

Witness Name:

Statement No.:

Exhibits:

Dated:

UK COVID-19 INQUIRY

WITNESS STATEMENT OF LYNNE TURNBULL

1. I, Lynne Turnbull, am the Chief Executive Officer (CEO) of Disability Positive, a Disabled People's Organisation (DPO) and registered charity based in Cheshire¹. Disability Positive currently supports in excess of 8,500 disabled people per year. Our members and staff have lived experience of disability and long-term health conditions.
2. Disability Positive has been in existence since 1992 and was previously known as Cheshire Centre for Independent Living (CCIL). Disability Positive provides services, opportunities and a voice for children, young people and adults with lived experience of disability or long-term health conditions and their families. Disability Positive runs services to assist disabled people with practical everyday tasks and helps them to integrate with their local community and to look after their own wellbeing. Disability Positive also offers advocacy services for disabled people in a variety of different situations. The organisation listens to and shares the experiences of disabled people to influence positive change in government policy.
3. Disability Positive supports the following groups of people:
 - i) **Disabled adults** who receive a direct payment for the social care personal budget and/or their families by:
 - a) Arranging appropriate care and support for their needs.
 - b) Providing support to take on the role of employer of a Personal Assistant (PA) via our Payroll Service.

¹ Reg Charity No: 1091744

- c) Helping them to manage their finances around their direct payment via our Supported Banking Service.
- d) Proving support with recruitment of a Personal Assistant (PA) via our North West Personal Assistance (NWPA), a job matching service
- e) Providing support with providing training for Personal Assistants (PAs) and for employers themselves and;
- f) Providing support to manage care needs through North West Care Cooperative (NWCC).

ii) **Disabled Children** via:

- a) Our range of inclusive social groups for disabled children and young people
- b) Our Community Connections service, which offers signposting, support with access to local activities and groups, and funding; and
- c) The services mentioned at i) a-e.

iii) **Disabled Adults** who need support to say what matters to them and understand their rights in a range of situations, via our Advocacy Service.

- 4. We are also a membership organisation. Our members join us to have an influence on our future direction and our policy and influencing work. They are able to tell us about their experiences through regular opportunities for feedback via surveys and focus groups.
- 5. Our policy influencing work is what we do to influence positive change with government and decision makers locally, regionally, and nationally. As part of this, we are members of DPO Forum England, the Disability Poverty Campaign Group (DPCG), Our Voices (a network of DPOs chaired by Disability Rights UK), Cheshire Disabled People's Panel and the government Disability Unit Regional Stakeholder Network.

Explanation of terms used

6. Disability Positive is a Disabled People's Organisation (DPO). In line with the Convention on the Rights of Disabled People (CRPD) definition², a DPO is a representative organisation of people. 100% of our members are disabled people and we are majority led, directed, governed, and staffed by disabled people.
7. In this witness statement, I will use the words 'lived experience of disability and long-term conditions', 'disabled people', to mean people facing disabling societal barriers due to their impairments or conditions (regardless of their age). This includes physical impairments, mental ill health, hearing impairments (including Deaf people with BSL as first language), visual impairments, learning difficulties, neurodiverse people, and those with chronic illness or fatigue. I will use the words 'we, us, our' to refer to Disability Positive.

Disability Positive's experience of the pandemic

8. As an organisation, we became increasingly concerned during February 2020 that we had received no guidance on what to do to safeguard our workforce, many of whom are outreach working and their work involves going into people's homes and working directly with disabled people, as well as being at greater risk from the impact of Covid 19 themselves. This was a cause of significant concern at this early stage in the pandemic. There was no briefing available to us from any government or decision-making body as to what procedures might apply to our organisation in the event of a pandemic. It is therefore my view that the UK's planning and preparedness was poor.
9. It is obvious that absolutely no account was taken for the impact of any pandemic on disabled people specifically, especially those who receive a direct payment and employ their own staff (Personal Assistants). More widely, it is clear that many of the arrangements that followed in the early days of the pandemic in March-June 2020 had not been appropriately assessed for their impact on disabled people. Had these arrangements been planned in advance, it is my view that many of the issues could have been overcome.

² UN Committee on CRPD General Comment No. 7 (2018)

10. As a result of this lack of planning we took on a large number of roles during the pandemic period including:
- a) Distributing PPE to clients for use by their Personal Assistants (PAs).
 - b) Making wellbeing calls to the Disabled people in our network.
 - c) Advising Local Authorities and the then Clinical Commissioning Groups (CCGs) on arrangements for vaccines for disabled people's Personal Assistants, including drafting clear and accessible communications.
 - d) Introducing Zoom meetings for our existing social groups for both young people and adults to continue to support mental health and reduce isolation.
 - e) Maintaining a dedicated Covid-19 page on our website with links to relevant information, guidance and advice.
 - f) Attending regular meetings with the Our Voices national group of DPOs, to share experiences that could be escalated to parliamentary select committees and government. This included writing letters to the Prime Minister, Care Minister and Minister for Disabled People highlighting key issues including language, access to vaccines, guidance for employers of PAs and concerns about the implications of the Coronavirus Act (2020).
 - g) Supporting disabled people facing 'blanket' Do Not Attempt Resuscitation (DNAR) notices through our Advocacy service.
 - h) Advising local police, retailers and the then CCGs on issues relating to wearing face coverings; and
 - i) Developing and introduced new services in response to the impact of the pandemic (such as the General Advocacy and Befriending and Counselling Service).
11. I will therefore address below the evidence we gathered over the course of the pandemic that suggests that the planning for disabled people in general, and specifically people who receive a direct payment, was poor.

The experiences of disabled people

Access to food

12. There was a hastily agreed system of food shopping delivery slots being available to certain groups. Once these were full, there was no choice but for disabled people to go in person to buy food. In the early days of the pandemic, people were required to maintain social distancing of 2 metres from other people. For many disabled people, this

was not possible for various reasons such as physical space taken up by a wheelchair or other mobility aid, lack of understanding, or being blind or partially sighted. Arrangements for community support varied by area and were communicated mostly by digital methods which meant many disabled people were unaware of available support.

Face coverings

13. Face coverings became mandatory in June 2020 on public transport and later in shops. It was immediately clear that no planning of the impact upon disabled people had gone into this. As an organisation, we took on another new role, meeting with both local police and retail to advise on how best to manage this requirement to avoid isolating and stigmatising disabled people who could not comply. The government belatedly issued guidance saying that people did not have to wear a face covering if they were unable to due to a disability or health condition.

Accessible communications

14. Communications from government about what action was needed were often far too complex and left those with lower levels of literacy confused and unclear about what exactly was required of them and what guidance did and did not apply to them. As an organisation, we heard from many clients and professionals about this confusion.
15. If pandemic planning had been more effective there could have been arrangements put in place to support with communicating complex information to these groups. Without such formal arrangements, it was left to organisations such as ours to step into the vacuum that this poor planning had created. We began hosting a 'FAQ' page on our website and supported the local (then) Clinical Commissioning Group (CCG) and local authorities with communicating key messages. We were contacted even by professionals unsure of how to interpret guidance for our client groups.
16. The introduction of the terms 'shielding' and 'self-isolation' did help give some disabled people the necessary language to describe why they could not go out. However, as an organisation, it is our view that the introduction of the term 'the vulnerable' and those with 'pre-existing conditions' was not just unhelpful but was dangerous to the human rights of disabled people. Disabled people are not inherently vulnerable. Rather,

disabled people are made vulnerable by political choices such as lack of access to care and support, poor accessibility in everyday life and poor access to information.

17. Furthermore, In the early stages of the pandemic many media outlets seized on this language to described deaths from Covid in the context of it being someone with a 'pre-existing condition', when in many cases this was probably a disability and did not always mean that their death from Covid was more likely and gives the impression that disabled people's lives are dispensable.

Categories for protecting people at risk

18. Over the course of the pandemic there were a series of overly complicated terms and categories applied to people. Terms such as 'vulnerable' 'shielding' where later changed to 'clinically extremely vulnerable' but often people were unsure whether this category applied to them. Additionally, we are aware of examples of people being sent letters advising them to shield where this was not necessary and others not receiving letters when they should have been.
19. It is my view that this complicated and disjointed approach also suggested a lack of planning. Any pandemic, whether it be a novel virus or Influenza, would require these kinds of categories.
20. Later rules were also overly complicated. The 'rule of 6' and then the tier system were very difficult to people with differing literacy levels to understand. There was not enough clear information, and again as an organisation we took on a role of interpreting and explaining this guidance to people who simply could not understand what was expected of them.

Coronavirus Act (2020)

21. In March 2020 the government passed emergency legislation (the Coronavirus Act (2020)). As part of this there was provision for easements to the Care Act 2014 which

removed disabled people's right to assessment of their care and support needs by replacing the duty of a local authority to meet care and support needs with a 'power' to meet them. In effect, this meant that the government removed the rights of many disabled people to care and support. This was a poor decision by government and gave disabled people the impression that government not only had forgotten disabled people in the pandemic but also wanted to remove any responsibility towards them.

22. This action resulting in a continuing backlog of cases. The (then) CCG locally conducted no assessments, resulting in many cases unstable placements without appropriate funding. The implementation of the Act also suggests that the government had not planned sufficiently for what local authorities should and would do in the event of a pandemic.
23. This decision was in my view, a reactive and panicked response that effectively confirmed that the government expected many local authorities would be unable to cope with the pressures of the pandemic and therefore disabled people became the least important in their list of priority responsibilities. This is in stark contrast with the principles laid out in the Care Act (2014) around safeguarding people with care and support needs who may be at risk of abuse or neglect.
24. In addition, there was too much focus on the status of key workers, rather than what key rights they were responsible for upholding. Instead of enhancing disabled people's rights during this period of disproportionate impact on disabled people, rights were taken away.
25. Whilst I recognise that in an emergency situation there was limited time for normal democratic process, there was no consultation whatsoever with disabled people or DPOs on the implications of the act. I have also seen no evidence of an equality impact assessment.

Individuals who received a Direct Payment

26. Direct Payment recipients who employ their own staff, and the PA workforce are not a small cohort of people. There are over 70,000 disabled people who employ their own

staff with an estimated 130,000 strong workforce of Personal Assistants (PAs).³ It is therefore, in my view, unacceptable that the government was not prepared for the impact upon them.

Access to Personal Protective Equipment (PPE)

27. In our experience, there was no evidence of any planning for the supply of PPE outside of the NHS including charities and people who work directly with disabled people.
28. In response to the growing crisis, the government made a supply of PPE available to employers in the social care sector for use by their employees in the early days of the pandemic, known as the National Supply Line.
29. However, it was clear that there had been no consideration of how to manage this for disabled people who receive a direct payment for the social care and employ their own staff. Disability Positive received many hundreds of calls from disabled people concerned that they had no idea how to access PPE.
30. As an organisation, we attempted to clarify the situation. We contacted the Local Authority Irrelevant and were advised that individual employers should seek to source it for themselves via the National Supply Line. However, on contacting the National Supply Line, they were told they could not because they were not an organisation. When we attempted to do this ourselves by contacting the National Supply Line, we were told that we could not order PPE because we were not an employer of social care staff.
31. Eventually, the Local Authority ordered a supply of PPE which was delivered to our offices and which we then took on a new role in distributing to our clients via volunteers.

³ Skills for Care (2022) Social Care Workforce Information, available at: <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/Topics/Individual-employers-and-personal-assistants.aspx>.

32. This experience serves to highlight that the planning for the pandemic had completely failed to consider this group of disabled people. We were also told that the procedures for distribution and ordering of PPE varied across the country.
33. It is important to note that problems accessing PPE caused enormous additional stress for many disabled people at a time of national crisis.

Furlough of Personal Assistants

34. There was no guidance at all for Direct Payment recipients until April 2020, several weeks after the first lockdown started. In my opinion, this suggests there had been no planning for this group of people.
35. During the early stages of the pandemic, social care staff were identified as key workers, and as such expected to continue to work. However, in some cases disabled people did not wish to have their Personal Assistants (PAs) coming to their homes, because of fear of transmission of Covid 19 and the risk to themselves or others in the home, however furlough of Personal Assistants was not permitted. This meant that in some cases people were continuing to pay their staff without getting the care and support they needed because they did not want someone coming into their home. There was no government guidance on furlough of Personal Assistants issued until June 2020.
36. This delay of nearly 3 months was completely unacceptable, and further illustrates a lack of planning and pandemic preparedness for the needs of disabled people.

Lessons to be learned

37. I will now lay out what I suggest could have been done to prevent the issues I have highlighted at points 8-36 and what may help improve pandemic planning in future.

Coproduction in pandemic planning

38. It is clear that there was an overall failure to plan for the needs of disabled people in the pandemic. This is made clearest by the fact that nearly 60% of deaths were disabled people.⁴ The government both nationally and locally could have planned better by engaging with disabled people and representative organisations in their pandemic preparedness. DPOs like Disability Positive have the experience and understanding to have foreseen many of the difficulties faced by disabled people. As an organisation, we were not called upon to support pandemic preparedness or planning at either a local or a national level prior to summer 2020.
39. As an organisation, we feel that there should have been, and was not, robust planning specifically for the following:
- a) Arrangements for distribution of PPE for people who employ their own care and support staff. DPOs could have played a role as a commissioned service, distributing emergency PPE for personal assistants. In any case, a consistent, clear arrangement should have been planned for the entire workforce across health and social care.
 - b) Arrangements for furlough for people who employ their own care and support staff.
 - c) Access to food. The initial phase of the pandemic involved having to queue to enter supermarkets, something that was impossible or at least very difficult for those with mobility and communication issues or who are neurodiverse. Planning at a government level did not seem to have occurred and so it was left to individual

⁴ ONS (2020) [Updated estimates of coronavirus \(COVID-19\) related deaths by disability status, England - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/peoplepopulationandcommunity/healthanddiseases/coronavirus/articles/updatedestimatesofcoronavirus(covid-19)relateddeathsbydisabilitystatus/england-officefornationalstatistics(ons.gov.uk))

essential shops what arrangements were made for people who could not queue. Those who were shielding had access to different arrangements, but this group did not include everyone who is a disabled person. There should have been centralised planning for how food shopping would work, that considered the needs of disabled people.

- d) Use of face coverings in public places and the impact on disabled people. When originally announced, exemptions were not described in the guidance. There should have been careful planning of how the use of face coverings would work, again in coproduction with Disabled People's Organisations. It is my view that this could have been foreseen before the Covid 19 pandemic, as face coverings could have applied to many pandemic scenarios.
- e) Better planning for vaccine rollout for disabled people and for personal assistants.
- f) Planning for accessible information for all key guidance, briefings, and advice, with a single point of access for accurate and up to date information, including in British Sign Language and easy read. Using local Disabled People's Organisations as trusted partners who could have taken on this role on a commissioned basis.
- g) An overall strengthening of Disabled People's Rights during the pandemic via emergency legislation. The Coronavirus Act (2020) took disabled people's rights away rather than strengthening them to provide additional protection in the pandemic. This could have been planned for in advance so that when it came to writing emergency legislation, disabled people could have been better protected in law in relation to the discrimination faced in a range of areas including the wearing of face coverings, lack of accessible information, access to PPE for use by them and their care and support staff, access to vaccines, access to food, and the use of 'blanket' Do Not Attempt Resuscitation (DNAR) orders.
- h) A better understanding of the breadth of the health and social care workforce in relation to supporting disabled people. Too often the role of PAs and unpaid carers was not understood, and this led to discrimination such as PAs not being allowed access to carer food shopping slots, not being permitted to accompany their

employer to hospital and not getting early access to vaccines along with the more traditional health and social care workforce.

- i) Implementation of Mental health support. Disabled people were disproportionately impacted by poor mental health during the pandemic due to the fear of Covid 19 and the associated risk to them, and the sheer isolation felt by many who were either told to stay at home, or who were too anxious to leave their home. This was further exacerbated by an assumed political climate of blatant disregard for the lives of disabled people.

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: 13/2/2023