UK COVID-19 INQUIRY

WITNESS STATEMENT OF RHIAN DAVIES ON BEHALF OF DISABILITY WALES

Disability Wales

- 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 2B of the Covid-19 Public Inquiry.
- 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 to the UK Government on reserved matters, with the aim of informing and influencing policy. DW engages in member campaigns, consultations, research, and policy development in order to influence government policy and practice in respect of Disabled people. 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.
- 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. As Chief Executive, I am responsible for overseeing the pursuit of our core goal of influencing and informing Welsh and UK Government policy, as well as management and development within the organisation, including managing staff, financial resources and implementing work programmes. I am supported by numerous members of staff spanning a range of specialisms, including but not limited to policy, research and administration. DW's policy and programme manager, Miranda Evans, is responsible for delivering our Policy and Public Affairs Strategy. This includes our internal policy development, advocacy, campaigning and representation. Miranda leads on policy regarding Disability Equality and Disabled People's Human Rights. DW is also assisted in the pursuit of our primary goals by Megan Thomas, our Policy and Research Officer. Megan works towards effecting change in public policy and influencing policymakers through the development of strong evidence-based policy positions, as well as integrating policy positions with our influencing, campaigning and communications activity.

How DW identified and monitored impact during the pandemic

- 5. DW is an umbrella organisation for over 100 specialist member organisations and issues of significance in the lives of Disabled people during the pandemic were frequently brought to our attention by representatives of those organisations. DW also uses a variety of formal and informal methods to understand the perspective of Disabled people. These include online surveys, email circulars, focus groups on thematic issues, member events such as the Annual Conference, and encouraging engagement via videos and blogs. For example, on 11 May 2020, DW launched the #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.
- 6. During the pandemic DW distributed Covid-19 Emergency Grants on behalf of the National Emergency Trust and Welsh Government to DPO in Wales. These enabled grassroots DPO to provide information, advice and peer support to local Disabled people and provided a valuable source of intelligence regarding how the pandemic was impacting Disabled people and the role of DPO in tackling these issues.

- 7. Views and experiences are also gathered from various formal stakeholder meeting mechanisms, such as the Cross-Party Group on Disability and the Disability Equality Forum (DEF). The substance of these meetings will be analysed in detail in the chronology of significant meetings with the Welsh Government (WG) at paragraphs 24 to 85.
- 8. Between 2020 and 2022 DW conducted, or was commissioned to engage in, several research projects that acquired data on the direct and indirect impacts of the epidemic, and what we now understand as disproportionate, impact of Government countermeasures.
- 9. One research project commissioned by the WG to collate the experiences of Disabled people in the pandemic resulted in the July 2021 report; "Locked-out: liberating disabled people's live and rights in Wales and beyond COVID-19", or Locked-out', produced as Exhibit [RD/1 - INQ000400623]. The Locked-out report was Commissioned from the Disability Equality Forum by the Deputy Minister and Chief Whip Jane Hutt MS, and was written by Professor Debbie Foster in coproduction with a Steering Group of Disabled people and Disability Equality Forum representatives (Please see paragraphs 48 - 66). It describes how pre-existing socio-economic inequalities in society for Disabled people were amplified during the pandemic. The resulting experience for many Disabled people was poorer outcomes, and the sense that their lives were less valued by Welsh society. The key findings of the report are categorised into five key themes: the social model of disability; human rights; health and wellbeing; socio-economic disadvantages and exclusion, accessibility and citizenship. At the beginning of each of the five sections, a summary narrative, agreed by the Steering Group that produced the report, is provided. Key findings are then presented that distil the evidence and a comprehensive list of recommendations are then presented.
- 10. In December 2020 DW released our own report; Bring us our rights: disabled people's manifesto, produced as Exhibit [RD/2 INQ000400634], which relied on data from a survey issued between 20 August and 15 September 2020 that received 120 responses. We also ran nine themed focus groups 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, and was aimed at influencing party political manifestos ahead of the May 2021 Senedd Elections.

- 11. In July 2021, we contributed to an 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; produced as Exhibit [RD/3 INQ000400648]. Our response was informed by multiple focus groups of Disabled people, a survey on Lockdown Easing, a call for information via email, and the views of participants from our aforementioned #LockdownLife video series on social media. In total, our response was informed by the views of 134 Disabled people.
- 12. The first key finding of evidence that we submitted to the committee's Inquiry 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 made available by WG, such as Easy Read. There were also concerns about the negative impact of increased use of face masks on D/deaf people. The second key finding was that respondents felt that services provided by Local Authorities, which are essential to Disabled people, were denied as they were incorrectly deemed nonessential during NPI decision-making. This caused Disabled people to over-rely on voluntary support services. Thirdly, in relation to access to healthcare, there were three key themes. The first was the difficulties that Disabled people faced accessing communications regarding shielding. For example, one Disabled person 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. Disabled people also experienced difficulties attending medical appointments due to not feeling safe on public transport. There were also concerns from Disabled people who were shielding that there was not a sufficiently clear timeline for leaving lockdown. As such, many of those who were shielding were unsure of the rules. The fourth key finding 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 during lockdown measures. The report did however find that there were some positives to NPI measures, such as the practise of working from home.

Early communications to aid WG knowledge of the potential impacts of the pandemic

- 13. I do not recall being made aware of the existence of Covid-19 by WG and was first made aware of COVID-19 in news reports that began to emerge in January 2020. I was not generally aware of what WG had planned in terms of pandemic strategy, particularly in respect of Disabled people. I would draw attention to the issues that were raised in DW's Module 1 statement in this regard. The statement is publicly available on the Inquiry website with reference INQ000183426.
- 14. I was first contacted by WG on Covid-related matters via email on 17th March 2020; produced as Exhibit [RD/4 -INQ000400660]. This correspondence was received from
 NR
 DW's lead contact on Disability Policy in the Equality Branch. She contacted me about circulating messages to stakeholders in relation to Covid-19 and requested that I relay sector-specific messages to her for WG to promote.
- 15. NR informed me via further email correspondence on 19 March that the Communities Division of WG had set up a specialist Covid-19 response team; produced as Exhibit [RD/5 INQ000400699]. NR explained that the team would henceforth seek regular updates from stakeholders to ensure that WG stayed abreast of developments. She requested that DW contribute to the process by keeping the team updated in relation to Disabled people's primary concerns.
- 16. I responded to <u>NR</u> on 19 March, Exhibit [RD/5], in which I linked a public statement on COVID-19; Exhibit [RD/6 INQ000400710], that had been released by DW earlier that day. This was the first public statement in which we communicated as an organisation about the pandemic and the issues arising. The public statement called on WG to act decisively to safeguard the well-being and survival of Disabled people and others categorised as being at high risk of contracting the virus. We described our concern that necessary measures to minimise fatalities in these groups were not being taken. In particular, we were concerned about the lack of resilience in the NHS due to under-funding. We also noted that it was impossible for certain groups of Disabled people to follow [social distancing] guidance in circumstances where they required daily assistance from personal assistants (PA's) and urged the WG to act quickly to offer support for this group. Similarly, we expressed concern about what quality of care could be delivered when care workers went into isolation or became

sick. We suggested that both the UK and Welsh Government must urgently coordinate plans on how to respond to a shortage of care workers. The statement served a warning that Disabled people 'are likely to face harm not just through the Coronavirus itself but through the general strain on the health and social care system as well as wider societal barriers.'

- 17. In the body of the 19 March email, Exhibit [RD/5] I confirmed that I was happy to speak on a regular basis to the WG to share information. I also drew **NR** attention to a further six emerging issues; lack of accessible [public health] information in a range of formats, confusion about what is meant by the term 'self-isolation' and what constitutes 'underlying conditions' for the purposes of risk-categorisation, difficulties in accessing appointments in relation to the receipt of Universal Credit, concerns regarding the lack of financial support for those Disabled people who are self-employed, the cost of telephone calls to 111, and the heightened susceptibility of some Disabled people to scams and bogus offers of help. I also relayed information that many Disabled people were suffering food accessibility issues. This was because of a lack of access to food delivery websites and the scarcity of delivery slots.
- 18. The shielding programme in Wales started four days later, on 23 March 2020, with 86,000 people receiving a shielding letter on 24 March 2020. Those individuals who were categorised as clinically extremely vulnerable (CEV) were identified through a narrow range of clinical conditions which often excluded Disabled people who were equally unable to leave their homes to attend the supermarket due to reasons associated with their impairment(s). It is evident that DW forewarned WG about food accessibility issues prior to the development of protective measures which ensured food access for CEV individuals. It is less clear that this crucial issue for the excluded cohort of Disabled people was factored into decision-making because we had to make several further representations (detailed below) about this issue as the pandemic evolved.
- 19. NR responded by email on 23 March 2020 to confirm that weekly meetings would be arranged via telephone, e-mail, or video call, Exhibit [RD/5]. On the same date, DW issued a public statement to our members, produced as Exhibit [RD/7 INQ000400717], in which we confirmed that we were in regular contact with WG and

that members should feel free to contact us with questions or issues in respect of the pandemic so that we could reflect these to WG.

- 20. On 24 March 2020, I sent a further email to **NR** in which I clarified the emerging issues to date. I reiterated that accessing food was proving challenging for many Disabled people, for reasons of scarcity of delivery slots and digital exclusion. I also explained that many people with learning disabilities were struggling to know how to order food that would last them for a week or more. I further informed WG that many personal assistants were self-isolating, potentially unnecessarily, and this was leaving many families to manage alone. I called for tests to be made available with urgency, whether at home or via drive-through centres. I also warned that PPE was not routinely available to personal assistants and their employers; this email is produced as Exhibit [RD/8 INQ000400718].
- 21. In response to the representations in that email, **NR** responded on 25 March 2020 that she had raised the issues with the specialist COVID-19 response team, who would ensure they were followed up through the correct channels; produced as Exhibit [RD/8].
- 22. DW is not in possession of all the WG correspondence that would be necessary to confirm the extent to which our representations were followed through and we would be grateful if the Inquiry could obtain copies of emails which could confirm how our concerns were escalated. Many of the issues that were brought to the attention of WG by DW in the early stages of the pandemic persisted throughout the pandemic and DW made several further representations on the issues raised in the 24 March 2020 email which will be returned to later in this statement.

Chronology of significant meetings and arising communications with WG on the impacts of national NPI policy on Disabled people.

23. DW is a member of numerous platforms that we used to make representations to the Welsh Government during the relevant period.

Weekly Covid-19 Meetings

- 24. It has already been mentioned that weekly meetings were set up by DW's primary WG contact, **NR**. These meetings provided a channel to raise concerns highlighted by our members, which were then followed up by **NR** with colleagues in WG.
- 25. The meetings were usually conducted by Microsoft Teams with occasional telephone calls although NR expressed that she was happy to consult via email and video call as well. It was not expected that DW provide documents ahead of the meetings, nor did either party (WG and DW), set and distribute formal agendas ahead of the meetings. In terms of record-keeping, WG would take an official minute and DW representatives would take notes that were necessary as regards their own responsibilities. The meeting note would contain formal actions for WG and the meeting minutes would then be updated with a 'post meeting note' which indicated that an action had been completed (or not). I believe this overall format worked well for these meetings due to their high frequency and their particular purpose to discuss issues as they emerge. A flexible format was appropriate. It was useful to have a regular platform of our own so that our voice could be heard clearly. In terms of how the implications of the decision-makers, I provide further explanation below in respect of representations made in these meetings on the impacts of national NPI policy.
- 26. Weekly meetings commenced on 8 April 2020; produced as Exhibit [RD/9 **INQ000400719**]. In this meeting, in respect of NPI strategy, we informed WG that we were developing a video series (which became the #LockdownLife series) on issues that were arising as a result of Lockdown measures; coping with self-isolation, shopping for essentials, and the impacts of reduced access to carers. There were five formal topics under the banner 'Current Issues / Concerns', three of which related directly to social distancing strategy. Firstly, on the issue of 'access to care', I said [summarised]: "many members have had to suspend their carers or Personal Assistants (PA's) due to the COVID-19 restrictions around self-isolation and social distancing, and fears of using support workers who are visiting more than one person. Members are now reliant on family members. Parents of Disabled children

are finding it particularly difficult having to look after them 24 hours a day with no respite." Secondly, on the issue of 'access to food', I said [summarised]; "some disabled people have received letters from the Chief Medical Officer identifying them as being in the vulnerable or shielded category but others are having difficulty accessing groceries and essential items if they are not." Finally, on the issue of 'pregnancy', I said [summarised]; "DW have a member who is 32 weeks pregnant and has been informed that her partner can only be present for the birth and not during labour but due to her impairments she is reliant on constant support, she is anxious and fearful of the situation as she feels the maternity staff will not have the capacity to support her sufficiently so it would be beneficial for her partner to be with her throughout." In all cases, the resulting 'action' was that the issue would be passed onto the relevant WG department and as far as I understand this was usually done via email-communication. It would be useful for the relevant departments to disclose to the Inquiry all emails related to the onward progression of the issues once they were made aware of them.

- 27. At this meeting, I also reported on the potentially positive impact that could evolve from 'working from home' which was that, going forward, it should be easier for Disabled people to evidence to employers that reasonable adjustments such as these are justified.
- 28. On 19 May 2020, Exhibit [RD/10 INQINQ000400624], I received email correspondence from NR with two documents attached related to the subject "what supermarkets are offering during the current Covid-19 pandemic." NR stated that these were forwarded to her by **NR** i, in relation to *"our meeting a few* weeks back." Unfortunately, I do not possess the minutes for this meeting to exhibit, however I understand that **NR** had a role in the WG's 'non-shielding people and wider needs' workstream. The documents are 'FAQ for the Third Sector' and 'Information on Supermarkets'. The former document produced as Exhibit [RD/11 -INQ000400625] states that WG is "considering what further support may be required" for individuals who do not fall within the shielding cohort. The chapter on 'non-shielding people and wider needs' states that "If people don't have family, friends or neighbours who can help them and would like to have some support for shopping, collecting medicines etc, they can be directed to their local Community Voluntary Council or use other arrangements put in place by the local authority." The

Information on Supermarkets document produced as Exhibit [RD/12 – INQ000400626] reiterates that those who are 'vulnerable' but not shielding should "ask friends, family or neighbours who are well to go out and get food and other essentials or use online services. If this is not possible, then the public sector, business, charities, and the general public are gearing up to help." This document was circulated to DEF members by **NR** on the same date, Exhibit [RD/13 – INQ000400627]. Despite the efforts made, DW's view is that the excluded cohort of Disabled people would have been better served, and guaranteed access to food, had the shielding policy been developed with understanding of the social model of disability. As it was, many Disabled people were reliant on charity and the 'kindness of strangers' for basic rights such as access to food, help which they would have to 'ring around' and source themselves.

- 29. The 28 May 2020 meeting attendees discussed, amongst other matters, the subject of guidance relating to the Coronavirus Act 2020 and the Act's implications on social care. These issues will be examined further later in this statement. The minutes are produced as Exhibit [RD/14 INQ000400628]
- 30. The next meeting took place on 8 June 2020, the minutes of which are produced as Exhibit [RD/15 INQ000400629]. In terms of the impacts of NPI's, I was clear 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." It was noted that the issue was previously discussed at the DEF meeting held on 21 May 2020, the minutes of which are produced in the relevant chapter of this statement (see paragraph 55). As such, the issue had already been raised with the CMO, but
 NR responded that she would raise the issue of delayed medical treatment with the CMO's office again, 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 2020, produced as Exhibit [RD/16 INQ000400630], nor in any subsequent meetings.
- 31. At the 24 June 2020 weekly meeting DW also communicated key points from two focus groups that we had conducted on the issues of Equality and Human Rights and

Employment and geared towards capturing the views of Disabled people on the lifting of Lockdown restrictions. Ten people attended each event, and the issues raised, as stated in the minutes, included "*isolation, not accessing services, there's an assumption of reliance on community services, wheelchair / motorised bed breakdowns not deemed a priority. Also social distancing in the environment, disabled people are not being taken into account – no availability of seating areas while queuing at supermarkets, etc.*" In relation to employment, we relayed concern from the participants that policy will focus on younger people, and the fear that they as Disabled people would not be able to get back into the job market. Participants called for work and employment programmes to span across all age groups and to be inclusive of Disabled people.

32. The subject of access to supermarkets/food arose again at the 24 June 2020 meeting. **NR** explained that **NR** from the "non-shielding vulnerable people" team had asked for feedback on issues for people with hidden impairments accessing supermarkets. I confirmed this was a question in a survey that DW was running until the end of the month and so more information would be available once the results had been collated.

Ad-Hoc Meetings

33. DW was able to engage in the occasional ad-hoc meeting with WG to alert them to specific issues. We met with WG on 22 April 2020 to discuss 'Access to Shopping'; produced as Exhibit [RD/17 – INQ000400631]. At the meeting, my colleague Miranda Evans and I explained why social distancing and shielding strategy was affecting the ability of Disabled people to access food. We explained, as we had explained in early communications with NR in March 2020, that there was a wider group who were not on the shielded patient list but who also could not go food shopping due to reasons associated with their impairments. I gave the example that visually impaired people rely on being close to people to lead the way (and they cannot necessarily do this is a social distancing context). These individuals had to rely on online shopping but were often unable to book delivery slots. I suggested that digital exclusion plays a significant role. For example, several local businesses were offering fruit and vegetable deliveries, however an individual needs to have access to social media to

be aware of them. I said [summarized]; "the whole of society is now online so [there is] an even bigger gulf between those who have the skills and those who don't."

- 34. The WG official at the meeting said that WG was "being active on this" but admitted that "people who previously shopped online are finding it easier but not those who would usually visit." This individual then confirmed that the "message is if you're not able to do it yourself can friends, family help." DW's view was that the problem with this 'message' is that it did not consider the people who do not have anyone to rely on in this way and it treated Disabled people as an afterthought.
- 35. There may have been other ad-hoc meetings that could be described as 'significant' in terms of representations made by DW on issues related to NPI strategy. I will be able to expand further on meeting minutes should the Inquiry present me with any. I do not hold all the records for all such meetings and would invite the Inquiry to obtain them from WG.
- 36. DW also provided advice in the relevant period, on an ad-hoc basis, to WG groups such as the Active Travel Board and the Accessible Information Group, and I would encourage the Inquiry to disclose the minutes of the meetings. I understand from the minutes provided for the 28 May 2020 'COVID-19 Weekly Meeting' [RD/14], that, on 14 May 2020, I had attended an Active Travel Board Meeting to raise concerns about the implications of the current exercise guidelines for electric wheelchair / scooter users and people with hidden impairments. At that meeting, it was acknowledged that inclusive language had been overlooked and officials from Public Health said they would be in touch to discuss further. On 1 June 2020 I received email , produced as Exhibit [RD/17A - INQ000409056], as correspondence from NR we had agreed that she would follow-up my concerns with Neil Surman and **NR** NR in the Active Travel Board team. She informed me that the guidance had changed from "staying home" to "staying local" and she expressed hope that the changes covered the concerns I had raised about motorised wheelchairs and scooters. On the same date, I responded that I would examine the guidance. I also stated that; "[1] Think that the Accessible Info Group will have a role to play in promoting inclusive language and images to be used with comms as regulations are updated. Talking of which, the surprise announcement yesterday about lifting some restrictions on people who are shielding has caused considerable consternation. This

has been as much about how it was done (on a Sunday, without warning, access to info & support) as well as concerns about the appropriateness of the changes (the science behind it and relevance re all conditions). We share the view of many that a more holistic approach is required regarding supporting individuals at particular risk as lockdown is phased out which should involve them and their representatives in both shaping and communicating about developments." The issues related to this Welsh Government announcement are explained further in this statement (please see paragraphs 56 - 58).

- 37. I also attended a Third Sector Partnership Council meeting held on 2 July 2020 on various topics, particularly Covid-19 recovery, citizen engagement and resilient communities; produced as Exhibit [RD/18 INQ000179713]. In the meeting, I presented a joint segment on 'inequalities' with Catherine Fookes from the Women's Equality Network Wales. It was discussed that COVID-19 has exacerbated inequalities for specific groups such as women, Disabled people, people from ethnic minorities, and LGBT+ people.
- 38. In terms of ad-hoc communications, I had informal telephone conversations with the Specialist Policy Advisor on Disability, Jon Luxton, but not with any other officials or Ministers. WhatsApp messages were not used.

Covid-19 Moral and Ethical Advisory Group (CMEAG)

- 39. The background to the convening of the Moral and Ethical Advisory Group relates to the issue of unlawful DNAR notices.
- 40. By way of context, 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/19 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, [Exhibit RD/3], 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 on 8 April 2020 addressed to the Chief Medical Officer for Wales, which I produce as Exhibit [RD/20 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/21 -INQ000400636]. The head of complex and unscheduled care for Disabled people at WG. NR also wrote to Learning Disability Wales on 4 May 2020 to confirm that WG was committed to ensuring at-risk and vulnerable people had the support they need. He said that Local Authorities and third sector and community organisations were best placed to provide this support. He said that, to assist Local Authorities, the Minister for Health and Social Services Vaughan Gething announced an additional £40 million to support adult social care in Wales and there was also a package of support for the Third Sector – produced as Exhibit [RD/22 – INQ000400637].

- 44. Most significantly, WG convened CMEAG in April 2020 to provide a framework for ethical decision-making in healthcare. Members convened monthly for two years from April 2020. The Terms of Reference for the CMEAG group is available at [RD/23 – INQ000400638]. The minutes for CMEAG meetings in April 2020 are publicly available at [COVID-19 Moral and Ethical Advisory Group Wales meetings] GOV.WALES]. The meetings were Chaired by Dr Heather Payne from WG Health division. The agendas and draft papers were circulated via email, often at short notice before each meeting. There was a wide range of stakeholders from the third sector in attendance, as well as faith organisations and public sector individuals, including senior healthcare practitioners. Representatives who were leading on relevant issues, for example from WG or Public Health Wales, would introduce the topic and then take feedback from members. These included issues related to shielding, vaccinations and moral distress, and many other issues. At the meeting on 23 April 2020 it "was agreed that national clinical ethics support is needed, building a Wales wide framework bringing together expertise from current committees rather than a separate new structure."
- 45. 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/24 INQ000400639]. Our role was to contribute further information and resources on ethical care. The public statement 'Covid-19 and the rights of Disabled people in Wales' 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/25 INQ INQ000400640]. This indicates the importance and influence of the public statement.

Cross-Party Group on Disability (CPG)

46. On 2 July 2020 DW co-organised a meeting between the Senedd CPG on Disability and Disabled individuals so that they could give lived-experience evidence on the wide-ranging impacts of COVID-19 directly to WG officials, produced as Exhibit [RD/26 – INQ000400642]. The meeting was chaired by Mark Isherwood MS and attended by the Deputy Minister and Chief Whip Jane Hutt MS.

47. At this meeting, Disabled contributors raised several issues that they were experiencing arising from the NPI strategy being implemented in Wales. One participant spoke about the difficulties experienced by people with sight loss during the Covid-19 pandemic as a result of social distancing. This participant also raised that vision impaired people were feeling increasingly lonely and isolated because of the lack of access to Rehabilitation Officers (for further detail on this issue see paragraph 97 below). Another participant who has a hearing impairment shared their experience of face mask policy. This person was very isolated at work because, as a lip reader, she was unable to communicate with others during her break. This person also faced discrimination when shopping, because shop staff were unwilling to drop their masks to enable lip-reading, and they had also refused to write messages down on paper. There was also an experience shared regarding the widespread use of 'remote appointments' as an infection control measure. The reduction in person-toperson contact presented communication challenges for many Disabled people, which in turn affected their ability to access care. In this case, 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.

Disability Equality Forum (DEF)

- 48. Before the pandemic, DEF was convened two or three times per year. However, between 16 April 2020 and 29 July 2020, we convened 5 times to discuss pandemic-related agenda items, where senior Welsh Government officials, such as the Welsh CMO, provided updates and invited feedback from members to inform relevant policy.
- 49. The meetings were conducted by video link and the formal agenda was circulated ahead of the meetings by WG. There was an opportunity for Forum members to

feedback on the agenda and if there were any omissions or suggestions, a revised agenda would be circulated. Documents were frequently shared before and after meetings, and the WG representative who was responsible for liaising with the DEF members would sometimes circulate ad-hoc information and updates with regards to the WG response, with a request that we share these amongst our networks, for example – see email produced as Exhibit [RD/27 – INQ000400643] and associated attachments; 'Newyddion Coronafeirws COVID-19' (Welsh Government Coronavirus bulletin), produced as Exhibit [RD/27A INQ000400644], and the English language version of that document, produced as Exhibit [RD/27B – INQ000409057].

- 50. In some cases, there were diverging views because barriers are encountered by Disabled people in different ways, depending on the nature of the impairment. For example, some Disabled people found mask wearing a barrier to communication, whilst others found that it contributed to feeling safe when in public or being supported by a PA or Care Worker. However, efforts were made to ensure DEF was an equal platform for all views. In terms of record-keeping, formal minutes were taken by WG officials. I found that the minutes usually reflected DW's views accurately. I also kept a personal written note, and in some cases, I shared this note internally with DW colleagues.
- 51. At DEF, I alongside representatives of DW's member organisations contributed details regarding the impact of NPIs on Disabled people on behalf of DW on several occasions.
- 52. At the 16 April 2020 meeting, produced as Exhibit [RD/28 INQ000400646] the social care implications of the Coronavirus Act 2020 and a related consultation were discussed, which will be discussed in the Coronavirus Act 2020 chapter of this statement (see paragraphs 87-104). The first action in the meeting related to the issue of access to food/shopping; the action stated that issues related to priority online shopping and accessible information would be raised with the relevant policy officials. The action was subsequently positively updated. In advance of the next meeting, the Deputy Minister and Chief Whip (DMCW) asked members to consider suggestions on what could be important to inform next steps to recovery. The agenda for the meeting is produced as Exhibit [RD/29 INQ000400647]. It is also worth noting that I thanked Ministers and officials for engaging with the Forum; I said the opportunity was vital to

ensure the Welsh Government heard the direct voice of Disabled people and had a feel for what was happening on the ground. I noted the DEF also provided a monitoring and accountability mechanism.

- 53. I will return to the issue of accountability as regards whether I consider that WG has taken adequate steps to address issues raised in DEF meetings and the *Locked-out*' report; see paragraphs 65-66.
- 54. At the 30 April 2020 meeting, produced as Exhibit [RD/30 INQ000400649, we also discussed the social care implications of the Coronavirus Act 2020 and consultation on Guidance [Agenda Item 3]. In discussion of agenda point 5, easement and preparation for the future, we discussed the recently published 'Leading Wales out of the coronavirus pandemic: a framework for recovery' document. Zoe Richards of Learning Disability Wales, a DW specialist member organisation, explained how they ran an employment programme for young people with learning disabilities and autism and were very aware that the landscape of employment was going to be very different [post-lockdown]. For my part, as part of agenda Item 6, I said it was vital that we ensured that the needs of Disabled women were considered in the development of plans to tackle domestic abuse during the Covid-19 pandemic and beyond because they are more at risk. I was aware that domestic abuse, particularly rising levels as a result of lockdown measures, was receiving greater attention, however I was keen to ensure that "all messaging included disabled people and that information was in accessible formats or there was a risk people would not know the message was for them. Many did not know they were being abused, their impairment could be used against them and some needed personal support from their partner who was also their abuser. It was also important for strong messages to be issued against perpetrators including signposting them to support organisations..." [para 6.2]. 'Action Point 9' stated that VAWDASV (Violence Against Women, Domestic Abuse and Sexual Violence) officials should liaise with me outside of the meeting to address WG messaging on this issue. On 11 May 2020, I was contacted by a WG senior policy manager in this area regarding the communications campaign; 'home shouldn't be a place of fear' - this email is produced as Exhibit [RD/30A - INQ000409058]. She informed me that she understood that the communications campaign was discussed at the recent Disability Equality Forum. She confirmed that the campaign's first aim was to "ensure that the messages were suitable for all, for any gender, any age, any

type of relationship, any race or for those with or without health conditions/disabilities" but that as the campaign progressed, there would be "some opportunity to be more targeted on messages, but our overall aim ... is that as many people as possible across Wales could see the message and feel it resonates with them." She said she would be happy to nominate me or a colleague from DW to the group to be involved in the development of the communications. I directed this invite to my colleague Miranda Evans, who subsequently attended two of the VAWDASV Communication Group meetings. However due to clashes with other commitments Miranda could not join regularly. We are not aware of any specific disability-related communication material being published.

- 55. At the 21 May 2020 meeting, minutes produced as Exhibit [RD/31 INQ000400650], concerns were raised about the suspension of needs assessments for people with vision impairments. At that meeting, I also emphasised the importance of digital inclusion for combatting social isolation and keeping mentally healthy in the context of social distancing. The agenda for the meeting is produced as Exhibit [RD/32 INQ000400651].
- 56. At the meeting on 4 June 2020, minutes produced as Exhibit [RD/33 -INQ000400622], 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. There were two reasons that I submitted this view on behalf of DW. As an organisation, we were aware that communications regarding shielding were sometimes difficult for Disabled people to understand. On 1 June 2020, three days prior to this DEF meeting, WG had 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, letter produced as Exhibit [RD/34 - INQ000400652]. The letter explained 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 were further described in 'Shielding how clear is it?' produced by our member organisation, Learning Disability Wales, Exhibit [RD/35 - INQ000400653].

- 57. 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.
- 58. In the DEF held on 4 June 2020, [RD/33], I described the poor timing of the announcement of the 1 June 2020 Guidance changes. The announcement had occurred the day before the guidance changes, on Sunday 31 May 2020. On behalf of DW, I explained that the decision to announce the lifting of restrictions on a Sunday resulted in many Disabled people being unable to contact their healthcare providers. 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.
- 59. At the 'Weekly Covid-19 Meeting' held on 8 June 2020, [RD/15], I was told that there would be further engagement with representatives of those Disabled people who were shielding in advance of the next Welsh Government review on 16 August 2020. However, there had been no contact with our member organisations by 23 June 2020 and so I raised this in the DEF meeting that day; produced as Exhibit [RD/36 INQ000400654]. 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. We received a copy of the guidance and we felt it had incorporated our concerns.
- 60. Prior to the DEF meeting on 23 June 2020, the agenda of which is produced as Exhibit [RD/36A INQ000400655], Welsh Government's Specialist Policy Advisor, Jon Luxton, discussed with me informally via telephone the need to put something in place that could reinvigorate the Disabled People's Movement in Wales post-pandemic. The lack of strong, grass roots DPOs in Wales with a clear disability rights focus has long been an issue in Wales. The majority of DPOs are volunteer run with limited funding and reliant on a small number of dedicated activists. At the meeting on

23 June 2020 [RD/36], following discussion around Agenda Item 3: future development of the Disabled people's movement, the Deputy Minister and Chief Whip asked Jon Luxton to work with me on collating evidence on the impact of Covid-19 on Disabled people on behalf of the Forum [Action Point 4]. The evidence that we collated via the Steering Group that was convened for this purpose eventually became the '*Locked-out* report'.

61. In the 23 June 2020 meeting [RD/36], members engaged in a thorough discussion of agenda item 1; the use of face coverings. There was a desire to have clear face masks [for the purposes of lip-reading] and the DCMO confirmed that, of the 260,000 masks available for UK medical settings, it was anticipated that Wales would receive a proportionate share of this, around 13,000. I also commented on an action from the previous meeting, which was for officials from the Shielding Branch to engage with Forum members in the lead up to the next review in Wales on 16 August 2020, but I said that members had yet to be contacted. A WG official confirmed that she was working with shielding officials on setting up this meeting and members would be notified of the arrangements shortly. The DMCO agreed it was important that this engagement happens. On 22 July 2020, I was CC'd into an email response from Jody Mellor to a consultation request issued by a WG shielding official. The email request, which was sent on 21 July, read; "Thank you so much for agreeing to be part of our small stakeholder group which takes a look at the CMO letter for us. I'm sorry about the very short turnaround but I am looking for reflections by noon tomorrow (22nd July) if at all possible please. This is not the final version and is subject to change as it has not yet been signed off by the CMO In case it helps as you are considering the letter: I do intend to publish this letter, unlike previous letters; I will ensure easy read and audio versions are available on the website; Ideally it shouldn't get any longer – if there is something new to go in, could we take anything else out?; Feel free to suggest what other support we need to provide in additional to the letter – e.g. support materials on the web, if you wish." In the email response that I was copied into, Jody Mellor thanked the official for sending the CMO letter for consideration and stated that she had no suggested changes to the letter. I had delegated this task to Jody as, in addition to her professional knowledge, she had direct experience on this issue. These emails are produced as Exhibit [RD/36C- INQ000409061] and the draft CMO letter is produced as Exhibit [RD/36B - INQ000409062].

- 62. I was not in attendance at the meeting on the 29 July 2020 which was attended by one of my colleagues, minutes produced as Exhibit [RD/37 INQ000400656], but I understand that the 'End of Shielding' was discussed and members raised concerns about how Disabled people who had been shielding would cope with this transition. The agenda for this meeting is produced as Exhibit [RD/37A INQ000400657].
- 63. On 21 October 2020, DEF convened to discuss the development of the COVID-19 Impact Report, the National COVID-19 Firebreak, Advice for people on the Shielded Patient List, and Schedule 12 of the Coronavirus Act 2020 and the Covid-19 Vaccination programme. The agenda is produced as Exhibit [RD/38 –INQ000400658] and the minutes, produced as Exhibit [RD/38A – **INQ000409063**]. The minutes reflect that I expressed thanks for the invitation to co-ordinate an impact report (which became the *Locked-out* report). I also raised the development of the Steering Group, which is discussed in greater detail in paragraphs 67-73. Comments on impacts and areas of concern for members of the Forum included:
 - The lack of accessibility of Covid-19 tests, difficulties experienced by those with sight loss in maintaining social distance, and adapting to the increase in street furniture, barriers and new cycling lanes.
 - Local Authority implementation of the guidance on creating safer public spaces needs to be Equality Impact Assessed.
 - The importance of communication and co-production between planning teams and people with lived experience e.g. on active travel initiatives.
 - Different interpretations of "active" the term has different implications for people who cannot cycle, and those for whom being active might require support from others, e.g. sighted guides to go out walking.
 - The need to apply the social model to the concept of active travel so that it begins to work for Disabled people and does not exclude them.
 - The need to explain rules more clearly, a bigger emphasis on mental health during this time and a need to consider the needs of those with learning difficulties.
 - Lockdown has compounded mental health issues for some people who would otherwise be able to manage without intervention.

The usual support mechanisms and daily strategies for managing mental health are now difficult to access.

- 64. In respect of the shielding letter that was to be issued by the CMO for Wales, a representative from Wales Council of the Blind, a DW member, stated that the organisation was producing accessible information about the Fire Break, and was trying to share this with as many blind and visually impaired people as possible. The DMCW asked DW to share this accessible information with WG officials.
- 65. In overview, I believe that that the WG resolved to set up an evidence-based impact enquiry (which became the 'Locked-out report) because of a growing realisation that many of the negative impacts being experienced were indirect rather than direct, in the sense that they were the result of policies rather than the disease itself. I believe that DEF was paramount to this shift in perspective. Indeed Jane Hutt MS, the Chair of the Disability Equality Forum, at a session of the Equality, Local Government and Communities Committee as early as 14 May 2020; produced as Exhibit [RD/39 -INQ000400659, said that; "I would have to say that this [unequal impacts] isn't just about the impact of COVID-19 in terms of infection and the disease, it's also about the impact of lockdown as well. Because, actually, one of the first groups that I met with was the disability equality forum...." She goes onto say that members of the forum wanted to "participate fully in any discussions or any decisions about policy" [page 9]. I believe that the 23 June 2020 DEF meeting [RD/36] on the future development of the Disabled people's movement was particularly integral to the WG decision, as the discussion was inspiring and challenged WG to take decisive action.
- 66. The *Locked-out* report was commissioned because of the serious nature of representations made by Disabled people and DPO members at DEF meetings. Although this does show accountability, in light of data about the disproportionate mortality experienced by Disabled people in Wales which has emerged since, I believe that commissioning an evidence report is a basic obligation. Indeed, the commission came after many Disabled people had lost their lives. A report published by WG on 11 March 2021; '*Coronavirus (COVID-19) and the impact on disabled people*', produced as Exhibit [RD/40 INQ000400661], cites many of these damning statistics. The 11 March 2021 report was published ahead of the *Locked-out* report to contribute and support the work of the DEF Steering Group and summarises the analyses available to the Steering Group up to 18 February 2021. It points, on page

17, to ONS statistics published on 11 February 2021 concerning the period 20 January 2020 to November 2020 about the increased risk of COVID-related death for Disabled people in England (3.1 times greater for men and 3.5 times greater for women). The analysis in the report states "that no single factor explains the considerably raised risk of death involving COVID-19 among disabled people, and place of residence, socio-economic and geographical circumstances, and pre-existing health conditions all play a part... an important part of the raised risk is because disabled people are disproportionately exposed to a range of generally disadvantageous circumstances compared with non-disabled people." As the contributing factors to the disproportionate mortality that Disabled people experienced are wide-ranging, a truly accountable response must be equally so. It is important that the response is structural rather than, for example, relying on WG officials relaying messages from department to department. That is why I agree in part with Jon Luxton's position that DEF played a crucial role in ensuring that important decisions made by Ministers were informed by the experience of Disabled people. I believe that DEF made a vital contribution to the principle of co-production which is core to the mission of DPOs. It enabled us to share two-way information and enabled access to Ministers and senior officials, such as the CMO. Meetings were conducted in a way which supported participation including from people with lived experience and enabled members to put challenging questions and comments to decision makers. Notwithstanding this high-level engagement, the way in which policy decisions were implemented by local authorities and agencies was inconsistent and excluding, if not discriminatory, of Disabled people throughout the relevant period. The scale of the crisis that was experienced by Disabled people requires institutional reform before the next pandemic and cannot rely on platforms of engagement such as DEF alone.

DEF Steering Group

67. I was the chair of the Steering Group which was convened in October 2021 as a platform to develop primary and secondary evidence for the *'Locked-out'* report that was commissioned by WG as a result of representations made in DEF meetings. The Steering Group met 6 times between 5 October 2020 and 16 January 2021. In total, the Steering Group gathered over 300 items of written evidence including secondary research and data analysis.

- 68. The format and mechanics of the DEF Steering Group were similar to the DEF meetings (see paragraph 49). However, as Chair, I was responsible for devising the agendas ahead of the meetings (alongside Professor Debbie Foster), rather than the WG.
- 69. Prior to the first Steering Group meeting, I met with the leading academic on the report, Professor Debbie Foster, with Jon Luxton from WG, and with five further Welsh Government officials on 16 September 2020; the minutes are produced as Exhibit [RD/41 - INQ000400662]. The meeting was specifically arranged to discuss arrangements for the production of "the evidence paper" which became the Lockedout report. We discussed the specifics of the remit of the report. The meeting also featured an update from WG official NR who had a role in gathering and collating data on COVID-19 and Disabled people for use in the report. He stated that there had been 23 information sources added to a lengthy document that he was developing called 'Potential impact of COVID-19 on Disabled People'; produced as Exhibit [RD/42 - INQ000400663]. The document contains over one hundred sources and the third column in the table analyses their key findings in respect of Covid-19 and Disabled people. The meeting minutes state that "these new sources include evidence from the DEF. Prof Foster's call to academics and new information in the NR WG's equalities repository." Action 1 in the meeting minutes states that should produce an updated key themes document to reflect additional information sources, by 23 September 2020, and thereafter I should share the document with DEF members. That document, produced as Exhibit [RD/43 -INQ INQ000400664], collates salient issues under the following key themes: education, work, living standard, health & social care, justice and participation.
- 70. In an email dated 5 October 2020, I sent the documents referenced above to DEF members as agreed; email produced as Exhibit [RD/44 INQ000400665]. I also sent the minutes of the 16 September 2020 meeting and an informal agenda, non-exhaustive, for the first DEF Steering Group that was due to take place later that day. Although I did not state it in the email, Steering Group members were aware that they could contribute ideas for agenda items for discussion at the meetings.
- 71. The Steering Group included several representatives of Disabled People's Organisations in Wales, as well as WG representatives who oversaw the process.

Prior to the first meeting in October, Disability Equality Forum members nominated individuals to sit on the Steering Group. On 25 September 2020 I sent an email to DEF members for nominations. There were three criteria: the Group should be led by Disabled people, there should be representation across impairment groups, and they should be committed to fortnightly meetings throughout Autumn; email produced as Exhibit [RD/45 – INQ000400682].

- 72. The first meeting took place on 5 October 2020, the minutes of which are produced as Exhibit [RD/46 INQ000400695]. We discussed group nominations and opportunities to integrate intersectional perspectives. Indeed, we held a focus group on 17 December 2020 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 are produced as Exhibit [RD/47– INQ000400696]. Black, Asian and minority ethnic Disabled people reported that they experienced unique challenges during the relevant period in relation to their experience of Covid-19 and related WG measures.
- 73. In the next meeting on 23 October 2020, some of the major topics discussed in relation to the impacts of NPI strategy were; awareness of evidence gaps, delayed medical treatments, work issues such as furlough, statistics around critical care workers, difficulties accessing food/shopping and the necessity of the social model of disability - [RD/48 - INQ000400697]. The major topics discussed at the meeting on 6 November 2020 were Black, Asian and Minority Ethnic representation, addressing evidence gaps, human rights, impacts of socio-economic factors on outcomes, issues related to pregnant disabled women, and the timeline for producing and drafting the report - [RD/49 - INQ000400698]. The major topics discussed at the meeting on 20 November 2020 were intersectionality, evidence gaps, statistics and drafting, vaccine decision-making, social care guidance and schedule 12 of the Coronavirus Act -Exhibit [RD/50 – INQ000400700]. The major topics discussed at the meeting on 14 December 2020 were changes to the Mental Health Act, evidence gaps, a health and wellbeing chapter, health policy recommendations and disproportionate mortality – Exhibit [RD/51 – INQ000400701]. The major topics discussed at the meeting on 19 January 2021 were adult social care, intersectionality, statistics, maternity leave, housing issues and Equality Impact Assessments, human rights, upskilling and

reskilling and employment issues. All of the aforementioned themes went on to be evidence in the *Locked-out* report.

Meetings in 2021

- 74. During the course of the Pandemic the frequency of meetings reduced over time.
- 75. On 2 February 2021; I updated WG officials on how well the [draft] Locked-out report had been received by DEF members; produced as Exhibit [RD/52 - INQ000400702 It was noted that I was soon due to meet Steering Group members Professor Debbie Foster, Jon Luxton, and Natasha Hirst to review a new draft of the paper incorporating the Forum's views. At that meeting, we were also due to discuss categorising the report recommendations into short, medium and longer term. We also discussed an action from the last meeting on 12 January 2021 which was for WG to investigate setting up a meeting between DW officials and the relevant WG official regarding social model language in the media. It was noted that this had been 'chased' twice [i.e. no response was yet forthcoming from WG]. It was acknowledged that if this meeting were to occur, it could "action one of the recommendations in the Covid-19 impacts paper regarding the media." In respect of the matters that concern this statement, I relayed the concerns of many members who were being refused entry to shops and public transport without face masks, despite being exempt. Some were also experiencing abuse and harassment as a result. I asked whether messaging by WG could be clearer on mask exemptions. A WG official asked me to compile these concerns into an email in order to send on to relevant colleagues within WG.
- 76. On 15 February 2021, I sent email correspondence to the relevant official in which I collated the following anonymised incidents produced as Exhibit [RD/52A INQ000409064]. I cannot verify these as they were collected as informal testimony, however they indicate widespread discrimination and harassment of people whose impairment prevented them from wearing a mask (the following is quoted);

- Disabled shopper refused services and expelled from supermarket because he wasn't wearing a mask. He said he was exempt and tried to show an exemption card, the card was dismissed as 'fake news'.
- Another man informed at supermarket as above that he must wear a mask. Wears
 mask but needs to remove it as [he] cannot breathe, told they are not accepting
 exemption cards so he must leave the shop.
- Woman experienced nasty comments from public when she went to supermarket but also heard talking about people who 'fake' illness to avoid wearing a mask.
- Disabled Veteran, one of whose conditions means he can't wear a mask, has an exemption card and lanyard, was subject to nasty and pointed discrimination at a shop due to not wearing a mask.
- Man denied entry to supermarket as not wearing [a] mask, told worker he is exempt, worker told him to 'find someone to shop for him' if he can't wear a mask.
- Man denied entry to 3 organisations despite being exempt from wearing a mask.
- Poster displayed at local society in Treorchy stating that masks must be worn, 'if you are exempt, don't come in.'
- Refused entry to bus twice by same driver for not wearing a mask. Driverrefused to accept the lady was exempt.
- 77. In this 15 February 2021 email, I stated that, as well as reviewing the guidance, producing appropriate public messaging about this issue would help tackle the problem.

The Disability Rights Taskforce (DRTF) and Prioritisation Working Group (PWG)

- 78. I have previously mentioned that my expectation during the relevant period was that the DEF meetings, and subsequently the DEF Steering Group meetings, would be a valuable instrument to engage the WG on issues impacting Disabled people and therefore a valuable tool for its accountability. However, the extent to which recommendations have been implemented is unclear.
- 79. The DEF Steering Group presented the *Locked-out* report to the First Minister Mark Drakeford MS in March 2021, prior to the report's publication in July 2021. Ministerial advice was issued on 25 June 2021 for the First Minister to agree to the

formation of a Disability Rights Task Force which would consider the report recommendations and draft an Action Plan to address these; Exhibit [RD/53 – **INQ000400703**]. The Advice accurately stated that the DRTF wished to "oversee the development of an action plan... in line with [their] wish that the report's recommendations are not seen as fixed, but rather as the beginning of a wider conversation across all government departments and involving a range of partners and delivery organisations." Such a conversation would centre on Disabled people and therefore make the social model of disability "the organising principle for action." The Advice also stated that the DRTF should be constituted by members of DEF and the DEF Steering group. This is how I came to be nominated as a representative of DW.

- 80. The formal Terms of Reference for the DRTF are produced as Exhibit [RD/54 INQ INQ000409078]. The document state that the First Minister committed to establishing a Disability Rights Taskforce for Wales in the new Senedd term. The Taskforce would consider the findings and recommendations of the *Locked-out* report, as well as other relevant data and evidence, and oversee the development of an action plan to roll back the damaging effects of the Covid-19 pandemic on Disabled people. The remit of the taskforce includes; "to develop and populate a Disability Rights Action Plan derived from the report's recommendations, consultation responses, Taskforce proposals and wider engagement. The Action Plan would include timescales for implementation and lead responsibility, enabling progress-monitoring, accountability, and evaluation."
- 81. The WG response to the *Locked-out* report was released on the same date of the report on 2 July 2021, Exhibited as [RD/55 **INQ000400705**] It confirmed that the First Minister had agreed to establish a Minister-led Taskforce to take forward work to address the inequalities highlighted by the report and to oversee the implementation of actions. The report stated that the "undeniable impacts" that were represented in the report were recognised, and delivered a progress update on the overarching themes in the report; the social model of disability, human rights, health and well-being, socioeconomic disadvantages, and exclusion, accessibility & citizenship.

- 82. At the inaugural meeting of the DRTF on 18 November 2021, produced as Exhibit [RD/56 – INQ000400706], the First Minister responded to the primary recommendation of the Locked-out report, which was, fundamentally, the integration of the social model of disability into political decision-making and the total rejection of the medical model of disability. He said that the social model should be "re-asserted and embedded into all of the work of the Taskforce." He then went on to discuss the "collective goal of co-producing the Disability Rights Action Plan" and lay out the key tasks moving forward. At this time in November 2021, my understanding was that the DRTF would produce the draft of the Action Plan within about 18 months. A Secretariat was set up to support the development of this draft, however it operated with only half the posts filled until Autumn 2023. As it stands, the draft Disability Rights Action Plan, which is the culmination of all the work from the Locked-out report, various thematic Working Groups and DEF and DEF Steering Group meetings, does not have a scheduled date in place for consultation. Further, an official has confirmed with me in person that she is unable to confirm when the draft will be ready for consultation. I discuss the reasons for this delay further in paragraph 85, but I suspect that the draft will not be published and ready for consultation until later in 2024.
- 83. The next meeting that I recall I attended in relation to implementing the recommendations of the *Locked-out* report was on 20 January 2022, as part of the membership of the 'Prioritisation Working Group'; Exhibit [RD/57 INQ000400707], which on this occasion decided the prioritisation of topics for the next DRTF. We discussed a diverse range of topics, such as access and citizenship issues. Specifically in terms of implementation, I asserted the need for WG policy leads to be involved. I relayed that the priorities identified in the previous meeting were: housing, transport and accessibility (to services and including communications). The Prioritisation Working Group noted the Taskforce would need to understand where there were already working groups in place which could input to the vision for the Taskforce. For prioritising work, it was confirmed that WG officials [not necessarily policy leads] would engage with colleagues across WG on work that had been identified from this meeting and the meeting on 18 November 2021 collectively were: Access to services (including accessible communications); affordable and

accessible housing; embedding and understanding of the social model of disability across Wales; employment & income; travel; children and young people and health, wellbeing and social care. This priority work programme was reflected in the next DRTF meeting on 3 February 2022, Produced as Exhibit [RD/58 – INQ000400708]

- 84. In the next meeting on 14 February 2022, Exhibit [RD/59- INQ000400709] we were told that; "Welsh Government recognises that having reliable and useable evidence is essential to understand the systemic inequalities citizens in Wales face and addressing the often-deep-rooted issues which adversely impact those with protected characteristics. Data often hides distinct and unique differences between minority identities and where there is intersectionality between two or more characteristics. We understand there is a need to ensure evidence truly reflects the lived experiences of the groups it is aiming to capture." As a result, WG has established three distinct units, each with their own evidence programme and lead. The Equality Evidence Unit, Race Disparity Evidence Unit and the Disability Disparity Evidence Unit. The Units will work together as the Equality, Race and Disability Evidence Units with an overarching strategic evidence plan to ensure synergy. As matters stand, we are working with the Disability Disparity Evidence Unit to develop research proposals related to Taskforce Working Group recommendations including how they can improve their coproduction approaches with Disabled people.
- 85. In overview, the work of the DRTF, including consideration of recommendations in the *Locked-Out* Report, has taken longer to progress than anticipated. There are several reasons for this. As mentioned, a Secretariat was set up to support the development of the Disability Rights Action Plan, but it operated with only half the posts filled until Autumn 2023. Furthermore, the wide-ranging policy agenda meant that, to give full consideration to specific issues (such as Access to Justice, Employment and Incomes, and Travel) thematic groups were deemed necessary. In total, nine thematic Working Groups were established, each of which has convened at least four times. The general procedure is that the *Locked-out* report recommendations are considered at the relevant thematic Working Group meeting and thereafter a final report is produced, which is delivered back to the DRTF. For example, I chaired the Independent Living (Social Care) Working Group which met between November 2022 March 2023. At the conclusion of this Working Group, a

final report was delivered to the DRFT, containing practical adaptations and updates to the *Locked-out* report recommendations, as well as some new proposals. Training sessions on topics were provided from WG to the DRFT and Working Group members. However, ensuring maximum participation from Disabled people has involved a range of access and communication support which has taken time to arrange. More could have been done by the WG to ensure sufficient resources to make these arrangements although it's right to say that there is also a shortage of Palantypists and BSL interpreters in Wales. My understanding is that progress with drafting the Action Plan awaits completion of the work of all the Working Groups, all of which have not yet finished. I do not know whether any of the *Locked-out* report recommendations have been acted upon independently from the work of the DRFT.

86. Given that the Locked-out Report was submitted by the DEF Steering Group to Welsh Government in March 2021, notwithstanding the factors that have delayed progress, the considerable investment of Disabled people's time and commitment to the process has yet to yield any tangible results in their lives. By comparison, Welsh Government's Anti-Racist Wales Action Plan (2022) and the LGBTQ+ Action Plan (2023) have each been drafted, consulted upon, published and implementation commenced in considerably less time. Moreover, the impact of the cost-of-living crisis on Disabled people, as evidenced in DW's 2023 report 'Barely Surviving', which is publicly available, has greatly worsened the social and economic circumstances of many. Our findings highlight that there has been little support targeted at Disabled people either by the UK or Welsh Governments, despite well-documented higher povertv levels and disability-related disproportionate living costs. For Disabled people in Wales, delivery and implementation of a robust, and well-resourced Disability Rights Action Plan cannot come soon enough.

Representations on the impact of Schedule 12, part 2 of the Coronavirus Act 2020 and related guidance on Disabled people in Wales

87. On 24 March 2020, DW released a statement raising concerns about the Coronavirus
 Bill's impacts on the Social Services and Well-being Wales Act (2014); Exhibit [RD/60 – INQ000400711]. The statement describes concern that the Bill suspends key

provisions in the 2014 Act, unless services are needed to protect an adult from abuse or neglect or a risk of abuse or neglect. Unlike the suspension of provisions in the Care Act (2014) In England, there was no express requirement to avoid breaches of the European Convention on Human Rights included in the requirements for suspension of duties related to social care in Wales. In the statement, we called on the Assembly to take action to protect the lives of many thousands of Disabled people by ensuring that no services were withdrawn without undertaking an assessment to verify whether there would be a breach of human rights. We warned that the Bill would almost inevitably leave many thousands of Disabled people without essential support, or any rights to request that support.

- 88. The Coronavirus Act 2020, and draft guidance related to the social care implications of that legislation, were the subjects of discussion at the DEF meeting on 16 April 2020; [RD/28]. The Deputy Minister for Health and Social Services (DMHSS) said there was a clear expectation that local authorities would continue to support people, wherever possible, pointing to the £40m of additional funding that had recently been announced for the sector. Another representative from WG argued that the guidance was clear in reinforcing expectations for local authorities to continue to work to the unmodified duties as far as reasonably possible, and maintain the rights provided to people under the 2014 Act. In response, I reiterated concerns that I had raised with WG at the beginning of the pandemic in March, associated with the insecurity of PA support for Disabled people in the context of, among other things PAs frequently having to selfisolate [see 19 March public statement and email sent from myself to DW's WG on 24 March; previously exhibited as RD/6 and RD/8 representative NR respectively].
- 89. Whilst acknowledging that local authorities were facing a crisis, it was my position, as reflected in the minutes, that there remained a lack of information, as well as confusing and contradictory guidance, which was causing anxiety and uncertainty for Disabled people who were not receiving adequate care and support. For reasons of accountability, I urged the WG representative to make a strong commitment to upholding Equality and Human Rights— similar to that which was made by the recently formed and aforementioned Moral and Ethical Advisory Group, where stand-alone guidance was issued on the ethical values and principles that are necessary to uphold human rights in clinical decision-making [RD/28]. It appears that some efforts were

made to better reflect the expectation that providers should uphold rights within the final version of the guidance regarding modified obligations; this is reflected at page 4 of the minutes of the 30 April DEF meeting; [RD/30]. However, it is our view that the rights of Disabled people would have benefitted from the publication of a stand-alone social care ethical framework.

- 90. The DMHSS confirmed that my comments in respect of social care would be used as part of the consultation process. I then pointed out that speed was of the essence, as Local Authorities were already reducing care and support. I suggested that the guidance should include more detail, such as real-life case studies and more detail about reasonable adjustments (Equality Act 2010), as this would enable Local Authorities to uphold people's rights. The DMCW confirmed that local authority leaders were aware that the meeting had taken place today, that the DMHSS spoke with them daily and that these issues would be raised with them. I had to trust that the issues would be raised with local authority leaders, but assurances such as these are not formal mechanisms, and feedback on the onward progression of our concerns was frequently not forthcoming, particularly if it concerned Welsh government having to communicate with local government at the implementation stage of law or guidance. Indeed, there was no feedback provided at the next DEF meeting on 30 April 2020 [RD/30] regarding Local Authorities' perspective on the above issues.
- 91. On 17 April 2020, DW submitted our formal response to the rapid engagement process on the draft guidance for Local Authorities on the provision of their duties under the 2014 Act; produced as Exhibit [RD/61 INQ000400712]. We wrote that "Since the [2020] Act passed into law, we have heard worrying accounts from members regarding the loss or reduction in their support services with it seems little or no consultation or regard for their wellbeing and human rights". We stated that the guidance "should be issued as a statutory code and include examples and case studies of what this means in practice". Our submission included an example case study; that of Eleri, who usually received three care and support visits of 45 mins each per week, which enabled her to have a bath three times a week. Without notice or consultation, these visits were cut by social services to half an hour, which meant there was insufficient time to bathe such that she was now only able to have a strip-wash. This caused Eleri considerable distress and a loss of personal dignity. We put forward several recommendations in relation to good practice, clearer definitions, areas that require greater clarity,

timescales and structure for review of the guidance/code, and we also warned about the implications of any guidance which may give rise to 'blanket' decision-making on the part of Local Authorities in the provision of social care. I understood from the WG official's comments in the DEF meeting, that this would be acknowledged in the guidance. Whether it was heeded in implementation by LAs is another matter.

- 92. As part of the consultation, we were also asked to identify any potentially significant unintended consequence of the guidance related to Schedule 12. We answered that "the national response to dealing with the coronavirus crisis has created a climate of fear and distrust among many disabled people. Access to life-saving treatment has been questioned, support services withdrawn, and difficulties encountered in getting food. Moreover, some local authorities are taking the approach that people requiring care and support should move in with their families during this crisis, regardless of whether this is appropriate either for the individual or their family. WG must use the statutory guidance/code to acknowledge and seek to address this climate of fear, otherwise it may cause lasting damage to the perception of disabled people in society."
- 93. At the 30 April 2020 DEF meeting, Exhibit [RD/30], the DMCW said that, as a result of members' contributions to the rapid engagement process, actions had been taken, and this demonstrated the positive influence members of this forum have. NR
 NR from WG proceeded to update on developments, but first apologised for only circulating the revised guidance immediately prior to the meeting. This, as NR acknowledged, meant that members did not have sufficient time to absorb the changes, hence reducing our ability to consult meaningfully on the updated guidance. In respect of this issue, the DMCW asked if it was possible to give members more time to consider the content of the revised document and submit any further comments they may have. Unfortunately, NR confirmed that although views on the impact of implementation could still be submitted, the document was already in the process of being published. He also confirmed that the guidance would be kept under review over the coming weeks and could still be changed or updated where needed.
- 94. This situation should highlight to WG the importance of sharing guidance documents with stakeholders with sufficient time ahead of meetings. However, despite failure to properly consult with DEF stakeholders on the updated guidance that was published, DW acknowledged that some meaningful changes were made to the draft guidance

resulting from the rapid engagement process. These were outlined in the meeting as follows;

- (a) Greater clarity that modifications should only be exercised where absolutely essential, and greater clarity that changes made must only be temporary, justifiable due to unavoidable local circumstances and removed at the first available opportunity;
- (b) A stronger reflection of core ethical values and commitment to equality drawn from the Ethical Framework for Healthcare;
- (c) More emphasis on the importance of people being able to influence and inform decisions, for example about duration and regularity of their care arrangements;
- (d) Assurance that local authorities will ensure that alternative care and support arrangements put in place during the pandemic are not used as evidence or rationale to determine how support would be provided in future.
- 95. In response to these changes, at the 30 April 2020 DEF meeting [RD/30], I welcomed the stronger emphasis on equalities and human rights. However, I noted that in DW's rapid engagement consultation response, we had advised using case study examples. I asked if there were any plans to input case studies, as I believe they are useful and important tools to contextualise guidance. In response, NR urged the DEF members to submit case study examples which could be published alongside the guidance as he said he had not been sent any. Although I had raised the importance of case studies at the previous DEF meeting on 16 April 2020; Exhibit [RD/28], this had not translated into a formal action point. As such, there is no formal record of NR asking Forum members to send case study examples, which may explain the slight delay. However, this was formally noted as 'Action 3' as well as 'Action 5' in the record for the 30 April 2020 meeting.
- 96. At the next DEF meeting on 21 May 2020; Exhibit [RD/31], there was no follow-up as regards the case studies or other action points, and **NR** was not in attendance. At the 'Covid-19 Weekly Meeting' on 28 May 2020; [RD/14], I raised concern to WG representatives that the 16 April 2020 DEF [RD/28] actions had not been reviewed at the 21 May 2020 DEF meeting. WG officials at the Covid-19 Weekly meeting contacted WG official Matt Jenkins for an update.

- 97. At the DEF meeting on 21 May 2020; Exhibit [RD/31], we discussed the significant impacts of the suspension of the statutory duty to undertake a needs assessment under the 2014 Act. Specifically, one DEF Forum member raised the struggle that many vision impaired people were experiencing in trying to access support from a Rehabilitation Officer. For context, 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. However, as Disabled people were unable to access Rehabilitation Officers.
- 98. As a result, in the meeting, I asked if WG was monitoring whether local authorities were modifying services as I was concerned to ensure they 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. 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. 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).
- 99. Further evidence regarding the pernicious impact that the near-cessation of needs assessments was having on visually impaired people emerged in the aforementioned CPG on Disability on 2 July 2020 [RD/26], at which Disabled people gave evidence on the wide-ranging impacts of COVID-19.One participant "*identified an increase in vision impaired people feeling lonely and isolated and spoke about the looming crisis for people requiring support from a Rehabilitation Officer for the Vision Impaired.*" She explained from lived experience that in Swansea "*there is already a 12-month waiting list for an assessment and this is steadily increasing.*" It is unclear whether, between the 21 May 2020 DEF meeting and the CPG in July 2020, WG dedicated any time or

resources into understanding how the suspension of the statutory duty to undertake a needs assessment under the 2014 Act was implicating visually impaired people in this way. DW would appreciate if the Inquiry would request disclosure that would aid understanding of how this issue was factored into decision-making.

- 100. The next invitation for consultation that DW received in respect of the Coronavirus Act 2020, particularly schedule 12, was in November 2020; *Rapid Engagement on the Retention or Suspension of section 15 of, and Part 2 to Schedule 12 to, the Coronavirus Act 2020*; minutes produced as Exhibit [RD/62 – INQ000400713]. We strongly advocated for suspension.
- 101. Our submission clearly states that the introduction of Schedule 12 was not compatible with the commitment that WG had made in the 'Framework for Action on Disability: the Right to Independent Living (2019)' where WG had committed to a policy approach underpinned by the Social Model of Disability and the UNCRDP; produced as Exhibit [RD/63 INQ000177837] We stated that since our previous consultation submission, we "have continued to gather evidence from members through focus groups and surveys regarding the impact of Covid-19 on disabled people including on the issue of social care... Furthermore, we circulated details of the rapid review to members and the responses received were in full support of suspension of Schedule 12." We relayed the consistent message from members across Wales "that social care provision has deteriorated noticeably since the pandemic" and that "there was an unrealistic expectation from Local Authorities that their needs could be met through family or community support."
- 102. It is significant that, in our April 2020 submission, we raised the alarm that "a potentially significant unintended consequence" of schedule 12 guidance is that it enables Local Authorities to take the approach "that people requiring care and support should move in with their families during this crisis, regardless of whether this is appropriate either for the individual or their family" this very risk that we warned about then materialised, such that, by November 2020, it was a central motivation for our advocacy for the suspension of Schedule 12. It is also worth noting that, in both of DW's submissions, we also took the opportunity to make representations about issues that are broader to the Coronavirus Act 2020, rather than specific to Schedule 12. In April 2020, we noted that the national response had "created a climate of fear and

distrust among many disabled people. Access to life-saving treatment has been questioned, support services withdrawn, and difficulties encountered in getting food." In the November 2020 submission, we presented statistical evidence on the development of some of these issues. For example, we presented ONS data from 20 August 2020 that 13% of Disabled people reported being most concerned about access to healthcare and treatment (compared with 3% of non-disabled people). Further, around one-quarter (25%) of disabled people who were receiving medical care before the coronavirus pandemic indicated they were currently receiving treatment for only some of their conditions (compared with less than 1 in 10 (7%) non-disabled people who had a physical or mental health condition or illness and were receiving care before the pandemic).

- 103. In the November 2020 submission we also responded to WG's assertion that no local authorities had deployed the provisions in Section 12. We stated that the EHRC captured the situation more accurately: "No local authorities in Wales are known [emphasis added] to have implemented easements"; produced as Exhibit [RD/64 INQ000400715]. This could be because, as I stated in the 5 October 2020 DEF steering Group; "in England, local authorities have to declare whether they have suspended social care provisions, but it doesn't seem that local authorities in Wales have to do so." Regardless, my position in the consultation was that the "everyday reality for disabled people in Wales is that they have seen a reduction in their social care and/or access to support whether or not Schedule 12 is deployed."
- 104. On 22 January 2021 participants in the November 2020 rapid review received a letter from Albert Heaney CBE, Chief Social Care Officer for Wales, in which he acknowledged that a key theme throughout the responses focused on concerns about how the pandemic had impacted on people's rights. Shared examples included the increased demands on unpaid carers and families; the absence of services generally, but specifically day services and clubs which act as vital support mechanisms and respite. Similarly, responses identified the impact of wider national measures such as social distancing, lockdown and shielding resulting in cancellation of visits to care accommodation and supported living arrangements as well as the associated opportunities to take family members out.' In his letter Mr. Heaney also acknowledged the disproportionate impact the pandemic was having on Disabled people and their

families, and that officials had been asked to prepare the necessary legislation to suspend the modifications to the Social Services and Well-being Wales Act 2014. He wrote that the regulations suspending the modifications would be laid in the first quarter of 2021. His letter is produced as Exhibit [RD/65 - INQ000400716].

Summary of core impacts and recommendations for the future

- 105. The *Locked-out* report details evidence of Disabled people experiencing poor outcomes and experiencing fear, loneliness, isolation, discomfort and the overriding sense that they were being discriminated against, as a consequence of pandemic restrictions which disproportionately affected them.
- 106. The reduction or cessation of access to public health services and, in particular, social support does not affect everyone equally. Disabled people are more likely to have pre-existing health conditions or other needs which leave them particularly exposed in circumstances where there is little or no access to these services. What may be an inconvenience for some is an erosion of human rights for others. DW was disheartened throughout the pandemic to hear testimonies of the severe mental and physical consequence of policies which restrict these services. As one contributor to our #LockdownLife campaign told us via recorded video; '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." To add insult to injury, reasonable adjustments to the emerging 'new normal' were few and far between. It is of little surprise therefore, that Disabled people felt that society was changing without them. 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. 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, and the landscape of

'remote healthcare' which emerged from it, exposed a severe consequence of the ongoing failure to address these dual issues. This is only one example of a diverse range that prove why the core message of the *Locked-out* report must be heard. Indeed, an analogy with the 'remote shopping' landscape is easy to draw for reasons that have been explained in this statement. The pandemic and its related policies not only exposed, but in many cases worsened, pre-existing inequalities that span all areas of Disabled people's lives.

- 107. As stated, ONS data suggests that 68% of deaths from COVID-19 were among Disabled people in Wales. These figures must be understood in the context that I have laid out, which is essentially the social model of disability. This is the core principle for understanding what happened to Disabled people and it must be the core principle for meaningful structural and institutional change. It is acknowledged in WG's own impact report [RD/40] that "an important part of the raised risk is because disabled people are disproportionately exposed to a range of generally disadvantageous circumstances compared with non-disabled people".
- 108. DW believes that a more robust governance and accountability structure is required in Welsh Government to address the root causes of the disproportionate direct and indirect impacts of Covid-19 on Disabled people, as well as to ensure that the proposed Disability Rights Action Plan delivers its objectives. We propose the following structures are implemented, which I will explain in turn:

Incorporation of the UNCRDP into Welsh Law

- 109. Incorporation of the UNCRDP in to Welsh law, as committed to by Welsh Government in its Programme for Government, produced as Exhibit [RD66 – INQ000066133], will provide a legal and accountability framework to ensure that: Disabled people's rights are embedded in policy design, policy makers and service providers have clear expectations in terms of the delivery of Disabled people's rights, and as rights holders Disabled people know what their rights are and how to exercise them.
- 110. WG has established a Human Rights Advisory Group and a Legislative Options Working Group to progress commitments to advance and strengthen equality and

human rights more widely, including incorporating treaties such as the UNCRDP. DW is represented on both Working Groups, however we believe that limited progress has been made to date. We attribute this to the heavy legislative timetable resulting from the introduction of several new laws, together with significant time needed to respond in detail to UK Government proposals related to the Bill of Rights and the Illegal Migration Act. It also appears that insufficient resources have been provided to undertake such a complex task. The responsibility for research and analysis regarding the feasibility of UN Treaty incorporation within the devolved context has been placed on civil society organisations without funding the capacity needed.

111. Taskforce Working Groups have made clear links to framing proposals and recommendations for the Action Plan within UNCRDP Rights. The Legislation Options Working Group aims to produce a Green Paper proposing a methodology regarding Human Rights incorporation within the current Senedd term. Also, in the Independent Living (Social Care) Working Group which I chaired, we proposed the need to: "develop and disseminate guidance, in coproduction with Disabled people related to the requirement that those exercising functions under the Social Services and Wellbeing Wales Act (2014) pay due regard to the UNCRDP (United Nations Convention on the Rights of Disabled People) in carrying out these duties." While this recommendation can be undertaken without incorporating the UN Convention, the fact that 10 years after the 2014 Act was enacted, no such guidance has been produced, illustrates why incorporation is essential to any systems change concerning a more rights-based approach to Disabled people.

The appointment of a Minister with direct responsibility for Disabled people's rights in their portfolio

112. There is no Welsh Government Minister with specific responsibility for the rights of Disabled people within their portfolio. Currently, matters related to Disabled people are distributed across several Ministers; disability is part of the wider equality and human rights remit of the Minister for Social Justice, Additional Learning Needs falls to the Minister for Education and Welsh Language, and health and social care-related issues falls to the Minister for Health and Social Services and Deputy Ministers. During the pandemic, the Deputy Minister and Chief Whip took a lead gathering stakeholder views and communicating issues to Cabinet colleagues and relevant departments in relation

to Disabled people, amongst other groups. However, a more systematic and joined-up approach is needed, with ministerial oversight and responsibility, to ensure there is focus on how policy and legislation impacts on Disabled people as well as the principles of the UNCRDP and Social Model of Disability. A Minister with designated responsibility for Disabled people and the delivery of the Disability Rights Action Plan would also play a vital role in ensuring external stakeholders, including in the wider public sector, are tackling the implementation gap between strategy and service provision. Given the proposed future expansion of the Senedd from sixty to ninety Members, and an increase in the number of Ministers from twelve to seventeen, it is feasible to include direct responsibility for disability rights within a ministerial portfolio.

Disability Rights Advisory Board

113. A governance structure, such as a publicly appointed Disability Rights Advisory Board, is required to ensure that Disabled people are fully involved in informing, monitoring, reviewing and reporting on WG progress with delivery of the Action Plan. Stakeholder engagement forums such as the DEF would continue to play a valuable role, feeding in grass roots views and experiences to the Advisory Board.

Leadership Pathways

114. A key finding of the *Locked-out* report was the lack of Disabled people in leadership roles, which means that key policy decisions affecting millions of people were (and are still) made without being informed by lived experience. WG has committed funding to short-term programmes which help address this deficit, such as the Equal Power Equal Voice Mentoring Programme and the Access to Elected Office Fund Wales. The leading role of Disabled people in co-producing the *Locked-out* report and on the DRTF, including as Working Group chairs, has also provided a vital opportunity for many to develop their skills and talents. Resourcing, on a long-term basis, leadership pathways for Disabled people employed by WG, is vital to progressing the disability rights agenda and challenging ableist perceptions.

Capacity Building of Disabled People's Organisations

115. Disabled People's Organisations (DPOs) at grassroots level represent the voice of Disabled people in their communities. Their role includes campaigning on disability rights issues such as access, providing information and advice as well as peer support. During the pandemic, many DPOs played a vital role in keeping Disabled people digitally connected and reducing loneliness and isolation. With funds from the National Emergencies Trust and WG, DW distributed grants to DPOs in Wales to support and broaden the reach of their work. However, these grants were short term and many DPOs are now struggling for funding and active members to run them. Local DPO members have participated in Taskforce Working Groups and made an invaluable contribution. To ensure the Disability Rights Action Plan is delivered at local level by statutory bodies, support for DPOs is needed to enable them to work co-productively with their respective councils and health boards as well as hold them to account. At a minimum, this includes funds to recruit and train new members, co-ordinate and hold meetings and events to gather and feedback views, as well as meet participant expenses and access support. DW is working with councils for voluntary services and grant funders to raise awareness of the role of DPOs and develop initiatives to build their capacity. Nevertheless, in line with the UNCRDP, governmental bodies have a responsibility to directly support DPOs as a vital element in ensuring that their services are inclusive and accessible. Measures to build the capacity of DPOs at national and local levels should be included in the Disability Rights Action Plan, with WG taking a lead in providing support and placing expectations on other public services to follow suit. Members of strong and active DPOs will also provide a talent pipeline for other leadership roles in public and political life, including the proposed Disability Rights Advisory Board.

Statement of truth

I believe that the facts stated in this 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.....

1st February 2024

Dated.....