Challenge

The Challenging Behaviour Foundation's newsletter

Enabling full and active lives

Winter 2025

The CBF vision is for all children, young people and adults with severe learning disabilities whose behaviour challenges, to have the right support and opportunities to live full and active lives.

We know there are so many barriers to making this a reality and this edition features some resources which we hope will help. Our new Adult Social Care Guide includes a chapter to help you explore the options available, from housing to community activities, to enable choices about support that works for your family.

The transition from child to adult services can be a particularly difficult time when services available to young people drop away. Our latest series of podcasts "Trials, Tribulations and Transition" share discussions between family carers about how they navigated this stage and two episodes feature Professor Luke Clements, answering questions about how the law changes as your young person transitions to adulthood. We want to see changes to the system to improve this experience so please do join our campaign by signing the open letter to #EndTheCliffEdge.

Families know best what a good life looks like for your relative and you should have access to everything you need to help enable that, including the latest evidence, the right information and training. The final article in this newsletter shows how one young man, with a severe learning disability whose behaviour challenges, is being supported to take part in a wide range of activities over the festive season. This has been made possible thanks to the transformative benefits of consistent, person-centred Positive Behaviour Support (PBS).

As we reflect on 2025, we are delighted that so many family carers have shared your lived experience in so many different ways over the year to provide peer support to other families and to inform and improve policy, practice and research. In a world that can sometimes feel divisive, we are grateful that the CBF community is full of families and professionals who are generous with your time and expertise, working together to make life better for others.

Wishing you all the best for the festive season.

Jacqui Shurlock, CEO

Contents

Resources in this Issue

All the resources featured in this edition of our newsletter (and many others) are available on our website. You can access any resources in this newsletter that are underlined by clicking on them. or by calling us on 01634 838739.

Facilitated Communication

Royal College of Speech and Language Therapists (RCSLT) issue new guidance about the discredited technique

By Professor Jill Bradshaw

> ***“I am delighted that the Royal College of Speech and Language Therapists (RCSLT) has considered the evidence and issued new guidance. RCSLT concluded that there is no evidence-base for facilitated communication.”***
> ***-Jill Bradshaw***

All communication occurs within a partnership and involves at least some interpretation. For example, we do not just listen to what people say, we also pay attention to how they say it. We might make judgements about how serious someone is about what they are saying or whether they are being sarcastic. People with severe to profound learning disabilities experience complex communication challenges. Communication partners might have to take on greater responsibility for the success or failure of a communicative exchange where they are interacting with someone who has fewer communication skills.

For example, communication partners might help the person to make a choice by offering two objects which represent activities. In doing so, we accept that we are limiting the choice. We accept this limitation because we are giving someone an opportunity to indicate if they have a preference between these two activities, usually in situations when they have no other means of indicating that preference. In this example, the person might point to or reach for the object to indicate their choice.

Communication partners can potentially have a lot of influence over how communicative behaviours are interpreted and responded to. This is particularly the case for those who have few symbolic ways of communicating or where they might be at the very early stages of developing communication skills. People might have idiosyncratic ways of communicating and we might have to rely on making judgements using very subtle cues. You can read more about this in the What Matters to Me project. Whenever we support someone to communicate, we need to think about our influence.

Facilitated Communication is a method whereby a person is supported by a ‘facilitator’ to point to letters, picture or objects on a communication board or a keyboard. This is usually done with physical support by the facilitator e.g. by holding the person’s hand, wrist or elbow. The method has been surrounded by controversy, with increasing concern over ‘authorship’ of the message and the influence of the facilitator. Studies suggest that facilitators are typically unaware of their influence over the message (but also often unwilling to put this to the test).

It is the position of the RCSLT that **Facilitated Communication is a discredited technique that should not be used in any circumstance.** You can read their full statement here

This is such an important and clear statement from the professional body for speech and language therapists. We have a duty to safeguard people who have complex communication challenges and it must not be assumed that messages that are produced via Facilitated Communication are authored by the person with a disability.

Groundhog Day

A family carer perspective

By Cristina Di Santo

This is a shortened version of a presentation given at November's Challenging Behaviour-National Strategy Group (CB-NSG) – you can watch the full presentation here.

Max is 13 and is our only child. His needs are complex and include non-speaking autism, ADHD, epilepsy and more. He also has a severe learning disability and displays behaviours that challenge. But to us he is simply Max; unique, loving, and deserving of every opportunity to shine.

We moved from London to Essex when Max was nearly 6, seeking better opportunities and a special school better suited to his needs; uprooting our lives and leaving behind family and friends. Initially the move worked for us, but as Max grew, his behaviours escalated and the school could no longer meet his needs.

Before moving to Essex, we had managed Max's needs with limited help – I had given up work to become a full-time carer – but things began changing. Our first introduction to Social Services came before I was due to have my second surgery for a benign brain tumour; I couldn't care for Max alongside recovery given his increasing needs. Our first referral was rejected, but the second opened the door to other services that we hadn't known existed.

> *“Navigating the system feels like playing a computer game without knowing the rules. The system seems to operate behind smoke and mirrors; rules change, and you never really know how to 'level up'”*

As things got harder, more services got involved. Exhaustingly, with each new team came the need to repeat our story and fill out yet more paperwork.

Medically, things worsened, not helped by a fight to be heard. Unexplained absence episodes were dismissed as “just part of his autism”. My concerns about seizures were ignored and it was only after Max had a major seizure which resulted in him being blue-lighted to the local hospital that I was finally listened to and epilepsy diagnosed. There were also times when we felt inadequate and blamed by professionals, resulting in me displaying trauma responses.

Viv founded the CBF in 1997 in response to her struggles to get the right support for her son Daniel. However, as my own family's story illustrates, sadly there remains work to be done. The system feels like it's trapped in Groundhog Day – the same trials and tribulations that Viv went through continue to this day.

So what needs to change to truly support families like mine?

- Services must stop, think, and truly listen – family carers have invaluable insights and experience, and their voices should be recognised and respected, not disregarded
- Too often, individuals are put on the 'too difficult' pile – this must stop
- The postcode lottery, service gaps and barriers to accessing support must end
- Services must be delivered through a trauma lens – the system's adversarial, combative approach and parent-blame culture causes trauma.

Change begins with us. By listening, working together, prioritising those most in need, promoting equality, recognising trauma, and taking a whole system and person-centred approach, we can build a system that truly supports families and helps every individual thrive.

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

#EndTheCliffEdge

It has been a busy few months for transition-related work at the CBF.

The CB-NSG Transition Subgroup has launched an open letter to government, alongside a series of short but powerful films focussing on the transition from children's social care to adult social care.

The films feature:

- Lina (a family carer)
- Kaiden (Lina's son)
- Jacqui (Chief Executive, the CBF)
- Katie (Chief Executive, Kids)

> ❝ *It was really scary and you feel overwhelmed. If someone was there supporting you and kind of guiding, you through the situation that would have really helped.* ❞
> - Lina (Family carer)

They depict the challenges Lina and her son Kaiden, plus many other families face: the cliff edge that young people can face when they reach adulthood; the lack of coordination between services; and the delay in planning for adulthood.

Currently, under the Care Act 2014, there is no statutory age at which transition planning must begin, only when it is deemed to be "of significant benefit" to the young person and their family. Unfortunately, this means that planning for adulthood often does not begin as early as it should, decreasing the likelihood that appropriate, local support is available.

We are asking the Government to:

1. Introduce a national, cross-departmental plan for transition co-produced by young people with SEND and their families
2. Introduce a named Transition Coordinator to facilitate a person-centred and ambitious approach to transition.
3. Amend the Care Act 2014 to introduce a statutory age (age 14) to begin transition planning, working collaboratively with other services across health, education, housing etc.

Thank you to everyone who has signed and shared the letter so far – we already have over 245 signatures. If you have not signed yet, we would be really grateful for your support. You can read and sign here. You can view all our transition resources here.

Instead of sending cards this festive season, why not make a donation to the **Challenging Behaviour Foundation?**

Your donation helps us continue being there for families who need us most. Give the gift of care and help the CBF continue to be a trusted source of information and support.

- **£10** provides a family without internet access receives a vital printed information pack
- **£30** means a family carer can receive a listening ear call from an expert in active listening who also knows what it's like to be a family carer.
- **£75** connects a family carer with a caseworker who can offer expertise and moral support in a virtual meeting
- **£125** enables a family to be supported in sharing their lived experience publicly, to influence policy and change for others.
- **£250** facilitates an episode of 'Challenge Accepted' our podcast giving family carers a voice and practical guidance wherever they are.

Every donation helps families feel less alone, and to say thank you, we'll send you a special CBF festive e-card to share with friends and family. You can donate online here here.

Trials, Tribulations and Transition

A guide to Season 3 of the CBF's podcast Challenge Accepted

Join Challenge Accepted' s third series as we take a look at the transition from children's services to adult services for young people with severe learning disabilities who may display behaviours described as challenging. Find the podcast wherever you usually get your podcasts or on the CBF website.

Episode 1: Getting to where you want to be

A taste of what's to come, we hear from family carers who've been through transition. Where are their relatives now? How did they decide what was best for them? Words of wisdom, witty observations and a whole lot of understanding from those who get it.

Episode 3: Hang on, I didn't know about that!

How do you know what is possible if nobody tells you?! Real families discuss the importance of connecting with others locally and nationally. With some top tips on how to prepare your young person, their siblings and yourself for some potentially huge changes and how to bond with the people who may be caring for your teenager on a day to day basis if they are moving away from home for the first time.

Episode 5: One of the good guys

Our much anticipated episode featuring Luke Clements, Cerebra Professor of Law at Leeds University. Hugely knowledgeable, a member of the Challenging Behaviour Foundation's Legal Panel and champion for family carers everywhere. We discuss the law; how it should work, how it sometimes doesn't work and how it changes as your young person transitions to adulthood.

Episode 2: So it IS possible

We are talking about a biggie - housing! Our family carers talk about how they secured a home for their relative and what they want you to know if you are on a similar journey. What's the HOLD scheme? How do you insist on the things you know are important, the non-negotiables? Whether you're overwhelmed by choices or feel constrained by limited options listen in for real life, real people and real understanding.

Episode 4: Nobody has the trump card

Our family carers continue their discussions diving deep into the complexities of navigating the system: deputyship, best interests, annual health checks, and the emotional realities of lifelong caring. If you've been wondering how to ensure your young person's rights are upheld, this episode is for you - jargon free explanations from those who are already living it.

Episode 6: CHC: Well met needs, two PALS complaints and the ombudsman…

Our chat with Luke Clements, Cerebra Professor of Law continues, looking at transition when your young person is funded by NHS Continuing Healthcare and what to do if you suspect some iffy decision making is taking place.

We hope whilst listening you laugh a bit, learn a bit and feel a bit inspired to plan an aspirational transition for your young person. Here are the links to some of the various resources and policy documents discussed in this series:

- Mental Capacity Act Code of Practice
- Disabled Children: a legal handbook
- Cerebra Accessing Public Services Toolkit
- Luke Clements 'resources' page
- Template letters Cerebra
- National framework for NHS continuing healthcare and NHS-funded nursing care (2022)

If you have an idea for a future series or episode, we'd love to hear it, you can tell us here.
You can contact our Family Support Team or call them on 0300 666 0126.

The PETAL Study

The CBF is supporting research into support for adults with learning disabilities who display aggressive behaviour. The CBF supports input from people with lived experience to the research which is led by Angela Hassiotis and Afia Ali at UCL.

It involves developing and then testing personalised therapy for individuals who are described as displaying aggressive behaviours and the people who support them. Therapists are trained to deliver a series of support sessions with the individual and their supporters/ family carers to understand the underlying reasons for the individual's behaviour and to address these through developing "capable environments". Input from people with lived experience is via two separate but interconnected groups- a group of people with learning disabilities and a group of family carers who have relatives with severe learning disabilities who are not be able to contribute their experiences directly.

The research is important because individuals who display aggressive behaviours are at risk of restrictions, inappropriate medication, restraint and exclusion and likely to have a poor quality of restraint and exclusion and likely to have a poor quality of life.

Understanding why the behaviour happens- and addressing the reasons - is key to delivering good outcomes for people.

The lived experience groups have shaped and influenced the research in multiple ways throughout the study, including co-developing the therapy structure and session content, inputting to therapists training and highlighting the importance of terminology and communication.

> **❝ Being part of this research project I feel we have had our opinions, based on years of lived experience, heard and valued. Our input, I believe has made this project more authentic and more accessible to the people it is designed to help. ❞**
>
> -Member of the Family carer group

The lived experience groups are valued members of the research team and members recently co-presented a workshop on the importance of lived experience at an international learning disability conference in Belgium.

More information can be found about the research here.

Adult Social Care and the Casey Commission

Adults with severe learning disabilities whose behaviour challenges have the same right to live in their local communities as anyone else – however, they might need support to do this. When their needs are successfully identified and met by adult social care, people with severe learning disabilities whose behaviour challenges can live good lives, but we know that in too many cases the support that's needed is not available.

At the CBF we've been working with the Casey Commission to share what is needed to make the adult social care system work for people with severe learning disabilities who behaviour challenges and their families. This includes sharing the co-produced action plan, which draws on the experiences of people with learning disabilities whose behaviour challenges and their families and sets out what actions are needed.

At our most recent Challenging Behaviour – National Strategy Group meeting in November, members of the Casey Commission joined to listen to families sharing their experiences and views on what would make a real difference to them and their relatives. The write-up of what families and other stakeholders said was needed will be shared with the Casey Commission and uploaded to our website in the New Year. You can also watch the recording of the main presentations here.

If you'd like to share your experiences of adult social care directly with the Casey Commission, you can share these here or scan the QR code.

SCAN HERE

New Legal Duty for Schools to Record Restraint and Report it to Parents

In February 2025, the Department for Education published a draft revised version of the 2013 use of reasonable force and other restrictive interventions in schools guidance for consultation. The guidance covers all schools in England.

This guidance was originally set to be effective from September 2025, however this deadline was missed. The guidance is now due to be published by the end of the autumn school term, and will come into force on the 1st April 2026. Alongside updated guidance the government will introduce a legal requirement for schools to record and report all "significant incidents" of use of force to parents and carers.

The Department for Education also updated that they are pursuing secondary legislation that mandates the recording and reporting of seclusion. This was not originally included in the published draft guidance, and therefore the guidance will be updated to reflect this. The draft guidance sets out the need for schools to develop a policy on the use of force and other restrictive interventions. The policy should set out whole school and individual approaches to prevent the need to use reasonable force and other restrictive interventions.

The CBF responded to the consultation on the draft guidance, which closed in April 2025. Whilst we welcome the new legal duty and strengthened guidance, we set out a number of concerns and areas where the guidance required amending as well as additional work that is required to safeguard children with severe learning disabilities. You can find out more about CBF's views on the consultation here.

Josh Babarinde OBE highlighted at PMQs the experience of his constituent, who was left injured and traumatised following a brutal and sustained inappropriate restraint on school transport. He set out the clear need for reform. We welcome the acknowledgement made by the prime minister that every child with SEND should have tailored support, including on school transport.

To find out more about the final guidance when it is published and what this means for parents and carers and schools please follow us on social media:

Facebook LinkedIn Instagram

The Forward Together Project – Building Networks, Improving Lives

Since 2024, the CBF-led Forward Together project has been building regional networks and hosting community of practice events in three regions of England, to improve the lives of individuals with a severe learning disability and behaviours that challenge, and their families.

Forward Together operates in Salford/Manchester, Black Country, and Kent/Medway. Each area has a dedicated family carer project worker, and multi-stakeholder regional networks are being established to facilitate Community of Practice meetings twice a year.

Network members are invited to Community of Practice events held in each region to bring together family carers and professionals to work collaboratively to understand the local challenges faced by individuals with severe learning disabilities, and their families.

> ***"I have come away with some hope! And valuable information thank you! "***
> \- Family Carer in the Black Country

Forward Together gives local level insights to identifying key issues, as well as scoping and sharing evidence of good practice which feeds into the CBF's national strategic influencing, including via our CB-NSG. So far, across the three areas, over 300 professionals and family carers have signed up to their region's network.

By increasing engagement, families gain access to targeted information, support, and connections to both local and national networks. The networks provide a forum to share helpful resources and good practice, cross-area learning, and to share updates on project progress and events.

In the summer of 2025, the first Community of Practice events across our three regions were held. 78 members attended across the events and the sessions focused on introducing the project, understanding the local landscape in regards to the how support and services operate for children, young people and adults with severe learning disabilities and behaviours that challenge, and their families, and how the networks could grow to have the best impact in the areas.

These events brought together a diverse group of stakeholders including family carers, professionals working across health, social care and education, commissioning teams, local authority teams and charity and voluntary sector organisations.

The Community of Practice events included discussion groups that set out:

- What's working well
- Areas for improvement
- Agreed actions to be taken forward either within the project scope or by feeding back to relevant stakeholders.

Our discussions were split into four groups related to the four communities of families that will be focused on - early years, transition, adults and older family carers and in/at risk of crisis. A summary of these discussions can be found here.

The Forward Together project aims to have a positive impact across all areas of our work so that families feel less isolated, better connected, listened to, and confident, and so professionals become better informed about family needs and can improve service delivery.

The regional networks are open to family carers living in, or professionals working in, one of the three areas covered by Forward Together. Members of the network will receive project updates, shared learning and resources and invitations to Community of Practice events. You can sign up to a regional network here.

For more information, contact forwardtogether@thecbf.org.uk

Adult Social Care (England) Resource - Knowledge is Power

When Social Care works well it can transform the life of an adult with severe learning disabilities, but when it's not going so well and doesn't meet their needs it can be a huge worry for their family and a massive contributor to challenging behaviour. We are pleased to have launched Adult Social Care (England): Support Options, Housing, Personalisation and Living a Good Life at our Challenging Behaviour - National Strategy Group meeting last month. This resource is specifically designed to help you understand and navigate the adult social care system, making it easier to access the support your relative needs to live a good life.

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

Adult Social Care (England)
Support options, housing, personalisation and living a good life

Navigating adult social care can be daunting. In fact, around 52% of families supported by the CBF Family Support Team need help with issues related to adult social care or NHS Continuing Health Care. Many families report feeling under-informed, with an average empowerment rating of just 5.6 out of 10 before accessing support from the CBF. With nearly 2,000 people visiting the CBF website's adult social care pages in the past year, it is clear families want clear, accessible information.

- **Written by families, for families:** developed in partnership with family carers, this guide understands the challenges faced by CBF families.
- **User-friendly and comprehensive:** the resource is structured to follow your journey with social care, from first contact to ongoing support, empowering you to make informed decisions at every stage (and confidently challenge any dodgy ones!).
- **Focus on empowerment:** rather than advocating on your behalf, the CBF aims to equip you with the knowledge to advocate confidently for your own relative – after all you know them best!

We know social workers are often stretched and may not have time to explain every detail. This resource fills that gap, providing detailed information that you can refer back to again and again.

What's Inside?

The information pack is divided into clear, practical sections covering:

- **Your Relative's Rights**: understand the legal framework and how it protects your loved one.
- **Assessing Needs and Care Planning**: practical guidance on planning for care, making joint decisions, and involving your relative as much as possible.
- **Choices**: explore the options available, from housing to community activities, and learn how to choose the support that works for your relative.
- **Funding**: learn how care is funded, how contributions are calculated, and how to ensure disability-related expenses are considered.
- **Reviews and Changes: w**hat to do if circumstances change, including how to request a review of a support plan.

- **Dealing with Problems:** advice on resolving issues, making complaints, and where to turn for help.
- **Keeping Your Relative Safe:** an overview of regulations, safeguarding, and practical steps for involving advocates.
- **Finding Additional Help:** signposting to organisations and resources for further support.
- **Helpful Tools**: including a list of questions to ask support providers and a plan

Whether you're just starting to think about adult social care or looking to improve your relative's current support, it's never too soon—or too late—to add this resource to your toolkit.
For more information, visit: CBF Adult Social Care or contact the CBF Family Support Team at info@thecbf.org.uk.

The Benefits of person-centred Positive Behaviour Support at Christmas

By Sally Balfour-Allen

At the CBF we are getting excited about the festive season. We are fetching our Christmas jumpers and decorations down from the loft, shopping for gifts, writing cards, planning time with family and filling our calendar with festive activities and celebrations.

Like many CBF families though, mine can find this time of year incredibly difficult and struggle to do the things most people/families take for granted. This calendar of lovely activities planned for my son Samuel, age 19, to do with family and staff over this festive season has made me reflect on how things have changed over the last year or two because of the transformative benefits of consistent, person-centred Positive Behaviour Support (PBS).

Samuel has been supported to enjoy new experiences, engage in community activities, have his voice heard and make choices. We have spent quality family time together doing things we never thought possible including a trip to the panto, cinema trips and meals out.

21 Nov: Dick Whittington Panto at theatre

30 Nov: Sleeping Beauty Panto at theatre

5 Dec: Santa Dash

6 Dec: Shop for Christmas decorations & cards

10 Dec: Christmas party with school friends and a visit from Santa

13 Dec: Cinema trip to see a Christmas film

15 Dec: Hand deliver Christmas cards to friends

17 Dec: Sing/sign Christmas carols at concert

19 Dec: Christmas dioramas display at garden centre

20 Dec: Go to a Christmas light trail

24 Dec: Walk to see the Christmas lights

25 Dec: Christmas lunch at a restaurant with family

4 Jan: Disney on Ice

You can access CBF's Positive Behaviour Support Resources here: Positive Behaviour Support - Challenging Behaviour Foundation

PBS is part of a range of CBF workshops developed to share and promote evidence based best practice that demonstrates how children, young people and adults with severe learning disabilities whose behaviours challenge can be supported to have a good quality of life within their community.

The two-part interactive PBS Workshop is co-designed, co-produced and co-delivered by family carers with lived experience alongside qualified practitioners, ensuring a comprehensive and practical learning experience.

The workshops facilitate partnership working, to enable staff and families to work together to identify appropriate individualised behaviour support strategies that can be used consistently in all settings.

Part 1: Understanding Challenging Behaviour (UCB)

This introductory workshop enables participants to understand what is meant by "challenging behaviour". It covers what challenging behaviour can look like, it's impact and reasons, and where/how to access ongoing support.

Part 2: Supporting Behaviour Change (SBC)

This workshop empowers participants with practical tools and strategies from evidence-based practices to address the reasons why challenging behaviour may happen and ways to prevent or reduce it and improve people's quality of life. The SBC workshop includes proactive and reactive strategies and how to develop a positive behaviour support plan.

We also offer the following workshops available online or in person:

- Pica Awareness
- PBS one day intensive – UCB and SBC combined
- Communication and Challenging Behaviour
- Trauma Awareness; A Family Perspective (for professionals only)
- Whole Family Approaches Workshop (for professionals only)

Upcoming Workshops:

	CBF Workshops	Date and time
Skills for Care	2-Part Positive Behaviour Support: Part 1: Understanding Challenging Behaviour Part 2: Supporting Behaviour Change	14/01/26 10:00-2:30 11/02/26 10:00-2:30
Skills for Care	Communication and Challenging Behaviour	22/01/26 10:00-2:30
Skills for Care	Pica Awareness Workshop	03/02/26 10:00-2:30
Open Access	2-Part Positive Behaviour Support: Part 1: Understanding Challenging Behaviour Part 2: Supporting Behaviour Change	13/02/26 09:00-1:30 13/03/26 09:00-1:30
Open Access	Pica Awareness Workshop	19/03/26 09:00-1:30
Open Access	Communication and Challenging Behaviour	02/03/26 09:00-1:30

For further information and to book:
visit Workshops - Challenging Behaviour Foundation
email: workshops@thecbf.org.uk or call us at 01634 838739

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** or visit the website **here** to donate. You can also telephone 01634 838739 to find out how you can help.

Donate here

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

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