

The Rt Hon Matt Hancock MP
Secretary of State
Department of Health and Social Care
39 Victoria Street
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By post and email: mb-sofs@dhsc.gov.uk

5 June 2020

Dear Mr Hancock

I am the CEO of a London based charity providing support services to people with learning disabilities.

I recently raised serious concerns with a range of MPs, CCGs and local authorities about the lack of Covid-19 testing for people with learning disabilities and the staff who support them. I believe that this situation is discriminatory and is resulting in preventable deaths. Despite my letter and similar concerns raised by disability organisations across the country, we have seen very little movement on the matter, which I am sure you can appreciate is deeply disappointing.

On Tuesday this week, it was reported by the Care Quality Commission (CQC) that the number of deaths among people with learning disabilities has more than doubled during the height of the Covid-19 pandemic.

These deaths relate to learning disabled people living in Registered Care, but do not take into account those people living in supported living accommodation and domiciliary care services. This means the death toll will be far higher than has been reported.

It is our assertion that the level of deaths of learning disabled people is partly due to a lack of testing in learning disability services as a whole and includes both CQC registered services and supported living. It has been our experience that in trying to access appropriate testing we are consistently facing bureaucracy and a lack of understanding about the sector. People with learning disabilities are not viewed as having the same level of vulnerability as older people. As a result a whole cohort of the community is being discriminated against.

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This is of huge concern given the well-known health inequalities in the Learning Disability and Autism population, with higher rates of diabetes, obesity, heart disease and other conditions. There are also extremely clinically vulnerable people with Profound Multiple Learning Disabilities and others who find the rules of distancing and hand hygiene difficult to follow.

Despite all this we have been repeatedly informed that our service users do not meet the criteria for testing. This may in part be due to confusion and ignorance over their accommodation and registration status. People living in small shared supported living services or their own flats do not qualify for testing in the same way registered care homes do and are therefore being denied access to testing. This is grossly unfair, discriminatory and exceptionally dangerous. For all these reasons, supported living and domiciliary care for people with learning disabilities will be the next scandal after care homes.

We have also been asked to admit people into services without prior testing and, despite our considerable efforts to protect vulnerable tenants and prevent any outbreak arising from the admission of untested people, we have been largely unsuccessful in obtaining tests through the formal channels.

Testing is needed in all care settings including supported living as a **prophylactic** measure. We are now entering into the Test and Trace period with no guidance for the social care sector. The impact of one worker becoming infected with a whole service being contacted to self-isolate at the same time poses serious risks to the viability of service delivery. Prophylactic testing, on the other hand, will reduce the risks to continuity of care and help manage the potential spread of the virus. However, proactive testing must be accessible to the whole sector, including learning disabled people and those living in supported living accommodation, and not just to care homes for the elderly.

Throughout this period we have continually met barriers and bureaucracy with trying to obtain testing. It was the same issue with trying to access PPE. This seems to be based on ignorance relating to the sector which does not recognise people living in supported living settings as being medically vulnerable. I can assure you that they are vulnerable, and in many cases are *the most* vulnerable people in society.

We are still awaiting clarification on antibody testing despite being told that the NHS and Care sectors are to be prioritised. We are concerned that any future vaccinations and / or initiatives will continue to exclude people with learning disabilities living in supported living accommodation and those under 65. It is frankly neglectful that, without urgent action, we will be lamenting the deaths of more people with learning disabilities and the people who are supporting them.

We are fast approaching **Learning Disability Week 2020**, which runs from 15 to 21 June. We call on senior ministers to make it a matter of priority to understand the learning disability sector better. Perhaps a way to do this would be to make virtual “visits” so that ministers can see what small supported living services look like and understand why their guidance does not reflect these settings, and why it is imperative that people with learning disabilities are included in every testing and vaccination plan as a matter of course.

I would be very grateful if you could let me know how the government intends to tackle the issues raised here and prevent more deaths of learning disabled people in the future.

I look forward to hearing from you.

Yours sincerely

A handwritten signature in black ink that reads "G Machell". The signature is written in a cursive style with a large, looped initial "G".

Gabby Machell CMr, FCMI
Chief Executive

cc: Lynne Peacock, Chair of the Board of Trustees,
The Westminster Society for people with learning disabilities