

Supporting people with a learning disability to access the COVID-19 vaccine



Advice for primary care staff, including GPs

Updated 9th February 2021

People with a learning disability are one of the most vulnerable groups to coronavirus. Data shows that people with a learning disability died at 6 times the rate of the general population during the pandemic, with those aged 18-34 dying at a rate 33 times higher than the general population. 65% of those who died during the first wave had a mild or moderate learning disability.

Not only are people with a learning disability more likely to have long term conditions that put them at clinical risk from coronavirus, but they are also more likely to miss out on the healthcare they need should they become unwell. In 2019 people with a learning disability were 4 times more likely to die from a cause that we would expect to be treatable with good quality healthcare. In addition, people are much more likely to be living with other people, in group settings such as supported living or a care home.

We estimate that most people with a learning disability are already prioritised for the vaccine:

- People with Down's syndrome are in Group 4
- People with severe and profound learning disabilities are in Group 6
- Many of the other healthcare conditions that disproportionately affect people with a learning disability are in group 6 including epilepsy, diabetes, cerebral palsy etc.
- Many others live in residential care settings.

However, there is a very high risk that it may not be possible to find those people because:

- Coding of people with a learning disability, together with associated conditions/syndromes is highly variable and unreliable.
- Many people will not be coded in a way which accurately describes or easily flags the severity of their learning disability.
- Many of those with particular syndromes, both diagnosed and undiagnosed, will have congenital heart problems which may not be easily picked up using clinical codes.
- Many people with a learning disability have severe recurrent chest infections, which may not be coded for.
- The likelihood supported living will not automatically be picked up due to differences in registration (a recurrent issue throughout the pandemic).

The easiest and most reliable way to find people with a learning disability may be to target all those on the Learning Disability Register.

The JCVI advice on priority groups (30th Dec 2020) states that ‘devolved administrations’ should ‘work together to ensure that inequalities are identified and addressed in implementation. This could be through culturally competent and tailored communications and flexible models of delivery, aimed at ensuring everything possible is done to promote good uptake in... groups who may experience inequalities in access to, or engagement with, healthcare services.’ The guidance goes on to advise that implementation of the COVID-19 vaccine programme should aim to ‘achieve high vaccine uptake’ and that ‘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..’

We are aware that some areas have already chosen to use their flexibility to either target all people with a learning disability or to allow clinicians to use discretion. There are examples of these decisions being made at practice level, primary care network level, through the CCG and at county level. **If you have any influence in the implementation of vaccine roll out in your area, please encourage decision makers to prioritise people with a learning disability.**

Find out more in this webinar

<https://www.youtube.com/watch?v=w3mQYfHJ93M&feature=youtu.be>

Top tips to ensure your patients with a learning disability can access the vaccine:

- Delivering the vaccine in a **familiar primary care setting** will help many who would simply not cope with a large scale vaccination centre. **Consider whether visits to care homes or supported living environments** would be beneficial for your patients, and for you!
- There are things you can do to **help people who struggle with anxiety**. Familiar staff, familiar settings and minimising waiting times can all make a huge difference. **Ask the person, their carers and supporters about how the person has been supported to access procedures like this before.**
- Encourage and enable the person and their supporters to do as much prep work as they can before the time comes to consent to the vaccine. **Provide accessible info, and encourage supporters and family carers to go through the information with the person beforehand.**
- Support those who are assessed as not having the capacity to decide about the vaccine for themselves – **ensure best interest decisions are made where needed, and ask for support on the MCA and best interest decision making where you need it. Involve the person’s family and supporters.**

- **Get to know the learning disability nurses in your area, and understand what help they can offer.** You may be lucky enough to have learning disability nurses working in your primary care network, or you could make contact with the health facilitation nurses in your local community learning disability team.
- **Communicate in a way the person can understand,** slowing down and explaining information clearly, and making sure any written information, or contact regarding the appointment is done in a way the person can understand.
- Do **follow up on any missed appointments** for people with a learning disability.
- **Signpost patients and their families and supporters to accessible resources** to help them understand more about the vaccine. Some useful links are:
 - Easy read resources from Mencap

<https://www.mencap.org.uk/advice-and-support/coronavirus-covid-19/coronavirus-help-stay-safe-and-well>

- A video explaining vaccines from NHS England

<https://youtu.be/M3Wh23PDnfE>

- Easy read information from Public Health England

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/951000/PHE_11843_Covid-19_Easy-read_leaflet.pdf

- Easy read from the Downs Syndrome Association

<https://www.downs-syndrome.org.uk/download-package/coronavirus-vaccine-easy-read/?highlight=vaccine>

You can also refer families to the Learning Disability Helpline from Mencap for more advice and support:

<https://www.mencap.org.uk/advice-and-support/our-services/learning-disability-helpline>