

Call for Written Information on Article 11 of the Convention 28th Session of the Committee on the Rights of Persons with Disabilities Submitted by The Advocates for Human Rights February 15, 2023

The Advocates for Human Rights (The Advocates) is a volunteer-based non-governmental organization committed to the impartial promotion and protection of international human rights standards and the rule of law. Established in 1983, The Advocates conducts a range of programs to promote human rights in the United States and around the world, including monitoring and fact finding, direct legal representation, education and training, and publications. The Women's Human Rights Program at The Advocates for Human Rights works to improve the lives of women by using international human rights standards to advocate for women's rights in the United States and internationally through research, education and advocacy initiatives. The Advocates holds Special Consultative Status with ECOSOC.

- 1. After the Russian invasion of Ukraine occurred on February 24, 2022, The Advocates for Human Rights reached out to its contacts of women's and human rights advocates, as well as others, in Ukraine to receive reports about their own experiences since the Russian invasion. The Advocates has conducted interviews and documented its findings. The scope of this report focuses on those firsthand reports received by The Advocates that focused on experiences of the disabled and ill, as well as those attempting to assist them.
- 2. As noted above, The Advocates has undertaken interviews and collection of data to report on the effect of the Russian invasion of Ukraine on those citizens, including those who are ill or disabled. The following is a recount of two firsthand accounts:¹
- 3. Interviewee #1: One woman (hereinafter referred to as N.N.), lives in Kiev with her elderly father. She has adult-onset Still's Disease (systemic onset juvenile idiopathic arthritis, which is a rare systemic inflammatory disorder) and breast cancer, which have left her wheelchair bound. As an initial matter, when the shelling began in Kiev on February 24, 2022, she could not evacuate. Her father stayed with her as she is homebound. She also cannot get to safe shelter and must stay in her apartment when shelling occurs. Similar reports were recounted by Al Jazeera, which states that individuals with mobility issues and in wheelchairs are often unable to access bomb shelters, resulting in a disproportionate risk of injury and death.² As for the impact of the conflict on her medical conditions:
- 4. She was without her medications for two months. One medication she takes called Tocilizumab is also used to treat COVID, so was already in short supply. and needs to be transported in a thermobox between 2 and 8 degrees Celsius. When the war began, transportation of this medication stopped, and she was not able to access it for two months. She was able to get her first IV immunotherapy dose in April 2022. She takes three other immunotherapy medications, tamoxifen, Medrol, and febuxostat, that she was only able to get through a humanitarian blood center.
- 5. She could not get care at the clinic she has been receiving care at (including her IV treatments), because the hospitals and clinics closed to any patients other than those who are wounded or have acute illness. Paid clinics were closed. Any treatment she had been receiving weekly at the clinic she had to forego. News reports and interviews conducted by other NGOs have corroborated a widespread lack of access to medications, food, and accessibility services faced by people with disabilities in Ukraine.³
- 6. N.N. has been a volunteer at a patient-rights organization called Women Against Breast Cancer. Through this organization, she was able to get additional assistance and medication deliveries.

¹ For purposes of protecting confidentiality, the citations to these interviews is redacted. Any content that is not otherwise cited is from these interviews.

² Al Jazeera, "What the war means for Ukrainians with disabilities," accessed Feb. 9, 2023,

https://www.aljazeera.com/features/2022/10/2/what-the-war-means-for-ukrainians-with-disabilities.

³ European Disability Forum, "War in Ukraine: over 143.000 persons with disabilities displaced," accessed Feb. 9, 2023, https://www.edf-feph.org/war-in-ukraine-over-143-000-persons-with-disabilities-displaced/.

- 7. She has received firsthand reports that the Russians have been targeting oncology hospitals with their bombing. Additionally, Russians have been taking ill and disabled people from hospitals and orphanages and transporting them to "filtration camps." N.N. has one friend in Mariupol who also has cancer, and she received word her friend had been transported to such a camp in Russia.
- 8. In conclusion, N.N. noted that those people suffering from cancer in Ukraine during the Russian invasion have little to no access to treatment and no voice. In her words, "they are slowly dying."
- 9. Interviewee #2: Another interviewee (hereinafter referred to as A.B.) evacuated Kiev prior to February 24, 2022 and is now in Lutsk in Western Ukraine. She is also a volunteer at the patients' rights organization "Affima Women Against Breast Cancer." As a volunteer in this organization, she has received communications from physicians and caretakers at various oncology clinics and hospitals around Ukraine.
- 10. A.B. heard directly from medical providers, including the head of the hospital, at the Kiev City Region Hospital Center for Oncology Patients located at 69 Verhovynma St. They reported to her that the hospital had to transport patients to three underground bunkers. The first bunker housed 17 patients who needed surgery. The surgery floor at the hospital was on the 9th floor and had been hit by a rocket. The second bunker housed ill children. The third bunker housed all other patients that they had to evacuate. At that point, they had no medications, including even the most basic of medicines.
- 11. The stress resulting from neglect, abandonment, lack of access to vital resources, difficult evacuation journeys, and the atrocities of war have resulted in worsening of health, particularly for children with disabilities.⁴ According to Disability Rights International, findings indicated that children with disabilities were being left behind while others evacuated. They are often left in unlivable conditions and without any documents indicating identities or medical histories. Children's needs largely cannot be met due to lack of resources, such as in the case of the children at the hospital mentioned by N.N., and neglect has also been severe and widespread.⁵
- 12. The experience in Kiev was similar across Ukraine. A.B. received reports from health care providers in Kharkiev, Mariupol and Kherson. All regions were requesting evacuations and medication. No medical distribution chains were working, in many cases because Russian soldiers were blocking distribution centers and engaging in active shooting. An NGO got involved to try to get medicine out of hospitals and distribution centers and delivered to patients where they were. Her most current concern was the hospital in Kherson that could not get access to medications. Additionally, where hospitals were targeted with shelling, they could not discharge patients because they lived in areas that were under shelling.
- 13. Additionally, patients were without access to funds to pay for their medication if it became available. A.B. described the entire process of getting medications to patients as broken. One physician in Western Ukraine requested permission from the government to personally

⁴ Al Jazeera, "What the war means for Ukrainians with disabilities," accessed Feb. 9, 2023,

https://www.aljazeera.com/features/2022/10/2/what-the-war-means-for-ukrainians-with-disabilities. ⁵ Disability Rights International, *Left Behind in the War: Dangers Facing Children with Disabilities In Ukraine's Orphanages*, by Eric Rosenthal, Halyna Kurylo, Marisa Brown, Eric Mathews, Laurie Ahern, Dragana Ciric

Milovanovic, Priscila Rodriguez, and Tetiana Biriukova (May 2022), 2-4.

drive to different cities to collect medications and re-distribute them where they were needed. This was an extremely dangerous undertaking.

- 14. This interviewee also knows individuals who were cancer patients that were transferred from hospitals against their will to "filtration camps." Another woman with lung cancer was in such a panic to escape that she followed Russian soldiers putting people on a bus to the Donetsk area of Eastern Ukraine. When she realized her mistake, she managed to escape and flee to Poland.
- 15. Cities not under attack are still having medical supply issues.
- 16. A.B. has been in contact with cancer patients in Gostomel and Bucha, Ukraine, whose homes were ruined and ransacked by Russian soldiers. One cancer patient's entire family was under occupation in their home by Russian soldiers that didn't allow him to get treatment.
- 17. Her entire work effort now is to help coordinate delivery of medicine to cancer patients across Ukraine. A.B. is a member of a Facebook group that has 17,000 patients and she is part of a Telegram channel that allows her to communicate and coordinate. They use volunteers, the post office, and humanitarian aid from the United States to coordinate distribution of medications. Just such an effort allowed her to help N.N. (above) get her medications.
- 18. Interviewee #3: Another interviewee (hereinafter referred to as N) lives in Kyiv with her two children, including her 18-year-old son who has disabilities. N is a representative of an organization that focuses on issues of persons with disabilities in Ukraine. The organization supports families who care for persons with disabilities which includes visiting previously occupied territories to deliver packages and resources. Before the war the organization had a network of over 1200 families, but now has about 600.
- 19. N highlights the need to support the socialization of children with special needs so that they can feel more comfortable within society. This is what her organization focused on before the war and continues to do so, by organizing social events for children with disabilities. "My son and others had bad experiences with that" N says, referring to how persons with disabilities are treated in Ukrainian society, so these engaging events help to create a supportive community for persons with disabilities and their families.
- 20. The lack of resources for persons with disabilities in Ukraine is impacting many families, as N mentions "at the beginning of war, there was significant supply and donations. Now it is much less than it used to be and it is difficult to get important products" such as diapers. Disruption to supply of resources has also impacted access to medication, N highlights that now drug stores are open again access to medicine in Kyiv has improved, although there are still delays and interruptions to this.
- 21. N highlights one of the biggest issues she and her son have experienced has been the disruption to rehabilitation as multiple appointments were cancelled month after month. The disruption to accessing rehabilitation has continued, despite Kyiv becoming more secure since the beginning of the war. N mentions that "we don't have rehab now because we don't have transport. Transport used to be provided by the state. Since the war started, we have not been able to go to rehab". The disruption to existing rehabilitation within Ukraine significantly impacts persons with disabilities reliant on these services. Conflict also increases the demand for rehabilitation as health facilities are impacted and more

people are subject to traumatic injury that require rehabilitation⁶. N expresses that the "lack of financing from the State" makes access to rehabilitation almost impossible for most families.

- 22. Another significant challenge N experiences with her son's disability is the legislative paperwork. As her son reaches the legal age of adulthood "we have started the process of registration of guardianship" as the State requires new documentation of his disability to continue receiving benefits. N expressed that this process has been complicated and humiliating and has spent several weeks trying to obtain specific documents to prove to the court she is an adequate guardian. "Before 18 no one asked if I could represent this child. I have already posted about my frustration with this process and I'm disappointed. Today I visited the hospital to obtain the official document to prove I am not mentally ill. No one asked for the past 18 years and no one cared, but now I need to prove". In order to receive government assistance for her son, N must complete this time consuming and complex process on a yearly basis.
- 23. Another complicated aspect of her son reaching adulthood is that "men who turn 18, even if in a higher category of special needs, need to go to the recruitment center. They will never be able to serve, so why do they need to go and prove this to the military services? Why can't they show the prior paperwork?".
- 24. As of June 2022, approximately 143,600 individuals with disabilities had been displaced as a result of the war.⁷
- 25. Stigma and stereotypes faced by people with disabilities have also contributed to the deepening of the crisis, partially owing to a lack of accessibility and understanding even prior to the war.⁸
- 26. In sum, the reports The Advocates has received suggest that there is a dire need for NGOs and humanitarian efforts to be better coordinated to find and provide evacuation assistance and medical treatment specifically to cancer patients. News reports have also corroborated the lack of accessibility incorporated into humanitarian efforts and response plans, both with regard to inclusion of essential medical supplies for individuals with chronic conditions as well as in evacuation logistics.⁹ This further reinforces the necessity of stronger and more inclusive planning by NGOs and humanitarian efforts.

⁶ Gosling, J. et al. (2022). We must not neglect rehabilitation in Ukraine. EClinicalMedicine, 50, pp.101537–101537. [Online]. Available at: doi:10.1016/j.eclinm.2022.101537.

⁷ European Disability Forum, "War in Ukraine: over 143.000 persons with disabilities displaced," accessed Feb. 9, 2023, https://www.edf-feph.org/war-in-ukraine-over-143-000-persons-with-disabilities-displaced/.

⁸ TIME, "The Informal International Network Getting Disabled Ukrainians Out of the War Zone," accessed Feb. 9, 2023, https://time.com/6161800/disabled-refugees-ukraine/.

⁹ World Economic Forum, "Ukrainians with disabilities are being left behind. It's time for concerted humanitarian action," accessed Feb. 9, 2023, <u>https://www.weforum.org/agenda/2022/05/ukraine-refugees-disabilities-humanitarian/</u>.