



THE PREVALENCE OF DISABILITY IN EUROPE AND EURASIA

Executive Summary

September 2009

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Introduction

This report was commissioned by the Social Transition Team in the USAID Bureau for Europe and Eurasia to raise awareness of the situation of people with disabilities and present information on the prevalence of disability in the transitional countries of Europe and Eurasia. The study presents social constructs of disability across Europe and Eurasia¹ and provides data on the region's prevalence of disability, issues of institutionalization of people with disabilities, and a description of how people with disabilities have been and are treated today. The social, political, and institutional systems left behind after the Soviet era and the ensuing economic difficulties that affected the region, which further marginalized people with disabilities are addressed. This report offers a cursory view of the diverse and complex issue of disability in Europe and Eurasia, rather than presenting country-specific analyses on precise topics, such as those detailing specific populations of people with disabilities, discrimination, abuse and neglect, as well as economic analyses of pension and social insurance systems in relation to disability.²

Methodology

In preparing this report, the author consulted international statistical databases, conducted internet searches, and engaged several disabled people's organizations (DPOs) across the region to locate national disability statistics, when available, and provide background information on the current situation of people with disabilities in Europe and Eurasia.

Geographic and Data Limitations

Presenting comprehensive information on the prevalence of disability across the region is complicated by a number of factors, among them the geographic span of the region; the types and usability of the data available; the social, economic and cultural differences between countries; differences among the rights and opportunities afforded to people with disabilities in each country; and the organizational development and experience of DPOs. Internationally-recognized, standardized data on the prevalence of disability for the Europe and Eurasia region are limited. Existing national data are primarily concerned with a narrow set of beneficiaries of the social welfare and pension systems. Furthermore, differing definitions of disability add to the complexity, while widely varying classifications and methodologies used to collect disability data and problems with conceptual frameworks restrict and potentially flaw the information. It is no surprise that DPOs across the region refute their national data and welcome the World Health Organization's (WHO) estimate that people with disabilities comprise 10 percent of any given population (WHO, 2003). Despite challenges in identifying the prevalence of disability, there is persuasive information to guide development agencies and organizations in their response to the development needs of people with disabilities.

¹ For the purposes of this report, the countries included in the Europe and Eurasia region include: Albania, Armenia, Azerbaijan, Belarus, Bosnia, Bulgaria, Croatia, Georgia, Kazakhstan, Kosovo, Kyrgyzstan, Macedonia, Moldova, Romania, Russia, Serbia, Montenegro, Tajikistan, Turkmenistan, Ukraine, and Uzbekistan.

² Several country-specific reports addressing disability within different sectors and topics have been conducted by international organizations such as the Center for International Rehabilitation's publication of the International Disability Rights Monitor, the EU Monitoring and Advocacy Program (EUMAP) of the Open Society Mental Health Initiative, the World Bank, the World Health Organization, the UNICEF Innocenti Research Centre, Handicap International and the Share-SEE initiative, Mental Disability Rights International, and Mobility International USA, as well as the national governments and local DPOs and advocacy groups.

Country Summaries: Official Disability Statistics for Europe & Eurasia

This report provides a basic overview of country-level statistical data. Efforts have been made to systematize the data and include information on the nationally-recognized population of people with disabilities, as well as information on the institutionalization of both children and adults with disabilities. Where national data are nonexistent or limited, the author presents internationally collected data. An overall estimation of the prevalence of disability throughout the region is presented in Table I. It should be noted that the compilation of these estimates do not infer comparability.

Country	Current Population³ (millions)	GDP 2008⁴ (US\$) (billions)	Population in Year of Most Recent Disability Data⁵ (millions)	Estimated Disabled Population	Estimated Disability Prevalence⁶
Albania	3.14	12.29	3.13 (2007)	94,804	3.0%
Armenia	3.08	11.92	3.07 (2006)	148,656	4.9%
Azerbaijan	8.68	46.26	8.58 (2007)	281,000	3.3%
Belarus	9.68	60.30	9.70 (2007)	512,500	5.3%
Bosnia- Herzegovina	3.77	18.45	n/a	n/a	n/a
Bulgaria	7.62	49.90	7.91 (2001)	263,143	3.3%
Croatia	4.43	69.33	4.44 (2001)	429,421	9.6%
Georgia	4.36	12.79	4.36 (2008)	137,806	3.2%
Kazakhstan	15.68	132.23	15.15 (2005)	403,400	2.7%
Kyrgyzstan	5.28	4.42	n/a	n/a	n/a
Macedonia	2.04	9.52	2.04 (2006)	26,781	1.3%
Moldova	3.63 ⁷	6.05	3.76 (2005)	164,891	4.4%
Montenegro	0.62	4.52	0.62 (2008)	67,000	10.8%
Romania	21.51	200.071	21.55 (2007)	539,241	2.5%
Russia	141.80	1,607.82	142.10 (2007)	13,014,000	9.2%
Serbia	7.35	50.06	n/a	n/a	n/a
Tajikistan	6.84	5.19	6.17 (2000)	104,272	1.7%
Turkmenistan	5.03	18.27	n/a	n/a	n/a
Ukraine	46.26	180.36	47.45 (2004)	2,500,000	5.3%
Uzbekistan	27.31	22.3	26.49 (2006)	n/a	n/a

³ *Population 2008*. World Development Indicators database, World Bank, 15 September 2009.

⁴ *Gross Domestic Product 2008*. World Development Indicators database, World Bank, 15 September 2009.

⁵ World Development Indicators database, World Bank.

⁶ Prevalence is based on the population estimate for the year in which the data was collected

⁷ Includes Transdniestr.

The data in Table 1 above are based on figures calculated using disability data reported by national governments and World Bank population data. Household survey data such as the Multiple Indicator Cluster Survey (MICS) disability module provides a valuable alternate source of information. The MICS disability module is particularly useful because it takes a biopsychosocial approach to disability, and rather than asking whether individuals in the household have been registered as disabled, it probes on how members of the household function and interact with their environment. That being the case, the results are quite different from the disability prevalence rates reported by national governments. Table 2 below illustrates the differences in the data and the lack of participation among a number of countries in the region.

Country	Prevalence in MICS study
Albania	11.1%
Armenia	Did not participate
Azerbaijan	Did not participate
Belarus	Excluded disability module
Bosnia-Herzegovina	6.5%
Bulgaria	Did not participate
Croatia	Did not participate
Georgia	14.4%
Kazakhstan	Excluded disability module
Kyrgyzstan	Excluded disability module
Macedonia	10.0%
Moldova	Did not participate
Romania	Did not participate
Russia	Did not participate
Serbia & Montenegro	11.3%
Tajikistan	Excluded disability module
Turkmenistan	Restricted access
Ukraine	Excluded disability module
Uzbekistan	2.0%

The countries with the largest variance between official reported data and household MICS data are Georgia and Albania. Further, some countries that do not have official data available, such as Bosnia-Herzegovina, Serbia, and Uzbekistan, have MICS data. These figures help shape the picture of the region.

Regional Challenges in Disability Data

Disability data collection in Belarus and throughout Central Asia is more problematic than in the rest of the former Soviet Union. Many DPOs and nongovernmental organizations (NGOs) working in Central Asia and Belarus share the common experience of an entangled bureaucratic system. National disability data for this region is particularly limited and practically no data were found on adults with disabilities in national statistical databases. The sheer lack of information is intriguing, as the 1986 Chernobyl nuclear reactor explosion in Ukraine had a significant impact on the health of citizens in Belarus, Ukraine, and Moldova, as well as the service men and their families from Central Asia, the Caucasus, and Russia who were sent to join the clean-up and liquidation efforts at the site. One would expect to find in-depth information about people with disabilities in Belarus and throughout Central Asia due to the attention Chernobyl brought to the region, but unfortunately it is absent.

Although disability statistics in Central Asia are currently lacking, the United Nations Economic Commission for Europe (UNECE) Statistical Division has recently been focusing attention on improving disability data collection in the region. Workshops and training events have been held with

representatives of the statistical community from Uzbekistan and Kyrgyzstan. In addition to the work of UNECE, the Japan International Cooperation Agency has generated disability reports for Uzbekistan and Tajikistan, verifying the difficulties encountered with the actual data as well as challenges in obtaining data. Civil unrest and conflict in the Abkhazia and South Ossetia regions, as well as in the Transdnestr area, have formed significant reporting challenges for disability in both Georgia and Moldova. Furthermore, migration and conflict in the Balkans have presented many challenges to disability data collection and service provision.

Conclusions

The biggest challenge in developing this report was the lack of consistent and comparable data across countries. Even within countries, definitions changed slightly over time, limiting their ability to be used to produce effective analyses for policy making.

In spite of those challenges, however, there were two findings from this effort:

1. The challenges in collecting the data and the questions about the validity of the data (given the differences in the definitions and models used) indicate that more rigorous data collection and reporting practices would improve the knowledge about disability in the region and increase the likelihood that effective services can be delivered.
2. In many countries, a disproportionate percentage of the individuals in institutional care are those with disabilities. Institutionalization remains a challenge in the region, and recent studies produced by USAID and others indicate that individual outcomes improve with community-based services.

Future Research

The ability to pinpoint and contrast the needs of one country versus another is complicated by the geographic scope of this report, the diversity of disability, and the differing legislative environments. Additional factors include the variations in effectiveness of DPOs in the region and lack of sound statistical studies of the people throughout this region. Data are too sparse and fraught with limitations to place greater priority on one country or group as compared to another. Even so, there is no contention over whether there is a need for disability-based programming; the question lies in how to meet the needs of this large and predominately excluded part of society. When designing a project, interested parties should ask questions such as, “Are people with disabilities involved in all stages of the project cycle, not simply as beneficiaries, but as participants and decision makers?”, “Can the project provide appropriate training and support for DPOs and cross-disability networks in the region?”, and “Is appropriate anti-discriminatory legislation in place to validate and justify host-country buy-in and ownership of the project?”

The information, including the gaps in information, identified in this study give rise to the question of whether donors should engage in further disability data collection efforts. Indeed, data collection efforts are integral to understanding the needs of a population and how to design program services. Given the severe shortage of comparable and consistent disability data observed during the course of this study, it is recommended that donors pursue opportunities to support improvement of data collection mechanisms and standardization of reporting. Studies should be designed within the context of programs or priority areas such as education; employment; micro-finance and access to credit; rule of law and the exercise of individual rights; gender; and maternal and child health. Research should be practical and include best practices and recommendations to assist currently-funded programs to become inclusive and inform new program development in this area.

Priority Program Areas

Priority areas for programming include labor and employment, education and training, and community and social integration. The ST team has produced separate analyses that provide lessons learned and effective practices in these areas for USAID Mission staff and others who might be responsible for meeting the needs of people with disabilities. Notably, readers interested in further programmatic recommendations in these areas should refer to the following documents:

- *The Job That Remains: An Overview of USAID Child Welfare Reform Efforts in Europe & Eurasia* (June 2009, DEC Doc ID: PN-ADO-922);
- *Best Practices in Vocational Training for People with Disabilities in Europe & Eurasia* (October 2009);
- *Best Practices in Inclusive Education for Children with Disabilities: Applications for Program Design in the E&E Region* (forthcoming in October 2009);
- *Emerging Practices in Community-based Services for Vulnerable Groups: A Study of Social Services Delivery Systems in Europe and Eurasia* (June 2006, DEC Doc ID:PN-ADG-301); and
- *Promising Practices in Community-based Social Services in CEE/CIS/Baltics* (October 2005, DEC Doc ID:PN-ADF-930).