



**The Challenging  
Behaviour Foundation**

making a difference to the lives of people with severe learning disabilities

## Building local capacity

Commissioning support for children, young people or adults with learning disabilities whose behaviour challenges



## Building Local Capacity

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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. Three are three strands to our work:



### **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.



### **Campaigning and influencing:**

Informed by our family support work, this strategic work focusses on ensuring that children, young people and adults with severe learning disabilities whose behaviour challenges and their families are included, engaged and represented in policy and practice at a national, local and individual level.



### **Promoting best practice:**

There is a range of evidence and practice that demonstrates how children, young people and adults with severe learning disabilities whose behaviour challenges 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, young people 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 promotes 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:



**Family Carer Engagement:** Helping areas and services engage positively and meaningfully with families as part of co-production of services and to understand what is and isn't working in the local area.



**Peer to Peer Support for Families:** Sharing learning and best practice to input to the development of new services helping families to share experiences and support each other.



**Community of Practice:** Supporting local families, services and professionals to continue the sharing of information and best practice.

The Challenging Behaviour Foundation also delivers workshops and supports local areas and researchers to engage with families. You can find out more about this in our “Positive Behaviour Support Workshops”, “Engaging and Listening to Families” 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 Engaging and Listening to Families work.



## 2. Outcomes

Building local capacity aims to support family carers and people with learning disabilities who use services to develop their knowledge, skills and confidence through community capacity building and peer support. This will increase local capacity and ensure it is effective and appropriate to your local area. Building local capacity will facilitate family carers and people with learning disabilities to be empowered, central and supported. In addition to ensuring best practice, this is key to meeting current government initiatives including the Care Act (2014), Transforming Care for People with Learning disabilities, Next Steps (2011) and Integrated Personal Commissioning (2015), which all promote the need to work jointly locally with family carers and people with learning disabilities as equal partners to ensure the right care is provided in the right place by a skilled and competent workforce.

By working with family carers, people with learning disabilities and professionals in your area, we will help you review current provision, develop an action plan for service development and implement the plan. We will help you to provide a service which will increase capacity locally and will leave you with a sustainable project following our involvement.

### 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 whose behaviour challenges. 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 takes a cross system and all age approach to ensuring good support for people with a severe learning disability whose behaviour challenges. The CBF has experience of working with a variety of partners across central and local government, the NHS and professional bodies. The charity 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 services 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.

### Family Carer Engagement

The Challenging Behaviour Foundation can support regional areas and services to engage positively and meaningfully with families as part of co-production of services, to understand what is working and to recognise and develop action plans to address what isn't working in their local area. We do this by:

- 1. Scoping and understanding current provision by:**
  - Completing desk research
  - Meeting with you, families and people across your organisation or community to understand the challenges, aims and the possible routes for family carer input and involvement
  - Identifying what approach and networks might be useful for engaging directly with families through this work
  - Agreeing with you your desired outcomes for family carer engagement, what specific projects you might want input to or what you'd like to know in respect to existing or planned services
  
- 2. Consultation with families:**
  - Working with our network of carers and those networks and families identified in step 1, we will assemble an initial group of families to share their experiences
  - This may involve a survey to engage a wider group of families, one to one interviews or facilitating a stakeholder group
  - Identifying from families what services they find useful, what barriers exist to accessing services and what they would like to see developed
  
- 3. Production of report which may include:**
  - A plan for family carer engagement
  - A vision of what good services locally would look like
  - A plan for how families could be involved
  
- 4. Support to develop your processes going forward.** We will share our learning from the project with you and meet with you to discuss the next steps.

We have a strong track record of successfully working with areas / local services.



## Case Study

### **Supporting Family carers to find their voice: A collaborative project between Gloucestershire County Council, the Challenging Behaviour Foundation and Carers Gloucestershire**

The CBF worked with key stakeholders to establish a group of family carers, the 'Have your Say' group. The group was established to meet regularly and engage with Gloucestershire County Council to have their say about developing support for people with learning disabilities whose behaviour challenges. With support from the CBF the group came together to work with the Council to co-produce aspects of the Challenging Behaviour Strategy at a strategic, operational, and individual level. This included appointing a coordinator to facilitate the Have Your Say group. The CBF worked with members of the group and Gloucestershire County Council in the tendering process to find a local organisation to host the project and employ a coordinator. A development worker was appointed and began to make links with other families and identify priorities for the group. The CBF supported the establishment of this post with suggested areas for development in the future. The group is an integral part of the Gloucestershire County Council Challenging Behaviour Strategy and has been involved in consultations and service reviews, challenging aspects of the Challenging Behaviour Strategy, and identifying key areas for review and development.

### **Feedback from the National Development Team for Inclusion's (NDTi) independent evaluation of Gloucestershire's Challenging Behaviour Strategy included:**

"New people working for Gloucestershire County Council are seen by families as a driving force for change, working towards positive outcomes and co-production."

**Sue Turner**

## Peer to Peer Support for Families

The Challenging Behaviour Foundation can support the development of new services helping families to share experiences and support each other. We do this by:

### **1. Scoping and understanding the current provision by:**

- Carrying out desk research
- Meeting with you and talking to families and people across your organisation or community to understand the current support available to families
- Identifying what approach and which networks might be useful for engaging directly with families through this work

## **2. Consultation with Families:**

- Working with our network of carers and those networks and families identified in step 1, we will assemble an initial group of families to share their experiences
- This may involve a survey to engage a wider group of families, one to one interviews or facilitating a stakeholder group
- Identifying from families what services they find useful, what barriers exist to accessing services and what they would like to see developed

## **3. Project development and delivery:**

- Working with you and the family group we will produce a plan for what a peer support service would look like
- Working closely with you to help your planning and development of the service using our previous experience in establishing peer to peer networks

## **4. As part of the development of a service we can work with you to:**

- Develop a robust project plan
- Plan referral routes and processes for providing support
- Create links with local organisations as delivery partners
- Recruit staff and volunteers with the right skills and values
- deliver training to volunteers and or staff to equip them with an understanding of the needs of families, the issues they face and how to support them
- Provide a referral service for families accessing peer support who have additional needs via our family support service
- Develop materials and resources for your new service

## **5. Follow up support once your project is launched which may include**

- Assisting with any concerns or difficulties that might arise
- Reviewing or supporting any new resources or materials developed
- Supporting you to measure the successes of the project and identify where development might be needed
- Mentoring key staff through this process to ensure the knowledge gained through the project is retained locally
- Helping you plan for the future of the project to ensure peer to peer support is embedded locally

## **6. Sharing Learning:** We will produce a full report on the project which you can use to share learning across the project, with local partners and as a tool to inform the project going forward.

We have a strong track record of successfully working with areas / local services.

## Case Study

### **Development of the Family Linking Scheme: Challenging Behaviour Foundation and Gloucestershire County Council**

The CBF worked with Gloucestershire City Council to explore the development of an enhanced family linking scheme, based on the CBF family linking scheme. The CBF worked with the council to recruit family link workers to ultimately provide emotional support to other family carers in Gloucestershire, thus building a sustainable local resource. The host organisation / development worker was guided and supported by the CBF on recruitment, ongoing support processes and options to further develop the scheme.

### **Feedback from the National Development Team for Inclusion's (NDTi) independent evaluation of Gloucestershire's Challenging Behaviour Strategy included:**

"Family members have become more confident and knowledgeable, and less stressed as a result of the family support project. There is more co-production and families said that services were more accountable to them."

## Community of Practice Development

The Challenging Behaviour Foundation can support the development of a forum for local families, services and professionals to work together to share information and best practice. We do this by:

### **1. Scoping and understanding the current provision by:**

- Carrying out desk research
- Meeting with you and talking to families, professionals and services across your organisation or community to understand the challenges they face and the types of learning and experience sharing they would like to gain from the establishment of a community of practice
- Identifying what approach and which networks might be useful for engaging all stakeholders in this work
- Agree with you how the community will be sustained after our involvement to shape how it is set up

### **2. Consultation with families & professionals:**

- Working with our network and those networks and families identified in step 1, we will consult with a wide range of stakeholders to develop an agenda and plan for the initial meeting and for how the community developing
- This may involve a survey to engage a wider group of families, one to one interviews or facilitating a stakeholder group

### **3. Project development:**

- Setting out a plan for delivery of the first year of community of practice meetings
- Supporting the development of sample agendas, materials and procedures to enable the community to continue meetings after our involvement

#### 4. Meeting facilitation:

- Delivering the first two meetings of the community of practice, setting agendas, finding and briefing speakers and coordinating evaluation of the events
- Supporting a locally identified partner to take on the organisation of a 3rd and 4th meeting

5. **Sharing Learning:** We will produce a full report on the project which you can use to share learning across the project, with local partners and as a tool to inform the project going forward.

### Case Study

#### **Successfully working in partnership: Developing forums for sharing information and best practice**

The CBF has much experience of successfully working in partnership with people with learning disabilities, family carers, professionals, researchers, service providers and practitioners. The Challenging Behaviour National Strategy Group is one example where the CBF facilitates a large range of partners to share information, best practice and drive change forward to make a real difference to the lives of individuals with learning disabilities whose behaviour challenges.

#### **Feedback from members of this group is highly positive, for example:**

“A progressive planning and co-production collaborative working. Impressive reinvigorating, good opportunity for networking and exchange of views and information.”

The CBF has successfully established a professional and a family carers email network which allow families / professionals across the UK to share experiences, information and receive support.

“It is good to get information, advice and encouragement from other families who have faced similar problems to ours. It is also good to be able to help others from our own experiences.”

#### **Family Carer**

## 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](mailto: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 plan 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](mailto:info@theCBF.org.uk) for a project plan and costing.

### What do we mean by 'challenging behaviour'?

Some children, young people 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 behaviour challenges. 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](http://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](http://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](http://www.challengingbehaviour.org.uk/supporting-you/for-families)
2. Professionals' email network [www.challengingbehaviour.org.uk/supporting-you/for-professionals/professionals-network.html](http://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](http://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, young people and adults with a learning disability whose behaviour challenges. 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](http://www.challengingbehaviour.org.uk/driving-change/national-strategy-group)