

3 March, 2022

I am writing this letter to accompany a Working Paper which presents a summary of the research project investigating the impact of COVID-19 on persons with disabilities in Ukraine. The final design of the report was being completed as the first missiles hit Ukraine on the 24th of February 2022 with Russia launching its lethal and coordinated attacks on the civilian and military infrastructure of Ukraine from land, air, and sea.

As a severe humanitarian crisis in Ukraine continues to unfold, hundreds of thousands of Ukrainians have crossed into neighbouring countries whilst millions of Ukrainians are being displaced internally. In addition, multiple and increasing civilian casualties are being reported and critical civilian infrastructure, including healthcare facilities, has been put under immense strain or is, increasingly, destroyed. Supply chains have been disrupted across Ukraine limiting access to food, medication, and other basic items. Numerous reports and eyewitness accounts of residential areas and critical infrastructure being deliberately targeted by Russian troops has prompted the International Criminal Court to commence an investigation of alleged war crimes and crimes against humanity that are being committed in Ukraine.

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 Disability (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 hits Ukraine as the country began to emerge from the consequences of the devastating COVID-19 pandemic. The pandemic, as our research suggests, magnified 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. Special Rapporteur notes that there is 'no such thing as an inherently vulnerable person, but only persons with disabilities placed in vulnerable situations' (UN General Assembly 2021, para 16). Our research suggests that a wide range of 'vulnerable situations' shaped lived experiences of persons with disabilities in Ukraine before COVID-19 was declared a pandemic in March 2020. Hundreds of thousands of internally displaced persons with disabilities and those in need of humanitarian assistance, as a result of the Russian military aggression against Ukraine in 2014, faced an additional layer of socio-economic vulnerability impeding their access to housing, healthcare and social services. COVID-19 and the political and economic responses to the pandemic amplified both the volume and the scale of such vulnerable situations.

The war that has been unleashed upon Ukraine in the last few days has turned these vulnerable situations into a humanitarian catastrophe falling heavily on persons with disabilities across Ukraine. Little verifiable evidence or testimonies can be collected at this stage; however, according to the initial reports by persons with disabilities and their organisations, persons with disabilities are being confronted with a range of issues, including lack of accessible and reliable information; disrupted or fully withdrawn access to medical services, including essential medicines; lack of accessible evacuation procedures, accessible evacuation or safe zones; increased exposure to COVID-19 in crowded shelters.

These life-changing challenges come on the top of the overall deterioration of the situation for all civilians caught up in this war, including degradation and destruction of essential services such as access to food, water and medical care; and, increasingly, indiscriminate targeting of the civilian population and the use of explosive weapons in populated areas.

In the current context where the course of this war is uncertain and the worst is expected, and as the humanitarian relief efforts are hindered by the escalating hostilities, organisations of persons with disabilities remain one of the last remaining systems of support for people they have been taking care of within the context of the pandemic and now within the context of this catastrophic war. They continue, where and when they can, to provide support to the most vulnerable individuals and their families. Their knowledge and expertise must inform all current and future relief efforts provided by the Government of Ukraine and by the international donors and humanitarian agencies. These efforts must foreground disability, respond to the difference of disability, and facilitate meaningful inclusion and participation.

In this challenging context, the National Assembly of People with Disabilities of Ukraine, the project's partner organisation in Ukraine, has been mobilising and reorganising its activities to provide support to its member organisations to coordinate and facilitate, where possible, efforts to support persons with disabilities across Ukraine.

We have provided their bank details below for any assistance and we encourage you to follow their Facebook page: https://www.facebook.com/vgonaiu.

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National Assembly of People with Disability in Ukraine: https://naiu.org.ua
Institute of Sociology, National Academy of Sciences of Ukraine: https://i-soc.com.ua/en/index

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Bank Details

For assistance in USD	For assistance in EUR	For assistance in GBP
Ukrainian Public Association "National Assembly of People with Disabilities"	Ukrainian Public Association "National Assembly of People with Disabilities"	Ukrainian Public Association "National Assembly of People with Disabilities"
Payment should be made to the following bank account: UA 83 322313 0000026001000039141	Payment should be made to the following bank account: UA 83 322313 0000026001000039141	Payment should be made to the following bank account: UA 42 322313 0000026009000042129
Name of the bank: JOINT STOCK COMPANY «THE STATE EXPORT-IMPORT BANK OF UKRAINE»	Name of the bank: JOINT STOCK COMPANY «THE STATE EXPORT-IMPORT BANK OF UKRAINE»	Name of the bank: JOINT STOCK COMPANY «THE STATE EXPORT-IMPORT BANK OF UKRAINE»
Branch Address: 11-b Bul'varno-Kudryavs'ka street, Kyiv, 04053, Ukraine	Branch Address: 11-b Bul'varno-Kudryavs'ka street, Kyiv, 04053, Ukraine	Branch Address: 11-b Bul'varno-Kudryavs'ka street, Kyiv, 04053, Ukraine
Correspondent Bank: Citibank N. A., New York, USA SWIFT: CITI US 33 USD Payment details: non-	Correspondent Bank: Deutsche Bank AG, Frankfurt am Main, Germany SWIFT: DEUT DE FF	Correspondent Bank: Citibank N.A. London Branch, London, United Kingdom
repayable financial assistance	EUR Payment details: non- repayable financial assistance	SWIFT: CITI GB 2L GBP Payment details: non- repayable financial assistance



The Impact

of the COVID-19 Pandemic on People with Disabilities in Ukraine

Perspectives of Organisations of People with Disabilities

Working Paper

March 2022













THE IMPACT OF THE COVID-19 PANDEMIC ON PEOPLE WITH DISABILITIES IN UKRAINE

Perspectives of Organisations of People with Disabilities

March 2022

Working Paper

(This working paper is incorporated as a summary within the main report which is released as a separate document)

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Background

Ukraine has at least 2,724,100 persons registered as having a disability, with actual figures likely to be higher due to the lack of reliable, detailed statistics. The COVID-19 pandemic has exacerbated existing problems with inadequate response by public authorities in Ukraine^[1] relating to the social and economic wellbeing of people with disabilities. As of 1st January 2022, 3,672,675 people in Ukraine had been diagnosed with COVID-19, and 96,089 deaths had been officially recorded. These figures are likely to be inaccurate, with real totals much higher, while no data is collected on COVID-19 infections disaggregated by disability.

The situation has become increasingly difficult in the conflict-affected east of Ukraine and for people who have been internally displaced by the conflict. This is particularly true for people with disabilities, where displacement exacerbates existing challenges. As of July 2021, there were 1,473,650 internally displaced persons (IDPs) registered in Ukraine including 51,586 persons with disabilities. The COVID-19 pandemic has affected access to health and social services, worsened existing issues with a lack of adequate housing for conflict affected populations (especially IDPs), and deepened poverty. Lockdowns also resulted in the closure of entry-exit points between government and separatist controlled areas of the country, severely curtailing the mobility of local populations.

Ш Hereinafter, references to 'public authorities' and/or 'public authorities at all levels of governance' [органи державної влади на всіх рівнях управління] refer to the complex system of governance in Ukraine, which is currently undergoing the process of decentralisation. The current system is set out [in Ukrainian] here: http://www.slg-coe.org.ua/wp-content/uploads/2021/03/Public_Authority.pdf Within the context of this report, 'public authorities at all levels of governance' should mean both legislative and executive branches of power at central (national) level, regional level ('oblast'), district level ('rayon'), and united local communities ('hromada') level. References to the 'Government of Ukraine' should mean the Cabinet of Ministers of Ukraine - the highest body of state executive power in Ukraine.

Little research, either quantitative or qualitative, exists to provide a comprehensive overview of the challenges faced by people with disabilities in Ukraine, especially those living in a situation of protracted displacement. There is also a lack of research and information regarding the impact that COVID-19 has had upon these populations, and the inadequate state response at local and national levels.

Purpose

This research engages with organisations run by people with disabilities in Ukraine (OPDs) in order to document the impact of the pandemic upon the people that they care for – including internally displaced persons with disabilities – and also the impact of the pandemic upon the work of their organisations. It is the first ever participatory community-based research project in Ukraine focussing on disability, being codesigned and co-delivered in partnership with people with disabilities in Ukraine, including IDPs.

The research is being delivered in four phases. This working paper covers the results of phase 1, which focusses on the views and perspectives of OPDs working people with disabilities from across Ukraine (excluding the temporarily occupied territories of Ukraine). Phase 2 of the project involves interviews with people with disabilities (including IDPS) from ten regions in Ukraine with the highest number of IDPs. Phase 3 relies on a system of written diaries and/or audio/video-testimonies self-recorded by internally displaced people with disabilities over a period of eight weeks. Phase 4 involves qualitative interviews with policymakers at both national and regional levels of governance in Ukraine to explore their perspectives on key messages emerging from this research.

Methodology

The research presented here is based upon an organisational survey of OPDs working with people with disabilities in Ukraine. The survey was co-designed with the National Assembly of People with Disabilities of

Ukraine, an umbrella organisation for 126 organisations operating at local, regional and national levels across Ukraine. These organisations care for a diverse range of people with disabilities including those who have long-term physical, mental, intellectual or sensory impairments.

150 organisations were invited to participate in the survey, which was hosted online via the Qualtrics platform. 108 responses were received, comprised of both closed and open-ended questions. The closed questions were used to produce a set of quantitative data, while the open-ended questions allowed respondents to describe the impact of the pandemic upon their organisation's work and the people that they care for in their own words.

A descriptive analysis of the quantitative data was performed using SPSS^[3] while the qualitative data were coded and analysed using an inductive thematic analysis through NVIVO^[4].

The survey responses describe the impact of the pandemic upon people with disabilities in Ukraine and the organisations which care for them. These two broad themes are summarised separately below.

Impact of the pandemic on people with disabilities in Ukraine

Impact on health and access to healthcare services:

A key theme which emerged as an outcome of the organisational survey analysis was the inaccessibility of healthcare. Respondents described a general deterioration in the health of people with disabilities due to long-term effects of COVID-19, chronic conditions becoming

Qualtrics is one of the internationally leading survey software tools. For further details please check: https://www.qualtrics.com/uk/core-xm/survey-software/
SPSS is a software platform which offers advanced statistical analysis. For further details see https://www.ibm.com/analytics/spss-statistics-software
International. For further details, see: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

aggravated through interrupted access to healthcare and a significant impact on psychological wellbeing. Access to healthcare was affected by the re-purposing of healthcare facilities into COVID-19 wards or difficulties in reaching services during extended lockdowns, particularly for rural populations. The need to make informal payments including 'charitable donations' imposed by healthcare providers or, in some cases, bribes to individual healthcare workers, was reported to be commonplace for treatments or medication which should have been free of charge.



Concerns were also raised over the increasing costs of medication and interruptions to the supply of prescriptions. Respondents also described difficulties obtaining PPE and paying for COVID-19 tests, or poor availability of free testing.

Psychological wellbeing, mental health and social isolation:

Increased social isolation of people with disabilities in Ukraine – linked to limited or fully withdrawn access to the pre-pandemic social and professional support systems – has been another key theme highlighted by our respondents. This included withdrawal or restriction of face-to-face contact with family, friends and carers combined with reduced access to leisure facilities such as parks and recreation areas, which had a particularly negative impact on children with disabilities.

Communication became more difficult through problems accessing digital technologies for online contact, or through the lack of provisions for people with hearing difficulties. Respondents also reported increased levels of stigmatization of people with disabilities.

Restricted mobility:

In response to the increasing number of COVID-19 cases, in March 2020 the Government of Ukraine introduced a series of restrictions nationwide including the closure of educational facilities; limitations on passenger transportation and mass gatherings; and suspension of catering, cultural, shopping and entertainment establishments. These restrictions (most of which had been lifted at the time of conducting the survey in May – June 2021) had significant impacts on persons with disabilities who have restricted mobility or relied on public transport or assistance from extended care networks.



The impact was more severe on rural inhabitants, as longer distances between shops, hospitals and places of employment made these completely inaccessible without access to private transport (e.g., owning a car). This was even more pronounced for those who needed to cross the contact line in the east of the country, where the closure of entry/exit points made it impossible to travel. Even following the resumption of some public transport, reduced timetables and new public health guidelines made it more difficult for people with disabilities to use the service.

Reduced and restricted access to social services, social support and education:

The pandemic deepened the poverty experienced by many people with disabilities in Ukraine. Although a small relief payment of 1,000 UAH^[5] was made available by the government (Cabinet of Ministers of Ukraine 2020a), this was insufficient to meet the needs of most people with

^[5] 1,000 Ukrainian Hryvnas or £29.89 or €34.18 using the exchange rate as recorded on xe.com as of 23 April 2020.

disabilities, and financial destitution meant that some individuals and households could not afford to buy basic supplies or pay for utilities and services. According to survey respondents, the deteriorating financial situation was linked to the ongoing impact of the pandemic through loss of jobs and income, and rising prices on food and medicines. Access to social services was complicated through lockdown restrictions and a reduction in the volume/scale of services offered, or inability to access informal support networks. Digital poverty, meanwhile, meant that many could not access online portals for government departments or online learning, while others found it difficult to access public health information regarding the pandemic due to a lack of accessible formats (e.g., captions and sign language).

Specific barriers and impact of the pandemic on specific groups of persons with disabilities:

The challenges faced by people with disabilities are specific to how certain health conditions manifest themselves in interaction with personal and environmental factors. Some survey respondents highlighted the ways in which the pandemic had intensified these difficulties:

- a) Children with disabilities or households where one or both parents were disabled experienced disproportionate poverty and a lack of services and support tailored to children. Children were susceptible to the impact of social isolation on mental wellbeing and development suffered if there were issues accessing online education and support networks.
- b) Older persons with disabilities had trouble with accessing 'technical means of rehabilitation'[6], obtaining PPE, hygiene items and disinfectants (to minimise exposure to COVID-19), combined with heightened difficulties accessing shops, hospitals, social services, and places of employment. They were more susceptible to poverty through job losses and were disadvantaged for finding work again. They were also reportedly

⁶ A state-funded system of supply/access to rehabilitation and assistive technologies in Ukraine.

- more likely to suffer digital poverty which resulted in poor access to online support networks and, subsequently, greater social isolation.
- c) People living in rural areas experienced greater difficulties accessing services and online resources.
- d) People who are blind or partially sighted faced additional barriers relating to the transfer of education and some social services online, where the problem of inaccessible websites was particularly acute. They also suffered from a lack of accessible information relating to the pandemic, a lack of caregivers and a lack of suitable adaptations within employment centres.
- e) People who are deaf or have a hearing impairment experienced significantly reduced or withdrawn access to sign language interpreters. There was also a lack of sign language interpretation on television broadcasts, which was critical during public health announcements regarding the pandemic. Face-coverings created a further communications barrier for those who rely on lipreading.
- f) Internally displaced people with disabilities continued to experience issues with housing, particularly access to housing adjusted to the specific needs of persons with disabilities. Poverty was common, linked to challenges in finding employment and accessing IDP and disability specific social security payments and



they continued to have problems accessing healthcare, education, and other services. This was often compounded by difficulties in registering as an IDP or person with disabilities in the absence of direct contact with relevant government officials.

They also experienced a lack of access to social support networks, and those with family or assets located over the contact line were particularly affected by the closure of the entry/exit points during lockdowns.

The impact of the COVID-19 pandemic on organisations of persons with disabilities in Ukraine

The survey generated 108 responses by non-governmental organisations of people with disabilities in Ukraine. At the time of publishing, this is the largest survey to explore the views and perspectives held by representatives of the disability movement and activist community in Ukraine on the impact of the pandemic on their own organisational activities.

Changes to mode of working and service delivery:

Of the organisations who had a dedicated office space, 40% had switched to hybrid working (online and offline) with 27% moving to fully remote working. Only 23% continued to operate as they had prior to the pandemic. 10% had suspended most of their activities. Almost 90% of respondents indicated that they had struggled to provide their members with some or any of the required IT equipment and internet access for online working. Organisations also noted that the move to online working resulted in reductions in the volume and quality of services they were able to offer. Some did continue with face-to-face interactions for the most vulnerable individuals, primarily to deliver humanitarian aid packages, assist with essential travel and provide care for family/pets when members of the household were hospitalised. Most organisations continued their advocacy work throughout the pandemic.

Organisational funding:

For many organisations, increasing costs to re-organise their service delivery and to provide additional support for people with disabilities were accompanied by decreased financing and a lack of support and communication with the state authorities. Overall, the analysis of the open-ended comments reveals a precarious financial situation for many

of the organisations, some of which are involved in the direct delivery of essential services to people with disabilities. This precarity was caused by the lack of funding to conduct core organisational activities, delayed or withdrawn funding, lack of knowledge about available funding opportunities, and the lack of resources and skills to comply with complex administrative requirements attached to the administration and reporting requirements.

Interaction with public authorities and volunteers:

Only 7% of organisations indicated that co-working/partnership with state authorities increased over the pandemic period. The remainder felt that there had been decreased levels of cooperation, meaningless cooperation ("tick-box" exercises) or non-constructive and ineffective cooperation. Organisations also indicated that support from volunteers had largely declined for a variety of reasons, including fear of infection; social distancing requirements and lack of face-to-face contact; financial difficulties faced by volunteers; and a general loss of motivation as everyday life became harder for everyone.

Positive organisational developments over the pandemic period:

A small number of organisations indicated that there had been positive developments during the pandemic, namely developing new partnerships and co-working with organisations, and beneficial outcomes from online working such as reduced barriers for access in the case of physical impairments and more opportunities for contact with service users and working partners. However, for those with sensory or intellectual impairments online working introduced further challenges and the need for urgent adaptations.

Decisions which authorities could have taken but failed to take in order to mitigate the impact of the pandemic on people with disabilities

The public authorities' response throughout the pandemic was criticised by organisations across several areas:

- a) Failing to ensure accessibility and availability of social services for people with disabilities, particularly a lack of humanitarian support packages (food, essential items, etc.), carer support, education, employment and public transport.
- b) Failing to ensure adequate access to essential healthcare services for people with disabilities. A lack of barrier-free access to hospitals and healthcare facilities was compounded by a failure to guarantee free healthcare, with the need to pay bribes (or mandatory 'charitable' contributions to the hospital) being commonplace.
- c) Failing to ensure access to public health information regarding the pandemic for people with disabilities, particularly those with sensory and intellectual disabilities.
- d) Failing to provide financial support to the most vulnerable and to community-based organisations.
- e) Failing to meaningfully engage and consult with people with disabilities and OPDs.

Support required from state authorities, donors, and partners:

The most pressing concern for the organisations surveyed was a lack of financial support from both donors and the government, followed by concerns about organisational stagnation and low levels of engagement from external donors and internal members. Organisations were also concerned about staff burnout and the lack of government oversight around the implementation of key reforms decentralising health services.

Summary of recommendations

The findings of this research were presented to disability experts and activists who were asked to comment and formulate a set of recommendations. This is a summary of the 11 recommendations formulated as an outcome of this process. A full version of these recommendations is presented at the end of the full report, which is released separately.

The research presented in this report demonstrates how political and economic responses to the pandemic have both magnified and amplified the intersecting inequalities of gender, age, socio-economic status, and location for people with disabilities in Ukraine. It is essential that public authorities in Ukraine at all levels of governance recognise and support the organisations of people with disabilities (OPDs) as key actors in ensuring and protecting the rights of the persons they are taking care of.

- 1. OPDs must be recognised as key stakeholders in planning for and sustaining the continuity of basic life support services in the event of any future public health or other emergencies. The Government and the Parliament of Ukraine should ensure that OPDs' unique functions and roles are recognised at the legislative level. The Government of Ukraine should establish clear criteria for registering OPDs and should maintain an up-to-date register of all OPDs in Ukraine. All decision-making bodies must systematically and openly approach, consult and involve, in a meaningful and timely manner, OPDs at all levels of governance in Ukraine.
- 2. The Government of Ukraine should continue supporting the organisational activities of OPDs. Some immediate measures to ensure the continuity of OPDs in the current environment may include: (a) enabling OPDs to lease state or communal property without holding an auction; (b) enabling OPDs to receive subsidies when leasing state or communal property; and (c) providing needsbased grant assistance towards electricity, water/sewage rates and other utility payments for registered OPDs.
- 3. The Government of Ukraine should allocate dedicated funding to support day-to-day organisational activities of OPDs. International donors should prioritise organisations 'of' persons with disabilities over organisations 'for' persons with disabilities, and should allocate funding to cover organisational costs in addition to supporting short-term events or projects.
- The Government of Ukraine, in close cooperation with OPDs, should develop a rapid response protocol to establish a mechanism

for rapid translation, interpretation, and dissemination of time-critical information in the event of current or any future public health or other emergencies. Public authorities in Ukraine must ensure that all information is available in accessible digital formats and, when required, through the provision of sign language interpreters, Easy Read text and plain language, Braille and tactile communication.

- 5. All public authorities in Ukraine must ensure that all electronic resources designed to facilitate the process of local democracy or 'open government' are fully accessible, including web-site interfaces.
- The Government of Ukraine should allocate dedicated funding and support to enterprises established by OPDs including tax exemptions and preferential government/ public procurement.
- 7. The Government of Ukraine must work with public authorities at all levels of governance to ensure that sufficient funding is allocated to deliver social services (of sufficient quality and quantity) to people with disabilities. OPDs should be actively involved in the process of continuous monitoring of the quality of the social services delivery. The Government, in close cooperation with OPDs, should develop a rapid response protocol to ensure the continuity of social services delivery in the event of any future public health or other emergencies.
- 8. The Government of Ukraine should provide further opportunities to develop competencies, knowledge, and the skills of OPDs (and their representatives) on the rights-based approach to disability.
- 9. The Government of Ukraine should ensure that OPDs are supported in their efforts to overcome any digital divides, including access to suitable devices and internet connection, as well as digital literacy.
- 10. The Government of Ukraine should require all public authorities to develop (in cooperation with OPDs) context-specific mechanisms to

involve OPDs in the decision-making, implementation, and evaluation process, and to give due consideration and priority to the opinions and views of OPDs when addressing issues directly related to persons with disabilities.

11. The Government of Ukraine should consider adopting a range of specific measures to encourage civic participation, engagement, and awareness among local communities to facilitate support and partnership between OPDs and volunteers, donors, and other stakeholders.

