Services for people with a learning disability and behaviour that challenges

How services can give people the right support

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What is in this guide?

- About this guide 1
- Finding out what people need 4
- Choice and control 7
- Planning care and support 10
- Families and carers 12
Services close to home

Short breaks

Choosing where to live

Children and young people

Going into hospital

Staff skills and training

How to find out more
About this guide

**NICE** wrote this guide. **NICE** is the short name for the National Institute for Health and Care Excellence.

We find out what works well in health and social care and write guides to give advice about it.

This guide is about services for people with a learning disability and **behaviour that challenges**. It gives advice about how to support people.
Behaviour that challenges can mean doing things that hurt yourself or others.

Behaviour that challenges can mean damaging things.

Behaviour that challenges can mean doing things that make life difficult for you or for other people.

Usually people do not behave in this way. But it can happen when things are not right for you.
Getting the right support can help stop people behaving in a way that challenges.

This advice will help staff and services work better together to give the right support.

It will help staff spot problems early. And help put things right quickly.

It will help you and your family or carers know what care and support to expect.
Finding out what people need

One person should be in charge of all **services** for adults and children with a learning disability.

**Services** mean things like healthcare, social care and education.

This person is called the **lead commissioner**.

The **lead commissioner** should have worked with people with a learning disability and **behaviour that challenges** before.
The **lead commissioner** in each area should find out what care and support people need.

They should work with people and their families to write a plan. The plan should say what services people need, now and in the future.

The **lead commissioner** should make sure people can get all these services close to home.

They should join together all the money that pays for healthcare, social care and education for adults and children with a learning disability.
Asking what you think

Services and staff working with you should ask you and your family or carers what you think about the services you use.

They should involve you in finding out how well services work.

They should ask you how services could work better for you. They should involve you in making services work better.
Choice and control

Staff supporting you should get to know you and what you want from life.

They should help you be active and independent.

And involve you in decisions about your care and support.

Staff should work with your family or carers if you want them to be involved.
Help to speak up

You should have help to say what you think in the way you want.

You should be given clear information in a way that you can understand.

Everyone should know if you need help to say what you want and the right ways to help you.

You should have an **advocate** if you want one.

An **advocate** is someone who can help you speak up and does not work for the service that supports you.

Your **advocate** should have worked with people with a learning disability before.
Having more say about money

You should have more control over how money for your care and support is spent.
Planning care and support

Staff should help you write a plan for your care and support.

They should involve everyone who supports you in writing your plan.

The plan should say what support you need to live as you choose.

Staff should plan how to help you as soon as there are problems. Spotting problems early can stop a crisis happening later.

A crisis is when you are having a bad time and your behaviour gets worse.
Your plan should be checked often, and whenever there is a big change in your life.

You should have a **named worker**.

The **named worker** knows about your needs and wishes. They make sure things happen.

The **named worker** should make sure everyone works together to do what is in your care and support plan.

The **named worker** should talk to your family, carers and everyone who supports you and listen to their views.
Families and carers

Services and staff working with you should:

- Give your family or carers training and information to help them care for you.

- Make sure your family or carers know how to get support from staff with special skills. These staff can help with things like communication or behaviour support.

- Give your family or carers their own advice and help to stay well.
Tell your family or carers how to get more help. This could be support from other families or advice by phone.
Services close to home

You should be able to get all the support you need close to home.

This includes help from staff with special skills if you need it. This could be things like behaviour support or speech therapy.

You should still get support close to home if your behaviour means you get into trouble with the police.

You should be able to see staff who have special skills in helping people with behaviour that challenges.
You should not have to move house or go to hospital for this help.

You should get this help as soon as you need it.

Help in a crisis

A crisis is when you have a bad time and your behaviour gets worse.

Your care and support plan should say what to do if you have a crisis.

Services should give you a telephone number that you or your family can ring in a crisis.
Staff should help you in your own home if you need it.

Staff should help you make a plan when things get better and crisis help is no longer needed.
You and your family or carers should have a choice of **short breaks** close to home.

**Short breaks** can mean a trip away or extra help at home.

Your **short break** should be right for you and let you do things you enjoy.

You should be able to plan when to have your break. You can visit first to see if you like it.

You should also be able to have a short break quickly if you need it.
Choosing where to live

You should be able to choose where to live.

You should be able to choose to live alone with support if it is safe for you.

If you share a house you should be with a small group of other people who need support.

It should feel like a home.
You should be able to stay in the area you know and close to family and friends if you want to.

If you have to move it should be for the shortest time possible.

You should still have the support you need.
Children and young people

Children and young people should have an education, health and care plan.

Staff from different services should all work together to do what is agreed in the plan.

If a child or young person shows behaviour that challenges, everyone who supports them should look at the plan together. They should talk about what support they need.
Residential care

Children and young people should only move into **residential care** if living at home means they cannot get the help they need.

Staff should talk to parents and carers about the different support they can have for their child before they think about **residential care**.

This includes thinking about whether their child needs more support with their education.

If children and young people move into **residential care** they should live close to their family.
They should have help to see and talk to their family.

A plan should be started for when they will go home, if that is right for them. This plan should be checked at least every 6 months.
Going into hospital

You should only go into hospital if it is not safe for you to live anywhere else.

Staff should think about all the other ways they could help you before you have to go to hospital.

You should be able to go to a hospital close to home, family and friends.

Your named worker should make sure you can talk to and see your family, friends and staff at home.
As soon as you get to hospital a plan should be started for when you will go home.

This plan should be checked at least every 3 months.
Staff skills and training

Staff supporting you should get on well with you. They should respect and understand what is important to you.

Staff should have the right skills to support you.

Staff supporting you should understand behaviour that challenges.

Services should involve you and your family or carer in finding and training new staff.
How to find out more

These people can give you more information about support for people with a learning disability and behaviour that challenges.

Their information is not written by NICE and might not be EasyRead.

Mencap

Telephone: 0808 808 1111

Website: www.mencap.org.uk
Foundation for People with Learning Disabilities

Website:
www.learningdisabilities.org.uk

The Challenging Behaviour Foundation

Website:
www.challengingbehaviour.org.uk

Include Me TOO

Telephone:
01902 711604 or 01902 399888

Website:
www.includemetoo.org.uk

The Judith Trust

Website:
www.judithtrust.org.uk