

Meeting the challenge 2

What does good support look like for adults with learning disabilities who display challenging behaviour?



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This factsheet describes what ‘good support’ should include for people with learning disabilities whose behaviour is described as challenging. Good support will help the person lead a full, active life and help avoid challenging behaviour escalating into a crisis.

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

Any signs of challenging behaviour should be identified as early as possible and the right support put in place to prevent a crisis situation developing. People need to be able to get the support they need in their local areas either with or near to family and friends. After the abuse of people with a learning disability at Winterbourne View hospital the Government has been very clear that people should be able to get the support they need locally.¹

If a person gets the support they need it will help them live a full life in their community. Challenging behaviour can be reduced to a level where it does not negatively affect a person’s quality of life. Families have an important role to play in helping their loved ones needs to be understood.

“Supporting people with a learning disability and behaviour that challenges is everyone’s job – social care and health professionals, commissioners, providers, housing and children’s services.”

Out of Sight report ²

“A high quality service means that people with learning disabilities or autism and behaviour which challenges will be able to say... I am supported to live safely in the community.”

Transforming Care report ³

¹ Transforming Care: A national response to the Winterbourne View Hospital. Department of Health Final Report. 2012

www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf

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

www.mencap.org.uk/outofsight

³ See ¹.



Top Tip

It is important to remember that decisions about care and support for your family member must be in line with the principles of the **Mental Capacity Act (MCA)**. This law says that everyone, whatever their disability, has the right to be involved in decisions about their lives and should be helped and supported to do so.

If someone lacks the ‘mental capacity’ to make a decision, then a decision must be made in their ‘**best interests**’, involving families and others who know them well. Family members can challenge professionals if they feel that they are not being involved in decisions. The MCA also says that people who lack capacity should receive their care and support in the least restrictive way possible.

You can read more about the MCA in factsheets 3 and 7.

How do I make sure my family member gets good support?

It is important to remember that all behaviour has a meaning for the person and is a way of communicating their needs however ‘challenging’ it appears from the outside (see factsheet 1 for more). Finding ways of understanding behaviour is a vital part of ensuring the person gets good support. It is essential that a range of structured assessments take place in order to fully understand the person’s needs.

Assessment and planning

- In adult services, the support offered to your family member will be determined through a **needs assessment**, which is carried out by your local authority. Health and housing needs should be considered as part of this assessment process. The local authority has a duty to meet all care needs that are deemed ‘eligible’ (i.e. they meet the ‘**eligibility criteria**’ for support).



Top Tip

It is important that your family member’s assessment is thorough. Don’t be afraid to ask for experts to be involved – for example, psychologists with expertise in behaviour that challenges. This will ensure the right support package is put in place and that any triggers for behaviour that challenges are minimised.

- If the person has a high degree of challenging behaviour, they may meet the criteria for **NHS Continuing Healthcare** (CHC) and have their whole package of care funded by the NHS. If the local authority thinks that might be the case they will ask the NHS to carry out an NHS Continuing Healthcare assessment.
- For people who display behaviour that challenges, an assessment of the person’s behaviour, called a “**functional assessment**”, can be an important part of the assessment process. A psychologist or specially trained learning disability nurse usually carries these out.

- Depending on the needs of the person they may also need a:
 1. **Speech and language therapy assessment** (communication)
 2. **Sensory assessment** (by an Occupational Therapist)
 3. Physical health check
 4. Mental health assessment
 5. **Trauma** support assessment



Top Tip

Contact your family member's GP, Social Worker/Care Manager or Community Learning Disability Team (see below for more on CLD teams) to ask how you access these assessments.

- The needs assessment will result in a care and support plan for your family member outlining what support they are eligible for and how their needs will be met. The **care and support plan** is a legal document.
- In addition to a care and support plan, it can be helpful for the person to have a **Person Centred Plan (PCP)** (a PCP can inform the care and support plan). Person Centred Planning is a way of enabling people to think about what they want and need now and in the future. It is about supporting people to plan their lives, work towards their goals and get the right support. This should be a plan that covers all aspects of their life. It is important that staff supporting a person work with the person and their families to develop the PCP. An important part of the PCP will be how the person wants to spend their time. This is important to all of us. Behaviour can be triggered or get worse if people are not understood and are frustrated or bored.
- A **communication passport** can be a helpful way of capturing how someone communicates. This can help people to get to know a person and understand how best to communicate with them and can be used across any setting.
- Following a functional assessment a **Positive Behaviour Support** plan should also be developed. This is an individually tailored step-by-step guide to help reduce challenging behaviour and improve the person's quality of life. The steps in the plan should be in line with an approach called Positive Behaviour Support (PBS). The focus of Positive Behaviour Support (PBS) is not on 'fixing' the person or on the challenging behaviour itself and never uses punishment as a strategy for dealing with challenging behaviour. There should be an emphasis in the plan on teaching new skills to enable the person to better communicate their needs and become more independent.
- Getting support from an **independent advocate** to support the person can help to ensure their needs, wants, and preferences are communicated clearly. The Care Act 2014 (which came into force in April 2015) places a new duty on local authorities to provide access to independent advocacy to those who would have substantial difficulty in being involved in the assessment process, care and support planning and reviews, and who have no appropriate individual(s) (e.g. family or friend) who can support their involvement.

There is already a right to advocacy in certain situations – for example, under the Mental Capacity Act 2005 if a person lacks capacity and is un-befriended then an **Independent Mental Capacity Advocate (IMCA)** must be instructed in relation to certain key decisions (e.g. serious medical treatment or changes in accommodation).

- You might hear about the **Care Programme Approach (CPA)**. This is an approach that is used to coordinate someone's care where they have mental health needs or a range of complex needs. People might start having CPA meetings in an inpatient unit, but it can be helpful for them to continue once they move on from inpatient care. They are a way of making sure someone's care and treatment is reviewed on an ongoing basis. It can be important to have ongoing and regular meetings to keep an eye on your family member's care/needs. This can help avoid crisis situations and keep everyone working well together.



More Information

Factsheet about functional assessments (The Challenging Behaviour Foundation):

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

Factsheet about Positive Behaviour Support (PBS) planning (The Challenging Behaviour Foundation)

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

More information about Communication passports (University of Edinburgh & My Communication Passport):

www.communicationpassports.org.uk

www.mycompass.com



More Information

More information about person-centred planning (PCP) (Helen Sanderson Associates):

www.helensandersonassociates.co.uk/reading-room/how/person-centred-planning.aspx

The Department of Health have produced information for families about the Care Programme Approach:

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/publicationsandstatistics/publications/dh_083650

NHS choices has a one page overview of the Care Programme Approach:

www.nhs.uk/Conditions/social-care-and-support-guide/Pages/care-programme-approach.aspx

What does good support look like?

- Staff who are supporting the person need to **understand how the person's behaviour changes** when they are ill or in pain, as the person may not be able to tell people this using words. It is important that staff **listen to families** and others who know the person well in order to understand the person's behaviour.
- It is important the person has **regular health check-ups** with their GP. People with a learning disability are entitled to an annual health check which will look at all aspects of their health in a holistic way. **Health action plans** and **health (hospital) passports** are useful tools for recording and sharing health information and helping the person stay healthy (see factsheet 1 for more on these). It is also important the person has **regular medication reviews** if they are taking medication.



More Information

More about annual health checks

www.improvinghealthandlives.org.uk/projects/annualhealthchecks

More about health action plans

[www.easyhealth.org.uk/listing/health-action-plans-\(leaflets\)](http://www.easyhealth.org.uk/listing/health-action-plans-(leaflets))

More about hospital (health) passports

[www.easyhealth.org.uk/listing/hospital-passports-\(leaflets\)](http://www.easyhealth.org.uk/listing/hospital-passports-(leaflets))

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

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

- Staff working with adults with learning disabilities who display challenging behaviour should be **skilled and have the right values and attitudes**. Staff will need different training depending on the person's individual needs e.g. epilepsy, communication needs or autism. However all staff supporting people who challenge should be trained in **person centred thinking** and **Positive Behaviour Support (PBS)**.
- It is important that there are both health and social care **professionals in the community who have expertise** in supporting people with learning disabilities who display challenging behaviour. They should help support individuals, staff and families to prevent and respond to someone's behaviour in the best way for them. They may be social workers, psychologists, psychiatrists, speech and language therapists, occupational therapists or learning disability nurses. It is important they understand how to assess behaviour and can help families and staff to implement an individualised Positive Behaviour Support plan.

- In some local areas these health and social care professionals will be part of what is called the **Community Learning Disability Team** and in others they may be part of an **Intensive Support Team**. However not all areas have these teams so you may need to contact them through a different route – e.g. your local authority’s social services department.



More Information

The Challenging Behaviour Foundation has information about some local ‘behaviour support teams’ (some are part of Community Learning Disability Teams and some are not):

www.challengingbehaviour.org.uk/about-behaviour/behaviour-support-teams.html

- If someone’s behaviour does reach crisis point they may need a short period of time out from the place where they are living. There should be options for this, for example, beds in a **short breaks (respite)** service that could be used. There should be a variety of ways of responding to a crisis, not just sending someone to an inpatient unit like an **Assessment and Treatment Unit (ATU)**.
- People shouldn’t need to go into an inpatient unit unless there is a **specific reason** why they need some inpatient assessment and / or treatment for a short period of time, and why this cannot be provided in the community. Most people with a learning disability should never need to go into a unit. They should be able to get the right support in the place where they are living or somewhere else in the community – the expertise should be brought to the person.



More Information

The Government has been clear that local support and services for people with behaviour that challenges should be developed. If you don’t think this is happening in your local area then you can tell your local Healthwatch. They can raise your concerns with the relevant health and social care services. Find your nearest local Healthwatch here:

www.healthwatch.co.uk/find-local-healthwatch

- If a person does need a short period of inpatient assessment and / or treatment (for instance, when someone has a complex mental health condition), the unit should be as **small and as near to home as possible**. The facility should be able to provide specialist assessment of the individuals’ needs and treatment of those needs, and enable the person to return to their local community as soon as possible.

- For people living in the family home, it is important there are **suitable short breaks services** to support families. This could be in a local short breaks service or in the family home. There are also creative options to explore – for example, some families have employed support workers to take the person out for the day to take part in activities they enjoy, and have even rented a caravan or hotel room for the weekend so the person can have a holiday, giving family a break.



Top Tip

It is always best if steps can be taken to prevent someone's behaviour reaching a crisis point. If someone can get the right support early on this will help. If you believe your family member is not getting the right support, don't be afraid to speak up. You are an expert in your family member's care. You probably take for granted all the knowledge you have. For example, what is important to them, what triggers or increases their anxiety or behaviour? Write down what you know and tell others. Good staff and services will want to listen. If they don't you can make a complaint or get legal advice.

- For people not living in the family home, it is important that individuals get the right support. As well as being supported by the right staff, the **right living environment** can be very important. For example, some people may need lots of space, or to live away from busy roads (if loud noise triggers behaviour). To work out what is the right environment for someone there will need to be a detailed assessment involving the person and their family to draw up a "housing specification" alongside a care plan.



More Information

Planning for the future factsheet (The Challenging Behaviour Foundation):

www.challengingbehaviour.org.uk/cbf-resources/information-sheets/planning-for-the-future.html



More Information

8 ways to get a house information pack (The Challenging Behaviour Foundation):

www.challengingbehaviour.org.uk/education-housing-social-care/8-ways-to-get-a-house-pack.html

Information about housing, funding and support (The Housing and Support Alliance):

www.housingandsupport.org.uk/housing-and-support-options

Ensuring quality services: Core principles for the commissioning of services for children, young people, adults and older people with learning disabilities and/or autism who display or are at risk of displaying behaviour that challenges (Local Government Association and NHS England)

www.local.gov.uk/documents/10180/12137/L14105+Ensuring+quality+services/085fff56-ef5c-4883-b1a1-d6810caa925f

What support is there for family carers?

Supporting someone with complex and challenging behaviour can be very stressful. It is important that you get the right support to help you in your caring role. As a family carer you can get an assessment and could be eligible to receive practical support in your own right. Services that you might receive could include things like respite care or support from a carer support worker. Don't be made to feel guilty that you want support for yourself. Keep a record of all you do on a day-to-day basis to help you prepare for a carer's assessment.



More Information

Information about carers' assessments (Carers UK):

www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment

How to achieve good support?

A person's package of support may be funded in different ways. Some people's package of care may be funded solely through social care by the local authority, whilst others may have a package of care funded jointly by the local authority and health (NHS) if there are specific health needs that need to be met. Some people with behaviour that challenges may meet the criteria for NHS Continuing Healthcare and have their whole package of care funded by the NHS/health.

There are ways that people can manage their own care and support. This allows people to have more choice and control over the services they receive to meet their needs. This is often referred to as 'self-directed support'.

A Personal Budget means that the person is allocated a pot of money to choose and pay for the care and support they want. It is important that people with behaviour that challenges are given the opportunity to have a Personal Budget. It could be funded by social care (Local Authority), or it could be a Personal Health Budget (if the person is funded by NHS Continuing Healthcare) or it could be a joint (integrated) personal budget combining health and social care funding.

There are different ways you can take and manage a Personal Budget. You can take it as a Direct Payment – which is where you are given a payment instead of services, to buy the services you want – or you can leave it to the local authority or NHS with the responsibility for commissioning services (whilst still choosing the services you want). Or, people can have a combination of both.



More Information

What do I need to know about NHS Continuing Healthcare? (Alison Giraud-Saunders, Foundation for People With Learning Disabilities)

www.learningdisabilities.org.uk/publications/continuing-healthcare/

In Control – helpline and information about direct payments and personal budgets

www.in-control.org.uk



More Information

Personal Health Budgets: Including People with Learning Disabilities (Think Local Act Personal):

www.thinklocalactpersonal.org.uk/library/Reports/TLAPIncludingLD.pdf

National organisations that provide information, advice and support

Factsheet 1 provides a list of organisations that can provide more information, as well as advice and support.

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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Summary - Good Support! What should I be looking for?

- The service/ staff are willing to work in **partnership with families** and recognise and value the contribution they bring and listen to what they have to say!
- Staff have had the **right training** – they understand how your family member communicates and they value and respect them.
- Staff have had training in **positive behaviour support** and are identifying the reasons for your relative's behaviour and helping them to develop new skills.
- Your loved one is cared for in the **least restrictive way** possible – you and your family member should be involved in planning how they should be supported. Medication or restraint should only be used if absolutely necessary and as little as possible.
- Your loved one has had a **proper assessment**, which includes a detailed assessment of their behaviour – to identify triggers and work out the best way to support them.
- They have got a **behaviour support plan**, and this is part of a wider person-centred plan which looks at their whole life, what is important to them, what they enjoy doing. It helps people support them in the right way and help makes sure the person is living the life they want.
- Your loved one is cared for **as an individual** with services based around their individual needs.

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Glossary

Mental Capacity Act

A law designed to protect and empower people who may lack capacity to make decisions, for example decisions about their own care and support, property or finances, because of a mental health condition, learning disability, brain injury or illness. 'Mental capacity' is the ability to make decisions for yourself. The law applies to people aged 16 or over.

Best interests

Under the Mental Capacity Act, decisions made in a person's best interest are made after weighing up all the evidence to decide what is best for a person. Best interest decisions are made when it is deemed that the person does not have the mental capacity to make the decision themselves. The MCA provides a checklist of factors that decision makers must work through in deciding what is in a person's best interests, including involving the person as fully as possible, and consulting with those who know the person well.

Needs assessment

The assessment that is carried out by the local authority to work out what someone's needs are. An individual is entitled to one if they have social care needs. Once a 'needs assessment' has been carried out, the local authority will determine which of the person's needs are "eligible" for support using "eligibility criteria". The Care Act has introduced national eligibility criteria, which local authorities must use.

NHS Continuing HealthCare

Sometimes called fully-funded care; care that is arranged and funded solely by the NHS/health for individuals who have complex ongoing healthcare needs. In this situation, the NHS is responsible for meeting both the health needs and the social care needs of the person.

Short breaks (respite) services

The term 'short breaks' or 'respite' is used to describe the time off that family carers and people with a learning disability can receive. Services come in different forms. Some families access short breaks centres or some may receive direct payments to buy their own support. Breaks are an essential part of the support needed by the whole family. They provide time off for the carer to rest and focus on other activities and family members, and a chance for those they care for to spend time with others and take part in different activities.

Assessment and Treatment Unit (ATU)

A type of inpatient unit designed to facilitate the assessment and treatment of people, where this cannot be done safely in community based settings. There are different types of inpatient units available for people with learning disabilities who require assessment and treatment; which sort of unit will depend on their individual need.

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Glossary

Functional assessment

A detailed assessment of what happens before and after behaviour to help understand the reason(s).

Speech and language therapy assessment

An assessment to understand any speech and language delays and difficulties and what help is needed.

Sensory assessment

We all have seven senses: sight, sound, touch, taste, smell, balance ('vestibular') and body awareness ('proprioception'). People can be over- or under-sensitive in any or all of these areas. A sensory assessment is usually carried out by an Occupational Therapist who looks at whether or not the person is under or over sensitive in any of these areas.

Trauma

The emotional shock that someone experiences following a terrible event that involves an actual or perceived threat to their physical or mental well-being. Trauma can also occur in response to witnessing a similarly terrible event involving someone else, or when being given sudden shocking news about a relative or someone you know well. For the event to be traumatic the person's response must involve intense, fear, helplessness, or horror and must overwhelm the normal coping mechanisms. (Respond definition)

Positive behaviour support (PBS)

An established and well-evidenced approach to supporting with people with learning disabilities who display challenging behaviour. PBS is based on a detailed understanding of the causes of the person's behaviour. A PBS approach reduces the likelihood of challenging behaviour happening in a range of ways including changing triggers, developing the person's skills and teaching alternative behaviours. A key part of PBS is increasing the person's quality of life.

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

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