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

Household Perspectives, Public Health Implications, and Considerations for Emergency and Post-Conflict Recovery

Project Report (Part 3)

GCRF

UKRI Arts and Humanities Research Council

Edinburgh Napier UNIVERSITY

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Household Perspectives, Public Health Implications, and Considerations for Emergency and Post-Conflict Recovery

Project Report (Part 3)

July 2023

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The project is funded by the Arts and Humanities Research Council (AHRC), on behalf of UK Research and Innovation, working in partnership with the UN Partnership to Promote the Rights of Persons with Disabilities Multi Partner Trust Fund (UNPRPD MPTF). This project is funded via the UKRI/ AHRC GCRF urgency grants scheme, project reference AH/V013505/1

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Published by Edinburgh Napier University
DOI: https://doi.org/10.17869/enu.2023.3147641 (English)
https://doi.org/10.17869/enu.2023.3147656 (Ukrainian)

ACKNOWLEDGMENTS

We are grateful to our participants – persons with disabilities and their families who took part in this study to tell us about their everyday life and how the COVID-19 pandemic affected them and their friends and families.

Our special thanks go to the members of the project's advisory team, a wider research team involved in the delivery of this project, and to a group of experts in disability rights (Valery Sushkevich, Oleg Polozyuk, and Alla Sotska).

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INTRODUCTION

This report presents the outcomes of the final phase of the project, which evaluated the impact of COVID-19 on persons with disabilities in Ukraine. Co-produced and co-delivered with the disability activists and organisations of persons with disabilities in Ukraine, this research explores specific challenges and struggles faced by persons with disabilities in Ukraine amidst the COVID-19 crisis. The project examined the socio-economic and health repercussions of the pandemic and of the government response to COVID-19 for persons with disabilities, including their access to critical information, healthcare and support services, and how well these provisions responded to disability considerations during the crisis.

This report is released later than we planned and hoped for. As a project team, we were in the final stages of our analysis when Russia launched a full-scale military invasion of Ukraine in February 2022. The invasion and the ongoing war significantly disrupted and delayed our work since the majority of our research team were based in Ukraine as of February 2022. The impact of the invasion is further reviewed in the 'Methodology' section below.

This report covers the final phase of the research project that was co-designed and co-delivered as fully participatory together with disability activists and persons with disabilities from Ukraine[1]. As far as we know, this is the first ever

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[1] See https://gtr.ukri.org/projects?ref=AH%2FV013505%2F1 and https://www.covidanddisability.com

participatory and co-produced project which meaningfully involved persons with disabilities and their organisations in Ukraine. The project was guided by their priorities and by what they thought was important to investigate, rather than by external funding or institutional agendas.

The National Assembly of Persons with Disabilities of Ukraine, which brings together over 100 organisations of persons with disabilities in Ukraine, was our key partner. Their contribution was essential to developing and delivering the project; their involvement ensured that the research methods were relevant, appropriate and sensitive to the realities and needs of persons with disabilities in Ukraine. The National Assembly served as a key facilitator in collecting data in Ukraine navigating a variety of challenges imposed by pandemic-related restrictions and by the protracted conflict in the east of the country. Their commitment and dedication under such challenging circumstances highlight the importance of local partnerships in delivering genuinely inclusive and participatory research[2].

The research included three phases. The initial phase involved a survey of over 100 organisations of persons with disabilities in Ukraine. During the pandemic, and especially in its early stages, these organisations provided essential support for thousands of vulnerable individuals with disabilities, whose specific needs were often overlooked within the context of the poorly planned and implemented pandemic response in Ukraine. The perspectives of these organisations on how the pandemic affected persons with disabilities in Ukraine, as well as its

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[2] For further discussion of our collaborative participatory research approach see https://www.covidanddisability.com/research-approach

impact on disability activism in Ukraine, are presented in the first part of this report (Sharapov et al., 2022a)[3].

The second phase consisted of interviews with over 300 persons with disabilities in Ukraine, including internally displaced individuals. The findings, detailed in Part 2 of the report (Sharapov et al., 2022b), indicate that the pandemic, coupled with specific responses from Ukrainian authorities, intensified existing disability-related inequalities and disadvantages. This further affected the lives of persons with disabilities, including those internally displaced after the Russian invasion of Ukraine in 2014.

The third phase was designed for more comprehensive engagement with a small group of households, each having at least one member with a disability. It focussed on the ways in which the pandemic affected the daily lives of persons with disabilities, echoing a suggestion by Mines and Lamb (2010, p.1) that significant insights into socio-cultural worlds can be gleaned from observing the routine actions of ordinary people as they navigate their lives, creating and experiencing their realities.

Analysing everyday life is a powerful approach to understanding the intricate processes through which individuals experience and interpret their lives and their surroundings. It allows us to explore how their lived experiences intertwine with broader societal structures and cultural norms. Focusing on deeply personal narratives of mundane routines and experiences helps reveal how these experiences had to evolve in response to the pandemic.

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[3] All previous publications for this project (in English and in Ukrainian) are available here: https://www.covidanddisability.com/publications

Yet, these narratives are not merely about individual resilience or adaptation; they also echo on-going societal discussions in Ukraine regarding norms, expectations, and the notions of ‘normality’ and disability. Our emphasis on everyday life within the pandemic’s context offers a glimpse into a rich mosaic of individual stories, interconnected by shared social structures, cultural norms, and the lived experience of disability in Ukraine.

This report does not purport to express a singular ‘disability perspective’, as if all people with disabilities perceive the world identically, as cautioned by Mackenzie and Scully (2007, p. 348). We recognise that experiences of disability are as diverse as the individuals who live them. Our study of everyday life, however, does reveal crucial insights. It extends beyond the personal and delves into the wider social context, exposing the dynamic interplay between individual experiences and the societal structures that shape them. This focus helps us understand how unique personal narratives are woven into the fabric of broader cultural norms, political systems, and social interactions all of which were altered by the COVID-19 pandemic in ways which often failed to foreground disability in social and economic responses.

The report is structured as follows. The Methodology section outlines the study’s methodology, including participant recruitment, data collection, storage, and analysis processes. This is followed by an Overview section, which introduces key themes identified through thematic analysis. A detailed exploration of these themes follows, incorporating, as far as possible, the voices of our participants. The report concludes with a set of reflective questions intended for policymakers, Ukrainian authorities, and national and international non-governmental organisations. We suggest these questions are used to guide their ongoing humanitarian efforts and future post-conflict reconstruction activities to ensure that disability considerations are systematically foregrounded in all their responses.

METHODOLOGY

This phase of the project was guided by the ethos of everyday life research, premised on the idea that paying attention to ordinary, mundane daily activities may reveal a lot about the broader social and economic context in which such everyday life unfolds — something that cannot be ordinarily captured by surveys or interviews. This is especially the case within the context of the COVID-19 pandemic which affected and altered every single facet of everyday life. The focus on everyday life within the context of the pandemic allowed us to delve deeper into the daily experiences and challenges of persons with disabilities in Ukraine and to understand their lived realities within this extraordinary context.

For this phase, we recruited 20 households of individuals with disabilities, with each participant anticipated to engage with data collection over an eight-week period. Participants were requested to generate at least two records per week, reflecting on their routine activities such as grocery shopping, work-related tasks, visits to the pharmacy, GP appointments, social and cultural activities, etc. They were also asked to document specific disruptions caused by COVID-19 and associated restrictions.

To capture the authentic textures of their everyday lives, we gave participants complete creative freedom in relation to the format of their records. They could choose to document their experiences through video or audio recordings, written notes (either typed or handwritten), photographs, or any other suitable means.

At the recruitment stage, we approached all community-based disability activists who had interviewed persons with disabilities across Ukraine during the second phase of the project and invited them to participate in the next phase.

We also issued additional invitations to their colleagues, and to people who were interviewed during the second stage of the project. While we did not rely on a precise quota system to recruit participants, we made concerted efforts to achieve gender balance and to include persons who had different disability 'groups' and types. It was also crucial for us to incorporate internally displaced persons with disabilities into our participant sample. As a result, our final sample included: 20 participants, including 12 women and 8 men. Eighteen participants were persons with disabilities (and were assigned a 'group' of disability as per the disability classification approach in Ukraine[4]), and two participants were parents of children with disabilities. Eight participants were internally displaced as a result of the 2014 Russian invasion of Ukraine. Our participants came from 10 regions of Ukraine, including the city of Kyiv. The table below provides further information about the type of disability for each of the participants and some details about their household. All other information (including geographical location, age, employment status, etc.) has been withdrawn to secure our participants' anonymity.

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[4] See Part 1 (Sharapov et al., 2022a, p. 41) and Part 2 (Sharapov et al., 2022b, pp. 24-25) discussion the system of allocating 'disability groups' in Ukraine.

Table 1. Participants / Households, Third Phase of the Project.

Participant	Gender	Disability Group and Impairment	Internally displaced?	Additional information
A	Female	Group 1, visual impairment	Yes	Mother of a child with disability
B	Male	Group 1A	Yes	
C	Male	Group 1, cerebral palsy	Yes	
D	Male	Group 1A, wheelchair user	No	Wife is also a person with disability, wheelchair user, Group 1
E	Female	Group 1, wheelchair user	No	Raising a small child (Together with her husband)
F	Female	Mother of a child with disability	No	A child with a disability / intellectual impairments. The participant also has a sick mother.
G	Female	Group 1, wheelchair user	No	There are three women in the household, two have disabilities, one is a pensioner
H	Female	Group 2	No	Lives with her mother, who is a pensioner.
I	Male	Group 2, orthosis user and cancer patient	Yes	Wife is a person with disability, Group 2.
J	Female	Group 1, wheelchair user	Yes	Husband is a person with disability.
K	Male	Group 1, wheelchair user	No	Wife is a person with disability, Group 1.
L	Female	Group 3	No	Husband is a person with disability, Group 2.
M	Female	Mother of children with disability	Yes	Mother of 3 children with disabilities (Groups 2 and 3): a daughter and 2 sons.

Participant	Gender	Disability Group and Impairment	Internally displaced?	Additional information
N	Male	Group 2	Yes	Wife is a person with disability, Group 2.
O	Female	Group 1, wheelchair user	No	Lives with her mother, who is a pensioner.
P	Female	Group 1, visual impairment	No	
Q	Male	Group 1, wheelchair user	No	Lives with his wife and his mother, who is a pensioner.
R	Female	Group 1B, visual impairment	No	Husband is a person with disability, Group 1, visual impairment.
S	Male	Group 1A, wheelchair user	Yes	Wife is a person with disability, Group 1, wheelchair user.
T	Female	Group 1, wheelchair user	No	

Participants who required but did not have access to video or audio recording equipment had the option to request it. All participants received a modest honorarium in the form of supermarket vouchers to acknowledge and recognise their contribution and time. All participants took part in an online orientation/training session run by the project team, which set out the expectations for this data collection phase and emphasised the importance of focusing on mundane everyday life activities. This training was designed to help participants recognise the value of rich, contextual details. Instead of simply stating ‘I went to see my GP but could not get an appointment’, they were encouraged to provide additional context, reflecting on the availability and accessibility of healthcare facilities, their journey to the hospital, as well as the quality of care they received.

To provide ongoing support, it was agreed that each participant would be contacted at least once or twice a week by a Ukraine-based project team member to offer guidance and encouragement; to answer any questions; and to ensure secure transfer of any recorded or collated weekly contributions. Similarly to the protocols established during the previous two phases of data collection, we maintained an arrangement with a Ukraine-based mental health professional. They were available throughout the data collection period to provide assistance to participants or research team members as needed.

In this report, we use ‘household’ and ‘participant’ interchangeably. Although we recruited individual participants for this phase of the project, we asked each of them to reflect upon their household’s daily life (taking into account privacy and data protection considerations). Given the focus of this phase on everyday life, we considered ‘household’ a more suitable term since it encompassed our participants’ immediate environment by definition. For some participants who might not have cohabitated with other people, but with cherished pets, these pets were seen as a fundamental part of their single-person household, parallel to the role of other human family members in the households of other participants.

The eight-week data collection period began on the 20th of September 2021 and continued until the 14th of November 2021. This was followed by a two-week window permitting participants to withdraw their consent after which all recordings — audio, video, digital photos, and text files — were anonymised. These records were digitised (if not already digitised by participants) and securely transferred to encrypted servers. Audio and video files were professionally transcribed, resulting in a set of 20 anonymised participant-specific folders, each containing an average of two entries for each week of the data collection phase. The majority of these entries consisted of audio files or written text.

Post-transcription, each video file was further reviewed, and additional context was added in a written format to enrich the participant's narrative where relevant. Electronic photographs served to supplement the textual or audio/video narrative and were treated as supplementary data, rather than as a primary unit of analysis.

All digitised materials were imported into NVIVO software for an iterative thematic analysis, performed in three steps. While the project had established a coding framework based on the initial two research phases, we developed a unique coding framework for this phase due to its focus on everyday life. The initial coding framework was inductively established following the first complete reading of all entries. This framework then guided the second iteration of reading and (re)coding, with the coding framework itself being further refined and adjusted as necessary. The third iteration involved further engagement with visual materials and identification of key themes based on core and secondary codes that emerged during the first two iterations.

This stage was followed by several consultations with Ukrainian disability activists to validate the emerging outcomes and verify the preliminary findings. However, these consultations were not as comprehensive or systematic as the participatory analysis workshops conducted during the first two project phases. This was due to the ongoing war in Ukraine, which substantially delayed and disrupted the project, which was in its critical stages of analysis and writing-up, when Russia initiated a full-scale military invasion of Ukraine in February 2022. As a consequence, all research activities had to be halted for a number of months. When it became feasible to resume research activities, the process of re-engagement proved complex and time-consuming. We faced a range of difficulties, including the need to reestablish communication with the project stakeholders, reassess the safety and feasibility of continuing research under new and constantly changing circumstances, and re-organise the project team in light of the ongoing conflict. These challenges, combined with the logistical and emotional impacts of the conflict, accounted for the substantial delay in the release of this report.

INTRODUCING KEY THEMES

Our thematic analysis of participants' accounts identified five main themes that highlight the experiences of people with disabilities during the pandemic, including: healthcare related challenges; COVID-19 specific challenges; everyday disruptions and struggles; day-to-day positivity and snippets of happiness; and participants views on the government pandemic response and mobilising against everyday abandonment.

Our participants encountered a range of challenges in accessing ***healthcare*** within the pandemic context. These challenges were not rare or exceptional, but rather an everyday reality faced by our participants in their interactions with various elements of the Ukrainian healthcare system — from the diagnostics to treatment of acute (including COVID-19) or underlying chronic conditions, to buying/accessing medication and essential rehabilitation aids. These challenges ranged from financial and logistical constraints in purchasing medication or receiving essential treatment (including, for example, having to pay for cancer treatment), poor availability and accessibility of healthcare facilities, as well as encounters with indifferent and, at times, incompetent medical staff.

Our participants reflected on the impact of ***COVID-19*** on their mental health, including heightened levels of fear and despair. They expressed their deep frustration with the insufficient enforcement of COVID-19 restrictions, which created additional risks for anyone who could be more susceptible to the severe form of COVID-19 infection due to their pre-existing medical conditions. A number of participants expressed a lack of trust in the vaccination process; others expressed concerns about low levels of awareness and high levels of disinformation about vaccines. This lack of confidence led to hesitancy and the perception of additional risks associated with potential side effects.

Our participants described various ***daily challenges or 'struggles'*** they faced in their day-to-day lives. While these struggles did not necessarily escalate into major crises like the loss of loved ones or serious health issues, they were significant in their own way. In our analysis, we referred to these challenges as 'quasi-events'. They constituted a kind of misery, inconvenience or difficulty that were not obviously dramatic but were so deeply embedded in individuals' lives that it resulted in both a sense of and actual abandonment. This abandonment had distinct socio-economic and cultural aspects. It ranged from financial difficulties and economic hardship to significant hurdles in accessing public spaces, healthcare facilities, and transportation. It also included a lack of information about changes related to the pandemic.

Amidst the challenges of the pandemic, our participants also found joy, optimism, and a sense of ***happiness in ordinary activities and positive events***. These 'snippets of happiness' served as antidotes to the harsh realities of the pandemic, recalibrating the disrupted monotony of their daily lives. Cooking, caring for pets, connecting with nature, maintaining everyday normality, and appreciating everyday beauty served as essential lifelines for the participants. They contributed to their emotional wellbeing, gave them a sense of control and normality, and most importantly, brought moments of joy and happiness during a time of crisis.

Our participants also expressed ***concerns about the government's pandemic response***. They pointed out delays and poor enforcement of pandemic measures, government disconnect from the public, double standards of politicians, and distrust in the government's ability to support persons with disabilities. The financial hardship experienced by the participants exposed a significant gap in the state's disability pension system; it underscored the economic vulnerability of persons with disabilities during crises.

The following sections provide a detailed exploration of these five themes. In addition to incorporating direct quotes from our participants whenever possible, we also present a selection of images shared by the participants themselves, and a series of illustrations, crafted specifically for this project in partnership with UK-based illustrator, Gavin Berriman.

1. HEALTHCARE RELATED CHALLENGES

All participants in our study encountered a range of challenges in accessing healthcare, including: (a) receiving routine or ongoing treatments related to their impairments; (b) the process of getting tested, diagnosed, and treated for COVID-19; and (c) the revalidation of their disability status through 'socio-medical commissions.' In most cases, these challenges were part of their everyday routine interactions with different components of the Ukrainian healthcare system. They ranged from financial constraints in purchasing medication (which should have been provided free of charge or at a reduced cost for certain disability categories/groups) to inaccessible hospitals and hospital wards lacking toilet facilities, as well as encounters with indifferent and, at times, incompetent medical staff.

The summary below reflects, to a significant extent, our findings published in Parts I and II, where similar concerns regarding the **quality, availability, and accessibility** of healthcare were expressed by representatives from Ukrainian organisations of persons with disabilities. Additionally, over 300 persons with disabilities were interviewed as part of this project, echoing similar concerns. Through thematic analysis of our participants' accounts of daily life during various stages of the pandemic, the following key themes emerged within the broader context of 'healthcare':

(A) Financial burdens placed upon individuals and households to cover healthcare expenses that should have been provided free of charge / at a reduced cost.

(B) The overall deteriorating state of healthcare, exacerbated by the immense strain brought about by the pandemic.

(C) Limited availability and inadequate accessibility of healthcare facilities for persons with disabilities.

(D) Specific challenges pertaining to the revalidation of disability status and accessing rehabilitation aids.

A. Financial pressures regarding COVID-19 and ongoing healthcare expenses

Our participants and their families experienced a range of financial pressures, primarily linked to having to pay for COVID-19 diagnostics and treatment, ongoing healthcare for impairments underlying individual disabilities, and other medical conditions. For most of our participants, essential medication should have been provided free of charge; whilst universal access to free healthcare in Ukraine remains a guaranteed constitutional right as set out by Article 49 of the Ukrainian Constitution and further clarified by the Constitutional Court of Ukraine in its judgment in relation to Case No. 1-13/2002[5]. However, our participants highlighted the burden of financing essential healthcare, resorting to measures such as taking out loans or using credit cards to pay for vital cancer treatments. Additionally, they often

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[5] See Part 1 of the Report (Sharapov et al., 2022a, p. 36).

found themselves spending more than their monthly state disability pension on essential medication, or having to pay for private COVID-19 tests or essential items such as syringes for blood tests in state-funded healthcare facilities.

> Previously, chemotherapy was done at the dedicated department, and they held your health record. And now you need to go to the registration desk and queue alongside 15 or 20 people to get an electronic ticket. Then with this ticket you go to the specialist doctor. You give your health record and the ticket to the consultant, who issues a ticket (referral) for chemotherapy. After that, you go to the registration office; then you go to the head nurse, the head nurse checks if they have the required medication. And if they don't, you need to buy whatever they do not have. We already knew that 2 ingredients [for chemotherapy] were missing. So we had to buy it at 4,500 UAH cost[6]. We have a credit card, I gave it to her [respondent's wife], I said: "Sweetheart, take it, go and buy anything that is needed'. I then kissed her goodbye and drove home.
>
> This means that I must pay 2,800 hryvnias[7] just for some basic medications...so I must spend my entire "huge" pension just to be able to afford them.

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[6] Or 125.07 GBP as of November 1st, 2021 (1.00 GBP = 35.98 UAH).

[7] Or 77.82 GBP as of November 1st, 2021 (1.00 GBP = 35.98 UAH).

B. The deteriorating state of healthcare exacerbated by the pandemic

The necessity to pay for essential healthcare services, which should have been provided free of charge, revealed a broader systemic issue: the alarming condition of the healthcare system in Ukraine, which faced further immense pressure and challenges due to the pandemic. This resulted in overcrowded GP surgeries and hospitals; some facilities were repurposed, reprofiled, and reallocated to treat COVID-19 patients. However, even these repurposed facilities struggled to handle the overwhelming numbers of patients with severe COVID-19 symptoms.

> But it's also scary, there is a very high incidence of illness in our city right now. Many of the people that I know are sick. The hospital is like some kind of apocalypse - there is a shortage of space. People are lying in the corridors. Prices are not cheap either. Many people simply don't go to the hospital because they can't afford treatment. It's frightening.
>
> This morning I had to take blood tests. The doctor at the polyclinic gave me a referral for free tests. However, I had to go to another polyclinic to get them done because our polyclinic's laboratory was dealing only with COVID tests since the beginning of the pandemic.

On numerous occasions, as reported by our participants, patients with suspected or confirmed COVID-19 diagnoses were not appropriately separated from other patients or visitors who were waiting for unrelated (to COVID-19) appointments, including pregnant women or individuals at high risk of severe illness from COVID-19. Several participants expressed concerns about the poor maintenance of hospitals, in addition to the accessibility issues discussed below. They were concerned about inadequate supplies, including a lack of oxygen for breathing machines, malfunctioning X-ray machines, insufficient heating in hospital wards, broken windows, and IT problems that hindered basic treatments, including, for example, prescribing insulin to patients dependent on it.

> The windows are so old they are rotting; [we can only dream of] UPVC windows. The mesh in the metal bed is sagging — it’s touching the floor.
>
> The doctor said he would examine me, but he wouldn't be able to give a definitive answer because their X-ray machine had been out of order for two months. After the examination, he said that either the ligaments or the bone was definitely damaged, but he needed my X-ray for the final diagnosis. To obtain an X-ray and receive a final diagnosis, I was referred to the nearest trauma centre.
>
> While I was waiting in line, the endocrinologist's office was right across from my room. It was a complete nightmare, naturally. People hadn't been able to see the doctor for 3 to 4 days just to get their insulin. The system was down, so neither the doctor nor the nurse could prescribe insulin. Folks were sitting there, complaining that they had run out of insulin the day before yesterday. One woman said, "I've been coming

here from 8 a.m. to 2 p.m. for three straight days and still can't get my insulin prescribed." A man who started coming on Monday is still showing up, and today is already Friday. He mentioned that he'd also run out of insulin. The nurse comes out, shrugs her shoulders, and says, "What can I do if the system is down? I'm unable to do anything anymore."

Figure 1: *Waiting Area at the Dental Surgery.*

The reassignment of specialist healthcare staff, including consultants, to COVID-19 care greatly reduced their ability to monitor and manage complex conditions related to our respondents' impairments regularly. Due to inadequate healthcare provision and issues with accessibility, some participants turned to self-care or self-medication. This varied from self-prescribing antibiotics for suspected COVID-19 and secondary infections to self-administering painkillers and other prescription medications, especially given the reduced number or complete lack of home visits from healthcare personnel due to the pandemic.

A number of participants expressed criticism towards healthcare staff, citing concerns about their professionalism and perceived lack of compassion.

> When she (the doctor) came to my house, she entered and immediately started expressing dissatisfaction, not asking about my health or inquiring about my symptoms or complaints. Instead, she expressed her frustration, saying, “You understand, I have so many sick people, and here I am having to drop everything and come to you" Well, I, too, got sick, and I didn’t call you for no reason, you know.
>
> The rheumatologist (whom I visited twice for the same issue) is a wonderful elderly man and an excellent specialist. His attitude towards me as a person is exceptional, and our discussions were remarkable. However, when it came to draining fluid from my knee, he held the syringe with shaking hands. His hands trembled, probably because of his age. When he injected me, the needle slightly grazed my bone, and he felt it. He took it out and tried again, but it wouldn’t go in. We managed to extract the fluid after all, but this memory has stayed with me. If I can’t think of any other alternative, I would have to go back and see him again.

Our GP is unique. When he saw that I came with my mother, he spoke not to me, a nearly 30-year-old adult, but to her. He didn’t even look at me or ask me any questions. It's very common in our hospitals when you have someone accompanying you and you have a disability. Doctors assume that you are unable to communicate, so they don’t talk to you. Well, he did eventually turn to me and asked about my symptoms. I made numerous attempts to draw attention to myself because, ultimately, I am the patient who came in for a consultation. Eventually, he spoke directly to me and asked about my symptoms.

After waiting in line for over half an hour, I finally entered my family doctor’s office. I came with a referral and explained my concerns. I mentioned that I needed a referral to a neurologist and an ultrasound examination of my breasts because I was at risk and had some issues there. I was under the care of a mammologist. The doctor listened to all of this and simply said, “What can I tell you? I won’t give you a referral for an ultrasound. You went to see the specialist, and he should have issued this referral because it’s his area of expertise. Yet everything is being shifted back to family doctors. But we’re not horses; we shouldn’t have to carry all this burden.” That was the response I received.

Figure 2: *A Ward in the Cancer Treatment Centre for Chemotherapy Treatment*

C. Inadequate Accessibility and Availability of Healthcare

Most participants mentioned a range of challenges related to accessibility of healthcare services, including lack of the very basic and essential adaptations such as ramps, elevators, accessible toilets, and signage tailored to accommodate individuals with visual disabilities. Additionally, participants pointed out that the absence of accessible transport options made it challenging, if not impossible, to get to healthcare facilities.

I was told, "If you are admitted to our hospital, we will provide free treatment and medication. But if you stay at home, then you have to buy the medicines yourself."

That’s how it is. I am a person with a disability, using a wheelchair for mobility, and I said, “Your infectious disease departments are not accessible, I can’t enter in a wheelchair.” They laughed.

We did not seek help from the hospital because, well, firstly, it would cost approximately 300 hryvnias[8] for a taxi to go to the hospital, and, besides, the district hospital is not accessible at all, that’s the problem. So we did not consult a doctor.

In general, people with disabilities, especially those using a wheelchair, have to deal with COVID-19 at home. Thankfully, we didn’t have to be hospitalised. But the hospitals...they are not designed for people with disabilities. We would have had so many issues - even just lying on a proper bed with a decent mattress.

It’s not that far, about 3 km, but we have to cover it in a wheelchair, you know, just to submit these documents to our family doctor.

Next, we have a trip to the district hospital, where there is a ramp that was recently built, but there is no accessible toilet for people with disabilities.

There is no accessible toilet in this ward or anywhere on the premises. I was the only one in the ward, and they covered me with all sorts of diapers, right up to my ears.

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[8] Or 8.34 GBP as of November 1st, 2021 (1.00 GBP = 35.98 UAH).

Figure 3: *Inaccessible Toilet in the Hospital*

When analysing these personal accounts, it was difficult to tell whether the greater source of terror for our participants was the fear of contracting COVID-19 or the apprehension of becoming trapped within an inadequate and inaccessible hospital environment. One participant aptly summarised their ordeal: "I was just fearful…fearful fearful fearful that I would die there [in the hospital] neglected'.

D. Challenges specific to the revalidation of disability status and accessing rehabilitation aids

The determination of disability status in Ukraine is facilitated through a process known as "medico-social expertise," governed by guidelines issued by the Cabinet of Ministers of Ukraine in 2009, which consist of two parts:

Regulations on Medico-Social Expertise, and Regulations on the Procedure, Conditions and Criteria for Establishing Disability (Cabinet of Ministers of Ukraine, 2009). This process involves specialised “medico-social expert commissions” responsible for the initial determination and assignment of a “disability group” based on individual circumstances (see Sharapov et al., 2022b, p.24). These commissions also establish the timeframe for subsequent reassessments, which may occur every 1 to 3 years. According to the guidelines, in cases of congenital defects, permanent irreversible morphological changes, organ system disorders, ineffective rehabilitation measures, and limited social adaptation, as well as an unfavourable prognosis for restoring work capacity, the “disability group” can be assigned indefinitely without the need for reassessments[9].

Both interviewees in our survey (see Part II) and participants in the 'everyday life' phase reported difficulties in obtaining or modifying individual rehabilitation programs, particularly in accessing new or replacement rehabilitative aids. These challenges were mainly due to inadequate healthcare facility accessibility, administrative errors, and the physical burden of visiting multiple specialists just to secure a document signature. During COVID-19-related restrictions, the requirement for reassessments was either temporarily suspended or, in some cases, replaced with remote and document-based evaluations. All previous decisions and determinations were extended until COVID-19 related

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[9] See Article 22 of the Guidelines: Regulations on the procedure, conditions and criteria for establishing disability

restrictions were lifted. However, once the restrictions were lifted, the arduous process, referred to as the 'circles of hell' by one of our participants, resumed:

> Three days ago, I went to my GP. She referred me, and I managed to see two doctors, just barely making it through. Today, I scheduled an appointment to have a blood test. Damn, I forgot my 20-millilitre syringe at home. Well, it's a good thing there's a pharmacy in the clinic. I went there and bought one. But when it comes to registering for a GP appointment, there's a line of people at the reception, oh my God! Probably around 40 people.

> During the quarantine period, we couldn't make the necessary changes to our rehabilitation programmes and missed the opportunity to receive orthopaedic footwear this year. This occurred because initially, the MSEC doctors didn't correctly record that we needed footwear. When we tried to rectify this, one member of the commission contracted coronavirus, forcing the rest into self-isolation. So this issue can now only be resolved at the end of December, leaving us without orthopaedic footwear for the year.

At the same time, having an up-to-date rehabilitation programme did not guarantee the receipt of the prescribed rehabilitation aids:

In relation to providing persons with disabilities with orthopaedic products, I was unable to obtain the orthopaedic footwear that had been prescribed to me for the past two years.

We face a significant problem concerning the acquisition of personal hygiene products. You see, for a person with a disability to venture outside for a walk, they must rely on these products. Whether it's diapers, urinary catheters, urinals, pads, or other types of catheters, these various products are prescribed by a doctor in an individual rehabilitation programme to help maintain the individual's dignity. Regrettably, in our country, obtaining this specific service for people with disabilities seems to always require struggle, persistence, and determination. One must fight tooth and nail to receive these essential hygiene products.

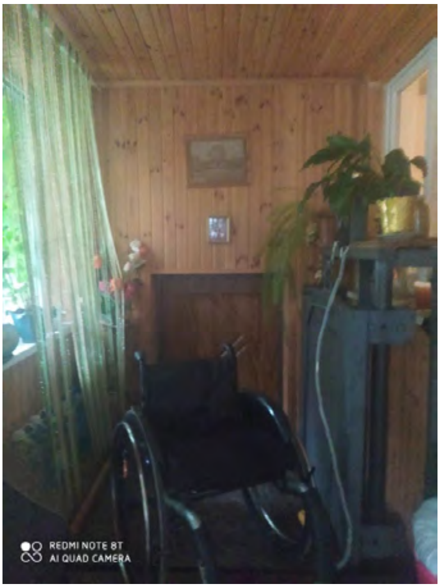

Figure 4: *A Wheelchair Belonging to one of our Participants.*

As a result, many of our participants, who depended on rehabilitation aids for their daily essential tasks and activities, found themselves financially responsible for obtaining crucial items that should have been provided at no cost. They also had to make essential adaptations to facilitate freedom of movement in and around their homes.

> We had to take a taxi for a 15 km journey from our district centre to the hospital where the Medical-Social Expert Commission (MSEC) was held. Generally, a one-way taxi ride costs 150 hryvnias, making it 300 hryvnias for a round trip[10]. This is quite a sum, especially when you consider that a person with a disability receives a pension of 2200 hryvnias[11]. We had to bear this cost to go through the MSEC process to secure an individual rehabilitation programme. This was particularly crucial for my wife, as obtaining a new wheelchair without it would have been challenging. Her current wheelchair is almost unusable, so she's waiting to get a new one.
>
> I face significant expenses too. I need an active-type wheelchair, and while I found one that meets my criteria, it will cost me 12,000 hryvnias, including the cushion.[12] I plan to purchase it through an intermediary who specialises in used wheelchairs, as saving up for a new one is not feasible for me.

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[10] 4.17 GBP one way or 8.34 GBP return as of November 1st, 2021 (1.00 GBP = 35.98 UAH).

[11] 61.15 GBP as of November 1st, 2021 (1.00 GBP = 35.98 UAH).

[12] 333.51 GBP as of November 1st, 2021 (1.00 GBP = 35.98 UAH).

So...right now I'm in saving mode and trying not to spend money on anything else, saving up for the improvements in my home. Besides household appliances, I'll also need to install a ramp, and most likely, I'll have to create a separate entrance to my home. It will require a lot of money. I don't have high hopes for my local authorities since it's challenging to ask for help from them.

At present, the programme only supplies us with hygiene products for a three-month period. While the allocated price and quantity have remained unchanged, the actual costs of these hygiene products have risen substantially. For instance, a urinary catheter that once cost 20 hryvnias now costs 46 hryvnias.[13] This is a significant problem, affecting not just people with disabilities in my region, but across the entire Ukraine.

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[13] 0.56 GBP and 1.28 GBP accordingly as of November 1st, 2021 (1.00 GBP = 35.98 UAH).

2. COVID-19

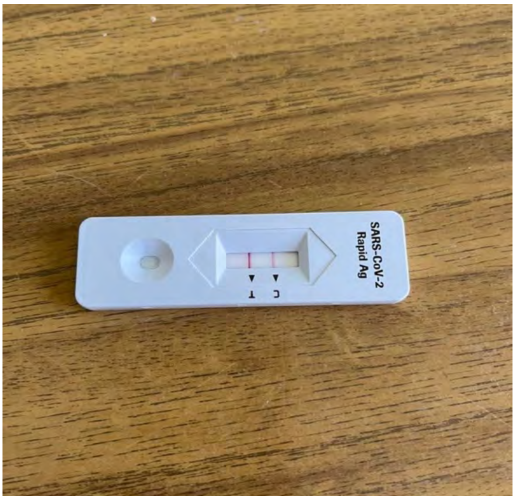

Figure 5: *Positive COVID-19 Test.*

The COVID-19 pandemic had a profound and far-reaching impact on persons with disabilities in Ukraine. It created heightened insecurity in their lives in terms of health, both mental and physical, as well as their financial well-being. As highlighted in the first two parts of the project report (Sharapov et al., 2022a and Sharapov et al., 2022b), the Ukrainian government's response to the pandemic failed to fully address the unique needs and considerations of persons with disabilities, further exacerbating the challenges they faced. The following aspects highlight the long-lasting and detrimental impacts experienced by our participants:

1. Emotional and physical well-being: for some of our participants, the pandemic brought about the tragic loss of acquaintances and/or work colleagues, causing immense grief and emotional distress. The overall climate of fear and anxiety surrounding the pandemic had a major impact on their mental and physical wellbeing. The absence of well-funded, well-planned and targeted support and resources to address their specific needs left them particularly vulnerable.
2. Disruption of rehabilitation services: Access to essential rehabilitation aids, as set out above, was severely disrupted during the pandemic. Our participants encountered challenges in renewing their rehabilitation programmes, adversely affecting their capacity to sustain or improve their functional abilities. This neglect in prioritizing the continuity of rehabilitation services compromised their overall health and wellbeing.
3. Limited access to non-COVID healthcare: most of our participants encountered difficulties in accessing non-COVID healthcare services, partly concerns about contracting the virus in healthcare settings. This led to delayed or unmet healthcare needs, leaving their existing health conditions unattended or worsening. This failure to prioritise their access to essential healthcare services appeared to further compromise their overall health outcomes.
4. Long COVID symptoms: some participants were grappling with the symptoms of long COVID, experiencing prolonged and debilitating effects following the initial infection. These persistent symptoms, such as fatigue, respiratory issues, and

cognitive impairment, significantly impacted their daily lives and further strained their physical and mental well-being.

5. Financial struggles: The economic fallout of the pandemic disproportionately affected persons with disabilities, resulting in heightened financial insecurity. Job losses, reduced work hours, and limited employment opportunities left many grappling with financial hardships. The lack of adequate and targeted financial assistance and inclusive economic policies further deepened their struggle to access healthcare, medications, means of rehabilitation and necessary support services.

The following specific concerns were common among most of our participants' responses and are described in more detail below:

A. Insufficient enforcement of COVID-19 restrictions in public spaces, such as social distancing, mask-wearing, and sanitisation measures; and a prevailing sense of disappointment and betrayal due to non-compliance with the rules by members of the public, endangering the lives of others and, particularly, those who were highly susceptible to the severe impact of COVID-19.

B. The adverse effects of COVID-19-related isolation and the detrimental impact of prolonged lockdowns on individuals' mental health, including heightened levels of fear and despair associated with the COVID-19 pandemic.

C. COVID-19 vaccinations.

Figure 6: *COVID-19 PCR Testing Facility.*

A. Insufficient enforcement of COVID-19 restrictions

Hesitation to enter public spaces where mask-wearing or other lockdown requirements (such as distancing and hand disinfection) were not enforced emerged as a significant source of anxiety, fear, and overall disappointment for almost all of our participants. This hesitation stemmed from a lack of adherence to these measures by both the general public, leading to a sense of disappointment in their ignorance, as well as individual organisations' and the authorities' failure to enforce these guidelines. The lack of enforcement was particularly noticeable in **healthcare facilities**, where the proper implementation of these measures was crucial:

> From today, a lockdown is in place in our region. Access will be allowed everywhere but only if you have received 2 vaccinations... Well, I see that nothing seems to have changed, there are not fewer people. I enter the polyclinic. They are not checking the temperature anymore. During the previous lockdown, there was a member of staff standing there checking everyone's temperature. I look at the registration desk, there are so many people, just like on Friday. What's going on? Where are all these people coming from? It's a lockdown, yet there are more and more people!
>
> Then we passed through this new entrance to the MSEK office. Naturally, there are quite a lot of people in the hospital, everyone is running around, coughing, sneezing. Some wear masks, some don't. Well, it's certainly an additional risk, you could get sick or catch this life-threatening virus.

Our participants commented on a similar lack of enforcement and carelessness of the public in other public spaces, including **markets and food shops**:

> At the market, almost no one wears masks at all. In some stores, they may still require them, but it is rare. Measures are needed from the government to control this process, enforce the proper regulations, and impose penalties for violations. Then people would still somehow protect themselves, wear masks, and avoid crowded areas. But in the market, it's almost impossible to find someone wearing a mask.

> So we are all cautious, we are afraid. And when I was walking home, I noticed that there were also a lot of people at the market. There is no mask-wearing or any remarks being made there. The hygiene measures are completely absent, and I didn't see any of it at any of the stalls.
>
> Whether it's at the market or in the shops, no one requires wearing masks, not even the shopkeepers. Everything is just left to chance.
>
> Today I went to the shop and noticed that people did not seem to care, walking around without masks. Even upon entering a large store, a hypermarket, the security guard doesn't enforce wearing masks. You understand, this is criminal.

Churches:

> We were very surprised that not a single person in the church was wearing a mask. No one was using a mask; everyone sat close to each other, greeted each other, hugged, and shook hands... Today is the same. No one uses masks, and when communion is administered in the church, they drink from the same cup of wine. And for a long time, I couldn't receive communion because of this. People are afraid. I spoke with people and asked if they were afraid to drink from the same cup. All the people in the church drink from the same cup. They say, "Of course." One woman told me that she was scared, she is afraid, but thank God, nothing happened, and everything was fine after everyone drank from the same cup. However, the pastor or deacon of the church, when he offers you the cup, carefully wipes the place where a person sipped with a napkin. I don't know if this helps, but he wipes the spot and passes the cup to another person.

Schools:

As before, I've noticed that at school, none of the staff—from the janitor to the principal and teachers—are wearing masks during training sessions. It leaves me wondering who these vaccination regulations are actually for, especially when even these minimal protective measures aren't being followed.

Public transport:

There weren’t many people on public transport, but what immediately caught my eye was that most of them were not wearing masks. And yet, it was announced again that we were entering the yellow zone of quarantine.

But here’s what I have been noticing more and more on public transport — people without masks. Their numbers are increasing. This is despite the discouraging statistics of COVID infections. It’s becoming increasingly common to hear the phrase “a new record of COVID cases has been set” in the news. And some of my acquaintances consider COVID to be some kind of conspiracy rather than a real illness.

No matter how many times I’ve travelled on the subway, I have never been checked, nor have I seen anyone else being checked for their vaccination certificates. People in the metro still wear masks to some extent, but some just lower them below their noses. In other words, the masks are just for show.

Figure 7: *Electronic Display on Public Transport:*

«ENTRY ALLOWED ONLY IF WEARING A SAFETY MASK»

Our participants also revealed a profound sense of disappointment as they witnessed a lack of empathy and disregard for the COVID-19 specific safety measures on a daily basis. They viewed this disregard not only as undermining any collective effort to combat the spread of the virus but also as reflecting a troubling disregard for the lives and health of those who were more susceptible to severe illness. The analysis indicated that some of our participants experienced a genuine and debilitating everyday fear of contracting the virus due to the careless actions of others. They were aware that their own compliance with the recommended guidelines alone might not be sufficient to safeguard themselves and their loved ones:

And I want to say that the attitude towards COVID-19 is somehow very contradictory. In general, people ignore this problem. If no one in their family has been sick or if the illness has passed lightly, they don't take it seriously. They say that diseases have always existed, it's all nonsense, and it doesn't help anything. But on the other hand, in our city, there is a hospital that is almost completely filled with people in critical conditions. And to these people, it probably doesn't seem like a mild illness, and one cannot ignore it.

If you get sick, be responsible, isolate yourself, don't go to public places, to shops, and isolate yourself during this period. If people are socially and collectively responsible towards others, the consequences of the virus and its spread can be significantly reduced.

Many people are getting vaccinated because they were told, "If you don't get vaccinated within a week, then the following week you will be in self-isolation, working from home; if you still don't get vaccinated after another week, submit a request for leave." Unfortunately, that's how it is in our country for now. But on the other hand, why should people like me suffer due to someone else's irresponsibility?

In shops, people walk without masks, and they are not served at the checkout until they wear a mask. If a person starts yelling, arguing, and you begin to say, "How is this possible? Why am I wearing a mask and you're not? I'm concerned, don't you care?" — then they will curse you so much that sometimes you don't even want to say anything, let alone leave the house.

B. The adverse effects of COVID-19 on individuals' mental health, including heightened levels of fear and despair

The periods of social isolation and confinement which accompanied various phases of the pandemic, particularly during lockdowns, were a significant concern for all of our participants, especially those who were not vaccinated or considered themselves clinically vulnerable to COVID-19. One respondent vividly expressed their frustration by likening their situation to that of Cinderella, who was confined to her home at the stroke of midnight. They felt that the quarantine measures kept them constantly on guard, as if the virus would strike as soon as they stepped outside their door:

> When the quarantine began, I recalled my confinement. We all remember that feeling, that today at 12 o'clock, like in the fairytale "Cinderella"...this COVID stands by your door and waits for you. You open the door, and it immediately attacks you.

This metaphor encapsulates the anxiety and sense of being trapped that many persons with disabilities experienced during the pandemic.

Another issue raised by the participants was the limited opportunities to see their relatives and friends face-to-face. The lack of in-person interactions further isolated them and hindered their ability to maintain social connections and support networks. This loss of social contact had a detrimental effect on their mental and emotional well-being:

> In general, it's not easy to be in this isolation. My nephew came to visit me. We only saw each other through the window, thanks to the fact that I live on the ground floor. Of course, I was very happy to see a loved one, but it's unfortunate that it was just a meeting like that. I really want to meet people in person. And we had to meet through the window because he has suspicions of having Covid, he hasn't taken the tests yet, and he is currently in self-isolation. He only goes out for groceries when necessary.

Everyday access to essential goods, such as food and essential medication, also posed challenges for participants who were self-isolating due to their vulnerability to the virus. Some respondents described the new methods they had to adopt, such as relying on others to shop for them while wearing gloves and leaving food parcels outside their homes. This included having to wait for some time to allow any potential airborne virus particles to dissipate before handling the groceries. These measures, although necessary for their safety, further contributed to their isolation and increasing dependence on others:

> And everything was done wearing masks and gloves, so they would place the groceries here in my hallway. They would carefully place the card as well, handing it over to

> each other. Or, if it was an order from the shop and they delivered it to you, there would already be a bill, and I would transfer the payment to the card. And they would also come and leave it at the doorstep. After some time, we would only take that bag, not immediately, but also wearing gloves. So, to let the COVID dissipate somewhere.

For those individuals who did not receive the COVID-19 vaccine due to contraindications or lack of information, the restrictions imposed by the government added another layer of isolation. They were often barred from entering non-food shops and other indoor spaces that required proof of vaccination. This restriction, aimed at curbing the spread of the virus, effectively cut off access to some services and further isolated persons with disabilities who were unable to get vaccinated and obtain vaccination certificates. This exclusion deepened their sense of isolation and heightened their feelings of being disconnected from society:

> From the 18th of the month, Monday, we entered the red zone. Now everything is closed except for grocery stores that can be visited. Clothing stores, household appliance stores are open, but they only allow people with vaccination certificates.
>
> Where can we go if everything is closed now except for food shops? Cinemas, for example, are not working. Well, they say it's for two weeks, but I doubt things will reopen because there are a lot of sick people.

Fear was a prevalent and pervasive emotion expressed by participants in relation to the COVID-19 pandemic. The fear encompassed various aspects, including the fear of contracting the virus, fear of the potentially fatal consequences of COVID-19, fear of health complications, fear of vaccines, fear of inadequate financial resources for treatment and suste-nance, fear of inaccessible healthcare facilities, and fear of social isolation and loneliness. While some of these fears are not unique to persons with disabilities, certain fears, such as the fear of hospitals, are indicative of the precarious conditions and the specific recognition—or lack thereof—afforded to persons with disabilities in Ukraine, both culturally and politically.

This fear played a significant role in influencing the daily lives of individuals with disabilities, leading many to self-isolate and withdraw from public activities. The fear stemmed not only from the disease itself, which was an unknown and dangerous infection, but also from the poorly conceived and managed pandemic responses and the behaviours of others who exhibited ignorance about the virus and its consequences. Our participants faced heightened levels of fear and uncertainty, exacerbating their vulnerability and the already challenging circumstances they encountered:

> I'm scared of hospitals, I'm scared of getting into a bad state, I'm scared of excessive costs. Of course, I don't want to die. I want to see my grandchildren, I want to be a grandmother for a very, very long time. But it's scary. Therefore, for anyone, Covid is a disaster, and for a person with a disability, especially with a spinal injury, God forbid.

> I see that... my fear is intensifying, and I don't want to go out on the street, go to work, or be in public places.
>
> Well, while my son is here, but he's leaving on Monday. I am fearful...how am I going to manage? In other words, well... honestly speaking, I have such a fear, well, not exactly fear, but some, maybe even anxieties, if I stay at home for a long time, a relatively long time.

One notable finding is that for some of our participants their fear and anxiety were more directed towards poorly equipped and inaccessible hospitals rather than the COVID-19 virus itself. While fear of contracting the virus was present, it was overshadowed by the deep apprehension of receiving adequate medical care and support in the event of falling seriously ill. Their previous everyday experiences and challenges in accessing healthcare services played a significant role in shaping such fears. Many expressed concerns about the lack of appropriate medical equipment, facilities, and trained personnel in hospitals that could cater to their specific needs. The fear of encountering inaccessible environments, both physically and in terms of communication, further intensified their anxiety:

> But the thing that scares me the most are the beds with mattresses that are not adapted for people who use wheelchairs. And the lack of sanitary and hygienic conditions. It's the most terrifying thing.
>
> And now, when you look, many people simply don't have enough oxygen, and that's very frightening. Oh my god...the fear to get sick. So once again, I try not to go anywhere.

> We haven’t had COVID-19, but I worry about what may happen if, God forbid, we or our friends, who have already been sick and experienced it, end up there, in that ward. The ward, as we call it, in the COVID-19 unit, where there is no accessible restroom for people with disabilities.
>
> The fear of ending up in a hospital, and this hospital being inaccessible. This is my biggest concern!
>
> Due to this situation with the coronavirus, personally, what I fear the most, perhaps, are hospitals and clinics. I try to go there as rarely as possible. If there is a possibility to manage without the clinic, without that treatment, I go without it.

The prospect of being unable to receive the necessary medical attention and support during the pandemic amplified our respondents’ concerns and instilled a deep sense of unease.

It is crucial to recognise that this fear of poorly equipped and inaccessible hospitals is not solely a consequence of the COVID-19 pandemic but is reflective of longstanding systemic issues faced by persons with disabilities in Ukraine. The pandemic exacerbated these preexisting challenges and shed light on the urgent need for inclusive and accessible healthcare services.

In addition to fear, the impact of the pandemic translated into a tangible sense of despair for many individuals:

> Well, I don’t know what awaits us. What lies ahead. I don’t want to get sick, I don’t even want to think about it. It’s such a hopeless situation, just a disappointment.

> I don't know when we might emerge from all of this. I don't want to end on a pessimistic note, with pessimistic thoughts, but [there is a feeling that] natural selection is really happening.
>
> And we hope that eventually we will start living a normal life because it's becoming unbearable. I wrote a letter to a charity asking for 12–15 thousand hryvnias[14] - the cost of the wheelchair I need. It's an absurd and demeaning amount, it's essentially the price of a washing machine, and yet I'm BEGGING. Despite having a job, I'm reduced to begging. I can't even explain that I still need to save up for my medication (the cost of just one prescription is 20 thousand hryvnias[15], every six months), and I'm already saving all I can on my treatment. The slogan of this week is 'helplessness'.
>
> So, everything is difficult and challenging, and I just want peace and dignity. But somehow, it's not working out yet.

This despair was a compounded result of the challenges our participants faced in accessing necessary healthcare services, the limitations imposed on their social interactions, and the overall disruption to their daily routines and support systems.

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[14] 333.52 GBP and 416.90 GBP accordingly as of November 1st, 2021 (1.00 GBP = 35.98 UAH).

[15] 555.86 GBP as of November 1st, 2021 (1.00 GBP = 35.98 UAH).

C. COVID-19 vaccinations

Our participants raised concerns about the COVID-19 vaccination process.

The lack of certainty and confusing information surrounding vaccinations was a prominent concern. Many expressed a lack of trust in the vaccination process; others questioned its effectiveness, especially when they observed how friends and family members were vaccinated yet still contracted COVID-19. This lack of confidence led to hesitancy and the perception of additional risks associated with potential side effects:

> If, as they say, such vaccines do not protect against anything at all, then it is generally unclear how they work. Everyone, absolutely everyone I know, says that they also got sick - some with severe others with mild symptoms. And they continue to get sick after getting vaccinated. So, I personally think that it is pointless to get vaccinated. This is just what I think.

In commenting on the lack of reliable and consistent information, one of the participants was frustrated with the manner in which official information and advice included pseudo-scientific viewpoints. This led to confusion and undermined trust in the vaccination campaign:

> There's some kind of mass psychosis on television, unfortunately, due to remarks made by the Minister of Health that go beyond any limits. Along with him, in other sources, predominantly on the Internet, comments from

other experts, candidates, and doctors of the medical sciences appear. And they are against mass vaccination due to numerous contraindications. Getting hold of reliable information about what is actually happening, apart from the fact that there is a large number of infected and deceased individuals, is not possible. This contradictory information on television and the Internet confused people who are simply unable to decide whether they should get vaccinated or not.

Some of our participants were fearful of getting vaccinated. They explained this fear by having concerns about the safety and efficacy of the available vaccines or anxieties related to potential adverse reactions:

We have not made a decision about vaccination yet. Why? Because one of the doctors told me that it was not worth doing, as it may worsen my current condition, get my tachycardia worse. That’s why we are not rushing with vaccinations for now. But still, we often think about it because, after all, we are getting more inclined to get them

> since they provide protection. If a person gets sick, the illness will not progress as severely or be as dangerous.
>
> There are many questions about what may happen next, and people are simply stressed, people are shocked. It's like, well, I don't know, really. For example, I'm afraid of getting sick, and I believe that getting vaccinated is necessary, although it is scary because no one guarantees what might happen after the vaccination. It is still not fully understood. But most people are not getting vaccinated and they are afraid to do so. That's the issue.

Interestingly, some participants expressed bewilderment towards individuals who exhibited vaccine hesitancy, not because they were concerned about potential contraindications, but rather due to misinformation and denialist attitudes towards vaccines or COVID-19 itself:

> My acquaintance doesn't just imagine; she firmly believes that vaccinations are the mark of the devil, as mentioned in the Bible before the last days.

Another respondent mentioned a clergy member who persuaded churchgoers not to get vaccinated:

> I spoke with a pastor — as I understood it, he is against vaccination — and he says, "Why bother doing it if people are still dying anyway?" Yes...what's important is not that he himself is against vaccination, he also encourages all churchgoers to refuse vaccination and people listen to him. As a result, the majority of people simply refuse to get vaccinated.

Rumours and hearsay regarding the efficacy and impact of COVID-19 vaccines were also a source of concern. Such unverified claims further contributed to doubts and reservations regarding vaccination:

> I went to a hairdresser and there were other clients and employees so I could not but hear how people felt about vaccinations. They were telling scary stories about how vaccinations led to infertility. They also mentioned that someone died in a village nearby after receiving the vaccine. Well, nobody knows whether it's true or not.

Some of our participants reported that it was possible to illegally purchase vaccination certificates without actually receiving the vaccine. This revelation raised concerns about the integrity of the vaccination process and highlighted potential loopholes in the system:

> From my relatives, I found out that it was possible to purchase vaccination certificates. It was on the news that police had started to arrest people who sold them.

Another grievance was the choice of vaccination centres, which participants described as undignified, such as supermarkets or other facilities that were deemed inappropriate for administering vaccines:

> I cannot accept this idea of getting vaccinated next to potatoes, vegetables, or fruit... My acquaintances were vaccinated not among the potatoes but near the toilet!

These issues and concerns highlight the complexity and multifaceted nature of the vaccination experience among persons with disabilities in Ukraine. Addressing these challenges demands a comprehensive approach including clear communication, accessible vaccination centres, tailored arrangements for individuals with disabilities, and efforts to combat misinformation and enhance public trust in the vaccination process.

3. EVERYDAY DISRUPTIONS AND STRUGGLES

This section examines the profound impact of the COVID-19 pandemic and government responses on the daily lives and routines of our participants and their households. The reason for studying the everyday impact of the pandemic is rooted in the understanding that the effects of major, life-altering events, which are external to the individual, often take time to fully manifest in their daily lives. While initial pandemic-related changes in everyday life may seem temporary on their own, they can accumulate over time, resulting in significant challenges for individuals. Therefore, we, as a project team, felt it was crucial to explore the intricate details of everyday life to gain a better understanding of the true impact of the pandemic on the lives of persons with disabilities in Ukraine.

A. Everyday normality

During the 8-week study period, our participants maintained diary entries that provided insights into their daily lives. These entries predominantly revolved around their 'normal' day-to-day routines, which encompassed essential household tasks such as cooking meals, cleaning, doing laundry, earing, socialising, taking care of pets or gardening, working from home or commuting to work (COVID-19 related restrictions allowing). By recording these mundane yet essential activities, participants shared the intricate details of their everyday routines:

> I came home hungry. I grabbed a bit. Now I'm resting a little bit and then I'll start ironing. I have a lot of laundry to iron this weekend. Now I need to feed our cat. My husband will come and will feed the dogs. And that's how our day goes. There are many more different calls to make, issues to resolve. But, thank God, we can still do it.

Figure 8: *'Our Breakfast' as Photographed by one of the Participants*

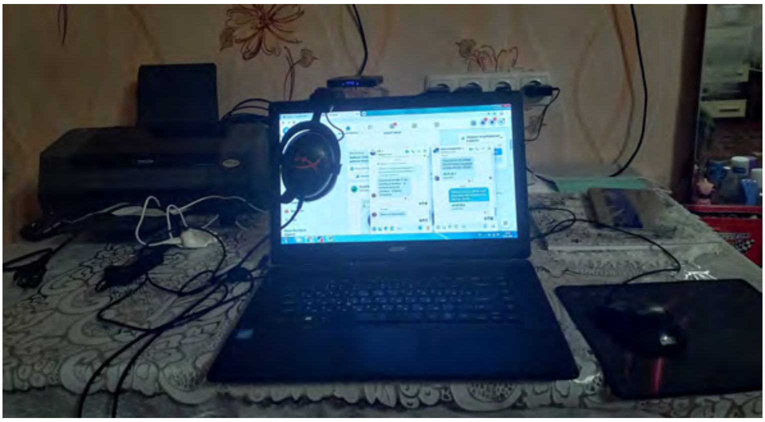

Figure 9: *My Workplace (at Home)*

I manage on my own at home. I get up in the morning and go to work. I come home, feed the dogs and cats, clean up after them. I do some chores around the house. And that’s how our days go.

It’s the weekend in Ukraine all over again. And we’re doing the chores at home. My husband is chopping firewood, my dad is helping him out. And my mother and I will do the housework. That’s how our day goes.

The day went on like a normal weekday for us. That is, I did the cooking, also did the laundry and cleaned up.

B. Daily Struggles of Everyday Life

Here, the focus shifts to the daily challenges faced by persons with disabilities during the pandemic. Although in most cases these struggles may not have reached the magnitude of full-blown crises, such as the loss of loved ones or major health issues, they can be described as 'quasi-events' as theorised by Povinelli (2011) in her exploration of power and the global distribution of life and death in late liberalism. Povinelli's concept of quasi-events refers to the everyday uneventful forms of misery and suffering that are pervasive in individuals' lives, contributing to a cumulative and chronic impact. These challenges manifest in the **disruption of familiar routines** and the **emergence of a new 'normal'** within the socio-economic and cultural context shaped by the pandemic:

> I increasingly notice that COVID-19 has indeed brought about changes. At work, all the events we organise have shifted online, and there are even more of them than before the pandemic. The pace of work is increasing.
>
> With the arrival of this dreadful COVID-19, our lives have really changed. Now we spend most of our time at home because we are afraid of catching the virus again.
>
> We no longer meet in cafes but see each other on the screens of our monitors in the Skype programme. However, we still hold cups of aromatic coffee in our hands and have something sweet on our plates to accompany our coffee. Unfortunately, the topic of the coronavirus is now part of our every conversation.
>
> We mainly communicate over the phone, in Zoom meetings, and on computers, with no face-to-face interaction. This is particularly difficult because my husband used to go swimming in the pool before current restrictions, back when there was a yellow zone. But now he can no longer do it as he is in a high-risk category.

> The day started as usual: we woke up, had breakfast, checked our blood pressure, took our medication, and watched the news. We found out the current quarantine status, the number of people who fell ill, and the number of people who recovered. We looked at the statistics for our region. Unfortunately, there was nothing to be optimistic about, but life goes on.
>
> I gathered my things for work, as usual, packed tissues, put hand sanitizer and two masks in my bag, and went to work.

The theme of **everyday financial difficulties** encompassed various problems identified by our participants. These included struggling to survive amid rising prices and making sacrifices in purchasing essential items. Participants also faced the dilemma of choosing between eating or heating due to limited financial resources. Additionally, they experienced job losses and relied on savings and credit to cover everyday costs. A significant portion of their disability pension was allocated to cover medical expenses and food costs. Lastly, they bore the financial burden of accessing healthcare and overcoming poor accessibility

After receiving my salary, I went shopping. I just understand how catastrophically prices are rising, and for a person with a disability in our country, living on a pension of 2,000, or 2,500 hryvnias[16] is tantamount to death. Because spending a thousand hryvnias[17] on groceries for a family for a

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[16] 55.59/69.48 GBP as of November 1st, 2021 (1.00 GBP = 35.98 UAH).

[17] 27.79 GBP as of November 1st, 2021 (1.00 GBP = 35.98 UAH).

few days — means nothing. There is food on the supermarket shelves. But every month there is a crazy price increase and you still need to buy medication, food, and pay the utilities. All of this is very difficult. But it seems that everyone in this country, including our government, has forgotten about it.

Now we've started spending our savings because the monthly income isn't enough for all expenses.

To save money, you just need to do some things yourself. Yesterday, I went to the well to get water. In stores, drinking water costs 1 hryvnia per litre[18]. So, I normally take 150-200 litres of water from the well at once. This normally lasts half a month if we are mindful of how we use this water.

We can't travel by public transport, it's not accessible, and it means taxis. And they are expensive!

It's already cold outside. It's cold at home too. Heating with electricity is too expensive, so we heat only at night. There's nothing you can do, but you have to live somehow within your means. Paying over 4,000 hryvnias[19] just for heating per month is expensive for us.

I planned to completely renovate this room in the an-nex this year. But we had to choose — spend money on my wife's health, or on repairs. Of course, we chose my wife's health.

---

[18] 0.03 GBP as of November 1st, 2021 (1.00 GBP = 35.98 UAH).

[19] 111.17 GBP as of November 1st, 2021 (1.00 GBP = 35.98 UAH).

Our participants commented on everyday difficulties and barriers in **accessing public spaces, healthcare facilities (reviewed above), government buildings, and transportation**, which were further exacerbated by the pandemic:

> When you already feel bad and you can't even get to the toilet in the hospital... your human dignity is not just humiliated, but simply trampled upon... Previously, the doors to the toilet in the hospital were so narrow, you won't pass through in a wheelchair. Now I was able to enter the toilet in a wheelchair. But this toilet would horrify anyone. There isn't even a toilet as such, just two steps and a hole in the floor. They attached a handrail to the wall. It looks like a joke : should I hang from it? That's why a person with a disability cannot use it.
>
> We prepared the documents and took them to the justice department. We chose the regional office, hoping it would be accessible. But, unfortunately, when we arrived, there were about ten steps to climb, and it was impossible to get in.

Figure 10: *Inaccessible Entrance to the Local Department of the Ministry of Justice.*

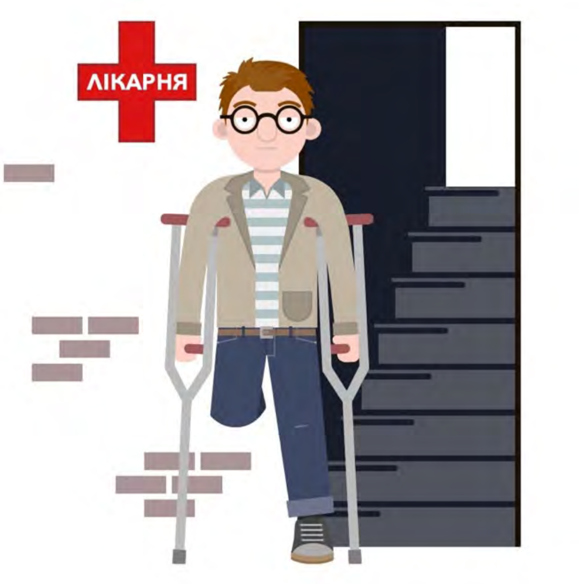
A number of participants reflected on the **challenges of using public transport** amidst the pandemic, including the suspension of public transport services to the general public without any specific measures to accommodate mobility requirements of persons with disabilities. Within this context, two primary aspects were highlighted: the inadequate accessibility and limited availability of public transport (findings that align with the outcomes presented in Part 1 and Part 2 of the report). Additionally, the participants emphasised the pivotal role of mobility, particularly during the period of pandemic-related restrictions, highlighting the importance of mobility in their everyday life:

> We are in the process of sorting out how to get wheelchair users onto minibuses. There is no lift and there are no access platforms. Perhaps we will be able to put together some wooden platforms to pull people onto the bus.
>
> I measured the temperature, and it was 37 degrees, so my mum suggested that I should see a doctor and take a COVID-19 test on Friday morning. That's exactly what we did. Early in the morning, my mother came to me, and we took a taxi to the hospital. Unfortunately, there are no suburban buses that are low-floor accessible.
>
> Currently, transportation is very challenging, especially in red zones. Not everyone is allowed to board, and minibuses depart before you can approach them. For example, how can a visually impaired person signal to the minibus to stop? It's only after the minibus has stopped that I can ask someone for its number, and then I attempt to approach and board it.

Another critical concern emphasised by our participants was the profound **lack of reliable and up-to-date information** regarding the virus and the relevant changes associated with the pandemic response, including government-imposed restrictions, vaccination protocols, alterations in healthcare services, and public transport arrangements. Such a lack of access to essential information significantly hindered our participants' ability to make informed decisions and effectively adapt to the evolving circumstances brought about by the pandemic. This information gap not only limited their understanding of the virus itself but also impeded their knowledge of resources and support available to them, exacerbating their vulnerability and potentially compromising their overall wellbeing:

> The media rarely features videos or similar materials about people with disabilities or rehabilitation facilities. Few people are aware of how to access such centres, where specialists are located, and what services are provided.
>
> Regarding outpatient patients, especially persons with disabilities, I believe that preventive measures should have been taken during this period, such as distributing leaflets on how to behave in these situations. People often receive information from their neighbours or from those who have been ill, and all of this results in more rumours. People are afraid of things that do not exist. Ideally, people should not be afraid, but instead should have accurate information and take the situation seriously. This would prevent panic, ensure cooperation with doctors, and encourage people to seek help rather than resorting to self-medication.

C. Everyday abandonment and the horrors of everyday life



In the context of the pandemic, our participants' everyday life experiences **revealed a specific pattern of abandonment and isolation**. While it may not be possible to directly attribute the responsibility for neglecting disability considerations to the government or its specific agencies (even though a number of our participants were particularly critical of the Ministry of Social Policy of Ukraine which has a specific 'disability' remit), such acts of economic and social neglect, although seemingly small and not significant in their own right, accumulated and were allowed to accumulate over time leaving persons with disabilities to cope with the challenges of the pandemic on their own.

For example (and as explained above in more detail), when healthcare services were technically available, the lack of accessibility meant that some of them were inaccessible for persons with disabilities. The absence of ramps or out-of-order lifts in healthcare facilities rendered them effectively inaccessible, despite the services being available. Similarly, although specialists were available to see patients, the lack of strict enforcement of mask-wearing created a fear among persons with disabilities, discouraging them from queueing up due to the heightened risk of catching the virus. Similarly, while essential transport services continued to operate for specific categories of workers during the strictest lockdowns, the unique needs of persons with disabilities were often overlooked. Individuals with disabilities rely on caregivers who may require transportation, and persons with disabilities themselves may need to travel to access pharmacies, healthcare appointments, or shops for essential supplies. However, these considerations were not taken into account by relevant authorities, leaving persons with disabilities without the necessary means to fulfil their essential needs.

In terms of the financial impact of the pandemic, the experiences shared by our participants highlight another example of what can be described as a ‘quasi-event’ of abandonment. Povinelli describes these as events which ‘never quite achieve the status of having occurred or taken place. They neither happen nor not happen’. For example, persons with disabilities in Ukraine do receive their state disability pension; however, for many of our participants this pension was not enough to pay for the very basic life-supporting medication which the state was failing to provide free of charge. Our participants spoke about their exhaustion as numerous ‘small’ events (failures, let-downs, and disappointments) accumulated. One of the participants noted: ‘There are so many bad things happening — in every aspect — that it is difficult to even say, with certainty, this — this one particular thing — is really bad’. This comment reflects what

Povinelli (2011) describes as ‘thisness’. She notes that even though ‘little things pile up’, they do not intensify ‘in such a way that a thisness is easily formed. It is hard to pull a thisness out of the ongoing flow of the everyday because so much decomposition happens below the threshold of aware-ness and theorization’ (Povinelli 2011, p. 132). By looking at the everyday life of our participants within the context of the pandemic, such processes of abandonment and decomposition which are made up of many ‘little things’ come to the fore: not having enough money to buy essential medication, or not being able to use a toilet in the hospital, or not being able to get into one’s apartment without having to wait for complete strangers to assist with getting over a set of stairs:

> I am really struck by the lack of responsibility in our medical system. Currently, this disease is very dangerous. Not only am I disabled, but I also have a rare condition, so it is unknown how it will affect me if I contract it [COVID-19]. I also have heart problems. However, it seems that nobody cares about my condition, and now I understand that I probably have to rely only on myself and not have high hopes for healthcare professionals.
>
> We turned to the local authorities, to the village head to ask for help in finding accessible housing. And after some time, we found an apartment. Of course, it was not fully adapted, in the sense that even entering the apartment was quite problematic, as there was no ramp.
>
> Unfortunately, there are only stairs [at the food store], and every purchase we make looks something like this. We ask someone to call the shop assistant, they come

> out, and we interview them: “Do you have this, do you have that, is this fresh, is this not fresh? Can you bring this to show us?” Well, I think these purchases are inconvenient for the shop assistant as well, as they have to run and come out to us, and for us, because it’s one thing when you plan in advance what to buy, and it’s another thing when you see something with your own eyes and want to buy it, for example. So, our purchases come down to strictly following the list. We tell them what we need, and they bring it. That’s how it is.
>
> Yesterday, my family doctor prescribed me a treatment that costs 600 something hryvnias. Today, I went to the regional doctor, where they also prescribed me a treatment. There, it costs a little more, a total of 800 hryvnias. How am I supposed to survive with my pension? How is my family supposed to survive? Honestly, I can’t even imagine how all of this is supposed to work.

One of the participants commented on the pervasive neglect of persons with disabilities in rural areas, highlighting a distressing reality where accessibility concerns for persons with disabilities were almost inconsequential due to the absence of fundamental services such as hospitals, transportation, and social welfare. This situation not only affected persons with disabilities but also extended to the wider community, as these essential services were not easily available to anyone in the region:

💬 I want to share our problems, how we live, how we exist here, how difficult it is for people with disabilities to live. Although my parents are nearby, they help; otherwise — I don’t know what we would do. They are already elderly.

> Later on, it will be very difficult for us, especially in the village. There is nothing here, and there is no help to expect from anyone.

Another participant compared their own predicament to that of other marginalised groups, specifically highlighting the plight of the homeless population — completely forsaken, overlooked, and disregarded by the state, lacking visibility and recognition:

> Homeless people, like the Roma, they spend the night at train stations, and they have not only these corona-viruses... they probably have tuberculosis, scabies, and all other... diseases. And, thank God, at least, well, that we are alive after this.

In response to such pervasive everyday neglect and abandonment, one of the participants called for a transformative, almost apocalyptic, end to the systems of neglect that perpetuated their disempowerment and marginalisation. However, this call was tempered by a sober realisation that substantive changes within the existing system were almost impossible to achieve:

> Now I fully understand and support those doctors and medical staff, who, unfortunately, moved abroad, leaving us alone with this epidemic. Sometimes it’s true, like in the Bible, you just want Sodom and Gomorrah to happen. And then, maybe, some brains would emerge in the right direction. Well, sometimes I feel like this, but then you pull yourself together and analyse that you will still be grinding in this same system. And your relatives and your loved ones will also be affected. But why? Well, for what?

In conclusion, this section includes a series of diary entries recorded by our participants, which, during data analysis, were coded as the ‘horrors of everyday life’. The incidents range from instances of wheels detaching from public transport vehicles to disconcerting advice from doctors suggesting patients remain at home for as long as possible to enhance their survival chances, instead of seeking hospital admission. The entries also document distressing moments of individuals falling out of their wheelchairs onto the road due to poorly constructed and non-compliant road crossings.

Our research clearly indicates that such ‘horrors of everyday life’ are not isolated or rare but are, rather, everyday realities that fill the lives of persons with disabilities in Ukraine. These examples highlight their heightened vulnerability, especially during the pandemic, and the disproportionate share of challenges they had to navigate on a daily basis. The data provided by our participants not only reveal the persistent challenges faced by individuals with disabilities in Ukraine, but also stress the urgent need for societal and infrastructural changes to improve their daily living conditions. Whether it is better maintenance of public transport, improvements in medical advice and healthcare access, or enhancements to physical infrastructure like pedestrian crossings, the call for action is clear. These ‘horrors’ provide a powerful argument for more inclusive and empathetic policies and practices that can and should mitigate the daily hardships endured by persons with disabilities in Ukraine:

> We have four vehicles from which wheels flew off on the road with passengers. The driver lost two wheels. It seems that two wheels came off on one side... this happens quite often.

> Doctors say that you can’t even imagine how much worse it would be for you in the hospital than at home. As long as your saturation is normal, don’t even think about the hospital. Overall, this is terrifying to me.
>
> The green light turned on, the guy abruptly pushes the wheelchair forward, causing the front wheel to move ahead, and there’s also a curb, which wasn’t perfectly shaved down, and I was thrown out of the wheelchair right onto the pedestrian crossing.

Our assessment of struggles and disruptions that persons with disabilities in Ukraine experienced on a daily basis within the context of COVID-19 pandemic highlights the challenges they had to navigate, ranging from financial struggles, access to public spaces, healthcare facilities and transportation, to information gaps on pandemic-related changes. These issues, while perhaps not immediately recognised as critical con-cerns, cumulatively accounted for significant disturbances in their daily lives. Such ‘quasi-events’ (Povinelli 2011) of daily struggles to get on with everyday life are reflective of an un-derstated yet profound degree of suffering and hardship that people with disabilities experienced throughout the pandem-ic. Our focus on what appears to be mundane activities offers nuanced insights into the lived experiences and well-being of individuals with disabilities, particularly in crisis situations like a global pandemic.

The recurring theme of neglect and abandonment emerging from our participants’ accounts signals the systemic gaps and shortcomings in state and government responses to disability needs during the pandemic. The lack of consideration for the unique requirements of persons with disabilities, as evident in the areas of healthcare services, public transporta-tion, and access to essential information, implies a pattern of societal and institutional neglect. Our findings align with exist-ing research that underscores the marginalisation of persons with disabilities in crisis responses and the ensuing increased vulnerability they face (World Health Organisation, 2020). Furthermore, the financial hardship experienced by our par-ticipants exposed a significant gap in the state’s disability pen-sion system and underscored the economic vulnerability of this population group during crises.

4. DAY-TO-DAY POSITIVITY / LITTLE SNIPPETS OF HAPPINESS

Over the data collection period, all of our participants docu-mented not only negative but also positive events and ordinary activities in their lives that fostered joy, optimism, and a sense of happiness. These included personal hobbies such as cooking (and eating), and interactions with nature or their beloved pets. These positive events served to recalibrate the disrupted monotony of their daily lives, especially during the trying times of the pandemic. One of the participants described them as “little snippets of happiness”. These snippets of joy served as antidotes to alleviate the harsh realities experienced by persons with disabilities amidst the ongoing pandemic in Ukraine. Cooking was one of the key activities, providing both a space to create but also serving as a means of expressing self-care and of caring for others. Whether it was cooking alone, or preparing meals with or for friends and family, the culinary process became an integral part of their daily routine. Some of our respondents shared their favourite recipes, accompanied by photographs of their creations, showing much pride and enjoyment that came with cooking and sharing meals.

Pets were identified as another significant source of positivity and support. Their companionship and unconditional love contributed significantly to the well-being of our participants, acting as comforting presence in their lives. Connecting with nature was another critical component in the everyday happiness of our participants. Engaging in activities such as walks in the park, visiting nearby forests, or looking after their gardens provided not only physical activity but also a much-needed mental respite, a sanctuary of sorts or 'me space' where they could retreat and replenish their mental resources.

These everyday occurrences may seem inconsequential or mundane, but for our participants they held profound importance. Recognising, documenting, and understanding these practices is crucial as they constitute the fabric of everyday life for persons with disabilities. By illuminating and recording these activities, the project highlights the situated meaning and the role of happiness and positivity in the context of disability, especially amidst the challenging circumstances brought about by a global health crisis.

A. Cooking, eating and food

For many of our participants, food played a far more significant role than merely serving as sustenance. It was a critical source of joy and positivity that permeated their everyday lives. The references to food ranged from the seemingly mundane act of buying food during routine trips to markets and supermarkets, to the more hands-on and intimate act of growing their own food. This latter aspect instilled a unique sense of satisfaction and accomplishment, the pleasure of knowing the origin of what they ate and the organic nature of their home-grown produce. The process of food preservation for winter also brought its own set of joys, engaging them in a traditional practice that promised rewards in the colder months. This not only fulfilled the need for a healthy diet but also provided a sense of self-reliance and independence, further enhancing the positive influence of food in their lives.

Figure 11: *Home Baking*

Additionally, the act of treating themselves and their families to tasty food turned cooking into an expression of care and love. The joy of watching loved ones enjoy a carefully prepared meal was an experience that added immeasurable value to the act of cooking. The sharing of food with friends became a means of sustaining and nurturing social connections, especially in between periods of self-isolation and lockdowns, fostering a sense of community and engendering a feeling of belonging. For our participants, food acted as a conduit for maintaining and deepening social ties amid the multiple challenges of living through the pandemic, including acts and feelings of abandonment and isolation. Overall, the relationship with food and the process of cooking, presented a unique and powerful way for persons with disabilities to influence their lives positively and to foster a sense of accomplishment and wellbeing, however transient, amid the COVID-19 related fears and uncertainties.

> At her summer house, she grows a variety of vegetables. The main ones are potatoes, cabbage, pumpkin, beets, carrots, and garlic. This greatly helps us in managing our household — so we get out own products, as well as saving our family budget.
>
> This week we made a lot of vegetable preserves for the winter for our daughter: pumpkin, zucchini, cauliflower, broccoli, cherry tomatoes...

Figure 12: *Dinner (as shared by one of the participants)*

> We were warmly welcomed, and we started making shashliks [barbequed meat] with a friend, while our wives were talking to each other. We lit a fire, skewered the meat, and enjoyed talking to each other and watching the meat cook. Then there was a small feast. We sat, reminisced, told how their year had gone, how ours had, what was new.

B. Pets

The experience of our respondents underscores the critical role pets play in the lives of persons with disabilities, especially during times of crisis. The presence of pets, to many of our participants, offered more than companionship. It introduced an element of structure, normality, and predictability in an otherwise volatile and uncertain environment caused by the pandemic. Almost all of our respondents who had pets living with them noted that caring for these animals was a consistent daily activity that, in many ways, remained unchanged despite the turmoil brought on by the pandemic. This care ranged from daily feeding schedules, walking routines, to regular grooming tasks such as combing and washing their pets. The continuation of these routines, in the face of an otherwise disrupted daily life, provided a unique sense of rhythm and stability.

The importance of these routines should not be underestimated. They acted as an anchoring point amid chaos, lending a sense of continuity when much of the world was changing rapidly. The consistency of these routines did more than maintain physical wellness for both the pet and the owner; it fostered psychological resilience by anchoring the participants to a familiar routine in their lives.

Furthermore, these daily interactions with pets cultivated powerful affective bonds that offered emotional comfort and support during these testing times. Pets became trusted companions in an isolated world, providing unconditional love, empathy, and alleviating feelings of loneliness and anxiety. The strength of these affective bonds became even more vital for our respondents, whose interaction with the outside world was further limited by the pandemic.

Figure 13: *Two Cats — Home Pets*

Also, I have pets, my two beloved cats — a male and a female. And a dog that we picked up in the winter. Someone had thrown her out into the frost, and we took her in.

Having lived in this house for a few days, a small kitten was left for us. So... at first, he cried a lot, calling for his mom, meowing. But then he settled down, got used to it, and now it's been a year since we've lived in this house. He has grown up, become strong, and often brings us his prey. These can be mice, birds, and so on.

The workday would have been almost standard (letters, appeals, etc.) if it wasn't for working from home. And this means that my furry guards are by my side! And here they are, in my opinion, clearly against me working.

C. Nature Breaks

***Figure 14:** Spending Time Outdoors with Friends and Barbequing Meat*

***Figure 15:** Vibrant Autumn Colours*

Our participants highlighted the profound role that nature played in their lives. The seemingly simple act of stepping out into nature, for a brief walk in the park or a day spent outside the city near a lake, river, or forest, held remarkable significance for them. Engaging with nature was not only a sensory experience but a therapeutic one, offering respite from the monotony of indoor confinement and allowing a sense of normalcy to seep into their everyday lives.

The vivid imagery of autumn colours offered a stark contrast to the harsh reality of life amid the pandemic. The sight of trees shedding their leaves was a small, yet potent reminder of life's continuity beyond the pervasive influence of COVID-19.

For our participants, these 'nature breaks' represented more than an opportunity for leisure or exercise; they were essential avenues for emotional relief and a source of resilience and hope:

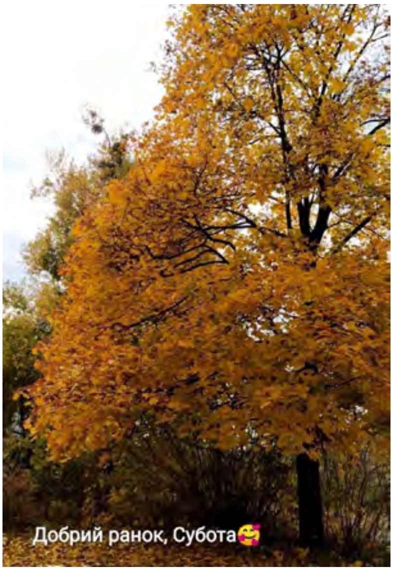


Figure 16: *'Good Morning, Saturday'*

> I'm already feeling a bit better. It is still warm, so I went for a walk along our avenue this weekend. As they say, enjoying the last warm days. The street is beautiful now, leaves of various shades, decorated the street with different colours.
>
> This weekend, we had very good weather, warm during the day, I walked outside for half a day. Breathed in the fresh air and enjoyed the sun. We cut off all the flowers, mom insulated our roses, we already prepared them for winter.
>
> There's such a living green zone with beautiful plants, such a beautiful landscape, where otters, coypus, ducklings, and domestic rabbits walk straight on the paths, between the trees — they don't really run anywhere in the area. We drove there with the kids.
>
> Driving through the forest, I wanted to stop and breathe in the air. Beautiful autumn forest. The road gently

> bends in the forest, the mood is just cool, just great. We stopped, walked in the forest for about 15 minutes. An inexplicable feeling fills the body, merging with nature, returning to youth, the best moments, a bit of sadness. God...Life is beautiful. In such moments, you realise that this is harmony.

D. Other 'snippets of happiness' and everyday beauty

Throughout the pandemic, individuals with disabilities faced significant changes to their daily lives, with many of their normal routines and habits disrupted or made impossible. In such a context, small, mundane activities, often overlooked or taken for granted by many, took on an increased importance for our participants. These simple activities provided a semblance of normality, joy, and continuity that was crucial in maintaining their mental and emotional wellbeing during an otherwise difficult period.

One such activity, for example, was attending theatre plays. The reopening of theatres following the lifting of pandemic restrictions not only provided an opportunity for social interaction but also represented a return to cultural activities that were sorely missed during the lockdowns. The joy and excitement of experiencing live performances again and of being part of an audience, were identified as pivotal moments of happiness and relief amidst the pandemic's challenges.

Shopping, too, became a treasured activity. Despite its simplicity, it allowed our participants to regain some control over their lives. It provided a sense of normality and routine, and also offered opportunities for social interaction. Similarly, meeting with friends and family served as a vital source of social support and companionship, helping to alleviate feelings of isolation and loneliness.

In essence, these 'snippets' of happiness — theatre plays, shopping, and social meetings and interactions — served as essential lifelines for our participants. They contributed to their emotional wellbeing, gave them a sense of control and normality, and most importantly, brought moments of joy and happiness during a time of crisis.

In the midst of the pandemic and its associated challenges, some of our participants found inspiration in the beauty of everyday life. For them, aesthetics played a significant role in shaping their daily experiences, providing comfort, and fostering resilience. Whether it was the change of seasons reflected in the transformation of nature, the elegance of a well-crafted object, or the warm glow of a sunrise or sunset, these moments of everyday beauty provided a diversion from the complexities and hardships imposed by

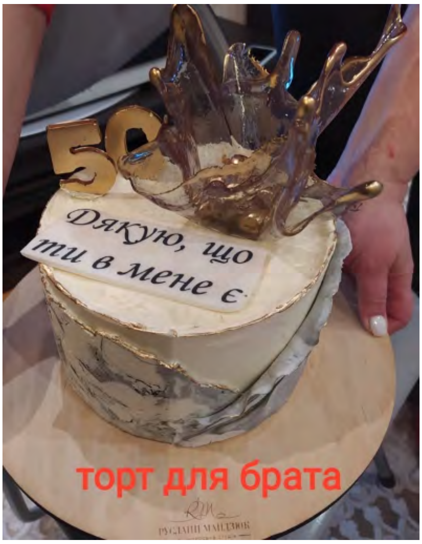


***Figure** 17: Cake for my Brother: Grateful for Having You in my Life* the pandemic. These seemingly small, ordinary details often carry profound significance, helping individuals make sense of their experiences, and find joy amid adversity. The appreciation of everyday beauty underscores the importance of positive aesthetic experiences in enhancing psychological well-being and demonstrates the profound resilience and adaptability of individuals with disabilities:

> When guests, friends, and acquaintances come to my place, I always treat them to coffee. I display all these things that please the eye, such as beautiful jars, large ones for salt and sugar, small ones for guests who can immediately use such things.
>
> On Friday, we had a shopping day. We saw a lot of decent fish, tasty herring, dorada, and we created a feast for ourselves. That’s it.

5. PARTICIPANTS' VIEWS ON THE GOVERNMENT PANDEMIC RESPONSE AND MOBILISING AGAINST EVERYDAY ABANDONMENT

In giving our participants free rein to record their individual accounts of everyday life, we did not ask them to specifically reflect on whether disability was foregrounded in the Ukrainian government's response to the pandemic. Even though the thematic analysis of participants' responses revealed this theme, it was not as dominant as one would expect in a context where: (a) national pandemic responses did, in most cases, heavily rely on a government-coordinated approach, and (b) such responses should have been guided by a single priority to safeguard and assist those who needed additional support to cope with significant social and economic disruptions.

While our participants recounted everyday struggles amidst the pandemic and related disruptions, direct criticisms towards the government were not as pronounced. This is aligned with one of the conclusions from the project's second phase, where the majority of more than 300 interviewees did not necessarily view the government as responsible for recognising and foregrounding disability in the social and economic aspects of life (see Sharapov et al., 2022b). This is also aligned with another theme recurring in this study: a specific form of recognition afforded to persons with disabilities in Ukraine. Despite the ratification of international documents and commitments, and the enactment of national legislation and policies, their poor implementation and underfunding, coupled with the dispersion of responsibility across various agents and institutions, render them virtually ineffective. In this context, persons with disabilities in Ukraine are 'bracketed' (or acknowledged in a static and limited manner) instead of being genuinely recognised.

Responses from participants criticising Ukrainian authorities can be organised under the four broad sub-themes:

A. Delays and Poor Enforcement of Pandemic Measures

Participants expressed concerns over the government's perceived inability to promptly implement and effectively enforce social distancing protocols and other pandemic-specific measures. This was viewed as a significant failure, contributing to the spread of the virus, and exacerbating the situation for clinically vulnerable individuals:

Some measures from the state are needed to control this process, to penalise for violating the rules, and then people would at least take some precautions, wear masks, and avoid crowds.

I am increasingly convinced that our government, unfortunately, leaves everything to chance... Everything must absolutely be under control, including this covid.

Our local government doesn't take many measures. Although on television they say that Ukraine is fully ready to counter the coronavirus. Well, in reality, it doesn't always turn out as they say on TV.

I simply have a question: where was the local government, where was the Ukrainian government, which did not establish clear requirements that an unvaccinated person would not be admitted to the workplace, they would not be able to enter public places without a covid certificate. In other words, clear guidelines were not put in place since the summer. Now we are reaping the fruits of our irresponsibility once again.

B. Government Disconnect from the Public

This theme points to the perceived disconnect between the government and ordinary citizens. Our participants believed that government officials were not only removed from the realities of ordinary citizens' lives, but also appeared uninterested in understanding or addressing their needs, particularly during a time of crisis:

> And the most unpleasant, the weakest link in this whole story that's happening to us — is the detachment of our government at any level from the people. Just listen to them — everything is fine. Even when the world is falling apart, we (the government) are arranging workshops, we have organised this, agreed on something, and by next week, literally in a day or two, by the end of the week, everything will be resolved?

C. Double Standards of Politicians

Another criticism related to perceived double standards among individual politicians. Participants expressed a sense of injustice in the enforcement of pandemic restrictions, suggesting that the rules applied differently for politicians compared to ordinary people:

> And once again, the government somehow sets itself apart as a distinct caste. You are not allowed to go to work unvaccinated, you are deprived of this and that, while we do the parliamentary work. More than half of the parliament sits without masks. Some of them have had the disease, some have confirmed antibodies, and some have definitely bought all these certificates. It all starts with them. For us — it's punishment, for them — justification. It's just surreal. That's why everything is so repulsive. It's repugnant, disgusting, and you understand that there's nothing you can do at your level.

D. Distrust in Government's Ability to Support Persons with Disabilities

The final theme that emerged from the criticisms involved a lack of trust in the government's capacity to support persons with disabilities within the context of the pandemic. Participants expressed scepticism towards the government's ability to provide essential support during the pandemic, further intensifying the spectrum of vulnerabilities that people with disabilities face:

> I don't have much hope for our local government, as they are not very active and it's very difficult to ask them for help.
>
> Because everyone here somehow fends for themselves, as best as they can.
>
> The government does not really care about persons with disabilities, or IDPs, or anyone who cannot materially improve individual politicians' lives. They care about themselves first. They enact policies and laws which do not really work - to show they care but in reality...

Our participants held a low level of trust in and had minimal expectations of the authorities, a sentiment deeply rooted in their lived experiences as persons with disabilities in Ukraine. At the same time, the majority were actively involved in various forms of activism and advocacy efforts. Their responses and accounts of everyday activism largely echo the specific demographics of the final phase of our project, where the overwhelming majority of our self-nominated respondents were disability activists prepared to contribute to the research. For many of them, dedicating time to this project and sharing their everyday experiences was nothing but a form of activism.

Most of our participants in this phase were members of organisations of persons with disabilities. Their activist work kept them occupied throughout the data collection period, including networking, organising and participating in various training opportunities, discussion groups, and meetings with local authority representatives (primarily concerning accessibility issues). Some of our participants were also members of local accessibility committees, offering advice to relevant authorities on accessibility considerations in planning and construction projects. For the majority, engaging in such activism was an opportunity to challenge the relative invisibility of persons with disabilities to local authorities, or to challenge the label of vulnerability and neediness during the rare and fleeting moments when authorities did pay heed to the specific needs of persons with disabilities.

The final quote calls for understanding the everyday experiences of persons with disabilities in emergencies, including daily struggles and moments of both joy and sorrow. In reflecting on the value of this research, our participants called for a holistic and empathetic approach (in both research and in policy-making) that values and takes into account the lived experiences of persons with disabilities:

And so this project comes to an end. For me, it was a new experience. On one hand, it was interesting to relive certain family moments, to mentally revisit some places while writing a weekly report about tasks and events... On the other hand, I had to find time to sit down, gather my thoughts, recall everything that happened during the week, and prepare to recount the events, tasks, and emotions. I wanted the person who would read my report to always be intrigued, to be able to immerse themselves in our family through my words, to feel our joyful family moments, and to understand how a person with a disability and their family are experiencing the pandemic and how it affects us. I hoped that even in printed words, notes of happiness or, conversely, sadness and pain would be felt...

POLICY CONSIDERATIONS FOR ENHANCING SOCIO-ECONOMIC AND HEALTH OUTCOMES FOR PERSONS WITH DISABILITIES DURING PUBLIC HEALTH EMERGENCIES

The ongoing war with Russia has severely impacted Ukraine, causing extensive damage to and destruction of civilian infrastructure and, above all, immense human damage. As a result of this aggression, hundreds of thousands of Ukrainians have been killed or injured, millions have sought refuge abroad, and disability rates have surged significantly. Russia's war has had a devastating impact on the Ukrainian economy and its environment. Despite these immense challenges, it remains imperative that the interests of persons with disabilities are central to all current and future recovery and rebuilding policies and actions, and to any future public health emergency response.

As with the previous project report which covered Phase 2 of the research (see Sharapov et al., 2022b), we issue a set of policy considerations, rather than recommendations, to inform and guide disability inclusive planning and action during this challenging period. These considerations aim to inform governmental responses at all levels, prioritising the safeguarding of welfare and the rights of persons with disabilities. An important element of this approach is meaningful inclusion of persons with disabilities and of their organisations in every stage of policy development and implementation. By foregrounding disability considerations, an equitable and inclusive strategy must be established for rebuilding a society deeply impacted by war and aggression to ensure that no one is marginalised in the pursuit of national recovery.

A. Availability, Accessibility and Quality of Healthcare during Public Health Emergencies

1. What strategies can be implemented to ***reduce the out-of-pocket health-related expenses*** for persons with disabilities, particularly the diagnostics and treatment of acute conditions, and for ongoing healthcare?
2. How can systemic issues within the healthcare system be addressed, including ***improvements to healthcare facilities, quality of care, and availability of resources*** to ensure better preparedness for any future public health emergencies?
3. What standards or guidelines can be introduced or enforced to ensure ***high-quality patient care and to improve professionalism*** and compassion among healthcare staff?

4. What measures can be introduced to ***enhance physical accessibility of healthcare services and facilities*** for persons with disabilities?
5. How can the process for ***re-validating disability status*** (‘group’) and ***accessing rehabilitation aids*** be made more efficient and user-friendly?

B. Responding to Specific Aspects of Public Health Emergences

1. Considering the emotional and physical wellbeing challenges faced by persons with disabilities during a public health emergency, what ***mental health and physical health support strategies*** can be integrated into public health emergency preparedness planning?
2. How to ***ensure the continuity of rehabilitation services*** during a public health emergency?
3. What measures can be implemented to ensure persons with disabilities have ***prioritised and unhindered access to non-emergency healthcare services during a public health crisis***?
4. What ***financial protection measures*** can be incorporated to safeguard persons with disabilities from the economic impacts of a public health emergency?
5. How can public health policy response ensure ***adequate enforcement of health safety measures in public spaces***, especially in the places frequently visited by persons with disabilities?

6. Given the impacts of isolation measures on mental health, how to ***mitigate the mental health effects of prolonged lockdowns and social isolation***?
7. How can policy responses incorporate clear communication strategies to ***address uncertainty and misinformation surrounding vaccination*** in public health emergencies?
8. How to ensure that ***vaccinations are delivered in a dignified, respectful, and accessible environment*** for persons with disabilities?

C. Responding to Everyday Challenges and Barriers

1. How to ***strengthen existing social protection schemes*** to ensure the basic needs of persons with disabilities are met, considering the rising costs and limited financial resources?
2. What actions could be taken to ***enhance the financial resilience of persons with disabilities*** during public health emergencies, acknowledging their economic hardships and vulnerabilities?
3. What specific strategies could be employed to ***enhance the accessibility and reliability of public transportation*** for persons with disabilities, recognising mobility's crucial role in their daily life?
4. What measures should be undertaken to ***improve the accessibility of healthcare facilities***, acknowledging the varied challenges faced by persons with disabilities in accessing these services?

5. How to ***improve the availability and reliability of information*** to persons with disabilities given the importance of timely and accurate information during a crisis?

D. Meaningful Inclusion of Disability Considerations in Policy Development and Implementation

1. How can ***government mechanisms be made more responsive and efficient*** in terms of ***implementing policies that ensure the safety and wellbeing of persons with disabilities***, particularly in crisis situations?
2. How can the government ***maintain the existing and develop new dialogues with persons with disabilities and their representative organisations*** to better understand and address their specific needs, especially during a crisis?
3. How can the government ***embed the lived experiences of persons with disabilities into the policy-making process***, ensuring that these policies reflect and address their real-world struggles, joys, and sorrows?

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