



Joint contribution of disability rights organisations to the 2021 EU-Ukraine Human Rights Dialogue

This submission focuses on the situation of children in institutions and the status of the deinstitutionalisation process in Ukraine.

Disability Rights International (DRI), European Network on Independent Living (ENIL) and Validity Foundation commend the commitment of European Union to promote the fundamental rights for persons with disabilities and in particular its commitment to deinstitutionalisation of children globally.

Human rights violations against children in institutions

According to UNICEF, at least 82,000 children are segregated from society in Ukraine's orphanages and boarding schools.¹ However, there are significant discrepancies among different data sources and the actual number of institutionalized children may be much higher.² Data collection processes lack of oversight and this leads to sometimes drastic inaccuracies.

An estimated 90-98% of children in orphanages have at least one living parent.³ Ukraine's growing rate of institutionalization is in reality fueled by a severe lack of community-based alternatives, a lack of support to families, and stigma against persons with disabilities.

In its [report](#) published in 2015, Disability Rights International exposed human rights violations faced by disabled children living in Ukrainian institutions – forced labour, routine beatings, sexual abuse, forced abortions, drugging, shackling, exposure to brothels operating from orphanage basements and trafficking for illegal organ transplants. Vulnerable children and their families often do not have access to community-based support, leading to their placement in institutions.

¹ TransMonEE UNICEF, *supra* note **Error! Bookmark not defined.**

² Pinning down numbers is hard because of the lack of a common understanding as to what constitutes an 'institution' and might be otherwise labeled a residential home, a small group home, a family-like arrangement, a boarding school, a mental health or treatment facility, etc. If any placement outside a family (biological family or kinship care) is considered an institution, numbers are much higher than official statistics would indicate.

³ Liudmyla Riabokon, *I want my mommy*, THE DAY (Oct. 11, 2005), available at <http://www.day.kiev.ua/en/article/day-after-day/i-want-my-mommy>. See also, Csaky, *supra* note **Error! Bookmark not defined.**, at 5.



Perhaps most serious of all, DRI's investigation shows that Ukraine's orphanages are a gateway to life-long institutionalization for children with disabilities. Children with disabilities rarely "graduate" from orphanages and are instead shuffled between adult wards in orphanages, psychiatric hospitals, and adult social care homes. Children who do graduate from orphanages face a harsh life on the streets— where suicide, trafficking, drug addiction and re-institutionalization are constant threats.

All children have the right to live and grow up with a family.⁴ The preamble of the Convention on the Rights of the Child (CRC) recognizes that for their "full and harmonious development", all children "should grow up in a family environment." Reflecting the CRC standards, the UN Convention on the Rights of Persons with Disabilities (CRPD) recognizes that the best interests of the child are the paramount consideration in all decisions affecting them (Article 7(2)), and places clear obligations on States to protect the right to family life (Article 23) and to live and be included in the community (Article 19). In the General Comment No. 5, the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) unequivocally states that "[f]or children, the core of the right to be included in the community entails a right to grow up in a family."⁵

There are no exceptions to the right to grow up in a family for any child, and the provision of care never justifies the denial of this right. All children, regardless of disability or social background, have the same right and should be given the same opportunity to have their basic emotional needs met by living and growing up in a family and establishing the emotional bonds necessary for their healthy development.

Concerns about the status of the reform

In the aftermath of DRI's report, the Government of Ukraine embarked on a promising process of transformation of its national care system for children by adopting the National Strategy of Reforming the System of Institutional Care and Upbringing of Children (2017-2026; henceforth deinstitutionalisation strategy) and the Action Plan for the implementation of its first stage. Despite progress, the reform so far has not been comprehensive and has been met significant challenges that serve to preserve the current institutional system and risk rolling back the overall process of deinstitutionalisation.

⁴ See Eric Rosenthal, "The Right of All Children to Grow Up with a Family under International Law: Implications for Placement in Orphanages, Residential Care, and Group Homes", 25 Buffalo Human Rights Law Review 101 (2019) (describing the development of the right to family under international law and summarizing research findings on the need and ability of all children to grow up in a family).

⁵ U.N. Secretary-General, *General Comment No. 5 (2017) on living independently and being included in the community*, U.N. Doc. CRPD/C/GC/5 (Oct. 27, 2017), para. 37. [hereinafter General Comment No. 5] (emphasis added).



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VALIDITY

On 16 January 2021, the Ministry of Social Policy started a public consultation concerning a new Cabinet of Ministers draft order, aiming to amend the deinstitutionalisation strategy. If adopted, the draft order would have the effect of excluding special boarding schools, education and rehabilitation centres and sanatoria (boarding schools) from the scope of deinstitutionalisation in the country. This will result in 51.089 children being left in various types of institutions across the country and will officially legitimise discrimination based on disability, allowing for the ongoing institutionalisation of such children and violation of their right to family life. Deprivation of family life on the basis of disability and placement of children in residential facilities amounts to discrimination and must be prohibited by law.

Furthermore, the order would suspend the coming into force of the legal moratorium on the placement of children under the age of 3 in baby homes until 2026. The effects institutionalisation can have on infants can be irreversible. Children who grow up in institutions can experience attachment disorders, cognitive and developmental delays, and a lack of social and life skills leading to multiple disadvantages during adulthood⁶. Long-term effects of living in institutions can include severe developmental delays, disability, irreversible psychological damage, and increased rates of mental health difficulties, involvement in criminal behaviour, and suicide⁷.

There should be no exceptions to the right to grow up in a family for any child, applying the principle of non-discrimination. The need for care, support services, treatment, socioeconomic status or education can never justify violating a child's right to family, and deprivation of family life with reference to impairment or disability status. Such actions amount to discrimination under international law and must be prohibited within domestic Ukrainian law.

By excluding some categories of children from the deinstitutionalisation strategy, the Government is failing to discharge its legal obligations towards some of the most vulnerable and forgotten children in Ukraine. The proposed order also contradicts the direction of travel in childcare reform, with Ukraine notably departing from the direction being pursued by its neighbours and across Europe as a whole.

Definition of institution

The Ukrainian disability strategy defines institutions as places “where more than 15 children live at the same time”. This definition is not in compliance with the existing human rights standards.

⁶ Nelson, C., Zeanah, C., et al. (2007) “Cognitive recovery in socially deprived young children: The Bucharest early intervention project”. *Science* 318 (no.5858); 1937–1940 (21st December 2007)

⁷ Mulheir, G. et al. (2012). Deinstitutionalisation – A Human Rights Priority for Children with Disabilities.



In 2020, the Lancet Commission, composed of leading children’s rights experts, defined an institution for children as “a publicly or privately managed and staffed collective living arrangement for children that is not family based. These institutions include orphanages, children’s institutions, group homes, infant homes, children’s villages, and similar residential settings for children”⁸. This definition is closely aligned with developing international standards in this area, namely the UN Convention on the Rights of Persons with Disabilities.

In its General Comment No. 5 concerning Article 19 of the CRPD, the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) unequivocally states that “[f]or children, the core of the right to be included in the community entails a right to grow up in a family”. It is important to note that the key language of the General Comment No. 5 applies to all children, and not just children with disabilities. Article 23(4) CRPD states that “in no cases shall a child be separated from parents on the basis of a disability either of the child or one or both of the parents.” This article protects “children” from family separation if their parents are disabled – or are perceived to be unable to keep or care for their children. Instead of breaking up the family, the CRPD requires that support is provided to the family.

The General Comment no.5 of the CRPD Committee in paragraph 16(c) states that:

“Both independent living and being included in the community refer to life settings outside residential institutions of all kinds. [...] Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. “Family-like” institutions are still institutions and are no substitute for care by a family.”

In view of the concerns set out above, the submitting organisations call on the European Commission to incorporate the following recommendations in their dialogue with Ukrainian Government:

- 1. Ensure that deinstitutionalisation reforms are fully grounded in international human rights law norms, notably in compliance with the UN Convention on the Rights of the Child and UN Convention on the Rights of Persons with Disabilities.**
- 2. Explicitly and publicly commit to promoting the right to family life for all children, including children with disabilities, and achieving full deinstitutionalisation to the maximum extent possible within available resources.**
- 3. Withdraw the proposed “Order on Amendments to the National Strategy for Reforming the System of Institutional Care and Upbringing of Children 2017-2026”.**
- 4. Develop a clear definition of “institutional care” in the legislation, in conformity with international human rights law. This definition should prohibit the use of concepts that hide institutional care and hinder deinstitutionalisation reform (i.e. pseudo-reform through institutions’ formal names change, or masking the institutions as the educational facilities, etc., which has already taken place), and should encompass all settings (public and private) that are not family based.**



ABOUT THE SUBMITTING ORGANISATIONS:

Disability Rights International (DRI) is a human rights advocacy organization dedicated to the protection and full community inclusion of children and adults with disabilities worldwide. DRI documents human rights violations, educates and engages the public through media campaigns, trains and supports activists working to bring change, and conducts strategic litigation to enforce the rights of people with disabilities. DRI's Worldwide Campaign to End the Institutionalization of Children is dedicated to promoting the recognition and enforcement of the right of all children to live and grow up with a family and not in any form of institution, orphanage, or group home. DRI is an organization led by people with disabilities and their families. **Website:** www.driadvocacy.org.

The European Network on Independent Living (ENIL) is an international network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organisations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross-disability and self-determination. **Website:** www.enil.eu

The Validity Foundation – Mental Disability Advocacy Centre is an international non-governmental human rights organisation which uses legal strategies to promote, protect and defend the human rights of persons with intellectual disabilities persons with psychosocial disabilities in Europe and Africa. Validity holds special consultative status with ECOSOC and participatory status at the Council of Europe. **Website:** www.validity.ngo.