

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

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 early enough to prevent the behaviour either developing or getting worse.
- Government policy is clear that children 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.
- Parents should expect to work in partnership with the professionals involved with their child's education and care and be fully involved in discussions and decision-making.

Introduction

This At a glance briefing is for family carers supporting a child 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.

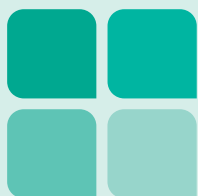
What is 'challenging behaviour'?

Behaviours that people find challenging can:

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

Problems are often caused as much by the way a child is supported – or not supported – as by their disabilities. Children 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 child 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.



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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 get older and are supported to develop better communication skills.
- Support should be flexible and personalised to the needs and circumstances of individual families.
- Support should be available early enough to prevent behaviours either developing or getting worse.
- It really helps to plan ahead – ideally before a crisis occurs.
- Every child 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 children 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 children 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.

Children have the right to live with their family, unless this is clearly not in their best interests. Government policy says that all children 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 children's family homes. It is reasonable for families to expect that their 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 team where necessary, as well as better access to 'mainstream' services (such as parks and public transport) that everyone uses.

But many services are only available to children and families who fit specific criteria set by councils/trusts. It's important to find out as much as you can about '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

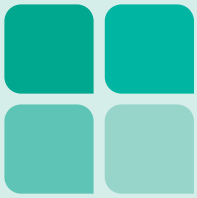
Every family regardless of where they live should have:

- access to healthcare – it is important to treat any medical conditions the child has, which may cause challenging behaviour or make it worse
- access to assessment, support and training in how to understand and support your child with their behaviour
- an advocate who knows how the system works and can support you 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 local individual need.

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

- access to healthcare: it is important to treat any medical conditions the child has, which may cause challenging behaviour or make it worse
- access to assessment, support and training in how to understand and support your child with their behaviour
- 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
- practical help with things like equipment e.g. bite-proof mattresses



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- 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 parents of children with behaviour described as challenging and professional staff who are willing to try new ways of working. It meets the needs of individual children and families and enables families of children 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.

- Children (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.
- Personal budgets (including direct payments), where children's 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/trust, private agencies, charities, community groups, neighbours, family and friends.

Behaviour support

Support with your child's behaviour should be available from a 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 children 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
- mental health check
- communication assessment
- social or environmental factors that may affect behaviour.

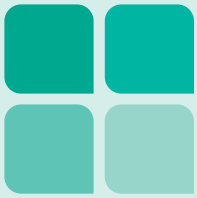
Using information from these assessments, a behaviour support plan should be developed, setting out how and why behaviours occur, what keeps them going, what is likely to prevent them and how families and carers can respond in more effective ways. It is vital to have a consistent approach across everyone 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 child with their behaviour. This should be recorded and regularly reviewed with a clear aim of eliminating their use. Parents 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

Parents should expect to work in partnership with the professionals involved with their child's



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education and care, and be fully involved in discussions and decision-making. Their knowledge of their child should be respected by all professionals working with them. Children 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 children being excluded from school and other local services.

Children 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. Parents can request reasonable adjustments e.g. a longer appointment slot with their GP or a first appointment of the day to avoid waiting in a waiting room.

Children with learning disabilities are entitled to live in their local communities and to have the same opportunities as every other child. But challenging behaviour can result in children being excluded, and families may feel increasingly isolated and confined to their home. That's why early support for families is so important – with the aim of preventing 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.

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 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. 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**
Fifth floor
2–4 Cockspur Street
London SW1Y 5BH

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