

## **Voluntary Organisations Disability Group**

### **Representation to the Health and Social Care Committee and Science and Technology Committee joint inquiry Coronavirus: lessons learnt**

**November 2020**

#### **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 is focused on enabling disabled people of all ages to live the lives they choose. VODG believes that an ambitious, trusted and vibrant voluntary sector that works together plays a unique role in achieving this aim. VODG members work with around a million disabled people, employ more than 85,000 staff and have a combined annual turnover in excess of £2.8 billion.

VODG welcomes the opportunity to submit this representation to the Health and Social Care Committee and Science and Technology Committee joint inquiry. This submission is informed by activity we have carried out since the start of the coronavirus (COVID-19) pandemic including member engagement and surveys, analysis of government (and its agencies) policies and data, and involvement in various stakeholder groups including the social care sector COVID-19 support taskforce learning disabilities and autistic people advisory group.

In submitting our representation, our aim is to highlight the impact and effectiveness (or lack thereof) of the government's response to COVID-19 specifically in relation to disabled people and the lessons that can be learned from that response.

#### **Context**

There are 14.1 million disabled people in the UK, representing 21% of the population and 19% of working age adults. In England, 21% of the population reports having a disability. The provision of essential services to disabled people in ways that promote independence, choice and control, as well as supporting their carers is a statutory obligation. The hallmark of a fair and equitable society includes fully meeting people's needs and enabling disabled people to have full choice and control over their lives, and to be included in society. These principles are enshrined in the Care Act.

## Introduction

Since the outset of the pandemic, disabled people, including people with a learning disability, autism, sensory and/or physical impairments, have been disproportionately affected by the disease itself as well as by policies introduced in response to COVID-19. However, these policy developments, instead of protecting all citizens against COVID-19, have seen disabled people and the staff and carers supporting them simply overlooked.

Our experience is that government was wholly unprepared for the pandemic – and because it did not have sufficiently strong relationships across all parts of the social care sector, it failed to engage the available expertise in identifying issues and solutions, and its understanding of the sector was somewhat partial. As a consequence, disabled people, and their support services, were often at the back of the queue when it came to the various interventions. Whether in terms of PPE supplies, testing, etc. And now we remain seriously concerned that government's implementation of the COVID-19 vaccination will continue to overlook disabled people and the sectors that support them.

Through this inquiry, there is an opportunity for the government to acknowledge how its response to COVID-19 could have better supported disabled people and social care more generally. In doing so, there is potential for policymakers and officials to ensure an equitable public health response is in place as we enter the winter months and a second wave of COVID-19 infections, as well as in preparation for when the COVID-19 vaccination is rolled out in 2021.

## Impact on the social care sector – what is social care?

Government's response to the pandemic in relation to social care has been one that has been largely focused on some client groups, and some forms of provision, over and above, a wider recognition of the full breadth of social care provision. In particular, the government's response has been largely centred on older people's care (and nursing) homes in the delivery of personal, protective equipment, COVID-19 testing and management of workforce issues.

The social care sector delivers care and support for working age adults, which accounts for 64% of the demographic pressures on adult social care budgets (including 38% relating to services for people with a learning disability), compared to 58% in 2019/20. Older people's services account for 36%.<sup>1</sup>

We are often puzzled by the government's approach to social care, because it tends to focus on older people living in nursing or residential homes when the sector is so much wider, including supporting people in their own homes, and to a wide range of people who use services.

While we understand the government's approach towards older people's care homes, which have undoubtedly been heavily impacted by the pandemic, this should

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<sup>1</sup> Association of Directors of Adult Social Services (ADASS) (2020) *Budget Survey 2020*. [www.adass.org.uk/media/7973/no-embargo-adass-budget-survey-report.pdf](http://www.adass.org.uk/media/7973/no-embargo-adass-budget-survey-report.pdf)

not have been at the oversight of other groups of people. Indeed, a review of the available data on the deaths of people with learning disabilities from COVID-19 in England found the death rate to be up to six times higher during the first wave of the pandemic than the general population.<sup>2</sup>

The government must recognise that the social care system supports many different people to maintain independence in their own communities. Disabled people, and the services that support them, including care homes that support working age disabled people, warrant the same focus and attention from central government. There must be an immediate and long-term shift in the government's COVID19 response, as well as in its overall understanding of social care, away from institutions to putting people who rely on care services at the centre of its approach.

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. This exclusion was evident in government's policy response as well as the preparedness of the Department of Health and Social Care to engage, in a timely way, on topics such as supported living. This pattern was also consistent across government's agencies – including the Care Quality Commission and Public Health England.

While much of government's policy developed in response to the pandemic has focussed on the most visible crisis in care homes for older people, it must now be recognised that much more attention is needed on those of all ages receiving care and support in other types of care homes, in the community or in their own homes.

### **Impact on the social care sector – funding**

Adult social care in England was chronically underfunded prior to the onset of the pandemic and in urgent need of reform. COVID-19 has brought about additional and significant financial pressures for the sector as well magnifying long-standing systemic issues that are in urgent need of address.

The increased costs associated in dealing with the pandemic, the severity of which is still unknown, alongside the long-standing underinvestment in the sector by central government, means many of the vital care and support services that enable people to live fulfilling and independent lives are under threat, and this will have a direct impact on the lives of disabled people as well as knock-on effect on other public services.

The impact of the government's failure to adequately address the current financial pressures in the system is reaching a tipping point. Even in addition to earlier funding provided to local authorities from central government in the form of the temporary and one-off £3.2 billion Emergency Funding and subsequent Infection Control Funds, the funding for social care put forward in the Spending Review 2020 falls far

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<sup>2</sup> Public Health England (2020) *Deaths of people identified as having learning disabilities with COVID-19 in England in the spring of 2020*  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/933612/COVID-19\\_learning\\_disabilities\\_mortality\\_report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933612/COVID-19_learning_disabilities_mortality_report.pdf)

short of what is needed to sustain adult social care services at such a crucial time. Furthermore, the experience of many voluntary sector providers during the first round of funding was that the allocated money did not reach them in an effective nor efficient way, if at all, and commissioners implemented inflexible and onerous terms, making it difficult for providers to ensure continuity of care. At a time of a pandemic, we would expect commissioners to hold tight on outcomes and looser on the means towards achieving those. Yet, providers remain concerned commissioners may seek to 'claw back' funding if activity was not delivered to the contract.

VODG fully understands that local authorities face significant financial pressures alongside increasing unmet need. There has been a significant reduction in confidence among directors of adult social services in meeting their statutory duties relating to adult social care - only 4% of directors are fully confident that their budget will be sufficient to enable them to do so; compared to 35% in 2019/20.<sup>3</sup> However, as an infrastructure body of more than 100 voluntary sector organisations supporting disabled people across England, we are concerned about the long-term sustainability of the social care sector and for disabled people who require support. This is another example of the how the government is overlooking people in most need.

If there is a lesson to be learned from the COVID-19 pandemic, it is that a full and proper review of the adult social care sector, with a robust plan for sustainable and workable long-term reform, is urgently required – not the short-term fixes that the sector has been subjected to by successive governments.

### **Impact on disabled people, their families and the workforce supporting them**

The impact of the pandemic on disabled people and their families has been far-reaching and has stretched across all aspects of life from accessing every-day care and support to employment to end of life care.

The Coronavirus Act introduced emergency provisions including the suspension of the legal duty on councils, under the Care Act, to assess and provide social care for adults, including disabled and older people and carers – people in some of the most vulnerable circumstances.

And while local authorities are not reporting the enactment of easements, increasing unmet need is rising. Just under a half of directors of adult social services have indicated an increase in unmet need since March 2020. 11% have reported an increase of 6-10%.<sup>4</sup> Furthermore, there has been no indication as to when these provisions will be 'switched off' meaning that even against a backdrop of increasing unmet need, local authorities can suspend their duties to provide care and support.

From the outset of the pandemic, disabled people and their families and carers, and the workforce supporting them, have been overlooked in government guidance on

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<sup>3</sup> ADASS (2020) *Budget Survey 2020*. [www.adass.org.uk/media/7973/no-embargo-adass-budget-survey-report.pdf](http://www.adass.org.uk/media/7973/no-embargo-adass-budget-survey-report.pdf)

<sup>4</sup> ADASS (2020) *Coronavirus Survey Report 2020*. [www.adass.org.uk/media/7967/adass-coronavirus-survey-report-2020-no-embargo.pdf](http://www.adass.org.uk/media/7967/adass-coronavirus-survey-report-2020-no-embargo.pdf)

infection control, personal protective equipment, and testing and there has been little recognition of the types of services supporting them. Care settings outside of older people's care homes were the last to be included in the government's routine testing programme, and still disabled people living in supported living settings and non-CQC registered settings are not fully included in the programme. This cannot continue and as we approach the roll out of a COVID-19 vaccination programme, disabled people must be given the same priority as care home residents have in the current plans.

The impact of the pandemic on disabled people is most acutely evident in the disproportionate number of deaths among disabled people from COVID-19. Disabled people made up 6 in 10 of all deaths involving COVID-19 between March and July in England and Wales.<sup>5</sup> Deaths from COVID-19 among people with learning disabilities is estimated to be up to six times higher than the general population.

Alongside this, were reports that disabled adults of working age were having Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices applied to their care plans without consultation with them or their families, of which the Care Quality Commission (CQC) is now undertaking a review. However, given the data CQC hold, CQC was very slow to initiate a response following calls by the sector to release data and to exercise its voice on DNACPR.

More recently, government proposals to restrict staff movement between care settings to reduce the risk of transmission of COVID-19 is the latest policy to disregard the impact its implementation will have on disabled people's services, many of which are much smaller than the larger older people's care homes for which such a policy is designed. The implementation of this policy will be problematic for care homes of all sizes but the impact of such a policy could be devastating on disabled people and the providers and workforce supporting them. Lessons must be learned from earlier in the pandemic about the consequences of inequitable policy approaches.

Finally, throughout the pandemic as government has issued a plethora of complex guidance and policy documents as well as given broadcast briefings and issued multi-media online communications, there has been a glaring omission for the consideration of accessibility of information. This is most striking when it comes to the Prime Minister's coronavirus televised updates. There is no supporting accessible information, despite on health matters the statutory accessible information standard, and that has meant that charities have had to stand in and translate.

The government must ensure the production of timely, accessible guidance and communications to ensure disabled people including people with learning disabilities, autistic people and people with sensory impairments, have the same information at the same time as everyone else.

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<sup>5</sup> Office for National Statistics (2020)

*Coronavirus (COVID-19) related deaths by disability status, England and Wales: 2 March to 14 July 2020:*

[www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/2marchto14july2020#:~:text=in%20Table%201,-.Disabled%20people%20\(those%20limited%20a%20little%20or%20limited%20a%20lot,\(27%2C534%20of%2046%2C314%20deaths\).](https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/2marchto14july2020#:~:text=in%20Table%201,-.Disabled%20people%20(those%20limited%20a%20little%20or%20limited%20a%20lot,(27%2C534%20of%2046%2C314%20deaths).)

## **Conclusion**

The decisions made throughout the pandemic, as well as those still being made today, are negatively impacting on disabled people need to be put right to ensure these mistakes are not replicated in future decision making. Action to address the impact of COVID-19 on the lives and deaths of disabled people cannot wait for further reports and reviews. VODG wants to work with government to ensure disabled people continue to receive the right care and support throughout this pandemic. Whilst a number of serious concerns have been raised in this submission, we are standing by to work with policymakers to ensure a more inclusive and equitable public health response in the future.

VODG is happy to prepare further written evidence or provide oral evidence to the Committees. If this would be helpful, please contact us at [research.policy@vodg.org.uk](mailto:research.policy@vodg.org.uk)

**Ends**