# INVOLVING FAMILIES IN RESEARCH

FOR RESEARCHERS FOCUSSING ON CHILDREN OR ADULTS WITH LEARNING DISABILITES 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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# Involving Families in Research

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This Involving Families in Research Brochure was produced by
the Challenging Behaviour Foundation in 2016.

*Registered charity in England and Wales: no. 1060714*

## 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:

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 promotes partnership working and high quality support for people whose behaviour challenges
- Support services and local areas to develop good relationships with family carers
- Share and promote best practice

## About this guide

This guide is aimed at researchers who are interested in involving and engaging family carers of children or adults with learning disabilities and behaviour described as challenging in their work. The National Institute for Health Research's guidance on involving the public in research encourages the active involvement of members of the public in projects to improve the quality and relevance of research through the addition of another perspective with different expertise.

This guide sets out how the Challenging Behaviour Foundation can support you to co-produce research or involve family carers in your research.

## 2. Outcomes

**Why involve family carers in research?**

Family carers can make a valuable contribution to your research by providing a different perspective. Family carers can assist researchers in many ways including making the language and content of information provided more appropriate and accessible; helping to ensure the method proposed for the study is acceptable and sensitive to the situations of potential research participants; and increasing participation.

*"No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well"*

**Professor Dame Sally Davies, Chief Medical Officer**

The National Research Ethics Service (NRES) will ask about the plans for public involvement in your research when applying for ethical approval. They will use this as part of their assessment process to ensure research is ethical, relevant and acceptable from a public perspective.

The National Institute for Health Research (NIHR) have developed a standard application form for all research programmes which includes a section asking applicants to describe how they involve the public in the design and planning of their study, as well as plans for further involvement throughout the research. Involving family carers in your research will positively influence your chances of successfully securing funding for your research.

**Why ask the Challenging Behaviour Foundation for support to involve family carers?**

The Challenging Behaviour Foundation has a long history of supporting researchers to understand the perspective of family carers and involve family carers in research.

We believe it is vital to build the evidence base about how best to support individuals whose behaviour challenges and their families. In order to ensure that research is translated into practice, it is essential to disseminate key research findings to family carers and practitioners. The Challenging Behaviour Foundation is in touch with a wide network of family carers and practitioners from across the UK enabling us to engage family carers in research and disseminate the findings.

## 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, which provides 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.

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 high quality research which builds the evidence base around providing effective support to children and adults with learning disabilities and behaviour described as challenging. We are flexible to suit the needs of your research team.

## 4. Co-producing research / Engaging family carers in research

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

- Partnering with researchers to co-produce research (as a named Project Partner or Collaborating Organisation)
- Contributing to steering groups (directly or by identifying a family carer to join the steering group and supporting their participation) to improve the quality of the research by adding another point of view to the design and conduct
- Supporting the involvement of family carers in research (e.g. recruiting family carers to take part in research)
- Supporting the dissemination of research findings

We have a strong track record of supporting research and have contributed to many research projects including:

- *Clinical and cost effectiveness of staff training in positive behaviour support*. University College London
- *Increasing the Quality of Health Service Support for Children with Intellectual and Developmental Disabilities*. Tizard Centre, University of Kent
- *Family based support to build capability and resilience in family carers of adults with learning disabilities and challenging behaviours*. Northumberland, Tyne and Wear NHS Trust
- *Who's challenging Who?: A cluster randomised controlled trial to test the effectiveness of a staff training intervention to improve support staff attitudes and empathy towards adults with learning disability and challenging behaviours*. University of Warwick
- *The MCA Deprivation of Liberty Safeguards and the Mental Health Act: A Matter of Choice?* University of Cambridge

**What our research partners say**

"*The Challenging Behaviour Foundation has been an excellent research partner on several funded grants and grant applications with which I have been involved. Their contribution to overall research questions and design has been very helpful, and their work on "Patient and Public Involvement" aspects of projects has been of particular high quality*."

**Professor Richard Hastings, University of Warwick**

*"The CBF CEO Viv Cooper has consistently provided invaluable feedback and support throughout. They have allowed us to utilise resources of the Foundation in surveying parent opinion on research projects and have helped us to think about disseminating our research to lay public and carers. Viv Cooper also took part in more specific aspects of research such as the development of patient and care information sheets and topic guides for our study interviews. She was a member of the qualitative study group which interpreted the information we received from parents and from participants with learning disabilities experience. Having the CBF as research partner, has offered us a first-hand family carer perspective and experience throughout our research. The CBF is a champion for family carers and works tirelessly to involve family carers in research to ensure their views are heard."*

**Professor Angela Hassiotis, UCL**

*"The Challenging Behaviour Foundation provides a vital perspective on the experiences and priorities of family carers and issues central to supporting people with severe disabilities and complex needs. Members of the CBF have served as trainers, advisory and steering group members on what have been my most successful projects, helping to shape funding applications, research designs, materials and procedures and to increase research impact through dissemination and use of findings. They have a somewhat unique ability to draw synergies between developments, organisations and stakeholders in the field and incredible expertise in articulating advice and guidance that brings unquestionable value to research quality and process. I am greatly indebted to their guidance and support"*

**Dr Nick Gore, Tizard Centre, University of Kent**

Challenging Behaviour Foundation project managers are experienced in fully participating in all stages of research projects and have led or contributed to a number of academic papers including:


- McGill, P., Papachristoforou, E., & Cooper, V. (2006). Support for family carers of children and young people with developmental disabilities and challenging behaviour. *Child: Care, Health and Development*, *32*, 159-165.
- Davies, K., & Honeyman, G. (2013). Living with a child whose behaviour is described as challenging. *Advances in Mental Health and Intellectual Disabilities*, *7*(2), 117 – 123.
- Cooper, V., & Ward, C. (2011). Valuing people: family matters ten years on. *Tizard Learning Disability Review, 16*, 44-48.
- Butcher, H. (2013). Book review: Caring for the Physical and Mental Health of People with Learning Disabilities. *Tizard Learning Disability Review*, *18*(3), 151 – 153.

- Cooper, V. (2012). Support and services for individuals with intellectual disabilities whose behaviour is described as challenging, and the impact of recent inquiries. *Advances in Mental Health and Intellectual Disabilities*, *6*(5), 229 – 235.
- Gore, N., & Umizawa, H. (2011). Challenging Behaviour Training for Teaching Staff and Family Carers of Children With Intellectual Disabilities: A Preliminary Evaluation. *Journal of Policy and Practice in Intellectual Disabilities*, *8*(4), 266–275.

## 5. Next Steps

If you would like to arrange to speak to our team about a research project please contact us on 01634 838739 or email info@thecbf.org.uk

Please provide a brief overview of your research and how you would like to involve the CBF and we will 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.

## 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.

**How do you disseminate information about research projects?**

There are a number of ways we can disseminate information about research projects to family carers or professionals working in the field of learning disability including:

1. **The CBF newsletter**. Our newsletter "Challenge" is produced three times a year and has a circulation list of 4800 people. Inclusion will depend on the theme of the newsletter and competition for space. Material for the newsletter needs to be provided several months in advance of the distribution of the newsletter.
2. **Family carers email network**. The network has approximately 300 members. Family carers include mothers, fathers, grandparents and siblings of children or adults with a severe learning disability and behavior described as challenging. We can circulate information at any time of the year.
3. **Professionals email network.** The network has approximately 360 members. Members are drawn from a range of professional backgrounds including teachers, speech and language therapists, psychologists, researchers, occupational therapists etc. We can circulate information at any time of the year.
4. **Challenging Behaviour – National Strategy Group core and associate members.** 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. There are approximately 80 core and 540 associate members.
5. **Facebook.** We have approximately 5300 'likes' on our page. We can circulate information at any time of the year.

**How do you recruit family carers to research projects?**

We will speak to the research team to identify which family carers you wish to recruit. We can then conduct a targeted mailing to the family carers who are the focus of your research. We never pass family carers' contact details to researchers without their express permission so we would always make the initial approach on behalf of the researcher.

To maximise the success of your recruitment we would recommend that you ask for our support to tailor the information leaflet about the research to ensure that it is accessible to all family carers.

## 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 time 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