

Witness Name: Inclusion London

Statement No.: 1

Exhibits:

Dated: 28 April 2023

UK COVID-19 INQUIRY

WITNESS STATEMENT OF SVETLANA KOTOVA

1. I, Svetlana Kotova, am the Director of Campaigns and Justice at Inclusion London and am authorised by them to make this statement on their behalf. I have worked in the field of disability rights for more than 17 years. As a Disabled person I campaign for our equality and human rights.
2. Save where otherwise indicated, the facts set out in this statement are within my own knowledge and are true; where facts are not directly within my own knowledge, I have indicated their source and they are true to the best of my knowledge and belief.
3. Inclusion London is a charity run by and for Deaf and Disabled people promoting equality and inclusion by supporting Deaf and Disabled People's Organisations ("DDPOs") and by campaigning for the rights for Deaf and Disabled people in the UK. We support over 70 DDPOs and, through them, over 70,000 Disabled people. The self-organisation of Disabled people through DDPOs, is a key principle of the Disabled people's rights movement and DDPOs have played a pivotal role in promoting and progressing rights and equality for Deaf and Disabled people. Through our own work, lived experience and in supporting other DDPOs, we are particularly well-placed to speak on behalf of Disabled people on issues that directly affect us. Our work is guided by the social model of disability, which regards disability not as an impairment, but as a social phenomenon occurring when individuals with an impairment are disadvantaged, excluded and discriminated against by barriers

operating in society. The barriers are wide-ranging, from physical, informational and attitudinal to systemic organisational and socio economic barriers. To make equality for Disabled people a reality, these barriers must be removed and Disabled people provided with the resources and support we need to live a normal and fulfilling life. Article 1 of The United Nations Convention on the Rights of Persons with Disabilities adopts a social model definition of Disability.

UK preparedness and pre-pandemic planning in relation to disabled people

4. Article 11 of the UN Convention on the Rights of Persons with Disabilities provides that states should take all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk and emergencies. On 24 November 2011, the UK submitted an initial report on the UNCRPD. In relation to Article 11 of the UNCRPD it said. *“The Civil Contingencies Act 2004 requires government, local authorities and emergency services to have plans to prepare for, respond to and recover from emergencies. The Public Sector Equality Duty requires them to take the needs of Disabled people into account so that they have the same level of protection and support. Government is undertaking further work to ensure that Disabled people have accessible information about what to do in the event of emergencies (SK1 - INQ000182690).*
5. However despite this legal framework I am not aware of any specific work that has been done to consider specific needs of Disabled people and plan support and communications accordingly. To the contrary it appears that the specific needs of Disabled people have not been taken into account during the planning stages. The Equality Impact Assessment for emergency legislation was published three months after the Coronavirus Act 2020 entered into force. The Act itself allowed for suspending duties of local authorities in relation to people who receive social care and Disabled children with special educational needs. There was no meaningful engagement with Disabled people and Disabled People’s Organisations during the planning of the response to the pandemic. We are also not aware of any specific analysis or expertise sought from the point of view of disability equality as opposed to medical or public

health related expertise. By disability equality expertise I mean analysing social factors and barriers Disabled people face, including structural barriers which may have an impact on greater risk of being infected, greater risk of not receiving treatment on time, barriers in complying with social distancing rules, barriers in maintaining employment, education and accessing services. The lack of the input from disability equality perspective led to the *approach to pandemic planning and response being largely medical, it failed to take into account preexisting inequalities and barriers disabled people faced and often was at odds with the reality of their lives. Moreover, some measures that were introduced were found to be discriminatory, others caused possibly unforeseen, but still devastating consequences for Disabled people. I believe if social factors impacting the lives of Disabled people, the barriers they face, the need to protect the human rights of Disabled people were sufficiently considered during the pre-pandemic planning, some negative impacts would have been foreseen and prevented with appropriate action.*

6. The Official figures from the Office for National Statistics record that Disabled people accounted for 60% of COVID-related deaths. Mortality rates were higher for certain groups of Disabled people. For example, younger people with learning difficulties were up to 30 times more likely to die of COVID 19 than their non-Disabled peers. Disabled people were much more likely to die from COVID-19 even after taking into account factors such as age, underlying health conditions, poverty and risk through living in care homes. Once these factors are accounted for, working-age Disabled women with higher support needs have been about 90 per cent more likely to die from COVID 19 than non-Disabled women of the same age and more Disabled men in the same age group were 74 per cent more likely to have died from COVID-19 than non-disabled men in the same age bracket SK2 - INQ000182685. The non-medical factors that can explain this discrepancy are unequal access to healthcare and life-saving treatment or living in conditions or receiving support in such ways which exposed them to greater risk. As a parliamentary inquiry found: "The disproportionately high mortality rates that people with learning disabilities and autistic people have suffered throughout the pandemic has highlighted the health inequalities faced by this group. While pre-existing health conditions undoubtedly contributed to the increased mortality risk, they were

compounded by inadequate access to the care people with learning disabilities needed at a time of crisis. This was a result of restrictions on non-covid hospital activity, and, significantly, because of access restrictions which prevented family members and other carers accompanying people with learning disabilities in hospital to perform their expected advocacy role. “Do not attempt CPR” notices were issued inappropriately for some people with learning disabilities, which was completely unacceptable. Plans for future emergencies should recognise that blanket access restrictions to hospital may not be appropriate for patients who rely on an advocate to express their requirements (SK3 - INQ000182686).

7. Those factors could and should have been foreseen in the pre-pandemic planning process and measures could have been developed to prevent those problems from happening.

Which decisions the government should have made differently, and why?

8. Some decisions or actions taken at the beginning of the pandemic had a direct negative impact on Disabled people. This demonstrates a significant failure to recognise the equal value of Disabled people’s lives and identify potentially discriminatory impact of policies in the planning stages for the pandemic response. Those for example include:
 - Weakening local authority’s duties to provide care and special educational needs support in the Coronavirus Act 2020.
 - A Parliamentary Committee on Human Rights found that: “decision-making relating to admission to hospital, in particular critical care, for adults with COVID-19 has discriminated against older and Disabled people” (SK4 - INQ000182687).
 - De facto restricting care home residents’ right to NHS services, including access to general medical services and hospital admission, as well as Individuals being discharged from hospitals into care homes often without testing.
 - Unlawful use of blanket Do Not Attempt Cardio-Pulmonary Resuscitation Orders (DNACPRs) on the medical notes of Disabled people. Some of whom were contacted by health professionals encouraging adoption of advanced DNACPR.
 - Prioritising medical resources for COVID patients instead of Disabled people with existing conditions.

- Blanket visitor bans to prevent people with communication and cognitive support needs from being admitted to hospitals without support.
 - Greater levels of isolation and restrictions for people in residential settings. People detained under the Mental Health Act were exempt from the right to go outside for exercise once a day. The total visiting ban meant ward activities and therapy ceased. Anecdotally, this led to increased bullying, assault, and self-harm. Disabled people in residential homes were subject to 14 days self-isolation if they left the home for contact with friends or family.
9. Other measures introduced during the pandemic had severe consequences, arguably because the complexity and reality of Disabled people's lives was not fully considered in the process of planning the response to the pandemic. For example: Disabled people were disproportionately impacted by lockdown and shielding due to a lack of access to vital services including social care and routine healthcare and did not receive care for existing health conditions (SK5 - INQ000182684).
 10. The lack of access to food and medicines was a major issue for Disabled people. Supermarkets were unable to identify Disabled customers. Once the Clinically Extremely Vulnerable list was in operation this had the impact of discriminating against Disabled people with mobility and sensory impairment for whom online shopping was the only accessible option before Covid. Survey data show that 60% of Disabled people struggled to access essential supplies, including food, in the early months of the pandemic. A Parliamentary Committee found that the pandemic had "profoundly adverse effects" on disabled people's access to services and focus on CEV as a proxy to support with accessing essentials was wrong (SK6 - INQ000182692).
 11. The approach of advising those who are extremely vulnerable to shield often failed to fully understand the reality of Disabled people's lives, many of whom rely on support from other paid or unpaid carers.

What could have been done better or differently

12. The response to the pandemic was largely medical, focusing on broad brush approach based on protecting those who were considered most at risk. It failed to take into account other social factors which as was demonstrated above had a profound impact on the experiences of Disabled people during

the pandemic. This has largely happened because there was no meaningful engagement with Disabled people or our representative organisations in pre-pandemic planning and in preparing the response. The disability equality expertise, as opposed to medical or public health expertise was lacking. I am not aware of the government receiving specific advice on disability equality or advice bodies, such as SAGE including experts in disability equality.

13. The government should have protected Disabled people's right to life on an equal basis with others, ensuring any measures introduced to ration resources or access to the NHS support did not disproportionately disadvantage Disabled people. It should have systematically looked at and identified the structural barriers Disabled people face, and taken steps to address those. For example this could have included recognising pre-existing health inequalities, negative attitudes, greater levels of poverty, the state of support structures people draw on, such as social care or special educational needs support. Or addressing specific communication barriers to ensure Disabled people receive all vital information they need.
14. The United Nations published a policy briefing outlining key principles for a disability inclusive policy response to the pandemic, those principles will be helpful in future pandemic planning, including the human rights approach to disability, non-discrimination, accessibility, participation and engagement with disabled people, accountability and data disaggregation (SK7 - INQ000182689). It is really important that planning for future pandemic or other public emergency includes specific assessments of the impact, including the social impact on Disabled people, identifying possible extra barriers Disabled people might face and putting plans in place to address those barriers. It is imperative that Disabled people themselves play an active part in this process, for this it is vital that the government engages with Disabled people and their representative organisations meaningfully and co-produces possible solutions.

Inclusion London's engagement with the government

15. As far as I am aware Inclusion London was not invited to engage with the government in relation to pandemic preparation and planning. It is worth noting

though that we as a DPO experienced many barriers in engaging with the government generally. This lack of engagement was recognised as a problem by the UN Committee on the Rights of Persons with Disabilities in its Concluding Observations to the UK Government in 2017 (SK8 - INQ000182691). After January 2020 we engage with the government during the passage of the Coronavirus Act 2020, we sent a letter to London Councils outlining suggested actions local authorities might want to take to support Disabled people in London (SK9 - INQ000182688). We then continued our engagement with the government departments, including the DHSC and DWP during the pandemic.

16. Similarly, Local government or Greater London Authority did not actively engage Inclusion London in emergency preparedness, prior to January 2020. However, engagement especially with GLA has significantly improved during the pandemic.

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.

Personal Data

Signed: _____

Dated: __05.05.2023_____

