

Mandate of the Special Rapporteur on the rights of persons with disabilities

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Excellency,

I have the honour to address you in my capacity as Special Rapporteur on the rights of persons with disabilities, pursuant to Human Rights Council resolution 35/6.

In this connection, I would like to bring to the attention of your Excellency's Government information I have received concerning draft legislation "On the Rights of Persons with Disabilities".

At the outset I would like to welcome the commitment of your Excellency's Government to improve the rights of persons with disabilities through establishing a new legislative framework.

I have been informed that in March 2018, the Association of Disabled People of Uzbekistan, uniting over 30 civil society organizations of persons with disabilities, developed a proposal for a bill "On the Rights of Persons with Disabilities" (hereinafter "the draft Bill") and submitted it to the Ministry of Health, with a request to establish a working group to develop a uniform draft Bill.

From April 2018 to July 2018, a working group formed of representatives of the Association of Disabled People of Uzbekistan and Government authorities developed a draft Bill "On the Rights of Persons with Disabilities".

Subsequently, the Ministry of Health made further amendments and modifications to the draft and submitted it to the Cabinet of Ministers. It has been reported that some of the amendments made at this stage reversed the earlier draft that was more in line with international standards, including with the Convention on the Rights of Persons with Disabilities, signed by Uzbekistan in February 2009.

Following an objection made in the press by the Association of Disabled People of Uzbekistan, the Cabinet of Ministers returned the draft law to the Ministry of Health for revision. It has been reported that the Ministry of Health did not involve civil society organizations in their revision of the Bill prior to submitting it for the second time.

In early 2019, the Cabinet of Ministers submitted the draft bill for consideration and adoption by Oliy Majlis (Parliament). It was passed on first reading in late August. I have been informed in early November that the draft Bill has already been passed to the Senate.

I submit these comments in a spirit of cooperation and as an opportunity to strengthen the framework of the country for the protection of the rights of persons with disabilities, and to bring the framework in line with human rights standards.

In this connection, I commend Uzbekistan for having signed the Convention on the Rights of Persons with Disabilities (CRPD) in February 2009. I further welcome your Excellency's Government's acceptance of recommendations about ratification of the CRPD made during the 3rd UPR cycle in May 2018. In line with the Vienna Convention on the Law of Treaties (VCLT), signing creates an obligation to refrain, in good faith, from acts that would defeat the object and the purpose of the treaty. Moreover, I highlight that the CRPD was adopted as a resolution by the General Assembly, and has standing as the most progressive interpretation of human rights standards for persons with disabilities. These rights are furthermore guaranteed by all other human rights treaties, including the ones ratified by Uzbekistan, such as the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Elimination of All Forms of Discrimination Against Women, and the Convention against Torture, and the Convention on the Rights of the Child.

Concerns and recommendations

Retention of a medical model of disability

Although the Bill makes important efforts to address discrimination and protect rights, it does not reflect the paradigm shift of the CRPD as it remains strongly based on medical model of disability, meaning that the emphasis is on the individual impairments instead of addressing the structural barriers that limit the participation of persons with disabilities. The Bill's retention of a medical model of disability is reflected first of all in the definition of a person with disabilities, which according to Article 4 of the draft Bill is "a person with stable physical, mental, intellectual or sensory impairment, the presence of which impedes his or her ability to live in the community on an equal basis with others". Such a definition attributes to the impairment the limitations to participation; when instead they should be attributed to the social barriers that in interaction with the impairments hinder the opportunities of persons with disabilities. This medical approach is prevalent throughout the draft Bill, including in several of its definitions and the provisions on rehabilitation (Articles 4, 30, 31, 32), social and medical assessments for adults and for children (Articles 4, 29), and social protection (Articles 4, 34). These provisions, reflect merely on medical considerations, as they focus mainly on assessing and understanding the impairment.

While, I welcome the attention to rehabilitation in Articles 4 and 30 of the draft Bill, I remain concerned that Article 30 relies on a very medicalized approach to rehabilitation, focused on "fixing" a person's impairment as a precondition for their participation in society. In this connection, I underline that the draft Bill's notion of "social rehabilitation" rests on an out-dated approach to rehabilitation that has been contested and it should therefore be revised. By contrast, under a human rights approach to disability, rehabilitation should be understood as broad set of interventions which are

interrelated with the enabling or restrictive conditions of the environment (A/HRC/40/32).

A human rights approach to disability moves away from the charitable and medical approaches, accordingly persons with disabilities are considered as rights holders, rather than as mere receivers of protection, rehabilitation and welfare. A human rights approach to disability centers on the environmental and social barriers and obstacles that need to be eliminated in order to ensure the full and active participation of persons with disabilities in society on an equal basis with others. Legislative efforts under the human rights approach are therefore aimed at removing such barriers. I encourage your Excellency's Government to take the opportunity to ensure that the draft Bill adopts a human rights approach to disability, as the one embodied in the CRPD, by focusing on addressing and eliminating discrimination and barriers and supporting persons with disabilities to participate actively in society. This entails reviewing all existing legal provisions related to the civil, political, economic, social and cultural rights of persons with disabilities, which would need to be reflected in the current draft.

Discrimination and equality

One of the key elements of an inclusive legal framework for persons with disabilities is the existence of a framework on equality and non-discrimination that prohibits discrimination on the basis of disability in all areas of life and ensures that reasonable accommodation is provided to persons with disabilities. While I welcome the draft Bill's references to discrimination and equality, the definitions provided under the draft Bill remain limited.

To ensure the Bill's adoption of a human rights approach to disability, one that would be in line with the CRPD, it would be important to expand the definition of discrimination the draft Bill to include reasonable accommodation as a measure to promote equality and eliminate discrimination. Reasonable accommodation means providing all the necessary and appropriate modifications and adjustments to accommodate a person's individual characteristics or differences, so as to ensure that persons with disabilities can enjoy all human rights, including accessing infrastructures, programmes and services, on an equal basis with others (A/71/314). In other words, the duty to provide reasonable accommodation entails a duty to remove barriers created by physical structures, policies and practices where these would place a person with disability at a disadvantage when compared with others. Under international human rights standards, the denial of reasonable accommodation would constitute discrimination.

As I have explained in one of my thematic reports, ensuring comprehensive accessibility and sustainable, consistent support services will not happen overnight. Therefore it is critical to apply the principle of non-discrimination immediately, including the provision of reasonable accommodation, so that persons with disabilities can access and benefit from policies and programmes right away (A/71/314).

Social assistance

The draft Bill's provision on social assistance covers a broad range of assistance aimed at securing the well-being of persons with disabilities. However, some of the provisions in Article 34 rest on a traditional disability-welfare approach which considers disability as a medical problem. I am particularly concerned at what appears to be a retention of institutions under Article 34 of the draft Bill, under the wording of "specialized inpatient facilities". This provision is in clear contradiction with the right to equality and non-discrimination under international human rights standards.

I would like to encourage your Excellency's Government to move towards intervention and social protection systems that promote active citizenship, social inclusion and community participation, while avoiding dependence and segregation. The ultimate aim should be to achieve the right to live independently and be included in the community. In this connection, I would like to refer your Excellency's Government to the recommendations towards key elements in a disability-inclusive social protection framework contained in my thematic report to the General Assembly in 2015 (A/70/297).

Right to Housing

I welcome the draft Bill's attention to the right to housing, however I would like to stress that social housing does not mean segregated buildings for persons with disabilities, whether by design or in practice. It would therefore be important to provide an explicit reference to the right to live independently in the community, as is guaranteed by international human rights law. In this connection, I would like to stress the importance of including a reference to individuals' will and preferences in choosing their place of living. Any support services and arrangements must be designed so as to enable direct choice and control by persons with disabilities. This would require support to living and being included in the community to prevent isolation or segregation from the community. Persons with disabilities should have the opportunity to choose where and with whom to live, and not be obliged to live in a particular living arrangement (A/HRC/34/58). The new law should guarantee to persons with disabilities the opportunity to plan and direct their own support; who provides it and how and whether it is provided in disability-specific services or in services offered to the general public. This would entail an obligation on the State to facilitate the transition of persons with disabilities from segregated facilities to home- and community-based residences.

Lack of inclusive education requirement

While the draft Bill contains provisions on inclusive education, it does not include an obligation to remove and phase out segregated, institutionalized and home-based schooling for children with disabilities. Children with disabilities and their families require different types of support services in education. This includes assistive technology, communication support and individualized education plans, and I encourage your Excellency's Government to ensure that support is provided and to ensure an

obligation to phase out segregated and institutionalized schooling for children with disabilities.

Right to employment

The draft Bill's Article 40 provides that "A person with a disability has the right to work in organizations with normal working conditions, at specialized enterprises, in workshops and at sites where persons with disabilities work, as well as to carry out individual-labour or other activities not prohibited by law".

Under the general right to equality and non-discrimination in international human rights law, the seemingly exhaustive denomination of which organizations people with disabilities have the right to work in seems unduly restrictive.

Participation of persons with disabilities in the drafting

I welcome the initial involvement of organizations of persons with disabilities in the drafting process. However, I regret that many of their proposals have not been taken into consideration in the second review of the draft. Participation 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. The active and informed participation of different groups, including persons with disabilities, is a requisite of a human rights based approach that ensures active citizenship, good governance and social accountability.

As I have noted in a report to the Human Rights Council, such participation can have a significant impact on policy and law affecting persons with disabilities, since persons with disabilities are best positioned to identify their own needs and the most suitable policies for meeting them. Their participation ensures that policies and programmes are devised on the basis of their needs and preferences. In addition, such involvement promotes agency and empowerment, a sense of ownership and responsibility vis-à-vis public decisions and may contribute to enhanced public trust (A/HRC/31/62).

In this context, the draft Bill's own provision in Article 11 on involving persons with disabilities in the social and political life of society and the State should include a reference to the right to be consulted and involved in public decisions.

I strongly encourage your Excellency's Government to revise the Bill in light of the above observations and to continue its consultation and involvement of persons with disabilities through their representative organizations to ensure that the Bill provides a framework for the rights of persons with disabilities in line with international human rights law, including the CRPD.

Please provide any additional information and/or comment(s) you may have on the above-mentioned allegations.

This communication, as a comment on pending or recently adopted legislation, regulations or policies, and any response received from your Excellency's Government will be made public via the communications reporting website within 48 hours. They will also subsequently be made available in the usual report to be presented to the Human Rights Council.

Please accept, Excellency, the assurances of my highest consideration.

Catalina Devandas-Aguilar
Special Rapporteur on the rights of persons with disabilities