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Abstract

Disability rights are often ignored in discussions of human rights. Recently, however, scholars and activists have begun producing a body of literature on disability rights in Russia and the former Soviet bloc states. Much of the literature focuses on children's rights with an emphasis on the right to inclusive education. The literature addressing adult issues includes articles considering civil society, civil rights, and community integration. Finally, several articles address the intersection of disability rights with gender rights and ethnic minority rights.

Keywords

Human rights, Russia, Soviet Union, Eastern Europe, Disability

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Disability Rights

By Annika Johnson

Disability rights are often ignored in discussions of human rights. Recently, however, scholars and activists have begun producing a body of literature on disability rights in Russia and the former Soviet bloc states. Much of the literature focuses on children's rights with an emphasis on the right to inclusive education. The literature addressing adult issues includes articles considering civil society, civil rights, and community integration. Finally, several articles address the intersection of disability rights with gender rights and ethnic minority rights.

Many children with disabilities in former Soviet states are placed in special institutions. The rights of parents are violated by doctors and other state officials who place pressure on them to relinquish guardianship of their children. Families who choose to raise children with disabilities in the home face a lack of adequate resources that exacerbate already poor economic circumstances. Due to low expectations, children in segregated institutions are often given a second class education, which poses a barrier to the attainment of higher education. Children with severe disabilities often graduate from children's institutions to institutions for adults. Many have advocated for more inclusive education that more closely approximates the Western model of mainstreaming. Integrative education is difficult where educators refuse flexibility in curricula. Architectural barriers also pose a barrier for children with physical disabilities in primary, secondary, and post-secondary general education settings.

Adults with disabilities often face appalling living conditions. The most prominent human rights violation in recent history has been the continued use of caged beds for adults with mental disabilities in the Czech Republic. A recent death attributed to the use of cages has prompted high profile attention from various NGOs. The continued problem of understaffing, however, has prompted Czech officials to continue using the cages, citing a lack of viable alternatives. Civil society organizations in several countries are trying to provide a viable alternative to institutionalization by providing community support services allowing adults independence and dignity. Lack of funding, however, makes NGO efforts limited.

Additionally, several articles address the intersection of disability rights with gender and ethnic minority rights. Many former Soviet bloc states have patriarchal cultures in which women are expected to be caregivers. However, in the Soviet period, women were expected to work outside the home as well, resulting in a dual burden. Mothers of children of disabilities who choose not to institutionalize their children face an even greater burden. Violence against women with mental disabilities is common in institutional settings. The Roma, an ethnic minority in much of Central and Eastern Europe, are often put into special schools for the mentally disabled due to ethnic discrimination and thus receive sub par education.

The future of disability rights in former Soviet states is unclear. Legal protections are granted by U.N. declarations, E.U. directives, and national legislation. The implementation of legal protections is difficult in many countries due to lack of adequate resources. Support from international disability organizations can help domestic NGOs in their attempt to provide services and advocate for people with disabilities in each national context.

Education

Batukhtin, V.D., A.D. Shcherbov, and E.A. Martynova. 1999. "Access to Higher Education for Disabled People: A Systematic Approach at Chelyabinsk State University in Russia." *Higher Education in Europe* 24 (3): 385-395.

Annotation: The article provides a general overview of access to higher education which they define as a person's ability to access the kind of higher education that they desire. The authors distinguish four different levels of access: institutional, regional, national, and global. People with disabilities have limited access to higher education due to "the absence of a barrier-free environment, lack of financial support for higher education establishments, underdeveloped distance education, the insufficient level of secondary education and health services, financial and transportation problems, etc."

Gindis, Boris. 1995. "The Social/Cultural Implication of Disability: Vygotsky's Paradigm for Special Education." *Educational Psychologist* 30 (2): 77-81.

Annotation: The author provides an overview of Les S. Vygotsky's contributions to the field of special education. Vygotsky is a 20th century Russian psychologist known for contributing to the field in the areas of methodology, cognitive development, psycholinguistics, and learning theory. The author claims that Vygotsky's study on defectology, literally the study of defect, "constitutes an important part of his scientific legacy." In "defectology," children with disabilities were categorized into four groups: hard of hearing, visually impaired, mental retardation, speech and language impaired. Children with emotional disorders and learning disabilities were not served under defectology. Vygotsky argued that it is society's reaction to the organic handicap, not the handicap alone, that is the more disabling for the child. The author concludes the article by admitting that Vygotsky did not provide a complete picture for special education, citing the need for further study, particularly cross-cultural studies, but pays tribute to Vygotsky's important contributions to providing a humane framework for special education in the 20th century.

Korkunov, Vladimir V., Alexander S. Nigayev, Lynn D. Reynolds, and Janet W. Lerner. 1998. "Special Education in Russia: History, Reality, and Prospects." *Journal of Learning Disabilities* 31 (2): 186-192.

Abstract: *To describe special education in Russia, this article (a) explains the background information on the formation of a Russian-American partnership, (b) offers an historical perspective of special education in Russia, (c) reviews the current status of special education in Russia and in particular the Svverdlovsk Oblast, and (d) forecasts the future of Russian special education. In considering new goals and future directions for special education in Russia, the authors suggest that the policies and legislation developed by the Provinces in Canada may offer a workable model for a Russian special education system.*

Leonhardt, Annette. 1995. "Educational Reform in Slovakia." *European Education* 27(2): 37-46.

Annotation: The final section of the article addresses educational reform and its effects on special education in Slovakia. While Slovakia continues to have special schools for children with various disabilities, educational reform has also focused on integrating them into non-disabled classrooms. There has been some resistance on the part of teachers to this integration who want to see children with disabilities put into special boarding schools but more parents are refusing. The author recognizes that integration can be a slow process but believes teachers and administrators must accept integration as a basic principle and offers several suggestions for educators to achieve that goal.

Malofeev, Nikolai N. 1998. "Special Education in Russia: Historical Aspects." *Journal of Learning Disabilities* 31 (2): 181-185.

Abstract: *Tracing the history of special education services in Russia from its beginnings in the early nineteenth century through the rapid expansion of both private and government-supported programs and institutions until the restrictive Soviet period provides both understanding and appreciation of current Russian special education services and institutions. Theoretical principles guiding special education formulated by L. Vygotsky, and sources outside the USSR, were officially repressed, as were testing and statistical data on handicapped individuals. Official mandates to bring students with handicaps up to state-approved standards resulted in the development of creative, effective approaches. The framework of special education changed little until the breakdown of the USSR. The new Russian Federation ratified U.N. resolutions protecting the rights of children. Categorical language is a recent development, and terms such as defective, retarded, and pedagogue are gradually being replaced. The final decade of this century is witnessing rapid change at the initiation of the Ministry of Education that is beginning to produce needed reform. One of the major initiatives is to provide LD specialists in all schools so that students will not need to be a great distance from home to receive needed services.*

McMillan, Ian. 2003. "Amnesty Report Condemns Russia's Human Rights Record on Children." *Learning Disability Practice* 6 (9).

Annotation: An Amnesty report claimed that the human rights of children with learning disabilities were being violated in Russia. Parents of newborns diagnosed with a learning disability were encouraged to relinquish guardianship and the children would go to live in a children's institution. Such institutions are understaffed and many children are confined to their beds. Children are written off as "uneducable" and have no chance of "review or release."

Neustadt, Nurit. 1998. "Breaking Boundaries: The Expansion of Services for Visually Impaired Estonians." *Journal of Visual Impairment & Blindness* 92 (8): 2.

Annotation: The author observes the changes in education available for both children and adults with visual impairments in Estonia. Orientation and mobility training, independent living skills, and mainstreaming have been introduced as concepts in the Estonian educational system post-independence. Orientation and mobility training is now offered as a part of the curriculum at the

special school for the blind. They also use the school's dormitories in the summer months to provide training for adults with visual impairments. In addition, the Federation for the Blind offers orientation and mobility training to newly blinded and older adults. Mainstreaming has become an option for children with disabilities with children with low vision being the primary beneficiaries. In the future, it is hoped that university support for people with visual impairments will be available.

Pervova, Irina. 1998. "Children and Youth with Special Needs in Russia, and Educational Services to Meet Them." *Education & Treatment of Children* 21 (3).

Annotation: The author provides an overview of the special education system in Russia in the second section of the article. The special education system is divided into various kinds of programs which included pre-schools and kindergartens, children's houses, special schools, special classes in regular schools, special vocational technical schools, psycho-medical pedagogical commissions, and centers of rehabilitation. The author addresses the scope of special education in Russia and notes an increase in the diagnosis of children with learning disabilities from 1991 to 1995. New standards in special education have been adopted. Special education remains primarily segregated from general education in contrast to western trends. The author favors integration of children with disabilities in education and believes that Russia could benefit from examples in the United States. Western examples of inclusion in education, however, may not be realistic given the cultural and economic context in Russia.

Racheotes, N.S. 1997. "The Education of Blind and Visually Impaired Children." *Journal of Visual Impairment & Blindness* 91 (5).

Annotation: The author uses personal interviews with individuals with visual impairments to assess the changes that have been made in Post-Soviet Russia with regards to educating the visually impaired. Even under the Soviet regime, people advocated for changes in early intervention and preschool, vocational and medical services, and greater family involvement. Later, Russia would adopt the Educational Rights of Disabled Children law that guarantees children with disabilities education from pre-school to post-secondary education. While there has been reform in special education, there has been a lack of enforcement of the new norms. Another problem lies in the centralization of the education system which may not allow for flexibility and creativity. While the author believes that special education teachers are better educated and better paid than in the past, lack of supplies, stubborn supervisors, and hardships in rural areas are barriers to effective education of individuals with visual impairments.

Radoman, Vesna, Virxhil Nano, and Alison Closs. 2006. "Prospects for Inclusive Education in European Countries Emerging from Economic and Other Trauma: Serbia and Albania." *European Journal of Special Needs Education* 21 (2): 151-166.

Annotation: The authors present a comparative analysis of the possibilities for inclusive education of children with learning disabilities in Serbia and Albania. They look at historical,

social, and economic factors that influence the viability of inclusive education. The role of NGOs and international funding are considered. Some barriers to inclusive education are societal apathy, poor economy, lack of infrastructure, additional needs of pupils experiencing poverty, social disruption, or other distress, a lack of flexibility in curricula, and educators' belief that children with learning disabilities are uneducable. The authors give an overview of small steps in each country toward inclusive education profiling one school in each country. In order for inclusive education to develop further, support from international NGOs, economic and social stability, and a political orientation toward Europe and inclusive standards will be necessary.

Rich, Vera. 1995. "First College for the Disabled Opens in Russia." *Lancet* 16 December: 1.

Annotation: Since social security benefits are only minimally adequate due to inflation, it has been necessary for people with disabilities to find work in order to earn an adequate income. The first college for disabled persons was established in order to meet this need. The Moscow State Social University provides degrees in business, finance, economics of technology, and management for individuals registered as disabled. The courses are fairly expensive at \$1200 a year with MSSU paying \$700 and local governments, personal sponsors, or social security necessary to pay the remainder. The establishment of a university is a step towards the integration of people with disabilities in Russian society.

Romanov, P.V. & E. R. Iaskara-Smirnova. 2006. "The Problem of Access to Higher Education." *Russian Education and Society* 48 (8): 54-71.

Annotation: The author looks at the barriers that people with disabilities face in access to higher education. While federal law guarantees equal access, architectural barriers, lack of resources for capital improvements, and lack of government funding in general complicate access. State policies addressing higher education for people with disabilities are still oriented toward segregated facilities in certain regions denying students choice. Another barrier to enrollment in higher education is the real or perceived lack of adequate secondary education that leads students to believe they are not qualified. While there is still discrimination in admission policies, the authors note development of higher education for people with disabilities. They also fear integration in a general higher education setting will not provide the necessary supports including barrier-free facilities and special equipment that they would receive in special schools. The authors cite the delay in the passage of the Law on Special education designed to regulate the integration of students with disabilities as another obstacle. Finally, attitudes of fellow students, staff, and faculty must be changed to accommodate students with disabilities in higher education.

Civil Society, Civil Rights, and Community Integration

Amariei, Razvan. 2003. "Including the Excluded." *Transitions Online*, 8 December.

Annotation: Under communism in Romania the goal was to hide people with disabilities either by leaving them with their families or institutionalizing them. State institutions were and are often abusive environments for the people living in them. The author offers an alternative citing Pentru Voi Center in western Romania as an example that allows for community integration of people with disabilities. Pentru Voi was started as a parent organization and developed into a day-care center for children (now adults) with disabilities. The center has since expanded its capabilities to include social and practical skills acquisition, housing placement, and support for employment. The center has limited resources and a high turnover rate since employees are paid approximately the same as public employees. The local government supports the center financially, to the extent that is possible, but laws regulating public-private partnerships make adequate support difficult. Although the center would like to reintegrate people with disabilities from an institutional to a community setting, the abusive environment of institutions can often cause violent behavior in clients and the center cannot help such people although the center's director would like to expand its services to include them. The author has a clear bias against institutions and the tone of the article suggests it is written for an activist audience.

2004. "Ban on Caged Beds Premature: Czech Officials." *Canadian Medical Association Journal* 171 (6): 557.

Annotation: People with mental disabilities were commonly restrained using caged or netted beds before such forms of restraint were banned in the Czech Republic, Slovenia, and Hungary. The problem of understaffing in institutions, however, may cause mental health officials to resort to worse forms of physical restraint of patients who are a danger to themselves or others. While most officials agree that the caged beds are a human rights violation, they believe a ban is premature given the reality of understaffing. In Hungary, the caged beds were phased out in July 2004. Slovenia, which had only two such devices, also plans to phase them out. The Czech Republic, however, had between 750-1000 such devices and phasing them out will cost millions of dollars. The director of a Prague psychiatric hospital said that "banning them is a political solution" and does not solve the problem of understaffing. This article shows the complexity involved in finding a solution to a specific human rights violation.

Bridge, Gillian. 2004. "Disabled Children and Their Families in Ukraine: Health and Mental Health Issues for Families Caring for Their Disabled Child at Home." *The Journal of Health Care Social Work* 39 (1/2): 89-105.

Abstract: *In the Eastern European countries included in the communist system of the USSR, parents of disabled children were encouraged to commit their disabled child to institutional care. There were strict legal regulations excluding them from schools. Medical assessments were used for care decisions. Nevertheless many parents decided to care for their disabled child at home within the family. Ukraine became an independent country in 1991, when communism was replaced by liberal democracy within a free market system. Western solutions*

have been sought for many social problems existing, but “hidden,” under the old regime. For more of the parents of disabled children, this has meant embracing ideas of caring for their disabled children in the community, and providing for their social, educational, and medical needs, which have previously been denied. The issue of disability is a serious one for Ukraine where the nuclear disaster at Chernobyl in 1986 caused extensive radiation poisoning. This almost certainly led to an increase in the number of disabled children being born and an increase in the incidence of various forms of cancer. This paper is based on a series of observation visits to some of the many self-help groups established by parents, usually mothers, for their disabled children. It draws attention to the emotional stress experienced both by parents and their disabled children in the process of attempting to come to terms with the disabling conditions, and the denial of the normal rights of childhood resulting from prejudice, poor resources, ignorance, and restrictive legislation. Attempts have been made to identify the possible role and tasks of professional social workers within this context. International comparisons show that many parents and their children do not benefit from the medical model of disability, and that serious consequences include the development of depressive illness among those who find that little help is available from public services.

1996. “Civil Rights Law.” *Journal of Visual Impairment & Blindness* 90 (2) (1996).

Annotation: In December of 1995, the Russian government passed a piece of disability rights legislation addressing pensions, rehabilitation services, and architectural barriers. The World Institute on Disability and the All-Russian Society of the Disabled worked for three years to get the legislation passed.

Holland, Daniel. 2003. “Grass Roots Promotion of Community Health and Human Rights for People with Disabilities in Post-Communist Central Europe: A Profile of the Slovak Republic.” *Disability & Society* 18 (2): 133-143.

Annotation: The author uses a case study of the Slovak Republic to demonstrate the ability of grassroots organizations to provide community support for people with disabilities and chronic illness in contrast to the highly centralized and institutional care most commonly in practice. Grassroots organizations provide support services and advocacy that allow people with disabilities to live in the community. The author notes the varying degrees to which economic and political support is given to disability NGOs and Civil Society more generally. The survival of such organizations will depend on their ability to connect with international networks of disability rights organizations to obtain information and collaborative grants.

Iarskia-Smirnova, Elena. 2001. “Social Change and Self-Empowerment: Stories of Disabled People in Russia.” In *Disability and the Life Course: Global Perspectives*, ed. Mark Priestley. Cambridge: Cambridge University Press: 101-112.

Annotation: The author uses a biographical narrative approach to understand the experiences of several adults with disabilities in Saratov, Russia between 1999-2000. The article uses the oral histories of two adults with disabilities, Anna Vassilievna Semionova and Yuri Nikolaevitch Kazakov, who lived during the Soviet and Post-Soviet periods. Both were disability rights advocates, fighting for the recognition and implementation of civil rights for people with

disabilities. The author concludes the article by comparing the gendered nature of the two stories epitomized in two quotes. Semionova's approach to disability involves negotiation while Kazakov's is a strategy of "noncompliance" and "rebellion." Each person's "social context," taking into account space, time, gender, and social class, shaped the identity of each person and led them to adopt different strategies of social change and self-empowerment.

Krosnar, Katka. 2006. "Czech Government to Be Sued over Caged-Bed Death." *The Lancet*, 6 October.

Annotation: In spite of a 2004 pledge to ban caged beds in the Czech Republic, a legal ban is still not in effect and there are still at least 700 such devices in use. The death of a woman in a Prague psychiatric facility who died in the cage by choking on her own feces has caused her family and a European NGO to file suit. The case will be fought out in the Czech courts before moving on to the European Court of Human Rights at Strasbourg. The director of the hospital defended its actions claiming the patient was a danger to herself and others. The mother of the woman said that when she visited her daughter she was caged, dirty, with her hair shaven. The director of the Budapest-based Mental Disability Advocacy Center argued against the use of the cages saying that they caused patients conditions to deteriorate since it was psychologically isolating and often unhygienic. The article is highly critical of the Czech government but does allow officials to defend their actions.

Otrebski, Wojciech. 2000. "Quality of Life of People with Mental Retardation Living in Two Environments in Poland." *Cross Cultural Perspectives on Quality of Life*, ed. Kenneth D. Keith & Robert L. Schalock. Washington, D.C.: American Association on Mental Retardation: 83-92.

Annotation: The author uses both objective and subjective indicators to compare "quality of life" of individuals with mental retardation in an institutional context and those that live in the open community in Poland. He combines the standardization of social services with the subjective opinions of people with mental retardation to ascertain quality of life. He studies a group of 57 individuals with mental retardation with subgroup A comprising 37 people living with families or in group homes and with subgroup B comprising 20 people who resided in institutions. He translated and adjusted the Quality of Life Questionnaire to Polish conditions. He finds a statistically significant difference in the quality of life of people with mental retardation living in a community context and those living in an institutional context with the former having the higher quality of life. The author has a pronounced bias toward deinstitutionalization and thus favors information supporting the theory that people with mental retardation have a better quality of life in a community context. He believes his findings support the reorganization of social services to allow people with mental retardation to live in the community.

Raymond, Paul D. 1989. "Disability as Dissidence: The Action Group to Defend the Rights of the Disabled in the USSR." In *The Disabled in the Soviet Union: Past and Present, Theory and*

Practice, ed. William O. McCagg and Lewis Siegelbaum. Pittsburgh: University of Pittsburgh Press: 235-252.

Annotation: Iurii Kiselev and Valerii Fefelov, both disabled in industrial accidents, and Faizulla Khusainov, a Crimean parapalegic, founded the Action Group to Defend the Rights of the Disabled in the USSR in May of 1978. They were prompted to found the group by the Helsinki accord of 1975 and asked Soviet approval for an all-union society for the disabled. Initially the group viewed themselves not as a dissident group but as a legally sanctioned official association. The basic objectives were (1) to collect and disseminate information on the situation of the disabled in the USSR; (2) to petition before competent Soviet organs for the improvement of social security for the disabled; (3) to garner help from world opinion in the event that their appeals were turned down and (4) to establish contact with international organization for the disabled. One of the most important demands was for improvements in accessibility and one of the first publications of the group addressed the issue of transportation. Despite the group's insistence that they were not politically motivated in the dissidence movement, the Soviet authorities began to harass members within weeks of its foundation. This brought two changes in the group: the first a shift from the view that the Soviet system would allow for change and the second an association of the group's activities with the broader human rights movement. The group produced Information Bulletin which distributed fourteen issues between 1978 and 1982 when Fefelov would emigrate to West Germany. The U.N. International Year of the Disabled in 1981 and the Soviet regime's nonobservance provoked harsh commentary in the Bulletin and the state responded by charging him. The article provides a useful history of the formation of an important disability rights organization in the Soviet period.

Smith-Davis, Judy. 2000. "People with Disabilities in Russia: Progress and Prospects." In Cross-Cultural Perspectives on Quality of Life, ed. Kenneth D. Keith & Robert L. Schalock. Washington, D.C.: American Association on Mental Retardation: 219-229.

Annotation: This article provides a general overview of the progress of rights of people with disabilities in Russia and places disability rights in the broader human rights framework. The author observes favorable changes in the legal status of people with disabilities in Russia in human rights, special education legislation, health care, material well-being, and self determination but has not observed a corresponding compliance with norms. Widespread pollution under the former regime has resulted in only 14 percent of children being considered "practically healthy." Children with physical and mental disabilities in the Moscow school system number close to 20 percent. Chemical, biological, and nuclear test cities of the former Soviet Union have an extremely high incidence of congenital birth defects. The health care system in Russia suffers from lack of equipment, lack of medical personnel, and a lack of public trust in the system leading to decreased numbers of people who seek medical advice. While unemployment and poverty are common problems for the entire Russian society, individuals with disabilities suffer disproportionately. While students with disabilities were segregated and their education was standardized under the Soviet regime, recently there has been an effort to bridge the gap between special and general education as well as individualize the education process. Civil society among citizens with disabilities grew under glasnost and have been

advocating for adults (particularly disabled veterans) and children with disabilities. Associational activity and cooperation with local officials have led to some local successes and have been important in involving people with disabilities in determining their own lives.

Thomson, Kate. 2006. "Disability Organizations in the Regions." In Russian Civil Society: A Critical Assessment, ed. Jr. Alfred B Evans, Laura A. Henry and Lisa McIntosh Sundstrom. New York: M.E. Sharpe: 229-245.

Annotation: The author examines the extent to which civil society can promote local welfare change by comparing the activities of two Russian nongovernmental organizations in two cities. The author provides a theoretical context of the state-voluntary sector relationship as well as a theoretical model of disability, which argues for a social or civil rights model that distinguishes between biological defect or impairment and disability as socially constructed. The author critiques herself by acknowledging the limitations of applying a "Western" approach to disability in the Russian context. The study was based on interviews with organization executives, other officials, or members and was supported by organizational documents. The study primarily focused on educational services and was decidedly anti-segregation.

UNICEF Innocenti Research Center. 2005. *Children and Disability in Transition in CEE/CIS and Baltic States*. United Nations Children's Fund (UNICEF).

Annotation: The report issued by U.N. ICEF outlines the human rights issues children with disabilities face in CEE/CIS and Baltic States. Segregation and institutionalization are noted as policies with good intentions but ones which have led to further disabling conditions as well as social stigma. The report addresses rates of disability, health, poverty and raising children in families, availability of benefits and support, educational services, welfare services, lack of accessibility, and recreation and leisure. They further outline what rights children with disabilities have (and ought to have), acknowledge progress, and provide suggestions for future progress.

Vann, Barbara H. & Jan Siska. 2006. "From 'Cage Beds' to Inclusion: The Long Road for Individuals with Intellectual Disability in the Czech Republic." *Disability & Society* 21(5): 425-439.

Annotation: The author's document Czech human rights abuses that take place in institutions that purport to serve people with intellectual disabilities the most prominent being the use of cage beds in psychiatric institutions. They cite NGOs who provide community support services as a viable alternative to institutional care. Czech laws pose barriers to the ability of NGOs to provide services specifically with regard to state funding which only recognizes community care for seniors. The authors argue that individuals with intellectual disabilities must become self-advocates. E.U. law supports the right of such persons to live a life of dignity and in the least restrictive environment possible.

Vardanyan, Arman. 2003. "The Bars That Bind." *Transitions Online*, 30 June.

Annotation: The author is the director of the Mental Disability Advocacy Center in Budapest and writes the article from an activist perspective. The article focuses on the human rights abuses against people with disabilities in institutional settings in the E.U. accession countries. People in psychiatric and other institutions have been caged for extended periods of time which is degrading, inhuman, and damaging. Institutions are overcrowded with 20-30 adults in one room. Abuse is common in such settings. The author argues for a shift from institutional settings to a community based model encouraging integration of people with disabilities. Authorities must take human rights into consideration when reforming the mental health care system.

Gender, Ethnicity, and Disability

Iarskia-Smirnova, Elena. 1999. "What the Future Will Bring I Do Not Know': Mothering Children with Disabilities in Russia and the Politics of Exclusion." *Frontiers: A Journal of Women's Studies* 20 (2): 68-86.

Annotation: The author uses personal narratives of Russian mothers of children with disabilities in Saratov Russia between 1995 and 1997 to provide a gendered critique of the disability framework in Russia. Families who choose to raise children with disabilities at home face social exclusion due to cultural stigma. She examines motherhood as a culturally institutionalized concept that is not easily adapted to accommodate children with disabilities. Mothers in Russia already face a dual burden of being the primary care giver and working outside the home. Since there is a powerful pressure to institutionalize children with disabilities, families who raise their children with disabilities at home are faced with inadequate resources. Women often rely on family support when raising a child with a disability but often face cold and rude attitudes from those from whom they seek support. Sometimes women must break their dependency on family and other social support networks. Diagnosis of children as defective can lead to feelings of guilt on the part of the mother. The author concludes by arguing for a shift from an emphasis on diagnosis to an emphasis on civil rights.

Pallaska, Eva Szeli & Dea. 2004. "Violence against Women with Mental Disabilities: The Invisible Victims in CEE/NIS Countries." *Feminist Review* (76): 117-119.

Annotation: The authors argue that women with mental disabilities are subject to discrimination on three levels in CEE/NIS countries. First, they are subject to gender discrimination often found in patriarchal societies. Second, they are discriminated against because they have a disability. Finally, they are discriminated against even within the disability community on the basis of having a mental disability. Women with mental disabilities are not viewed as credible and thus violence against them is often ignored. Such women in institutional settings are subjected to physical and sexual abuse, forced abortions, and forced sterilizations. Often women who seek support when in an abusive situation are labeled as mentally disabled. The social

stigma associated with the label can cause women to lose the support of their communities, family, and lose custody of their children. The authors offer legal remedies including various forms of anti-discrimination, anti-domestic violence, and rights-protective legislation. They also propose more support for community based services.

Spritzer, Dinah A. 2005. "Often Shunted into Special Schools, Gypsies Fight Back." *The New York Times*, 27 April.

Annotation: The article focuses on the human rights abuses of Roma as it relates to disability in the Czech Republic. According to the State Department's human rights report, 90 percent of children in special schools for the mentally retarded are Roma. Tests diagnosing Roma children are in Czech putting the Roma speaking children at a disadvantage. Advocates for Roma rights say that Roma children receive a second-class education and many do not make it past the eighth grade. Government officials counteract accusations of bias by charging parents with a lack of involvement in their children's education. The government has, however, taken steps to improve the education of Roma children by standardizing tests which remove cultural bias, increase the number of Roma teaching assistants, and allow children attending special schools to take an extra year of coursework and apply to regular high schools. Since measures came too late for some students, 18 teenagers from Ostrava are filing suit against the government saying that their rights had been violated under Czech and European law.