# Submission on Situation in Ukraine, reference CRPD/27th session

from

**All Ukrainian NGO Coalition for Persons with Intellectual Disabilities**

**(which brings together 118 NGOs in all regions of Ukraine, representing 14,000 families of people with intellectual disabilities)**

**On the rights of Ukrainians with Intellectual Disabilities**

## The present Submission is more concentrated on the effects of the war on Ukrainians with Intellectual Disabilities (further mentioned as ID) and observations of different aspects of those human rights which are guaranteed by CRPD Article 11. Situations of risk and humanitarian emergencies.

**Changes in human rights of persons with ID after CRPD ratification**

It should be noted that The Coalition considers that during the years after the CRPD ratification in Ukraine (2010) implementation of the human rights of Ukrainians with ID was changed in the way overviewed below.

**Improvements** could be seen regarging human rights guaranteed by:

**CRPD Article 24**. Education, due to the efforts of the Parliament and the Government on the steady growth of both legislation and practices of inclusive education which became partially accessible to children with ID along with those with the other disability types.

**CRPD Article 26.** Some new rehabilitation centers for Ukrainians with ID were established owing to the efforts of some municipalities, but it should be noted that the new municipal rehabilitation centers have no sustainable financial support guaranteed.

**CRPD Article 27**. Supported employment cases are promoted as the demonstrative cases owing to the efforts of civil society organizations, disabled people organizations, social enterprises.

**Deteriorations** could be seen regarging human rights guaranteed by:

**CRPD Article 4.3.** Numerous requests of The Coalition to the national authorities on the need to develop and approve of the special procedures of the consultations with persons with ID with the use of Plain Language were ignored, the view of persons with ID is never taken into account.

1. g., the new plan of post war recovery of Ukraine <https://www.kmu.gov.ua/storage/app/sites/1/recoveryrada/ua/social-protection.pdf> was developed without any consultations with Ukrainians with ID which resulted in the big gap in the Plan, namely, the lack of a plan to deisntitualise care of persons with intellectual disability.

Another example - in 2021 Kyiv city Department of Social Policy had decided to change the Director of the municipal rehabilitation centre “Tramplin” for Persons with ID. Although the service users with ID and their parents asked to remain the acting director, their view was ignored which is allowed by Ukrainian legislation, users with ID got no explanations why. The Coalition received numerous complaints about deterioration of “Tramplin” services thereafter.

**CRPD Article 19.** The program of day care services for adults with ID based on 38 DPOs and financially supported from the state budget (public finances) since 2008 was closed in 2019, more than 300 persons with ID lost community based services.

**CRPD Article 25.** Access to health care was significantly deteriorated by the Psychiatric care reform held in Ukraine in 2020: many outpatient mental health facilities were cut, it became more difficult to be received by the Psychiatrist on whom the social protection of a person with ID is dependent as all the disability fees and access to social services are still dependent on the medical (Psychiatric) solutions.

**CRPD Article 31.** Statistics and data collection being not perfect before, was changed in such a way that no figures about the number of persons with intellectual disability could be provided. The last time the official request of The Coalition to the Ministry of Health of Ukraine on the number of persons with ID was answered in 2013.

**Situation on human rights of persons with ID before the war**

Still, the key problems on systemic discrimination of Ukrainians with ID remained from 1990s, the Soviet times, and are institualization of care and legal incapacity and guardianship systems.

Just before the Russian invasion, on the 1 Feb 2022, the UN Human Rights Monitoring Mission in Ukraine issued a report “The human rights situation of persons with intellectual and psychosocial disabilities in Ukraine” following monitoring the human rights situation of persons with intellectual and psychosocial disabilities. The briefing note presented the results of this work described human rights violations and concerned affecting persons with intellectual and psychosocial disabilities in Ukraine and provided recommendations, see <https://ukraine.un.org/sites/default/files/2022-07/BRIEFING.>

The main conclusions of the Mission about human rights situation of Ukrainians with Intellectual Disabilities (further mentioned as ID) and Psyhosocial Disabilities are the following:

*Persons with intellectual and psychosocial disabilities are the group that is most represented in institutions in Ukraine. They continue to be placed in long-term care facilities, which remain almost the only option for accommodation and social care. Many facilities accommodate over a hundred residents, without the capacity to provide individualised social services and support. Persons living in such facilities are cut off from local communities, the social and medical services provided there, and official employment. Only in rare examples can they return to living in the community. Most of the persons are trapped in long-term care facilities for life. Grave human rights violations, such as torture, ill-treatment, involuntary medication, forced labour and deprivation of personal liberty occur in such institutions. Denial of the right to private life and family life, as well as the right to sexual and reproductive health, is another pervasive human rights concern in long-term care facilities.*

*A decade after Ukraine ratified the Convention on the Rights of Persons with Disabilities, no measures have been taken to start the implementation of article 12, on equal recognition before the law. Denial of legal capacity continues to be widespread in Ukraine and more than 40 thousand people are not allowed to make decisions about their own lives. A human rights violation per se, the denial of legal capacity of persons with intellectual and psychosocial disabilities also affects other human rights. The law explicitly prohibits incapacitated persons to vote in elections and referendums, establish or join civil society organizations and political parties, dispose of their property and social payments.*

*A complete move away from institutionalising persons with intellectual and psycho-social disabilities and amending the civil legislation on legal capacity could take years or decades. An important start to this process are the efforts of the Government of Ukraine to develop access to social services in the community, which are the precursors of these two major reforms. The briefing note contains recommendations to address the human rights concerns outlined in the paper, including for deinstitutionalisation of persons with intellectual and psycho-social disabilities and reform of the system that regulates legal capacity, and suggests possible directions for cooperation between government, international partners and civil society.*

**Negative war effects on human rights of Ukrainians with ID**

The report by the Office of the High Commissioner for Human Rights (OHCHR) “Situation of Human Rights in Ukraine in the context of the Armed Attack by the Russian Federation” which covers violations of international humanitarian law (IHL) and international human rights law that have occurred in the course of the ongoing armed attack by the Russian Federation against Ukraine within the period from 24 February 2022 until 15 May 2022 mentions about persons with disabilities:

*The situation of adults and children with disabilities, both residing in communities and long-term care facilities, has also deteriorated. OHCHR observed that persons with disabilities often lack access to bomb shelters and evacuation trains and have to rely on the assistance of their family members and other people.*

In addition to those two facts, namely, lacking access to bomb shelters and evacuation trains, persons with intellectual disabilities survived the special negative effects on their psychological condition leading to the onset of their challenging behavior and often aggression to the care giver (mainly mother). Their daily routine ruined as all rehabilitation and social services stopped. All the fragile system of care that their families in partnership with service agencies had been developing for decades broke, the new system would hardly be build within the next months. So, both a person with ID and the family are surviving a double beat irrespective of their place of residence - the territory of active war actions or a relatively calm area.

So, below is the description of the **negative war effects on Ukrainians with ID that need help from the UN Committee** on the Rights of Persons with Disability as the rights of Ukrainians with ID are violated, presented per CRPD articles.

**Article 2.** In the translation of the definition “communication” the world “plain language” is translated with a mistake into the Ukrainian version of CRPD. As a result, plain language is not legilised in Ukraine and not used to inform persons with ID and to arrange a special way of communication with them.

In the war time it affected provision of information on safety issues, many persons with ID not realizing the war dangers may be subject to the risk to life and health in the war situations like bombing, evacuation, occupation, etc.

**Article 9.** as above, while mentioning the “the public signage”, the Ukrainian translation of CRPD refers the expression “in easy to read and understand forms” to Braille, conjunction “and” was ommitted. Thus, “easy to read” is treated as the characteristic of Braille and not as a separate format of information presentation for persons with intellectual disabilities. As a result, in the war time not a single piece of information was produced by the authorities for persons with intellectual disabilities in a format accessible to them.

The lives of persons with intellectual disabilities are at risk because of the inaction of the Parliament which was addressed by The Coalition asking in 2020, 2021 to legalize the notions “plain language” and “easy to read” in order to start and produce information in the accessible format starting with that on personal safety issues in the situations of risk and humanitarian emergencies.

**Article 11.** Those persons with ID and their families which live in the front line territories and nearby need special attention, they need special programs of safety protection and special support to evacuation. Those persons with ID and their families who lost their living space suffer not only from the fact itself, but also need the new permanent accommodation as soon as possible in a more safe place. This principle should become an obligatory part of the state policy.

**Article 19.** Lack of the alternatives to institutional care is made specially acute in the time of war. Many family care givers of persons with ID may perish, be wounded, all of them suffer from additional burning out and may lose capacity to provide care. Far more persons with ID may need external care, mainly the professional one than it was before the war. Thus, the Government had simplified the procedure of the intake of legally incapable persons to the institutions through introduction of appropriate changes to their tyical statutes approved of by the decrees of the Cabinet of Ministers of Ukraine as of 14/12/2016 No957 and 2/09/2020 No 772. Both the quality of care and the quality of life will definitly drop as the new building will not appear, the institutions will be overcrouded with the new flow of users, the staff will be overloaded. Still, no solution was made by the national authorities to reinforce the family placement for the care of a person with ID as is considered by issue X.I.5 of the National plan of action on implementation of the UN Convention on the rights of persons with disabilities till 2025 approved by the Cabinet of Ministers of Ukraine on 07/04/2021 No 285-p.

Article 28. The war caused economic hardships and put barriers to access to social services. Numerous investigations identified the view of the families taking care of a Ukrainian with ID that they excercise extreme poverty, they suffer from the lack of supportive services. All has to be addressed by the Ukrainian social policy.

Article 32. So far, the needs of persons with intellectual disabilities are not among the priorities of the international assistance to Ukraine in disability area. By the urgent needs we mean here the need to be supported with the living space for those persons with ID and their families who lost it (like the families from Mariupol), the need for the DPOs to be supported to restore their services to Ukrainians with ID on regular basis until the national and local authorities in Ukraine are capable to do so.

The DPOs and non-governmental social service suppliers need to be supported to provide community based day services and introduce the supported living programs (group homes, foster family care) to prevent a significant growth of the institutional placement of persons with ID in Ukraine during and after the war.

**Post-war reconstruction of Ukraine**

The Plan of the post-war reconstrction of Ukraine should meet the following needs:

1. Be developed after a close consultation with Ukrainians with ID among other stakeholders according to special procedures accessible to them with the use of plain language to be developed.
2. The Plan shoud obligatory include a separate Program or at least Project on prevention of institualization of Ukrainians with intellectual and psychosocial disabilities.