

Witness Name: Dr Jim Elder-Woodward OBE

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Exhibits: 57

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UK COVID-19 INQUIRY

WITNESS STATEMENT OF DR JIM ELDER-WOODWARD OBE ON BEHALF OF INCLUSION SCOTLAND

I, Dr Jim Elder-Woodward OBE will say as follows: -

1. I am the Co-Convenor of the Board of Inclusion Scotland. I have held this position since November 2023. I have been a Board member of Inclusion Scotland since 2005. My responsibilities and duties in this role are to oversee the governance of the organisation and represent its Board at some meetings and functions. I am also the Convener of the Scottish Independent Living Coalition and the Glasgow Centre for Inclusive Living.
2. The Convenor and Chief Executive Officers of Inclusion Scotland between January 2020 and April 2022 are no longer in post due to resignation.
3. Established in 2001, Inclusion Scotland is a registered charity (SC031619) and a Disabled People's Organisation (DPO) – meaning led by d/Deaf and Disabled people ourselves. Inclusion Scotland works to achieve positive changes to policy and practice, so that we Disabled people are fully included throughout all Scottish society as equal citizens. The majority of Inclusion Scotland's work is confined to Scotland, but we do engage at a UK level on some reserved issues impacting Disabled people in Scotland, such as the applicable reserved benefits.

4. We are an independent, non-party political, representative organisation of Disabled people across Scotland with a network of over 50 DPO members and partner organisations, alongside our individual members. We reach thousands of Disabled people across Scotland, many of whom experience profound exclusion and intersectional barriers to participation in society.

What we do

5. Inclusion Scotland represents our member DPOs and individual Disabled people. We also support Disabled people to take part in employment, politics, policy-making and influencing, and research through our projects, some of which are described below.
6. Inclusion Scotland believes in and is founded upon the social model of disability, we are Disabled by the barriers we face rather than our impairments themselves. Inclusion Scotland is a pan-impairment DPO, meaning that we represent all Disabled people regardless of impairment type.
7. Inclusion Scotland leads on the development and delivery of projects designed to promote and involve the voice and choices of Disabled people in public policy to create a more equal society. These projects include, but are not limited to:
 - Informing Disabled people of their rights and working with them to gather and share their lived experience and solutions for change with policy makers;
 - Empowering Disabled people to use their experiences to inform the Scottish Government as to how social care support can be improved;
 - Working with employers to make their recruitment and operational practices more accessible and inclusive for Disabled people;
 - Offering advice and support to Disabled people to become more involved in political life, from joining a political party to running for elected office;
 - Engaging with DPOs from across the UK to collaborate on UK-wide and international issues such as engagement with the UN Committee on the Rights of Disabled People.
8. Inclusion Scotland's operational focus is on Disabled people in the community rather than those in residential settings. This is due to a number of factors including our focus on human rights to independent living and being supported to play an equal part in our community, and resource considerations.

Impact of the virus and the counter measures taken to combat it on Disabled people in Scotland

9. Going into the pandemic, Disabled people did not enjoy the human rights set out in the UN Convention on the Rights of Persons with Disabilities ('UNCRPD')(Exhibit JEW/55 - INQ000365995). Instead, Disabled people already experienced unequal outcomes and lacked the support and resilience to deal with such an emergency. It was transparently clear that this was compounded by the negative impacts of COVID-19 and core decisions taken by the Scottish Government.
10. The Scottish Government had been extensively and robustly informed by Inclusion Scotland, and others about the structural discrimination, everyday barriers and denial of human rights that Disabled people faced, and what the solutions to these issues were.
11. This information, based on Disabled people's lived experience and expertise gathered by Inclusion Scotland, includes the Civil Society Shadow Report to the UN Committee on the CRPD(2017)(Exhibit JEW/56 - INQ000365996).
12. In 2016 the UN Committee on the UNCRPD conducted an Inquiry into Disabled people's enjoyment of UNCRPD Articles 19, 27 and 28 by UK governments. The Inquiry report declared that there had been "grave" and "systematic" violations of disabled people's human rights (Exhibit JEW/57 - INQ000365997).
13. By 2020 Disabled people in Scotland were more likely to be living in poverty than non-Disabled people. The employment gap between Disabled and non-Disabled people stood at 33.4 percentage points and the pay gap at almost 20% (Exhibit JEW/58 - INQ000365998)(Exhibit JEW/59 - INQ000365999).
14. Research in 2019 by the disability charity Scope showed that on average Disabled people in Scotland faced £641 per month impairment-related costs for things like heating, laundry, insurance and therapies meaning they have less money to spend (Exhibit JEW/60 - INQ000366000). The low levels of benefit payments and restrictive eligibility criteria to access them, highlighted in the UN Inquiry report 2016, also drove Disabled people's financial inequality.

15. Disabled people were more likely to live in inaccessible housing unsuited to their needs. 61,000 Disabled people in Scotland need adaptations to their homes and 10,000 are on waiting lists for suitable housing. Inclusion Scotland's Independent Living in Scotland project Summit 'Our Place, Our Space' in 2016 highlighted that Disabled people were experiencing mental health issues living in inaccessible and unusable spaces with some living in one room and unable to cook or use the bathroom and facing the threat of being removed to residential care (Exhibit JEW/61 - INQ000366001). That report also noted that Disabled people had limited opportunity to move to more suitable housing in another local authority area because carer packages were not portable.
16. It was against this background, known to the Scottish Government, that Disabled people entered the pandemic and experienced all of the impacts of both the virus itself but also measures introduced to combat the virus. A study of mortality rates in Scotland (Exhibit JEW/62 - INQ000366002) (called for by Inclusion Scotland – see Disability Roundtable on 12 November 2020 at para 65) between March 2020 and January 2021, found that deaths of Disabled people accounted for almost 6 in 10 (58%) deaths involving COVID-19. The Scottish Learning Disabilities Observatory noted that during the period January to August 2020 learning disabled people were twice as likely to be infected (Exhibit JEW/63 - INQ000366003).
17. The detrimental impact of COVID-19 and the consequences of policies and the delivery of Non-Pharmaceutical Interventions (NPIs) were felt across all parts of daily life including health, social care support, education, employment, income from employment and benefits, communication, food and energy, and connections with and equal participation in our communities.
18. Inclusion Scotland's Rights at Risk (Exhibit JEW/64 - INQ000366004) report presents the findings of a survey of 800 members of the disability community carried out in April 2020. Respondents said they felt 'abandoned' and a number reported feeling suicidal. They told us about isolation and loneliness, the impact of the loss of essential social care support for independent living, difficulties accessing food and other necessities, fears about being denied treatment if they got the virus and of involuntary Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices being placed on their medical records. The key responses to that report are set out below.

Impact on care and health services

19. There is anecdotal evidence of Disabled people finding out that DNACPR notices had been placed on their records without any notice, discussion or consent (Exhibit JEW/65 - INQ000366005). This is in direct contravention of standard policy and despite the Scottish Government stating in their response to a Freedom of Information request that:

“Neither the Scottish Government, nor individual Health Boards, have ‘ordered’ the use of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms for any individuals or groups of patients and there has been no change to the Scottish Government guidance on the use of DNACPR forms during the Covid 19 outbreak. As with all other clinical treatments, decisions about CPR should be made by clinicians, based on the individual clinical circumstances and wishes of the patient, recorded appropriately and updated when medical circumstances change.” (Exhibit JEW/66 - INQ000366006)

Inclusion Scotland attempted to gather data on this, but it was not possible as death certificates do not specifically record disability status. We were, however, able to gather qualitative evidence of people’s experiences (Exhibit JEW/67- INQ000366007)(Exhibit JEW/68 - INQ000366008).

20. Non-residential social care support for Disabled people was suddenly withdrawn or reduced. This support was essential for independent living including taking medication, washing, food preparation and eating, domestic cleaning, toileting and other daily activities and to support Disabled people to live participative lives.
21. People were still being charged for social care support that had not been delivered, exacerbating financial issues. Social care charging is unfair and the abolition of it is one of the key campaigns Inclusion Scotland has been involved in since before the pandemic. One family reported to Inclusion Scotland that they were being fined for non-payment of charges and threatened with legal action.
22. For many Disabled people social care support did not return to pre-pandemic levels and there were delays in being reassessed to take account of changing needs despite the extra funding released to Local Authorities (see further at paragraphs 94 and 95 below).
23. Family members or other informal carers took on caring roles, many were Disabled people themselves. This often created dangerous situations for the Disabled people they

cared for as lifting and other techniques would be required. Some Disabled people had challenging behaviours requiring specialist support. Informal carers often had no training on how to accommodate for the wide range of care they now needed to provide. They had limited support and often no respite, leading to or exacerbating mental health issues for both the carer and those they were caring for.

24. There were also no plans in place for Disabled people whose care was now provided by informal carers if their carers tested positive and had to self-isolate (Exhibit JEW/69 - INQ000366009). People were asked to prepare plans themselves.
25. Disabled people lost access to health services for existing impairments and ill-health conditions (Exhibit JEW/70 - INQ000366010). Support to manage conditions and relieve impairments fell away as pressure grew exponentially on health and allied services and as social care support was withdrawn. As a result, Disabled people's physical and mental health outcomes worsened and new conditions, whether arising from the virus or not, took hold.
26. Changes to health services made in accommodation of the virus, such as moving to online and telephone or video-only services excluded Disabled people who faced communication barriers such as d/Deaf, visually impaired and learning disabled people, and all those who were digitally excluded.

Access to food and medication

27. Informal carers and Personal Assistants of people who 'self-shielded' struggled to find details of local Hubs, announced by the Cabinet Secretary on 25 April 2020, to obtain supplies of PPE. A Disabled person who lived in a different local authority area than the one their GP was registered in was refused help by both Local Authorities.
28. From March 2020 almost 180,000 people on the 'shielding' list (because they were deemed 'highest risk due to having a listed impairment or ill-health condition, or at their clinician's discretion) had access to support from Humanitarian Assistance Centres (see further at paragraph 94 below) for things like free food boxes, door-stop deliveries of medicines, and free supermarket delivery slots, assuming supermarket deliveries were available in the area they lived in. However, food boxes were not matched to people's dietary requirements e.g. for allergies or soft food to prevent choking.

29. Other Disabled people who 'self-shielded' voluntarily because of the risk to their health and the potential denial of health treatment were left vying for limited and costly 'pay-for' supermarket delivery slots. Those with special diets found that supplies quickly ran out with priority given to deliveries for those on the 'shielding' list. When supplies did run low, Disabled people could not queue outside stores without seating or heating.
30. Some parents with children on the autistic spectrum with limited food tolerance resorted to social media to get supplies of these foods. For some Disabled women accessing supplies of sanitary products was problematic (Exhibit JEW/71 - INQ000366011). They were left to rely on family or voluntary networks where these options were possible or, despite the risks to their lives, they broke self-imposed shielding.
31. One respondent to Inclusion Scotland's survey said "*I have had to break my [shielding] to buy food, putting myself at risk. Medicine pre-ordered online now needs 7 days' notice to allow GP surgeries/chemists to cope with demand. Also, I usually collect my medicines from local chemist, it's proving difficult to change this to have it delivered during Covid-19 pandemic. Again, I've had to break [shielding] to queue and collect my meds*" (Exhibit JEW/64 - INQ000366004/18).
32. A survey conducted by Public Health Scotland during the summer of 2020, found that those on the shielding list who were living in poverty were more likely to report negative impacts on their mental health and struggled more to access food that met their needs (Exhibit JEW/72 - INQ000366012).

Impact on employment and financial support

33. Disabled people at high risk of infection from the virus, and household members who cared for them, who were in employment found themselves having to choose between income and safety if they were a key worker or when lockdown eased (JEW/73 INQ000366013). A survey by Citizens Advice in England also found that women and Disabled people were at higher risk of redundancy or reduced hours. The charity surveyed 6,000 advice seekers in England and found that over one in four Disabled people were facing redundancy and that almost half of those that were in the shielded group were at risk of redundancy (Exhibit JEW/74 - INQ000366014).

Impact on families and education

34. Those caring for Disabled children highlighted the impact of the loss of specialist educational support and respite. Parents with Disabled children, including parents who were Disabled people themselves, struggled with the additional strain of having to educate them at home without the skills or tools necessary. There were an estimated 10,000 children in Scotland with 'complex additional support needs' prior to the pandemic. Many lost some or all of the specialist education and support they relied on (Exhibit JEW/75 - INQ000366015).
35. Parents reported that the Disabled children and young people they cared for were experiencing increased anxiety which sometimes resulted in violent behaviours, self-harm, and very low mood. Much of this was attributed to the removal of structure, daily activity and routine and no help was provided to replicate these features at home.
36. One parent said "*Our son has ASD and self-harms/has suicidal thoughts. He is also really volatile and can hit out. I can't get out the house at all, as he won't come with me and can't be left alone.*" This was at a time when Child and Adolescent Mental Health Services (CAMHS) were least able to provide support. By September 2021 almost 2,000 children with mental health issues had waited a year or more for support from CAMHS (Exhibit JEW/76 - INQ000366016)(Exhibit JEW/77 - INQ000366017).
37. The potential long-term impact on the educational attainment of Disabled children, and those who were already in further or higher education, is still to be entirely seen (Exhibit JEW/78 - INQ000366018).

Impact on reasonable adjustments

38. Face coverings presented communication barriers to deaf and hard of hearing people when interacting with services as they could no longer lip read. Some frontline service providers refused to step back and remove their mask, or to use an alternative means of communication like pen and paper (Exhibit JEW/79 - INQ000366019).
39. When wearing face coverings was mandatory or highly advised, Disabled people were excluded from using public transport and other places and services where masks were not being worn by others because they felt unsafe. Another Scottish DPO heard from

some Disabled people who were unable to wear face coverings and were worried about public reaction (Exhibit JEW/80 - INQ000366020).

40. The Scottish Test, Trace and Protect testing kit¹ was difficult for Disabled people to use without support especially those with visual impairments or issues with manual dexterity, or if they could not travel to a test centre.
41. Testing was not widely available in all the situations it was needed. A caller to Inclusion Scotland (28 April 2020) spoke of how support workers in their son's residential home were being tested and having positive results for the virus, however, the people residing in the home were not being tested.
42. The Covid-status Certification system also presented barriers to Disabled people and potentially excluded Disabled people who required support to access vaccination or who could not have a vaccination. The certificate, and information about it and how to request it was initially digitalised so excluded Disabled people who were not online. Certificates could be requested by telephone exacerbating the problem for D/deaf people who were not online.
43. When the vaccination programme opened Disabled people were concerned about whether testing of the vaccine had taken account of underlying health conditions and medications (Exhibit JEW/81 - INQ000366021).
44. Inaccessible information and communications were an issue for Disabled people throughout the pandemic, heightening people's stress and fears about what would happen to them. Disabled people have communication needs which need to be met both to obtain information and to respond to it. Examples of this include BSL interpretation, EasyRead publications, and advocacy support to understand the message. This meant that Disabled people did not always receive the information they needed at the same time as others. See for example the EasyRead version of The Framework for Decision Making which was not published until 15 May 2020².

Engagement with the Scottish Government in connection with core decisions taken by it in the COVID-19 pandemic response

¹ See Scottish Government Guidance – *Covid-19 Test, Trace, Isolate, Support – A Public Health approach to maintaining low levels of community transmission of Covid-19 in Scotland* (May 2020)

² www.gov.scot/publications/covid-19-framework-decision-making-easy-read/

45. Inclusion Scotland had multiple engagements with the Scottish Government relating to the pandemic response. In preparation for this statement, we have conducted a search of our records, however, this has brought up a large number of documents and communications and we have not yet been able to identify if all relevant communications have been exhibited to this statement. I hope to have exhibited the key documents, however, if other relevant documents come to my attention, I will provide them to the Inquiry.
46. With regard to the communications referred to below, where we have found a response, we have exhibited it, therefore, if no response is provided this is either because one was not received or we have been unable to locate it.
47. General Comment 7 to the UNCRPD on the "*participation of persons with disabilities...through their representative organisations in the implementation and monitoring of the CRPD*" (Exhibit JEW/82 - INQ000366022) declares that State parties to the Convention should "*systematically and openly approach, consult and involve, in a meaningful and timely manner*" DPOs and that "*due consideration and priority*" should be given to their input and they should be informed of the outcomes and given an explanation of the decisions made (paragraphs 22 and 23).
48. Inclusion Scotland is a DPO and an intermediary organisation grant funded by the Scottish Government and therefore would expect to be involved in influencing decisions that relate to Disabled people. Although it was our experience that DPOs were consulted about the lived experience of Disabled people, we were not specifically informed about what influence it did or did not have on decision making and this was not always obvious from published policies. It was also the case that we were not engaged at the start of the pandemic and when engagement was sought at later stages this could be after a decision has been made and there was limited opportunity to amend it. Consequently our influence was about remedying the shortfalls Disabled people experienced because of those decisions.
49. The basis for Inclusion Scotland's engagement with the Scottish Government was driven, first and foremost, by Disabled people's experiences of COVID-19 and the solutions needed rather than by the Scottish Government's programme planning.

50. Taking a tripartite approach to influencing decisions, Inclusion Scotland -
- Gathered Disabled people's experiences of the pandemic and reported on these.
 - Positioned this evidence through publications and at Scottish Government meetings and Roundtables and via Scottish Parliament Committee evidence sessions.
 - Responded to policies and planned policies, where there was opportunity to do so, highlighting where these were likely to have a negative impact for Disabled people.

Engagement during 2020

51. Prior to the pandemic Inclusion Scotland had access to generally good communications with Scottish Government Ministers and officials. This included direct links with officials and meetings with Ministers, representation on groups and at bespoke meetings across many policy areas of relevance to Disabled people. We were able to be open and frank.
52. Inclusion Scotland convenes the Scottish Independent Living Coalition (SILC) made up of Scotland's strategic DPOs. DPO members of the SILC were collectively and independently engaging with the Scottish Government prior to January 2020.
53. Despite it having been abundantly clear to the Scottish Government that Disabled people would be gravely and disproportionately affected by COVID-19 and actions taken to mitigate it, this previously good level of engagement reduced suddenly as the pandemic took hold. This was presumably so that the Scottish Government could reset to deal with the emergency.
54. On 23 April 2020 the Scottish Government published The Framework for Decision-Making (Exhibit JEW/83 - INQ000366023) which included the principles of 'human dignity' and 'equality' and stated that the Scottish Government would 'listen to best evidence'. Had these objectives prevailed and had the Scottish Government planned to meet Disabled people's human rights and quickly addressed DPOs' well-evidenced calls for action (Exhibit JEW/84 - INQ000366024), Disabled people would likely not have suffered the continual detriments they did, or not to the same extent.
55. Six days prior to the publication of The Framework for Decision-Making, on 17 April 2020, Inclusion Scotland had issued a SILC statement and press release (Exhibit

JEW/85 - INQ000366025)(Exhibit JEW/86 - INQ000366026) warning that Disabled people's lives and rights were under threat and raising the need for the 'Disability Community' to be involved in decision making. It highlighted the need for the involvement of the Disabled community and DPOs and made calls for immediate action including widening the scope of those eligible for 'shielding' support, providing support for informal carers including immediate access to PPE, and ending the pressure being put on Disabled people by health professionals to accept DNACPR notices on their health records. It also called for more engagement with DPOs.

56. Copies were sent to the Cabinet Secretary for Health and Sport (Exhibit JEW/87 - INQ000366027), the CMO, the Chief Nursing Officer, the Direct General Health and Social care, The National Clinical Director, NHS Scotland Boards, the Confederation of Scottish Local Authorities, the BMA, Royal Colleges and others.
57. The press release prompted a journalist question at the First Minister's Briefing and the issue was taken up by Jeane Freeman. Following this, Lisa Bird (Deputy Director Equalities, Human Rights and Third Sector) and the then CEO of Inclusion Scotland spoke on the telephone about setting up regular engagement pathways. This was the Disability Roundtable.
58. According to Inclusion Scotland's records, the Roundtable met seven times from May 2020 to December 2020. This was bi-weekly in May and June and further meetings took place in July, November and December. Its purpose was to focus on the impact of the pandemic on Disabled people and the mitigating actions required. It also acted as a link between the DPOs (Inclusion Scotland, Glasgow Disability Alliance and Disability Equality Scotland) and policy teams across the Scottish Government who were contributing to COVID-19 actions.
59. Condensed action points from meetings were provided by the Scottish Government (Exhibit JEW/88 - INQ000366030) (Exhibit JEW/89 - INQ000366031) (Exhibit JEW/90 - INQ000366032) (Exhibit JEW/91 - INQ000366033) (Exhibit JEW/92 - INQ000366034) (Exhibit JEW/93 - INQ000366035). I would be grateful if the Inquiry could please request any full minutes of these meetings taken by the Scottish Government. The meetings were mostly about sharing information on emerging evidence, opportunities to speak to policy officers from teams focussed on COVID-19, being informed about forthcoming plans on things like public information campaigns and an opportunity to comment on the barriers they would likely present to Disabled people.

60. The Minister for Older People and Equalities, Christina McKelvie, attended the Disability Roundtable on 26 May 2020 (Exhibit JEW/89 - INQ000366031). DPOs were told that it was still possible to feed into the Framework for Decision Making and the route map out of Coronavirus. This was to be sent to the responsible team via an email inbox address.
61. At the Roundtable on 26 May 2020, the DPOs also highlighted the following issues: that many Disabled people were worried "*over food insecurities*"; that "*social isolation and loneliness [were a] big issue now and going forward*"; "*digital exclusion – many people have no kit or broadband – steps need to be built in if we're using online tools*"; "*Employment – issues around how that will look going forward?*"; "*Messaging issued from Government needs to be clear and consistent*"; "*Mental health issues will be exacerbated over a longer time and that this may be further exacerbated as some people are able to leave their homes and others are not. The adverse impact on the mental health of the latter may be greater than when no one can leave their home*" (Exhibit JEW/89 - INQ000366031).
62. Inclusion Scotland additionally participated in a number of one-off engagements with Ministers and officials. The Cabinet Secretary for Health Jeane Freeman made it clear to the CEO of Inclusion Scotland early on that she was open to being contacted and this was welcomed. Access to the relevant notes and social media exchanges are unfortunately no longer available.
63. Inclusion Scotland was aware that the Deputy First Minister was leading a Communities and Public Services Ministerial Group in twice weekly meetings and this group would focus on service delivery and urgent priorities for people at risk. Inclusion Scotland cannot ascertain if our evidence was used by this group.
64. Inclusion Scotland contacted the Scottish Government about amendments to the Coronavirus (Scotland) (No.2) Bill highlighting that allowing changes to the use of pavements for hospitality purposes would cause access issues for Disabled people. The Cabinet Secretary for Constitution, Europe and External Affairs responded by letter on 27 May 2020 (Exhibit JEW/94 - INQ000366036) recognising the issues. Use of pavement space for hospitality when lock down eased did in fact create many barriers for Disabled people trying to access services and in the subsequent reduction of Blue Badge accessible parking spaces.

65. At the Roundtable on 12 November 2020, Inclusion Scotland made a call for data on Disabled people's deaths during the pandemic. Officials responded that there were issues with using Census data from 2011 and they were reminded that this was the basis for equivalent analysis produced for England by the Office of National Statistics (ONS).
66. At the Roundtable on 7 December 2020, the official lead for the vaccination programme reported that details of the vaccination programme would be sent to people on the shielding list and that people classed as 'clinically vulnerable' would be vaccinated in Group 4. It was not confirmed 'clinically vulnerable' was equivalent to people on the shielding list. The eventual programme (Exhibit JEW/95 - INQ000366037), published in January 2021 referred only to 'clinically extremely vulnerable' and no definition was given.
67. Following the Roundtable on 7 December 2020, SILC met with the official responsible for public communications for the vaccination programme, Jamie MacDougall, on 6 January 2021. He reported the programme was based around who was dying rather than on the jobs people did but this appeared not to be the case except for people living in care homes. Disabled people living at home were placed in Group 4 regardless of the high risk they faced.
68. Inclusion Scotland asserts that the Scottish Government should have engaged with DPOs including Inclusion Scotland when they started to develop plans and policies and not when they were in draft form or being delivered. This could have prevented or at least minimised some of the harms for Disabled people described.
69. People First Scotland, a learning disabled people's DPO raised the issue of clinician's defaulting to Adults with Incapacity legislation and the need for them to instead provide for supported decision making for vaccinations, as expressed in their briefing from that period (Exhibit JEW/96 - INQ000366038). No response appears to have been given to this issue.
70. Following multiple mentions of the importance of accessible communications for Disabled people in meetings, public information became more readily available in alternative formats such as EasyRead (graphic supported easy to understand text) and British Sign Language (BSL). Similarly, when the First Minister first started to deliver

daily televised briefings Inclusion Scotland informed Scottish Government officials that BSL interpretation must be provided for these briefings to support Deaf BSL users. This suggestion was quickly implemented.

Engagement through 2021

71. On 2 June 2021 Inclusion Scotland participated in an equality and human rights focussed Roundtable on Domestic Covid Status Certification led by Cabinet Secretary for Health and Social Care, Humza Yousaf, and Minister for Older People and Equalities, Christina McKelvie (Exhibit JEW/97 - INQ000366039). A number of senior officials were in attendance including the National Clinical Director and the Deputy CMO.
72. Inclusion Scotland raised a number of issues at this meeting including about certification exemptions for those who could not be vaccinated, accessibility of certificates and testing (see internal briefing (Exhibit JEW/98 - INQ000366040)). Subsequently, paper certificates for people who are digitally excluded, and exemption certificates were provided.
73. As lockdown eased and the Scottish Government began to focus on 'renewal', Inclusion Scotland attended the Deputy First Ministers Stakeholder Recovery Roundtables between May and August 2021 (Exhibit JEW/99 - INQ000366041)(Exhibit JEW/100 - INQ000366042)(Exhibit JEW/101 - INQ000366043)(Exhibit JEW/102 - INQ000366044). This was an opportunity to inform the Covid Recovery Strategy: For a Fairer Future published on 5 October 2021. Inclusion Scotland recognises that this included positive initiatives around benefit take up, fuel poverty and support for long-term unemployed people raised by Inclusion Scotland and others at these meetings.
74. Inclusion Scotland participated in and provided evidence (Exhibit JEW/103 - INQ000366045) to the independent Social Renewal Advisory Board (SRAB), Age and Disability Circle. The SRAB was set up by the Scottish Government to develop transformational ideas to deliver real change. Published in January 2021, their *If Not Now, When?* (Exhibit JEW/104 - INQ000366046) set out many calls for action, some of which were implemented such as funding for Connecting Scotland (to improve digital inclusion). The Scottish Government's response to this report, published in March 2021, tended to set out commitments and many of these were pre-existing (Exhibit JEW/105 - INQ000366047)

Engagement with the UK Government

75. Taking account of the devolved nature of key delivery areas throughout the pandemic such as health and social care, Inclusion Scotland's key focus was on Disabled people in Scotland. Our engagement with the UK Government was therefore limited.
76. Our usual engagement at UK level focuses on reserved benefits and poverty measures residing at UK level and is delivered via briefings for Scottish MPs and written evidence to Parliamentary committees. It also includes work, alongside UK DPOs, to deliver shadow Civil Society Reports to the UN Committee on the CRPD to support their periodic reviews of the UK and 2016 Inquiry.

Recommendations on engagement

77. Addressing the functionality and structure of the main advisory groups and roundtables that Inclusion Scotland was involved in (see paragraphs 58 to 66 above), Inclusion Scotland welcomed the broad membership of these groups. This representation including from organisations representing other protected characteristic communities such as gender and race, supported discussions around intersectional barriers.
78. Overall, however, it was Inclusion Scotland's experience that there was a sense of disconnect between groups as we repeatedly contributed the same evidence and lived experience of Disabled people, for example on the need for accessible public communications. We received little dedicated response outlining how that evidence had been used and what difference it had made.
79. By autumn 2020, Disabled people were reporting frustration that they were providing information via consultations and surveys but seeing little impact. They were providing details of lived experience which was passed to the Scottish Government by the DPOs including Inclusion Scotland. The impact of this and decisions taken to address the issues were not always seen in everyday life and not with the urgency required.
80. Another recurring theme was that Inclusion Scotland was increasingly presented with near final draft policies and plans at meetings and therefore had only minimal scope to influence key decisions such as whether to ease lockdown given that Disabled people who were shielding would have to reduce their access to outside space given the risk that the R-number would increase again.

81. Inclusion Scotland welcomes the Scottish Government's statement in their opening submission (Exhibit JEW/106 - INQ000370953) paragraph 38 and its intention to learn lessons and to make 'fundamental and lasting changes'. Whilst paragraph 39 highlights that 'The Scottish Government has been committed to the eradication of inequalities in health and social care for years' this is yet to make the necessary difference.
82. Had these commitments been met before COVID-19, Disabled people would have gone into the pandemic better supported and more resilient and would potentially have come through it with fewer or reduced negative impacts.
83. Inclusion Scotland recognised early in the pandemic that many of the negative impacts for Disabled people of the NPIs in Scotland were deeply rooted in the structural inequality that preceded the pandemic including lack of lack of accessible information and advocacy, unmet social care support needs, inaccessible services and a lack of accessible housing, and low employment and educational outcomes.
84. Inclusion Scotland asserts that formal engagement with Inclusion Scotland and other intermediary DPOs should have been established as soon as it became clear that there was a risk to Disabled people's lives and rights and before seismic changes were initiated. DPOs should have been involved at the outset in any decisions likely to impact Disabled people's lives. This involvement should extend to being told if and why our advice was not heeded so that we could offer alternatives. DPOs should have been specifically resourced to enable engagement in emergency situations recognising the breadth of policy areas covered.

Adequacy of Equality and/or Human Rights Impact Assessments (EQIAs) conducted by the Scottish Government.

85. Inclusion Scotland would have expected EQIAs to have been completed as part of the formation of new policy and main revisions to existing policies. The role of EQIAs is not only to negate potential negative impacts, but also an opportunity to positively promote equality. Inclusion Scotland responded to EQIA's where we were given the opportunity to do so (subject to our capacity at that time).

86. Prompted by Disabled people's fears of being denied equal access to health care or having involuntary DPACPR placed on their health records, Inclusion Scotland responded to the EQIA on COVID-19 Clinical Guidance contesting the use of clinical frailty score to determine access to treatment. The ensuing revision of the Guidance (version 3) took note of this and confirmed that the frailty score was not to be used to deny or ration Disabled people's access to health care (Exhibit JEW/107 - INQ000366048).
87. There were times when we would have expected to have been involved in an EQIA process and were not, such as development of the Routemap Phase 1 of lockdown easing which made little mention of Disabled people despite the clear need to address the situation they were in.
88. We do not know if EQIA's were carried out in all the cases they should have and there appears to be no central record of EQIA's on COVID-19 carried out by the Scottish Government.

Proportionality, Reasonableness and Effectiveness of Core Government Decisions

89. Six out of every ten deaths in Scotland were Disabled people (during the period recorded by National Records of Scotland (NRS) (Exhibit JEW/62 - INQ000366002). Whilst Inclusion Scotland understands that the Scottish Government was responding to a worldwide pandemic and needed to protect the whole population, the health service and the economy this statistic, and the evidence provided by Inclusion Scotland of Disabled people's lived experience, paints a clear picture.
90. Had Inclusion Scotland and other DPOs been involved in pre-pandemic emergency planning, many of the grave impacts for Disabled people could have been avoided or at least minimised. Inclusion Scotland has previously provided evidence to the Inquiry about lack of engagement in emergency planning before the pandemic³.
91. It would have been obvious to the Scottish Government that Disabled people were more susceptible to the virus and that the disability community had both less resilience to face the pandemic and that particular needs had to be met, such as accessible

³ Witness Statement of Heather Fiskien dated 13 April 2023, [INQ000148409](#)

communication. Decision-making from the outset and as the impacts for Disabled people emerged should have taken account of this and been given more urgency.

92. Equality and human rights were rightly listed as guiding principles and objectives in policy frameworks and the Scottish Government provided many well-intentioned policies and supports during COVID-19, such as the Framework for Decision Making. Despite this, these policies failed to protect Disabled people from all the harms they endured.
93. Inclusion Scotland believes that the Scottish Government could have initiated lockdown sooner based on evidence about the spread and effect of the virus.
94. The Scottish Government determined that only those Disabled people deemed at 'highest risk' because they had certain ill-health conditions would be included on the official shielding list and thus able to access support to shield during lockdown. This not only meant that Disabled people identified at 'higher risk' could not access support but also those who required everyday support and care despite not being clinically vulnerable to the virus.
95. The extra financial help provided to Local Authorities were reasonable steps for the Scottish Government to take, however, the Scottish Government did not appear to properly manage Local Authorities' accountability for this extra support meaning that it did not reach the Disabled people who needed it, or did not do so quickly enough. For example, the Scottish Government released £100 million (March 2020) in extra funding to councils to stop social care from being withdrawn or reduced. Yet it was evidentially clear to Inclusion Scotland that social care continued to be withdrawn or reduced despite the extra funding (Exhibit JEW/108 - INQ000366049)(Exhibit JEW/109 - INQ000366050).
96. On 24 March 2020 Deputy First Minister John Swinney announced local Hubs of Humanitarian Assistance Centres and said he had 'every confidence in the capability of Scotland's resilience community' (Exhibit JEW/110 - INQ000366051). Hubs were set up to support people on the 'shielding list'. However unpaid carers and Personal Assistants could only access PPE from 25 April when Cabinet Secretary Jeane Freman announced this.

97. £45 million, as part of the £350 million additional funding package announced by the Communities Secretary Aileen Campbell in March 2020, was released to the Scottish Welfare Fund to make Community and discretionary Crisis Grants (Exhibit JEW/111 - INQ000366052). This was a necessary response to the hardships people were facing but not enough yet Disabled people still faced financial hardship, due in no small part to their situation prior to COVID-19.

Collation of Data specific to Disabled people

98. On 19 June 2020, the Office for National Statistics (ONS) released figures offering a provisional analysis of the number of disabled people in England who had died of COVID-19 between 2 March and 15 May 2020. The ONS continued to publish these figures up to March 2022.
99. Inclusion Scotland called on the Scottish Government to publish equivalent figures for Scotland (including at the Disability Roundtable on 12 November 2020, see para 65). This data would focus the Scottish Government's decision-making on the need for action to address the disproportionate health outcomes of the virus on Disabled people and their rights to equal access to health, social care support, and access to accessible information.
100. NRS eventually released these figures on 24 March 2021 for Scotland covering the period March 2020 and January 2021 in their report 'Deaths involving coronavirus (COVID-19) in Scotland Week 11 (15 March 2021 to 21 March 2021)'. This confirmed similar outcomes for disabled people in Scotland; that 6 out of 10 deaths from COVID-19 were disabled people.
101. Inclusion Scotland does not know why the Scottish Government did not publish figures sooner. Inclusion Scotland also does not know why the Scottish Government did not repeat this analysis periodically so that the deaths of Disabled people from COVID-19 could be charted against the impact of government decision-making and the pattern such as vaccinations.

Enforcement of regulations

102. Inclusion Scotland were unfortunately not able to apply resources on this issue during the pandemic.

Key challenges and lessons learned

103. Whilst Inclusion Scotland recognises the pressure that Ministers and officials were under throughout this period and the need for rapid policy development and delivery, we and other DPOs should have been involved in any and all decisions that would impact Disabled people. This affirms the mantra of the Disabled People's Movement 'Nothing about us without us'.
104. It was obvious from the outset that COVID-19 would (and did) have disproportionate and negative impacts for Disabled people. Inclusion Scotland considers that too many of the most strategic decisions, such as to implement lockdowns and to ease them, were taken without due consideration of those predictable outcomes for Disabled people.
105. Scotland was unprepared for the pandemic and what planning was in place, such as Exercise Cygnus, was out of date and did not take account of the reality of the Disabled community's everyday lives in 2020. Such a plan should have addressed the rights in the International Covenant of Economic, Social and Cultural Rights with unique reference to the rights in the Convention on the Rights of People with Disabilities.
106. As set out above, there was no suitable plan for essential services like social care support for Disabled people in the event of a pandemic and lockdown, and if there was it did not work. Public messages, especially about health measures and details of support available, should have been readily accessible and inclusive and the systems in place for this before COVID-19.
107. The Scottish Government should have turned more rapidly to DPOs as soon as it was clear that the virus was going to change daily life and created a space for us to influence the seismic changes that would be required. We would have informed their draft decision making about the likely impacts for Disabled people and the specific support that would be required, before the negative impacts took effect.
108. As this did not happen, Inclusion Scotland and other DPOs were in a position only to influence less key decisions, such as on accessible communications, which should in fact have been a given, or offer challenge where policies already in action were already having a negative impact on the Disabled community, and to offer and ask for solutions. The Equality Unit Disability Roundtable and the Social Renewal Advisory Board were

helpful in this regard but could be classed as 'too little, too late'. Even so, our input was not always addressed to the extent and with the haste required by Disabled people.

109. Nevertheless, the existence of a dedicated Equality Unit with the Equality and Human Rights Division under the (then) responsibility of Christina McKelvie, Minister for Older People and Equalities provided Inclusion Scotland and DPO members of the SILC with a dedicated route to accessing and informing Ministers and officials. Other approaches are and were possible such as via participation in Advisory and Steering Groups and correspondence. These things provided ease of access and were useful. We understand that our peer DPOs in England did not benefit from the same engagement opportunities with the UK Government.
110. One of the key challenges for Inclusion Scotland and DPOs was historic underfunding and lack of capacity. This is not a new challenge but DPOs also had to make rapid changes to protect Disabled project participants and staff and to de-prioritise and re-focus funded outcomes. Some DPOs were service providers and had to quickly focus on supporting individual Disabled people in new ways with only some additional funding to reflect these new demands.

Future recommendations

111. The Scottish Government, NHS Scotland, Local Authorities and other public bodies should involve DPOs in emergency planning. This is an urgent requirement given the possible resurgence of COVID-19, the impact of climate change and the possible terrorist threat. When these plans are enacted, DPOs should be immediately involved in decision making.
112. DPOs should be funded, including in all localities across Scotland, so that they are sustainable in the long-term and able to respond to and support the delivery of future pandemic and other emergency responses and decision-making.
113. The Scottish Government, as it continues on its path to rebuilding Scotland should work to support and address the rights of those who have been left behind; Disabled people who are still shielding and those with Long-Covid.
114. The Scottish Government should follow through on its plan to incorporate human rights into Scots law, in particular the UNCRPD. This should apply to emergency planning and

should be trained on dismantling the structural inequalities that meant that Disabled people went into the pandemic lacking the support they needed. This includes its commitment to reform Adult Social Care and to end charging for social care support.

115. Scottish Government should ensure that it has all the data it requires to make decisions in an emergency situation.

116. Scottish Government should investigate why well-intentioned policies and emergency funding, are either not delivered or not fully delivered in practice and resolve the issues it identifies.

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings 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 of its truth.

Signed:

Personal Data

Dated: 15/12/2023