Technical Note on the Implementation of the Convention on the Rights of Persons with Disabilities in Uzbekistan





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Technical Note on the Implementation of the Convention on the Rights of Persons with Disabilities in Uzbekistan

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Uzbekistan).

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This compilation of nine sectoral technical briefs analyzes in great detail the problems faced by persons with disabilities in Uzbekistan under all areas of life and formulates detailed recommendations, providing the evidence base for a Strategic Note that aims to guide Uzbekistan's next five-year National Action Plan (NAP) for implementing the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in the country. This document is produced under the "Roadmap and building blocks towards the implementation of CRPD in Uzbekistan" grant under the Rapid Social Response Adaptive and Dynamic Social Protection (RSR-ADSP Umbrella Program).

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Acronyms

ADMSS	Agency for Development of Medical and Social Services under the Ministry of Public Heath
AD	assistive device
ASD	autism spectrum disorder
CMD	Cabinet of Ministries Decree
CRPD	United Nations Convention on the Rights of Persons with Disabilities
CVD	cardiovascular disease
ESC	Employment Support Center
FTUU	Federation of Trade Unions of Uzbekistan
GDP	gross domestic product
HEMIS	Higher Education Management Information System
ICF	International Classification of Functioning, Disability, and Health
ICF-CY	International Classification of Functioning, Disability, and Health – Children and Youth
ICPD	Interagency Council for Persons with Disabilities
ILO	International Labor Organization
IQ	intelligence quotient
IRP	individual rehabilitation program
MEPR	Ministry of Employment and Poverty Reduction
MHESI	Ministry of Higher Education, Science and Innovations
MPSPE	Ministry of Preschool and Public Education
MPH	Ministry of Public Health
MPPC	Medical-Psychological-Pedagogical Commission
MSEC	Medical-Social Expert Commission
NAP	National Action Plan
NCHR	National Center for Human Rights
NDV	National Database of Vacancies
NEC	National Ethics Committee
NGO	nongovernmental organization
OPD	organization of persons with disabilities
PD	Presidential Decree
PHC	primary health care
SDG	Sustainable Development Goal
SEN	special educational needs
SRH	sexual reproductive health
SRSP	Single Registry for Social Protection
TMR	technical means for rehabilitation

UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UPP	training and production enterprise
VKK	Medical Consultative Commission
VTEK	Medical and Labor Expert Commission
WASH	water, sanitation, and hygiene
WHO	World Health Organization



Introduction

This compilation of technical briefs lays out the key problems faced by persons with disabilities in Uzbekistan under all areas of life and formulates detailed recommendations, providing the evidence base for a Strategic Note that aims to guide Uzbekistan's next five-year National Action Plan (NAP) for implementing the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The findings and recommendations are structured across nine sectors: (1) accessibility and mobility; (2) effective protection of the rights of persons with disabilities; (3) employment; (4) social protection; (5) social services and independent living; (6) education; (7) health; (8) social participation; and (9) implementation and monitoring of the CRPD.

Around 16 percent of the Uzbek population has disabilities, according to survey data. However, according to a World Bank survey, 13.5 percent of the total population aged three years and older have some form of disability, and 3.5 percent have severe disabilities.\(^1\) Moreover, the survey showed that 45 percent of households have a person with disabilities, and 14 percent of households have a person with a severe disability. The prevalence of disability is closely related to age, with 54 percent of people aged 60 and over having some form of disability.\(^2\) The World Bank survey questionnaire incorporates the Washington Group Short Set of Questions on Functioning, which is considered an adequate instrument to sense the real size of the population with disabilities.\(^3\)

In December 2022, 845.3 thousand people in Uzbekistan were certified as having a disability, representing 2.3 percent of the total population.⁴ The percentages are the highest in Navoi (3.6) and Syrdarya (3.1) regions and the Republic of Karakalpakstan (2.9). Out of the total number, there are significantly more people certified with a disability in the rural areas: 313.3 thousand live in cities, and 532 thousand live in villages, while the total urban and rural populations are quite similar in size (49.57 percent live in the urban area in 2021). Also, 142.3 thousand people are children with disabilities under 18, and 396.7 thousand people are up to retirement age (55-year-old for women, 60-year-old for men). There are more men (475.8 thousand) than women (369.5 thousand) with a certified disability.

The disability assessment process in Uzbekistan is still medicalized, categorizes persons in disability groups non-compliant with CRPD, and labels individuals with discriminatory labels regarding their capacity to work. The current disability assessment and determination system in Uzbekistan is based on a medical approach consisting of assessments conducted by specialized medical commissions for children (VKK) and adults with disabilities (VTEK), under the Agency for Development of Medical and Social Services (ADMSS). During the disability assessment process, persons with disabilities are categorized into three groups based on an evaluation of their capacity to work and the level of assistance needed. For instance, group I, the one considered most at risk, is defined as being comprised of "persons who have completely lost the ability to work and need outside help or care." The employability is labeled with the extreme verdict of "unfit for work," "can work in specially created conditions," to "can carry out certain types of work," or "fit to work." Considering CRPD, disability assessments should look at disability as functional limitations as well as social-contextual factors based on the human-rights approach to disability assessment. 5 The assessment approach and three groups⁶ to which persons with disabilities are assigned as its result are not CRPD compliant. The government of Uzbekistan has approved a concept of gradual transition from the traditional medical disability assessment model to the modern

¹ World Bank 2021.

² These survey results are congruent with the most reliable estimates on the typical size of the disability population in overall population; for example, the World Report on Disability in 2022 estimated that about 15 percent of the world's population lived with some form of disability, of whom 2–4 percent experienced significant difficulties in functioning.

³ Washington Group on Disability Statistics - WG Short Set on Functioning (WG-SS). https://www.washingtongroupdisability.com/question-sets/wg-short-set-on-functioning-wg-ss/.

⁴ According to data from the ADMSS. There isn't any reasonable expectation that the percentage of persons registered as unemployed matches the percentage calculated based on survey data; however, there are suspicions that the disability assessment system may exclude persons with disabilities, which may lead to an underestimation of the number of persons eligible to be officially registered as having a disability in administrative data. This suspicion is analyzed in the technical brief dedicated to social protection.

⁵ Waddington and Priestley 2020.

⁶ Disability groups are: (1) group I: persons who have completely lost the ability to work and need outside support or care; (2) group II, persons who have completely lost the ability to work but do not need outside support or care; (3) group III: persons who have partially lost the ability to work.

social model, to be piloted by 2026.7

Persons with disabilities face multiple forms of social exclusion in Uzbekistan. The accessibility of the physical, communications, and information environment is extremely limited, hindering persons with disabilities from using infrastructure and services in all domains of life. Many persons with mental disabilities are deprived of their legal capacity, which violates their fundamental rights, and there are no decision-making support services available for persons with disabilities who may need them to exercise their legal capacity. Many persons with disabilities cannot have their capacity to work fully recognized because of the disability evaluation and determination process, and they are about four times less likely to find a job than persons without disabilities. Disability benefits are currently granted without considering differing types and levels of disability and without accounting for extra disability-related costs, resulting in specific needs not being addressed. Institutionalization is the only social service available for most persons with disabilities, while communitybased services in support of independent living are almost inexistent. Most persons with disabilities learn in segregated settings, while an unknown number of children are out of school altogether or are home-schooled because of structural constraints. More than one-quarter of persons with disabilities reported they had unmet medical needs, almost 2.5 times more than persons without disabilities. Only a small share of persons who need assistive devices (ADs) receive them from the government. There is limited availability of habilitation and rehabilitation services. Furthermore, persons with disabilities are ensured limited participation in cultural life, sports and tourism, the electoral process, and public life. For a more detailed presentation of findings, see Table 1.

Key problems faced by persons with disabilities and determinants across nine sectors

1. Accessibility and mobility

1.1. Limited access to the physical environment

Persons with disabilities in Uzbekistan report insufficient levels of accessibility of public places, as well as their own homes. In a 2019 study,8 between a third and a half of persons with disabilities rated access to and usage of public infrastructure (such as schools, hospitals, workplaces, shops, and others) as being difficult or relatively difficult, varying by type of infrastructure. The lowest levels of accessibility were reported for healthcare institutions (52 percent), social welfare agencies (55 percent), and schools (55 percent). The laws and regulations that outline the accessibility of public buildings and structures are not comprehensive. The routes of access among destinations in the public space are interrupted. The current urban planning process does not consider the voice of persons with disabilities or organizations of persons with disabilities. There is no consistent imposition and collection of fines, despite the national legislation sanctioning the failure to comply with accessibility requirements.

to transportation

1.2. Limited access For most persons with disabilities in Uzbekistan, public transportation is inaccessible. A survey carried out by UNDP in 2015 shows that 77 percent of persons with disabilities rate the accessibility of public transportation as unsatisfactory or extremely unsatisfactory.9 The rates are the highest for persons with mobility disabilities (93 percent) and persons with visual disabilities (100 percent). There is insufficient public transportation and related infrastructure to meet the needs of persons with disabilities. There are no or very poor pedestrian traffic guidance facilities for persons with disabilities. Only 27 percent of persons with disabilities who need a wheelchair (one of the most expensive assistive devices) currently have one.

The concept is designed for 2022-2026 and will be implemented in two stages: (1) 2022-2024: based on international experience, legislation and other regulatory legal documents related to the field, necessary methodological, informational, and training materials will be developed, and field workers will be trained; (2) 2024-2026: an inventory will be made of favorable conditions that need to be created for the free movement and employment of persons with disabilities in all regions of the republic, as well as accessibility facilities for receiving and conveying information, public transport, social and other infrastructure objects.

⁸ UN 2019b, 85.

⁹ UNDP 2015, 72.

communications

1.3. Limited access Persons with disabilities generally have less access to information than persons without to information and disabilities. Data from a 2019 study¹⁰ indicate that the share of persons with disabilities considering they have complete access to the information they need is 54 percent compared with 70 percent for persons without disabilities. Currently, there is no strategy shaping the long-term policy vision for ensuring full accessibility to information and communications and for preparing and implementing measures to this end. Sign language has a limited legal status as a "means of interpersonal communication," and it is not recognized as an official language.

2. Effective protection of the rights of persons with disabilities

2.1. Limited possibility of persons with disabilities to exercise their legal capacity

In Uzbekistan, some persons with mental disabilities are deprived of their legal capacity, which violates their fundamental rights. Furthermore, certain groups tend to be more affected by the limitation of their legal capacity, such as persons with disabilities living in institutions or persons admitted against their will to mental health care facilities (psychiatric institutions). Current legislation allows for the restricted legal capacity of persons with disabilities based on their mental capacity. Representatives of the Uzbek justice system (such as judges, lawyers, prosecutors, or police) are unfamiliar with equal rights in terms of the legal capacity of persons with disabilities. At present, there are no decision-making support services available for persons with disabilities who may need them to exercise their legal capacity in Uzbekistan.

2.2. Limited access to justice

Persons with disabilities encounter barriers in the justice system, limiting their access to justice. Main barriers include: (1) limited physical, information, and communications accessibility of justice system buildings; (2) unaffordable fees for special accommodations or other judicial expenses for most persons with disabilities; (3) lack of an enabling environment for persons with disabilities to take up roles in the judiciary system; and (4) insufficient training of justice system staff on providing access to justice for persons with disabilities. Although physical accessibility is required for all public buildings, almost none of the country's courts operate in fully accessible facilities.¹² Persons with disabilities who may need accommodations such as sign language interpretation or audio-video recordings (for which special recording equipment is needed) must request these from the court before the beginning of the trial, and must bear the cost themselves. Persons with disabilities in Uzbekistan rarely take up roles in the judiciary system.

3. Employment

market

3.1. Limited access Based on administrative data, In Uzbekistan, persons with disabilities are about four to the open labor times less likely to find a job than persons without disabilities. A 2019 study¹³ found that, compared to 30 percent of the population of working age (men, 16-59; women, 16-54) who were employed, only 7.1 percent of registered, working-age persons with disabilities were employed in 2019. In Uzbekistan, the disability commissions assess not only disability level but also capacity to work. Depending on the degree of disability, VTEK commissions rate employability from the extreme verdict of "unfit for work," "can work in specially created conditions," to "can carry out certain types of work," or "fit to work." This assessment works against the rights of persons with disabilities to work. According to data provided by the Ministry of Employment and Poverty Reduction (MEPR), in 2019, out of more than 630,000 registered persons with disabilities older than 18,14 only 162,200 people (26 percent) were labeled as "able to perform certain types of work activities. Even if a certificate indicates that a person is "incapable of work," he or she can contact the relevant VTEK to obtain information about the ability to work and engage in a particular professional activity. This system as burdensome, as the persons with disabilities need to obtain another document on top of the existing disability certificate. Furthermore, the persons receiving disability benefits are excluded from unemployment benefits.¹⁵ The disability employment quotas are not enforced and monitored, making it difficult for the MELR to assess the efficiency of this policy. A small number of employers (less than 10 percent of all surveyed employers in Uzbekistan in 2019) are aware of the benefits and preferences for employing persons with disabilities.16

10 UN 2019b.

- 11 CRPD, Art. 9 and CRPD Committee 2014b, paras. 6 and 37.
- 12 Isakov 2021; as highlighted by participants of a consultation workshop carried out with relevant stakeholders for the finalization of the present technical note on October 12-13, 2022, in Tashkent.
- 13 UN 2019b.
- 14 It is the official number of registered persons with disabilities reported by the MELR, while the administrative data provided by the Statistics Agency under the President might be different. Each government agency might have it is own administrative data on the registered number of persons with disabilities.
- 15 The law "On state pension provision of citizens."
- UN 2019a.

to vocational training programs

3.2. Limited access Vocational low-quality education is taught at segregated specialized boarding schools, which severely reduces the post-graduation chances of adults with disabilities due to their limited professional and social skills. In 2021, a total of 768 students from all over the country studied at vocational schools. Modern vocational training programs have only recently started being piloted, thus such opportunities are still limited.

3.3. Limited social and economic security at work

Existing barriers to entering the formal sector force persons with disabilities to disproportionately go into informal employment. Persons with disabilities informally employed do not have access to insurance systems, and are more exposed to unfair treatments and harsh working conditions. Specialized enterprises of OPDs provide a limited number of low-skilled jobs; this outdated system promotes segregation rather than disability-inclusive employment.

4. Social protection

4.1. Inadequacy of existing disability-specific social protection schemes to provide for extra disability-related costs

Disability benefits are currently granted without consideration of differing types and levels of disability, resulting in specific needs not being addressed. Compared with the current average monthly salary in Uzbekistan, disability benefits in Uzbekistan are clearly insufficient to provide appropriate support. Disability benefits are provided to all registered beneficiaries regardless of the type and severity of disability or the level of need to cover basic and extra disability-related costs. Only 46 percent of children and working-age adults with severe forms of disability can access disability benefits, with no significant gender gap.¹⁷ Persons in disability group III are denied disability benefits irrespective of the individual costs of disability. The disability assessment, as the gateway to the social protection system, is still medicalized, even after the new Law on the Rights of Persons with Disabilities came into force on January 16, 2021:18 impairments and their medical causes are assessed (such as diseases of the blood, the endocrine system, the nervous system, respiratory and oncological diseases) and indicated as "reasons of disability," while the interaction of various impairments with environmental factors is not considered, as in the CRPD framework. The definition of the groups is not CRPD compliant, e.g., "group I: persons who have completely lost the ability to work and need outside help or care." The government of Uzbekistan has approved the concept of a gradual transition from the traditional "medical" disability assessment model to the modern "social" model, to be piloted by 2026.19

to mainstream poverty reduction schemes

4.2. Limited access The poverty rate among persons with disabilities is 26 percent compared with 21 percent among the general population.²⁰ The median income per capita for a family with a member with a disability is 18 percent less than that of the average Uzbekistan household.21 Some eligibility criteria of the existing disability benefits need to be further reconsidered, after the recent improvements, as they might discourage applicants, including persons with disabilities.

5. Social services and independent living

5.1. Deinstitutionalize persons with disabilities

Residential institutions are the main social service provided to persons with disabilities in Uzbekistan. At the end of 2021, a total of 9,361 persons with disabilities lived in 35 boarding houses under the ADMSS. According to ADMSS data, in December 2021, there were 2,160 children with disabilities institutionalized in 7 "Muruvvat" facilities. The approach taken in all these facilities is purely medicalized and generates multiple forms of extreme social exclusion. Deinstitutionalization of children or adults with disabilities is not a national priority recognized by current laws, strategies, or other policy document. Moreover, considerable investments are still being made to extend or improve residential care infrastructure and staff salaries.

L2CU household survey in 2018. See L2CU (Listening to the Citizens of Uzbekistan) (dashboard), World Bank, Washington, DC, https://www.worldbank.org/en/country/uzbekistan/brief/l2cu.

¹⁸ Law "On the rights of persons with disabilities."

¹⁹ The concept is designed for 2022-2026 and will be implemented in two stages: a) the first stage is designed for 2022-2024: based on the international experience, during this period, legislation and other regulatory legal documents related to the field, necessary methodological, informational, and training materials will be developed, and field workers will be trained; b) the second stage is intended for 2024-2026, during which an inventory will be made of the creation of favorable conditions for the free movement and employment of persons with disabilities in all regions of the republic, as well as accessibility facilities for receiving and conveying information, public transport, social and other infrastructure objects.

²⁰ UNICEF 2019, 18. The poverty rate of 21 percent estimated from the L2CU dataset uses a relative poverty threshold of 50 percent of the median income per capita for the entire population. See L2CU (Listening to the Citizens of Uzbekistan) (dashboard), World Bank, Washington, DC, see: https://www.worldbank.org/en/country/ uzbekistan/brief/l2cu.

²¹ UNICEF 2019, 18.

5.2. Improve the access to community-based social services for

Most types of community-based services for persons with disabilities are unavailable in Uzbekistan. There are 12 rehabilitation and prosthetic centers for persons with disabilities under the ADMSS, but other types of community services are lacking. Persons with disabilities are forced to rely exclusively on family members and other informal caregivers for independent living support. A wide area of community social services has to be provided, e.g.: counseling and information services, early diagnostic and intervention, and lifelong rehabilitation services, counseling for independent living, support for employment, specialized support for primary caregivers, peer counseling/support groups for persons with disabilities or family members, respite care and short break services, home care (or in-home care and support), assistive technology and equipment, home adaptation services, personal assistance, adapted transportation, assisted decision-making, interpretation services.

6. Education

6.1. Limited access to general education

One-third of children with disabilities reported as enrolled in school are registered as homeschooled, two-thirds are schooled in special educational units (most at boarding schools), and very few are integrated into mainstream institutions (83 students for the 2021-22 school year). According to a 2019 study,²² over two-thirds of the general population think that special schools are the best choice for children with disabilities. A network of special education institutions for various disabilities and diseases currently operate in Uzbekistan. The geographic distribution of special schools makes them inaccessible to many children unless they accept the boarding option. The recent wave of educational reforms in Uzbekistan has opened the way for changes that could lead to inclusive education, although some measures still promote segregated education; take a medical approach to disabilities; and do not adhere to adapted teaching methods or curricula. The vast majority of Uzbek teachers are not trained in the field of inclusive and special education, nor do they have any practical experience in teaching children with disabilities. Uzbek schools have not been made accessible to persons with physical disabilities in a systematic way.

6.2. Limited access to preschool education

Data from the MPH in 2019^{23} show that 26,154 children aged two to five years old had been issued a disability certificate. Of these, only 5,729 are reported as enrolled in special preschool education,²⁴ resulting in an estimated rate of enrollment of preschool-age children with disability certificates in special formal education at 22 percent. By comparison, in 2019, the enrollment rate for preschool education among the general population was about 40 percent.25 The scarce availability of early identification and intervention programs for children is a major concern. The recent reform led to enlargement of the national preschool education system, with the number of pupils attending preschool education doubling in the last decade. However, children with disabilities are mainly offered segregated preschool options in specialized institutions or in mainstream institutions but as part of segregated classes. As a result of recent reforms, both the number of special multi-profile kindergartens and children enrolled in them have been drastically reduced, but there is no record of what happened to the children who left the system.

6.3. Limited access to tertiary education

There are very few students with disabilities enrolled in Uzbek universities, and many children and youths with disabilities do not view the idea of attending an institution of higher learning as realistic. Youths with disabilities have little chance of accessing tertiary education due to their previous exclusion from or poor quality of their secondary education. Affirmative action measures aim to support the enrollment of youths with disabilities in higher education, but the quota slots remain partly unfilled. Most Uzbek university buildings are not accessible to students with disabilities.

²² UN 2019b: 138.

²³ Age composition of children with disabilities under 16 is available at: https://ssv.uz/ru/open_ministry/view/16eshgacha-blgan-nogiron-bolalarning-esh-tarkibi; World Bank calculations.

²⁴ Transmonee data is available at: https://transmonee.org/country/uzbekistan/.

National statistical data on the distribution of men and women populations, by age groups, and on the number of children in preschool education, available at: https://gender.stat.uz/uz/asosiy-ko-rsatkichlar/demografiya, World Bank calculations.

7. Health

7.1. Limited access to health services, including habilitation and rehabilitation

There is a high prevalence of cardiovascular diseases (CVDs) that leads to disabilities among Uzbekistan adults. Over the past decades (between 1990 and 2019), the overall burden of disease in Uzbekistan weighted more towards noncommunicable diseases leading to disabilities, versus communicable and other diseases or injuries. The main risk factors currently causing permanent disabilities among adults are high blood pressure, unhealthy eating habits, smoking, alcohol consumption, and having a high body mass index. Congenital diseases are the leading cause of childhood disabilities. In 2019, more than onequarter of persons with disabilities reported they had unmet medical needs, almost 2.5 times more than persons without disabilities (27 percent of persons with disabilities versus 11 percent of those without disabilities).²⁷ The percentage of persons with disabilities who are unable to afford doctor-prescribed medications (41.7 percent) is three times higher than the percentage of persons without disabilities (14.2 percent). In 2019, 44 percent of persons with disabilities needed ADs, but half of those who did could not obtain them. The state list of discounted prosthetic and orthopedic products and other assistive devices is limited and does not meet the needs of persons with disabilities. Uzbekistan faces significant coordination gaps among institutions that manage health care services for persons with disabilities. The primary health care system is understaffed and lacks efficiency. Uzbekistan's provision of psychiatric support services suffers from shortcomings, especially with respect to the early identification of mental disorders and the quality of mental health services. Existing screenings carried out at birth to identify conditions that lead to disability are limited. Persons with disabilities have limited access to rehabilitation, which is mostly available in the capital city and major cities, at insufficient levels across these areas as well.

7.2. Limited exercise of the right to sexual and reproductive health

In Uzbekistan, the sexual and reproductive health (SRH) of persons with disabilities, particularly women and girls, is not a priority for the health care system, and the coverage of services and programs to this group is unknown. Staff from medical, social services, and education institution does not receive adequate training to provide SRH education and services to persons with disabilities. Based on qualitative research, women with disabilities experience higher rates of gender-based violence, sexual abuse, neglect, maltreatment, and exploitation than women without disabilities.

7.3. Limited access to medical care provided with dignity and respect

Qualitative research indicates that dignity is infringed often in the provision of medical services to persons with disabilities. It suggests a dominant perception of persons with disabilities as beneficiaries of philanthropic actions rather than rights holders who can make and participate in their health decisions. Finally, persons with disabilities, or members of their families, are often unaware of their rights or feel ashamed to assert them. Health care staff is not trained on the rights and needs of persons with disabilities and how to assist them. Healthcare providers' compliance with the rights of persons with disabilities is not monitored.

8. Social Participation

8.1. Limited participation in cultural life

Persons with disabilities do not participate in social life, including cultural activities, at the same levels that others do. Qualitative research for this report reveals the reasons behind this include the low level of income and unreliability of income sources, mobility problems, lack of accessibility of the cultural infrastructure, and lack of awareness regarding the few accessible places. The opportunities for persons with disabilities to access cultural sites in other regions of Uzbekistan are even fewer than in the capital city. The legislation does not provide standards regarding access to cultural activities (such as the provision of close captioning for the hard-of-hearing and books in alternative formats for the visually impaired). There is currently no official data on the volume of accessible information, although a 2018 decree of the cabinet of ministers made such data collection mandatory. According to a report of the Association of Persons with Disabilities of Uzbekistan,²⁸ mass media and television do not sufficiently reflect the lived experiences and challenges faced by persons with disabilities. Some large-scale information campaigns to raise public awareness about persons with disabilities have been implemented in the past, but they must be conducted on a regular basis.

8.2. Limited participation in

Persons with disabilities are less likely to participate in sporting and physical activities than those without disabilities. According to a 2019 study, only 5.7 percent of persons sports and tourism with disabilities participate in sports and physical exercises, compared with 11 percent of those without disabilities.²⁹ A recent decree on enhancing sports participation mentions the creation of opportunities for persons with disabilities. However, it does not set target indicators related to persons with disabilities. The government stresses the importance of developing the Paralympic movement, which should be however built on the broader engagement in sports by persons with disabilities. Educational institutions and sports and training clubs lack accessible infrastructure and qualified personnel specializing in working with persons with disabilities.

²⁶ According to data from the Institute for Health Metrics and Evaluation 2021.

²⁷ UN 2019a.

Association of Persons with Disabilities of Uzbekistan 2020.

UN 2019b: 30.

8.3. Limited
participation
in the electoral
process and public
life

Candidates with disabilities have been elected in local elections, but general elections have featured very few candidates with disabilities. A 2019 study³⁰ highlights that 90 percent of persons with disabilities and only 81 percent of persons in the disability group I participated in voting for the most recent presidential election, compared to 95 percent of persons without disabilities.

9. Implementation and monitoring of the United Nations Convention on the Rights of Persons with Disabilities

9.1. Lack of a coordination mechanism for CRPD implementation

Uzbekistan has not yet designated focal points within the government to ensure that the CRPD is implemented and the rights of persons with disabilities are respected. To properly implement their role in alignment with CRPD provisions, appointed focal points must have adequate resources, including dedicated staff, disability rights training, and, in the case of the lead focal point, authority and convening power. In addition to designating focal points, establishing a national coordination mechanism or revision of an existing coordination mechanism to promote, protect and monitor the CRPD should be considered. The Interagency Council for Persons with Disabilities (ICPD) could be designated as the national coordination mechanism in Uzbekistan, but it would need to build its capacity and strengthen its engagement of OPDs. Persons with disabilities must be systematically involved in the development, implementation and monitoring of policies that affect them.

9.2. Limited involvement of independent mechanisms for CRPD implementation monitoring

The following types of organizations can serve as independent mechanisms for CRPD implementation monitoring: national human rights institutions, ombudsman offices, OPDs, special bodies under UN treaties, human rights organizations, trade unions, research centers, and universities.³¹ While an important actor in CRPD implementation monitoring, the Ombudsman Office in Uzbekistan is limited to complying with the Paris Principles to serve as the designated independent mechanism.

9.3. Limited involvement of persons with disabilities and their representative organizations in the monitoring process

Civil society in Uzbekistan is still undergoing a capacity development process following recent social and political changes.³² Although the government introduced several mechanisms to support civil society development,³³ including the adoption of the concept of civil society development in Uzbekistan by 2021–25,³⁴ NGOs in Uzbekistan still face challenges because of: (1) recent limitation of civic space put in place during the COVID-19 pandemic and not yet lifted;³⁵ (2) difficulties in registration of self-initiative NGOs; and (3) limited financial resources of NGOs that are mainly relying on foreign grants.³⁶ The CRPD Committee considers that OPDs involved should be rooted, committed to, and fully respect CRPD principles, but few OPDs exist in Uzbekistan according to CRPD recommendations.³⁷ Uzbekistan must increase its investment in building capacity of OPDs to be fully involved and participate in the monitoring of the implementation of the CRPD.

Several key stakeholders coordinate and implement the policies for the protection of rights of persons with disabilities. The Interagency Council for Persons with Disabilities (ICPD) coordinates the activities of state bodies implementing policies on ensuring the rights of persons with disabilities and consists of representatives of relevant ministries, state organizations, and civil society organizations, including OPDs. In light of its mandate, the ICPD has been designated in the draft NAP as entity responsible for coordinating the implementation of the CRPD. The ADMSS serves as ICPD's secretariat. The ADMSS is a structural body of the Ministry of Public Health in the field of providing medical and social services to the elderly, persons with disabilities and other segments of the population in need of social protection. Under the Agency, several institutions for the support of persons with disabilities function: boarding houses "Sakhovat" and "Muruvvat," National Center for Rehabilitation and Prosthetics of Persons with Disabilities, regional rehabilitation centers for persons with disabilities, and Republican Inspectorate of Medical and Social Expertise and its territorial divisions. The National Center for Human Rights (NCHR) of the Republic

³⁰ UN 2019a.

³¹ MDAC 2011, 47.

³² International Center for Not-for-profit Law (ICNL) Civic Freedom Monitor: https://www.icnl.org/resources/civic-freedom-monitor/uzbekistan

³³ Yuksalish and PeaceNexus Foundation 2022.

³⁴ Presidential Order No. 6181/2021, "On approval the concept of civil society development in Uzbekistan by 2021–2025."

³⁵ Criminal charges for spreading false information have been amended to the criminal code in March 2020, after the first COVID-19 case has been officially registered in Uzbekistan. Art. 244-6 of the Criminal Code of Uzbekistan.

³⁶ Decree of the Cabinet of Ministers No. 328/2022, "On approval of the regulations on the procedure for the interaction of local non-state non-profit organizations with state authorities in the implementation of international grant projects."

³⁷ CRPD Committee 2018, para. 11.

of Uzbekistan is leading the process of preparing the first National Action Plan following Uzbekistan's ratification of the CRPD in June 2021, and will also be responsible for regular reporting on CRPD implementation. The President of the Republic of Uzbekistan leads the reform of the social policy system for persons with disabilities. Following coming to power in 2016, President Mirziyoyev initiated several presidential decrees to improve the system of state support for persons with disabilities. There is also a Parliamentary Committee on Labor and Social issues of the Legislative Chamber of Oliy Majlis (Parliament) that works on disability issues.

Although the Uzbek government showed recent commitment to ensuring that persons with disabilities are fully included in society, these efforts have yet to be aligned with the CRPD. In 2017, the country had for the first time a presidential decree with concrete proposals to improve the quality and standard of living of persons with disabilities; to provide them with medical and social assistance; to assist in their realization of rights, freedoms, and legitimate interests; and to play an active role in society: the Decree of the President of the Republic of Uzbekistan "On measures for cardinal improvement of the state support system for persons with disabilities." The law "On the rights of persons with disabilities" superseded the previous law in 2021 and introduced the principle of non-discrimination based on disability. However, the decree does not propose a clear implementation mechanism. Moreover, it still defines persons with disabilities in medical terms and is not based on a social model, as the CRPD proposes.

A NAP, which is in the public consultation process, is expected to operationalize the CRPD in all policy areas and domains. While significant steps towards the "paradigm shift" in attitudes and approaches to persons with disabilities have been taken, substantial work still needs to be accomplished by the Government in aligning the legislative documents with CRPD concepts, revising all programs and measures related to persons with disabilities, consolidating efforts of governmental and nongovernmental bodies and agencies toward the common goals, and eventually preparing a comprehensive strategy for persons with disabilities in the CRPD framework. To do that, the Uzbek Government needs to develop, approve, and follow a Roadmap for implementing the CRPD, which should include a set of concrete actions across the main areas of life, with deadlines, results indicators, and coherent implementation arrangements. The country has already prepared a first draft of the NAP to support implementation of the CRPD (currently in a consultation process).

The present document provides the evidence and programmatic base for a Strategic Note aiming to guide the NAP for the upcoming years and, more generally, the future direction of disability policies in Uzbekistan. The measures in the NAP were selected using an ad hoc approach (without a systematic perspective of the problems faced by persons with disabilities in all areas of life), raising the possibility that some critical measures were missed. In 2021, the National Presidential Administration requested the World Bank's support to provide inputs to improve and finalize the action plan. For this, the World Bank team conducted an extensive review of the available evidence, complemented by interviews with persons with disabilities, representatives of authorities and organizations representing persons with disabilities, and other stakeholders. This document presents the analytical work carried out, together with concrete recommendations.³⁹

³⁸ Before that, between 2017 and 2020, there was a strategy for persons with disabilities in place, but it was modest regarding the number of actions required to be implemented for the CRPD, and it is unclear to what extent its measures have been implemented.

³⁹ The Compilation is structured across nine relevant policy sectors, with a limited number of problems (two or three) being discussed in each sector. In each sector, key problems are raised in two sections: (1) a description of the problem, where the problem profile and scale are laid out; i.e., who is affected, in what ways, and to what extent; and (2) an explanation of the problem, where various explanatory factors are tackled, such as the strategic and legislative framework, the institutional set-up, and the cultural barriers and social norms.



CHAPTER 1

Accessibility and mobility

Accessibility, which covers access to the physical environment, transportation, information and communications (including IT technologies and systems) is unequivocally guaranteed by Art. 9 of the Convention on the Rights of Persons with Disabilities (CRPD) and a core element of the CRPD's other articles.⁴⁰ States parties to the CRPD are obligated to enact all necessary laws and regulations to ensure that persons with disabilities have barrier-free 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.

вох 1

Definitions of key terms related to accessibility

Accessibility means the capacity to use, understand, or approach something. In the laws and standards on accessibility for persons with disabilities, accessibility usually consists of requirements for the design or adaptation of products, programs, or services so they can be used, understood, or approached by persons with disabilities.

Reasonable Accommodation means, according to the CRPD, necessary and appropriate modifications and adaptations that do not impose a disproportionate or unjustified burden when needed, and that allow persons with disabilities to enjoy or exercise all of their human rights and fundamental freedoms on an equal basis with others.

Universal Design means the design of products, environments, programs, and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. Universal design will not exclude assistive devices for particular groups of persons with disabilities where this is needed.

Progressive Realization constitutes a recognition of the fact that full realization of all economic, social and cultural rights will generally not be able to be achieved in a short period of time.

The core issues addressed under this sector are:

Limited access to the

physical environment

Limited access to transportation

Limited access to information and communications

1.1. Limited access to the physical environment

At present, limited access to the physical environment poses challenges for persons with disabilities in residential areas, workplaces, public service buildings, and other public institutions and spaces. Accessibility obstacles⁴¹ impede the rights of persons with disabilities in all dimensions of their lives, negatively impacting their access to healthcare, education, labor, civic participation, tourism and leisure, sports, and culture.



Description of the problem

Persons with disabilities in Uzbekistan report insufficient levels of accessibility of public places, as well as their own homes. In a 2019 study,⁴² between a third and a half of persons with disabilities rated access to and usage of public infrastructure (such as schools, hospitals, workplaces, shops, and others) as being difficult or relatively difficult, varying by type of infrastructure. The lowest levels were reported with respect to healthcare institutions (52 percent), social welfare agencies (55 percent), and schools (55 percent) (see Table 2).

TABLE 2

Percent of persons with disabilities reporting ease of access to and use of necessary public infrastructure without an accompanying person (percent)

Buildings, territories, and conditions of stay

At home or in their neighborhood	65
In shops, post offices	63
In their mahalla/apartment complex/street	60
Public transportation	57
In public places - bazaars, cinemas, etc.	57
In their workplace	56
In their school and its territory	55
In khokimiyat, social welfare agencies	55
In the last healthcare institution they visited	52

Notes: SitAn Survey Indicator 66: Accessibility of physical environment (by types of institutions) as measured in the ratio of the number of persons with disabilities (including caregivers of children with disabilities) that rated it easy or relatively easy for them (or their children with disabilities) to attend public institutions and use related services to the total number of persons with disabilities (including caregivers of children with disabilities); by types of institutions.

Source: UNICEF 2019, 85.

Accessibility and mobility

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⁴¹ The barriers are often specific to the type of disability the person has, hence the measures to remove them impact persons with disabilities differently: (1) the removal of physical barriers might be more relevant for persons with disabilities that affect their capacity for moving; (2) persons with visual disabilities might benefit more from the provision of information in accessible forms, such as large print, embossed Braille, tactile-contrasting signs and indicators, sound and voice signals, and guide dogs; (3) persons with hearing disabilities should be provided features like sign language interpreters, visual signs, and image boards.

⁴² UN 2019b, 85.

In Tashkent, persons with disabilities have limited access to the physical environment and the situation is even more challenging in the rest of the country. According to the Public Council under the Tashkent municipality, 85 percent of buildings and social infrastructure facilities are not adapted for the use of persons with disabilities.⁴³ More than 71 percent of surveyed persons with disabilities⁴⁴ did not consider Tashkent as being accessible, according to a study carried out in 2015.⁴⁵

Explanation of the problem

Inadequate construction and renovation norms

Existing legislation provides several norms and regulations regarding building construction and operation to ensure access for persons with disabilities. The law provides a list of types of public buildings and structures in which conditions must support the barrier-free access of persons with disabilities.⁴⁶ This list includes shops, theaters, cinemas, showrooms, catering establishments, restaurants, pharmacies, parks, healthcare facilities (clinics, hospitals, dispensaries, etc.), rehabilitation facilities, social, educational and production centers, libraries, means of transportation, public transportation stops, airport buildings, markets, shopping malls, educational institutions, communication and information enterprises, and specialized residential buildings. There is no systematic data on these buildings' rate of compliance with accessibility norms. However, persons with disabilities have reported, in qualitative data collected for this report, the lack of accessibility of all these types of public buildings, even headquarters of public institutions.

Main laws and regulations that outline the accessibility of public buildings and structures are not comprehensive. The existing legal provisions are focused primarily on norms and standards regarding physical accessibility and the needs of persons with mobility disabilities, without being comprehensive for this category. For example, the specifications of SNK 2.08.02-09 "Public buildings and structures" on elevators exemplify the legislative gaps with respect to physical barriers. The provisions of this law require mandatory elevators only for: (1) buildings above four stories; (2) buildings with a story height above 8 meters; (3) special residential buildings for the elderly; and (iv) residential buildings for families with a person with disabilities with a height story level above 3 meters.⁴⁷ While these criteria in themselves are not sufficient to ensure physical access of persons with disabilities to these buildings, there are numerous other types of inaccessible residential and nonresidential buildings, and no legal requirements to provide elevators to enable access. The gaps include standards on accessibility to information and communications, the needs of persons with other types of disabilities and the needs of persons with hearing or visual disabilities.

Interrupted routes of access

Persons with disabilities are not ensured continuous access routes to get from their homes to schools, workplaces, hospitals, or government organizations. This is largely driven by a lack of coordination between government agencies, such as the Ministry of Construction, Housing and Communal Services, and municipalities engaged in urban planning and construction. For instance, some of the bus stop platforms are constructed above ground, which reduces the ability of persons with disabilities to get on and off the bus. This not only significantly challenges access to the bus stop, but also hinders the use of

- 43 See https://mytashkent.uz/2020/06/29/proekt-gorod-dlya-vseh-zachem-i-dlya-kogo/.
- 44 The greatest share of persons with disabilities experiencing difficulties in accessing the physical environment are those with musculoskeletal system conditions (86 percent), visual disabilities (84 percent), other disability-causing diseases (73 percent), and hearing disabilities (54 percent).
- 45 UNDP 2015.
- 46 Sanitary rules and norms No. 0266-09 "Design and construction of residential and public buildings, residential places used by persons with disabilities and low-mobility groups of children and adults."
- 47 UNECE 2015.

public transportation by persons with disabilities. Similarly, there are cases of persons with disabilities trying to reach health centers for rehabilitation, who are restricted by barriers to using crossroads along the way, as indicated by the qualitative research carried out for this report. For example, for reaching the Tashselmash medical center in Tashkent, persons in wheelchairs cannot cross the road without assistance. Another example is related to the pedestrian crossing bridges that were constructed without elevators or escalators in one of the districts in Tashkent (see Box 2). Only some bridges are equipped with elevators or escalators, but even these are often out of service, while "an unbroken chain of movement should be ensured, so that persons with disabilities may perform every single action required to achieve a certain goal, not only some of them."⁴⁸

BOX 2

Crosswalks can be inaccessible to persons with disabilities

"Our apartment complex is near a busy interstate where I have to cross several roads to reach my bus stop. However, I have significant sight issues and the traffic lights are not equipped with sound or other notification systems. Therefore, I often have to rely on other people crossing the street with me, as getting to the other side may threaten my safety."

Source: Qualitative research, interview with a person with disabilities from Tashkent.

Blocked pathways prevent persons with disabilities from accessing public infrastructure in virtually all sectors and types of services. A recent study shows there are access routes that are completely unavailable or cut off, which makes persons with disabilities less likely to visit theaters, museums, cinemas, or social clubs.⁴⁹ Due to physical inaccessibility in mainstream secondary schools, children with disabilities are often forced out of school or into homeschooling, which hampers their social life and restricts their access to information and communication. Similar findings are observed for higher education institutions, where accessibility is highlighted as a problem for students who use wheelchairs (for instance, the ramps are lacking).⁵⁰ Attempts to increase the employment of persons with disabilities are often unsuccessful as a result of the lack of barrier-free pathways.⁵¹ As indicated by the qualitative research carried out for this report, in addition to many other factors excluding them from the labor market, physical barriers also prevent them from accessing their job location. The situation occurs in all sectors and throughout the lifecycle.

Accessibility efforts for persons with disabilities are sporadic and ad hoc, resulting in inconsistency in the same locality, and between the urban-rural divide. Many of the efforts to make an accessible physical public environment for persons with disabilities are limited to creating accessible spots within a locality, unreachable to persons traveling from other areas. For example, in Tashkent, only some of the subway stations have elevators, which makes it difficult for persons with disabilities to plan their journey using this means of transportation. Due to a lack of coordination between ministries, agencies, and civil society representatives of persons with disabilities, the mobility of persons with disabilities is not ensured across pathways. According to interviews with persons with disabilities carried out under the qualitative research for this report, persons with disabilities living in remote districts of Tashkent experience greater difficulties in accessibility compared to those living in the center of the city. For instance, they highlight that some pedestrian paths and crossroads in the center of the capital are more suitable for persons with visual disabilities. At the same time, accessibility to physical infrastructure for residents with disabilities outside the capital city is generally much lower.

Accessibility and mobility

⁴⁸ World Bank 2022a.

⁴⁹ UN 2019b.

⁵⁰ See https://cabar.asia/ru/uzbekistan-kak-obespechit-dostupnost-vysshego-obrazovaniya-dlya-lyudej-s-invalidnostyu.

⁵¹ See Section 3 on Employment for further details.

Lack of public consultation and participation when designing, commissioning, constructing, or upgrading social infrastructure

The current urban planning process does not take into account the voice of persons with disabilities or organizations of persons with disabilities (OPDs). For example, the draft Concept of Urbanization in the Republic of Uzbekistan until 2030,⁵² developed in 2019 by the previous Ministry of Economic Development and Poverty Alleviation, determines the goals, objectives, priority areas, and stages of further development and management of urbanization in the long term, without input from persons with disabilities and without making reference to their specific needs. Considering that Uzbekistan has ratified the CRPD, it is crucial to embed specific measures for taking into account the voice of persons with disabilities, including in terms of their accessibility and mobility. A public mechanism for coordinating territorial development, preferably one that is formally established and includes representatives from government agencies and civil society, is currently lacking.

There are several laws that provide for OPDs to be involved in the planning and operating of the built environment, but, in practice, this rarely occurs. The involvement of OPDs is required in the design of social infrastructure facilities on the basis of the law "On public control" and the law "On social partnership". Moreover, Art. 23 of the law "On the rights of persons with disabilities" states that constructed and reconstructed social and cultural facilities can be rendered into use solely when representatives of OPDs are included in the official commission for final reception and approval. As such, creating conditions for persons with disabilities to access facilities and services is a mandatory part of construction projects. However, the documentation for this report did not identify significant or consistent instances of compliance with these legal provisions, or participation of OPDs in urban planning. It is important for OPDs to be effectively engaged in all stages of planning, tendering, and procurement, so as to reflect the needs of all types of disabilities that require adaptation and that can ensure universal design.

Non-compliance with the rules and lack of implementation of sanctions

While legislation provides general guidance on ensuring access to physical infrastructure, its provisions are poorly implemented. According to Art. 9 of the law "On the rights of persons with disabilities," persons with disabilities must have equal access to buildings, transportation, information and communication technologies and systems, and facilities and services. This is in line with Art. 9 of the CRPD which obliges States parties to "take appropriate measures to ensure persons with disabilities access, on an equal basis with others, to the physical environment." However, currently, in Uzbekistan, the design of public and apartment buildings does not take into account the needs of persons with disabilities, and there are no consistent programs underway to increase their accessibility. Even in buildings of medical and labor expert commissions, where disability status certificates are issued, accessibility features are often lacking: there are steep ramps, which do not meet the norms of slope and gauge, with tight curbs, without handrails or with handrails placed too high; there are restrooms without appropriate turning space for wheelchairs; parking lots constructed on the territory adjacent to public buildings do not have reserved adapted spaces for persons with disabilities.⁵³

Consequently, persons with disabilities report an insufficient level of accessibility to schools, hospitals, workplaces, post office, cinemas, shopping facilities, and even their own homes (see Box 3).

⁵² See https://regulation.gov.uz/ru/d/4490.

⁵³ As indicated by the qualitative research carried out for this report.

Difficulties accessing the physical environment

"The barrier-free environment in Uzbekistan so far consists of only barriers. Most institutions where there are ramps do not meet the standards and requirements. Lots of dangerous ramps. Few people use them, because you can even get injured. Almost always in state institutions, you have to carry persons with disabilities in your arms. Even in the VTEK 54 of the Mirzo-Ulugbek district, there is no ramp. We had to apply for disability [certificate] on the street, because we had neither the strength, nor the opportunity to lift persons with disabilities and bring the wheelchair to the medical and labor expert commission." (Persons with disabilities from Tashkent)

Source: Interviews carried out for https://anhor.uz/society/parallelynie-miri-kak-menyaetsya-zhizny-posle-invalidnosti-v-uzbekistane/.

Built areas for persons with disabilities are not in line with CRPD and they do not even comply with accessibility standards. The Association of Persons with Disabilities of Uzbekistan, which consists of 35 public OPDs across the country, in accordance with the law "On public control," monitored the accessibility of new residential facilities in the Choshtepa mahalla, built specifically as a permanent residence for persons with disabilities as part of a public project of building accessible housing for vulnerable groups in the capital city. Such development of segregated residential spaces dedicated to persons with disabilities contradicts the provisions of CRPD. Furthermore, the Choshtepa mahalla buildings are not even observing accessibility requirements. For example, ramps are sloped above the permitted 8 percent inclination; the height of ramps is not always under 60 centimeters; and the entrance doors are narrower than the accepted standard of 0.9 m in width, preventing a person in a wheelchair to pass through. The constructed apartments do not comply with many other legislated requirements as well. Se

There are accounts of infrastructure developers refusing to implement legislative norms. Construction projects of residential buildings, managed by private real estate developers, often violate the law "On the rights of persons with disabilities" regarding construction norms and rules.⁵⁷ Art. 23 of the law states that the design, construction, and reconstruction of public buildings and structures, regardless of the organizational and legal form, should be carried out with the needs of persons with disabilities in mind. However, over the past three years (2018–21), only 30 tenders available on the public procurement portal contained the words "ramp" and "elevator".⁵⁸ This is evidence that existing construction or renovation works of public places fail to consider minimum accessibility for persons with disabilities.

The scarce data available shows that there is no consistent imposition and collection of fines, despite the national legislation sanctioning failure to comply with accessibility requirements. Art. 51 of the Code on Administrative Responsibility (as amended in 2013)⁵⁹ specifies that failure to comply with requirements that allow persons with disabilities unhindered access to buildings, structures, transportation, information and communications, including information and communication technologies and systems, as well as for failing to equip hotels with at least one room adapted for persons with disabilities out of the total stock, is punishable with a fine from 10 to 15 basic calculated values,⁶⁰ which does not exempt them from complying with accessibility requirements. If the same law violation is found again within a year from the first fine, the value of the new fine rises to 15 to 30 basic calculated values. Information about the use of fines is inconsistent, unreliable and outdated. Between January and June 2012, 8,828 public and private organizations and enterprises were fined for failing to comply with accessibility rules, but in the same period

- 54 VTEK (Medical and Labor Expert Commission) is the institution responsible for disability certification.
- 55 See https://www.gazeta.uz/ru/2019/08/07/accessible-environment/.
- 56 Moreover, such residential complexes that cluster apartments for persons with disabilities and separate them from the community lead to their segregation, which is contrary to the provisions of CRPD, Art. 19, stating that the isolation or segregation from the larger community should be prevented.
- 57 According to interviews with persons with disabilities carried out under the qualitative research for this report.
- 58 See https://anhor.uz/society/accessibility/.
- 59 See https://lex.uz/acts/97661.
- 60 One basic value is equal to UZS 300,000 (approximately US\$28).

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of 2018, only 7 organizations were fined. This is allegedly due to a change in procedure introduced by the amended Code of Administrative Infractions concerning the collection of fines: whereas the 2012 procedure allowed the responsible MEPR to collect the fines directly from the offenders, the current system includes a compulsory application to the administrative court. The fact that the process was made much more cumbersome has resulted in a significant drop in monetary sanctions. Furthermore, fines sanctioned for 2018 have not been collected.⁶¹

Recommended measures

LIMITED ACCESS TO THE PHYSICAL ENVIRONMENT

etc.).

The Ministry of Construction, Housing and Communal Services to coordinate the 1 revision of the legal requirements on physical, information, and communication accessibility for residential and nonresidential buildings, such as adopting universal design and reasonable accommodation approaches and ensuring alignment with internationally accepted construction and renovation codes⁶² for persons with all types of disabilities; requirements should cover all types of accessibility outlined in the CRPD and should be compiled in a dedicated Accessibility Code with technical specifications and measures needed to guarantee accessibility, developed by an expert group including OPD representatives and other organizations representing the rights of persons with disabilities (it is recommended to involve authorized representatives of the Society of the Disabled of Uzbekistan, the Association of Persons with Disabilities of Uzbekistan, other interested public organizations of as well as NGOs working for persons with disabilities), urban planning specialists (architects, urbanists, etc.), and representatives of services essential for persons with disabilities (such social protection, health care, education, housing, employment,

- The Ministry of Construction, Housing and Communal Services to coordinate the preparation and implementation of a national construction and renovation program for a barrier-free environment with targets on increasing the accessibility of public space for persons with disabilities.
- The Ministry of Economy and Finance, Ministry of Construction, Housing and Communal Services, and regional municipalities to embed the fundamental elements of accessibility and mobility for persons with disabilities, as defined by the new/revised Accessibility Code, into the construction norms and urban development plans.
- The Ministry of Construction, Housing and Communal Services to design and devise an accessibility assessment tool that reflects the revised Code, as an integral element of issuing certificates of urban compliance as well as construction permits for new projects.
- The Ministry of Construction, Housing and Communal Services to establish construction inspectorates at the national level and in each region that are responsible for conducting periodic inspections to ensure conformity with the Code's revised legal standards at different stages of construction of the infrastructure and approval for public use, with involvement of OPDs, human rights organizations, and other civil society representatives in the assessment campaigns.
- The Ministry of Construction, Housing and Communal Services to carry on accessibility inspections, with the possibility of the organizations representing the rights of persons with disabilities with expertise in the field to participate.

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⁶² The World Bank Technical Note on Accessibility lists numerous other international policy documents relevant when setting goals and standards for accessibility, such as the Agenda 2030 for sustainable development, adopted in 2015 by the UN General Assembly, the New Urban Agenda, The Sendai Framework for Disaster Risk Reduction, the Charter on Inclusion of Persons with Disabilities and others.

- 7 The Ministry of Construction, Housing and Communal Services to ensure that the organizations of persons with disabilities are involved systematically in all reception commissions validating new constructions of buildings open to the public and can signal accessibility barriers that have to be addressed.
- The Ministry of Justice to strengthen and simplify the enforcement of penalties on the violation of accessibility norms, and make available the data on fines.
- **9** The Ministry of Economy and Finance to establish a state fund for reasonable accommodation of public services for persons with disabilities.
- The Agency for Development of Medical and Social Services (ADMSS) under the Ministry of Public Health to coordinate capacity building training for all the state bodies involved in approving construction and renovation works, checking the conformity with accessibility norms and enforcing fines, as well as the representatives of the organizations working for and with persons with disabilities
- The ADMSS to implement awareness-raising campaigns on the right of persons with disabilities to accessible services and infrastructure.

1.2. Limited access to transportation

Ensuring equal access to transportation and infrastructure guarantees that persons with disabilities can access public facilities. By ratifying the CRPD, state parties are responsible for ensuring full and equal access of persons with disabilities to transportation.⁶³ This right is essential for enabling persons with disabilities to access other rights and live independently in the community.



Description of the problem

For most persons with disabilities in Uzbekistan public transportation is inaccessible. A survey carried out by UNDP in 2015 shows that on average, 77 percent of persons with disabilities rate the accessibility of public transportation as unsatisfactory or extremely unsatisfactory. Most persons with mobility, visual, hearing, and other types of disabilities are affected by this issue and have such assessments (see Table 3), specifically 93 percent of persons with mobility disabilities and all persons with visual disabilities.

TABLE 3

Accessibility of public transportation rated by persons with disabilities (percent)

	Satisfactory	Unsatisfactory	Extremely unsatisfactory
Persons with mobility disabilities	7	75	18
Persons with visual disabilities		89.5	10.5
Persons with hearing disabilities	41.9	46.5	11.6
Persons with mental disabilities	88.9		11.1
Persons with other types of disabilities	26.7	33.3	40

Source: UNDP 2015.

Apart from private cars, persons with disabilities use every other means of transportation less than persons without disabilities. Only 4 percent of persons with disabilities use airplanes compared to 12 percent of those without disabilities; 14 percent use trains, compared to 22 percent (see Table 4). Of all respondents with disabilities surveyed, 3 percent did not use any means of transportation.

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⁶³ CRPD, Art. 9.

⁶⁴ UNDP 2015, 72. The survey data is the most recent quantitative information identified on this specific topic.

Transportation use by persons with and without disabilities (percent)

	Persons with disabilities	Persons without disabilities
Bus	37	56
Fixed route taxi/minibus	38	63
Train	14	22
Taxi	34	35
Private car	65	56
Airplane	4	12

Note: Access to transportation (by type), as measured by the ratio of the number of people (including children) who used specific means of transportation (by type) to the total number of people (including caregivers of children); calculated for both persons with and without disabilities, breakdown by types.

Source: UN 2019b.



Explanation of the problem

While the right to accessible transportation is guaranteed in Uzbekistan by law, persons with disabilities still face obstacles in accessing transportation and infrastructure. Art. 9 of the law "On the rights of persons with disabilities" is in line with the CRPD and specifies transportation as an important accessibility element that must be guaranteed to persons with disabilities. Art. 24 of the same law, focusing on the accessibility of vehicles and road infrastructure, specifies that "the accessibility of vehicles and road infrastructure is ensured by organizations (regardless of the organizational and legal form) that provide transport services to the population, with the participation of public associations of persons with disabilities through: equipping public transport with special means to create accessibility for persons with disabilities, including equipping separate bays, information boards for the hearing impaired and voice announcements of stops; reproduction in large print of contrasting colors of routes and signs of urban and rural public transport; equipping passenger train cars with special seats and equipping platforms, as well as railway stations with specialized mechanical ramps; equipping stopping areas, taking into account urban planning norms and rules, including the installation of ramps and railings, the use of tactile coverage on areas in front of the entrance doors of the vehicle, as well as the installation of electronic information boards; adaptation of pedestrian crossings and intersections, public streets and roads in accordance with the needs of persons with disabilities; installation of sound and visual signaling systems at intersections; escorting persons with disabilities to vehicles at airports and air terminals, at large railway stations, as well as in the subway; equipping special waiting areas for persons with disabilities." However, specific issues related to the adaptation of transportation and related infrastructure affect persons with disabilities who need to use public transportation within or between localities.

There is insufficient public transportation and related infrastructure to meet the needs of persons with disabilities. This hinders wheelchair users and those with low mobility from equally accessing transportation. For example, the Association for Persons with Disabilities visited one of the newly constructed metro lines in Tashkent to assess its accessibility to persons with disabilities and identified a series of obstacles that significantly

hamper access.^{65, 66} Similarly, persons with disabilities have trouble accessing transportation between localities; for example, trains on regional railways are not adapted for wheelchair users (see Box 4).

BOX 4

Lack of accessibility of trains

"I live with my elderly parents and they assist me when we want to visit our relatives in another region. However, the entrance to the trains consists of a series of small stairs. Even my parents have difficulties getting on the train, and I feel devastated when they help me climb. In addition, there is a big gap between the train and the platform, so persons with disabilities have to literary jump to get on the train. This prevents me from traveling and visiting other regions as a tourist. I hope that the government will take this into consideration." (Person with disabilities)

Source: Qualitative research.

There are no accessibility features and adaptations for persons with disabilities in transportation vehicles, stops, or on the roads. For example, a person with low vision may require magnified signs, high color contrasts, and brightness. As it stands, the size and color of bus route numbers are not easily read. According to the UNDP survey, 75 percent of persons with disabilities consider inadequate bus platforms to represent a major accessibility barrier (see Table 5).⁶⁷ Moreover, while most sidewalks are asphalted, in some cases there are paving stones of different textures. Pavements are often uneven, rocky, or in disrepair, making it difficult to move around. On some roads, the sidewalks are not fenced and are not higher than the level of the road. In most cases, sidewalk exits to the carriageway of the streets do not contrast with the texture and color of the main surface.⁶⁸

TARLE 5

Persons with disabilities for whom engineering infrastructure facilities create additional difficulties (percent)

	Percent of respondents
Sidewalks	29
Ground pedestrian crossings	59
Underground pedestrian crossings	49
Bus stations	75

Source: UNDP 2015.

There are no or very poor pedestrian traffic guidance facilities for persons with disabilities.

There are too few traffic lights equipped with special sound devices for pedestrians with visual disabilities,⁶⁹ even though they are required by current urban planning norms and rules.⁷⁰ In some cases, crossroads do not have traffic lights, which makes them completely inaccessible and dangerous to persons with disabilities. Even roads that have working traffic lights lack painted, marked pedestrian crossings or other street signs.⁷¹

⁶⁵ For example, one of the subway stations was not equipped with an elevator or escalator; the installation of ramps was not feasible due to the steep slope of the staircases; ticket booths were not accessible for persons with disabilities; there were significant gaps between the edge of the metro trains and the platform; tactile tiles for passengers with visual disabilities were laid on the platforms of new underground and elevated metro stations, but the tactile track was located too close to the edge of the platform, creating a risk of falling; tactile tiles were laid only along the platforms, and not from the entrance throughout the station.

⁶⁶ See https://www.gazeta.uz/ru/2020/09/11/accessible-metro/#.

⁶⁷ UNDP 2015. More specifically, the unsuitability of bus stops creates the greatest problems for 97 percent of persons with visual disabilities, 68 percent of persons with mobility disabilities, 67 percent of persons with other types of disabilities, and 65 percent of persons with hearing disabilities.

⁶⁸ UNDP 2015.

⁶⁹ According to interviews with persons with disabilities carried out under the qualitative research for this report.

⁷⁰ See https://lex.uz/ru/docs/5049549.

⁷¹ Association of Persons with Disabilities 2015.

The design and construction of bus stops indicate that the standards for barrier-free access are not accounted for during planning, as the law requires.72 A monitoring visit by the Association of Persons with Disability showed that bus stop design varies and does not follow standard legal provisions. The majority of bus stops visited have shops and retail outlets that can affect the initial design of the stop, creating additional barriers for persons with disabilities. In stopping areas, there is no information for persons with hearing disabilities, and no signs for wheelchair users. Persons with disabilities encounter barriers such as steps, the lack of ramp access, handrails, and lifts, and long distances from building entrances to the means of transport (such as a train) or platform, narrow doors and turnstiles, the absence of Braille, large and contrasting signs, and much more. These barriers make such trips possibly dangerous. Moreover, persons with disabilities pointed out that buses sometimes stop to pick up passengers before or after the designated bays (see Box 5). Overall, over half (57 percent) of persons with disabilities reported needing help moving around the city of Tashkent.73 All these barriers make the transportation fare benefits that many persons with disabilities can benefit from useless,74 since they are unable to use them independently.

BOX 5

Lack of accessibility of bus stops and other access issues created by transportation by bus

"The bus stops around town are very different. Some bus stops have two or more stairs or very steep steps that lead to the platform. So, persons with disabilities need to jump or ask others for assistance. During wintertime, if it snows, it is impossible to use the bus stops. They do not consider adding a low-angle ramp with handles for wheelchairs. The bus stops are not the only problem. Buses stop very inconveniently and leave fast. When I slowly try to get on the bus, the driver yells or acts very frustrated. He thinks that because of people like me, he will be behind other buses and lose customers, [this being a private operator]. So, I ask others to assist me to get on the bus. When the bus is approaching the stop, people indeed need to run in order to get inside. I am not sure how people like me or with other disabilities should handle this problem." (Person with disabilities)

Source: Qualitative research.

The mobility of persons with disabilities is also limited by and influences their income. In cities, the insufficient accessibility of public transportation has a negative socioeconomic impact on persons with disabilities, including their employment (see Box 6).⁷⁵ Only 27 percent of persons with disabilities who need a wheelchair (one of the most expensive assistive devices) currently have one.⁷⁶ Nearly 8 percent of persons with disabilities think they are unable to secure employment due to their inability to access transportation.⁷⁷

BOX 6

Impact of inaccessible transportation on persons with disabilities

"Presently, I do not work full time and I have plenty of free time that I wanted to spend on culture and personal development. However, these goals are not viable for me, as to attend various clubs (speaking, debate, etc.) and other places, such as education centers, I can only take a taxi, which is very expensive. If the transportation such as subways and busses were adapted for us, I could have developed myself." (Person with disabilities)

Source: Qualitative research.

⁷² Regulations of the State Committee of the Republic of Uzbekistan for Architecture and Construction dated 10.01.2008 No. 2.07.02-07.

⁷³ UNDP 2015, 70.

⁷⁴ See https://lex.uz/acts/39857.

⁷⁵ World Bank 2021.

⁷⁶ See more details on assistive devices on assistive devices in the sectoral technical brief on social protection.

⁷⁷ UNDP 2015, 65.

Recommended measures

(iv) the participation of OPDs.

LIMITED ACCESS TO TRANSPORTATION

The Ministry of Transportation to outline an action plan for adaptation of the 1 transportation vehicles and infrastructure for accessible transportation of persons with all types of disabilities, to ensure, in line with the Accessibility code and the CRPD, inter alia: (i) development of a typical transportation stop layout accessible for persons with all types of disabilities, including light and sound information boards for persons with hearing and vision impairments, installation of ramps and railings, the use of tactile coverage on areas in front of the entrance doors of the vehicle, special waiting areas for persons with disabilities, as well as the installation of electronic information boards, etc.; (ii) information poles with route numbers in an accessible design, arrival/departure timetables that are adapted for persons with disabilities; (iii) any other devices and features of the transportation infrastructure or vehicles necessary for persons with disability (such as traffic lights with sound and color sequence buttons, street and station signs that point out special places, a "running line," voice messages, signal buttons, route number announcements at bus stop and station entrances, route numbers written in large-format writing displayed prominently on the vehicle for the visually impaired, adequate waiting times at the crossing and during stops of the transport means, escorting services for persons with mobility impairments, and any other accessibility requirements);

- The Ministry of Economy and Finance to allocate the required funds to change production lines for new transportation vehicles and reconstruction lines of the existing ones and to properly equip them with necessary adaptations needed to ensure accessible transportation for persons with all types of disabilities.
- The Ministry of Transportation to work with municipalities, private and private transportation enterprises, and any other stakeholders for the implementation of the plan, ensuring the measures are implemented adequately and sustainably, including from a financial point of view.
- The Ministry of Transportation should train all personnel engaged in the transportation system (e.g., drivers, ticket dispensing, and ticket checking personnel), on all types of transportation means (buses, underground and overground trains, airplanes, and others).
- **5** The Ministry of Transportation to establish in the legislation administrative responsibility for the lack of parking spaces for personal vehicles of persons with disabilities.
- The Ministry of Transportation to coordinate the preparation of accessibility maps of the transportation networks.
- The Ministry of Transportation and organizations representing persons with disabilities to monitor the implementation of transport accessibility requirements.
- The Ministry of Transportation to ensure that fines are being collected from the organizations managing transport infrastructure that does not comply with accessibility norms.

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1.3. Limited access to information and communications

Access to information and means of communication is a core dimension of overall accessibility for persons with disabilities. Persons with reduced mobility and sensory disabilities have an increased need to access information and communication on which they rely for guidance in the physical environment or delivered to them as part of virtual services. To ensure that persons with disabilities have satisfactory conditions to live independently and participate fully in all aspects of life and ensure compliance with the CRPD, it is important for state parties to tackle any deficits in access to information and communications, including access to technologies and communication systems.

Art. 9 of the CRPD states that state parties shall take appropriate measures to: (1) promote appropriate forms of assistance and support to persons with disabilities to ensure their access to information; (2) promote access for persons with disabilities to new information and communications technologies and systems, including the Internet; and (3) promote the design, development, production, and distribution of accessible information and communications technologies and systems at an early stage, so that they become accessible at minimum cost.



Description of the problem

Persons with disabilities generally have less access to information, compared to persons without disabilities (see Table 6). Data from a 2019 study indicate that the share of persons with disabilities considering they have complete access to the information they need is 53.9 percent compared with 70.4 percent of persons without disabilities. Difficulties and obstacles in accessing information and communications can arise as a result of the lack of availability of sign interpretation services, alternative and augmented means of communication, and a lack of requirements and practices for presenting services offered by public and private providers in accessible formats. For instance, there is almost no information available in alternative formats for persons with visual and hearing disabilities or those with intellectual disabilities, no easy-to-understand formats, and no sign language/captioning of televised public debates or news.⁷⁸ The lack of easy-to-understand and easy-to-read formats includes legislation and reports regarding the promotion and implementation of the rights of persons with disabilities. Such shortfalls contribute to their very low level of awareness of the main legislation on disability rights.⁷⁹

⁷⁸ UN 2019b.

⁷⁹ The percentage of persons with disabilities familiar with disability rights legislation range from 3.3 percent in the case of knowledge of the CRPD to 7 percent regarding the law "On social protection of persons with disabilities" and 7.5 percent regarding the Decree of the Cabinet of Ministers on measures to further strengthen targeted social protection and support for the elderly and persons with disabilities (UN 2019b).

Persons who state they have complete access to information they need (percent)

		Persons with disabilities	Persons without disabilities
All		53.9	70.4
Anna an maridan an	Urban	56.1	73.0
Area or residence	Rural	52.2	67.5
Ago	Children*	47.2	51.4
Age	Adults	55.3	79.7
Gender	Female	52.9	72.0
Gender	Male	54.7	68.3
	1st group	42.7	
Category of disability as per disability certificate	2nd group	55.3	
	3rd group	65.5	

Note: * in the case of children, the statement is made by their caregivers.

Source: UN 2019b.



Explanation of the problem

Inadequate policy design, coordination, and implementation

There is a lack of coordination in ensuring the accessibility of information and communications for persons with disabilities. Currently, there is no strategy shaping the long-term policy vision for ensuring full accessibility to information and communications, or for preparing and implementing measures to this end.

Isolated measures to improve access to information and communication have been implemented. In 2019, the Ministry of Emergency Situations first launched, through Presidential Decree, a dispatch service for social support of persons with hearing and speech disabilities. This service operates around the clock and receives video calls and text messages.

Inadequate status and use of sign language

Access to sign language is not regarded as a fundamental right. The status of sign language was defined in the law "On the social protection of persons with disabilities in the Republic of Uzbekistan," which recognized a limited legal status of sign language as a "means of interpersonal communication." The wording, and therefore the status of the language, did not change with the adoption of the law "On the rights of persons with disabilities" in 2020. The government might want to consider recognizing sign language as an official language which would assist in its development and usage in the educational sphere and for other basic services. This recognition would help in professionalizing Sign Language for many teachers in specialized boarding schools for deaf and hard-of-hearing children who teach but are not formally trained in sign language. Students' use of sign language is often limited as well, the main emphasis being on developing the ability to read lips and acquiring oral speech (articulation).⁸¹

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⁸⁰ See https://lex.uz/ru/docs/4245430.

⁸¹ See more details in the sectoral technical brief on education.

There are some small achievements, but their effectiveness is hindered by the lack of an integrated intervention framework. A *Surdo-Online* sign language hotline was introduced. When visiting pharmacies, banks, railway ticket offices, and other public institutions that joined the *Surdo-Online* hotline in Tashkent, deaf persons can access services of online sign language interpreters through available tablets or with the representatives of these offices. However, the significant shortage of qualified sign language interpreters in Uzbekistan significantly limits the effectiveness of this service.

There is an acute shortage of qualified sign language interpreters in Uzbekistan. Interpreters are vital and can be required in numerous areas to serve persons with disabilities. For instance, in courts, in interactions with the police, banks and tax offices, during examinations by the VTEK, as well as in daily interactions. According to unofficial data for 2020, in Tashkent and Tashkent region, there are only about 10 sign language interpreters for about 5,000 deaf people.⁸² Given that sign language is not recognized as an official language, it is not seen as a profession which results in most interpreters being relatives of persons with hearing disabilities. In Uzbekistan, sign language services are not included in the list of public services provided to persons with disabilities.⁸³

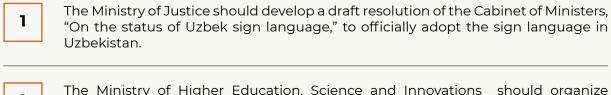
There is still limited TV and radio broadcasting for persons with disabilities. State TV channels must ensure that news programs are broadcast with sign language interpretation or subtitles. In 2020, only 3 out of 20 public and private TV channels broadcasted some TV shows with sign-language translation. In practice, the legal status of sign language should require all institutions to provide sign language interpretation services to persons with hearing disabilities once it had been made an official sign language.

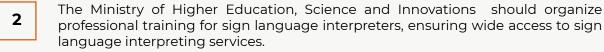
⁸² See https://www.gazeta.uz/ru/2020/09/23/sign-language/.

⁸³ See https://www.gazeta.uz/ru/2020/09/23/sign-language/, https://www.gazeta.uz/ru/2020/10/24/rights/.

Recommended measures

LIMITED ACCESS TO INFORMATION AND COMMUNICATIONS





- The Ministry of Public Health should include sign language services in the list of rehabilitation services funded by the state budget.
- The Ministry of Digital Technologies (MDT) should implement incentive schemes or contribution deductions for mobile networks to establish state and private partnerships to provide affordable mobile video communication services and preferential rates for deaf and hard-of-hearing subscribers.
- The MDT to coordinate the introduction of subtitles as part of the national TV channels broadcasts, based on newly developed technology for automatic recognition of Uzbek speech.
- The MDT to introduce in the law the conditions that call for mandatory sign language accompaniment/electronic captions of programs in the media/cinema/theaters and public events.
- 7 The Ministry of Justice to establish a set of accessibility guidelines, considering the W3 guidelines, and a department to inspect and monitor the accessibility of public websites.

Accessibility and mobility

⁸⁴ See https://www.w3.org/Translations/WCAG20-ru/.



CHAPTER 2

Effective protection of the rights of persons with disabilities

All States parties must ensure effective and equal protection of the rights of persons with disabilities. Persons with disabilities should be equally recognized by law and not face any discrimination to enjoy their freedoms and exercise their rights, including the right to work, marry, vote, or take any other decision. At the same time, persons with disabilities should be able to access justice, seek and be granted adequate legal remedies (means of protection) if their rights are violated, and the law should guarantee their participation in all legal procedures of the judicial system.⁸⁵

The core issues addressed under this sector are:

2.1 Z

persons with disabilities

to exercise their legal

capacity

2.2 7

Limited access to justice

⁸⁵ To this end, the following CRPD articles are particularly relevant: Art. 12 on "Equal recognition before the law," Art. 13 on "Access to justice," Art. 14 on "Liberty and security of person," Art. 15 on "Freedom from torture or cruel, inhuman or degrading treatment or punishment," Art. 16 on "Freedom from exploitation, violence and abuse," Art. 17 on "Protecting the integrity of the person."

2.1. Limited possibility of persons with disabilities to exercise their legal capacity

As per Art. 12 of the CRPD, all persons with disabilities have the right to equal recognition before the law. However, equality cannot be ensured if they are denied their legal capacity and lack control over their own lives, such as being unable to manage their own property or sign contracts. Legal capacity is essential for persons with disabilities to fully exercise their rights, be in control of their lives, and fully participate in society. Persons with disabilities who need decision-making support should be provided such services at the community level to enjoy their full rights as citizens.



Description of the problem

According to the CRPD Committee, perceived or actual deficits in mental capacity must not be used as justification to deny legal capacity,86 as currently takes place in Uzbekistan. In Uzbekistan, some persons with mental disabilities are deprived of their legal capacity, which violates their fundamental rights. Furthermore, certain groups tend to be more affected by the limitation of their legal capacity, such as persons with disabilities who live in residential institutions, or those admitted against their will to a mental health care facility (psychiatric institution). The number of persons who are admitted long-term to psychiatric institutions is unknown. Neither is the number of persons deprived of their legal capacity. Depriving persons with disabilities of their legal capacity violates their fundamental rights and should not be imposed based on the controversial concept of mental capacity. The CRPD Committee clarifies the important distinction between legal capacity and mental capacity to illustrate that a person's mental capacity should not limit a person's legal entitlements. While legal capacity is the ability to hold and exercise rights and duties, mental capacity refers to a person's decision-making skills, which vary from person to person and depend on environmental or social factors.⁸⁷ Depriving persons with disabilities of their legal capacity violates their fundamental rights.

Legal capacity can be exercised with the help of appropriate decision-making support services that should be available for all persons with disabilities who may need them, regardless of mental capacity. Unfortunately, Uzbekistan has no plans to discuss creating an enabling environment to provide such possibilities for persons with disabilities.



Explanation of the problem

Uzbekistan's current legislation allows for the legal capacity of persons with disabilities to be restricted based on their mental capacity. A person with disabilities with restricted capacity cannot have a job, own property, sign agreements, or access justice. Art. 30 of the Civil Code of Uzbekistan states that "a citizen who, due to a mental disorder (mental illness or dementia), cannot understand the meaning of his/her actions or control them, may be

⁸⁶ CRPD Committee 2014a, para. 13.

⁸⁷ CRPD Committee 2014a, para. 13.

declared legally incompetent by a court in the manner prescribed by law, and guardianship is established over him/her." Special courts (courts of the first instance) are the ones that decide whether a person with disabilities should be fully or partially incapacitated (see description of steps in Box 7),88 based on mandatory psychiatric assessment according to Law no. 690/2021 "On mental health care," Art. 24. Such a request to the special court is initiated by a family member or other third party, including a criminal/administrative/civil court if relevant to an ongoing case. Parties are exempt from any court fees in cases of legal capacity determination.89

BOX 7

Steps for limiting a person's legal capacity in court

- 1. Submission of an application for recognizing a citizen as fully or partially incapacitated. A case may be initiated at the request of family members, guardianship authorities, prosecutor, medical institutions and other state authorities, self-government bodies of citizens and public associations. The application is filed with the court at the place of residence of this citizen, and if this person is placed in a medical institution, then at the location of this institution. The application must contain circumstances indicating a mental disability, as a result of which a person cannot be accountable for his actions or manage them.
- **2. Preparation of a case for trial.** Having received the application, the judge, in order to prepare the case for trial, if there is insufficient data on the mental disorder (mental illness or dementia) of the citizen, appoints a forensic psychiatric examination to determine the person's mental state. If the citizen evades undergoing a forensic psychiatric examination, the court may issue a ruling on a forcible examination.
- **3. Case consideration.** The court considers the case on recognizing a citizen incompetent with the participation of the prosecutor and a representative of the guardianship and guardianship authority. The citizen in respect of whom the case is being considered is summoned to the court session if this is possible due to the state of health.
- **4. Court decision.** The court decision is the basis for the appointment by the guardianship authority of a partially incapacitated a trustee, and a fully incapacitated person a guardian. The court is obliged to notify the guardianship authority from the person's place of residence by sending a copy of the decision to establish trusteeship or guardianship within three days from the decision's entry into force.

Source: Arts. 310-314 of the Civil Procedure Code of the Republic of Uzbekistan.

Psychiatric assessment is carried out within a psychiatric institution.⁹⁰ Psychiatric assessment is conducted after obtaining informed consent from the person or parent, or, in special cases, without it. In this case, the psychiatric institution will file a case to the court to approve forcible hospitalization, and the court has 48 hours to issue a decision.⁹¹ If a disability is identified and a mental health diagnosis is assigned, the person is included in a registry for persons with mental disorders (administrated by the MPH). There is no public information on how many persons are in this registry.⁹² Psychiatric assessment can also be carried out at the persons' request, for example, to obtain a disability certificate.

Persons whose capacity was fully or partially limited by a decision of special courts are appointed a trustee or guardian by the Guardianship Institution.⁹³ According to law no. 690/2021 "On mental health care," guardianship is appointed "for the best interest of a person" by khokim of a district or city. The Guardianship Institution assigns a legal guardian who takes decisions on their behalf and mediates the services they receive. These legal provisions limit the legal actions and freedoms of persons with disabilities, who rely on their legal guards.

⁸⁸ See the Civil Procedure Code of Uzbekistan, Art. 27, and the Resolution of Plenum of the Supreme Court of Uzbekistan No. 14 "On some issues in the application of the norms of civil proceeding legislation by the court of the first instance," para. 17.

⁸⁹ Civil Procedure Code of Uzbekistan, Art. 316. However, if the court establishes that the family members who filed the application, acted in bad faith with the aim of knowingly unreasonable restriction or deprivation of legal capacity of a citizen, recovers court costs from them.

⁹⁰ Law no. 690/2021 "On mental health care," Art. 24, para. 1-4.

⁹¹ Law no. 690/2021 "On mental health care," Art. 28.

⁹² https://anhor.uz/society/psihiatriya/

⁹³ Civil Procedure Code of Uzbekistan, Art. 314. Khokimiyat of a district or city has a registry for guardianship and oversees appointing and revoking guardianship, as per law "On guardianship."

Potential situations of exploitation and abuse of persons with limited legal capacity by trustees or guardians are unknown. Situations in which legal guardians are suspected of abuse or exploitation (of children or adults) may be raised to the Guardianship Institution. However, there are no available statistics on complaints or situations that have been resolved.

Data on persons with disabilities who cannot exercise their legal capacity is not public, although information is collected by local authorities. As per Annex 2 of law "On guardianship," a state register of registration of persons under guardianship is established and maintained by local government authorities in the form of an electronic document based on information received from the guardianship and guardianship authorities. On persons who are legally incapacitated and limited, the register includes the full name of the person; their date and place of birth, citizenship, and nationality; the court decision declaring their limitation of capacity; and information about the properties owned by the person. The number of persons who are incapacitated is not public.

Data is unavailable also with regard to the number of persons who recovered their legal capacity. Art. 315 of the Civil Procedure Code of Uzbekistan states that persons can only be regranted their legal capacity by court decision, but there is no evidence of cases submitted for the recovery of persons' legal capacity or how many may have been solved.

вох 8

Key elements for setting up supported decision-making alternatives by States parties

- (a) Supported decision-making must be available to all. A person's level of support needs, especially where these are high, should not be a barrier to obtaining support in decision-making;
- (b) All forms of support in the exercise of legal capacity, including more intensive forms of support, must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests;
- (c) A person's mode of communication must not be a barrier to obtaining support in decision-making, even where this communication is non-conventional, or understood by very few people;
- (d) Legal recognition of the support person(s) formally chosen by a person must be available and accessible, and States have an obligation to facilitate the creation of support, particularly for people who are isolated and may not have access to naturally occurring support in the community. This must include a mechanism for third parties to verify the identity of a support person as well as a mechanism for third parties to challenge the action of a support person if they believe that the support person is not acting in accordance with the will and preferences of the person concerned;
- (e) [...] States parties must ensure that support is available at nominal or no cost to persons with disabilities and that lack of financial resources is not a barrier to accessing support in the exercise of legal capacity;
- (f) Support in decision-making must not be used as justification for limiting other fundamental rights of persons with disabilities, especially the right to vote, the right to marry, or establish a civil partnership, and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty;
- (g) The person must have the right to refuse support and terminate or change the support relationship at any time;
- (h) Safeguards must be set up for all processes relating to legal capacity and support in exercising legal capacity. The goal of safeguards is to ensure that the person's will and preferences are respected.
- (i) The provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity.

Source: CRPD Committee, 2014a, Art. 29.

At present, there are no decision-making support services available for persons with disabilities who may need them to exercise their legal capacity in Uzbekistan. States parties' obligations require both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives. To ensure the development of decision-making support services, legislation needs to be reformed. Their development should be done in consultation with OPDs, and services should be flexible and provide tailored support. The specialists who provide such support are supposed to explain information in

⁹⁴ The state register also includes information about other groups of people who need a legal guard, such as orphaned children.

⁹⁵ CRPD Committee 2014a, para. 28.

ways that can be understood by the person with disabilities.⁹⁶ In this regard, international best practices can be introduced and tested in Uzbekistan to support persons who may need supported decision-making services in understanding their rights and taking their own decisions.

BOX 9

Best practices of supported decision-making services

Spain: Support-Girona is an independent NGO providing global and individualized support to persons with disabilities, promoting their social inclusion and human rights. Its mission is to support persons with intellectual disabilities, psychosocial disabilities, or elderly persons experiencing some type of disability due to the aging process to achieve social inclusion and exercise their rights. The organization prioritizes developing a supported decision-making service for persons with disabilities as well as promoting and implementing the deinstitutionalization of the persons the organization supports. The organization works towards offering a personalized and coordinated service, networking with professionals and organizations, to support persons with disabilities in exercising their right to make their own decisions.

Sweden: The Personal Ombudsman is a Swedish-supported decision-making service that has operating nationwide since 2000 initially developed as a pilot project by persons with a history of psychiatric diagnosis. Service staff work under a contract with persons with psychosocial disabilities or mental health problems who are most vulnerable and socially isolated, helping them with the decisions that they need to take in all aspects of life. The support relationship begins as a relationship of trust, and the contract can be suspended at any time at the request of the person with disabilities. The service has been permanently funded by the State budget since 2013 and has been proven to reduce long-term costs for care and psychosocial services. As of 2014, there were 310 Personal Ombudspersons who were supporting six thousand people.

Source: https://www.mhe-sme.org/member-spotlight-february-2021/, https://zeroproject.org/policy/sweden-2/

Representatives of the Uzbek justice system (such as judges, lawyers, prosecutors, or police) are unfamiliar with equal rights regarding the legal capacity of persons with disabilities; so is the society at large and even persons with disabilities themselves. Training carried out so far was limited to general concepts and principles of the CRPD, but did not go into depth on the importance or essence of each article. Furthermore, these trainings were one-off sessions and not continuous enough to ensure the transfer of knowledge and sustainability, especially for newcomers to the system and sector. Targeted training on legal capacity (especially for various professionals who specialize in mental disabilities) can support change in the perception and treatment of persons with disabilities with respect to their capacity to make their own decisions.

Recommended measures

LIMITED POSSIBILITY OF PERSONS WITH DISABILITIES TO EXERCISE THEIR LEGAL CAPACITY

1	The Ministry of Justice, with methodological support from organizations of persons with disabilities (OPDs) to review and amend the Civil Code, the Civil Procedure Code, and other legal acts and provisions (e.g., in the fields of justice, employment, or social protection), that allow the restriction of legal capacity based on disability.
2	The "Anti-Corruption and Judicial Affairs Committee" and "Commission on Regulatory Terms" of the Legislative chamber of the Oliy Majlis of Uzbekistan (Parliament), in consultation with OPDs to review the Law "On the rights of persons with disabilities" to include provisions that secure the right of persons with disabilities to exercise their legal capacity and introduce supported-decision making services.
3	Training and re-trainings of acting judges to recognize the legal capacity of persons with disabilities and guarantee their rights, based on a special curriculum developed by the Supreme School of Judges under the Supreme Judiciary Council of Uzbekistan.
4	The Agency for Development of Medical and Social Services under the Ministry of Public Health and the Ministry of Employment and Poverty Reduction, shall design, pilot, regulate, and establish supported decision-making services for persons with disabilities, as well as support the development of such initiatives when raised by sectoral state bodies and civil society organizations.
5	The Ministry of Justice and the Statistics Agency under the President of the Republic of Uzbekistan to develop a system to collect data on persons with disabilities who cannot exercise their legal capacity, and publicly report it in accessible ways.

2.2. Limited access to justice

Persons with disabilities must have free access to justice to defend their rights. Access to justice means that a citizen is able to: (1) use the courts to resolve their disputes without any de jure (prescribed by law) and/or de facto (prescribed by unwritten customs) obstacles; and (2) have a fair trial and access to adequate legal remedies when their rights are violated. According to Art. 13 of the CRPD on access to justice, persons with disabilities must be provided with procedural accommodations that facilitate their participation in all legal proceedings and at all stages of the judicial process (which may include investigations). The institutions involved in ensuring access to justice may not only include courts, but also police offices, prosecution offices, defense lawyers, forensic-medical examination institutions, detention facilities, transportation, and penitentiary institutions. Persons with disabilities should also be able to take up roles in the justice system, serving as lawyers or judges. Art. 5 of the CRPD, in line with other international treaties such as the International Covenant on Civil and Political Rights, is based on the general principle that discrimination on the basis of disability is not permitted.



Description of the problem

Persons with disabilities encounter barriers in the justice system, limiting their access to justice. The main barriers include: (1) limited physical, information, and communications accessibility of justice system buildings; (2) unaffordable fees for special accommodations or other judicial expenses for most persons with disabilities; (3) lack of an enabling environment for persons with disabilities to serve in the justice system; and (4) insufficient training of justice system staff on providing access to justice for persons with disabilities. The following categories of persons with disabilities are largely deprived of access to justice in Uzbekistan: (1) persons with specific accessibility needs; (2) persons deprived of their legal capacity; (3) persons with a low standard of living; (4) persons with intellectual disabilities; and (5) women with disabilities.⁹⁹ While there is no existing data on the number of legal cases submitted by persons with disabilities, qualitative information suggests that such cases are rare. At the same time, persons with disabilities take up roles within the system only in exceptional cases, due to: (1) legal limitations; (2) accessibility barriers; and (3) behavioral attitudes.

However, legislation in Uzbekistan describes equal access to justice of citizens. The Constitution states that "everyone is guaranteed the judicial protection of his/her rights and freedoms, the right to appeal to the court against illegal actions of state bodies, officials, public associations" and any discrimination is prohibited. Procedural law states that the "administration of justice is based on equality of citizens before the law and the court" and "justice on criminal cases is carried out on the basis of the equality of citizens before the law and the court, regardless of gender, race, nationality, language, religion, social origin, beliefs, personal and social status."

⁹⁷ The following CRPD articles are also particularly relevant to the analysis carried out under this section: Art 5. On "Equality and non-discrimination," Art. 6 on "Women with disabilities," Art. 9 on "Accessibility," Art. 14 on "Liberty and security of person," Art. 15 on "Freedom from torture or cruel, inhuman, or degrading treatment or punishment," Art. 16 on "Freedom from exploitation, violence and abuse," and Art. 17 on "Protecting the integrity of the person."

⁹⁸ CRPD Committee 2014a, para. 38.

⁹⁹ In Uzbekistan, women are often victims of domestic violence due to traditional society, the weak legal protection system, and the impunity of perpetrators, and the situation is worse for girls and women with disabilities, particularly intellectual disabilities. Thus, women with disabilities risk having their rights violated via two discriminatory factors: disability and gender.



Justice system buildings and activities must be accessible

Although all public buildings in Uzbekistan are required to be physically accessible to all,¹⁰⁰ almost none of the country's courts operate in fully accessible facilities.¹⁰¹ Accessibility of court buildings and courtrooms (if separate) is vital to enable persons to access justice and is required by Art. 9 of the law "On the rights of persons with disabilities." This includes the provision of special ramps, elevators, sound alerts, handrails, or access roads.¹⁰² However, courts and other justice system buildings (such as police stations) rarely meet such criteria.¹⁰³ To address the difficulty that persons with physical disabilities have traveling, in the case of divorce, Art. 34 of the Civil Procedural Code of Uzbekistan states that "claims [...] may be filed with the court at the place of residence of the plaintiff,¹⁰⁴ when it is difficult for him/her to travel to the interdistrict, district (city) court for civil cases at the place of residence of the defendant due to the fact that he/she has minor children, and also due to [physical] disability or serious illness." Being able to submit cases online, which was introduced during the COVID-19 pandemic, also makes it easier for persons with mobility disabilities to access justice.

BOX 10

On the physical accessibility of courts

"There are no ramps or elevators in courts if the courtroom is on the second or third floor, or on basement, or elevators are so small that wheelchair can't fit. Usually, police officers, court guards, or court workers help us to get into the court building and facilities." (Person with physical disabilities)

Source: Qualitative research.

Note: As per current norms, elevators should be installed for buildings with more than 4 floors (see sectoral technical brief on accessibility and mobility for more details).

Similarly, accessible information and clear communication are vital for persons with visual, hearing, and intellectual disabilities to access justice, but current legal provisions do not fully enable this right. Art. 4 para. 1(b) of the CRPD calls on States parties to institute the necessary mechanisms to ensure that persons with disabilities can participate in all judiciary proceedings without any barriers or discrimination. This requires the provision of reasonable accommodations¹⁰⁵ during legal proceedings. In Uzbekistan, procedural codes on civil and criminal cases refer to the possibility of using translators during court hearings and receiving translated versions of final decisions/judgments, but such translation does not include sign language interpretation or hard-copy documents in Braille.¹⁰⁶ Moreover, persons with disabilities who may need accommodations such as sign language interpretation or audio-video recordings (for which special recording equipment is needed) must request these from the court before the trial begins, and must bear the cost themselves.¹⁰⁷ Persons with intellectual disabilities encounter significant difficulties in starting legal proceedings,

- 100 CRPD, Art. 9 and CRPD Committee 2014b, paras. 6 and 37.
- 101 Isakov 2021.
- 102 See the sectoral technical brief on accessibility and mobility for more details.
- 103 As highlighted by participants of a consultation workshop carried out with relevant stakeholders for the finalization of the present technical note on October 12–13, 2022, in Tashkent.
- 104 As a general rule, all complaints in civil cases must be submitted to the permanent residence district/city of a respondent, as per the Civil Procedure Code of Uzbekistan, Art. 33.
- 105 CRPD. Arts. 5 and 9.
- 106 CRPD, Art. 11; Human Rights Council 2020, para. 87.
- 107 The Criminal Procedure Code, Art. 19, prohibits audio-video recording in closed court hearings. All court hearings are open, except for cases in which: (1) parties or one of the party requests to close the case; (2) details include state secrets; (3) minors are involved; or (4) a person's dignity is concerned. Requests for audio-video recording are possible.

and may need support to understand the procedural complexities involved in litigation, even if they are represented by legal guardians.¹⁰⁸

Special accommodations should be ensured for persons with disabilities and other judicial expenses must be affordable

If persons with disabilities need to resort to the justice system, they must fully cover all related judicial costs, ¹⁰⁹ including those related to court fees, legal representation, and special assistance, prior to the start of the hearing. There are some situations in which persons with disabilities may obtain free special assistance during court hearings, but only if: (1) they make a request in advance; and (2) the court has a budget available to cover the costs (e.g., for sign interpretation, or rendering documents to be more accessible). Persons who are part of vulnerable groups, including persons with disabilities, have the right to submit a claim for the other party in the case to reimburse their legal expenses, based on a justification. However: (1) they must advance all costs for their case to be processed; and (2) the judge may partly or fully deny the request (for example, if the justification was not strong enough or was challenged by evidence from the other party). The law considers a reduction or delay in payments, depending on the circumstances, but does not explicitly state what these might be.¹¹⁰

Persons with disabilities in Uzbekistan already live on low incomes, making the services of a lawyer or court fees unaffordable.¹¹¹ In many cases, persons with disabilities who request accommodations and other assistance cannot afford the increased costs. The only way a person with disabilities can avoid paying out of pocket is if they are represented by a public OPD.¹¹² According to Uzbekistan's tax law, public OPDs are exempt from paying court fees in all types of claims¹¹³ if they: (1) are a party of the court hearing; (2) represent a person with disabilities; and (3) request an exemption from the court. Such exemption does not include costs for reasonable accommodation or special needs that must be requested separately. Despite the existence of this provision in the tax code, it is the court which decides whether a tax exemption can be applied or not. Moreover, public OPDs cannot represent all persons with disabilities in all cases. In this regard, providing free legal aid for persons with disabilities unable to cover such costs would support their access to justice.¹¹⁴

¹⁰⁸ Representatives of the judicial system consider persons with disabilities, and especially those with mental disabilities, to be incapable of making decisions. As such, information provided to them is very limited (Art. 42 of the Civil Procedural Code).

¹⁰⁹ Judiciary bills depend on the subject of the complaint. The minimum judiciary fee is 1 basic accounting rate, whereas disputes connected to any property will be 4 percent of its value, as per law no. 600/2020 "On state fees." As of June 2022, the basic accounting rate is equal to 300,000 UZS (approx. US\$27), and the minimum wage is 920,000 UZS (approx. US\$83.6). See https://uzreport.news/society/s-1-iyunya-v-uzbekistane-povishayutsya-zarplati-brv-i-mrot

¹¹⁰ Civil Procedure Code of Uzbekistan, Arts. 132–135.

¹¹¹ Isakov 2021. For more on the earnings of persons with disabilities, see the sectoral technical brief on social protection, and for their access to employment, see the sectoral technical brief on employment.

According to the Civil Procedure Code of Uzbekistan, Art. 67, contractual (voluntary) representatives can be: (1) defense lawyers; (2) relatives in the direct ascending and descending or lateral line, as well as the husband (wife) or his (her) relatives; (3) employees of legal entities - on the cases of these legal entities; (4) authorized representatives of non-profit organizations - on the cases of members of these organizations; (5) authorized representatives of non-profit organizations who are granted by law the right to protect the rights and interests of other persons; (6) one of the accomplices on behalf of other accomplices; (7) persons admitted by the court considering the case as representatives of an individual. Only defense lawyers can be engaged in professional activities in conducting cases in court as a representative. However, in case if suspect, accused, defendant or their relatives cannot find any defense lawyer within twenty-four hours in criminal cases or criminal investigations, such defense shall be appointed by the territorial department of the Chamber of Advocates of the Republic of Uzbekistan upon request either by a person behind the bar or the court.

¹¹³ Tax Code of Uzbekistan, Art. 329.

¹¹⁴ A draft law on free legal assistance was developed in 2018, that includes persons with disabilities in a list of eligible vulnerable groups. However, the draft law was not adopted at the time of drafting the present report.

Persons with disabilities should have the possibility to serve in the judicial system

Persons with disabilities in Uzbekistan rarely take up roles in the judicial system. The CRPD Committee mentions that the right to access justice also includes persons with disabilities serving in judiciary roles, such as lawyers or judges.¹¹⁵ In Uzbekistan, however, requirements for appointing judges include a clause that excludes candidates who are not in "good health."¹¹⁶ Thus, any type of disability perceived as an illness can represent an obstacle for a person with disabilities seeking to become a judge in Uzbekistan. On the other hand, requirements for defense lawyers¹¹⁷ and prosecutors¹¹⁸ do not include any special clauses on health conditions, but should they pursue such a path, persons with specific disabilities are excluded by, for example, lack of accessibility. For example, justice system buildings such as detention facilities and court and prosecution buildings are not physically accessible to persons with disabilities. During his visit to Uzbekistan, the UN Special Rapporteur on the independence of judges and lawyers highlighted the access to justice for persons with disabilities, particularly regarding their roles in the system, which are insignificant or entirely lacking.¹¹⁹ Currently, there are no provisions to encourage persons with disabilities to take up roles in the judiciary. To stop the exclusion of persons with disabilities, financial and human resources are required over a long period of time.

Justice system staff must be trained on the rights of persons with disabilities

Staff in the judiciary are not trained to ensure that persons with disability can access justice in court. Training is a requirement to ensure effective access to justice under Art. 13 (2) of the CRPD, and the CRPD Committee frequently recommends engaging in training to States parties. Available training in Uzbekistan only covers the CRPD's legal dimension and general principles in overview courses on international law and practice. While Uzbekistan only ratified the CRPD in 2021, such issues should be swiftly assessed.

Qualitative information suggests that courts, police officers, and other first responders do not give the same weight to complaints and statements from persons with disabilities as they do to other citizens.¹²⁰ Due to the absence of disaggregated statistics on disability, it is unclear how many persons with disabilities complained to the police, law enforcement agency, or other entity that is part of the justice system. Moreover, feedback is not collected systematically to understand if persons with disabilities who interact with the justice system are satisfied with how their issue was treated or whether they faced discrimination. Qualitative information from civil society suggests that persons with disabilities are perceived as being rather weak and in need of "mercy," and their issues are not satisfactorily addressed.¹²¹

Following its reform in 2017, the Ombudsman Office¹²² became active in human rights protection, but it is no quantitative measure of the attention paid to realizing the rights of persons with disabilities. The last published report¹²³ states that 18,738 rights violation complaints were submitted to the Ombudsman Office in 2021, whereas 16,559 were submitted by citizens, 2,120 from persons in detention facilities and prisons, and 59 by foreign citizens. Statistics show that 40 percent of complaints pertain to personal and fundamental

- 115 CRPD Committee 2014a, para. 38.
- 116 Law of Uzbekistan no. 703/2021 "On courts," Art. 67.
- 117 Law of Uzbekistan no. 349-I/1997 "On Advocacy/Bar," Art. 3.
- 118 Law of Uzbekistan no. 257-II/2001 "On Prosecution," Art. 43.
- 119 Human Rights Council 2020.
- 120 CRPD Committee 2014a, para. 39.
- 121 As highlighted by participants of a consultation workshop carried out with relevant stakeholders for the finalization of the present technical note on October 12–13, 2022, in Tashkent.
- 122 Law no. 669-II/2017 "On Ombudsman."
- 123 http://ombudsman.uz/ru/docs/ozbekiston-respublikasi-oliy-majlisining-inson-huquqlari-boyicha-vakili-ombudsmanning-2021-yildagi-faoliyati-togrisidagi-hisoboti

rights and freedoms; 30 percent to social rights; 24 percent to economic rights; 6 percent to political rights; and 1 percent to environmental rights. While statistics are disaggregated by region and gender, they are not disaggregated by disability.

Persons with disabilities themselves are not aware of their rights. While persons with intellectual and psychosocial disabilities, and those in institutions and closed facilities (such as residential centers, psychiatry hospitals, or prisons) are most vulnerable, qualitative information suggests that they generally have limited awareness of their rights.

Recommended measures

LIMITED ACCESS TO JUSTICE



- The "Anti-Corruption and Judicial Affairs Committee" of the legislative chamber of the Oliy Majlis of Uzbekistan (Parliament) and the Ministry of Justice, with methodological support from OPDs and in consultation with the Supreme Court of Uzbekistan, to review Uzbekistan's procedural codes in order to: (1) demand that courts provide both decisions and necessary case materials in accessible formats, as well as sign language translations to ensure persons with disabilities have access to information upon the request of any party; and (2) establish that expenses that ensure access for persons with disabilities shall be covered by the court budget upon the request of any party, and without the need for persons with disabilities to advance the respective cost.
- The Ministry of Justice, in consultation with the Chamber of Advocates of Uzbekistan and OPDs, to design and implement a program to provide free or affordable legal assistance and legal representation for persons with disabilities who lack the means to pay for legal aid.
- The Supreme Court of Uzbekistan to include physical accessibility requirements (such as ramps, accessible toilets, elevators, court, and waiting rooms) in their plans to renovate court buildings throughout the country, through funds ensured by the Ministry of Finance.
- The Supreme School of Judges under the Supreme Judiciary Council of Uzbekistan, the Law Enforcement Academy of Uzbekistan, the Center for Training and Retraining of Lawyers under the Ministry of Justice, the Chamber of Advocates of Uzbekistan, and other relevant educational institutions, with methodological support from OPDs, to train and retrain judiciary personnel, law enforcement, and defense lawyers on the CRPD and work with persons with disabilities, to treat persons with disabilities equally without any discrimination and ill-treatment, and guarantee their procedural rights and right to obtain legal remedies, on the basis of curricula newly developed to this end.
- The "Anti-Corruption and Judicial Affairs Committee" of the legislative chamber of the Oliy Majlis of Uzbekistan (Parliament), with methodological support from OPDs and in consultation with the Supreme Court of Uzbekistan, the Prosecutor-General's Office, and Chamber of Advocates of Uzbekistan to review legislation that regulates the functioning of courts, prosecutors, and advocates (defense lawyers) in Uzbekistan and include provisions for special temporary measures, such as quotas and in-work promotion mechanisms to provide opportunities and incentives for persons with disabilities to be employed in the judicial system.



CHAPTER 3

Employment

Persons with all types of disabilities should have equal rights and opportunities to effectively access general technical and vocational guidance programs, placement services, and vocational and continuing training to find decent employment in the labor market, which should be open, inclusive, and accessible.¹²⁴

Persons with disabilities should have equal access to an open, inclusive, and accessible labor market. According to Art. 37 of the Constitution of Uzbekistan, everyone has the right to work, free choice of work, and fair conditions of labor and protection against unemployment. At the same time, Art. 42 of the recently adopted law "On the rights of persons with disabilities" provides persons with disabilities the right to work in organizations with normal working conditions, in specialized enterprises, in workshops, and in sectors of the economy that employ persons with disabilities, as well as to carry out individual labor or other activities not prohibited by law. Importantly, for the first time, the law has introduced the principle of non-discrimination on the basis of disability in relation to all forms of labor and aspects of the workplace, including conditions of employment, retention of work, and professional promotion, as well as the provision of safe working conditions.

Persons with disabilities should have equal access to mainstream vocational training, guidance programs, and placement services. Apart from the existing barriers to the open labor market, lower levels of education and vocational training limit the access of persons with disabilities to decent employment opportunities. Despite the fact that as per the law, the government guarantees persons with disabilities the opportunity to receive inclusive education, most are still educated in segregated institutions or at home, which does not meet the standards or requirements of mainstream education programs. As a result, after graduation, adults with disabilities lack quality academic, social, and vocational skills required for effective inclusion in the open labor market. The existing specialized vocational schools offer outdated curricula, while the mainstream vocational training programs are not inclusive or accessible to persons with disabilities.

Persons with disabilities should have access to decent jobs and be protected from any external risks, and enjoy social and economic security at work. Yet even if they can find employment, their work is usually unprotected, low-skill, or underpaid. Due to the existing barriers to the formal labor market, persons with disabilities find insecure jobs in the informal market. The COVID-19 pandemic and associated quarantine measures severely affected informally employed persons with disabilities and revealed the health and financial risks they face. Moreover, the CRPD Committee highlights that segregated jobs, such as those in sheltered workshops for persons with disabilities, especially when they become permanent, and not just a training and preparation stage, laying the foundation for the person's entry into the open labor market, should not be considered a measure of progressive realization of the right to work. In contrast, this right can only be realized by free choice or accepted employment in an open and inclusive labor market.¹²⁶

The core issues addressed under this sector are:

3.1 7

Limited access to the open labor market

3.2

Limited access to vocational training programs

3.3

Limited social and economic security at work

¹²⁴ The vision and key aspects to be addressed with regard to employment build on CRPD Art. 27 on "Work and employment," which provides the rights of persons with disabilities to decent work and employment in the open, inclusive, and accessible labor market.

¹²⁵ See the technical note on education for a full discussion on the limited access.

¹²⁶ CRPD Committee, 2022a, Art. 15.

3.1. Limited access to the open labor market

The right to work on an equal basis with others is key for the full inclusion of persons with disabilities. According to Art. 27 of the CRPD, "States parties must promote the realization of the right to work and take appropriate steps, inter alia, to promote employment in the private sector and to ensure that reasonable accommodation is provided in the workplace. States parties are called upon to employ persons with disabilities in the public sector." Persons with disabilities should be able to freely choose the type of employment (e.g., in the open labor market, including the private or public sector) that allows them to sustain adequate standards of living.

Disability-inclusive employment is beneficial to all and increases the social cohesion of communities and societies. Reasons why this is true include:

- The employment of persons with disabilities in decent jobs increases their level of independence and allows them to achieve a higher quality of life, reducing their dependency on social benefits. Like education, work is among the most important means of being included and valued in society. Through employment in the open and inclusive labor market, persons with disabilities can achieve their potential by applying their vocational and professional skills and knowledge and avoid exclusion and segregation.
- Between 73 and 80 percent of workers with disabilities do not need any special workplace conditions.¹²⁷
- Moreover, companies that employ persons with disabilities typically receive tax benefits and preferences from the state, which is the case in Uzbekistan.
- Inclusive and accessible workplaces that meet the needs of all employees and allow them to unleash their full potential helps private businesses become attractive and competitive. Workplace inclusion is an inalienable part of corporate social responsibility. Inclusive work practices ensure the private sector's sustainable development and allow companies to gain public trust, become respected, and improve their reputation, thereby creating an opportunity to attract new customers, as well as to develop creative and responsible employees.
- The lack of decent employment opportunities for persons with disabilities not only puts them at higher risk of social and economic vulnerability, but also reduces economic development at the level of society as a whole. The International Labor Organization (ILO) estimates the economic losses from excluding persons with disabilities from the labor market to be in the range of 3–7 percent of Gross Domestic Product (GDP). Therefore, fulfilling the right of persons with disabilities to decent work is not only necessary from a human rights perspective, but also favors economic development. Persons with disabilities should not be seen as a burden, but rather a resource that wants and can contribute to Uzbekistan's ongoing development.

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¹²⁷ United Nations Department of Economic and Social Affairs factsheet on Disability and Employment. See: https://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities/disability-and-employment.html.

¹²⁸ ILO. 2020. "The price of exclusion: The economic consequences of excluding people with disabilities from the world of work." See: https://www.ilo.org/skills/pubs/WCMS_149529/lang--en/index.htm.

Description of the problem

The government of Uzbekistan inadequately measures the unemployment of persons with disabilities, which results in unreliable official data. The unemployment level of persons with disabilities is currently measured from the number of formally registered persons with disabilities (receiving pensions and social benefits). The unemployment rate of all persons with disabilities (registered and unregistered) may be much higher. The Washington Group Short Set (WG-SS) on Functioning has not been included in the upcoming (2023) population census. This could allow for the collection of reliable data not only about disability's prevalence in the country, but also the actual level of employment of all persons with disabilities.

In Uzbekistan, persons with disabilities are about four times less likely to find a job than persons without disabilities. A 2019 study found that, compared to 30 percent of the working age population (men, 16–59; women, 16–54) who were employed, only 7.1 percent of registered, working-age persons with disabilities were employed in 2019. The employment situation of persons with disabilities is slightly better in urban areas, where 8.5 percent of registered persons with disabilities were formally employed, compared to 5.8 percent in rural areas. Women with disabilities are in a more vulnerable position compared to men: 4.4 percent of working-aged women versus 8.9 percent of men were employed. Almost half of all employed registered persons with disabilities (48 percent) work part-time (less than 8 hours a day), compared to only 31 percent of persons without disabilities.¹³²



Explanation of the problem

Since the current presidential administration came into power in late 2016, the government has introduced several measures to address the employment problems of persons with disabilities, but their impact has not yet been assessed. In 2017, one of the first presidential decrees on disability and inclusion, "On measures to radically improve the system of state support for persons with disabilities," aimed to improve "the system of employment of persons with disabilities, ensuring their involvement and active participation in the socio-economic life of society." The decree prepared the ground for developing the new law, "On the rights of persons with disabilities," which contains Section 7 (Chapter 7) on work and employment of persons with disabilities. For the first time, the law included, through Arts. 4, 6, and 18, "non-discrimination on the basis of disability", including employment as a basic principle for ensuring the rights of persons with disabilities. Furthermore, Uzbekistan ratified the CRPD on June 7, 2021. In December 2021, the Decree of the President of the Republic of Uzbekistan "On additional measures to provide comprehensive support to persons with disabilities, to promote their employment and further increase their social activity" introduced additional measures to promote the employment of persons with disabilities and further increase their social participation. The decree provided more incentives for disability-inclusive employers, vocational training opportunities for persons with disabilities, promotion of their employment in the public sector, and other measures. The effectiveness of all these state measures now relies on implementation by the relevant government bodies and agencies, in cooperation with OPDs.

¹²⁹ The estimates of the unemployment rate of persons with disabilities are based only on the number of officially registered persons with disabilities. In 2020, 718,300 persons with disabilities were officially reported in Uzbekistan, which accounts for only about 2 percent of the country's population. However, the UN and World Bank estimated that in 2020 there were in total of 4.5 million persons with disabilities, including 1.15 million persons with severe disabilities. UN, 2020.

¹³⁰ The WG-SS measures difficulty in functioning in six basic, universal actions (capabilities) that, in an unaccommodating environment would place an individual at risk of restricted social participation. It is anchored in the International Classification of Functioning, Disability and Health (ICF). See: https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/.

¹³¹ UN 2019b, 147-148.

¹³² UN 2019b, 147-148.

There are many institutional, attitudinal, and infrastructural barriers that hinder the participation and inclusion of persons with disabilities in the labor market. In particular, a review of the existing evidence shows that these barriers include: (1) an outdated system of disability assessment that equates disability with loss of employability; (2) widespread stigma and discrimination on the basis of disability in the open labor market, and lack of legal protection and awareness of job seekers with disabilities; (3) lack of enforcement of obligatory disability employment quota in the public and private sector; (4) lack of accessible workplaces; (5) low awareness among employers of tax benefits and preferences provided by the state for employment of persons with disabilities; and (6) labor legislation that is overdemanding with the employers' obligations.

The following key elements must be ensured for equal access to the open labor market of persons with disabilities:

- Reform the system of disability assessment to ensure persons with disabilities have sustainable access to the open labor market.
- Strengthen legal protection and awareness of labor rights and the prohibition of discrimination based on disability.
- · Monitor and enforce disability employment quotas.
- Encourage employers to provide accessibility and inclusion in the workplace, by raising their awareness of state-provided incentives.

Reform the system of disability assessment to ensure persons with disabilities have sustainable access to the open labor market

In Uzbekistan, the disability commissions assess not only disability level, but also the capacity to work. Disability assessment commissions, called Medical Labor Expert Commissions (VTEK), determine the presence of physical or mental disabilities, as well as a person's suitability for work. The VTEK's examination contains "medical-expert," "professional and labor," and "social-expert" recommendations that can negatively impact the already meager employment chances of persons with disabilities. Depending on the degree of disability, VTEK commissions rate employability from the extreme verdict of "unfit for work," "can work in specially created conditions," to "can carry out certain types of work," or "fit to work." Moreover, although VTEKs are expected to indicate the degree of loss of professional ability to work in percentage terms based on the established procedures for disability assessment, in many cases, this column on the certificate of disability is filled in as "unfit for work," and in some cases left completely blank. 134

¹³³ The wording of the certificate is not standardized by law, so it varies. Example of a more elaborate formulation: "The state of health impedes the performance of professional duties or threatens the health and safety of the disabled person or other persons."

¹³⁴ UN 2019b, 148-149.

On assessment of persons being unfit for work

"In 95–98 percent of cases, the VTEK commissions write "unemployable" on the disability certificate of persons with Down Syndrome. When our children transition to adulthood, VTEK gives a disability status of group II with no expiration date of this label "unfit for work." This deprives them of the right to formal work. VTEK should apply the ICF." (Mother of a young person with Down Syndrome)

"There are many more employable persons with disabilities than the 162,200 people announced by the Ministry [of Employment and Labor Relations of Uzbekistan]. Most persons with disabilities can be employed if accessible working conditions are created for them. It is necessary to carry out a separate record of persons with disabilities to ensure their employment and systematic monitoring, as well as to protect and support their labor rights." (Representative of the Association of Persons with Disabilities of Uzbekistan)

"When I was at the Employment Support Center, they told me as an argument that I should not work, because the state gives me a disability pension and because of this, the VTEK certificate says 'It is not recommended to work." (Person with disabilities)

Source: Qualitative research or interviews carried out for the article: Dilmurad Yusupov, "Where are our workplaces?" December 3, 2019. See: https://www.gazeta.uz/ru/2019/12/03/workplace/.

Most disability certificates are issued with a resolution that does not favor employability. According to data provided by Uzbekistan's MEPR, in 2019, out of more than 630,000

registered persons with disabilities older than 18,135 only 162,200 people (26 percent) are "able to perform certain types of work activities." 136 This estimate is based on the administrative registries of VTEK commissions. Wrong assessment may affect the employability of all persons with disabilities of working age, as the assessment conflates disability with an inability to work. This VTEK "recommendation" excludes many persons with disabilities from the labor market. A potential employer, having seen this specification on the disability certificate, will not want to risk hiring a person who is legally found to be unfit for work. Or, they may prefer to hire a person without disabilities, instead of creating "special conditions" for the applicant with disabilities.¹³⁷ In addition, such a record may serve as a legal basis to refuse employment. 2020 data show that most persons with group I and II disabilities (the most severe ones) are evaluated as not being able to work, while only one-third of persons with group III disabilities receive this resolution (see Figure 1).¹³⁸ Administrative data based on the personal tax reference number of 162,200 people recognized as "employable" showed that only 21,100 people (13 percent) were economically active, meaning they were in formal employment. However, this estimate did not include persons with disabilities who were informally employed and therefore not registered with the national tax bodies.

¹³⁵ It is the official number of registered persons with disabilities reported by the MEPR, while the administrative data provided by the Statistics Agency under the Peresident of Uzbekistan might be different. Each government agency might have it is own administrative data on the registered number of persons with disabilities.

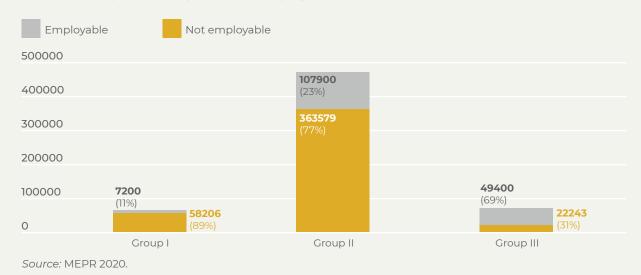
¹³⁶ Ministry of Employment and Poverty Reduction of the Republic of Uzbekistan. Press-release, July 27, 2020. See: https://t.me/mehnatvazirligi/2580.

¹³⁷ Dilmurad Yusupov, "Where are our workplaces?" See: https://www.gazeta.uz/ru/2019/12/03/workplace/.

¹³⁸ The groups are defined as follows: **group 1**, persons who have completely lost the ability to work and need outside help or care; **group 2**, persons who have completely lost the ability to work but do not need outside help or care; and **group 3**, persons who have partially lost the ability to work.

FIGURE 1

Distribution of registered persons with disabilities recognized as employable, by disability group, 2020



The government recently tried to reform the system and introduced a new employment referral system. On March 26, 2020, VTEK commissions offered a band-aid solution to this problem, by adopting recommendations for persons with disabilities on employment, together with the MPH and the MEPR, on the basis of the joint resolution "On approval of regulatory documents for the rational employment of persons with disabilities." VTEK argued that according to an existing Decree, 139 disability group II was recognized as "unfit for work," which was accordingly reflected in the disability certificates. VTEK argued that this information was "advisory in nature and is not a direct contraindication to the employment or rational employment of persons with disabilities."140 To obtain information about their ability to work, persons with disabilities must contact the local VTEK, where they undergo a disability assessment. VTEK then studies the current state of a person's health, inquiries about his/her education, profession, desire to work, ability to practice, and existing working conditions, and makes a referral to the Employment Support Centers (ESCs). In addition, VTEK can provide information on possible work types and conditions based on a letter of request from the employer. In other words, even if a certificate indicates that a person is incapable of work," he or she can contact the relevant VTEK to obtain information about. the ability to work and engage in a particular professional activity.

However, the new system is bureaucratic and denies the inherent right of persons with disabilities to work according to their choice. The new employment referral system is burdensome for persons with disabilities, especially those living in rural areas, who need to obtain another document on top of the existing disability certificate on which the "unfit for work" entry remains unchanged. Therefore, there is a need to reform the system of disability assessment to cease conflating disability with the loss of working capacity.

Persons with disabilities fear losing their disability status and social benefits if they become employed. As VTEK uses the degree of loss of working capacity as a major criterium for disability assessment and determination, disability benefits can be regarded as compensation for being "unfit for work." Therefore, many persons with disabilities who would like to work fear that being reassessed by VTEK may end up reclassifying them from disability group I and II to group III, thus depriving them of the benefit.^{141, 142} Although by law persons with disabilities of groups I and II do not stop receiving a disability pension while working, some still believe that they will stop receiving benefits if they were to take

¹³⁹ Decree of the Cabinet of Ministers of the Republic of Uzbekistan No. 328 of July 17, 1992, before adoption of the Decree of the Cabinet of Ministers No. 175 of August 8, 2008.

[&]quot;How to change the entry 'unfit for work' in the VTEK certificate?" August 5, 2021. See: https://ishplus.uz/news/kak-izmenit-zapis-netrudosposobnyi-v-spravke-vtek-98?lang=ru.

¹⁴¹ UN 2019b, 148-149.

¹⁴² Yusupov and Abdukhalilov 2022.

up formal employment.¹⁴³ From January 1, 2019, all working pensioners are paid a pension in full (pensioners are also understood to be recipients of a disability benefit¹⁴⁴). According to Art. 15 of the law "On state pension provision of citizens," disability pensions are assigned to persons recognized as part of disability groups I and II, in the manner prescribed by law. However, before these amendments were introduced, persons with disabilities were not entitled to receive disability benefits if they were found in formal employment.

Persons with disabilities are not considered unemployed. According to Art. 45 of the law "On employment of the population," persons who are entitled to a pension (regardless of pension type) are not recognized as unemployed. The right to a pension is granted to persons recognized as in disability groups I and II in accordance with the law "On state pension provision of citizens," for persons who are 18 years old and above (children with disabilities up to 18 years old receive disability benefits since childhood). Art. 47 of the same law guarantees financial support for the unemployed – that is, the payment of unemployment benefits; scholarships are paid for vocational training, retraining, or advanced training under the supervision of the labor authorities, and this period is included in the total length of service. In accordance with the above articles, persons recognized as in disability groups I and II are not entitled to receive unemployment benefits as specified in Art. 47.

The lack of robust statistical data on the implementation of activation measures has made it challenging to measure their impact on the employment of persons with disabilities. There is no evidence about unemployment of all persons with disabilities of working age, because no survey or census gathers this data. Thus, there is a need to include questions about disability in the general household survey and, particularly, in the labor force surveys conducted by the MEPR, as government bodies and other stakeholders currently rely only on the administrative data of persons with disabilities who were able to register their disability status at VTEK. The ILO's labor statistics web portal mentions that what was used for the labor force survey conducted in 2000–20 did not include a variable on the "unemployment by sex and disability status". Such data is crucial, among others, for monitoring the country's progress regarding Sustainable Development Goal (SDG) indicator 8.5.2, which focuses on unemployment rate by sex, age, and disability.

Strengthen legal protection and awareness of labor rights and the prohibition of discrimination based on disability

The government of Uzbekistan has made efforts to protect the right to decent work of persons with disabilities. According to Art. 3 of the law "On the rights of persons with disabilities," "discrimination on the basis of disability is any separation, exclusion, restriction due to disability, the purpose or result of which is the denial of recognition or implementation, on an equal basis with others, of the rights and freedoms of persons with disabilities in political, economic, social, cultural, civil or other fields." Arts. 3, 6, and 18 of the law establish the principle of non-discrimination on the basis of disability, according to which any separation, exclusion, restriction, or preference against persons with disabilities, as well as the refusal to create conditions for the access of persons with disabilities to objects and services, is legally considered to be discrimination on the basis of disability, which is prohibited by law. Any measures of positive discrimination, such as special measures aimed at ensuring equal opportunities for persons with disabilities and their inclusion in society and the state, are not considered to discriminate against other citizens.

Persons with disabilities cannot practice their right to non-discrimination in the open labor market on the basis of disability. Despite the adoption of the law "On the rights of

¹⁴³ Yusupov and Abdukhalilov 2022.

Para. 1 of the Decree of the President of the Republic of Uzbekistan "On additional measures to strengthen social support for pensioners and improve the efficiency of the pension system for citizens." According to Art. 3 of the law "On state pensions," the types of state pensions include old age pensions, disability pensions, and survivors' pensions.

¹⁴⁵ International Labor Organization, ILOSTAT, Uzbekistan country profile. See: https://www.ilo.org/dyn/normlex/en/f?p=NORMLEXPUB:11110:0::NO::P11110_COUNTRY_ID.

¹⁴⁶ SDG Indicators: Metadata repository, Goal 8. Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all. See: https://unstats.un.org/sdgs/ metadata/?Text=&Goal=8&Target=8.5.

persons with disabilities," and the introduction of the principle of non-discrimination based on disability, in practice, it is almost impossible to hold employers accountable should they violate the labor rights of persons with disabilities, as there is no administrative or any kind of liability for such offense. Many persons with disabilities lack the legal knowledge and resources to seek justice after experiencing discrimination in the labor market. There is no evidence of the Federation of Trade Unions of Uzbekistan (FTUU) developing any strand of work on representing labor rights of persons with disabilities in the country. As a result, violators remain unpunished for discriminating actions or lack of action to provide equal access to employment. Importantly, such denial contradicts the provisions of Art. 2 of the CRPD and is considered to be discrimination on the basis of disability. The government of Uzbekistan should ensure prohibition of discrimination in all aspects of work, including recruitment processes, work conditions, promotion, and termination of employment. Particular attention should be paid to women with disabilities and those living in rural areas.

Monitor and enforce disability employment quotas

Uzbekistan has legislation about a mandatory disability employment quota. Section 7, Art. 43 of the law "On the rights of persons with disabilities" requires state institutions and private enterprises with 20 employees or more to reserve at least 3 percent of jobs for persons with disabilities. Officials of organizations that do not comply with this quota can be held administratively liable. Failure to fulfill the obligation to allocate quota jobs to persons with disabilities is subject to an administrative penalty that amounts to 10 to 20 basic calculation values – BCV (UZS 2.45–4.9 million), and repeated failure to fulfill the obligation during the indicated year is subject to a subsequent fine of 20 to 30 BCV (UZS 4.9–7.35 million).¹⁴⁷

According to the legislation, there is a mechanism to link employers with persons with disabilities, but the system is not efficient. Each year, both private and public sector enterprises must declare the workplaces they provide for persons with disabilities, and local government (*khokimiyat*) must approve a "list of enterprises and organizations with the minimum number of jobs (in a specified year) for persons in need of social protection, who have difficulty finding a job and cannot compete on equal terms in the labor market", in cooperation with the regional ESCs. According to procedure, persons with disabilities apply to the ESC and are referred to an employer that has secured a quota for persons with disabilities. However, in practice, it seems that many employers are not even aware of the obligations to secure such jobs. Importantly, information about quota jobs is not publicly available and/or published online, so job seekers with disabilities usually struggle to access such information.

BOX 12

On the difficulty of finding employment despite the existence of the quota system

"Many managers are not aware of the existence of the quota, which means that in practice there is no such quota at all. I turned to the ESC to at least be allocated a workplace at a 3 percent quota, but even there they told me that this quota is allocated for street sweepers and welders, and could not be allocated for teachers. Neither the head of District Department of Public Education, nor the Tashkent city department of public education, nor the Ministry of Public Education recognize this quota... There are more than 30 schools in my area, and for more than a year now I can't find a job as a teacher of Uzbek language and literature... Can you tell me how many people can quit their jobs or take maternity leave? I appealed to the district prosecutor's office to bring to administrative responsibility the head of the Mirzo-Ulugbek district department of public education for his refusal to provide me with work. The most interesting thing is that the employees of the district prosecutor's office handed over this case to the ESC, which then referred the case to the Ministry of Preschool and Public Education. In short, they ping-pong me from one authority to another. There is a law, but there is no implementation of it—that's the problem." (Unemployed woman with a disability category II certificate).

Source: Interview carried out for the article: Dilmurad Yusupov, "Where are our workplaces?" - https://www.gazeta.uz/ru/2019/12/03/workplace/.

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¹⁴⁷ Code of the Republic of Uzbekistan "On administrative liability," Arts. 49 and 50.

¹⁴⁸ This list is formed according to Art. 17 of the law "On employment of the population," Art. 43 of the law "On the rights of persons with disabilities," and Decree of the President of the Republic of Uzbekistan dated March 5, 2019 "On ensuring employment of the population in 2019 and creating new jobs," Decision No. PK-4227 on state order. Approved by the decision of the Cabinet of Ministers of the Republic of Uzbekistan No. 965 of December 5, 2017.

There is minimal monitoring and enforcement of mandatory disability employment quotas. It is therefore difficult for the MEPR to assess the efficiency of this policy. A fund to support persons with disabilities¹⁴⁹ was established under the ADMSS,¹⁵⁰ which among others is replenished by 10 percent of the fines imposed for failing to create a minimum number of jobs for persons with disabilities. However, there is no information available regarding the work of this fund or the imposed fines for not fulfilling the disability employment quota.

The State Labor Inspectorate under the MEPR should monitor this process, together with the Tax office under the Ministry of Economy and Finance by developing an automatic process run by the tax authority. If relevant employers do not comply with the 3 percent employment quota, the tax authority should automatically impose a penalty. Based on the data provided by the State Labor Inspectorate, as of 2021, there were 36,765 violations of the law in the field of labor relations and employment, of which 255 cases included violations for not establishing a minimum number of jobs for persons with disabilities, and failure to provide information (concealment) on the readiness of jobs for the employment of persons with disabilities.¹⁵¹ For failing to comply with the district (city) decisions of khokims on establishing the minimum number of jobs for persons with disabilities, 255 employers were fined UZS 643,845,000, and 20 employers were fined UZS 38,395,000, for an unreasonable refusal to accept work for quota jobs. The current enforcement and monitoring system seems to work, but the State Labor Inspectorate lacks capacity in terms of trained staff who could increase coverage of inspections. This can also be achieved by automating the system. The current mechanism is not properly digitalized and is still manual, although the MEPR is currently developing a National Database of Vacancies (NDV)¹⁵² where it is expected to publish quota jobs for persons with disabilities.

Encourage employers to provide accessibility and inclusion in the workplace

There are several incentives for employers to become disability-inclusive:

- According to Art. 337 of the Tax code of the Republic of Uzbekistan, organizations that
 outperformed the 3 percent employment quota are exempt from corporate income tax
 in the amount of 1 percent for each percentage exceeding 3 percent of the quota rate
 for jobs for persons with disabilities. Moreover, taxpayer organizations—such as OPDs, in
 the total number of which persons with disabilities account for at least 50 percent, and
 the wage fund for persons with disabilities is at least 50 percent of the total wage fund—
 are entitled to a 0 percent tax rate.
- In 2020, the government introduced microcredits financed through/by the State Fund for Employment Assistance to enterprises that create jobs for persons with disabilities for up to 25 times the BCV for each job created. In general, not more than 500 times the BCV for 3 years with a 1-year grace period at the main rate of the Central Bank is provided.
- Moreover, state subsidies for adapting workplaces and working conditions to the needs
 of persons with disabilities are provided in the amount of up to 40 times the BCV for
 each adapted workplace. The procedure for allocating such subsidies is developed by
 the MELR. The subsidy is paid to adapt workplaces after workplace assessment for
- 149 This is different from the State Fund for Employment Assistance; it is not clear that the money collected to the fund to support persons with disabilities from fines imposed as a result of non-compliance with the quota mechanism are used for labor market activation measures.
- 150 It currently functions under the Cabinet of Ministers of the Republic of Uzbekistan. Decree of the Cabinet of Ministers of the Republic of Uzbekistan "On the Fund for Support of Persons with Disabilities under the Agency for Development of Medical and Social Services of the Republic of Uzbekistan."
- 151 "Information on the work done by the State Labor Inspectorate of the Ministry of Employment and Labor Relations of the Republic of Uzbekistan in 2020," MELR, February 3, 2021. See: https://mehnat.uz/uz/news/uzbekiston-respublikasi-bandlik-va-mehnat-munosabatlari-vazirligining-davlat-mehnat-inspekciyasi-tomonidan-2020-yil-davomida-amalga-oshirilgan-ishlar-haqida-malumot.
- 152 See: https://ish2.mehnat.uz/vacancies.
- 153 Decree of the President "On additional measures aimed at attracting entrepreneurship, increasing labor activity and vocational training of poor and unemployed citizens, as well as ensuring employment of the population."

persons with disabilities.

- Employers who hire persons with disabilities using the State Fund for Employment Assistance will be given a monthly subsidy of 1.5 times the BCV for each employee, for 6 months.¹⁵⁴
- The amount of social tax employers pay for persons with disabilities is fully refunded from the state budget. 155

However, less than 10 percent of all surveyed employers in Uzbekistan were aware of the benefits and preferences for employing persons with disabilities in 2019. There is a lack of information on the number of companies that receive these benefits and privileges for disability-inclusive employers. Importantly, the role of such benefits in motivating employers to hire persons with disabilities has not yet been evaluated. The MEPR, together with the relevant state agencies and OPDs working in the field of disability-inclusive employment, should conduct research based on qualitative interviews and surveys with employers in both private and public sectors to evaluate the efficiency of the introduced mechanism and policies. There are no guidelines for employers that could explain the benefits and procedural requirements or how to apply for them.

At the same time, labor legislation is overdemanding with employers, which may disincentivize them from recruiting persons with disabilities. Art. 220 of Uzbekistan's Labor Code prescribes working no more than 36 hours per week for disability groups I and II, without salary reduction. They also receive extended paid leave of at least 30 calendar days annually. Moreover, workers from disability groups I and II can be eligible for leave without pay for up to 14 calendar days per year. Employers can hire workers with disabilities for overtime work with the written consent of the worker. VTEK also provides recommendations on part-time work, workload reduction, and other working conditions for persons with disabilities. All the additional costs related to the recruitment and employment of persons with disabilities are to be covered by employers, and thus may act as a disincentive, particularly for employers in the private sector.

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¹⁵⁴ Decree of the President "On additional measures to support persons with disabilities in all sides, support their employment and further increase their social activity."

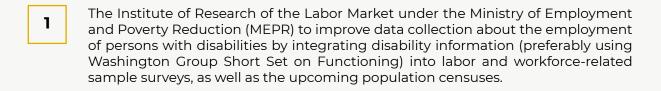
¹⁵⁵ Decree of the President "On additional measures to support persons with disabilities in all sides, support their employment and further increase their social activity."

¹⁵⁶ UN 2019b.

¹⁵⁷ However, persons without disabilities benefit from 24 working days to which non-working days add up, resulting in similar totals of the number of days of paid leave.

Recommended measures

LIMITED ACCESS TO THE OPEN LABOR MARKET



- The MEPR to monitor the effectiveness of the quota mechanism.
- The Medical Labor Expert Commissions (VTEK), as part of the reform of the disability assessment and determination system, to eliminate from the disability certificate the discriminatory qualification "unfit for work" and the percentage of work capacities.
- The government of Uzbekistan to amend the legislation to not consider disability benefits and pensions as compensation for the loss of working capacity, but rather to incentivize persons with disabilities to enter the open labor market.
- The government of Uzbekistan to amend Art. 46 of the Law "On employment" by including persons with disabilities among the groups entitled to the unemployment benefit and legally recognized as unemployed (including those in groups I and II).
- The government of Uzbekistan to raise awareness of the illegality of discrimination based on disability when recruiting or employing persons with disabilities (for example, through public media campaigns that also aim to raise the awareness of persons with disabilities about their labor rights including disability benefits, by publishing accessible guidelines, in partnership with OPDs).
- 7 The Ministry of Justice to introduce administrative liability in the national legislation for employers who discriminate on the basis of disability and penalize those who do not comply according to the Code on Administrative Liabilities.
- The MEPR, Ministry of Economy and Finance to strengthen the Labor Inspectorate's monitoring and enforcement of the 3 percent disability employment quota by developing a monitoring mechanism Monitoring results should be made public each year, to hold employers accountable to their obligations under the law.
- The Employment Support Centers under the MELR to digitalize disability inclusive and disability priority job opportunities provided by public and private enterprises, as new categories of the national recruitment web portal, ish2.mehnat.uz, as well as a specialized online recruitment service, ishplus.uz, for persons with disabilities, in partnership with local OPDs.
- The Employment Support Centers (ESCs), in partnership with OPDs, to raise employers' awareness of state incentives (tax benefits, microcredit, subsidies for adapting workplaces) to become disability-inclusive through developing and disseminating guidelines and carrying on information campaigns for employers.

- The MEPR to reinforce the capacities of the ESCs by recruiting persons with disabilities, in partnership with OPDs, to provide employment promotion services to help other persons with disabilities enter the open labor market.
- ESC staff members and job counselors to be trained to understand disability through the disability rights-based approach embedded in the CRPD.
- The Employment Promotion Fund (under the MEPR) to provide subsidies to adapt workplaces before the work is carried out (rather than after), to facilitate employers' investment in accessibility and inclusion.
- The Institute for Research of the Labor Market (under the MEPR) to evaluate the effectiveness of incentives for employment activation of persons with disabilities and propose a system where the incentives are appropriate and tailored to the needs by type of disability.
- The government of Uzbekistan to revise the incentive system, maintaining the ones deemed as efficient, tailoring them better to the needs of the persons with disabilities by type of disability and funding them from public resources.
- The government of Uzbekistan to build capacity and develop a grievance redressal mechanism for acts of discrimination based on disability in the recruitment processes.
- The government of Uzbekistan to ratify the ILO Convention No. 159 on Vocational Rehabilitation and Employment.

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3.2. Limited access to vocational training programs

Apart from the institutional and legislative barriers to the open labor market, persons with disabilities lack access to quality education, skills development, and vocational training, which further undermines their employment opportunities.



Description of the problem

Working-age persons with disabilities lack enough education to enter the open labor market. In 2020, out of 162,000 people who were recognized by VTEK as "fit to work," only 9,200 had tertiary education (5.7 percent) and 25,300 had secondary special education (15.6 percent), while the rest have no education or only primary and secondary school education. Low quality education provided at segregated specialized boarding schools severely reduces the post-graduation chances of adults with disabilities, due to their limited professional and social skills.

Some specialized vocational training facilities exist, but they are segregated and teach skills that are not relevant to the labor market. After graduating from secondary specialized schools, persons with disabilities have very few vocational training options. There are only four vocational colleges for persons with disabilities in the country, located in Tashkent city, Samarkand, and Fergana regions. In 2021, a total of 768 students from all over the country studied at vocational schools. As shown in Table 7, most of the courses offered at these schools) are out of date and do not meet the demands of the contemporary open labor market. Importantly, these specialized vocational schools are disability-exclusive and represent segregated institutions. The access of persons with disabilities to mainstream vocational training is quite limited, and there is no data on how many access the existing opportunities every year. 159

TABLE 7

List of specialized vocational schools for persons with disabilities, 2021

Region	Name		No. of students	Occupations
Fergana	Specialized vocational school for persons with disabilities in Fergana City	11	185	1. Seamstress
Region				2. Seller-cashier
				3. Shoe repair
				4. Master of radiotelephone communication repair
				5. Master of processing digital information

¹⁵⁸ MEPR Press release, July 27, 2020. See: https://t.me/mehnatvazirligi/2580.

¹⁵⁹ To learn about the access of persons with disabilities to higher education, see the related technical note.

Samarkand	Specialized vocational school for persons with disabilities in Samarkand district	10	235	1. Seamstress
Region				2. Home appliance repair
				3. Shoe repair
				4. Carpenter and master of floor works
				5. Hard- and software setter/tuner
Tashkent	Specialized vocational school for persons with disabilities #1 in Tashkent City	10	161	1. Tele and radio appliance repair
city				2. Home appliance repair
				3. Hard- and software setter/tuner
				4. Hard- and software setter/tuner (blind)
				5. Independent garment sewer
				6. Independent garment sewer (hearing disability)
				7. Shoe maker/repair
				8. Master of textile and clothing
Tashkent	Specialized vocational school for persons with disabilities #2 in Tashkent City	13	197	1. Automobile repair, master mechanic
city				2. Spinner
				3, 4. Seamstress (separate classes for persons with learning/hearing disabilities)
				5. Carpenter and floor master
				6. Pastry cook (cook/confectioner)
				7. Recreation park and landscape park building, master
				8. Master of utilities and housing

Source: Babaev.



Explanation of the problem

The access of persons with disabilities to quality and modern vocational training opportunities can be widened through institutional and legislative reform that aims to develop inclusive vocational training programs adapted to the needs of persons with disabilities and the open labor market. Taking this into account, the following key problems will be discussed in detail:

- Persons with disabilities are enrolled in outdated and low-skilled vocational training programs.
- Mainstream vocational training programs are not accessible or inclusive.

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Persons with disabilities are enrolled in outdated, low-skilled, and segregated vocational training programs

Persons with disabilities only have access to vocational training for low-skilled jobs. The list of eligible professions is legally defined by a 2007 joint decree of relevant government bodies, including the Ministry of Labor and Social Protection of the Population of the Republic of Uzbekistan (currently the Ministry of Employment and Poverty Reduction), the Center for Secondary Specialized and Vocational Education of the Ministry of Higher Education, Science and Innovations, the Ministry of Economy and Finance, and the MPH. This list of outdated and low-skilled professions severely constrains professional choice and reinforces stereotypes.

There is also a list of recommended occupations and positions for persons with disabilities, that guides the work of the VTEK. On March 26, 2020, the MPH and the MELR adopted the resolution, "On approval of the necessary regulations for the rational employment of persons with disabilities." Annex 1 to the resolution provides a "Model List (Classifier) of Recommended Occupations and Positions for Persons with Disabilities." Based on this resolution, VTEK should make recommendations on the vocational guidance of persons with disabilities in accordance with this standard list (classifier) of occupations and positions recommended for persons with disabilities, indicating the types of work, in accordance with the health and capabilities of persons with disabilities.

BOX 1.7

On choosing a profession

"There is a classification of what professions can be mastered by persons based on their disability type. How did the VTEK commission get into a position where it can control what professions persons with disabilities can have? Persons with disabilities should decide for themselves what kind of profession they like, as the potential of every individual is different. Everyone has their own potential. Why do they limit? This is something wrong. Under the CRPD, any person with a disability should have the right and freedom to choose any profession and work. I don't understand why they make such a list." (Mother of a young person with Down Syndrome).

Source: Qualitative research.

In 2022, the government of Uzbekistan approved recommendations to adapt jobs and professions for the activities of persons with disabilities. These recommendations are applied to the labor relations of persons with disabilities working in all organizations. Recommendations are made regarding the equipment of specially created workplaces for persons with disabilities. In particular, it is recommended to equip adapted workplaces for blind people. It was also recommended to provide special workplaces for persons with hearing disabilities with sound-amplifying equipment and loudspeaker phones, taking into account the performed work function. Also, the legal document provides a sample list (classifier) of working professions and service positions recommended for persons with disabilities and a list of professions in which they can work, as well as recommendations on working conditions.¹⁶¹

Existing vocational training schools are segregated institutions that continue the legacy of the Soviet Union. These institutions are closed settings that are outside of the mainstream vocational system. Importantly, even these segregated schools are outside the reach of persons with learning disabilities who receive the special school graduation certificate that prevents one from enrolling in further vocational and tertiary education. In recent years, the specialized vocational schools for persons with disabilities were transferred to the MELR system, and the Ministry intends to repair and re-equip 30 institutions, while maintaining their segregated status of delivering education only for pupils with disabilities. 162

- 160 Decree of the Ministry of Labor and Social Protection of the Population of the Republic of Uzbekistan, the Center for Secondary Specialized and Vocational Education of the Ministry of Higher and Secondary Specialized Education of the Republic of Uzbekistan, the Ministry of Economy of the Republic of Uzbekistan, the Ministry of Public Health of the Republic of Uzbekistan.
- 161 Decree of the Cabinet of Ministers of the Republic of Uzbekistan "On measures to create favorable conditions for the work of persons with disabilities."
- 162 This number includes mono-centers "Ishga marhamat" and specialized vocational colleges for persons with disabilities.

In 2021–25, these training centers are slated to provide vocational training and retraining to 1,000 persons with disabilities every year.

Modern vocational training programs have only recently started being piloted, thus such opportunities are still limited. Since 2020, Ministry of Youth Policy and Sports¹⁶³ and the Educational Center "Najot Ta'lim" have been organizing a project called "Imkon" ("Opportunity") to provide free vocational education to young people with disabilities and teach them modern professions such as web programming, graphic design, motion graphics, social media marketing and digital marketing.¹⁶⁴ This pilot program was adopted by the government and starting from August 1, 2022, 500 young persons with disabilities (aged 14–30) were planned to receive subsidies from the state for up to UZS 15,000,000 to cover the costs of professional training at nongovernment educational institutions.¹⁶⁵ In addition, OPDs are also trying to deliver vocational courses in accounting, computer skills, and more.¹⁶⁶ According to the recent presidential decree,¹⁶⁷ the MEPR shall also organize permanent vocational training courses on professions recommended for persons with disabilities and that are in demand in the Uzbek labor market (e.g., foreign languages, computer literacy, the basics of computer programming, etc.) at the mono-centers "Ishga Markhamat" (Welcome to Work).

The presidential decree from December 22, 2021, aims to provide more vocational training opportunities to persons with disabilities. 169 The Uzbek government has introduced vocational education subsidies (up to 50 times the BCV ≈ US\$1,246) for up to 500 young persons with disabilities, managed by the Ministry of Youth Policy and Sports. These subsidies can be used to cover the costs of vocational training (including living expenses and transportation costs) to study information technologies, computer programming, general education disciplines, and foreign languages at nongovernment educational organizations. The subsidies can also be used to purchase equipment and tools (sewing equipment, computers, tools for craftsmanship, etc.) for those who have successfully completed and have received a special certificate showing vocational training, retraining, advanced training, entrepreneurship, or professional training, or who have registered with the state as an entrepreneur or self-employed person. In addition, 20 young people, selected on a competitive basis, will be financially supported by the El-yurt umidi (Nation's Hope) Fund and the Ministry of Youth Policy and Sports to study in person or online with leading foreign higher educational institutions. The Ministry of Higher Education, Science and Innovations shall organize quarterly short-term vocational training courses for persons with disabilities at vocational schools, colleges, and technical schools in all regions of Uzbekistan.

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¹⁶³ The initiative started with the Agency for Youth Affairs which was established in 2020 and was abolished in December 2022. Since January 1, 2023 the Agency is an integral part of the Ministry of Youth Policy and Sports.

[&]quot;Opportunity" project, Agency of Youth Affairs, April 14, 2021. See: http://yoshlar.gov.uz/en/project/%22imkon%22-lovihasi/.

¹⁶⁵ Decree of the Cabinet of Ministers of the Republic of No. 341, "On approval of administrative regulations for the provision of public services for the social support of youth with disabilities."

¹⁶⁶ See: https://ishplus.uz/courses/18/kurs-obuceniya-sovremennomu-kompyuteru-78; https://ishplus.uz/courses/40/kurs-buxgalterii-96.

¹⁶⁷ Decree of the President of the Republic of Uzbekistan, "On additional measures to provide comprehensive support to persons with disabilities, to promote their employment and further increase their social activity."

¹⁶⁸ Mono-center "Ishga markhamat" is a center under the MELR that provides employment for the unemployed, organizes professional training courses in various areas, and provides social support. Detailed information can be found at: https://mehnat.uz/en/subordinate-organizations/position/248.

¹⁶⁹ Decree of the President of the Republic of Uzbekistan, "On additional measures to provide comprehensive support to persons with disabilities, to promote their employment and further increase their social activity."

Mainstream vocational training programs are not accessible or inclusive

Persons with disabilities are not able to receive scholarships for vocational training, retraining, or advanced training organized by the ESCs at the mono-centers under MEPR because they receive state benefits. Art. 47 of the law "On state pension provision of citizens" implies that persons receiving state benefits are not given scholarships for vocational training. Yet without scholarships, persons with disabilities are unable to access mainstream professional training opportunities. Moreover, it is unclear whether the monocenters have accessible infrastructure, reasonable accommodation, or trained personnel (e.g., personal assistant service, sign language interpreters) to provide quality vocational education to persons with various disabilities.

There is no data for an assessment of employment outcomes of persons with disabilities who studied at national universities on 2 percent admission quota places. In 2022, 960 youths with disabilities graduated from national universities due to a special 2 percent quota for persons with disability groups I and II introduced by the government in 2018. However, there is no evidence of their current employment status and there is no electronic database on their field of specialization.

BOX 14

On the situation of youths with disabilities who graduated from university

"For example, how many are lawyers, how many are accountants, how many are pedagogues or architects, etc. In fact, this database should be formed by the ADMSS. Then they should work together involving the MELR. Because this ministry is responsible for the employment of persons with disabilities. But these two organizations did not act, in my opinion." (Representative of the Association of Persons with Disabilities of Uzbekistan).

Source: Mirolim Isajonov, "There is a distrust of disabled people in state organizations." Hundreds of disabled people who graduated from higher education institutions remain unemployed" See: https://www.gazeta.uz/oz/2022/10/06/nogironlar/.

¹⁷⁰ Dilmurad Yusupov, "Uzbekistan: How to Ensure Higher Education Accessibility for People with Disabilities?" See: https://cabar.asia/en/uzbekistan-how-to-ensure-higher-education-accessibility-for-people-with-disabilities.

Recommended measures

LIMITED ACCESS TO VOCATIONAL TRAINING PROGRAMS

1	The Ministry of Employment and Poverty Reduction (MEPR) and relevant stakeholders to make sure that the vocational training curriculum for persons with disabilities includes modern professions that are required on the labor market and to scrap lists of professions regarded as being suitable for persons with disabilities.
2	The Ministry of Preschool and Public Education (MPSPE) to remove any barriers and limitations created by receiving a certificate of graduation from a special boarding school or homeschooling, in order to enable graduates with disabilities, particularly those with learning disabilities, to continue their education by enrolling in vocational, secondary special, or tertiary education.
3	The MEPR to provide necessary, reasonable accommodation (e.g., tutors for persons with learning disabilities, sign language interpreters for deaf and hard-of-hearing persons), assistive technology and equipment (e.g., Braille displays for blind and visually impaired persons), and adapted curriculum for the training courses in the mono-centers.
4	The government of Uzbekistan to amend the Law "On state pension provision of citizens" to allow persons with disabilities to receive scholarships for vocational irrespective of them receiving state benefits.
5	Vocational educational institutions to offer students with disabilities support provided by occupational therapists, psychologists, sign language interpreters, etc.

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3.3. Limited social and economic security at work

Employed persons with disabilities face social and economic insecurity at work.



Description of the problem

Persons with disabilities are more likely to work in insecure, part-time employment than persons without disabilities. As of 2019, almost half of persons with disabilities (48 percent) worked part-time, e.g., less than eight hours a day, while only a third of persons without disabilities (31 percent) were in part-time employment. 171 Also, is it reported that a considerable share of persons with disabilities is employed in the informal sector, higher than in the case of persons without disabilities. There can be specific risks for persons with disabilities regarding informal employment, such as increased social and economic vulnerability, generally and especially during the COVID-19 pandemic and related quarantine measures. 172

Persons with disabilities have lower salaries than persons without disabilities, regardless of whether they work in formal or informal sectors. A 2019 study¹⁷³ found that the average wage of persons with disabilities in the formal sector is significantly lower than that of persons without disabilities—specifically UZS 612,000 compared to UZS 827,000.¹⁷⁴ In urban areas, formal work pays even less for persons with disabilities as compared to their peers. In the informal sector, the average wage of persons with disabilities is less than half than that of persons without disabilities. Again, the gap is considerably wider in urban areas (see Table 8).

TABLE 8

Average wage of persons with and without disabilities, 2019

	Persons with disabilities	Persons without disabilities	Average wage of persons with disabilities as share of general average wage
Formal employment	612,000	827,000	74.0
Urban areas	557,000	968,000	57.5
Informal employment	365,000	822,000	44.4
Urban areas	441,000	1,120,000	39.4

Source: UN 2019a, 147, authors' calculations.

171 UN 2019b, 147.

172 ILO 2020.

173 UN 2019b, 147.

174 However, the study does not control for the level of education of two groups who are compared, the difference in which could account for the gap in earnings.

Explanation of the problem

Due to institutional, legislative, and attitudinal barriers to formal employment, persons with disabilities must find livelihood opportunities in the informal labor market, which has proved to be difficult, particularly during the COVID-19 pandemic. At the same time, jobs provided by specialized enterprises under OPDs are limited, low-skilled, and underpaid.

Existing barriers to entering the formal sector force persons with disabilities to disproportionately go into informal employment. Notably, many employers prefer recruiting persons with disabilities informally to avoid the burdens associated with their formal employment. Persons with disabilities working informally do not have access to insurance systems, and are more exposed to unfair treatments and harsh working conditions. A 2019 survey offered insight into perceived obstacles preventing persons with disabilities from taking up work or from transitioning from informal to formal employment. Among the reasons for staying in the informal sector that persons with disabilities with informal working experience declared were indifference to the formality of employment (15.1 percent); better employment conditions in the informal sector (7.6 percent); and inability to find a job in the formal sector (21.3 percent). 175, 176

BOX 15

On informal employment

"We have been working on the market for more than eight years. Now we are eight people and all without a workbook. Through the Society of the Deaf, we several times applied in writing to the district khokimiyat and to the tax office to be officially employed in the parking lot. We were ready to pay for the patent and all taxes. But despite all our appeals and letters, no one wants to formalize our work properly," Informal parking attendant at one of the markets of Tashkent." (Informal parking attendant at one of the markets of Tashkent).

Source: Interview for Dilmurad Yusupov, "Deaf parking attendants are in danger!" See: https://www.gazeta.uz/ru/2019/09/27/deaf-parking-attendants/#!

Benefit design and the incentives built into the system should prevent workers from completely cutting off from work after accidents that result in a partial disability. A recent study shows that benefits are not generally designed to absorb shocks and encourage the return to employment of persons with disabilities following a work accident. One of the main disincentives is the loss of benefits upon return. As such, people resort to prolonged sick leaves or use disability pensions and unemployment as a substitute for early retirement.

The COVID-19 pandemic severely impacted persons with disabilities disproportionately employed in the informal sector, as they had no protection against being fired, furloughed, or experiencing wage cuts. The ILO noted that many persons with disabilities already experienced significant exclusion and discrimination in the labor market before the pandemic. It is uzbekistan's general deteriorating socioeconomic situation exposed persons with disabilities to even greater difficulties, as tough quarantine measures introduced by the government in 2020 caused job insecurity. According to the ILO, in the context of the pandemic, the employment of persons with disabilities in the informal sector greatly increased the risk of infection and made them more vulnerable, both health-wise and financially.

Specialized enterprises of OPDs provide a limited number of low-skilled jobs and this outdated system promotes segregation rather than disability-inclusive employment. Data on employment of persons with disabilities at sheltered workshops of major OPDs in 2012 showed that there were about 147 such enterprises across the country, that employed

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¹⁷⁵ UN 2019b.

¹⁷⁶ Additionally, at the time of the study, 7.4 percent of persons with disabilities with informal work experience declared the fear of losing disability status as a reason for choosing/remaining in the informal sector. However, at the time national legislation considered disability pension as incompatible with being employed.

¹⁷⁷ Weiner et al (2017).

¹⁷⁸ ILO 2020.

only 2,290 persons with disabilities, whose share in the total number of employees of these enterprises accounted for 69.3 percent.¹⁷⁹ The sheltered workshops offer low-skilled manual jobs with low wages and adverse working conditions and there is no evidence that they facilitate access to the open labor market. In 2019, the Society of the Deaf of Uzbekistan had 10 such specialized production enterprises across the country, which employed about 250 deaf and hard-of-hearing people.¹⁸⁰ According to the Society of the Deaf, as of 2019, more than 21,600 persons with hearing disabilities were officially registered in the country, including about 5,700 students studying at specialized boarding schools. To date, there are about 10,100 members of the society.

The current sheltered workshops system is inherited from the Soviet era, and it proved unsustainable in the post-Soviet transformation from planned to market economy. During the Soviet era, training and production enterprises (UPPs) under the Society of the Deaf and the Society of the Blind used to employ many persons with hearing and visual disabilities. They functioned thanks to generous subsidies from the communist state and enjoyed a monopoly status to produce certain types of goods, which were then purchased through state orders. However, in the context of the post-Soviet transformation from planned to market economy, these sheltered workshops proved to be uncompetitive due to poor management and lack of transparency. As a result, they drastically reduced scale of output, vocational training, and employment of persons with disabilities. However, even during the Soviet era, this type of segregated employment was accessible only to persons with hearing and visual disabilities, while persons with physical, learning, and mental disabilities were deprived of their right to work and employment, or had to engage in low-skilled, manual labor at home.

BOX 16

On sheltered employment

"I suggest that they apply for a job at our specialized enterprise [UPP]. There are job offers from other companies. They don't agree. Working conditions at enterprises do not suit them: 10–12-hour working day, salary of about UZS 1,000,000. They [deaf parking attendants] have more money in the parking lot. And we can't blame them for that. The man is looking for the best place.

In the Soviet era, up to 450 deaf people used to work at such large enterprises as the Chkalov Tashkent Aviation Production Association; 250 deaf people worked at the Tashselmash plant and about 70 people at the Tashkent tractor plant. Moreover, the Society of the Deaf itself employed 500–700 people at Tashkent UPP No. 1. Deaf workers coming to the capital cities from the rural areas were provided with flats in the organization's dormitories. However, after the collapse of the Soviet Union, many deaf and hard-of-hearing people from rural areas found employment in the informal sector. Now, there are no dormitories for deaf people from districts and villages at regional UPP." (Representative of the Tashkent regional branch of the Society of the Deaf of Uzbekistan).

Source: Interview for Dilmurad Yusupov, "Deaf parking attendants are in danger!" See: https://www.gazeta.uz/ru/2019/09/27/deaf-parking-attendants/#!.

The government of Uzbekistan took a number of measures to support sheltered employment, but this outdated system still promotes segregation rather than disability-inclusive employment. There are several state measures to support specialized training and production enterprises under dominant OPDs:

- Arts. 337 and 467 of the tax code imply that enterprises owned by public associations
 of persons with disabilities, including the Nuroniy Fund, the Chernobyl Association
 of Uzbekistan, and veterans of the war and the labor front of 1941–45, which employs
 persons with disabilities remunerated with not less than 50 percent of the total wage
 fund, are exempt from a single tax payment.
- The Resolution of the President of the Republic of Uzbekistan "On additional state measures to support public associations of persons with disabilities" provides for a number of measures to stimulate enterprises of public associations of persons with disabilities that employ persons with disabilities, which include providing state customers with state orders "for the purchase of goods (works, services) from legal entities, the only participants of which are public associations of persons with disabilities, in the total

¹⁷⁹ UN 2019b.

¹⁸⁰ Dilmurad Yusupov, "Deaf parking attendants are in danger!" See: https://www.gazeta.uz/ru/2019/09/27/deaf-parking-attendants/#l.

- number of which persons with disabilities make up at least 50 percent and the wage fund of persons with disabilities is at least 50 percent of the total wage fund."
- In 2021, through the Decree of the President of the Republic of Uzbekistan "On additional measures to provide comprehensive support to persons with disabilities, to promote their employment and further increase their social activity," government bodies were allowed to enter into contracts with legal entities registered on the portal of the electronic cooperation exchange, including public associations of persons with disabilities where persons with disabilities make up at least 50 percent of the employees and the wage fund of persons with disabilities is at least 50 percent from the general wage fund, signing direct contracts for the purchase of their products. However, the mechanism of mandatory state procurement of the goods and services produced by the specialized enterprises of OPDs is not clear and has not worked properly during the COVID-19 pandemic¹⁸¹ due to OPDs' lack of awareness of such opportunities and their reduced production capacity to fulfill state orders.

BOX 17

On contracting public associations of persons with disabilities

"The problem is that the Ministry of Finance has set quotas for public associations of persons with disabilities, but for unknown reasons, state organizations do not make contracts with our enterprises. The products manufactured by the subsidiary of the Society of the Disabled are essential during the pandemic—these are washing liquids." (Representative of the Association of Persons with Disabilities of Uzbekistan).

Source: Qualitative research.

International organizations like the UNDP tried to promote in Uzbekistan a new type of "social enterprise" linked to OPDs, through pilot projects, but these policy initiatives aimed at establishing social enterprises in keeping with the CRPD vision failed so far, as only one out of five companies transitioned to sustainable business. 182 Such failure can be explained by poor management of the specialized enterprises of OPDs, outdated modes of production that do not allow the production of competitive goods and services, and the low level of organizational transparency, particularly in asset management and the distribution of financial flows (e.g., large concessional loans). As a result, these enterprises turn out to be not profitable and unattractive to persons with disabilities.

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¹⁸¹ Dilmurad Yusupov, "Inclusive employment: what adjustments has the pandemic made?" See: https://www.gazeta.uz/ru/2020/12/03/inclusion/.

¹⁸² UN 2019b, 151.

Recommended measures

LIMITED SOCIAL AND ECONOMIC SECURITY AT WORK

- The Ministry of Employment and Poverty Reduction (MEPR) to provide incentives for sheltered workshops to increase their coverage, to improve their vocational training programs and become transitional workplaces towards the open labor market.
- The MEPR to coordinate a program for business accelerators for entrepreneurs among persons with disabilities, with financial and legal assistance.
- The MEPR to provide more incentives for persons with disabilities and their employers to get out of informal employment via: (1) raising awareness on the benefits of formal employment in terms of access to social insurance systems and protection of the employees' rights; (2) information campaigns for employers on the benefits and preferences in formally employing persons with disabilities; (3) simplifying the registration process of economic activity and making the whole process accessible for persons with various forms of disabilities.



CHAPTER 4

Social protection

Persons with disabilities have the right to access an adequate standard of living for themselves and their families. This includes basic needs such as adequate food, drinking water, clothing, and shelter, as well as continuous improvement of their quality of life. Persons with disabilities need to have access to two types of social protection measures: (1) benefits that cover the extra disability-related costs; 183 and (2) benefits for the general population (mainstream schemes). 184 State parties should take appropriate measures to safeguard and promote the realization of these rights free of discrimination based on disability. 185

The core issues addressed under this sector are:

4.1 $^{-7}$

Inadequacy of existing disability-specific social protection schemes to provide for extra disability-related costs 4.2

Limited access to mainstream poverty

reduction schemes

¹⁸³ Extra disability-related costs relate to the additional income that a person with a disability needs to maintain the same standard of living as a person without a disability (Mitra 2017). Furthermore, persons with disabilities, "in addition to having to spend more to achieve the same standards of living... also tend to earn less income due to barriers in employment and opportunity costs incurred by family members providing support. Together, those additional expenses and forgone income constitute the disability-related costs which prevent them to seize economic opportunities and achieve a similar standard of living and participation" (Mont and Cote, 2020).

¹⁸⁴ Social services are also part of social protection, but they are covered under the sectoral technical brief on social services and independent living.

¹⁸⁵ The vision for ensuring an adequate standard of living and social protection builds on CRPD Art. 28 on "Adequate standard of living and social protection." In addition to this article, the government of Uzbekistan should provide a minimum standard of living and social protection to persons with disabilities under Art. 11 of the International Covenant on Economic, Social, and Cultural Rights, which Uzbekistan joined in 1995. Arts. 22 and 25 of the Universal Declaration of Human Rights of 1948 provide the rights of each member of society to social security and a standard of living adequate for the health and well-being of himself and his family, including the right to security in the event of unemployment, sickness, disability, widowhood, old age, or other lack of livelihood in circumstances beyond one's control.

4.1. Inadequate existing social protection schemes to provide for extra disability-related costs

Persons with disabilities have extra disability-related expenses, on top of already lower incomes. These additional expenses are diverse in nature; they vary by type and level of disability and contextual factors such as the availability of an accessible environment. Moreover, such costs can depend on the person's level of participation. For example, those who commute to the workplace need additional income to ensure access to accessible transportation. However, existing disability benefits in Uzbekistan are limited in coverage and provide inadequate financial support that does not consider differences in type and level of disability.

The coverage of social protection schemes aimed at persons with disabilities in Uzbekistan is limited by how disability is assessed. The disability assessment system is not compliant with the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the International Classification of Functioning, Disability, and Health (ICF) approach to disability. Persons with disabilities face barriers to entering the disability assessment process, which does not respect the dignity, autonomy, and privacy of all persons with disabilities. The system is prone to fraud and corruption, creating additional obstacles and legal challenges to the disability assessment and certification process. As a result, almost half of those who should be eligible for disability benefits are left behind by the social protection system.



Description of the problem

There are three main disability benefits in Uzbekistan: the contributory social insurance disability pension; the disability allowance for persons who have had a disability since childhood; and the disability social pension for those who acquired a disability during their adulthood but do not contribute to the Pension Fund. In 2019, of the 484 thousand registered persons with disabilities receiving one of these benefits, 66 percent received the contributory social insurance disability pension; 30 percent received the disability allowance; and 4 percent accessed the disability social pension.

Disability benefits are currently granted without consideration of differing types and levels of disability, resulting in specific needs not being addressed. Art. 39 of Uzbekistan's constitution requires that pensions, benefits, and other types of social assistance must not be lower than the officially established minimum subsistence levels, and yet disability benefits provide less than minimum wage. Moreover, using official subsistence levels as a minimum does not provide adequate resources to persons with disabilities. Compared with the current average monthly salary in Uzbekistan, disability benefits in Uzbekistan are clearly insufficient to provide appropriate care for a child with a disability who, for example, may require specialized services such as a speech pathologist, technical rehabilitation

¹⁸⁶ Mont et al. 2022.

¹⁸⁷ Ministry of Justice of the Republic of Uzbekistan 2019, see: https://minjust.uz/ru/press-center/news/93693/.

equipment, or needed medicine. Disability benefits are provided to all registered beneficiaries regardless of the type and severity of disability or the level of need to cover basic as well as extra disability-related costs. This one-size-fits-all approach leaves those with severe types of disabilities with their related costs at a significant disadvantage.

BOX 18

Inadequacy of existing disability benefits

"Disability benefits increase every year, but the benefits increase does not lead to an improvement in the situation. Why? Because the pension is increased by 10 percent, and the price of meat is increased by 15 percent. Our financial situation is deteriorating. Our proposal is to link the increase in pensions with the increase in inflation." (Representative of OPD)

Source: Qualitative research.

A minimum consumer spending basket was introduced, but it does not account for extra disability-related costs. Beginning in 2021, the government of Uzbekistan, through the Decree of the Cabinet of Ministers, "On the Enactment of the Procedure for Calculating the Cost of Minimum Consumer Expenses," approved a procedure for calculating the minimum consumer spending basket to use in assessing poverty and as a tool for calculating various social protection benefits. In January 2022, the basket was increased from UZS 440 thousand to UZS 498 thousand per month and the intention is to update it regularly to inflation. However, extra disability-related costs are not included in the calculation.

Not everyone who should receive disability benefits undergoes a disability assessment. Children and adults with disabilities who are not formally registered with the VKK VTEK ¹⁸⁹are ineligible to receive cash transfers, in-kind transfers, or social services. Many children and adults with disabilities are therefore excluded from existing social protection schemes either because they are unaware of their existence or because they face institutional barriers to accessing them. A recent analysis found that, in 2019, the coverage of disability benefits was less than half the total number of persons with disabilities, registered or unregistered.¹⁹⁰ Although the child disability benefit is the key program for supporting children with disabilities, a survey conducted by the World Bank found that the scheme reaches only 52 percent of children with a severe disability. Only 46 percent of children and workingage adults with severe disabilities are able to access disability benefits, with no significant gender gap.¹⁹¹

Persons in disability group III are denied disability benefits irrespective of the individual costs of disability. In accordance with Art. 15 of the law "On State Pension Provision of Citizen" issued in 2011, disability pensions are awarded to those recognized as persons in disability group I or II in accordance with the procedure established by law. The logic behind this reform is not clear, and no rigorous analysis has been carried out to date. However, persons in disability group III still have disability-related needs that incur costs.

Parents and caregivers of persons with disabilities do not receive adequate support. Beginning on March 1, 2019, mothers of persons with congenital disabilities who reach retirement age (60 years old) but who have not contributed to a pension for the required length of time are entitled to social benefits in the amount of UZS 243 thousand.¹⁹³ There is no official data on the number of mothers receiving such benefits, and the focus on this

¹⁸⁸ Statistics Agency under the President of the Republic of Uzbekistan, see: https://t.me/uzstataxborot/28990.

¹⁸⁹ VKK is responsible for conducting disability assessment of children with disabilities under the age of 18, and VTEK conducts disability assessments of adults over the age of 18.

¹⁹⁰ UN 2019a.

¹⁹¹ L2CU household survey in 2018. See L2CU (Listening to the Citizens of Uzbekistan) (dashboard), World Bank, Washington, DC, see: https://www.worldbank.org/en/country/uzbekistan/brief/l2cu.

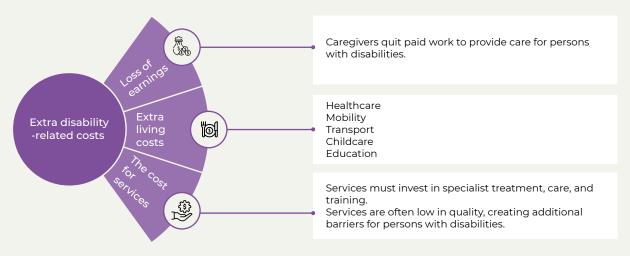
¹⁹² Persons in the disability group 3 with disabilities triggered by the Chernobyl disaster are excepted, according to para. 163 of the Resolution of the Cabinet of Ministers "On approval of regulatory legal acts aimed at further improving the procedure for the appointment and payment of state pensions."

¹⁹³ Decree of the President "On the State Program for the Implementation of the Action Strategy in five priority areas of development of the Republic of Uzbekistan in 2017–2021 in the Year of Active Investments and Social Development," "Mothers of children with disabilities without job experience will receive social benefits."

subgroup neglects mothers of children with acquired disabilities, single fathers, and parents who provide care but have not reached retirement age. On April 1, 2022, a new social benefit was introduced in an amount higher than the minimum consumer spending basket of UZS 500 thousand per month for the caregivers of children with disabilities and certain medical needs requiring constant care. 194,195 The eligibility criteria are defined by a list of diseases that require children to seek outside (specialized) care. The amount of this benefit is slightly above the minimum consumer expenditure basket, which is two times less than the minimum wage (UZS 920 thousand per month), while the average salary in Uzbekistan in 2022 is UZS 2.78 million per month. 196 The coverage of this benefit remains unknown.

FIGURE 2:

Disability-related expenses that might reduce the standard of living of persons with disabilities and their families



Source: UNICEF 2019.



Explanation of the problem

The following key elements will be discussed in detail:

- 1. The need to reform the disability assessment to consider the social, economic and environmental context of the lives of persons with disabilities and their families;
- 2. The importance of increasing investment in the social benefits for persons with disabilities to increase coverage and value of transfers;
- 3. The need to establish a single state body on social protection to avoid fragmentation and increase the effectiveness of social protection support to children and adults with disabilities.

¹⁹⁴ Decree of the President of the Republic of Uzbekistan "On additional measures to support persons with disabilities and categories of the population in need of social protection."

¹⁹⁵ As of January 11, 2022, the minimum consumer expenditure basket is UZS 498 thousand calculated based on the results of surveys conducted in 2021 of 106 thousand households in all regions of the country. As a result of the survey, the minimum food consumption of 2,200 kcal per capita was determined.

¹⁹⁶ As of January 2022, based on data provided by the State Tax Committee of the Republic of Uzbekistan (currently, structural body of the Ministry of Economy and Finance), August 2, 2022, see: https://t.me/soliqnews/8810.

The need to reform disability assessment to consider the social, economic and environmental context of the lives of persons with disabilities and their families

The disability assessment is an important mechanism for providing access to persons with disabilities to the national social protection system. It is a process for making an authoritative determination about the type and severity of a person's disability, which is part of a larger administrative process referred to as *disability determination*. The disability assessment serves as the gateway to the social protection system for persons with disabilities and their caregivers.

Disability assessments in Uzbekistan are still medicalized, reflecting the current definition of disability. The current disability assessment and determination system in Uzbekistan is based on a medical approach consisting of assessments conducted by specialized medical commissions for children and adults with disabilities (VKK¹⁹⁸ and VTEK). This approach is not CRPD-compliant. Considering CRPD, disability assessments should look at disability as functional limitations as well as social-contextual factors based on the humanrights approach to disability assessment. 199 The current approach to disability assessments reflects the actual definition of disability in the legislation, which is not compliant with the CRPD. The previous law "On the social protection of persons with disabilities in the Republic of Uzbekistan" defines a person with disabilities as one "who, due to the limitation of vital functions as a result of physical, mental, psychological and sensor disorders, was recognized as a person with a disability in the order established by the law and is in need of social protection and assistance." The latest legislative developments did not make the shift toward a social, rights-based model of understanding and defining disability. The new law "On the rights of persons with disabilities," which came into force on January 16, 2021, still defines disability in purely medical terms. Disability is conflated with multiple medical conditions and diseases included on the official list of the VTEK, which is responsible for disability assessments and determinations. While impairments and their medical causes are assessed (such as diseases of the blood, the endocrine system, the nervous system, respiratory and oncological diseases) and indicated as "reasons of disability," the interaction of various impairments with environmental factors is not considered, an approach that does not comply with the CRPD's principles and provisions. Persons with one of the 39 approved medical conditions with clearly anatomically visible signs of disability, can receive disability status for an indefinite period.²⁰⁰

Furthermore, the three groups to which persons with disabilities are assigned as a result of disability assessment are not CRPD compliant or in line with other internationally recognized disability analytical frameworks. Many other factors prevent persons with disabilities from working, including but not limited to the lack of accessible infrastructure, stigma, discrimination, and exclusionary policies and norms. During the disability assessment process, persons with disabilities are categorized into three groups based on an evaluation of their capacity to work and the necessary assistance. A disability assessment conducted by the authorized VTEK is required to determine one's eligibility for disability benefits and services. Eligibility for and value of disability benefits are based on a medical examination to determine the severity of the impairment measured against the person's ability to care for themselves (e.g., in terms of personal hygiene), move, orient themselves, communicate,

¹⁹⁷ Bickenbach et al. 2015.

¹⁹⁸ In 2021, the assessment and determination of disability for children was transferred to the Pediatric Medical and Social Expert commissions. Since August 1, 2022, in Tashkent, a new electronic registration and examination information system for persons with disabilities has been introduced and it is foreseen to be extended to all other regions since January 1, 2023. Currently, 130 medical and social expert commissions are operating. Of these, 14 are regional, 83 are district, 14 are specialized (4 are psychiatrics and pulmonology, and 10 are psychiatry), and 19 are pediatric medical and social expert commissions. Two commissions function in each of the regions of the Republic of Karakalpakstan, Andijan, Kashkadarya, Samarkand and Fergana, and one in Tashkent.

¹⁹⁹ Waddington and Priestley 2020.

²⁰⁰ Decree of the President of the Republic of Uzbekistan "On the activities of the medical and social expertise service and measures to further improve the system of determining children's disabilities." As a 2019 analysis of the Ministry of Justice and Ministry of Public Health reveals, due to the lack of coordinated VTEK activities, those with conditions that are not expected to improve over time, such as cerebral palsy, and amputation of the arms or legs, were usually assessed several times over many years.

control their behavior, learn, and work.²⁰¹ The disability groups are: (1) group I, persons who have completely lost the ability to work and need outside help or care; (2) group II, persons who have completely lost the ability to work but do not need outside help or care; (3) group III, persons who have partially lost the ability to work.²⁰² Primary human capacities for self-care, mobility, orientation, communication, behavior control, learning, and working abilities are also categorized as three degrees of severity of restrictions, with the lower degrees indicating less severe restrictions.

TABLE 9

Criteria for disability group assignment

Primary human activities	Group 1	Group 2	Group 3
Self-care	Severity degree 3	Severity degree 2	Severity degree 1
Mobility	Severity degree 3	Severity degree 2	Severity degree 1
Orientation	Severity degree 3	Severity degree 2	Severity degree 1
Communication	Severity degree 3	Severity degree 2	Severity degree 1
Behavior control	Severity degree 3	Severity degree 2	Severity degree 1
Learning	-	Severity degrees 2 and 3	Severity degree 1
Working	-	Severity degrees 2 and 3	-

Source: Resolution of the Cabinet of Ministers of the Republic of Uzbekistan No. 195 "On the approval of regulatory legal acts aimed for further improvement of the procedure for certification of citizens, the establishment of disability and the degree of loss of working capacity by a medical occupational expert commission."

The government of Uzbekistan has approved the concept of gradual transition from the traditional "medical" disability assessment model to the modern "social" model, to be piloted by 2026.²⁰³ The new model requires the ADMSS to work with relevant government bodies to develop a draft presidential resolution.²⁰⁴ Relatedly, the draft Decree of the President of the Republic of Uzbekistan "On measures to further improve the medical and social services provided to the elderly and persons with disabilities" has been developed, and the concept for the "Gradual transition to the social model of determining disability in the Republic of Uzbekistan" is expected to be approved in the decree's first appendix. ²⁰⁵ The document outlines how the "social model" of disability assessments will be gradually introduced in the Syrdarya region beginning January 1, 2025, and in other regions beginning in 2026.²⁰⁶

A person undergoing a disability assessment faces administrative, financial, and accessibility barriers. There are major concerns regarding the current disability assessment and determination procedures:

²⁰¹ Aliev 2017, 201.

²⁰² According to the registration of documents for disability determination, see the single portal of interactive government services, Life Situations, Social protection for persons with disabilities, see: https://my.gov.uz/ru/life-situations/10.

²⁰³ The concept is designed for 2022-2026 and will be implemented in two stages: (1) 2022-2024: based on international experience, legislation and other regulatory legal documents related to the field, necessary methodological, informational, and training materials will be developed, and field workers will be trained; (2) 2024-2026: an inventory will be made of favorable conditions that need to be created for the free movement and employment of persons with disabilities in all regions of the republic, as well as accessibility facilities for receiving and conveying information, public transport, social and other infrastructure objects.

²⁰⁴ Decree of the President of the Republic of Uzbekistan "On the approval of the strategy for social protection of the population of the Republic of Uzbekistan," Appendix 3, Clause 2.

²⁰⁵ Press release of the ADMSS, August 30, 2022. See: https://telegra.ph/%D0%8Ezbekiston-Nogironlar-associaciyasi-ra%D2%B3bari-Olsakovning-08-30.

²⁰⁶ The correlation between the reform of the social protection system for the elderly and the one for persons with disabilities is one critical area that has to be considered as part of the reform, in order to ensure that adverse consequences are prevented, for example, overburdening the disability system with more generous benefits and fewer obstacles for access.

- Almost half (42 percent) of persons with disabilities and parents/guardians of children with disabilities rate the disability assessment procedures as "difficult" or "very difficult."²⁰⁷
- Nearly a quarter of all persons with disabilities and a third of persons with children with disabilities claim that the disability assessment is "expensive" or "too expensive."²⁰⁸ Even though there is no formal payment required, expenses for such items as transportation, document collection,²⁰⁹ and informal payments result in an actual cost exceeding UZS 1 million.²¹⁰ Such costs are also associated with the VTEK requirements to receive inpatient medical treatment as a formal requirement of the disability assessment.²¹¹
- The VTEK premises, where disability assessments are conducted, are often not accessible to those with reduced mobility or to those with hearing and visual disabilities.²¹²
- Because of the lack of doctors, including neurologists, oculists, and surgeons, in medical institutions, an insufficient number of staff units, and irregular working hours, persons with disabilities spend an average of eight to 10 days filling out a medical certificate of referral,²¹³ the basis for the initial examination by VTEK.²¹⁴

Professionals conducting disability assessments lack expertise in CRPD, ICF, as well as other more specialized professional skills, such as rehabilitation. The disability assessment is a gateway not only towards social protection benefits, but to other medical, vocational, and social rehabilitation services as well. VTEK has an "electronic program" into which data related to a person's disability is entered within three days of the evaluation and automatically shared with the Pension Fund under the Ministry of Finance, which is responsible for the allocation of social benefits. VTEK specialists also provide recommendations for medical, vocational, and social rehabilitation on the disability certificate, 215 which are then transferred to the Individual Rehabilitation Program. However, because VTEK staff are not usually qualified rehabilitation specialists, their reports are often technically unsound. 216

- 208 There is no data available on the impoverishment effects of disability costs. However, some types of disability might incur health costs as well, and a World Bank analysis shows that 7% of all households are at risk of impoverishment, impoverished or further impoverished as a result of this type of expenditure (World Bank, 2020).
- 209 In order to ensure that the medical documents related to disability are sent electronically to the medical and social expert commissions, relevant work was carried out on the development and introduction of the electronic information system "Medical-social expertise," which has been implemented in Tashkent since August 2022. Chairmen of 176 medical advisory commissions in the system of the General Health Department of Tashkent city and IT operator-nurses were provided with logins and passwords. From January 1, 2023, the electronic information system will be introduced in all regions of the republic. In this regard, on the basis of a schedule approved by the Ministry of Public Health, seminars and trainings are being held in all regions and specialists are being prepared to work in this system.
- 210 World Bank 2020.
- According to the regulations on the procedure for assessing individuals in VTEKs, a person with a long-term disease (except tuberculosis) who remains incapable of working for more than four consecutive months is admitted for an initial disability assessment. The period of compulsory inpatient treatment ranges from 4 to 12 months depending on the nature of the disease. For a preliminary disability assessment, the person must provide a referral from a medical institution with a summary of their medical history, certified by signatures of the attending physician, the department head, the chief physician; the institution's stamp; and an outpatient card. Therefore, those with disabilities and long-term diseases must undergo four to six months of medical treatment, which entails high costs for transportation to the medical facility; treatment; and informal costs, such as bribes to VTEK staff—even though physical, sensory, and learning impairments could be easily identified by a nonexpert. Although primary health care services are officially free of charge, persons with disabilities report that they have to spend about UZS 1.5 million on in-patient treatment to navigate the disability assessment procedures. According to a study by the Ministry of Justice on the practice of determining disability from 2019, see: https://www.minjust.uz/ru/press-center/news/93693/.
- 212 The Association of Persons with Disabilities of Uzbekistan, a cross-disability organization of persons with disabilities that unites 27 organizations from across the country, conducted accessibility monitoring of the buildings where VTEK are located in Tashkent city and Tashkent region. The results show that VTEK premises are inaccessible to persons with disabilities. See https://youtu.be/Ujjs0EdLu4s.
- 213 This medical document is referred to as "Referral for medical and social examination by a medical organization," Form No. 88.
- 214 Ministry of Justice, see https://www.minjust.uz/ru/press-center/news/93693/.
- 215 Based on the order of the Ministry of Finance of the Republic of Uzbekistan "On the approval of the rules for issuing and keeping examination acts in medical and labor expert commissions."
- 216 UN 2019a, 53.

²⁰⁷ UN 2019a, 42-43.

Inspection of the disability assessment system needs strengthening. In 2019, the Ministry of Justice, together with the MPH, analyzed VTEK's activities in the field of disability assessment.²¹⁷ The study revealed several problems contributing to the poor quality of services. Over 300 offenses were identified. To prevent future problems, 50 administrative proposals were made, to ensure that those who committed offenses are held responsible, resulting in 63 persons receiving disciplinary penalties and 5 being held administratively accountable. In 2021, according to the Decree "On measures to further improve the activities of the service of medical and social expertise and the system for establishing the disability of children," the Republican Inspectorate for Medical and Social Expertise and its territorial divisions (the Inspectorate) were transferred to the ADMSS. The Inspectorate and its territorial regional divisions are responsible for the social inspection of Uzbekistan's disability assessment system. However, they are not well-staffed or trained in the CRPD framework.

The importance of increasing investment in the social protection system to support persons with disabilities

The national social protection system for persons with disabilities is not sufficiently funded. Uzbekistan currently invests 9.7 percent of its gross domestic product (GDP) to sustain its national social protection system, one of the highest rates of public spending among middle-income countries, reaching the share spent in some high-income economies. Child disability benefits account for 0.14 percent of GDP; the disability allowance for adults with disabilities since childhood accounts for 0.22 percent of GDP; the disability social pension accounts for 0.01 percent of GDP; the disability pension accounts for 0.98 percent of GDP; and investment in adult disability benefits accounts for 1.2 percent of GDP, below the high-income country average of 2.1 percent of GDP.

The need to establish a single state body on social protection to avoid fragmentation and increase the effectiveness of support to children and adults with disabilities

There is not a single body that is responsible for social protection in Uzbekistan. Because the social protection system is fragmented across multiple ministries and departments, none of which is responsible for the coordination, integration, and implementation of a unified state policy,²¹⁹ there is neither a single vision nor a coordinated strategy. While each department has established a vertical organizational structure, horizontal communication between government agencies is lacking, significantly reducing the coverage, quality, and effectiveness of services for children and adults with disabilities.²²⁰ The fragmentation of the social protection system ultimately results in redundancy of functions among different departments, inefficiency of spending, low coverage of social services and benefits, and the lack of a unified database and statistical information on persons with disabilities.

Social protection 83

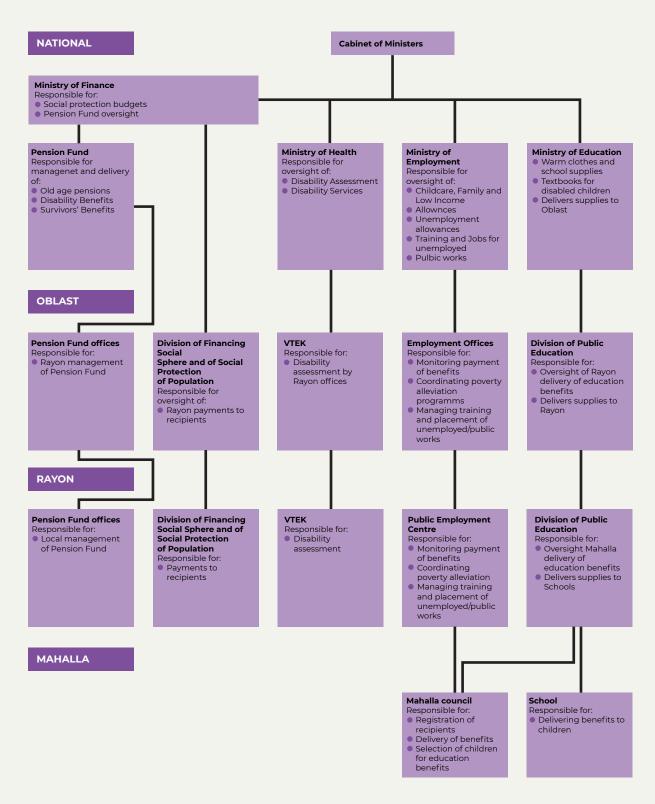
²¹⁷ Ministry of Justice 2019, see: https://www.minjust.uz/ru/press-center/news/93693/.

²¹⁸ UNICEF 2019.

²¹⁹ ILO, UNICEF, and World Bank 2020.

²²⁰ UNPRPD MPTF 2021.

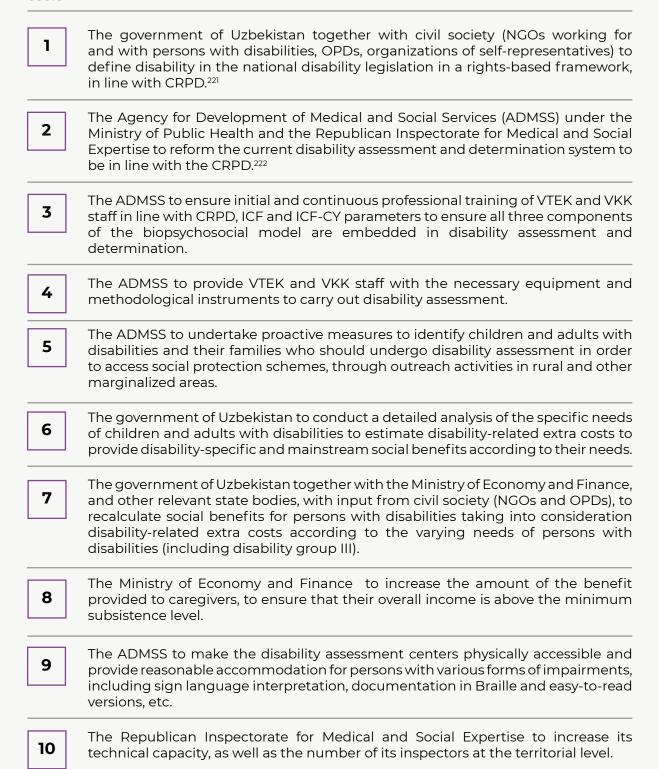
Summary of the main social protection responsibilities of ministries and state entities at the national, regional (oblast), district (rayon), and mahalla levels in Uzbekistan



Source: ILO, UNICEF, and World Bank 2020.

Recommended measures

INADEQUATE EXISTING SOCIAL PROTECTION SCHEMES TO PROVIDE FOR EXTRA DISABILITY-RELATED COSTS



Social protection 85

²²¹ As per the preamble of the CRPD, disability should be legally defined as an evolving concept that "results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others."

²²² The Agency should make a paradigm shift from the impairment and functional limitations approach to disability to a human rights-based and social approach to disability, in line with CRPD.

4.2. Limited access to mainstream poverty reduction schemes

Social protection programs aimed at reducing poverty should be designed, implemented, and monitored in a way that considers the needs of persons with disabilities and their families, who are typically represented in disproportionate numbers among the poor.²²³ There are two main social protection programs aimed at poverty reduction in Uzbekistan, carried out through the Single Registry for Social Protection (SRSP) information system: (1) allowances for families with children under the age of 18;²²⁴ (2) allowances to caregivers with children with disabilities and (3) material assistance to low-income families as well as additional monthly payments to purchase flour and bread. The SRSP was initially piloted in the Syrdarya region in 2019 and by the end of 2020 had been scaled up to include all regions of Uzbekistan. Means-testing is currently done through interconnected database crosschecks. As of March 2022, government bodies in Uzbekistan exchanged real-time data from around 50 administrative databases. The Ministry of Economy and Finance is the sole agency responsible for administering the system. While the SRSP system generates errors as well, and further research is needed in this area, it is still preferable to the alternative currently available, which would be a highly subjective mahalla-level means testing, considering that a professional local social assistance system does not exist. During the past three years of SRSP implementation, over 1.6 million families with children received low-income benefits to overcome the challenges caused by social and economic vulnerabilities, especially during the COVID-19 pandemic.²²⁵



Description of the problem

In Uzbekistan, persons with disabilities and their families are at a higher risk of poverty than others. Persons with disabilities have lower incomes than those without disabilities and face exclusion from the open labor market. The income gap is particularly large for youth in their 20s, as well as for those in their 40s.²²⁶ Their families are also more likely to have lower incomes: the median income per capita for a family with a member with a disability is 18 percent less than that of the average Uzbekistan household.²²⁷ A person with a disability is therefore more likely than a typical peer to experience poverty. The poverty rate among persons with disabilities is 26 percent compared with 21 percent among the general population.²²⁸

²²³ The principles of and provisions for inclusiveness of social protection systems are enshrined in Arts. 19 and 28 of the CRPD.

²²⁴ A monthly allowance of UZS 500 thousand was introduced for the legal representative engaged in the care of children under the age of 18 through the Decree of the President of the Republic of Uzbekistan "On additional measures to support persons with disabilities and the population in need of social protection."

²²⁵ Ministry of Finance administrative data.

²²⁶ Ministry of Finance administrative data. As of 2019, the median per capita household income for persons with disabilities amounted to UZS 234 thousand, compared with UZS 283 thousand for persons without disabilities. For the 20–24 age group, the median monthly per capita household income for persons without disabilities is about UZS 320 thousand, while the same income for persons with disabilities was only about UZS 180 thousand. The gap is also particularly large in the 45–49 age group.

²²⁷ UNICEF 2019, 18.

²²⁸ UNICEF 2019, 18. The poverty rate of 21 percent estimated from the L2CU dataset uses a relative poverty threshold of 50 percent of the median income per capita for the entire population. See L2CU (Listening to the Citizens of Uzbekistan) (dashboard), World Bank, Washington, DC, see: https://www.worldbank.org/en/country/uzbekistan/brief/12cu.

Moreover, a recent study found that a household that includes a family member with a disability is twice as likely to experience severe deprivation.²²⁹ After Uzbekistan gained independence, the government began to practice targeted assistance to vulnerable segments of the population (i.e., poverty targeting), leading to a sharp decrease in social benefits coverage.



Explanation of the problem

Considering the problem as described above, the following key elements will be discussed in detail:

- 1. Eligibility criteria for poverty reduction schemes need to be reconsidered; and
- 2. SRSP data should be disaggregated by disability for improved monitoring.

Eligibility criteria for poverty reduction schemes need to be reconsidered

The disability inclusiveness of benefits has increased. However, some eligibility criteria need to be reconsidered, as they might discourage applicants, including persons with disabilities. To be eligible for all three types of low-income benefits household per capita income cannot exceed UZS 440. In 2021, disability benefits were excluded from the calculation, making more families that include persons with a disability eligible. However, the SRSP system can reject an application for other reasons, including if there is a car that was manufactured within the past seven years registered in the name of the applicant or a member of the applicant's household.^{230,231}

SRSP data should be disaggregated by disability for improved monitoring

The SRSP's current monitoring data are not disaggregated by disability. SRSP data should allow reporting on the presence of family members with disabilities, as there is a cell in the dashboard t to track this information. At a minimum, the system should be able to identify which applicants receive pensions and allowances (through verification crosschecks). However, such data is not available. It is, therefore, unclear how many households that include a child and/or adult with disabilities have benefited from the program so far. Such data are essential to identifying instances of discrimination.

²²⁹ UN 2019a. In the report, severe deprivation is defined by households' purchasing power when a household has insufficient funds to buy basic food. Based on the results of the survey conducted in 2019, 14 percent of households with members with disabilities, compared with 6 percent of households without members with disabilities, have insufficient purchasing power to buy basic food.

²³⁰ Decree of the Cabinet of Ministers of the Republic of Uzbekistan "On measures for further improvement of the social protection system of the population and wide implementation of modern information and communication technologies in the field."

²³¹ Due to inaccessible public infrastructure in Uzbekistan, an adapted vehicle is an essential means of mobility, and should not be considered a luxury item. A personal car can therefore be vital to a person with reduced mobility.

Recommended measures

LIMITED ACCESS TO MAINSTREAM POVERTY REDUCTION SCHEMES

1	The Ministry of Economy and Finance of the Republic of Uzbekistan, together with the Agency for Development of Medical and Social Services under the Ministry of Public Health, to make the Single Registry for Social Protection more disability-inclusive by looking at international best practices to avoid unintentional disability bias in application, and, where the case, adjusting the means-testing procedures with respect to the eligibility criteria used, and drop those criteria that might lead
	with respect to the eligibility criteria used, and drop those criteria that might lead
	to exclusion errors, including against households with persons with disabilities.

The Ministry of Economy and Finance to disaggregate data on the recipients of social protection benefits by disability, among other relevant socio-economic and demographic factors.



CHAPTER 5

Social services and independent living

Persons with disabilities have the right to live independently and be included in the community, with the freedom to choose and control their future. They must be able to do this while being supported by accessible general services and specific services centered on their needs. Independent living happens only outside any type of residential care facility, which is characterized by depersonalization, group treatment, isolation and social distance, and lack of control over everyday decisions. This vision of independent living is based on Art. 19 of the CRPD dedicated to "Living independently and being included in the community," one of its widest-ranging and most intersectional articles, that is considered integral to its full implementation.²³²

The core issues addressed under this sector are:

5.1 \nearrow

Institutionalization of persons with disabilities

5.2

7

Lack of access to community-based social services for independent living

²³² CRPD Committee 2017, 1. Other relevant articles relevant to the analysis in this sectoral technical brief include, but are not confined to, Art. 5 on "Equality and non-discrimination", Art. 12 on "Equal recognition before the law", Art. 14 on "Liberty and Security of the Person".

5.1. Institutionalization of persons with disabilities

Institutionalization contradicts Art. 19 of the CRPD and represents a "discriminating practice against persons with disabilities." ²³³ The policies, practices, and beliefs supporting the institutionalization of persons with disabilities in Uzbekistan disregard all fundamental demands of the CRPD. Institutionalization prohibits freedom of choice, independent decision-making, and the right to equally participate in community life. Segregation from society and isolation in an institutional setting cumulatively endanger a person's overall health conditions, learning capacities, and personal development. Furthermore, research finds that there is no strong evidence that community-based models of care are inherently more costly than institutions, once the comparison is made on the basis of comparable needs of residents and levels of quality of care, while the outcomes of community living are much higher. ²³⁴ Additionally, the segregation of persons with disabilities in residential care facilities leaves them behind the global development commitments and agendas. ²³⁵



Description of the problem

Residential institutions are the main social service provided to persons with disabilities in Uzbekistan. At the end of 2021, 35 boarding houses functioned under the ADMSS, with a capacity of 9,789 persons. A total of 9,361 persons with disabilities lived in these boarding houses. The ADMSS structure also includes 11 sanatoriums for the elderly, persons with disabilities, and war and labor veterans. According to the legislation,²³⁶ there are several types of residential houses that host a variety of persons with disabilities selected through their age, gender, group, type and severity of disability, and household situation (whether they live alone or not).

TABLE 10

Residential care institutions by type, capacity and number of beneficiaries, December 2021

	Number	Capacity (persons)	Total no. of residents
"Sakhovat" boarding house elderly and disabled people	for 6	1,205	905
"Muruwat" boarding house women with disabilities	for 10	2,972	2,966
"Muruwat" boarding house men with disabilities	for 11	3,452	3,452
"Muruwat" boarding house children with disabilities	for 7	2,160	2,038
Republican boarding house war and labor veterans	for 1	220	142
Total	35	9,789	9,361

Source: ADMSS..

233 CRPD Committee 2022b.

234 Mansell et al 2007, UNICEF 2021.

235 UN 2019b.

236 The types of social services are regulated by the Presidential decree PQ-5038 from March 25, 2021. The procedures of admission of persons with disabilities to the boarding houses, their rights and obligations, and the types of services provided to the residents of these facilities are governed by Decree of the Cabinet of Ministers "On the Approval of medical-social institutions' charters."

The approach taken in all these facilities is purely medicalized and generates multiple forms of extreme social exclusion. For instance, in the case of children's "Muruvvat," room assignments are made based on labels such as "laying children's groups" or "crawling children's groups," each a clustered group consisting of 5-6 children. Such practice of clustering children with disabilities within the already discriminatory institution reinforces the institutionalized ableism²³⁷ deeply rooted in the social welfare system and its residential institutions, and lacks any consideration of children's choices and preferences. According to ADMSS data, in December 2021, there were 2,160 children with disabilities institutionalized in 7 "Muruvvat" facilities, of which 38 percent living in two "Muruvvat" institutions based in Tashkent city and the remaining 62 percent distributed in 5 out of the 12 regions in the country. Furthermore, human rights advocates and disability rights activists in Uzbekistan have reported the inhumane treatment of persons with disabilities in residential institutions at the hands of institution staff.²³⁸



Explanation of the problem

Deinstitutionalization of children or adults with disabilities is not a national priority recognized by current laws, strategies, or other policy documents. Deinstitutionalization is a political and social process that shifts from institutional care and other isolating and segregating settings to independent living. Effective deinstitutionalization occurs when a person placed in an institution is allowed to become a full citizen and to take control of their life (if necessary, with support). Essential to the process of deinstitutionalization is the provision of affordable and accessible housing in the community, access to public services, personal assistance, and peer support. Deinstitutionalization is also about preventing institutionalization in the future, ensuring that children can grow up with their families and alongside neighbors and friends in the community instead of being segregated in institutional care.²³⁹ Decree of the President of the Republic of Uzbekistan No. 5215/2021 "On measures to introduce a radically updated system of the upbringing of orphans and children left without parental care" promotes the deinstitutionalization of children living in orphanages and supports their biological or foster families to provide them with a welcoming family environment. However, the document does not mention disability, children with disabilities, or "Muruvvat" institutions. The current version of the National Action Plan (NAP) on implementing the CPRD in Uzbekistan through 2025 lacks any deinstitutionalization objectives and measures.

Moreover, considerable investments are still being made to extend or improve residential care infrastructure and staff salaries. For example, between 2017 and 2021, 27 residential care institutions, including "Sakhovat" and "Muruvvat" facilities, have been reconstructed for USZ 267.2 billion, creating or refurbishing 1,327 beds for their residents.²⁴⁰ Furthermore, the wages of employees working in these institutions were raised by between 1.2 times to 2 times, incentivizing job retainment in residential care institutions for persons with disabilities and older people. Additionally, UZS 428 billion will be allocated for the reconstruction, and refurbishment, of 35 residential care institutions during 2021–24.²⁴¹

²³⁷ Turdiev 2022, 176.

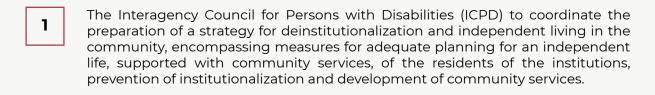
²³⁹ European Network of Independent Living - ENIL, https://enil.eu/independent-living/definitions/

Decree of the President of the Republic of Uzbekistan no. UP-6195/2021 "On Social Support for Elderly and Persons with Disabilities, and Further Development of Internat Homes 'Sakhovat' and 'Muruvvat'."

²⁴¹ It includes the construction of the following new residential care institutions (in addition to the reconstruction of dozens other institutions): (1) additional building for 120 new beds in "Sakhovat" in Namangan city, Namangan region; (2) additional building for 100 new beds and warehouse in men's "Muruvvat" in Qorakul district, Bukhara region; (3) additional building for 100 new beds and warehouse in men's "Muruvvat" in Nurota district, Navoi region; (4) additional building for 300 new beds and facilities in men's "Muruvvat" in Urgut district, Samarkand region; (5) additional building for 300 new beds and facilities in women's "Muruvvat" in the Tashkent region; and (6) new "Muruvvat" for children for 300 new beds in Sharof Rashiov district, Jizzakh region.

Recommended measures

INSTITUTIONALIZATION OF PERSONS WITH DISABILITIES



- The government of Uzbekistan should commit to stop building new institutions, and extend the capacity of existing ones, and shift funding towards deinstitutionalization and developing community services.
- The Agency for Development of Medical and Social Services (ADMSS) under the Ministry of Public Health to commission a comprehensive study on financial, social, and administrative costs of institutional care versus community care.
- The ICPD to facilitate training for decision-makers, persons with disabilities and their representative organizations on independent living and deinstitutionalization in the CRPD framework.
- The ADMSS to review national legislation to identify the legal provisions that conflict with the CRPD's provisions related to the independent living of persons with disabilities in communities on an equal basis with others and address these gaps.

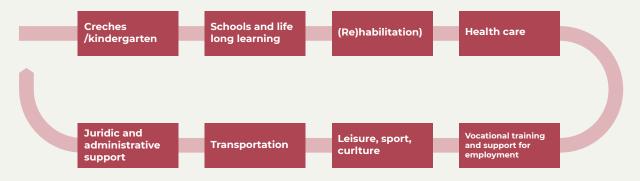
5.2. Lack of access to community-based social services for independent living

The concept of independent living is central to the CRPD. This concept played a key part in drafting Art. 19, which sets out the right of persons with disabilities to choose where, with whom, and how to live. The concept is correlated to that of self-determination, as well as to the fact that persons with disabilities must be in control of their lives and make choices on an equal basis as others.

Independent living is possible through a combination of various environmental and individual factors that allow persons with disabilities to have control over their own lives.²⁴² A wide range of mainstream and specialized support services must be available, accessible, and provided in communities. Independent living requires that the built environment, transport and information are accessible, and that assistive devices, personal assistance, and/or community-based services are available. From birth to old age, persons with disabilities should have the same access, as everybody everyone else, to a broad spectrum of community-based services. These services should be available, accessible, and affordable to all people persons with disabilities, as close as possible to their homes.

FIGURE 4:

The spectrum of mainstream, specific and support services that should be available to persons with disabilities in every community



Most types of community-based services for persons with disabilities are unavailable in Uzbekistan. There are 12 rehabilitation and prosthetic centers for persons with disabilities under the ADMSS, but other types of community services are lacking. The absence of community-based services such as centers for independent living, counseling programs, early intervention services, recovery services, respite services, vocational training, guidance and mediation regarding the labor market, adapted means of transportation, and assisted decision-making services leave persons with disabilities without choice and dependent on institutionalized services.

²⁴² European Network of Independent Living - ENIL, https://enil.eu/independent-living/definitions/

Persons with disabilities are forced to rely exclusively on family members and other informal caregivers for support. Family members or other informal caregivers of persons with disabilities are not adequately incentivized for their work with persons with disabilities.

BOX 19

Typology of the most prevalent community-based support services in countries where the independent living agenda is more advanced

- 1. The first layer of services includes day services that aim to counsel and inform persons with disabilities about their rights, entitlements they might access, and existing services and facilities in their communities.
- Counseling and information services: information on disability, disability-related entitlements, and
 facilities (cash benefits, accessible locations and services, community resources that are accessible to
 all, including persons with disabilities), as well as on relevant social, medical, and support services that
 are active in the region.
- Early diagnostic, early intervention, and lifelong rehabilitation services: these specialized services are often located in the capital city or large municipalities, within hospitals or medical facilities. The most in-demand types of rehabilitation services are physiotherapy (services that develop, maintain, and restore maximum movement and functional abilities throughout life), speech therapy (services addressing speech and/or language disorders),²⁴³ and other therapies for persons with mobility problems (developmental disorders, learning disabilities, including specific therapies for persons with autistic spectrum disorders, etc.).
- Counseling for independent living: this service is usually provided in a daycare facility, for children, youth, or adults. Persons with disabilities learn to progressively control their own lives, manage daily instrumental activities, practice preventative behaviors related to risks, and choose among various community living opportunities. Personal development is also included in this service.
- Support for employment: this service includes vocational training and retraining, job seeking and job
 coaching, as well as post-employment assistance for persons with disabilities. The service is usually
 provided by a multidisciplinary team of social workers, occupational psychologists, and job coaches.
 They provide information and counseling on professional skills and qualifications, assess the professional
 abilities of persons with disabilities, and support these persons as they prepare for employment. For
 some clients, they also provide job seeking and mediation with employers.
- Specialized support for primary caregivers: in many cases, the family members, relatives, or volunteers
 ensure the first line of care and support for persons with high in-home needs. They are called "primary
 caregivers." They assume total responsibility for the dependent persons, assisting them in the execution
 of daily activities and functions. Their role is essential to maintaining the person at home as long as
 possible, with adequate care, in a friendly and supportive environment. To perform their role, primary
 caregivers have to receive financial, psychological, and social support services.
- Peer counseling/support groups for disabled people or family members: the groups of support, consisting
 of peers or friends, volunteers, and neighbors, could offer short-term breaks but also counseling, social
 and practical information, and emotional support that facilitates the delivery of care at home.
- 2. The second layer of services is represented by complex emergency and support activities for persons with disabilities and their families that require overnight stays:
- Respite care and short break services: these help families take a break from the daily routine and its associated stresses. Services can be provided in the client's home or in various out-of-home settings. Respite care is an essential part of the overall support that families may need to keep at home for their child or adult with a disability or chronic illness. Respite care services occur more often after hospitalizations or when the primary caregivers need to rest and recharge for long-term care. It is recommended that a certain number of respite care hours are agreed upon as part of the long-term care for every client. Usually, respite services are attached to medical facilities or rehabilitation centers because they need easy access to emergency equipment. Each respite care service usually has a mobile team.
- 3. A third layer of services is composed of support for inclusion and independent living, that can be provided in various manners, at a specific location or at a person's home.
- Home care (or in-home care and support): a type of support that allows persons with disabilities to stay in their own homes. It is appropriate for persons with disabilities but also for people who are getting older, chronically ill, or recovering from surgery. These services include: (i) personal care or simple assistance with daily activities (such as bathing, dressing, feeding, hydration), and support for instrumental activities (like cooking, housekeeping, shopping, paying bills, representing the person in dealings with contractors, organizing doctor appointments, providing transportation support, arranging for small home repairs, gardening, managing the basic care of domestic animals etc.); (ii) counseling and/or direct support for instrumental activities of daily living (such as housekeeping and managing).

A speech disorder refers to a problem with the actual production of sounds, whereas a language disorder refers to a difficulty understanding or putting words together to communicate ideas.

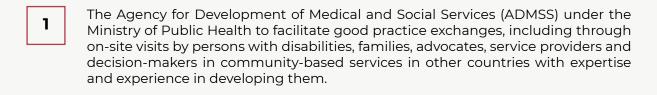
money) over an extended period of time; (iii) health care, including medical procedures and services that require the presence of specialized staff (management of sores, injections, wound treatment, post-surgical care, etc.); (iv) specialized services such as physiotherapy, speech therapy, occupational therapy, home adaptations, etc.

- Provision of assistive technology and equipment: assistive technology is a generic term that includes assistive, adaptive, and rehabilitative devices, as well as the process used to select, locate, and use them.
- Home adaptation services: equipment or arrangements made in the home that allows greater safety or independence to access the home and its facilities.
- Personal assistant services: these represent the most important support service for independent living, in terms of Art. 19 of the CRPD. The typical duties of a personal assistant can be categorized into three areas: (i) support for the mobility of persons with disabilities, such as pushing a wheelchair, guiding someone, assisting with transitions and transfers; (ii) support with domestic tasks, such as cleaning, cooking, laundry, shopping, reading, or note taking; (iii) support for personal care, like dressing, feeding, toilet assistance, etc. In EU Member States, eligibility for personal assistance is partially decided by assessment of needs or is based on an evaluation of disability severity.
- Adapted transportation: accessible fleet of transportation means required by public transportation providers or offered at the level of municipalities.
- Assisted decision-making: a much-needed service for people who have trouble making decisions on their
 own, including persons with intellectual disability, mental illness, acquired brain injury, or age-related
 conditions that affect capacity. The service offers support, through trained professionals or people of
 trust, to explain, accompany, counsel, and otherwise help these persons make decisions that reflect
 their needs and interests. The service is relatively new at the international level, and many countries are
 setting up legislation and procedures for its implementation. This service is connected to the effort to
 eliminate guardianship from the civil codes.
- Interpretation services: interpreters for sign language or tactile communication (in the case of deaf/blind persons) represent one of the main support services for independent living. Sign language interpreters facilitate communication between people who are deaf or hard of hearing and people who can hear.

Source: Author's desk review.

Recommended measures

LACK OF ACCESS TO COMMUNITY-BASED SOCIAL SERVICES FOR INDEPENDENT LIVING



- The ADMSS to coordinate a sound and robust needs assessment of social services performed in all regions.
- The ADMSS to coordinate national-level programs for the development of community services for independent living.
- The ADMSS to organize national-level awareness campaigns on the right to independent living supported by community level service.
- The ADMSS to establish a network of personal assistants at local level.



CHAPTER 6

Education

Children and youth with disabilities have the right to quality and inclusive education in their community at all levels, starting with preschool, continuing through primary and secondary education, and including the possibility of vocational and tertiary education. For these rights to be realized, the development of a functional, inclusive national education system is needed—one that neither excludes nor separates any child from their family but that instead nurtures every child's mental and physical abilities to their fullest potential. Such a system can only be built on an understanding that *disability* is the relationship between a child's health status and his or her environment. It is vital to ensure that educational units include professionals and staff who are well-trained in the field of disability and can provide accessible learning environments equipped with the necessary assistive devices and technologies.²⁴⁴

The core issues addressed under this sector are:



²⁴⁴ The vision and key issues addressed in this technical note are especially based on the following articles of the CRPD: Art. 5 on "Equality and non-discrimination," Art. 9 on "Accessibility," Art. 24 on "Education," Art. 25 on "Health," and Art. 26 on "Habilitation and rehabilitation," as well as on General Comment no. 4 on Art. 24 (CRPD Committee 2016a).

6.1. Limited access to general education

To ensure that children with disabilities have access to quality inclusive education, a national education system with a truly inclusive architecture is needed. Building such a system will require advancing systemic and structural reforms, which will need to be supported and monitored to ensure their full implementation. Children with disabilities should remain with their families, stay in their communities, and learn in mainstream schools alongside other children. Mainstream teachers trained in special and inclusive education, with the help of specialized support staff, must offer their students the chance to learn using adapted strategies, methods, accessible content and inclusive approaches. Learning must take place in an accessible environment and be reasonably adapted to the needs of every child. The goal is to help all students develop to their fullest potential, including learning abilities and skills that they can later use to access vocational or tertiary education or in the labor market.



Description of the problem

The size of the population of school-age children with disabilities is not well known. There are children with disabilities who lack a certificate because no one has requested it or because their type of disability is ineligible; and there are other children with disability certificates who do not have particular needs that require adaptations to the educational environment. The MPH reports that, in 2019, there were 81,007 school-age children (6–15 years) with a disability certificate,²⁴⁵ representing 1.4 percent of the general population in that age group.²⁴⁶

Some school-age children with disabilities are excluded from formal education, while most of those in school learn in non-inclusive settings. One-third of those reported as enrolled in school are registered as homeschooled, two-thirds are schooled in special educational units (most at boarding schools), and very few are integrated into mainstream institutions. According to the Ministry of Preschool and Public Education (MPSPE), during the school year 2021–22, 42,218 children with special educational needs (SEN) were enrolled in the public primary and secondary education system, either in special education or as homeschooled (see Table 11). Notably, 33 percent of the children reported as included in the education system are being homeschooled; 67 percent are in special education—11 percent in day units, and 56 percent at boarding schools. Only very few children with SEN are officially integrated into mainstream education (83 students for the 2021-22 school year). Some children with disabilities are enrolled in the mainstream education system as regular students with no adaptations made for their needs, but there are no estimates as to how many. And because the size of the total population of children with disabilities is unknown, it is difficult to estimate the number of children who are totally excluded from formal education.

²⁴⁵ Age structure of children with disabilities under 16 available at: https://ssv.uz/ru/open_ministry/view/16-eshgacha-blgan-nogiron-bolalarning-esh-tarkibi; World Bank calculations.

²⁴⁶ National statistical data on the distribution of populations of men and women by age group available at: https://gender.stat.uz/uz/asosiy-ko-rsatkichlar/demografiya; World Bank calculations.

Number of children enrolled in the special education system, 2021–22

	Total	Special education		Homeschooling
		Day units	Boarding schools	
Number of children enrolled	42,218	4,572	23,587	14,059
Percentage of children enrolled	100	10.8	55.9	33.3
Number of schools		20	88	
Average number of children per school	_	229	268	

Source: MPSPE, World Bank calculations.



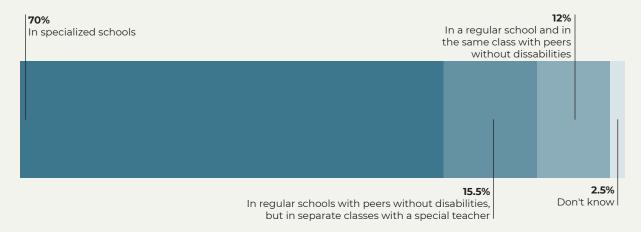
Explanation of the problem

Stereotypes and misconceptions around the best education for children with dis/abilities still prevail in the country. Uzbekistan has inherited a national tradition of educating children with disabilities in segregated institutions, with many placed at a young age in specialized institutions depending on the type and level of disability. For these children, adulthood does not provide an avenue to participate in society; many persons with disabilities either remain in institutional care or are cared for by their families. This approach has affected the public's perception of children with disabilities, an invisible population with whom many are unaccustomed to interacting. This has led to misconceptions and inculcated thinking that children with disabilities, especially those with learning and intellectual disabilities, are "unteachable." The lack of access to inclusive education for children with disabilities has only very recently entered the public discourse; stereotypes and misconceptions about children with disabilities still prevail in the country. These negative attitudes are spread among parents of children without disabilities, creating obstacles to the proper inclusion of children with disabilities in mainstream schools. Teachers' attitudes can also hinder progress toward inclusive education.

According to a 2019 study,²⁴⁷ over two-thirds of the general population think that special schools are the best choice for children with disabilities. According to this study, which included representative samples of households with and without persons with disabilities, almost 70 percent of respondents who did not live with a person with a disability believe that special schools are the best way to educate children with disabilities; only 12 percent of respondents believe that inclusive education—in mainstream schools with peers without disabilities—is best. There is no evidence of an attitudinal change among younger generations since there is not a statistically significant difference in opinion between youth and adults over 30 years; and there is no evidence of a difference in opinion between urban and rural populations.

FIGURE 5:

Views regarding the best way to provide education to children with disabilities, 2019



Source: UN 2019a: 138.

Types of education available to children with disabilities

A network of special education institutions for various disabilities and diseases currently operates in Uzbekistan. There are special boarding schools for children with physical, psycho-emotional, and intellectual disabilities; sanatorium-type boarding schools for children with tuberculosis, bone, and respiratory diseases; and special daycare schools for children with intellectual disabilities (see Table 12). These schools provide the compulsory years of formal education: primary (grades 1–4) and lower secondary (grades 5–9). Only the boarding schools offer upper secondary education (grades 10–11/12—11th grade for the general population and an additional 12th grade for those receiving special education). Children with intellectual disabilities who are studying in special daycare schools are only offered the option of graduating from lower secondary school. Consequently, tertiary education is not available to them. The network of special education units is financed by regional budgets and offers superior material conditions to mainstream schools, including free warm meals and boarding facilities.

TABLE 12

Special education network and student enrollment, 2021–22

	Number of units	Number of students	Percentage of students
Total	108	28,159	100
Special boarding schools	66	17,113	60.8
Children with blindness or visual impairment	14	3,440	12.2
Children with deafness or hearing impairment	18	5,189	18.4
Children with intellectual disabilities	30	7,474	26.5
Children with physical impairment	3	796	2.8
Children with speech disorder	1	214	0.8
Special daycare schools	20	4,572	16.2
Sanatorium-type boarding schools	22	6,474	23.0
Tuberculosis	11	3,168	11.3
Bone disease	10	3,193	11.3
Respiratory disease	1	113	0.4

Source: MPSPE.

The geographic distribution of special schools makes them inaccessible to many children unless they accept the boarding option. Of the 20 special daycare schools, 15 are in and around Tashkent and the Tashkent region; only 5 are situated elsewhere (see Annex-Table 1 in the Annex). Boarding schools are distributed more evenly by region. Still, access remains an issue because they are mainly located in the regions' capital cities and available without the boarding option only to children living in these big cities. Children with disabilities from other regions have no option but to accept boarding schools and only visit their families during holidays.

Homeschooling is a type of social exclusion. A number of 14,059 children with disabilities are registered as being homeschooled. In many cases, a child with SEN may begin in a mainstream school, but when unable to meet the general requirements set for all students, a school council decides that the educational services offered by the school are not suitable for the child and recommends special education (that can be accessed after evaluation by a commission) or homeschooling to the parents. Some parents are unwilling to have their child assessed for special education enrolment because they fear the stigma; some do not accept the commission's decision to assign their child to a boarding school, opting for homeschooling instead. Homeschooling involves the teaching of general subjects outside of school, based on adapted curricula for children with somatic diseases or physical, intellectual, or psycho-emotional disabilities. Teachers from the relevant district's mainstream or special school conduct the lessons. Theoretically, this educational path leaves open the door to higher education, so long as the student passes the national exams. But since the national exams are not adapted to their needs, few children with SEN register for and pass these exams.

The recent wave of educational reforms in Uzbekistan has opened the way for changes that could lead to inclusive education, although some measures still promote segregated education, take a medical approach to disabilities, and do not adhere to adapted teaching methods or curricula. The political will to support inclusive education emerged in 2019, with the first mention of the concept in national legislation during the implementation of the Sustainable Development Goals.²⁴⁸ Inclusive education is mentioned in law no. 637/2020 "On education," but a clear definition is not provided. A dedicated policy package, the Concept for the Development of Inclusive Education 2020–25, including a roadmap and indicators, was approved by presidential decree in 2020.²⁴⁹

BOX 20

Definitions of types of education for children with disabilities

"The Committee highlights the importance of recognizing the differences between exclusion, segregation, integration and inclusion. **Exclusion** occurs when students are directly or indirectly prevented from or denied access to education in any form. **Segregation** occurs when the education of students with disabilities is provided in separate environments designed or used to respond to particular or various impairments, in isolation from students without disabilities. **Integration** is a process of placing persons with disabilities in existing mainstream educational institutions, as long as the former can adjust to the standardized requirements of such institutions. **Inclusion** involves a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences. Placing students with disabilities within mainstream classes without accompanying structural changes to, for example, organization, curriculum and teaching and learning strategies, does not constitute inclusion. Furthermore, integration does not automatically guarantee the transition from segregation to inclusion."

Source: CRPD Committee 2016a.

Mainstream general schools officially opened to children with disabilities in the 2021–22 school year, initially as a limited-scale pilot project promoting both integrated and segregated education. Attempts to support the introduction of inclusive education preceded this moment, financed by international organizations implementing small

²⁴⁸ Decree of the President of Uzbekistan no. 5712/2019 on approval of the Concept for the Development of the Public Education System of the Republic of Uzbekistan until 2030.

²⁴⁹ Decree of the President of Uzbekistan no. 4860/2020 on measures to further improve the system of education and education of children with special educational needs, including the Concept for the Development of Inclusive Education 2020–25.

pilot projects.²⁵⁰ These projects promoted integrated forms of education, ultimately laying the ground for the president's decree that opened mainstream schools to children with disabilities. Two alternatives for special education have been advanced. One admits two children with SEN in one first-grade class in several general schools. The other creates "correctional classes" in selected mainstream schools, each integrating 8–10 children with similar disabilities who are supposed to study separately from their peers without disabilities. During the last school year (2021–22), 83 children with mild and moderate disabilities were enrolled in 46 classes at 31 schools. Additionally, four "correctional classes" were instituted in four mainstream schools, admitting a total of 33 students. The 2022–23 school year proposal would enlarge the project, maintaining the four correctional classes and increasing the number of children enrolled in regular classes to almost 500 (232 classes in 194 schools).

TABLE 13

Children with disabilities enrolled in mainstream education

	2021–22	2022–23
Number of children with disabilities enrolled	83	477
Number of classes	46	232
Number of schools	31	194

Source: MPSPE.

The project limits potential beneficiaries to children with mild and moderate disabilities, excluding from mainstream education those with severe disabilities. Assessments are based on a list issued by the MPH, reflecting the system's medical approach to assessing disability. At the moment, the list includes 39 types of disabilities that, if determined to be moderate, make the child eligible for mainstream education. Children with severe forms of disability such as blindness and deafness, as well as those with disabilities not on the list, such as cerebral palsy and epilepsy, are automatically excluded.

Because the enrollment of children with disabilities in mainstream schools does not attract any assistive resources, nor are teachers adequately trained to address their learning needs, this alternative to segregated education remains so far, the only form of integrated education. Children with disabilities were transferred into mainstream classes without proper preparation of the system. Most teachers and principals in mainstream schools have little to no understanding of educating children with disabilities. The only resource offered to support the inclusion of children with disabilities was a 72-hour online training on inclusive education delivered before the beginning of the school year to teachers involved in the project. Assistive devices are not present in mainstream schools, nor are manuals or other educational materials adapted to the needs of children with disabilities. Given the lack of preparedness among mainstream schools, some parents still opt for special education units for fear their children will face stigma, be bullied by their peers, and be left behind by teachers who cannot address their specific needs. A month after the start of the current school year, just over 20 percent of the target of 500 children with disabilities enrolled in mainstream education had been achieved.

²⁵⁰ UNICEF (2005-06); ADB (2006-09); USAID (2009-10); EU, (2014-16).

On integration of children with disabilities to mainstream education

"My son went to special school last year. We decided to go to special school because I felt that children and teachers in mainstream school may offend my son, may tease him. But when I got the information that an inclusive class had opened in my district, we decided to try. School children were a little aggressive and one teacher didn't pay much attention to what was happening in the class. My son was just sitting in the class because the curriculum was a bit difficult for him and there was no one to help him. After the second semester, we decided to go back to special school. I think our society is not ready to accept children with disabilities." (Mother of child with autism spectrum disorder)

Source: Qualitative research.

The newly introduced correctional classes are organized exclusively for children with SEN and operate in mainstream schools; they are therefore still a form of segregated education. In the 2021–22 school year, four classes were launched in the Bukhara, Khorezm, and Andijan regions, as well as in Karakalpakstan Republic, each with eight to ten children per class, for a total of 33 children. The children are expected to continue through fifth grade in such classes, after which there is not yet a defined path. In schools with correctional classes, interactions between children with disabilities and their peers without disabilities are expected to occur in communal areas during breaks. However, in practice, the special status of these correctional classes and their proximity to regular classes often exacerbates the social exclusion of children with disabilities and discrimination.

Disability certification

The state certifies disabilities in two ways: through commissions subordinate to the MPH and to the Ministry of Preschool and Public Education. Medical-social expert commissions (MSECs) issue disability certificates based on medical documents issued by local polyclinics, which entitle beneficiaries to certain social benefits. Medical-psychological-pedagogical commissions (MPPCs) certify the special educational needs of children with disabilities and serve the legal role of advising children's assignment to mainstream schools, special schools, or homeschooling. Recent reforms have sought to better control the activities of MPPCs. In 2019, their number was reduced from 254 district-level commissions to 14 regional-level ones. This reduction made the commissions less accessible to potential beneficiaries, with the cost of evaluation becoming prohibitive for many families. Notably, MPPC members do not receive remuneration for their work; they are required by law to work pro bono.

While parents officially have the right to choose the type of educational institution most suitable for their children, the MPPCs are actually the primary decision makers. According to the law, the commission's resolution is only consultative, with parents making the final decision but, in reality, most parental decisions ultimately align with the recommendation of the commission, even if there is initially differing opinion. This is partly attributable to the persistence of the old system under which "it is known" that special education is the place for children with disabilities, so some parents do not even question such a recommendation of the commission. Other parents would prefer their child be in a mainstream school, but the school uses its legal power to prohibit the enrollment of children with disabilities.

Both commissions use a medical model of disability,²⁵¹ operating with diagnoses, which has an important influence on the whole approach the system takes to the inclusion of children with disabilities in education. An alternative would be to identify children's characteristics and the barriers they face in their surrounding environments,²⁵² thereby fostering their potential and focusing on removing barriers. From the perspective of the MPPCs, the system can support children by correcting their deficiencies in order to allow them to participate in formal education along with their peers without disabilities. From here arises the orientation of present public policy regarding children with disabilities: that

²⁵¹ The International Statistical Classification of Diseases and Related Health Problems (ICD-10).

²⁵² As they are standardized in the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY).

only those with moderate and mild conditions, which can be corrected, are admitted into mainstream education; those with severe disabilities can only enroll in special education or homeschooling. The current situation of the mainstream system reflects this approach in that it does not offer any adaptations for children with disabilities—they have to meet the same requirements as regular students (with the possibility to be redirected to special education if they cannot meet them), there are no adapted methods and instruments for teaching.

BOX 22

On options for children with disabilities to participate in formal education

"I placed my daughter in mainstream school last year. The school director is a nice person. My daughter finished her first grade, and in the beginning of the second semester I was invited to school and the director informed me that my daughter cannot master the school curriculum and that her grades will affect the teacher's rating.. I was offered homeschooling. The documents for homeschooling are usually issued by the pediatrician of the local polyclinic, who refused to issue such documents because Down Syndrome was not on the list of disabilities of the MPH. So, I was forced to send my daughter to a local boarding school. But I refused, because I didn't want my daughter to be away from our family and insisted to do homeschooling. And what about social adaptation? This is a big question for me." (Mother of child with Down syndrome)

Source: Qualitative research.

Not only does the mainstream system lack adaptations for children with disabilities, but it functions under a paradigm wherein all students must comply with the same requirements. At the moment, mainstream education is available to a limited number of children with disabilities—those whose disabilities are moderate—and only in an integrated alternative. But even though this form of education is legally accessible to these children, many are de facto excluded, a problem exacerbated by secondary legislation. For example, after children with disabilities are enrolled in a mainstream school, a school council responsible for monitoring their performance is formed. Under the supervision of the school principal, the council includes school staff such as deputy directors, teachers of integrated classes, support and medical staff. If the council determines that a child with disabilities is not meeting the educational standards set for all students, the school principal is empowered to send the student to a special school or to be homeschooled, regardless of the MPPC's recommendation. This serves to exclude children with permanent disabilities incompatible with the requirements set for children without disabilities.

Human resources involved in education for children with disabilities

The vast majority of Uzbek teachers are not trained in the field of inclusive and special education, nor do they have any practical experience in teaching children with disabilities. Because the country is just beginning to introduce inclusive education, most teachers are unfamiliar with the concept, many continuing to adhere to the defectology approach, according to which children can attend mainstream classes only if they can cope with the requirement levels set for all students. The concept of inclusive education was not introduced during their initial training. And because there were no children with disabilities in mainstream schools until very recently, teachers lack practical experience in dealing with their special educational requirements. Significant and urgent resource investments are needed to remedy the situation: initial training of teachers must equip them to provide inclusive education and continuous training must compensate for the gap in special educational training for existing personnel.

The topic of inclusive education is only discussed during teacher training at the Master's level, and then only as an elective; most presented content remains under the defectology paradigm. A very limited number of places is available for this Master's program annually (five to eight), and not all graduates get to work as teachers. To properly train teachers, lecture hours must be consistently allocated to special education at universities, allowing teachers to develop competencies in dealing with various types of disabilities. Such lectures must be compulsory and must align with the concept of inclusive

education. Pedagogical practice hours should also give aspiring teachers the opportunity to gain practical experience in teaching children with disabilities. Until the system manages to integrate a sufficient number of children with disabilities into mainstream education, to the point that teaching mainstream schools assumes contact with children with disabilities, practice hours could be divided between mainstream and special schools.

Under the Ministry of Preschool and Public Education, the Laboratory of Inclusive Education was established in 2021, utilizing the existing personnel of the Republican Center for Vocational Guidance and Psychological and Pedagogical Diagnosis of Students. This national resource center is responsible for the development of inclusive education, including providing teacher training in inclusive education and overall assistance to teachers in inclusive schools; however, it still operates under the defectology paradigm. The main goals of the laboratory are to create conditions for inclusive education in secondary schools, to develop criteria for determining the quality and effectiveness of inclusive education, and to monitor their implementation. But even at this level, the approach to disability is in the defectology paradigm, which is of major concern as the laboratory provides training on the newly introduced concept of inclusive education, while in fact it continues to advocate for correcting deficiencies. The laboratory must abandon the defectology paradigm as soon as possible, or most of its efforts will only nurture a system incompatible with inclusive education.

The national system for the continuous training of teachers has been reformed, creating a framework for delivery of inclusive and special educational training, but it still needs to be improved to properly cover these topics. Before this 2021 reform, teachers were required to take continuing education courses every three years. As part of the educational reforms launched in 2019, namely the Concept for the Development of the Public Education System, a learning management system was established, 253 a national knowledge platform that is supposed to constantly update the content of its curricula, in order to reflect modern teaching approaches and changes in educational needs. Another source of training for existing teachers is the Strengthening Practice of Inclusive Education in Uzbekistan project, implemented by Japan's Tsukuba University, with financing from the Japanese government. It aims to train a team of trainers in inclusive education in 2022, including international good practices. The members of the Laboratory of Inclusive Education are among the project beneficiaries. Over the next two years, this team of trainers is expected to provide guidance and facilitate the scaling up of the countrywide implementation of inclusive education.

It is crucial to have well-trained support staff for children with disabilities available in mainstream schools, but such human resources are virtually nonexistent in Uzbek schools. In addition to properly trained mainstream teachers who can adapt their teaching methods and curricula to the needs of students with disabilities, some children with disabilities require the support of other specialized staff to benefit from an effective education. International good practice demonstrates how the participation of a multitude of specialists yields optimal results for inclusive education. Special education teachers can work as counselors at the school level, offering support to mainstream teachers and also delivering one-to-one or group teaching/therapy sessions to children with disabilities. Schools can also use shadow teachers to offer one-to-one assistance to children whose special educational needs require such support. Psychologists/therapists can also contribute to the improvement of educational services. National legislation does not prohibit such specialists in mainstream schools, as there is a provision for their inclusion in a multidisciplinary team, if present, but there still remain very few specialists in Uzbek schools.

The Uzbek school system currently lacks a feasible solution for providing needed support teachers in mainstream schools. According to national legislation, every school is supposed to have one support teacher. At present, these positions are unpaid, and supposed to be filled by pedagogy students during their compulsory practice period. Because such students have limited time, and because they are concentrated in university areas, they lack sufficient availability, and due to their status as students themselves, their tenure in the support teacher role would be brief. There is also a disconnect between the supposed role of a support teacher to offer guidance on educational services for children with disabilities and the lack of experience among those in the role.

²⁵³ The learning management system was established by the Resolution of the Cabinet of Ministers no. 106/021 on measures for the further improvement of the management system of vocational educational institutions, as well as retraining and professional development of pedagogical staff.

Making mainstream schools accessible

Uzbek schools have not been made accessible to persons with physical disabilities in a systematic way. Therefore, children with physical disabilities continue to face challenges in relation to barrier-free environments at school. Most Uzbek schools are not currently accessible to persons with mobility disabilities because they have inherited old architecture and design, and because national scale initiatives and investments aimed at correcting this situation are lacking. The condition of school buildings varies considerably across the country, with rural and remote areas even having problems with basic features such as electricity and heating.

The renovation and reconstruction of Uzbek schools is supposed to take place as part of a national program, but increasing accessibility is not one of the objectives. In 2019, the president launched the Modern Schools program through Resolution no. 4537/2019 on measures for the creation of "modern schools" to develop and enforce compulsory standards for the construction of new schools and the renovation of existing ones. These standards address architectural and construction requirements as well as devices and technologies present in schools for pedagogical purposes. A first step toward building accessible schools does not require major investments. Adding some elements and paying attention to the design of others can make a school's physical environment accessible, including adding ramps and making thresholds, doors, and light switches accessible. But these issues are not addressed in the Modern Schools program, reflecting the lack of political will to make schools accessible to children with disabilities.

Various national policies have as a stated objective to make the national network of mainstream schools inclusive and accessible, but there is a lack of proposed follow-up measures to advance this goal, indicating a lack of political will. For schools to be accessible, it is not enough to address only the physical environment. An inclusive learning environment for children with disabilities includes assistive devices and technologies, computer-based learning programs, Braille and voice technologies, and mobile and adapted furniture—all placed in mainstream schools prepared to include all children. The presidential decree No. 5712/2019 approving the Concept for the Development of the Public Education System includes as an objective that by 2030, all 10,000 mainstream schools will be "inclusive," although its highest priority is to equip special boarding schools with adaptive devices. The Presidential Decree no. 4860/2020 on education for children with disabilities/SEN states that "inclusive education and primary basic correctional classes will be organized in schools equipped with appropriate accessible infrastructure for students," but the law's roadmap in Appendix 2 does not include any measures to ensure that schools are accessible.

BOX 23

On the accessibility of mainstream education

"I graduated from a mainstream school. When I was at school, I couldn't see the board and what was written on it. Also, textbooks' letters were very small, and this created difficulties to read them. I was behind my classmates because no support was provided at school. Now, I have low literacy." (Young girl with visual disability)

Source: Qualitative research.

Financing education for children with disabilities

The allocation of funds for the education of children with disabilities further indicates a lack of political will to advance inclusive education. As noted, important laws and policies have been put into effect in recent years, that can form the basis for inclusive education for children with disabilities in Uzbekistan—all with laudable objectives and some being translated into measures for their realization. However, funds have not been allocated to implement these measures. Examples, as previously noted, include the legal requirement that all schools have support teachers, but unpaid positions are filled by university students as part of their compulsory practice period. MPPCs play a major role in school placement for children with disabilities, but their work is also uncompensated. The Laboratory of Inclusive

Education was established to develop methodologies and instruments for inclusive education and to offer training and guidance to teachers, but no funding has been allocated for its functioning; it only utilizes existing human resources.

There is a discrepancy in financial resources allocated to special versus mainstream schools for equipment and human resources. As previously noted, the present orientation of public policy regarding the education of children with disabilities is to support special education over inclusive education in mainstream schools. Important investments are planned, with some already implemented in special schools. Differences can also be seen in the remuneration of staff intended to work with children with disabilities: a teacher at a special school receives a 100 percent salary bonus plus other benefits, while mainstream teachers only receive a 10 percent bonus for every child with SEN included in their classroom, with a maximum of three children.

Recommended measures

LIMITED ACCESS TO GENERAL EDUCATION

1	The Government of Uzbekistan to develop and approve the law on inclusive education in line with the CRPD, ICF-CY and the Sustainable Development Goals and informed by international good practice.
2	The Government of Uzbekistan to develop a clearly defined inclusive education policy at all levels (preschool, general, and higher) that ensures visionary leadership, improves interagency coordination, and ensures adequate funding, including the salaries, distributed based on a fair allocation formula.
3	The Ministry of Preschool and Public Education (MPSPE) in cooperation with the National Media Company and the Association of Persons with Disabilities of Uzbekistan to initiate and implement a national public information and awareness program on inclusive education and non-discrimination, with activities mainly based in schools, that targets teachers, school principals, parents, children, community members, and other stakeholders.
4	The MPSPE and the state statistics department to develop a functional information management system for data collection on education, including for children with disabilities/SEN.
5	The MPSPE to revise the overall concept of the medical-psychological-pedagogical commissions (MPPC) and the assessment criteria based on the ICF/ICF-CY, and the composition and training programs of specialists included in the commission.
6	The MPSPE to develop a comprehensive teacher-training program (pre- and inservice) on inclusive education using a child-centered paradigm.
7	The Uzbek Agency for Technical Regulation under the Ministry of Investments, Industry and Trade to develop national standards for the accessibility of educational institutions, including universal design principles.
8	The MPSPE to coordinate a national accessibility audit of schools.
9	The MPSPE to revise legislation and policies to provide ample opportunities for parent commissions, including parents of pupils with disabilities, to get involved in the management of schools for ensuring a disability-inclusive education.

6.2. Limited access to preschool education

Formal education offered to preschool-age children with disabilities must be of high quality and inclusive, provided by professionals trained in the field of special education for a multitude of disabilities. In the case of preschool education, this is of extreme importance as it contributes to achieving the provision of the CRPD regarding early identification and intervention.²⁵⁴ Interventions are more successful when properly delivered at a young age, thus maximizing the chance for a child with a disability to benefit from effective formal education at the primary and secondary levels. Furthermore, it is during this early educational stage when competencies for socialization are formed, making it vital that all children are able to interact with peers, including those with disabilities. It is also crucial that the parents of children with disabilities receive guidance and training on dealing with their child's issues, and trained personnel in educational units can provide this role at the school or make referrals to other specialists.



Description of the problem

The number of preschool-age children with disabilities is unknown, but estimates indicate that many do not receive a formal education compared with the general population. Data from the MPH in 2019²⁵⁵ show that 26,154 children ages two to five years had been issued a disability certificate. Of these, only 5,729 are reported as enrolled in special preschool education,²⁵⁶ resulting in an estimated rate of enrollment of preschool-age children with disability certificates in special formal education at 22 percent. By comparison, in 2019, the enrollment rate for preschool education among the general population was about 40 percent.²⁵⁷



Explanation of the problem

The scarce availability of early identification and intervention programs for children is a major concern. Early intervention learning programs for children under three years of age with disabilities are of paramount importance to their further progress into preschool and primary school. Such programs should be delivered in an integrated package that supports families with psychological evaluations and counseling; health services; and habilitation and rehabilitation services such as speech therapy, occupational therapy, or physical therapy. As it stands, scarce rehabilitation services and medical treatments are provided through national programs to preschool-age children in Uzbekistan, through MPH policies. There are also some pilot initiatives trying to bring early childhood education to vulnerable children, one of them being implemented with the collaboration of the Ministry of Preschool and Public Education (MPSPE) (see Box 24). It is crucially important to work with the families of infants, toddlers, children, and youth with disabilities at the earliest stage possible. Helping parents effectively participate in their children's education and development is vital to their futures. Partnering with professionals and policy makers to improve outcomes for all children with disabilities can improve the country's educational services.

- 254 Early identification and intervention require strong cooperation between health care, social protection and education systems; for discussions on early intervention from the perspective of the health care and social protection systems, please see the respective sectors.
- 255 Age composition of children with disabilities under 16, available at https://ssv.uz/ru/open_ministry/view/16-eshgan-nogiron-bolalarning-esh-tarkib; World Bank calculations.
- 256 Transmonee data available at https://transmonee.org/country/uzbekistan/
- 257 National statistical data on the distribution of men and women populations, by age groups, and on the number of children in preschool education, available at https://gender.stat.uz/uz/asosiy-ko-rsatkichlar/ demografiya, World Bank calculations.

BOX 24

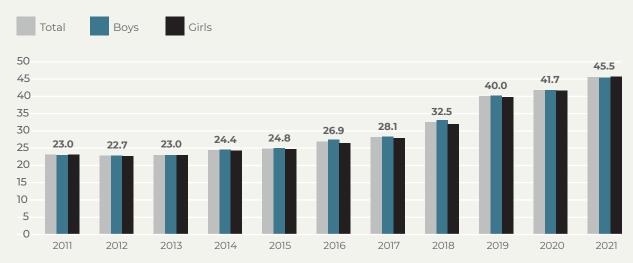
An alternative to formal preschool education, for vulnerable children

Starting with the year 2021, MPSPE (before 2023, pre-school was separate ministry), with World Bank support, launched two pilot early learning HUBs, in Samarkand and Namangan regions. These are centered in pedagogical colleges, being comprised of teams of specialists employed by the Ministry, who deliver three services ((i) a home visiting program, (ii) an early learning playgroup, and (iii) a home-based program for children with development delays and special needs. The beneficiaries are selected through the local mahallas from those that are not yet reached by public preschool services. Besides offering educational services to children, the HUBs also provide counseling for parents, some health services, social protection, parenting workshops, and family events to the families of their beneficiaries. They are evaluated as models of good practice, yet there are still efforts to be made in order to institutionalize a model of good practice and not rely on the exceptional implication of local staff.

The Uzbek national preschool education system has grown considerably in recent years. It is part of a set of ongoing reforms that have put preschool education for children with disabilities on the public's agenda. The youngest age for admission in the preschool system is 2 years; kindergartens offer education to children until the age of 6. Until recently, only a small number of preschool-age children were engaged in formal education. In 2011, fewer than one in four children were enrolled in a preschool educational institution. Figure 6 illustrates the growth in the percentage of children enrolled in preschool education over the past 10 years. The growing attention of national policy makers to the issue of early childhood education resulted in the creation of the MPSE in 2017. In 2019, the state began instituting a series of reforms aimed at creating an inclusive system of preschool education by adopting a legislative and policy package, but some of the measures continue to promote segregation or integration over inclusion.

FIGURE 6:

Percentage of children ages two to five years enrolled in preschool, 2011–21



Source: The Statistics Agency under the President of Uzbekistan data on the distribution of men and women populations by age groups, available at: https://gender.stat.uz/ru/osnovnye-pokazateli/demografiya and on the number of children in preschool education, available at: https://gender.stat.uz/ru/osnovnye-pokazateli/obrazovanie); World Bank calculations.

Traditionally, preschool education was offered to children with disabilities in segregated specialized institutions, which for most of these children has meant institutionalization. Children were enrolled in segregated special kindergartens based on their medical diagnosis, such as speech disorder; musculoskeletal, visual, or hearing impairment; tuberculosis; or

hepatitis. They were segregated both from their peers without disabilities as well as from

²⁵⁸ Law on Preschool Education no. 595/019; Resolution of the Cabinet of Ministers of the Republic of Uzbekistan no. 391/2019.

other children with disabilities of a different type. However, these kindergartens did offer conditions like fewer children per classroom, fewer children per teacher, warm meals, and other supports not catered for in regular mainstream schools.

The 2019 reform proposes a new organization of the preschool system for children with disabilities, maintaining the segregated institutions and piloting new ones, along with introducing a form of segregation within mainstream kindergartens, at a limited number of institutions. At the moment, the available alternatives for preschool education for children with disabilities are all segregated in nature:

- Special multi-profile kindergartens for children with physical, developmental, and intellectual disabilities. These are the old special kindergartens, reorganized to admit children with different disabilities. Children placed in this type of kindergarten are provided with special education teachers who practice the defectologist approach. Groups are small in size—eight to ten children who engage in activities together but who are also offered one-on-one sessions. Individual educational plans are executed along with a curriculum dedicated to special education.
- Mainstream kindergartens with one or two groups of children with disabilities. Legislation refers to these as *inclusive groups*, however, they are segregated groups of children with disabilities integrated into mainstream kindergartens. They are only inclusive in terms of their potential for becoming true inclusive education. Importantly, many kindergartens are not open to the idea of accepting groups of children with disabilities; the scant few per region that do accept such students are referred to as "combined type kindergartens." However, these schools only admit children with mild disabilities and slight developmental delays, as evaluated by the MPPCs. Children with severe disabilities are not eligible for this type of education. In addition, education is not inclusive because no real adaptations are made, institutions are not accessible, support for addressing special educational needs is not provided, and there are no individual educational plans—the educational objectives for children with disabilities are the same as for children without disabilities.
- Special kindergartens with rehabilitation services known as "IMKON", take a multidisciplinary approach to providing medical and pedagogical assistance, with the goal of offering specialized assistance at one institution. The first rehabilitation boarding kindergartens "IMKON" were piloted in Nukus, Karakalpakstan Republic, starting in 2019 and in Kibray, Tashkent region, starting in 2022. Each has the capacity to enroll 150 children with disabilities. Considerable investments have been made in modern equipment and technologies to be used for the rehabilitation services offered to children enrolled in these institutions.

Preschool education is scarcely available to children with sensory disabilities. Most children with visual and hearing disabilities are not in preschool, mainly due to the lack of institutions receiving them. Because there are very few specialists for persons with visual and hearing disabilities available, there are also very few educational units that offer preschool education to children with sensory disabilities. Because these impairments are not considered, the children are ineligible for admission into mainstream education, and only a few primary-level boarding schools offer preschool educational services to this population, and they only serve children older than five.

As a result of recent reforms, both the number of special multi-profile kindergartens and children enrolled in them have been drastically reduced, but there is no record of what happened to children who left the system. One of the aims of the government reforms has been to reduce the number of special multi-age kindergartens, and the total number of institutions has dropped by more than half, from 188 in 2018 to 72 in 2021. The number of children enrolled has dropped even more—from 21,335 in 2018 to 5,729 in 2021. Data presented in Table 14 shows that the number of children with certified disabilities has diminished only slightly, with the reduction resulting from the fact that most children with SEN but without certified disabilities have left the special kindergartens. Interestingly, the reduction by half in the number of schools between 2020 and 2021 resulted in the doubling of the average number of children with certified disabilities per school. This may be indicative of the fact that such schools are these children's only alternative at the moment, and reducing their number only makes them less accessible.

The evolution of the specialized multi-profile kindergarten system, 2018–21

	2018	2019	2020	2021
Number of specialized multi-profile kindergartens	188	149	144	72
Number of children enrolled	21,335	14,183	9,251	5,729
Number of children with certified disabilities		3,043	2,855	2,975
Average number of children enrolled in school	113	95	64	80
Average number of children with certified disabilities in school		20	20	41

Source: Transmonee data available at https://transmonee.org/country/uzbekistan/, World Bank calculations.

MPPCs conduct disability-level assessments to decide whether to admit children with disabilities into formal preschool education; their conclusions take precedence over the opinions of parents. The commissions are organized separately for preschool and general education but operate according to the same principles. Their main evaluation tool is an intelligence quotient (IQ) test given to children based on their age. The notable difference between the commissions is that for preschool education there is only one commission at the national level, conducting regional evaluations. In theory, the commissions aim to conduct two evaluations per month at each regional center, but with only one working team, this is not possible. Children diagnosed with a disability or whose parents or educators suspect that they are experiencing developmental delays are referred to the commission. Often, when the commission's recommendation is to send a child for special education at a boarding school, parents are opposed. Legal provisions asserting the parents as the ultimate decision makers are not observed; the recommendation of the commission is imposed instead. Parents who opt for their child to be placed in mainstream schools despite the MPPC's recommendation of special school are often told that their child's level of development is not suitable for the requirements of mainstream kindergarten. As a result, some parents choose to keep their preschool-age children out of the education system.

It is technically possible but rare for children to be transferred from special to mainstream education based on their performance at the special school. Following the MPPC evaluation, a referral is issued for special or mainstream education for six months to two years. The performance of enrolled children is monitored, and those who make developmental progress, whose existing delays are corrected or made worse can potentially, according to the law, be transferred to a different type of institution. But, in reality, transfers from special to mainstream education are rare and usually attributable to the exceptional involvement of parents, including investments in private therapies.

Curricula in mainstream education has recently been changed to a competence-based model, and while a corresponding curriculum for preschool children with SEN has been developed, it is only used in special education. Part of the national educational reforms involves shifting from a knowledge-based model to a competence-based model for national-level curricula. At the preschool level, the existing Early Learning Development Standards, which have been revised to correspond to the new orientation, include child-centered teaching methods. Subsequently, a new preschool curriculum, "First Step/Ilk Kadam," has been developed in line with these standards. A corresponding curriculum for children with SEN has also been developed, designed to be used only in special education units. It is not intended for all children with SEN enrolled in public kindergartens. This reflects a more general problem for children with SEN enrolled in mainstream kindergartens: requirements have not yet been relaxed for these students, nor are their needs being addressed through adapted teaching methods. Mainstream kindergartens have still not implemented the use of individual educational plans.

MPSE launched an online platform with materials and guidelines for the development of individual learning plans for children with SEN, but the posted resources remain limited and used by a small number of teachers. The platform, "Children's Academy/Bolalik academiyasi," created with the support of UNICEF Uzbekistan, provides resources for teachers, educators, speech therapists, defectologists, and caregivers, to help them develop individual educational plans for children with disabilities. It is based on Learning Passport, a platform developed by UNICEF and powered by Microsoft in response to the COVID-19 crisis. But because the creation of individual learning plans is still not enforced in public education, only a few teachers use these limited resources to improve their performance in relation to children with disabilities.

Most educators are not trained to work with children with disabilities, and the topics of special and inclusive education are at most marginally included in their initial and continuous training. Because policy makers have only recently become interested in inclusive education for children with disabilities, the vast majority of mainstream kindergarten personnel is not trained in special and inclusive education. Their initial training did not cover these topics and, even now, inclusive education is only part of the master's degree curriculum for preschool teachers, and the master's program only graduates about 15 student per year, not all of whom secure jobs in education.

To ensure inclusive learning for children with disabilities, the education system invests primarily in the continuous training of special education teachers, but even for special kindergartens is difficult to provide the needed human resources. In preschool education, special education teachers (defectologists) are provided with a compulsory continuous training course once every three years, consisting of 144 hours of training in three weeks. For the 2020–21 school year, 107 teachers benefitted from this course. But even for the special education institutions, as well as the mainstream ones, there are challenges to recruiting the needed specialists, including a lack of specialists to work with children with visual or hearing disabilities.

Widespread discriminatory attitudes and misconceptions lead to cases of children with disabilities being excluded from mainstream preschool. Policy makers, preschool administrators, teachers, parents, and the general public have low levels of awareness and information about the rights of children with disabilities to access mainstream education, resulting in the marginalization of children with disabilities. Moreover, there is scant understanding of the important role that child-to-child interactions have on child development, whether the children have disabilities or not. Such socialization builds healthy attitudes toward relating to peers, fosters compassion, contributes to a successful and happy adult life. The qualitative research identified cases of children initially integrated into mainstream kindergartens who were later transferred to special education units due to parents of children without disabilities putting pressure on principals because they fear that the children with disabilities will be a bad influence on their own children's cognitive development.

BOX 25

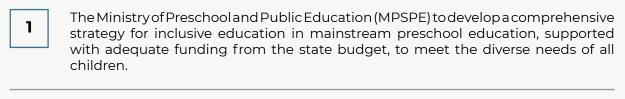
On discriminatory attitudes related to integration of children with disabilities in mainstream kindergartens

"When my son was in kindergarten, I got to know that during classes he was taken for a walk, because he interfered with other children in the group, because he was noisy and maybe didn't understand the teacher's instructions. After a few months, the kindergarten principal asked me to take him to specialized kindergarten because all parents requested that my son not attend this kindergarten. According to them, my son is a bad influence on the behavior of the other children." (Mother of child with autism spectrum disorder)

Source: Qualitative research.

Recommended measures

LIMITED ACCESS TO PRESCHOOL EDUCATION



- MPSPE with the Ministry of Public Health (MPH) to develop an early identification of disability risks and early intervention program for children of ages zero to three that includes medical, social, and educational components.
- The MPSPE and the MPH to develop parent information, training and community resource centers for parents in every region and community.
- The MPSPE to coordinate with pedagogical universities to ensure that inclusive education is a compulsory subject for all teachers.
- The MPSPE to monitor the development and implementation of individual educational programs for children with SEN and/or disabilities through regional and district preschool administrations.
- The MPSPE, in cooperation with nongovernmental organizations, to develop a community awareness and information campaign targeting parents, teachers, and specialists to raise support for an inclusive mainstream preschool education system.

6.3. Limited access to tertiary education

Preparing universities to include students with disability, offering the same opportunities to students regardless of their disability status. The physical environment, information, and communications of tertiary education must be accessible to students with disabilities during the admission process, studies, and evaluations. It is crucial to provide adaptations to the infrastructure and to make available support technologies and personnel so that students with disabilities have the means to achieve an independent and fulfilling life, able to meet the demands of the labor market with abilities and competencies gained through formal education.

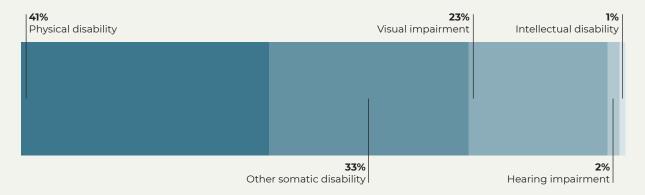


Description of the problem

There are very few students with disabilities enrolled in Uzbek universities, and many children and youth with disabilities do not think it is realistic to attend an institution of higher learning. The Ministry of Higher Education, Science and Innovations (MHESI) reports that for the 2021–22 academic year, 6,321 students with disabilities were pursuing a bachelor's degree, representing a mere 0.8 percent of the total student population of 808,400,259 a very low percentage compared with other countries.260 Most (41 percent) of the students registered as having a disability have a physical disability; only 2 percent have a hearing disability, and only 1 percent have an intellectual disability, indicating that access to tertiary education is even more restricted for these groups (see Figure 7).

FIGURE 7:

Students with disabilities in national universities per type of disability, 2021–22



Source: MHSSE.

²⁵⁹ National statistical data on the number of students in higher education institutions at the beginning of the academic year, available at https://gender.stat.uz/en/main-indicators/education.

²⁶⁰ Hauschildt et al. (2021) indicates that an average of 15 percent of European students reports having a disability, impairment, or long-standing health problem that limits their studies. However, there is little comparability between these figures, as they are administrative data on one hand and self-reported status on the other.

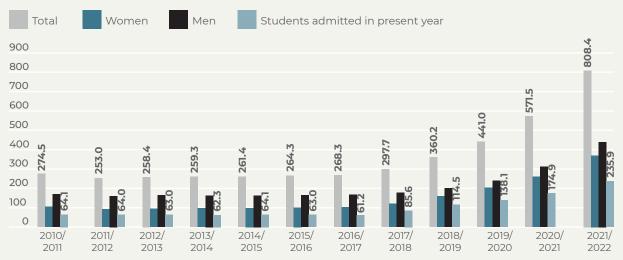
Explanation of the problem

Youth with disabilities have little chance of accessing tertiary education due to their previous exclusion from or poor quality of their secondary education. Some children with disabilities who attend formal education only graduate from lower secondary education, especially those with intellectual disabilities enrolled in special daycare schools, which only offer education through ninth grade, thereby excluding graduates from advancing to tertiary education. Children who do graduate from 11 years of formal education still often face the problem that the level of knowledge acquired during the years in special education is insufficient for attending university.

A series of reforms to higher education aims to increase the number of enrolled students, as well as the share of higher education students in the youth population, but no mention is made of students with disabilities. In 2019, in line with the general reforms to the educational sector, the President approved through Decree no. 5847/2019 the Concept of the Development of a Higher Education System through 2030. The document, which defines strategic goals, priorities, and objectives, as well as medium- and long-term stages of higher education development, is being used as a basis for the development of programs and comprehensive measures in this area. According to this Concept, there is a planned increase in the share of students in the youth population (ages 18 to 30) to 50 percent by 2030.²⁶¹ The number of admitted students has been increasing year on year, steeply increasing in the 2018–19 academic year, as a result the number of students almost tripling in four years (see Figure 8). Even so, admissions to Uzbek universities are highly competitive, with about eight applicants for every available spot. The Concept also seeks to improve the higher education system by enhancing the quality of the learning process, modernizing teaching methods, and introducing information and communications technology to the teaching process. However, the Concept does not provide for equal learning opportunities for youth with disabilities, including by the use of the promoted technologies.

FIGURE 8:

Number of current and admitted students to higher educational institution at the beginning of the academic year, 2010–22 (in thousands)



Source: National statistical data, available at https://gender.stat.uz/ru/osnovnye-pokazateli/obrazovanie.

²⁶¹ An estimation indicates that at present the percentage of youth aged 18–29 years enrolled in tertiary education is around 12 percent (National Statistical data on the number of students in higher education, available at https://gender.stat.uz/ru/osnovnye-pokazateli/obrazovanie, and on the distribution of male and female populations by age group, available at https://gender.stat.uz/uz/asosiy-ko-rsatkichlar/demografiya; World Bank calculations).

Affirmative action measures support the enrollment of youth with disabilities in higher education. As per the Decree of the President of Republic of Uzbekistan no. 5270/2017, from the beginning of the 2018–19 academic year, every university has a 2 percent admissions quota for students with disabilities. Passing grades are reduced by 30 percent for applicants with disabilities, a measure that implies an assumption that youth with disabilities are less prepared than their counterparts. The evaluations are being conducted by a special commission that includes representatives of the higher education institution, the MPH, and nongovernmental organizations for persons with disabilities. This process aligns with the national approach to evaluating disabilities, which is still based on a medical model. Students with disabilities who are admitted based on this process are offered state scholarships for the entire length of their university studies, which only cover tuition —they neither provide compensation for the costs associated with disabilities nor pay for meals and transportation. Notably, the 2 percent quota spots are only available to those with a degree 1 or 2 disability, excluding those with milder conditions (degree 3), among whom are most persons with disabilities who can legally seek employment in the labor market.²⁶²

BOX 26

On barriers to admission in higher education for persons with disabilities

"I had difficulty during admission to the university. I have cerebral palsy and use a walker. I could hardly handle the pen to fill in the testing answers during the examination. In the first year, I couldn't get the appropriate score, although I knew most of the answers. My mother is a lawyer and next academic year she could arrange a personal assistant during the entrance exams. I was able to get a high score and entered the state university." (Student with disabilities)

Source: Qualitative research.

The number of students with disabilities admitted through the quota system has increased by the year, but there are still unfilled slots (see Table 15). Students with disabilities have been admitted to national universities in all available forms of study—full-time, part-time, and evening classes. One estimate indicates that there are many more open slots for students with disabilities, with only two-thirds filled in the 2021—22 academic year. ²⁶³There is probably an insufficient number of applicants due to existing barriers to accessing higher education related to the quality and accessibility of upper secondary education, and current affirmative action measures do not provide sufficient support to students with disabilities in the admission process. For example, it is not enough to lower the passing grade for admission, it is also important to adapt the conditions of the exam to the special needs of persons with disabilities (see Box 26).

²⁶² According to the law, the commissions that certify disability status also evaluate the working capacity of persons with disabilities. Most persons with a degree 1 or 2 disability are not evaluated as having the capacity to work.

During the 2021–22 academic year, 235,900 students have been admitted to national universities. Assuming all available places have been filled, there should have been 4,718 places available for students with disabilities, out of which only 3,155 have been filled.

TABLE 15

Number of students with disabilities admitted to higher education through the quota system

	2019–20	2020–21	2021–22
Total number of admitted students with disabilities	2,068	2,799	3,155
Full-time	1,629	2,072	2,270
Part-time	400	627	754
Evening classes	39	100	131
Total number of students admitted	138,000	174,900	235,900
Number of places for students with disabilities (estimate)	2,760	3,498	4,718
Filled places for students with disabilities (percent)	74.9	80.0	66.9

Source: MHSSE, World Bank calculations.

Most Uzbek university buildings are not physically accessible to students with physical disabilities, presenting significant barriers to accessing education. Ensuring the accessibility of social infrastructure, including educational institutions, is stipulated by several legislative acts and regulatory documents 264 that outline how the state administration, local government, and organizations must create conditions for unhindered access for persons with disabilities, including those using wheelchairs and guide dogs, to all social infrastructure such as housing; public and industrial buildings, structures, and facilities; healthcare and sports facilities; cultural and entertainment venues; and educational and other institutions. However, no budget is allocated for implementing these requirements. As a result, most public buildings, including those at public universities, are physically inaccessible to persons with limited mobility. In 2020, the Association of Persons with Disabilities of Uzbekistan conducted a study of 10 universities in the city of Tashkent to assess the presence of various features related to physical access and elements facilitating access to information and communications. According to the monitoring results, most university academic buildings and dormitories lack even basic accessibility features, such as proper ramps—ramps may exist but are too steep or lack handrails—or wheelchair-accessible elevators, toilets, and thresholds. Another problem is the fact that dormitories are located far from the academic buildings, posing a significant obstacle to students with disabilities due to the absence of provided transportation.

BOX 27

On physical accessibility of universities

"I have classes on the fifth floor. It takes me considerable time and effort to reach my class. There is no elevator installed in the building where I study. I use a walker, but I have peers who use wheelchairs. The entrance to the building is not equipped with a ramp. Some of our friends help them to get into the building by carrying them up." (Student with disabilities)

Source: Qualitative research.

²⁶⁴ Law of the Republic of Uzbekistan no. 641/2020 on the rights of persons with disabilities, Art. 23, design, construction, and reconstruction of social infrastructure facilities to meet the needs of persons with disabilities; sanitary rules and norms, June 4, 2009 No. 0266–09 "Design and construction of residential and public buildings, residential places used by persons with disabilities and low-mobile groups of children and adults"; Regulations of the State Committee of the Republic of Uzbekistan for Architecture and Construction, January 10, 2008 No. 2.07.02-07 "Designing a living environment taking into account the needs of persons with disabilities and low-mobile population groups."

Access to information, technology and communications is not ensured at public universities, making it very difficult or impossible for students with sensory disabilities to attend courses. In addition to a physically accessible environment, higher education institutions must also ensure the accessibility of information, technology and communications. Information must be made available in formats that students with disabilities can understand; and sign language interpreters, notetakers, and books in Braille must be provided—resources currently absent at all public universities.

BOX 28

On information and communications accessibility of universities

"Istudy at the Journalism and Media University. I have hearing problems and use lip reading during the conversation. But it is very challenging for me to understand my teachers during lectures and therefore I started using speech to text conversion software, in Russian, on my telephone. It would be more difficult if I would attend an Uzbek faculty, because there is no such assistive program in Uzbek language. I wish the University administration would provide a sign language translator for those students with hearing impairments, to provide quality of higher education." (Student with disabilities)

Source: Qualitative research.

Recommended measures

LIMITED ACCESS TO TERTIARY EDUCATION



The MHESI to develop legislation so that participative councils, with input to

the management of issues related to inclusive education and accessibility, to be established at every university, comprising students with and without disabilities, teachers, and representatives of civil society organizations for persons with

10

disabilities.



CHAPTER 7

Health

Persons with disabilities have the right to well-being and to lead an active life.²⁶⁵ As per Art. 25 of the CRPD, persons with disabilities have the right to attain the highest standard of health care, without discrimination. This standard includes immunization, primary and specialized medical care, screening for communicable or non-communicable illnesses, dental care, and sexual and reproductive health, the same as the general population. As per Art. 26 of the CRPD, persons with disabilities must have access to habilitation and rehabilitation services, in line with the human rights-based approach to disability. As per Art. 28 of the CRPD, persons with disabilities must have access to all mainstream and disability-specific programs and services on an equal basis with others, including all social programs, housing, nutrition, health, and water, sanitation, and hygiene (WASH).

The core issues addressed under this sector are:

7.1 $\overline{}$

Limited access to health services, including habilitation and rehabilitation 7.2

Limited exercise of the right to sexual and reproductive health 7.3

 $\overline{/}$

Limited access to medical care provided with dignity and respect

The vision in this sectoral technical brief is based on the following articles of the CRPD: Art. 25 on "Health," Art. 26 on "Habilitation and rehabilitation," Art. 28 on "Adequate standard of living and social protection."

7.1. Limited access to health services, including habilitation and rehabilitation

Persons with disabilities should have equal access to affordable, accessible, quality, and culturally-sensitive health services. They should be able to access health services aimed at the whole population, as well as specialized services that address disability-specific needs. According to Art. 25 of the CRPD, affordable care includes early identification, early intervention (such as early childhood screening), and planning for targeted service provision. Furthermore, Art. 26 calls on States parties to organize, strengthen, and extend comprehensive rehabilitation services and programs, which should be provided through state funding as early as possible, based on a multidisciplinary assessment of individual needs and strengths, including the provision of assistive devices and technologies.

Persons with disabilities generally have worse health because of their exclusion from health services and underlying health impairments.²⁶⁶ They however face barriers in accessing routing health services, general health services, and specialist services (including rehabilitation), generated by accessibility, affordability, limited training of health professionals or attitudinal issues. These lead to poorer health outcomes than persons without disabilities. Women with disabilities are three times more likely to have unmet needs for health care.²⁶⁷



Description of the problem

There is a high prevalence of cardiovascular diseases (CVDs) that leads to disabilities among Uzbekistan adults. Over the past decades (between 1990 and 2019), the overall burden of disease in Uzbekistan weighted more towards noncommunicable diseases leading to disabilities, versus communicable and other diseases or injuries.²⁶⁸ The main risk factors currently causing permanent disabilities among adults are high blood pressure, unhealthy eating habits, smoking, alcohol consumption, and having a high body mass index. CVDs have the highest prevalence among adults in Uzbekistan – being diagnosed in 12 percent of the total population and responsible for 53 percent of the general mortality among middle-age population (30–70 years) in Uzbekistan.

Congenital diseases are the leading cause of childhood disability. Although on decline in recent years (see Figure 9), congenital diseases still reach high levels due to limited medical genetic screening and counseling, and limited application of basic reproductive health practices. Specifically, consanguinity, which is still culturally prevalent in Uzbekistan, increases the risk of congenital diseases and nearly doubles the risk of neonatal and

²⁶⁶ World Bank 2019, 130 and World Bank 2022b, 2.

²⁶⁷ World Bank 2019, 56.

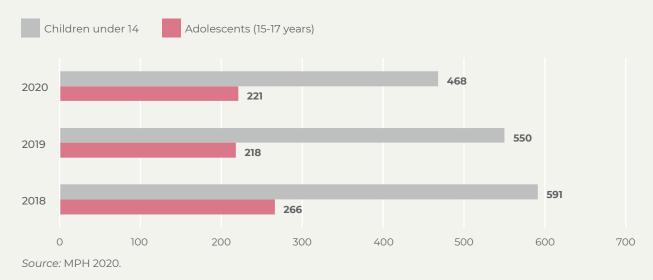
²⁶⁸ According to data from the Institute for Health Metrics and Evaluation (2021).

²⁶⁹ For example, over the last decade in Tashkent city, congenital diseases occupied second place as the reason for childhood disability, while they are ranked as the third cause of infant mortality (see Mamatkulov and Avezova 2015).

²⁷⁰ Consanguinity is when a child's parents are related by blood.

FIGURE 9:

Prevalence of congenital diseases in children (per 100,000 children)



In 2019, more than one-quarter of persons with disabilities reported they had unmet medical needs, almost 2.5 times more than persons without disabilities (27 percent of persons with disabilities versus 11 percent of those without disabilities). A share of persons with disabilities reported encountering obstacles to accessing health care services to prevent, diagnose, and treat medical conditions, as well as to obtain ADs. Respondents also mentioned having to sometimes make informal payments to receive public medical services, or relying on private hospitals for diagnostic procedures that should have been free. All these out-of-pocket payments expose households to extremely high health care costs.²⁷³ Despite government efforts to facilitate access to health care in the private sector, persons with disabilities cannot regularly benefit from services in private clinics, because of the unclear and non-transparent provision mechanisms.

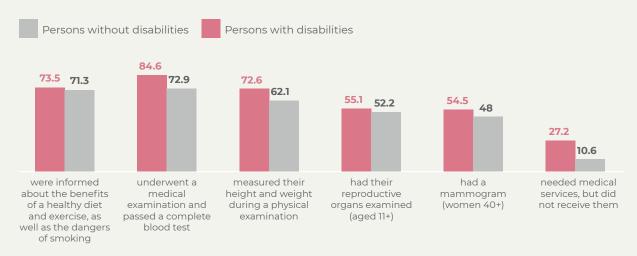
²⁷¹ See https://www.uzreport.news/society/obnarodovan-protsent-rodstvennih-brakov-v-uzbekistane

²⁷² The number of closely related marriages in rural areas is 25 percent, and in cities, up to 10 percent. See the press release on the Senate website about the meeting of the Republican Public Women's Council https://www.senat.uz/ru/lists/view/2768

²⁷³ UN 2019a.

FIGURE 10:

Percentage of persons with and without disabilities meeting their medical needs



Source: UN 2019a.

ROX 29

Legislation and policies aimed at improving access to medical services

According to the law "On health protection of citizens," persons with disabilities access general health care services free of charge, like the rest of the population. General health needs include health promotion, preventive care (immunization, general health screening), and primary treatment of acute and chronic illnesses.

Medical assistance and medical services for persons with disabilities should be provided by the state and include (1) recognition of a citizen as a person with a disability through disability assessment;* (2) habilitation and rehabilitation of persons with disabilities; (3) provision of prosthetic and orthopedic products and assistive devices (AD); and (4) provision of health services to persons with disabilities on an equal basis with other citizens.**

The government focuses on improving the quality of and access to primary health care (PHC) services, especially after the COVID-19 pandemic, during which people were faced with limited access to healthcare services. It tried to improve access to private health services by launching special President's Resolutions*** which obligated private medical facilities to provide free services to vulnerable and poor populations equal to the amount of their tax waivers.

Sources: ** Law of the Republic of Uzbekistan No. 641, *** President's Resolution No. 3450 "On the creation of additional conditions for the further development of private medical organizations" and President's Resolution No. 2863 "On measures for the further development of the private sector of healthcare."

Note: * See further details on the disability assessment process in the sectoral technical brief on social protection.

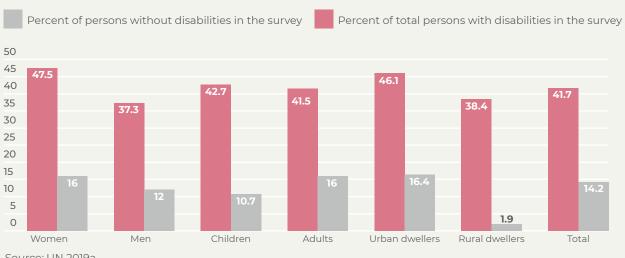
The need for dental care is rarely covered for persons with disabilities. In Uzbekistan, all dental care became private at the beginning of the 1990s, limiting the access of most of the population to such services, including persons with disabilities. To increase dental care access, especially in rural areas, the government used two solutions. First, in the framework of two health projects carried out with support from the World Bank ("Health-1" and "Health-2"), stomatology sets were distributed to doctors from remote rural areas and to the district-level multifunctional policlinics all over the country. Dentists working part-time were assigned to PHC facilities to provide primary dental care to the entire population, including persons with disabilities. Second, the State guaranteed package for health care, approved in 2021 by the MPH, and the previous Ministry of Finance and Ministry of Economic Development and Poverty Reduction, includes only a basic dental care plan.

The percentage of persons with disabilities who are unable to afford doctor-prescribed medications (41.7 percent) is three times higher than the percentage of persons without disabilities (14.2 percent) (see Figure 11). Among adults, the percentage is 41.5 percent in

the case of persons with disabilities compared to 16 percent of those without disabilities, and for children, the difference is even higher: 42.7 percent compared with 10.6 percent. At the same time, women with disabilities are more vulnerable compared to women without disabilities: 47.5 percent compared to 16 percent report unmet needs in coverage with medicines (see Figure 11).

FIGURE 11:

Percentage of persons with and without disabilities who could not afford medicines they were prescribed by a doctor



Source: UN 2019a.

Uzbekistan's provision of psychiatric support services suffers from shortcomings, especially with respect to the early identification of mental disorders and the quality of mental health services. Despite the adoption of Presidential Decree PD-3606 in 2018, psychiatric health care is still characterized by a limited number of beds and a shortage of doctors. According to official statistics, there are only 0.24 adult psychiatrists and 0.15 child psychiatrists per 10,000 population. There are 57 psychotherapists, or 0.002 per 10,000 population. Most qualified specialists are concentrated in hospital facilities in the capital and there is no national program on mental health. Although some measures have been adopted for the improvement of mental health care in the younger population (see Box 30), unfortunately, few of these measures were implemented by the time this report was drafted.

BOX 30

Measures adopted to improve mental health in the young population

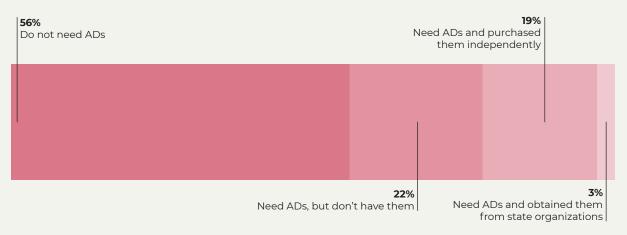
According to Presidential Decree No. PP-3827 from 2018, several measures were adopted to improve the mental health of students and teachers:

- Every educational institution should have a psychologist to conduct targeted work with students and teachers;
- At the beginning of the school year, students will undergo psychological assessments to identify those who may be considered part of a "risk group;"
- Stimulate scientific and practical activities in the field of suicidology;
- · Develop websites with information on ways to get out of difficult situations and cope with stress;
- Organize seminars and trainings for teachers to identify at-risk students;
- Open new positions for "suicidologist" and "medical psychologist" in health care institutions to provide assistance to people at risk, etc.

Only a small share of persons who need assistive devices (ADs) receive them from the government. In 2019, 44 percent of persons with disabilities needed ADs, but half of those who did could not obtain them: 3 percent of persons with disabilities needed ADs and obtained them from state organizations and 19 percent purchased them independently (see Figure 12). For instance, only 27 percent of persons with disabilities who needed a wheelchair (one of the most expensive items on the list) owned one. Children with disabilities have significantly higher unmet needs than adults in terms of ADs for movement and self-care, communication, and hygiene and sanitation (see Figure 13). Only in the case of visual disabilities, adults have greater unmet needs for ADs than children.

FIGURE 12:

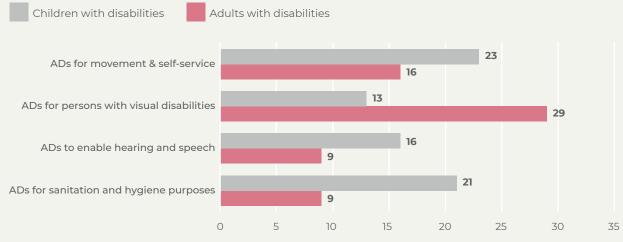
AD needs among persons with disabilities in Uzbekistan (percentage)



Source: UN 2019a.

FIGURE 13:

AD needs among persons with disabilities, by age and type of disability (percentage)



Source: UN 2019a.



BOX 31

Legislation and policies aimed at improving access to medical services

The government made efforts to improve access to ADs. By the end of 2022, the ADMSS, in collaboration with the MPH, must provide hearing aids to all pupils in special schools. Starting with 2023, the process of procuring hearing aids will take place regularly. Also, veterans with disabilities who participated in the Afghan War will receive appropriate modern prosthetic and orthopedic products, made by individual measurement.

Source: Presidential Decree No. 230.

A series of barriers hinder the equal access of persons with disabilities to health care services. These include:

- · Limited coordination in providing health care services for persons with disabilities.
- Limited capacity of the primary health care (PHC) system in providing medical services to persons with disabilities.
- · Limited screening programs and genetic testing.
- The system of issuing special vouchers for free specialized health care is not always effective for patients with disabilities.
- · Limited availability of rehabilitation services.
- · Inexistence of palliative care services.
- · Limited access to appropriate, affordable, and high-quality assistive devices.
- Health care services and medicines can be expensive for persons with disabilities.

Limited coordination in providing health care services for persons with disabilities

Uzbekistan faced significant coordination gaps among institutions that manage health care services for persons with disabilities. Medical care for persons with disabilities was mainly provided by the ADMSS²⁷⁴ and the MPH. One of the main causes of limited access to medical treatment and rehabilitation was the poor past coordination between these two stakeholders, as there was no clear designation of responsibility for medical treatment and rehabilitation within health care facilities of both main stakeholders. Staring from January 1, 2023, the ADMSS became a structure under the MPH through the Resolution of the President no. PR-269 "On measures for the implementation of administrative reform in the new Uzbekistan." This change brings may enhance the coordination in health care service provision.

²⁷⁴ Established in March 2021 in accordance with Presidential Decree no. PD-6195 and Presidential Decree no. PD-5038.



The current administrative organization of medical services makes it difficult to implement the "continuum of care" and "patient-oriented care" principles. At present, the provision of medical services is highly dependent on their territorial distribution (which is uneven), the human factor of the health care authority, and patients' awareness of their rights. In some districts of the capital—for example, in the Mirzo-Ulugbek district—essential PHC services are available to patients with disabilities. Conversely, in rural areas, the provision of medical services is poor. Although there are visits foreseen by medical professionals to the homes of persons with low mobility, these are carried out as a formality or even only "on paper," and persons with disabilities remain without medical services.

Health sector laws, bylaws, and regulations are poorly disseminated and implemented in health care facilities. Uzbekistan has successfully developed several fundamental legislative acts, but these are poorly implemented in the territory. For example, although CMD no. 411 "On approval of the regulation on the procedure for providing people in need with prosthetic and orthopedic devices and technical means of rehabilitation" was launched in 2021, not all health care facilities were properly informed about it, and some continued to use the previous regulatory document.²⁷⁵ Another example is the recognition of disability principles: health authorities and medical staff still use medical labor expertise and the medical forms from CMD no. 195 "On medical labor expertise," although it expired after the launch of CMD no. 62 "On establishing medical social expertise" on February 8, 2022. Considering the need to align legislation and regulations with the CRPD, actions that enhance parties' knowledge and capacity should be carried out, as ADMSS mentioned insufficiently specialized lawyers and limited cooperation, knowledge-sharing with and experience of NGOs as reasons for the inefficient process of updating laws and regulation documents.

BOX 32

New health screening program in Uzbekistan

In accordance with Presidential Decree no. UP-6110, "On measures to introduce fundamentally new mechanisms into PHC institutions and further improve the effectiveness of the health-care reforms," issued at the end of 2020, targeted screening must be carried out: (1) to discover helminthiasis; (2) for women's health, mostly to reveal problems with fertility and early detection of breast cancer; and (3) for persons aged 40 and over, to reveal noncommunicable diseases. For the last group, the evaluation includes measuring anthropometric data (height, weight, body mass index), blood pressure, pulse, and main nutrition habits (intake of fruits and vegetables, salt, physical activity). Data must be collected in a unified web-based database with closed access. Based on defined indicators, the entire population was divided into groups: (1) base group: people presenting no health issues; (2) low-risk group: people with risk factors such as obesity, high blood pressure, and a higher risk of developing CVDs; (3) medium risk group: people with chronic diseases and other NCDs; (4) high-risk group; and (5) others.

After identifying those with an average and high risk of NCDs (groups 3 and 4), in-depth clinical check-ups were organized. For this purpose, 65 mobile teams of doctors were created (with 11 specialists in each team). These teams travel to districts according to a preset schedule and conduct in-depth clinical examinations of people included in groups 3 and 4. The screening checkups are organized in 26 areas. After analyzing the pilot results, the screening is extrapolated to the rest of the country.

Moreover, each family policlinic should enlarge its staff to include a special instructor on healthy lifestyle and nutrition, as well as patronage nurses to make home visits to check on the health status of people from at-risk groups.

Limited capacity of the PHC system in providing medical services to patients with disabilities

PHC physicians are overloaded with different categories and cohorts of patients. They must perform screening visits to households and identify different types of at-risk population groups under different national programs (such as dispenserization, ²⁷⁶maternity and childhood health care, tuberculosis, noncommunicable diseases, or COVID-19) and are unable to allocate sufficient time to provide medical care to persons with disabilities (such as identifying first symptoms or risk factors, providing referrals to specialist doctors for

²⁷⁵ Instruction no. 1229, issued by the Ministry of Public Health and approved by the Ministry of Justice on March 27, 2003.

²⁷⁶ Dispenserizations is a legacy of the Soviet health system that requires all patients with chronic conditions to undergo complete medical check-ups one or more times per year, regardless of the need for it.

diagnostic and treatment recommendations, or supervision of treatment recommended by specialists doctors). Moreover, as current regulations guide PHC physicians to prioritize persons with disabilities who live by themselves (see Box 33), other patients with disabilities may end up being overlooked.

BOX 33

The PHC system's focus on persons with disabilities living alone

Based on the CMD no. 264 "On approval of the Regulations on the procedure for compiling a list of lonely elderly and persons with disabilities who need outpatient care," ADMSS prepared and distributed a special questionnaire for PHC facilities to assess the volume of social and medical assistance needed by these target groups. A team composed of a family doctor and a general practitioner (GP) nurse visits the person with disabilities living by themselves and fills out the questionnaire. Based on the information collected, the team decides the needed treatment and social support that must be provided by the Inspection.

In practice, medical and social workers use: (1) CMD no. 62 issued on February 8, 2022, where a general procedure for examining persons with disabilities is given; and (2) CMD no. 264 "On approval of the Regulations on the procedure for compiling a list of lonely elderly and persons with disabilities who need external care."

Often, patients with disabilities must wait a long time to be referred for diagnostic, therapeutic, and rehabilitation measures, or in the roll-out of national programs. The medical staff at PHC level is insufficient, and there are unclear criteria and no well-defined processes for PHC medical staff to refer patients with disabilities. When implementing national programs, for example, a new national program for supporting women (a special database called "Women's notebook") provided an opportunity for women with disabilities and women raising children with disabilities to obtain one-time financial assistance or medical and social support.²⁷⁷ However, interviews with persons with disabilities and their relatives revealed that the process of including women in this database depends on the human factor and personal attitude of community leaders. Overall, without community outreach, families must seek medical services on their own.

Another factor making it difficult for patients to navigate the health care system is their low health literacy. Low health literacy can make people reluctant to seek health care because they may not fully understand the importance of preventive health care or health risks, on top of having trouble communicating with health staff, hence this may result in low adherence to services proposed by PHC staff.

Despite the recent focus to increase access to dental care through national health projects "Health 1" and "Health 2," only basic stomatology services were made available, by means of equipment that is outdated or doesn't work. Most importantly, the services included in the guaranteed package for health care include anesthesia, filling burns, tooth extraction, and opening of any abscess, while other services must be paid out-of-pocket by patients. Members of the Association of Veterans and Disabled Soldiers interviewed for this analysis point out that there is a high need for dental prosthetics and implants among veterans. There are no waivers or discounts for dental care for persons with disabilities.²⁷⁸

PHC capacity in the mental health field is also limited. Mental health screening and treatment face several challenges: (1) there are insufficient PHC specialists familiar with basic symptom identification and management of mental health issues; (2) screenings of the general population did not so far include initial symptoms for mental disorders to identify those who are at risk of mental disorders (e.g., the one launched in January 2021); (3) community-based mental health is not defined among national priorities and community-based mental health care is not developed, despite the high need,²⁷⁹ and as result, persons

²⁷⁷ CMD no. 145 "On measures to study and solve the system of women's problems."

²⁷⁸ Some private dental clinics implement discount systems. For example, doctors from a private stomatology polyclinic in Tashkent city interviewed for the present analysis, reported providing dental care for persons with disabilities with a 30 percent discount if the person has a certificate that confirms a disability of group I or II. On occasion, they even provide fully discounted services as charity.

²⁷⁹ Only one 2008 project addressed the provision of community-based rehabilitation for persons with disabilities, including psychological support by trained specialists – JICA newsletter, www.jica.go.jp/uzbekistan/english/activities/c8h0vm0000bq156e-att/41.pdf

with such issues may end up in long-term psychiatric care or residential institutions; ²⁸⁰and (4) there is widespread stigma among the general population regarding services provided by psychologists or psychiatrists, resulting in untimely or no use. A 2021 WHO study shows that mental health conditions costed the Uzbek economy an estimated UZS 4.8 trillion in 2019, equivalent to 0.98 percent of its GDP, adding up to health care expenditure, lost productivity due to premature mortality, disability and reduced workplace productivity. Increased investment and management of mental health would provide economic benefits (UZS 4.4 trillion), which would significantly outweigh the estimated costs of implementation (UZS 3.86 trillion).²⁸¹

Limited screening programs and genetic testing

Existing screenings carried out at birth to identify conditions that lead to disability are limited. According to Art. 25 of the CRPD, affordable care includes early identification and early intervention. This includes early childhood screening and planning for targeted service provision. Uzbekistan has two national screening programs carried out at birth in all maternity hospitals for two main pathologies: phenylketonuria and congenital hypothyroidism. The level of implementation of these two screening programs and their coverage of the newborn population is not clear, and monitoring systems and fail safe mechanisms are not clearly defined to enable an accurate analysis and policy redesign (for example, to add more types of screenings at birth, as per international best practices). Moreover, in 1998, a "National Program for the early detection of congenital and other pathologies in newborns and pregnant women" was adopted to prevent congenital disabilities, with screening to detect such conditions at 14–16 weeks of pregnancy.²⁸²

Other screenings and registers are carried out or planned with regard to specific congenital disabilities. The Republican Center for Screening of Mother and Child maintains a Register of Congenital Pathologies with data submitted by maternity hospitals. Other registries are maintained by different research centers and the collected data is used for scientific purposes only. According to interviews, the Republican Center for Screening of Mother and Child together with the ADMSS are planning to maintain a register of patients with spinal muscular atrophy, as of July 1, 2022. The integration of this register into day to day work of the different categories of health staff is still to be planned. The Republican Specialized Scientific and Practical Medical Center on Pediatrics is expected to start diagnosing and maintaining a register of patients with cystic fibrosis (under piloting at the time of this analysis), in accordance with Presidential Decree no. PD 217 dated April 25, 2022.

The limited genetic testing is explained by a lack of genetics labs, high costs that are not compensated, and a shortage of specialists. Laboratories for genetic testing are few, found only in the capital city, and private. It is possible to conduct a number of genetic tests, but they are costly, and patients are not reimbursed for incurred expenses. There are only 43 clinical geneticists in Uzbekistan. The only dedicated university training programme was a master's program for training clinical geneticists at the Tashkent Medical Academy, which was closed in 2021. Medical genetics has become the subspecialty course of neurology. PHC staff do not have guidelines for following a genetic pattern at family history level.

²⁸⁰ For example, in the case of elderly people with psychological problems who need long-term care support. Moreover, because options in the community are lacking and there are a limited number of beds for long-term care for this group in psychiatric institutes, such patients find themselves placed in elderly nursing homes, where the conditions are very poor, and specific mental health services such as regular psychiatric and psychotherapeutic care are absent.

²⁸¹ WHO, 2021.

²⁸² In accordance with the Decree of the Cabinet of Ministers no. 14 "On the establishment of the state system 'Examination of mother and child."

Patients with disabilities do not always benefit from the system of issuing special vouchers for free, specialized health care

A special voucher can be issued to obtain specialized medical services in state-funded health care facilities of secondary and tertiary level, but obtaining it can be cumbersome and take 6–12 months. The absence of appropriate coverage of the health insurance system in Uzbekistan led to the development of financial waivers for providing medical services to vulnerable groups, such as the special voucher for accessing free specialized health care (see Box 34). With the special voucher, a patient can be treated at a specific hospital, which issues a reimbursement bill to the State Health Insurance Fund. Delays in obtaining the special voucher occur, as many regions have a limited number of available beds, staff, or the e-platform through which the system is managed, launched by the MPH, malfunctions. Many PHC doctors write down wrong diagnoses on the special vouchers or miss attaching all required documents, delaying patients' hospitalization. The process may be lengthy even when all supporting documents are in order. For example, in 2021, a malfunction of the electronic platform forced representatives from national specialized hospitals to register patients' requests and produce special vouchers by hand.

BOX 34

On accessing specialized secondary and tertiary care

The Republic of Uzbekistan has chosen to guarantee access to state-funded basic health services at the district level, while retaining cash payments (with some exceptions) for pharmaceuticals and specialized medical services. The guaranteed basic package was approved by a joint order of the MPH, Ministry of Finance, and Ministry of Economic Development and Poverty Reduction. The package includes emergency and urgent medical care; primary health care (outpatient and consultative-diagnostic care, day hospitalization, inpatient care on the secondary level, obstetric care); medical rehabilitation, and palliative care for certain population groups.

Specialized care is free of charge for 16 categories of patients on the condition they apply for it in advance: (1) children under 18 with pathologies from the list approved by the MPH; (2) persons of military age by the referral of special military commissions; (3) pregnant women with pathologies from the list approved by the MPH; (4) patients with endocrinology pathologies from the list approved by the MPH; (5) patients with STD pathologies from the list approved by the MPH; (7) patients with cancer pathologies from the list approved by the MPH; (8) persons with disabilities and veterans of WWII; (9) non-working pensioners; (10) members of the labor front of 1941–45; (11) persons with disabilities from childhood; (12) persons with disabilities from groups I and II; (13) persons from low-income families from the Single Registry for Social Protection (SRSP) information system; (14) warriors-veterans from international wars; (15) persons with disabilities following the Chernobyl nuclear power plant accident; and (16) children who are orphaned of both parents.

Many of the diagnostic examinations and treatments necessary for persons with disabilities are not available in the basic guaranteed health package. To obtain the necessary services in secondary or tertiary level hospitals, according to Presidential Decree no. 5199, "On measures to further improve the system of providing specialized medical care in the sphere of health care," patients must apply in advance for special vouchers – an instrument that ensures that the State Health Insurance Fund will cover their medical expenses. Applications are registered in a centralized e-platform launched by the MPH in 2021, and a voucher is generated following the application.

Moreover, the e-platform does not provide an option to request special vouchers for emergency hospitalizations. Hence, patients might get admitted to hospitals directly, without special vouchers, and can face many logistical, financial, and organizational issues. Overall, both patients and medical workers interviewed for this analysis acknowledge that the e-platform makes the process of hospitalization longer and more bureaucratic.

Limited availability of rehabilitation services

The availability of treatment and rehabilitation services varies within and across regions. In Uzbekistan, medical rehabilitation therapy is typically provided in tertiary-level units and in national hospitals under the MPH, as well as in the Center for Rehabilitation and Prosthetics of Persons with Disabilities and its branches under the ADMSS. Medical rehabilitation is almost never available at community level. Most services are available in the capital only. Follow-up medical rehabilitation, therapy, and assistive devices used to be provided in the National Center for Rehabilitation and Prosthetics of Persons with Disabilities

and its branches.

Persons with disabilities have limited access to rehabilitation. In line with a recommendation from the British Society of Rehabilitation Medicine (BSRM)²⁸³ on needing 60 in-patient beds for every 1 million people, approximately 2,100 in-patient rehabilitation beds should be available in Uzbekistan. However, the total number of available beds dedicated only to rehabilitation is three times lower—705, of which 505 are at the Center for Rehabilitation and Prosthetics for Persons with Disabilities and its regional branches, and 200 are at the National Centre in Tashkent.²⁸⁴ Many patients prefer to obtain rehabilitation services at the National Center for Rehabilitation and Prosthetics of Persons with Disabilities, because it is well-equipped and free of charge. According to official data, out of 111,850 children with disabilities, 87,218 (78 percent) underwent recovery (rehabilitation) programs in 2021, of which 34,918 were in hospitals, 50,067 were in out-patient facilities, and 2,233 were in special sanatoriums.²⁸⁵

There is also limited availability of rehabilitation specialists. Doctors with specific expertise in medical rehabilitation include psychiatrists, rehabilitation doctors, or physical and rehabilitation specialists. Although the rehabilitation doctor specialty is mentioned in the national classification of medical specialties, there are no statistics about how many such professionals there are in the country. In practice, medical specialists such as psychiatrists, pediatricians, geriatricians, ophthalmologists, neurosurgeons, and orthopedic surgeons, as well as a broad range of therapists, are involved in rehabilitation medicine. Existing specialists completed only a short vocational training because there is no initial education for rehabilitation doctors. To tackle this issue, the ADMSS initiated joint educational projects with the Commonwealth of Independent States (CIS) countries, such as Russia and Armenia.

According to national law, an Individual Rehabilitation Program (IRP) must be developed for each person with disabilities, but only a third reported having one. Half of persons with disabilities did not know about the existence of the IRP, and 18 percent reported that they did not receive such medical service.²⁸⁶

Inexistence of palliative care services

Palliative care is not provided by the health care system in Uzbekistan. Quite often, holistic care and pain management medication are needed much earlier than an imminent terminal diagnosis. Persons with disabilities with life-limiting and life-threatening illnesses suffer from symptoms such as pain, nausea, shortness of breath, fatigue, or sleep disorders that negatively impact activities of daily living. Children with rare diseases may suffer from such symptoms for years. Unfortunately, this type of care is not available in Uzbekistan, because palliative care is not recognized as a separate medical specialty.

BOX 35

Definition of palliative care

"Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. [...] Palliative care is explicitly recognized under the human right to health. It should be provided through person-centered and integrated health services that pay special attention to the specific needs and preferences of individuals."

Source: https://www.who.int/news-room/fact-sheets/detail/palliative-care

- 283 See BSRM Standards for Rehabilitation Services: https://www.bsrm.org.uk/downloads/standardsmapping-final.pdf
- 284 Since 2014, a significant number of beds was cut to decrease expenses at hospital-level health care. This increases the waiting time of patients with disabilities trying to obtain the special voucher, because they need different types of treatment more often than persons without disabilities. Attempts to provide specialized hospital medical services in the PHC facilities by organizing "home stay hospitals" and "day stay" hospitals did not meet existing needs, because the human and material resources in ambulatory are limited.
- 285 Open Data Portal of the Republic of Uzbekistan: https://data.gov.uz/ru/datasets/17906
- 286 UNDP 2019.

Limited access to appropriate, affordable, and high-quality assistive devices

The state list of discounted prosthetic and orthopedic products and other ADs is limited and does not meet the needs of persons with disabilities. In Uzbekistan, the procedure for providing ADs is regulated by CMD no. 411 "On the approval of the Situation on the procedure for providing needy persons with prosthetic and orthopedic devices and technical means of rehabilitation." The state list of prosthetic and orthopedic products and ADs includes 18 items, which should be provided at the expense of the state budget. The list of provided ADs must be updated every two years. Not only is the share of persons receiving ADs from the government very low (see Figure 12), as per the UN survey carried out in 2019, many ADs that persons with disabilities needed were not even available on the state list. Out of the 35 assistive devices and products listed in the study as being needed by persons with disabilities in Uzbekistan, only 18 were provided by state organizations (see Annex-Table 2).

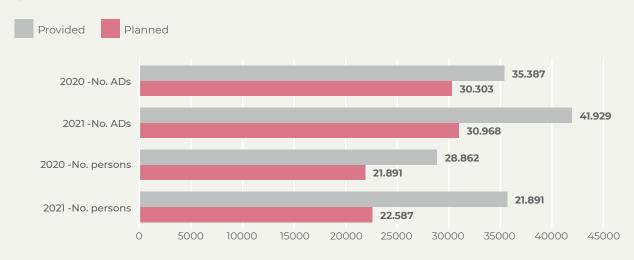
BOX 36

Procedure for providing ADs to a patient with disabilities

According to the developed procedures given in CMD no. 411, a person with disabilities must submit to the District Inspectorate of the ADMSS their application and a medical conclusion from a PHC facility that confirms their condition and need for a specific AD. Information about AD needs should be collected by district (city) departments for the development of medical and social services before December 15 of each year by compiling a list of persons who will need them in the following year (persons with disabilities, including children with disabilities and elderly without a disability group). Hence, the provision of prosthetic and orthopedic products for low-income persons is covered by state funds. Applicants are provided a certificate that gives them the ability to purchase ADs from any local manufacturer. However, if the price of an AD exceeds the one indicated in the certificate, the difference is to be covered by the applicant.

Government's ADs distribution needs a wider outreach and improved planning. Government-provided ADs described in Figure 14 cover only a small share of the actual need. As was estimated for 2019 by UN (see Figure 12), 3 percent of persons with disabilities who need ADs receive them from government). Comprehensive information about the actual overall need of ADs is lacking at present. There is no unified database to collect data on coverage of needs or status of applications, available both for PHC providers and the ADMSS central office. As per data provided by the ADMSS and interviews carried out with the institutions' representatives, the number of persons who were provided ADs by the end of both 2020 and 2021 was higher, with approximately 30 percent and 55 percent respectively, compared to the number of persons who initially submitted applications for these calendar years. While the ADMSS has managed to cover these needs in a much higher amount than initially planned, data confirms that the AD needs are not well known and addressed.

Planned and provided ADs and persons with disabilities with government-provided ADs (2020 and 2021)



Source: ADMSS.

The lack of a certification system for prosthetic and orthopedic ADs manufactured in Uzbekistan results in low quality products, which is highly problematic for their users. Currently, six enterprises produce ADs in Uzbekistan. Their products often have technical faults; for instance, prostheses are bulky, uncomfortable, and deteriorate rapidly. According to the interview carried out for this analysis with representatives of the ADMSS, the low quality of ADs produced in Uzbekistan is caused by: (1) a deficit of qualified product developers, engineers, and craftsmen; and (2) the lack of systems for accrediting manufacturers and certifying materials and manufactured products. On March 18, 2022, during a meeting with the medical community, the President of the Republic requested the establishment of an entity for the modern production of prosthetic and orthopedic products on the premises of the prosthetic factory of the National Center for Rehabilitation and Prosthetics of Persons with Disabilities.

Health care services and medicines can be expensive for persons with disabilities

Persons with disabilities often cannot afford to pay for services, especially those in private clinics, as well as pharmacies. The special voucher system does not cover medical services in the private health sector, nor the provision of medicines. However, according to President's Resolution, there is an opportunity to obtain free services in private clinics for vulnerable and poor population equal to amount of tax waivers for private clinics, but this is hindered by the absence of a mechanism monitoring the whole system of tax waivers ²⁸⁷spent by the private sector for providing medical services for persons with disabilities and other vulnerable groups. Most medications needed by persons with disabilities are too expensive for households, so they are unaffordable even if they are on the list with fixed prices, according to Presidential Decree no. PP 2647. Moreover, there is no system of reimbursement if patients purchase medicines regularly. Compensations to persons with disabilities are sporadic. Similarly, dental care is private and persons with disabilities are not in a position to afford the costs. The developing health insurance system does not include principles of collecting premiums from unemployed individuals with disabilities. It does not cover services in private clinics, including stomatology, or the provision of medicines to persons with disabilities.

²⁸⁷ This system should be monitored by the state agencies such as the MPH, National Tax Committee, or NADMSS.

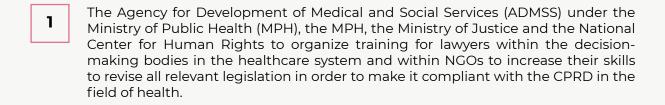
BOX 37

Policy measure to ensure vulnerable citizens' access to medicines

The government adopted a long-term strategy for self-sufficiency in essential medicines to overcome its reliance on expensive imports. In 2013 and 2016, the government attempted to start an administrative regulation of costs in pharmacies. In 2013, CMD no. 204 and the Order of the MPH no. 244 were launched to regulate the provision of medicines on the primary health care level. In 2016, the President's Resolution no. PP 2647, "About measures to further improve the provision of the population with medicines and medical products," mentioned the list of medicines that have to be controlled by the government, sold at fixed prices through a network of cheap pharmacies, called "Arzon apteka." Few medicines, such as contraception pills or insulins, are provided by the PHC system.

Recommended measures

LIMITED ACCESS TO HEALTH SERVICES, INCLUDING HABILITATION AND REHABILITATION



- The Interagency Council for Persons with Disabilities (ICPD) to establish a working group of lawyers to review and harmonize healthcare laws and bylaws in line with the CRPD.
- The ADMSS and the MPH to develop a system for communicating updated information about new regulatory documents on healthcare and rehabilitation services to healthcare providers and final beneficiaries.
- The MPH to develop a guidebook on the main responsibilities and work protocols of healthcare workers involved in delivering curative and rehabilitation services for persons with disabilities.
- The MPH to increase the capacity of regional rehabilitation centers in terms of modern equipment and qualified and trained staff.
- The ADMSS to make rehabilitation services available locally for those who need them by embedding rehabilitation services into primary healthcare facilities, including community-based rehabilitation.
- The MPH and the Ministry of Economy and Finance to implement an extended screening program, by: (i) increasing the national list of screening programs at birth (including the screening of congenital malformations among children and mental disabilities); (ii) developing the human capacity; and (iii) equipping Maternity Houses and National Screening Centers and regional branches with appropriate devices and tests.
- The MPH to create valid unified electronic registries of persons with disabilities with congenital pathologies.
- The MPH to organize centers for early diagnosis of young children with congenital disorders, using modern medical genetics and molecular laboratory methods, on the premises of the Republican Center "Screening of Mother and Child" and its regional branches.
- The MPH to increase the availability of specialists in genetics by restoring dedicated higher education courses organized by Tashkent Medical Academy, with international specialists invited as trainers, and by organizing internships in international clinics.

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The MPH to strengthen services for early detection of disability and intervention in the primary healthcare facilities, aiming that the latter: (i) conduct early detection examinations of children and mothers; (ii) provide comprehensive developmental support and educational support for parents of children with disabilities; (iii) include parents in the process of rehabilitation and habilitation of children; (iv) ensure continuity of healthcare services for children in different medical facilities at

different levels of intervention.

- The MPH to increase the capacity of the healthcare workforce and system to provide mental health interventions, including integrating mental health into primary health care, strengthening community service provision and delivering school-based prevention programs.
- The MPH with Council of Women and Family under the Ministry of Employment and Poverty Reduction to organize awareness, education and information campaigns to influence the social norms in order to reduce the percentage of marriages among close kins and pass the medical examination and genetic test before marriage, as prescribed by the national law.
- The ADMSS to conduct a survey to study the need for assistive devices among persons with disabilities.
- The ADMSS with Uzbek Agency for Technical Regulation under the Ministry of Investments, Industry and Trade to introduce a certification system for assistive devices, as well as an accreditation system for local producers of assistive devices, in order to increase the quality of the offer of assistive devices.

7.2. Limited exercise of the right to sexual and reproductive health

Persons with disabilities must have the freedom and opportunity to enjoy their SRH. According to Art. 25 of the CPRD, women and girls with disabilities are guaranteed access to sexual and reproductive health care, information, and education.²⁸⁸ Persons with disabilities need proper information about SRH, and adequate access to SRH services, to prevent negative long-term consequences for their general health status, family life, and social inclusion. These might include unwanted pregnancies, complications from sexually communicable infections and diseases, pregnancy and childbirth complications, sexual violence, and avoidable deaths caused by cervical cancer.

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Definition of sexual and reproductive health

Good sexual and reproductive health is a state of complete physical, mental, and social well-being in all matters relating to the reproductive system. It implies that people are able to have a satisfying and safe sex life, the capability to reproduce, and the freedom to decide if, when, and how often to do so. To maintain one's sexual and reproductive health, people need access to accurate information and a safe, effective, affordable, and acceptable contraception method of their choice. They must be informed and empowered to protect themselves from sexually transmitted infections. And when they decide to have children, women must have access to skilled health care providers and services that can help them have a fit pregnancy, safe birth, and healthy baby. Every individual has the right to make their own choices about their sexual and reproductive health.

Source: https://www.unfpa.org/sexual-reproductive-health.

For their right to SRH to be protected, persons with disabilities must have access to information and adapted services provided by professionals who understand their disability-specific needs.²⁸⁹ More specifically, the following three conditions are key: (1) persons with disabilities must have access (both in and out of school) to age-appropriate information on reproductive health and family planning, so they can make healthy and informed choices; (2) persons with disabilities must be able to access the same range of SRH services as those provided to other people, including access to family planning, screenings and vaccinations to prevent reproductive diseases, and pre- and postnatal care, and must be of the same range, quality, and standard of affordability as for persons without disabilities; and (3) professionals who deliver SRH information and education programs and services must be trained to meet the specific needs of persons with disabilities.



Description of the problem

In Uzbekistan, the health care system does not prioritize the SRH of persons with disabilities, particularly women and girls, and coverage of services and programs for this group is unknown. SRH services include family planning, maternal health care, preventing and managing gender-based violence, and preventing and treating sexually transmitted infections, including HIV/AIDS. Most SRH services are provided in Uzbekistan

²⁸⁸ This article is also relevant from the perspective of Sustainable Development Goal (SDG) Indicator 5.6.2, that seeks to measure the extent to which countries have national laws and regulations that guarantee full and equal access to women and men aged 15 years and older to sexual and reproductive health care, information, and education.

²⁸⁹ World Bank 2019.

by family doctors, gynecologists, and midwives. A National Reproductive Health Program was adopted and regulated by several decrees and normative acts since 2014,²⁹⁰ but these do not highlight persons with disabilities.

While initiatives to provide SRH education exist, they are not consistent and their impact on persons with disabilities is not documented. In the past, Uzbekistan had more SRH information and education programs with wider coverage.²⁹¹ At present, information and education campaigns are limited in number and efficiency. A 2017 UNFPA study showed that recent initiatives did not reach expected results-classes were too large to foster acquisition of new information, teachers were insufficient, and some were not well prepared to deliver the program.²⁹² The study also highlights that specific measures should be taken to protect some categories of youth, including those with disabilities. Moreover, a "Week of Health Improvement for Women of Fertile age, Children and Teenage Girls" is organized every year for the general population. Women from cities as well as remote and hard-toreach areas receive medical examinations and ultrasounds. Qualified specialists provide counseling on mother and child health. Information sessions about reproductive health and a healthy lifestyle are organized targeting young people in mahallas (neighborhoods), schools, colleges, and universities. Its coverage among women with disabilities is unknown. Moreover, there are no official statistics about coverage with SRH services for women with disabilities.

Based on qualitative research, women with disabilities experience higher rates of gender-based violence, sexual abuse, neglect, maltreatment, and exploitation than women without disabilities. At the end of 2019, there were 295,500 women and girls with disabilities registered, of which 48,800 girls were under the age of 16. Women with disabilities are at increased vulnerability to abuse, especially those living in institutional settings and with intellectual disabilities. They are often prevented from making informed and independent decisions about their SRH. Violence against women with disabilities can also take the form of forced medical treatment or procedures, including forced sterilization. As a result of the increased risk of sexual violence, women with disabilities are also at risk of becoming infected with HIV and other sexually transmitted diseases.



Explanation of the problem

Uzbekistan has no specific policies aimed at increasing the access of persons with disabilities to SRH information, education, and services. There are many laws, bylaws, and regulations on SRH; however, there are no minimum specific quality standards for SRH services (including their social dimension), and no protocols for routinely providing persons with disabilities with SRH education, services, or supplies. Even the proposed Roadmap for the implementation of CRPD adopted in 2021 does not include measures to improve SRH services for persons with disabilities. Moreover, existing materials on SRH are not adapted to the needs of persons with disabilities. For example, they are not available in Braille or audio format. Provision of services may be partially covered, to provide general medical services to persons with disabilities (which excludes the whole range of SRH services, but includes contraception), several Presidential Decrees²⁹³ organized patronage teams composed of a family doctor, assistants in internal diseases and pediatrics, middle-level medical workers, patronage nurses, and midwives. However, no information is available about the actual coverage and outcomes of these teams' activities.

The National Reproductive Health Program was adopted on the basis of Presidential Decree PD-2221 in 2014. It was revised in 2019 and supplemented by Presidential Decree PD-4513, a new National Program of Measures to Improve the Quality and Further Expanding of the Coverage of Medical Care Provided to Reproductive Aged Women, Pregnant Women, and Children for 2019–23. Also in 2019, the law of the Republic of Uzbekistan no. 528 "On the protection of the reproductive health of citizens" was adopted.

²⁹¹ UNFPA 2016, 44.

²⁹² Institute of Social Studies under the Cabinet of Ministers of Uzbekistan 2017.

²⁹³ Presidential Decrees no. 2857, 3039, and 4890.

Staff from medical, social services, and educational institutions do not receive adequate training to provide SRH education or services to persons with disabilities. Some SRH training is provided for some types of doctors, nurses, and midwives as part of their initial or ongoing education. However, it does not address SRH for persons with disabilities. Based on qualitative research, health workers often feel uncomfortable providing information on SRH to young or unmarried people, especially to those with special needs. Moreover, the limited capacity of PHC staff due to patient-to-specialist ratios reduces their ability to respond to the SRH needs of persons with disabilities.

Children and youth with disabilities have limited access to SRH education both in and outside schools or medical facilities. Mainstream training programs on SRH in educational institutions are not accessible or inclusive. There are no adequate materials on SRH developed for persons with different kinds of disabilities (for example, with low vision or blindness, cognitive issues, etc.). There are no special training programs on how to provide SRH education for children and youth with disabilities. Despite the government's order for SRH to be taught in schools, most teachers feel ill-equipped to teach this subject. Most health classes for young people address personal hygiene and disease prevention (78.6 percent), family values (50.1 percent), psychology of relations with the opposite gender (49.5 percent), and maturity and readiness for family life (44.1 percent). Fewer classes talk about sex and reproductive education (33.1 percent), sexually transmitted infections (29.2 percent), contraceptives, and prevention of unwanted pregnancy (16.6 percent).²⁹⁴ As a result, knowledge of reproductive health issues is low and few youths turn to health providers when they need SRH counseling. There are no data about the coverage of SRH education among children and youth with disabilities, specifically.

Limited access to SRH services is caused not only by structural issues with provision but also by social norms. Medical specialists are not concerned with or sometimes ignore the SRH needs of persons with disabilities. The special training programs on how to provide SRH education for persons with disabilities have to be adapted to the cultural context. The conservative local traditions, beliefs, and customs are a significant barrier for many women and adolescents to access SRH services. Traditional parent-child relationships in Uzbekistan discourage frank discussion about sex and SRH. Women are seen as responsible for contraception.²⁹⁵

²⁹⁴ UNFPA 2017.

²⁹⁵ A 2020 study revealed that "family planning, use of contraceptives to avoid unwanted pregnancy [are] regarded as the sole responsibility of women," (UN 2020, 32) as an explanation to why data showed men having significant gaps in understanding reproductive health notions. Nevertheless, in a 2016 study, 65 percent of surveyed men reported making decisions on contraception jointly with their spouses (UNFPA 2016, 44).

Recommended measures

LIMITED EXERCISE OF THE RIGHT TO SEXUAL AND REPRODUCTIVE HEALTH

- The Ministry of Public Health (MPH) to adopt a national strategy for SRH, with measures ensuring the rights of persons with disabilities to sexual and reproductive health (SRH) and modern contraception.
- The MPH to collect statistics on SRH and contraception needs among persons with disabilities.
- The National Center for Professional Development of Medical Workers and other institutions that deal with continued medical education to adapt the "Education on Health, including Reproductive and Sexual Health" curriculum to the needs and rights of persons with disabilities.
- The MPH to adopt practice guidelines for primary health care staff, including patronage teams, for the provision of SRH services to persons with disabilities.
- The National Center for Human Rights and the National Society of Persons with Disabilities, in consultation with OPDs, to modify the mandatory minimum specific quality standards for social services, by introducing an obligation for specialized staff to complete training on how to provide persons with disabilities with information on how to exercise their SRH rights.
- The ADMSS to implement awareness campaigns on the right of persons with disabilities to sexual and reproductive health.

7.3. Limited access to medical care provided with dignity and respect

According to Art. 25 of CRPD, persons with disabilities have the right to use quality health care services on an equal basis with the rest of the population and not be discriminated against by persons who provide medical care services. Despite the legislative recognition of equal rights in obtaining medical care for persons with disabilities, they cannot always receive it on an equal basis with persons without disabilities. At least three requirements must be met to ensure access to health care with dignity and respect: (1) health care personnel should know the rights of persons with disabilities and be sensitive to their needs; (2) health care personnel should be trained to assist patients with disabilities; and (3) the compliance of health care providers with the rights of persons with disabilities should be monitored.



Description of the problem

Based on qualitative research, respondents mentioned that dignity is often infringed upon when medical services are provided to persons with disabilities. In Uzbekistan, there is legislative recognition of all citizens' equal right to obtain medical care. Although a UN survey points out that persons with and without disabilities in Uzbekistan are equally satisfied with how they are treated by health care providers (87 percent compared to 88 percent),²⁹⁶ qualitative research indicates otherwise. It suggests a dominant perception of persons with disabilities as beneficiaries of philanthropic actions rather than rights holders who can make and participate in decisions about their health. Finally, persons with disabilities, or members of their families, are often unaware of their rights or feel ashamed to assert them.



Explanation of the problem

Health care staff were not trained on the rights and needs of persons with disabilities or how to assist them. Since Uzbekistan's endorsement of the CRPD in June 2021, no training has been organized to promote the rights of persons with disabilities in light of the CRPD among health care staff. Interviews conducted among medical staff and management of PHC services revealed that they were unfamiliar with topics such as the human rights-based model of disability, or the need for accessible information and communication with persons with disabilities.

Ethical standards for the provision of health care services to patients with disabilities are not developed, but should regulate the medical practice. The National Ethics Committee (NEC)—an informal body under the MPH—deals specifically with ethical issues that arise in research, clinical trials, and health services for transplantations. But NEC did not develop national ethical standards for regulating the provision of health care services to patients with disabilities. For example, there are frequent reports of medical interventions that were performed without informed consent, both for persons with and without disabilities. The current form through which patients confirm their informed consent used in many medical facilities is limited only to patients acknowledging the potential adverse events.

²⁹⁶ According to data from the Institute for Health Metrics and Evaluation 2021.

Health care providers' compliance with the rights of persons with disabilities is not monitored. There is no available data to assess whether the patients' rights are respected, although the state guarantees nondiscrimination against patients, including those with disabilities, as a core value. However, the plan-do-check-act cycle is not implemented at every level of health care services provision. Also, public hospitals and most private hospitals lack patient feedback mechanisms. The need for these feedback systems is signaled by the large flow of complaints about medical services registered on the Unified Portal of Public Services in Uzbekistan or on the MPH website, where there is an electronic form for submitting appeals.²⁹⁷ A system for accrediting health care facilities²⁹⁸ is currently under development and could feature instruments for assessing patient satisfaction and mechanisms for monitoring how the rights and needs of persons with disabilities are observed by health facilities, at some minimum required standards.

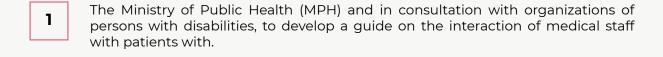
Persons with disabilities, or members of their families, were not informed of or trained on their rights. Since Uzbekistan's endorsement of the CRPD in June 2021, no national campaigns or awareness events have been organized for the general population. There are no information leaflets or guidelines developed or adapted for persons with disabilities to inform them of their rights. The stigma associated with disability often prevents people from seeking necessary care and services. Despite the law asserting the nondiscriminatory right to health care for all citizens, the social stigma around disability persists.

²⁹⁷ The form for submitting appeals is available on the Ministry of Public Health website: https://ssv.uz/en/message.

²⁹⁸ Announcement of tenders on the MPH website to this aim: https://ssv.uz/ru/tenders/kompanija-va-firmalar-rabarlarini-diatiga-zbekiston-respublikasi-solini-salash-vazirligi-tibbiet-tashkilotlari-uchun-akkreditatsija-standartlarini-ishlab-chiuvchisini-anilash-uchun- tanlov-savdolarini-elon-iladi

Recommended measures

LIMITED ACCESS TO MEDICAL CARE PROVIDED WITH DIGNITY AND RESPECT



- The MPH to provide medical education programs on the rights of persons with disabilities to staff (medical and non-medical) of healthcare facilities.
- The National Ethics Committee under the MPH and professional medical associations, in consultation with OPDs, to develop and implement ethical standards in line with the rights of persons with disabilities and provide appropriate training to all medical professionals for their implementation.
- The National Accreditation Body for Health Care Facilities under the MPH to include as accreditation criteria for hospitals and outpatient facilities the requirement to train and regularly re-train their staff on the rights and needs of patients with disabilities.
- The National Accreditation Body for Health Care Facilities under the MPH to include as accreditation criteria for hospitals and outpatient facilities the requirement to evaluate patient satisfaction, including patients with disabilities.
- The Ministry of Employment and Poverty Reduction (MEPR) to provide community-based training to educate parents on the development of children with disabilities.
- The MEPR and the National Center for Human Rights, in consultation with OPDs and NGOs, to increase awareness of patients with disabilities and their families by developing informative resources, including websites, and providing community-based training on: (1) the rights of persons with disabilities; and (2) the administrative organization of medical services.

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CHAPTER 8

Social participation

Persons with disabilities should have the same opportunities as persons without disabilities to fully participate in political and public life. To ensure equal participation of persons with disabilities in cultural life, recreational and leisure activities, and sports, the government of Uzbekistan should ensure the accessibility of formats (e.g., sign language, Braille, closed captioning) at venues such as cinemas, theaters, museums, monuments, parks, recreation sites, and sports centers. Moreover, according to Art. 30 of the CRPD, States parties must ensure the physical accessibility of venues for cultural, leisure, or sports activities. According to Art. 29 of the CRPD, the government should facilitate and encourage persons with disabilities to participate in government and other civic activities, vote, run for public office, and to engage in political and civic organizations.

The core issues addressed under this sector are:

8.1 Zimited participation in cultural life

8.2 Zimited participation in sports and tourism

Limited participation in the electoral process and public life

8.1 Limited participation in cultural life

According to Art. 30 of the CRPD, States parties must recognize the right of persons with disabilities to participate in cultural life on an equal basis with others. States must take all appropriate measures to ensure that persons with disabilities: (1) can access cultural materials in accessible formats; (2) can experience cultural activities in accessible formats, including television programs, films, and live theater; (2) have physical access to venues for cultural performances or services, such as theaters, museums, cinemas, libraries, and tourism offices, and, to the extent possible, to monuments and sites of national cultural importance; and (4) have the opportunity to develop and utilize their creative, artistic, and intellectual potential as artists and producers of culture. Cultural activities can give persons with disabilities an all-encompassing sense of involvement in all areas of social life. The problems of persons with disabilities and their needs can be broadcast to society through works of art and literature, films, and concerts. In turn, this would increase societal awareness about problems a person with disabilities might face. Because persons with disabilities can be both producers of cultural products and active visitors of cultural activities, it is essential to eliminate all barriers to their social participation.



Description of the problem

Persons with disabilities do not participate in social life at the same levels that others do. Qualitative research for this report reveals the reasons for this include the need for a sustainable income, mobility problems, and lack of awareness regarding places accessible to someone with particular types of disabilities.

There are fewer opportunities for persons with disabilities to access cultural sites in the regions of Uzbekistan than in the capital city. For example, a special department for blind people in the National Library of Uzbekistan has 36,000 books in Braille, and special computers designed for the blind have been installed. However, this library can only be conveniently accessed by those who live in the capital.²⁹⁹



Explanation of the problem

Social participation of persons with disabilities requires an inclusive environment

Legislative provisions to facilitate the participation of persons with disabilities in cultural and social life have been introduced in recent years, but national legislation does not sufficiently address some aspects of CRPD Art. 30. There are no standards regarding access to cultural activities (such as the provision of close captioning for the hard-of-hearing and books in alternative formats for the visually impaired). There are currently no official data on the actual volume of accessible information, although the 2018 decree "On improving the system of statistical registration of persons with disabilities" of the cabinet of ministers made such data collection mandatory. Sign language is not officially recognized, and there are no measures for recognizing and supporting the linguistic and cultural identity of deaf people.

There are scattered examples of initiatives aimed at including persons with disabilities in cultural performance events. To increase social awareness about the challenges that

299 Association of Persons with Disabilities of Uzbekistan 2014.



those with disabilities face, for example, Ilkhom Theater initiated a process for professional actors to perform on the same stage as children with disabilities, creating an empowering environment for persons with disabilities to showcase their talents.³⁰⁰ The Uzbek Society for the Blind publishes a special online and print journal—*Bir Safda*—and has established its own ensembles of folk art. The Law "On the Rights of Persons with Disabilities" guarantees the right to participate in social life, leisure, and sports under Art. 27. However, there is no allencompassing policy framework that governs the initiatives and creates an environment for the inclusive participation of persons with disabilities in social life.

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Small regional survey on issues related to youth with disabilities

In 2021, UNICEF carried out a small survey in the Andijan region—located in the Ferghana Valley in the eastern part of Uzbekistan with a population exceeding 3,000,000. The survey results concluded that youth with disabilities need more robust integration into social life. Andijan youths with and without disabilities were surveyed with a U-report online platform on what help they thought persons with disabilities needed. Among the respondents without disabilities, 29 percent claim that youth with disabilities participate in or are present at youth events in Andijan, while 34 percent have different experiences: 13 percent do not see persons with disabilities at such events, and 21 percent say they do so very rarely. The survey also asked what would increase the quality of leisure activities for persons with disabilities. Respondents with disabilities say that they need to be taught crafts (22 percent), to receive support to take nature sightseeing trips (22 percent), to be helped in visiting cinemas and theaters (12 percent), and to be offered gym subscriptions (8 percent).

Source: https://uzbekistan.ureport.in/story/872/.

Increased awareness is needed of problems associated with the social participation of persons with disabilities

Media, television, and film need to portray persons with disabilities in a nondiscriminatory way. Mass media and television do not sufficiently reflect the lived experiences and challenges faced by persons with disabilities.³⁰¹ As a result, many in society still have various stereotypical views of persons with disabilities and are not informed about the issues that impact them. Persons with disabilities are rarely shown as successful individuals integrated into society. For example, movies do not show persons with disabilities as businessmen, craftsmen, or artists. Athletes with disabilities are portrayed on television as examples of those who achieve top results despite their health problems.

Large-scale information campaigns to raise public awareness about persons with disabilities are being implemented, but they must be conducted on a regular basis. In 2015, the Association of Persons with Disabilities of Uzbekistan conducted a joint national information campaign with the UN Development Programme; the UN Educational, Scientific and Cultural Organization; UNICEF; and the Ministry of Employment and Poverty Reduction. The campaign distributed 30,000 posters; placed 120 billboards on the rights of persons with disabilities; and created two documentaries, 16 audio-video clips, and other materials. More than 80 journalists across the country have been trained in adequate coverage of disability issues. The campaign also organized a contest for the best information product on disability issues. Over 60 informational materials (articles, radio, and television programs) were submitted from different regions of Uzbekistan. In a similar vein, to increase social awareness of the problems of persons with disabilities, in 2019, the Art and Culture Development Foundation, under the Ministry of Culture and Tourism, initiated and organized the first international half-marathon in the history of Uzbekistan: the Samarkand Half Marathon. The event aimed to draw public attention to the problem of inclusion and accessibility of cultural services, events, and institutions for persons with disabilities. As part of the event, the first-ever tactile exhibition was organized in Uzbekistan, also equipped with audio commentary technology making it accessible to the blind and persons with other visual disabilities. These events broadcasted messages about the problems that persons with disabilities face. Going forward, such events must be conducted regularly and with a consistent message. Joint awareness and information campaigns are limited because each

^{300 &}lt;a href="https://cabar.asia/ru/uzbekistan-lyudi-s-invalidnostyu-malo-otstaivayut-svoi-zakonnye-prava-2">https://cabar.asia/ru/uzbekistan-lyudi-s-invalidnostyu-malo-otstaivayut-svoi-zakonnye-prava-2

³⁰¹ Association of Persons with Disabilities of Uzbekistan 2020.

ministry is financed separately out of the state budget. They, therefore, lack mutual funds to organize such campaigns.

Accessibility of cultural infrastructure for persons with disabilities must be ensured

Numerous problems must be solved to ensure the accessibility of cultural infrastructure for persons with disabilities. In Uzbekistan, there are 39 theaters; 350 museums; 59 cultural and recreational parks; 7,476 cultural heritage sites; and other institutions under the jurisdiction of the Ministry of Culture and Tourism.³⁰² At the end of August 2019, with the initiative of the Foundation for the Development of Culture and Art under the Ministry of Culture and Tourism, and based on a social partnership with the Association of Persons with Disabilities of Uzbekistan, a pilot monitoring study—"Sharoit Plus" was carried out on the accessibility of cultural and leisure infrastructure facilities in the capital. The monitoring was conducted in eight facilities, including theaters, museums, parks, and the State Institute of Arts and Culture. A methodological tool comprising 20 items was compiled especially for this monitoring activity. The results are mixed. The monitoring of theaters shows that, for example, the Alisher Navoi Theater, which underwent reconstruction in 2015, is now compliant with nearly all the construction norms and standards of accessibility for persons with disabilities. At the same time, the Youth Theater has steep ramps and restrooms unsuitable for persons with disabilities, and the nearby territory consists of steps that restrict movement in a wheelchair. An assessment of amusement parks shows that most park entrances are unsuitable for wheelchair users. The entrances either do not have ramps or have ramps with a very steep angle. The restrooms are not accessible for persons with disabilities, and the maintenance personnel tries to restrict persons with disabilities from using them. The general findings of the monitoring show that numerous obstacles need to be removed to ensure the accessibility of cultural infrastructure for persons with disabilities.³⁰³ According to the Association of Persons with Disabilities of Uzbekistan. 90 percent of cultural and tourism facilities do not have infrastructure accessible to persons with disabilities. The unsuitability of the facilities at cultural, tourism, and sports venues to the needs of persons with disabilities does not allow for their full inclusion and involvement in cultural and sporting activities.304

BOX 40

On accessibility to infrastructure in public parks

"None of the three public toilets in the park are accessible for wheelchair users. The lady in charge of the toilet began to kick us out, shouting that, they say, only she lacked us, and it would be better for her to die than to face us. She added at the end: 'Why do you demand accessible toilets as if disabled people go to the park every day?' But, of course, all responsibility for accessibility lies with the park administration."

Source: https://www.gazeta.uz/ru/2019/11/02/monitoring/#

Public monitoring reveals that students with disabilities cannot easily access cultural educational institutions. The monitoring of the accessibility of the State Institute of Arts and Culture by Sharoit Plus shows that the buildings are generally equipped with ramps that satisfy construction norms. However, the elevator in the main campus building is turned off, and the size of the elevators does not meet the norms of accessibility. The administration building does not have an elevator, and the lecture theater does not have ramps that would allow students with disabilities to attend. The stage and art rooms are unsuitable for students with disabilities to perform and practice. The dormitory rooms also fail to comply with the norms for students with disabilities to live and study, restrooms do not have facilities for persons with disabilities, and the building does not have elevators. The general finding is that students with disabilities encounter numerous obstacles to accessing the facilities.

^{302 &}lt;a href="https://madaniyat.uz/en/">https://madaniyat.uz/en/

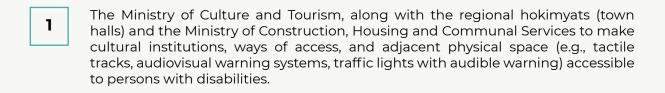
³⁰³ https://www.gazeta.uz/ru/2019/11/02/monitoring/#!

³⁰⁴ Association of Persons with Disabilities of Uzbekistan 2014.

Theater buildings and other cultural institutions were constructed prior to Uzbekistan's independence, which explains their limited accessibility. All new buildings (including those dedicated to culture or leisure) and structures must account for accessibility requirements for persons with disabilities, as enshrined in Art. 28 of the Law "On the Rights of Persons with Disabilities," and according to building codes and regulations. Many cultural sites, such as theaters, were built before the 1990s, in the absence of fixed requirements for a barrier-free environment. This is one of the reasons it is difficult to reconstruct, adapt, and reequip facilities to meet the needs of persons with disabilities and other persons with limited mobility. Moreover, because cultural buildings are often state-protected architectural monuments, it is challenging to coordinate across numerous departments to make structural adaptations that meet accessibility requirements.

Recommended measures

LIMITED PARTICIPATION IN CULTURAL LIFE



- The Ministry of Culture and Tourism, in partnership with organizations working for and with persons with disabilities to conduct regular monitoring of the accessibility of cultural and artistic institutions, and sanction/fine institutions that fail to comply with accessibility standards.
- The Ministry of Culture and Tourism, in partnership with organizations working for and with persons with disabilities, to create an online platform that provides information on the accessibility of various cultural institutions.
- The Ministry of Culture and Tourism, and the Ministry of Economy and Finance to finance mass-media programs—broadcasting, digital, and print—covering the problems and challenges that persons with disabilities face, and inform and educate the public about the rights of persons with disabilities.
- The Ministry of Culture and Tourism to request that television channels broadcast programs and films in formats accessible to persons with disabilities.
- The Ministry of Culture and Tourism to finance a grant program for cultural and art projects that involve persons with disabilities or promote their rights.
- 7 The Ministry of Culture and Tourism to develop and adopt a comprehensive policy framework on the development of cultural and art institutions, accounting for the inclusiveness and participation of persons with disabilities in the creation of the cultural content.
- The Ministry of Culture and Tourism, Ministry of Youth Policy and Sports, Cultural Heritage Agency and the Parliament to implement an awareness campaign on the right of persons with disabilities to participate in cultural life, sport, tourism and public life.

8.2 Limited participation in sports and tourism

Art. 30 of the CRPD protects the right of persons with disabilities to participate in cultural, recreational, leisure, and sporting activities. According to Art. 30(5), it is vital to enable the equal participation of persons with disabilities in recreational, leisure, and sporting activities. States parties must take appropriate measures to encourage and promote, to the fullest extent possible, the participation of persons with disabilities in mainstream sports at all levels and ensure they have opportunities to organize, develop, and participate in disability-specific sporting and recreational activities. To this end, States parties must provide appropriate instruction, training, and resources to persons with disabilities on an equal basis with others; ensure access to sporting, recreational, and tourism venues; guarantee equal access to playgrounds, recreational facilities, and leisure and sporting activities—including in the school system.

Persons with disabilities who participate in sports and tourism experience various positive benefits to their quality of life. Such involvement improves mental and psychological health, increases cognitive and social capital, and promotes social integration. Sporting and tourism activities should therefore be accessible to children and adults with disabilities. Moreover, the quality of rehabilitation services for persons with disabilities directly relates to their ability to engage in sporting activities.



Description of the problem

Persons with disabilities are less likely to participate in sporting and physical activities than those without disabilities. According to a 2019 study, only 5.7 percent of persons with disabilities participate in sports and physical exercises, compared with 11 percent of those without disabilities.³⁰⁵

The inaccessibility of transportation also hinders persons with disabilities from participating in sports and tourism. The lack of accessibility in bus, train, and airport terminals restricts many from moving around with ease. The results of qualitative research and published media show that, despite various efforts by the government to promote inclusive tourism, persons with disabilities cannot equally enjoy cultural benefits and travel within Uzbekistan. In 2019, only 13.8 percent of persons with disabilities used trains, and only 4.4 percent used airplanes, compared with rates of 21.5 and 11.6 percent, respectively, among those without disabilities.³⁰⁶

BOX 4

On barriers to participation in tourism among persons with disabilities

"Uzbekistan is a touristic country. However, as a person with a physical disability, I cannot visit such places as Bukhara and Samarkand. The government has established a fast train to these cities. However, getting on this train is like overcoming all possible barriers that a person with disabilities may face. For example, there is a significant difference between the train platform and the train entrance. So, once I nearly had to climb up with the help of others to get on the train. Once the train reaches its destination, you literally need to jump down. Apart from that, to exit the train station, you need to walk over the railway path that has many barriers for persons with disabilities. Traveling by airplane is even worse. The passenger takes a shuttle to the airplane (which is also hard to access for a person with disabilities) and then must climb up many stairs to enter the plane." (Adult with a physical disability)

Source: Qualitative research.

305 UN 2019b, 30.

306 UN 2019b, 86.

Explanation of the problem

There are legal provisions in Uzbekistan aimed at facilitating the participation of persons with disabilities in sports and tourism, but all the CRPD provisions have yet to be transferred to national legislation. Art. 42 of the Uzbek constitution guarantees to all citizens the right to enjoy cultural benefits. Corresponding secondary legislation includes provisions on the accessibility of cultural and sports facilities and services, however, enforcement mechanisms are not defined. Art. 27 of the Law "On the Rights of Persons with Disabilities" discusses the right to participate in cultural life, recreation, and sports. A 2015 Decree of the Cabinet of Ministers of the Republic of Uzbekistan, "On some issues of tourism development in the Republic of Uzbekistan," introduces discounts of 50-100 percent to persons with disabilities of groups 1 and 2 and residents of "murruvat" boarding homes for a range of cultural and recreational facilities. The discounted rates are compulsory only for state-owned establishments; they remain optional for private sector establishments and include only persons with disabilities who are citizens of Uzbekistan. The Law of the Republic of Uzbekistan "On amendments and additions to the Law of the Republic of Uzbekistan on physical culture and sports" includes among the main directions of state policy on physical culture and sports the promotion of physical culture and sports for persons with disabilities and other persons with limited physical abilities. Nevertheless, the law calls for the practice of adaptive sports in segregated environments such as special schools and rehabilitation centers rather than the participation of persons with disabilities in facilities used by the general population.

A recent decree on enhancing sports participation mentions the creation of opportunities for persons with disabilities; however, it does not set target indicators related to this group. According to the 2020 Presidential Decree no. 5924 "On measures for the further improvement and popularization of physical culture and sports in the Republic of Uzbekistan," to provide persons with disabilities the opportunity to participate in physical culture and sports, every sports facility should create conditions amenable to persons with disabilities. In addition, a program was designed to involve persons with disabilities in sporting activities and healthy lifestyles. Art. 5.2 of the decree calls for the following measures to increase participation rates in sports among persons with disabilities and persons in need of social protection: create conditions that allow for participation, including equipping sports facilities with special equipment; develop dedicated methods, programs, and technologies; and train specialized personnel. Special education institutions should provide conditions for practicing sports, and sports schools should allow children and youth with disabilities to attend. The activities in this decree are funded by the Ministry of Youth Policy and Sports, the National Olympic Committee, sports federations, the state budget, and other means. However, the target indicators for 2020-25 do not cover persons with disabilities; they are instead solely focused on sports events for those without disabilities. No hard data exist to evaluate the effectiveness of program implementation so far.

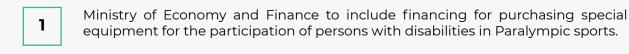
The government stresses the importance of developing the paralympic movement. Accordingly, the national Paralympic Committee was founded in 2021 (replacing the National Paralympic Association). Furthermore, the above-mentioned presidential decree also set the core objectives for paralympic sports. Nevertheless, it is noteworthy that while political support for excellence in sports is needed, the paralympic movement involves only a very small number of persons with disabilities. However, the movement can achieve a broader impact if it focuses on making sports accessible for all and promotes universal engagement in sports by persons with disabilities, from which paralympic athletes will ultimately be selected.

In 2022, the Ministry of Culture and Tourism set up a center to support entrepreneurs with disabilities who are engaged in tourism and leisure activities. The main functions of the center are to implement joint projects for the development of inclusive tourism, support the free movement of persons with disabilities, and monitor conditions created to provide access to persons with disabilities at tourist attractions. The center can draft state programs and legal documents and organize state-supported charity events. It is expected to create accessible routes at tourist sites such as Samarkand, Bukhara, Khiva, and Karakalpakastan.

Educational institutions and sports and training clubs lack qualified personnel who specialize in working with persons with disabilities. This lack of qualified personnel limits the effectiveness of measures to adapt sports equipment for persons with disabilities. The equipment is purchased with budgeted funds, but there are no competent specialists to assist persons with disabilities. Presidential Decree no. 5924, in the 2020–25 roadmap, notes the need to expand and improve the quality of the system for training personnel in the field of physical culture and sports, incorporating advanced international educational standards and requirements.

Recommended measures

LIMITED PARTICIPATION IN SPORTS AND TOURISM





- The MYPS to prepare a legislative document that stresses the requirement that each district have accessible sports fields and playgrounds for children and youth with disabilities in public places, such as parks and community (mahalla) centers, and that construction and renovation tenders for such places include a universal design or reasonable adjustments and include the purchase of accessible equipment.
- The Ministry of Culture and Tourism, in partnership with nongovernmental organizations working for and with persons with disabilities to develop a methodological guide to ensure the accessibility of tourist sites by persons with disabilities, and implementation should be regularly monitored.

8.3 Limited participation in the electoral process and public life

Art. 29 of the CRPD highlights that persons with disabilities should be guaranteed political rights and the opportunity to enjoy them on an equal basis with others. Moreover, the government must create an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs without discrimination and on an equal basis with others, and encourage their participation in public affairs. States parties must ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity to vote and be elected. This can be achieved by: (1) ensuring that voting procedures, facilities, and materials are appropriate, accessible, and easy to understand and use; (2) protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, to stand for elections, to effectively hold office and perform all public functions at all levels of government, including facilitating the use of assistive and new technologies where appropriate; and (3) guaranteeing the free expression of the will of persons with disabilities as electors and, to this end, where necessary and at their request, allowing voting assistance by a person of their choice.



Description of the problem

Improvements have been made to voting access in recent years, but problems remain.

Candidates with disabilities have been elected in local elections, but general elections have featured very few candidates with disabilities. A 2019 study³⁰⁷ highlighted that there is limited participation in policy-making by persons with disabilities, and they and their families do not feel adequately represented by organizations of persons with disabilities. Moreover, barriers to voting, including physical and informational access, meant that persons with disabilities participated less in the last general election. A survey of persons with and without disabilities indicates that, in general, persons with disabilities and caregivers of children with disabilities participated at lower rates than those without disabilities in the last presidential election (Table 16).³⁰⁸

³⁰⁷ UN 2019b.

³⁰⁸ Political participation rate, as measured by the number of adults with disabilities who voted in the last election/total number of adults with disabilities; the number of adults without disabilities that voted in the last election/total number of adults without disabilities (UN 2019b).

TABLE 16

Data on political participation rates in the 2016 presidential elections (percent)

	Persons without disabilities	Persons with disabilities
Total	94.6	90.0
Urban	94.2	90.1
Rural	95.1	89.9
Female	95.3	88.9
Male	93.7	90.9
Disability group 1		80.9
Disability group 2		90.6
Disability group 3		96.7
ICD F ^a		69.3

Source: UN 2019b: 163.

Note: Mental, behavioral, and neurodevelopmental disorders.

Very few persons with disabilities are aware of international treaties and laws that are supposed to protect their rights. On average, only 6 percent of survey respondents with disabilities were aware of the international treaties and laws protecting their rights (Table 17). A number of large organizations of persons with disabilities actively operate in the country, such as the Uzbek Society of the Deaf, the Society of the Blind, and the Society of Persons with Disabilities. However, a 2015 study by the Consultative Council indicates that many persons with disabilities do not understand the rationale or usefulness of these organizations. Indeed, 2019 data show that only 18 percent of persons with disabilities and guardians of children with disabilities think they are adequately represented by organizations of or associations for persons with disabilities.³⁰⁹

TABLE 17

Awareness of disability-related rights among persons with disabilities, 2019 (percent)

United Nations Convention on the Rights of Persons with Disabilities	3.3
Law on the Social Protection of Persons with Disabilities	7.0
Decree on measures to further enhance the effectiveness of medical, social, and professional rehabilitation of persons with disabilities	6.3
Decree on measures to further strengthen targeted social protection and support for the elderly and persons with disabilities	7.5
Decree on the approval of regulatory and legal acts aimed at further improving examination procedures for citizens to establish disability status and the degree of loss of professional capacity for work by medical labor expert commissions	6.0

Source: UN 2019b: 166.

Explanation of the problem

Barriers to the involvement of persons with disabilities in political life include:

- The lack of accessible environments at polling stations;
- Inaccessible political campaigns, including a dearth of information in alternative formats for visually and hearing-impaired persons, a lack of easy-to-understand information; and the absence of sign language and close captioning in televised public debates.

Most people do not frequently associate with persons with disabilities, resulting in their making judgments based on myths and stereotypes. Many without disabilities have a limited understanding of all but the most obvious types of physical disabilities. The willingness of some to enter into social relationships with a person with a disability depends on how close they are to the person and the nature of the disability. Some people are prepared to accept a neighbor who has a disability but not a colleague or spouse. Physical disabilities are more acceptable than mental disabilities to many. There is a strong belief that children with disabilities should be educated in specialized schools, but opinions are polarized about the value of residential schools and the care of orphaned children with disabilities.

The education system does not offer sufficient training in the area of disability studies and rights. Existing curricula in academic institutions do not adequately incorporate theoretical and practical material on the rights of persons with disabilities or the legislation that governs the social, public, and economic lives of persons with disabilities. For example, subjects such as human resource management, law, and journalism do not offer students cases or theoretical material related to persons with disabilities.³¹⁰

While attempts have been made to adapt polling stations to the needs of persons with disabilities, they have not been conducted in line with the construction norms outlined in building codes and standards. Monitoring of several polling stations in Tashkent performed by the Association of Persons with Disabilities of Uzbekistan shows that these stations have numerous shortcomings, such as:

- · Insufficient light in the booth;
- · Absence of magnifying glass for persons with visual problems;
- · Lack of signs with directions for persons with disabilities;
- · Restrooms not adapted to the needs of persons with disabilities; and
- · Steep and slippery ramps, of varying heights.

Persons with disabilities are rarely included in parties' outreach strategies or political campaigns. Even when they are targeted, the communication methods are often both inaccessible and noninclusive, posing several challenges to persons with disabilities. For example:

- A person with a disability is interested in joining a political party, but the website is inaccessible to screen readers (a technology commonly used by persons with visual disabilities), making it nearly impossible to find accurate information.
- A person who is deaf or hard of hearing struggles to understand a television or online video advertisement for a political candidate if close captioning or sign language interpretation is not provided.
- Easy-to-read materials are rarely available to persons with intellectual or developmental disabilities.

In addition, when they are not shown or referenced anywhere in communication materials, it sends a signal to persons with disabilities that they are not seen as part of the target audience.

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³¹⁰ As highlighted by participants of a consultation workshop carried out with relevant stakeholders for the finalization of the present technical note on October 12–13, 2022, in Tashkent.

Persons with disabilities actively participate in the voting process at the national level, but there are not enough data to assess regional-level participation. At the national level, several measures have been taken to address the accessibility of elections for persons with disabilities. The 2016 presidential elections brought improvements to the accessibility of the voting process for persons with disabilities, as most polling stations were located in stepfree facilities, ballots were available in Braille, and home voting was authorized for individual voters physically unable to vote in person.311 A memorandum of cooperation was signed between organizations of persons with disabilities and political parties in 2017, committing political parties to nominate candidates with disabilities in elections at multiple levels. The memorandum has been better followed in local elections (where parties nominated candidates with disabilities, 11 of whom were elected) than in national elections (general or presidential), where very few if any candidates with disabilities were nominated.³¹² During the 2019 elections for the legislative chamber of the Oliy Majlis, 4,158 persons with disabilities were involved in election commissions at various levels. According to the Central Electoral Committee, persons with disabilities made up 5 percent of the members of the district electoral committee.³¹³ At the same time, no data are available to calculate the number of persons with disabilities that announced their candidacy or were elected to regional offices. Preceding the last presidential elections, in May 2021, a new memorandum of cooperation was signed between the Central Electoral Committee and the Society of the Disabled, the Society of the Blind, the Society of the Deaf, and the Association of Persons with Disabilities of Uzbekistan. Taking into account the needs of blind voters, stencils were issued for filling out ballots in Braille. For deaf and hard-of-hearing voters, sign language interpreters were invited to polling stations on voting day if their support was requested in advance. Television programs about the election were broadcast with sign language translation and subtitles, and materials for the blind were published in special magazines using the Braille alphabet. All polling stations had to install ramps for persons with disabilities, as per the planning of accessibility measures.

While there is a desire by local public offices to adapt polling stations for the needs of persons with disabilities, these adaptations are not carried out in consultation with persons with disabilities or local nongovernmental organizations. Qualitative research shows that persons with disabilities are very active in exercising their rights. However, according to the qualitative research carried out for this analysis, many note that when voting is taking place, for example, during parliamentary elections at polling stations in their communities, such as schools, school representatives do not contact them to advise on how to adapt the polling stations.

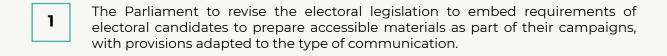
³¹¹ UN 2019b, 162-63.

³¹² UN 2019b, 162-63.

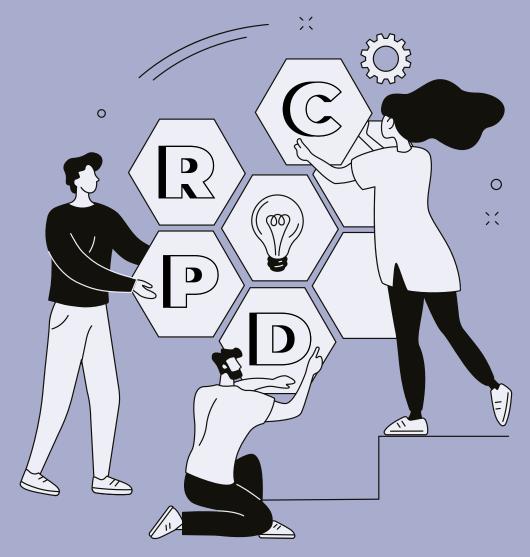
³¹³ https://www.uzdaily.uz/ru/post/64498

Recommended measures

LIMITED PARTICIPATION IN THE ELECTORAL PROCESS AND PUBLIC LIFE



- The Statistics Agency under the President of Uzbekistan to collect data about the participation of persons with disabilities in elections.
- The Parliament and the Ministry of Economy and Finance to set up a general election fund to support reasonable accommodations and other campaign costs for candidates with disabilities.
- The Parliament and other relevant decision-makers to consider alternative voting arrangements for persons with mobility impairments, such as postal voting, electronic voting, and extended voting timeframes, and implement adaptive solutions.
- The Parliament to introduce a quota system allocating a set number of parliamentary seats for persons with disabilities.



CHAPTER 9

Implementation and monitoring of the United Nations Convention on the Rights of Persons with Disabilities

As part of ensuring that the rights of persons with disabilities are respected and protected, States parties to the CRPD are required to develop a framework for its implementation and monitoring, with meaningful participation of persons with disabilities and their representative organizations. Art. 33 on "National Implementation and Monitoring" requires States parties to: (1) "establish one or more focal points within government for matters relating to the implementation of the Convention, and give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels;" (2) "maintain, strengthen, designate or establish a framework, including one or more independent mechanisms... to promote, protect and monitor implementation of the Convention;" and (3) actively involve persons with disabilities and their representative organizations in the monitoring process. Following the ratification of the CRPD in June 2021, Uzbekistan is in process of developing its framework for CRPD implementation and monitoring.

BOX 42

Key elements to ensuring the observance of rights of persons with disabilities at national level

To ensure the observance of rights of persons with disabilities, States parties must ensure cooperation within government institutions and participation of persons with disabilities and their representative organizations. Specifically, governments must:

- Establish one or more institutions to act as national focal point and potentially set up a coordination mechanism.
- The focal point may be a person, a department, an agency, or a ministry, equipped with sufficient human and financial resources for the task of overseeing CRPD implementation, and located at the highest possible government level to ensure institutional force to safeguard the rights of persons with disabilities. The focal point must collaborate with state institutions on matters related to the implementation of the CRPD, engage persons with disabilities in policy formulation, implementation and operational monitoring, and collect and make public operational monitoring data on CRPD implementation. As disability policy is cross-cutting and involves ministries from different sectors (labor, education, health, transportation, etc.), several focal points can be designated at the level of all institutions responsible for implementing related measures to ensure that the rights of persons with disabilities are respected.
- The coordination mechanism may be newly set up, or it may be an existing national mechanism assigned and capacitated to undertake this new role, for example, a council or committee dedicated to coordinating disability policy, joining key institutional actors and persons with disabilities and representative organizations. The coordination mechanism should facilitate dialogue between these actors.
- Support independent mechanisms tasked with observing the rights of persons with disabilities, that
 may be ombudsmen offices, human rights organizations, etc. Monitoring mechanisms look at how the
 government took measures to safeguard the rights of persons with disabilities, and the results that were
 obtained. They must oversee that services and programs provided for persons with disabilities are free
 from exploitation, violence and abuse.
- Ensure that persons with disabilities participate in decision-making that concern their lives. Persons with disabilities and their representative organizations must be involved in monitoring measures taken by the government to ensure they enjoy their full rights. Governments must support them in formulating well-informed opinions and must take them into account. Persons with disabilities and their organizations can prepare and submit to the CRPD Committee "alternative country reports" that present their view on how the rights of persons with disabilities are observed.*

Sources: CRPD Art. 33, Art. 35, Art. 36, HRC 2009, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/committee-on-the-rights-of-persons-with-disabilities-3.html

Note: * The CRPD Committee is comprised of independent experts who monitor States parties' implementation of the CRPD. It meets via two to three sessions per year. The CRPD Committee considers regular reports that States parties are obliged to submit following ratification: (1) an initial comprehensive report within two years, on measures taken to fulfill obligations under the CRPD and progress made in this timeframe; and (2) subsequent reports at lease every four years or at the request of the CRPD Committee. The CRPD Committee will consider each report and make suggestions and general recommendations that the State party may respond to. The CRPD Committee may also issue General Comments, authoritative guidance about the meaning of the CRPD provisions, or cross-cutting themes.

The implementation of Art. 33 provides the necessary infrastructure and support for the State parties realization and observance of the substantive article of the CRPD. States parties should start the implementation of the CRPD guided by the indications in Art. 33. Setting up a national framework for the implementation and monitoring of the CRPD consolidates the institutional setup necessary to ensure a common narrative and identify

whether national policies and practices are CRPD compliant. It also establishes a baseline and the various roles and responsibilities the State party has towards implementing the articles. These measures serve to effectively improve the lives of persons with disabilities through developing a common scope, defined by time-bound actions, the implementation of which is monitored through coordination within government and between government and civil society.³¹⁴

The core issues addressed under this sector are:

9.1 -

Limited capacity to coordinate CRPD implementation 9.2

/

Limited involvement of independent mechanisms for CRPD implementation monitoring 9.3

Limited involvement of persons with disabilities and their representative organizations in the monitoring process

9.1. Limited capacity to coordinate CRPD implementation

Uzbekistan has not yet designated focal points within the government to ensure that the CRPD is implemented and the rights of persons with disabilities are respected.³¹⁵ Art. 33(1) expressly calls for the designation of one or more focal points. The designation of focal points at the level of government ministries recognizes that the full and effective implementation of the CRPD requires concerted action within government.³¹⁶ Focal points, as envisaged in Art. 33 have the following roles: (1) serve as the CRPD contact point for government and civil society; (2) spearhead the CRPD and its values across and throughout government; (3) ensure coordination within government; (4) secure civil society involvement; (5) conduct a baseline analysis at the time of CRPD ratification; (6) publish a national CRPD implementation plan; (7) collate data and statistics; and (8) liaise with domestic and international human rights mechanisms.³¹⁷ These functions can be distributed among several focal points. Focal points are ideally designated within all central institutions responsible for implementing measures relevant to the lives of persons with disabilities.³¹⁸ If there is a designation of more than one focal point, a lead should be appointed to oversee and coordinate other focal points.³¹⁹ Good practice suggests and recommends that the lead focal point is appointed at a high level within the government (prime minister level) to enable coordination of other ministries (and focal points) and ensure continued strong support from the government.³²⁰ At present, the designation of a lead focal point in Uzbekistan has yet to happen.

To properly implement their role in alignment with CRPD provisions, appointed focal points must have adequate resources, including dedicated staff, disability rights training, and, in the case of the lead focal point, authority and convening power. Four essential elements for focal points must be followed to ensure the implementation of Art. 33: (1) there should be an adequate number of dedicated staff to carry out all functions and roles of a focal point; (2) all members or staff of the focal point must understand the CRPD concepts, principles, and framework and must have a rights-based approach to disability; (3) they should have adequate funding to exercise their role and functions; and (4) the lead focal point should have the authority to ensure that action is taken horizontally and vertically, including to convene meetings with, obtain information from, and instruct colleagues in government to take action.³²¹

In addition to designating focal points, the CRPD also recommends that States parties consider establishing a national coordination mechanism or revising an existing one to promote, protect and monitor the CRPD. In the event that more focal points are designated within government, a national coordination mechanism should be established to: (1) represent a permanent structure that enables coordination of institutional actors through

³¹⁵ CRPD Committee 2018, paras. 34–39.

³¹⁶ HRC 2009, para. 25.

³¹⁷ MDAC 2011, 26.

³¹⁸ For States parties, these can include various ministries, such as ministry of labor and social affairs, or ministries of finance, health, housing, education, employment.

³¹⁹ See HRC 2009 and discussions during the Seventh session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities, 10–12 June 2014 (https://www.un.org/development/desa/disabilities/conference-of-states-parties-to-the-convention-on-the-rights-of-persons-with-disabilities-2/seventh-session-of-the-conference-of-states-parties-to-the-convention-on-the-rights-of-persons-with-disabilities-10-12-june-2014.html).

³²⁰ MDAC 2011, 38.

³²¹ MDAC 2011, 38.

the participation of focal points that represent their institutions;³²² (2) ensure coordination at all levels; and (3) ensure the participation of civil society and OPDs. 323 The mechanism should ideally be presided over by the lead focal point in the government.³²⁴ Alternatively, States parties can appoint the lead focal point to take the role of a coordination mechanism.³²⁵ Through participation in this mechanism, central ministries will be able to avoid duplication of activities and optimal use of resources in their activities and policies that benefit persons with disabilities.³²⁶ The national coordination mechanism should have sufficient political leadership to drive a process of change and to distribute and mobilize leadership throughout government.³²⁷ To ensure traction and coordination across the government in implementing the CRPD, a coordination mechanism could be set up within the prime minister's office with the lead focal point at its helm to compensate for any limitations and ensure that actions are taken.³²⁸ Although the CRPD is not specific on the functions of the coordination mechanism, as these depend on each State party legal and administrative systems. Good practice suggests that it could tentatively include: (1) monthly meetings of senior servants across relevant ministries; (2) working groups to analyze and review relevant laws and policies; (3) annual meetings to check the progress and challenges in CRPD implementation; and (4) online resources to ensure transparency and accountability.

Uzbekistan has key actors in the field of disability that already fulfill roles similar to those comprised in Art. 33, but responsible bodies for each role were not yet formally designated:³²⁹

- The National Center for Human Rights (NCHR) of the Republic of Uzbekistan is the independent state body that fosters the interaction between state bodies and other organizations to fulfill the international obligations of the Republic of Uzbekistan in the field of human rights.³³⁰ The NCHR is in charge of drafting national action plans on the implementation of international treaties, preparing country reports to the UN treaty bodies, and other activities related to Uzbekistan's international obligations. In support of its monitoring activities, it conducts research in close cooperation with state bodies and has an Academic Council. The NCHR, together with other civil society organizations, monitors the implementation of ratified international treaties on human rights and annual reports to the Presidential Administration, Parliament, and Cabinet of Ministers. Following Uzbekistan's ratification of the CRPD in June 2021,³³¹ the country prepared its first draft National Action Plan (NAP-pending approval at the time of this writing) to support its implementation, which should explicitly setup the national monitoring system. The NCHR is leading this process and, by existing law, will also be responsible for regular reporting on CRPD implementation, including the initial report due by the Government of Uzbekistan in June of 2023.
- The Interagency Council for Persons with Disabilities (ICPD), recently established by the Cabinet of Ministers, could be designated as the national coordination mechanism in Uzbekistan, however, to meet the threshold of Art. 33, the ICPD would need to build its capacity and strengthen its engagement of OPDs. The ICPD resembles the role and structure of a coordination mechanism, as it: (1) coordinates the activities of state bodies implementing policies on ensuring the rights of persons with disabilities; (2) consists of representatives of relevant ministries, state organizations, and

³²² HRC 2009, paras. 25, 36.

³²³ HRC 2009, para. 34; UN, OHCHR, and IPU 2007.

³²⁴ HRC 2009, para. 36.

³²⁵ MDAC 2011, 37.

³²⁶ HRC 2009, para. 36.

³²⁷ MDAC 2011, 28.

³²⁸ MDAC 2011, 37.

³²⁹ As example, structures for setting up the implementation and monitoring of the CRPD are listed for European Union Member States on the Fundamental Rights Agency website: https://fra.europa.eu/en/cooperation/eu-partners/eu-crod-framework

The NCHR was established in 1996 as a nongovernmental organization (NGO) and in 2018 became an independent state body under the direct supervision of the president. See Decree of the President No. 4056/2018, "On strengthening the National Center for Human Rights of the Republic of Uzbekistan."

³³¹ Law of Uzbekistan No. 695/2021, "On ratification of the Convention on the rights of persons with disabilities."

civil society organizations, including OPDs;³³² and (3) is chaired by the chairperson of the Chamber of Commerce and Industry.³³³ The ADMSS under the Ministry of Public Health serves as its secretariat,³³⁴ but lacks a dedicated department, staff, financial resources, or capacity from a rights-based approach.³³⁵ The ICPD gathers at least once every six months and has its own staff.³³⁶ In light of its mandate, the ICPD has been designated in the draft NAP as responsible for coordinating the implementation of the CRPD.³³⁷ However, the ICPD currently lacks: (1) clear regulations on the daily work and capacity of its staff;³³⁸ and (2) an online tool or platform to publish accessible information on the progress and challenges of the CRPD implementation. Furthermore, although formal cooperation has been established with civil society organizations, the approved list of the council members shows that out of 16 participating civil society organizations, only one is an OPD.³³⁹

Persons with disabilities must be systematically involved in the development, implementation, and monitoring of policies that affect them. They must be able to transmit their concerns to the focal points and coordination mechanisms.³⁴⁰ Should they lack the capacity to do so, States parties should provide capacity-building opportunities to foster their engagement in the policy process.

There are limited resources to carry out operational monitoring of CRPD implementation in Uzbekistan. The CRPD recommends that States parties conduct baseline research before CRPD ratification and they develop national CRPD implementation plans. Such research justifying the urgency and necessity of the ratification has been developed over the years by the NCHR and civil society organizations, in cooperation with the international donor community, including the UN.³⁴¹ These organizations collected data that served as a baseline for the NCHR's development of the NAP³⁴² which is accessible to civil society organizations upon request. This was carried out without the close involvement of the ICPD. Following the finalization of the NAP, the development of a monitoring mechanism is planned and needed. Future monitoring of CRPD implementation entails that a high volume of data will need to be regularly collected and analyzed, which requires the allocation of human and financial resources to ensure the proper expertise and capacity.

³³² Law of Uzbekistan No. 641/2021, "On the rights of persons with disabilities," Art. 15.

³³³ Charter of the ICPD, para. 11 (https://static.norma.uz/doc/doc_5/769.pdf).

³³⁴ Charter of the ICPD, para. 12 (https://static.norma.uz/doc/doc_5/769.pdf).

Verified by participants of a consultation workshop carried out with relevant stakeholders for the finalization of the present technical brief on October 12–13, 2022, in Tashkent.

³³⁶ Law of Uzbekistan No. 695/2021, "On ratification of the Convention on the rights of persons with disabilities," Art. 15.

³³⁷ According to NCHR representative observations during a consultation workshop dedicated to Art. 33 of the CRPD in October 2022, the current NAP is not yet specific regarding the allocation of responsibilities as per Art. 33 because: (1) Uzbekistan doesn't have experience in such monitoring and coordination; and (2) the NAP will be amended once best practices from other countries are analyzed and these responsibilities are clarified.

³³⁸ Verified by participants of a consultation workshop carried out with relevant stakeholders for the finalization of the present technical brief on October 12–13, 2022, in Tashkent.

³³⁹ Order of the Cabinet of Ministers No. 769/2021, "On measure for strengthening activities of the Interagency Council for persons with disabilities."

³⁴⁰ CRPD Committee 2018, para. 26.

³⁴¹ The UN in Uzbekistan established a task force on persons with disabilities, which coordinated mainstreaming of "Leaving No One Behind" and implemented various programs. The latest effort was the situational analysis on persons with disabilities (UNPRPD MPTF 2021) whose baseline outcomes served as entry points for advocacy of the CRPD ratification by civil society organizations and OPDs.

³⁴² In this regard, one of the main partners of the NCHR in developing the NAP is the Association of Persons with Disabilities of Uzbekistan, the largest OPD in Uzbekistan.

Recommended measures

LIMITED CAPACITY TO COORDINATE CRPD IMPLEMENTATION

Senate of the Oliy Majlis of Uzbekistan, in consultation with the Ministry of Justice and OPDs, to revise the Law "On the Rights of Persons with Disabilities" to align it with Art. 33 of the CRPD to support the following: (i) establishing one or more CRPD focal points in relevant ministries, agencies, and other relevant public organizations (if more focal points, establish a lead focal point at the highest decision level); (ii) designating the national coordination mechanism to oversee the implementation and monitoring of the CRPD; (iii) allocating sufficient human and financial resources for the operation the focal points, lead focal point/secretariat of the coordination mechanism; and (iv) establishing a transparent mechanism for structured participation of and consultation with civil society and OPD within this framework.

- The National Center for Human Rights (NCHR) to facilitate training on the CRPD with the view to increase their competence regarding disability rights for the staff of all focal points and of the national coordination mechanism to receive training on the CRPD.
- The NCHR, together with the Interagency Council for Persons with Disabilities (ICPD), in consultation with OPDs, to set up a comprehensive monitoring mechanism for implementing the National Action Plan (NAP).
- The ICPD, with support from the NCHR, to elaborate and make publicly available regular operational monitoring reports of the implementation of the NAP.
- All government structures to ensure accessibility of all materials of public interest (such as minutes or reports) related to implementing the CRPD on official web pages and other official communication channels.
- The lead focal point and/or the ICPD to manage a resource online site on the CRPD implementation and monitoring.

9.2. Limited involvement of independent mechanisms for CRPD implementation monitoring

In line with CRPD Art. 33(2), Uzbekistan is required to establish a framework composed of at least one independent mechanism to promote, protect, and monitor the implementation of the CRPD. The following types of organizations can serve as such bodies: national human rights institutions in accordance with Paris Principles, ombudsman offices, OPDs, special bodies under UN treaties, human rights organizations, trade unions, research centers, and universities.³⁴³ Furthermore, in relation to the CRPD, the Paris Principles state that: (1) an independent monitoring mechanism shall be formally established; (2) persons with disabilities shall be members of this mechanism; (3) all laws and policies must be analyzed to identify contradictions to the CRPD; and (4) data must be available and accessible for meaningful monitoring.³⁴⁴ It is important that this mechanism be financially secured to ensure independence and impartiality. Members of the independent mechanism are highly recommended to declare any conflict of interest to ensure public trust.

The independent monitoring mechanism shall encompass three main functions: promoting, protecting, and monitoring the implementation of the CRPD. Promoting means raising awareness through information, training, and research campaigns on fundamental rights and making the paradigm shift to the social model of disability rights. Protecting means settling complaints about alleged human rights violations through mediation and amicus curiae in court, representing the victims, and providing legal assistance to people who assert their rights. Monitoring means assessing compliance with the legislation and practice related to the rights of persons with disabilities by carrying out general surveys and reporting to the relevant authorities.³⁴⁵ It must also ensure the engagement of persons with disabilities and their representative organizations in the process.

BOX 43

Case studies from the Czech Republic and France on formally engaging persons with disabilities and their representative organizations in the independent monitoring process

Czech Republic

In 2018, the ombudsman office in the Czech Republic established a special advisory body on the protection of rights of persons with disabilities. Since then, the ombudsman office is conducting independent monitoring of the effective implementation of measures set by the Czech government under the CRPD. The advisory body consists of persons with disabilities and disability advocates, and it cooperates directly with persons with disabilities, organizations of persons with disabilities, and other relevant nonprofit organizations and groups.

³⁴³ MDAC 2011, 47.

³⁴⁴ MDAC 2011, 48.

³⁴⁵ De Beco 2011, 94-96.

France

The ombudsman of France has the general mission to ensure the protection of rights and freedoms and to promote equality. In 2011, it was appointed by the government as an independent mechanism for monitoring the CRPD implementation. In this capacity, it ensures, in conjunction with persons with disabilities and their representative organizations, a mission of protection, promotion, and monitoring of the implementation of the CRPD. The ombudsman coordinates a Monitoring Committee for the implementation of the CRPD, which was established in 2012 to bring together, in a national forum, the main actors involved in CRPD implementation for making the protection of the rights of persons with disabilities more effective. The committee meets, on average, twice every year, and its members include:

- The French Council of Persons with Disabilities for European Affairs
- The General Controller of Places of Deprivation of Liberty
- · The National Advisory Commission on the Rights of the Child
- The National Advisory Council for People with Disabilities

Additionally, the state, represented by the French Minister of State for Disabled People, may be invited to participate as an observer.

Sources: "Monitoring of Rights of Persons with Disabilities," Ombudsman (Public Defender of Rights), Czech Republic website: https://www.ochrance.cz/en/pusobnost/ochrana-prav-osob-se-zdravotnim-postizenim/; "The Defender of Rights: An Institution for the Defense and Promotion of Your Rights," Defender of Rights, Republic of France website: https://www.defenseurdesdroits.fr/fr/institution/organisation/defenseur/; Defender of Rights, Republic of France (2020).

While an important actor in CRPD implementation monitoring, the Ombudsman Office is limited to complying with the Paris Principles to serve as the designated independent mechanism. The institution reports to the Oliy Majlis of Uzbekistan and was strengthened in 2017³⁴⁶ through the provision of more functions in monitoring human rights in the country as well as the freedom to work closely with civil society organizations.³⁴⁷ The Ombudsman Office works closely with different state bodies, institutions, human rights organizations, and OPDs on various human rights issues, including disability.³⁴⁸ For example, the Ombudsman reviewed 52 cases of violations of the rights of persons with disabilities,³⁴⁹ and the Association of Persons with Disabilities was a member of the National Mechanism for Torture Prevention and monitored selected prisons where persons with disabilities are doing their time.³⁵⁰ Furthermore, the Ombudsman Office in Uzbekistan includes two ombudspersons: one human rights ombudsperson who acts as head of the institution and a deputy ombudsperson who focuses on the rights of children. Civil society, through Uzbekistan's largest OPD, the Association of Persons with Disabilities of Uzbekistan, proposed as an analog the appointment of an ombudsperson dedicated to the rights of persons with disabilities, but a decision on this request was put on hold.351 However, the government establishes its budget, administrative structure, as well as its main priorities. Therefore, the Ombudsman Office is not fully independent and is limited to complying with the Paris Principles to serve as the independent monitoring mechanism.

³⁴⁶ Law No. 669-II/2017 "On Ombudsman."

For example, a national torture prevention mechanism was established in 2021 that includes several human rights organizations as its core members for monitoring torture. See "Activities of the Human Rights Representative (Ombudsman) of the Oliy Majlis to prevent torture and other cruel, inhuman or degrading treatment and punishment" on the Ombudsman of Uzbekistan website: <a href="http://ombudsman.uz/uz/docs/oliy-majlisning-inson-huquqlari-boyicha-vakilining-ombudsmanning-qiynoqqa-solish-va-boshqa-shafqatsiz-gayriinsoniy-yoki-qadr-qimmatni-kamsituvchi-muomala-hamda-jazo-turlarini-qollash-holatlarining-oldini-olish-boyicha-amalga-oshirgan-ishlari.

This institution should not be confused with the Business Ombudsman (Commissioner for the Protection of the Rights of Entrepreneurs), which is a separate independent institution under the president of Uzbekistan.

³⁴⁹ See "Ensuring the implementation of the rights of persons with disabilities by the Ombudsman of Uzbekistan,"

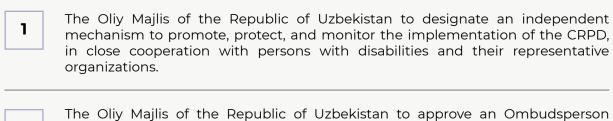
Ombudsman of Uzbekistan website: http://www.ombudsman.uz/ru/docs/obespechenie-realizatsii-pravinvalidov-ombudsmanom-uzbekistana.

³⁵⁰ See "Briefing by the Ombudsman on monitoring visits in 2021 as part of the National Preventive Mechanism for the Prevention of Torture," Ombudsman of Uzbekistan website: http://www.ombudsman.uz/ru/docs/ombudsmanning-qiynoqlarning-oldini-olish-boyicha-milliy-preventiv-mexanizm-doirasida-2021-yilda-amalga-oshirilgan-monitoring-tashriflari-boyicha-brifing-3. A recent analysis of the situation of persons with disabilities in Uzbekistan concluded that more research and monitoring of closed institutions is needed, the access to these institutional being almost impossible at the moment.

³⁵¹ Verified by participants of a consultation workshop carried out with relevant stakeholders for the finalization of the present technical brief on October 12–13, 2022, in Tashkent.

Recommended measures

LIMITED INVOLVEMENT OF INDEPENDENT MECHANISMS FOR CRPD IMPLEMENTATION MONITORING



- dedicated to the rights of persons with disabilities.
- The Ombudsman Office to regularly assess activities carried out on CRPD implementation and publish online accessible reports.
- The Ombudsman Office, together with OPDs based on a transparent participatory mechanism, to regularly visit institutions for persons with disabilities and publish online accessible reports on situations of human rights violations.

9.3. Limited involvement of persons with disabilities and their representative organizations in the monitoring process

Persons with disabilities and their representative organizations must be involved in the monitoring process.³⁵² The disability rights movement is governed by the slogan "Nothing about us, without us!" which emphasizes the principle of meaningful participation. It is vital that States parties provide financial, legal, economic, and social means to foster the active participation of interest groups in the monitoring of the CRPD.

Civil society in Uzbekistan is still undergoing a capacity development process following recent social and political changes.³⁵³ The importance of civic space development has been declared by the president, pointing to political change toward civil society organizations.³⁵⁴ According to official statistics, there are more than 10,200 registered NGOs in Uzbekistan, of which so-called GONGOs (government-affiliated NGOs) represent 65 percent, and self-initiative NGOs are 35 percent.³⁵⁵ Although the government introduced several mechanisms to support civil society development,³⁵⁶ including the adoption of the concept of civil society development in Uzbekistan by 2021–25,³⁵⁷ NGOs in Uzbekistan still face challenges because of: (1) recent limitation of civic space put in place during the COVID-19 pandemic and not yet lifted,³⁵⁸ (2) difficulties in registration of self-initiative NGOs; and (3) limited financial resources of NGOs that are mainly relying on foreign grants.³⁵⁹

The CRPD Committee considers that OPDs involved should be rooted, committed to, and fully respect CRPD principles, but few OPDs exist in Uzbekistan according to CRPD recommendations.³⁶⁰ They should be those organizations led, directed, and governed by persons with disabilities, with a majority of members being persons with disabilities.³⁶¹ These organizations are different from NGOs that are "for" persons with disabilities, which provide

- 352 CRPD, Art. 33(3).
- 353 International Center for Not-for-profit Law (ICNL) Civic Freedom Monitor: https://www.icnl.org/resources/civic-freedom-monitor/uzbekistan
- 354 https://uz.sputniknews.ru/20171224/novaya-politika-mirziyoeva-10-tezisov-kotorye-izmenyat-stranu-7142284.

 html
- 355 Yuksalish and PeaceNexus Foundation 2022.
- 356 Yuksalish and PeaceNexus Foundation 2022.
- 357 Presidential Order no. 6181/2021, "On approval the concept of civil society development in Uzbekistan by 2021–2025."
- 358 Criminal charges for spreading false information has been amended to the criminal code in March 2020, after the first COVID-19 case has been officially registered in Uzbekistan. Art. 244-6 of the Criminal Code of Uzbekistan.
- 359 Decree of the Cabinet of Ministers no. 328/2022, "On approval of the regulations on the procedure for the interaction of local non-state non-profit organizations with state authorities in the implementation of international grant projects."
- 360 CRPD Committee 2018, para. 11.
- 361 CRPD Committee 2018, para. 11.

services and/or advocate on their behalf. ³⁶²However, few such OPDs exist in Uzbekistan owing to registration difficulties. ³⁶³ Despite the existence of clear procedures, including the necessary documentation for registering an NGO, ³⁶⁴ the process is unsuccessful or delayed for many self-initiative groups (because of repeated rejections or delayed procedure), while GONGOs experience a fast registration process. Furthermore, among registration authorities, there is a lack of knowledge on the CRPD and the key participatory dimension of OPDs.

States parties must submit an initial report within two years from ratification to the CRPD Committee, followed by regular reports every four years. Civil society is encouraged to also submit their own alternative reports to the CRPD Committee, as per the Guiding Rules. This enables the CRPD Committee to have a more nuanced perspective and garner whether the policies in place are implemented and impactful. In this process, the capacity of civil society to ensure reliable data and sources of information that may not be in line with the State position or report is key. At the same time, NGOs that submitted alternative reports can also participate in the sessions discussing the country reports together with the State party.

Uzbekistan must increase its investment in building capacity of OPDs to be fully involved and participate in the monitoring of the implementation of the CRPD. Involvement and participation should be meaningful and take place at all the stages of the monitoring process, which should be accessible, respectful of the diversity of persons with disabilities, and gender- and age-sensitive. To this end, it is of utmost importance to have the relevant organizational capacity, knowledge and expertise, which can be developed through informational events and training on both general and specific topics related to the CRPD and the monitoring of its implementation.

³⁶² CRPD Committee 2018, paras. 13-14.

³⁶³ https://www.gazeta.uz/ru/2020/03/20/ngo/

³⁶⁴ Existing legislation, such as laws on NGOs, public associations, trade unions, and public funds create the main legal framework regulating NGO activities in the country. Apart from these, there are bylaws that set procedural rules for registration and donor involvement in the country.

The Republic of Uzbekistan intends to submit its initial report in July 2023 (http://www.nhrc.uz/en/menu/nogironlar-uulari-bjicha-mita).

³⁶⁶ CRPD Committee 2016b, para. 20.

[&]quot;Organizational capacity, knowledge, and expertise means: (1) skills to participate in monitoring activities; (2) skills to engage in policy formation and implementation; (3) the confidence and skills to participate in meetings and challenge exclusion; (4) knowledge about human rights, including the CRPD; (5) knowledge about how to exercise those rights; (6) knowledge about who the key people with respect to domestic implementation of the CRPD; and (7) an understanding of the relevant policy issues and how policy is formed" (MDAC 2011, 24).

Recommended measures

LIMITED INVOLVEMENT OF PERSONS WITH DISABILITIES AND THEIR REPRESENTATIVE ORGANIZATIONS IN THE MONITORING PROCESS

- Ministry of Justice to introduce and add OPD with its status as a type of NGO in the NGO code.
- The government of Uzbekistan to finance advocacy activities that promote the CRPD carried out by civil society and OPDs.
- The National Center for Human Rights to provide training to civil society and OPDs on the CRPD to enable them to provide feedback on laws and policies affecting the rights of persons with disabilities and build their capacity for monitoring progress and results in implementing CRPD.
- The Agency for Development of Medical and Social Services under the Ministry of Public Health to improve the capacity for monitoring the implementation of policies and programs for persons with disabilities by: (i) extracting all the relevant information disaggregated on disability from the Household Budget Survey; (ii) implementing a special survey to collect, in three waves, baseline, mid-term and expost data on the realization of the rights of persons with disabilities in Uzbekistan.

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Annexes

ANNEX TARLE

Special education network per region, 2021–22

									Е	Boarding	scho	ol													
			1.0	ow.				Hard of		Intellectual		Physical			Sanatorium type							Special daycare		Total	
	Blind		vision			Deaf	hearing		disability		disability		Speech disorder		Tuberculosis		Bone		Lung		so	chool			
															. 45010410313		disease		problem						
	No. of schools	No. of students	No. of schools	No. of students	No. of schools	No. of students	No. of schools	No. of students	No. of schools	No. of students	No. of schools	No. of students	No. of schools	No. of students											
Total	13	3,125	1	315	13	3,921	5	1,268	30	7,474	3	796	1	214	11	3,168	10	3,193	1	113	20	4,572	108	28,159	
Karakalpakstan	1	262			1	244			1	346					1	220	1	158			1	158	6	1,388	
Andijan	1	174			1	210	1	243	4	1,012					1	353	1	268			2	456	11	2,716	
Bukhara	1	266			1	237			2	688					2	673	1	296					7	2,160	
Jizakh	1	286			1	163	1	236	1	268													4	953	
Kashkadarya	1	250			1	467			1	252					1	379	1	298			1	288	6	1,934	
Navoi	1	136		_	1	249			1	253													3	638	
Namangan	1	236			1	305			3	786			1	214	1	306	1	321					8	2,168	
Samarkand	1	264	1	315	1	419			3	737					1	372					1	148	8	2,255	
Surkhondaryo	1	334			1	429			1	360					1	277	1	555					5	1,955	
Syrdaryo									1	241					1	248							2	489	
Tashkent region					1	219	,		4	657	1	236			1	76	1	210			6	1173	14	2,571	
Ferghana	2	339			1	504			5	1,232	1	242					1	239					10	2,556	
Khorezm	1	191			1	254	1	204	1	334					1	264	1	261	1	113			7	1,621	
Tashkent city	1	387			1	221	2	585	2	308	1	318					1	587			9	2349	17	4,755	

Necessary ADs and those provided by the state

	List of ADs as needed by persons with disabilities, according to the 2019 UN survey	List of ADs provided by the state				
1	ADs for movement & self-service					
1	Orthopedic shoes	Orthopedic shoes				
2	Prosthetic legs, arms, or other implants (except dental)	Prosthetic legs, arms or other implants (except dental)				
3	Cane	Cane				
4	Crutches	Crutches				
5	Wheelchair	Wheelchair				
6	Walking aid	Walking aid				
7	Dental braces, dental implants	Dental braces, dental implants				
8	A disability-adjusted car	A disability-adjusted car				
9	Non-prosthetic, reaching or grabbing devices					
Ш	ADs for visually impaired and blind persons					
11	Glasses and contact lenses	Glasses and contact lenses				
12	Tools for reading and writing in Braille	Tools for reading and writing in Braille				
13	Large, printed materials	Large, printed materials				
14	Audiobook/talking book					
15	Recording audio devices (such as dictaphone), electronic notebook, etc.					
16	Projector to magnify text or images and display them on external screens and PC/TV					
17	Computer with Braille, large print, or a speech synthesizer					
18	Guide cane	Guide cane				
19	Guide dog					
Ш	ADs to hear better and for speech (for communicating with other people)				
20	Hearing aid	Hearing aid				
21	Computer for communication (e-mail, chats, instant messengers)					
22	Devices/accessories for a telephone that allow one to hear clearly with a hearing aid, or with a light, vibrating signal, with a minicomputer that outputs an audio message in the form of printed text					
23	Device for messaging or other devices and accessories					
24	TV with subtitles or with subtitle converter so that audio information is converted into scrolling texting line					
25	Amplifier (acoustic, infrared)					
26	Visual (light) or vibrating signal/alarm (e.g., to see/hear a doorbell or fire alarm.)					
27	A prosthetic ear or other device to amplify sounds					
28	Any sound amplifier (such as a megaphone) to hear or speak better					
29	Computer or keyboard					
30	Communication board containing symbols and pictures for meaningful interaction					
IV	Sanitary and hygienic products					
31	Urinary and other catheters					
32	Urinals					
33	Colostomy bags					
34 35	Bedsore mattresses and cushions					

Source: UN 2019a.

ANNEXES 189

Official list of prosthetics and orthopedic products and technical means of rehabilitation

Types I. Prosthetic and orthopedic products Hand prostheses: shoulder prosthesis, arm prosthesis after shoulder removal, wrist prosthesis, palm Foot prostheses: hip prosthesis, leg prosthesis after hip removal, leg prosthesis 3 Orthopedic products for the arm and leg, plastic corsets Corset 5 Breast exoprosthesis Belt holder for arms and legs 8 Advanced orthopedic shoes and prosthetic shoes II. Technical means of rehabilitation **Hearing aid** 10 Axillary crutch 11 Cane 12 Elbow crutch 13 Cane for the blind 14 Walking device 15 Urine receiver 16 Fecal receiver 17 Room wheelchair 18 Outside (street) wheelchair

Source: Cabinet of Ministers Decree (CMD) no. 411 issued in June, 2021.