



The Westminster Society
Your Learning Disability Network for London

Soon to be



14 May 2020

Dear Sir/Madam

I am the CEO of a London based charity providing support services to children and adults with learning disabilities in Westminster and neighbouring boroughs.

I am writing to you to raise my serious concerns 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 many deaths which could have been prevented

Today the CQC have reported over 2,400 excess deaths of people with Learning Disabilities and Autism between 10th April and 8th May. We are a leading provider of learning disability services in London, and believe that the increase in deaths is partly due to a lack of testing in learning disability services. It is our experience that in trying to access appropriate testing we are consistently facing bureaucracy and a lack of understanding about the sector. We have found that people with learning disabilities are not viewed as having the same level of vulnerability as older people (over 65) despite our organisation being registered with the CQC. As a result a whole cohort of the community is being discriminated against.

This is of huge concern. We support many people who live in a learning disability service *and* are over 65 and have all the comorbidities of the elderly population in general. It is important to note that the Learning Disability and Autism population experience well known health inequalities with a higher rate of diabetes, obesity, heart disease and other health conditions. This also includes people with Profound Multiple Learning Disabilities (PMLD) who have pre-existing health conditions which fall into extremely clinically vulnerable groups, as well as people with Autism who find the rules of distancing and hand hygiene difficult to follow. This means that they are at increased risk of infection. As it stands at the moment, unless a person lives in a care home with a primary need for over 65s, they have to be symptomatic before qualifying for testing.

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This means we support learning disabled people over the age of 65 who have dementia and myriad underlying health conditions. However, we have been repeatedly informed that our service users do not meet the criteria for testing.

We believe that this may be due to confusions over their accommodation and CQC registration status. Over the years, direction of national policy has been to diversify the provision of support for learning disabilities, including the de-registration of care homes and promotion of the rights of learning disabled people to have a tenancy and live in supported housing. This means that many former Registered Care Homes are now Supported Living Services.

We still provide support to adults with learning disabilities in registered care homes, but also many more people who live in small shared supported-living services and in their own and individual flats. These services are registered with the CQC under their domiciliary care regulations, but do not qualify for testing in the same way registered care services do.

As a result, people with learning disabilities living within supported housing services are being denied access to testing as they do not live in a “care home”. This situation is grossly unfair, discriminatory and exceptionally dangerous.

In addition, we have also been asked to admit people into services without prior testing, in our view placing other people with learning disabilities and our staff at considerable risk. Therefore we insist that there must be agreements on testing before admission to protect existing vulnerable tenants and prevent any outbreak. However, despite our considerable efforts and multiple attempts via various avenues, which has taken considerable time, we have been largely unsuccessful in obtaining tests.

This situation is unacceptable. For all the reasons highlighted above, supported living and domiciliary care for people with learning disabilities and mental health services will be the next scandal after care homes.

From our perspective, the data on targets for testing conducted and the lack of access for people we, and many organisations like us, support does not make sense. The national testing figures show that we are under the 100,000 tests a day. This is because there is an entire population who are not having fair and equal access to testing and while we lobby for local and national response to this, people are dying and will continue to die unless this situation is urgently addressed.

Our sector is heavily reliant on the BAME population which is also currently an area identified as higher risk. Without frequent testing for people who are asymptomatic we believe our staff are at higher risk as they may be working within the PHE guidance on use of PPE but exposed to asymptomatic tenants / residents / colleagues when a test (and frequent re-testing) would offer change to PPE and

practice at an earlier stage. Therefore we need to roll out testing in all care settings including supported living and conduct proactive testing as a prophylactic measure.

We have raised this with local public health leads, the local authorities in which we work and through campaigning groups like Voluntary Organisations Disability Group (VODG) but we continue to meet barriers, bureaucracy and bewilderment. We find that we get referred from one pillar of testing to another, are given another contact or email address, but this matter never gets resolved.

Tonight, as every Thursday night, the country comes together to acknowledge the efforts of key workers supporting the most vulnerable in our community. It is appalling and 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.

I would be extremely grateful if you could look into the issues raised as a matter of urgency.

I have copied this letter to the MPs in whose constituencies our services are located, and other interested parties as listed below, in the hope that collectively we can effect a vital change to policy.

Yours sincerely



Gabby Machell CMr, FCMI
Chief Executive

Simon Jarrett PhD – Editor, Community Living Magazine
Edward Argar - Health Minister
Helen Whately - Care Minister
Karen Buck - MP for Westminster North
Sir Keir Starmer – MP for Holborn and St Pancras
Jeremy Corbyn – MP for Islington
Nickie Aiken – MP for Cities of London and Westminster
Tulip Siddiq – MP for Hampstead and Kilburn
Emily Thornberry – MP for Islington South and Finsbury
Felicity Buchan – MP for Kensington
Rachael Robathan – Leader of WCC
Bernie Flaherty – Bi-borough Executive Director of Adult Social Care
Dominic Stanton – Acting Director of Adult Social Care, Bi-borough