

# **The Impact**

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

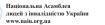
> **Perspectives of Organisations** of Peoplewith Disabilities

> > **PROJECT REPORT** (PART 1)











Edinburgh Napier

UNIVERSITY



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

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Project Report (Part 1)







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Project Report (Part 1)

February 2022

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## **List of Abbreviations**

| AHRC     | _ | Arts and Humanities Research Council (United Kingdom)                |
|----------|---|--|
| COVID-19 | _ | Coronavirus disease-19, caused by the novel coronavirus (SARS-CoV-2) |
| CRPD     | _ | Committee on the Rights of People with Disabilities (United Nations) |
| DESA     | _ | Department of Economic and Social Affairs (United Nations)           |
| ECOSOC   | _ | United Nations Economic and Social Council                           |
| EIGE     | _ | European Institute for Gender Equality                               |
| GCRF     | _ | Global Challenges Research Fund (United Kingdom)                     |
| HRMMU    | _ | The UN Human Rights Monitoring Mission in Ukraine                    |
| IDMC     | _ | Internal Displacement Monitoring Centre                              |
| IDPs     | _ | Internally displaced persons   |
| IOM      | _ | International Organisation for Migration (United Nations)            |

THE IMPACT OF THE COVID-19 PANDEMIC ON PEOPLE WITH DISABILITIES IN UKRAINE Perspectives of Organisations of People with Disabilities

| NAPDU | _ | National Assembly of People with Disabilities of Ukraine             |
|-------|---|--|
| NMS   | _ | National Monitoring System   |
| OCHA  | _ | Office for the Coordination of Humanitarian Affairs (United Nations) |
| OECD  | _ | Organisation for Economic Co-operation and Development               |
| OHCHR | _ | Office of the High Commissioner for Human Rights (United Nations)    |
| ONS   | _ | Office for National Statistics (UK)                                  |
| OPDs  | _ | Organisations of persons with disabilities <sup>1</sup>              |
| OSCE  | _ | Organization for Security and Co-operation in Europe                 |
| PPE   | _ | Personal Protective Equipment  |
| SSSU  | _ | State Statistical Service of Ukraine                                 |
| UNDP  | _ | United Nations Development Programme                                 |
| UNHCR | _ | United Nations High Commissioner for Refugees                        |
| WHO   | _ | World Health Organisation  |

<sup>&</sup>lt;sup>1</sup>As set out by the General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention (see CRPD 2018).

## **Executive Summary**

#### Background

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

The situation has become increasingly difficult in the conflict-affected east of Ukraine and for people who have been internally displaced by the conflict. This is particularly true for people with disabilities, where displacement exacerbates existing challenges. As of July 2021, there were 1,473,650 internally displaced persons (IDPs) registered in Ukraine including 51,586 persons with disabilities. The COVID-19 pandemic has affected access to health and social services, worsened existing issues with a lack of adequate housing for conflict

<sup>&</sup>lt;sup>2</sup>Hereinafter, references to 'public authorities' and/or 'public authorities at all levels of governance' [органи державної влади на всіх рівнях управління] refer to the complex system of governance in Ukraine, which is currently undergoing the process of decentralisation. The current system is set out [in Ukrainian] here: http://www.slg-coe.org.ua/wp-content/uploads/2021/03/Public\_Authority.pdf Within the context of this report, 'public authorities at all levels of governance' should mean both legislative and executive branches of power at central (national) level, regional level ('oblast'), district level ('rayon'), and united local communities ('hromada') level. References to the 'Government of Ukraine' should mean the Cabinet of Ministers of Ukraine- the highest body of state executive power in Ukraine.

affected populations (especially IDPs), and deepened poverty. Lockdowns also resulted in the closure of entry-exit points between government and separatist controlled areas of the country, severely curtailing the mobility of local populations.

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

#### **Purpose**

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

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

#### Methodology

The research presented here is based upon an organisational survey of OPDs working with people with disabilities in Ukraine. The survey was co-designed with the National Assembly of People with Disabilities of Ukraine, an umbrella organisation for 126 organisations operating at local, regional and national levels across Ukraine. These organisations care for a diverse range of people with disabilities including those who have long-term physical, mental, intellectual or sensory impairments.

150 organisations were invited to participate in the survey, which was hosted online via the Qualtrics<sup>3</sup> platform. 108 responses were received, comprised of both closed and open-ended questions. The closed questions were used to produce a set of quantitative data, while the open-ended questions allowed respondents to describe the impact of the pandemic upon their organisation's work and the people that they care for in their own words.

A descriptive analysis of the quantitative data was performed using SPSS<sup>4</sup> while the qualitative data were coded and analysed using an inductive thematic analysis through NVIVO<sup>5</sup>.

The survey responses received detailed the impact of the pandemic upon people with disabilities in Ukraine (Part I) and the organisations which care for them (Part II). These two parts are summarised separately below.

<sup>&</sup>lt;sup>3</sup>Qualtrics is one of the internationally leading survey software tools. For further details please check: https://www.qualtrics.com/ uk/core-xm/survey-software/

<sup>4</sup>SPSS is a software platform which offers advanced statistical analysis. For further details see https://www.ibm.com/analytics/ spss-statistics-software

<sup>5</sup>NVIVO is a qualitative data analysis computer software package produced by QSR International. For further details, see: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

## **Summary of Part I**

# Impact of the pandemic on people with disabilities in Ukraine

#### Impact on health and access to healthcare services

A key theme which emerged as an outcome of the organisational survey analysis was the inaccessibility of healthcare. Respondents described a general deterioration in the health of people with disabilities due to long-term effects of COVID-19, chronic conditions becoming aggravated through interrupted access to healthcare and a significant impact on psychological wellbeing. Access to healthcare was affected by the re-purposing of healthcare facilities into COVID-19 wards or difficulties in reaching services during extended lockdowns, particularly for rural populations. The need to make informal payments including 'charitable donations' imposed by healthcare providers or, in some cases, bribes to individual healthcare workers, was reported to be common-place for treatments or medication which should have been free of charge. Concerns were also raised over the increasing costs of medication and interruptions to the supply of prescriptions. Respondents also described difficulties obtaining PPE and paying for COVID-19 tests, or poor availability of free testing.

#### Psychological wellbeing, mental health and social isolation:

Increased social isolation of people with disabilities in Ukraine – linked to limited or fully withdrawn access to the pre-pandemic social and professional support systems – has been another key theme highlighted by our respondents. This included withdrawal or restriction of face-to-face contact with family, friends and carers combined with reduced access to leisure facilities such as parks and recreation areas, which had a particularly negative impact on children with disabilities. Communication became more difficult through problems accessing digital technologies for online contact, or through the lack of provisions for people with hearing difficulties. Respondents also reported increased levels of stigmatization of people with disabilities.

#### **Restricted mobility:**

In response to the increasing number of COVID-19 cases, in March 2020 the Government of Ukraine introduced a series of restrictions nationwide including the closure of educational facilities; limitations on passenger transportation and mass gatherings; and suspension of catering, cultural, shopping and entertainment establishments. These restrictions (most of which had been lifted at the time of conducting the survey in May – June 2021) had significant impacts on persons with disabilities who have restricted mobility or relied on public transport or assistance from extended care networks. The impact was more severe on rural inhabitants, as longer distances between shops, hospitals and places of employment made these completely inaccessible without access to private transport (e.g., owning a car). This was even more pronounced for those who needed to cross the contact line in the east of the country, where the closure of entry/exit points made it impossible to travel. Even following the resumption of some public transport, reduced timetables and new public health guidelines made it more difficult for people with disabilities to use the service.

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

The pandemic deepened the poverty experienced by many people with disabilities in Ukraine. Although a small relief payment of 1,000 UAH<sup>6</sup> was made available by the government (Cabinet of Ministers of Ukraine 2020a), this was insufficient to meet the needs of most people with disabilities, and financial destitution meant that some individuals and households could not afford to buy basic supplies or pay for utilities and services.

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

<sup>&</sup>lt;sup>6</sup>1,000 Ukrainian Hryvnas or £29.89 or €34.18 using the exchange rate as recorded on xe.com as of 23 April 2020.

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

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

- a) Children with disabilities or households where one or both parents were disabled experienced disproportionate poverty and a lack of services and support tailored to children. Children were susceptible to the impact of social isolation on mental wellbeing and development suffered if there were issues accessing online education and support networks.
- b) Older persons with disabilities had trouble with accessing 'technical means of rehabilitation'<sup>7</sup>, obtaining PPE, hygiene items and disinfectants (to minimise exposure to COVID-19), combined with heightened difficulties accessing shops, hospitals, social services, and places of employment. They were more susceptible to poverty through job losses and were disadvantaged for finding work again. They were also reportedly more likely to suffer digital poverty which resulted in poor access to online support networks and, subsequently, greater social isolation.
- c) People living in rural areas experienced greater difficulties accessing services and online resources.
- d) People who are blind or partially sighted faced additional barriers relating to the transfer of education and some social services online, where the problem of inaccessible websites was partic-

<sup>&</sup>lt;sup>7</sup>A state-funded system of supply/access to rehabilitation and assistive technologies in Ukraine.

ularly acute. They also suffered from a lack of accessible information relating to the pandemic, a lack of caregivers and a lack of suitable adaptations within employment centres.

- e) People who are deaf or have a hearing impairment experienced significantly reduced or withdrawn access to sign language interpreters. There was also a lack of sign language interpretation on television broadcasts, which was critical during public health announcements regarding the pandemic. Face-coverings created a further communications barrier for those who rely on lip-reading.
- f) Internally displaced people with disabilities continued to experience issues with housing, particularly access to housing adjusted to the specific needs of persons with disabilities. Poverty was common, linked to challenges in finding employment and accessing IDP and disability specific social security payments and they continued to have problems accessing healthcare, education, and other services. This was often compounded by difficulties in registering as an IDP or person with disabilities in the absence of direct contact with relevant government officials. They also experienced a lack of access to social support networks, and those with family or assets located over the contact line were particularly affected by the closure of the entry/exit points during lockdowns.

## **Summary of Part II**

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

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

#### Changes to mode of working and service delivery:

Of the organisations who had a dedicated office space, 40% had switched to hybrid working (online and offline) with 27% moving to fully remote working. Only 23% continued to operate as they had prior to the pandemic. 10% had suspended most of their activities. Almost 90% of respondents indicated that they had struggled to provide their members with some or any of the required IT equipment and internet access for online working. Organisations also noted that the move to online working resulted in reductions in the vol-

ume and quality of services they were able to offer. Some did continue with face-to-face interactions for the most vulnerable individuals, primarily to deliver humanitarian aid packages, assist with essential travel and provide care for family/pets when members of the household were hospitalised. Most organisations continued their advocacy work throughout the pandemic.

#### **Organisational funding:**

For many organisations, increasing costs to re-organise their service delivery and to provide additional support for people with disabilities were accompanied by decreased financing and a lack of support and communication with the state authorities. Overall, the analysis of the open-ended comments reveals a precarious financial situation for many of the organisations, some of which are involved in the direct delivery of essential services to people with disabilities. This precarity was caused by the lack of funding to conduct core organisational activities, delayed or withdrawn funding, lack of knowledge about available funding opportunities, and the lack of resources and skills to comply with complex administrative requirements attached to the administration and reporting requirements.

#### Interaction with public authorities and volunteers:

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

#### Positive organisational developments over the pandemic period:

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

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

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

- a) Failing to ensure accessibility and availability of social services for people with disabilities, particularly a lack of humanitarian support packages (food, essential items, etc.), carer support, education, employment and public transport.
- b) Failing to ensure adequate access to essential healthcare services for people with disabilities. A lack of barrier-free access to hospitals and healthcare facilities was compounded by a failure to guarantee free healthcare, with the need to pay bribes (or mandatory 'charitable' contributions to the hospital) being commonplace.

- c) Failing to ensure access to public health information regarding the pandemic for people with disabilities, particularly those with sensory and intellectual disabilities.
- d) Failing to provide financial support to the most vulnerable and to community-based organisations.
- e) Failing to meaningfully engage and consult with people with disabilities and OPDs.

#### Support required from state authorities, donors, and partners:

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

#### **Summary of recommendations**

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

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

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

Public authorities in Ukraine must ensure that all information is available in accessible digital formats and, when required, through the provision of sign language interpreters, Easy Read text and plain language, Braille and tactile communication.

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

- 10. The Government of Ukraine should require all public authorities to develop (in cooperation with OPDs) context-specific mechanisms to involve OPDs in the decision-making, implementation, and evaluation process, and to give due consideration and priority to the opinions and views of OPDs when addressing issues directly related to persons with disabilities.
- 11. The Government of Ukraine should consider adopting a range of specific measures to encourage civic participation, engagement, and awareness among local communities to facilitate support and partnership between OPDs and volunteers, donors, and other stakeholders.

## Introduction

As of January 2021, 2,724,100 persons in Ukraine (or 6.5% of the population) were registered as having a disability (State Statistical Service of Ukraine (SSSU), 2021a, p. 1; SSSU, 2021b, p. 59). According to OPDs in Ukraine and as reported by the United Nations (UN) in Ukraine (Office of the High Commissioner for Human Rights (OHCHR), 2020b), the actual number of people with disabilities is estimated to be much higher and has continued to increase. The inadequate government systems for collating statistics related to disability were criticised by the Council of Europe (Smusz-Kulesza, 2020) for providing only an aggregate number of people with disabilities and overlooking well-known barriers to official registration as a person with disability, including:

- (a) Unavailability and inaccessibility of state-sponsored 'socio-medical commissions' (the only mechanism through which an individual can be recognised as a person with disability in Ukraine).
- (b) Lack of identity documents.
- (c) Homelessness.
- (d) The link between official registration as a disabled person and losing other social security benefits, which discourages significant numbers of people with disabilities from registering as such.

As a result, there is an absence of reliable data on the number of people with disabilities in Ukraine, which should be disaggregated, at a minimum, by types of disability, sex, age and dis/location. Combined with the systematic undercounting of people with disabilities, any government programme in relation to the economic and social wellbeing of people with disabilities – at both national and regional levels – can be deemed as inadequate in its scope, reach and funding, reflecting a state-level failure to respond to the actual situation 'on the ground'. This failure has been further magnified by the COVID-19 pandemic with devastating consequences for Ukraine's most vulnerable people (United Nations Development Programme (UNDP), 2020). According to the United Nation's (OHCHR, 2020b, p. 1) initial assessment of the impact of the pandemic on persons with disabilities in Ukraine, released in October 2020:

The COVID-19 crisis has exacerbated existing institutional, attitudinal and environmental barriers that persons with disabilities face in exercising their rights and accessing basic services. HRMMU's monitoring of the human rights situation of persons with disabilities indicates that during the pandemic their access to healthcare, habilitation and rehabilitation services, education, social protection, work and employment has been further impeded. The COVID-19 crisis has also exposed a large gap between social services that are available in the community and the real needs of persons with disabilities. The lockdown also further aggravated the isolation and exclusion of persons with disabilities in Ukraine.

As of 1<sup>st</sup> January 2022, the total number of people diagnosed with COVID-19 stood at 3,672,675, including 3,474,931 people who recovered from the disease and 96,089 deaths (Government of Ukraine, 2022). The Government of Ukraine does not collect data on COVID-19 infections disaggregated by disability (OHCHR, 2020b, p. 6). The distribution of confirmed cases by gender and age is provided by the Centre for Public Health (part of the Ministry of Health of Ukraine). As of 1<sup>st</sup> September 2021, among the 2,228,371 confirmed cases 60% were women and 40% were men. About 37% of all confirmed cases were among the 30-49 age

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group, 39% among the 50-69 age group, and 9% among the 70+ age group (Centre for Public Health, 2021). At the early stages of the pandemic concerns were also raised about the underreporting of its scale due to the unpreparedness of the Government to respond to a complex public health emergency including insufficient testing capacity (Kossov, 2020a, 2020b). According to the 2021 assessment by Nesteruk (preprint, 2021), the actual number of COVID-19 cases in Ukraine at the end of 2020 could have been underreported by a factor of up to 4.1.

As the COVID-19 crisis continues to exacerbate existing inequalities and vulnerabilities in Ukraine (OHCHR, 2021), the hardships and deprivations faced by the conflict-affected population in eastern Ukraine and by people internally displaced by the conflict have also intensified (OHCHR, 2020a). At a meeting of the UN Security Council in February 2020 (before the pandemic hit Europe and Ukraine), the crisis in and around Ukraine was described as "the most pressing security challenge in Europe", with the Organization for Security and Co-operation in Europe (OSCE) Chair comparing Eastern Ukraine "to a post-apocalyptic landscape with thousands of people — many elderly and sick — in search of medical help" (UN, 2020b, para. 9). As of July 2021, 1,473,650 persons were registered as internally displaced by the Ministry of Social Policy of Ukraine, including 51,586 persons with disabilities (Ministry of Social Policy of Ukraine, 2021). Internally displaced persons (IDPs) are part of the overall estimate of 3.4 million people in need of humanitarian assistance, including people living in territories controlled by armed groups and along the 'contact line' in government-controlled areas.

The June 2021 situation report released by the United Nations Office for the Coordination of Humanitarian Affairs (OCHA) (2021b, p. 3) notes that "[m]illions of people in the region already drained by the on-going conflict have been forced to deal with a health emergency on top of insecurity, reduced livelihood opportunities and insufficient access to health care and other basic services".

In order to gather data and publish information on IDPs in Ukraine the UN International Organisation for Migration (IOM) relies on a series of reports produced within the context of the National Monitoring System (NMS) (IOM, 2020, p. 8). This longitudinal data collection series reaches more than 15,000 conflict-affected persons across Ukraine, including internally displaced persons, to collect information on different aspects of their lives and provides a narrow glimpse into a set of challenges faced by IDPs, including persons with disabilities in Ukraine. A recent NMS report issued in June 2020 highlights the heightened vulnerability of IDPs to the impacts of COVID-19, including problems with housing, receiving social payments, and reducing food expenses as a coping strategy. Among the internally displaced households with people with disabilities that are included in the project's sampling frame, 14% had to limit food expenses to make ends meet and 46% had enough money only for food (IOM, 2020, p. 17). The coping strategies used to mitigate this include spending savings (46%), borrowing money (25%), and reducing health expenditure (35%) (IOM, 2020, p. 19). Even though internally displaced people with disabilities have been identified as particularly at risk from COVID-19 (OHCHR, 2020b, p. 2), little gualitative or guantitative research exists to provide a comprehensive account of challenges faced by people with disabilities in Ukraine who live in a situation of protracted displacement, nor the impact of COVID-19 and the inadequate pandemic response by public authorities on their health and socio-economic wellbeing.

The research presented in this report is based on a survey of non-governmental organisations of people with disabilities in Ukraine (organisations of persons with disabilities, or OPDs). The organisational survey forms Phase 1 of a larger project to evaluate the impact of COVID-19 on people with disabilities in Ukraine, with a particular focus on internally displaced people with disabilities. Funded by the UK's Global Challenges Research Fund (GCRF) and Arts and Humanities Research Council (AHRC), the project is the first ever participatory community-based research project in Ukraine focussing on disability. It was co-designed and is being

co-delivered in close partnership with people with disabilities in Ukraine, including internally displaced people with disabilities. The disability rights movement's slogan 'Nothing About Us Without Us' has been the guiding principle which informed the project's research questions and our methodological approach from the outset. Phase 1 of the project focusses on the views and perspectives held by the OPDs from across Ukraine. Phase 2 of the project involves interviews with people with disabilities (including IDPs) from ten regions in Ukraine with the highest number of IDPs. Phase 3 relies on a system of written diaries and/or audio/video-testimonies self-recorded by internally displaced people with disabilities over a period of eight weeks. Phase 4 involves qualitative interviews with policymakers at both national and regional levels of governance in Ukraine to explore their perspectives on key messages emerging from this research and to record their views on how the development and implementation of policies across all domains of socio-economic life could meaningfully integrate and respond to the diverse perspectives, views and needs of people with disabilities.

The remainder of this document covers data and methods relied upon to deliver Phase 1 of this research. This is followed by an overview of the results, which cover OPDs' views on the impact of the pandemic on people with disabilities in Ukraine (Part I), and their own organisational activities (Part II). The report is concluded by a list of recommendations on improving current policies to mitigate the impact of the pandemic on people with disabilities in Ukraine, and on ensuring better preparedness in the event of any future public health or other emergency. н

## Methodology

The assessment of the impact of COVID-19 on people with disabilities in Ukraine is based on the analysis of responses to a series of open-ended questions which were included as part of the organisational survey of OPDs in Ukraine. The survey was co-designed with the National Assembly of People with Disabilities of Ukraine (NAPDU) – an umbrella organisation which brings together 126 OPDs operating at central, regional and local levels across Ukraine and working with people with long-term physical, mental, intellectual or sensory impairments.

This is the first ever survey of the OPDs in Ukraine, which was designed and administered in collaboration with disability activists in Ukraine and which involved more than 100 organisations as participants.

The survey ran between 27<sup>th</sup> May and 1<sup>st</sup> July 2021 and was hosted on the Qualtrics platform<sup>8</sup>. 150 organisations were contacted with an individual link to the questionnaire; 108 completed responses were received. The survey included both closed and open-ended questions. Open-ended questions invited respondents to describe, in their own words, the impact of the pandemic on persons with disabilities they were taking care of. Respondents were not specifically asked or provided with any prompts to assess the impact of the pandemic on different aspects of individual lives of people with disabilities, for example, access to health care, social services, transport, education and information. The discussion below is therefore based on what these organ-

<sup>&</sup>lt;sup>8</sup>Qualtrics is one of the internationally leading survey software tools. For further details, see: https://www.qualtrics.com/uk/corexm/survey-software/

isations perceived as key negative impacts of the pandemic on people with disabilities in their care. Whilst these responses cannot be translated into a series of quantitative indicators, a qualitative thematic analysis allowed the identification of the key themes which are described below. Overall, out of 108 responses only four organisations indicated that the pandemic had little or no impact on people with disabilities in Ukraine – a finding which can be summarised by quoting one of the respondents: "COVID-19 did not change much. We were already at rock bottom".

A descriptive analysis of the quantitative data was performed using SPSS<sup>9</sup>. The qualitative data were coded and analysed in NVIVO<sup>10</sup> using inductive thematic analysis (Braun & Clarke, 2006) to identify key themes. The outcomes of these two strands of analysis were combined and presented as a discussion paper for the Participatory Analysis Workshops (two workshops conducted via Teams); each of these workshops included 6 disability experts and activists who were asked to comment on the interim findings and formulate, where relevant, a set of recommendations. Their feedback was integrated as part of the findings presented below.

The findings presented in this report should not be used to make generalised statements and should be considered alongside analyses of other survey data and qualitative research to inform and inspire innovative and strategic policymaking in this area.

<sup>&</sup>lt;sup>9</sup>SPSS is a software platform which offers advanced statistical analysis. For further details, see: https://www.ibm.com/analytics/ spss-statistics-software

<sup>&</sup>lt;sup>10</sup>NVIVO is a qualitative data analysis computer software package produced by QSR International. For further details, see: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

## Part I

## People with disabilities and COVID-19: multiple and intersecting jeopardies

#### **Setting out the context**

As a fuller picture of the socio-economic impact of the COVID-19 pandemic across the world began to emerge, its disproportionate impact on the most vulnerable individuals and communities became clear (UN, 2020c). Due to their high degree of socio-economic marginalisation, women, older persons, children, persons with disabilities and internally displaced persons have been identified as some of the 'at-risk populations' by the UN, requiring specific attention in the immediate development of responses to the pandemic (UN, 2020c, p. 7). The intersectional impact of the pandemic has also highlighted the deeply embedded nature of structural inequalities across societies and communities. For many of our co-researchers from the community-based organisations and for all of our respondents, disability remains a significant (if not the most significant) part of their identity. However, disability is not the only aspect of their identity which influences the impact of the pandemic on their health, psychological wellbeing and socioeconomic situation. Gender, sexuality, ethnicity, socio-economic situation and stage of life create diversity but, at the same time, multiple layers of discrimination and social exclusion (Traustadóttir, 2006, p. 2).

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A year and a half since the World Health Organisation (WHO) declared the novel coronavirus (COVID-19) outbreak a global pandemic (WHO, 2020c), its disproportionate impact on people with disabilities has been acknowledged across the world. As documented by Kubenz and Kiwan (2021, p. 9) people with disabilities can have a range of health conditions which make them more susceptible to serious infection and death. In England, according to the UK's Office for National Statistics (ONS, 2021), people with disabilities made up six in ten of all COVID-19 related deaths between March and November 2020; in comparison, only 17.2% of the study population were people with disabilities, suggesting the disproportionate impact of the pandemic on this group. However, not all people with disabilities have health conditions that make them especially susceptible to COVID-19, meaning that caution is needed when interpreting these figures to avoid furthering stereotypes and misrepresenting all people with disabilities as vulnerable or weak (Kubenz & Kiwan, 2021, p. 9).

For example, people with disabilities may be more at risk of contracting COVID-19 not because of poor health, but because they face additional barriers to implementing additional hygiene precautions. This can be due to general inaccessibility in the environment, difficulty in enacting social distancing, the need to use touch to obtain information or physical support, and difficulties accessing public health information (WHO, 2020, p. 2).

We know that people with disabilities are disproportionately represented among older people. According to the UN, more than 46% of people aged 60 and over have disabilities, and more than 250 million older people across the world have moderate to severe disabling conditions (Department of Economic and Social Affairs (DESA), n.d.). The disproportionate impact of the pandemic on older people has become clear with the COVID-19 related fatality rates for people over 80 years of age recorded as five times the global average (UN, 2020a).

We also know that people with disabilities are disproportionately represented among those living in poverty. In Europe, more than 28% of all persons with disabilities lived in poverty and experienced social exclusion in 2018 – even before COVID-19 hit the continent (Uldry & Leenknecht, 2021). Emerging research from across the world demonstrates that the effects of COVID-19 are likely to have worse consequences for people from lower socio-economic backgrounds (Whitehead, Taylor-Robinson & Barr, 2021; World Bank, 2020).

In addition, disability remains a deeply gendered phenomenon and disability and gender have been argued to "operate together to create the experiences of disabled people" (Traustadóttir, 2006, p. 2). In its review of the gendered nature of the pandemic's impact, the European Institute for Gender Equality (EIGE, 2021) suggests that COVID-19 derailed gender equality gains across Europe. This impact is felt not only in health outcomes but also across education, employment, mobility and an increased risk of abuse and violence (Kubenz & Kiwan, 2021, pp. 25-26, 34, 39, 47).

Finally, forced displacement (including conflict-related internal displacement) amplifies existing discrimination and barriers in access to services for internally displaced people with disabilities, however, as noted by the Internal Displacement Monitoring Centre (IDMC), "data and research on the number, location, and experiences of IDPs with disabilities...is still lacking" (Yasukawa, 2021, p. 1).

Due to the poor quality or absence of official statistics in Ukraine on both disability and displacement (Smusz-Kulesza, 2020), evaluating the impact of COVID-19 on the lives of people with disabilities becomes a challenging task – particularly in its intersection with the pre-existing 'structures of dominance'<sup>11</sup> patterned by age, social class, gender, ethnicity and (dis)location. The following section sets out the outcomes of the

<sup>&</sup>lt;sup>11</sup>See the discussion of how Patricia Hill Collins's (1990) 'structure of dominance' approach can be applied to make "visible the multiple levels of dominations that stem from the societal configuration of race, class and gender relations" in the lives of people with disability in Traustadóttir (2006, p. 82).

survey analysis which explores the views of the OPDs in Ukraine, documenting the impact of the pandemic on the people with disabilities they were 'taking care of'<sup>12</sup> when the pandemic hit and as the inadequate and uncoordinated government response followed. It is organised by themes which emerged in the process of analysing these responses and offers a glimpse into what the United Nations described as the 'devastating consequences' of the pandemic for Ukraine's most vulnerable people (UNDP, 2020).

#### Impact on health and access to healthcare services

#### <u>Context</u>

Multiple studies have shown that people with pre-existing or underlying conditions have markedly increased risks of hospital admission and death from COVID-19 (Center for Disease Control and Prevention, 2021; Laosa et al., 2020; Poblador-Plou et al., 2020; Williamson et al., 2021). Within this context, unimpeded access to healthcare services (including access to medications) for the routine management of chronic conditions, and careful management of COVID-19 transmission risk at healthcare facilities can be described as key dimensions in reducing the risk of mortality from COVID-19 for people with disabilities. According to an assessment of the impact of COVID-19 on human rights in Ukraine conducted by the United Nations Human Rights Monitoring Mission in Ukraine (HRMMU) between March and December 2020, "during the pandemic, persons with disabilities found their access to healthcare, habilitation and rehabilitation services...further impeded" (OHCHR, 2020a, p. 21); this was coupled with severe shortages or lack of access to personal protective equipment

<sup>&</sup>lt;sup>12</sup>This explicit reference to 'OPDs taking care of people with disabilities' was suggested by the project's research participants to emphasise the relation of care and support rather than dependency in their interaction with what could have been described as a 'client group' or 'recipients of support and/or services'.

(PPE) (OHCHR, 2020a). The introduction of quarantine restrictions in March 2020 exacerbated pre-existing barriers for people with disabilities to access health care services and created new ones including indefinite suspensions of planned treatments and face-to-face consultations, re-purposing of specialized hospitals into COVID-19 health facilities, and the suspension of public transport (OHCHR, 2020a). Restrictions on mobility had a profound impact on people with disabilities residing in rural areas and compounded the existing difficulties of crossing the 'contact line' for civilian victims of the conflict in the east of the country. As reported by OHCHR (2020a, p. 5), all five entry-exit points from government-controlled areas into those controlled by separatists were closed between March and June 2020, reducing the average number of crossings from 1.1 million (over the same period in 2019) to 300,000. Access to healthcare was one of the main reasons cited by civilians for crossing the line in both directions (OHCHR, 2020a, p. 10).

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 judgement in relation to Case No. 1-13/2002<sup>13</sup>. Since gaining independence in 1991, the Ukrainian health system continued to function in a "virtually unchanged form throughout the entire period after the collapse of the Soviet Union" (Romaniuk & Semigina, 2018, p. 2) including, as one of the key tenets, free universal care for all. At the same time, as admitted by the Ukrainian Ministry of Health, "budget deficits, economic crises, and a lack of reform resulted in a 'parallel world' where one had to solve healthcare problems through out-of-pocket informal payments and bribes" (Ministry of Health of Ukraine, n.d., para. 1).To address this the *Nation-al Health Reform Strategy for Ukraine 2015-2020* was developed to foster "regulatory transformation and

<sup>&</sup>lt;sup>13</sup>For Constitution of Ukraine and Case No. 1-13/2002 in English see: https://www.globalhealthrights.org/wp-content/up-loads/2013/11/1-132002.pdf and https://rm.coe.int/constitution-of-ukraine/168071f58b. For Ukrainian versions see: https://konstitutisiya.com.ua/ru/st-49 and https://zakon.rada.gov.ua/laws/show/v010p710-02#Text.

implementation of new financial mechanisms promoting human rights in health care" (Ministry of Health of Ukraine, 2015, p. 5); it was followed by the new health financing *Law on 'Government Financial Guarantees of Health Care Services' (Law 2168)* and a raft of related by-laws (see WHO & World Bank, 2019). The most recent WHO assessment of the reform, which acknowledges the impact of the pandemic, suggests that the pandemic and the attendant economic crisis presented national and local authorities with "unparalleled public health challenges, with reforms ongoing and incomplete", placing "great strain on health facilities and local budgets" (WHO, 2021a, pp. 1, 34).

In 2018, Ukraine's health expenditure per capita stood at 228 in current USD, placing it at 116<sup>th</sup> position (among 189) below Iraq and Tonga, and above Samoa and Bolivia (WHO, 2021b). At 8% of GDP this compares favourably with neighbouring countries such as Romania and Poland, where healthcare expenditure is around 6% of GDP<sup>14</sup> (WHO, 2021b). However, it is estimated that almost half of this expenditure in Ukraine is private-ly funded meaning that individuals must pay themselves, often through 'out-of-pocket payments' (Lekhan, Rudiy, Shevchenko, Nitzan Kaluski & Richardson, 2015, p. xviii) creating inequity in access to healthcare. This is reflected in an elevated mortality rate of 14.7 per 1,000 people in 2019, higher than all neighbouring countries: Belarus (13), Moldova (12), Poland (11), Romania (13), and Slovakia (10) (World Bank, 2021a). As of July 2021, it was estimated that the COVID-19 pandemic had resulted in close to 80,000 excess deaths, in comparison to the average mortality data available (Organisation for Economic Co-operation and Development (OECD), 2021, p. 1).

<sup>&</sup>lt;sup>14</sup>With higher GDP this smaller percentage nevertheless translates into greater individual spend, with Poland at 979 USD and Romania 687 USD per capita (WHO, 2021b).

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#### <u>Analysis</u>

A key theme which emerged as an outcome of the organisational survey analysis can be summarised by one of the responses: "Inaccessible healthcare became even more inaccessible". The multi-dimensional impact of COVID-19 on health of people with disabilities, as reported by disability activists, included:

- (a) The overall deterioration of health in the absence of access to healthcare, including long terms effects of COVID-19 (long covid<sup>15</sup>); flare-ups of chronic conditions, including conditions which underly individual impairments becoming worsened by interruptions to routine and emergency healthcare; and a significant impact on psychological wellbeing (reviewed in more detail below).
- (b) In cases where people with disabilities did manage to get access to healthcare facilities for the treatment of COVID-19 or for treatments related to underlying conditions, the treatment itself was not guaranteed and, sometimes, denied due to the closure and re-profiling of routine healthcare facilities into COVID-19 wards and because of the patients' inability to pay for services and medications which should have been provided free of charge. Respondents also commented on the inaccessibility of repurposed COVID-19 facilities where accessibility was not considered a priority.
- (c) Lack of access to free or subsidised PPE including masks, face coverings and disinfectants; lack of the financial means to pay for COVID-19 tests; lack of availability and accessibility of free COVID-19 testing.

<sup>&</sup>lt;sup>15</sup>See https://www.nhs.uk/conditions/coronavirus-covid-19/long-term-effects-of-coronavirus-long-covid/

(d) Direct experiences of COVID-19 related death through deaths of people with disabilities and their family members, and/or deaths of organisational staff: "Over the pandemic period, about 40% (or more than 200 people) of our members got sick with COVID-19, and five people died".

One of the reported concerns for people with disabilities who self-assessed as having contracted COVID-19 was the inability to access free (provided by the government) COVID-19 tests, especially during the first 'wave' of the pandemic. Free of charge COVID-19 tests were introduced by regional authorities as the pandemic response unfolded (Kyiv City Council, 2021a) however they required a 'family doctor' (GP) referral, which remained a barrier for some due to the difficulties of accessing the GP and/or registering as a GP patient<sup>16</sup>.

The conditionality of receiving healthcare, including COVID-19 treatments, upon the receipt of payments emerged as a key theme in the analysis of organisational responses. The necessity to pay for hospital-based treatments in the form of either (a) 'voluntary' contributions to healthcare providers, and/or (b) 'under the table' payments to individual health professionals, or (c) supplying own medication was mentioned by a number of participants, who suggested that without such payments even emergency treatment could be withdrawn, or only substandard treatment provided. One of the respondents noted:

The stories of people who are partially sighted and who got COVID-19 and were hospitalised are both frightening and shocking. They say that the so-called free treatment of this condition [COVID-19] cost them no less than 20,000 hryvnia [about 540 GBP]<sup>17</sup>.

 $^{17}$ Rate of exchange 1 GBP = 37.1714 UAH as of 6 August 2021.

<sup>&</sup>lt;sup>16</sup>In Ukraine, the process of registering with the 'family doctor' (an equivalent of 'General Practitioner' in the UK or 'Primary Care Physician' in the US) is described as 'signing a declaration'. This process is governed by a dedicated decree issued by the Ministry of Health of Ukraine on the 'Procedure for choosing a medical practitioner to provide primary healthcare'. Available (in Ukrainian): https://zakon.rada.gov.ua/laws/show/z0347-18#Text

For persons with ongoing medical needs another concern was the inability to access routine inpatient treatment or outpatient care due to the closure or re-profiling of healthcare facilities to accommodate COVID-19 patients. Lack of access to rehabilitation and impairment-specific healthcare services (including access to free health-resort treatments as a type of rehabilitation service) was another prominent concern. Under Ukrainian legislation<sup>18</sup>, people with disabilities are entitled to a full range of rehabilitation services (as determined by health professionals) which should be provided free of charge.

The closure of rehabilitation establishments or lack of access (due to the withdrawal or limited availability of public transport) was mentioned as having a particularly negative impact on people with disabilities in a context where pre-pandemic access to such services was already problematic for many. One respondent described an ordeal faced by a partially sighted patient in one of the COVID-19 wards, highlighting a complete disregard for their specific needs:

...if others can see the corpses, which are placed near the shower rooms or in the shower rooms of the wards, until they [hospital staff] have time to move the corpses, sighted people can still enter [the shower room], but people with visual impairments they fall over these corpses.

Concerns were also raised about the general increase in the price of medications and other essential healthcare items, and about interruptions to the supply of subsidised or free prescriptions which are available for certain categories of disability (see Verkhovna Rada of Ukraine, 1991).

<sup>&</sup>lt;sup>18</sup>Article 38 of the Law of Ukraine 'On the Fundamentals of Social Protection for Persons with Disabilities in Ukraine'. For more information (Verkhovna Rada of Ukraine, 1991 [In Ukrainian]).

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Some participants highlighted difficulties with validating the category (or 'group') of disability over the course of the pandemic. This process is described as 'medical-social commission' which assesses the extent of the 'loss of health' and involves, primarily, medical experts. A 2020 Council of Europe report criticised this system for not being adjusted to different types of disability, its inflexibility, and its bureaucratic nature, noting that:

Even people with severe permanent disabilities e.g. without a leg or legs must go through the tests several times. Apart from this, there is no possibility to acquire a duplicate of certificate in case of [...] losing it, to get a certificate in such a case the person must undergo the tests one more time. (Smusz-Kulesza, 2020, p. 29)

Participants reported cancelled and delayed appointments with no alternative mechanisms put in place to either determine the 'group' of disability for the first-time applicants or re-validate it for persons whose previous validation expired over the period of the pandemic. In March 2020, the Parliament of Ukraine suspended the requirement to undergo a re-validation of disability status as a pre-condition for the payment of disability pensions over the period in which national quarantine measures were in force (see Verkhovna Rada of Ukraine, 2020).

## Psychological wellbeing, mental health and social isolation

#### <u>Context</u>

Emerging research on the social impact of COVID-19 highlights the role of the pandemic in magnifying social isolation of people with disabilities (see, for example, den Houting, 2020; Rose et al., 2020). For most people with disabilities this has long been a feature of their lives and of their identity formation. In her analysis of loneliness in life stories by people with disabilities in Finland, Tarvainen (2021, p. 878) links alienation –

originating from ableism – to social isolation, which, she argues, generates an "othering condition and harms identity construction". The COVID-19 pandemic has not necessarily created new ruptures in the lives of people with disabilities but it has intensified long-standing social and structural inequalities around the world. As Schormans, Hutton, Blake, Earle, and Head (2021, p. 84) note, "pandemic responses – marked by ableism – reveal that governments have failed to consider disabled persons' living situations, support requirements, and daily realities in pandemic planning". Speaking from the perspective of Canadian disability activists, they highlight how the imposition of social distancing restrictions highlights a lack of understanding or dismissal by the authorities of the importance of everyday life routines, mundane activities, personal support and networks of support for people with disabilities (Schormans et al., 2021, p. 86). In commenting on the impact of the pandemic lockdowns, den Houting (2020, p. 104) notes that:

Many autistic and otherwise disabled people live lives of isolation not motivated by preference, but motivated by self-preservation. Exclusion, bullying, harassment, and abuse; inaccessible physical and social environments; and a lack of appropriate services and supports can mean that for many, self-isolation is the only option.

The growing volume of research on the psychological impact of COVID-19 highlights the overall detrimental impact of the pandemic on mental health, psychological wellbeing, and social interactions. For example, in their assessment of the impact of the pandemic on the mental health and social interactions of older people with physical disabilities in England, Steptoe and Di Gessa (2021, e365) concluded that "[p]eople with physical disability might be at particular risk for emotional distress, poor quality of life, and low wellbeing during the COVID-19 pandemic, highlighting the need for additional support and targeted mental health services". In addition, a qualitative study of the restricted access to educational services for people with disabilities in Turkey noted that:

Part I

[T]he educational delay, combined with the pressure of the preventive measures against Covid-19 was associated with (i) difficulties in emotional well-being, structured routines, learning, and socialization, (ii) enhanced feelings of isolation and pain, and (iii) negative perceptions of academic-self-efficacy and therapy-related outcomes. (Sakız, 2021, p. 1)

In their analysis of mental health responses to the COVID-19 pandemic based on the UK Household Longitudinal Study, Pierce et al. (2021, p. 617) identified that people living in "the lowest income areas were more likely to have mental health declines [as a response to the pandemic, which] suggests that existing mental health inequalities are being accentuated". In the US, based on the analysis of the nationally representative population surveys, Swaziek and Wozniak (2020, p. 731) conclude that "mental health has worsened for individuals across the board. All identifiable demographic groups report worse mental health in the pandemic era than in a comparable pre-pandemic source".

For people with disabilities who have mental health needs, the COVID-19 pandemic has severely affected both their ability to access services and the quality of care available in institutionalised settings (OCHA, 2021a, p. 72). In 2018, prior to the pandemic, up to 4% of Ukraine's population – or 1,847,113 persons – accessed mental health services in the country (Skokauskas et al., 2020, p. 738). Recent reforms to these services aim to improve access and address challenges such as low social awareness of mental health illnesses and stigmatisation of those affected (WHO, 2020b).

However, the implementation of these reforms (potentially impacted by the COVID-19 pandemic) has not been entirely successful with state psychiatric hospitals reporting significant budget cuts of up to 50% (Skokauskas et al., 2020, p. 738-739). In a context where most mental health support is sought and received in institutionalised settings (Weissbecker et al., 2017) and public opinion indicates a reluctance to integrate mental health into community settings (Quirke, Klymchuk, Suvalo, Bakolis, & Thornicroft, 2021), the pandemic has made accessing all health care difficult for many Ukrainians (Martsenkovskyi & Martsenkovsky, 2020) and exacerbated issues relating to the centralisation of mental health services (OCHA, 2021a, p. 73). This is especially problematic for IDPs, soldiers and conflict-affected populations in the east of the country, who have a higher prevalence of mental illnesses such as post-traumatic stress disorder (PTSD), depression and anxiety (Colborne, 2015; Kuznestsova, Mikheiva, Catling, Round, & Babenko, 2019; Roberts et al., 2019).

#### **Analysis**

Increased social isolation of people with disabilities in Ukraine – linked to limited or fully withdrawn access to the pre-pandemic social and professional support systems – has been one of the key themes highlighted by the organizational respondents. This has been aptly encapsulated by one of the respondents, who suggested that "they [people with disabilities] have always been living in isolation so not much changed for them; it is simply that the rest of the population stepped into their shoes".

The following impacts, which can be grouped under the broad theme of 'social isolation' have been reported by the respondents:

- (a) Withdrawal of, or restricted opportunities for, 'real-life' (i.e., physical) contact with families, friends and community activists. Increased feelings of loneliness and abandonment leading, in some cases, to complete isolation and breakdown of the pre-covid social support networks.
- (b) Lack of access to leisure facilities, such as public parks and recreation areas (with a particularly negative impact on children with disabilities).

- (c) Unaffordability of smart phones, laptops and/or of the internet connection for 'online' communication with social and professional support networks.
- (d) Impeded communication and access to information for people with hearing difficulties who rely on lipreading to communicate and access information.
- (e) Increased stigmatization of people with disabilities.

Social isolation and lack of communication were linked to a range of negative psychological responses, including a general deterioration of mental health and increased levels of fear and worry (including fears to contract/get sick with COVID-19); apathy and indifference; stress; aggression; panic attacks; and depression. In reporting increased levels of psychological distress among people with disabilities, a number of organisational respondents expressed serious concerns about both the willingness of some people to come forward and seek help (fearing additional stigmatisation) and about the capacity of the psychological services and psychiatric care in Ukraine to recognise and respond to the increased levels of psychological and psychiatric disorders.

### **Restricted mobility**

#### **Context**

An increasing volume of research has been focussing on the impact of the pandemic on the availability of public transport in both urban and rural areas, and the impact of the public transport restrictions on the daily lives of individuals and communities across the world. It is estimated that lockdowns and public behaviour

changes resulted in a drop ranging from 70-90% in the use of public transport across major cities in China, Europe, Iran, the U.K. and the U.S. (see, for example: Aloi et al., 2020; Bucsky, 2020; Jenelius & Cebecauer, 2020; Van Audenhove et al., 2020). Whilst levels of transport use fluctuated according to the restrictions in place and current levels of infection in local populations (Gkiotsalitis & Cats, 2021), the pandemic has the potential to reshape levels public transport use even once all restrictions are lifted (Beck & Hensher, 2020; Vickerman, 2021). However, public transport remains an important form of mobility for the poor (Guzman & Oviedo, 2018) and the impact of reduced levels of service during and, potentially, post-pandemic may serve to worsen existing inequalities (Gutiérrez, Miravet, & Domènech, 2020). For people with disabilities the reduction in services or loss of transport options altogether has emerged as a key issue (Kubenz & Kiwan, 2021: 44).

For the majority of people with disabilities, mobility remains one of the key factors determining their quality of life. However, as noted by Warren, Ayton and Manderson (2014, p. 4097), most research on disability and quality of life "does not adequately or specifically address the impact of limits on mobility, possibly due to the conflation of functioning and mobility". In considering the notion of 'access' within the context of a healthcare system, Penchansky and Thomas (1981) identify five dimensions: availability, accessibility, accommodation, affordability and acceptability. These dimensions, as Warren et al. (2014) argue, can be applied to evaluate the link between mobility and impairments, and the role of mobility in quality of life in the context of disability. In its *Combined Second and Third Report on the Implementation of the Convention on the Rights of Persons with Disabilities (for 2015-2019 period)*, the Government of Ukraine (2020) sets out a range of measures implemented in relation to the availability and accessibility of the public transport infrastructure for people with disabilities in Ukraine. However, the 2020 Council of Europe's *Draft Report on the Needs Assessment with Respect to Policy and Legal Framework Revision in the Area of Rights of People with Disabilities in Ukraine* (Smusz-Kulesza, 2020) identifies a series of challenges with both availability and accessibility of transport for people with disabilities in

Ukraine. One of the report's recommendations to the Government is to ensure that "public transport, including school buses should be made accessible for all people with disabilities" (Smusz-Kulesza, 2020, p. 60).

#### **Analysis**

In response to the increasing number of COVID-19 cases in March 2020, the Government of Ukraine introduced a series of restrictions nationwide, including closure of educational facilities; limitations on passenger transportation and mass gatherings; and suspension of catering, cultural, shopping and entertainment establishments (OCHA, 2020). Depending on the epidemiological situation, some cities withdrew access to all public transport (for example, Chernivtsi – in March 2020), whilst others restricted access to the employees of 'critical infrastructure<sup>19'</sup> by introducing a system of permits issued by local administrations (for example, Kyiv). In July 2021 the Kyiv Administration announced a set of measures in preparation for any future 'waves' of infections, making no provision for exempting personal assistants and caregivers from restrictions on the use of public transport (Kyiv City Council, 2021b). According to the survey responses, these restrictions (most of which have been lifted at the time of conducting the survey in May – June 2021) had a considerable impact on the following groups of people with disabilities:

- Persons with disabilities whose mobility was already restricted before the pandemic for one of the following reasons: (a) the nature of their impairment (for example, fully immobile people with particularly complex physical impairments); (b) poor accessibility and lack of disability-specific adaptations; (c) the lack of financial means and of government support to improve personal mobility.

<sup>&</sup>lt;sup>19</sup>In Ukrainian: "критична інфраструктура"

- Persons with disabilities whose impairment may have less bearing on their mobility but who relied on routine forms of mobility via public transport to maintain their wellbeing, including routine visits to the hospital, habilitation and/or rehabilitation services, or pharmacies.
- Persons with disabilities relying on assistance provided by caregivers, including family members, friends, and communal networks and support groups.

Overall, the use of public transport became increasingly associated with the risk of contracting COVID-19. Some of the specific concerns highlighted by the respondents included:

- (a) The disproportionate impact of public transport restrictions in rural areas where the pre-pandemic availability of public transport was already limited and the distances involved to get to and from shops, hospitals, places of employment, etc. were longer. Reduced timetables or withdrawn services had reduced or completely removed access to critical services or employment for anyone without access to private cars or other private arrangements.
- (b) The disproportionate impact of the withdrawal of transport services on internally displaced people with disabilities, making the process of getting to and of crossing the 'contact line' impossible.
- (c) The disproportionate impact of transport restrictions on people with disabilities with certain impairments. For example, the requirement to be seated (rather than stand) when using buses created difficulties for partially sighted or blind people.
- (d) Following the easing of restrictions, when transport providers were permitted to operate adhering to social distancing requirements, some private providers of public transport did not resume their services since they were unable to operate profitably when transporting a reduced number of passengers.

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

#### **Context**

The 2018 flagship report by the United Nations on disability and development is unequivocal in stating that "persons with disabilities, and their households, are more likely to live in poverty" (DESA, 2019, p. 34). A systematic review of poverty and disability in low- and middle-income countries (Banks, Kuper, & Polack, 2017) found strong evidence for a link between disability and poverty, suggesting that they operate in a cycle with each reinforcing the other.

Ukraine has a Human Development Index (HDI) of 0.779 for 2019 – the most recent year available – slightly below the European average of 0.791; adjusted for inequality, Ukraine's level falls 6.5% to 0.728 which is a lower-than-average drop for the region (UNDP, 2020). However, GDP per capita in current USD for Ukraine is 3,727, significantly lower than neighbouring Poland (15,656) and Romania (12,896) (World Bank, 2021b). In terms of wealth distribution, Ukraine lags behind Europe and its neighbouring countries with the median wealth per adult estimated at USD 2,529 per adult in 2020, in comparison to USD 26,423 in Europe or USD 23,550 in Poland (Credit Suisse, 2021, p. 108). About 80% of Ukrainian pensioners receive income that is less than the minimum subsistence level with women's pensions being, on average, 30% below those of men (Bachelet, 2021).

In 2015, the United Nations Committee on the Rights of Persons with Disabilities (UN CRPD, 2015) noted the difficulties facing Ukraine because of the ongoing conflict in the east and expressed concern about the level of state disability pensions, which were deemed insufficient to meet basic human needs including nutrition, medical and social needs (Ministry of Social Policy of Ukraine, n.d.). The average monthly disability

pension in Ukraine in 2020 was 2,641 UAH or 71 GBP<sup>20</sup> (SSSU, 2021b, p. 21). This compares to the minimum 2020 'subsistence level' as set out by the Government of Ukraine at 2,189 UAH (or 59 GBP) (SSSU, 2021b, p. 13). However, the 'factual subsistence level' which is calculated by the Ministry of Social Policy of Ukraine to take into account current prices (calculated in addition to the 'subsistence level' as set out by the yearly Law on the State Budget of Ukraine) was set at 3,845.21 UAH (or 103 GBP)<sup>21</sup>. This means that almost 1.5 million people with disabilities who receive state pension due to disability (SSSU, 2021b, p. 21) and for whom a disability pension was the main source of income lived in poverty. In April 2020, the Ministry of Social Policy allocated a one-off 'social support' payment of 1,000 UAH (or 27 GBP) to people with disabilities whose monthly pension (including all statutory allowances) did not exceed 5,000 UAH (or 135 GBP) (Cabinet of Ministers of Ukraine, 2020).

No information on the labour market participation of people with disabilities (or government efforts to promote inclusive labour market) is currently available on the websites or in any of the publications by the SSSU or the Ministry of Social Policy of Ukraine. The only reference to the overall number of people with disabilities in employment in Ukraine is provided in the *Combined Second and Third Reports of Ukraine on the Implementation of the Convention of the Rights of Persons with Disabilities* (Government of Ukraine, 2020, p. 44), which provides an aggregate figure of 776,000 employed persons with disabilities (as of July 2020), including 3% of people with the most complex disabilities ('Group 1'), followed by 28% of people classified as belonging

<sup>&</sup>lt;sup>20</sup>Rate of exchange 1 GBP = 37.1714 UAH as of 6 August 2021

<sup>&</sup>lt;sup>21</sup>According to the Statistical Service of Ukraine, overall, in the first six months of 2020, the income of 28.3% of all households in Ukraine was below the 'factual subsistence level' of 3,845.21 UAH (an increase of 2.8% in comparison to 2019). The Ukrainian law defines the substance level as the cost of essential food as well as a minimum set of non-food products needed to meet the basic social and cultural needs of the individual. See https://ukrstat.org/uk/operativ/operativ2018/gdvdg/vrdulpiv2020.zip

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to 'Group 2', and 69% to 'Group 3'22. According to the National Assembly of People with Disabilities of Ukraine (NAPDU), among 224,500 people with disabilities who were registered at the State Employment Service of Ukraine between 2015 and 2019 only 65,900 thousand (or 29%) were able to find employment (NAPDU, 2020, p. 92). In the absence of detailed statistics on the employment of people with disabilities it can, however, be assumed that as with virtually all areas of socio-economic life in Ukraine, the pandemic would have had an adverse impact on the already problematic situation with labour market participation of people with disabilities. Studies that began to emerge from other national contexts (see, for example, Emerson et al., 2021; Banks, Davey, Shakespeare, & Kuper, 2021; Maroto, Pettinicchio, & Lukk, 2021) demonstrate how the pandemic and disability-blind government responses had a negative impact on employment situations for workers everywhere, including people with disabilities. A study of COVID-19's effects on employment among people with disabilities in Canada (Maroto et al., 2021), for example, suggests that the pandemic accentuated pre-existing structural disadvantages and inequalities in the labour market.

#### Analysis

According to the survey respondents, the deteriorating financial situation of persons with disabilities and their households in Ukraine was linked to the ongoing impact of the pandemic (loss of jobs and income, rising prices on food and medicines), which put the livelihoods of persons with disabilities at risk through

<sup>&</sup>lt;sup>22</sup>Disabilities in Ukraine are classified into groups. Smusz-Kulesza (2020, p.22) explains that: "Pursuant to art. 7 of the Law of Ukraine 'On Rehabilitation of Persons with Disabilities in Ukraine', depending on the degree of persistent impairment of bodily functions caused by illness, trauma (its consequences) or congenital impairments and possible limitation of everyday activities while communicating with outside environment caused by the loss of health, persons recognised as having a disability, are assigned to one of the three disability groups: group I, group II, or group III".

malnutrition, poor health, and financial insecurity. Unemployment, lack of employment opportunities, and pandemic-related job losses among people with disabilities and within their households was highlighted as a particular concern. In addition to financial difficulties and poverty, respondents were concerned about the continuing decline in quality of life due to the poor availability and accessibility of social services, which were further degraded (to the point of a complete withdrawal) by the pandemic. Concerns included:

- (a) Lack of access to local authorities (including 'hromadas'), including providers of social services, the pension fund, civil-military administrations.
- (b) Reduced volume/scale or complete withdrawal of social services provided to people with disabilities, including informal support networks (due to sickness, fear of infection and/or lack of public transport).
- (c) Lack of access to e-portals of various government departments due to digital poverty (i.e., lack of the financial means to access internet and devices<sup>23</sup>).
- (d) Impeded or withdrawn access to food shops (due to self-isolation, shop closure or lack of transport connections), and, in some cases, destitution including the inability to buy basic food supplies and/or pay for utilities due price increases.

<sup>&</sup>lt;sup>23</sup>As a term, 'digital poverty' is understood as affecting people who cannot afford or access the required technology to engage in online and information society, and also those who are not considered to be 'in poverty' economically, but nevertheless lack the skills or means to access digital technologies (Barrantes, 2007, pp. 49-51).

A number of respondents mentioned reduced or complete lack of access to education as educational and training programmes were transferred online (remote learning) in response to social distancing requirements. For some persons and children with certain types of disability (including physical impairments) the transfer to online learning removed the need to navigate inaccessible physical/built environments and public transport. However, for persons and children with sensory impairments these changes made learning less accessible due to the lack or poor accessibility of web content. The primary limitation for the majority of people and/or children with disabilities to access online learning was digital poverty, including a lack of the financial means to purchase the required IT equipment, internet connectivity, and/or secure study space. Lack of access to online learning and social isolation were also mentioned as reasons for the 'roll-back' of skills and an increasing attainment gap for children with disabilities, in particular children with intellectual disabilities/learning difficulties.

Lack of access to public health information was also highlighted as a concern, including widespread confusion and lack of information on the nature of the virus (how it spreads and how to reduce the risk of catching coronavirus) at the early stages of the pandemic; lack of information on the availability and accessibility of COVID-19 health services; confusion about the changing social distancing requirements and the availability of services; and lack of information delivered in accessible formats and languages. Accessibility of the public health messaging improved over time, including the use of captions and sign language interpretation on national and some of the regional TV channels.

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

The pandemic and its aftermath will continue to affect individuals and communities differentially in intersection with aspects of their identity, including (dis)ability, gender, socio-economic situation, age, (dis)location, sexuality, ethnicity, etc. Even though the impact of the pandemic on people with disabilities has, overall, magnified and intensified already existing structural barriers and inequalities, the challenges faced by people with disabilities are specific to how certain types of health conditions manifest themselves as disabilities in interaction with personal and environmental factors. Our organisational survey included a range of OPDs working with people with different types of disabilities (including long-term physical, mental, intellectual or sensory impairments). Some of the concerns, expressed by the respondents, related to the specific types of disabilities and specific categories of people with disabilities, where some of the aspects of identity mentioned above intersected to intensify the impact of the pandemic on individual lives.

At the same time, as noted in the Disability under Siege literature review, "nuance is required to recognise the varying levels of risk faced by different groups of disabled people to avoid perpetuating the stereotype of all disabled people as inherently 'vulnerable' or 'weak'" (Kubenz & Kiwan, 2021, p. 9). Not every person with disability is, by default, more susceptible to COVID-19 on the ground of their impairment or was disempowered to the same extent by the way in which specific pandemic responses evolved. Overall, participants reported various increased difficulties in securing inclusive and barrier-free environments and a "de-prioritisation of disability" in the government's COVID-19 response. Some specific concerns emerged (in addition to the ones mentioned above) in relation to the following groups of people with disabilities/

# Children with disabilities and households with one or both parents having disabilities

Respondents mentioned the disproportionate impact of the pandemic on children with disabilities themselves and on households with children who have a disability, including:

- (a) Social isolation and its impact on children's mental wellbeing and development.
- (b) The impact of the deteriorating economic situation and household poverty (including food insecurity).
- (c) Developmental delays due to the inaccessibility of online education and support networks, especially for children with intellectual disabilities.
- (d) Lack of access to social and rehabilitation services for children. One of the respondents reported a complete lack of support mechanisms in cases where a single parent may have contracted COVID-19 and needed to be hospitalised: "We were faced with a situation where a single mum got sick and there was nobody to take care of the child. It is frightening!"

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### Older persons with disabilities.

Reduced or lack of access to social services was reported by respondents as having a particularly severe impact on older persons with disabilities. This included:

- (a) Accessing personal protective equipment, hygiene items and disinfectants.
- (b) Inability to get to shops, hospitals, social services and places of employment due to the closure of public transport networks or inaccessibility of the limited public transport that was running.
- (c) Poverty and destitution (including inability to buy food and medication), compounded by losing jobs and unemployment in a pandemic-affected, shrinking job market dominated by younger unemployed candidates.
- (d) Loss of social support networks in the absence of physical contact and due to digital poverty.
- (e) Digital poverty- lack of access to the Internet and electronic devices, lack or poor understanding of how to use information technologies to access services which were fully transferred online in response to the government-imposed lockdowns and social distancing restrictions.

### People with disabilities living in rural areas.

Before the pandemic, people with disabilities living in rural areas faced additional challenges in accessing services which, when the pandemic arrived, became either unavailable and/or less accessible in the absence of any transport connections (with many being "entirely cut off from civilisation"). Availability and accessibility of the Internet and IT equipment (digital poverty) were also mentioned as significant limiting factors in accessing services and support.

### People who are blind or partially sighted:

- (a) Additional barriers related to the transfer of education and some social services online where the problem of inaccessible websites was particularly acute.
- (b) Inability to access information in relation to the pandemic.
- (c) Lack of caregivers to assist with visual mobility especially in outdoors settings.
- (d) Lack of adaptations in potential employment settings where partially sighted people could be gainfully employed (including call centres which began to recruit additional staff in response to the increased demand for call centre services within the context of the pandemic).

#### People who are deaf or have a hearing impairment:

- (a) Significantly reduced or withdrawn access to sign language interpreters.
- (b) Insufficient level of sign language interpreting in television programmes, which became a barrier to accessing critical information about the pandemic, its spread and prevention.
- (c) Difficulties in communicating with health professionals in the absence of interpreters or inability to connect to the Internet-enabled sign language interpreting service.
- (d) Difficulties in communication due to the requirement to wear face coverings (and lack of transparent face coverings in healthcare settings) which became a barrier to people who rely on lipreading.

#### Internally displaced people with disabilities.

A half of all organisational respondents indicated that they were working with/providing support to internally displaced people with disabilities. These organisations were asked to identify any specific problems facing internally displaced people with disabilities. Only five organisations suggested that internally displaced people with disabilities faced no additional challenges, with one of the respondents suggesting that "there are no special issues; we are all facing the same problems". However, other respondents described a range of issues specific to people with disabilities who have remained in the situation of protracted displacement since 2014:

- (a) Ongoing issues with accessing housing, in particular access to housing adjusted to the specific needs of persons with disabilities<sup>24</sup>.
- (b) Poverty and overall difficult financial situations, including challenges in finding employment and difficulties in accessing IDP and disability specific social security payments (compounded by the closure of the government offices during the lockdowns).

<sup>&</sup>lt;sup>24</sup>Despite a variety of initiatives by the Government of Ukraine to meet IDPs' specific needs, "from temporary housing, social housing for vulnerable groups, and affordable long-term housing solutions" (GP20, 2020, p. 196), a range of IDP-specific housing problems remains. The 2019 Council of Europe's assessment of the legal framework for the protection of human rights of IDPs in Ukraine concluded that "the lack of the appropriate financial support to ensure the rights of internally displaced persons to housing from the state budget of Ukraine is obvious; financial allocations in the State Budget are insufficient to cover the housing needs of internally displaced people" (Council of Europe, 2019, p. 82).

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- (c) Concerns about the lack of access to healthcare, education, and other services (banking, shopping, childcare) compounded by the difficulties of getting registered as an IDP or as a person with disabilities in the absence of direct contact with relevant government officials.
- (d) A range of challenges specific to conflict-related displacement, including the closure of exit-entry points along the 'contact line' and the withdrawal/suspension of public transport links. This prevented some internally displaced people with disabilities from travelling to and from temporarily occupied territories to visit relatives and extended families and/or check on properties or any other assets.
- (e) Lack of access to existing and reduced opportunities to develop new social support networks because of lockdowns and social distancing requirements.

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

#### **Context**

### Non-governmental organisations in Ukraine working with people with disabilities

In his comparative analysis of civil societies in post-communist Europe, Howard (2003, 2012) comments on the lasting weakness of civil society in the region, linking it to the post-communist legacy of mistrust in institutions, the persistence of friendship networks and post-communist disappointment (Howard, 2012, p. 139). A similar assessment is extended to Ukraine in recent debates on the role of Ukrainian civil society within the context of the ongoing democratic transitions, including Ukraine's 'Dignity Revolution' of 2014 (Cleary, 2016; Way, 2014). Others argue that civil society in Ukraine has begun to adjust to new challenges including the proliferation of "less visible...forms of day-to-day civic activism" (Burlyuk, Shapovalova & Zarembo, 2017, p.6) which are in the process of 'hybridization' whereby "civil society groups do not perform a watchdog function

(holding government to account) but instead do the job for the state" (Burlyuk et al., 2017, p. 11). In her 2009 overview of the disability rights movement in post-Soviet Ukraine, Phillips (2009, p. 277) described the movement as "one of the most dynamic yet understudied post-Soviet social movements", which remains the case at the time of writing this report in 2021. This part of the report presents an analysis of organisational responses to the survey which explored the views of civil society organisations working with people with disabilities in Ukraine, documenting the impact of the pandemic on their organisational activities. Overall, it offers a glimpse of the dynamism, dedication and commitment of disability activists in Ukraine, who carry on their mission to "influence the world for the better" in the face of extreme adversities, magnified by the pandemic, and in the context of what can be described as a cascading 'organised state abandonment'<sup>25</sup>, neglect and devaluation of human life in Ukraine<sup>26</sup>.

At the national policy level, the development of civil society in Ukraine is facilitated by periodic strategy documents published by the Government of Ukraine. In September 2021, President of Ukraine signed the Presidential Decree on the *National Strategy to Facilitate the Development of Civil Society in Ukraine in 2021-2026* (President of Ukraine, 2021). The main principle underpinning the policy, according to the CSO Meter (2021, para. 2), is "no decisions for civil society without civil society" echoing the global disability rights mot-to 'Nothing About Us Without Us'. The latest official set of data on civil society organisations in Ukraine was published in 2018 by the State Statistical Service of Ukraine. This data suggests that, as of 2017, there were almost 26,000 'governing bodies' representing civil society organisations registered with the Ministry of Jus-

<sup>&</sup>lt;sup>25</sup>A concept discussed by Bhandar (2018) in relation to the Grenfell Tower tragedy in the UK. See https://criticallegalthinking. com/2018/09/21/organised-state-abandonment-the-meaning-of-grenfell/

<sup>&</sup>lt;sup>26</sup>51% of the Ukrainian population were estimated to live in poverty according to Ella Libanova (Co-Investigator on this project): https://biz.liga.net/pervye-litsa/all/interview/akademik-ella-libanova-karantin-i-distantsionnoe-obuchenie-usilivayut-neravenstvo

tice of Ukraine, indicating a membership of almost 20 million people (SSSU, 2018, pp. 6-7). The overall income declared by the Ukrainian civil society organisations in 2017 was about £214 million<sup>27</sup>; of these, 2.7% were allocated from the state budget of Ukraine; 3.4% from local budgets; 9.8% from membership fees; and 52.3% from charitable activities, including individual and organisational charitable contributions (SSSU, 2018, p. 8).

The development and functioning of non-governmental organisations working in the field of disability rights in Ukraine is governed, primarily, by two pieces of legislation, including the Law of Ukraine (875-XII), on the Fundamentals of Social Protection of Persons with Disabilities in Ukraine (1991), and the Law of Ukraine On Pub*lic Associations* (2012). Some organisations working with people with disabilities were formed before Ukraine gained independence in 1991 and continued to operate once Ukraine became an independent state, including the 'All-Ukrainian Union of Organisations of Persons with Disabilities of Ukraine'28. The declaration of independence in 1991 set the stage for the development of vibrant and (at that time) hopeful civil society, which saw the coming together of already existing networks of support and the creation of new ones in response to the worsening economic situation and the retrenchment of the Soviet-era welfare state – described by Phillips (2011, p. 6) in her analysis of disability in post-socialist Ukraine as shrinking "social safety nets and the privatization of responsibilities previously allocated to the state or to work and other collectives, as citizens are cut loose from much state support to fend for themselves". Initially, these organisations focused on specific types of disability and operated primarily at the local level. This was followed by a process of consolidation into larger associations operating at regional and national levels, including, for example, the Ukrainian Association of the Blind, and the Ukrainian Association of the Deaf which were established in 1993. In 2004 the 'Coalition for the Protection of the

 <sup>&</sup>lt;sup>27</sup>Rate of exchange 1GBP = 34UAH (average for 2017 as indicated by https://fxtop.com/en/historical-exchange-rates.php)
 <sup>28</sup>See https://www.soiu.com.ua/

Rights of Persons with Intellectual Disabilities' was formed and, as of September 2021, operates as an umbrella organisation bringing together 116 non-governmental organisations from across Ukraine to provide social support and advocate for the rights of people with intellectual disabilities<sup>29</sup>.

The National Assembly of People with Disabilities of Ukraine<sup>30</sup> (a key partner organisation in this project) was established in September 2001 to bring together OPDs in Ukraine to coordinate and consolidate responses at the national level to protect human rights of persons with disabilities across Ukraine. In all of its activities, the Assembly is guided by the UN Convention on the Rights of Persons with Disabilities; in 2010, it received a Special Consultative Status at the UN Economic and Social Council (ECOSOC). As of September 2021, the Assembly membership includes 126 national and regional non-governmental organisations.

The diversity of organisations of persons with disabilities and other civil society groups working with persons with disabilities is reflected in the sample which were invited to take part in this project's survey of organisational perspectives on the impact of COVID-19 on people with disabilities in Ukraine. Overall, 150 organisations were invited to take part, including 126 member organisations of the National Assembly of People with Disabilities of Ukraine. The survey received 108 responses (with a response rate of 72%) which represent organisations working at different administrative levels across Ukraine and with people with different types of disabilities.

Among the 108 respondents, 52% focused on one type of disability and 48% focused on multiple types of disabilities in their organisational activities. From the first group, the majority (69%) worked with people with physical impairments, followed by sensory impairments (21%). Among the organisations focusing on multiple types of disabilities, the two most common types were physical (87%) and intellectual impairments (67%).

<sup>&</sup>lt;sup>29</sup>See http://inteldisabilities-coalition.com.ua/

<sup>&</sup>lt;sup>30</sup>Registered as a public association "All-Ukrainian Public Association "National Assembly of People with Disabilities of Ukraine" or «Громадська спілка «Всеукраїнське громадське об'єднання «Національна асамблея людей з інвалідністю України» [in Ukrainian]

Most organisations (39%) operated at the regional ('oblast') level, 35% worked at the local level, and 22% of organisations operated at the national level. Some organisations provided an additional clarification to highlight their operations at the district level.

# The impact of COVID-19 on non-governmental organisations working with people with disabilities in Ukraine

The majority of respondents (97%) reported that the pandemic has had a negative impact on their organisational activities. Only three respondents (out of 108) indicated that the pandemic had little or no impact on their organisations. Key organisational impacts included:

- (a) Changes to their mode of working, in response to government-imposed lockdowns and social distancing requirements and restrictions.
- (b) A reduction or complete withdrawal of external funding support (by the government and non-governmental donors).
- (c) A reduction or withdrawal of support provided by volunteers.
- (d) A reduction in communication with and support from the state authorities.

In addition to the negative impacts, a number of respondents commented on some positive developments. These were primarily linked to the alternative (online) ways of working forced upon them by the pandemic and also the consolidation of efforts and resources as a result of new partnership work.

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### Changes to mode of working and service delivery

Among the 78 respondents who had a dedicated office at the time of completing the survey (72% of all respondents in this survey), 40% switched to a combination of online/offline working, 27% shifted to working fully remotely, 23% of organisations continued to operate as they did before the pandemic, and 10% suspended most of their activities. About 18% of all respondents did not have an office before the pandemic, and about 4% lost their office during the pandemic. Approximately 72% of all respondents had to suspend or cancel events involving physical contact in group settings, including internal meetings.

Of all respondents, 11% indicated that they were able to provide their members with the required IT equipment and, where needed, to purchase access to the Internet to enable distance/online working. 31% could only provide for some of these requirements, and the majority of 54% were unable to provide either IT equipment or Internet access for its members. In such cases, some of the organisations relied on the personal equipment and Internet connections of their members, including personal resources provided by volunteer members.

Some organisations noted the difficulties of transferring specific services to online provision, including, for example, individual consultations or counselling sessions for people with intellectual disabilities. In some instances, the move to online working could not compensate for cancelled or suspended events. This, inevitably, resulted in reductions of both the volume and quality of some of the services provided, which had a negative impact on persons with disabilities relying on these services.

Some of the open-ended comments reflected a lack of access to the basic IT infrastructure or skills required to use online technology:

We could not transfer all of our members to online working because not everyone knows how to use these online services or do not have appropriate equipment.

For some organisations, especially those in rural areas where access to the Internet and to mobile networks remained problematic, landline phones became the only medium of communication during the most restrictive phases of the government-imposed lockdowns.

Some organisations did continue providing individual face-to-face assistance and essential services to the most vulnerable individuals: delivering humanitarian aid packages, including food, personal hygiene items and medicines; assisting with the essential travel to hospitals and pharmacies; and taking care of family members, children and pets when members of the households were hospitalised. At the start of the pandemic, amid wide-spread confusion, lack of reliable information about the virus and its spread, and severe shortages of PPE, most delivery companies suspended door-to-door deliveries of food. In addition, some social workers suspended their assistance visits and some people with disabilities began shielding, which involved refusing almost any contact from outside of their immediate household. This presented an additional challenge for organisations in delivering assistance to those who needed it most. In some extreme cases, a pulley system was used by activists to deliver food via kitchen windows to a family shielding in their apartment.

Survey respondents were also asked to assess how the pandemic influenced their human rights advocacy work. This question allowed a multiple choice of answers to understand the breadth and scope of work and adaptations. Only two organisations (or less than 2% of the overall sample) halted their advocacy work. A further 30% cancelled or postponed some of their advocacy activities, with the remainder continuing to advocate on behalf of people with disabilities by relying on a variety of approaches, including developing new programmes and adopting the use of various internet platforms to stay active.

Overall, only 47% of the organisations were satisfied with how their organisation developed during the pandemic; 36% indicated that there was almost no development and 9% suggested that their organisations could be dissolved soon due to the ongoing challenges brought about by the pandemic. About a quarter of

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organisations provided additional commentary in response to this question. Resilience and the determination to carry on was one of the key themes and can be summarised by this brief response: "inspiration to help others will always give us the strength to survive in any situation".

Some organisations noted that even if the overall volume of their activities decreased over the course of the pandemic, there was a notable increase in the volume of work which required additional time and resources to adapt to the new ways of working, learn new skills, and re-build co-operation and partnership work.

### **Organisational funding**

For many organisations, increasing costs to re-organise their service delivery and to provide additional support for people with disabilities were accompanied by decreased financing and a lack of support and communication with the state authorities.

Between April 2020 and April 2021, 54% of respondents applied for external funding to support their organisational activities. However, only 17% of those who did apply received the funding requested; 47% received partial funding which was insufficient to cover the most basic organisational costs and 36% were unsuccessful and received no funding.

Only 25% of organisations received financial support from overseas donors. Among these organisations, only one received funding to provide direct support to people with disabilities; the remaining organisations received financial support towards project-based expenses and, partially, towards organisational costs.

Overall, the analysis of the open-ended comments reveals a precarious financial situation for many of the organisations, some of which are involved in the direct delivery of essential services to people with disabilities. This precarity was caused by the lack of funding, delayed or withdrawn funding, lack of knowledge about

available funding opportunities, and the lack of resources and skills to comply with complex administrative requirements attached to the administration and reporting requirements. Some of the organisations operated entirely on the basis of voluntary contributions, including non-paid members' time, without any financial support from the government or other donors.

# Interaction with central and local authorities, territorial communities and volunteers

Only 7% of organisations indicated that co-working/partnership with the state authorities increased over the pandemic period. The remaining 93% provided a range of responses (respondents had a choice of options to describe the nature of this relationship, therefore percentage responses do not accumulate to 100%), including: decreased levels of co-operation (29%), meaningless co-operation so that the authorities could "tick the engagement box" (41%), and non-constructive and ineffective cooperation (30%). Some of the comments reflect frustration among the respondents about the level of cooperation:

- "They are only putting in the roadblocks and we are left to our own devices"
- "They seem to hear and agree but there's no progress"
- "Only a few of our requests are responded to in full or in part. A lot of things are done for us but without considering our needs"
- "This [lack of cooperation] slows down the implementation of our projects. There is no flexibility on the part of the authorities to support organisations that continue to operate throughout the pandemic"

context, 'volunteers' refers to individuals who are not volunteer members of such organisations (i.e., people working for an organisation on a charitable basis without pay) but provide support with some of the organisational activities. About 16% of respondents indicated that the volunteers' support increased. However, 43%, felt that it decreased over the pandemic period and 14% assessed it as inefficient and a 'tick-box' exercise. Key concerns in relation to the levels of voluntary support included volunteers shielding and worried about H becoming infected; volunteers observing lockdowns and social distancing requirements; financial difficulties and the general loss of interest in volunteering when everyday life is getting more difficult for everyone; and

#### Positive organisational developments over the pandemic period

a lack of face-to-face organisational activities which may have required volunteer support.

A small number of organisations reflected on positive impacts of the pandemic, attributing these to changes in working arrangements which can be grouped into two broad subheadings:

An equally concerning response was received in relation to the support received from volunteers. In this

Developing new partnerships and co-working with other organisations. The relative ease of or-(a) ganising online meetings enabled organisations equipped with the appropriate technology to reach out to new partners, resulting in improved and new relationships with private companies and other charitable organisations. Some organisations highlighted the positive impact of social networks in attracting volunteer support; others mentioned closer co-working with other organisations working with people with disabilities allowing a more efficient use of shared resources (for example, assisting partner organisations without own office or technical capabilities to hold online meetings) and developing a shared advocacy platform.

- (b) Positive outcomes from online working. About 22% of respondents provided positive examples of online working. This has been perceived as more productive and less restrictive as it reduced the requirements to navigate accessibility barriers when having to attend 'physical' (rather than 'online') meetings, including:
  - New opportunities to participate in online trainings, forums, meetings etc.
  - Additional opportunities to provide direct support to persons with disabilities via online meetings (including information and psychological support).
  - Additional opportunities for online advocacy work, including some innovative approaches which were not practised before the pandemic.

However, several organisations also commented on the difficulties of adapting to new ways of working, including difficulties of access for their own members and for people with sensory impairments and intellectual disabilities who relied on the assistance and support of these organisations.

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

On April 14, 2021 – more than a year since the World Health Organization declared the rapidly spreading coronavirus outbreak a pandemic – the Government of Ukraine published a Decree issued by the Cabinet of Ministers of Ukraine (2021a) *On Approval of the Action Plan to Support Persons with Disabilities for the Period of Quarantine Established by the Cabinet of Ministers of Ukraine and in Relation to the Enhanced Anti-epidemic Measures in Connection with the Spread of Acute Respiratory Disease COVID-19 Caused by Coronavirus SARS-CoV-2, Minimizing its Consequences*. The document, which consists of five paragraphs, ap-

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proves a plan of actions (attached as an appendix to the Decree) aimed at supporting people with disabilities over the period of quarantine. It also requires government ministries, other government departments and authorities, and regional administrations to rely on and implement recommendations issued by the World Health Organisation (2020a) in its *Disability Considerations during the COVID-19 Outbreak* document, and further recommendations contained in the briefing note on the impact of the pandemic on people with disabilities issued by the UN Human Rights Monitoring Mission in Ukraine (OHCHR, 2020b). To monitor the implementation of the Plan of Action, the document requires state authorities to submit quarterly progress reports to the Ministry of Health, which, in turn, should provide implementation reports for consideration to the Cabinet of Ministers of Ukraine. The Plan of Actions includes a list of 20 actions, which can be grouped into the following subheadings:

(a) Accessibility, including adapting the official COVID-19 information portal and healthcare information systems to the needs of persons with sensory impairments; improvements to mobile applications used in healthcare settings and for reporting medical emergencies; ensuring accessibility of information on COVID-19 and government responses relayed via COVID-19 'hot lines' and via television broadcasts. In addition, the document requires that 'recommendations are developed' on how people with disabilities could 'independently' request GP and other healthcare related appointments online, and introduces amendments to a procedure which allows private healthcare providers to request the services of sign language interpreters (Actions 1–7, 11). The Plan of Action also mandates the development of standardised solutions to ensure accessibility of healthcare facilities (Action 15).

- (b) Measures specific to people with disabilities residing in areas affected by disasters and emergency situations, mandating amendments to the 'Procedure for identifying persons with disabilities and other low-mobility groups living in the area of emergency or potential damage, and ensuring their livelihood needs are met' (Action 8).
- (c) Measures specific to the identification and treatment of COVID-19: ensuring access to free COVID-19 tests for people with vision impairments, persons with severe mobility impairments, and persons with psychological and intellectual impairments (Action 9) and for inpatient health-care professionals (Action 14); supply of the required medicines and medical equipment for the prevention and treatment of COVID-19 to inpatient healthcare and social care facilities (Action 16); provision of PPE for healthcare workers (Action 18); and ensuring that healthcare staff are trained in the identification and treatment of COVID-19 (Action 17).
- (d) Ensuring provision of social services to people with disabilities and children with disabilities whose carers are unable to provide care due to being diagnosed with COVID-19 (Action 10); access to free specialised transport for certain groups of people with disabilities (Action 13); ensuring that hospitalised patients are provided with access to their legal representatives via telephone and video links (Action 19); and ensuring that learners with disabilities (both adults and children) are provided with access to the Internet to facilitate online learning (Action 20).
- (e) Simplifying the process of individual 'socio-medical' assessments, the only mechanism through which an individual can be recognised as a person with disability in Ukraine, and of developing individual rehabilitation programmes for persons recognised as having a disability (Action 12).

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Whilst setting out a broad range of actions to mitigate the impact of COVID-19 on persons with disabilities in Ukraine – more than a year since the beginning of the pandemic – the document does not specify how these actions are to be funded nor does it allocate a specific budget for any of the actions. Despite references to the WHO's *Disability Considerations* document, which sets out specific actions for a range of stakeholders, including national governments, neither the Decree nor the Plan of Action include any mention of meaningful and inclusive engagement with people with disabilities or their representatives (including non-governmental organisations) in formulating and implementing responses to the pandemic. The timeframe of the document – limited to the duration of guarantine as determined by the Cabinet of Ministers of Ukraine – suggests a very short-lived duration for these measures which disregards the long-lasting impact of the pandemic and its disproportionate socio-economic impact on people with disabilities. Such an approach aligns with the deep sense of anger and disappointment expressed by our survey respondents in their assessment of what the government of Ukraine could have done but failed to do to mitigate the impact of the pandemic on people with disabilities in Ukraine. The following key themes emerged when analysing organisational responses to the question on what could have been done but did not happen:

- (a) Failure to ensure both availability and accessibility of social services for people with disabilities.
- (b) Failure to ensure adequate access to essential healthcare services for people with disabilities.
- (c) Failure to ensure access to information in relation to COVID-19 and pandemic response for people with disabilities.
- (d) Failure to provide financial support for the most vulnerable and for community-based organisations, some of which took on provision of essential life support services in the absence or withdrawal of support and care by the state.

## Failing to ensure accessibility and availability of social services for people with disabilities

The respondents criticised the lack of dedicated funding to ensure essential social services were available in response to the specific needs of people with disabilities within the context of the pandemic. They commented on the invisibility of people with disabilities within the initial government response to the pandemic at both national and regional levels. The majority of respondents suggested that the pandemic did not necessarily create new challenges in delivering barrier-free access to social services for people with disabilities; in most cases, it simply exacerbated the challenges and difficulties that already existed, including poor accessibility and availability of disability-specific social services, their inadequate volume and scope, and, in some cases, their inadequate quality. Some respondents criticised the lack of planning, the absence of any meaningful engagement, and the failure to conduct needs assessments, which should have been undertaken and continuously reviewed by the Government as the pandemic unfolded and its disproportionate impact on people with disabilities became clear.

Some of the responses included specific comments in relation to social services and socio-economic support (excluding healthcare which is analysed as a separate issue below):

- Lack of government-funded provision of humanitarian support including food, medicines and personal hygiene items. Access to these was severely restricted or halted for some persons with disabilities in the context of government-imposed lockdowns and social distancing restrictions.
- Lack of government response in a situation where carers and personal support assistants were unable to provide essential care to people with complex disabilities (due to illness, lack of transport links, or fear of infection).

- Lack of government response to the closure of essential rehabilitation services.
- Lack of dedicated support to educational institutions (under the framework of inclusive education) to ensure that people with disabilities, including children, were not left out due to digital poverty or lack of access to the Internet once learning transitioned online.
- Lack of measures to facilitate the (re)employment of people with disabilities in the context of a disrupted labour market, increasing unemployment and increasing competition for lower-paid, low-skilled jobs.
- Lack of measures to ensure barrier-free online access to governmental departments and services over periods where physical access was restricted because of lockdowns.
- Lack of measures to ensure increased awareness among relevant healthcare professionals of specific challenges facing people with disabilities and the increased susceptibility of some people with disabilities to COVID-19 due to the nature of their impairment.
- Lack of measures to ensure access to public transport when access was only available to holders of special permits allocated to employees of critical/essential services. In August 2021, the Kyiv City Council announced the launch of an electronic portal to enable companies to apply for such permits as a pre-emptive measure in response to any future lockdowns. No provision has been made to allocate permits to persons with disabilities in need of continuous access to healthcare or rehabilitation facilities.

# Failing to ensure adequate access to essential healthcare services for people with disabilities

The issue of healthcare was a prominent theme highlighted by the majority of respondents. Some of the concerns that were raised are not specific to the pandemic; rather, they reflect an overall assessment of the pre-existing deficiencies and inequities of the healthcare system in Ukraine. Problems included:

- Lack of barrier-free access to and within hospitals, including lack of accessible COVID-19 treatment facilities.
- Lack of genuinely free healthcare; respondents commented on the need to make '(in)voluntary' contributions or 'under-the-table' payments to healthcare staff (i.e. bribes) as a pre-condition for treatment.<sup>31</sup>
- Lack of financial assistance to people who required ongoing clinical care for health complications following COVID-19 illness.
- Lack of access to free or subsidised drugs and medicines (as set out by the legislation regulating access to free healthcare for people with disabilities).

<sup>&</sup>lt;sup>31</sup>A clarification published by the Ministry of Health of Ukraine (2018) suggests that forcing patients to make 'voluntary' financial contributions in exchange for treatments is illegal and encourages anyone who may have been requested to make such payments to file a complaint. See (in Ukrainian): https://moz.gov.ua/article/news/blagodijni-vneski-u-medzakladah-chi-mozhna-ih-zbirati-i-scho-robiti-jakscho-vas-primushujut-stati-blagodijnikom. However, a report on healthcare reform and economic accessibility of healthcare in Ukraine issued by the European Asylum Support Office (2021) suggests that corruption (including the payment of bribes and out-of-pocket payments in exchange for healthcare) has been institutionalised in Ukraine.

- Lack of government-funded psychological support services in response to the increasingly negative impact of the pandemic on the psychological wellbeing of people with disabilities.
- Lack of a carefully designed strategy of vaccinating people with disabilities as a priority group, including a system of vaccinating people with complex mobility issues or those shielding in their own homes.

#### Failing to ensure access to information for people with disabilities

Respondents' comments about the lack of accessible, reliable information for people with different type of disabilities, including intellectual and sensory impairments, were not limited to the information about the virus and its spread, but highlighted a range of broader concerns, including:

- Lack of accessibility generally in response to the different needs of people with sensory and intellectual disabilities. This included a lack of sign language interpretation on TV channels at the start of the pandemic and a lack of accessibility features on the 'e-service' portals of key government agencies and banks, access to which became essential with the closure of offices and service centres.
- Lack of access to information about the rights and benefits available to people with disabilities under current legislation. One of the participants suggested that the government should have provided accessible 'road-maps' to set out which services were available and how to access them within the context of the pandemic.
- Lack of clear and up-to-date information on how to reduce the risk of infection, pandemic-related restrictions, and alternative ways of accessing essential services for people with disabilities.

# Failing to provide financial support to the most vulnerable and to community-based organisations

In relation to the economic impact of the pandemic, survey respondents identified two challenges which were overlooked in the government pandemic response:

- Lack of targeted financial support for people with disabilities whose only source of income were disability 'pensions'<sup>32</sup> which remained well below the 'factual subsistence level' (as mentioned in Part I of this report).
- Lack of targeted financial support to non-governmental organisations which took over provision of social services (including a broad range of supported living services) when these were abruptly withdrawn by the government-funded providers due to covid-related restrictions.

#### Failing to engage and consult with people with disabilities

A number of respondents criticised the lack of meaningful consultation between the government – at both central and regional levels – and non-governmental organisations on how to best mitigate the impact of the pandemic on individuals and communities they were working with.

Regarding the overall influence of non-governmental organisations on government decision-making in relation to issues affecting people with disabilities, the responses reflect a varying degree of co-operation and involvement: 43 out of 88 respondents (or 49%) felt that their views and perspectives informed government

<sup>&</sup>lt;sup>32</sup>State disability benefit which varies depending on the 'group' of disability and is conditional on the length of employment before the fact of disability was ascertained by the 'medical-social expertise'. See (in Ukrainian): https://www.msp.gov.ua/content/invalidam.html

policymaking and implementation at different levels of decision-making. However, the other half of respondents suggested that such co-operation was all together absent or superficial, ranging from a complete lack of co-operation or contact, to some levels of engagement. This was described by one of the respondents as "disability-washing", when some level of co-operation with OPDs was maintained for "PR purposes", to the detriment of any meaningful involvement of these organisations in decision-making.

Some concerns were also raised about the lack of expertise, understanding, engagement and interest in all things to do with disability at the level of local self-government, which was concerning in the context of the transfer of power, resources and responsibilities from central to local levels as part of the 'Decentralisation of Power' reform in Ukraine<sup>33</sup>.

### Support required from state authorities, donors, and partners

Survey respondents were asked to summarise their views in relation to the support they required to continue their organisational activity and overcome challenges. Their vision of the immediate and future organisational challenges reflected, to a large extent, their assessment of the current problems facing both the organisations and people with disabilities they were taking care of. The most pressing concern was the lack of financial support from both donors and the government. One survey respondent explained: "To date, we are faced with the fact that most of our business partners and donors, despite the weakening of the quarantine, are in a state of 'anabiosis' and are unable to help us".

This was followed by concerns about organisational stagnation and poor levels of engagement and interest in the issues facing persons with disabilities, not only by external partners (including other organisations,

<sup>&</sup>lt;sup>33</sup>For further information on decentralisation of power in Ukraine see https://decentralization.gov.ua/en/about

volunteers, government authorities, donors) but also by their own members. The psychological impact of the pandemic, the unabating pressures of adapting to new working conditions, and increasing levels of work-related stress promoted some respondents to suggest that staff's burnout would put the existence of some of the organisations at risk. Weak rule of law, lack of parliamentary and government oversight around the implementation of decentralisation reforms, lack of stability and concerns about the negative impacts of any future legislative changes were also perceived as significant organisational threats. Some participants were also daunted by the task of undoing the damage caused by the pandemic to the rights of people with disabilities, their increased stigmatisation, and the increased tensions within the disability movement in Ukraine. In relation to specific aspects of support required by organisations, the following two priorities were iden-

tified:

- (a) financial support.
- (b) partnership working.

### **Financial support**

For 69% of respondents, financial and organisational support was a priority, including:

- Direct support to cover basic organisational costs (including office rent, utilities, IT equipment, Internet access, access to online communication platform, and costs to pay key members of staff).
- Financial support allocated for the provision of direct services to people with disabilities including rehabilitation services and assisted/supported living services.

- Indirect financial support through tax benefits to companies who employ people with disabilities and tax benefits/deductions to organisations making charitable contributions to support people with disabilities.
- Project-specific support via grants and tenders from the government and private donors including rapid support for the provision of specific services during public health or other emergencies.
- Indirect support through subsidised access to specific training opportunities for disability activists to develop and improve organisational capacities.

#### **Partnership working**

A number of organisations also identified partnership working as a priority including:

- Partnerships with other non-governmental organisations working with and/or led by people with disabilities to share best practice, knowledge and experience, and for collaborative working on specific projects, initiatives, and funding applications.
- Genuine and equitable partnership with government authorities at regional and central levels, including better and clearer lines of communication and better information sharing. Some respondents suggested the need for the establishment of an office of the commissioner for the rights of persons with disabilities at the regional level, and involving people with disabilities as participants in the independent evaluation of accountability and public spending on all issues involving people with disabilities.

- Collaborative work with international partners including disability activists from other countries and with international donor agencies, such as meaningful engagement with the donor agencies in identifying priority funding areas.
- Meaningful engagement with other organisations involved in the provision of public services, including law firms (to help increase awareness of people with disabilities of their rights) and health care providers (to improve awareness of people with disabilities of habilitation and rehabilitation services available).

## Recommendations

As of January 2022, the socio-economic challenges in Ukraine continue to be compounded by the escalating military conflict in the east, the occupation of the Autonomous Republic of Crimea, and by the COVID-19 pandemic. The research presented in this report demonstrates how the political and economic responses to the pandemic have both magnified and amplified the intersecting inequalities of gender, age, socio-economic status, and location for people with disabilities in Ukraine. Our research project documents how some of the pre-pandemic 'fault lines' turned into deadly chasms for persons with disabilities and their families as a direct consequence of poorly planned, funded and coordinated policy responses. The research also documents how some of the significant human rights gains achieved by the dynamic and vibrant disability rights movement in Ukraine were reversed in a matter of months following the announcement of the pandemic by the World Health Organisation in March 2020.

Our findings broadly reflect a suggestion by Shakespeare et al. (2021, p. 1331) of the "triple jeopardy" which explains the differentially negative impact of the pandemic on people with disabilities, including "the increased risk of poor outcomes from the disease itself, reduced access to routine health care and rehabilitation, and the adverse social impacts of efforts to mitigate the pandemic".

In such challenging circumstances, it is essential that organisations of persons with disabilities (OPDs) are fully recognised and supported as key actors in ensuring and protecting the rights of the persons they are

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taking care of. Ukraine ratified the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) (United Nations General Assembly, 2007) in 2010. As a ground-breaking human rights treaty, UN CRPD sets out a positive duty for state parties to ensure effective and meaningful participation of persons with disabilities through their representative organisations. This obligation encompasses "access to public decision-making spaces and also other areas of research, universal design, partnerships, delegated power and citizen control" (UN CRPD, 2018, para. 17). Within this context, public authorities in Ukraine at all levels of governance are required to support, as much as possible, the activities of the Ukrainian OPDs in compliance with Ukraine's obligations under UN CRPD.

In exploring the impact of the pandemic on people with disabilities in Ukraine, this research project was collaboratively designed and delivered with many of the leading OPDs in Ukraine. It included the largest survey to date of OPDs in Ukraine that explored their views on the extent of their participation in some of the most important and fundamental decision-making processes which concerned the wellbeing of persons with disabilities in Ukraine within the context of the pandemic.

The outcomes of our research suggest that a lot more remains to be done by public authorities in Ukraine to ensure effective and meaningful participation of persons with disabilities in public life, including the involvement of their representative organisations. The following set of recommendations has been developed as an outcome of participatory analysis workshops, where the key themes emerging from the research were presented to, and discussed, with representatives of the Ukrainian OPDs.

1. The UN CRPD and Article 10 of the General Comment to the UN CRPD reiterate the role of OPDs in ensuring their meaningful participation in decision-making processes. In clarifying the scope and meaning of state obligations as codified by the Convention, the General Comment (UN CRPD, 2018,

para. 10) suggests that the proper implementation of the UN CRPD requires state parties to "define the scope of organizations of persons with disabilities and recognize the different types that often exist". Our research demonstrates that in responding to COVID-19, the Ukrainian authorities often failed to promptly identify and react to the specific and disproportionate impact of the pandemic on people with disabilities in Ukraine. At every level of government decision-making, the role of OPDs in helping secure the very basic survival needs of the most vulnerable individuals with disabilities was overlooked. Such lack of recognition and support was most noticeable during the early stages of the pandemic and over the periods of government mandated 'lockdowns', where both the availability and access to the very basic survival infrastructure (healthcare, food and information) was completely withdrawn or severely restricted.

OPDs must be recognised as key stakeholders in planning for and sustaining the continuity of basic life support services in the event of any future public health or other emergencies. The Government and the Parliament of Ukraine should ensure that the unique characteristics, types, and functions of OPDs, including distinctions between OPDs and other civil society organisations, are acknowledged at the legislative level. The Government of Ukraine should establish clear criteria for registering OPDs and should maintain an up-to-date register of all OPDs in Ukraine.

This will enable decision-making bodies relevant to the implementation and monitoring of the UN CRPD to systematically and openly approach, consult and involve, in a meaningful and timely manner, OPDs at all levels of governance in Ukraine. The recognition and the support of OPDs as key stakeholders will further empower OPDs to involve, engage and represent the interests of the persons with disabilities as mandated by the UN CRPD's Article 4 (3) and Article 33 (3).

- 2. Our research demonstrates that OPDs in Ukraine continue to experience a lack of access to facilities, including, first and foremost, affordable office space to conduct their activities. The impact of the pandemic has only magnified this challenge. The Government and the Parliament of Ukraine should facilitate the process of amending the Law of Ukraine *On the Lease of State-owned and Communal Property* (in particular, Article 15) to include OPDs as entities eligible to lease state and communal property without holding an auction (as a way of determining the highest bidder) (Verkhovna Rada of Ukraine, 2019a). In addition, the Government of Ukraine should include OPDs as entities eligible to receive a subsidy to lease (rent) state and communal property (as currently determined by Decree 630 of the Cabinet of Ministers of Ukraine (2021b)). The Government of Ukraine should also provide needs-based grant assistance towards electricity, water/sewage rates and other utility payments for registered OPDs.
- **3.** Our research demonstrates that OPDs experienced significant difficulties in securing sustainable organisational funding within the context of the pandemic<sup>34</sup>. One of the key concerns for OPDs in Ukraine is the continuity of their organisational activities and their dependency on funding allocated for delivering specific, time-limited projects or events rather than funding allocated towards their continual, dayto-day organisational / institutional needs and activities. The Government should ensure that yearly funding allocations from the State Budget of Ukraine under the dedicated 'Financial Support of OPDs' funding programme are not exclusively allocated towards stand-alone projects or events but are also used to support day-to-day organisational activities of OPDs. The latter should include, as a minimum, core organisational activities (accounting, human resources), human rights advocacy work, participation

<sup>&</sup>lt;sup>34</sup>On the challenges of securing funding for OPDs, see United Nations General Assembly (2016).

in decision-making, monitoring and implementation processes<sup>35</sup>. International donors should equally diversify their funding models by prioritising Organizations 'of' persons with disabilities over Organizations 'for' persons with disabilities (UN CRPD, 2018, para 13), and by allocating funding towards the ongoing organizational costs in addition to supporting specific, short-term events or projects.

- 4. Our research identified a range of concerns in relation to the availability, accessibility, and reliability of COVID-19 information disseminated by public authorities, especially at the early stages of the pandemic. We identified that no meaningful consultation or engagement with OPDs took place to ensure that this crucial information was delivered in accessible formats and responded to the specific concerns of people with disabilities. The Government of Ukraine, in close cooperation with OPDs, should develop a rapid response protocol (action plan) to establish a mechanism for rapid translation, interpretation, and dissemination of the time-critical information within the context of the ongoing pandemic, and in the event of any future public health or other emergencies. The Government of Ukraine, including the Ministry of Digital Transformation of Ukraine, and all public authorities must ensure that all information, including the websites of *all* public bodies, is available in accessible digital formats and, when required, through the provision of sign language interpreters, Easy Read text and plain language, Braille and tactile communication.
- **5**. All public authorities in Ukraine must ensure that all electronic resources, including web-site interfaces, designed to facilitate the process of local democracy or 'open government' (for example, a website enabling citizens to vote for/select a city masterplan) are fully accessible.

<sup>&</sup>lt;sup>35</sup>The Budget of Ukraine for 2021 allocates 91,426,000 UAH (or about £2.5 million – rate of exchange as of 28 December 2021) specifically towards supporting OPDs in Ukraine. See Verkhovna Rada of Ukraine (2021).

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- 6. Our research collated the evidence of the deteriorating economic situation (including bankruptcies and closure) of enterprises established by OPDs caused by the pandemic. To mitigate the wider so-cio-economic impacts of the pandemic, the Government of Ukraine should continue supporting enterprises established by OPDs<sup>36</sup> by allocating additional funding via dedicated funding programmes, tax exemptions, and through preferential government/ public procurement.

Our research identified a number of cases where essential social services for people with disabilities such as supported living, supply of food, medications, personal hygiene items, mobility assistance, fuel and other essential items, plus other key services<sup>37</sup> were either not available pre-pandemic or were withdrawn or significantly reduced at the start of the pandemic. We collated evidence of the essential social services' quality falling below reasonable quality thresholds In June 2020, the Cabinet of Ministers of Ukraine approved (by a decree) *The Procedure for Monitoring the Provision and Assessment of the Quality of Social Services*. See Cabinet of Ministers of Ukraine (2020b).

7. The required volume and of sufficient quality to sustain the basic level of care. OPDs should be actively involved in the process of continuous monitoring of the quality of the social services delivery. The Government of Ukraine should consider amendments to the current legislation to identify OPDs as preferred providers of social services for people with disabilities within the context of public procurement associated with the delivery of social services in Ukraine. The Government, in close cooperation with OPDs, should develop a rapid response protocol to ensure the continuity of social services delivery in the event of any future public health or other emergencies.

<sup>&</sup>lt;sup>36</sup>As of December 2021, Ukraine does not recognise 'social enterprise' as a legal entity.

<sup>&</sup>lt;sup>37</sup>Described as 'complex social services', 'complex specialized social services' or 'ancillary social services' by Article 16 of the Law of Ukraine on 'Social Services' See Verkhovna Rada of Ukraine (2019b).

- 8. To develop and strengthen capacity of OPDs for effective and meaningful participation in policymaking and decision-making, the Government of Ukraine should provide further opportunities to develop competencies, knowledge, and the skills of OPDs (and their representatives) on a rightsbased approach to disability. The Government should provide regular training opportunities to OPDs' / representatives on the evolving legal and policy-making landscapes in relation to human rights and disability-specific issues. The Government of Ukraine and other non-governmental / international funding agencies should provide continuous pre-application support to OPDs on developing funding applications for specific funding programmes, and post-award support to successful applicants on managing the grant, including financial reporting.
- **9.** The accelerated move towards remote and/or flexible work arrangements requires, as a minimum, the availability of the Internet, access to suitable devices, and a corresponding level of digital skills and awareness. Our research demonstrates that for many OPDs these minimum requirements could not be met without external support. We found compelling evidence of 'digital exclusion' among OPDs and, more generally, among people with disabilities. The Government of Ukraine should ensure that OPDs are supported in their efforts to overcome any digital divides, including access to suitable devices and internet connection, as well as digital literacy.
- 10. Our research identified a number of examples where public authorities in Ukraine failed to involve and/ or give due consideration and priority to the legitimate opinions and views of OPDs when addressing issues directly related to persons with disabilities especially in relation to the COVID-19 pandemic. To fulfil its duty to closely consult on a timely basis with, and actively involve, persons with disabilities

through their representative organizations, the Government should require all public authorities in Ukraine to develop (in cooperation with OPDs) context-specific mechanisms to involve OPDs in the decision-making, implementation, and evaluation process, and to give due consideration and priority to the opinions and views of OPDs when addressing issues directly related to persons with disabilities. This recommendation can be operationalized by the Government of Ukraine by:

- Maintaining an up-to-date database of all registered OPDs and introducing a mandatory requirement for all public authorities (or private companies acting on behalf of public authorities) at all levels of governance in Ukraine to systematically and openly approach, consult and involve OPDs in a meaningful and timely manner. Consultations with and the involvement of OPDs should become a mandatory step prior to the approval of laws, regulations, and policies, whether mainstream or disability specific. This could pave the way towards the introduction of the disability equality duty at the legislative level.
- Amending the existing policies and procedures to include an explicit requirement for the involvement of OPDs at different levels of decision-making, including two decrees issued by the Cabinet of Ministers of Ukraine, which set out the procedures for the involvement of wider civil society into policy making and policy implementation processes: Decree 599-2009 (17 June 2009) on the *Issue of Consultative, Advisory and Other Subsidiary Bodies Established by the Cabinet of Ministers of Ukraine (*Cabinet of Ministers of Ukraine, 2009); and Decree 996-2010 (3 November 2010), *On Ensuring Public Participation in the Formation and Implementation of Public Policy* (Cabinet of Ministers of Ukraine, 2010).

- Requiring 'united local communities' (as a key unit of local self-governance) to include a dedicated provision within their statutes setting out a transparent mechanism for the meaningful participation of, and consultation with, OPDs on all matters of local self-governance related to persons with disabilities.
- Requiring that OPDs are represented on regional coordination councils set up to foster the development of civil society and to implement the *National Strategy to Facilitate the Development of Civil Society in Ukraine in 2021-2026* (President of Ukraine, 2021).
- Enabling OPDs to access (upon request) meetings of public authorities (at all levels of governance) in an observer capacity.
- Disseminating examples of best practice in meaningful and impactful collaboration between public authorities and OPDs in relation to the implementation of the UN CRPD.
- 11. Our research recorded evidence of a decreasing volume of collaboration, support, and cooperation between OPDs and other stakeholders, including private companies, charities, other civil society groups and non-governmental organizations, and individual volunteers. The Government of Ukraine should undertake a detailed assessment of the impact of the pandemic on these collaborative relationships and consider launching a package of support measures to strengthen the existing links and develop new intersectoral partnerships. The Government of Ukraine should consider adopting a range of measures to encourage civic participation, engagement and awareness among local communities, including school and university students.

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