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**Working paper on best practice to maintain
States obligations under the UN Convention
on the Rights of Persons with Disabilities
during public health crises**

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1. Introduction

This working paper sets out the applicable standards for States to maintain their obligations towards persons with disabilities under international law in situations of emergency such as the Covid-19 pandemic. About 15% of the world population (c. 1 billion people) are living with impairments¹ which would fall within the definition of a ‘person with a disability’ under the CRPD². The paper takes the UN Convention on the Rights of Persons with Disabilities (CRPD) as its normative framework and focuses on States Parties’ obligations towards those individuals with regard to their health and wellbeing in public health crises, taking a broad definition of those terms. As Armitage and Nellums note, even prior to the pandemic, persons with disabilities were less likely to access health services, while being more likely to experience ‘greater health needs, worse outcomes, and discriminatory laws and stigma’³, contrary to States parties’ obligations under the CRPD.

The paper then examines laws, policies and practices of the ResPoNCE project countries (Ireland, UK, Spain, France, Germany, Sweden, Italy), highlighting contraventions of the requirements of the CRPD and other relevant international norms, as well as identifying good practices which have emerged in response to the pandemic. This is not intended as an exhaustive overview of all the areas of incompatibility which have arisen due to the project countries’ legal and policy approaches to the pandemic as they have impacted on persons with disabilities. Its purpose is rather to provide a broad overview of the way in which that response has impacted on the lives of persons with disabilities, impacting on both their health and wellbeing. In doing so, it is intended to serve as an initial scoping exercise on key

¹ ‘Ageing and Disability | United Nations Enable’ <<https://www.un.org/development/desa/disabilities/disability-and-ageing.html>> accessed 9 December 2021.

² Article 1 of the CRPD 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.

³ Richard Armitage and Laura B Nellums, ‘The COVID-19 Response Must Be Disability Inclusive’ (2020) 5 The Lancet Public Health e257.

rights issues which have arisen and will be interrogated further in the later stages of the ResPoNCE project.

The paper finishes by making proposals for best practice in public health crises such as the Covid-19 pandemic. States and relevant authorities have been asked 'to be open and transparent in their decision-making and willing to listen to and respond to criticism' in their response to the pandemic and that 'those seeking to scrutinize or critique the effectiveness of government actions must be able to play their part'.⁴ This working paper is intended to provide that critique, based on the human rights model of disability.⁵ This will then be disseminated to relevant stakeholders. The conclusions will be complemented by the qualitative research which the research team will be carrying out with people with disabilities in the project countries. All of these elements will form the basis of the final recommendations made at the end of the project.

2. Methods

Online searches for relevant materials and commentary were conducted via both general search engines and legal databases using the search terms: 'CRPD', 'disabilities', 'Covid-19', 'pandemic', 'healthcare', 'vaccination', 'treatment', 'wellbeing', 'education', 'employment'. These terms were also searched in combination. An initial review and refining of the search results was carried out. Inclusion criteria were: the methods employed by the authors, relevancy (both in terms of time, cohort analysed and jurisdiction), as well as the centrality of the disabled voice. Further resources were provided directly to the research team by members of the project advisory board,

⁴ United Nations, 'COVID-19 and Human Rights: We Are All in This Together' (2020), p. 13 <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> accessed 26 October 2021.

⁵ Theresia Degener, 'A Human Rights Model of Disability' in Peter Blanck and Eilionóir Flynn (eds), *Routledge Handbook of Disability Law and Human Rights* (1st edn, Routledge 2016); Theresia Degener, 'A New Human Rights Model of Disability' in Valentina Della Fina, Rachele Cera and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer International Publishing 2017); Theresia Degener, 'Disability in a Human Rights Context' (2016) 5 *Laws* 35.

particularly from jurisdictions outside of Ireland and the UK where language competence was an initial barrier for the research team. In-text citations within all of these materials resulted in ‘snowballing’ of additional relevant references.

3. State obligations towards persons with disabilities in public health crises: the requirements of the CRPD

The CRPD is a treaty based on the principles of equality and non-discrimination⁶. It had ground-breaking levels of involvement by the rights-holders and this drafting dynamic is reflected in its requirement that States Parties ‘closely consult with and actively involve persons with disabilities’ in decision-making processes concerning them through their representative organizations⁷.

The Convention 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’⁸, 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’.⁹ 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.¹⁰

⁶ CRPD, Article 5

⁷ CRPD, Article 4(3)

⁸ CRPD, Article 4(1)(c)

⁹ CRPD, Article 4(1)(i)

¹⁰ United Nations, ‘COVID-19 and Human Rights: We Are All in This Together’ (2020) 10 <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> accessed 26 October 2021.

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 impairments¹¹, as well as the greater probability of contracting the virus in institutional settings, where persons with disabilities are disproportionately represented¹², 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 disadvantage¹³. People with disabilities,

¹¹ Anne Kavanagh and others, ‘Health and Healthcare for People with Disabilities in the UK during the COVID-19 Pandemic’ [2021] *Disability and Health Journal* <<https://linkinghub.elsevier.com/retrieve/pii/S1936657421001370>> accessed 3 November 2021.; European Union and Agency for Fundamental Rights, *Coronavirus Pandemic in the EU: Fundamental Rights Implications. Bulletin #1, 1 February - 20 March 2020. Bulletin #1, 1 February - 20 March 2020.* (2020), p. 30; Mehrunisha Suleman and others, ‘Unequal Pandemic, Fairer Recovery: The COVID-19 Impact Inquiry Report’ (The Health Foundation 2021), p. 4 <<https://www.health.org.uk/publications/reports/unequal-pandemic-fairer-recovery>> accessed 3 November 2021; Tom Shakespeare, Florence Ndagire and Queen E Seketi, ‘Triple Jeopardy: Disabled People and the COVID-19 Pandemic’ (2021) 397 *Lancet* (London, England) 1331., 1331 ‘Intellectual and Developmental Disability and COVID-19 Case-Fatality Trends: TriNetX Analysis - ScienceDirect’ <<https://www.sciencedirect.com/science/article/pii/S1936657420300674>> accessed 8 December 2021.; Bhathika Perera and others, ‘COVID-19 Deaths in People with Intellectual Disability in the UK and Ireland: Descriptive Study’ [2020] *BJPsych Open*.

¹² Sureshkumar Kamalakannan and others, ‘Health Risks and Consequences of a COVID-19 Infection for People with Disabilities: Scoping Review and Descriptive Thematic Analysis’ (2021) 18 *International Journal of Environmental Research and Public Health* 4348, 7.; Martin Knapp and others, ‘Crystallising the Case for Deinstitutionalisation: COVID-19 and the Experiences of Persons with Disabilities’ (Care Policy and Evaluation Centre: London School of Economics and Political Science 2021).

¹³ World Health Organization, *COVID-19 and the Social Determinants of Health and Health Equity: Evidence Brief*, iv (World Health Organization 2021) <<https://apps.who.int/iris/handle/10665/348333>>

especially disabled women, are also more likely to experience violence and abuse than their non-disabled peers¹⁴, and the risk of this is thought to have increased during the pandemic¹⁵. Persons with disabilities are also more likely to be older and therefore at greater risk of contracting the virus.¹⁶

Of relevance also is Article 10 of the CRPD, which requires States to take all necessary measures to ensure the effective enjoyment by persons with disabilities on an equal basis with others of their right to life. As such, decisions relating to distribution and use of resources, from medical treatment and vaccination to goods and services, must not discriminate on the basis of a perceived or actual impairment. The vindication of the right to life also extends to ensuring the provision of reasonable accommodation, as well as adequate, appropriate and sufficiently funded accessibility measures.

Barriers to healthcare and employment for people 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.¹⁷ Article 9 of the CRPD requires States to identify and eliminate obstacles and barriers to accessibility in all aspects of

accessed 7 December 2021; UNICEF, 'COVID-19 Response: Considerations for Children and Adults with Disabilities', 1 (March 2020) <https://sites.unicef.org/disabilities/files/COVID-19_response_considerations_for_people_with_disabilities_190320.pdf> accessed 26 October 2021.

¹⁴ Karen Hughes and others, 'Prevalence and Risk of Violence against Adults with Disabilities: A Systematic Review and Meta-Analysis of Observational Studies' (2012) 379 *The Lancet* 1621.; Sonali Shah, Lito Tsitsou and Sarah Woodin, 'Hidden Voices: Disabled Women's Experiences of Violence and Support Over the Life Course' (2016) 22 *Violence Against Women* 1189.; Andrea García-Santesmases and Asunción Pié Balaguer, 'The Forgotten: Violence and (Micro)Resistance in Spanish Disabled Women's Lives' (2017) 32 *Affilia* 432.

¹⁵ Emily M Lund, 'Interpersonal Violence against People with Disabilities: Additional Concerns and Considerations in the COVID-19 Pandemic' (2020) 65 *Rehabilitation Psychology* 199.; Tom Shakespeare, Florence Ndagire and Queen E Seketi, 'Triple Jeopardy: Disabled People and the COVID-19 Pandemic' (2021) 397 *Lancet* (London, England) 1331, 1332.

¹⁶ 'Ageing and Disability | United Nations Enable' (n 1).

¹⁷ Committee on the Rights of Persons with Disabilities, 'General Comment No. 2 (2014) Article 9: Accessibility' (22 May 2014) para 7.

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.¹⁸ 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.

Article 25 of the CRPD recognises the right to the enjoyment of the highest attainable standard of health of person 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

¹⁸ 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 <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>> accessed 8 November 2021.

information inaccessible'.¹⁹ 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 Accessibility²⁰ 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'.²¹ 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'.²² 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'.²³

In a separate statement²⁴ 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 people with disabilities who require support to engage in day-to-day activities. She also linked the requirement of reasonable accommodation - for both the person themselves and their families and

¹⁹ Committee on the Rights of Persons with Disabilities, 'General Comment No. 6 (2018) on Equality and Non-Discrimination' (26 April 2018), para 66.

²⁰ "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)

²¹ *ibid*, para. 2

²² *ibid*, para. 7

²³ *ibid*, para. 6

²⁴ Special Rapporteur on the rights of persons with disabilities, 'OHCHR | COVID-19: Who Is Protecting the People with Disabilities? – UN Rights Expert' <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25725&LangID=E&fbclid=IwAR0BtrEp7xOtFIARx_MRhcdxTyNJCvymIS0eBi55zc8Q4P9QysdtzvZDS3k> accessed 26 October 2021.

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'.

Article 19 of the CRPD requires States to vindicate the right of persons with disabilities to live independently and be included in the community, including a right to both disability-specific supports such as personal assistance, as well as access to general services on an equal basis with others. This is of particular relevance in light of the compounding effects that institutional settings will be shown to have had on outcomes for persons with disabilities during the pandemic later on in this paper.

4. Examples of practices which contravene the CRPD

Mortality rates of persons with disabilities

The mortality rate amongst persons with disabilities has been multiples higher than that of the non-disabled general population. In England, 59.5% of all deaths from 4 January to 20 November 2020 involving Covid-19 were of persons with disabilities.²⁵ Deaths of people with learning disabilities were six times higher than the general population during the first wave.²⁶ And these increased rates of mortality from Covid-19 have not been confined to congregated settings such as residential facilities, nursing and care homes and psychiatric hospitals. In the UK, Dunn *et al.* noted 'significant increases' in mortality for individuals receiving social care at home, with 96% increase in deaths occurring in that population between 11 April and 19 June 2020 compared with the same periods from 2017 to 2019. Further, the authors suggest

²⁵ Office for National Statistics, *Updated estimates of coronavirus (COVID-19) related deaths by disability status, England: 24 January to 20 November 2020* (11 February 2021).

²⁶ Public Health England, *Deaths of people identified as having learning disabilities with COVID-19 in England in the spring of 2020* (12 November 2020)

that this is likely to be an underestimate of the true toll, as the data relied on did not include people who receive home-based support from self-employed carers.²⁷

These disparities in mortality rates as between persons with disabilities and other sections of the population is the starkest example of the inequalities which persist for the former group. They also represent a breach of the right to life of persons with disabilities due to States' failures of protection and support, examples of which will now be set out.

Information provision

The provision of accessible information is a fundamental aspect of decision-making and is relevant to all aspects of life. It has particular importance in the context of public health emergencies such as the pandemic, where decision-making around not only medical care and treatment, but also broader questions of day-to-day living, including personal assistance, access to goods and services and compliance with pandemic-related restrictions, needs to be in a format which is appropriate for the individual.

In Ireland, IHREC noted initially inadequate provision of accessible public health information to people with disabilities, and how this increased their level of risk. The absence of Irish Sign Language provision in public health advice at the beginning of the pandemic was given as an example of this and reflected a failure to consult with representative DPOs (disabled persons' organisations).²⁸ In Sweden, for the first 33 days of press conferences held by government and other agencies to inform the public about developments regarding the pandemic, no Swedish Sign Language interpretation was provided and information in Easy-to-Read format was slow in being produced.²⁹

²⁷ Phoebe Dunn and others, 'Briefing: Adult Social Care and COVID-19 after the First Wave' 54, 25.

²⁸ Irish Human Rights and Equality Commission, 'The Impact of COVID-19 on People with Disabilities: Submission by the Irish Human Rights and Equality Commission to the Oireachtas Special Committee on COVID-19 Response' (Irish Human Rights and Equality Commission 2020) para 31.

²⁹ 'The Impact of COVID-19 on Disabled Citizens in Sweden | IHuman | The University of Sheffield' (22 October 2020) <<https://www.sheffield.ac.uk/ihuman/covid-19-blog/disability-and-covid-19-global-impacts/impact-covid-19-disabled-citizens-sweden>> accessed 13 November 2021.

In the UK, not everyone who considered themselves to be 'high risk' actually received notification advising them to 'shield' (i.e. remain at home). As such, those who did not receive such official requests 'needed to make the choice about whether and how to electively shield due to specific health concerns, but without the formal protections and benefits accrued through receiving a letter'.³⁰ Communication about reductions in restrictions was also unclear for many, leading to uncertainty.³¹ In a survey of people with disabilities in Sweden, 6 out of 10 stated that it was difficult to find reliable information about the pandemic.³² In the UK, the government has been criticised for not ensuring that all legal measures such as Notices and Directions under the Coronavirus Act 2020 were easily accessible, leading to a lack of clarity around issues such as school closures and eligibility for continued school attendance for students with disabilities.³³

Barriers to pandemic-related information extended to contact tracing technology. For example, in Spain, the contact tracing app proved to be inaccessible to blind and visually impaired people who used iPhones due to a flaw in how screen readers interacted with the technology.³⁴

Scherer *et al* carried out a content analysis of international guidance documents on access to water, sanitation and hygiene (WASH) based on EquiFrame, a tool used to assess the extent to which policies are disability inclusive. They found that the

³⁰ Tom Shakespeare and others, 'Disabled People in Britain and the Impact of the COVID-19 Pandemic' *n/a Social Policy & Administration* 10 <<https://onlinelibrary.wiley.com/doi/abs/10.1111/spol.12758>> accessed 30 November 2021.

³¹ *ibid.*

³² Funktionsrätt Sverige and Novus, 'Funktionsrätt Sverige' (2020) 7 <<https://funktionsratt.se/wp-content/uploads/2020/09/Novusrapport-Funktionsratt-Sverige-sommaren-2020.pdf>> accessed 15 October 2021.

³³ Joint Committee on Human Rights, 'The Government's Response to COVID-19: Human Rights Implications' (House of Commons 2020) Seventh Report of Session 2019–21 para 180.

³⁴ 'Flaws in Spain's COVID-Tracking App Are Exposing the Blind to Virus' (*euronews*, 8 September 2020) <[https://www.euronews.com/2020/09/08/flaws-in-spain-s-covid-tracking-app-are-exposing-blind-people-to-virus->](https://www.euronews.com/2020/09/08/flaws-in-spain-s-covid-tracking-app-are-exposing-blind-people-to-virus-) accessed 28 October 2021.

guidance generally focused on access to services and facilities, but rarely addressed the role of carers in providing support. The documents also made very few references to specific cohorts and their needs, e.g. children with disabilities, nor to the affordability of services.³⁵

The failure to adapt general public health information reflects a global trend which was observed by Kim *et al* in their analysis of 26 guidelines relating to Covid-19 published by both NGOs and governments. The authors found that many of these documents did not tailor the information for the community that they were addressing, and that the formats provided were frequently limited, e.g. did not include audio, braille or pictogram versions.³⁶ They also noted a particular absence of guidance for persons with disabilities who lived in remote and/or developing geographic locations.³⁷ A corollary of this has been the survey findings of the COVID-19 Disability Rights Monitor (DRM) that persons with disabilities living in remote and rural areas ‘faced additional barriers to accessing food, medication, and health care’ as well as concerns around ‘adequate access to information in areas without access to the internet, phones, and other technologies’.³⁸

Face masks/coverings

In France, members of the deaf community and those with hearing impairments were reported to have been unable to read lips or facial expressions due to the low supply of transparent masks.³⁹ Eskytè *et al* note that in the UK, government guidance on how to make face coverings from unwanted T-shirts did not make suggestions for the making of transparent versions, and that this was not improved in the revised version

³⁵ Nathaniel Scherer and others, ‘Are the Rights of People with Disabilities Included in International Guidance on WASH during the COVID-19 Pandemic? Content Analysis Using EquiFrame’ (2021) 11 *BMJ Open* e046112.

³⁶ Jeong-hyun Kim and others, ‘An Analysis of COVID-19 Global Guidelines Published in the Early Phase of the Pandemic for People with Disabilities’ (2021) 18 *International Journal of Environmental Research and Public Health* 7710, 9–10.

³⁷ *ibid* 10.

³⁸ COVID-19 Disability Rights Monitor (DRM) Coordinating Group, ‘Disability Rights during the Pandemic’ (2020) 39.

³⁹ Défenseur des droits, ‘Rapport annuel 2020’ (2020) 46.

of the guidance.⁴⁰ The authors go on to contrast this with the exemption from the requirement to wear a face covering for people who travel with or assist individuals who rely on lipreading and visual cues – which was little publicised. They conclude that ‘[t]his suggests that while the government is reluctant to support the development of deaf-friendly face masks ... it is willing to accept the risk of these people spreading or contract the virus’⁴¹.

Discriminatory treatment decisions

Triage

The potential for Covid-19 laws, policies and practices to negatively impact on persons with disabilities arose at an early stage in the pandemic, with the publication in March 2020 of guidance by the National Institute for Clinical Excellence (NICE) on critical care for adults with Covid-19 in the UK. This proposed the use of the ‘Clinical Frailty Scale’ (CFS) in the determination of admission to critical care. Opposition from NGOs and DPOs⁴², who expressed their concern that the blanket application of the CFS could result in persons with disabilities falling outside the criteria for such care, resulted in the guidance being revised.⁴³

Such an approach to triage which discriminates on the grounds of actual or perceived disability is directly contrary to the World Medical Association’s position on medical ethics in the event of disasters, which states that:

⁴⁰ Ieva Eskytė and others, ‘Out on the Streets - Crisis, Opportunity and Disabled People in the Era of Covid-19: Reflections from the UK’ (2020) 14 *Alter* 329, 333.

⁴¹ *ibid.*

⁴² Shaun Lintern, ‘Coronavirus: U-turn on critical care advice for NHS amid fears disabled people will be denied treatment’ *The Independent* (25 March 2020)

⁴³ NICE, *NICE updates rapid COVID-19 guideline on critical care* (25 March 2020) <https://www.nice.org.uk/news/article/nice-updates-rapid-covid-19-guideline-on-critical-care>

In selecting the patients who may be saved, the physician should consider only their medical status and predicted response to the treatment, and should exclude any other consideration based on non-medical criteria.⁴⁴

A discriminatory approach to treatment decisions also emerged in Italy, with the SIAARTI (Italian Society of Anaesthesia, Analgesia, Intensive Care) issuing guidelines⁴⁵ to apply to persons with disabilities based on severe comorbidities, functional status, and disability and to older persons based on survival probability and life expectancy, which could lead to their exclusion from care on those grounds.⁴⁶ Contrasting the approach taken in Italy to that of France, Orfali remarks that:

The Italian guidelines explicitly state that “an age limit for an ICU admission might be ultimately need to be set,” while the wording of the French guidelines tends to avoid any explicit age- or disability-related exclusion criterion (although these categories are taken into account in the prognosis).⁴⁷

She notes that in reality, however, an age threshold for access to an ICU bed was ‘de facto’ established in the regions of France which were most overwhelmed, with an ‘informal triage’ operating based on the idea that people with disabilities, particularly those in institutions would not ‘do well’ on a ventilator.⁴⁸ When the lack of clear guidance to ensure non-discriminatory access to healthcare was challenged at the Conseil d’Etat (the supreme court) by a number of organisations representing both nursing homes and the disabled community, the response from the Court was based

⁴⁴ ‘WMA - The World Medical Association-WMA Statement on Medical Ethics in the Event of Disasters’, s 8.3.1 <<https://www.wma.net/policies-post/wma-statement-on-medical-ethics-in-the-event-of-disasters/>> accessed 8 December 2021.

⁴⁵ Marco Vergano and others, ‘IN CONDIZIONI ECCEZIONALI DI SQUILIBRIO TRA NECESSITÀ E RISORSE DISPONIBILI’ (6 March 2020).

⁴⁶ Italian Disability Forum (Forum Italiano sulla Disabilità - FID), ‘CAT - Convention against Torture and Other Cruel Inhuman or Degrading Treatment or Punishment 70 Session (09 Nov 2020 - 04 Dec 2020) Adoption of Lists of Issues Prior to Reporting Submission by the Italian Disability Forum - FID 2020’ (2020), 3.

⁴⁷ Kristina Orfali, ‘What Triage Issues Reveal: Ethics in the COVID-19 Pandemic in Italy and France’ (2020) 17 *Journal of Bioethical Inquiry* 675, 3.

⁴⁸ *ibid.*

on the official guidelines which did not explicitly endorse age or disability-based exclusion criteria, and so no discrimination was therefore found.⁴⁹

DNACPR

In the UK, early in the first wave of the pandemic there were accounts of ‘do not attempt cardiopulmonary resuscitation’ (DNACPR) decisions being made regarding persons with disabilities, particularly those with learning disabilities, without the consent of the person⁵⁰ - a practice which had already been criticised prior to the pandemic in the Concluding Observations of the CRPD Committee.⁵¹ This was despite a joint statement being issued by the British Medical Association, the Care Provider Alliance, the Care Quality Commission (CQC), and the Royal College of General Practitioners emphasising that advance care planning should be based on individual assessments and that DNACPRs should not be applied based on the basis of a particular characteristic.⁵² NHS England and NHS Improvement also issued a statement in which they stated that DNACPR orders ‘should only ever be made on an individual basis and in consultation with the individual or their family’ and that, as such, ‘blanket policies’ were inappropriate ‘whether due to medical condition, disability, or age’.⁵³ The Joint Committee on Human Rights noted that there had already been ‘longstanding concerns about the discriminatory application of DNACPR notices to older and disabled people and the way that they have been administered in some instances’ and that the pandemic ‘has brought these concerns sharply into focus’.⁵⁴

⁴⁹ *Accès aux soins des personnes résidant en EHPAD – Décision en référé du 15 avril [2020] Conseil d’Etat 439910.*

⁵⁰ James Tapper, ‘Fury at ‘do not resuscitate’ notices given to Covid patients with learning disabilities’ *The Guardian* (13 February 2021)

⁵¹ CRPD Committee, *Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland*, CRPD/C/GBR/CO/1 (3 October 2017)

⁵² Care Quality Commission, ‘Joint statement on advance care planning’ (3 April 2020)

⁵³ Ruth May and Stephen Powis, ‘Letter to: Chief Executives of All NHS Trusts and Foundation Trusts CCG, Accountable Officers, GP Practices and Primary Care Networks, Providers of Community Health Services’ (7 April 2020) <<https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/maintaining-standards-quality-of-care-pressurised-circumstances-7-april-2020.pdf>> accessed 9 December 2021.

⁵⁴ Joint Committee on Human Rights (n 33) para 74.

The CQC's final report on how such DNACPR decisions were made and used during the pandemic found that while people's experiences of decision-making varied, older people, people with dementia and people with a learning disability overwhelmingly stated that they had not felt adequately supported in advance care planning conversations, and that the information used in the process was not accessible.⁵⁵ The report identified the training and support of staff, provision of accessible information and communication, as well as adequate oversight and ongoing review of decisions, as being crucial factors in ensuring that a rights-based approach was taken to decision-making around advance care planning, and specifically DNACPR.⁵⁶

Institutionalisation and its compounding effects

The pandemic has also demonstrated the consequences of the continued existence of institutional settings and coercive practices. In Ireland, 56% of all deaths up to October 2020 occurred in nursing homes. The Irish Human Rights and Equality Commission noted that '[o]f the nearly 30,000 people living in nursing homes, there is estimated to be approximately 19,500 people with dementia' and who would fall within the CRPD's definitions of 'persons with disabilities'.⁵⁷ Ireland's Mortality Census of Long Term Residential Care Facilities (which covered the period from the 1st of January to the 19th of April 2020) found that of the 73 deaths of persons with disabilities in those settings during that period, 16 were deaths due to Covid-19, either based on confirmed lab-tests or high probability. For mental health care facilities, this amounted to 14 Covid-19 deaths out of a total of 51.⁵⁸ In the UK, people with learning/intellectual

⁵⁵ Care Quality Commission, 'Protect, Respect, Connect – Decisions about Living and Dying Well during COVID-19: CQC's Review of "Do Not Attempt Cardiopulmonary Resuscitation" Decisions during the COVID-19 Pandemic - Final Report' (Care Quality Commission 2021) <https://www.cqc.org.uk/sites/default/files/20210318_dnacpr_printer-version.pdf> accessed 9 December 2021.

⁵⁶ *ibid.*

⁵⁷ Irish Human Rights and Equality Commission (n 28) para 20.

⁵⁸ Department of Health, 'Mortality Census of Long Term Residential Care Facilities' (Department of Health 2020) 1 <<https://www.gov.ie/en/publication/868ad8-mortality-census-of-long-term-residential-care-facilities-1-january-/>> accessed 5 October 2021.

disabilities living in residential care settings have had a higher probability of dying with Covid-19 than others living in care homes.⁵⁹

There has also been an inappropriate practice of placing younger persons with disabilities in nursing homes in Ireland, with the Ombudsman noting that some of those individuals had been informed that they were not permitted to leave during the Covid-19 pandemic due to the risk of transmission that they might pose to other residents upon their return.⁶⁰

In Ireland, the Oireachtas Special Committee on Covid-19 Response's report identified the State's continued reliance on institutional models of care with systemic issues for 'vulnerable populations' as playing a significant role in the high levels of mortality of people with disabilities in nursing homes. These included:

- Sick residents being unable to isolate due to shared bedrooms and bathrooms.
- The decision to continue to place individuals in nursing homes with known lack of compliance around infection control.
- The lack of a coherent policy on the care of older people which has meant 'the continuation of long-term institutional care in large settings where ownership has flipped from the public to the private sector over the past 30 years'.
- The failure to prioritise empowering older persons to remain at home and develop models of care that are integrated into towns and city community areas.⁶¹
- The lack of income support for workers in nursing homes (and other congregated settings), which resulted in them feeling compelled to work even where they may have been at risk of transmitting the virus. The report also noted that some of these workers were themselves resident in congregated

⁵⁹ Dunn and others (n 27) 27.

⁶⁰ Peter Tyndall, 'Wasted Lives: Time for a Better Future for Younger People in Nursing Homes' (2021), pp. 62–63 <<https://www.ombudsman.ie/publications/reports/wasted-lives/OMBWastedLives2021.pdf>> accessed 28 October 2021.

⁶¹ Houses of the Oireachtas: Special Committee on Covid-19 Response, 'Final Report: Special Committee on Covid-19 Response' (Houses of the Oireachtas 2020) 33 SCCR 004 para 14.

settings such as direct provision (Ireland's reception system for those seeking international protection which places them in institutional centres while they await the outcome of their asylum application).⁶²

Also in Ireland, the National Disability Authority (NDA) has raised the fact that despite national policy indicating the State funding should only be provided to centres with a maximum of four residents, there were still a number of centres which did not meet this requirement and instead had between 5 and 9 people with disabilities living with support staff. The NDA flagged this as posing potential problems for self-isolation. In addition, the fact of some staff 'living in' and others living in the broader community gave rise to increased chances for cross-contamination.⁶³ There had also been issues around access to adequate supplies of PPE in congregated settings.⁶⁴

In Italy, up to 40% of individuals in residential facilities were infected with Covid-19, with high rates of mortality. Lockdown measures were also continued for much longer in these settings than in the community.⁶⁵ One DPO provided the example of an institution for women with psychosocial disabilities in the city of Brescia which had 320 residents where 22 people died over the course of just one week.⁶⁶

Changes to mental health laws

Irish mental health legislation was also amended under emergency legislation⁶⁷ in response to the pandemic. The amendments included provision for remote mental health tribunals, the membership of which could be reduced from three (a consultant psychiatrist, a lawyer and a lay member) to tribunals with a lawyer being the sole member. The changes also provided for the carrying out of 'second opinion'

⁶² *ibid* 16.

⁶³ National Disability Authority, 'NDA Advice: Specific Issues for Persons with Disabilities Regarding Implications of COVID-19', 2 <<https://nda.ie/Publications/Health/Covid-19/NDA-Advice-Specific-Issues-for-Persons-with-Disabilities-regarding-implications-of-COVID-191.pdf>> accessed 10 December 2021.

⁶⁴ *ibid* 3.

⁶⁵ Italian Disability Forum (Forum Italiano sulla Disabilità - FID) (n 46) 6.

⁶⁶ Italian Disability Forum (Forum Italiano sulla Disabilità - FID) (n 46).

⁶⁷ Emergency Measures in the Public Interest (Covid-19) Act 2020

examinations by independent consultant psychiatrists remotely or, where that was not possible, for them to form their opinion as to the validity of the detention of the person based on the interactions with the patient's treating psychiatrist and the patient's medical records. In addition, the previous power of the person being detained to request a 14-day extension of an admission order was extended to the tribunal itself where it was 'satisfied that it is necessary due to the exigencies of the public health emergency'. This latter provision increasing the time for which a person can be involuntarily detained in a psychiatric unit before the validity of their detention is reviewed is particularly concerning given the increased risk of contracting Covid-19 in institutional settings.

Similarly, in the UK, the Schedule 8 of the Coronavirus Act 2020 contained amendments to the Mental Health Act 1983. These included provisions which allowed for:

- The making of an admission order on the basis of one medical recommendation rather than the usual two if it would be 'impractical or would involve undesirable delay'.
- The twelve-week total time limit on remands to hospital for the purposes of a report on a person accused of a criminal offence's mental condition no longer applying.
- The removal of a requirement for a second opinion where it was proposed to continue to treat a person without their consent for a period longer than three months if it would be impractical or would involve undesirable delay.

Although the UK amendments were ultimately not brought into force, their enactment points to the situational vulnerability of persons with psychosocial disabilities to legal responses which limit further their rights under mental health laws which provide for involuntary detention and treatment.

More generally, laws which authorise the detention and treatment of persons with psychosocial disabilities are themselves in contravention of Article 12 (which recognises the legal capacity of all individuals), Article 14 (which prohibits detention on the basis of the existence of a disability, either solely or in conjunction with other

grounds), Article 19 (the right of individuals with disabilities to live independently and be included in the community), and Article 25 (the right to health, which includes the right to provide informed consent to all medical treatment).

Visiting restrictions

In the early months of the pandemic, the UN High Commissioner for Human Rights, Michelle Bachelet, stated that:

Restrictions on visits to closed institutions may be required to help prevent COVID-19 outbreaks, but such steps need to be introduced in a transparent way and communicated clearly to those affected. Suddenly halting contact with the outside world risks aggravating what may be tense, difficult and potentially dangerous situations.⁶⁸

In the UK, blanket visiting restrictions on young people with learning disabilities and/or autism detained in ‘Assessment and Treatment Units’ (a practice which had already been found to be unlawful by the Joint Committee on Human Rights⁶⁹) in combination with a suspension of routine inspections, has led to ‘increased use of restraint and solitary confinement, and the vulnerability of those in detention to infection with Covid-19 (due to underlying health conditions and the infeasibility of social distancing)’.⁷⁰

Barriers to accessing medicine, other essentials and services

Due to a rise in the cost of living, as well as a reduction or removal of social and financial support, persons with disabilities in the UK have had to choose between purchasing medication and other essential items, as well as being prevented from accessing healthcare due to lack of accessible transport and loss of personal

⁶⁸ ‘OHCHR | Urgent Action Needed to Prevent COVID-19 “Rampaging through Places of Detention” – Bachelet’

<https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25745&LangID=E>
accessed 10 December 2021.

⁶⁹ Joint Committee on Human Rights, *Second Report of Session 2019, The detention of young people with learning disabilities and/or autism*, HC 121 / HL Paper 10 (1 November 2019)

⁷⁰ Joint Committee on Human Rights, *Seventh Report of Session 2019–21: The Government’s response to COVID-19: human rights implications*, HC 265 / HL Paper 125 (21 September 2020), pp. 39-40

assistance services.⁷¹ And this has been reflected in other jurisdictions, with the COVID-19 Disability Rights Monitor (DRM) survey finding that 25% of respondents from France and the UK stated that persons with disabilities did not have sufficient access to food during the pandemic and concluded that most governments ‘did not take the appropriate steps to safeguard and promote the right to access food’.⁷² One in three people with a disability in Sweden surveyed stated that they had experienced a cancellation or postponement of non-Covid-19 related health or care services.⁷³

In the UK, there have also been accounts of people with disabilities who were in receipt of personalised independence payments (PIP) in order to employ personal assistants (PAs) having difficulties in accessing personal protective equipment (PPE) as they were not recognised as needing it.⁷⁴ There were accounts of DPOs providing PPE for their members.⁷⁵ Similar questions around responsibility for obtaining PPE for persons who directly employ their PAs arose in Ireland, as well the provision of training on the correct use of those items by assistants.⁷⁶

Impacts on disability-specific services

Reductions in at home support and personal assistance services were universally reported in all of the project countries.

In Ireland, the suspension of day services for people with disabilities and children’s disability services such as occupational therapy has been perceived to have had negative outcomes.⁷⁷ It had a particular impact on those in residential settings given

⁷¹ COVID-19 Disability Rights Monitor, *Disability rights during the pandemic: A global report on findings of the COVID-19 Disability Rights Monitor* (2020), pp. 42-43. Available at https://www.internationaldisabilityalliance.org/sites/default/files/disability_rights_during_the_pandemic_report_web_pdf_1.pdf

⁷² COVID-19 Disability Rights Monitor (DRM) Coordinating Group (n 38) 31.

⁷³ Funktionsrätt Sverige and Novus (n 32) 12.

⁷⁴ Joint Committee on Human Rights, ‘The Government’s Response to COVID-19: Human Rights Implications’ (House of Commons 2020) Seventh Report of Session 2019–21, para 70.

⁷⁵ Shakespeare and others (n 30) 6.

⁷⁶ National Disability Authority (n 63) 4.

⁷⁷ Houses of the Oireachtas: Special Committee on Covid-19 Response (n 61) para 232.

that these services can be a primary source of socialisation and contact with the broader community.⁷⁸ People with disabilities who were in receipt of personal assistance services expressed concern about the impact of social distancing requirements on their day to day lives, as well as how systems of personal assistance would operate in cases where they need to be hospitalised due to Covid-19. There was also concern that guidance for health and social care workers which had been issued by the Health Service Executive was not being followed by service providers.⁷⁹

Research with persons with disabilities in the UK by Shakespeare *et al* revealed how their health care and support had changed significantly during the pandemic, with routine physiotherapy, speech and language therapy, and occupational therapy being cancelled. This had a particular impact on younger people with disabilities, and efforts to provide these services via either phone or video conferencing technology was not felt to have been particularly successful. Provision and maintenance of assistive devices was also affected, with consequent impacts on the disabled person in terms of lack of functioning and increased dependency.⁸⁰ Further, these changes also took place in the broader context of a suspension of the Care Act 2014 (by way of the Coronavirus Act 2020), which paused the obligation on local authorities to assess the care and support needs of persons with disabilities.

The House of Commons Health and Social Care and Science and Technology Committees heard from Mencap that from a survey of over 1,000 family carers that it did at the early stages of the pandemic during the first lockdown in 2020, around 70% had experienced a reduction or cut to the social care support they and the person with

⁷⁸ National Advocacy Service for People with Disabilities and Patient Advocacy Service, 'Advocacy Matters: Advocating for People with Disabilities in Residential & Day Services During the Covid-19 Pandemic' (2021), p. 19 <<https://advocacy.ie/app/uploads/2021/10/NAS-Impact-of-COVID-Report-1-of-4-Final-web.pdf>> accessed 27 October 2021.

⁷⁹ 'ILMI – Independent Living Movement Ireland – Disabled People Call on HSE to Provide Clarity and Direction in Relation to Provision of Supports during Covid19 Public Health Emergency' <<https://ilmi.ie/disabled-people-call-on-hse-to-provide-clarity-and-direction-in-relation-to-provision-of-supports-during-covid19-public-health-emergency/>> accessed 7 November 2021.

⁸⁰ Shakespeare and others (n 30) 5.

a disability they supported were getting. When this was followed up in November 2020, 80% still had not had services reinstated.⁸¹

Similar issues have arisen in Italy, where rehabilitation services have been severely impacted due to a prioritisation of resources to emergency settings in light of the pandemic⁸², as well as in France.⁸³

Education

The use of distance learning programmes is of least benefit to children with disabilities.⁸⁴ In Ireland, a number of submissions to the Special Committee on Covid-19 Response highlighted the disproportionate impact of school closures on children with 'special educational needs', both in terms of learning and socialisation.⁸⁵

In April 2020, the UK's Secretary of State for Education modified section 42 of the Children and Families Act by way of a Notice under the Coronavirus Act 2020. Section 42 had previously placed a duty on local authorities to secure special educational provision for children with disabilities based on the support needs that they had been assessed as requiring which are set out in Education, Health and Care (EHC) plans. The change made by the Secretary of State meant that local authorities' obligations were reduced to demonstrating that they had used their 'reasonable endeavours' to put in place such provision. The Parliamentary Joint Committee on Human Rights found that this fact, combined with general school closures in response to the pandemic, had 'a significant impact' on many children with disabilities due to the loss

⁸¹ House of Commons Health and Social Care and Science and Technology Committees, 'Coronavirus: Lessons Learned to Date: Sixth Report of the Health and Social Care Committee and Third Report of the Science and Technology Committee of Session 2021–22' (2021) HC 92 102.

⁸² 'Living with a Disability during the Pandemic. "Instant Paper from the Field" on Rehabilitation Answers to the COVID-19 Emergency - PubMed' <<https://pubmed.ncbi.nlm.nih.gov/32406226/>> accessed 14 December 2021.

⁸³ Défenseur des droits (n 39) 46.

⁸⁴ United Nations, 'Policy Brief: The Impact of COVID-19 on Children' (United Nations 2020) 8 <https://unsdg.un.org/sites/default/files/2020-04/160420_Covid_Children_Policy_Brief.pdf> accessed 9 November 2021.

⁸⁵ Houses of the Oireachtas: Special Committee on Covid-19 Response (n 61) para 137.

of specialist support. In addition, the Joint Committee found that, despite the Department for Education stating that children with ECH plans were classed as ‘vulnerable’ and therefore authorised to continue attending school, this guidance was not followed by all schools, with some refusing to accept such children during the first lockdown.⁸⁶ Further, initial provision for home-learning did not take into account the specific needs of children with disabilities, with learning materials frequently found to be ‘inaccessible or inappropriate’.⁸⁷

In Italy, an estimated 284,000 students with disabilities did not attend school due to pandemic related restrictions, but were not provided with alternative educational provision. The Italian Disability Forum estimates that 45% of students with disabilities did not receive any remote school support (e.g. online distance learning), and that another 35% only received such provision between one and three times a week.⁸⁸ In Sweden, one in ten people with disabilities (with this rising to 45% for those under 30 years of age) responded to a survey that their education had been impacted during the pandemic period.⁸⁹ 43% of the total respondents felt that their education had been negatively affected during the pandemic.⁹⁰

Employment, Income & Cost of living

In Ireland, concerns were raised by the NDA around the impact of the pandemic on progress that had been made on employment outcomes for persons with disabilities under the *Comprehensive Employment Strategy for Persons with Disabilities*⁹¹, aggravated by the fact that many were employed in sectors which were particularly vulnerable to both the measures put in place in response to the pandemic as well as the economic downturn - such as retail, catering and hospitality.⁹² The disadvantage

⁸⁶ Joint Committee on Human Rights (n 33) para 176.

⁸⁷ Shakespeare and others (n 30) 6.

⁸⁸ Italian Disability Forum (Forum Italiano sulla Disabilità - FID) (n 46) 11.

⁸⁹ Funktionsrätt Sverige and Novus (n 32) 19.

⁹⁰ *ibid* 21.

⁹¹ Department of Children, Equality, Disability, Integration and Youth, ‘Comprehensive Employment Strategy for People with Disabilities (2015-2024)’ (13 July 2019) <<https://assets.gov.ie/18906/1120bc6ad254489db9571c74e8572f44.pdf>> accessed 14 October 2021.

⁹² National Disability Authority (n 63) 6.

of workers with disabilities was compounded by the fact that ‘high-risk’ individuals with disabilities would no longer receive the Pandemic Unemployment Payment or the Covid-19 enhanced Illness Benefit after their workplace reopened.⁹³ Also in Ireland, 57.3% of persons with disabilities who responded to a survey perceived the costs of living with a disability to have increased during the pandemic, with 22% reporting costs to have significantly increased.⁹⁴ In Sweden, 20% of respondents with disabilities stated that their financial situation had been negatively impacted by the pandemic,⁹⁵ with more than half drawing on their savings.⁹⁶

The Italian DPO, FISH, has reported that only one in three people with disabilities had access to ‘lavoro agile’ (‘smart working’).⁹⁷ Under Italian law, the definition of smart working emphasises organisational flexibility, the voluntariness of the parties signing the individual agreement and the use of equipment that allows remote work (e.g., laptops, tablets and smartphones).⁹⁸ Conversely, FISH found that approximately 20.8% of interviewees continued to work in person-facing roles.⁹⁹

Digital exclusion

The measures taken by States to respond to the pandemic resulted in a sudden shift to internet-based living, including healthcare provision, education, employment, access to goods and services, as well as more general socialisation. With such a shift attaches a corresponding obligation on States and health services to ensure the accessibility of those new forms of information delivery for persons with disabilities.

⁹³ Houses of the Oireachtas: Special Committee on Covid-19 Response (n 61) 8.

⁹⁴ Indecon International Research Economists, ‘The Cost of Disability in Ireland: Final Report’ (2021) 78.

⁹⁵ Funktionsrätt Sverige and Novus (n 32) 31.

⁹⁶ *ibid* 32.

⁹⁷ FISH and IREF, ‘LA PANDEMIA VISTA DAI LAVORATORI CON DISABILITÀ: Instant Report Del Progetto JobLab’ (2020) 2 <https://www.fishonlus.it/progetti/joblab/files/Report_Covid.pdf> accessed 30 November 2021.

⁹⁸ ‘Lavoro agile’ (*Miur - Ministero dell’istruzione - Ministero dell’università e della ricerca*) <<https://www.miur.gov.it/lavoro-agile>> accessed 15 November 2021.

⁹⁹ FISH and IREF (n 97) 2.

In the UK, the self-advocacy organisation, People First, publicised the impact of digital exclusion on people with disabilities, noting that in 2017, 56% of adult internet non-users were disabled. Though the percentage of disabled adults not using the internet has been declining, in 2018, it was 23.3% compared with only 6.0% of those without a disability.¹⁰⁰ The UK's Joint Committee on Human Rights noted the potential for such exclusion to impact on contact tracing and consequent testing.¹⁰¹

For children with autism and intellectual disabilities in Ireland, digital exclusion in the form of access to technology was noted as a barrier to engaging with home-based education during the school closures.¹⁰² The Special Committee on Covid-19 Response in Ireland found that a 'digital divide' existed for persons with disabilities during the pandemic. This was attributed to a number of factors, including 'digital poverty, low digital literacy, co-ordination difficulties in using phones and laptops/tablets and living in areas with low internet connectivity'.¹⁰³

5. Examples of good practices

Exemptions from pandemic related restrictions

(i) Exceptions to travel restrictions and curfews

In an analysis of the impact of the responses to the pandemic on rights, the European Union Agency for Fundamental Rights (FRA)¹⁰⁴ noted that the French government, in its legislative response to the pandemic¹⁰⁵, created an exemption¹⁰⁶ to a curfew which operated in late 2020 in order to provide caring for 'vulnerable persons' and

¹⁰⁰ People First, 'Self Advocacy, Independent Living and Digital Inclusion' (2020) 2.

¹⁰¹ Joint Committee on Human Rights (n 33) para 166.

¹⁰² Houses of the Oireachtas: Special Committee on Covid-19 Response (n 61) para 138.

¹⁰³ *ibid* 237.

¹⁰⁴ European Union and Agency for Fundamental Rights, *Coronavirus Pandemic in the EU: Fundamental Rights Implications : Focus on Social Rights. Bulletin #6, 1 September - 31 October 2020. Bulletin #6, 1 September - 31 October 2020.* (2020), p. 30.

¹⁰⁵ Décret n° 2020-1262 du 16 octobre 2020 prescrivant les mesures générales nécessaires pour faire face à l'épidémie de covid-19 dans le cadre de l'état d'urgence sanitaire 2020 (2020-1262).

¹⁰⁶ *ibid*, Article 51.

transportation for people with disabilities¹⁰⁷. Similar exemptions have been provided for in Italian legislation, which allowed one individual to travel during curfew and outside of the limitation area where the purpose of their movement was to provide care to dependent persons. Further, even in regions which were subject to strict restrictions on movement and travel, an exception was created for the provision of 'social and health activities' for persons with disabilities.¹⁰⁸

(ii) Exceptions to physical/social distancing and masking requirements

In almost all jurisdictions examined, specific exemptions to requirements for social distancing and the use of masks in public spaces were created for persons with disabilities. For example, in Italy, persons with physical, intellectual and sensory disabilities who required supported were exempted from the 1 metre distancing requirement.¹⁰⁹

Treatment decisions

In a letter in March 2021, the UK's National Medical Director and other senior officers within the health service affirmed that:

Blanket policies are inappropriate whether due to medical condition, disability, or age. This is particularly important in regard to DNACPR orders, which should only ever be made on an individual basis and in consultation with the individual or their family.

¹⁰⁷ 'Déplacements ...pour l'assistance des personnes vulnérables ... des personnes en situation de handicap et de leur accompagnant.'

¹⁰⁸ DECRETO DEL PRESIDENTE DEL CONSIGLIO DEI MINISTRI 3 novembre 2020 Ulteriori disposizioni attuative del decreto-legge 25 marzo 2020, n. 19, convertito, con modificazioni, dalla legge 25 maggio 2020, n. 35, recante «Misure urgenti per fronteggiare l'emergenza epidemiologica da COVID-19», e del decreto-legge 16 maggio 2020, n. 33, convertito, con modificazioni, dalla legge 14 luglio 2020, n. 74, recante «Ulteriori misure urgenti per fronteggiare l'emergenza epidemiologica da COVID-19». (20A06109) (GU Serie Generale n.275 del 04-11-2020 - Suppl. Ordinario n. 41) <<https://www.gazzettaufficiale.it/eli/id/2020/11/04/20A06109/sg>>

¹⁰⁹ DECRETO-LEGGE 14 gennaio 2021, n. 2 Ulteriori disposizioni urgenti in materia di contenimento e prevenzione dell'emergenza epidemiologica da COVID-19 e di svolgimento delle elezioni per l'anno 2021. (21G00002) (GU Serie Generale n.10 del 14-01-2021) <<https://www.gazzettaufficiale.it/eli/id/2021/01/14/21G00002/sg>>

The NHS is clear that people should not have a DNACPR on their record just because they have a learning disability, autism or both. This is unacceptable. The terms “learning disability” and “Down’s syndrome” should never be a reason for issuing a DNACPR order or be used to describe the underlying, or only, cause of death. Learning disabilities are not fatal conditions.

Every person has individual needs and preferences which must be taken account of and they should always get good standards and quality of care.¹¹⁰

Such messaging is vital in reaffirming the non-discriminatory basis upon which treatment decisions should be made. Nevertheless, Baksh *et al* found that massive inequalities still existed in terms of outcomes for patients with intellectual disabilities. Those admitted to hospital with Covid-19 in the UK were 37% less likely to receive non-invasive respiratory support, 40% less likely to receive intubation, and 50% less likely to be admitted to the ICU. This group also had a 56% increased risk of dying from Covid-19 after they were hospitalised and died 1.44 times faster than controls.¹¹¹ This speaks to a more profound problem within healthcare provision and ethical decision-making which violates the rights to life and health of persons with disabilities.

Vaccination

All of the project countries included people with disabilities (and in some cases their family members and carers) in priority groups for vaccination. For example, France included people living in institutional settings in the highest priority group and Germany, France and Ireland all expressly included people with Down syndrome in priority groups (although in the case of Germany, this prioritisation came about as a result of strong advocacy efforts by DPOs).¹¹² The rollout of the vaccination

¹¹⁰ Stephen Powis and others, ‘Re: Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) and People with a Learning Disability and or Autism’ (4 March 2021) <<https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C1146-dnacpr-and-people-with-a-learning-disability-and-or-autism.pdf>> accessed 9 December 2021.

¹¹¹ R Asaad Baksh and others, ‘Understanding Inequalities in COVID-19 Outcomes Following Hospital Admission for People with Intellectual Disability Compared to the General Population: A Matched Cohort Study in the UK’ (2021) 11 *BMJ Open* e052482.

¹¹² European Union and Agency for Fundamental Rights, *Coronavirus Pandemic in the EU: Fundamental Rights Implications: Vaccine Rollout and Equality of Access in the EU. Bulletin #7, 1 March - 30 April 2021. Bulletin #7, 1 March - 30 April 2021.* (2021) 18–19.

programme in Italy did not include the prioritisation of persons with disabilities generally, although staff and residents in residential facilities were included as priority first phase groups. The second phase included persons with ‘neurological conditions and disabilities (physical, sensory, intellectual, psychological)’ as well as persons with Down syndrome.¹¹³

While still problematic in its position on the administration of vaccines to persons found to lack decision-making capacity, the guidance issued by the health service in Ireland for disability services emphasises the need to ensure that informed consent is obtained before a vaccine is administered to a person with a disability, as well as the need to: establish the individual’s will and preferences, the inclusion of the person’s circle of support, and the provision of accessible information. It is also clear that vaccination is not mandatory and that it is not permissible to vaccinate an individual against their wishes without legal authority.¹¹⁴

FRA has highlighted how the Swedish Association of Local Authorities and Regions worked closely with local disability services in an effort to ensure that the information on vaccination was accessible.¹¹⁵ In France, people with disabilities who were unable to travel alone to a vaccination centre could access transport by taxi or ambulance (if required by their state of health) and have the cost covered in advance by health insurance.¹¹⁶

Testing

FRA has also highlighted good practice in a number of jurisdictions regarding the testing of both residents and staff in institutions, with the Irish National Public Health

¹¹³ Ministero della Salute, *Adozione Piano strategico nazionale dei vaccini per la prevenzione delle infezioni da SARS-CoV2* (2 January 2021). <<https://www.trovanorme.salute.gov.it/norme/renderNormsanPdf?anno=2021&codLeg=78657&parte=1%20&serie=null>>

¹¹⁴ Marie Kehoe, ‘Guidance and Practical Resource Pack in Preparation for COVID-19 Vaccination Programme in Disability Services’ 69.

¹¹⁵ European Union and Agency for Fundamental Rights, *Coronavirus Pandemic in the EU* (n 112) 25.

¹¹⁶ ‘Prise en charge des frais de transport jusqu’au 31 décembre pour les personnes à mobilité réduite’ <<https://www.service-public.fr/particuliers/actualites/A14687>> accessed 3 December 2021.

Emergency Team providing tests for all residents and staff of long-term residential care. By the end of April, around 80% of residents had been tested.¹¹⁷ However, the Mental Health Commission has highlighted that this was not a flawless process, and that '[t]he extent of planning, testing and the communication of test results varied significantly across geographic areas' and that there were significant delays in the provision of test results.¹¹⁸

Financial support

In Italy, as part of the pandemic recover plan, the government has committed €150 million to support and strengthen assistance and independent living projects for people with disabilities.¹¹⁹ In France, the government provided a 'bonus' of €100 to the financial aid paid to adults with disabilities ('l'allocation aux adultes handicapés') where they met the criteria of having at least one child and were also in receipt of the housing allowance ('aide personnalisée au logement').¹²⁰

Addressing the digital divide

Shakespeare *et al* highlight the actions of two organisations, Glasgow Disability Alliance and The Family Fund, in ensuring digital accessibility for their communities. They made the decision to divert funds that otherwise would have been used for social events and holidays towards the provision of technology and internet access.¹²¹ While

¹¹⁷ European Union and Agency for Fundamental Rights, *Coronavirus Pandemic in the EU: Fundamental Rights Implications: With a Focus on Contact-Tracing Apps. Bulletin #2, 21 March - 30 April 2020. Bulletin #2, 21 March - 30 April 2020.* (2020) 4.

¹¹⁸ Mental Health Commission, 'COVID-19 PAPER 1: Supervising, Monitoring and Supporting Irish Residential Mental Health Services during COVID-19' (2021) 7 <<https://www.mhcirl.ie/sites/default/files/2021-01/Mental-Health-Commission-Covid-19-paper-1%20%281%29.pdf>> accessed 16 December 2021.

¹¹⁹ DECRETO-LEGGE 6 maggio 2021, n. 59 Misure urgenti relative al Fondo complementare al Piano nazionale di ripresa e resilienza e altre misure urgenti per gli investimenti. (21G00070) (GU Serie Generale n.108 del 07-05-2021) < <https://www.gazzettaufficiale.it/eli/id/2021/05/07/21G00070/sg>>

¹²⁰ Handicap.fr, 'Prime de 100 € et plus Pour Certains Titulaires de l'AAH' (*Handicap.fr*) <<https://informations.handicap.fr/a-prime-solidaire-aah-covid-12818.php>> accessed 28 November 2021.

¹²¹ Shakespeare and others (n 30) 9.

an example of good practice in terms of its impact, such actions should not fall to third sector organisations and should instead be driven centrally by government policy in light of States' obligations under the CRPD.

Virtual treatment for mental health difficulties

In Ireland, the Mental Health Commission noted that in response to the pandemic, 'home based or virtual treatment programmes' were introduced, allowing individuals who could not or did not wish to attend a service to receive treatment 'acute' mental health issues, with full multi-disciplinary team involvement.¹²²

6. Proposals for best practice in light of the requirements of the CRPD

Active participation of persons with disabilities in legal and policy responses

The design and implementation of best practice to maintain States obligations under the CRPD during public health crises such as the Covid-19 pandemic must be based on the principles of equality and non-discrimination. However, as has been illustrated in the above examples, the failure on the part of States to embed the requirements of the CRPD within its public structures and practices has meant that persons with disabilities and their needs were not sufficiently considered in legal and policy responses to the pandemic to date. This has been echoed in the findings of the COVID-19 Disability Rights Monitor (DRM), which has noted that one of most common issues which has impacted on people with disabilities during the pandemic has been the failure, both nationally and globally, to include persons with disabilities in the collective response. They conclude that policymakers 'appear to have reverted to treating persons with disabilities as objects of care or control, undermining many of the gains of recent years to enhance citizenship, rights, and inclusion'.¹²³

¹²² Mental Health Commission, 'COVID Paper II: Examining the Impacts and Response in Residential Mental Health Services' (2021) 16.

¹²³ COVID-19 Disability Rights Monitor (DRM) Coordinating Group (n 38) 7.

The *Sendai framework for disaster risk reduction* echoes the requirements of Article 4(3) of the CRPD in stating that disaster risk reduction ‘requires an all-of-society engagement and partnership’ as well as ‘inclusive, accessible and non discriminatory participation, paying special attention to people disproportionately affected by disasters’.¹²⁴ The framework emphasises that a disability perspective should be integrated into all policies and practices.¹²⁵ It recognises that:

Persons with disabilities and their organizations are critical in the assessment of disaster risk and in designing and implementing plans tailored to specific requirements, taking into consideration, inter alia, the principles of universal design ...¹²⁶

This duty to ensure inclusion of persons with disabilities in all areas of planning is echoed in both the World Humanitarian Summit’s *Charter on inclusion of persons with disabilities in humanitarian action*¹²⁷, as well as the Inter-Agency Standing Committee’s *Guidelines for the inclusion of persons with disabilities in humanitarian actions*¹²⁸.

Compliance with the CRPD therefore requires States to ensure the full inclusion and active participation of persons with disabilities through their representative organisations in planning, implementation and monitoring of the response across all aspects of life and society, including ensuring that these organisations have sufficient funding to undertake such activity and maintain their involvement over the long term.

¹²⁴ United Nations, ‘Sendai Framework for Disaster Risk Reduction 2015 - 2030’ (2015) para 19(d).

¹²⁵ *ibid.*

¹²⁶ *ibid* 36(a)(iii).

¹²⁷ World Humanitarian Summit, ‘Charter on Inclusion of Persons with Disabilities in Humanitarian Action’ <<http://humanitariandisabilitycharter.org/wp-content/themes/humanitarian-disability-charter.org/pdf/charter-on-inclusion-of-persons-with-disabilities-in-humanitarian-action.pdf>> accessed 13 November 2021.

¹²⁸ IASC Inter-Agency Standing Committee, ‘Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action’ (2019) <https://interagencystandingcommittee.org/system/files/2020-11/IASC%20Guidelines%20on%20the%20Inclusion%20of%20Persons%20with%20Disabilities%20in%20Humanitarian%20Action%2C%202019_0.pdf> accessed 13 November 2021.

Information provision

The provision of public health information in inclusive and accessible formats has been a failure of a number of States throughout the pandemic. Adequate and appropriate information provision is a vital element in the vindication of the rights to legal capacity and health under the CRPD. Information on pandemic related restrictions (and exemptions), self-isolation, testing, and vaccination should be provided in multiple formats, including Braille, Easy Read/plain language, captioning, and sign language. This information should be made available via various media, including television, radio, print media and internet. The information should also be compatible with assistive technologies such as screen readers.

Healthcare

Triage

All treatment decisions should be made on non-discriminatory grounds and should not be based on either the existence of a disability or the age of the person. A crucial safeguard in this regard would be the inclusion of DPOs or individuals with disabilities in the drafting and adoption of clinical or professional guidance on triage decisions, as well as membership of clinical ethics committees. Independent oversight of the operation of triage decision-making is particularly important where healthcare services are operating under resource constraints.

Vaccination

Consistent with the right to the highest attainable standard of health under Article 25 of the CRPD, and in light of both their inherent and situational vulnerabilities, persons with disabilities and their supporters should be included in priority groups for vaccination. Particular emphasis should be placed on vaccine provision to people with disabilities in institutional settings, given the increased risk of transmission in such settings. Where required and requested, transport to and from vaccination sites should be provided to persons with disabilities and should not result in the person incurring any costs.

General healthcare

Access to general healthcare services, including mental healthcare, should be adapted so as to ensure continued provision to the greatest extent possible. This may include remote/telehealth services, or via apps or messaging services. However, such adaptations should not completely replace the option of in-person support unless that option is completely unviable, given the digital divide which exists for a disproportionate number of people with disabilities. There should be no barriers to the use of support by the person in accessing and engaging with such services - this should fall within authorised exemptions to public health restrictions.

In accordance with Article 25(d) of the CRPD, all healthcare should be provided to persons with disabilities on the basis of free and informed consent, recognising the legal capacity of all persons with disabilities. Ensuring that this occurs requires the ongoing training of health professionals in rights-based care. As has been stated above, the provision of accessible information, where applicable, should be an integrated part of the process of obtaining either informed consent or informed refusal.

Deinstitutionalisation

In light of the increased risk to persons with disabilities who either reside or are detained in institutions (including care homes, psychiatric facilities, nursing homes and prisons), independent monitoring and inspection of institutions should be maintained, with a particular focus on how public health guidance is being implemented. Priority should be given to testing and offering vaccination to both persons with disabilities and staff in those settings. The need to recover from Covid-19 should not be used as a basis for keeping an individual in an institution where that convalescence could take place in the community. Equally States should not impose regressive changes to mental health laws which further infringe the rights of persons with psychosocial disabilities.

Focus should be placed on compliance with Article 19 and the realisation of the right of persons with disabilities to live independently and be included in the community. As such, processes of deinstitutionalisation should be accelerated, alongside prohibitions on further admissions to institutional settings. This rapid deinstitutionalisation will

require the provision of appropriate and individualised community supports for those persons who have been in institutional settings, including around housing, employment, healthcare and education. Placement in other institutional settings such as homeless shelters or segregated refugee accommodation is not appropriate.

Disability-specific services

Given the detrimental effects on persons with disabilities of the discontinuation of supports such as personal assistance, as well day and respite services, States should ensure the continuation of these services to the maximum extent possible, and their transition to the home environment where appropriate. Where such services need to be paused, their recommencement should be prioritised.

In situations where a person with a disability uses forms of personal assistance, personal protective equipment, as well as training in its use, should be provided to PAs by health services. The person with a disability should not have to choose between providing PPE themselves or risking infection and/or loss of their service, regardless of whether the PA is provided via the public service or is privately employed by the person with a disability. The PPE should be appropriate to the needs of the individual with the disability, i.e. translucent facemasks in the case of members of the Deaf community or those with hearing impairments.

Access to education

The experience of children with disabilities in accessing education has highlighted the need to ensure that transitions to home-based learning take into account their various support and accessibility needs, as well as recognising that remote learning will not be appropriate for all children with disabilities. As such, where a child with a disability wishes to continue attending school during periods of school closures, they should be recognised as qualifying for continued attendance. State authorities should also ensure that the provision of personal assistance for education is not linked to the school the child attends and is instead attached to the child themselves, allowing flexibility and adaptability over time. Education authorities should also ensure the provision of accessible learning materials.

The pandemic has revealed the adverse consequences of segregated schools for children with disabilities, particularly where all other forms of support and healthcare are attached to that setting. They also replicate many of the risk factors in terms of transmission of the virus which exist in other institutional settings. Separate educational provision for children based on the existence of a disability fundamentally contravenes Article 24 of the CRPD, which requires States parties to create inclusive education systems based on support and reasonable accommodation. Such practices are also in violation of Article 7, which requires States to ‘take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children’. A public health crisis such as the Covid-19 pandemic therefore represents an opportunity for a transition away from such practices and the building of integrated and inclusive education options for children with disabilities.

Employment support

The widespread transition to remote working, something which was campaigned for and pioneered by persons with disabilities themselves, has allowed many people with disabilities to continue working throughout the pandemic. Yet the employment gap between persons with disabilities and those without is still substantial, and risks being exacerbated by a public health emergency such as the Covid-19 pandemic, in contravention of Article 27 of the CRPD. Persons with disabilities are also more likely to work in public-facing roles which are not easily adaptable to home working. Social and financial support, including protection from redundancy and demotion, should therefore be put in place in order to ensure their quality of life is maintained while they cannot work and that they can return to employment at a time appropriate for them. Employment initiatives based on reasonable accommodation and accessibility should be put in place so as to ensure access to chosen employment for persons with disabilities.

Access to food, medicine and other essentials

Supply chains should be prioritised so as to ensure that persons with disabilities retain access to food, medicine, and other essential items, including delivery services. This is particularly relevant where the person with a disability, or their family members or

carers, are required to self-isolate. The transition to electronic payments should not act as a barrier to accessing these items and alternative methods of payment should continue to be accepted.

Exemptions to legal and policy responses to the public health emergency

Persons with disabilities should not be de facto isolated in their homes due to limitations on being accompanied outdoors by support persons. In addition, disability-based exemptions to rules around mask-wearing and social distancing should be widely publicised to both persons with disabilities and the wider community in order to ensure public awareness and understanding, thereby reducing the risk of aggression and violence towards those availing of such exemptions.

Social protection

Disability-inclusive policies of sick pay and benefits should be provided by States where persons with disabilities are unable to work due to legal restrictions in response to the pandemic. These financial supports should be disability-specific, taking into account the additional costs experienced by persons with disabilities, as well as the particular constraints under which persons with disabilities are placed in terms of employment options during a public health emergency, which may extend beyond those which exist for other members of the population. Such financial support should also extend to family members and carers who are required to change their employment situation in order to support a person with a disability.

Disaggregated data collection

Data on the public health emergencies and their effects should be disaggregated by disability in order to assess the impact of State responses on persons with disabilities and identify practices which do not comply with the requirements of the CRPD and ensure that legal and policy responses are evidence-based. Such information should be made publicly available so that it can be accessed by all relevant stakeholders.