

How the CBF can help involving family carers in research

Research focussing on children, young people, or adults with learning disabilities whose behaviour challenges and their families.



Involving family carers in research

Contents

1. Introduction	3
About the Challenging Behaviour Foundation.....	3
About this guide.....	3
2. Why work with the Challenging Behaviour Foundation?.....	4
Co-producing research.....	4
3. Next Steps and Frequently Asked Questions.....	7
4. CBF Resources & Networks	8

1. Introduction

About the Challenging Behaviour Foundation

The Challenging Behaviour Foundation (CBF) is the only UK charity focussed specifically on the needs of people with a severe learning disability whose behaviour challenges and those who support them. You can read more about the work that the CBF do on our website [here](#).

About this guide

This guide is aimed at researchers who are interested in the co-production of research with family carers of children, young people, or adults with learning disabilities whose behaviour challenges. The [National Institute for Health Research's guidance on co-producing a research project](#) emphasises the importance of researchers and those affected by research working together, sharing power and responsibility from the start to the end of the project.

This guide sets out how the CBF can support you to co-produce research.

"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



2. Why work with the Challenging Behaviour Foundation?

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.

The CBF has experience of working with a variety of partners across government, the NHS, professional bodies, and voluntary organisations. We are involved in supporting the development of policy and best practice, and its implementation with a practical approach to engaging with local families and services.

The CBF:

- ✓ Ensures all our work stems from lived experience as the starting point for assessing where systems and services are working or where they can be improved.
- ✓ Has 27 years' experience in working with and supporting families and is currently in contact with around 4,000 families across the UK.
- ✓ Focuses on real-life outcomes for families in assessing where systems and services are effective, and we support our partners to do this too.
- ✓ Is recognised by many for our expertise in championing the needs of people with severe learning disabilities and their families.
- ✓ Is dedicated to supporting high quality research which builds the evidence base around providing effective support to children, young people and adults with learning disabilities and whose behaviour challenges.
- ✓ Is flexible to suit the needs of your research team.



Co-producing research

The CBF has a long history of supporting researchers to understand the perspective of family carers and involve family carers in research via co-production.

We believe it is vital to build the evidence base about how best to support individuals whose behaviour challenges and their families. To translate research into practice, it is important to proactively disseminate key research findings to family carers and practitioners utilising engaging communication methods. The CBF is in touch with a wide network of family carers and practitioners across the UK enabling us to engage family carers in research and disseminate the findings.



We can support you to:

- Involve family carers to ensure lived experience informs all stages of the research.
- Join a Trial Steering Committee/Study Management Group to take joint ownership of key decisions in the governance of the research.
- Ensure the language and content of information provided is more accessible.
- Co-produce engaging research outputs e.g. web clips/social media clips.
- Help to ensure the method proposed for the study is acceptable and sensitive to the situations of potential research participants.
- Increase participation.
- Disseminate research findings and support their translation into policy and practice.

Patient and Public Involvement & Engagement (PPIE) Lead

We are currently involved in supporting a number of funded research projects as a PPIE lead including:

- **Mapping and Evaluating Services for Children with Learning Disabilities and Behaviours that Challenge (MELD)** Lead Investigator: Professor Richard Hastings, University of Warwick. PPIE Leads: Viv Cooper & Gemma Grant. Find out more [here](#).
- **Video Interaction Guidance (VIG-LD)** Lead Investigator: Dr Vaso Totsika, University College London. PPIE Lead: Gemma Grant. Find out more [here](#).
- **Personalised approaches for support for individuals who display aggressive behaviour (PerTa/Petal)** Lead Investigator: Professor Angela Hassiotis, University College London. PPIE Lead: Viv Cooper. Find out more [here](#).
- **Trauma Aid: (Peter Langdon) NIHR – PTSD (Eye Movement Therapy) Research.** Lead Investigator: Professor Peter Langdon, Swansea University. PPIE Lead: Viv Cooper. Find out more [here](#).
- **Harmful sexual behaviour in men with intellectual disabilities (Glyn Murphy). Randomised Control Trial of group cognitive Behavioural Treatment for men with intellectual and/or developmental disabilities and harmful sexual behaviour: the HaSB-IDD trial** Lead Investigator: Professor Glynis Murphy, University of Kent. PPIE Lead: Viv Cooper. Find out more [here](#).
- **Early Positive Approaches to Support (E-PATs) Randomised Control Trial** Lead Investigator: Dr Nick Gore, University of Kent. PPIE Lead: Gemma Grant. Find out more [here](#).
- **An evaluation of Care (EduCation) and treatment reviews for people with Learning disabilities and Autistic people (CECILIA)** Lead Investigator: Professor Peter Langdon, University of Warwick. PPIE Lead: Viv Cooper. Find out more [here](#).

CBF PPIE Leads are experienced in fully participating in all stages of research projects and have led or contributed to a number of academic papers. You can find out more about our current and past involvement in projects and academic research [here](#).

What our research partners say



“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, University College London



“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



“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



3. Next Steps and Frequently Asked Questions

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 for one of our PPIE Leads to call and discuss your needs and provide a brief project plan and costing. We can support with co-producing the research application prior to submission.

How do you recruit family carers to research projects?

We will speak to the research team to identify family carers with the particular experience you wish to recruit and will ensure that a diverse population of family carers are contacted. This includes diversity in age of both the family carer and the person they care for, gender, ethnicity, relationship to the person they care for, nationality, geographical location etc. We can then conduct a targeted mailing to the family carers who are the focus of your research or an open recruitment via advertising on our networks and social media. We never pass family carers' contact details to researchers without their express permission and we always approach on behalf of the researcher.

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

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. These include social media and a number of CBF networks which are outlined in more detail in the next section.



4. CBF Resources & Networks

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 web clips 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](#). We are happy to collaborate with researchers to disseminate research via a co-produced event or report. Please see our early intervention report for a recent example of a co-produced seminar and report available [here](#).

News



Our free newsletter “Challenge” is produced twice a year and has a circulation list of approximately 6,050 people. These newsletters are shared virtually via our mailing list, and, are printed (subject to funding availability) to ensure that the newsletter is as accessible as possible and can still reach those who do not have access to digital technology. 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. To join our newsletter mailing list, click [here](#).

The ‘News’ page on our website shares news updates, statements, and opportunities to get involved in research, support, or campaigning. This page is regularly viewed by many individuals each month and shared more widely. View this page [here](#).

Workshops

We offer a range of workshops including:



**POSITIVE BEHAVIOUR
SUPPORT***



PICA AWARENESS



TRAUMA AWARENESS



**COMMUNICATION AND
CHALLENGING BEHAVIOUR**



**WHOLE FAMILY
APPROACHES**

These workshops are effective in reducing challenging behaviour. CBF workshops are co-produced and delivered by Family Carer Trainers and Positive Behaviour Support Trainers. This ensures training is supported by evidence-based theory and practice in a way that is accessible for everyone. We can deliver our workshops at your organisation, workplace, or support group. They can be delivered to staff and families together or independently. [Click here for more information.](#)

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.

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Networks

Family carers email network. The network has approximately 460 members. Family carers include mothers, fathers, grandparents and siblings of children, young people or adults with a severe learning disability and behaviour described as challenging. We can circulate information at any time of the year. Sign up to join this network [here](#).

Professionals email network. The network has approximately 1,110 members. Members are drawn from a range of professional backgrounds including teachers, speech and language therapists, psychologists, researchers, etc. We can circulate information at any time of year. Sign up to join this network [here](#).

‘What Matters To Me’ network. This network is for anybody who is interested in connecting with other people interested in the project, which is focussed on engaging with young people with complex communication challenges. Members receive project updates, discuss important topics, sharing good practice, and learn about similar work in the UK. Sign up to join this network [here](#).

Social Media

Facebook. We have approximately 16,000 ‘likes’ and 19,000 followers on our page. We can circulate information at any time of the year. View this page [here](#).

Twitter. We have approximately 6,600 Twitter followers. Information and updates on research projects can be posted at any time. View this page [here](#).