From Policy to Action: Young People with Disabilities in the ECA Region

Background Paper on

YOUNG PEOPLE WITH DISABILITIES IN THE EUROPE AND CENTRAL ASIA REGION (ECA)

Rome, May 2007

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I. YOUNG PEOPLE WITH DISABILITIES

BACKGROUND

Across all societies, starting an independent livelihood is not easy, especially for youth with disabilities. Independent living promotes life skills, including self-advocacy. It is the key to opening opportunities is one’s track record—in good habits, social and job-related skills, and paying medical and personal expenses. According to the World Development Report: Development for the Next Generation 2007 (WDR), “Developing and deploying youth’s human capital become special challenges for the 21st century.” If this is the case, why are the estimated 130 million young people with disabilities invisible to employment, educational and youth transition policies?

On March 30th, 2007 the Convention on the Rights of Persons with Disabilities and its Optional Protocol began to change this view when it opened up for signature. As of May 2007, 90 member states plus the European Union have signed the Convention that was adopted during the sixty-first session of the United Nations General Assembly. Guided by international human rights standards, the new convention reaffirms the inherent dignity and the equal and inalienable rights of persons with disabilities. The new treaty includes and article 7 on children and youth with disabilities. It 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. The treaty provides a strong normative framework to guide national policies and actions and ensure the effective enjoyment of human rights by persons with disabilities.

Market oriented transitions and large public sector reforms in many ECA countries have excluded youth in general and young people with disabilities in particular from their nation’s social and economic development. On account of these efforts, states, government agencies, and multilateral organizations such as the World Bank that are active in the region have begun mainstreaming disability into their work.

Regional Influences

Young people with disabilities are largely hidden from public view and disability in the region has traditionally been treated as a personal tragedy. Factors that contribute to this situation are widely held myths and prejudices that saturate the culture about

The Disability Cycle:
The World Bank has found that there is a strong link between disability and poverty. People that acquire disabilities due to accidents, aging or armed conflicts, tend to slip into poverty due to severe physical and attitudinal barriers to reach employment. People that live in poverty on the other hand can develop disabilities due harsh living conditions and disease. In the Balkans, rapid deterioration in economic and social support is reflected in the fact that between 1990 and 1994, countries of the region dropped on average 32 positions in their ranking on the Human Development Index (Tobis, 2000). The Balkan wars left hundreds of thousands of people permanently injured.

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2 Approach and Methods: The background paper did not seek to articulate a comprehensive or unitary position on the issues of youth policy for youth with disabilities: instead, the author(s) consulted and solicited inputs from a broad range of existing documentation, historical data, and key gaps in studies, policies and state planning. They also reviewed reports on youth, youth policies in general and youth with disabilities in particular, with emphasis on policies and programs for equal opportunities, active participation and inclusion in the society and in particular in the labor market. They have incorporated governmental and non-governmental sources (like youth NGOs, institutes, Ministries, international organizations, etc.) and thus aim to fully capture the richness and the diversity of these perspectives.

disability as a tragedy. Furthermore, inadequate support for families and parents of young people with disabilities further perpetuate this exclusion. Families often lack information about specific ailments and thus trap the individual in predetermined set of expectations of what the individual can and cannot do. The group Disability Rights Advocates (DRA)\(^4\) reports that the myth that a disabled person is not capable of leading a fully productive life which contributes to the society is a key reason for exclusion and have to a great part defined a common approach toward the disabled. Governmental assistance is sporadic. The Russian NGO Perspektiva and the Association of Disabled Students Belgrade estimate an unemployment rate in the region between 80-90% for young people with disabilities.

The level of social and economic exclusion is far greater for young people with disabilities than for their non-disabled peers. In Albania only a handful of people with disabilities live independently, though often in segregated settings and in severe poverty. Few public resources were directed towards de-institutionalization and community based rehabilitation.

### Policy Challenges and Opportunities

New opportunities for the social inclusion of the most marginalized members of society including people with disabilities are taking hold in industrialized economies. The situation of people with disability in Commonwealth of Independent States is often paradoxical. The legacy of the previous socialist system in addition to general poverty, economical crisis, and instability, deteriorated the opportunities for people with disabilities. However, progressive policies in Serbia, Macedonia, Croatia and Lithuania allowed for a few young people with disabilities to realize leadership through participatory planning and implementation of social reforms.

### Lack of Data

As a research area of social importance, the topic of disability is poorly investigated. Disability statistics and formal documentation on people with disabilities are scarce (Axelsson et al., 2004). Resources are rare, sporadic, unreliable and inaccessible. According to the World Health Organization approximately 10% of the population lives with significant intellectual, physical or sensory impairments. Ursic (1996) claims that in the available literature “no statistical data seem to refer to the population of people with disabilities from the point of view of demographic data, socio-economic situation, etc.” Arguments of the definition what constitutes a disability and who is disabled have further created problems with cross comparisons. Governments must enact programs to standardize measures of disability in the social and economic spheres.

\(^4\) A national nonprofit disability rights firm specializing in precedent-setting and socially significant civil litigation. http://www.dralegal.org
EDUCATION AS CITIZENSHIP

Article 24, Education

“States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning. Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live”.

Source: UN Convention on the rights of persons with disabilities.

Educational systems, policies and structures are the main culprits for the deprivation of rights of youths with disabilities. Close to 98% of secondary schools in the ECA region are not physically accessible. Public education at all levels is necessary to dispel the deeply rooted prejudice against children with disabilities. In Azerbaijan, as in most countries in the region, special schools exist for the blind and deaf but continue to segregate and isolate the student from the general community. The biggest barrier in the education of children with disabilities is the existence and strong divide between two parallel systems: “special” and “mainstream” education. In Bulgaria special schools are the primary options for elementary and secondary education for disabled children. The curricula of special schools are shortened, children are segregated, and the programs have increasingly become boarding schools.

The programs in special schools are mostly linked to the specific type of disability (physical, sensorial, or intellectual). Many students enrolled in special education are capable and ready to be integrated in the mainstream schooling. In Azerbaijan, children with intellectual disabilities are treated as non-educable and placed in residential institutions or are sent home. UNICEF (2006) reported that the available data on number of children with intellectual disabilities is probably not accurate because many of them stay at home, and therefore are not accounted for.

Serbia’s Poverty Reduction Strategy Paper identified the key problems in special education as segregation and the lack of quality education. Only 30% of children with disabilities who completed primary school continued their education, compared to 79% of the general population (World Bank, 2004). Students after finishing primary education are usually directed to vocational schools. These are, however, segregated and organized by disability or medical diagnosis. Lately, these vocational schools are loosing their momentum due to the fact that many of the vocations previously thought as “suitable” for people with disabilities are not in demand.

Although the countries of the region are undergoing a change in this area, primarily through legislation and through the introduction of pilot projects, poor enforcement mechanisms perpetuate their disenfranchisement and marginalization.

Fact #1: Azerbaijan

It was commonly believed that children with disabilities were ill and needed to be separated from other children and institutionalized.

Fact #2: Serbia

Students with visual impairment are trained for telephone operators, a job that is decreasing in modern economies because of the new technologies.

“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, Source: UNICEF
Influence of Defectology

Education for children with disabilities in Uzbekistan still heavily relies on Soviet science of Defectology. The name “defectology” reflects the medical approach to disability – a person with a disability has defects that need to be fixed by experts in the field. Unfortunately, this philosophy remains a powerful approach of further disenfranchisement in the region. New person-oriented approaches have been successfully integrated in social services in the Slovak Republic, allowing young people with disabilities and their families to direct their own care.

Higher education

Changes in labor markets have highlighted the importance and the role of higher education in the development of professional careers. New industries, employment opportunities, and the increasing complexity of information and commerce demand higher levels of training and education. Higher education enhances the chances of gainful and satisfactory employment (National Council on Disability, 2003). For people with disabilities, higher education provides the opportunity to compete in open markets with their non disabled peers.

Students with disabilities in Moldova rarely decide to pursue higher education. When looking at Eastern Europe DRA reports found that, “virtually all of the universities and graduate schools, as well as research institutes, are not accessible to wheelchairs users or people with mobility limitations” (p. 10). Students with disabilities in ECA countries face both physical and attitudinal barriers that contribute to their social segregation and isolation.

Central Asian nations have little legislation that regulates discrimination in higher education. The academic community and other relevant institutions (such as the ministries of education, rector’s offices, and student peers, professors, university administrators and staff) are not sensitive to the rights of students with disabilities. Throughout the region students with disabilities are not sufficiently empowered and skilled to pursue their rights (Association of Students with Disabilities, 2004). Recently, the new laws for higher education in Bulgaria, Serbia, Lithuania, Russia, and others included chapters concerning the rights of students with disabilities. These laws are not being fully implemented.
TRANSITION TO EMPLOYMENT

Article 27, Work and Employment

“States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labor market and work environment that is open, inclusive and accessible to persons with disabilities.”

Source: UN Convention on the rights of persons with disabilities.

State Vocational Programs

The socialist and communist legacy is a system of vocational rehabilitation, based on medical diagnosis rather than on choices, and sheltered employment (Axelsson et al., 2004). In Central Asia as in much of the region, high unemployment and people with disabilities are usually excluded from open markets and therefore more likely to fall into poverty. In Montenegro, young people with disabilities are most frequently only token employees in a company and retire after only six months to two years, with the aim to gain a right to pensions. A pension acquired in this manner is very low and people with disabilities are once again dependent on the government and their families.

Many barriers to employment are prevalent across the region: lack of physical access or special accommodations at the workplace, disabled people are provided token employment, there is little or no accessible transportation, employers still hold many stereotypes about people with disabilities. Young people with disabilities experience low self-esteem and are often not prepared to independently enter the work force, and when they do, they oftentimes fail due to a lack of support. All of these barriers and work disincentives also confront students with disabilities leaving technical schools or universities, with often nobody available to help them secure a job and hold it.

State employment bureaus across the region fail to provide information for and on qualified young people with disabilities. Companies willing to offer employment are inaccessible to persons with disabilities. State employment agencies fail to provide employers with practical solutions for accommodating disabled employees.

In Uzbekistan for example, the majority of students with disabilities are cared for and taught at home with little chance of transitioning into employment.

Estonia’s labor force status represents the general situation in ECU countries. Employment among persons with disabilities is lower. However, in the national statistics large segments of people with disabilities are classified as inactive as opposed to unemployed.
ENABLING ACCESS

Article 9. Accessibility

“To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.”

Source: UN Convention on the rights of persons with disabilities.

Physical accessibility

In most countries of the region architectural barriers represent the first impediment for people with disabilities to any participatory activity. Lately some regulations of accessibility for wheelchair users have been coming into use. Accessibility regulations for blind and visually impaired people as well as people with hearing problems are extremely rare. Strong and enforceable sanctions against institutions that do not respect general accessibility regulations should be enacted in partnership with civil society and national disability councils.

Communication

The ability to access information in alternative formats is essential for people with auditory or visual impairments. Internet accessibility is a pressing issue that requires the adoption of existing standards. Universal design standards apply not only to the built environment but also to electronic communications. Public forums without sign language interpretation, television programming without closed captioning, or telephone numbers without TTY make it impossible for someone who is hard of hearing to access information. Likewise written material that is not provided in electronic format or in Braille makes it impossible for a young person with a visual impairment to read and respond to.

Personal assistance

Non-governmental organizations are introducing “personal assistance” pilot projects in the region. The goal of these projects is to document the need of self-directed personal care. It was successfully introduced in Serbia and Hungary. Personal assistant programs support independent living, empowerment, physical emancipation and the full participation of people with disabilities in public life.

Fact #6: Belarus

The Republican Association of Disabled Wheelchair Users (RADWU) estimated that over 75 percent of persons with disabilities were unable to leave their homes without assistance.

Fact #7: Croatia

Media reported on repeated acts of violence and sexual abuse in a home for mentally incapacitated children operated by the Catholic charity Caritas in Brezovica.
Transportation
Accessible public transportation usually is not available. In major cities and capitals of the region there are special means of transport for people with disabilities but these are often limited.

Health and Rehabilitation
Access to health and rehabilitation can come in many forms. Most importantly, through medical professionals who can provide knowledge and information about maintaining and managing medical conditions. Access to rehabilitation equipment including orthopedics, and other durable medical equipment is important. For people with auditory or visual impairments adaptive technology is essential.

FOSTERING ENGAGEMENT

**Article 29. Participation in political and public life**

“States parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others.”

*Source: UN Convention on the rights of persons with disabilities*

New NGOs function outside of the state bureaucracy, providing innovative community-based, citizen-driven solutions and programs for people with disabilities (Holland, 2003). They mainly work with cross disability principles in mind. The NGOs have helped to introduce a new approach to disability by emphasizing the social model with the stated purpose being the full integration of disabled persons into society. Newer cross disability youth organizations were created across the region. They are addressing the most pressing problems facing young people with disabilities.

1. Lack of resources
2. Myopia and Social Stygma
3. Underdeveloped as decision makers
4. Difficulty forming identity

These organizations were primarily created to support students and education efforts of youth with disabilities. They embrace the role of mainstreaming and are seen as important stakeholders by their governments. The nascent disability rights movements in throughout the republics of the former Yugoslavia have already initiated small and successful changes and is shaping policy and public perception in line with the social model. By 2003 NGOs in Serbia were regional players whose proponents have passed laws, initiated media campaigns, and have been introducing a broader understanding of disability.

**Youth Development and Leadership**

Youth Development is a process that prepares young people to meet the challenges of adolescence and adulthood through a coordinated, progressive series of activities and experiences to gain skills and competencies. Youth leadership is part of that process.
II. PRIORITY AREAS FOR INVESTMENT

The above diagnostic provided an overview of the following points relating to the conditions youth with disabilities are facing throughout the ECA region. This is also the starting point from which to approach policies that will enhance capabilities for youth with disabilities.

CHALLENGES

Youth with Disabilities throughout ECA region face similar challenges:
1. Poverty longer lasting longer for disabled youth and for disabled adults
2. Integration and inclusion programs not as successful for disabled adults
3. Second, and third chances accommodate for medical or personal complications
4. Breaking into the job market requires multi-sectoral approach In more developed countries low literacy and knowledge of basic skills are low despite special (segregated) schools.
5. Children at special schools struggle to integrate or feel part of the society
6. There is insufficient access to secondary and tertiary institutions
7. Face Few job opportunities
8. No platform for civic engagement preferences

OPPORTUNITIES

Change disabling public attitudes and physical environments
• Strengthen existing anti-discriminatory regulation, oversight by independent national council on disability.
• Execute youth driven public media and education campaigns involving youth as creators of the media.
• Setup network of youth organizations with and without disabilities to survey existing physical barriers in the local communities.
• Enforce access to public infrastructure by eliminating physical barriers to public buildings and public transportation.

De-institutionalize and build community-based support
• Promote independent living by funding in-home personal assistants through existing social service programs.
• Setup transitional programs run by youth with disabilities to provide peer support and counseling.
• Fully fund centers for independent living as community resources and advocacy centers not simply as housing facilities.
• Create a community registry of accessible and affordable housing options.
• Create a community registry of personal assistants and provide them with training and information.

Improve economic capacity of youth with disabilities
• Ensure equal and meaningful participation of students with disabilities in higher education, taking into account the higher financial needs of these students.
• Adopt higher-education anti-discrimination legislation.
• Establish offices of disability services (ODS) at universities to work closely with students with disabilities and their professors to establish accommodations and provide equal academic access, such as alternative exam formats, additional time, tutors to assist with coursework, readers, classroom note takers, registration assistance or priority class registration, textbooks on tape, adaptive technology, and sign language interpreters.
• Introduce services to assist students in the transition from elementary to high school and from high school to university.
• Provide dignity, equality of opportunities in employment, vocational training and lifelong learning for youth with disabilities.
• Create employer awareness of people with disabilities as contributors to society, as an important part of the workforce and not as recipients of social benefits.
• Promote travel abroad opportunities for students with disabilities.

Integrate youth in setting goals and shaping services
• Promote full participation of young people with disabilities in society.
• Represent young people with disabilities in all youth networks/NGYOAs as well as their active participation and self-representation in their networks/NGYOAs at the local, regional, national and international level.
• Eliminate of barriers for participation as active citizens, such as accessibility to buildings and public environment, transportation systems, information and telecommunication systems.
• Ensure participation of young people with disabilities through their involvement in decision-making bodies at all levels.
• Create mentoring activities designed to establish strong relationships with adults with and without disabilities through formal and informal settings.
• Supply peer-to-peer mentoring opportunities for youth with and without disabilities.
• Promote exposure to role models with disabilities in a variety of contexts.
• Provide training in skills such as self-advocacy and conflict-resolution.
• Encourage exposure to personal leadership and youth development activities, including community service.
• Offer opportunities that allow youth with disabilities to exercise leadership and build self-esteem through internship and community involvement programs.
III. BEST PRACTICES

New project to address work-site accommodations and job development in Russia

In September 2003, Perspektiva, a Russian NGO began a project on access to employment for people with disabilities. The project, funded by the Ford Foundation, was implemented in 5 regions - Moscow, Nijniy Novgotod, Samara, Toliatti and Rostov to motivate youth with disabilities to seek job skills training and employment opportunities, while promoting an inclusive access to employment approach in Russia amongst members of the community at the national and local levels.

Project activities included leading seminars and trainings for young people with disabilities, government officials and employment agency professionals, organizing job fairs for people with disabilities, and working closely with the media to promoting an inclusive approach to employment. During the project, more than 200 reports, broadcasts and radio shows appeared on local and national TV. In addition, employment agencies were organized in 4 cities. More then 5,000 people with disabilities participated in job fairs, and thousands of people were provided consultations and over 100 people found jobs. Working relationships with government officials dealing with employment issues improved significantly. In Moscow alone, 35 companies / employers participated in the last job fair. After seeing the productive and positive nature of a partnership with Perspektiva or one of its partner disability NGOS, employment agencies have begun negotiating with them to organize more disability employment outreach.

The Access to Employment project helped identify problems and some of the solutions, but most of all, it has demonstrated the enormous need for an agency or program that will specialize in employment for people with disabilities. In 2005, Perspektiva, with funding from the Ford Foundation, is starting a new project that includes activities more focused on providing job development and career development services for young people with disabilities, particularly, students. The project will continue to conduct pre-employment trainings and consultations for employers and people with disabilities and will also address the process of work-site accommodations and adaptations and job development for individuals.

Source: Perspektiva NGO. www.perspektiva.ru
Innovative Fund promotes community-based care and deinstitutionalization in Ukraine

The Ukraine Social Investment Fund Project: USIFP aims to develop innovative community-based care strategies as an alternative to the more conventional residential care interventions. Implemented by NGOs, it will include interventions such as CBR, day care centers, foster care services, training families of disabled people and social workers, minor repairs on buildings, and some educational programs. Since local NGOs do not have enough experience working on community based care, international organizations will provide technical support and guidance. The project seeks to not only test innovative demand-driven social care services, but also to inform national policy so as to make the reforms more sustainable.

The Ukraine project aims to inform national policies by testing innovative approaches towards deinstitutionalized social care services for the disabled. Due to the political and economic transition in Ukraine, there has been shift from traditional institutionalized social care towards deinstitutionalized community based care. USIFP seeks to develop the operational knowledge necessary to translate this shift into both policy and practice.

Youth-led disability rights movement in Kyrgyzstan

There are basically two main groups of Disabled Peoples' Organizations in the Kyrgyz Republic. One is the Independent Association of Women with Disabilities of the Kyrgyz Republic, led by Ms. Asipa Musaeva (President) who is also the National Coordinator and Council Member under the Ministry of Social and Culture Development. This Group is collaborating with the Union of Young Disabled People, led by Mr. Shamyrbek Ydyrysov, an APCD ex-trainee (CBSHOD 2005).

The other group is the Public Movement of the Disabled Young People of Kyrgyz Republic, led by Mr. Mirbek Asangariev, also an APCD ex-trainee (CBSHOD 2004). This organization has two supporting organizations; one is the National Organization Workers Association and the other is Bishkek University, which provides office space and student volunteers. The Public Movement of the Disabled Young People of Kyrgyz Republic is aiming to form a political party with people with disabilities participating in policy making and raising a voice of their own. Presently, there are 270 members. APCD mission had a meeting with both groups to encourage them to establish a National Assembly to unify the voices of persons with disabilities and collaborate with each other.

According to the Director-General of the Department of Social and Culture Development, there is the National Coordination Council under the Prime Minister. The members include several Ministries such as the Ministries of Education, Public Health, Transportation and Construction. There are also three NGO Representatives; Presidents of the Blind Association, Women Independent Association of Disabled of Kyrgyz Republic and Parent Association of Disabled Children. The Vice-Prime Minister is the Chairman and Vice-Ministers are members. They are seeking barrier-free accessibility for the built environment for transportation, job placements and promoting the sales of goods produced by people with disabilities.

Source: Asia Pacific Development Center on Disability. http://www.apcdproject.org/missions/2006/kg-03.html
### IV. APPENDIX

**Table 1: ECA Youth Disability Barriers to Citizenship and Employment**

<table>
<thead>
<tr>
<th>COUNTRY</th>
<th>ANTI-DISCRIMINATION LEGISLATION</th>
<th>EDUCATION</th>
<th>EMPLOYMENT</th>
<th>HEALTH CARE ACCESS</th>
<th>OTHER STATE SERVICES</th>
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</tbody>
</table>

Key: 1=No Law; 2=No enforcement of law; 3=Discrimination is a problem; 4=Discrimination is a problem. Some improvement; 5=Some Discrimination; 6=Some Enforcement; 7=Enforced law; 8=Effectively enforced law with sanctions.

*Source: US Department of State Human Rights Report 2006; Victor Pineda Foundation.*
Table 2: Education enrollment and labor force status, Estonia, 2000 (%)

<table>
<thead>
<tr>
<th>Age</th>
<th>In Education</th>
<th>Employed</th>
<th>Unemployed</th>
<th>Labor Inactive</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>of total persons at corresponding age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15-19</td>
<td>83.3</td>
<td>7.2</td>
<td>4.2</td>
<td>4.7</td>
<td>0.6</td>
</tr>
<tr>
<td>20-24</td>
<td>21.0</td>
<td>51.1</td>
<td>12.3</td>
<td>14.9</td>
<td>0.7</td>
</tr>
<tr>
<td></td>
<td>of persons with disabilities at corresponding age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15-19</td>
<td>67.8</td>
<td>4.3</td>
<td>2.5</td>
<td>25.4</td>
<td>-</td>
</tr>
<tr>
<td>20-24</td>
<td>15.2</td>
<td>24.3</td>
<td>7.2</td>
<td>53.3</td>
<td>-</td>
</tr>
</tbody>
</table>

REFERENCES


