The Challenging Behaviour Foundation

making a difference to the lives of people with severe learning disabilities

STRATEGIC PLAN 2026-2029

Who we are here to support

The Challenging Behaviour Foundation (CBF) is the **only** UK charity **specifically focused** on the needs of children, young people and adults with severe learning disabilities whose behaviour may be described as challenging, and their families.

30,000+ people **in the UK** **who have a severe learning disability and are at risk of developing behaviours that may be described as challenging.**

The term "challenging behaviour" has a specific and precise use in relation to people with a learning disability who might have difficulties communicating. It refers to behaviour which presents a serious risk to the person themselves or to those supporting them.

Individuals with a severe learning disability will have little or no speech, find it very difficult to learn new skills, need support with daily activities such as dressing, washing, eating and keeping safe, have difficulties with social skills and need life-long support.

Examples of challenging behaviour include self-injury, hurting others, destructive behaviours, running off or ingesting inedible objects or substances. **It is not the person that is challenging – it is the behaviour**. Challenging behaviour often represents a person's only way of demonstrating an unmet need and getting that need met. Reasons for behaviour may include pain, sensory needs, anxiety, a need to escape or to get something.

When individuals do not communicate verbally, the onus is on services and professionals to understand, support alternative communication approaches and ensure a good quality of life. If this is done well, it can prevent behaviours that challenge developing. Too often, this does not happen and people respond with fear, restriction and even punishment to challenging behaviours, rather than with curiosity, advocacy and enablement.

Individuals whose behaviours challenge are at greater risk of restrictive responses which compromise their rights and their quality of life. Family carers are at risk of poor outcomes too, including physical and mental-ill health, physical injury, and increased financial burdens. This is not inevitable and can be avoided with the **right support**, in the **right place** at the **right time**.

Case Study - Eoghan, enjoying life at home

When Eoghan was three years old he was diagnosed with learning disabilities and autism, his challenging behaviour began at the age of 4. He faced more difficulties than other children in school and we were told we had to do something in order for him to stay in school. At that stage we had no choice but to agree to medication in order to keep him in education.

Transitioning to secondary school was really difficult, Eoghan was misunderstood and heavily medicated, which led to further issues and eventually he was excluded from school. Before this point Eoghan's challenging behaviours were mostly at school, only occasionally at home.

Being at home all the time meant Eoghan did not have his usual activities and routine and behaviour became even more challenging. Eventually I was convinced to voluntarily admit Eoghan to a psychiatric unit. There were promises of behaviour therapy, education and a huge range of therapies and support for Eoghan. Within a week he was a different person, but not in the way I had been promised. None of the therapies or inputs happened. Eoghan was heavily sedated and his condition deteriorated, leading to his sectioning under the Mental Health Act. He was detained for 18 months which was devastating.

This was when I asked for help from the CBF who supported me during the 18-month battle to get Eoghan out of the hospital and into appropriate care. The Family Support Team were amazing during this period, it was a horrible time and I still find it really difficult to talk about.

I did a lot of work, supported by the CBF, to get Eoghan discharged, to transition him to adult services and to find a care company that would look after him. I was often opposed by professionals in my efforts to get him discharged.

When Eoghan did finally move out of the hospital things did not go smoothly. He went into a phase which I call "hospital at home". He did not want to leave his room or to get out of bed. He was sleeping all day and awake in the night which was a routine he had developed in hospital in order to cope with how overstimulating the hospital was for him in the daytime.

A psychiatrist confirmed he was suffering from post traumatic stress disorder due to his experiences in the hospital and he had gained a lot of weight due to the medication.

The CBF supported me during this period as we tried to work out what to do for Eoghan.

Now we are finally in a better place and Eoghan is starting to live a good life in the community. He is living in a house with a garden and has had a stable staff team for a year. He has a routine and takes part in activities he enjoys involving art, music and exercise. Eoghan now enjoys proper meals, goes out into the garden every day, looks after his plants and exercises outdoors, including playing basketball. This is a huge step forward from when he would not leave his room and tomorrow is his first trip out in the car to go running on the athletics track, an activity he loves but which he has not been able to do for a very long time.

It has been a long road to reach this point, the things which have made the real difference include:

- My determination as a mum. It is a job to the professionals involved, I know they care but I am the one who loves him and wants the best for him. I was on my own and the support and advocacy I had from the CBF was vital. Professionals often get their say but the CBF gives families a voice too.
- Eoghan now has a staff team willing to work with me and listen to me.
- The Positive Behaviour Support (PBS) practitioner and the PBS plan. When staff reported that Eoghan would not get out of bed the PBS practitioner considered why and asked what they had done to help him get out of bed. He supported them to try playing soothing music, using a visual timetable so Eoghan would know what was happening next to reduce anxiety and these methods worked.
- Putting the PBS plan into place and showing staff how to do this helped Eoghan to get outdoors. He had his plants in the conservatory at first, then we gradually helped him to progress towards the door with arrows on the ground and the plants just outside. It took time but now he loves going in the garden every day and he is able to cope with the extra stimulation from the car park next door.
- Eoghan finds car journeys stressful so we have adapted the inside of the car to make a better sensory environment with lights and other features, Eoghan has been involved in converting the car and I hope this will mean he can make it to the athletics track.
- A stable routine, built around activities Eoghan enjoys and a stable staff team. Eoghan knows and trusts the staff, including his art therapist who he has known since he was little.
- A house where Eoghan can live on his own and have his own space which is what works best for him.
- Good legal representation for Eoghan, funded through legal aid, when we have had to take issues to the Court of Protection.

There are still a lot of things to sort out. I would like a review of Eoghan's medication and the side effects and I would like to ensure that he has a home for life. I will never stop battling on his behalf. But I am so pleased we have kept him out of hospital and he is enjoying his life in his own home.

By Rosemarie, Mum to Eoghan

Why we were established and what we have learnt

The CBF was established in 1997 by a family carer to ensure that children, young people and adults with severe learning disabilities have the right support and opportunities to live full and active lives. An important part of this is raising awareness of why children, young people and adults with severe learning disabilities may display behaviours described as challenging, how to support individuals well and how to stop responses which compromise people's rights or restrict their lives.

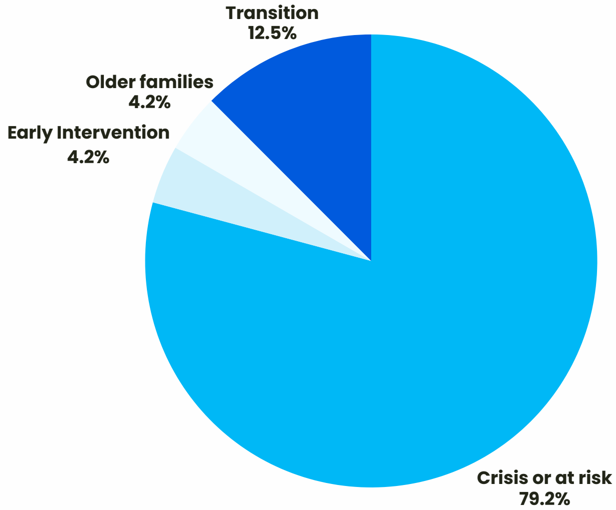
Family carers are key to their relative's lives but often face isolation due to the unusual challenges they face. Despite their critical role in advocating for their relative, families are too often side-lined or faced with parent blame. The system that should be there to support families is often itself a direct cause of trauma.

Often when families contact the CBF for support, it is because they are in crisis. For example, services are saying they cannot provide support due to the severity of challenging behaviour, their relative has been inappropriately detained in a mental health setting, is being abused or neglected or they have serious concerns about health, education, housing or care.

After struggling to find practical information and support for her son who has severe learning disabilities and displays a range of behaviours described as challenging Viv Cooper OBE started the CBF in her garage with no resources other than the determination to make the system work better. From the earliest days, Viv believed in working in partnership and co-production, pooling expertise, and sharing information and good practice which were, and remain, core principles.

Much of our direct work involves supporting families through these crises and working hard to influence the system to avoid such situations.

We have learnt over the years through our family support work and through research and best practice that there are key points in time when families need additional support and that with the right support crisis situations and associated trauma can be prevented.



Key focus of family support casework, 2024-2025

- When children are young, **early intervention,** to optimise child development at this key stage and equip families with the information, skills and support network they need, sets them on a path to a good quality of life, with the tools they need and the knowledge of where to seek help if things get difficult.
- When individuals are going through **transition** points, there will always be risks. Providing additional support to negotiate these transitions, especially the transition from child to adult services, can mitigate entirely preventable crises and trauma, including moving out of area and far from home and admission to a mental health unit for inpatient care.
- When families have been key to their relative's support, **getting older** brings worries about future care when they are no longer around. This is an important time for families when extra help is needed to plan for the future.

Much of our work focuses on research, best practice and influencing change in these three areas alongside **crisis support and prevention**. If the system provided the **right support** in the **right place** at the **right time** there would be no need for the support the CBF provides to families in crisis. For this reason, sharing best practice and strategic influencing are just as important as direct support to families, to encourage a shift towards better early intervention and prevention by statutory services.

Context we are operating in

We would like to reach a point where the CBF is no longer needed, because children, young people and adults with severe learning disabilities and their families are well supported by a joined-up system. Unfortunately, there is a long way to go and the external context we are operating in means there is almost more need for the CBF now than when we were first established nearly thirty years ago.

We are concerned to see an increasing number of organisations supporting children, young people and adults with severe learning disabilities and their families closing their services due to financial difficulties or saying they cannot meet people's needs. Local community teams in some areas are unable to support people with more complex needs. Some national charities are also reducing their support.

The current financial landscape and pressures on public sector services mean many families of children, young people and adults with severe learning disabilities are almost at breaking point, filling the gaps where the system is not meeting their relative's needs, often in fragile situations, which can lead to crisis and restrictive approaches if they break down.

We know that many individuals and families face overlapping and interconnected forms of discrimination or disadvantage, and that people with learning disabilities from minority ethnic groups in particular face significant inequalities.

There are opportunities for UK-wide change on the horizon, but there is also a great deal of disjointed organisational and policy change underway across all the services people with a severe learning disability rely on – health, education, social care, housing and local government.

This puts more of a premium than ever on the need to deliver the CBF vision.

Our vision is for all people with severe learning disabilities, whose behaviour may be described as challenging, to have the right support and opportunities to live full and active lives.

Golden threads

There are two golden threads which run through everything we do to achieve our vision:

1. Co-production

Our work is driven by lived experience of severe learning disability and challenging behaviour and everything we do is co-produced with families

Everything we do at the CBF is co-produced with families, based on the principle that family carers should be full and equal partners in their relative’s care and support, with equal access to information and evidence about best practice. For example, all our training workshops are co-developed and co-delivered by family carers alongside trainers.

Over the past decade we have also been developing and testing an innovative methodology for directly seeking the views and perspectives of young people and adults with severe learning disabilities whose behaviour may be described as challenging. We are now confident we have a robust approach and can use what we find to encourage change in the systems and services around individuals.

Children, young people and adults with severe learning disabilities whose behaviour may be described as challenging need support from a wide range of services but are routinely excluded from consultation and participation activities either because people think they are not capable of contributing or because their inclusion is seen as too difficult, inappropriate or unethical.

We believe that family carers’ views and the perspectives of individuals with severe learning disabilities should be routinely sought and valued by professionals and decision makers at all levels.

2. Partnership working

We work collaboratively with everyone who has a role to play in improving the lives of children, young people and adults with severe learning disabilities whose behaviour may be described as challenging, and their families.

We believe that bringing family carers together to work in partnership with other experts is the best way to learn, share best practice and influence change. In our experience, effective change is driven by lived experience, informed by evidence and professional practice.

We established the Challenging Behaviour – National Strategy Group (CB-NSG) as a key forum for partnership working. It involves families, academics, policy makers, professionals, providers and regulators, all working together, motivated to drive change forward to make a real difference to the lives of individuals with learning disabilities whose behaviour challenges.

As a small charity, we also work in partnership with other charities, self-advocates, researchers and other organisations where we have aims in common.

Sometimes working in partnership is more complicated than working alone but we believe that learning from others and working together strengthens what we are able to achieve for individuals with severe learning disabilities and their families.

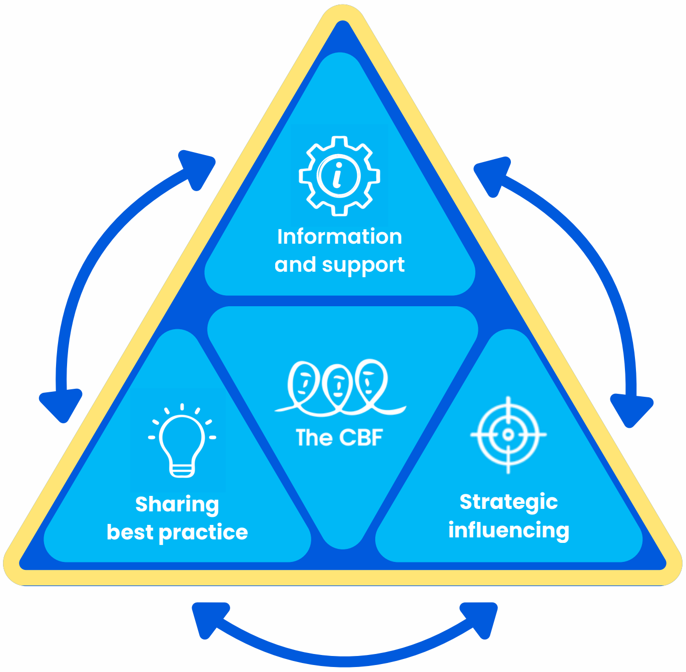
We will work towards our mission and vision through four strategic aims which will guide our work over the next three years. When we discussed this strategic plan with family carers we had very clear feedback endorsing these goals:

> *"Keep doing what you are doing"*

> *"My son would not be living his best life without the CBF"*

> *"The CBF made me feel heard"*

Our **mission** is to make a difference to the lives of people with severe learning disabilities whose behaviour may be described as challenging, and their families, working together through three interconnected areas of activity



Strategic goals

Goal 1

Families of children, young people and adults with severe learning disabilities whose behaviour may be described as challenging, have the information and support they need to support their relatives to realise their rights and to live full and active lives.

To deliver this goal over the next three years we will:

Maintain and strengthen our Family Support Service providing vital information, support and complex casework support for as long as families need it **1**

Actively communicate and raise awareness across different networks so families who may need the CBF can find out about our support **2**

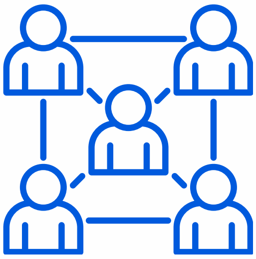
Continue to facilitate peer support, including through our email networks, listening ear calls and podcasts **3**

Keep information resources up to date and develop new resources which will be helpful to families and the professionals who support them **4**

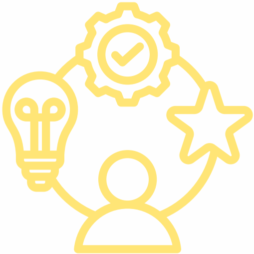
Goal 2

Families, professionals and staff understand more about the reasons for challenging behaviour displayed by individuals with severe learning disabilities and about best practice in supporting a good quality of life.

To deliver this goal over the next three years we will:



1. Deliver the Forward Together project to reduce isolation and connect families up to improve local services in Kent/Medway, Manchester/Salford and the Black Country/Birmingham



2. Provide lived experience input to high quality research studies and share the findings widely to inform evidence-based practice, including early intervention and preventative approaches.

3. Continue to deliver co-produced and co-delivered training workshops across the UK

4. Build on the What Matters to Me project which engaged directly with young people to find out what mattered to them and encourage others to adopt the approach

Goal 3

Key decisions makers engage with people who have lived experience of severe learning disability and behaviour described as challenging to inform systemic change

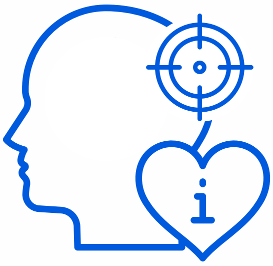
To deliver this goal over the next three years we will:

1. Review and update the membership of the Challenging Behaviour National Strategy Group (CB-NSG) to ensure a representative and active membership
2. Continue to hold bi-annual CB-NSG meetings with an action-focused approach, to breaking down the systemic barriers to a good life for individuals and families
3. Continue the work of the CB-NSG subgroups to focus on family-carer driven change which will have the biggest impact on people's lives, including the Homes not Hospitals Campaign Families Group, Protecting Rights; Eliminating Restraint Group, Campaigns Group, Data Group, Housing Group, Legal Panel Group and Transition Group
4. Advocate for co-production with people with lived experience in key areas of policy reform across the UK

Goal 4

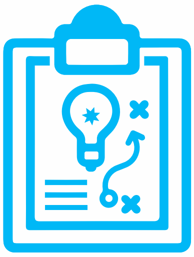
The Challenging Behaviour Foundation continues to be a sustainable and efficient place to work and volunteer

To deliver this goal over the next three years we will:



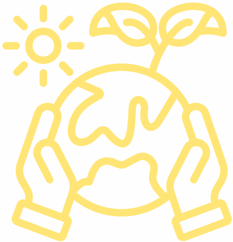
1 Continue to be guided in all that we do by family carers and the experiences of individuals with severe learning disabilities whose behaviour may be described as challenging, and review the ways families are supported to input to the CBF so we can strengthen current arrangements

2 Seek funding from Grants and Trusts whose aims align with our goals to ensure we are able to continue with the actives set out in the plan alongside steps to diversify our income sources



3 Seek paid work from organisations keen to understand the perspectives and experiences of individuals with severe learning disabilities whose behaviour may be described as challenging, and their families

4 Take steps to pro-actively maintain the wellbeing of our staff and volunteers



5 Continue to use our funds wisely and be mindful of our environmental impact

How we will measure progress towards our goals

We have developed and tested an impact measurement framework over the past two years. In order to achieve our vision we ultimately want to see widespread systems change and behaviour change within organisations at all levels but as a small charity we need to be realistic about what we can measure.

Families have been really clear that they get asked a lot of questions and so we will only measure what we are able to meaningfully use to guide our work. We have identified three key questions, which will guide our impact measurement over the next three years.

Strategic influencing

Has lived experience informed key policy decisions and systems change? This includes input and perspectives from both family carers and individuals with severe learning disabilities. We will track this input to key policy areas and research studies because we know from long experience that when people with lived experience have an equal seat at the table, better decisions are made.

Information and support

Have we improved the wellbeing of family carers? We know from the evidence that this has a direct impact on the quality of life of relatives with severe learning disabilities who may display behaviours described as challenging too. We will commission an independent evaluation of our family support service alongside collecting regular feedback.

Sharing best practice

Has our work to share and promote best practice resulted in positive changes in the way individuals with severe learning disabilities and their families are supported? We will collect and monitor feedback and evaluation of our workshops to track change in professional and family carer practice following this training.

We will take positive steps over the next three years to make sure we reach more families from minoritised ethnic communities, lower-income or more deprived areas, and from all nations across the UK. We will track progress as part of our routine data collection.

Our **values** underpin everything we do:

Inclusion

We embrace diversity and actively ensure every perspective is sought, valued, and included respectfully and with dignity

Understanding & Compassion

We aim to comprehend diverse perspectives with empathy and openness, to support and help make things better for people in need

Co-production and collaboration

Our work is co-produced, and we work collaboratively

Integrity & Independence

We ensure that our work is not compromised by conflicts of interest and our core focus is on getting the right support in the right place at the right time, upholding honest and ethical principles in all our work

Advocacy

We champion the rights and wellbeing of individuals with severe learning disabilities and their families with passion and dedication.

Learning through experience

We record, reflect together and learn from our work and its outcomes to improve and amplify our impact.

How we developed this strategic plan

This strategic plan draws on evaluations of and learning from previous and current CBF work. It was developed over a six-month period of review and reflection drawing on discussions with family carers, people with learning disabilities, CBF Trustees and staff and key external stakeholders, including the CB-NSG Steering Group, academics and professionals.

Thank you to everyone who took part in these discussions and reviewed the plan.

Acknowledgements

With thanks to Jan Seamer - As a family carer and supporter of her son who has severe learning disabilities and behaviour described as challenging, Jan was involved in the work of the CBF since the very early days of the charity. Jan was instrumental in the development of our behaviour workshop materials, she co-delivered the workshops for many years and helped train and support many of the current co-trainers, both family carers and professionals. Jan was a founding member of the Challenging Behaviour-National Strategy Group amongst many other achievements. Jan left a legacy to the CBF in her will which, as well as enabling us to provide free training workshops to families and update many information resources, has also enabled us to take forward the work to develop this strategic plan to guide our work for the next three years. We are hugely grateful for everything Jan has done to support the CBF.

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