

ENGAGING AND LISTENING TO FAMILIES

COMMISSIONING SUPPORT FOR CHILDREN OR ADULTS WITH
LEARNING DISABILITIES AND BEHAVIOUR DESCRIBED AS CHALLENGING



**The Challenging
Behaviour Foundation**
making a difference to the lives of people with severe learning disabilities

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Engaging and Listening to Families

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1. Introduction

About the Challenging Behaviour Foundation

The Challenging Behaviour Foundation (CBF) is the only UK charity focussed on the needs of people with a severe learning disability whose behaviours challenge and those who support them. There are three strands to our work:

- 1. Information and support:** Developing and sharing a range of accessible, practical information and resources to equip and empower families and professionals, promoting early intervention and prevention, supporting families whose relatives are at risk, and providing casework to families in complex situations.
- 2. Campaigning and influencing:** Informed by our family support work, this strategic work focusses on ensuring that children and adults with severe learning disabilities who display behaviour described as challenging and their families are included, engaged and represented in policy and practice at a national, local and individual level.
- 3. Promoting best practice:** There is a range of evidence and practice that demonstrates how children, young people and adults with severe learning disabilities who display behaviour described as challenging can be supported to have a good quality of life within their local community. The CBF is committed to actively sharing and promoting evidence-based best practice, including working with researchers and practitioners.

What does the CBF do?

We want to see children and adults with a learning disability whose behaviour challenges and their families getting the right support, in the right place at the right time. To work towards making this vision a reality we:

- Provide information and support to family carers
- Facilitate peer to peer support for family carers and professionals
- Deliver Positive Behaviour Support workshops to families and paid carers
- Listen to the experiences of families and use these to highlight the needs of individuals whose behaviour challenges and their families on a national and local level
- Chair the *Challenging Behaviour – National Strategy Group* which promote partnership working and high quality support for people whose behaviour challenges
- Support services and local areas develop good relationships with family carers
- Share and promote best practice

About this guide

This guide is aimed at service providers and local area commissioners across health, education and social care. It sets out how the Challenging Behaviour Foundation can support you to work more closely with families caring for someone with a learning disability whose behaviour challenges. We can support you with:

- Engaging family carers in steering groups and projects
- Facilitating family carer consultation events / focus groups
- Developing information resources for family carers
- Delivering tailored support to engage family carers in your work

The Challenging Behaviour Foundation also delivers workshops, supports local areas to build capacity and supports researchers. You can find out more about this in our “*Building Local Capacity*”, “*Positive Behaviour Support Workshops*” and “*Involving Families in Research*” brochures. The work set out in this brochure can either be commissioned individually or in any combination with our positive behaviour support workshops and building local capacity work.

2. Outcomes

The Challenging Behaviour Foundation believes that family carers and people with learning disabilities who use services are best placed to help design them. The CBF's vision is that co-production becomes the norm and people with learning disabilities and their family carers are included and consulted from the start to the end of any new development or change to existing services and support. We want to see genuine partnership working where families' voices are listened to and acted on so that local services deliver better outcomes for people with learning disabilities whose behaviour challenges.

Individuals with a severe learning disability whose behaviours challenge are the least likely to be involved in consultation events requiring specialist support to help them engage meaningfully. Families are likely to be amongst those most isolated from support networks and hard to reach by standard consultation methods. They are also the group most likely to have the most complex and intensive needs and therefore fall between the gaps in service provision.

There are clear duties to provide information to family carers of children and adults with learning disabilities and behaviour described as challenging. There is a duty in the Children & Families Act 2014 to have a local offer setting out all services available for children with SEN and disabilities. There is a duty in the Care Act 2014 to provide information and advice specific to the carer's requirements as part of a carer's assessment.

We work with service providers and local areas to facilitate the involvement of family carers to co-produce services, support and information resources. We can help you engage family carers to enable you to deliver improved outcomes.

3. Why work with the Challenging Behaviour Foundation?

The Challenging Behaviour Foundation (CBF) was founded by our CEO, Vivien Cooper, the parent of a child with severe learning disabilities and behaviour described as challenging. Co-production with families is central to everything we do and a strong element of all our work. The CBF is led by a family carer and we have families represented at every level across the organisation and all of our projects providing valuable input from lived experience. All of our project managers are experienced and have up to date and working knowledge of policy, guidance and best practice.

Support from the Challenging Behaviour Foundation (CBF) takes a cross system and all age approach to ensuring good support for people with a severe learning disability whose behaviours challenge. The CBF has experience of working with a variety of partners across central and local government, the NHS and professional bodies and is involved not only in supporting the development of policy and best practice but also its implementation with a hands on approach to engaging with local families and services.

All our work stems from using lived experience as the starting point for assessing where systems and services are working or where they can be improved. We focus on the real life outcomes for families in assessing where systems and services are effective and we support our partners to do this too.

The CBF has 20 years experience in working with and supporting families and is currently in contact with around 4,000 families across the UK. The CBF is recognised by many for its expertise in championing the needs of people with severe learning disabilities and their families. In 2012 our CEO Vivien was awarded an OBE for service to people with severe learning disabilities and their families.

“Families matter and Viv has always been a fantastic champion for those families whose lives are indeed challenging but who believe in the ability of everybody, whatever their complexity of needs, to lead a fulfilling life.”

Dame Philippa Russell

We are dedicated to supporting service providers and local areas to provide good quality support in the long term and we believe that this is best achieved by increasing local capacity and embedding work locally. Our offer is to work with your team just as long as needed for them to carry on the project with local resource. We are flexible to your needs and the needs of the people you provide services for. Our aim is to leave a project with robust systems and resource to carry out without our involvement and make a real difference to the people in your community.

4. Our Support

We can offer a range of different types of bespoke support which are outlined below.

Engaging family carers in steering groups and projects

The Challenging Behaviour Foundation supports projects which benefit children, young people or adults with severe learning disabilities whose behaviour is described as challenging and/or family carers. We do this by:

- Contributing to steering groups (directly or by identifying a family carer to join the steering group and supporting their participation)
- Supporting the involvement of family carers in the project
- Supporting the dissemination of the project's findings

We have a strong track record of working with a variety of partners across central and local government, the NHS and professional bodies. In addition we have led our own projects such as *The Paving the Way Project: early intervention for children with learning disabilities whose behaviour challenges* in partnership with the Council for Disabled Children. The independent evaluation of *The Paving the Way Project: early intervention for children with learning disabilities whose behaviour challenges* found that:

“The project was universally seen as a strong and effective advocate for families and through its work has given a voice to children and their carers.”

Ivana La Valle

Case Study

In the summer of 2015 NHS England approached the CBF to facilitate an event to secure feedback from a range of children's stakeholders on the new service model *“Supporting people with a learning disability and/or autism who have a mental health condition or display behaviour that challenges.”* This request was based on the charity's expertise and the track record of the CBF in successfully bringing different groups of stakeholders to work together.

In September 2015 the CBF brought together family carers, national stakeholders from health and education and representatives from local areas representing good practice in supporting this group of children. Two family carers opened the event explaining what worked well in their support and what could have been better. This helped to ground discussions throughout the day in reality. Other family carers attended to take part in all the group discussions and provide a “reality check”. A report of the event can be found at pavingtheway.works

Attendees considered the service model in detail and came up with a set of **suggestions to refine the service model** so it is applicable to children, young people and their families, many of which were subsequently adopted by NHSE. The event also made a significant amount of headway in identifying the key issues to be addressed to ensure successful **implementation** of the service model for children, young people and their families. NHS England commissioned the CBF to facilitate a follow up event in January 2016 to consider implementation issues in more detail.

Facilitating family carer consultation events/focus groups

The CBF can assist organisations or agencies wishing to listen to and act on the views of family carers by arranging and facilitating consultation events or focus groups. Families of people with severe learning disabilities and behaviour described as challenging are likely to be amongst those most isolated from support networks and hard to reach by standard consultation methods.

We can provide a full package of support or any one of the following elements of support depending on your requirements and the nature of the consultation event or focus group:

- Recruitment of family carers
- Organisation of the event (venue(s), catering, family carer travel)
- Planning the event/focus groups to ensure the aims are met
- Facilitation of the events/groups (including graphic facilitation where required)
- A record and analysis of the views of family carers delivered in an agreed format (e.g. report, graphic, transcript etc.)

The Challenging Behaviour Foundation has a long history of working with organisations to ensure the views of family carers are heard and has delivered many consultation events and focus groups including the following:

- National Institute of Clinical Excellence guidelines on '*Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*' (see case study below)
- Department of Health consultation on the '*Statutory Guidance for Adults with autism*'
- Department of Health consultation on '*Strengthening corporate accountability in health and social care*'

Case study

The Guideline Development Group (GDG) for the NICE Guidelines on '*Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*' approached the Challenging

Behaviour Foundation (CBF) to organise and facilitate two focus group events for family carers. The aim of the focus groups were to ensure that the voice of family carers of adults, young people and children with learning disabilities who display behaviour described as challenging would be fed into the consultation process about what needed to be included in the Guidelines.

The CBF were keen for family carers' voices to be heard as part of the consultation process and therefore agreed to take on this work and deliver a report detailing the views of family carers within a tight budget and timeframe.

The CBF recruited family carers for the event with a tailored application process to ensure that all family carers met the criteria for being involved in the consultation and that the family carers selected to take part in the focus groups were as representative as possible.

All the logistics (venues, catering, family carers travel etc.) were taken care of by the CBF staff team who regularly organise small, medium and large multi-stakeholder meetings and events.

The CBF worked collaboratively with NICE to agree the consultation questions and then facilitated the events, analysed the findings and produced a 24 page report detailing the views of family carers which was submitted to the GDG to inform the guidance.

Developing information resources for family carers

The Challenging Behaviour Foundation can work with you to produce information resources for family carers. Empowering family carers with information to enable them to make informed decisions is vital to ensuring good outcomes for both the person with a learning disability and family carers themselves. We provide support to family carers of children and adults who are accessing a range of services across health, education and social care and therefore have a wide base of knowledge and experience to draw on.

We can provide a full package of support or any one of the following elements of support depending on your requirements and the nature of the resource you wish to produce:

- Developing an outline of a resource
- Consulting family carers on the proposed outline plan and at key points in the development of the resource
- Writing/creating the resource
- Designing the resource including providing suitable images etc.

The Challenging Behaviour Foundation has provided information resources to family carers for the last 20 years. We have developed an extensive range of information sheets, frequently asked questions, DVDs and video clips for family carers. We have worked collaboratively with other organisations including the Social Care Institute for Excellence, Mencap and the PBS Academy to co-produce information resources for family carers.

Case study

The Challenging Behaviour Foundation worked with the Social Care Institute for Excellence to produce three resources for family carers supporting people whose behaviour is described as challenging. There are separate guides for adults, teenagers and children, which help family carers understand what to expect from local services.

The guides describe what good support and services look like, to enable family carers to ask for the support that both they and the individual need, and to work in partnership with the professionals who are involved with the family.



Delivering tailored support on engaging family carers in your work

We can deliver tailored support on engaging family carers who have a relative with learning disabilities and behaviour described as challenging in your work. We can help you reach family carers who are often left out of consultation and engagement activity.

If you would like support to identify or engage local family carers or you have a particular piece of work in mind then do get in touch to discuss this with us.

5. Next Steps

If you'd like to arrange to speak to our team about a piece of work you have planned contact us on 01634 838739 or email info@thecbf.org.uk

Please provide a brief overview of your current plans and the type of project you're interested in working with us on and we'll arrange a time to for one of our project managers to call and discuss your needs.

We will provide you with a brief project plan and costing which you can then decide how to take forward. The project pan will set out what we can offer and what support your team will need to bring to the project.

6. Frequently Asked Questions

How much does it cost?

Costs vary. As a guide our daily rate for attendance at steering group and project meetings and planning and facilitating consultation events is £500 plus expenses.

Once we have some information about your plans we will provide you with a project plan and costing to enable you to decide how to proceed. Please contact us on 01634 838739 or email info@theCBF.org.uk for a project plan and costing.

What do we mean by 'challenging behaviour'?

Some children and adults with severe learning disabilities typically display behaviour which may put themselves or others at risk, or which may prevent the use of ordinary community facilities or a normal home life. This behaviour may be in the form of aggression, self injury, stereotyped behaviour or disruptive and destructive behaviours, such as:

- Hitting
- Kicking
- Hair pulling
- Destroying objects
- Headbanging
- Eating inedible objects
- Smearing faeces
- Sitting down & refusing to move

What do we mean by 'severe learning disabilities'?

Severe learning disability is a developmental disability and refers to individuals who have either no speech or limited communication, a significantly reduced ability to learn new skills and who require support with daily living skills such as dressing and eating.

If in doubt consider:

- Does the person have either no speech or limited communication skills?
- Does the person have a significantly reduced ability to learn new skills?
- Does the person require support with daily living skills such as eating and dressing?

7. Other CBF Resources

The CBF offers a range of opportunities and resources which might help support your work and the families you work with.

Information resources

We produce a range of information resources including information sheets, frequently asked questions and DVDs on a wide range of topics relevant to families, professionals and organisations supporting people with a severe learning disability whose behaviours may challenge. All our resources are available free to family carers and for a small fee for professionals.

A full list can be found here: www.challengingbehaviour.org.uk/information

Newsletter

The Challenging Behaviour Foundation's newsletter "Challenge" is produced three times a year. Subscription is free of charge. To join our mailing list for "Challenge" please contact us with your email address.

Workshops

Our Positive Behaviour Support workshops are effective in reducing challenging behaviour. The workshops are presented by a Positive Behaviour Support trainer and family carer co-trainer.

We can deliver our workshops at your organisation, workplace or support group. They can be delivered to staff and families together or independently.

For more information see: www.challengingbehaviour.org.uk/workshops/pbs-workshops

Networks

We have several networks you can join to receive information or share experiences and receive support. For further information or details of how to sign up see the links below:

1. Family Carers' email network www.challengingbehaviour.org.uk/supporting-you/for-families
2. Professionals' email network www.challengingbehaviour.org.uk/supporting-you/for-professionals/professionals-network.html
3. Early intervention reference group www.challengingbehaviour.org.uk/driving-change/early-intervention/early-intervention-project.html

The Challenging Behaviour National Strategy Group (CB-NSG)

The CB-NSG is an action focussed group which meets twice a year to discuss the policy and best practice around a variety of issues related to the care and support of children and adults with a learning disability whose behaviours may challenge.

Members of the CB-NSG are drawn from a range of backgrounds across government, professional bodies, services and charities and include families and people with a learning disability.

To find out more and to sign up for associate membership (free of charge) to receive updates see: www.challengingbehaviour.org.uk/driving-change/national-strategy-group