



## Working Together, Driving Change

Winter 2024

This newsletter will be my last as I step down as CEO at the end of December, although I will remain involved in the work of the CBF in other ways (and of course my ongoing role as a family carer will continue as a connection). After a carefully planned and rigorous recruitment process, I am delighted to welcome Jacqui Shurlock as the new CEO, who brings a wealth of experience and a fresh perspective to the CBF to lead us into the future. ([Read the full announcement here](#))



Jacqui has been working in partnership with families throughout her career, is passionate about the work of the CBF and committed to ensuring that family carers remain at the centre of all we do.

When my son was diagnosed with Cri du Chat syndrome and started to display behaviours that challenged us, I struggled to find practical information and support. This led to me starting the CBF to ensure that families like mine could access the right support in the right place at the right time.

We started in my garage with no resources other than the determination to make the system work better for children and adults with severe learning disabilities whose behaviours challenge, and their families – so they can lead the lives they have a right to live. From our earliest days, we believed in working in partnership and co-production, pooling expertise, and sharing information and good practice which were, and remain, core principles. Many people have contributed to what we have achieved together over the past 27 years, but there is still much to do. I am confident that every member of the CBF team, and all the people it works alongside, will continue to work together and drive change.

This edition of Challenge highlights the incredible efforts and achievements of individuals and organisations to improve the lives of people with severe learning disabilities whose behaviours challenge. It includes resources, updates and provides opportunities to work together, share information and best practice. You will find stories of resilience and transformation, such as Jonah's journey towards a better quality of life. We also explore the positive impact of collaborative care and community-based support systems. I hope you find this edition both informative and inspiring.

Thank you for all your continued support – together we do make a difference.

**Vivien Cooper, Family carer and CEO of the CBF**



## Resources in this Issue

All the resources featured in this edition of our newsletter (and many others) are available on our [website](#) (scan the QR code). Visit the website for news, opinion, information, resources, opportunities, and support!



You can find a digital copy of all our newsletters in the News section of the website. You can access any resources that are underlined by clicking on them. If you would like to receive our newsletters electronically you can subscribe [here](#). You can request paper copies of our resources by calling us on 01634 838739.

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# Collaborative Care

## Improving Lives through Partnership and Practice Leadership

*Life isn't straightforward for anyone, and the road to living a good life is often bumpy, especially for people with severe learning disabilities whose behaviours may be challenging. This article is written by a care provider who, with the help of Talking Mats, has adopted a truly person-centred approach and worked with the person's family to improve their quality of life.*

We started supporting Jonah when his community placement had broken down. Prior to this community placement Jonah had been an in-patient in an assessment and treatment unit. Jonah is diagnosed with a learning disability, autism and a history of behaviours that challenged services.

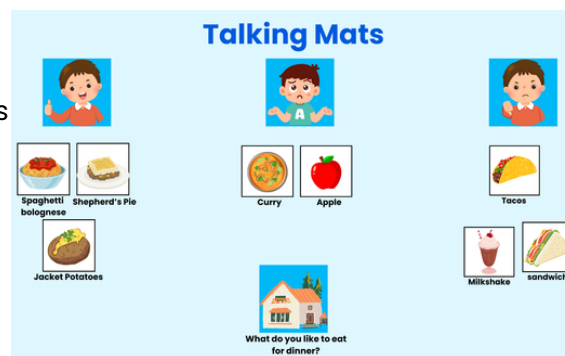
Despite the rigorous staff training, induction and transition we were struggling to maintain a consistent staff team to support Jonah. Staff turnover and injuries sustained while supporting Jonah were a common feature. Jonah would articulate that he wanted friends, to go on holidays, everything that a young man his age would want for himself. None of this was possible though as his behaviours practically excluded him from every community facility.

It was not safe for Jonah to travel on public transport and despite the availability of a car for his sole personal use, Jonah found accessing and participating in his local community extremely stressful and challenging. Over a period of two and a half years, Jonah completely stopped going out of the house and started confining himself to his bedroom. He then reversed his sleep pattern and would remain awake all night and sleep during the entire waking day. Whenever staff tried to coax him into any form of activity during the day, he would physically aggress towards them and cause significant property damage.

The above regression had a toll on Jonah's support staff team and his family, and the relationship became tense and uncomfortable for all. All along Jonah had a dedicated part-time PBS Lead to support the staff team. The situation intensified to the point where even the PBS and Operations Leads were getting burnt out.

There was a real risk of Jonah's placement breaking down and a possible readmission to hospital. A referral was made for the input of a psychologist from our local Learning Disability Community Team. Jonah's mother sought advocacy from a Caseworker at the Challenging Behaviour Foundation.

In Jan 2024, a Circle of Support Network was formed comprising of the psychologist above and his senior, the CBF Caseworker, Operations and PBS Leads from Marcus & Marcus Ltd, Jonah's mother and the Community Psychiatrist, and we met once every six weeks to review matters. This forum represented a safe space where all stakeholders could engage honestly, share ideas and suggestions and collectively agree on achievable short-term goals, that we reviewed at the start of each meeting.



At times tensions arose but as this was a safe and supportive space, it allowed for honesty and enabled all of us to work towards the common good and at a pace that was sustainable for the support team from Marcus & Marcus.

Our immediate goal was to try and reset Jonah's sleep pattern so that he could be meaningfully engaged during the waking day. Through an exchange of ideas and suggestions, we successfully managed to reverse and "normalise" Jonah's sleep pattern.

***It was always felt that Jonah's voice must be heard and his involvement in his care and support was fundamental. The support staff team were trained in using Talking Mats, which was deployed very successfully to encourage Jonah to venture afield and try new items of food.***

Through the strength and support of the network, we utilised talking mats with the sole aim of improving Jonah's quality of life. This included enriching Jonah's repertoire of foods that he ate, meaningfully engaging Jonah in activities of daily living such as laundry, hoovering his bedroom, making his bed and watering the plants at home, doing daily yoga and exercises.

Building on this, Jonah now eats his meals away from his bedroom and now has even started using the activity room to watch TV. Further, the extreme verbal and physical aggression together with the significant property damage that Jonah used to be defined by is a memory of the past. Incidents of aggression have almost totally dissipated, and we are now poised to push the boundaries further by thinking of community access, albeit at Jonah's pace.

## Communication Resources

For more information about Talking Mats, please visit [www.talkingmats.com](http://www.talkingmats.com).

The CBF can assist you in enhancing your team's communication skills and implementing a whole family approach through our workshops. For details, see <https://www.challengingbehaviour.org.uk/workshops/workshops-what-we-offer-2/>



Families seeking support to advocate for their relative can find assistance and guidance through the CBF Family Carer Advocacy resource. Scan the QR code or see <https://www.challengingbehaviour.org.uk/information-and-guidance/rights-and-the-law/00-family-carer-advocacy-resource/>, or by contacting the Family Support Service on 0300 666 0126 or emailing [support@thecbf.org.uk](mailto:support@thecbf.org.uk)

# Emergency accommodation – helping to stop people getting stuck in hospital

One of the biggest reasons that people with a learning disability get stuck in hospital is because there isn't the right support available in the local community. At the CBF we hear from a lot of people whose relative has been detained in hospital, or is at risk of being admitted, because there is an issue with their support – including where they live – and there is nowhere that they can go while this is being resolved.

Some parts of the country have developed alternative and emergency accommodation that can be used by people with learning disabilities, as well as autistic people and other people with complex needs, if they need housing and/or support to stop them from going into hospital. Recognising that it would be possible to prevent people being admitted to hospitals if there was somewhere safe in the community that could be used by people who need somewhere to stay that isn't their home, the Black Country has developed a '[Crash Pad](#)'. People with learning disabilities and autistic people who are at risk of being admitted to hospital can use the Crash Pad on a short-term basis to receive intensive support – helping to avoid hospital admissions.

Alongside their [Emergency Response Team](#) – a team of skilled support workers, who are on call 24/7 and who work with a person's team to develop ways of supporting them in the least restrictive environments possible – the Black Country's Crash Pad has helped people with learning disabilities and autistic people who would otherwise have been admitted to hospital to get support in their local community.



Are you aware of any good examples of emergency accommodation, or of barriers to getting this kind of accommodation in place? Let us know by emailing [daisy.fry@theCBF.org.uk](mailto:daisy.fry@theCBF.org.uk)

This article is partly based on a [presentation](#) about the [Housing](#) section of the co-produced [action plan](#) – including information about the housing issues facing people with severe learning disabilities and their families, and recommendations for what needs to be done to address these.

## Resources

- Scan the QR code or see [CBF's guide to getting a house](#)
- [Overcoming housing barriers – includes resources and good practice examples](#)
- [Example of a housing journey – where things go wrong, and how to stop this happening](#)





# CB-NSG Reception at Westminster

On Wednesday 20th November, the Challenging Behaviour – National Strategy Group (CB-NSG) hosted a reception at Central Hall Westminster to raise awareness of the issues facing children, young people, and adults with learning disabilities and autistic people. This reception focussed on the importance of reforming the Mental Health Act, and the need for concurrent investment in community support. There were over 100 attendees in total, including MPs, people with lived experience and family carers, and other key stakeholders. A key outcome of this event is the urgent need to work together to drive the necessary changes which are outlined in the co-produced, lifelong action plan so people with learning disabilities and autistic people will have good lives in their local communities.



***There was so much evidence of action, enthusiasm and commitment in the room and particularly good to have such a strong contingent of voices of people who live day in day out with the consequences of a system that does not yet meet people's needs.***

***Jo Wilcox, Senior Lecturer, UCLan***



**Every turn of the wheel  
is a revolution:**  
**developing community CAMHS services  
for children and young people with  
intellectual disability in Northern Ireland**

**Dr Heather Hanna & Siobhan Rogan**

The Southern Health and Social Care Trust set up Northern Ireland's first fully integrated Child and Adolescent Mental Health Service (CAMHS) team for children and young people with intellectual disability in 2014. Our guiding vision was equal access to CAMHS for all children and young people – nothing more and nothing less. This shouldn't be a revolutionary idea, but we know that our children experience health inequalities and barriers to accessing health services. A picture of a bicycle on the wall of a famous pub has been our hallmark, it says "every turn of the wheel is a revolution".

In Northern Ireland, CAMHS services are organised according to a Stepped Care Model; designed so that children and young people can access timely support whether they need early, targeted interventions or increasing levels of specialist care.

Despite a growing policy imperative, children and young people with intellectual disability have not had equal access to this range of support. Across our systems and structures, there is an incontrovertible need for change.

In 2014, CAMHS-ID was born. This was possible because of integration within wider CAMHS structures and collaboration with Paediatric and Children with Disability services. We adopted a 'no wrong front door' approach to ensure timely access to services. Many young people present to the service with behaviours that challenge, others with evident mental health conditions. Most of the young people we see are autistic. Having the same front door for everyone, with access to specialist teams, ensures that children and young people get to see the right people at the right time. A simple concept, but fundamentally a right-based issue – equal access to healthcare.

Whilst our ambition is to provide equal access to CAMHS, providing this often means an extraordinary level of resource including time and practitioner expertise. We cannot expect to sit in clinics and talk our way through difficulties our children experience, and so we often see children in homes, schools and short breaks facilities.

***Our motto is to “journey with children, young people and their families, giving hope by working for and with the child, to ensure the best possible quality of life.”***

***“Where, after all, do universal human rights begin? In small places, close to home – so close and so small that they cannot be seen on any maps of the world”.***

***Eleanor Roosevelt***

Families value the flexible and responsive nature of the team; they appreciate their child's wellbeing and quality of life being central to our approach.

The reality is that our systems are complex and often struggle to meet children and family's basic needs. Systems can be outdated in their culture and practice and overwhelmed by fear or a drive for self-preservation.

We know that our children and young people can become very distressed, and systems become very overwhelmed when trying to understand and meet their needs. People fall back on automatic ways of thinking which in the past has led to institutionalisation – exclusion from school, a view that only a psychiatrist and pharmacology can fix the problem, reliance on restrictive practices.

It is important to bring challenge and solution, empowering people to make the system work for the child.

***Helping people to see and do things differently is part of our job.***

When you reframe behaviour referred to as challenging, often the challenge is the child facing barriers to having their fundamental needs met.

Developing services in Northern Ireland faces significant obstacles. External networks of support are vital because, as a wise person once cautioned, “revolution is exhausting”.

Change is possible. The team has been recognised for its innovation and outcomes in a range of national and regional forums. Of note, there have been no admissions to inpatient care for more than five years.

In 2021 Northern Ireland's ten-year mental health strategy recognised the need to ensure children and young people with intellectual disability have equal access to CAMHS. The development of CAMHS-ID teams across the region has been identified as a funding priority. We are not there yet, but every turn of the wheel is a revolution.

Learning Disability  
Professional Senate  
Learning and Listening Event  
2024

"Working Together  
to Stay Well"



Dr Ashok Roy OBE,  
Co-Chair  
Learning Disability  
Professional Senate



Viki Baker,  
Co-Chair  
Learning Disability  
Professional Senate



Scan the QR code on  
the left to watch the  
recording.

## Working together to stay well

On 17th October, over 180 people attended the listen-and-learn event, "Working Together to Stay Well", held by the Learning Disability Professional Senate and jointly organised by the Challenging Behaviour Foundation. Throughout the event, more than twenty professionals gave thought-provoking presentations sharing research and best practice to improve the lives of children and adults with a learning disability. To watch the recording of the event, click [here](#) or scan the QR code.

## Forward Together

Forward Together, the CBF's new 3-year project funded by the National Lottery Community Fund, aims to connect families and professionals within 3 project localities – Kent & Medway, Manchester & Salford and Black Country & Staffordshire, and provide facilitated forums for the networks to identify local issues, support each other to overcome challenges, and to improve co-production and working practices.



In June 2025, we will be hosting the first Community of Practice event to bring the regional networks together and connect families with each other. The in-person event will bring together a diverse range of professionals to share collective perspectives and provide support to regional networks.

The community of practice events will feed into the CBF's National Strategy Group work, providing opportunities to strategically address local and national issues and to share good practice across the country.

This approach will help the project engage families and service providers to share best practice, strengthen national partnership and influence policy and practice. The project will also increase the engagement of families who have a relative with a severe learning disability and behaviours that may challenge, to ensure they have access to targeted information and support and are connected into local and national networks. You can read more about the Forward Together project on our [website](#).

# 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, focussing 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?

Website: <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: 03000 616161 interpreter services available

Email: [enquiries@cqc.org.uk](mailto:enquiries@cqc.org.uk)

#ShareForBetterCare



# YOUR QUESTIONS FROM THE EMAIL NETWORK

*Hello all,  
I wonder if anyone has any ideas on how to get my 25yr old son to allow the nurse close enough to have his vaccinations? I'd leave it, but he has a team of 9 staff who work with him, and they often turn up to work with colds etc. If my son gets ill, I don't know how we would manage him. Any ideas?*  
Hopeful, A



*Hello A,  
I really sympathise. Have you tried getting your jab done at the same time so he can see what happens? We were also offered the option of the nurse coming out to the car to do it. With our son, if we have everything ready and then bring him in, distract, jab and leave within about 10 seconds, it works. I suspect doing this at home would be off-putting and might risk 'contaminating' a safe space.*



*Hi A,  
Our daughter has a general anaesthetic every 3 years for a dental check-up, any necessary treatment, ECG, blood tests and haircut. This year the hospital has also offered to do her flu and Covid vaccines. If your son has to have this approach, you could ask them to do his vaccines?*



**Our Family Carer 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](mailto:network@theCBF.org.uk) or call 0300 666 0126 to find out more and be connected.**

## Listen to the Challenge Accepted Podcast

Christmas is just round the corner, and we know that it can be a stressful time for families as they juggle multiple tasks and rush to get things ready for the holidays. Finding little moments of peace in hectic times can be difficult — you can find top tips on taking care of yourself during the holidays in the CBF Challenge Accepted podcast.

The podcast is specifically focussed on family perspectives on well-being, connecting with others and spending time together as a family. There are also some lighter hearted stories which listeners have told us made them laugh out loud. There is also information on accessing carers assessment and respite. The series is available everywhere you can access a podcast from and on the Acast player on our website. Look out for the special Christmas episode "Christmas Time, Shredded Paper and Dough Balls". We hope you enjoy listening!



***“ Its so wonderful hearing from other parents, making my very abnormal life seem normal! ”***

The series is available everywhere you can access a podcast from and on the Acast player on our [website](https://www.theCBF.org.uk), we hope you enjoy listening! Scan the QR code on the right to listen to the podcast.





# New Communication and Behaviour Workshop

At the CBF, we are pleased to announce the launch of our updated Communication and Behaviour Workshop – fully co-designed, co-produced and co-delivered by family carers with lived experience and qualified practitioners.

Effective communication lies at the heart of understanding and addressing behaviours that challenge. Yet, for many, finding the right strategies and approaches can feel overwhelming. The workshop aims to empower families, carers and professionals who support people with severe learning disabilities with practical tools and knowledge to enhance communication and support positive behaviour changes. This practical 4.5 hour workshop is aimed at anyone who wants to understand how to improve communication with individuals with severe learning disabilities – in turn improving their quality of life, choice and behaviour.

## Learning Outcomes

- **Practical Techniques:** Evidence-based strategies, including a total communication approach, to support communication needs and understand and respond to behaviours that challenge effectively
- **Personalised Insights:** Understand family-centred communication and best practice, co-delivered by a family carer with lived experience
- **Interactive Learning:** Opportunities to build confidence and skills through group activities and real-life scenarios
- **Supportive Environment:** Engagement with like-minded individuals and experienced facilitators who really understand the complexities involved.

**For further information and how to register:** visit our website:

<https://www.challengingbehaviour.org.uk/workshops/> or email: [workshops@thecbf.org.uk](mailto:workshops@thecbf.org.uk) or call us at 01634 838739

## Our full range of workshops



Positive Behaviour Support



Pica Awareness



Trauma Awareness for Professionals



Communication & Behaviour



Whole Family Approaches

For professionals, our full range of workshops also include Trauma Awareness and Whole Family Approaches. These are available to be commissioned for your staff team. For further information, scan the QR code or visit our website to download our brochure [here](#).



We are delighted to welcome Sally Balfour-Allen to the team as our new Workshops Manager starting January 2025. Sally has been involved with the CBF for many years and brings a wealth of experience both in workshop design and delivery as well as lived experience. Sally joins us at an exciting time as we roll out our new range of workshops.

## Free workshops funded by Skills for Care

We are offering fully funded workshops, including Positive Behaviour Support, Pica Awareness and Communication & Behaviour. Our workshops support learning and development, confidence and skills, of Personal Assistants and the family carers who employ them (Individual Employers). Replacement support costs available. [See our website: Skills for Care training workshops](#)



## What Matters to Me

Exciting developments have been made with the What Matters to Me project and we are looking forward to launching the multi-media manifesto in the House of Commons next spring!



What Matters to Me raises awareness about the value and importance of seeking the views and understanding the experiences of people with severe or profound and multiple learning disabilities. This project focuses on directly engaging with young people with complex needs and using our learning to influence policy and shape services and support. With the new government, we have new opportunities to highlight the issues identified through the project and recommend ways to implement its learnings to improve the lives of young people with complex needs, and their families.

By understanding the overarching principles to engaging successfully with people with complex needs, we can gain a true understanding of what is important to and for them. The project highlights that more steps should be taken to proactively engage directly with those who are often overlooked, to ensure their experiences can help shape the support and services they and their families receive.

You can keep updated with the project progress through our network forum: [‘What Matters to Me’ Project](#).

# THANK YOU

A big Thank You to all our supporters this year!

**Steven Lee** and **Catherine Warner** completed the London Big Half raising funds for us.

**Collette Watson** did Dry January and **Helen Marron** ran the Brighton marathon and two weeks later the London marathon.

We have received donations in lieu of birthday/anniversary cards and presents.

## In Memory

Donations received in memory of:

**Louise Novak Dr Paul Sutton Mr Robin Hunkin Davies**

Though these contributions come during a difficult time for family and friends, they are greatly appreciated and significantly support our ongoing work.

## Join our 100 club!

CBF 100 Club – Stuck for gift ideas, how about purchasing a 100 club membership as a Christmas present? Membership is £12 for a year, each month there is a draw for a prize of £25 and in November the prize is £50. To join, use this link: [Fundraise with us – Challenging Behaviour Foundation](#) or email [admin@thecbf.org.uk](mailto:admin@thecbf.org.uk)



## Fundraising for free

Why not use Everyclick, Give as you Live or Easy Fundraising when doing your online shopping to support CBF for free. [Click here to know more](#)

We rely on donations, grants and fundraising to continue our work helping families. Find out how you can help us [here](#) or telephone 01634 838739.



**We are very grateful to every single person who donates to our charity – thank you!**

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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.

To view past editions or to sign up a colleague to receive an electronic version, please see our [newsletter sign-up page](#). Subject to funding, we are sometimes able to send out a printed version of our newsletter, delivered directly to people's homes, for people 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.