

# **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

*June 2020*



**Coimisiún na hÉireann um Chearta  
an Duine agus Comhionannas**  
Irish Human Rights and Equality Commission

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## Executive Summary

The Irish Human Rights and Equality Commission is both the national human rights institution (NHRI) and the national equality body (NEB) for Ireland. The Commission is the designate Independent Monitoring Mechanism for Ireland under the UN Convention on the Rights of Persons with Disabilities (UNCRPD). In this submission, the Commission considers the human rights and equality impact to date of the COVID-19 pandemic, and the State's response to it, on people with disabilities.

COVID-19 has given rise to significant risks of discrimination and the undermining of rights for persons with disabilities. Any assessment of the human rights and equality impact of COVID-19 on people with disabilities must be against a standard of equal dignity and equal participation. The COVID-19 emergency has highlighted in sharp relief that if a standard of equal dignity and equal participation is not met in 'normal' times, it can rapidly become a casualty in times of crisis.

This is particularly relevant to the experience of people who live in congregated settings. However, it is also true of the experience of people with disabilities whose full participation in economic, social and cultural life is dependent on the availability of appropriate and accessible services, and reasonable accommodation.

Experience at home and abroad suggests that the collective living arrangements in congregated care settings made already vulnerable people particularly susceptible to COVID-19. This situation has wide-ranging human rights implications. In circumstances where the World Health Organisation has warned that COVID-19 may never go away, a new approach to care consistent with the highest international human rights standards appears to be urgently necessary.

In Ireland, we have made progress in the move from an old charitable, medical model of support for people with disabilities, towards a more holistic rights-based perspective, supporting people to live inclusive, independent lives, culminating in Ireland's ratification of the UN Convention on the Rights of Persons with Disabilities in 2018.

The Commission recommends that an explicit human rights and equality-based approach be taken to build a transition out of COVID-19 that is fully inclusive of people with disabilities. More work needs to be done, both administratively and legislatively, to give the UNCRPD legal effect and practical meaning in the lives of disabled people. Positive measures must be taken across a range of areas to ensure that all groups of people with disabilities transition out of the emergency phase on an equal basis with each other and the rest of the population. The alternative risks a permanent erosion of the human rights and equality of people with disabilities.

## Introduction

1. The Irish Human Rights and Equality Commission ('the Commission) is both the national human rights institution (NHRI) and the national equality body (NEB) for Ireland. Under the *Irish Human Rights and Equality Commission Act 2014*, the Commission is mandated to keep under review the adequacy and effectiveness of law and practice in the State relating to the protection of human rights and equality. In its *Strategy Statement 2019-2021*,<sup>1</sup> the Commission prioritises the advancement of disability rights.
2. The Commission is the designate Independent Monitoring Mechanism for Ireland under the UN Convention on the Rights of Persons with Disabilities (UNCRPD). The Commission has established a Disability Advisory Committee, composed of a diverse group of persons with lived experience of disability, to ensure the direct participation of persons with disabilities and their representative organisations in monitoring how the UNCRPD is implemented in Ireland.<sup>2</sup>
3. Under the UNCRPD which Ireland ratified in March 2018, the State has an obligation to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”.<sup>3</sup>
4. Article 4(1) UNCRPD includes the undertaking that State Parties will take all appropriate measures to eliminate discrimination on the basis of disability by any person, organisation or private enterprise. Equality legislation, principally the *Employment Equality Acts 1998-2015* and the *Equal Status Acts 2000-2018*, prohibits discrimination on the ground of disability in employment and in the provision of goods and services, and impose obligations on public and private employers and on service providers in terms of reasonable accommodation.
5. In addition, the constitutional right to equality (Article 40.1) is increasingly understood as referring to those immutable characteristics of human beings that are central to their identity and sense of self and which, on occasions, have given rise to discrimination or stereotyping. Disability is such a characteristic and measures treating persons with disabilities less favourably than persons without disabilities, without legitimate justification, have been held to be contrary to Article 40.1. of the Constitution.
6. As Ireland’s national human rights institution and national equality body, the Commission seeks to set out here an independent consideration of the human rights and equality impact to date of the COVID-19 pandemic, and the State’s response to it, on people with disabilities.

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<sup>1</sup> IHREC (2019), [Strategy Statement 2019-2021](#).

<sup>2</sup> More information about the Commission’s monitoring role and the DAC is available at [ihrec.ie/crpd](http://ihrec.ie/crpd).

<sup>3</sup> Article 1 CRPD. In the context of care for older people and persons with disabilities, dignity has been conceptualised as empowerment that enables self-determination and individual freedom; a person in receipt of care will have dignity when they are empowered to exercise their capabilities effectively, and health workers can respect dignity by enhancing these capabilities. See Brendan Kelly, *Dignity, Mental Health and Human Rights: Coercion and the Law*. Routledge. Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons are also the first of the general principles set out in Article 3 UNCRPD. In order to make one’s own choices, one need legal and functional capacity.

7. As Article 1 UNCRPD states, “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”.<sup>4</sup> The Committee will note that this definition encompasses mental impairments and that the rights of people with mental health issues are protected under the UNCRPD.
8. Having regard to this definition, the Commission recognises the diversity among persons with disabilities in terms of age and gender and other equality grounds.<sup>5</sup> Many persons with disabilities are students and employees. Many live with family or in independent living arrangements. Persons with disabilities live in congregated settings, including disability services, mental health establishments, and prisons. Some older people – and, in particular, many older people living in nursing homes – are people with disabilities.<sup>6</sup> There are also many younger people with disabilities inappropriately accommodated in nursing homes.<sup>7</sup>
9. While all of UNCRPD rights are relevant to the COVID-19 crisis, some are of particular relevance. These include: Article 9 *Accessibility*; Article 10 *Right to Life*; Article 11 *Situations of risk and humanitarian emergencies*; Article 16 *Freedom from exploitation, violence and abuse*; Article 19 *Living independently and being included in the community*; Article 24 *Education*; Article 25 *Health*; Article 27 *Work and Employment*; and Article 28 *Adequate standard of living and social protection*. There is also an intersectional dimension to rights of persons with disabilities and of older people. A recent UN Policy Brief on the impact of COVID-19 on older persons, states that “COVID-19 exacerbates global economic inequalities and exposes existing inequalities that affect older persons [including] older persons with disabilities.”<sup>8</sup>
10. The Commission also draws the Committee’s attention to Article 19 ‘*Living independently and being included in the community*’. Article 19 is one of the key articles of the UNCRPD, reflecting the right of all persons with disabilities to live in the community on an equal basis with others. Article 19 expressly forbids forcing persons with disabilities to live in a particular living arrangement, and places an obligation on the State to provide the necessary services that allow all persons with disabilities to live in the community in a meaningful and integrated way.<sup>9</sup> These are relevant to important reiterations of existing political goals, as set out in the

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<sup>4</sup> Article 1 CRPD.

<sup>5</sup> Danlami Basharu and María Soledad Cisternas Reyes, [Joint Statement: Persons with Disabilities and COVID-19 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](#).

<sup>6</sup> UN Special Rapporteur on the rights of persons with disabilities, [Paradigm shift needed to end human rights abuses of older people with disabilities, says UN expert](#).

<sup>7</sup> A 2018 report found there to be almost 1,500 young people with disabilities living in nursing homes. See Maria Pierce, Sophia Kilcullen and Mel Duffy, [The situation of younger people with disabilities living in nursing homes in Ireland - phase 1](#), September 2018.

<sup>8</sup> UN (May 2020) *Policy Brief: The Impact of COVID-19 on Older Persons*.

<https://unsdg.un.org/sites/default/files/2020-05/Policy-Brief-The-Impact-of-COVID-19-on-Older-Persons.pdf>

The newly-appointed UN Independent Expert on Older Persons Dr Claudia Mahler stated that there was a pressing need for a universal legal instrument to promote and protect the rights of older persons and that was particularly urgent in light of the current COVID-19 pandemic (GANHRI Webinar, 22 June 2020, “Protecting the rights of older persons in COVID-19 responses and recovery: The role and experiences of National Human Rights Institutions”).

<sup>9</sup> Committee on the Rights of Persons with Disabilities, *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5. Available to download from: <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>.

*Time to Move on from Congregated Settings* policy, and calls by the broader disability rights movement.

## Areas of Concern

11. COVID-19 has given rise to significant risks of discrimination and the undermining of rights for persons with disabilities. The Commission notes CRPD Article 11 '*Situations of risk and humanitarian emergencies*', which places an obligation on the State to take all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk.
12. Areas of particular concern to the Commission include: the lack of an explicit and systematic consideration of human rights and equality; the very limited participation of persons with disabilities and Disabled Persons Organisations in the development and oversight of the COVID-19 response; the differential treatment of persons with disabilities; and the lack of measures to address the differential impacts of COVID-19 both on impairment groups and persons with disabilities who are members of other equality groups. Further, the Commission is concerned about:
  - the situation of persons in residential settings, including nursing homes;
  - the lack of publicly available, real time disaggregated data both by impairment and membership of equality groups<sup>10</sup>;
  - the disruption of supports and services for both persons with disabilities and for family carers and the lack of provision of COVID-19 specific supports including PPE and social care;
  - the accessibility of information;
  - awareness of disability and representation of persons with disabilities;
  - education and employment for persons with disabilities;
  - intersectional disadvantage and discrimination.
13. The Commission acknowledges the efforts of the State to address concerns that have been raised in these areas, but regrets that these and other disability issues were not considered from the outset of the crisis and were addressed only following the significant awareness-raising efforts of disabled people and disability representative organisations. The Commission remains concerned that the effectiveness of those interventions that have been put in place remains in doubt.
14. Any assessment of the human rights and equality impact of COVID-19 on people with disabilities must be against a standard of equal dignity and equal participation. The COVID-19 emergency has highlighted in sharp relief that if a standard of equal dignity and equal participation is not met in 'normal' times, it can rapidly become a casualty in times of crisis.

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<sup>10</sup>There is lack of comprehensive and disaggregated data by impairment and by groups protected under equality legislation. The Commission is concerned that this disaggregated data is not routinely collected, that the quality of data can be poor even when there is a service requirement, and that such data is not in the public domain.

This is particularly relevant to the experience of people who live in congregated settings. However, it is also true of the experience of people with disabilities whose full participation in economic, social and cultural life is dependent on the availability of appropriate and accessible services, and reasonable accommodation.

15. The impact of COVID-19 on people with disabilities in the initial phase of the pandemic must therefore be considered in the context of Ireland's current provision of services and relevant supports for people with disabilities, including those services for people who may have a disability due to age. While progress has been made, significant gaps and vulnerabilities in existing policy and services – including slow progress in implementing the State's own policy of de-congregation, and the contingent nature of some supports, such as personal assistants – has resulted in a disproportionate impact on people with disabilities.
16. This disproportionate impact is at variance with the sentiment and message of collective solidarity in the face of the pandemic. It is critical that the lessons of the initial, acute phase of the COVID-19 crisis inform policy, practice and national planning as we move into a longer-term accommodation with the virus.

## Institutional Settings

17. Data published by the Central Statistics Office on 5 June showed that the rate of COVID-19 infection per 100,000 persons was somewhat higher for people with disabilities (530) than for those without disabilities (499). However, the COVID-19 mortality rate was 41 per 100,000 for people with disabilities compared to 23 per 100,000 without a disability.<sup>11</sup> The CSO does not provide any analysis of these comparative figures. However it is clear that these significantly higher death rates for people with disabilities are related to the higher rates identified for vulnerable people living in long-term care settings including nursing homes and more generally to the higher risk faced by older people who have a greater likelihood of being disabled.
18. International human rights experts noted the particular risks faced by people with disabilities in institutions from the onset of the pandemic.<sup>12</sup> For many people in these settings, containment measures such as social distancing and self-isolation may be impossible for those who rely on the support of others to eat, dress and bathe.<sup>13</sup> Persons with disabilities are often at increased risk of serious health complications and restrictive measures to lower the risk of contamination in these settings were therefore necessary, but limiting contact with family and friends can have the impact of undermining that person's rights and removes what can often be the person's closest advocates.<sup>14</sup> The use of Personal Protective Equipment such

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<sup>11</sup> CSO, [COVID-19 Deaths and Cases Series 3](#), 5 June 2020

<sup>12</sup> UN High Commissioner for Human Rights Michelle Bachelet, [Urgent action needed to prevent COVID-19 "rampaging through places of detention"](#), 25/03/2020. Council of Europe Commissioner for Human Rights, [Persons with disabilities must not be left behind in the response to the COVID-19 pandemic](#).

<sup>13</sup> UN Special Rapporteur on the rights of persons, [COVID-19: Who is protecting the people with disabilities? – UN rights expert](#).

<sup>14</sup> UN Special Rapporteur on the rights of persons, [COVID-19: Who is protecting the people with disabilities? – UN rights expert](#)

as facemasks poses a range of communication problems for people with disabilities, making adherence to public health advice challenging.<sup>15</sup>

19. As of 4 June 2020, some 650 people in disability services had been identified as having COVID-19 symptoms, and 430 of these had their diagnosis confirmed in a lab. Among the cases, 57% were staff and 43% were residents, while a total of 14 people in disability services have died from the virus.
20. As stated above, many older people in nursing homes, where the impact of the virus has been most acute, are likely to be people with disabilities. Of the nearly 30,000 people living in nursing homes, there is estimated to be approximately 19,500 people with dementia, representing close to three quarters of the nursing homes population.<sup>16</sup> The impact on persons living in nursing homes has been hugely disproportionate to that of the population as a whole. As of 14 June 2020, the HPSC had reported 258 clusters or outbreaks in nursing homes, associated with 5,371 COVID-19 cases (21% of total cases) and 943 of the 1,446 total deaths associated with COVID-19.<sup>17</sup>
21. The Commission notes UN guidance on the impact of COVID-19 on mental health services, including institutional settings.<sup>18</sup> As last published by the Mental Health Commission, there were 17 deaths of residents of mental health services,<sup>19</sup> with nine of these deaths occurring in one facility.<sup>20</sup> Throughout the crisis, the Mental Health Commission consistently raised concerns about various issues in mental health facilities, including the need for clarity on public health guidance,<sup>21</sup> testing of staff,<sup>22</sup> and staff isolation capacities.<sup>23</sup> The Commission recognises the significant work undertaken by the Mental Health Commission to continue its regulatory role and to operate virtual Mental Health Tribunals.<sup>24</sup> It considers that an evaluation of the operation of virtual Mental Health Tribunals, including human rights and equality issues, would provide valuable insights for future models of practice.
22. A number of issues have been put forward as having contributed to the rapid spread of the virus in nursing home and residential care settings. These have been documented to include:

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<sup>15</sup> See Helen Grote and Fizz Izagaren, [COVID-19: The communication needs of D/deaf healthcare workers and patients are being forgotten](#), blog post, 7 May 2020.

<sup>16</sup> As reported in Hennelly N and Cahill S (2020) [‘The impact of COVID-19 on people living with dementia in Ireland’](#). Report available at LTCcovid.org, International Long-Term Care Policy Network, CPEC-LSE, 2 June 2020, pp.4-5.

<sup>17</sup> As report by the Department of Health to the Committee in its *Nursing Homes - Summary paper provided to Special Committee on COVID-19 Response*, 15 June 2020, pp.4. Available to download at: <https://www.gov.ie/en/collection/8d7df-department-of-health-nursing-homes-papers-special-COVID-19-committee-june-2020/>

<sup>18</sup> UN, [Policy Brief: COVID-19 and the Need for Action on Mental Health](#), 13 May 2020.

<sup>19</sup> Mental Health Commission, [Notable decrease in COVID-19 cases across mental health facilities: Mental Health Commission expresses concern that staff testing took so long to complete](#), press release, 26 May 2020.

<sup>20</sup> Mental Health Commission, [Mental Health Commission Statement on Maryborough Centre](#), press release.

<sup>21</sup> Mental Health Commission, [Clarity required on COVID-19 guidance for mental health services](#), press release, 19 May 2020.

<sup>22</sup> Mental Health Commission: [Assurance required on COVID-19 test results for mental health staff](#), press release, 11 May 2020; [Inconsistencies remain in staff testing across mental health services](#), press release, 4 May 2020.

<sup>23</sup> Mental Health Commission, [Work ongoing to protect 3,800 residents of mental health facilities](#), press release, 20 April 2020.

<sup>24</sup> See Mental Health Commission, [Mental Health Commission welcomes safeguards for involuntary patients during COVID-19 crisis](#), press release.

inadequate supplies of Personal Protective Equipment, inadequate physical distancing in facilities, low staffing levels, cases of nursing home staff who tested positive for the virus being asked to continue working, poor communication by nursing homes about the welfare of residents with relatives, lack of infection controls within the homes; staff working in both one or more care facilities as well as in general hospitals.<sup>25</sup>

23. Concerns were raised about mixed staffing arrangements where some staff are 'living-in' and others attend on a rota over the course in the day, giving rise to further opportunities for cross-contamination between the community and the residents in the centre.<sup>26</sup> Concerns were also raised about provision of accessible communication to residents on social distancing, self-isolation measures, and the use of PPE.<sup>27</sup> In addition to what happened within the facilities themselves, concerns have also been raised about the inadequacy of clinical oversight in these settings,<sup>28</sup> as well as the State's response to concerns that were raised by HIQA as the regulator.<sup>29</sup>
24. Without commenting on any specific complaint, the Commission considers that these general issues, if proven, could engage the human and equality rights of those affected, including under the *Equal Status Acts*, the European Convention on Human Rights and the UNCRPD.
25. The measures required to mitigate the impact of any potential further outbreaks of infection in institutional settings have been well laid out by others, and include: testing, contact tracing and social distancing; accessible public health information; adequate PPE provision; equal access to healthcare services; and oversight of the preparedness of institutional settings.<sup>30</sup> In terms of upholding the human rights principles of autonomy and dignity in such a situation, the Commission urges that participation in decision-making, supported by comprehensive access to independent advocacy services, is an essential safeguard for the rights of persons in institutional settings.<sup>31</sup>
26. Further, the Commission notes the requirements, under the Public Sector Equality and Human Rights Duty, that service providers prevent discrimination and uphold the rights of services users in policies and programmes adopted in response to COVID-19. The Commission also stresses that it is imperative that all service providers, whether public or private, ensure that their policies and practices are equality proofed to ensure compliance with their obligations under the *Equal Status Acts*.
27. Experience at home and abroad suggests that the collective living arrangements in congregated care settings made already vulnerable people particularly susceptible to COVID-19. This situation has wide-ranging human rights implications. In circumstances where the World Health Organisation has warned that COVID-19 may never go away, a new approach to

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<sup>25</sup> As report in complaints received by HIQA. See Simon Carswell, '[COVID-19: Watchdog received 280 complaints on nursing homes](#)', *Irish Times*, Monday 8 June 2020.

<sup>26</sup> National Disability Authority, [NDA Advice: Specific Issues for Persons with Disabilities regarding implications of COVID-19, April 2020](#),

<sup>27</sup> National Disability Authority, [NDA Advice: Specific Issues for Persons with Disabilities regarding implications of COVID-19, April 2020](#),

<sup>28</sup> Martin Wall, Jennifer Bray, Simon Carswell, '[No national clinical oversight of care being delivered to those in nursing homes, watchdog to tell TDs](#)', *Irish Times*, 26 May 2020.

<sup>29</sup> Martin Wall, Jennifer Bray, Simon Carswell, '[Department was warned of 200 'high risk' nursing homes](#)', *Irish Times*, 12 May 2020.

<sup>30</sup> Centre for Disability Law and Policy, NUIG, [Letter to the Taoiseach and the Minister for Health](#), 29 April 2020.

<sup>31</sup> Centre for Disability Law and Policy, NUIG, [Letter to the Taoiseach and the Minister for Health](#), 29 April 2020.

care consistent with the highest international human rights standards appears to be urgently necessary.

## Community Settings

### Disruptions to services and supports

28. Many of the issues faced by people in institutional settings also apply to people with disabilities living in the community with the support of family and services such as home help or Personal Assistance. For these people, the risk of contamination, or indeed isolation while continuing to ‘cocoon’ from the virus, is very real. Persons using personal assistance services expressed concern about the lack of central guidance regarding how their services, so essential to their everyday life, was to continue in the case of them or their PA contracting the virus.<sup>32</sup>
29. The Commission is concerned that the primary focus of the response has been on health care settings rather than social care, family care and persons living independently, where disruption to service provision has been challenging.<sup>33</sup> Of further concern is that ‘social care’ was not always prioritised as an ‘essential service’ throughout the full duration of the crisis period. This will have caused significant strain on both people with disabilities and family carers, as for example day supports and respite services became unavailable for the approximately 19,500 people with intellectual disabilities living at home with parents, siblings, relatives or foster parents.<sup>34</sup>
30. The importance of such supports for family care arrangements, and the difficult circumstances of these arrangements generally, is indicated by the level of anticipated need for disability services for people with intellectual disabilities prior to COVID-19.<sup>35</sup> There are particular risks for both people with disabilities and their families in cases where care is provided by older family members, who may themselves have a disability due to age or otherwise. The Commission is aware of concerns regarding inadequate provision of PPE to people with disabilities and their families and carers as well as the additional costs of remaining at home, adding to the cost of disability and placing people at greater risk of poverty.

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<sup>32</sup> 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](#), press release, 25 March 2020.

<sup>33</sup> National Disability Authority, [NDA Advice: Specific Issues for Persons with Disabilities regarding implications of COVID-19, April 2020](#), p.5.

<sup>34</sup> Sarah Hourigan, Sarah Fanagan and Caraíosa Kelly, [HRB Statistics Series 37: Annual Report of the National Intellectual Disability Database Committee 2017 Main Findings](#), p.12.

<sup>35</sup> It is estimated that up to 4,500 new service placements may be required to meet service need. See Sarah Hourigan, Sarah Fanagan and Caraíosa Kelly, [HRB Statistics Series 37: Annual Report of the National Intellectual Disability Database Committee 2017 Main Findings](#), p.16.

## Access to information

31. The initially inadequate provision of accessible public health information for disabled people and the Deaf community, in contravention to the *Irish Sign Language Act 2017*,<sup>36</sup> compounded the risk to persons with disabilities in community settings.<sup>37</sup> The Deaf community expressed serious concern about being unable to adhere to public health advice due to the initial lack of provision of Irish Sign Language in public health advice.<sup>38</sup> The Commission is of the view that active early engagement with disabled people through their representative Disabled Persons Organisations (DPOs),<sup>39</sup> as is required under Article 4(3) UNCRPD,<sup>40</sup> would have helped to identify such issues and alleviate risk. The Commission notes concerns that have been raised about the provision of sustainable core funding to DPOs and disability advocacy organisations.<sup>41</sup>

## Awareness raising

32. Adapting to public health advice can be complicated for some people with disabilities, in part due to inaccessible environments and negative societal attitudes. Some people with Autism report encountering significant problems with measures such as wearing facemasks and queuing outside shops due to restrictions on capacity.<sup>42</sup> Blind and visually impaired people have reported encountering problems with social distancing in public spaces, and subsequent hostility and negative attitudes from non-disabled people towards them.<sup>43</sup> The Commission believes that negative attitudes could have been mitigated against by proactive awareness raising of the situation of persons with disabilities in the context of the public health advice. This could have taken the form of, for example, public health information campaigns outlining

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<sup>36</sup> As set out in the legislation, the *Irish Sign Language Act 2017* is mandated for commencement within three years of its enactment, meaning it is due to be commenced in December 2020 at the very latest.

<sup>37</sup> The Chairpersons of the Irish Deaf Society raised these concerns – see John Cradden, '[Coronavirus highlights the continuing marginalisation of the Deaf community](#)', *Irish Times*, 7 April 2020.

<sup>38</sup> John Cradden, '[Coronavirus highlights the continuing marginalisation of the Deaf community](#)', *Irish Times*, 7 April 2020.

<sup>39</sup> Representative organisations, Disabled Persons Organisations (DPOs) or “organisations of persons with disabilities” are rights-focused organisations that are led, directed and governed by persons with disabilities. A clear majority of their membership are persons with disabilities themselves. The UNCRPD requires that States give particular importance to the views of these such organisation, as distinguished from both “organisations for persons with disabilities”, which provide services for or advocate on behalf of persons with disabilities, and civil society organisations more generally. See Committee on the Rights of Persons with Disabilities (2018) *General Comment No.7 on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention*. CRPD/C/GC/7. Available to download from: <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>.

<sup>40</sup> Article 4(3) UNCRPD states as follows. “In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.”

<sup>41</sup> Recent illustrative cases include the National Platform of Self-Advocates, the Irish Deaf Society, and Inclusion Ireland. See: National Platform of Self-Advocates, '[Closure of the National Platform of Self-Advocates](#)', press statement, 3 December 2019; Irish Deaf Society '[Statement from IDS Board and CEO to update you on our current situation](#)', press statement, 22 February 2019; Inclusion Ireland, '[Inclusion Ireland responds to significant funding cuts to the organisation in 2019](#)' press statement, 10 May 2019.

<sup>42</sup> See As I Am resources for Autistic people: [Letter regarding Face Coverings](#); [Letter for Retailers](#); [Printable letter to explain autism/difficulties with social distancing](#); [Guide for Frontline Staff on treating Autistic People](#).

<sup>43</sup> Aisling Maloney, '[Cohort of cocooners facing additional challenges](#)', RTE, 12 May 2020.

these kinds of issues while also representing people with disabilities as active participants in the collective effort to suppress COVID-19.

33. Having regard to the absence of positive representation and proactive awareness raising measures, the Commission is concerned by the return to prominence of medicalised understandings and perceptions of disability, which have accompanied the discourse around COVID-19 and its framing of disabled people as necessarily 'vulnerable persons' whereas COVID-19 has in fact highlighted 'vulnerable systems' of services and supports.

#### Education and employment

34. Immediate issues related to the disruption of education for pupils with intellectual disabilities and Autism have been documented.<sup>44</sup> Breaks in routine and the lack of interaction with peers is causing children with disabilities to develop mental health issues and regress in terms of behaviour and social skills, leaving parents feeling overwhelmed.<sup>45</sup> The Commission acknowledges efforts being made to establish a Summer Provision education programme for children with disabilities, including the strand to accommodate home-based schooling<sup>46</sup>, but notes concerns regarding poor planning of the scheme and that some children with disabilities will not be provided for.<sup>47</sup> It is important that medically vulnerable children are adequately provided for with home schooling over the summer and beyond as required if they cannot return to school settings while we live with COVID-19 to address their needs and to support families.<sup>48</sup> The delivery of services like occupational therapy, physiotherapy, and speech and language therapy to such children will be crucial to ensuring they do not regress disproportionately to their peers.<sup>49</sup>
35. The Commission recently noted Ireland's stark employment gap between people with and without disabilities prior to the crisis,<sup>50</sup> and expressed its concern that discrimination on the grounds of disability remains persistent, pernicious and prevalent in Ireland's workplaces and recruitment practices.<sup>51</sup> The Commission is concerned there is a real risk that such discrimination may become even more widespread in the coming period of economic turbulence. In combination with rising additional costs of living with a disability due to expenditure on PPE, any such further exclusion from the labour market places persons with

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<sup>44</sup> Inclusion Ireland's survey of 733 parents found there are huge barriers to educating at home for parents, identifying issues of access to educational materials, technology and broadband; inconsistent supports from schools; and an absence of State education support for working parents. See Inclusion Ireland, [The Implications of COVID-19 on the Education of Pupils with Intellectual Disabilities and Autism](#).

<sup>45</sup> Carol Barron, 'How has COVID-19 affected children with special needs?', RTE News, 23 June 2020.

<sup>46</sup> See Department of Education and Skills, [Summer Provision 2020](#).

<sup>47</sup> <sup>47</sup> Concerns has been raised that the scheme 'continues to exclude cohorts of children with disabilities and has been characterised by poor planning'. See [Special Committee on COVID-19 Response, Thursday, 25 June 2020](#), p.39.

<sup>48</sup> Such provision is recommended by the WHO, see WHO, [Disability considerations during the COVID-19 outbreak](#), p.5.

<sup>49</sup> Such provision is recommended by the WHO, see WHO, [Disability considerations during the COVID-19 outbreak](#), p.5.

<sup>50</sup> Recent figures show that Ireland's employment rate of people with disabilities (32.2% in 2017) remains well below the EU average (50.6%). See [Country Report Ireland 2020, Accompanying the document Communication from the Commission to the European Parliament, the European Council, the Council, the European Central Bank and the Eurogroup](#), 26/02/2020, p.38.

<sup>51</sup> IHREC, [Submission to the Department of the Taoiseach on the European Semester 2020 and the National Reform Programme, March 2020](#), p.7.

disabilities at increased risk of poverty and social exclusion.<sup>52</sup> The Commission reiterates its view that integrating reasonable accommodation into routine recruitment, selection and employment processes is essential to addressing the employment gap for people with disabilities.<sup>53</sup>

#### Intersectional disadvantage and discrimination

36. The Commission is concerned that certain people with disabilities are facing intersectional discrimination and disadvantage. Deaf and disabled Travellers will have faced, along with the Traveller community more broadly, particular challenges in terms of limited access to clean water and overcrowding due to poor conditions on sites.<sup>54</sup> Persons with disabilities living in Direct Provision face additional barriers to adherence with public health advice, in terms of meeting social distancing requirements while sharing facilities in centres.
37. Evidence suggests that globally and in Ireland domestic violence has risen since the outbreak of COVID-19.<sup>55</sup> The Commission notes that it will be important to identify the experiences of women and girls with disabilities including concerning the significant increase in rates of domestic violence. While the crisis has impacted mental health widely,<sup>56</sup> disruptions to mental health services and supports have a significant impact on persons with pre-existing mental health issues.<sup>57</sup> People with intellectual disabilities have told of anxiety and difficulties with isolation and breaks in routine.<sup>58</sup> As noted above, parents of children with disabilities have reported children developing mental health issues due to school closures and breaks in routine.

## Building a Disability-Inclusive Recovery

38. The Commission acknowledges that the scale and speed of the onset of the COVID-19 crisis period was very challenging for policy makers and service providers. We would like to take this opportunity to commend the work that was done by frontline health and social care providers, at considerable risk to their own personal health. However, it is essential that the lessons of the initial, acute phase of the COVID-19 crisis be learned quickly. The State had a positive obligation under Article 2 of the European Convention on Human Rights — and, arguably, under Article 40.3.2 of the Constitution — to make effective regulations compelling nursing homes and other care providers (both public and private congregated care settings) to adopt appropriate measures for the protection of their patients' lives.

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<sup>52</sup> See UN, [Policy Brief: A Disability-Inclusive Response to COVID-19](#), May 2020, p.6.

<sup>53</sup> IHREC, [Submission to the Department of the Taoiseach on the European Semester 2020 and the National Reform Programme, March 2020](#), p.7

<sup>54</sup> Pavee Point, [‘Concerns for vulnerable Travellers being taken on board by Government in plan to fight COVID-19’](#), press release, 18 March 2020.

<sup>55</sup> Oireachtas Library & Research Service, [Domestic violence and COVID-19 in Ireland](#).

<sup>56</sup> [COVID-19 Mental Health Survey by Maynooth University and Trinity College finds high rates of anxiety](#), Thursday, April 16, 2020.

<sup>57</sup> UN, [Policy Brief: COVID-19 and the Need for Action on Mental Health](#) 13 May 2020.

<sup>58</sup> Inclusion Ireland, [‘Paul Alford talks about keeping a good routine during COVID-19 lock down’](#); [‘Tomás Murphy talks about COVID-19’](#).

39. Beyond these more immediate concerns, the Commission draws attention to the longer-term lessons to be drawn regarding institutional models of care. Article 19 of the UNCRPD guarantees the right to live independently in the community, including not being obliged to live in a particular living arrangement and the right to in-home, residential and community support services, including personal assistance, necessary to support living in the community.<sup>59</sup> Article 19 requires States to phase out institutional care and to divert funds to developing community-based alternatives.<sup>60</sup>
40. The HSE's *Time to Move on from Congregated Settings - A Strategy for Community Inclusion* document, published in 2011, endorsed this very course of action when recommending that all congregated settings for people with disabilities be closed by 2018,<sup>61</sup> but this has not happened.<sup>62</sup> Of the 9,064 registered residential places at the end of 2019, 2,914 of these were located in congregated settings, with 2,368 registered places in campus-based settings and 546 registered places in large standalone residential houses.<sup>63</sup> Although the policy undoubtedly requires much greater urgency behind its implementation, it may be the case that the basic framework for change is already in place, and that a revised Strategy for Community Inclusion could form the basis of a new model of community-based social care, assistance and support in light of the challenges posed by COVID-19 in congregated care settings.
41. HIQA has noted that legislative reform of the current regulatory framework could enable innovation and flexibility in the delivery of community-based services while also upholding standards in such services.<sup>64</sup> The Commission is of the view that the application of such innovative thinking and an appropriate degree of urgency could accelerate the deinstitutionalisation process and help to bring Ireland into compliance with its international human rights obligations.
42. The history of how people with disabilities have been treated in this country is one that chronicles abuse, neglect, stigma, and inequality. In recent times, positive gains have been made to move away from this past, culminating in Ireland's ratification of the UN Convention on the Rights of Persons with Disabilities in 2018. We have made progress in the move from an old charitable, medical model of support for people with disabilities, towards a more holistic rights-based perspective, supporting people to live inclusive, independent lives. We risk losing much of this progress if we fail to address the human rights and discrimination risks outline above, to build a transition out of COVID-19 that is fully inclusive of people with disabilities. Positive measures must be taken across a range of areas to ensure that all groups of people with disabilities transition out of the emergency phase on an equal basis with each other and the rest of the population. The alternative risks a permanent erosion of the human

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<sup>59</sup> Article 19 UNCRPD.

<sup>60</sup> Committee on the Rights of Persons with Disabilities, *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5. Available to download from: <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>.

<sup>61</sup> HSE, *Time to Move on from Congregated Settings A Strategy for Community Inclusion*, June 2011.

<sup>62</sup> HSE, *Time to Move on from Congregated Settings: A Strategy for Community Inclusion: Annual Progress Report 2018*. HSE, *Review of Policy Implementation 2012-2017: Time to Move On From Congregated Settings: A Strategy for Community Inclusion*.

<sup>63</sup> HIQA, *Annual Report 2019*, p.32.

<sup>64</sup> HIQA, *Executive summary: Exploring the regulation of health and social care services. Disability and older people's services*, March 2017

rights and equality of people with disabilities.<sup>65</sup> Non-retrogression of rights is a core human rights principle and obligation of the State.

43. The Commission recommends that an explicit human rights and equality-based approach be taken to the transition from COVID-19. According to the UN, the key principles to inform such an approach from a disability rights perspective include non-discrimination, intersectionality, participation, accessibility, accountability, and data disaggregation.<sup>66</sup> Acting on these principles, the recovery programme should underpin the rights of people with disabilities, guarantee disabled people's right to live independently in the community and mitigate the risk of human rights abuses and discrimination.
44. Reasonable accommodation measures in education, employment, health care and beyond will be fundamental to enabling people with disabilities to participate in society as we live with and seek to recover from COVID-19. Reasonable accommodation measures can facilitate people with disabilities to continue their education, remain in employment, access services, and participate in society. Applied more broadly, simple solutions such as dedicated shopping hours in supermarkets can serve as an example of how to keep public services accessible to all.<sup>67</sup>
45. Further, the Commission recommends the full establishment and resourcing of the Decision Support Service be expedited as a matter of priority. The Commission has previously expressed its concerns about the slow progress being made in this regard.<sup>68</sup> The Decision Support Service will oversee the roll out of new supported decision-making structures that will facilitate people who have difficulties making decisions, including persons who are currently Wards of Court,<sup>69</sup> to exercise their legal capacity and make decisions about their lives. This will enable people with disabilities to make legally binding decisions, including for example in the area of Advance Healthcare Directives establishing their will and preferences where needed.
46. The Public Sector Equality and Human Rights Duty offers a pathway to this more social model of inclusion and care. The Duty places a legal obligation on all public bodies to promote equality, prevent discrimination and protect the human rights of employees and persons to whom they provide services. The law requires public bodies to undertake an assessment of the equality and human rights issues relevant to their function and purpose; take actions to address these issues; and report on progress made. This provides an important framework to systematically consider and reflect the particular needs of staff and service users at risk of inequality, discrimination or disproportionate impact, and helps to mitigate and avoid unintended consequences.
47. The Commission has repeatedly expressed its concern that accountability mechanisms can be weakened where the State delivers its functions through private, non-State actors, such as in

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<sup>65</sup> See UN, [Policy Brief: A Disability-Inclusive Response to COVID-19](#), May 2020

<sup>66</sup> UN, [Policy Brief: A Disability-Inclusive Response to COVID-19](#), May 2020.

<sup>67</sup> Section 4 of the *Equal Status Acts* sets out the obligations on services providers in the provision of reasonable accommodation.

<sup>68</sup> IHREC, [Submission to the UN Committee against Torture on the List of Issues for the Third Examination of Ireland](#), January 2020.

<sup>69</sup> Not all Wards of Court are residing in institutional settings.

the area of health and social care.<sup>70</sup> The State must put in place robust independent inspection mechanisms that are human-rights based and that incorporate all public, voluntary and private health and social care providers.

48. The Commission is also of the view that public funders should ensure that the Public Sector Equality and Human Rights Duty should be met where publicly funded services are provided through non-State actors.<sup>71</sup> There also exists an opportunity adopt a more holistic, rights-based approach to standard-setting in State procurement of services, as public procurement regulations now make compliance with certain international social conventions a permissible selection criterion.<sup>72</sup> Comprehensive engagement with these kinds of mechanisms could play a significant role in ensuring the State meets its obligations to uphold the rights of with disabilities.
49. More work needs to be done, both administratively and legislatively, to give the UNCRPD legal effect and practical meaning in the lives of disabled people. This means accelerating legislative reform and policy implementation processes, such as commencement of the *Assisted Decision Making (Capacity) Act 2015*,<sup>73</sup> and implementation of the *Time to Move on from Congregated Settings – A Strategy for Community Inclusion* policy.<sup>74</sup> Supports that enable people with disabilities to live independently and participate in the community in fulfilment of CRPD Article 19 rights, such as home help and Personal Assistance Services, must be better resourced and more effectively administered.
50. Data collection systems must be strengthened to collect data disaggregated by impairment type (including mental health), as well as age,<sup>75</sup> gender,<sup>76</sup> and socio-economic status. The care provided by family members and friends to people with disabilities must be better recognised, resourced and supported.<sup>77</sup> Proactive measures must be undertaken to ensure continued participation in education and employment. The immediate recovery from the COVID-19 emergency period will have to protect persons with disabilities the right to health, but it will also have to account for a range of other rights and ensure their participation in planning and oversight. Addressing the vulnerability of our systems and disability support services will be essential in this regard.

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<sup>70</sup> IHREC (2019) [Ireland and the Convention on the Elimination of Racial Discrimination. Submission to the United Nations Committee on the Elimination of Racial Discrimination on Ireland's Combined 5th to 9th Report](#), at p. 119

<sup>71</sup> IHREC (2020), [Submission to the UN Committee against Torture on the List of Issues for the Third Examination of Ireland January 2020](#), p.8.

<sup>72</sup> Regulation 18(4)(a) provides: 'In the performance of a public contract, an economic operator shall comply with applicable obligations in the fields of environmental, social and labour law... established by European Union law, national law, collective agreements or by international, environmental, social and labour law'. These regulations have been in force since 18 April 2016.

<sup>73</sup> The *Assisted Decision Making Capacity Act 2015* will reform Ireland's capacity laws by providing legally recognized decision-making support structures. It establishes the Decision Support Service to oversee the operation of the new structures. It also provides for the making of Advance Healthcare Directives.

<sup>74</sup> The Commission has previously expressed its concern about the slow progress on both of these matters. On the *Assisted Decision Making (Capacity) Act 2015*, see IHREC, [Submission to the UN Committee against Torture on the List of Issues for the Third Examination of Ireland](#), January 2020. On the slow progress of the deinstitutionalisation programme, see IHREC, [Comments on Ireland's 14<sup>th</sup> National Report on the Implementation of the European Social Charter](#), April 2017.

<sup>75</sup> Article 7 UNCRPD specifically recognises the rights of children with disabilities.

<sup>76</sup> Article 6 UNCRPD specifically recognises the rights of women with disabilities.

<sup>77</sup> See IHREC, [Submission to the Citizens' Assembly on Gender Equality](#), March 2020.

51. In the immediate term, it is essential that the practical measures required to give effect to the rights of people with disabilities and to guard against discrimination, indirect or otherwise, are factored into service planning and contingency planning for life with COVID-19.
52. In the medium to longer term, the policy measures which can mitigate the kind of disproportionate impact of an event like the COVID-19 pandemic on people with disabilities include those which have already been identified to bring Ireland into compliance with the UNCRPD. Therefore, what is needed is not a new departure, but rather a real commitment to expedite the journey to a destination that has already been agreed.



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