

Human Rights Bulletin

Protection and Safety of Children with Disabilities in the Residential Institutions of War-Torn Ukraine: The UN Guidelines on Deinstitutionalization and the Role of International Donors

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ABSTRACT

This bulletin considers the situation of children with disabilities in Ukraine, who at the time of the onset of the armed conflict were living in institutional care. DRI investigations have revealed that despite abundant international assistance, the government of Ukraine and international relief agencies have failed to ensure the safety and protect the lives of these children within institutions – or to ensure their safe return to families in the community.

KEYWORDS

Ukraine; conflict; war; children; disabilities; institutionalisation

The COVID-19 pandemic resulted in large numbers of deaths and extensive human rights violations against children and adults with disabilities placed in congregate settings, increasing the already serious dangers facing this population. In 2020,

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Disability Rights International (DRI) collaborated with a coalition of disability rights groups on a global survey to document the impact of COVID-19 on people with disabilities.*1 The study revealed the global pattern of increased death, abuse, and discrimination against children with disabilities. Survey respondents described the increased isolation they experienced in both residential facilities and the community as a result of the pandemic. Especially inside essential facilities, that isolation was accompanied by violence, abuse, exploitation, denial of essential medical care and prevention services.

As a result of this painful experience, the United Nations Committee on the Rights of Persons with Disabilities (CRPD Committee) initiated a series of global consultations to examine how the promise of the disability convention could be ensured during times of emergency, including both public health emergencies and war. Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) guarantees the right of all persons with disabilities to live independently in the community, and CRPD Article 11 requires governments take ‘all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies, and the occurrence of natural disasters’. Article 32 of the Convention extends these legal requirements to international cooperation, requiring that international support advance ‘the purpose and objectives of the convention’. Until now, there has been little guidance to governments or international donors with regard to how to ensure the protection and safety people with disabilities in congregate settings (institutions) during times of emergency.

The CRPD Committee sponsored global consultations and reached out for assistance to DRI and seven other international disability rights groups that formed a new Global Coalition on Deinstitutionalization (GC-DI). With the drafting assistance of the GC-DI, the CRPD Committee has adopted the UN Guidelines on Deinstitutionalization,*2 including during times of emergency. Given the inherent dangers of institutionalisation – and increased risk to this population in times of emergency – the UN Guidelines make clear that the best way to provide for the safety and protection of people detained in institutions during times of emergency is through the acceleration of deinstitutionalisation efforts. The UN Guidelines specify what has already been established in the UN CRPD’s General Comment No. 5, that international donors should not fund institutions except in very limited circumstances to prevent life-threatening conditions.*3 The Guidelines add:

*During emergency situations, such as pandemics, natural disasters and conflicts, States parties should continue and accelerate efforts to close institutions [...] Targeted efforts are needed to ensure inclusion in evacuation, humanitarian relief, and recovery measures, ensuring full accessibility in situations of emergency and risk. Emergency, and recovery funding should not support continued institutionalisation. Instead, plans for accelerated deinstitutionalisation should be included in recovery efforts and national deinstitutionalisation strategies, and implemented immediately in emergencies.*4*

Tragically, the war in Ukraine has demonstrated the importance of the UN Guidelines on Deinstitutionalization – and has shown how the international donors are now falling short of the requirements of the CRPD with regard to children with disabilities in the country's institutions.

The dangers facing children with disabilities in the country's vast system of institutions includes more than 100,000 children in what are called residential care facilities, orphanages, group homes and boarding schools. To understand the immediate challenges facing Ukraine during the war, it is essential to recognise that these children were living at significant risk even before the war, segregated from society and denied the opportunity to live and grow up with a family. In 2015, after a three-year investigation, DRI published *No Way Home*, a report documenting atrocious conditions, forced labor and trafficking within these institutions – and the lack of support in the community for families of children with disabilities. Following the release of DRI's report, Ukraine adopted an impressive National Strategy to Reform the Institutional Childcare System to reform institutional care for children 2017–2026.*5 Yet there was never a strong political will to implement it, whole portions were suspended, and children with disabilities were systematically left out of reforms. At the time the government blamed some families for being neglectful or inadequate and rationalised thus: that families of children with disabilities lacked adequate support to keep children with disabilities at home with them. There was little international support for the community inclusion of children with disabilities.

In 2019–2020, the government of Ukraine delayed the deinstitutionalisation policy and that translated into the country's de facto policy of leaving children with disabilities to languish in institutions without the hope of returning to the community, explicitly stating that children with disabilities would be left out of deinstitutionalisation reforms.*6 DRI and other disability and children's rights groups protested this dangerous and discriminatory policy of segregation.*7 In June 2021 and again in August 2022, the United Nations special rapporteurs on human rights and disability sent Joint Communications to the Government of Ukraine raising concerns about human rights violations in Ukraine's institutions and objecting to the proposed policy – and actual practice – of systematically segregating children and adults with disabilities from society.*8

As war came to Ukraine, children with disabilities already at risk because of a misguided and dangerous policy and practice of segregation, are now in grave danger. In August 2022, the CRPD Committee held hearings on the situation of people with disabilities during the war in Ukraine,*9 and the government testified that more than 7,700 persons with disabilities remain in institutions in the areas of hostilities or under temporary occupation by Russian forces. Those children and adults are clearly in great danger in a war that has threatened the lives of millions of Ukrainians.

For 100,000 or more children not immediately threatened by fighting, the war has also brought about great dangers – and many of these have been made worse by policies and practices that put children at increased risk. At the start of the war, Ukraine again rapidly discharged at least 42,000 children*10 from institutions

(including boarding schools) without any assessment or follow-up. According to the government, children were sent back to families. These were the very same families who, just two years earlier, the government said were incapable of keeping their children at home or lacked adequate support. In practice, many of these children were out of contact with families for months or years, and there has been no systematic effort to ensure that the children actually made it back to safe family placements. This responsibility lies with the social workers at the local level (the ‘oblast territorial unit’) but the number of social workers is woefully insufficient – and a majority of local authorities do not have any social worker on staff to do this work.*11 During a CRPD Committee hearing on Ukraine on August 15, 2022, UNICEF testified that there is already evidence that such children are abandoned and neglected and some children have starved to death without support. Immediate international assistance is needed to help Ukraine find, identify, and support these children.

The children who remain in Ukraine’s institutions face greatly increased risks. DRI visits to institutions in western Ukraine have shown that children with disabilities have been transferred from war-torn areas to already inadequate institutions in the western part of the country. Despite abundant international assistance, the government of Ukraine and international relief agencies have failed to ensure safety and protect the lives of children with disabilities still detained in institutions – or to ensure their safe return to families in the community. Unless urgent action is taken to support families, bring children from institutions back to safe family environments and prevent new placements in institutions, the international support flowing to institutions will inevitably result in a strengthening of the country’s system of institutions, perpetuating segregation and discrimination – in violation of international law.

Findings from DRI’s April and June 2022 Investigations

Early in the war, DRI learned of international efforts to evacuate children from Ukraine’s institutions and noted that most of the children appeared to be children without disabilities. DRI therefore conducted investigations into facilities administered by the Ministry of Social Policy – where children labelled/deemed ‘uneducable’ were placed. DRI’s investigations confirmed that children with disabilities were transferred from facilities in the war-torn east to already inadequate facilities for children with disabilities in the western parts of the country. Some children with no disabilities or few support needs were evacuated abroad – but children with the greatest needs were left behind in already abusive facilities.*12

Disability Rights International sent two investigative teams in April and June 2022. The visits covered several oblasts of Western Ukraine – Zakarpattia Oblast in April 2022 and facilities in Chernivtsi, Ivano-Frankivsk and Vinnytsya oblast in June 2022. DRI investigators were accompanied by journalists from NBC and the BBC who documented and corroborated the findings in news coverage and a documentary based on both visits.

DRI documented the immediate risk to health and safety of children – emotionally and physically neglected, abused and exploited within the institutions,

thousands of children discharged without adequate follow-up, or in harm's way in or near areas of hostilities and Russian-controlled territories.

The report after the initial investigation, 'Left Behind in the War', documented the threats to children moved from orphanages in the east, when placed in the now crowded and overwhelmed facilities in the west of the country. In addition to experiencing the trauma of being relocated to places where they did not know anyone, some children reported losing contact with relatives who they no longer knew how to reach. The children with high support needs were transferred without any medical records and the local staff reported to DRI not only being overwhelmed by the numbers of new children, but also by the fact that they arrived with impairments and support needs they did not know how to respond to.

In institutions, DRI documented lack of medical care and dangerous treatment practices (e.g. feeding people in bed with attendant risk of choking, allowing the spread of disease by the sharing of bottles and utensils, failure to check or monitor effects of medications), malnutrition, inactivity and limited human contact as children were left to rock back and forth alone in beds on filthy mattresses, or in yards eating grass and dirt in a situation of total neglect. Without staff to monitor basic safety, children are left tied down to beds, chairs and benches for long period of time in a manner that constitutes nothing less than torture. Residents of some of these facilities are forced to work in fields and in building new wards for the expected new arrivals from the East as the war progresses.

Impact of International Assistance to Institutions – Condoning Abuses and Strengthening Institutions Instead of Families and Communities

While many institutions DRI visited received various forms of financial or in-kind support from international charities before the war, DRI's investigation found a striking lack of international assistance to address the human rights concerns of children with disabilities in Ukraine's institutions. Support had included funding for an electric generator and washing machines. In another facility an international relief organisation now funds six of the Ukrainian direct care staff, one physical therapist and one massage therapist at the facility. Nevertheless, the staff were already overwhelmed by feeding, changing diapers and attempting to keep the children clean. Despite the international support for staff, DRI investigators observed children lined up in wheelchairs and strollers for hours in total inactivity. Children were tied down to benches and beds. International support for facilities where neglect and abuse takes place signals to the facility that abusive practices will be tolerated – or will certainly not stop a facility from receiving funding.

In one of the facilities receiving international support, DRI found a child tied to a bench who had parents living fifteen minutes away. The international staff supervisors interviewed by DRI reported that the war was not the reason for the delay in returning children back to families if support were available and nothing about the war conditions would have stopped a program to get children into families.*13 They

reported that the decision to support the institution instead of the family was made at the headquarters of the organisation outside of Ukraine. Two senior supervisors for the organisation said they would be pleased to begin immediate efforts to help children return to families if they received support and direction from their organisational headquarters to do so.

In the same facility, DRI investigators encountered other internationally-funded experts who assumed that all international support had to be provided at the facility and not the community. Researchers from a local university were conducting a 'needs assessment' of children at the facility funded by UNICEF. When asked whether there was any effort to assess the steps necessary to get children back into families, the experts said that this was outside the mandate of their assessment. When asked why they were not examining how to get children into families, their only answer was: 'this is Ukraine'. Apparently, it is understood in Ukraine that these children would need to remain inside of institutions.

As winter approaches, there is now an active effort on the part of non-government organisations to raise money to rebuild and refurbish institutions for people with disabilities of all ages. Such a call went out, for example, on the Age and Disability Technical Working Group on August 22, 2022. The request for funds came from a non-governmental organisation, but the working group is itself organised by the United Nations.

Failure to Reach Families of Children with Disabilities

DRI has been in contact with more than 400 families of children with disabilities since the start of the war. DRI was able to make contact with these individuals through others included in training programs conducted years earlier and through contacts made on social media. The great majority of these individuals report great hardship and difficulties in surviving – but have received no form of international aid or support. DRI was able to put them in contact with Save the Children who has been able to provide some cash assistance to these families. Some international assistance programs have, to their credit, provided direct support to a small number of existing disability advocacy groups who have been able to distribute aid to their members. The reality is, however, that many families of children with disabilities were not affiliated with any particular community-based organisation. As a result, these families were left out of international support programs.

Immediate action is needed to protect children with disabilities to live in the community and remain with families now, even during the war. DRI interviews on the ground with staff and directors of institutions, international aid workers and Ukrainian disability and family activists, demonstrate a common sense that – if decisions were made at the top to promote family inclusion – the war would not be a hindrance to immediate efforts to reintegrate children into families and provide them with the support they need to live in the community. Complete safety cannot be assured for anyone during a war or emergency, but children with disabilities and their families should not be denied the opportunity to live as safely as all others.

Conclusion

DRI's findings in Ukraine reinforce the need for the UN Guidelines on Deinstitutionalization – which provide a roadmap for action to protect children in institutions during a time of war. DRI has published detailed recommendations to the government of Ukraine and to international donors as part of its report, 'Left Behind in the War'. In addition, DRI and the Better Care Network (BCN) convened a meeting July 7, 2022 of Ukrainian disability and family activists, along with international relief organisations operating in Ukraine. That report provides additional details of actions that international donors can take to protect children with disabilities in Ukraine's institutions during wartime.

Failure to implement the community inclusion mandate of the UN Guidelines will almost certainly leave Ukraine with a strengthened and reinforced system of segregated services that will further endanger children with disabilities. International support for institutions – from washing machines to electric generators to direct care staff – have already sent a strong message to Ukraine's services providers that neglect, abuse and practices that amount to torture can be tolerated and will not stop international support.

Such support has been justified by the claim that these facilities are necessary because immediate alternatives do not exist and 'the priority is to save lives'. Not only are these facilities unsafe – even with international support – DRI has found families in the community desperately struggling to keep their children at home. The same support now being used to help institutions should be used to support families in the community.

As the DRI-BCN report shows and as DRI has recommended, urgent support is needed for disability groups, family peer support programs, medical and psychological support and other programs based in the community. Such programs can immediately reach out to and help stop abuses and save the lives of children living in institutions, without directly supporting the institution in which the child is placed. An essential component of these programs would be to find and identify families in the community – the children's original family, extended family, or foster families – and provide them the support needed to bring children out of institutions into a loving, caring, and supportive family-based situation. Even in times of emergencies and among internally displaced populations – especially during times of war – family structures continue to operate and are in need of immediate support.

CRPD's Article 11 requires governments to ensure the 'protection and safety' of people with disabilities during times of emergency and war. As DRI's findings in Ukraine demonstrate – and as called for in the UN CRPD Guidelines on Deinstitutionalization – protection and safety can only be guaranteed in family-based care and support for such placement is needed even during time of war. During the immediate crisis in Ukraine, international donors should re-direct emergency funds toward family protection as this war continues. As international donors and relief agencies prepare for future crises, careful planning is needed to provide

for such action in any country and in any conflict where the CRPD's promise of fully community inclusion has not yet been fully implemented.

NOTES

- *1. Disability rights during the pandemic: A global report on findings of the COVID-19 Disability Rights Monitor, <https://covid-drm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf>
- *2. UN CRPD Guidelines on Deinstitutionalization, CRPD/C/27/3 (September 9, 2022). Available at <https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpd-273-guidelines-deinstitutionalization-including> (accessed 21/09/22).
- *3. Rosenthal, Eric, 'Residential Care Controversy: The Promise of the UN Convention on the Rights of Persons with Disabilities to Protect All Children' published in the *International Journal of Disability and Social Justice*, November 2021, Vol. 1, No. 1 (November 2021), pp. 101. Available at <https://doi.org/10.13169/intljofdis.socjus.1.1.0095> (accessed 21/09/22).
See also: "States parties should ensure that public or private funds are not spent on maintaining, renovating, establishing buildings or creating any form of institution or institutionalization. Furthermore, States parties must ensure that private institutions are not established under the guise of "community living". CRPD Committee, General Comment No. 5 (2017) on living independently and being included in the community, para. 51. Available at <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/328/87/PDF/G1732887.pdf?OpenElement> (accessed 21/09/22).
- *4. UN CRPD Guidelines on Deinstitutionalization, para. 106.
- *5. <https://zakon.rada.gov.ua/laws/show/526-2017-p#Text> (accessed 21/09/22).
- *6. Deinstitutionalization for Children with Disabilities in Ukraine Brief // the Global Study of Children Deprived of Liberty http://regionalmaster.net/wp-content/uploads/2021/11/Country-Brief_Ukraine.pdf (accessed 21/09/22).
- *7. See, for example, https://enil.eu/wp-content/uploads/2021/04/2021-EU_Ukraine_HRD-by-disability-rights-organisations.pdf (accessed 21/09/22).
- *8. UN Special Rapporteur, letter to Ukraine government, Ref AL UKR 5/2021, 30 June 2021, at <https://spcommreports.ohchr.org/TMResultsBase/DownloadPublicCommunicationFile?gId=26477> (last accessed 29/09/22). The August 11, 2022 report also raises concerns about discharge of children without adequate follow-up and about Ukraine's efforts to keep refugee children in congregate settings. See <https://www.ohchr.org/en/press-releases/2022/08/ukraine-un-experts-sound-alarm-situation-children-disabilities> (accessed 21/09/22).
- *9. Recording available at <https://media.un.org/en/asset/k1w/k1wbnlvoct> (accessed 21/09/22).
- *10. Naira Avetisyan's presentation on July 7, 2022 DRI and BCN joint webinar; Sarah Slobin and Joanna Plucinska, 'Emptying Ukraine's Orphanages: Ukraine seeks to trace thousands of "orphans" scattered by war,' 09/09/2022 (updated 12/09/22), available at <https://graphics.reuters.com/UKRAINE-CRISIS/ORPHANS/dwpkrxzwvm/index.html> (accessed 27/09/22).
- *11. DRI interview with authorities in the Chernivtsi Oblast, June 9, 2022.
- *12. DRI, No Way Home (2022), available at <https://docs.google.com/document/d/1nIlZcAN8g50AnqVTwW5r0vFFH0BkgHDC/edit> (accessed 21/09/22).
- *13. Interview with the director of the facility, June 7, 2022, Chernivtsi oblast.