

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

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 children and 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, services and schools 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 a teenager or young adult with severe learning disabilities and behaviour described as challenging, who is approaching transition to adult services. 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.

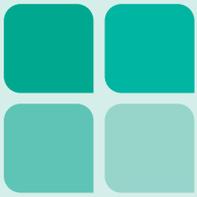
What is 'challenging behaviour'?

Behaviours that people find challenging can:

- put a person's safety at risk
- disrupt home life
- stop the 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 young 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 young 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 carers in their caring role, and to have a life of their own alongside caring.



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

What do we know?

- Challenging behaviour can usually be reduced or avoided with good support.
- Some children with learning disabilities may have challenging behaviour in their early years that improves as they become young adults and are supported to develop better communication skills.
- 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 young person whose behaviour challenges should have a clear plan setting out the support they need immediately, the support they need through the transition process, and that they are likely to need in the years ahead.
- Families of young 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 is clear that children and adults with learning disabilities have the same rights as everyone else. They and their families are entitled to the same opportunities in life that anyone else would expect. They have the right to be included in their local communities and to have their voices heard.

Teenage children have the right to live with their family, unless this is clearly not in their best interests. Government policy says that all children and young people have the right to be educated in mainstream, inclusive, local schools,

if this is what their parents wish. Sometimes, due to lack of suitable local support, parents request a residential school place for their child that offers education and care 52 weeks a year. Residential schools are often far away from young people's family homes. It is reasonable for families to expect that their teenage child will not be placed in a residential school simply in response to a crisis caused by persistent challenging behaviour.

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. specialist challenging behaviour teams where necessary, as well as better access to mainstream services (such as parks and public transport) that everyone uses.

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

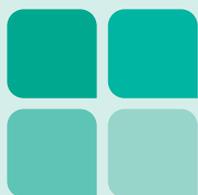
Family carers have the right to an assessment of their own needs. They should also have a say in the support they need to manage their caring responsibilities and to have a life of their own.

Support with challenging behaviour

Every young person regardless of where they live should have:

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



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

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

- opportunities for short breaks, tailored to the particular needs of the family. It is the council's responsibility to make short breaks available – even if traditional local respite services find it hard to provide the support required
- 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 young people with behaviour that challenges, their families, and professional staff who are willing to try new ways of working. It meets the needs of individual young people and families, and enables families of young 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.

- Teenagers and young adults (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 adulthood.
- Personal budgets (including direct payments), where young people and their families control directly how the 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, private agencies, charities, community groups, neighbours, family and friends.

Community services and specialist behaviour support

Local community learning disability teams (CLDTs), who assess people's needs and help arrange housing, work, education and other day placements, will provide support to adults with learning disabilities and challenging behaviour. They will be involved in the transition to adult services. Education, health and social services should work together, with the person and their family to ensure a well planned transition.

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.

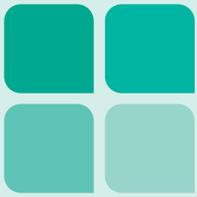
Speech and language therapists and occupational therapists should also be involved, to help teenagers find effective ways of communicating with the people around them.

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 teenagers

- 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 their child more confidently and avoid hurting themselves or their child. 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 young person should be respected by all professionals working with them. Teenagers and young people should be supported in a positive way by everyone who works with them – family, teachers, care workers – to help

them learn to develop including improving communication skills. Support at an early stage for children and families can prevent a crisis occurring and help avoid teenagers being excluded from school and other local services, and having their options limited as they progress into adulthood.

Young people 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.

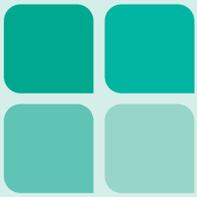
Young people with learning disabilities are entitled to live in their local communities and to have the same opportunities as every other young person. But challenging behaviour can result in young people being excluded, and families may feel increasingly isolated and confined to their home. This is why early support for families 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.

Planning ahead

It is vital to plan ahead for services for young adults with behaviour that challenges well before they move into adults' services. Parents are often concerned that their son or daughter will not get the support and services that they need once they move to adulthood.

Good transition arrangements involve:

- planning early for the transition from children's to adults' services, and staff communicating well with each other and with families. Transition planning should start when the person is 14 at the latest
- support based on individual needs, with input from all those who know the individual well



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

- high expectations for all people with complex disabilities, to enable them to live as 'ordinary' a life as possible with the support they require
- young people being happy and having a good life, with choices and the chance to learn new things. They are treated with respect and are part of the community.

All support and services, including placements in residential or day care, should be appropriate for the young person and tailored to their needs. They should help the young person develop their communication skills, allow them to continue receiving education, and enable them to interact with their peers.

Choosing where to live in adulthood

Young adults with learning disabilities should be able to choose, as far as possible, how and where they want to live as they get older. For many 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, and 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.

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. Care managers should work with families to consider this option.

Residential placements

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

Within residential care, medication should not be an alternative to good behaviour support. If medication is given, or physical interventions such as restraint is used, families should be able 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 should not decide to move someone out-of-area just because there is a lack of services locally.

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

Education, work and other opportunities

Young adults whose behaviour challenges are entitled to a life of their own that extends beyond the services they receive. Wherever people are



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

living, they should have access to education, employment, leisure and social opportunities.

If people are excluded from day services because of their challenging behaviour, councils 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.

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 Children's Services or the Director of Adult Services at your local council. 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. Further advice and information is available from the following organisations:

Carers UK
www.carersuk.org

Challenging Behaviour Foundation
www.challengingbehaviour.org.uk

Contact a Family
www.cfamily.org.uk

Mencap
www.mencap.org.uk

National Autistic Society
www.autism.org.uk

Princess Royal Trust for Carers
www.carers.org

Transition Information Network
www.transitioninfonetwork.org.uk

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. The Challenging Behaviour Foundation 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**
Goldings House
2 Hay's Lane
London SE1 2HB

tel: 020 7089 6840
fax: 020 7089 6841
textphone: 020 7089 6893
www.scie.org.uk

Registered charity no. 1092778
Company registration no. 4289790