

04 | BITE-SIZE GUIDE TO PATIENT INSIGHT:

HELPING PEOPLE WITH A LEARNING DISABILITY TO GIVE FEEDBACK

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With the right support, people with a learning disability can have their say about the NHS.

This is important because they are the experts on their experience of using services.

They know what works and what does not work for them so working in partnership with people to make changes means improvements will be based on what real people want and need.

Support for people to have their say can include things like:

- ▶ Making sure people have the chance to make a real difference – not being asked about things that have already been decided
- ▶ Providing easy information that helps people understand what they are being asked about
- ▶ Not asking too many questions at once
- ▶ Giving people enough time to think about information and to give answers
- ▶ Giving people the chance to communicate in the ways that suit them best
- ▶ Considering whether they need help in explaining what is working well for them and what is not

- ▶ Involving advocates, support workers and carers who can help people speak up
- ▶ Choosing an accessible place for meetings
- ▶ Making connections with local self-advocacy groups who can help you include others with a learning disability.

Defining “learning disability”

A learning disability affects the way a person understands information. They will have a lifelong difficulty learning new skills and understanding information. They may also socialise differently. This affects each person differently. But people are also disabled by the way society does not meet their needs.

In relation to direct healthcare provision, Sir Jonathan Michael wrote:

“I have since recognised that addressing the difficulties faced by people with learning disabilities in accessing general healthcare services does not require specialist knowledge about learning disabilities; the issues they face are relevant to all members of society. What matters is that people with learning disabilities are included as equal citizens, with equal rights of access to equally effective treatment. I have also learnt that ‘equal’ does not always mean ‘the same’ and the ‘reasonable adjustments’ that are needed to make services equally accessible to people with learning disabilities, are not particularly difficult to make.”

Healthcare For All: Report of the independent inquiry into access to healthcare for people with learning disabilities 2008

All of these points should shape how we ask people to feed back to us.

Including people with a learning disability in feedback and engagement work

Whether providing feedback through surveys or co-designing new ways of getting support from health services, people with a learning disability have ideas and experience that will help you understand and improve the service they receive.

Services cannot be designed only to meet the needs of the majority of people and it is vital that we listen to the needs of people for whom standard services do not fit well. Commissioners need to meet their legal duties to reduce health inequalities and promote equality.

Engagement about specialist services for people with a learning disability must of course include the people who will be affected by the work. But most services used by people with a learning disability are the same mainstream services used by everyone else, so it is really important that they too have a chance to participate in engagement and feedback about those services.

Tapping in to local networks and voluntary organisations

Local groups will be invaluable in helping you reach a larger number of people with a learning disability, many of whom may not be connected to other networks. Many groups will also have the knowledge and skills to help you make your engagement more effective and to help you develop high quality accessible information.

Groups could include self-advocacy groups (for example, People First organisations), or other local regional or national forums such as the [NHS England Learning Disability and Autism Forum](#) which is facilitated by the Learning Disability Engagement Team. The team can be contacted at LDengage@nhs.net and they may be able to help link you to other networks too.

Ensure work plans allow enough time to involve people, and for networks to spread news to people who may not be well-connected through other routes such as email updates. Remember also that producing accessible information, discussed in the next section, can be time-consuming, so plan enough time for commissioning and production of any such information.

If you are asking people to be involved in your work, ensure expenses are covered. See for example the [NHS England Patient and Public Voice Expenses Policy](#) for good practice around expenses and involvement payments. There is an easy read version of this in use at NHS England. To request more information, contact LDengage@nhs.net.

Work is being done to increase [employment of people with a learning disability in the NHS](#) and other organisations. NHS Employers provide a range of [tools and case studies](#). It may be valuable to employ someone with a learning disability to work alongside you, as NHS England does, to help bring insight from their perspective. There are a number of [resources to support employing people with a learning disability](#).

Accessible information

Information and questions presented as part of a survey or other feedback initiatives should be made easy to understand. Focus on the key information that people need to know.

Involving people with a learning disability in drafting, checking and even presenting information is the best way to ensure accessibility. [Resources supporting the NHS Accessible Information Standard](#) can also help guide the production of accessible information, though there is no real substitute for co-producing with people.

Visit pages 76-79 of [NHS England's guidance on implementing the Friends and Family Test](#) for information about making this near real-time feedback tool, which is now in use across most of the NHS, more accessible for people with a learning disability. A balance is struck between keeping to the 'standard' question – so that the responses of people with a learning disability can be included or contrasted with those of others – and adapting the question to make it easier to understand so that people are better able to participate. [Additional resources to support those implementing Friends and Family Test work](#) are also available. These include example easy read formats for the FFT.

Some people will find it easier to talk about the detail of their direct lived experiences than to say what broad issues have arisen from these experiences; and may find it difficult to formulate ideas about changes.

Some people will need support to have their say: this may be from support staff, trained advocates, or carers and family members. This is particularly true for people with a more severe learning disability.

Accessibility can be affected by the timing of when information is given or input is sought. As a general rule, the closer to an experience you ask for someone's feedback – such as immediately after an episode of care or an interaction with a health professional - the easier it will be for them to respond.

Accessible events

Involve people with a learning disability in designing and running your feedback event so that it is a more engaging and effective session.

If your engagement is being done through gathering people together, the venue must be accessible. As well as physical considerations such as ramps and accessible toilets, consider how easy it is to navigate to the correct meeting room once in the building. Some people may require a more accessible toilet than the standard 'disabled toilet'. Seek venues that have a Changing Place or consider hiring a mobile unit: Changing Places are larger and better-equipped. See www.changing-places.org for further information and for links to existing Changing Places and services that hire mobile units.

Consider also the ease with which people can get to the venue – the nearer it is to a main transport hub, the less people will have to rely on buses, themselves not always very accessible, with information that tends to be hard to follow. Some people may need taxis due to barriers to using public transport and this cost should be met by your organisation because, if nothing else, it is vital that people are reimbursed for expenses. Bear in mind that some people may need an alternative to payment into a bank account.

People with a learning disability may travel on concessionary passes that cannot be used before a certain time of day; or they may be reliant on shared support staff and transport. A good rule of thumb is to start no earlier than 11.00, with registration from 10.30.

Arrangements should take account of people's wellbeing. Have regular breaks because you will probably be asking people to think about big and complex issues and ideas, which is tiring and even more so if people are discussing negative experiences. Have a break-out room in case people get upset or overwhelmed: as well as emotive subject matter, this could be a response to the sensory environment.

Consider whether the best approach to making an accessible event will be for everyone to do the same things - for example, to answer the same questions in the same ways - or to engage in parallel activities. This is most relevant to events attended by both people with a learning disability and people without, but can also be a way of making learning disability-specific events more inclusive. Remember that people with a learning disability are not a homogenous group. If running different, parallel engagement activities within the same event, make sure that the people with a learning disability have an equal opportunity to give feedback and that their work is given recognition as being as valuable as anyone else's.

Some people with a learning disability may feel stigmatised by being asked to do something different to those without a learning disability; others will prefer the chance to have their say without so much competition from others with different perspectives or greater confidence in communicating. Where possible, give people a choice between inclusive workshops and workshops that are more tailored to people with a learning disability.

Involving people with a learning disability in the development and delivery of an event brings a critical eye to such sensitivities; explanation of the reasons for running parallel activities can underline that it is a way of valuing – rather than side-lining and devaluing – the participation of people with a learning disability.

Empowerment

There are ways you can ensure that people feel more empowered during any event where you are encouraging people to have their say about healthcare:

- ▶ Take care to get the right balance between the number of health professionals and other people who are taking part.
- ▶ Ensure people have the time and support to have their say even if they are less confident communicators or they communicate in ways other than speaking.
- ▶ Make sure that inclusion is a key part of facilitators' roles.
- ▶ Hold events in community venues.
- ▶ Offer alternatives to events as ways of getting involved helps ensure people are not disempowered by any difficulty in attending meetings.

Visit [NHS England's Involvement Hub](#) for a range of resources to support participation, including the participation of people with a learning disability.

CONTACT US

This guide is part of a short series intended to help health-care providers and commissioners to make greater use of patient insight: <http://www.england.nhs.uk/ourwork/insight/insight-resources>

The work is overseen by the Insight & Feedback Team. The content of this guide was led by specialists in NHS England's Learning Disability Engagement Team, who can be contacted at LDengage@nhs.net.

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This information can be made available in alternative formats, such as easy read or large print and may be available in alternative languages upon request. Please contact 0300 311 2233 or email england.contactus@nhs.net