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SITUATION ANALYSIS ON CHILDREN AND ADULTS WITH DISABILITIES IN UZBEKISTAN

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SNAPSHOTS



SITUATION ANALYSIS
ON CHILDREN AND ADULTS WITH DISABILITIES IN UZBEKISTAN

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Published by UNITED NATIONS
Task Force for Joint Situation Analysis of Persons with Disabilities
UNDAF RG on Social Protection

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Snapshots



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ACKNOWLEDGEMENTS

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This Situation Analysis on Persons with Disabilities in Uzbekistan was commissioned by the Government of the Republic of Uzbekistan and UN agencies, namely UNDP, UNESCO, UNFPA, UNICEF and WHO in Uzbekistan.

The United Nations in Uzbekistan is grateful for the personal commitment of Mr. Aziz Abdulkhakov, Deputy Prime Minister of the Republic of Uzbekistan. His support was instrumental in bringing all relevant stakeholders together to contribute to the study.

This study was carried out under the overall guidance of Ms. Helena Fraser, UN Resident Coordinator for the Republic of Uzbekistan and Mr. Sascha Graumann, UNICEF Representative in the Republic of Uzbekistan/Chair of the UN Results Group on Social Protection, as well as Mr. Afshin Parsi, UNICEF Deputy Representative in the Republic of Uzbekistan and Mr. Farid Garakhanov, who served as UNDP Deputy Resident Representative in the Republic of Uzbekistan through August 2014- February 2019.

The Core team was led by Ms. Yana Chicherina of UNICEF and Mr. Jamoliddin Ismailov of UNDP who coordinated the research with the Government of the Republic of Uzbekistan and within the UN Family. The final report synthesizing the five research streams (a legal review, an institutional review, a statistical capacity assessment, a KAP Survey and a needs-assessment study) was prepared by Ms. Chicherina and Mr. Ismailov. The core team consisted of experts who worked on the five research streams namely, Ms. Mina Mojtahedi (Inception report), Mr. Peter Grimes and Kamol Jiyankhodjaev (Education Policy review), Ms. Guzal Adilova (Review of Legislative documents), Mr. Abdullo Abdulkhalilov, Ms. Aleksandra Plotnikova, and Ms. Natalya Plotnikova (Political participation of persons with disabilities), Mr. Arustan Joldasov, Mr. Anton Tujilin, Ms. Mira Dauletbaeva, Ms. Aysholpan Dauletbaeva and Ms. Mavlyuda Eshtukhtarova (of LLC "Expert Fikri Konsalting", responsible for the KAP and needs-assessment surveys), Ms. Paula Frederica Hunt, Ms. Janina Arsenjeva, Mr. José-Manuel Fresno, Mr. Stefan Meyer, and Mr. Skye Bain (of Fresno Servicios Sociales S.L., consolidated research and made additional analysis of legislation, qualitative and quantitative data).

The team benefited from technical guidance from Ms. Deepa Sankar, Chief of Education, UNICEF; Ms. Anna Maria Vangoor, M&E specialist, UNICEF and Mr. Zokir Nazarov, Child Rights Monitoring Specialist, UNICEF. The team would like to acknowledge also Ms. Yulia Oleinik, Chief of Social Policy, UNICEF; Ms. Matluba Umurzakova, Development Coordination Officer, UN Resident Coordinator's Office in Uzbekistan, and Ms. Kamila Mukhamedkhanova, Leader of Cluster on Good Governance, UNDP; for management of the components for the study within the joint UN plans respectively; Ms. Vazira Nazarova, UNICEF Early Childhood Development Officer, for the coordination of UNICEF component on the analysis of inclusive education; Mr. Atul Kumar, Chief of Communication, UNICEF, for guidance on advocacy and Ms. Alice Alan, Consultant on communication, UNICEF, for editorial support. The team would also like to thank the UNICEF office and UN Disability Task Force for their support throughout the study.

This study would not have been possible without the engagement of various individuals and institutions from diverse areas. The team would like to place on record and gratitude to one and all who contributed and enriched this report. Special mention goes to all children and adults with disabilities as well as their families who participated in the study and various discussions. This study also hugely benefited from the participation and contributions of experts from various Disabled People Organizations (DPO), particularly: Mr. Oybek Isakov, Mr. Farkhod Abdurakhmanov, Ms. Marina Teperina, Ms. Guljakhon Makhmatkulova, and Ms. Shakhnoza Ikramova. Generous support from officials of the Government of Uzbekistan made this research truly collaborative and informative. The team would like to specifically mention the support of Mr. Bahodir Sharapov (the Office of the President of the Republic of Uzbekistan); Ms. Elmira Basitkhanova, Ms. Barno Abdusamatova, Mr. Umarali Nazarmatov, Mr. Farrukh Sharipov, Mr. Alisher Inakov, and Mr. Naim Khamraev (Ministry of Health); Mr. Azizbek Mutaliev and Ms. Sabokhat Mirjalilova (Ministry of Public Education); Ms. Galina Goleva and Mr. Janpolat Kudaybergenov (Ministry of Higher and Secondary Specialized Education); Mr. Erkin Avezov (Ministry of Employment and Labour Relations), and Mr. Khabibilla Murodkhujaev (State Committee on Statistics).

This report is dedicated to all girls, boys, women and men with disabilities in Uzbekistan.



INTRODUCTION

INTRODUCTION

This Situation Analysis on People with Disabilities in Uzbekistan was commissioned by the Government of Uzbekistan and UN agencies, namely UNDP, UNESCO, UNFPA, UNICEF and WHO in Uzbekistan. It provides a “snap-shot” of the current situation in the country and provides a baseline for future work. This study feeds into the Government’s commitment towards fully integrating people with disabilities, as expressed in the presidential decree “On measures for fundamental enhancement of public support system of people with disabilities” adopted in December 2017.

This report summarizes findings from five research streams: a legal review, an institutional review, a statistical capacity assessment, a KAP Survey and a needs-assessment study (n=3,049 households with a person with a disability; n=1,782 households with persons without disabilities). A mixed-methods approach was undertaken to generate a comprehensive picture. First-person accounts from people with disabilities, their families and disability advocates were also included, gathered in the form of interviews and statements. The report follows the structure of the Convention on the Rights of Persons with Disabilities.



KEY FINDINGS



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Identifying disability

In Uzbekistan disability is defined using a blend of medical and charity models. There are procedural concerns with the current formal identification of disability: the existing List of Diseases (and corresponding ICD-10 (international classification of disease) codes) describe only a disease and not an impairment, but often attempts to quantify a degree of severity. However, despite the seeming simplicity of the procedure, 1) the list of diseases is not exhaustive; 2) evidence indicates that there is no correspondence between the severity of a disease and a degree of impairment; 3) a lack of established methodology and specific tools allows for discretionary powers in assessment; 4) it does not take into consideration cultural and environmental factors.

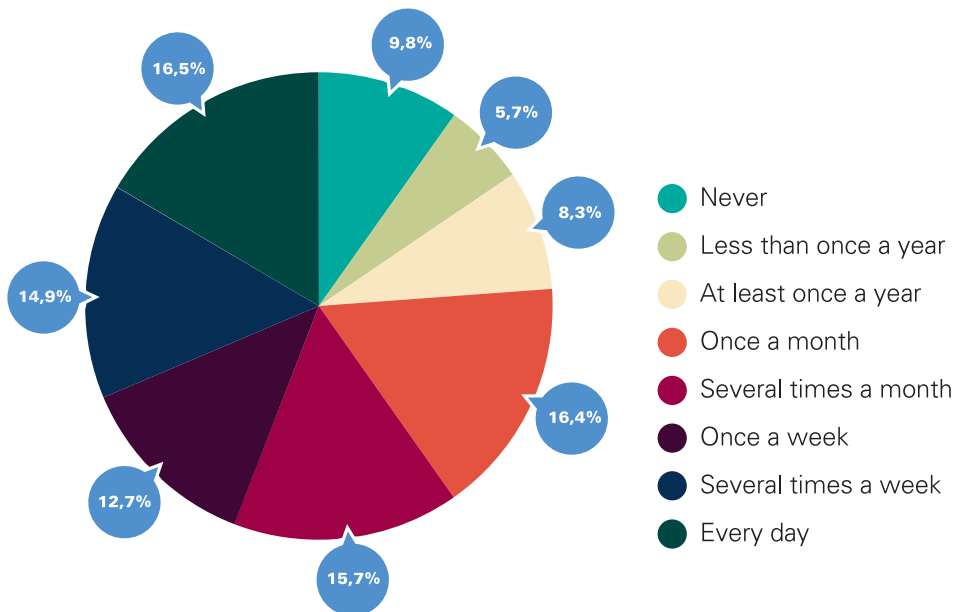
Knowledge, attitudes, practices (KAP) towards people with disabilities

People with disabilities remain “invisible” for the general public, which leads to charity-focused attitudes and social rejection. In the KAP survey, few people saw or had people with disabilities in their places of study or work, or among friends or close relatives. Only a third saw them in their mahallas and another third didn't know any person with a disability. 10 per cent of respondents reported they had never communicated with a person with disabilities, and 14 per cent that they had contact with a person with a disability once a year, or less.

People associated disability predominantly with the provision of non-personal assistance compassion, pity, the need for mercy, the desire to help. When asked of their sentiments towards people with disabilities, almost half of people without disabilities surveyed felt pity towards them and 23 per cent wished to help them. every fifth reported: “I think about myself and I am grateful that I do not have a disability”. Only a very limited share of respondents had a normalizing approach towards people with disabilities.

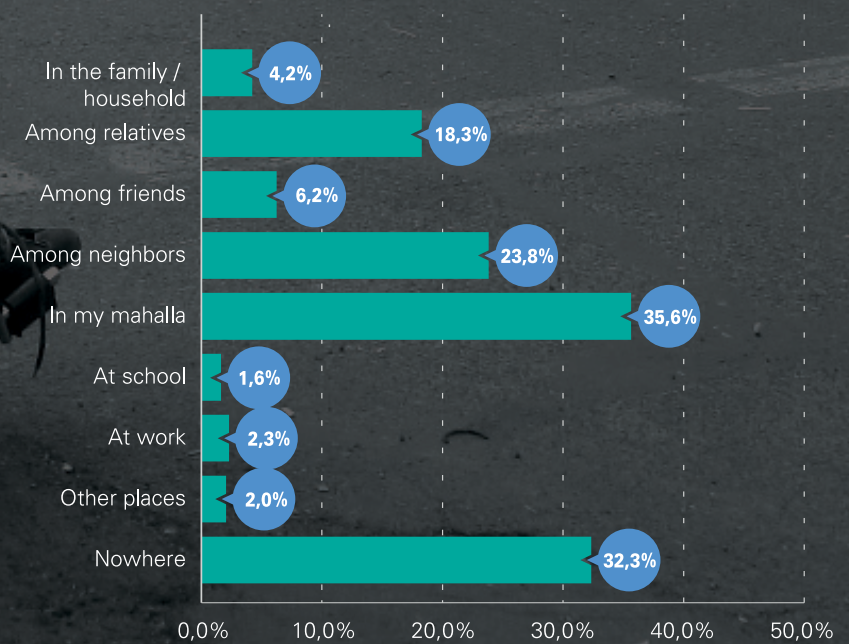
Almost 70 per cent of respondents believed that specialised schools are the best way to educate children with disabilities. While the majority of respondents (36 per cent) were fully against the idea that children with disabilities should live in residential institutions instead of with their families, more than one in four (28 per cent) respondents strongly agreed with this practice.

FREQUENCY OF MEETING WITH PEOPLE WITH DISABILITIES
percentage of people without disabilities





ACQUAINTANCE WITH PEOPLE WITH DISABILITIES
percentage of people without disabilities who have/see people with disabilities in their environment/neighborhood





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Legislation, equity and justice

Despite positive commitment from the Government to starting the process of ratifying the CRPD, in Uzbekistan, half as many people with a disability report that they enjoy their rights as those without a disability.

Currently, legal measures do not adequately protect disabled people from discrimination, indeed they sometimes generate exclusion of disabled people. Legal language speaks of “special needs of the handicapped” with emphasis on “disorders” and “illness” and their need in special, segregated services and non-personal assistance.

Mental and intellectual disability is routinely cited as reason to remove legal capacity. People with disabilities are disadvantaged by the loose wording of current legislation which may allow others to make important decisions for them. The Law on Medicines and Pharmaceutical Activities allows for the participation of legally incapacitated people in clinical trials of pharmaceutical or medical products on the basis of a written consent their parents or legal guardians and they are required only if possible, to personally sign and date the consent form. This is in clear opposition to Article 15(1) CRPD.

KEY FINDINGS

Right to accessibility

National legislation regulates issues of accessibility of transport, facilities and means of communication, and contains provisions concerning access to housing and social infrastructures, design, construction, and retrofitting of infrastructures. It stipulates fines for non-compliance with access requirements to transport and other social infrastructure. However, users with disabilities report insufficient level of accessibility to essential public places, such as schools, hospitals, workplace, services (post office, cinemas, and shopping facilities) and homes. Less than 60 per cent of respondents rated it easy or relatively easy for them to attend these places. Apart from passenger cars and minibuses, transport is inadequately accessible to people with disabilities, who are often dependent on private cars and taxi services.

ACCESS TO INFORMATION

percentage of people (caregivers of children) that state they (or their children) have complete access to the information they need (by strata and domains)



Right to independent living and participation in cultural life, recreation, leisure and sport

Uzbek law does not currently recognise the rights of people with disabilities to be included in community or facilitate their participation. Rather than supporting independent living, provision is made in residential institutions. Of those who choose to live at home, almost none receive personal assistance from the state.

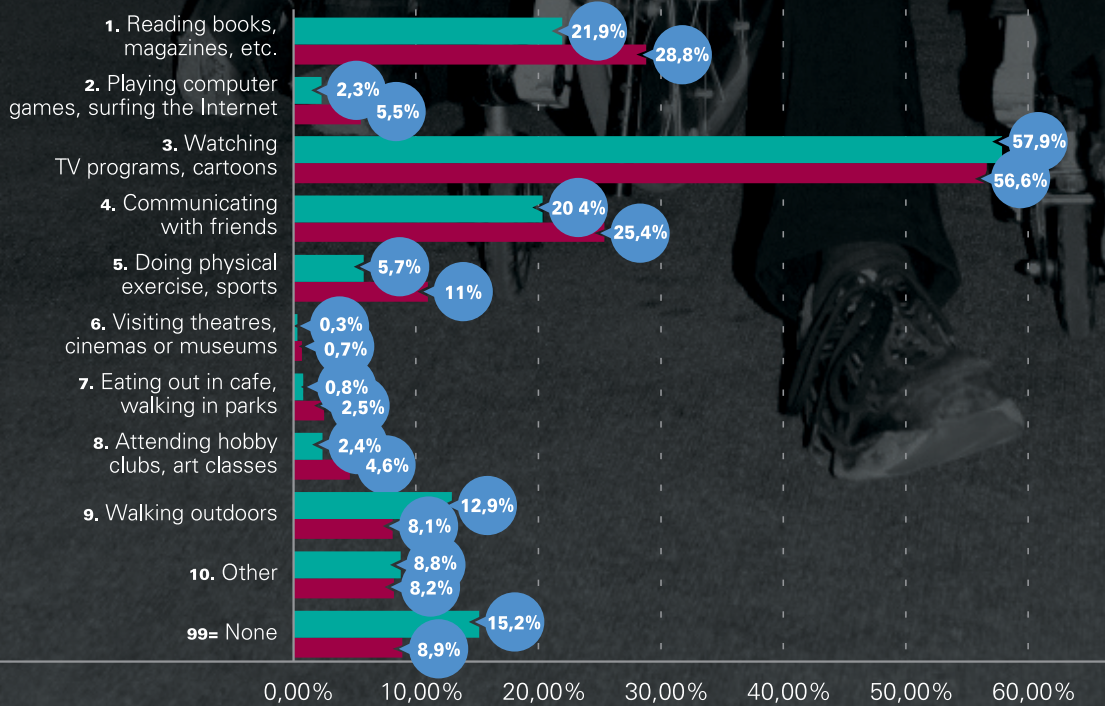
Overall, people with disabilities, and adults who have children who are disabled are less likely to leave their houses to socialize with other people. They are two times less likely to practice sport and physical exercise, visit theatres, cinemas or museums or attend hobby classes than people without disabilities. They are three times less likely to eat out in cafés and lounges, which is widely considered to be the main social pastime in Uzbek culture.

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PARTICIPATION IN LEISURE, RECREATIONAL OR SPORTING ACTIVITIES
percentage of people with and without disabilities



● People with disabilities ● People without disabilities



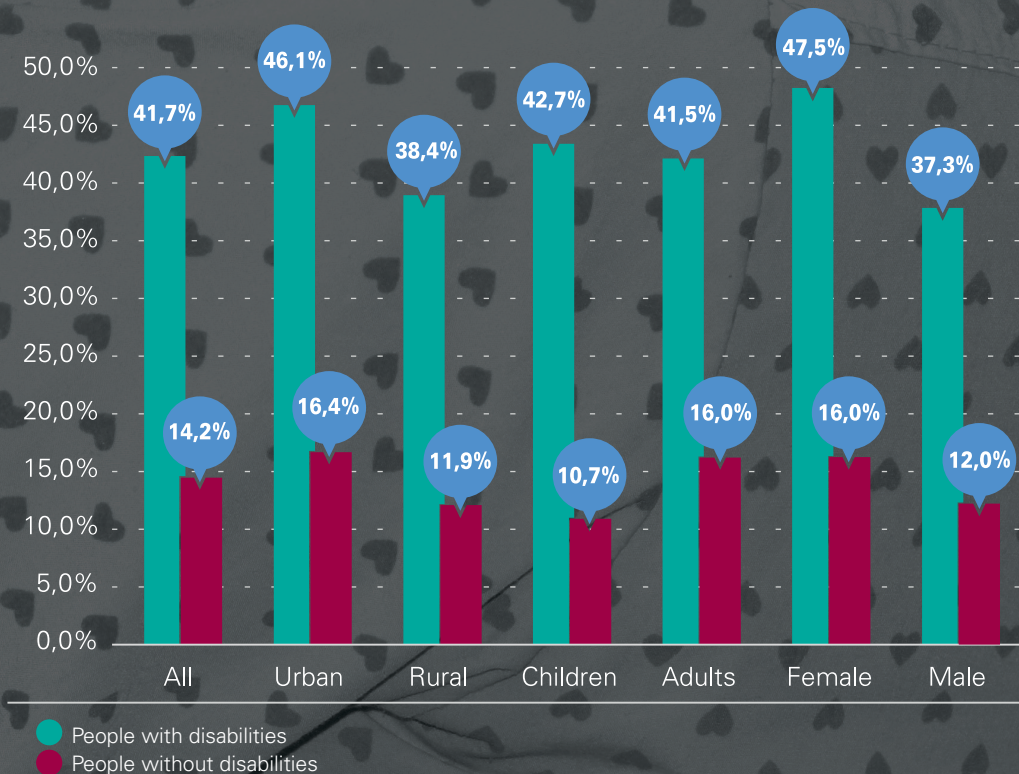
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Right to Health

The medical model claims to ensure access to and quality of healthcare services. However, the survey shows that one out of four people with disabilities report not to receive required healthcare as compared to one out of ten people without disabilities. People with disabilities are almost 3 times more likely to lack access to prescribed drugs. Although legislation on privileges and benefits makes healthcare services free of charge for people with disabilities at all levels, barriers to health care are caused by disable people having insufficient money to pay for examinations/diagnostics; doctors' services; medicines; and transportation.

INACCESSIBILITY OF ESSENTIAL MEDICINES

percentage of people who needed medications prescribed by a physician, but could not buy them due to their high cost



Right to Rehabilitation

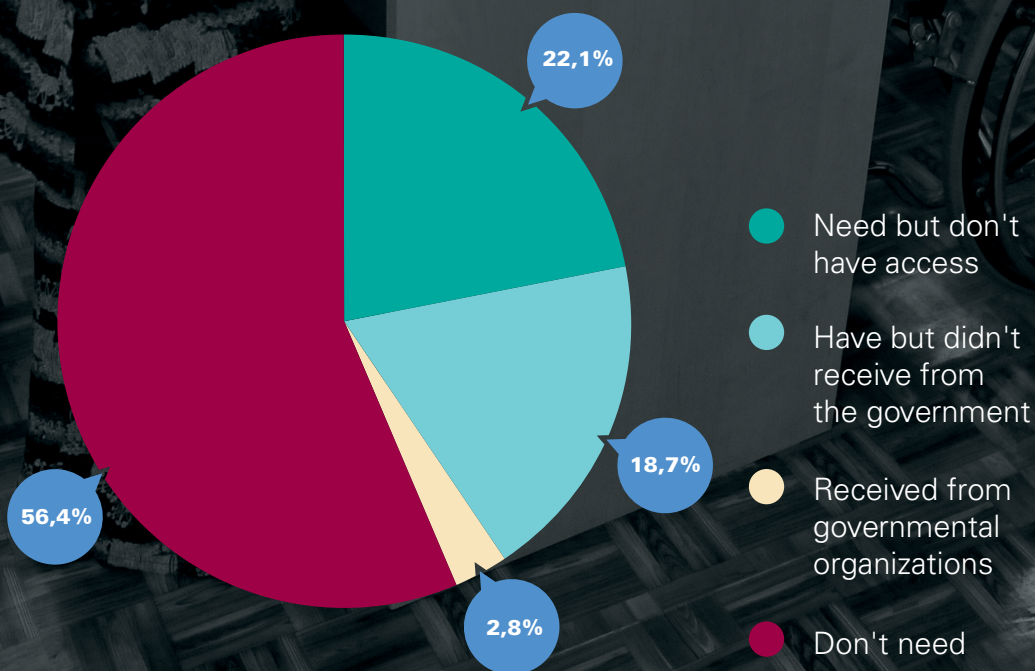
Responding effectively to disabilities needs early intervention services, multidisciplinary and holistic approaches for assessment or evidence-based educational and social interventions. In Uzbekistan, legislative or conceptual frameworks to facilitate this are not yet in place.

Rehabilitation is assigned on the basis of an Individual Rehabilitation Plan (IRP). In the absence of a multidisciplinary approach, the IRP is drafted by doctors who are not specifically trained to write them. Only 37.3 per cent of respondents reported having received an IPR; 50 per cent were not aware about the existence of an IRP, and 17.9 per cent reported that they had not received one.

There are no consulting services for those caring for children with developmental disabilities. There are no relevant protocols and standards, and the human resources of the health system do not have sufficient capacity in early development screening and interventions.

In addition, the survey reveals that many of the devices that are needed by disabled people are not currently available to them. From the total number of people with disabilities, 43.6 per cent need personal assistive devices and products, 21.5 per cent have access to them and only 2.8 per cent have received them from Governmental organizations. Importantly, children with disabilities, compared to adults with disabilities, have a significantly greater unmet need for movement and self-care assistive devices, aids for better hearing and communicating as well as hygiene and sanitation products.

NEED AND USE OF PERSONAL ASSISTIVE DEVICES AND PRODUCTS percentage of people with disabilities



Right to adequate standard of living and social protection

The Uzbekistan Wealth Index shows that severe deprivation is twice as common in households with members with disability in both rural and urban environments. Households with members with disabilities are three times less likely to find themselves in the most affluent category.

Self-assessments demonstrate significantly poorer conditions in households who have members with disability, due to extra disability related expenses. Self-declared expenditure per household member is about a third higher than in households without a member with a disability and, in rural areas, expenditures is nearly twice as much.

Coverage by existing social protection schemes and services is insufficient - for example, uptake of social transfers and tax exemptions is below fifty percent.

The identification of disability is principally linked to determining eligibility for benefits and services, it has a direct impact on ensuring the well-being of people with disabilities. There are serious concerns about obstacles to the procedure for identification of disability. In the survey 42 per cent of people with disabilities and parents/guardians of children with disabilities assessed the procedure of applying for disability status as "difficult" and "very difficult". Those surveyed also reported that the costs associated with the disability eligibility procedure are often prohibitive: nearly a quarter of all people interviewed (a third of those with children with disabilities) estimated that the cost was "expensive" or "too expensive". Although there is no formal payment for disability assessment, applicants are faced with costs such as transportation, collecting documents, informal payments, etc.

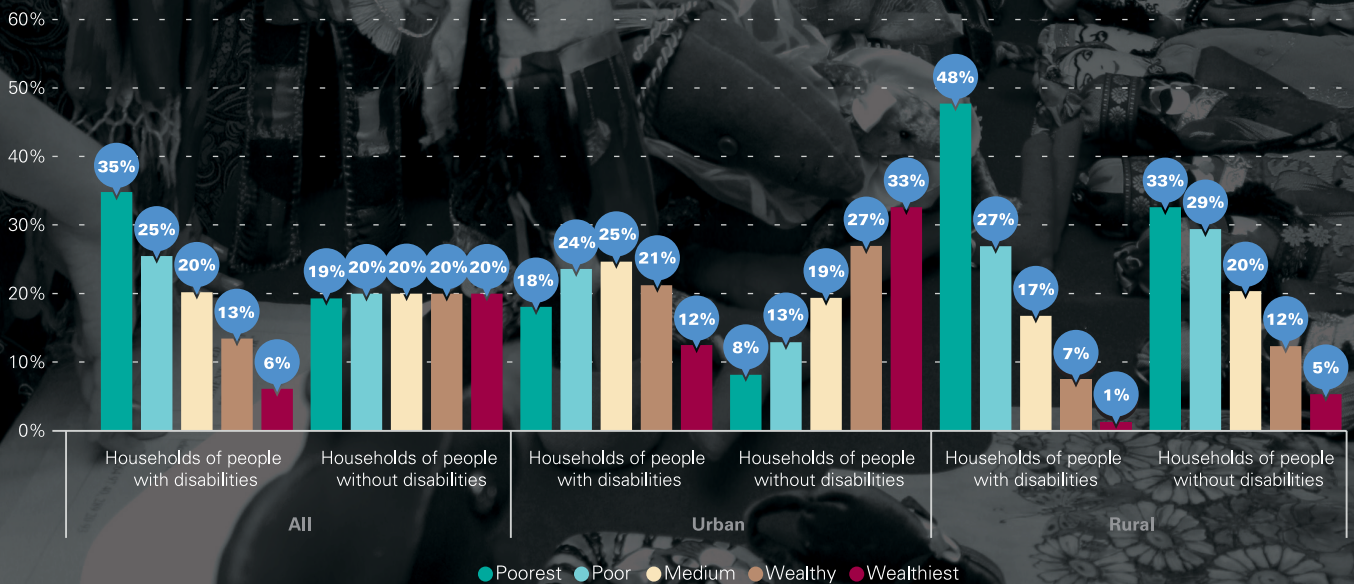
There are no data on an exact number of children and adults with disabilities in residential institutions but State data reports that over 80 per cent of state residential institutions are established for people with disabilities. Importantly, legislation on specialized institutions for people with disabilities contains no provision for independent authorities to monitor them to protect people with disabilities from exploitation, violence, and abuse.

SPENDING PER HOUSEHOLD MEMBER thousand soums





THE UZBEKISTAN WEALTH INDEX



Right to (inclusive) Education

Although access to secondary school stands at 99.8 per cent for people without disabilities, for those with a disability it is only 84 per cent. Access to pre-school is nearly 20 per cent lower for children with disabilities, to secondary schooling is 22 per cent less and 46 per cent less to secondary vocational schools.

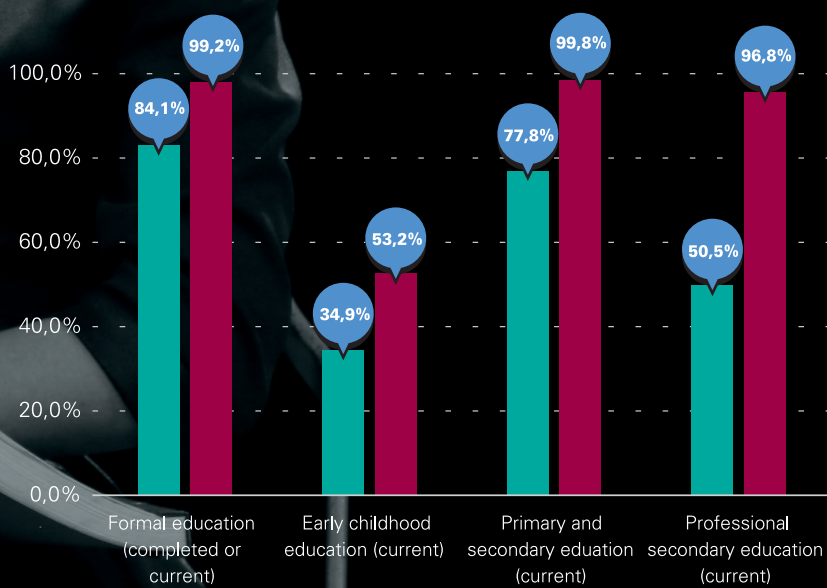
None of the legal norms and regulations currently in place takes into consideration the obligation of the State to provide education in inclusive settings. On the contrary, if children fail to fulfill the pre-existing conditions of mainstream education, they often enter further segregated settings. Lastly, many child residents of Murravats are denied a basic education which stands in direct violation of Article 24 – Right to Inclusive Education.

The restricted curriculum of «special schools for children with delays in intellectual development» violates their right to the same high-quality curriculum as other children in mainstream schools and limits their opportunities to develop their potential to the fullest. The school certificate which these children receive is of a different type and does not allow them to be admitted to vocational colleges or higher education. Legislation, policy and regulations do not make any reference to adaptation of assessment and examinations for people with disabilities who are seeking admission to colleges or universities (this is excluding people with visual disabilities). This raises concerns about the overall access of children with disabilities to any type of vocational or higher education which can lead to employment and independent living.



ACCESS TO EDUCATION

percentage of people with and without disabilities having formal education



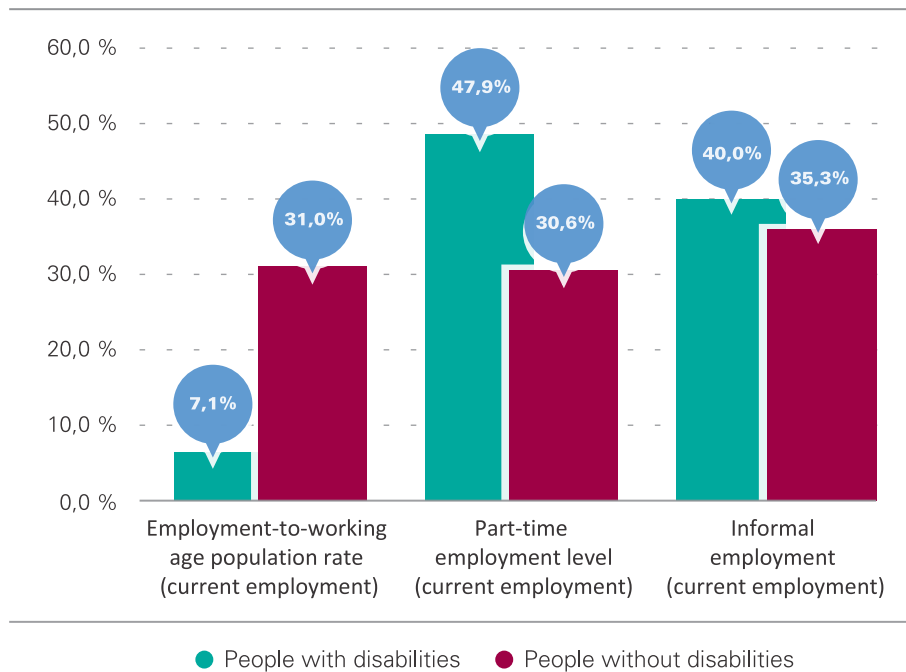
● People with disabilities ● People without disabilities

Right to Work and Employment

While there are some incentives for working people with disabilities, in reality these disincentivise employers from engaging workers with disabilities due to the associated burden. Data shows that people with disabilities are 4 times less likely to be employed than people without disabilities. The rate of formal employment of caregivers of children with disabilities is 21 per cent.

The average wage of people with disabilities in the formal sector is considerably lower (612,000 UZS) than people without disabilities (827,000 UZS). People with disabilities are discriminated against in the informal sector as well: their salaries in the informal sector are almost two times lower than those in the formal sector, whereas for people without disabilities, salaries are equal in both formal and informal sectors.

ACCESS TO EMPLOYMENT percentage of people with and without disabilities



AVERAGE MONTHLY SALARY thousand soums





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Statistics and data collection

Information on disabilities, available in the annual reports of Goskomstat, is scarce. Reporting is done by the types of diseases as per International Classification of Diseases. Special surveys that focus on disabilities or have disabilities as a specific component have been not been undertaken.

However, to rectify this the Government is introducing Washington Group Questions on functional limitations into the standard household surveys as well as several disability related indicators into the system of departmental statistics.



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Right to political participation

Improvements to voting access have been made in recent years. Although within local elections, candidates with disabilities have been elected, general and presidential elections have featured very few disabled candidates.

Barriers to voting including physical and informational access meant that people with disabilities participated less in the last general election.

There is limited participation in policy making and people with disabilities and their families do not feel adequately represented by disabled people's organisations.



**POLICY
RECOMMENDATIONS**

POLICY RECOMMENDATIONS

First, Uzbekistan should revise the legislation on implicit human rights violations, formulate strict anti-discriminatory policies and mainstream disability to promote equity and equal recognition. To stay on course, the government should establish a monitoring system within and across ministries to track the development and enforcement of strict anti-discriminatory policies that ensure the rights of all people with disabilities in all arenas of life. As a fundamental base for all further actions, it is necessary to include the CRPD definition of disability in all legislation and enforce the “working definitions” used by all line-ministries and regional/local institutions.

Second, Uzbekistan has the opportunity to develop a system of statistics that can be both innovative and exemplary in the region by harmonizing its methodology, tools and criteria with existing international standards. Census and household surveys that are nationally representative and use the Washington Group on Statistics’ guidelines are respectful of the CRPD and provide data that is useful across multiple sectors and across multiple segments of the population.

Third, all professionals must possess minimum knowledge and minimum standards of conduct, inclusive of disability. Effective inclusion and media campaigns and social encounters to change the public image of disability should be promoted.

Forth, responsible professionals within each line ministry should be provided with the capacity to address issues of accessibility and Universal Design, and effective enforcement mechanisms should be put in place ensuring that no public expenditures create or perpetuate barriers. This includes making non-discrimination and accessibility for people with disabilities a requirement in all public procurement. Dissemination of state regulations and standards on physical accessibility and support of implementation by guidelines for monitoring is crucial.

Fifth, it is necessary to ensure that mechanisms exist to prevent, monitor and respond to the abuse/neglect of people with disabilities at all levels and by all stakeholders, starting with independent monitoring and evaluation of the living conditions of adults and children with disabilities in institutional care. It is particularly important that the legislation revise concepts and norms related to legal capacity, independent living, loss of capacity to work, guardianship and regulations leading to institutionalization of care, as they stand in direct violation of the CRPD.

Sixth, ensure all children – including children with disabilities - have access to early childhood development and school readiness opportunities. Engage in twinning programmes with international universities with a good track record of teacher preparation on inclusion and initiate the process of re-professionalization of the teaching force and peripheral support professionals. This is essential to the adequate transition of children with disabilities from special schools to regular schools, and an active incentive to keeping children with disabilities within their most immediate family.

Seventh, investing in preventative and universal measures such as screening for functional limitations, outreach by family doctors and early intervention has many proved economic and social benefits. All health care professionals should possess minimum knowledge regarding the International Classification of Functioning and the bio-psycho-social model of disability, leading to a greater understanding of their role within the scope of the multidisciplinary methodology of the identification and assessment of disability.

Eighth, multi-professional approaches in rehabilitation should be reinforced. It is also critical to reinforce a multi-professional approach that responds in an integrated and person-centred manner to the needs of people with disabilities.

Ninth, social protection has to take into account disability-related expenses and compensate for disadvantages with non-conditional monetary transfers. A number of personalized community-based social services can ensure autonomy and integration in the community. Many of these services act upstream, are preventive and are often less cost-intensive than medical interventions.

Tenth, support the strengthening of the capacity of NGOs and DPOs (disabled people's organisations) in general to speak on behalf of ALL people with disabilities and to partner with government. Because children have needs and strengths that are specific to their age and level of development, DPOs should be provided with opportunities to develop their capacity in relation to child rights, including by engaging in consultations with children with and without disabilities on issues that relate to them (and are of their choosing).





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