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The impact of the COVID-19 pandemic on people with disabilities: Perspectives from people with disabilities

The report was released as the war continues to rage across Ukraine.

As a severe humanitarian crisis in Ukraine continues to unfold, millions of Ukrainians have now fled their country in search of safety and security, millions more have been displaced internally or remain stranded in affected areas[1].

In addition, multiple and increasing civilian casualties are being reported; critical civilian infrastructure, including healthcare facilities, is being deliberately targeted and destroyed.

Supply chains have been disrupted across Ukraine interrupting and, in some cases, severely limiting access to food, medication, and other basic items.

Within the context of this unfolding catastrophe, it is crucial to remember that 15% of the civilian population caught up in the conflict will have a disability. Article 11 of the United Nations Convention on the Rights of Persons with Disabilities (UN General Assembly, 2007) requires State Parties to take all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict. This and all other provisions of UN CRPD apply at all times and cannot be suspended during national emergencies, foreign occupation, natural disaster, or armed conflict. As set out in the report of the UN Special Rapporteur on the Rights of Persons with Disabilities in the Context of Armed Conflict (UN General Assembly, 2021), international criminal and humanitarian law fully incorporates disability considerations. In addition, UN Security Council Resolution 2475 (UN Security Council, 2019) calls upon Member States and parties to armed conflicts to protect persons with disabilities in conflict situations and to ensure they have access to justice, basic services, and unimpeded humanitarian assistance. However, as the Report notes, 'Persons with disabilities tend to be disproportionately affected by armed conflicts. This seems not to register as an important reality to the extent that it should' (UN General Assembly, 2021, para. 47).

This war hit Ukraine as the country began to emerge from the consequences of the devastating COVID-19 pandemic. The pandemic, as our research suggests, magnified the vulnerability of persons with disabilities in Ukraine by limiting their access to healthcare, social services, and transport. It increased their social isolation and undermined their economic security. The pandemic has shattered the resilience and vitality of organisations providing support to persons with disabilities.

Methodology

Our research collaboration was informed by three principles: 'Nothing About Us Without Us' has been the starting point and the organising framework for this project.

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[1] See: https://www.state.gov/russias-filtration-operations-forced-disappearances-and-mass-deportations-of-ukrainian-citizens/

The project seeks to build the evidence base about the impact of the coronavirus pandemic on persons with disabilities in Ukraine.

The key objective of building the evidence base about the impact of COVID-19 on persons with disabilities in Ukraine demanded a truly collaborative approach. Our project has been designed and implemented in close partnership between persons with disabilities and social science researchers.

We are aware of the continuing debates around the issues of positionality and intersectionality: every person with disability experiences dynamic and often interlocking systems of oppression (based on their disability, gender, sexuality, ethnicity, nationality, age, location) which are unique to them and their circumstances; their response and resistance to these systems would similarly be different. However, as Charlton noted back in 1998, the key point here is that ‘people with disabilities are oppressed and resist this oppression individually and collectively in ways that are generalizable’ (Charlton, 1998: p. 5). Participatory research offers tool to explore both individual and collective strategies and narratives of such resistance. The value of meaningful participation is also recognized by the UN Convention on the Rights of Persons with Disabilities and is further clarified in General Comment No. 7 issued by the UN Committee on the Rights of Persons ‘On the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention’.

This paper covers Phase 2 of a larger AHRC/GCRF-funded project ‘The impacts of COVID-19 on Persons with Disabilities in Ukraine’ (with a particular focus on internally displaced Persons with Disabilities).

Phase 1 relied on an online survey to engage with more than one hundred organisations of persons with disabilities in Ukraine to record unique organizational perspectives on the impact of the pandemic and their views on potential strategies for inclusive recovery. The outcomes of Phase 1 are presented in the full report (Sharapov et al., 2022a) and a stand-alone working paper.

In this phase of the project, we conducted 301 interviews with people with disabilities. Interviews took place between June and September 2021; the majority were conducted by telephone to minimise contact and comply with the social distancing regulations, eliminating, as much as possible, any potential for COVID-19 transmission. Some interviews were conducted outdoors where interviewees’ specific disabilities made a videoconferencing or telephone conversation impractical.

Interviews were conducted by 34 community-based researchers (CBIs) — disability activists affiliated with the National Assembly of People with Disabilities (NAPDU) — either as the Assembly’s regional representatives, or as representatives of the Assembly’s member organisations.

Among 301 interviewees, 266 (or 88%) were people with disabilities, and 35 (or 12%) were carers or guardians speaking on behalf of persons with disabilities they were taking care of.

In this paper, no distinction is made between persons with disabilities and their carers since most of the carers were close family members speaking on behalf of persons (mostly with severe intellectual and mental disabilities) they were assisting in their everyday life. Within the context of this report, all 301 interviewees (also identified as ‘participants’ or ‘respondents’ throughout the report) are referred to as ‘persons with disabilities’. Geographically, most interviewees lived in the East of the country at the time of being interviewed. The project purposefully focused on regions (‘oblast’) of Ukraine with a higher concentration of IDPs. As a result, about 50% of our interviewees were internally displaced people with disabilities, located in 10 regions of Ukraine as listed in (Kyiv region, Dnipropetrovs’k, Donets’k, Poltava, Sumy, Zaporizhzhia, Vinnytsia, Kharkiv, Luhans’k regions, and city of Kyiv).

At the time of interviewing, the majority of our interviewees lived in urban areas (83.7%), including 38.2% who lived in large cities (defined, for this project, as cities with more than 500,000 inhabitants). About 70% of the Ukrainian population lived in urban areas as of 2020, with more people moving to urban areas each year (World Bank, 2021). Similar to other internal displacement contexts (see UNHCR, 2020: p. 33), Ukrainian IDPs are predominantly located in urban areas. There were more female (57.1%) than male interviewees (42.9%) with the majority of interviewees in the 36–59 age category (54.8%), followed by those in the 18–35 age group (22.9%) and finally those who were over 60 (22.3%).

Approximately half of the interviewees had the most complex types of impairments and were classified as belonging to Group 1 of the official system of disability classification in Ukraine. The core element of this system is socio-medical commissions which allocate individuals to four groups (1A, 1B, 2 and 3) of disability, based on the ‘degree of persistent dysfunction of the body due to disease, injury (its consequences) or birth defects, and possible limitation of life in interaction with the environment due to loss of health’. Among our interviewees, 18.2% were classified as belonging to ‘Group 1A’ and 30.6% to ‘Group 1B’. Interviewees classed as belonging to ‘Group 2’ comprised 29.2%, with ‘Group 3’ at 20.3; the remaining 1.7% did not specify their ‘group’ of disability.

Findings

Firstly, it is worthy to mention ***sources of information and its availability and accessibility.***

Interviewees were asked to identify key sources of information about the pandemic. Among those who relied on one source, the most popular sources of information were the Internet and Social Networks. Most interviewees, however, relied on two sources of information with the most popular combination being the Internet & Social Networks plus Radio and Television.

With a range of sources to select from, interviewees were asked to assess whether they received enough information. The majority of interviewees confirmed they could access information about COVID-19 and the pandemic response; however, most of the interviewees expressed concerns about the trustworthiness of this information and its limited focus. Interviewees were also concerned about the trustworthiness of information which was circulated on various social media platforms, and which was used to fill in the ‘information vacuum’ in the absence of clear guidance from the government and primary healthcare professionals, including family doctors.

Most participants in our research relied on more than one source of information about the pandemic: the Internet and Social Networks were the most popular source of information, followed by Radio and Television, and Relatives and Friends. The level of reliance on and trust in the information available on the official webpages of public authorities was low. For the majority of participants, the three key information gaps were in relation to symptoms and treatment of COVID-19; reliable information on vaccines; and how to avoid infection. There appears to be a link between the availability of trustworthy information about the vaccine and the preparedness of our participants to get vaccinated. The availability and accessibility of information was affected by limited access to smartphones, the internet and other digital devices; participants affected by 'digital poverty' were least likely to have access to key public health information.

Health and wellbeing remain a key concern for most, if not all, people with disabilities in the context of any PHOE (public health and other emergencies). The COVID-19 pandemic magnified already challenging and negative experiences of daily life as a person with disability in Ukraine, including the overall poor state of the national healthcare system and the availability and accessibility of healthcare.

Now we get down to ***severing difficulties with accessing primary healthcare, in this case it is access to family doctor during the pandemic***.

In 2017, the Parliament of Ukraine initiated a structural reform of the Ukrainian healthcare system, described by the Ministry of Health of Ukraine as developing a system driven by its "focus on patient needs".

According to the survey, 74% of the Ukrainian population were satisfied with the quality of primary healthcare provided by their family doctor in 2020[1]. However, our findings portray a far less optimistic picture, in which both access to and quality of primary healthcare received by people with disabilities reflect a system unresponsive to their needs, including those who are internally displaced. The majority of interviewees (96.0%) were registered with a family doctor (by 'signing a declaration'). However, having a registration did not guarantee access to primary healthcare when it was required. A number of issues were identified, some of which are likely to have been caused by severe COVID-19 pressures on the weak Ukrainian healthcare system. However, some examples of what appears to be neglect and/or negligence reflect discriminatory attitudes towards people with disabilities held by some healthcare professionals which are not specific to the pandemic. In addition, we identified evidence highlighting the lack of adequate logistical and financial systems of support and care for people with disabilities at the primary healthcare level, including:

1. Annulments of registrations.
2. Refusals to provide medical care.
3. A cycle of cross-referrals.

Some interviewees reported not having an option of receiving care or advice by telephone or via online appointments, which meant that the only way to receive treatment was to personally visit the GP practice. For the interviewees who were shielding to avoid exposure to COVID-19 this was not a viable option.

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[1] See: http://health-index.com.ua

Moreover, it is worthy to mention ***recovering from COVID-19 at the hospital***.

Concerns expressed by interviewees who experienced serious symptoms of COVID-19 but who decided to stay and recover at home (rather than be hospitalised) was the expectation that healthcare facilities — including those repurposed as COVID-19 wards — would be inaccessible to people with disabilities. All interviewees who were hospitalised were asked to describe, in their own words, the extent to which hospital facilities for the treatment of COVID-19 were accessible in relation to their own individual needs and requirements. Overall, 16 interviewees assessed them as inaccessible, and 12 interviewees described them as accessible. Some examples provided by our interviewees are harrowing and distressing; they tell the story of individual humiliation and suffering, and of cases of institutional neglect and abandonment of critically ill people with disabilities in health care settings in Ukraine.

All 28 interviewees who were hospitalised because of COVID-19 were asked to comment if there were other problems they may have experienced during the time spent at the hospital. Only 25% of the interviewees said that their needs were met. The remaining 75% mentioned a range of concerns, which we group into the following list of problems and shortages: lack of toilet and shower facilities, shortages of professional staff, lack of adjustable beds, lack of sign language interpretation.

Our participants experienced: severe difficulties with accessing both primary and specialist healthcare (including the issues of availability and accessibility further compounded by public transport withdrawals); restricted access to the technical means of rehabilitation; negative experiences of contracting and recovering from COVID-19 at home and in hospital; limited availability of vaccination options and information about vaccines. They felt deprioritised and were often left to cope with extremely difficult circumstances on their own.

Concerning ***accessing other healthcare*** all interviewees, regardless of whether they had COVID-19, were asked whether they received ‘planned’ or ‘routine’ treatments as part of their long-term condition management (related to their disability) during the pandemic[1]. This was to assess the extent to which non-COVID-19 related medical care was impacted by the reprofiling of healthcare facilities and by the withdrawal of healthcare services because of COVID-19. Among the 280 interviewees who responded to this question, only 34.6% received their planned treatment and 65.4% did not. Among the interviewees with the most complex disabilities (classified as ‘Group 1A’ or ‘Group 1B’), only 31.7% received on-going medical care and 68.3% did not. A number of interviewees provided additional comments to explain the impact of the pandemic and of the Government pandemic response on their access to non-COVID-19 related healthcare services.

Among those who did not receive care, only 14 respondents (7.6% of 183) said they did not require ongoing care; however, some of the open-ended responses also mentioned lack of availability.

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[1] All interviews took place between 22 June and 30 September 2021 –– more than a year since the Government of Ukraine introduced the nationwide state of emergency related to the spread of coronavirus on March 25, 2020 (see: https://www.kmu.gov.ua/news/uryad-zaprovadiv-rezhim-nadzvichajnoyi-situaciyi-po-vsij-teritoriyi-ukrayini).

Conclusions

Our 'COVID-19 as a looking glass'[1] findings presented in both parts of the project report paint a picture of entrenched economic and social deprivations experienced by people with disabilities in Ukraine, patterned by the intersecting and reinforcing inequalities of gender, age, locality, displacement, and socio-economic status, and exacerbated rather than created by the pandemic. It is fair to suggest that war and all the violence and devastation that it brought over the last few months made these inequalities and deprivations much worse. Part 1 of the project report made a series of recommendations to public authorities in Ukraine (Sharapov, Anderson, Burova, Polishchuk, and Nazarenko, 2022). As a project team, we do not feel we possess any ethical authority to make wide-ranging recommendations at this time and in this context. Instead, we formulated a series of 'Guiding Questions' for each key theme that this report considers. These questions are presented at the end of the report. We suggest that they inform all responses by any agency, including public authorities in Ukraine and the increasing number of international public and private donors, in supporting the people of Ukraine in a way that foregrounds disability, human rights and justice. The key question, however, remains: as the war continues, how can disability considerations be foregrounded to support some of the most vulnerable women, men and children in Ukraine? And, importantly, how can this be done to ensure that the post-conflict recovery and rebuilding give due consideration to disability and inclusion at all levels and stages of what will undoubtedly be a lengthy and challenging process?

Here are some parts from interviews:

"We needed more information about the treatment of COVID. There was a lot of information that simply drove us into a state of fear... a state of frenzy. And you just had to control yourself. Because what was in the media — a stream of terrible numbers and hopelessness, right? The information was given in such a way that you did not know what to do. There was no information from the media, or a family doctor, about a clear plan of action — what to do if someone in our family fell ill... I have an elderly mother — in general, what should we do in these situations?"

"We had a lot of information. Cars drove around here, talking over the loudspeaker about COVID, saying that you need to wear masks all the time. And on the one hand, all this is good, but, probably, they had to make a bit of an effort to select a better timbre of the voice which comes through the loudspeaker, because it happened 20-30 times a day and every time we shuddered from this voice."

"*This is my fourth registration: the first two doctors resigned; the third one is on maternity leave, and I need to register now for the fourth time.*"

"The first doctor retired; the second one went on maternity leave, and I do not know what is going on now... they said they would transfer my registration over but I do not know when, or who would take it on."

"They have so many patients waiting to be seen... and queuing is a challenge for a person with disability, so you have to pre-arrange an appointment; it's difficult to get seen

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[1] Kennedy-Macfoy (2021) uses a similar analogy in relation to COVID-19 in her editorial for the *European Journal of Women's Studies*. She describes COVID-19 as a 'looking glass'.

if it is on a first-come-first-served basis. If you are sick and have a fever, it is impossible to stand there and wait.”

“Whenever I call them [a GP] they just say: there’s no petrol (to visit you at home). That’s it — I cannot come to you. So, they consult on the phone, prescribe medication on the phone. But how can you treat somebody without seeing them? Yes, she listened to me... but what kind of doctor is this? If my abdomen hurts on the left side, it could be anything — appendicitis, liver, intestine, kidney, urea — it can be any of this. And based on words only, she decided — this is that and we will treat it like this. We treat this... but it’s not what, in reality, should be treated.”

“They have so many patients waiting to be seen... and queuing is a challenge for a person with disability, so you have to pre-arrange an appointment; it’s difficult to get seen if it is on a first-come-first-served basis. If you are sick and have a fever, it is impossible to stand there and wait.”

“There was no opportunity to see a doctor in person without coming to the clinic. That is to call them and consult, ask... so that I do not have to go to the clinic to collect prescriptions.”

“A number of interviewees suggested that some GPs refused to see them or even schedule an appointment: ‘I had a fever, I was in a really bad state. My kidneys were affected and all the muscles [were aching]... it felt like hell, like being minced in a meat grinder. I called the receptionist to get an appointment with my GP and it was such bad luck because my family doctor went on annual leave on that day. And the doctor, who was standing in for her, she refused to see me. I called four days in a row, I had a fever, I felt so unwell... I was coughing and started to choke (suffocate)’.”

“Even the beds were not accessible. They had orthopaedic beds with a large, tall mattress... it was very difficult to move from a wheelchair onto this mattress. There was a toilet in the room, but it was inaccessible... the wheelchair would not go through the door... the doorframe was too narrow. So, I had to use the chair: I would hop on the chair... and then hop from the chair onto the toilet and it was very uncomfortable. It was the same — hopping — to get to the sink... the reception [of the hospital] was all glitzy... like in Europe... but once you are in — it’s all dire.”

“There was no hot water at the hospital...and there was no way to have a shower... to maintain some basic hygiene. I was in a ward and there was a toilet, but it had no toilet seat... I had to buy it myself and I cleaned myself by heating water in a kettle.”

“I could not get treatment for my chronic conditions during the pandemic because all of the healthcare staff were redirected to treat COVID-19 patients and all the chronic conditions had to be put aside and forgotten about... because doctors did not have time or interest to provide treatment. They would not even want to talk to you; they would just say — wait until the better times.”

“I did not receive any treatment. There was no treatment for me anyway — even before COVID-19.”

Our findings do not offer a magical solution to protect people with disabilities in the context of an ongoing war; however, they offer a unique perspective — based on what our members have told us — about what matters to them in times of upheaval and turmoil.

The next paper will describe the following issues:

what should be done to improve the standard of healthcare for people with disabilities in Ukraine;

the psychological impact of COVID-19 direct support during the pandemic and public authorities' response to the pandemic.

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The impact of the COVID-19 pandemic on people with disabilities: Perspectives from people with disabilities

In this paper, we relied on co-researching with persons with disabilities in Ukraine not as a means of understanding the epidemiology of this disease, or of its impact on human health. We approached COVID-19 and the Ukrainian authorities' response to the pandemic as proxy, or a magnifying glass, to better understand the everyday life of persons with disabilities in Ukraine, and to explore how things could and should be done differently in the context of public health or other emergencies. The pandemic unsettled and disrupted the meanings of personal space and time for virtually everyone across the world; it unmasked, reinforced and reconfigured existing inequalities, cascading them into further injustices of (im)mobility and access. This is especially true for persons with disabilities. Kennedy-Macfoy uses an analogy in relation to COVID-19. She describes COVID-19 as a 'looking glass'. Our 'COVID-19 as a looking glass' findings presented in both parts of the project report paint a picture of entrenched economic and social deprivations experienced by people with disabilities in Ukraine, patterned by the intersecting and reinforcing inequalities of gender, age, locality, displacement, and socio-economic status, and exacerbated rather than created by the pandemic.

This article is devoted to the second part of the extensive study «The Impact of the COVID-19 Pandemic on People with Disabilities in Ukraine». In this article, the authors elaborate on the methodology of the second phase of the study and the views of people with disabilities on the issues of communication about the COVID pandemic and access to medical care during a pandemic for people with disabilities.

Keywords: *COVID-19, disability, internal displacement, human rights, disability organizations, inequality, discrimination, accessibility*

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Вплив пандемії COVID-19 на людей із інвалідністю в Україні: погляди людей з інвалідністю

Стаття присвячена методології дослідження проблем інформування про пандемію COVID-19 та доступу до медичного забезпечення під час пандемії для людей з інвалідністю, а також поглядам людей з інвалідністю на ці проблеми. У статті автори спиралися на спільні дослідження з людьми з інвалідністю в Україні не просто як на засіб розуміння епідеміології цього захворювання або його впливу на здоров'я людини. Автори звернулися до COVID-19 та реакції української влади на пандемію як фактор, що оголив та увиразнив всі проблеми людей з інвалідністю, тобто послугував тригером всіх проблем. Це мало на меті краще зрозуміти повсякденне життя людей з інвалідністю в Україні та вивчити, як можна і потрібно діяти *по-іншому в контексті проблем системи охорони здоров’я та інших соціальних проблем, що не розв’язуються.*

Пандемія сколихнула і зруйнувала уявлення про особистий простір та час практично для всіх у всьому світі; вона виявила, зміцнила і реконфіґурувала наявну нерівність, перетворивши її на подальшу несправедливість у сенсі (не)мобільності та доступу до різних послуг. Особливо це стосується людей із обмеженими можливостями. Кенеді-Макфой використовує аналогію щодо COVID-19 як «задзеркалля», і висновки авторів збігаються з її думкою.

Висновки авторів, представлені в обох частинах звіту про проєкт, змальовують картину вкорінених економічних та соціальних поневірянь, з якими стикаються люди з інвалідністю в Україні, подібних до нерівностей на підставі статі, віку, локації, переміщення. Ці фактори, що перетинаються з економічним становищем, посилила, а не створила пандемія.

Ключові слова: *COVID-19, інвалідність, внутрішнє переміщення, права людини, організації людей з інвалідністю, нерівність, дискримінація, доступність*