**Media brief**

**Ensuring deaths of people with learning disabilities and/or autism are fully acknowledged**

**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.

**The call for transparency in the death of disabled people**

The government’s social care response to the COVID-19 pandemic has totally overlooked the needs, rights and entitlements of disabled people. This can be seen in the way the government’s response is almost always focused on older people living in care homes. While this is an important focus, the government must recognise that the social care sector supports many different people to maintain independence in their own communities. Disabled people, and the services that support them, warrant the same focus and attention.

Understanding care home deaths has been critical to planning service responses within the social care sector. Much of that understanding has been built from the reporting, collation and availability of data looking at the situation in care homes. Such reporting needs to take place across all social care services, including those that are regulated by the Care Quality Commission and those that are not.

VODG has been calling on government and its agencies to release data on the deaths of people with a learning disability. Representations have been put forward to the Care Quality Commission and NHS England and NHS Improvement to release data[[1]](#footnote-1), and one group is crowdfunding the legal costs[[2]](#footnote-2) to ensure full transparency and release of data under the banner *Every Death Counts*.

**Mounting concerns**

The lack of attention given to disability issues has resulted in limited information and has frustrated efforts to understand the impact of the pandemic on disabled people and services that support them.

VODG recently partnered with Lancaster University on a short audit to understand testing and death rates among social care providers. On 21 April 2020, VODG published

data[[3]](#footnote-3) that warned deaths from COVID-19 among people with a learning disability were still more common than general population death rates for the same age group.

NHS England and NHS Improvement do not have a good track record in the timely and frank release of the data that VODG and other groups have been calling for in order to support better service design. The handling of previous reports from the Learning Disabilities Mortality Review (LeDeR) programme[[4]](#footnote-4) is one good example, and another is the delayed release of information about people with a learning disability still held in long-stay inpatient units[[5]](#footnote-5).

We have reached the point where government and its agencies can no longer supress data about the death of people with a learning disability. This is information that is in the public interest. We understand that NHS England and NHS Improvement are at the very least reaching a position to release this data. VODG is calling for this to be done with the greatest possible transparency and will respond in full once the data have been released.

**Commentary (13 May 2020)**

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

*“Government must shift its response to be more inclusive of all groups using social care services, including disabled people. We cannot continue to have a situation whereby disability services are continually neglected from government’s policy responses.”*

*“Every death must count and we are urging NHS England and NHS Improvement to be open and transparent in the release of data on the deaths of people with a learning disability. We must measure all lives lost. The consistent routine reporting and publication of data can build the necessary intelligence to help inform current and future service responses.”*

Chris Hatton, Professor of Public Health and Disability at Lancaster University, adds:

*“We have seen throughout the COVID-19 pandemic that timely information and analysis on who is more likely to die can change what we do and save lives. We keep being told that the information is there for people with learning disabilities and autistic people, but that we’re not allowed to know what it is. There is every reason for this information to be made public, now.”*

**Ends**

1. The Health Service Journal has reported a detailed representation to the Minister for Care from the Shadow Minister for Social Care Liz Kendall: [www.hsj.co.uk/download?ac=3045738](http://www.hsj.co.uk/download?ac=3045738)
 [↑](#footnote-ref-1)
2. Every death counts: [www.crowdjustice.com/case/every-death-counts/](https://www.crowdjustice.com/case/every-death-counts/) [↑](#footnote-ref-2)
3. #  New data from adult social care providers reveals urgent need to better support disabled people and their services through the coronavirus (COVID-19) pandemic:

[www.vodg.org.uk/news/new-data-from-adult-social-care-providers-reveals-urgent-need-to-better-support-disabled-people-and-their-services-through-the-coronavirus-covid-19-pandemic/](https://www.vodg.org.uk/news/new-data-from-adult-social-care-providers-reveals-urgent-need-to-better-support-disabled-people-and-their-services-through-the-coronavirus-covid-19-pandemic/) [↑](#footnote-ref-3)
4. #  Learning Disabilities Mortality Review (LeDeR): [www.bristol.ac.uk/sps/leder/](http://www.bristol.ac.uk/sps/leder/)

 [↑](#footnote-ref-4)
5. #  Address the national scandal of long-stay inpatient units – VODG report calls on incoming government to take action to transform care:

[www.vodg.org.uk/news/address-the-national-scandal-of-long-stay-inpatient-units-vodg-report-calls-on-incoming-government-to-take-action-to-transform-care/](https://www.vodg.org.uk/news/address-the-national-scandal-of-long-stay-inpatient-units-vodg-report-calls-on-incoming-government-to-take-action-to-transform-care/) [↑](#footnote-ref-5)