

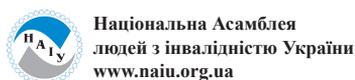


COVID-19 | Disability | Displacement in Ukraine
a gcrf ahrc funded research project

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

*Perspectives of People with Disabilities
& Implications for Public Health
and Other Emergencies,
including Conflict and Post-conflict Recovery*

Project Report (Part 2)



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Project Report (Part 2)

September 2022

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List of Abbreviations

CBIs — community-based interviewers.

OPDs — organisations of persons with disabilities which were set up, are led by and/or bring together people with disabilities in Ukraine.

Family Doctor — a general practitioner (GP) providing primary healthcare; there has been a move from the system of ‘district doctors’ (in the Soviet system) to ‘family doctors’ within the context of the current healthcare reform in Ukraine.

GP practice or GP surgery — a ‘policlinic’ within the context of the Ukrainian healthcare system; a dedicated healthcare facility that treats outpatients (normally, not part of a hospital).

PHOE — public health and other emergencies.

A Note on Terminology

Authorities: references to ‘authorities’ and/or ‘public authorities’ [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.

COVID-19: within the context of this report, references to COVID-19 signify references to an infectious disease caused by the SARS-CoV-2 virus¹.

COVID-19 pandemic response: within the context of this report, references to ‘COVID-19 pandemic response’ signify a series of responses by public authorities in Ukraine to mitigate the spread and the impact of COVID-19 on public health in Ukraine.

Participants and **interviewees** are used interchangeably in the context of this report.

¹See <https://www.who.int/health-topics/coronavirus>

INTRODUCTION

This report is released as the war continues to rage across Ukraine as of September 2022 — more than half a year since Russia launched 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, millions of Ukrainians have now fled their country in search of safety and security², millions more have been displaced internally³ or remain stranded in affected areas, and estimated hundreds of thousands have been forcibly deported/relocated to Russia by the occupying forces⁴.

In addition, multiple and increasing civilian casualties are being reported⁵; critical civilian infrastructure, including healthcare facilities, is being deliberately targeted and destroyed⁶.

²<https://data.unhcr.org/en/situations/ukraine>

³<https://www.unhcr.org/ua/en/internally-displaced-persons>

⁴<https://www.state.gov/russias-filtration-operations-forced-disappearances-and-mass-deportations-of-ukrainian-citizens/>

⁵<https://www.grid.news/story/global/2022/07/21/how-many-civilians-have-died-in-the-ukraine-war/> and <https://www.theguardian.com/world/2022/may/10/ukraine-civilian-deaths-higher-official-toll-un-warns>

⁶In total, as of June 1, 581 health care facilities, including 557 in the public sector, were reported damaged or destroyed. See <https://documents1.worldbank.org/curated/en/099545009082226957/pdf/P1788430ed0fce0050b9870be5ede7337c6.pdf> (p. 83)

Supply chains have been disrupted across Ukraine interrupting and, in some cases, severely limiting access to food, medication, and other basic items. Numerous reports and eyewitness accounts of war crimes against civilians, including rape and summary executions, of residential areas and critical infrastructure deliberately targeted by Russian troops prompted the International Criminal Court to commence an investigation of alleged war crimes and crimes against humanity that are being committed in Ukraine⁷.

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).

⁷<https://www.icc-cpi.int/ukraine>

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.

The UN Special Rapporteur on the Rights of Persons with Disabilities 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 the 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 unleashed upon Ukraine in February 2022 turned these vulnerable situations into a humanitarian catastrophe falling heavily on persons with disabilities across Ukraine. Despite the UNSC Resolution 2475 “recognising the need for timely data and information on, and analysis of, the impact of armed conflict on persons with disabilities” (UN General Assembly, 2021, preamble), little reliable research co-produced with persons with disabilities and their organisations in Ukraine exists as of today. According to the initial reports by persons with disabilities and their organisations, including the National Assembly of People with Disabilities of Ukraine — our co-investigator on this project — people with disabilities have been confronted with a range of

life-changing challenges, including lack of accessible and reliable information; disrupted or fully withdrawn access to medical services, including essential medication; food shortages; lack of accessible evacuation procedures, accessible evacuation or safe zones; increased exposure to COVID-19 in shelters.

As the war and atrocities inflicted by the Russian state intensify, more persons with disabilities are now confronted with homelessness, limited availability and accessibility of the evacuation options and, increasingly, new sets of challenges as the internally displaced, forcibly deported/relocated, or as refugees. These challenges are distributed unevenly not only in relation to where people are in Ukraine, but also in terms of how their individual impairments intersect with other social identities and contexts, including gender, ethnicity, age, socio-economic situation, sexuality, family status, and access to family and friends (in Ukraine and abroad) and local communities.

This report is being published as a stand-alone document however it constitutes Part 2 of the overall project report associated with the GCRF/AHRC funded project ‘The impacts of COVID-19 on Persons with Disabilities in Ukraine (with a particular focus on internally displaced Persons with Disabilities)’⁸. Part 1 of the project report was published several days after Russia invaded Ukraine in February 2022. It documents the views of organisations of persons with disabilities on the pandemic and the pandemic response by the authorities in Ukraine.

The publication of Part 2 has been delayed for several reasons. All of our project partners in Ukraine, including our community-based interviewers, have been affected by the escalating violence; their safety and security (both physical and

⁸<https://gtr.ukri.org/projects?ref=AH%2FV013505%2F1>

psychological) remained our key priority. Some of them were forced to leave Ukraine seeking refuge across Europe and beyond. We know that some of our interviewees (whose views and opinions are presented in this report) are no longer in touch and we are unable to ascertain what happened to them.

Another reason to delay the publication of Part 2 was the understandable overshadowing of any COVID-19 concerns in Ukraine with violence and daily atrocities committed against Ukrainian women, men, and children on an unprecedented scale. The scale and gravity of these atrocities have not abated as we are releasing this report in September 2022 with no realistic de-escalation trajectory in sight. The key focus of this report is our interviewees' views and perspectives on how COVID-19 and the pandemic response by public authorities affected them as persons with disabilities in Ukraine. We believe that some of the findings presented in this report — as they relate to the handling of the unprecedented public health emergency which cut across all areas of life — will have relevance to public health and other emergencies (PHOE) generally. Our findings do not offer a magic solution to safeguarding persons with disabilities in the context of the ongoing war; however, they offer a unique perspective — informed by what our participants told us — about what matters to them at the time of disruption and turmoil.

In this project, 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, described by Mitchell and Snyder (2020, p. 52) as one of the ‘devalued populations’ for whom the process of ‘active abandonment by the state’ transforms impairment into disability and the everyday life experience of disablement and disadvantage. 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’.

... that *amplifies* all that we *always already* knew about how power works to create, uphold and tighten structural inequalities in this world. The COVID-19 looking glass does not show us a world turned upside down because of the effects of a global pandemic; it shows us more starkly than ever how unequal our world *is*, has always been.

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.

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, 2022a). 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?

METHODOLOGY

This report 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)’⁹. Phase 1 relied on an online survey to engage with more than one hundred organisations of persons with disabilities in Ukraine to record unique organisational 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 (Sharapov et al., 2022b) published in March 2022.

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.

⁹<https://gtr.ukri.org/projects?ref=AH%2FV013505%2F1>

As a project, we set up a series of support structures to help our CBIs with interviewing focussing on three distinct but interrelated issues:

- (a) interviewers' and interviewees' safety, and ethical considerations in the context of qualitative research with persons with disabilities;
- (b) interviewing skills and disability considerations in participatory research;
- (c) human rights as a framework for meaningful and inclusive research.

We organised two series of online workshops. The first one focussed on conducting participatory research with people with disabilities by people with disabilities and was delivered by Dr Susie Balderston — a disability activist and researcher (currently, at the time of writing this report, a Research Fellow in the School of Law at the University of Strathclyde¹⁰). This series of three workshops covered the following topics: principles for good research; ethics, safety, and interviewing skills; and how to use research findings to foster change, and who do we need to tell our findings to¹¹.

The second series focussed on using human rights as the framework for researching with persons with disabilities, and as a framework for removing barriers to being and doing. It was delivered by Dr Jo Ferrie, a co-investigator on this project and Senior Lecturer at the University of Glasgow¹² (at the time of writing).

¹⁰See <https://www.strath.ac.uk/staff/balderstonsusiedr/>

¹¹Copies of the training materials for both series are available here: <https://www.covidanddisability.com/training-materials>

¹²See <https://www.gla.ac.uk/schools/socialpolitical/staff/joferrie/>

Throughout the interview period, all CBIs were supported by Olena Polishchuk, a research fellow on this project and a disability activist, based at the National Assembly of People with Disabilities, who provided day-to-day support and served as a first point of contact for all CBIs for any queries or concerns. Our research collaboration was informed by three principles (reviewed on the project's website¹³): co-researching in dialogue, situated togetherness, and emancipatory research.

The design of the interview schedule was led by our co-investigators in Ukraine and involved a consultation process with disability activists in Ukraine. The starting point were these two questions:

- As a disability activist and as a person with disability, what do you think we need to know about the impact of COVID-19 on persons with disability in Ukraine?
- What data or evidence would help you and your organisation (of persons with disabilities) to advocate and campaign on behalf of people with disabilities in Ukraine?

We organised a series of research design workshops to discuss different views and agree on the interview schedule. As a result, the interviews broadly focussed on the following 8 themes: availability and accessibility of information about COVID-19; experiences of getting infected with COVID-19 and of recovery; availability and accessibility of healthcare during the pandemic including non-COVID-19 related healthcare services; the impact of the pandemic on employment and education; the impact of the pandemic on the individual financial situation and cost of living; accessibility and availability of public transport; psychological impact of the pandemic; and assistance/help received from public authorities to cope with the pandemic.

¹³See <https://www.covidanddisability.com/research-approach>

We relied on our CBIs to identify all interviewees in this sample. Since all of our CBIs represented different community-based organisations of persons with disabilities, they relied on their existing community contacts to invite persons with disabilities to take part in this study. In this study, we relied on quota sampling, as a form of non-probability sampling, to acquire data from specific population subgroups. Our participants were selected non-randomly and based on convenience since all participants were known contacts of our CBIs. In conversation with our co-investigators at the National Assembly of People with Disabilities, we established a series of fixed quotas (i.e., quotas non-proportional to the actual population distribution) at the outset which guided our participant recruitment. These quotas included: that all of the participants should self-identify and be registered (through the Ukrainian system of ‘disability groups’) as a person with disability, and at least 40% should be registered as having a Group 1 disability¹⁴; at least 50% of all interviewees should self-identify and/or be registered as an internally displaced person; an equal distribution of participants by gender; at least 20% of participants should be of 60 years old of age and above to ensure that the views of older persons with disabilities are included; at least 20% of participants should reside in rural areas. Table 1 below demonstrates the extent to which these quotas were achieved within the context of our final sample of 301 interviewees.

All interviewees had at least three engagements with our community-based interviewers (CBIs). Firstly, they were approached by CBIs informally with an invitation to take part in a research project which investigated the impact of the pandemic on persons with disabilities in Ukraine. At this stage, we

¹⁴The most complex group of disability as per the Ukrainian system of classification based on the International Classification of Impairments, Disabilities and Handicaps rather than the International Classification of Functioning, Disability and Health.

Table 1. Sampling quotas

Quota	Planned	Achieved
People with disabilities	100%	100%
Internally displaced people with disabilities	50%	55.9%
Registered as having Group 1 of disability	40%	48.8%
Gender (female / male)	50% / 50%	57.1% / 42.9%
Participants who are 60 years old and above	20%	22.3%
Participants who live in rural areas	20%	16.3%

emphasised that this was an academic project funded by the UK Government, co-delivered with the National Assembly of People with Disabilities of Ukraine, and that it was completely independent of the Ukrainian authorities. CBIs used their existing lists of organisational contacts which included persons with disabilities who may have: contacted the organisation previously with a query; received support, advice or service from the organisation previously; subscribed to the organisational electronic bulletins, or followed the organisation on their social media. The second round of telephone conversations was organised with the participants who said they would be interested to take part. These conversations focussed on what this project was about, organisations participating in the project, its aims and objectives, methods, and anonymity and confidentiality considerations. All CBIs used the project information sheet and consent forms which were designed as part of the ethical review for this project (approved by the ethics committee of the Institute of Sociology of the National Academy of Sciences of Ukraine). At the end of these conversations, all participants (including their carers or guardians — see below) were offered a copy of the information sheet and of the consent form (in appropriate accessible formats). All participants were encouraged to get in touch with CBIs with any questions and to either confirm or withdraw their interest in

the project. The third engagement was the interview. At the start of the meeting, ethical considerations were once again reviewed, and all participants were asked to confirm their consent. We emphasised participants' right to withdraw consent (and any recorded data) at any stage of the interview and during a two-week period following the interview, before the recording and transcripts were fully anonymised. Once the informed consent was given, the interview itself included two parts, collecting the demographic data for each participant and a series of project-specific questions around the 8 identified themes (see above). All interviews were securely recorded using recording devices provided by the project to our CBIs; during the interview, CBIs made notes on the interview form which was provided in advance. After the interview, audio files were assigned coded names to protect the identities of the interviewees, securely transferred to the National Assembly of People with Disabilities of Ukraine, and securely uploaded onto a dedicated encrypted project drive. Following each individual interview, CBIs completed an electronic survey which was hosted on Qualtrics Platform to record responses which could be quantified or transformed into a multiple-choice answer using a series of options which were pre-designed (as explained above) as part of the interview schedule development. CBIs summarised responses to open-ended questions, based on the notes taken during the interview, entering them into the Qualtrics questionnaire to assist with the analysis. All audio-files were transcribed by a dedicated member of staff before being uploaded into and analysed using NVivo. The identified key themes were discussed during a series of on-line participatory analysis workshops involving our colleagues at the National Assembly of People with Disability of Ukraine. The outcomes of these workshops informed the content of this report and our 'Guiding Questions'.

WHO OUR INTERVIEWEES ARE

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 report, 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, as shown on the map below. The project purposefully focussed 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 Table 2.

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 (see World Bank, 2022). Similarly 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%).

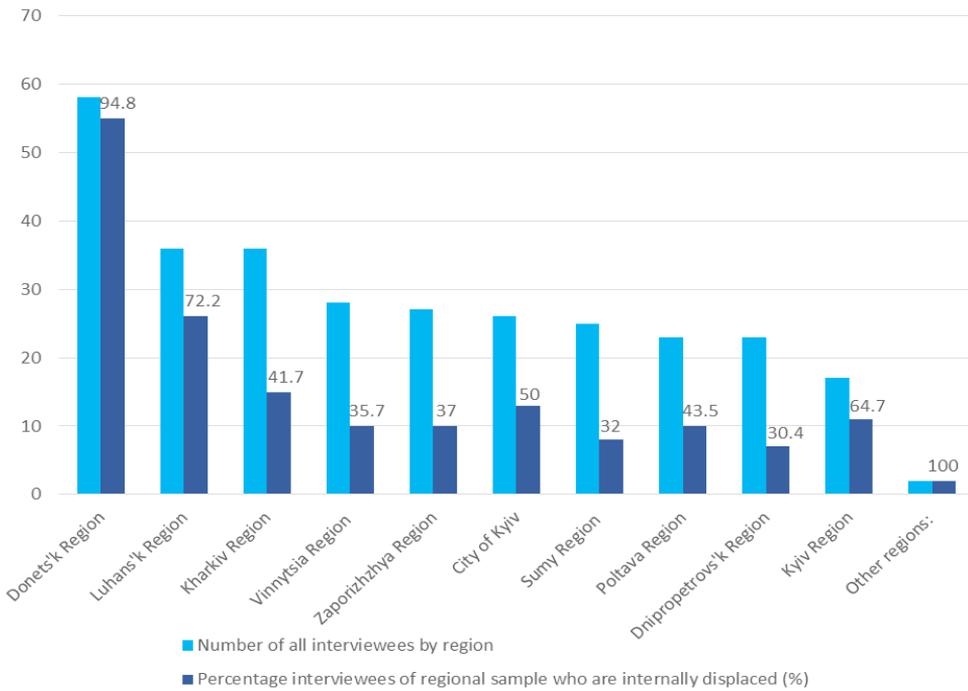
Table 2. Distribution of Interviewees by Region and Displacement Status.

Location / Region	Number of all interviews by region (% of the overall sample of 301)	Number of internally displaced interviewees by region (% of the regional sample)
Donets'k Region	58 (19.3%)	55 (94.8%)
Luhans'k Region	36 (12.0%)	26 (72.2%)
Kharkiv Region	36 (12.0%)	15 (41.7%)
Vinnitsia Region	28 (9.3%)	10 (35.7%)
Zaporizhzhya Region	27 (9.0%)	10 (37.0%)
City of Kyiv	26 (8.6%)	13 (50.0%)
Sumy Region	25 (8.3%)	8 (32.0%)
Poltava Region	23 (7.6%)	10 (43.5%)
Dnipropetrovs'k Region	23 (7.6%)	7 (30.4%)
Kyiv Region	17 (5.7%)	11 (64.7%)
Other regions:	2 (0.7%)	2 (100%)
Total	301 (100%)	167 (out of 299 who agreed to confirm their IDP/non-IDP status) or 55.9%

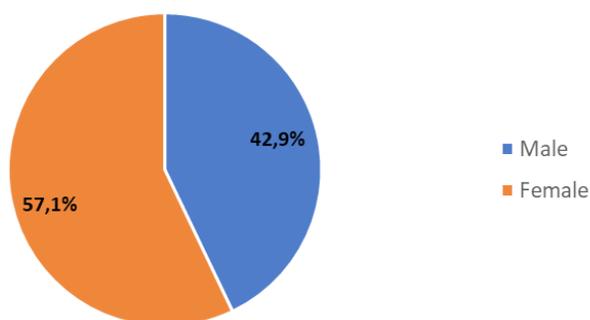
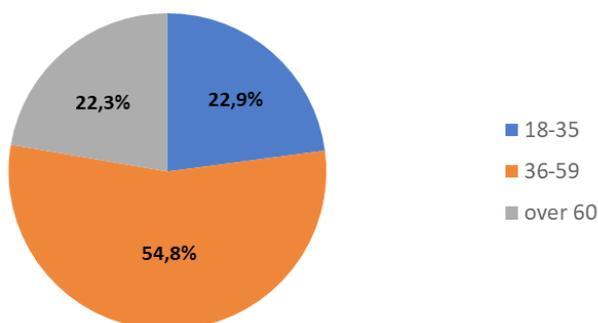
Figure 1. Regions of Ukraine Included in the Survey¹⁵



Figure 2. Interviewees by Region and % Internally Displaced



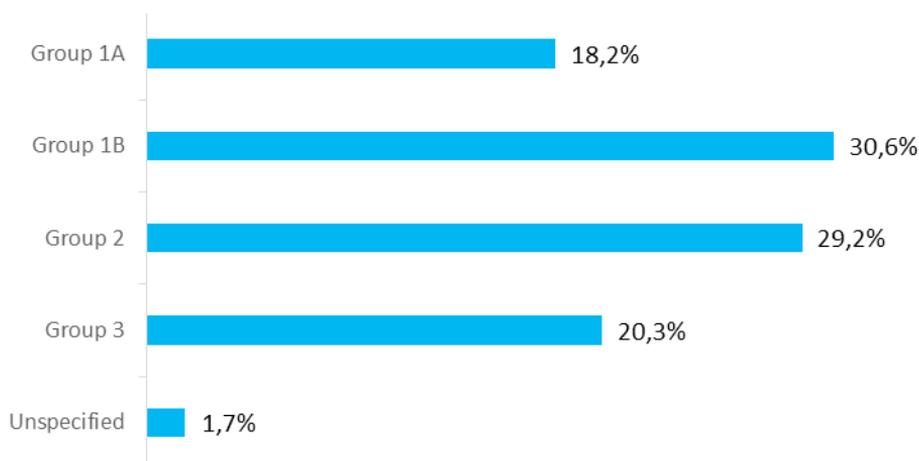
¹⁵Map generated on <https://paintmaps.com/map-charts/221/Ukraine-map-chart>

Figure 3. Distribution of Interviewees by Gender**Figure 4.** Distribution of Interviewees by Age

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’¹⁶.

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.

¹⁶For a more detailed discussion of key criticisms of this system see Part 1 of the report (Sharapov et al., 2022a, p.41).

Figure 5. Distribution of Interviewees by Disability Group

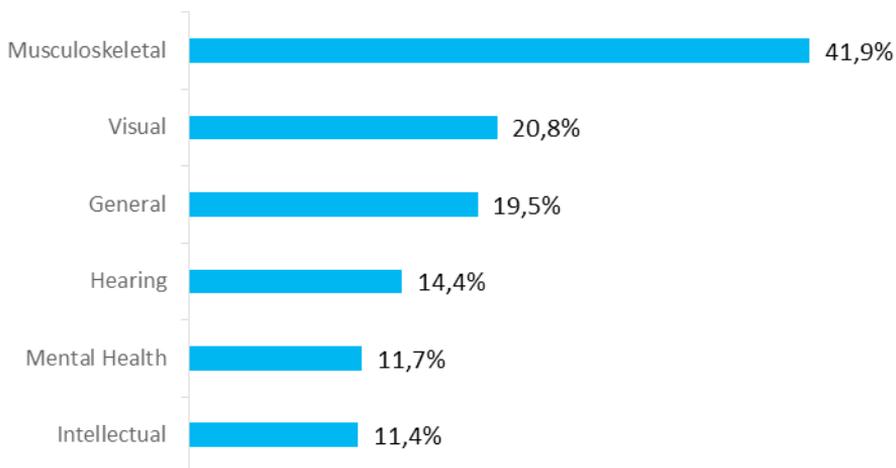
In addition to the state-allocated ‘group’ of disability, which remains a key pre-requisite for accessing all disability-specific benefits in Ukraine, all participants were asked to indicate the type of functional impairment underlying their disability. Of the 298 interviewees who answered this question, the majority (82.6%) reported having one type of impairment; this was followed by 12.8% who reported having two types of impairments, and 4.7% who reported having three and more types of impairments.

Overall, musculoskeletal impairments (including impairments which required the use of wheelchair) were the most prevalent type among participants in this survey (41.9%); these were followed by visual impairments (20.8%), ‘general conditions’ including cancer-related disabilities, cardiovascular conditions, diabetes etc. (19.5%), hearing impairments (14.4%), mental health (11.7%) and intellectual (11.4%) impairments. When disaggregated by IDP/non-IDP status, there was a noticeable difference between the following types of impairments (in percentage terms): hearing (about 17% among those who described themselves as internally displaced vs. 11% among those who were not internally displaced), visual impairments (17% vs. 24%), intellectual disabilities (7% vs. 17%), and ‘general

conditions' (26% vs. 11%). These differences can only be treated as indicative (and calling for further investigation as to the link between the type of impairment and the likelihood of mobility as a coping response to conflict and war) rather than representative due to the nature of the convenience sampling in this survey.

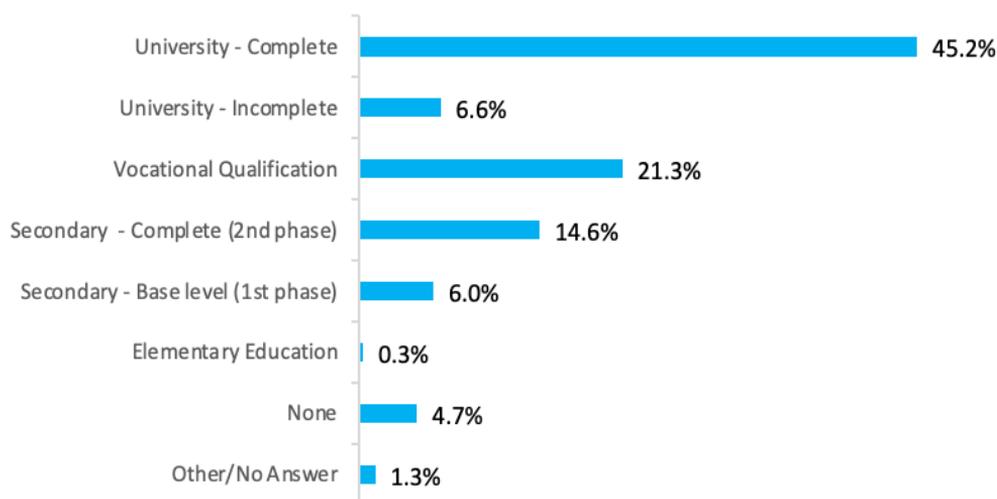
About 55.5% of participants (n=167) identified themselves as an internally displaced person; 2 participants did not answer this question; which means that the remaining 132 (or 43.9%) were not internally displaced.

Figure 6. Distribution of Interviewees by Type of Impairment

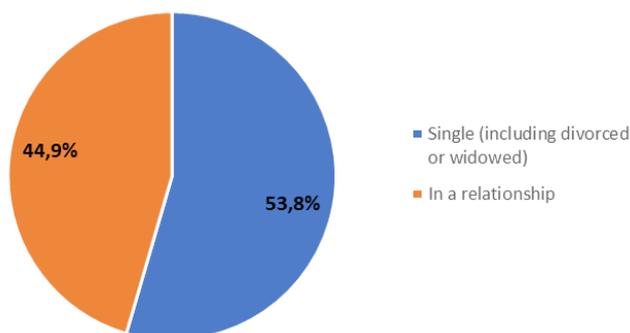


In terms of education¹⁷, the majority of interviewees had university (higher education) degrees, either complete (45.2%) or incomplete (6.6%): 21.3% of participants had a vocational qualification; 14.6% had fully completed secondary general education ('second phase'); 6.3% had a base level of secondary general education ('first phase'); one participant had only elementary education; 4.7% of participants indicated that they had no education; and 1.3% selected 'Other' or 'Would rather not answer'.

¹⁷For an overview of the current education system in Ukraine, see <https://wenr.wes.org/2019/06/education-in-ukraine>

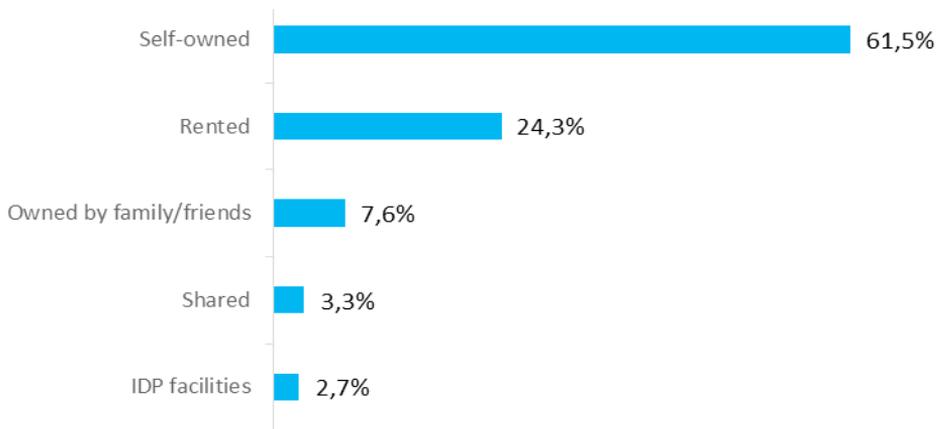
Figure 7. Distribution of Interviewees by Educational Level

Respondents were asked about the size of their household: 27% (81 out of 301) lived by themselves; 45% lived in a 2-person household; 14% lived in a 3-person household and the remaining 14% in a 4 and more person household. 53.8% of our interviewees were single, including those divorced or widowed; 44.9% said they lived with their husband/wife or a partner.

Figure 8. Distribution of Interviewees by Marital Status

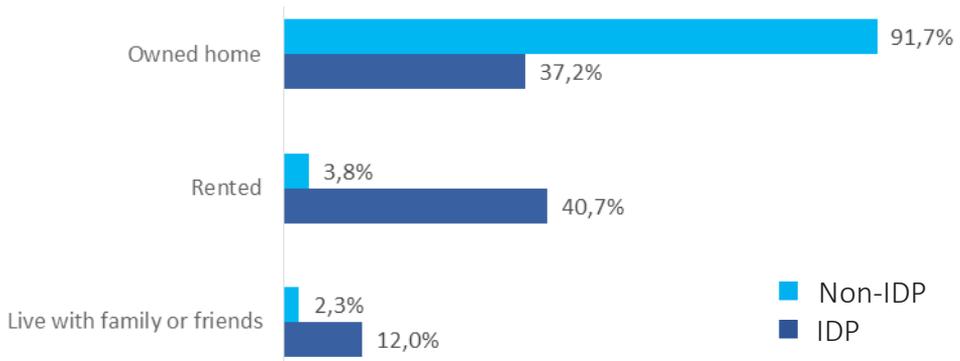
The majority of participants (61.5% of 301 individuals) lived in self-owned accommodation. This was followed by rented accommodation (24.3%); accommodation owned by their family members or friends (7.6%); shared accommodation ('гуртожиток') (3.3%); and shared dwelling facilities for IDPs (2.7%).

Figure 9. Type of Accommodation (IDP Interviewees)



Once disaggregated by IDP/non-IDP status, the outcomes of our survey are also reflective of significant differences in home ownership: among IDP respondents in our survey, 37.2% (of 167) said that they owned their housing (in comparison to 91.7% of non-IDP respondents); 40.7% lived in rented accommodation (in comparison to 3.8% of non-IDP respondents); 12.0% lived with family or friends (in comparison to 2.3% of non-IDP respondents)¹⁸.

Figure 10. Home Ownership by Non-IDP/IDP Status



¹⁸Access to accommodation remains one of the key problems for IDPs in Ukraine: a 2021 report issued by Norwegian Refugee Council (NRC, 2021) estimates that the rate of housing ownership in Ukraine was 92% for non-IDP households and 11% for IDP households. Other studies estimate that around 62% of IDPs within in Ukraine live in rented accommodation (IOM, 2021, p. 7), and that owning housing is a priority for all IDPS, but especially for vulnerable groups such as people with disabilities (OCHA, 2022, p. 33).

PHASE 2. FINDINGS

Information about COVID-19 and the pandemic

The World Health Organisation's (WHO, 2020) 'Disability Considerations during the COVID-19 Outbreak' identifies access to public health information by people with disabilities as one of the key considerations needed for people with disabilities during the COVID-19 outbreak and calls for all governments to ensure that public health information is available and is accessible (WHO, 2020, p. 2). Despite this, access to information for people with disabilities has been constrained throughout the pandemic, with much essential public health messaging on the virus and accessing healthcare not available in suitable formats for those with alternative communication needs, such as sight or hearing loss (OHCHR, 2020, p. 8). In an overview of the impact of the pandemic on people with disabilities in low and middle-income countries, Kubenz and Kiwan (2020, pp. 16 – 18) identified inaccessible information, technological barriers and language/literacy issues as the main obstacles preventing access to public health messaging.

People with disabilities have been found to experience higher levels of anxiety regarding the pandemic than other members of the public, which is exacerbated by this lack of information and the accompanying spread of misinformation regarding the virus and pandemic responses (OHCHR, 2020, p. 6). While social media such as Twitter has been suggested as one means for

people with disabilities to access information about the pandemic (Thelwall & Levitt, 2020), research has also found that there was a significant rise in unreliable information available there (Gallotti et al., 2020). This is accompanied by studies which found that people relying on social media and private information sources were less knowledgeable about the virus and less likely to follow social distancing guidelines (Fridman et al., 2020), increasing public health risks.

The provision of easily accessible information from public health bodies is therefore crucial for people with disabilities, to ensure that health messaging is accurate and reliable. However, a study of information accessibility found that more than 95% of national health services across the globe were found to have only partially followed Web Content Accessibility guidelines for making their websites accessible to people with disabilities, with Ukraine's containing the 3rd highest number of errors (Dror et al., 2020).

Prior to the pandemic, much public information and communication was not available in accessible formats for people with disabilities in Ukraine (Smusz-Kulesza, 2020, p. 28), suggesting that this will remain an issue during and after the pandemic. To explore the extent to which people with disabilities in Ukraine had access to critical information during the early stages of the pandemic, interviews included a set of questions dedicated to the availability and accessibility of information on COVID-19 and the COVID-19 pandemic response. We specifically asked interviewees to identify which sources of information they relied upon to understand the nature of COVID-19 (including symptoms) and how to minimise the risk of infection and transmission; whether they had access to the sufficient information and, if not, which information was missing; and whether information was available in accessible formats.

Sources of Information

Interviewees were asked to identify key sources of information about the pandemic. Among those who relied on one source (24.3% of all interviewees), the most popular sources of information were the Internet and Social Networks (for 58.9% interviewees relying on one source only), followed by Radio and Television (28.8%). Most interviewees (36.5%), however, relied on two sources of information with the most popular combination being the Internet & Social Networks plus Radio and Television (38.2% among those who relied on two sources), followed by the Internet & Social Networks plus Relatives and Friends (27.3%); and Radio and Television plus Relatives and Friends (13.6%). About a quarter of interviewees (24.9%) relied on three sources; and the remaining 14.3% relied on four or more sources of information about COVID-19 and the pandemic. Among all interviewees (whether they relied on one source of information or many), the most popular sources of information were the Internet and Social Networks, followed by Radio and Television, and Relatives and Friends (see Figure 13 below). Only 21% of interviewees relied on the official webpages of the Ukrainian authorities (at either central and local levels), and the overwhelming majority of those who did, considered these as one of the few but not the only source of information. These findings are summarised below.

Table 3. How many sources of information interviewees relied upon to learn about COVID-19 and COVID-19 pandemic response

Sources of Information	% of all interviewees
One source only	24.3
Two sources	36.5
Three sources	24.9
Four or more	14.3

Figure 11. Sources of Information (one source only)

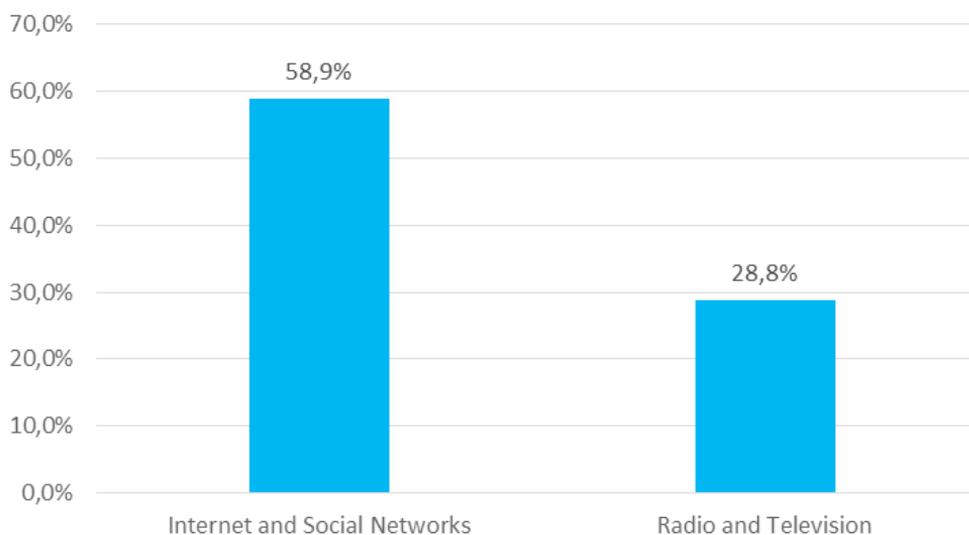


Figure 12. Sources of Information (two sources)

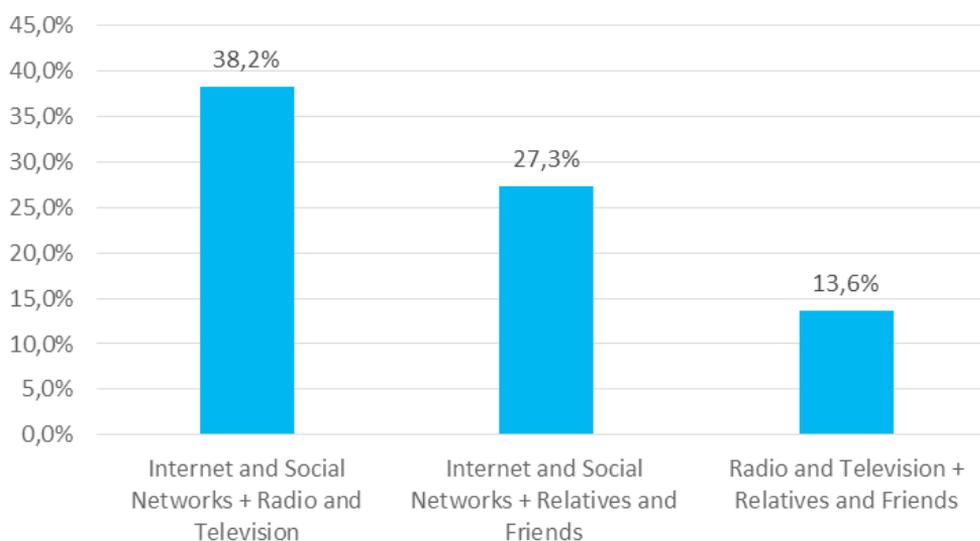
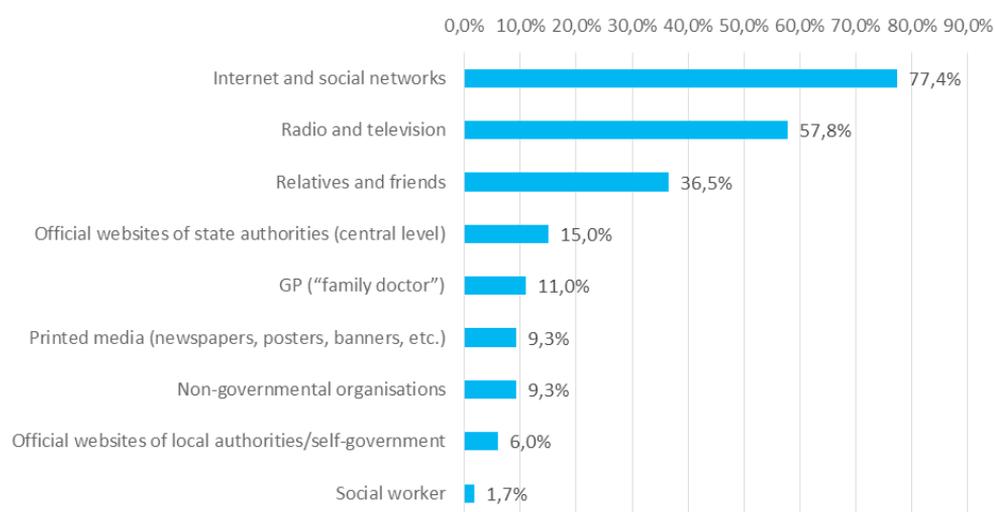


Figure 13. Respondents Who Relied on This Source (as the only source or as one of the few sources)



Availability of Information

With a range of sources to select from, interviewees were asked to assess whether they received enough information. The majority of interviewees (75.8%) 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. Some participants referred to an ‘overload’ of frightening information — especially at the early stages of the pandemic — which provided statistics on the number of infections and deaths rather than practical advice on how to avoid getting infected and what to do in case of suspected COVID-19 infection¹⁹. Interviewees were also concerned about the trustworthiness of information which was circulated on various social media platforms, and

¹⁹See, for example, Nicomedes & Avila (2020) discussing how health-related anxieties related to COVID-19 were magnified by specific media reporting.

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.

The vaccination programme in Ukraine commenced at the end of February 2021, and studies have noted that a lack of confidence in COVID-19 vaccines among the Ukrainian public has affected uptake (Holt, 2021; OECD, 2021). This is reflected in the responses from our interviewees, who commented on the lack of reliable information about different vaccination options, the efficacy of vaccinations, and potential side-effects. This lack of information did little to alleviate interviewees’ concerns about the potential impact of vaccinations on health conditions underlying their disability (see section ‘Getting vaccinated against COVID-19’ below).

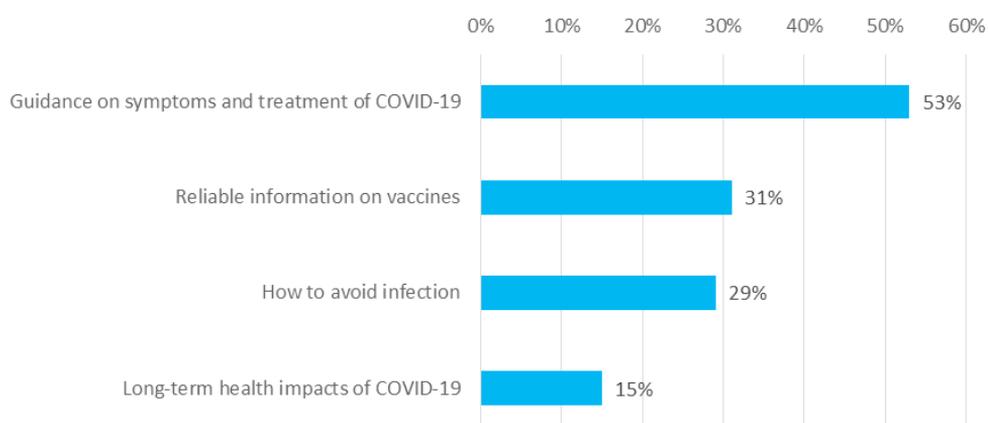
Similar concerns were raised among the 20.9% of interviewees who said there was not enough information about COVID-19. These participants were particularly concerned about the extent of the conflicting information about COVID-19. Others in this group commented on a range of negative psychological impacts due to the continuous stream of COVID-related information, which frightened and terrified them; as a result, some interviewees consciously and purposefully avoided any information on COVID-19:

- 🗨️ 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.

To better understand the existing information gaps, all interviewees, regardless of their opinion on the volume or relevance of information, were asked what information may have been missing. Among the 68 interviewees who answered this question (interviewees could identify more than one concern) the most pressing concerns were: lack of guidance on what to do if one develops COVID-19 symptoms and how to treat COVID-19 at home (53%); lack of reliable information about the vaccines and their side effects (31%); lack of information on how to avoid getting infected with COVID-19 (29%); and lack of information on the long-term health impacts of COVID-19 (15%).

Figure 14. Most Pressing Concerns Regarding Lack of Information



Accessibility of Information

Interviewees were also asked to evaluate the accessibility of information about COVID-19 and the pandemic. Information accessibility is particularly pertinent for people with sensory impairments including persons with visual and/or hearing disabilities, and for people with intellectual disabilities. Among the 34 interviewees with hearing disabilities who commented on the accessibility of information all but one agreed that they were able to access information, including TV programmes and internet videos accompanied by closed captions. Some, but not all, TV news bulletins were accompanied by sign language interpretation, and some interviewees relied on the sign language interpretation service provided by the ‘Ukrainian Society of the Deaf’.

Among the 42 interviewees with a visual disability, who commented on the accessibility of information, 35 interviewees (83%) thought that information was overall accessible since they were able to either listen to the news about the pandemic on TV, radio or video sharing websites like YouTube, or have this information read out to them by relatives or friends. However, 8 interviewees who also accessed information as text (using screen readers), reported that some websites, including government websites, were not accessible (including instances where information/text were saved or emailed as images and could not be processed by screen readers), or when the descriptive commentary for tables, charts and images was missing. Another concern was the affordability of assistive technology, including laptops and specialised software:

- Well, you know, it depends. In most cases, it is accessible. However, if you look at the website of the Ministry of Health, often things like news, or other similar sites... provide information as infographics [images], but for a blind person it is difficult...because screen readers do not read what is shown on the image...of course, I’d like to have the infographics accompanied by text.

-  Computers, laptops and assistive software are not considered as ‘means of rehabilitation’...so my laptop is not up to date and its capacities are limited. So, I cannot use the software which is available for free. JAWS — a screen reader — would work on my laptop but it is not free and it costs 20 — 30 thousand...I do not remember...but it does not matter because who can afford it?
-  Most of the information I rely on comes from the internet. Yes...it is accessible if it is on the internet...but as for healthcare facilities — no. Inaccessible.

The 8 interviewees with intellectual disabilities said that they were able to understand most of the information, including 4 interviewees who were helped by relatives, friends or OPDs. Among the 19 interviewees who were supporting and taking care of people with intellectual disabilities (mostly relatives), the majority observed that no information was provided by health or other public authorities in an Easy Read format. All of them had to interpret complex and often confusing and conflicting information about the pandemic to make it more accessible for the people that they were taking care of. Some of the interviewees praised the role of OPDs in disseminating Easy Read guidance as the pandemic unfolded. One of the interviewees commented:

-  ...the information was not in an Easy Read format. We are now aware of what the Convention [on the Rights of Persons with Disabilities] says...but there was no information for people like my son. And for this reason, as his guardian, I was the only source who could translate the information that was available into something that he could understand. He did, of course, watch the television...but mostly the information came from me, from our family.

As of February 2022²⁰, the official website ‘Coronavirus in Ukraine’ — hosted by the Ministry of Health of Ukraine — provided no guidance in Easy Read or in large print versions.

Discussions around the accessibility and availability of information brought up the issue of digital poverty, indirectly highlighting high poverty rates among people with disabilities in Ukraine. The availability and accessibility of information was severely limited for those who were unable to purchase computers, tablets, or smartphones, or were unable to afford an internet connection. The impact of digital poverty, which was identified as a concern by OPDs (see Part 1 of the project report), is explained by one of the interviewees:

- There are not many people in Ukraine who have modern gadgets, especially older people. And given that we live in a rural area, people here do not have modern gadgets so that they can be connected to the internet. There is no good internet connection to access information from social networks. So, people who live in rural areas mainly received information on radio and television. And this information was more frightening than explanatory or reassuring.

The impact of the pandemic on the economic situation of our interviewees is reviewed under “The impact of COVID-19 on the economic situation of people with disabilities and their access to education” below.

²⁰The last update on the number of COVID-19 infections and deaths was posted on February 24, 2022 — the day when Russia invaded Ukraine. See <https://covid19.gov.ua>

Health and Wellbeing

Health was unsurprisingly a key concern for all of our interviewees; for the majority, their challenging and often negative lived experiences of daily life as a person with disability in Ukraine have been compounded by the impact of the pandemic on their health (through illness, fears of becoming sick, or the deterioration of health linked to restricted or withdrawn access to non-covid healthcare), restricted or withdrawn access to essential social services, severely restricted mobility and restricted access to everyday life essentials. The key dimensions identified by our interviewees (corresponding to the key codes which emerged as an outcome of the qualitative analysis) include:

- Severe difficulties with accessing primary healthcare ('Family Doctor') during the pandemic.
- Restricted access to the 'Technical Means of Rehabilitation' during the pandemic.
- Experiences of contracting and recovering from COVID-19 at home and in hospital; fears of exposure and contracting COVID-19.
- Accessing other healthcare.
- Getting vaccinated against COVID-19.
- Unpreparedness of the Ukrainian Healthcare System for the COVID-19 pandemic.

The review of these themes is followed by a summary of our participants' view on what can be done to improve the standard of healthcare for people with disabilities in Ukraine.

Severe difficulties with accessing primary healthcare ('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” (Ministry of Health of Ukraine, n.d.). Transition to the system of ‘family doctors’ at the primary care level has been declared as one of the key directions of this reform. The most recent evaluation of these significant changes was completed in 2020 and is summarised in the 2021 Report by the European Asylum Support Office. According to this report, by March 2020, as the COVID-19 pandemic was declared by the WHO, about 30 million people in Ukraine (about 80% of the population) registered with a ‘family doctor’ (EASO, 2021, p. 13).

Described as ‘signing a declaration’, the process of registration reflects a so-called ‘money-follows-the-patient’ model, where each primary care provider (an individual general practitioner) is paid by the National Health Service of Ukraine proportionately to how many patients he/she takes on. Patients were given a freedom of choice in registering with any family doctor with no residency/location restrictions. The EASO report (2021, p. 14) comments on the increasing levels of patients’ satisfaction with the quality of primary care recorded by the “Health Index Ukraine” annual survey. The survey (supported by the International Renaissance Foundation²¹) relies on a representative population sample and encompasses all regions of Ukraine (apart from non-government-controlled areas). According to the survey, 74% of the Ukrainian population were satisfied with the quality of primary healthcare provided by

²¹<https://www.irf.ua/en/about/>

their family doctor in 2020²². 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.

1. Annulments of registrations. Annulments arise where an existing GP registration (a ‘family doctor declaration’) is cancelled because of staff changes (GPs resigning, retiring, going on maternity leave), resulting in patients being deregistered without being notified or proactively offered the option of registering with another GP. These are problematic as a patient seeking primary care will be refused treatment without a registration, and while a registration with another GP at the same healthcare facility may be offered this is not guaranteed due to the limited capacity that exists within the system:

²²<http://health-index.com.ua>

- 🗨️ We were registered but then our family doctor resigned, and nobody told us. When I went to get an appointment — there was nobody that could see us...they told me I had to sign a new declaration with a new doctor. I said OK. But then they told me that all other doctors had their maximum number of registered patients already so there was nothing they could do. In the last two weeks, I went to this practice four times now, but they do not have a doctor who could take new patients on. A lot of their doctors resigned and those who are still there cannot take more than 2,000 patients overall. But what do they do with these thousands of patients when doctors resign? I do not know what to do.
- 🗨️ 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.

Among the 8 interviewees who were not registered with a GP at the time of the interview, 3 were not registered because they could not find a new GP/practice who would take on new registrations after their existing registrations were cancelled because of their previous GPs' retirements or resignations; one interviewee did not know how or where they could register.

2. Refusals to provide medical care. For some of our interviewees having a GP registration did not necessarily mean they could access healthcare they needed. Our interviewees described significant difficulties they faced, from not being able to get through to the GP practice on the phone to multiple examples where healthcare was refused by their GPs. The most common instances of refusals to provide medical care by GPs included:

2.1. Interviewees reported not being able to schedule GP appointments. Scheduling an appointment was often impossible with telephone lines either always engaged or disconnected. For interviewees who managed to get through to the GP or the receptionist, the availability of GPs was extremely limited: some participants reported having to wait for several weeks to be seen. In some cases, appointments were only available on a first-come-first-served basis, which meant that interviewees had to spend hours queuing in crowded corridors — often standing as seating was not available — increasing their potential exposure to COVID-19:

-  Yes, we were registered with the GP...but when our GP was on annual leave...and you are waiting in a queue, and it has neither beginning nor end, and you are waiting, and you have no idea who is going to see you in the end.
-  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.

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:

-  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.

2.2. Direct refusal by GPs to see patients and provide treatment. 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).
-  I went to see the GP.. at the initial appointment — they refused to see me. The second appointment was by phone and the GP refused to issue a COVID-19 test referral. The third time, I went to see her again...3 days in a row. I came to see her. I insisted that she would give me the test referral...so she made a ‘favour’ and gave me the referral. On the same day, they did this, within 10 minutes. The test came out positive.

2.3. Refusals of home visits even to interviewees with severe mobility impairments. In this case, care was not refused as such, but access to care was severely limited by GPs refusing to visit patients with significant mobility difficulties at home. In some cases, these refusals were explained by “not having petrol to fill up the car to visit patients.” In some, but not all cases, an alternative arrangement was offered in the form of one or more telephone consultations, which often did not live up to the interviewees’ expectations on how their complex conditions should be treated:

-  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.

- And the GP could not visit me [at home] because...hm...as she said, she had a lot of other work to do.

When home visits did take place, the quality of healthcare often remained extremely low. In some instances, interviewees — even those with severe symptoms of COVID-19 including fever and breathing difficulties — were expected to go to the pharmacy to buy their own medication and then to self-inject at home:

- And on Tuesday...I was in a terrible state. And the doctor on duty arrived late in the evening [for a home visit] and immediately said that it was COVID. He wrote a long list of drugs and said: “quickly, go to the pharmacy, start injecting now, do it now, this minute.” And my friends brought these medicines at 10 pm. So, we started making injections. My daughter and I (she also has a disability) were left on our own: no one would come in, everyone was afraid. So, my daughter, who was also sick, had to inject me. So, it was just the two of us...she crawled around me making these injections.
- They did not have specially adapted beds or mattresses [for people with disabilities in the hospital] so I had to stay at home. My GP wrote a treatment plan, prescribed antibiotics. So, we had to administer these injections ourselves...at home. Taking the medicine.

3. A cycle of cross-referrals. A number of interviewees reported what can be described as a cycle of cross-referrals in relation to the treatment of COVID-19, where interviewees with acute and potentially life-threatening symptoms could be referred by the ambulance/emergency care service operator to their GP, whilst the GP, after undertaking a telephone-based 'triage', would refer interviewees back to the ambulance/emergency service:

-  I first called an ambulance. To which I was told: “we are not dealing with this now, you need to call your family doctor.” I called the family doctor. I really liked the answer of the family doctor: “Why did you call me? Call an ambulance.”
-  Well, yes, when I called the family doctor and said that my temperature was 37.2, my sense of smell disappeared and so on, some kind of condition. He told me: “Well, why are you calling me? Call the hotline.” And the hotline says to call the family doctor.

In addition, interviewees raised concerns about the management of their long-term conditions where referrals for specialist care had to be issued by their GPs. This arrangement required interviewees to navigate a complex system of contacting their GP practice to arrange appointments every time they needed a specialist referral, including the difficulties of getting through to the GP booking system (either by telephone or by physically going to the GP practice). This was followed by a lengthy wait for a GP appointment, followed by a lengthy wait for a specialist appointment. In some cases, the consultants required (specialising in a particular medical field or condition) were simply not available in the local area:

-  I could not get an appointment with a specialist consultant. For example, I need a neurologist. But to get an appointment with a neurologist, I need to go through my GP first; and it was a huge challenge to get to see a GP.

- Do we even have an ophthalmologist in town? A young girl [a newly employed specialist] appeared, but you need to wait for 2 or 3 months to see her. That's it!

Restricted access to the 'Technical Means of Rehabilitation' during the pandemic

Access to the 'technical means of rehabilitation'²³ (TMR), or assistive technologies, and to rehabilitation services (including access to rehabilitation sanatoriums) remains essential in the daily life of our interviewees and in the management of their complex health needs. Among the 231 interviewees who responded to this question²⁴, 151 did receive TMR and/or rehabilitation services, and 80 did not.

A key concern for many of the interviewees was reduced or fully withdrawn access to the socio-medical commissions which ascertain a 'group' of disability, and which are required to issue or reissue (every 2 years) an 'Individual Programme of Rehabilitation' (IPR) which set outs which TMRs can be allocated free of charge:

- Well, I needed to renew my Individual Programme of Rehabilitation and to make some changes. But the socio-medical commissions at the hospital in the district were not running because of the quarantine. They also refused to do home visits...well, because of the quarantine, too. And because of this, there were issues. So, it means that we cannot renew the IPR. They have just begun to carry out these commission meetings once every 2 weeks, or once

²³A state-funded system of supply/access to rehabilitation and assistive technologies in Ukraine

²⁴Of the 70 interviewees who did not respond to this question most did not require TMR or rehabilitation services.

a month at the district hospital, and we are just...so we need to take this opportunity, but they refused to visit us at home even though we have two persons who are wheelchair users. Again, all is justified by the quarantine. That is, we would need to take a taxi and go there and stay there all day so that they could issue these IPRs for us, since they are needed to get a wheelchair and in order to have some rehabilitation — sport or physio — anything!

- 

Yes, I waited until COVID was over so that I could get the orthopaedic shoes, walking sticks, walkers, and a wheelchair.
- 

Yes, a wheelchair, crutches, at that time I had to postpone the receipt of these technical means, because I didn't really want to send my grandmother or my mother to collect them at the hospital, I didn't really want to go there myself. Well, I did receive all the TMR that I needed after, well, let's say, the peak of the pandemic had passed.

Some participants could not get to the locations where TMR were available for collection because of the lockdown-related suspensions of public transport. One of the interviewees relied on insulin injections which could only be provided based on blood test results, which could not be carried out due to the restrictions on the use of public transport.

The bureaucratic nature of the process for obtaining TMR - and its exacerbation due to pandemic-related restrictions — can best be described by the quotes below. In the first, an interviewee is commenting on the need to have a new Individual Programme of Rehabilitation re-issued, which required a new assessment by the socio-medical commission, just for the sake of getting a walking stick issued free of charge as TMR:

🗨️ I am registered with the Department of Social Protection and have my documents, they are all there, including the programme of rehabilitation and that's it, I receive social assistance from there...it all used to happen without any problems. But now they require me to go and get another Individual Programme of Rehabilitation just so I could get that walking stick!

Another interviewee has been waiting for their place at the rehabilitation sanatorium for 7 years:

🗨️ Well, they offered me a referral to the sanatorium. So, they said that we would put you on the waiting list, because after a heart attack I needed this sanatorium treatment and I was very happy they offered it. But, unfortunately, I'm still waiting and it's been 7 years.

Another interviewee asked for a bath-lift; however, their request was refused since they already were allocated a wheelchair:

🗨️ I asked for a bath-lift, but they said that a bath-lift equals a wheelchair (in their list) and since we received a wheelchair a year ago, we should not be allocated a lift for the bath.

A number of interviewees thought that the pandemic had only aggravated an already difficult situation regarding access to and distribution of TMR due to a lack of state funding:

🗨️ I applied for an internal wheelchair, it's time to get a new one because the old one is broken. I submitted all of the documents and in good time but [there is no] funding...there is no funding not because of COVID — pandemic or not, the state has little money for these things, and it all drags on and on.

-  We registered with the Department of Labour and Social Protection but the funding was allocated only for a limited number of people. So...in any case, rehabilitation is postponed until there are funds in the local budget, and nobody knows if it will be this year or not. And when will we move on the waiting list...who knows? As to the other means of rehabilitation, except for orthopaedic shoes and orthopaedic insoles...as it were, there are none. We applied for shoes, for insoles, but again, there has been no funding allocated yet this year.

Some participants reported shocking levels of precarity and poverty when describing efforts to get by in the absence of any support from the state:

-  Since I am renting a room (no even a flat), I can't bring too much here, even what I'm supposed to have.
-  I am a disabled person of Group 1A. I do not have any diapers, and I do not have a wheelchair. Because nobody helps us financially, my sister has to wash used diapers.
-  Poor quality prosthesis. The state increased the service life from 3 years to 6 years from 2021. It was possible to get a new set of the prosthesis for walking after 1 year, now it is 2 years. There are better quality prostheses available, but they would not issue these and I do not have any money to buy them.
-  My daughter is bedridden, she lies all the time on the sofa bed with 3 big holes. She needs an orthopaedic bed, which we cannot get.

As the pandemic continued, healthcare facilities resumed appointments to develop Individual Programmes of Rehabilitation; however, these appointments (essential in ensuring access to rehabilitation) took place at healthcare facilities which provided no separation from visitors with

suspected or confirmed cases of COVID-19. Some interviewees felt as if they faced a difficult choice: renewing these programmes (which must be renewed every two years) and potentially getting infected with COVID-19, or not renewing their programme and having their access to TMR cut off.

🗨️ If diapers count, then yes. That is, they didn't give us any when the quarantine was tough – they didn't give any diapers. Now, it seems, they started giving them out but we have a problem. Every two years, we need to review an Individual Programme of Rehabilitation, so we need to renew it now as two years have passed. I have to go with Pavlo²⁵ to the hospital, to the polyclinic and it is a health risk, because you need to go and see all of the doctors. There are queues everywhere. Even before COVID, we would always catch a virus after going to the hospital so Pavlo would always get sick. And now I'm even scared to go to the polyclinic...even a healthy person would just go and catch a virus, and maybe COVID. But going there is a must if you need an individual plan, which is a must for getting diapers...so now I am faced with the option of either not going and not getting diapers, or going and getting infected.

Problems with getting access to TMRs (all of which must be publicly funded) were particularly acute for the most vulnerable categories of interviewees — internally displaced people with disabilities. Among 125 internally displaced persons with disability, 46% experienced problems with getting TMRs. This is in comparison to 29% of persons with disabilities who were not internally displaced:

²⁵Name changed to protect our interviewee's identity.

Unfortunately, my condition flares up twice a year- in spring and autumn. So, I need constant medical attention and go see the doctor regularly. However, there's no use for it; if there were — it would be great. For example, when we were in Donetsk, thank God, they gave us vouchers [for a course of rehabilitation treatment] at the sanatorium²⁶ – it helped me a lot. But over here...I can't get anything. Sanatorium? I should forget this all together. Free medicine? No way! You can ask but you might as well just forget about it. I try to save up money so that I can get the injections I need at least twice a year. This, of course, does not help as much as it did in those days when I went through a full set of treatments in a hospital or at the sanatorium...it was much better. In general, they somehow do not like internally displaced people much here... It was easier in Odessa, when we registered as IDPs, they treated us differently. But here...you can't get anything; they would not even let us apply for a sanatorium referral.

Only a few interviewees were positive about their access to TMR and rehabilitation. For one of the interviewees, there were no issues with getting hold of TMR, and another interviewee suggested that the pandemic reduced demand for rehabilitation at sanatoriums (for the fear of getting infected with COVID-19) which meant it became easier to get a place at one of such rehabilitation sanatoriums for those who were prepared to travel:

- Unlike the stories we hear, on the contrary, everyone helps me, I can get everything as long as I phone or request it. The local council gave us a wheelchair, a walker, and bedside tables. And a chair for the toilet. Everything you need.
- Getting a referral to a sanatorium used to be a problem. Now, maybe because everyone is afraid to travel in public places, there's more availability...or God knows why.

²⁶ In former Soviet Union republics, the term sanatorium described a healthcare hotel-like facility which provides a combination of resort-style recuperation with medical services for treatment of long-term conditions.

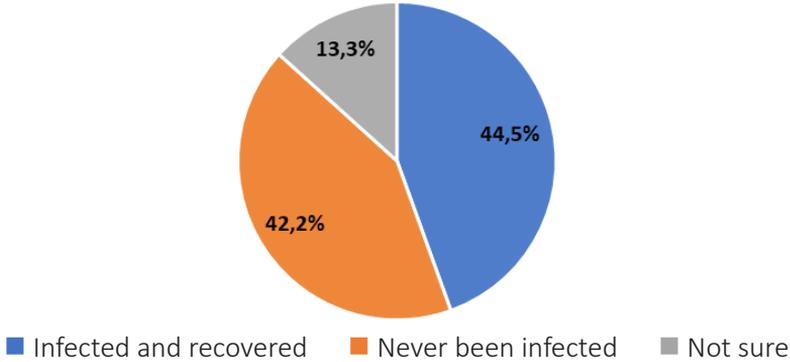
Experiences of contracting and recovering from COVID-19 at home and in hospital; fears of exposure and contracting COVID-19

1. Fear of getting infected with COVID-19. Among all interviewees — including those who had not been infected with COVID-19 at the time of interviewing or had been infected and recovered — fear of infection was one of the prominent concerns (see below for further details on experiences of having COVID and section ‘Psychological impact of COVID-19’). Participants with complex health needs were particularly fearful since pre-existing health conditions were reported as one of the key factors in the increased mortality from COVID-19. The fear of death from COVID-19 and of prolonged suffering and pain were magnified by a range of concerns related to: (a) the inadequate provision of healthcare, (b) having no money to afford treatment (including informal payments to healthcare staff and the purchase of medications), and (c) the impact of illness or death on their relatives, including other members of the family with disabilities. For example, one of the participants, a single mother, noted:

-  We were worried that, God forbid, we would both get sick — my child and I. Because I am well aware that if I get sick, my 11-year-old child may not pull me through. If my child gets sick, I may not pull him through this because there’s no money.
-  This is the biggest fear – to get sick.
-  Well, I worry, of course - to not get infected anywhere, to not get sick. Before I got sick, I was worried; and even after getting and recovering from it [COVID-19], I am still scared. Well, wearing masks is annoying, of course. But you are also so afraid to get sick. Because you understand even though there were no complications when I had it first, it may not be as unproblematic the second time and I may get hospitalised. It’s very scary...because the hospital is totally inaccessible. Well, it’s better for wheelchair users not to get into hospitals. This is the fear.

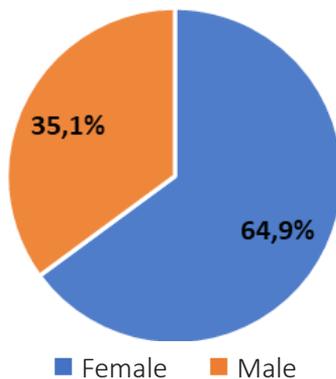
2. Experiences of having COVID-19. A little less than half of interviewees (44.5%) reported to have recovered from COVID-19 at the time of the interview; about 13.3% were not sure if they had been infected with and recovered from COVID-19; and 42.2% said they had never been infected.

Figure 15. Experiences of Having COVID-19



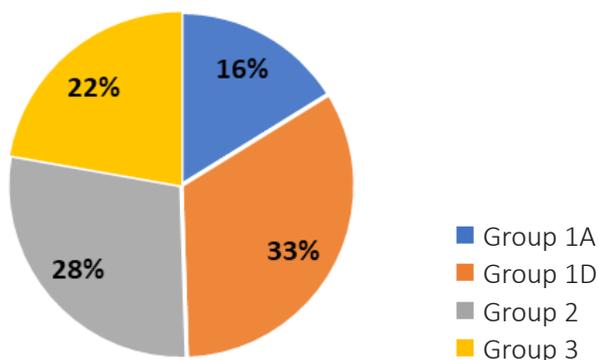
Among the 134 interviewees who had had COVID-19²⁷, there were more women than men (64.9% women and 35.1% men); most were in the 36 – 59 age category (53.0%); and the majority were placed in Disability Group 1B (33%), followed by Group 2 (28%); Group 3 (22%), and Group 1A (16%).

Figure 16. COVID-19 Infections by Gender (%)



²⁷134 (the number who reported to have had COVID-19).

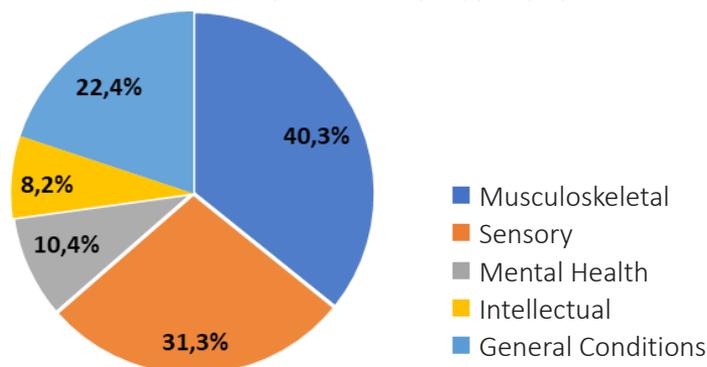
Figure 17. COVID-19 Infections by Disability Group (%)



As noted earlier in this report, all interviewees were asked to identify which of the long-term physical, mental, intellectual, or sensory impairments they had, and all interviewees could identify one or more impairments in their answers. Among the interviewees who said they had COVID-19, the most frequently identified impairment was musculoskeletal/physical (40.3%); followed by sensory impairments (vision and hearing) (31.3%); mental health impairments (10.4%); intellectual impairments (8.2%); and general conditions (including cancer, cardiovascular, diabetes) (22.4%).

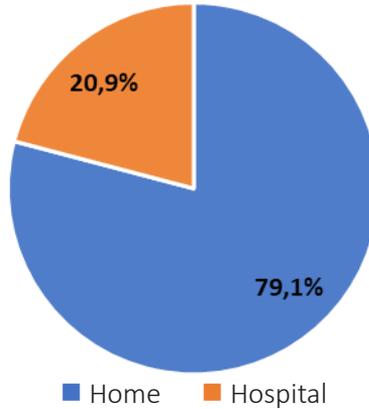
There was no significant difference between interviewees based on their internal displacement status: overall, 56% of all interviewees were internally displaced and among those who reported as having had COVID-19 50% were IDPs.

Figure 18. COVID-19 Infections by Disability Type (%)



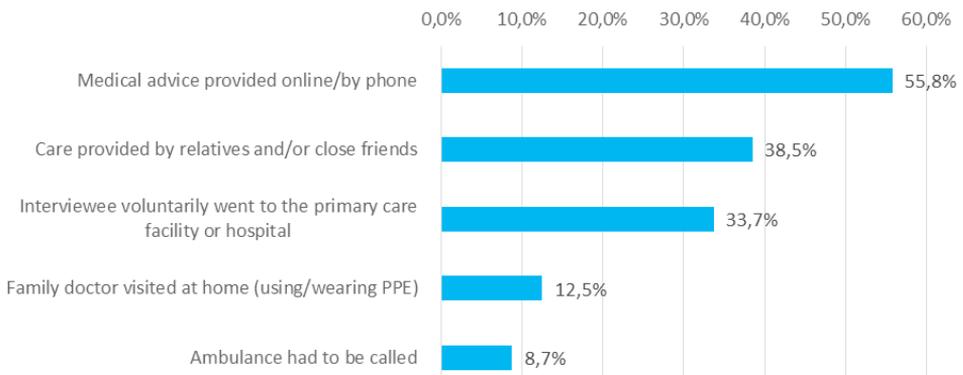
Interviewees who said they had been infected with COVID-19 and recovered were asked whether they were hospitalised because of COVID-19 or recovered at home without having to spend time at hospital. The majority, or 79.1%, recovered at home (106 interviewees); and 20.9% had to be hospitalised (28 interviewees).

Figure 19. Recovery Location



3. Recovering from COVID-19 at home. The interviewees who recovered at home (n=106) were asked to identify what kind of medical help/care they received and who provided this care. We received 104 responses and the following types of medical assistance/care were mentioned (some interviewees mentioned more than one type of assistance/care).

Figure 20. Type of Medical Help Received at Home



Overall, interviewees reported a range of experiences with receiving primary medical care. Some of the examples were extremely positive:

-  I had a mild form of COVID-19...I did not have any breathing difficulties or cough...the family doctor visited me at home and then they prescribed some medications and asked us to stay in touch; they said that if I start to get worse, we should call the ambulance...so we were always in touch with our family doctor.

Whilst others found themselves abandoned, ignored, and isolated at a time when they required professional attention, care and support:

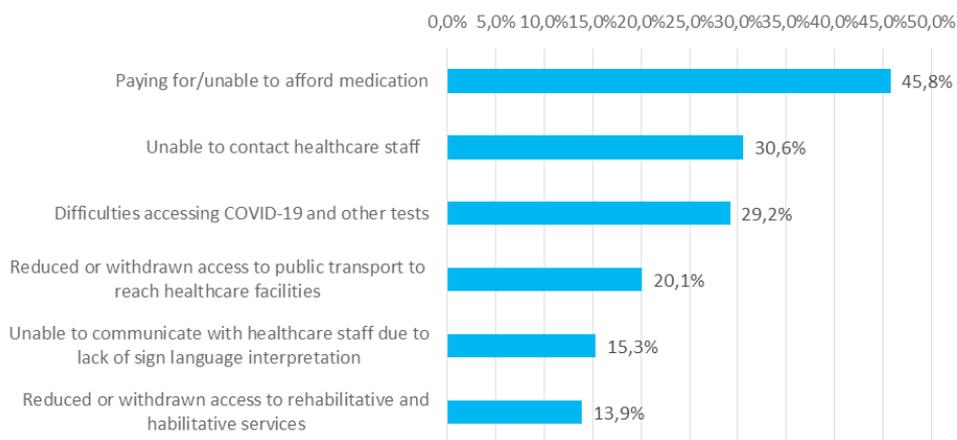
-  I phoned the ambulance, and it never came...they did not have any cars available. They told us to get a private ambulance...but if I call for a private ambulance...it is ten thousand²⁸ and this is just to get them to come...the treatment itself would have been much more...There is no service, there is no support...our healthcare is incapable of delivering anything. I paid for all of my medication and my COVID-19 test.
-  In relation to family doctors...there was no care which you would expect, especially these days...it's just...indifference. You can literally fall and die at their office door and they won't care. The waiting time, queues...

All interviewees who had recovered from COVID-19 at home were asked to identify specific issues or problems in relation to the medical assistance/care they obtained as they were recovering, and whether there was anything (medication, medical services or tests) that they needed but could not receive.

²⁸Approximately 230 GBP (August 2022 rates).

72 interviewees (out of the 104 respondents who had recovered from COVID-19 at home) expressed a range of concerns which were categorised by our interviewers as follows²⁹:

Figure 21. Type of Medical Help Received at Home



These categories are also reflected in the codes that developed when the interviews were coded and analysed using NVIVO and will be discussed below (see section ‘Unpreparedness of the Ukrainian Healthcare System’).

4. Recovering from COVID-19 at the hospital. One of the 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.

²⁹Due to the large number of different responses, those below 10 % are not recorded.

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:

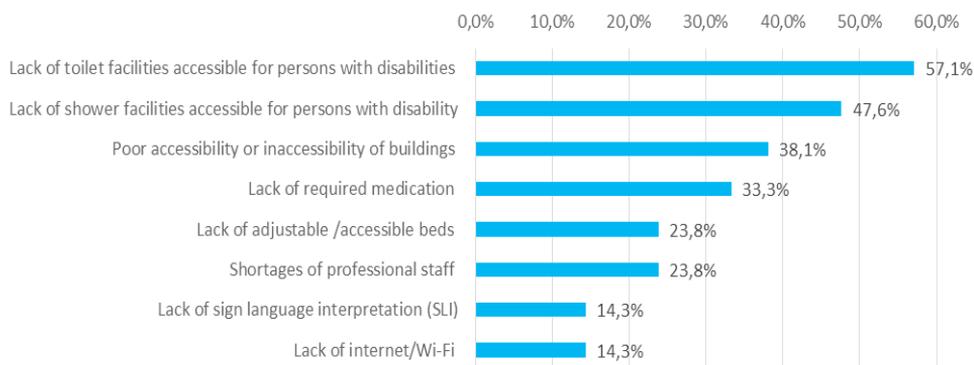
- 🗨️ No...the hospital was not accessible...absolutely not! There were no tactile [Braille] displays for the blind; there were no call buttons — when you are really unwell — nobody will come even if you cry for help...you can hear people crying for help from their wards and nobody comes...this is surreal...The wards can have up to 7 people in them and when there's a changeover of staff, they sometimes simply forget to administer an IV drip...If you are on a ventilator, they do not allow you to even leave the room...so they say: either use the diapers to relieve yourself, or if you can get up — stand by the bed and use a bucket or a bedpan. My mum was given a bucket like this, but she cannot get out of bed without help. So...she asked for help but they [hospital staff] told her: use diapers, we have no obligation whatsoever to help you with this. And this is how people use the diapers: they have these old beds with a metal mesh base and these bases are sagging in the middle...so you are lying on this bed...your head is up, your legs are up and everything that's inside that diaper — if you are using diapers that is...is leaking down your back [when you move] ...this is how things are in the hospital wards. Nobody cares if you are a person with disability.
- 🗨️ 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.

🗨️ I could not breathe...and had a very low oxygen saturation... because of my disability, my knee joints are completely out — they are not working...I can barely walk but I had to get in and out of the ambulance car; they took me to the infectious diseases ward of the city hospital [City A] and there were stairs...this was impossible for me. It took them an hour to get me registered even though I was the only person there at that time and I started to lose consciousness in the triage room...this hospital...it is complete humiliation not just for people with disabilities... complete and utter humiliation. I do not know how to put it mildly...these are inhuman conditions. Horror...horror...it is just horrible. And it applies to everything: treatment, living conditions — everything. On day 2, they moved me to another hospital — to [City B] — and they had a special ward for people who had COVID-19. And I think...I am sure...had they not moved me, I would have died [in the hospital in City A]...it is like...black and white...if you compare these two hospitals. If [City A] hospital is black, then [City B] hospital is white...this is the only way you could compare these two places. No other way.

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:

Figure 22. Problems, issues, and shortages during COVID-19 related hospital stays



- At the hospital...they did not have enough staff; they did not even have enough thermometers — it is laughable! There was nothing to take your temperature with. I had to pay for everything...they would give you a piece of paper and then the healthcare staff themselves would go and buy whatever medication you required [i.e., patients had to give money to healthcare staff so that healthcare staff could go to the nearby pharmacy to buy medication prescribed to this patient].
- They had those large self-made...they looked like they were self-made...oxygen ventilators at the hospital...there was only one and there were 3 or 4 of us in this ward. We were rationing: who breathes and how long for...we would take turns and wake each other during the night — because there was only one ventilator and everyone had low [oxygen] saturation, so we all had to breathe.
- 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 live by myself...and I could not get up but I was also afraid to call anybody to ask them to come and see me [so that they won't get infected]...and for two days — there was not enough food and nobody could come and visit me [and bring some food]...one day I was [so hungry]...I almost had a blackout and my neighbour [another hospital patient in the same ward] — she could barely move but she brought over to me what I had stored in [the hospital/ward] fridge...I call her my Mother Theresa now...she could barely move but she managed...thanks God. She got better. So did I.
-  You can call for a nurse to come...at night...and sometimes your oxygen mask would come off your face and people would call and cry for help but nobody would come because there were no call buttons and nurses would be asleep. There was a case when a woman — her mask fell off and they [other patients] knocked and called [for help]...she managed to phone her daughter. Her daughter then came by taxi in 15 minutes and she was knocking on the hospital windows for two hours to wake them up [and open the doors] and when she managed, her mum was already dead. She was 55...such an absurd death...running out of oxygen. Her daughter was screaming and crying and saying that she would complain, and that she would do whatever it takes [to get justice] but these are all words. They would trust the doctors and not the patients.

Among the interviewees who were treated for COVID-19 at hospital, the majority (78.6%) had to pay in full or in part for their medication to treat/alleviate symptoms of COVID-19.

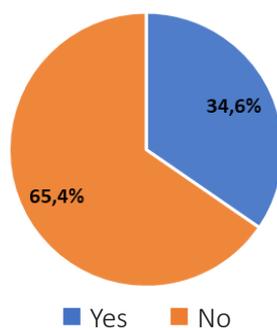
-  I phoned the hospital and I said that I had pneumonia, so that I can get a referral for computer diagnostics: and, of course, I have to pay for it. All the medicines — I had to pay for them.

- In the morning, once the doctors are done with their morning rounds, we will have nurses who will then get prescriptions from the doctor, they will then get my bank card and [having purchased any prescribed medication at the pharmacy] will bring the medication to me.
- They put me onto the oxygen ventilator and prescribed medication, which I had to pay for. Nothing was free of charge.

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 pandemic³⁰. 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.

Figure 23. Routine treatment continued during the pandemic?



³⁰All 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>)

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:

- 🗨️ I could not get to the specialist doctor. I needed to see a neuropathologist but to see him, I had to go to the family doctor first and I could not...there was no transport...so a taxi would be the only option, but it is expensive so I can't afford it and there's no way to tell if the taxi driver had Covid or not.
- 🗨️ 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.
- 🗨️ Rehabilitation centres were shut down...I did not get any treatment...I was scared to get infected at the hospital... and I needed treatment...I keep on falling all the time because of the problems with coordination and encephalopathy...and to see the neurologist I need to see the family doctor first and all of this is in different [hospital] buildings and then you need to go the third building for [blood] tests and this is a problem because of my musculoskeletal and coordination disorders. I have a wheelchair but its heavy and cumbersome and I cannot get it down from the third floor. So...at my own risk...I am moving using a walking stick.

-  Access to healthcare services was limited...I was scared to go to the primary care practice because even though you have a timed appointment, you could sit and wait there for hours... and, also, the day hospital was shut down...so when my health deteriorated, I could not get a specialist appointment. I get medication once every six months...so we do travel, by taxi and get it. But any accompanying treatment — to relieve symptoms — I could not get for 9 months — everything was shut down. It was impossible to get an appointment.

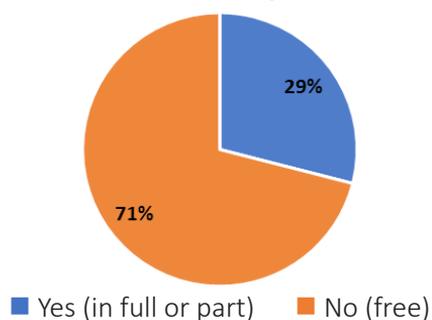
Among those who did not receive care, only 14 respondents (7.6% of 183) said they did not require ongoing care; however some of the open ended responses also mentioned lack of availability:

-  I did not receive any treatment. There was no treatment for me anyway — even before COVID-19.
-  My diagnosis is urolithiasis. When the bleeding began, the doctors refused because the department was closed because of the pandemic; there was no space for me at other departments either.
-  Couldn't get in-person care because of the pandemic.
-  I went to the family doctor, but there was almost no treatment, the doctor wrote a prescription, saying that I should stay at home and when the pandemic ends, they would treat me.
-  Sometimes I could not get an appointment with a doctor, I did not receive any medicines.
-  All medical personnel were reallocated to treat COVID, and doctors did not have time for chronic diseases.
-  I am not transportable. When my carer went to the clinic and asked to get a home visit from a neurologist — we had to pay for this; but we did not have the money.
-  There was no access to doctors and hospitals. The operation to remove the cataract had to be done in a private clinic.

Getting tested for COVID-19

All participants were asked if they had any tests for COVID-19. Out of 300 who responded, 58% did (173) and 42% (127) did not. Among those who had a test, 71% had a free test (did not have to pay) (122 out of 173) while 29% did make a payment for all or some of the tests they took (50 out of 173).

Figure 24. Paid for COVID-19 Testing?



Unpreparedness of the Ukrainian Healthcare System for the COVID-19 pandemic

While the preceding sections focussed on individual experiences of how the pandemic affected health and wellbeing of people with disabilities, this section sets out key themes and issues regarding the state of the Ukrainian healthcare system during the pandemic in relation to the needs of persons with disabilities. These issues emerged in the process of coding and analysing the whole body of 301 interviews; the vast majority existed before COVID-19 and, as our analysis suggests, magnified the negative impact of the pandemic on persons with disabilities. The nine issues discussed in this section include:

1. Poor accessibility of healthcare facilities.
2. Poor availability of healthcare.
3. Overall poor state of healthcare facilities.

4. Lack of qualified staff further exacerbated by the healthcare crisis caused by the pandemic.
5. Systematic underfunding and unequal and inequitable distribution of limited healthcare resources.
6. De-prioritisation of people with disabilities within the national healthcare system.
7. Having to pay for treatment.
8. Excessive and inflexible healthcare bureaucracy.
9. Experiences of abandonment, indifference and direct discrimination within healthcare.

1. Poor accessibility of healthcare facilities (GP surgeries, hospitals etc.) Participants commented on the inaccessibility of healthcare facilities, including poor accessibility of buildings for people with physical disabilities and a lack of adaptations for people with sensory and/or intellectual disabilities.

-  I don't understand how they read state building regulations, I don't understand where all of this money goes...at the end we still have high door thresholds, there are still no ramps...there are curbs around the entire circumference and there is no lowering.
-  In the urology department, for example. There are wards on the first floor, there are all these grannies with kidneys — they go back and forth. There is no toilet. Toilet for staff only. Urology. Toilet on the second floor.
-  That is, the whole system (of booking an appointment with a doctor) is not adapted for a person who may not have a telephone. And very often it is people with intellectual disabilities who don't have telephones, don't know how to use them or don't have the money to buy such phones...they use push-button phones, and not those that can be used for the internet...and this is, of course, a big systemic omission.

2. Poor availability of healthcare. Interviewees provided numerous examples where essential and/or specialist healthcare was not at all available or was not easily available and required additional efforts to access it. These examples related to both primary (as reviewed above) and specialist healthcare and included:

- GPs refusing or failing to make home visits;
- Hospitals refusing admissions and referring patients to GPs or recommending home-based self-observations, including situations where hospitals were either full or were not equipped to admit a person with a particular type of disability;
- Healthcare facilities being completely shut down due to the pandemic without any alternative arrangements put in place.

Some examples provided by interviewees could be interpreted as acts of neglect and negligence:

-  I was very worried, I suffered a heart attack. Then I could not use a social taxi³¹ to get to the hospital. Because we live on the outskirts of the city and there is no way for me to get to the hospital in a wheelchair...I could not order a social taxi for myself and so I was sick but had to stay at home. They called an ambulance, but due to the pandemic, the ambulance didn't even take me to the hospital, although the heart attack was already visible on the cardiogram they had done. We then showed this cardiogram to a cardiologist, and she said: you already have a heart attack here.

³¹'Social taxi is a dedicated transport service for persons with disabilities provided and funded by regional administrations in Ukraine. It is intended for persons with disabilities whose mobility is severely limited to enable them to make their way to 'socially significant objects' (see, for example, https://wiki.legalaid.gov.ua/index.php/Соціальне_таксі) As of February 2022, there was no detailed information on the extent of the 'social taxi' coverage, availability and eligibility across all regions of Ukraine.

🗨️ I called an ambulance, they said: we can't come and collect you because your temperature is not high enough. And the fact that I was suffocating was of no interest to anyone.

Some of the interviewees highlighted how government responses to the pandemic exacerbated both the accessibility and the availability of healthcare in Ukraine. This included the reprofiling of specialist and essential healthcare facilities into COVID-19 wards/treatment wards and blanket restrictions on the use of public transport, which cut off some people with disabilities from the essential healthcare they needed. In sum, healthcare became much less available and much less accessible, contributing to what we describe as the process of de-prioritising people with disabilities in healthcare.

3. Overall poor state of healthcare facilities including dilapidated buildings and structures, obsolete equipment, and lack of basic services (like toilets, showers, elevators). Some interviewees spoke about being left starving for days since hospitals did not provide food in sufficient quantities.

🗨️ The hospitals are in a terrible condition. The entire inventory...is in such a terrible state. It seems that it's almost like the Soviet Union at times. Everything is old. Half-ruined, derelict. Everything. And the [hospital] departments are just empty. That department was closed, this one is closed, that one is closed.

🗨️ And there may not even be an elevator in a hospital or a clinic, or it does not work, or it's been out of service.

🗨️ People can lie three, four weeks without having a shower [in a hospital]. They only have access to a washbasin and a toilet- that's all. And no hot water.

The poor quality of the facilities meant that they were even less prepared or completely incapable of responding to the increased demand for COVID-19 specialist care. A number of participants reported the lack of separation of patients with suspected cases of COVID-19 from patients with other non-transmissible conditions. Others reported cases of extreme overcrowding with more than 10 patients crammed into small hospital wards, people lying in corridors, and people getting their tests and injections done in the middle of hospital corridors.

When we arrived at the hospital, there was a floor full of people with and without COVID. And they take tests, and then go to the surgeon, and anywhere — and it's all on the same floor — I don't understand how people with COVID — they are on the same floor [without any separation] — with people who come with children, and on the floor above there are pregnant women, older people, and other risk groups. Absolutely nothing has been done to reduce the number of infected people [coming into contact with those who are not infected].

4. Lack of qualified staff further exacerbated by the healthcare crisis caused by the pandemic. Participants commented on the lack of and/or decreasing number of qualified healthcare staff in Ukraine (including primary and specialist care) highlighting low levels of professionalism and training on the one hand, and, more specifically, the lack of understanding and training among healthcare staff on how to provide healthcare to patients with disabilities. This is in addition to concerns (reviewed above) about the lack of access to doctors or consultants specialising in particular medical fields/ conditions.

Hospitals are understaffed. There is a lack of specialist doctors...of professionals. It is mostly pensioners who are still employed by hospitals, and those who sit there just

for show. Because all the younger [staff] got scared and ran away from medicine, because there is no development in this healthcare system, there are no prospects. Nobody cares about medicine. Doctors work for a penny and suffer. And they don't want to, people just don't want to work in medicine for these pennies. So, healthcare is being ruined by the state.

I can go to my family doctor to get a referral for some free tests. For all the rest — things like consultations, some appointments, I go, take money and go to a private clinic, and go to a normal doctor who will provide me with the care I need. It is the same with specialist doctors, who, in principle, do not even exist. Let's say there is no neurologist. There is no dentist in the clinic. Oculist, ophthalmologist. Same story. They simply don't exist!

Our GP does not know these treatment protocols, because, unfortunately, there is no such treatment for people with disabilities and with various associated conditions in Ukraine...And medical institutions need to educate students in a completely different way, to train these students, and future doctors, including nurses, so that they are focused on how to help people with disabilities.

5. Some interviewees linked the poor and precarious state of healthcare in Ukraine to its **systematic underfunding** and the unequal and inequitable distribution of the limited healthcare resources in the country:

Well of course I would prefer that specific funding was allocated to help people with disabilities, because they are limited in their ability to earn money...so there should be more money allocated. We still need some help from the state.

6. De-prioritisation of people with disabilities by the national healthcare system. All of these issues and challenges came together in being further exacerbated by the various impacts of the pandemic, resulting in what can be described as de-prioritisation of disability within the context of the national healthcare and abandonment of people with disabilities and their healthcare needs. For example, interviewees reported cancellations of essential medical procedures because of the reallocation of limited resources within the national healthcare system towards pandemic responses. These ranged from simple procedures such as injections to more complex ones, as described by one of the interviewees:

- Yes, I was not a priority for the doctors: we are too busy now to deal with your illnesses. Coronavirus is the priority right now. Even if I wanted to go to the hospital with my problems, for example, I have a five-year-old burn, I had to get a skin graft. And because of this pandemic, the local burn hospital was closed. I couldn't get a skin graft. I wanted to go to the hospital for a drip, because I have a nervous system condition, my spine is damaged. I needed to have a series of annual injections — as prevention. I couldn't do it either. Because you can't go to the hospital. All that was a priority is the coronavirus. Everything else did not matter.
- I understand that there were people with COVID-19...I understand. But the fact that all the wards where I was treated were closed means that I could not receive any treatment...and the pulmonology department was fully allocated to treat COVID patients. Yes, this is necessary. But I haven't been treated for 2 years.
- I could not treat my chronic conditions during the pandemic, because all healthcare professionals were sent to treat patients with COVID-19, and all chronic

diseases had to be put aside and forgotten about because there was no time for doctors, no willingness to treat these conditions. They didn't even really make contact and said that I should be patient and wait until better times.

7. Having to pay for treatment. One of the key concerns expressed by interviewees was having to make private payments in order to receive healthcare in a context where healthcare should be provided free of charge (See Part 1, also Danyliv et al., 2012; Lekhan et al., 2015; WHO/European Observatory on Health Systems and Policies [EOHSP], 2021). Interviewees mentioned different forms of payments.

These included having to pay for anything that went beyond a very basic blood test and basic medications. More complex tests (including computer diagnostics, X-rays, complex blood tests) or medications, which were essential in managing interviewees' complex medical conditions, had to be paid by interviewees themselves, including in a hospital setting. Another form of payment was having to make a financial 'contribution' to the healthcare facility. Even though described as 'voluntary', participants commented on a direct link between making a contribution and being admitted for treatment or receiving a better standard of care.

A number of participants mentioned having to give money (out-of-pocket informal payments or bribes) directly to individual healthcare staff in order to receive any care (in cases of limited availability of space at healthcare facilities) or better care (in cases of shortages of staff, supplies or medicines). Other participants mentioned having to make significant annual payments to rehabilitation facilities for undergoing preventative or rehabilitation treatments which were essential to the management of the long-term health conditions.

-  If you don't pay everywhere, if you don't put some money into their pockets, no one would even look at you. Once you've given the money - good, come over here, we will treat you. If you don't give the money — nobody would call or treat you. It's all bureaucracy and corruption.
-  I called the hospital, said that I had pneumonia and asked to be booked in for a CT scan, of course, for a fee. I bought all the medicines with my own money. The hospital said they were busy and only five days later I was admitted for a CT scan. I came for a CT scan, it was the 12-13th day of my illness. I had 35% lung damage. After that CT scan with a high temperature and I already felt really bad, I went to the Covid department to be seen by the doctors. But, unfortunately, we spent an hour and a half with my sick mother in the emergency department. The nurse came out and said that, firstly, they would not accept me without a referral and, secondly, they had no space and no one would admit me to the hospital.

8. A number of interviewees commented on the **excessive and inflexible bureaucracy**, which affected their daily experiences of both accessing and receiving healthcare especially in the context of their complex health needs (for more on bureaucracy and healthcare in post-Soviet states see Rivkin-Fish, 2011; on bureaucracy and healthcare in Ukraine see Owczarzak et al., 2021). One of the key concerns was having to go through a lengthy and physically demanding (especially for interviewees with reduced mobility) process of arranging an appointment with a GP even for straightforward requests, such as issuing a referral for an ordinary test (as part of regular management protocols for already diagnosed health conditions):

-  To get this certificate, to get any of this, you must first make an appointment with your GP. To get an appointment, you

need to be there at 7 or 8 am [to start queueing] to get a ticket [as confirmation of your place in the queue]. But the doctor only starts seeing patients at 12 noon.

- According to our legislation, for some reason it is necessary to constantly extend the sick leave. Every time I had to do it, I had to see a doctor. The doctor prescribed me medication for the first three days, and three days later I had to see the doctor again. On the same day, when leaving the doctor, I made an appointment for another consultation. I had to pay for each consultation. And three days later I called a taxi again and went to the clinic, in order to extend the sick leave, and for the doctor to assess my condition.

A number of interviewees were concerned about having to wait for a GP appointment to be referred to a specialist consultant, including for already diagnosed conditions, or to see a consultant who may routinely help interviewees manage their condition:

- Access is very problematic. You need to make an appointment with a GP a week in advance to see him. Then your GP gives you a referral to see the consultant, so you wait another week. Everything is so ill-considered. All of this time the person is sick and they cannot get to see the doctor.

9. Apart from describing their lived experiences of healthcare at the time of COVID, interviewees relayed a sense of **abandonment and indifference** towards them, as people with disabilities, and, sometimes, experiences of **direct discrimination**.

- I had to call the Commissioner for the rights of people with disabilities - only then did they do an X-ray, and that was it, so, the truth is, my neighbour helped me. I went with her and she started brandishing the legislation in front of them [at the hospital].

- It is a complete lack of interest or empathy.
- I called an ambulance on the recommendation of our Ministry of Health. They said: “Contact your GP.” I said, “I can’t go to my GP because I have COVID.” I already suspected that I would not be affected badly but my wife was really unwell. They start asking questions, “Who are you?” - “I am a pensioner”, “And who is the wife?” I say: “My wife works, she also has a disability, but she works in a bank.” That’s when they agreed to send an ambulance and came here to my house. But when they arrived, they tested only my wife, and they immediately identified COVID. I said: “Are you going to test me?” They say “No”. I said why? - “Because you are a pensioner.” Do you understand? It’s real. They told me: “You are not important to us. You are a pensioner, you have a mild illness. Stay at home.” And my wife went to the hospital, and they did an X-ray of her lungs.
- So I went to my new GP. She talks to me like...I don’t know... as if I am subhuman. Plus, I reissued the rehabilitation map, this individual ILP [Independent Living Plan]. She was writing it down...we discussed with her that I did need a wheelchair and an anti-decubitus pillow. These are vital for me. And then she said “it [the pillow] is not allowed.” Why shouldn’t I have a pillow? I then went to the social security office. Over there, the girls said that I could get it...like five times. I went back to the hospital [GP practice]. And again, they made it so difficult for me. They showed me a table which says ‘This service does not exist’. So, it is not mentioned on their list of services. In the end however they did write it in — this anti-decubitus pillow.
- Generally speaking, besides being blind, I have no particular problems. For example, I called the diagnostic centre, I had a little thyroid problem. They say: “You

must come in person, we won't give you an appointment by phone." So I went. The receptionist, after she saw me, then said: "Oh, why didn't you say that you can't see? I would make an exception for you and so on and so forth." I have come across some good [healthcare] staff. But in general, all people are different...one time there was a gynaecologist who tried to make money on me: she found a bunch of diseases that another gynaecologist could not find. Tried to sell drugs and so on and so forth. This was a very unpleasant situation.



Well, I want to put it this way, people with disabilities...we are absent from society. We are outcasts because we need medical help and support. As soon as a doctor sees that they have a person with disability coming to see them, they treat them like, as it were, a second-class person.

Getting vaccinated against COVID-19

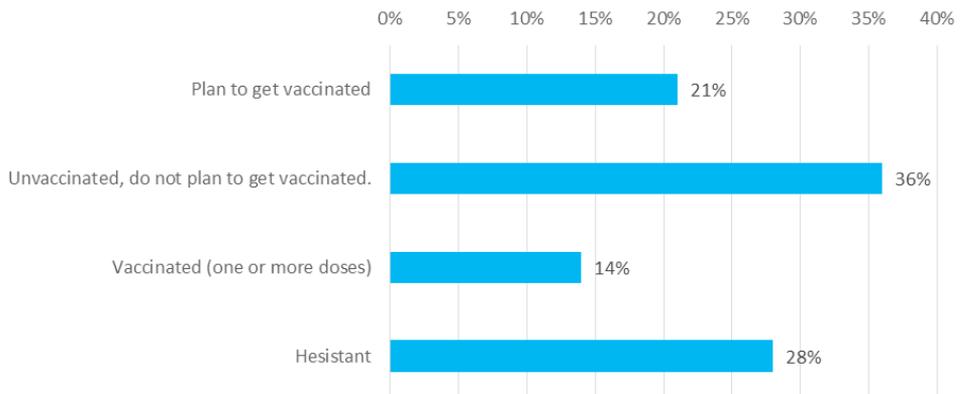
In addition to problems with testing and access to healthcare, Ukraine has one of the lowest vaccination rates in Europe, with only 34% of the population fully vaccinated as of January 2022, compared to a European average of 63% (Ritchie et al., 2022). As the pandemic advanced and case rates rose throughout the latter half of 2021 (Zinets & Karazy, 2021), this led to increasing levels of hospitalisation for the unvaccinated; in October 2021, it was estimated that 94.2% of the 27,488 people hospitalised due to COVID-19 in Ukraine were unvaccinated (UNICEF Ukraine, 2021). Low levels of vaccination are partially attributable to vaccine hesitancy (Holt, 2021), together with a government vaccination programme which prioritised healthcare workers³² and security personnel over the elderly and those with chronic health conditions, meaning that

³²Due to rising cases in November 2021, the Ukrainian government made vaccination mandatory for medical and municipal workers, in addition to earlier mandates for teachers and staff within state institutions (Polityuk, 2021).

free vaccination was delayed for vulnerable groups (Matiashova et al., 2021). However, a survey of people in Ukraine found that even were the vaccine free of charge, 60% of respondents would not take it (OECD, 2021, p. 2). In comparison, another study found that if the vaccine were free and guaranteed safe 61% of respondents would take it, while also finding indications that there was considerable suspicion and distrust of the vaccine and its safety amongst Ukrainians (Giles-Vernick et al., 2021, see also; Health Cluster Ukraine, 2022a, pp. 20 – 21).

All participants in our study were asked about their plans to get vaccinated: 21% (64/301) were planning to get vaccinated; 14% were already vaccinated (one or two doses) at the time of the interview (42/301); 36% did not plan (107/301) and 28% were hesitating (85).

Figure 25. Vaccination Status.

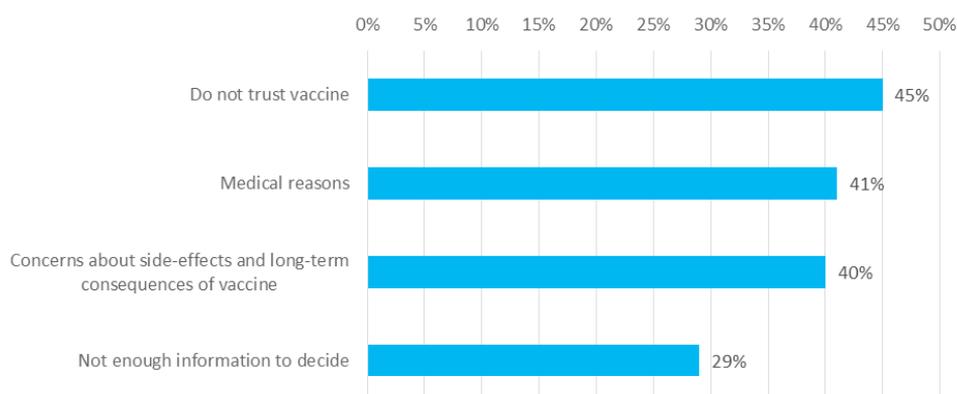


Those who did not plan or were hesitating (64% of our sample), were asked to explain why:

- (a) The most frequently mentioned reason was lack of trust in COVID-19 vaccines (45% among those who did not plan or were hesitating);
- (b) The second most frequently mentioned reason was not being able to get vaccinated for medical reasons (41%); followed by

- (c) Concerns about the side effects and long-term consequences of the vaccine (40%);
- (d) About 29% felt they did not have enough information about the vaccines to make a definitive decision.

Figure 26. Reasons For Not Being Vaccinated
(more than one could be chosen)



Most participants who said they lacked trust did not offer any detailed explanations, however this quote is indicative of the overall levels of mistrust in the vaccination programme:

🗨️ I don't trust our state. Moreover, these vaccinations, which we are constantly being lied to about in the Ukrainian media. They are just lying. You will never hear any truthful information. I simply do not believe that they will bring a normal vaccination over here... they will just prick us with some kind of fruit drink!

Some participants — especially those who indicated they were hesitant about getting vaccinated — commented on the lack of information about the vaccines, including their side-effects and contra-indications. Some of the concerns in relation to the potential adverse interaction between the vaccine and interviewees' health included:

- 🗨️ In fact, I've always had contraindications to vaccinations. I have not decided yet whether to get vaccinated or not because I do not know how my body would respond, whether there would be any adverse reaction.
- 🗨️ There are some health-related contraindications. Well... there is no confidence in a certain vaccine yet, because they offer three different vaccines and...there is no more accurate information on it. All information is blurred. Some vaccines help, others do not; some are well tolerated, others are tolerated with a high temperature.

Other participants were simply scared and fearful of the vaccine — without mentioning any contraindications or conditions that may have interacted with the vaccine:

- 🗨️ I would like to have it but at the same time — I am scared. I do not know what the consequences may be. Where is the guarantee that if I get vaccinated, nothing is going to happen to me? What if I die? Who is going to ask the questions then?

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

All interviewees were asked what improvements they felt should be introduced to the healthcare system for persons with disabilities in Ukraine. The key message is that the overall healthcare system requires significant improvements and that disability considerations alone are not sufficient if the healthcare system remains underfunded, understaffed and under-equipped. The following key themes were identified:

1. Ensuring that the existing healthcare legislation and policies are implemented at the point of delivery and are fully funded.
2. Improving the overall standards of healthcare, including physical infrastructure, equipment and staff.
3. Disability-specific improvements and considerations.

1. Our interviewees emphasised the need to ensure that the existing reforms are fully implemented and the **need for the national oversight of the existing healthcare standards**. A number of participants directly commented on the patchy implementation of the existing standards:

-  It is imperative that the accessibility for people with disabilities is not only on paper, but is a reality, that it is implemented in hospitals.
-  The orders of our Minister of Health need to be carried out locally. Because a decree could say one thing, but the reality is completely different. There is a discrepancy between the laws and their implementation. The laws are fine, the decrees are good, but their implementation is zero.
-  There needs to be a law: that a person with a disability knows that they have a right to rehabilitation, to medical care. And so that everyone knows that this is the law. And there need to be consequences if the law is violated. But here...it's all like this: you can do it this way, or maybe you can do it that way... and in the end, people with disabilities get practically nothing, except for a wooden stick as a means of transportation.

Some interviewees went further to suggest that the ongoing healthcare reforms failed to foreground disability considerations and made things worse for persons with disabilities:

- These reforms did not result in any improvements in the services available to persons with disabilities, but, on the contrary, to the deterioration, to limited opportunities and deprivation of all rights and opportunities. I asked to have the MRI done as a disabled person — either with a discount or for free. I received a complete refusal, a categorical refusal. For this reason, I cannot get a referral to see a consultant. There is no assistance available to a person with disability. None.
- The medical reform is a complete sham. In fact, there are no improvements in services available to people with disabilities. Absolutely. It got even worse.

2. Another prominent theme was the need **to improve the quality of the existing public health infrastructure** as a foundation for high-quality, responsive, accessible and safe services. A number of participants were concerned about the low levels of professionalism across the healthcare system, including specialised consultants. They called for a sustained investment in medical education and training to ensure the availability of qualified and empathetic medical staff who are trained to provide care to people with disabilities:

- Our medical universities teach how to provide medical care only to ordinary and healthy people. And as for people who have complex impairments...they are not taught this, they have no practice. For example, they do not know how to combine Covid treatment protocols with other conditions. They should educate them in a completely different way, prepare these students and future doctors and nurses so that they are oriented on how to help people with disabilities.

- And most importantly, most of our doctors do not know what to do with us. Most of them. Recently, I went to get a certificate issued by a neurologist, and he said: “Why did you have a surgery?” I had a tumour in my spine. “Why was this surgery necessary? You could have just irradiated everything”. And I told him: “How can you talk about this without knowing the details of my case? Actually, it’s the first time you’ve ever seen me!
- The first task is to start thinking about how to teach doctors to work with people with disabilities. So that they don’t say that “You can’t give birth...what will we do with you?” These are some weird questions they ask. But, on the other hand, I now understand why they are asking such questions; why they are saying this. Because they are not taught. We simply do not have people who know how to work with people with disabilities.

A number of participants commented on the indifference and lack of humanity shown by medical professionals, calling for a culture change which would challenge the ‘invisibility’ of persons with disabilities in the eyes of healthcare staff:

- They need to see people with disabilities... see them for who they are. They just do not want to see us. Even if you go to the management, they put on their blinkers and they do not see you. You then mention the law, and they do not listen/hear.

In response to the harrowing stories of being treated in dilapidated and under-equipped healthcare facilities, the majority of interviewees called for improvements in the quality of healthcare infrastructure:

- 🗨️ The hospital buildings are terrible. The equipment that is there is in such a terrible state. It seems that it's still the Soviet Union times. Everything is old and dilapidated. Everything.
- 🗨️ The quality of healthcare needs to be improved. I was lucky that my doctors were experienced. But I hear from my colleagues, it is not always possible to get an experienced doctor. And this may lead to doctors mis-diagnosing — they treat one condition, but a person will have a completely different one.

Some participants called for a proactive and preventative approach to health management and support rather than a system based on an episodic, acute care model:

- 🗨️ Doctors must actually diagnose a person, and treat this person according to the diagnosis. That will reduce the time, maybe even the period of disability, or the person will not even become disabled and can fully recover.

Some participants called for improved availability and accessibility of healthcare in rural areas.

One of the key concerns was the cost of healthcare, which as reviewed in Part 1 of this report (Sharapov et al., 2022a, p. 31) should be free as guaranteed by the Constitution of Ukraine, including access to a full range of rehabilitation services for people with disabilities.

Our participants called for measures to eliminate corruption, which some described as endemic across the healthcare system in Ukraine (including bribes and 'under-the-table' payments — see Anderson and Sharapov, 2022, pp. 14 — 16), and to ensure that all healthcare including medical procedures, complex tests, and medication are provided free of charge to persons with disabilities:

🗨️ This is bureaucracy and corruption, and you cannot escape it: unless you pay, unless you put a penny into someone's pocket — they won't even look at you. But if you give the money — well...come here...come here, we will work with you. If you don't bribe, nobody will call you or will treat you. Bureaucracy. Corruption. Lack of specialists. And the government does not care, they do not think about improving healthcare.

3. Most of our interviewees called for specific **disability considerations to be funded, supported and embedded as a priority across all healthcare settings in Ukraine.** One of the key suggestions called for a dedicated member(s) of staff at all healthcare facilities with a specific responsibility to assist persons with disabilities in organisational matters related to health (including appointments, issues of access, identifying appropriate support).

🗨️ First of all, I would like a communication service to be created in Ukraine, which would not be dependent on any hospitals, and that each hospital employs such a communicator. When a patient with a disability is admitted to the hospital, a patient who does not speak, or does not see, or does not hear, then this communicator could help the staff and doctors to organise appropriate care for this patient.

🗨️ It would be good to have a dedicated person, a doctor, a specialist who can be called and consulted, in the broad sense of the word. What to do, which specialist to contact, which medication to take, which means of rehabilitation to use in a particular situation. That is...as in the bank, there is a personal banker for gold card holders who can be called at any time of the day, and they will answer all the questions that the client may have...so something like this for persons with disabilities but in a health care setting.

One of the key concerns for our interviewees was improving physical and informational accessibility of healthcare settings and ensuring that the overall healthcare system (in all of its aspects) is barrier-free:

- First of all, healthcare needs to be accessible. We have a large city and not all medical facilities are accessible. When I was sick, I had to do a fluorography. And in a city of a million people, only one hospital has facilities to do the fluorography for a person who can't walk. Everywhere else — only for people who can stand. Healthcare should be available to all people. So that you don't travel around the city and look for one hospital where they can provide services, so that it is comfortable and affordable.
- This applies to the entire country: first of all, medical facilities should be accessible to people with disabilities. For a blind person, for a person in a wheelchair — they must be able to get to this hospital, use the toilet, and so on. Unfortunately, this is not always the case. Ramps are appearing in hospitals, but so slowly; toilets are generally a problem. The elevators do not work, you have to ask someone to somehow persuade the doctor to come down to you to see you. Or you need to look for people to carry you around the floors like a bag of potatoes, which is not very comfortable and pleasant for a person. First of all, what needs to improve is architectural accessibility.
- To have architectural and informational accessibility. So that there are signboards on the doors of offices hospitals, polyclinics and that they are duplicated in Braille; tactile signs should be on the doors, at the entrance and in the room itself.

Some participants called for improved mobility and having accessible and free transport arrangements:

- A person with a disability needs accessible transportation, either public or specially arranged to get them where they need to be. During the pandemic, it was impossible to use public transport without special tickets — it was a challenge.

Participants also called for improved availability and quality of home visits for persons with disabilities, including visits by consultants rather than a GP:

- I would like healthcare staff to be able to make home visits when it is needed so that there is no need be around other people in polyclinics. This should include both a family doctor (GP) and specific consultants. If a person without a disability can walk to a polyclinic, a person with disability faces difficulties in getting there.

A lot of recommendations called for the improvements in the system of primary care, including both the availability and accessibility of family doctors; and removing the need for referrals via family doctors for chronic conditions/impairments for persons with disabilities:

- At a minimum, clean up this madness with family doctors. All healthcare needs are channelled through them. To get to a consultant who is specialist in your underlying condition, you have to see the family doctor first. They have carried out this reform and turned it all into a complete madhouse. You walk 10 times in the same circle.
- It is necessary to change the system of family doctors, because it is very difficult to get an appointment, they have a long queue, and it is not convenient for a person with a disability to stand in line at all, and you need to sign up in advance. If there is a live queue, it is very difficult to get in. And if you are sick, you can't stand and wait there if you have fever.

Some interviewees called for the overhaul of the state system which recognises disability (see Sharapov et al., 2022a, p. 41) and for streamlining current procedures for the allocation of means of rehabilitation:

-  Why is it not possible for people who have severe disabilities not to have the rehabilitation program renewed every 2 years? What could change over these two years? Will this person get in good health? Will they grow a leg? An arm? Will they suddenly start walking? So that I can go to a prosthetist to order new rubber for the wheelchair, I have to go and get the new rehabilitation programme issued. This is absurd.

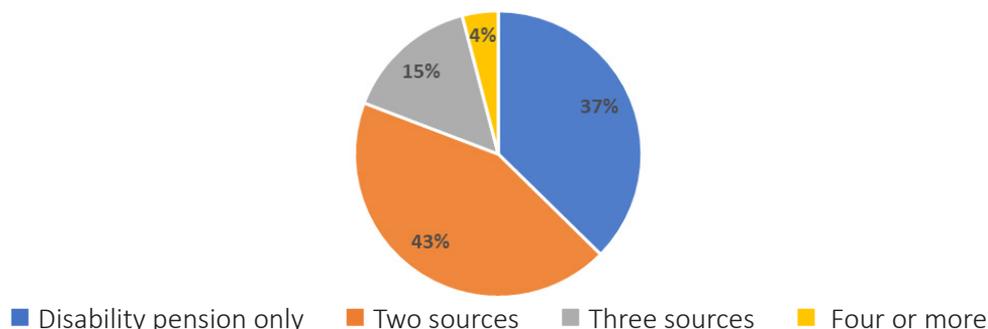
COVID-19 and economic situation of people with disabilities

As anywhere else in the world, the pandemic had a substantial and detrimental impact on the Ukrainian economy and placed additional burden on its welfare system, which had already been weakened by the ongoing conflict in the east of the country (OCHA, 2022; UNICEF Ukraine, 2022). As set out in Part 1 of this report, the disability pension in Ukraine remains below the factual subsistence level, pushing millions of people with disabilities in Ukraine into poverty. Within this context, additional sources of income — from employment, self-employment, support from relatives or charities — became essential in avoiding destitution and homelessness.

All interviewees were asked to identify their main sources of income and each interviewee could identify several sources. Overall, 296 interviewees shared this information. Disability pension was the main and the only source of income for 37% of interviewees. For interviewees who said they had two sources of income (43%, these were, in most cases, a combination of one of the three types of state-funded benefits - a disability pension,

a social pension or an IDP benefit - supplemented by another source (another type of benefit or salary). The rest of our interviewees identified three (15%) or four (4%) sources of income.

Figure 27. Main Sources of Income



The shuttering of the Ukrainian economy to reduce COVID-19 transmission and infection rates led to the wholesale closures of public and private companies, including enterprises established by organisations of people with disabilities. For our interviewees who were employed before the pandemic, this meant one of the following outcomes: losing a job all together; taking unpaid leave; having the volume of work significantly reduced; and/or moving to the new way of online home-based working. Some interviewees who were employed in one of the six areas of economic activity most affected by lockdown closures (as identified by the Government of Ukraine) were able to claim 8,000 UAH as a one-off assistance provided by the government³³. A few interviewees who were able to move to online working described this a positive development since it removed the necessity to negotiate external accessibility barriers; one of the respondents suggested that this helped her to find a job more easily:

³³<https://www.kmu.gov.ua/en/news/mihajlo-fedorov-pidpriyemci-mozhut-otrimati-dopomogu-vid-derzhavi-v-rozmiri-8-tis-grn-u-diyi>

- Well, paradoxically, during the pandemic, I found a job. Well, in principle...because of the pandemic there may be more vacancies, which did not exist before, in the sense that remote work is now a priority. And for people with disabilities, it's very convenient and such a convenient way to work, because not everyone can go to work and work at the workplace but with the remote working — we have more employment options.

However, interviewees who had lost their jobs reflected on the devastating impact of this upon their everyday life:

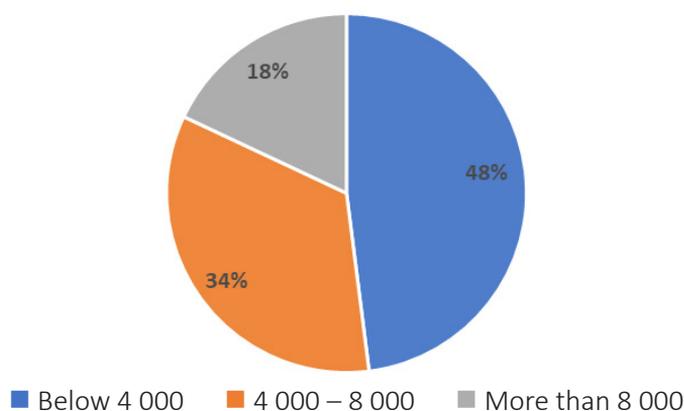
- Our income has been more than halved because of the lockdown. My wife didn't work, I worked remotely.
- And our financial situation has worsened a little, of course... not just a little, but noticeably. We have 2 persons with disability in the family. And, well, everything is connected with money, that is, there are fewer opportunities, well, it's harder to pay utility bills and rent, and again, there is less money for yourself, that is, for food, for clothes, for life, in short.
- I was left without a job. Just coincidentally, I was robbed in 2019, I could not have a surgery, and my health got worse, plus the pandemic began. Companies started to close and in the end I was left without a job. As a result, the financial situation of our family has got worse. It was very hard. And morally, it began to oppress me... financially, without work, it is much more difficult to live on one pension.
- Lockdown number 1, which was strict, it was last year, during which you could not work, which means we did not work. The danger is that if a person does not work, then he does not receive a salary. If you don't get a salary, what is there to eat?

Overall, almost all of our interviewees relied on one or a combination of benefits provided by the state, which put them in a precarious economic situation. As noted in Part 1 of this report (Sharapov et al., 2022a, pp. 49 — 50, the average monthly disability pension (2,641 UAH in Ukraine for 2020 falls below the government’s own estimate of what is required to cover the cost of living (3,845 UAH), a shortfall of more than 30%. This places many people with disabilities who rely on these pensions as their only source of income at risk of poverty.

To evaluate the extent of daily economic pressures, we asked all interviewees to assess their personal monthly income: we received 283 responses. Almost half (48%, estimated their monthly income falling below 4,000 UAH including 9% interviewees whose income was below 2,000 UAH and 39% whose income was between 2,000 and 4,000 UAH. The remaining 34% of our interviewees estimated their monthly income to be between 4,000 and 8,000 UAH, and only 18% as more than 8,000 UAH.

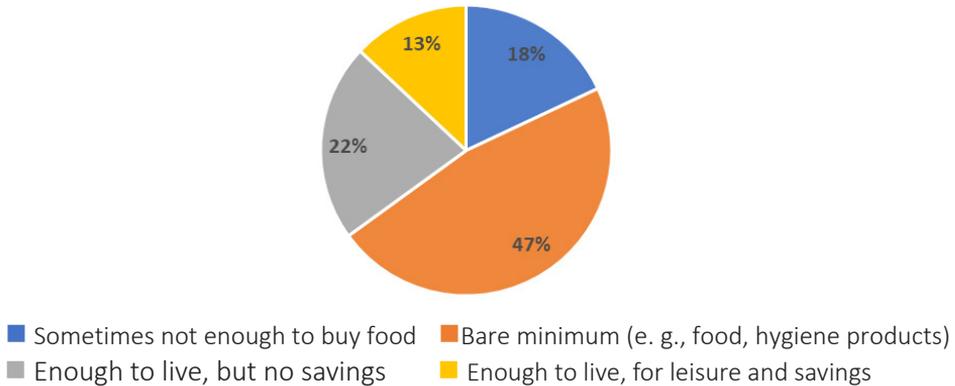
All interviewees were asked to assess whether their income was sufficient to secure basic necessities. We received a variety of responses which paint a picture in which disability, poverty and abandonment (by the state) are intertwined with isolation and despair.

Figure 28. : Monthly Income (in UAH)



The 290 responses to this question can be broken down into the following four categories: 18% of our interviewees said that sometimes they did not have enough money to buy food; 47% said that they could only afford the bare minimum such as food and personal hygiene items; 22% said they had enough money to live on but had no savings, and only 13% said they had enough money to live on, spend on leisure and/or make savings.

Figure 29. Income Sufficiency



- 🗨️ The fear is not to be [so destitute so that you are] left in the street. With pensions and income like this...it is simply impossible to survive like this. Under the Soviet Union, it was not like this...there was some kind of...somehow everything was stable. Of course, nowadays it's better in some ways [than it was in the Soviet Union] but in other ways — we are being annihilated; the winter is coming and it's the costs of heating and electricity...and nobody really knows anything about how it is going to turn out...everyone says there will be another increase [in the cost of living]. And if there is an increase, then you understand, with my income — how can I survive... how?
- 🗨️ It became harder to live — especially in terms of finances. I had to take loans. I never take loans, and in autumn 2020 I had to take a big loan. Just to survive. To buy medicines, food. I had no choice.

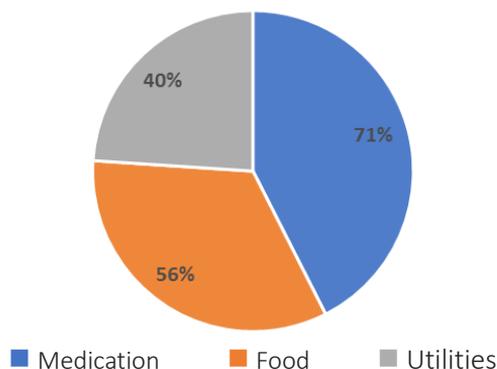
-  Life got worse — that's clear. Because the prices at the market, at the pharmacy — they are increasing daily. One day it's one price and then the very next day the same pills are more expensive. Prices are rising like yeast. It's scary to even come [into the shop or the pharmacy]. But you can't do without them [food or medicines].
-  There are even more financial difficulties now, because my mother and I live together, our income is small — only enough to buy the essentials...not always [enough]. We spend more than half of our income on medicines.
-  We are paying the rent and we have a credit card to borrow the money. Then we are trying to cover the credit card payments...somehow...at least until the end of the month so that they do not add interest at the start of the next month. But we are still constantly in debt and even then we are not able to patch all of the holes in our finances. Our eldest daughter needs to get braces fitted but for us...it is impossible. I'm not even talking about myself...I haven't had my teeth treated for 6 years. So there...
-  During the lockdown, when I locked myself at home, I almost had no money left at all and I literally had nothing to eat or to go and buy food at the shop. This is how it was.

We also asked interviewees to assess which (if any) specific costs increased over the pandemic period. For the majority, their spending increased on medication (71% of the 286 interviewees), followed by food (56%) and utilities (40%). The increased spending on basic necessities can be explained by a combination of factors, including inflationary pressures³⁴ and lifestyle changes

³⁴ In 2021, consumer prices increased by 10% in comparison to December 2020, see https://ukrstat.gov.ua/druk/publicat/kat_u/2022/zb/03/zb%20ICC_2021.pdf

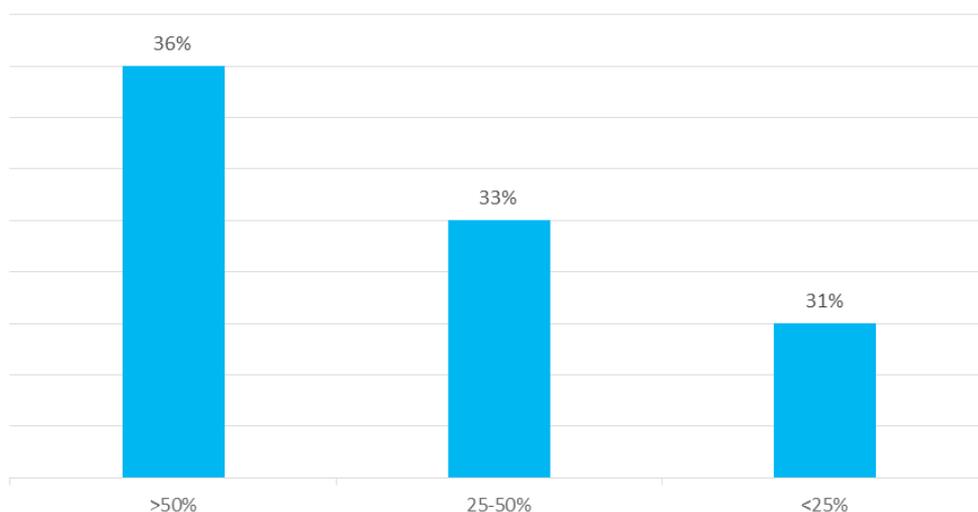
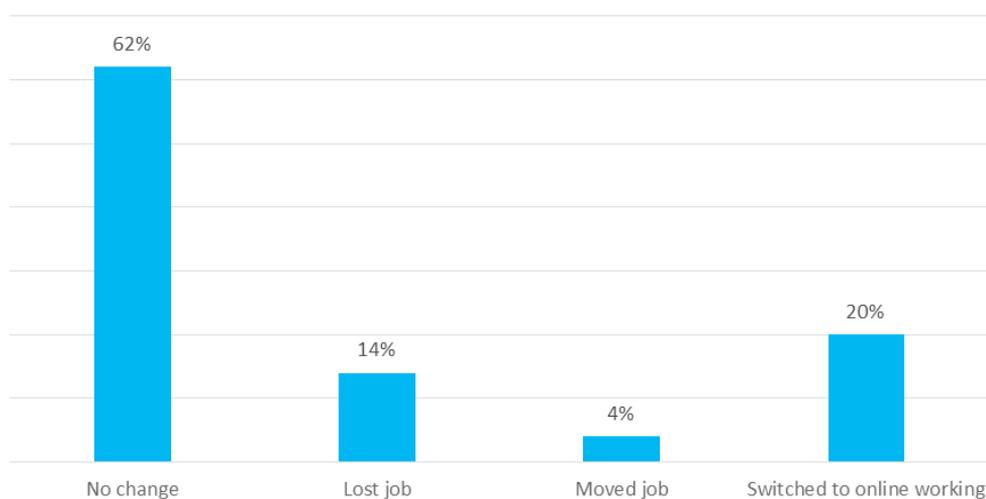
forced upon by the pandemic. For example, some interviewees noted that their public transport costs decreased, however for others such costs increased (including taxi fares) especially for interviewees who to travel to work or to receive healthcare when access to public transport was restricted or fully withdrawn.

Figure 30. Perceived Cost Increases during Pandemic



Overall, more than 36% of interviewees spent in excess of half of their personal income on healthcare, including buying their own medication and paying for medical and rehabilitation services. About 33% spent between a quarter and a half of their income on healthcare, and the remaining 31% spent less than a quarter of their income. Some participants noted that paying their housing/accommodation rent trumped all other expenses and that whatever was left after paying rent and basic food items, was being spent on healthcare.

All interviewees were asked to assess how the pandemic impacted their employment situation. For the majority — 62% of the 273 interviewees who provided an answer to this question — the situation did not change i.e., they either continued working or remained unemployed or unable to work due to their disability; 14% lost their job/employment; 4% found a new job; and 20% had to adopt/switch to online working.

Figure 31. % Income Expended on Healthcare**Figure 32.** Change in Working Conditions

In commenting on the nature of these changes, interviewees mentioned a range of difficulties:

- (a) Some interviewees had to resign or leave their jobs so that they could take care of their children and/or other family members, since home-based care and/or schooling remained the only option over the lockdown periods.

- (b) Some interviewees had to resign or leave their jobs only because they were unable to get to their places of work due to the withdrawal of public transport.
- (c) Some of the interviewees who shifted to online working mentioned lack of support — both financial and with developing their skills — to enable them to work online.
- (d) Interviewees who lost their job and/or were looking for a new job, mentioned the problems with both availability and accessibility of private recruitment agencies and of the State Employment Service of Ukraine.
- (e) Some interviewees were concerned that no specific solutions or assistance were offered by the government to recognise and respond to the unique challenges faced by persons with disabilities when looking for a job/employment — either as an employee or as self-employed.
- (f) Interviewees who lost their jobs were also concerned about the overall impact of the pandemic on employment in Ukraine. Such concerns are encapsulated in this quote:
 -  People without disabilities face problems finding a new job or are getting laid off...and us [persons with disabilities]... how would we find a job in all of this?

COVID-19 and Access to Education

All interviewees were asked to confirm whether they were in education and if so, what impact the pandemic had on their education. About 13% of all participants (n=39) were enrolled on some educational programme when the COVID-19 pandemic began and all of them were affected. A majority of interviewees in this group (70%) mentioned lack of accessibility considerations when teaching and other educational activities

were moved online; 49% said they did not have sufficient knowledge or skills for distance learning; 36% did not have access to the appropriate IT equipment and/or sufficient internet connectivity; some interviewees could not continue with their education having lost access to their carers or support networks:

 In the end, I had to leave my studies: distance learning was not provided in an accessible format, and it was not accompanied by sign language interpretation. There was no way for me to study remotely. It was very difficult for me to connect to the online format, since teachers spoke on the screen and as a deaf person, I needed sign language. And so, I had to drop out of due to the lack of funding; I had to pay for my studies, separately I had to pay for the services of an interpreter, hire [them], and also pay teachers for their work.

Participants with school-age children also commented on the difficulties both they and their children faced with moving to online/home-based schooling. Among 19 interviewees (6% of the overall sample) who provided specific comments on online/home-based schooling, the key themes were:

- (a) Lack of skills and experience among parents to facilitate education at home;
- (b) Having to take time off or give up jobs to ensure that children were engaging with their teachers and friends online throughout the day and to ensure that they were browsing the internet safely;
- (c) Lack of experience or support available to teachers, who seemed to have been left with the responsibility for reorganising the delivery of education to online formats in a very short period of time;

- (d) Perceived deterioration in the quality of education and in the breadth and depth of skills and knowledge developed by children;
- (e) Lack of specific arrangements for children with intellectual disabilities and overall poor accessibility of online teaching for children and parents with sensory and intellectual disabilities

There were problems with my child's education when the quarantine began. They started showing tutorials on TV. Or you could watch them on the internet. There was no sign language translation. There were no subtitles. And my child did not have the opportunity to learn at that time.

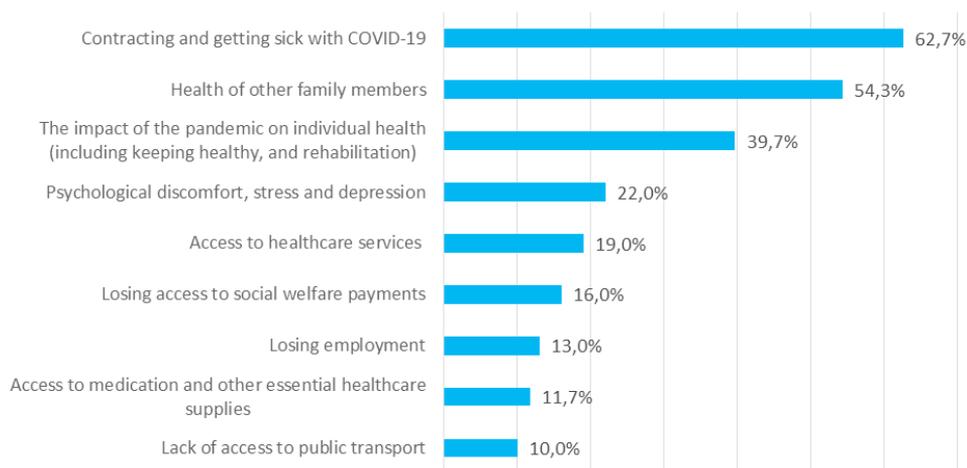
Psychological Impact of COVID-19

Existing research demonstrates that the pandemic and government responses to the pandemic had a significant impact on the psychological wellbeing of all people, but especially people with disabilities. For people with disabilities, being designated as particularly vulnerable to and at risk of contracting COVID-19 raised anxiety levels, whilst exclusion from most pandemic response planning meant that there was a general failure to account for their unique circumstances and everyday needs (Kubenz & Kiwan, 2021; Schormans, Hutton, Blake, Earle, & Head, 2021; Shakespeare et al., 2021).

As a result, existing isolation and loneliness for people with disabilities was exacerbated due to the loss of social contact through social distancing regulations and the move to online medical care and education (Dickinson & Yates, 2020; den Houting, 2020; Jeste et al., 2020; Rose et al., 2020).

All of our respondents were asked about their main concerns and worries caused by or associated with the pandemic. Among 292 respondents, the most often cited concerns (mentioned by at least 10% of respondents, all of whom identified more than one worry or concern) are listed in Figure 33 below.

Figure 33. Main Concerns during Pandemic



1. Fear of getting sick and concerns about family members.

The majority of respondents linked anxieties and fears of contracting COVID-19 to the fear of the unknown, especially at the early stages of the pandemic. The initial lack of reliable (and, in some cases, accessible) information about the spread and dangerousness of the virus was made worse by the unfolding ‘social media panic’ (Depoux et al., 2020) and the heightened attention of the mainstream media to the increasing number of deaths linked to COVID-19. A number of participants commented on the never-ending newsreels of hospitals (both in Ukraine and elsewhere) overrun with dying patients and exasperated and helpless healthcare workers. For many participants, such fears were further magnified by the emerging (yet patchy) data and news reports on the increased rates of morbidity and mortality for individuals with pre-existing medical conditions, including persons with disabilities. For interviewees living with family

members who were their key providers of care and support, or for persons with disabilities taking care of other family members with more complex disabilities and care needs, anxiety about contracting COVID-19 appeared to be most prominent amounting, in some cases, to a ‘visceral fear for life’.

For most interviewees, elevated levels of anxiety and fear in relation to COVID-19 translated into a range of direct, real and often damaging consequences: from avoiding crowded spaces when going about essential daily tasks (like shopping for food or medicines) to situations of complete withdrawal from the outside world. In some cases (see Sharapov et al., 2022, p. 66), the fear was such that humanitarian packages with food and essential supplies were delivered from the outside via a kitchen window using a system of pulleys and cables to avoid any contact— including not opening the front door of the apartment to anyone from the outside who could be a potential source of infection. Some interviewees reported cancelling hospital appointments which were essential for the routine management of their complex health needs.

- 🗨️ Yes, yes, we were terrified we will get sick. Just some kind of panic, we were panicking.
- 🗨️ Because I have a serious underlying condition, of course, I was afraid of contracting COVID. I live in a hostel and not everyone follows safety precautions, wears masks or wants to disinfect their hands. The chances of COVID spreading in a confined space in a hostel is very high. I’m afraid that it will happen in the hostel. And then...we are all done!
- 🗨️ My wife had a psychosis [because of COVID]. For some reason, she thinks that we will all go somewhere, move, and one of us will bring this virus. It’s fear, fear of getting sick. It’s like an obsession. This is my wife’s fear.

2. Fears and the reported impacts of COVID-19 on individual health. Interviewees reported a range of fears and real impacts of the pandemic on their overall health, including (a) the impact of stress and anxiety on physical health, (b) the impact of long COVID-19, and (c) the impact of social distancing and lockdown restrictions, which restricted movement on physical health. The complex relationship between the elevated levels of stress and anxiety related to COVID-19 and physical health has been documented in a number of studies, including, for example, Tsamakis et al. (2020).

In their review of the impact of COVID-19 related anxiety in Cardiology, Paediatrics, Oncology, Dermatology, Neurology and Mental Health, Tsamakis and colleagues (2020) report that “the enormous individual and societal anxiety caused by this biothreat affects a wide spectrum of physical and mental pathologies and may even hamper their treatment”. A number of respondents reported that their pre-existing conditions got worse; some participants reported developing a range of new ailments which they associated with the increased levels of stress and anxiety about COVID-19:

-  My mum... she died just during the pandemic period ... she had an illness. And she loved to talk, so she used to go out for a walk. But then when the lockdown started... she had practically no communication. And she just burnt down — in front of my eyes.
-  For a year and a half, my child’s physical condition has been deteriorating. And we also received a secondary diagnosis in the end. So, COVID just “swallowed” us.
-  The pandemic has affected my cardiovascular system and I also affected my mental health. And I have a chronic disease, pancreatitis and I feel it is getting worse.

- My hearing deteriorated sharply; I began to speak with a difficulty, my pressure is high all the time, shortness of breath appeared, pain in my heart, memory loss...I can have gaps of several hours in my memory. I also started to lose my bearings.
- There has been a significant change. When the pandemic began, my illnesses worsened. My chronic illness...and even more, I was even paralyzed. Now I am bed-ridden.
- What I understood later is that I lived through and experienced severe emotional stress, which has now resulted in an additional illness for me.
- Well, as far as I am concerned...it's depression, chronic despondency, physical weakness...panic moods. It is as if I were a prisoner.
- I have this feeling of immense weakness — psychological weakness. After spending so much at home — with or without illness, I developed a tremor, which sometimes affects me a lot when I get nervous or anxious.

Some interviewees were concerned about the long-term consequences of having COVID-19 ('long COVID-19'), concerns which were further magnified by their lack of trust or confidence in the capacity of the Ukrainian healthcare system to cope with these impacts and deliver accessible care when and where needed:

- Well, my only fear is: if you get sick how could this be treated? To clarify: how to pay for treatments? This is my fear. Well, and, of course, then after COVID-19 itself, there are also further complications: if you have some issues with your health, they become problems. People with kidney condition — their kidneys begin to fail; people with heart condition — their heart will stop. Well, in general, I don't know yet how much my body will be able to withstand COVID-19 and its treatment.

-  So, I understand...and you read, and research what consequences or manifestations of surviving COVID there may be but still there is no such information. And there is no information on how to treat this.
-  I have a fear of getting sick again, because the immune system weakens every time after this disease, as far as we know. Fear of losing your job — it is not known how long you can be out of work; someone is sick for a week, someone for months. It takes a long time to recover from this illness.

3. Psychological impact of the pandemic and (government) responses to the pandemic. For the majority of interviewees, COVID-19 as a deadly disease and the associated socio-economic effects appear to have had a significant and long-lasting impact on their mental wellbeing: fear or direct experiences of death or disease; of not being able to receive appropriate and accessible health care; concerns about relatives and friends; fears and lived experiences of losing jobs and income and becoming destitute; social isolation and abandonment. These fears and, in many cases, direct experiences of living through these traumatic events and experiences had a profound impact on all interviewees in our sample. Our respondents spoke about panic attacks, low mood, constant psychological discomfort, depression, feelings of loneliness and abandonment, and loss of hope:

-  And this is a terrible thing... visceral fear! Something creeps into your head, something awful, it felt as if I was sitting in some kind of an ice hole. [My relatives] would put on three pairs of socks on my feet, and I...just close my eyes and I'm in this ice. Scary. It was horrifying. And this was constant: you will die, you will die. Death.

-  I would say that I got depressed. I was afraid that I would not be able to help my relatives if something happened to them...because I was unemployed. I was afraid that I would not be able to find a job, because the pandemic has been going on for a very, very long time, and it still has not finished. Well, this isolation oppressed me, made me feel useless, alone.
-  I was shocked, I was crying. I would get really upset for no reason...And now I'm starting to have gaps in my memory.
-  I was really very terrified. Really. Then I felt so bad that they even prescribed some kind of antidepressants. Well, that was only later, when I could access treatment.

For many of the interviewees, concerns about access to healthcare services, losing access to social welfare payments, losing employment, accessing medication and other essential healthcare supplies, and lack of access to public transport materialised as real-life barriers (as reviewed in both parts of this report) which magnified their economic, social and psychological vulnerability.

Mobility and Access to Transport

It is recognised that the availability and accessibility of transport options (including public and private transport) is vital for persons with disability to undertake essential daily activities (including access to healthcare), access socioeconomic opportunities, and maintain their social connections (Wang et al., 2022). Article 9 of the UN CRPD requires State Parties to ensure that persons with disabilities have access, on an equal basis with others, to transportation. The need for equitable and inclusive transport provision becomes more acute in situations of public health or

other emergencies. In 2016, the National Assembly of People with Disabilities of Ukraine published a comprehensive report which assessed the accessibility of transport infrastructure for persons with disabilities in Ukraine (NAPDU, 2016). In highlighting the key role of public transport networks in everyday life of persons with disabilities in Ukraine, the report identifies multiple and significant accessibility problems within the existing infrastructure (NAPDU, 2016). We recognise that poor accessibility of public transport is only one part of what Sheller (2018, p.62) describes as mobility injustice, which, within the context of disability, encompasses “varied forms of inaccessibility built into our cities, and the intersected ways in which these limit and constrain diverse kinds of bodily mobility”.

Within the context of our study, our focus was on understanding the impact of the pandemic on the existing infrastructure rather than assessing the extent of “uneven mobility and differential impairment” (Sheller, 2018, p. 63) which pre-dated COVID-19. For this reason, we included a specific question regarding the availability and accessibility of public transport within the context of various restrictions imposed as a response to the pandemic. The majority of our interviewees who did rely on public transport in their pre-pandemic everyday life commented on the significant challenges in relation to both the **availability** and **accessibility** of public transport brought about by COVID-19.

Availability of public transport during the pandemic

In relation to **the availability**, our interviewees were confronted with a range of challenges brought about by the government-imposed restrictions on the use of public transport or, in some cases, its complete withdrawal. The severity of restrictions varied depending on the ‘wave’ (or severity) of COVID-19 infections and the region of Ukraine. In some regions,

public transport services were completely withdrawn (completely cutting off individuals and communities dependent on public transport in their daily life from vital services). In other regions, local authorities imposed severe limitations on who could access public transport; in most cases, this was achieved via a system of special passes or permits which were designed to prioritise the employees of the ‘critical infrastructure’ (which can be described by using the UK terminology of ‘frontline workers’). However, no consideration was given to persons with disabilities who required barrier-free access to public transport on a regular basis to access healthcare (for further discussion of the availability and accessibility of public transport as viewed by the organisations of persons with disabilities in Ukraine see Sharapov et al., 2022, pp. 45 — 48). These restrictions on the availability had a significant and in some cases life-changing impact on our interviewees:

-  I couldn’t use public transport at all when there were red zones and when they required passes to be able to travel... We travelled by taxi, because trolleybuses and minibuses were not available to us.

Restrictions on the availability of public transport were more pronounced in rural areas because the poor state of public transport infrastructure (which predated the pandemic, and included poor availability of taxis) was further compounded by the longer distances involved in getting to healthcare or other essential services:

-  Public transport passes by our yard. Three times a day. But if you didn’t get on it, that’s it, public transport has passed you by.
-  Let’s say there are one or two disabled people living in a village who use wheelchairs. Nobody will run minibuses or anything similar for their sake. And I am sure that nobody will do anything for the next several decades. Moreover, nobody will start running public transport for them.

Such restrictions resulted in people not being able to get to hospitals, pharmacies, rehabilitation centres, or food shops:

- 🗨️ I couldn't go to have my dressings done every day, because the transport would not stop for me, I didn't have a special pass.

Another interviewee told us about not being able to access their disability pension:

- 🗨️ They did not delay the payment of pensions. But when there was the first wave last year, the bank cards which we used to receive social assistance expired. The branch of the bank, which is within walking distance from us, was shut; only the central branch worked, but we could not get there by public transport, because we did not have special passes.

One of the interviewees was unable to access a job centre to continue their job search; some interviewees were forced to resign from their jobs since they could not afford to pay for daily taxi rides:

- 🗨️ I was looking for a job, but I couldn't find anything because transport was unavailable, employment centres were unavailable.
- 🗨️ It became impossible to go to work, I had to hire either a taxi, or somehow get there, because I work in Kyiv, and getting from my village is quite far from work. It was necessary to take a taxi, and even when the transport stopped, the director told everyone to go to work. I wrote a few complaints, but it all came down to a few times I went to work — it's a big expense, I went by taxi, and so I applied for unpaid leave.
- 🗨️ I worked, but I had to quit, because it was impossible to get there, there were no trolleybuses.

Furthermore, the withdrawal of the dedicated transport services for persons with disabilities ('social taxi'), including specially adapted people carriers or buses for persons relying on wheelchairs, did not simply 'restrict' but removed the only mobility option for some of our interviewees:

- Yes, in our city where we live, there is no public transport that could be used by a person in a wheelchair. And the social taxi did not work during the quarantine

Some interviewees told us about not being able to use public transport (when restrictions were lifted) because they were unable to buy facemasks:

- In March 2020, I was shocked that the transport stopped running and I had to wear masks. There was a shortage of masks in the pharmacy. I had to make my own mask out of gauze, a bandage, a wet wipe. Once I was stopped by the police and they demanded that I put on a mask. Although I didn't understand the question at first. They managed in their own way, in their own sign language, to show: here, you need to put it on your nose, mouth, you need to cover it with a handkerchief, gauze, whatever you have there. And they wanted to fine me.

Other interviewees were concerned about relying on public transport because of their fear of infection, since not everyone was complying with the requirements to wear masks or observe social distancing, and compliance was not enforced:

- It was scary because people weren't wearing masks. I was afraid to use public transport. Some people themselves organized some kind of trips in private cars, minibuses. There were things like this, but I did not use them — I was afraid to get sick.

To overcome such restrictions, some of our interviewees relied on friends, relatives, neighbours, volunteers and organisations of persons with disabilities to access food and medicines. Others spent their savings on taxis as the only option to access food and to stay alive. Others complained about having to cover long distances between home and work, or home and hospitals or food stores by walking. Some of our interviewees had no choice but to compromise their own safety to deliver essential supplies to family members:

- 🗨️ My mother is at that age, she is 80 years old ... There were difficulties - I can't see, and my mother is far away. The transport didn't work. We walked 10 kilometres to bring her some food. We walked along the road with a cane, because there was no other option.

Once restrictions were relaxed but not fully lifted (i.e., restricting the number of passengers, or requiring all passenger to sit on a bus, etc.) some of our interviewees continued to experience significant difficulties due to the lack of disability considerations:

- 🗨️ Well, of course, it was difficult for persons with visual disabilities to use public transport, especially when the number of seats was limited. I don't know if the bus is full or not, 50 percent or how many? You enter, say, a trolleybus, and they tell you: there are no seats.
- 🗨️ The buses won't let you on. It was a nightmare. Once, I was left in tears: I was coming back from work and the driver would not let me on even though there were seats designated for [people like] me. And now I also have to get up an hour earlier to take a bus to go around, all the way to the final stop and then back. Because otherwise they won't take on any more people at my stop.

- And when they allowed to use public transport, with masks and only if you are seated, I had to skip several buses, because all the seats were occupied.
- To get on, I had to queue — and there are two of us, myself and the accompanying person. The people are scared and I understand them: it's every man for himself. When they saw a person with a cane, there were lots of comments like: why aren't you sitting at home? Coming here with your stick [cane]?

Accessibility of public transport during the pandemic

In addition to the limited availability, there were significant difficulties with the **accessibility** of public transport especially for people in wheelchairs. It appears that the unsatisfactory situation with the accessibility of public transport turned into a forgotten concern during the pandemic; once restrictions began to ease, the situation often failed to return to the pre-pandemic levels — a situation described by some of our interviewees as 'accessibility rollback' or 'barrier-free rollback':

- In our city, there is no public transport accessible to a person in a wheelchair. And the social taxi did not work during the quarantine.
- I am a completely blind person, and it is difficult for me to travel by train or bus.
- There is no public transport accessible for people with disabilities...there is no lowering ramp...a person in a wheelchair is unable to get on or off the minibus.
- No, we do not have accessible buses and minibuses. So I have to go to court by taxi.

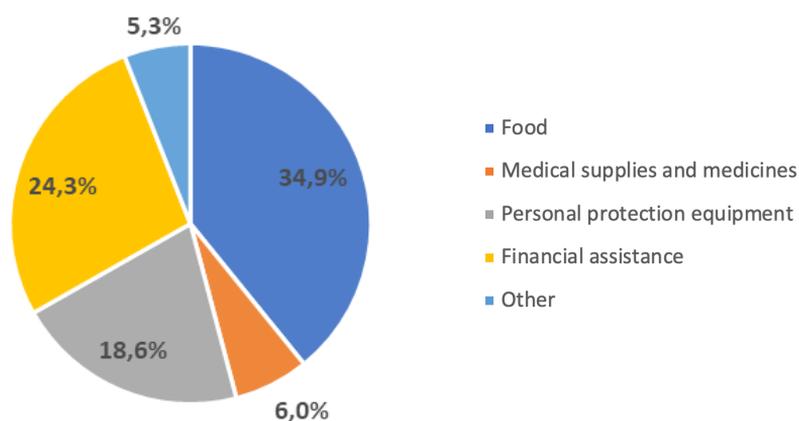
- It is good that there are low-floor bus routes, but there are few of them. We are lucky that there is such a route where I live. Otherwise, it becomes impossible to travel; you would need to be carried in and carried out [of a bus]. It becomes inaccessible to us all together.
- I live in a village, and the roads here are in a deplorable condition. In principle, if you try, you can get to public transport. But again, you have to try. There are trolleybuses here, with a ramp, everything is as it should be, but you have to cover 700 meters off-road to get to it.

Severe COVID-19 related restrictions on mobility ('пересування' in Ukrainian) magnified and exacerbated already existing inequities and inequalities of access for persons with disabilities in Ukraine. These restrictions varied in their scope depending on the severity of government-imposed lockdowns. Overall, they can be described as an inability to access — whether by walking, cycling, taking private or public transport — essential services such as food shops, rehabilitation and healthcare establishments, leisure facilities (including public parks, gyms, walking paths), jobs, and social support networks (family and friends). These restrictions also significantly varied in terms of their impact on persons with disabilities: some of the interviewees had sufficient resources to make alternative arrangements (depending on their financial situation, community or family support, and/or location), such as relying on food delivery companies, taking walks in a nearby park, keeping in touch with family and friends via video-chats, or working from home. Others had to cope with life-changing circumstances of not being able to access essential healthcare, food (especially interviewees living in rural areas), losing jobs (and financial security), coping with being left in almost complete isolation as their carers and/or family members were unable to travel/access them because of the government restrictions on movement and withdrawal of public transport.

Direct support during the pandemic and public authorities' response to the pandemic

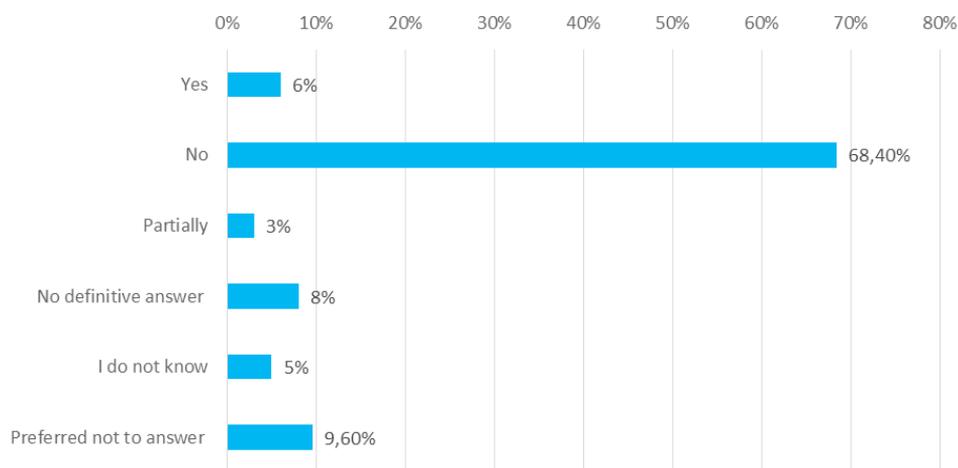
The last block of questions focussed on the provision of direct support to persons with disabilities and their views on whether the authorities did all they could to support persons with disabilities during the pandemic. As explained in Part 1 of the Report, almost 1.5 million people with disabilities in Ukraine who received state pension due to disability (SSSU, 2021, p. 21) and for whom a disability pension was the main source of income lived in poverty as of 2021 (Sharapov et al., 2022a, p. 50). We asked our interviewees whether they experienced any delays with receiving their disability pensions and/or other welfare payments during the pandemic. Among those who responded to this question (293 interviewees), only 10.2% experienced delays which ranged from several days to several weeks depending on the location and the type of payment/benefit. We also asked whether interviewees received any other support during the pandemic from any other agency, including authorities at central or regional levels, non-governmental or private organisations. Most respondents (59.8%) received one or several types of support; and the remaining 40.2% received none. Responses to this open-ended question can be categorised as follows (by the type of support, however not where this support came from)³⁵:

Figure 34. Additional Support Received during the Pandemic



Some respondents received more than one type of support, the chart above shows % of all survey respondents. This was an open-ended question and not every interviewee provided further details about the type of support, however the majority of the interviewees who mentioned financial assistance were referring to the one-off ‘social support’ payment of 1,000UAH (or 27 GBP) provided by the Ministry of Social Policy to persons with disabilities in April 2020. Most of other types of support (such as medicine, food parcels) came from non-governmental organisations rather than public authorities. We asked all participants to assess, based on their own experience of living through the pandemic, whether Ukrainian authorities did all they could to support persons with disabilities during the pandemic. We received 272 responses, about 90% of the overall sample (301 participants). About 9.6% of our participants preferred not to answer this question and among those who did, about 5% explicitly described this as a difficult question to answer. About 5.0% (15) responded with ‘I do not know’ (rather than refusing to answer all together); and 8.8% (24) did not provide a definitive answer which could be categorised under any of the following three categories: Yes, No, or Partially.

Figure 35: Did the Authorities Do All They Could to Support People with Disabilities during the Pandemic?



Only a few of our interviewees who thought of authorities as doing all they could to support persons with disabilities during the pandemic could explain what made them think so. For example, one of the interviewees shared their positive experiences of accessing healthcare and online food deliveries. Such experiences, however, considered within the context of the overall hardship described by our participants, can be described as an exception:

-  I think yes. The authorities are trying: the government, our city mayors, the city administration. Of course, I would prefer that more is done, I would like it to be better. But I do not think I can complain. Everything is available; healthcare is still available, there are still doctors, pharmacies are supplied with medicines. Yes, prices [are increasing], of course, that's understandable. Otherwise, everything is organized. Well done. During the first wave in spring, I had my food delivered home. I could phone the "ATB" supermarket, order what I needed, they would bring it to you, you pay and that's it! Of course, perhaps things were even better elsewhere. But I believe that at this moment for our Ukraine, which is still moving upwards, these are great achievements.

The majority of interviewees (68.4%) did not think authorities did all they could to support persons with disabilities during the pandemic. When analysing this category of responses, we differentiated between a 'Categorical No', where the interviewees provided a definitive No answer (which was further probed by our interviewers); a 'Soft No', where interviewees did not say 'No' as such but provided an account of coping through significant difficulties without much or any support from authorities; and a 'Justified No', where interviewees said No but provided a justification as if to 'excuse' the authorities for their inadequate response. The majority of those who said NO, said it categorically (75%), followed by 'Soft No' (23%) and Justified No' (2%)

- 🗨️ No. Definitely not. [We are] The most unprotected- by nothing and no one. Pensioners and people with disabilities are not protected at all. We rely only on ourselves.
- 🗨️ There is no support, never has been and never will be. It is my opinion.
- 🗨️ Interviewer: In your opinion, have the public authorities done everything they should have done...
Participant [interrupts the interviewer]: Zero...
Interviewer: To support you during the...
Participant: Zero. You can write it like that.
- 🗨️ Interviewer: In your opinion, has the state done everything it should have done...
Participant [interrupts the interviewer]: 300 times - no!
Interviewer: I will write it down, 300 times
Participant: That's right. You should write it down like this.
- 🗨️ I believe that the state failed to do all it should have done not just for me but for the whole country and for all Ukrainian people. Nothing was done what should have been done. Purchasing vaccines on time, vaccinating people on time, and service at the polyclinic-I have already talked about it. It was very difficult. There were queues to take a test or get anything done. People with fever sat next to others and possibly infecting them. I think this is a mess. This should not have happened.
- 🗨️ If I am to rate how the state helped me personally on a 10-point scale, I would say that it is probably below zero, which is minus one. Minus 1. The state only harmed me during the pandemic. Because it limited my movement, forbade me to use public transport...It didn't help me. Minus 1. And maybe more minuses.

Among those who did not think that everything was done to support persons with disabilities to live through the pandemic, some of the key themes that emerged as an outcome of the thematic analysis include:

(a) Being abandoned by the state:

-  I believe that the state did nothing to support me during the quarantine and during this pandemic. They didn't provide bandages, or medicines, or vitamins, absolutely nothing. Nothing, no one, just go and take care of yourself. And from the authorities? Absolutely no help.
-  I have the impression that the state just let everything take its course. Live as you wish. Absolutely. It was like that before, but during the pandemic it manifested itself very sharply. Previously, at least somehow it was possible to go and put pressure on them, sometimes with scandals, but now everything is closed. This is terrible. The state, I think, did nothing. Didn't do its job.
-  The first year was difficult for everyone. But the pandemic has shown that, unfortunately, many things that concern people with disabilities are solved on a leftover basis. That is, first they are sorting people: who can be productive? Those who can give something [be productive], those who can work...they the first to get help. And people with disabilities, well, whoever survives will survive.

(b) The sense of being abandoned by authorities at this challenging time was often aligned and reinforced participants' assessment of COVID-19 reality as having nobody to rely for survival but themselves:

-  I don't think the government has done anything at all. Absolutely nothing for people. If you can pay — you are treated. If you have no money — you are surviving as best you can. All by myself.

-  No, I didn't expect that. I didn't even hope. So...I perfectly understand where we live. I am relying only on myself.
-  Expectations? My God, well, since I never receive any special services from the state, except for technical means of rehabilitation, and, in principle, I had no expectations. I have only one expectation — relying on myself, on my family. I have no expectations for the state. For this country...
-  I somehow...managed on my own. I am used to relying only on myself.

(c) Additional barriers created by the pandemic itself (for example, risk to health and avoiding such risks as much as possible) and further magnified by the way the authorities in Ukraine responded to the pandemic. This included the deprioritisation of disability considerations in healthcare, the withdrawal of access to transport, failing to recognise the impact of the pandemic on the cost of living for the most precarious individuals. In responding to this question some interviewees echoed our previous finding that in addition to new pandemic-specific barriers, the government response amplified and reinforced inequalities and inequities in the lives of persons with disabilities which define the pre-pandemic lived experience of 'getting by' for many people with disabilities in Ukraine:

-  Well, this is a difficult question, because the state itself does not know what to do and cannot fix the system itself. For people with disabilities, issues remain unresolved, regardless of the pandemic, there are a lot of them. And the pandemic itself did not really affect these problems. They remain regardless of the pandemic.

By analysing responses to this question coded under the categories of ‘Yes’, ‘Partially’ and ‘No Definitive Answer’ (17% of responses overall), one of the findings is a noticeably low level of expectations for the state expressed by our interviewees³⁶:

-  Overall, by and large, we didn’t have corpses lying around in the streets, there was no insane mortality, that is, in principle, people could not get to the hospital for just a few days, and the rest of the time it was possible to get to the hospital for treatment. That, I think, is normal. Maybe not quite... well, moderately normal...satisfactory.
-  But I generally think that the state did nothing at all. I really don’t need anything from it. If they just pay my pension and otherwise just leave me alone. Nothing has been done and nothing is being done. During the pandemic, it got even worse, they even removed benefits. They didn’t do anything, let’s just say. And they did not want to do anything.
-  I never expected anything from the state. And the fact that it did nothing...it actually did not surprise me.

This low level of expectations was often coupled with the ‘pardon’ given to the state for failing to ensure that the rights of persons with disabilities in Ukraine were foregrounded in all its activities:

-  I am not upset by my country; it is now just getting on its feet, and what can I expect from the state. Help? Now it itself needs help, my country. So how can I expect help from it? I did not expect it, I did not hope for it and I do not take offense at the state. The country needs to get up on its feet first.

³⁶One of the key responsibilities for all authorities in Ukraine remains ensuring and promoting ‘...the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability’ as required by Article 4 of the UN CRPD <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-4-general-obligations.html>

- How can I tell you this...it's a sin to scold the state, because the situation is already difficult in this country. But to say that there was support...well...they could try to do some things better for people with disabilities

Another finding was a noticeable degree of reluctance among the interviewees to answer a direct question which enabled participants to give their own evaluation of the government efforts to support persons with disabilities during the pandemic. This reluctance was unlikely to be caused by interviewees' concerns about their anonymity (since the issues of informed consent, confidentiality and anonymity were foregrounded by our CBIs); instead, we identified two themes in this context: **(a) self-perception of being 'a burden on society'**, and not just the lack of expectation which characterised some of the responses which criticised the government response to COVID-19 but the **(b) lack of awareness of the state's responsibilities and obligations to ensure and promote human rights of persons with disabilities** (i.e., self-perception of being a rights-holder rather than the objects of state and public charity):

- No matter how much we give to people (with disabilities), it will never be enough. As for COVID-19, we bought everything with our own money and everything was fine. There were no offers of help, and we ourselves did not ask for it. So...it seems, as it were, the state has done everything for us.
- Well, the state is not made of rubber, it did everything it could during that time
- Well, you know, as it were...I'm probably not competent enough to point out to the state [what it must have done].
- I have never thought about it and I don't think that the state can do something for someone personally. Well, in general, they did something for everyone.

CONCLUDING SUMMARY AND GUIDING QUESTIONS

Information

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.

The availability and accessibility of reliable and trustworthy information remains a key consideration at the time of emergency:

- How could public authorities and other stakeholders ensure that the essential information which covers safety and security, and information related to the essential daily needs of persons with disabilities in the context of PHOE is available, accessible, reliable, and trustworthy?

- How can it be ensured that this information is communicated via the channels/sources that are trusted by, and accessible to, people with disabilities?
- How could the spread of misinformation (especially via social networks) be addressed in a timely manner?
- How can it be ensured that people with disabilities without access to smartphones, the internet or other digital devices have access to key information, especially if digital channels are prioritised in disseminating urgent public health/emergency information in the context of PHOE?

Health and Wellbeing, and Healthcare System

Health and wellbeing remain a key concern for most, if not all, people with disabilities in the context of any PHOE. 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. 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.

There is a significant degree of vaccine hesitancy among people with disabilities in Ukraine. The absence of reliable and clearly communicated information about the vaccine options, their side-effects and contraindications puts people with disabilities at further risk of getting infected with the virus.

- How can the system of registration for primary healthcare in Ukraine be flexible, non-discriminatory and ensure equality of access regardless of location or place of residence (especially in the context of PHOE leading to the large-scale displacement of the population)?
- How can it be ensured that primary healthcare is sufficiently funded and is available and accessible to all?
- How can the availability and accessibility of healthcare in rural settings be improved?
- How can it be ensured that the system of primary healthcare facilitates (rather than impedes) access of persons with disabilities to the specialist healthcare?
- How can persons with disabilities' access to Technical Means of Rehabilitation be: (a) simplified, (b) de-linked from patient location/place of residence, (c) prioritised in cases where social distancing requirements (or other restrictions on the freedom of movement) are imposed by local authorities?
- How can it be ensured that accessibility considerations inform all decisions in relation to temporary or repurposed healthcare facilities?
- How can it be ensured that the re-purposing of healthcare facilities in the context of PHOE does not compromise people with disabilities' access to long-term, continuing, and/or specialist care?
- How can all healthcare services remain free to persons with disabilities, including access to diagnostic tests and procedures, and free prescriptions?
- How can it be ensured that access to healthcare is not dependent on patients having to make 'voluntary' contributions to healthcare providers or bribes to individual healthcare workers?

- How can it be ensured that training in medicine and allied disciplines includes disability considerations, and that the overall levels of skills and training in the Ukrainian healthcare system are improved?
- How can it be ensured that complaints related to the quality of care are easy to make and that these complaints are fully and timely investigated by an independent regulator/complaints adjudicator service?
- How can persons with disabilities be prioritised for vaccinations and receiving vaccine boosters?
- How could vaccine hesitancy among people with disabilities be addressed, including concerns about potential side effects and vaccine interactions with health condition(s) underlying individual impairments?

Economic situation

As noted in Part 1 of the project report (Sharapov et al., 2022a, p. 50), almost 1.5 million people with disabilities in Ukraine who receive state pension due to disability and for whom this was the main source of income lived in poverty (or below the factual subsistence level). PHOE are known to have significant economic impact on individuals by limiting economic opportunities and by increasing the cost of essential goods and services at the same time. Our participants who were employed before the pandemic experienced a range of negative labour market outcomes (including job losses) and significant reduction in income; most of our participants were faced with an increased cost of living, including additional costs to purchase medication and PPE; increased price of basic food items; and, in some cases, increased burden of relying on taxis in the absence of public transport.

- How can it be ensured that disability pensions and other social/welfare payments are aligned with the factual subsistence level to account for the increasing price of living within the context of PHOE?
- How can PHOE-related restrictions on basic freedoms (including freedom of movement) be sensitive, where possible, to disability considerations?
- How can any loss of earnings by persons with disabilities as a result of PHOE be mitigated via welfare payments?

Education

Pandemic-related closures of schools, colleges, universities, and other educational establishments had a negative impact on all of our interviewees who were in education. The most affected were individuals who lacked basic digital skills and/or financial means to pay for access to the internet and/or had no means to purchase suitable devices. In most cases, disability considerations were not prioritised as learning was transferred fully online.

- How can it be ensured that digital poverty does not impede access to online education?
- How can accessibility considerations be built into the design of online learning or all other alternatives for when face-face education is disrupted?
- How can additional support be made available to address any gaps in learning and attainment related to PHOE?

Psychological impact

PHOE have a significant impact on the psychological wellbeing of all people, but especially people with disabilities. For people with disabilities, being designated as particularly vulnerable to and at risk of contracting COVID-19 raised anxiety levels, whilst exclusion from most pandemic response planning meant that there was a general failure to account for their unique circumstances and everyday needs. As a result, existing isolation and loneliness were exacerbated due to the loss of social contact through social distancing regulations and the move to online medical care and education. Our participants were worried about contracting and getting sick with COVID-19, their family members contracting COVID-19, and the impact of the virus on their individual health. Overall, they experienced significant levels of psychological discomfort and stress.

- How could information about PHOE be presented in a way that is sensitive to the psychological impact on people with disabilities?
- How could psychological services be better prepared to respond to the increasing demand for mental health support during PHOE?

Mobility and access to transport

Severe COVID-19 related restrictions on mobility (‘пересування’ in Ukrainian) magnified and exacerbated already existing inequities and inequalities of access for persons with disabilities in Ukraine. These restrictions varied in their scope depending on the severity of government-imposed lockdowns. Overall, they can be described as an inability to access — whether by walking, cycling, taking private or public transport — essential services such as food shops, rehabilitation and healthcare establishments, leisure facilities (including public parks, gyms, walking paths), jobs, and social support networks (family and friends).

Our interviewees experienced significant challenges in relation to both the availability and accessibility of public transport brought about by the pandemic. The unsatisfactory pre-pandemic situation with the accessibility of public transport turned into a forgotten concern during the pandemic; once restrictions began to ease, the situation often failed to return to the pre-pandemic levels.

- How could PHOE-related restrictions on the use of public transport incorporate disability considerations, including both the availability and accessibility of revised public transport schedules?
- What can be done to provide alternative means of transportation for people with disabilities (and their carers) who rely on public transport to access essential services such as healthcare, accessing food shop, pharmacies?

Direct support during the pandemic and public authorities' response to the pandemic

Some of our respondents received one or more types of direct support during the pandemic. In most cases such support comprised of one-off allocations of food, financial support, and/or PPE. This was insufficient to mitigate for a wide-ranging negative impact of the pandemic. About 70% of respondents did not think public authorities in Ukraine did all they could to support people with disabilities through the pandemic. Consequently, many of our respondents felt abandoned by the state and relied on nobody else but themselves for survival. Our research suggests that the government response amplified and reinforced inequalities and inequities in the lives of persons with disabilities which defined pre-pandemic lived experience of 'getting by' by many people with disabilities in Ukraine.

- How can it be ensured that all actions affecting persons with disabilities in Ukraine within the context of PHOE, from distribution of the humanitarian assistance to undertaking research, are co-produced and, where possible, co-delivered with persons with disabilities ensuring their meaningful representation and participation — individually and through their organisations?
- How can it be ensured that the key partners in all initiatives are organisations **of** persons with disabilities, rather than organisations **for** persons with disabilities?
- What kind of direct support could other institutional actors (including international humanitarian agencies) provide in situations of PHOE?
- What infrastructure is required to deliver such support and what can be done to facilitate the development of such infrastructure, paying specific attention to disability considerations from the outset?
- How can persons with disabilities and their organisations be meaningfully involved in a sustained and continuous data collection effort, monitoring and research to evaluate the impact of war on persons with disabilities, including the following groups: internally displaced persons with disabilities; persons with disabilities who left Ukraine as refugees; persons with disabilities forcefully deported to Russia; persons with disabilities who remain stranded in the affected areas; and persons with disabilities who remain in the same location as they were before the invasion?

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