

Meeting the challenge **1**

Understanding
challenging
behaviour and
getting advice
and support



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Understanding challenging behaviour and getting advice and support

This factsheet provides information and signposting to help you understand challenging behaviour and how to go about getting support for your family member.

Words in **blue** are explained in more detail in the glossary at the end of the factsheet.

What is challenging behaviour?

'Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.'¹

This behaviour may include:

- Aggression – physical or verbal (e.g. hitting other people, swearing at other people)
- Self-injury (e.g. hitting their own head, eye poking)
- Destruction (e.g. throwing furniture, smashing equipment)
- Other behaviours (e.g. running away)

Behaviour like this is challenging because it can - and often does - put the safety of the person or other people at real risk and can have a significant effect on the quality of the person's everyday life. Family carers and professionals can find behaviour like this distressing and difficult to cope with.

“Joe has a severe learning disability and behaviour that challenges. He doesn't use many words. When communicating with Joe, staff need to listen to him and repeat back to him what he has said. They must not try to pass it off with saying: “Ok Joe, yes mate,” if they don't understand what he is trying to say, as Joe will become frustrated and upset by this, which will lead to incidents happening.”

Joe's mum, Out of Sight report ²

¹Challenging Behaviour: A Unified Approach, Royal College of Psychiatrists, et al, 2007

www.rcpsych.ac.uk/files/pdfversion/cr144.pdf

²Out of Sight, Mencap and the Challenging Behaviour Foundation, 2012

www.mencap.org.uk/outofsight

Why does it happen?

All behaviour happens for a reason, but it can be hard to work out and understand what the causes are.

Most children without learning disabilities display lots of challenging behaviour during the “terrible twos”. Usually this doesn’t last because most 2-year olds develop a range of communication and social skills that help them to get what they want and need more easily. Many people with learning disabilities will not develop these skills as they grow older. They have the same needs as other people their age, but may be less able to communicate them and get them met. This means they may continue to display challenging behaviour.

Some common reasons for challenging behaviour include:

- To gain attention
- To get something e.g. a drink
- To escape something or someone
- Sensory needs e.g. bright lights or loud noises

Challenging behaviour can also be related to:

- Physical pain
- Emotional distress
- Mental ill health
- Trauma such as abuse



More Information

Factsheet about ‘understanding challenging behaviour’ (The Challenging Behaviour Foundation)

www.challengingbehaviour.org.uk/cbf-resources/information-sheets/understandingcb.html

Challenging behaviour is sometimes confused with a mental health problem, but they are not the same. Sometimes a person with a learning disability may display challenging behaviour because they have a mental health problem but in many cases it will be due to one of the other reasons described above. It is really important to find the cause of the behaviour.

A person with a learning disability whose behaviour is described as challenging may also have or develop a mental health problem - just like anyone else (e.g. depression or anxiety). This may or may not make the challenging behaviour that they display worse.

It is important that people with a learning disability get the treatment they need for physical and mental health problems. Unfortunately we know that physical and mental health problems are sometimes missed because professionals put symptoms or behaviour down to the person having a ‘learning disability’ and don’t explore them properly.

It is important that people with a learning disability get regular health checks which look at their physical and mental health.



Top Tip

If the behaviour of your family member changes, or is new, or has suddenly increased then it may be because they are in pain. Checking for health problems can be a good first step.

Make sure your family member has an **annual health check** and has a **health action plan** and **hospital (health) passport** which are up-to-date! – see factsheet 2 for more information on these.



More Information

Factsheet on health and challenging behaviour (The Challenging Behaviour Foundation):

www.challengingbehaviour.org.uk/cbf-resources/information-sheets/health.html

Factsheet on mental health problems in people with learning disabilities (The Challenging Behaviour Foundation):

www.challengingbehaviour.org.uk/cbf-resources/information-sheets/mental-health-problems.html

How do you make sure a person whose behaviour challenges gets the right support?

Factsheet 2 explains more about what good support looks like and how you can get it. It includes information about some of the best approaches for understanding, assessing and supporting a person who has behaviour that challenges.

Who can give you advice and support?

Local health services and your **local authority social services** department should be able to provide you with information and advice about what support and services are available in your area and how to get them. But many people also want to talk to other families and voluntary organisations that are providing support to families.

Coping with ‘challenging behaviour’ can be an emotional experience for family carers – you may feel angry or depressed about the lack of support your family member is getting. Talking about it with others who have “been in your shoes” and can understand and listen may be helpful. There are a number of organisations (see the section below) who may be able to provide support and link you up with other families who have had similar experiences.



More Information

The Challenging Behaviour Foundation's Family Carers' Email Network and Family linking scheme are specifically for family carers who have a family member with severe learning disabilities and behaviour described as challenging. They enable families to link up, ask questions and share information:

www.challengingbehaviour.org.uk/supporting-you/for-families/family-carers-email-network.html

www.challengingbehaviour.org.uk/supporting-you/for-families/linking-scheme.html

If you have had to fight to get your family member the support they need it can sometimes feel like a long and lonely battle. There are a range of national and local charities that can provide free information and support and may be able to link you up with other families who have faced similar difficulties.

Challenging Behaviour Foundation – a small national charity that specialises in supporting families who have a relative with severe learning disabilities and behaviour described as challenging. Offers individual support to families by telephone and email, a family carers' email network and a family linking scheme.

www.challengingbehaviour.org.uk

Disability Law Service – a charity providing free advice on community care law, disability discrimination, education, employment, welfare and benefits.

www.dls.org.uk

Hft – a national charity supporting people with learning disabilities and their families. Its Family Carer Support Service offers one-to-one support, workshops and publications for family carers supporting a relative with a learning disability, anywhere in England.

www.hft.org.uk/familycarersupport

Mencap – a UK learning disability charity that campaigns with people with a learning disability and their families for a better future, provides services and has a telephone advice and information service for anything related to learning disability.

www.mencap.org.uk

Mind – a mental health charity that provides advice and support to people experiencing a mental health problem, including an infoline and legal line, and that campaigns to improve services, raise awareness and promote understanding.

www.mind.org.uk

National Autistic Society – a UK charity for people on the autism spectrum and their families, providing information, support and services, and campaigning for a better world for people on the autism spectrum.

www.autism.org.uk

Respond – a charity that works with children and adults with learning disabilities who have experienced abuse through psychotherapy, advocacy, campaigning and other support. They offer support to families through their family support service.

www.respond.org.uk

See **Meeting the challenge: Frequently asked questions about the law** written by Irwin Mitchell Solicitors for more information about your family member's legal rights: www.irwinmitchell.com/meetingthechallenge

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Glossary

Local health services

Health services found in your local area. Clinical Commissioning Groups (CCGs) commission most of the hospital and community NHS services in the local areas for which they are responsible (e.g. most planned hospital care and community health services). Some very specialist services remain the responsibility of NHS England.

Local authority social services

Local authorities (local councils) provide a range of services within a locality; this includes the provision of community care services – that is, services provided to people who have care and support needs. The adult social care department, part of your local authority's social services, is responsible for assessing people's need for 'community care' or 'social care' services.

Annual health check

Adults who have moderate, severe or profound learning disabilities, or people with a mild learning disability who have other complex health needs, are entitled to a free annual health check. People with learning disabilities often have difficulty in recognising illness, communicating their needs and using health services. Regular health checks for people with learning disabilities can uncover treatable health conditions. You should speak to your local GP surgery for more information about arranging a health check for your family member.

Health action plan

it is recommended that people with learning disabilities have a health action plan which outlines information about their health needs, and includes specific actions to address these. The plan should be based on a full health check.

Hospital (health) passport

A hospital (health) passport is to assist people with learning disabilities to provide important information about them and their health. It should include things like how to communicate with the person and how the person shows pain. This can be used in places like hospitals to help ensure the person gets good health support.

Severe learning disabilities

Some people may have a mild or moderate learning disability; others may have a severe or profound learning disability. The level of support someone needs depends on individual factors, including the severity of their learning disability. People with a severe learning disability will need a significant amount of support with daily activities such as washing and dressing, and keeping safe. They are also more likely to have little or no speech.

For more information visit
www.mencap.org.uk/meetingthechallenge

Mencap 123 Golden Lane, London, EC1Y 0RT
Charity number 222377 (England, and Wales); SC041079 (Scotland) 2014.106

