

## **Addressing the situation of children with disabilities in residential care as part of the Ukraine response**

### **Background and overview**

On 7 July 2022, the Better Care Network (BCN) and Disability Rights International (DRI) organised **an event with disability and child protection actors focused on the situation of children with disabilities in residential care in Ukraine** (including those children who have been returned to families or evacuated from facilities since 24 February 2022). The impetus for the event came about as a result of multiple discussions with actors involved in the response who highlighted the need to identify concrete programmatic recommendations to address the current gaps, needs and challenges, the interventions and services that are required, and how actors can work together to better respond to them. It was with the aim of identifying concrete programmatic recommendations that shaped the purpose of the event.

The event was focused on practitioners, technical experts, and policymakers, and aimed to hear from care, protection, and disability actors working in Ukraine and to explore with them how to best direct the support and funding required to address the significant challenges faced by children with disabilities in residential care.

### **Event sessions**

The event commenced with a brief overview from DRI of the key challenges faced by children with disabilities in residential care as part of the Ukraine response. This was followed by four core sessions:

- **Session 1:** Overview of mapping, registration, and assessment
- **Session 2:** The immediate life-saving measures needed to protect children in institutions
- **Session 3:** Community services to support reintegration and family-based care: What is required?
- **Session 4:** Integrating systems reforms into the emergency response

In each session, the gaps, needs, challenges, and required programmatic actions were presented. Participants were encouraged during the event to make additional recommendations both verbally and on Jamboards that corresponded with each session. It is these recommendations provided by the presenters as well as the participants that form the basis of this report.

### **Presenters, moderators and participants**

In total, 73 individuals participated. Participants represented international donor governments, international non-governmental organisations (NGOs) and UN agencies, and Ukrainian national NGOs and civil society organisations. The event was moderated by representatives from BCN, DRI and USAID. Presenters included Naira Avetisian (UNICEF

Ukraine, Chief of Child Protection, Session 1); Dr. Seth Keller (Neurology Associates of South Jersey, Neurologists, Session 2), Marisa Brown (Adjunct Faculty, Georgetown University, Session 2); Marianna Onufryk (Head of Family for Children with Disabilities, Session 3); and Galina Bulat (Lumos, Director of Ukraine Country Office, Session 4). The event was interpreted in English and Ukrainian.

### **Background and summary of key challenges faced by children with disabilities in residential care as part of the Ukraine response**

Ukraine has a history of institutionalisation of children, which started during the Soviet era, thereby predating the current crisis. Until 2015, children with disabilities, children without disabilities, children from low-income families, and children of Roma origin, as well as other groups of children were placed in institutions and received State-funded care. Since 2015, changes have occurred due to the launch of a de-institutionalisation reform process. However, children with disabilities have been largely excluded from the de-institutionalisation reform, which has led to their increased marginalisation and invisibility. The medical model of disability, segregated facilities, and the widespread belief that institutionalisation is the only way to ‘care’ for children (and adults) with disabilities have resulted in a policy of institutionalisation that has resulted in the institutionalisation of thousands of children and young adults with disabilities.

Since 24 February, a triage approach has been employed in which children with less severe disabilities have been evacuated across borders, while children with more complex disabilities have either been moved to institutions in safer locations in Ukraine or have remained in institutions in occupied areas or areas experiencing active conflict. The reasons that have been provided for not evacuating these children include insufficient staffing numbers to accompany children and a lack of transportation, highlighting a system of care that has been inadequate.

There is also a lack of data with regards to the number of children living in institutions as well as those sent home from institutions. Even before the war, there were conflicting official reports as to the number of children in different kinds of institutions and under different ministries. The lack of information on exact numbers and locations of children is particularly serious, at this time, since the government has “sent” home large numbers of children since the start of the war. According to UNICEF, there was a similar process of sending home children during the COVID pandemic when more than 30,000 children were sent home and local social work authorities lack resources to track the safe placement of these children. UNICEF mentioned that more than 40,000 have now been sent home since the start of the war. The lack of reliable information about the whereabouts and immediate needs of these children presents an immediate threat to their safety and well-being.

While there are immediate needs and health risks to children placed in institutions, international support to institutions has limited efficiency and is harmful in the long-term. Any funding directly to residential facilities for children perpetuates the system of institutionalisation. General Comment No. 5 of the UN Committee on the Rights of Persons

with Disabilities strongly advises against direct support of institutions for this reason. The solution is to support families and communities to care for their children.

### **Session 1: Overview of mapping, registration, and assessment**

It is essential to understand the needs of children with disabilities in residential care to plan for the provision of services to support these children and their families. A key challenge faced in Ukraine is the prevalence of the medical model and charity model of disability combined with a limited understanding of the social model. The dangers of the medical model are exemplified by the profession of “defectology” that labels a child by his or her deficits – and assumes that once such assessment at a given time in the child’s life would determine the child’s fate for the long-term. Thus, children labelled “uneducable” at age four may then be denied an education throughout their childhood. It is not only a matter of willingness to change the system, but also the attitudes and behaviours of how children with disabilities and their care are perceived. To change mindsets, it is essential to show appropriate models that support the prevention of unnecessary separation and promote family-based care as opposed to institutional care.

In early 2018, **159,044 children with disabilities under the age of 18 years** were registered in Ukraine (approximately 2 percent of the total child population of the country). This number is most likely an underestimate and pertains specifically to those children who have disability status. It is challenging to obtain accurate figures of children with disabilities nationally or children with disabilities in residential care. The most recent figure provided by the government is around 90,000 children in residential care. However, no unified database exists. In Ukraine, institutionalisation is used as a strategy by the State to mitigate family poverty and family migration, and to address the needs of children with disabilities, and other vulnerable categories of children. There is also a high rate of infants (children between 0-3 years of age) in residential care. COVID-19 and the 2014 conflict have further strained the socio-economic conditions of many families in Ukraine, which has resulted in an increase in children being referred to residential care, including to boarding schools where they perceivably gain a better education. The unnecessary separation of children from parental care is an attitude that is reinforced by poverty, social exclusion, stigma, and discrimination and leads to further family vulnerability.

The government of Ukraine prioritises national funding for residential care facilities as opposed to other forms of alternative care, such as family-based care or community social services. De-institutionalisation requires increased budget allocation as well as a comprehensive assessment of each existing institution and each individual child. Such assessments are required to support the reintegration of children into family-based care and to prevent further institutionalisation.

A comprehensive reform agenda is critical. Prior to the current situation, there were various reforms under way in Ukraine: decentralisation, de-institutionalisation, and healthcare reform; however, these reform processes were not linked to one another. To prevent the institutionalisation of children, particularly those with disabilities, decentralisation that supports families and communities, and includes preventive measures is essential. Integrated

social services requires a change in mindsets, which is possible, but it is firstly necessary to provide local authorities with the tools to support children with disabilities in families and communities.

**The total number of children sent back to their families according to some sources since 24 February is around 43,000**, but it is not clear (1) how many are children with disabilities and (2) whether there was any follow-up to ensure they were safely moved to family-based care where essential supports are available to meet their most basic needs. Given the lack of community-based care or social work services in many areas of Ukraine, immediate action is needed to protect these children. This includes efforts to identify where children with disabilities in residential care or in the community are located to ensure they receive protection for their health and safety. Families of children with disabilities should be supported to prevent possible institutionalisation or re-institutionalisation (for those who returned home from institutions). Immediate action is needed to introduce and promote family-based alternative care options for children with disabilities, for instance, specialised foster care. Children living with disabilities require a continuum of services that support their care. A strong gatekeeping system is necessary at the community level that includes services that provide timely support to families to prevent unnecessary separation, early intervention, referral and service provision, and case management. It is necessary to support the Ukrainian government in these areas.

### ***Key Recommendations***

- Facilitate a mapping of existing institutions and assessment of the needs of children living in institutions.
- Identify and assess the needs of all children discharged from institutions since the start of the crisis. Ensure that families have access to information and resources to provide essential support for the health and safety of these children. Compare lists of children in institutions and children discharged from institutions to identify gaps that require follow-up.
- Establish an online database to gather and analyse data on children in institutions.
- Collect data across the response that are disability disaggregated to inform evidence-based programming and advocacy.
- Establish an assessment system to identify children with disabilities at birth, including the supports needed within families to raise the child in family-based care in their community. For children placed in institutions, assessments should identify supports necessary to return children to families, extended families, or supported foster care.
- Immediately stop new placements by directing funding to assessing families, including foster families, and supporting them to care for their children through services and supports (such as cash assistance and mental health support to address emotional needs resulting from trauma experienced).
- Facilitate comprehensive “best interest” assessments for every child in institutional care and determine the supports needed so that children can be safely reunified with parents or other family members followed by an action plan that includes providing

resources on family reunification. Review individual childcare plans at least every 3 months.

## **Session 2: The immediate life-saving measures needed to protect children in institutions**

All health conditions must be understood within the broader threat of raising children without the love and care of a family member to look out for them. The impact of emotional neglect will create long-term damage to a child’s emotional and physical health. Even when adequate food and care is available from staff, children will suffer from a global “failure to thrive” as a result of this emotional neglect. Children are also more prone to abuse when family and friends are not available to look out for them.

According to observations of medical experts visiting institutions in Ukraine, many children and adults with Intellectual and Developmental Disabilities (IDD) were found to be in immediate crisis. The types of disabilities that are seen predominantly in institutions, including of children below the age of three, are cerebral palsy, autism, and other genetic syndromes, such as Down syndrome. Many individuals with disabilities also have complex healthcare needs that pose further challenges to them, such as swallowing dysfunction or movement disorders. Currently, based on recent observations, children with these healthcare needs are not being adequately treated, which leads to other healthcare issues, such as malnourishment and reduced body weight. There was evidence of severe scoliosis, contracture of joints and untreated spasticity resulting in pain, and heightened risk of infections and clots, and death from aspiration pneumonia and heart failure.

These healthcare issues are preventable if there is early intervention. Assessment and data collection is essential. There is currently a lack of an assessment system that prevents institutionalisation by identifying the support needs within each family, as well as a lack of independent monitoring of the system. Immediate attention to avoid healthcare complications in children with intellectual and developmental disabilities requires:

- Securing a team of experts (who should not be part of the institution staff) to provide triage assessments for the most vulnerable children.
- Determining appropriate levels of nourishment and means of delivery (currently all children on the visit appeared to be eating the same diet irrespective of their weight, healthcare needs, etc.).
- Implementing life-saving modes of nourishment and positioning that do not promote or exacerbate aspiration pneumonia – a leading cause of death among people with developmental disabilities.
- Adapting physical and emotional supports to optimise receipt of nutrients.
- Determining causes and treatment for those in pain, including people with self-injurious behaviours that may have a root cause in a physical ailment.
- Team of experts needs to have access to the health delivery system in each community.

### ***Key recommendations***

Immediate attention that is needed to address the gaps, and the resources that are required include:

- Independent monitoring of all residential care facilities by teams that are inclusive of people living with disabilities and the family members of people with disabilities (teams must be funded vs. voluntary). Results of the findings of the monitoring teams must be publicly posted. Locally-based, independent advocacy organisations, including organisations run by people with disabilities and family members of children with disabilities, should be engaged in monitoring institutions. These independent organisations should be given full access to observe, monitor, and offer advice and assistance on plans for reform and community inclusion.
- Provide family support services, such as information and training to caregivers, referrals to healthcare and community services, assistance with childcare or the provision of specialised nutritional formulas (for instance through mobile teams), personal assistance, respite care, or rehabilitation and assistive equipment and technologies.
- Train caregivers of children with disabilities on at home therapies, and nutrition and feeding support (including feeding training beyond food provision).
- Identify and train foster families that can care for children with complex disabilities. Funding and training is needed to ensure the availability of supported and therapeutic foster care; foster care must be an option available to all children, regardless of disability or level of support needs, who happen to be without immediate biological or extended family options.
- Identify and train special education experts, including the provision of remote learning options. Promote parenting/caregiver peer-to-peer support groups in communities for families with children with disabilities.
- Funding for immediate life-saving and necessary habilitation and supports measures should be established for children currently residing in institutions. Such funding should be provided to independent authorities so that the funding “follows the child” rather than supports the institution. As soon as family placement can be arranged, such funding should be shifted to support family-based care.
- Provide temporary shelter care only until family or extended family reunification is brought about.

### **Session 3: Community services to support reintegration and family-based care**

Ukrainian government officials, civil society organisations and businesses recently met in Switzerland to discuss plans for rebuilding Ukraine once the conflict has ended. Three main efforts were discussed:

- **Reconstruction** – the restoration of destroyed social infrastructure and housing to help the country recover from the conflict.
- **Modernisation** – a set of changes to move the social and persons with disability’ rights protection spheres to the next level of development.
- **European integration** – the adaptation of the Ukrainian legislation to a European one to acquire EU membership.

It will be essential to advocate for the construction of services that support children and their families as opposed to the reconstruction of institutions (which has recently been raised by some). These include the construction and reconstruction of kindergartens, schools that are inclusive, healthcare infrastructure, rehabilitation centres, and the strengthening of social service providers. Regarding modernisation, it is important to expand and systematise services for children with disabilities. While there are some examples in Ukraine of services that support children with disabilities, they remain few. For instance, there is legislation related to inclusive education, which exists, but it is not mainstreamed. It is essential that there are also daycare centres for children with disabilities and respite care for parents and caregivers, such as supported employment at the community level. It is important to focus on modernisation with the aim to establish and promote services that support children with disabilities and their families as opposed to reconstructing the former system. All infrastructure that is rebuilt must be made available, accessible, acceptable, affordable, inclusive, and meeting quality standards for children with disabilities. There is an opportunity to work together to establish a new system that is inclusive, to change legislation, and to advocate for de-institutionalisation.

### ***Key recommendations***

- Facilitate rapid assessment in communities affected by the conflict to determine service availability.
- Raise awareness to change mindsets, attitudes, knowledge and behaviours away from institutionalisation to community services that support children with disabilities and their families. Leverage learning from neighbouring countries, for instance Moldova, on de-institutionalisation.
- Strengthen capacities of foster care networks in communities, community social workers, healthcare workers, public authorities, local organisations, and families themselves.
- Improve community services and service provision, and mandate communities to provide necessary social services and supports to families, including programmes that provide basic income and other economic supports, such as child benefits and disability benefits; funding streams to provide services that meet basic needs, such as health, education, and early childhood development; access to daycare and respite care, early intervention, and inclusive education.
- Provide inclusive education support services, including trauma-informed early childhood development programmes.
- Modernise and renovate existing community-based rehabilitation centres. There are rehabilitation centres in Ukraine that offer a wide range of services for children who are living with families in the community, but which need to be renovated. Such facilities must be physically accessible and appropriate for children with all disabilities and integrated into the communities where children are living.
- Design programmes that provide specialised services and supports to families, such as mental health and positive parenting.
- Promote mechanisms for cross-sectoral collaboration at the community level.

#### **Session 4: Integrating systems reforms into the emergency response**

Ukraine inherited a widespread system of residential care (also known as “institutions, baby houses, boarding schools, or orphanages”) from the Soviet regime, and after independence, few changes were made. As a result, the same paradigm exists with institutionalisation being considered as the only and best solution to respond to the needs of children with disabilities. The current crisis in Ukraine has deepened the pre-existing inequalities and exposed the extent of the exclusion of children with disabilities. At the same time, the crisis is revealing the many weaknesses of residential care.

The residential care system must be reformed based on a) a holistic approach to child protection, and b) the socio-ecological model which addresses all the main protective elements necessary for the protection and well-being of children. The focus must be on the development of community-based support services for children and families, and family-based alternatives to replace institutions. To achieve this, it is necessary to address the drivers of the institutionalisation of children with disabilities, such as poverty and the lack of availability of community services, while also building the capacities of families, service providers, community members, and others to strengthen protective systems.

**As a first step, the Ukrainian government must withdraw the decision that was made in June 2021 to exclude children with disabilities from the de-institutionalisation reform process.** The transformation of the care system must take place and be articulated in national policies. Advocacy on family-based care must also take place. Conditionalities on funding from international donors should be in place to avoid re-institutionalisation and to emphasise family- and community-based care. Investments must instead be made to strengthen community services and to build protective systems to ensure the rights of children with disabilities are respected.

#### ***Key recommendations***

- Every level of government should commit to policies and practices that promote the right to family life for all children with disabilities and the reform of a social service system that does not segregate children with disabilities from society by placing them in residential institutions. Full inclusion in society and support for family life are requirements of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) article 19 and 23.
- Review and update the national level de-institutionalisation action plan to ensure clear targets, timeframe, cost and budget, and local level interventions to build alternative care arrangements and services. Include the strengthening of capacities for education and social assistance to cover additional costs of disability in the de-institutionalisation reform plan.
- Advocate for national budget and donor funding to be directed towards supporting family-based care and disability inclusion over institutionalisation or re-institutionalisation.

- Ensure subsidies for services by using funding available through the reallocation of funds from institutions and support the government to provide clearer budgetary regulations on spending on social services for families and children.
- Promote the social model of disability.
- Ensure a disability first approach to reform work that is led by persons with disabilities.
- Increase funding to local and national disability actors to lead the reform.
- Develop quality national standards on service provision to guide local decision-making, such as staffing structures, to support families with children with disabilities.
- Integrate the various reform processes and support regional approaches that can more closely match the intentions of the population and adhere to cultural and linguistic norms and preferences.
- Strengthen the social service workforce, including scaling up the number of child protection social workers.
- Leverage and use technology to connect social workers and other professionals to children with disabilities and their families.
- Promote greater awareness and change in attitudes, knowledge, and behaviour of the importance of family-based care in the protection of children with disabilities amongst government, community members and families, for instance, through a nationwide communications strategy that focuses on shifting attitudes towards de-institutionalisation.
- Ensure systematic reforms – aimed at full family inclusion for all children with disabilities – are included in the humanitarian response plan, linking up with the various humanitarian coordination mechanisms in Ukraine and host countries.
- Link to the Child Protection Coordination Group and Unaccompanied and Separated Children Taskforce in Ukraine to develop a concrete action plan to support development and humanitarian actors in working together on reform in a cross-sectoral manner.
- Establish a cross-sectoral disability inclusion task force or working group to support advocacy and coordination across sectors to ensure humanitarian response plans are inclusive and address the needs of adults/children with disabilities. Both domestic Ukrainian and international disability and family groups, as well as families of children with disabilities, have knowledge and expertise that should be tapped as part of this planning and reform process.
- Ensure the humanitarian response is disability inclusive and incorporates long-term sustainable solutions.
- Monitor and evaluate disability inclusive programmes and services to generate evidence to scale up models that are proven successful.
- Promote the active participation of children and adults with disabilities across the response. These organisations are often unfunded and have often been left out of international civil society support programmes. Given the historic lack of support, discrimination, and marginalisation of disability and family groups, targeted funding for these organisations is essential for protecting children with disabilities ensuring their full inclusion in society and ensuring the sustainability of reform efforts.



- Promote policy change and education reform in Ukraine that encourages inclusive education.
- Establish a national training programme on developmental paediatrics to be included as part of medical training to promote a system of monitoring of child growth and development across the country.