

Guidance

Blood tests for people with learning disabilities: making reasonable adjustments - guidance

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Introduction

This guidance is to help health professionals who need to take blood from someone with learning disabilities. It may also be of use to paid social care or health staff and family members when they are supporting someone to have a blood test.

Under the Equalities Act 2010^{[footnote 1](#)}, public sector organisations have to make changes in their approach or provision to ensure that services are accessible to disabled people as well as everybody else. This guidance shares information, ideas and good practice about the provision of reasonable adjustments for blood tests for people with learning disabilities

We searched for policy and guidelines that relate to people with learning disabilities needing blood tests. A summary of this information is below. We looked at websites to find resources that might be of use for people with learning disabilities who need a blood test but are very anxious about this.

We put a request out through the UK Health and Learning Disability Network, a major email network for people interested in services and care for people with learning disabilities. We asked people to send us information about what they have done to support people with learning disabilities to have blood tests that they need.

Despite there being good reasons for many people with learning disabilities to be afraid of needles, such as past experiences of forcible administration of sedatives, there is little relevant research or policy. The guidance describes the online resources we found and where you can access them. There is also a separate [selection of case studies and examples of reasonable adjustments made to support people with learning disabilities in tolerating blood tests](https://www.gov.uk/government/publications/blood-tests-and-people-with-learning-disabilities/blood-tests-for-people-with-learning-disabilities-reasonable-adjustments-case-studies) (<https://www.gov.uk/government/publications/blood-tests-and-people-with-learning-disabilities/blood-tests-for-people-with-learning-disabilities-reasonable-adjustments-case-studies>) available online.

Blood tests for people with learning disabilities

Why is this an important issue?

There are a number of findings from the Confidential Inquiry into the Deaths of People with Learning Disability (CIPOLD)^{[footnote 2](#)} that highlight the importance of timely blood tests for people with learning disabilities:

- problems with diagnosis and treatment were the most common reasons for premature deaths – blood tests are often a vital part of diagnostic investigations and can support a treatment pathway

- blood tests are important for monitoring the efficacy and side-effects of some medication – this includes anti-epileptic drugs, which are more likely to be prescribed to people with learning disabilities

Evidence and research

A literature search identified minimal relevant research. There is evidence that blood tests are one aspect of the annual health check that can cause anxiety for people with learning disabilities^[footnote 3].

A small study which involved talking to people following a health check found that most of them (81%) liked seeing their doctor but 34% indicated a dislike of needles or refused a blood test or vaccination^[footnote 4].

CIPOLD^[footnote 2] found that almost a sixth (16%) of people with learning disabilities were described as having a significant fear of contact with medical professionals such that it might affect healthcare interventions. This included a fear of needles and it was recommended that such anxiety should be addressed by desensitisation work.

Since the introduction of the incentivised annual health check scheme for people with learning disabilities there has been an increase in the number of blood tests requested. A large study of data on over 8,000 patients with learning disabilities showed that more blood tests were done by GP surgeries that were providing annual health checks^[footnote 5].

Research has identified concerns around informed consent in relation to blood tests for people with learning disabilities^[footnote 6]. This study found that consent procedures were often inadequate. An understanding of information about the procedure is an essential requirement for informed consent and in most cases this was not checked by the health professional. Participants reported needing clear, accessible information and simple verbal explanations without jargon being used. The authors highlighted the need for healthcare professionals to have a good understanding of the consent process and the mental capacity act.

The literature search identified two published case studies. Obviously case studies only provide anecdotal evidence but they can be useful in illustrating the scale of the challenge in some instances and the diversity of solutions. The first described how a young woman with moderate learning disabilities and severe autism was supported to have a number of blood tests despite her phobia of needles^[footnote 7].

A desensitisation programme was developed, which necessitated a lot of input from the community learning disability nurse and involvement from Sara's family, her supporters, a speech and language therapist and a phlebotomist. The process is reported in detail in Edwards and Northway (2011)^[footnote 7].

Although there were considerable time demands required, Sara was able to have multiple blood tests in different settings so her learning was maintained and transferred. This enabled a health problem to be diagnosed and hopefully will help Sara's access to healthcare in the long-term. Collaborative working between

primary care and learning disability services was crucial to the success of this intervention.

The second described the input needed in order to get a blood test done for a 9-year-old boy with severe learning disabilities and autism^[footnote 8].

It took 15 weeks and 7 appointments to get the blood sample and it was only successful with the input of an anaesthetist. The authors concluded that with better communication and planning the family could have had an easier experience. They recommended that professionals need to adapt existing systems to meet the specific needs of individuals and that this requires careful planning. We hope that the [good practice case studies \(https://www.gov.uk/government/publications/blood-tests-and-people-with-learning-disabilities/blood-tests-for-people-with-learning-disabilities-reasonable-adjustments-case-studies\)](https://www.gov.uk/government/publications/blood-tests-and-people-with-learning-disabilities/blood-tests-for-people-with-learning-disabilities-reasonable-adjustments-case-studies) will help provide some guidance on how this can be done successfully.

Policy and guidance

Clinical holding

We have not been able to identify any policy or guidance specifically addressing blood tests for people with learning disabilities. There is some guidance around clinical or therapeutic holding which may be useful to consider. The Royal College of Nursing has issued guidance for nursing staff on 'Restrictive physical intervention and therapeutic holding for children and young people'^[footnote 9]. The Faculty of Dental Surgery has published 'Clinical guidelines and integrated care pathways for the oral health care of people with learning disabilities'^[footnote 10].

Both documents are clear that clinical holding should be used as infrequently as possible and only when all other approaches have been tried or considered.

Some of the relevant principles from these documents are:

- clinical holding must be underpinned by an ethos of caring and respect for the individual's rights
- there should be a risk/benefit assessment prior to the intervention – this should include careful consideration of whether the procedure is necessary and if there are any alternatives to clinical holding
- there must be a sufficient number of staff who are appropriately trained and confident in the process
- accurate record keeping is essential – this should include why the intervention was necessary and details of what it involved

The dental guidance states that clinical holding is preferable to the use of a general anaesthetic. This should be considered as the ultimate in physical intervention as an unconscious person is unable to withdraw consent.

Consent

As with any medical intervention, there are issues of capacity and consent to consider. In order for a person to have the best chance to make an informed decision about having an injection or blood test, they need to be able to understand what the process involves and the implications of refusing it. [Table 2](#) lists easy-read resources and films that can be used to support someone to understand the decision they are taking. If the person is assessed as not having the capacity to take the decision then a best interests decision should be made in line with the Mental Capacity Act.

Reasonable adjustments

Avoidance

When someone with learning disabilities who is anxious about needles requires a blood test or an injection there should always be consideration of less invasive alternatives. This would include the use of the nasal spray flu vaccine. It should also include the possibility of a finger prick blood test as opposed to venepuncture. Finger prick blood tests can be adequate for haemoglobin tests, diagnosing and monitoring Type 2 diabetes and for limited thyroid testing.

People being prescribed antiepileptic drugs or lithium need therapeutic drug monitoring which is traditionally done via regular blood tests. It is possible for this to be done by checking saliva levels rather than blood levels and this could be a reasonable adjustment for someone with learning disabilities who is anxious about needles.

Preparation

For people who have a needle phobia and are in need of an injection or blood test, the first approach is generally desensitisation work. This is usually a systematic programme supporting the individual to relax and gradually introducing them to the feared stimulus. It is about building up the individual's confidence at each stage until they are ready to have the blood test. It might start with someone getting used to the environment and then over time being exposed to the equipment and then the different steps of the process. With sufficient repetition through practice, the anxiety around the injection or blood test can be reduced.

Amelioration

Other reasonable adjustments may include the use of topical applications to numb the skin prior to needle insertion.

These include:

- Lidocaine and prilocaine cream – needs to be applied at least an hour before needle insertion and must be covered with a plastic wrap
- Tetracaine gel – needs to be applied 30 to 45 minutes beforehand and should not be left on for longer
- Ethyl chloride – this provides local pain relief when sprayed topically onto the skin; it has no anaesthetic properties but rather works as a vapo-coolant and is applied immediately before needle insertion - it can be very useful for those who are allergic to topical anaesthetics, or for those who get very upset when the cream is applied before tests

The '[Step-by-step guide to Health Checks for people with a learning disability](http://www.rcgp.org.uk/clinical-and-research/resources/toolkits/health-check-toolkit.aspx)' (<http://www.rcgp.org.uk/clinical-and-research/resources/toolkits/health-check-toolkit.aspx>) from the Royal College of GPs provides further information on the use of topical applications.

We have been sent many good practice examples where alternatives to needles have been considered or where people have been supported to tolerate them. A selection of these is presented later in this guidance.

Resources

The 3 tables that follow list all the information and resources we have found in relation to supporting people with learning disabilities to have blood tests.

- [Table 1](#) lists websites and resources that may be of use to professionals/family members and carers who want more information and resources
- [Table 2](#) lists the easy-read resources and films we have found. This is where you can find information to use with people with learning disabilities
- [Table 3](#) lists the relevant free apps we have found about having blood tests or injections

Some resources may be available from more than one site, but we have only given one link. We have only included resources that are free to download, although some of the websites may also include resources you can buy.

Table 1: resources about blood tests for professionals/family members and carers

Theme

[Health Facilitation Service: Supporting people who have a learning disability to give](https://www.ndti.org.uk/uploads/files/Health_Facilitation_Service_Supporting_people_who)
(https://www.ndti.org.uk/uploads/files/Health_Facilitation_Service_Supporting_people_who)

Theme

[For families and carers: giving blood samples \(http://www.downs-syndrome.org.uk/for-families-and-carers/giving-blood-samples/\)](http://www.downs-syndrome.org.uk/for-families-and-carers/giving-blood-samples/)

Table 2: easy-read and accessible resources about blood tests/injections

Theme

[Blood test card \(http://easyhealth.org.uk/sites/default/files/blood%20test%20card_0.pdf\)](http://easyhealth.org.uk/sites/default/files/blood%20test%20card_0.pdf) ▶

[Blood test \(http://easyhealth.org.uk/sites/default/files/null/Bloodtest.pdf\)](http://easyhealth.org.uk/sites/default/files/null/Bloodtest.pdf)

Theme

[Fasting blood test \(http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/acute-procedures/Fasting_Blood_Test.pdf\)](http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/acute-procedures/Fasting_Blood_Test.pdf)

[Having a blood test \(http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/prin-procedures/Having_a_blood_test_GHP1150-04-12.pdf\)](http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/prin-procedures/Having_a_blood_test_GHP1150-04-12.pdf)

[Having a blood test \(http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/prin-procedures/Having-a-blood-test1.doc\)](http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/prin-procedures/Having-a-blood-test1.doc)

[Having a blood test \(http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/acute-procedures/Having_A_Blood_Test.pdf\)](http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/acute-procedures/Having_A_Blood_Test.pdf)

[Going for a blood test \(http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandli-adjustment=108\)](http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandli-adjustment=108)

[You are having a blood test \(http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandli-adjustment=162\)](http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandli-adjustment=162)

Theme

[Easyread patient information - having a blood test](http://www.chesterfieldroyal.nhs.uk/dl/10264_4180732163.pdf/as/Having%20a%20Blood%20Easy%20Read%20Patient%20Information.pdf?_ts=1464&_ts=1464)

(http://www.chesterfieldroyal.nhs.uk/dl/10264_4180732163.pdf/as/Having%20a%20Blood%20Easy%20Read%20Patient%20Information.pdf?_ts=1464&_ts=1464)

[Having a blood test \(https://www.ndti.org.uk/uploads/files/Having_a_blood_test.pdf\)](https://www.ndti.org.uk/uploads/files/Having_a_blood_test.pdf)

[Getting a blood test - social story \(http://www.oneplaceforspecialneeds.com/main/library\)](http://www.oneplaceforspecialneeds.com/main/library)

[Having a blood test](#)

[Blood test \(http://bit.ly/2NkHOSq\)](http://bit.ly/2NkHOSq)

Theme

[Having a blood test at Bedford Hospital \(http://bit.ly/2PEcIUu\)](http://bit.ly/2PEcIUu)

[What happens when you have a blood test? \(http://bit.ly/2wOHhhl\)](http://bit.ly/2wOHhhl)

Table 3: apps related to blood tests

Theme	Description	Provider
Blood Test (https://itunes.apple.com/gb/app/blood-test/id960832103?mt=8)	This app is designed for people with learning disabilities who are due to have a blood test. It is in an easy-read format with colourful clear graphics, large text and supporting narrative audio	Christopher Hardy
Pablo the Pufferfish app (http://www.healthline.com/health/big-shots-get-shots-iphone-application#.WCRLXS2LTcs)	This app is designed to help children overcome their fear of needles by distracting them with something fun. It is an interactive storybook which follows Pablo the Pufferfish as he learns to overcome his fear of needles. It includes puzzles and games	Healthline

Conclusion

Blood tests play an important part in assessing, monitoring and treating the health of people. Therefore it is important to find a way to make the procedure possible, even for people who are needle phobic. This guidance has signposted a lot of resources that can be used to support people and the range of case studies have illustrated approaches that can help.

In summary, there are a number of steps that should be taken when giving a blood test to someone with learning disabilities:

- work in accordance with the Mental Capacity Act; start with a presumption of capacity, provide accessible information about the procedure to help someone take the decision and make a decision in their best interests if appropriate
- remember that not everyone is worried about needles - the person should be asked neutrally if they are happy to have a blood test
- always find ways to avoid needles if possible – use a finger-prick test rather than venepuncture if this will be sufficient
- work with the person to desensitise them; it is likely that most people will face a situation where needles are required at some time so it can be easier to be proactive about this and prepare someone rather than address their needle phobia in an emergency situation
- always use skin numbing creams
- organise a local familiar place where people can go for blood tests when they need to - this should involve the most skilled practitioner for taking blood
- prepare and reward if possible
- sedation and restraint should only be considered when all other practical steps have been taken and are unsuccessful; a decision to proceed with this needs to be taken in the person's best interests and the reasons for this intervention must be clearly documented

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