

## MEDIA BRIEF

### Understanding the impact of COVID-19 testing on disability charities

#### Introduction

As part of its COVID-19 Recovery Strategy<sup>1</sup>, the government set out a target of providing a COVID-19 test first to every staff member and 'resident' in care homes for older people with dementia. From 7 June, eligibility was expanded to all remaining adult care homes for all residents and asymptomatic staff through the government's digital portal. The Department of Health and Social (DHSC) expect these care homes to cater for adults with learning disabilities or mental health issues, physical disabilities, acquired brain injuries and other categories for younger adults under 65 years.

Whilst a welcome step forward, concerns remain for people who use wider care services such as supported living settings, extra care settings and domiciliary care, for which eligibility for testing still does not apply, and for the workforce supporting them. Furthermore, poor implementation of the government's testing programme to date and a question mark over the achievement of its targets, has led to low confidence in the roll out of this next phase.

The recent launch of the NHS Test and Trace programme has also generated concern among social care providers, particularly around the impact the programme will have on the ability to protect people using services, staff and carers and secure a sufficient workforce for these services.

There are also concerns about the accessibility of the programme for disabled people.

From the outset the Voluntary Organisations Disability Group (VODG)\* has challenged government to protect all citizens through the testing programme and to not overlook disabled people and the staff and carers supporting them.

Following the launch of NHS Test and Trace, VODG undertook a rapid audit of leaders of disability organisations. The findings demonstrate that three months into this pandemic, leaders are still reporting significant issues with government's approach to testing.

#### Key messages

- There is growing distrust at the discrepancy between government announcements, experience on the ground and scientific advice.
- 91% of respondents have sought tests for people with symptoms.
- More than four out of five respondents were dissatisfied with the availability of tests for the people they support and more than half were dissatisfied about the availability of tests for staff.
- Less than half of respondents said they usually or always were able to get tests for the people they support.

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<sup>1</sup> <https://www.gov.uk/government/publications/our-plan-to-rebuild-the-uk-governments-covid-19-recovery-strategy>

- 63% of leaders are worried for the staff or people they support because of the availability of testing.
- 59% of leaders are worried for the staff and people they support or seriously concerned about the likelihood of a tragedy.
- 26% said it has been a 'battle' to get the tests they urgently need.
- All but eight have required support from the local Health Protection Team, Public Health England, their Local Authority or others in accessing tests.
- None felt confident in having all the support they need to keep the people they support safe.
- None have all the support they want for testing.
- Only 3 were satisfied with the introduction of the NHS Test and Trace programme and 35 were dissatisfied or very dissatisfied.
- Concerns about the NHS Test and Trace programme are based on the potential for whole staff teams to isolate separately, the availability of prompt testing, a lack of consideration for social care in policy making overall. In particular there was significant concern about disabled people's services being 'forgotten', and the difficulty in supporting people with complex needs with such 'chaotic' policy implementation.
- Providers continue to express concerns about testing generally, including discrimination against certain groups of people who use social care services (especially towards disabled people aged under 65) and an overall lack of understanding about the importance of getting the approach right for people who use social care services and their carers and staff.

## Breakdown of findings by theme

### Satisfaction with COVID-19 testing

- 20% were satisfied with the availability of COVID-19 tests **for the people they support** and 80% were not.
- 44% were satisfied with the availability of COVID-19 tests **for their staff** and 56% were not.

### Access to testing

- 91% have sought tests for people with symptoms.
- 17% have always been able to access tests when people they support or staff currently working with them have exhibited COVID-19 symptoms.
- 26% have usually been able to access tests and 46% have sometimes been able to access tests.

### Support with testing

- 37% have been able to access tests from the government portal directly on at least one occasion, however only 8 of these have not also required additional support to access tests for other services or occasions.
- 11% have sought help from the Department of Health and Social Care.
- 48% have sought help from the Local Health Protection Team.
- 28% have sought help from Public Health England.
- 15% have sought help from their local Clinical Commissioning Group.

- 46% have sought help from the Local Authority.
- 22% have sought help from others including the Care Quality Commission.

### **Confidence in keeping the people who use services safe**

- None have all the support they want for testing.
- 15% felt it could be better, but they were not worried.
- 26% felt it had been a battle, but they are now getting what they need.
- 57% are worried for the staff and people they support.
- 2% are seriously concerned about the likelihood of a tragedy.

### **Confidence in keeping staff safe**

- 7% have all the support they want for testing staff.
- 13% felt it could be better, but they were not worried.
- 28% felt it had been a battle, but they are now getting what they need.
- 50% are worried for the staff and people they support.
- 2% are seriously concerned about the likelihood of a tragedy.

### **Satisfaction with the introduction of Test and Trace**

- 78% were dissatisfied or very dissatisfied.

Concerns about NHS Test and Trace included:

- The implications for social care have not been thought through.
- The implications of staff having to self isolate for 14 days.
- Concerns about further increased sickness absence related to COVID-19.
- Concerns about whole staff teams being put into separate isolation.
- The absence of support for immediate testing of social care staff.
- The continuing absence of entitlement to testing in non-elderly services.
- The absence of antibody testing.
- Test and Trace may require providers to move staff from other services and use agency staff.
- It has been introduced hastily and lockdown eased before testing has been embedded.
- Lack of clarity and full guidance not available.
- Time taken to get test results back.
- Distrust that the government is following genuine scientific advice.
- The financial impact on providers.
- Concerns about disclosing confidential information.

More detailed comments about NHS Trace and Test included:

*“It is unworkable in some social care settings, especially those with complex needs.”*

*“Residents with complex needs or disabilities who test positive cannot go into isolation because they require support. It has not been well thought through on how it will affect certain groups.”*

*“It has taken too long to introduce it and then has been hastily introduced without all of the parts of the system in place. It is difficult to trust that the Test and Trace system will get the*

*timescales right on positive results. It is difficult to trust that any of our staff contacted through Test and Trace will get a test quickly enough if there is a surge in demand for tests as a result of Test and Trace. That will potentially lead us back to high levels of COVID-related staff absence with risk of unsafe staffing levels.”*

*“No clear answers to the fundamental question about what happens if a whole shift of staff have to self-isolate due to being contacted - this brings into play the whole question of the viability of the service.”*

*“It is difficult to see how this would work in a setting like ours. We can't isolate all the contacts one front line worker might have had over a number of days. It would mean isolating most of the people we support on site and losing half our staff at one go.”*

*“There has been little consideration for how care homes will be able to operate if a whole shift of staff have to self isolate as a consequence of being in contact with someone who becomes symptomatic. We have worked hard to keep a stable staff team with no additional staff joining the team and no agency staff. With the problems we have experienced re testing I believe that we would struggle to maintain staffing levels if we lose a lot of people needing to self isolate at the same time and not being tested so needing to stay away from work for 14 days. The absence of antibody tests also makes this a tough call.”*

### **Additional concerns about testing generally**

The most frequent comments concerned:

- Lack of understanding of the breadth of social care.
- Dissatisfaction with the lack of support for testing social care staff.
- Poor availability and slow turnaround of tests.
- Accuracy of test results.
- Discrimination against people in social care services not living in elderly persons care homes.
- Government statements are far from reality.
- Consent issues and support for people unable to understand an invasive test.

Comments about the testing programme included:

*“There remain gaps for young adults in care homes with other registration categories, and in other social care settings who may be particularly vulnerable to COVID-19 due to other health conditions, and shared living arrangements/reliance on carers.”*

*“The lack of whole home testing for learning disability and mental health services is also deeply discriminatory. It is clear that the Department of Health and Social Care doesn't understand the social care part of its own remit. Initiative after initiative is rolled out without any thought for the implications, without any clear process and without any clear communication. This leaves us having to assume and interpret, whilst trying to instil confidence in staff who are worried about the people they support and frightened for themselves and their families.”*

*“Whilst tests, albeit sporadically, are starting to come through for our care homes, this represents a small element of the work we do with people we support. There is no community testing for people we support who live in supported living services - in our case*

*this represents over 2000 people. There does not appear to be any understanding centrally of this whole sector of support for people with a learning disability and/or other complex health care needs. Some of whom are particularly vulnerable to the impact of coronavirus.”*

### **Commentary (8 June 2020)**

Dr Rhidian Hughes, chief executive of the Voluntary Organisations Disability Group (VODG) says:

“The findings of our audit reveal the extent to which leaders of disability organisations have had to battle to get testing into their services and the dissatisfaction with the testing programme to date.

“The most recent announcement that eligibility for testing has been expanded to all remaining adult care homes is a welcome step forward but it does not address the fact we need a testing programme that applies across the entire social care sector.

“For more than 15 years, government policy has been to promote supported living settings in preference to residential care, so it is illogical that its approach thus far has been so focused on the care home environment at the exclusion of the wider range of support services.

“Disabled people who use support services in their own home or in supported living settings deserve an equal right to testing, particularly when so little is known about the risks of transmission.

“We are more than three months into the pandemic and there is still not a fair and effective testing programme in place for disabled people and for the people supporting them. This is a national scandal. People who rely on social care services deserve to be at the heart of an equitable public health system.

“We are calling for government to commit to a date by which the wider roll out of testing for disabled people across all social care settings – for people who use services and the staff supporting them, whether asymptomatic or not – is fully implemented.

“The decisions made today that are negatively impacting on disabled people need to be put right to ensure these mistakes are not replicated in future decision making.”

### **About the survey**

VODG undertook a survey between 29 May and 2 June and received 46 responses within five days from disability charities supporting over 100,000 people. A large majority of respondents operate care homes and supported living services and many support people with a learning disability. The organisations contributing to the audit together provide around £1.6 billion a year of care and employ more than 58,000 staff.

Number of respondents who provide

- Nursing homes - 17
- Care homes - 39
- Specialist colleges - 5
- Supported living - 43
- Domiciliary care - 28
- Extra care housing - 4
- Shared lives - 6
- Advocacy - 4
- Day services - 30
- Employment support - 15

Needs supported by these organisations

- Acquired brain injury - 12
- Autism - 38
- Children and young people - 9
- Learning disability - 43
- Mental health - 21
- Older people (65+) - 12
- Physical disability - 26
- Sensory impairment - 19

**\*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.