LOOKING BACK, LOOKING FORWARD

Special Edition for 21 Years of the CBF - funded by DAC Beachcroft LLP

What’s in this Newsletter?

This special edition of Challenge celebrates 21 years since I founded the CBF. Inside we look back at the ways we have made a difference (page 4) and hear from families about the support we’ve given them (page 8). Turning 21 is a time when many young people with learning disabilities need support to increase their independence, as seen in an article about Rebecca (page 2). A bumper Supporters News thanks the efforts of our many and varied fundraisers over the years (page 10).

CBF was built on solid foundations

I think it was 1996 that Vivien Cooper visited myself and colleagues (Jim Mansell and Glynis Murphy) at the Tizard Centre. The Centre had for many years been trying to improve provision for people with behaviour described as challenging.

Vivien was trying to find the best possible education and support for her son Daniel. The CBF did not yet exist … so it would have to be invented! Vivien outlined her plans to develop an organisation that would inform and support families. She signed us up to write information leaflets and contribute to CBF videos. These were the seeds of much more extensive collaboration over the years.

The CBF has made a substantial difference over the last 21 years in a whole host of ways. One early ambition was to encourage the development of local support for Vivien’s son and other young people with related needs. It took years, but eventually a new, local service opened to provide residential and educational support for four young people (including Daniel) who had previously been placed out of area. This simply would not have happened without the CBF pushing it forward in partnership with local statutory agencies.

The CBF is a national charity and its aspirations reach beyond Medway. In 2008, this led to the development of the Challenging Behaviour National Strategy Group (CBNSG), an initiative informed by experience of duplication and a failure to make coordinated national progress on challenging behaviour. The CBNSG, led throughout by the CBF, set out to address this problem and has been consistently successful in encouraging families, professionals and policy-makers to work together to support change. In particular, the existence of the CBNSG made it much easier for everyone, perhaps especially families, to engage with events post-Winterbourne View, and ensure that it was not possible for the Government to get away with a report, some recommendations and a few platitudes. These are two highlights of how the CBF has made a difference.

The CBF’s work to support families facing all kinds of difficulties in gaining good quality support for their relative and themselves is less often in the spotlight. This is where the difference made is most fundamental for the individuals and families involved. The CBF’s capacity to support such families, in turn, allows its influencing work to draw on a reservoir of direct experience that speaks truth to the powerful and (at least sometimes) holds sway over rhetoric, PR and policy speak.

My best wishes to the CBF for the next 21 years. Let’s hope the improvements we all want to see in services and family support mean that there are fewer needs for the CBF to meet, and that it continues to make a difference where so required.

Peter McGill
Professor of Clinical Psychology of Learning Disability at Tizard Centre, University of Kent and former CBF Trustee.
Turning 21...

Rebecca, like the CBF, turned 21 this year. Rebecca is fun, happy, nurturing, sociable and intriguing. She challenges her family and professionals – when you think you know her she surprises you. Rebecca has learning disabilities and visual impairment. She lives at home with her mum, step-dad, step-brother and two dogs, one she adores and one she laughs at.

When Rebecca was 6 months old, her family were told to be prepared she may never walk and talk. Over 21 years, Rebecca has proved that wrong on every level. She didn’t hit her milestones but she still achieved them all at her own pace. The biggest barrier she has overcome is being able to engage with people. Once you have met Rebecca, you don’t forget her. She has achieved at school, surpassing everyone’s expectations.

As Rebecca has got older, she has been able to make more choices and needs less visual prompts. Her personal assistants follow her lead for what she’d like to buy or what activities to do, the only problem being she wants to go bowling every day!

Rebecca is supported to volunteer with young disabled people, a role that she loves and sees as her work. Her caring nature makes her ideal to support her peers, allowing them to engage with people more through her outgoing personality. Rebecca wears a uniform and when she first put on the t-shirt and fleece, it helped her feel she belonged and was part of something. The staff have supported her to feel part of the organisation and a sense of responsibility. Volunteering is great for her confidence.

Having enjoyed supporting other young people so much, Rebecca would like to continue working with and helping people. She is going to attend a vocational independent college, where she will have a supported work experience placement. This may be in a residential home for older people, which Rebecca would love.
Who is the resource for?
This resource is for family carers of someone with a learning disability, autism or both who are looking for information about psychotropic medication.

What is the resource about?
Psychotropic medication is a term for several types of drugs usually given to help with mental health needs. The resource covers topics such as:
* What you need to find out before your relative starts taking medication
* What the alternatives are to medication
* How medication should be monitored
* What to do if you have concerns about your relative’s medication.

NEW RESOURCE:

**Medication Pathway**

for families of people with learning disabilities, autism or both who are prescribed or may be prescribed psychotropic medication

How can I get the resource?
Go to medication.challengingbehaviour.org.uk to use the interactive medication pathway online.

Contact the CBF for a paper copy medication information pack: email info@thecbf.org.uk or call 01634 838739.
1. Established the **Challenging Behaviour National Strategy Group** and led it for nine years, coordinating positive actions from many professionals in partnership with family carer members.

2. Helped family carers understand their relative’s behaviour, with our **information resources, workshops and family support service**.

3. Enabled 323 members of our **Family Carers’ Email Network** to share ideas, information and offer support.

4. Encouraged and supported the use of ‘**Experts by Experience**’ in Care Quality Commission inspection teams.

5. Instrumental in the **closure of Calderstones Hospital**, the biggest NHS hospital for people with learning disabilities.

6. Influenced the **Transforming Care programme** to reduce the use of mental health hospitals for people with learning disabilities, using vital knowledge of families’ situations.

7. Triggered the **Public Accounts Committee’s audit of the Transforming Care programme**.

8. Enabled four young people to return to Medway from residential school and similar placements, and to **establish new lives in their local community**.

9. Contributed to several important **research projects** looking at Residential School placements, capturing families experiences and shedding light on what was happening or young people with severe learning disabilities.

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**Since its beginnings in 1997 (see original team photo above), the CBF has tirelessly fought to make a real difference for families. It has...**

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**CBF NEWS**

**Volume 1 Issue 1 APRIL, 1997**

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**Early CBF leaflets**

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10. Encouraged the dissemination of research findings on challenging behaviour to families and professionals to improve practice.

11. Ran around 30 workshops a year since 2010, giving family carers and frontline staff basic skills in using Positive Behaviour Support for the children and adults they support.

12. Made sure that senior managers and politicians hear directly from families about the difficulties their loved ones’ face.

13. Held those with power to account for the actions they have agreed to, such as policy changes.

14. Secured Margaret Hodge MP to hold a select committee in Parliament about the post-Winterbourne view failings.

15. Created the Challenging Behaviour Charter that gives a clear picture of the support a person with learning disabilities should expect.

16. Gave families practical and emotional support to get their relatives out of Assessment and Treatment Units (ATUs) as quickly as possible.

17. Encouraged research into use of medication and the creation of STOMP (Stopping the over-medication of people with learning disabilities, autism or both).

18. Jointly led the first Early Intervention Project to focus on children and young people who display challenging behaviour - which became Paving the Way.

19. Kept those responsible focussed on getting it right for everyone, including children, e.g. informed policymakers of relevant evidence and family experiences, and built constructive relationships with the Children’s Commissioner and children’s rights organisations.

20. Supported a past employee of the CBF to set up a new charity called CBF Japan and translate CBF information resources into Japanese.

21. Acted as a genuine voice for people with learning disabilities, taking every opportunity to campaign for what is right.

The CBF will continue until we meet our ultimate aim of not having to exist anymore because all the right support and services are in place!
Did You Know the CBF Has 21 Information sheets?

Readers may not have come across all the CBF’s resources, as there is such a variety of information topics. We list them here as a handy reference.

1) Understanding Challenging Behaviour (Part 1)
2) Finding the Causes of Challenging Behaviour (Part 2)
3) Positive Behaviour Support (PBS) Planning (Part 3)
4) Communication and Challenging Behaviour
5) Health and Challenging Behaviour
6) Self-Injurious Behaviour
7) Pica and Polydipsia
8) Difficult Sexual Behaviour in men and boys
9) Mental health problems in people with learning disabilities
10) Physical Interventions for challenging behaviour
11) Use of Medication for challenging behaviour
12) Impact of caring on families
13a) Getting a Statement
13b) Getting an Education Health and Care Plan
14) Transition and moving services
15) Getting legal deputyship for property or welfare decisions
16) Getting the best support package: Ten Top Tips
17) Specialist Equipment and Safety Adaptations
18) Family Carer Information Directory
19) Booklist for Professionals
20) 52 Week Schools
21) Teaching new skills

To order CBF information sheets contact info@thecbf.org.uk or 01634 838739
Q: I took my son for an ultrasound at his local hospital but my son has a real fear of anything medical and especially dark rooms filled with medical equipment. Does anyone know whether this investigation can be done with a mobile unit at his residential home, at another location or in another non-threatening part of the hospital? The residential home manager has said they may have to set up a best interests meeting if sedation is needed to carry out the procedure.

A1: I suggest you ring the hospital and see if they have a specialist learning disability matron or liaison nurse. Our local hospital does, and we can ring her in advance to talk through how to make the appointment or procedure work best. She attends the appointment with us as well. I hope your hospital has a similar service.

A2: I don’t think that is possible to have the ultrasound at home. Sedation may be the only way, but you can try an appointment using help of hospital liaison nurse and if that doesn’t work then talk about sedation.

A3: I’ve had a lot of success with X-rays as they’re not invasive. I tell my son he’s having an 'X-ray photograph' as he likes photos and then a reward to follow. But you need ‘reasonable adjustments’ so the room isn’t dark as it doesn’t need to be. Ultrasound machines can be really small. My surgeon used his computer and a small scanner with me and did mine in a small bright room with very little equipment.

A4: Hospital is not a place my son likes and gets very anxious about going and being there. I have used the services of the Learning Disability Liaison Nurse at the hospital. I have also made a hospital passport, which I send to the Nurse in advance of the appointment so that she can share it with all the medical professionals involved. I also make a plan with the Nurse, starting from leaving home, through the hospital stay and returning home. Even down to what clothes are easier for him to wear if he needs to undress and making sure I am present at all times, every where he goes in the hospital. Also take familiar distractions and rewards. It is not an easy process but can work well with the minimum of disruption and anxiety. With the correct support my son has shown remarkable resilience.

Want to ask your own questions or share your experience?

Join the Family Carers’ Email Network or the Professionals’ Email Network, by emailing network@thecbf.org.uk for an application form.
21 of the families the CBF have supported

In this article we let families speak for themselves, to say why they have come to the CBF for support and how the charity has helped them.

Emotional support for family carers:

‘Thanks for the invaluable help to me as a parent of three sons with challenging behaviour, especially for the one with severe challenging behaviour. I don’t feel so alone and helpless with support from CBF.’

‘My husband and I had reached our wits’ end with our son’s challenging behaviour and were struggling to get support that would accommodate his learning difficulties. After a long phone call with [Family Support Worker], we feel we have some strategies we can now put in place. That phone call — so calm, compassionate and helpful — made me feel listened to and now I’m focussed enough to really support my son.’

‘There are so many awful things happening to people with a learning disability and their families. I can’t thank you enough so far for your patience and your support through an incredibly difficult period.’

‘Just speaking to a member of the CBF team gives me the inspiration to carry on, and to know that there’s still hope.’

‘The staff are patient, kind and the most empathetic people. Without this charity I, along with others in my position, would have no power and not have our voices heard.’

‘I couldn’t have gone on for so long without the CBF continually being there for me all the times I was struggling to persevere.’

‘Our son self-injures, which is one of the most isolating conditions of his autism. Loving someone so much, but feeling powerless to stop them damaging themselves, is so desperately painful. We took immense support from the CBF’s Family Carer’s Email Network: reading about others, and how families and supporters were willing to share experiences and advice, freely and honestly. The magazine was always well read and the workshops were excellent too.’

‘We were able to speak out about what was happening in our family and the sheer lack of support for those dealing with self-injurious behaviour knowing that we were not alone and we were not to blame but could effect change.’

‘The CBF family support workers I have been in contact with have been a truly invaluable resource. Thank you only scratches the surface of my gratitude for the CBF’s existence. In a care system that is harsh, at times brutal and always misunderstands my son’s complex needs, the CBF have always provided an oasis.’

Specialist information and expertise:

‘The case worker has, from the outset, provided invaluable support and advice. The CBF, in my experience, are the only agency who have in-depth experience and training in providing support for people — and their relatives — who have challenging behaviour.’

‘I would like to thank you so very much for your superb support and materials. I have been in contact with many support organisations over the years but yours is by far superior to any other I have had dealings with. You should be proud of the compassionate help and expertise you offer.’

‘I just wanted to say thank you for the PBS workshops, I found them most helpful and it has given me a great insight to challenging behaviour and the possible functions and triggers. I feel a bit more empowered to deal with my son.’
Life-improving casework:

‘We would very much like to thank you for all the help and support you have provided this year. You have been truly amazing and we wouldn’t have been able to do it without you. You helped us prevent X from being sectioned and for that we are truly grateful — so thank you so very much.’

‘I now have the confidence and information to approach adult services and know what my son is entitled to, and ask for it’.

‘As parents of young children/adults with behaviour that challenges, we have to have many hands of expertise. Not just the hands-on care of managing behaviours that challenge, teaching communication skills, norms of behaviour, toileting skills, sleeping patterns, diet, equipment, remedies/medications etc., but also the formal paper work that flows in from an LA. The CBF have helped me write endless letters, tirelessly helping me seek a better quality of life for my son. The CBF have not only backed my mission for him in a practical way with information on MCA, MHA, DoLs, Housing, Human Rights, Care Plans, Positive Behaviour Support plans; they have also delivered information to me with a passion and empathy for change that is genuine.’

Helping people move out of hospital into the community:

‘My son was in an assessment and treatment unit (ATU) for just over a year. It was the most difficult time of our lives. We had support from CBF throughout. I don’t know where we would be now without that support. The CBF helped raise many safeguarding issues for us and then also raised my son’s case to local commissioners. This then helped with my son’s discharge from the ATU.’

‘Our family have valued the CBF’s support so much over the last few years. Their help was vital when my son was detained under the Mental Health Act. They knew all the correct legislation to apply pressure on the local authority to source a property for my son. Now he’s out, they regularly check in to see how he’s getting on in the community.’

‘It was amazing to see how CBF were able to mediate the decision of finally letting my son transition from the hospital to community living. What I was not able to do in ten years since my son was sectioned, they achieved in a matter of months and I cannot express how grateful I am.’

‘The CBF gave me the confidence and courage to fight to get my son out of hospital. They equipped me with knowledge and gave me the platform to tell my story and network with those that could make things happen. My son now lives in his own home, is surrounded by caring staff, he lives 20 minutes away from his family, has choices and is out every day. Without CBF’s life-changing support, this dramatic change in quality of life would not have happened.’

‘When our son hurt a member of staff and a student at his day centre, everything went pear-shaped. A change of living accommodation and a vast increase in his medication only resulted in everything getting worse. Finally, he was sectioned and sent to a private hospital in a different county. During his two years in hospital, the CBF’s family support worker was invaluable. She was the only person I was able to talk to a person who understood and also offered good advice about his future. Fortunately, things have worked out a lot better for our son since, but I shall never forget how supportive the CBF was during that time.’
Supporters’ News

Celebrating our Fundraisers

The CBF does not have any regular guaranteed income and relies on grants and donations to continue making a difference for people with severe learning disabilities. Without our amazing fundraisers and supporters, the CBF would not be able to continue. Here we look back at 21 types of fundraisers who have supported the CBF over the years. There’s not enough space to thank them all individually, so we’ve picked out a few to illustrate that every fundraising initiative helps – from selling bacon sarnies to sky diving!

1. The marathon runners

The first salute must go to the CBF’s very first fundraiser John Bishop who completed the London Marathon in 1997 and raised more than £1,200. Other marathon runners have included: William Dennington who ran the 2001 Hempstead Valley Half Marathon; Nick Gore took on the London Marathon; Tom Moore ran the Vitality Hackney half Marathon; Shelley Brady ran the London ‘Run to the Beat’ half marathon; and recently CBF staff Helen Marron who ran the London Marathon and Carina Down who ran Brighton. Tom Crossland went above and beyond by running 170 miles around the Grand Canyon!

2. The mud runners

Huge thanks for getting filthy go to Catherine McIntosh and Jane Parry, the ‘mad Maldon Mud runners’; Wesley Beverley and team raised over £2,000 running the GRIM challenge through 8 miles of mud; and a Kent team did the NUTS challenge in 2014.

3. The fun runners

Sue Utley organised ‘team George’ at Crystal Palace 5K fun run and raised around £1,500; CBF staff and families raised money in silly sponsored runs Santa Run and Colour Run.

4. The walkers

Over the years a group of walkers including Lynn Walton, Lol Ireland, Karen McKane, Fiona Simon and Michelle Curzon, along with their families and dogs, did the North Downs Walk in Kent many times. They raised hundreds of pounds for the CBF.

5. The cyclists

CBF supporter Lawrence Nasralla cycled from Manchester to Blackpool in 2017 and raised a fantastic £2,510; Adam Grant and team cycled through London at night in the Nightrider; and Last year Peter Baker, Patrick Piper and Duncan Feathers, cycled Land’s End to John O’Groats to raise money for the CBF.

6. The rowers

In September 2007, the Motley Crew Dragonboat Team raced for the CBF and raised a fantastic £3,000! A year later, the Mythical Creatures Dragonboat Team won best dressed team, thanks to the creativity of Rochester University students.

7. The thrill seekers

Susan Kinsella braved a 12,000 ft skydive and inspired by her, a whole CBF team did skydives together in 2013 at Headcorn, Kent.

8. The local heroes

Fundraisers Lynn Walton and Sue Kemsley gained ‘Local Hero’ awards from Sainsbury’s and raised a fantastic total of £1,350. Lynn Price, Sue Kemsley and Lynn Walton have worked tirelessly over the years, organising quiz nights, discos, fashion events, sponsored walks.

9. The quizzers

The same local team have run regular quiz nights in Rainham for 21 years - top marks!

10. The fair ladies

Thanks to all the fundraising volunteers who have run stalls at fairs to fundraise for the CBF, dressing up in Victorian clothes at the Rochester Dickens Festival and in 1940s outfits at Salute to the 40s at Chatham Dockyard.

11. The shoppers

Many supporters raise money for the CBF for free when shopping online, using Easy Fundraising or Give as You Live. Special thanks to Claire Garrod-Pullar, for raising over £400!
Supporters’ News

12. The party animals
Debbie Dennington organized a Christmas Disco in 1997 and in 2011 Rachel and Mick Hancock held a spooky Halloween party!

13. The romantics
Mr & Mrs Corner, Mr & Mrs Nurse and Mr & Mrs Yager asked for donations rather than gifts for their Wedding Anniversaries.

14. The birthday gifters
Margaret Holliday and Clare Pierce both kindly asked for donations to the CBF instead of birthday presents.

15. The singers  Julia Genders and the choir she sings in raised money for the CBF at a concert in Hertfordshire.

16. The young fundraisers
In 2012, Daniel Bird who was 16 and has autism, came 50th in his first marathon and raised more than £2,000; Lily Matthews, age 9 put on a cake sale for the CBF; and siblings Sylvy, Annie, Lorcan and Francis Birch ran a school fundraiser for the CBF, in memory of their cousin William Asquith who had severe learning disabilities.

17. The creatives
In November 2015, artists donated over 50 pieces of artwork at an art exhibition at which an auction and quiz night raised £2,200. The following summer, the Woodlands Festival held an arts market together with music, dance and poetry workshops, and stand-up comedy in benefit of the CBF.

18. The entertainers  Events involving singers, comedy acts and a Michael Buble tribute have all brought in funds.

19. The fear-facers  Chatham fundraisers faced spiders, snakes and even a clown at a Face-Your-Fears night in 2014.

20. The blue-sky thinkers
In 2016, Sue Carmichael and husband held a table top sale in their street and sold 48 bacon sarnies for the CBF; Lol Ireland organised a car treasure hunt; and in 2004 Chris Lewton, Jason Molloy and Hosam El Harmell, had their legs waxed!

21. In memory  We are very grateful for the donations that have been made in memory of several people who passed away. Their legacy is funding the work of the CBF, enabling us to continue making a difference.

CBF staff who keep the charity running, Helen and Carina, both kept running themselves - for 26 miles! Carina ran the hilly Brighton Marathon and Helen ran the sizzling hot London Marathon a week later. Both were there to cheer the other on and their team effort raised £2,500!

CBF supporter Julia Dawson walked CaminoLB in Spain in memory of her brother Anthony and others who have died preventable deaths. She said “The route tested my endurance. When the going was very tough I reminded myself why I was there.” Julia raised over £400.

Winners of the £25 prize in early 2018:
January - Mary Parsons, Kent
February - Matthew Goddard, Herts
March - Sean & Kym McMillan, Kent
April - Louise Jones, Kent

Join for just £12 for a chance to win each month - email info@thecbf.org.uk

CBF marathon success!
Julia walks the Camino
Hundred Club Winners

We rely on donations, grants and fundraising to continue our work helping families. Find out how you can help us by visiting www.challengingbehaviour.org.uk