that:

> the family, as the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community. . . .[12]

The right to community integration for children with disabilities is established in Article 23.[13] Article 23.1 of the CRC recognizes that:

> a mentally or physically disabled child should enjoy a full and decent life, in conditions that ensure dignity, promote self-reliance and *facilitate the child's active participation in the community* (emphasis added).[14]

In addition to recognizing the right to active participation in the community, the CRC requires that States parties create the educational and social service systems necessary for its enforcement. Thus, service systems:

> shall be designed 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 fullest possible social integration and individual development* . . . (emphasis added).[15]

The right to community integration is a core principle that has gained increasing recognition over the past 20 years in human rights declarations of the UN General Assembly

and the Council of Europe. In 1971, the UN General Assembly recognized as a general principle in the Declaration on the Rights of Mentally Retarded Persons that "[w]herever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life."[16] The UN expanded the meaning of this right in the 1991 Principles for the Protection of Persons with Mental Illness (the MI Principles), which recognize not only the right "to live and work, as far as possible, in the community" but also "the right to be treated and cared for, as far as possible, in the community in which he or she lives."[17] The 1993 Standard Rules on Equalization of Opportunities for Persons with Disabilities (StRE) recognize that the right to community integration applies to all people with mental or physical disabilities and recognize the right to community-based services to make such integration possible.[18] In the absence of a specialized convention on the rights of people with disabilities, UN General Assembly resolutions are particularly important as a guide to the requirements of other UN human rights conventions as they relate generally to people with disabilities.[19]

There has been a parallel recognition of the right to community integration in the Council of Europe.[20] In 1973, the Committee of Ministers adopted Resolution 73(1) on the Social Services for Physically or Mentally Handicapped Persons, which stated:

> The general objective of this policy should be to give handicapped persons every opportunity to be as much integrated as possible into society. Whatever the cause, type and degree of their handicap may be, the handicapped should be given all opportunities for their personal development and for maximum participation in the activities of the community.[21]

The Council of Europe reaffirmed the policy of community integration and recognized it as a "right" in a 1992 recommendation.[22] This recommendation calls on states to "guarantee the right of people with disabilities to an independent life and full integration into society, and recognize society's duty to make this possible. . . ."[23] It applies to "[a]ll

people who are disabled or are in danger of becoming so" and states that they "should have the right to the individual assistance required in order to lead a life as far as possible commensurate with their ability and potential. . . ."[24] These services should enable a person to "be as free as possible from institutional settings and constraints" except where "unavoidable."[25]

Despite Article 23 of the CRC and extensive international recognition of the right to community integration, there has been little international effort to promote the implementation of this right. In the absence of a specialized international convention on the rights of people with disabilities, the rights of persons with disabilities have long been overlooked by the international human rights and international development communities.[26] The lack of such a convention also explains why there is a lack of uniformity in the way the right is expressed—as the right to "the fullest possible social integration" in the CRC, the right to "live in the community" in the MI Principles, and the right to "social integration" or "maximum participation in the community" in the Council of Europe's resolutions. For purposes of clarity and consistency, this article refers to a right to "community integration." The CRC, UN General Assembly Resolutions, and the Council of Europe resolutions all recognize both the right to community integration, as a matter of principle, and the right to the education, health, and social services necessary to enforce that right.

The lack of a specialized convention on the rights of people with disabilities is one problem. In addition, international cooperation to promote the right to community integration has been stymied by the complex challenges to its implementation in countries undergoing rapid economic and political transition, such as Russia. Enforcement of the right to community integration requires careful planning and the investment of financial resources to create community-based services and support systems for children with disabilities. As will be seen below, international development and relief organizations geared to crisis response have often failed to build on successful models of community integration used in their own countries.

Building on Successful Models of Reform

Reform efforts in Russia and other countries of Central and Eastern Europe should be informed by the findings of 30 years of experience in the U.S. and Western Europe. Enormous changes in social service programs have permitted people with the most severe developmental disabilities to be effectively integrated into their communities. When they are provided with accessible and appropriate community services and support systems—including appropriate, integrated, accessible education; habilitation services; supports for families (counseling, respite care, housing, and financial support); and human rights oversight mechanisms to protect against discrimination and abuse in institutions and in the community—children and adults with disabilities experience a greater quality of life than they would in an institution.[27] Children with mental disabilities may require an additional comprehensive system of community care, support, and advocacy to be effectively integrated into the community.[28]

The case for community integration is the strongest at the earliest stages of life. Children 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.[29] Children who grow up in congregate facilities are exposed to higher rates of avoidable health risks, including risks of infectious illness and malnutrition, than those who grow up in a home-like setting.[30]

While stigma against people with disabilities is common in many societies, public support for community integration commonly develops once people with disabilities have the opportunity to demonstrate for themselves that they can live safely in the community as good neighbors.[31] Once support systems are established, families overwhelmingly choose to keep children with disabilities at home.[32] In the U.S. and Europe, advocacy by people with disabilities and their family members has been critical to the creation of community-based service systems and to the public pressure needed to ensure sustained support for such services.[33]

Dilemmas and Dangers of the International Crisis Response

International publicity has created an invaluable opportunity for international action to protect the rights of children with disabilities in Russia. Yet there are also great dangers. Under pressure to demonstrate a response to abuses in orphanages, the Russian government and international development organizations may adopt stopgap measures in lieu of programs that address the underlying causes of abuse. Over the last decade, reform efforts throughout Central and Eastern Europe have been plagued by the lack of a long-term, coordinated strategy by governments and international donors.[34] While there is an immediate need to protect children in institutions, investments in improving orphanages may inadvertently strengthen an outmoded system of segregated services.

There are important lessons from experience in Romania since the fall of Ceaucescu in 1989. Under international pressure to improve conditions in institutions, the Romanian government increased spending for orphanages while permitting support for families and children in the community to decline.[35] Conditions within institutions improved, but this created new incentives for impoverished families to give up their children in the hope that they would receive food, heat, and basic medical care in an institution. From 1989 to 1996, the Romanian orphanage population increased dramatically (by as much as 37%, according to some estimates).[36]

A greater focus on outplacement and domestic adoptions was adopted in the mid-1990s, and accordingly the Romanian government adopted a national plan for the establishment of a foster care system.[37] Despite this, an MDRI investigation in 1996 found that community support systems for children with disabilities remain extremely limited throughout Romania. MDRI interviewed the four major USAID-funded agencies responsible for internal Romanian adoption, and found that none regularly included children diagnosed with mental disabilities within their programs. Staff workers at these programs reported that the adoption of children with mental disabilities was nearly impossible to arrange in

the absence of appropriate community supports. NGOs made up of families of children and adults with disabilities, who might have served as a resource for the development of community support programs, received little attention or support from the international community.

While it may be easiest to integrate non-disabled children back into the community, children with disabilities have the same rights to community and family life. To ensure the inclusion of children with disabilities, the experience in Romania (and elsewhere) demonstrates that community-based services and support systems for children with disabilities must be established at the outset of the reform process. Without community-based services and support systems, it will be difficult for most children to return to the community, whether or not they are labeled as "disabled." Without attention to the concerns of children with mental disabilities, community integration programs intended to assist children in institutions will effectively exclude a large portion of the population most in need of assistance.

These lessons from Romania are directly relevant to the current situation in Russia. As in Romania during the mid-1980s, the income and social supports available to families in the community are declining. Thus, the need for an immediate investment in community-based services and support systems is necessary to avoid large increases in institutional placements and greater segregation of children with disabilities, as was experienced in Romania. Without immediate efforts to provide support for families in order to stem the tide of new placements in Russia, the human rights abuses experienced by children with disabilities will be far greater in the coming years.

Promoting Rights in a Time of Economic Hardship

The difficult economic transition in Russia in the last decade has had a disastrous effect on many sectors of the population, particularly on children with disabilities and their families. The cycle of poverty and the corresponding rise in out-of-home placements in Russia dates back as far as the economic stagnation of the early 1980s, however, when social service programs were restructured as part of the Gorbachev-era reforms designed to "revitalize socialism."[38]

In May and November 1998, when MDRI conducted its investigation, economic pressures on families were acute. The MDRI team interviewed numerous parents of children with disabilities desperately struggling to keep their children at home despite inadequate government support. Parents who had barely been able to make ends meet before the crisis are under greater pressure today, and more of them have been forced to place their children in institutions.

Staff at institutions report that "troubled families" frequently place their children in institutions because they cannot afford to provide adequate food. We heard reports of authorities taking children away from families because of the parents' failure to provide for their basic needs such as food and clothing, which have become increasingly hard to afford. Most of the institutions we visited in November 1998 report an increase in the number of children brought to institutions for care over the course of the last year.

In addition to creating burdens on private citizens, the economic crisis has led local and regional governments to decrease budgets for social services. Thus, social service agencies and institutions for children are now being asked to serve more and more children with fewer resources. Russia's economic difficulties help 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 from its responsibility for rights enforcement.[39] The CRC requires States parties to "undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in this Convention."[40] Enforcement of the CRC's civil and political rights provisions (e.g., protections against abuse) may require positive efforts, including the investment of economic resources.[41] With regard to protections that may be considered economic and social rights (e.g., the right to the highest attainable standard of health), the CRC requires that "States Parties shall undertake such measures to the *maximum extent of their available resources* . . . (emphasis added)."[42] Economic limitations are real, and the creation of new services systems may take time. But the CRC does create an immediate obligation on States parties to establish policies and programs designed to bring about full enforcement of all rights under the con-

vention.[43] Thus, States parties to the CRC must commit themselves immediately to policies that promote community integration, with a recognition that full enforcement will take place over time.

The Russian Context

The problems that Russia faces in making the transition from institution-based services are not unique. Two UN Special Rapporteurs on Human Rights and Disability found that long-term institutionalization of people with mental disabilities represents a serious human rights problem around the world.[44] MDRI has documented the segregation of people with psychiatric disabilities in Central Europe and Latin America.[45] Unlike most countries, however, Russia and other former Soviet-bloc countries have experienced little or no movement toward community integration over the last thirty years. In large part, this is because the lack of independent civil society made it impossible for citizens to challenge the status quo and to demand enforcement of the rights of people with mental disabilities. As other countries modernized service systems and developed support systems to give people with disabilities the opportunity to live a full life in the community, segregated service systems became more and more entrenched in the Soviet bloc.

Defectology and the Ideology of Segregation

The current system of services for children and people with disabilities in Russia is a product of the centralized planning of the Soviet era, reflecting an underlying ideology that justified segregation. Collectivized, state-controlled child-rearing was consistent with an evolving communist theory that denigrated the role of the private sphere of the family. One of the authors of the 1918 Soviet Code on Marriage, the Family, and Guardianship wrote that:

> Our state institutions of guardianship . . . must show parents that social care of children gives far better results than the private, individual, inexpert and irrational care by individual parents who are "loving," but in the matter of bringing up children ignorant.[46]

Families were viewed as particularly unsuited to raise children with disabilities. Parents who deviated from accepted norms of behavior were viewed as unhealthy or dangerous for young children. As one researcher has observed, "in allegedly perfect societies it was vital to ignore the existence of many social problems and to define them as the product of individual pathology (for instance, alcoholism) or the result of deviations from state-approved behavior."[47] Thus, services for children with disabilities were built on a medical model that emphasized "curing" or "correcting" the individual child's disabilities rather than creating flexible services that could accommodate the needs of each child and permit maximum community integration.[48]

A number of schools of special education and developmental psychology that had grown up in Russia and other countries of Central and Eastern Europe in the early 20th century were curtailed during the communist era. In Russia, the major discipline responsible for the education of people with disabilities is known as *defectology*. The Institute of Defectology, established in Moscow in 1929 by the renowned developmental psychologist L. S. Vygotsky, was widely influential and progressive for its time. During the 1930s, however, a new educational philosophy was imposed in the Institute. The new approach was based on the view that all children must brought up to a common standard of "normal development."[49] Thus, "correctional" schools were set up throughout Russia to bring children up to this standard. Children who could not be brought up to accepted norms were labeled "uneducable" and were relegated to lifetime custodial care in closed institutions.

While each country of Central and Eastern Europe has its own professional variant on this approach, the medical model of deficiency that justifies segregation still pervades the structure of educational and social services throughout the region.[50] There are, however, hopeful signs of reform in Russia and other countries. In recent years, schools of social work have been established.[51] In some cases, schools of thought and practice from the region that predated the communist era have been revitalized. In other cases, models of

community integration are being imported from other parts of the world. The MDRI team of investigators identified a number of impressive new programs established at the instigation of innovative service providers at the local level.

Institutionalization of Children with Disabilities in Modern Russia

The Russian system of services for children reflects the Soviet-era preference for institution-based rather than community-based care. The modern Russian system of services still weeds out children with disabilities from the mainstream at every level. Physicians recommend to parents of children who are born with certain visible and obvious impairments that they place their child in an institution. Some parents report being advised to place their child immediately, "before they become attached" to the child.

Despite such advice, many families return home with their child and do their best to make do with little assistance from the social service system. For such families, home care without support may become overwhelming or unaffordable, forcing them to give up their child at a later date. Other children are referred to a Medical-Pedagogical Commission for diagnosis at a later age.[52] These referrals 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 may not correspond with any actual limitation on the child's ability to succeed in mainstream education or community life.

The task of the Medical-Pedagogical Commissions is to evaluate a child, determine his or her 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 team, which met with professionals in Kaliningrad, Saratov, and Moscow to discuss the procedures and methods used by these commissions, was unable to identify any 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 various

specialists on the commissions. In some cases, the administration and interpretation of these exams appear to be left entirely to the discretion of a particular expert. The evaluation process may be cursory, or it may take place over a number of months.

Structure of 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 but cannot dictate policy directly to regions. Regions finance their own institutions and set their own policies. Services for children in institutions are divided among three ministries: Health, Education, and Labor and Social Protection. The Ministry of Health is charged with care of newborn to four-year-old children in a *dom rebyonka*, or baby house. In these baby houses, children have a range of conditions and abilities. In many cases, parents have abandoned babies to the baby house because of a physical deformity or a family situation that is perceived as emotionally or economically unstable. Many babies arrive at the baby house because they come from a large family with simply no means to support another child.

When children in a baby house reach age four, they are evaluated by a team to determine whether they should be placed in an *internat* (institution) run by the Ministry of Education or in one run by the Ministry of Labor and Social Development. Children considered "educable" are generally placed in facilities under the Ministry of Education, and those deemed "uneducable" are placed under the Ministry of Labor and Social Development.

In both types of institutions, personal attitudes of directors and staff play a large role in determining children's activities, programs, and level of interaction with staff. In some cases, there appeared to be no difference between the children in a Ministry of Education *internat* and those in a Ministry of Labor and Social Development *internat*. In many cases, there was no apparent reason why some children had the benefit of staff interaction while others were left in bed, almost untouched.

Children who reach the age of eighteen in a Ministry of Labor and Social Development *internat* will almost certainly

go on to live in an institution for adults with disabilities. There are Ministry of Labor and Social Development *internat*s where self-care skills and various activities of daily living are being taught, but there are also rooms where certain children never leave their beds. It is telling that the staff in these institutions are called "cleaners." In many cases children get only the minimal custodial care necessary to keep them alive. In the Ministry of Labor and Social Development facilities visited, there were little or no systematic efforts to habilitate, rehabilitate, or educate the children.

Among the institutions visited by the MDRI team, living conditions under the authority of the Ministry of Education and Ministry of Labor and Social Development appeared to be more or less comparable. Most *internat*s house between 150 and 200 children between 5 and 18 years old. The larger *internat*s 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. Some *internat*s, however, have what are called "family" living arrangements, in which children of mixed ages live together in one section of the *internat*. These children do not, however, have the benefit of a consistent adult caregiver that they would have with their own parents or a foster family.

A number of Russian government officials emphasized to the MDRI team that many families do keep their children at home and that there is a de facto integration of children with disabilities in many communities. The team was unable to measure or document the actual number of children with disabilities in mainstream schools. It did, however, receive reports from educators, professionals, and parents contradicting these official claims. Interviews with parents associated with the Down Syndrome Association in Moscow led the team to believe that almost no children with mental disabilities are educated in mainstream schools.[53]

The official statements about community integration may be a product of the over-inclusion of children in the category of those diagnosed with an illness or disability. Children labeled "disabled" at mainstream schools may not

achieve the usual level of performance but would likely not meet any internationally accepted definition of disability.

There is no question that many children with disabilities are cared for in the home. These children, however, receive almost no public support other than the disability pension from the government, which is inadequate to meet the needs of a child with a disability. Through their own family network and information dissemination campaigns, the Down Syndrome Association has encouraged and aided several families in caring for their children at home in the community.

Implementing the Right to Community Integration in Russia

Russia's system of orphanages and segregated special schools inherently isolate children from the community and are thus inconsistent with international human rights principles. Community-based services and support systems that would help enable children with mental disabilities to remain with their own families are almost nonexistent. 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. Despite the great efforts of many committed, professional, and well-meaning staff, placement in an orphanage rather than in an integrated, family-like environment hinders a child's social integration. Without close relatives with whom to form attachments, children in institutions may experience delayed or inhibited individual development.

Implementation of the right to community integration in Russia will require the establishment of new policies and programs at all levels of government that reflect a broad commitment to community integration over institutional care for children. Full enforcement of the right to community integration will require, over time, the creation of a network of community-based services, including family support systems and integrated educational programs for children with disabilities.

Right to Family and Community Support

International human rights law requires the creation of family support programs as needed to prevent unnecessary institutionalization. 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. . . ."[54] Thus, the family "should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community."[55]

In contrast, social service programs in Russia are constructed to remove the child from the family that is considered "troubled." Family support and counseling programs for the parents of children with mental disabilities are almost nonexistent. In the Russian system, any child with or without a disability or health problem may be placed in an institution because of parental troubles. Children may be institutionalized because of a parent's disability or because their parents simply lack the economic resources to take proper care of them. 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 institutions were the only service available to children from troubled families. Nevertheless, 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. . . ."[56] Family support and counseling programs must be developed and expanded to prevent unnecessary institutionalization of children. These programs would be the cornerstone of the community-based service system necessary to permit community integration of children with disabilities.

Russia currently provides a disability pension benefit to families of children with disabilities, but this benefit does not begin to cover the cost of raising a child with a disability in the community. The CRC requires that such programs be appropriate for the special needs of all children.[57] Cash pay-

ments to parents of children with disabilities have proven to be one of the least costly and most effective ways of preventing unnecessary institutionalization. Russian authorities must ensure that adequate benefits are made available to children with disabilities and their families in the community.

Programs to support families and children in the community must be fully comprehensive to be effective.[58] With comprehensive support, counseling, and education, many families in Russia will be willing and able to keep children with disabilities at home. The vast majority of children from "troubled families" can safely remain at home if parents receive appropriate supports.

Russian authorities should make substitute family programs (e.g., foster care) available to all children who do not have a family. The CRC requires that "alternative care," which may include foster care or adoption, be available for children not able to remain with their parents.[59] Substitute family arrangements should be made available to all children; institutional placement should only be used as a last resort.

Right to the Highest Attainable Standard of Health and Development

The CRC requires States parties to "ensure to the maximum extent possible the survival and development of the child."[60] In addition, children have a right "to the enjoyment of the highest attainable standard of health. . . ."[61] MDRI's findings in Russia's institutions suggest that placement in an institution creates serious health risks, particularly for young children. The team observed caring staff members working hard to provide care to children. Yet staffing levels are simply not high enough to provide each child with the individual attention required for optimal growth and development. The situation is particularly serious for children with severe disabilities, where the demands on staff are even greater.

Staff are not trained to provide habilitation programs to teach these children basic self-care skills. We also observed large numbers of children with physical deformities that could have been prevented through regular exercise, repositioning, and physical therapy. In many institutions where trained staff do provide physical therapy, they are overwhelmed by the

large numbers of children in need and cannot provide adequate assistance to all children.

While higher staff ratios and more trained staff will ameliorate some conditions, international experience indicates that protection of health and maximization of individual social and psychological development will require community integration.

A major increase in resources for institutions and higher levels of staff may reduce many of these dangers, but research suggests that higher rates of risk for institutionalized children cannot be entirely eliminated.[62] Thus, the health and development of children in institutions will be most effectively promoted through the establishment of community reintegration programs.

Even when bonds have been broken with families, children in institutions will benefit from substitute family programs to reintegrate them into society. While they are awaiting placement, children would benefit from physical therapy and habilitation programs that might prevent increased disabilities. Programs to train direct-care workers would be a valuable contribution to the health of institutionalized children. Where possible, newly trained staff should not be employed by institutions but rather by local community authorities. In this way, trained staff can shift the locus of their activities from institutions to the community as new community placements for children become available.

Minimum standards of treatment as well as human rights and oversight mechanisms must be established to protect rights in the community and in institutions. Monitoring, evaluation, and oversight are essential to ensure that basic medical care and minimum levels of habilitation are provided in each institution. To make standards effective, central authorities should create quality-assurance and human rights oversight systems based on regular inspections.

Citizen Participation and National Planning

Article 12.1 of the CRC recognizes the right of children to express his or her views and to have those views "given due weight" in matters that affect them. A parallel right to participation has been established for family members and organizations representing people with disabilities. The StRE

call 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." States should "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."[63] Also involved should be "local communities" and "non-governmental organizations and other interested bodies."[64]

In Russia, people with disabilities and their families have not historically been a part of the process of developing or implementing social policies on matters that affect them. In the Soviet era, officially recognized nongovernmental organizations had little independence from the government. While a few advocacy leaders have emerged in recent years and have played an important role in shaping the public understanding of disability rights issues, the great majority of people with disabilities and their families remain marginalized and excluded from the policy debate.

To implement their right to participate, people with disabilities, their family members, and community allies should be included in all aspects of planning, design, implementation, and evaluation of service, support, and human rights oversight programs. The right to participation by key stakeholders (i.e., people with disabilities and their families) should be recognized as a matter of law. Active outreach, training and support programs are necessary for effective democratic participation. National and local authorities should sponsor independent, self-governing advisory committees, or "disability councils," to ensure outreach and involvement of stakeholders. These disability councils should then be funded within a structure that ensures maximum democratic participation and independence from authorities. The majority of advisory committee members should be nongovernmental.

A Human Rights Framework for International Action

International experience suggests that effective human rights protection for children in institutions will require well-planned, sustained programs to support the creation of a community-based service and support system. The human rights law that obliges the Russian Federation to promote commu-

nity integration can also be employed as a framework to develop programs that will promote structural reform in Russia's social service system. This section describes the key components of such an approach.

The development of model community-based service programs would be helpful to advocates in pushing for new community integration policies in Russia. At present, many professionals and policymakers do not believe that children with mental disabilities could live in a community or that the support systems necessary to permit community integration could operate effectively in Russia. Model programs could demonstrate how support systems could be implemented in Russia.

Effective model programs would include a full range of community services. Funding would be sustainable; preferably, international assistance would be premised on support for sustainable funding from local authorities. Early "buy-in" to pilot projects from government sources may be needed to ensure that projects will be funded from government sources after international support is terminated. To be most effective, programs will be generated within Russia. Pilot programs that have already been implemented by Russians or other service providers from the region are more likely to be replicated by other local authorities than those developed outside the region.

It is critical that funding for model programs be linked with advocacy for systemic reform. Isolated model programs will not bring about systemic reform without active advocacy efforts by Russians committed to their success. Rigorous analysis of pilot programs will be needed to convince professionals, policymakers, and the public of the effectiveness of these programs. Thus, programs will be more likely to succeed if donors provide funds to document, evaluate, and disseminate information about the operation of each model program. Monitoring, evaluation, and oversight will be needed to ensure quality of care and rights enforcement in all community-based programs on an ongoing basis. Ideally, Russian professionals and nongovernmental advocates—including people with disabilities and their family members—will be trained to perform these functions.

Advocacy by people with disabilities and their family

members has been critical to reform efforts around the world. In Russia, there are a number of impressive NGOs dedicated to the rights of people with mental disabilities. As in many countries of the world, however, these disability rights groups have not received the same level of international support or recognition as have other human rights organizations. The development of effective advocacy in Russia will require support for the development of basic infrastructure for these NGOs, including membership outreach.[65]

Advocacy training for people with disabilities, their family members, and other advocates can greatly assist disability rights organizations and can make a major difference in the ability of activists to participate in policymaking and the implementation of new programs. 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. MDRI has had excellent results using an informal adult education model that 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. Because it builds on the knowledge activists possess about their own service system, the informal education approach is easily adaptable to foreign contexts.

International support for the rule of law and human rights enforcement will be an important component of reform. These programs can be used to help Russians establish human rights oversight and enforcement mechanisms within institutions and in the community. Model laws and human rights oversight mechanisms from other countries will be valuable, but these programs must be adapted to the Russian context. Programs that bring together international Russian legal experts with key Russian stakeholders to collaborate on legislative reform will be most effective. Such projects will be more likely to succeed when they include background training in disability rights for Russian attorneys and lay advocates. Internships for Russian lawyers and lay advocates to observe the operation of disability rights enforcement mechanisms in other countries would be valuable.

Funds for the development of model programs will be

more effective if they are linked with professional development and training. Short-term, practical training may be emphasized at the outset to permit immediate implementation of pilot programs. Professionals will benefit greatly from advocacy training programs that expose them to disability rights enforcement and community integration models. Professionals have been leaders in reform movements in other countries, and their role in bringing about reforms in Russia will be critical. In the long run, it will also be valuable to develop university programs to train professionals and educators in the full range of services required for community integration.

International donors dedicated to emergency relief for children in urgent need of assistance can use their funds strategically to promote systemic reform, although it is not likely that the amount of emergency foreign assistance available will meet the needs of all children with disabilities within institutions or communities. International donors will have to make difficult choices about which children to assist with their limited resources. If they assist children living in communities who are at the highest risk of placement in an institution, international funders will help children in great need, prevent unnecessary new placements in institutions, and strengthen community-based systems for delivering services and supports. Also effective would be relief efforts that support the work of family advocacy organizations, which are uniquely positioned to identify children and families at risk of imminent breakup. Family groups can help to identify the needs of children and develop effective strategies to keep children at home.

International development programs relating to people with disabilities should be sure to include the major stakeholders in the design, development, and implementation of these programs. Without such consultation, international funders risk creating programs that are not truly responsive to the needs of the stakeholders or that do not account for culturally specific barriers to reform. One vehicle to ensure citizen participation would be the disability advisory council. Disability advisory councils may be used on the local level to advise on the development of a specific project, or they may operate at a regional or national level to promote

citizen participation in public policy.

In societies that place a great value on professional training and experience, the introduction of nonprofessional participants may meet with opposition or resistance. Once people with disabilities and their family members are introduced into jobs and perform effectively, resistance to their participation will be greatly diminished. International funders can play a key role in ensuring that people with disabilities and their 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.

Resistance to reform may come from the general population. 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 someone with a severe disability can lead a safe, productive, and meaningful life in the community. Popular support for community integration will be difficult until the public learns about the potential for reform. A public education campaign through the mass media may change attitudes about people with disabilities and raise public support for reform.

Conclusion: International Commitment to Implement the CRC's Integration Mandate

A comprehensive and integrated approach to the enforcement of rights in institutions and in the community is needed to respond to the discrimination against and abuse of institutionalized children. Human rights organizations often fail to develop effective advocacy for people with disabilities because they fall into the trap of focusing exclusively on abuses within institutions. Inhuman and degrading treatment in institutions falls safely into the category of internationally recognized "civil and political rights," the traditional focus of many human rights organizations. In contrast, community services draw their protection from "economic and social rights," often a lesser priority or outside the mandate of human rights organizations. As this article shows, access to services in the community is inextricably linked to the prevention of abuses within institutions. Indeed, a narrow effort to respond to in-

human and degrading treatment within institutions may be self-defeating without the creation of accessible and appropriate health, education, and social support in the community. The "right to community integration" for children in institutions avoids a potentially dangerous dichotomy of rights and provides an effective framework for action to assist institutionalized children.

People with disabilities who seek enforcement of the right to community integration ask no more than what other individuals expect as a matter of right—to make the most basic and fundamental decisions about where they will live, work, play, study, or receive health care.[66] Effective human rights enforcement for people with disabilities will require the creation of realistic opportunities for children and adults with disabilities to make such decisions. The first step in effective human rights protection requires the inclusion of people with disabilities and their family members in the design and implementation of human rights enforcement and service projects that fundamentally affect their lives.

While this article has focused largely on the need to support grassroots activists, disability rights NGOs, service providers, and policymakers within Russia, international accountability is needed as well. The rights of children and adults with mental disabilities must be more actively included in the mainstream agenda of international human rights NGOs, UN and other intergovernmental human rights oversight bodies, and international development organizations. International funding and support should be explicitly conditioned upon the enforcement of the rights of people with disabilities.

The CRC provides a framework to guide international action to promote community integration and entails an obligation to do so for all States parties, including donor countries.[67] The CRC Preamble emphasizes "the importance of international co-operation for improving the living conditions of children in every country. . . ."[68] The CRC creates an obligation to "promote, in the spirit of international cooperation, the exchange of appropriate information," including "access to information concerning methods of rehabilitation, education, and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen

their experience in these areas."[69] Civil society programs that promote the transfer of skills to empower people with disabilities and development programs that draw on such skills constitute an important step in meeting the obligations of donor countries.

International development and human rights organizations can play a particularly important role in directing funding and international attention to rights issues that are often ignored in times of economic hardship. While conditions throughout Russian society are harsh, the best new programs may be adopted in the worst of times. Most successful change takes place when bold, new initiatives are adopted that generate public interest and excitement. The very urgency of the humanitarian concerns facing children in institutions may provide a unique opportunity to gain public support for community integration and reform. The Russian government, NGOs, and international donors should 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.

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References

1. "Rights of Child" Program, Independent Association of Child Psychiatrists and Psychologists, NAN: No to Alcoholism and Drug Addiction, et al., *Russian NGOs Alternative Report to the Committee on the Rights of*

the Child (Moscow, 1998), p. 10. It is difficult to obtain exact statistics on the number of children in Russian institutions, both because there is no centralized system of compiling this data and because federal and local ministries collect information on children in different ways. Information on children with disabilities is particularly complicated because there is no uniform system for defining disability. The Russian Federation's report to the UN Committee on the Rights of the Child states, for example, that there are 30,700 children in "boarding institutions for disabled children," 277,200 in "special schools for less seriously affected children," and 202,200 in "special boarding schools for mentally and physically retarded children." See Government of the Russian Federation, *Periodic Reports Submitted by States Parties under Article 44 of the Convention on the Rights of the Child* (Moscow, 1998), UN Doc. CRC/C/65/Add.5, paras. 236–37. The report fails to clarify the meaning of the above terms, and it is not clear whether these statistics include children in baby houses, children deemed "uneducable," or children placed in mental health facilities or psychiatric hospitals.

2. Human Rights Watch, *Abandoned to the State: Cruelty and Neglect in Russian Orphanages* (New York, 1998), p. 19.

3. Government of the Russian Federation (see note 1), para. 205. The report cautions that part of the increase is the product of an improved mechanism for identifying and registering these children.

4. *Foreign Operations, Export Financing, and Related Programs Appropriations Bill, 1999*, 105th Cong., 2d sess., S. Rept. 255, p. 30; *Making Omnibus Consolidated and Emergency Supplemental Appropriations for Fiscal Year 1999: Conference Report to Accompany H.R. 4328*, 105th Cong., 2d sess., H. Rept. 825, p. 1151 (statement of managers).

5. Human Rights Watch (see note 2).

6. Convention on the Rights of the Child, G.A. Res. 44/25, UN GAOR, 44th Sess., Supp. No. 49, at 166, UN Doc. A/44/25 (1989). Entered into force September 2, 1990. Ratified by the USSR June 13, 1990. Entered into force in Russia, legal successor to the USSR, September 15, 1990. Article 23 pertains to children with disabilities and is reproduced in full in note 13.

7. Mental Disability Rights International, *Children in Russia's Institutions: Human Rights and Opportunities for Reform* (Washington, DC: MDRI, 1999). The report is available from MDRI at http://www.MDRI.org. The Russian translation is available from UNICEF or from MDRI at 110 Maryland Ave. NE, Suite 511, Washington, DC 20002, USA.

8. MDRI (see note 7).

9. MDRI (see note 7), p. 9.

10. M. A. Burke, UNICEF, *Child Institutionalization and Child Protection in Central and Eastern Europe* (Florence: International Child Development Centre, 1995). Professional thinking in Central and Eastern Europe was heavily influenced by the ideology of the Communist era; see K. Pringle, *Children and Social Welfare in Europe* (Buckingham: Open University Press, 1998), p. 110.

11. Significant protections for the family are included in the Preamble, Articles 2, 8, 9, 16, 18, and 27, and elsewhere in the CRC (see note 6).

12. CRC (see note 6), Preamble.

13. Article 23 reads in full:

> 1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.
> 2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.
> 3. Recognizing the special needs of the disabled child, assistance extended in accordance with paragraph 2 shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed 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 fullest possible social integration and individual development, including his or her cultural and spiritual development.
> 4. States Parties shall promote in the spirit of international cooperation the exchange of appropriate information in the field of preventative health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

14. CRC (see note 6), art. 23.1.

15. CRC (see note 6), art. 23.3.

16. The Declaration states that "[w]henever 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 institution only if it "becomes necessary." Declaration on the Rights of Mentally Retarded Persons, G.A. Res. 2856, UN GAOR, 26th Sess., Supp. No. 29, at 99, UN Doc. A/8429 (1971), section 4.

17. "Every person with a mental illness shall have the right to live and work, as far as possible, in the community." MI Principles, G.A. Res. 119, UN GAOR, 46th Sess., Supp. No. 49, Annex, at 188–92, UN Doc. A/46/49 (1991), principle 3. Where treatment is necessary, "[e]very 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." MI Principles, principle 9(1).

18. Standard Rules on the Equalization of Opportunities for Persons with Disabilities, G.A. Res. 96, UN GAOR, 48th Sess. (1993). The Preamble of the StRE states that "intensified efforts are needed to achieve the full and equal enjoyment of human rights and participation in society by persons

with disabilities." Rule 3 states, "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."

19. UN disability rights resolutions can be used as a guide to the application of treaty-based rights in other UN conventions, such as the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), and the CRC. See E. Rosenthal and L. Rubenstein, "International Human Rights Advocacy under the 'Principles for the Protection of Persons with Mental Illness,'" *International Journal of Law & Psychiatry* 1993, 16: 270.

In a landmark case on the rights of people with disabilities under international law, this use of the MI Principles was recently affirmed by the Inter-American Commission of Human Rights, Report 29/99, Case 11,427, Ecuador, adopted by the Commission in Sess. 1424, OEA/Ser/L/VII.102, Doc. 36, March 9, 1999, p. 8, n. 7. The Commission used the MI Principles as a guide to the interpretation of the American Convention on Human Rights, citing the analysis by Rosenthal and Rubenstein referenced above.

20. The Council of Europe has taken a much more active role in defining children's rights than has the European Union. While its resolutions are non-binding, the Council of Europe is larger and includes many former Soviet-bloc countries. Pringle (see note 10), p. 150.

21. Committee of Ministers, Resolution 73(1) on the Social Services for Physically or Mentally Handicapped Persons, adopted January 19, 1973 at the 217th meeting of the Ministers' Deputies and reprinted in *The Rights of the Child: A European Perspective* (Strasbourg: Council of Europe Publishing, 1996), Section I.A.1.

22. Committee of Ministers, Recommendation No. R(92)6 of the Committee of Ministers to Member States on a Coherent Policy for People with Disability, adopted April 9, 1992 at the 474th meeting of the Ministers' Deputies.

23. Committee of Ministers (see note 22), Section I.4. Section I.1 of the recommendation also calls on countries to adopt policies "guaranteeing full and active participation in community life."

24. Committee of Ministers (see note 22), Section I.2.

25. Committee of Ministers (see note 22).

26. Widespread abuses against people with disabilities have been documented around the world by two UN Special Rapporteurs on Human Rights and Disability, yet there is no specialized international convention to protect this group. As a result, people with disabilities must seek protection under the more general protections of other human rights conventions, such as the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the European and American conventions, and the CRC. See Rosenthal and Rubenstein (note 19), p. 259.

27. D. A. Frank, P. E. Klass, F. Earls, and L. Eisenberg, "Infants and Young Children in Orphanages: One View from Pediatrics and Child Psychiatry," *Pediatrics* 1996, 95; J. W. Conroy and V. J. Bradley, *The Pennhurst*

Longitudinal Study: A Report of Five Years of Research and Analysis (Philadelphia: Temple University Developmental Disabilities Center and Boston: Human Services Research Institute, 1985); S. Larson and C. Laken, *Deinstitutionalization of Persons with Mental Retardation: The Impact on Daily Living Skills* (Minneapolis: University of Minnesota Institute on Community Integration, 1989); S. Larson and C. Lakin, "Deinstitutionalization of Persons with Mental Retardation: Behavioral Outcomes," *Journal of the Association of Persons with Severe Handicaps* 1989, 14(4): 324–32. Since the publication of the 1989 articles, Larson and Laken have conducted a review of seventeen more recent studies that confirm the findings of the earlier literature. This material is currently in preparation for publication. Telephone interview with Professor Charlie Laken, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, March 12, 1999.

Studies that demonstrate a relatively favorable outcome for children in orphanages compare outcomes with children who are refugees in war-torn countries where community-based services and support systems are absent. R. Desjarlais, L. Eisenberg, B. Good, and A. Kleinman, *World Mental Health: Problems and Priorities in Low-Income Countries* (New York: Oxford University Press, 1995), pp. 156–57. Controlled, longitudinal studies that compare children within institutions and their counterparts receiving community services are limited because so few children remain in institutions in Western countries.

28. V. J. Bradley, *Deinstitutionalization of Developmentally Disabled Persons: A Conceptual Analysis and Guide* (Baltimore: University Park Press, 1978); UNICEF, *Children at Risk in Central and Eastern Europe: Perils and Promises* (Florence: International Child Development Centre, 1997), pp. 102–6.

29. Frank et al. (see note 27), p. 572; S. Kaler and B. J. Freeman, "Analysis of Environmental Deprivation: Cognitive and Social Development in Romanian Orphans," *Journal of Child Psychology & Psychiatry* 1994, 35: 769.

30. Frank et al. (see note 27), p. 570.

31. S. Ruxton, *Children in Europe* (London: NCH Action for Children, 1996), p. 329.

32. Ruxton (see note 31), p. 373; UNICEF (see note 28), p. 71. MDRI has conducted interviews with family members in Armenia, the Czech Republic, Hungary, Romania, and Russia that are consistent with research findings in the West.

33. G. Dybwad and H. Bersani Jr. (eds), *New Voices: Self-Advocacy by People with Disabilities* (Cambridge: Brookline Books, 1996). Family advocacy has been more effective in countries with a strong independent sector. Ruxton (see note 31), p. 395.

34. UNICEF (see note 28), p. 101.

35. E. Zamfir and C. Zamfir, "Children at Risk in Romania: Problems Old and New," *UNICEF International Child Development Centre Innocenti Occasional Papers*, September 1996, p. 37.

36. Sources vary on the exact numbers. The most conservative analysis we found estimates that the number of children in institutions went up from 40,500 in 1989 to 41,986 in 1994. This study observes that, "[g]iven

that the number of newborn infants fell by more then 30 percentage points during these years, this climb in cases of institutionalization must be considered dramatic." Zamfir and Zamfir (see note 35), p. 40. According to other estimates, there were more than 10,000 new placements of children in homes for the disabled, and the overall rate of institutionalization went up between 1989 and 1995 by 37%. UNICEF (see note 28), p. 66.
37. UNICEF (see note 28), p. 110.
38. Judith Harwin, *Children of the Russian State: 1917–1995* (Aldershot, UK: Ashgate Publishing, 1996).
39. United Nations Economic and Social Council, Commission on Human Rights, *Study of the Implications for Human Rights of Recent Developments Concerning Situations Known as States of Siege or Emergency*, UN Doc. E/EN.4/1982/15 (prepared by N. Questiaux).
40. CRC (see note 6), art. 4.
41. P. Alston, "The Legal Framework of the Convention on the Rights of the Child," *Bulletin of Human Rights: The Rights of the Child* 1992, 91(2): 5.
42. CRC (see note 6), art. 4.
43. Alston (see note 41), p. 10. For a discussion of the obligation to enforce civil and political rights as well as economic and social rights for people with mental disabilities, see Rosenthal and Rubenstein (note 19), p. 280.
44. L. Despouy, Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, *Human Rights and Disabled Persons: Human Rights Study Series* 6 (New York: United Nations, 1993), p. 27; E.-I. Daes, *Principles, Guidelines, and Guarantees for the Protection of Persons Detained on Grounds of Mental Ill-Health or Suffering from Mental Disorder*, UN Doc. No. E/CN.4/Sub.2/1983/17, paras. 145–47.
45. Mental Disability Rights International, *Human Rights and Mental Health: Hungary* (Washington, DC: MDRI, 1997); Mental Disability Rights International, *Human Rights and Mental Health: Uruguay* (Washington, DC: MDRI, 1995). MDRI's fact-finding missions in Armenia, the Czech Republic, Romania, and Mexico have found similar patterns of segregated services.
46. Harwin (see note 38), p. 5.
47. Pringle (see note 10), p. 110.
48. N. N. Malofeev, "Special Education in Russia: Historical Aspects," *Journal of Learning Disabilities* 1998, 31(2): 182.
49. Malofeev (see note 48).
50. Burke (see note 10), p. 1; Harwin (see note 38), p. 1.
51. Harwin (see note 38), p. 1.
52. In Russia, interdisciplinary Medical-Pedagogical Commissions determine whether children will be placed in institutions. Each region of Russia has one regional commission and a certain number of local commissions. In the areas visited by MDRI, 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 a pediatrician.
53. The MDRI team met with members of the Down Syndrome Association in May and November, 1997 and heard many individual stories of the difficulty of keeping children in mainstream schools. Vera Koloskov, the

daughter of Sergei Koloskov, President of the Down Syndrome Association, is educated in a mainstream school. Mr. Koloskov reports that Vera is one of very few members of the association throughout the Russian Federation who is educated in a mainstream school.
54. CRC (see note 6), Preamble. Significant protections for the family are included in Articles 2, 8, 9, 16, 18, and 27 and elsewhere in the CRC.
55. CRC (see note 6), Preamble.
56. CRC (see note 6), art. 18.2.
57. CRC (see note 6), art. 26.1 and 26.2.
58. UNICEF (see note 28), p. 102.
59. CRC (see note 6), art. 20.3.
60. CRC (see note 6), art. 6.2.
61. CRC (see note 6), art. 24.
62. CRC (see note 6), art. 24.
63. StRE (see note 18), Rule 14(2).
64. StRE (see note 18), Rules 14(5) and 16(2).
65. UNICEF (see note 28), p. 107.
66. A. Ely Yamin, "Defining Questions: Situating Issues of Power in the Formulation of a Right to Health under International Law," *Human Rights Quarterly* 1996, 18: 398.
67. Alston (see note 41), p. 25.
68. CRC (see note 6), Preamble. See also Articles 23.4 (cooperation relating to children with disabilities), 24.4 (cooperation on health), and 28.3 (cooperation in education).
69. CRC (see note 6), Preamble and Article 23.4.