

Witness Name:

Statement No.:

Exhibits:

Dated:

UK COVID-19 INQUIRY

WITNESS STATEMENT OF HEATHER FISKEN ON BEHALF OF INCLUSION SCOTLAND

I, Heather Fisken, will say as follows: -

1. I am Head of Policy and Research at Inclusion Scotland and make this statement on its behalf. Established in 2001, Inclusion Scotland is a registered charity (SC031619) and '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.
2. 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

3. Inclusion Scotland represents our members which include Disabled People's Organisations and individual Disabled people. Beyond our membership, 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.

4. 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.
5. 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.

Pre-pandemic preparedness and Inclusion Scotland's involvement

6. At the outset it should be noted that Article 11 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) states that:

“States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.”

Taken together with Articles 3 and 33 which require the participation of Disabled people in society and in monitoring implementation of the Convention, Disabled people should have been involved in all aspects of the pandemic preparedness planning.

7. Prior to January 2020 we were not invited to engage with government (UK, Scottish or local) regarding the extent to which inequalities and vulnerabilities should be factored into emergency preparedness and pandemic planning. We have routinely highlighted the obligation on the UK and Scottish governments to involve Disabled people in the development of law and policy, decision-making and in monitoring the implementation of the UNCRPD. Failure to do this adequately meant that inequalities faced by Disabled people were not sufficiently factored into emergency preparedness and pandemic planning.
8. We understand that the Scottish and UK governments ran pandemic preparedness exercises between 2015 and 2018. We were not aware of these at the time and were not invited to take part or contribute. Disabled people and their organisations should have been involved in the exercises because many Disabled people are at greater risk during emergency situations in terms of detrimental health impacts and facing more barriers to accessing essential services and our involvement would have highlighted these issues and the steps needed.

Pre-pandemic preparedness and consideration of inequalities

9. Having now reviewed the reports of the preparedness exercises, and taking account of Disabled people's experiences throughout the Covid-19 pandemic, we are of the view that the UK and Scottish governments were not adequately prepared for a pandemic. The report of Exercise Cygnus which took place in 2016 explicitly stated this:

“the UK's preparedness and response, in terms of its plans, policies and capability, is currently not sufficient to cope with the extreme demands of a severe pandemic” (Exercise Cygnus Report, HF/1) (pg.6).

The evidence gathered from our members and other Disabled people following the outset of the pandemic clearly demonstrated this unpreparedness to be the case.

10. We believe that the UK's pandemic planning and emergency preparedness took inadequate account of the pre-existing structural inequalities and risks experienced by Disabled people. We are aware that the UK Government published an equality impact assessment alongside its 2011 UK Pandemic Preparedness Strategy (The UK Pandemic Preparedness Strategy 2011: Analysis of Impact on Equality, HF/2) (UK Influenza Pandemic Preparedness Strategy 2011, HF/3). Although it does identify some of the potential impacts on Disabled people, we believe that it was not comprehensive. For example, it does not take an intersectional approach.
11. We reviewed the reports of the pandemic preparedness exercises and found no consideration of the equality impacts. The UK government exercise did, nevertheless, identify possible issues with social care support in the event of a pandemic. The Exercise Cygnus report stated that:

“It is understood that the Social Care sector is currently under significant pressure during business as usual...Any extra pressure on the Social care sector...could be very challenging’. (Exercise Cygnus Report, HF/1) (pg.25)

12. It also identified that:

“It is likely that there will be vulnerable people who are reliant on private support which might not be available at the time of a pandemic (those reliant on families and friends for example)” (pg.24).

Beyond this, there was no consideration of the potential for widespread loss of social care support and access to wider services, and the impact that this would have on individuals, specifically Disabled individuals, and the need for mitigating actions.

13. Despite one of the Scottish Government workstreams in Exercise Silver Swan focussing on health and social care, little specific attention appears to have been given

to social care support. The report does acknowledge that there would be a “likely impact on this sector and increased demand” (pg.24), and that:

“The ability of all parts of health (primary care and acute services), and wider social care, to cope with the surge in demand for services is dependent on many factors, such as other pressures in place at the time and the ability to effectively reprioritise services.” (Exercise Silver Swan Report, HF/4) (pg.9)

14. Like the UK exercise, there was no consideration of how this and the other issues identified in the report might disproportionately impact specific groups of people and how these impacts could be addressed.

15. One of the Exercise Silver Swan recommendations for further action was to “Produce multi-agency influenza pandemic plans which include Health and Social Care Partnerships”. However, it has been reported that the care sector was not even involved in the preparedness exercise (Healthandcare.scot article, ‘Scotland’s pandemic planning left out care sector’ HF/5) and we are unaware of the involvement of any Disabled people’s organisations.

16. After the onset of the Covid-19 pandemic, Audit Scotland found that “Progress in addressing recommendations from pandemic preparedness exercises has been slow” and that at the time of writing, the Scottish Government’s flu pandemic guidance for health and social care had still not been published (Audit Scotland – NHS in Scotland 2020, HF/6).

17. Another report prepared for the Scottish Covid-19 inquiry stated that:

“There is little mention of inequalities in strategic guidance on emergency preparedness, nor in lessons learned from emergency planning exercise.” (University of Edinburgh - Pandemic Preparedness, HF/7)

Evidence of Disabled people’s experiences in emergencies

18. We are of the view that Disabled People’s Organisations and other organisations representing equality groups should have been involved in pandemic planning and in

preparedness exercises. Evidence existed about the experiences of Disabled people during emergency situations prior to the onset of the Covid-19 pandemic which could have been utilised to try to prevent or minimise the worst impacts.

19. Such evidence has shown that Disabled people are more likely to be disproportionately impacted by emergencies and “are more likely to be marginalised by poverty and other social barriers that make them less likely to be evacuated safely, more prone to health risks and less likely to have insurance that protects their assets and homes” (Inclusion Scotland - It’s our planet too: Climate change, disabled people and climate action in Scotland, HF/8). Emergencies can also seriously affect Disabled people’s access to food and nutrition, safe drinking water and sanitation, health-care services and medicines, education and training, adequate housing and access to decent work.

20. It was therefore foreseeable that Disabled people were going to be disproportionately negatively impacted by a pandemic. Had the UK and Scottish governments properly consulted with organisations, including DPOs, pandemic planning would have been much more robust and could have prevented or minimised much of the suffering experienced by many Disabled people.

21. A report prepared for the Scottish Covid-19 inquiry said:

“Given what is already known about significant inequalities within Scottish society, it bears considering whether a more proactive approach to assessing and mitigating the risks to different groups, including disadvantaged and minoritised groups, could have been taken, as part of Scotland’s approach to pandemic preparedness.” (University of Edinburgh - Pandemic Preparedness, HF/7)

How governments could have planned better

22. We consider that a range of things could have been done better in relation to UK and Scottish government pandemic planning and emergency preparedness in the context of pre-existing inequalities and vulnerabilities including, but not limited to:

- a) Taking an equality and human rights based approach to pandemic planning;
- b) Involving Disabled people and their organisations in planning and preparedness exercises;
- c) Undertaking comprehensive impact assessments, identifying actions as a result of these and delivering on these actions;
- d) Utilising existing evidence about the impact of emergency situations on Disabled people to identify and plan for measures that could be taken to mitigate harm;
- e) Involving and adequately funding third sector organisations to respond rapidly to emergency situations e.g. by providing basic items such as food; supporting people living alone and those without access to the internet; producing accessible communications;
- f) Ensuring that ear-marked funding reaches those individuals who need it. This must be done by having the necessary protocols in place to direct funding to organisations that have a proven track record of effectively using public money to benefit the public;
- g) Ensuring adequate supplies of PPE which can be easily accessed by those who need it.

23. Overall, we consider that more should have been done and more needs to be done to address the existing inequalities which disproportionately affect Disabled people at all times, not just during emergencies so that we are better able to deal with developing emergencies, the responses to them and the aftermath.

Our work after the onset of the Covid-19 pandemic

24. We intend to submit a further statement detailing our work done after the onset of the pandemic as this is relevant to Module 2. However, in summary, from March 2020, we engaged with government on how to deal with the ongoing impacts of the pandemic on Disabled people. We alerted the Scottish Government to the impacts as they emerged and suggested solutions as to how they could be minimised. This engagement was in relation to the Covid-19 pandemic, rather than emergency preparedness and pandemic planning generally.

25. We responded to numerous consultations and calls for evidence and produced briefings and other reports to raise awareness of the impact of the pandemic on Disabled people (some of which are listed below).

26. We had regular email correspondence with various Scottish Government policy officials and departments regarding the impact of the pandemic on Disabled people. This included emails about the use of Do Not Attempt Cardiopulmonary Resuscitation notices and the shielding list. We were also in regular contact with the Scottish Government Equality Unit which held fortnightly meeting for a group of DPOs from May 2020.

Decisions that government should have made differently in relation to pandemic planning and preparedness

27. We intend to provide a further statement in Module 2 addressing government decisions covering the time frame under examination in that module. For now, we have identified the following decisions that could have been made differently by the UK and Scottish governments in relation to pandemic planning and preparedness, but note that this is not a comprehensive list:

- a) The failure to plan for stopping or reducing social care support packages without recourse to alternatives – this had a devastating impact on many Disabled people who were left without basic care.
- b) The failure to plan for the impact of the pandemic on people in care homes, with consequences including the decision to discharge people from hospitals to care homes without testing.
- c) The failure to plan adequate social care and other support for those who may need to isolate, their families and carers, and to identify what guidance may be required.
- d) The failure to plan to ensure any communications around public health would be accessible.
- e) The failure to consider the impact on Disabled people of social distancing/lockdown measures.

- f) The failure to consider what further financial measures should be implemented (e.g. benefit increases) to ensure Disabled people who could not work due to the need to isolate to protect against an airborne virus did not fall into increased financial hardship and destitution.

Lessons for future pandemics

28. Inclusion Scotland believes that a number of lessons can be learned for future pandemics, including:

- a) Governments must meaningfully involve Disabled people in policy and decision-making at all times and particularly in relation to emergency planning. Disabled people and their organisations must be involved in pandemic/emergency planning before future pandemic/emergencies take place. This is the only way to ensure that Disabled people's needs are addressed from the outset of the emergency/pandemic and includes making mainstream services fully accessible now, so they are accessible during an emergency/pandemic.
- b) Governments must close the implementation gap between law and policy intention, and reality. Laws and policies in place to protect Disabled people such as the Equality Act are not consistently applied.
- c) Governments must improve the collection of data about Disabled people, particularly intersectional data, ensuring it is publicly available and regularly updated and useful.
- d) Governments must recognise the legacy of exclusion experienced by Disabled people prior to the pandemic which meant that Disabled people were much less prepared and resilient, and our access and inclusion needs not understood or considered by decision-makers responding to the pandemic. Governments must address the systemic inequality which put Disabled people in this position.
- e) Governments must recognise the value of Disabled People's Organisations and fund them appropriately. DPOs stepped in to provide services and support and were a lifeline for many Disabled people during the pandemic. Disabled people and their organisations have many of the solutions needed to address

the barriers experienced by Disabled people and this must be recognised and valued by decision-makers.

- f) Governments must ensure that extra funding is readily available from the outset of an emergency and that it reaches those individuals who need it. This must be done by having the necessary protocols in place to direct funding to organisations that have a proven track record of effectively using public money to benefit the public.

Inclusion Scotland publications

29. Reports

- Inclusion Scotland (2020) - [Initial findings of Inclusion Scotland's Covid-19 survey](#) (7 May 2020) (HF/9).
- Inclusion Scotland (2020) - [Disabled people's lived experience of shielding: key survey results](#) (8 July 2020) (HF/10).
- Inclusion Scotland (2020) - [Rights At Risk - Covid-19, Disabled people and emergency planning in Scotland - a baseline report from Inclusion Scotland](#) (October 2020) (HF/11).
- Inclusion Scotland (2021) - ["We have been completely abandoned": Experiences of social care during the 2020 lockdown](#) (July 2021) (HF/12)

30. Briefings, written submissions and oral evidence

- Scottish Independent Living Coalition (SILC) of Disabled People's Organisations (2020) - Statement - Call for immediate action: Disabled people's human rights to life and health under threat (21 April 2020) (HF/13).
- Inclusion Scotland (2020) – [Written submissions to the House of Commons Women and Equalities Committee: Coronavirus and the impact on people with protected characteristics in the UK](#) (30 April 2020) (HF/14).
- Inclusion Scotland (2020) - [Written submissions to the Scottish Parliament Equalities and Human Rights Committee: on the 'Impact of COVID-19 pandemic on Equalities and Human Rights'](#) (19 May 2020) (HF/15).

- The Scottish Parliament (2020) - [Official report - COVID-19 Committee - Wednesday 10 June 2020](#) (Inclusion Scotland oral evidence) (HF/16).
- The Scottish Parliament (2020) - [Official report - Equalities and Human Rights Committee - Thursday 18 June 2020](#) (Inclusion Scotland oral evidence) (HF/17).
- Inclusion Scotland (2020) – [Written evidence from Inclusion Scotland \(COV0177\) Written submissions to the UK Parliament’s Joint Committee on Human Rights on ‘The Government’s response to COVID-19: human rights implications’](#) (22 July 2020) (HF/18).

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: 13/04/2023

Index of Exhibits

Audit Scotland (2021) - NHS in Scotland 2020

Department of Health (2011) - The UK Pandemic Preparedness Strategy 2011: Analysis of Impact on Equality

Department of Health (2011) - UK Influenza Pandemic Preparedness Strategy 2011

Healthandcare.scot article (2023) - 'Scotland's pandemic planning left out care sector'

Inclusion Scotland (2020) - Disabled People's Lived Experience of Shielding: Key Survey Results

Inclusion Scotland (2020) - Initial Findings of Inclusion Scotland's Covid-19 Survey

Inclusion Scotland (2020) - Response 894069412 to The impact of the Covid-19 Pandemic on equalities and human rights - Scottish Parliament - Citizen Space

Inclusion Scotland (2020) - Rights at Risk- Covid-19, disabled people and emergency planning in Scotland – Full Report

Inclusion Scotland (2020) - Written evidence from Inclusion Scotland (COV0177) Written submissions to the UK Parliament's Joint Committee on Human Rights on 'The Government's response to COVID-19: human rights implications'

Inclusion Scotland (2020) - Written Submission House of Commons Women and Equalities Committee: Coronavirus and the impact on people with protected characteristics in the UK.

Inclusion Scotland (2021) - "We have been completely abandoned": Experiences of social care during the 2020 lockdown

Inclusion Scotland (2021) - It's our planet too: Climate change, disabled people and climate action in Scotland

Public Health England (2017) - Exercise Cygnus Report, Tier One Command Post Exercise - Pandemic Influenza 18 to 20 October 2016

Scottish Independent Living Coalition (SILC) of Disabled People's Organisations (2020) - Statement - Call for immediate action: Disabled people's human rights to life and health under threat.

The Scottish Government (2016) - Exercise Silver Swan - Overall Exercise Report

The Scottish Parliament (2020) - Official report - COVID-19 Committee - Wednesday 10 June 2020

The Scottish Parliament (2020) - Official report - Equalities and Human Rights Committee - Thursday 18 June 2020

University of Edinburgh Usher Network for COVID-19 Evidence Reviews (2022) - Uncover-Portfolio 1 - 1 Pandemic Preparedness