Helping people with a learning disability to give feedback
The NHS belongs to everyone – including people with a learning disability.

People must be given the chance to have their say about the NHS. You can do this by saying what works for you, and how the NHS can help.

Finding out what works for different people helps the NHS meets everyone’s needs.

This guide is about how to make sure people with a learning disability are given an equal chance to have their say.
We have made this easy read guide so that people with a learning disability know what the NHS is told about how to do this work.

- People can have their say by giving feedback about health services they have used.

- And people can have their say by helping develop new ideas about how the NHS works.

We have made this easy read guide so that people with a learning disability know what the NHS is told about how to do this work.

Staff with a learning disability can also use this in their work.
Important things to remember

- Most of the health services people with a learning disability use are the same services as everyone else.

- People with a learning disability should have the chance to say what they think about all services, not just specialist learning disability services.

- People with a learning disability must have the chance to make a real difference. This means acting on their feedback and involving them in planning before decisions are made.
• Communicate with people with a learning disability in a way they understand

• People with a learning disability might need extra time to think about information and to give answers

• Involving carers, family members, advocates and support workers can help some people speak up

• Always choose accessible places for meetings and for getting feedback from people.
Information and questions should be made easy to understand. Focus on the important information that people need to know.

It is usually easier for people to tell you about their own experiences.

But some people will find it harder to say what should be done to make things better.

Some people may need support to have their say. This might be from support staff, trained advocates, or carers and family members.
Written questionnaires are difficult for some people with a learning disability. They might prefer to give feedback by talking to someone.

Think about who should ask questions. It may be hard to give honest feedback to staff that did a bad job.

Some people will find it a lot easier to think about a service soon after using it.

It might be harder to remember what was good or bad about the service after a few days.
All health services now invite people to give feedback on their care and treatment through the Friends and Family Test. This asks people if the care they got would be good enough for their friends and family.

Services can get advice on how to help people with a learning disability to give their feedback. This advice is here: [https://www.england.nhs.uk/ourwork/pe/fft/fft-inclusive/](https://www.england.nhs.uk/ourwork/pe/fft/fft-inclusive/)

**Accessible events**

People with a learning disability should be included in events about improving health services.

1. Make sure accessible information is available:
• Involve people with a learning disability in making the accessible information for your event.

Allow enough time for this designing and testing.

2
Design the event so everyone can take part

Including people with a learning disability in your work can help you to design and run accessible events.

• The work people with a learning disability do at an event should be valued as much as the work everyone else does.
Local self-advocacy groups can help you. They will help get you in contact with people who have a learning disability who are not part of other networks.

Self-advocacy groups could include People First organisations and other local, regional and national forums.

The NHS England Learning Disability Engagement Team can help you link to other groups. Email them at: learningdisabilityautismengage@nhs.net
- It might be helpful for people with a learning disability to do a different version of the work at an event if this will make it more accessible.

Give people the choice to join the more accessible activity or the main work of the event.

3
Make the event easy to attend

- The event should be held at an accessible venue with wheelchair access.
• A Changing Places toilet will help you meet the needs of more people. http://www.changing-places.org

• Use a venue near to a big train station so people do not have to travel far.

• Some people may need to use a taxi. This should always be paid for by your organisation.

• People with a learning disability may have bus passes that can only be used after a certain time of day. A good idea is to start events after 10:30.
• People should be supported to claim back expenses. This might include the cost of support staff and travel for staff or carers.

• Make sure there are enough breaks. Have a place that people can take a break from the event if they need to.

• People may need extra support if they are talking about upsetting experiences.
NHS England’s Involvement Hub has resources to help involvement work.
www.england.nhs.uk/participation

NHS England has made an easy read version of its expenses policy.

Email learningdisabilityautismengage@nhs.net to get a copy of this.

Guidance to help you employ people with a learning disability
www.england.nhs.uk/about/equality/equality-hub/ld-emp-prog/

Resources about the NHS Accessible Information Standard
www.england.nhs.uk/ourwork/accessibleinfo/
This is an easy read version of a guide for NHS services about how to get feedback from people with a learning disability.

It is part of a set of bite-size guides giving advice and information on gathering feedback.

You can see the others at https://www.england.nhs.uk/ourwork/insight/insight-resources/

The work is overseen by NHS England’s Insight & Feedback Team, who can be contacted at england.insight-queries@nhs.net.

Contact the Team if you want this guide in a different format.

The content of this guide was led by NHS England’s Learning Disability Engagement Team, who can be contacted at learningdisabilityautismengage@nhs.net.