

Challenging behaviour: a guide for family carers on getting the right support for adults

Key messages

- Challenging behaviour can usually be reduced or avoided with support.
- Support should be flexible and personalised to the needs and circumstances of individual families.
- Support should be available to prevent challenging behaviour developing or getting worse.
- Government policy is clear that adults with learning disabilities have the same rights as everyone else.
- Support should be available from a behaviour support team or equivalent.
- A comprehensive behaviour assessment should include: a functional assessment of behaviour, medical health check, mental health check, communication assessment and social and environmental factors that may affect behaviour.
- A behaviour support plan should be developed, setting out what is likely to trigger the behaviour and how families and services should respond.
- Families should expect wherever possible to work in partnership with the professionals involved with their family member's care and support.

Introduction

This At a glance briefing is for family carers supporting an adult with severe learning disabilities and behaviour described as challenging. It will help you understand what you should expect from local services.

The briefing will help you understand what good support and services look like, to enable you to ask for the support you and your family need, and to work in partnership with the professionals who are involved with your family. The way things are done will vary between different areas. There is information at the end about what to do and who to contact if you are concerned that your family's needs are not being met.

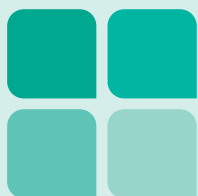
What is 'challenging behaviour'?

Behaviours that people find challenging can:

- put a person's safety at risk
- disrupt home life
- stop a person taking part in ordinary social, educational and leisure activities
- affect a person's development and their ability to learn.

Problems are often caused as much by the way a person is supported – or not supported – as by their disabilities. People often behave in a 'challenging' way if they have problems understanding what's happening around them or communicating what they want or need.

Caring for a person whose behaviour challenges can put families under great pressure and often restricts what you are able to do. That's why it's essential to have the right support in place. Services should support parents and other family



Challenging behaviour: a guide for family carers on getting the right support for adults

carers in their caring role, and to have a life of their own alongside caring.

What do we know?

- Challenging behaviour can usually be reduced or avoided with good support.
- Teaching new communication skills is a key way to reduce challenging behaviour.
- Support should be flexible and personalised to the needs and circumstances of each individual and their family carers.
- Support should be available to prevent behaviours developing or getting worse.
- It really helps to plan ahead – ideally before a crisis occurs.
- Every person whose behaviour challenges should have a clear plan setting out the support they need immediately, and the support they are likely to need in the years ahead.
- Families of people whose behaviour challenges have high levels of stress and often have emotional or physical health problems of their own. These difficulties are often made worse by the problems many families experience in getting effective help and support.

Your rights

Government policy makes clear that people with learning disabilities have the same rights as everyone else. They and their family carers are entitled to the same opportunities in life that anyone else would expect. They should have the opportunity to make decisions for themselves, to be included, and to live independently with the support they need. They have the right to speak up and be heard about what they want for their lives, and they should be supported by an advocate if they are unable to speak for themselves.

A range of national policies sets out the type of services and support that should be available locally. This should involve specialist services e.g. a specialist challenging behaviour team where necessary, as well as better access to the 'mainstream' services (such as public transport) that everyone uses.

Many services are only available to people who fit specific criteria set by councils/trusts. It is important to find out as much as you can about how councils decide 'who gets what'.

Family carers have the right to an assessment of their own needs. They should also have a say in the support they need to manage their caring responsibilities and to have a life of their own.

Support with challenging behaviour

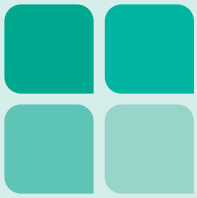
Every individual regardless of where they live should have:

- access to healthcare: it is important to treat any medical conditions the person has, which may cause challenging behaviour or make it worse
- access to assessment and support to ensure their behaviour is properly understood and supported
- an advocate who knows how the system works and can help access support.

Families should be able to access a range of support and services to meet the needs of their family. Support should be flexible and personalised to meet individual need.

Every family caring at home for a person with behaviour that challenges should have:

- opportunities for short breaks, tailored to the particular needs of your family. It is the council's/trust's responsibility to make short breaks available – even if traditional local respite services find it hard to provide the support required



Challenging behaviour: a guide for family carers on getting the right support for adults

- practical help with things like equipment e.g. bite-proof mattresses
- access to advice and funding for adaptations to the family home e.g. adapting a bathroom to a wet room to prevent flooding
- advice and training in how to understand and manage difficult situations.

What does good support look like?

It's based on good relationships and genuine partnership between people with behaviour described as challenging, their family members, and professional staff who are willing to try new ways of working. It meets the needs of individuals and families and enables families of people with severe learning disabilities and challenging behaviour to live as 'ordinary' a life as possible.

Choice and control

Everyone with learning disabilities should receive support that is personalised to their particular needs and circumstances.

- They (and their families) should have much more choice and control over their lives – with information to help them make decisions, choice in how their needs are met, and access to universal services such as transport, education and housing, regardless of disability.
- These choices should apply to their lives now, and as they plan for the future.
- Personal budgets (including direct payments), where people and their families control directly how money is spent are a way of making this happen.
- Personal budgets allow for a much more flexible support plan, bringing in support from different places – the council/trust, private agencies, charities, community groups, neighbours, family and friends.

Community services and specialist behaviour support

Local community learning disability teams (CLDTs) assess people's needs, and help arrange housing, work, education and other day placements. They include staff from health and social services, and will provide support to adults with learning disabilities and challenging behaviour. Health and social services should work together with the person and their family to ensure support and services are holistic and coordinated.

Sometimes help is needed from a specialist 'behaviour support team', or equivalent.

This team includes, or works closely with, a range of professionals including clinical psychologists and psychiatrists who have expertise in understanding and assessing challenging behaviour.

Speech and language therapists and occupational therapists should also be involved, to help people communicate effectively with those around them.

A 'positive behaviour support' approach is recommended by the key professional bodies. It includes:

- treating the person with dignity
- creating meaningful relationships
- teaching new skills to replace behaviours which challenge
- not using punishment
- having access to meaningful activities.

A comprehensive behaviour assessment should include:

- a functional assessment of behaviour (to look at reasons or 'functions' for challenging behaviour)
- medical health check



Challenging behaviour: a guide for family carers on getting the right support for adults

- mental health check
- communication assessment
- social or environmental factors that may affect behaviour.

Using information from these assessments, a behaviour support plan should be developed, setting out how and why behaviours occur, what keeps them going, what is likely to prevent them and how families and carers can respond in more effective ways. It is vital to have a consistent approach across everyone supporting the person.

Physical intervention – including restraints such as arm-splints or helmets – should only ever be used as a last resort. If they are employed, it should be with clear guidelines on their use, and alongside a range of other ways of supporting the person with their behaviour. This should be recorded and regularly reviewed with a clear aim of eliminating their use. Carers should ask for training in physical aspects of behaviour management, to help them support the person more confidently and avoid hurting themselves or the person with behaviour that challenges. Medication similarly should only be used if there is a clear and specific reason for its use (e.g. depression or epilepsy).

Emergency support should be available 24 hours a day, seven days a week.

Working together

Family carers should expect to work in partnership with the professionals involved with their family member's care and support unless there is clear evidence that this is not in the person's best interests. Most families should be fully involved in discussions and decision-making, depending on the capacity of the individual to make decisions for themselves. Their knowledge of the individual should be respected by all professionals working with them. Individuals should be supported in a positive way by

everyone who works with them. Early support can prevent a crisis occurring and help avoid individuals being excluded from local services, and having their options limited.

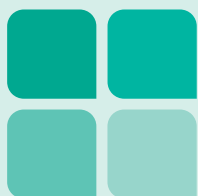
Adults with learning disabilities and behaviour that challenges are often expected to 'fit in' to services. However, services and support should make reasonable adjustments to enable everyone to access them e.g. a longer appointment slot with their GP, or a first appointment of the day to avoid waiting in a waiting room.

Individuals with learning disabilities are entitled to live in their local communities and to have the same opportunities as everyone else. But challenging behaviour can result in people being excluded, and individuals and families may feel increasingly isolated and confined to their home. This is why early support is so important – it can prevent behaviour becoming such a problem. Support should not simply be 'advice' from professionals, but should be about getting the right support, in the right place, at the right time.

Choosing where to live

Adults with learning disabilities should be able to choose, as far as possible, how and where they want to live. For most people, living in their own home or in a small residential home, near their family and friends, will be the right decision. Housing should be available that people want to live in, with the support they need to live there.

Families should be fully involved in making decisions (unless the adult they care for is able to express a wish that their family should not be involved). They should be offered genuine choices. For example, families should not be put in a position of 'choosing' between coping at home without the support they need, or sending a family member away to residential care.



Challenging behaviour: a guide for family carers on getting the right support for adults

Independent supported living

Independent supported living is an option not only for people with relatively low levels of need, it is also possible for adults with very high or complex needs.

'Ordinary' housing is often the best choice for many people with learning disabilities and challenging behaviour, ideally near their family and friends. Home ownership or assured tenancies can be coordinated to support adults living independently, either on their own or with a group of friends. Social workers should work with families to consider this option.

Residential placements

Adults living in residential care should have a care plan that is based on their needs as an individual, including their cultural needs. They should also have access to all the services they need, such as therapies, psychiatry and any behavioural support they need. Some residential homes are simply too large to readily provide personalised support. Councils/trusts should look instead for small-scale options that offer people a good quality of life.

Within residential care, medication should not be given as an alternative to good behavioural support. If medication is given, or physical intervention such as restraint is used, families should be given adequate information and enabled to ask why.

Government policy says that if a residential placement is the best option for an individual, it should be offered as close to people's homes as possible. A residential placement outside a person's home area is called an 'out-of-area' placement. Sometimes an out-of-area placement will be the right decision for a particular individual – for example, if the person's family has moved to a new area, or if it is particularly suitable for their religion or culture. But councils/trusts should not

decide to move someone out-of-area just because there is a lack of services locally.

If a council/trust does place an adult out-of-area, that council/trust is responsible for checking regularly that the placement is right for the person and meets their needs. The council/trust that makes the placement should also tell the council/trust in the new area (where the placement is located) that the person has been placed there. The new council/trust is responsible for making sure that key services (such as psychological support) are provided where needed.

Education, work and other opportunities

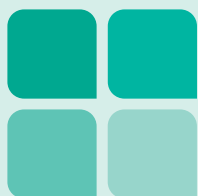
Adults whose behaviour challenges are entitled to a life of their own that extends beyond the services they receive. People should have access to education, employment, leisure and social opportunities.

If people are excluded from day services because of their challenging behaviour, councils/trusts should provide an alternative service or support that meets their needs.

People with complex needs should receive the support they need to help them to take part as fully as they wish in their local community. Support may take a number of forms – one example is 'Circles of support', a group of 'supporters' who meet regularly with a person with challenging behaviour to help them achieve their personal goals.

What does a good service look like?

- It meets people's needs as individuals and is run by staff who know individuals well.
- It's based on good relationships and communication between the individual, their family and professionals.



Challenging behaviour: a guide for family carers on getting the right support for adults

- Everyone has high expectations for all people with complex disabilities to enable them to live as 'ordinary' a life as possible with the support they require.
- People are happy and have a good life, with choices and the chance to learn new things. They are treated with respect and are part of the community.
- It's run by committed staff who are willing to try new ways of working.

If you are not receiving the support you need...

If you and your family are concerned that you are not receiving the support you need, you can raise your concerns with the Director of Adult Services at your local council/trust. In England, if you have a complaint about your council that it is unable to sort out, you can contact the Local Government Ombudsman (0300 061 0614), which considers individual complaints about councils. In Northern Ireland, complaints can be made to the Commissioner for Complaints (0800 343423), and support in making a complaint can be provided by the Patient and Client Council (0800 917 0222). Further advice and information is available from the following organisations:

Carers UK
www.carersuk.org

Challenging Behaviour Foundation
www.challengingbehaviour.org.uk

Mencap
www.mencap.org.uk

National Autistic Society
www.autism.org.uk

Princess Royal Trust for Carers
www.carers.org

About this briefing

The Social Care Institute for Excellence (SCIE) is an independent charity that promotes good practice in social care services for adults and children throughout the UK. We recognise the central role of people who use services and carers, and we aim to ensure that their experience and expertise is reflected in all aspects of our work.

This briefing has been written in partnership with the Challenging Behaviour Foundation National Strategy Group. CBF is a registered charity which wants to see children and adults with severe learning disabilities and behaviour described as challenging, having the same life opportunities as everyone else, including home life, education, employment and leisure.

www.challengingbehaviour.org.uk

SCIE wants to ensure that our resources meet your needs and we would welcome your feedback on this summary. Please send comments to info@scie.org.uk, or write to Publications at the address below.

**Social Care
Institute for Excellence**
Fifth floor
2–4 Cockspur Street
London SW1Y 5BH

tel: 020 7024 7650
fax: 020 7024 7651
www.scie.org.uk

Registered charity no. 1092778
Company registration no. 4289790