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**Children with Disabilities in Tajikistan
A Situational Analysis Report**



CHILDREN WITH DISABILITIES IN TAJIKISTAN

The status and rights of children with disabilities have become high-profile issues on the global stage and, interestingly, in the CEE/CIS Region in particular in the past decade. In 2006, the new UN Convention on the Rights of Persons with Disabilities was adopted. In 2005, UNICEF published a benchmark study¹ on children and disability in the Region in the wake of the breakup of the Soviet Union. At the same time, in 2003, a situational analysis of children with disabilities in Tajikistan was carried out by the National Commission on Child Rights. It was recognized that children with disabilities in Tajikistan face numerous challenges. The aim of the situational analysis was both to gain a better overview of those challenges and to highlight prominent issues such as the legacy of institutionalization of children with disabilities and the particular concerns of parents.

MAIN FINDINGS

1 The analysis noted the high rate of institutionalization of children with disabilities in Tajikistan, a direct legacy of the Soviet approach across the Region. A review of existing institutions found that, overall, they lacked the capacity to provide children with proper education, rehabilitative services and life skills. Examination of children in the institutions found that many were malnourished and had various health problems as a result of poor conditions in the institutions. The institutions are overcrowded and, therefore, cannot provide proper care for all children. There is a lack of mechanisms to implement and comply with minimum international standards of care.

2 Current international wisdom--as well as the 1989 UN Convention on the Rights of the Child (CRC)--is clear that institutionalization of children must be an option of last resort. In this environment, de-institutionalization of children with disabilities is a policy goal across the Region. However, the analysis finds many obstacles both to keeping and getting children out of residential facilities. Above all, there is a lack of alternatives, e.g. community-based day centres or integrated classrooms.

1. "Children and Disability in Transition in CEE/CIS and Baltic States," UNICEF, Innocenti Research Centre, 2005.

3 Parents who have children with disabilities simply do not have access to adequate and up-to-date knowledge about disabilities and how to raise children with disabilities. The analysis notes, however, that parents' knowledge simply reflects the information they receive from local medical specialists who assess child disabilities. The situation is especially difficult for families living in rural areas: medical experts are few and, lacking transferred knowledge, parents are unlikely to detect disabilities early in their child's life.

4 Lack of resources characterizes the entire environment around children with disabilities in Tajikistan. This shortfall applies to health, social and education issues. It involves political priorities, public attitudes and prejudicial behaviours--not to mention funding. The bottom line is that human rights do not yet form the basic framework around disabilities in Tajik society--and poverty remains an aggravating factor.

METHODOLOGY

An Expert Group of the National Commission on Child Rights conducted the situational analysis with UNICEF technical assistance. To assess the legal environment around disabilities, the Expert Group examined the laws and conventions signed by Tajikistan. The group also gathered information through questionnaires distributed to and returned by government ministries, directors and educators of institutions, local authorities, NGOs and parents of children with disabilities.

OBJECTIVES

The main objectives of the Expert Group included: introducing international norms related to defining disability; promoting early detection of childhood disabilities; implementing inclusive education, raising awareness about disability and social inclusion; changing attitudes towards persons with disabilities; and analyzing the number of children with disabilities, the extent of their disabilities, and the problems that their families face. Finally, the Group sought to develop an overall picture of the situation of children in institutions and introduce alternative care programs.

DEFINING DISABILITY

What exactly do we mean by "disability"? The answer varies significantly both between and within countries and, indeed, in the minds of different members of society; for example, between doctors and teachers, parents and police, neighbours and peers. The definition is, however, invariably subjective, i.e. reflecting a point of view. Nonetheless, the definition of disability is a powerful mechanism. It can determine who is diagnosed as disabled, affecting not only individual lives but national profiles on the prevalence and incidence of disability; who receives social welfare benefits and access to other public services; and, for better and for worse, who wears the label 'disabled', a status that can confer inclusion and support or exclusion and prejudice depending on the family, community and society. There is also a broader discourse about the social dimensions of disability over and above the medical aspects of any condition. While varying definitions of disability may serve a specific purpose in terms of medical diagnosis or

even access to supports, it is important that countries establish an overarching definition of disability that is in keeping with international definitions, norms and standards that champion the human rights of persons with disabilities.

TAJIKISTAN'S DEFINITION

Tajikistan defines childhood disability as “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.” This definition is, however, interpreted differently by the various government ministries which have a responsibility for children with disabilities; e.g. the Ministry of Labour and Social Protection, Ministry of Health and Ministry of Education.

The Medical Consultation Commission (MCC), which falls under the jurisdiction of the Ministry of Health and operates through local polyclinics, has responsibility for assessing children as to disability and issuing certificates attesting to the positive. Such a certificate is necessary if a parent wants to claim a state pension for a child under age 16 with a disability. To be placed in an institution, a child must be referred by a Medical Pedagogy Commission (MPC)² after an assessment by a psychiatrist, neurologist, speech therapist as well as vision and hearing specialists. Problematically, however, the MPC has a history of sending children with even minor disabilities to institutions. Meanwhile, there are very few alternatives to institutional referral.

The state provisions in place for a family with a disabled child do not meet the needs of such a family. Responses from parents for this analysis revealed that families with a child who has a disability have an average of four children and an average income of 6 to 20 somoni per week. If parents claim a state pension for their child, they receive an average 20 somoni extra per month or another 5 somoni a week added to the family income. Since the pension is so low, most parents do not bother to claim it. The Expert Group recommends a review of the system so bureaucracy is streamlined and more funds are available to families.

INTERNATIONAL DEFINITION OF DISABILITY

The United Nations uses this definition: “Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”³ This description captures two crucial aspects of disability: the medical/health definition that refers to the physiological functions of the person; and the social barriers, such as prejudice and inaccessible buildings, which keep people from participating in society. In this definition of disability, the assessment of a child includes not only the abilities/inabilities of the child but how society contributes to or mitigates his or her disability. A medical-social definition of disability is embraced by the Convention on the Rights of the Child and the WHO 2001 International Classification of Functioning, Disability and Health (ICF). It is important that Tajikistan rise to these international standards and obligations.

2. *The Commission in Dushanbe is now called a Psychological Medical Pedagogy Consultation at Polyclinic No 12.*

3. *UN Convention on the Rights of Persons with Disabilities (2006).*



HUMAN RIGHTS COMMITMENTS

Tajikistan has ratified a number of international human rights treaties, including the Convention on the Rights of the Child, the Convention on Economic, Social and Cultural Rights, the Convention on the Elimination of Discrimination against Women and the International Covenant on Civil and Political Rights. The Tajikistan Constitution also protects the rights of persons with disability, outlining their rights to medical services, education, housing and leisure facilities, as well as their equality in the society. However, Tajikistan, like other countries in the Region, is still far from delivering on these duties.

BARRIERS TO DISABILITY RIGHTS

Social prejudice and exclusion

In many ways, the most significant barrier is public attitudes towards persons and children with disabilities. The predominant view is very narrow. Children with disabilities are treated much differently than able-bodied children in terms of basic respect and acceptance. Children with disabilities can be seen as cursed, inferior or objects of charity. They may be shunned, hidden away or abused. Even accepting attitudes often still view children with disabilities in terms of limitation rather than potential. Exclusion is a common practice and is sometimes conducted actively and sometimes just through neglect. Changing people's minds means de-mystifying disability and, in effect, normalizing it as an authentic part of human diversity which, in fact, it is. Eliminating prejudice begins by promoting knowledge and understanding about disability; advancing concepts such as equality and human rights; and identifying discrimination and acting to counter and prevent it.

Prevention and early recognition of disability

A shortfall in knowledge, practices and technology affects the prevention, early diagnosis and early management of disabilities. Maternal health, including good nutrition and regular medical checkups, is important as are prenatal practices such as taking folic acid supplements and refraining from alcohol and tobacco use. Pre-pregnancy screening of parents can detect genetic markers that present a risk of disability and prenatal testing such as ultrasound and amniocentesis can reveal disabilities allowing timely interventions. Currently, there is a huge gap between access to prenatal testing in urban and rural areas of Tajikistan, e.g., in 2000, 98% of mothers in Dushanbe had prenatal tests compared to 3% in countryside. Medical staff need access to up-to-date knowledge and techniques—as well as technology—related to child development and disabilities, as well as systematic upgrading in their training. Parents, too, need access to current knowledge, interventions and management practices for children with disabilities. This knowledge and participation extends to all the actors in a child's life, especially the major players in the crucial early years of development, e.g., family members, neighbours, caregivers and teachers. This is especially true because many disabilities can go unnoticed until the child misses major developmental milestones such as walking and talking, or begins to have learning or behavioural problems in school.

Institutionalization

The practice of placing children with disabilities in institutions remains common in Tajikistan. Under Tajik law, parents are responsible for bringing up their children whatever their health or ability status. However, in the current environment, parents often do not have the capacity to adequately care for a child with disabilities. This lack of resources applies to everything from prejudicial attitudes to family poverty. Children who are placed in institutions have a wide range of disabilities, both physical and mental; also children with "mild disabilities" are often placed in institutions due to family poverty. Parents attested that they may place a child in an institution as they cannot afford the costs of medical care and schooling.

The questionnaires given to parents with children in institutions shed further valuable light on their reasons for placing a child in an institution. Parents said that they felt that the institution was the best place for the child as they would receive proper medical, rehabilitative and educational services. Yet institutions are not meeting these expectations. Moreover, they commonly fail to meet international standards for care of those with disabilities.

In fact, many children in institutions exhibit signs of malnutrition. Past analysis of institutions in Tajikistan raised concerns that humanitarian aid in the form of food and supplies is being supplied to institutions but it is not reaching the children who live in the institutions. Institutions also lack proper facilities for the number of residents, with children living in very tight quarters. They also do not have their own clothing or possessions. The children do not receive appropriate education and lack any significant amount of social integration, contrary to the CRC command that children with disabilities have the "fullest possible social integration and active participation in the community." Finally, not only are there inadequate provisions to keep children with disabilities from being institutionalized in the first place, but, again contrary to the CRC, children in institutions do not receive regular assessments as to whether the living arrangement is in their best interests. Once a child is placed in an institution, the reality is that she or he stays there permanently.

There needs to be a new monitoring system in place that will regulate both the situation in institutions and what measures are being taken to control who is being admitted. In order to

reduce the number of children in institutions the government needs to provide alternatives. Large impersonal facilities can be devolved into smaller family-style group homes in the community. Similarly, foster care and guardianship settings can be developed to provide an alternative family for those children with disabilities who inevitably are separated from their families of origin. The inclusion of children in regular schools and the development of day-care facilities and other supports and services in the local community make it much easier for children with disabilities to claim their right to live with their families—and to help those families take up their responsibilities to raise their children.

Living at home

Children with disabilities who live at home also need greater access to education, rehabilitation services and life skills counselling. Most parents say that their children visit doctors regularly but do not have access to life-skills and rehabilitation services nor, indeed, to education. There are no programmes in Tajikistan for home-based education for disabled children with disabilities.

Parents said that the most needed and most beneficial supports for their children are: more education (38% of parents); increased monetary support (23%); and greater medical help (15%). Parents' responses to the questionnaire also revealed the difficulties they face in taking care of their children with disabilities: 27% lack an understanding of the child's needs and medical issues; 20% need more money; and 3% simply do not have time to care for their child.

Children with disabilities also need to be provided with appropriate equipment, such as wheelchairs, crutches and prosthetics. With this equipment, they would be able to be more active and mobile.



RECOMMENDATIONS

- 1 There is an overarching need to create a social environment where children with disabilities are included, respected, valued and able to claim their human rights. National awareness campaigns should be conducted that are aimed at the public, the professions (including teachers and doctors), employers, public servants, and all those who work in disability field.
- 2 At the same time as social barriers are addressed, concrete physical and programming steps need to be taken to include children with disabilities in public places, e.g. parks, libraries and recreation centres.
- 3 The Government should adopt the ICF definition of disability, which includes both physiological and social dimensions, and begin the work of implementing the new classification system, including training for relevant professional groups. Notably, the ICF promotes a holistic assessment of the person, reflecting their abilities as well as disabilities and capturing the degree of any impairment. Overall, a more precise and nuanced assessment should result, allowing better insights into current and future needs of the child.
- 4 The distribution of state benefits for families with children with disabilities needs to be restructured in order to target the neediest families.
- 5 Inclusive education should be adopted so that children with disabilities are included in the same schools and/or same classrooms as regular students. This involves training for teachers and school staff, the addition of specialists to staff as required, making schools physically accessible and developing curricula which serve a more diverse student population. Inclusive education reaches out both to children with disabilities who currently reside in institutions and those who live at home but go without schooling.
- 6 Institutions for children with disabilities crucially need to be restructured. The goal should be to get out and keep out as many children as possible. Alternative care and education settings need to be developed, including day-care centres and local group homes. Gatekeeping mechanisms need to be established so that it becomes harder for children to enter institutions. Finally, where institutions remain a necessary measure, national minimum standards and monitoring systems should be put in place to ensure adequate care, health and education levels for the children. The costs saved through transforming or closing institutions can be turned to community-based supports and services.



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