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SITUATION ANALYSIS ON CHILDREN AND ADULTS WITH DISABILITIES IN UZBEKISTAN

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BRIEF REPORT





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Brief report



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SITUATION ANALYSIS
ON CHILDREN AND ADULTS WITH DISABILITIES IN UZBEKISTAN

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CONTENT

ACKNOWLEDGEMENTS.....	4
INTRODUCTION.....	6
FINDINGS.....	8
Identifying disability.....	9
Knowledge, attitudes, practices (KAP) towards people with disabilities	11
Legislation, equity and justice	21
Right to accessibility.....	25
Right to independent living and participation in cultural life, recreation,leisure and sport.....	28
Right to Health	31
Right to Rehabilitation	34
Right to adequate standard of living and social protection.....	39
Child Protection	45
Right to (Inclusive) Education	46
Right to Work and Employment	50
Statistics and data collection	52
Right to political participation	53
POLICY RECOMMENDATIONS	56



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

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



INTRODUCTION

INTRODUCTION

This Situation Analysis on People with Disabilities in Uzbekistan was commissioned by the Government of Uzbekistan and UN agencies and it provides a “snap-shot” of the current situation in the country. It provides a baseline for future work and elaborates on actions to be taken to successfully broaden the rights and inclusion of both children and adults with disabilities in Uzbekistan.

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



FINDINGS

Identifying disability

Disability is defined using medical and charity models rather than the CRPD's rights-based, enabling perspective, nor does it focus on systemic problems within society or the environment. Defining disability according to a list of diseases/severity is not an accurate or consistent way to ascertain an individual's capacity to function or needs.

In Uzbekistan disability is defined using a blend of medical and charity models: "a disabled person is a person who, due to limitations of functioning resulting from their physical or mental impairments is in need of social assistance and protection. Limitation of functioning of a person is characterized by their full or partial loss of capacity or ability to self-service, move around, orientate, communicate, control their behavior, and work." This deficiency-based official definition stands in contrast to the social definition of disability contained in the CRPD. This is focused on empowering, enabling and guaranteeing human rights, includes an appraisal of the environment and perceives an individual as self-reliant when given adequate support.

The formal identification of disability is based upon a medical assessment which is not in alignment with that the CRPD. There are procedural concerns with the current approach: the existing List of Diseases (and corresponding ICD (international classification of disease) codes) describe only a disease and not an impairment, but often attempts to quantify



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a degree of severity. However, despite the seeming simplicity of the procedure, 1) the list of diseases is not exhaustive; 2) evidence indicates that there is no correspondence between the severity of a disease and a degree of impairment; 3) a lack of established methodology and specific tools allows for discretionary powers in assessment; 4) it does not take into consideration cultural and environmental factors.

FINDINGS

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

Most people without disability have little association with people with disabilities which results in judgement based on myths and stereotypes.

People without disabilities had limited understanding about all but the most obvious physical disabilities.

When asked for their first thoughts about people with disabilities, some people without disabilities cited reactions ranging from pity, to mercy, and a desire to help. However, a majority of responses cited pejorative associations, and only a small minority mentioned feelings related to respect and equality. In terms of emotional reactions, only a small minority had a normalising approach towards people with disabilities.

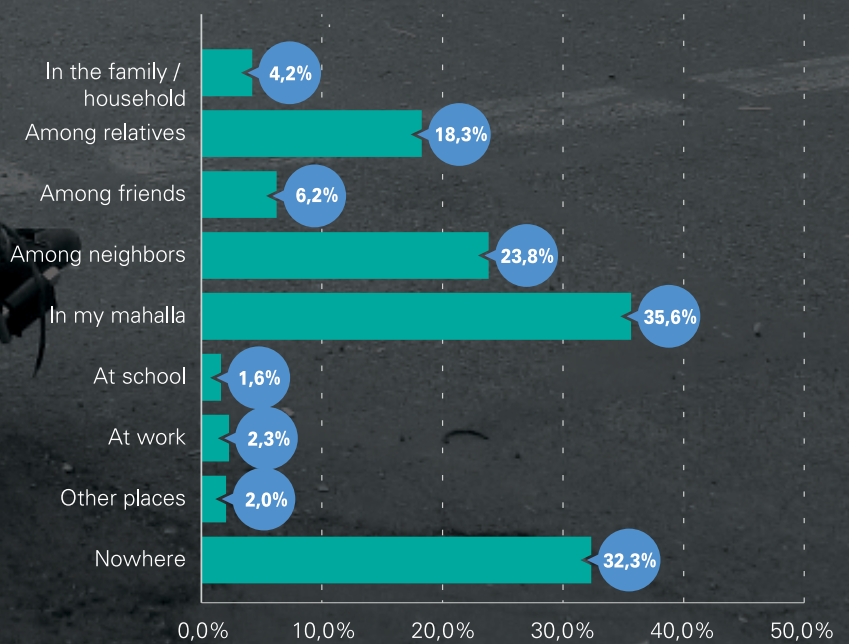
Peoples' willingness to enter social relationships with disabled people depended on the closeness of that relationship and the nature of the disability ie. people were ready to accept a neighbour with a disability, but not a colleague or spouse. Physical disabilities were more acceptable than mental disabilities.

There is a strong belief that disabled children should be educated in specialised schools, but polarised beliefs about the value of residential schools and care of orphaned disabled children exist. Almost a third of people believed that children with disabilities should live in murravats (orphanages) rather than with their families.

People with disabilities remain “invisible” for the general public, which leads to charity-focused attitudes towards people with disabilities and their social rejection.



Graph 1. **ACQUAINTANCE WITH PEOPLE WITH DISABILITIES**
percentage of people without disabilities who have/see people with disabilities in their environment/neighborhood

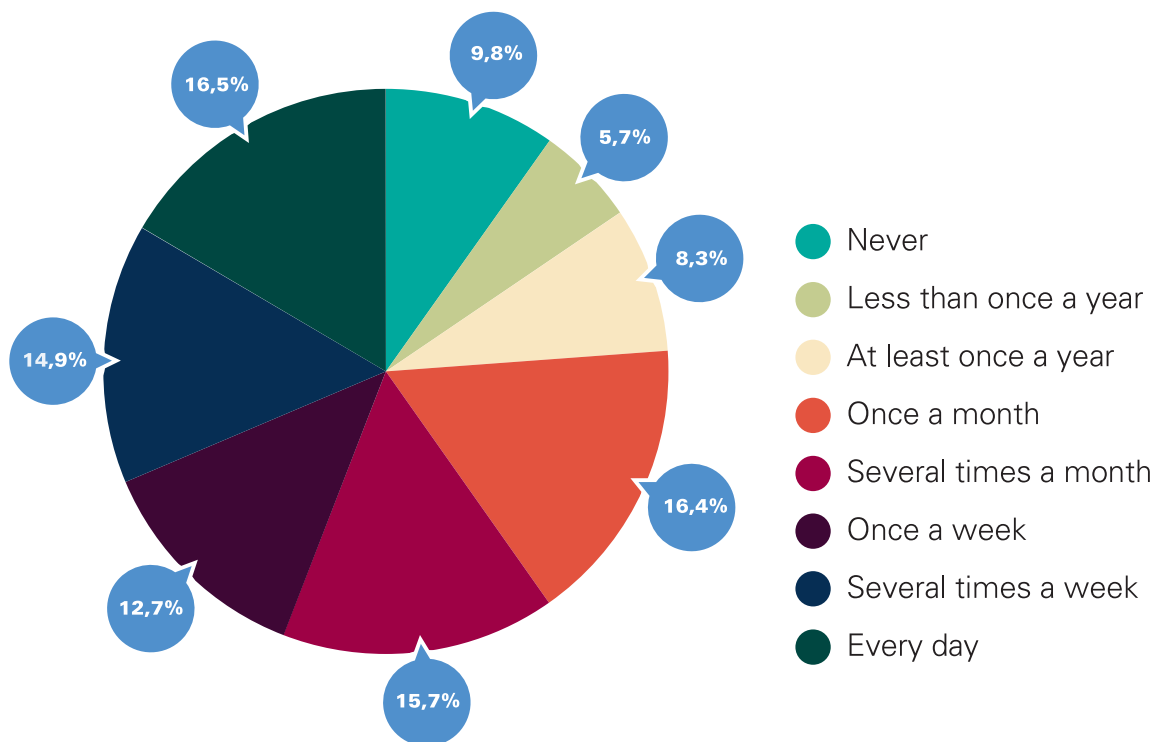


FINDINGS

In the KAP survey few people saw or had people with disabilities in their places of study or work, or among friends or close relatives, and only a third saw them in their mahallas. Another third didn't know any person with a disability (graph 1).¹,

10 per cent of respondents reported they had never communicated with a person with disabilities, and 14 per cent that they had contact with a person with a disability once a year, or less (graph 2).

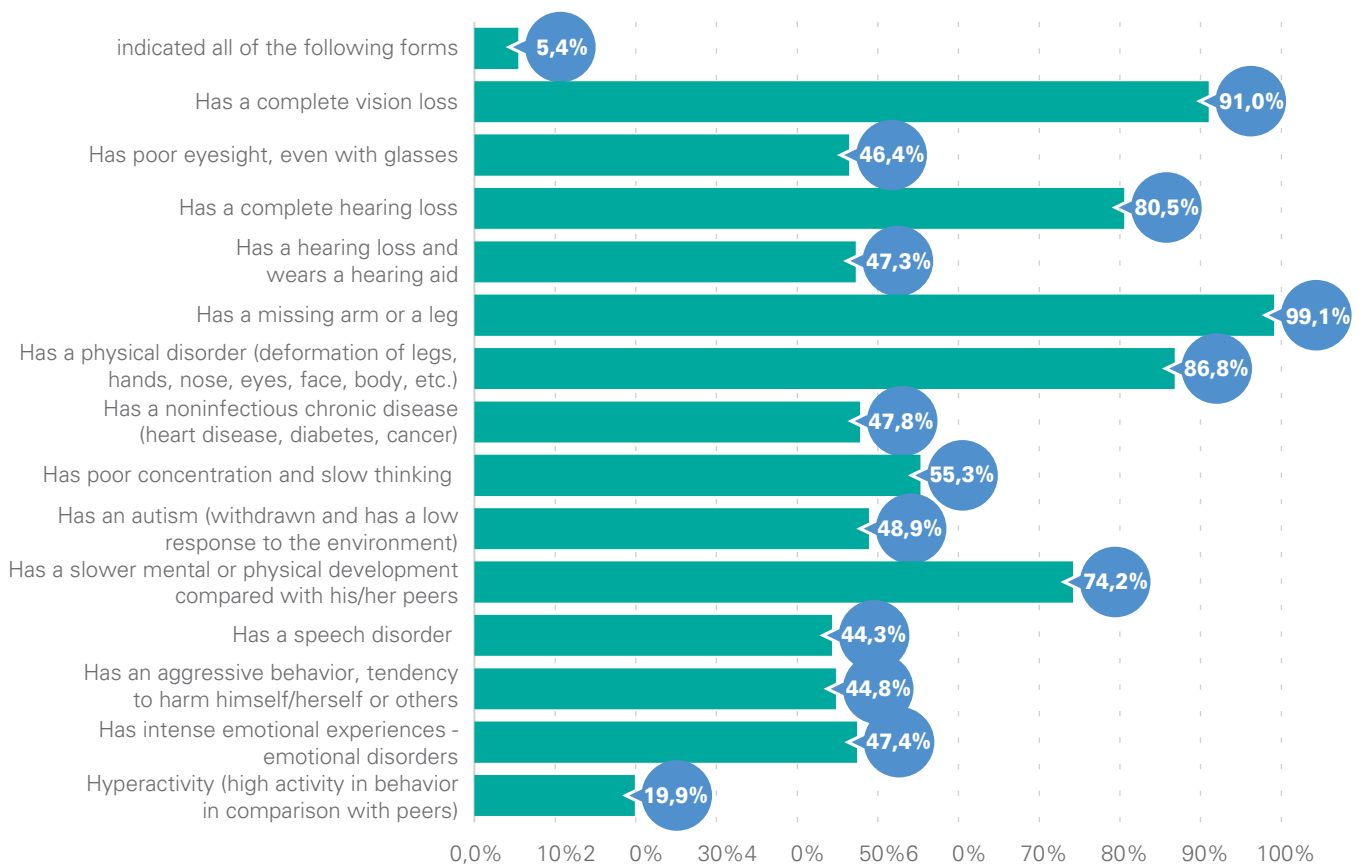
Graph 2. **FREQUENCY OF MEETING WITH PEOPLE WITH DISABILITIES,** percentage of people without disabilities



¹ The source of data for all graphs is the KAP survey and the survey on the assessment of needs of persons with disabilities. Thus, data sources are not indicated under the graphs

Only 5 per cent of respondents recognised all types of disorders and impairments in the survey as signs of disabilities (Graph 3). Impairments of a physical/mobility nature were recognised as an indicator of disability (such as missing limbs or “deformation” of body parts, as were extreme sensory impairments such as complete loss of vision and complete hearing loss, and delays in mental or physical development. However, there was less awareness of other sensory impairments, mental health issues and behavioral conditions.

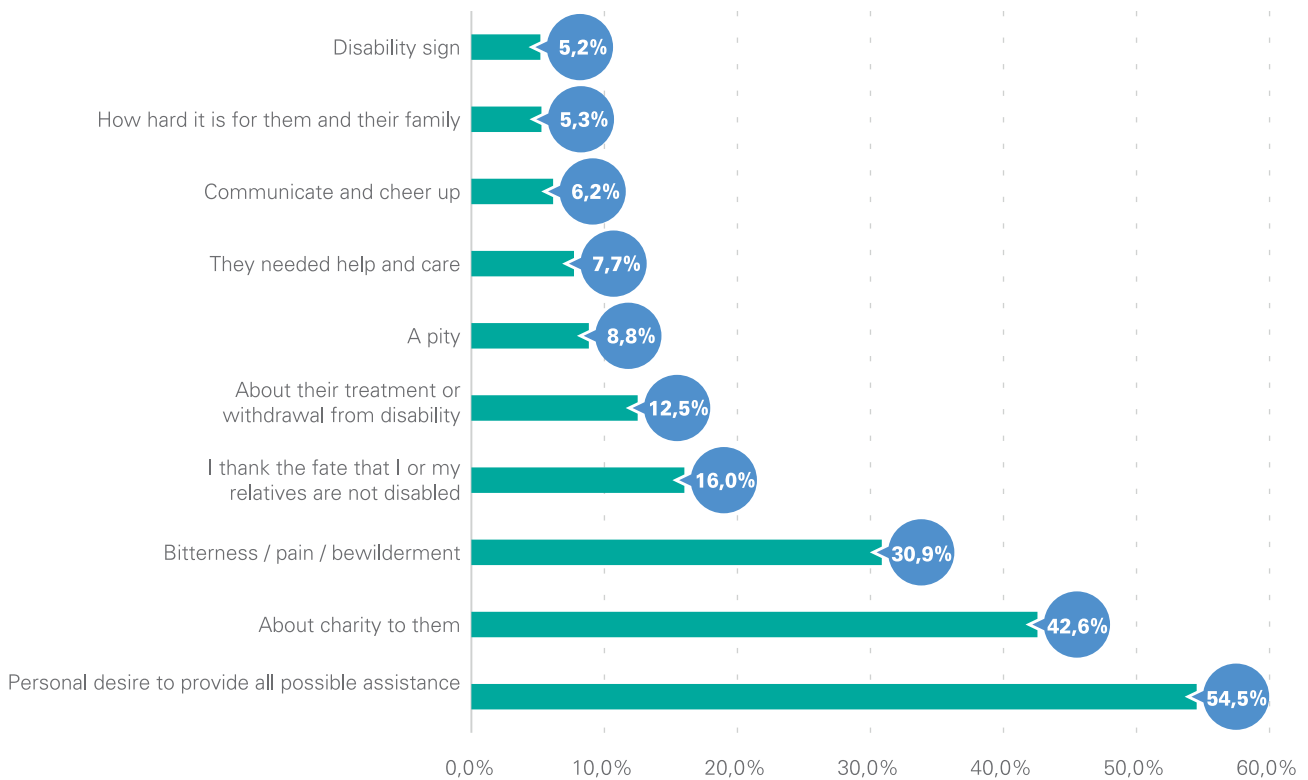
Graph 3. **DISTRIBUTION OF PERCEPTION OF IMPAIRMENTS/DISORDERS ASSOCIATED WITH DISABILITY**
percentage of people without disabilities



FINDINGS

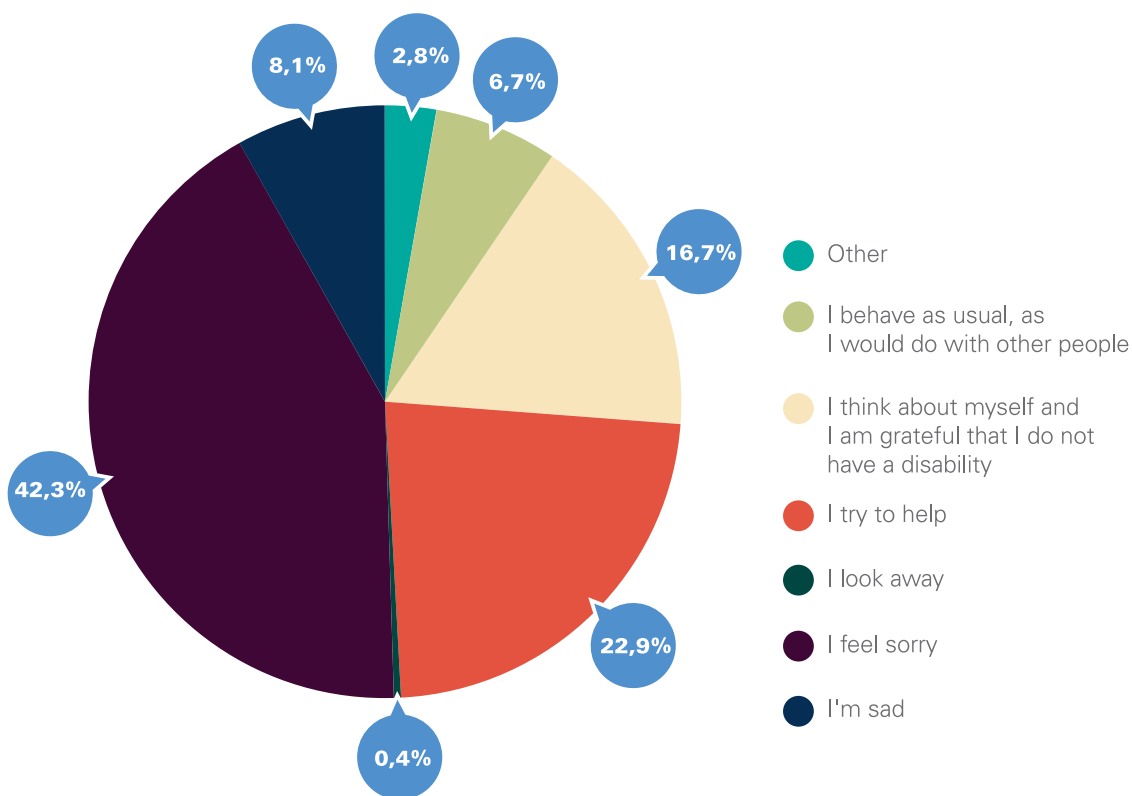
People associated disability predominantly with the provision of non-personal assistance (31 per cent) compassion (5 per cent), pity (5 per cent), the need for mercy (22 per cent), the desire to help (20 per cent). Pejorative associations made up 31 per cent of responses and there were some indications of a rejection of people with disabilities. Only 1 per cent of responses showed an association with respect and equality and only 0.2 per cent showed mentioned the integration of people with disabilities into society or creating conditions for life and rights (Graph 4.).

Graph 4. **TOP 10 IDEAS THAT COME FIRST TO MIND WHEN THINKING ABOUT PEOPLE WITH DISABILITIES**
percentage of respondents



When asked of their sentiments towards people with disabilities, almost half of people without disabilities surveyed felt pity towards them and 23 per cent wished to help them. every fifth reported: "I think about myself and I am grateful that I do not have a disability." Only a very limited share of respondents had a normalizing approach towards people with disabilities (Graph 5.).

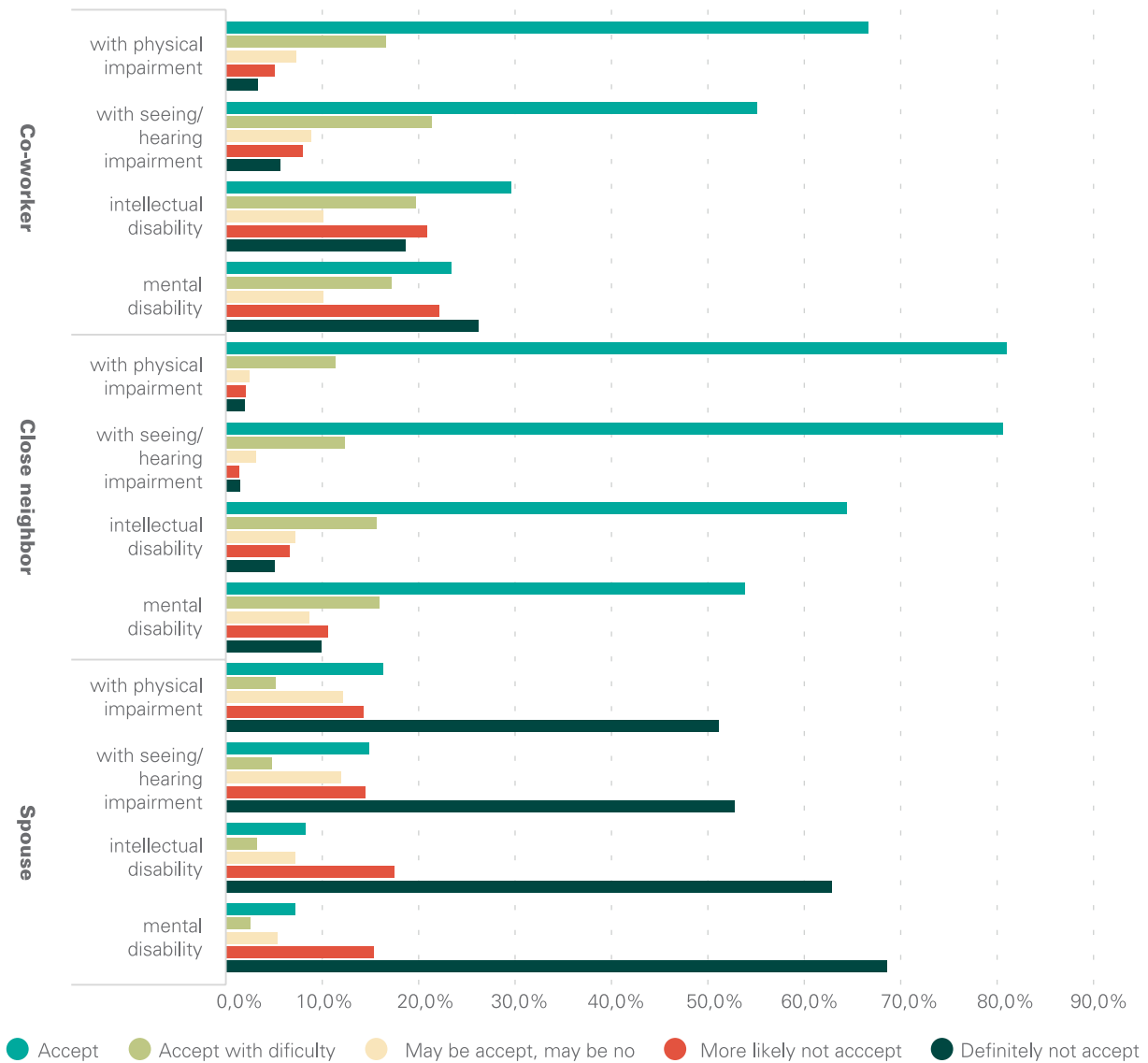
Graph 5. **FEELINGS OF RESPONDENTS WHEN THEY MEET A PERSON WITH A DISABILITY**
percentage of people without disabilities



FINDINGS

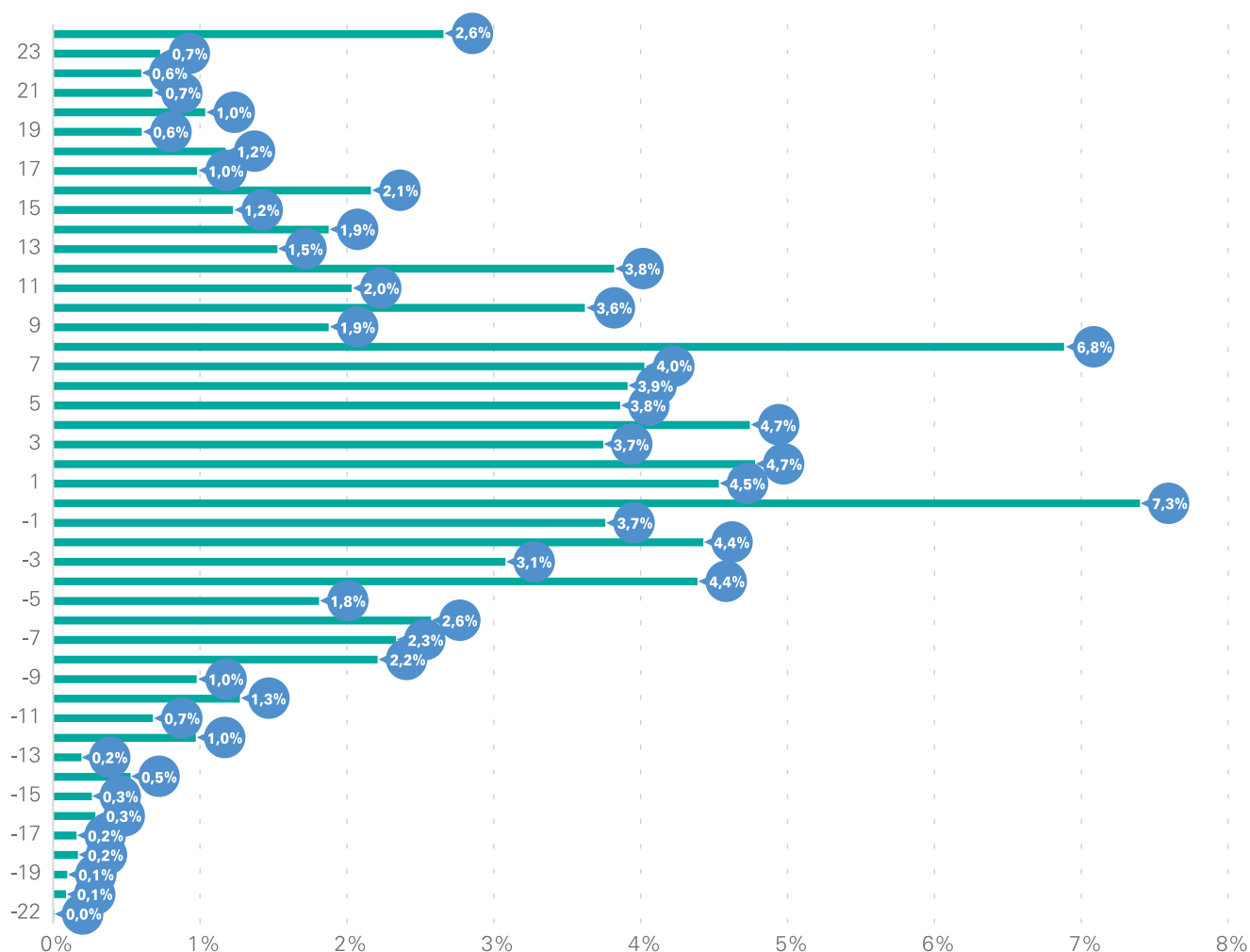
Survey responses showed a varying willingness to accept people with disabilities depending on social distance and type of disability. Respondents were more likely to accept people with disabilities as a neighbor (87 per cent) or colleague (74 per cent) rather than as a spouse (20 per cent). As per global research, survey data confirmed that respondents were less willing to accept people with intellectual disabilities and more willing to accept people with physical disabilities (Graph 6.).

Graph 6. **WOULD YOU ACCEPT A PERSON WITH A DISABILITY**
percentage of respondents



The values of the social distance index vary between -24 and +24. In Uzbekistan, average scoring was positive, but at +3.99 only minimally so and represents only 16.6% of the maximum possible score. The most frequent score among respondents was zero (Graph 7).

Graph 7. THE DISTRIBUTION OF THE SCORES OF THE SOCIAL DISTANCE INTEGRAL INDEX percentage of people without disabilities

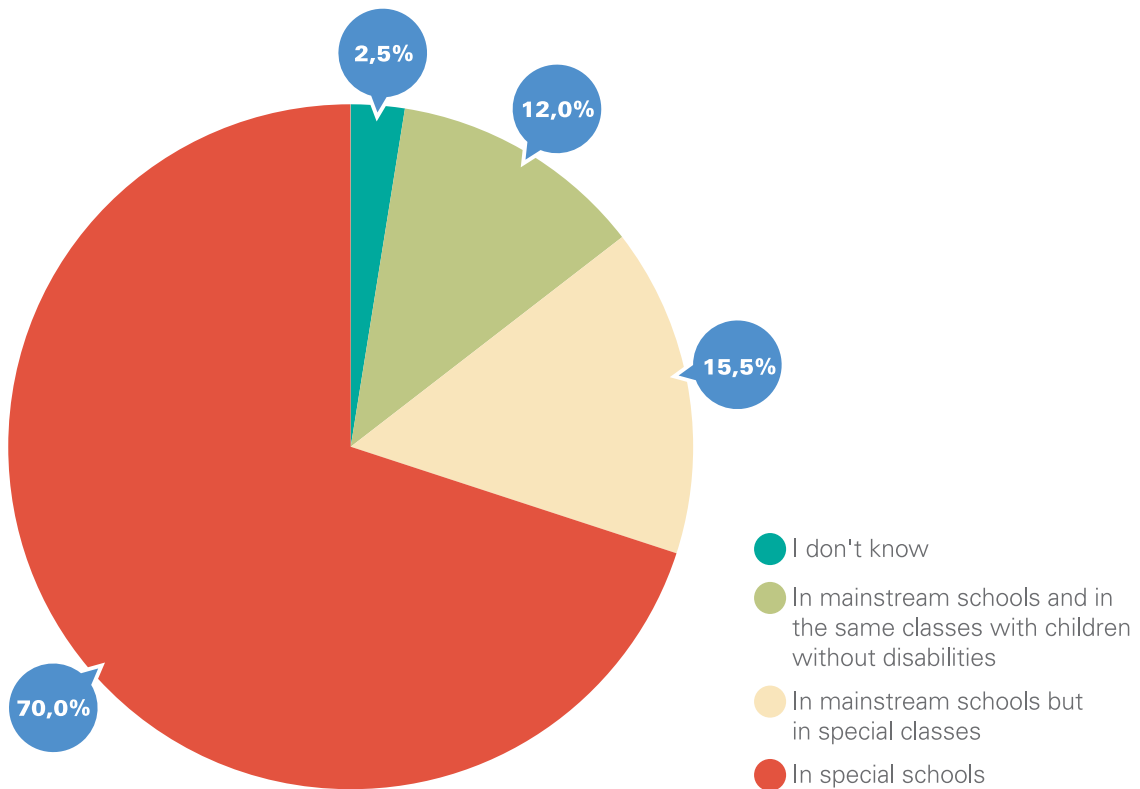


Note: the index was constructed based on questions about how the respondent would react to the fact that his/her new colleague or new close neighbor has certain types of impairment (physical, hearing, seeing, mental impairments) or whether s/he would marry such a person. The responses have the following scores: +2 = Perceived as an ordinary, +1 = Perceive, but with difficulty, 0 = Can be perceived, and maybe not perceived, -1 = Rather, I will not accept, -2 = Definitely will not accept. Further, the scores about the relation to the alleged are multiplied by three and those about relation to the disabled among employees on work are inflated by two. The score for each respondent is the total sum of scores based on this methodology. Scores vary from -24 to +24.

FINDINGS

This attitude is similar for children with disabilities. Almost 70 per cent of respondents believed that specialised schools are the best way to educate children with disabilities (Graph 8.).

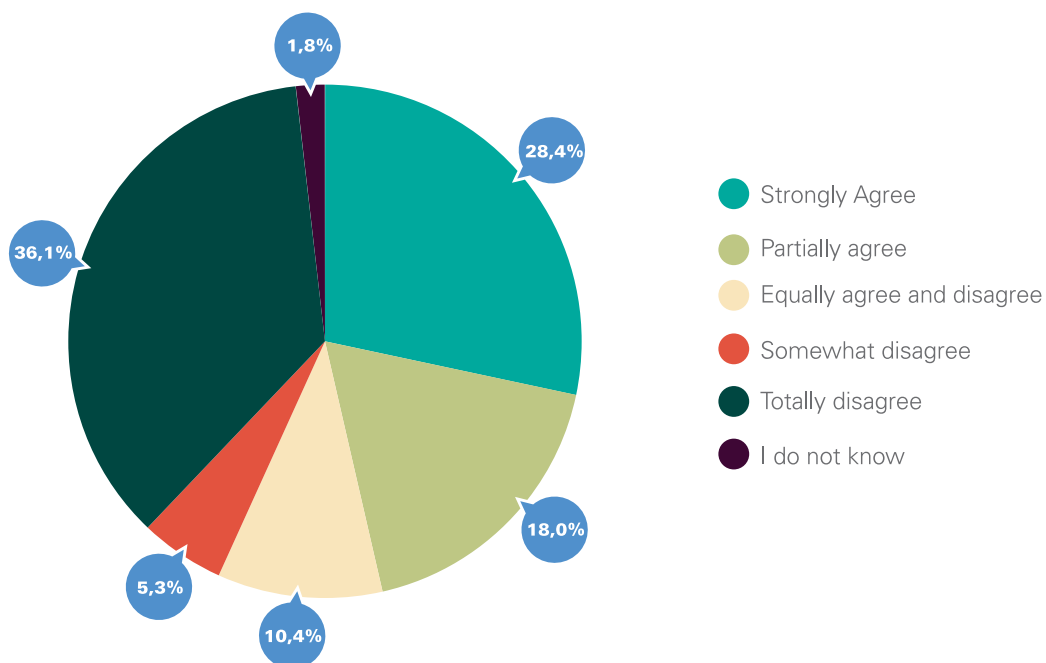
Graph 8. PUBLIC NORMS ON THE BEST PLACE FOR THE EDUCATION OF CHILDREN WITH DISABILITIES
percentage of respondents



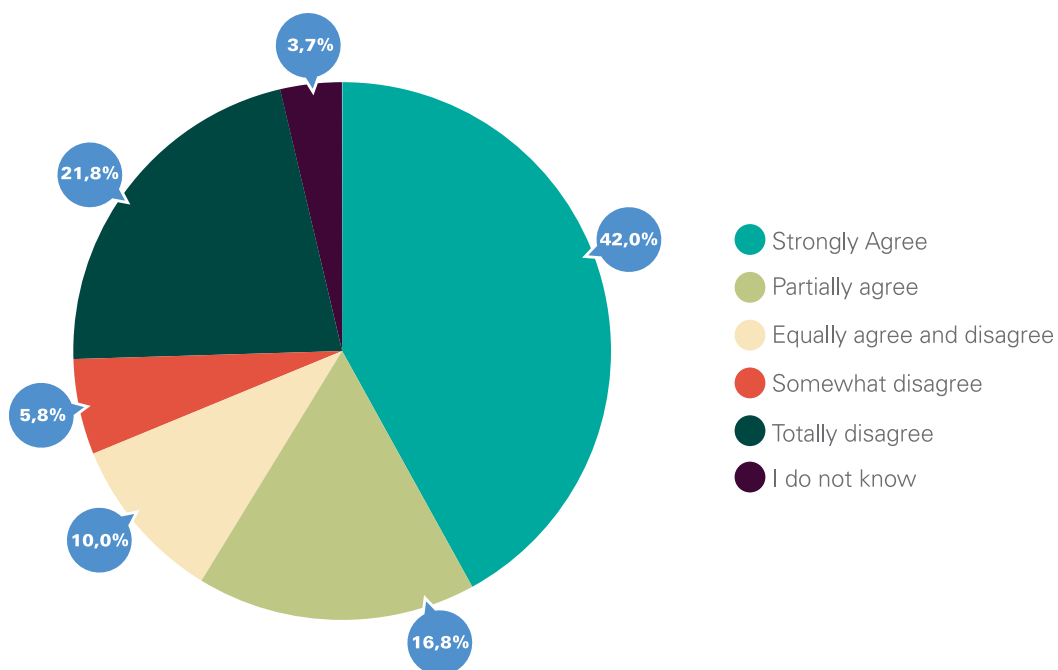
While the majority of respondents (36 per cent) were fully against the idea that children with disabilities should live in residential institutions instead of with their families, more than one in four (28 per cent) respondents strongly agreed with this practice (Graph 9). At the same time, more respondents are more inclined towards the idea of placing them into residential institutions (46.4 per cent against 41.4 per cent).

While 42 per cent of respondents strongly agreed that children with disabilities who are orphaned would be better off living with a foster family than in residential institutions, 22 per cent believed the opposite (Graph 10).

Graph 9. **PUBLIC NORMS ON PLACING CHILDREN WITH DISABILITIES IN SPECIALISED INSTITUTIONS AND NOT LIVING IN THEIR FAMILIES**
percentage of respondents



Graph 10. **PUBLIC NORMS ON ORPHAN CHILDREN WITH DISABILITIES LIVING IN A FOSTER FAMILY RATHER THAN IN A SPECIALISED INSTITUTION**
percentage of respondents



Legislation, equity and justice

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

Currently, legal measures do not adequately protect disabled people from discrimination, indeed they sometimes generate exclusion of disabled people.

Mental and intellectual disability is routinely cited as reason to remove legal capacity. People with disabilities are disadvantaged by the loose wording of current legislation which may allow others to make important decisions for them.

Sign language is not recognised as an official language in Uzbekistan and the cultural identity of deaf people is not supported.

Only a small percentage of people with disabilities were aware of legislation on disability.

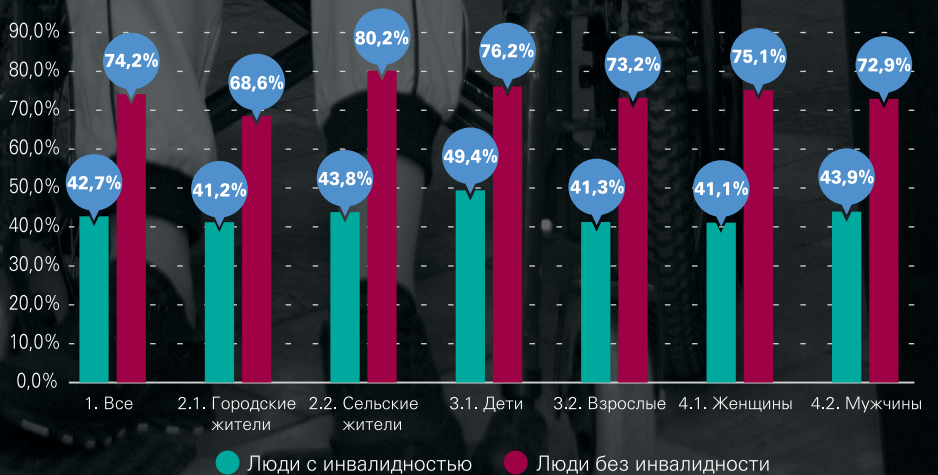
A recent decree of the President of the Republic of Uzbekistan¹ has set in motion a number of significant processes, including drafting of a comprehensive Law on the Rights of People with Disabilities and a state programme². Most significantly, the Presidential Decree has started the lengthy process towards ratification of the CRPD by the Republic of Uzbekistan.

However, current national legislation does not explicitly protect people with disability and sometimes generates exclusion. Disability is not explicitly included among the legally established protections for non-discrimination.

¹ "On measures for fundamental enhancement of public support system of people with disabilities" December 2017

² "On comprehensive measures to further enhance support system of people with disabilities and strengthen protection of their rights and freedoms"

Graph 11. **SATISFACTION WITH ENJOYING RIGHTS**
percentage of people that state they feel they (or their children) fully enjoy their rights



FINDINGS

When legal measures to protect from discrimination on the grounds of disability are included, “discrimination” is not sufficiently defined.

Survey results show that currently only 43 per cent of people with disabilities perceive themselves to be fully enjoying their rights as provided by the Constitution and laws of Uzbekistan; this stands in contrast to 74 per cent of people without disabilities (Graph 11).

Denial of legal capacity, appointment of a guardian “due to mental or intellectual disability” and substituted decision-making are standard procedures, and can be used to render citizens legally incompetent. Since the citizen is summoned to a court session only “if it is possible, taking into account his health” people with disabilities at risk of losing their legal capacity are at a disadvantage.

Equally, the Law on Medicines and Pharmaceutical Activities allows for the participation of legally incapacitated people in clinical trials of pharmaceutical or medical products on the basis of a written consent their parents or legal guardians and they are required only if possible, to personally sign and date the consent form. This is in clear opposition to Article 15(1) CRPD.

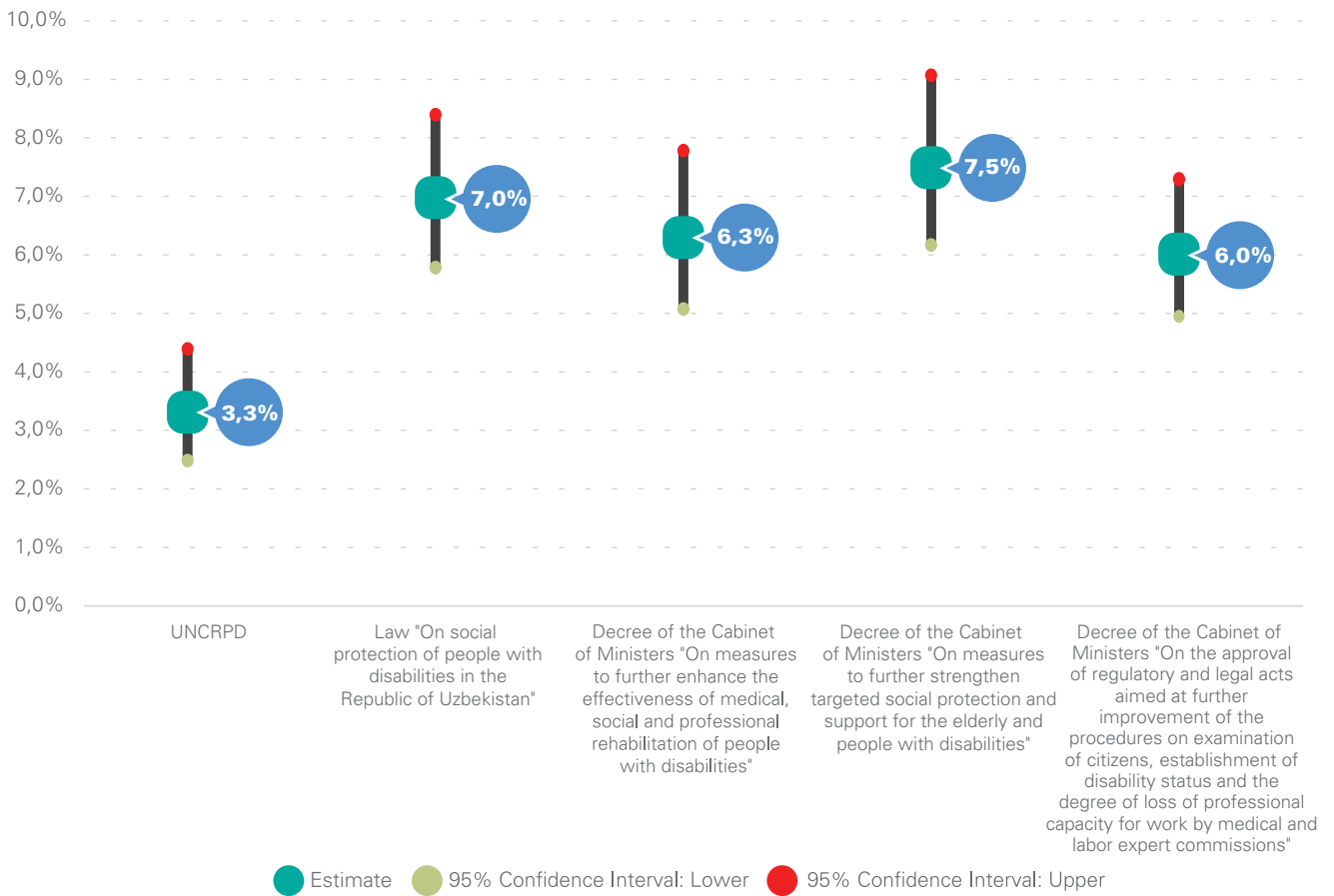
Sign language is not recognized as official, nor are there measures to recognize and support the linguistic and cultural identity of deaf people.

The medical model of disability prevailing in national legislation tends to generate exclusion; legal language related to education speaks of “special needs of the handicapped” with emphasis on “disorders” and “illness”. Children with disabilities are often described as patients. Legislation focuses on different forms of “special” and “segregated” education and there is no reference to equitable access, participation or ensuring that children with disabilities have access to the same high-quality education as other children.

In many cases the special recommendation of a commission is needed for children and young people with disabilities to access mainstream education.

The survey showed that only 3-7 per cent of people with disabilities were aware of the main legislation on their rights (Graph 12).

Graph 12. KNOWLEDGE PREVALENCE ABOUT DISABILITY RELATED RIGHTS
percentage of people with disabilities (caregivers of children with disabilities) who are familiar with disability related legislative acts



Right to accessibility

Legislation is in place to regulate accessible housing, transport, communication etc. However, fines for non-compliance with access requirements are ineffective and inconsistent. Therefore, despite improvements, many users still find it difficult to access workplaces, services and homes and many rely on private transport to get about.

National legislation regulates issues of accessibility of transport, facilities and means of communication, and contains provisions concerning access to housing and social infrastructures, design, construction, and retrofitting of infrastructures. However, despite these advances there is a widespread lack of information (in any format) with regards to rights, responsibilities, services or benefits of people with disabilities.

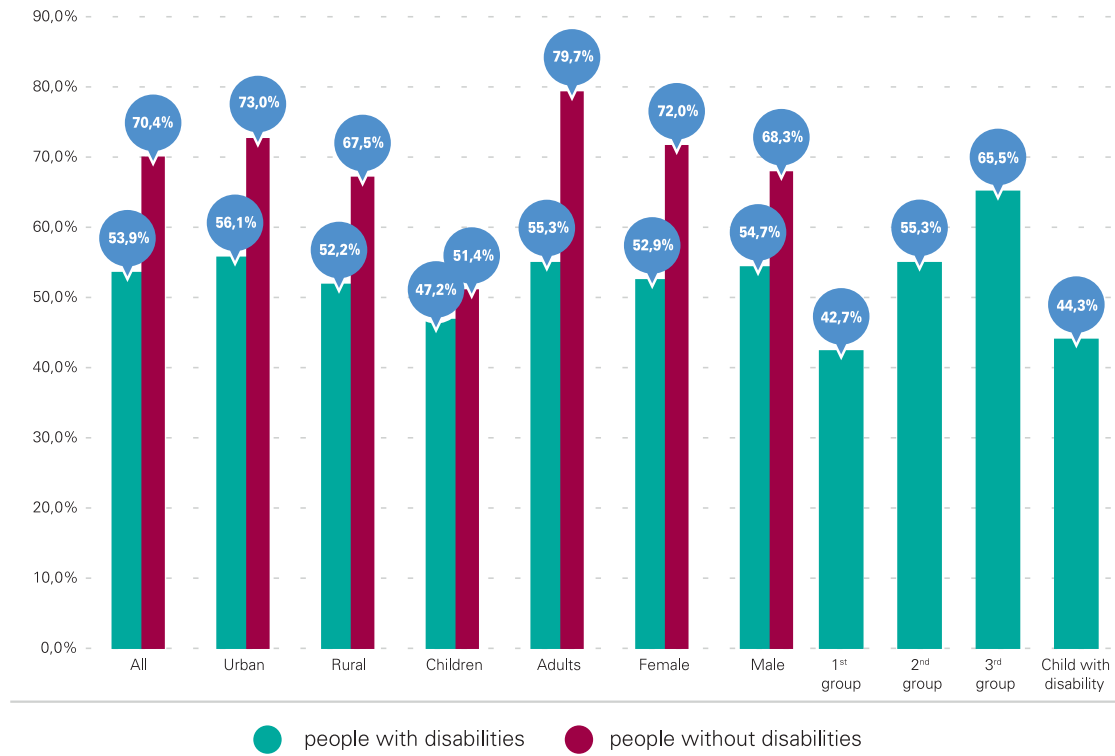
The survey indicates (Graph 13) that in general, necessary information is less accessible to people with disabilities (53.9 per cent) as compared to people without disabilities (70.4 per cent). Furthermore, because there is no recognition of an official Sign Language and alternative and augmented means of communication are not available, difficulties in communication exist.

National legislation stipulates fines for non-compliance with access requirements to transport and other social infrastructure. However, these are largely ineffective and inconsistent. Users with disabilities report insufficient level of accessibility to essential public places, such as schools, hospitals, workplace, services (post office, cinemas, and shopping facilities) and homes. Less than 60 per cent of respondents rated it easy or relatively easy for them to attend these places (Graph 14).

Apart from passenger cars and minibuses, transport is inadequately accessible to people with disabilities, who are often dependent on private cars and taxi services (Graph 15).

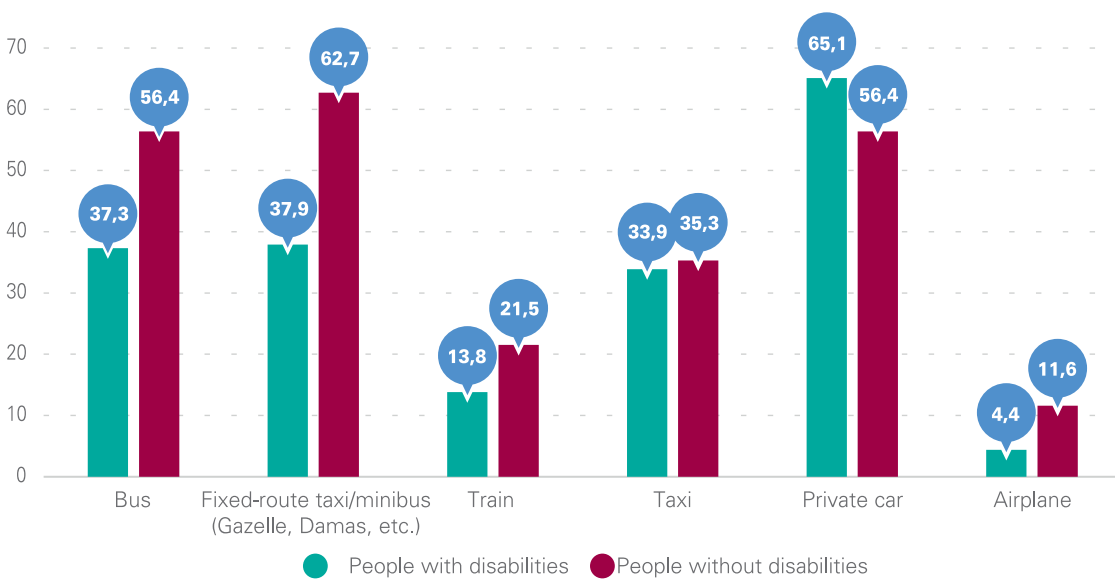
Graph 13. **ACCESS TO INFORMATION**

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



Graph 15. **USE OF TRANSPORT MODALITIES**

percentage of people who have used various means of transport



Graph 14. ACCESSIBILITY OF PHYSICAL ENVIRONMENT

percentage of people with disabilities who rated easy or relatively easy to attend institutions and use related services without an accompanying person



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

Many CRPD provisions related to independent living remain to be incorporated into Uzbek legislation. Uzbek law does not currently recognise the rights of people with disabilities to be included in community or facilitate their participation.

Rather than supporting independent living, provision is made in residential institutions. Of those who choose to live at home, almost none receive personal assistance from the state.

Few people with disabilities receive home care, and a large majority contribute privately towards services received.

Home based support is only provided for those people without a disability who do not have an 'able-bodied' carer; this prevents these carers from seeking other employment. People with mental and infectious diseases are not eligible for home-based care.

Less than a quarter of people with a disability participate in leisure activities and they (and their parents/carers) have limited participation in common social activities.

Key terms and concepts envisioned in the CRPD such as “independent living” “inclusion and involvement», «personal assistance» still need to be transposed fully to Uzbek legislation. In addition, the law does not recognize the right of people with disabilities to be included in the community; does not include obligations of the state to provide a sufficient number of qualified specialists to determine practical solutions for removing barriers to independent living in the local community in accordance with the requirements and preferences of the individual; and does not include commitments to provide people with complex communication requirements appropriate assistance, enabling them to develop and report on their choices, decisions and preferences.

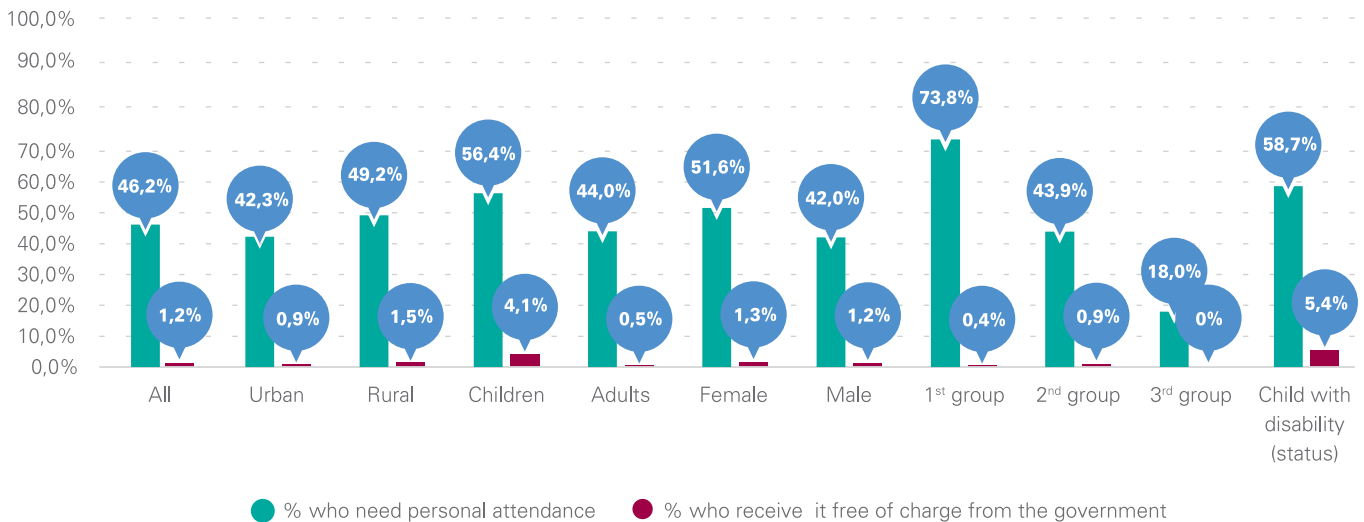
The notion of independent living is absent from legislation. Institutionalisation of both adults and children is the standard prescription for people with disabilities in need of support and in-home services are not the current reality of people with disabilities. National legislation provides support for people with

FINDINGS

disabilities to live independently in the community through the provision of home-based services. However, in-home support services are provided only to people with disabilities who live without «able-bodied» family members, placing an undue burden on family members who could otherwise be in paid employment. In addition, people with mental or infectious diseases are not provided with in-home support services.

48.2 per cent of all respondents to the survey (Graph 16) indicated their need for personal assistance, requiring, on average 86 hours of personal assistance per week. Of these, only 1,2 per cent respondents with disabilities or guardians of children with disabilities received such personal assistance at home from the State.

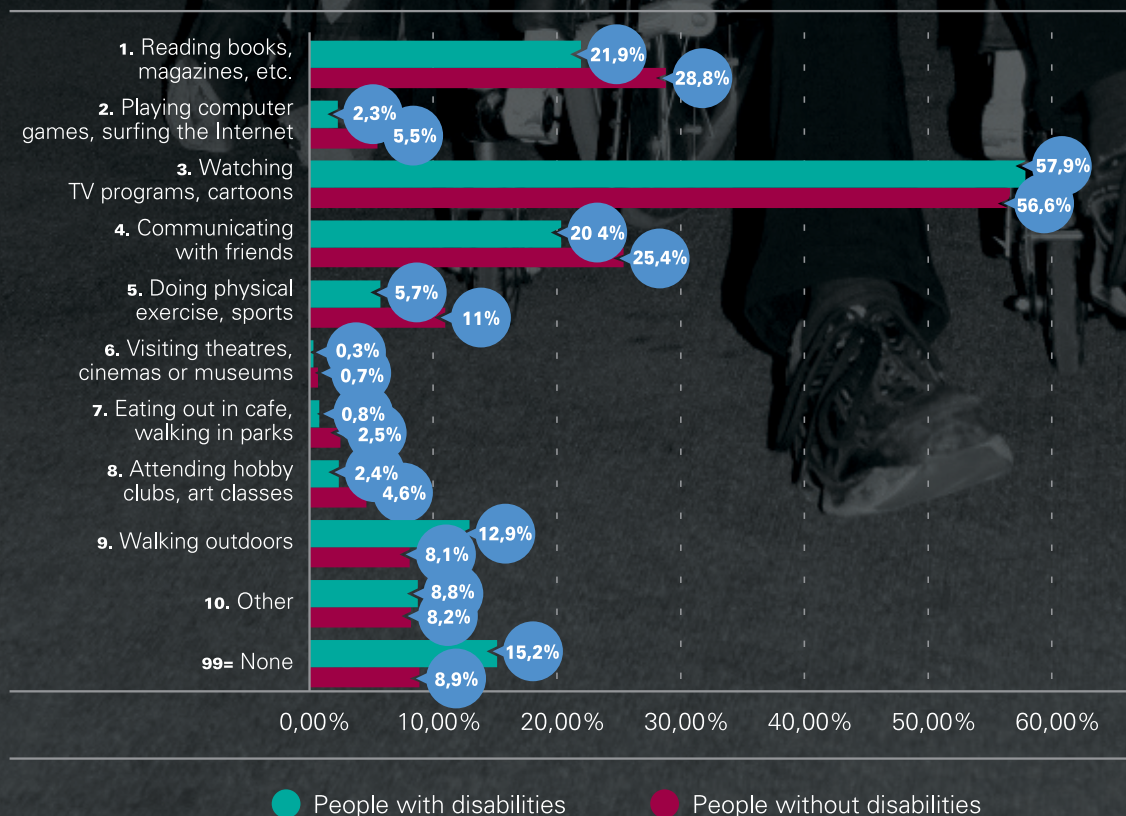
Graph 16. THE NEED FOR PERSONAL ASSISTANCE
Percentage of people with disabilities



People with disabilities twice less against people without disabilities doing sport and physical exercises, visiting theatres, cinemas or museums, attending hobby classes. Three times less eating out in café and lounges, widely considered to be the main social pastime in Uzbekistan culture (Graph 17).

Overall, people with disabilities, and adults who have children who are disabled are less likely to leave their houses to socialize with other people. This includes attending social functions in cafés and restaurants, widely considered as a main pastime in Uzbek culture.

Graph 17. PARTICIPATION IN LEISURE, RECREATIONAL OR SPORTING ACTIVITIES
percentage of people with disabilities



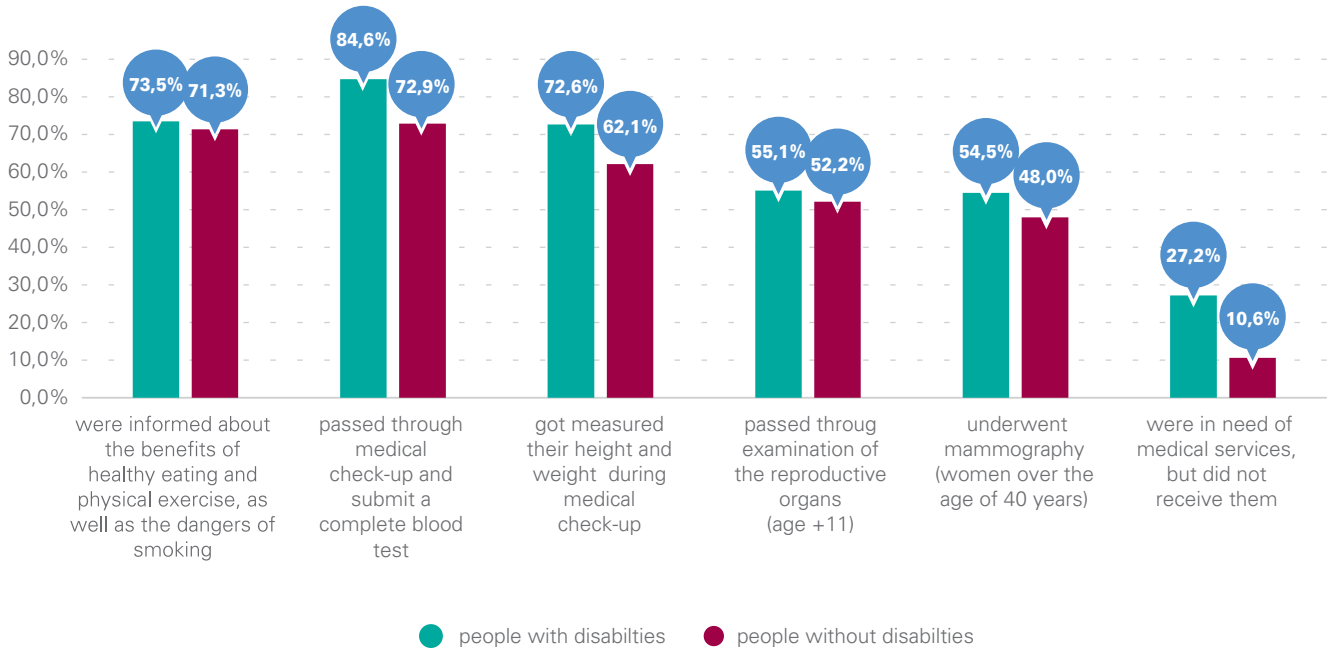
FINDINGS

Right to Health

Health checks are less common among disabled people and a quarter of people with a disability still do not receive necessary healthcare, and report lack of access to prescribed drugs, a much higher figure than non-disabled people. This is due to inability to pay for associated medical services, drugs and transportation and lack of information about where to access said services.

The medical model claims to ensure access to and quality of healthcare services. However, the survey shows that one out of four people with disabilities report not to receive required healthcare as compared to one out of ten people without disabilities (Graph 18).

Graph 18. PERCENTAGE OF PEOPLE WITH AND WITHOUT DISABILITIES (from their total numbers) who...





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People with disabilities are almost 3 times more likely to lack access to prescribed drugs (Graph 19). Although legislation on privileges and benefits makes healthcare services free of charge for people with disabilities at all levels, barriers to health care are caused by disabled people having insufficient money to pay for examinations/diagnostics; doctors' services; medicines; and transportation. Twice as many people with disabilities (5 per cent) reported not knowing where to go to find medical services than people without disabilities.



Graph 19. INACCESSIBILITY OF ESSENTIAL MEDICINES
percentage of people with and without disabilities who needed medications prescribed by a physician, but could not buy them due to their high cost



Right to Rehabilitation

Despite a range of rehabilitation services being offered, individual rehabilitation plans are not regularly assigned, and relevant staff are not adequately trained to write them. Non-medical adaptive services are extremely lacking.

Early intervention services are not yet in place in Uzbekistan and information for families is extremely limited. This damages the potential long-term development of children with disabilities.

The Government provides some types of assistive devices to people with disabilities but not everyone who needs them are currently getting them.

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

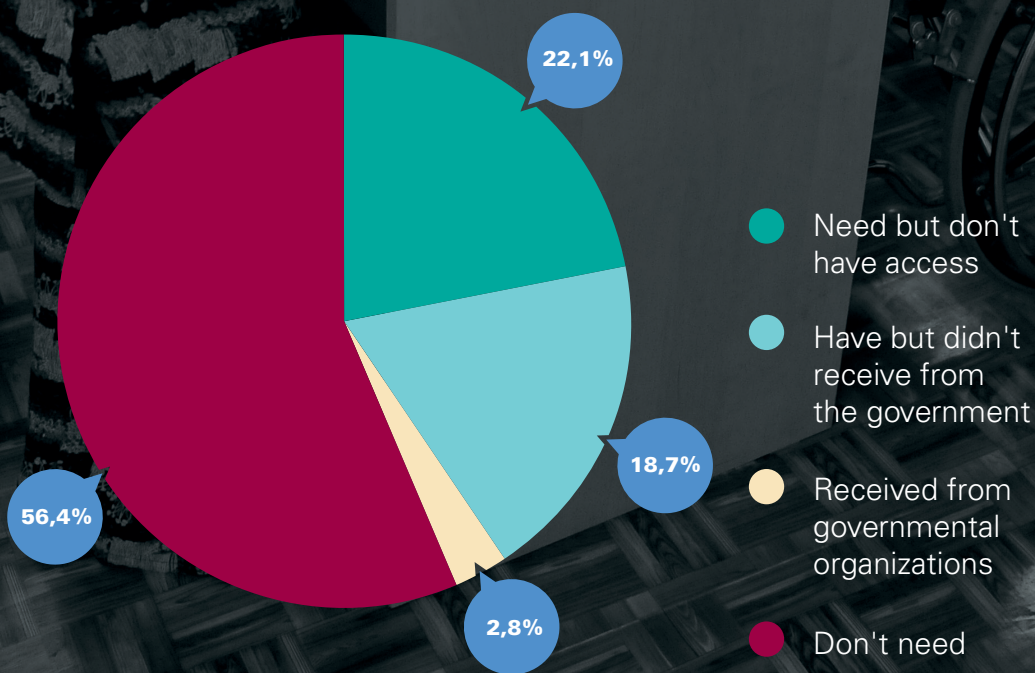
Social rehabilitation is meant to provide a range of psychological, educational and cultural and legal support. However, these were not mentioned in interviews indicating a low awareness and coverage of non-medical rehabilitation services.

Responding effectively to disabilities needs early intervention services, multidisciplinary and holistic approaches for assessment or evidence-based educational and social interventions. In Uzbekistan, legislative or conceptual frameworks to facilitate this are not yet in place. In the absence of outreach and information, families have to search for health and rehabilitation services. There are no consulting services for those caring for children with developmental disabilities. There are no relevant protocols and standards, and the human resources of the health system do not have sufficient capacity in early development screening methods.

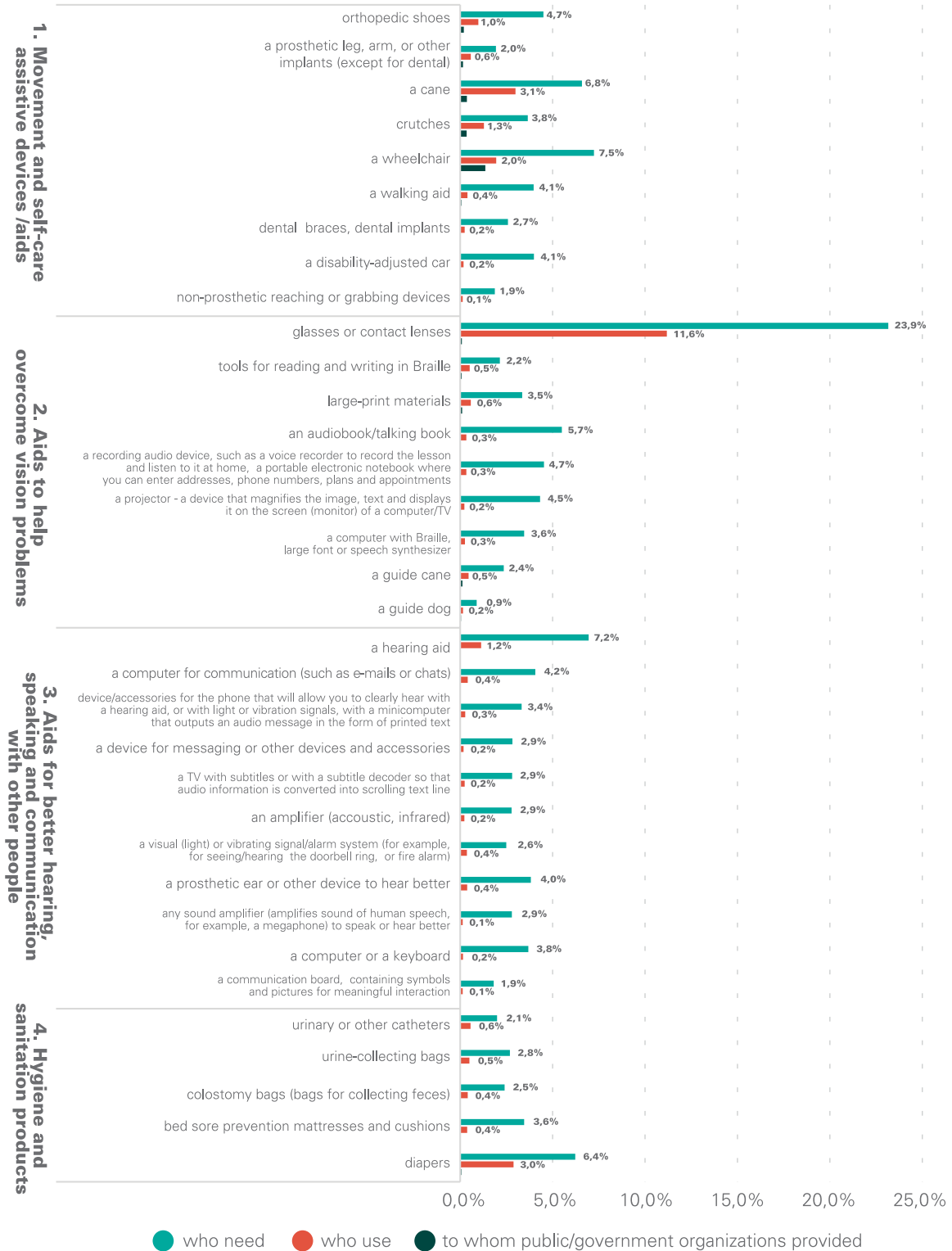
In addition, the survey reveals that many of the devices that are needed by disabled people are not currently available to them.

There are many other types of assistive device that are needed that are not part of the Government list of funded items (e.g. a guide dog) and must be privately funded (Graphs 20).

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

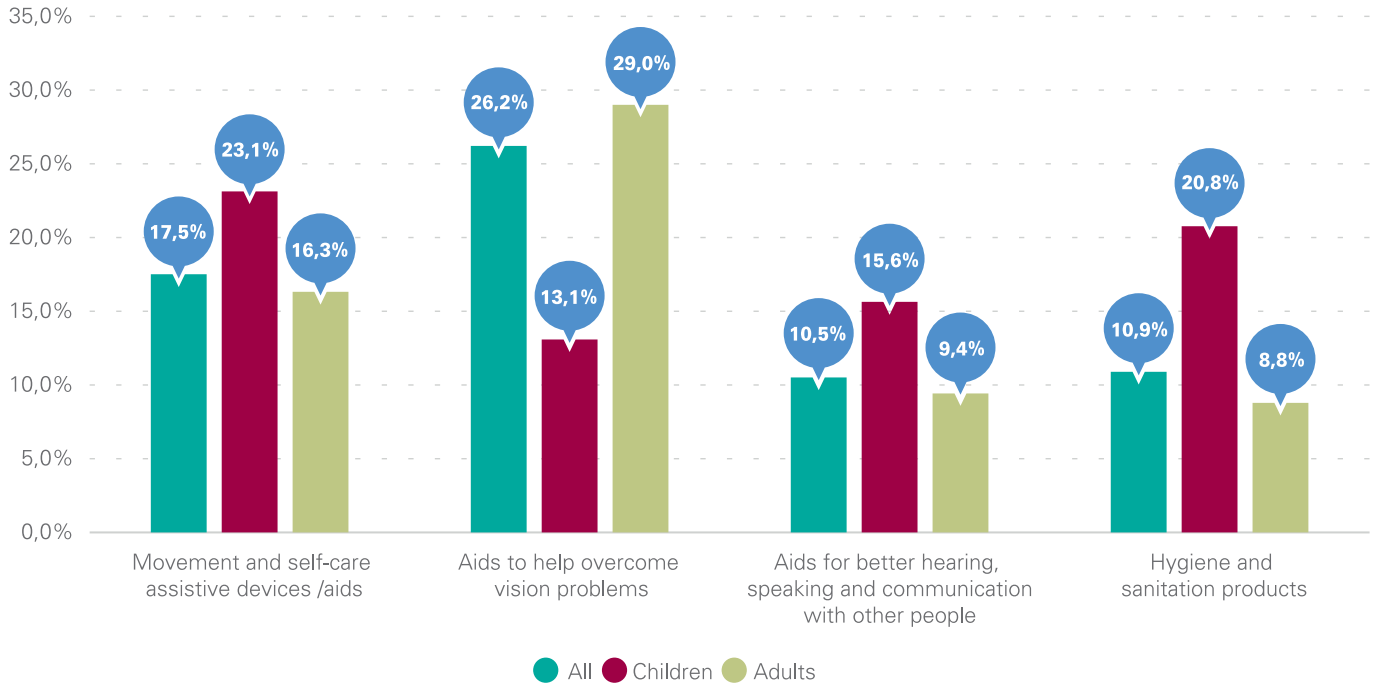


Graph 20. PERCENTAGE OF PEOPLE WITH DISABILITIES (FROM THEIR TOTAL NUMBER) WHO HAVE NECESSARY PRODUCTS OR ASSISTIVE DEVICES



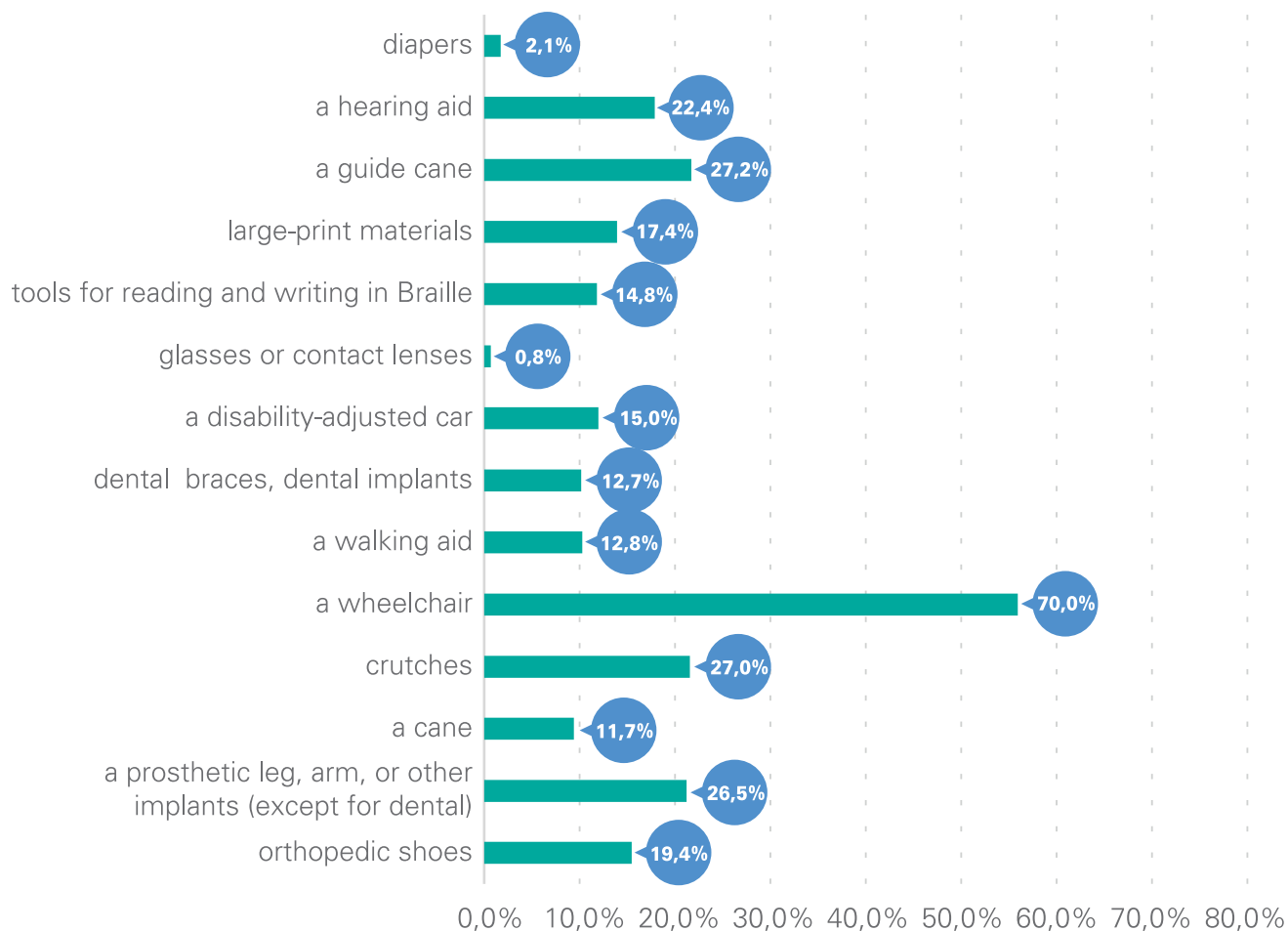
FINDINGS

Graph 21. **PERCENTAGE OF PEOPLE WITH DISABILITIES (FROM THEIR TOTAL NUMBER) WHO NEED ASSISTIVE DEVICES AND PRODUCTS**



From the list of 34 assistive devices and products indicated in Graph 20, only 14 are provided by governmental organizations (Graph 22). These are predominately movement and self-care assistive devices and aids. Interestingly, some people with disabilities are still using the disability adjusted cars that used to be provided before independence (more than 28 years ago), although they make up less than 0.03% of the total number of people with disabilities interviewed. Moreover, only 26.9 percent of people with disabilities who need a wheelchair (one of the most expensive items on the list) are currently using them. The question as to how the 73.1 per cent of people with disabilities who need a wheelchair address their mobility issues remains to be answered. As a whole, from the total

Graph 22. **PERCENTAGE OF PEOPLE WITH DISABILITIES WHO USE NECESSARY ASSISTIVE DEVICES AND PRODUCTS PROVIDED BY GOVERNMENTAL ORGANIZATIONS, FROM THE TOTAL NUMBER OF USERS**



number of people with disabilities who participated in the survey, 43.6 per cent have a need for personal assistive devices and products, 21.5 per cent have access to them and only 2.8 per cent have received them from governmental organizations.

Importantly, children with disabilities, compared to adults with disabilities, have a significantly greater unmet need for movement and self-care assistive devices, aids for better hearing and communicating as well as hygiene and sanitation products.

Right to adequate standard of living and social protection

People with disabilities (and their carers) in Uzbekistan have a lower welfare level than others, due to lower pay levels, exclusion from the job market, insufficient size of disability allowances and disability-related expenses.

Severe deprivation is twice as likely among households with a disabled family member.

Families report that disability allowance does not take into account the severity of the disability and does not cover the extra costs of disability. The uptake of existing social protection schemes is inadequate.

Disabilities that go unrecognised by formal assessment may lead to individuals being ineligible for services and suffering financial hardship. The process for establishing disability is reported to be difficult and expensive, especially for the poorest families.

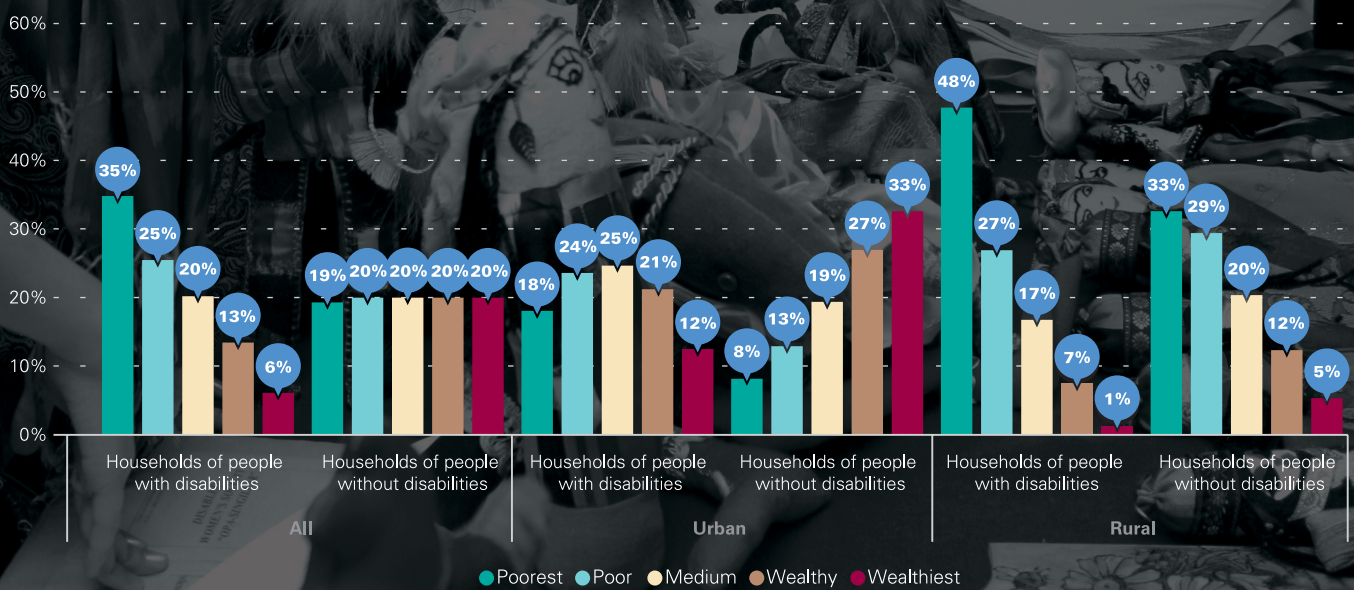
Social service support is lacking, and individual assessments that take into account the living situation of the person with a disability are not carried out, which leads to disconnected service provision and poor efficiency.

Few families of people with disabilities know their rights or are aware of what rehabilitation services may be available.

People with disabilities in Uzbekistan have a significant lower welfare level than people without disabilities. This is related to a number of factors, most prominent being disability related expenses and disadvantages in the labour market together with lower pay levels. This also applies to their carers.

The Uzbekistan Wealth Index (Graph 23) shows that severe deprivation is twice as common in households with members with disability in both rural and urban environments. Households with members with disabilities are three times less likely to find themselves in the most affluent category.

Graph 23. THE UZBEKISTAN WEALTH INDEX

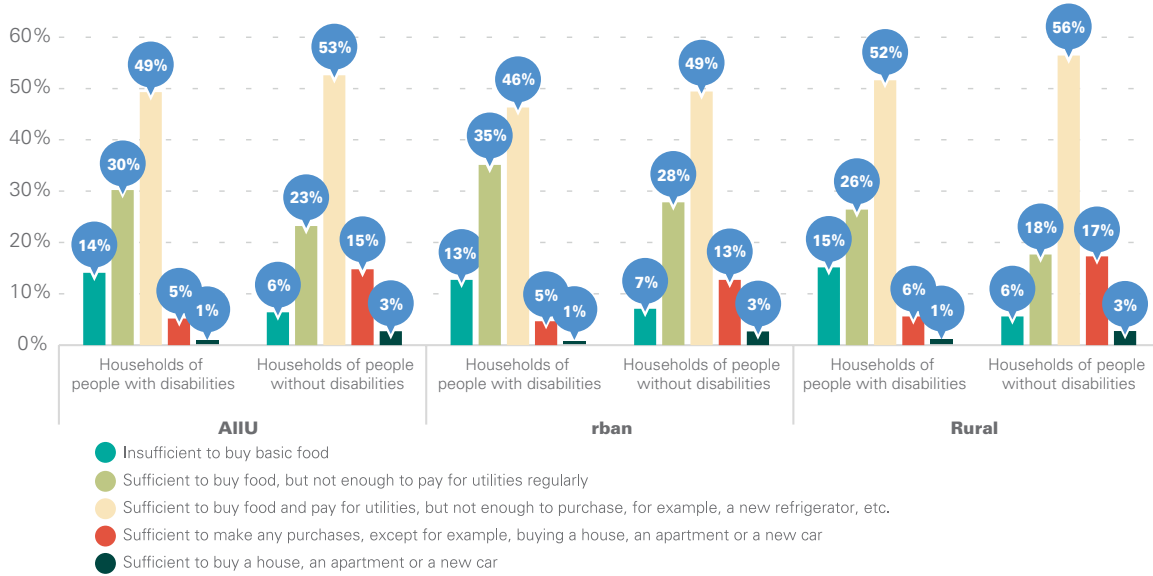


Note: For the conceptual and methodological framework of the Wealth Index, see Fry K., Firestone R., Chakraborty N.M. (2014). *Measuring Equity with Nationally Representative Wealth Quintiles*. Washington, DC: PSI.

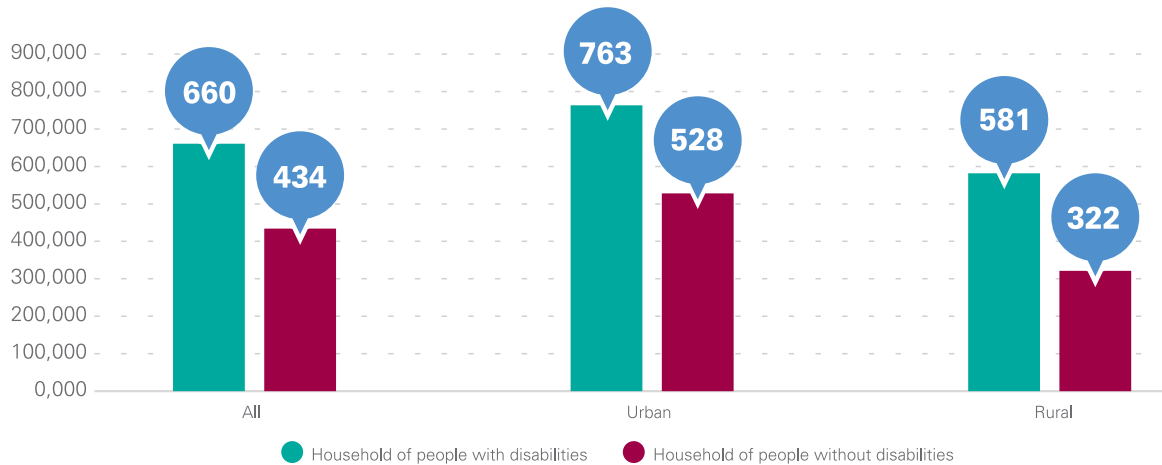
FINDINGS

Self-assessments demonstrate significantly poorer conditions in households who have members with disability, due to extra disability related expenses (Graph 24).

Graph 24. **SELF-ASSESSMENT OF HOW HOUSEHOLDS ARE MAKING ENDS MEET**
percentage of households



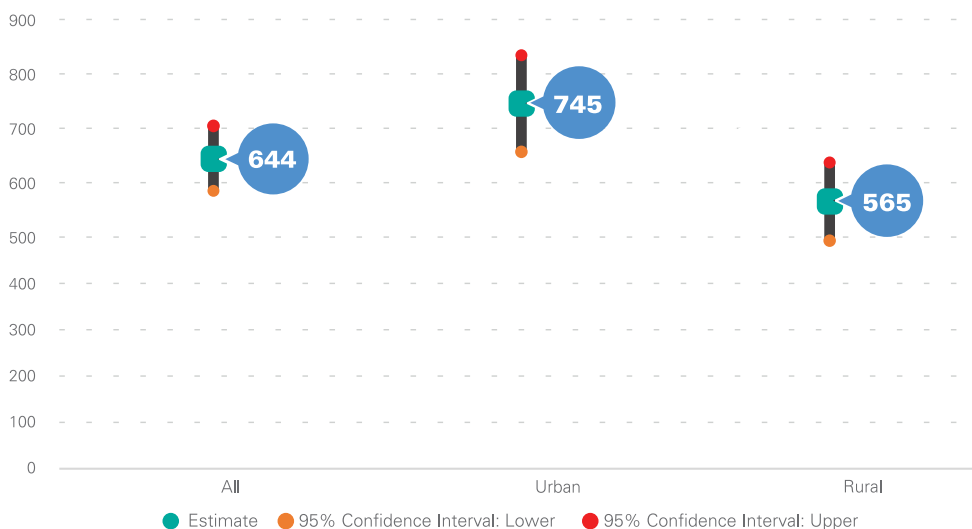
Graph 25. **SPENDING PER HOUSEHOLD MEMBER**
thousand soums



Self-declared expenditure per household member (Graph 25) is about a third higher than in households without a member with a disability (UZS 660.000 against UZS 434.000) and, in rural areas, expenditures is nearly twice as much (UZS 581.000 against UZS 322.000).

Disability allowances do not take into consideration the type or severity of the disability and are reportedly not sufficient to cover the costs (hidden and explicit) of having a family member with a disability. Average monthly spending of households due to disability is UZS 643.800 (Graph 26). The size of the disability allowance for children is UZS 327.741, for adults without an employment record who haven't contributed to a pension fund it is UZS 206.720. An average disability pension for those who have contributed to the contributory social protection scheme is UZS 435.581.

Graph 26. **SPENDING DUE TO DISABILITY OF A HOUSEHOLD MEMBER**
thousand soums



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

Moreover, because the identification of disability is principally linked to determining eligibility for benefits and services, it has a direct impact on ensuring the well-being of people with disabilities.

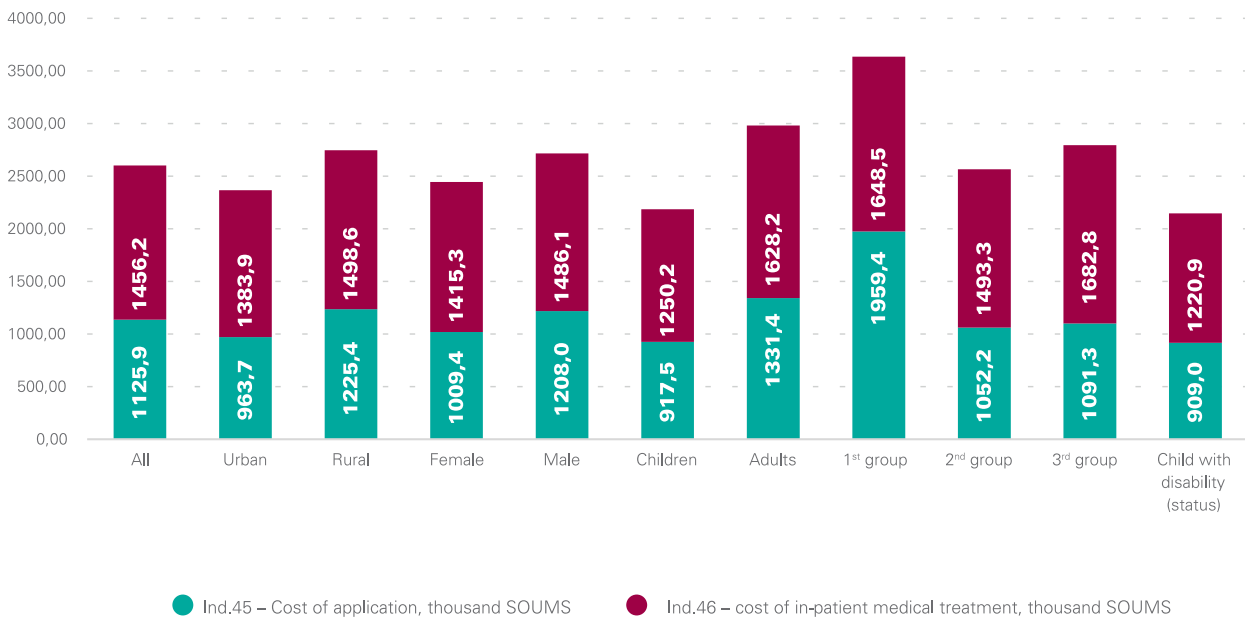
There are serious concerns about obstacles to the procedure for determining disability. In the survey 42 per cent of people with disabilities

FINDINGS

and parents/guardians of children with disabilities assessed the procedure of applying for disability status as «difficult» and «very difficult». Of these respondents 66 per cent were from households with low welfare levels.

Those surveyed also reported that the costs associated with the disability eligibility procedure are often prohibitive: nearly a quarter of all people interviewed (a third of those with children with disabilities) estimated that the cost was “expensive” or “too expensive”. Although there is no formal payment for disability assessment, applicants are faced with costs such as transportation, collecting documents, informal payments, etc. The survey revealed that the cost of applying for disability status exceeds 1 mln.UZS (Graph 27). In addition, applicants have to receive in-patient medical treatment as a formal requirement for application for disability assessment. Although primary medical treatment is also free of charge, respondents reported that they spent about 1.5 mln.UZS on this. The State Committee on Statistics’s data in the year when the survey was conducted gives the average monthly wage as 1.294 mln.UZS.

Graph 27. **SPENDING WITHIN DISABILITY ASSESSMENT**
thousand soums



Demand exceeds supply of social services, which are oriented to crisis services rather than preventive social services, or early intervention services.

Uzbekistan lacks professional social work services or case-managed social support of people with disabilities. A range of services are provided separately which renders the large funds being allocated to the social protection of people with disabilities relatively inefficient..

A lack of outreach services and limited access to information outside of large cities leads to parents of children with disabilities reporting that they do not know their rights or what to do upon finding out about a disability. Around one in ten people with disabilities were not aware of specialized services provided for their rehabilitation or well-being.

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Child Protection

Physical violence is a recurrent among interviews with children with disabilities.

Data is lacking on the number of children and adults with disabilities in state residential institutions, but currently the vast majority of those in residential care appear to be children and adults with disabilities.

Despite the fact that some individuals may have mental (though not communicative) capacity, consent of the adult or child with a disability is not needed for placement in a murruvat home, and once placed, very few individuals ever leave. Legislation does not provide for independent monitoring and inspection of institutions to prevent violence, exploitation and abuse.

Uzbekistan does not have a coherent Child Protection Law. Although the Family Code and the law On Guarantees of the Rights of the Child offer legal protections, physical violence was a recurring theme in the interviews with children with disabilities. This was violence received from other children with disabilities as well as violence perpetrated by adults onto children with disabilities.

There are no data on an exact number of children and adults with disabilities in residential institutions but State data reports that over 80 per cent of state residential institutions are established for people with disabilities.

As of 2014, there were 27 murruvat residential institutions for adults ages 18 years and older, and 6 for children aged 4-18 years old. The placement of children and adults is made on the basis of an application of an (adoptive) parent, guardian or trustee and the consent of neither adults nor children is required to authorize it. This points to the fact that the (majority of) murruvat residents do not have legal capacity under the law, a de facto restriction of their exercise of the right to live independently. Although the muruvvat Resolution specifies that only adults belonging to disability groups 1 or 2 and children with disabilities having significant mental impairments are accepted to murruvat homes, anecdotal information indicates that some residents are people with other disabilities who are unable to communicate in a conventional way but do not, otherwise, fall within any of the specified categories above. In practice, cases of leaving an institution are virtually unknown. More importantly, legislation on specialized institutions for people with disabilities contains no provision for independent authorities to monitor them to protect people with disabilities from exploitation, violence, and abuse.

Right to (Inclusive) Education

Fewer children with disabilities access pre-school education compared to children without disabilities.

Access for young people with disabilities is also limited to secondary schools, in particular to secondary vocational schools.

Little adaptation to assessment or examinations is allowed for in Uzbek legislation which may impact on equitable access to professional education and employment opportunities for young people with a disability.

Overall, the legislative framework contributes to education being largely segregated and specialised, rather than providing education in inclusive settings.

Residents in murruvats do not have access to continuous education that would contribute to the full development of their potential.

Some positive trends in widening access of children and adults with disabilities are taking place.¹

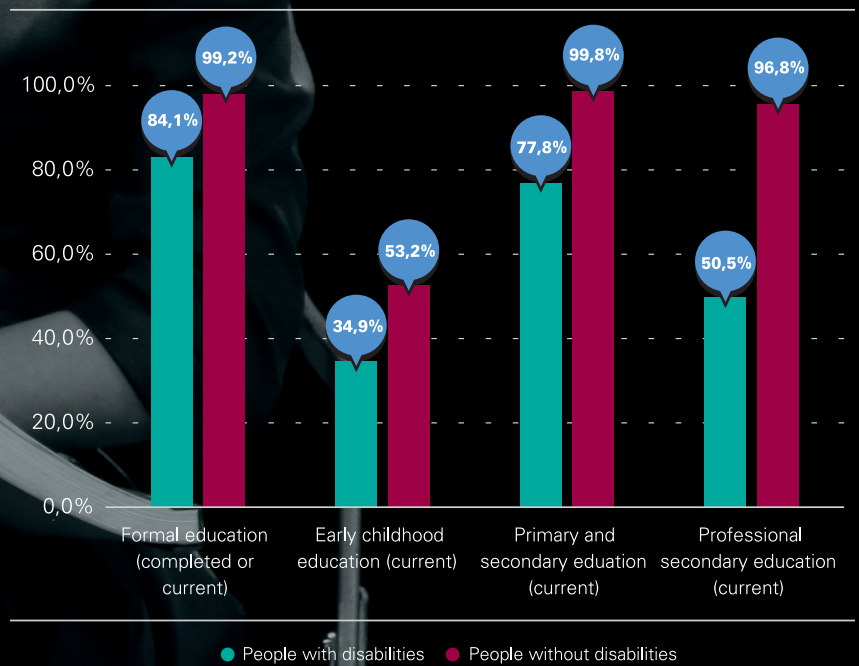
According to Article 41 of the Constitution of the Republic of Uzbekistan, everyone should be able to fulfill their right to education and the state shall guarantee free secondary education. However, although access to secondary school stands at 99.8 per cent for people without disabilities, for those with a disability it is only 84 per cent (Graph 28).

Likewise, access to pre-school is nearly 20 per cent lower for children with disabilities, a situation that is likely to aggravate rates of retention of children with disabilities in the upper grades. Access to secondary schooling is 22 per cent less for students with disabilities and 46 per cent less to secondary vocational schools.

¹ Order of the Minister of Public Education # 2685 "On transfer of learners with physical and/or mental impairments from one special education institution to another special education institution or general education institution for receiving inclusive education" dated June 17, 2015; Resolution of the Cabinet of Ministers No. 417 of June 2, 2018 "On Approval of the Regulations on the Procedure for Admission of People with Disabilities to Higher Educational Institutions for Training on Additional Quotas on the Basis of a State Grant"



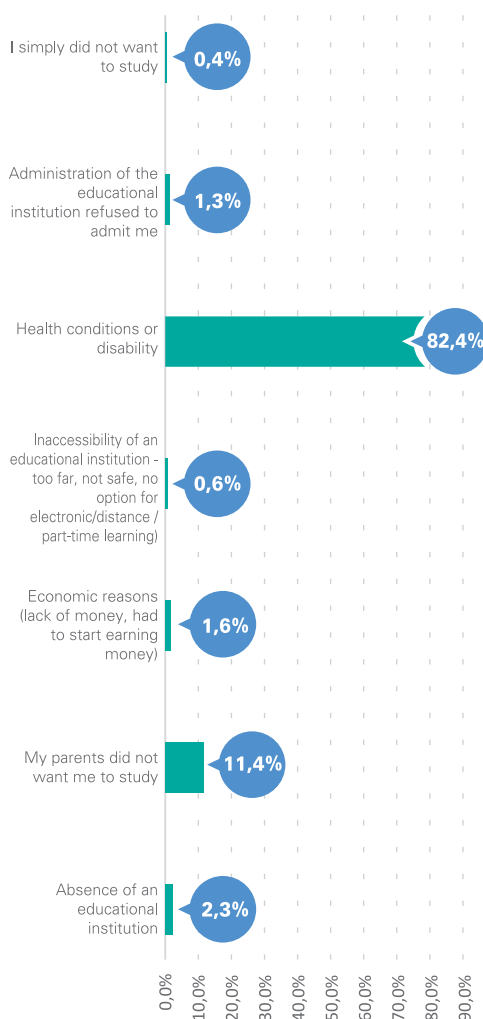
Graph 28. **ACCESS TO EDUCATION**
percentage of people with and without disabilities (from the total number)
having formal education



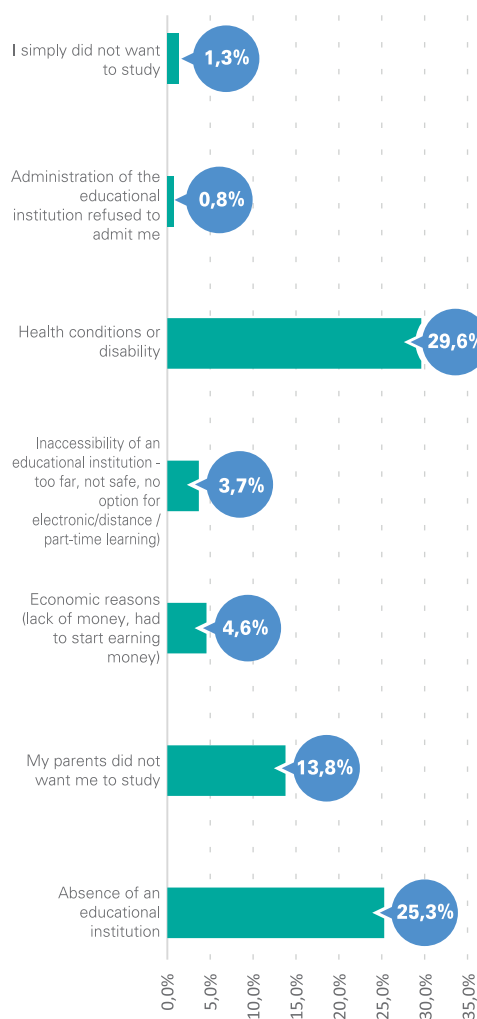
In graphs 29a and 29b, reasons for never attending an educational institution (mainstream or special) or interrupting studies were indicated. As can be seen from these graphs, people with disabilities blame their health conditions or disability rather than an inaccessible environment. In relation to mainstream education, this reason is indicted by more than 82 per cent of people with disabilities. Surprisingly, parents are among main factors given for not studying.

Graph 29. PERCENTAGE OF PEOPLE WITH DISABILITIES WHO DIDN'T ATTEND AN EDUCATIONAL INSTITUTION OR WHO INTERRUPTED STUDIES DUE TO THE FOLLOWING REASONS

a) a mainstream educational institution



b) a special educational institution



FINDINGS

The legislative framework indicates, «if the health of disabled children excludes the possibility of their stay in preschool institutions, pre-school education for disabled children is carried out in specialized educational institutions, including boarding homes.” It also states that «specialized educational institutions are created for training, education and treatment of children and adolescents with disabilities in physical or mental development, as well as those who need long-term treatment». Thus, none of the legal norms and regulations currently in place takes into consideration the obligation of the State to provide education in inclusive settings. On the contrary, if children fail to fulfill the pre-existing conditions of mainstream education, they often enter further segregated settings. Lastly, despite indicating that residents in a murruvat should access a range of services, including education, legislation also states “for groups of children who are not eligible for education a job place for an educator is not being established.” This denies child residents of murruvats the basic education that would contribute to the full development of their potential, which stands in direct violation of Article 24 – Right to Inclusive Education.

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

Right to Work and Employment

While there are some incentives for working people with disabilities, in reality these disincentivise employers from engaging workers with disabilities due to the associated burden. Legislation does not address discrimination or access issues in the field of employment.

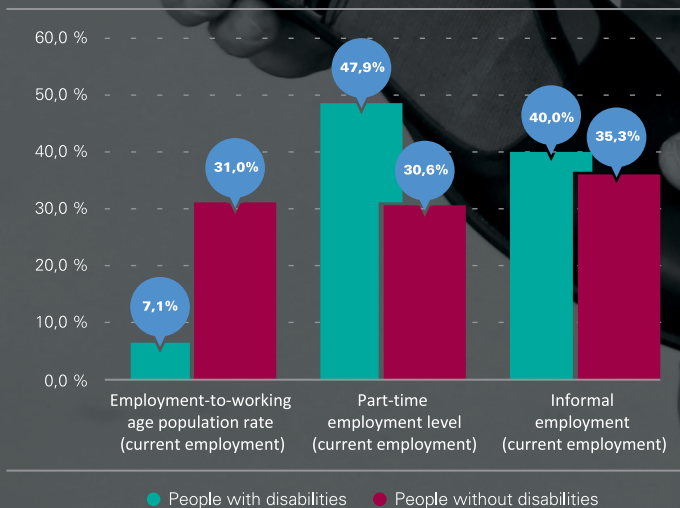
People with disabilities and caregivers of children with disabilities are less likely to be employed and earn less than non-disabled people.

The Law on Social Protection of People with Disabilities regulates the employment of people with disabilities, making the right to employment fit the person's "fitness to work," introducing quotas, and granting to workers with disabilities extra incentives (i.e. entitlements to a full-time salary while working part time, extended annual leave taken in the order of priority, and complex letting go procedures). However, actions have an unintended negative effect, discouraging employers from engaging workers with disabilities to avoid the associated burden.

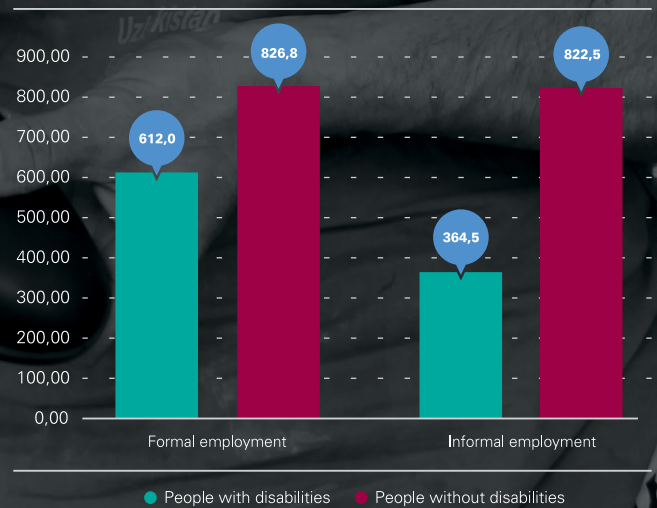
As reported in official statistics, in Uzbekistan, there are 346.084 people with disabilities of working age and only 5 per cent are employed. Data shows that people with disabilities are 4 times less likely to be employed than people without disabilities; 48 per cent of people with disabilities work part-time, as opposed to 31 per cent of people without disabilities (Graph 30). At the same time 87 per cent of people with disabilities responded that they are not working due to poor health/ serious disability.

The rate of formal employment of caregivers of children with disabilities is 21 per cent; the average wage of people with disabilities in the formal sector is considerably lower (612,000 UZS) than people without disabilities (827,000 UZS), with an increased discrepancy in the informal sector: 365,000 UZS for people with disabilities, as compared to 822, 000 UZS for people without disabilities (Graph 31). People with disabilities are discriminated against in the informal sector as well: their salaries in the informal sector are almost two times lower than those in the formal one (for people without disabilities salaries are equal in formal and informal sectors). Such differences are not observed among people without disabilities.

GRAPH 30. ACCESS TO EMPLOYMENT
percentage of people with and without disabilities



Graph 31. AVERAGE MONTHLY SALARY
thousand soums



Statistics and data collection

Household data about people with disabilities is not internationally comparable although measures are being taken to address this.

Information on disabilities, available in the annual reports of Goskomstat, is scarce. No disaggregation (by type of impairment, age, gender, region etc.) is undertaken. Reporting is done by the types of diseases as per International Classification of Diseases. Special surveys that focus on disabilities or have disabilities as a specific component have not been undertaken.

During the sampling phase of this study, insufficiencies in the lists of people with disabilities were detected, in both primary medical institutions and mahalla committees. There are both uncompleted records of people with disabilities themselves, as well as a lack of consolidation of the records of people with disabilities between medical institutions and the Mahalla committees. In practical terms, this is likely to lead to inadequate coverage of people with disabilities with the necessary services.

However, to rectify this the Government is introducing Washington Group Questions on functional limitations into the standard household surveys as well as several disability related indicators into the system of departmental statistics.¹

¹ Resolution of the Cabinet of Ministers RUz # 210 "On the improvement of the system of statistics on people with disabilities" dated March 22, 2018



Right to political participation

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

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

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

At the national level, a number of measures have been taken to address accessibility of elections to people with disabilities¹. Progress towards accessibility of elections was noted in the 2016 presidential election, where most polling stations were located in step-free facilities, ballots available in Braille and home voting authorized for individual voters physically unable to vote in person.

A Memorandum on cooperation was signed between organizations of people with disabilities and political parties in 2017, committing political parties to nominating candidates with disabilities in elections at different levels. These have been more diligently followed in the local elections (where parties did nominate candidates with disabilities, 11 of whom eventually got elected) than the general or presidential elections that have so far featured no or very few candidates with disabilities.

However, a large number of people with disabilities remains disenfranchised. The barriers include:

- The lack of accessible environment to enable people reach the polling station

¹ E.g. Resolution No 773 of 8 November 2016 of the Central Election Commission

- Inaccessible political campaigns (no information in alternative formats for visually and hearing-impaired people, no easy-to-understand information; no sign language/captioning of televised public debates).

The survey indicates that in general, people with disabilities and caregivers of children with disabilities participated less than those without disabilities in the last presidential election, especially people who were identified as having mental or intellectual disabilities.

Active participation of representative organizations of people with disabilities in policy-making is an obligation under the CRPD (Article 33.3). However, Article 5 of the Law on Social Protection of People is worded “may participate”.

Although a number of organizations of people with disabilities actively operate in the country, only 18 per cent of people with disabilities and guardians of children with disabilities consider that they are adequately represented by organizations/associations with similar disabilities.







**POLICY
RECOMMENDATIONS**

It is important to keep in mind that the CRPD calls for a dual focus on disability: On the one hand, the CRPD promotes a disability-mainstreaming trajectory. In fact, the entire development Agenda 2030 speaks to people with disabilities, with 15 out of the 17 SDGs including disability-mainstreaming targets and benchmarks. On the other hand, it recognizes that people with disabilities have specific needs that need to be addressed. Thus, the list below includes both recommendations for all (including people with disabilities) and recommendations for disability-specific legislation, policy and services.

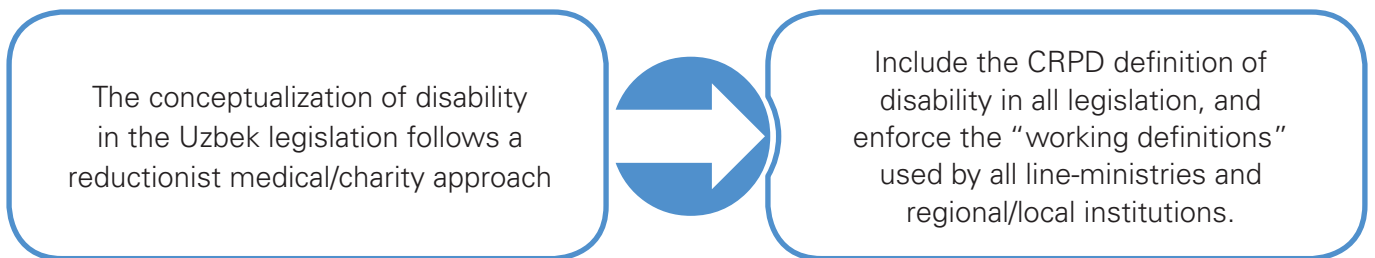
While the CRPD (Art.4) calls for the progressive realization of the rights of people with disabilities, some flexibility is afforded to developing States in achieving the objectives of the Convention. However, “States parties shall take measures, to the maximum of their available resources, with the aim of achieving progressively the full realization of the economic, social and cultural rights set out in article 4 (2). States parties should move as expeditiously and effectively as possible to that goal, including by establishing strategies and programmes, with clear targets, benchmarks and time frames”

First, people with disabilities in Uzbekistan must be counted and accounted for.

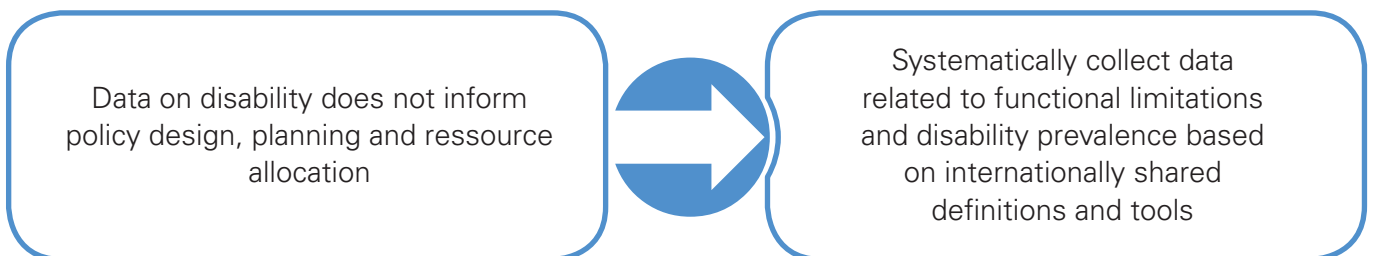
At this time of transition, Uzbekistan has the opportunity to develop a system that is innovative and can be exemplary in the region by harmonizing methodology, tools and criteria with existing international standards.

For this, the definition of disability must be aligned with the CRPD and include both an impairment component and its interactions with the

environment. This bio-psycho-social definition of disability, when enforced at national and regional levels, can clarify the pathway for rigorous data collection for decision-making and, more importantly, set up a system of eligibility that is equitable and takes each person into account. Because Uzbekistan is a State Party to the Convention on the Rights of the Child and aims to be able to set internationally comparable standards, it should harmonize all legislation to ensure children are considered as such until age 18, with particular strengths and needs that differ from those of adults (and thus require a different focus).



Rigorous data on disability is important. But, even more important, is collecting data that indicates the proportion of the population that has functional limitations in specific domains (and includes people with disabilities). This is critical data for smart investments that target the greatest number of users, not a small segment of the population. Census and household surveys that are nationally representative and use Washington Group on Statistics’ guidelines are respectful of the CRPD and provide data that is useful across multiple sectors and across multiple segments of the population.



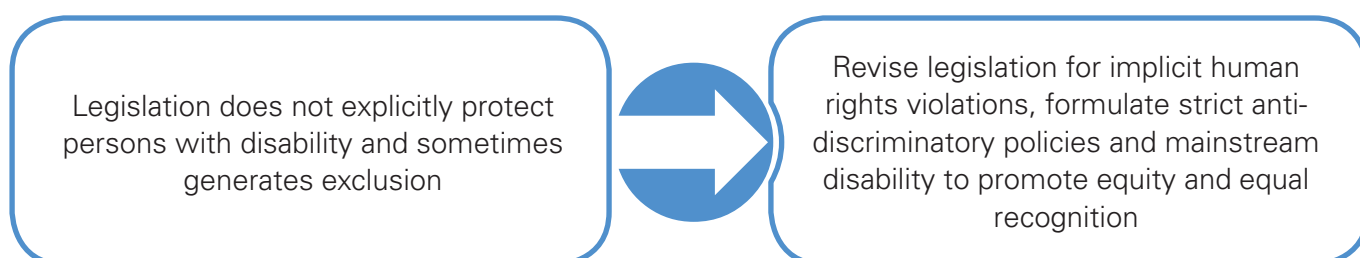
Upholding the rights of people with disabilities is a question of political will as demonstrated by Uzbekistan’s commitment to ratifying the CRPD. Within

POLICY RECOMMENDATIONS

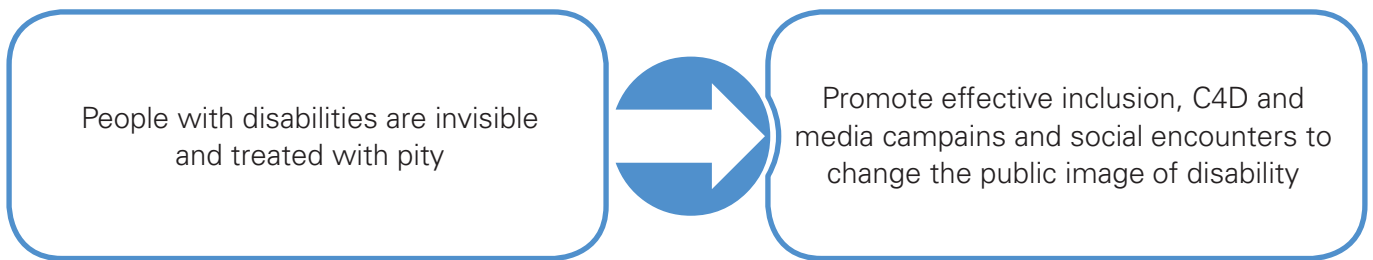
this process, engagement at the highest political level on issues related to the rights of people with disabilities as outlined in the CRPD is necessary, and a review of the legislation with a view to ensure a disability-mainstreaming effort and harmonization should be prioritized. It is important to create new pathways to inclusion within legislation; but it is equally important to ensure legislation does not create or maintain barriers to inclusion.

To stay on course, the government of Uzbekistan should establish a monitoring system within and across ministries to track the development and enforcement of strict anti-discriminatory policies that ensure the rights of all people with disabilities in all arenas of life. Institutional discrimination, stigma and attitudinal barriers must be addressed across all sectors. For disability-mainstreaming to become a reality all professionals must have minimum knowledge and minimum standards of conduct, inclusive of disability. It is important to determine a baseline of professionals and service providers' Knowledge, Attitudes and Practices related to people with disabilities and their families that can lead to focused advocacy and tailored needs – based capacity-building of professionals.

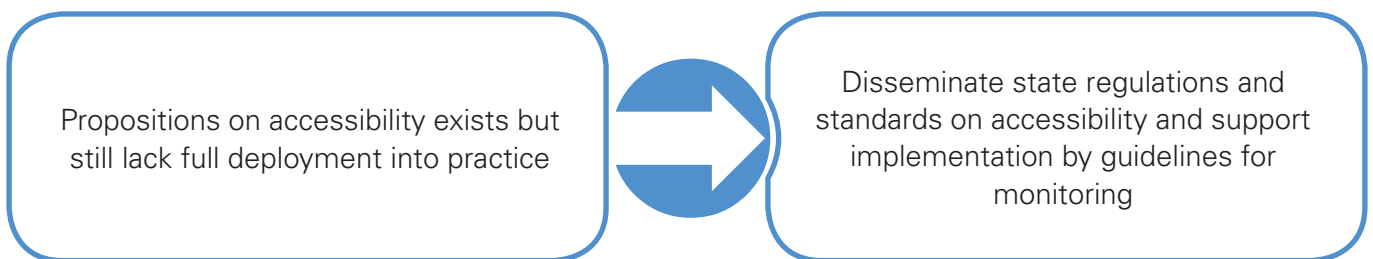
The government of Uzbekistan should respect the principle of “Do No Harm” and ensure their commitments to the CRPD are fully funded. Uzbekistan already has high expenditure in the social sector. A plan of “reallocation of funds away from programmes and services that are inconsistent with human rights commitments, towards inclusive alternatives is necessary. Ensuring that no public expenditures create or perpetuate barriers, including by making non-discrimination and accessibility for people with disabilities a requirement in all public procurement will also be necessary.



In Uzbekistan the general public still has a perceptions of people without disabilities based on deficiencies and pity. Their responses are largely charity-focused. People with disabilities, of all kinds, lack visibility in the public sphere. The state has to promote a change in cultural norms which fully acknowledges the rights and potential of each member of society and fosters an attitude of respect.



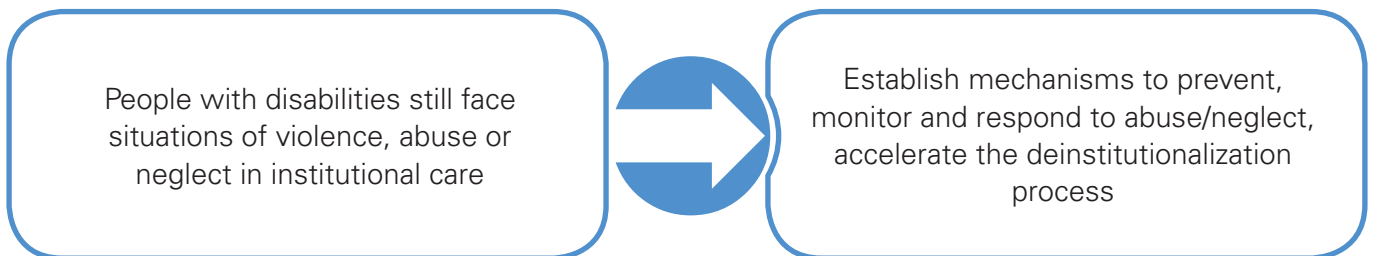
The principles of Universal Design¹ are critical in developing a country for all. Responsible professionals within each line ministry should be provided with the capacity to address issues of accessibility and Universal Design, and effective enforcement mechanisms should be put in place. Ensure some professionals within each relevant line ministry have a broad understanding of reasonable accommodation vs. individualized accommodations, and financial and human resources are available to implement and monitor cost-effective Universal Design (UD), Assistive Technology (AT) and Information and Communication Technology (ICT) solutions that are costly to add after-the-fact.



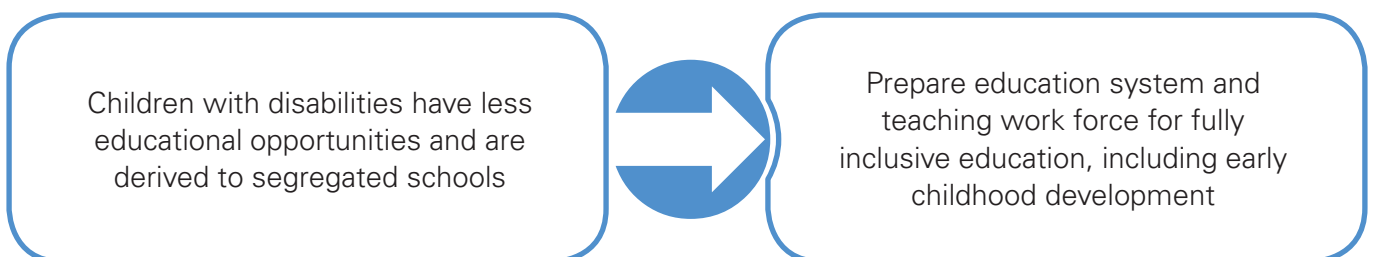
¹ “Universal design” means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. “Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed. Article 2, CRPD

POLICY RECOMMENDATIONS

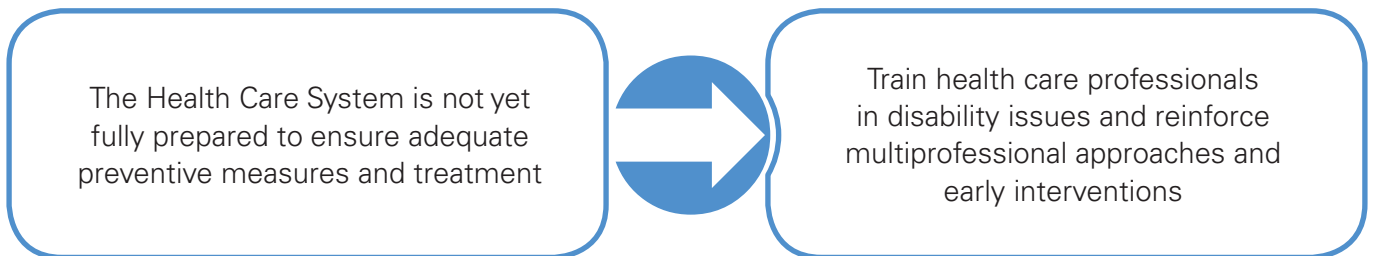
Ensure all laws and policies related to prevention of violence, abuse or neglect reflect the spirit and letter of the CRPD, and that mechanisms exist to prevent, monitor and respond to abuse/neglect of people with disabilities at all levels and by all stakeholders, starting with independent monitoring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



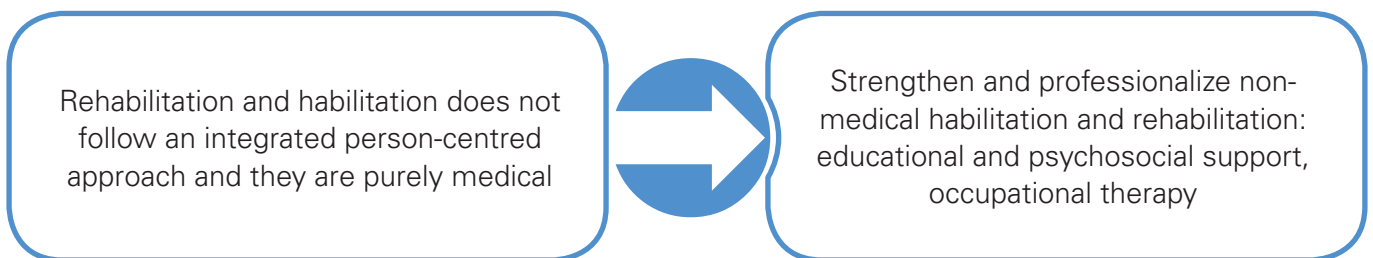
Initiate national dialogue to promote Inclusive Education that is respectful of the CRPD Article 24 and its General Comment n°4. Ensure all children – including children with disabilities - have access to early childhood development and school readiness opportunities. Engage in twinning programmes with international universities with a good track record of teacher preparation for inclusion and initiate the process of re-professionalization of the teaching force and peripheral support professionals. This is essential for the adequate transition of children with disabilities from special schools to regular schools, and an active incentive to keeping children with disabilities within their most immediate family.



Create a health care system that is proactive instead of reactive. Invest in health promotion and health education, including parent education on child development and ensure that preventative and universal measures such as screening for functional limitations are done to identify needs before they occur, and encourage outreach by family doctors and local community health centres. All health care professionals should have minimum knowledge regarding the International Classification of Functioning and the bio-psycho-social model of disability, leading to a greater understanding of their role within the scope of the multidisciplinary methodology of identification and assessment of disability.



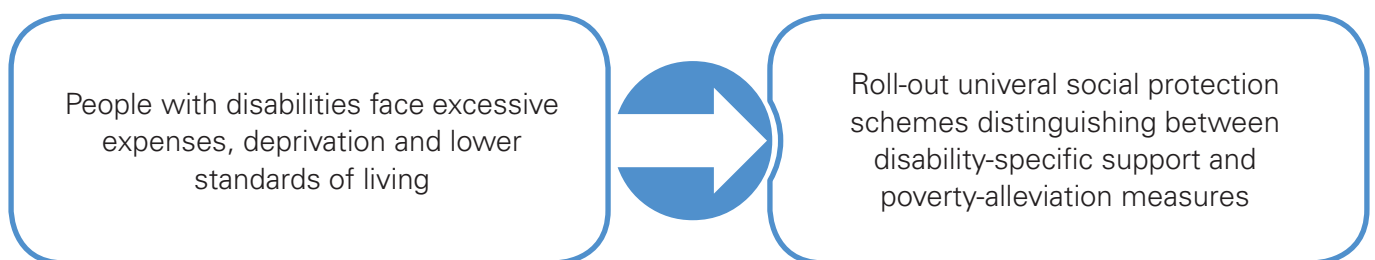
Reinforce a multi-professional approach that responds in an integrated and person-centred manner to the needs of people with disabilities by fostering and ensuring their autonomy. Individual Rehabilitation Plans can be a useful instrument but need a better design, and take into account all areas of the person's life, and better fit-for-purpose. These plans should be developed and implemented not only by doctors, but also by paramedical and non-medical professionals: occupational therapists, speech therapists, psychologists and social workers. It is necessary to organize their adequate pre-service and in-service training.



POLICY RECOMMENDATIONS

The Uzbek welfare state has to fully take into consideration disability-related expenditures and provide some defined unconditional support, in cash, in kind and services, in order to compensate for the disadvantages felt by people with disabilities and their families. Distinctions must be made explicit between disability-specific support and poverty-alleviation measures.

Deepening social protection for people with disabilities requires recalculating and redesigning social benefit and pension schemes, as well as articulating social services with an outreach country wide. Child Disability Benefit is a key programme. However, uptake is limited as the scheme only reaches 52 per cent of children with severe disabilities despite its universal character. Social protection has to take into account disability-related expenses and compensate for disadvantages with non-conditional monetary transfers. It is important to integrate incentives to meaningful employment into the benefit schemes and ensure that no traps are created that punish participation in work with reduction of payments.



Social services should be designed as a self-standing pillar of the welfare system. Community-based intervention and case management approaches need to be developed and rolled out. Systematic development of staff profiles and retraining of human resources is an essential condition for success.

A number of personalized social services can ensure autonomy and integration in the community. Much of these services act upstream, are preventive and often less cost-intensive than medical interventions.

At the same time, people with disabilities are generally excluded from the world of gainful employment. The right to work is not widely acknowledged

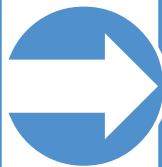
Social services are fragmented, non-preventive and focused on institutionalization



Strengthen social services and case management practices

as a way of fostering inclusion for people with disabilities. There are inbuilt disincentives in the certification of disabilities and in the social benefit schemes that create barriers to employment. Public employment agencies are not sufficiently capacitated to foster job placement for people with disabilities and promote adaptation of workplaces.

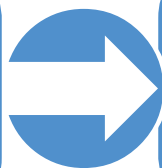
People with disabilities have low levels of employment and are excluded from the world of work



Revise incentive structures of disability certification and requalification, raise skills levels of people with disabilities and prepare public employment service for effective job placements

Support the strengthening of the capacity of NGOs and DPOs (disabled people's organisations) in general to speak on behalf of ALL people with disabilities and partner with government in creating an inclusive environment for all. While some DPOs are knowledgeable and capable with regards to people with specific impairments, it is imperative that the rights of all people with disabilities be advocated for by organizations that speaks on behalf of all, with only one voice, and without regard for special interests. Because children have needs and strengths that are specific to their age and level of development, DPOs should be provided with opportunities to develop their capacity related to child rights, including by engaging in consultations with children with and without disabilities on issues that relate to them (and of their choosing).

Policy dialogue with civil society and organizations of people with disability is limited and lacks impact



Strengthen participatory and consultation mechanisms, promote democratic representation and reinforce the social economy





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