

People's Covid Inquiry February-June 2021

Citizen Witness Statement

Clare Phillips

Session 4 7 April 2021

Impact on the population (1 of 2) including families, social care, disabled people

STATEMENT

I (name) Clare Phillips

Job title/ role/ occupation Operations Manager, Supported Living Services for adults with learning disabilities

will say as follows:

1. I make this statement for the purposes of the People's Covid Inquiry, which is to be held on 7 April.
2. I am able to attend and give evidence. If unable to attend, I agree to my statement being considered by the Inquiry.
3. What is your job/ role/ occupation – how long doing this for/ brief summary of background/ experience - if possible, attach CV to statement

I have worked in adult social care since 1993, primarily with adults with learning disabilities, but also across a spectrum of support needs including Autism, mental health, physical disabilities, complex health needs and dementia. I currently work for a charity, as a senior manager and Autism lead, responsible for a group of supported living services in several London boroughs. I recently completed a MA in Intellectual and Developmental disabilities at the Tizard Centre, University of Kent.

4. What is your connection/ interest/ background/ experience relevant to the pandemic in England?

As a social care provider, I have been at the forefront of the pandemic, so have witnessed and experienced first-hand the huge challenges faced over the past year.

5. How are you able to assist the Inquiry – what is your expertise/ knowledge/ specialism?

My experience of providing social care during this pandemic is by no means unique, and will resonate with other providers. I hope my testimony will shed light on the particular impact on people with learning disabilities, and the health inequalities in this population. It has also been traumatic for

frontline staff, not only in trying to keep service users safe, but because many are themselves in high risk groups, primarily black women in what is a low paid sector.

6. What in your view were the original vision and principles underpinning the NHS?

The original vision for the NHS was healthcare for all, no matter your circumstances, free at the point of need.

Please briefly outline your testimony below or attach or reference an article which will provide the panel with relevant information.

4.4 The pandemic has highlighted the lack of integration between health and social care, which has existed for as long as I can remember. Many people with learning disabilities (LD) have additional health needs, commonly conditions such as Epilepsy, and have poorer health outcomes. The rate of death for people with LD from preventable causes such as constipation is far higher than the general population. There is a fundamental lack of knowledge about this vulnerable group in health care settings, and unfortunately many examples of people not receiving the same level of care, because of their LD. Very treatable conditions may be missed, or not investigated thoroughly. For those with more severe LD, who may be non-verbal, conditions may be difficult to diagnose, with clinicians relying on information from support staff, who know the person well. Unusual behaviours may be put down to the person's LD, rather than as a symptom of an underlying health condition.

https://www.theguardian.com/society/2020/nov/19/covid-19-deaths-must-prompt-better-healthcare-learning-disabilities?CMP=Share_AndroidApp_Other

<https://www.hqip.org.uk/resource/the-learning-disabilities-mortality-review-annual-report-2018/#.YGmwL-hKiM8>

A major issue during the pandemic has been the assumption that people with LD live in 'care homes', which employ nurses. Pre Covid, this has resulted in unsafe discharges, where the person with LD ends up back in hospital. Many people with LD live in supported living services- a tenancy in small group homes based in the community, in ordinary housing. Support staff are of course trained to provide health support, but supported living still relies on primary health care as we all do- access to GP's, district nurses.

At the start of the pandemic, I undertook a large piece of work in relation to 'Hospital Passports'- widely used documents that provide essential information about the person with LD for hospital staff. In normal times, many would be supported to the hospital with support staff. This has not been permitted during the pandemic, causing distress for the person and the support team. The hospital passports have therefore been crucial. The statement below was added to all passports, to ensure that people with LD were afforded the same healthcare.

COVID-19 STATEMENT

The Human Rights Act states that staff in public bodies (including NHS), must always protect and respect my human rights, including during the Coronavirus period and when making decisions about restrictions and actions relating to the Coronavirus.

NICE guidelines on COVID -19 state that:

Anybody with a learning disability should have an independent assessment for critical care treatment and they should *not* be assessed by the Clinical Frailty Scale (CFS).

The independent assessment should include input from carers, family and advocates as necessary.

People with LD have been disproportionately affected by DNAR orders, often without the knowledge of the person, family or support staff. DNAR orders were widespread before the Covid pandemic, so we were right to be fearful that their use would increase.

4.5 'We put a protective ring around our care homes' ¹ [Matt Hancock May 2020]

The claim of a 'protective ring' has been a dangerous falsehood. The consistent story through this is that supported living does not register on the government / public health systems. 'Care Homes' mean older peoples care homes. We are providing the same care and support to people with LD, many of whom are in clinically extremely vulnerable groups, and many are elderly. My experience has been that people with LD have been largely forgotten in the pandemic, with recent high profile stories in the media raising awareness. [COVID-19: Jo Whiley offered job before vulnerable sister who has now tested positive for coronavirus | UK News | Sky News](#)

It has been left up to individual care providers to navigate their way through, many without the necessary resources to do so. Government cuts have had a huge impact, particularly over the last decade.

PPE, Testing and Vaccines

Initially the most critical issue was access to PPE. The new PPE requirements were a problem, as we had no existing supply chains we could use. We were fortunate with donations of masks and visors and creative with supplies of gloves from motor trade, aprons from hospitality as examples. Government guidance has often changed, and has had to be interpreted for supported living services, and re written so that our staff teams could understand what was expected. Training was an issue, for example, the correct infection control procedures, correct 'donning and doffing' of PPE. Before the pandemic, support staff would use PPE such as gloves and aprons, but only for personal care support, contaminated laundry and day to day cleaning.

Policies were written and re written on weekends as guidance and rules changed often on a Friday.

The needs for people with learning disabilities and the services that support them have been ignored by the government throughout this period. Our CEO wrote open letters to senior ministers and had little or no response. There is a fundamental lack of understanding of the type of services that are commissioned locally for people with LD.

Access to testing has been very limited until recently. It has varied significantly according to the borough we are working in, and for much of the pandemic, has only been available for support staff. This has meant that in practice, we have had to explain to staff that they couldn't be tested because they worked in a service in a London borough that was wasn't offering testing, which is wholly unacceptable.

Social care is a poorly paid sector, but comes with huge responsibility. Our staff have showed resilience, commitment and compassion to the people we support, despite the risks of Covid. Many of those staff are also at greater risk from Covid due to their ethnicity and health needs. Boris Johnson had the audacity in July 2020, to make a statement appearing to blame staff for the high number of deaths in care homes. This was a painful insult, and created a lot of anger. We have collectively experienced unprecedented trauma, with staff blaming themselves for Covid infections. Access to regular testing for staff and service users has only come about in the last few months, which is a

¹ <https://www.reuters.com/article/us-health-coronavirus-britain-carehomes-idUSKBN22V1P3> Matt Hancock, House of Commons. 19 May 2020

disgrace. During the second wave, we are relieved if Covid tests come back negative. It means people we support and our staff are safe for now; we have got through another day.

[Boris Johnson refuses to apologise for blaming care homes for coronavirus death toll | The Independent | The Independent](#)

Although vaccination has been offered to support staff, we have had to be very proactive in coordinating, again because we are reliant on what is happening in individual boroughs. In one borough, we have worked with public health to set up vaccination hubs. Vaccination for people with LD has been difficult to access, despite evidence that people with LD are 6 times more likely to die from Covid. People with Down's syndrome were added to the clinically extremely vulnerable list in August 2020, but we still need to chase GPs to get those people vaccinated. The assumption of 'care homes' has again been a challenge, as some GPs have come back to us saying LD patients were left off their lists, because it was assumed that as a 'care home', we would be vaccinating people. It has been a slow process, and very stressful for everyone involved. The LD community nursing team in one local authority accessed vaccination training, and were then able to vaccinate service users in their homes. This is an example of good practice that could and should be replicated.

<https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities/covid-19-deaths-of-people-identified-as-having-learning-disabilities-summary>

https://www.theguardian.com/world/2020/nov/12/covid-deaths-for-people-with-learning-disability-in-england-six-times-average?CMP=Share_AndroidApp_Other

<https://www.england.nhs.uk/publication/covid-19-deaths-of-patients-with-a-learning-disability-notified-to-leader/>

https://www.theguardian.com/world/2021/feb/24/people-with-learning-disabilities-should-be-prioritised-for-covid-vaccines-says-jcvi?CMP=Share_AndroidApp_Other

https://www.theguardian.com/world/2021/feb/13/new-do-not-resuscitate-orders-imposed-on-covid-19-patients-with-learning-difficulties?CMP=Share_AndroidApp_Other

In advance of the second wave, and the concerns about the new Covid variants, we developed procedures that went beyond government guidance. This included reviewing non-permanent care bank / sessional workers, to limit their working to one service only, to minimise the spread of infection. We also provided scrubs so that staff could change their clothes. From December 2020, we provided enhanced PPE to services where there had been a Covid outbreak- FFP3 masks, disposable gowns, shoe covers and sleeves. We also purchased 'fogging' machines to disinfect areas.

I believe that a crucial factor in mitigating the spread of Covid in LD supported living settings, has been a move away from large services to small community homes. Many supported living services have very elderly service users, some with many health needs, including dementia.

This differs from large elderly care settings. As an example, an average supported living service may only have 6 service users. This has made it easier to ensure high levels of infection control, and keep to small cohorts of staff in each service. This was of course a challenge in the first wave, when there was no access to testing, but many staff off sick with suspected Covid symptoms. There was no requirement to wear masks at the start, so the focus was on excellent infection control.

We have thankfully only experienced a small number of deaths related to Covid. This has been in spite of a government that has not taken seriously the devastating impact it has had on the most vulnerable

in our communities. Health and social care were already under huge pressures because of lack of resources. The pandemic has highlighted the lack of integration between health and social care, and highlighted the existing health inequalities for people with LD.

I confirm that the opinions I have expressed represent my true and complete opinions on the matters to which they refer.

cphillips

4-4-2021

SIGNED

DATE

Please return to inquiry@keepournhspublic.com

Thank you
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Secretary to the panel
The People's Covid Inquiry

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