



Things to consider when planning COVID vaccinations for people with learning disabilities



Why is it important to vaccinate people with learning disabilities?

People with learning disabilities are more likely to have other physical health problems such as obesity and diabetes, and certain kinds of learning disability, such as Down's syndrome, can make people more vulnerable to respiratory infections, which can increase the risk of dying from COVID.

451 per 100,000 people registered as having a learning disability died with COVID between 21 March and 5 June, a death rate 4.1 times higher than the general population after adjusting for other factors such as age and sex. As not all people with learning difficulties are registered on these databases, researchers estimate the real rate may have been as high as 692 per 100,000, 6.3 times higher.

The death rate for people aged 18 to 34 with learning disabilities was 30 times higher than the rate in the same age group without disabilities

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933612/COVID-19_learning_disabilities_mortality_report.pdf

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933613/COVID-19_learning_disabilities_mortality_report_easy_read.pdf

Reasonable Adjustments when preparing for and giving vaccinations – things to consider

The Equality Act 2010 states that organisations have a legal responsibility to make changes in their approach or provision to ensure services are accessible to disabled people as well as everybody else.

Issues that will require further consideration here include:

- Accessible information
- Capacity and Consent
- Access and physical environment where vaccination will take place

Accessible information

It is important that people with learning disabilities and their families and carers can access reliable information about the vaccination to support decision making. Information needs to be accessible and suited to the needs of the individual.

Ideally information will be shared with the individual more than once and they will have the opportunity to discuss it with different people.

Public Health England and several of the leading charities / organisations who support people with learning disabilities have produced Easy Read information about the vaccination:

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

[Vaccines ER Final Version 8-12-20 \(2\).pdf \(mencap.org.uk\)](#)

Accessible information

Although Easy Read documents with associated symbols and pictures are useful for many people with learning disabilities, some people prefer documents without pictures.

Public Health England have also produced their guidance in this format on their website:

[Information on COVID-19 vaccination: easy-read guide - GOV.UK \(www.gov.uk\)](https://www.gov.uk/guidance/information-on-covid-19-vaccination-easy-read-guide)

Other sources of useful information

Alongside the documents referenced above, there are also some useful videos and websites produced by organisations working alongside people with learning disabilities to support others:

A video of frequently asked questions:

<https://www.youtube.com/watch?reload=9&v=M3Wh23PDnfE>

A useful website with frequently asked questions:

https://www.keepsafe.org.uk/vaccine-questions?fbclid=IwAR3XT2mIKAvQ1LBq0WgqFEtopO_GqEfztyQDKmsOO5j1E0aoqUnEwzTJ9FQ

Assessing capacity to consent

It is important that the correct procedures are followed when considering a person's capacity to consent for the COVID vaccine.

If the person is not able to make this decision for themselves, it is important the right people are involved in making the decision on their behalf.

It is the responsibility of the person giving the vaccine to assess and record the person's capacity to make this decision but partnership working between families, care providers and health practitioners is key to getting this right.

Mencap have developed a useful guide to assessing capacity in people with learning disabilities:

[mental capacity act resource pack 1.pdf \(mencap.org.uk\)](https://www.mencap.org.uk/publications/mental_capacity_act_resource_pack_1.pdf)

Capacity to consent

COVID vaccinations are an intrusive procedure. It is essential that the practitioner administering the vaccine is satisfied that:

The individual has been provided with accessible information about the COVID vaccination and has shown that they are able to understand, retain and weigh up that information and can communicate their decision to the vaccinator.

Or

An appropriate capacity assessment has taken place (as above) but the individual was found to lack the capacity to make this decision and therefore a practitioner-led best interest decision has been made for the individual to receive the vaccine.

Best interest decisions

If the person is not able to understand, remember or weigh up the pros and cons of having a vaccine, or if they are not able to communicate their wishes, this may indicate that they do not have the capacity to make the decision.

In this case it is important to find out if there is a Lasting Power of Attorney / Deputy for Health and Wellbeing in place.

If so, they should be contacted and asked about their thoughts and wishes regarding vaccination; ideally this will take place prior to the call for vaccination.

Best interest decisions

If there is no-one appointed who can support the decision, it will fall to the health practitioner giving the vaccine to determine whether or not the vaccine can be given under a Best Interest decision.

Where a Best Interest decision is needed, it is important to include people who know the individual well, for example family members or health professionals.

If there is no-one who knows the individual well and can champion their wishes within this process, referral for an independent advocate to act on their behalf may be considered (see [Contact Details](#) slide for details)

Things to remember

- Previous capacity assessments, or consent sought for other vaccines, CANNOT be utilised for this COVID vaccination as the assessment of capacity is always time and situation specific.
- In line with the Mental Capacity Act, next of kin, family members or friends MAY NOT consent to COVID vaccination on behalf of the individual.

If you want to keep a record of the support you have given to help inform someone about the COVID vaccination, you could record it on the form in the ‘*Capacity Guidance For Family and Carers*’ document [here](#)

Capacity and consent

It would be helpful if care providers, be that residential or supported living, provisionally group residents into three categories to help prepare staff who will be giving the vaccine:

- Residents who are likely to have capacity to consent
- Residents who have an appointed Lasting Power of Attorney / Deputy for Health and Wellbeing to consent on their behalf
- Residents who may need a best interest decision to be made on their behalf

Capacity and consent for people with severe learning disabilities

The Challenging Behaviour Foundation has written some guidance for families of individuals with severe learning disabilities to support them and others to understand the needs of their family member:

[covid19vaccine13.pdf\(challengingbehaviour.org.uk\)](https://www.challengingbehaviour.org.uk/covid19vaccine13.pdf)

Use of restrictive practices

Where a person lacks capacity to make the decision whether or not to have the vaccine, careful consideration should be given to ensuring that any use of restriction or force required to carry out the procedure is proportionate to the anticipated benefits. Those involved in the individual's care should carefully weigh up the pros and cons for the individual of having the vaccine using force (and associated distress this may cause) versus not having the vaccine.

Locally, the Intensive Health Outreach Team (IHOT) have produced an information and consent pack to support the vaccination process when a person lacks capacity and may require the use of restrictive practices in order to facilitate the vaccination (click [here](#))



[Click here to
access IHOT
Pack on GCare](#)

Access and environment

Things to consider:

- If using text messages or emails for invitations, does the person have access to these communication methods?
- If using written invitations, is there someone to support the person to read the invitation letter?
- It is likely that a family member or carer will need to accompany the individual, how will this work at the surgery or vaccination centre?
- Is there a familiar member of staff or family member available at the time of the appointment to accompany the person for their vaccine?
- Is the person using public transport? (if so, offer appointment after 10.30 am to allow them to use their bus pass)
- Can the person access the surgery / vaccination centre? Or will a home visit be required?

- Is there a separate waiting area or way of “skipping” the queue for those who can’t tolerate waiting?
- Is there a quiet area, away from the mass vaccination area, where people with learning disabilities and / or autism can be seen?
- Can longer appointment times be offered?
- Is additional support required to assess capacity to consent?
- Is the vaccination centre wheelchair friendly?
- Are there any potential issues with sensory overload (e.g. very noisy, bright lights, flickering lights, strong smells (cleaning products), etc)
- Is there a quiet area for people to wait post-vaccine?
- Is it possible for the person to leave straight away? Could advice be given to carers about aftercare on this instance?
- Are there any individual risks that need to be considered?
- Is additional support required from the Community Learning Disabilities Team (CLDT) or Intensive Health Outreach Team (IHOT)?

Contact details

Having read this document, if further information or advice is required on this matter it may be accessed via:

The **Community Learning Disabilities Teams** (CLDTs) have a duty system in place which can be used for general advice around meeting the needs of people with learning disabilities. Where possible the duty clinician will answer queries or signpost to appropriate information. It is important to remember that not all people with learning disabilities living in Gloucestershire are known to the CLDT so they may not be able to give individualised advice.

Gloucester: 01452 894280 **Stroud and South Locality:** 01453 563103
Forest of Dean: 01594 593075 **Cheltenham & North Locality:** 01242 634300

POhWER Advocacy: 0300 003 1162 Or click [HERE](#)

For non urgent advice, or to pass on information regarding capacity to consent or reasonable adjustment requirements, consider emailing your GP. Where possible please try to avoid telephoning the GP unless urgent.



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