

P-05-1116 Prioritise people with a learning disability to be vaccinated against COVID-19 in Wales, Correspondence – Petitioner to Committee, 04.02.21

Response to Ministerial Statement on Petition – from the Rev'd Dr. John Gillibrand

Dear Ms Finch-Saunders,

Firstly, I wish to thank you for giving me the opportunity to respond to the letter you received from the Health & Social Services Minister on January 28th

Our son Adam is now in his 20s. He is on the autistic spectrum with significant learning disability and highly challenging behaviours. As a family we struggled for many years to access appropriate residential provision for him and more recently to ensure that such provision was reasonably close to us and other family members. He is largely non-verbal and would not be able to make representations of this nature on his own behalf.

It is against this lived experience as a family carer, that I started the petition and whilst I understand that the Minister is committed to following the JCVI guidelines, I am naturally concerned like many parents, and family members for our loved ones, especially those living in residential/supported living settings.

I understand that the Wales Learning Disability Consortium has this week launched its campaign, which focuses on the need to prioritize people with a learning disability in residential/supported living houses like my son Adam.

<https://www.ldw.org.uk/ask-your-member-of-the-senedd-to-support-people-with-a-learning-disability-and-their-family-carers-on-vaccine-issues/>

People in those support settings are at higher risk of infection due to the shared, communal nature of their living settings and that they will have a wide range of staff coming into their homes and recently an academic at a Welsh University wrote:-

We understand that people with learning disabilities will be naturally considered for vaccine at various stages of the guidance e.g. those over 70 will be offered the vaccine when it is time to vaccinate the over 70's in the population. However, in order to mitigate against health inequalities the JCVI advises flexibility in the vaccination program e.g. with regard to younger adults in care homes the Green book advice is that given the high risk of exposure in these settings, the closed environments and risk to the population group where a high population in the setting would be considered eligible it would be prudent and beneficial to vaccinate the whole resident population.'

There are currently about 3,500 people with a learning disability living in supported/residential settings in Wales. Many of those might already be picked up due to other underlying health conditions or age, which might see them placed in Categories 2 to 4, however many, like my son are being told that they will be placed in priority group 6 despite living in residential/supported living settings which can exacerbate their risk of catching and dying of Covid.

Naturally as a parent of a young autistic man who also has a learning disability, I am concerned that the recent Leder report states that he is 30 times more likely to die of Covid, than people of his own age without a learning disability.

<https://www.gov.uk/government/news/people-with-learning-disabilities-had-higher-death-rate-from-covid-19>

Adam and others with similar communication difficulties associated with their learning disability or autism will struggle to indicate that they have symptoms and I was very angry to learn this week that Adam who was living in a residential home but has now been moved to a supported living house has been moved from Category 4 to Category 6.

So in response to the Minister's letter to you, I fully understand that the JCVI guidelines are developed with academic and medical expertise, but there is growing evidence of the risk to people with a learning disability in specific housing settings.

In England, Mencap and others are campaigning for all people with a learning disability to be vaccinated in groups 1 to 6, but in Wales the Learning Disability Consortium which is made up of Learning Disability Wales, Mencap Cymru, All Wales Forum of Parents and Carers, All Wales People First, Down Syndrome Association Wales and Cymorth Cymru are taking a very pragmatic stance and asking for particular attention to be given to those living in supported living or residential settings. They have done this because they recognize the particular risk within these settings but also accepting that only 1 in 4 of the 65,000 learning disabled population in Wales is known to services. GP registers of learning disabled citizens in Wales is not yet advanced enough to highlight every person with a learning disability.

Given this I would ask that the Committee contact the Minister again and ask if Welsh Government is prepared to look at people of ALL ages with a learning disability living within residential or care home settings like my son Adam.

I leave you with the sobering thought that people with a learning disability are 6 times more likely to die of Covid and 30 times more likely than their peers aged 18 to 34, so as a parent of a 27 year old son you can imagine how scared we are as a family for his life.

Yours sincerely,

John Gillibrand