

## A FAMILY RAISING A CHILD WITH COGNITIVE DISORDERS: PROBLEMS AND DEVELOPMENT TRENDS

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### Annotation

This article examines the specificity of the attitude of the Uzbek society towards children with intellectual and mental disabilities. The aim of the study is to reveal the reasons for the inhibiting processes of integration of children with intellectual and mental disabilities into society and leading to social alienation of this category of children and their families. The study was carried out on the basis of a systematic structural approach, in particular, by analyzing regulatory documents and analyzing research conducted to study this area. As a result of the study, it was revealed that in the process of changing the consciousness of Uzbekistan's society in relation to persons with disabilities, it is associated with strengthening public control over the implementation of laws by developing the activities of civil society institutions, as well as raising awareness of the population about the needs of this category of citizens. The results of this study can be used in scientific and theoretical research, as well as in the development of programs to further improve the system of social protection of people with disabilities in the Republic of Uzbekistan.

**Keywords:** intellectual and mental disabilities, social adaptation, inclusive education, rehabilitation, exclusion, discrimination, stigmatization, labeling, medical and social services, specialized institution

### Introduction

Over the past few decades, there has been an important shift in the understanding of disability. The world community has recognized the need for attention and care for people with disabilities. Currently, disability is perceived as a consequence of human interaction with the environment, which does not always allow people with disabilities to participate fully in the life of society, and restricts them in the exercise of their rights and freedoms.

Being an international standard in the protection of the rights of people with disabilities, the Convention on the Rights of Persons with Disabilities insists that disability is determined not only by the state of health, but also by factors external to a person and the surrounding (relational) barriers prevailing in society. The problem

of disability is considered in the Convention "as a pathology of society", i.e. as a consequence of the inability of societies to embrace everyone without exception and absorb individual differences[1]. Societies need to change, not individuals, and the Convention provides a roadmap for such a change.

Until recently, the theoretical basis of the phenomenon of disability was mainly a medical approach, which firmly linked it with the statement of the disease, emphasizing at the same time the social nature of the disease and disability. According to Foucault [2]. The medical model that defines today's interpretation of disability suggests that any somatic trait that does not correspond to an idealized norm should be corrected or eliminated.

The study of the process of social integration of persons with disabilities in Uzbekistan revealed some difficulties associated with both existing stereotypes regarding people with disabilities and the unwillingness of people to close contact with people with disabilities and situations that do not allow them to realize their opportunities on an equal basis with everyone. The greatest distance can be observed in relation to people with intellectual disabilities and mental illnesses. People with intellectual disabilities are often labeled deviant, they are attributed to lack of abilities, not success [3].

People with intellectual disabilities are particularly vulnerable and socially unprotected among persons with disabilities, as they belong to the most socially maladapted groups of the population [4].

Studies show that employers are less likely to hire people who are considered to have intellectual disabilities, are less likely to rent apartments to them, and are more likely to knowingly bring charges of violent crimes against them [5].

It should be emphasized that families raising children with intellectual disabilities are the most vulnerable, since in most cases they are stigmatized by society. The birth of a child with a disability in the family, especially with an intellectual one, creates great difficulties for the family [6].

These families feel isolated and do not feel the support of public resources that could help them cope with their circumstances and optimize the child's abilities. Caring for a child with an intellectual disability generates stress that affects the lives of all family members in physical, cognitive, emotional and social terms [7]. Stress often arises from the direct impact of the disease and its treatment, as well as the social stigma it causes.

According to the World Disability Report, the life chances of people with intellectual disabilities are often still low, and their protection and support almost entirely rests on the shoulders of their families and loved ones [8].

In addition to the isolation of people with disabilities from public life, there is a problem of material support for families raising children with disabilities. Since the family in which a child with a disability is brought up bears additional costs associated with disability, which in turn contributes to a decrease in their standard of living.

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According to various estimates, additional family costs can range from 10 to 50% of total household expenses [9].

According to WHO, 80% of people with disabilities live in developing countries, and the proportion of people with disabilities living below the national or international poverty line is higher, and in some countries twice as much as among people without disabilities, besides, the average income of people with disabilities is 18% lower than the rest population [8].

Studies show that raising a child with a disability in the family affects the lives of all family members, both on a personal and socio-professional level [10]. Other studies have concluded that a family that receives support from the state and society adapts better and more easily overcomes difficulties associated with their child's disability[11].

A review conducted by the Government of the Republic of Uzbekistan and regional UN agencies revealed that people with disabilities cause feelings of compassion, pity and rejection among the population. 42.3% of the population of our country feel sorry when meeting people with disabilities, 22.9% of people replied that they are trying to help them, 16.7% of respondents feel grateful that they do not have a disability, 6.7% of respondents behave as usual, 8.1% replied that they are upset at the sight of a person with a disability, 2.8% noted other options and 0.5% of respondents turn away.

This review shows that there is a lack of public awareness in Uzbekistan and a stereotypical attitude towards people with disabilities. People with disabilities remain "invisible" to the majority of the population, which leads to an attitude focused on charity and social exclusion [12].

This attitude is fueled by the mass media, illiterate presenting the image of people with disabilities to the population. There is an erroneous opinion about inclusive education in society.

In most cases, the care of a child with a disability falls on the shoulders of the mother, who in addition has household, marital responsibilities. As a result, most mothers are unable to work, which in turn limits the material support of such families and increases the risk of poverty, since disability and poverty are closely related concepts. Thus, according to the study, in Uzbekistan, the level of official employment of persons caring for children with disabilities is 21%, and 5% of those caring for children with disabilities are unofficially employed. [13]

In Uzbekistan, a key program to support families raising children with disabilities is a benefit for children with disabilities. However, according to a study conducted by the UNICEF Children's program in Uzbekistan in 2019, this program covers only 52% of children with severe disabilities, despite the fact that it is offered to all children with disabilities regardless of income or property status [14].

Unfortunately, in Uzbekistan, as in other post-Soviet countries, the practice of placing children with intellectual disabilities in institutional institutions immediately after their birth still persists.

One of the main reasons that families with children with intellectual and intellectual disabilities choose in favor of institutional institutions, which we mentioned above, is that parents often find themselves alone with difficulties that are accompanied by the upbringing of a child with intellectual disabilities, they do not have the necessary economic, social and informational support to ensure the child needs the necessary care and attention. Nevertheless, it is widely recognized that even in a well-staffed institution, a child rarely receives the attention that he would receive from his own parents and family [15]. In addition, children with disabilities in these conditions are deprived of the important advantage of imitating "other" children, which is a necessary element of their successful integration.

It is important for the Uzbek society to realize that disability is not a disease, but a social problem and a human rights problem that requires a multilateral approach to its solution.

The relevance of the problem under consideration is also increased by the fact that every year the number of people with mental and intellectual illnesses is steadily growing. According to WHO, one child out of 160 children suffers from (ASD) autism spectrum disorder [16]. However, scientists from the US Centers for Disease Control and Prevention published new statistics in 2020, according to which ASD occurs in every 54 children [17].

It is necessary to recognize that every child, regardless of his state of health, has weaknesses and strengths. When teaching children with special educational needs, it is important to start from the capabilities of each child, and determine which program (individual, adapted, special) the child will study.

As the experience of many countries has shown, many children who would previously have been automatically enrolled in specialized schools can satisfactorily study in regular schools with the necessary support provided in accordance with their individual needs, often within the framework of an individual educational program. We are talking about children with mental disabilities, for example, with Down syndrome, or with autism spectrum disorders, some of whom exceeded expectations by receiving secondary education and successfully passing state final exams at school [18].

There are many examples when people with cognitive disorders have achieved the highest results in science, politics and creativity. Among them we can single out Albert Einstein, who found it difficult to get in touch with people, Mozart, to whom loud and harsh sounds caused physical pain, Charles Darwin did not like to communicate with people, and maintained communication through letters, Stanley Kubrick, a famous director who had Asperger's syndrome. He was often rude to his actors and could get

hung up on little things. Thomas Jefferson is the president of the United States, who found it difficult to get in touch with people, and it was difficult to speak in front of an audience. Loud noises irritated him. Leonardo da Vinci, his pursuit of perfection sometimes became an obsession.

Currently, the education system of children with disabilities in Uzbekistan includes preschool education; boarding schools; general education schools, secondary vocational education and home-based education. The basis for recommending a form of education to a child with a disability is an individual rehabilitation and habilitation program (IPR), which is developed by specialists of medical and social expertise on the basis of existing functional disorders of the child, without taking into account the opinions and wishes of parents and teachers.

There are 86 specialized schools and boarding schools for "children with physical and mental disabilities" in all regions of the country, as well as 21 sanatorium-type schools for children susceptible to tuberculosis and bone diseases.

Of 86 specialized schools and boarding schools for "children with physical and mental disabilities", 80 are under the department of the Ministry of Public Education, 49 of them are specialized schools for children with intellectual disabilities, 6 of them are boarding houses "Muruvvat" for children with disabilities in which children with disabilities permanently reside disability of groups I and II aged from 4 to 18 years, with pronounced or significantly pronounced mental disorders, which are managed by the Agency of Medical and Social Services under the Ministry of Health of Uzbekistan. 52-58% of pupils of specialized schools and boarding schools are children with intellectual disabilities[19].

The education of such a large number of children with this category of disability in specialized educational institutions is due to the fact that if the education of children with disabilities in general education schools that provide conditions for inclusive education may still be possible, then it is still not available for children with mental and mental disabilities. Although there are different degrees of severity of the disease among children with these disorders – from low and medium to high-functional.

Another factor in the physical isolation of children with cognitive disabilities is that at the present day, a child with a disability graduating from a specialized school is issued a certificate that is significantly different from the certificate of outstanding after graduating from ordinary secondary schools. This is one of the obstacles that block the way for children with intellectual and mental disabilities to continue their studies in schools, colleges and universities. As a result, after graduating from specialized schools, children are forced to stay at home, which is a factor contributing to complete social exclusion, as well as deterioration of the physical and cognitive well-being of these children.

However, despite a number of the above shortcomings and factors complicating the life of people with disabilities, it must be emphasized that significant changes have



been taking place in the social policy of our country in recent years. Thus, since 2017, 2% additional quotas have been provided for the admission of persons with disabilities of groups I and II to higher educational institutions on the basis of a state grant, which is the first step towards ensuring accessibility of higher education for people with disabilities. In September 2020, a new Law "On Education" was adopted, which introduced the concept of "inclusive education" for the first time. In October 2020, the law "On the Rights of Persons with Disabilities" was adopted, on the basis of which the concept of "discrimination on the basis of disability" was introduced into legislation. In June 2021, the "Convention on the Rights of Persons with Disabilities" was ratified, which was signed by Uzbekistan in 2009. A number of laws have also been adopted, the purpose of which is to develop inclusive education in Uzbekistan, improve the education system and upbringing of children with special educational needs, improve the quality of educational services provided to them.

### **Conclusion**

1. The most urgent tasks facing the state and society in relation to people with disabilities are to fully ensure the protection of their rights and freedoms, allowing them to lead a full-fledged lifestyle, receive quality inclusive education, be able to find a job, thereby become equal and active participants in the economic, social and political life of society, fulfill their civic duties.
2. The existence in Uzbekistan of a multitude of normative legal documents regulating the protection of the rights and freedoms of people with disabilities does not guarantee the protection of the rights and fundamental freedoms of persons with disabilities. An important condition for the implementation of laws is inextricably linked with the improvement of public control over the implementation of laws and the improvement of legal literacy of the population, the development of the activities of civil society institutions.
3. It is extremely important to raise awareness of the population of Uzbekistan about the peculiarities of people with mental and mental illnesses from early childhood. This will give us an opportunity to study and understand their characteristics and needs more closely, and will also allow us to raise a generation that will perceive people with disabilities as an integral part of our society and destroy stereotypes that prevent them from fully socializing.

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