MODULE 2 COVID INQUIRY UK

CLOSING ORAL SUBMISSION ON BEHALF OF DISABILITY RIGHTS UK, DISABILITY WALES, INCLUSION SCOTLAND, DISABILITY ACTION NORTHERN IRELAND

INTRODUCTION

1. Disabled people have lived through and died of Covid with the knowledge that what happened to them, as 60% of the Covid fatalities, and what happens to them in the future, as 20% of the population, is largely a matter of political and social choice.

2. In our opening submissions we made nine criticisms of the Covid Emergency State. The evidence you have heard reinforces those criticisms. They concern the way we are governed and by extension – under a democracy - the way we allow ourselves to be governed.

TREATMENT

System

3. Starting with the system. Disabled people did not exist in UK emergency pandemic planning prior to 2020. Yet the basics of what would happen to them during Covid were foretold by the UN Committee on the Rights of People with Disabilities in 2017. It effectively found the UK in breach of its legal duties over consultation, data collection and emergency planning. In a separate investigation, the Committee concluded that the resilience of Disabled people had been placed in abject jeopardy by ten years of austerity.

4. These were landmark findings by the Committee against a Western State. It's a rule of law issue that at no stage in any of the papers does anyone recognise these rights, or the fact that the UK could conceivably breach them. This is not an accident. Since 2010 the leadership of the Conservative party has increasingly defined itself by its opposition to what it considers the inconveniences of international law, especially the law of human rights, and breaches of such law. The UNCRPD is the global toolbox for real change and, given the Government don't and won't recognise these breaches, My Lady must.

Plan

5. The second failure is that when the pandemic broke out not only was there no plan for Disabled people, but the failure to plan was not recognised then and it is not recognised still.

6. Proper recognition would have publicly confronted from the outset that cuts in benefits and services had compromised the resilience of Disabled people to deal with the life changes that the NPIs were about to create.

7. It would have declared clearly that the fact that there was no whole society pandemic planning for the UK would rebound terribly on Disabled people.

8. It would have identified deficiencies in the gathering and use of data as the single greatest decision-making impediment going forward.

9. It would have assembled DPOs and other parts of the Third Sector into an Emergency network, with properly funded participation, and coordination between representative leaders and groups, dedicated experts and the right members of government.

10. It would have immediately made clear that if a significant connection between the Covid state and society was going to take place on the internet, then a large part of the disabled population were going to be disenfranchised, unable to access essential services and not able to work from home.

11. It would have done everything not only to recognise the predicament of Disabled people but to substantially redistribute financial resources to meet their basic needs.

12. That level of public reckoning and consequential planning did not happen.

13. Instead, the testimony of Ministerial witnesses produced two highly problematic answers to why it did not matter that there was no plan. The first, from Tomlinson, Badenoch, Gove and Johnson, was essentially that the risks of Covid to Disabled people were so obvious that all of Government was no doubt working on them. My Lady, they were obvious to everyone but the responsibility of no one. No one was responsible for holistic cross government leadership and identification of gaps, and when civil servants were finally pushed to deliver ambitious proposals after Michael Gove's October 2020 letter about terrible missed opportunities and time running out for the second wave, none of the major proposals were adopted.

14. The second problematic answer came from the previous Minister for Disabled people, Justin Tomlinson (the witness nominally responsible for producing a plan). His repeated response to our questioning as to why there was no plan was "That's not how Government works".

Machinery

15. Tomlinson's answer leads to our third criticism, of the machinery of government. Instead of a Department of State for Inequalities, which includes Disabled people in its portfolio, we have a Disability Unit that deals only with policy.

16. My Lady, to borrow Mr Gove's analogy, equality issues are shoved into the Cabinet Office portmanteau and then divided inefficiently across other Departments. Justin Tomlinson was not a lead Minister for Disabled People, he was, in effect, a Minister for Disability Benefits who did some front of house meetings with Disabled groups.

17. The writing out of Disabled People from Kemi Badenoch's investigation into Disparities is a case in point. Who directed it? Badenoch said she discussed it with Liz Truss, but any such decision was not written down. Tomlinson knew nothing about the decision. Hancock, who saw the purpose of Badenoch's review "to improve understanding of drivers for disparities to inform decision-making" was never told that those drivers for Disabled people were going to be overlooked. Boris Johnson did not know why they were either, but going back to the no one being responsible, he assured you it was all being done elsewhere. In our submission they all said that, because they know now it should have been, but it was not.

Expertise

18. Our fourth criticism is about expertise. Not the integrity with which it was provided, but its gaps and unexposed assumptions. Pandemic science is not socially neutral. That is because the impact of pandemics is fundamentally determined by inequalities, such that the outcomes of "clinical" advice cannot be hermetically sealed from social consequences.

19. These distinctions matter to Disabled people because their struggles are so often rationalised as inevitable due to their conditions, rather than socially conditioned by our treatment of them. That is why the case for more diverse representation of expertise in the provision of advice was so strong, not only for those within the advisory groups to contemplate the broad horizons of what they were advising about, but – as Professor Vallance noted - for those within government structures to ask the pertinent questions of their advisers.

Recognition

20. Our **fifth** criticism is that in real time the predicaments of Disabled people went largely unrecognised. We know from the DHSC Battleplans that the primary focus was on the clinically vulnerable. Broader health and social inequalities were not part of initial planning. Strategies to protect the vulnerable – and the overlaps and distinctions between clinical and social vulnerability – failed in ways that most of the witnesses you have heard from have either not been able to comprehend, or admit. There are several examples relating to food, other essential supplies and social care.

21. My Lady, reflect please on Down's Syndrome. The question for the medical officers was not who is to blame for why people with Down's were not designated as "Clinically Extremely vulnerable" earlier than November 2020, when the potential risk was flagged in June 2020. The question was what could have been done to speed that designation up?

22. It is difficult to comprehend Professor Whitty's answer that the delay was caused by the need to balance the nature of the risk with the social imposition of lockdown. It was the duty of the medics to advise on the risks. And then the responsibility of Government to facilitate a sufficient shielding package.

Neither do we accept Professor Harries' answer that the epidemiological situation was too uncertain before an earlier date. Apart from anything, Covid O received the recommendation to add Down's Syndrome to the CEV list as of 1 October. But the letter did not go out until a month later.

23. Overall, the answers around Down's syndrome are disappointing. The medical advisers were unwilling to engage with the fact that this was a disastrous event. That the delay was caused by:
    - Not acquiring data quickly enough
    - The absence of sufficient data collecting systems.
    - And the lack of coordination with the Down's community and their carers to get that data earlier and work on better shielding packages.

Engagement

24. Our sixth criticism is the lack of real engagement. When people refer to consultation, they often do not mean the same thing. When Government and Civil Servants talk about consultation, they can mean set piece meetings. Or discussions with those who speak *for* people, rather than speaking with the people themselves. Most often they mean some form of questionnaire on the internet.

25. When DPOs (and other representative groups of marginalised people) talk of consultation they mean collaboration as equals between elected officials, experts and themselves. They mean Co-Production and Co-Design. My Lady, we don't apologise for introducing this language that will potentially be new to some; and note in any event that it was used by Mark Sedwill and others. The language reflects the method to make the needed change happen. Entitlement to this collaborative consultation also represents a human right

under the UNCRPD, as opposed to some sort of discretionary gift of Government.

26. One of the lessons of this module is that we still tolerate an old fashioned elite system of club government (literally in a Georgian town house) where good chaps, willing to ask their "stupid laddie questions" of civil servants and experts, even in language they are ashamed of when made public, is regarded as somehow enough, and even something to aspire to. Covid showed all too painfully that it is not. The practical benefit of Co-production and Co-design would have been to bring diverse lived experience and, where necessary, rebel voices into the room. People capable of speaking to elites as equals and without mediation. In a fast-moving emergency that type of engagement can provide vital knowledge to Government that will otherwise only be recognised after the damage is done.

Data

27. Our seventh criticism concerns data. Even if obliged to plan from scratch, Government could have known more about clinical and social risks earlier. It could have logged into local communities and representative groups and been more intelligent about the consequences of its decisions.

28. If data was Covid decision making's Achilles heel, we press again that not one witness has recognised that data collection and utilisation in this area is a human right of Disabled people. Gavin Freeguard summarised Government reports over three decades, including 15 published since the UK signed the UNCRPD, none of which mention Article 31 of that Convention, which requires the collection of data based on individual impairment; and, (contrary to Kemi Badenoch's approach) understands a duty to collect data that relates

disability to a range of other characteristics including race, sex, gender, income and geography, in order to properly understand it.

29. This deficiency is still far from resolved. A July 2022 ONS paper found that the health service is still not collecting data on individual impairments and fails to take into account other social factors. All in all, in this country – especially for Disabled people - we are in a state of ignorance by design.

Protection

30. Our eighth criticism, is that in fundamental ways, Disabled people were left without protection during Covid. Like others the DPO focus on the care sector. It was not wrong to try to protect hospitals. What was wrong was to do so little to protect those in care in the name of protecting hospitals. In their evidence both Professors Van Tam and Harries had to confront how obvious it would have been to any public health practitioners that mass release of hospital patients into care settings would create "devastating" consequences both through patient infection, and multiple movements of the workforce. In the situation of Mid-March 2020, neither saw any practical alternative, because available facilities and structures offered none.

31. And this week, despite the evidence of his own Minister for Care, the present Prime Minister sat here and failed to acknowledge that low pay drove care staff to work in multiple locations inadvertently spreading the virus and that this must change.

Redistribution

32. The DPO final criticism concerns pandemic economics and its deliberate failure to redistribute to those most in need. Mr Sunak when Chancellor of the Exchequer on 11 March 2020 made a promise "to support...the most

vulnerable people in the form of a safety net for those who could not work, whether they were ill themselves or not at work as they were self-isolating."

33. Those words are revealing. The safety net would only exist for those who had been able to work, but were able to do so no longer. The provision of extra funding was to maintain the economic status quo for these people, to provide temporary assistance to what we referred to in our opening submissions as the politically idealised person under our contemporary economics, who is autonomous, independent and self-sufficient. There was no proper safety net for those deemed "unproductive", or recognition that those only just scraping by after a decade of cuts to benefits and services would face further financial hardship. During the pandemic 1.5 million Bounce Back Loans worth £47 billion were provided to business. In contrast, universal credit was topped up by twenty pounds a week, but there was no top up for those on legacy benefits, and no top up for Carer's allowance in England, despite demand on carers' responsibilities and time increasing sharply.

34. Helen Macnamara's evidence referred to decision makers often failing to see the human consequences of decisions. Covid economic policy involved a chronic failure of imagination and empathy.

- A failure to think through what it means if you or the person you care for can no longer get supermarket deliveries so you have to go to your corner shop, which is more expensive.

- If you have to stay inside because public spaces are closed, so your heating bills go up.

- If you have to pay for taxis because public transport is unsafe.

In the early days of the pandemic 100,000 unpaid carers were using foodbanks and 226,000 cut back on food just to get by. That arose from governmental choice. Wales and Scotland made additional payments to unpaid carers during the pandemic. England did not. £67.25 per week for full time unpaid care was apparently enough.

CONCLUSION

35. Where do these nine criticisms leave us? First, it's tempting to believe that replacement of bad leadership will necessarily lead to better outcomes. However, this disaster was a long time in the making. Our system of government, including Cabinet Government, the civil service and the seriously outdated relationship between central, and local government and civil society could not handle this type of crisis. It was hubris to believe that it could; and it would be even greater hubris to think it can in the future.

36. Second, since the 1980s we have lacked a positive vision of the state in this country that we once had. We do not see it as a source of public good; and when it was called upon to be just that, not surprisingly it faltered.

37. Finally, there is what McNamara has called a want of humanity as a feature of the bureaucratic mindset. The Covid saga reveals a dire confusion of values; and in the end begs the question of what we as a collective of people care about. Certainly for now - caring about caring and being cared for - is not recognised as the primary value of social life, and central principle of any form of good governance, but it should be.

38. For Disabled people, who know that the question on that White Board – "who will look after [those] who cannot survive alone" – was never answered, the imperative to care about caring and being cared for, for them, is a fundamental

one. And given that we are all vulnerable, born vulnerable, vulnerable at the end of life, and face vulnerability at any moment in our lives, we should all care about it too.

39. My Lady, what do these matters have to do with you, and why are they relevant to this Inquiry fulfilling its function? With respect, you cannot just produce a brilliant chronology with intermittent criticisms. You hold a pen over the way we live, and in substantial ways, the way we can die. Mention has been made that the Inquiry cannot be political or be expected to solve all manner of problems. We understand, but we have important caveats.

40. Being non-political is being political when it takes the status quo as a given. It is political not to say anything in reporting about the extent to which inequalities – including their denial and diminishment – played a causative role in Covid's outcomes. Equally, declaring that one cannot change the world is a means of overlooking the ways in which you can.

41. The resignation that these matters are too big for this Inquiry should never be accepted. *If not in this forum*, despite the compelling expert and witness evidence which links negative covid outcomes to chosen societal inequality, when or where could such matters truly be engaged with? That is what this Inquiry is particularly empowered to do, and should do. It must make the necessary findings and recommendations in the search for new governmental structures and values that were too often lacking in the Covid response.