Voluntary Organisations Disability Group

MEDIA BRIEF

Coronavirus (COVID-19) testing for disabled people using social care services

As a country, we have been, and will continue to face an unprecedented crisis in the form of the Coronavirus (COVID-19) pandemic. While the Voluntary Organisations Disability Group (VODG)* recognises that government's response must protect all citizens, we are concerned that its current programme for coronavirus (COVID-19) testing[1] continues to overlook disabled people and the workforce supporting them.

As the government expands the availability of testing, it must recognise that the social care sector supports many different people. Furthermore, its strategy for testing must reflect the risk to individuals as well as the risk of transmission. Without shifting its response away from institutions to putting people who rely on social care services at the centre of its approach, the risk is that future policy responses will affect disabled people disproportionately. The decisions policymakers are making today, which are negatively impacting on disabled people, risk being replicated in the future.

Testing for working age adults using social care services

Case study
"In one area, we support young adults with very complex medical and care needs (as a registered nursing home). When the manager rang the local health protection team and asked for 80 testing kits so all staff and residents could be tested. They said they could not help and the manager was referred to the new national portal and turned down because the CQC location number was not a registered older people/dementia care home. This is despite the vulnerability of the residents.

"We tested to see if the portal would accept an application for another service that is registered to support older people (as well as younger adults) and this was also rejected as older people is not the 'primary/sole' client group'. On phoning to query this, we were diverted back to CQC (or HPT) to access tests for symptomatic residents only."

- Government priorities during the pandemic have shifted over time, initially from protecting the NHS when there was a heavy emphasis on building capacity, supporting discharges from hospital to care homes, and admission prevention. The emphasis switched to care homes as officials became aware of the extent to which people were dying in those services. However, this focus was at the expense of a wider approach tackling the coronavirus in other services, including those for younger adults and the staff who work with them as well, as people who directly employ their own support staff (e.g. through direct payments).

- The Secretary of State for Health and Social Care has said that government's policy was based on "those who are most clinically vulnerable" and stated that "age is the biggest

[1] The current programme is for antigen tests administered to people exhibiting the symptoms or suspected to have been exposed to the virus recently. Antigen testing is currently (20/5/2020) available by 4 routes: for symptomatic people, in registered care homes, via the Care Quality Commission and via Clinical Commissioning Groups.

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factor in terms of risk of coronavirus"[2]. However, while age may well be a significant factor in terms of risk to the individual who has contracted coronavirus, testing should also be about containment of the spread of the virus in any setting.

- The Secretary of State for Health and Social Care has also said that "one of the things I have been very worried about as Secretary of State throughout my time in the job is to ensure that we get support to people in care homes for those of working age as well as elderly care homes. It's so important that we do that and we have done that throughout this issue too.[3]" However, the only provision for social care testing is exclusively for care homes and exclusively for those over 65 years old. Furthermore, government policy for many years has been to move away from care homes towards supported living for people with a learning disability and those facilities are explicitly excluded from the testing approach. Like residential care, supported living is often provided in clusters or small groups and the circumstances in which people are supported means that social distancing (from other tenants and staff) can be difficult, if not impossible to manage. The need for testing is no less important in these settings than it is in care homes.

Case study
A charity in the South East operates services for people with physical disabilities and a range of similar needs. Whilst some of their services are for people aged over 65, that is not their main CQC registration category. As a result, the charity has been denied access to the care home testing facility and has not received a response to their appeal against this decision. The local CCG has not yet nominated a local clinical lead to whom concerns should be raised. Until recently the nearest testing centre was a 50 mile each way trip and a test centre in a neighbouring town would not be offered as it is in a different county. The charity has offered to host a pop-up testing station but the CCG has not taken up this offer.

Getting disabled people who use services and staff to testing centres

If testing is conducted anywhere other than at home it requires the means of travel to a testing station. Regardless of PPE, the person transporting someone to a test is at significant risk of infection – unless the provider has access to a large minibus style vehicle and the person to be tested could and would safely travel to and from the test and comply with the requirements of the test at the back of the vehicle.

- The member of staff driving to this test would not be eligible for a test themselves. The vehicle would also require full disinfection after the journey. In many services, the only available transport would be the staff member's private car. No responsible provider would ask or allow a member of staff to transport someone who uses their services to a test in these circumstances.

- People with sensory impairments represent an additional risk, especially when travelling to unfamiliar places because of the need for physical guidance for mobility and orientation which cannot be provided at a two-metre distance, the need to be more

2 https://www.gov.uk/government/speeches/health-and-social-care-secretarys-statement-on-coronavirus-covid-19-15-may-2020

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tactile, and the communication needs of people who depend on lip reading.

- Transport may be an issue in London where there is a greater reliance on public transport than in other parts of the country. Travelling on public transport for a coronavirus test whilst symptomatic is unacceptable.

- People who use care services are more likely than the general public to rely on support for transport and services for working age adults are less likely than older people's services to have access to a large vehicle.

Administering of tests in social care settings

- The antigen test requires swabbing of the back of the throat and nose. People with a learning disability, for example, may be unable to understand this process and will require additional support. This may potentially include familiar people well inside the two-metre social distancing limit, additional reassurance exceeding the "one other member of their household" limit to being accompanied and accessible information in easy read, pictorial and social-story formats, none of this accessible information is prepared by government or its agencies.

Key messages

- As government expands the availability of testing, disabled people who use care services, of all ages, and the staff supporting them, must become a priority group for antigen testing now and for antibody testing when it becomes available.

- The strategy for testing should reflect the risks to the individual and the risks of transmission. For example, social care workers whose work is inconsistent with following the social distancing directions are therefore at greater risk of contracting and sharing the virus than some other groups of essential workers.

- As policy moves towards reducing lockdown restrictions, people in community settings, those who are more active and less able to adjust to the "new normal" and the staff supporting them will represent greater risks of transmission even if not being at greater risk from the virus itself. It is important therefore that we build on the response created by the emerging evidence on learning disability mortality rates[4] to ensure that disabled people using care services, and the staff supporting them, are immediately prioritised for testing as well as a priority for any vaccine programme if and when it becomes available.

- It has taken external pressure on the Care Quality Commission and NHS England and NHS Improvement to release data it has available that would help to inform responses to the pandemic. These public bodies should be working with stakeholders to ensure the data it holds is being made publicly available in a timely and open way so we can understand how many disabled people are being infected, and some sadly dying, from COVID-19.

4 Figures published by LeDeR on 19th May reveal that for the five weeks to the end of April 400 deaths were COVID related out of 690 deaths of a person with a learning disability. That is 58% of all deaths compared with 34% (29,315/87,529) for the general population indicating that there are almost twice as many COVID related deaths in the learning disability population.

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- The United Nations has recognised how disabled people have been disproportionately impacted by the pandemic, and that we need to ensure that they are not left behind and discriminated against in the course of the COVID-19 response and recovery[5] - an endorsement that VODG welcomes.

Commentary (21 May 2020)

Dr Rhidian Hughes is Chief Executive of the Voluntary Organisations Disability Group (VODG) and says:

"At every turn this government's approach to social care is to simply view the sector in relation to older people living in care homes. Whilst this is an important focus, as we respond to the pandemic we cannot continue to have a situation whereby disabled people and the care services that support them are overlooked.

"The testing of disabled people has all but been excluded in the current plan. The approach is to use crude Care Quality Commission registration categories as the basis by which services can access tests for the people they support. This means that unless their main category is to provide services for older people, then people will not be able to be tested. There are some exceptions where services have managed to secure local workarounds with supportive Clinical Commissioning Groups and others. But without a clear plan for the whole sector, government is putting lives at risk.

"We need people who use all social care services to be at the heart of the testing approach and for the approach to be built around them. This needs to recognise current configurations in services rather than abstract notions of what might work.

"The Care Quality Commission and NHS England and NHS Improvement both need to sharpen up how they are using and sharing data. Every death matters and it has taken these arms lengths bodies far too long to begin to look at the data they hold on how COVID-19 may be impacting specific groups and the services they use. These are matters of high public interest which demand openness and transparency in statutory bodies.

"We are deeply concerned that government is developing an approach that will be flawed in the longer term. We risk repeating mistakes and for the inequities we currently see in the system being repeated over time. Whether we experience a second wave in infections, or plan the roll out of public health measures or any vaccine, what we need is for government to address this in a way that is right, fair and balanced. We are far from that at the moment."

ENDS

***About VODG**

The Voluntary Organisations Disability Group (VODG) is the national infrastructure body representing organisations within the voluntary sector who work alongside disabled people. Our members work with around a million disabled people, employ more than 85,000 staff and have a combined turnover in excess of £2.8billion.

[5] https://eeas.europa.eu/delegations/un-new-york_en/79621/Joint%20Statement%20on%20the%20UN%20Secretary-General's%20call%20for%20a%20Disability-inclusive%20response%20to%20COVID-19%20%E2%80%93%20Towards%20a%20better%20future%20for%20all

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