UNPRPD MPTF
Partnership on the Rights of Persons with Disabilities

UNITED NATIONS
UZBEKISTAN

SITUATIONAL ANALYSIS
OF THE RIGHTS OF PERSONS WITH DISABILITIES

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COUNTRY REPORT 2021

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COUNTRY REPORT

November 2022

About UNPRPD:

The United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD) is a unique partnership that brings together UN entities, governments, OPDs and broader civil society to advance the rights of persons with disabilities around the world.

The Partnership was created to foster collaboration between its members and complement their work around disability inclusion through UN Joint programming. The Partnership operates through a Multi-Partner Trust Fund (MPTF) established to channel resources for participating UN organizations (PUNOs).

The UN entities participating in UNPRPD are ILO, OHCHR, UNDESA, UNDP, UNESCO, UNICEF, UNFPA, UN Women and WHO. Other UNPRPD members include the International Disability Alliance and the International Disability and Development Consortium (IDDC).

The main contributors to the UNPRPD MPTF are Australia, Finland, Norway, Sweden, United Kingdom.

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This report was written by the UNCT in Uzbekistan with collaboration from partners including OPDs, UN agencies, and local colleagues. Technical support was provided by the UNPRPD Technical Secretariat throughout the process.

Disclaimer:

The data and information presented in the report are based on the situational analyses conducted at the country level and were drafted by the UN country teams. Methodology for data collection included a desk review of relevant literature, key informant interviews and focus groups, stakeholder mapping exercises and consultative workshops with key stakeholders. The UNPRPD has not edited the report or verified the findings for accuracy. This report does not necessarily reflect the position of the UNPRPD.

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1. ACRONYMS AND ABBREVIATIONS

CBR	Community-based rehabilitation
CEDAW	Convention on the Elimination of all Forms of Discrimination against Women
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
CSO	Civil Society Organisations
EIEI	Early identification and early intervention
GBV	Gender-based violence
GONGO	Government-organized non-governmental organization
Goskomstat	The State Committee on Statistics of the Republic of Uzbekistan
ICD	International Classification of Diseases
ICF	International Classification of Functioning
ICT	Information and Communication Technology
ILO	International Labour Organization
IPR	Individual Programme of Rehabilitation
Mahalla	Local self-government body of citizens that function at the community level
MPPK	Medico-Psychological Pedagogical Commission
MPTF	Multi-Partner Trust Fund
Muruvvat	Residential care institutions for adults or children with disabilities under the Agency for the Development of Medical and Social Services
NPA	National Plan of Action
OHCHR	Office of the High Commissioner for Human Rights (of the United Nations)
OPD	Organisation of persons with disabilities
	RCSAC Republican Center for Social Adaptation of Children
SDGs	Sustainable Development Goals
SPPWD	Law “On Social Protection of Persons with Disabilities”
UNCT	United Nations Country Team
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNHRIG	United Nations Thematic Group on Human Rights and Inclusion
UNICEF	United Nations Children’s Fund
UNPRPD	United Nations Partnership for the Rights of Persons with Disabilities
UNSDCF	United Nations Sustainable Development Cooperation Framework
VKK	Medical Consultative Commission
VTEK	Medical and Labour Expert Commission
WHO	World Health Organisation

2. EXECUTIVE SUMMARY

The recent years have undoubtedly seen the rise of acknowledgement that the rights of persons with disabilities belong on the national human rights agenda, manifested by the adoption of the new Law on the Rights of Persons with Disabilities in 2020 and the long-awaited ratification of the UN Convention on the Rights of Persons with Disabilities in 2021. The national institutional make-up has also seen changes, adding the Agency for the Development of Medico-Social Services under the Cabinet of Ministers, the Interagency Disability Council and several ministries with key roles for promotion of the rights of persons with disabilities.

There is a pressing need to see these initiatives produce a systemic reform at the legal, policy, budgetary and communication levels for **persons with disabilities experience discrimination and exclusion** in nearly every area of life in Uzbekistan. Stigma and prejudice are pervasive, with most people being perceived as either patients or objects of charity by the society and the professionals.

The disability civil society, led by the Association of Persons with Disabilities, one of the most representative organisations of persons with disabilities in the country today, is the driving force behind the many encouraging developments of late. However, the **many members of the disability community remain underrepresented in decision-making**, with women, people with psychosocial and intellectual disabilities and families of children with disabilities being the most obvious absences. Support to efforts to further diversify and strengthen the national disability community is urgently needed in light of pervasive discrimination experienced by these groups.

Notably**, women and girls with disabilities are subject to discrimination based on their disability and gender,** and report higher levels of unemployment, financial insecurity and family violence. They experience significant inequalities in access to health care services, including sexual and reproductive health.

Owing to societal prejudice and **lack of early identification and early intervention services**, children with disabilities are placed in segregationist settings and deprived of access to essential services necessary for their development. This includes placement in residential institutions and boarding schools, subpar health and rehabilitation services, and lack of inclusive education at all levels. These shortcomings prevent children with disabilities from having a fair start in life and putting them at a lifelong disadvantage.

The **national framework of support services**, formed during the Soviet times, has not yet caught up with the modern inclusive individualised approaches. Most services are concentrated in residential care homes, with only a primitive range of services available in the community to a narrowly defined eligible population. **Specialists for both children and adults** are few and far between: services of speech therapists, physiotherapists, occupational therapists, social workers, inclusive education support staff are not easily obtained, especially in rural areas. Access to **assistive devices** is equally limited and not based on individual needs.

A number of targeted initiatives to support the development of **inclusive education for children with disabilities** have taken place in recent years, with an explicit commitment to develop a system of inclusive education for children with disabilities. Nevertheless, the reliance on segregation continues. The pilot inclusive education initiative, kicking off with 42 “inclusive classes” throughout the country in September 2021 is a welcome beginning but not without significant flaws.

Key recommendations to the Republic of Uzbekistan include making national legislative and policy frameworks compatible with international human rights standards with a specific focus on women and girls with disabilities, children and adults with learning and psychosocial disabilities and other groups which are left behind. This can be achieved through better collection of disability disaggregated data and mainstreaming disability inclusion by through development of community-based services and early identification, operationalizing human rights based approaches to disability assessment and determination, social protection, health and rehabilitation, inclusive education and employment.

3. BACKGROUND

Building on a key priority of the new Uzbekistan UN Sustainable Development Cooperation Framework 2021-2025 (UNSDCF) to enhance access of the most vulnerable populations, including persons with disabilities to gender-sensitive quality public services, a task force on human rights and inclusion (UNHRIG) was established to ensure coordinated UNCT approach to disability programming and implementation. The UNCT, including UNICEF, UNDP, UNFPA and OHCHR joined efforts to attract resources for the transformation of social service delivery for children, youth and women with disabilities in line with the human rights-based approach, leave no one behind and the global standard set in the UN Convention on the Rights of Persons with Disabilities. Within the fourth call for proposals of the UN Partnership on the Rights of Persons with Disabilities Multi-Partner Trust Fund (UNPRPD MPTF), Uzbekistan's expression of interest was selected for submission of a full-fledged proposal.

This research builds and expands on the findings of the 2019 Situation Analysis of children and adults with disabilities.[1]

2019 Situation Analysis on Persons with Disabilities in Uzbekistan

The 2019 Situation Analysis consolidated and summarised the findings of five research streams undertaken by the UN organisations between February 2016 and December 2019, aimed at defining the landscape of disability in Uzbekistan and provide a baseline for future work. The research streams included (1) a legislative analysis, (2) an institutional analysis of government organisations delivering services to persons with disabilities, (3) an analysis of the state statistics on persons with disabilities and data collection systems, (4) a study of knowledge, attitudes, and practices towards persons with disabilities, and (5) a needs assessment: a quantitative and qualitative survey of a significant number of persons with disabilities. This strand included 14 in-depth interviews of about 1-1.5 hours with officially registered children with disabilities and their parents or caregivers. Additionally, a standardised survey collected over 3000 responses from households of officially registered persons with a disability and 1700 responses from households without persons with disabilities.

The Situation Analysis demonstrated that a small part of the Uzbek society had regular contact with persons with disabilities, and those that did mostly acted from the place of pity, otherness, and rejection. Purely medical and charity understandings of disability are still prevalent both within the government bodies and society in general which treat persons with disabilities as 'sick patients' or 'passive recipients of charity' rather than active citizens who also have rights and should be equal with others.

The research found the legislation governing the situation of persons with disabilities at the time of writing was outdated and not in compliance with the CRPD, and called for a full legislative review not only of the Law on Social Protection of Persons with Disabilities, but also the legal acts regulating civil and political rights of persons with disabilities, their access to education, health & rehabilitation, employment, support services in the community and child protection, among others. The study further strongly recommended the overhaul of the data collection system and the development of the monitoring mechanisms to gauge progress towards the rights-based model of disability.

The Situation Analysis identified significant gaps in delivering early intervention services and multidisciplinary evidence-based social interventions. Rehabilitation services were largely unavailable to most individuals with disabilities, with children particularly disadvantaged in access to age-appropriate self-care assistive devices. Access to social protection was described as "difficult" by persons with disabilities, with households with members with disabilities significantly poorer than those without members with disabilities.

Significant discrimination in access to education was observed for children with disabilities at all levels, and none of the legislative or policy provisions on inclusive education in place.

Altogether, the Situation Analysis formulated 38 recommendations addressing different branches of the central and local government, the international donor community, and organisations of persons with disabilities. The recommendations addressed all areas of public policy, including interagency coordination, monitoring and data collecting, training of professionals of all profiles, developing of

[1] UN Uzbekistan (2019) Situation Analysis on children and adults with disabilities in Uzbekistan. Brief report. Tashkent: United Nations Uzbekistan. Full version of the report is on file with the research team.

community-based services, particularly early identification and early intervention, and participation of organisations of persons with disabilities.

The exercise at hand has been, firstly, to revisit and update the 2019 report with the newest developments and, secondly, investigate the bottlenecks in the realisation of human rights of some of the most vulnerable groups, such as women and girls with disabilities, and children with (intellectual) disabilities who today experience effects of multiple discrimination compounded by the factors of gender, age, socioeconomic status and barriers to accessing resources at an equal basis with others. As a result, these groups find themselves at risk of neglect, institutionalisation, and violence, perpetuating their marginalisation and invisibility. It is the aspiration of this research to shed light on some of the most entrenched human rights violations of children and women with disabilities in Uzbekistan today, with the view to designing a long-term intervention plan involving the UN family, national authorities, and organisations of persons with disabilities and their families.

Purpose of analysis

The ambition of this Situation Analysis is not merely to point at problems but to lay ground for solutions by identifying the opportunities and catalytic forces emerging today. The report looks at the necessary preconditions for realisation of human rights of persons with disabilities, particularly women, girls, and boys with disabilities, such as a robust equality and non-discrimination framework, availability of inclusive and accessible services in the community, disability inclusive financial and coordination mechanisms, transparent monitoring and accountability systems and meaningful participation of persons with disabilities.

The specific objectives of the report are to:

1. Support the national and international community to better understand the critical issues regarding disability-inclusive policies, gaps, and opportunities as they are informed by the rights of children and women with disabilities, particularly those at risk of or with experience of institutional care and build a base of mutual understanding to co-design programmes.
2. Provide information and recommendations to inform UNPRPD country programming
3. Serve as a baseline for future interventions
4. Provide recommendations for further in-depth analysis of new and emerging issues, including those that could not be sufficiently explored in the present study due to limitations of scope, timing, and COVID-related restrictions
5. Support working relations between various stakeholders in the field of the rights of persons with disabilities, including marginalised and under-represented groups
6. Strengthen the capacity of the above stakeholders to provide impactful high-level interventions to improve the enjoyment of human rights by all persons with disabilities.

Introduction to disability in Uzbekistan

Uzbekistan is a lower middle-income[2] country in Central Asia which gained its independence from the Soviet Union in 1991. Uzbekistan is the most populous nation in Central Asia and as of 2020 its total population reached 33.9 million people almost half of which (49.4%) lives in rural areas.[3] For the last years the population of Uzbekistan has considerably increased to 34.6 million in April 2021.[4] 60 percent of the population are younger people under 30 years old.[5]

The officially reported number of persons with disabilities is likely underestimated at 2.1% of the population, given that an estimated 15 percent of people around the world have some form of impairment, and about 80 percent of them live in developing countries.[6]

[2] As of 2021, the World Bank includes Uzbekistan in lower middle-income group of countries. Lower-middle-income economies are those in which 2019 GNI per capita was between $1,036 and $4,045.

[3] Based on the official data provided by the State Committee on Statistics of the Republic of Uzbekistan.

[4] The State Committee of the Republic of Uzbekistan on Statistics, Demography. ND. "The Number of Urban and Rural Population by Region."

[5] UNICEF Uzbekistan. 2020. *Youth of Uzbekistan: Challenges and Prospects*.

[6] World Health Organization and World Bank. 2011. *World Report on Disability*.

In Uzbekistan, contemporary understandings and practices related to disability at a policy level have been heavily influenced by the programmes for disabled people that were developed in the USSR. In the Soviet Union, disability was determined based on the degree of loss of working capacity and all state measures were aimed at assisting a disabled person to regain his/her ability to work. The Soviet disability policies still have strong implications for contemporary definitions of disability and has been influencing current policies and practices in Uzbekistan. This can be evidenced from the survival of the Medical Labour Expert Commissions (VTEK) for adults with disabilities and Medical Consultative Commissions (VKK) for children with disabilities under age 18 which have all the power to determine an official disability status and assign relevant state benefits.

4. APPROACH

Guiding principles

Following the principle *"Nothing about us without us"* the research team tried to ensure direct involvement of local organizations of persons with disabilities (OPDs), representatives of local NGOs and civil society institutions, as well as unofficial self-help groups of persons with disabilities in formulating the research agenda and its directions.

The inception report was validated by them during an online meeting held on 19 May 2021. Further, to ensure meaningful participation of persons with disabilities in the development of the Situation Analysis, the following measures have been employed:

- The core research team has been expanded to include a Local Researcher representing a network of parents of children with intellectual disabilities. In addition to her close personal involvement with the issue and an excellent knowledge of the disability movement in the country, she is an experienced researcher, trainer and project manager, bringing in the additional coordination experience to the team;
- The Association of Disabled People of Uzbekistan participated as co-writers of the report, leading the evaluation of the law and policy changes since 2019 (the publication of the previous Situation Analysis) and the assessment of the current interagency coordination mechanisms;
- The cross-disability Advisory Expert Group composed of four persons with physical, visual and hearing impairments and one parent of a child with a disability, represented in their personal and expert capacity, assisted the research team in conducting interviews and focus group discussion and validating the findings and recommendations from the data collection phase. A significant effort was made to ensure diversity of impairments, genders, and expertise in the composition of the group whose role was to monitor the due inclusion of the views of persons with disabilities in the interviews and evaluate the process for transparency, quality, and efficiency.

The draft Situation Analysis has undergone a thorough validation process with the OPDs, participating UN Agencies and other relevant stakeholders. The draft report (including an executive summary translated into Russian) had been circulated to them ahead of the online validation workshop held on 5 July 2021. The workshop featured interventions by the members of the Advisory Expert Group who presented the outcomes of the research and shared their views on the participative dimension of the process. Following the workshop, the participants were invited to contribute to the draft report in writing. Their comments were integrated into the draft report, which was once again disseminated for final approval.

Methodology used

The methodology of working on the Situation Analysis is adapted to the condensed timeline of the UNPRPD programming cycle and is built on the findings of the 2019 Situation Analysis as well as the analysis of recent changes in the national legislation and policies towards persons with disabilities in Uzbekistan. It follows closely the Guidance document disseminated by the UNPRPD to the pre-selected UNCTs.

The research was based on a combination of methods: literature review, in-depth interviews with key informants and thematic group discussions. The list of informants for the study was established under the guidance of the Local Researcher and in close consultation with the Advisory Expert Group based on the informants' professional experience in the field of rights of persons with disabilities or related issues. A particular effort was made to involve representatives of grassroot-level peer support groups and networks, particularly those working with women and children with disabilities. Other key informants include UN Country Team staff, national authorities, and providers of social support services.

The list of research participants is attached in Annex I. In total, 16 in-depth interviews were conducted with the representatives of ministries and state agencies, international organizations. Within these

interviews the research team also spoke to four representatives of local OPDs representing women with physical impairments, the umbrella cross-disability organizations represented by a man with physical impairment, a woman representing a network of parents of children with learning disabilities as well as a man with a visual impairment representing local academia in social work and disability studies. Moreover, 34 participants took part in five thematic focus group discussions including persons with disabilities representing organizations of women and girls with disabilities, parents of children with Down Syndrome, autism, spinal muscular atrophy, persons with HIV, deaf, hard-of-hearing and deafblind persons and other groups. The list of questions for interviews and focus group discussions is attached in Annex II. The Terms of Reference of the Advisory Expert Group is attached in Annex III.

Scope and limitations

It is essential to note an important deviation from the classic Situation Analysis design that envisages in-depth consultations with the rights holders. While in the current research, such rights holders would be persons with disabilities, particularly women and children and those in or at risk of institutional care, the condensed timeframe and limited resources do not allow for a meaningful roll-out of this exercise.

It is submitted that the ultimate **principle of "do no harm"** could not be guaranteed if children and women with disabilities, particularly those with experience of institutional care, were to be personally interviewed for the research. The development of methodology and protocols, particularly ensuring integration of the "do not harm" principles and ethical considerations, as well as training the researchers, would involve a time and resource investment that the team did not have at their disposal.

It has therefore been decided **not to conduct in-depth interviews with individual rights holders who are persons in vulnerable situations.** This difficult decision is partially mitigated by an emphasis on grassroots organisations and disability peer support groups and the close involvement of the Advisory Expert Group in the research. It is hoped that in the absence of direct information from the rights holders, in-depth consultations with their associations will be the next best thing to generate evidence.

The ongoing global pandemic has put a further limitation on the methodology and approach, making international travel to Uzbekistan impossible. While the two lead consultants are currently based outside Uzbekistan, this limitation is mitigated by the active involvement of the Local Researcher and the Advisory Expert Group, and the reliance of online research tools.

5. FINDINGS

Stakeholder and coordination analysis

Key findings

Charity approaches towards persons with disabilities are prevalent in Uzbekistan. Social model of disability remains largely unknown[7] and medical understanding of disability is a dominant perspective. Uzbekistan's disability movement is in development. In recent years, the emergence of a new advocacy movement has been noted, but it is in strong need of recognition, diversification, support, and capacity building. Involvement of OPDs in decision-making is tokenistic and superficial. Grassroots organisations and those representing marginalised groups experience significant barriers to formal establishment and access to funding. No activists with psychosocial disabilities have been identified. Capacities of NGOs for service delivery for children and adults with disabilities at the community-level is also rather weak.

Despite the large number of governmental stakeholders, there is a lack of smooth coordination of all government efforts towards realisation of rights of persons with disabilities. This results in dispersed energy, inefficient spending of resources and limited transparency. The creation of the Agency for the Development of Medical and Social Services and its placement under the Cabinet of Ministers is a positive step forward; however, there is still no comprehensive coordination structure in the country

[7] Feruza Zagirtdinova, "Disability in Uzbekistan: when will the social model of disability arrive?", Disability & Society, 2005.

with horizontal and vertical responsibilities for all questions relating to the CRPD and the capacity to show overall leadership. Although the Government of Uzbekistan established the Interagency Council on Disability Affairs on 29 April 2021,[8] it remains tokenistic in terms of participation of grassroots OPDs and NGOs working with and for persons with disabilities.

The Society of the Disabled of Uzbekistan, which mainly represents adults with physical impairments, is the only OPD which was included as a member of the recently established Interagency Council on Disability Affairs under the Cabinet of Ministers. The Association of Disabled People advocated for the inclusion of other OPDs as fully-fledged members of the Interagency Council stating that its current composition violates Article 15 of the Law "On the Rights of Persons with Disabilities" and Article 33 of the CRPD.[9] As of 28 May 2021, the Agency for Development of Medical and Social Services made a written commitment to consider including more ODPs in the Interagency Council but it is not clear whether it will be fulfilled

International disability NGOs are not present in Uzbekistan probably due to the restrictive legal environment for operation of INGOs in the country which was in place up until September 2016.[10] Since the re-opening that started in 2017, the NGO legislation has not changed considerably,[11] although several INGOs were allowed to re-open their representative offices and branches in the country.[12] However, disability INGOs are still not represented in Uzbekistan. The active UN agencies working in the field of disability inclusive development include UNICEF, UNDP,, UNFPA and OHCHR. OSCE Project Co-ordinator in Uzbekistan has also joined UNCT in supporting the Government of Uzbekistan. UNICEF is coordinating these efforts among UNCT and OSCE by supporting the National Human Rights Centre in the ongoing validation of the National Action Plan (NAP) on UN CRPD and provision of technical expertise on the best practices and international standard on implementation of the rights of persons with disabilities.

Organisations of persons with disabilities, civil society and academia

The Uzbek civil society landscape consists of NGOs established by the government (government-organized NGOs or GONGOs) which are referred to as *"systemic NGOs"* and independent organizations or *"self-initiative NGOs"*, registered at a grassroots level by civil society activists.

Uzbekistan's active OPDs are mainly concentrated in the capital city, Tashkent. Ministry of Justice of the Republic of Uzbekistan reports that there are 613 NGOs "*protecting the rights and legitimate interests of persons with disabilities*"[13], but this number includes their regional, city, and district branches. According to unconfirmed sources, more than 70 NGOs are working to promote disability rights and inclusive development in Uzbekistan. Out of this number about 15 can be considered self-initiative organizations of persons with disabilities representing mainly physical disabilities. Additionally, it is understood that there is an unknown number of active self-initiative groups that are not formally registered (either due to lack of capacity or administrative barriers).

Four main impairment-based OPDs are the Society of the Deaf of Uzbekistan, the Society of the Blind of Uzbekistan, the Society of the Disabled (uniting mainly persons with physical impairments), and the Association of Disabled People of Uzbekistan a recently established cross-disability umbrella organization. The first three OPDs operate at the national level and have in total 380 branches across the country and were established by or with the support of the Soviet government and inherited the

[8] The Resolution of the Cabinet of Ministers dated April 29, 2021, No. 257 "On the organization of the activities of the Interagency Council for Persons with Disabilities", https://www.norma.uz/novoe_v_zakonodatelstve/sozdan_mejvedomstvennyy_sovet_po_delam_lic_s_invalidnostyu

[9] Dilmurad Yusupov and Oybek Isakov, "Council About Us Without Us", Gazeta.uz, 27 May 2021, (accessed on 1 June 2021) (English translation).

[10] International Centre for Not-For-Profit Law (ICNL), Uzbekistan country profile (accessed on 24 July 2021)

[11] Human Rights Watch World Report 2021: Uzbekistan.

[12] "IREX is returning to Uzbekistan after 15 years", Gazeta.uz, 14 April, 2021.

[13] Analytical report "The State of the Third Sector in Uzbekistan: realities and development prospects", Independent Institute for Monitoring the Formation of Civil Society, 2018.

Soviet approach to disability policy through organization of specialized training and production enterprises for adults with sensory impairments.

The Association of Disabled People of Uzbekistan was established in 2018 and is an umbrella cross-disability OPD currently uniting 31 NGOs and OPDs working in the field of disability. The Association currently has 11 regional branches across the country. Its main goal is to coordinate the actions of public organizations of persons with disabilities to ensure their rights and create an inclusive society through the implementation of the CRPD. On August 30, 2021, the Association gained a consultative status of the UN Economic and Social Council (ECOSOC), approved by the UN Committee on Non-Governmental Organizations.

Kibray district Society of Women with Disabilities "Opa-singillar" (Sisters) is a regional organization supports women and girls with disabilities and single mothers of children with disabilities in difficult life situations. This support includes the provision of social and legal information, support in obtaining education, in employment, and the provision of targeted material assistance to those in need.

Youth social and legal rehabilitation center for disabled people "Millennium" in Tashkent supports young persons with disabilities by promoting independent skills and improving their quality of life.

Public Association of Disabled People of Tashkent city "Sharoit Plus" conducts Disability Equality Trainings (DET), peer counselling support services, and training in independent thinking skills for persons with disabilities. In December 2021 the organization launched a disability inclusive recruitment web portal[14] and is piloting it in Tashkent city to support employment of persons with disabilities.

The Republican Centre for Social Adaptation of Children (RCSAD) was established in 2004 to provide comprehensive medical, social, psychological, and pedagogical assistance and advice as well as legal assistance to children belonging to socially vulnerable groups (including children with disabilities, children with severe chronic diseases, and minors in specialized educational institutions).

Center for Youth and Children with Disabilities under the Youth Union of Uzbekistan (Mehrli Qo'llar) was established in December 2017 to protect the interests of youth with disabilities, create equal opportunities in society, provide legal, psychological and pedagogical assistance, and engage in charitable activities. The center has an online charity platform, "Mehrli Qo'llar," which raises funds through social networks for children and youth with disabilities and their families.

Republican NGO "Avlod Baraka" is a comprehensive system of interdepartmental support for children and adolescents with developmental disabilities (including autism spectrum disorder).

Samarkand Help Centre for Persons with Disabilities focuses on the adaptation and socialization of persons with special needs; informs the population about the problems of persons with special needs; and employs persons with special needs.

Support Center for Children with Disabilities and their Parents "Umidvorlik" provides social support to children, adolescents and young persons with various types of impairments and their parents through educational, awareness-raising and other development and socialization programs. Currently, about 100 families raising children, adolescents and young people with various types of disabilities are members of the organization.

While women and girls with disabilities are the dominant focus of work for some of the above-mentioned organisations, notably, "Opa-singillar" and "Sharoit Plus", there is no umbrella organisation led by women and girls with disabilities that would represent their interests at the national level and in the official workings with the government. The two above-mentioned organisations, while practising the rights-based approach to working with women and girls with disabilities, are active at the local level in Tashkent city and Tashkent region and mostly operate as service providers, doing only limited advocacy for a systemic reform and inclusion of women with disabilities in the law and policies.

Several organisations working for and with women or on gender issues have been involved in the research as stakeholders. While actively engaged in the discussion, many of them were open about their

[14] www.ishplus.uz

lack of understanding of specific issues concerning women and girls with disabilities, and limited possibilities to provide fully inclusive and accessible services today due to inaccessible facilities and communication, limited exposure to disability and lack of a robust network of contacts.

The field of disability studies remains largely underdeveloped in Uzbekistan and is included in the social work education provided at the National University of Uzbekistan named under Mirzo Ulugbek, where a person with a disability and Vice-Chairperson of the Association of Persons with Disabilities is Associate Professor of Social Work. Local OPDs are involved in the academia through forums and conferences on development of social work in the country and this cooperation can serve as a good role model.

Government stakeholders

Agency for the Development of Medical and Social Services provides medical and social services to the elderly, persons with disabilities, and other groups in need of social protection. It is considered to be a focal point for disability issues, but its management is not inclusive of persons with disabilities and their OPDs. Formerly accountable to the Ministry of Health, the Agency became subordinate and accountable to the Cabinet of Ministers in March 2021.[15] The Agency is responsible for the residential care institutions "Sakhovat" and "Muruvvat"; the Republican Inspectorate of Medical and Social Expertise and its territorial divisions and the national rehabilitation services, among others.

The Inter-Agency Council on the Affairs of Persons with Disabilities at the Cabinet of Ministers of the Republic of Uzbekistan is a recently established coordination mechanism[16] to facilitate the activities of bodies implementing state policy in the field of ensuring the rights of persons with disabilities, as well as local self-government bodies; participates in the implementation of state programs for rehabilitation, social protection, and protection of the rights of persons with disabilities; provides assistance in education, vocational training, retraining, advanced training, and employment of persons with disabilities; and helps create favourable conditions for the full participation of persons with disabilities in society and the state. Although a welcome initiative in principle, concerns have been raised about transparency of the functioning of the Council and meaningful participation of organisations of persons with disabilities in its work (see page 38).

The Ministry of Health provides medical aid and support for the prevention of illnesses for persons with disabilities; organizes rehabilitation services for persons with disabilities; creates rehabilitation, medical, and diagnostic centres; and trains specialists for medical and preventative services.

The Extrabudgetary Pension Fund under the Ministry of Finance is responsible for provision of disability benefits for persons with disabilities belonging to disability group I and II through its district (city) departments. The Ministry of Finance is currently working on the Single Registry for Social Protection (Single Registry), an information system that enabled streamlining the process of distributing social benefits and allowances through digitalization.

The Ministry of Public Education is responsible for the development of inclusive general education and the transformation of care from institutionalization to family-based care. In 2020 it established an "Inclusive Education Laboratory" at the Republican Centre for Vocational Guidance and Psychological and Pedagogical Diagnostics of Students, which is responsible for creating the conditions for inclusive education in general secondary schools, developing criteria for determining the quality and effectiveness of inclusive education, and monitoring its implementation across Uzbekistan.

The Ministry of Preschool Education is responsible for the development of inclusive preschool education for children aged 2-7 and the organisation and correctional, pedagogical and rehabilitation assistance to children with disabilities in specialised preschool establishments.

The Ministry of Employment and Labour Relations is responsible for providing employment support to persons with disabilities. It established district-level Employment Assistance Centres, where persons

[15] Before the Agency functioned under the Ministry of Healthcare, Resolution of the President of the Republic of Uzbekistan "On the Organization of the Agency for the Development of Medical and Social Services of the Republic of Uzbekistan", 25 March, 2021, No. PP-5038.

[16] Resolution of the Cabinet of Ministers of the Republic of Uzbekistan, No. 257 29 April 2021 (accessed on 1 June 2021).

with disabilities can access job referrals, free consultations, free professional training or retraining. The ministry also has a national database of vacancies; the section on quota-based jobs for persons with disabilities was still in development as of July 2021.

The Ministry of Economic Development and Poverty Reduction is a government body responsible for the development and implementation of long-term strategy and integrated development programs, conducting a well-thought and balanced socio-economic policies aimed at addressing the following major tasks: ensuring of macroeconomic stability, sustainable, balanced and dynamic economy; and formation of multi-functioning economy, providing leadership on private property, the development of market infrastructure; creation of new jobs and strengthening targeted social protection of the population, sustainable and steady growth in living standards, development of social infrastructure.

The Ministry for the Support of Family and Mahalla is responsible for the timely identification of women's problems, and the provision of social, legal, psychological, and material assistance to women in need of help and in difficult social situations, including women with disabilities. The ministry's Public Fund for the Support of Women and the Family allocates money to provide women and children with disabilities with assistive devices (e.g., wheelchairs, hearing aids) and surgeries. It also coordinates the activities of self-governing bodies (mahalla committees). The Ministry works on Aollar Daftari (Women's notebooks)

The Youth Affairs Agency of Uzbekistan was established on 30 June 2020 and is a government body with regional branches for the development and implementation of state youth policies. Its purposes are norm-setting, upbringing and enlightenment work, protecting the rights of young people, assisting them in obtaining education abroad, employment, doing business, etc.

International cooperation

The disability community of Uzbekistan has few interactions with the global disability movement, notably the **International Disability Alliance that currently does not have a dedicated regional structure for Central Asia**. The language barrier is a significant obstacle that prevents better international exposure of Uzbekistan's disability movement. Central Asian regional cooperation among OPDs remains quite limited, with Russian being a lingua franca in the region. More research is needed into challenges for closer regional cooperation and opportunities for fostering it with a medium-term view to improving the representation of the Central Asian disability movement in global structures. UN Human Rights and Inclusion Task Force, co-chaired by UNICEF, meets regularly to discuss focus areas and priorities in the area of disability inclusion as well as joint efforts needed to support the Government as "one-UN" in order to overcome any duplication. UNICEF, as co-chair of the Task Force, represents UNCT in supporting the Government of Uzbekistan in the area of disability inclusion. OSCE has joined UNCT efforts in provision of technical expertise on the best practices and international standards on implementation of the rights of persons with disabilities. UNICEF and UNDP have recently recruited UN Volunteers with disabilities and further aim to enhance its programming on disability inclusion through advocacy and capacity building of staff and partners, as well as ensuring that all events and premises accommodate the needs and accessibility requirements of the persons with disabilities.

Equality and non-discrimination

Key findings

Existing legislation, including the latest legislative initiatives, are based on the medical model of disability and do not address all civil, political, economic, social, and cultural aspects of human life. Legislation in force promotes plenary removal of legal capacity and substituted decision-making and lacks concepts such as universal design and reasonable accommodation.

There are no legal provisions to protect women and girls with disabilities from gender-based violence and ensure their equitable access to sexual and reproductive health. Access to reproductive health rights is extremely limited for girls and women with disabilities who report lack of accessibility of information about their reproductive rights, discriminatory and disdainful attitudes on behalf of the medical corps and unmet needs in relation to protection of sexual, physical and psychological violence within the family.

Negative perceptions and discriminatory attitudes are at the core of continued exclusion and segregation of persons with disabilities. Double discrimination experienced by women and girls with disabilities puts them at an increased risk of deprivation, exclusion, sexual and physical violence, and abuse. The stigma is prevalent not only among the general population, but also in the professional and policy-making sphere, slowing down advancement of disability policies in line with the Convention.

After more than 10 years of impasse following the 2009 signature of the Convention, the President of Uzbekistan signed the bill into law in June 2021. The formal instrument of ratification was deposited with the UN on 28 June 2021. The Optional Protocol to the Convention has not been ratified or signed.

In addition to the CRPD, Uzbekistan is also a State Party to the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the UN Convention on Elimination of All Forms of Discrimination against Women and to the Convention on the Rights of the Child, among others.

The **Law "On the Rights of Persons with Disabilities**,"[17] in force since 16 January 2021, repeals and replaces the outdated 2008 Law on the Social Protection of Persons with Disabilities. It introduces the **principle of non-discrimination on the basis of disability** and defines it in Article 3 as

> "*any segregation, exclusion, removal or limitation on the basis of disabilities that has as purpose or effect the denial or recognition or realisation of rights and freedoms of persons with disabilities in the political, economic, social, cultural, civil or any other field on an equal basis with others".*

Article 3 also introduces a new **definition of a person with a disability**, defining them as

> "*a person with long-term physical, mental, sensory or psychological impairments in need of social assistance and protection, creation of conditions for a full and effective participation on an equal basis with others in the political, economic, social life*".

Despite this welcome development, the country continues to practice a combination of medical and charity models of disability, focusing on medical diagnosis as activity limitation and social assistance schemes to compensate for this alleged limitation. The recently repealed 2008 Law defined a person with a disability as

> "*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 characterised by their full or partial loss of capacity or ability to self-service, move around, orientate, communicate, control their behaviour, and work".*[18]

This medical definition of disability is largely preserved in the 2021 Law:

> *"a person with a disability is a person with long-term physical, mental, sensory or psychological impairments in need of social assistance and protection, creation of conditions for full and effective participation on an equal basis with others in political, economic, social life of the community and state".*

This Situation Analysis will demonstrate that the outdated definition still very much governs the legislative and policy realm, and significantly limits people's rights.

In her letter to the Uzbekistan Ambassador to the UN of 9 December 2019, the then UN Special Rapporteur on the Rights of Persons with Disabilities Catalina Devandas-Aguilar offered her

[17] Law of the Republic of Uzbekistan 'On the Rights of Persons with Disabilities', No. ZRU-641 from 15 October 2020 (in Russian).

[18] 2008 Law on Social Protection of Persons with Disabilities, repealed in 2021 by the Law on the Rights of Persons with Disabilities.

commentary to the draft Law on the Rights of Persons with Disabilities and proposed a set of recommendations. Specifically, the Special Rapporteur raised her concern over the retention of the medical approach to disability manifested by the draft Law's emphasis on "fixing" a person's impairment rather than removing environmental and attitudinal barriers. The Special Rapporteur further advised that a failure to include a concept of reasonable accommodation in the legislation would strip people of disabilities from a powerful tool to claim full equality. She offered constructive criticism of the segregationist approach to housing, education, employment and provision of social assistance and reminded that meaningful participation of persons with disabilities is a "*core human rights principle that is firmly rooted in international law, and it is a basic condition for democratic societies as it allows individuals to play a central role in their own development, as well as in the development of their communities.*"[19]

The right to equal recognition before the law

Despite the best efforts, it has not been possible to ascertain the situation with **legal capacity** in Uzbekistan, including number of people under guardianship in the country, typical circumstances surrounding the removal of legal capacity or consequences of the incapacitation decision on human rights of the individuals concerned.

In the course of the research, the widespread lack of understanding of the issue of legal capacity or interest towards it by all stakeholders has been observed. Even when asked directly, neither governmental nor civil society respondents were able to provide commentary to the current situation with guardianship and substituted decision-making. The initially planned focus group discussion aimed at exploring the issues related to deprivation of legal capacity, such as forced institutionalisation and treatment, arbitrary deprivation of liberty, violation of political, civil and property rights, could not be organised due to failure to identify competent stakeholders.

To the best of our knowledge, the issue is not currently the focus of any advocacy or awareness raising efforts by either the disability movement or the international community in Uzbekistan.

It can therefore be safely assumed that the status quo presented in the 2019 Situation Analysis holds today: plenary guardianship and substituted decision-making are routinely used for many persons with disabilities, particularly those with intellectual and psychosocial impairments. Legal incapacitation strips the person of all rights and makes them fully dependent on their legal guardian that is usually a family member or, in case of persons in institutional care, the director of the social care establishment. There are no known cases of restoration of legal capacity.

> ***"We had never thought of a procedure of incapacitation for Misha until we faced difficulties with notarization of some documents. When we came to a notary, as soon as she saw him, she refused to even talk with Misha until we brought a medical certification that he is capable. She even didn't know that he has difficulties in communication, it was enough for her to see his wheelchair. …When we try to challenge this conclusion, we are told that if someone cannot speak, it automatically means that he is retarded. Every time it is very difficult"***
> *- Mother of 25 year-old young man with mobility and communication disabilities*[20]

The recent ratification includes a regrettable reservation to CRPD Article 12 whereby the Republic of Uzbekistan reserves its right to continue practice substituted decision-making. The reservation manifests the current unpreparedness or unwillingness of the state to address this most pervasive and consequential violation of human rights of persons with disabilities and goes against Uzbekistan's commitment under the Sustainable Development Agenda to "Leave No One Behind".

In the absence of active, visible and knowledgeable civil society activists, including persons with disabilities engaged in the reform of legal capacity, legislation and practice, the chances of positive developments remain slim.

[19] OL UZB 4/2019, 9 December 2019.

[20] As quoted in the 2019 Situation Analysis. Supra, nr 1.

While the adoption of the Law is a significant step towards a better understanding of the rights-based approach to disability, the Law itself falls short of full compliance with the CRPD. Largely based on the **medical model of disability**, it does not address civil and political rights of persons with disabilities (including the right to legal capacity, access to justice, right to vote and be elected, to name a few), lacks enforcement, implementation and monitoring mechanisms and does not address multiple discrimination faced by women and girls with disabilities and those belonging to marginalised and invisible groups.[21]

While the legislative framework governing the rights of persons with disabilities can and should continue being improved aiming for full compliance with the CRPD, it is submitted that the emphasis of the current efforts should be on activating the provisions of the legislation in force, many of which already provide an opportunity to build a more resilient and disability-inclusive society. The upcoming drafting of a National Plan of Action for implementation of the Convention, foreseen by the National Centre for Human Rights is one such opportunity to reinforce the ideological commitments with practical mechanisms of implementation, budgeting, collection of data, monitoring and participation of organisations of persons with disabilities. However, there are significant concerns about the rushed process understood to be governing the drafting of the NPA that risks leaving little room for a meaningful consultation with all stakeholders, including organisations of persons with disabilities.

Discriminatory attitudes and perceptions

Negative image of persons with disabilities is pervasive in Uzbekistan and affects all spheres of life and all aspects of public policy: from data collection to development to social services to participation of persons with disabilities in the community. People with disabilities are usually portrayed as objects of pity or heroes, rarely seen in roles such as spouses, parents, professionals, or imagined having hobbies or (bad) habits, such as playing chess, socialising with friends, smoking.

Stigma surrounding disability are among the factors explaining the choice of many parents of children with disabilities and adults with disabilities not to apply for disability status. Along with some financial benefits and theoretical access to state rehabilitation services (that usually is not realised in practice), the disability status brings along stigma, prejudice, exclusion from access to good mainstream education and future opportunities. When financially feasible, parents prefer to seek private support, rehabilitation and education support services for their children instead.

Having a family member with a disability damages the whole family's reputation and risks ostracising its other members, including in employment, marriage prospects and social acceptability. As a result, people with disabilities are more often than not hidden from the public eye, making it extremely difficult to reach them for data collection or research, or estimate the demand for support services. Importantly, the negative and discriminatory attitudes of service providers combined with purely medical perceptions of disability is causing parents to abandon their children with disabilities at maternity hospitals which considerably increases the risk of institutionalization and deprivation of family-based care.

Every stakeholder interview – without exception – invoked a negative image of persons as factors slowing down the development of policy solutions on the ground. For example,

> ***"People with disabilities are so hidden away, it's almost impossible to reach out to them. Because of the stigma and shame attached to disability they don't come forward. We struggle to involve them: the official data is not reliable, and we are forced to rely on word of mouth to identify them for our social innovation work."*** *- Representative of the Situation Analysis Advisory Expert Group, Associate Professor of social work*

> **"*Shelters for victims of violence providers have never worked with women with disabilities, they are a bit afraid of them, thinking women with disabilities will need a lot of complex medical interventions.*" -** *UN Agency*

[21] For a more complete analysis of the 2020 Law, cf. "We now have rights but how to implement them?" by O.Isakov and D.Yusupov (accessed on 23 June 2021).

> **"*I expect that prejudice against children with disabilities voiced by parents of children without disabilities will be the main obstacle at the beginning of the inclusive education reform".* -** *Laboratory of Inclusive Education*

> ***"When I took my baby [with a disability] to see the paediatrician for the first time, he manifested disdain and squeamishness in his every move, how he touched my child, how he looked at him and at me. I don't show my child to the doctors in my town anymore. We get substandard service there".*** *Representative of a parents' peer support group, Andijan*

The alarming social prejudice and stigma that surrounds disability in Uzbekistan does not go unnoticed by the international community: in 2003, the CRC Committee recommended Uzbekistan to "*undertake awareness-raising programmes, including campaigns, on eliminating discrimination against children with disabilities, and strengthen its enforcement mechanisms for ensuring compliance with its legislation prohibiting such discrimination."*[22]

Patriarchal gender stereotypes continue to dominate the society of Uzbekistan. In 2015, the CEDAW Committee noted its concern in relation to deep-rooted stereotypes concerning the roles of women and men in the society,

> "*which discriminate against women and perpetuate their subordination within the family and society and which, among other things, are reflected in women's educational and professional choices, their limited participation in political and public life, their unequal participation in the labour market and their unequal status in marriage and family relations. […S]uch stereotypes are also root causes of violence against women and expresses concern at the prevalence of harmful practices that discriminate against women, such as child and/or forced marriage and polygamy, and that, to date, the State party has not taken sustained measures to modify or eliminate discriminatory stereotypes, negative traditional attitudes and harmful practices.*"[23]

Violence, abuse and exploitation of women and girls with disabilities

The heightened risk of violence experienced by women and girls with disabilities has been well documented by the international expert bodies, including the UN High Commissioner for Human Rights[24] and the CRPD Committee.[25] It often results from harmful stereotypes, invisibility and perceived inherent vulnerability of women with disabilities, but also desire to control or "protect" them. Acts of violence include but are not limited to physical, psychological and sexual violence, neglect, denial of personal mobility and communication assistive devices and aids, denial of food, water and hygiene, forced marriage and pregnancy, irreversible and invasive medical procedures, economic exploitation, withdrawal of care, and other crimes.

Governments are required to take comprehensive measures to prevent, address and sanction violence against women, including:

- Legislative and policy measures in the field of gender equality, non-discrimination in access to and quality of healthcare, prohibition of non-consensual medical interventions, sexual education, and criminalisation of family-based violence, among others;
- Prevention and protection programmes and initiatives against gender-based violence must be fully accessible and inclusive of women.

[22] CRC/C/UZB/COt/3-4,para 50(a).

[23] CEDAW/C/UZB/CO/5, 24 November 2015, para 15.

[24] Thematic study on the issue of violence against women and girls and disability, UN OHCHR, 30 March 2012, A/HRC/20/5.

[25] CRPD Committee General Comment No. 3 (2016). Article 6: Women and girls with disabilities, 2 September 2016, CRPD/C/GC/3.

In the absence of the official statistics on prevalence of gender-based violence in Uzbekistan, it is estimated that at least one in three women experience physical, psychological or sexual violence in the family in her lifetime.[26] NGOs report that 4,847 women filed gender-based violence cases to the police in 2020 alone, with physical violence sharing the highest percentage of cases reported at 49.9 % followed by psychological violence at 40.2 %.[27] This information is however considered very conservative with the majority of violence cases underreported due to society pressure, fear of victimisation and social conditioning.

The available unofficial data on gender-based violence is not disaggregated by disability, nor is there any available official information on violence against women and girls in Uzbekistan. In 2010, the UN Committee on the Elimination of Discrimination against Women expressed concern that very limited information and statistics were available on vulnerable groups of women, including women with disabilities, and stressed that these women "*often suffer from multiple forms of discrimination, especially with regard to access to education, employment and healthcare, protection from violence and access to justice."*[28]

Peculiarly, the next round of CEDAW review of Uzbekistan does not contain a single reference to women and girls with disabilities[29], while none of the alternative submissions to the ongoing sixth round of review as much as mention women with disabilities, let alone explore the nuances of the double discrimination they experience. It is submitted that this phenomenon is not the result of a positive trend but, on the contrary, points towards a dangerously hidden nature of intersectional discrimination of women and girls with disabilities.

Indeed, the issue is largely misunderstood and little known in Uzbekistan:

> ***"Before 2017, violence against women was a taboo in our country. No one talked about it and very few organisations worked on this subject. It's a very new topic to us, and the number and quality of NGOs active in the field is growing, albeit slowly. However, there is still very little knowledge about women with disabilities in the sector, it's a learning curve for the NGOs."*** *UN Agency*

More recent research confirms that discussion of domestic and gender-based violence remains a socially unacceptable topic in Uzbekistan today: in the eyes of many, it should be dealt with privately, with but a minimal involvement of the local mahalla committee. Domestic violence is seen as socially acceptable, with 65% of women and 60% of men convinced that there are justifications for a husband to beat his wife.[30]

Neither national legislation nor policy and programmes documents in force reflect the double burden experienced by women and girls with disabilities. Regrettably, these include the three most recent legislative initiatives, the 2019 Law on Guarantees with Respect to Equal Rights and Opportunities for Women and Men,[31] the 2019 Law on Protection of Women from Harassment and Abuse[32] as well as the 2021 Law on the Rights of Persons with Disabilities.

Draft Strategy for Achieving Gender Equality in the Republic of Uzbekistan in 2020-2030[33] may be interpreted as an indirect reference to women with disabilities in formulation of "groups in need of social

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[26] Alternative report for the CEDAW Committee, Tashkent 2021, Civic Initiatives Support Centre, NIHOL, p 6.

[27] Ibid, p 7.

[28] CEDAW Concluding Observations to the fourth periodic report to Uzbekistan, 26 January 2010, CEDAW/C/UZB/CO/4, para 40.

[29] CEDAW/C/UZB/CO/5.

[30] UN Uzbekistan, United Nations Common Country Analysis: Uzbekistan, 2020 (accessed on 27 July 2021), p.31.

[31] Law of the Republic of Uzbekistan "On guarantees with respect to equal rights and opportunities for women and men", No LRU-562, 02.09.2019

[32] Law of the Republic of Uzbekistan "On protection of women from harassment and abuse", No LRU-561, 02.09.2019

[33] 'Uzbekistan develops Gender Strategy for 2020-2030', Kun.uz, 1 February 2020.

protection". It does not, however, develop any concrete measures to address the intersectional discrimination experienced by women and girls with disabilities.

In the recent years, some measures have been introduced to tackle violence against women that is rampant in Uzbekistan, including the launch of a hotline for victims of domestic violence and a system of referrals to newly established social rehabilitation and adaptation centres. As per a Presidential Resolution of May 2021, a further 29 shelters would be opened under the Ministry of Mahalla and Family Support. However, it is reported that the current system lacks sustainability due to shortage of confirmed long-term funding and lack of knowledge and skills to provide assistance to victims of violence. Lack of skills to address the issue is also observed at the level of mahalla committees. There are also serious concerns that the new services would not be inclusive of women and girls with disabilities as the design of the shelters does not include considerations of physical accessibility requirements. The impact of the governmental measures on women with disabilities to-date is not known since the data on services provided is not disaggregated by disability. It is suspected that the number of clients with disabilities is low owing to the lack of awareness about gender-based violence and about the existence of support services.

The absence of visibility of the issues concerning women and girls with disabilities, including double discrimination, violence, exploitation and abuse and lack of data on these human rights violations is at least in part linked to the underrepresentation of women with disabilities in the national advocacy movement. While the few activists who have been identified (and interviewed for this research) are committed to promoting the rights of women with disabilities as set out in CRPD Article 6, their grassroots-level work, largely focused on provision of services and training, cannot cover the gap in expertise, resources and dedication to fighting against violence against women with disabilities in Uzbekistan. As such, the vicious circle of exclusion and invisibility continues: pervasive and deeply rooted, violence and abuse against girls and women with disabilities continues permeating the Uzbek society without being brought to the attention of national and international decision-makers who continue omitting the intersection of gender and disability in legislative and policy initiatives.

Inclusive service delivery

Key findings

The bureaucratic, inaccessible, corrupt, and stigmatising identification/assessment processes discourage persons with disabilities from undergoing the identification process. Disability is conflated with the lack of working capacity. Adults with disabilities who are officially recognized as *"unfit to work"* and are thus in receipt of disability support benefits, are prevented from entering the labour market.

Lack of support services in the community and exclusion from the labour market of persons identified as belonging to groups I and II further prevent persons with disabilities from coming forward. The social protection system of Uzbekistan is being reformed to increase the coverage of marginalized and underrepresented groups of children and adults with disabilities. However, the disability benefits, pensions and other allowances are not entirely adequate, sufficient and the coverage is limited, ignoring additional disability-related extra costs. Poverty and lack of adequate measures of disability-inclusive social protection contribute to a high rate of institutionalisation while the COVID-19 pandemic further exacerbates the situation.

The labour market quotas for persons with disabilities are ineffective and have failed to stimulate access to decent work for persons with disabilities, especially women. Low levels of education and limited vocational training opportunities are making persons with disabilities less competitive in the labour market.

The national healthcare system perpetuates the medical model of disability, where the person with a disability is seen as sick, infirm and, in case of limited resources, deserving substandard care. Discrimination in healthcare starts at birth and continues throughout the life span, whereby women, poor households and those living in rural and remote areas are doubly discriminated.

Individual plans of rehabilitation only exist on paper: a very small minority of people has a plan. This is due to widespread unavailability of services that could be included in the IPR, and the lack of

knowledge of the majority of persons with disabilities about their rights. The quality of services and assistive devices is low, and there is no individual needs-based choice for the person.

Despite some progress in improving access to education for children with disabilities, 'inclusive education' continues to be misunderstood and often confused with integration. Most often, segregation in specialist/correctional classes is considered the most suitable form of education for children with disabilities. The inclusive education reform, adopted without meaningful participation of persons with disabilities, happens in a rushed and unprepared manner: two months before the first experimental 'inclusive classes' are to open on 1 September 2021, the range of support services provided to children was unknown pending the adoption of a decision by the Ministry of Education. Shortage of professionals of all profiles is noticeable, and the focus is on training defectologists rather than providing necessary support to classroom teachers. The system of tutors is not employed.

A prerequisite for realisation of human rights of adults and children with disabilities is availability of accessible universal public services such as housing, healthcare, education, culture and information. [34] This must be complemented with a range of sufficiently developed support services, such as social support, rehabilitation, personal assistance, or respite care. This combination creates an enabling environment and facilitates independence and inclusion of all persons.

Access to a range of individualised support is a precondition to independent living and realisation of human rights for many persons with disabilities.[35] Support must be considered a right rather than a form of medical or charity care. The Special Rapporteur on the Rights of Persons with Disabilities defines support as "*a wide range of formal and informal interventions, including live assistance and intermediaries, mobility aids and assistive devices and technologies. It also includes personal assistance; support in decision-making; communication support, such as sign language interpreters and alternative and augmentative communication; mobility support, such as assistive technology or service animals; living arrangements services for securing housing and household help; and community services. Persons with disabilities may also need support in accessing and using general services, such as health, education and justice"*.[36]

It has become evident in the course of research that neither mainstream services nor disability-specific services currently available in Uzbekistan are in compliance with the CRPD. The realisation of human rights in the country thus continues to be hampered.

Determination and assessment of disability

Medical Labour Expert Commissions («*врачебно-трудовая экспертная комиссия*», VTEK) is the structure responsible for disability assessment and determination. VTEK functions under the Agency on Development of Medical and Social Services and determines the "severity of disability", assigns disability groups, identifies causes, time of onset, and terms of disability and defines measures of medical, social, and professional rehabilitation for adults over 18. Children under 18 are assessed by the Medical Consultative Commissions («*врачебно-консультативная комиссия*», VKK). The determination of child disability – or "delays in psychological development" - becomes possible at the age of 3 years old when the child can be assessed by the VKK.[37]

[34] CRPD/C/GC/5, para 32.

[35] Committee on the Rights of Persons with Disabilities General Comment Nr. 5 on the right to independent living, CRPD/C/GC/5, 27 October 2017.

[36] A/HRC/34/58, 20 December 2016, para 14.

[37] Disability determination for children between the ages of sixteen and eighteen was also carried out by VTEKs but the 2021 Law "On the Rights of Persons with Disabilities" provided that children under the age of 18 are examined by Medical Consultative Commissions (VKK).

Disability classification system is inherited from the Soviet Union where persons with disabilities were referred to as *"invalids"* and disability was defined as the loss of working capacity[38]:

Figure 4. Disability Groups based on the Degree of Loss of Labour Capacity

Source: Registration of documents for obtaining disability, Single portal of interactive government services, https://my.gov.uz/ru/life-situations/10 (assessed on January 17, 2021). Author's own illustration.

In other words, disability is conflated with various medical conditions and diseases included in the official list of diagnoses.[39]

> ***"Currently, the determination of disability depends on the determination of disease based on the ICD-10[40], and as a result of the disease a person's functioning is limited and we still rely on identifying the disease in determining the disability. We cannot move from ICD-10 to ICF. The reason is that they are both a family of classifications. ICF is also a classification that complements ICD."***
>
> Deputy Director at the Medical Labour Expert Commission (VTEK)

Presentation of the full package of required medical documents is necessary to apply for disability assessment to the VTEK.[41] For a preliminary disability assessment, a person with a disability must provide a referral from a medical institution with an extract from the medical history, certified by the signature of the attending physician, the head of the department, the chief physician and the round stamp of the institution and an outpatient card. In a 2019 survey, 42 per cent of persons with disabilities and parents/guardians of children with disabilities evaluated the procedure of obtaining the disability status as "difficult" and "very difficult".[42]

Disability assessment and determination procedures are heavily bureaucratized which leads to regular cases of corruption committed by VTEK personnel.[43] Persons with disabilities are obliged to undergo a 4-6 months' medical treatment which requires extra costs (transportation to a medical facility, treatment costs, informal costs, such as bribes to VTEK staff) although their physical, sensory and learning impairments can be easily identified even by a non-expert.

> ***"Previously, it was necessary to confirm that a person was treated for 4 months without any breaks or 6 months with breaks. If there were interruptions, they had to be confirmed by a doctor's prescription for 6 months… Now if the disability status is clearly evident, they will be sent to VTEK without additional checks and no examination will be made. The disability status is clear. For example, a person has no arms, no legs, or blind in one eye, or some of the organs are amputated. The disability status is now clear. Even if you extend the treatment for 6 months or treat it for 10 months, it will not change."***

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[38] Madison, B. (1989) 'Programs for the Disabled in the USSR', in McCagg, W. O. and Siegelbaum, L. (eds) The Disabled in the Soviet Union: Past and Present, Theory and Practice. 1 edition. Pittsburgh; Chicago: University of Pittsburgh Press, pp. 167–198.

[39] Indicators Persons with Disabilities, Number of women and men first recognized as persons with disabilities for reasons of disability, The State Committee of the Republic of Uzbekistan, Gender Statistics of Uzbekistan, (accessed on 15 July 2021).

[40] ICD-10 is the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD), a medical classification list by the World Health Organization (WHO). It codes for diseases, signs and symptoms, abnormal findings, complaints, social circumstances, and external causes of injury or diseases.

[41] Regulations on the procedure for examining citizens in medical and labor expert commissions, APPENDIX N 1 to the Resolution of the Cabinet of Ministers of the Republic of Uzbekistan dated 01.07.2011 N 195,

[42] Supra, nr 1, p. 56.

[43] Yusupov D., "On bureaucracy and corruption in disability registration", Gazeta.uz, December 28, 2019, (in Russian).

Deputy Director at the Medical Labour Expert Commission (VTEK)

The state development program for 2021[44] included measures to mitigate the complex process of disability determination and assessment by allowing assignment of a disability status for an indefinite period to citizens with explicit anatomical defects that have clear signs of impairment without additional examination to obtain clinical and functional information.[45] The compulsory in-patient observation and treatment previously required as part of the identification process has now been lifted.

The certificate of disability entitles its holder to a state-guaranteed disability benefit and a limited set of concessions. The certificate includes recommendations to be included in the Individual Programme of Rehabilitation (IPR). However, as VTEK staff do not usually have a qualification of rehabilitation specialists, the value of recommendations is questionable.[46]

It is submitted that the current system of disability assessment and determination leaves behind about 48 per cent of children with severe impairments between the ages of 3-17 based on the data of the Listening to the Citizens of Uzbekistan 2018 household survey. [47][48] Red tape, inaccessibility of the determination procedure and its cost all contribute to discouraging the potentially eligible people from applying for a disability status.[49] For many people, economic, social and emotional costs associated with the disability status may outweigh the disability benefit, with the shrinking public budget since the beginning of the ongoing COVID-19 outbreak has further limited the eligibility for benefits and social services.

In December 2020, the President pointed out that there would be *"a step-by-step transition to the social model of the definition of disability corresponding to world standards"*.[50] However, there is still a lack of understanding among expert groups and the population in general on what does "social model of disability" imply.

[44] Decree of the President of the Republic of Uzbekistan 'On the state program for the implementation of the strategy of action in five priority areas of development of the republic of Uzbekistan in 2017 - 2021 in the "Year of supporting youth and strengthening the health of the population"', No. UP-6155, 3 February 2021

[45] Idem.

[46] Supra nr 1, p 56.

[47] Study - Listening to the Citizens of Uzbekistan (L2CU), The World Bank, for the first time in Uzbekistan included the Washington Group Short Set of Disability Questions.

[48] UNICEF Uzbekistan (2020) *Building a national social protection system fit for Uzbekistan's children and young people*, p. 41.

[49] Supra, nr 1, p 56.

[50] President Shavkat Mirziyoyev's Address to the Oliy Majlis, 29 December 2020 (accessed on 15 July 2021).

The **UN Joint Program on Social Protection** started on 1 January 2020 and is implemented until 31 December 2021. It is aimed at supporting Uzbekistan's government in building and delivering a high-quality social protection system that offers all citizens—particularly those at risk of being left behind—income security and social support throughout their lives jointly with the government and civil society.[51] By introducing the International Classification of Functioning (ICF) in the assessment of disability and moving away from the medical approach, the Programme is expected to enable greater access for persons with disabilities to social protection and promote their full inclusion in various aspects of social life. The Programme already started piloting international norms in disability assessment and determination by conducting professional training of the VTEK staff and providing them with the necessary equipment.[52]

In the area of disability inclusion, UNICEF jointly with UNDP are supporting the Government of Uzbekistan in strengthening the capacity to develop disability sensitive policies for children through introduction of the social model of disability assessment, within wider system reform. UNICEF is planning to conduct a cost benefit analysis of transition from medical to social model of disability assessment among children. UNDP is supporting strengthening the Government' capacity in conducting disability inclusive data collection and reporting as well as building uniform databases and enhancing accessibility of social public services for persons with disabilities.

Disability support services

The right to grow up in a family-like environment

In its preamble the UN Convention on the Rights of the Child recognizes that "*the child, for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding*."[53] Article 7 provides the right to know and be cared for by his or her parents. Article 9 requires states parties to ensure non-separation of a child from his or her parents against his or her will except legally justifiable cases when such a separation is necessary for the best interests of the child. The UN Guidelines for the Alternative Care of Children provide that "*states should implement effective measures to prevent child abandonment, relinquishment and separation of the child from his/her family*."[54] The states should provide supportive social services, such as day care, mediation and conciliation services, substance abuse treatment, financial assistance, and services for parents and children with disabilities. Such services should preferably be of an integrated and non-intrusive nature and directly accessible at the community level and should actively involve the participation of families as partners, combining their resources with those of the community and the carer.[55]

Article 19 of the CRPD recognizes the equal right of persons with disabilities to live independently and be included in the community so that they could have the opportunity to choose their place of residence and have access to a range of in-home, residential and other community support services including required personal assistance to support living and inclusion in the community, and to prevent isolation or segregation from the community. Article 23 of the CRPD requires states parties to ensure that "*children with disabilities have equal rights with respect to family life*" and to realize these rights by preventing concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families. Importantly, children's or parent's disability should not be a reason for separation of a child from his or her family.

[51] "The UN Joint Programme on Social Protection", UNDP Uzbekistan, 16 July, 2020,

[52] Piloting international norms in disability assessment and determination, UNDP Uzbekistan (accessed on 26 July, 2021).

[53] Convention on the Rights of the Child.

[54] Guidelines for the Alternative Care of Children, A/RES/64/142, 24 February, 2010.

[55] Idem.

Stakeholder interviews showed that shortage of sufficient affordable support services in the community coupled with negative stereotypes is the predominant reason behind institutionalisation and segregation of children and adults in Uzbekistan.

The first experience of parents of children with congenital disabilities is overwhelmingly negative: many face **discriminatory attitudes on behalf of healthcare workers in the maternity wards**, routinely presented with a negative picture of raising a child with a disability and encouraged to place their child in state care.

> ***"When her child was born, the doctor quickly told her it was Down Syndrome. He recommended giving up the child and offered to tell her family that the child was stillborn. The doctors painted a very black picture, said the child would be a vegetable, prone to aggression, using very rude words to describe her baby. They tried to make her afraid of her own child. They were very quick and efficient to give her instructions on the procedure to give up her child, but no information about available support. She was so ashamed she left the maternity ward via the side entrance.***
>
> ***She came to an orphanage in Tashkent to place the child into care. There was no counselling, no asking her about the reasons. It was by chance that she met a nurse who said something nice about the baby and gave her alternative information about Down Syndrome. She came to our centre with a 10-day old baby and received counselling, support and services. She changed her mind and her now school-age child lives with her at home."-*** *Representative of a support and learning centre for children with disabilities, Tashkent*

The frequent pattern of abandonment of babies with disabilities in maternity wards is well known in the country. Disturbingly, however, **blaming the parents for the decision to place their child with a disability in state care** is not unheard of in Uzbekistan. Indeed, it transpired in some stakeholder interviews that such parents are often seen as irresponsible, overdependent on state support, in denial of their parental duties and weak. The context in which the parents – usually mothers – are forced to make such a decision is often left out of the conversation: the factors of poverty, stigma, ignorance, near absolute lack of disability-sensitive social and medical support services that are pervasive in the society and that often determine the fate of the child with a disability and their family are either not well understood or not critically discussed.

Nevertheless, the government has acknowledged the problem of abandonment of newborns and reports that steps are being taken to curb it. Positively, the activists note that recently the practice of abandonment has become less pervasive than before. Parental associations call for urgent action to build on this positive development and take action to end stigma against disability in the medical sector, including in the neonatal and paediatric services.

> ***"Mothers need support at the very beginning. With love and support, most mums come to her senses and want to take care of their babies. Instead of looking for the guilty party or listing everything that is wrong, the support should focus on what is right and what can be done". -*** *Representative of a local peer support group of parents of children with Down Syndrome, Bukhara*

A strict code of ethics binding all medical practitioners in the country and based on the principles of human rights, equality and dignity of all persons and celebrating the equal value of life of a person with a disability is urgently needed to fight against the encouragement of abandonment.

Eligibility to social support services is limited to persons with disabilities belonging to disability groups I and II living alone. The person's family (including children, parents, spouse, siblings as well as guardians, trustees etc) bear primary legal responsibility for supporting their members with disabilities; this service is expected to be provided free of charge. Those who do not have family are eligible for in-

home services (mostly day-to-day tasks) upon authorisation of the local authorities. They also "have the right" to apply for placement in a residential care institution.[56] Indeed, residential care is heavily relied upon for the majority of adults and children with disabilities in need of support, with mobile social services and day centres for persons in need of support representing an insignificant share of available services.[57]

The national legislation does not define what "institution" is. In practice, these include baby homes for children under 4 managed by the Ministry of Healthcare; orphanages ('*mekhribonlik')* for those aged 4 to 18, Murruvat orphanages for children with disabilities managed by the Agency for Development of Medical and Social Services; boarding schools for children with special learning needs managed by the Ministry of Public Education, sanatorium-type kindergartens managed by the Ministry of Preschool Education and SOS Children's Villages[58].

There are non-residential special schools for children with disabilities; boarding-schools for children with hearing and visual impairments where they study and reside during weekdays and visit their families on weekends with some exceptions when children with disabilities do not visit their families and are deprived of family-based care; sanatorium-type boarding schools for children with long-term illnesses where they reside on a regular basis.

Based on international definitions, all the above-mentioned are considered as institutions. Residential care institution is a collective living arrangement where children are looked after by adults who are paid to undertake this function. Children in public institutional care broadly refer to those children under the full-time care of the State either on a permanent or temporary basis Children in non-public institutional care refer to children in SOS villages and other NGOs-run services, financed in total or in part by non-State sources. Children who are not being cared for on a full-time basis like at sanatorium-type kindergartens and specialized boarding schools which are attended on a week-day basis only are not included in this category.[59]

In 2019, 135 children's institutions were functioning in Uzbekistan where almost 30 thousand socially vulnerable children including children with disabilities were raised.[60] According to the latest official data, the proportion of children living in institutions and specialized boarding schools in Uzbekistan is 255 per 100 thousand of the children population, which is more than double the average worldwide (120 children per 100 thousand).[61] The Government of Uzbekistan has adopted a number of legal acts to strengthen the social protection system for orphans and children left without parental care. The decree of President Shavkat Mirziyoyev provided that by 1 June 2019 the relevant ministries and departments had to develop a program of measures for the deinstitutionalization of Mekhribonlik houses in 2019-2023.[62] However, it is unclear whether this state program has been developed and adopted by the government.

The Situation Analysis of Children in Uzbekistan conducted by UNICEF[63] revealed that **children with disabilities are clearly and increasingly over-represented in this type of care**: 69% of all children placed in institutions had disabilities in 2010 and 84% in 2016. Most children with disabilities in

[56] Supra nr 39, p 66.

[57] Supra nr 39, p. 38.

[58] https://www.sos-kd.uz

[59] Monitoring of Situation of Women and Children in Europe and Central Asia. TransMonEE. UNICEF

[60] Based on the data provided by the Ministry of Public Education of the Republic of Uzbekistan.

[61] "Uzbekistan proposed not to open new orphanages", Gazeta.uz, 30 June 2021.

[62] Decree of the President of the Republic of Uzbekistan "On additional measures to strengthen the social protection of orphans and children left without parental care" No. PP-4185 from 11 February, 2019.

[63] Situation Analysis of Children in Uzbekistan, UNICEF, 2019.

institutions are in the 7-17 age group. Given that these are children of school-age, they are likely placed in institutions for educational purposes.

Importantly, the decree and the overall state policy contains a number of contradictions and inconsistencies, and critics argue that the deinstitutionalization reform is not effectively implemented and coordinated among the relevant state bodies, NGOs and OPDs.[64] For instance, rather than transforming the system of social care for vulnerable children and developing a system of alternative family care (e.g., foster families), the government continues to invest in residential-type establishments. Moreover, the specialised institutions are renamed to "children's towns" or "family-type children's towns" while retaining their institutional culture and depriving children of the right to live and be brought up in family surroundings and get community-based care and social services.

As of 2020, a total 86 specialized schools and boarding schools for children with physical or intellectual disabilities functioned across the country and total of 21,200 children were educated at these specialized educational institutions, including 6,100 who went to 21 sanatorium-type boarding schools (for children with tuberculosis and bone diseases), and 13,300 children in need of long-term medical treatment were taught at home on an individual basis.[65] The majority of children with disabilities who are home-schooled have physical and intellectual impairments, while those with sensory impairments usually study at specialized boarding schools. Based on Ministry of Public Education data from 2019, 29% of children with impairments of the musculoskeletal system and 28% of those with learning disabilities studied at home, which exacerbates their social isolation and creates problems adapting when they are older.[66]

The 2003 CRC Committee Concluding Observations to Uzbekistan noted with concern that the high number of children with disabilities in institutions (40 000 at the time of adopting the Observations) points at a significant lack of social and other family support services for children with disabilities.[67]

Some research stakeholders stated that placing children with disabilities in specialized and boarding schools is unavoidable as long as the lack of alternative forms of receiving education and socialization of children is not addressed. Yet others blamed the "parasitical approach of parents" who send their children with disabilities to specialized and boarding schools entirely supported by the government budget.

> ***"Children who are placed in a boarding school did not get proper correctional rehabilitation support during the preschool period, so they cannot enter a general educational institution."*** *- Representative of the Ministry of Public Education*

This point of view seems to ignore the obvious fact that parents are more often than not left on their own with limited social support provided by the government and lack of inclusive day care and education alternatives. Moreover, mothers of children with disabilities are usually blamed for giving birth to children with various impairments and have to bear the burden of raising their children relying solely on their own resources. Birth of a child with a disability in many instances can cause divorce, leaving single mothers on their own without adequate social protection and support.

On 28 July 2021, unexpected changes occurred in the system of care and education of children with disabilities, orphans and children left without parental care. At the suggestion of the President Mirziyoyev, Mehribonlik houses (orphanages) and children's towns were transferred from the system of the Ministry of Public Education to the system of the National Guard of Uzbekistan. For this, a new

[64] "Uzbekistan: Why the Reform of "Merciless" Houses is Stuck?", Cabar.asia, 22 June 2020 (accessed on 5 July 2021).

[65] Resolution of the President of the Republic of Uzbekistan "On Measures for Further Improvement of the System of Education and Upbringing of Children with Special Educational Needs," No. PP-4860 from 13 October, 2020.

[66] Idem.

[67] CRC/C/UZB/CO/3-4, para 45.

position of a Deputy Commander-in-chief is introduced in the structure of the National Guard, and a new department working with children's institutions is to be created. While the actual impact of the sudden decision is yet to evaluate, it is feared that the move, undertaken without prior consultation with the civil society, may hamper the deinstitutionalization reform[68] initiated by the government in 2019.

Early identification and intervention services

The first five years are fundamental building blocks in the life of every child when she acquires behavioural competencies and learns social skills necessary for development and inclusion in the society. Early identification and intervention (EIEI) for children with disabilities is a multi-disciplinary mechanism, triggered at birth or the earliest possible after that, aiming to support the child in achieving her maximum potential, remedy impairments and create a positive experience for the whole family. [69]

In addition to the child's parents or other caregivers, the professionals that may be involved in EIEI are home visiting nurses, family doctors, paediatricians, specialist physicians as well as paramedical professionals, such as speech, physical and occupational therapists, social workers and teachers. Working together, the team conducts functional assessment of the child, with active participation of the parents or caregivers, and develops a person-centred age-appropriate individual rehabilitation plan. Early intervention mechanisms must not reinforce the medical model of disability that leads to segregation and exclusion from education and other mainstream services.[70]

Availability of community-based social support services is the main prerequisite for realisation of the child's right to grow up in a family environment. Conversely, absence of age-appropriate affordable and non-discriminatory support services is often the reason behind placement of children into state care.

It is the consensus of parent associations that **EIEI is not yet developed in Uzbekistan**. The coverage of the issue in the national legislation is patchy: while neither the 2019 Law on Pre-school Education nor the 2020 Law on Education[71] mention EIEI, the 2020 Concept of Inclusive Education indicates that the "*improvement of the system of early identification and support of children with special education needs*" is a priority for inclusive education.

The 2020 Law on the Rights of Persons with Disabilities defines "habilitation" in Article 32 as "*a set of medical, social, educational, psychological and other corrective measures, aimed at forming of the missing (congenital) and/or underdeveloped human functions for the adaptation of the life in the society.*" The services of habilitation are offered to children belonging to the risk group, i.e those "*under the age of 3 with high likelihood of physical and/or mental delays in the absence of early intervention*".

Although the national definition is somewhat unbalanced in disproportionately emphasising "correction" and "delays" and underplaying the importance of social support and quality of life, it is a workable definition that should now be developed into practical measures to ensure the availability of EIEI services for children from birth on.

Identification of some impairments and support needs is arguably less than straightforward, autism spectrum disorder being a classical example. There is little information about autism in the country, and often even people with medical background are not able to correctly place or name the condition. A

[68] Decree of the President of the Republic of Uzbekistan "On additional measures to strengthen the social protection of orphans and children left without parental care" No. PP-4185 from February 11, 2019.

[69] Bailey, D. B., Bruder, M. B., Hebbeler, K., Carta, J., Defosset, M., Greenwood, C., & Barton, L. (2006). Recommended outcomes for families of young children with disabilities. Journal of Early Intervention, 28(4), 227–251 (Bailey et al., 2006).

[70] Annual report of the UN High Commissioner for Human Rights: habilitation and rehabilitation under article 26 of the Convention on the Rights of Persons with Disabilities, A/HRC/40/32, 21 January 2019, para 28.

[71] 2019 Law on Preschool Education, 2020 Law on Education.

family of medics whose child was diagnosed with autism spectrum disorder had but rudimentary knowledge about autism, and some parents report first diagnosing the child with help of Internet-based resources instead of by a trained medical professional. Until recently, most children suspected of autism were diagnosed as having "schizophrenia". On a positive note, there is a growing number of registered children with autism in the country and the increased awareness of parents about autism due to the improvements in the quality of diagnosis and distribution of professional information about autism. There is still a large gap between the patchy official data on the number of children with autism and the informal estimates of parents' associations. This in its turn, slows down the development of multidisciplinary early intervention services and training of professionals.

The 2019 Situation Analysis reports the absence of a legislative or conceptual framework for "early intervention services, multidisciplinary and holistic approaches for assessment or evidence-based educational and social interventions" or family information and support systems:

> "***We (parents of children with Down' Syndrome) with our children don't know where to go, what doors to knock on. We start with curing: neurologists, psycho neurologists, as if Down' Syndrome can be cured. We cannot grow one more chromosome with medicines. We all understand this, but still we cure, cure and cure! Our road is already limited: we go to a special kindergarten and then a special school, where vocational training starts from 5th grade. But in the end, no one who graduates from these schools is employed. Because when our children become adults, they all are registered with a second group of disability and not capable of employment. You cannot be employed with this certificate. (…) But, after ten years, I realized that the most terrible thing is to realize that your child has no future. And this is not because he really can't do anything, but because the most important moment for development was lost; while you are searching for information, the child's further development path is blocked by the system".*** *– Parent of a child with disability and founder of a chain of inclusive children's development centres, December, 3rd, 2018*[72]

The Ministry of Health is responsible for early identification and intervention. Unfortunately, current system is fragmented, and health care providers don't have appropriate knowledge and skills. The referral system and multisectoral collaboration is lacking due to the **absence of standards and protocols and limited staff capacity, particularly in rural and remote areas**. Families' only local contact in healthcare are general practitioners at outpatient Primary Health Care (PHC). They are often not equipped with knowledge on early diagnosis and as result, children do not get timely referral to receive qualified interventions and services. Early intervention services are not available at district level and most disadvantaged families have limited access to services available only at regional or national levels.

Availability of public services in the community is largely limited to the **Republican Centre of Social Adaptation of Children (RCSAC)**.[73] While the Tashkent Centre and its three regional branches in Fergana, Samarkand and Karshi provide useful and necessary services to children and young people with disabilities, they are hardly able to respond to the ever increasing demand for rehabilitation services in the community: according to the RCSAC website, each branch services up to 1500 children with disabilities a year.

Since 2011, RCSAC, in cooperation with the Ministry of Healthcare, has piloted a project on integrating Early Assistance Service in five multidisciplinary polyclinics in Uzbekistan. This service was initially named as "early intervention service" and then renamed to "early assistance service" and was created at children's departments of district (city) central multidisciplinary polyclinics in the form of "primary care" rooms for the early detection of children with a threat of lagging in physical and psychosocial

[72] Reprinted from supra, nr 1.

[73] http://rcsad.uz/

development, contributing to the provision of medical and pedagogical assistance to such children according to an individual program, equipping these rooms with the necessary pedagogical and rehabilitation equipment.[74] Currently, the work on integrating professional staff members able to provide such early intervention assistance is being introduced at multidisciplinary health centres.

The families that can afford to do so turn to private service providers in Uzbekistan or abroad but in reality, the cost of a private intervention is more likely than not prohibitive for a family in a rural or remote area.

Mainstream services

Social protection

For persons with disabilities, social protection measures include disability allowances, concessions, and social services. They report that the allowances are inadequate and do not take into account the actual support needs associated with the impairment.[75] The child disability benefit is for children with disabilities under 16 and HIV-infected people under the age of 18; as of 2020 it amounted to Som 513,350 (less than $50) per month. This scheme covers only 52 percent of children with severe disabilities, and many families struggle to get access.[76]

Benefits and concessions include preferential access to free prosthetic and orthopaedic products, technical means of rehabilitation, and wheelchairs. They can also receive discounts for purchasing a house, free public transport (those in disability group I, blind and those accompanying them, etc).

Based on administrative data, out of registered 484,000 persons with disabilities, 66% receive the contributory social insurance disability pension, 30% receive the disability allowance (reserved for people having never contributed to the labour market), and only 4% have access to the disability social pension that is provided to those who acquired a disability in adulthood but are not contributing to the pension fund.[77] An old age benefit is awarded to mothers if their children have (had) congenital impairments and they lack work experience once they reached the age of 50.[78]

The national structural set-up has been criticized for its fragmentation and lack of coordination in implementation of a single state policy in the field of social protection and inclusion of persons with disabilities.[79] Due to the limited scope of interagency communication, there is no common vision and a coordinated strategy for implementation of the rights of persons with disabilities. Despite the fact that a vertical organizational structure has been established within each department, the horizontal communication is lacking between various government agencies, which significantly reduces the quality, coverage and effectiveness of social services provided for children and adults with disabilities.

Participants of this study confirmed the lack of professional social services and case-managed support for children and adults with disabilities at the grassroots level. They national system of provision of social services is fragmented and there is a lack of interagency communication and coordination between various ministries and departments compromises the services' effectiveness and efficiency.[80] Starting from academic year 2021–2022, the staff of the local self-government bodies (mahalla committees) can

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[74] Resolution of the President of the Republic of Uzbekistan "On Improving the Quality and Further Expanding the Coverage of Medical Care Provided to Women of Reproductive Age, Pregnant Women and Children", No. PP-4513 from 8 November 2019.

[75] United Nations (Uzbekistan), 2019, Situation Analysis on Children and Adults with Disabilities in Uzbekistan.

[76] UNICEF Uzbekistan, "Building a National Social Protection System Fit for Uzbekistan's Children and Young People," May 2020.

[77] Ibid.

[78] Decree of the President of the Republic of Uzbekistan "On the State Program for the Implementation of the Strategy of Action for the Priority Directions of the Development of the Republic of Uzbekistan in 2017-2021 in the Year of Active Investments and Social Development," from January 17, 2019.

[79] An assessment of the social protection system in Uzbekistan Based on the Core Diagnostic instrument (CODI) A joint report by ILO, UNICEF, and the World Bank, 30 October 2020.

[80] The investigative team of the Columbia School of Social Work, Social Intervention Group, Final Report "The Social Services Workforce (SSW) in Uzbekistan: Strengths, Challenges, and Ways Forward," 2018.

study social work (in various fields of activity) at higher educational institutions with the National University of Uzbekistan being the leading institution for the development of educational and methodological literature on qualification requirements, curricula, subject and other training programs.[81]

Health and rehabilitation

The UN Special Rapporteur on the Rights of Persons with Disabilities warns against conflating disability and health, citing the historical perception of people with disabilities as sick patients in need of "curing" and "fixing". She contrasts this outdated view with the CRPD that moves away from medical approaches to disability towards a human rights approach that sees persons with disabilities as equal citizens with a right to the full enjoyment of the right to the highest attainable standard of health in Article 25. The right to health applies to all aspects, including access to sexual and reproductive health services, access to population-based public health programmes, the provision of services as close as possible to the people's communities, including in rural and remote areas, the provision of disability-specific health services, provision of services on the basis of free and informed consent, training of health professionals and promulgation of ethical standards, access to health insurance and prohibition of denial of healthcare on the basis of disability.[82]

Article 26 of the Convention addresses the right to rehabilitation that must be based on a "*unifying framework for the provision of coordinated and comprehensive rehabilitation services that are voluntary, individualised and community-based, [starting] at the earliest stages possible and be based on a multidisciplinary assessment while supporting participation and inclusion."*[83] Rehabilitation is an evolving concept that is deeply specific to the age, circumstances and needs of the person. It involves a range of functional interventions, such as medical, employment-related, educational or social. It must be based on individual rehabilitation plans that are person-centric and goal-oriented. A formal disability status should never be required as a precondition to obtain rehabilitation services. Rehabilitation includes multidisciplinary services, access to assistive devices and technologies, and peer support.[84]

Significant lack of universal access to affordable health care services has been raised by the majority respondents representing organisations of persons with disabilities. The irregularities concern persons with all impairments and throughout the lifecycle. The UN 2019 Situation Analysis of children and adults with disabilities in Uzbekistan showed that 25 percent did not receive the required healthcare services (compared to 10 percent of those without disabilities) and persons with disabilities are almost three times more likely to lack access to prescribed medication.[85]

Although persons with disabilities are legally entitled to privileges and benefits including free healthcare, they face numerous barriers to accessing medical services such as a lack of transport to health facilities (especially in rural areas). The UN found that twice as many persons with disabilities as those without disabilities reported not knowing where to access health services. Medical institutions lack appropriate accessible infrastructure such as ramps, elevators, and sign-language interpretation services; persons with disabilities also reportedly face mistreatment by medical staff.[86] Discrimination starts at birth, whereby children with congenital disabilities and disabilities acquired at birth are often prevented from accessing early diagnostic and intervention services, the emphasis being made on their presumed quality of life that is de facto expected to be low. Parents' associations, particularly those working with families in regions and small settlements, report stigma, neglect and reluctance to provide their children with the best available care in hospitals.

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[81] Resolution of the Cabinet of Ministers of the Republic of Uzbekistan "On measures to improve the training system for citizens' self-government bodies," No. 3 from January 8, 2021.

[82] Report on the right to health of persons with disabilities, Special Rapporteur on the Rights of Persons with Disabilities, 16 July 2018, A/73/161, paras 7, 13.

[83] Annual report of the UN High Commissioner for Human Rights: habilitation and rehabilitation under article 26 of the Convention on the Rights of Persons with Disabilities, A/HRC/40/32, 21 January 2019, para 10.

[84] Idem.

[85] Supra, nr 1.

[86] Idem.

As children age, discriminatory attitudes deepen, discouraging parents from seeking care for their children close to home and choosing instead to travel to regional centres or to Tashkent where the quality of care is comparatively better, not least thanks to the presence of well-established parents-led support services and their cooperation with the medical practitioners. This solution is not available to poorer households and/or those living in remote areas far away from the capital city. This violates the core principle of the CRPD Article 25 whereby health services must be provided as close as possible to people's own communities, including in rural areas.

> ***"Children with Down Syndrome easily get pulmonary infections that turn into pneumonia and require rapid medical interventions. The emergency room doctors are not trained to work with children with disabilities. All they see is Down Syndrome, not the infection. Our parents must learn to advocate for their child. It's scary the first time, but with time the parents learn what treatment works best for the child and advise doctors. The doctors don't like this attitude, they don't think parents are experts. But at the same time, they are sometimes incompetent when it comes to sick children with Down Syndrome. Sometimes, instead of a treatment for routine medical problems, such as diarrhea or fever, parents hear recommendations to place their child into state care. We are also forced to sign waivers of right to file a complaint should something go wrong with the treatment".*** *- Representative of a local peer support group of parents of children with Down Syndrome, Bukhara*

The 2020 alternative report to the UN Committee on Economic, Social and Cultural Rights of the Association of Persons with Disabilities of Uzbekistan stresses the lack of individualised approach to (re)habilitation and support needs and the non-respect of the obligation to provide every person with a disability with an age-appropriate plan of rehabilitation (IPR) based on comprehensive evaluation of barriers, needs and preferences of the person in all areas of life as one of the biggest obstacles on the way to realisation of human rights of persons with disabilities.[87]

While the legal framework[88] specifies that persons with disabilities, including children, have to right to medico-social assistance, to all types of rehabilitation, provision of medicines, prosthetic and orthopaedic materials, mobility aids at advantageous conditions, as well as professional training, the shortage and inadequate quality of rehabilitation goods and services is evident. It is reported that an overwhelming majority of persons with disabilities have never heard of the Individual Programme of Rehabilitation (IPR) that they are entitled to by virtue of national legislation. In the absence of an individualised approach, the only social support services and assistive devices that are available to a person with a disability are those that are pre-defined for all persons of the same disability group with the same impairment.

The 2020 submission to the Committee on Economic, Social and Cultural Rights by the Association of Persons with Disabilities notes the absence of a comprehensive assessment of the situation of a person with disabilities, comprising social, medical, psychological and economic components and non-compliance with the right to an individual rehabilitation programme. The Association further observes that an excessively long waiting list (5-7 years) to a residential rehabilitation cure provided in 12 outdated rehabilitation centres and 5 sanatoriums with a monopoly to provide rehabilitation services.

The stakeholders repeatedly voice their concern over a significant lack of paramedical and rehabilitation professions, social work and various other services such as occupational therapy, mental health professionals, clinical psychologists and others.

Access to sexual and reproductive health services for women and girls with disabilities

[87] Association of Persons with Disabilities, alternative report to the UN Committee on Economic, Social and Cultural Rights, 2020.

[88] Law on Protection of Public Health, Article 22, Law on the Rights of Persons with Disabilities, Article 32.

Access to sexual and reproductive health services is regulated by the **2019 Law on Protection of Citizens' Reproductive Health.**[89] While the Law does not mention women with disabilities or, indeed, women belonging to marginalised or vulnerable groups specifically, it does contain a number of declarative provisions that reaffirm the right of equal access to health for this group of citizens. Namely, Article 6 guarantees realisation of reproductive rights free from discrimination, threats and violence and non-interference with the private life of citizens, as well as realisation of the right to independent decision-making. Article 14 guarantees access to verifiable and complete information about reproductive health.

None of the research stakeholders invoked the Law, its drafting process or the expected impact on women and girls with disabilities. This may confirm the thesis voiced by a UN agency and some NGO stakeholders: sexual and reproductive health rights of women with disabilities is a deeply misunderstood and stigmatising issue, with but a few stakeholders equipped with information and knowledge about the issue to comment on it constructively.

In 2015, the CEDAW Committee noted its concern at the absence of age-appropriate education on sexual and reproductive health and rights and schools and recommended to Uzbekistan to review curricula to integrate such topics, targeting adolescent girls and boys and focusing on responsible sexual behaviour.[90]

(Inclusive) education

The right to inclusive education is protected under CRPD Article 24. According to the CRPD Committee, it entails "*a transformation in culture, policy and practice in all formal and informal educational environments to accommodate the differing requirements and identities of individual students, together with a commitment to removing barriers that impede that possibility. It involves strengthening the capacity of the education system to reach out to all learners. It focuses on the full and effective participation, accessibility, attendance and achievement of all students […and…] requires an in-depth transformation of education systems in legislation, policy and the mechanisms for financing, administering, designing, delivering and monitoring education."*[91]

The Committee distinguishes 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 a particular impairment or to various impairments, in isolation from students without disabilities.* ***Integration*** *is the process of placing persons with disabilities in existing mainstream educational institutions with the understanding that they 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 the 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."*[92]

While universal access to education is a legal right guaranteed to all by the Constitution of Uzbekistan, both children and adults with disabilities in rural and urban areas are at a significant disadvantage compared to their peers without disabilities, according to the 2019 Situation Analysis that showed a consistent difference of 14-22 percentile points between people and without disabilities.

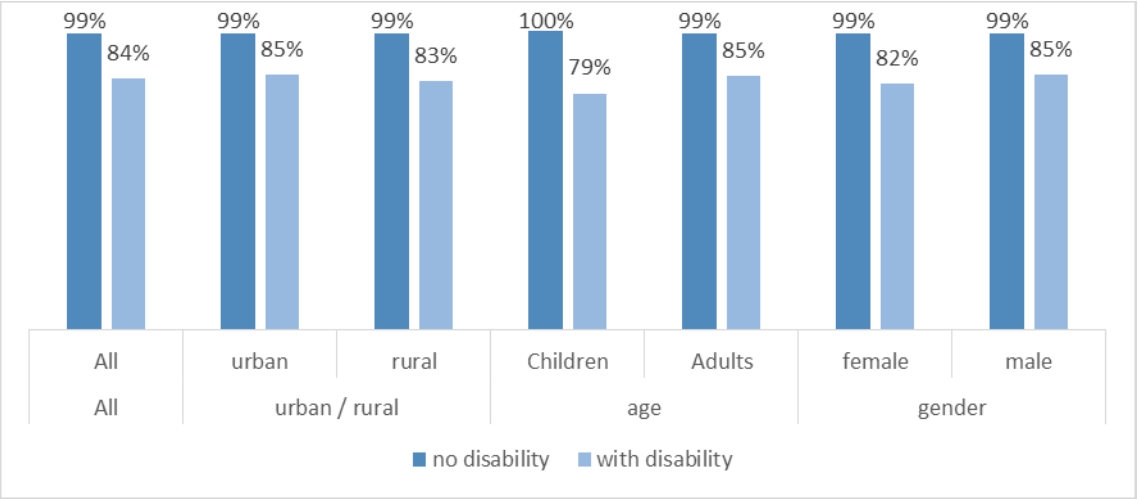
[89] 2019 Law on Protection of Citizens' Reproductive Health.

[90] CEDAW/C/UZB/CO/5, 24 November 2015, paras 24-25.

[91] CRPD Committee General Comment No. 4 on the right to inclusive education, CRPD/C/GC/4, 26 November 2016, para 9.

[92] Ibid, para 11.

Figure 5 – Access to education



Source: Situation Analysis of Children and Adults with Disabilities in Uzbekistan, UNICEF 2019

The same research indicated that disability or health were the main obstacles explaining lack of access to education:

Table 1 – Obstacles to education for children with disabilities

Health conditions or disability	82.4%
My parents did not want me to study	11.4%
Absence of an educational institution	2.3%
Economic reasons (lack of money, had to start earning money)	1.6%
Administration of the educational institution refused to admit me	1.3%
Inaccessibility of the educational institution	0.6%
I simply did not want to study	0.4%

Source: Situation Analysis of Children and Adults with Disabilities in Uzbekistan, UNICEF 2019

Early education and care

Recent series of educational reforms have brought the situation of children with disabilities in education to a new light. The creation in 2017 of the Ministry of Preschool Education and the adoption of a legislative and policy packages on preschool education in 2019[93] has signalled the growing national attention to the issue of early childhood education and care,[94] including that of children with disabilities. In 2019, a Resolution of the Cabinet of Ministers[95] launched a reform of specialised pre-school kindergartens, aiming to reduce the overall number of children in specialised pre-school education and simplify the system of referral.

As a consequence of these reforms, the rate of children attending preschool education has gone up from 25% in 2017 to 53% in 2019-2020. The number of children with disabilities in specialised kindergartens has dropped from around 21,000 children in 98 specialized kindergartens in 2015[96] to 6106 children with "limited health functioning", including 2878 children with confirmed disabilities in 71 specialised kindergartens in July 2021. An additional number of children with disabilities "whose medical diagnosis does not require a specialised educational environment" attend general kindergartens.[97]

[93] 2019 Law on Preschool Education.

[94] Supra, nr 1, p 54.

[95] Resolution of the Cabinet of Ministers on measures for further enhancement of preschool educational establishments, No 391 of 13 May 2019.

[96] Supra, nr 69, p. 55.

[97] Quote from a submission of the Ministry of Preschool Education.

Monitoring of functioning of preschool educational establishments conducted by the Ministry of Preschool Education jointly with Ministry of Healthcare in 2018-2019 showed that between 70 and 94% of all children in specialised kindergartens for children with disabilities did not, in fact, have an impairment. Their referral to specialised kindergartens was the result of a diagnostic mistake or, more likely, corruption, these kindergartens having better material conditions than general kindergartens. While children with disabilities continued to be underserved in preschool education and care, the state spending for specialised kindergartens was significant. The reform of preschool educational establishments triggered by the Resolution of the Cabinet of Ministers No 391 of 13 May 2019 had as the objective achieving a better transparency in the work of specialised kindergartens and their gradual reduction, bringing along a reduction on state spending.

This background explains, in the words of the Ministry for Preschool Education, the drastic reduction of the number of children in specialised kindergartens from 21,000 in 2015 to 6,000 in 2021.

The Ministry of Preschool Education has confirmed that there are no more sanatorium type preschool educational institutions but children with disabilities, particularly those from rural and remote areas with no access to community-based services close to home, can be enrolled in specialised boarding groups from Monday to Friday and reunited with their families for the weekend.

The basis for placement of the child in a specialised kindergarten is the official list of diagnoses[98] and a recommendation of the MPPK **medical-psychological-pedagogical commission (**«*медико-психологическая педагогическая комиссия»,* MPPK) for preschool education. The preschool education reform has reduced the number of 254 MPPK at district level to 14 MPPK at the regional level, working in pro bono capacity. According to the Ministry of Preschool Education, the MPPK reformed envisaged a better oversight of the work of individual commissions and a reduction in the number of children who are enrolled in specialised preschool education without a medical necessity. In its post-reform work, the MPPK prioritises individual approach to the child's need for specialised or inclusive education, and the decision is taken in consultation with the child's parents. There are concerns, however, that the reduction in the number of commissions makes them less available for children in rural and remote areas and may create a case backlog.

Children referred to specialised groups can be transferred to the general preschool educational institutions upon the completion of the correctional/rehabilitation cycle that lasts from 6 months to 2 years. The criticism of the correctional/rehabilitation cycle includes its medicalised approach to disability and an emphasis on 'correcting' the child to prepare her for the 'integration' in the community, rather than making the mainstream educational establishment fully accessible and welcoming.

A pilot multidisciplinary specialised kindergarten "Imkon" with an attached rehabilitation centre was opened in 2019 in Nukus (Karakalpakstan). With a capacity of up to 150 children, the boarding-type kindergarten accepts children with physical, sensory and intellectual disabilities and offers an ensemble of educational, rehabilitation and boarding services for children aged 2-7.[99] Despite a significant lack of specialists trained to work with the modern equipment and technologies available at "Imkon", the kindergarten is considered a good practice nationally, with plans to open similar boarding services in other regions foreseen for 2021.

While the effort and the technical equipment of this pilot initiative are welcome, it is submitted that it cannot be considered as compliant with the inclusive education requirements of CRPD Article 24 that bind the Republic of Uzbekistan. The segregated boarding-type education, particularly for young children, cannot replace inclusion in everyday life, and a targeted effort to make the children's communities fully inclusive must match the effort now directed in the development of specialised education.

[98] https://lex.uz/docs/4333345

[99] https://www.gazeta.uz/ru/2019/04/05/imkon/

Encouragingly, some initial steps in this direction have been taken with the establishment of 'combined-type' kindergartens that include specialised as well as inclusive groups. In practice, the main obstacle to full inclusion of children with disabilities in the inclusive groups is the resistance of children without disabilities and teachers to welcome children with disabilities. This tendency demonstrates to the fullest the urgent need to invest in education, training and disability awareness raising of both the professional corps and the society in general.

General education

The concept of "inclusive education" was introduced in the national legislative framework in 2020, specifying that inclusive education aims to guarantee equal access to education for all learners with special educational needs and individual capacities.[100] However, the Law does not define "inclusive education" as such, leaving it open to interpretation. Further, it retains the reliance on special schools, leaving it up to the MPPK to determine the type of education most suitable for the child. As per Article 55 of the 2020 Law "On Education"[101], the MPPK takes the decision based on consultations with parents or other legal representatives. It is understood, however, that the decision is based on a purely medical understanding of disability, and the voices of children with disabilities and their parents/caregivers are usually not taken into account.

While there is global consensus that specialised educational establishments are harmful to the development of the child with a disability, this battle is yet to be won in Uzbekistan, including among disability activists who had gone through the boarding school system themselves.[102] Lack of trained professionals, inaccessible infrastructures and societal stigma are sometimes given as reasons for perpetuating segregating in education.

> ***"There is a need for propaganda work among parents, in mahallas, so that they can actively take up this matter, so that the children live in families. Of course, a boarding school is a closed institution where children do not see how their "healthy"[103] peers live, what they do, what they are interested in. They can get this only in a mainstream school."*** *- Representative of the Ministry of Public Education*

Blaming the parents for their continued reliance on special schools was a common discourse among service providers heard during the research. So was the failure to understand that inclusive education is not about the child's adapting to the system (for example, via a surgical cochlear implantation) but about the system adapting to the individual and providing them with appropriate and acceptable schooling (for example, using national sign language).

> ***"If we talk about children with hearing impairments, the state has now launched a lot of work on the cochlear implantation of children. There are a lot of centres that carry out rehabilitation work with these children. And in fact, they are ready to go to study with their peers at home. However, even these children are today placed in boarding schools. This speaks of the irresponsibility of parents. They [parents] only think about handing over their children somewhere. They do not think about the future of their child."*** *- Representative of the Ministry of Public Education*

Following the adoption of the Law on Education, a policy package adopted by the President's Resolution No 4860 on 13 October 2020 presents a mechanism of realisation of inclusive education in the country. It comprises a **Concept of Development of Inclusive Education 2020-2025 and a Roadmap for its**

[100] Law of the Republic of Uzbekistan "On education" No ZRU-637, 23.09.2020.

[101] Idem.

[102] CRPD Committee General Comment Nr. 4 On Inclusive Education, 26 November 2016, CRPD/C/GC/4, paras 11-12.

[103] Quotation marks are added by the author.

realisation, as well as outcome indicators for development of inclusive education for children with disabilities until 2025. The Concept commits to an increase of the share of inclusive general secondary educational institutions to 51% by 2025 from the current 18.4 %.[104]

Methodological supervision of realisation of the Concept of Inclusive Education lay with the Laboratory of Inclusive Education Tashxis – a structure established by the Concept and attached to the under the Republican Centre for Vocational Orientation and Psychological and Pedagogical Diagnosis (Tashxis) under the Ministry of Public Education. Tashxis is now revising the education curriculum and expressed its intention to develop programs for teacher training on how to adapt mainstream curriculum to the various needs of children with disabilities. However, there is a considerable lack of support services and assistive technologies for children with various forms of impairments.

The Concept of Inclusive Education foresees the introduction, as of 1 September 2021, of **42 inclusive pilot classes in mainstream schools** to welcome two children with special educational needs per class in accordance with the assessment and referral of the MPPK and decision of the child's parents or legal guardians. Additionally, the Concept foresees the opening of **14 correctional classes** in selected pilot regions grouping up to 12 children with the same impairment and educational needs per class. The initiative is rolled out as an experiment; its progress will be monitored and evaluated on a rolling basis with the view to systematise it in the national system of education.

Without negating the significance of ongoing reforms in the field of education, there are concerns that the rolling out of inclusive education may done in a hasty and unprepared manner without due attention to full physical and informational accessibility of educational establishments, availability of teaching methodologies and trained specialists and of a comprehensive package of support services to make for a fulfilling learning experience for pupils involved in the pilot initiative.

Access to justice

Realistically, courts are the only venue available to most people for adjudication of their rights. However, national administrative, civil and criminal processes are not accessible for persons with disabilities. The report the United Nations Special Rapporteur on the independence of judges and lawyers Diego García-Sayán outlined the issues of accessibility of courts and tribunals for persons with disabilities in Uzbekistan:[105]

> ***"During his visit, the Special Rapporteur assessed the accessibility of courts and tribunals. The mandate has observed on a number of occasions that the effective exercise of the right of access to justice on an equal basis with others can be violated where architectural barriers or language obstacles prevent or limit the access of certain groups of individuals, such as persons with disabilities and older persons, to court buildings or court proceedings."[106]***
>
> United Nations Special Rapporteur on the independence of judges and lawyers

The Special Rapporteur pointed out that although recently refurbished buildings of courts were made accessible through the construction of ramps, handrails, and lifts, even the recently built premises turned out to be not fully accessible. The report points out that "the majority of court premises remain fully inaccessible for persons with disabilities, especially outside the main cities."[107] Moreover, the judicial processes are not accessible for deaf and hard of hearing citizens due to the lack of sign language interpretation services, insufficiency of the documents such as court decisions in accessible formats for persons with sensory, intellectual, or psychosocial disabilities. Importantly, persons with disabilities are

[104] Appendix No. 3 to the Resolution of the President of the Republic of Uzbekistan "On Measures for Further Improvement of the System of Education and Upbringing of Children with Special Educational Needs."

[105] Visit to Uzbekistan, Report of the Special Rapporteur on the independence of judges and Lawyers, 20 April 2020, A/HRC/44/47/Add.1, 20 April 2020

[106] Idem.

[107] Idem.

not directly involved in the judicial system as lawyers, judges, court officers or law enforcement officials.[108]

Participation in political and public life

In 2016 presidential elections a number of positive steps were undertaken to ensure accessibility of polling stations for votes with physical impairments and reduced mobilities, ballots in Braille for persons with visual impairments and home voting. However, the 2019 parliamentary elections were not fully accessible for blind voters due to inappropriate Braille ballots.[109]

Despite efforts of the People's Democratic Party of Uzbekistan which considers persons with disabilities as its key electorate, to promote their candidacies in the elections at different levels, persons with disabilities are not represented in the Parliament, nor in the executive decision-making bodies. The political party signed a memorandum of understanding with the three main OPDs (the Society of the Deaf, the Society of the Blind, the Society of the Disabled). However, only 11 candidates with disabilities nominated by the party won the local elections of people's deputies, but the presidential or parliamentary elections have not seen any candidates with disabilities.

The Association of Disabled People of Uzbekistan regularly conducts public oversight over the implementation of the requirements of national legislation in the field of protecting the rights of persons with disabilities and actively participates in the legislative process. For instance, the recent Law "On the Rights of Persons with Disabilities" was adopted based on the draft of the Association and about 60% of their proposals were approved by the government.[110]

It is submitted that while the outreach and advocacy potential of leading disability rights organisations like the Association of Disabled People is strong, it is arguably not fully inclusive of Uzbek-speaking persons with disabilities, particularly those based outside the greater Tashkent area. **More efforts are needed to strengthen participation of young people, children, and women with disabilities, persons with intellectual and mental impairments and those with multiple impairments in the disability movement**, particularly since the current legal environment is not favourable to the establishment of new representative OPDs.

Characterised by overregulation, bureaucratic hurdles, and red tape for registration of civil society organizations, the system effectively prevents equal participation of underrepresented groups of persons with disabilities and their families in the national decision-making processes.[111] The existence of the above-mentioned GONGOs is often understood to be the reasons for refusal to register new emerging organisations, inhibiting their efforts to improve visibility.

> ***"I tried to register an NGO, but it didn't work. It is very difficult for us. There are parents who are ready to work on this, but unfortunately there are problems with the bureaucracy, with the legal side of registration of NGOs."*** *– Father of a child with autism from FGD 5.*

There are many active parents of young children with disabilities prepared to work on the advancement of human rights of their children with disabilities, but they are not united in a formally established organization that could be involved in the advocacy and campaigning work.

> ***"Although there are many active parents who are ready to fight, learn and be educated, they are scattered, many simply do not know each other. It would be good to create one group, one public meeting of parents, where parents could share***

[108] Idem.

[109] "Fiction, not an accessible ballot", Gazeta.uz, 25 December 2019

[110] "We have rights but how to implement them?", Gazeta.uz, 24 October 2020 (English translation)

[111] "Regulation of NGOs in Uzbekistan: Control or Partnership?", CABAR.asia, 13 March 2020.

their experiences, pass on information to each other." *– A mother of a child with autism representing an informal self-help group of parents.*

The voices of marginalized and underrepresented groups such as children and adults with learning disabilities (e.g., autistic spectrum disorder, Down Syndrome, etc.), persons with deafblindness, children with rare (orphan) diseases (e.g., Spinal Muscular Atrophy), persons with psychosocial disabilities are not yet represented by formally recognized OPDs, in part due to legal barriers for NGO registration. Lack of a legal NGO status deprives such groups of grant support provided by international donors and legal leverage to exert pressure on the government to recognize them in the laws, policies, budgets, and social services available for mainstream groups of persons with disabilities.

"It has already been a year since we began our activities to open an NGO. We hired a lawyer, who submitted documents to the Ministry of Justice three times and received three refusals. They found deficiencies but provided no practical support." *– A representative of a self-help group of parents of children with spinal muscular atrophy from FGD 5.*

A young group of deaf activists was **denied registration** of a new NGO "Association of the Deaf of Uzbekistan" because there was already the Society of the Deaf.[112] In other words, the existence of the disability organisations, organized by and financially dependent on the government, such as the Societies of the Deaf, the Blind and the Disabled, often governed by persons without disabilities, inhibits the formation of independent OPDs.

In the **absence of a systemic approach to development of the civil society in the country**, local OPDs have to rely on the limited funding opportunities available within the country (e.g., grants provided by the Fund for the Support of NGOs and Other Civil Society Institutions under the Oliy Majlis (Parliament) of the Republic of Uzbekistan[113]) and sporadic foreign grants. However, local organizations still need to get approval for the use of external funding provided by INGOs and other donors.[114]

Accessibility

Key findings

There is a narrow understanding of accessibility as an issue which is relevant to only a minority group of persons with disabilities. Current legislation provisions on accessibility which pertain mainly to the physical accessibility of public infrastructure are not effectively enforced due to the lack of involvement of OPDs in the monitoring of construction projects. Marginalized and underrepresented groups such as deaf and hard of hearing people, deafblind, persons with intellectual and psychosocial disabilities lack reasonable accommodation.

Accessibility is a human right in itself and a precondition for the enjoyment of all other human rights. CRPD Article 9 stipulates that there are two equally important venues for achievement of accessibility: (1) strict enforcement of national accessibility standards based on universal design to new facilities, goods and services, and (2) gradual elimination of existing barriers in a continuous and systematic manner with the view to achieving full accessibility.[115] The obligation to provide accessibility applies to the built environment, roads, transportation, information, communication and emergency services. It should include schools, hospitals, workplaces, law enforcement agencies,

[112] "Nothing about us without us: Why are deaf people governed by hearing people?" Hook Report, 28 October, 2020.

[113] http://fundngo.uz/

[114] Resolution of the Cabinet of Ministers of the Republic of Uzbekistan "On approving the procedure for accepting the receipt of funds by non-governmental non-profit organizations from foreign states, international and foreign organizations, citizens of foreign states or, on their instructions from other persons", October 9, 2019 (in Uzbek)

[115] CRPD Committee General Comment on Accessibility, 22 May 2014, CRPD/C/GC/2, para 14.

courts, prisons, cultural, religious and sports establishments, as well as universal services such as post and banking.
Since accessibility is an obligation of progressive realisation, the justification of limited national resources does not apply to it: instead, the governments must take gradual measures outlined in a national action plan to move towards full accessibility. The enforcement of accessibility obligations must be supported by continuous monitoring and includes dissuasive sanctions for failure to comply with the accessibility standards.

Lack of accessibility permeates all areas of life of persons with disabilities in Uzbekistan: research respondents have mentioned inaccessibility of educational establishments, healthcare services, shelters for victims of domestic violence.

Despite the theoretical existence of sanctions for failure to provide barrier-free access to buildings, transport and information and communication technologies since 2008 (Law on Social Protection of Persons with Disabilities), up to 85% of infrastructures in the capital city Tashkent remain inaccessible due to absence of concrete enforcement mechanisms.[116] This figure is expected to be even higher in rural and remote regions of the country: it is estimated that only around 10% of the built environment is accessible for persons with disabilities.[117] In 2019, only 5% of persons with disabilities found air transport accessible.[118] The nearly universal lack of accessibility significantly slows down inclusion of persons with disabilities in other areas of life, such as employment, education or independent living.

According to the State Statistics Committee, only three television programmes were accompanied with sign language interpretation and 17 programmes had closed captions. Of the 107 official websites that were monitored, 88 were accessible for visually impaired persons but no website had information in sign language. Persons with disabilities continue being excluded from culture and tourism, 90% of cultural facilities being inaccessible.[119] As of July 2021, Uzbekistan was not a party to the Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired or Otherwise Print Disabled.

Access to sign language interpretation is minimal: there is but a minimal legal entitlement for provision of sign language interpretation services, which is not considered a public service.

> ***"In Uzbekistan, hearing aids are included in the list of the assistive devices provided by the state budget, but sign language interpretation services are not included. What's in the problem? The central board of the Society of the Deaf of Uzbekistan presented problems and proposals to the Committee on Labour, Health and Social Affairs under the Legislative Chamber of the Oliy Majlis, as well as the Senate Committee on Science, Education and Health to include sign language interpretation services at the expense of the state budget. But the issue is not being resolved."***
>
> Representative of the Society of the Deaf of Uzbekistan

A 24-hour dispatch service for social support of persons with hearing and speech impairments was open on 1 July 2019 pursuant a President's resolution.[120] This service accepts requests from deaf and hard of hearing people through video calls, text messages and specialised software. However, deaf and hard of hearing people expressed their doubts about the effectiveness of this emergency system as the JusTalk

[116] https://mytashkent.uz/2020/06/29/proekt-gorod-dlya-vseh-zachem-i-dlya-kogo/

[117] Association of Persons with Disabilities of Uzbekistan: alternative report to the fourth periodic review of Uzbekistan by the UN Committee on Economic, Social and Cultural Rights, 2019.

[118] Supra, nr 1.

[119] Supra, nr 106.

[120] Resolution of the President of Uzbekistan "On additional measures for social support for persons with hearing and speech impairments", No ПП-4242 of 18 March 2019.

mobile application was malfunctioning and there was no single unified app that would enable easy and accessible communication with the emergency services through sign language.

Only teachers with visual impairments working at mainstream secondary specialized schools can apply for the services of the interpreter-secretary funded by the Ministry of Public Education.[121] However, such reasonable accommodation is not currently available for children and adults studying at mainstream pre-school educational establishments and the higher education.[122]. To avoid further segregation and institutionalization there is an acute need for reallocation of funding to specialized residential and educational institutions to develop community-based support services.

Lack of understanding of universal design-based accessibility, lack of enforcement and dissuasive sanctions and failure to consistently include organisations of persons with disabilities in the development, implementation and monitoring of standards have been identified as challenges. The legal framework, imperfect as it is, is not implemented: the standards in the 2007 Building Code and not well known or used; the fines for failure to provide access foreseen in the 2013 Code of Administrative Responsibility are rarely collected and reported.[123]

The 2020 Law on the Rights of Persons with Disabilities addresses these only partly. On the one hand, it states in Article 9 that accessibility for persons with disability must be ensured "on an equal basis with others", and demands in Article 23 that organisations of persons with disabilities be involved in the standardisation work and quality control of new infrastructures. Potentially encouraging and innovative is Article 6 of the Law that defines the refusal to provide access as a form of discrimination.

On the other hand, regrettably, the 2020 Law remains vague concerning the enforcement mechanism, including sanctions parties failing to comply with the accessibility requirements or compensation for persons with disabilities who face barriers. Further, the Law makes no reference to the obligation to develop binding national standards on accessibility of physical infrastructures, transport, goods and services, and information and communication technologies, leaving the interpretation of accessibility up for discussion. The CRPD principle of "universal design" is not mentioned in the law.

The disability community has long called for the adoption of a nationwide programme on accessible environment, complete with measurable objectives and indicators and an earmarked budget, but their demands are yet to receive a constructive reaction from the authorities.

CRPD-compliant programming and budgeting

Key findings

There is limited publicly available data for analysis of CRPD-compliant budgeting and financial management. Considerable amount of the national budget allocated for social protection is directed towards older age pensions while the number of recipients of disability benefits has been reducing for the last ten years which indicates to the austerity measures implemented by the government. Lack of involvement of OPDs in the decision-making process regarding budget allocation results in measures that undermine disability-inclusive development and are not aligned with the CRPD.

Recognizing the available national budgets and spending is crucial to effectively implement the provisions of the CRPD. Uzbekistan as a lower-middle income developing economy faces significant fiscal constraints which are exacerbated by the ongoing COVID-19 pandemic and associated state measures to counter it. Therefore, prioritization of public spending towards disability-inclusive programs and policies and budget allocation aligned with the CRPD is essential to lift the barriers that children and adults with disabilities are facing in their daily lives.

It is argued that one of the main reasons for the postponement of the CRPD ratification process by Uzbekistan was "*the high budget allocations required to comply with the terms of the Convention,*

[121] Order No. 406 from 28 December 2019 signed by the Ministry of Public Education in coordination with the Ministry of Finance, the Ministry of Employment and Labour Relations.

[122] Dilmurad Yusupov, "Uzbekistan: How to Ensure Higher Education Accessibility for People with Disabilities?", CABAR.asia, 1 March 2019.

[123] Supra, nr 1.

especially for improved access, mobility aids, retrofitting infrastructure" among others.[124] There is limited publicly available data on the public spending towards implementation of the rights of persons with disabilities. Therefore, there is a need for the explicit recognition of the national budget to be spent for CRPD implementation.

Currently, Uzbekistan spends 9.7% of its GDP on sustaining the national social protection system which is financed by a mixture of social insurance contributions and general tax revenues.[125][126] However, a considerable part of this investment (6.95 per cent) goes to old age pensions schemes despite the fact that about 60 per cent of its population is under 30, 0.75 percent goes to the system of child benefits and 1.2 per cent to adult disability benefits.[127] Child disability benefit accounts for 0.14% of GDP, allowance for working age persons with disabilities from childhood – 0.22% of GDP, disability pension – 0.98% of GDP.[128] The country inherited the Soviet universal child benefit system but by 1994 the public spending on this scheme decreased dramatically from 11.7 per cent of the state budget. In the late 1990s, the Uzbek government introduced a targeted system of child benefits with a budget spending increasing to 7.3 per cent of the budget.[129]

Apart from the targeted social protection measures to support children and adults with disabilities, the governments still spend scarce resources to sustain further institutionalization of persons with disabilities rather than supporting their independent living and providing social and medical services at the community-level. The 2019 UN Situation Analysis showed that "of those who choose to live at home, almost none receive personal assistance from the state."[130] For instance, **in 2019, the government increased the salaries and the staff at specialized institutions including Mehkhribonlik houses (orphanages), children's towns by 1.5 times**.[131] Moreover, the government is spending the budget on improvement of the material and technical base of the specialized educational institutions and boarding schools for children with disabilities and introducing *"correctional classes"* at mainstream primary schools which is not aligned with Article 24 of the CRPD and the principles of inclusive education.

According to observations and stakeholder interviews, **disability inclusion in the work of international donors present in the country is not yet systematic** either. Positive steps include funding for local NGOs and OPDs in implementing small-scale projects in 2020 offered as part of the UN Joint Program on strengthening social protection in Uzbekistan UNDP[132] and planned recruitment of disability specialists by UNDP Uzbekistan[133] and UNICEF Uzbekistan.[134]

Accountability and governance

Key findings

The national implementation and monitoring framework are underdeveloped and under resourced. Monitoring is made difficult by the lack of credible data on the number and situation of persons with disabilities and the use of the outdated monitoring indicators. The nomination of structures for participation on the CRPD Article 33 processes has not been accompanied with additional resources, capacity or awareness to the bodies potentially concerned. There are serious concerns about the impartiality and independence of the monitoring mechanisms. Organisations of persons with disabilities

[124] United Nations Common Country Analysis: Uzbekistan, January 2020, p. 35.

[125] Supra nr 1, p 189 (full report).

[126] UNICEF Uzbekistan (2020) Building a national social protection system fit for Uzbekistan's children and young people.

[127] Ibid, p. 32.

[128] Ibid, p. 28.

[129] Idem.

[130] Supra, nr 1.

[131] Resolution of the President of the Republic of Uzbekistan 'On Additional Measures to Strengthen the Social Protection of Orphans and Children Left without parental care', No. PP-4185, 11 February 2019.

[132] "Finalists of the competition for support of small social initiatives of organizations of people with disabilities have been determined" UNDP Uzbekistan, 10 November 2020,

[133] https://www.unv.org/index.php/vo/uzbr000212-9716

[134] https://www.unv.org/vo/uzbr000215-9938

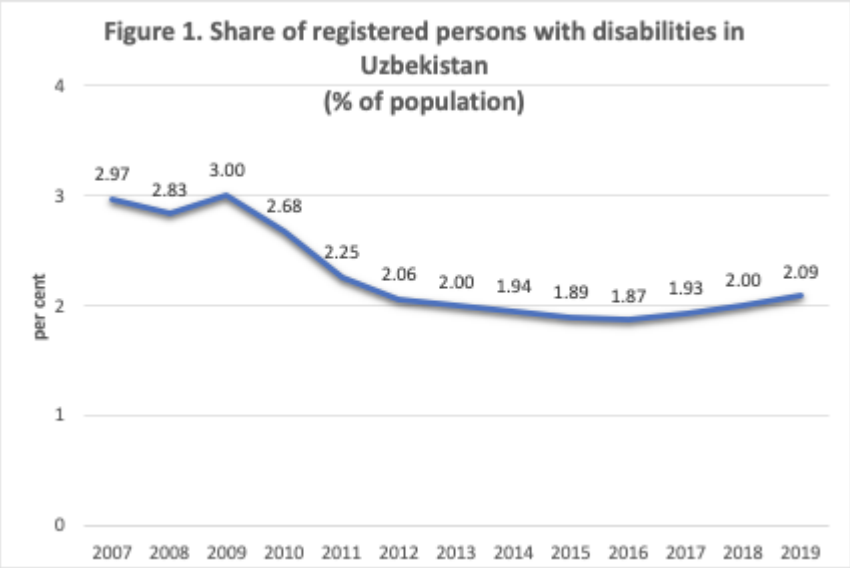
have not been properly included in the Interagency Council on the Affairs of Persons with Disabilities, excluding a large portion of persons with disabilities from participation.

Quantifying persons with disabilities

The official disability data in Uzbekistan has been inadequate, while essential disability-disaggregated data to understand the situation of persons with disabilities in the country in terms of their access to quality education and vocational training, livelihoods and employment, healthcare services, rehabilitation and assistive devices, political and social participation is missing.

As of January 2019, 693.9 thousand people were officially registered as persons with disabilities which is only **about 2% of the total population**. Until recently the official prevalence of disability in the country was reported based on the administrative data of the VTEK which are responsible for determining the extent of impairment and employability, dividing people into disability categories (I, II or III disability groups) based on the severity of impairment and assigning social benefits.

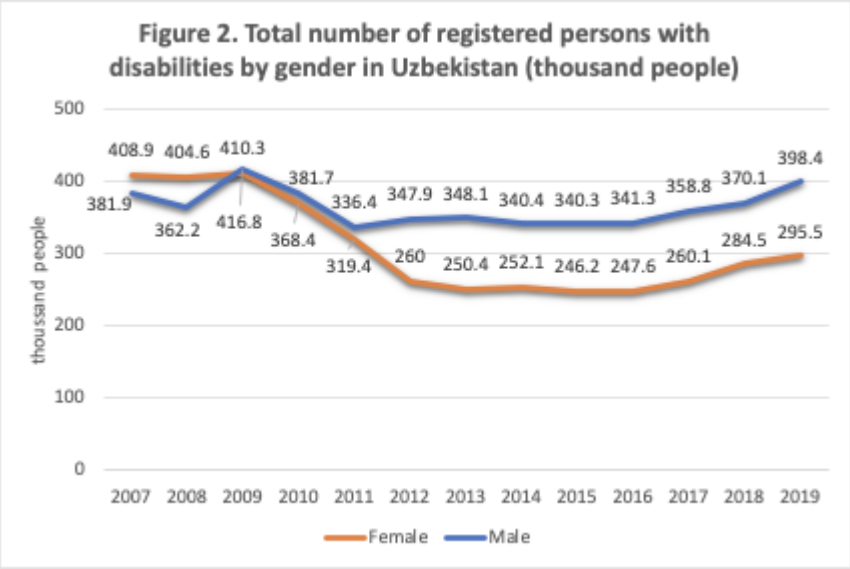
Figure 1 reveals that there has been a gradual fall in the registered total number of persons with disabilities in Uzbekistan since 2007 when the share of registered persons with disabilities in the population was almost 3 percent.



Source: The State Committee of the Republic of Uzbekistan on Statistics, Gender Statistics of Uzbekistan, www.gender.stat.uz
Author's own calculation and illustration.

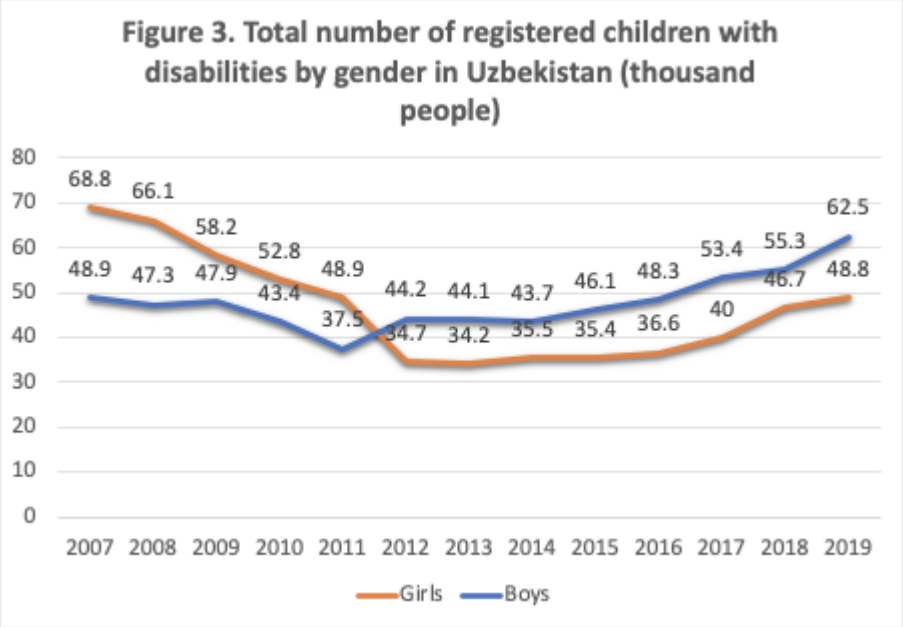
Uzbekistan Gender Statistics web portal provides gender-disaggregated data on the reported number of persons with disabilities receiving pensions and social benefits from 2007 to 2019.[135] The total number of registered girls and women with disabilities has decreased from 408.9 thousand in 2007 to about 295.5 thousand women in 2017, while the number of registered boys and men with disabilities has been stable at about 350 thousand persons.

[135] The State Committee of the Republic of Uzbekistan on Statistics, Uzbekistan Gender Statistics (accessed on 5 July 2021).



Source: The State Committee of the Republic of Uzbekistan on Statistics, Gender Statistics of Uzbekistan, www.gender.stat.uz
Author's own calculation and illustration.

This trend may seem contradictory as women usually tend to live longer and represent a larger share in the elderly population, which is more prone to disability. For instance, in 2019 female life expectancy at birth in Uzbekistan was 77.4 years compared to 72.8 years for males. Moreover, if we consider age composition of population by sex, women aged 60 and older account for almost 4 percent of the total population, while men at the same age range only 3.24 percent.[136]



Source: The State Committee of the Republic of Uzbekistan on Statistics, Gender Statistics of Uzbekistan, www.gender.stat.uz
Author's own calculation and illustration.

Figure 3 shows a similar diminishing trend for the reported number of children with disabilities under 16 years old (see Figure 5). Although the number of girls with disabilities in 2007 was comparatively higher at 68.8 thousand, this amount has been halved to about 34 thousand in 2013 and was followed by a slight increase during consequent years. In the interview conducted as part of this study, **a representative of the VTEK could not explain the reason for such a gradual decrease of the reported number of children and adults with disabilities in Uzbekistan.**

This diminishing trend is striking as according to WHO over one billion people or about 15% of the global population are considered to have some form of disability and this number has been rapidly

[136] The State Committee of the Republic of Uzbekistan on Statistics, Demography (accessed on 5 July 2021).

increasing as a result of ageing and a surge in chronic noncommunicable illnesses such as diabetes, heart diseases, cancer and mental disorders.[137] Moreover, it is reported that 80% of persons with disabilities worldwide are living in low and middle-income countries and Uzbekistan according to the World Bank is a lower-middle income country.[138]

Collected solely for the purposes of a disability pension system, the reported official disability data in Uzbekistan does not show the actual disability prevalence in the country. Experts argue that social benefits can create a significant burden for a developing economy when direct costs of disability increase. Thus, governments try to limit disability benefits to those who are the most eligible and have the most severe impairments.[139] Therefore, persons with mild impairments are probably left behind in the administrative data sets and consequently in the officially reported disability statistics.[140]

Finally, the reason for the very low number of registered persons with disabilities may be attributed to cultural factors specific to the context of Uzbekistan. As the VTEK representative confirmed in the interview, family members might be ashamed of registering their children with disabilities due to related **stigma, discrimination, and burden**. Many parents, particularly in rural areas, tend to hide their children with disabilities as recognition of their existence may affect the prospects of their other children without disabilities to get married. Importantly, girls and women with disabilities may face double discrimination on the basis of gender and disability and may feel it is embarrassing to be regularly re-examined by VTEK to confirm their official disability status.

Indeed, assessment of disability is carried out following the medical model of disability and includes a mandatory hospital stay of around 10 days. While the child can be accompanied by a parent, the expenses linked to the parent's participation are not reimbursed, and this option remains financially prohibitive for many families. Assessment must be repeated at regular intervals regardless of the nature of the impairment: parents of children with Down syndrome confirm that their children must be regularly re-assessed.

> ***"The assessment process is lengthy, exhausting and humiliating for everyone. It eats up the scarce resources that could otherwise be re-directed to development of inclusive services. Right now, we have no early identification and early intervention services to speak of: all that legwork to do the assessment just to get the 2 monthly minimum wages' worth of social benefits and a lot of stigma."*** *- Representative of a support and learning centre for children with disabilities, Tashkent*

Inclusive evidence and data gathering systems

Article 31 of the CRPD obliges States Parties to collect appropriate statistical and research data to enable them to design and implement effective disability inclusive policies based on the Convention. Such data should be collected complying with international ethical standards and principles respecting confidentiality and privacy of persons with disabilities. Importantly, the collected data should be disaggregated and used to support monitoring of the implementation of the CRPD by identifying barriers that children and adults are facing in realization of their guaranteed rights on equal basis with others. The State Parties to the CRPD should also ensure that the evidence is publicly available and accessible for persons with various forms of disabilities. Finally, the collected disability data should be comparable worldwide and not rely only on one source and collection method but use a variety of sources and methods including through surveys and population censuses.

Other than the VTEK administrative data set, the national census and surveys have not been used to identify children and adults with disabilities, the barriers they are facing and their support needs. Uzbekistan has not conducted a population census since 1989, when the USSR conducted the last census in its history. National household surveys have never incorporated any disability questions and as it was

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[137] *"World Report on Disability"*, Geneva: World Health Organization and the World Bank, 2011.

[138] Data for Uzbekistan, Lower middle income, The World Bank (accessed on 24 July 2021).

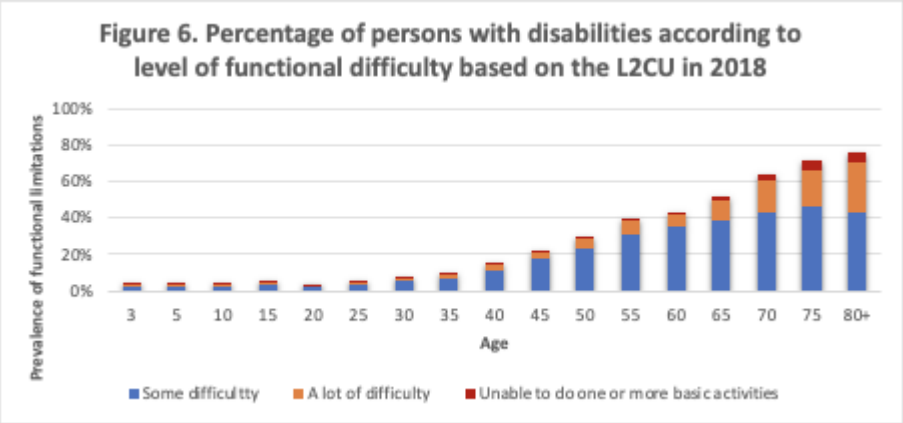
[139] Mont, D. (2007). *Measuring disability prevalence* (No. 39508; p. 1). The World Bank.

[140] Yusupov, D. (2018). Who is left behind in statistics? Analysis of factors affecting the measurement of disability indicators in Uzbekistan. *CABAR.asia*.

mentioned above the official disability data mainly comes from the VTEK administrative registries. The first population census in Uzbekistan which was planned to be conducted in 2022 but due to the COVID-19 pandemic it was postponed to 2023.[141] Despite joint ongoing advocacy of the national disability movement and the international community for inclusion of the Washington Group Short Set of Disability Questions in the upcoming 2023 population census, the State Statistics Committee refused, pointing to the lack of resources and expertise to include disability questions in the census. [142]

A nationally and regionally representative household survey Listening to the Citizens of Uzbekistan (L2CU) conducted in 2018 by the World Bank and UNICEF in Uzbekistan[143] included for the first time the Washington Group Short Set on Functioning[144] and found that about **13.5% of the population aged 3 and above had some form of impairment and 3.5% severe forms of impairments**,[145] while 2.7 per cent of children have some form of disability and 1.3 per cent of children have a severe disability.[146] The quantitative research conducted by the UN and World Bank revealed there were 4.5 million persons with disabilities in Uzbekistan, of whom 1.15 million persons have severe impairments. However, only 670,800 persons are registered by VTEK and VKK, which indicates not only a weak system of disability determination and assessment, but significant undercoverage of children and adults with disabilities by the national social protection system.[147] As a result, **there is considerable underestimation of disability prevalence in Uzbekistan** and the reported 2% are only those with severe impairments who managed to go through the burdensome disability assessment and determination procedures at VTEK and VKK and obtain an official disability status.

The L2CU survey results also showed that 45% of households had a member with a disability and 14% had such a member with severe impairments. Moreover, disability prevalence tends to increase with ageing and 54% of persons aged 60 and above have disabilities (see Figure 6 below).



Source: UNICEF Uzbekistan (2020) *Building a national social protection system fit for Uzbekistan's children and young people*

There are several recent initiatives to improve the national data collection system, including the 2017 presidential decree[148] and the 2018 decree of the Cabinet of Ministers "On Improvement of the System

[141] Resolution of the Cabinet of Ministers of the Republic of Uzbekistan No. 710 of November 11, 2020 "On measures to organise and conduct the population census of the Republic of Uzbekistan in 2023".

[142] "They won't count us?", Gazeta.uz, 3 July, 2019; 'Disability questions were not included in the census program', Gazeta.uz, March 3, 2020, ; Dilmurad Yusupov "Disabled People are Left Behind in the First Ever Census in Uzbekistan", 14 November, 2020.

[143] https://www.worldbank.org/en/country/uzbekistan/brief/l2cu

[144] The Washington Group Short Set on Functioning defines 'disability' as having 'some difficulty' at least in one functioning domain including seeing, hearing, walking, cognition, self-care and communication. While 'severe forms of disability' as having 'a lot of difficulty' at least in of the six functional domains.

[145] Supra, nr 120.

[146] Building a Better Future: A child-sensitive social protection system for Uzbekistan, UNICEF, January 2019.

[147] Ibid.

[148] Supra, nr 128.

of Statistical Registration of Persons with Disabilities"[149]. However, the implementation of these mechanisms remains patchy: the available official data on disability is based only on the reported number of registered persons with disabilities and does not reflect the actual disability prevalence in the country. Importantly, the administrative disability data on the total number of persons with disabilities does not allow to assess the barriers to participation of persons with disabilities in social, economic and political life. Although there is a limited gender disaggregated data on the reported number of women and men receiving pensions and social benefits, the existing administrative data of the VTEK cannot address multiple and intersecting identities such as age, gender, economic status, religion, belonging to marginalised and underrepresented groups.

National accountability mechanisms

Ratification of the CRPD by Uzbekistan is expected to make the government accountable for the implementation of the rights of persons with disabilities: it carries along an obligation to submit periodic reports to the CRPD Committee (the first one two years after entry into force of the Convention) and a requirement to set up national implementation and monitoring mechanisms. Both these obligations must be fulfilled with active and meaningful participation of persons with disabilities and their representative organisations. However, it is submitted that the capacities of local OPDs in the reporting of the implementation of the CRPD is weak and the independent grassroots organizations lack financial resources to carry out monitoring activities across the country.

The Agency for Development of Medical and Social Services under the Cabinet of Ministers of the Republic of Uzbekistan is considered to be the **focal point** overseeing the implementation of the CRPD. The National Centre for Human Rights is a **state body that ensures coordination between state bodies and other organizations** in fulfilling Uzbekistan's international human rights obligations.[150] Although by its legal status the Centre is an independent authority for monitoring legislation and law enforcement it does not represent an independent monitoring mechanism as it's reporting is not impartial. The Centre can receive complaints from the citizens on violations of the rights of persons with disabilities and take timely measures to eliminate the causes and conditions that contribute to the occurrence of violations of human rights and freedoms. However, there is no publicly available evidence on the number of complaints received from persons with disabilities and what measures were undertaken by the Centre to fulfill their human rights.

The Commissioner of the Oliy Majlis of the Republic of Uzbekistan for Human Rights (Ombudsman) and Deputy Commissioner / Commissioner for Children's Rights are officially independent from other state bodies and officials during the accomplishment of his/her powers and are accountable to the Oliy Majlis of the Republic of Uzbekistan.[151] The Ombudsman currently holds 'B' status accreditation with the Global Alliance of National Human Rights Institutions (GANHRI)[152] as the body partially compliant with the Paris Principles Relating to the Status of National Human Rights Institutions[153].

The Ombudsman's Office has not been formally nominated to serve as the independent monitoring mechanism under CRPD Article 33(2). Nevertheless, the Deputy Commissioner regularly conducts monitoring visits to residential care institutions for children with disabilities.

The Association of Disabled People of Uzbekistan is the main OPD that performs monitoring functions on behalf of the civil society of persons with disabilities. It carries out public oversight on the implementation of the national legislation in the field of protection of the rights and legitimate interests

[149] Decree of the Cabinet of Ministers of the Republic of Uzbekistan "On Improvement of the System of Statistical Registration of Persons with Disabilities", No. 210 from 22 March, 2018, Tashkent.

[150] Resolution of the President of the Republic of Uzbekistan 'On Improving the Activities of the National Center of the Republic of Uzbekistan for Human Rights',

[151] http://www.ombudsman.uz/en/managements/leaderships

[152] https://ganhri.org/wp-content/uploads/2021/01/Status-Accreditation-Chart-as-of-20-01-2021.pdf

[153] UN General Assembly Resolution A/RES/48/134, 4 March 1994.

of persons with disabilities, including monitoring of accessibility of built environment[154][155] and public transportation[156][157].

Uzbekistan adopted, localized and approved 206 national SDG indicators which were integrated into the national development strategies and programs. On 7 February 2020 Parliamentary Commission to monitor and facilitate the implementation of the SDGs was established. First Voluntary National Review (VNR) was presented on 15 July 2020.[158] One of the challenges outlined in the VNR was the inaccessible public infrastructure for persons with disabilities and disproportionate impacts of the COVID-19 pandemic on persons with disability, older people, and children in closed institutions.[159] Improvement of medical and social services for persons with disabilities was included in Uzbekistan's Development Strategy for 2017-2021.[160]

COVID-19 and disability

The ongoing COVID-19 pandemic and the strict quarantine measures introduced by the government of Uzbekistan in 2020 have further exacerbated the already vulnerable situation of children and adults with disabilities as well as their parents and carers. COVID-19 negatively impacted physical and mental health of persons with disabilities particularly those living in institutions who were under greater risk of contracting the virus due to direct exposure to staff of institutions. Uzbekistan's government did not present any disability-disaggregated data on the number of infected persons and COVID-19 related deaths. Therefore, it is difficult to evaluate the real impact of the pandemic on persons with disabilities except for some evidence and data from the international organizations operation in the country.

The World Bank "Listening to the citizens of Uzbekistan" (L2CU) survey identified community-level COVID-19 impact risks for persons with disabilities, including reduced access to specialized health, rehabilitation, and social services during lockdowns and raised concerns regarding the accessibility of information about COVID-19 for children and adults with disabilities.[161] Many persons with disabilities struggled to access markets during the strict quarantine measures introduced by the government in 2020.[162] Persons with disabilities and women reported worsened mental health during the lockdown: from July to December 2020, on average 51 per cent of persons with disabilities evaluated their mental health as only "fair" and "poor"; the peak was in August 2020, when it increased to 61 per cent.[163] Nearly one-quarter (24 per cent) of mahalla leaders surveyed mentioned persons with disabilities' increased needs during the pandemic.[164]

The Centre for the Coordination of Sponsorship Assistance was established under the Ministry of Mahalla and Family Support in April 2020 to coordinate the activities of volunteers and distribute basic goods to vulnerable members of the public, including persons with disabilities. A telephone hotline was created, but it was inaccessible to deaf and hard-of-hearing people. The government also introduced "iron notebooks" (*temir daftar*)—lists of five types of vulnerable groups in need of social protection: families with persons with disabilities and chronically ill family members; families consisting of lonely elderly people, widows, low-income people, and people in need of care; families with five or more

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154 "Unreachable Commissions", Gazeta.uz, 7 September 2019; Video.

155 "Unaffordable inaccessible housing", Gazeta.uz, 7 August 2019, Video.

156 "Monitoring results on access of people with disabilities to public transportation", 17 June, 2015

157 "Metro: new level", Anhor.uz, 6 September 2020.

158 Voluntary National Review of Uzbekistan, 2020 (in Russian).

159 Implementation of National Sustainable Development Goals and Voluntary National Review of the Republic of Uzbekistan.

160 The state program for implementation of the national action strategy on five priority development areas 2017-2021 in the year of active investments and social development.

161 William Seitz et al. ND. *Uzbekistan: Identifying Community-Level COVID-19 Impact Risks.* World Bank Group.

162 Idem.

163 William Seitz. 20201. *Crisis and Recovery in Uzbekistan: Economic and Social Impacts of COVID-19*. World Bank Group. (in Uzbek).

164 Idem.

children; citizens who have lost their jobs and sources of income as a result of quarantine measures, including returned migrants; and families below the poverty line in need of help and financial support.[165]

However, **persons with disabilities and their OPDs were not involved in the decision-making process regarding the allocation of support during the COVID-19 pandemic.** OPDs were rather treated as passive recipients of basic goods which were distributed through a single coordination centre based on a top-down approach. As a result, emergency services and provision of basic products were not effective and did not reach the most marginalized and underrepresented groups. For example, deaf and hard of hearing people could not access the "1197" hotline to request support during the lockdown which severely affected adults with hearing impairments who were involved in informal economic activities.

The data and information that monitor the delivery and outcomes of COVID-19 interventions and services has not been disaggregated by disability and the specific data points relating to persons with disabilities have not been included. The official data on COVID-19-related infections and deaths is not disability-disaggregated and, therefore, it is impossible to assess who the COVID-19 pandemic affected children and adults with disabilities as well as their parents and carers. The only available data comes from the L2CU survey which incorporated the Washington Group Short Set of Six Disability Questions on functioning and disability

[165] Gazeta.uz. "On Social Support during the Pandemic," August 14, 2020.

6. CRITICAL GAPS AND OPPORTUNITIES

ON PRECONDITION EQUALITY AND NON-DISCRIMINATION

The period between 2018 to-date has witnessed more legislative and policy initiatives than two preceding decades since Uzbekistan regained independence in 1991. If the few instruments adopted previously had dealt with provision of socio-medical assistance to older people and persons with disabilities, the ambition of the newer initiatives is to address human rights, the most significant being the **2020 Law on the Rights of Persons with Disabilities** and the **2021 ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD)**.

The importance of these initiatives must be recognised, as it fosters the dialogue between the government and the organisations of persons with disabilities and facilitates awareness raising about the Convention on all levels.

Stigma, **negative stereotypes,** and rampant discrimination of persons with disabilities in all areas of life have been invoked by every single stakeholder in the research as **critical gaps** to inclusion. Having a friend or a family with a disability is considered shameful in Uzbekistan: at best, it will provoke pity and charity, at worst - aggression and harassment. Either way, it perpetuates and deepens the vicious cycle of exclusion. The **gap** between the Convention requirement to cultivate a positive image of persons with disabilities and the prevalent perceptions in Uzbekistan is striking.

Ratification of the Convention creates legitimately high expectations from all girls, boys, women and men with disabilities in Uzbekistan. Unfortunately, as discussed above, **the 2021 Law** adopted as a preparatory move for the ratification of the CRPD, includes a number of serious shortcomings, including the retention of the medical approach to disability, absence of key definitions and limited scope excluding nearly all civil and political rights. As such, it does not yet meet the high standard set by the Convention. Other legislative and policy instruments are yet to be revised and brought into compliance with the CRPD.

A systemic approach to ensuring equality and non-discrimination at legal, policy, budgetary and communication levels is called for. Firstly, legislation must provide tools to improve visibility of persons with disabilities: disability mainstreaming of draft laws and policy proposals must become routine. Secondly, this must be addressed as budgetary conditionality by the national government and international donors alike: no public money can be spent if its intention or outcome is to exclude, segregate or discriminate against persons with disabilities. Thirdly, monitoring and data collection matter. A mechanism to monitor instances of expression of discriminatory or stigmatising views, discriminatory statements in the media, disability-based hatred must be developed, for example at the Ombudsman's office under its mandate under CRPD Article 33(2). Finally, awareness raising activities at schools, hospitals, media, and employers' associations must be undertaken under the leadership of representative disability organisations. The **opportunity** to undertake these steps has been created by the ratification of the CRPD and the adoption of the first post-Convention legislative acts. The government's commitment to achieving the global 2030 Agenda is a further **opportunity** to advocate for disability-inclusive development at all levels.

ON STAKEHOLDER PARTICIPATION

A strong participative well-informed and committed community of stakeholders is instrumental to the shaping and implementation of the disability policy in line with the CRPD. However, to contribute effectively, it is in need of further development. **The most critical gaps** include the lack of understanding of the requirements of the CRPD Articles 4(3) and 33 on the composition and functioning of different layers of the national implementation mechanism and the participation of organisations of persons with disabilities in it.

The creation of the Agency for the Development of Medico-Social Services and its strategic placement with the Cabinet of Ministers in the governmental structure is a significant way forward, despite the

unfortunate and misleading name of the Agency, as is the creation of the Interagency Disability Council, foreseen by the 2020 Law. However, the composition, mandate and functioning of these structures are in need of further reflection, particularly in what concerns the meaningful and continuous involvement of organisations of persons with disabilities.

The national disability movement is in active development, and the positive recent shift from the monopolistic government-owned organisations towards pluralistic and dynamic human rights-based activism has already been observed. Several excellent organisations, namely the Association of Persons with Disabilities of Uzbekistan, have emerged in recent years. However, much remains to be done to diversify the movement, particularly to fully include women and girls with disabilities, as well as marginalised and under-represented groups in the movement. While a few respected women with disabilities have greatly contributed (and continue doing so) to making women with disabilities more visible on the national agenda, they cannot and should not be expected to replace a **representative organisation governed by women with disabilities**. Establishment of such an organisation is currently challenged by the administrative barriers, low capacity of activists and limited support that is available to them.

The urgency of development of the feminist disability movement is manifested in the continued invisibility of girls and women with disabilities from the national policy making and programmatic interventions, including key initiatives such as the recently adopted Law on Sexual and Reproductive Health and the national gender equality policies. Misconceptions about disability and gender are reportedly making the service providers for victims of violence reluctant to accommodate women and girls with disabilities fleeing family violence.

The absence of a representative organisation uniting **families of children with disabilities** across Uzbekistan is equally noticeable against the backdrop of exclusion and segregation children with disabilities experience today. Families of children with disabilities spearhead some of the most significant interventions today, such as the development of early identification and early intervention services. Lack of recognition and support results in their inability to scale work to the national level, to reach out to the families in remote and rural areas, to gauge the real needs of children on the ground, and to provide a united legitimate and constructive contribution to national policy proposals.

Persons with intellectual and psychosocial disabilities remain completely excluded from the national agenda setting: owing to deeply rooted stigma and lack of support for self-advocacy, issues such as legal capacity, supported decision making, fight against arbitrary deprivation of liberty and forced interventions could not be properly assessed in the present research. The discussion of civil and political rights of persons with disabilities rarely goes beyond physical and informational accessibility of voting booths and court buildings: without minimising the importance of these issues, the **complete disenfranchisement of people under guardianship** is palpable. The development of the national disability movement must include activities to reach out to and support activists with psychosocial disabilities.

The recent ratification of the Convention has paved the way for a more systematic approach to the building of the national implementation framework, including the governmental agencies, independent mechanism and meaningful participation of organisations of persons with disabilities. The upcoming initial review of Uzbekistan by the CRPD Committee is an **opportunity** to revisit and strengthen the existing structures. Cooperation models used by other countries can be used as inspiration, while the specifics of the Uzbekistan's situation must be taken into account.

Uzbekistan's commitment to achievement of Sustainable Development Goals presents an opportunity to reach out to underrepresented groups of persons with disabilities and women with disabilities without whom the "leaving no one behind" approach cannot be realised. The high profile and professionalism of the Association of Persons with Disabilities should be capitalised on to support the development of a disabled women-led advocacy structure. Inspiration and experience for the future organisation can be drawn from the similar processes in the neighbouring countries (Central Asian Network of Women with Disabilities). The international community that supports the ongoing government initiative to set up new shelters for victims of violence must use this opportunity to insist that these services are fully accessible for and inclusive of women and girls with disabilities.

In the same vein, support for the **establishment of the organisation of families of children with disabilities** run by parents and by young persons themselves must be considered a priority in the run-up to the initial report of Uzbekistan to the CRPD Committee. The process of establishment of the organisation should capitalise on the energy and readiness for coordinated advocacy expressed many parent representatives, and tap into the ongoing inclusive education reform. While the decision to establish new NGOs rests with the government, the international community can actively support the case for **the diversification and professionalisation of the national disability movement.**

ON PRECONDITION INCLUSIVE PUBLIC SERVICES

Residential care homes remain the main provider of social services for persons with disabilities. As the result of limited availability of support services in the community, the obligation to propose to every person with a disability an individual programme of rehabilitation (IPR) is routinely violated: an overwhelming majority of eligible people does not have an IPR nor is aware of the mechanism. Social support services in the community are limited to some in-home help but the eligibility conditions are strict and only persons without family support are entitled to it. Multidisciplinary coordination between medical, habilitation, social support and education services is not adequate. **Community-based rehabilitation** is at the stage of conception, despite some successful pilot initiatives in selected regions in 2010.

The **absence of a systemic approach to early identification and early intervention**, particularly in the case of children with intellectual and developmental disabilities, is the most **critical gap** according to parents of children with disabilities as it puts children at a lifelong disadvantage and at risk of institutionalisation. **The lack of specialists** is well documented: services of speech therapists, physiotherapists, occupational therapists, social workers, inclusive education support staff are not easily obtained. Specialists are usually concentrated in regional hubs, and children and adults with disabilities living in remote and rural areas are significantly underserved.

The challenge to develop inclusive community-based services is made more difficult by the **scarce reliable data about persons with disabilities.** The identification of persons with disabilities is based on the outdated medico-charity model, focused on the person's capacity to work, and used to determine eligibility for cash benefits. An evidently **missed opportunity** to include Washington Group questions in the forthcoming national census is regretful. However, the opportunity to collect disaggregated data on persons with disabilities is still presented by the various SDG instruments. It should rely on the support materials on SDG-CRPD resource package developed by OHCHR in 2020[166].

The development of disability-inclusive, gender- and age-appropriate support services in the community has been identified as a core priority of future interventions to support full inclusion of persons with disabilities in accordance with the Leave No One Behind principle and Uzbekistan's commitment to the global SDG agenda. In this sense, the ongoing involvement of the UNCT in the development of integrated social service delivery and its commitment to support the government in developing EIEI services are a major opportunity.

On inclusive education (part of precondition Inclusive services)

Absence of a CRPD compliant definition of inclusive education in the national normative framework makes it difficult to ascertain the extent of the intention of the government to fully comply with the principle of inclusion (as opposed to segregation or integration) established in CRPD Article 24 and developed in the CRPD Committee General Comment No 4 on inclusive education. Lack of meaningful in-depth consultation with representative organisations of persons with disabilities and their families in the drafting process of the Concept of Inclusive Education has been reported, further augmenting the potential dissonance between the national initiative and the international CRPD standard.

[166] https://www.ohchr.org/EN/Issues/Disability/Pages/SDG-CRPD-Resource.aspx

A number of targeted initiatives to support the systemic reform of education for children with disabilities have taken place in recent years, with an explicit commitment to develop a system of inclusive education for children with disabilities. Nevertheless, **the reliance on segregation** continues.

The pilot inclusive education initiative, kicking off with 42 "inclusive classes" throughout the country in September 2021 is a welcome **opportunity** to initiate the reform but nevertheless, it is not without a few significant red flags, including the lack of involvement of the disability community in and emphasis on inclusive "classes" (instead of "schools"). Despite public campaigns to 'recruit' children in "inclusive classes", doubts have been voiced about parents' willingness to do so due to lack of clarity about the extent of support, **misconceptions about inclusive education** and, possibly, resistance of parents of children without disabilities.

The reform should undoubtedly continue supported by a longer-term vision, complete with assessment and mitigation of risks. Firstly, the reform must operate in a transparent fashion with meaningful and continued involvement of organisations of persons with disabilities as equal partners. Secondly, it must be accompanied by a preparatory stage targeting pre-school age children to prepare them for inclusive education with a range of early intervention support measures. Thirdly, **training of professionals** must continue, with the emphasis on support and training of classroom teachers and resource specialists, moving away from the 'defectology' approach.

ON PRECONDITION ACCESSIBILITY

Despite the long existence of the national disability legislation requiring accessibility of public buildings and infrastructure for persons with physical and sensory impairments, in practice the legal norms are rarely enforced. The reasons are the lack of involvement of low capacities of local OPDs for participation in the design and planning of new urban construction projects while the CRPD concept of "universal design" is omitted from current legislation. Moreover, narrow understanding of the concept of 'accessibility' leave behind underrepresented and marginalized groups in these processes without providing them with reasonable accommodation and assistive devices.

Ensuring participation of public associations of people with physical, sensory, intellectual and psychosocial disabilities in the new procedure for coordination of construction projects and technical councils of the Main Department of Architecture and Construction of Tashkent (GlavAPU) and the permanent participation of all cross-disability OPDs in the Interdepartmental Council on the Affairs of Persons with Disabilities is required to achieve disability-inclusive planning, design and building in urban and rural areas. There is a strong need for strengthening administrative liability and other forms of sanctions and control for violations of the established constructions norms and rules with the identification of the state body responsible for such enforcement and monitoring. The national legislation should be reviewed to be in line with the principles and provisions of the CRPD on accessibility through wider understanding of this concept.

ON PRECONDITION CRPD-COMPLIANT PROGRAMMING AND BUDGETING

Persons with disabilities are currently reflected in only a handful of national SDG targets, most notably on social protection (in what concerns entitlement to benefits) and inclusive education. In order to make measurable progress towards achievement of the ambitious disability rights agenda that the Uzbekistan's government has taken upon itself, investment must be made to create a favourable national environment at all levels. In parallel, disability mainstreaming must become an integral part of all programmatic efforts of international donors present in Uzbekistan: all grant-making activities must be checked for their inclusion of women, men, and children with disabilities, not just the most obvious social inclusion projects. International donors should use their leverage with the government to demand the same from it for all internationally funded governmental activities. The **opportunity** to foster disability-inclusive programming is provided by the SDG achievement framework (and its supporting tools) and the commitment of the UN to promote and mainstream right of persons with disabilities outlined in the UN Disability Inclusion Strategy.

ON PRECONDITION ACCOUNTABILITY AND GOVERNANCE

Lack of reliable and disaggregated administrative and survey data on disability makes accountability and governance difficult as many persons with disabilities might have been left behind by the social protection system. Current estimates of disability prevalence seem to be severely underestimated at about 2% of the total population based on the administrative data registries. The government is refusing to include the Washington Group Short Set of Disability Questions in the upcoming 2023 population census arguing that it lacks necessary expertise and financial support. There are several national accountability mechanisms and with the ratification of the CRPD it is expected that the government will be accountable to the CRPD committee for its implementation. The focal point for disability policy is the Agency for Development of Medical And Social Services under the Cabinet of Ministers of Uzbekistan which coordinates the works of the Interagency Council on Disability Affairs.

To improve accountability and governance based on evidence-based policy making it is necessary to upgrade skills and knowledge of the local experts at the State Statistics Committee in disability-disaggregated data collection and analysis using available international tools such as the Washington Group Short Set of Disability Questions. Integrate and mainstream disability questions within general surveys and all other national instruments to generate indicators and disability-disaggregated data. Advance disaggregation by gender, age, sexuality, economic conditions, religion, location, etc., across sectors education, employment, healthcare, accessibility, social protection and poverty, etc.). Improve the existing administrative data using ICT and modern databases. Use the opportunity of including the Washington Group short set of disability questions in the upcoming population census in 2023.

7. KEY RECOMMENDATIONS TO THE REPUBLIC OF UZBEKISTAN

ON EQUALITY AND NON-DISCRIMINATION

REC 1 – to conduct a full review of the national legislative norms in light of Uzbekistan's obligations under the CRPD and introduce such a review of all forthcoming proposals, addressing preconditions for CRPD realisation such as equality and non-discrimination (including multiple discrimination), reasonable accommodation, universal design, accessibility and meaningful participation of OPDs.

Responsible parties: Cabinet of Ministers, Oliy Majlis

Role of UNCT: UNCT, according to their respective mandates, should provide technical and financial support (incl facilitation of exchanges with the international expert community) to analysing and revising national legislation in accordance with the international norms

REC 2 – to mobilise the efforts to address the complete invisibility and exclusion of persons, particularly those with psychosocial disabilities, under guardianship. To make available data on the number of persons under guardianship, reasons and duration of incapacitation and cases of reversal of incapacitation decision; provide training for the relevant government officials, judiciary, healthcare professionals and social workers on the international standard on CRPD Article 12 and CRPD Committee General Comment No 1 on equal recognition before the law; to support the creation of self-advocates with lived experience of guardianship; to adopt the national plan of action to move towards supported decision-making and the removal of Uzbekistan's reservation under CRPD Article 12.

Responsible parties: Ministry of Justice, Supreme Court, Oliy Majlis

Role of UNCT: OHCHR should use all available platforms to conduct training and awareness raising exercise targeting the relevant Ministries, judiciary, Ombudsperson, medical corps and service providers on the substance of Article 12; it should serve as the point of contact between the national OPD community, supporting the advocacy to lift the Uzbekistan's reservation to CRPD Article 12

REC 3: Engage in a comprehensive and evidence-based campaign to create a positive image of girls, boys, women and men with disabilities in Uzbekistan as well as address negative stereotypes and norms and support efforts countering gender-based violence. It should cover a broad range of issues, such as accessibility, access to resources, reproductive rights, gender roles and violence, and target professionals, policy makers, mahalla, mass media, civil society and private sector. It should be led by organisations of persons with disabilities, including women with disabilities, and have a broad outreach, including in rural and remote areas and residential care institutions.

Responsible parties: Ministry of Employment and Labour Relations, organisations of persons with disabilities

Role of UNCT: UNFPA should include girls and women with disabilities in all its communication and awareness raising work on women's rights and gender-based violence. It should also work directly with the NGOs, government and local authorities to address the specific barriers experienced by women with disabilities. Disability mainstreaming in reproductive rights should be included in UNFPA own programmatic work.

REC 4: To introduce in the national legislation CRPD compliant definitions such as "universal design", "reasonable accommodation" through amendment of the national law "On the Rights of Persons with Disabilities" and making it compliant with the principles and provisions of the CRPD; strengthen the capacities of OPDs and relevant government agencies in ensuring the accessibility standards and individualized reasonable accommodation and assistive technologies for persons with various forms of impairments.

Responsible parties: Ministry of of Employment and Labour Relations Oliy Majlis

Role of UNCT: UNCT, according to their respective mandates, should provide technical and financial support (incl facilitation of exchanges with the international expert community) to drafting proposals in compliance with the CRPD Committee General Comment No 2; it should facilitate training activities for the national stakeholders, including the relevant Ministries, standardisation bodies and professional unions on international accessibility standards.

ON STAKEHOLDER PARTICIPATION

REC 5 – to facilitate and support the process of formal recognition of new and emerging organisations of persons with disabilities and self-help groups of families of children with disabilities, persons with intellectual and psychosocial disabilities, girls and women with disabilities and persons with rare and/or complex impairments such as deafblindness. As the first step, the establishment of a women's committee within the Association of Persons with Disabilities should be considered, with its chairperson nominated to the Board of the Association and mandated to represent the Association externally.

Responsible parties: Ministry of Justice, organisations of persons with disabilities, Association of Disabled People of Uzbekistan

Role of UNCT: UNCT, according to their respective mandates, should identify and support the development of skills and capacities of interested and qualified women with disabilities and involve them as experts in their activities. They should specifically target young women, women from under-represented groups and women from remote and rural areas. The UNCT should provide technical and communicational support to women activists interested in getting organised and, in due time, support the administrative steps for the establishment of an association.

REC 6 – to significantly increase technical and financial support to grassroots organisations and peer support groups of marginalised and under-represented groups, particularly from Uzbek-speaking community, youth and women. Support must be based on the human rights model of disability and promote meaningful participation in decision-making processes. It should focus on inclusive and representative disability advocacy and enhancing capacities in results-based programme management including on gender and disability mainstreaming.

Role of UNCT: according to their mandates, the UNCT should make their activities inclusive of and accessible to persons with disabilities, including to those from marginalised and under-represented groups. This includes ensuring accessibility of venues and communications of UNCT events, providing accessibility/reasonable accommodation budget to enable participation of persons with disabilities, earmarking funds to ensure that experts with disabilities are consulted and remunerated for their services, considering establishing an employment/volunteering/internship programmes targeting persons with disabilities; specifically target persons with disabilities, especially women and young people, for UN-organised training opportunities.

ON INCLUSIVE PUBLIC SERVICES

REC 7 – to speed up the reform of disability assessment and determination processes in compliance with the bio-psycho-social model of disability based on the ICF that is focused on the assessment of not only medical conditions but barriers and individual support needs; to urgently improve accessibility of the procedure, including physical and communication accessibility of the VTEK centres; to make the procedure financially affordable; to involve local community structures, professionals and organisations of persons with disabilities.

Responsible parties: Agency for the Development of Medical and Social Services

Role of UNCT: UNICEF, UNDP. The UNCT should strengthen the cooperation with the Agency for the Development of Medical and Social Services by concluding a Memorandum of Understanding (or similar) with the Agency to identify and address the specific barriers to the introduction of the ICF classification.

REC 8 – to use a unique opportunity provided by the upcoming 2023 population census to include Washington Group Short Set of disability questions in the questionnaire and use the results of the census to develop user-led services at the community level; to support the ongoing grassroots advocacy efforts of OPDs and civil society activists to include disability questions in the upcoming census.

Responsible parties: The State Committee of the Republic of Uzbekistan on Statistics, Ministry of Health, Agency for the Development of Medical and Social Services

Role of UNCT: UNFPA should relaunch its call to the State Committee on Statistics urging it to adopt the Washington Group Set of questions in the 2023 census. It should, if necessary, engage the support of the international expert community to collect the positive experiences of other countries in this process.

REC 9: improve availability of and access to community-based support services for children with disabilities and their families as a tool for prevention of institutionalisation. This should include initiatives to improve the availability of support from birth on (including counselling, respite care, peer support, financial support, habilitation etc); development of networks of family-like services, such as fostering; improvement of the system of monitoring of admissions of children into institutional care.

Responsible parties: Ministry of Labour and Social Affairs, Ministry of Health, Ministry for Support of Mahalla and Family, Agency for the Development of Medical and Social Services

Role of UNCT: UNICEF should provide technical and financial support to the relevant Ministries and agencies for the development of a comprehensive system of age-appropriate community-based support services. It should be based on the ongoing modelling exercise currently implemented by UNICEF in selected local communities and will include the development and introduction of relevant practices and procedures in these communities. UNICEF should also support the government in conducting the legislative review and the economic analysis of costs of institutionalisation that helps make necessary budget reallocations.

REC 10: build the model of EIEI using good practices from other countries and taking into account national particularities. Adopt a programme of EIEI development that should include multidisciplinary coordination, development of human resources, ethical codes for professionals, involvement of families of children with disabilities and earmarked budget. Build capacity of community-based primary healthcare providers to identify developmental delays and refer patients to the comprehensive system of early diagnosis and early intervention.

Responsible parties: Ministry of Health, Ministry of Preschool Education, Ministry for Support of Mahalla and Family, Agency for the Development of Medical and Social Services

Supporting UNCT: UNICEF should provide necessary technical and financial support to develop a comprehensive system of EIEI, bringing in expertise from other countries, supporting the participation of OPDs and parent community and training government stakeholders.

REC 11: Invest in health promotion and health education, including universal access to screening and preventive care for all, including persons with disabilities. Improve availability of age-appropriate and gender-sensitive support and rehabilitation services at local level, using the WHO Community-Based Rehabilitation Guidelines for Persons with Disabilities; create multidisciplinary teams at the mahalla level coordinated by a community-member trained in community-based rehabilitation and the human-rights model of disability.

Responsible parties: Ministry of Health, Ministry for Support of Mahalla and Family

Role of UNCT: UNDP, UNICEF should assist the above-mentioned national agencies in the development of the national CBR program to be implemented with direct participation of OPDs and other stakeholders.

REC 12: mainstream women and girls with disabilities in all legislative, policy and funding instruments concerning reproductive health; conduct training and awareness-raising on non-discriminatory disability-sensitive reproductive health for health care professionals; work with local-level associations and communities to fight against stigma surrounding access of women with disabilities to reproductive care.

Responsible Parties: Ministry for Support of Mahalla and Family, Ministry of Health

Role of UNCT: UNFPA should advocate for the disability-inclusive timely revision of the existing legislative and policy instruments, include the disability dimension in all its activities, specifically those targeting healthcare professionals, and provide technical and financial support to its NGO partners to provide disability-inclusive services on the ground.

REC 13: Transform the existing network of services for survivors of gender-based violence to be inclusive of and accessible for women and girls with disabilities; raise awareness and build capacity of service providers working with women and girls with disabilities/survivors of violence (law enforcement, healthcare, psycho-social services) on the rights-based disability-inclusive approaches; ensure disability mainstreaming in all instruments against gender-violence; ensure disaggregation of data on recipients of services by age and disability.

Responsible Parties: Ministry for Support of Mahalla and Family, Ministry of Interior, Ministry of Justice

Role of UNCT: UNFP should conduct a needs assessment on services provided to women with disabilities who have been victims of violence, which will serve as the basis of a proposal for a comprehensive national programme for prevention and addressing of family violence against girls and women. Itshould develop a training module for service providers on provision of disability-inclusive services to victims of GBV and pilot it in selected communities and shelters for the victims of domestic violence.

REC 14: To support disability-inclusive employment practices in the open labour market by encouraging local employers to hire persons with disabilities; in partnership with OPDs; strengthen monitoring and oversight of the implementation of 3% employment quota by the local OPDs in partnership with the Ministry of Employment and Labour Relations; the public oversight and social partnership is mandated by the Law "On Public Monitoring" and "On Social Partnership"; limit state support to segregated employment practices in favour of inclusive employment projects.

Responsible parties: Ministry of Employment and Labour Relations

Role of UNCT: UNDP should provide technical and financial support to OPDs for building their capacity to promote disability-inclusive employment in the open labour market through vocational training and labour support of persons with disabilities. UNDP should specifically address challenges for girls, women and marginalized groups and young people with disabilities through enforcement of affirmative action measures together with OPDs.

REC 15: To review social protection budgets to make them more CPRD compliant, by including budgets for reasonable accommodation and extra costs related to the disability.

Responsible parties: Ministry of Finance, Ministry of Employment and Labour Relations

Role of UNCT: UNDP and UNICEF together with the national agencies should ensure that the local budgeting and financial management is CRPD-compliant by assisting in budget analysis, making government commitments to disability inclusion and mitigating the COVID-19 related austerity measures. Both UN agencies are to ensure that the costs for reasonable accommodation (e.g., minimum guaranteed hours of sign-language interpretation services per year, personal assistant services) and extra disability-related costs are included in the national budgets.

REC 16: To develop a professional social work system in the communities based on case-management; invest in children with disabilities at early stages of their development by creating a community-based support system for parents and carers

Responsible parties: Ministry of Employment and Labour Relations, Ministry for Support of Mahalla and Family

Supporting UNCT: UNICEF should further support the development of a national system of child protection through enhancing the professionalisation of social work and other services that respond to and care for children with disabilities on an individual basis within the family environment.

ON INCLUSIVE EDUCATION

REC 17: Improve the transparency of the ongoing inclusive education system and involve organisations of persons with disabilities and parents of children with disabilities in the conception, implementation and monitoring of the next steps of the reform. Develop a coordination mechanism between MPPK, local authorities, support service providers and schools to better understand and address challenges and opportunities in the local context. Invest in the development of inclusive education auxiliary professionals, such as support teacher, speech therapist, occupational therapist, while creating optimal conditions to support the classroom teacher who must remain the main provider of inclusive education to all children.

Responsible parties: Ministry of Education, Ministry of Preschool Education

Supporting UNCT: UNICEF should provide technical and financial support to the development of an active and professional community of families of children with disabilities. It should showcase positive international models of development of inclusive education and facilitate the exchange with the international expert community to develop an interlinked approach to early intervention, support services and inclusive education.

ON CRPD-COMPLIANT PROGRAMMING AND BUDGETING

REC 18: To provide participation of persons with disabilities and their respective organizations in budget and procurement processes; to mainstream disability inclusion in general programs that focus on economic development and improvement of livelihoods at the community; to collect and analyse data on the overall budget allocations allocated to the inclusion of persons with disabilities by distinguishing which state expenditures explicitly contribute to community-based inclusive development (e.g., social services, promoting inclusive education, supporting disability-inclusive employment in the open labour market, etc.).

Responsible Parties: Cabinet of Ministers, State Committee on Statistics, Ministry of Economy, Ministry of Finance, UNCT

Role of UNCT: UNCT, according to their mandates, should ensure disability inclusive criteria in their respective programmes and initiatives with the Government of Uzbekistan; they should monitor the implementation of these programmes in line with the indicators on disability-inclusive development. UNCT should, according to their mandates, work to improve the awareness of their respective government counterparts on disability mainstreaming using the training and support materials developed by the international disability community, and advocate for disaggregation of all national data by disability.

REC 19: to make all programmatic interventions funded by international donors fully inclusive of persons with disabilities in line with the CRPD article 32 and the UN Disability Inclusion Strategy[167]; use indicators developed by the international community[168] to ensure that the international support is not used to build or perpetuate the circle of exclusion of persons with disabilities, with particular emphasis on accessibility, independent living and underrepresented and marginalised groups.

Responsible parties: UNCT, according to their mandates, should ensure disability inclusive criteria in their respective programmes and initiatives with the Government of Uzbekistan; they should monitor the implementation of these programmes in line with the indicators on disability-inclusive development.

ON ACCOUNTABILITY AND GOVERNANCE

REC 20 – to design the national CRPD implementation and monitoring mechanisms based on the CRPD Article 33 and international authoritative guidance. The name and tasks of the Agency for the Development of Medical and Social Services must be revisited in the spirit of Uzbekistan's obligations under the Convention, and the Agency should be strengthen to fulfil its tasks as the national focal point. The appointment of disability focal points in different ministries and services should be considered to improve awareness about the CPRD and disability mainstreaming in all policies. The composition and working methods of the newly established Inter-Agency Council on Disability Affairs at the Council of Ministers should be revisited to ensure its full transparency, pluralistic representation of persons with disabilities and sustainability. The Ombudsman's Office should be strengthened and formally appointed as the independent monitoring mechanism for the CRPD; steps should be taken towards its 'A' status accreditation by GANHRI, while improving its capacity to monitor the Convention in all areas.

Training in CRPD Articles 4.3 and 33, based on the CRPD Committee General Comment Nr 7 on participation of persons with disabilities in the implementation and monitoring of the Convention[169] is needed to ensure meaningful participation of organisations of persons with disabilities in all processes.

Responsible parties: Cabinet of Ministers, Ministry of Employment and Labour Relations, Agency for the Development of Medical and Social Services, Ombudsman's Office, Oliy Majlis

[167] UN Disability Inclusion Strategy.

[168] https://www.ohchr.org/EN/Issues/Disability/Pages/SDG-CRPD-Resource.aspx

[169] CRPD/C/GC/7, 9 November 2018.

Role of UNCT: UNICEF and OHCHR should work with the above-mentioned government stakeholders to improve their understanding of the CRPD requirements on national implementation and monitoring mechanisms; they should provide training and technical support to establishing or strengthening the necessary elements of these mechanisms in Uzbekistan. The UNCT should support the development of an transparent and participatory coordination structure that is inclusive of organisations of persons with disabilities in the implementation and monitoring process.

8. ANNEX I – LIST OF KEY INFORMANTS

In-depth interviews

	Organization	Title
1.	Ombudsman's Office of the Republic of Uzbekistan	Deputy Ombudsman / Commissioner for Children's Rights
2.	Ministry for support of mahalla and family of the Republic of Uzbekistan	Head of social support department
3.	Ministry of Public Education of the Republic of Uzbekistan	Head of Inclusive Laboratory
4.	Ministry of Employment and Labour Relations of the Republic of Uzbekistan	Head Employment of the Unemployed Population Department
5.	Ministry of Preschool Education of the Republic of Uzbekistan	Hear of health care, healthy nutrition and coordination of Specialized Kindergartens department
6.	Ministry of Finance of the Republic of Uzbekistan	Director of Budget Policy in Social Protection of the Population and State Social Services Department
7.	Medical-psychological-pedagogical commission	Deputy head of medical labor expert commission
8.	National Human Rights Center	Deputy director
9.	NGO "Opa-Singillar"	Chairperson (a woman with physical impairment)
10.	Non-government educational organization "UMNICHKA	Director (a mother of a boy with Down Syndrome)
11.	National University of Uzbekistan named after Mirzo Ulugbek	Associate Professor at the Department of Social Work (a man with a visual impairment)
12.	Association of People with Disabilities of Uzbekistan	Chairperson (a man with a physical impairment)
13.	UNDP in Uzbekistan	Programme Associate on Public Policy
14.	UNFPA in Uzbekistan	Assistant Representative Gender specialist
15.	OHCHR in Uzbekistan	National Programme officer
16.	UNICEF in Uzbekistan	Child protection team

The following were approached by were not available for the interview:

	Organization	Title
1.	Agency for the Development of Medical and Social Services under the Cabinet of Ministers of the Republic of Uzbekistan	Director
2.	Commissioner of the Oliy Majlis of the Republic of Uzbekistan for Human Rights	Ombudsperson
3.	Ministry of Economic Development and Poverty Reduction	Deputy minister
4.	Ministry of Internal Affairs	Head of women issues department
5.	Republican children fund «Sen yolq'iz emassian»	Director

Focus group discussions

FGD 1: Revisiting the 2019 Situation Analysis

ORGANIZATION	POSITION
1. Association of Disabled People of Uzbekistan	Chairperson (man with a physical impairment)
2. Department of Social Work, National University of Uzbekistan	Associate Professor (man with a sensory impairment)
3. NGO "Opa-singillar" in Qibray District, Tashkent region	Chairperson (woman with a physical impairment)
4. NGO “Millenium”	Chairperson
5. Association of Entrepreneurs with Disabilities “NUR”	Chairperson
6. ADB projects	Individual consultant
7. NGO “Umidvorlik” the Support Centre of Children with Disabilities	Chairperson
8. NGO “Status”	Chairperson

FGD 2: Women and girls with disabilities

ORGANIZATION	POSITION
1. NGO “Sharoit Plus” in Tashkent city	Chairperson (woman with a physical impairment)
2. NGO "Opa-singillar" in Qibray District, Tashkent region	Chairperson (woman with a physical impairment)
3. NGO “Rahimdillik Jamiyati in Samarkand	Director
4. NGO “Inklyuziv Jamiyat” in Tashkent city	Chairperson
5. NGO “Oydin Nur” in Bukhara	Director
6. Fergana Regional Branch of the Centre for Support of Civil Initiatives (TSPGI)	Director
7. Republican Center for Rehabilitation and Adaptation of Victims of Violence	Representative

FGD 3: Inclusive public services in the community and prevention of institutionalization: grassroot perspective of disability movement

ORGANIZATION	POSITION
1. Non-government Educational Organization “Angels on Earth” in Bukhara	Coordinator
2. Self-help group of children with Down Syndrome “Andijon Qiyoshchalari” in Andijan	Coordinator (mother of a boy with Down Syndrome)
3. Self-help group of parents of children with autism	2 representatives (mothers of children with autism)
4. Republican Centre for Social Adaptation of Children (RSCAD) in Samarkand	Director
5. Non-government Educational Organization “UMNICHKA”	Leader of Self-help group pf parents of children with Down Syndrome (mother of a boy with Down Syndrome)
6. Republican Centre for Social Adaptation of Children (RSCAD) in Karshi	Director
7. Republican Centre for Social Adaptation of Children (RSCAD) in Ferghana	Director

8. Republican NGO “Avlod Baraka”	Chairperson

FGD 4: Inclusive public services in the community and prevention of institutionalisation

ORGANIZATION	POSITION
1. Republican Centre for Social Adaptation of Children (RSCAD)	Head of the Department for the Study of the Problems of Children Left without Parental Care
2. International expert on foster care for children without parental care, Russian Federation/Uzbekistan	Representative
3. Ministry of Pre-school Education	Head of medical-psychological-pedagogical commission
4. Ministry of Public Education	Head of medical-psychological-pedagogical commission
5. Ministry of Public Education	Head of Inclusive Laboratory
6. Ministry of Health, Children's neuropsychiatric hospital named after Kurbanov	Head doctor

FGD 5: Participation of under-represented and marginalized groups

ORGANIZATION	POSITION
1. NGO “Ishonch va Hayot”	Deputy chairperson
2. Self-help group of youth with HIV	Social activist
3. Central Asian Youth Autism Centre (CAYAC)	Director, Kazakhstan
4. NGO “Kapalak Bolalar” (Deti Babochki)	Chairperson
5. Self-help group of parents with children with muscular spinal atrophy	2 representatives

9. ANNEX II – QUESTIONS TO KEY INFORMANTS

Questions to policy makers

1. Please describe your function and place it within the existing structure of your institution/region?

2. Please describe the existing interagency coordination between different government arms on the subject of persons with disabilities. [*Probe for coordination between social affairs, health, education, employment, but also entrepreneurship, transport, finance and international affairs.*]

3. What are the most important measures that the government has developed for (1) children with disabilities? (2) adults with disabilities? (3) equality and non-discrimination? women and girls?

4. What are the most important challenges/bottlenecks, according to you? What is the reason for these difficulties, to the best of your knowledge?

5. What are the international standards, national laws and bylaws that are applied to develop these measures? Do you and your colleagues have sufficient awareness about these instruments? Have you ever received training on it? [*Probe the level of awareness of the interviewee about the CRPD and other Conventions, SDG and others*]

6. To what extent do you think the rights of people with disabilities are being fulfilled in your geographic area / professional expertise area? Please elaborate.

7. Please elaborate on the government's strategy, work plans, focus, and budget to implement the national policies that are specific to people with disabilities and/or women and girls? What is the role of each ministry in this regard?

8. Can you please describe, to the best of your knowledge, what are the different types of public services that exist for adults or children with disabilities in your [area of responsibility and regional area, as appropriate]? Are these services offered in sufficient volume? Are they age- and gender-sensitive? What about their quality? Who evaluates their quality?

9. Does the government differentiate between people with different types and degrees of disability (sensory, learning, physical, other) in their eligibility to support services? Please elaborate how this differentiation works and how eligibility for support is determined.

10. To the best of your knowledge, how accessible are the public facilities [*buildings and inside infrastructure*] in your field of competence [or geographic area] for persons with disabilities? Is the conception of these public facilities based on universal design?

11. To the best of your knowledge, is there enough available data/ information on persons with disabilities for evidence-based decision making? Is this data disaggregated by gender and age?

12. Do you think that you have enough trained professionals on issues related to disability issues to ensure proper implementation of policies nation-wide?

13. Is there authoritative, generally accepted and well-known guidance (such as guidebooks, courses, online resources) to guide professionals in their job on the ground?

14. What do you think is the general public's view (awareness and attitudes) of people with disabilities (women, men, girls and boys)? What about professionals? If you can identify any misconceptions, why do you think they exist?

15. Do you know someone who is a person with a disability? Please briefly explain how you know them (family member, close friend, distant relative, colleague, acquaintance etc).

    a. If yes: how much has this person influenced your professional work?

    b. If no: Would you allow your son/daughter to be friends with, marry or constitute a family, living independently with a woman or man with a disability? Why or why not?

16. Do you know any DPOs or other organizations working on the rights of children/women with disabilities in your area? Which ones? Are they doing a good job, according to you?

17. What about women's rights organisations? Do they include women with disabilities?

Questions to service providers

1. Could you please describe the type of service to persons with disabilities you provide? Who is your main constituency (type, age, gender, severity of disability, regional distribution, socio-economic background, etc)?

2. Is your service/expertise essential in determining specific services and/or cash benefits that persons with disabilities receive? [*This question aims to identify the eligibility of persons with disabilities to seamless and continuous support. Please probe for early identification and intervention for children with disabilities, conditionality of eligibility for a service on obtaining a specific status]*

3. To what extent is your work setting accessible and appropriate for your main client constituency? [*Probe for physical and informational accessibility and comfort, as well as age-appropriateness: is there a playground on the premises, or child-friendly information? Also pay*

attention to clients in remote and rural areas – are they sufficiently serviced? If general service for women, probe for its accessibility for women and girls? Do they have clients with disabilities?]

4. Please explain how the service you provide is funded. Who pays for the service and how? Is the public funding sufficient? How does the price affect the quality and availability of the service provided? [*Probe for exclusion of poor people with disabilities, extra out-of-pocket expenses for clients to ensure a better service or a speedier resolution of the problem, or the readiness of the state to invest in services for persons with disabilities*]

5. What are the challenges you face in working with persons with disabilities? [*Please ask to elaborate and probe for issues such as stigma and prejudice, difficulties to communicate, adversarial nature of the client-service provider relationship, lack of support, absence of appropriate services sought by clients, cultural barriers*]

6. To what extent have you and others in your work setting been trained to work with persons with disabilities? Could you describe it (content, regularity, who provided it)?

7. Do you have any collaboration with other service providers outside of your immediate area of expertise? Please describe all that is relevant. [*Probe for referrals for cases of abuse, violence, exploitation etc… Do they know how to deal with people having trauma?*]

8. Are there any service providers in the community than cannot accommodate persons with disabilities within their service provision? Please elaborate. [*Probe specifically for early childhood education and care services, schools and extracurricular activities for children, sexual and reproductive healthcare, childcare]*

9. How would you describe the level of awareness and attitude towards persons with disabilities in general? Is it different for men and women?

10. Could you please give us any example of good practice related to your service delivery for children and adults with disabilities?

11. In your view, can persons with disabilities be included in society? Why or why not?

Additional questions for providers of gender-specific services

12. How to you reach women and girls with disabilities (referral, advertisement, show up at the door etc)? [*Aim to understand how easy it is to reach women with disabilities. By extension, you may be able to understand if there are women who would benefit from this service but experience barriers to accessing it]*
13. Do you find that your clients are well-informed about the availability of services for women with disabilities (or general services that are also accessible for women with disabilities)?
14. What issues do you deal with most often? Have you come across issues such as […]?
    a. Sexual or physical violence or abuse
    b. Irreversible medical procedures such as sterilisation or abortion?
    c. Separation from children
    d. Forced marriage
    e. Modern-day slavery (incl forced domestic work)?

Questions to organisations of persons with disabilities

1. Please describe your organisation: when it was established and by whom; how it is governed and managed; if it is a membership organisation, who are its members? [*Try to establish the legitimacy and representativity of the organisation: is it led by persons with disabilities? Are democratic procedures in place? Is it representative of all persons with disabilities? Does it exclude*

intentionally or unintentionally some groups of persons with disabilities? Are the working methods transparent?]

2. Please describe the type of activity or a service to children/adults with disabilities and their families your organization provides. Describe the typical client that turns to your organisation to receive services. How do they find you?

3. Does your organisation participate in policy-shaping (e.g advocacy activities)? At what level (municipal, national)?

    a. If yes: could you estimate the proportion of time and investment for service provision and for policy-shaping activities?

    b. Is your organisation funded to participate in policy-shaping?

4. What are the challenges you face in working with persons (children/adults) with disabilities and their families, and what are the possible measures to overcome these?

5. To what extent have you and others in your organization been trained to work with persons (children/adults) with disabilities? What about specific issues, such as gender-based violence, abuse or trauma? What about survivors of psychiatry and/or residential care?

6. Where does the funding needed to support your organization work come from? Does your organization have a specific budget allocation for services for persons (children/adults) with disabilities?

7. As far as you are aware, have there been cases of persons (children/adults) with disabilities experiencing physical and/or emotional abuse [E.g. mocking, physical abuse, intimidation, etc.]? How do you address these? Is there a referral system?

8. If 'yes': by whom? What are the measures you take to prevent physical, sexual and emotional abuse, neglect or exploitation of persons (children/adults) with disabilities? Does your organization provide legal advice or specific child protection measures to respond to these situations?

9. How would you describe the level of awareness and attitude towards persons (children/adults) with disabilities, in general, in the geographic area where you work? Is it different for women and men? Please describe.

10. To what extent are the rights to health, education, employment and protection for persons (children/adults) with disabilities fulfilled in the geographic area where you work? Please describe.

11. In your view, can persons (children/adults) with disabilities be included in society? Why or why not? What are the main challenges for their inclusion? And the main opportunities for improvement? Please elaborate with examples.

12. To what extent do you receive any support related to the services you provide to persons (children/adults) with disabilities from local officials or other professionals/service providers in the form of guidelines or other means? Please elaborate with examples.

13. In your view, what kind of support (additional or new) do you require for proper service provision to children with disabilities from: (i) government, (ii) non-governmental organizations, and (iii) communities?

10. ANNEX III – TERMS OF REFERENCE FOR THE ADVISORY EXPERT GROUP

Date: **07 June 2021**

Subject: **Note for Selection of the Expert Group from members of OPDs for implementation of the UNPRPD programme "Transformation of Social Service Delivery: Implementing Human Rights-Based Approach for Children, Youth and Women with Disabilities in Uzbekistan".**

Background and Justification:

Under the UNPRPD guidance for conducting Situational Country Analysis, persons with disabilities and their representative organizations (OPDs) and informal peer support groups are pivotal to gaining a nuanced understanding of the rights of persons with disabilities and can provide unique insights and expertise. As the leading organization advocating to progress the rights of persons with disabilities, PRPD programs should complement, amplify and support the work of OPDs. Collaborative analysis between OPDs and UNCTs allows the UN to develop an understanding of the local disability context, develop and/or strengthen working relationships, and understand the operational realities, strategies and priorities of persons with disabilities. This is important for informing the focus and design of PRPD program, which is built on equal partnership with persons with disabilities and their representative organizations.

UNPRPD guidance focuses on OPD engagement at every stage of the implementation. At minimum OPDs should be:

Formally involved in overall steering and accountability within the analysis process – such as being involved in a steering committee or advisory board. This group should be regularly updated and provide feedback on the process planned, data collection tools, and analysis. Participation should be funded.

Consulted and involved as key stakeholders in data collection; analysis and validation of findings; recommendation setting; dissemination; and future program planning. [170]

In line with the UNPRPD guidance note, UNICEF Uzbekistan has identified the following criteria for selection of individuals to the **Expert Group** and **short term Consultants**, those are within the scope of the interventions, in line with proposed responsibilities and qualifications of the selected candidates, specifically:

- Focus of the Situational Analysis. In Uzbekistan's case it is the most marginalized children and women, including the institutionalized and/or under the risk of institutionalization and victims of GBV.
- Previous research experience in the area including prior training on ethical standards and qualitative methods of data collection.
- Cross-disability representation, including various forms of impairments, including but not limited to: acquired, congenital, intellectual, brain, neurologic, sensory, mobility, mental health, episodic, etc.
- Representation of the rights and interests of the grassroots OPDs and self-help groups, as well as peer support groups at the community-level.

[170] UNPRPD Guidance on conducting Situation Analysis.

Considering the above noted selection criteria, taking into consideration the requirements of the UNPRPD and assessing the experience of candidates in the field of disability at grassroots/community levels, the following representatives of OPDs have been selected as members of the **Expert Group** and short term **Consultants**:

1. **Ms. Mukhabbat Rakhimova (physical impairment)**– Chairperson of the Public Association of Disabled People of Tashkent city NGO "SHAROIT PLUS" uniting mainly women and girls with physical impairments and working on various small-scale projects with women and girls with disabilities and single mothers of children with disabilities at the community-based level in Tashkent city. She is a National Coordinator of Disability Equality Training (DET) Forum in Uzbekistan[171], peer-counselling and independent living expert.

2. **Mr. Abdullo Abdukhalilov (visual disability)** – PhD, Associate Professor at the Department of Social Work, National University of Uzbekistan under M. Ulugbek, Deputy Chairperson at the Association of Disabled People of Uzbekistan on Strategic Planning. He was trained in the USA under the international leadership program "Disability Issues and Advocacy" and in Japan under the program "Leadership Development and Exchange of Experience among Persons with Disabilities". His expertise lies in public administration, social work, disability and inclusive education. He is a certified Disability Equality Trainer.

3. **Ms. Natalya Plotnikova (physical impairment)** – Chairperson of the NGO "Opa-Singillar" uniting women and girls with disabilities for more than 25 years. She is also a mother of children with disabilities. Ms. Plotnikova has managed projects in social field, gender-based violence and human rights activist.

4. **Mr. Mamur Akhliddinov (hearing disability)** – Author of the Blog of the Society of the Persons with Hearing disabilities of Uzbekistan, student of the University of Mass Communications and Journalism. Deeply understands problems of marginalized and under-represented groups as he has expertise in working with people with hearing disabilities, and those with both hearing and visual disabilities in Uzbekistan, which are the most underrepresented because of the communication and information barriers they face.

5. **Ms. Rano Esanova (a mother of a child with autism)** – Leader of a self-help group of families with children with autism uniting more than 60 families. Founder of educational center focused on early development educational programs for children with intellectual disabilities. She has successfully completed a number of courses on psychology, inclusion of children with autism etc.

6. **Mr. Oybek Isakov (physical impairment),** Chairman of the Association of ODPs of Uzbekistan. Has 23 year of experience on promoting the rights of PWDs. Graduated from the National Law Academy of Ukraine. Has been actively involved in the development and amendment of the normative and legal framework in Uzbekistan. Mr. Isakov received numerous training on CRPD and Disability Inclusion.

7. **Mr. Farkhad Abdurakhmanov (physical impairment)**, First Deputy Chairman of the Association of ODPs of Uzbekistan. Graduated from Tashkent Economical Istitute. Has been working on a number of projects on the accessibility, rights of PWD and disability inclusion. Mr. Abdurakhmanov received numerous training on CRPD and Disability Inclusion.

This Note for Selection is intended to document the recruitment of the **Group of Experts** and **short-term Consultants** from the Organization of Persons with Disabilities (OPDs). The contractual terms

[171] DET Forum Uzbekistan.

will be established under the terms of the Low Value Contract (LVC). If decided, contracts can be extended based on UNICEF Procedures and Guidance.

The **Experts Group** will be represented from the following members, who will be supporting international and national consultant at every stage of the study and will provide the following deliverables below:

1. **Ms. Mukhabbat Rakhimova**
2. **Mr. Abdullo Abdukhalilov**
3. **Ms. Natalya Plotnikova**
4. **Mr. Mamur Akhliddinov**
5. **Ms. Rano Esanova**

Deliverables of the Expert Group:

The assignment timeframe is 5 working days in the period of June – July, 2021 distributed as follows:

Activity	Timeframe	Deliverables
Data Collection Phase		
Providing feedback and recommendations to the data collection instruments developed by the international consultant	2 day	Brief report with suggestions and comments
Providing feedback and recommendations on the list of respondents within key informant interviews (KIIs) and focus group discussions (FGDs).		
Data Analysis Phase		
Attending the training on ethical standards, qualitative data collection methods and data analysis	2 day	Summary from FGDs with key findings and important areas for focus to be presented to consultants during the call
Participating in the KIIs and FGDs based on the thematic areas		
Inputs to the analysis of the qualitative data collected through KIIs and FGD discussions to support international and national consultant in the deeper thematic analysis		
Validation of Findings		
Participating in the validation workshop with UN, Government and OPDs and presentation of own findings and recommendations	1 day	Presentation during the Validation Workshop and feedback to the draft SitAn
Revising and contributing to the draft Situational Analysis based on their research experience and inputs with concrete qualitative evidence and data.		
Total:	**5 days for each**	

Individual short-term Consultants:

The team of **short-term Consultants** will be represented by the following members to provide technical expertise in the Report Writing phase and providing the following deliverables:

1. **Mr. Oybek Isakov**
2. **Mr. Farkhad Abdurakhmanov**

Activity	Timeframe	Deliverables
Report writing Phase		
Development of the report on the recent developments since 2019 in the area affecting the rights of persons with disabilities, specifically including: ● Changes in the legal and normative framework. ● Challenges affecting inter-sectorial coordination. ● The role of the recently established Council on PWD and on what it means for improving the coordination.	**5 days**	Draft report for review and UNICEF feedback
Validation Phase		
Integrating UNICEF feedback and suggestions and submission to UNICEF	**2 days**	Final report endorsed by UNICEF
Total	**7 days each**	

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