Witness Name: Nuala Toman
Statement No.: 2
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UK COVID-19 INQUIRY

WITNESS STATEMENT OF NUALA TOMAN ON BEHALF OF DISABILITY ACTION NORTHERN IRELAND

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1. I, Nuala Toman, Head of Innovation and Impact at Disability Action Northern Ireland ('Disability Action'), make this statement on behalf of Disability Action, on matters which are being examined in Module 3 of the Covid-19 Public Inquiry.9

Disability Action

2. Disability Action operates within the region of Northern Ireland but engages with Westminster and the UK Government on matters of relevance.

3. Disability Action is the largest pan-disability organisation in Northern Ireland. We work with people with various disabilities including physical disabilities, learning disabilities, sensory disabilities, hidden disabilities and mental health disabilities. We are a membership organisation representing more than 300 organisations who are all majority led, directed, governed and staffed by Disabled people. We use the term 'Disabled people' to mean people facing societal barriers as a result of their impairments or conditions.

4. As a Disabled person's led organisation (DPO), we advocate for the rights of d/Deaf and Disabled people and provide services which are developed by and for 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.

5. As part of its work, Disability Action is funded by the Department of Health to support the implementation of the Department of Health NI's Physical and Sensory Strategy. The vision of the strategy is to:

- Support disabled people to become well informed and expert in their own needs;
- Promote health, wellbeing and maximise potential of individuals;
- Encourage the social inclusion of disabled people and work to address the stigma associated with disability;
- Encourage family and person-centred services and the promotion of independent living options;
- Ensure services are tailored to meet the changing needs of people over the course of their lifetime; and
- Continue to promote and enable balanced risk taking, as laid out in our Physical and Sensory Disability Strategy and Action Plan 2012-2015.

6. Disability Action supports the physical and sensory strategy by engaging Disabled people in the co-design of health services. Disability Action provides information and advice which assists Disabled people to access health related services and to transition from residential settings to independent living. We provide information and advice services to support Disabled people in their transition from hospital care to home, from school to employment or further education, and from children's to adult health and social care services. This includes guidance on accessing benefits and dealing with discrimination. Disability Action have been involved in the co-design, implementation, delivery and monitoring of key Ministerial directives and Departmental statutory duties including the Mental Health Strategy, the Accident Prevention Strategy, the Reform of Adult Social Care and the Domestic and Sexual Abuse Strategy.

7. Up until March 2023 we were funded by the Department of Health to deliver mental health services in the context of the Covid-19 pandemic.

8. We support Disabled people in domestic settings, supported accommodation, care homes, and those detained under the Mental Health Act.

The work of Disability Action during the pandemic

9. During the relevant period, Disability Action provided the following specific services to Disabled people in Northern Ireland, which included health related services:

   a) Provided information, support, and advocacy, including intensive casework on access to healthcare and services to Disabled people by phone, email, and via socially distanced appointments.

   b) Transportation services for Disabled people to attend healthcare and vaccine appointments.

   c) A mental health and wellbeing service that provided bespoke counselling to d/Deaf and Disabled people, their families and carers. In response to the decline in mental health amongst Disabled people accessing Disability Action's services, we established the Disability Action Mental Health and Wellbeing Hub. This began initially as a pilot. Following the pilot we received funding from the Department of Health NI through the Mental Health Support Fund. Through this funding Disability Action provided 16 sessions of bespoke counselling to 106 Disabled people in the context of the mental health impacts of the pandemic.

   d) Emotional and practical support for Disabled people facing Do Not Attempt Resuscitation (DNAR) notices, and their families.

   e) Coordinated and hosted regular group meetings on Zoom in order to address social isolation experienced by Disabled people during the pandemic. More than 2,400 disabled people availed of these sessions.

   f) Provided support to bereaved families of Disabled people who died during the pandemic.

10. In addition to the provision of services to d/Deaf and Disabled people during the relevant period, Disability Action also:

    10.1. 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. These contributions were submitted orally to the Ad Hoc Review of the impact of Covid-19 on Deaf and Disabled people which was hosted by the Assembly All Party Group on Disability. Disability Action is the secretariat for the All- Party Group.

    10.2. Engaged with the Northern Ireland Executive and Assembly in respect of the impact of Covid-19 on deaf and Disabled people from the onset of the pandemic.

How Disability Action gathered information during the pandemic

11. As an organisation that provides healthcare and supports people to access healthcare, we have several formal and informal mechanisms for engaging with individuals and recording lived experiences.

12. As set out above, we provide advocacy and casework services to Disabled people and their families including in relation to access to healthcare. This casework provided significant insight into the range of issues that were faced by Disabled people during the pandemic. Disability Action use Advice Pro to log case work in line with GDPR processes. Maintaining client confidentiality, Disability Action identify key challenges and issues which are impacting on Disabled people which can be addressed through campaigns and which Disability Action work to resolve through direct advocacy. We also engage Disabled people in consultations and evidence sessions to improve services and develop policy, practice and legislation.

13. As stated, during the relevant period, Disability Action hosted regular Zoom meetings, where our members had an opportunity to discuss the impact of the pandemic on their daily lives. Issues raised within these meetings inform our research and policy development and recommendations made to Government and service providers.

14. During the pandemic, our bereavement services became a crucial informal mechanism to understand the inequality of treatment of Disabled people in healthcare settings during the pandemic. Particularly, the inappropriate use of DNAR notices, which the main body of this statement explains in further detail.

15. We also conducted an online survey regarding the experiences of Disabled people, their families and carers during the pandemic. Between 1 and 30 April 2020, we received 404 completed surveys, including over 1300 written statements. Analysis of the data collected included both qualitative and quantitative approaches. A thematic approach was taken to analysis of text responses, with common themes identified within a report published in September 2020 called '*The impact of COVID-19 on disabled people in Northern Ireland*', produced as Exhibit [NT/1 – **INQ000142172**. These are referred to in this statement as the 'April 2020 survey' (or the associated 'September 2020 report').

16. From November to December 2021, Disability Action held a series of nine meetings with 431 d/Deaf and Disabled people and undertook a survey of 83 d/Deaf and Disabled people in Northern Ireland. As a result of this engagement, we published the '*Alternative Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland'* produced as Exhibit [NT/2 – **INQ000142174** on 22 February 2022. This report is referred to in this statement as the 'February 2022 Alternative Report'.

17. The February 2022 Alternative Report was a broad project intended to shed light on areas of policy, practice and legislation within Northern Ireland which are non-compliant with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which Northern Ireland has yet to incorporate into law. The conclusions and findings of the report support DA NI's view that the failure to incorporate the UNCRPD into law means Disabled people experience inequality and discrimination in all sectors of public life, including healthcare settings, employment, social security and education. Health was one of the key topics raised in the stakeholder discussions, with a range of concerns identified, many of which reflect the priorities of the UNCRPD. Of particular relevance to matters relevant to

Module 3, was evidence that individuals spoken to expressed that DNAR orders were used inappropriately, that access to medical treatment was restricted during Covid-19, that health information was inaccessible and that health providers communicated with carers when they should have communicated with the Disabled patient directly see page 62-63).

18. The data acquired and used in the February 2022 Alternative Report was commissioned by the Equality Commission for Northern Ireland in order to review the work on the UNCRPD undertaken in Northern Ireland. As such there is a separate joint report based on this data, entitled *'Progress Towards the Implementation of the UNCRPD in Northern Ireland'* [NT/3 – **INQ000142173** which is referred to in this statement as 'The February 2022 Progress Report'. The Equality Commission for Northern Ireland and DA NI jointly conclude that there was a range of shortfalls regarding delivery in Northern Ireland relative to the UNCRPD. The purpose of the February 2022 Progress Report was to assist the Independent Mechanism for Northern Ireland, which is a focal point for the Executive to promote the Rights of Persons with Disabilities, as part of their independent monitoring role. The purpose of the aforementioned February 2022 Alternative Report was to provide a separate, independent report produced by DA NI.

19. Due to concerns about the inadequacy of information being provided to Disabled people during the pandemic, we also set up a 'Coronavirus Updates' page on our website. We updated this page regularly with news, information, signposting and advice for our members and all Disabled people and their carers.

Access to healthcare during the pandemic

20. Through our engagement activities, as well as monitoring changes to our own provision, Disability Action identified early in the pandemic that Disabled people had lost access to essential healthcare and treatments because of the closure of services. The results of our April 2020 survey demonstrated the severe effect this was having on pre-existing physical and mental health inequalities.

21. In our April 2020 survey, Disabled people with pre-existing physical health conditions frequently described the difficulties accessing routine healthcare.

For example, one respondent in our April 2020 survey described that *"GP's are not physically seeing patients. Consultants have cancelled appointments",* whilst another was concerned about being cut off from the primary care of their District Nurse, who would *"no longer attend unless the matter is urgent…"* (See page 24). A Disabled respondent to our February 2020 report explained further that, *"Financially, it is almost impossible. The health service is on its knees and support for chronic conditions is gone. If you are lucky enough to get a GP appointment, you will likely get a locum who is reluctant to change a treatment. Second class service for disabled people"* (See page 25).

22. In addition, we are aware that Disabled people faced significant difficulties accessing medication from pharmacies. Thirty-nine respondents to our April 2020 survey described that accessing medication was becoming problematic. This related to delays in receiving medications from pharmacies; individuals reported that it was *"Slow to get medicines…"* and also issues in relation to supply shortages; one respondent reported that *"Medicines frequently out of stock, went six days without pain relief…"* (see page 28). One clear impact of being unable to access treatments from pharmacies was the worsening of pre-existing physical health conditions. This was particularly the case for pain and discomfort: *"I have no meds for three days and apart from the pain which is horrendous I now have to suffer excruciating withdrawal symptoms…"* (see page 24).

23. As well as physical decline, over half (57%) of the respondents to our April 2020 survey explained that disruption to their access to primary healthcare had negative implications for their mental wellbeing. Difficulties accessing food and medication were reported to decrease self-reliance: One respondent said that *"Loss of independence and relying on others for basics of living like food and medicine. I have found this loss of independence very challenging…"* (see page 29). Privacy was also a concern, as some people were forced to rely on others to collect medicines from pharmacies for them; *"Because I cannot go to pharmacy it means family know what my medication is…"* (see page 29).

24. As well as primary healthcare, many Disabled people struggled to access more specialised treatments and therapies associated with their disability. We were told that these services were also critically impacted. For example,

one respondent said there was *“No longer any assistance from Allied Health professionals…”* (see page 24 of the September 2020 report). Allied Healthcare Professionals are clinicians who provide ongoing treatments and therapies. They have a range of specialities, such as rehabilitation, nutrition expertise and management of disorders. The impact of changes to the provision of these services during the pandemic could be very severe, depending on the ongoing medical issue at stake.

25. Disability Action Northern Ireland was not involved in relation to ambulance service policy and therefore we are not in a position to comment in respect of the impact of changes of provision in this area.

26. Disability Action Northern Ireland was not involved in relation to the provision of palliative care to Disabled people in the pandemic and therefore we are not a position to comment in respect of this area.

27. Disability Action Northern Ireland is not able to comment on the impact of Covid-19 testing policies for Disabled people working in healthcare settings. Nor is DANI able to provide any evidence regarding the allocation of work and work spaces to Disabled employees in healthcare settings. In terms of discrimination in the workplace, DA NI is extremely concerned that Disabled people experience discrimination in this capacity, including but not limited to healthcare settings. Our February 2022 Alternative Report thematically summarises the qualitative data collected through our surveys in relation to such discrimination (see page 36), which evidenced ‘*Extensive evidence of experiences of employment and workplace discrimination*’. We would also draw attention to page 27 of the same report which refers to the fact that Northern Ireland has the lowest rate of employment for d/Deaf and Disabled people in the UK, with only 37.8% in employment compared to 80.1% for non-deaf and Disabled people.

Mental health services

28. In our April 2020 survey, 72% of respondents reported that pandemic restrictions were affecting their mental health. The responses had three prevalent sub-themes; feelings of anxiety about contracting COVID-19, being isolated from family and friends, and not being able to access existing

support from a General Practitioner or Mental Health Team. Several responses outlined on page 26 of the September 2020 report indicate the decline of a pre-existing condition: *"Weekly Hospital appointments cancelled for mental health…"* and *"Not being able to see my mental health team…"*.

29. Similar experiences were reflected in our February 2022 Alternative Report. A Disabled person with a long-term health condition who contributed to our research reported the distress she was experiencing because of the sudden withdrawal of services; *"People with disabilities are being failed by our government during the pandemic, we have no access to day centres and there is not enough support for carers. We are being completely ignored by our Health Minister at every wheel and turn."* (see page 16).

30. Barriers in accessing mental health care as a result of Covid-19 also contributed to the institutionalisation of Disabled people. This was both because of the lack of available support in the community and also as a result of changes that were made to legislation. The Mental Health (NI order) 1986 and the Mental Capacity (NI) Act 2016 were amended to allow for a relaxation of the requirements in respect of qualifications, training and experience of people undertaking mental capacity assessments, and to ease the time limits for assessment and involuntary detention, with no mechanism for scrutiny. As described in the introduction, DA NI was in receipt of funding from the Department of Health to deliver mental health services during this period. Our own specialist employees and contractors reported to us that these legislative changes were resulting in the detention of Disabled people in instances in which they may otherwise have remained in the community. In addition, we heard that Disabled people were detained for a longer period than they would have been prior to the pandemic, causing disruption and distress in their lives.

Confusing health communications and guidance

31. We found that Disabled people's access to healthcare was further hindered by the lack of accessible health communications. In our April 2020 survey, people who had difficulty understanding health communications cited a lack of clarity and consistency in such communications. Other times, information could be slow to arrive and, for some, in an inaccessible format.

32. Our 2020 April Survey found evidence of poor communication particularly with regards to the guidance identifying people as ‘clinically extremely vulnerable’, ‘vulnerable’ or ‘at-risk’. In respect of the quality of risk-category communication itself, one respondent explained that *“There’s limited information from organisations, but the advice is somewhat conflicting and vague, due to government guidelines and a lack of clarity on which groups are truly vulnerable…”“* (see page 30). Another respondent told us that they *“have yet to receive any communication re shielding despite one of us being exceptionally high risk…”* (see page 22). Indeed, many experiences suggested there were delays in confirming eligibility in risk categories. As a result, many people did not receive their shielding letter when they should have. One individual reported that they had to survive four weeks of lockdown *“without any help”* because they did not receive the shielding letter which would have confirmed their priority status. The impact was that they had to *“pay a fortune for local shop delivery”* (see page 34). Another individual reported that the delay in receiving the shielding letter resulted in difficulties accessing medication, and the leaflets providing information about how to access help to collect medication did not provide for the appropriate level of support. However, that individual was told by volunteers that in order to receive further help to access their medication, the volunteers would need the *“letter as proof of my condition and my needs.’* (see page 34).

33. At the time of our survey in April 2020, only ninety-six respondents had received a shielding letter. In our summary section, at page 44, we point to academic reports which reveal differences between government lists and GP records and the resulting “grey area” that emerged in terms of shielding such that some individuals did not receive shielding letters when they should have. We believe this difference may explain the discrepancies that subsequently arose. Overall, we summarise that the impact of these “grey areas” surrounding risk-category and vulnerability on Disabled people was widespread confusion and uncertainty, particularly in terms of what qualifies a person for support, leaving people uncertain of where to turn.

34. In terms of broader public health communications and guidance, there are usually two main factors in relation to Disabled people accessing information: Disabled people are less likely to be able to access the information than the

general population, and, depending on conditions and impairments, they are less likely to be able to understand and/or follow it physically without appropriate adjustments. In our casework, we engaged with people with vision impairments who were sent postal letters from their health providers including hospitals, health trusts and Primary Care services to convey vital information with no consideration being given to how such individuals would in fact access the information being provided. In other instances, people with vision impairments were being asked to take photographs of their ailments in order to access healthcare, again, with no consideration of their ability to do so in light of their vision impairment.

35. Outside our own work, we were aware of the 2020 study from ARC (NI), *A review of the impact of COVID1-19 on learning disability services provided mainly by the voluntary sector in Northern Ireland*, produced as Exhibit [NT/4 **INQ000396817** which analysed guidance produced by public health agencies in the UK and within Northern Ireland. The study found that 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. Pages 19-22 of the study refer to the fact that, within Northern Ireland, there were numerous bodies issuing guidance in relation to settings which provide care for people with learning disabilities. From May 2020 onwards, as lockdowns were being eased, more specific guidance started to appear, but also previous guidance was being revised in the light of experiences, which compounded uncertainty around the 'proper' procedures that different agencies within Northern Ireland were recommending. This was especially so when the guidance had to be interpreted and applied to particular groups (such as people with learning disabilities) in service settings which supported them. Indeed, different service settings which support people with learning difficulties often have very different approaches and ways of working. For example, there is often vast differences in work practices between supported living environments compared with nursing and residential care homes. This area of the report accurately describes a sense of confusion regarding public health guidance that emerged, and which DA NI picked up on, during the time.

The impact of confusing infection prevention and control policies in healthcare settings

36. I have been asked to address any concerns that DA NI has regarding the impact of and/or issues caused by infection prevention and control measures in healthcare settings. One of our main concerns in this regard is the Public Health Agency (PHA) guidance *'Covid-19: Guidance for Nursing and Residential Care Homes in Northern Ireland'* which was released on 17 March 2020 and produced as Exhibit [NT/5 – **INQ000120717** This guidance was confusing in 3 major respects.

37. First, the guidance refers in paragraph 14 to 'general interventions' such as 'increased cleaning activity' but does not explain the specific steps involved. Similarly, it suggests keeping rooms 'properly ventilated by opening windows whenever safe and appropriate'. This afforded a wide degree of discretion to care home workers, who then had to decide how to balance the need for ventilation with a Disabled person's right to comfort and safety. This was a particularly acute consideration if the person was isolated in their room due to displaying symptoms of the virus.

38. Second, in respect of PPE, the March 2020 guidance was also inappropriately focused on *access* to PPE rather that its appropriate *use.* Although there was a well-documented shortage of PPE access in healthcare settings in Northern Ireland during this time, it was equally important that care workers had access to instructions on how to use it, or else access is redundant. DA NI considers this should have been a *'key message'* at the top of page 1. Furthermore, we consider that subsequent paragraphs which refer to the use of PPE are short, lack detail or inappropriately refer the reader to English guidance.

39. Third, in respect of visitation policies, the guidance also falls short. In paragraph 7, it advises that care homes should restrict visits whilst simultaneously stating there was no ban in place. As such, there was a lack of clarity about when restrictions were and were not appropriate, especially since the very same paragraph also notes that *'visits are essential – and important to patient well-being'*. Sentences such as *'you will wish to give careful consideration to the frequency and nature of pastoral and chaplain visits'* are unhelpful and do not adequately address the necessary balancing

of an individual's rights. (paragraph 9). Telling care home workers to ask a visitor to ask themselves *'If your visit is essential'* is also unhelpful, especially as the guidance also says *'one adult visitor'* is allowed per day (paragraph 10). In DA NI's view, visitation guidance was not sufficiently clarified on these matters until updated guidance from PHA arrived on 26 April 2020. Many Disabled people and healthcare employees were in a position of confusion in the interim and importantly, many Disabled people had their access to visits inappropriately curtailed as a result.

40. Indeed, DA NI was aware of publicly documented cases that revealed particularly acute impacts where visitation policy was concerned. One particularly harrowing example of the impact of visitation restrictions was reported by BBC News Northern Ireland, produced as Exhibit [NT/6 – INQ000346130]. Orla McKenna, a 52-year-old woman with a learning disability, lived in Abingdon Manor Care Home in Belfast during the relevant period. Before the pandemic, she came home to visit her parents every weekend. However, by November 2021, she had not been able to return home to visit her family at all for 20 months. They in turn had very limited opportunities to visit her in the Home. Describing the impact that visitation restrictions had on her daughter, Orla's mother Peggy said: *"She doesn't know what's happened to us, we're there and then we're not there."* She asked; *"Where's my child's life coming into this... my child's civil rights and her rights to be a human being?"*

41. Visiting restrictions were not the only policies that severely negatively impacted Disabled people living in care homes and nursing homes during the pandemic. Policies regulating when Disabled people could leave the premises, and therefore interact with support workers or voluntary carers in day-centre settings designed for well-being, also severely undermined their quality of life. Referring to her sister's experience, in the BBC article referred to above, Brenda McKenna paints a clear picture of the disproportionate impact on care home residents; *"even if it was only a bus taking them as a bubble, out somewhere for a run or an ice-cream a couple of times a week or even having access to that day centre where in the evenings you could bring them down to do an activity - it's just the bus, getting out, a change of scenery, it could really have a positive impact on their lives."*

Do Not Attempt Resuscitation (DNAR) Orders

42. On 12 May 2020, Disability Action became aware of a resuscitation policy in Northern Ireland hospitals affecting older people unfairly during Covid-19 – See Exhibit {NT/7 – INQ000346133]. As described in the news article, Northern Ireland did not have the same legal protections as the rest of the UK to prevent elderly people from facing discriminatory practices in the NHS during the COVID-19 crisis. This raised the alarm to DA NI that an environment existed in Northern Ireland whereby discriminatory practices within healthcare settings may be able to proliferate.

43. DA NI was already concerned that there was a discriminatory environment emerging because respondents to our April 2020 survey expressed concern that they or someone they care for would not be able to access treatment for existing medical conditions or would be denied treatment if they contracted COVID-19: *'I worry about what will happen to me if I get the virus, will I get treatment, will I be made to sign DR against my wishes…'*. One respondent whose mother is also Disabled told us *'Out of hours Dr told me to talk to my mother about DNR for her. I will not do that…'* (see page 23). As the pandemic progressed, our concerns about Disabled people being subject to unjust DNAR orders worsened. Our bereavement officers heard firsthand accounts from families who believed that their loved ones had been subject to discriminatory and/or nonconsensual DNAR orders. A Disabled woman in our February 2022 Alternative Report stated that: *"Our lives are seen as disposable. That has been clear throughout Covid. Either they give us a DNR without our consent, say that we should not live our life to the fullest or our deaths are expected and not warranted of sympathy" (see page 15).* Another case, from a Disabled carer who is also a Disabled man himself, featured in the February 2022 Progress Report. As stated on page 249, this case was presented because it exemplified qualitative data which was showing a theme of Disabled people being ignored, pushed out, left to die, neglected and abused. The man says that *'from personal experience of caring for an elderly disabled person, they were treated as expendable. From personal experience during the pandemic, the hospital staff stated that they would refuse to give treatment and pushed for me to sign a 'Do Not Resuscitate''*. (Please see page 249).

44. The experiences being reported through our own work was supported by media reports indicating that the issue of discriminatory DNAR orders was widespread in Northern Ireland and affecting Disabled people. The BBC article produced as Exhibit [NT/8 – INQ000276254] includes a contribution by Amanda Paul, who recounted her experience at the inaugural sitting of the Disabled person's Parliament in Stormont on 3 December 2021. Ms Paul was hospitalised during the pandemic after becoming seriously ill with septicaemia. She recalled that: *"The consultant then addressed me and in his words I quote directly: "Due to your disability and your weight if things go south from here I see no point in pummelling your chest, I think it's best we put a DNR (Do Not Resuscitate order) on you".* Ms Paul then described being *"left reeling"* that someone could pronounce what she felt was a death sentence on her without discussion or recourse. She was left in tears wondering if she was going to die.

45. Disability Action Northern Ireland had particular concerns about the message sent by placing a DNAR on a Disabled person's record and its practical effect as lessening the value of a Disabled person's life. This issue exacerbates a longstanding concern that the lives of Disabled people are afforded less weight, particularly in healthcare decisions. A Disabled young woman who contributed to the February 2022 Alternative Report study described this pervasive sense of prejudice: *"Until society changes its attitude towards disabled people it is my fear that disabled people will continue to face abuse".*

Disproportionate number of deaths of Disabled people

46. Disabled people were disproportionately more likely to die during the pandemic than those without disabilities. The Northern Ireland Statistics and Research Agency (NISRA) published an equality group analysis of deaths due to COVID-19 which showed that Disabled people were 42% more likely to die of COVID-19 – produced as Exhibit [NT/9 – **INQ000438343** UK-wide ONS statistics released on 11 February 2021 revealed that 59.5% of Coronavirus deaths up to November 2020 were of Disabled people (30,296 of 50,888 deaths) – produced as Exhibit [NT/10 – **INQ000396814** Disabled people made up just 17.2% of the study population, which starkly illustrates the disproportionate mortality of Disabled people. The Department of Health

in Northern Ireland did not publish data regarding the impact of the pandemic on Disabled people. However, a recent English study, over three waves of the pandemic from 24 January 2020 to 20 July 2022, found that the risk of COVID-19 related death was higher among people with a vision, hearing or both impairments than those without such impairments – produced as Exhibit [NT/11 - **INQ000396815**

47. It is Disability Action's view that mortality differences must be understood in the context of the failure to consider the communication needs of Disabled people when providing public health information. Ensuring everyone in society is able to access and understand public health information during a pandemic is not only a matter of inclusion; it is fundamental as a basic ingredient for the preservation of life. It is Disability Action's view that the absence of accessible health communications left disabled people more exposed to infection and illness from Covid-19. Disabled people faced significant barriers to safe and accessible healthcare compounded by a lack of appropriate transport to and from health care facilities, high out-of-pocket expenditure, and stigma and discrimination which further exacerbate health inequalities. Disability Action, DPOs, voluntary organisations and NGOs stepped in to fill the void left by tenuous system responses. Disability Action were instrumental in advocating for inclusive adaptations to response measures, translating information into accessible formats and distributing food and medicines.

Submissions made by Disability Action to the Department of Health and others during the pandemic

48. During the course of the pandemic, Disability Action had contact with the Department of Health and other organisations at various stages to advocate on behalf of Disabled people and raise concerns about the impact of the pandemic on Disabled people.

49. In response to the publication of the National Institute for Health and Care Excellence (NICE) Guidance 'COVID-19 rapid guideline: critical care' on 23 March 2020, Disability Action issued a public statement outlining our deep concern about the use of frailty to assess eligibility for critical care - Exhibit [NT/12 – INQ000276258]. In partnership with Disabled people and their organisations, we called on NICE to include specific further guidance in

partnership with Disabled people and their organisations. This led to NICE amending their advice about the application of their guidance on 25 March 2020. The revised guidance made it clear that the clinical frailty scale should never be used to assess patients aged under 65, or patients of any age with stable long-term disabilities (for example cerebral palsy), learning disabilities or autism.

50. On 22 April 2020, we wrote an open letter to Health Minister Robert Swann, Chief Medical Officer Dr Michael McBride and Chief Social Worker Sean Holland, outlining the need for an ethical framework for the treatment of Disabled people: Exhibit [NT/13 - INQ000396819 This letter arose out of concerns that Disabled people were not receiving equal access to healthcare and were not being consulted in respect of guidelines being produced during the course of the pandemic.

51. On 29 April 2020, the Health Minister responded and endorsed the guiding principles we had set out in our letter, Exhibit [NT/14 – INQ000396820

52. We were subsequently invited to meet with a sub-group of the NI COVID-19 HSC Clinical Ethics Forum to discuss the issues raised in our 22 April 2020 letter. On 6 May 2020 we attended a meeting, and we subsequently provided input into a draft framework - please see Exhibit [NT/15 – INQ000396821 The finalised guidance is produced as Exhibit [NT/16 – INQ000396822 and reaffirms non-discriminatory and ethical medical treatment.

53. Despite the publication of the Ethical Advice and Support Framework, Disability Action's concerns about the experiences of Disabled people increased as the pandemic progressed.

54. On 25 November 2021, Disability Action wrote to the Health Minister Robert Swann to request an urgent meeting due to concerns about the disproportionate number of Disabled people dying from COVID-19 as well as concerns about access to essential health and social care Exhibit [NT/17– INQ000396827 We said *"[a]lmost two thirds of people who have died due to coronavirus were d/Deaf and Disabled People. Research undertaken by Disability Action regarding the experience of disabled people during the pandemic has shown that health social care services for disabled people had*

experienced significant disruption and that many disabled people have experienced a decline in physical and mental health. This was a result of the removal and reduction in access to key services and support. Our research also showed that disabled people had challenges in accessing medication and food". We called on the Department of Health to consider rights under the ECHR and UNCRPD in its approach to dealing with COVID-19 and to provide reassurance to Disabled people that they would have equal access to hospital treatment, health and social care services.

55. On the same date, we also wrote to members of the Executive to request an urgent meeting to discuss these issues. Please see correspondence with:

- The First, Deputy First and Junior Ministers, Exhibit [NT/18 – **INQ000396828**
- Paula Bradley MLA, Exhibit [NT/19 – **INQ000396829**

56. On 13 December 2021, we received a response from the Minister of Health which acknowledged the disproportionate impacts of the pandemic on Disabled people and the *"immediate work"* that needed to be done (see Exhibit [NT/20 – **INQ000396838** Unfortunately, Mr Swann did not feel that a meeting with us at that juncture would be helpful.

57. On 20 December 2021, we wrote to the Chair of the Health Committee, Colm Gildernew, to note that we had previously written to the First and Deputy First Ministers, Junior Ministers, the Minister of Health and the Department of Health raising concerns about the impact of Covid-19 on d/Deaf and Disabled People; Exhibit [NT/21 – **INQ000396844** We informed him that we had yet to receive assurance that the matters which we raised were being appropriately addressed. We reiterated our concerns about the removal and reduction in access to key services for Disabled people and asked to engage with the Health Committee. We did not receive a response to that letter.

58. On 27 January 2022, we received correspondence from the First Minister and Deputy First Minister accepting the request for a meeting made on 25 November 2021, produced as Exhibit [NT/22 – **INQ000396849** This meeting did not proceed due to the resignation of the First Minister.

59. Unfortunately, despite follow-up correspondence from us in February 2022 which reiterated the urgent need for a meeting, this never materialised. Please see:

- Letter dated 7 February 2022 to First Minister Paul Given and Junior Minister Gary Middleton, Exhibit [NT/23 – INQ000276250].
- Letter dated 7 February 2022 to Deputy First Minister Michelle O'Neill and Junior Minister Declan Kearney, Exhibit [NT/25 – INQ000276252].

60. Michelle O'Neill did visit Disability Action on 13 April 2022 and engaged with us on the impact of Covid-19. However, this meeting was not an Executive Meeting as Michelle O'Neill was not in a Ministerial position.

61. Unfortunately, our calls for the Executive and Assembly to both engage with us as a representative organisation and to publicly acknowledge the impact of Covid on d/Deaf and disabled people were left unanswered.

Recommendations

62. A central failing of the healthcare response to the pandemic in Northern Ireland was that Disabled people themselves were frequently excluded from decision-making. The absence of co-production frequently resulted in decisions which exhibited an offensive lack of awareness, particularly where different communication needs were concerned. In turn barriers to accessing health guidance and advice presented acute health consequences for Disabled people. As I have laid out, this situation is likely to have contributed to the disproportionate deaths of Disabled people.

63. Government, decision makers and health and care professionals need to value disabled people's expertise through properly recognising the value of lived experience and ensure Disabled people's voices are central to any plans right from the start. They need to actively involve Disabled people in planning and design of policies. This has long been recognised by Disabled people and DPOs through the slogan 'Nothing about us, without us'. Key to

this involvement is health and care services understanding and valuing the expertise people that Disabled people hold. This means services and the people using them can come together to ensure that solutions start with people themselves, rather than with what the system thinks will work. Services can start to address inequalities by understanding the barriers that people face to accessing health and care and co-designing person-centred, effective, sustainable solutions.

64. Until co-production is institutionalised, healthcare bodies will continue to produce policies that reveal a lack of understanding about what it really means to be a Disabled person and will repeat the same mistakes. The establishment of clear and consistent channels of co-production in healthcare will contribute to upholding the principle of non-discrimination in the allocation of scare medical resources during the next pandemic. It is essential to ensure that:

64.1. There are guidelines on the assessment, provision, and evaluation of treatment and care provided to individuals during the Covid-19 pandemic developed in collaboration with Disabled people's organisations and representatives from human rights bodies.

64.2. Disabled people's individual chance of benefiting from treatment is not influenced by how their lives are (de)valued by society.

64.3. Pre-existing health conditions or impairments that are unrelated to Disabled people's chances of benefiting from treatment do not play any part in decisions related to their right to access such treatment.

64.4. The levels of social care and support needs that a Disabled person receives does not influence health staff to assume that they will not benefit from treatment.

64.5. Measures are put in place to protect the safety of d/Deaf and Disabled people in congregate living or health facilities.

64.6. Mental health interventions are inclusive of d/Deaf and Disabled people.

64.7. Disabled people are fully involved in decisions about their own lives, including life and death decisions.

64.8. Data is collected on disability and healthcare to allow disaggregation, and;

64.9. Disabled people receive clear and accessible public health messaging that is always appropriate for them.

Statement of truth

I believe that the facts stated in this witness statement are true. I understand that proceedings for contempt of court may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief in its truth.

Signed.............Personal Data..................................

Dated...........21/11/2023...