

The Covid 19 Vaccine and people with learning disabilities: A Short Report



Background

Since November 2020, Learning Disability England members, alongside partners, have been campaigning for ALL people with learning disabilities and their unpaid family carers to be made a priority for Covid 19 vaccination.

This short report looks at the beginnings of the campaign, the reasons behind the campaign, the current situation and ongoing concerns.

It also includes quotes and case studies from Learning Disability England members and partners, capturing not only their concerns but also the resources which have been developed and shared, in the hope they will help others.

How and why the campaign started

In November 2020, some of the vaccines that were still being tested were nearly ready for approval.

The UK government announced that at risk groups would be vaccinated before Christmas, and most over-50s before the spring. At that time, the government said these at risk groups would be elderly people and health and social care workers.

Learning Disability England members began to talk more about who would get the vaccine first. A lot of members said they wanted to see ALL people with a learning disability and their family and friends who were unpaid carers made a priority for the vaccine.

This was because we knew from [Public Health England's statistics](#) published on 11 November 2020 that people with learning disabilities are 6 times as likely to die as a result of COVID than the general population.

Different people and groups began campaigning and writing to the government to say this and ask for people with learning disabilities were made a priority.

On 27 November, Learning Disability England's Representative Body co-chairs [sent a letter to Helen Whatley MP](#) to put forward why they think people with learning disabilities should be high on the list for getting the vaccine.

On the same day, Learning Disability England along with partner organisations sent [an Open Letter to Professor Wei Lin](#), the chair of the Joint Committee on Vaccines and Immunisation (JCVI).

This is because the government said the JCVI would be the group that decided who would be a priority for the vaccine. They said the JCVI would make sure decisions were independent and based on facts.

Why this matters

People with learning disabilities have been marginalised in health and care for decades. The health inequalities and discrimination they experience has been shown to lead to worse outcomes and dying younger.

The last [annual Learning Disability Mortality Review](#), published in 2020 and based on 2019 data prior to the outbreak of Covid 19, found that women with a learning disability died on average 27 years earlier than women in the general population, and men with a learning disability died on average at 22 years earlier than men in the general population.

People from 'BAME' groups with a learning disability were found to die at an even younger age.

Many of these deaths were caused by treatable conditions and in some cases even minor ailments. And they were not limited to people with 'profound and

multiple' learning disabilities. In particular, Chapter 3 stated: "*pneumonia was the most frequently recorded cause of death in people with learning disabilities whose deaths were reviewed in 2019, as was the case in previous years.*"

When Public Health England released the [statistics of deaths of people with learning disabilities who had died from Covid 19](#) in November 2020, these showed that people with learning disabilities were dying with Covid 19 at a rate of up to 6 times higher than the general population.

This was spread across all age ranges, not just people over 50. And it was not limited to people with' profound and multiple' learning disabilities.

The combination of these two reports painted a bleak picture. People with learning disabilities were at a higher risk of dying from a respiratory illness, particularly pneumonia, than the general population. This had been the case for a number of years. And with Covid 19, this was translating into a 6x higher death rate for people with learning disabilities compared to the rest of the population.

"I live alone and I don't have any paid support. The figures of people dying has really frightened me. I would feel much safer doing what I need to do like buying food if I had the vaccine. I am frightened to leave my house."

Self advocate with a learning disability

Learning Disability England members felt this was an unacceptable risk that had a simple solution: address the impact of Covid 19 by prioritising every person with a learning disability for the vaccine.

"My worry is that so many people with learning disabilities are dying. Intense sensory issues prevent many people with learning disabilities and autistic people from wearing masks. This increases their risk of catching and transmitting Covid. To make reasonable adjustments in the interests of equality legislation to protect people with learning disabilities, and also to help keep the broader population safe, people with learning disabilities should become a high priority for vaccinations."

Family carer

The learning disability population in England is relatively small as a part of the overall population. At the vaccination rates the government were predicting, it

would take the equivalent of approximately one day to vaccinate every person with a learning disability.

The growing voice across the learning disability community

On 2nd December, the Joint Committee on Vaccination and Immunisation (JCVI) published updated guidance on priorities for who would get the vaccine first.

People with ‘severe and profound’ learning disability were included in the list alongside other people who were deemed extremely clinically vulnerable because of a medical condition.

However Learning Disability England members, along with many members of the wider learning disability community, did not feel this went far enough. So on 3rd December, Learning Disability England began to encourage members to write to their MPs.

By 16 December, Learning Disability England and partner organisations had not had a reply to the letters sent in November. Roll out of the Pfizer vaccine had started. And members felt it was really important to keep the pressure on. So the Representative Body Co Chairs [wrote to Jonathan Van Tam, the Deputy Chief Medical Officer](#) to ask him to intervene.

On 18 December, the [JCVI replied to the Open Letter](#) sent on 27 November. The letter advised that they had made the decision that they would **not** prioritise all people with learning disabilities for the vaccine:

“Those considered clinically extremely vulnerable have been prioritised for vaccination as have those in clinical risk groups aged 16 years and over. In early November 2020, adults with Down’s Syndrome were added In comparison, whilst persons with learning disabilities not associated with Down’s Syndrome had elevated risks related to COVID-19, these were not of the same order of magnitude as persons with Down’s Syndrome.”

Letter from JCVI Secretariat dated 18 December 2020

Over the next 6 weeks, the voice of the learning disability community demanding priority vaccination for all people with learning disabilities grew louder. Some of the activities, amongst many, included:

- Sunderland People First self advocates [raising the issue across local media](#) and fighting for greater media awareness and coverage
- The British Medical Journal (BMJ) [publishing an article](#) written by three well respected medical professionals
- The CEO of Enham Trust making a [video blog](#)
- Mencap writing a [briefing for ministers](#) and beginning a campaign encouraging people to [write to their MPs](#).

The current JCVI guidance

The [current JCVI guidance](#) still does not prioritise all people with a learning disability for the vaccine. There has been no direct acknowledgement of the fact that the LeDeR research data showed that [65% of people](#) with a learning disability who died from Covid in the first wave had a mild or moderate learning disability.

Whilst the guidance does prioritise people with severe and profound learning disabilities, and also epilepsy, members are reporting that individual GPs are not interpreting and applying this in a consistent way, leading to significant distress amongst people with learning disabilities and their families:

“It just isn’t fair that some people [with learning disabilities] are getting the vaccine and others are not because their doctor won’t listen or has the wrong thing on their records. My life would be just as valuable if I lived in the North or on the South coast. How am I meant to argue with my doctor? I can’t even get through to the surgery.”

Self advocate with a learning disability

“I have a son with severe learning disability including cerebral palsy and epilepsy. As such I had thought he would be in cohort 4 with me as Extremely Clinically Vulnerable, I have COPD.

I spoke to my surgery 3 weeks ago and was told that when I am called for my Covid 19 vaccine I should ring surgery and they would book my son in so he was able to receive his vaccine at the same time as me. My son has 24/7 care support.

I received a text this morning asking me to book my Covid vaccine appointment, which I have done but when I rang my surgery I was told that doctor did not deem him to be suitable for ECV cohort 4 as he doesn't have Downs Syndrome and therefore he would not permit him to be vaccinated with me this coming Saturday.”

Family carer

There has also not yet been any official guidance about adjustments to vaccination delivery so reasonable adjustments in receiving the injection can be offered (like place, timing etc as we know for other interventions), though we have been advised that this is being developed by NHS England. There are also apparently no nasal versions of the vaccine on the immediate horizon where someone is not able to tolerate injections for a range of reasons.

A postcode lottery? – the risks of the current approach

There are some local areas, and some individual GPs who are interpreting the guidance and the local flexibility in such a way that they are offering people with learning disabilities a priority vaccine:

*“Implementation should also involve **flexibility in vaccine deployment at a local level** with due attention to:*

- ***mitigating health inequalities, such as might occur in relation to access to healthcare and ethnicity***
- *vaccine product storage, transport and administration constraints*
- ***exceptional individualised circumstances***
- *availability of suitable approved vaccines, for example for specific age cohorts”*

JCVI guidance as updated on 6 January 2021

For example, Kent and Medway have made a decision, based on the LeDeR statistics and death rates of people with learning disabilities from Covid 19, that all people with learning disabilities living in their area will be given a priority vaccine.

We have been given anecdotal information that Oxfordshire are about to follow suit.

This means that vaccination for people with learning disabilities is rapidly becoming a postcode lottery; a situation that Learning Disability England finds completely unacceptable.

Case Study:

Prioritising people with learning disabilities for the Covid 19 vaccination in Kent and Medway

During both the first and second wave of the pandemic Kent and Medway saw a large increase in the number of deaths of people with learning disabilities being reported to LeDeR. There was a significant spike of people dying of covid-19.

Having spent the months following the first wave carrying out rapid assessments of reported LeDeR deaths, it was clear the second wave was

following the same pattern - disproportionately affecting people with learning disabilities.

Everyone was very concerned about what January and February would bring. Local commissioners, the GP Clinical Lead for Learning Disability and Autism, and the Senior Responsible Officer in the CCG discussed the actions they could take and made the recommendation to include all adults with learning disabilities on the GP Registers in Phase 1 for the COVID-19 vaccination programme.

This was a pragmatic, clinical decision based on local evidence that there was a clear health inequality affecting people with learning disabilities.

The approach will see people with learning disabilities living in care homes and supported living or those receiving domiciliary care being vaccinated with group 1.

The JCVI priorities do not include people with a 'mild' or 'moderate' learning disability, and locally the level of learning disability does not appear to have been a factor that affects the risk of catching, becoming sick, or dying from COVID-19. Living in congregate settings and receiving domiciliary care see higher levels of risk of infection, illness, and death.

We know current GP records do not allow us to easily identify who has mild, moderate, severe or profound learning disabilities. Vaccinating everyone on the learning disability register is a more efficient approach than asking overstretched GPs to complete significant amounts of admin work.

Therefore, everyone on the GP learning disability register who has not been vaccinated through groups 1-3 will be vaccinated in group 4. This is because the national and local evidence shows that people are facing significant health inequalities.

Working together between the local authority, CCG, NHS Community Trust, and primary care networks we have created efficient lists of who needs vaccinating, so this can be delivered at an operational level.

Initially, there was some concern it may look like we were going against the JCVI priorities. However, the 30th December 2020 JCVI guidance, and the 7th January 2021 national Enhanced Service specifically state that there should be "flexibility at a local level".

This means CCGs and GPs can prioritise people based on their individual circumstances or to address local health inequalities. We broadly agreed with

their prioritisation but acknowledge we have additional local issues that must be taken into consideration. Adapting the priority list to reflect evidenced local need will not disrupt other vaccination priorities but allow the inclusion of an additional clinically vulnerable group.

To us this has been the clearly justifiable and right course of action. It is reassuring to see that as we have been moving forward with this approach, others have also been recommending and campaigning for it.”

What next?

Media coverage has been increasing, lending their voice to that of people with learning disabilities, their families and their paid supporters.

Two people with learning disabilities have [issued court proceedings](#) through Bindmans LLP with 39 Essex Street Chambers against Matt Hancock, the Secretary of State for Health, seeking priority access to the Covid 19 vaccine for all individuals with learning disabilities, on an equal basis with other highly clinically vulnerable individuals.

Learning Disability England will continue to campaign and raise awareness about this issue in the hope that both the government and the JCVI recognise and acknowledge that the lives of all people with learning disabilities are as important as any other by prioritising them for the vaccination as soon as possible.

"Learning Disability England has been campaigning for several months for all people with a learning disability and their unpaid (family) and paid supporters to have the vaccine as a priority.

This has included writing to Helen Whately MP and Dr Jonathan Van-Tam, and co-ordinating and co-signing an Open Letter to the JCVI.

While we are pleased that some people with a learning disability and some family carers are now a priority for the vaccine, the PHE's statistics that people with learning disabilities are 6 times as likely to die as a result of COVID than the general population are stark.

We will continue to campaign for priority vaccination to be extended to all."

Self advocate and Learning Disability England Rep Body member

With thanks to all the members and partners who have shared their stories and resources.

Appendix A

Useful Resources about the vaccine

As part of this work, Learning Disability England collected and shared useful resources about the vaccine from members, partners and government bodies.

Thank you to everyone who has shared their resources, including easy read, posters and videos, which we have added to our [Coronavirus Hub](#).

You can also find some of the resources here:

[Template to write to your MP](#) from Speak Up self advocacy group

[Guide and checklist](#) from Learning Disability England to help paid supporters to prepare the people they support for the covid vaccination.

[Covid-19 Easy Read from Challenging Behaviour Foundation](#)

[Covid-19 Vaccine leaflet: Easy read](#) – developed by Camden Learning Disability Service

[Vaccine consent form and letter for adults](#)

[Vaccine consent form and letter for social care staff](#)

[A guide to your COVID vaccination](#) – Easy read from Public Health England

[Easy read letter](#) to GPs from NWTDT / Pathways and the Dalesview Partnership they successfully used to make sure the people they support are recorded as a priority for vaccination

[Checklist for GPs](#) from Leeds and York NHS Partnership to make sure they have accurately recorded people with learning disabilities

39 Essex Chambers have done a [briefing about mental capacity and the vaccine here](#)

PossAbilities CIC have made a [video social story](#) about having the Covid vaccine.

[What is a vaccine? Video from NHS England](#)

[Covid-19 vaccination programme – What do I need to know?](#) – a blog from The Disability Unit

[Vaccine information for siblings](#) – from Sibs UK

[COVID-19 vaccines: Booking a vaccination](#) – Easy read from Suffolk Learning Disability Partnership

[Covid-19 Vaccination, First phase priority groups: Easy Read](#) – from Public Health England

[Poster of priority groups for Covid-19 vaccine](#) from Keep Safe / PhotoSymbols

[Coronavirus vaccine: Easy Read](#) – from Mencap

In Control / Be Human have run a webinar about Personal Assistants, vaccines and testing. [You can see the slides from the session here.](#)

[Resources about the vaccine](#) from Public Health England