





WORKSHOP SUMMARY AND RECOMMENDATIONS

ON THE IMPLEMENTATION OF THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES IN UZBEKISTAN

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Expert Discussion

On 30 September, the International Commission of Jurists (ICJ), the National Movement Yuksalish and the Office of the UN High Commission of Human rights (OHCHR) Regional Office for Central Asia (ROCA) held an Expert Discussion on the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) in Uzbekistan. It was held under the EU funded project "Enhancing the quality of Uzbekistan's application of international law" (EQUAL). The expert discussion was attended by international experts and local stakeholders including individual experts, NGOs and other civil society institutions working with the rights of persons with disabilities. During three sessions, participants heard national and international perspectives, including by civil society, on the obligations and priorities for Uzbekistan following ratification of the CRPD.

This paper summarizes the key points of the Expert Discussion and outlines the recommendations for implementation of the CRPD and ensuring a greater protection for the rights of persons with disabilities in Uzbekistan, made by participants during the event. They do not represent the views of the ICJ, OHCHR, Yuksalish or the EU. In order to make it more practical, avoid repetition and present the substance of the discussion in a concise structured manner, this summary does not attribute specific statements or recommendations to any one speaker or speakers representing institutions. Rather, it summarises some of the key messages and recommendations which were presented at the event.

Introduction

International human rights law protects human rights of all persons on an equal basis, including the rights of people with disabilities.² The Convention on the Rights of Persons with Disabilities (the CRPD) is an international human rights treaty that reinforces the guarantees for the human rights by persons with disables and particularly strengthens protection for non-discrimination in relation to persons with disabilities. The Committee on the Rights of Persons with Disabilities (the CRPD Committee) oversees compliance with the Convention by the States parties.³ The Convention entered into force in May 2008. The Optional Protocol to the CRPD, which entered into force simultaneously with the Convention, establishes an individual complaints mechanism for the Convention and the jurisdiction of the CRPD Committee.⁴

Uzbekistan signed the CRPD in 2009⁵ and ratified earlier this year on 7 June 20216. It made a reservation concerning Article 12 of the CRPD reserving the right to continue to use substitute decision making for persons with disabilities.⁷ It has not yet ratified the Option Protocol to the CRPD. In January 2021, a new Law on the Rights of Persons with Disabilities entered into force.⁸

https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en_accessed 29 October 2021

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¹ The EQUAL is a three-year EU funded project implemented by the ICJ in cooperation with the National Movement "Yuksalish". The main objective of the EQUAL project is to promote, by supporting civil society, equal protection of ESC rights for groups particularly vulnerable to discrimination in Uzbekistan.

² "Overview of International Legal Frameworks For Disability Legislation" available at

https://www.un.org/esa/socdev/enable/disovlf.htm accessed 11 October 2021

³ CRPD Committee page https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx accessed 11 October 2021

⁴ CRPD Committee page https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx accessed 11 October 2021

⁵ CRPD ratification status by countries

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⁷ United National Treaty Collection, Status of Treaties, Convention on the Rights of Persons with Disabilities, https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en.

⁸ Law of the Republic of Uzbekistan on the Rights of Persons with Disabilities < https://lex.uz/ru/docs/5694817 > accessed 29 October 2021

Having ratified an international treaty such as the CRPD, Uzbekistan undertook to be legally bound by it and implement it in good faith. Experts suggested that, in implementing the CRPD, Uzbekistan should be guided primarily by the CRPD and the general comments and the jurisprudence of the CRPD Committee. No State should simply copy and paste practices of other countries especially those which have not effectively implemented the CRPD. Although many countries around the world may have good practices in relation to ensuring disability rights, it would be a mistake to consider that any of them has come close to fully realising all the rights of persons with disabilities. The methods of implementation that are effective in one country will not necessarily work elsewhere: this is why States should be guided by the recommendations of the CRPD Committee, its case law and interpretations, rather than merely by the practices of other countries.

The CRPD: introducing the human rights model of disability

The CPRD requires States parties to guarantee in law and in practice non-discrimination against persons with disabilities, and to guarantee substantive equality of persons with disabilities by taking the reasonable accommodation measures that are needed. Article 2 of the CRPD defines reasonable accommodation as being the necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms. A failure to provide reasonable accommodation amounts to discrimination on the basis of disability.

The CRPD also requires that the legal capacity of persons with disabilities is fully realized including before courts, as examples: legal capacity to draw up wills, to marry, to consent to medical operations and to participate in legal processing impacting on their rights and interest. Any need that persons with disabilities may have for support in decision-making process must be accommodated procedurally.¹² In many cases persons with disabilities and their organizations struggle to have access to State institutions and systems including the courts, police and other mechanisms and institutions of the justice system.

Importantly, the CRPD makes a paradigm shift from the "medical" and "charity" models a human rights model of disability.

A disability model is how State policy approaches and understands disability and issues relating to persons with disabilities through national legislation, policies, strategies, budgets or even through professional and societal mind-set. According to an understanding of disability influenced by the **medical model of disability**, persons with disabilities have historically been treated as having "defects to be fixed by medical means". Similarly, the **charity model** understands disability and treats persons with disabilities as objects "to be pitied and cared for". Under these models the failure of social inclusion is caused by individual impairments rather than by societal barriers including public and professional attitudes and legislative provisions. Persons with disabilities are therefore frequently subjected to various forms of discrimination and exclusion on the grounds of their impairments. Their placement to various segregated medical, housing, educational or other institutions puts them at a higher risk of being subjected to violence or the denial of their civil, political, economic, social and cultural rights.

By ratifying the CRPD the States Parties assume the obligation to end the systemic discrimination and social exclusion of persons with disabilities and to switch from highly discriminatory policies, legislation and practices based on medical and charity models of disability to a **human rights model of disability**. To ensure the enjoyment of rights by persons with disabilities on an equal basis with others State Parties to the Convention must provide necessary and required support to

⁹ Vienna Convention on the Law of Treaties, Done at Vienna on 23 May 1969. Entered into force on 27 January 1980. Article 26 [acceded to by Uzbekistan on 12 July 1995].

¹⁰ Article 5 of the CRPD

¹¹ Article 2 Article 5 of the CRPD

¹² https://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/LegalCapacity.aspx

¹³ See General Comment No 8(2018), on equality and non-discrimination, CRPD/C/GC/6, 26 April 2018, which discusses in greater detail approaches to disability through the medical, charitable and human rights models.

them. It is the role of the State to eliminate barriers that hinder persons with disabilities from effective, full and equal participation in society.

The substance of the human rights model is embedded throughout the provisions of the CRPD. Article 1 of the CRPD establishes as one of the main objectives of the Convention, which is the promotion of respect for the inherent dignity of persons with disabilities, while medical and charitable models of disability deny the dignity of persons with disabilities through the lack of appreciation of them as fully able individuals, including legal restrictions on the rights and freedoms of persons with disabilities. Article 3 of the Convention specifies the human rights model of disability. It includes non-discrimination, autonomy and making one's own choices.

Today, people with disabilities around the world are frequently excluded from participating in decision-making on issues concerning them and face obstacles in accessing their human rights. This practice is fostered by the lack of legislative scrutiny for compliance with the human rights of persons with disabilities and nurtured by negative stereotypes of society.

States Parties must abolish all discriminatory laws and eliminate the inequality of persons with disabilities on the ground of impairment. By way of example:

Article 12 of the CRPD provides for equal recognition before the law, which is often denied to persons with mental health conditions by national legislation. Persons suffering from such mental health conditions are considered incapacitated, which, in turn, means they cannot make their own decisions.

Article 14 of the CRPD on liberty and security of the person requires the abolition of the use of all involuntary and non-consensual treatment and/or commitment to mental health institutions. Laws and policies regulating mental healthcare must be based on human rights, and the CRPD in particular.

Article 29 of the CRPD provides for the rights of persons with disabilities to vote and to stand for elections, which is impeded without the provision of necessary infrastructure which ensures accessibility.

Article 17 of the CRPD guarantees integrity of a person, by, as examples, abolishing coerced abortion and sterilization which disproportionately impacts girls and women with disabilities.

Under Article 24 of the CRPD, States Parties are obliged to end segregated forms of education and instead to provide inclusive (mainstream) education for all children including by providing for adequate budgets to cater for the accommodation of children with disabilities at mainstream educational institutions. Such accommodations include the provision of educational materials in sign language and in Braille or other alternative modes of communication, appropriate to the specific needs of particular children.

Often, persons with disabilities are unemployed or employed in low paid jobs or work in segregated workplaces. Under Article 27 of the CRPD State Parties must promote the realization of the right to work and create an open, accessible and inclusive working environment so that persons with disabilities can compete in the labour market on an equal basis with others.

The CRPD requires State Parties to create the necessary conditions for independent living of persons with disabilities. State Parties also undertake to ensure the right to live in a family environment and that persons with disabilities should not be required to live in segregated residential institutions. Instead States should ensure the provision of community-based support and access to community services available for general population.

The CRPD contains specific provisions on the protection of particularly marginalized groups of persons with disabilities, including women and children with disabilities. In particular, women with disabilities face multiple, compounding forms of discrimination on intersecting grounds of

discrimination. Women with disabilities should be protected against all forms of gender-based discrimination including sexual abuse, non-consensual abortion and sterilization. State Parties undertake to identify and abolish discriminatory legal provisions and practices.

National context and the ratification of the CRPD by Uzbekistan

The implementation of the rights of persons with disabilities is supported by the Constitution of Uzbekistan, in particular its article 18 (equal recognition before the law), article 39 (social protection) and article 45 (State protection). In recent years over two hundred laws and regulations concerning persons with disabilities have been enacted. Between 2017-2020 over forty presidential acts were adopted which directly or indirectly concern the rights of people with disabilities.

Yet, there is no reliable statistical data on persons with disabilities in Uzbekistan. Official statistics vary from one state body to another and are not sufficiently disaggregated. The disaggregated data mainly includes the total number, gender, type of disability and location of persons with disabilities. Official statistics do not include people who have not registered their disability with the relevant authority, which means their disability remains unknown.

According to the information provided at the event, currently, over 750,000 people in Uzbekistan have registered their disability¹⁴ with the Medical and Social Expert Commission (MSEC) under the newly created Agency for the Development of Medical and Social Services.¹⁵ This Agency categorizes persons with disability into three groups – from the first to the third group – depending on the level or severity of impairment.¹⁶ In total, 71,000 persons fall under the first group disability, over 500,000 to the second group and over 62,000 to the third.¹⁷ This disaggregation does not appear to correspond to the total number stated earlier in this paragraph, since it follows from the grouping that there are approximately 633,000 disabled people in the country, if such estimates are somewhat plausible it may leave more than 100 000 persons with disabilities unaccounted for.

However, it may be the case that none of these two figures above reflect the actual state of affairs concerning persons with disabilities accurately. According to the WHO, over one billion or 15 percent of the world's population have some form of disability. If the same 15 percent rate applies to Uzbekistan at least approximately. One this basis it may be estimated that the actual total number of persons with disabilities in Uzbekistan may reach as many as 3 to 5 million people.

The new Law on the Rights of Persons with Disabilities was adopted in 2021.¹⁹ The draft was developed with the participation of the Association of Disabled People of Uzbekistan, which is acknowledged by the Uzbekistan experts as a positive development. Many of the provisions of this draft were included in the final version of the Law adopted by Parliament. It was of importance particularly because in Uzbekistan, as is the case throughout the world, civil society organisations

¹⁴ Conference of the parliamentary Committee for labour and social issues (Lower chamber) on "Legal protection of persons with disabilities: national and international practice, perspective plans"https://parliament.gov.uz/ru/events/committee/35264/?sphrase_id=7826673 > 02 November 2021

¹⁵ The Agency was established according to the Presidential Decree No.5038 of 25 March 2021 and is the legal successor of the Agency for Medico-social services under the Ministry of Health of Uzbekistan. The medical and labour expert commission (BTЭK), formerly responsible for establishing the fact of disability, has been replaced with the MSEC.

¹⁶ Disability group I applies to persons who have completely lost their ability to work and need outside help and care; disability group II applies to persons who have completely lost their ability to work and do not need outside help or care; disability group III applies to persons who have partially lost their ability to work. https://my.gov.uz/ru/life-situations/10 accessed 01 November 2021

¹⁷ Data provided by a speaker of the event – Kadir Juraev - a member of the Legislative Chamber Committee of the Parliament on International Affairs and Inter-Parliamentary Relations

¹⁸ World report on disability, WHO < https://apps.who.int/iris/handle/10665/44575> accessed 03 November 2021

¹⁹ Law of the Republic of Uzbekistan on the Rights of Persons with Disabilities < https://lex.uz/ru/docs/5694817 > accessed 29 October 2021

(CSOs) working on the rights of persons with disabilities have a high level of expertise concerning the rights of persons with disabilities and are made up of those who encounter the barriers to disability rights in their everyday life.

The National Centre for Human Rights has drafted a national action plan for the implementation of the CRPD. The draft of the action plan was developed together with the relevant authorities and CSOs representing persons with disabilities. Ten out of thirty experts who participated in drafting the action plan represented CSOs.²⁰ The plan includes over one hundred twenty measures divided into six parts including: the legal framework of the rights of persons with disabilities, ensuring for them accessible infrastructure; inclusive education; reintegration and rehabilitation measures; ensuring respect for the dignity of persons with disability; preparation and submission of periodic report to the CRPD Committee.

In Uzbekistan, there is an Agency for the development of medical and social services, which provides medical and social services for persons with disabilities. Besides, there are twelve ministries and governmental departments that are in charge of addressing certain issues concerning persons with disabilities. However, division of these functions among different authorities and the fragmentary nature of their activities do not allow for coherent policy development concerning persons with disabilities to be coordinated and consistent.

In accordance with article 15 of the Law, an Interdepartmental Council for Disabled People was established, which currently includes representatives of 15 ministries and departments and the only one non-governmental organization (Узбекское общество инвалидов – Uzbek Society of Disabled People). Persons with various forms of disability are underrepresented in the Council. In this regard, it is necessary to include representatives of NGOs of persons with disabilities, including NGOs advocating for the rights and interests of the people with seeing and hearing disabilities, in the activities of the Council.

Starting from April 2021, people with disabilities can apply for disability allowances online. Yet, persons with disability receiving disability allowance are not eligible for unemployment benefits. Considering the fact that the amount of the disability allowance is too low in the country.

Recommendations of the international and national experts on the implementation of the CRPD in Uzbekistan

In the course of the event, participants, including the civil society and international representatives, put forward recommendations which should be implemented by the State following the ratification of the CRPD. These recommendations were not necessarily shared by all participants in the discussion, but to avoid repetition, the recommendations are listed and grouped below based on their substance rather than on the specific expert who put them forward.

In order to ensure more effective and faster implementation of the CRPD, participants proposed that relevant State authorities should take the following actions.

In regard to international law and mechanisms

- ratify the optional protocol to the CRPD allowing for an individual complaints procedure to provide for more effective legal remedies; and
- withdraw the reservation to Article 12 of the CRPD as this reservation contradicts the spirit of
 the CRPD as well as Article 7 of the Universal Declaration of Human Rights and Article 26 of
 the International Covenant Economic, Social and Cultural Rights. The CRPD as a whole,
 including but not limited to Article 12, requires substituted decision making to be replaced
 by supported decision making.

²⁰ Public discussion on the implementation of the CRPD in Uzbekistan http://www.nhrc.uz/ru/news/obsuzhdena-realizatsija-konventsii-oon-o-pravah-invalidov-v-uzbekistane accessed 01 November 2021

In regard to CRPD Implementation Process

- implement the CRPD provisions not only through national legislation but also all other
 necessary measures including court decisions and processes, effective law enforcement,
 and taking account of the jurisprudence of the UN Committee on Economic, Social and
 Cultural Rights, the UN Committee on the Rights of Persons with Disabilities and the
 quidelines of the Special rapporteur on the rights of persons with disabilities;
- establish a Regional Council regarding the self-realization of persons with disabilities;
- develop a national action plan and road map for the implementation of the CRPD in close consultation with persons with disabilities and the organizations of persons with disabilities. Sufficient budgetary allocations and clear implementation timelines should be provided for such a national action plan;
- explicitly and fully recognize and implement in law and in practice the human rights model of disability in line with the CRPD;
- develop indicators for measuring the progress in implementation of the CRPD;
- develop a national programme "Barrier-free environment" for study, work and free movement of persons with disabilities;
- undertake awareness raising campaigns across society about the rights of persons with disabilities and their contributions to the society;
- undertake trainings and capacity building about the obligations of the State under the CRPD for legal professionals, judges and prosecutors and the professionals working with persons with disabilities including medical staff and teachers. Organizations of persons with disabilities should be involved in the design of trainings of public officials;
- review and improve the system for collecting data on persons with disabilities. Collect, analyse and disseminate disaggregated data on persons with disabilities including sex, age, ethnicity, type of impairment, socio-economic status, employment, place of residence and the barriers faced by persons with disabilities in society. In particular, it is recommended to follow the methodology prepared by the Washington group of disability statics as recommended by the CRPD Committee.²¹ As the national population census is expected to take place soon, in 2023, it is the right to moment to obtain reliable statistical data on persons with disabilities, which is important for informed and targeted decision-making.

In regard to legislation

- clearly define discrimination on the ground of disability in law consistently with the definition provided by the CRPD; enact anti-discrimination legislation with relevant provisions on discrimination on the ground of disability;
- introduce into legislation the concepts of "reasonable accommodation" and "universal design"; and guarantees for unhindered access for persons with disabilities to justice;
- develop legislation concerning persons with disabilities in close cooperation with relevant NGOs and other civil society organizations, as was the case with the Law on the Rights of Persons with Disabilities;
- conduct an extensive review of national legislation, regulation and policies through the lens
 of the CRPD including but not limited the Law on the Rights of Persons with Disabilities,
 Civil Code, Labour Code, Law on Education and mental health related legislation. Involve
 CSOs in this process, particularly organizations of persons with disabilities. In this regard,
 use the general comments of the CRPD Committee to better understand the Convention
 provisions:
- bring in line with the CRPD the concepts of "persons with disabilities" and "discrimination on the ground of disability" in the current national legislation;
- prescribe in law precise instructions and measures to be taken by emergency authorities to protect persons with disabilities in the event of natural disasters or other emergencies.

²¹ The Washington Group on Disability Statistics (WG) promotes and coordinates international cooperation in the area of health statistics focusing on the development of disability measures suitable for census and national surveys. The use of a set of questions developed by the WG allows States to obtain more reliable statistical data on persons with disabilities. According to WHO over one billion people in the world live with some form of disability.

Quarantine measures (mandatory mask wearing or vaccination) during epidemics and pandemics should take into account particular needs and circumstances of persons with disabilities;

- guarantee through law an adequate standard of living for persons with disabilities. Article 39 of the Constitution of the Republic of Uzbekistan states that pensions and benefits should not be lower than the subsistence minimum, but the concepts of "consumer basket" and "minimum living wage", which are an important factor in determining the amount of pensions and benefits for persons with disabilities, have not yet been introduced;
- pay unemployment benefits (as is the case for people without disability) during the period of job search;
- restructure procedural legislation to allow persons with disabilities to be accommodated, supported and to be able to participate in court proceedings, including, incorporation into legislation provisions on individual mobility;

In regard to institutions and procedures

- establish and support with a sufficient budget a national human rights institution as an independent monitoring body for the implementation of the Convention and ensure its independence. It is of utmost importance to ensure effective and meaningful participation of representative organizations of persons with disabilities in the monitoring activity of such an institution;
- create mechanisms for meaningful and effective support and consultation with various organizations of people with disabilities, paying attention to diversity of persons with disabilities including persons with intellectual and psychosocial disabilities, autistic persons, women and children with disabilities, persons with disabilities living in rural areas and those requiring a higher level of support.
- it is important to ensure the independence of the organizations of persons with disabilities;
- establish an agency specifically authorized to solve issues of social support, including social support for persons with disabilities;
- establish a platform of social services where people with disabilities can apply for and receive social services;
- be guided by the principle "nothing about us without us" concerning disability rights work and involve in relevant institutions, to the extent possible, to ensure broad representation of the civil society working on disability rights including those with different types of impairment;
- create a data base of targeted assistance under the Ministry of mahalla and support for family;
- adopt a Regulation on personal assistants for persons with disabilities;
- in line with Article 9 of the CRPD, make social and economic infrastructure objects (schools, parks, hospitals, public transport, et.) accessible for person with all persons disabilities to visit, including as an example, those persons with guide dogs. Make Invataxi and minibuses with a ramp available to person with disabilities in wheelchairs.