



Cultures and Co-Production

Summer 2024

This edition of Challenge focuses particularly on cultures and co-production. Cultures are difficult to define but can be broadly described as the shared beliefs, values and behaviour of groups of individuals, whilst co-production is a way of working that brings people with different perspectives together to jointly decide on an action and how to take it forward. Both require social interaction, establishing relationships and involve good communication.



Within our society there is an emphasis on independence and becoming self-sufficient, but the reality is that we are all interdependent: we all interact with other people and establish and maintain relationships, and these relationships are built on understanding and trust. The culture of an organisation or service we use is important to all of us, particularly if it is an organisation or service we rely on.

Positive organisational cultures are often heavily influenced by individuals who lead by example and demonstrate the values of honesty, openness and transparency, treating people with dignity and respect and valuing their contributions. Within these cultures, working practices like co-production and good communication thrive and reinforce feelings of value and shared vision. In contrast “closed cultures” can develop, operating in the opposite way – and toxic and abusive practices can become the norm.

Many abuse scandals have been exposed by the media in services for people with learning disabilities, including the recent [Hesley review](#) but going back decades ([Winterbourne View](#), [Whorlton Hall](#) and [Cawston Park](#)) causing significant harm and trauma. All have had closed cultures which have been allowed to develop and where “the system” has failed to act on warning signs.

In this newsletter, we explore how positive cultures can be created and how closed cultures can be exposed and challenged. Working together, with families and individuals as equal partners at every level is the key to high-quality support and services that meet peoples’ individual needs – and this edition of Challenge showcases some of the work that is being taken forward.

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](#). Visit the website for news, opinion, information, resources, opportunities, and support! Remember that you can receive our newsletters directly in your inbox if you subscribe [here](#). We can post copies of resources to families call us on 01634 838739.



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Summer 2024

Cultures



Is Now a Good Time to Talk?

Twenty years ago, the Valuing People paper (March 2001) acknowledged the unique and important role of family carers –

“Caring for a family member with a learning disability is a lifelong commitment, which continues even when the person is living away from the family home. Carers make a vital contribution to the lives of people with learning disabilities, often providing most of the support they need. They are a crucial resource for ensuring that people with learning disabilities can live in the community.”

In 2020 Baroness Hollins, Chairperson of the Independent Care (Education) and Treatment Review (IC(E)TR) programme for people with a learning disability and autistic people in inpatient settings, wrote, “Families are being excluded in several ways, and in most cases, they are not being recognised as essential members of the team responsible for ensuring the person’s best interests are being met. They are excluded from receiving regular information and updates about the care of their family member, being unable to check that their relative is safe and being prevented from talking to or visiting them regularly, even though when they do visit, they provide comfort and reassurance to their detained relative.”

At the Challenging Behaviour Foundation, we know that working in partnership presents challenges for both professionals and families alike. However, we also see first-hand in our Family Support Service the positive change that can be brought about when communication is open, honest and consistent.

Rosemarie, a family carer, tells us –

“I am a parent of a young 21-year-old son who was in a hospital unit for 18 months. With a lot of fighting and great support from the CBF, I got my son back into the community. However, he had been so traumatised that he struggled, and it became apparent the company supporting my son was unable to meet his needs.”



**“GOOD MANAGEMENT
WHO ARE
WILLING TO LISTEN
IS THE KEY AND THAT
MUST COME FROM THE TOP.”**

We then found a new provider and at first, it appeared everything was settling down, however, things started to go downhill again, and communication had broken down. I approached the CBF again to ask for their help and a meeting was set up with the company, myself and a CBF Caseworker.

We talked about our concerns and the company were happy to listen and put some needed changes in place. These included support and training for staff, maintaining the property and clarifying the lines of communication between staff, management, the family and my son. I can say that things have improved although we still have a long way to go, and it is essential communication continues in a positive way and we all work together to support my son.

The most important lesson I have learned from this is that good management who are willing to listen is the key and that must come from the top."



Communication Agreements

When communication breaks down between support providers and families, tensions may be running high, and it can be difficult to know where to start to improve it. Often the root cause isn't because staff don't care; they may be busy and focussed on supporting the person. Equally, families aren't trying to ask questions at the most inconvenient time – it just so happens that their first free moment in the day coincides with staff handover in the service.

Agreeing what and when to communicate is a good first step. The Family Support Team suggest thinking about three levels of priority for communication:

- **Things I would like to be informed of immediately** such as an admission to hospital, ambulance needing to be called, a safeguarding concern or a medication mistake.
- **Things I would like to be informed of as soon as possible** such as an incident of challenging behaviour, damage to property or suspected illness.
- **Things that I would like to be informed of during our planned daily/weekly communication** such as a food diary, staff changes or changes to planned activities.

Of course, these examples are suggestions only, and priorities will differ depending on the individual. The planned daily or weekly catch-up is key, however, the timing of this may need to be negotiated to ensure it works for everyone and so time can be taken to properly talk. The spirit of this approach is to work out what works best for everyone involved to ultimately improve the quality of life of the person being cared for through good communication.

Please do let us know how you get on!

Resource: Planning for Adulthood

Thinking about the future for a young person with a severe learning disability is a daunting task. Whilst Local Authorities have a legal obligation to start thinking about transition in Year 9, all too often it is left to families to do the actual exploration of what is possible and what will work for their young person.

With this in mind, the CBF have written Planning for Adulthood, a complete guide to transition for families.

- What should happen to support a young person as they reach age 18?
- Where will they live?
- What should I ask to know if a support provider is the right fit?
- Where will the money come from?
- Do I get a say in any of this?

Answering these and many more questions, this resource is enriched with real-life stories, providing not just information but also inspiration and reassurance. It aims to empower families with the knowledge and confidence to advocate effectively for their loved ones, ensuring they lead fulfilling and happy lives as adults.

Whether you're just beginning to think about the future or already deep in the planning process, Planning for Adulthood is an essential companion.

Families can download a copy of Planning for Adulthood from the CBF website [here](#) or contact the Family Support Service for a paper copy on 0300 666 0126.





CULTURES

Working together to deliver good support for people with learning disabilities, building positive cultures, and identifying – and addressing – closed and poor cultures

Members of the Challenging Behaviour – National Strategy Group (CB-NSG) recently met for one of our twice-yearly national meetings. In this meeting, which was held on Monday 20th May, over 60 people – including people with a learning disability, family carers, and people working in different roles throughout the system – came together to learn from each other about how to build positive cultures to support people with a learning disability.

The meeting started with a series of films and presentations. The first film was by Crystal, Jack, Julien, Nathan and Stephen, who all have a learning disability, talking about what makes a good culture, the impact of good and bad cultures, and what people can do to make sure cultures are positive. Liz Durrant, NHS England's Deputy Director of Mental Health, Learning Disability and Autism Quality, gave a pre-recorded presentation about the new culture of care standards for mental health inpatient services, including services for people with a learning disability and autistic people, which were co-produced with a wide range of stakeholders, including people with lived experience and their families. Attendees were then also shown a video from the Insider Voices project, which you can read more about later in this newsletter.

The main focus of the day was on sharing work that CB-NSG members and other partners have been doing to support people with a learning disability and their families. People created posters to share their work and presented them to attendees, who went around in groups. Attendees were encouraged to think about how each piece of work they were shown links to what they are doing, and how they could adopt, adapt, or connect to it. These posters will be shared on the CBF website when the full write-up of the day is published, so please stay tuned!

The meeting finished with Dr Ken Courtenay, NHS England's new national clinical director for learning disability and autism, giving his reflections on the day and answering questions from attendees.

The day was an opportunity for people to come together and work collaboratively to share good practice, learning and ideas to help create more positive cultures and improve the lives of people with a learning disability.

If you're interested in learning more about the CB-NSG you can do so [here](#).



Nothing Without Us

Co-Production that is Meaningful,
Collaborative, Focused and Personal

Co-Production, when done well, can play a vital role in developing and maintaining a positive culture. The term co-production refers to a way of working whereby everybody works together on an equal basis to agree on what the issue is, what is needed to address it, and to create a solution or come to a decision which works for them all. It has clear links and is grounded in person-centred approaches and ensures that everyone's contributions are heard and valued.

***'Co-production as an approach can only succeed when all parties involved feel valued, and most importantly, that the person with the disability is truly at the centre and heart of designing outcomes.'* – CBF Family Carer**

The Challenging Behaviour Foundation and family carers have developed the resource 'Nothing Without Us' which provides an overview of how we do co-production at the CBF, as well as top tips from family carers on how professionals can ensure that, when working in co-production with family carers, it is meaningful, truly collaborative and worthwhile.

The approach is based on four principles of Equality, Diversity, Accessibility and Reciprocity to ensure co-production is inclusive of all voices, and not simply a tokenistic approach.

The resource 'Nothing Without Us', co-produced with family carers, is also accompanied by a case study demonstrating co-production in action to see how these tip tops can be applied in practice, as well as the CBF's Guidance on payment for family carers. The resource can be found [here](#).

CO-PRODUCTION IS NOT ❌



HEARING WHAT YOU
WANT TO HEAR



INCLUDING FAMILIES AS
A TICK BOX EXERCISE

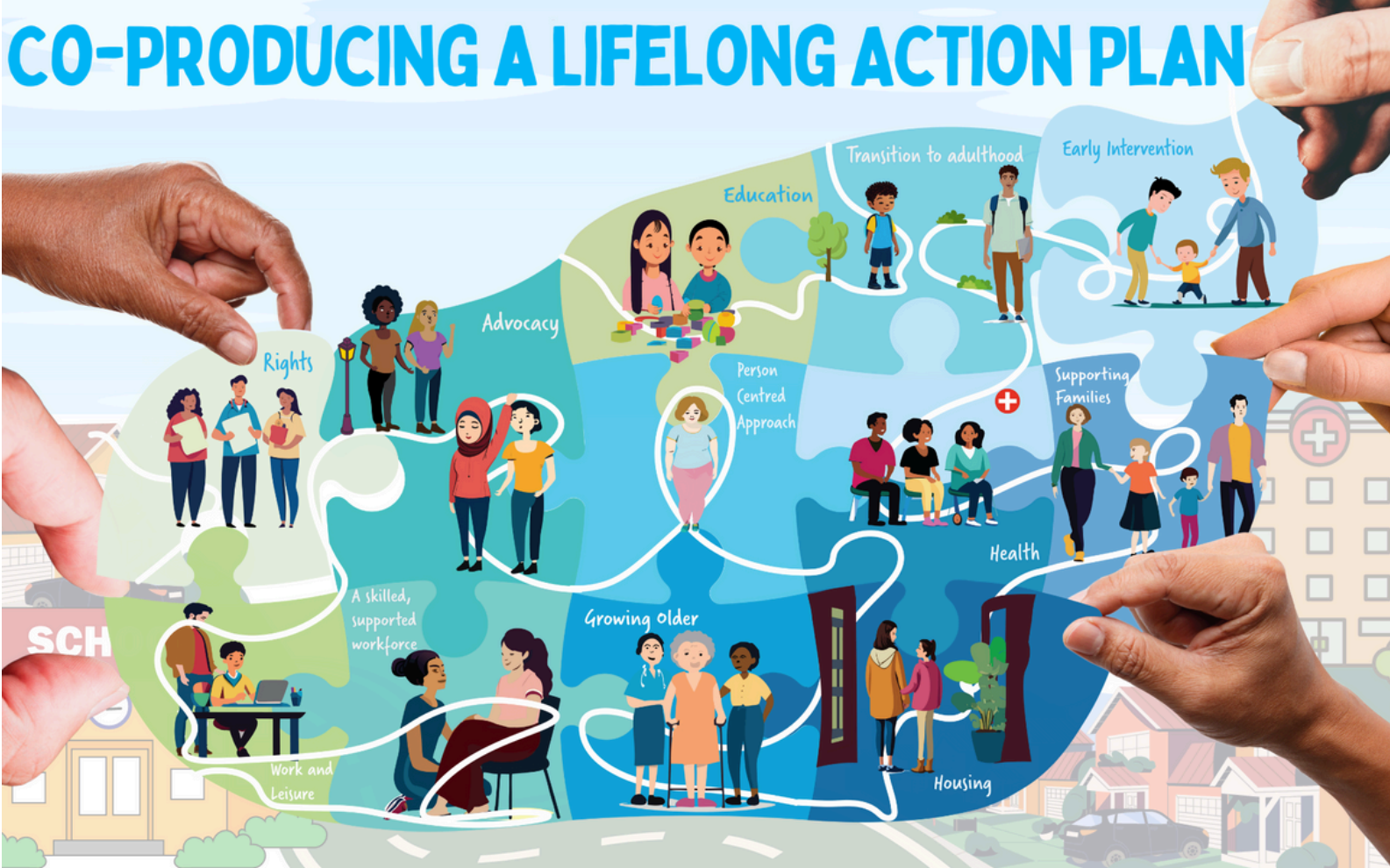
CO-PRODUCTION IS ✓



CONSIDER ALL CONTRIBUTIONS,
EVEN IF THEY ARE DIFFERENT
FROM WHAT YOU EXPECTED



EVERYBODY CONTRIBUTING
IN AN EQUAL WAY



Over the past two years, people with lived experience, families, and people working across all parts of the system have been working together to co-produce a lifelong action plan, setting out what is needed to support children, young people, and adults with a learning disability throughout their lives.

Building on decades of work, action and good practice, this plan takes a lifelong approach that brings all parts of the system together, combining recommendations for policymakers with actions that are being taken here and now.

With over 2000 people with a learning disability and autistic people still detained in inpatient settings, now more than ever we need political leaders, and all parts of the system, to step up and commit to making a difference for children, young people and adults with a learning disability.

This plan is a living document, reflecting progress and identifying new issues - and solutions - as they arise.

This co-produced plan is now available on the CBF's website, and can be viewed - and used - by anyone who is interested in trying to make a difference. We are working with partners to develop an easy-read version and we hope it will be available soon.

If you want to get involved in this work, please email actionplan@thecbf.org.uk





Aimed at frontline nurses, the film celebrates nurses who uphold people's human rights, ensuring dignity and equality are at the forefront of their practice.

Insider Voices features leaders in the nursing profession and family carers providing insights into the importance of positive cultures and how to create them in services. The film is a powerful demonstration of the lasting impact nurses have when they work in partnership, seek to connect with the people they support and their family carers and are creative in their approach.

The film's concept was co-produced by a working group of nine family carers with lived experience of inpatient units, along with a representative from the Royal College of Nursing and NHS England.

There has been sustained media coverage over the past decade of the abuse and neglect of people with learning disabilities in inpatient units. This has cast a spotlight on how the leadership and culture of an inpatient unit have a significant impact on the people who use the service.

Jonathan BeeBee, Royal College of Nursing Professional Lead in Learning Disabilities and Neuroscience, Salli Midgley, Executive Director of Nursing, Professions and Quality at NHS Sheffield Health and Social Care NHS Foundation Trust and family carers share their advice on how to spot the warning signs of a closed or harmful culture and what action to take.

BE
CREATIVE

You can watch the film on CBF's website [here](#) when it launches on 6th August, 2024.

We all have the power to make a difference and become an agent of culture change. Your voice matters!

Becoming an agent of culture change

"Cultures can be really positive, and they can also be quite detrimental, not just for staff, but also for the people using the services." says Salli Midgley, Director of Nursing in the opening of our new film Insider Voices.

"Culture is about how things are done in practice, the unwritten rules and things that staff tell you when you join a team that might not be written down in policies or procedures but are expected behaviours and values of when you're working in the team. Nobody joining a new team wants to be unpopular or talked about, and this means most people will conform to the existing culture of the service." adds Salli, a leader in learning disability nursing.

It is human nature to conform and fit in with the culture of a service and that is why it is so important to focus on culture and ensure positive cultures are developed and maintained in services.

The Insider Voices film is a powerful demonstration of the significant and lasting impact nurses have when they work in partnership, seek to connect with the people they support and their family carers and are creative in their approach.

Positive Culture, Positive Outcomes

Julie, a family carer emphasises the role of dignity, respect and valuing people and their families *"It's quite amazing, actually the difference that a really good member of staff can make to a person's experience. There was a senior nurse who was so kind. More than anything else, he made us feel like humans, like people. We were not just a sort of, a unit or something to be counted or ticked off or not ticked off, or somebody who was in the way. He was just kind and understanding, and it made a massive difference."*

It's important that services listen to the people they support and their families and ensure that people can give feedback – and that there is a culture where staff respond openly and positively. Listening to feedback and acting on it is key says Huw, family carer "All we wanted was a willingness to listen to what we were saying and preparedness to act if they agreed with the points we were making".

To improve the culture of services Jonathan Beebee, Royal College of Nursing's Professional Lead for Learning Disability Nursing and Neurosciences recommends identifying your allies, questioning how things are done and starting small and working towards bigger goals, "I think starting small and asking questions – a questioning nature can be a really positive start in turning to turn a positive culture. If you think there are things that need changing and start small and then work to bigger ones".

KEY MESSAGES

- It is human nature to want to adopt the culture of your workplace and fit in and it's hard to challenge it if you are stressed or anxious
- Listening to families, being empathetic and treating people with dignity builds strong connections and makes a difference
- Starting with small changes and working towards bigger ones can create ripple effects in your workplace
- Thinking outside the box and working at a very individualised level results in better outcomes

Often lots of small contributory factors coalesce to influence and lead to the overall culture of a service and your individual, and what may seem minor, changes can create a ripple effect.

Breaking the culture cycle

Insider Voices sets out the actions that staff can take to address concerns about the culture of a service.

Salli identifies trusting your instincts and raising your concerns with leaders as a key action to turn around a culture. "You must raise your concerns, because if you don't and everybody else stays silent we know that in extreme cases, people are harmed and that means that they really struggle to recover from what should have been a rehabilitative or a stabilising period of time in a unit. This actually becomes the source of significant psychological and potentially physical distress and undermines the trust that people put in the NHS to care for their loved ones. So, if you're worried, go to your leaders. If your leaders aren't listening, you need to go to the most senior people in your organisation."

KEY ACTIONS

- Uphold people's human rights and ensure dignity and equality are at the forefront of your practice
- Be creative with a person-centred approach and seek to connect with the people you support and their families
- Listen to families and treat them as human rights defenders, not as a problem
- Work in partnership with people and their families NOT in isolation and this will bring lasting results
- Identify colleagues who are your allies and take people with you to make change happen
- Trust your instincts and talk to your leaders. If they don't listen, identify someone more senior you can approach.
- If you have serious concerns about your work culture, take advice on whistleblowing and report your concerns to the Care Quality Commission. Find out more in our resource.

Learn more about how to navigate negative cultures by watching Insider Voices. Find out more and watch a preview and checkout our downloadable resource [here](#).

What Matters to me

The CBF are making progress on an exciting new project called **What Matters to Me: influencing policy with the experiences, preferences and views of young people with severe or profound and multiple learning disabilities.**

This piece of work explores how to engage with young people with complex needs to enable them to influence things that directly impact their lives. Carrying out direct engagement work with young people with complex needs requires investment to dedicate time, patience, flexibility and familiarity.

With the correct principles in place, meaningful engagement with this group of young people can take place and in turn, we can learn about their experiences, preferences and views and provide a platform for this to positively influence, drive change and shape services and support.

Later this year, we will pull together the project learning and share this in a multi-media manifesto to highlight the necessity and value of engagement with young people with severe or profound and multiple learning disabilities. Using their views and experiences, this multi-media manifesto can be utilised to influence relevant policy and decision-makers.

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



YOUR QUESTIONS FROM THE EMAIL NETWORK

Hello,

My brother is in his own property with a tenancy. There is a provider providing his care 24/7.

He has his own bus through mobility which staff drive. Staff seem to have no respect and one staff member has bumped it. The manager's response was we will wait until it's due its service to report it.

Also, a staff member has damaged his kitchen worktop. There just doesn't seem to be any respect. His house is dirty, and his bus is also dirty inside. Has anyone's relative been in a similar set up and have any advice on what's worked for them?

B



Hi B


Sorry to hear about the disrespect your brother is experiencing. Only advice we can give is to complain to those in power and to keep complaining till they sort it out.

Tell the CQC and his social worker if he has one. Another thing you could do, if affordable, is hire his own cleaner. Good luck.

L



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 or call 0300 666 0126 to find out more and be connected.



Motability insurance royal sun alliance MUST be told of accident when it happens. Do you have accidental damage insurance for house? If work needs done and staff are the cause, get a quote and request provider pays it. They should have insurance for their staff. Can social worker help?



Contact the social worker as this is so wrong. You're doing a fantastic job with supporting your brother, but don't deal with it directly yourself, as it's so much pressure.



Hi,

If you haven't already done so, I would strongly advise applying for Deputyship through the Court of Protection. It sounds a scary process, but it's not too bad; you can use a solicitor to help you – it's the most important thing I have ever done for my daughter.

S



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Creating Cultures of Co-Production

Working in social care, co-production has become a familiar term over the years with its emphasis on collaboration between people who use our services, their family carers, and professionals, to design and deliver effective support systems. At its core, co-production transcends traditional hierarchical structures, recognizing the expertise and experiences of people with lived experience as essential components in shaping services.

But how well do services integrate co-production principles into their work and team culture?

The Challenging Behaviour Foundation training workshops play a pivotal role in supporting professional teams by fostering cultures of co-production and facilitating meaningful engagement which goes on to help families get better support. The workshops bring people together to share ideas and make plans that really work.

All our workshops are co-designed and co-delivered with family carers to ensure the information participants are receiving is underpinned by a culture of working together.

The workshops enable the people and families receiving support to make their voices heard. That means individuals, their families, and caregivers can say what they need and want. Instead of just being told what to do, they get to contribute to making decisions. This creates an environment of shared control and mutual respect.

By offering a collaborative environment where diverse perspectives are valued, these workshops pave the way for participants to consider their work culture around co-production and create innovative solutions tailored to the unique needs of individuals and families your organisation supports.



We emphasise the importance of embedding co-production throughout the organisation, ensuring it informs all practices and values.

Our workshops serve as catalysts for creating cultures of co-production in social care, where the voices of service users are valued, and partnerships between stakeholders are prioritized. By embracing co-production principles, social care systems can not only enhance the quality and effectiveness of services but also help build a social care system that's fair, respectful, and inclusive for everyone.

If you'd like to know more about our workshops, you can visit the [CBF website](http://www.thecbf.org.uk) or email workshops@thecbf.org.uk.

A Cruel Culture

The BBC broadcast a Panorama programme “Undercover school: cruelty in the classroom” in June. Undercover filming by reporter Sasha Hinde showed pupils at a school for children with special educational needs being abused. Staff boasted about assaulting children under the guise of physical intervention, and then falsifying records to cover it up. Read our response [here](#).



‘A NEED, NOT A WANT’

As a part of the Getting It Right project (2019–2013), the Challenging Behaviour Foundation worked with family carers and professionals to improve support and services for children and adults with severe learning disabilities and their families in the Black Country. The project identified the need to find ways to improve engagement with these families and to understand the barriers they may face in accessing local services and getting their voices heard.

This resource, commissioned by Black Country Healthcare NHS Trust, builds on that work and consists of a short film and a reflective checklist which was developed in co-production with family carers from the Black Country.



‘A Need, not a Want’ identifies key principles and practical solutions from family carers’ direct experience to support positive engagement and meaningful co-production between professionals and families and includes ways to share information with them, and how families can influence and shape local support and services.

The resource aims to drive a more positive culture of professionals and services listening and acting upon family carers’ advice and guidance, fostering more positive relationships and improving the way services are delivered to individuals who have severe learning disabilities.

Watch the film [here](#).

THANK YOU

Marathon Fundraisers

This summer, CBF's Finance and Fundraising Lead Helen and Team Administrator Carina took on marathon challenges to raise funds for the CBF! After preparing together for months, Helen took the challenge of two marathons in two weeks! Carina first ran the marathon virtually then travelled to London to cheer on Helen. They successfully completed the marathons and raised £2000 to support the CBF!



In Memory

Thank you to **Helen Clarke** for raising £2000 for the CBF in memory of **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!

Our 100 Club helps fund our organisational costs like printing and postage. For £12 per year, you will be entered into a monthly draw with a chance to win £25 each month or £50 for the November winner. It also makes an ideal gift! More info, visit www.challengingbehaviour.org.uk/donate

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.

This edition of the newsletter has been sent out electronically. 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.