Challenge

The Challenging Behaviour Foundation's newsletter

Good Communication for Good Lives

Meeting the communication needs of children, young people and adults with severe learning disabilities is a fundamental human right. If your relative can't tell other people what they need or want (or don't need or don't want), challenging behaviour becomes more likely. The Challenging Behaviour Foundation (CBF) is here to support families facing this challenge.

We have updated our free challenging behaviour resources and we have also updated the content of our communication and behaviour workshop, which is available to families and professionals.

This edition of Challenge Newsletter features the What Matters to Me project which used individualised communication approaches with 11 young people. It involved working in partnership with families and staff who knew the young people well to better understand their views and perspectives. The information gathered over three years helped to improve the activities available to the young people who took part in the project and to many others. It is also influencing national policy.

Good communication and a desire to understand people's perspectives should be routine for everyone with a severe learning disability. Family carers are often experts at understanding and advocating for their relative. But too often, outside of the family, it is the exception, rather than the norm.

This edition of Challenge also features an article by Mary and Chris, sharing the devastating consequences of the use of 'facilitated communication' with their son Alex, who is autistic and has a severe learning disability. This is a discredited intervention which NICE guidelines say should not be used with autistic adults. We are grateful to Mary and Chris for sharing their family's experiences and we support their campaign for stronger guidance.

As well as focussing on how we communicate with individuals, we also explore in this edition why good communication is key to good support when we talk about the needs of individuals with severe learning disabilities whose behaviours challenge.

I have now been in post as CEO of CBF for six months and it has been great to meet and work in partnership with so many family carers during that time. Although Viv Cooper has retired from the CEO role, you will be pleased to see her feature in this Newsletter as she is leading CBF input to a number of research projects and continuing to advocate for families in all that she does.

Jacqui Shurlock, CEO

Resources in this Issue

All the resources featured in this edition of our newsletter (and many others) are available on our website or by calling us on 01634 838739. Visit the website for news, opinion, information, resources, opportunities, and support! You can access any resources in this newsletter that are underlined by clicking on them.

Contents

What Matters to Me

It is possible to find out what matters to people with severe or profound and multiple learning disabilities! It is possible to use what matters to make a difference!

What Matters to Me was a 3-year project (2022 – 2025) led by CBF that involved engaging directly with 11 young people who have severe or profound and multiple learning disabilities. We worked in partnership with the Universities of Kent and Birmingham to develop an appropriate and robust method to seek the experiences and preferences of the young people, who are often excluded from consultations or decision-making processes. We worked with family carers, staff and experts on the project advisory group to find out what mattered to young people as they transitioned from childhood to adulthood. The What Matters to Me project demonstrates that, by taking the time to build relationships, using evidence-based approaches and learning about individual ways of communication, it is possible to meaningfully engage with young people with severe or profound and multiple learning disabilities, to find out what is important to and for them, and to use what we learn to influence policy and shape the support and services that impact upon their lives. We launched the findings from the project during an event at the House of Commons with the young people central to the event. This was followed by an online launch event which you can watch back here. Over 100 professionals and family carers attended and contributed through discussions and interactive activities. During the event, four short films containing the project findings were broadcast and best practice examples were shared.

Following the launch we have produced a number of resources including the What Matters to Me Practical Toolkit which provides materials and resources that can be used by both professionals and families to improve how people with severe or profound and multiple learning disabilities are consulted with and engaged in processes that impact their lives.

What Matters to Me Resources

- Join the What Matters to Me network
- What Matters to Me Practical Toolkit
- Co-Producing a Lifelong Action Plan
- Co-Production Best Practice

What Matters to Me short films:

- What Matters to Me Overview
- Using What Matters: The Circles of Influence
- Influencing What Matters: Transition to Adulthood
- Finding out what matters: The Principles of Meaningful Engagement

With thanks to our funders who have made this important work possible:

Facilitated communication nearly destroyed our son's life

By Mary and Chris

An article by Gary Nunn published on 11 June 2025 describes some of the consequences of the use of discredited facilitated communication, the struggle we faced in tackling it and dealing with the highly prejudicial consequences for our son, Alex's life. Like so many other parents we have had to fight for everything our son needs and needed from education to health and social care, from the earliest years. We did not always succeed and at 15 our son went to residential special school and then to a long-established specialist residential college in the south west, given the lack of local provision, in particular from social care in the form of short breaks. We always knew the importance of planning for his transition but could not find any public body to engage or listen. We then reverted to using other means to try and compel them to engage including the use of Care Education and Treatment Reviews (CETRs) and NHS England's Ask Listen Do process. With an agreed Life Plan we thought we were finally getting somewhere.

> ***“The idea that someone with Alex's diagnoses could suddenly develop sophisticated literacy skills and complex reasoning defies both scientific understanding and common sense. ”***

However, the college's speech and language therapy service began to use new communication methods with our son involving a communication device and hand on hand techniques. As the iNews article describes, this generated communication that raised our suspicions as it was at odds with our son's long-standing diagnoses of a severe learning disability and autism. These were written into his Education, Health and Care Plan and were a big part of the reason for his securing adult Continuing Healthcare (CHC) funding while he was at the college. We are also Court Appointed Care and Welfare and Property and Affairs Deputies from 2019. The idea that someone with Alex's diagnoses "could suddenly develop sophisticated literacy skills and complex reasoning" as Howard Shane from the Harvard Medical School says in the iNews article, "defies both scientific understanding and common sense".

Mary, Alex and Chris

However sadly, despite facilitated communication also being prohibited under NICE clinical guideline CG142, it was used in a Deprivation of Liberty Safeguards (Dols) reassessment at the college in March 2024, which we were not involved in or present at, and called into question Alex's whole diagnoses. This was conveyed to the CHC teams in the two Integrated Care Boards (ICBs), one of whom also saw it being used. Instead of positively planning Alex's future they sought to remove Alex's diagnoses in a meeting with us and the college in May 2024, where we were ambushed, and to drop him entirely when, as we later found out, Alex had "said" through facilitated communication he wanted to live in a town in another region where he knows no one. This caused us to appoint Independent Clinical Experts to reassess Alex which happened in July 2024.

The ICBs and the college accepted the appointment. We obtained the final report at the end of August 2024 which reconfirmed all his diagnoses. We also learned important new things. When we obtained the report we realised there was clinical failure in the college and we withdrew Alex. Efforts to remedy the failures through formal complaints to the Chief Executive, Trustees and Governors over a number of months did not lead to a satisfactory resolution. Safeguarding complaints sent in early January 2025 to the Chief Nursing Officers of the two ICBs about their role in nearly destroying Alex's life through reliance on the results of facilitated communication have not received a substantive response. Concerns raised with the Care Quality Commission has not yet led to anything. We complained to the Local Authority about the conduct of their Dols contractors which was not upheld and is now being considered by the Local Government and Social Care Ombudsman.

Meanwhile we are still trying to rebuild our son's life.

Support and Information

The Family Support Service can provide information and support about the needs of your family member with a severe learning disability and behaviour described as challenging. Our support is confidential, and we won't judge you or tell you what to do. You can call the Family Support Service on 0300 666 0126 or email us at support@thecbf.org.uk

Let's Start at the Very Beginning...

We've updated one of our key resources - a three-part guide to challenging behaviour. These are our most downloaded resources, offering a deep dive into supporting your relative's behaviour, broken down into manageable chunks.

Understand the theory behind positive behaviour support and start to develop a plan to support your relative at home.

Part 1: Understanding Challenging Behaviour

There is always a reason for challenging behaviour. In many cases, it's a way for a person to control what is going on around them and to get their needs met. They also might be ill or in pain. Understand what we mean by challenging behaviour and why it might be your relative's best way of communicating what they need. There is no quick fix, but a lot can be done to prevent or reduce challenging behaviour and this resource will help you start to think about what might work for your relative.

Part 2: Finding the Reasons for Challenging Behaviour

Challenging behaviour is unlikely to come 'out of the blue', this resource helps you to think about the different stages in your relative's behaviour.

- **Green** 'Proactive' phase: where a person is mostly calm and relaxed
- **Amber** 'Active' phase: where a person starts to become anxious. Quick action must be taken to avoid challenging behaviour
- **Red** 'Reactive' phase: where challenging behaviour occurs
- **Blue** 'Post-Reactive' phase: where the person starts to relax again.

Functional assessment is a good way to find out the exact causes of a person's behaviour. This is usually carried out by a psychologist or behaviour nurse and waiting lists for these can be long. We explain how keeping a record can help you find out why your relative is behaving in a certain way, and what to record if you don't have access to professional support right now.

Part 3: Supporting Behaviour Change

The third information resource in this series introduces positive behaviour support (PBS) plans to help you develop a step by step guide to supporting challenging behaviour based on the phases mentioned above and information you have recorded.

Two important parts of the plan are:

1. **Proactive strategies** These are used to make sure that the person has what they need and describe ways to teach the person communication and other skills.
2. **Reactive strategies** are designed to keep the person and those around them safe.

A good plan has more proactive than reactive strategies. Everyone involved with your relative's care should be involved and the templates will help you to produce a document that will get you all on the same page working to improve your relative's quality of life.

> "***We live with PBS for Laura and I know it has changed her life and given her a voice, but it has also been a great support tool for all her staff. It has enabled them to have an excellent rapport and relationship with Laura putting her at the heart of all they do.*** - family carer"

We know these resources are helpful—but also that finding time to read them isn't always easy. For a quicker option, try our Quick Read Challenging Behaviour Guide. If you have questions, or you want to discuss what may be causing your relative's behaviour to become challenging you can contact our Family Support Team or call them on 0300 666 0126.

The term "challenging behaviour"

A family carer perspective on the often-misunderstood term

By Vivien Cooper, Karen Jankulak and Kate Sanger

The term challenging behaviour has a very specific and precise meaning for people with learning disabilities. Using the right terms for the situation and the individual is vital, not only in providing an accurate description, but also in maintaining consistency across professionals and families, ensuring mutual understanding, and ultimately making sure the right support is provided to individuals when they need it.

Alternative terms for challenging behaviour, such as distressed behaviour, or behaviours of concern tend not to convey an accurate description of the reasons for, and severe implications of, the behaviour of our relatives. For instance, an individual displaying behaviour that challenges is not always distressed, though they may be exhibiting behaviour that is challenging for their family and support staff. For example, my relative displays pica behaviour, and though they may not be distressed at the time of eating the inedible object, there have been significant impacts, including the need for emergency life-saving surgery. This challenging behaviour can have a significant impact on a person's quality of life and can be life-threatening, therefore, the terminology used to describe it should reflect these challenges.

Using consistent terminology is important to ensure that the people with the right skills and knowledge work with the individual and their family. It is essential that families, support staff and other professionals are on the same page in order to agree the actions needed to deliver the right outcomes and support for the individual. It is also essential to have terminology that accurately describes the behaviours that our relatives are displaying so there is an understanding of the reasons behind it, access to knowledge and skills to get the right support and ultimately for their human rights to be respected so they have a good quality of life.

> ***"One of the 'challenges' is that my son will be risk-assessed (understandably) to the extent that he does nothing. I am so grateful that his current provider is almost as ambitious as I am with respect to quality of life and variety, but, equally important, aware of the importance of knowing him well enough to see the tiny signs that he is struggling"***

Project CECiLiA

Project CECiLiA (An evaluation of Care (EduCatIon) and treatment revIews for people with Learning dIsabilities and Autistic people) have launched a **national survey study** to find out more about how people experience C(E)TRs. The survey has been co-designed with Lived Experience Advisory groups, including people from CBF, National Autistic Society and Learning Disability England. The study is an important opportunity to share your experiences of C(E)TRs and includes the option to take part through accessible formats. Choices include Talking Mats interviews, and surveys in standard text, easy read, audio, braille, and translated options. People who have attended a C(E)TR within the last year are invited to take part. There is a 30 minute survey or interview option for people with a learning disability, autistic people and autistic people who have a learning disability. Family members and carers are invited to take a survey. C(E)TR workforce members, including experts by experience, and health, education, and social care professionals are also invited to share their experiences by completing a survey.

If you would like to take part please **complete the online expression of interest form**. If you would like more information or don't have access to the online form please **email** **Cecilia@contacts.bham.ac.uk** or **call** 0121 414 3086

Introducing Our Updated Communications Workshop

We are thrilled to announce the launch of our updated Communication and Challenging Behaviour Workshop - part of a range of workshops designed to empower families, carers, and professionals who support children, young people and adults with severe learning disabilities and behaviour described as challenging. This engaging 4.5-hour workshop is an introduction to the links between communication and behaviour, aimed at anyone who wants to understand how to improve communication with individuals with severe learning disabilities. Effective communication lies at the heart of understanding and addressing behaviours that challenge, yet finding the right techniques and approaches can feel overwhelming. That's why this workshop focuses on equipping participants with practical tools and strategies to enhance communication and support positive behaviour changes. Our workshops are **co-designed**, **co-produced** and **co-delivered** by family carers with lived experience alongside qualified practitioners, ensuring a comprehensive and practical learning experience.

We offer a full range of online and in-person workshops. These can be commissioned for staff teams or booked individually with our new Open Access Workshops for Professionals.

We have just had the good news that we have been awarded funding by Skills for Care to deliver 2-part PBS, Pica Awareness and Communication and Challenging Behaviour workshops to Individual Employers (IEs) and their Personal Assistants (PA) between now and March 2026. Keep an eye on our website for dates coming soon. If you are an IE you can apply directly to Skills for Care for funding to train yourself and your PAs. It can be used to cover training costs to develop your skills as an employer, direct costs of completing training qualifications, hiring replacement support whilst your usual PA is attending training courses and for travel.

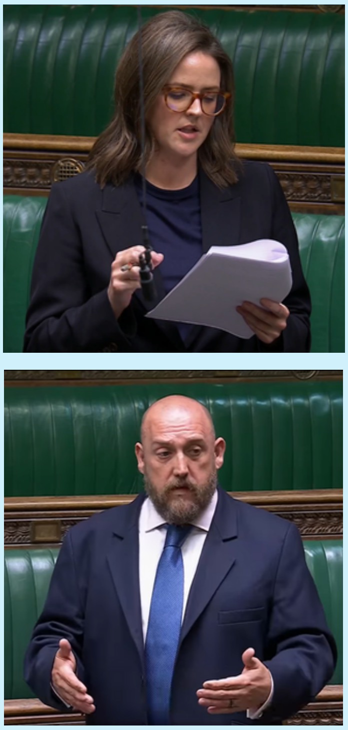
For further information and to book our workshops:
visit our website, call 01634 838739 or
email workshops@thecbf.org.uk

Mental Health Bill and Community Support

CBF has been working in partnership with families and a range of other organisations and campaigners to call for the Mental Health Act to be changed so that people with a learning disability and autistic people cannot be detained in hospital if they don't have a mental health condition.

In November last year, the government introduced the Mental Health Bill. One of the changes that the Bill will make is that people with a learning disability and autistic people can only be detained for treatment under section 3 of the Mental Health Act if they also have a mental health condition that needs treatment in hospital. This is a big step forward, but this change will only be made when there is "sufficient community support" in place – so we want to see a plan for achieving this.

We have been working hard with MPs and peers to raise the need for a plan for community support which is co-produced with people with lived experience and families. The Campaign Families Group met recently to share their experiences and ideas about what makes good community support with NHS England's Community Ingredients team. Our Challenging Behaviour – National Strategy Group (CB-NSG) meeting in May focused on the Bill and how to implement the changes successfully. We have shared insights from this with the Department of Health and Social Care (DHSC). DHSC officials also attended on the day to hear directly from CB-NSG members. We wrote to Health and Care Minister Stephen Kinnock earlier this year with the other organisations we are campaigning with and we will continue to encourage him to meet people with lived experience once the Bill has gone through Parliament and the focus moves on to implementation.



Lauren Edwards MP and Kevin Mckenna MP speaking about the importance of a co-produced plan for community support in the House of Commons.

Read our news article if you are interested in learning more

> ***“ I encourage the Minister to meet families to better understand the impact of inappropriate detention on people with a learning disability or autism and their families. ”***
>
> *Lauren Edwards MP - Speaking at the House of Commons*

Share for Better Care

The Care Quality Commission (CQC) is running the Share for Better Care campaign. CQC is working in partnership with Healthwatch England on this campaign and in collaboration with organisations that represent and advocate on behalf of people, families and carers, including The Challenging Behaviour Foundation. The aim of the campaign is to encourage everyone to give feedback on their experiences of care, focusing on people who are most likely to have a poorer experience of care as we know they are less likely to feedback.

What does CQC do?

CQC is the independent regulator of health and social care in England.

CQC inspection framework consists of five key questions:

- Is the service safe?
- Is the service effective?
- Is the service caring?
- Is the service responsive?
- Is the service well lead?

Services can then be given one of four ratings; outstanding, good, requires improvement or inadequate. Inspection reports are available on the CQC website.

How is my feedback used?

CQC reviews all the feedback it receives. However, they cannot help to resolve complaints, so it is important to complain directly to the service too if you are raising a concern. Equally if you are making a complaint about a service, you should tell CQC about it as well.

There are a number of actions CQC may take. These include:

- asking the care provider to give them their response to the feedback
- meeting with management at the care provider to discuss the feedback
- sharing information with other relevant agencies that need to know about it
- carrying out an urgent inspection or bringing forward a planned inspection
- warning, fining or placing conditions on how a care service operates.

In the most serious cases CQC can force a care provider to close.

How can I share my relative’s care experiences?

Online: https://www.cqc.org.uk/give-feedback-on-care

Deaf or Hard of Hearing and Text Relay: https://www.cqc.org.uk/contact-us/general-enquiries/get-help-contacting-us-if-youre-deaf-or-hard-hearing

Phone: 0300 061 6161 interpreter services available

Email: enquiries@cqc.org.uk

#ShareForBetterCare

Carers’ Catch Ups

In June, we made some changes to the Carers’ Catch Ups to better support our families. These online meetups are a friendly, safe space hosted by two volunteers where families can chat, share stories, and support each other. One big change is that the sessions are now split into two groups: one for family carers of children and young people up to 18, and one for family carers of adults. We are hoping by holding two different sessions, families will get the relevant information and support for the age of their loved one.
If your relative is transitioning to adult services, you are welcome to join both so you can hear from families who have gone through this experience. We are also hoping to welcome guest speakers to join some of the sessions throughout the year. Guest speakers will range from professionals to family carers who have extensive experience in a specific area. Keep an eye on social media or for further updates on future speakers! For more information or to join the Carers’ Catch Up sessions, please visit our Peer Support webpage, call us on 0300 666 0126 or email support@thecbf.org.uk.

Don’t forget your mug!

Questions from the Family Carers’ Email Network

We have a severely autistic, non-verbal, 24-year-old son with other health conditions, including epilepsy. He uses an iPad as his communication tool, which is essential for his day-to-day living. Unfortunately, he is a “thrower” and has damaged many iPads, which is proving very costly. He currently has a 9th gen iPad with a shockproof sturdy case and uses the PECS app, but it’s now irreparably damaged. I’ve tried screen protectors, but nothing has worked. I am desperate— without his iPad, he cannot function. Can somebody please help?

Hi, I know how essential communication tools are, so this must be really difficult. Maybe look at Panasonic Toughbook tablets — our school uses them and they're very rugged. We also use old-fashioned PECs (Velcro strips and cardboard symbols) as a backup. It depends on your son's PECs level — mine is still at basic ‘I want’ requests, so we only use around 60 symbols.
Good luck, I hope you find a solution.

Same problem. We have a great case which has to be screwed on as our son would dismantle it. It’s from Inclusive Technology. They are brilliant to talk to. I can send a photo but I’m not at home at the moment. Will if you need it; have a look at their website.

Our Family Carers’ Email Network is just one of the ways in which we connect families across the UK to share experiences, concerns and tips with others experiencing similar challenges. Email network@thecbf.org.uk or call 0300 666 0126 to find out more and be connected.

Planning for the Future Resource

In Carers Week 2025, we published our newly developed resource for older families. Planning for the Future is a resource developed to help family carers to prepare for all eventualities. Family carers have told us that while they recognise the importance of future planning, they often feel overwhelmed or unsure of where to begin. This resource aims to bridge that gap by providing a clear template that helps families gather and organise vital information.

The template includes sections to add key details about the person being cared for on health needs, important financial information and support requirements, all of which can be shared with other such as extended family members, support workers or advocates.

Bringing all the information together in one place simplifies the process and offers peace of mind. You can find the resource here or scan the QR code.

THANK YOU

We are very grateful to every single person and organisation who donates or fundraises for us

Vicki ran the London Marathon

Dickins Lodge held a fundraising event

Hannah ran the Brighton Marathon

Sue organised a tabletop sale

Thank you to those who have donated to CBF in memory of a loved one.
We very much appreciate you thinking of us at such a difficult time.

Thank you to the following trusts and foundations for their support:

Pears Foundation

Garfield Weston Foundation

phf Paul Hamlyn Foundation

Supported by BBC Children in Need

John Ellerman Foundation

Blagrave. investing in young people

Proudly supporting youth social action #iwill

Department for Culture, Media & Sport

Community Fund

Masonic Charitable Foundation

We rely on donations, grants and fundraising to continue our work helping children, young people and adults with severe learning disabilities whose behaviour may be described as challenging, and their families. Regular donations are particularly valuable as they allow us to plan for the future. **Scan the QR code to donate** or telephone 01634 838739 to find out how you can help

https://www.challengingbehaviour.org.uk/donate/

Donate here

Supporting CBF with a legacy

A recent legacy has enabled us to provide additional free training workshops to family carers and to update the information we provide to families. Understandably your first priority will be looking after your loved ones and leaving a gift to charity in your will reduces the tax liability of your estate — helping you to do more with what you leave for future generations.

The Challenging Behaviour Foundation relies on the generosity of our donors whose support enables us to continue to be there for people with severe learning disabilities and their families. Not everyone is able to give in their lifetime and a gift in your will ensures that your impact will live on long after you have gone.

If you'd like more information or an informal chat about remembering The Challenging Behaviour Foundation in your will please **contact Emma** at emma.deabill@thecbf.org.uk

While every care is taken in the compilation of this newsletter, the Challenging Behaviour Foundation cannot be held responsible for any errors or omissions, nor accept responsibility for any goods or services mentioned.

Subject to funding, we are sometimes able to send out a printed version of our newsletter, delivered directly to people's homes, for those without access to the internet. If you know somebody who wants to be added to the mailing list for future printed copies ask them to call us on 01634 838739.