



Innocenti Insight

CHILDREN AND DISABILITY IN TRANSITION IN CEE/CIS AND BALTIC STATES

For every child
Health, Education, Equality, Protection
ADVANCE HUMANITY

CHILDREN AND DISABILITY IN TRANSITION IN CEE/CIS AND BALTIC STATES

Acknowledgements

This report has been prepared by a team of UNICEF IRC staff with contributions and assistance from a large number of collaborators. The core team was composed of Szilvia Altorjai, Martin Bax, Monica Dowling, Gáspár Fajth, Jane Foy, Roumiana Gantcheva and Virginija Eidukiene, Timothy Heleniak and Anita Svarckopfa. Professor Monica Dowling of the School of Health and Social Welfare, Open University, Milton Keynes, UK, and Jane Foy have served as writers and editors. Gáspár Fajth is the volume editor of the report.

Special thanks are extended to Dr Martin Bax, Chair of the European Academy for Childhood Disability, and Professor Mel Ainscow Professor of Education, University of Manchester, for their comments, advice and insights which have contributed substantially to the text. Valuable inputs have also been provided by Mary Anne Burke, Health Analyst/Statistician, Global Forum for Health Research, Geneva, and by Dr Gregor Wolbring, Chair of the Disabled People's International Bioethics Taskforce, and Biochemist and Bioethicist, University of Calgary, Canada. Dr Mikael Ostergren, WHO Regional Office for Europe, Copenhagen; Peter Evans, OECD/CERI, Paris; Tine Rostgaard of the Danish National Institute of Social Research, Copenhagen; Francesca Perlman of Department of Epidemiology and Public Health, University College, London; Marc Suhrcke, WHO European Office for Investment for Health and Development, Venice, and Nadezdha Aleshina, Georg Stahl and Gerry Redmond are thanked for their comments and contributions to the first phase of the research.

Key contributions to the design and methodology of the study were made in an expert review and briefing held in May 2002, with the participation of Barbara Czeizel, Budapest Korai Fejlesztő Központ, Budapest; Dr Leslie L. Davidson, Reader in Public Health Medicine, National Perinatal Epidemiology Unit, Oxford University; Dr Susan Keane, Central Remedial Clinic, Nicoleta Carmen Olteanu, Bucharest; Dr Audrone Prasauskiene, Vilnius, Lithuania, and Ecaterina Vrasmas, President of Association RENINCO, Bucharest.

Dr Martin Bax organized a series of consultations with senior professionals and also arranged field visits by members of the European Academy for Childhood Disability in Eastern European countries. Professor Hubert Haberfellner and Dr Owen Hensey visited Kaliningrad; Dr Martin Bax and Professor Gregory O'Brien visited Kiev and Chernihiv; and Dr Bax visited Sarajevo, a visit expedited by Bengt Lagerkvist. Their expert visits and surveys provided invaluable insights into the quality of services, particularly of health-related services, for children with disabilities in Eastern Europe.

The qualitative research for the study, including focus-group discussions and related interviews, in Bulgaria, Latvia and Russia was carried out by Oxford Research International. Special thanks are given to Silvia Iacuzzi, Christoph Sahm and team who helped the core team develop the necessary guides and questionnaires. Warm thanks go to the young people who offered their sincere views and their time in these discussions.

Encouragement and unflinching support for this study have been provided by senior colleagues in the UNICEF Regional Office for Central and Eastern Europe, Commonwealth of Independent States and the Baltics (CEE/CIS); in particular: Maria Calivis, Regional Director and Shahnaz Kianian-Firouzgar, Deputy Regional Director; Philip O'Brien, Regional Director for Europe, Marta Santos Pais, Director of the UNICEF Innocenti Research Centre, David Parker, Deputy Director, and Eva Jespersen, Chief, Socio-Economic Analysis Unit, IRC.

The Report has benefited from the help and comments of many UNICEF colleagues including Nigel Cantwell, Virginia della Pozza, Maryam Farzanegan, Patrizia Faustini, Angie Hawke, Salvador Herencia, Michael Miller, Martha Rajandran, Olga Remenets. Judita Reichenberg reviewed the complete draft report and provided valuable comments and suggestions.

Appreciation is given to Bernadette Abegglen-Verazzi, Andrea Brillì and Cinzia Iusco Bruschi for administrative support.

David Goodman has edited the text. Bernard Chazine and his staff are thanked for their work on the design and layout of the report.

This study could not have been produced without the participation of the Central Statistical Offices of the countries of the region. Thanks are due for their many contributions, including country analytical papers, to the following persons and to others working with them. These individuals bear no responsibility for the way data are used or presented in the report.

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Layout: Bernard & Co, Siena, Italy

Front cover picture: UNICEF/SWZK00286/GIACOMO PIROZZI

GEORGIA 2004 - A child with cerebral paralysis at the Inclusive Education Kindergarten Number 16 in the Capital, Tbilisi.

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ISBN: 88-89129-20-8

The UNICEF Innocenti Research Centre

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The opinions expressed are those of the authors and editors and do not necessarily reflect the policies or views of UNICEF.

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FOREWORD

*I want you to write down that I don't consider myself ill.
On the contrary: it is good to be alive when you are young.*

Valya, 17, child with disabilities living at home, Bulgaria

In 2005, UN delegates gather to draft a convention on the rights of persons with disabilities. Guided by international human rights standards, the new convention is expected to reaffirm the inherent dignity and the equal and inalienable rights of all members of the human family, including persons with disabilities. The new treaty is framed by the principles of dignity, individual autonomy, non-discrimination, inclusion of persons with disabilities as equal citizens and participants in all aspect of life, respect for difference, and equality of opportunity. It will provide a strong normative framework to guide national policies and actions and ensure the effective enjoyment of human rights by persons with disabilities.

Children have already become an important focus for the attention of the international community. Six of the eight UN Millennium Development Goals (MDGs)¹ directly relate to child well-being, and the 'World Fit for Children' outcome of the 2002 UN Special Session on Children is an agenda for global action. The 1989 UN Convention on the Rights of the Child is the most widely ratified international treaty in history.

This new *Innocenti Insight* brings these two historical processes together by focusing on children with disabilities, and by doing so in a particularly historic setting: the transition countries of Central and Eastern Europe and the Commonwealth of Independent States (CEE/CIS). In so doing, the report has two goals: first, to use the transformative context of the 15 CEE countries and 12 CIS countries that emerged from the collapse of the Soviet Union and former Yugoslavia to highlight the evolving status of children with disabilities, a group that has received relatively little global attention until quite

recently; and, second, to cast children with disabilities as a bellwether indicator of the progress of CEE/CIS nations in the pursuit of open, democratic and rights-based societies.

This *Insight* builds upon the significant body of research and policy direction accrued at UNICEF Innocenti Research Centre (IRC), with the support of national statistical offices in the 27 countries of the region. UNICEF IRC has tracked and explored the impact on children and their families of economic and social changes in the region since transition began.

This report draws upon three new pieces of research that include data, a qualitative survey and first-person interviews. The results highlight the legacies of the past, the momentum for change and areas where action is needed. Institutionalization, segregation and discrimination are still prominent features of the environments in which children with disabilities live across the region. However, there are also widespread signs that social attitudes towards disability are changing, and there are many concrete examples of ways in which children with disabilities are being integrated into society. The single-most important change needed in order to advance the rights of children with disabilities in the region is to end the common practice of putting them in institutions and segregated schools. This requires the development of community-based resources and better supports for families of children with disabilities – important steps in the historic efforts to rebuild democratic civil societies in these transition countries.

Disability is a human rights issue with particular significance in the CEE/CIS. The treatment of persons

with disabilities under communism was characterized by a social environment in which disability was a source of shame and denial, and a public environment in which the state took on the role of caretaker. For too many children with disabilities, this meant spending their lives in large institutions or special schools, distant from family and isolated from community. This study inquires into how the reported numbers and rates of children with disabilities have changed during the transition period, and considers a range of issues – including health, education and protection – crucial to child well-being and child rights.

At a time when the international community is committed to enhance the rights of persons with disabilities, we have the opportunity to give children the priority attention they deserve. This *Innocenti Insight* is a contribution to that process. Inspired by a mother interviewed in the context of the research, it aims to help ensure that “the child feels like a member of society, as every one else”.

Marta Santos Pais
Director Innocenti Research Centre

Note

- 1 The Millennium Development Goals were adopted by the United Nations General Assembly in September 2000 (see www.un.org/millenniumgoals/). Inclusion International, a global federation advocating for the human rights of people with intellectual disabilities, has developed the response document, ‘Achieving the Millennium Development Goals for All’. See www.inclusion-international.org.

CONTENTS

Foreword	v
Introduction	ix
The CEE/CIS Region: A Snapshot	x
Chapter 1: Official Facts and Figures	1
1.1 MAIN FINDINGS	2
1.2 DEFINITIONS, CONCEPTS AND APPROACHES IN CEE/CIS	2
1.3 RATES OF DISABILITY AMONG CHILDREN IN CEE/CIS	4
1.4 DISABILITY AND HEALTH IN CEE/CIS	8
1.5 INSTITUTIONS AND SPECIAL SCHOOLS FOR CHILDREN WITH DISABILITIES	14
1.6 POVERTY AND RAISING CHILDREN WITH DISABILITIES IN FAMILIES	23
1.7 AVAILABILITY OF BENEFITS AND DISABILITY SUPPORTS	26
CHAPTER 2: A Professional Opinion	31
2.1 MAIN FINDINGS	31
2.2 METHODOLOGY	33
2.3 HEALTH CARE SERVICES	34
2.4 EDUCATION, CARE REGIMES AND DISABILITY SUPPORTS	39
CHAPTER 3: Voices of Children and Parents	47
3.1 METHODOLOGY	47
3.2 FAMILY CARE	48
3.3 INSTITUTIONAL CARE	50
3.4 HEALTH AND WELFARE SERVICES	50
3.5 EDUCATION	52
3.6 RECREATION AND LEISURE	54
3.7 THE DISABLING PHYSICAL ENVIRONMENT	54
3.8 THE RIGHTS OF CHILDREN WITH DISABILITIES	55
3.9 PROGRESS AND THE FUTURE	55
CHAPTER 4: The Way Forward	59
BOXES	
Box I Naming and defining disability	xvii
Box 1.1 New WHO classification focuses on functioning	2
Box 1.2 Disability screen	5
Box 1.3 The children of Chernobyl	9

Box 1.4 Efforts to control rubella and measles in Kyrgyzstan	14
Box 1.5 Giving up: Why families surrender children with disabilities to institutions	15
Box 1.6 The 'special needs' of schools for children with disabilities in Turkmenistan	17
Box 1.7 Poverty risk among families raising a child with disabilities	24
Box 1.8 Improving access to community-based care	28
Box 2.1 EACD guiding principles for disability supports and services	32
Box 2.2 A professional prescription for managing disability	36
Box 2.3 Defectology: Theory, Practice and Potential	39
Box 2.4 Therapies made in CEE/CIS	40
Box 2.5 Out and about: Breaking down physical barriers	43
Box 2.6 Key role for parents' groups and NGOs	44
Box 2.7 Positive initiatives in CEE and CIS countries	45
Box 3.1 Reaching parents	54
Box 3.2 Laws and National Mechanisms	55
Box 4.1 Experimental survey tool for capturing lived experience	60
Box 4.2 A model for turning institutions into community-based support systems	61
Box 4.3 'House of Mother and Child Development Initiatives' in Kyrgyzstan	62

FIGURES

Figure I: Political map of CEE and CIS region	x
Figure II No. of children with disabilities in institutions or receiving cash benefits in CEE/CIS, 2002	xiv
Figure III Number of registered disabled children in 11 countries, 1990-2002	xiv
Figure IV Infant mortality rates in CEE and CIS countries: Official and survey estimates	xiv
Figure V Number of disabled children in public institutional care, 1990 and 2002	xv
Figure 1.1 Disabled population and people in need of daily personal assistance by age, Estonia, 2000	5
Figure 1.2 Rates of infant mortality and congenital anomaly, Czech Republic, 1970-2002	6
Figure 1.3 Rates of congenital anomaly and infant mortality in 15 CEE and CIS countries 2002	7
Figure 1.4 Perinatal mortality rates in 33 European and Central Asian nations, 1989 and 2001	8
Figure 1.5 Child disability by cause in Ukraine, 1992-93 and 2000-2001	9
Figure 1.6 Percentage of women at full-term pregnancy with anaemia, 1989-2001	12
Figure 1.7 Stunting and under-5 mortality rates in CIS and Asian countries, late 1990s	12
Figure 1.8 Enrolment in basic special education programmes, 1989 and 2001	19
Figure 1.9 No. of children with disabilities in special schools and integrated education in Lithuania	21
Figure 1.10 Basic special education in Poland	21
Figure 1.11 Special education enrolment by grades in Russia, 1989-2002	22
Figure 1.12 Per cent of households with consumption expenditure under national poverty lines	25
Figure 1.13 Disability pension compared to average wages in 14 countries	27

TABLES

Table I Human development indicators in CEE and CIS countries, 2001	xi
Table 1.1 No. of registered children with disabilities in 11 CEE and CIS countries	6
Table 1.2 Child disability prevalence by disease group in Latvia, 1994-2001	10
Table 1.3 Morbidity among children by disease group in Belarus, 1990 and 2001	11
Table 1.4 Measles, rubella and hepatitis incidence in CEE and CIS countries, 1989 to 2002	13
Table 1.5 Number of children with disabilities in CEE/CIS in public institutions, 1990 – 2002	16
Table 1.6 Education enrolment and labour force status, disabled and total, Estonia	23
Table 2.1 Schedule of health check-ups for children in Turkmenistan, 2002	35

MODELS

Model 1 A family centre for children with disabilities	61
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INTRODUCTION

There are currently some 5.6 billion different people in the world. Some have a difference called disability.

Disability Dimension in Development Action: Manual on Inclusive Planning²

When country reports for the 2002 UN Special Session on Children were reviewed, a startling pattern emerged in the CEE/CIS: reported rates of disability among children had doubled, tripled and more during the decade following the collapse of communism.³ UNICEF set out to investigate the causes of this dramatic increase.

This report is a result of that inquiry. It is a first attempt to pull together and analyse data on children with disabilities on a region-wide basis. The portrait that has emerged is somewhat patchy, due largely to data limitations, but it is still compelling. For one, there is the simple fact – and attendant mental image – that at least 317,000 children with disabilities in the region live in residential institutions, often for life. For children with disabilities, this may be the defining legacy of the communist past: the purposeful institutionalization of huge numbers of children, often in large facilities segregated from community and cut off from family.

However, as this report explores, the reasons behind this practice are more complex than might first appear. Philosophically, communism held the belief that the state should act as a kind of caretaker to all citizens. In this context, persons with disabilities (including children) were officially recognized and registered by the state as ‘dependents’ and received supports such as pensions. At the same time, the state promulgated ‘defectology’ – a Soviet discipline that emphasized ‘special education’ as the best remedial treatment for children with disabilities. While these strategies had some positive intentions and outcomes, their implementation – imbued as they

were with deep stigma around persons with disabilities – resulted in many children with disabilities being shut away in institutions. It was not uncommon for infants and children with medium and severe disabilities to be placed in residential schools, only to ‘graduate’ to an adult institution for life.

Even children who stayed in their families had little chance of a normal life, given that streets and buildings were not accessible, community-based education and recreation were largely unavailable, and children with disabilities and their families were often shunned in public spaces or so shamed that they avoided venturing out in public. When transition began, children with disabilities were largely out of public sight. Their parents and families fared little better. As a result, there is now an opportunity – and, indeed, a compelling urgency – to improve the lives of children with disabilities and their families.

The CEE/CIS Region: A Snapshot

Few historical events can match the rapid social, economic and political transformation of such a large region of the world, running from the heart of Europe to the Pacific Rim. In 1989 the Berlin Wall was felled by people in the streets; in 2004, eight Eastern European countries joined the European Union; in between, 27 countries were born where once there were eight (see Figure I).

The dramatic changes in the region have been associated with plunging economic output in the early years, war and ethnic conflict, social upheaval, an erosion of education, health and social services, and greater economic disparity within populations and among countries. Marriage rates and fertility rates have fallen widely. In 2002, there were 102.0 million children in the region compared to 122.1 million in 1990. Poverty has grown immensely in several countries. Since the mid-1990s, economies in the region have tended to stabilize at lower levels; some have rebounded. The countries have tended to diversify and, by subgroups, to diverge in terms of social, economic and political paths. As a result, the countries of the CEE/CIS region span a wide range of human development.

Table I presents the 27 countries in this context. It ranks the countries by under-five mortality rates and includes two other indicators: the share of children enrolled in preschool, and the GDP per capita

expressed in US dollars. The under-five mortality rate is a proxy for the general environment for child development; preschool enrolment is a proxy for education capacity; and per capita national income points to the country's level of economic development (and, by inference, sensitivity to international aid dollars). The stronger any or all of the indicators, the better the prospects for a supportive environment for children with disabilities. Countries with strong indicators have a greater capacity to secure good health, provide early child development and care services, and to purchase expertise, drugs and equipment in the international marketplace. For countries with low per capita GDP, international aid may be needed to secure such additional resources.

As Table I shows, CEE countries tend to fare better than CIS countries. Not only do results decline from west to east in the region, but from north to south. Among CEE countries, Albania, Bulgaria, Romania and some former Yugoslav states post poorer outcomes, as do the Caucasian and Central Asian states in the CIS part of the region. For example, Albanian and Macedonian children are five or six times more likely to die before age five than Slovenian children, who live just a few hundred kilometres to the north. To the east, in the CIS subregion, Russian and Ukrainian children face risks almost as high as children in Albania or Macedonia, but these are still five times lower than those of Turkmen or Azeri children in southern CIS. Across the

Figure I: Political map of CEE and CIS region



The publication of this map does not imply on the part of UNICEF the expression of any opinion concerning the legal status of any country, its authorities, or its frontiers

region, several southern countries have seen war and ethnic conflict over the last decade, most are poor, but some possess large mineral resources that are reflected in relatively high per capita income.

(Note: The countries that are enumerated and highlighted in bold are ones where health professionals participated in a questionnaire developed and carried out by the European Academy of Children with Disabilities as one of the core pieces of research for this report. The table shows that the EACD questionnaire included all CEE/CIS subregions. The results are analysed in Chapter 2.)

Source: UNICEF Regional Monitoring Report No. 8, 2001

Table I Human development indicators in CEE and CIS countries, 2001*

Countries (and subregions)	Under-5 mortality rate (per 1,000 births)	Preschool enrolment rate (per cent)**	GDP per capita (us\$)***
CENTRAL AND EASTERN EUROPE			
1. Slovenia	5	68.3	\$ 9,873
Czech Republic	5	86.6	5,547
2. Hungary	9	86.4	5,083
3. Croatia	**9	42.2	4,385
4. Poland	9	50.4	4,739
Slovakia	9	69.5	3,696
5. Lithuania	**11	52.6	3,417
6. Estonia	12	80.3	4,094
Latvia	14	65.6	3,269
7. Bulgaria	16	73.6	1,679
8. Bosnia-Herzegovina	18	8.7	1,259
Serbia and Montenegro	19	44.0	1,390
9. Romania	21	67.7	1,804
10. FYR Macedonia	26	28.5	1,718
11. Albania	30	33.5	1,378
COMMONWEALTH OF INDEPENDENT STATES			
Belarus	**12	68.9	1,239
12. Ukraine	20	43.9	776
13. Russia	21	66.4	2,137
14. Georgia	29	30.2	694
Moldova	32	40.8	375
15. Armenia	35	24.6	680
Kyrgyzstan	61	9.0	321
Uzbekistan	68	19.4	255
Tajikistan	72	5.9	168
16. Kazakhstan	76	13.9	1,491
17. Turkmenistan	98	21.4	541
Azerbaijan	105	18.1	705

Notes: * The indicators represent human development (understood as an aggregate of longevity, educational achievement and per capita income) with proxies that relate to children with disabilities. The table shows all 15 CEE and 12 CIS countries by geographical subregion in rank order of under-five mortality. The 17 countries that participated in the 2003 EACD-UNICEF qualitative assessment, 'Provision of Services for Children with Disabilities in CEE/CIS', are shown numbered and in bold type. **Source is the UNICEF TransMONEE database.

*** \$US at market exchange rates that reflect differences in economic capacity rather than disparities in living standards. (To measure living standards, GDP at purchasing power parities is generally used because currencies of poorer countries tend to buy relatively more goods in domestic rather than international markets).

Sources: *The State of the World's Children 2004*, UNICEF; TransMONEE Database 2003, UNICEF IRC; European Bank of Reconstruction and Development (EBRD).

Research strategy for this report

If the rates of disability among children were simply a reflection of child health, the lowest rates in the region would be found in Central European countries and the highest in the Caucasus and Central Asia. However, disability rates reflect a complex interplay of congenital realities, the incidence of infectious diseases and traumatic injuries in a country, and the degree of social equality and human rights in a society.

In its effort to look at these convergent aspects of disability – and to counter the dearth of available data in CEE and CIS countries – UNICEF IRC undertook a three-part investigative strategy.

1. First, the research project solicited data and analysis on children with disabilities from the national statistical office in each of the CEE and CIS countries. It asked each country for data on a set of topics including numbers of children with disabilities, institutionalization, education, support and family and care arrangements.
2. Second, IRC approached the European Academy of Childhood Disabilities (EACD), a well-established association of professionals, to carry out a survey questionnaire and interviews with well-placed doctors and health professionals in CEE and CIS countries. The goal was to get front-line information about health services and supports for children with disabilities. The EACD also conducted site visits in three countries with the facilitation of UNICEF country offices.
3. Finally, in partnership with a private-sector professional agency, Oxford Research International Ltd., UNICEF IRC conducted focus group discussions and individual interviews with children with disabilities, their parents and professional caregivers in three countries, Russia, Latvia and Bulgaria.

Reading this report

This report reflects the tripartite research approach. The following three chapters focus on one of the primary research modules:

1. **Official facts and figures** (Data analysis): *The statistical story of children with disabilities in CEE and CIS countries.*
2. **A professional opinion** (Qualitative assessment): *Health professionals assess existing services for children with disabilities in the CEE/CIS region.*
3. **Voices of children and parents** (Focus groups and interviews)

This structure explicitly recognizes that research on children with disabilities in the CEE/CIS region is still at the beginning stage. Rather than force the research findings to fit a narrative analysis, this report invites the reader to hold the three basic pieces of research in association and join in the triangulation exercise of drawing connections, looking for resonance and raising questions. This process of triangulation yields evidence of greater awareness and better recognition of children with disabilities in

the region – a positive outcome of reforms. Information from the three different sources points to this welcome trend in both CEE and CIS countries, as evidenced by these anecdotes:

- Mother in Latvia: “Before, when I walked down the street with my child, I was looked at as if I was leprous. When I walk now, I am not treated that way.”
- Mother in Bulgaria: “It seems to me that people in Sofia became more used to seeing different children. This problem was more serious some years ago.”
- Statistician in Georgia: “Formerly families tried to hide cases of disability, while at the present time [they] hope to gain help by registering their children.”
- Russian teacher: “In the Soviet era, education for the disabled was profession-oriented and ...isolating. [Now] we have adapted the Western attitude.”
- A Polish doctor concludes: “Disability has now a better social basis.”

It is hoped that this study authentically reflects the current state of knowledge about the lives of children with disabilities who live in this vast region – and prompts better data collection, further research and positive action in terms of public awareness and public policy.

A framework for analysing disability rates

The primary data source on disability among children in the CEE/CIS region is the disability rate reported in national statistics. The first assumption may be that the lower the rate, the better. Some may also be tempted to compare rates between countries and try to explain the differences. But these approaches may ultimately leave the researcher bewildered. The reasons include: disability rates only seem to go so low and no lower; lower rates are not always better; and because trying to explain the differences in country rates authoritatively is very difficult since definitions and data collection around disability are often not comparable. (This challenge is discussed in more detail in Chapter 1).

Defining disability

This report generally uses the term ‘disability’ to include moderate and severe impairments that are self-evident, e.g., blindness, inability to walk, mental disorder. ‘Special needs’ refers to milder conditions that may not be readily apparent or suspected until school-age, and includes learning disabilities and, to some extent, related behavioural disorders. Further, it is estimated that 20 per cent of the world’s population is affected by disability either directly, or indirectly as family members and carers.

This report navigates this complex terrain by using an international benchmark for a minimum disability rate – and compares official country rates to this standard. This method was adopted because there are no reliable, international estimates or comparable data on numbers and rates for children with disabilities.

To arrive at this benchmark, this report analysed research and data gathered over years in countries with the highest human development rankings.⁴ The data indicates that there is a plateau at which disability rates appear to settle. In other words, in countries assumed to have the best overall environments for human well-being, there is a ‘core’ incidence of children with disabilities, much of it due to congenital impairments. (This resistance may yet yield to research, particularly with advances in genetics.)

Disability as diversity

The disability benchmark of 2.5 per cent resonates with the position that congenital anomalies and other functional impairments are a normal part of human diversity. This perspective emphasizes creation of social and physical environments that embrace the full range of human functioning, rather than a focus on the prevention, medical remedy and otherwise ‘fixing’ of the individual to meet or approach social norms.

On the basis of the data from industrialized countries and decades of its own research and medical practice, the European Academy of Childhood Disabilities considers a disabled children rate of at least 2.5 per cent to be the ‘norm’ (with 1 per cent having serious conditions).⁵ This report considers this a benchmark against which rates reported by CEE and CIS countries can be compared. If the reported rates are significantly higher, it may indicate that more attention needs to be paid to public health issues such as infectious diseases, accidents and traumatic injuries, malnutrition, maternal, prenatal and neonatal health. If prevalence rates are significantly lower, it may indicate that moderate and severe disabilities are under-recognized, and/or that there is high mortality in-utero, around birth or early in life – deaths that are not captured in disability registers.⁶

In recent years, the concept of ‘special needs’ has been appended to disabilities. As a category, ‘special needs’ overlaps with disabilities, especially milder forms of impairment, and includes a growing range of learning disabilities, developmental delays, psychological issues and behavioural disorders that are now identified as health problems – for example, foetal alcohol syndrome, attention deficit and hyperactivity disorder.

In this context, EACD considers that an additional 8 per cent of the child population has learning and/or behavioural disorders. This makes the overall share of children with disabilities and special needs in any given population about 10 per cent. These benchmarks are in keeping with data from industrialized countries.

In the United States, household survey data from the *National Health Interview Survey* in the early and mid-1990s found that the share of children with functional limitations to be between 6 and 12 per cent.⁷ Further analysis of the survey data revealed that 1.3 per cent of all school-age children were limited in mobility, 0.9 per cent had a self-care limitation, 5.5 per cent a communication limitation, and 10.6 per cent a limitation in learning ability.⁸ The

1994/95 US Census Bureau *Survey of Income and Programme Participation* found that 9.1 per cent of children aged 0 to 14 were reported as disabled, with 1.1 per cent seriously disabled.⁹

Similar data come from other industrialized countries. In Germany, 1 per cent of the child population is considered to have a serious disability. In Canada, a 1991 survey found 8 per cent of boys and 6 per cent of girls aged 0 to 14 were disabled. In New Zealand, the 1996 *Disability Counts* survey, using a 'special needs' education-oriented questionnaire, counted 11 per cent of children aged 0 to 14 as disabled.

It should be noted that the 1-in-10 estimate that encompasses 'special needs' remains unsettled and even contested. 'Special needs' are often defined administratively, reflecting meanings that are socially constructed and, therefore, differ in national and even district contexts. Recognition and measurement varies accordingly. Also, as noted above, there is an inherent thrust in innovation-driven societies to develop new and/or more articulate descriptions of the human condition. It is pertinent too that the pharmaceutical industry funds roughly half of all health research in the world.¹⁰ This tendency to parse and pathologize many behaviours and conditions has a range of both positive and negative consequences. Some stakeholders see this expansion as 'mainstreaming' and a constructive blurring of the discriminatory lines between disabled and non-disabled persons; others argue that it subsumes the urgent and specific claims of children with disabilities into a universal soup of needs. This is a discourse where politicians, policy makers, rights advocates and other stakeholders continue to engage.

Disability rates nevertheless still serve as an indicator of how much or how well a society recognizes and supports children with disabilities – or children with differences which are disabling in the societies in which they live.

On the basis of data and analysis submitted to UNICEF for this report, it is estimated that 1.5 million children – three times as many as a decade ago – receive basic disability supports in the 27 CEE and CIS countries. At first glance, the tripling of a condition that is typically associated with inequality and disadvantage is worrisome. However, the data and analysis presented in this report suggest that greater formal recognition of disability – including an increase in benefit claims by parents – is, by far, the bigger factor in higher rates of disability among children in the region, rather than increases in congenital anomalies and impairments from disease and trauma.

The increase in recognition and support of children with disabilities is striking. However, given the child population of 102 million in the region, the benchmark prevalence of 2.5 per cent suggests that at least one million children are 'missing' from national disability registers.

As the 'missing million' suggests, there is still a long way to go in many countries to better recognize and support children with disabilities. While the more open social and political climate in many transition countries has created a more conducive envi-

ronment (a 'pull') for public recognition of disabled citizens, it appears that parents seeking rights for their children have been the key agents in pushing disabled children rates closer to international benchmarks. This process has not been without its tensions, as reflected in focus group discussions and interviews conducted for this report and presented in Chapter 3: Voices of Children and Parents.

It is critical to note that the main public services – health care, education and social welfare – involved in the support of children with disabilities (indeed, *all* children) have been seriously impacted by the transition. This is especially the case in countries of South-eastern Europe and the CIS subregion. Before transition, the region basically had universal access to these services. However, especially in the early years of transition, a shrinking state, plunging public expenditure and even war compromised the quality and availability of public services in many countries. The degree to which these services have recovered since the mid-1990s – and whether they returned to past practices or introduced new approaches – varies greatly among the countries of the region.

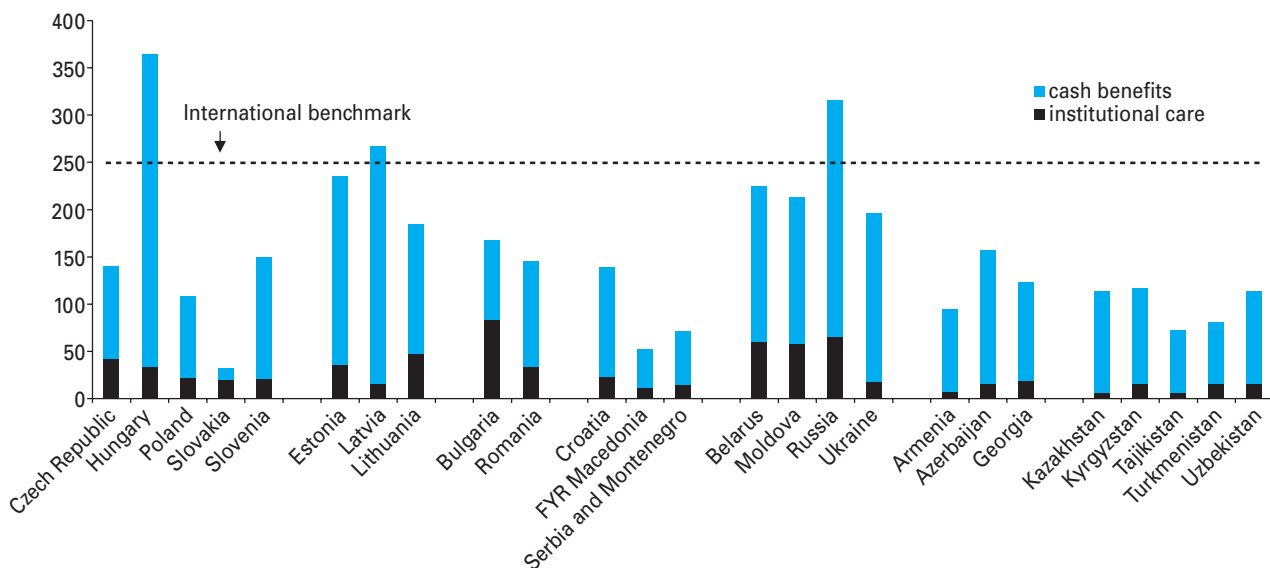
Following are three figures that fill in some of the details of this picture.

Recognition of children with disabilities in CEE/CIS

Figure II (page xiv) presents a portrait of children with disabilities in the region. It shows two sets of children with disabilities recognized in official records: children with disabilities whose families make claims for available cash benefits from the state, and children with disabilities in residential care as reported in the Country Reports. The graph presents 2002 data that are available for 25 of the 27 CEE and CIS countries and compares them with the international benchmark established above. The figure makes it clear that, despite some positive changes, most countries in the region still have gaps in terms of recognizing children with disabilities (let alone children with special needs). The number of children with disabilities, according to Figure II, reaches the 2.5 per cent disability benchmark in only three countries – Hungary, Latvia and Russia.

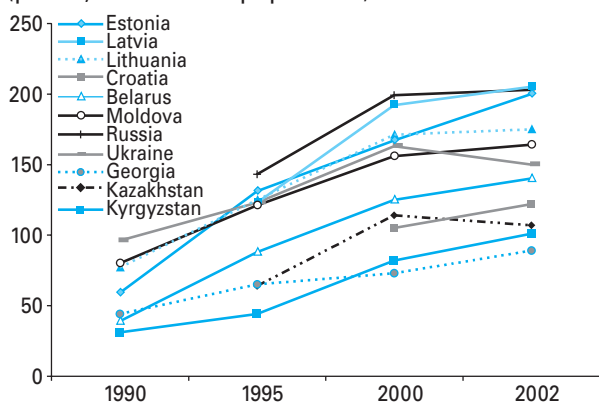
Russia is important not only because it is the largest and most populous country in the region, but because it remains very influential. However, the strong recognition of disability in Russia is also reflected in its having the second-highest incidence (after Bulgaria) of institutional care. Hungary's strong showing reflects the fact that disability benefits are also claimed by some children who have special needs, as defined above. (In that light, the 3.6 per cent prevalence rate is far from the minimum 10 per cent benchmark for 'disabilities + special needs' described earlier.) Latvia has the lowest rate of institutionalization of these three countries that meet or surpass the benchmark for recognizable disability. Meanwhile, six countries (Armenia, FYR Macedonia, Serbia and Montenegro, Slovakia, Tajikistan and Turkmenistan) report that less than 1 per cent of children receive either cash benefits or institutional care.

Figure II Number of children with disabilities in institutions or receiving cash benefits in CEE/CIS, 2002
(per 10,000 relevant population)



Source: TransMONEE Database, 2003 edition, UNICEF IRC

Figure III Number of registered disabled children in 11 countries, 1990-2002
(per 10,000 relevant population)



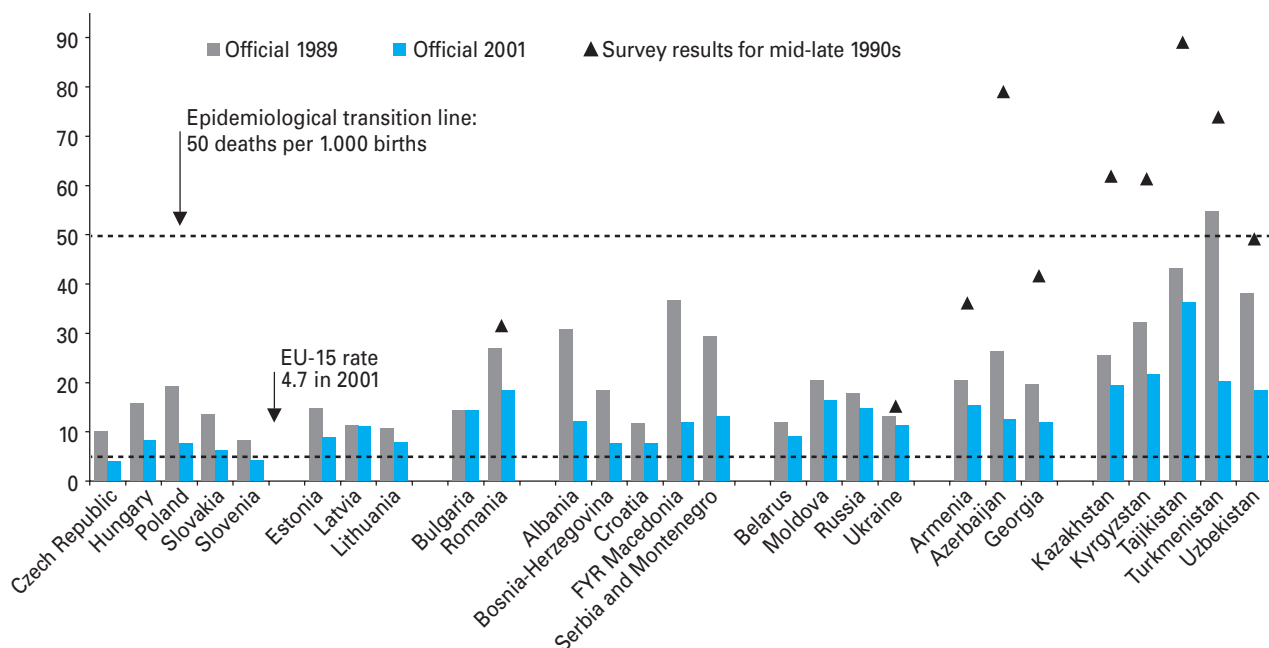
Source: TransMONEE Database, 2003 edition, UNICEF IRC

The fact that in almost all CEE and CIS countries but one more children with disabilities receive cash benefits at home than care in a public institution is, nevertheless, a remarkable outcome of the transition: before 1989 the majority of children with disabilities were placed in residential care.

Registered rates of children with disabilities

Nine CEE and CIS countries submitted reports to the 2002 UN General Assembly Special Session on Children, detailing national progress on the 1990 to 2000 plan of action from the 1990 World Summit for Children. In six of the countries, disability rates among children had soared – doubling in Albania and Tajikistan, rising 2.5 times in Kyrgyzstan, increasing threefold in Uzbekistan, fourfold in Latvia and fivefold in Russia.

Figure IV Infant mortality rates in CEE and CIS countries: official and survey estimates (per thousand live births)



Source: TransMONEE Database, 2003 edition, UNICEF IRC

Figure III (page xiv) presents official disability registration rates for 11 countries for which such information was available in 2002. More than 2 per cent of children in Latvia, Russia and Estonia were registered by health and social security authorities as having a disability; 12 years earlier the share was barely more than 0.5 per cent – an increase in recognition of disability of almost fourfold.

Even though countries like Georgia, Kazakhstan and Kyrgyzstan register lower disability rates than Western CIS countries, current rates are still two to three times higher than before transition. In many other countries, it is difficult to assess the change in disability rates over time as no registers exist or there have been changes in the way children are registered. Nevertheless, it appears that increases in disability rates among children, even if smaller in scale, have also taken place in other countries in the region.

Analyses differ as to the causes of the overall rises in rates of registered children with disabilities during the transition period. Both statisticians and doctors in Russia cite evidence of deterioration in child health, implying that at least part of the rise is due to poorer maternal and child health and reduced access to services. Meanwhile, analysts and service providers in Central Europe say that better capacity on the side of the health profession has played a significant role in higher disability rates through wider recognition of disability in children. The incentive of cash benefits for children with disabilities is also named as a major factor in CEE countries, as well as in the Baltic States and Caucasus countries.

By 2002, rates of children with disabilities in many countries were just beginning to approach international benchmarks, suggesting that greater formal recognition of disability (by parents and health care

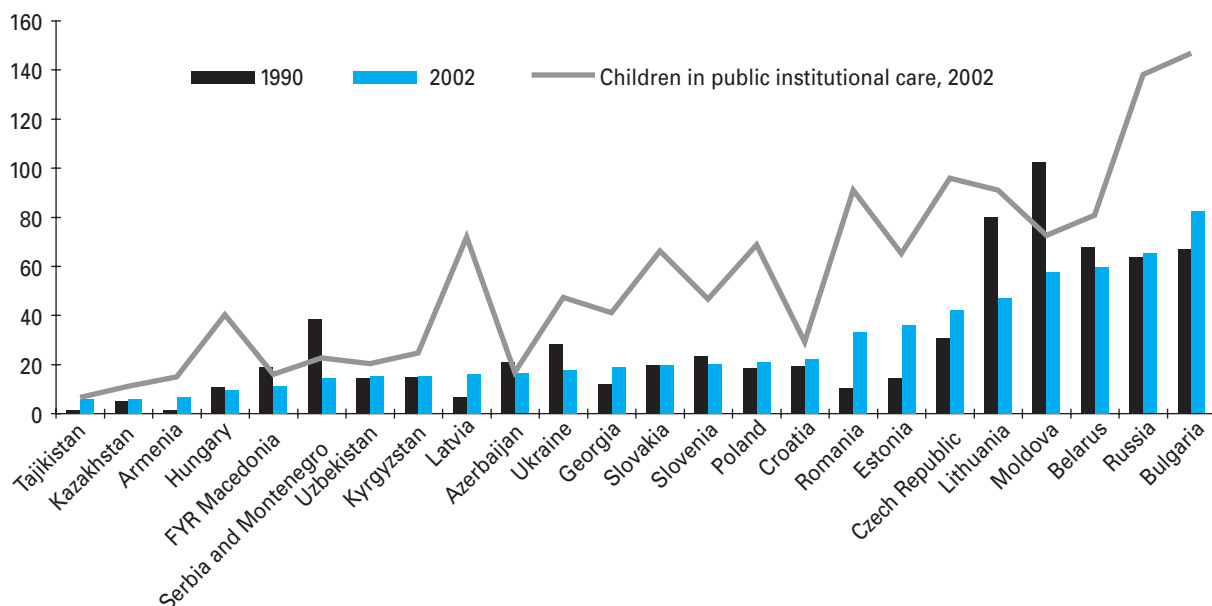
professionals) – rather than poorer child health – has played the main and greater role.

CEE and CIS countries that are more industrialized and urban tend to report higher rates of children with disabilities (as an aggregate of cash-benefit claims and institutionalization). Countries that are poorer and largely agricultural report that they place fewer children with disabilities in institutions – but they also distribute less cash benefits for children with disability. This outcome reflects that there is less formal recognition of children with disabilities in poorer countries than in more affluent ones; but it may also point to another factor suggested by Figure IV.

Figure IV (page xiv) presents official infant mortality rates (IMR) for 1989 and 2001 for all 27 CEE/CIS countries. It also shows the ‘epidemiological transition point’ of 50 deaths per 1,000 births, the threshold around which the major causes of morbidity and mortality shift from acute infectious and deficiency diseases to chronic non-communicable diseases.¹¹ The 2001 infant mortality rate for the European Union (EU) is also presented. It is interesting to note that Czech Republic and Slovenia both post rates below the EU average, almost halving their pre-transition IMR. This also points to how much some countries have gained during transition, and how the economic and development disparity in the region is widening.

At the other end of the spectrum and region, Figure IV posts mid-1990s survey data on infant mortality for Caucasus and Central Asian countries that show much higher IMR than officially reported in both 1989 and 2001. This discrepancy suggests that infant mortality is under-reported in these subregions. By inference, newborns with congenital anomalies and/or weak health and infants who fail to thrive or

Figure V Number of disabled children in public institutional care, 1990 and 2002
(per 10,000 relevant population)



Source: TransMONEE Database, 2003 edition, UNICEF IRC

experience malnutrition, infectious disease or trauma have low survival rates. In other words, many children with disabilities may simply not survive birth or the first year of life.

Levels of institutional care in CEE and CIS countries

In CEE and CIS countries, it has been common to exclude children who live in institutions from disability registers. This practice draws a clear line between home life and institutional life, and, in a way, between visibility and invisibility. This disability divide is reflected in the language that children and teenagers in institutions use. In the focus groups, Russian teenagers, for example, talked about the 'free side' and the other side of the 'border' when referring to children living with their families.

CEE and CIS countries maintain a variety of types of institutions in which children with disabilities with disabilities reside. Children with disabilities find themselves in – among others – infant homes, hospitals, special institutions or *internats* (boarding schools) run by the education ministry, boarding homes for the severely disabled operated by social services, and children's homes administered by the health department.

It is important to note that, in many CEE and CIS countries, it is not uncommon for doctors and health professionals to suggest or recommend to parents that they place newborns or infants with physiological impairments in 'infant homes' or the equivalent. Invariably, it is a first step that leads to lifelong institutionalization.

Figure V (page xv) draws together data from the Country Reports and statistical files sent to UNICEF IRC for this report. It shows the rates of children in public institutional care across the region and changes since 1990. By ranking countries according to their current rates, the graph makes clear what Figure IV has already suggested: Country practices result in huge differences in outcomes. Which raises the question: Are children in Moldova, Belarus, Russia or Bulgaria in greater need of or better served by care in institutions than are children in Hungary, Azerbaijan, Latvia, Slovenia or Poland? By showing the total number of children in residential care per 10,000 children across the region (grey line), the figure suggests another explanation: that countries which place a higher share of children with disabilities in institutions are countries where the institutionalization of children such as orphans and children with disabilities is generally accepted.

The main message from Figure V is the relative stability of rates of children with disabilities in institutional care over the transition period. With a few exceptions – Moldova, Lithuania, Estonia, Serbia and Montenegro – rates changed little between 1990 and 2002. This suggests that the rises in registered rates shown in Figure III represent new need rather than a concerted trend to redirect children from institutional care. However, as Chapter 1 describes, there is also a significant demand in a number of countries to build new institutions to accommodate

this newly identified need. Indeed, the Country Report from Kazakhstan notes 'a dangerous tendency to shut down specialized institutions for children with developmental defects'. This is, indeed, a concern if alternative capacities to fulfil the rights of children with disabilities have not been developed in families and communities.

Conditions in and around institutions for children in the region have undoubtedly changed over the transition period. In some countries and during some years of transition, institutions (including regular schools and hospitals) have been hard pressed for resources, including services such as basic as heat. Sometimes, parents insist that institutions meet their child's needs better than they can – from better rehabilitative services to something as simple as more meat in the diet. And, some institutions have taken advantage of new ideas and forged opportunities to connect more closely with communities.

"Conditions vary considerably from one residential school to another, and, despite certain improvements, the worst ones are for the disabled children. The living conditions are not up to the special requirements of such cases, nor are the food, sanitary standards, or opportunities for person-to-person contacts."

—Kyrgyzstan Country Report, 2002

In the focus group discussions and interviews for this report, some parents described institutions as being "like prison." At the same time, children with disabilities participating in the focus groups and interviews were clear about their desire to stay with parents and families. Fedor, aged 11 and living in an institution in Russia, says: "I know what I want: get out of this school as soon as possible! Where to? Home!"

In poignant commentary that speaks to the degree of isolation and stigma that children with disabilities face in society, some children interviewed see advantages to living in an institution rather than in a home or community. A number of the children in the focus groups mentioned that it was only in institutions that they feel safe and understood and find true friends. Lauma, a 17-year-old girl living in a boarding school in Latvia, captures this dilemma: "Thank God we have this school, where all are disabled.... Nobody is calling [us] names, everybody understands."

"For me, my first home was the nursery, then school and friends from school...How can I say it? ...Well, there is something wrong with that. This is a family too; we are all friends, but..."

—Luda, 17, living in an institution, Russia

Box I Naming and defining disability

The 1975 *UN Declaration on the Rights of Disabled Persons* uses 'disabled person' to mean "any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities." The new UN Convention on disabled persons that is in the works will likely create a new definition.

In the intervening years, the disability movement persuaded public opinion to use the term 'person with disability' rather than 'disabled person' in order to focus on the person first and the disability as a secondary characteristic; indeed, 'children with disability' is the terminology used throughout this report. (More recently, some disability advocates have reclaimed 'disabled person' to convey the message that the person is disabled by the social and physical environments.)

More sophisticated definitions of disability today recognize its complexity. They hold that disability is a dynamic interaction between bodily impairments and the social and physical environments. This means that disability, in degree and impact, can vary greatly depending not only on physical health or care opportunities but on how supportive and enabling society is. This is a relationship that can vary not just from place to place but over the lifespan of an individual – even without change in the person's physical or mental state.

One advocacy-oriented research centre defines disability as "limitations in carrying out activities of daily living and to participating in the social, economic, political and cultural life of the community. Such limitations may arise from:

- a physical, sensory, intellectual, emotional or other personal condition such as a long-term health problem;
- societal stereotypes about such human conditions; ;
- ways of organising social, economic and built environments that, in their effects, exclude or impede the participation people with such conditions."*

Another proponent writes that "disability is natural and it can be redefined as a 'body part that works differently.' A person with a physical disability label has legs (or arms) that work differently, a person with a cognitive disability label learns differently, a person with a label of autism has a brain that works differently, and so forth. And when we recognize that the body parts of people without disability labels are also different, we'll also recognize that it's the 'degree of difference' – and the way these differences affect a person and/or the need for services, entitlements, or legal protection – that dictates the use of labels."**

Sources:

* 'Moving In Unison Into Action: Towards a Policy Strategy for Improving Access to Disability Supports', The Roeher Institute, Toronto, 2001.

** 'People First Language', Kathie Snow, Disability is Natural, 2004. Accessed June 22, 2004 at www.disabilityisnatural.com/peoplefirstlanguage.htm

"For me, it is better to be in a family, because in this home, everyone will leave, we will separate... The family can support you and give you everything."

—Misho, 13, living in an institution, Bulgaria

Since 1989, coincident with transition, the placement rates of *all* children aged 0 to 3 in infant homes have increased rather than decreased across the region. This is, no doubt, related to other trends such as large increases in unemployment and poverty, huge drops in marriage rates, and substantial rises in children born to teenage parents and/or outside of marriage. Children with disabilities with impairments and other perceived differences have a particularly high risk of being institutionalized.

Approaches and language around disability

Language, conceptual models, terms and definitions are powerful tools both in setting and reflecting social relationships. Vigorous debate in this area accompanies many movements for social change, including the current rights-driven disability campaign. This discourse, widely described in the literature, is only sketched out here in order to situate this report.

Human rights rising

The dynamic created by the 'medical model' versus 'social model' discussion of disability is related to a larger dialogue – that of charity versus human rights. The charity approach has long held sway and has framed persons with impairments or functional limitations as misfortunates who must rely on the support of families and the kindness of the community or state. Today, there is an historic shift towards a human-rights approach to disability. Persons with disabilities have the same rights as any individual, and in order to have their rights realized, may need different but equalizing treatment in society. In this scenario, persons with disabilities claim not so much supports as entitlements. The 'social welfare' approach that characterizes many modern states is, arguably, a transition between these two philosophical approaches.

CEE and CIS countries, like nations around the world, still conceptualize disability using a 'medical' model, i.e., disability is, first and foremost, a chronic medical condition of the individual. The main response is to offer health care, rehabilitation and social supports such as special education and pensions. There is, typically, a conflation of impairment, illness and disability. The goal is, simply described, to extend some measure of 'normal' life – e.g., economic capacity, learning achievement – to the disabled individual.

In the last 20 years, however, there has been an accelerating shift internationally towards the 'social model' of disability. This is an approach that emphasizes the disabling aspects of the social and physical environments – e.g., attitudes and work standards, access to buildings and transportation. The social

model implies that policies should be directed at the removal of barriers to full participation for people with disabilities, rather than ‘problematizing’ the disabled person. This suggests that policy should be concerned with identifying disabling situations rather than disabled persons, e.g., enacting building codes that promote ‘universal design’ by reducing barriers to access and use. The social model typically distinguishes among impairment, illness and disability. The goal, simply put, is to change society so that it better reflects and enables the participation of its diverse citizenry in keeping with their rights.

Conclusion

This report represents an effort to provide a basic picture of the state of children with disabilities in the CEE/CIS region. It recognizes and hopes to emphasize that the differences among countries and subregions can be substantial.

The goal of the report, in keeping with the global mandate of UNICEF, is to provide information and analysis that can be used to protect children with disabilities and promote the fulfilment of their rights. The report advances knowledge about the state of children with disabilities that can be taken up and acted upon by policy makers and decision makers of many stripes in CEE/CIS countries and international circles alike – health and education professionals, social service workers, opinion leaders, the media, corporate citizens, civil organizations including non-governmental and faith-based groups, the disability movement and its champions, and most importantly, politicians, parents and children with disabilities themselves. The report also points towards directions for positive change in policies and practices. Finally, it aspires to stimulate further research, including better data collection, on children with disabilities living in the region.

Notes

- 2 National Research and Development Centre for Welfare and Health (STAKES), ‘Disability Dimension in Development Action: Manual on Inclusive Planning’, Ministry of Social Affairs and Health, Finland, 2000. www.stakes.fi/sfa/sfab.html.
- 3 Out of nine CEE and CIS countries reporting on child disability rates to the 2002 UN Special Session on Children, six reported that rates had at least doubled during the 1990s. Rates doubled in Albania and Tajikistan, rose by 2.5 times in Kyrgyzstan, by threefold in Uzbekistan, fourfold in Latvia and fivefold in Russia. See individual country reports at www.unicef.org/specialsession/how_country/.
- 4 The United Nations Development Programme (UNDP) publishes a ranked Human Development Index in its annual human development report. The 2004 report ranks 177 nations, and groups them into high-, medium- and low-development categories. See www.undp.org.
- 5 ‘Provision of Services for Children with Disabilities in Central and Eastern Europe and the Commonwealth of Independent States’, Report to UNICEF from the European Academy for Childhood Disability, December 2003; Oral communication with Dr Martin Bax, Chairman of the EACD. These benchmark figures exclude chronic illnesses like diabetes.
- 6 This means reducing ‘prevalence’ but not ‘incidence’. While statistics from most developing and some industrialized countries tend to indicate much smaller prevalence rates – at times putting the share of disabled children at less than 1 per cent – a significant part of such differences appears to relate to measurement and conceptual issues (e.g., considering only very serious cases). Indeed, a major survey carried out in Bangladesh – one of the poorest developing countries where almost 1 out of 10 children do not survive until their fifth birthday – found that 6.8 per cent of children aged 2 to 9 had disabilities, and 1.6 per cent had serious disabilities. See Zinkin, P. and H. McConachie (eds.), ‘Disabled Children and Developing Countries’, in *Clinics in Developmental Medicine*, No. 136, 1995.
- 7 Wenger, B.L. et al. (1996) estimated that 6.1 per cent of the US population under 18 years of age have disabilities, based on 1992 National Health Interview Survey data. Wenger, B.L., S. Kaye and M. P. LaPlante, ‘Disabilities Among Children’, *Disability Statistics Abstract* (15), Washington, D.C., March 1996. National Institute for Disability and Rehabilitation Research at <http://dsc.ucsf.edu>. Hogan, D. P., M.E. Msall, M.L. Rogers and R.C. Avery, ‘Improved Disability Population Estimates of Functional Limitation Among American Children Aged 5-17’, *Maternal and Child Health Journal*, Vol. 1, No. 4, pp. 203-216, 1997, http://www.pstc.brown.edu/disability/docs/hogan_improve-d-dis.pdf.
- 8 Hogan, D. P., M.E. Msall, M.L. Rogers and R.C. Avery, ‘Improved Disability Population Estimates of Functional Limitation Among American Children Aged 5-17’, *Maternal and Child Health Journal*, Vol. 1, No. 4, 1997, pp. 203-216, http://www.pstc.brown.edu/disability/docs/hogan_improve-d-dis.pdf.
- 9 Disability was defined as the person having difficulty in carrying out some basic functions, such as seeing, hearing, walking or working at a job or doing school work. Serious disability was defined as the person being unable to carry out these functions and/or needing assistance from another person to perform basic activities. U.S. Bureau of Census, ‘Disabilities Affect One-Fifth of All Americans’, *Census Brief*, (CENBR/97-5), December 1997, www.census.gov/prod/3/97pubs/cenbr975.pdf.
- 10 Global Forum for Health Research, ‘Monitoring Financial Flows for Health Research 2004’, Geneva, 2004.
- 11 “The general shift from acute infectious and deficiency diseases characteristic of underdevelopment to chronic non-communicable diseases characteristic of modernization and advanced levels of development is usually referred to as the ‘epidemiological transition’.... It has, however, become apparent that this transition is more complex and dynamic: the health and disease patterns of a society evolve in diverse ways as a result of demographic, socioeconomic, technological, cultural, environmental and biological changes. [The transition] is rather a continuous transformation process, with some diseases disappearing and others appearing or re-emerging.... It is also important to note that several stages of transition may overlap in the same country.” From Wahdan, M.H., ‘The epidemiological transition’, *Eastern Mediterranean Health Journal*, WHO, Vol. 2, Issue 1, pp. 8-20, 1996.

1

OFFICIAL FACTS AND FIGURES

Data Analysis

■ *The statistical story of children with disabilities in CEE and CIS countries*

Statistics and data – and the concepts and methodologies behind them – are the primary research ‘lens’ used to look at the status of any group in society. Official facts and figures – or the lack of them – capture not only current levels of disability services and supports in society, but reflect societal attitudes and approaches towards persons with disabilities. Data and analysis also provide essential information for planners and service providers, and help policy makers see what needs to be done and how. They also allow evaluation of current approaches and can point to better strategies.

Made to measure

The issue of measuring ability/disability raises interesting questions. Does more aggressive measuring simply add more children to the disabled ranks – and expose them to the attendant stigma? Do more expansive definitions like ‘special needs’ similarly swell the pool of ‘non-abled’ children – and, perhaps, draw limited resources away from more seriously disabled children? Does mainstreaming children with disabilities risk a new form of ‘invisibility’? Is it more effective to measure barriers to equality and social participation for all children? Does the increasingly fine parsing of human functioning broaden the embrace of disability more than advance enablement, inclusion and diversity? Why do measures, indicators and data focus almost entirely on the individual rather than on the community or public services?

The official ‘lens’ for gathering information is so important that in 2001 WHO published a new International Classification of Functioning, Disability and Health (ICF) that it describes as a ‘radical shift’ in approach because it attempts to mainstream disability by integrating it into the broader range of human functioning (see Box 1.1). The impact of this new system remains to be seen because surveys and disability registers around the world still primarily use existing, more medically oriented national concepts and international classifications. DISTAT, the disability database of the UN system, is to be reformulated to ICF standards, but first the availability and comparability of statistics on persons with disabilities must be improved at the national level.

Importantly, however, there are presently no distinct approaches to data collection on disabled persons that pay particular attention to children with disabilities. One promising development is that there is currently an international working group that is drafting a child/youth version of the ICF system for classifying disability and health.

In the past, household surveys have rarely asked about disability, and administrative files that contained numbers and information related disability supports and services were rarely analysed. For this report, through the support of prominent statisticians and national statistical offices in the region, all 27 countries sent relevant data to UNICEF, and all but two – Uzbekistan and Bosnia and Herzegovina – submitted a related country report that responded to a set of questions developed by UNICEF for this research.

Box 1.1 New WHO classification focuses on functioning

The new WHO classification system for health and disability casts a broad net. As WHO states: “The new ICF mainstreams the experience of disability by placing it in a broad continuum of human functioning. It recognizes that disability is not something that happens to a minority of people, but is a universal human experience. Most people experience some degree of disability at some time in their lives.”

ICF embodies a number of new concepts compared to its 1980 predecessor pilot.

- It focuses on an individual’s whole range of functioning – in the case of a child with disabilities it prompts evaluation of all the child’s abilities, rather than simply his or her physiological limitations. It grades functioning on a scale from ‘no impairment’ to ‘complete impairment’.
- It does not limit itself to a medical diagnosis, such as Down syndrome or cerebral palsy. WHO argues that shifting the focus from cause to impact, ICF places all health conditions on equal footing.
- It recognizes and measures the presence and impact of environmental factors, whether those relate specifically to the individual or to broader social aspects such as the lack of accessible buildings.

In practice, an ICF evaluation uses alpha-numerical codes to describe and measure a range of body structures, functions, activities, participation as well as personal and environmental factors. Together, the codes can be used as coordinates to map an individual’s functioning at a particular point in time, and to serve as a baseline for future evaluations.

For example, code B21021-1 indicates the person has mild problems with colour vision. In the case of red/green colour blindness, this may involve disabling environmental factors such as red/green traffic lights and related occupational limitations. Decoded, the alpha-numeric label reads:

- **B2** – problems with **sensory** functions;
- **B210** – problems with **seeing** functions;
- **B2102** – problems with **vision quality**;
- **B21021** – problems with **colour vision**;
- **B21021-1** – to a **mild** degree.

As yet, no CEE or CIS country has indicated concrete plans to implement the new global standards, and regional classifications are not readily comparable to the WHO international classification system.

Note: ICF replaces the 1980 International Classification of Impairments, Disabilities, and Handicaps, the first system developed by WHO.

Sources: Keep as ICF, 2001; *Towards a Common Language for Functioning, Disability and Health (ICF)*, WHO Geneva, 2002. ICF home page at www.who.int/classifications/icf/en/

1.1 Main findings

There has been a threefold increase, on average, in rates of children with disabilities in the CEE and CIS region during the transition years. It appears, on analysis, that this surge is largely due to greater recognition and/or admission of disability rather than to actual increases in impairments.

These main findings emerged from analysis of the country reports and available data.

- The total number of children recognized as disabled in official data across the region tripled, from about 500,000 at the onset of transition, to 1.5 million in the 27 countries. (See Figure II in the Introduction.)
- The data lack international comparability in the strict statistical sense. However, applying the international benchmark noted in the Introduction – a disability rate of 2.5 per cent – suggests that one million or more children with disabilities are uncounted.
- Some 317,000 or more children with disabilities lived in institutions in 2002. Country rates vary considerably, suggesting again that recognition of disability rather than incidence of impairments account for most of the differences.
- Families with children with disabilities tend to be poorer than those without. Family poverty can be seen as both a cause and consequence of disability, but the relationship is complex.
- The main forms of support continue to be disability pensions for children, increased family allowances or institutional placement.
- ‘Special education’ in segregated facilities (as prescribed by the Soviet discipline of ‘defectology’) is still the overwhelming policy approach across the region. There has been significant progress in attitudes and, to a lesser degree, in action on integrating children with disabilities into mainstream schools. Strikingly, however, there has also been a bigger demand for and creation of special schools for children with disabilities in many countries.
- There are a number of issues around data and statistics collection. Countries typically lack national definitions of disability; data is largely drawn from administrative sources such as enrolment in special schools or claims for disability pensions. As a result, data is neither comprehensive nor comparable, and lacks a qualitative dimension.
- All CEE and CIS countries – like other high- and middle-development countries – still approach disability as, firstly, a medical issue and, secondly, a social welfare demand. However, most countries have taken the step of enacting rights-based legislation related to persons with disabilities.

1.2 Definitions, concepts and approaches in CEE/CIS

The data and analysis in several Country Reports emphasize disabilities in children that are associated with congenital anomalies – conditions present at birth and recognized immediately or in early childhood. However, it appears that the distinction between congenital conditions and disability is

often missing, even though it is clear that not all congenital anomalies need lead to impairment or disability. Nonetheless, it is still possible that the simple fact of a diagnosis is enough on its own to trigger the direction of that child to an institution.

More broadly, official definitions of disability in the region, even recent ones, are anchored in functional limitations – that is, the person is incapable in some elemental way. One example is Hungary's 1998 *Act on the Rights of Disabled Persons*:

Disabled is a person who either to a significant extent or fully is not in possession of the capabilities of his faculties, more specifically his visual and/or hearing senses, of his organs of locomotion and mental capacities, or is significantly restricted in personal communication, and this constitutes lasting disadvantage for him in the participation of social life.¹²

The equation of 'disability' and 'disadvantage' in definitions is problematic and confines children who meet the criteria to a stigmatizing truth: to be disabled means to have 'lasting disadvantage'. In 2000, Belarus passed legislation on disabled persons that captures this double bind: "A person shall be considered disabled if due to physical or mental handicaps that limit his or her vital activity he or she requires social assistance and protection."¹³

Countries typically have no authoritative national definition of disability; instead, different definitions exist in relation to various public services such as education, social security and employment. As the Albania Country Report notes: "Definitions of children and adults with disabilities vary, depending on what is the purpose of a particular act [of legislation]." These technical definitions of disability vary greatly among CEE and CIS countries, as the Country Reports highlight.

Hungary has at least seven definitions of disability in various articles of legislation and regulation; even its 1998 act on the rights of disabled persons does not use a single 'umbrella' concept. Some countries, like Poland, set a condition that impairment from illness is considered disability if the conditions last at least 12 months, while other countries do not consider chronic illness as disability. In Croatia, a child with severe diabetes, haemophilia or similar chronic disease is considered a child with disability from the medical point of view, but not from the educational point of view.¹⁴

The situation is no different throughout the EU, where recent research shows countries use multiple concepts for disability, usually related to technical reasons and the allocation of scarce resources through the administration of social policies.¹⁵ The European Commission notes this multiplicity can "be a barrier to the development of comparative analysis and policy evaluation."¹⁶

The portrait of children with disabilities in the region must thus be pieced together from a variety of sources, sometimes contradictory, occasionally overlapping and sometimes incomplete.

Disability registers

Many CEE and CIS countries have national disability registers that, though they may sound comprehensive and authoritative, are not. They are, however, one important source of data. The registers capture children and adults who have been issued disability certificates by doctors or government medical-pedagogical committees. This certification is usually a prerequisite for claiming disability supports, such as cash benefits, from the state. It is, in effect, a basic means test.

Medical data

CEE and CIS countries often interchange statistics on chronic health problems and certain medical conditions and symptoms with data on disability. In Central and South-Eastern European countries, where health ministries are not in charge of disability registers for children, the results of health screening of infants and school-aged children are often presented as proxy data on disability prevalence. For example, the Czech Country Report details congenital anomaly rates among newborns; the Hungarian Country Report refers to a list of chronic diseases and deficiencies found in children examined at kindergarten age and in grades 5,9 and 11; and the Serbia and Montenegro Country Report cites asthma incidence as noted by school doctors.

The Soviet concept of disability, which prevailed in all CIS countries before transition, relied upon a set list of medical conditions for defining disability. Several CIS states have enlarged the list, which has had the effect of expanding the disabled population. Armenia, for example, introduced a new list of medical conditions for the definition of disability in 1995 that has been associated with an increase in the number of children with disability status and related benefit claims.¹⁷ Such a list can create errors of exclusion (e.g., when it is not current with new knowledge norms) as well as errors of inclusion (e.g., when it is applied without regard for individual capacity and potential).

Few countries provide data on functional limitations related to children with disabilities. Most publish detailed data only by disease code. However, Russia, does publish data for children with disabilities broken down by 'disability-inducing diseases' and 'functional classification'.¹⁸

Many countries use a Soviet-style three-tier system of classification for administrative purposes. For example, in Estonia, the social security system defines disability as *moderate* if it involves "the loss or impairment of an anatomical, physiological or mental structure or function, as a result of which the person needs partial assistance in coping with his/her daily life;" *severe* if "assistance or supervision all day or all night long;" and *profound* if care is needed "24 hours a day."

Social security data

Most of the Country Reports imply that social security files, disability pension claims or similar cash-benefit records offer the most comprehensive

administrative information on the prevalence of children with disabilities. Responsibility for children with disabilities is typically divided among various government ministries; data and other important information is seldom shared or linked.

Administrative definitions of disability are typically restrictive because they are designed to target entitlements and benefits to a needy population. For adults, the determination of disability is closely linked to activity limitations – the ability to carry out activities related to daily living and work. However, in the case of children¹⁹, what constitutes disability is much less clear.²⁰

Restrictive concepts are inherently exclusionary. They are designed to focus resources on a target group but may, at the same time, deny access to a part of the population it seeks to serve. This phenomenon, described as ‘targeting error’, especially affects persons from disadvantaged groups.²¹ For example, many individuals may fall into the gaps between various administrative definitions. This is one reason why many disability groups and stakeholders prefer a broad concept of disability.²² Restrictive definitions may also prompt families and health care providers to necessarily describe a child’s needs in a way that gains access to or maximizes benefits. In other words, making the child fit the system, rather than the other way around.

The targeting paradox

Social supports invariably ‘target’ specific groups of claims-holders in order to get resources to those whose needs and rights are unmet. Ironically, such a well-intentioned approach has fundamental flaws. It requires families who are already short of resources to spend precious effort negotiating the administrative requirements of various agencies and, in effect, to ‘swim’ from island to island of support to collect the resources they need for their child to live a ‘normal’ life.

Data from state institutions

Children with disabilities living in residential homes, boarding schools, hospitals and other institutions are typically not included in disability registers or social security records because they receive inclusive care from the institution. Data are available on the numbers of children in institutions. There are limitations, however, as data for some institutions – e.g., hospitals or long-term care health facilities – are not rigorously disaggregated as to the reason for residence. Data for general orphanages, which house large numbers of children across the region, may not recognize or indicate how many resident children have disabling impairments. Even data from institutions for the disabled have limitations: Children with disabilities are often housed in institutions for adults, and some portion of children in institutions for the disabled are, in fact, not disabled.

Census and survey data

Disability, especially among children, has been little

addressed in household surveys and national census in CEE and CIS countries. The Country Reports make clear that before transition very few household surveys addressed disability. More recently, some surveys and censuses have begun to employ questions on disability, and though this counts as progress, many limitations in inquiry and gaps in knowledge remain.

Household surveys still use medical concepts of disability, and often lump together children who are ‘disabled,’ ‘chronically ill’ or ‘sick or with disease – hindering analysis. The age limit for ‘children’ tends to be 14 to 16 years (rather than the international standard of 18 years), and there is no particular recognition of children with disabilities as a distinct population. For example, the 2000 Census in Hungary asked about the top four types of disability in the general population, but nothing was specific to children.

Shades of disability

Most persons with disabilities are adults, and conditions associated with ageing are the most common causes of disability. Children with disabilities are a distinct population. Their impairments that result in disability are primarily congenital anomalies and, to a much lesser degree, the effect of infectious disease or traumatic injuries. In terms of life experience, there are also substantial differences between being born with a disabling impairment and becoming disabled through impairment, and significant shades of impact in between. A child born to cerebral palsy and a teenager paralysed in a car accident and a grandparent with crippling arthritis all have different expectations of and experiences with disability.

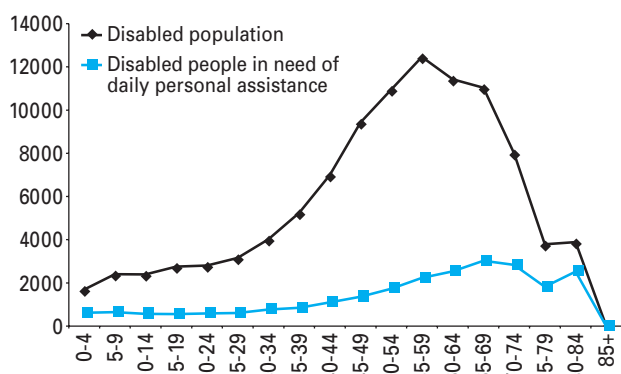
Some surveys, such as the 2000 Census in Estonia, simply ask whether the person has a ‘disability certificate’ which replicates the problems noted earlier in counting children with disabilities through social security records. Questionnaires tend to ask parents whether certain medical conditions exist rather than soliciting information on functioning as has become standard in international instruments such as the Multiple Indicators Cluster Survey (MICS).²³ For example, the 2000 Census in Estonia (with parents responding for underage children) asks:

- “Have you any long-term illness or disability that has been determined by the medical commission of experts and has lasted or probably will last for one year or longer?”
- If ‘yes’: “Do you need assistance in taking care of yourself?”

1.3 Rates of disability among children in CEE/CIS

It is surprising that, at the outset of the transition, many CEE and CIS countries reported very low rates of children officially recognized as being disabled. In

Figure 1.1 Disabled population and the number of people in need of daily personal assistance by age group, Estonia, 2000



Source: Population and Housing Census, Estonia, 2000

Box 1.2 Disability screen

To help identify children with disabilities, Bulgaria uses population-based surveys as a source of information. For example, the Health Interview Survey includes a module of questions aimed at measuring locomotion, hearing, vision and self-care.

The following questions are asked in reference to what one is normally capable of doing:

1. What is the distance that you can walk without stopping and without difficulties?
Answer: Only a few steps. More than a few steps but less than 200 meters. Two hundred meters and more.
2. Can you get in and out of bed on your own?
Without difficulties. With some difficulty. Only with someone's help.
3. Can you dress and undress yourself on your own?
Without difficulties. With some difficulty. Only with someone's help.
4. Can you wash your hands and face on your own?
Without difficulties. With some difficulty. Only with someone's help.
5. Can you feed yourself? Without difficulties. With some difficulty. Only with someone's help.
6. Can you get to and use the toilet on your own?
Without difficulties. With some difficulty. Only with someone's help.
7. Can you do shopping yourself? Without difficulties. With some difficulty. Only with someone's help.
8. Is your hearing good enough to follow the TV programme at a volume that others find acceptable?
Yes. No.
If no: Can you follow a TV programme with the volume turned up? Yes. No.
9. Can you see well enough (with glasses or contact lenses, if necessary) to recognize a man at a distance of 4 meters? Yes. No. If no: Can you see well enough (with glasses or contact lenses, if necessary) to recognize a man at a distance of 1 meter (at arm's length)? Yes. No.

Source: Bulgaria Country Report, 2002.

Poland, the 1988 census found that only 0.5 per cent of children aged 0 to 14 were disabled. In many countries, the share of children registered as disabled was even less. In 1989, Estonia reported 0.47 per cent, Georgia 0.43 per cent, and Kyrgyzstan 0.28 per cent of children aged 0 to 15 years as disabled based on health and social security records. (Data for 1989 are not available for Russia, the largest country in the region, but 1980 figures show 0.17 per cent of children aged 0 to 15 years were registered as disabled.)

These very low official rates – 5 to 10 times lower than the benchmark discussed in the Introduction of this report – can partly be explained by narrow medical definitions of what constitutes disability. As importantly, the systematic practice of segregating children with disabilities in special schools and institutions means their numbers do not appear in national disability registers or social security records, so they are often missing from these reported disability rates. Similarly, parents may have refrained from having a child identified as 'disabled' because of the social stigma attached to disability or the practice of segregating children with disabilities. In these instances, the child remained in the family, but lacked access to needed supports.

Trends over transition

The rising trend in the prevalence of disability among children is most striking in countries of the former Soviet Union, which have health and social security registers for children with disabilities: the Baltic States, Western CIS countries, and the nations of the Caucasus and Central Asia. However, this trend manifests in several other countries as well.

As noted in the Introduction, the surprising finding of an apparent region-wide surge in the prevalence of children with disabilities first came to light in national reports prepared for the 2002 UN General Assembly Special Session on Children. However, none of the national reports attempted to explain why and how this happened in their country. Table 2.1 tracks this trend by presenting available data from four transition years (1990, 1995, 2000 and 2002) for the three Baltic States, seven CIS countries and Croatia on the absolute numbers of children registered with disability and rates calculated per 10,000 relevant population.

Analysing rising trends

Some may be tempted to link the higher rates of children with disabilities to health problems caused by the enormous economic and social hardships of the 1990s in the transition countries. On closer investigation, it seems that the main cause for the rising rates of disability is greater identification of disability rather than a general increase in the actual incidence. Evidence for this finding comes in various forms. Greater identification may result from an increase in medical diagnoses, detection in schools, and families coming forward to claim supports.

If greater poverty and worse health were the *main* causes behind higher registered disability figures for

Table 1.1 Number of registered children with disabilities in 11 CEE and CIS countries

	Number of children				Rates per 10,000 of relevant population			
	1990	1995	2000	2002	1990	1995	2000	2002
Estonia	2187	4097	4409	4923	59	131	167	200
Latvia	-	6637	8591	8409	-	123	192	205
Lithuania	6875	10710	12725	12034	77	125	171	175
Croatia	-	-	9793	11301	-	-	105	122
Belarus	9749	20563	29115	30253	39	88	125	140
Moldova	9673	13857	14056	13480	80	121	156	164
Russia	-	462275	554867	620342	-	143	199	203
Ukraine	93156	120374	153927	147325	96	123	163	150
Georgia	6874	8502	8534	10041	44	65	73	89
Kazakhstan	-	32000	49806	47722	-	64	114	107
Kyrgyzstan	5358	7732	14839	17760	31	44	82	101

Notes: The data tend to exclude children with disabilities in residential care. Age group 0 to 15 years in Estonia, Latvia, Lithuania and Moldova, and for 1990 and 1995 in Belarus, for 2000 in Russia; children 0 to 14 years in Georgia. Otherwise data refer to ages 0 to 17. Kazakhstan: number of disability pension recipients under age 18. The earlier year is 1991 for Lithuania and Moldova, 1992 for Ukraine, 1995 for Latvia and Kazakhstan, 1996 for Russia and 2000 for Croatia.

Sources: TransMONEE Database; Country Reports to UNICEF IRC.

children, then countries that experienced a harsher transition should post higher prevalence rates. However, during the 1990s, steady rises in the prevalence of children registered as disabled have occurred both in richer and poorer countries. As Table 1.1 shows, some of the highest official rates are posted by countries that are relatively wealthy and stable, rather than in poorer countries with slower reforms and/or a recent history of armed conflict.

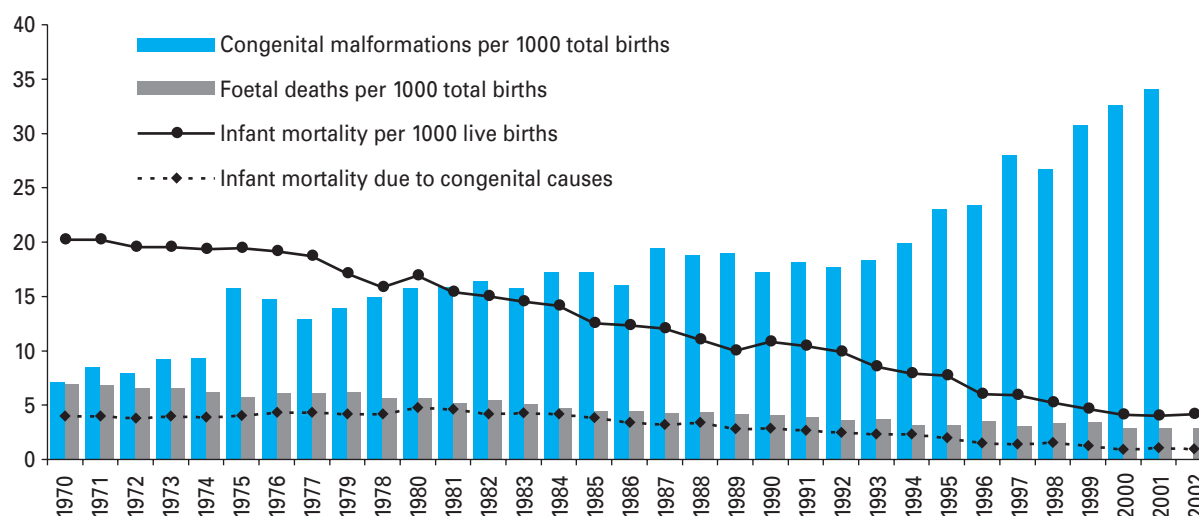
Looking at rates of infant mortality and congenital anomaly in CEE and CIS countries, Figures 1.2 and 1.3 suggest a similar conclusion: Social and economic progress leads to higher reported rates of children with disabilities.

Figure 1.2 shows the inverse relationship between

infant mortality rates and congenital anomaly prevalence by focusing on long-term data from the Czech Republic, a Central European country that currently presents one of the lowest perinatal mortality rates in Europe. The figure demonstrates how successful reduction of infant mortality and stillbirth rates is paralleled by increased identification and reporting of congenital anomalies.

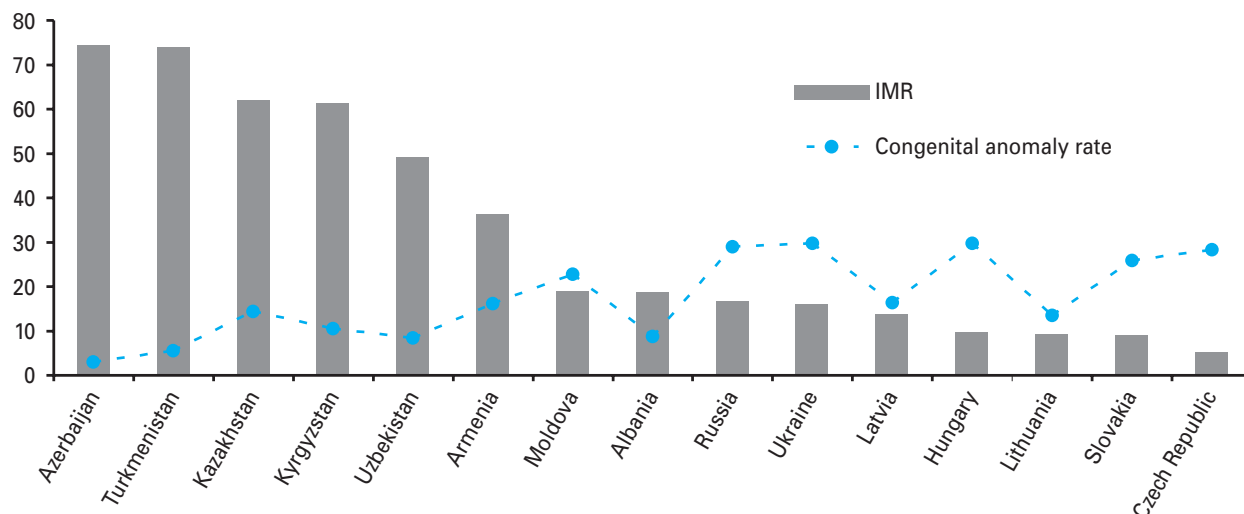
Figure 1.3 shows congenital anomaly data reported to WHO by 15 CEE and CIS countries. Almost all of these countries greatly under-report the rate of congenital anomaly: only a few report a prevalence that even comes close to international norms (e.g., 33 cases per 1,000 births as reported in the US). The figure illustrates that countries with better infant survival rates tend to report higher prevalence of

Figure 1.2 Rates of infant mortality and congenital anomaly, Czech Republic, 1970-2002



Source: WHO

Figure 1.3 Rates of congenital anomaly and infant mortality in 15 CEE and CIS countries, 2002
(per 1,000 live births)



Source: WHO

congenital anomalies, which suggests increased survival of high-risk babies and a greater identification of congenital anomalies.²⁴

Congenital anomalies – literally, differences at birth – are present in 3 to 5 per cent of newborns. Serious anomalies have about a 1 per cent probability. Some anomalies, like neural tube defects, entail very high mortality risk. Others, such as cleft lip and palate, can be addressed through surgery and speech therapy. Many, like Down Syndrome, are lifelong. About three-quarters of serious congenital anomalies and one-third of other anomalies will lead to disability, according to an EACD estimate.

In this regard, many CEE and CIS countries are playing ‘catch-up’ with Western industrialized countries, which typically post higher disability rates among children. It also appears that a rise in newly registered cases of children with disabilities had already begun in several countries before 1990. Hungary, where the political climate was more liberal than in other countries, was already reporting higher rates of children with disabilities in the 1980s. The 1990 Population Census found that 1.6 per cent of children were disabled, while about 3 per cent of the beneficiaries of the universal child allowance were children with disabilities or chronic illness – rates that were several times higher than in most transition countries at that time.

During the 1990s, it also seems that the ranks of children with disabilities grew because of low exit rates rather than spiralling entry rates. In Lithuania, for example, the number of children aged 0 to 15 who were newly registered as disabled increased by 32 per cent between 1991 and 1996, while the ‘stock’ of children with disabilities in the registers grew twice as rapidly in the same period, by 65 per cent.²⁵ This reflects a scenario where children are on the registry for longer periods (indicating, perhaps, identification at younger ages).

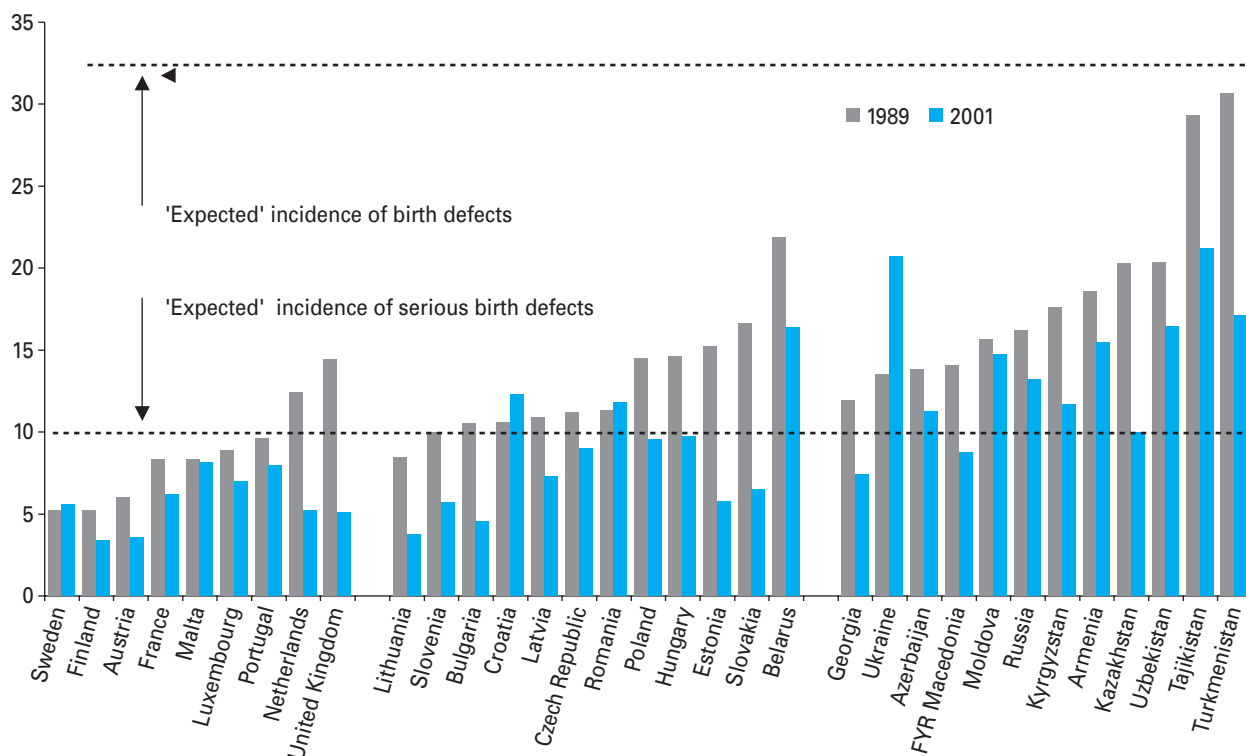
Perinatal mortality rates

In most parts of Central and Eastern Europe, babies have a better chance of surviving to birth and beyond, and children have a better chance of reaching adulthood than they did before transition. Figure 1.4 shows changes in perinatal mortality rates between 1989 and 2001, according to official statistics, for 33 European and Central Asian countries.

The fact that stillbirth and neonatal mortality rates are approaching very low levels in many European countries means that a greater share of babies with serious health problems and birth anomalies are surviving the risky period around birth (see dotted line on graph for ‘expected incidence of birth defects’). A substantial share of these children will have some impairments, so – unless other factors are changed, such as better neonatal care, greater supports to families, changing attitudes in society, removal of barriers to participation – there may be an associated increase in the prevalence of children with disabilities in coming decades.

The situation around perinatal health is not so clear. Available statistics may not be providing a reliable picture of maternal and child health. Official data largely show declines in infant and perinatal mortality over the last decade, but recent international surveys and studies have found evidence that actual child mortality may be several times greater than official figures, as noted in the Introduction of this report. This evidence finds that in some Caucasian and Central Asian countries, infant mortality rates appear to be close to 100 deaths per 1,000 live births – meaning newborns have a higher risk of dying in these countries than in most developing countries. It is not known to what extent this was also the case in late Soviet times; it is evident, however, that the restrictive ‘Soviet concept’ of live birth has played a role in disguising actual levels of neonatal mortality.²⁶ If many newborns who show signs of life are not considered to be ‘alive’ by the Soviet definition – as still happens in several CIS

Figure 1.4 Perinatal mortality rates in 33 European and Central Asian Countries, 1989 and 2001
(number of still births and infant death 0-6 days per 1,000 total births)



countries – then the official data are not only under-reporting, and the child’s rights to care and protection may not be respected.

Defining birth

The Soviet concept of live births excludes infants who are born with no breath, but with other signs of life, who then die; as well as infants born before the end of the 28th week of pregnancy, weighing less than 1,000 grams or 35 cm in length and who die during the first seven days of life.

1.4 Disability and health in CEE/CIS

Dismantling disabling attitudes and environments may be the big new push in empowering persons with disabilities, but public health strategies still have a decisive role to play in the CEE/CIS region. In the case of children, this means preventing infectious diseases, reducing traumatic injuries and addressing congenital impairments through good health practices.

Is prevention a cure?

‘Prevention’ of ‘disabilities’ is a sensitive subject. Few may argue against child safety seats in cars that prevent or reduce permanent injuries. There would also seem to be little reason to resist public health initiatives such as fortifying foods with essential micronutrients – e.g., folic acid and iron – or undertaking vaccination programmes against measles and polio (though resistance does

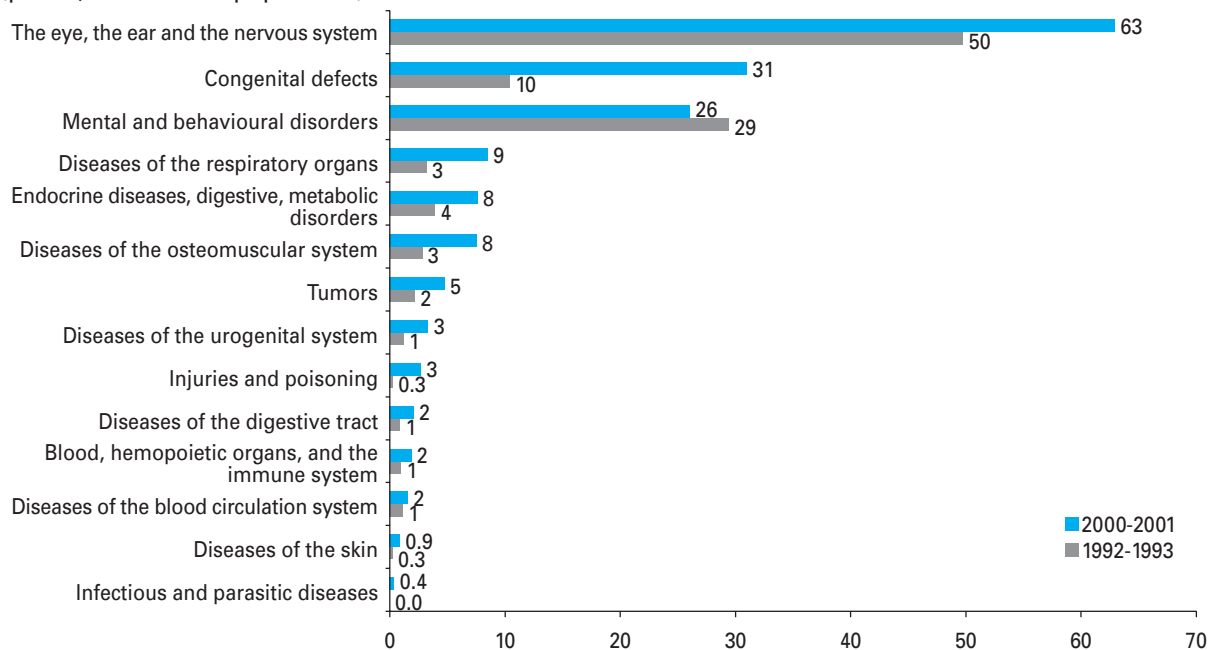
exist). Discussion is much more heated around congenital conditions. For example, there have been legal cases that pit foetal health against the rights of the pregnant woman, e.g., the use of alcohol or drugs. Disability rights advocates have argued that prenatal diagnostic tests like amniocentesis prompt ‘prevention’ through termination of the pregnancy. Many argue the focus of ‘prevention’ should be on attitudes and barriers in society.

Medical causes of impairment

As noted, much of the data collected on children with disabilities in the region are health-related. However, the concept of health here is narrow, focusing on impairment and functional limitations. The list of conditions associated with disability varies significantly among CEE/CIS countries and subregions (e.g., congenital anomalies are more frequently reported in Russia than in Central Asia). This variance may reflect differences in concepts, awareness, diagnostic capacity and even actual incidence. However, most disability among children is associated with three types of health issues: congenital anomalies; neurological disorders (such as cerebral palsy) where dysfunction or damage to the brain; and intellectual and behavioural problems.

Figure 1.5 details the medical causes of disabilities for children in Ukraine for two different periods: 1992 to 1993 and 2000 to 2001. Here, as in Russia, Belarus and most other CEE and CIS countries, the prevalence of disability in this age group has almost doubled since the early 1990s, from less than 1 per cent in 1992 to 1.7 per cent by 2001. The figure shows that

Figure 1.5 Child disability by cause in Ukraine, 1992-93 and 2000-2001
(per 10,000 relevant population)



Note: Registered children with disabilities aged 0 to 15

the increase in reported cases of disabilities tends to cover almost all types of disorders and diseases, rather than being concentrated in one or a few causes – fortifying the argument that increased identification and reporting are responsible for greater disability rates rather than real growth in incidence.

It is tempting to conclude that the threefold rise in congenital anomaly prevalence is related to the Chernobyl nuclear accident that happened 18 years ago.²⁷ However, while the impact of Chernobyl on child health was considerable, there is little scientific evidence that the nuclear disaster has led to a major rise in the incidence of congenital anomalies (see Box 1.3).

Despite a fourfold increase since 1992, injuries appear to play a relatively small role in childhood disability in Ukraine, as in other CEE and CIS countries. This is somewhat surprising given that the fatal injury rate among children and young people is significantly higher in CEE and especially CIS countries than in Western industrialized countries. It may mean injury-related impairments do not always show up in childhood disability registers.

The only health condition showing a decline over the comparison period is 'mental and behavioural diseases' which was, however, still indicated for 1 out of 7 children in the register – 0.3 per cent of all Ukrainian children under age 16 in 2001. A decline in intellectual disorders has also been reported from other countries, e.g., in Serbia and Montenegro it fell from the second to third most-reported disabling condition. It must be noted, however, that the whole area of intellectual disability among children in the region warrants much more study than has been possible to present in this report.

Rates of congenital anomalies are, indeed, on the rise in almost all CEE and CIS countries where data on children with disabilities is available by disease code.

Box 1.3 The children of Chernobyl

Visitors to institutions for children with disabilities in Ukraine, Belarus and Russia may still be introduced to a 'Chernobyl Child'. However, the health fallout from the world's worst nuclear accident on April 14, 1986, appears, so far, to be much less than feared, according to a significant body of international research.

Children, however, have been one of the groups most affected by the disaster because the childhood thyroid gland is very radiosensitive. WHO reports a tenfold increase in thyroid cancer among children in affected areas, and 100 times greater in the Gomel region of Belarus. Still, absolute numbers have been relatively small – about 700 cases in the three countries – and the most common forms of thyroid cancer are very treatable. Consuming radiation-contaminated milk and vegetables is a main pathway for exposure.

Researchers have also looked for other and future cancers, birth abnormalities in pregnant women exposed to radiation, and psychological disorders. Studies have found no evidence of increased cases of childhood leukaemia and no increase in congenital malformations, stillbirths or premature births that could be linked to radiation exposure. One study of 138 Belarusian children exposed in utero found only slightly lower intellectual capacity and slightly more emotional disorders than children from non-contaminated areas.

Sources: Chernobyl on the Web (http://f40.iaea.org/worldatom/Press/Focus/Chernobyl-15/cher-no15_main.shtml)
Chernobyl: Assessment of Radiological and Health Impacts: 2002 Update of Chernobyl: Ten Years On (<http://www.nea.fr/html/rp/chernobyl/>)
World Health Organization, *Children Affected by the Chernobyl Accident*, (http://www.who.int/ionizing_radiation/research/children/en/)

In Russia, the numbers of children aged 0 to 15 who were registered as having congenital anomalies grew from 78,000 to 111,000 between 1996 and 2000, despite a significant fall in the birth rate. In Latvia, numbers rose from 1,000 to 2,300 between 1994 and 2001, accounting for about one in five registered cases of children with disabilities. In 2001, the prevalence of children with disabilities related to congenital anomaly was 0.3-0.4 per cent in Ukraine and Russia, and 0.5 per cent in Latvia (Table 1.2). This means that despite apparently large increases, statistics still do not report a level of children with disabilities from congenital anomaly that reaches even the minimum benchmark – 1.0 to 1.5 per cent of the child population – established in industrialized countries.

The only exception is Belarus. At the end of 2001, it reported almost 500,000 ‘sick’ children as out-patients under observation at clinics. About 27,000 of these children – 1.5 per cent of all children aged 0 to 14 – were diagnosed with congenital anomalies; however, not all of these children were considered disabled.²⁸ (Notably, 315,600 children were said to be suffering late effects of the Chernobyl disaster.)

A number of Country Reports – especially in Western CIS – attribute the higher prevalence of registered children with disabilities to deteriorating health conditions rather than greater awareness. One reason for this could be an apparent fit with higher child and adolescent morbidity rates that have been reported in the general child population since 1990. However, the links between morbidity and disability are unclear.

Morbidity and disability

Table 1.3 shows new morbidity cases in Belarus for children aged 0 to 14 and adolescents aged 15 to 17

in the years 1990 and 2001. The 50 per cent increase in the incidence of all types of illness in the child population (about 50 per cent in respiratory problems, the most common complaint; one third for injuries and poisoning in the younger group, and almost triple for uro-genital diseases in the adolescent group) resonate with reported increases in ‘psycho-physical development disorders’ in the same country, e.g., diminished hearing or speech up by a third, posture disorders almost double, and scoliosis almost triple.

In Soviet times, nearly all children received regular health check-ups, a practice continued in most CEE and CIS countries, including Belarus. So, the increase in reported morbidity is not explained by selectivity bias, e.g., a new scenario where poor children now have access to medical check-ups. However, two factors do seem to be at work: the first is greater poverty and its related health impacts, such as malnutrition; the other is greater sensitivity on the part of parents and health providers to identifying health problems. The latter may be fuelled by heightened concerns in the wake of the Chernobyl disaster, as noted above.

Greater and/or significant morbidity has also been reported from many other countries as well. Hungary, for example, reports more asthma, deformation of carriage, hypertension and hearing impairment in its school-aged population.²⁹ Latvia finds two fifths of its children under age 15 are sickly.³⁰ In Russia, results from a nationwide medical examination, covering 30.4 million children (95 per cent of the total child population) found 34 per cent of the children ‘healthy’, compared to 45 per cent less than a decade earlier when the country embarked on market reforms.³¹

Table 1.2 Child disability prevalence by disease group in Latvia (per 10,000 relevant population)

	1994	1995	1996	1997	1998	1999	2000	2001
Total	110.8	123.1	147.2	158.6	177.7	181.7	1922.8	1996.5
<i>of which:</i>								
Neoplasm	3.8	4.4	5.2	5.5	6.4	6.4	6.9	7.9
Endocrine, nutritional and metabolism diseases, immunity disorders	-	-	-	-	10.0	9.7	10.2	8.2
<i>of which: diabetes mellitus</i>	4.0	4.6	5.2	5.6	5.8	5.1	5.1	4.8
Mental disorders	20.7	22.4	25.6	26.8	30.3	27.6	29.3	27.8
Nervous and sense diseases	44.9	49.3	55.9	61.7	57.5	56.8	57.5	60.2
Respiratory diseases	5.0	5.8	8.0	9.2	11.1	11.2	11.5	11.5
<i>of which: asthma</i>	4.7	5.4	7.4	8.2	10.0	10.2	10.5	10.6
Congenital anomalies	19.8	22.1	28.9	29.4	43.6	47.2	51.8	54.7
Diseases of the skin and subcutaneous tissue	0.5	0.5	0.6	0.7	0.7	0.8	0.9	0.8
Traumas and poisoning	0.3	0.4	0.4	0.5	0.7	0.7	0.8	0.9
Other diseases	9.2	10.7	13.9	15.7	17.4	21.4	23.5	27.5

Source: Latvia Country Report to UNICEF IRC

Note: Registered children with disabilities aged 0 to 15 years at the end of the year.

Table 1.3 Morbidity among children by disease group with a first-time diagnosis in Belarus

	Children aged 0-14		Adolescents aged 15-17	
	per 100,000 relevant population			
	1990	2001	1991	2001
Total number of cases	95.3	142.6	61.1	91.4
<i>Including:</i>				
Diseases of the respiratory organs	67.5	100.3	36.0	55.4
Injuries and poisoning	5.3	7.1	7.1	7.7
Diseases of the nervous system and sense organs	3.7	7.8	4.3	5.4
Infectious and parasitic diseases	7.8	8.9	2.6	3.1
Diseases of the skin and subcutaneous fat	3.4	5.5	3.0	5.4
Diseases of the digestive organs	3.2	4.4	2.6	3.7
Diseases of the osteomuscular system and connective tissue	0.3	1.2	1.0	2.8
Diseases of the urogenital system	0.5	1.3	0.9	2.5
Mental disorders	0.4	1.1	1.3	2.1
Diseases of the endocrine system. nutrition disorders. metabolic and immune system disorders	1.3	0.8	1.3	1.4
Circulatory diseases	0.3	0.7	0.5	1.2
Diseases of the blood and hemopoietic organs	0.5	1.0	0.1	0.1
Congenital anomalies (developmental defects)	0.2	0.4	0.1	0.1
Tumors	0.1	0.1	0.1	0.2

Source: TransMONEE Database; Belarus Country Report.

The rising trend in childhood illness over the transition period should provoke questions and concerns. Unfortunately, available statistical evidence does not allow a clear answer as to how the growth in childhood morbidity is linked to the growth in prevalence of childhood disability.

Individual and public health factors

■ Low birthweight

Premature birth and/or low birthweight are both associated with impairments. Babies born weighing less than 2,500 grams face increased risk of impaired immune function, diabetes and heart disease later in life. Low birthweight babies are also more likely to grow up malnourished and have lower IQs and cognitive disabilities. Experts esti-

mate, for example, that half of babies with cerebral palsy had low birthweights, although the relationship between the two issues is complex.

The risk of birth complications has increased in many CEE and CIS countries since 1989, an outcome perhaps of the many stresses – physical, psychological, social and economic – associated with the transition. Between 1989 and 2001, the proportion of birthweights under 2,500 grams increased in four of the eight CEE countries that became new EU member states in 2004. In Bulgaria and Romania, (both in line for EU accession), official data suggest that 1 out of 10 to 12 children are born with low birthweight, rising to 1 out of 6 to 7 among teenage mothers (the only age group with increasing birth rates in many CEE and CIS countries). Despite a recent decline, low birthweight incidence is similarly high in the new EU member Hungary.

■ Micronutrients

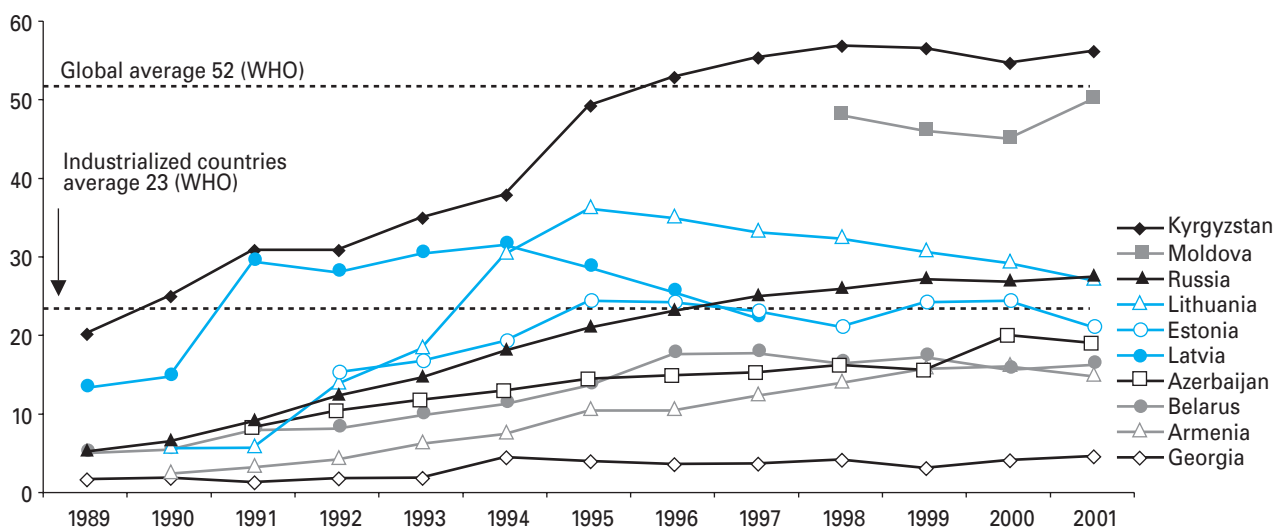
Poor nutrition is a factor in child mortality and morbidity risks, but its relationship with disability is less straightforward. However, it is clear that diets poor in certain micronutrients are associated with premature delivery and low birthweight, mortality, congenital anomalies, immune system and vision problems, intellectual disabilities and under-development. Folic acid (a Vitamin B12 component), Vitamin A, iodine and iron are especially important in prenatal health, and there is evidence of a lack of these micronutrients in several CEE and CIS countries.

Adding iodine to salt is a standard and inexpensive way to ensure that populations get adequate amounts. However, since the break-up of the Soviet Union, iodization and distribution of salt has broken down in the CIS subregion. A 1997 UNICEF evaluation found that most CEE and CIS countries again report moderate or severe prevalence of iodine deficiency disorders, with 350 million to 400 million persons at risk in countries such as Bulgaria, Kazakhstan and Ukraine.³²

Folic acid is a potent and well established preventative agent for some of the most common and serious congenital anomalies, but there was little evidence in the Country Reports that folic supplements were an integral part of maternal care regimens. Maternal anaemia caused by an iron deficit, as Figure 1.6 shows, has risen across the region over the transition, and is especially prevalent in impoverished countries like Kyrgyzstan and Moldova. Many CEE and CIS countries also report rises in anaemia prevalence among children.³³

Vitamin A deficiency is usually a sign of poor nutrition; high infant mortality rates – such as survey data indicate for Caucasus and Central Asia – are a useful proxy for widespread malnutrition.³⁴ A small 2002 study by the Kazakh Academy of Nutrition suggests that, at least in poor and environmentally damaged areas of Central Asia, severe vitamin A deficiency is a concern.³⁵ Figure 1.7 plots the relationship between mortality and stunting rates (low height for age due to chronic malnutrition). It shows that poor nutrition affects a considerable share of young children in CIS

Figure 1.6 Percentage of women at full-term pregnancy with anaemia, 1989-2001



countries, putting them in the company of Asian countries known for widespread malnutrition.

Infectious diseases

Communicable diseases are a major cause of disability worldwide³⁶ and they are still problematic in parts of the CEE/CIS region. Significantly, the entire region is currently polio-free due to concerted efforts in the past 15 years to immunize children. For example, in Russia, 97 per cent of 1-year-olds were immunized against polio in 2002, up from 67 per cent in 1989. However, other infectious diseases that have disabling potential for children are still endemic in parts of the region, as Table 1.4 attests.

As congenital conditions, passed from mother to baby before or during birth, diseases such as rubella and hepatitis can have serious and lifelong consequences. Rubella can result in congenital rubella syndrome (CRS), which includes birth anomalies

such as blindness, deafness, mental retardation, heart disease and lung abnormalities. Measles is the leading cause of preventable blindness in low-income countries where Vitamin A deficiencies are present, a profile that some CIS countries fit. Box 1.4 details efforts in Kyrgyzstan to control measles and rubella epidemics.

Alcohol, tobacco and STIs

There is relatively little in the Country Reports about disability in children linked to 'lifestyle' practices. Alcohol and tobacco use – both implicated in foetal development, premature birth and various congenital anomalies – were widespread before the transition. But there is evidence that since transition, younger people have taken up these habits at an even greater rate than did their parents, especially smoking among girls and young women.³⁷

Alcohol is responsible for a wide range of perinatal

Figure 1.7 Stunting and under-5 mortality rates in CIS and Asian countries, late 1990s

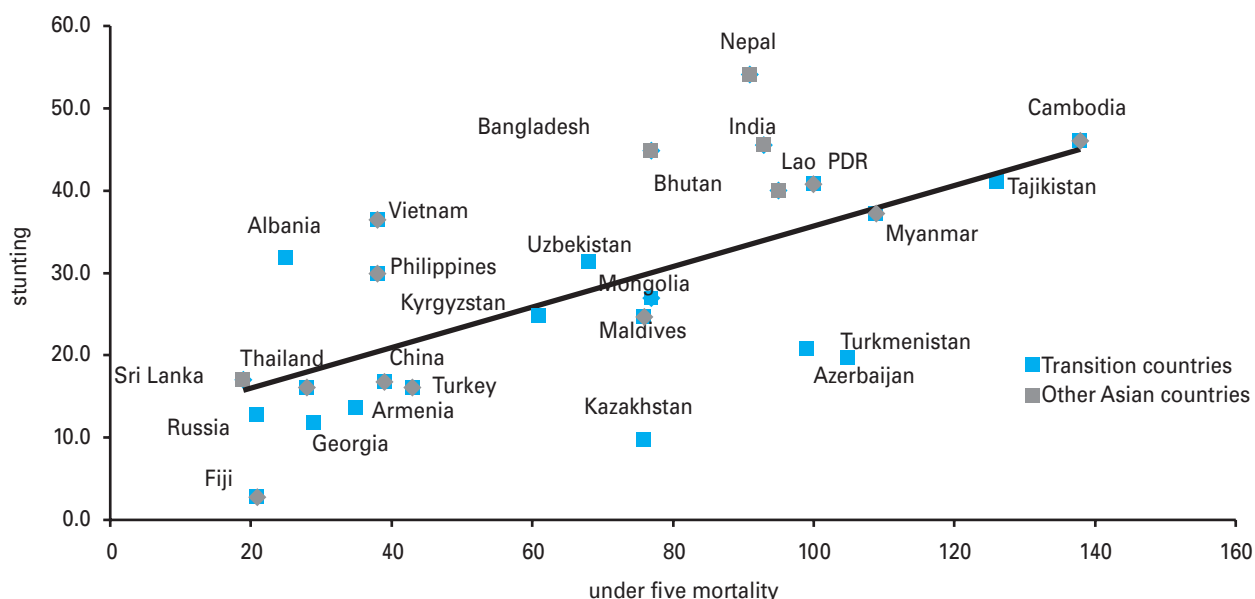


Table 1.4 Infectious disease incidence in CEE and CIS (number of new cases per 100,000 population)

	Measles incidence			Rubella incidence			Hepatitis incidence		
	1989-91	1994-96	2000-02	1989-91	1994-96	2000-02	1989-91	1994-96	2000-02
Czech Republic	10.5	0.1	0.1	46.5	17.7	15.6	30.3	22.8	17.1
Hungary	54.5	0.1	0.1	83.6	4.2	0.7	23.0	16.6	7.2
Poland	57.7	1.9	0.2	128.8	163.4	148.0	80.0	74.3	13.0
Slovakia	1.8	3.1	0.0	16.2	8.0	0.1	43.3	31.8	18.8
Slovenia	4.5	9.0	0.0	232.5	5.2	0.3	37.7	3.7	2.5
Estonia	10.5	6.1	0.2	93.9	59.4	18.1	81.5	44.3	69.4
Latvia	0.6	0.2	0.0	46.8	83.0	42.8	248.7	117.2	65.8
Lithuania	4.2	4.7	1.2	18.7	306.7	19.5	67.7	148.9	15.5
Bulgaria	8.9	3.9	0.2	132.5	327.4	126.8	219.9	94.7	94.1
Romania	14.9	13.7	0.1	63.1	201.1	32.1	298.3	120.9	106.6
Albania	1384.2	12.4	7.1	0.0	0.0	17.2	1130.9	137.8	44.5
Bosnia-Herzegovina	36.8	3.8	0.1	15.6	0.3	0.9	79.1	2.4	2.9
Croatia	9.6	6.9	0.2	61.8	11.7	0.2	37.5	16.7	17.9
FYR Macedonia	36.0	25.2	1.0	61.8	41.5	2.9	131.3	90.9	47.2
Serbia and Montenegro	50.8	5.6	0.6	262.7	226.4	11.1	60.6	64.8	25.3
Belarus	5.6	8.9	0.3	132.5	339.2	94.6	344.6	65.4	94.8
Moldova	42.9	42.0	55.2	100.6	69.5	112.7	277.6	254.6	164.0
Russia	14.5	9.8	1.7	163.2	184.9	317.9	203.5	147.6	158.1
Ukraine	10.7	13.3	17.5	100.0	112.1	194.3	270.4	314.4	94.4
Armenia	17.0	20.9	1.3	23.3	41.0	83.9	190.7	83.2	35.4
Azerbaijan	41.1	30.9	8.7	8.7	3.5	7.6	250.7	618.5	25.2
Georgia	5.3	5.0	2.2	16.3	8.9	8.7	212.7	125.8	96.5
Kazakhstan	7.2	4.6	0.8	155.5	56.6	167.8	445.2	313.8	138.1
Kyrgyzstan	11.3	1.9	0.2	50.4	17.4	18.5	611.0	398.7	266.3
Tajikistan	93.7	3.7	5.3	20.2	7.1	4.2	736.7	260.9	141.4
Turkmenistan	46.9	23.2	0.9	6.0	6.4	1.3	458.8	259.0	161.4
Uzbekistan	6.1	2.5	0.2	3.5	9.0	3.3	223.2	499.6	174.8

Notes: Average of annual rates. Albania and Serbia-Montenegro data refer to 2000-2001.

Source: TransMONEE Database, UNICEF IRC.

health problems. Alcohol is one of the most common causes of foetal damage and preventable mental retardation. It is implicated in major heart defects, cleft lip and cleft palate, hearing and vision impairments and, most dramatically, in foetal alcohol syndrome (FAS). FAS causes physical and mental disorders, growth retardation, and central nervous system problems. Individuals with FAS can have problems with learning, memory, attention span, problem-solving, speech and hearing as well as social behaviour.³⁸ Given the widespread and elevated use of alcohol in much of the region, the use of alcohol during pregnancy is an important area for public awareness and care regimens.

New lifestyle risks have also emerged, particularly

the use of illicit drugs, including intravenous drug use, and the re-emergence of syphilis and the introduction of HIV/AIDS, especially in Western CIS. The registration of new cases of syphilis in adults has risen in Russia alone by 26 times between 1990 and 2001, from 7,910 to 207,157 cases. Pregnant women are routinely tested and treated if they receive routine antenatal care, but antibiotics are not always available or may be out of date. Congenital syphilis can lead to stillbirth, perinatal mortality and effects ranging from blindness to failure to thrive.

Since transition began, the incidence of registered HIV cases has climbed sharply in parts of the region, with some Baltic and CIS countries recording among the steepest rate increases in the world. HIV/AIDS is

Box 1.4 Efforts to control rubella and measles in Kyrgyzstan

In Kyrgyzstan, a Central Asian country of 10 million people, measles has been cresting every three or four years, with national health authorities registering several thousand cases in a year. About 2,000 rubella infections are registered every year. In keeping with the WHO *Health for All in the 21st Century* strategy and the European Region Strategic Plan for Integrated Measles Elimination and Congenital Rubella Syndrome Prevention, the Kyrgyz Republic developed a Measles Elimination and CRS Prevention Plan for 2000-2007. The main focus is to eradicate measles and rubella through mass immunization and incorporation of an effective system of epidemiological control into national health-care practices.

The Kyrgyz plan focuses on the following strategies:

- attaining and maintaining a very high (more than 98 per cent) first-dose measles vaccination coverage level in all administrative units;
- guaranteeing a high (not less than 95 per cent) second-dose measles vaccination coverage level in all administrative units;
- ensuring protection for reproductive-age women by achieving a high level of one-dose rubella vaccination coverage; and
- organizing and launching an effective epidemiological control system involving a thorough investigation of each particular case and its laboratory confirmation.

In 2001, backed by international donors, Kyrgyzstan successfully implemented a national immunization campaign against measles and rubella, providing vaccine to 1.8 million people, most in the 7 to 25 age group. As a result, the number of measles cases fell drastically in 2002, but rubella is still being reported, particularly in the 3 to 6 age group.

Source: Kyrgyzstan Country Report, 2002

a global emergency and a priority for action worldwide; however, this report touches upon only the aspects linked to disability in children. Mother-to-child transmission of HIV can occur at birth, or sometimes be passed through breast milk. The progress of congenital HIV infection into AIDS tends to happen much more quickly in children than in adults. It also manifests differently in some ways, notably retarded growth and development, as well as signs of damage to the central nervous system.

Babies born to HIV-positive mothers are assumed to be HIV-positive because the most available tests cannot detect antibodies to the virus until the child is at least 18 months old. In countries where infant homes and institutionalization of children remain strong practices, it is not uncommon for parents (especially if the mother is an injecting drug user or sex trade worker) to surrender or abandon a child who is believed to be HIV-positive to such facilities, with the attendant adverse impacts on their development. HIV-positive children are typically classified as 'disabled' in order for their families to collect benefits.

A special boarding kindergarten for HIV-positive children was established in Kaliningrad in 1999 – the only one of its kind in Russia. It was a response to the growing numbers of HIV-positive who are children given up or abandoned, typically by mothers who were working in the sex trade or using injecting drugs.

Maternal health in Moldova

Interviews conducted with disability specialists in Moldova from 1991 to 1996 – part of a major statistical survey on families raising children with disabilities – identified the following risks of giving birth to a child with 'chronic pathologies' (in order of importance): alcohol consumption; the mother's health and age; infectious diseases; complications during pregnancy and at delivery; counter-indications to conception or delivery; hard labour conditions; a period of less than two years between deliveries; contact with harmful chemicals; work with tobacco. The survey found that about 4 in 10 children with disabilities were born prematurely (compared to 1 in 10 healthy children). More than one third of the mothers said they had chronic diseases, and every fourth mother with a child with disabilities had been advised to terminate her pregnancy.

– Moldova Country Report, 2002

1.5 Institutions and Special Schools for Children with disabilities

"Four decades of work to improve the living conditions of children with disabilities has taught us one major lesson: There is no such thing as a good institution."

Children in Russia's Institutions,
Gunnar Dybwad, UNICEF, 1999

Overall residential care rates for infants and children are still higher in CEE and CIS – especially among its high- and middle-income countries – than in most developing or industrialized countries. At the end of the 1990s, 900,000 children, almost one per cent of all children, were reported to be living in residential care in the 27 countries. Other forms of out-of-home care – adoption, international adoption, guardian and foster care – are also considerable across the region, currently accounting for as much as two thirds of new placements of children.

Legacy systems

The large, centralized state institution is a hallmark of the Soviet and communist past. Independent associations or community-based services were very weak. Children with disabilities were placed in a wide range of residential institutions – from infant homes to boarding schools, hospitals and orphanages.

Institutions typically hold over 100 children (some have more than 300 places), making individual and community-linked care impossible. The primary challenge in the region is for countries and communities to shake off this past and forge ahead on keeping children with disabilities in their families and home communities.

As many as 500,000 children with disabilities may have been in institutions in CEE and CIS countries in 1990.³⁹ In Russia alone, 255,000 children lived in children's homes and boarding schools for the disabled in 1990, and many more younger children with disabilities were living in infant homes. Putting children with disabilities in institutions was common in other countries as well – Belarus, Moldova, Bulgaria, Romania, Lithuania, the Czech Republic, and Hungary. Institutionalization was less common in countries of the former Yugoslavia, Caucasus and Central Asia. One reason for the difference is that, in the latter countries, the tradition of strong family networks in more rural societies made public care less widely used.

Research has shown that living in institutions is

deleterious to children's happiness, their development and their futures. It has negative impacts on children in terms of emotional and psychological disturbances (such as attachment issues, aggressive or passive behaviour); developmental delays and learning disabilities (such as hyperactivity, language and cognitive disorders); and may jeopardise their physical health (such as exposure to Hepatitis B and D).⁴⁰ However, institutions for children are ubiquitous around the world.

Rates of institutionalization

As Table 1.5 shows, the rate of children registered with disabilities has risen steadily in the 11 countries presented – from less than 0.5 per cent to about 1.5 per cent. This represents a threefold rise on average over a 12-year period. As noted, these figures are from social security registers. Considering that at the beginning of the period many countries had fewer children with disabilities living with their parents than in institutions (and the latter were normally excluded from registers for pensions and other cash benefits), the question arises as to whether these increases simply represent a

Box 1.5 Giving up: Why families surrender children with disabilities to institutions

The Country Reports reveal that the overriding reason why families surrender their children with disabilities to institutions is a lack of care-giving capacity. This can be a result of social values and individual beliefs, knowledge and training, or a gap in material and economic support. Understanding these gaps can help to identify intervention points aimed at keeping children with disabilities at home, in their families and communities.

For example, in Georgia, where almost one third of children with disabilities are institutionalized, parents cite these reasons: social attitudes that shame the family that has a child with disabilities; lack of skills to provide appropriate nursing care; financial difficulties; and the belief there is very little chance a child with disabilities can be integrated into society.

In Kyrgyzstan, residential homes for children with disabilities primarily admit those whose parents either have many children, or are single parents, pensioners or disabled themselves. Croatia reports that children in special institutions tend to be severely disabled or come from a community where there is no appropriate education and care available, and for whom no foster family near appropriate facilities could be found. Tajikistan reports that many parents who place their children in a residential school feel they don't have the time or resources to help their child with disabilities with their studies and believe they will be taught better in residential schools; others count on public institutions to provide their children with food and clothing. According to a study conducted by NGOs in Tajikistan, 62 per cent of parents whose children are in institutions agreed that, as soon as the family's financial situation improves, they will take the child home.

The Czech Republic, like Georgia, cites a number of reasons why parents institutionalize their children with disabilities:

- a lack of information on the prospects for the child's development and on available social support mechanisms;
- the inability of parents to carry out rehabilitation measures, special education methods, social adaptation strategies, and the inculcation of necessary everyday habits for their children;
- the impossibility of guaranteeing the hours of care that a child with disabilities requires (e.g., lack of non-working family members, no access to day-care facilities, or sources of economic support);
- a lack of money (total child pension and child-care allowance equals only one third of the survival minimum per person);
- a disinclination by some parents (especially single parents, who make up a large share of families raising children with disabilities) to limit other personal and family affairs in order to care fully for a child with disabilities.

On the other hand, Turkmenistan reports that a sample survey, done in 2000 with the cooperation of UNICEF, asked the question "Would you like to hand your disabled child over to a specialized children's institution?" Only one rural family, mentioning the complete absence of conditions needed to care for a child with disabilities at home, agreed. The other families were categorically against institutionalization, citing moral and ethical considerations, as well as saying it would be too painful to part with the children; they would be unable to visit them often; and they were not certain it would be better for the children.

Sources: Country Reports, 2002

Table 1.5 Number of children with disabilities in public institutional care in 24 countries

	Number of children				Rates per 10,000 of relevant population			
	1990	1995	2000	2002	1990	1995	2000	2002
Czech Republic	11395	12045	12783	12806	30.6	33.4	40.4	42.3
Hungary	3128	2896	1840	2183	10.9	10.8	7.8	9.6
Poland	32575	33100	31776	33996	18.6	19.2	19.0	21.0
Slovakia	4190	4423	3533	3663	19.7	21.0	18.1	19.7
Slovenia	1796	1404	1207	1294	23.4	19.6	18.3	20.3
Estonia	634	389	1045	1151	14.5	10.2	31.3	36.1
Latvia	397	723	805	768	6.7	12.6	15.6	16.0
Lithuania	9750	5068	5481	4754	80.0	44.5	52.3	47.1
Bulgaria	15493	12484	13292	14032 ¹	67.0	61.5	76.0	82.2 ¹
Romania	6919	7809	1204	902	10.4	13.2	2.4	1.8
Croatia	3348	3047 ²	5154	3266	19.3	18.42	34.9	22.2
FYR Macedonia	1132	853	649	592	19.0	14.7	11.9	11.0
Serbia and Montenegro	11127	9774	9453	-	38.3	35.6	36.7	-
Belarus	18849	14454	13880	12934	67.7	54.6	59.5	59.6
Moldova	11381	5253	4788	4770	102.6	47.0	53.9	57.8
Russia	255484	201030	183976	174432	63.6	52.5	63.3	65.2
Ukraine	33000 ³	26100	17300	15400 ¹	28.3 ³	23.7	18.8	17.61
Armenia	185	336	384	436	1.5	2.7	3.5	4.5
Azerbaijan	3326	1878	2979	3219	21.0	10.8	15.1	16.3
Georgia	1897	1128	1697	2115	12.0	8.7	14.5	18.7
Kazakhstan	-	2824	2721	2927	-	5.0	5.5	6.1
Kyrgyzstan	7187	3389	3536	2993	37.4	17.5	17.6	15.1
Tajikistan	3782	1339	1337	1687	14.8	4.8	4.6	5.8
Uzbekistan	13918	11306	15208	16245	14.3	10.5	13.8	15.0
Total	450893	363052	336028	316565	28.6	23.0	26.5	25.5

¹ 2001² 1996³ 1992*Sources:* TransMONEE Database, Country Reports, UNICEF IRC.*Notes:* Children with disabilities in public institutional care refers to children in institutions for the physically/mentally disabled.

The type of institution varies by country, as follows:

Lithuania, Albania, Belarus, Moldova, Ukraine, Armenia and Georgia: include children in boarding schools for the disabled.

Hungary: schools for mentally disabled.

Bulgaria: included 3,019 children in homes for the disabled for 2002, according to the definition of children in institutions in the Law for Child Protection.

As age range is not identical in different countries and in different institutional care forms, all rates should be seen as estimates, including the averages for the 24 countries.

shift from institutional care back to family care.

As Table 1.5 shows, the absolute numbers of children with disabilities placed in institutions fell slightly over the transition period, but this is mainly due to demographic change – i.e., the absolute numbers of children in the region have declined significantly during the transition, from 120 million to 102 million, as noted earlier. The bottom line is that institutional placement of children with disabilities,

as a share of the population aged 0 to 17 years, has remained quite stable over the transition, at about 0.2 to 0.5 per cent of all children. Overall, countries in the region are putting children with disabilities in institutions at roughly the same rate they did before transition began.

That does not mean, however, that little has changed. Given the threefold increase in the reported prevalence of children with disabilities over the

Box 1.6 The 'special needs' of schools for children with disabilities in Turkmenistan

In Turkmenistan, there are 14 residential schools for pupils with disabilities: three are for children with diminished hearing or who have not been deaf from birth; one is for blind and weak-sighted children; and 10 are for mentally and physically disabled children. All are run by the government. In October 2002, interviews were conducted with the heads of these institutions in order to identify the problems of supporting and educating children with disabilities. Most special schools grow vegetables and fruits and ask for support from parents, NGOs, and business to supplement their financing. Schools devote a lot of attention to sport: the fact that disabled seventh grader Babajan Rozybaev won the gold medal in 400-metre track race in Almaty, Kazakhstan, was mentioned with pride. The school principals interviewed noted the following problems.

Poor physical condition of buildings and lack of facilities

The *internat* (boarding school) for children with diminished hearing in Ashkhabad, the capital city, needs financing to renovate its plumbing and sewer systems. Other institutions have also made urgent requests to fix sewer systems and create new bathing and laundry facilities. The need for kitchen equipment and transportation, e.g., a new microbus, was also noted.

Crowded dormitories, shortage of beds and linen

At Residential School No. 5, which cares for deaf children from all parts of the country, the 250-bed dormitory constantly needs additional beds, mattresses, blankets, pillows and bed linen. In Residential School No. 2, 140 children live in a dormitory intended for 100. Residential School No. 4, which produces its own food, has a 160-bed dormitory in which 220 children live. (Both schools are for intellectually challenged children.) Shortage of bed linens was mentioned by almost all headmasters interviewed.

Short supply of medicine, special aids and equipment

Several institutions noted lack of medicines, special AIDS such as wheelchairs or hearing AIDS, special beds, dishes, chairs, and tables for children with limb problems. Several schools noted the need for footwear, clothing, warm clothing, sports clothes, hand tools and school supplies; some also wanted a television and a music centre (tape player, phonograph and speakers), and others noted the lack of sewing and cabinet-making supplies.

Lack of trained special teachers

In Soviet times, Turkmen *surdopedagogs*, teachers of the deaf and hearing impaired, were trained in other Soviet republics where such facilities existed. Now, since the Ministry of Education does not have the economic means to send teachers for training in what are now other countries, assistance is needed from international organizations.

Lack of proper referral and 'gatekeeping' mechanisms

While these issues were not addressed by schoolmasters as such there is some evidence that residential schools recruit new inmates through announcements in newspapers.

Lack of contact with parents

Most children, but not all, sleep in the residential schools. For example, one child out of five in the auxiliary residential school for the mentally retarded in the city of Turkmenbashi go home after supper at 7:00 p.m. and come back the next morning at 8:00 a.m. While some schools claim that resident children go home on weekends and parents stay in touch by mail, others say there is practically no contact between the children and their parents. Parents are largely blamed for this lack of family contact: Schoolmasters say many parents are drug addicts, alcoholics or mentally retarded. (However, there may be very different cases, e.g., the headmaster from Auxiliary Residential School No. 1 in the city of Mary says the school is in regular contact with the children's families and holds courses in psychology and defectology for parents.)

Gaps in family support services

Even though few schoolmasters note this directly, it appears from their comments that while their children are at school the parents are relieved from care duty, but no other types of family support exist, e.g., the availability of respite care for short periods, the assignment of a social worker to each case. The role of the institutions is seen to be to feed and educate the children and provide them with some medical services. There is little evidence, however, of individualized and goal-oriented care.

Source: Turkmenistan Country Report, 2002

transition period, the evidence that institutionalization is relatively stable is significant. More children with disabilities are staying in their families and communities, but that does not mean they are getting the support to which they have a right and access to participation in those communities.

Box 1.6 highlights the difficulties observed in services for pupils with disabilities in Central Asian Turkmenistan.

As past IRC Regional Monitoring Reports have concluded, infant homes have had a major role in keeping institutionalization rates for all children high in the former communist countries. In Bulgaria, for example, where no fewer than 1 in 100 children in this age group were placed in infant homes at the end of the 1990s, a 2001 UNICEF study⁴¹ found that the share of these children with health and development problems increases the longer they are in the infant home. While other factors may be at work

here, it is also certain that poor living conditions in institutions are a key determinant.

Illness in institutions

Illness and contagious disease are common features in institutions. In Bulgaria, in 2001, there were more than 15,000 cases of disease registered in institutions, an average of five cases per child. Half were among children under one and respiratory diseases were most common. One in five children, more than 600 altogether, were sent to hospitals; 101 died, 88 from congenital anomalies.

Data from Moldova reveal that almost three quarters of children in institutions surveyed had chronic illnesses, and a vast majority had two or more conditions at the same time. Typically, a child received medical treatment only for acute conditions. Preventive medical examinations were held in as few as half of the institutions.

A cycle of discrimination is at work here:

Institutional placement at a very young age is particularly detrimental, while infants demonstrating signs of delayed development have a greater risk of being placed in and staying in institutional care (never reunited with parents, placed in foster care or accepted for adoption). The harmful consequences of child institutionalization and the beneficial impact of family-based care has been rigorously demonstrated, for example, in recent British research that followed up the health, cognitive and social development of young children adopted to the United Kingdom from Romania in the early 1990s.

The site visits and interviews of doctors carried out by the EACD for this report revealed that service providers in several countries still do not understand the importance of family upbringing. They are unversed in child development and, especially, the scientific evidence for 'attachment theory' – that children need a consistent, caring, nurturing emotional and physical bond with their primary caretaker for healthy development. For this reason – although individual institutions vary widely in terms of healthy caring – institutional care tends to exacerbate child disability. In addition, a lack of adequate life-skills further disables institutionalized children and limits their opportunities for independent living. As Larisa, a social worker from Latvia, said in an interview for this report: "[These] children don't even know how the tea gets sweet."

Most children with serious disabilities who do not live with their parents are placed in 'homes' for the mentally and physically disabled in the region. In addition, a significant number of school-aged children with disabilities are living in boarding schools. This is not the wish of the parents, but it results from a lack of access to special schools in their own communities. Rita, a mother from Latvia, says: "[Our son] has been staying [in an institution] for four years now, because we do not live close to the school and we cannot manage to go there every day and spend four hours commuting."

The Salamanca Statement

The 1994 World Conference on Special Needs Education (UNESCO) produced a statement and framework for action which argues that regular schools with an inclusive orientation are "the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system."

– UNESCO

Special education

Before the transition, most children with disabilities were provided education in special schools, often as part of a boarding arrangement. Special education was largely shaped by 'defectology', the Soviet discipline that classifies children by the main symptom of disability (e.g., hearing, vision or speech problems) and segregates them in special schools with a remedial curriculum (see Box 2.3). This approach may capture children with obvious and serious disabilities but does not really recognize or respond to the special needs of children with milder disabilities or more subtle learning disorders.

Although special kindergartens existed before the transition, most young children with disabilities were either placed in infant homes offering residential care or stayed with their families without receiving specialized early education and care services. Similarly, there were only a few programmes for children with physical and learning disabilities who were past compulsory school age. In most countries, less than 1 per cent of 15 to 17 year-olds received upper secondary education in special forms and these were typically in vocational education.

Overall, the growing rates of children officially recognized as having disability or special needs in the CEE/CIS region has increased pressure on education systems. Despite a drop in child populations across the region during the transition period, this growing recognition has opened up the doors to identifying not only the 2 per cent of the population generally recognized as 'disabled', but the other 8 per cent who have 'special needs' related to milder forms of impairments and learning disorders.

■ Special education enrolment

In 1989, 837,000 children across the region were receiving basic education in special schools for the mentally and physically disabled. In 2001, about 1 million children were enrolled in basic special education. This increase in absolute numbers must be viewed against a background of 2.2 million fewer children enrolled in overall basic education due to falling fertility rates. What it indicates is that a far greater share of children are being identified as having disabilities, even though the response is invariably that they end up in special schools rather than mainstream schools.

The reality is that the enrolment numbers for either year account for only a small part of the special education needs of children in the region. The 1989 and 2001 data mean respectively that 1.5 per cent and 2 per cent of all basic-school students were in special schools – roughly equivalent to global rates for serious disabilities. These low rates imply that children with learning disabilities and related disorders are not included.

Figure 1.8 shows changes in 23 CEE and CIS countries where information on pupils with ‘special needs’ – covering the broad range of disabilities and disorders – was made available to the Innocenti Research Centre. Belarus and Lithuania report that about 10 per cent of their basic-education students have special needs – a share that fits well with international benchmarks – while Estonia reports 15 per cent. The Czech Republic and Hungary report about 6 per cent, while most South European, Caucasian and Central Asian countries report around 1 per cent. Like much else, the variation across the region is considerable.

One way countries have been addressing the growing numbers of children identified as disabled has been to increase the number of facilities that offer special education. In the Czech Republic, integration is part of the education strategy – in part to allow special schools to focus more resources on children with serious disabilities – but the number of special and remedial schools has risen considerably since 1989.

“There should be schools with classes for deaf children in every region, so that a child can go home in the evening. Then there would not be a situation that a child does not see his parents for two weeks or more.”

Megija, teacher, Latvia

“I need more [love and affection]. I am in a boarding school. I see my parents rarely.”

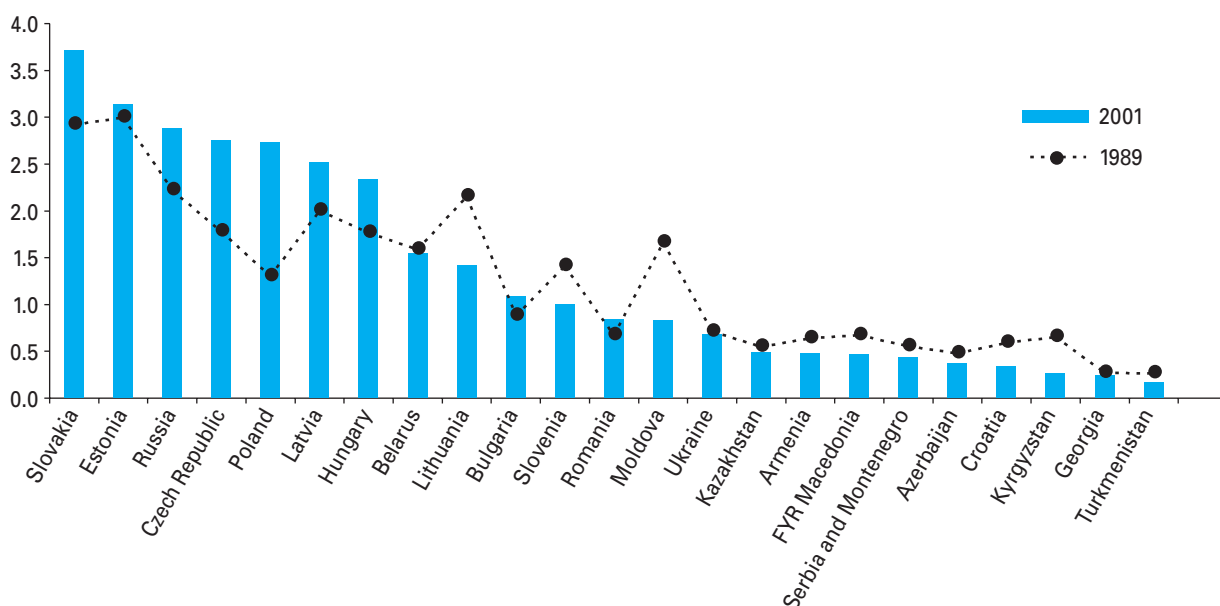
Eva, 12, living in an institution, Latvia

Such strategies may not necessarily lead to more children being deprived of a family upbringing, at least in affluent, smaller and densely populated countries, or in countries where the housing and labour markets are flexible enough to allow parents to move with their children. However, the negative implication for family care may be considerable in bigger countries where parents will have great difficulties taking children to school daily and problems just to visit them or take them home on weekends and holidays.

In this light, current efforts, such as in Russia, to create more special schools and build more boarding facilities to handle growing demand appear to be a costly and retrograde strategy. In Russia, more than 200,000 children (11 per cent of whom are orphans) live and study in 1,439 boarding schools or *internats*; 30,000 children (half of whom are orphans) with severe mental and physical difficulties are cared for in 151 boarding homes under the social protection system; and, finally, 20,000 young children, most abandoned, live in 249 infant homes belonging to the health care system. Even still, most institutions have long waiting lists, a demand pressure that pushes authorities to create more facilities.

The Kyrgyz Country Report puts it: “The number of children with special needs is presently growing, whereas the network of institutions, which educate and care for these children, is shrinking.” As Figure 1.8 shows, enrolment in special education programmes have dropped in several countries, including Ukraine, Moldova, Armenia, Azerbaijan, Kyrgyzstan, Turkmenistan and Tajikistan. In the last country, only 116 children with disabilities lived in boarding homes in 2001, half as many as 12 years earlier; in the same period, enrolment in special schools has fallen from 4,000 to 1,500 children. Partly, but not entirely, falling enrolment in special schools is linked to a shrinking capacity to provide food and shelter – boarding arrangements – as well as education and medical services.

Figure 1.8 Enrolment in basic special education programmes, 1989 and 2001
(rates per 100 of relevant population)



In some CEE and CIS countries, special school enrolment rates are inflated by the practice of placing children from all sorts of vulnerable families in these facilities. In Hungary, for example, many children from disadvantaged families who have neither physical nor learning disabilities end up in special schools that have a 'lighter' curriculum. Armenia reports that up to two fifths of its children in special education schools are not disabled, but from socially vulnerable families.

■ Special needs

The introduction of the concept of 'special needs' in the context of learning is also changing the picture in CEE and CIS countries. In Western countries, the pool of children with disabilities has been expanded to include those with 'special needs' – typically learning disorders like dyslexia and dyscalculia, and related disorders such as attention deficit hyperactivity disorder. In some parts of the region, these disorders were included among the 'mentally disabled' before transition, but most of these conditions were neither diagnosed nor given attention. For example, in Albania, where 900 pupils attended special schools in 1995, a study carried out by the Ministry of Education identified 12,000 school-age children with special needs; more than 90 per cent of them had no access to any kind of special needs education.⁴² (It should be noted that the concept of pupils with 'special needs' is quite different than the Soviet concept of 'special schools' for children with disabilities.)

There is only a partial overlap between students registered as having special needs and those registered as disabled: Many children with disabilities do not need special schools or special education, while special needs pupils are often not considered disabled. Across CEE countries from Croatia to Latvia, governments consider a child with chronic disease to be a 'child with special needs' but not disabled.

Sometimes countries define the term 'special needs' very broadly, a development related to transition.⁴³ One reason for this appears to be the strong medical connotation of the term 'disability'. Similarly, 'disability' is seen as serious in nature, whereas 'special needs' is more modest; another reason for this broadened definition is the social stigma still attached to disability status. In some instances, the term 'special needs pupils' has become a euphemism for at-risk children and those with disadvantaged backgrounds. This practice underlines that once segregation occurs on the basis of any disadvantage, there is a risk that disadvantaged persons of all types will be treated through segregated systems.

■ Integrated education

Starting in the early 1990s, the policy goal of keeping children with disabilities in their families and communities and to integrate the education of children with disabilities into mainstream education has taken hold in many countries. But the evidence on integration is complex. Overall, most CEE and CIS countries have made only limited progress in the integration of children with disabilities into main-

stream school or have seen increased enrolment in special needs programmes in addition to existing special schools programmes.

Educated debate

The education debate is still very active. There are arguments that integration of children with disabilities into mainstream classrooms can be a drawback for some students, both disabled and non-disabled. That may be a question of adequate resources – a persistent and important issue. There is a case in the CEE/CIS region for linking special education schools with local mainstream schools to help to break down the tradition of segregation. In some Western countries, there is a trend to co-locate special schools on the same site as mainstream schools in the belief it provides the 'best of both worlds'.

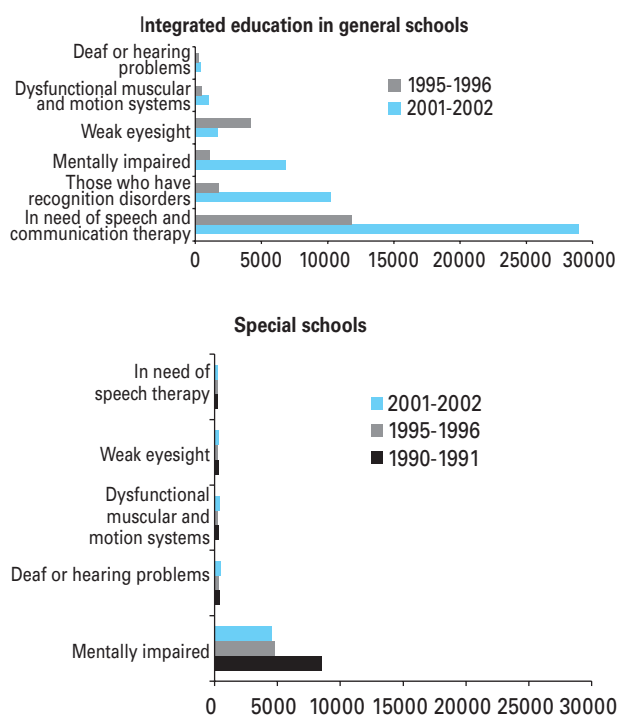
Serious efforts towards integration are being made in some countries, notably Bulgaria, Hungary, Romania and Macedonia. Where integration has occurred, it is largely accomplished by being at the same location as and/or mixing with mainstream students, rather than integrated or inclusive classrooms. Curricular integration, where children with disabilities learn together in the same classrooms with the general student population, is still seldom seen in the region – and where it is, it is often unplanned and, therefore, unsupported.

In Albania in 1996, as the Country Report notes, for the first time "the integration of pupils with disability in regular school" became a declared policy goal – although the details of how to do this were not specified. A recent survey by the Albanian Disability Rights Foundation found that the integration of children with disabilities was quite limited and done largely in response to pressure from parents of children with moderate disabilities. In Hungary, where the special school system was retained, enrolment of children with disabilities in mainstream schools started spontaneously in the mid-1990s. However, schools "did not have the technical, pedagogical and conceptual conditions necessary for the integrated education" of children with disabilities.⁴⁴

The resistance of attitudes against the integration of children with disabilities in mainstream schools cannot be underestimated. In echoes of the 'charity' treatment of children with disabilities, parents and others may support integration only conditionally, e.g., the proviso that including children with disabilities in a regular classroom does not detract resources from non-disabled students. Additionally, there is substantial passive resistance incumbent in existing education systems and other social services.

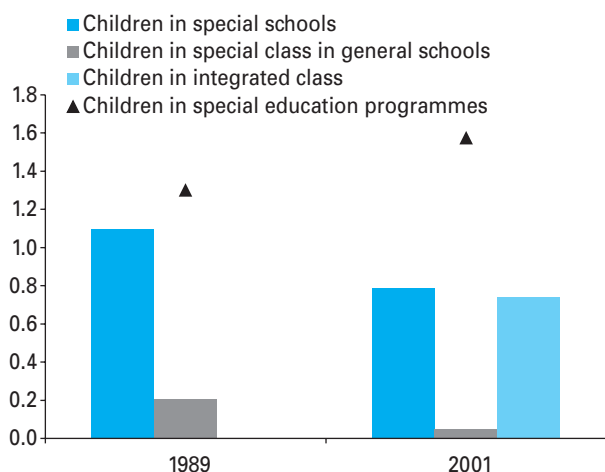
Figure 1.9 illustrates, with the case of Lithuania, a scenario that seems to be present in many other countries as well. As the graph on the left shows, enrolment in special needs education programmes offered in mainstream schools was considerable in Lithuania by 1995 and has progressed further but more slowly since. In the early transition, many children were redirected from special schools to special

Figure 1.9 Number of children with disabilities in special schools and in integrated education in Lithuania



needs programmes in mainstream schools. Since there are far more regular schools, this also meant that these children could stay in their families and communities. However, as the graph on the right shows, since the mid-1990s this process has slowed down, leaving a considerable number of children – about half of the numbers in the early 1990s (11 per cent of all special needs students and one per cent of all Lithuanian pupils) – in special schools. A similar ‘hard core’ of disabled and special needs pupils remaining in segregated education is also evident in many other CEE and CIS countries. In Poland (Figures 1.10 and 1.11) and Russia, for example, the growth of integrated programmes (mainly special classes in regular schools) has reduced, but not eliminated, enrolment in special schools.

Figure 1.10 Basic special education in Poland (per cent of relevant population)



Policy, law and practice have been linked in Lithuania to make strong progress for special needs education. The 1991 Law on Education recognized the right of children with special needs to be educated in schools closest to home. School committees started using more restrictive criteria for accepting children into special schools – a crucial gatekeeping function. Amendments in 1998 gave precise definitions of the role of pedagogical-psychological services in assessing special education needs, and gave parents and children the right to choose the form and place of education. The law stresses integrated education and the right of persons, even those with complex or severe disabilities, to be educated.

– Lithuania Country Report, 2002

Staffing issues

The lack of teachers who are adequately trained to work with children with learning disabilities, behavioural problems and milder intellectual disabilities (a substantial population largely overlooked before the transition) is an issue for all CEE and CIS countries. However, staffing resources affect even countries that have increased the overall size of their special needs programmes. The Lithuania Country Report notes that “pedagogues in general schools lack knowledge and skills necessary for educating of children with special needs who learn in the same class with their peers.”⁴⁵ This despite the fact that the number of special staff working with children with disabilities in general schools rose by 58 per cent between 1996 and 2002.⁴⁶ However, these integration specialists are still fewer in number than teachers employed in special schools.

Staffing is also an issue for special schools. In Hungary, for example, institutes of special education, especially in rural areas, cannot attract enough staff, due primarily to low wages, low morale and difficult working conditions.

■ Excluded from education

Many children with disabilities, especially those considered disabled from birth and those with intellectual disabilities, are still at risk of being excluded even from special education. In Kazakhstan, the majority of children with severe mental retardation, multiple handicaps, and severe motor problems are not covered by the special school system; their rights to education are simply unrecognized and unmet. In Azerbaijan, only 5,000 children – one quarter of children aged 7 to 17 who are registered as ‘disabled’ by national health authorities – attend specialized education. In Kyrgyzstan, the known number of disabled school-age children who do not attend any school grew from 1,500 in 1997 to 2,300 in 2002. In Tajikistan, only 25 per cent of children with disabilities aged 7 to 15 attend school. Even in the Czech Republic, children with disabilities can still be given “exemption from compulsory school attendance.”

Some of the children who do not attend schools may receive education at home. In Georgia, for

example, the law on education stipulates that children with physical disability who live in families should receive home education from visiting school teachers in the community. In reality, due to lack of funds, schools cannot provide this service: the Ministry of Education registered scarcely any cases where this service was accessed. Azerbaijan runs two 'mobile schools' where teachers come to the homes of children with disabilities. In some countries, like Hungary, home teaching for the disabled remains 'under development'.

Children with disabilities often drop out of school or complete basic education over a long time frame. In Estonia, for example, where school completion rates for students with disability are stable at around 90 per cent, the 2000 Population Census found that the majority of children with disabilities have only primary education; just one third have any form of secondary education. In Hungary, the 1990 Population Census found that among people with disabilities aged 7 and older, the share who have not completed any school grade was 11 per cent – several times higher than in the total population.

■ Early childhood programmes

The critical importance of early childhood care and education is increasingly understood and embraced in international circles. This development approach is perhaps even more important for children with disabilities.

One strategy that some CEE and CIS countries are using to reduce the 'stock' and 'flow' of students in special schools is to improve access to special preschool programmes. Some students may be redirected from special schools and others diverted before they ever enter. This approach appears to be used more in countries that already have high overall rates of preschool attendance. In the Czech Republic, for example, where kindergarten enrolment is over 80 per cent, the number of special kindergartens has increased from 177 to 235 between 1990 and 2000, providing service to 2 per cent of all children in preschools.

Many other countries post much lower shares of children with disabilities participating in preschool education. In Hungary, 0.4 per cent of children attending kindergartens were in special programmes (although that is double the share in 1990). In Croatia, special groups for children with disabilities covered only 0.5 per cent of preschool pupils in 2001.⁴⁷

■ Secondary education

In wealthier countries with clear commitments to special school enrolment, there have been increases in the number of school units and students at the secondary level. These include enrolment in special schools, vocational and technical institutions. In the Czech Republic, for example, new schools have opened for children with disabilities to continue their studies at upper secondary levels: In 1990, only eight secondary technical schools existed for children with

disabilities; a decade later, there were 133. During the same period the number of vocational schools increased from 90 to 167. The rise of new, predominantly non-state schools in basic and secondary special education has opened up opportunities for Czech students with disabilities: In 1990 15,100 pupils attended upper-secondary special-education programmes; in 2000 19,000 pupils attended (3.6 per cent of all young people aged 14 to 17).

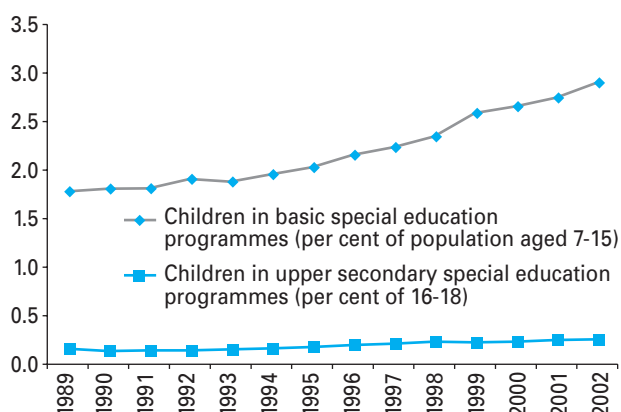
In Russia, as Figure 1.11 shows, the rate of students in special education at grades 9 to 11 has seen a tenuous increase, though it remains low compared to basic education figures or rates seen in the Czech Republic. In poorer countries, however, educational opportunities for children with disabilities have diminished during the 1990s (see Figure 1.10). In Tajikistan, disabled students can enter secondary specialized schools and higher educational institutions without taking entry exams and without competing with other applicants. The numbers, however, are very small: In 1999/2000, only 57 disabled students studied in secondary educational institutions, and in 2001/2002 just 15. In the same year, only nine young people with disabilities studied in higher education institutions.

■ Higher education

The Ukraine Country Report highlights some of the obstacles to tertiary education faced by children with disabilities, including fees for preparatory education and a lack of prep programmes suitable for students with disabilities. Ukraine nevertheless reports a positive trend in the number of students with disabilities enrolled in higher education. The number of students with disabilities attending tertiary institutions at accreditation levels 1 and 2 more than doubled between 1994 and 2001, to a total of 3,500 individuals; the number at accreditation levels 3 and 4 almost tripled, totalling 2,500 individuals. However, their share of relevant student populations remains very small – 0.6 per cent of the student body at tertiary levels 1 and 2, and just 0.2 per cent at tertiary levels 3 and 4.

Once children are past the age of compulsory school attendance, administrative statistics tend to lose track of them. Population census data, however,

Figure 1.11 Special education enrolment by grades in Russia, 1989-2002



er, may offer some insights into how children with disabilities do when it comes to access to higher education and/or employment.

Table 1.6 presents data from Estonia to illustrate that most young people with disabilities have great difficulties in entering universities or finding a job.

“Children, especially orphans, have no life experience. They are fully dependent and cannot live alone. Those who leave us at age 18 to 20 call us and ask how to turn on a gas cooker. They are unable to manage their money.... We cannot teach them all those things.... This is the entire system, the approach to them.”

Aida, institution caregiver, Russia

“I wish we could also offer vocational training for children, so that they could get at least some specialization, which would be useful for their future. They should also be taught the most basic things – how to go shopping, how to go to the health centre – because many do not know this.”

Larisa, social worker, Latvia

“We have to use outdated equipment, so when children start working in factories and plants, they find themselves surrounded by new machines in an unfamiliar working environment. And being disabled, they already are at the bottom of the list of candidates.”

Yulia, institution caregiver, Russia

“We cannot be those who do physical work. We need to be intellectuals.”

Luda (female), 17, institution resident, Russia

“They are not ready for an adult, independent life and many become alcoholics. They do not have something to call home... so many go nowhere. What they need is a family. And this family is not this institution....”

Petr, doctor, Russia

1.6 Poverty and raising children with disabilities in families

Links between disability and poverty are well established in both developing and developed countries.⁴⁸ However, there is a dearth of evidence on how families with a child with disabilities are affected by poverty and how different types of families – the extended family, nuclear family and the single-parent family – actually manage children with disabilities or chronic disease. It must also be remembered that children with disabilities are a diverse group with wide-ranging needs and, as importantly, that these needs change, sometimes considerably, throughout the life cycle, as do available supports.

The Estonian Population Census data quoted in Figure 1.1 shows that even when using a narrow definition of disability, no more than one out of four children with disabilities are “in need of daily personal assistance.” Once a wider concept of disability is used (i.e., children with learning disabilities and behavioural problems are also included) the share of children in need of permanent personal assistance can shrink to just one out of 15 or 20 children. Still, it is clear that raising a child with disabilities tends to create economic pressures on families, reduce parental earning capacity and contribute to family break-up. These factors can contribute to decisions to place a child in an institution. Box 1.7 reviews international evidence on the poverty risk among families with a child with disabilities.

As noted earlier, under-reporting of perinatal mortality and the presence of disabilities happens frequently in CEE and CIS, especially in the poorer countries. It can be assumed that infants with congenital anomalies born to better-off families – and presumably better prenatal health and health care conditions – both have a better chance that they will survive the period around birth and that any impairment will be identified.⁴⁹ On the other hand, high mortality and low recognition rates may reduce the number of children with disabilities identified as living in poor families through household surveys. (Alternatively, it can be argued that the greater inci-

Table 1.6 Education enrolment and labour force status, Estonia, 2000
(per cent)

Ages	In education	Labour force status			
		Employed	Unemployed	Inactive	Unknown
of total persons at corresponding age					
15-19	83.3	7.2	4.2	4.7	0.6
20-24	21.0	51.1	12.3	14.9	0.7
of persons with disabilities at corresponding age					
15-19	67.8	4.3	2.5	25.4	-
20-24	15.2	24.3	7.2	53.3	-

Source: 2000 Population Census, <http://www.stat.ee/>

Box 1.7 Poverty risk among families raising a child with disabilities

Evidence of the links between poverty and disability is relatively thin. Until recently, few household surveys captured disability of family members properly, and many people with disabilities still remain hidden from statistics. As a result, many of the studies that have been done are based on anecdotal evidence, a limited amount of hard data, and many of the links still need to be explored. More research and data collection has been done in developed countries than in developing countries, partly because of their more developed statistical and research capacities. From the evidence available, the following patterns emerge:

Increased family expenditure

Raising a child with disabilities increases family expenditure while it tends to reduce opportunity to earn income. Because of the lower incomes and higher costs of raising children with disabilities, it is not surprising to find a higher percent of families who have children with disabilities among the poor. According to a Canadian study, for example, 29 per cent of children with disabilities live in the lowest or lower-middle income quintiles, compared to 17 per cent of non-disabled children.

Reduced employment opportunities

The most significant indirect cost associated with raising a child with disabilities is the reduced employment opportunities for parents. A US study found that 62 per cent of mothers with a child who had a mild or moderate disability did not have a paying job, and 79 per cent of those with a child with a severe condition were out of the workforce.* In Canada, of parents of children with disabilities, 39 per cent worked reduced hours and 46 per cent worked alternative schedules.

Direct costs

Direct costs may also be substantial: Children with disabilities or chronic conditions and diseases may need medication and/or special food and clothing and supplies; adjustments in housing, medical and rehabilitation services; aids preferably designed and adjusted to personal needs; accessible transportation, shelter, tutors, after-school and extracurricular services. A 2001 study in the UK, using data from a 1998 survey covering 300 families raising a child with disabilities, found that parents of children with disabilities spend almost twice as much on comparable items as parents of non-disabled children. This raises the issue of adequate supports for the family.

High hours of unpaid care

Parents spend a great deal of time managing the disabling aspects of their child's life, as well as the care that parents typically undertake. In Canada, research shows parents of children with disabilities spend 50 to 60 hours per week on tasks related to the disability – more than the equivalent of a full-time job. This underscores the fact that parents, particularly primary carers, need sources of care and support for themselves as well.

Workplace barriers

Parents may be unable to take some types of jobs and employers may be unwilling to hire a person who has a child with disabilities, especially women, typically the primary carers in the family. According to the Canadian study cited, 68 per cent of parents of children with disabilities do not work overtime, and 72 per cent passed up promotions because of its competing demands with the care of their child. This means that, in the absence of broader societal support such as more flexible working conditions, the parent who needs more income must pass it up and the employer who wants to benefit from a desirable employee lets the opportunity go.

Household stress

The extra expenditure currently needed to raise a child with disabilities tends to create a huge pressure on the family to increase income. According to one study in the United States, two-parent families with no disabled members had a somewhat lower average annual household income than two-parent families who have a child with disabilities. It is probable that a selection effect is also at work here, i.e., partners who manage to increase their earnings stay together. However, coping strategies, such as fathers or mothers taking additional jobs, may not be sustainable over the longer term. In any case, families with a child with disabilities tend to have a higher chance of becoming single-parent families, with the father typically leaving the home. In Canada, for example, 18 per cent of single-parent families include a child with disabilities; by comparison, 14 per cent of two-parent families have a child with disabilities.

Coping strategies

The extra expenditure needed for a child with disabilities may also crowd out other expenditures, and/or prompt strategies that expand the household economy, such as having generations live together. The 2001 UK study found parents striving to have enough to spend on their child with disabilities, reducing spending on themselves and cutting costs wherever they could.

There are also opportunity costs incurred in raising a child with disabilities, as future earnings may be foregone. There may be also a forced saving effect as parents try to increase savings in anticipation of a future where their child faces inadequate opportunity and social support.

The relationship between poverty and disability contributes to the vulnerability and exclusion of disabled persons and their families. The higher poverty risk of families may amplify the disabling effect of a child's basic impairment and impact on the family's ability to support opportunities for siblings. Therefore poverty, apart from being an outcome of raising children with disabilities, can be a determinant when it affects maternal and child health through malnutrition, higher risk of infectious disease and exposure to unsafe working and living conditions.

Sources:

* Meyers, Marcia M., Anna Lukemeyer, and Timothy M. Smeeding, 'The Cost of Caring: Childhood Disability and Poor Families', *Income Security Policy Series Paper No. 16*, July 1997.

Dobson, Barbara, Sue Middleton and Alan Beardsworth. *The Impact of Childhood Disability on Family Life*, YPS. Joseph Rowntree Foundation, York, UK, 2001.

LaPlante, Mitchell P., Dawn Carlson, H. Stephen Kaye and Julia E. Bradsher, *Families with Disabilities in the United States*, Disability Statistics Center, University of California, San Francisco, Report 8, September 1996.

Roeher Institute, *Count Us In! A Demographic Overview of Childhood Disability*, 2000.

dence of children with disabilities in large, and typically poorer, families may be connected to a scenario where better-off parents with plans for fewer children also have access to prenatal tests and, in most CEE and CIS countries, legal medical abortion.)

Considering the above, it is striking that household surveys in the region still mainly find children with disabilities at the lower end of family-income ranges across the region. In Moldova, one third of households that have a child with disabilities fall into the lowest-income quintile, while only 8 per cent were in the highest quintile (each quintile represents 20 per cent of all households).⁵⁰ In Romania, households that have children with disabilities have 65 per cent of the per capita income as those without.⁵¹ In Hungary, the income of households that have a child with disabilities is 79 per cent – and with a chronically ill child, 91 per cent – of the average of all households with children.⁵² In Estonia households with disabled members aged 0 to 24 years of age have incomes that are 84 per cent of those households with no disabled members.⁵³

Poverty rates

Statistics from the region show that families with children generally face a higher risk of poverty than families without children (with the exception of some of the poorest countries, where a very large part of the population lives in absolute poverty, e.g., below US\$2.15 at purchasing power parities, the region-wide poverty line established by the World Bank).⁵⁴ The generally disadvantaged position of families with children offers poor prospects for families with *disabled* children who – due to increased costs, lower employment opportunities and inadequate supports and services – have an even higher risk of poverty.

Data from Romania show that households with disabled children have poverty rates (25 per cent) more than double the average (12 per cent); the Armenia Country Report suggests that 60 per cent of children with disabilities live in extremely poor families.⁵⁵ Poverty among rural households with a disabled member is particularly pronounced in many countries. In Georgia, for example, 36 per cent of such households

are in the lowest one fifth of household incomes.⁵⁶

Data from the Living Standard Measurement Survey in Russia, for example, suggest that households with disabled and sick children had only a slightly higher poverty rate than all households with children: 30 per cent compared to 29 per cent. Also, in Georgia, households with a disabled member are under-represented in the lowest income quintile in urban areas (15 per cent).

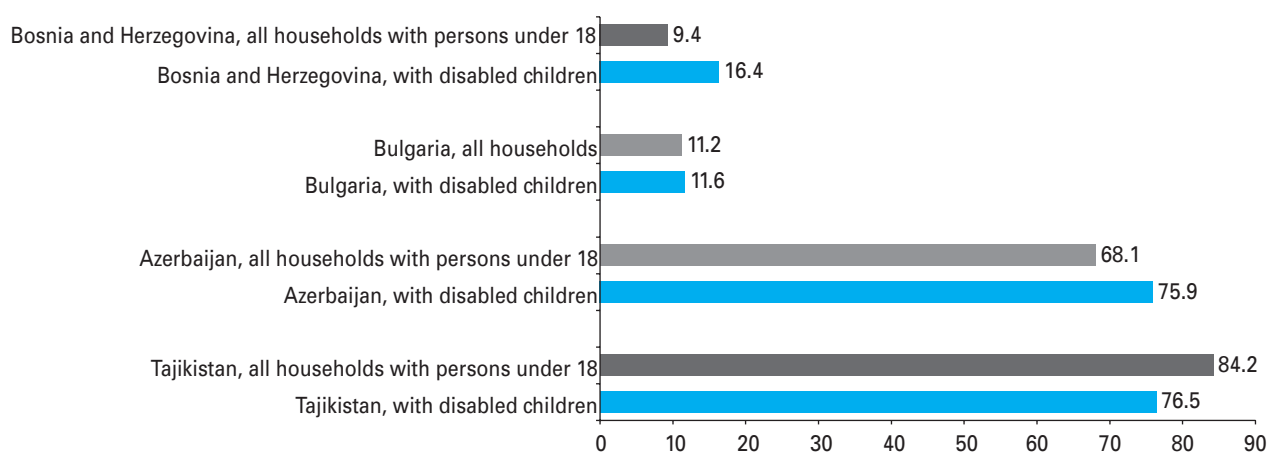
While no comparable data across the region exist on poverty rates among families raising children with disabilities, Figure 1.12 makes an effort to offer a broader view of the issue. It shows the share of households with consumption expenditure under national poverty lines in four countries where detailed data on the poverty status of families with and without disabled (and/or sick) children is available.

The graph shows that if poverty is defined as household consumption below certain thresholds, families raising a child with disabilities do not necessarily post higher poverty levels than all families with children. In two of the four countries presented in Figure 1.12, households with a child with disabilities do have higher poverty rates, but this does not appear to be the case in Bulgaria – where poverty risks are roughly comparable – and in Tajikistan, where families raising a child with disabilities have on average a *lower* risk of being under the national poverty line. It is unclear, however, how much this outcome reflects positive coping strategies or failure on the side of the state to avoid the separation of children with disabilities from their poor parents through early death or entry into public care. The apparently very low rates of children with disabilities in institutions in Tajikistan makes it probable that there are high rates of early death of children with disabilities, possibly even among those in residential care.

Disability and ethnic discrimination

Ethnicity may contribute to income disadvantage of families raising a child with disabilities. Several studies have found that the Roma ethnic group is at particularly high risk of living in poverty in Central

Figure 1.12 Per cent of households with consumption expenditure under national poverty lines



Source: Living Standard Measurement Study of the World Bank (<http://www.worldbank.org/lsm/>).

and Eastern Europe, including Moldova, Romania and Hungary; there is also a well-established link between belonging to disadvantaged ethnicity and having a disability. For example, both 1990 and 2000 Population Census data from Hungary showed higher disability risk among the Roma than among the general population (despite the Roma having on the average much younger ages).

Belonging to disadvantaged ethnic groups increases the probability that the family will have a member identified as disabled. But that 'diagnosis' may be rooted in social stigma and systemic bias, e.g., regular 'scholastic aptitude' tests are tuned to the dominant culture. Moreover, ethnicity may be a factor in the income disadvantage of families raising a child with disabilities, even independently of extra care and support needs. Discrimination in the labour market may be particularly strong when minority ethnic status and family responsibility related to a child with disabilities coincide: in such cases parents – especially women – may have to confront double discrimination when looking for employment.⁵⁷ This makes it very difficult to break out of poverty.

There is also a pattern in some CEE countries (e.g., Hungary, Romania, Bulgaria, Czech Republic and Slovakia) of putting Roma children in institutions, as well as in segregated education; this may be done not necessarily because they are impaired, but because they are different and discriminated against. With terrible irony, there is much evidence that such institutionalization actively contributes to developmental delay and behavioural problems for able and disabled children alike.⁵⁸

The Roma experience a cycle of disability, discrimination and disadvantage. The 1990 Census in Hungary found a very high rate of disability among the Romany minority – representing 1.4 per cent of the total population, but 2.5 per cent of disabled persons; with 58 per cent of Roma disabled reported as having mental disabilities, compared to 19.5 per cent in the overall disabled population. Also, 41 per cent of Roma disabled were under age 14, compared to 9 per cent of total disabled; and 34 per cent of Roma disabled age seven and over have no schooling, compared to 11 per cent of the total disabled population over age seven.

The high referral rate of Roma children to special schools is at least partly excused as an alternative to mainstream schools that cannot accommodate them. The European Roma Rights Centre in Budapest is involved in a court case in Croatia where Romany parents say their children's rights are being violated by being placed in separate classes with 'special' education programmes that the parents consider inferior. A lower court ruled that the suit was unfounded because the Roma children did not speak Croatian fluently and were thus unable to attend classes with other children. Official figures report that 60 per cent of Romany children in that single county are in separate classes.

Perhaps, nowhere is the corrosive relationship between social stigma and disablement more clear.

1.7 Availability of benefits and disability supports

"Without the support from relatives I could do nothing. It is the only thing. Both the psychological and material support from relatives [...] you feel alone and ignored. You are with your child without any special education. I was 20 when she was born. It was very hard."

Vilhelmine, mother, Latvia

CEE and CIS countries have, for the most part, strong institutional traditions of offering parents benefits and services. When the market-oriented transition began in 1989, most countries had generous maternity leaves, some family allowance schemes, and extensive preschool and after-school care programmes. Some of the early negative effects associated with market reforms and privatization, like the closure of nurseries formerly run by state enterprises, have been partially offset by the introduction or extension of parental leave schemes, while some former price subsidies and non-cash transfers to families were replaced by cash benefits. However, during the mid- and late 1990s, several countries trimmed their family support programmes and some re-oriented support towards poverty reduction, given the huge increases in poverty across the region. How have entitlements for families raising a child with disabilities changed in this process and where are the gaps in current public support?

Subsidies and non-cash transfers

While many families raising children with disabilities must certainly have been affected by overall reductions in non-cash transfers in social services, the evidence in the country reports submitted to UNICEF IRC suggests that CEE and CIS countries have generally maintained subsidized or free access to services linked directly to disability. Nevertheless, what these comprise is interpreted more narrowly in the poorer countries. While Armenia, Azerbaijan or Kazakhstan mention free prostheses and support to buy various technical devices, the Czech Republic, Hungary or Poland also mention personal assistance services, free transportation to take a child with disabilities to school, discounted travel on public transport, parking privileges, loans to buy an accessible vehicle, and access to telecommunications. Interestingly, in Poland, the carer of a child with disabilities is entitled to move to the front of the line at public institutions and shops. In Romania, public transportation is free and NGOs provide free transportation to schools or treatment.

In some countries, families with disabled members are offered easier terms in rental of public housing (Romania), residential mortgages (Latvia) or public utilities (Kyrgyzstan), although such support is usually only available when disability is severe. For example, in Kyrgyzstan families with a child assigned to the first or most severe disability category receive reductions in gas, water and electricity bills.

"I have huge [money problems]. We live only on sausages. And I'm sick of those sausages."
 Justine (female), 14, living at home, Latvia

"She very much needs massages. I took her to Sofia for a series of massage sessions. Paying for three sets drained me financially. People with a lot of money go there. I cannot pay."
 Stefka, mother, Bulgaria

"There are money problems. Right now we are surviving, not living."
 Rita, mother, Russia

"How is it possible with 30 leva [€15] in child support and 28 leva [€14] in invalid support...to feed your child, to buy textbooks, notepads and pay all the school fees?"
 Ralitsa, mother, Bulgaria

Disability pensions and family allowances

CIS countries offer special disability pensions for children with disabilities; CEE countries largely use their child/family allowance schemes to deliver cash support to families that have children with disabilities. In Armenia, for example, children under age 16 who live with their families or in boarding schools are entitled to a disability pension (but not those who live in homes for the disabled or orphanages). In Croatia, on the other hand, a special child allowance is granted to a child with disability until the completion of his or her education and rehabilitation, up to age 27. Generally, child/family allowances offer increased benefits; e.g., in Romania, the regular monthly allowance is doubled if the child is disabled.

Figure 1.13 shows the value of the disability pension of children compared to the average wage in the region since 1989. High inflation in the early 1990s

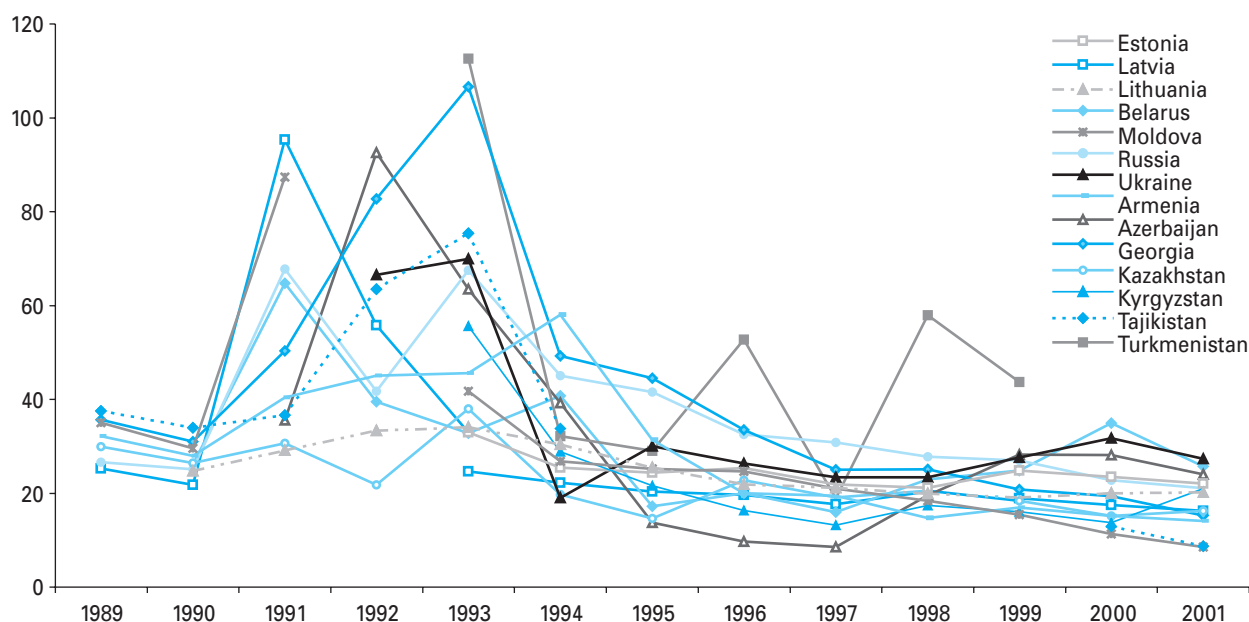
blurs the picture (most of the sharp hikes visible on the graph reflect the fact that December pension values compare falsely with average monthly wages when there is high inflation throughout the year). However, the main message is clear: benefit values have declined in comparison to 1989. The differences in the initial year, when the Soviet Union was still intact, show that the same flat-rate benefit translated into 25 per cent of the average wage in relatively affluent Latvia, compared to 36 to 38 per cent in poorer Georgia and Tajikistan. In 2002, on average they were worth slightly less than 20 per cent of wages in the 14 countries for which data were available. In real terms the decline was, of course, much bigger as average wages plunged in the 1990s in all these countries.

A disability pension that is equivalent to 20 per cent of the average wage may seem quite low (and indeed may fall well below the subsistence minimum). However, this ratio is actually higher than in most industrialized countries where monthly benefits for children with disabilities can equal as little as 4 per cent (Luxembourg) to 13 per cent (Belgium) of the average wage.⁵⁹ Of course, both the CEE/CIS pension and average wage will likely buy relatively less in terms of a basket of goods.

Child care and parental leave

Day care for children under age 2 was never universal in CEE and CIS countries before transition; during the 1990s, enrolment has fallen to levels of less than 10 to 15 per cent, implying a rather sparse network (similar to what is available in Western countries).⁶⁰ However, there is little information on the extent to which young children with disability have access to early care services through day care. In Hungary, for example, only one third of nursery schools ensured places for children with disabilities, who make up 1 per cent of total enrolment and less

Figure 1.13 Disability pension for children compared to average wages in 14 countries
 (in percent)



than 0.1 per cent of children aged 0 to 2. Even though access to early childhood care and education may be particularly important for disabled infants and toddlers (as well as their parents), transportation problems and gaps in accessibility and/or in service quality may prohibit use.

Parental leave, on the other hand, has become a popular care form for children under age 2 in most CEE countries and the better-off CIS ones; several countries seem to offer entitlements to parents raising a child with disabilities. In Bulgaria or the Czech Republic, for example, the employed parent of a child with disability who is in need of intensive care has a right to paid leave until the child's seventh birthday. In Hungary, the leave threshold for parents raising children with disabilities is age 10, while in Romania, it is age 3. In some countries, parents also have a right to short-time jobs and compensation for time dedicated to caring for their child with disabilities. In the poorer Southern belt of the region, maternity leave is basically the only option available for parents of a child with disabilities.⁶¹

After-school and home-care services

In many Western countries, domiciliary services – home help services and/or care allowance for the carer or cared-for person to purchase services provided by the state, NGOs or private persons – are very important for families with disabled members. In Germany, for example, basic care and housework services, provided by care centres or professional individuals, are paid for by the state for families with disabled members – to a value of €383 to €1,917 annually (12 to 60 per cent of the average wage).⁶² In the United Kingdom, respite care, home care, personal care and help with house chores is widely available even though families may be on a waiting list for some services. In France, there is an allowance for 'parent presence' (ranging from €243 to €485), a benefit paid to a parent who has stopped or reduced employment activity to care for a seriously disabled child up until the child reaches age 20.

Such benefits and services are still not very common in CEE and CIS countries. Since 1989, some countries have made progress in developing similar entitlements, though the related benefits are modest. In Estonia, for example, a carer's allowance (€15 to €26 per month) is available for non-employed parents or guardians who are raising a child with disabilities aged 3 to 16 or 18. Poland offers a universal care benefit to carers, if the child needs permanent treatment and rehabilitation, up to age 16 or a maximum of 24 years. The benefit is not payable when the child stays in a social care home, treatment centre or residential care home. Hungary has a nursing allowance (about €75 per month, less than half of the minimum wage) available to citizens who care for a seriously disabled or chronically ill person under age 18. A few countries also offer a reduced workload for parents of children with disabilities. However, in most CIS countries parents who do not have employment opportunities because they are caring for a child with disabilities do not receive compensatory benefits in

Box 1.8 Improving access to community-based care

"Parents should be able to provide care at home. I would like them to have a day-care centre to drop a child, if necessary, for a day, weekend, a holiday. Holiday activities and joint activities for children and the same for adults, not only those odd family get-togethers. Be honest, take them seriously."

Maya, nurse/therapist, Russia

Increasing choice is a key goal of transition societies. Building up the middle range of care options – between large state institutions and unsupported families – is essential to fulfilling the rights of children with disabilities. Estonia has established a number of day care centres in recent years, some dedicated to children with severe and profound intellectual disabilities and multiple disabilities. Special day-care service allows children with disabilities who live at home to spend a few hours or a few days at a centre. In the Czech Republic, respite care is also growing quickly. And, in Croatia, a child with disabilities who lives at home has a right to temporary, weekly, all-day or half-day accommodation in a specialized institution.

In 1994, there were only 33 rehabilitation institutions for children with disabilities in Russia; by the beginning of 2000 there were as many as 237 rehabilitation centres, as well as 296 rehabilitation departments in various institutions in the social protection system. In 2000, the rehabilitation centres for children with special needs served 112,000 children with disabilities and 98,400 families. The centres teach the parents of children with disabilities rehabilitation methods that they can use independently at home, and they offer psychological, pedagogical and legal assistance. Rehabilitation institutions have boarding departments as well as daytime departments; which gives parents a chance to work while their child is in care.

Over 300,000 families with children with disabilities – one in every two registered as disabled – receive some type of assistance from the social support system. For almost one in three children with disabilities, the social-medical committees have established an individual medical, occupational, and social rehabilitation programme.

Belarus has established 97 centres for children with disabilities since September 2002. They include facilities for corrective and educative schooling and rehabilitation.

In Armenia, with international assistance, new methods of rehabilitation treatment have been introduced. This features a comprehensive approach implemented by a team "where the central role is given to the child and the family." The parents are actively involved in the work of the team. The team includes a rehabilitation specialist, therapist, nurse, orthopaedics specialist, pedagogue and a psychologist; and, if needed, a neurologist, plastic surgeon and other specialists.

Source: Russian Country Report, Belarus Country Report, Armenia Country Report

their own right, and home-help services are underdeveloped even in CEE countries.

Links to institutional care

In both poorer and richer countries in the CEE/CIS region, many forms of support are either available only through boarding facilities or through an institutional setting. Rehabilitation institutes, which have an important role in Hungary, for example, usually provide family-based care as after-care from boarding service. Respite care – a temporary, short-term care form aimed at giving parents and children a break from usual routines – is available almost exclusively through public institutional care in CEE and CIS countries. It is clear that securing respite care or rehabilitation services through boarding

institutions helps maintain attitudes that accept institutional care as a norm.

Long-term institutional care for children with disabilities is often readily available and is low-cost for users, e.g., losing a disability pension or child allowance. At the same time the overt and hidden costs of family-based care are still only partially absorbed by existing disability pensions, family allowances and parental employment support schemes. In some countries, poor choice among providers may also be a factor – with public institutions widely resistant to reforms. Meanwhile, in other countries, the presence of the private sector and NGOs may provide an impetus for change. In Slovenia, for example, individual support services are secured by NGOs rather than the state.

Notes

- 12 Hungary Country Report, 2002. It is worth comparing this definition with one from a British government ministry: "Long-term impairments, leading to social and economic disadvantages, denial of rights, and limited opportunities to play an equal part in the life of the community." From *Disability, Poverty and Development*, Department for International Development, London, February 2000.
- 13 Belarus Country Report, 2002.
- 14 Croatia Country Report, 2002.
- 15 Countries tend to use different disability criteria and even different disability-assessment processes for allocating benefits that are rival in consumption (i.e., one person's use excludes use by another). Issues of defining disability tend to arise more sharply in the allocation of cash than in the provision of services and benefits-in-kind. See 'Definitions of Disability in Europe: A Comparative Analysis', Brunel University, UK, September 2002, www.brunel.ac.uk/depts/govrn/research/disability.htm.
- 16 Ibid.
- 17 Armenia Country Report, 2002.
- 18 The classification criteria are the ability to: behave adequately; communicate with people; move around; use one's arms; have control over one's body; and take care of oneself.
- 19 'Children' are typically understood to be those under 15 years of age, i.e., below legal working age.
- 20 The Polish Country Report notes: "There is a lack of consent among doctors, pedagogues and psychologists as to the notion of 'the disabled child'. Some think that this term should only apply to the children whose psycho-physical ability is visibly impaired due to organic disease. Others think that this term should not be used to describe children with slight disability of organs or functions. There is an on-going debate as to whether the term 'disabled child' should include children with emotional behavioural difficulties." The Tajikistan Country Report quotes a 1985 Soviet demographic handbook: "Disability in childhood is a permanent social disadaptation, resulting from a chronic disease or pathological condition and seriously restricting the possibility of integrating the child in the environment suited to its age. Disabled children are in need of constant additional and special care."
- 21 Cornia, Giovanni Andrea and Frances Stewart, 'Two Errors of Targeting', *Innocenti Occasional Papers*, Economic Policy Series, UNICEF International Child Development Centre, Florence, 1993.
- 22 Czech Republic Country Report, 2002.
- 23 Some surveys do employ the '10 questions questionnaire' or some version of the TQQ approach, e.g., the MICS in Tajikistan or a survey in Bulgaria.
- 24 It is important to distinguish between greater identification and better survival rates of disabled children. Using the terms 'incidence' to denote new cases recognized, and 'prevalence' to capture those who are alive at a given point in time would help distinguish these two effects, but the literature does not use these terms consistently.
- 25 Lithuania Country Report, 2002.
- 26 UNICEF, *Innocenti Social Monitor No. 2*, UNICEF Innocenti Research Centre, Florence, 2003; Aleshina, Nadezhda and Gerry Redmond, 'How high is infant mortality in Central and Eastern Europe and the CIS?', *Innocenti Working Papers No. 95*, UNICEF Innocenti Research Centre, Florence, November 2003.
- 27 There are other areas of intensive environmental concerns that relate to health and disability. For example, the effects of 40 years of nuclear-weapons testing (ending in 1991) at the Semipalatinsk Range in Kazakhstan, and the ecological disaster of the desiccation of the Aral Sea (once the world's eighth-largest inland sea or lake, and now its fourth-largest) caused by excessive irrigation, greatly impacting the environment, economy and population health in all five Central Asian countries.
- 28 In Belarus, disability related to congenital anomaly was reported in 2001 to be 0.045 per cent of the child population aged 0 to 17, higher than at any time before. Assuming that these children will stay on the disability register an average of 15 years, the birth defect-related disability prevalence rate would be 0.7 per cent, still below international benchmarks.
- 29 Hungary Country Report, 2002
- 30 According to the definition in the Country Report, these children "fall ill frequently, for lengthy periods, with a marked post-disease period characterised by fatigue or irritability, sleep disturbances or loss of appetite, etc." Latvia Country Report, 2002.
- 31 It should be noted that the two surveys are not fully comparable.
- 32 Victora, C. G., CEE/CIS 1997: An Evaluation of UNICEF Support to the Control of Iodine Deficiency Disorders in Eastern Europe, the Commonwealth of Independent States and the Baltic States, Evaluation Database, UNICEF. Accessed 09 June 2004 at www.unicef.org.
- 33 In Kyrgyzstan, for example, anaemia prevalence during pregnancy has doubled since the early 1990s, while the number of anaemic children grew approximately 1.5 times in that period, making 16.5 cases per 1,000 children aged 0 to 14 in 2001. Kyrgyz Country Report, 2002.
- 34 WHO reported mild sub-clinical (i.e., marginal) vitamin A deficiency in certain areas of Romania and Uzbekistan in the mid-1990s, while countries like Poland and Russia were keeping vitamin A deficiency under control; noting, however, the lack of information for most of the 27 CEE and CIS countries. World Health Organization, *Indicators for assessing Vitamin A deficiency and their application in monitoring and evaluating intervention programmes*, (WHO/NUT/96.10), Geneva, 1996.
- 35 The survey, which was carried out in two oblasts (administrative divisions) of Kazakhstan and one oblast of Tajikistan, indicated vitamin A deficiency in both countries greater than the 20 per cent cut-off rate. UNICEF CARK, *CARK MCH Forum: Report of the VI Annual Meeting, Ashgabat, Turkmenistan, Almaty, Kazakhstan, 2003*.

- 36 The World Health Report 2004 reports that infectious and parasitic diseases account for one quarter of Disability-Adjusted Life Years (DALYs), or lost years of health through death or disability, WHO.
- 37 See Chapter 2 in UNICEF, *Young People in Changing Societies*, Regional Monitoring Report No. 7, UNICEF IRC, Florence, 2000.
- 38 Streissguth, A.P., H.M. Barr, J. Kogan and F. L. Bookstein, 'Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)', *Final Report to the Centers for Disease Control and Prevention (CDC)*, Seattle, Tech. Rep. No. 96-06, (1996).
- 39 This should be seen as a conservative estimate because the institutional care system was complicated and far from being transparent. Many children with disabilities were placed in hospitals, and a significant number of children in 'normal' orphanages and child homes had unreported disabilities.
- 40 Doolittle, T., et al., 'The Long Term Effects of Institutionalization on the Behavior of Children From Eastern Europe and the Former Soviet Union: Research, Diagnoses, and Therapy Options', *The Parent Network for Post-Institutionalized Children*, 1995, www.mariashildren.org.
- 41 Gantcheva, R. and A. Kolev, 'Children in Bulgaria: Growing Impoverishment and Unequal Opportunities', *Innocenti Working Papers No. 84*; UNICEF Innocenti Research Centre, Florence, 2001.
- 42 Albania Country Report, 2002.
- 43 This concept refers to much bigger pools of children, e.g., in Belarus, centres for correctional and educative schooling and rehabilitation registered 119,400 children, including 13,894 children with disabilities, as of 1 September 2002. Slovenia notes that its definition of 'special needs' has been extended to include chronic diseases as well as behavioural problems; this appears to have happened in many other countries, as well.
- 44 Hungary Country Report, 2002.
- 45 According to the Lithuania Country Report, 2002, "in special schools, 2,000 pedagogues worked with disabled children, of which 81 per cent had higher education; just 47 per cent of them had higher special pedagogical education. Since 2001, jobs of social pedagogues in addition to special pedagogues, logopaedists, psychologists and health care specialists have been established in general schools."
- 46 Of the 1,595 staff in 2002, 563 were logopedists, 323 were social pedagogues and social workers, 246 were special teachers, and 237 were medical staff. Lithuania Country Report, 2002.
- 47 However, children may participate in other programmes that are not included in these statistics. Hungary, for example, provides normative financing to local governments for supporting conductive pedagogy, early development and nursing and development preparation programmes; it is unclear how these relate to preschool attendance figures.
- 48 In particular, the presence of a disabled adult is associated with poverty risks. In the United States, for example, two-partner households without a disabled member had an average income of US\$36,708, while those with a disabled partner had an average income of US\$28,795 and those with a disabled child had an average income of US\$37,558. LaPlante, Mitchell P., Dawn Carlson, H. Stephen Kaye and Julia E. Bradsher, 'Families with Disabilities in the United States', *San Francisco Report 8*, Disability Statistics Center, University of California, September 1996.
- 49 While there is no direct evidence that babies with congenital anomalies born to more affluent families have a better chance of survival and recognition of the disability, there is evidence from the region that birthweight is higher among better-educated women; infant mortality rates can be several times higher among mothers with basic education (or less) than among women with secondary education. Koupilová, Ilona, Martin McKee and Jan Holcík, 'Neonatal Mortality in the Czech Republic during the Transition', *Health Policy*, Vol. 46, No. 1, 1998, pp. 43-52. UNICEF, *A Decade of Transition*, Regional Monitoring Report, No. 8, UNICEF IRC, Florence, 2001.
- 50 Moldova Country Report, 2002.
- 51 National Institute of Statistics of Romania, *Household Budget Survey 2001*, cited in Romania Country Report, 2002.
- 52 Hungary Country Report, 2002.
- 53 Estonia Country Report, 2002.
- 54 At the end of the 1990s, there were nearly 18 million children in the CEE/CIS Region living in households with income of less than US\$2.15 per person per day.
- 55 Armenia Country Report, 2002.
- 56 Georgia Country Report, 2002.
- 57 While there is little evidence on discrimination against families raising children with disabilities, studies have found employers discriminating against women with family responsibilities in general. For example, using ILO data, Paukert found evidence of gender bias in the recruitment process of employers in Hungary, Poland, the Czech Republic and Slovakia. Newell and Pastore showed that when all variables are taken into account, marital status remains the main explanation of gender difference in job hunting success. Newell, Andrew and F. Pastore, 'Labour Market Flows in Poland: Some Empirical Evidence Using the Polish Labour Force Surveys', University of Sussex, 1998. Paukert, L., 'Economic Transition and Women's Employment in Four Central European Countries, 1989-1994', *Labour Market Papers, No. 7*, International Labour Organization, Geneva, 1997.
- 58 British researchers who have tracked the progress of Romanian babies adopted by English parents have found that the length of time that adopted children spent in orphanages correlates negatively with cognitive scores, behavioural difficulties and family and social relationships. Rutter, M. et al., 'Developmental Catch-up and Deficit: Following Adoption after Severe Global Early Privation', *Journal of Child Psychology and Psychiatry*, Vol. 39, 2000, pp. 465-76; Rutter, M. et al., 'Recovery and Deficit Following Profound Early Deprivation', in P. Selman (ed.), *Inter-country Adoption: Development, Trends and Perspectives*, BAAF, London, 2000.
- 59 Sweden actually has a basic scheme offering about 288 Euro (11 per cent of the average wage) and a supplementary scheme of about 1,249 Euro (47 per cent). Rostgaard, Tine, 'Disability allowance/pension for children', manuscript prepared for UNICEF IRC, 2003.
- 60 At the end of the 1990s, only 1 to 2 per cent of Czech or Romanian children aged 0 to 2 were in day care, rates similar to those in Italy or Greece. The highest day-care coverage in CEE/CIS was 18 per cent in Estonia, compared to rates of 20 per cent in England and 35 per cent in Sweden. Rostgaard, Tine, 'Day care and nursery education for all preschool children', manuscript prepared for UNICEF IRC, 2003.
- 61 Rostgaard, Tine, 'Indicators of statutory leaves schemes', manuscript prepared for UNICEF IRC, 2003.
- 62 Rostgaard, Tine, 'Domiciliary care', manuscript prepared for UNICEF IRC, 2003.

2

A PROFESSIONAL OPINION

Qualitative Assessment

■ *Health professionals assess existing services for children with disabilities in the CEE/CIS region*

Countries in the CEE/CIS region are making significant efforts to prevent, identify and assess childhood disability and to provide services and benefits that respond to the needs of children with disabilities and their families. However, as Chapter One of this report makes clear, it is very difficult to assess progress and quality related to support and services on the basis of available data. National needs assessments and reviews of service quality are largely missing, as are comparisons across CEE and CIS countries.

In light of the rising official rates of children with disabilities in the region, UNICEF took steps to close this knowledge gap by asking the European Academy of Childhood Disability⁶³ (EACD) to carry out an assessment of services for children with disabilities in CEE and CIS countries. In response, EACD developed a questionnaire that was completed by health practitioners in 17 CEE and CIS countries, and conducted a number of interviews and site visits. The goals of the research were to:

- better understand the role of the health sector in caring for children with disabilities and provide some first-hand impressions of the present quality of services;
- explore the role of health professionals in promoting inclusive and participatory practices in all areas of care, service and support;
- explore the potential for bringing services to children and families rather than children to services

(to help replace institutional care with family-based care);

- offer an exchange of information related to service approach and provision for children and their families in different parts of Europe.

2.1 Main findings

The EACD assessment provides an important snapshot at a key moment – as eight CEE countries join the EU and many states in the region demonstrate growing confidence in the pursuit of their own development strategies. The assessment finds that prevention and management of disabilities is often more difficult under present conditions in CEE and CIS countries than in the past, but that there is also a greater openness and capacity in the region for recognizing children with disabilities and adopting more inclusive attitudes and behaviours towards children with disabilities. The overall challenge, therefore, is to act on these new approaches. Following are some of the key findings of the EACD assessment.

- Respondents confirm what data suggests: that the rate of children with disabilities has remained unchanged or gone up in the region.
- Doctors in better-off parts of the region ascribe any increase to greater visibility of children with disabilities, due to improved diagnosis or recognition, and greater incentive to register a child as disabled. However, in Russia and several poorer CIS countries, health providers say a general decline in maternal and child health is also a factor.
- Medical and social services for children with dis-

Box 2.1 EACD guiding principles for disability supports and services

In 2003, following a review of services in 14 EU countries, the European Academy for Children with Disabilities made a series of recommendations to be used as a basis for disability services throughout Europe. The three key points can also apply to CEE and CIS countries.

1. Services should be based on the needs and aims of the family and child rather than on particular treatment orientations or organizational structures favoured by professionals.
2. Certain facilities should be available as a basic right in a caring society, rather than having to meet a scientific test of effectiveness. While research into the most effective way of helping children with disabilities is ongoing, it is not possible to wait for the results of studies before providing a service for children with disabilities and their families.
3. Management of a child's programme should be goal-oriented and specifically adapted to that child's wishes and circumstances.

Source: 'Services for Children with Disabilities in European Union Countries,' European Academy for Children with Disabilities, London, 1997.

abilities are better where services for children in general are better.

- Differences in service are substantial both among and within countries, with a significant divide between CEE and CIS subregions, north and south, richer and poorer countries, urban and rural populations.
- Health services, once considered comparable with the West, face problems related to lack of adequate equipment, training and financing. Maternal and antenatal health care that can impact on the incidence and/or severity of impairments has deteriorated in some poorer countries.⁶⁴ For example, safe delivery conditions – a hospital setting and access to procedures such as Caesarean-section – may be inadequate or lacking.
- Several countries fail to use micronutrient programmes, which are inexpensive and effective, to maintain natal health and guard against impairments – e.g., preventing Vitamin A, iron and iodine deficiency, and promoting folic acid to women of fertile age.
- The protocol for antenatal medical visits is quite strong in almost all countries, but there is evidence that the range of tests and techniques is quite varied.
- Similarly, schedules for physical check-ups for infants and children are substantial, but assessments tend to overlook developmental and behavioural dimensions of health. Indeed, paediatricians in some countries lack adequate training in child development theory, and this knowledge gap is also broadly evident in care regimens.

- Assessments are done regularly and by specialists, but full assessments with a coordinated multidisciplinary team are still lacking in many countries, including Russia, and outside large centres.

"Disabled children are diagnosed by a commission, which decides to which type of institution to refer a child. Such diagnoses should be revised, but it is rarely done. Often diagnoses and revised diagnoses meted out to mentally retarded children prove sufficiently erroneous. Even if children have a good development record, nothing is done to move them elsewhere or to assign them a different status. They stay where they have been originally placed, so that more or less normal children have to live in institutions intended for severely intellectually or physically handicapped children, which is absolutely inadmissible."

– Kyrgyz Country Report, 2002

- The practice regarding reassessments varies widely across the region, but what is most striking is that once a diagnosis is made, it is rarely changed. This is especially true for children deemed 'ineducable' (or unteachable) and placed in institutions.
- Most common impairments are diagnosed, but there is less knowledge and diagnostic capacity in the region related to the many genetically inherited disorders⁶⁵, like Fragile X (a genetic condition that causes learning disabilities in males), that cause up to 25 per cent of congenital anomalies and may be a factor in a further 25 per cent of birth abnormalities.
- There is a lack of access to special diagnostic equipment like MRIs (magnetic resonance imaging). Drugs are also not readily available and their cost is often high; there is also a marked difference between CEE and CIS countries in the use of drugs for certain conditions.
- More profound is the rather limited training, compared to Western countries, on disabilities for health and other social service professionals. In CIS countries, disability-related training also follows the Soviet discipline of 'defectology' that emphasizes special education for children with disabilities.
- Segregation of children with disabilities in special schools still dominates in CIS countries, but overall in the region there is a move towards integration in mainstream schools, though progress is spotty. Integration of children with intellectual disabilities is far less common.
- Respondents comment on the gap between positive laws and the realities of implementation. The respective responsibilities of local and central governments, and the roles of the public and private sectors seem to be ill-defined and lacking resources.
- The most positive and potentially transformative

development is the changing attitudes of parents, service providers and decision makers. As one survey respondent, a Polish doctor, put it: "Disability has now a better social basis!"

Clearly, several problems raised in the EACD assessment may best be solved as part of health- and social-sector reforms that make public services more efficient and client-oriented. Greater public and private efforts, better coordination and clear policy directions are needed before there is a breakthrough in the development of inclusion-oriented services and environments for children with disabilities.

Health and disability

According to WHO: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." Health is increasingly understood as a dynamic state arising from the interplay of many factors. This framework raises disability from an individual medical matter to a broad social concern. It raises questions about: the conflation of disability and illness; the role of public health in both the prevention of disability and the support of persons with disabilities; the key role of health professionals as decision makers and opinion leaders; and the growing voice of persons with disabilities. Better levels of individual and population health are constantly sought worldwide, and the expectations of disabled children are similarly raised.

2.2 Methodology

The EACD evaluation was based on a questionnaire of service providers in 17 countries, as well as a number of interviews and site visits in CEE and CIS countries. Most respondents were paediatricians with a disability-related speciality, but they also included child protection officers, physiotherapists, psychologists and social workers.⁶⁶ In some cases, responses represented a collaboration of four or five persons.

The questionnaire results were followed up by consultations with service providers in Bosnia and Herzegovina, Croatia, Hungary, Lithuania, Romania, and in Ukraine and Russia, with site visits and local consultations in Kiev and Kaliningrad. These activities were led by the EACD Chairman and carried out with UNICEF providing various forms of assistance.

Qualifications

The assessment should by no means be interpreted as representative. The respondents were selected on the basis of their EACD membership and/or their recognized professional excellence, as well as their broader knowledge of practices in their countries. This, however, means that respondents tend to work in leading medical institutions in capital cities that are normally better equipped than average health units – and respondents themselves note this selection bias. Moreover, professional and national pride may also influence responses.

In light of the qualitative and non-representative nature of the survey, it has not been possible to check the responses provided; however, efforts have been made to reduce the risk of major errors. In Bosnia and Herzegovina, Croatia, Estonia, Hungary and Poland, two questionnaires were filled in by different persons and/or teams, and this offers some insights into the robustness of results. About two thirds of these 'double' responses show agreement and a further smaller share shows differences that are not very significant, or reflect a misinterpretation of the question. Still, it appears that for about one out of five issues, professionals tend to disagree and/or lack knowledge. This may suggest that some issues are not discussed much publicly or professionally so that there is no coherent view among service providers. It also indicates that practices and realities differ, at times significantly, within countries, as independent consultations with health care providers also suggest. Finally, the site visits in Russia and Ukraine provided some important qualifications to the often highly positive views expressed in the questionnaire regarding technical equipment, training and/or the quality of care.

Disability rates

Chapter One of this report analyses the official data on disability rates gathered for this research, but the EACD assessment also asked health care providers about changes in the incidence of disability over the last decade and about subnational variance in their countries.

EACD definition of disability

EACD defines disability not as an illness but as a long-lasting condition caused by congenital (present from birth), inflammatory (usually infections), traumatic, genetic and degenerative disorders. It does not include chronic health problems, such as diabetes, as a disability. By these measures, 1 to 2 per cent of the population has a moderate or severe disability (e.g., inability to walk or communicate), and up to 10 per cent have a less severe but often highly significant disability such as a learning disorder.

Respondents from Croatia, Hungary and Slovenia say the incidence has not changed, while the Ukraine response is that incidence has changed for "almost all types of disabilities." Generally, doctors seem to be aware that there has been a rise in registered disability figures but they say greater awareness, better recognition and, at times, better survival rates of vulnerable children explain this. A respondent from Poland says, for example, "Since 10 years we can observe a modification of the mentality of parents: Disabled children are not hidden at home ...". Better observation is explicitly mentioned by many country respondents as the main cause of the rises in autism cases. Respondents also make reference to changes in disability criteria. However, doctors from Russia and several other CIS countries tend to think there has been deterioration in child health since the early 1990s and that this has impacted disability incidence as well.

Only Russia with its huge territory indicates significant sub-national variance (prevalence rates range from 1.47 to 1.75 per cent between the central and Ural regions). However, no cause for the variance is noted, and generally respondents think the statistics are not very reliable. The respondent from Albania, one of the smallest CEE countries, speculates about higher childhood disability rates in some parts of the country, but this is yet to be confirmed by proper research.

Overall, the questionnaire responses show patterns that mirror the socioeconomic development, history and geographical position of the countries. The results indicate that economic factors are important and that the general quality of health and education service is also a strong determinant. This means bigger gaps in service provision, practices that are more outdated in poorer countries than in richer ones, and worse services for children with disabilities in those countries where children generally receive less support. However, this is not always the case. There is evidence of positive initiatives and practices that support children with disabilities in countries that are poor and have serious difficulties in providing health and education services for their population. The field visits also confirm that despite poor physical and financial conditions, there are also many positive aspects to services in the former communist countries, e.g., the inherited strengths of the social sector and the new opportunities created by political and social changes since the early 1990s.

2.3 Health care services

Health care services were assessed through questions on delivery conditions, preventative measures, health checks, disability diagnoses and related procedure and facilities, reassessment, training in childhood disability, involvement of child psychiatrists, and use of medications for certain conditions. (The survey did not address the issue of abortion related to children with disabilities, due to the sensitivity of the issue.)

Delivery conditions

As some childhood disabilities are birth-related and others are identified at birth and may require immediate intervention, access to quality maternal and child health service at delivery is important. The questionnaire specifically asked about the share of deliveries that take place in hospitals and the ratio of births by Caesarean section.

In CEE and CIS countries, it has long been standard for child deliveries to take place in hospitals and this practice was confirmed by the survey. However, respondents from six countries in the Southern belt of the region – Albania, Bosnia and Herzegovina, FYR Macedonia, Romania, Armenia, Kazakhstan and Turkmenistan – said 5 per cent or more of deliveries take place at home. Home delivery is a less safe option for mothers and babies, especially when birth complications arise. Also, for newborns with

low birthweight and/or birth anomalies, there is a greater risk that proper care will not be provided.

The ratio of Caesarean section to child delivery is important for two reasons. First, there are cases when surgery is indicated to save the life of the mother and/or baby and to prevent birth trauma that can result in cerebral palsy – one of the most common forms of disability from birth, and one that is wide-ranging in its degree of impairment. As a recent American report highlights, only when the C-section rate is above 15 per cent does a statistical association with cerebral palsy incidence disappear.⁶⁷ (In 1985, WHO issued a guideline of 15 per cent for surgical intervention in birth.⁶⁸) Secondly, low C-section ratios may point to poor availability of obstetric services (since only doctors can perform the procedure); hence it is an indicator of access to quality maternal health services.

In the EACD survey, the C-section ratio was estimated at 20 to 25 per cent in Hungary; 20 per cent in Bulgaria, Lithuania, and Poland; 16 per cent in Ukraine; and 10 to 15 per cent in Albania, Bosnia and Herzegovina, Croatia, FYR Macedonia and Georgia. Respondents from four countries put the ratio at less than 10 per cent: 6 to 7 per cent in Slovenia and Armenia, and 3 per cent in Turkmenistan and Kazakhstan. In Russia, with the most recent figures dating from 1993, the ratio also varies widely – from 1 to 13 per cent – across the country. (By comparison, rates are around 22 per cent in the United Kingdom and the United States and 40 per cent in Chile.⁶⁹)

Preventative measures

Antenatal check-ups are an important part of maternal and child health care in CEE and CIS countries. In Slovenia, for example, it is standard practice for all pregnant women to undergo six antenatal check-ups. In Lithuania, five visits are normal and 12 to 15 visits for women with high-risk pregnancies. In Georgia, four antenatal visits are the norm. In FYR Macedonia, mothers older than 35 years of age are recommended for an amniocentesis test, where amniotic fluid is withdrawn from the womb and analysed for genetic markers that indicate conditions such as Down Syndrome.⁷⁰ Overall, regular visits to gynaecologists are well established in many countries, a practice that could serve as a sound base for antenatal checks and ameliorative care related to impairments.

The survey asked about both antenatal prevention and preventative procedures around birth (sometimes called neonatal prevention). Half of the respondents named only the four preventative measures explicitly queried: folic acid use, HIV screening, phenylketonuria (a genetic mutation resulting in developmental delays) and hypothyroid. Other measures mentioned vary widely. This suggests that there is no coherent practice across the countries, a situation that needs attention. The responses also indicate that practices differ considerably even within countries, with women in rural areas generally

receiving less service and attention than those living in cities.

Taking a folic acid supplement is a safe, effective and inexpensive way of protecting against a range of birth defects, especially neural tube defects that impair development of the brain and spinal cord. It is therefore a serious concern that respondents from about half of the countries – Bosnia and Herzegovina, Croatia, Estonia, Lithuania, Ukraine, Georgia, Kazakhstan and Turkmenistan – did not confirm the use of folic acid; in Estonia, the supplement is given only to mothers who take anti-epileptic drugs.

Rates of sexually transmitted infections have increased substantially in a number of countries, and transmission to newborns, with its potentially damaging consequences, is a particular area of concern. In Russia, where almost 1 in 100 young women had syphilis just a few years ago⁷¹ and the gonorrhoea rate is also very high, control for maternal infections seems to be part of antenatal protocol. In some other countries, however, doctors appear to exercise wide latitude in checking for maternal infection. This can mean missing opportunities to prevent congenital syphilis or neonatal eye problems due to gonorrhoea. HIV screening of pregnant women is standard medical practice now in several countries (including Russia, Ukraine and Kazakhstan). This reflects the seriousness of the HIV epidemic, especially in Western CIS, and the efforts being taken to contain the spread of the disease. However, from this assessment, it appears that widespread HIV testing of pregnant women is still the exception in all CEE and many CIS countries. In some countries, such as Poland, HIV testing is only done for at-risk populations, although it is not clear who exactly this includes.

Respondents from several countries, including Hungary and Russia, note the use of ultrasound for checking the foetus. In Turkmenistan, pregnant women undergo ultrasound examination at 16 to 24 weeks of pregnancy. However, standard ultrasound techniques only detect major malformations, such as missing limbs.

Testing newborns through the 'heel prick' for phenylketonuria (PKU) is widely carried out, but respondents from Albania, FYR Macedonia and Turkmenistan do not report use of the procedure, and in Kazakhstan it seems to be available only in urban areas. Bosnia and Herzegovina reports that one out of five women has access to the test.

Many countries check for hypothyroid problems in infants because lack of iodine is a serious public health concern in parts of the region. Iodine deficiency is implicated in intellectual disability and learning problems and is recognized as the leading cause of preventable brain damage.⁷² In Russia, however, this check is carried out only in some maternal and child health units, and Albania, Bosnia and Herzegovina, Ukraine, Kazakhstan and Turkmenistan do not seem to employ it regularly.

Health check-ups

Respondents largely agreed that checkups are widely and routinely available in the region. However, protocols and their implementation vary significantly, reflecting different national approaches and the availability of medical capacity. For example, Croatia is the only country where a neonatal screening programme for deafness is indicated. And, generally, access to health checks seems uneven, with fewer checkups done in rural areas.

It also appears that, although there are many checkups scheduled in childhood, most assessments focus on physical rather than developmental and behavioural health. This reflects protocols that were established decades ago and have changed little since. As the Bulgarian respondent notes: "Less attention is paid to learning disabilities ... there is no regular screening for every child at preschool age. Few programmes fulfil selective screening of high-risk babies when they reach five years of age." Some countries, such as Slovenia, have recently begun to pay more attention to developmental assessment.

In Hungary, a physical and developmental assessment is done monthly up to six months of age. In preschool years (ages 1 through 3 to 6), complex physical, developmental and behavioural assessments take place. During school years, school doctors decide on the necessity of further checks. In Russia, on the other hand, the norm is that both developmental and physical examinations take place three times during the first month of life (two times in Kazakhstan), then monthly up to age one, and quarterly from age 1 to 2. In Kazakhstan, the quarterly schedule extends up to age 3, and then an annual examination between 4 and 15 years of age. In Ukraine, examinations carried out at 3 months, 3 years and 17 years of age seem particularly thorough.

In Slovenia, a routine psychological assessment takes place at age three to look for behavioural

Table 2.1 Schedule of health check-ups for children in Turkmenistan, 2002

Age of child	Frequency of health check
3-40 days	Twice a week
40 days - 3 months	Four times a month
3-6 months	Twice a month
6-12 months	Once a month
1-2 years	Every three months
2-3 years	Every three months
3-18 years old	Twice yearly + yearly check-up by specialist

Source: 'Provision of Services for Children with Disabilities in Central and Eastern Europe and the Commonwealth of Independent States: A Qualitative Assessment,' Report to UNICEF from the European Academy of Childhood Disability, 2004.

problems. However, in most CEE and CIS countries, assessment for development and especially for behaviour seems to be carried out only if a problem is already indicated. And, as the Turkmen response notes, the skills of family doctors tend to be weak in this regard and need to be improved.

Diagnosis of disabilities

The survey answers on this subject demonstrate that most common disabilities are regularly diagnosed, such as motor disorders, cerebral palsy, and visual and hearing problems. However, the genetic disorder known as Fragile X – the second-most

Box 2.2 A professional prescription for managing disability

In its work on reviewing and looking ahead at health care approaches to individuals with disabilities, the EACD has developed the following seven-step strategy:

1. Prevention

Both public and individual health practices can lower the incidence of disability among children. These include: effective immunization programmes against diseases like measles and rubella; lower birth rates and spacing out births; good prenatal obstetric care. Maternal health and family poverty are important determinants of disability, as are alcohol, smoking and nutrition. Good antenatal and neonatal care can reduce impairments associated with premature, low birthweight and otherwise-stressed newborns. Tests at birth, such as the heel prick for phenylketonuria, can trigger treatment that may prevent or reduce potential disability. Traumatic injuries can be reduced by measures such as child car-seats, safety codes (e.g., fences required around swimming pools) and public awareness and practice of safer behaviours (e.g., driving under the influence of alcohol).

2. Diagnosis

Once disability is suspected or identified, health services try to diagnose the cause of the child's condition. Diagnosis has many outcomes. It can provide the family with an explanation of the causes and characteristics of an impairment, as well as a prognosis and course of treatment. Diagnosis also contributes to the knowledge base for national and sectoral statistics as well as health research, leading to preventative public health measures or individual remedies. Diagnostic processes, however, can require complex facilities and tools.

3. Assessment

An assessment explores the nature and 'range' of the disability in the individual. A child with Down Syndrome can have cognitive ability that ranges from near-normal to very low. Assessment should look at the child's whole functioning, including gross and fine motor function, vision, hearing, speech and language, perceptual and cognitive skills, behavioural status, and social and emotional development. Full assessment requires well-trained staff, typically a multidisciplinary team, with the resources to evaluate each individual case.

4. Treatment

Technically, treatment is curative and for that reason, by definition, does not exist for most children with disabilities. A simple example would be that a child who is born with certain vision problems could be treated (or cured) with laser eye surgery, but more typically would manage the impairment with a strong pair of glasses. A child who is born with a significant degree of myopia (short-sightedness) can benefit from a strong pair of glasses and the impairment may be largely remedied. Similarly, a conductive hearing loss can be corrected – but not cured – with appropriate hearing aids.

5. Management

Children with disabilities may need life-long service and supports. The goal of health care is to ameliorate and develop the functional abilities of the child as far as possible, and in keeping with the goals of the child and his or her family. Management not only involves health service, but educational services and social supports. It typically means that children with disabilities see a range of therapists (speech, physiological, occupational, and psychological). Management will also involve liaison and involvement with social services, e.g., helping the child and family access income supports and appropriate housing.

Care and counselling

Care overlaps with management, but here it implies the provision of an additional service to the child for aspects of her condition that remain unmitigated. Such care can cover a wide range of needs, from training parents to perform at-home interventions like massage, to 24-hour nursing service for a child with severe or complex disabilities. The family of a child with disabilities also needs care and counselling, including good information, psychological support, stress management, and referral to organized peer groups.

Re-assessment

It is essential that children with disabilities be regularly re-assessed for many reasons. Assessment of intellectual and motor function as well as vision is difficult at an early age; hence, there is a risk of error. Social deprivation can give young children the appearance of intellectual impairment, and being labelled 'disabled' may preclude appropriate remedies. Furthermore, as children age, they deserve continuing access to new standards in diagnosis, treatment and management, as well as recognition of the success of supports, interventions and their own efforts.

Source: Bax, Martin and Susan Keane, 'Assessing Childhood Disability', Background paper prepared for UNICEF Innocenti Research Centre. 2001.

common inherited learning disability – is not diagnosed in Bosnia and Herzegovina and Turkmenistan, reflecting a lack of diagnostic capacity. Most countries diagnose specific learning disorders, such as attention deficit hyperactive disorder (ADHD), dyslexia and dyscalculia. Developmental coordination disorders are reportedly diagnosed as they are in the West. However, ADHD is not mentioned in the Russian response.

Availability of diagnostic equipment

Generic facilities such as ultrasound appear to be widely available, but special equipment, such as electro-encephalographs (EEGs), are not. MRI scanners, which provide clear images of the brain, and more simple CT scanners, as well as newer biochemical and genetic tests are also not readily available in many countries and not at all in some. For example, no genetic testing was reported from Bosnia and Herzegovina, and few of the diagnostic facilities listed in the questionnaire were affirmed from Kazakhstan. The Turkmenistan response noted that, in fact, access to diagnostic facilities are increasingly limited due to costs and the lack of chemical reagents and devices required for testing. It was noted that Slovenia regularly uses British, Dutch, Italian and German institutes for procedures involving certain DNA markers and enzymes. A further Ukraine visit qualified a positive survey response on the availability of MRI scanning for children. It appeared that this was only available in the capital.

Assessment procedures

Overall, assessments in CEE and CIS countries appear to take place in health care settings, as they do in Western industrialized countries. In some countries though, such as Croatia, assessments may also be conducted in kindergartens. In all countries responding, paediatricians are involved in assessments, but not necessarily teachers. Some countries, like Hungary, include a role for visiting nurses.

A basic diagnosis and assessment provide important information about the child, but a full assessment of her or his functioning is essential to developing a management plan and providing services and supports that *enable* the child in the fullest way. This type of comprehensive assessment requires a multidisciplinary team of specialists.

According to country respondents, such assessments are done by groups of specialists. However, the type and composition of the group can differ – even within the same country. In Russia, for example, psychological-medical-pedagogical commissions (PMPC), medical-social expertise (specialist) bureaus and children's polyclinics can all carry out such evaluations. And, in some countries like Russia, the specialists in the group each see the child but they do not work as team. This is a crucial distinction that Western experience suggests results in poor information exchange and hinders coordinated service.

Where teams do exist in the region, one specialist

typically acts as leader and, sometimes, other team members act simply as 'consultants'. In some countries, such as Croatia and Kazakhstan, teams appear to be available only in a few or bigger centres. In most countries, different disorders are assessed by different teams. Specialized teams work in Slovenia, but not in other parts of former Yugoslavia. This suggests that progress towards such assessments has been more rapid in some countries than in others.

Interestingly, the specialties of physiotherapy and occupational therapy (basic to disability services in the West) do not exist in Russia, and physiotherapists are not listed in Ukraine among the disciplines involved in assessments. On the other hand, psychologists do seem to be generally involved. In Hungary, child psychiatrists work alongside paediatricians and/or are referred to when a behavioural disorder is indicated.

Use of pharmaceutical agents

Most respondents did not give concrete examples in this area, which may reflect either little availability of drugs or uncertainty about their indicated uses. In some countries, like Bosnia and Herzegovina, respondents say most children with neurological disorders (cerebral palsy, autism, specific learning disabilities, ADHD) do not receive any pharmaceuticals. In countries where pharmaceuticals are used, respondents from different countries cite different drugs for the same condition. Overall, the use of pharmaceutical agents for childhood conditions across the region appears to be driven more by supply factors than by demand, and demand is restricted by financial constraints. Site visits carried out by EACD confirm that many medications are not available and the cost of drugs is high. Moreover, many doctors do not seem to have sound knowledge and clear orientation about the use of such agents. This is how EACD doctors sum up their observations:

The information about drugs available is not very helpful, and some of the drugs listed are not widely used now in Western Europe, and are of doubtful efficacy, Cerebrolysin for example. We suspect that the situation may be worse than realized. In several places, we became aware that the range of drugs available for the treatment of epilepsy was very limited, and furthermore, cost was a problem. ...In Chernihiv, we discovered that the total drug budget for the province was very small, and that after the age of six, children would not get free medication. Furthermore, the only anti-epileptic medication available was Phenytoin. Ritalin, used for the treatment of ADHD (with some reasonable evidence to support this) was not often mentioned.

Re-assessment

Responses in this area show little consistency across CEE and CIS countries and differ at times between respondents from the same country. One

reason could be that the reassessment protocol depends on factors such as the diagnosis, therapeutic programme and form of rehabilitation. In Hungary, re-evaluation is called for at age one, preschool age, school-starting age (six years) and then at least every five years thereafter. In Ukraine, re-evaluation is called for every two to five years. In most countries (e.g., Slovenia, Croatia, Bosnia and Herzegovina, Estonia, Bulgaria, Turkmenistan) reassessment is scheduled every one to two years, while in others (e.g., Romania) reviews take place at shorter intervals (e.g., every six months). Interestingly, FYR Macedonia notes that reviews take place 'on request', which may be closer to the reality than the normative schedules outlined above suggest. Some countries, including Albania, did not answer this question.

Importantly, health practitioners in the region generally say that an initial diagnosis is changed very infrequently. EACD comments: "We were struck particularly when we saw the written-in comments ...that the diagnosis rarely changed." Thus a child regarded as severely learning disabled (mentally retarded) at preschool age will likely have that assessment for the rest of his life. Some respondents did report an evolving approach. From Hungary, it was noted that "as the child's actual needs are changing (due either to pathology or achieved results) reassessment is important." And from Poland: "The three main diagnoses ... are cerebral palsy, autism and dyslexia. These diagnoses are modified after several years."

The fact that there are substantial check-up and assessment protocols in many countries may seem at odds with observations that diagnoses – or perhaps, more importantly, prognoses – seldom change in a positive way. This may involve a number of mutable factors: entrenched attitudes that impairment is a static or deteriorating condition; lack of or limited treatment regimens; lack of or limited enabling supports in the physical and social environment. For example, the rules for receiving benefits such as a disability pension may require periodic reassessments in order to substantiate a claim. In situations where public services such as social security and education have rigid eligibility requirements, parents and care providers may be reluctant to formally change a diagnosis if it threatens access to useful benefits, supports and services.

Very little is known about practices in institutions where a reassessment that led to a re-diagnosis might result in a major change in the life of the child, e.g., being released from the institution. Professionals from some countries (e.g., Russia) note that it is extremely hard to change the diagnosis of a child in an institution and, for example, to say that a child who was once declared 'ineducable' is now 'educable.' There would be, in all likelihood, systemic resistance to such a change. Of course, current thinking – and, in fact, current human rights instruments like the Convention on the Rights of the Child – hold that not only is every child educable, but they have the right to be educated.

Training of health care professionals

Survey responses confirm the existence of specific training in childhood disability for Albania, FYR Macedonia, Georgia and Kazakhstan, but few concrete examples were described. Only Poland mentions, for example, conductive training in the Hungarian Peto method (see Box 2.4). The EACD site visits suggest that, in comparison to the West, post-graduate (i.e., specialty) training for doctors is very short in duration in Russia and other former Soviet countries. EACD comments:

A person can become a paediatric neurologist 15 months after qualifying [as a doctor], whereas in the West this training would take 5 to 7 years with a training programme organized so that the person gets wide experience of all types of disability before becoming a fully qualified practitioner.

Also:

We had to form a judgement that for some of the paediatric neurologists in parts of the countries we visited, the level of training was similar to a nurse's training in Western Europe.... Unfortunately, we found little evidence of training courses for health personnel which were specifically directed towards diagnosis, management and care of children with disabilities.

Moreover, EACD doctors doing site visits in CIS countries found that even leading health professionals are not up on current research and treatment literature; they lack regular access to the Internet and, therefore, international medical journals. Training also appears to be an issue in CEE countries. As the Bulgarian respondent notes: "Recognition of paediatric neurology as a sub-specialty for paediatricians is necessary."

Low status of caregiving

Therapeutic training is just one of the many staffing issues related to working with children with disabilities. These jobs can be physically and emotionally challenging, especially when working with children who have a complex disability or those with emotional and behavioural problems. Many of the caregivers are women who are typically challenged to balance their own work and family lives, and who are systematically underpaid compared to men. Workers in the field often suffer from stress, low morale and low professional esteem because the low value attached to disabled children by societies is transferred to those who work with them, resulting in low-status, low-paying jobs. This is a recipe for continuing problems.

– Moving in Unison into Action, Roeher Institute, 2002

"The personnel of hospitals and residential schools are trained within their frame of reference, but hospitals have no social workers or family advisers on their staff. Residential school personnel have even less

training. Children are tended by women with no formal education, the only people with whom the children have daily contacts. These employees urgently need to be retrained as teachers and psychologists. Trained teachers, defectologists, psychologists and psychotherapists, who may enjoy a higher status and better pay in other spheres, believe there is little prestige in working with mentally retarded and abandoned children."

– Kyrgyz Country Report

2.4 Education, care regimes and disability supports

The EACD questions on education were limited because both those who developed and those who answered the questionnaire were mainly health providers. The questionnaire did ask about preschool education of children with disabilities; whether all school-age children with disabilities receive education and what share are in long-stay facilities; and what special schools exist in the country. It inquired whether special therapists or special teachers are involved with children whose school performance is affected by motor, hearing, sight disorders and learning difficulties. There were also questions on individual disability management programmes; programmes for behavioural problems; use of drug therapy in programmes; drug management; family therapy; and services for transition to adult programmes.

Defectology

In order to talk about education and social services in the region, it is necessary to understand the Soviet science of 'defectology' (see Box 2.3). This approach makes special education the prime remedy for disability, to such an extent that the line between education and health services blurs. "Unlike service delivery in the West, the role of the special teacher [or defectologist] appears to encompass areas of health care and social service," states the EACD. Their report continues:

Interestingly, specialist teachers would be involved with severe learning difficulties according to almost all respondents, whereas only half of them mention speech therapists, and physiotherapists are only mentioned specifically on one questionnaire as being present. Occupational therapy does not seem, therefore, very widely available either for this group of children. About half of the respondents say a psychologist would be involved. Interestingly, the specific questions about deafness produces a picture which we find somewhat odd: ENT [ears, nose and throat] consultants and audiologists as well as developmental paediatricians do not seem to be involved in many countries, so it is hard to understand what medical input, if any, these children

Box 2.3 Defectology: Theory, Practice and Potential

Defectology – literally 'the study of defect' – is a science unique to the CEE/CIS region. The philosophy and approach – that special education is the best way to offset limitations associated with disability – still drives much of the thinking and action related to children with disabilities in the region.

Defectology was developed in the USSR during the 1920s by L. S. Vygotsky. The discipline holds that the loss or weakness of biological functions can best be compensated through development of higher psychological functions. The theory posits that intellectual capacity has endless potential and, if helped by proper educative methods, personal contact and stimulation, it can correct or circumvent impairments in lesser bodily functions. Importantly, special education was supposed to compensate not only for 'primary' defects (i.e., organic impairments in the body), but also to prevent, correct and remedy 'secondary' effects (i.e., the disabling effects of social factors on higher functions) through psychological and pedagogical means. This attention to social causes of disability makes Vygotsky's theory resonate with the current-day social model of disability – and makes it a topic of rediscovery for Western scholars today. However, unlike the social model, defectology focused primarily on changing disabled individuals rather than their social and physical environments.

Defectology was taken up by the Soviet state, and special education was emphasized as the main remedial tool for children with disabilities. In practice, special education was carried out in residential schools and institutions, a practice that segregated children with disabilities and virtually cut them off from society, community and even family. Many children with disabilities were simply deemed 'ineducable' and practically shut away from society. In this way, the practice of defectology has effectively contributed to high rates of child institutionalization in the region.

Since transition, defectology has come under fire in the region, rejected like many other Soviet legacies. Few 'institutes of defectology' exist anymore in CEE and CIS countries, as education centres that offer training in disability rehabilitation change their names. However, defectology remains influential and deeply embedded in many countries of the region.

Indeed, the benefits of 'special education' for children with disabilities – integrated or segregated – is still roundly debated in international circles. And the long-standing use of special education practices based on theories of defectology have proved difficult to change. However, revisiting Vygotsky's work with a fresh eye could help turn defectology in a new direction, and existing practices could provide a stepping stone for more inclusive and rights-based approaches in the CEE/CIS region.

Sources: Ainscow, Mel and Memmenasha Haile-Giorgis, 'The Education of Children with Special Needs: Barriers and Opportunities in Central and Eastern Europe', *Innocenti Occasional Papers*, Economic and Social Policy Series, 67, UNICEF IRC, 1998.

'The Fundamentals of Defectology (Abnormal Psychology and Learning Disability)', book review, *American Journal on Mental Retardation*, Vol. 100, No. 2, 1995, pp. 214-216.

'Vygotsky Centennial Project' (website), Massey University, New Zealand, 1998, <http://www.massey.ac.nz/~alock/virtual/project2.htm>

are having. Again much of the work seemed to be done by specialist teachers. There is a similar pattern for children with vision problems with ophthalmologists and neuro-paediatricians being involved in only half the cases. It is difficult to see how diagnoses for these children are arrived at.

In Russia, for example, training for defectologists involves a basic health curriculum. These 'teachers' then specialize in a specific class of disability: *oligophrenopedagogs* for mentally retarded children; *tiphlopedagogs* for blind and visually impaired children; *surdopedagogs* for deaf and hearing impaired children; *logopedists* for children with speech, mainly articulation, problems. The responses confirm that these special education teachers are involved in rehabilitative services for motor disorders, deafness, visual handicaps and severe learning disorders in CEE/CIS countries alike.

Box 2.4 Therapies made in CEE/CIS

CEE and CIS countries have had limited access to the pharmaceutical drugs used to treat disability in Western industrialized countries. However, a number of notable physical therapy regimens have been developed, and they are viewed as respected alternatives to conventional therapies even in the West. Most are based on the premise that there is a rehabilitative feedback loop between physical therapy and the central nervous system limitation. The idea is that if brain damage limits mobility, then regimented physical motion can teach the brain to govern movement. The therapies are typically directed at children with cerebral palsy.

The Peto Institute in Budapest, Hungary is, perhaps, the best known for its 'conductive education' programme. Teachers, or 'conductors', lead children in how to move, stand, and walk, repeating the exercise routines in an intensive daily regimen of 40 hours per week. The basic theory is that if damage to the brain prevents nerve signals from controlling movement, then putting the muscles and body through the motions repetitively will teach the brain, in reverse, how to make movement possible. Children come to the institute from all over the world and the Peto approach, established 60 years ago by Hungarian doctor Andra Peto, has spread to other countries, including the United States.

The Dévény Method, or DSGM (Dévény Special Manual Technique and Gymnastics Method), is another physical education regimen for children with cerebral palsy; it was developed by Anna Dévény, a Hungarian physiotherapist and rhythmical sport gymnastics trainer. The Dévény Method uses prescribed hand-massage to return mechanical function to contracted tendons, ligaments and joints, and follows up with an applied programme of rhythmic movement.

Sources: 'Mind and Muscle', *60 Minutes*, CBS News, August 18, 2004, <http://www.cbsnews.com/stories/2004/02/24/60ll/main601944.shtml>.

Anna Dévény, 'Brief Summary of the Dévény Method', Budapest, November 19, 1999, www.deveny.hu.

Preschool education and therapy

Questionnaire responses confirm the existence of special education for preschool-aged children with disabilities. Availability, content and funding of such programmes vary across countries. Even within relatively affluent Central Europe, some countries, like Hungary, appear better equipped than others, like Poland. This reflects established practices as well as differences in overall availability of preschool services. In Hungary, for example, 86 per cent of all 3- to 5-year-old children are enrolled in kindergartens, while in Poland the share is about 50 per cent. Preschool enrolment can have a positive role in early identification of health problems and development disorders and in securing access to health and nutrition programmes.⁷³

Availability of preschool special programmes seems to vary greatly even within the same country, with programmes largely accessible in towns and cities rather than in rural areas. Most often the programmes are offered in kindergartens or other types of centres. In some countries (e.g., Slovenia and Hungary) state-funded programmes are sometimes also provided as home services. However, in poorer countries (e.g., Bulgaria, Ukraine, Kazakhstan) parents are expected to pay for early childhood education and care services provided in their homes.

Forward-looking early development programmes

Some countries, like Croatia and Lithuania, now have integrated kindergartens, such as Montessori kindergarten, but in most cases programmes seem to be provided in special centres. Doctors estimate that about two in five young children have access to such programmes. In Hungary, several early development centres now exist that offer a range of rehabilitation programmes, including movement regimens such as Peto and DSGM (see Box 2.4), and speech therapy tailored to the needs of each child. These programmes are the results of NGO initiatives funded partly by state and partly by private contributions. However, as there are no formal registers, assessing actual service need and scaling up such initiatives is difficult.

Generally, preschool programmes for children with disability appear to be scarce in villages and remote areas. Many respondents say if such kindergartens exist they are largely privately funded. In some smaller and war-affected countries, like Bosnia and Herzegovina or Georgia, international organizations like UNICEF and NGOs have had a major role in securing such services, but access remains limited. In Armenia, for example, some facilities exist in Yerevan, but most young children registered with disability across the country do not have access to such programmes. Many survey respondents also note the lack of trained instructors for early development programmes.

Access to education

Most respondents report that not all children with disabilities are in schools; some are placed in long-

stay social facilities, such as orphanages, while others reside in hospitals or health centres. Few respondents could provide the actual numbers of children with disabilities who are not in school, but estimates ranged from 5 to 30 per cent. In Kazakhstan, for example, 6 per cent of children with disabilities are in long-stay health facilities, with another 4 per cent in social facilities. In some countries, such as Albania, doctors explicitly say that the share of such cases is 'not known'. In Russia, doctors also say it is difficult to answer this question because there are three ministries with jurisdiction – health, education and social care – and each keeps its own statistics.

The respondent from Hungary noted that only children with the most severe disabilities are placed in hospitals. In Bulgaria, doctors say that most children with 'mild mental retardation' attend special schools. In Turkmenistan, children with disabilities attend school only if parents or other relatives are available to accompany the child; generally no special help is provided. In several countries, doctors say that school-age children can be educated in their home by school teachers, but this rarely seems to happen.

Going to school – even in a special education programme – is especially difficult for young children who have been placed in infant homes soon after birth, given up by their parents or separated by a court decision. In Russia, for example, one out of every five young children who move on from infant homes to other forms of care at age four are deemed 'ineducable'. In 1999, for example, 1,261 young children were transferred from infant homes to 'social protection residential institutions' for this reason. EACD comments:

Clearly in countries in many parts of Eastern Europe some young children are placed when they leave hospital at the age of around four weeks, in some sort of 'orphanage'. Children with disabilities seem to move on from these orphanages around the age of four to some special provision. Involvement of parents in these facilities is minimal. Virtually in all Western European countries now large orphanages or residential schools for children with disabilities have been substantially reduced in number over the last 40-50 years. The emphasis is now on placement of children, where possible, within mainstream schools, most importantly with maintenance of children in their own homes. Appropriate services are provided in the school and the home.

Special education programmes

The system of special schools, largely built up before the transition, is still in place in the CEE and CIS region, but country respondents confirm that the idea of inclusive education is gaining hold. Many CEE countries have special schools for children with visual impairments and for children with hearing and speech problems. Some CIS countries, like Ukraine and Armenia, also have special schools

for children with movement (motor) disorders, usually those with cerebral palsy. In Russia, eight types of special schools exist: blind, visually impaired, deaf, hearing impaired, motor problems, speech problems, development delay, and mental retardation. This pattern is largely repeated in other countries that were formerly part of the Soviet Union. Armenia for example, has the same types of schools, as well as special schools for children with behavioural problems. (The Russian respondent says the latter should also exist in Russia, though not as part of the special school system for children with disabilities.) This 'defectology' type of classification system raises questions about how well children with complex or multiple disabilities fare in these highly specialized settings.

Residential schools

In theory, even highly specialized schools can operate as day schools; indeed, in some countries, most special schools do not have boarding facilities. However, accessible transportation can be a problem even in cities, and it is almost insurmountable in rural areas. In smaller communities, there are also simply too few children with disabilities to justify running special schools. The more specialized education is, the greater the probability that it will only be available as a residential school, which means needy children will largely grow up in institutions away from their families. In Armenia, for example, it was estimated that about two-fifths of children in special schools are in boarding arrangements. Aside from any initial impairment, these children face the attendant risks and impacts of institutionalization on their physical, cognitive, psychological and social development. On the other hand, special schools are often seen in a positive light because they offer peer contacts for children with disabilities in ways, such as friendships, that may not be available in communities due to stigma and discrimination. In countries where few special schools exist in rural areas, children with disabilities often miss going to school altogether.

There is little other than anecdotal information available about the quality of services and life in boarding schools and homes. The EACD comments, "The reputation of these residential facilities is not good," and quotes a UK visitor's impression of military-style methods: "unquestioning acquiescence... went beyond obedience to the point that [children] would stand up or sit down straight away without being asked, and this was clearly born out of fear."

Intellectually, children with disabilities are at particular risk of exclusion. In Russia, in 1999, facilities for children with developmental delays included 173 special homes holding some 10,000 children, and 198 special boarding schools with another 25,000 children. Most of the children were considered intellectually disabled. The Russia Country Report says a further 7,000 intellectually disabled orphans and children deprived of parental care were placed in other special schools for the disabled. The EACD comments:

One feature of that report is that it outlines the feeling about the attitudes of many Eastern European countries towards disability and that is that the children were not really accepted by the community. The placement of these children in large residential settings away from the main urban areas means that disabled people were not seen and had a very low status within their communities. It seemed to us that the general public lacked compassion for the disabled because for many years they had been regarded as 'sub-citizens'.

The Mental Disability Advocacy Center (MDAC) is an international non-governmental organization based in Budapest that promotes and protects the human rights of people with mental health problems and intellectual disabilities in the CEE/CIS Region. MDAC has been particularly active in pursuing the ban of 'cage beds' used to restrain disabled residents in public institutions. www.mdac.info

Managing children with behavioural problems

Survey responses show quite a difference between CEE and CIS countries in terms of support for children with behavioural problems. In Russia and most CIS countries, children with behavioural disorders can easily find themselves in *internats* (boarding schools) for young offenders, as few if any family-centred management programmes exist. Educational programmes are only offered in institutions of a 'corrective' nature, and several CIS countries frequently use drug treatment for behavioural problems.

On the other hand, in Central European countries, as well as Bulgaria and Romania, drugs are used infrequently and both specific management programmes and special educational programmes are offered to help children with behavioural problems. Family therapy – involving psychologists, psychiatrists and, at times, special teachers – is available, but access is limited. This appears to be particularly true in countries of the former Yugoslavia: in Croatia, educational programmes exist only for children with ADHD, and in Slovenia, only one private institution offers programmes and at a fee. Bosnia and Herzegovina and FYR Macedonia have neither specific management nor special educational programmes for such children.

Education integration

There is some evidence that children with disabilities in CEE and CIS countries have greater access to attendance at mainstream schools. In the EACD questionnaire, two thirds of the respondents say this approach is possible. Still, many say only children with minor or certain types of disabilities can attend mainstream schools. And, as noted earlier, defining a wider swathe of children as disabled or having special needs may give the illusion of greater integration.

Minor or physical disabilities can, indeed, be addressed by environmental adjustment or by technical aids such as wheelchairs rather than by enrolment in specialized programmes. Still, as some respondents note, there are problems: "There are talks about inclusion but it happens very rarely" (Russia); "The process of integration has a spontaneous and unmanageable character" (Kazakhstan). Integration also sometimes happens out of necessity because the network of special schools is insufficient, e.g., geographically sparse and, therefore, unavailable on a day-school basis.

To support children across the range of disabilities in mainstream education, schools require proper infrastructure, transport and support services, well-trained teachers and aides. The lack of such services hinders integration, even in countries where the law requires mainstream schools to accept children with disabilities. In Albania, for example, such a law remains poorly implemented due to financial and human resource constraints. Similarly, the Polish respondent notes, "Integration...is very good in theory but not in reality because of lack of well-prepared teachers.... In classes with integration, a special learning therapist helps the teacher, but not sufficiently." More respondents note little support for children with disabilities in mainstream schools: "Up to five extra individual teaching hours weekly can be assigned" (Slovenia); "So far, no special help is available, but a project on training of teachers and caregivers is in progress" (Georgia); "Regular schools are not ready for accepting children" (Turkmenistan), with the added suggestion that efforts focus on teacher training, text books, and special equipment for children attending special schools.

Access to public spaces

Transportation and the built environment still present significant barriers to the participation of children with disabilities in society. The 20 survey respondents rated access to each of the five aspects of the physical environment noted above as 'simple' or 'difficult'. Of the 100 results, respondents said access was 'easy' just 18 times, and 'difficult' 82 times.

Helping families at home

Disabled families

Typically, when a child is disabled, so is the family. Disadvantage of the family may be a contributing factor to or a result of children with disabilities – or both. Fulfilling the rights of the child with disabilities clearly involves supporting the family's capacity to carry out its duties to the child. Families and their members also experience discrimination and harmful stigma associated with disability. The financial, social, physical and emotional resources of the family are likely stressed, sometimes severely. Siblings may feel a lack of attention or assets. Families can break apart, with the father typically leaving or failing to contribute to the care of the child with disabilities. Families can also be enriched

Box 2.5 Out and about: Breaking down physical barriers

"This year my child has not attended school for three weeks altogether. It was not his fault – it was either the driver who was ill or the bus was broken."

Modrite, mother, Latvia

"He cannot go to school because of the stairs."

Mariana, mother, Bulgaria

"We have a taxi provided by social services, but this is not really of help because you are only allowed to use it once every two weeks."

Luka, father, Russia

"[I wish] that I could take part in events, go somewhere where children who are not disabled can go."

Krista, girl with disabilities

The modern disability movement dates back to the 'Rolling Quads', a small group of wheelchair users in California in the late 1960s who insisted on being allowed to attend university and live on campus. Access to buildings, transportation, public places and public spaces, information and communication are critical first steps to the participation and inclusion persons with disabilities.

In Poland, the 'PEGASUS' initiative of the Government Ombudsman for the Disabled provides interest-free loans for individuals and families to buy or retrofit a vehicle to accommodate a disability. Building regulations state that all newly built public buildings must be accessible. The State Fund for the Rehabilitation of Disabled Persons (POFRON) provides loans and financial contributions for removal of barriers in existing buildings, both residential and service, cultural and public institutions. Streets are also being adapted, e.g., low curbs, audio signals at pedestrian crossings. NGOs and public media have contributed considerably through a campaign called 'a struggle against three steps' (*Integracja*, 2001).

In Chisinau, the capital of Moldova, a communication centre for all children and teenagers was opened with the help of UNICEF and international NGOs in 2001. According to the Moldova Country Report, "Almost all the disabled children coming to that centre have an experience of more than one year of reclusion in their apartments." Psychological support is an important first support for these isolated children and youth, most of whom either have cerebral palsy or are teenagers with spinal column traumas. Newcomers are taught to communicate with other children of their age, to move around in a wheelchair, to observe basic rules of personal hygiene and food consumption, to develop the skills of managing without external assistance. "Unfortunately, that centre is but a small oasis available only to those living in the capital city."

The Georgia Country Report says that despite a special authority to supervise accessible building, "the situation in the country as regards accessibility is very complicated" and includes problems such as hard financial conditions, challenging geography, inherited structures and attitudes, and lack of political action. No 'accessibility' priorities are set and no rules defined, making implementation and enforcement difficult. "Mass media facilities do not meet the needs of the disabled. No books in Braille are published. Informational and other telecasts are not translated into dactylic [finger spelling for the hearing impaired]; currently there is only one TV channel that broadcasts one daily 15-minute informational program. There are no special transport facilities for disabled people, and so on."

In some central districts of the capital Tbilisi, an NGO called League of Disabled Persons has arranged special slopes from the pavements to the roadway. "The League has also imported special buses from the USA, the back doors of which were designed for the disabled people. During a number of years these buses moved along the city routes, but however the back doors never functioned. Certainly the efforts of this single organization are not enough to solve the general problem," states the Georgia Country Report.

In Kyrgyzstan, with support from international NGOs, the National Specialized Residential School for Blind Children has purchased a Braille printer. There are already pilot Braille textbooks in the Kyrgyz language. The school has a computer class equipped with talking computers for the blind.

Sources: Georgia Country Report, Poland Country Report, Moldova Country Report, Kyrgyzstan Country Report, 2002.

by the inclusion of a 'special' child, but that does not lessen their need for support. The bottom line is that supports and services must consider the whole family, not just the child with disabilities.

Facilitating de-institutionalization and inclusiveness is directly related to adequate supports for families of children with disabilities. The EACD assessment notes a number of ways these services need to be improved. It is a very positive outcome of social reforms over the last 15 years that most countries in the region have built up a network of public social workers who help disadvantaged families in their

own homes. However, as the EACD assessment shows, refinements are needed to make this network effective for children with disabilities and their families. For example, social workers trained in dealing with children with disabilities seem to be lacking; and only two country respondents (Estonia and Croatia) claim to have a system where social care and health care is integrated. Generally, social workers are not notified when doctors diagnose a child as disabled. Some countries, like Turkmenistan, still do not have a network of social workers.

While most respondents say therapists and teachers are available to help children at home, this actually

seems to be the exception rather than the rule. Respondents from Russia and Albania explicitly say home-based therapy does not exist.

Respite care

In Western countries, placement in alternative care for a short time (e.g., a weekend or holiday period) to offer the child with disabilities a new experience and her or his parents a break is now seen as one of the most important measures to help families of children with disabilities at home.⁷⁴ The trend is to develop community facilities and host families to provide this care. It is striking that this form of support is practically unknown in CEE and CIS countries. None of the 21 respondents say respite care is available as an established family- or community-based service. Existing solutions for urban families usually mean putting the child in a hospital (Ukraine and Slovenia say special kindergartens accept children for short periods), while rural families turn to relatives and other informal arrangements.

Participation of parents

It is clear from the EACD assessment that families

have very little involvement in decisions that affect the life of their child with disabilities, in CEE and CIS countries alike. This is in sharp contrast with developments in Western countries, where parental involvement is now a well-established, basic principle of all aspects of services for children with disabilities. Respondents from countries as distinct as Hungary, Bosnia and Herzegovina or Russia agree that “provisions in health and education services for children with disabilities are not the subject of parental choice.” Several other respondents – from Slovenia, Bulgaria, and Georgia – say that parents can choose whether the child goes to an institution or remains at home, and what centre the child goes to, but these responses imply parents are given only the barest of choices. The Armenia respondent says the law stipulates parental consultation but suggests this does not always happen.

Parental groups and NGOs

In Western countries, parental groups and NGOs have played a lead role in improving choices and delivering services for children with disabilities and their families. Some progress in this regard also

Box 2.6 Key role for parents' groups and NGOs

Around the world, parents' groups and civil organizations have played a pivotal role in promoting and achieving positive change for disabled children. Local, national and international NGOs are growing to varying degrees across CEE and CIS countries but, first, they must overcome a legacy in which the state ran centralized institutions and organizations organized by type of disability. Disability-specific associations were long the dominant form of organization in Western nations, as well, and have evolved in response to grassroots disability groups that have emphasized disability rights, independent living and the societal aspects of disablement.

The Croatia Country Report captures the distinction: “In spite of their undoubtedly important positive role in the life of disabled persons, unfortunately, [national disability-specific organizations] somehow encourage the isolation of persons with a particular disability, having in mind that persons with the same disability will presumably socialise among themselves and thus make their own closed little circle. Another type of associations for rendering aid to persons with disabilities are those that gather like-minded persons, with or without disabilities, whose aim is to help their co-inhabitants with disabilities through their activities.” Of the latter type, the report mentions IDEM (‘I go’), a group dedicated to integrated education, and the Association for Promotion of Inclusion, devoted to independent living for adults with mental retardation.

The Czech Republic Country Report also notes the difference: “After the principal social changes at the end of the 1980s, the disabled began to feel a different approach. Whereas disabled persons were associated in a single state-controlled organization (Association of the Disabled) during the totalitarian system, dozens of both state and non-state institutions care for them in the last ten years.”

As the Ukraine Country Report notes: “Today NGOs for the disabled in Ukraine are an important indicator of the formation of civil society, and its ability to organize itself. Of the 18,000 non-governmental organizations in Ukraine, more than 900 engage mostly in the problems of the disabled, while 38 organizations have disabled people among their members.”

In Poland, there are over 6,200 NGOs concerned with disabled persons, most founded by persons with disabilities and family members. Almost 2,000 groups are dedicated to disabled and sick children; their work deals with access to education, medical benefits and drugs, rehabilitation and new therapy methods, and integration into the community.

In 2001, the National Society of the Red Crescent of Turkmenistan provided humanitarian aid, toys, gifts and celebration events for hundreds of children with disabilities. In Kyrgyzstan, through state undertakings with the UN and INGOs, the Ministry of Public Health and Save the Children (Red Barnet) cooperated in the establishment of a centre for the re-integration and rehabilitation of orphaned and disabled children. Since 1999, the first Kyrgyz day-care centres for children with disabilities have been built with funding from Mercy Corps USA, and Save the Children, Denmark.

Sources: Croatia Country Report, Czech Republic Country Report, Ukraine Country Report, Poland Country Report, Turkmenistan Country Report, Kyrgyzstan Country Report, 2002.

seems to have taken place in CEE and CIS countries over the last decade (see Box 2.7). Croatia, Estonia and Ukraine respondents say parents meet regularly to plan their child's future, but this is less the case in most other countries, including Hungary, Poland, Lithuania, FYR Macedonia, Russia and those in the Southern belt of the region. But, even in these countries, doctors say local and international NGOs now deliver important services and act as interest groups where parents can get information and support.

Becoming an adult

The transition from childhood to adulthood is an especially critical passage for disabled youth – and it is often marked by a crucial gap in services and supports. Indeed, survey responses to this question mention few opportunities for disabled young adults in CEE and CIS countries. It appears that, in most cases, they stay with parents (at least while the parents remain alive), and many, especially those in difficult conditions, go to boarding institutions for disabled adults or long-stay hospitals. Lithuania had one of the few respondents who reported a planned handover to adult services. The Bulgaria respondent said, "Some programmes for persons with blindness, deafness and cerebral palsy have started over the last years but no special programmes for the mentally retarded [exist]." The Slovenia response notes that "some adolescents attend day-time workshops where they perform craftsmen products."

Family formation

The Estonia Country Report was the only one to address the issue of family formation among young people with disabilities. It reported that one in four disabled persons in the age group 15 to 29 are married or cohabit. Most live in two-member households, and two thirds are married to or cohabit with a person with disabilities. Another 28 per cent live on their own in single-member households. In terms of household status, 68 per cent of young people with disabilities belong to the same household as their parent(s) and have no spousal partner or child in the same household; 3 per cent have the status of spouse; 7 per cent are cohabitation partners; 2 per cent are single parents; 12 per cent live in one-person households; and 8 per cent have some other status in the household.

– Estonia Country Report 2002

Policy intentions

Almost half of the respondents in the EACD-UNICEF Survey left blank the open-ended question about the guiding intentions behind existing policy and legislation. This may indicate that government objectives are not clearly defined and/or communicated to key service providers. Answers given include "improving living" (Ukraine – though in practice this often means institutional placement); "non-institutional rehabilitation" (FYR Macedonia); "early intervention" (Lithuania); "harmonizing legislation with EU"

(Bulgaria); and "human rights" (Armenia). The Hungary response mentions equal opportunities, as does Russia, along with the goal of improving living standards. The Bosnia and Herzegovina response says there are "no really clear guiding intentions, legislation is mostly older than 30 years."

When explicitly asked, most respondents agree that keeping the child with the family is a guiding policy intention, but few mention concrete policies and programmes that support this intention. Financial

Box 2.7 Positive initiatives in CEE and CIS countries

Many promising initiatives for the disabled have taken root in CEE and CIS countries. Many, if better implemented and/or scaled up, could considerably improve the quality of life of children with disabilities. Here are some examples mentioned by respondents to the EACD-UNICEF questionnaire:

- *Hungary* – The law requires all public and private institutions to provide access with elevators and ramps.
- *Poland* – Improved services and structures are available for parents of autistic children. Neonatal services, such as the Warsaw Institute of the Mother and Child, place increasing emphasis on the social aspects of care provision.
- *Bosnia and Herzegovina* – Integrated education started in 2002 when 120 elementary schools began accepting children with mild learning disabilities.
- *Armenia* – A Disability Register was established in 2001 by the Ministry of Social Security for persons recognized as disabled by a government medical-social committee. The country has a de-institutionalization strategy for children with disabilities promoted by UNICEF, the Ministry of Social Security and NGOs active in this field.
- *Georgia* – A resource centre for psychosocial and cognitive development of children has been set up with help from UNICEF.
- *Ukraine* – More than 200 'social societies' offer an alternative to institutes of the disabled for young persons with disabilities.
- *Russia* – Since 1995, rehabilitation centres for children and youth with disabilities have been opened under the jurisdiction of the Social Care Department. One of the aims is to provide support to 'ineducable' children and to act as an alternative to institutional care.
- *Kazakhstan* – Where once no programme existed for families with children with behavioural problems, the SATR Centre now offers family therapy.
- *Turkmenistan* – Most of the effort for mainstreaming children with disabilities comes from local government through quasi-NGOs like the Youth Union, Women's Union; NGOs like the Para-Olympic Committee and local groups; and international charities and businesses.

Source: 2002 Country Reports to UNICEF IRC; "Provision of Services for Children with Disabilities in Central and Eastern Europe and the Commonwealth of Independent States: A Qualitative Assessment," Report to UNICEF from the European Academy of Childhood Disability, 2004.

constraints, poor coordination among different services, poor implementation of legislation, lack of day care and family-based services, and discriminatory public attitudes all play a significant role in

compromising the opportunities for an adequately supported family upbringing. Several respondents, however, expect a greater role for health services in keeping families together.

Notes

- 63 EACD is well situated to conduct a qualitative account of services for children with disabilities in CEE and CIS countries. It is an authoritative association of European health professionals, including many members in formerly non-EU CEE states. It previously conducted an assessment of services for children with disabilities in 14 EU states, a useful reference for assessing services in Eastern Europe.
- 64 See the review of maternal and infant mortality rates in Chapter 2 of this report, and the evidence that the quality of maternal and child health services varies greatly in CEE and CIS countries.
- 65 More than 9,000 different single-gene conditions have been identified as causes of congenital anomaly.
- 66 Respondents to the EACD health professionals survey included 8 paediatric neurologists, 3 general doctors and/or paediatricians, and one of each of the following professions: paediatric neonatologist, neuropsychiatrist, developmental neurologist, psychologist, paediatric psychiatrist, developmental paediatrician, child protection officer, social worker, disability specialist, physiotherapist, director of rehabilitation centre.
- 67 Nelson, Karin B., 'Can we prevent cerebral palsy?', *The New England Journal of Medicine*, Vol. 349, No. 18, October, 2003, pp. 1765-1769.
- 68 World Health Organization, 'Towards a Common Language for Functioning, Disability and Health: ICF (The International Classification of Functioning, Disability and Health)', 2002, www3.who.int/icf/beginners/bg.pdf.
- 69 Dosa, Laszlo, 'Caesarean section delivery, an increasingly popular option', *Bulletin of the World Health Organization*, Vol. 79, No. 12, Geneva, 2001. [http://whqlibdoc.who.int/bulletin/2001/issue12/79\(12\)1171-1173.pdf](http://whqlibdoc.who.int/bulletin/2001/issue12/79(12)1171-1173.pdf)
- 70 Amniocentesis raises concerns, as the invasive procedure carries a risk of inducing miscarriage and because disability advocates maintains it is associated with the termination of pregnancies where positive test results are received.
- 71 See UNICEF, *Women in Transition*, Regional Monitoring Report No. 6, UNICEF International Child Development Centre, Florence, 1999.
- 72 World Health Organization, 'Eliminating Iodine Deficiency Disorders', Nutrition/Micronutrient Deficiencies, www.who.int/nut/idd.htm.
- 73 UNICEF, *Children at Risk in Central and Eastern Europe: Perils and Promises*, Regional Monitoring Report No. 4, UNICEF International Child Development Centre, Florence, 1997.
- 74 In a recent qualitative survey in the United Kingdom, for example, parents of children with disabilities gave priority to respite care over access to other measures when asked about their support needs. Cited in Dowling, Monica and Linda Dolan, 'Families with Children with Disabilities: Inequalities and the Social Model', *Disability and Society*, Vol. 16, 2001, pp. 21-35.

3

VOICES OF CHILDREN AND PARENTS

Focus Groups and Interviews

■ *Children, parents and service providers on life for children with disabilities*

Who is taking into consideration children's rights? No one is.

Sergei, 16, living at home, Bulgaria

The right of a child to express her or his views and to participate in the decisions that affect them is an important principle of the UN Convention on the Rights of the Child. However, the voices of children with disabilities have historically been little heard. This study takes some small steps towards addressing that deficiency. This chapter presents the results of focus groups and individual interviews of children with disabilities, their parents and service providers. The interviews were conducted by Oxford Research International Ltd. on behalf of UNICEF IRC.

The qualitative research was conducted in three countries: Russia, Latvia and Bulgaria. The limitations of doing research in only three of the 27 countries in the region are recognized. However, these countries represent three different stages of the regional transition from communism, and each country is distinguished in its own way.

Russia is also the largest country by far in the region, in terms of territory and population. It not only has the largest number of children with disabilities, but still exerts significant influence on its CIS neighbours when it comes to policies and practices. This original research, speaking with those most affected by disability, would also add an important voice to concerns about the human rights of children with disabilities in Russia.

Latvia, one of the small Baltic States, formally joined the European Union on May 1, 2004. It must meet the 'Copenhagen criteria', which state that it be 'a stable democracy, respecting human rights, the rule of law, and the protection of minorities'. This provides an important impetus for promoting and protecting the rights of children with disabilities.

Finally, Bulgaria, which has applied for EU accession and hopes to join in 2007, is a South-Eastern European country that has been internationally criticized for institutionalization of persons with disabilities and contravention of their rights.⁷⁵

The aim of this research was to understand the lives of children with disabilities from the perspective of the children themselves, their parents and the providers of services. Nevertheless the research illustrates the meaning of disability for children, their parents and their providers in their countries and could be a qualitative model for other countries who may wish to conduct their own research and to compare findings. Not only is the topic and the client group under-researched, but there is a general dearth of published work from CEE and CIS countries.

3.1 Methodology

Children, their parents and service providers from particular regions in all three countries were interviewed individually and in focus groups. Parents and children and young people often felt more confident to express their views in the larger focus group. When the views of the group are conveyed, they are common to all members and do not represent any one member's viewpoint.

Focus groups and in-depth interviews were held in February and March 2003 by researchers from Bulgaria, Russia and Latvia. Twelve focus groups – four per country – were organized with children with disabilities between 8 and 17 years. The range of disabilities included: spina bifida, muscular dystrophy, hearing and sight problems, bone tuberculosis, and cerebral palsy. (The fact the children could participate in standard discussion techniques indicates a certain level of communication skill – a selection effect that points to an inherent limitation of this investigative technique.) Two age cohorts were developed so that younger children had as much opportunity to have their say as teenagers. To understand the differences for children living at home and those in institutions, 18 in-depth interviews were conducted – half with children living at home and half with those living in an institution.

Parents took part in nine focus groups – three per country – and 18 in-depth interviews – six per country. Service providers took part in 30 in-depth interviews. In each country, there were interviews with: three educationalists, three doctors/therapists and two care providers in institutions, and two social workers.

In total, 245 children, parents and service providers provided a range of answers to a series of open-ended questions on disability, its effect on their lives and the effectiveness of services provided. While the findings are not representative, they are illustrative and provide important insights into the experiences of both those children with disabilities and those who care for them.

3.2 Family Care

Children, parents and care providers generally agreed that it is better for a child with disabilities to live at home rather than in an institution. (Only 62 out of 124 children involved in this research were living at home). However, in some countries, there remains a practice of advising parents of an infant with disabilities to immediately place the child in an institution. In Bulgaria, for example, the number of young children in ‘infant homes’ – about 3,000 children in some 30 institutions – remained relatively unchanged over the transition period, from 1991 to 2001; about one third of these children were considered ‘unhealthy’, and most of those had disabilities. As the Czech Republic Country Report states: “Prospects for the child’s development are often explained to parents without participation of a social worker, and it is mainly the medical aspect of the problem discussed. If the parents themselves are not capable of seeking out more detailed information, the decision to place the child in an institution is prompted by a lack of objective information on the family’s future prospects.”

Children with disabilities frequently stated their preference for being with their families:

“For me, my first home was the nursery, then school and friends from school. Now this is not like my second family, but ... how can I say

it ... well, there is something wrong with that. This is a family too; we are all friends, but...”

Luda, 17, living in an institution, Russia

“For me, it is better to be in a family, because in this home, everyone will leave, we will separate [...] the family can support you and give you everything.”

Misho (male), 13, living in an institution, Bulgaria

Most discussants stressed that more effort was needed to enable children with disabilities to live at home:

“Support for the mother is needed and she will then do everything for her child. She knows her child better than anybody else. All children are different, an individual approach is necessary. So care about the mothers and they will make their children happy.”

Vera, mother, Russia

It was noted from several perspectives that the presence of a child with disabilities often means increased stress for the entire family. In this study, children who were cared for at home often came from single-parent households:

“Typically fathers go into a deep depression and do not participate [in family life] any longer or, more often, leave their family.”

Karina, mother, Russia

“The father of my daughter simply could not bear it. He could not accept that his child is like this, and we separated.”

Vilhelmine, mother, Latvia

“Usually the able-bodied children are pushed away in the family and they start to hate the child.”

Ilvija, doctor, Latvia

“In a family where there is a disabled child and a normal child, the normal one is deprived of a normal childhood.”

Nina, mother, Bulgaria

“I have a healthy child who helps him, but I also understand how I am burdening him.”

Irena, mother, Bulgaria

“My daughter feels constant discomfort at having a disabled sister. She is not open about that with her friends.”

Polina, mother, Russia

Public prejudice results in the whole family suffering, not only the child with disabilities:

“Seniors, I mean 60 and older, are openly hostile. ‘How horrid!’ is the most frequent comment I’m used to hearing from them. They are pretty sure that if a child is ill, then the parents are either alcoholics or just bad people [...] I also know one lady who tried to commit suicide after hearing bad jokes about her and her child.”

Violetta, mother, Russia

“When my child was three or four years old – I will never forget this – we were in a park and

he went towards other children. His movements were less coordinated, but he was happy; he did not understand mockery at this age. The children looked at him with interest, but the two mothers took their children's hands and took them to the other end of the park."

Nina, mother, Bulgaria

The most acute issue for parents in all three countries was financial difficulty. Many parents said they had to stay at home to care for their child with disabilities and thus they did not have enough money to support their family. They reported discrimination when applying for jobs and lack of flexibility to look after their child or children when they did succeed in getting work:

"How is it possible with 30 leva [15 euro] in child support and 28 leva [14 euro] in invalid support [...] to feed your child, to buy textbooks, notepads and pay all the school fees?"

Ralitsa, mother, Bulgaria

"There are money problems. Right now we are surviving, not living."

Rita, mother, Latvia

"We need twice or three times more money."

Irena, mother, Bulgaria

"[What needs to improve is] the standard of living. Families should be able to take care of their children... [Also,] the awareness of society, because many times families with disabled children are not treated well by their neighbours. But the most important is the financial aspect. Such a child needs more care, special medical treatment. It is very different when a family is financially stable and the mother can stay at home and take care of the child."

Kristina, institutional caregiver, Bulgaria

Parents also raised the issue of better incentives, such as tax breaks to promote donations, sponsorships and other forms of contributions from individuals, community groups, NGOs, businesses and philanthropic organizations. The idea is that private and corporate citizens would prefer to make charitable donations to disability-related initiatives if it reduces their taxes:

"Private firms and individuals can also help if there is a change in legislation – for example, a law on sponsorship. If I am a businessperson and I have to pay the state 100 leva [50 euro] in taxes, I will prefer to give it to a child so that parents can pay for a high-quality medical examination."

Alexandra, mother, Bulgaria

"At home I am a rehabilitator, a pedagogue, a service provider, and everything [...] I am already on the edge. I feel that I am almost at the end of my tether, both physically and mentally."

Violeta, mother, Bulgaria

"Without the support from relatives I could do nothing. It is the only thing. Both the psychological and material support from relatives [...] You feel alone and ignored. You are with your child without any special education. I was 20 when she was born. It was very hard."

Vilhelmine, mother, Latvia

The problem of isolation was stressed by parents. Western research shows that stress is particularly great for mothers who are almost exclusively the primary carer in the home, the one to forfeit employment opportunities and almost invariably the head in a single-parent household. Significantly, parents said they preferred communicating with other parents of children with disabilities. They explained that they knew they would be understood and they could communicate much better than with other people:

"I had to give up my career; I had no strength to combine it."

Aelita, mother, Latvia

"We cannot visit someone, nor can somebody visit us."

Irena, mother, Bulgaria

"You stop contacting people. Your friends forget about you."

Ralitsa, mother, Bulgaria

"I like communicating with parents who have a problem similar to mine, because we understand each other at a glance. It is not necessary to say that it is hard. If I see [people like the ones here in the group] or someone else, I know exactly how they feel. They do not have to tell me."

Nina, mother, Bulgaria

Parents expressed interest in organizing self-help groups – which have proven to be very effective sources of support and advocacy in western countries – but they stressed that they would need support in order to start up such groups:

"Maybe we, the parents, should meet like this and try to help each other somehow. If we count on institutions, nothing will ever get done."

Veronika, mother, Bulgaria

"I have a suggestion: I visited a centre in St. Petersburg... It is organized by parents themselves, in many districts of the city, and parents work there as carers in shifts. This is not mandatory, but actually everybody likes to participate. Other people with similar problems come [...] Everything is organized by parents."

Grigory, father, Russia

"We'd [like to] build a house for us, invite sponsors and do work for them and for ourselves."

Karina, mother, Russia

3.3 Institutional Care

Most participants believed that children with disabilities should be raised at home. However, some felt that institutional care can have positive aspects. This divergence of opinion is largely attributable to the lack of supports for keeping children with disabilities in their families and communities, and the economic hardships experienced by many families:

"It is not possible to argue that institutions [special schools, boarding schools] should be closed down. Such institutions are especially important for disabled children from disadvantaged families."

Leonards, teacher, Latvia

Institutions were seen as offering better access to educational services, primarily because all necessary services were accessible on-site, and financial support existed:

"Well, in the first place it is truly better to be in a family. But there are things in families which are not available. They don't have the possibility to provide a computer, to give you new sports shoes, new clothes or to eat meat twice or three times a week."

Milena (female), 16, living in institution, Bulgaria

Parents complained that children living in institutions received more money from the state than those living at home:

"If a child is in a boarding school, then the state pays 150 lats [240 euro] for a child per month. How can it be compared [to what we receive]? If a child grows up in a family, the only money the family receives is 35 lats [56 Euro] in disability allowance."

Amanda, mother, Latvia

Children in institutions generally had little or no contact with their parents:

"I need more [love and affection]. I am in a boarding school. I see my parents rarely."

Eva (female), 12, living in an institution, Latvia

The Azerbaijan Country Report notes: "There was never a single reason for a family to institutionalize their child. It was always a combination of factors, including poverty, unemployment and the break-up of the family."

Most of the children enjoyed supportive relationships with peers. However, major difficulties appeared when young people were due to leave the institution. Service providers admitted that young people are badly prepared to move on from institutions:

"They are not ready for an adult, independent life and many become alcoholics. They do not have something to call home [...] so many go nowhere. What they need is a family. And the family is not this institution..."

Petr, doctor, Russia

For institutionalized children with no family to support them, their entry into adult life can be forced

and abrupt. They are at high risk of poverty and homelessness, alcohol and drug use, violence and abuse, economic, sexual and criminal exploitation, and further involvement with state systems such as prisons, hospitals for the mentally ill and intellectually disabled, and other adult institutions.

Although children did not talk about it directly, the researchers noted that those who live in institutions appeared less mature. Because children are cut off from family and community life, they do not learn how to respond effectively to the demands and opportunities of everyday life. Additionally, poor preparation for the job market means youth were not ready to move into the workplace – which is equally ill-prepared to take them up. Service providers blamed the inadequate life skills of these young people on the nature of institutions, insufficient funding and lack of cooperation among organizations:

"We have computers but we need a specialist to teach the children how to use them. We were also thinking about a 'young housewife room' – a little kitchen where they can learn how to cook [...] The financing could be better; this way we could do more for their future."

Kristina, institutional caregiver, Bulgaria

"I wish we could also offer vocational training for children, so that they could get at least some specialization, which would be useful for their future. They should also be taught the most basic things – how to go shopping, how to go to the health centre – because many do not know this."

Larisa, social worker, Latvia

"We have to use outdated equipment, so when children start working in factories and plants, they find themselves surrounded by new machines in an unfamiliar working environment; and being disabled, they already are at the bottom of the list of candidates."

Yulia, institutional caregiver, Russia

3.4 Health and Welfare Services

Strikingly, children believed that keeping themselves healthy is their most important challenge. In keeping with an inclusive philosophy, some young people defined themselves as 'different' rather than 'ill' and wanted the same opportunities as other young people:

"I want you to write down that I don't consider myself ill. On the contrary, it is good to live when you are young."

Valya (female), 17, living at home, Bulgaria

"[I wish] that they would look at a disabled child like at a healthy one. So that they [children with disabilities] would have the same rights as them; so that they would be cared for."

Armands (male), 14, living in an institution, Latvia

"You should fight to prove you are normal too."

Momchil (male), 13, living at home, Bulgaria

For parents, the time of initial diagnosis of their child is their primary point of reference. Many blamed medical services for inappropriate and/or late diagnosis or even for the disability of the child. At the same time, parents complained there were no formal consequences for health care professionals:

"[My son] became disabled right after birth. The baby was dropped and after dislocation of vertebrae, he got spastic paresis of his lower limbs. He had a lot of operations— seven – without any result."

Tina, mother, Bulgaria

"The majority of those placed in here are being treated for our local doctors' mistakes."

Katia (female), 17, living in institution, Russia

"Most children are disabled because of doctors' mistakes, for sure, and there is no compensation for this, no law."

Dona, mother, Bulgaria

"With paresis, if in the first three months you undertake proper physiotherapy, you can help the child a lot. But in all this bureaucracy often a year goes by before you finally get see to the specialist, who tells you what to do. And this year is already lost."

Zinta, mother, Latvia

Parents also discussed the cost of medical services. Many said they could not afford to provide their child with what they needed:

"If we want to get it [rehabilitation] for free, we have to wait for two years. We do not have the money to do it sooner, so [our daughter] only receives what is offered at school – massages and gymnastics."

Niklavs, father, Latvia

"She very much needs massages. I took her to Sofia for a series of massage sessions. Paying for three sets drained me financially. People with a lot of money go there – I cannot pay."

Stefka, mother, Bulgaria

Parents in all three countries criticized the medical profession for lack of support, reluctance to treat or examine children with disabilities, and recommending institutionalization:

"I have heard this often: 'Leave your child and you will solve your problem. You are so young, leave your child. You will give birth to another one and you will forget this problem'"

Dona, mother, Bulgaria

"The doctor told us the diagnosis – deaf child. I didn't know what to do. There was no help, no support."

Vilhelmine, mother, Latvia

"In Gorna Bania, the doctors were very rude. They said there was no use in examining him."

Lily, mother, Bulgaria

"I went to a psychiatrist. He never touched the child or examined her. He told me that the child had mental and psychological disorders [...]"

and he said that every child who has hearing problems is not normal, according to him."

Aneta, mother, Bulgaria

"[The doctor] said that he [my son] is with one foot in the grave: 'Give up, he will never be useful.' I was fighting against a wall. Now I have fought so much during those 14 years that I have no more strength...I have gone through hell."

Rita, mother, Latvia

"We were advised not to bring her up, [to] reject her, send her to an institution."

Vera, mother, Russia

However, medical practitioners interviewed were also critical of some parents and emphasized the primary responsibility of parents for their children with disabilities:

"They just take the benefits and abandon them. Law for protection of children should take the parental rights away from such parents."

Borislav, doctor, Bulgaria

"Better parents." [In answer to a question on what would encourage more children to be raised at home].

Petr, doctor, Russia

These counterpoints suggest a need for increased awareness on the part of both parents and health care professionals – and better communication and collaboration between these two key players in the life of the child with disabilities.

Parents were frustrated and upset by what they experienced as unnecessary bureaucracy and humiliation in their dealing with social services:

"There is a lot of bureaucracy. It is true that documentation is needed, but in order to receive two pairs of orthopaedic shoes for my child, I have to go twice a year for a disability status check."

Kalina, mother, Bulgaria

"We have to go there again and again, and every two years doctors ask the same questions [...] although they already have all the documents in front of them."

Aelita, mother, Latvia

"I prefer not to go to social services and ask for anything, because this is too humiliating."

Izabelle, mother, Latvia

"Everything related to social services – that is everything you receive for free – is all about humiliation."

Leonid, father, Russia

Parents and service providers were concerned that little or no support or information was available to families of children with disabilities. In Bulgaria, it was reported that although special programmes to help parents of children with disabilities existed (e.g., personal assistant) they were not accessible to many parents:

"There is no help from doctors. They do not give information to parents. Parents don't know that their children can attend a kindergarten."

Dora, teacher, Bulgaria

"Once I read in a newspaper that I have the right to receive a nursing allowance. When I went and asked them in the social services office, they said they didn't know anything about it. Only when I pointed to the article with my finger, they seemed to remember."

Ieva, mother, Latvia

"We can never receive support from these programmes [personal assistant] ...because we are 'so rich'!"

Dona, mother, Bulgaria

"In Bulgaria, very few things are done for finding such children, and telling their parents what they should do."

Lora, mother, Bulgaria

"There is very little information. If we – the mothers – ourselves do not go and show interest, nobody, not even a doctor, will inform us."

Bernadeta, mother, Latvia

There were some examples of good practices noted:

"My GP, who is a paediatrician, always says: 'I hope you do not mind, but I gave your telephone number to a mother, who has a problem, so you can tell her where to go and what to do:'"

Irena, mother, Bulgaria

"At school the cooperation is quite good [...] We solve problems together."

Megija, teacher, Latvia

Social workers agreed that lack of information and resources affected access to services:

"We can help, but it is difficult if they [parents] don't come here."

Lana, social worker, Latvia

"Our agency does not do anything – 8 leva [4 euros] for the telephone and double child allowances. This is not enough."

Margarita, social worker, Bulgaria

"Everything depends on accessibility of information. If I can give an answer, I help. If I don't know – what can I do?"

Sabine, social worker, Latvia

"Social support should definitely be improved. We don't even have a computer and [...] we have to beg the colleagues from next door to use theirs sometimes."

Margarita, social worker, Bulgaria

Lack of cooperation among professionals taking care of children with disabilities was discussed by parents and service providers. Parents and service providers discussed the need for doctors to advise and help parents; better cooperation among professionals; and a more holistic approach to children

with disabilities. At the same time, the need for more active involvement of parents was requested by some service providers.

"There is no system which would integrate the child, his or her family and the therapy he or she needs."

Nadya, mother, Bulgaria

"The problem is that they [doctors, teachers, social workers] cooperate very little. We solve separate problems, but we lose the child as a whole."

Ilvija, doctor, Latvia

"The problem is that different specialists – teachers, doctors and social workers – work under different ministries. Cooperation should start at the ministry level."

Stefka, institutional caregiver, Bulgaria

"The doctor gives the diagnosis, but he does not say where to go and what to do. There is no communication between the doctor and social services."

Astrida, mother, Latvia

"Parents should be more involved. Now we meet only twice a year. This contact should be more regular, not only when conflicts occur."

Larisa, social worker, Latvia

3.5 Education

Notably, children with disabilities understood that studying and a good education was particularly important for their future as a disabled adult. Overall, children with disabilities are satisfied with their education and some were full of praise. Parents and service providers acknowledged that there have been positive changes in the education system, with more children with disabilities integrated into regular community schools:

"I want to thank my teachers, who have been helping me to continue my education. Teachers who are so good and dedicated are seldom found."

Kolio (male), 13, home-living, Bulgaria

However, parents of children with severe disabilities are concerned about the lack of special schools for their children. Lack of accessible transportation to school prevented some children with disabilities from getting an education:

"I have achieved many things by myself, because we also have faced the problem that there are no proper preschool institutions for such children [children with severe disabilities]."

Nadina, mother, Latvia

"There should be more centres...in different regions ...both for the less and more severe disabilities."

Krasimira, mother, Bulgaria

"There are no institutions which would combine special teaching and special rehabilitation."

Alta, mother, Latvia

"This year my child has not attended school for three weeks altogether. It was not his fault – it was either the driver who was ill or the bus was broken."

Modrite, mother, Latvia

"There are children who are forced to sit at home because the money social services can give you for going to school allows you to go only once a week."

Sabine, social worker, Latvia

Parents were also frustrated by the negative attitudes of some teachers and support staff to educational integration:

"She is doing fine mainly because of our efforts at home [...] She is getting little help from the teachers at school. Even if she [the teacher] decides to pay more attention to her, she considers it an effort that is not worth it."

Monika, mother, Bulgaria

"We have a psychologist in our school who is good at working with able-bodied children, but doesn't understand disabled children, so she cannot help them."

Larisa social worker, Latvia

"There are teachers for integrated education of children with impaired vision. They make great efforts: they communicate with the classmates of the child and the teachers. But I do not think these teachers receive much support from the ministry of education, for example."

Maria, mother, Bulgaria

Children in institutions were especially aware of the limited access to education beyond primary level. Access to universities seemed to be particularly problematic in Latvia and Russia. Lack of access to buildings and not taking the needs of children with disabilities into consideration were stressed as the most important obstacles:

"My child is now in the fourth grade of a special school. This school takes children up to eighth grade and the question is what we are going to do in four years time? [...] I will be forced to leave my job, which I respect, like and have studied for. Or, I will have to find someone to look after my child at home, if they do not open a place for children who cannot continue their education."

Nina, mother, Bulgaria

"Well, the special high schools they attend give them some professional qualifications; say, girls can study hairdressing, boys can become carpenters, etc. But we wish our children did much more."

Sasha, mother, Russia

"We cannot be those who do physical work, we need to be intellectuals."

Luda, 17, living in institution, Russia

"I will never get there [into university]."

Boris (male), 15, living at home, Russia

"Studying at university can be very problematic, because I'm in a wheelchair."

Toms (male), 17, living at home, Latvia

"Universities should review their attitude to people with special needs. Now they don't do anything to make studying possible for disabled people."

Leonards, teacher, Latvia

The problem of access to education for minority children was also raised:

"There is a problem with integration of Russian-speaking disabled children in society and in the education system. If they don't know Latvian, they have problems with getting an education."

Larissa, teacher, Latvia

Improvements to the education system that were suggested by children, parents and service providers included: more vocational training, equal opportunities for university education, better access to computers, more materials for the disabled and more specialized support staff:

"For example, textbooks in Braille or some other materials – there are none."

Villy (female), 17, living at home, Bulgaria

"They have difficulties using a pen... Such children have problems with speech, so they cannot easily communicate by telephone. If they had computers, they would be able to communicate via the Internet."

Katerina, mother, Russia

Staff in institutions that provided education expressed concern at the lack of coordination and continuance with other educational institutions:

"Our school is like an oasis – children come here to study but we don't know what happens to them later. We should have better cooperation with the other organizations."

Asnate, institutional caregiver, Latvia

Importantly, parents generally preferred their children to be educated locally, whether in mainstream schools or special education facilities. There were many examples of children living in institutions because there was no local education for them near their families. This was a concern to providers as well as parents:

"We began with [the institution] as it was the only place, but when a special school [for children with hearing disabilities] was opened in town, we moved... For our children [the first institution] is all fears. If we mention that institution [...] they are afraid."

Tania, mother, Russia

"[Our son] has been staying [in an institution] for four years now, because we do not live close to the school and we cannot manage to go there every day and spend four hours commuting."

Rita, mother, Latvia

"There should be schools with classes for deaf children in every region so that a child can go home in the evening. Then there would not be a situation that a child does not see his parents for two weeks or more."

Megija, teacher, Latvia

3.6 Recreation and Leisure

Parents pointed out that after-school activities, youth provision and summer camps were necessary to allow children to develop and integrate with other children. However, there was little provided in the community. Access to leisure-time activities appeared to be better in institutions; events and clubs for children with disabilities were organized, but there was little contact with children or adults outside the institution:

"They take us to summer camps, theatre and different games."

Milen (male), 13, living in institution, Bulgaria

"Recreation and entertainment activities happen only because of parents' initiative."

Dzintra, mother, Latvia

"[I wish] that I could take part in events, go somewhere where children who are not disabled can go."

Krista (female), 11, living at home, Latvia

"We can't go out at all..."

"They watch us as if we were extraterrestrials..."

"Where can we go with these wheelchairs? Children do not have fun."

Various parents, Bulgaria

"We once attended a concert. [The] centre organized the tickets. Children were brought in wheelchairs. There was no space to accommodate those wheelchairs, so we had to sit them under the stage next to the monitors."

Olecia, mother, Russia

"Why do summer camps not accept the disabled? Many are not well equipped. Say they have no appropriate shower facilities. A healthy kid can wash his feet somewhere in a stream and use a hole as a toilet."

Anna, mother, Russia

"Children need a special car to go out and have fun. If we call the person from [the service] company and say that we need the state-provided special [bus] to take the children to [the amusement park] or to have fun, she will put the phone down on us."

Alexandra, mother, Bulgaria

3.7 The disabling physical environment

"Have you any idea why they [people with mobility disability] do not go out? Right, because there are no ramps and lowered curbs."

Luda (female), 17, living in an institution, Russia

Box 3.1 Reaching parents

It is very beneficial when parents are partners with public institutions in the lives of children with disabilities. But evidence from Country Reports indicates that, for varied reasons, parents do not make demands on public services.

The FRY Report says family attitudes themselves can be prejudicial. Families, it says, may treat children with disabilities with 'exaggerated care' that is itself limiting, or with an attitude that 'God said so, and let God take care of them', or they may be 'totally neglected'. The report also points out that families may not only lack information about available services, but lack knowledge about the needs and potential of children with disabilities.

The Tajikistan Report refers to the 'passive attitudes' of parents in pursuing the education and development of children with disabilities. It says that, in the year surveyed, just 47 per cent of parents of children with disabilities turned to health care facilities for help, 26 per cent to social protection agencies, and 11 per cent for other types of assistance to educate their children.

The Poland Report refers to 1996 research which showed that 45 per cent of parents of children with disabilities did not approach any service for help. Of the remainder, 33 per cent went to health care centres, and another 22 per cent visited social help centres. The report, however, further notes that these institutions mainly provide medical assistance and, decreasingly, financial help. On the other hand, parents 'very often' reported the need for recreation for their disabled children, contact with their peer group and activities that promote social integration.

Sources: FRY Country Report, Tajikistan Country Report, Poland Country Report, 2002.

For many participants, this was too obvious a topic to be discussed at length. It was agreed that buildings and public transport were generally not accessible to children with mobility problems, particularly those in wheelchairs. There was a lack of appropriate signalling at crossings, and no ramps or elevators for people with mobility problems. There was some special disabled transport in Russia, however, quotas for the transport were seen as too low:

"Old buses – all of them are a torture for people with mobility disorders. Without help of another person, it is impossible to move around in the city."

Leonards, teacher, Latvia

"There are only few pedestrian crossings with [audio-visual] signalling in Riga. That limits visually impaired people. That's why they always have to feel dependent while being out in the street."

Asnate, institution carer, Latvia

"He cannot go to school because of the stairs."

Mariana, mother, Bulgaria

"We live on the fifth floor and when we want to go out, the elevator is broken. I need to take the child downstairs, find somebody to watch him, and then I go back to the fifth floor to get the wheelchair down. This is the usual procedure for a walk."

Irena, mother, Bulgaria

"We have a taxi provided by social services, but this is not really of help because you are only allowed to use it once every two weeks."

Luka, father, Russia

3.8 The Rights of Children with Disabilities

Parents were quite aware of human rights and their applicability to children with disabilities. However, both parents and service providers said that existing laws to protect the rights of children with disabilities are largely ineffective because they are not vigorously implemented:

"The European Parliament should say that laws ought not only to be written and passed, but they should also be applied. This does not happen in Bulgaria."

Milen, father, Bulgaria

Box 3.2 Laws and National Mechanisms

Evidence submitted in the Country Reports shows that many CEE and CIS countries do, indeed, have legislation and mechanisms in place to advance the rights of persons with disabilities. As parents interviewed for this report clearly state, the challenge is to close the gap between intentions and realities.

Twelve countries have a national law specifically on persons with disabilities; six have laws on child rights or protection that specifically mention children with disabilities. Sixteen countries have national mechanisms or programmes related to improving the status of persons with disabilities, including children with disabilities. These bodies include:

- Belarus: National Interdepartmental Council on the Problems of the Disabled
- Bulgaria: National Council on Rehabilitation and Social Integration of Disabled People
- Croatia: Government Board for Persons with Disabilities; National Strategy of Uniformed Policy for Persons with Disabilities, 2002 – 2006
- Czech Republic: Government Board for People with Disabilities; 1992 National Plan of Actions for Handicapped Persons; 1992 National Plan of Measures to Reduce the Negative Impact of Disability
- Kyrgyzstan: Council for the Affairs of the Disabled
- Latvia: National Council of Disabled Persons' Affairs
- Lithuania: Council of Disability Affairs of Lithuania
- Romania: 1992 State Secretariat for Handicapped Persons
- Hungary: National Disability Programme
- Poland: Government Ombudsman for the Disabled

"[Tell the politicians] to put things into practice. There are parts of the law which have not yet started to function."

Stefka, institutional caregiver, Bulgaria

"I would like that they [politicians] would follow the rules which exist. The rules are not bad."

Amanda, mother, Latvia

"Rights for disabled children are [there to] to help them be integrated in society; [to] feel as the able-bodied – not worse."

Einars, institutional caregiver, Latvia

"Who is taking into consideration children's rights? No one is."

Sergei (male), 16, living at home, Bulgaria

"According to me, disabled children in Bulgaria and disabled people in general have no rights at all. They only exist on paper."

Nadya, mother, Bulgaria

"Rights are not respected in society. Someone who refers to rights is often regarded as a yammerer. Instead, an individual negotiation [...] achieved with the help of a bribe, is often very much respected."

Xenia, social worker, Russia

"[The laws] are very good if they are followed. They are not known and they are not respected. Parents don't have information about the rights of their children."

Dora, teacher, Bulgaria

"The biggest problem is that there is no information on what our legal rights are. I have received all the information about my daughter by chance, from strangers."

Nadya, mother, Bulgaria

"The law is very good but void – no one bothers... People are not used to appealing and referring to rights when they need something or defend themselves."

Violetta, mother, Russia

3.9 Progress and the future

Parents and service providers in all three countries said there had been some positive improvements for children with disabilities during the transition period – some integration of children with disabilities in regular community schools, more tolerant and inclusive attitudes of other children in community schools, and some improvements in access to appropriate services. But, parents and service providers in all three countries still felt there was a lot more to do.

Parents reported that individual determination was a decisive factor in raising a child with disabilities at home. In order to promote the retention of children with disabilities in the family home, parents suggested that more support from the state, paired with better working conditions for them (more flexible working hours and better earnings) was necessary. Service providers also mentioned the need for bet-

ter financial support, but said social attitudes towards children with disabilities need to improve as well so that it is more likely that children with disabilities will be kept in the family home.

“Determination – this is me, I have it. You cannot change his condition. Nothing can help him. All the things you listed simply do not matter.”

Valentina, mother, Russia

“Parents need to be very determined, but in the first place, you need support from the state.”

Kalina, mother, Bulgaria

“Parents should be able to provide care at home. I would like them to have a day-care centre to drop a child, if necessary, for a day, weekend, a holiday. Holiday activities and joint activities for children and the same for adults, not only those odd family get-togethers. Be honest, take them seriously.”

Maya, nurse/therapist, Russia

“It is crucial to improve living and working conditions for parents. Centres like Korytovo and computers with Internet for children can solve more than a half of all problems! Children will get education and parents will get time off.”

Xenia, social worker, Russia

Suggested Solutions

Parents, providers and children had many positive and useful solutions to the problems they faced. They included: gradually transferring resources from institutions to families; flexible working hours and better earnings; more specialist support, integrated schools, day-centres and summer camps; the provision of respite care; and changing societal attitudes towards disability.

A practical and essential grassroots perspective on disability can be provided by soliciting the views of service users and providers. Those with personal experience can speak authoritatively about what services could positively benefit them in their countries. The policies, proposals and programmes suggested here aim to prevent family disability – that is, the family as a whole being disabled, not by the ‘burden’ of a child with disabilities, but by the burden of inadequate finances, lack of respite or alternative care, inaccessible buildings and poorly planned day care, transportation and accommodation.

The main issues to consider are:

- The need to change attitudes towards the disabled in the medical profession, institutions and communities. Greater integration of the disabled in society should be promoted. This requires awareness-raising campaigns and increased visibility of people with disabilities in public life. Improved access to regular schools and leisure-time activities (more integration programmes, better transport and access to buildings) alleviates the extra demands put on parents, and also helps children become more independent. Additionally, increased exposure to people with

disabilities helps break down prejudices, and thereby improves chances of integration.

- More financial assistance is needed in order to allow parents to cope with the demands of raising a child with disabilities at home. Parents suggested tax breaks and sponsorship from individuals and businesses who wish to contribute to organizations for children with disabilities.
- The development of community support for parents so that newly born and young children diagnosed as disabled can be looked after in the family. More professional psychological help should be offered to parents, especially at the early stages. Service providers should be better informed about the opportunities and options available to parents of children with disabilities, and should receive more training on offering support to parents. There is a need for visible, practical community support for families with children with disabilities so that other families will be encouraged to support these children.
- Assistance is needed to establish and manage self-help groups for parents. This would provide a forum for parents to share experiences, and also give them more flexibility and time for themselves. These organizations can also offer training for parents on how to deal with problems and issues related to raising a child with disabilities.
- Better access to employment for parents would help solve financial difficulties that families with children with disabilities face, and reduce the risks of social isolation. This needs to be complemented by increased availability of day-centres and in-home day-care assistants.
- The re-introduction of children into families and communities – either to their families of birth, foster or adoptive families, or integrating young people into communities – so they can live as independent adults.
- Better future employment opportunities for children with disabilities need to be developed. More extensive vocational training and better access to secondary and tertiary education is necessary. Improving attitudes and employment practices of employers are needed to encourage young people with disabilities into work placements.
- Better information and support are necessary to help parents. This is especially important at the time of diagnosis, when parents need to organize their lives. Information centres with at least a regional data-base of children with disabilities need to be created and updated regularly to allow service providers to contact, help and inform families with children with disabilities.

Conclusion

For parents, societal factors associated with their child’s disability appear to dominate all areas of life. Because they felt they were alone in dealing with raising the child in every aspect – home care, education, health care – many were overburdened and

frustrated. Parents said they felt isolated and were unable to pursue careers or enjoy a social life, since everything had to be adjusted to meet the needs of the child with disabilities. Yet, it was clear they were willing to take care of their child at home, rather than sending her or him to an institution. This indicates that increased support from social workers, doctors and other service providers is essential.

Children with disabilities in these countries need to be targeted for action. A lack of planning resources and continuing public prejudice continues to affect their identity, life chances, education, accommodation and health. The majority come from families where, if poverty was not overwhelming before the child with disabilities was born, poverty threatens to

overwhelm them if they look after their child themselves. For those families who have been advised and chosen to put their children into institutions for financial or other reasons, the state then carries the financial and life responsibility for these children. Alternative plans for these institutionalized children are also essential.

The aim of this qualitative research has been to uncover the real experiences of children, families and care providers in dealing with what many in Bulgaria, Russia and Latvia still see as a shameful secret. The report highlights what it is necessary to achieve if children with disabilities are to enjoy the same opportunities and rights as children without disabilities.

Note

75 European Union,
www.europa.eu.int/comm/enlargement/pas/europe_agr.htm.

4

THE WAY FORWARD

Children are neither the property of their parents nor are they helpless objects of charity. They are human beings and are the subject of their own rights.

UN Convention on the Rights of the Child

The UN Convention on the Rights of the Child offers a good guide to what needs to be done for children with disabilities in the CEE and CIS region.

The Convention – which has been signed by all CEE and CIS countries – considers all children to be ‘citizens with equal rights’, rather than just dependents of parents or recipients of public interventions. This spirit of equity clearly demands appropriate supports for those who are disabled. The need for a novel approach is felt even within the walls of the old children’s institutions: “The talk about disabled people has just started. They have new privileges,” says Stefka, an institutional care provider in Bulgaria. Or, more accurately, they are making new claims to equal rights.

Based upon the evidence and the commitments of rights legislation, this report puts forward a five-point strategy for promoting and supporting the inclusion and participation of disabled children in CEE and CIS societies. All of the key areas require public and private action from a broad and dynamic coalition of stakeholders.

The Poland Country Report describes this concerted effort as taking place at “the macro-social level, the institutional level and the family level.” The Ukraine Country Report says the challenge of integrating children with special needs must be met “not through individual acts of kindness, but through creating a comprehensive system of social adaptation.”

4.1 Change disabling public attitudes and physical environments

The evidence reviewed in this report suggests that CEE and CIS countries have far to go in changing traditional attitudes that are built into the physical and social environments – from accessible buildings and transportation, to integrated classrooms and informed public opinion. Professionals, decision-makers, opinion leaders and the media clearly have a role to play in this regard. Local governments also have a tremendous amount of power to make everything from city sidewalks to voting ballots accessible to as many people as possible.

A key stakeholder group is children themselves. There is a body of research that shows younger generations are substantially more progressive in outlook and more open to change than older generations. The important concept here is that change can advance in leaps, rather than steps, between one generation and the next. So it is not only a wise strategy to practise inclusion at the youngest ages, but also to recognize the potential of children and youth as opinion-leaders and as active participants in the design of policies and programmes. Parents interviewed for this report confirmed that they find young people generally more tolerant around people with disabilities, while older people often react in

Box 4.1 Experimental survey tool for capturing lived experience

The Roeher Institute in Canada, an organization dedicated to research on disability issues, has piloted a qualitative survey in Romania that aims to capture the experience of children and youth with disabilities, their families and support organizations. It explores the inclusiveness of communities, the degree of involvement of children, youth, families and disability organizations in the collection and analysis of information about issues that affect them, and of gaps in existing knowledge. The 52-question survey focuses on these themes:

- The physical, mental, social, moral and spiritual well-being and development of children and youth with disabilities and their families.
- The lived reality of young people with disabilities and their families compared to the promises held out in the Convention on the Rights of the Child and other international human rights instruments.
- The source of knowledge about these realities and issues.
- Gaps in information and knowledge.
- How this knowledge can be used to transform communities so they are able to meet the promises of the Convention in a way that is inclusive of children and youth with disabilities and their families.

For example, questions ask the child to rate (never=1, regularly=5) their feelings about how well they are accepted in various relationships; whether they feel valued; if they experience frustration; whether anyone asks about their hopes and dreams. It also asks questions about hunger, abuse, inappropriate touching, recreation, participation and job preparation.

This data can help policymakers learn how to improve ways for disabled children and youth to participate in society.

Source: 'Revisiting the Convention on the Rights of the Child: Building a Knowledge Network on Realities of Inclusion for Children with Disabilities: Survey of Children and Youth', The Roeher Institute, Toronto, 2002. www.roeher.ca

more stigmatizing ways. Service providers also said that students from schools with an integration programme were more open-minded about disability.

- Anna, a mother from Russia, says: "Young people are neutral. They usually help to carry her, hold a door but show neither sympathy, nor turn her down."
- Tina, a mother from Bulgaria, observes: "Young people are very careful.... The older, and the women, on the other hand, they do not respect us."

An encouraging finding of the qualitative research has been the often confident and affirmative manner in which children with disabilities think about themselves.

- Teddy and Milena, both 16 and living in an institution in Bulgaria, talk about relations with their non-disabled peers: "They just don't know how things are. They are so ignorant." Or: "Maybe

because they still don't know us. For example in our school, we study with children from town. In the beginning, they thought 'who are they, they are invalids' but when they got to know us, they adopted very different attitude towards us and now they even count on our support."

4.2 De-institutionalization and building community-based supports

The biggest existing challenge for CEE and CIS countries is to get children with disabilities out of institutions and boarding schools and back into their families and communities. A multi-pronged interdependent strategy is necessary: moving to local schooling and integration with mainstream schools; setting up 'gatekeeping' mechanisms and processes that serve to keep children from ever entering institutions; restructuring public services to be child-centred and client-driven; building up the capacity of families and communities to include children with disabilities.

Gatekeeping

Gatekeeping is defined in a recent UNICEF/World Bank report as 'the effective and exclusive targeting of services to specific end users'. In the context of disabled children in CEE and CIS countries, gatekeeping needs to make it harder for disabled children to be placed in institutions, and easier for children to be de-institutionalized and rejoin their families and communities. Recognizing this, the Ukraine Country Report states that 'the system now in place favours institutional care rather than preventing it', and that there is a need for 'an evaluation of the existing procedures and mechanisms for documenting the disability of a child from the perspective of avoiding his or her institutionalization.'

– Ukraine Country Report, 2002

The second important task for the inclusion of children with disabilities is the provision of enabling supports and services that are affordable, accessible and community-based. Seeing children on the streets of the community and in shops is only a beginning; children have the right to access the same types and levels of health, education, leisure and social services as other children. Adding participation to visibility makes an enormous contribution in changing public attitudes and accepted norms.

The Ukraine Country Report asserts: "Preventing the institutionalization of disabled children could primarily be done through two [practices] which might act simultaneously, in parallel, or in cooperation with one another: 1) The institution of foster families for disabled children, whether operating on a permanent or temporary basis. 2) The institution of day-care centres that are capable of: providing effective services to children with functional limitations and members of their families; extending services to the

disabled for as long as they live; and providing a complete range of services (medical, educational, social) that help them realize their creative abilities, widen their circle of acquaintances, get training and job placement, and protect their housing and property rights.”

The Estonia Country Report remarks on ‘a new development in social welfare’, as a number of day centres have been established in recent years to provide various social services to senior citizens and adults and children with disabilities. In larger cities, special centres have been established for children with severe and profound mental disabilities and multiple disabilities. There are also new special day-care services for disabled children who stay at home and do not attend any other childcare institution. Parents can place children there for a few hours, or even a few days a week.

This report finds a huge gap between the high priority assigned to mainstreaming education by parents and children with disabilities themselves, and the half-hearted, inconsistent efforts by public authorities to develop more inclusive education systems. The qualitative research shows that parents and children alike consider both the cognitive and social development aspects of education essential.

- Katia, a 17-year-old girl living in an institution in Russia, declares: “Disabled, without education – deadly!”

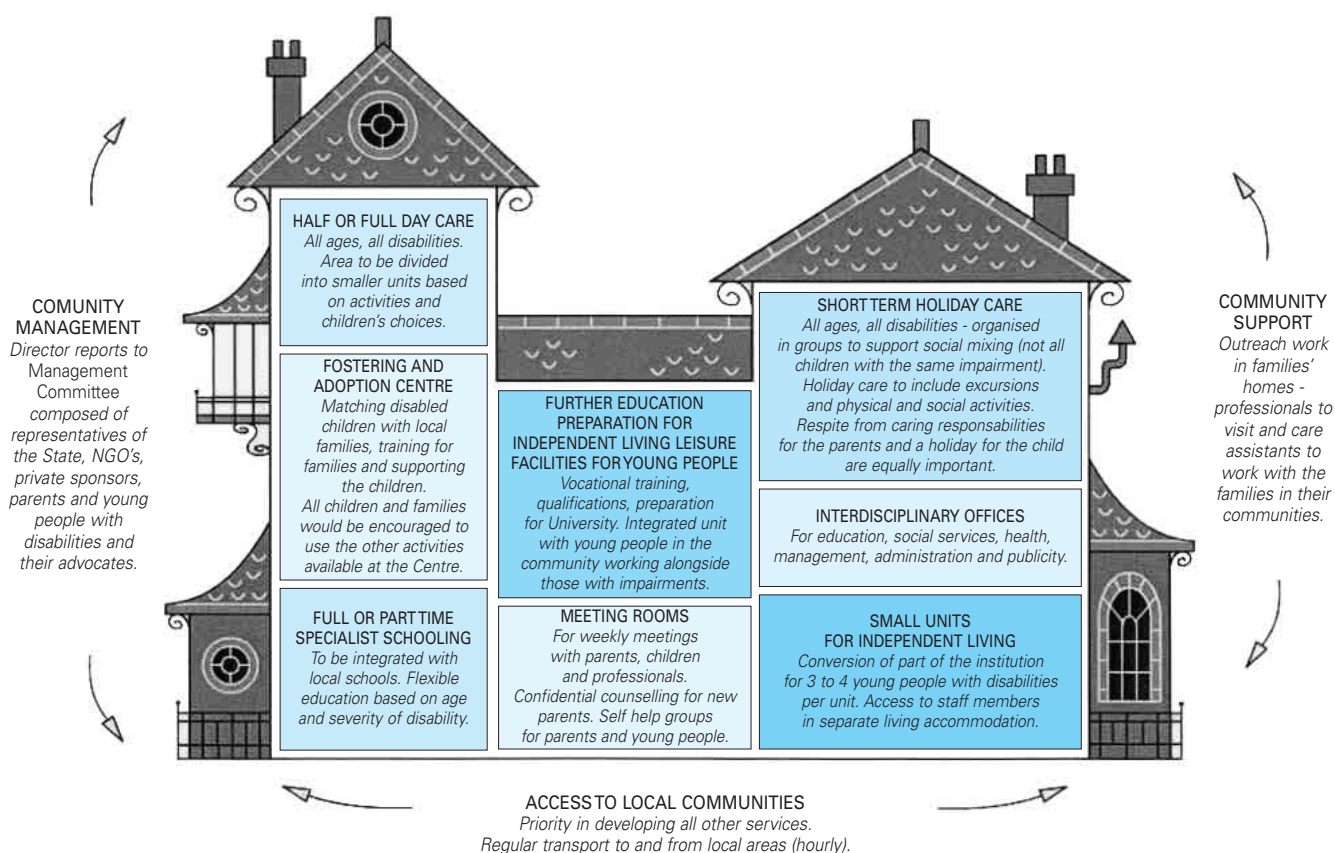
Box 4.2 A model for turning institutions into community-based support systems

The transition from residential institutions to community-based support for children with disabilities is an enormous challenge in CEE and CIS countries. Some find it hard to make the philosophical leap required, while others cite lack of funding and other resources. But all countries can take the important step of building up models, mechanisms and practices in their communities. For example, the Hungary Country Report states that during the 1990s, several institutes experimented buying small dwellings in their area and then relocating 10 to 12 residents into these homes – a process known as ‘fragmenting out’. This transitional tactic has also been used in the United Kingdom, where it is known as a ‘core and cluster’ approach.

As an exercise for this report, the core team developed a model for re-casting an institution into a family centre (see Model 1). While the model presents the re-envisioned centre as a single physical facility, it could, in fact, be spread out in different sites, provided that all parts be coordinated to act as an integrated system of support.

Source: Professor Monica Dowling, School of Health and Social Welfare, Open University, UK, 2003.

Model 1 - A family centre for children with disabilities



- Silvia, mother of a child with disabilities in Bulgaria, states: “The important thing is that he or she feels like a member of society like everyone else, and that there is no isolation.”

All countries speak of the importance of education integration, but the actual implementation of such strategies varies considerably. Some smaller and wealthier countries with long traditions of special education, like the Czech Republic, rely on building a denser and, therefore, more accessible network of education services. Some bigger and less densely populated countries like Poland appear to focus on gradual integration. In others, there is a *de facto* ‘spontaneous’ integration of pupils with milder disabilities. In some, like Lithuania, serious and coordinated steps have been taken to develop a framework of legislation, policy and implementation initiatives that supports the goal of integrated education.

The goal of truly inclusive education, sport, culture and leisure is to benefit not only the children now labelled as disabled, but also the broader spectrum of children who fall outside current norms, including those with poor learning achievement, who drop out or miss school altogether.

4.3 Participation of parents in setting goals, making decisions, shaping services

Parents are not only experts in raising their own children, they are duty-bearers who are charged with fulfilling the rights of their child. Parents must have the capacity to act accordingly: they must be informed, supported and empowered. The report finds that there has been more progress on parental participation in some CEE and CIS countries than in others. For example, some Central European countries have taken up the Western practice of teaching parents to be active carers for their child with disabilities. However, field trips arranged for this report in two CIS countries found that collaboration and communication between rehabilitative service providers and parents still lag far behind Western practice.

- Vera, a mother from Russia, declares: “Support for the mother is needed and she will then do everything for her child. She knows her child better than anybody else.”

A Polish ‘Hedgehog’

This handbook is aimed at the parents of children with disabilities. It contains advice and information about rights, benefits and raising a disabled child; available treatment and rehabilitation programmes; and education options. It includes the first comprehensive list of integrated schools in Poland, including information about their architectonic adaptations; names of superintendents and inspectors in charge of integrated education; and selected NGOs and institutions working for the benefit of disabled children.

– Poland Country Report, 2002

Box 4.3 ‘House of Mother and Child Development Initiatives’ in Kyrgyzstan

The Meerim International Charitable Foundation has established a learning centre for children with disabilities where the operating principle is a ‘triple alliance comprising the mother, the doctor and the teacher’. The centre serves children with disabilities, aged 3 to 16, who have traditionally fallen outside the catchment of mainstream institutions. This includes children with locomotor limitations: epilepsy, mental retardation, behavioural problems and those whose impairments have been compounded by social and educational exclusion.

The centre practices a highly individualized approach based on the specific needs of each child. It employs a multidisciplinary team (defectologist, speech therapist, psychologist), mixed-media learning (music, computers, pictorial art, applied art) and mixed-age groups. It also incorporates life-skills training including basic self-care and balanced nutrition, and socialization skills such as how to carry out instructions. The goal is to help children with disabilities be more organized, disciplined and self-reliant. The centre is intended as a staging ground for integration into mainstream day-care centres and schools.

The centre operates in a larger context of family respite, especially support and relief for the mothers of disabled children. The centre aims to support mothers by enabling them to pursue employment opportunities and have time for other demands. Attendance schedules for children are individualized and take parents’ circumstances into account: some children attend mornings, others stay for a full day; some come two days a week, others three and still other five. The centre also offers seminars and consultations for parents. Parents often participate in classes.

At the time of reporting, after three years in existence, there were 30 children attending the school on a regular basis. Another 20 had graduated on to mainstream day-care centres and schools, and more than 100 parents had received consultations. At the time, the Mother-Child Centre was the only one of its kind in Kyrgyzstan. The staff were highly commended for their tremendous effort, especially their self-directed search for new and effective approaches for realizing the potential of disabled children. It was noted that their efforts are impeded by the general lack of anticonvulsive, psychotropic and sedative medications in the country, as well as the issue of poverty: families cannot afford either therapeutic treatments for their disabled children or even a balanced nutritional diet.

– Kyrgyzstan Country Report, 2002

One very positive development in the CEE and CIS region is the establishment of parent self-help groups in many countries. So far, the groups seem to focus on peer support and networking, although there are examples of such groups pushing advocacy strategies in their communities. Similarly, few countries yet include a role for such civil organiza-

tions in developing initiatives such as legislation and policy, but Western experience shows that these groups, especially when they form umbrella associations and strategic partnerships, can and do play a very influential role in public opinion and decisions.

The model of parental participation related to children with disabilities is applicable to all parents. Creating a culture where parents are active in all decisions that affect their children, and where there is a strong collaborative relationship among parents, service providers, communities and governments would be beneficial for overall child well-being.

4.4 Improve the economic capacity of families

Life is easier for families with children with disabilities in countries where parents can count on supportive legislation and a climate where employers support family commitments with flexible working conditions. One of the positive legacies of the Soviet system is the administrative entitlement to generous parental leaves and other work-related supports – at least on paper. For example, in Tajikistan, mothers have the right to take up to six years of uninterrupted job leave, without loss of seniority, to care for a child with disabilities (an important factor in the calculation of old-age pensions.) They are also entitled to retire with full pensions at age 54, three years earlier than normal.

However, securing employment in the first place may be difficult and, as in most countries (including Western nations), finding a work environment that is supportive of such entitlements may also be a challenge. Natasha, a mother in Russia, says: “If I ask administration for an extra day off or two hours to which I am entitled – bear in mind, I am working in a state organization – I will be fired in a moment. I will be advised to forget my child and work normally.”

For families with children with disabilities, flexible employment possibilities and incentives are of particular importance. However, options such as part-time work or flexible work hours were virtually non-existent under the full-employment policies of the former command economies, and they have yet to develop much in the new economies. This report found many parents of disabled children pass up promotions and other job opportunities because they compromise their ability to meet family commitments.

Access to employment and disability supports is better in the more affluent CEE countries than in the poorer CIS countries, where even the general support of preschool care services is much weaker or missing altogether. The overall elimination of price subsidies as part of market reforms has also affected the availability and the value of free disability supports. Adequate benefits for children with disabilities and/or tax credits have a crucial role to play here.

The report finds that overall, parents in the CEE and CIS region get much less support than in Western

industrialized countries in terms caregiving and professional services. Putting the parent as well as the child at the centre of supports – for both cash benefits and social services – is a good strategy for reducing economic hardship and poverty among families raising a child with disabilities. This, in turn, could reduce institutional placement rates.

4.5 Prevent family dislocation

In supporting a child with disabilities, the well-being of his or her entire family is a matter of public concern. The first important step is to avoid the separation of the child from the family. Counselling, providing information and training is also crucial in helping parents to stay together and keeping the father from leaving; securing respite care and family programmes is important in this regard. These services are particularly needed in countries where families are generally small and where the separation of parents (and indeed of children) is an accepted social norm. They are also needed in more traditional societies, as community stigma around having a child with disabilities may be particularly devastating.

- Zinta, a mother from Latvia, says: “Especially in the beginning, when the families learn about a serious diagnosis, I think there should also be a psychologist there to help overcome this strain.”

The significant trend in the region of more children born outside marriage – current rates range from 7 per cent in Azerbaijan to 56 per cent in Estonia⁷⁶ – can make the child with disabilities and mother particularly vulnerable to family break-up. Many pro-family policies have disappeared (e.g., marriage as a precondition for access to housing), and social attitudes are more permissive regarding cohabitation and other forms of conjugal relationships.

If the driving principle in the CEE and CIS countries is to include children with disabilities in society and pursue de-institutionalization with vigour, the most important environment for the child becomes, as it should be, the family; and, in particular, the family as the transparent building block of an open and supportive community.

4.6 Conclusion

These five areas for action will not be achieved overnight or even very soon, especially if they are done properly. Effectively implementing these actions requires linking initiatives to broader reforms and permanently mobilizing a wide range of stakeholders. It also requires statistical and performance monitoring to provide feedback and new information for policy and programme directions.

The 15 countries of Central and Eastern European region and the 12 nations in the Commonwealth of Independent States are emerging from their historic transition on the right track. Linking the issues of child rights and well-being to that of children with disabili-

ties can accelerate progress on both fronts. Countries that are setting their long-term child welfare objectives in line with child rights will need to seriously address disability issues. With a new UN convention on the

rights of persons with disabilities in the making, there is a timely opportunity to transform the treatment of children with disabilities from being a source of public shame to being a measure of human progress.

Note

76 UNICEF, *Innocenti Social Monitor No. 2*, UNICEF IRC, Florence, 2003.

ISBN: 88-89129-20-8

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