

## Sumission to the Independent Commission on UK Public Health Powers

## **Call for Evidence- February 2023**

Disability Action is the largest pan-disability organisation and charity in the UK and Ireland. We are a Disabled person's led organisation (DPO) advocating for the rights of d/Deaf and Disabled people. We provide services which are developed for and by d/Deaf and Disabled people. These services include: employment support services, human rights and independent advocacy, campaigns, community integration and digital connectivity, transport, information and advice, mental health and wellbeing and disability specialist support.

Disability Action operates within the region of Northern Ireland but engages with Westminster and the UK Government on matters of relevance. Disability Action represents deaf people, Disabled people and organisations which extend across all disabilities.

Disability Action Northern Ireland delivers services developed for and by d/Deaf and Disabled people. Our abovementioned services are designed by Disabled people for Disabled people to enhance their wellbeing. The Disabled people that we support includes those in domestic settings, supported accommodation, care homes, and detained under the Mental Health Act. Disability Action has also supported the bereaved families of Disabled people who have died during the pandemic and Disabled people who have been subject to unjust 'Do Not Attempt Resuscitate' ('DNAR') orders.

Disability Action Northern Ireland has taken the following steps to support its members in relation to the pandemic. We have delivered these services to thousands of Disabled people in Northern Ireland:

- (a) Provided information, support, and advocacy, including intensive casework on access to healthcare and services to d/Deaf and Disabled people by phone, email, and via socially distanced appointments.
- (b) Held frequent regular group meetings on Zoom since March 2020.
- (c) Supported Deaf and Disabled people facing challenges in accessing food and services.
- (d) Campaigned for the rights of Disabled people to be protected throughout the pandemic.
- (e) Provided digital programmes to address social isolation and exclusion.
- (f) Provided opportunities for Disabled people from various backgrounds and diverse situations to contribute their experiences to the Ad Hoc Review of the impact of Covid-19 on Deaf and Disabled people.
- (g) Provided transport for Disabled people to healthcare and vaccine appointments.
- (h) Supported Disabled people facing DNAR notices.
- (i) Hosted political engagement sessions in which Deaf and Disabled People could engage directly with political parties.
- (j) Established a mental health and wellbeing service that provides bespoke counselling to Deaf and Disabled people, their families, and carers.
- (k) Engaged with the Northern Ireland Executive and Assembly in respect to the impact of Covid-19 on deaf and Disabled people from the onset of the pandemic.
- (I) Provided advocacy for Disabled people and people with learning disabilities throughout the pandemic including those in supported living, care homes and residential homes.
- (m) Provided information and advice to deaf and Disabled people throughout the pandemic including welfare benefits advice.
- (n) Provided advocacy and support to Disabled workers throughout the pandemic.

Disability Action has published several reports on the impact of the pandemic on Disabled people in Northern Ireland, including:

(a) 'The Impact of Covid-19 on Disabled People in Northern Ireland', published in September 2020.1

 $<sup>^{1} \</sup> Available \ at: \ \underline{https://www.disabilityaction.org/Handlers/Download.ashx?IDMF=fdb4ec49-e3b3-472c-b31a-57d87523b71a}$ 

- (b) 'Progress Towards the Implementation of the UNCRPD', published in February 2022.<sup>2</sup>
- (c) 'Alternative Report on the Implementation of the UNCRPD', published in February 2022.<sup>3</sup>

These reports document that Disabled people were disproportionately affected by Covid-19, accounted for the majority of deaths due to Covid-19, struggled to access food and medicines, were socially isolated, experienced a collapse in service provision, and experienced declining physical and mental health. Disability Action also produced a number of articles during the pandemic, including:

- (a) Regular updates relating to the Covid-19 pandemic.<sup>4</sup>
- (b) 'Reflection: One year on since the first COVID-19 lockdown', published on 25 March 2021.<sup>5</sup>
- (c) 'Where is the Outcry About the Impact of Covid-19 on d/Deaf and Disabled People?', published on 15 March 2022.<sup>6</sup>
- (d) 'Light Up Purple or Wear Purple to mark International Day of Disabled People 2021', published on 18 November 2021.<sup>7</sup>

Disability Action question the degree to which the NI Executive and the Westminster Government adequately considered Disabled people in their decision making. Disability Action are particularly concerned about the impact of Northern Ireland's position in early 2020 (in that there was no functioning Executive for three years up until 9 January 2020) on the response to the pandemic. This meant that as the new Executive was forming, it was being required to respond to an unprecedented pandemic. Consequently, we are concerned that the newly formed Executive was not adequately equipped to give appropriate consideration to vulnerable groups including Disabled People.

https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/UNCRPD%20investigations/UNCRPD-Implementation-NI.pdf

<sup>&</sup>lt;sup>2</sup> Available at:

<sup>&</sup>lt;sup>3</sup> Available at: <a href="https://www.disabilityaction.org/Handlers/Download.ashx?IDMF=20d76cea-27aa-480f-8180-fce8ee51d004">https://www.disabilityaction.org/Handlers/Download.ashx?IDMF=20d76cea-27aa-480f-8180-fce8ee51d004</a>

<sup>&</sup>lt;sup>4</sup> Available at: https://www.disabilityacRetion.org/covid-19-coronavirus

<sup>&</sup>lt;sup>5</sup> Available at: <a href="https://www.disabilityaction.org/news/reflection-a-year-on-since-the-first-covid-19-lockdown">https://www.disabilityaction.org/news/reflection-a-year-on-since-the-first-covid-19-lockdown</a>

<sup>&</sup>lt;sup>6</sup> Available at: <a href="https://viewdigital.org/where-is-the-outcry-about-the-impact-of-covid-19-on-d-deaf-and-disabled-people/">https://viewdigital.org/where-is-the-outcry-about-the-impact-of-covid-19-on-d-deaf-and-disabled-people/</a>

<sup>&</sup>lt;sup>7</sup> Available at: <a href="https://www.disabilityaction.org/news/light-up-purple-or-wear-purple-mark-iddp21#:~:text=On%20Friday%203rd%20December%202021,the%20rights%20of%20disabled%20people">https://www.disabilityaction.org/news/light-up-purple-or-wear-purple-mark-iddp21#:~:text=On%20Friday%203rd%20December%202021,the%20rights%20of%20disabled%20people</a>

Many of the areas of concern regarding the impact of Covid-19 on deaf and Disabled people in Northern Ireland are devolved matters, particularly health, transport, education, communities, and employment. There are particular questions as to whether the absence of an island-wide approach and coherence between the Executive and Assembly and the Irish Government generated particular challenges for Disabled people resulting in impacts which may have been avoidable. There does not appear to have been co-ordinated response between UK and ROI in the period preceding the reformation of the Executive in January 2020.

The collapse of the institutions in January 2017 led to a legislative hiatus which further complicated the challenges within the region associated with the legacy of the recent conflict. The institutions became operational again in early 2020 but have faced ongoing challenges in the context of the ongoing Covid-19 crisis and the implications of Brexit. Decision making structures within the Executive and Assembly recommenced on 11 January 2020. Therefore, there were no functional decision-making mechanisms at the early stage of the Covid-19 pandemic.

There does not appear to have been engagement between the NIO and Executive Departments in the period preceding the re-establishment of the Executive. The time period taken to close schools is core to identifying whether the right decisions were taken at the right time. The decision was taken only after significant pressure was placed on the NI Executive<sup>8</sup>. Therefore, there was a delay in closing schools and commencing lockdowns<sup>9</sup>. Schools did not formally close until 18<sup>th.</sup> There was a failure to pause flights entering the region<sup>10</sup>.

A disproportionate number of d/Deaf and Disabled people have died due to Covid-19. The Northern Ireland Statistics and Research Agency (NISRA) published an equality group analysis of wave one deaths due to Covid-19 which showed that Disabled people were 40% more likely to die of Covid-19.<sup>11</sup> People with learning disability have experienced greater excess deaths from Covid-19 as well as being disproportionately affected

<sup>&</sup>lt;sup>8</sup> https://www.theguardian.com/world/2020/mar/14/coronavirus-northern-ireland-schools-will-close-for-at-least-16-weeks

<sup>&</sup>lt;sup>9</sup> https://www.belfastlive.co.uk/news/belfast-news/coronavirus-northern-ireland-school-takes-17925485

<sup>&</sup>lt;sup>10</sup> https://www.belfasttelegraph.co.uk/business/northern-ireland/belfast-international-airport-open-for-passengers-but-monitoring-unprecedented-health-crisis-39056408.html

<sup>11</sup> Available at: https://www.nisra.gov.uk/publications/covid-19-deaths-and-equality-wave-one

by the lock-down procedures implemented by the UK Government and the devolved administration.<sup>12</sup>

The degree to which the emergency response of the Executive to the Covid-19 crisis included people with disabilities and addressed their needs has been called into question<sup>13</sup>. Initial guidance from government agencies was not attuned to the needs of persons with learning disabilities and their living situations; particularly for those in supported living arrangements rather than residential homes. The guidance from different agencies was contradictory and had not been developed through consultation with organisations and personnel with the necessary expertise.<sup>14</sup>.

The Coronavirus Act raises many concerns in regard to the rights of disabled people as a whole, and this includes disabled women. At least 10 disabled MPs and peers have signed a letter calling on the prime minister to ensure that the government improves its support for disabled people in its response to the coronavirus pandemic, saying that disabled people's rights are at risk, including the right to healthcare, the right to social care and support, and the right to information<sup>15</sup>

The Executive published a Covid recovery plan in August 2021<sup>16</sup> following a limited 1-week consultation with only a small number of disability and other organisations including the Equality Commission for Northern Ireland and one DPO. It is our understanding that comments to the draft Covid Recovery Plan were not reflected in the final publication. One of the significant failings of the plan is that it focuses mainly on aspirational statements intended to describe the general intention and direction of travel to achieve economic, health and societal recovery. The Plan contains no detailed consideration of equality issues

ARC (NI), 'A review of the impact of COVID-19 on learning disability services provided mainly by the voluntary sector in Northern Ireland', November 2020 p16, available at: <a href="https://arcuk.org.uk/northernireland/files/2021/02/Final-report-ARC-Review-17th-November-2020.pdf">https://arcuk.org.uk/northernireland/files/2021/02/Final-report-ARC-Review-17th-November-2020.pdf</a>
 ECNI (2020) People with disabilities must not be left behind by response to COVID-19 (accessed 5 November 2021).

<sup>&</sup>lt;sup>14</sup> ARC (NI) (2020) <u>A review of the impact of COVID-19 on learning disability</u> <u>services provided mainly by the voluntary sector in Northern Ireland</u> p.8 (accessed 5 November 2021)

<sup>15</sup> https://www.disabilitynewsservice.com/coronavirus-mps-and-peers-ask-pm-for-a-disability-inclusive-response-to-pandemic/?fbclid=lwAR3xMcwQblf3xloqdUuush2U0mLm64S14-RuWK1MN3LnAHvtglhufTbU0ek

<sup>&</sup>lt;sup>16</sup> TEO (2021) <u>Building Forward: Consolidated Covid-19 Recovery Plan</u>. (accessed 5 Nov 2021)

or human rights perspectives and the issue of disability<sup>17</sup> is only referenced once in the Plan in relation to a focus on needs-based skills enhancement and transformation of the 14–19-year-olds training and information landscape. The Plan lacks actions or quantifiable outcomes to address issues faced by disabled people as a result of the pandemic. The Plan contains equally aspirational measures and talks about addressing vulnerability and does not adopt a human rights-based model approach. The Plan draws attention to a wide range of existing strategies, policies and programmes published prior to Covid-19 pandemic.

The differential treatment of Disabled people in respect of healthcare in response to Covid-19 including disruption in accessing medicine meant that their interests had not been adequately considered when responding to the pandemic.<sup>18</sup> For example, NICE Guidelines for critical care published on 21 March 2020 failed to take into account the impact of disabilities on the score range and needed to be revised on 25 March 2020 following active representations on behalf of Disabled people. The Women and Equalities Committee Inquiry into the unequal impact of coronavirus on disability and access to services found that it was potentially discriminatory. 19 The inappropriate use of DNAR notices for Disabled people, particularly the elderly and people with learning disabilities, resulted in the potential waiving of life-saving treatment for Covid-19.20 The delay in recognising and responding to barriers to effective communication for Disabled people. For example, the widespread use of facemasks resulted in barriers to effective communication for people with hearing loss when communicating with healthcare professionals (and others).<sup>21</sup> It was recognised that there was a need for transparent facemasks to be approved for use and distributed to NHS trusts.

Research conducted by Disability Action demonstrates that 8 out of 10 Disabled people did not feel that they had the opportunity to be involved

<sup>21</sup> Ibid p22

<sup>&</sup>lt;sup>17</sup> Ibid, p.10

<sup>&</sup>lt;sup>18</sup> DANI, The Impact of Covid-19 on Disabled people in Northern Ireland (n1) p27; The Health foundation, "The forgotten crisis: exploring the disproportionate impact of the pandemic on Disabled people, 21 February 2021, available at: <a href="https://www.health.org.uk/news-and-comment/blogs/the-forgotten-crisis-exploring-the-disproportionate-impact-of-the-pandemic">https://www.health.org.uk/news-and-comment/blogs/the-forgotten-crisis-exploring-the-disproportionate-impact-of-the-pandemic</a>

<sup>&</sup>lt;sup>19</sup> House of Commons, Women and Equalities Committee, "Unequal impact? Coronavirus, disability and access to services: Full Report, Fourth Report of Session 2019 – 21 p42 available at: <a href="https://committees.parliament.uk/publications/4068/documents/40461/default/">https://committees.parliament.uk/publications/4068/documents/40461/default/</a>

<sup>&</sup>lt;sup>20</sup> House of Commons, Women and Equalities Committee, "Unequal impact? Coronavirus, disability and access to services: Full Report, Fourth Report of Session 2019 – 21, p18 available at: https://committees.parliament.uk/publications/4068/documents/40461/default/

in the planning response to Covid-19, and that 8 out of 10 Disabled people felt that planning did not effectively protect Disabled people. Qualitative data collected within research conducted by Disability Action demonstrates the negative impact of the restrictions on health and social care services on Disabled people. This data also shows that there was an increased reliance on food banks, increased isolation, and continuing difficulties in accessing medicine and healthcare. Barriers in access to health and social care (HSC) as a result of Covid-19 have contributed to the institutionalisation of Disabled people. Work to complete the resettlement of the patients remaining in Muckamore Abbey Hospital is ongoing, although in common with other health and social care activity, the pace of the resettlement programme has been impacted by the Covid-19 pandemic.

Through the advocacy and information work of Disability Action and our research we have significant concerns regarding the use of DNAR orders. Disabled people and their families, including parents of autistic children and carers of people with learning disabilities are reporting that they have been asked to complete DNAR orders, in case they become critically ill, with no consultation.<sup>22</sup> There have been instances in which medical treatment has been withheld or withdrawn from d/Deaf and Disabled people with devastating impacts.<sup>23</sup>

Through our information and advocacy work we are concerned about the increased risk of domestic violence and abuse of deaf and Disabled people. Lockdown measures, collapse of health and social care, and social distancing increased the dependency of deaf and disabled people on others and restricted people within their own homes and residential settings. Deaf and disabled people had reduced access to advocacy and advice. Calls to domestic abuse services escalated. Isolation created an environment for abuse to occur. It also means that many will find it much harder to flee dangerous situations, or to find the refuges and services they need to make that decision. This will affect most those who have already struggled to access support and justice, including disabled women. Women with learning difficulties did not have in person one to

<sup>&</sup>lt;sup>22</sup> Byrne, B (ND), 'How the pandemic is further alienating the Disabled community' available at: <a href="https://www.qub.ac.uk/coronavirus/analysis-commentary/pandemic-alienating-the-disabled/">https://www.qub.ac.uk/coronavirus/analysis-commentary/pandemic-alienating-the-disabled/</a>

<sup>&</sup>lt;sup>23</sup> Ruck Keene, A.C.E and Lee, A., 'Withdrawing life-sustaining treatment: a stock-take of the legal and ethical position. J Med Ethics. 2019 Dec;45(12):794-799, 2019, available at,: <a href="https://pubmed.ncbi.nlm.nih.gov/31488520/">https://pubmed.ncbi.nlm.nih.gov/31488520/</a>

<sup>&</sup>lt;sup>24</sup>Hughes, K. et al (2012): Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies. Hughes, K. et al. The Lancet, 2012, Vol. 379. 30; Trevillion, K. et al. (2012): Experiences of domestic violence and mental disorders: a systematic review and meta-analysis.

one access to their advocates as before, deaf women are having communication issues, not just because of BSL access but also because of the social distancing and communication to be handled by phone.

The degree to which the emergency response of the Executive to the Covid-19 crisis included people with disabilities and addressed their needs has been called into question by d/Deaf and Disabled people and by the Equality Commission for Northern Ireland.<sup>25</sup> Initial guidance from government agencies was not attuned to the needs of persons with learning disabilities and their living situations; particularly for those in supported living arrangements rather than residential homes. The guidance from different agencies was contradictory and had not been developed through consultation with organisations and personnel with the necessary expertise. Revised guidance has been made available, but a lack of consultation remains an issue beyond the Covid-19 pandemic.<sup>26</sup>

Concerns have been raised regarding the roll-out of the vaccine programme and whether the programme has been inclusive to d/Deaf and Disabled people.<sup>27</sup> Vaccine information materials were developed in accessible formats to people, but the vaccine letters were sent out to people in inaccessible formats.<sup>28</sup> There was little consultation with d/Deaf and Disabled people regarding the vaccine rollout strategy.<sup>29</sup>

The 2020 report, 'An Affront to Dignity, Inclusion and Equality'<sup>30</sup> argues that there has been a failure to provide reasonable adjustments to people with disabilities during the ongoing Covid-19 crisis leading to widening inequality. The report concluded that the Government failed to take

<sup>29</sup> Leonard Cheshire (ND), 'Delivering a disability-inclusive COVID-19 vaccine programme: Guidance note', Section 1, p.2, available at: <a href="https://www.leonardcheshire.org/sites/default/files/2021-04/COVID-19-vaccine-programme.pdf">https://www.leonardcheshire.org/sites/default/files/2021-04/COVID-19-vaccine-programme.pdf</a>

<sup>&</sup>lt;sup>25</sup> ECNI, 'People with disabilities must not be left behind by response to COVID-19', available at: <a href="https://www.equalityni.org/Blog/Articles/April-2020/People-with-disabilities-must-not-be-left-behind-b">https://www.equalityni.org/Blog/Articles/April-2020/People-with-disabilities-must-not-be-left-behind-b</a>

<sup>&</sup>lt;sup>26</sup> ARC (NI), 'A review of the impact of COVID-19 on learning disability services provided mainly by the voluntary sector in Northern Ireland', November 2020, p8, available at:

https://arcuk.org.uk/northernireland/files/2021/02/Final-report-ARC-Review-17th-November-2020.pdf voluntary Organisations Disabilities Group (ND), 'VODG calls on government to ensure Disabled

people are not left behind in rollout of COVID-19 vaccine', available at: <a href="https://www.vodg.org.uk/news/vodg-calls-on-government-to-ensure-disabled-people-are-not-left-behind-in-rollout-of-covid-19-vaccine/">https://www.vodg.org.uk/news/vodg-calls-on-government-to-ensure-disabled-people-are-not-left-behind-in-rollout-of-covid-19-vaccine/</a>

<sup>&</sup>lt;sup>28</sup> Ibid p7

<sup>&</sup>lt;sup>30</sup> Tidball, M., Lawson A., Herring J., Sloan, B., Holloway, D. and Ryan, S, 'An Affront to Dignity, Inclusion and Equality: Coronavirus and the Impact of Law, Policy, Practice and Access to Services on People with Disabilities in the United Kingdom' (Oxford University Disability Law & Policy Project and the Bonavero Institute of Human Rights), 2020, available at: <a href="https://www.law.ox.ac.uk/news/2020-07-02-affront-dignity-inclusion-and-equality-coronavirus-and-impact-law-policy-practice">https://www.law.ox.ac.uk/news/2020-07-02-affront-dignity-inclusion-and-equality-coronavirus-and-impact-law-policy-practice</a>

appropriate steps to include d/Deaf and Disabled people in planning across all policy areas in response to the Covid-19 crisis.<sup>31</sup>

The Executive published a Covid-19 recovery plan in August 2021,32 following a limited 1-week consultation with only a small number of disability and other organisations including the Equality Commission for Northern Ireland and one DPO.<sup>33</sup> Disability Action consider that one of the significant failings of the plan is that it focuses mainly on aspirational statements intended to describe the general direction of travel to achieve economic, health and societal recovery. The Plan contains no detailed consideration of equality issues or human rights perspectives. The Plan draws attention to a wide range of existing strategies, policies and programmes published prior to the Covid-19 pandemic and takes a medical model approach (addressing vulnerability) rather than a human rights-based approach. Disability<sup>34</sup> is only referenced once<sup>35</sup> whilst the Plan lacks actions or quantifiable outcomes to address issues faced by d/Deaf and Disabled people because of the pandemic. The associated Action Plan contains no actions or quantifiable outcomes to address issues faced by Disabled people because of the pandemic. The Action Plan contains equally aspirational measures and talks about addressing vulnerability and does not adopt a human rights-based model approach. The Plan draws attention to a wide range of existing strategies, policies and programmes published prior to Covid-19 pandemic.

In 2020, the Minister for Communities committed to extending the mitigations beyond the March 2020 'Cliff Edge'.<sup>36</sup> While the necessary legislation was not passed in time due to the Covid-19 crisis, the Department for Communities confirmed that payments would continue to be made for all the existing mitigations schemes via contingency

<sup>&</sup>lt;sup>31</sup> Tidball, M., Lawson A., Herring J., Sloan, B., Holloway, D. and Ryan, S. (2020): 'An Affront to Dignity, Inclusion and Equality: Coronavirus and the impact of law, policy and practice on people with disabilities in the United Kingdom, Executive Summary', p.3, available at:

https://www.law.ox.ac.uk/sites/files/oxlaw/executive\_summary\_0.pdf

<sup>&</sup>lt;sup>32</sup> TEO, 'Building Forward: Consolidated Covid-19 Recovery Plan', 2021, available at: <a href="https://www.executiveoffice-ni.gov.uk/topics/making-government-work/building-forward-consolidated-covid-19-recovery-plan">https://www.executiveoffice-ni.gov.uk/topics/making-government-work/building-forward-consolidated-covid-19-recovery-plan</a>

<sup>&</sup>lt;sup>33</sup> The research team preparing this report engaged with a number of DPOs and Northern Irelandwide disability organisations and found that only 1 DPO had been consulted and that their views on the Covid Recovery Plan were not reflected in the final publication of The Executive Office (2021), available at: <a href="Covid Recovery Plan">Covid Recovery Plan</a>

<sup>34</sup> Ibid p10

<sup>&</sup>lt;sup>35</sup> In relation to a focus on needs-based skills enhancement of 14–19-year-olds.

<sup>&</sup>lt;sup>36</sup> Law Centre NI, 'Cliff Edge Welcomes Minister's Commitment to Extend Welfare Mitigations But Concerns Remain Over Families Hit by Bedroom Tax and Benefit Cap', 2020, available at: <a href="https://www.lawcentreni.org/news/cliff-edge-welcomes-ministers-commitment-to-extend-welfare-mitigations-but-concerns-remain-over-families-hit-by-bedroom-tax-and-benefit-cap">https://www.lawcentreni.org/news/cliff-edge-welcomes-ministers-commitment-to-extend-welfare-mitigations-but-concerns-remain-over-families-hit-by-bedroom-tax-and-benefit-cap</a>

arrangements.<sup>37</sup> A draft Bill to provide for mitigation payments for people affected by the Social Sector Size Criteria policy has been shared with the Executive. <sup>38</sup>

The Department for Communities established an Emergencies Leadership group. While this was welcome and DfC provided funding for food and support, there was no engagement with Disabled People's Organisations, meaning that Disabled people were not specifically targeted within the measures with significant risk<sup>39</sup>. Please note The Now Group is a social enterprise supporting learning Disabled people into employment. It is not a Disabled person led organisation and while their involvement is welcome, the NOW Group cannot provide a clear pathway directly to Disabled people or organisations.

Between February and July 2020, over one third of nursing and residential care homes (36%) in Northern Ireland experienced an outbreak of either Covid-19 or a flu like illness (FLI). The peak of the pandemic in care homes occurred between late March and early May 2020, with the largest number of both outbreaks and deaths reported during April 2020. The majority of deaths within Care Homes were Disabled people. Between March and July 2020, 429 death certificates issued in respect of care home residents referenced Covid-19. Between March and June 2020 there were 336 excess deaths in care homes.<sup>40</sup>

Disability Action is concerned that particular decisions were made in the absence of consideration of the impact on deaf and Disabled people. This includes decisions related to or affecting:

- (a) Lockdown measures which had a disproportionate impact on Disabled people particularly people with learning disabilities. This includes the disproportionate impact of Covid-19 on deaf and Disabled people in terms of morbidity and mortality.
- (b) The cessation of respite and day care services. The cessation of services, particularly those which were provided to people with intellectual or psychosocial disabilities was particularly

NICVA, 'Emergencies Leadership Group meets again to drive progress', 3 April 2020, available at <a href="https://www.nicva.org/article/emergencies-leadership-group-meets-again-to-drive-progress">https://www.nicva.org/article/emergencies-leadership-group-meets-again-to-drive-progress</a>
 The Regulation and Quality Improvement Authority, 'The Impact of COVID-19 on Care Homes in

<sup>&</sup>lt;sup>37</sup> Housing Rights, 'Welfare Mitigation Payment Update', 2020, available at: <a href="https://www.housingrights.org.uk/news/welfare-mitigation-update">https://www.housingrights.org.uk/news/welfare-mitigation-update</a>
<sup>38</sup> Ibid

Northern Ireland: February 2020 to July 2020', p4, available at: <a href="https://www.rqia.org.uk/RQIA/media/RQIA/The-Impact-of-Covid-19-on-Care-Homes-in-NI,-Feb-Jul-2020.pdf">https://www.rqia.org.uk/RQIA/media/RQIA/The-Impact-of-Covid-19-on-Care-Homes-in-NI,-Feb-Jul-2020.pdf</a>

problematic with parents, carers and service users left in anxious and unstable situations which caused significant disruption<sup>41</sup>. The cessation of services also placed significant pressure on the voluntary sector to intervene<sup>42</sup>. The report recognised that it is essential that contingency plans are in place for further Covid-19 surges or similar emergencies. The safety of disabled persons should be at the core and their emotional and social well-being prioritised.

- (c) Access to food and medicine.
- (d) The lack of provision of social care leading to deaf and Disabled people facing institutionalisation during the pandemic.
- (e) Lack of clarity on mask wearing in the initial stages
- (f) Lack of access to PPE
- (g) Inconsistency in provision across the health trusts
- (h) It is unclear what Trust-provided respite care facilities are still operational, and what if any additional services are being provided in each area.
- (a) Inaccessibility of public messaging with respect to Covid-19. Early press briefings did not include sign language interpretation. There was an absence of accessible information for visually impaired people.
- (b) Inaccessibility of vaccine programmes and the reduction in access to vaccines by carers.
- (c) Access to support for the increased number of Disabled people experiencing domestic violence and abuse.
- (d) Cessation of education provision for Disabled children. Closure of special schools with limited support for digital learning
- (e)Restrictions on accompanying people in hospital meant that disabled people did not have access to essential advocacy regarding provision of treatment
- (f) Barriers in accessing healthcare.
- (g) Ensuring effective prevention measures were in place when social care services resumed to protect against transmission.
- (h) Resuscitation guidelines which prioritised neurotypical patients<sup>43</sup>
- (i) Lack of provision of clear face masks
- (j) There are concerns regarding the withholding and withdrawing of medical treatment of d/Deaf and disabled people. Attitudes and

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<sup>&</sup>lt;sup>41</sup> Ibid, p.8

<sup>&</sup>lt;sup>42</sup> Ibid, p.7

<sup>43</sup> https://www.qub.ac.uk/research-centres/DisabilityResearchNetwork/News/COVID-19.html

- stereotypes of d/Deaf and disabled people have been linked to carelessness, neglect, disregard, and ignorance all of which has been linked with violations of the right to life.
- (k) There is deep concern that the lives of d/Deaf and disabled people were accorded less weight than non-disabled people; seemingly dispensable when decisions need to be made about critical care and access to ventilators.
- (I) There are concerns regarding the inappropriate use of Do Not Resuscitate (DNR) Orders. Disabled people and their families, including parents of autistic children and carers of people with learning disabilities, are reporting that they have been asked to complete Do Not Resuscitate (DNR) order forms, in case they become critically ill, with no consultation.
- (m) Families and carers were not only cut-off from face-to-face support, and this was compounded by the abrupt closure of statutory services, such as day centres, respite care and professional services. The withdrawal of these services left many family carers unsupported. The slow and reduced opening of these services has prolonged the carers' stress and anxiety<sup>44</sup>. The immediate closure of face-to-face services in late March created unprecedented pressures on the non-statutory sector. New forms of support, based around various information technologies, evolved jointly with service-users. The most popular and successful ones should be incorporated into future provision<sup>45</sup>.
- (n) Failure to extend £20 UC uplift to disability benefits

A political crisis emerged when the First Minister, Paul Givan, resigned on 3 February 2022 in protest of the lack of progress made within negotiations between the UK Government and the EU<sup>46</sup> with respect to the Northern Ireland Protocol<sup>47</sup>. This has resulted in the absence of a clear mechanism to resolve the crisis and continuing challenges for disabled people in accessing services. We continue to operate without

<sup>&</sup>lt;sup>44</sup> Ibid, p.10

<sup>&</sup>lt;sup>45</sup> Ibid, p.9

<sup>&</sup>lt;sup>46</sup> Irish Times (2022): <u>Paul Givan resigns as First Minister of Northern Ireland in DUP protocol protest</u> (accessed 19 February 2022).

<sup>&</sup>lt;sup>47</sup> DfEEU (2018): New Protocol on Ireland/Northern Ireland and Political Declaration. London: HMSO. Article 2 Rights of Individuals (accessed 29 November 2021).

devolved Government meaning that regulations and practice has remained in place without review.

Disability Action have identified the following lessons:

- (a) Our individual chance of benefiting from treatment should we have Covid-19 must not be influenced by how our lives are valued by society.
- (b) Where we have existing health conditions or impairments that are unrelated to our chance of benefiting from treatment, they must not play any part in decision-making regarding our equal right to access such treatment.
- (c) The fact that we might have significant levels of social care and support needs, or that we may do so in future as a result of the pandemic, should not make health staff think that we will not benefit from treatment.
- (d) We have the right to be fully involved in decisions about our own lives, including life and death decisions. Decisions should never be made without our involvement, or consideration of our best interests. There is no justification for policies based on age or learning disability that do not treat each of us with respect and as individuals.
- (e) We all, and our advocates, have the right to know about decisions that may be made about us that will affect us.
- (f) Guidelines on the assessment, provision, and evaluation of treatment and care provided to individuals during the Covid-19 pandemic must be developed in collaboration with Disabled people's organisations and representatives from human rights bodies.
- (g) The need to include deaf and Disabled people in decision making.
- (h) The importance of measures to protect the safety of deaf and Disabled people in congregate living or health facilities.
- (i) The importance of working with Disabled persons organisations to ensure access for deaf and Disabled people to food deliveries, internet, Covid-19 testing, water, sanitation and hygiene facilities.
- (j) The need for the adequate support for Disabled people living alone or where family members or support workers are self-isolating or affected by Covid-19.
- (k) The need for clear public health messaging and accessible messaging.

- (I) The need to maintain access to medical treatment, including rehabilitation.
- (m) The need to collect data on disability to allow disaggregation.
- (n) Implement a programme of reform within the provision of health and social care services to d/Deaf and Disabled people in order address service challenges and increase accessibility in the context of the ongoing Covid-19 crisis.
- (o) Ensure mainstreaming of disability in all Covid-19 response and recovery together with targeted actions. A combination of mainstream and disability-specific measures is necessary to ensure systematic inclusion of d/Deaf and Disabled people. It is essential that d/Deaf and Disabled people play a key role in the process and are actively engaged in decision making.
- (p) Ensure accessibility of information, facilities, services and programmes in the Covid-19 response and recovery. Accessibility is fundamental to the inclusion of d/Deaf and Disabled people in the immediate health and socio-economic response to Covid-19. If public health information, the built environment, communications and technologies, and goods and services are not accessible, people with disabilities cannot take necessary decisions, live independently and isolate or quarantine safely, or access health and public services on an equal basis with others.
- (q) Ensure meaningful consultation with and active d/Deaf and Disabled people and their representative organisations in all stages of the Covid-19 response and recovery. d/Deaf and Disabled people have important contributions to make in tackling the crisis and building the future. Many d/Deaf and Disabled people have experience of thriving in situations of isolation and alternate working arrangements that can offer models for navigating the current situation. Perspectives and lived experiences of disability contribute to creativity, new approaches and innovative solutions to challenges.
- (r) To understand the different ways in which people with disabilities experience the impact of COVID19, and to monitor their inclusion in all phases of the response and recovery the collection and availability of disaggregated data by disability is essential.

- (s) Multi-stakeholder consultations on the development of a disability inclusive vaccination strategy which d/Deaf and Disabled people.<sup>48</sup>
- (t) Ensure non-discrimination in the allocation of scarce medical resources.
- (u) Ensure mental health interventions are inclusive of d/Deaf and Disabled people. Anxiety, lockdowns, isolation, and information consumption, loss of livelihoods and support systems due to the pandemic impact on mental health of all people, including persons with disabilities.
- (v) Vaccine roll out and treatment strategies should give priority to d/Deaf and Disabled people and their support networks.
- (w) Vaccine centres must be accessible for people with a range of disabilities. Disability accessibility audits should be undertaken to ensure that all vaccination centres have ramps or step free access and are fully accessible.

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<sup>&</sup>lt;sup>48</sup> Ibid