

MEDIA RELEASE

EMBARGO: 10:00am GMT, 5 OCTOBER 2005

Innocenti Insight Children and Disability in Transition

KEY FINDINGS

- The number of children with disabilities in the 27 countries of Central and Eastern Europe and the Commonwealth of Independent States tripled during the transition years – from about 500,000 in 1990 to around 1.5 million in 2000. This surge is largely due to greater recognition of disability rather than to actual increases in impairments.
- Based on disability rates in countries with high levels of human development – the report suggests that there may be an additional one million or more children with disabilities are unaccounted for in official statistics.
- Some 317,000 or more children with disabilities lived in institutions in 2002.
- 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’¹) is still the overwhelming policy approach across the region.
- 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.
- Attitudes and laws relating to children with disabilities are changing, albeit slowly. More needs to be done to protect and support their rights.

¹ Defectology – literally ‘the study of defect’ – is a science unique to the region, based on the idea that special education is the best way to offset limitations associated with disability. It was developed in the USSR in the 1920s by L. S. Vygotsky and still drives much of the thinking and action related to children with disabilities in the region. The theory says 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. In practice, special education has been carried out in residential schools and institutions, segregating children from society, community and family. Many have been deemed ‘ineducable’. The benefits of special education for children with disabilities is still a matter for debate in international circles. Revisiting Vygotsky’s work with a fresh eye could help turn defectology in a new direction.

MEDIA RELEASE

- 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.
- Most countries have taken the step of enacting rights-based legislation related to persons with disabilities. However, all countries still approach disability as primarily a medical issue and, secondly, a social welfare demand.

Services for Children with Disabilities

While prevention and management of disabilities is often more difficult today than in the past, there is also a greater openness and capacity in the region to recognise children with disabilities and adopt more inclusive attitudes and behaviours towards them. The overall challenge is to act on these new approaches. The report's key findings on service provision are:

- Medical and social services for children with disabilities 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, lack adequate equipment, training and financing. Maternal and antenatal health care that can reduce the incidence and/or severity of impairments has deteriorated in some poorer countries.
- 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 childbearing age.

Assessing Disability

- Despite regular physical check-ups for infants and children, routine assessments tend to overlook the developmental and behavioural dimensions of health.

MEDIA RELEASE

- Assessments are done regularly and by specialists, but full assessments with a coordinated multidisciplinary team are still lacking in many countries, including the Russian Federation, especially in rural areas.
- Diagnoses of disability, once made, are rarely changed. This is especially true for children deemed 'ineducable' and placed in institutions.
- Drugs are not readily available and their cost is often high.
- There is only limited training for health and other social service professionals about disabilities. In CIS countries, disability-related training 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.
- There is a 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.
- 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."

Solutions

Greater public and private efforts, better coordination and clear policy directions are needed before there is a breakthrough in the development of services and environments for children with disabilities that promote their inclusion in society.

Children with Disabilities Speak for Themselves

This Innocenti Insight includes the voices of children, parents and service providers in Bulgaria, Latvia and the Russian Federation.

On institutionalization:

"For me, it is better to be in a family, because ...the family can support you and give you everything."

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

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

MEDIA RELEASE

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

On supporting families:

"Care about the mothers and they will make their children happy."

Vera, mother, Russia

On isolation:

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

Ralitsa, mother, Bulgaria

On stigma:

"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

On 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

On rights for children with disabilities:

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

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

* * *

NOTE TO THE EDITORS

Embargoed media materials and copies of the Insight in English and Russian are available from the Centre's Innocenti Newsroom:

<http://www.unicef-icdc.org/presscentre/indexNewsroom.html>

Related video footage is available free to download on: <http://www.unicef.org>

MEDIA RELEASE

For more information, contact:

UNICEF Innocenti Research Centre

Salvador Herencia, tel (+39 055) 203 3354, email: sherencia@unicef.org

Patrizia Faustini, tel (+39 055) 203 3253, email: pfaustini@unicef.org

UNICEF Regional Office for CEE/CIS and the Baltics

Angela Hawke, UNICEF CEE/CIS, tel (+4122) 909 5433, email: ahawke@unicef.org

Lynn Geldof, tel (+4122) 909 5429, email: lgeldof@unicef.org