Witness Name: Lyn Pornaro
Statement No.:
Exhibits:
Dated: 11/01/2024

UK COVID-19 INQUIRY

WITNESS STATEMENT OF DISABILITY EQUALITY SCOTLAND

I, Lyn Pornaro, Chief Executive of Disability Equality Scotland, will say as follows: -

1. Disability Equality Scotland is a national charity working to make life more accessible, equal and inclusive for all disabled people in Scotland. I am writing this statement as Lyn Pornaro, Chief Executive Officer since 31 October 2022.

2. We promote access in its widest sense. This includes access to the built and natural environment and access to the same opportunities as are enjoyed by others in our communities. Thus we promote a life of dignity, respect, choice and independence. This extends beyond physical access to include access to information, access to inclusive communication and inclusion in decision-making, whether with planners over inclusive design, transport providers about accessible travel and many other areas of society.

3. We represent the views of individuals with any type of impairment. We also represent the view of disabled people's organisations, disability organisations and those organisations who share Disability Equality Scotland's values.

4. We are also the umbrella organisation for all disability Access Panels in Scotland. We are the principal provider of support and guidance to the Access Panels presently representing disabled people at a local level throughout Scotland. Access Panels are committed to improving access and equality in its

widest form, which means access to the physical environment, Education, Housing, Health, Transport, Leisure & Recreation and Social Justice amongst other areas.

5. We are membership led. Our Board has a requirement to include at least 51% of disabled people – this is currently at 75%. Our membership has ranged between 800 and 1464 members over the course of the relevant period. This was made up of Individual members (between 612 and 1284), organisational/corporate members (between 112 and 125), Young People members (between 0 and 17), and our Access Panels (between 36 and 38).

6. Our members direct the work that we undertake by completed annual surveys, through member questions and research. They prioritise the work that we do and we aim to influence and inform at a National level by sharing disabled people's voices from the local level.

7. We are not a service delivery charity – we work strategically to ensure that disabled people's voices are heard and listened to. We follow the social model of disability and independent living movement's ethos. We are positivity focused where we will share the reality (however hard) but also provide potential solutions to make things better and we offer some training/

8. Our current work undertakes a multitude of areas – from accessible travel, inclusive communication, hate crime, human rights, climate change, Easy Read, Equality and Human Rights Impact Assessment, social security, social care, health and of course during this relevant time, a large focus was on Covid-19 and the impact for disabled people.

9. It should be noted that this statement is only a high level approach as the leadership in post both within the charity and its Board during the relevant period, have all left the organisation. New leadership in these areas took over from August – October 2022.

10. We found that disabled people were at a bigger disadvantage than non-disabled people over this period. We started to send out weekly questions to our members regarding many areas that the pandemic impacted, and the resulting statement is a summary of these.

11. From the very start of the pandemic, disabled people told us that 97% of members did not receive any contact from their GP to discuss access to medical care, in light of the COVID-19 pandemic.

12. Although due to the media information about Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) being put on patient's files without their knowledge, we asked if our members were aware of this and their current situation.

13. Although most members had not had any discussion with medical staff, we did hear from some who indicated:

> "I have lost confidence in my practice since receiving a phone call asking if I would be prepared to forgo treatment in favour of a younger, presumably non-disabled person. I feel like I have been written off as surplus to requirements and a drain on society."
>
> "Community nurse asked on behalf of doctor if in result of getting COVID-19, if I wanted to be resuscitated. I am 68 years of age, fit and reasonably healthy (I know COVID-19 doesn't discriminate) but really this question staggered me, I asked my family what they thought, thank goodness they said don't be silly Mum. So, if necessary, please resuscitate."
>
> "Having read other people's comments online, I would not mention my autism diagnosis in case I was deprioritised for ventilation support."

14. We now know, therefore, that this impacted disabled people indirectly before they even caught Covid-19, implying that they were less valuable in society than non-disabled people.

15. As disabled people have higher than average medical appointments/medications etc, we found that disabled people were discriminated against when GP and hospital appointments changed to online or digital access only. Some comments from our member were:

> "There is a notice outside GP surgery that says "Closed to patients. Consultations are now being made by telephone only. But I cannot use telephones due to being deaf."
>
> "I had a long-awaited hospital appointment replaced by a phone appointment, but I am severely hearing impaired and I couldn't understand what was going on. I couldn't be in a private room because of the living situation and everyone having to be in the house. They didn't make any adjustment for the fact I'm deaf and just counted it as the appointment had happened. I got a letter a couple of weeks later full of errors, I am so upset."

16. In June 2020 we found that 78% of our members who were on the shielding list, did not feel they had sufficient information or support during this period. This percentage did not change over the course of the relevant period. With confusion regarding the lockdowns, who could do what, differences between health and social care as well as different government messages, this did not improve.

17. As lockdowns were slowly lifted, we found, and still do, that many disabled people who had been on the shielding list, were uncomfortable and unconfident about returning to more normal activities. Guidance was continued for a period of time but then the scrapping of the High Risk Group and informing them that

they should follow the guidance of the general public, increased this anxiety even further.

> "After having self-isolated since the beginning of the pandemic, I am really scared about going to shops, going on buses. Scared I may catch the virus after having obeyed the rules for so long. Far too many have not been obeying the rules."

18. By May 2020, 68% of our members indicated that Covid-19 had negatively affected their mental health. We know that disabled people are more likely to live with mental health impairments than non disabled people. Some deal purely with mental health concerns and others deal with this on top of additional impairments.

19. "I was having regular visits to a mental health team over many years, talking, support, medication reviews, etc. but it all stopped at lockdown. I have not seen anyone since late February. I received a telephone call after 7 weeks checking on me. Staff now working from home or part in office but not actually seeing anyone. I feel abandoned and very alone."

20. "Lack of NHS support directly attributable to the lockdown and the local mental health team resorting to telephone consultation. At the current time due to loss of physical contact with the team and essential support I am feeling increasingly isolated, alone, and my mental health is certainly declining, mood dropping and psychosis becoming more complex."

21. When you add in all the other aspects of support that disabled people require but was impacted – social care, social inclusion, digital exclusion, education, hobbies etc – the cumulative impact was huge and continued to grow over the relevant period.

22. As society moved on and the relaxation of legal requirements was brought in, we asked our members whether they agreed with the relaxation or not and what the impact would be to accessing medical support. 66% of our members indicated they disagreed with this and in regards to NHS and its accessibility, comments were made like:

> "I have a son who has been waiting for a CT scan asked for by his orthopaedic consultant in early November 2021 and was told this week (March 2022) that there is now a 26-week backlog and that is rising every day. There should be no relaxation until there are no hospital admissions on COVID type illnesses."

23. For those in the high risk groups we heard comments like:

> "As a shielder, I will be too afraid to go anywhere indoors once we become cannon fodder."
>
> "I am in the highly vulnerable group and therefore at high risk from COVID. I will be watching infection rates closely before I consider going to any public indoor setting."
>
> "It will make me terrified to go out. I just can't risk the chance of getting COVID and becoming seriously ill. I think it's crazy that people can go out and spread this."

24. Members shared consistently their concern around catching COVID-19, lack of support to prevent this from happening, concern over whether they would or would not be treated equally if required to attend hospital or whether they would die. When members did come out of hospital to their own homes, or care homes, support wasn't always available. A member shared:

> "My son was discharged from a brain injuries unit earlier than planned to shield him from COVID-19 and free up bed space in hospital chain. No

social care kicked in and appointments deferred indefinitely. Very unsatisfactory, although unit is offering temporary remote support it is not a managed transition.

25. We now know that disabled people who died because of Covid-19, were disproportionately higher compared to non-disabled people. We believe that this is due partially to co-morbidities, causing more complications with health. However, we also believe this is due to the systemic barriers, perceptions and procedures that have continued to discriminate against disabled people for many, many years. The cumulative effect is that society in the UK do not value the lives of disabled people, the contributions they make to society or the impact that they have on other people's lives in positive manners.

26. We would recommend that our governments involve disabled people in planning for a future emergency. That there are clear communication routes for all disabled people to clearly understand the support that is available to them. We would recommend that our health and social care system, improves their disability competence. This would enable messages to be clearly delivered, in a manner that is inclusive and engaging and does not discriminate against those whom their impairment excludes them.

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: ___11 January 2024______________________________