Witness Name: Rhian Davies
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Exhibits: 17
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UK COVID-19 INQUIRY

WITNESS STATEMENT OF RHIAN DAVIES ON BEHALF OF DISABILITY WALES

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1. I, RHIAN DAVIES, Chief Executive of Disability Wales/Anabledd Cymru, make this statement on behalf of Disability Wales, on matters which are being examined in Module 3 of the Covid-19 Public Inquiry.

Disability Wales

2. Disability Wales/Anabledd Cymru ('DW') is a registered charity and company limited by guarantee (Registered Charity no: 517391; Registered Company no: 0199862). Our core role is to represent the views and priorities of our members to government, primarily to the Welsh Government but also the UK Government on reserved matters, with the aim of informing and influencing policy.

3. DW has 100 member organisations across Wales, 29 of which are full member Disabled People's Organisations, run by and for Disabled people. We use the term 'Disabled people' as our members do, to mean those facing disabling societal barriers due to their impairments or conditions. This includes physical impairments, mental health conditions, hearing impairments, d/Deaf people with BSL as their first language, visual impairments, learning disabilities, those with chronic health conditions and neurodiverse people.

4. DW engages in member campaigns, consultations, research, and policy development in order to influence government policy and practice in respect of Disabled people.

5. We host an annual programme of regional events, conferences and workshops for members and stakeholders on topical issues. We also offer bespoke equality training delivered by and for Disabled people across the Public, Private and Third sectors.

How issues are brought to the attention of Disability Wales

6. DW is an umbrella organisation for over 100 members and matters of significance for Disabled people are frequently brought to our attention by representatives of those specialist organisations who are members. In addition, DW uses a variety of methods for gathering the views of Disabled people. These include online surveys, email circulars and focus groups on thematic issues, member events such as the Annual Conference, and formal mechanisms including the Cross Party Group on Disability. We also gather personal experiences via videos and blogs. Views and experiences are also gathered from participants in DW projects.

7. During the pandemic we distributed Covid-19 Emergency Grants on behalf of the National Emergency Trust and Welsh Government to DPOs in Wales. These enabled grassroots DPOs to provide information, advice and peer support to local Disabled people and also provided a valuable source of intelligence regarding how the pandemic was impacting Disabled people and the role of DPOs in tackling these issues.

8. During the relevant period, Disability Wales was involved in a major research project commissioned by the Welsh Government to collate the experiences of Disabled people in the pandemic, including their experiences of the Welsh healthcare system. This research project arose following discussions at the Welsh Government's Disability Equality Forum, which DW attends, about the adverse experiences of Disabled people during the pandemic.

9. I was the chair of the Steering Group of that research project which convened regularly in the period October 2020 to February 2021. The Steering Group

included a number of representatives of Disabled People's Organisations in Wales.

10. The Steering Group was a platform to develop primary and secondary evidence for *"Locked-out: liberating disabled people's live and rights in Wales and beyond COVID-19",* Exhibit [RD/1 - **INQ000177836** The report describes how pre-existing socio-economic inequalities in society which influence poorer health outcomes for Disabled people were amplified during the pandemic. The resulting experience for many Disabled people was the sense that their lives were less valued by Welsh society. This was particularly prevalent in evidence relating to the accessibility of public services, including public health services.

11. The *Locked*-out report was based on evidence gathered through the work of DPOs who sat on the Steering Group, and over 300 items of written evidence including secondary research and data analysis. We also held a focus group (the 'Focus Group on Intersectionality') to hear the lived experience of Disabled people from Black and Minority Ethnic communities, who did not have a representative member on the Steering Group. The minutes of this Focus Group are produced as Exhibit [RD/1A – **INQ000400696** Black and minority ethnic Disabled people reported that they suffered unique challenges during the relevant period in relation to their experience of the healthcare system; which are discussed later in this statement.

12. DW also gathered information about Disabled people's experiences during the relevant period as part of our December 2020 report; *Bring us our rights: disabled people's manifesto;* produced as Exhibit [RD/2 - **INQ000400634** The data gathering process for that report involved conducting a survey between 20 August and 15 September 2020 of Disabled people, which received 120 responses. We also ran nine themed focus groups, including one on health and social care, and conducted individual interviews. Our manifesto was inspired by the disproportionate number of deaths of Disabled people in the pandemic. It highlights key areas for advancing equality for Disabled people, as well as offering policy solutions, which I have addressed further in the recommendations section of this statement.

13. On 11 May 2020, DW launched our #LockdownLife social media campaign. For this project, we heard direct testimony from Disabled people across Wales who used their mobile phones or other devices to film their experiences which were then collated into short films. We heard experiences from people who depend on health and social care services and had been affected by changes to the provision of these services.

14. DW also contributed to a written evidence report in response to an Inquiry instigated by the Senedd Equality, Local Government and Communities Committee, regarding the impact of the pandemic on Disabled people; Exhibit [RD/3 – **INQ000400648**]. Our response was informed by multiple focus groups of Disabled people, the total attendance of which was 23 people. Our response was further informed by a survey on Lockdown Easing which was responded to by 86 people, a call for information via email which received 16 responses, and the views of participants from our aforementioned #LockdownLife video series on social media, of which there were a total of 9 participants. In total, our response was informed by the views of 134 Disabled people.

15. The first key finding of this evidence report was that many Disabled people felt they had suffered discrimination during the pandemic. One of the reasons for this was the lack of accessible health communications, such as Easy Read. Secondly, there were also concerns about the negative impact of increased use of face masks on D/deaf people. Thirdly, the report found that services provided by Local Authorities, which are essential to Disabled people, were denied as they were incorrectly deemed as not essential, causing an overreliance on voluntary support services. Fourth, the report found that, in relation to access to healthcare, there were three key themes identified: difficulties in accessing shielding letters, difficulties attending medical appointments due to not feeling safe on public transport, and concerns from shielding Disabled people that there was not a sufficiently clear timeline for leaving lockdown such that those who were shielding were unsure of the rules. The fifth finding of the evidence report was that there had been a worsening of pre-existing inequality issues, such as the impact of rising levels of domestic abuse on Disabled women. The report did however find that there were some positives to lockdown and Disabled people preferred the approach of the Welsh Government to exiting lockdown.

Consultations and submissions on the impact of the pandemic on Disabled people experiencing the Welsh healthcare system.

16. Disability Wales is a member of numerous platforms that we use to make submissions to the Welsh Government.

17. DW is a member of the Welsh Government's Disability Equality Forum (DEF), which is chaired by a Minister and whose membership includes a range of stakeholders in the Disability field and officials from several Government departments, including health.

18. Before the pandemic, DEF was convened two or three times per year. However, between 16 April and 21 October 2020, we convened seven times to discuss pandemic-related agenda items, including health-related items where senior Welsh Government health officials, such as the Welsh CMO, provided updates and invited feedback from members to inform relevant policy. As part of the DEF, I provided relevant information on several matters on behalf of DW. At the 21 May meeting, I emphasised the importance of digital inclusion for combatting social isolation and keeping mentally healthy. At the meeting on 4 June, I asked for a commitment from Welsh Government to involve people from shielding groups, and their representatives, in the review and planning for future arrangements. This is discussed further below.

19. From May to October 2020, DW also engaged in separate consultations with the Welsh Government, as part of our obligations in receiving the Equality and Inclusion Grant. These meetings usually took place quarterly for monitoring purposes. In 2020 the frequency of these meetings increased to twice per month as an opportunity to provide a regular flow of two-way communication on COVID-19 related matters, as well as more general issues. Alongside the DEF, these meetings provided a means for us, as well as many of our member organisations, to raise concerns with the Welsh Government and provide feedback on policies.

20. DW was also represented on the Welsh Government's COVID-19 Moral and Ethical Advisory Group (CMEAG) which met monthly for two years from April 2020. The purpose of the group was to combine members' expertise to offer

an ethical and moral perspective on a range of COVID-19 related healthcare policies.

21. In June 2020, along with a coalition of disability and health related organisations with shared concerns around shielding arrangements, DW contributed to writing a letter which raised concerns about shielding and the response to the policy from the First Minister; which will be exhibited and discussed later in this statement.

Disproportionate health impacts of inaccessible healthcare and changes in the provision of services

22. Disabled people are more likely to have pre-existing health conditions which leave them particularly at risk in circumstances where there is little or no access to primary healthcare. For many who relied on these services for daily life prior to the pandemic, the sudden withdrawal or rationing of primary provision, often at short notice, had serious mental and physical consequences. One contributor to our #LockdownLife campaign told us in a recorded video that *’the first thing that changed was I stopped having my arthritis treatment eight weeks ago because it was all cancelled due to COVID-19. It meant that the pain I have has increased exponentially, and I’ve now ended up in an electric wheelchair, which I was trying to avoid.*”

23. DW co-organised a Cross Party Group (CPG) on Disability on 2 July 2020 at which Disabled people gave evidence on the wide-ranging impacts of COVID-19. DW played a key role in identifying and supporting the individuals who took part; Exhibit [RD/4 – **INQ000400642** The key healthcare-related issues that were raised were: vision impaired people experiencing increased loneliness and isolation; confusing public health messaging; suspension of access to treatment for pre-existing conditions; and exclusions from remote healthcare practices and settings.

24. In terms of the suspension of access to healthcare, one participant shared that she normally received treatment for MS every six months to slow down the progression of the condition. However, since the pandemic began, the MS Unit had become a Covid-19 ward and her treatment had been suspended.

25. Another participant spoke about the difficulties experienced by people with sight loss during the pandemic. In particular, a "looming crisis" for people requiring support from a Rehabilitation Officer for the vision impaired. At that time in Swansea, there was already a 12-month waiting list for a needs assessment and that was steadily increasing. This was a particularly significant impact of the suspension of the statutory duty to undertake a needs assessment under the Social Services and Wellbeing (Wales) Act 2014.

26. As Disabled people were unable to access needs assessments, in turn those with vision impairments were then unable to access Rehabilitation Officers. Rehabilitation Officers assist people to live independently by providing assistance in overcoming physical disorientation which can occur because of poor quality specialist aids and equipment. They also assist in the development of new skills, such as Braille, which is crucial for people with a vision impairment to be able to understand written public health communications. This service is therefore acutely important to prevent health risks and even death in a pandemic context. For this reason, and due to our wider concern about Disabled people not being able to access vital services, at a DEF meeting on 21 May 2020; Exhibit [RD/5 **INQ000400650**, I asked if the Welsh Government was monitoring whether local authorities were modifying services (see paragraph 3.5). I was concerned to ensure that the government were aware of whether local authorities had chosen not to provide statutory services and in turn were monitoring the impact of this on Disabled people.

27. At that meeting, the Welsh Local Government Association (WLGA) stated that they had contacted all local authorities in Wales asking if any of them had eased their statutory duties. Around half responded, all of which indicated that provision had not changed (paragraph 3.6). However, this was contrary to the experience of DW and its members, who found that needs assessments for rehabilitation services were badly affected by COVID-19, resulting in inconsistent provision, with each local authority taking a different approach. The evidence received for the *Locked-out report* was that, in many instances, no assessments were taking place or, if they were, they were being undertaken remotely (*Locked-out,* page 83). Remote healthcare presented unique communication challenges for many Disabled people, some of which are discussed later in this statement.

28. In a meeting between myself and two Welsh Government officials on 8 June 2020, produced as Exhibit [RD/6 – INQ000276274], I told them that "*non-Covid related health issues are at the forefront of concerns at the moment. The suspension or delay of medical treatments, scans, diagnostics, etc are having a significant impact*" (paragraph 3.3). **NR**, a Welsh Government representative, responded that she would raise the issue of delayed medical treatment with the CMO's office, identify the relevant policy lead and seek a response. This response was not forthcoming and thus, this action was not formally closed in the subsequent meeting on 24 June, produced as Exhibit [RD/7 – **INQ000400630**], nor in any subsequent meetings.

29. On top of the suspension of treatment for pre-existing or non-Covid related health conditions, DW was also concerned that the pandemic was affecting the willingness of Disabled people to seek treatment for these issues. For example, one attendee at the Intersectionality Focus Group **RD/1A - INQ000400696** told us that Disabled people experiencing mental health issues were not attempting to access mental healthcare because they were concerned about being a burden on the services. This is consistent with the statistical picture that emerged, where fewer people with mental health conditions contacted their GPs across Wales in 2020 than at the same time in the previous year (*Locked-out,* page 42). Our written evidence in response to the Senedd Equality report **RD/3 - INQ000400648** indicated that some Disabled people missed healthcare appointments because they felt uncomfortable or unsafe travelling on public transport. In many cases, this is because Disabled people felt harassed or uncomfortable being asked intrusive questions about their journey. One survey respondent said: *'Been questioned by a driver the purpose of the journey, wanting to know if it's an essential one. This person was on their way to a medical appointment'* (see page 22). As a result, DW was concerned that Disabled people were missing appointments or were not making appointments that they needed.

30. Another limitation on the ability of Disabled people to access healthcare during the pandemic was the result communication failures between NHS departments and agencies within Wales, and between Wales and England (*Locked-out,* page 46). Disjointed communications between healthcare providers, particularly in the referrals processes, resulted in Disabled service users, often with multiple impairments, being expected to facilitate actions

between different specialists, or across borders, at a time when they were unwell and needed support (*Locked-out*, page 46). Unnecessary and distressing healthcare barriers such as these can increase stress, exacerbate pre-existing health conditions, and contribute to poor mental health. Indeed, high levels of 'worry' and 'anxiety' were reported among Disabled people during the pandemic, and the Office of National Statistics recorded that inaccessible public services were a key contributor to this (*Locked-out,* page 49).

31. Disability Wales was not involved in relation to ambulance service policies and therefore we are not in a position to comment in respect of the impact of changes of provision in these areas.

32. Disability Wales 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.

33. Disability Wales does not work directly with Disabled people employed in healthcare settings and therefore has no comment in respect of the impact of the pandemic on Disabled people working in healthcare settings during the relevant period.

Challenges Disabled people experienced communicating within healthcare settings.

34. As well as the sudden rationing of primary healthcare, the way in which healthcare was provided also shifted during the pandemic, due to the widespread use of 'remote appointments' as an infection control measure. Remaining healthcare provision that was not withdrawn was largely delivered in a 'remote' rather than 'in-person' setting. This presented communication challenges for many Disabled people, which in turn affected their ability to access care. In the CPG meeting referred to above RD/4 - INQ000400642 a Disabled contributor shared her communication difficulties in relation to GP appointments and obtaining blood test results. As the individual's GP surgery had been closed, patients were required to order repeat prescriptions by phone. Due to the individual's hearing loss, she was unable to communicate using this technology. As such, she made two requests for a video appointment, yet on both occasions, the GP inappropriately contacted her by telephone. As her efforts to communicate in a remote setting via an appropriate medium were

ignored, the only solution was for her daughter to communicate with the GP instead, leaving the individual excluded from the process.

35. As is apparent from the example above, the move to phone consultations presented particular barriers for D/deaf people. This situation exacerbated pre-existing exclusions that D/deaf people face trying to access the Welsh primary healthcare system, in part caused by the fact that many D/deaf people are not recorded as being D/deaf in their primary healthcare records, meaning that their communication needs can be overlooked. One of the reasons for this is that new patient forms at GP surgeries often do not ask about hearing, so if people attend for a screening appointment this information may be recorded, but it is rarely collated on health databases or central systems. In cases where a provider does understand the communication needs of a D/deaf patient, many surgeries do not know local arrangements for booking BSL interpreters to enable the individual to engage in meaningful discussions at health appointments. Attempts to make reasonable adjustments therefore often fail. The pandemic exposed a severe consequence of the ongoing failure to address these dual issues, which significantly contribute to health inequality for Welsh D/deaf people.

36. In consideration of communication barriers faced by D/deaf and Disabled people in healthcare settings, it is important to have regard to intersectional issues. In the Intersectionality Focus Group RD/1A -INQ000400696 which informed the *Locked-Out* report RD/1 -INQ000177836 an individual who is from an ethnic minority group and also D/deaf reported on the 'double discrimination' that is often faced by people who are a member of both communities. This individual stressed that people from ethnic minority communities and foreign language communities all have different values and needs yet are often facing similar discriminatory treatment. He referenced the language/communication barrier, noting that when he goes to the doctor, he is unable to access this service in his first language. In his view, many Covid-19 related deaths of Disabled people during the pandemic were caused by communication challenges which prevented them accessing health services.

37. An autism specialist and member of the Chinese community was also in attendance at the Intersectionality Focus Group. Similarly, she cited the language barrier as a contributor to the discrimination faced by Chinese autistic people in Wales in healthcare and other settings. This individual also discussed

the missed opportunity for Regional Partnership Boards (RPB's) to represent the voices of ethnic minority Disabled people. Earlier in the meeting, it was discussed that RPB's are situated in each health board area and are in place to support co-production in improving the delivery of health and social care services. However, RPB's are largely represented by health board officials, public servants and members of the third sector, whilst only one citizen and one carer representative are present. This is disempowering in terms of Disabled people not having the opportunity to communicate their contributions directly. The individual responded to these points that the process of making RPB's more representative must also involve having at least one representative from the ethnic minority groups in every RPB. Although she recognised that even this may not be sufficient, as all minority groups present with slightly different intersectional issues. She said that the effect of intersectional voices being hidden for a long time is that people incorrectly assume that the relevant problems faced by ethnic minority Disabled people are extremely uncommon, when they are not. The point that intersectional perspectives are marginalised in healthcare, as well as other settings, and this continued to be the case throughout the pandemic, was one that was made frequently throughout the meeting, and thus also featured in the *Locked-out* report.

Disproportionate deaths of Disabled people

38. The difficulties experienced by Disabled people attempting to access healthcare during the pandemic directly contributed to the disproportionate mortality that materialised. *Locked-out* cites ONS data that suggests that 68% of deaths from COVID-19 were among Disabled people in Wales. Poor and patchy public services, as well as inaccessible public health information, are factors that significantly contributed to this figure (see page 8).

39. As I stated in my online summary of *Bring us our rights: disabled people's manifesto* RD/2 INQ000400634 our human rights research was inspired by the starkly disproportionate mortality experienced by Disabled people in Wales during the pandemic, which reflects *"the stark inequalities faced by disabled people in society, and widespread instances of their human rights being* [breached] *or potentially breached."* This includes breaches of rights within the Welsh healthcare system.

Unlawful DNAR notices

40. Some GP surgeries in the UK, including one in Maesteg, sent blanket communications to Disabled and older patients asking them to consent to DNAR notices, despite them having stable health conditions. Photographs of these blanket communications were featured in a BBC News article in April 2020; produced as Exhibit [RD/7A – **INQ000400633**]. The letter states that *'completing a DNACPR will have several benefits'* and that consenting to an order will enable *'scarce ambulance resources'* to *be 'targeted to the young and fit who have a greater chance [...].'*

41. As part of DW's written evidence to the Inquiry instigated by the Senedd Equality, Local Government and Communities Committee **RD/3 - INQ000400648** we presented concerns from our focus groups that they *"felt pressured into signing these letters, which seemed to imply that their lives were not worth the same as the "young" and "healthy" lives that they were attempting to conserve resources for."* Indeed, the EHRC found DNAR notices being applied to care plans for older or Disabled people in residential homes without proper consultation (see *Locked-out,* page 43).

42. Disability Wales is a member of the Disability Reference Group (DRG) which is constituted by us and three of our member organisations: Learning Disability Wales, Wales Council of the Blind, and Wales Council for Deaf People. Due to our concerns regarding the application of blanket DNAR notices, collectively, we worked to secure over 1400 signatures to a statement addressed to the Chief Medical Officer for Wales, which I produce as Exhibit [RD/8 - **INQ000400635**] - *Coronavirus (COVID-19) and the rights of disabled people in Wales*. The statement reaffirmed Disabled people's rights to benefit equally from treatment within the health service, whether for coronavirus or for any other health issue, arguing that this must not be influenced by the way Disabled people's lives are devalued in society.

43. In response to our statement, the Chief Medical Officer and Chief Nursing Officer wrote to Health Board Chief Executive Medical Directors on 17 April 2020 to confirm that *'Age, Disability or long-term condition alone should never be a sole reason for issuing a DNACPR order against an individual's wishes. It remains essential that decisions are made on an individual and consultative basis with people. It is unacceptable for advance care plans, with or without*

DNACPR form completion to be applied to groups of people of any description.' - produced as Exhibit [RD/9 - INQ000300106

44. As part of our role in CMEAG, DW contributed to the development of guidance for healthcare services when making decisions during the coronavirus outbreak; '*Ethical Values and Principles for Healthcare Delivery*', Exhibit [RD/10 – INQ000081000 . Our role was to contribute further information and resources on ethical care. The public statement on Covid-19 and the rights of Disabled people in Wales, attached to Welsh Government emails as Exhibit [RD/11A - INQ000276264], was noted to have been very helpful in influencing the final version of the Guidance. A request to reference the public statement within the CMEAG Wales document was made in these Welsh Government emails, which are produced as Exhibit [RD/11 – INQ000400640 . This indicates the importance and influence of the public statement.

45. In DW's view, 'explanations' for instances of medical discrimination towards Disabled people in the pandemic have tended to suggest they were unintentional acts that occurred in crisis conditions. However, we question this analysis and believe an investigation is needed into the extent to which under-investment in social and health services, which has seen an accountancy culture increasingly replace values of collective welfare and an ethical approach to evaluating human need, has had a pernicious effect on health-care decision-making in relation to Disabled people. Healthcare rationing was already a feature of the NHS pre-pandemic. Decisions about the allocation of scarce NHS resources are essentially political and reflect dominant social values and priorities, often rooted in the medical model of disability. This model defines Disabled people by their medical conditions and has been criticised for primarily focusing on what people cannot do because of their differences, rather than what they could do if barriers in society were removed. Many Disabled people consider that the medical approach to their identity dominated during the pandemic, and this left them feeling mischaracterized and misunderstood by healthcare professionals, and in healthcare settings. Consequently, Disabled people told us that during the pandemic they felt neither valued, nor a priority. According to our survey conducted in 2020 RD/2 - INQ000400634 only 15% of respondents felt that their rights were being enforced in health and social care. The pandemic thus reaffirmed why it is so important that medical professionals and clinicians, as well as politicians involved in key decision-making about

resources, understand the social model of disability as the foundation for an ethical approach to understanding human need and valuing human life.

Shielding

46. In the relevant period, DW became aware that Disabled people on the Welsh Shielded Patient List were having difficulty accessing shielding letters and had to get friends and family to contact their GP for these. Our written evidence to the Senedd Equality, Local Government and Communities Committee **RD/3 - INQ000400648** features an email response from a Disabled member who told us that *"I did not get a shielding letter from my GP at first but my sister rang my GP surgery because she thinks I should be shielding officially. I have breathing problems, my windpipe is smaller than it used to be and I can't cough so the virus would probably affect me severely. I have received a shielding letter from my GP surgery now recommending I stay at home for the next 12 weeks"* (email edited for clarity), page 15.

47. We were also aware that communications regarding shielding were sometimes difficult for Disabled people to understand. On 1 June 2020, the Welsh Government updated the guidance on shielding to allow the shielding group to exercise and meet with others from another household, outdoors. DW was one of 32 signatories to write to the First Minister to raise concerns about the new guidance, produced as Exhibit [RD/12 – **INQ000400652**

48. The letter explains the confusing burden concerning the measure of 'reasonableness' that was to be applied. For people with learning disabilities, trying to understand the new guidelines and what measure of 'reasonableness' was appropriate in various factual contexts, was incredibly taxing. These issues are further described in *Shielding – how clear is it?* produced by our member organisation, Learning Disability Wales, Exhibit [RD/13– **INQ000400653**].

49. In the letter, we also described that the manner and timing of the shielding changes had led to confusion and anxiety. As a group of charities supporting many of those people who were shielding, we raised concerns that we had not been given advance notice of the guidance, which would have allowed us to provide information and support over the weekend.

50. In a Disability Equality Forum meeting held on 4 June 2020, Exhibit [RD/14 INQ000400622 I also raised concerns about the poor timing of the announcement of the 1 June Guidance changes as these had only been announced the day before, on Sunday 31 May. On the behalf of Disability Wales, I explained that the decision to announce the lift on restrictions on a Sunday resulted in many Disabled people being unable to contact their healthcare providers (see page 3). I also asked if there was any form of consultation or Equality Impact Assessment carried out. The CMO for Wales, Dr Frank Atherton, apologised for this omission and confirmed that Equality Impact Assessments should be incorporated into the next phase of recovery (see page 3).

51. At a separate meeting with myself and two WG officials on 8 June 2020, produced as Exhibit [RD/15 – INQ000282156 I was told that there would be further engagement with representatives of those Disabled people who are shielding in advance of the next Welsh Government review on 16 August.

52. However, there had been no contact with our member organisations by 23 June 2020 and so I raised this in a DEF meeting that day. NR from the Welsh Government confirmed that she was working with shielding officials on setting up a meeting and members would be notified of the arrangements shortly. As a result, consultation meetings took place and DW also had an opportunity to comment on the draft guidance which was to be sent to those who were shielding.

DW's Recommendations

53. In our view, the incorporation of the UN Convention on the Rights of Persons with Disabilities (UNCRDP) into Welsh and UK law is the essential foundation to address inequalities that Disabled people face. DW submits that many discriminatory practices and inequalities experienced by Disabled people during the pandemic may have been prevented if the UNCRPD had been incorporated into Welsh or UK law.

54. The UNCRPD comprehensively outlines Disabled people's healthcare rights. Article 25 states that people with disabilities have the right to enjoy the highest attainable standard of health without discrimination. This includes the

provision of health services needed by Disabled people specifically because of their impairments, and the requirement that health professionals provide care of the same quality to Disabled people as to others. Crucially in relation to the issue of DNAR orders, Article 25 prohibits the denial of treatment or the provision of life-saving materials, such as food or fluids, on the basis of disability. Yet without incorporation into law, these rights stand simply as aspirational ideals, rather than legal guarantees. Allied to this, we should not ignore the symbolism of incorporation. Law is a powerful symbolic tool - incorporation of the UNCRDP would send out the strongest possible message to health care workers, and Disabled people themselves, about the equal value of Disabled people's lives. This would therefore provide the best chance of life-saving treatment, such as resuscitation, not being withheld in a future pandemic.

55. Also in terms of impact, where international standards are embedded into a legal system it promotes better awareness and understanding of those rights, and greater attention to rights amongst politicians and law-makers. At a more granular level, legal duties lead to formal processes for confirming that rights have been taken into account in policy development. This is likely to ensure that crucial mechanisms for equality for those with protected characteristics, for example Equality Impact Assessments, are not forgotten or overlooked. DW has described in this statement that Equality Impact Assessments did not always occur when they should have during the pandemic, particularly when easing shielding provisions. Had the UNCRPD been incorporated into law before the pandemic, we submit these issues would have been less prevalent.

56. DW also submits that the utilisation and proper understanding of the social model of disability by medical professionals is paramount to improving the way that we identify individuals as 'high-risk' in a future pandemic. This is particularly crucial as Covid-19 and its variants are proving to be a feature of our lives and are likely to be for many years to come. It is important that the way that healthcare systems and policies approach 'risk' urgently modernises to include a social as well as medical context. For Disabled people to experience healthcare equality in a future pandemic, those working in the field must be trained in inclusive, consultive practice that puts 'nothing about us without us' and the social model at the front and centre of the approach.

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.

Personal Data

Signed…………………………………………………..

22nd January 2024

Dated…………………………………………………..