



ResPoNCE (Respecting Persons with disabilities' Needs and rights in Crisis and Emergency): Final report

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Centre for Disability Law & Policy



ResPoNCE (Respecting Persons with disabilities' Needs and rights in Crisis and Emergency)

Final report

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Introduction

The ResPoNCE (Respecting Persons with disabilities' Needs and rights in Crisis and Emergency) project was a project which ran from January 2021 to May 2023. It was funded by Ireland's Health Research Board. The Principal Investigator was Professor Eilionóir Flynn and other team members were Dr Suzanne Doyle Guilloud (Postdoctoral Researcher) and April Parker (Research Assistant). The research team was based at the Centre for Disability Law and Policy at the University of Galway.

The project sought to examine whether the rights of persons with disabilities were respected in accordance with the UN Convention on the Rights of Persons with Disabilities (CRPD) during the Covid-19 pandemic. In doing so it examined the impact of the pandemic-related laws and policies in seven European countries – Ireland, the UK, Spain, France, Sweden, Italy and Germany - on the health and wellbeing of people with disabilities.

Methodology

The project adopted a human rights-based disability research methodology.¹ This approach recognises the historical marginalisation of people with disabilities in disability-related research and the extractive practices which have been used by non-disabled researchers and draws on emancipatory, participatory and inclusive research approaches to create a methodology which places itself within the human rights model of disability, as contained within the CRPD. In conducting their research, the project team were guided by the key questions that researchers much ask when using this methodology:

- Does the research align with the social model of disability?
- Is it free from paternalism towards disability and disabled people?
- Does the research enable equality?
- Does the research, at all stages, challenge and confront cultural attitudes that marginalise disabled people?
- Are the processes for research design, implementation and distribution accessible to and inclusive of disabled people?²

Based on this, there are three core principles for rights-based disability research:

- i. The research should be initiated and led by voices from the disability community.
- ii. The research should respond to a rights concern in the disability community.
- iii. Outputs from the research should directly address the rights concerned and be returned to the community in accessible formats.³

In assessing whether the rights of persons with disabilities were respected in the legal and regulatory responses to the pandemic, the project sought to respond to the concerns raised by Disabled Persons Organisations (DPOs), as well as other civil society actors, as to the impact of those measures on the disability community, and the research questions were informed by those concerns. The project also had an advisory group whose membership included individuals with lived experience which provided

1 Anna Arstein-Kerslake and others, 'Introducing a Human Rights-Based Disability Research Methodology' (2020) 20 Human Rights Law Review 412.

² *ibid* 424.

³ *ibid* 426.

input and feedback on the work of the project at regular intervals. A core output of the project was toolkits for use by DPOs to support their advocacy in ensuring that both States and health and social care professionals comply with their human rights obligations under the CRPD in the context of public health emergencies.

Methods

The initial phase of the project focused on identifying the international human rights standards applicable to people with disabilities (primarily under the CRPD) in times of public health crises and the consequent obligations attaching to States. Examples of good practice were also gathered. This legal analysis formed the basis of a working paper which can be found [here](#). For that reason, this final report will primarily focus on the findings made by the research team in subsequent qualitative phases of the research, as well as the broader project conclusions and recommendations.

The project team undertook qualitative research with key informants – DPOs, health and social care professionals, and policymakers or researchers engaged with policy analysis - in each of the seven jurisdictions in the form of semi-structured interviews. Further interviews were conducted with these three cohorts focusing on Ireland, the UK and Spain. The project also conducted focus groups with impairment groups whose views might not have been adequately captured by the interview process in Ireland, the UK and Spain. These groups were people with intellectual disabilities, people with psychosocial disabilities, Deaf people, and children with disabilities. A questionnaire was also open to people with disabilities living in Ireland, the UK and Spain. The focus within all three of these methods was the collection of data relating to the legislative response to the pandemic, the clinical response, and the lived experience of people with disabilities during the public health emergency.

In recruiting participants for the qualitative phase of the project, the definition of ‘persons with disabilities’ contained in Article 1 of the CRPD was applied. This provision states that:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

The project team conducted a total of 49 interviews, 8 focus groups, and received 92 questionnaire responses. Quotes from research participants have been anonymised with ID codes for all project outputs.

Data analysis

The collected data was then analysed using reflexive thematic analysis.⁴ This method of analysis was chosen due to its flexible nature, as well as its capacity to both incorporate theoretical frameworks such as the human rights model of disability, as well as the positionality of researchers in relation to the subjects of their research. This was particularly important in light of the aforementioned practices of exclusion and objectification which people with disabilities have experienced when they have participated in research.

The analysis of the data identified a number of overarching themes regarding the legislative and policy response of States to the pandemic, the approach of health and social care professionals to the public health crisis, and the experiences of people with disabilities in light of these legal and clinical frameworks.

Overarching themes

Three overarching themes were developed based on the qualitative data:

1. Adaptation and change

The impact of the adaptations and changes that were put in place by States and health and social care systems on people with disabilities, as well as the individual adaptations and risk assessments which people with disabilities were (and, in some cases, continue to be) required to make during the pandemic.

2. Failure

The failure on the part of the State and health and social care structures to understand the distinct needs and experiences of people with disabilities and the consequent failure to meet their human rights obligations, particularly under Article 11 of the CRPD, which states that:

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, 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.

⁴ Virginia Braun and Victoria Clarke, 'Using Thematic Analysis in Psychology' (2006) 3 *Qualitative Research in Psychology* 77; Virginia Braun and Victoria Clarke, 'Toward Good Practice in Thematic Analysis: Avoiding Common Problems and Being a Knowing Researcher' (2022) 0 *International Journal of Transgender Health* 1; Virginia Braun and Victoria Clarke, 'One Size Fits All? What Counts as Quality Practice in (Reflexive) Thematic Analysis?' (2021) 18 *Qualitative Research in Psychology* 328; Virginia Braun and Victoria Clarke, 'The Ebbs and Flows of Qualitative Research' in Bryan C Clift and others (eds), *Temporality in Qualitative Inquiry* (1st edn, Routledge 2021) <<https://www.taylorfrancis.com/books/9781000356625/chapters/10.4324/97810003083504-2>> accessed 12 December 2022.

It is notable that Article 11 does not qualify that measures taken in respect of people with disabilities should be 'on an equal basis with others', as is stated in some of the other provisions of the CRPD. It is therefore likely that this allows (and in some cases would require) that the protection and safety of persons with disabilities be ensured as a priority by States, including their health and social care systems, with corresponding legal and regulatory measures, as well as resources, being put in place to support this.

3. Entrenchment of discrimination

As a result of pandemic related changes and the aforementioned failures, the pre-existing inequalities which persons with disabilities already experienced in various aspects of their lives were further amplified.

These three overarching themes will now be explored in the context of the findings made by the project team based on the qualitative research.

Themes and subthemes

Greater restrictions on the lives of disabled people

Institutions

People with disabilities experience a number of discriminatory practices which impact disproportionately upon them. Two of the principal rights violations which they are subject to are denials of legal capacity and denials of liberty – both based on the existence (or perceived existence) of a disability. Almost all European countries have practices of institutionalisation for persons with psychosocial and/or intellectual disabilities, as well as for older people. In many cases this intersects with a denial of the legal personhood of the personhood of the individual, removing their right to make legally recognised and respected decisions about where they live, the medical treatment they receive, and their financial affairs. Denials of legal capacity also occur for those not detained in institutional settings, with persons with disabilities having their decisions in all, or very many, aspects of their lives made by others – such as legal guardians or courts and tribunals.

These practices are contrary the rights to equal legal personhood (Article 12), the right to liberty (Article 14), the right to live independently and be included in the community (Article 19), and the right to health (Article 25). In some cases, certain practices may also violate the right to life (Article 10), the guarantees against torture or cruel, inhuman or degrading treatment or punishment and from exploitation, violence and abuse (Articles 15 & 16), as well as the right to respect for physical and mental integrity (Article 17) of the CRPD. The CRPD Committee has produced clear interpretations and guidance to States on their obligations to eliminate denials of legal capacity based on the existence of a disability, as well as systems of institutionalisation.⁵ These requirements take on a greater urgency

⁵ Committee on the Rights of Persons with Disabilities, 'General Comment No. 1 (2014) - Article 12: Equal Recognition before the Law' <<https://documents-dds->

in public health emergencies such as the Covid-19 pandemic, when the mortality and morbidity risks for people with disabilities are increased when compared with non-disabled members of the population. This risk is further increased for persons in institutions, due to both environmental and structural factors, such as the presence of staff who interact with multiple residents, as well as the barriers to social distancing and inadequate WASH facilities inherent in the infrastructure of institutions.

Yet these practices still persist, and the ResPoNCE project found that in many jurisdictions, systems of institutionalisation resulted in additional harms to people with disabilities. In some cases, lockdown measures were either deliberately or mistakenly interpreted as requiring blanket bans on discharges into the community and prohibitions on visiting.

I think it is also important to put it on record, we all know colleagues who are living in a nursing home or residential home, that despite the fact that when doors were opened to everyone, despite this, some nursing homes or residential homes where people with intellectual disabilities live did not let them go out. There are people with disabilities who have been locked down much longer because they made this decision unilaterally.⁶

In a minority of cases, the need to remove people from institutional settings was understood, but there was a general failure to ensure that sufficient supports were put in place in the community to ensure that this was fully achieved. Institutional settings were generally prioritised within vaccination hierarchies and protocols based on an understanding of increased risk. But there was a failure on the part of States and health and social care services to connect this prioritisation with the need for emergency deinstitutionalisation and the more general requirement to dismantle institutional structures.

Pandemic-related restrictions also resulted in changes to the monitoring of institutions and group homes. In most jurisdictions, in-person inspections of psychiatric facilities, nursing homes and other institutions ceased for periods of the pandemic. Efforts were made to continue some form of oversight by way of 'virtual' inspections. However, health and social care professionals involved in these acknowledged that this resulted in reduced and less thorough scrutiny.

... in one or two inspection of care standards, I mean that just stopped. CQC [the independent regulator of health and adult social care in England] was non-existent, to be honest. And all they did was ask ... I mean there was no monitoring of ... because normally CQC would come in and they would talk to people who were being supported and they would check their wellbeing and check how they

ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement> accessed 8 November 2021; Committee on the Rights of Persons with Disabilities, 'Annex to the Biannual Report of the Committee on the Rights of Persons with Disabilities - Guidelines on the Right to Liberty and Security of Persons with Disabilities' (2017) A/72/55

<https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolNo=A/72/55&Lang=en> ; Committee on the Rights of Persons with Disabilities, 'Guidelines on Deinstitutionalization, Including in Emergencies' (United Nations 2022) CRPD/C/27/3.

⁶ SPID

are. And there was no attempt to even find a way in for them to somehow speak to people who were being supported in services to find out their experiences. There wasn't even an attempt to do that. I mean they could have quite happily have asked care services somehow through technology to give them a space to talk to people and find out their experiences and what's going on. But they didn't even attempt to do that. No on-the-ground monitoring. I mean that was their policy.⁷

Even where in-person inspections were maintained or reinstated, inspectors felt that masking requirements, social distancing measures and time limits on visits meant that their understanding of what was actually occurring in the facilities was impeded.

Changes to services and supports

There were substantial changes made to disability-related supports and services in almost all jurisdictions based on public health measures. Day and respite services were closed for extended periods of time, and efforts to compensate by way of either telephone or digital support were felt by research participants to have been largely unsuccessful. In some cases, this was linked to the digital exclusion experienced disproportionately by people with disabilities (which will be examined further in the context of accessibility below). Chosen services and supports are a core element of the right to live independently and be included in the community under Article 19 of the CRPD, as well as underpinning the rights to chosen habilitation and rehabilitation (Article 26). In some jurisdictions, this failure to adequately protect disability-related supports and services was linked to a perception (at least at the political level) that disability and institutions were synonymous. This resulted in supplementary funding being provided for the maintenance of institutions, and the resourcing needs of community-based services being forgotten.

... it was made very clear that many people were forgotten, many settings were forgotten. The model of independent living was not included. We didn't receive any financial extra support to cover increased costs, for example for these things like masks or disinfectant.⁸

Challenges and delays in securing PPE meant that in-home support (where that was maintained) was also affected. People with disabilities faced a choice between receiving ongoing support provided by staff with inadequate PPE or temporarily withdrawing from receiving services based on their own risk assessment. There were a number of accounts of people with disabilities using their own money to purchase PPE for support staff - an increase in the 'cost of disability', i.e. the additional costs which people with disabilities are already required to pay for that others do not.⁹ In a number of jurisdictions, governments did not respond sufficiently rapidly to ensure the financial security of persons with disabilities who were incurring such costs, or who may not have been able to return to

⁷ UKHSC5

⁸ GRDPO1

⁹ Indecon International Research Economists, 'The Cost of Disability in Ireland: Final Report' (2021).

work at the same time as other members of the population due to the health risks which such a return would pose.

A recurring theme throughout the research was disabled people's sense of having been forgotten and abandoned by the State and, linked to this, in many instances having to make personal risk assessments regarding their lives and interactions, taking measures to try to ensure their health and survival.

... although there's a real issue about people with greater support needs and people with profound and multiple intellectual disabilities where particularly those living with families, many families felt that because of the sort of structural working conditions of PAs working at home you know there was sort of many different PAs coming in and not having sick leave time if they had COVID symptoms, so many, many families have sort of withdrawn from using that kind of PA support or did for quite a long time because of the risk and many families are still in that position or in effect what the UK choses to call shielding, so living very, very restrictive lives, so there's been a kind of, there was a quite serious kind of withdrawal of social care support and some of that is coming back but not to the level it was.¹⁰

At the same time, some members of the disability community felt that there were some positive developments as a result of the pandemic and the response to it.

I would have noticed a massive change within the Deaf community with everything moving online, anything from there were fitness sessions, there were games that were on online, conversations, discussions, all of these things, I'm not just talking about locally, I'm talking about these became like a global interactions with people all over the world, people were making connections with people from all over the world, so it was a big explosion in that part of the Deaf community ...¹¹

Others felt that there was a greater awareness of the needs of people with disabilities after shared experiences of lockdown and other pandemic-related limitations. However, this sense of progression was overshadowed by a concern that these changes would be short-lived, as well as frustration that what had previously appeared impossible when it only concerned disabled people, suddenly became the understood norm.

I found it really interesting in, as soon as lockdown came, suddenly accommodations that disabled people have been looking for and being refused for years, overnight became available to everyone. Like, being able to log on and attend a class remotely, or things like that. And it was just like, okay, so it is actually possible to do this, and you couldn't be arsed – pardon my expression, but you just couldn't be arsed before now, because it didn't affect the majority of

¹⁰ UKPR3

¹¹ UKDPO3

the people. And I think a lot of people felt that was just a huge slap in the face – and it just showed just the level of... it showed a level of disrespect, and how reasonable accommodation just... it's done in the minimal amount possible, rather than maybe best practice, and what is in the best interest of the student. Or even staff member. And now that things are going back to in-person, on-campus, things are... those accommodations that have enabled disabled students to really thrive in that academic space, they're being rolled back on now, because it's no longer seen as necessary because people can attend in person.¹²

State response and civil society compensation

Reasonable accommodation

The pandemic saw States put in place public health measures such as social distancing, mask wearing, and lockdown requirements. While most jurisdictions made provision for exemptions to these rules for people with disabilities, the research found many incidents in which people with disabilities were challenged about their use of this exemption and, in some cases, were refused certain services as a result. People with disabilities sometimes experienced incidents of harassment and aggression when they relied on exemptions.

... unfortunately, there were occasions in which people with disability were harassed in the streets so for example especially those people whom disability is not visible say for example people with autism that of course you cannot tell just by the look that they have some disability, they were often attacked verbally I mean from other people so for example they would say things like, 'Why are you not wearing your mask? Put your mask on' ...¹³

In some jurisdictions, medical evidence was required before an exemption was authorised. In health and social care services where a requirement for people to attend appointments and services alone existed, there were incidents where people with disabilities experienced resistance when they wished to be accompanied by a supporter, such as a personal assistant. This was mirrored by barriers which people with disabilities experienced in accessing other services where they wished to be accompanied by a supporter. These occurrences are contrary to Article 5(3) of the CRPD which requires States to 'take all appropriate steps to ensure that reasonable accommodation is provided'. Denial of reasonable accommodation amounts to discrimination under the CRPD.

... in the times of severe lockdown there was talks about autistic people going outside having to have an identifying mark, so for example wearing a blue vest, and then some parents and other family members and advocacy groups refused, because they were pointing out that they were being... that they were being pointed out as having a disability.¹⁴

¹² IRLDPO4

¹³ ITDPO1

¹⁴ SPPR3

Lack of consultation

This failure to incorporate the specific rights and needs of people with disabilities can be linked to State failures to consult with and actively involve persons with disabilities through their representative organizations, in accordance with their obligation under Article 4(3) of the CRPD. Key informant DPOs consistently conveyed the failures on the parts of governments to consult with them regarding the impact of pandemic-related measures on the disabled population, as well as any specific legislative or policy requirements that would be needed to ensure compliance with the CRPD. While the urgent nature of the crisis and the response provides some justification for initial deficiencies in ensuring the inclusions and incorporation of the views of the disability community, there was no lawful excuse for States' ongoing failures throughout the pandemic to ensure that those perspectives were included in legislative and policy responses. This failure could have been avoided by States having pre-established systems and protocols for rapid consultation already in place.

The failure to consult with representative organisations is part of a wider sense of disconnection that people with disabilities experienced throughout the pandemic and which was reflected in the contrasting perspectives of policymakers, health and social care professionals and DPOs on the pandemic. For the most part, the first two categories of stakeholders were of the opinion that the measures taken by both the State and health and social care structures were, if not entirely adequate, then the best possible approach that could have been taken in the circumstances. Conversely, the disability community felt abandoned and excluded in respect of almost every aspect of the pandemic response. While this was felt to have improved over time, almost all of the disabled research participants felt that there were ongoing issues and inequalities being experienced by the disability community in relation to the pandemic response.

Civil society compensation

The exclusion of the disability perspective was also the basis of another key finding of the research – the measures taken by DPOs and other civil society organisations in order to compensate for gaps in the State response in respect of the rights of persons with disabilities. This ranged from lobbying governments to raise awareness of the need for accessible information and vaccine prioritisation, to providing that accessible information (including interpretation) or basic essentials themselves. In many jurisdictions this was a continuation of the work that DPOs and other civil society stakeholders have historically been required to do in order to 'fill the gaps' created by inadequate and underfunded government policies impacting on the lives of people with disabilities.

Like, they didn't know who to ask for help and my heart was broken as a volunteer. I was running around the place trying to provide food and different things for people who were vulnerable and whatever it was. But I felt honestly so disheartened that the Deaf people in Ireland were just forgotten and they were pushed to the side. And when we brought it up to people saying, oh, you know those services are now cancelled? They were like, oh, we never heard about that. And I'm like, oh. And even into those services being like, did you know you had deaf vulnerable in your area that you guys aren't catering to? And they were like, oh, we never knew, we never heard about these people. So, it's just that deaf

people were being marginalised by society over and over and it became very apparent in the pandemic.¹⁵

Data collection

An adequate State response to disabled people's needs in a public health emergency also requires accurate and disaggregated data on the disabled population, in accordance with Article 31 of the CRPD, as well data on as infection, vaccination and mortality and morbidity rates. This data should be the subject of constant review so that legislative and policy responses can be adapted in an ongoing manner. The research found that in most jurisdictions, there were data points which had not been gathered at an official level.

I think it's important to note that when you look at the statistics of people who have died of COVID-19, it does not include people with disabilities.¹⁶

(In)accessibility

Lack of accessibility

A key finding of the research was the legacy and implications of failures in accessibility and universal design across a number of aspects of life during the pandemic. A core example of this was the provision of information related to the pandemic. The research found that, with notable exceptions, there was a lack of accessible information available to people with disabilities regarding both Covid-19 itself (e.g. the nature of the pandemic, risk factors, prevention of transmission), as well as regarding the rules and regulations which States put in place. Research participants highlighted incidents of lack of sign language and/or captioning on public information broadcasts and failures to provide information in Easy Read and/or Plain Language formats.

In one of our meetings a self-advocate rang the 119 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.¹⁷

... everything that had to do with the subtitling of the press conferences where the Ministry of Health and the expert body that was dealing with Pandemic regulations were not subtitled. So, there was this kind of claim for the press conferences where the citizens got to know about the new regulations was in place....at a different phase there were many changes to the regulations. So that was important information, and it was not accessible.¹⁸

Inaccessibility of information also extended to the health and social care sector, where people with disabilities provided accounts of lack of clarity and confusion regarding whether they fell within high-

¹⁵ IRLDPO2

¹⁶ SPDPO1

¹⁷ UKDPO1

¹⁸ SPPR3

risks groups, as well as challenges in accessing vaccination and testing centres due to their physical inaccessibility and lack of explanatory signage.

Immense confusion at start. Was I on or off shielding list? Finally confirmed I was on. (didn't want to be!) after first lockdown information improved and was first priority for vaccination which reduced anxiety for my family. Advice for family (of a clinically vulnerable person) unclear - should children isolate or not, should they go to school, would they be vaccinated? Should partner go into office/travel for work? This caused a lot of anxiety for my children and partner...¹⁹

I got my vaccine dose from my GP, after weeks of ringing and delays (cohort 4). 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...²⁰

There were a number of examples of good practice, however, with some research participants outlining the efforts made to ensure the accessibility of vaccination centres for neurodiverse people, especially children.

... 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 [panicked] 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.²¹

Covid-19 test results were also not accessible for all disabled people, with a number of access issues being encountered:

... 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 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.²²

¹⁹ MU-UK-2

²⁰ MU-IRL-3

²¹ IRLHSC5

²² SPD

The research found that the inaccessibility of public spaces increased in many cases during the pandemic, with research participants highlighting the impact of social distancing measures and the placement of sanitation/hand hygiene equipment when they were based on ableist assumptions about the physical functioning of those using services and facilities.

... most places, public or shops where you could buy food which were never lockdown, which were never closed, had these sanitation or hygienic, to disinfect your hands at the entrance but it was not at lower place so if you were in a wheelchair or if you had no hands, you had no possibility to disinfect yourself and also when you were required or are required in order to enter a building where you need to scan a QR Code in order to enter, this is not a level of wheelchair users or people who have to sit down to use their feet or who have to you know whatever it's impossible to scan that QR Code because it is mostly at eyelevel, at a regular standing person, average person standing, eyelevel ...²³

The impact of digital exclusion

The research found that the provision of telehealth during the pandemic provided many people with disabilities with additional flexibility around accessing healthcare. However, accessibility barriers such as resistance to the inclusion of interpreters in medical consultations and the failure to provide additional time to people with intellectual disabilities (who may experience greater challenges in accessing and using remote technology) meant that there were those who could not benefit as much from that transition. Where these accessibility issues were highlighted, there were reports of resistance on the part of health and social care professionals to providing in-person appointments.

They started to put everything back online, they were online access, I have a person who is not very au fait with IT, prior to the pandemic they would have went to the GP practice, made their appointment at reception and then attended after that but when the lockdowns then came in, you had to call through, it was the only way to get an appointment with your GP, this person really struggled, they went to the GP practice, physically went to the door and they weren't allowed in and this client ended up contacting me, so then I had to make the call on their behalf to try and see if it was possible to set up a special arrangement for this client because they weren't very au fait with IT, to see if there was a way that they would be able to access the practice on a face to face basis, I did try to support them when the signed video service came in, the video relay service came in but this person really, really struggled with IT and it was just a constant and not just this client but quite a few clients, older generation clients would have struggled a wee bit with the IT set up.²⁴

The digital exclusion and divide which was already disproportionately experienced by people with disabilities prior to the pandemic had consequences across a number of other areas, including information provision, which was heavily weighted towards digital platforms such as websites and apps, without consistent accessibility measures being taken. In employment, digital exclusion was also a disadvantaging factor for people with disabilities. And while remote working was generally a positive experience, some groups found that this posed new challenges.

²³ GRPR1

²⁴ UKDPO3

... it's very difficult to have support to do your job when you're kind of working face-to-face to working over a Zoom. So, setting up, so people, supporters often had to actually kind of go round to individual houses and set up accounts like Zoom or set up home email accounts so that they can actually then work ... so that they can be taught how to actually log in but it is still a big barrier on ... So, depending on your level of learning difficulty, if I can put it like that, your support is needed, the person needs support in a particular way so the relationship between the person with learning difficulties doing the job and support and the support is actually personalised, so I think that we know that online is here to stay but it's actually getting the people that think about what support people need in work to think about much more than just working in an office, it's about supporting them at home...²⁵

On the whole, the experience of students and their families in accessing education during the pandemic proved to be challenging as a result of the digital divide, as remote learning was not felt to have sufficiently incorporated accessibility measures to ensure the inclusion of children with disabilities.

... schools and universities were all closed. So, all people with disabilities, including children with disabilities, had to return home and continue their education from home and in some instances, they did not have the basic conditions to follow classes, online classes virtually. So... not only individual support was not given but that no funding was given to school, including primary or secondary schools or even universities in order to make their own online platforms more accessible. So, there no support given with extraordinary measures in terms of funding in order to make online learning more accessible ...²⁶

For the young people who were able to benefit from the resumption of education, it was often by video means... which has rendered necessary the purchase of adapted computer equipment when possible and the presence of a third party, often the parent, to take on the role of the life assistant.²⁷

Clinical decision-making and practice

Resource allocation

The strain on clinical resources – general hospital and ICU beds, medications, oxygen and ventilators – saw the use of resource allocation measures, included triage protocols, by clinicians. Any such approach to resource allocation such be undertaken on a non-discriminatory basis, in accordance with the requirements of Article 5 of the CRPD, as well as based on Article 25 of the CRPD, which

²⁵ UKDPO1

²⁶ SPPR2

²⁷ FRDPO1

states that persons with disabilities have the right to an equal enjoyment of the highest attainable standard of health and that they should be provided 'with the same range, quality and standard of free or affordable health care and programmes as provided to other persons' (Article 25(a)). Article 25(f) stipulates that States must:

Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Despite this, a number of research participants explained how discriminatory triage protocols were put into effect, at least for parts of the pandemic.

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 ... 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.²⁸

Another research participant spoke about the well-publicised and highly controversial triage guidance which emerged early on in the pandemic in the UK:

... the NICE [National Institute for Health and Care Excellence] 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'.²⁹

The drafting of such guidance in the UK had implication beyond that jurisdiction's borders, with one Irish DPO representative explaining:

²⁸ SPDPO4

²⁹ UKPR1

... 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 where disabled people are.³⁰

One UK policymaker set out discriminatory practice which had arisen around the placement of 'Do Not Attempt Cardio-pulmonary Resuscitation' (DNACPR) orders that some medical personnel had placed on the files of some people with disabilities without their consent:

... 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.³¹

The research also found discriminatory practices in decision-making around transfer to hospital, particularly for those at the intersection of older age and disability. One research participant 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...³²

Failures to appropriately prioritise people with disabilities for vaccination also arose in a number of the countries examined in this research.

... 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? ... 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.'³³

In general, changes to these vaccination protocols so as to prioritise people with disabilities came about due to the advocacy of DPOs and other civil society organisations.

³⁰ IRLDPO1

³¹ UKPR2

³² FRHSC1

³³ UKPR1

Informed consent

The legacy of denials of legal capacity varied depending on the jurisdiction. In some cases, more recent CRPD-focused reform of legal and policy systems, as well as more rights-focused clinical practice, meant that the decision-making of people with disabilities and their will and preferences on issues such as consent to treatment and/or vaccination were respected - even in circumstances where family members and/or other supporters objected.

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 I think it's been upsetting for some people, very upsetting, and people have been very cross with us. But others have been really happy with it, that the message has been clear. And we also know, you can't get everywhere, it's a huge programme – millions of people, there's been millions of vaccines. Is proxy consent still going on? Of course, it is. But at least the message is starting to him home, do you have the legal authority to make this decision or not.³⁴

However, in other cases, pre-existing practices of substitute decision-making and the provision of proxy consent were maintained, contrary to the requirements of Article 12 of the CRPD.

There was nothing in place before COVID and definitely nothing in place after it. And 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.³⁵

Conclusion

The Covid-19 pandemic resulted in changes to laws, policies and practices which had consequences for almost every aspect of life. It was also the first global test of States' commitment to the norms and obligations contained in the CRPD, particularly the requirement under Article 11 to ensure the protection and safety of persons with disabilities. Overall, it is clear their rights failed to be vindicated in numerous respects throughout the public health emergency. Indeed, our research has demonstrated a regression in a number of areas which has not yet been completely addressed in the purported 'recovery' period.

³⁴ IRLHSC1

³⁵ SPDPO3

The current work of the UN Committee on the Rights of Persons with Disabilities towards the adoption of a General Comment on Article 11 of the CRPD is therefore to be welcomed and will be the authoritative interpretation of States' obligations in situations of risk and emergencies.

Detailed recommendations on both State and health and social care professional's obligations towards persons with disabilities in the context of public health emergencies are set out in the two toolkits produced for this project. But a number of more general principles based on the CRPD can be set out, based on the findings of this research:

- The need for a non-discriminatory approach to measures taken in public health emergencies, based on Articles 5 and 11 of the CRPD.
- The requirement for a review of existing laws and policies applicable in public health emergencies, in order to 'future proof' against violations of the rights of persons with disabilities in similar situations.
- For all reviews and reform of laws and policies regarding public health emergencies to be conducted based on consultation with and the active involvement of persons with disabilities through their representative organisations.
- The urgent need to realise the rights to legal capacity and to live independently and be included in the community of people with disabilities contained in Article 12 and 19 of the CRPD respectively.
- Increased public awareness of supported decision-making and advance planning options.
- The central importance of accessibility and the application of the principles of universal design to all areas of service delivery.
- The key role of monitoring and oversight by both State and non-State during public health emergencies in order to prevent human rights violations and abuses.
- The need for health and social care professionals to be provided with rights-based training on service provision and clinical practice with respect to persons with disabilities in public health emergencies. This training should ensure the centrality of the voice and experience of disabled people.

Suggestions for future research

Based on these findings, as well as a recognition of the defined scope of this research, we suggest the need for research on the experiences of persons with disabilities in low and middle-income countries during the pandemic. There is also a need to examine the implications of 'long Covid' and/or post-Covid conditions for legal and policy approaches to disability, particularly in the areas of accessible healthcare and eligibility for social protection mechanisms within a rights-based model of disability. Longitudinal research on the extent to which both State actors and health and social care professionals have implemented changes as a result of learnings from the Covid-19 pandemic should also be undertaken.

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