People with a learning disability and behaviour that challenges
Our advice about good, safe support

EasyRead version of NICE guideline NG11 May 2015
About NICE

NICE is the short name for the National Institute for Health and Care Excellence.

NICE finds out what works well in health and social care and writes advice about it.

The advice says what care and support people using services should have.

Doctors, nurses, care workers and support workers should use the advice to help them give good care and support.

People who use services and their families, carers and advocates should know what NICE says too. It can help them get the right care and support.

Advocates are people who can help you speak up and who do not work for the service that supports you.
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1 About this information

NICE wrote this information.

This information is our advice about what can help people with a learning disability who behave in a way that is challenging.

Challenging often means something that is difficult - when people supporting them are not sure what to do.

There is more about what behaviour that challenges means later.
We wrote this advice so that you and everyone supporting you can understand about people who behave in a way that is **challenging** and what can help.

When we say **you** we mean a child, young person or adult with a learning disability and behaviour that challenges.

When we say **everyone**, we mean staff, family or carers who support you.
2  What is behaviour that challenges?

**Behaving** in a way that is challenging includes:

- doing things that hurt yourself or others
- damaging things
- doing things that make life difficult for you or for other people.

Usually people do not behave in this way. It happens when things are not right for you.
This may be because you:

- cannot make other people understand what you want or how you feel
- feel like you have no control
- are unhappy about your service or support
- are ill or in pain.

Getting the right support can help stop people behaving in a way that challenges.
3 Working together

Working with you

Services or workers supporting you should:

- Involve you in decisions about your care and support.

- Help you be as independent as possible and get the most out of life.

- Treat you with respect so you understand and trust each other.

- Give you clear information.
• Make sure you know who to tell if you are worried about your care or support.

• Tell you how to get support from an **advocate**. This is someone who can help you speak up.

• Involve your family or carers in decisions. And give them help so they can support you.

**Supporting you**

Everyone who works with you should be trained so they understand people with behaviour that challenges.

They should:

• Think about what is important to you, your health and your needs.
• Know how to help calm you.

• Help you learn other ways to let people know you are angry or upset.

• Give you support in or near to your home or in other places you are used to. For example, your school or college.

• Want to change the behaviour, not you.

Spotting things early

Everyone should look for things that might make people behave in a way that challenges.
The types of things they should look for are:

**Things about you**

- Difficulty understanding things or letting people know how you feel.
- Health problems.
- Changes because of your age. For example, becoming an adult.

**Things around you**

- Being somewhere too busy or too quiet.
- Being asked to do things that are difficult for you.
• The wrong support.

• Changes to people or places you know.

If people think there is a risk for you or other people, they should ask for an **assessment**.

Part 5 tells you more about assessments.
4 Health problems

Everyone should think about how your health might affect your behaviour.

Your doctor should offer you a health check each year. Someone who knows you well should go with you.

Your doctor should make sure you have the right medicine or treatment for any health problems or pain.
5 Assessments – understanding behaviour

You will have assessments to find out more about the behaviour that challenges.

The assessments will look at things like:

- what the behaviour is like
- things that might make it happen
- how it affects you and other people.
This information goes into a **behaviour support plan**. This helps everyone give you the right support.

There is more about the behaviour support plan in Part 6.

### During the assessments

Everyone should make sure:

- You have support to understand what is happening.
- They involve your family and carers.
- They find out what is important to you and what would make things better for you.
After the assessments
The people who did the assessments should explain what they found out.

They should involve your family and carers to help you understand what the assessments mean.

They should involve an advocate if you ask for one.

They should write the behaviour support plan as soon as possible.
You might need more assessments if:

- the behaviour does not get better when everyone uses the behaviour support plan
- the behaviour changes.

The assessments may involve people with special skills to look at what causes the behaviour.
6 Things that might help

Changing what you do or where you go can help stop behaviour that challenges.

Your behaviour support plan should say things like:

- What changes could make your life better.

- Which places might upset you.

- What needs to change about the things you do or the times you do them.
- If there are people who might upset you.

- If there are any risks to you or to other people.

- How to support you when your behaviour is challenging.

- How to support you to communicate.

- How to make sure you know when your behaviour is not challenging.
- Ways to help you deal with your feelings.

- Ways to help you if you have problems sleeping.

- Who will make sure things happen.

- When the plan will be checked.

- Who to contact about the plan.
Behaving in a way that challenges is not an illness. Medicines should not be used to help stop it unless:

- Everyone has tried all the things in your behaviour support plan for an agreed time but they are not working.
- You have had treatment for other health problems but this has not helped your behaviour.
- There is a big risk to you or to other people.
Everyone should still use your behaviour support plan as well.

If you do have medicine your doctor should talk with you and your family or carers about which medicine to have and how to use it.

You should have regular checks to see:

- how the medicine is working
- if it is causing you any problems
- when it can be stopped.
8 Keeping people safe when they behave in a way that challenges

Even if you have a good behaviour support plan, your behaviour may still be challenging sometimes.

If this does happen, everyone should know how to support you safely.

The behaviour support plan will say what to do if the behaviour starts. The aim is to calm things down and keep you and other people safe.

There are laws about when and how to do this if it is the only way to keep people safe.
People might need to:

- hold you

- give you more space

- give you an injection.

They should only do these things:

- when nothing else works
for the shortest time possible

as part of your behaviour support plan.

If possible, everyone should involve you, your family or carers in planning and checking what happens.

They should write down what they do and use this to think about whether they could support you differently or better.
9 How to find out more

These people can give you more information about behaviour that challenges. Their information is not written by NICE.

**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.includemetoо.org.uk

**The Judith Trust**
Website: www.judithtrust.org.uk
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