

## SOCIOGRAPHY

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### ***The impact of the COVID-19 pandemic on people with disabilities in Ukraine: Perspectives of the organisations of persons with disabilities***

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### *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 (IDPs) 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 focusing on disability, being co-designed and co-delivered in partnership with people with disabilities in Ukraine, particularly IDPs.

The research is being delivered in four phases. This working paper covers the results of Phase 1, which focuses on the views and perspectives of OPDs working people with disabilities across Ukraine (excluding the temporarily occupied territories of this country). Phase 2 of the project involves interviews with people with disabilities (including IDPs) from ten regions in Ukraine with the largest numbers 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 consists of 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 throughout 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 non-governmental 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 in their own words the impact of the pandemic upon their organisation's work and the people that they care for. A descriptive analysis of the quantitative

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1 UK Research and Innovation (UKRI) is the national funding agency investing in science and research in the UK. The Global Challenges Research Fund (GCRF) supports cutting-edge research to address challenges faced by developing countries. AHRC funds outstanding original research across the whole range of the arts and humanities. For further details visit the UKRI website (<https://www.ukri.org>).

data was performed using SPSS while the qualitative data were coded and analysed using an inductive thematic analysis through NVIVO<sup>1</sup>.

## *Results*

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

**The impact of the pandemic on people with disabilities in Ukraine.** A key theme which emerged as an outcome of the organisational survey analysis was *the inaccessibility of healthcare*. Respondents mentioned a general deterioration in the health of people with disabilities due to long-term effects of COVID-19, chronic conditions becoming aggravated through interrupted access to healthcare and a significant impact on psychological well-being. Access to healthcare was affected by the repurposing 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, the necessity to give 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 growing costs of medication, as well as interruptions to the supply of prescriptions. Respondents also described difficulties obtaining personal protective equipment (PPE) and paying for COVID-19 tests (or poor availability of free testing).

*Psychological well-being, 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 with accessing digital technologies for online contact, as well as owing to the lack of provisions for people with hearing impairment. Respondents also reported increased levels of stigmatisation of people with disabilities.

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, as well as suspension of catering, cultural, shopping and entertainment establishments. These restrictions (although most of them had been lifted by the time of conducting the survey in May–June 2021) had a considerable impact on persons

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1 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>. NVIVO is a qualitative data analysis software package produced by QSR International; for further details see <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>

with disabilities who had 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 unreachable 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 UAH 1,000<sup>1</sup> was made available by the government [Ministry of Social Policy of Ukraine, 2020], this was insufficient to meet the needs of most people with 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 worsening financial situation was linked to the ongoing impact of the pandemic through loss of jobs and income, as well as 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, implied that many could not access online portals for government departments or online learning, whereas 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 particular 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:

- Children with disabilities or households where one or both parents are 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 well-being; besides, their development suffered if there were issues accessing online education and support networks.
- Older persons with disabilities had trouble with accessing «technical means of rehabilitation»<sup>2</sup>, obtaining PPE, hygiene items and disinfectants (to minimise exposure to COVID-19). That was combined with heightened difficulty reaching shops, hospitals, social services and places of employment. They were more susceptible to poverty through job losses and were disadvantaged in terms of finding work again. They were also reportedly more likely to suffer from digital poverty which resulted in poor access to online support networks and, subsequently, greater social isolation.

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1 1,000 Ukrainian hryvnias amounted to US\$36.96 or £29.88 according to the exchange rate of the National Bank of Ukraine as of 23 April 2020 (<https://tables.finance.ua/ru/currency/official/-/1/2020/04/23>).

2 A state-funded system of access to rehabilitation and assistive technologies in Ukraine.

- People living in rural areas experienced greater difficulty in accessing essential services and online resources.
- People who are blind or partially sighted encountered 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.
- 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 in television broadcasts, which was critical during public health announcements regarding the pandemic. Face coverings created a further communication barrier for those who rely on lip-reading.
- 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 specific social security payments (for IDPs and persons with disabilities). Moreover, these people continued to have problems with accessing healthcare, education and other services. This was often compounded by difficulty in registering as an IDP or a person with a disability in the absence of direct contact with relevant government officials.

IDPs with disabilities also faced 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 pandemic on the organisations of persons with disabilities in Ukraine.** As it was mentioned earlier, 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 upon their own organisational activities.

*Changes to the 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 were struggling 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 had resulted in reductions in the volume and quality of services they were able to offer. Some did carry on 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 reorganise 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 perform core organisational activities, delayed or withdrawn financing, the lack of knowledge about available funding opportunities, as well as the lack of resources and skills to comply with complex administrative 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 interaction, meaningless communication («tick-box» exercises) or nonconstructive and ineffective cooperation. Organisations also noted that support from volunteers had largely declined for a variety of reasons, including fear of infection, social distancing requirements and thus a lack of face-to-face contact, financial difficulties encountered by volunteers, as well as a general loss of motivation because 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. They also mentioned beneficial outcomes from online working such as reduced barriers to 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:

- 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;
- 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;
- failing to ensure access to public health information regarding the pandemic for people with disabilities, particularly those with sensory and intellectual impairments;
- failing to provide financial support to the most vulnerable and to community-based organisations;
- 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 worried 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 prepare 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 ought to 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 needs-based grant assistance towards electricity, water/sewer 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 ought to allocate funding to cover organisational costs in addition to supporting short-term events or projects.
4. The Government of Ukraine, in close cooperation with OPDs, should develop a rapid response protocol to set up 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 texts 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 website interfaces.

6. The Government of Ukraine should allocate dedicated funding and support to enterprises established by OPDs, including tax exemptions and preferential government (or 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 adequate quality and quantity) to people with disabilities. OPDs should be actively involved in the process of continuous monitoring of the quality of the social service delivery. The Government, in close cooperation with OPDs, ought to develop a rapid response protocol to ensure the continuity of social service 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 skills among 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; furthermore, 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 in order to facilitate support and partnership between OPDs, volunteers, donors, as well as other stakeholders.

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## **КИРИЛО ШАРАПОВ, ДЕВІД АНДЕРСОН, ОЛЬГА БУРОВА, ВІКТОРІЯ НАЗАРЕНКО, ОЛЕНА ПОЛІЩУК**

### **Вплив пандемії COVID-19 на людей з інвалідністю в Україні: з погляду організацій осіб з інвалідністю**

*Згідно з даними Національної соціальної служби та Пенсійного фонду, в Україні станом на початок 2021 року було зареєстровано щонайменше 2 724 100 осіб з інвалідністю. Утім, фактичні цифри можуть бути вищими через брак достовірної докладної статистики. Пандемія коронавірусу загострила проблеми, пов'язані з недостатньою реакцією органів державної влади України щодо соціально-економічного самопочуття людей з інвалідністю. За інформацією Міністерства охорони здоров'я, станом на 1 січня 2022 року в Україні було діагностовано коронавірусну хворобу у 3 672 675 осіб, офіційно зафіксовано 96 089 смертей. Ці цифри теж можуть бути неточними. Реальні загальні показники можуть виявитися значно вищими, а дані про інфікування COVID-19 з розбивкою за видом інвалідності не збиралися взагалі. На Сході України, що постраждав від збройного конфлікту, та для людей, які зазнали внутрішнього переміщення внаслідок воєнних дій, ситуація на момент опитування була ще складнішою. Особливо це стосувалося людей з обмеженими можливостями, для яких переміщення тільки посилює наявні проблеми. Згідно з даними Міністерства соціальної політики, станом на 6 липня 2021 року в Україні було зареєстровано 1 473 650 внутрішньо переміщених осіб (ВПО), зокрема 51 586 людей з інвалідністю. Пандемія коронавірусу істотно вплинула на доступ цих груп людей до медичних і соціальних послуг, погіршила їхню житлову ситуацію та поглибила бідність. Локдаун також призвів до закриття пунктів в'їзду/виїзду між районами країни, контрольованими українським урядом і сепаратистами, що значно обмежило мобільність місцевого населення. Наразі виконано мало досліджень (як кількісних, так і якісних), що могли би дати всебічний огляд проблем, з якими стикаються люди з інвалідністю в Україні, — зокрема ті, що живуть у ситуації тривалого переміщення. Також бракує досліджень та інформації стосовно впливу COVID-19 на ці групи населення та відповідної реакції держави на місцевому й регіональному рівнях. Подане в цій статті опитування покликане певною мірою заповнити цю прогалину.*

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

## **КИРИЛЛ ШАРАПОВ, ДЭВИД АНДЕРСОН, ОЛЬГА БУРОВА, ВИКТОРИЯ НАЗАРЕНКО, ЕЛЕНА ПОЛИЩУК**

### **Воздействие пандемии COVID-19 на людей с инвалидностью в Украине: с точки зрения организаций лиц с инвалидностью**

*Согласно данным Национальной социальной службы и Пенсионного фонда, в Украине по состоянию на начало 2021 года было зарегистрировано по меньшей мере 2 724 100 лиц с инвалидностью. Впрочем, фактические цифры могут быть выше ввиду отсутствия достоверной подробной статистики. Пандемия коронавируса обострила проблемы, связанные с недостаточной реакцией органов государственной власти Украины относительно социально-экономического положения людей с инвалидностью. Согласно информации Министерства здравоохранения, по состоянию на 1 января 2022 года в Украине коронавирусная болезнь была диагностирована у 3 672 675 лиц, официально зафиксировано 96 089 смертей. Эти цифры тоже могут быть неточными. Реальные общие показатели могут оказаться значительно выше, а данные об инфицировании COVID-19 с разбивкой по виду инвалидности не собирались вообще. На Востоке Украины, который пострадал от вооруженного конфликта, и для людей, которые подверглись внутреннему перемещению вследствие военных действий, ситуация на момент опроса была еще сложнее. Особенно это касалось людей с ограниченными возможно-*

стями, для которых перемещение только усиливает существующие проблемы. Согласно данным Министерства социальной политики, по состоянию на 6 июля 2021 года в Украине было зарегистрировано 1 473 650 внутренне перемещенных лиц (ВПЛ), в частности, 51 586 людей с инвалидностью. Пандемия коронавируса существенно повлияла на доступ этих групп людей к медицинским и социальным услугам, ухудшила их жилищную ситуацию и углубила бедность. Локдаун также привел к закрытию пунктов въезда/выезда между районами страны, контролируемые украинским правительством и сепаратистами, что значительно ограничило мобильность местного населения. Пока выполнено мало исследований (как количественных, так и качественных), способных дать всесторонний обзор проблем, с которыми сталкиваются люди с инвалидностью в Украине, — в частности, те, которые находятся в ситуации длительного перемещения. Также не хватает исследований информации касательно влияния COVID-19 на эти группы населения и соответствующей реакции государства на местном и региональном уровнях. Представленный в этой статье опрос призван в какой-то мере восполнить этот пробел.

**Ключевые слова:** COVID-19, инвалидность, внутреннее перемещение, права человека, организации людей с инвалидностью, неравенство, дискриминация, доступность

## KIRIL SHARAPOV, DAVID ANDERSON, OLGA BUROVA, VIKTORIA NAZARENKO, OLENA POLISHCHUK

### The impact of the COVID-19 pandemic on people with disabilities in Ukraine: Perspectives of the organisations of persons with disabilities

*According to the data from the National Social Service and Pension Fund, 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 and detailed statistics. The coronavirus pandemic has exacerbated existing problems with inadequate response by public authorities in Ukraine relating to the social and economic well-being of people with disabilities. According to the data published by the Ministry of Health, 3,672,675 people in Ukraine had been diagnosed with COVID-19 by 1 January 2022, and 96,089 deaths had been officially recorded. These figures are likely to be inaccurate either, with real totals much higher, while no data has been collected on COVID-19 infections disaggregated by disability. At the time of the survey, the situation was even more difficult in the conflict-affected east of Ukraine and for people who had 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. These are figures provided by the Ministry of Social Policy. The coronavirus 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. Lockdown also resulted in the closure of entry/exit points between government-controlled and separatist-held areas of the country, severely curtailing the mobility of local populations. So far, little research, either quantitative or qualitative, has done 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, as well as the inadequate state response at local and national levels. The survey presented here is supposed to fill somewhat this gap.*

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