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THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES AND ACCESS TO COVID-SPECIFIC HEALTHCARE BY PERSONS WITH DISABILITIES: A COMPARATIVE ANALYSIS

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ABSTRACT

The Covid-19 pandemic was a global public health emergency which impacted on almost every aspect of life and society. Yet the impact on persons with disabilities was particular and unique – combining as it did pre-existing inequalities and discrimination with a failure on the part of States and State actors to adequately respond to their needs and rights.

This chapter draws on research conducted by the ResPoNCE (Respecting Persons with disabilities' Needs and Rights in Crisis and Emergency) project to focus on the specific experience of persons with disabilities in accessing Covid-specific healthcare in seven European jurisdictions. It grounds its analysis in the human rights model of disability contained in the UN Convention on the Rights of Persons with Disabilities. Qualitative data collected for the study is relied upon to assess States' compliance with the requirements of the Convention. Recommendations are then made for human-rights based approaches to accessing healthcare in public health emergencies in the context of disability.

1. INTRODUCTION

The Covid-19 pandemic has heralded huge changes for society in general and persons with disabilities in particular. According to World Health Organisation, 15% of the world's population has a disability. In Europe, this accounts for more than 135 million people.¹ To consider the impact of the pandemic on this group, one must reflect on the definition of disability and the timeline of this international public health emergency. As a modern human rights treaty, centred upon dignity and equality, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) seeks to include, rather than exclude. It is guided by the social model, with its focus on the barriers (physical, social, attitudinal, technological) encountered by people living with impairments (physical, intellectual, psychosocial, sensory.)² The rights-based protections therein can also be extended to persons with complex medical needs, people with chronic illnesses, those who identify as autistic and/or neurodiverse.

Like the definition of disability, the concept of the pandemic is fluid and subject to change. The first confirmed case in Europe in January 2020 was swiftly followed by the declaration of an epidemic and ultimately, a pandemic; from establishing supplies of personal protective equipment (PPE) to the rollout vaccination and beyond. Many persons with disabilities, especially those who are immunocompromised or otherwise high risk are continuing to live with Covid-19, grappling with high infection rates, ever-changing public health guidance, perceptions around testing, treatment and vaccination. Disability is the one of the only marginalised groups that anyone can become a member of at any time. This is a harsh reality, known all too well by the newest cohort of persons with disabilities; those experiencing debilitating symptoms of Long Covid.

The ResPoNCE (Respecting Persons with disabilities' Needs and Rights in Crisis and Emergency) project sought to investigate the impact of the pandemic on persons with disabilities in Ireland, UK, Spain, France, Italy, Germany and Sweden. This work was completed by researchers at the University of Galway, funded by the Health Research Board as part of their Covid-19 Rapid Response Funding Opportunity. The research team adopted a human-rights

¹ WORLD HEALTH ORGANISATION 'Disability Fact Sheet' (2019) available here: <https://www.who.int/europe/news-room/fact-sheets/item/disability> accessed 1 March 2023.

² M. OLIVER 'The Individual and Social Models of Disability' (1990) p. 2

based methodology, guided by the principles of emancipatory research.³ The participants for the study self-identified as having a disability/being disabled and were valued as experts by experience. When it came to key informants who were disability-adjacent (service providers, policymakers, researchers) the research team sought a wide range of opinions and perspectives, ultimately adhering to the disability-rights mantra ‘nothing about us, without us.’

This research was divided into two work packages (WP1/2) with the aim of capturing the experience of different groups in different countries at various stages of throughout the 2-year project. WP1 encompassed extensive desk research and key informant interviews with representatives of Organisations of Persons with Disabilities (OPDs), health and social key workers as well as policymakers and/or researchers across the 7 countries. Whereas WP2 was designed as a more in-depth study of the situation in Ireland, the UK and Spain. This required more extensive key-informant interviews in the target countries, as well as participatory research. The direct involvement of persons with disabilities was facilitated via a questionnaire (various formats). This was supplemented by the delivery of impairment/age specific focus groups to reach marginalised groups who may not otherwise have the chance to contribute e.g., children with disabilities, Deaf adults. The data was then analysed using reflexive thematic analysis.⁴

This chapter will focus on the findings of the ResPoNCE Project in relation to Covid-specific healthcare. This is as opposed to general healthcare (routine General Practitioner visits, dentist visits, access to Accident and Emergency for injuries) and disability-specific healthcare (mental health services, outpatient therapies e.g., physiotherapy, occupational therapy, access to specialist medical/surgical intervention to manage one’s impairment.) For the purposes of this paper, Covid-specific healthcare encompasses new dimensions of healthcare that were created, developed or prioritised as a direct result of the pandemic i.e., testing, treatment and vaccination for the Covid-19 virus itself. These are key components of the health system which are applicable to the general population, but which may have a disproportionate impact on persons with disabilities, especially with regard to the design or implementation of guidance for health and social care professionals, the implementation of human rights-compliant standard of care, resource access to information about public health measures, the accessibility of testing and vaccination centres for persons with different types of support needs, the prioritisation and adaption of service delivery for persons on the basis of disability. This includes those who face additional barriers due to the combination of ableism and/or racism, sexism, homophobia, xenophobia. As well as the challenges faced by those who may face require decision-making support to exercise their rights before the law, especially the role of informed consent, bodily integrity as it relates to Covid-specific healthcare.

There is a dearth of data relating to the experiences of persons with disabilities living in institutions. But there can be no doubt that this group are the most at-risk in the context of any public health emergency. While, this research is predominately focused on the lived experience of persons with disabilities living in the community, however the team would like to acknowledge the unique challenges faced by this hidden cohort in accessing Covid-specific healthcare and call for the implementation of the Guidelines on Deinstitutionalisation, Including in Emergencies.⁵

This paper will contain an overview of international human rights law (IHRL) on access to healthcare in times of crisis/emergency. This will be coupled with a summary of findings, drawing attention to examples of good practice. Ultimately, the paper will provide an assessment of compliance with human rights standards, along with key recommendations for change.

2. IHRL STANDARDS ON ACCESS TO HEALTHCARE IN TIMES OF CRISIS/EMERGENCY

³ E. STONE and M. PRIESTLEY ‘Parasites, Pawns and Partners: Disability Research and the Role of Non-Disabled Researchers’ (1996) 47 (4) *The British Journal of Sociology* pp. 699-716

⁴ BRAUN, V., and CLARKE, V., ‘Reflecting on reflexive thematic analysis’ (2019) 11(4) *Qualitative Research in Sport, Exercise & Health* pp.589-597; BRAUN, V. and CLARKE, V., ‘One size fits all? What counts as quality practice in (reflexive) thematic analysis?’ (2021) 18(3) *Qualitative Research in Psychology* 328-352; BRAUN, V. and CLARKE, V., *Thematic Analysis: A Practical Guide*, Sage, California (2022)

⁵ CRPD/C/5 “Guidelines on Deinstitutionalisation, Including in Emergencies.” (2022)

2.1 CRPD STANDARDS

This section will focus primarily on the CRPD as setting out the applicable human rights standards to provide healthcare for persons with disabilities, including in times of emergency. The CRPD sets out general obligations of particular relevance to situations of emergency, such as the requirement to include consideration of ‘the protection and promotion of the human rights of persons with disabilities in all policies and programmes’⁶, as well as to promote the training of professionals and staff working with persons with disabilities on the rights contained in the CRPD ‘so as to better provide the assistance and services guaranteed by those rights’.⁷ The non-discrimination requirement at the heart of the CRPD has been reflected in the United Nations recognition early on in the pandemic that, in ensuring that everyone is protected from Covid-19 and its impact, ‘special measures and protection for particular groups most at risk or disproportionately impacted’ may be required.⁸

Article 11 of the CRPD directly addresses situations of risk and humanitarian emergencies, referring to existing obligations under international humanitarian law and international human rights law, and requiring that States parties take ‘all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.’ This obligation on States is of particular relevance in the context of the Covid-19 pandemic, given the increased mortality and morbidity risk where the disease is contracted by persons with certain impairments⁹, as well as the greater probability of contracting the virus in institutional settings, where persons with disabilities are disproportionately represented¹⁰, due to lack of space to physically distance and limitations on hygiene facilities and their availability. In addition, the potential impact of pandemic-related measures and restrictions on the lives of persons with disabilities is heightened due to pre-existing systemic inequalities and discrimination, including the fact that persons with disabilities are more likely to be living in situations of socio-economic disadvantage.¹¹ Persons with disabilities are also more likely to be older, and therefore at greater risk of contracting the virus.¹²

Barriers to healthcare for persons with disabilities predate the pandemic, with the Committee on the Rights of Persons with Disabilities noting the impact of the absence of accessible transport on these areas of life, as well as the equally relevant deficits in implementation and resourcing of accessibility measures to ensure access to information and communication.¹³ Article 9 of the CRPD requires States to identify and eliminate obstacles and carriers to

⁶ CRPD, Article 4(1)(c)

⁷ CRPD, Article 4(1)(i)

⁸ United Nations, ‘COVID-19 and Human Rights: We Are All in This Together’ 23.04.20 Available at https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2020/04/un_policy_brief_on_human_rights_and_covid_23_april_2020.pdf last accessed 26 October 2021.

⁹ A. KAVANAGH and others, ‘Health and Healthcare for People with Disabilities in the UK during the COVID-19 Pandemic’ (2022) 15 (1) *Disability and Health Journal*.

EUROPEAN UNION AND AGENCY FOR FUNDAMENTAL RIGHTS ‘Coronavirus Pandemic in the EU: Fundamental Rights Implications’. Bulletin #1 (2020), p. 30.

THE HEALTH FOUNDATION ‘Unequal Pandemic, Fairer Recovery: The COVID-19 Impact Inquiry Report’ (2021) p. 4 <https://www.health.org.uk/publications/reports/unequal-pandemic-fairer-recovery> last accessed 3 November 2021;

T. SHAKESPEARE and others, ‘Triple Jeopardy: Disabled People and the COVID-19 Pandemic’ (2021) 397 (10282) *The Lancet* pp. 1331-1333

M.A. Turk and others ‘Intellectual and Developmental Disability and COVID-19 Case-Fatality Trends: TriNetX Analysis’ (2020) 13(3) *Disability and Health Journal*

B. PERERA and others, ‘COVID-19 Deaths in People with Intellectual Disability in the UK and Ireland: Descriptive Study’ [2020] 16 (6) *BJPpsych Open*

¹⁰ KAMALAKANNAN and others, ‘Health Risks and Consequences of a COVID-19 Infection for People with Disabilities: Scoping Review and Descriptive Thematic Analysis’ (2021) 18 (8) *International Journal of Environmental Research and Public Health*
CARE POLICY AND EVALUATION CENTRE ‘Crystallising the Case for Deinstitutionalisation: COVID-19 and the Experiences of Persons with Disabilities’ (2021). Available at: <https://www.lse.ac.uk/cpec/research/coviddeinstitutionalisation> last accessed 1 March 2023

¹¹ WORLD HEALTH ORGANISATION, ‘COVID-19 and the Social Determinants of Health and Health Equity: Evidence Brief, IV’ (2021) Available at <https://apps.who.int/iris/handle/10665/348333> accessed 7 December 2021.

UNICEF, ‘COVID-19 Response: Considerations for Children and Adults with Disabilities’, (2020)

<https://sites.unicef.org/disabilities/files/COVID-19_response_considerations_for_people_with_disabilities_190320.pdf> last accessed 26 October 2021.

¹² UNITED NATIONS ENABLE ‘Ageing and Disability’

¹³ Committee on the Rights of Persons with Disabilities, ‘General Comment No. 2 (2014) Article 9: Accessibility’ (22 May 2014) para 7.

accessibility in all aspects of life. This obligation not only includes access to physical spaces, but also the right to access information, as well as personal assistance for the facilitation of accessibility and the utilisation of technology. Failure to vindicate the right to accessibility under Article 9 of the CRPD may result in barriers to the exercise of legal capacity and, as such, amount to an additional breach of Article 12 of the CRPD.¹⁴ Article 12 is also engaged separately in light of its obligations to respect the decision-making capacity of persons with disabilities and provide support to enable such decision-making where chosen. It also places a duty on States to be guided by the will and preferences of the individual rather than external, ‘objective’ determinations of what decision should be made. This has particular relevance for healthcare decision-making and ethical guidance for healthcare providers in the context of the pandemic, especially in the context of informed consent to treatment or vaccination for Covid-19.

Article 25 of the CRPD recognises the right to the enjoyment of the highest attainable standard of health of persons with disabilities without discrimination on the basis of disability. It requires States Parties to provide persons with disabilities with the same ‘range, quality and standard of free or affordable health care and programmes as provided to other persons’; to provide health services that may be needed by persons with disabilities specifically because of their disabilities, including early identification and intervention, and services designed to minimize and prevent further disabilities, including among children and older persons’. Health professionals are required to ‘provide care of the same quality to persons with disabilities as to others’ which includes ‘raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care’. In its General Comment on equality and non-discrimination, the CRPD Committee has been clear that States parties ‘must prohibit and prevent discriminatory denial of health services to persons with disabilities’ and ‘must also address forms of discrimination that violate the right of persons with disabilities that impede their right to health through violations of the right to receive health care on the basis of free and informed consent, or that make facilities or information inaccessible’.¹⁵

2.2 STATEMENTS OF OTHER UNITED NATIONS ACTORS

In a joint statement in April 2020, the UN Committee on the Rights of Persons with Disabilities and the Special Envoy of the UN Secretary-General on Disability and Accessibility¹⁶ highlighted that Article 11 includes ‘the protection of their access to the highest attainable standard of health without discrimination, general wellbeing and prevention of infectious diseases’.¹⁷ The Joint Statement also affirmed that States should continue providing persons with disabilities with the health services they require ‘specifically because of their disabilities’ and ‘prevent discriminatory denial of health care or life-saving services, food or fluids on the basis of disability’.¹⁸ The Statement called on ‘all relevant authorities’ to ‘adopt measures to appropriately respond to the COVID-19 pandemic, ensuring inclusion and the effective participation of persons with disabilities’.¹⁹

In a separate statement²⁰ which was endorsed by the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members and the Independent Expert on the enjoyment of all human rights by older persons, the Special Rapporteur on the rights of persons with disabilities at the time, Catalina Devandas, emphasised the particular impact that legal and policy measures such as social distancing and self-isolation were having on persons with disabilities who require support to engage in day-to-day activities. She also

¹⁴ Committee on the Rights of Persons with Disabilities, ‘General Comment No. 1 (2014) - Article 12: Equal Recognition before the Law’ (19 May 2014) para 37 .

¹⁵ Committee on the Rights of Persons with Disabilities, ‘General Comment No. 6 (2018) on Equality and Non-Discrimination’ para 66.

¹⁶ “Persons with Disabilities and COVID-19” - Joint Statement by the Chair of the United Nations Committee on the Rights of Persons with Disabilities, on behalf of the Committee on the Rights of Persons with Disabilities and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility (Adopted 1 April 2020)

¹⁷ *ibid*, para. 2

¹⁸ *ibid*, para. 7

¹⁹ *ibid*, para. 6

²⁰ OHCHR ‘Covid-19: Who is protecting the people with disabilities?- UN Rights Expert.’ 17.03.20 available at: <https://www.ohchr.org/en/press-releases/2020/03/covid-19-who-protecting-people-disabilities-un-rights-expert> last accessed 26 October 2021

linked the requirement of reasonable accommodation - for both the person themselves and their families and caregivers - in facilitating a reduction in social contacts and a consequent lowering of the risk of transmission, including by working from home or receiving paid leave from employment. She emphasised that ‘persons with disabilities deserve to be reassured that their survival is a priority’ and called for States to ‘establish clear protocols for public health emergencies to ensure that, when medical resources are scarce, access to healthcare, including life-saving measures, does not discriminate against people with disabilities’.

These commitments are further reflected in the WHO guidance issued early in 2020 on disability considerations during the Covid-19 outbreak. This provided separate guidance for key actors, including governments and healthcare professionals, as well as for disability service providers in the community and institutional settings, to minimise the spread of the virus while respecting the human rights of persons with disabilities. Targeted actions for governments included the need to make all communications about the pandemic accessible in different formats including Braille, sign language, captioning, Easy to Read, etc. Governments were also advised to work directly with persons with disabilities through their representative organisations to disseminate public health information. Targeted actions for the healthcare sector echoed these requirements, and required services to address barriers to accessing the physical infrastructure of settings in which Covid-19 healthcare was provided, as well as delivering home-based and telehealth consultations for persons with disabilities, including for Covid-19 related needs. Importantly, this guidance required healthcare providers to ‘ensure that decisions on the allocation of scarce resources (e.g. ventilators) are not based on pre-existing impairments, high support needs, quality of life assessments, or medical bias against people with disability’.

Taken collectively, these statements from key UN mandate holders and agencies such as the WHO reaffirm the commitment to human rights obligations in the delivery of healthcare services including vaccinations and medical treatment for Covid-19 to persons with disabilities during the ongoing public health emergency of the pandemic. The following section will address the extent to which these human rights obligations were adhered to, or ignored, in the experiences of persons with disabilities throughout the European countries included in the ResPoNCE study.

3. FINDINGS ON THE EXPERIENCE OF ACCESS TO COVID-SPECIFIC HEALTHCARE BY PERSONS WITH DISABILITIES

In assessing the extent to which States complied with the rights of persons with disabilities, it is necessary for the voices of those individuals (and their representative organisations) and their experience of accessing Covid-specific healthcare to be centred. This section will set out some of the experiences of persons with disabilities in accessing Covid-specific healthcare, identifying the specific issues which arose – which are not homogenous - as well as contrasting the perceptions of policymakers and health and social care professionals. This latter perspective is relevant in understanding the legal, policy, and practice perspectives which informed the approach to the creation and operation of systems of Covid-specific healthcare, as well as any gaps in understanding which exist between and within these groups.

3.1 ACCESSIBILITY

Accessible information

The accessibility of information on Covid-specific healthcare is a central part of ensuring that decision-making by persons with disabilities is informed. A recurring issue for persons with disabilities in a number of jurisdictions was the accessibility of information relating to Covid-19 healthcare. For example, in many cases there was failure to produce Easy Read and/braille versions of information that was intended to inform the public about Covid-specific healthcare. One OPD for persons with intellectual disabilities stated:

‘The quantity and speed of information that was being shared at the beginning of the pandemic was overwhelming and it was extremely challenging to understand what was going on with the lack of accessible information.’

One UK OPD linked this problem to a pre-existing failure to produce accessible information more generally.²¹

An issue that arose for the Deaf community was the use of new Covid-related terminology and its translation into sign language:

‘So, with testing, you know, like the words or the phrases, I didn’t know what they meant. It was easier when they were translated. At first, I didn’t know. It is hard using that terminology. It wasn’t possible for the deaf community, I feel.’²²

One striking example was provided by an OPD based in the UK:

‘In one of our meetings, a self-advocate rang the 119 number [the NHS Test and Trace service telephone number] and actually asked for the information in easy read. And the person on the other end said, “What’s easy read?” So, the actual packs, the actual, if you wanted to have a ... get a test, the information on how to use the test wasn’t in easy read.’²³

In some jurisdictions, clear efforts were made by the health services to ensure the provision of accessible information regarding Covid-specific healthcare, including the co-production with persons with disabilities of Easy Read and Plain English information on vaccination. For example, the Irish health service developed online information videos, including with sign language, as well as documents in braille.²⁴ From their perspective, this meant that in congregated settings:

‘The majority of residents that we did speak to, they really understood vaccination.’²⁵

However, for some persons with disabilities, what was considered to be ‘accessible’ information fell short of their needs and they suggested:

‘Making pictures bigger and clearer, the book needs to be simpler, less words, there should just be pictures with four or five steps, large print and big writing, we need a demonstration, it works much better when you see someone doing it, maybe good videos you can watch would be good, I want bigger pictures or maybe a video of someone demonstrating it.’²⁶

The concern around the accessibility of information regarding Covid-specific healthcare was shared by one researcher:

‘I’m far from sure how good any accessible information actually produced over time actually was at an official level. I know that lots of organisations raced forward and sought to, you know fill the gaps, if you see what I mean, in different ways.’²⁷

Accessibility of testing and vaccination

In a focus group with Deaf people in Ireland, the inaccessibility of a testing centre was explained by one participant:

‘... going into the testing centres, we nearly felt like robots. Obviously everybody had to wear masks, everyone had to have this and that, but it wasn’t very personal. We felt like cattle being shoved in and we didn’t know where we were going because obviously people were wearing masks and they were talking through their masks. I couldn’t hear them, so I would nearly try looking at their visual cues and then... But it wasn’t even... Like, we didn’t know timewise how things were going to work and like, it was nearly like being in a foreign country is the way I can

²¹ UKDPO4

²² A participant in a focus group for Deaf people in Ireland

²³ UKDPO1

²⁴ IRLHSC5

²⁵ IRLHSC2

²⁶ UKDPO4

²⁷ UKPR1

actually put it in that we didn't know where we were going, we didn't know what we were doing. Accessibility when you're in the testing centre was really, really poor.'

Similar issues were described by an OPD in the UK:

'And we would have found experiences where people would have arrived and some people who would have known how to use the tests would have been fine, some people wouldn't because it's all English based the introductions on how to take your test, so some of the staff members would have been trying to use body language, and gesturing, but it would have become quite panicked because sometimes they would have been too agitated, almost too, it was quite distracting, you couldn't really follow what they were supposed to be doing because it was almost too animated.'²⁸

One questionnaire respondent in the UK contrasted her inaccessible experience of accessing vaccination with that of a person without a disability:

'Vaccination was a problem, I had to go to difficult to access places on all 3 occasions. There was no flexibility allowed to accommodate the fact that I am a wheelchair user. For the first 2 vaccinations, I had to do a journey that could have involved 2 bus journeys and a train, and would still have left me about 1/2 mile from the venue. As it was by lots of manipulation and changing of dates, I was able to arrange a lift. For the third one, I had to undertake 2 bus journeys. The round trip took 5 hours once queuing at the venue was included. My non-disabled husband was able to go to the GP practice down the road for his first two. I cannot see why the wheelchair user wasn't allowed to do the same!'²⁹

A questionnaire respondent in Ireland set out the inaccessible aspects of their vaccination centre experience:

'I went to the local walk-in clinic for my booster. This was accessible, but the staff were poorly trained. They spoke to my family member instead of me re: allergies and touched my wheelchair without permission.'³⁰

One French OPD highlighted problems with transport for persons with disabilities as a barrier to accessing vaccination centres.³¹ A German OPD noted that while most testing and vaccination centres were accessible, there were often deficiencies in signage for those with visual impairments. In addition, some people encountered difficulties where they wished to be accompanied by their personal assistant, as well as a failure to provide accessible parking at some centres.³² Similar issues were raised by a Spanish OPD:

'During the vaccination phase, I noticed that the places where you could get vaccines did not take into account accessibility, but in regards to the vaccination site itself, it was way too small, and they didn't take into account that it had to be large enough for a person using a wheelchair to access. It was way too small, way too restricted. I think that they failed to keep in mind true accessibility for people with physical [disabilities]. Neither did they have any type of alternative format, no sign language format. They really did not keep in mind people with visual [disabilities]. There was no accessibility for them.'³³

The communication of results of Covid-19 tests were also problematic for Deaf people, as explained by a focus group participant from Spain:

... in the case of when they did the COVID test, they will call you and tell you that if it was negative, they'll send you a text but if it was positive, they will call you to tell you. So, in our

²⁸ UKDPO3

²⁹ PD UK 8

³⁰ MU-IRL-3

³¹ FRDPO1

³² GRDPO1

³³ SPDP02

case it was the other way around then because it was, when we didn't get the text, we knew that we had the COVID.

An OPD for persons with intellectual disabilities based in Scotland listed some of the accessibility issues that their members had encountered:

'... demonstrations and videos seemed to help but sometimes members found them difficult to follow, one member found the test distressing to watch, the NHS easy-read document online was not updated for the new type of test when the change happened and this also caused confusion. Many members have said they needed individual support in order to do the testing and most members did not find ordering tests online accessible. Many members got out a box from the local pharmacy and had a family member who helped them occasionally to do the test.'³⁴

The strong focus placed on using online platforms as the primary means of communication and service provision was criticised by one UK OPD of persons with intellectual disabilities, which felt that many of its members did not find ordering tests online to be accessible.³⁵

OPDs stepping in to provide accessibility

A consistent finding from the project was the work of OPDs and other civil society organisations to try to ensure the provision of accessible information where there had been State failures to do so. Some of this work was funded by the State, while much was undertaken voluntarily by the organisations. As one Scottish policymaker explained:

[There were] 'challenges with easy read format. It fell to charities actually very often to lobby the government and then the government said, 'Well fine, you do it and we'll pay you for that.'³⁶

A Deaf focus group participant in Spain provided another example of civil society stepping in to address the accessibility gap:

'During the confinement, first of all, was really scary at the beginning because we didn't know what was happening and then little by little we started to obtain information and they start to create information in our language and what happened and then the Confederation for Deaf People in Spain start to create material that made that information accessible for us, the positive part was that it was a huge movement from deaf people in social media and which help us to inform each other ...'

Deaf people in Germany had a similar experience:

'... the information was also a big problem. Like in the very beginning, I remember when the politicians held their press conferences, it was only in German language. It was not written. It was no sign language. For weeks, for months. So, the first wave was not... Information was so bad. Let's say this. And again, people had to become very loud to create a change and improving it.'³⁷

An OPD for persons with intellectual disabilities in the UK set out the work that they had had to do, in collaboration with other civil society organisations, to compensate for inaccessible information:

'... our members weren't getting any kind of information that made sense to them, so a lot of our members stayed indoors, so if I could give an example: one of our members stayed in and they thought that if I went into my own garden, I'd get COVID.'³⁸

³⁴ UKDPO4

³⁵ UKDPO4

³⁶ UKPR2

³⁷ GRDPO1

³⁸ UKDPO4

3.2 VACCINE ROLLOUT

State failures to prioritise

An issue which arose in a number of jurisdictions was the failure of States and health services to prioritise the offering of the Covid-19 vaccine to persons with disabilities who had been shown to be at higher risk of contracting the virus and/or experiencing higher levels of morbidity and mortality. A questionnaire respondent with a physical disability based in Spain relayed the fear that resulted from the manner in which vaccination was prioritised in that jurisdiction:

‘In the vaccinations they were going through gradually, backwards towards younger generations. I’m 47, but high risk, so I should have been considered one of the first ones after the elderly. But they left me behind with the younger generation. I didn’t mind, as I wasn’t going out. But I said, I might not be going outside, but Covid has come to visit me through my care workers and PAs. It was a scary time. They told me I had to wait like everyone else, it was frustrating.’³⁹

One researcher based in the UK was highly critical of the amount of time it took for the need for some persons with disabilities to be prioritised in the vaccination schedule to be understood and translated in prioritisation:

‘... there was... for it felt like a disturbingly large number of months a kind of ‘Why aren’t you listening to the fact that there’s a group of people who clearly require vaccination? Or that the... the basis upon which you are proposing to prioritise older people, that basis applies just as much to these groups of people, because they’ve got specific issues, which means that if they catch Covid they’re just in just as serious, if not more serious trouble than a person who’s older.’⁴⁰

A similar approach to prioritising age over disability arose for the first months of the vaccination programme in France.⁴¹

Failures to formally prioritise carers occurred in Scotland, as one policymaker set out:

‘... family carers and informal carers were never included. There was tranches, so what you might have is the ridiculous situation of someone who cares for a person taking them to their vaccination, that person getting vaccinated but the carer not getting vaccinated but having been exposed to all of those people in a mass vaccination centre. And also that carer having the challenge of having to go to the shops and having to go, you know, and get things and all the rest of it. So, it was a real challenge in terms of making sure the right people were vaccinated at the right time.’⁴²

Civil society advocacy on vaccination

In a number of jurisdictions, lobbying by civil society went some way towards addressing the initial failures on the part of States to appropriately prioritise the vaccine programme. As a researcher in Ireland explained:

‘... there was fairly immediate criticism from several high profile advocacy groups about the lack of prioritisation for persons with disabilities in the initial drawing up of vaccine cohorts and from memory, very quickly after those criticisms were aired a change was made and at least some people falling into that category were moved from, I think it was group seven up to group four or thereabouts in terms of priority, so there certainly was a concern that initially in the conception of the vaccine rollout, not enough regard was paid to making sure there was regard

³⁹ PD-ESP-12

⁴⁰ UKPR1

⁴¹ FRPR1

⁴² UKPR2

for persons with disabilities and there the specific health and other benefits that could come from them being prioritised for a vaccine ...⁴³

A similar need to advocate for vaccine prioritisation was outlined by an Italian OPD:

‘the associations had a crucial importance in this because probably if they didn’t intervene probably people with disability would have been the last group being vaccinated.’⁴⁴

3.3 INFORMED CONSENT FOR TESTING, VACCINATION AND/OR TREATMENT

A health and social care professional voiced his view on the operation of informed consent during the first waves of the pandemic:

‘I think that informed consent has been a real challenge during the pandemic. I mean in my case, for example, very often we didn’t have the time or the possibility to have a conversation because people that... our patients, they had a respiratory failure that... I mean it was a huge obstacle to conversations. So, you could just talk with someone and try to plan ahead for a few days. But of course, you couldn’t do real advanced care planning or share decision making process with the patients and families.

A participant in a focus group with persons with psychosocial disabilities in Spain spoke about his distressing experience regarding informed consent to be vaccinated:

‘When I had the ... the second and first vaccine, I asked the nurse, I told her I take psychiatric medication, is there any contradiction with the vaccine, and she told me, oh well, we know so little, we don’t really know anything. And then she proceeded to put the vaccine, to apply the vaccine on me, and I was left in a state of shock because I was doing this because of... I was taking the vaccine because of my job, working situation. And then I was left with this feeling that I didn’t know what was going to happen ...’

One UK researcher remarked on how the process of the Covid-19 vaccine rollout highlighted broader issues of consent to other medical treatment and the existence of (potentially extra-legal) substitute decision-making:

‘... you then realise the extent to which vast numbers of people had previously been entirely missing out on... well either missing out on the flu vaccine, because no one knew what to do, or were getting it in circumstances where if you actually looked at what was happening, it was like ‘Can you tell me whether this vaccine was delivered on the basis of consent or on the basis of some weird ‘We thought it was in your best interests, but we didn’t ... or ‘We just got your Mum to sign it.’⁴⁵

This legacy of paternalism also impacted on the environment in which health and social care professionals who wished to respect a person’s will and preferences to be vaccinated operated. One based in Ireland highlighted:

‘... we would have had some of those people who were verbal, and so the person themselves with the intellectual disability – this is where it got really difficult – were saying ‘Yes, please vaccinate me. I want to be vaccinated. I want to go out with my friends. I want to go to day services. I want to be vaccinated.’ And we have families saying ‘Over my dead body. I am in control of this person. You cannot vaccinate them, and I am taking it to the High Court.’ There were quite a number... I don’t know if there was ever one that went to the High Court, but

⁴³ IRLPR3

⁴⁴ ITDPO1

⁴⁵ UKPR1

certainly there were several threats of High Court... going to the High Court, and several providers were threatened that they were going to be taken to the High Court if they did it.’⁴⁶

A Spanish health and social care professional also relayed how guardians (substitute decision-makers for people who have had their legal capacity removed), provided formal consent to vaccination, although efforts were also made to speak to the individual concerned.⁴⁷ A Spanish OPD placed this in the broader context of the paternalism around decision-making by persons with disabilities in that jurisdiction:

‘... that the model in which they’re working with is that someone chooses for you, so very paternalistic. And in terms of accessing healthcare, anything to do with health issues, there is that guardianship model in which someone takes a decision for you, thinking that they know better, they know what you need. So, there’s no support for allowing independent decision-making.’⁴⁸

In contrast, in Ireland, a health and social care professional explained how staff prioritised the wishes of persons with disabilities, even in circumstances where family members may have been in disagreement:

‘They still went ahead and vaccinated the person, because it was the person’s will – they wanted to be vaccinated – but that’s where we did have some very significant issues around the families just could not understand how a provider could arrange the vaccination for somebody that they felt didn’t have capacity, but that the provider felt ‘Actually, I work with this person all the time. I understand them. I understand their needs. I understand what they’re communicating to me, and they do want to be vaccinated.’⁴⁹

The concerns of people with disabilities around the non-consensual use of ‘Do Not Resuscitate’ orders

A fear that was mentioned by research participants was the imposition of ‘Do Not Resuscitate’ orders (DNRs) on persons with disabilities by health and social care professionals without their consent. A representative of an Irish OPD explained:

‘I think DNR, do not resuscitate is a huge fear – huge fear for a lot of people. That if somebody got COVID and ended up in hospital, that they wouldn’t receive the same level of treatment as a non-disabled person. That was a huge fear, and that wasn’t just in Ireland, that was cross-jurisdictional. I think there is that fear anyway, but in a pandemic situation – when you’re hearing on the news that nursing homes and residential homes for disabled people were literally abandoned by staff in other countries. And they were abandoned by staff, and basically residents all died, because they’d literally just been left to die. When you’re hearing that kind of stuff on the news, that does get inside your head, and it does really affect people. So, that heightens the fear. While there was nothing quite so overt here, fears weren’t exactly realised here in that kind of way, it was just... sorry, this is a hard one.’⁵⁰

An OPD based in the UK echoed similar concerns:

‘One of our main concerns of the pandemic was also the fact that so many people with learning disabilities had ‘Do not resuscitate’, put on their forms when they were in hospital without asking the person or their family, this is shocking, no other group of citizens would be experiencing being failed by the health system like this without far bigger headlines in the news.’⁵¹

⁴⁶ IRLHSC5

⁴⁷ SPHSC1

⁴⁸ SPDPO3

⁴⁹ IRLHSC5

⁵⁰ IRLDPO4

⁵¹ UKDPO4

One Scottish policymaker thought that this issue would continue to be the subject of litigation:

‘... there are people who essentially through their GP and the power of attorney essentially had a blanket DNR put on them during the pandemic, with little justification or understanding of why that happened and what safeguards actually are in place in the system. So, I think, I don’t think we’ve seen it yet but I think we will certainly see maybe a class action around some of that.’⁵²

3.4 CLINICAL DECISION-MAKING & RESOURCE ALLOCATION

Health and social care professionals in a number of jurisdictions recounted how a view was formed amongst some clinicians that there should be an agreed approach to triage – in particular admission to intensive care units but also hospital admission and access to oxygen – in circumstances where there were insufficient resources. One health and social care professional in Italy explained:

‘... for the first recommendations we were accused of being ageist and discriminatory because we stated that COVID was deadly for very elderly people, the severe form of COVID, I mean, requiring intubation and ICU and mechanical ventilation. And so, we stated, and this was controversial, of course, that in case of a severe shortage of resources, when you have many people dying outside of the ICU, if you want to save as many lives as possible, you have to admit to the ICU the people with a reasonable chance of survival. And that means maybe not admitting an elderly, frail patient with a very severe form of COVID because that patient will die almost certainly and keeping that bed occupied for many days or for weeks, would cause or allow many avoidable deaths by preventing other patients with reasonable chances of survival from an ICU admission. But we didn’t mention disability, of course. I mean it wouldn’t even make sense.’⁵³

Another health and social care professional in France echoed this approach to triage based on age in certain areas for a period of time:

‘I think that there was no triage prioritisation at the entry of ICU units, only maybe in some regions, Alsace, in the Paris area for instance I think one or two days or one or two nights at the beginning of April 2020 and we know that one weekend at least or one night it was a kind of saturation of services and they had to say, ‘Okay we cannot take any person age of, I think it was depending on the places, age more than 60 or 65 or 70’, they told us. So in some hospitals one day or one night they had to have these kind of criteria which is not disability criteria but an age criteria, this does not mean that those people didn’t get any healthcare, they get healthcare but they couldn’t go to the ICU but it was in a very, very limited period of time, it was not one night or one day at maximum ...’⁵⁴

And this approach to triage was a clear concern that emerged for persons with disabilities. As one UK OPD representative put it:

‘So, as disabled people, the fact you know, it’s a really basic kind of equation you know. If your treatment is going to cost more than your life’s worth under the QALY system you won’t get the treatment. So, we were told at the start of the pandemic, oh we might not be able to take you into hospital if you get COVID, but we’ll drop a package of morphine off for end-of-life care, you know.’⁵⁵

⁵² UKPR2

⁵³ ITHSC1

⁵⁴ FRHSC1

⁵⁵ UKDPO5

Members of Irish OPDs shared similar worries:

‘... disabled people were worried about, what happens if I get COVID, what happens if I go to hospital, what happens if there’s a lack of ventilators, now is the NICE criteria going to kick in...’⁵⁶

These concerns around ethical decision making were not without basis. A health and social care professional highlighted how, at the height of the first wave in Italy, clinicians felt the need to have some framework for triage decisions. He recalled that it reached the point where:

‘... there was sort of a clinical decision support tool with the NHS [UK health service], with the logo, that started to circulate last year, very early I think, in April or May, with a score of frailty, a very simple score with chronic illnesses, without any officialities. But it became very popular all across Europe, even Italy. So, people keeping a coloured copy of this flow chart in their pocket in hospital and calculating the score when they had to decide between patients. And then the NHS stated officially that it was not an official document, it was a draft. ... I don’t know how much it was utilised but it was well known, it circulated among colleagues. And still, some of my colleagues now, they think it is an official clinical support tool from the UK, when it’s not. Because if you search on the web, you can find the page where officially the NHS states that that support tool is not an official tool approved and endorsed by the NHS.’⁵⁷

A UK researcher explained how this ‘tool’ (a different document to the NICE guidance referenced above) – which itself was a revision of a document which had previously been rejected for being too discriminatory based on age - originally came into existence:

‘The guideline then was not then formally approved or published at that time. So, the Department of Health didn’t effectively take ownership of this. But this tool had been distributed to doctors in hospital as part of the consultation process. We were aware that some of them were looking at it and thinking about how they might use it and he said of them were using it, he admitted. And a source involved in drawing up the triage tool from the Intensive Care Society said it was sent to a wide population of clinicians from different hospitals, including special respiratory doctors, dealing with the most seriously ill COVID-19 patients. We tracked down several of those doctors working around the country, the book says, who said they were forced to deploy the tool, or a version of it. They said that they were faced with an impossible situation with far too many severely coronavirus patients requiring intensive care when there are insufficient beds or staff availability. The government commission age based tool was the only guidance they’d been given, so they used it systematically to exclude the elderly and frail and patients with underlying illnesses in critical care. This is... yeah. And it says ‘These patients would not be given lifesaving mechanical ventilation regardless of the severity of their condition.’ The age based criteria is alleged to be applied by hospitals in London, Manchester, Liverpool, Central England and the southeast. Many of those who died after being excluded by the triage criteria might well have survived if they had been admitted to intensive care. Of the few patients over the age of 80 who were given critical care treatment, close to 4 in 10 were discharged alive.

A QALY refers to a ‘Quality-adjusted life year’. It is used as part of a ‘cost-effectiveness’ analysis in clinical decision-making in a number of European jurisdictions, as well as in Australia and Canada. The UK’s National Institute of Health and Care Excellence define a QALY as: *A measure of the state of health of a person or group in which the benefits, in terms of length of life, are adjusted to reflect the quality of life. One quality-adjusted life year (QALY) is equal to 1 year of life in perfect health. QALYs are calculated by estimating the years of life remaining for a patient following a particular treatment or intervention and weighting each year with a quality-of-life score (on a 0 to 1 scale). It is often measured in terms of the person’s ability to carry out the activities of daily life, and freedom from pain and mental disturbance.*

⁵⁶ IRLDPO1

⁵⁷ ITHSC1

Now, that's not very different to younger patients, because it was about half and half if you got into ICU, to get out.'⁵⁸

In contrast, a German health and social care professional felt that:

'... despite there were fears that there would be a shortage of care and health facilities but that did not happen at any stage. Everyone who needed healthcare supports received them throughout the pandemic. The setting in which that happened depended mostly on how severe the illness was, so where there was a more severe version of COVID, they had to be looked after in hospital but where that wasn't the case, they continued to receive care and support at home and there is a clear regulation on that, that wherever possible, the support will be provided in the usual settings.'⁵⁹

Civil society advocacy on triage protocols

A UK researcher explained how the much-publicised initial UK triage guidance was, in his opinion, a result of political inaction on the topic, as well as how it was ultimately revised due to advocacy, and the spectre of litigation, by OPDs:

'... a huge amount of what was going on, especially in the first wave, was not related to formal legislation at all. It related to medical bodies having to take decisions about how they do things in the absence of formal legislation, or I mean just to give one example which directly impacted on persons with disabilities was the NICE guidance, which was issued quite early on about, well it was treated as being about when do you escalate treatment, and it caused a huge fuss, because it made reference to the clinical frailty score without making specific reference to the fact that the clinical frailty score is actually designed for a specific cohort of people in a specific position, and it was, that was rushed out by NICE – The National Institute for Health and Clinical Excellence – and it was only because they were judicially reviewed, or was a threat of judicial review that they then changed it to say 'Please don't use this for anything other than that which it's designed for.' So, that's not NICE reaching out and engaging with disabled persons organisations. That is a group of people with disabilities saying 'Hang on a minute, this is impacting us. We're going to do something about it.'⁶⁰

A health and social care professional involved in the development of the first draft of the NICE guidelines had a different perspective on both their content, as well as their response to public criticism:

'... we brought it out very, very rapidly because things were looking so urgent and we rapidly modified the first draft following being contacted by disability groups. We didn't change the fundamental moral principles of triage but what we did was to absolutely emphasise that the presence of an underlying disability in and of itself and it was similar with age as well by calendar age in and of itself is not like the presence of an underlying disability and morally relevant criteria for decision-making. So, we brought that out and emphasised it so in the second iteration of our guidance we very clearly responded to the concerns of disability rights groups and amended the guidance accordingly and the guidance framing was better for it. One of the difficulties there of course is if you're bringing out guidance in 10 days, if people are clamouring how do you move swiftly to meet potential need in the midst of kind of the peak of a pandemic but I think there was a sense very rapidly, there was a sense that there was a great alertness to the potential discriminatory impact of some of these policies and certainly we adapted ours very

⁵⁸ UKPR4

⁵⁹ GRHSC1

⁶⁰ UKPR1

rapidly as a result and it went through our equality inclusion and culture function which bought in and they internally raised concerns about its potential discriminatory impact.’⁶¹

As in many other areas, the work of civil society proved to be important in changing policy and clinical approaches to triage. One Spanish OPD explained:

‘In the most difficult moment of the pandemic, the government released a guideline, that only lasted for a very short amount of time, that established who had priority to access hospitals. It produced a situation of discrimination towards people with intellectual disabilities because in the difficult moment – I’m talking about the difficult moment in the pandemic, understood? In order to get into the intensive care units, there was a priority list, and elderly people and people with disabilities were at the bottom of the priority list. This did not happen everywhere in Spain. It only happened in some regions, for example, in Madrid. When this happened, all the organizations and associations for people with disabilities complained and denounced it, and this ended in very short amount of time. It only lasted for approximately 15 days.’⁶²

In one case, an apparent policy decision that some persons with disabilities would not be transported to hospital for treatment resulted in civil society organisations in Spain creating their own private ambulance service in order to ensure that persons with disabilities would receive treatment.⁶³

3.5 INSTITUTIONAL SETTINGS

The distinct experience of persons with disabilities living in institutional settings during the pandemic exposed instances of increased risk and discriminatory practice. A Spanish OPD stated:

‘I’m going to take Madrid as an example. The community of Madrid.

So, the decision was made that people in these sorts of residences, elderly people, the decision of the State was not to transfer them to hospitals even though they were extremely poorly in health.

So, the consequence of that it was that 7,000 people only in the community of Madrid have died of the pandemic.’⁶⁴

A similar practice arose in some institutions in France, as one health and social care professional explained:

‘... some people in nursing homes decided that they would not send these patients to the hospital or that some emergency unit going to their house of somebody try to help him at home and not given his age or his supposed frailty didn’t send him to the ICU unit so we know that we do not have any, for now, we do not have any numbers about this, we know that this existed but we cannot say if it was important or not so there were two criteria, first age, second what is called frailty and they used criteria of frailty where you could have a discrimination against people with disabilities and elderly people with also with some kind of disability.’⁶⁵

Perspectives regarding the management of institutional settings also varied depending on the stakeholder. For example, one health and social care professional stated:

⁶¹ UKHSC1

⁶² SPDPO4

⁶³ SPHSC3

⁶⁴ SPDPO1

⁶⁵ FRHSC1

‘... there was an immediate move to try and get people home, get people into less risky settings. And that was literally, probably the first week in March, there was massive moves to move people. Not so much... older disabled people, yes – disabled people under 60.’⁶⁶

However, a representative of an OPD from the same jurisdiction recounted that:

‘I know from personal experience that somebody who basically was... they were basically driven over an hour’s journey, while the two-kilometre restriction was in place, to basically leave them to stay with an elderly parent – and I don’t think that was right at all, because the person in question was vulnerable, and the elderly parent was vulnerable, and it just made the life of the staff in the residential setting easier not to have those people around. And I don’t think... it was like, the more people they could offload on the family, that’s what they did.’⁶⁷

Another health and social care professional based in the UK relayed the concerns of some service providers in terms of transmission of Covid-19 to residents:

‘... some of our managers felt that the hospitals were quite dishonest when they were telling care homes about whether somebody had been tested. Sometimes they said they had been tested when they hadn’t been tested.’⁶⁸

The prioritisation of institutional or ‘congregated’ settings was viewed positively by health and social care professionals:

‘... the vaccination programme was prioritised for people in congregated settings. They were the first to be vaccinated, and the whole programme, there was a huge speed at trying to get that out, because congregated settings are more infectious, it can spread much quicker. In terms of testing as well, it was a prioritisation.’⁶⁹

Conversely, in Germany, one researcher observed that the approach to vaccination in institutions reflected a broader policy understanding that persons with disabilities mainly resided in institutional settings, to the detriment of the majority who actually live in the community:

‘... as long as you lived in an institution you were prioritised in the beginning and people living at home which is the majority of disabled people and people living with chronic illness they were not prioritised until DPOs and the disability commission of the federal government intervened and then they opened the prioritisation by just giving it out to the doctors, the GPs... if you could reach your GP you could be prioritised, but completely they have completely forgotten first of disabled people and only by the clear thinking of institution. I mean, disabled people have to be institutionalised in order to be prioritised and then there were no other disabled people, according to their thinking, I would say.’⁷⁰

3.6 EXAMPLES OF GOOD PRACTICE (E.G. ACCESSIBLE ENVIRONMENTS, CONSENT TO TESTING/VACCINATION)

Accessibility

⁶⁶ IRLHSC1

⁶⁷ IRLDPO4

⁶⁸ UKHSC5

⁶⁹ IRLHSC1

⁷⁰ GRPR1

In Ireland, the needs of neurodiverse children and young people were taken into account by the creation of a specific facility for the provision of vaccination to that cohort. As one health and social care professional explained:

‘... we developed a bespoke ... neurodiverse clinic where there were all kinds of things done. They were given a specific part ... of the vaccination centre was just for neurodiverse children. They were... there were beanbags, there were... the beds were down on the ground, if they wanted a bed to lie down on, there were toys, there were... it was specifically arranged so that the exit door was right next to where this was, so that if they needed to get out and run around for a while, they could do that, if they got scared, if they got anxious. There was way more time allowed per vaccination when they were scheduling them, so that a person could come in, they could make an attempt, if he just freaked out and couldn’t do it, he could go off, he go out, run around outside for a little bit, the team would go out to him, sit him on a... he could sit on a bouncy ball, one of those gym balls, if that was where he was more comfortable, and he’d be vaccinated there.’⁷¹

Efforts were made to ensure that this approach was replicated in other vaccination venues:

‘That was impossible to replicate all around the country, so what we did was – because they didn’t have the space – what we did then was in the SOP that we did for the vaccination centres for the 5 to 11 year olds, and the 12 to 15 year olds, we would have identified those kinds of themes. We would have said ‘You might not have the space to do a whole bespoke area, but you know, keep some of these things in mind. Maybe give, certainly give them longer time to be vaccinated, have a beanbag, have a gym ball, put a little bed on a ground, have colourful posters on the walls, and then turn off the fans, some of them, you know sensory, some kids will be hyper acoustic, so there was things like turning off the fans if that was needed. Others would like music, so... so there was all of that. Just that whole idea of be aware of the individual needs of that particular child.’⁷²

Another Irish health and social care organisation provided desensitisation training for staff working with people who had a fear of needles or of the vaccination itself, or of PPE.⁷³

Respecting Legal Capacity and Informed Consent

One Irish health and social care organisation explained how they had prioritised informed consent for vaccination:

‘I remember the urgency at the time vaccinations came out, I remember being getting a phone call on a Friday morning when a vaccination clinic was planned for a Saturday morning because a batch of vaccination had been made available and I remember we insisted and were successful at insisting that that would be delayed to Monday or Tuesday to allow an informed consent process to be fully worked through with all of those people who might receive the vaccine. So, for us the informed consent priority went hand in hand with the delivery of the vaccine so both of those were really important.’⁷⁴

Another Irish health and social care professional felt that the vaccine programme had meant that questions of legal capacity and informed consent received required attention:

‘... we were quite strong that nobody should be forced to be tested, the same way nobody should be forced to be vaccinated. That if their will is that they’re really clearly pushing you away, then... so, that’s been our consistent message all along, whether it’s testing or vaccinating that you really follow the will. ... And in spite of the difficulties, the vaccination programme has been an opportunity to really reinforce who consents for who. ... And also, people saying, well

⁷¹ IRLHSC5

⁷² IRLHSC5

⁷³ IRLHSC3

⁷⁴ IRLHSC3

I want you to be my proxy, I want you to make the decision. ... The whole thing of advanced planning, pre-COVID, you'd be really struggling to get anyone to listen to you. And now, people are all about advanced planning, and want to talk about it and want to think about it, and see the value of it – it's great.⁷⁵

That same individual noted that recorded webinars (which remained available) had been held for those administering vaccines which addressed topics around informed consent, concerns about decision-making capacity, the meaning of will and preferences, as well as alternative forms of communication.

4. CONCLUSIONS AND RECOMMENDATIONS

The CRPD has set out clear standards on the human rights obligations of States in public health emergencies, requiring that all necessary measures be taken to ensure their protection and safety. The Covid-19 pandemic and the legal and policy response to it in the countries examined in the ResPoNCE study exposed many persons with disabilities to increased risks. While some of these were as a result of impairments that persons with disabilities experience, many were brought about as a result of pre-existing discrimination and inequalities, as well as deficiencies and failures in State and health and social care responses. This is despite the fact that the need to ensure that the rights of persons with disabilities were upheld was highlighted by a number of human rights authorities, as well as the World Health Organization itself, in the earliest days of the pandemic.

The Covid-19 pandemic has provided unfortunate lessons in the lack of preparedness of States to respect and vindicate the rights of persons with disabilities in the context of pandemic-related healthcare. In light of the authors' findings, the following recommendations should be incorporated into future public health emergency planning. Persons with disabilities, through their representative organisations, should be actively consulted and involved in the design and implementation of legal and policy responses to public health crises, in accordance with Article 4(3) of the CRPD. Initial key areas of focus which the ResPoNCE study has identified as requiring inclusion in such reviews include the accessibility of both information and of healthcare itself. Infrastructure linked to testing, vaccination and treatment and treatment (as well as ancillary services such as transportation) should also be accessible. Evidenced based prioritisation of both treatment and vaccination (where applicable) should be done in a rights-based, non-discriminatory manner. Training and guidance on the requirements of the CRPD in relation to legal capacity, decision-making, informed consent and resource allocation should be provided to health and social care professionals – making it clear that public health emergencies do not provide a justification for derogation from these obligations. In light of States human rights obligations, as well as the clear increased risk posed to those living in institutions, a CRPD-compliant process of deinstitutionalisation should be prioritised. It is important to emphasise that these recommendations are merely starting points in a more holistic assessment of the approach to disability in situations comparable to those of the Covid-19 pandemic, in order to ensure full compliance with the requirements of the CRPD, read through the lens of Article 11.

The authors leave the final word to a study research participant with a disability:

Don't treat us as weak, victims, drain on resources, not deserve to live. We are just as important. Public health should protect all'.⁷⁶

⁷⁵ IRLHSC1

⁷⁶ CI IRL 2