



Professor Jonathan Van-Tam
Deputy Chief Medical Officer

16th December 2020

Reply to: info@LDEngland.org.uk

By e mail

Dear Jonathan Van-Tam

Making people with a learning disability a priority for COVID vaccination

We are writing to ask you to use your influence to add people with learning disabilities to the list of people who should be prioritised for vaccination against COVID 19.

As the only national membership organisation that brings together members with learning disabilities, families, professionals and organisations, we have already raised this issue. As the Representative Body Co Chairs, we wrote to the **Rt Hon Helen Whatley MP** on 27 November, asking her to use her influence as the Minister for Care to add people with learning disabilities to the list of people who should be prioritised for vaccination against COVID 19. Learning Disability England also coordinated and was a joint signatory to the Open Letter sent to **Professor Wei Shen Lim at the JCVI** on the same date. We were glad to be joined by partners as a reflection of the importance of this issue to our members and the wider learning disability community.

To date we have not had a response to either letter, and we are therefore contacting you to ask that you take action to support the addition of people with learning disabilities to the priority list. We attach a copy of our letters to Helen Whatley and the JCVI for your information. Those letters set out the background and attendant statistical information to our request, and we would ask that you take the content of these letters into consideration as part of this request.

We know from PHE's statistics that people with learning disabilities are **6 times as likely to die as a result of COVID** than the general population; and that the death rates for people with learning disabilities aged 35-44 are higher than for those in the general population aged 65-74.

Our proposal is straightforward. As with flu vaccinations now (many of the risk factors for people with learning disabilities are similar), put adults with learning disabilities of all ages registered with GPs as one of the most urgent priorities for COVID-19 vaccinations. In total this would be around 250,000 people in England, a fairly small population. Working through GP registrations means there is an infrastructure to find people without complicated gatekeeping. An equal priority for vaccination would be people who are in regular, close contact with the person, including family (many of whom are likely to be in current high priority vaccination categories) and paid workers

Learning Disability England c/o Anthony Collins Solicitors, 134 Edmund Street, Birmingham, B3 2ES
P- 0300 1110444 E- info@LDEngland.org.uk W- www.learningdisabilityengland.org.uk



supporting people. As well as saving lives amongst a group of people who already experience considerable health inequalities and have been disproportionately hit by COVID-19, it will potentially make a difference to a group of people ONS data suggests have been disproportionately by Covid, especially their wellbeingⁱ.

Whilst we recognise that people with learning disabilities who are in the Clinically Extremely Vulnerable (CEV) group and those over 65 will qualify for priority vaccination, we believe that this will not adequately protect and safeguard people with learning disabilities for the following reasons:

1. Information at the detailed level about **why** more people with learning disabilities are dying from COVID-19 is not currently available. We believe there is therefore an urgent need to act and prioritise those with learning disabilities on the basis of the statistically significantly greater risk of death from COVID-19. For example, death rates for younger adults with learning disabilities are higher than for older people in the general population who are currently a higher vaccination priority: the most common age of death for COVID-19 amongst people with learning disabilities is 55-64.
2. Many people with a learning disability live in congregate settings, which we know poses a statistically higher risk of infection. Many of these people are of working age compared to the older population predominant in registered care settings. Indeed, only 16% of people with learning disabilities live in registered care. Most live in congregate but unregulated or supported living shared environmentsⁱⁱ.
3. The conditions listed for the CEV and 'at risk' groups, we believe, may well miss out some conditions particularly relevant for people with learning disabilities (e.g. dysphagia); and the criteria doesn't take into account the risk experienced by a number of people with a learning disability of having multiple health conditions.
4. Evidence indicates that GPs don't reliably record the information that would be needed to decide who amongst people with learning disabilities come into the CEV and 'at risk' categories. For example, we know GPs records do not currently reliably record Down Syndrome, as borne out by recent challenges in contacting people affected by being added to the CEV list. GPs records similarly may not record whether a person has severe or profound learning disabilities (needed for the 'at risk' group), and they are unlikely to have the severity of health conditions recorded for people with learning disabilities in a way that would inspire confidence if used for COVID-19 vaccine prioritisation. A potential consequence of this is that GPs could easily get tied up in complex bureaucratic processes in deciding who amongst the population of adults with learning disabilities is eligible for a prioritised vaccine at different levels. This is

potentially wasteful and inefficient at a time when health services are under pressure. It also means that the reasonable adjustments needed to make COVID-19 vaccinations possible for the maximum number of adults with learning disabilities may not be given due attention, leading to further discriminatory impact.

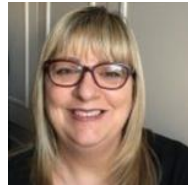
On the basis of all the evidence, we consider it would be much more efficient and equitable to place every adult with learning disabilities registered with their GP as a high priority for a COVID-19 vaccine.

There is an information and support infrastructure ready (GP practices and learning disability nurses), with sufficient volume and focus for a strategy to prepare people for the vaccine and apply the reasonable adjustments required. Time wasted on deciding eligibility could be used to vaccinate people and those closest to them.

We believe that with your intervention we can begin to address the stark inequalities people with learning disabilities are experiencing during this pandemic.

We and colleagues at Learning Disability England are happy to provide further briefing, and to meet and to discuss the best way to take these priorities forward.

Yours sincerely



Jordan Smith Wendy Burt Scott Watkin, BEM
Representative Body Co Chairs

Encs.

Letter to Rt Hon Helen Whatley, MP dated 27 November 2020
Letter to Prof Wei Shen Lim, JCVI dated 27 November 2020

i

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/coronavirusandthesocialimpactsondisabledpeopleingreatbritain/may2020>

ii [Build Back Fairer: The COVID-19 Marmot Review - IHE \(instituteofhealthequity.org\)](#)