

M1/WINVIS/01

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UK COVID-19 INQUIRY

WITNESS STATEMENT OF Claire Glasman on behalf of WinVisible (women with visible and invisible disabilities)

I, Claire Glasman, will say as follows:

Who we are

1. WinVisible (women with visible & invisible disabilities) is a grassroots multi-racial community organisation formed in 1984 to enable disabled women of all backgrounds to have a voice. Our work is based on collective self-help. We are based at the Crossroads Women's Centre in London. We have a London-wide and UK-wide network.
2. We focus on financial independence for all disabled women, and winning recognition that for disabled women, coping with disability and ill-health is hard work for which we deserve an income, and our workload should be reduced via accessibility, support services, and so on. We support the Global Women's Strike call for a Care Income for all who care for people and planet. We enable disabled women to get the benefits and statutory support services we are entitled to, and to combat discrimination of all kinds. We tackle the particular discrimination faced by those of

us who are disabled women of colour, asylum-seeking, refugee and immigrant, lbtqi+, mothers and other carers, low-income, older and younger, and many other situations.

3. We:

- Provide self-help information, support and advocacy by and for disabled women, by phone, email and in person.
- Have group meetings, and Zoom workshops open to the public.
- Run a blog with current information, campaigns and personal stories.
- Disabled women in our group and network, from various backgrounds and diverse situations, contribute our experiences and recommendations to local, London-wide, national and UK-wide coalitions, campaign groups, consultations, letters to the press, Parliamentary Select Committee inquiries, to highlight disabled women's particular situations and demands, unmet needs and neglected issues.
- Support legal challenges, and highlight injustices relevant to disabled women of all backgrounds.
- Co-ordinate the Disabled Mothers' Rights Campaign, for the right to start a family and keep our children. Against forced adoption, fostering and the unjustified separation of children from mothers by social services and the family courts.

COVID-19

4. Emergency planning for COVID-19 was the first stage where our survival was at stake and was dismissed. Many government and scientists' meetings were held, so the policies then implemented were carried out with full knowledge that deaths would result. The government, former Secretary of State for Health and Social Care Matt Hancock and others must be held to account for the many thousands of deaths which could have been prevented. They have our blood on their hands.
5. The government did not take COVID-19 seriously early on. Boris Johnson appeared to be dismissive, despite COVID killing people in China, Italy and other countries. Behind closed doors, apparently, there was discussion of "herd immunity" rather than protection. COVID could have been stopped coming in to the UK especially as the UK is a group of islands.

6. Many thousands of care home residents, disproportionately women and people of colour, as well as care staff, died from COVID being spread from hospitals into care homes, when the government already knew about transmission, as was proven in the court case brought by Cathy Gardner. It is outrageous that the government treated older and disabled people as if we are dispensable. Care workers were denied adequate PPE and many have to work across several homes in order to earn enough, or as agency workers, so COVID spread that way too. This could have been easily foreseen if there had been any concern for the older and disabled people or conditions of care workers.

7. Many thousands more died from neglect under the cover of COVID: at home and in care homes and hospitals. This is despite the valiant efforts of relatives, family carers and friends who fought to stay in touch with loved ones and tried to take them out of care homes so they could care for them at home -- but were prevented.

8. WinVisible member Micheleine Kane, from Scottish COVID-19 Bereaved Families for Justice, said:

"As a bereaved daughter whose disabled mother with multiple sclerosis was left to starve in a care home and was frightened into not going to hospital, I am one of many let down and robbed of our family members due to the measures enforced by UK and 'devolved' governments. I wanted my mother to come and live with me, but the care home said no, she couldn't leave because of lockdown. I was only allowed window visits. As a result, my mother died a slow, painful, inhumane, lonely death at their hands."

9. In our experience, government planning prioritised the survival of the fittest. The emergency and the impunity the government granted itself with Parliament's backing, were used to bring in measures that operated against us, whether by:
 - the government and its Coronavirus Act deprioritising social care support through the Care Act so-called "easements"
 - Matt Hancock the Secretary of State for Health who, it was proven in Cathy Gardner's court case, knew about transmission
 - NICE with the critical care guidelines for NHS staff (*CG/1 - INQ000188814*) which determined those disabled people who should not get medical attention in the

emergency, and named some such health conditions (partially amended in March 2020 following a challenge by disabled people and threat of judicial review)

- the NHS COVID-19 “decision support tool” (**CG/2 - INQ000188825**) which was used to refuse critical care to older and disabled people. People who scored very high on the Clinical Frailty Scale, usually older, with long term conditions or disabled, were left to die without the ambulance or a GP coming, as happened to Natalie Wolfson, an 85-year-old resident of a care home in Scotland, who had fractured her arm. (**CG/3 - INQ000188832**)
- the BMA guidance to doctors (**CG/4 - INQ000188833**)
- the issuing of “do not attempt resuscitation” notices without the knowledge or consent of disabled patients or our families (**CG/5 - INQ000188834**).

Denial of medical supplies

10. WinVisible member **Sue Elsegood** writes about how people already using ventilators were treated:
11. “I have muscular dystrophy and rely on breathing support. During the COVID-19 pandemic I was put in the unenviable position of needing to threaten legal action against the hospital which I am a patient under for respiratory health issues.”
12. “This was because I was told that despite the general public being advised by government to use PPE, and lockdown, we as outpatients using ventilators no longer would be supplied with anti-bacterial/anti-viral filters for our ventilators -- because according to the hospital, we didn’t need them -- even though pre-pandemic they were prescribed. We are at high risk of chest infections, etc., and the filters help prevent infection.”
13. “It seemed to me that disabled outpatients using ventilators long-term were being treated less than equally to inpatients on ventilators. I think the hospital was put in this position because **the government failed to have adequate stocks ready** in the case of a pandemic. Health workers told me there was a shortage of filters which were being shipped from China (where the COVID outbreak began) and would take at least three months to arrive. They said there was no guarantee the filters would be fit for purpose as they would most likely not reach the British safety kite mark

standards for use. My impression was that outpatients were being told filters were not needed because of the shortage of supplies. These filters could have been manufactured to required standards in the UK ... why not? They could have been stored and delivered in a timely manner, why not?"

14. "This did not make logical sense especially during the pandemic."
15. "After the complaint I made with the support of WinVisible, Disabled People Against Cuts and a legal firm [*sending a letter before action*], the hospital conceded and sent me ventilator filters and said they would be supplied to other outpatients as long as supplies allowed. This was very stressful to have to complain to a hospital that had supported me so well up to that point for a policy during the pandemic that discriminated against disabled outpatients on ventilators. The cause being central government's inadequate planning and response pre- and during the pandemic -- yet again treating disabled people as disposable."
16. "Baroness Jane Campbell arranged for questions to be asked in the House of Lords on the matter via one of her peer colleagues (**CG/6 - INQ000188835**), I do not know what the results were of this." (end of quotes from Sue Elsegood)
17. It seemed that the situation of disabled people was addressed only in a negative and discriminatory way. Government and statutory agencies deliberately bypassed and neglected the needs and vulnerabilities of disabled people and how we were likely to be affected in particular ways. **Government planning and the priorities chosen, operated directly against our survival. We believe the opportunity was taken to "cull" older and disabled people, majority women, who were 60% of those who died in England and 68% of those who died in Wales. ONS figures from the 2021 census indicate a drop in the proportion of disabled people. (CG/7 - INQ000188836)** According to ONS figures on COVID-19 related deaths by gender and ethnic group, **women/people of colour, including care workers, are also disproportionately represented among those who died** (see letter to the Inquiry on the draft Terms of Reference from Bhatt Murphy solicitors, Submissions on behalf of Representative Organisations of Disabled People, 7 April 2022, especially paragraphs 6 and 16). (**CG/8 - INQ000188813**)

18. At the same time, obscenely, Conservative politicians took the opportunity to profiteer from the need for PPE and other medical supplies, much of which when paid for, turned out to be unusable **(CG/9 - INQ000188837)**. The Public Accounts Committee reported that: *"The Department for Health & Social Care (DHSC) lost 75% of the £12 billion it spent on personal protective equipment (PPE) in the first year of the pandemic to inflated prices and kit that did not meet requirements – including fully £4 billion of PPE that will not be used in the NHS and needs to be disposed of. There is no clear disposal strategy for this excess but the Department says it plans to burn significant volumes of it to generate power – though there are concerns about the cost-effectiveness and environmental impact of this "strategy".*
(CG/10 - INQ000188815)

19. Matt Hancock himself **(CG/11 - INQ000188816)** and Michelle Mone **(CG/12 - INQ000188817)** are two of those under investigation for these profiteering arrangements. This is more terrible given how many care staff, nurses, doctors and others did not have PPE but had to improvise with towels, bin bags and tape, and put their lives on the line to help patients. Many such staff were among the first to die of COVID.

20. Also at the same time, non-COVID vital treatment for sick and disabled people was postponed, causing further lifelong issues and death. For some people, it's too late for treatment to help them now.

21. The approach taken in the pandemic has also set a new low in health and social care, including with lack of access to GP appointments, ambulance delays, social care assessment delays, and so on, again causing more death.

22. Further to the issues already cited. Some severely disabled women in our group were never contacted by any statutory agency or professional to ask how they would cope or were faring in the pandemic, whether by their GP, DWP or council. This is despite being identifiable as sick or disabled through medical records, being in receipt of disability benefits, or being known to councils via adult social care, council tax reduction, etc.

23. The "Clinically Extremely Vulnerable" list was too limited, **only helping an estimated 10% of the UK's disabled people.** **(CG/13 - INQ000188818)** Many disabled people,

including in our network, were not prioritised for supermarket delivery slots and could not access food. Some people only survived because they got help from friends, neighbours, mosques and gurdwaras, etc. Most food parcels delivered to those on the “Clinically Extremely Vulnerable” list (CEV) did not cater for special diets and the food could not be eaten safely, and food deliveries were left on the doorstep without considering how disabled people, majority women, some who can’t manage handling hot pans, were going to manage to cook and eat the food, such as dried pasta. We were distraught that many people could not get out of bed without assistance or they had to cut down on drinks as they had no one to help them get to the toilet – this dehydration and holding urine leads to kidney infection, pneumonia and death. Those we could message, we encouraged to call the duty social worker of their local council. The Public Accounts Committee found that poor data and lack of joined-up systems led to 800,000 people in urgent need not being in the CEV scheme, and it not being known how many had been reached somehow (BMJ 2021; 373: n1033). These problems persist today, for example, some people who need to shield are still receiving free COVID tests, while others do not.

24. There were no procedures for the emergency provision of care services or getting prescriptions and other medical supplies if the government scheme was not suitable.
25. **In some places, the death rate of people on the homecare register, mostly NOT COVID, was two or three times the usual rate.** See Bureau of Investigative Journalism report (*CG/14 - INQ000188819*) and Care Quality Commission data (*CG/15 - INQ000188820*) .
26. We are not aware of any adequate preparedness to support disabled people in a positive way.
27. One exception we know of was Hammersmith & Fulham Council’s genuine commitment to disabled people during lockdown. Disabled staff in the policy team organised for council outreach to disabled residents, and encouraged residents to get in touch to say what they needed. **The fact that Hammersmith & Fulham does not charge for homecare, which is currently unique in the whole of England, meant that people have not dropped out due to unaffordable charges, and so more people were getting services which promoted their survival.** Staff did a lot of outreach to disabled residents directly by letter and phone, and in accessible ways.

Disabled staff instructed colleagues not to assume it was enough to put out generalised messages on a website -- as some people, especially those of us who are disabled, older, lost out on literacy, cannot access the internet. **(CG/16 - INQ000188821)**

28. The emergency planning which could have been done better includes:

- Immediately increasing benefit payments to meet extra costs (along the lines of the cost of living payments but done more quickly)
- Prevention of infection and adequate provision of proper PPE, etc.
- Enabling visiting by relatives, friends and supporters to care homes and hospitals (see Micheleine Kane quoted above, and Ida Sullivan, mother of Susan Sullivan) **(CG/17 - INQ000188822)** and enabling care home residents to go home to their families, instead of relatives being denied (managers imposing that relatives don't have authority to do that without being given power of attorney by the resident, or other legal procedures).
- Social care support including to eat, drink.
- Communication in different accessible ways, including have BSL interpreters at all government COVID announcements and in plain English for people with learning disabilities, as well as in-person communication and outreach to excluded groups such as visually impaired people and those of us whose first language is not English.
- How food supply would reach sick and disabled people, including those of us without internet access who can neither order online nor get to shops.
- Access to medical attention without discrimination.

29. The UK is a signatory to the UN Convention on the Rights of Persons with Disabilities, which includes Article 11:

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.

(CG/18 - INQ000188823)

30. **Local government.** We are based in the London borough of Camden. In March 2020 we wrote to the Cabinet member for adult social care, and adult social care team. Among other issues, we raised that:
- There was no phone number given out on the Council advice webpage.
 - What were they going to do about disabled women and men who had dropped out of homecare due to unaffordable charges (charges which Camden had hiked up a couple of years prior), and others known to the council who were not on the homecare register? (This also relates to the problems with the CEV list not including many people in need, para 23 above.)
31. They didn't address these points and simply replied that the council and voluntary organisations were working together to ensure that the needs of vulnerable people continued to be met. They added that we could refer people to adult social care. We already knew that, whereas **only the council has the addresses and contact details of all who used to be on their register, and knows the disabled people in the borough via Housing Benefit, Council Tax and other records.**
32. In April 2020 we wrote a letter raising concerns to the *Camden New Journal*. No response was made in the paper or otherwise by the leader of the Council or key councillors and officers. **(CG/19 - INQ000188824)**
33. **Central government.** We joined with other disability, women's and community organisations to campaign together, campaigns such as the Inclusion London-led campaign against the Coronavirus Bill, supporting the Rights for Residents petition, and signing the Disability Rights UK open letter to scrap Coronavirus Act provisions. **(CG/20 - INQ000188826)**
34. **We sent testimony to the Parliamentary Select Committee inquiries** as a place where our concerns could be heard, as some Committee Chairs were critical of government policy and were investigating the disproportionate impact of COVID and the COVID measures on disabled people and/or discriminated groups covered by the Equality Act.
35. We submitted experiences from our group and network to these Select Committees:
- **Women and Equalities** urgently looking into the impact of the Coronavirus measures on discriminated groups. **(CG/21 - INQ000188827)**

- **Environment, Food and Rural Affairs** (EFRA) food supply and food access inquiry *(CG/22 - INQ000188828)*
- **EFRA** held a follow-up inquiry as problems with food supply continued during Lockdown 3 in January 2021. WinVisible was among 42 concerned organisations and individuals asked to update our previous testimony. *(CG/23 - INQ000188829)*
- **Health and Social Care** inquiry, Social care: funding and workforce, where we highlighted what had happened to women both at home and in care homes during lockdown. *(CG/24 - INQ000188830)*

36. Most of the public initiatives we were involved in were posted on our blog at the time. *(CG/25 - INQ000188831)*

37. We did not engage with central government before or after January 2020.

38. Local government did not consult us on emergency preparedness, prior to January 2020.

39. *With the benefit of hindsight into the UK's response to the Covid-19 pandemic, which decisions do you consider, the government should have made differently, and why?*

40. The government passed the Coronavirus Act in March 2020, which **suspended Care Act legal obligations and other duties**. This suspension of Care Act obligations was kept when the Act was first reviewed, and took a long time to be officially removed after Parliament had voted it down. Though the number of councils that officially used the measure was said to be a small number, **the fact that it was in legislation gave it massive influence, as tragically borne out by the death rate of people on the homecare register**. See para 25 above.

41. The Coronavirus Act gave powers that people in mental distress could be sectioned on the opinion of one doctor only, and that people could be detained longer, or released early — possibly without any support in the community. These powers were ended in December 2020.

42. The Care Act “easements” measures were **an abdication of legal responsibility towards disabled adults, the opposite of considering disabled people in**

pandemic planning. (Disabled children's support services were similarly abandoned and children and young people left to the care of families alone.) We were part of the urgent campaign by disability organisations and others against the Coronavirus Act.

43. Statutory agencies **should have consulted immediately with disabled people** on what our needs were, they **should have protected those of us who are older and the most at risk**, instead of bringing in policies of survival of the fittest. GPs and other medical professionals **should have been available to us as a priority**, they should not have been sending out Do Not Resuscitate letters. Government should have made health and survival information accessible in different ways at all times.

44. *What lessons can be learned for future pandemics? Why do you hold those view(s)?*

Disabled people are not homogenous but diverse, for example, are majority women, many of us have caring responsibilities for children and other people, on top of coping with our own ill-health and disability. Disabled women and others facing particular risks need to be included in future pandemic planning in a meaningful way, not just as a token gesture to be seen to fulfil Equality Act duties. Disabled people's recommendations and demands need to be acted upon. This is even more vital for disabled women, people of colour who already suffer worse health inequality, and other discriminated and excluded groups. Relevant information needs to be given in accessible formats like BSL or Easy Read and through in-person outreach to groups such as visually impaired people.

45. The government's response needs to be based on the UNCRPD Article 11.

(CG/18 - INQ000188823) Disabled people's lives were not valued and this led to high death toll. As we said at the beginning, **the government have our blood on their hands as their policies caused many thousands of preventable deaths.** They are additionally responsible for the **obscene profiteering they orchestrated by giving contracts to friends** who were not even qualified and enriched themselves from our death and suffering. At the same time and since, **health and care workers** who risked (and lost) their lives during the Covid emergency **are being denied the wage increases and proper staffing they deserve** in order to protect the NHS and all our lives. We are outraged. **The disability and older community and our families will never forget or forgive the culling we were the targets of under cover of COVID, and the way health and care workers are being treated.**

46. Are there any other organisations which you believe may hold relevant information or material in relation to the questions asked above?

The groups that were involved in widening the terms of the Inquiry to include the disproportionate impact of COVID measures on disabled people, women, people of colour and others covered by equality law (see also letter from Bhatt Murphy solicitors *(CG/8 - INQ000188813)*).

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: 4 May 2023