THE CHALLENGING BEHAVIOUR FOUNDATION

England & Wales · Charity number 1060714

Details

Other names	CBF, THE CBF
Status	Registered
Legal form	Charitable company
Company number	03307407
Registered	1997-02-14
Register	View on the Charity Commission register

Contact

Address	Challenging Behaviour Foundation The Old Courthouse New Road Avenue Chatham Kent ME4 6BE
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Activities

Objects: TO RELIEVE THE SUFFERING AND DISTRESS OF PERSONS WITH SEVERE LEARNING DIFFICULTIES AND CHALLENGING BEHAVIOUR AND THEIR FAMILIES AND CARERS: CHALLENGING BEHAVIOUR - BEHAVIOUR OF SUCH INTENSITY, FREQUENCY OR DURATION THAT THE PHYSICAL SAFTEY OF THE PERSON, OR OTHERS, IS LIKELY TO BE PLACED IN SERIOUS JEOPARDY, OR BEHAVIOUR WHICH WILL LIMIT OR DENY ACCESS TO THE COMMUNITY OR IMPAIR A CHILD'S GROWTH AND DEVELOPMENT

Activities: To demonstrate that children and adults with severe learning disabilities whose behaviour is described as challenging can enjoy normal life opportunities when their behaviour is properly understood and appropriately supported, and to support parents and carers through education and information to enable this to happen.

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Classification

- **How:** Provides Advocacy/advice/information, Other Charitable Activities
- **What:** Disability
- **Who:** People With Disabilities

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-01-31	£543,061	£593,382	£792,383	19
2024-01-31	£836,108	£571,304	£842,704	19
2023-01-31	£530,446	£522,982	£577,900	14
2022-01-31	£610,424	£516,484	£570,436	14
2021-01-31	£595,267	£507,520	£476,496	11

Trustees

Name	Role	Appointed
Dr David Gerwyn Allen	Chair	2022-07-27
Alexander Paul Rook		2022-07-27
CLARE JOSEPHINE MILLION		2017-01-21
Karen Anne Jankulak		2023-07-15
Kathleen A Sanger		2023-07-15
Priti Sanjay Joshi		2024-10-26
Sophie Emily Cooper		2016-01-16

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THE CHALLENGING BEHAVIOUR FOUNDATION

England & Wales - Charity number 1060714

Accounts

The Challenging Behaviour Foundation

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

ANNUAL REPORT

2024–2025



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1. Foreword

From Dr David Allen

Chair of Trustees



This has been another momentous year for The Challenging Behaviour Foundation (CBF). We have seen the well-earned retirement of our former CEO, Viv Cooper. Viv started the charity from scratch and has overseen its growth into the thriving organisation that CBF has become today. She is entirely unique and quickly became one of the UK's most passionate, dedicated, and hard-working champions of people with severe learning disabilities and their family carers. Her achievements are too numerous to mention here, but it is sufficient to state that our whole landscape of policy and practice for this group would look entirely different had Viv not taken on the huge task of founding CBF in 1997. We wish Viv a long and happy retirement – but are also delighted that her knowledge and expertise will not be entirely lost to us as she has agreed to take on a time-limited role of Family Carer Research Advisor.

We have also been delighted to welcome our new CEO, Jacqui Shurlock, who took up post early in 2025. Jacqui has worked for us previously and will already be known to many of you. She quickly hit the ground running, is bringing lots of new ideas about how CBF can develop in the future and has been extremely busy in her first few months in post. The Board of Trustees was delighted to offer Jacqui the post and extremely pleased that she is there to steer the charity forward.

We saw the election of a new government in the past year and, as always, that brought challenges in terms of maintaining and developing our strategic influencing work. Jacqui and colleagues have been very active in terms of trying to forge links with new ministers and MPs in order to ensure that the needs of the people that we support are not just widely understood but acted upon.

The present financial climate is difficult for all charities, and we are working hard to ensure our future financial stability. The legacy of the Jan Seamer Fund has helped enormously in terms of managing the current choppy economic waters and in the past year enabled us to undertake important strategic work in relation to succession planning, completing some key resource updates, and providing a series of memorial workshops for family carers.

As ever, we are hugely indebted to the many families, donors, and volunteers who have contributed to our work over the past year – we are so grateful to you for your continuing support. Finally, I would also like to thank the brilliant staff team, whose output and quality of work always manages to astonish me, and a wonderful team of trustees who have made managing the last year such a positive and productive experience.



Dr David Allen, **Chair of Trustees**

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2. Report of the Trustees

For the year ended 31st January 2025

The Trustees who are also the directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31st January 2025. The Trustees have adopted the provisions of the Statement of Recommended Practice (SORP) 'Accounting and Reporting by Charities' issued in 2015.

Objectives and aims

The Challenging Behaviour Foundation (CBF) exists to improve the quality of life of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families.

Our Values

Inclusion – We embrace diversity and actively ensure every perspective is sought, valued, and included respectfully and with dignity, promoting connections and collaboration.

Understanding and 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 and Independence - We ensure that our work is not compromised by conflicts of interest (e.g. through accepting funding from a particular source) and we retain our core focus 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 well-being of individuals with severe learning disabilities and their families with passion and dedication.

Learning through experience - We record, reflect and learn from our work and its outcomes to improve and amplify our impact.

We are 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.

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

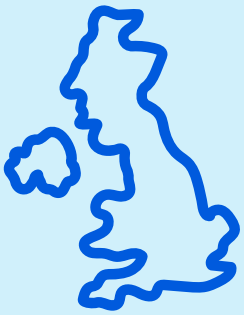
Our **mission** is to make a difference to the lives of people with severe learning disabilities, whose behaviour challenges, and their families, working together to:

- Champion their rights
- Ensure timely information and support
- Raise awareness and understanding
- Promote and share best practice

What is Challenging Behaviour

The term 'challenging behaviour' first came into widespread use in the UK through a publication by the King's Fund Centre. This clearly explained that the term emphasises: *'... that such behaviour represents challenges to services rather than problems that individuals with learning disabilities in some way carry around with them. If services could rise to the "challenge" of dealing with these behaviours they would cease to be "problems". The term challenging behaviour places the focus of discussion on services rather than on the individuals showing the behaviours.'**

The NHS estimates that there are over 30,000 people in the UK who have a severe learning disability and are at risk of developing behaviours that challenge. A person with a severe learning disability may have little or no speech, find it difficult to learn new skills and need ongoing support to carry out daily activities such as washing and dressing.



30,000+ people **in the UK** have a severe learning disability and are at risk of developing behaviours that challenge

Challenging behaviour has **a formal definition**

Terminology: challenging behaviour

* Blunden, R. & Allen, D. (eds.) Facing the Challenge. An ordinary life for people with learning difficulties and challenging behaviour. King's Fund Centre

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Challenging behaviour has a **formal definition** and is a term used to refer to a variety of behaviours which some people with a learning disability may display. These behaviours vary and include aggression, eating inedible objects, severe self injury or significant obsessive repetition, typically putting the safety of the person or others at risk and/or restricting their access to ordinary life opportunities.

Without appropriate support, children, young people and adults with severe learning disabilities whose behaviour may challenge find themselves at greater risk of poor healthcare, poor life prospects and abuse. Families often find themselves isolated from their local community, unsupported by local services and separated from their relatives. Our work focuses on family-led carer support and adopts a Positive Behaviour Support (PBS) approach.

We have carefully built a reputation within the field of learning disability for advocating strongly for this client group, for proactively joining people and organisations up, and for making a difference at an individual, organisational and national level. Lived experience and co-production is embedded in all our work, and we are focused on delivering good outcomes for individuals and their families.

PBS - your questions

“People whose behaviour challenges have the same needs as everyone else, in addition to special needs for help to overcome the problems their behaviour presents. They do not surrender their needs for personal relationships, for growth and development or for anything else because their behaviour presents a challenge to services. They have the same human rights as everyone else.”

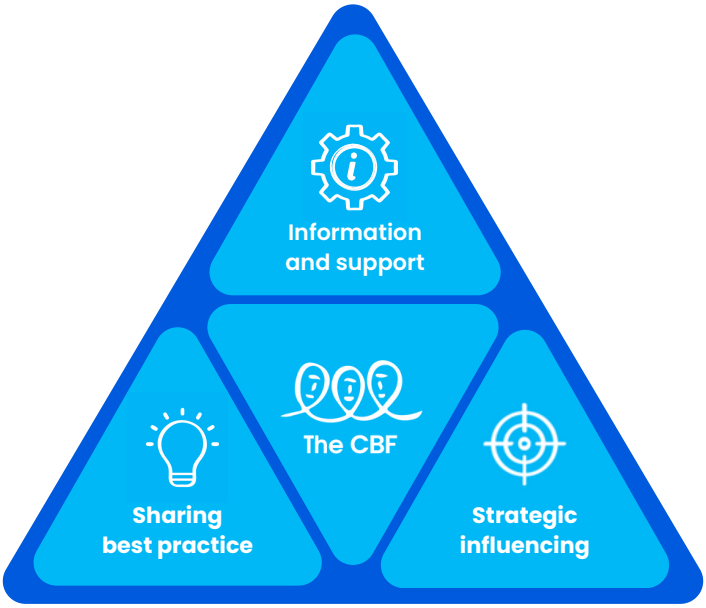
– Mansell 2, 2007



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How we work

Our primary objective is to ensure that with good support each individual can live a happy, active life in their community with access to healthcare, employment, leisure and education, as well as a fulfilling family life. Our focus is enabling children, young people and adults to exercise their rights to participate in ordinary life opportunities through a proper understanding of their behaviour and access to appropriate support.



Families have to deal with a wide range of services across health, education, social care and housing to get the support they need for their relative. These services are not joined up, and we support families to navigate this complex system by providing **information and support**. Based on what we hear from families, we work to change and improve the system through **strategic influencing** and to deliver the right support in the right place at the right time by **sharing best practice**. These three strands of our work together effect change at an individual and strategic level and aim to tackle discrimination, marginalisation and the root causes and barriers that create problems for this disadvantaged and vulnerable group. More information about the work of the charity can be found on our website.

CBF's website

Lived experience is embedded within the organisation and informs and shapes all our work. As an organisation we prioritise families' needs over administrative convenience. The range and scope of our work is wide as it reflects the breadth and complexity of the systems and services that families must navigate through to secure the support they and their relative needs. We adopt a lifelong human rights approach across education, health, and social care, using legal, policy and best practice frameworks to drive change.

More can be achieved by working together. Although our focus is on supporting families, we know that working collaboratively with a range of other partners can achieve good outcomes. We therefore provide a range of information and support to professionals and families involved in supporting children and adults with severe learning disabilities whose

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behaviour challenges.

As a charity we rely on support from our generous funders and donors who make it possible for us to provide essential services. Without their help, we simply wouldn't be able to offer the level of support that is desperately needed. In addition to partnering with us on specific projects and research, the unrestricted core funding we receive is particularly valuable as it enables us to operate effectively and have an impact for the families who need us.

As a small charity with limited resources, we need to carefully consider the impact of our work on an ongoing basis. We are grateful to Paul Hamlyn Foundation, who funded consultancy support which allowed us to undertake a Theory of Change exercise last year. From this we were able to develop a new approach to impact measurement across four key communities where we can have the greatest impact on people's quality of life:



- Early years – early intervention and prevention



- Transition – moving from child to adult services



- Older family carers – planning ahead



- Risk of crisis (at any age) - helping families to get additional support to meet their relatives' needs

Through our three strands of work, we will particularly focus on these four communities, trialling this approach to impact measurement. We will review and embed it as we go forward, developing and working towards long-term outcomes.

Internships

This year we have been able to offer another two internships at CBF. We have now had thirty-four paid internships since 2011 covering family support, policy, research and communications. Each internship is for one year and provides valuable experience in learning disability, working with a range of professionals in the field, and gives insight into the experience of family carers. Our Interns are paid the Real Living Wage.

Previous Interns have gone on to:

- Senior policy and communications roles in the voluntary and public sector
- Practitioner roles such as: social work, learning disability and mental health nursing and special needs teaching
- Further study at Masters and PhD level in related fields and to secure work as a Postdoctoral Researcher in the field of learning disabilities

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“Interning for The Challenging Behaviour Foundation has been an entirely positive, and profoundly rewarding experience, which I could not recommend highly enough. From my very first day, I was able to take part in meaningful and practical tasks, including writing consultation responses, assisting in the development of online meetings and webinars, and contributing to ongoing research projects. The CBF team have been incredibly helpful and supportive – I could not have asked for a better team of colleagues, and I am grateful to everyone at CBF for providing me with such a wonderful workplace environment.

What stands out most about this internship is how fulfilling it has been. Being part of an organisation which makes a clear difference in people’s lives has been incredibly motivating. This experience has been instrumental in building both my skills as an employee but has also developed my personal growth. I am extremely grateful for the opportunity that CBF has given me, and that opportunity to contribute meaningfully to the work of CBF.”

Florence, 2024 Policy and Research Intern

Information and Support



Objectives and activities

Lived experiences gathered from our information and support service drives our strategic influencing work which interconnects with sharing best practice. Our family support service offers a range of free, confidential, and expert resources to families including support delivered through:

- Telephone helpline
- Ongoing in-depth casework
- Information by email
- Digital, printed and video resources on a range of topics
- Information through our website
- Peer support email networks
- Listening ear calls with trained family carers
- A closed Facebook group
- Online carer catch-ups

Support for families | **Support for professionals**

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Strategic Influencing



Objectives and activities

Our strategic influencing work is informed by the lived experience of families gathered through our family support team, utilising examples of evidence-based best practice. This work focuses on ensuring all parts of a complex system work well together and deliver positive outcomes for children, young people and adults with severe learning disabilities whose behaviour challenges, and their families. These activities require an understanding of the holistic context, particularly within systems that are often fragmented and organisationally disconnected.

We are solution focused, believe more can be achieved by working together and facilitate joined up, collaborative working. We actively identify, seek out and engage with the many individuals and organisations in the sector to build strong relationships and foster collaboration and co-production.

We established and continue to chair the influential Challenging Behaviour - National Strategy Group (CB-NSG), a unique multi-stakeholder group which brings together members including family carers, senior representatives from health, education and social care, government departments, regulators, service providers, clinicians, and researchers.

CB-NSG

We promote and highlight the need for an early intervention approach, to work with and invest in families as valued partners, and with full and meaningful co-production. In partnership with others, we work to find ways to seek the views and input of children, young people and adults with the most complex needs and share and promote their engagement. We have developed positive relationships with researchers to amplify the voice of the families of individuals with severe learning disabilities in research, and we support them to input into national policy making and service development. Our work aims to push forward the agenda for better and timely local provision, investment in family support and promotion of enhanced skills and training for support workers and paid carers.

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Sharing Best Practice



Objectives and activities

Sharing best practice is embedded in our strategic influencing work and our information and support. Best practice provides evidence that **it is entirely possible to deliver the right support in the right place at the right time.**

Sharing, modelling, and actively promoting best practice in real-world settings is a core thread running through all our work. We do this through our family support casework, information and resources, strategic influencing work, and family carer and professional email networks, as well as through specific projects involving local authorities, government departments, and other partners.

We have used our reserves to invest in additional capacity, to support, build on and deliver the best practice learning from our project work. We continue to work with local family carers and stakeholders in specific geographical areas to provide additional resources and experience to empower local families and facilitate their input at a strategic level.

> *"The importance of hearing from a professional trainer and a family carer trainer. By co-hosting, both professionals and families can get a better understanding of the other and how important both roles are in supporting loved ones. A person's life can be greatly improved when everyone supporting them understands their way of communication."*
>
> Professional - workshop participant

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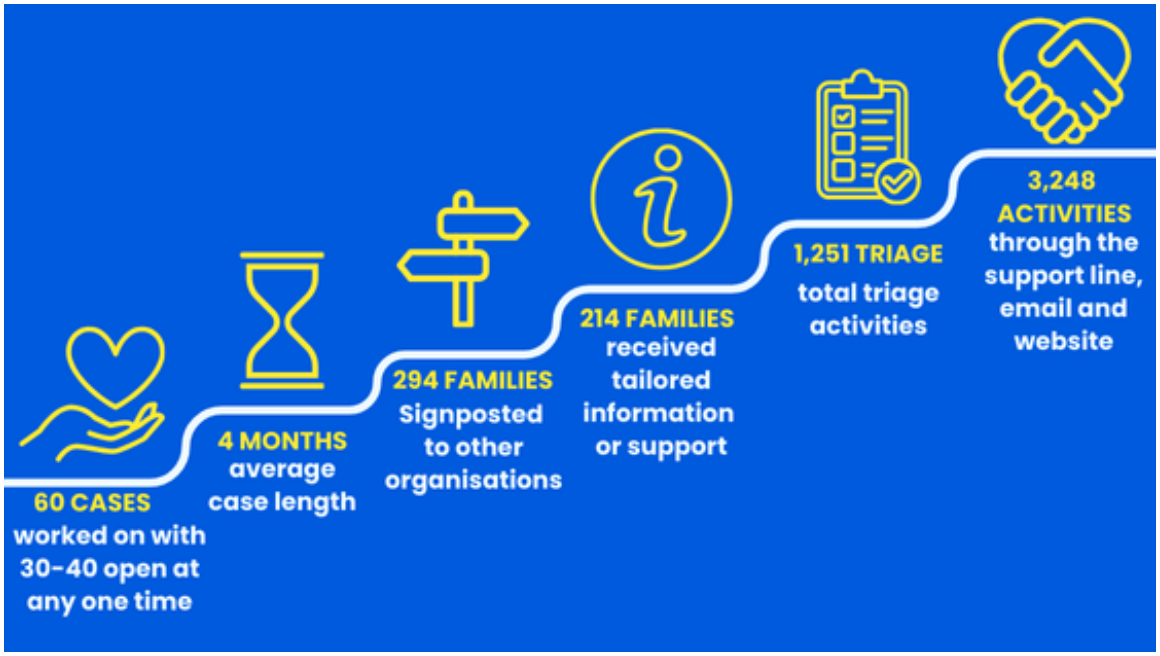
Information and Support



Achievements and performance

Family support service

Our family support service has responded to 3,248 individuals through our support line, email and website this year, an increase of 0.4% on the previous year. We had 39,970 resources downloaded from our website, a 2.49% increase on the previous year. Many families who have relatives with severe learning disabilities require ongoing support through complex situations and caseloads remain high within the team with sixty cases worked on and anywhere between thirty to forty cases open at any one time. These are shared between the Family Support Lead and Caseworkers. Each case is given individual and personalised support with an average case length of four months (113 days).

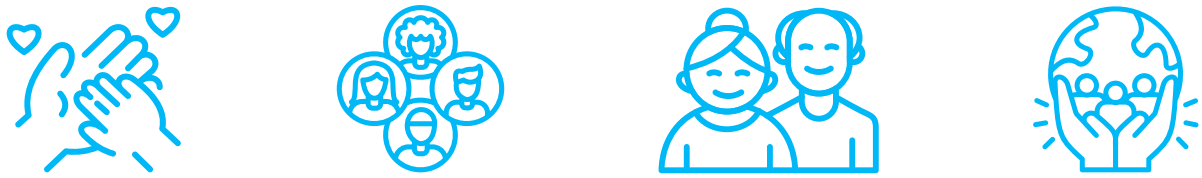


The family support triage function continues to be successful and when contacting the Triage Administrator, a family may be offered a call with a caseworker or signposted. This year the service has supported 1,251 triage activities, provided 214 families with tailored support or information and a further 294 families by signposting to other organisations more appropriate for their needs.

At the start of 2024 we saw a 25% increase in occasions where family carers were signposted to other organisations as their relative does not have a severe learning disability and there were other peaks with increased all rates throughout the year. This may be due to other organisations closing or temporarily suspending their helplines.

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This year we began to classify cases using the four communities identified through our Theory of Change; early intervention, transition, crisis or at risk of crisis and older families. Most of our casework this year involved supporting families at risk of crisis.



In addition, we have been tracking feedback and comments from the family carers that we support, as well as evaluating through self-scoring before and after receiving support for 6 areas; wellbeing, isolation, current situation, making changes, empowerment and hope for the future.

Case Study

In May 2023 CBF's Family Support Team received a call from a family carer who lives in Medway. Her thirty-three year old son (K) has a severe learning disability and epilepsy and displays behaviours described as challenging. He lives in the family home and his parents were finding it difficult to meet K's needs. He is peg fed, incontinent and has seizures each day.

K attends a Day Centre three days per week and is supported with his personal care by Community Care Workers for an hour each morning. The parents had the services of a PA who provided a sitting service four hours per week. K's parents wanted support to obtain some respite but do not have internet access or use emails. All contact is on the telephone or via letters in the post.

The Caseworker agreed to communicate with social care on their behalf. However, maintaining contact with the parents on the telephone and by post provided some challenges. The Caseworker contacted Adult Social Care. They were aware of K's need for respite and were waiting to allocate a social worker. A carers assessment was not due until November 2023.

Following contact by the Caseworker, a review of K's needs was carried out in June 2023 and his parents informed social care their caring role was becoming harder and requested overnight respite. A panel meeting agreed the local authority would provide twenty-eight days respite per year including overnight stays. However, brokerage could not source a respite service.

The Caseworker contacted Adult Social Care in July 2023 who visited the parents to complete a carers assessment. The Direct Payment (DP) hours were increased to eight hours per week. The Caseworker continued to contact Adult Social Care but due to four changes in social workers, delays occurred and in February 2024, they informed the parents they could not locate a respite service. K's parents asked the Caseworker to request overnight respite in the home. Social care needed to agree funding for DP's. However, due to a delay in providing the DP the parents asked the Caseworker to help them to make a complaint.

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A draft complaint letter was written and submitted on 1st May 2024. The complaint detailed the delay carrying out a review of K's care plan, completing a carers assessment and the delay in providing services during and after the assessment process. On 1st July 2024 Adult Social Care informed the parents the care package had been increased to twenty-four hours of care in the home twenty-eight times per year. This information was not provided in writing and the DP was not organised for some time.

K's parents were worried they would have to find places to go in order to benefit from the respite hours on a regular basis but as they had received a carers assessment and their needs had been identified, the Caseworker asked the LA for funding for them to access accommodation away from the family home whilst care was provided for K. This was initially declined and a referral was made to a local carers service for one off funding.

The Caseworker was asked to contact social care again and very soon after receiving the Caseworker's email, the parents received £600 from social care to use towards accommodation costs whilst waiting for the one-off payment. The family now have access to local overnight accommodation whilst the council continue the search for respite accommodation for K.

Legal Panel

The Legal Panel, which is convened and chaired by CBF and consists of specialist legal experts from all of the leading law firms specialising in the law as it affects people with learning disabilities, continues to provide valuable expertise and support on a voluntary basis. Six referrals have been made to the Legal Panel this year and we have also supported families to access Rook Irwin Sweeney's Social Justice fund. Families are also supported to find legal representation outside of the Legal Panel using the list of solicitors that we keep within the team.

Of note: it is becoming increasingly difficult to find a solicitor who has the time or capacity to take our families' cases via the Legal Panel or otherwise. This means that families with urgent concerns are reliant on the statutory complaints process which can be subject to delay and sometimes ineffective in bringing about the desired change.

Helpline collaboration

The CBF continues to convene and facilitate the Helpline Collaboration (made up of charities that provide helpline support to families of people with learning disabilities) which meets monthly. This helps to identify common issues and provide peer support to staff.

Resources

Thanks to a legacy from Jan Seamer we were able to update eight resources this year, making sure that information is fully up to date and informed by the latest evidence. We also produced four brand new resources.

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New resources:
- Nothing without us
- A need, not a want
- Adult Social Care
- Insider Voices

Updated resources:
- Learning Disability Nurses resource.
- Making It Happen (Assessing Risk)
- Going to Hospital
- Communication
- Planning for the Future (now Transition Planning)
- Sexual Behaviour
- Communication and Challenging Behaviour
- Specialist Equipment and Safety Adaptations

Updated web pages:
- The cost of living
- Finding a school
- Wellbeing and resilience
- Professional development

Widely promoted:
- Advocacy guide

Peer support

Families tell us that peer support is incredibly valuable and helps to address feelings of isolation. We continue to provide a range of peer support including:

- Local Champion volunteers were supported to attend a number of events in their local communities to share information about CBF's support with other families. A workshop was also delivered to a Local Champion's group in Southend.
- The Family Carer Email Network is very active and currently has 525 members. Families can ask questions, share solutions, and seek support.
- Families can also ask our Professional Email Panel questions, with 1,250 practitioners across health education and social care who also use this forum to share information and learning.
- Listening Ear Calls are a fifty-minute call with a family carer who has a counselling background. They are offered to complement casework by offering active listening and a chance for family carers to offload how they are feeling.
- Carers' Catch-Ups continue to be held on the first Monday of the month with fifty-six family carers signed to receive information and updates about these sessions.



We are proud to have developed our podcast, Challenge Accepted, which focuses on sharing the lived experiences of family carers and offering tips for wellbeing. The podcast features conversations with family carers about maintaining their wellbeing and has been downloaded over 1,300 times.

This year, two episodes focused on the summer holidays, including honest conversations about keeping everyone happy and entertained, the challenges of accessing play schemes and respite and the simple joy of a hose pipe in the garden! Thanks to funding from The Masonic Charitable Foundation, we have launched a new series of podcasts focused on transition and will release more episodes in the coming year.

Masonic Charitable Foundation

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Strategic Influencing



Achievements and performance

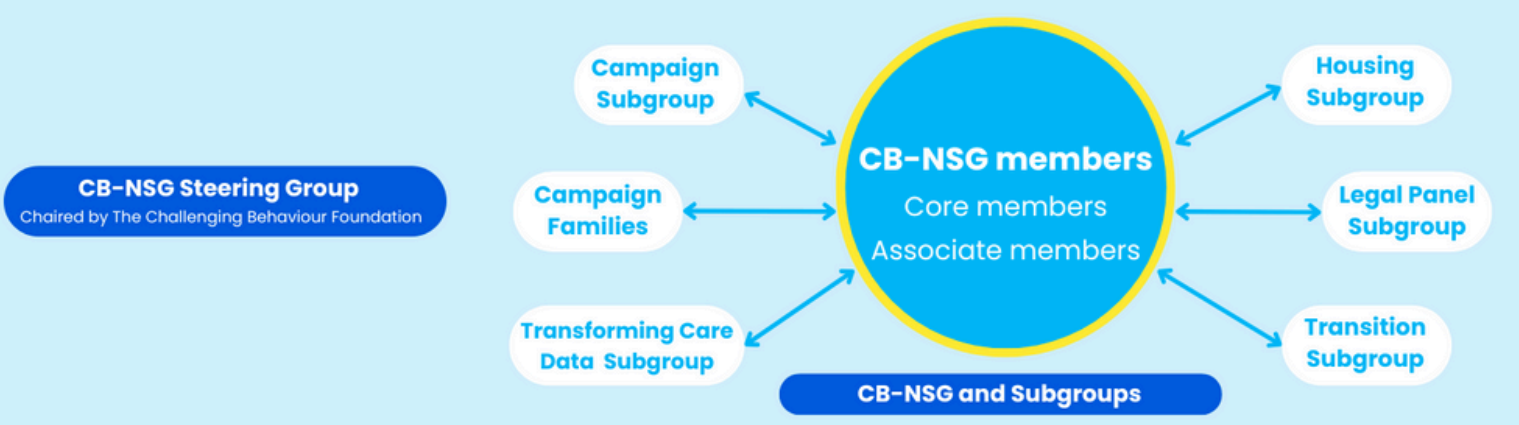
As a small charity we can achieve much more by specifically informing and encouraging individuals and organisations in positions of power and influence to increase their understanding and awareness of the issues individuals and families face, and to influence their activity. We aim to drive progress through the promotion of collaboration. The three strands of our work are inextricably linked and closely aligned. In practice, this means that the experiences of family carers coming through our helpline and casework steer our influencing work. We continue to raise concerns and challenges to a range of senior individuals and organisations at both a local and national level where the human rights of individuals are being breached.

The "system" which should be there to support individuals with severe learning disabilities whose behaviour challenges and their families in reality, is complex, disjointed and difficult to navigate. Our strategic work is therefore wide-ranging across education, health, social care and housing, and across child and adult services. We often work in partnership with others where our aims align, in order to make the most impact for the families we represent.

We submitted twenty consultation responses on issues relevant to people with severe learning disabilities and challenging behaviour this year.

Challenging Behaviour-National Strategy Group (CB-NSG)

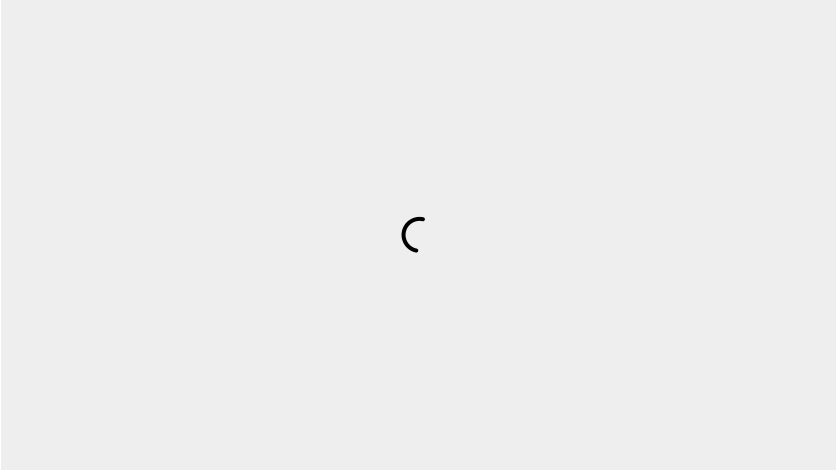
We are very grateful to John Ellerman Foundation and Paul Hamlyn Foundation for their continued support and funding towards the CB-NSG and its work. The CB-NSG includes representatives from professional bodies, networks, charities, and the government alongside family carers, people with learning disabilities and researchers, who are all equal partners in the group. It is based on the principle that if all the individuals and organisations who have a role to play in supporting this group work together in a coherent and coordinated way it will deliver better outcomes.



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There are currently over ninety core CB-NSG members who have significant knowledge and expertise or lived experience and/or a senior level role in supporting and delivering services to people with learning disabilities, and over six hundred associate members who commit to working with the values and principles of the co-produced Challenging Behaviour Charter.

We held a national CB-NSG meeting in May on 'Cultures: Working Together to Ensure Good Support for People with Learning Disabilities', with a focus on how to get things right from the start and how to identify and address issues. This meeting launched the Insider Voices film. The concept of this film was co-produced with a group of nine family carers who have 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 and the film explores how the leadership and culture of an inpatient unit has a significant impact on the people who use the service and their families.



> *"Too often the concerns raised by the families of those with learning disabilities and/or autism are considered to be hostile, the families are seen as the problem. This is unacceptable, they must be recognised as human rights defenders and, other than in exceptional circumstances, be fully involved in all relevant discussions and decisions."*
>
> *Baroness Hollins*

The meeting included nineteen 'talking posters' - a chance for attendees to share current initiatives and research that they are involved in including: housing; how to ensure co-production is meaningful and impactful; supporting family carers to plan for the future, and advocacy.

The CB-NSG subgroups took forward a wide range of strategic influencing this year including:

- Work by the **Data Subgroup** which resulted in confirmation from NHS Digital that the Assuring Transformation dataset would continue to be published for the next two years. This means we can continue to track inpatient numbers of people with a learning disability and autistic people.

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- The **Legal Panel**, and representatives from thirty-nine Essex Chambers, Access Social Care, the Association for Real Change (ARC) England and Fieldfisher agreed strategic approaches that can be taken to use the law to improve the lives of children, young people and adults with a learning disability and autistic people. The meeting, which was chaired by Steve Broach KC, focused on issues identified by CBF's policy and family support teams.
- The **Transition Subgroup** was established in July to focus on this key community identified through our Theory of Change work as outlined earlier in this report. Membership and terms of reference have been agreed, and initial work is focusing on video case studies demonstrating issues around transitioning from childhood to adulthood for young people with severe learning disabilities.
- Members of the **Housing Subgroup** presented at the September meeting of the National Housing Community of Practice (NHCoP). As part of this presentation, a resource was developed showing the pathway that someone with a severe learning disability goes down when they are trying to get a suitable house, the points where things go wrong, and how these points can be addressed at each stage. Follow-up work was agreed by NHS England and our resource was shared with the Department of Health and Social Care. The presentation was well-received by stakeholders at the National Housing Community of Practice meeting, who particularly noted that the family carer testimonies were powerful.
- Some activity and influencing work – specifically that planned by the **Campaign Subgroup** and **Campaign Families** – had to be put on hold due to the general election in July. Instead, we focused our activities on making sure the new Government and the new intake of MPs were well briefed, and that influencing work focused on the areas set out in the King's Speech most likely to impact on people with severe learning disabilities. This work is summarised below.

Co-produced Action Plan

A significant piece of work led by the CB-NSG, the Co-produced Action Plan draws on lived experience, research and best practice. It sets out how to make a positive difference to the lives of children and adults with a learning disability and how to ensure that they get the right support, in the right place at the right time. It includes actions for policy makers, CB-NSG members and individuals. It has been co-produced with families, people with learning disabilities and CB-NSG members, thereby reflecting all parts of the system.

The co-produced action plan was published on CBF's website in early 2024 alongside an easy-read version. It was formally launched in November at a reception hosted by the CB-NSG at Central Hall in Westminster. This event was an opportunity to share examples of good practice and discuss the opportunities for the new government to make policy changes that will improve the lives of people with learning disabilities and their families.

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There were over 100 attendees at the reception including several MPs, a lived experience group from Campaign 4 Change, family carers, professional representatives from NHS England and Care Quality Commission, representatives from Kids, BASW, CDC, Inclusion London, Mencap and Bild amongst others. Work has taken place following this meeting to start or continue to engage with key stakeholders, including through follow-up discussions with MPs and peers.





Co-ordinated Campaigns Group

The CBF brought together a new group of over ten campaigning organisations to co-ordinate campaigning work.

VoiceAbility

VODG Voluntary Organisations Disability Group

Learning Disability Professional Senate

National Autistic Society

mencap

LDE Learning Disability England

BASW England The professional association for social work and social workers

ARC England

Rightful Lives

AUTISM ALLIANCE UK

COUNCIL FOR DISABLED CHILDREN

These include organisations that have not historically worked together but who all agree that in a general election year we would have greater success in making an impact with key messages about people with learning disabilities and autistic people if we worked together.

All of the organisations shared our campaigning activities to develop a calendar of events, so that activities were co-ordinated and mutually supported. The aim was to amplify the campaign messages and to join up the work. One of the benefits of this has been that the campaign activity to reduce inpatient numbers, jointly run by CBF and Mencap was formally endorsed and supported by other organisations.

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Mental Health Bill

The Mental Health Bill was announced in the King's Speech on 17 July 2024 and is a significant opportunity to reduce the number of people with learning disabilities and autistic people inappropriately detained. The CBF's policy team has worked closely this year with the co-ordinating campaigns group to understand the implications of the Bill, share information with our community and provide briefings for MPs and Peers. Key issues for the CB-NSG are the development of good community support and they have produced a briefing on funding issues related to this.

The CBF attended a meeting of the All-Party Parliament Group on Autism, which was focused on the Mental Health Bill, and which was also attended by Stephen Kinnock MP (Minister of State for Care). Following this meeting, we wrote to Stephen Kinnock to emphasise the need to develop community support. We have also been working with the Children and Young People's Mental Health Coalition to share key messages.

Other Strategic influencing activities

Protecting Rights; Eliminating Restraint Group (PR;ERG)

At the start of the year parliamentary questions and Ministerial Correspondence from this group led to publication of research by the Department for Education (DfE) into restraint in schools. The CBF published a statement in response to the research which was shared widely by other group members. Plans by DfE to consult on changes were put on hold due to the election.

There was media coverage in April and June of two examples of abuse and restraint in schools which CBF followed up with the Child Safeguarding Review Panel, DfE and Ofsted. The PR;ERG met twice this year and had updates from each nation in the UK regarding restraint. The group wrote to MPs expressing concern around a lack of action on restraint in their nations, including John Swinney MSP, Bridget Phillipson MP, Claire McClelland DoE NI, and Lynne Neagle MS.

Local Services for Children

The CBF were involved in a research study which identified that there appears to be no service for children with learning disabilities whose behaviour challenges in as many as eleven local authorities and across ten Integrated Care Boards (ICBs) in England. We have completed follow-up work to understand the offerings in the local areas and have contacted them about their service provision. We have also sent letters, co-signed by Mencap, to the Chief Executive of each respective ICB to follow up on these potential service gaps.

The External Support Group

The External Support Group (ESG) brings together experts with significant experience of supporting people with complex needs in community settings. Members of the ESG supported an individual in a Trust this year– their input was helpful, and progress was made. We are also working with a provider to consider further ESG input for another person which is due to commence summer 2025.

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CBF's Response to the National Safeguarding Review

This Review was led by Dame Christine Lenehan following the abuse uncovered at schools in the Hesley Group. The response by the previous government to the recommendations from this review was weak. CBF followed up through a number of channels including the National Building the Right Support Children and Young People Steering Group chaired by Anne Longfield.

CBF's Response to the Law Commission

The Law Commission announced a major review of disabled children's social care legislation. We consulted with family carers via a focus group and survey as well as holding a Legal Panel and Transition Sub-group meeting to inform our position, before submitting a detailed consultation response.



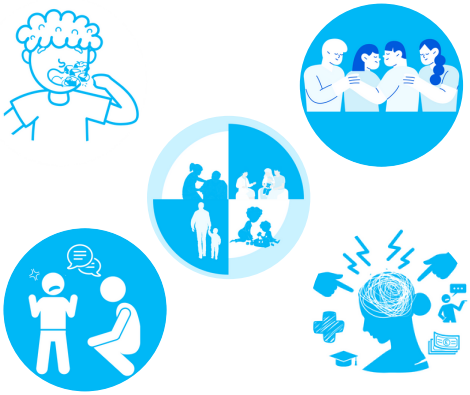
Sharing Best Practice

Achievements and performance

The principle of sharing and actively promoting best practice runs through all aspects of our work from our family support service to our national influencing work. This includes disseminating information via all members of CB-NSG and our extensive networks, including our family carer and professional email networks. We are regularly invited to contribute to research projects—ranging from recruiting advisory group members to leading public and patient involvement, facilitating focus groups with family carers, and supporting trial recruitment.

Training Workshops

Our workshops have all been co-designed with families on topics where they have identified gaps in knowledge and understanding. The workshops are uniquely co-produced and co-delivered with family carers, modelling the partnership working approach that we promote.



Our workshops include:

- Trauma Awareness
- Pica behaviour
- Whole Family Approaches
- Positive Behaviour Support (Understanding challenging behaviour and supporting behaviour change)
- Communication and challenging behaviour

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This year we delivered thirty-five training workshops and were also commissioned to deliver additional workshops, including a series funded by Skills for Care to provide training for Individual Employers and Personal Assistants. We have updated our Communication and Behaviour Workshop in partnership with family carers and developed a new communications plan to promote wider awareness of the workshops we offer to new audiences. We have started work to explore the best way to evaluate the effectiveness of the workshops, which is ongoing.

What Matters to Me

What Matters to Me is an innovative three-year project which built on previous approaches led by CBF and involved directly engaging with eleven young people who have severe or profound and multiple learning disabilities, and their families and support circles.

This year CBF successfully identified two project partner sites to work with and one individual who we engaged with at home. We worked with the expert advisory group to develop a methodology for engagement which can be completely personalised for each young person. A number of engagement sessions were held throughout the year with the 11 young people participating in the project, and we held family carer focus groups.

We have carried out celebration and soft launch events at both project partner sites to recognise and celebrate the contributions of the young people throughout this project in familiar settings. We welcomed local MP Kevin McKenna, who attended, met the young people and spoke to their families to find out about the focus of the What Matters to Me project and what CBF does more broadly.

We have interest nationally from disabled children's organisations and locally from Kent County Council, working with their Social Care Involvement Officers and attending the Learning Disability Partnership Board Meeting.

Forward Together

This is a new three-year project which started in April 2024, working with three regions to bring together families, professionals and commissioners to create regional Communities of Practice. The aim is to improve local support for families of people with severe learning disabilities. A Family Carer Project Worker will be recruited, and a set of our training workshops will be delivered in each region.



Care Quality Commission Share for Better Care project

The Care Quality Commission (CQC) recruited partners, including CBF to help raise awareness of their Share For Better Care Campaign. We shared information about the campaign on social media, in our newsletter, and across our email networks, encouraging families to give feedback to CQC on their experiences.

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MindEd

CBF supported family carers as co-authors to help write the session content for ten STOMP/STAMP MindEd modules which we have promoted through our communication channels.

Getting it Right – Black Country NHS Foundation Trust

Following on from our successful Getting it Right project we were commissioned by Black Country NHS Foundation Trust to deliver actions from the action plan developed during the project. We co-produced A Need, Not a Want, a resource comprising of a short film and reflective checklist to highlight the benefits of engaging with families who have relatives with a learning disability to shape local support and services and an information pack on transition to adulthood which were disseminated within the Black Country. Additionally, we identified two local organisations who were able to deliver an early intervention programme and worked with them to develop a costed proposal.

We were also commissioned to deliver Positive Behaviour Support workshops to family carers and professionals in the Black Country and Pica Awareness and Trauma Awareness to professionals. Feedback included: "Brilliant, friendly, non-judgmental and understood everything. Just brilliant! Would highly recommend." (family carer, Positive Behaviour Support Workshop) and "Everyone working with adults with learning disabilities or autism should do this training!" (Professional, Trauma Awareness)

NHS England – re-design of inpatient services for children and young people

NHS England commissioned CBF to consult family carers with lived experience of their child or young person having an inpatient admission or lived experience of their child or young person receiving intensive support in the community. The focus of the consultation was the proposed re-design of NHS inpatient services, and the needs of children and young people with a moderate-severe learning disability, and their family carers. In July 2024, a small focus group was held with five family carers in London and the write-up of the event was shared with NHS England to inform revisions to guidance for commissioners. Positive feedback was received from NHS England regarding this work:

> ***"Really helpful summary of the day and some absolutely brilliant feedback, points that we can now pull into the commissioner guidance."***

As part of this work, we also recruited nine family carers with lived experience of an inpatient admission when their relative was of transition age, and an autistic person who was detained following a failed discharge at transition stage to speak to NHS England online. The nine online meetings went ahead over the summer, with participants sharing their views on what could have been done to prevent the admissions. NHS England have since shared a report internally with the senior management team.

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Learning Disability Professional Senate Conference

In 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 CBF. Post-conference meetings have been held about the need for a national learning disability strategy and a public health focus for this population, connecting with the Intergrated Care Board Learning Disability Leads.

Child Poverty Taskforce

We were commissioned by Save The Children to consult with family carers to inform the government's new Child Poverty Strategy. An online focus group was held with six family carers in November 2024. The meeting was attended by a Senior Member of the Cabinet Office who is part of the Taskforce. The meeting was transcribed, and key quotes were shared with Save the Children detailing the impact of poverty on children with severe learning disabilities and their families.

Input to research projects and influencing a national research strategy

In line with our aim of sharing families lived experiences and building evidence to inform our strategic influencing work, we have continued to support and shape a variety of research applications and funded projects with a wide range of academics and researchers. We have continued to provide input to steering and advisory groups and supported paid family carer participation in consultations and focus groups, including translating research findings into practice.

This year we have been involved in ten research projects. We have also updated the 'Involving Families in Research' brochure to better reflect the work CBF does to co-produce research with family carers and professionals. We have held a number of meetings throughout the year to press for a national learning disability research strategy and for a research lead in NHSE to take this forward. We understand that a new research lead will take up post in NHSE soon.

Newsletter

We produced two electronic and printed newsletters on the topics of Cultures and Co-Production in Summer 2024 and Working Together, Driving Change in Winter 2024, Both newsletters went out to nearly 4,000 people electronically and the Winter newsletter also went to 3,000 people in hard copy, thanks to funding from the CQC, to ensure families throughout the UK without digital access were not excluded.





Social Media

We continue to use our social media platforms to share news, statements, best practice information and practical resources. All our social media platforms have all seen an increase in followers this year and we have started work to introduce a more strategic approach to our social media channels.

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3. Financial review

Financial Position

Incoming resources for the year amounted to £543,061 compared with £836,108 in 2023/24. However, the previous year's figure was pushed up by the receipt of a one-off legacy of £316,004. Excluding the legacy, incoming resources rose by £22,957, including a £169,064 increase in grant income. This consists mainly of the first tranche of £144,871 for a three-year project, Forward Together, funded by the National Lottery Community Fund. Higher grant income was largely offset by reduced earnings from charitable activities, especially sharing best practice. This type of work is, however, made up mainly of ad hoc projects which inevitably fluctuate from year to year, although the tightening of budgets in the public sector undoubtedly contributed to the reduction in this source of income.

Resources expended rose from £571,304 in 2023/24 to £593,382, an increase of 3.9%, the result of a slightly higher level of charitable activity, combined with the inflationary pressures felt across the economy.

As in the previous year, expenditure within unrestricted funds exceeded the associated income. Despite careful planning and stringent budget management, this negative position is expected to continue in the next financial year, reflecting the increasingly challenging external financial environment.

As noted above, grant funding remains crucial in enabling CBF to continue its work, and indeed represented 69% of total incoming resources in 2024/25. We would like to extend our grateful thanks to all those who have provided this support. The grant from the National Lottery Community Fund has enabled us to expand our sharing best practice activities, while funding from the Blagrave Trust and John Ellerman Foundation have allowed us to further our policy and influencing work. We are grateful to Paul Hamlyn Foundation which has supported our policy work relating to young people and transition while the Colyer-Fergusson Charitable Trust, the Masonic Charitable Foundation and Alex Ferry Foundation have helped to fund our family support service. Thanks are also due to the Garfield Weston Foundation and Pears Family Charitable Foundation for their invaluable contributions towards CBF's core running costs, which, although essential for the efficient and effective running of the charity, are always particularly difficult to fund.

Looking ahead, the financial environment is growing increasingly challenging. Grant funding is subject to fierce competition and usually one-off or relatively short-term. Paid work, always unpredictable and fluctuating in volume, is becoming harder to secure due to severe financial pressures in the public sector. At the same time, inflation continues push up costs, exacerbated by the recent increases in employers' National Insurance Contributions.

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The CBF's overall short-term financial position has been boosted by the legacy received in 2023/24. This is, however, one-off income, and does not in itself provide underlying financial sustainability. The legacy is being used, via the Jan Seamer Memorial Fund, to invest in measures to bolster the charity's longer-term sustainability, for example through the recent recruitment of a full-time fundraiser, providing a sharper focus on income generation going forward.

Reserves Policy

The Trustees have reviewed the key risks across the organisation and have set a target of holding closure costs plus six months running costs in general funds to ensure the charity is in a stable position to:

1. Fulfil notice periods, statutory redundancy and meet all other obligations and liabilities in event of closure of the charity
2. Provide effective staffing to seek alternative funding and support the development of alternative forms of support for families in need of long-term casework in the event of a downturn in income or closure (we typically provide casework support to families for a period of six months to three years)
3. Enable the organisation to respond to unforeseen external challenges such as an increase in demand similar to that experienced during the COVID-19 pandemic.
4. Provide a level of flexibility to respond to any opportunities that may arise at short notice to influence national policy on behalf of our beneficiaries. In taking any decision to use reserves in this manner the Trustees take account of CBF's charity's financial position ensuring that any risks do not impact on its sustainability.

In determining the reserves strategy, the Trustees have taken a holistic and strategic approach, considering carefully the reasons for maintaining reserves as well as the logistics of utilising them.

This includes consideration of the external factors that may affect reserves such as demands on capacity and the high competition for and relatively short-term nature of grant funding, which forms a large part of the charity's income, and often involves a long lead time to secure.

General funds amounted to £365,905 at 31 January 2025, representing approximately 4.6 months of running costs, after taking account of estimated closure costs, based on predicted expenditure for 2025/26. This is below the target and reflects the challenges CBF faces in securing funding for its work.

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4. Our plans for the coming year

Although our ultimate aim as an organisation continues to be that we are not needed because the 'system' works, we know this is a long-term aim and in the interim, we need to sustain and develop our work to maximise our impact. To support this, we will continue to focus on our key communities; early years, transition to adulthood, supporting older family carers and supporting individuals in or at risk of crisis.






In January 2025 our CEO retired from her role as part of a carefully planned succession process. Following open competition we recruited a new CEO (who previously worked for CBF for nine years) and there was a month-long handover period in January. Thanks to the legacy donation from Jan Seamer in 2022, we are able to take forward this period of leadership transition for the charity with minimal risk to delivery. The new CEO is planning to develop a strategic plan for the charity, to start in 2026 which will guide CBF's activity over the next three years. A period dedicated to learning, reflection, and review will be an essential part of this process.

We have also recruited a new Training Workshops Manager and a new Fundraising and Communications Lead, who both started their roles in January 2025. This has resulted in some review of our work in these areas, to build on and develop the work done to date.

We will recruit two new paid interns in the coming year as our current interns reach the end of their contracts. Internships require skilled investment from our Senior Management Team (SMT) and a comprehensive induction and line management process. As a result of this investment, our internships have proved very successful and provide recent graduates with valuable work experience and insight into the issues faced by families, as well as giving CBF additional capacity delivering good value for money.

Following the general election and with a new intake of MPs we will focus on:

- Building relationships with the new government and key MPs likely to have an interest in our work
- Maintaining strong relationships with current stakeholders

We will trial our new impact measurement framework during the first half of the year aiming to embed impact measurement across all our work by the end of 2025.

We will review staff wellbeing and development as leadership change can be a challenge for staff, but we feel positive the next year will bring an opportunity to build on what has gone before to drive the charity forward.

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Funding challenges continue as the pandemic costs are repaid alongside the impact of the cost-of-living crisis on our organisation, the families we support, and the wider community. Trustees are mindful of potential future financial risks and plan accordingly, including close financial monitoring. In addition, the General Election in 2024 created additional disruption, uncertainty and delays to the systemic change we work with others to drive forward.

Our core aim remains to ensure that "the system" and society enable individuals with severe learning disabilities, and their families, to receive the right support in the right place at the right time. Our approach, and all our work, is carefully planned, thought through and regularly reviewed to consider outcomes and impact. In the coming year we will continue to focus on our successful model of three key interconnected areas of work. Our many years of experience have informed and refined our work and how it is delivered to achieve impact and good outcomes. The change we want to see is significant and systemic and takes time. Although we are acutely aware of the urgency and are ambitious and impatient for change, we are realistic regarding our capacity, the inertia and resistance to change within the system, and the need and investment required to work collaboratively.



Information and Support

Future plans

We plan to continue to ensure our specialist family support and information service is maintained, continues to be family centred, and provides high quality independent expertise and advocacy for families in need. The families we support are often in very complex situations, navigating through disjointed education, health and care systems, and experiencing marginalisation, "parent blame" and exclusion often simultaneously. Families clearly describe "the fight" for the support and services their relatives need, and their experiences of discrimination and basic human rights being ignored.

We are grateful to Pears Foundation, Garfield Weston Foundation, Masonic Charitable Foundation and Alex Ferry Foundation who generously provide core funding for our specialist family support helpline and casework which are vital to enable this work to continue. As some multi-year funding ends, we will continue to prioritise seeking further funding to ensure we can maintain and develop the support and information we provide for families who are often in crisis.

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We will continue to offer our:

- Peer support Facebook group
- Family Carer Email Network to cater for the differently-technologically-suited groups of families
- Listening Ear Telephone Service to provide trained and supported peer support

Work will continue to:

- Review the diversity of the families who use CBF'S information and support service.
- Offer Language Line interpreters for those whose first language is not English and those who do not have access to the internet
- Send paper newsletters (subject to identifying funding) and information resources to families who do not use the internet or who request hard copies of resources.
- Work with the Helpline Collaboration to review how we support people over the coming twelve months.
- Further improve relationships with other family support organisations and charities that run helplines by continuing to lead the co-ordination of regular meetings
- Ensure our resources are tailored particularly to our four identified priority groups
- Co-produce new resources for older family carers
- Promote the new comprehensive family carer advocacy guide



Due to the success of Challenge Accepted, CBF's podcast, and thanks to funding from The Masonic Charitable Foundation we will be launching a series of podcasts focused on transition to adulthood. The first episode will be released in February 2025 and following consultation with families, the focus of the remaining five podcast episodes in the series is being finalised. These podcasts will form part of a wider package of resources for the transition stage alongside web and video content.

A planned review of all of our information resources will take place over the coming year. Resources will be updated or rewritten to provide the most up to date information and to ensure they are accessible to families.

Our family support and information service take a lifelong approach and we will consider how we target families in particular situations to increase our impact. As part of that, we have begun to track feedback and comments from the family carers that we support across six areas; wellbeing, isolation, current situation, making changes, empowerment and hope for the future. When we have a full year's worth of data we will begin to analyse this.

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Strategic Influencing



Future plans

We will continue to ensure that families' views are represented in all key policy discussions about people with severe learning disabilities.

In 2025 we plan to:

- Focus on reducing inappropriate admissions and on developing good community support
- Continue to share and promote the co-produced action plan
- Influence the Mental Health Bill, Code of Practice and plans for sufficient community support
- Continue to work with the co-ordinated campaigns group so we can amplify shared key messages
- Follow up our Westminster event by holding meetings with MPs and Peers
- Ensure co-production and health and wellbeing of children, young people and adults with a learning disability remain a priority for practice including input to the Louise Casey review of social care
- Maintain scrutiny of inpatient numbers and ensure reduction of inpatient numbers remains a priority
- Support the family carer campaign group with Mencap
- Deliver two engaging and influential CB-NSG meetings on relevant themes
- Ensure families have a voice in the development of the priorities for the new learning disability research hub IDRIS at Birmingham University
- Support housing/emergency accommodation influencing work

Protect children from restrictive interventions in school:

- Respond to consultation to ensure September guidance is strengthened on issues of seclusion, training and children's rights
- Support Whitehills families to campaign
- Hold two impactful Protecting Rights; Eliminating Restraint Group meetings
- Ensure that the roll out of mental health teams in schools includes special schools
- Share What Matters to Me transition findings with key stakeholders and contribute to the transition policy paper

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Sharing Best Practice



Future plans

We will continue to ensure that families' views are used to share best practice for people with severe learning disabilities.

In 2025 we plan to:

Continue to deliver co-produced and co-delivered training workshops

- Quality assure and update all courses and materials, review and refine processes and ensure all trainers are equipped to deliver
- Deliver workshops funded via grants and contracts, and market and deliver two to three additional workshops per month

Continue work on the What Matters to Me project:

- Finalise the videos and share the multi-media manifesto and all What Matters to Me resources on a new webpage.
- Launch the manifesto at a House of Commons in person launch and an online webinar launch of What Matters to Me
- Disseminate and share the resources

Continue work on the Forward Together project:

- Recruit family carer leads for all Forward Together areas
- Deliver three Forward Together community of practice events in Kent, Manchester and Black Country in the spring and three in the autumn

Continue our strategic approach to learning disability research, including:

- Working with and influencing a range of researchers and research projects that benefit children and adults with severe learning disabilities and their families
- Promoting the implementation of evidence based practice in policy and services
- Ensuring strong links and relationships with IDRIS to maximise opportunities

Deliver locally commissioned work including:

- Black Country project focussed on all age keyworker support
- ESG support to areas requiring support to discharge people into the community and develop good local support

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5. Structure, governance and management

Governing Document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

Recruitment and appointment of new Trustees

Trustee skills are reviewed annually to ensure the board has the range of skills and experience required. Any gaps in specific skills are identified and addressed through training or pro bono consultancy input or through the recruitment of new members to the Trustee Board. We also have a network of Trustee Advisors who are supported, involved, and contribute to CBF and we are exploring new ways for family carers to input strategically through additional online meetings with Trustees.

Organisational structure

The Trustees, who are directors for the purpose of company law and Trustees for the purpose of charity law, who served during the year and up to the date of this report, are set out on the following page. Members of the charitable company guarantee to contribute an amount not exceeding £10 to the assets of the charitable company in the event of winding up. Day-to-day management of the charity's activities is delegated by the Trustees to the Chief Executive Officer (CEO). Following several years of careful succession planning, a new CEO was successfully recruited and started in January 2025. The Trustee Board meets quarterly to review achievements and performance, finances, and future plans.

Risk management

The Trustees have a duty to identify and review the risks to which the charity is exposed, including ensuring appropriate controls are in place to provide reasonable assurance against fraud and error. The Trustees have a risk management strategy in place, comprising an annual review of the risks the charity may face, the establishment of systems and procedures to mitigate risks identified, and the implementation of procedures designed to minimise any potential impact on the charity should any of these risks materialise. In common with many voluntary organisations, the risks are ongoing due to the nature of the work and the context in which we operate.

The trustees have identified as a major risk funding shortfalls, potentially leading to a lack of financial sustainability, as a result of pressure on public sector finances, along with increased competition for grant funding. In mitigation, a full-time fundraiser has recently been recruited to provide increased focus on income generation, while the regular updating and review of financial projections and tight budget management are also key elements in the management of this risk. The receipt of a significant legacy in 2023/24 has also helped to strengthen the charity's financial position in the short term.

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Another major risk is loss of senior staff members, especially in the light of the ongoing inflationary pressures on salaries, although CBF is fortunate to have a highly motivated and experienced senior management team. Attention has also focused on areas such as reputational, governance and compliance risks, ensuring that suitable mitigating actions are in place.

6. Reference and administrative details

Registered Company number

3307407 (England and Wales)

Registered office

c/o The Old Courthouse, New Road Avenue, Chatham Kent ME4 6BE

Registered Charity number

1060714

Trustees

Dr D Allen (Chair)
Ms. S Cooper
Mr. J Dodd
Dr N J Gore
Dr K Jankulak
Ms P S Joshi (Appointed October 2024)
Ms. D E Lightfoot (Resigned October 2024)
Mrs C Million
Mr. A Rook
Mrs K Sanger

Company Secretary

Mrs C Million

Auditors

Xeinadin Audit Ltd
12 Conqueror Ct
Sittingbourne
Kent
ME10 5BH

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Public Benefit

The charity provides public benefit by providing free information and support to families caring for individuals with severe learning disabilities and behaviour described as challenging.

Someone with a severe learning disability may have little or no speech, find it difficult to learn new skills and need ongoing support to carry out daily activities such as washing and dressing. The NHS estimates that there are around 350,000 people in the UK with a severe learning disability. Around 10- 15% of people with severe learning disabilities are likely to develop behaviours described as challenging.

Challenging behaviour is a term used to describe a range of behaviours which some people with severe learning disabilities may use to communicate their needs or exert control over a situation. Behaviours can vary from hair pulling or aggression to eating inedible objects, obsessive repetition or making inappropriate noises. In many cases these behaviours are not intended to cause disruption or distress but offer a form of communication to children and adults with learning disabilities who find verbal communication difficult.

In addition to the immediate health and safety concerns becoming known as "challenging" can mean that an individual can find themselves excluded from local services and left with little control over how their support is provided. Families often find themselves isolated from their local community, unsupported by local services and separated from their relative. Without appropriate support children and adults with severe learning disabilities whose behaviour may challenge find themselves at greater risk of poor healthcare, poor life prospects and at greater risk of abuse. We believe that with good support each individual can live a happy active live in their community with access to healthcare, employment, leisure and education, as well as a fulfilling family life.

More information about the work of the charity can be found at www.challengingbehaviour.org.uk.

The trustees have paid due regard to Charity Commission guidance on public benefit in deciding what activities the charity should undertake.

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7. Statement of trustees responsibilities

The trustees (who are also the directors of The Challenging Behaviour Foundation for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditors are unaware; and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

Auditors

The auditors, Xeinadin Audit Ltd (via Calcutt Matthews Ltd), will be proposed for re-appointment at the forthcoming Annual General Meeting.

Report of the trustees, incorporating a strategic report, approved by order of the board of trustees, as the company directors, on 31 August 2025 and signed on the board's behalf by:



Mrs C MILLION - Trustee and Company Secretary

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8. Report of the Independent Auditors

Opinion

We have audited the financial statements of The Challenging Behaviour Foundation (the 'charitable company') for the year ended 31 January 2025 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 January 2025 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

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Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Report of the Trustees has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Trustees.

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

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Responsibilities of trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

Our responsibilities for the audit of the financial statements Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Our objectives in performing the audit are to identify and assess the risk of material misstatement in the financial statements due to fraud or error and to obtain sufficient audit evidence to support this. We also evaluate and respond to the risk of material misstatements.

Audit procedures performed by the engagement team included:

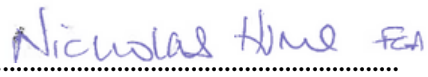
- Gaining an extensive knowledge entity and environment
- Obtaining a sufficient understanding of the internal environment, including control systems in place for the detection and prevention of fraud.
- Evaluating said systems to determine whether they are operating to a satisfactory level and are providing the right level of control and authorisation within the entity.
- Understanding the entity's current activities, assets and liabilities and comparing these to the entity's charitable objectives and aims.
- Discussions with management and those charged with governance as to any known or suspected instances of noncompliance with laws and regulations, including fraud.
- Reading minutes of meetings of those charged with governance and comparing these to what is reflected in the statutory accounts.

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A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Nicholas Hume FCA (Senior Statutory Auditor)
for and on behalf of Xeinadin Audit Ltd
12 Conqueror Ct
Sittingbourne
Kent
ME10 5BH

Date: ....10 September 2025....

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9. Statement of Financial Activities

for the Year Ended 31 January 2025

	Notes	General funds £	Designated funds (Unrestricted) £	Restricted funds £	31.01.25 Total funds £	31.01.24 Total funds £
INCOME AND ENDOWMENTS FROM						
Donations and legacies	2	78,620	-	315,461	394,081	545,193
Charitable activities	5					
Information and Support		7,150	-	-	7,150	9,349
Strategic Influencing		9,147	-	-	9,147	73,877
Sharing Best Practice		88,613	22,650	-	111,263	202,272
Other trading activities	3	4,477	-	-	4,477	2,187
Investment income	4	16,943	-	-	16,943	3,230
Total		204,950	22,650	315,461	543,061	836,108
EXPENDITURE ON						
Raising funds	6	22,913	-	-	22,913	22,507
Charitable activities	7					
Information and Support		58,952	2,434	56,417	117,803	93,144
Strategic Influencing		20,852	-	105,774	126,626	116,883
Sharing Best Practice		90,399	21,156	160,553	272,108	240,993
Core Funding		23,932	30,000	-	53,932	97,777
Total		217,048	53,590	322,744	593,382	571,304
NET INCOME/(EXPENDITURE)		(12,098)	(30,940)	(7,283)	(50,321)	264,804
RECONCILIATION OF FUNDS						
Total funds brought forward		378,003	337,545	127,156	842,704	577,900
TOTAL FUNDS CARRIED FORWARD		365,905	306,605	119,873	792,383	842,704

The notes form part of these financial statements

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10. Balance Sheet

31 January 2025

	Notes	General funds £	Designated funds (Unrestricted) £	Restricted funds £	31.01.25 Total funds £	31.01.24 Total funds £
CURRENT ASSETS						
Debtors	12	17,256	-	1,832	19,088	21,891
Cash at bank		422,411	306,605	182,202	911,218	937,681
		439,667	306,605	184,034	930,306	959,572
CREDITORS						
Amounts falling due within one year	13	(73,762)	-	(64,161)	(137,923)	(116,868)
NET CURRENT ASSETS		365,905	306,605	119,873	792,383	842,704
TOTAL ASSETS LESS CURRENT LIABILITIES		365,905	306,605	119,873	792,383	842,704
NET ASSETS		365,905	306,605	119,873	792,383	842,704
FUNDS	14					
General funds					365,905	378,002
Designated funds					306,605	337,546
Unrestricted funds Total					672,510	715,548
Restricted funds					119,873	127,156
TOTAL FUNDS					792,383	842,704

The financial statements were approved by the Board of Trustees and authorised for issue on 31 August 2025 and were signed on its behalf by:



Mrs C MILLION - Trustee

The notes form part of these financial statements

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11. Cash Flow Statement
for the Year Ended 31 January 2025

	Notes	31.01.25 £	31.01.24 £
Cash flows from operating activities			
Cash generated from operations	1	(45,995)	242,561
Gift Aid		2,589	4,846
Net cash (used in)/provided by operating activities		(43,406)	247,407
Cash flows from investing activities			
Interest received		16,943	3,230
Net cash provided by investing activities		16,943	3,230
Change in cash and cash equivalents in the reporting period		(26,463)	250,637
Cash and cash equivalents at the beginning of the reporting period		937,681	687,044
Cash and cash equivalents at the end of the reporting period		911,218	937,681

The notes form part of these financial statements

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Notes to the Cash Flow Statement for the Year Ended 31 January 2025

1. RECONCILIATION OF NET (EXPENDITURE)/INCOME TO NET CASH FLOW FROM OPERATING ACTIVITIES

	31.01.25 £	31.01.24 £
Net (expenditure)/income for the reporting period (as per the Statement of Financial Activities)	(50,321)	264,804
Adjustments for:		
Interest received	(16,943)	(3,230)
Gift Aid Income	(1,891)	(3,744)
Decrease in debtors	2,105	3,184
Increase/(decrease) in creditors	21,055	(18,453)
Net cash (used in)/provided by operations	(45,995)	242,561

2. ANALYSIS OF CHANGES IN NET FUNDS

	At 01.02.24 £	Cash Flow £	At 31.01.25 £
Net cash			
Cash at bank	937,681	(26,463)	911,218
	937,681	(26,463)	911,218
Total	937,681	(26,463)	911,218

The notes form part of these financial statements

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12. Notes to the Financial Statements

for the Year Ended 31 January 2025

1. ACCOUNTING POLICIES

Basis of preparing the financial statements
The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

- Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity
- Designated funds are unrestricted funds earmarked by the trustees for particular purposes.
- Restricted funds are subject to restrictions on their expenditure imposed by the donor or through the terms of an appeal.

Income
All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure
Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Allocation and apportionment of costs
Support costs are allocated pro rata to staff numbers involved with each charitable activity.

Taxation
The charity is exempt from corporation tax on its charitable activities.

Fund accounting
Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity.

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Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Pension costs and other post-retirement benefits
The charitable company operates a defined contribution pension scheme. Contributions payable to the charitable company's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

2. DONATIONS AND LEGACIES

	31.01.25 £	31.01.24 £
Donations	16,229	18,566
Gift aid	1,891	3,744
Legacies	-	316,004
Grants	375,961	206,879
	394,081	545,193
Grants received, included in the above, are as follows:		
BBC Children in Need	-	44,571
Colyer-Fergusson Charitable Trust	12,333	14,800
John Ellerman Foundation	30,000	30,000
Garfield Weston Foundation	30,000	-
The Stonewall Park Charitable Trust	1,500	1,500
The Esmee Fairbairn Foundation	-	10,500
Pears Family Charitable Foundation	25,000	25,000
The Blagrave Trust	45,792	45,508
The Baily Thomas Charitable Fund	-	10,000
Paul Hamlyn Foundation	50,000	25,000
Masonic Charitable Foundation	19,485	-
The National Lottery Community Fund – RC England Wide	144,871	-
Alex Ferry Foundation	4,000	-
Skills for Care (ULO workshops)	12,980	-
	375,961	206,879

3. OTHER TRADING ACTIVITIES

	31.01.25 £	31.01.24 £
Fundraising activities	4,477	2,187

4. INVESTMENT INCOME

	31.01.25 £	31.01.24 £
Deposit account interest and other interest received	16,943	3,230

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Notes to the Financial Statements Continued
for the Year Ended 31 January 2025

5. INCOME FROM CHARITABLE ACTIVITIES

	Information and Support	Strategic Influencing	Sharing Best Practice	31.01.25 £ Total activities	31.01.24 £ Total activities
Contract and Other Non Grant Income	7,150	9,147	111,263	127,560	285,498

6. RAISING FUNDS

	31.01.25 £	31.01.24 £
Raising donations and legacies		
Staff costs	22,300	22,061
Fundraising	613	446
	22,913	22,507

7. CHARITABLE ACTIVITIES COSTS

	Direct Costs £	Support costs* £	Totals £
Information and Support	117,803	-	117,803
Strategic Influencing	126,626	-	126,626
Sharing Best Practice	272,108	-	272,108
Core Funding	48,944	4,988	53,932
*See note 8	566,481	4,988	570,469

8. SUPPORT COSTS

	Totals £
Core Funding	4,988

9. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	31.01.25 £	31.01.24 £
Auditors' remuneration	2,200	2,200

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Notes to the Financial Statements Continued
for the Year Ended 31 January 2025

10. TRUSTEES' REMUNERATION AND BENEFITS

One trustee received a total of £608 in expenses for the year ended 31 January 2025. There were no trustees' expenses paid for the year ended 31 January 2024.

One trustee received a total of £743 in expenses for travel and replacement care costs whilst carrying out voluntary work, not as part of their role as trustee.

No trustee or any person related to the charity had any personal interest in any contract or trustee transaction entered into by the charity during the year other than as disclosed above and in Note 15.

11. STAFF COSTS

No employee was paid over £60,000 in the year.

The average monthly number of employees during the year was as follows:

	2025	2024
Information & Support	4	5
Strategic Influencing	6	5
Sharing Best Practice	4	4
Core/General	5	5
Total	19	19
Total full time equivalent number of employees	13	12

12. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.01.25 £	31.01.24 £
Trade debtors	15,389	19,294
Other debtors	1,832	32
Gift Aid reclaimable	1,867	2,565
	19,088	21,891

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Notes to the Financial Statements Continued
for the Year Ended 31 January 2025

13. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.01.25 £	31.01.24 £
Trade creditors	14,747	5,299
Social security and other taxes	8,079	6,302
VAT	1,287	3,556
Funds held for other organisations	9,414	15,423
Accruals and deferred income	104,396	86,288
	137,923	116,868

Funds held for other organisations £9,414 (2024: £15,423) represents monies held by the charity where it is working with other charities on joint projects. At 31 January 2025 these are as follows:

Learning Disability Senate	£6,831
Employment Dissemination	£2,583

14. MOVEMENT IN FUNDS

	At 01.02.24 £	Net movement in funds £	At 31.01.25 £
Unrestricted funds			
General Funds	378,003	(12,098)	365,905
Training Designated Fund	21,541	1,494	23,035
The Jan Seamer Memorial Designated Fund	316,004	(32,434)	283,570
	715,548	(43,038)	672,510
Restricted funds			
John Ellerman Foundation	24,401	3,118	27,519
The National Lottery Community Fund – RC England Wide	-	44,927	44,927
The Baily Thomas Charitable Fund	6,000	(6,000)	-
CB-NSG	4,198	(4,198)	-
SHIEC	3,572	-	3,572
Asquith Legacy	2,792	(2,792)	-
National Lottery People's Project	20,105	(11,220)	8,885
Colyer-Fergusson Charitable Trust	2,314	(2,314)	-
The Blagrave Trust	23,638	2,937	26,575
BBC Children in Need	38,386	(38,386)	-
Paul Hamlyn Foundation	1,750	(30)	1,720
Masonic Charitable Foundation	-	6,675	6,675
	127,156	(7,283)	119,873
TOTAL FUNDS	842,704	(50,321)	792,383

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Notes to the Financial Statements Continued
for the Year Ended 31 January 2025

14. MOVEMENT IN FUNDS - CONTINUED

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General Funds	204,950	(217,048)	(12,098)
Training Designated Fund	22,650	(21,156)	1,494
The Jan Seamer Memorial Designated Fund	-	(32,434)	(32,434)
	227,600	(270,638)	(43,038)
Restricted funds			
John Ellerman Foundation	30,000	(26,882)	3,118
The National Lottery Community Fund – RC England Wide	144,871	(99,944)	44,927
The Baily Thomas Charitable Fund	-	(6,000)	(6,000)
CB-NSG	-	(4,198)	(4,198)
Skills for Care	12,980	(12,980)	-
Asquith Legacy	-	(2,792)	(2,792)
National Lottery People's Project	-	(11,220)	(11,220)
Colyer-Fergusson Charitable Trust	12,333	(14,647)	(2,314)
The Blagrave Trust	45,792	(42,855)	2,937
BBC Children in Need	-	(38,386)	(38,386)
Paul Hamlyn Foundation	50,000	(50,030)	(30)
Masonic Charitable Foundation	19,485	(12,810)	6,675
	315,461	(322,744)	(7,283)
TOTAL FUNDS	543,061	(593,382)	(50,321)

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Notes to the Financial Statements Continued
for the Year Ended 31 January 2025

14. MOVEMENT IN FUNDS - CONTINUED

Comparatives for movement in funds

	At 01.02.23 £	Net movement in funds £	At 31.01.24 £
Unrestricted funds			
General Funds	423,251	(45,249)	378,002
Training Designated Fund	27,772	(6,230)	21,542
The Jan Seamer Memorial Designated Fund	-	316,004	316,004
	451,023	264,525	715,548
Restricted funds			
John Ellerman Foundation	25,335	(934)	24,401
The Esmee Fairbairn Foundation	5,613	(5,613)	-
The National Lottery Community Fund – RC England Wide	38,716	(38,716)	-
The Baily Thomas Charitable Fund	-	6,000	6,000
CB-NSG	4,197	-	4,197
SHIEC	3,572	-	3,572
Asquith Legacy	3,199	(406)	2,793
National Lottery People's Project	27,395	(7,290)	20,105
Colyer-Fergusson Charitable Trust	1,568	747	2,315
The Blagrave Trust	17,282	6,355	23,637
BBC Children in Need	-	38,386	38,386
Paul Hamlyn Foundation	-	1,750	1,750
	126,877	279	127,156
TOTAL FUNDS	577,900	264,804	842,704

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14. MOVEMENT IN FUNDS - CONTINUED

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General Funds	297,571	(342,820)	(45,249)
Training Designated Fund	45,151	(51,381)	(6,230)
The Jan Seamer Memorial Designated Fund	316,004	-	316,004
	658,726	(394,201)	264,525
Restricted funds			
John Ellerman Foundation	30,000	(30,934)	(934)
The Esmee Fairbairn Foundation	7,501	(13,114)	(5,613)
The National Lottery Community Fund – RC England Wide	-	(38,716)	(38,716)
The Baily Thomas Charitable Fund	10,000	(4,000)	6,000
Asquith Legacy	-	(407)	(407)
National Lottery People's Project	-	(7,290)	(7,290)
Colyer-Fergusson Charitable Trust	14,801	(14,054)	747
The Blagrave Trust	45,508	(39,153)	6,355
BBC Children in Need	44,571	(6,185)	38,386
Paul Hamlyn Foundation	25,000	(23,250)	1,750
	177,382	(177,103)	279
TOTAL FUNDS	836,108	(571,304)	264,804

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Notes to the Financial Statements Continued
for the Year Ended 31 January 2025

14. MOVEMENT IN FUNDS - CONTINUED

A current year 12 months and prior year 12 months combined position is as follows:

	At 01.02.23 £	Net movement in funds £	At 31.01.25 £
Unrestricted funds			
General Funds	423,251	(57,346)	365,905
Training Designated Fund	27,772	(4,737)	23,035
The Jan Seamer Memorial Designated Fund	-	283,570	283,570
	451,023	221,487	672,510
Restricted funds			
John Ellerman Foundation	25,335	2,184	27,519
The Esmee Fairbairn Foundation	5,613	(5,613)	-
The National Lottery Community Fund – RC England Wide	38,716	6,211	44,927
CB-NSG	4,197	(4,197)	-
SHIEC	3,572	-	3,572
Asquith Legacy	3,199	(3,199)	-
National Lottery People's Project	27,395	(18,510)	8,885
Colyer-Fergusson Charitable Trust	1,568	(1,568)	-
The Blagrave Trust	17,282	9,293	26,575
Paul Hamlyn Foundation	-	1,720	1,720
Masonic Charitable Foundation	-	6,675	6,675
	126,877	(7,004)	119,873
TOTAL FUNDS	577,900	214,483	792,383

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Notes to the Financial Statements Continued
for the Year Ended 31 January 2025

14. MOVEMENT IN FUNDS - CONTINUED

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General Funds	502,521	(559,867)	(57,346)
Training Designated Fund	67,801	(72,538)	(4,737)
The Jan Seamer Memorial Designated Fund	316,004	(32,434)	283,570
	886,326	(664,839)	221,487
Restricted funds			
John Ellerman Foundation	60,000	(57,816)	2,184
The Esmee Fairbairn Foundation	7,501	(13,114)	(5,613)
The National Lottery Community Fund – RC England Wide	144,871	(138,660)	6,211
The Baily Thomas Charitable Fund	10,000	(10,000)	-
CB-NSG	-	(4,197)	(4,197)
Skills for Care	12,980	(12,980)	-
Asquith Legacy	-	(3,199)	(3,199)
National Lottery People's Project	-	(18,510)	(18,510)
Colyer-Fergusson Charitable Trust	27,134	(28,702)	(1,568)
The Blagrave Trust	91,301	(82,008)	9,293
BBC Children in Need	44,571	(44,571)	-
Paul Hamlyn Foundation	75,000	(73,280)	1,720
Masonic Charitable Foundation	19,485	(12,810)	6,675
	492,843	(499,847)	(7,004)
TOTAL FUNDS	1,379,169	(1,164,686)	214,483

The Training Designated Fund represents funds set aside by the trustees to invest in CBF's capacity to deliver training and help diversify the charity's income.

The Jan Seamer Memorial Designated Fund is to be used to reflect Jan Seamer's support of CBF and designated for the specific purposes of promoting the sustainability of CBF and to fund development opportunities that cannot be funded elsewhere.

15. RELATED PARTY DISCLOSURES

Two trustees received remuneration and out of pocket expenses totalling £170 for their roles in Patient and Public Inclusion and Engagement (PPIE) in research projects, by sharing their lived experience of caring for an individual with severe learning disabilities whose behaviour is described as challenging.

Dr K Jankulak received £100 remuneration and £15 expenses.
Mrs K Sanger received £50 remuneration and £5 expenses.

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www.challengingbehaviour.org.uk Tel. 01634 838739
Registered charity no. 1060714.
Reg office: The Old Courthouse, New Road Avenue, Chatham, Kent ME4 6BE

THE CHALLENGING BEHAVIOUR FOUNDATION

England & Wales - Charity number 1060714

Accounts

The Challenging Behaviour Foundation

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

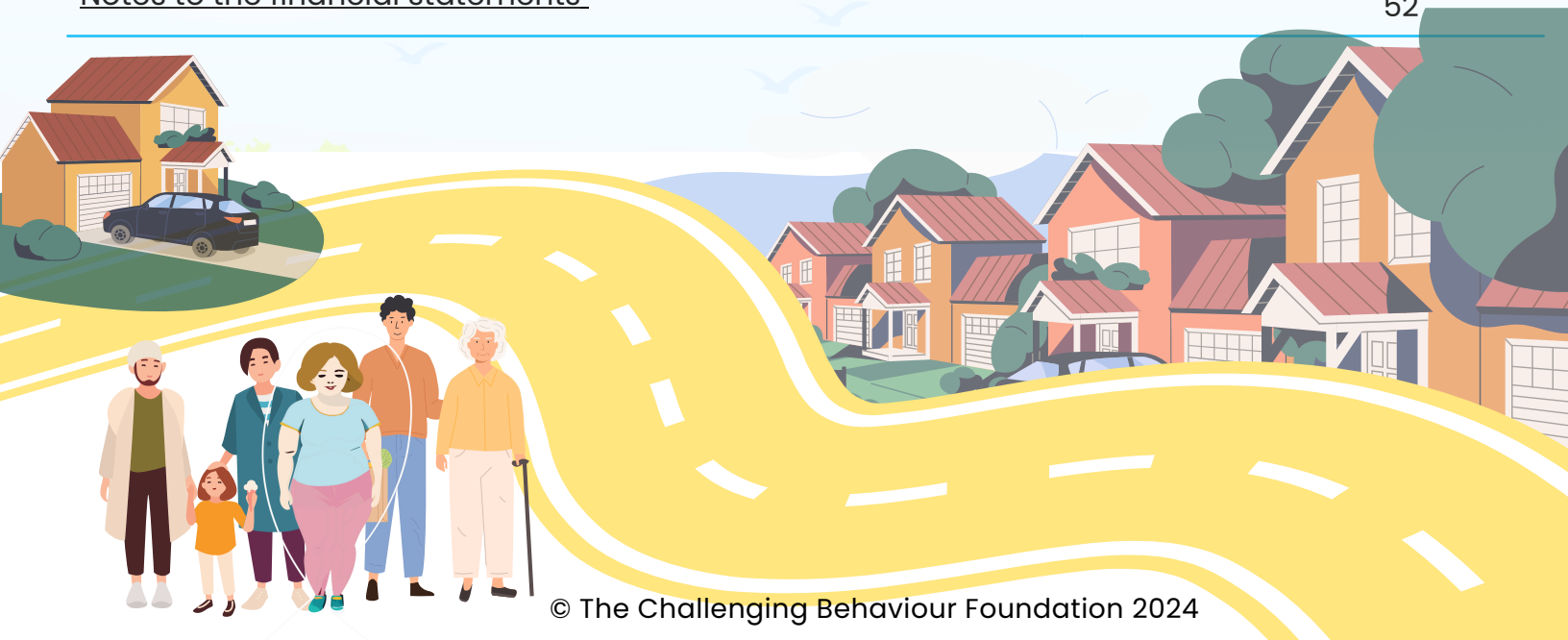
ANNUAL REPORT

2023–2024



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Foreword

From our Chair, Dr David Allen

It's a huge honour and privilege to have recently taken on the position of Chair of Trustees of this remarkable charity. My experience of the CBF goes back to 1999, when I was asked to write a commentary on an article that our CEO, Viv, published in the Tizard Learning Disability Review about how services had essentially failed her son, Daniel. Our paths have crossed many times since because, although starting from different points, we were on the same journey of trying to ensure the best possible quality of life for children and adults with severe learning disabilities and complex behavioural challenges. As a clinical psychologist and academic who was also an NHS senior manager, the CBF acted as a beacon of good practice and had a set of values and objectives that perfectly matched my own. It was both a safe haven and an inspiration as it always reminded me that, when battling organisational systems seemingly designed to make you give up, we should never accept 'No' for an answer.

My predecessor, Diane Lightfoot, has set a high bar in terms of how our chair should operate and will do my utmost to match the standards she has set. All our thanks are due to Diane for the commitment and expertise that she has shown as chair over an incredible period of ten years. Big shoes to fill doesn't really cover it, but I'm blessed to inherit a Trustee Board which is a fantastic blend of family carers and expert professionals.

We're a small organisation but one whose impacts are completely disproportionate to our size. The volume and breadth of activity described in this report is testament to that. We know that it's long, but please do take the time to read it. Even if you think you're familiar with all that the CBF does, I guarantee that at some point you will think "Wow! I never realised that the CBF did that!" As trustees, we are routinely astonished what our team and volunteers achieve and appreciative of how much this is valued from the feedback received from those we support.

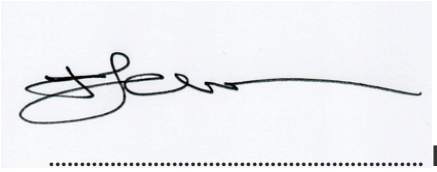
Family carers are embedded within the CBF and its work and is pivotal to our work and the impact it has. I would like to pay particular tribute to the late Jan Seamer who supported the CBF from its early beginnings and who has left the CBF a generous legacy fund. This fund is designated in her name to ensure the sustainability of the charity and its work with families, an approach which she worked tirelessly to promote. She demonstrated the importance of working with families as equal and valued partners, dedicating her time and expertise to really make a difference to the lives of many people. She is greatly missed. **CBF tribute to Jan Seamer: https://www.challengingbehaviour.org.uk/news/family-carer-workshops-and-tribute-film-in-memory-of-jan-seamer/**

To misquote Voltaire, if the CBF did not exist, it would be necessary to invent it. Our strategic aim as a charity is to work towards the day when we're no longer needed because all the supports that children and adults with severe learning disabilities and challenging behaviour deserve are routinely, reliably, and comprehensively available. In recent times, that day has seemed to be retreating rather than coming closer. The work that we do will therefore remain important for some time to come and much remains to be done. We are therefore deeply indebted to everyone who helps to make it happen in a big or small way. Without you, there would be no CBF.

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Thank you to everyone who has made a difference this year.



..... **Dr David Allen, Chair of Trustees**

"The CBF is such a huge achievement and..... such an influential advocate and expert voice for people with challenging behaviour, their families and the wide network of services which should in theory support them. The CBF is a powerful force to be reckoned with on the national agenda."

"We all owe a huge thank you because you have done so much to raise the profile of the people and the families who live with challenging behaviour and to change attitudes and expectations at a time of (sadly) decreasing resources. And, most importantly and not least, you have always been wonderful in seeing, engaging and listening to the families like mine, who are so easily overlooked as they desperately try to create good lives for their children."

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Report of the Trustees

For the year ended 31st January 2024

The Trustees who are also the directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31st January 2024. The Trustees have adopted the provisions of the Statement of Recommended Practice (SORP) 'Accounting and Reporting by Charities' issued in 2015.

Objectives and Activities

Objectives and aims

The Challenging Behaviour Foundation (CBF) exists to improve the quality of life of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families.

Our Values

Inclusion – We embrace diversity and actively ensure every perspective is sought, valued, and included respectfully and with dignity, promoting connections and collaboration.

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 (e.g., through accepting funding from a particular source) and we retain our core focus 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 well-being of individuals with severe learning disabilities and their families with passion and dedication.

Learning through experience - We record, reflect and learn from our work and its outcomes to improve and amplify our impact.

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

Our mission is to make a difference to the lives of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families by: -

- Championing their rights
- Providing timely information and support
- Raising awareness and understanding
- Promoting and sharing best practice

We are the **only** UK charity **focussed specifically** on the needs of children, young people and adults with a severe learning disability whose behaviours may challenge, their families and those who care for them.

What is Challenging Behaviour

The term 'challenging behaviour' first came into widespread use in the UK through a publication by the King's Fund Centre. This clearly explained that the term emphasises: '....that such behaviour represents challenges to services rather than problems that individuals with learning disabilities in some way carry around with them'. If services could rise to the "challenge" of dealing with these behaviours, they would cease to be "problems." The term challenging behaviour places the focus of discussion on services rather than on the individuals showing the behaviours.'

The NHS estimates that there are over 30,000 people in the UK who have a severe learning disability and are at risk of developing behaviours that challenge. A person with a severe learning disability will have little or no speech, find it difficult to learn new skills and need ongoing support to carry out daily activities such as washing and dressing.

Challenging behaviour has a **formal definition (www.challengingbehaviour.org.uk/understanding challenging-behaviour)**



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and is a term used to refer to a variety of behaviours which some people with a learning disability may display. These behaviours vary and include aggression, eating inedible objects, severe self injury or significant obsessive repetition, typically putting the safety of the person or others at risk and/or restricting their access to ordinary life opportunities.

Without appropriate support, children, young people and adults with severe learning disabilities whose behaviour may challenge find themselves at greater risk of poor healthcare, poor life prospects and at greater risk of abuse. Families often find themselves isolated from their local community, unsupported by local services and separated from their relatives. Our work focuses on family-led carer support and adopts a Positive Behaviour Support (PBS) approach**.** **https://www.challengingbehaviour.org.uk/information-and-guidance/positive- behaviour-support/pbs-your-questions/**

> ***People whose behaviour challenges have the same needs as everyone else, in addition to special needs for help to overcome the problems their behaviour presents. They do not surrender their needs for personal relationships, for growth and development or for anything else because their behaviour presents a challenge to services. They have the same human rights as everyone else.***
>
> ***– Mansell 2, 2007***



Our objectives are to ensure that with good support each individual can live a happy, active life in their community with access to healthcare, employment, leisure and education, as well as a fulfilling family life. Our focus is enabling children, young people and adults to exercise their rights to participate in ordinary life opportunities through a proper understanding of their behaviour and access to appropriate support.

To meet these objectives, we have identified and prioritised three interconnected main areas of need: **'information and support'**, **'strategic influencing'** and **'sharing best practice'**, as described below in more detail. We build on, refine and enhance our work in these three areas as they have shown to be effective. More information about the work of the charity can be found on our website.

www.challengingbehaviour.org.uk



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How we work

As a small charity with limited resources, we carefully consider the impact of our work. Our Theory of Change work identified four key communities across the lifespan where we can have the greatest impact on people's quality of life, and we will focus our work around these groups. These are:

- Early years – early intervention and prevention
- Transition – moving from child to adult services
- Older family carers – planning ahead
- Risk of crisis (at any age) – supporting families to get additional support to meet their relatives needs

We will particularly focus on these throughout our three areas of work: **'information and support,' 'strategic influencing'** and **'sharing best practice'** and explore new ways to measure our impact.

Lived experience is embedded within the organisation and informs and shapes all our work. All our training workshops are co-produced and co-delivered by a PBS practitioner and a family carer with lived experience, modelling the partnership approach we promote.

As an organisation we prioritise families' needs over administrative convenience. The range and scope of our work is wide as it reflects the breadth and complexity of the systems and services that families must navigate through to secure the support, they and their relative needs.

We adopt a lifelong human rights approach across education, health, and social care, using legal, policy and best practice frameworks to drive change at an individual and strategic level.

More can be achieved by working together. Although our focus is on supporting families, we know that working collaboratively with a range of other partners can achieve good outcomes. We therefore provide a range of information and support to professionals and families involved in supporting children and adults with severe learning disabilities whose behaviour challenges. This year we have co-produced new resources with family carers including setting out how we at the CBF work with families in co-production along with good practice examples: **https://www.challengingbehaviour.org.uk/what-we-do/sharing-best-practice/co-production/**

In all our work, our approach is one of 'working with – not doing for' as this shares knowledge and skills and promotes a sustained legacy. This is in alignment with our long-term goal which is there is no need for the CBF to exist because the system works for children, young people, adults, and their families to deliver the right support in the right place at the right time. It is this ultimate goal that shapes everything we do.

> ***''Nothing is ever done without us' - This is key to the CBF's mission statement, and above all with a restorative, 'How can we help' ethos. When systems are broken, people get broken, the CBF and their members help each other to mend, heal and thrive.' Family Carer***

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Internships at the CBF

This year we have again been able to offer an internship at the CBF. We have now had thirty-two paid internships since 2011 covering Family Support, Policy, Research and Communications. Each internship is for one year and provides valuable experience in learning disability, working with a range of professionals in the field, and gives insight into the experience of family carers. Our Interns are paid the Real Living Wage.

Previous CBF interns have gone on to:

- Senior policy and communications roles in the voluntary and public sector
- Practitioner roles such as: social work, learning disability and mental health nursing and special needs teaching
- Further study at Masters and PhD level in related fields and to secure work as a Postdoctoral Researcher in the field of learning disabilities

We continue to have discussions to explore the development of our intern scheme through partnering with an academic centre and a support provider but due to capacity and other priorities we have not been able to progress this further. We remain hopeful that this is something we will be able to do in the future.

> ***"The internship at the CBF provided a unique opportunity to collaborate with professionals in health, social care, education, and research I would not have encountered otherwise. Throughout the internship, I have gained valuable knowledge about learning disability and developed transferable skills. I had the chance to contribute to various charity and research projects. The welcoming and supportive environment at the CBF put me at ease from day one, allowing me to openly discuss any questions or concerns with my colleagues. I am grateful for the opportunity to be part of such a fantastic team. I highly recommend this internship to anyone passionate about learning disabilities who wants to make a meaningful difference in the lives of individuals with learning disabilities and their families." – CBF Intern***

Objectives and activities

Information and Support



Lived experiences gathered from our information and support service drives our strategic influencing work which interconnects with sharing best practice.

Our family support service offers a range of free, confidential, and expert resources to families including support delivered through:

- telephone helpline
- ongoing in-depth casework
- email information

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- printed and filmed resources on a range of topics
- website information
- peer support networks including 'listening ear' calls with trained family carers, email networks, closed Facebook group and online carer catchups.

Further information on our family support service can be found here: https://www.challengingbehaviour.org.uk/for-family-carers/

Information for professionals can be found here: https://www.challengingbehaviour.org.uk/for-professionals/



"Thank you for all the literature and support I have received through your magazine over the last couple of decades - it has been a great support emotionally and very informative on so many topics. - a huge thank you" – family carer

"Thank you, as always, for your invaluable help and support. It makes a huge difference to know we have this informed help and that you 'have our backs" – family carer

"Your resources are written so well, I didn't expect to find so much detailed information which I enjoy reading and find very useful, I really like and appreciate your holistic approach and describing challenging behaviour in a gentle helpful way, not scaring parents/carers" – family carer

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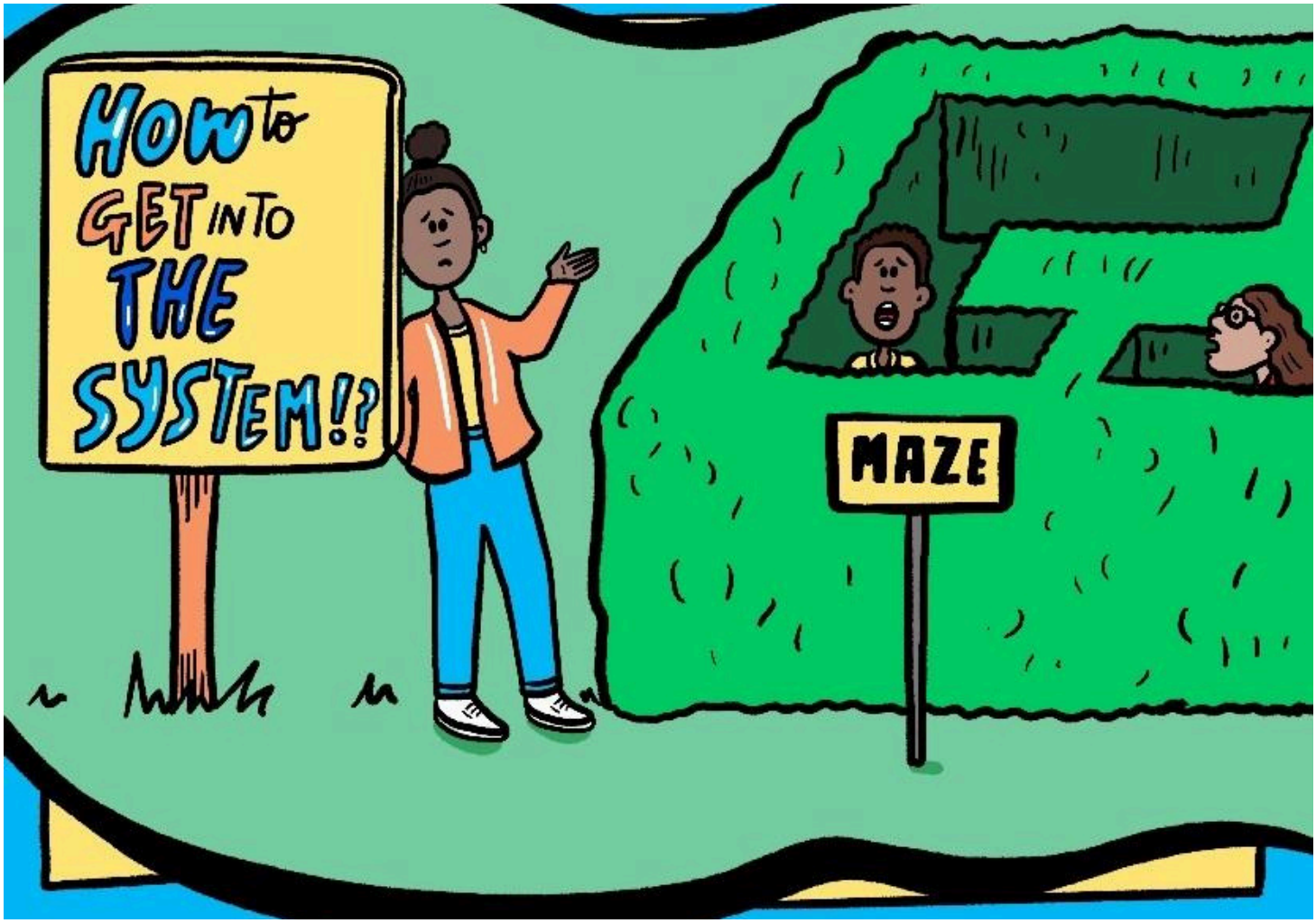
Strategic Influencing



Our strategic influencing work is informed by families lived experience gathered through our family support team and utilises examples of evidence-based best practice.

Our strategic influencing work focusses on ensuring all parts of a complex system work well and deliver good outcomes for children, young people and adults with severe learning disabilities whose behaviour challenges and their families.

This work requires an understanding of the holistic context in a system that is often organisationally disjointed and fragmented.



There are numerous individuals and organisations working within the sector and we work hard to identify and work with them to develop good relationships and facilitate and promote collaborative working and co-production.

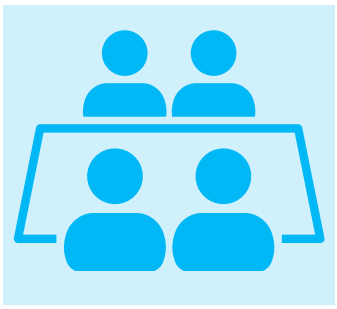
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We are solution focussed, believe more can be achieved by working together and facilitate joined up and collaborative working. We established and continue to chair the influential 'Challenging Behaviour - National Strategy Group' (CB-NSG), a unique multi- stakeholder group whose members include family carers, senior representatives from health, education and social care, government departments, regulators, service providers, clinicians, and researchers. **https://www.challengingbehaviour.org.uk/what-we-do/national-strategy- group/**



We promote and highlight the need for an early intervention approach, to work with and invest in families as valued partners, and with full and meaningful co-production.






'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

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In partnership with others, we work to find ways to seek the views and input of children, young people and adults with the most complex needs and share and promote their engagement. We have developed positive relationships with researchers to amplify the voice of families of individuals with severe learning disabilities in research, and we support families to input to national policy making and service development. Our work aims to push forward the agenda for better and timely local provision, investment in supporting families and promotion of enhanced skills and training for support workers and paid carers.

> ***"Thank you very much for this, they are such a great group, they have just blown us away during this project! Please do pass on our thanks" - Researcher***

Objectives and activities

Sharing best practice



Sharing best practice is embedded in our strategic influencing work and our information and support. Best practice provides evidence that **it is entirely possible to deliver the right support in the right place at the right time.**

Sharing, modelling and actively promoting best practice on the ground runs through all our work. We do this through our family support casework and resources, strategic influencing work, and family carer and professional email networks, as well as through specific projects involving local authorities, government departments, and other partners.

We have invested additional capacity, using our reserves, to support, build on and deliver best practice learning from our project work. We continue to work with local family carers and stakeholders in specific geographic areas to provide additional resource, capacity, and experience to empower local families and facilitate their input at a strategic level.



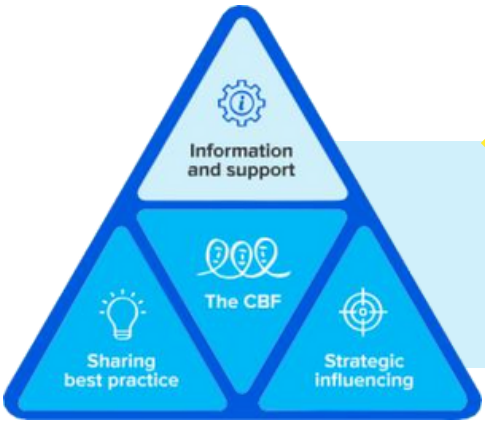
> ***The knowledge I have gained is priceless and will ensure I improve my practice – workshop participant***
>
> ***Very informative and also eye opening to see things from the parents perspectives – workshop participant***

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Public Benefit

In planning and reviewing the charity's activities to meet these objectives, the Trustees have taken account of the Charity Commission's guidance on public benefit. The CBF delivers public benefit by providing information and support to families and professionals caring for and supporting children, young people and adults with severe learning disabilities whose behaviour challenges. All our information and support is provided free of charge to family carers. We also work to improve the understanding of behaviours that challenge amongst professionals and the wider public, helping others to provide better support and services and more opportunities.

Achievements and Performance



Achievements and Performance

Information and support

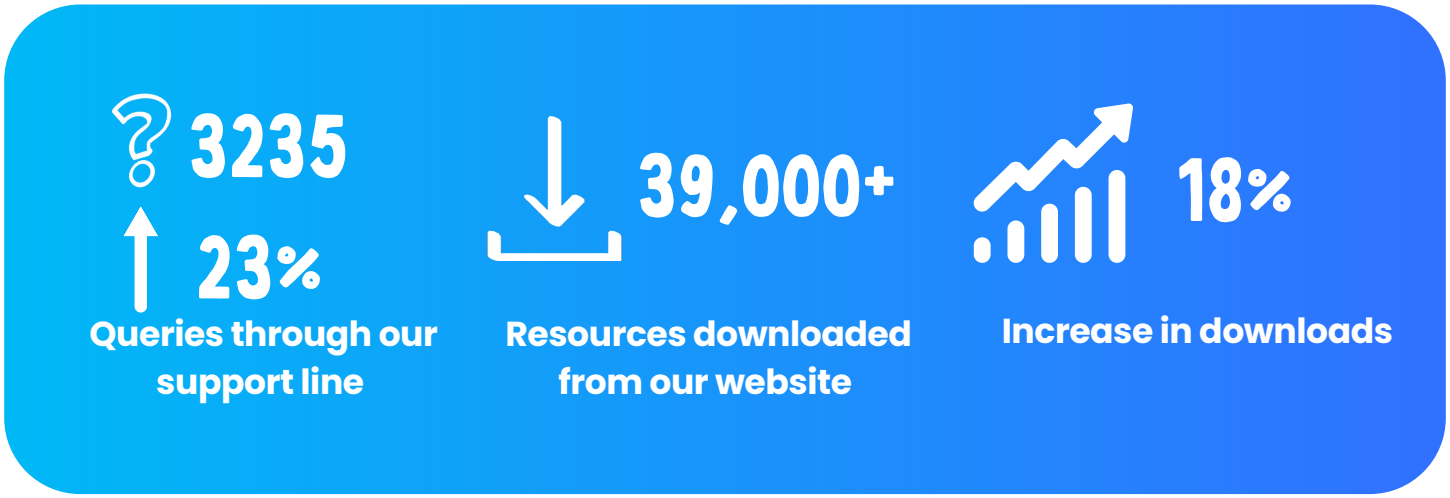
> ***"I just wanted to say I am so blown away by the amount of support and knowledge this network has, and everyone is always so willing to help" – family carer***

Family Support

Our family support service has responded to 3235 queries through our support line, email and website this year which is a 23% increase on the previous year.

We had over 39k resources downloaded from our website, an 18% increase from last year. The large amount of information available on our website ensures that the families we support have 24-hour access to information around the key issues that impact on their lives. Our family carer review panel and professional volunteers help us to review and update our resources, to ensure they are current and helpful.

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Family carers who contact the CBF may need differing levels of support and information, and are initially triaged. The triage role continues to be an efficient way of prioritising and signposting enquiries and access to specialist caseworker support. Family carers who contact the CBF may be offered a range of free resources (https://www.challengingbehaviour.org.uk/information-and-guidance/) which can be emailed or downloaded from the website. We are aware that a proportion of the families we support are digitally excluded and therefore we adjust to ensure they receive our information and support. If required, our resources can be posted out as some families may have limited access to IT.

Some family carers will need to speak to an experienced family support team member about a specific issue or query which may take the form of one or two calls/emails. Other family carers may have more complex situations and will require more ongoing casework support which can range from three calls/emails to ongoing support spanning months or years. This level of ongoing support reflects the complexity of the situations that families are managing for their relative which can include significant health issues, concerns over care and support, rights and the law, financial disputes around the funding of the support package, safeguarding, transition and being served 28 days' notice to leave current provision.

Families are trying to navigate all these issues against the backdrop of a cost of living crisis and cuts to services.

Families approaching us with these multiple complex issues often require intensive casework over a long period. The average period of support is four months with some families returning over many years for further support as new issues emerge. To meet the diverse needs of the family carers we support we offer translation services via Language Line and share relevant information from other organisations as appropriate.

> ***"If it wasn't for the help of CBF, I wouldn't know how to help my son get discharged and his quality of life would have significantly declined. Since CBF's involvement, my son is a lot happier, he is able to speak properly and go out and about with carers. I really owe it to the staff at CBF for all that they have done for me and my son."***

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Case Study

P's family had purchased a property for P to live in. They intended for D, P's lifelong friend to move in to live with him as they had been separated when their old care home closed down during the pandemic. The process was delayed and initially the CBF supported P's mum to request a Best Interests meeting to decide whether he should live in the bungalow.

It was decided it was in P's best interests but the Local Authority (LA) were unwilling to pay for the model of support that P would need in the bungalow from a provider the family had found. The CBF caseworker supported the family to attend meetings and it looked as if things were progressing. However, the LA then changed their position.

A referral to a solicitor was made and a letter before action was sent. Following some initial time consuming reassessments, a Commissioner was bought on board to look at the case. Within 12 days P was moved into the bungalow with support provided by the preferred provider.

The CBF are providing ongoing support to D's family, and it is hoped that they will also move into the property this year.

The CBF's support has encouraged the professionals involved to 'think outside the box' when arranging support to ensure that P and D's Human Rights are upheld, and that support is truly person centred.

Legal Panel

The Legal Panel of specialist legal experts representing all the leading law firms specialising in learning disability law, convened and chaired by the CBF, continues to provide valuable expertise and support on a voluntary basis. We continue to play a vital role in enabling and supporting families to be aware of the legal framework and to access legal advice and support to take appropriate action. During the year we have referred a number of families to the panel. They received the specialist legal support required to take their issues forward or were given support specific to their circumstances. (See page 21 for further information about the strategic work of the Legal Panel)

> ***"...when you call, they (CBF) answer immediately and provide support and guidance when you need it most, all for free and with empathy and a vast knowledge about multiple issues. They have sent me so much information via post and been a listening ear when we have been through a really traumatic time in the last few months." – Family Carer***

Peer Support

Families report feelings of isolation – and that peer support is incredibly valuable and helps to address this. We continue to support range of initiatives that provide different types of peer support to meet the varying support needs of families who contact us
https://www.challengingbehaviour.org.uk/for-family-carers/peer-support/

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> ***"I wanted to say that I love this network, and the Challenging Behaviour Foundation. What a gift! I so love all of this.! It's the behaviours that challenge that I want advice and guidance with, and this network is perfect. It is really encouraging to hear from parents whose children are now in their 20s and 30s and the parents are now real pros at this. – Family Carer***

Our peer support includes:

Listening Ear calls We continue to support committed family carers who offer listening ear calls to our families. These are opportunities for families to speak to people who understand and are non-judgmental. The feedback has been extremely positive.

> ***"I enjoyed having a conversation with her, we spoke for 45 minutes and would have carried on. Thank you for introducing me to the Listening Ear service, good to know this session is available whenever I need one". – Family Carer***

Email Networks

Our family carer email network now has around 520 members and continues to be regularly used with 350 questions and responses circulated on 132 different topics. This forum continues to enable families to ask one another questions, share solutions and seek support around issues impacting their daily life, support package or relative's behaviour that might be described as challenging.

Families can also ask our Professional Panel questions via our professional email network, a network of around 1200 practitioners from across the health, education and social care sectors who also use this forum to share information, learning and asking their peers questions to support their work and disseminate good practice. This year 76 questions and responses were circulated on thirty-four different topics.

Carers Catch up

During the pandemic, we started online carer catch up group meetings. These are led by a volunteer CBF Local Champion and provide an opportunity for family carers to meet online to share experience and support their wellbeing as we know that most families who contact us describe feelings of isolation. Now that the pandemic has passed, we continue to facilitate these groups and working with families we plan to develop some themed carers catch up meetings. We are reviewing feedback and consulting families about what they find helpful and useful as part of our ongoing review of our support and impact.

The CBF Family Forum (closed Facebook group)

This forum continues to enable family carers to support each other in 'real time.' Currently the group has around four hundred members and membership is limited to individuals with a relative with severe learning disabilities to ensure that the group is an understanding and empathetic forum. The group is monitored for safeguarding concerns by volunteer family carer local champions supported by CBF staff.

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***I'd also like to take the opportunity to thank you and the CBF team. They have been a wonderful support to us and the CBF network has made us feel that there are people out there who understand M's disabilities and are on his and our side.* - Family Carer**

Helpline Collaboration

The CBF, in response to our understanding that families often get passed to several helplines and charities before they find the right one for them, continues to convene and facilitate a Helpline Collaboration made up of a range of organisations that run helpline support for families of people with learning disabilities. Meetings happen once a month via Teams, and we share information about each of our services and resources, identify common issues coming to us from families and provide peer support to each other, which is especially appreciated by those who attend. This year we delivered our Trauma Awareness training workshop to the helpline collaborative as a way of sharing knowledge and best practice.

Challenge Accepted (CBF podcast)

With generous funding from the Colyer Fergusson Charitable Trust we were able to produce a series of six podcasts focused on the wellbeing of family carers living in Kent. Episodes included a mix of families speaking about their lives caring for their relative, describing what they do to support their own wellbeing and information about support available with a focus on promoting carers assessments. The podcast has been downloaded 531 times with 'Another Way of Not Meeting People', a conversation between three family carers about their experiences, being the most popular episode. This was closely followed by 'So much of life is I'm terribly sorry, I'm so sorry' which included a conversation with the writers of the BBC show 'There She Goes' who have a teenage daughter with severe learning disabilities. A special Christmas episode was also well received.



Achievements and Performance

Strategic Influencing

As a small organisation we can achieve much more by specifically informing and encouraging individuals and organisations in positions of power and influence to raise their understanding and awareness of the issues individuals and families face, and to influence their activity. We aim to promote collaboration to drive progress. The three strands of our work are inextricably linked and closely aligned. In practice the family carer experiences via our helpline and casework steer our influencing work. We continue to raise concerns and challenges to a range of senior individuals and organisations both at a local and national level where individuals' human rights are being breached.

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The "system" which is there to support individuals with severe learning disabilities whose behaviour challenges, and their families, is complex, disjointed and difficult to navigate. Families have to identify support through education, health and social care- which is divided between child and adult support with different eligibility criteria and regional variations. The legal and regulatory systems provide further levels of complexity. Our strategic work is therefore wide-ranging and varied and aims to influence all parts of the complex system which is meant to be working in a coordinated way to deliver good outcomes to children, young people and adults and their families.



Challenging Behaviour National Strategy Group (CB-NSG)

We are very grateful to the John Ellerman Foundation and Paul Hamlyn Foundation for their continued support and funding towards the National Strategy Group and its work. The CB- NSG includes representatives from professional bodies, networks, charities, and the government alongside family carers, people with learning disabilities and researchers, who are all equal partners in the group. It is based on the principle that if all the individuals and organisations who have a role to play in supporting this group work together in a coherent and coordinated way it will deliver better outcomes. **https://www.challengingbehaviour.org.uk/what-we-do/national-strategy-group/** There are currently over ninety core CB-NSG members who have significant knowledge and expertise or lived experience, and / or a senior level role in supporting and delivering services to people with learning disabilities, and over six hundred associate members who commit to working following the values and principles of the co-produced Challenging Behaviour Charter.

> ***"You had a good balance of family members and professionals. There was a great deal of expertise at the meeting and people who felt passionate to make a difference. The current system is so difficult to change, and we are definitely stronger together."***
>
> ***"Thank you for getting us all together to think about life changing decisions and policies."***
>
> ***"I wish to place on record my thanks to the CBF team and policy staff for organising and delivering such a worthwhile event."***

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Co-produced lifelong Action plan

Work has continued on the co-produced, lifelong action plan that was started at the Campaign Families day (September 2022) and which has been built on since, including at the CB-NSG meetings. CBF staff presented the work that has been done so far at a parliamentary reception for Learning Disability Week, sharing this work with parliamentarians and other key stakeholders. Work has also been underway to gain input from wider stakeholders outside of the CB-NSG to ensure that this plan is properly co-produced, including work to gain the input of people with a learning disability.



Campaigns Sub-group (including Campaign Families)

CB-NSG members continue to meet regularly to share information about policy and practice and agree campaigning priorities, including aligning with, and supporting activities by other individuals and organisations. Over the past year the Campaign Families group have taken part in a range of influencing activities:

- Provided input to multiple consultations including Mental Health Act Consultation activities
- Participated in the All-Party Parliamentary Group Meetings
- Agreed campaigning priorities for the coming year including campaign work in the run up to the government missed target of reducing the number of people with a learning disability and autism in inpatient units by half by the end of March 2024

We have initiated and convened meetings of a collaborative group of charities that campaign in this area to meet and share campaign activity and timetables. The aim is to ensure our work is coordinated and complimentary- and to share each other's campaign work to amplify the messages.

Legal Panel Sub-group

We continue to maintain our established legal panel consisting of specialist lawyers and barristers who provide pro-bono information and support to families who contact our family support service. The aim is to ensure free initial access to timely specialist legal advice with the CBF supporting the family through this process. This year, we continued to take forward the strategic legal work identified by our legal panel and built on our collaborative working relationship with key experts in the legal field. Highlights include:

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- Continuing to provide legal advice to families referred from and supported through our family support team
- Planning and contributing to a wider legal strategy meeting with families, advocacy organisations and providers to identify key issues, share resources and co-ordinate activity
- Continuing to take an interest in legal opportunities to challenge the failure of the 'Transforming Care' programme and to work with other organisations who share our concerns

The legal panel members continue to work together to consider and address key areas of legal challenge both related to the inequalities for people with learning disabilities which have arisen because of the cost of living crisis and the ongoing inequalities due to failures in Transforming Care.

Positive Behaviour Support/Research Sub-group

This group has appointed co-chairs and will link together some key research initiatives with CB-NSG member involvement including the PBS academy, Sharland Foundation Development Disabilities ABA Research and Impact Network (SF-DDARIN) and the Tizard Centre. Plans are in place to commence this working group.

Data Sub-group

We remain concerned about meaningful data collection- and how it is analysed and used to inform policy and practice in "the system."

The group has continued to focus on reviewing and using the data published by NHS England (NHSE) and the Care Quality Commission (CQC), particularly regarding unit characteristics, a regional breakdown of patients currently receiving inpatient care who do not need it according to their care plan, along with further details about individuals working towards discharge. The group members provided input to a researcher studying the data collected by the CQC and whether it could be used to predict poor or abusive care in services, sharing their insights in two meetings.

The data group has continued to highlight the need for improved data collection across children, young people and adults with NHS Digital around the Assuring Transformation and Mental Health Services Data Sets. This work is linked to the campaign group work, and in partnership with Mencap we continue to produce and share regular infographics setting out the data about inpatients.



Housing Sub-group

This has included working closely with NHSE Strategic Housing Lead for Learning Disabilities and Autism at NHS England to feed into their work to develop a housing strategy for people with a learning disability and autistic people. Housing Group members, have also linked in with the 'National Housing Community of Practice', a group organised by NHSE in conjunction with the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS).

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Other strategic influencing

Protecting Rights: Eliminating Restraint Group (PR:ERG)

Formerly known as the Reducing Restrictive Interventions and Safeguarding Children (RRISC) group, this group focusses on children and takes a UK-wide approach with members from all four nations. The group has continued to meet twice a year sharing progress and initiatives to drive change across the UK. Additionally, the group met to input to the Department for Education Call for Evidence on the Use of Restraint in Schools. This meeting was attended by a wide range of stakeholders from the PR;ERG group and officials for the Department for Education. Over the next year we will continue to work to ensure that the government upholds its commitment to introduce a legal duty to record and report restraint to parents in England.

The External Support Group (ESG)

The External Support Group (ESG) brings together a number of individuals with significant practical experience in supporting people with complex needs in community settings, including developing individualised packages of support and maintaining that support to provide good outcomes for individuals. Areas of expertise in the group include experience in clinical/medical practice, commissioning, inspection and regulation, research and evidence, advocacy, the third sector and family support. A co-produced animation of the work of the ESG is here: **External Support Group (ESG)** **https://www.challengingbehaviour.org.uk/what-we-do/projects-and-research/support-and-services/the-external-support-group-esg/**

ESG members have agreed to review and reflect on the work of the ESG so far, and a report with recommendations has been produced which will be taken forward in the coming year.

STOMP/STAMP

The STOMP (Stopping Over-Medication of People with a Learning Disability, Autism or Both) STAMP (Supporting Treatment and Appropriate Medication in Paediatrics) programmes are initiatives within NHS England (NHSE) to try to address the issues around medication. We provided a short report from family carers of their experiences of the impact of STOMP and STAMP. This highlighted the need for greater progress and included recommendations for the next steps which NHSE are still considering.

Older family Carer work

We have worked with older family carers to hear their experiences, which has enabled us to identify what specific issues older family carers face, and what support they need. We have worked with family carers to use what they have told us to begin to pilot a resource which aims to help family carers plan for the future and offer peer support alongside using the resource.

National safeguarding review

This review was commissioned following abuse exposed at Hesley Services, providing 52 week residential school provision for children and young people with complex needs. It was led by Dame Christine Lenehan at the Council for Disabled Children who produced two reports. The CBF provided input in multiple ways during the review and including ensuring that family carer experiences were gathered as part of the development of the recommendations. The CBF also suggested contributors for round table events to review the findings and contribute to the recommendations within the final report. **CBF input to Child Safeguarding Review**: **https://www.challengingbehaviour.org.uk/news/child-safeguarding-practice-review-panel-publish-phase-2-report-into-hesley-group-settings/**

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Sharing Best Practice

The principle of sharing and actively promoting best practice runs through all aspects of our work. We share and promote best practice through our family support work, including casework and resources, and our national influencing work. This includes disseminating information via the CB-NSG, its core and associate members, our family carer and professional email networks as well as our extensive networks. We are invited by researchers to contribute to a range of projects which vary from recruiting members to advisory or reference groups to leading Public and Patient Involvement (PPI) facilitating focus groups with family carers to ensure their input to the research and its dissemination and supporting recruitment to trials.

Workshops

All our workshops have been co-designed with families on topics where they have identified gaps in knowledge and understanding. The workshops are co-produced and are co-delivered with family carers, modelling the partnership working approach we promote.

Our range of workshops include:

- Trauma Awareness
- Pica behaviour
- Whole Family Approaches
- Positive Behaviour Support (Understanding challenging behaviour and supporting behaviour change)
- Communication and challenging behaviour



We continue to recruit, train and support co-facilitators with in-built evaluation and quality monitoring procedures and provide additional support to family carers delivering the workshops to ensure they are not further traumatised by the sensitive and difficult content.

Building on previous work to raise awareness of the trauma experienced by family carers in their interaction with 'the system' in trying to get support for their family members, and in response to evaluation feedback, we have co-produced new materials to deliver a longer and more in-depth workshop. The workshops convey the voices and consistent messages of the families, are co-facilitated with a family carer and provide awareness of the issues and key areas for changes in practice. We invest in robust recruitment and provide training and ongoing support for co-facilitators.

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The Tizard Centre at Kent University commissioned KMTV to produce a short documentary film which highlights the issues, the research and the workshops. **Family Trauma: A Broken Care System**: **https://www.youtube.com/watch?v=eZ_C-_CnxaQ**

A collaborative conference to highlight the issues with Kent University (the Tizard Centre), Leeds University, Cerebra and the CBF, was held, at the suggestion of CBF, in the summer of 2024.

Direct Engagement – hearing the views and experiences of children and young people with learning disabilities and complex communication challenges

What Matters to Me

Influencing policy with the experiences, preferences and views of young people with severe or profound and multiple learning disabilities



Step 1: Identify the area for improvement

Step 2: Build relationships & learn communication methods

Step 3: Engage in activities to evidence experiences, preferences and views

Step 4: Share evidence to influence positive changes

Following our successful 'Seldom Heard Voices' project (report provided to NHS England but not published) and in recognition of the need to get better at seeking the views of children, young people and adults with learning disabilities and more complex communication challenges, we secured funding from The Blagrave Foundation and Children in Need to work with children, young people and those who know them well to gather their views about policies that affect their everyday lives. The three year 'What Matters to Me' project builds on previous work by CBF, the Tizard Centre and others. In year two we worked with partners and individuals with complex needs and their families to gather their experiences and identify areas and issues of key importance to them, which will be shared in an accessible youth manifesto in year 3.

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Advocacy

There are two main areas of work around advocacy that have continued into this year: A national review which CBF has provided input to and regional work in two areas.

National work

The CBF has been a member of a steering group for a national review of advocacy support provided to people with learning disabilities and/or autistic people. CBF also gathered the views of family carers both in their role as advocates and their views about advocacy support provided to their adult relatives. Other steering group members collected input from other stakeholders and all the individual reports were collated into a national report which was due to be published in March 2022. The report was eventually published in November 2023.

We have pressed for the report recommendations to be considered and acted on by the Department of Health and Social Care, and initiated, drafted and sent a joint letter from the steering group to the Minister, which resulted in meetings to discuss the report and recommendations. We continue to highlight the need for the recommendations to be resourced and implemented.

Regional work

The CBF partnered with organisations in two local areas to identify family carers experiences of advocacy and of advocating for their relatives and what would be helpful to support them in this role. A comprehensive, co-produced resource was produced and is now available for family carers online and in print. **Family Carer Advocacy Resource - Challenging Behaviour Foundation**: **https://www.challengingbehaviour.org.uk/information-and-guidance/rights-and-the-law/00-family-carer-advocacy-resource/**

Getting It Right Project



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We finished a three-year project funded by The National Lottery Community Fund building on our previous work and experience of local area and national strategic work. We completed our work with Camden including holding a stakeholder event to bring together family carers and professionals to agree an action plan and working with an independent evaluator to learn from the third year of the project.

We are grateful to Black Country NHS Foundation Trust for funding the CBF to employ a project worker to support the delivery of the action plan developed during Year 2 of the Getting it Right Project. This work will focus on early intervention, transition and ensuring family carers voices are heard in strategic planning.

Additionally, we were delighted to bring together our partners from West Sussex (year 1), Black Country (year 2) and Camden (year3) to a CB-NSG meeting to reflect on the project as a whole. We have taken this learning and subject to funding hope to build on this work this year.

https://www.challengingbehaviour.org.uk/what-we-do/projects-and-research/support-and-services/getting-it-right/

Keyworker Project

Following on from CBF's work to support partners in the Black Country to develop a peer support service we completed an evaluation of the service. These evaluations reported that family carers felt more listened to and understood, more in control and more hopeful after receiving family peer support.

> ***"The keyworker and Family Peer Worker were able to talk to both of us and understand how we were feeling. But it gave us a wider understanding that we were not alone and there is someone to listen to us. It gave us that grounding and initial understanding and helped us cope with ourselves before we could start helping our son and helping the family" - Family carer***

The keyworker pilot in the Black Country was identified as a good practice case study for Integrated Care Boards (ICBs) in the Statutory Guidance on Working with People and Communities. In particular, the co-production with children, young people and families was central to the success of the project. Co-production was in place from start and present throughout the strategic and operational levels of the creation of both the keyworker and peer support worker roles.

Key worker pilot - Challenging Behaviour Foundation:
https://www.challengingbehaviour.org.uk/key-worker-pilot/

Input to Research Projects

In line with our aim of sharing family lived experiences and building evidence to inform our strategic influencing work, we have continued to support and shape a variety of research applications and funded projects with a wide range of academics and researchers. We have continued to provide input to steering and advisory groups and supported paid family carer participation in consultations and focus groups, including translating research findings into practice.

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> ***"The collaboration with the PCAG (Parent Carer Advisory Group) has gone extremely well so far and has been very effective for study processes. We attribute this to the collaboration with a very experienced PPI (Patient and Public Involvement) partner and an organisation (the Challenging Behaviour Foundation) that has experience in supporting PPI in research, including processes and infrastructure (e.g., through their intern training scheme supporting PCAG work, ways to compensate parents for their time). Importantly, the CBF are committed to genuine PPI engagement which aligns well with the values of the rest of the research team."***

We continue to encourage and support families to contribute to consultations and calls for evidence so that their experience and views are heard and included in any response that the CBF submits. We have responded to a range of consultations/calls for evidence with input from families to highlight the issues for children, young people and adults with severe learning disabilities whose behaviour challenges and their families.



MindEd

We continued to support the development of resources for this free online educational resource focussed on mental health, by supporting family carers as co-authors of materials relating to issues of importance to people with learning disabilities and their families. For this year, resources for the STOMP/STAMP programme have been developed. The CBF has supported family carers as co-authors to help write the session content for ten modules. The first six of these modules have been launched with the final four delayed slightly in their final stages of completion with a plan to launch the modules by March 2024. MindEd are hoping to further this work with modules on STAMP (Supporting Treatment and Appropriate Medication in Pediatrics) and the CBF will aim to continue supporting this work.

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Newsletter

We produced an electronic and printed newsletter on the topics of 'Health Matters' and 'Connections and Co-Production' which was sent out to around four thousand people electronically and three thousand people in hard copy to ensure families throughout the UK without digital access were not left out. **www.challengingbehaviour.org.uk/news/challenge- newsletter-spring-2023-health-support-post-covid/**

We will continue to seek funding and partnership opportunities for hard copies of our newsletters to be sent out in the future.



Challenge

Newsletter of the Challenging Behaviour Foundation

Catalysing Positive Cultures

Summer 2024

Welcome to this edition of Challenge - we are all connected in various ways to other people and places – with those connections varying in strength and importance. It is no different for children and adults with severe learning disabilities – sometimes these connections can be even more important for them. This newsletter is themed around connections and co-production - connecting to people and working together.

When you have a relative with severe learning disabilities who displays behaviours that challenge, it is important to connect to people who can provide practical information and support – and in turn for everyone to be "joined up". Sadly, the education, health and social care system that we need for that support and those services is often fragmented and disconnected. Trying to find a way through it to connect things together to get the right support for relatives can be frustrating, time consuming and relentless. Everyone getting together as equals and jointly deciding what's needed and how to proceed (co-production) is the way forward. It is likely to result in better outcomes, and we need to promote working together in this way.

This edition of Challenge provides some examples of great connections and joined up ways of working that deliver good outcomes for people and families. We share some practical resources, and families describe what has helped them to get the support they and their relatives need and have a right to receive. We know it's not easy and that having someone that can provide timely, practical information and support is key. Our role at CBF is to help make those connections - between families, with professionals and across different systems – so children and adults get the support they need - in the right place and at the right time. I hope this edition of Challenge is helpful.

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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Social Media

We continue to use our social media platforms to share good practice information and practical resources. All our social media platforms have all seen an increase in followers this year allowing us to reach more people.

Looking back over the year

This year has seen a combination of continuation of ongoing work and support as well as new projects, all encompassed within our three core strands of work - and all with lived experience and co-production at the core.

As a small team with limited resources, we have to work efficiently, flexibly and effectively, ensuring that we always focus on outcomes and impact. We have many years of experience that inform all our activities and approach, and we evaluate our work to ensure we continue to make a difference. We are exploring opportunities to access external expertise for impact measurement and will take this forward when resources allow.

We know that the change we want to see for everyone will not happen quickly - and that it will only be achieved by persistence and working collaboratively. Collaborative working requires investment in building and sustaining relationships and approaches, and identifying shared objectives and messages and we will continue to create opportunities to do this. We will continue to champion and independently advocate for the rights of individuals and their families to be upheld, and for investment in early intervention and community support and services to ensure the system delivers what it needs to - the right support in the right place at the right time.

Financial review

Financial position

Incoming resources for the year amounted to £836,108 compared with £530,446 in 2022/23, the increase being the result of a generous legacy of £316,004 received from the late Jan Seamer. Excluding the legacy, incoming resources reduced slightly to £520,104 reflecting principally the end of a three-year grant from the National Lottery Community Fund, offset by an increase in earnings from charitable activities, especially sharing best practice. This type of work is, however, made up mainly of ad hoc projects which inevitably fluctuate from year to year.

The increase in resources expended from £522,982 in 2022/23 to £571,304 in 2023/24 reflects the higher level of charitable activity combined with the inflationary pressures felt across the economy. The financial situation continues to be very challenging as indicated by net expenditure within general funds for the year of £45,248, despite careful planning and stringent budget management. Overall, however, receipt of the Jan Seamer legacy resulted in total funds showing net income of £264,804. The support of trusts and foundations remains vital in enabling us to carry out work to increase the CBF's impact while helping to maintain its financial viability. We would like to extend our grateful thanks to all supporters who have enabled us to achieve this. Grants from BBC Children in Need, the Blagrave Trust and the John Ellerman Foundation have enabled us to further our policy and influencing work, while the Paul Hamlyn Foundation has supported our activities relating to young people and transition. Thanks are also due to the Colyer-Fergusson Charitable Trust and the Baily Thomas Charitable Fund which have helped to fund our family support service and to the Pears Family Charitable Foundation and several smaller foundations for supporting core costs.

Looking ahead, the funding environment is becoming more challenging than ever, especially in the light of the poor state of the UK's public finances. Most paid work is ad hoc, unpredictable and fluctuates in volume, while grant funding is one-off or relatively short term and subject to fierce competition. Inflation continues to push up costs making the recruitment and retention of staff more difficult. In the light of this challenging situation, the Trustees have decided to designate the Jan Seamer legacy for the purposes of promoting the longer-term sustainability of the CBF and its work with families and, over the next few years, to fund development opportunities that cannot be funded from other sources.

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Reserves policy

The Trustees have reviewed the key risks across the organisation and have set a target of holding closure costs plus six months running costs in general funds to ensure the charity is in a stable position to:

1. Fulfil notice periods, statutory redundancy and meet all other obligations and liabilities in event of closure of the charity
2. Provide effective staffing to seek alternative funding and support the development of alternative forms of support for families in need of long-term casework in the event of a downturn in income or closure (we typically provide casework support to families for a period of six months to three years)
3. Enable the organisation to respond to unforeseen external challenges such as an increase in demand similar to that experienced during the COVID-19 pandemic.
4. Provide a level of flexibility to respond to any opportunities that may arise at short notice to influence national policy on behalf of our beneficiaries. In taking any decision to use reserves in this manner the Trustees take account of CBF's charity's financial position ensuring that any risks do not impact on its sustainability.

In determining the reserves strategy, the Trustees have taken a holistic and strategic approach, considering carefully the reasons for maintaining reserves as well as the logistics of utilising them. This includes consideration of the external factors that may affect reserves such as demands on capacity and the high competition for and relatively short-term nature of grant funding, which forms a large part of the charity's income, and often involves a long lead time to secure.

General funds amounted to £378,002 at 31 January 2024, representing approximately five months of running costs, after taking account of estimated closure costs, based on predicted expenditure for 2024/25. This is slightly below the target and reflects the challenges the CBF faces in securing funding for its work.

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Our Plans for the Coming Year

Although our ultimate aim as an organisation continues to be that we are not needed because the 'system' works, we know this is a long-term aim and in the interim, we need to sustain and develop our work and maximise our impact. To support this, we will continue to focus on our key communities (Early years, transition to adulthood, supporting older family carers and supporting individuals in or at risk of crisis). If and when more capacity is required, we intend to utilise consultants who have been through our core training, to enable flexibility without long-term financial commitment, unless there are new opportunities for funding fixed term posts which arise for project work we want to take forward.

We plan to recruit two new paid interns in the coming year: internships require skilled investment from our Senior Management Team and a comprehensive induction and line management process.

Our internships have, as a result of this investment, proved very successful and provide recent graduates with valuable work experience and insight into the issues faced by families, as well as providing the charity with additional capacity that delivers good value for money.

Funding challenges continue as the pandemic costs are repaid alongside the impact of the cost of living crisis on our organisation, the families we support, and the wider community. Trustees are mindful of potential future financial risks and plan accordingly, including close financial monitoring. In addition, the General Election in 2024 will create additional disruption, uncertainty and delays to the systemic change we work with others to drive forward.

Our core aim remains to ensure that "the system" and society enable individuals with severe learning disabilities, and their families, to receive the right support in the right place at the right time. Our approach, and all our work, is carefully planned and thought through with regular reviews to consider outcomes and impact, and in the coming year we will continue to focus on our successful model of three key interconnected areas of work. Our many years of experience have informed and refined our work and how it is delivered to achieve impact and good outcomes. The change we want to see is significant and systemic and takes time. Although we are acutely aware of the urgency and are ambitious and impatient for change, we are realistic regarding our capacity, the inertia and resistance to change within the system, and the need and investment required to work collaboratively.

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Future Plans

Information and Support



We plan to continue to ensure our specialist family support and information service is maintained, continues to be family centred, and provides high quality independent expertise and advocacy for families in need. The families we support are often in very complex situations, navigating through disjointed education, health and care systems, and experiencing marginalisation, "parent blame" and exclusion often simultaneously. Families clearly describe "the fight" for the support and services their relatives need, and their experiences of discrimination and basic human rights being ignored. Our Family Support "offer" includes a range of information and support, delivered in different ways to meet the diverse needs and preferences of families.

Funds generously provided by Pears Foundation, Colyer Fergusson Charitable Trust and the Baily Thomas Charitable Fund for our specialist family support helpline and casework are vital to enable this work to continue. As some multi-year funding ends, we will continue to prioritise seeking further funding to ensure we can maintain and develop the support and information we provide for families who are often in crisis.

We will continue our peer support Facebook group to offer families the option of different forms of peer interaction and communications. This runs alongside the existing 'Family Carer Email Network' to cater for the differently-technologically-suited groups of families who benefit from having access to online interaction and peer support. In addition, we will continue to offer a telephone "listening ear" service to provide trained and supported peer support to those who cannot access or prefer not to use our online support networks.

Work will continue to review the diversity of the families who use CBF'S information and support service. Initial observations show that a wide range of families contact us for support including those for whom English is not their first language and those who do not have access to the internet. We will continue to offer Language Line interpreters and send paper newsletters (subject to identifying funding) and information resources to families who do not use the internet or who request hard copies of resources. As so much information is now available online only, we are mindful of the "digital divide" which causes greater marginalisation and isolation. We will work with the Helpline Collaboration to review how we support people over the coming 12 months.

We will further improve relationships with other family support organisations and charities that run helplines by continuing to lead the co-ordination of regular meetings which has proved highly beneficial, providing peer support, problem solving and opportunities for joint working. This helpline collaborative enables efficient signposting to others when appropriate and helps us to identify any gaps in support. We will continue to facilitate this group and to identify joint working and training and other opportunities as well as inviting any new members to join the group.

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Due to the success of Challenge Accepted, the CBF's podcast, we will be recording new episodes. The first two will focus on the summer holidays and will be published in July. Family Carers will be invited to a family day to share their experiences as feedback has suggested that listeners enjoy the open, honest discussion and it reduces feelings of isolation in listeners. We also plan to record a series focusing on the transition from children to adult services as this is a known pinch point where families are at risk of entering crisis. This will be published towards the end of 2024 to encourage families to think about transition well before the end of the school year.

We will ensure our resources are tailored particularly to our four identified priority groups. Work to co-produce new resources for older family carers will continue and we will pilot these in the coming year. The new comprehensive family carer advocacy guide will be promoted and shared, and our regular programme of reviewing and updating our resources will continue, with an updated transition guide prioritised.

A planned review of all of our information resources will take place over the coming year. Resources will be updated or rewritten to provide the most up to date information and to ensure they are accessible to families.

Our family support and information service take a lifelong approach and we will consider how we target families in particular situations to increase our impact and as part of that, we have reviewed how we record information to enable us to collect data and when we have a full year's worth of data we will begin to analyse this.

Future Plans

Sharing best practice



Last year, we used some of our unrestricted reserves to invest in piloting a new role leading this strand of our work. The aim was to use this pilot role to test opportunities that emerge from our project work demonstrating delivery of a tested and locally sustained model. It aimed to focus on good outcomes that properly engage local families as valued expert partners at a strategic and grass roots level, and to promote this approach through our co-produced and co-facilitated workshops.

Co-production is and always has been a key principle of all the work of CBF and will continue to be so. To help promote this approach and measure its impact, we worked with families to develop a resource outlining what family carers expect from co-production. This resource will be used and promoted as a measure of our own performance and the underpinning principles of working with partners.

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Promotion of early intervention approaches, both in terms of support in early childhood as well as early support with emerging behaviours that challenge, will remain a key feature in all three strands of our work. We will continue to collate and present evidence of the positive benefits of early intervention, and work with researchers and academics to achieve this.

We plan to work with researchers to utilise our **Early Intervention report** published with partners in 2022 and to continue to promote investment in families and availability of timely specialist support.



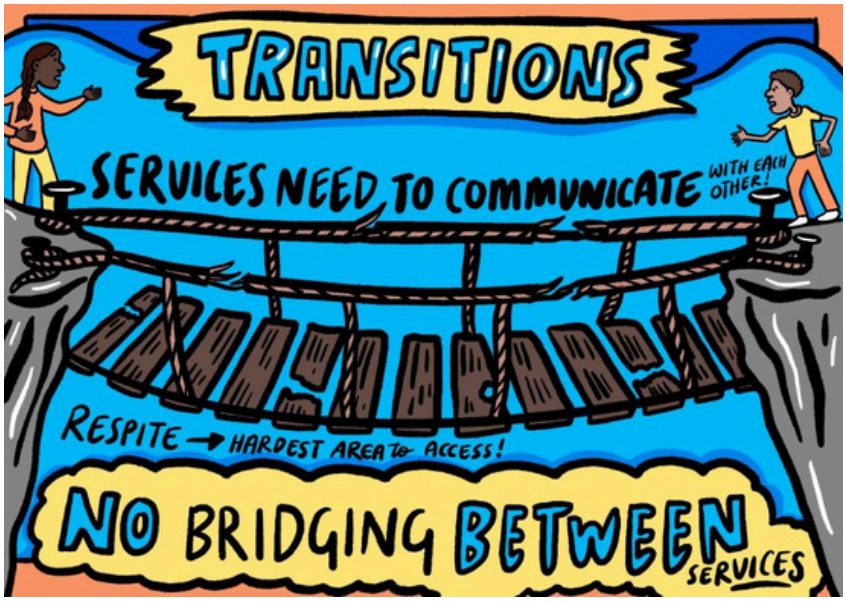
The views and experiences of children and adults with severe learning disabilities are often disregarded as they are unable to attend or use traditional methods such as focus groups or surveys – but it is important that we adapt our approach to enable their views to be captured.

We will therefore continue to develop our work on engagement with children, young people and adults with complex needs, collaborating with other leaders in this field, to find innovative ways to seek their views, and to demonstrate that it is possible to consult with them in a meaningful way. At the same time, we will take every opportunity, in our own work and the work of other organisations, to ensure that families of children, young people and adults with complex needs can share their lived experience to drive forward change.

We will build on the work of the 'What Matters To Me' project, alongside and in partnership with our two project partners and the active engagement with the young people as we co-produce an accessible Manifesto for change. As this project enters its final year, we will work with steering group partners to co-design the next steps for this work and identify potential funding sources to take it forward.

In the coming year we plan to focus on transition (age 14-25) due to identifying it as one of our four key priorities in our Theory of Change. We know this is a time of change and increased risk of the system not being joined up, gaps in support and challenges with transitioning to new support and services and how they are funded.

There is a high instance of admission to inpatient units during this age range. We will focus on this area, with activities including; inputting to the law commission review and working with officials on key government programmes. We plan to revise and update our 'moving into adulthood' resource and our work in the Black Country will produce a bespoke resource around local transition support.



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We will work with an independent consultant funded by the Paul Hamlyn Foundation as part of their grant offer, to develop a framework to measure our impact around transition.

We will set up a new CB-NSG subgroup for transition to bring together a range of stakeholders to identify actions to include within the co-produced action plan.

CBF workshops are an accessible way to share core messages and approaches and fulfil our charitable objectives. The method of co-production and co-facilitation delivery models the approach we promote. Having invested in new workshops and recruiting training and supporting new facilitators we plan to promote these more widely now we have increased our capacity for delivery. New promotional materials have been co-produced and will be disseminated and we will prioritise securing funding opportunities to enable us to deliver more workshops in the coming year.



We will work with researchers to apply for funding for further formal evaluation of our PBS workshops, and other research initiatives will be pursued in partnership with a range of other individuals and organisations.

We will work to promote the need to develop a national learning disability research strategy.

Having recruited, trained and supported new co-facilitators over the past 12 months we will promote 'Whole Family Approaches' and Pica (eating inedible objects) workshops with a range of stakeholders including family carers and the Health and Social Care Workforce.

Family experiences of trauma will continue to be an important area of work for the CBF. Our newly recruited and supported co-facilitators will enable us to promote and disseminate these to a wide range of professionals who have a role to play in supporting families. Now that the Tizard Centre, KMTV and CBF 12-minute documentary film is completed and available it will help with awareness raising and dissemination of the key messages from families about the trauma the system creates. **Family Trauma: A broken Care System: https://youtu.be/eZ_C-_CnxaQ**

We are working in partnership with colleagues from Leeds University to arrange a national conference that will focus on this issue, which will be held in the Summer of 2024.

Building on our national and regional advocacy work, now that our Family Carer Advocacy resource is completed and available, we will continue to promote the need for accessible, robust and independent advocacy for individuals and families, and to raise awareness of the advocacy role that families fulfil. **Family Carer Advocacy Resource: https://www.challengingbehaviour.org.uk/information-and-guidance/rights-and-the-law/00-family-carer-advocacy-resource/**

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We have worked with SF-DDARIN to develop a project to make research findings more accessible for family carers. The aim of the Research Engagement, Access and Dissemination (READ) project is to generate engaging and accessible research summaries of key publications and highlight key learning points and implications from the studies. A working group and an outline project plan have been established. In the coming year we plan to recruit a family carer to join the working group and consult with family carers to shape the development of the project. We hope to secure further funding to pilot the project.

We will continue to work with MindEd to co-produce resources with family carers, to publish the four remaining modules funded last year, and co-develop further modules about STAMP (Supporting Treatment and Appropriate Medication in Pediatrics).

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Future Plans

Strategic Influencing



We are ever mindful that we operate in the wider context of the learning disability, carer, social care, education, health and voluntary sectors. Investing in, developing and maintaining relationships with others with similar related aims to the CBF will increase our collective impact. Our collaborative, solution-focused, and evidence-based approach will continue to be prioritised. Working collaboratively takes longer and requires time and skilled management to build positive relationships and trust to focus on shared aims and objectives rather than differences of opinion. We strongly believe we can achieve more by working together and, by employing our well established co-production approach, can deliver better outcomes.

Our influencing agenda will of course continue to be responsive to the changing political circumstances and challenges that arise. Constant reorganisations and changes in education, care and health systems and key post holders continue to pose challenges through lack of continuity, delays, and inertia. Following the General Election there is likely to be a period of inertia during the election of new MPs and Ministers being appointed, inducted to their brief and setting priorities. Whilst this can be a period that is frustrating it is also a period of opportunity- to confirm and refine our collective key messages, present a united front and make the case for the changes we want to see. We will bring together a group of learning disability organisations to co-ordinate and amplify our messages and increase our collective impact, although we do not underestimate the challenges this will bring.

We remain committed to continuing to challenge the failure of the Transforming Care agenda. The long called for cross Government approach, now tokenistically and ineffectively adopted, must be challenged based on their own missed targets and lack of investment in community support and services. We will continue to keep this on the national and local agenda. This work has the potential for a very significant impact for our client group and specific multi-year funding support to pursue this work to enable this vital long-term work to progress will be prioritised. There is no “quick fix” solution - it requires leadership, vision and strategic patience, as well as commitment and determination.

We will continue to bring together a diverse range of stakeholders, through our CB-NSG members and associates, and work in partnership to identify ways to drive forward the change needed, developing workable initiatives that build on experience and existing knowledge, and delivering a solution-focused approach. The co-production work we have been leading to develop a Lifelong Action Plan will continue. It will set out what needs to change, what can be built upon and what

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needs prioritisation and investment. This will be an overarching framework for activities and a tool for delivering good outcomes and campaigning. Our continuing strategic influencing work will include the following with a particular focus on our four key communities:

- We will build on our regional work to embed valuing and investing in families and will explore ways (subject to funding) to deliver co-production with all stakeholders using the CB NSG national model.
- We plan to review and reflect on the learning from the External Support Group (ESG) work, a CBF led initiative, bringing together a group of senior experienced clinicians and professionals to provide support to local teams who are supporting individuals.
- Our work targeting professionals who work with families, increasing their awareness of need and the issues families face, will continue. We are planning to continue the strategic legal work identified by our legal panel members and the individuals and organisations who have participated in our legal strategy meetings so far. Promoting a joined-up approach to enable easier and timely access for families to legal support and information, and ensuring best use of limited resources will continue. We will aim to convene a meeting of legal experts to work together to explore the strategic legal challenge options available. This work, linked to the CBF Legal Panel work may require seeking additional specialist capacity to drive this forward.
- The Legal Panel members identified a need to develop a resource for individuals (and their families and advocates) who are in inpatient settings with "delayed discharge" due to the community support not being available, explaining the specialist legal support they can access. We will work with the Legal Panel, other charities, advocacy groups and others to share and publicise it. We will also liaise with NHS England and the Department of Health and Social Care to identify opportunities to promote and share the resource through their system processes.
- Reducing the use of restrictive interventions will continue to remain a priority, and it will be taken forward via the multi stakeholder UK wide PR;ERG (Protecting Rights Eliminating Restraint Group) which we convened and chair.
- We will continue to promote the NHS England STOMP and STAMP programmes, which aim to address the inappropriate medication of individuals with learning disabilities and will explore opportunities to take forward further work identified by families, subject to capacity and resources.
- Working with older families we will co-produce a resource to aid proactive and positive planning for the future and will seek funding to progress this area of work.

Joined up working

In the coming year we will continue to progress our work in all three key areas, regularly reviewing our activities and their impact. Following our Theory of Change work, we will have a renewed focus on our four key client groups (young families, people in transition, older family carers and families in crisis). We will seek opportunities to enhance our impact measurement to evaluate our impact on an ongoing basis in a way that is robust and useful but proportionate. As a small team with limited capacity and resources, we are ever mindful of the need to target our efforts carefully and influence those in positions of power who can make change happen, and who have a wider reach and more resources. A General Election will be called in the coming year, and this will impact our work- providing both challenges and opportunities. We will carefully consider how we can maximize the opportunities and minimise the challenges.

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Our organisational approach is to arrange our work in a family-centred way, focussed on delivering good outcomes for families at an individual and strategic level. Our work is wide-ranging because it reflects the multiple issues and systems that families have to negotiate and contend with, and we know that there are many areas of work that need to be taken forward concurrently. All elements of our work and projects are interconnected. We work proactively but are also able to respond quickly to opportunities and needs as they arise - as evidenced in our response to the pandemic - and having sufficient reserves is a key enabler in this respect. We know there will be significant challenges ahead - in terms of the needs of the families we support, the financial challenges we will face as a small charity to secure funds for our work and the political upheaval of a General Election. We will take all the necessary steps we can to ensure we are able to continue our much-needed work, making a difference to the lives of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families.

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Structure, governance and management

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

Recruitment and appointment of new Trustees

Trustee skills are reviewed annually to ensure the board has the range of skills and experience required. Any gaps in specific skills are identified and addressed through training or pro bono consultancy input or through the recruitment of new members to the Trustee Board. This year we appointed two new Trustees who are family carers. We have a network of Trustee Advisors who are supported, involved, and contribute to the CBF and we are exploring new ways for family carers to input strategically through additional online meetings with Trustees.

Organisational structure

The Trustees, who are directors for the purpose of company law and Trustees for the purpose of charity law, who served during the year and up to the date of this report, are set out on the following page. Members of the charitable company guarantee to contribute an amount not exceeding £10 to the assets of the charitable company in the event of winding up. Day-to-day management of the charity's activities is delegated by the Trustees to the Chief Executive Officer. Having enlisted external expertise and proactively planned for succession for several years, those plans have been implemented since the year-end with a transition to a new Chair of Trustees and the recruitment of a new CEO, who will start in early 2025.

The Trustee Board meets quarterly to review achievements and performance, finances, and future plans.

Risk management

The Trustees have a duty to identify and review the risks to which the charity is exposed, including ensuring appropriate controls are in place to provide reasonable assurance against fraud and error. The Trustees have a risk management strategy in place, comprising an annual review of the risks the charity may face, the establishment of systems and procedures to mitigate risks identified, and the implementation of procedures designed to minimise any potential impact on the charity should any of these risks materialise. In common with many voluntary organisations, the risks are ongoing due to the nature of the work and the charity context in which we operate.

Currently one of the key risks identified is the transition to a new CEO in the next few months. Actions to mitigate this risk include succession planning, which has been underway for several years, a robust recruitment process and a detailed handover and induction programme for the new CEO. The CBF benefits from having a strong and experienced senior management team and this will help to ensure continuity.

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Funding shortfalls continue to represent a major risk especially given the challenging wider financial environment. Regular updating and review of financial projections and tight budget management are key elements in the management of these risks. Attention has also been focused on non-financial areas such as reputational risk and suitable mitigating actions are in place. The pandemic highlighted the importance of ensuring that the CBF can respond to national or international-scale incidents that lie beyond our control, and these are now included in our risk register.

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Reference and administrative details

Registered Company number
3307407 (England and Wales)

Registered office
c/o The Old Courthouse, New Road Avenue,
Chatham Kent ME4 6BE

Registered Charity number
1060714

Trustees
Dr D Allen (Chair since April 2024)
Ms. S Cooper
Mr. J Dodd
Dr N J Gore
Dr K Jankulak (Appointed July 2023)
Ms. D E Lightfoot (Stepped down as Chair April 2024)
Mrs C Million
Mr. A Rook
Mrs K Sangar (Appointed July 2023)

Company Secretary
Mrs C Million

Auditors
Xeinadin Audit Ltd
12 Conqueror Ct
Sittingbourne Kent
ME10 5BH

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Statement of trustees responsibilities

The trustees (who are also the directors of The Challenging Behaviour Foundation for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to;

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

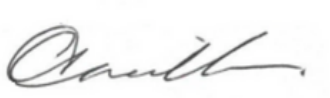
In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditors are unaware; and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

AUDITORS

The auditors, Xeinadin Audit Ltd (via Calcutt Matthews Ltd), will be proposed for re-appointment at the forthcoming Annual General Meeting.

Report of the trustees, incorporating a strategic report, approved by order of the board of trustees as the company directors, on 20th July 2024 and signed on its behalf by:



.....

Mrs C MILLION - Trustee/ Company Secretary

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Report of the Independent Auditors to the Members of the Challenging Behaviour Foundation

Opinion

We have audited the financial statements of The Challenging Behaviour Foundation (the 'charitable company') for the year ended 31 January 2024 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).
In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 January 2024 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.
Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the

extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Report of the Trustees has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Trustees.

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists.

Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below: The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Our objectives in performing the audit are to identify and assess the risk of material misstatement in the financial statements due to fraud or error and to obtain sufficient audit evidence to support this. We also evaluate and respond to the risk of material misstatements.
Audit procedures performed by the engagement team included:

- Gaining an extensive knowledge entity and environment
- Obtaining a sufficient understanding of the internal environment, including control systems in place for the detection and prevention of fraud.
- Evaluating said systems to determine whether they are operating to a satisfactory level and are providing the right level of control and authorisation within the entity.
- Understanding the entity's current activities, assets and liabilities and comparing these to the entity's charitable objectives and aims.
- Discussions with management and those charged with governance as to any known or suspected instances of noncompliance with laws and regulations, including fraud.
- Reading minutes of meetings of those charged with governance and comparing these to what is reflected in the statutory accounts.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Nicholas Hume FCA

Nicholas Hume FCA (Senior Statutory Auditor) for and on behalf of Xeinadin Audit Ltd
12 Conqueror Ct Sittingbourne Kent
ME10 5BH

Date: 20 July 2024

Statement for Financial Activities for the Year Ended 31 January 2024

	Notes	General funds	Designated Funds (Unrestricted)	Restricted funds	31.1.24 Total funds	31.1.23 Total funds restated
		£	£	£	£	£
INCOME AND ENDOWMENTS FROM						
Donations and legacies	2	51,806	316,005	177,382	545,193	390,465
Charitable activities	5					
Information and Support		9,349	-	-	9,349	14,425
Strategic Influencing		73,877	-	-	73,877	34,828
Sharing Best Practice		157,122	45,150	-	202,272	89,399
Other trading activities	3	2,187	-	-	2,187	673
Investment income	4	3,230	-	-	3,230	656
Total		297,571	361,155	177,382	836,108	530,446
EXPENDITURE ON						
Raising funds	6	22,507	-	-	22,507	21,140
Charitable activities						
Information and Support	7	75,090	-	18,054	93,144	86,713
Strategic Influencing		49,178	-	67,705	116,883	60,478
Sharing Best Practice		98,267	51,382	91,344	240,993	210,413
Core Funding		97,777	-	-	97,777	144,238
Total		342,819	51,382	177,103	571,304	522,982
NET INCOME/(EXPENDITURE)		(45,248)	309,773	279	264,804	7,464
RECONCILIATION OF FUNDS						
Total funds brought forward		423,251	27,772	126,877	577,900	570,436
TOTAL FUNDS CARRIED FORWARD		378,003	337,545	127,156	842,704	577,900

The notes form part of these financial statements

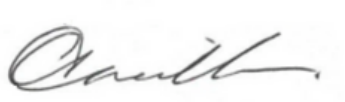
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Balance Sheet

31 January 2024

	Notes	General funds £	Designated Funds (Unrestricted) £	Restricted funds £	31.1.24 Total funds £	31.1.23 Total funds £
CURRENT ASSETS						
Debtors	12	21,891	-	-	21,891	26,177
Cash at bank		401,665	345,546	190,470	937,681	687,044
		423,556	345,546	190,470	959,572	713,221
CREDITORS						
Amounts falling due within one year	13	(45,554)	(8,000)	(63,314)	(116,868)	(135,321)
NET CURRENT ASSETS		378,002	337,546	127,156	842,704	577,900
TOTAL ASSETS LESS CURRENT LIABILITIES		378,002	337,546	127,156	842,704	577,900
NET ASSETS		378,002	337,546	127,156	842,704	577,900
FUNDS	14					
General funds					378,002	423,251
Designated Funds					337,546	27,772
Unrestricted Funds Total					715,548	451,023
Restricted funds					127,156	126,877
TOTAL FUNDS					842,704	577,900

The financial statements were approved by the Board of Trustees and authorised for issue on 20th July 2024 and were signed on its behalf by:



.....

Mrs C Million - Trustee

The notes form part of these financial statements

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Cash Flow Statement
for the Year Ended 31 January 2024

	Notes	31.1.24 £	31.1.23 £
Cash flows from operating activities			
Cash generated from operations	1	242,561	69,398
Gift Aid		4,846	1,417
Net cash provided by operating activities		247,407	70,815
Cash flows from investing activities			
Interest received		3,230	656
Net cash provided by investing activities		3,230	656
Change in cash and cash equivalents in the reporting period		250,637	71,471
Cash and cash equivalents at the beginning of the reporting period		687,044	615,573
Cash and cash equivalents at the end of the reporting period		937,681	687,044

The notes form part of these financial statements

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Notes to the Cash Flow Statement for the Year Ended 31 January 2024

1. RECONCILIATION OF NET INCOME TO NET CASH FLOW FROM OPERATING ACTIVITIES	31.1.24 £	31.1.23 £
Net income for the reporting period (as per the Statement of Financial Activities)	264,804	7,464
Adjustments for:		
Interest received	(3,230)	(656)
Gift Aid Income	(3,744)	(994)
Decrease in debtors	3,184	19,649
(Decrease)/increase in creditors	(18,453)	43,935
Net cash provided by operations	242,561	69,398

2. ANALYSIS OF CHANGES IN NET FUNDS	At 1.2.23 £	Cash flow £	At 31.1.24 £
Net cash			
Cash at bank	687,044	250,637	937,681
	687,044	250,637	937,681
Total	687,044	250,637	937,681

The notes form part of these financial statements

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Notes to the Financial Statement for the Year Ended 31 January 2024

1. ACCOUNTING POLICIES

Basis of preparing the financial statements
The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

- Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity
- Designated funds are unrestricted funds earmarked by the Trustees for particular purposes.
- Restricted funds are subject to restrictions on their expenditure imposed by the donor or through the terms of an appeal.

Income
All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure
Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Allocation and apportionment of costs
Support costs are allocated pro rata to staff numbers involved with each charitable activity.

Taxation
The charity is exempt from corporation tax on its charitable activities.

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Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Pension costs and other post-retirement benefits

The charitable company operates a defined contribution pension scheme. Contributions payable to the charitable company's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

Continued...

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Notes to the Financial Statement - Continued for the Year Ended 31 January 2024

2. DONATIONS AND LEGACIES

	31.1.24 £	31.1.23 £
Donations	18,566	20,589
Gift aid	3,744	994
Legacies	316,004	-
Grants	206,879	368,882
	545,193	390,465

Grants received, included in the above, are as follows:

	31.1.24 £	31.1.23 £
BBC Children in Need	44,571	-
John Ellerman Foundation	30,000	30,000
Sylvia Adams Charitable Trust	-	5,000
The Stonewall Park Charitable Trust	1,500	1,000
The Esmee Fairbairn Foundation	10,500	32,500
The University of Warwick	-	16,500
National Lottery Community Fund	-	131,291
Pears Family Charitable Foundation	25,000	25,000
Kent Community Foundation	-	3,000
National Health Service England (NHSE) Covid Recovery	-	83,625
The Blagrave Trust	45,508	25,083
Beechwood Trust	-	1,000
Baily Thomas Charitable Fund	10,000	-
Colyer-Fergusson Charitable Trust	14,800	14,883
Paul Hamlyn Foundation	25,000	-
	206,879	368,882

During the year, a review was done to determine the underlying nature of grant funding and as a result, it has been reflected as part of Voluntary Income rather than Charitable Activities.

3. OTHER TRADING ACTIVITIES

	31.1.24 £	31.1.23 £
Fundraising activities	2,187	673

continued...

Notes to the Financial Statement - Continued for the Year Ended 31 January 2024

4. INVESTMENT INCOME

	31.1.24	31.1.23
	£	£
Deposit account and other interest received	3,230	656

5. INCOME FROM CHARITABLE ACTIVITIES

	Information and Support	Strategic Influencing	Sharing Best Practice	31.1.24 Total activities	31.1.23 Total activities
	£	£	£	£	£
Contract and Other Non Grant Income	9,349	73,877	202,272	285,498	138,652

6. RAISING FUNDS

Raising donations and legacies

	31.1.24	31.1.23
	£	£
Staff costs	22,061	20,853
Fundraising	446	287
	22,507	21,140

7. CHARITABLE ACTIVITIES COSTS

	Direct Costs	Support costs (see note 8)	Totals
	£	£	£
Information and Support	93,144	-	93,144
Strategic Influencing	116,883	-	116,883
Sharing Best Practice	240,993	-	240,993
Core Funding	93,558	4,219	97,777
	544,578	4,219	548,797

Sharing Best Practice activities have long been embedded in the core work of the CBF and this year we have invested in formalising this strand of work with a dedicated role employed to lead it. These accounts disclose separate lines for Sharing Best Practice activities within both income from and expenditure on charitable activities. The comparative figures for the year ended 31 January 2023 have been restated to reflect the same breakdown.

continued...

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Notes to the Financial Statement - Continued for the Year Ended 31 January 2024

8. SUPPORT COSTS

	Governance costs
	£
Core Funding	4,219

9. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	31.1.24	31.1.23
	£	£
Auditors' remuneration	2,200	1,355

10. TRUSTEES' REMUNERATION AND BENEFITS

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 January 2024 nor for the year ended 31 January 2023.

Two Trustees received a total of £456 in expenses whilst carrying out voluntary work and sharing lived experience for research, not as part of their role as Trustees.

No Trustee or any person related to the charity had any personal interest in any contract or Trustee transaction entered into by the charity during the year other than as disclosed above.

11. STAFF COSTS

No employee was paid over £60,000 in the year.

The average monthly number of employees during the year was as follows:

	2024	2023
Information & Support	5	4
Strategic Influencing	5	5
Sharing Best Practice	3	3
Core/General	6	4
Total	19	16
Total full time equivalent number of employees	12	12

continued...

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Notes to the Financial Statement - Continued for the Year Ended 31 January 2024

12. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.1.24	31.1.23
	£	£
Trade debtors	19,294	17,102
Other debtors	32	657
Gift Aid reclaimable	2,565	3,667
Accrued income	-	4,512
Prepayments	-	239
	21,891	26,177

13. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.1.24	31.1.23
	£	£
Trade creditors	5,299	4,886
Social security and other taxes	6,302	8,457
VAT	3,556	1,359
Funds held for other organisations	15,423	15,423
Accruals and deferred income	86,288	105,196
	116,868	135,321

Funds held for other organisations £15,423 (2023: £15,423) represents monies held by the charity where it is working with other charities on joint projects. At 31 January 2024 these are as follows:

Learning Disability Senate	£12,840
Employment Dissemination	£2,583

continued...

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Notes to the Financial Statement - Continued for the Year Ended 31 January 2024

14. MOVEMENT IN FUNDS

	At 1.2.23 £	Net movement in funds £	At 31.1.24 £
Unrestricted funds			
General Funds	423,251	(45,249)	378,002
Training Designated Fund	27,772	(6,230)	21,542
The Jan Seamer Memorial Designated Fund	-	316,004	316,004
	451,023	264,525	715,548
Restricted funds			
John Ellerman Fund	25,335	(934)	24,401
The Esmee Fairbairn Foundation	5,613	(5,613)	-
The National Lottery Community Fund	38,716	(38,716)	-
Baily Thomas Charitable Fund	-	6,000	6,000
CB-NSG	4,197	-	4,197
SHIEC	3,572	-	3,572
Asquith Legacy	3,199	(406)	2,793
National Lottery People's Project	27,395	(7,290)	20,105
Colyer-Fergusson Charitable Trust	1,568	747	2,315
The Blagrave Trust	17,282	6,355	23,637
BBC Children in Need	-	38,386	38,386
Paul Hamlyn Foundation	-	1,750	1,750
	126,877	279	127,156
TOTAL FUNDS	577,900	264,804	842,704

continued...

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Notes to the Financial Statement - Continued for the Year Ended 31 January 2024

14. MOVEMENT IN FUNDS - continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General Funds	297,571	(342,820)	(45,249)
Training Designated Fund	45,151	(51,381)	(6,230)
The Jan Seamer Memorial Designated Fund	316,004	-	316,004
	658,726	(394,201)	264,525
Restricted funds			
John Ellerman Fund	30,000	(30,934)	(934)
The Esmee Fairbairn Foundation	7,501	(13,114)	(5,613)
The National Lottery Community Fund	-	(38,716)	(38,716)
Baily Thomas Charitable Fund	10,000	(4,000)	6,000
Asquith Legacy	-	(407)	(407)
National Lottery People's Project	-	(7,290)	(7,290)
Colyer-Fergusson Charitable Trust	14,801	(14,054)	747
The Blagrave Trust	45,508	(39,153)	6,355
BBC Children in Need	44,571	(6,185)	38,386
Paul Hamlyn Foundation	25,000	(23,250)	1,750
	177,382	(177,103)	279
TOTAL FUNDS	836,108	(571,304)	264,804

continued...

Notes to the Financial Statement - Continued for the Year Ended 31 January 2024

14. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1.2.22 £	Net movement in funds £	Transfers between funds £	At 31.1.23 £
Unrestricted funds				
General Funds	422,723	27	500	423,251
Training Designated Fund	24,413	3,359	-	27,772
	447,136	3,386	500	451,023
Restricted funds				
John Ellerman Fund	-	25,335	-	25,335
The Esmee Fairbairn Foundation	9,888	(4,274)	-	5,614
The National Lottery Community Fund	39,138	(422)	-	38,716
CB-NSG	4,215	(18)	-	4,197
SHIEC	3,572	-	-	3,572
Peoples Postcode Trust	2,177	(2,177)	-	-
RRISC	978	(478)	(500)	-
Asquith Legacy	3,199	-	-	3,199
National Lottery People's Project	32,650	(5,255)	-	27,395
Colyer-Fergusson Charitable Trust	2,483	(915)	-	1,568
Steele Charitable Trust	20,000	(20,000)	-	-
The Dulverton Trust	5,000	(5,000)	-	-
The Blagrave Trust	-	17,282	-	17,282
	123,300	4,078	(500)	126,877
TOTAL FUNDS	570,436	7,464	-	577,900

continued...

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Notes to the Financial Statement - Continued for the Year Ended 31 January 2024

14. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General Funds	167,557	(167,530)	27
Training Designated Fund	42,507	(39,148)	3,359
	210,064	(206,678)	3,386
Restricted funds			
John Ellerman Fund	30,000	(4,665)	25,335
The Esmee Fairbairn Foundation	32,501	(36,775)	(4,274)
The National Lottery Community Fund	131,291	(131,713)	(422)
CB-NSG	-	(18)	(18)
Peoples Postcode Trust	-	(2,177)	(2,177)
RRISC	-	(477)	(477)
National Lottery People's Project	-	(5,254)	(5,254)
Colyer-Fergusson Charitable Trust	14,883	(15,798)	(915)
NHSE Covid Recovery	83,624	(83,624)	-
Steele Charitable Trust	-	(20,000)	(20,000)
The Dulverton Trust	-	(5,000)	(5,000)
Kent Community Foundation	3,000	(3,000)	-
The Blagrave Trust	25,085	(7,803)	17,282
	320,382	(316,304)	4,078
TOTAL FUNDS	530,446	(522,982)	7,464

continued...

Notes to the Financial Statement - Continued for the Year Ended 31 January 2024

14. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined position is as follows:

	At 1.2.22 £	Net movement in funds £	Transfers between funds £	At 31.1.24 £
Unrestricted funds				
General Funds	422,723	(45,222)	500	378,002
Training Designated Fund	24,413	(2,871)	-	21,542
The Jan Seamer Memorial Designated Fund	-	316,004	-	316,004
	447,136	267,911	500	715,548
Restricted funds				
John Ellerman Fund	-	24,401	-	24,401
The Esmee Fairbairn Foundation	9,888	(9,888)	-	-
The National Lottery Community Fund	39,138	(39,138)	-	-
Baily Thomas Charitable Fund	-	6,000	-	6,000
CB-NSG	4,215	(18)	-	4,197
SHIEC	3,572	-	-	3,572
Peoples Postcode Trust	2,177	(2,177)	-	-
RRISC	978	(478)	(500)	-
Asquith Legacy	3,199	(406)	-	2,793
National Lottery People's Project	32,650	(12,545)	-	20,105
Colyer-Fergusson Charitable Trust	2,483	(168)	-	2,315
Steele Charitable Trust	20,000	(20,000)	-	-
The Dulverton Trust	5,000	(5,000)	-	-
The Blagrave Trust	-	23,637	-	23,637
BBC Children in Need	-	38,386	-	38,386
Paul Hamlyn Foundation	-	1,750	-	1,750
	123,300	4,357	(500)	127,156
TOTAL FUNDS	570,436	272,268	-	842,704

continued...

Notes to the Financial Statement - Continued for the Year Ended 31 January 2024

14. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General Funds	465,128	(510,350)	(45,222)
Training Designated Fund	87,658	(90,529)	(2,871)
The Jan Seamer Memorial Designated Fund	316,004	-	316,004
	868,790	(600,879)	267,911
Restricted funds			
John Ellerman Fund	60,000	(35,599)	24,401
The Esmee Fairbairn Foundation	40,002	(49,889)	(9,887)
The National Lottery Community Fund	131,291	(170,429)	(39,138)
Baily Thomas Charitable Fund	10,000	(4,000)	6,000
CB-NSG	-	(18)	(18)
Peoples Postcode Trust	-	(2,177)	(2,177)
RRISC	-	(477)	(477)
Asquith Legacy	-	(407)	(407)
National Lottery People's Project	-	(12,544)	(12,544)
Colyer-Fergusson Charitable Trust	29,684	(29,852)	(168)
NHSE Covid Recovery	83,624	(83,624)	-
Steele Charitable Trust	-	(20,000)	(20,000)
The Dulverton Trust	-	(5,000)	(5,000)
Kent Community Foundation	3,000	(3,000)	-
The Blagrave Trust	70,593	(46,956)	23,637
BBC Children in Need	44,571	(6,185)	38,386
Paul Hamlyn Foundation	25,000	(23,250)	1,750
	497,764	(493,407)	4,357
TOTAL FUNDS	1,366,554	(1,094,286)	272,268

The Training Designated Fund represents funds set aside by the Trustees to invest in the CBF's capacity to deliver training and help diversify the charity's income.

The Jan Seamer Memorial Designated Fund is to be used to reflect Jan Seamer's support of the CBF and its work with families, and designated for the specific purposes of promoting the sustainability of the CBF and to fund development opportunities that cannot be funded elsewhere.

continued...

Notes to the Financial Statement – Continued for the Year Ended 31 January 2024

15. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 January 2024.

THE CHALLENGING BEHAVIOUR FOUNDATION

England & Wales - Charity number 1060714

Accounts

The Challenging Behaviour Foundation

Annual Report

2022-2023



Making a difference to the lives of people with severe learning disabilities whose behaviour challenges.

The Challenging Behaviour Foundation

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The Challenging Behaviour Foundation

Foreword

From our Chair, Diane Lightfoot

Last year marked 25 years since the Challenging Behaviour Foundation was founded. It was started and is still led by a parent of a child with a severe learning disability who displays a range of behaviours described as challenging, because there was no one organisation focused on supporting this group of marginalized families. Knowledge and information was out there, but not getting through to the people who needed it the most, especially families. The Challenging Behaviour Foundation was formed to fill this gap.

From its roots and to the current day, the CBF develops and delivers its activities and priorities based on families' experiences. The families we have contact with will often provide a lifetime of love and support. The "system" to access services and support remains complex and disjointed – education, health and social care, and the legal and regulatory frameworks are complicated to navigate and to challenge when the right support is not available or forthcoming. Our work is diverse - reflecting the diversity of issues families face - and we aim to provide a holistic approach to all our work, doing what is needed, not what is easiest or administratively convenient for the CBF.

We have reflected on how much we have achieved over the past 25 years and how far there is still to go for children, young people and adults with severe learning disabilities whose behaviour challenges and their families to get the right support in the right place at the right time.

The learning disability landscape is tough, and our resources are limited so we continually evaluate our impact to confirm that we are "making a difference" at a grass roots, local and national level. The positive feedback and kind words we receive from families we have supported encourages and inspires us to continue our work with them. As a small charity with limited resources, we cannot fix a broken system, but we can support families to navigate it and strategically influence those who can change policy and practice. We do this through co-production and working collaboratively, bringing people together to drive change, and truly valuing and acting on the experience of knowledge of family carers. We are also progressing our work with partners to proactively seek ways to gather the views and experiences of individuals with complex communication challenges themselves.

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The Challenging Behaviour Foundation

As we emerge from the pandemic and various lockdowns, we have seen an increase in both the number and complexity of enquiries we receive from families and the professionals who support them. In addition, with the current cost of living crisis, sadly we expect this increase to continue for some time to come. This will bring challenges to the CBF and Trustees plan carefully to ensure our much-needed work can continue.

We as Trustees are very proud of all our staff, volunteers and supporters who consistently go above and beyond to promote the rights of, and provide the best possible support to, children, young people and adults with severe learning disabilities whose behaviour challenges, and to their families and those who support them.



Thank you to everyone who has made a difference this year.

Diane Lightfoot, Chair of Trustees

> **The support the CBF have given me over the years has been second to none. I really don't know how I would have coped without your continuous support with all the battles that I've been put up against**
>
> **- Family Carer**

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The Challenging Behaviour Foundation

Report of the Trustees

For the year ended 31 January 2023

The Trustees who are also the directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 January 2023. The Trustees have adopted the provisions of the Statement of Recommended Practice (SORP) 'Accounting and Reporting by Charities' issued in 2015.

Objectives and activities

Objectives and aims

The Challenging Behaviour Foundation (CBF) exists to improve the quality of life of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families.



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



Our mission is to make a difference to the lives of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families by: -

- Championing their rights
- Ensuring timely information and support
- Raising awareness and understanding
- Promoting and sharing best practice

We are the **only** UK charity **focussed specifically** on the needs of children, young people and adults with a severe learning disability whose behaviours may challenge, their families and those who care for them.

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The term 'challenging behaviour' first came into widespread use in the UK through a publication by the King's Fund Centre. This clearly explained that the term: '...emphasises that such behaviour represents challenges to services rather than problems that individuals with learning disabilities in some way carry around with them. If services could rise to the "challenge" of dealing with these behaviours, they would cease to be "problems". The term challenging behaviour places the focus of discussion on services rather than on the individuals showing the behaviours.

The NHS estimates that there are between 30,000 and 35,000 people in the UK who have a severe learning disability and are at risk of developing behaviours that challenge. A person with a severe learning disability will have little or no speech, find it difficult to learn new skills and need ongoing support to carry out daily activities such as washing and dressing.



Challenging behaviour has a **formal definition** and is a term used to refer to a variety of behaviours which some people with a learning disability may display. These behaviours vary and include aggression, eating inedible objects, severe self-injury or significant obsessive repetition, typically putting the safety of the person or others at risk and/or restricting their access to ordinary life opportunities.

Without appropriate support, children, young people and adults with severe learning disabilities whose behaviour may challenge find themselves at greater risk of poor healthcare, poor life prospects and at greater risk of abuse. Families often find themselves isolated from their local community, unsupported by local services and separated from their relatives.

Our work focuses on family-led carer support and adopts a Positive Behaviour Support (PBS) approach.

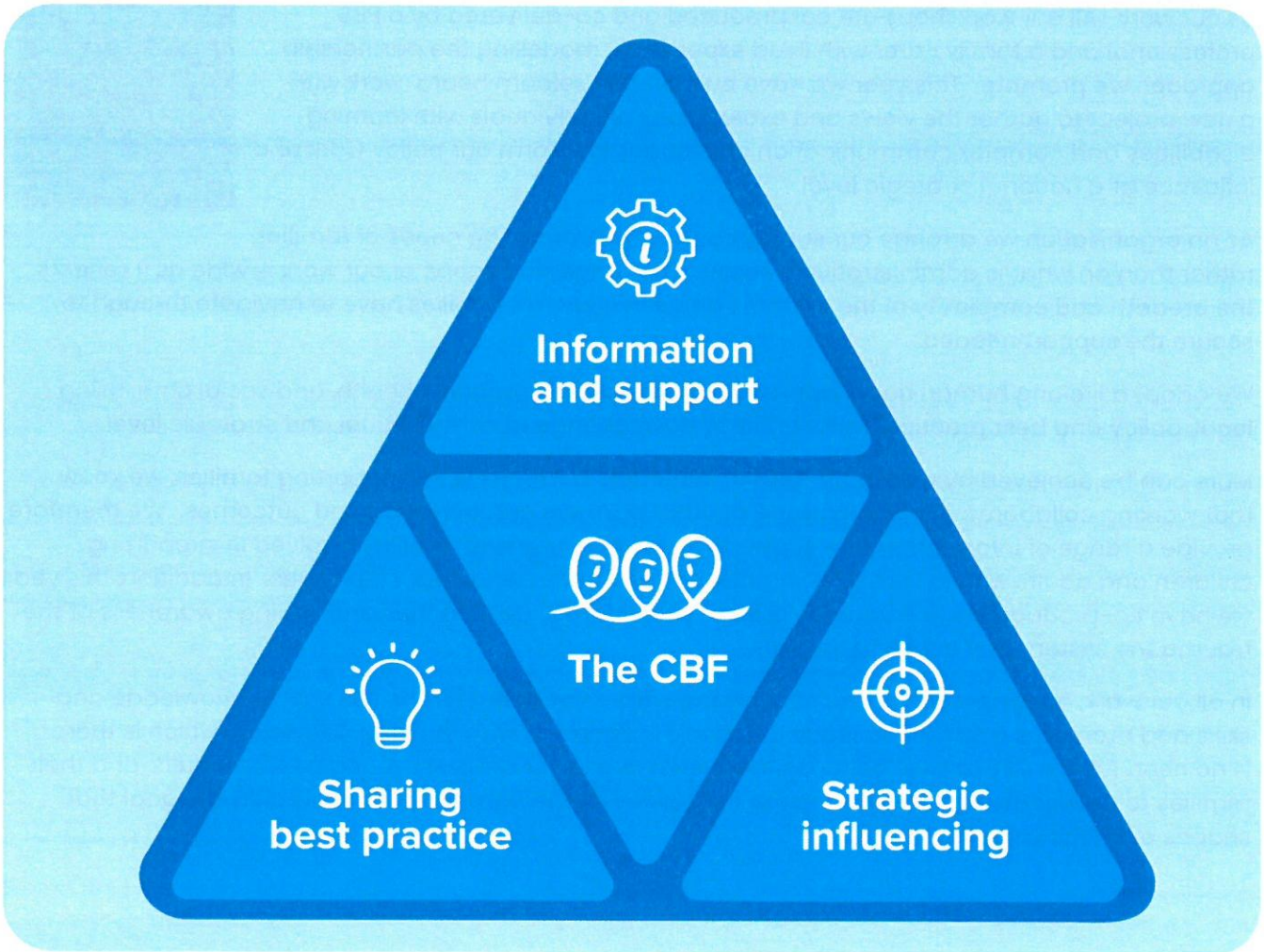
> **People whose behaviour challenges have the same needs as everyone else, in addition to special needs for help to overcome the problems their behaviour presents. They do not surrender their needs for personal relationships, for growth and development or for anything else because their behaviour presents a challenge to services. They have the same human rights as everyone else.**
>
> **- Mansell 2, 2007**

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Our objectives are to ensure that with good support each individual is able to live a happy, active life in their community with access to healthcare, employment, leisure and education, as well as a fulfilling family life. Our focus is enabling children, young people and adults to exercise their rights to participate in ordinary life opportunities through a proper understanding of their behaviour and access to appropriate support.

To meet these objectives, we have identified and prioritised three interconnected main areas of need: **'information and support'**, **'strategic influencing'** and **'sharing best practice'**, as described below in more detail. We build on, refine and enhance our work in these three areas as they have shown to be effective. More information about the work of the charity can be found on our website:

www.challengingbehaviour.org.uk



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How we work

As a small charity with limited resources, we carefully consider the impact of our work, and retaining our independence is funfamental. This year we carried out a formal Theory of Change exercise to review and confirm our overall aim and the steps we are taking to achieve it. We have identified four key communities across the lifespan where we can have the greatest impact on people's quality of life. These are:

- Early years - early intervention and prevention
- Transition - moving from child to adult services
- Older family carers - planning ahead
- Risk of crisis (at any age) - supporting families to get additional support to meet their relatives needs

We will particularly focus on these throughout our 3 areas of work: **'information and support'**, **'strategic influencing'** and **'sharing best practice'**.

Lived experience is embedded within the organisation and informs and shapes all our work. All our workshops are co-produced and co-delivered by a PBS professional and a family carer with lived experience, modelling the partnership approach we promote. This year we have built on our 'seldom heard' work with a new project to gather the views and experiences of individuals with learning disabilities and complex communication challenges to inform our policy work and influence at a national strategic level.



As an organisation we arrange our support and work around the needs of families rather than on what is administratively easier. The range and scope of our work is wide as it reflects the breadth and complexity of the systems and services that families have to navigate through to secure the support needed.

We adopt a lifelong human rights approach which spans education, health, and social care, using legal, policy and best practice frameworks to drive change at an individual and strategic level.

More can be achieved by working together. Although our focus is on supporting families, we know that working collaboratively with a range of other partners can achieve good outcomes. We therefore provide a range of information and support to professionals and families involved in supporting children and adults with severe learning disabilities whose behaviour challenges. In addition, this year we have co-produced new resources around whole family approaches and raising awareness of the trauma the system can cause to families.

In all our work, our approach is one of **'working with – not doing for'** as this shares knowledge and skills and promotes a sustained legacy. This is in alignment with our long-term goal which is there is no need for the CBF to exist because the system works for children, young people, adults, and their families to deliver the right support in the right place at the right time. It is this ultimate goal that shapes everything we do.

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Internships at the CBF

This year we have again been able to offer 2 internships at the CBF. We have now had 31 paid internships since 2011 covering Family Support, Policy, Research and Communications. Each internship is for one year and provides valuable experience in learning disability, working with a range of professionals in the field, and gives insight into the experience of family carers.

Previous CBF interns have gone on to:

- Policy and communications roles in the voluntary and public sector
- Practitioner roles such as: social work, learning disability and mental health nursing and special needs teaching
- Further study at Masters and PhD level in related fields

We continue to have discussions to explore the development of our intern scheme through partnering with an academic centre and a support provider but due to capacity and other priorities we have not been able to progress this further. We remain hopeful that this is something we will be able to do in the future.



"The CBF internship has been a brilliant introduction to working in the charity sector and to the field of learning disability. Right from the start I was given the opportunity to be meaningfully involved in the CBF's work and I've gained really valuable skills, knowledge and experiences. The CBF team are really supportive and their enthusiasm and knowledge is inspiring – I'd recommend this internship to anyone who's interested in working either in the field of learning disability or in the charity/policy sector more generally. **– CBF Intern**



"The knowledge I have gained and experiences I have had during my internship at the CBF have been invaluable and I am so grateful. The whole team are amazingly kind and will ensure that you gain as much as possible during your time with them. **– CBF Intern**

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The Challenging Behaviour Foundation

Objectives and activities
Information and Support



Lived experiences gathered from our information and support service drives our strategic influencing work which interconnects with sharing best practice.

Our family support service offers a range of free, confidential, and expert resources to families including support delivered through:

- telephone helpline
- ongoing in-depth casework
- email information
- printed and filmed resources on a range of topics
- website information
- peer support networks including 'listening ear' calls with trained family carers, email networks, closed Facebook group and online carer catchups.

Further information on our family support service can be found here:

www.challengingbehaviour.org.uk/for-family-carers/

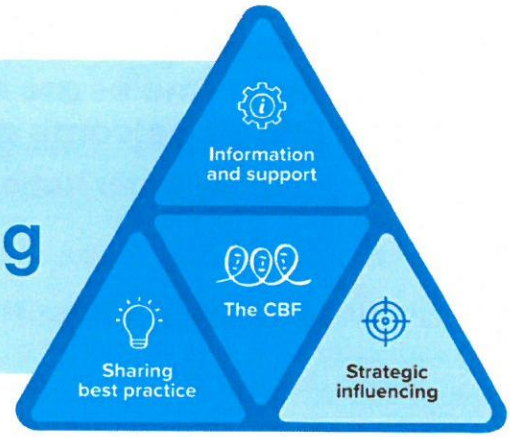
Information for professionals can be found here:

www.challengingbehaviour.org.uk/for-professionals/

> **Your resources are written so well, I didn't expect to find so much detailed information which I enjoy reading and find very useful, I really like and appreciate your holistic approach and describing challenging behaviour in a gentle helpful way, not scaring parents/carers. it means a lot for us to read your information and advice**
>
> **- Family Carer**

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Objectives and activities
Strategic Influencing



Our strategic influencing work is informed by families lived experience gathered through our family support team and utilises examples of evidence-based best practice.

Our strategic influencing work focusses on ensuring all parts of a complex system work well and deliver good outcomes for children, young people and adults with severe learning disabilities whose behaviour challenges and their families.

This work requires an understanding of the holistic context in a system that is often organisationally disjointed and fragmented.

> **"Supporting a child with severe learning disabilities whose behaviour is challenging on a daily basis is difficult enough- but added to that is the major challenge of trying to navigate your way through a disjointed and fragmented system to get support – it's exhausting and relentless**
>
> **- Family Carer**

We are solution focussed, believe more can be achieved by working together and facilitate joined up and collaborative working. We established and continue to chair the influential 'Challenging Behaviour - National Strategy Group' (CB-NSG), a unique multi- stakeholder group whose members include family carers, senior representatives from health, education and social care, government departments, regulators, service providers, clinicians, and researchers.

www.challengingbehaviour.org.uk/what-we-do/national-strategy-group/

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> **It was a great day thanks so much for inviting me. The fact that families are so integrated is so meaningful and unique. I feel so welcome and at home**
>
> **- Family Carer National Strategy Group Member**

Our aim is to ensure the system focusses on early intervention rather than crisis.

> **The CBF promotes and highlights the need for an early intervention approach, to work with and invest in families as valued partners, and with full and meaningful co-production**
>
> **- Professor Richard Hastings, Director of the Centre for Research in Intellectual and Developmental Disabilities, University of Warwick**

In partnership with others, we work to find ways to seek the views and input of children, young people and adults with the most complex needs and share and promote their engagement.

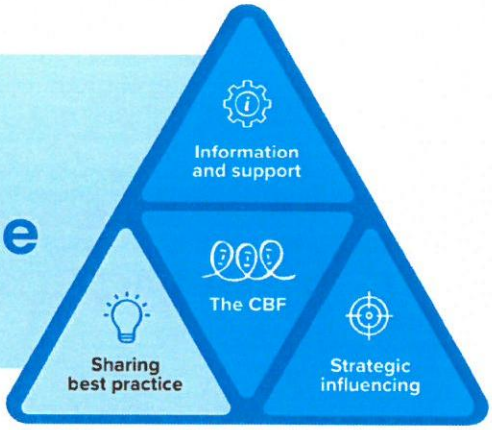
We have developed positive relationships with researchers to amplify the voice of families of individuals with severe learning disabilities in research, and we support families to input to national policy making and service development. Our work aims to push forward the agenda for better and timely local provision, with enhanced skills and training for families, support workers and paid carers.

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Objectives and activities

Sharing best practice



Sharing best practice is embedded in our strategic influencing work and our information and support.

Best practice provides evidence that **it is entirely possible to deliver the right support in the right place at the right time.**

Sharing, modelling and actively promoting best practice on the ground runs through all our work. We do this through our family support casework and resources, strategic influencing work, and family carer and professional email networks, as well as through specific projects involving local authorities, government departments, and other partners.

We are investing additional capacity, using our reserves, to support, build on and deliver best practice learning from our project work. This has included co-production of new workshops (for example, 'whole family approaches' and 'trauma awareness') as well as working with local family carers and stakeholders in specific geographic areas to provide additional resource, capacity, and experience to empower and facilitate local families input at a strategic level.

Public Benefit

In planning and reviewing the charity's activities to meet these objectives, the Trustees have taken account of the Charity Commission's guidance on public benefit. The CBF delivers public benefit by providing information and support to families and professionals caring for and supporting children, young people and adults with severe learning disabilities whose behaviour challenges. All our information and support is provided free of charge to family carers. We also work to improve the understanding of behaviours that challenge amongst professionals and the wider public, helping others to provide better support and services and more opportunities.

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Achievments and performance

Information and Support



> **Thank you, as always, for your invaluable help and support. It makes a huge difference to know we have this informed help and that you 'have our backs'**
>
> **- Family Carer**

Our family support service has responded to 2625 queries through our support line, email and website this year which is a 70% increase on the previous year. With the Triage Officer in place, this increase now shows a more accurate picture of all the enquiries received and responded to, including signposting and providing one-off information as well as family support and casework.

We had over 33k resources downloaded from our website, a 20% increase from last year. The large amount of information available on our website ensures that the families we support have 24-hour access to information around the key issues that impact on their lives. Our family carer review panel and professional volunteers help us to review and update our resources, to ensure they are current and helpful.

2625
Queries through our support line

33,000+
Resources downloaded from our website

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Family carers who contact the CBF may need differing levels of support and information. They will initially be triaged. The triage role continues to be an efficient way of prioritising and signposting enquiries and access to specialist caseworker support. Family carers who contact the CBF may be offered a range of free resources which can be emailed or downloaded from the website. If required, these resources can be posted out as not all families will have access to the internet or a printer.



www.challengingbehaviour.org.uk/information-and-guidance/

Some family carers will need to speak to an experienced family support team member about a specific issue or query which may take the form of one or two calls/emails.

Some family carers may have more complex situations and will require more ongoing casework support which can range from three calls/emails to ongoing support spanning months or years. This level of ongoing support reflects the complexity of the situations that families are managing for their relative which can include significant health issues, concerns over care and support, rights and the law, financial disputes around the funding of the support package, safeguarding, transition and being served 28 days' notice to leave current provision.

Families approaching us with these multiple complex issues often require intensive casework over a long period. The average period of support is six months with some families returning over many years for further support as new issues emerge.

Case Study

P contacted the CBF when her son D was living in a children's home in another local authority. P was concerned about the support that D was receiving and wanted him to move closer to home. P felt that the funding authority were not listening to their concerns or request and the relationship between P and the professionals had broken down. The CBF have been providing support to P for three years, this has included support to:

- Request a move back to the local area
- request a mental capacity assessment and best interests decision
- request family visits at Christmas time (that were initially refused)
- facilitate family involvement at medical appointments via three way calls
- meet with an MDT to coproduce a PBS plan
- develop a working relationship between P and staff at a new school
- engage with Court of Protection process including meeting with P's solicitor
- raise a serous safeguarding concern including liaising with the Police

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- maintain a working relationship between P and professionals
- respond to 28 days notice to leave from the current provider – ensuring a longer transition period
- consider a potential new care provider
- request a medication reduction plan

It was not possible to support P with these issues in isolation, one by one. As often happens for families of disabled children, young people and adults, one issue affected or was intertwined with another. This can be overwhelming and highly emotive for the families we support. The caseworker was able to devote time to understanding P's views, which built a trusting relationship, whilst picking apart complicated parts of the 'system' and helping P to understand them.

The Legal Panel of specialist legal experts representing all the leading law firms specialising in learning disability law, convened and chaired by the CBF, continues to provide valuable expertise and support on a voluntary basis. We continue to play a vital role in enabling and supporting families to be aware of, understand and navigate the legal framework and to access legal advice and support to take appropriate action. During the year we have referred a number of families to the panel. They received the specialist legal support required to take their issues forward or were given support specific to their circumstances. (See page 21 for further information about the strategic work of the Legal Panel)

> **"The CBF has been an invaluable support to my family for almost 3 years now. From when my son had to leave his school setting earlier than planned, they helped me to get a solicitor for unfair dismissal for discrimination. We won the case for that, and then also when he was held in an ATU they helped me constantly with supporting me to challenge the people in the ATU and the CCG. I will never forget their help and support which is still going on to this day as there is always something to challenge**
>
> **- Family Carer**

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Peer support

We continue to support a range of initiatives that provide different types of peer support to meet the varying support needs of families who contact us.

www.challengingbehaviour.org.uk/for-family-carers/peer-support/

> **Without the CBF I would not have been able to understand my rights as a parent of a disabled adult. Being part of the Family Email Network, I feel very much part of a community who share the same problems and joys of looking after a disabled adult**
>
> **- Family Carer**

This includes:

Listening Ear Calls

We continue to support two committed familly carers who offer listening ear calls to our families. These are opportunities for families to speak to people who understand and are non-judgmental. The feedback has been extremely positive.

Email Networks

Our family carer email network now has around 500 members and continues to be regularly used. This forum continues to enable families to ask one another questions, share solutions and seek support around issues impacting their daily life, support package or relative's behaviour that might be described as challenging. Families can also ask our Professional Panel questions via our professional email network, a network of over 1400 practitioners from across the health, education and social care sectors who also use this forum to share information, learning and asking their peers questions to support their work and disseminate good practice.

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Carers Catch Ups

During the pandemic, we started online carer catch up group meetings. These are led by a volunteer CBF Local Champion and provide an opportunity for family carers to meet online to share experience and support their wellbeing as we know that the majority of families who contact us describe feelings of isolation. Now that the pandemic has passed, we continue to facilitate these groups and working with families and plan to develop some themed carers catch up meetings. This year we have extended our catch-up meetings to carers catch up plus and piloted wellbeing activities within the groups. We are reviewing feedback and consulting families about what they find helpful and useful.

> **I always look forward to Carers'Catch Up which is valuable for me as I share my problems and joys with other families around the country via Zoom**
>
> **- Family Carer**

The CBF Family Forum (closed Facebook group)

This forum continues to enable family carers to support each other in 'real time'. Currently the group has around 350 members and is limited to individuals with a relative with severe learning disabilities to ensure that the group is an understanding and empathetic forum. The group is monitored for safeguarding concerns by volunteer family carer local champions supported by CBF staff.

> **I'm lost for words!! This looks just like what I'm looking for! I can't thank you enough**
>
> **- Family Carer**

Helpline Collaboration

The CBF, in response to our understanding that families often get passed to several helplines and charities before they find the right one for them, continues to convene and facilitate a Helpline Collaboration. This year membership has increased and now includes Mencap, the National Autistic Society, Contact, Cerebra, Unique and Mencap Cymru. Meetings happen once a month via Teams, and we share information about each of our services, identify common issues coming to us from families and provide peer support to each other, which is especially appreciated by those who attend.

> I find the Helpline Collaboration Meetings very useful. It is great to be able to share good practice with other organisations and to find out what everyone else does on a day-to-day basis - which in turn, makes it easier to signpost families to specific organisations for specific issues. **- Group Member**

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Achievments and performance
Strategic Influencing



As a small organisation we can achieve much more by specifically informing and encouraging individuals and organisations in positions of power and influence to raise their understanding and awareness of the issues individuals and families face, and to influence their activity. We aim to promote collaboration to drive progress. The three strands of our work are inextricably linked and closely aligned. In practice our family carer experiences steer our influencing work. We continue to raise concerns and challenges to a range of senior individuals and organisations both at a local and national level where individuals' human rights are being breached. Our strategic work is wide-ranging and varied and aims to influence all parts of the complex system which is meant to be working in a coordinated way to deliver good outcomes to children, young people and adults and their families.

Challenging Behaviour National Strategy Group (CB-NSG)

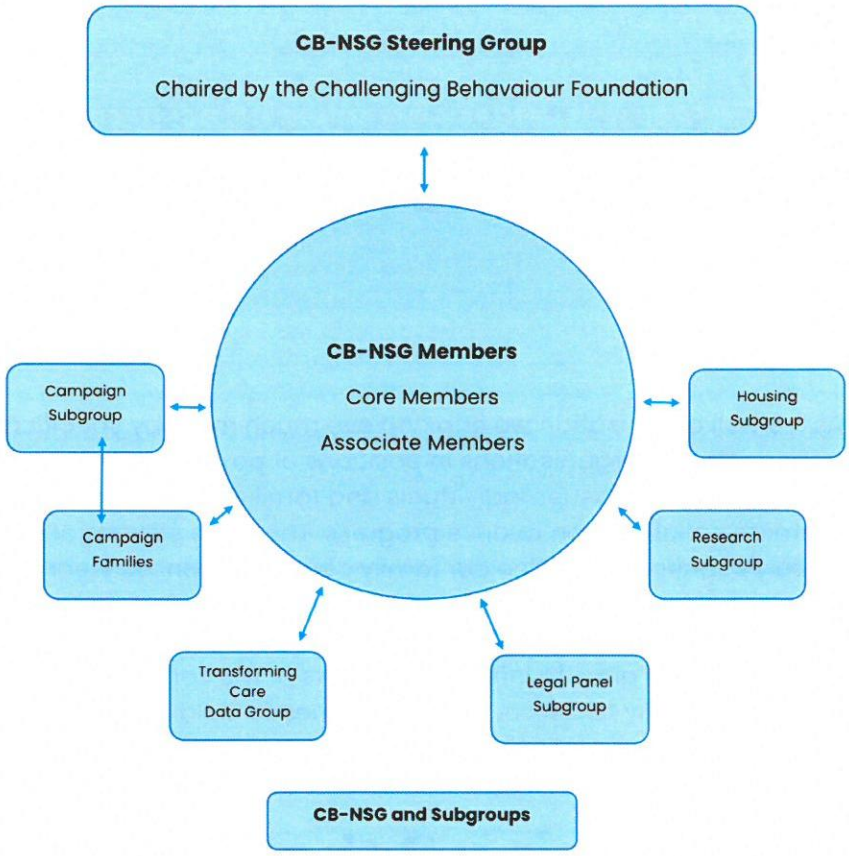
We remain very grateful to the Esmee Fairbairn Foundation for their continued support and funding towards the National Strategy Group and its work. The CB-NSG includes representatives from professional bodies, networks, charities, and the government alongside family carers, people with learning disabilities and researchers. It is based on the principle that if all the individuals and organisations who have a role to play in supporting this group work together in a coherent and coordinated way it will deliver better outcomes.

www.challengingbehaviour.org.uk/what-we-do/national-strategy-group

> **Great day today, thank you to you and the whole team, it takes a lot to bring everyone together and it's so useful**
>
> **- National Strategy Group Member**

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There are currently over 90 core CB-NSG members who have significant knowledge and expertise, and a senior level role in supporting and delivering services to people with learning disabilities, and over 600 associate members who commit to working following the values and principles of the co-produced Challenging Behaviour Charter.



Campaigns Sub-group (including Campaign Families)

CB-NSG members continue to meet regularly to share information about policy and practice and agree campaigning priorities, including aligning with, and supporting activities by other individuals and organisations.

Over the past year the Campaign Families group have taken part in a range of influencing activities:

- Provided input to multiple consultations including the Mental Health Act Consultation
- Responded to the 'Building the Right Support' Action Plan
- Participated in the All-Party Parliamentary Group Meetings
- Agree campaigning priorities for the coming year

Legal Panel Sub-group

We continue to maintain our established legal panel consisting of specialist lawyers and barristers who provide pro-bono information and support to families who contact our family support service. The aim is to ensure free initial access to timely specialist legal advice with the CBF supporting the family through this process. This year, we continued to take forward the strategic legal work identified by our legal panel and built on our collaborative working relationship with key experts in the legal field. Highlights include:

- Continuing to provide legal advice to families referred to and supported through our family support team
- Planning and contributing to a wider legal strategy meeting with families, advocacy organisations and providers to identify key issues, share resources and co-ordinate activity
- Continuing to take an interest in legal opportunities to challenge the failure of the 'Transforming Care' programme and to work with other organisations who share our concerns. We have met with the Equalities and Human Rights Commission to consider legal options

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The legal panel members continue to work together to consider and address key areas of legal challenge both related to the inequalities for people with learning disabilities which have arisen as a result of the cost of living crisis and the ongoing inequalities due to failures in Transforming Care.

Positive Behaviour Support/Research Sub-group

This group will link together some key research initiatives with CB-NSG member involvement including the PBS academy, Sharland Foundation Development Disabilities ABA Research and Impact Network (SF-DDARIN) and the Tizard Centre. New co-chairs have been appointed, an academic and a family carer, and the group will be developed in the coming year.

Data Sub-group

The group has continued to focus on analysing and using the data published by NHS England and the Care Quality Commission (CQC), particularly regarding unit characteristics, a regional breakdown of patients currently receiving inpatient care who do not need it according to their care plan, along with further details about individuals working towards discharge.

The data group has continued to highlight the need for improved data collection across children, young people and adults with NHS Digital around the Assuring Transformation and Mental Health Services Data Sets and feeding into various consultations including the SEND Green paper review.

Other strategic influencing

Protecting Rights Eliminating Restraint Group (PRER)

Formally known as the Reducing Restrictive Interventions and Safeguarding Children (RRISC) group, members have agreed to change the name to better reflect the approach from reducing (which could be by a relatively small amount) to eliminating inappropriate restraint. This group focusses on children and takes a UK-wide approach with members from all four nations. The group has continued to meet twice a year sharing progress and initiatives to drive change across the UK.

The External Support Group

The External Support Group (ESG) brings together a number of individuals with significant practical experience in supporting people with complex needs in community settings, including developing individualised packages of support and maintaining that support to provide good outcomes for individuals. Areas of expertise in the group include experience in clinical/medical practice, commissioning, inspection and regulation, research and evidence, advocacy, the third sector and family support. An animation showing the work of the ESG has been co-produced to explain the approach on a dedicated webpage on the CBF site.



www.challengingbehaviour.org.uk/what-we-do/projects-and-research/support-and-services/the-external-support-group-esg/

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STOMP/STAMP

The STOMP (Stopping Over-Medication of People with a Learning Disability, Autism or Both) STAMP (Supporting Treatment and Appropriate Medication in Paediatrics) programmes are initiatives within NHS England to try to address the issues around medication. There has been a renewed NHS England focus on the STOMP/STAMP work, and we have been commissioned to work with their team to gather the views of family carers on what is needed and what would help to progress this work.

https://www.challengingbehaviour.org.uk/what-we-do/projects-and-research/changing-poor-practice/medication/

We supported family carers to input to the National Children's safeguarding enquiry into abuse at 52-week schools run by the Hesley Group. The review led by Dame Christine Lenehan was in two phases. We supported family carers to input to the work and review the recommendations arising from it. We will continue to work to monitor and promote implementation of the recommendations.

https://www.gov.uk/government/publications/safeguarding-children-with-disabilities-in-residential-settings

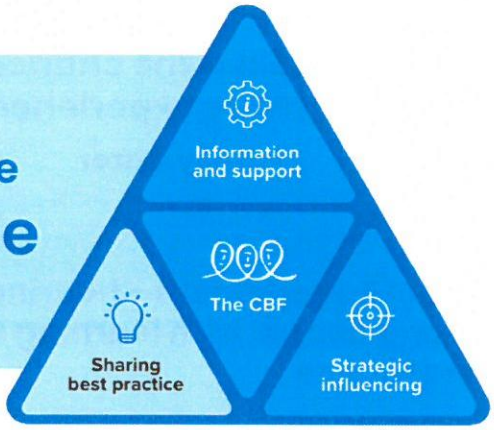
> **The views of parents have significantly influenced the development of the Report and I am really pleased that the panel have used a lot of the information and insight from the Challenging Behaviour Foundation**
>
> **- Dame Christine Lenehan, Director National; Children's Bureau**

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Achievments and performance

Sharing best practice



The principle of sharing and actively promoting best practice runs through all aspects of our work. We share and promote best practice through our family support work, including casework and resources, and our national influencing work. This includes disseminating information via the CB-NSG, its core and associate members, our family carer and professional email networks as well as our extensive networks. We are invited by researchers to contribute to a range of projects which vary from recruiting members to advisory or reference groups to leading Public and Patient Involvement (PPI) facilitating focus groups with family carers to ensure their input to the research and its dissemination and supporting recruitment to trials.

Workshops

All our workshops have been co-designed with families on topics where they have identified gaps in knowledge and understanding. The workshops are co-produced and are co-delivered with family carers, modelling the partnership working approach we promote.

This year we have extended our range of workshops to include Trauma Awareness, PICA behaviour and Whole Family Approaches, alongside our existing Positive Behaviour Support and Communication workshops. We continue to recruit, train and support co-facilitators with in-built evaluation and quality monitoring procedures.

Building on previous work to raise awareness of the trauma experienced by family carers in their interaction with 'the system' in trying to get support for their family members, we have developed new materials to deliver a longer and more in-depth workshop. This was because of feedback from the initial pilot and the wishes of the families involved in making the films. The workshops need to convey the voices and consistent messages of the families, be co-facilitated with a family carer and provide awareness of the issues. We invest in robust recruitment and providing additional support to family carers delivering the workshops to ensure they are not further traumatised by the sensitive and difficult content.

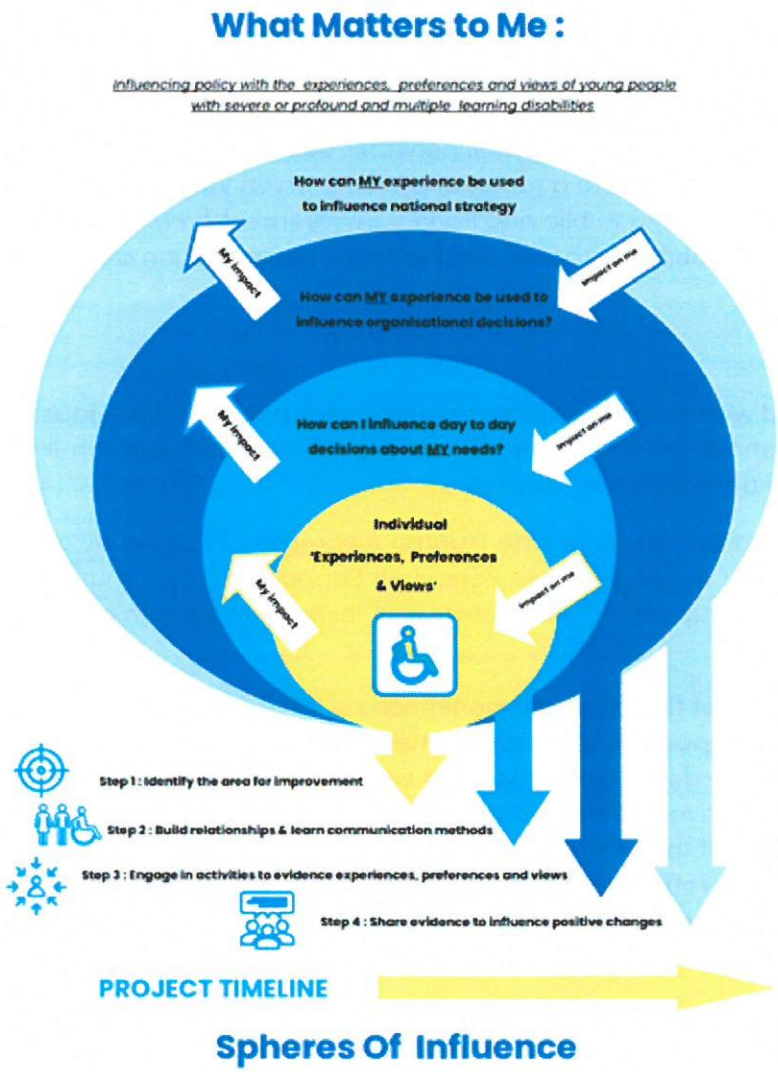
> **Thank you, I really enjoyed it and would highly recommend it. The co-trainers are fantastic**
>
> **- Family Carer**

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> **I liked the chance to meet other people in the same shoes and share experiences**
>
> **- Family Carer**

Direct Engagement - hearing the views and experiences of children and young people with learning disabilities and complex communication challenges



Building on our successful 'Seldom Heard Voices' project (report provided to NHS England but not published) and in recognition of the need to get better at seeking the views of children, young people and adults with learning disabilities and more complex communication challenges, we have started a three year project funded by The Blagrave Foundation and Children in Need to work with children, young people and those who know them well to gather their views about policies that affect their everyday lives. This project is called 'What Matters to Me' and will build on previous work by CBF, the Tizard Centre and others with the aim of producing an accessible youth manifesto in year 3.

www.challengingbehaviour.org.uk/what-we-do/projects-and-research/valuing-individuals-and-their-families/what-matters-to-me-project/

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Advocacy

There are two areas of work around advocacy: A national review which CBF has provided input to and regional work in two areas.

National work

The CBF has been a member of a steering group for a national review of advocacy support provided to people with learning disabilities and/or autistic people. CBF has also been commissioned to gather the views of family carers both in their role as advocates and their views about advocacy support provided to their adult relative. Other organisations on the steering group have collected input from other stakeholders and all the individual reports have been collated into a national report which was due to be published in March 2022. The revised date for publication has been set for March 2023 – at the time of writing this report the report remains unpublished with no new date set.

Regional work

The CBF partnered with organisations in two local areas to identify family carers experiences of advocacy and of advocating for their relative and what would be helpful to support them in this role. A comprehensive, co-produced resource is being developed and will be available for family carers online and in print.

Getting It Right Project

We are coming to the end of a three-year project funded by The National Lottery Community Fund building on our previous work and experience of local area and national strategic work. In year one we worked with West Sussex, year two with the Black Country and year three with Camden. We are currently awaiting the final evaluation of the project and will take forward the findings.



www.challengingbehaviour.org.uk/what-we-do/projects-and-research/support-and-services/getting-it-right/

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Keyworker Project

The CBF continued to work with Black Country Transforming Care Partnership (TCP) to enable development of a peer support model as part of their Key Working for Children and Young People pilot. This pilot is one of a number funded by NHSE across the country. The CBF and the Council for Disabled Children called for keyworkers in the publications Paving the Way and the Lenehan review, based on the findings of our joint Early Intervention Project.

The aim of the pilot is to employ key workers from a range of backgrounds. These key workers will work as a team supporting each other to provide flexible and timely input to children and young people, families and carers across the Black Country, dependent upon the demand identified through the Black Country dynamic risk register. The CBF and Dudley Voices for Choice worked together to establish peer support for families once they step down from keyworker support.

Input to Research Projects

In line with our aim of sharing family lived experiences and building evidence to inform our strategic influencing work, we have continued to support and shape a variety of research applications and funded projects with a wide range of academics and researchers. We have continued to provide input to steering and advisory groups and supported paid family carer participation in consultations and focus groups, including translating research findings into practice.

We continue to encourage and support families to contribute to consultations and calls for evidence so that their experience and views are heard and included in any response that the CBF submits. We have responded to a range of consultations/calls for evidence with input from families to highlight the issues for children, young people and adults with severe learning disabilities whose behaviour challenges and their families.

www.challengingbehaviour.org.uk/what-we-do/strategic-influencing/consultations/

MindEd

We continue to support the development of resources for this free online educational resource focussed on mental health, by supporting family carers as co-authors of materials relating to issues of importance to people with learning disabilities and their families. For this year, resources for the STOMP/STAMP programme have been developed.

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Newsletter

We produced an electronic and printed newsletter on the topic of 'Health and Support Post Covid' which was sent out to around 3000 people in hard copy to ensure families throughout the UK without digital access were not left out.

We will continue to seek funding and partnership opportunities for hard copies of our newsletter to be sent out in the future.


Challenge
The Challenging Behaviour Foundation
Health & Support Post Covid
Resources in this issue
Contents

https://www.challengingbehaviour.org.uk/news/challenge-newsletter -spring -2023-health-support-post-covid/

Social Media

We continue to use our social media platforms to share good practice information and practical resources. All our social media platforms have seen an increase in followers this year allowing us to reach more people.

Looking back over the year

This year has seen a combination of continuation of ongoing work and support as well as new projects, all encompassed within our three core strands of work - and all with lived experience and co-production at the core.

As a small team with limited resources, we have to work efficiently, flexibly and effectively, ensuring that we always focus on outcomes and impact. We have many years of experience that inform all our activities and approach.

We know that the change we want to see for everyone will not happen quickly - and that it will only be achieved by persistence and working collaboratively. We will continue to champion and independently advocate for the rights of individuals and their families to be upheld, and for investment in early intervention and community support and services to ensure the system delivers what it needs to **- the right support in the right place at the right time.**

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Financial Review

Financial position

Incoming resources for the year amounted to £530,447 (£610,424 in 2021/22) and resources expended were £522,982 (£516,484 in 2021/22), giving net income of £7,465 (£93,940 in 2021/22). The reduction in income is due to a fall in earnings from consultancy and other paid-for services, which amounted to £138,652, compared with £222,284 the previous year. These are ad hoc activities which inevitably fluctuate from year to year. The lower net income for 2022/23 also reflects the tightening of the external financial situation, with increasing pressure on costs and competition for funding, although grant income remained consistent with 2021/22.

The support of trusts and foundations remains vital in enabling us to remain independent and carry out work to increase the CBF's impact while helping to maintain its financial viability. We would like to extend our grateful thanks to all supporters who have enabled us to achieve this. The receipt of a three-year grant from the National Lottery Community Fund has enabled us to raise awareness of our evidence-based approach much more effectively. We wish to thank the Esmee Fairbairn Foundation, the John Ellerman Trust and the Blagrave Trust for supporting our policy and influencing work, and the Colyer-Fergusson Charitable Trust for helping to fund our family support service. Thanks are also due to the Pears Family Charitable Foundation and several smaller foundations for supporting core costs.

Looking ahead, there is no doubt that the funding environment is becoming more challenging than ever. Most paid work is ad hoc, unpredictable and fluctuates in volume, while grant funding is one-off or relatively short term and subject to fierce competition. Several multi-year grants have recently ended and are proving difficult to replace. In the light of this, the Trustees recognise the critical importance of scrutinising regular forward projections, reviewing closely the financial performance of individual projects and identifying pre-emptively any funding gaps and the actions needed to address them.

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Reserves policy

The Trustees have reviewed the key risks across the organisation and have set a target of holding closure costs plus six months running costs in free reserves (unrestricted funds) to ensure the charity is in a stable position to:

1. Fulfil notice periods, statutory redundancy and meet all other obligations and liabilities in event of closure of the charity.

2. Provide effective staffing to seek alternative funding and support the development of alternative forms of support for families in need of long-term casework in the event of a downturn in income or closure (we typically provide casework support to families for a period of six months to three years).

3. Enable the organisation to respond to unforeseen external challenges such as an increase in demand similar to that experienced during the COVID-19 pandemic.

4. Provide a level of flexibility to respond to any opportunities that may arise at short notice to influence national policy on behalf of our beneficiaries. In taking any decision to use reserves in this manner the Trustees take account of the CBF's charities financial position ensuring that any risks do not impact on its sustainability.

In determining the reserves strategy, the Trustees have taken a holistic and strategic approach, considering carefully the reasons for maintaining reserves as well as the logistics of utilising them. This includes consideration of the external factors that may affect reserves such as demands on capacity and the high competition for and relatively short-term nature of grant funding, which forms a large part of the charity's income, and often involves a long lead time to secure.

Free reserves amounted to £450,522 at 31 January 2023, representing approximately six months of running costs, after taking account of estimated closure costs, based on predicted expenditure for 2023/24. We anticipate that reserves will reduce during the next financial year in the light of the difficult financial outlook, unless we are able to secure funding in excess of the level anticipated in our 2023/24 budget.

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Our plans for the coming year

We plan to recruit 1 new intern in the coming year. We will also invest in a new post to take forward our co-production and engagement work under the sharing best practice stream. This new role will be piloted for a year and funded from our current reserves. Our core aim of making society inclusive and the statutory support systems work effectively for children, young people and adults with severe learning disabilities whose behaviour challenges and their families remains and shapes all our work and plans.

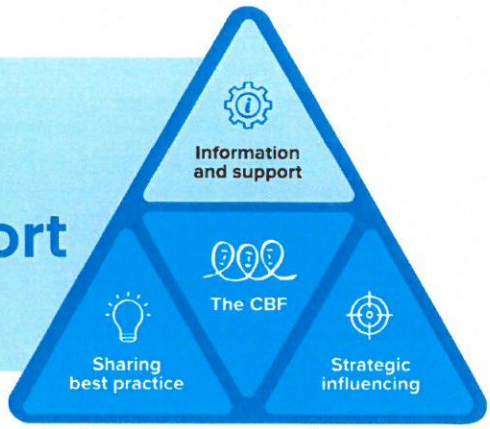
Our ultimate aim as an organisation is not to be needed because the 'system' works, although we know this is a long-term aim and in the interim, we need to sustain our work. If and when more capacity is required, we intend to utilise consultants who have been through our core training, to enable flexibility without long-term financial commitment, unless there are new opportunities for funding fixed term posts which arise for project work we want to take forward.

We continue to see funding challenges emerge as the pandemic costs are repaid and the impact of the cost of living crisis on our organisation, the families we support and the wider community is felt. Trustees are mindful of potential future financial risks and plan accordingly, including close financial monitoring.

Our core aim remains to ensure that "the system" and society enable individuals with severe learning disabilities, and their families, to receive the right support in the right place at the right time. Our approach, and all our work is carefully planned and thought through with regular reviews to consider outcomes and impact, and in the coming year we will continue to focus on our three key interconnected areas of work. Our many years of experience have informed and refined our work and how it is delivered to achieve impact and good outcomes. The change we want to see is significant and takes time. Although we are acutely aware of the urgency and are ambitious and impatient for change, we are realistic regarding our capacity, the inertia and resistance to change within the system, and the need and investment required to work collaboratively.

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Future plans
Information and Support



We plan to continue to ensure our specialist family support and information service is maintained, continues to be family centred, and provides high quality independent expertise and advocacy for families in need. The families we support are often in very complex situations, navigating through disjointed education, health and care systems, and experiencing marginalisation, "parent blame" and exclusion often simultaneously. Families clearly describe "the fight" for the support and services their relatives need, and their experiences of discrimination and basic human rights being ignored.

Funds generously provided by Pears Foundation, the Garfield Weston Foundation, Colyer Fergusson Charitable Trust and The Steele Charitable Trust for our family support helpline and casework are vital to enable this work to continue. As some multi-year funding ends, we will continue to prioritise seeking further funding to ensure we can maintain and develop the support and information we provide for families who are often in crisis.

We will continue our peer support Facebook group to offer families the option of different forms of peer interaction and communications. This will run alongside the existing 'Family Carer Email Network' to cater for the differently technologically-suited groups of families who benefit from having access to online interaction and peer support. In addition, we will continue to offer a telephone "listening ear" service to provide trained and supported peer support to those who cannot access or prefer not to use our online support networks.

Due to reduced capacity in the team this year, we have not been able to take forward our review of the diversity of the families who use the CBF's information and support service and work to increase inclusion for a broad range of families, particularly those from 'hard to reach' communities. We aim to carry out this review in the coming 18 months. We will continue to send paper newsletters (subject to identifying funding) and information resources to families who do not use the internet or who request hard copies of resources.

We plan to scope out producing podcasts with a mix of family carers and professionals on a range of topics which will provide a new way to share information in an informal and engaging way.

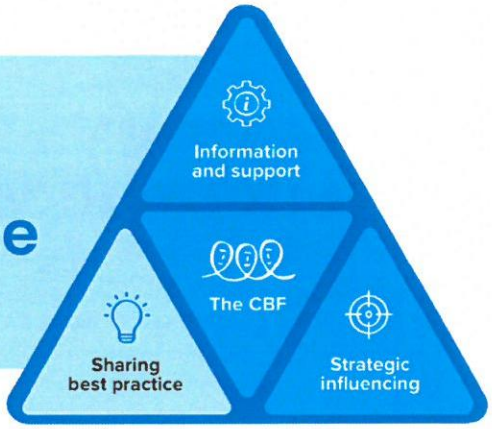
We will be producing new resources for older family carers along with an updated and comprehensive advocacy guide.

Our family support and information service takes a lifelong approach and we will consider how we target families in particular situations to increase our impact and as part of that, we will review how we record information to enable us to collect and analyse data.

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Future plans
Sharing best practice



Using our unrestricted reserves, we will invest in piloting a new role leading this strand of our work. We will use this pilot role to test opportunities that have emerged from our project work demonstrating the delivery of a tested and locally sustained model. It will focus on good outcomes that properly engage local families as valued expert partners at a strategic and grass roots level.

An example of our work moving from a strategic influencing project to local implementation is the Getting it Right Project which initially targeted three local areas, each with intensive and specialist input for one year. This year we will take forward further work with one of these areas to help deliver the actions identified in the project and employing and supporting a local family carer to deliver and embed this work and sustain the momentum. Likewise, our input to a Keyworker Pilot has resulted in further work to sustain peer support and evaluate the impact.

Co-production is a key principle of all the work of CBF and will continue to be so. To help promote this approach and measure its impact, we will work with families to develop a resource outlining what family carers expect from co-production. We will use this resource as a measure of our own performance and the underpinning principles of working with partners.

Promotion of early intervention approaches, both in terms of support in early childhood as well as early support with emerging behaviours that challenge, will remain a key feature in all three strands of our work. We will continue to collate and present evidence of the positive benefits of early intervention, and work with researchers and academics to achieve this. We plan to work with researchers to utilise our Early Intervention report published with partners in 2022 and to continue to promote investment in families and availability of timely specialist support.

www.challengingbehaviour.org.uk/news/new-report-launched-investing-in-early-intervention/

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The views and experiences of children and adults with severe learning disabilities are often disregarded as they are unable to attend or use traditional methods such as focus groups or surveys – but it is important that we adapt our approach to enable their views to be captured. We will therefore continue to develop our work on engagement with children, young people and adults with complex needs, working with other leaders in this field, to find innovative ways to seek their views, and to demonstrate that it is possible to consult with them in a meaningful way. At the same time, we will take every opportunity, in our own work and the work of other organisations, to ensure that families of children, young people and adults with complex needs can share their lived experience to drive forward change. We will be completing the scoping phase of the 'What Matters To Me' project, identifying two project partners to work with and beginning the active engagement with the young people.

www.challengingbehaviour.org.uk/what-we-do/projects-and-research/valuing-individuals-and-their-families/what-matters-to-me-project/

Our PBS workshops for family carers and professionals supporting children and adults with learning disabilities are well established with positive feedback, and we will promote them to increase delivery this year. We will work with researchers to apply for funding for further formal evaluation of our PBS workshops, and other research initiatives will be pursued, both with academic partners and through our CBF/ Tizard Family Carer research group, to further build the evidence base. In partnership with a range of other individuals and organisations we will work to develop a national learning disability research strategy.

We will build on our newly developed and piloted 'Whole Family Approaches' and PICA (eating inedible objects) workshops and will promote these with a range of stakeholders including family carers and the Health and Social Care Workforce.

Family experiences of trauma will continue to be an important area of work for the CBF. Funding secured from Skills for Care has been used to refine and pilot our co-produced Trauma Awareness Workshop. Feedback from participants has been extremely positive as the resource shares the authentic and direct views and experiences of families. With our newly recruited and supported co-trainers, we will promote and disseminate these to a wide range of professionals who have a role to play in supporting families. Additionally, we have been approached to write a book chapter which describes how the resource was co-produced and the issues the families have highlighted. We are also working with the Tizard Centre and KMTV to produce a short 12-minute documentary film which will be widely available and help with awareness raising and dissemination of the key messages from families about the trauma the system creates.

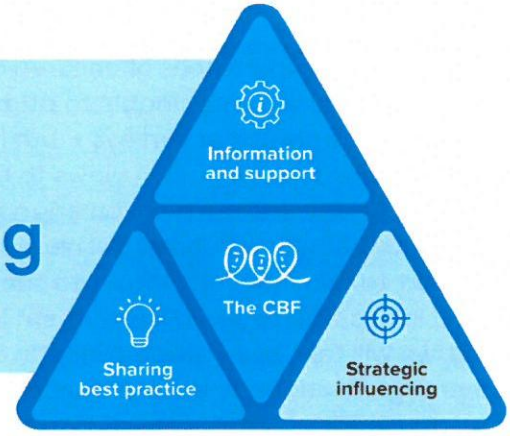
Building on our national and regional advocacy work, we will continue to promote the need for accessible, robust and independent advocacy for individuals and families, and to raise awareness of the advocacy role that families fulfil. We will finalise and disseminate the online advocacy resource.

We will work with SF-DDARIN to make research findings more accessible for family carers through support for our Intern programme.

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Future plans
Strategic Influencing



We are ever mindful that we operate in the wider context of the learning disability, carer, social care, education, health and voluntary sectors. Developing and maintaining relationships with others with similar related aims to the CBF will increase our collective impact and our collaborative, solution-focused, and evidence-based approach will continue. Working collaboratively takes longer and requires skilled management to build trust and focus on shared aims and objectives rather than differences of opinion, but we believe we can achieve more by working together and, by using this co-production approach, can deliver better outcomes.

Our influencing agenda will of course continue to be responsive to the changing political circumstances and challenges that arise. Constant reorganisations and changes in education, care and health systems and key post holders continue to pose challenges through lack of continuity, delays, and inertia. We remain committed to continuing to challenge the failure of the Transforming Care agenda. We have long called for a cross Government approach, which was initially rejected but now adopted, and we will continue to monitor whether this results in any action that makes a difference and keeps this on the national and local agenda. This work has the potential for a very significant impact for our client group and specific multi-year funding support to pursue this work to enable this vital long-term work to progress will be prioritised. There is no "quick fix" solution - it requires strategic patience, commitment and determination.

We will continue to bring together a diverse range of stakeholders, through our CB-NSG members and associates, and work in partnership to identify ways to drive forward the change needed, developing workable initiatives that build on experience and existing knowledge, and delivering a solution-focused approach. We will arrange a workshop at a CB-NSG meeting to bring together people involved in each of the three Getting It Right (GIR) sites, to share learning and outcomes and identify potential opportunities to work together to build on the GIR action plans and their legacy.

We will build on, and expand the External Support Group (ESG), a CBF led initiative, bringing together a group of senior experienced clinicians and professionals to provide support to local teams who are supporting individuals. Over the last year, the ESG has had meetings with senior Department of Health and Social Care and NHS England officials to describe the approach and how it could be utilised to support the transformation of care. As a result, the group has been approached by a Trust who have commissioned support for one individual they needed additional specialist help with. The aim is that through working with this individual, their family and the team around then, learning will be shared with the local team who will be better equipped to support other local individuals overseen by ESG members, reflecting our 'doing with not doing for' approach.

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Our work targeting professionals who work with families, increasing their awareness of need and the issues families face, will continue. We are planning to continue the strategic legal work identified by our legal panel members and the individuals and organisations who have participated in our legal strategy meetings so far. Promoting a joined-up approach to enable easier and timely access for families to legal support and information, and to ensure best use of limited resources will be ongoing. This work, linked to the CBF Legal Panel work may require seeking additional specialist capacity to drive this forward.

The Legal Panel members identified a need to develop a resource for individuals (and their families and advocates) who are in inpatient settings with "delayed discharge" due to the community support not being available. This resource will explain the specialist legal support they can access to help resolve this. The Legal Panel will develop this resource and work with CBF, other charities, advocacy groups and others to share and publicise it. We will liaise with NHS England and the DHSC to identify opportunities to promote and share the resource through their system processes.

Our work on reducing the use of restrictive interventions will continue, via the PRER (Protecting Rights Eliminating Restraint) group, and other initiatives such as the NHS England STOMP and STAMP programmes, which aim to address the inappropriate medication of individuals with learning disabilities. The PRER group updated its name from RRISC (Reducing Restrictive Interventions and Safeguarding Children) to ensure it reflects the group's goal to eliminate inappropriate restrictive practices.

Joined up working

In the coming year we will continue to progress our work in all three key areas, regularly reviewing our activities and their impact. As a small team with limited capacity and resources, we are ever mindful of the need to target our efforts carefully and influence those in positions of power who can make change happen, and who have a wider reach and more resources. Our work is wide-ranging because it reflects the multiple issues and systems that families have to negotiate and contend with, and we know that there are many areas of work that need to be taken forward concurrently. All elements of our work and projects are interconnected, we work proactively but are also able to respond quickly to opportunities and needs as they arise. This is evidenced in our response to the pandemic: and having sufficient reserves is a key enabler in this respect. We know there will be significant challenges ahead - both in terms of the needs of the families we support, and the financial challenges we will face as a small charity to secure funds for our work. We will take all the necessary steps we can to ensure we are able to continue our much-needed work, making a difference to the lives of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families.

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Structure, governance and management

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

Recruitment and appointment of new Trustees

Trustee skills are reviewed annually to ensure the board has the range of skills and experience required. Any gaps in specific skills are identified and addressed through training or pro bono consultancy input or through the recruitment of new members to the Trustee Board. This year, we have appointed two new Trustees through this process.

We are currently reviewing how our network of Trustee Advisors are supported, involved, and contribute to the CBF and will implement new arrangements following the review.

Organisational structure

The Trustees, who are directors for the purpose of company law and Trustees for the purpose of charity law, who served during the year and up to the date of this report are set out on the following page. Members of the charitable company guarantee to contribute an amount not exceeding £10 to the assets of the charitable company in the event of winding up.

Day-to-day management of the charity's activities is delegated by the Trustees to the Chief Executive Officer. The Trustee Board meets quarterly to review achievements and performance, finances, and future plans.

Risk management

The Trustees have a duty to identify and review the risks to which the charity is exposed, including ensuring appropriate controls are in place to provide reasonable assurance against fraud and error.

The Trustees have put in place a risk management strategy, comprising an annual review of the risks the charity may face, the establishment of systems and procedures to mitigate risks identified, and the implementation of procedures designed to minimise any potential impact on the charity should any of these risks materialise. The work has identified as major risks a significant reduction in funding, together with the loss of key staff members, particularly due to inflationary pressures on salary levels, reflecting the difficult financial and staffing environment resulting from the COVID-19 and cost of living crisis. The regular updating and review of financial projections and tight budget management are key elements in the management of these risks. Attention has also been focused on non-financial area such as reputational risk and suitable mitigating actions put in place, while the pandemic has highlighted the importance of ensuring that the CBF is able to respond to national or international-scale incidents that lie beyond our control.

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Reference and administrative details

Registered Company number

3307407 (England and Wales)

Registered Charity number

1060714

Registered Office

c/o The Old Courthouse
New Road Avenue Chatham
Kent
ME4 6BE

Trustees

Dr D Allen (Appointed July 2022)

Ms S Cooper

Mrs V A Cooper (Resigned July 2022)

Mr J Dodd

Ms A K Giles (Resigned October 2022)

Dr N J Gore

Ms D E Lightfoot (Chair)

Mrs C Million

Mr A Rook (Appointed July 2022)

Company Secretary

Mrs C Million

Auditors

Xeinadin Audit Ltd
Becket House
36 Old Jewry
London
EC2R 8DD

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Statement of Trustees' Responsibilities

The trustees (who are also the directors of The Challenging Behaviour Foundation for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

- There is no relevant audit information of which the charitable company's auditors are unaware; and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information, prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

AUDITORS

The auditors, Xeinadin Audit Ltd (via Calcutt Matthews Ltd), will be proposed at the forthcoming Annual General Meeting.

Approved by the order of the board of trustees on 15 July and signed on its behalf by:

Mrs C MILLION - Trustee/Company Secretary

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Report of the independent auditors

to the members of The Challenging Behaviour Foundation

Opinion

We have audited the financial statements of The Challenging Behaviour Foundation (the 'charitable company') for the year ended 31 January 2023 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 January 2023 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for our opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

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Conclusions related to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Report of the Trustees has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Trustees.

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

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Responsibilities of trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Our objectives in performing the audit are to identify and assess the risk of material misstatement in the financial statements due to fraud or error and to obtain sufficient audit evidence to support this. We also evaluate and respond to the risk of material misstatements.

Audit procedures performed by the engagement team included:

- Gaining an extensive knowledge entity and environment
- Obtaining a sufficient understanding of the internal environment, including control systems in place for the detection and prevention of fraud.
- Evaluating said systems to determine whether they are operating to a satisfactory level and are providing the right level of control and authorisation within the entity.
- Understanding the entity's current activities, assets and liabilities and comparing these to the entity's charitable objectives and aims.
- Discussions with management and those charged with governance as to any known or suspected instances of noncompliance with laws and regulations, including fraud.
- Reading minutes of meetings of those charged with governance and comparing these to what is reflected in the statutory accounts.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

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Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Nicholas Hume FCA

Nicholas Hume FCA (Senior Statutory Auditor)
for and on behalf of Xeinadin Audit Ltd
Becket House
36 Old Jewry
London
EC2R 8DD

Date: 18 July 2023

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Statement of Financial Activities

for the Year Ended 31 January 2023

	Notes	Unrestricted funds £	Restricted funds £	31.1.23 Total funds £	31.1.22 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	21,583	-	21,583	26,694
Charitable activities	5				
Information and Support		81,542	101,508	183,050	202,700
National Influencing		16,500	218,874	235,374	171,291
Core Funding		88,911	-	88,911	207,455
Other trading activities	3	673	-	673	2,138
Investment invome	4	656	-	656	146
Total		210,064	320,382	530,446	610,424
EXPENDITURE ON					
Raising funds	6	21,140	-	21,140	19,587
Charitable activities	7				
Information and Support		65,638	127,643	193,281	167,365
National Influencing		687	186,007	186,694	153,886
Core Funding		119,213	2,654	121,867	175,646
Total		206,678	316,304	522,982	516,484
NET INCOME		3,386	4,078	7,464	93,940
Transfers betwen funds	15	501	(501)	-	-
Net movement in funds		3,887	3,577	7,464	93,940
RECONCILIATION OF FUNDS					
Total funds brought forward		447,136	123,300	570,436	476,496
TOTAL FUNDS CARRIED FORWARD		451,023	126,877	577,900	570,436

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Balance Sheet

31 January 2023

	Notes	Unrestricted funds £	Restricted funds £	31.1.23 Total funds £	31.1.22 Total funds £
CURRENT ASSETS					
Debtors	13	25,938	239	26,177	46,249
Cash at bank		522,105	164,939	687,044	615,573
		548,043	165,178	713,221	661,822
CREDITORS					
Amounts falling due within one year	14	(97,020)	(38,301)	(135,321)	(91,386)
NET CURRENT ASSETS		451,023	126,877	577,900	570,436
TOTAL ASSETS LESS CURRENT LIABILITIES		451,023	126,877	577,900	570,436
NET ASSETS		451,023	126,877	577,900	570,436
FUNDS	15				
Unrestricted funds				451,023	447,136
Restricted funds				126,877	123,300
TOTAL FUNDS				577,900	570,436

The financial statements were approved by the Board of Trustees and authorised for issue on 15th July 2023 and were signed on its behalf by:

Mrs C Million - Trustee

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Cash Flow Statement

for the Year Ended 31 January 2023

	Notes	31.1.23 £	31.1.22 £
Cash flows from operating activities			
Cash generated from operations	1	69,398	(41,888)
Gift Aid		1,417	(1,123)
Cash flows from investing activities			
Interest received		656	146
Net cash provided by investing activities		656	146
Change in cash and cash equivalents in the reporting period		71,471	(42,865)
Cash and cash equivalents at the beginning of the reporting period		615,573	658,438
Cash and cash equivalents at the end of the reporting period		687,044	615,573

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Notes to the Cash Flow Statement

for the Year Ended 31 January 2023

1. RECONCILIATION OF NET INCOME TO NET CASH FLOW FROM OPERATING ACTIVITIES

	31.1.23 £	31.1.22 £
Net income for the reporting period (as per the Statement of Financial Activities)	7,464	93,940
Adjustments for:		
Interest received	(656)	(146)
Decrease in debtors	18,655	43,655
Increase/(decrease) in creditors	43,935	(179,227)
Net cash provided by/(used in) operations	69,398	(41,888)

2. ANALYSIS OF CHANGES IN NET FUNDS

	At 1.2.22 £	Cash flow £	At 31.1.12 £
Net cash			
Cash at bank	615,573	71,471	687,044
	615,573	71,471	687,044
Net cash provided by/(used in) operations	615,573	71,471	687,044

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Notes to the Financial Statements

for the Year Ended 31 January 2023

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

- Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity
- Designated funds are unrestricted funds earmarked by the Trustees for particular purposes.
- Restricted funds are subject to restrictions on their expenditure imposed by the donor or through the terms of an appeal.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Allocation and apportionment of costs

Support costs are allocated pro rata to staff numbers involved with each charitable activity.

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1. ACCOUNTING POLICIES - continued

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Plant and machinery - 20% on cost

Fixtures and fittings - 20% on cost

Taxation

The charity is exempt from corporation tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Pension costs and other post-retirement benefits

The charitable company operates a defined contribution pension scheme. Contributions payable to the charitable company's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

2. DONATIONS AND LEGACIES

	31.1.23 £	31.1.22 £
Donations	20,589	25,565
Gift aid	994	1,129
	21,583	26,694



3. OTHER TRADING ACTIVITIES

	31.1.23 £	31.1.22 £
Fundraising events	673	940
Sales and earned income	-	1,198
	673	2,138

4. INVESTMENT INCOME

	31.1.23 £	31.1.22 £
Deposit account interest	656	146

5. INCOME FROM CHARITABLE ACTIVITIES

				31.1.23	31.1.22
	Information and Support £	National Influencing £	Core Funding £	Total activities £	Total activities £
Grants	101,508	235,374	32,000	368,882	359,162
Contract and Other Non Grant Income	81,542	-	56,911	138,453	222,284
	183,050	235,374	88,911	507,534	581,446

Grants received, included in the above, are as follows:

	31.1.23 £	31.1.22 £
Colyer-Fergusson Charitable Trust	14,883	2,483
John Ellerman Foundation	30,000	-
Sylvia Adams Charitable Trust	5,000	-
	49,883	2,483

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5. INCOME FROM CHARITABLE ACTIVITIES - continued

	31.1.23 £	31.1.22 £
Brought forward	49,883	2,483
The Sobell Foundation	-	16, 667
Garfield Weston Foundation	-	25,000
Department of Health and Social Care (DHSC) Covid Recovery	-	41,378
The Stonewall Park Charitable Trust	1,000	1,000
The Sir James Roll Charitable Trust	-	1,000
The Esmee Fairbairn Foundation	32,500	40,000
The University of Warwick	16,500	5,500
National Lottery Community Fund	131,291	131,291
Lloyds Bank Foundation - COVID	-	18,737
The Steele Charitable Trust	-	20,000
The Dulverton Trust	-	30,000
Pears Family Charitable Foundation	25,000	25,000
The Paypal Giving Fund UK	-	356
The Grace Trust	-	750
Kent Community Foundation	3,000	-
National Health Service England (NHSE) Covid Recovery	83,625	-
The Blagrave Trust	25,083	-
Beechwood Trust	1,000	-
	368,882	359,162

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6. RAISING FUNDS

Raising donations and legacies

	31.1.23 £	31.1.22 £
Staff costs	20,853	17,000
Fundraising	287	346
	21,140	17,346

Other trading activities

	31.1.23 £	31.1.22 £
Bad debts	-	2,241
Aggregate amounts	21,140	19,587

7. CHARITABLE ACTIVITIES COSTS

	Direct Costs £	Support Costs (see note 8) £	Totals £
Information and Support	193,247	34	193,281
National Influencing	186,694	-	186,694
Core Funding	111,596	10,271	121,867
	491,537	10,305	501,842

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8. SUPPORT COSTS

	Governance Costs £
Information and Support	34
Core Funding	10,271
	10,305

9. NET INCOME

Net income/is stated after charging:

	31.1.23 £	31.1.22 £
Auditors' renumeration	1,355	1,856
Depreciation - owned assets	-	6

10. TRUSTEES' RENUMERATION AND BENEFITS

Vivien Cooper was employed full time as Chief Executive Officer with the express permission of the Charity Commission in recognition of her unique skills and experience. She is enrolled in a workplace pension scheme for her role as Chief Executive Officer. Vivien Cooper retired as a Trustee in July 2022.

A Trustee received £3,700 (£1,116 : 2021/2022) for managing a project that required their specific skillset and knowledge, not for their role as a trustee.

No Trustee or any person related to the charity had any personal interest in any contract or Trustee transaction entered into by the charity during the year other than as disclosed above.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 January 2023 nor for the year ended 31 January 2022.

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11. STAFF COSTS

No employee was paid over £60,000 in the year.

The average monthly number of employees during the year was as follows:

	2023	2022
Information, Support & Training	6	6.5
National Influencing Work	8	8
Total	14	14.5

12. TANGIBLE FIXED ASSETS

	Plant and machinery £	Fixtures and fittings £	Computer equipment £	Totals £
COST				
At 1 February 2022	8,161	1,258	5,075	14,494
Disposals	(8,161)	(1,258)	(5,075)	(14,494)
At 31 January 2023	-	-	-	-
DEPRECIATION				
At 1 February 2022	8,161	1,258	5,075	14,494
Eliminated on disposal	(8,161)	(1,258)	(5,075)	(14,494)
At 31 January 2023	-	-	-	-
NET BOOK VALUE				
At 31 January 2023	-	-	-	-
At 31 January 2022	-	-	-	-

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13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.1.23 £	31.1.22 £
Trade debtors	17,102	34,397
Other debtors	657	3,013
Gift Aid reclaimable	3,667	7,985
Accrued income	4,512	-
Prepayments	239	854
	26,177	46,249

14. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.1.23 £	31.1.22 £
Trade creditors	4,886	4,851
Social security and other taxes	8,457	4,826
VAT	1,359	8,271
Funds held for other organisations	15,423	15,423
Accruals and deferred income	105,196	58,015
	135,321	91,386

Funds held for other organisations £15,422 (2022: £15,422) represents monies held by the charity where it is working with other charities on joint projects. At 31 January 2023 these are as follows:

Learning Disability Senate	£12,840
Employment Dissemination	£2,582

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15. MOVEMENT IN FUNDS

	At 1.2.22 £	Net movement in funds £	Transfer between funds £	At 31.1.23 £
Unrestricted funds				
Core Funding	422,723	27	500	423,251
Training Designated Fund	24,413	3,359	-	27,772
	447,136	3,386	500	451,023
Restricted funds				
John Ellerman Fund	-	25,335	-	25,335
The Esmee Fairbairn Foundation	9,888	(4,274)	-	5,614
The National Lottery Community Fund	39,138	(422)	-	38,716
CB-NSG	4,215	(18)	-	4,197
SHIEC	3,572	-	-	3,572
Peoples Postcode Trust	2,177	(2,177)	-	-
Rrisc	978	(478)	(500)	-
Asquith Legacy	3,199	-	-	3,199
National Lottery People's Project	32,650	(5,255)	-	27,395
Colyer-Ferguson Charitable Trust	2,483	(915)	-	1,568
Steele Charitable Trust	20,000	(20,000)	-	-
The Dulverton Trust	5,000	(5,000)	-	-
The Blagrave Trust	-	17,282	-	17,282
	123,300	4,078	(500)	126,877
TOTAL FUNDS	570,436	7,464	-	577,900

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15. MOVEMENT IN FUNDS - continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
Core Funding	167,557	(167,530)	27
Training Designated Fund	42,507	(39,148)	3,359
	210,064	(206,678)	3,386
Restricted funds			
John Ellerman Fund	30,000	(4,665)	25,335
The Esmee Fairbairn Foundation	32,501	(36,775)	(4,274)
The National Lottery Community Fund	131,291	(131,713)	(422)
CB-NSG	-	(18)	(18)
Peoples Postcode Trust	-	(2,177)	(2,177)
Rrisc	-	(478)	(478)
National Lottery People's Project		(5,254)	(5,255)
Colyer-Ferguson Charitable Trust	14,883	(15,798)	(915)
NHSE Covid recovery	83,624	(83,624)	-
Steele Charitable Trust	-	(20,000)	(20,000)
The Dulverton Trust	-	(5,000)	(5,000)
Kent Community Foundation	3,000	(3,000)	-
The Blagrave Trust	25,085	(7,803)	17,282
	320,382	(316,304)	4,078
TOTAL FUNDS	530,446	(522,982)	7,464

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15. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1.2.21 £	Net movement in funds £	At 31.1.22 £
Unrestricted funds			
Core Funding	321,672	101,051	422,723
Training Designated Fund	39,032	(14,619)	24,413
	360,704	86,432	447,136
Restricted funds			
The Esmee Fairbairn Foundation	5,138	4,750	9,888
The National Lottery Community Fund	32,788	6,350	39,138
The Lloyds Bank Foundation	2,712	(2,712)	-
Baily Thomas Charitable Fund	20,000	(20,000)	-
CB-NSG	4,305	(90)	4,215
SHIEC	3,572	-	3,572
Peoples Postcode Trust	4,227	(2,050)	2,177
Rrisc	978	-	978
Asquith Legacy	3,689	(490)	3,199
National Lottery People's Project	35,999	(3,349)	32,650
Lloyds Bank Foundation Covid Fund	2,384	(2,384)	-
Colyer-Ferguson Charitable Trust	-	2,483	2,483
Steele Charitable Trust	-	20,000	20,000
The Dulverton Trust	-	5,000	5,000
	115,792	7,508	123,300
TOTAL FUNDS	476,496	93,940	570,436

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15. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
Core Funding	277,705	(176,654)	101,051
Training Designated Fund	32,164	(46,783)	(14,619)
	309,869	(223,437)	86,432
Restricted funds			
The Esmee Fairbairn Foundation	40,000	(35,250)	4,750
The National Lottery Community Fund	32,788	(124,940)	6,350
The Lloyds Bank Foundation	18,738	(21,450)	(2,712)
Baily Thomas Charitable Fund	-	(20,000)	(20,000)
CB-NSG	-	(90)	(90)
The Sobell Foundation	16,666	16,666	-
Peoples Postcode Trust	-	(2,050)	(2,050)
Asquith Legacy	-	(490)	(490)
National Lottery People's Project	-	(3,349)	(3,349)
DHSC - Covid Recovery	41,378	(41,378)	-
Lloyds Bank Foundation Covid Fund	-	(2,384)	(2,384)
Colyer-Ferguson Charitable Trust	2,483	-	2,483
Steele Charitable Trust	20,000	-	20,000
The Dulverton Trust	30,000	(25,000)	5,000
	300,555	(293,047)	7,508
TOTAL FUNDS	610,424	(516,484)	93,940

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15. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined position is as follows:

	At 1.2.21 £	Net movement in funds £	Transfer between funds £	At 31.1.23 £
Unrestricted funds				
Core Funding	321,672	101,078	500	423,251
Training Designated Fund	39,032	(11,260)	-	27,772
	360,704	89,818	500	451,023
Restricted funds				
John Ellerman Fund	-	25,335	-	25,335
The Esmee Fairbairn Foundation	5,138	476	-	5,614
The National Lottery Community Fund	32,788	5,928	-	38,716
The Lloyds Bank Foundation	2,712	(2,712)	-	-
Baily Thomas Charitable Fund	20,000	(20,000)	-	-
CB-NSG	4,305	(108)	-	4,197
SHIEC	3,572	-	-	3,572
Peoples Postcode Trust	4,227	(4,227)	-	-
Rrisc	978	(478)	(500)	-
Asquith Legacy	3,689	(490)	-	3,199
National Lottery People's Project	35,999	(8,604)	-	27,395
Lloyds Bank Foundation Covid Fund	2,384	(2,384)	-	-
Colyer-Ferguson Charitable Trust	-	1,568	-	1,568
The Blagrave Trust	-	17,282	-	17,282
	115,792	11,586	(500)	126,877
TOTAL FUNDS	476,496	101,404	-	577,900

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15. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
Core Funding	445,262	(344,184)	101,078
Training Designated Fund	74,671	(85,931)	(11,260)
	519,933	(430,115)	89,818
Restricted funds			
John Ellerman Fund	30,000	(4,665)	25,335
The Esmee Fairbairn Foundation	72,501	(72,025)	476
The National Lottery Community Fund	262,581	(256,653)	5,928
The Lloyds Bank Foundation	18,738	(21,450)	(2,712)
Baily Thomas Charitable Fund	-	(20,000)	(20,000)
CB-NSG	-	(108)	(108)
The Sobell Foundation	16,666	16,666	-
Peoples Postcode Trust	-	(4,227)	(4,227)
Rrisc	-	(478)	(478)
Asquith Legacy	-	(490)	(490)
National Lottery People's Project	(1)	(8,603)	(8,604)
DHSC - Covid Recovery	41,378	(41,378)	-
Lloyds Bank Foundation Covid Fund	-	(2,384)	(2,384)
Colyer-Ferguson Charitable Trust	17,366	(15,798)	1,568
NHSE Covid Recovery	83,624	(83,624)	-
Steele Charitable Trust	20,000	(20,000)	-
The Dulverton Trust	30,000	(30,000)	-
Kent Community Foundation	3,000	(3,000)	-
The Blagrave Trust	25,085	(7,803)	17,282
	620,937	(609,351)	11,586
TOTAL FUNDS	1,140,870	(1,039,466)	101,404

The Training Designated Fund represents funds set aside by the Trustees to invest in the CBF's capacity to deliver training and help diversify the charity's income.

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16. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 January 2023.

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THE CHALLENGING BEHAVIOUR FOUNDATION

England & Wales - Charity number 1060714

Accounts

Annual Report
2021-2022

The Challenging Behaviour Foundation



Making a difference to the lives of people with severe learning disabilities whose behaviour challenges.

The Challenging Behaviour Foundation

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The Challenging Behaviour Foundation

Foreword

From our Chair, Diane Lightfoot

25 years ago (February 1997) the Challenging Behaviour Foundation (CBF) was set up by the parent of a child with severe learning disabilities who displayed a range of behaviours described as challenging. It was established because even though a great deal of knowledge and information was available about how to support children and adults with these needs well, it was hard to locate. It was especially difficult for families to find out what was possible - and how to use that information to make a good quality of life a reality.

The overarching aim of the CBF is to enable children, young people and adults with severe learning disabilities whose behaviour challenges, and their families, to get the right support in the right place at the right time. It is this key aim - to make "the system" work and deliver good outcomes for children, young people, adults, and their families - that continues to drive all our activities.

The ongoing pandemic and restrictions imposed have continued to highlight the significant challenges and inequalities that families with children and adults with severe learning disabilities whose behaviour may challenge face. A research study of family carer experiences back in 2004 concluded:

> **"The over-riding sense is of their being isolated, excluded and left to get on with a task which is too difficult or beyond the expertise of qualified professionals.**

The pandemic has demonstrated that when the system shuts down, it is families who provide a safety net and continue to support their relatives. The responses to the pandemic and its waves resulted in stressful uncertainty. In addition to concerns about the virus itself and the risks associated with it for their relative, including accessing healthcare support, routines and access to support and services were disrupted and ordinary activities significantly restricted. There continued to be many families who had to take on the responsibility to find creative ways to support their relatives to maintain a quality of life often with little or no external support and at significant cost to their own wellbeing.

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The Challenging Behaviour Foundation

> **I would like to thank you and tell you how grateful I am for all the time you have taken to support myself and my son. This meeting is the first time that I felt I have been listened to and your input is invaluable, I actually feel a bit of a weight has finally been lifted from my shoulders. I know it is still going to be an uphill slog even when he gets his own home, but, with the correct instructions and the help of my family, I am more confident it can be achieved.**
>
> **– Family Carer**

This report demonstrates the wide range of work the CBF is taking forward – because it reflects the wide range of issues that families have to navigate and negotiate to get the right support. Our work is delivered by a small team of paid staff and volunteers who all work to a high standard, with shared values and commitment to deliver good outcomes for individuals and their families. It is a team effort and the experiences and input from families remains core to all that we do. We are grateful for the support and expertise of everyone who contributes and makes a difference.

We are sincerely grateful to all those who have funded our work. Your support is greatly appreciated, and we work hard to ensure the funds deliver good outcomes and impact. It is likely that there will be funding challenges ahead and Trustees monitor this carefully to ensure that our much-needed work supporting families can continue, as well as our policy and influencing work.



Thank you to everyone who has made a difference.

Diane Lightfoot, Chair of Trustees

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The Challenging Behaviour Foundation

Report of the Trustees
For the year ended 31 January 2022

The Trustees who are also the directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 January 2022. The Trustees have adopted the provisions of the Statement of Recommended Practice (SORP) 'Accounting and Reporting by Charities' issued in 2015.

Objectives and activities

Objectives and aims

The Challenging Behaviour Foundation (CBF) exists to improve the quality of life of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families.



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

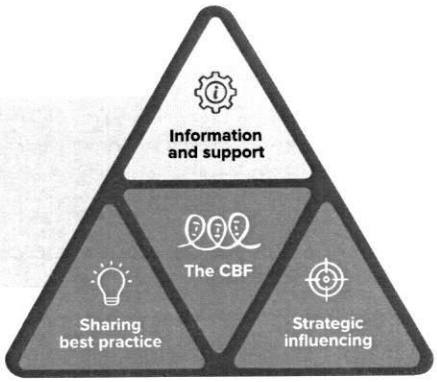


Our mission is to make a difference to the lives of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families by: -

- Championing their rights
- Ensuring timely information and support
- Raising awareness and understanding
- Promoting and sharing best practice



We are the **only** UK charity **focussed specifically** on the needs of children, young people and adults with a severe learning disability whose behaviours may challenge, their families and those who care for them.



Objectives and activities
Information and Support

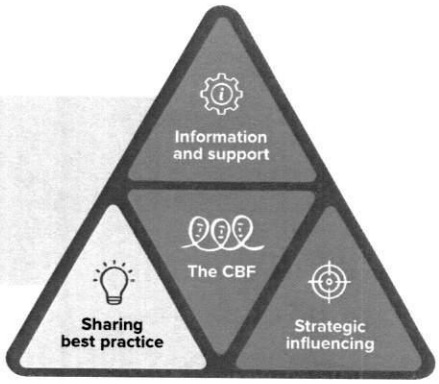
Lived experiences gathered from our information and support service drives our strategic influencing work which interconnects with sharing best practice.

We offer a free, confidential, and expert telephone support and casework service to families of children, young people and adults with severe learning disabilities whose behaviour challenges. We facilitate email and local peer-to-peer support networks and have developed a comprehensive library of information guides and resources which are widely shared. All of this aims to equip family and professional carers to understand behaviour that may be described as challenging and empower them to access good quality support. We have worked with families to co-produce a range of training workshops for families, unpaid carers and professionals around positive behaviour support, and specific behaviours, that are informative, practical and focussed on good outcomes for individuals. This models a collaborative and consistent approach to supporting individuals with evidence-based strategies, grounded in lived experience, which is emphasised through the joint delivery by family carers and Positive Behaviour Support trainers.

In addition to helping families better understand their relative's behaviour and secure better support and services, we are also concerned with carers' own welfare and the services and support available to them. Family carers of children and adults with learning disabilities often face significant challenges including being respected as valued partners by those providing and commissioning care and support. There are also barriers to accessing relevant information and legal advice to effectively resolve the issues they and their relative are facing. The CBF addresses these issues through our unique longer-term family centred casework, where we support families through complex situations over many months.

> **"It made me sad and shed some tears at the realisation that people have listened. Thanks, and best wishes to you all for doing a great job. I feel truly supported ~ immense gratitude.**
>
> **– Family Carer**

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Objectives and activities
Sharing best practice

Our information and support service along with our strategic influencing is enhanced and informed by best practice. Best practice provides evidence that **it is entirely possible to deliver the right support in the right place at the right time.**

Sharing, modelling and actively promoting best practice on the ground runs through all our work. We do this through our family support casework and resources, strategic influencing work and family carer and professional email networks, as well as through specific projects involving local authorities, government departments and other partners.

We believe it is crucial that our three strands of work are interconnected and inform each other and reflect the multiple interrelated challenges families face. For example, what families tell us when asking for support feeds into our strategic influencing work to ensure lived experiences of families are reflected accurately, and that learning from all stakeholders is widely shared to improve experiences and understanding for all.

In planning and reviewing the charity's activities to meet these objectives, the Trustees have taken account of the Charity Commission's guidance on **public benefit.** The CBF delivers public benefit by providing information and support to families and professionals caring for and supporting children, young people and adults with severe learning disabilities whose behaviour challenges. All our information and support is provided free of charge to family carers. We also work to improve the understanding of challenging behaviour amongst professionals and the wider public, helping others to provide better support and services and more opportunities.



As a nurse for people who have a learning disability, I have continued to be very impressed by the material that you print and make available and for the enormous support you give and campaigning you do for people with learning disabilities and their families. Thank you. It really does help people to feel better supported and informed, including those who work in this field and ultimately to make a massive difference to people's lives.

– Learning Disability Nurse

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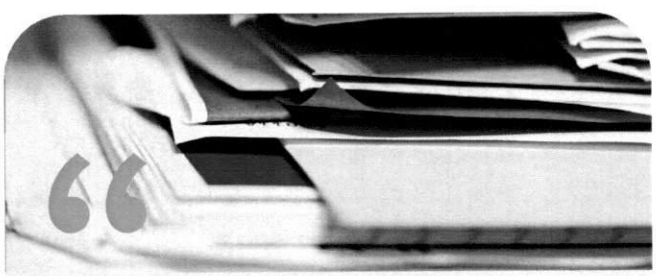
Achievements and Performance

> **How do we do it year after year? I have great admiration for all of us. Thank you to you all who have given me advice over the years and for the CBF without whom, this year and last year, I would have possibly gone mad with worry and anxiety.**
>
> **– Member of Family Carer Email Network**

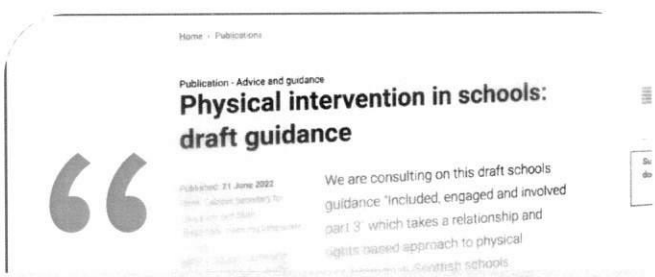
The ongoing impact of the COVID-19 pandemic

The ongoing pandemic and subsequent restrictions continued to impact the whole CBF staff team working arrangements including Trustees and volunteers.

The families we support are a marginalised community facing numerous barriers, often isolated within their local community with little opportunity to connect with their peers. Evidence has been collected to show that the pandemic has exacerbated an already complex environment for our client group. With increased demand and issues, we have maintained and expanded our existing support offer through our family support service and policy work.



> As a very small organisation, they did amazing work supporting families in desperate situations and communicating this effectively to Government.
>
> **– Head of Policy, large charity**



> With so much Government information and guidance available and changing daily, it was very helpful to have a source focused on the needs of families like ours.
>
> **– Family Carer**

We remain very grateful to our current grant funders for their flexibility around existing projects which we have adapted and restarted this year.

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In addition, we were able to secure emergency COVID-19 recovery funding, which will be used over the start of 2022 to continue working collaboratively with other voluntary sector partners and respond to the increased challenges faced by children, young people and adults, and their families due to the pandemic.

> **There were specific groups of people who we were concerned were at high risk (in the pandemic), with high support needs, in immediate need of support. And they (the CBF) have direct access to these families.**
>
> **- Senior official, NHSE**

The pandemic continues to highlight the existing inequalities within society, including within this marginalised client group. As this includes inequalities in access to online resources and information, we have continued prioritising ensuring that hard copies of information and newsletters have been proactively posted to families, encouraging other organisations to do the same. We know that many families do not have internet access or prefer printed materials, whereas for organisations it is cheaper and easier to only produce online resources. We have continued to provide printed resources and newsletters to provide relevant, practical, and accessible information specifically tailored to our client group.

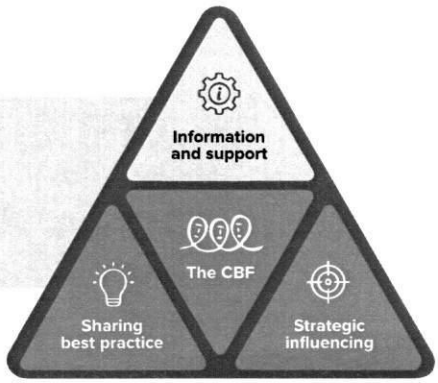
> **I quite like reading information, I sometimes find surfing the internet quite difficult ... when it's in a little booklet, well, I'm probably going to look at it from beginning to end, it's not that long is it, I just like the way that's laid out.**
>
> **- Family Carer**

As the Government encouraged the opening up of society, the CBF transitioned back to office-based working, learning from and retaining the benefits of hybrid approaches as appropriate.

> **We have been able to extend our offer to families now that virtual meetings are taking place - we can sometimes join a virtual meeting to support a family whereas we would not be able to do that in person. Likewise, we have confirmed the value and importance of CBF family support team members working together in the office as a team - for emotional and peer support as well as for practical solution focussed discussions on complex situations families are experiencing.**
>
> **- CBF family support team member**

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Achievements and Performance
Information and support



Due to the changing circumstances and subsequent lockdowns, restrictions, and guidance, we have regularly reviewed and updated all of our relevant resources for example 'wearing a facemask' and 'returning to school'. We will continue to review all our resources to ensure they are current and provide practical and tailored information for the families we support.

> **They are a fantastic service. At times of desperation, I've thought - someone in the CBF will know! ... Knowing that the helpline was there all the time (in the pandemic), that was fantastic.**
>
> **- Family carer**

Our family support service has responded to 1540 queries through our support line, email and website this year which is a 21% increase on the previous year. We had over 27k resources downloaded from our website which is a slight increase from last year. The large amount of information available on our website ensures that the families we support have 24-hour access to information around the key issues that impact on their lives. Our family carer review panel and professional volunteers help us to review and update our resources, to ensure they are current and helpful.

1540
Queries through our support line

27,000+
Resources downloaded from our website

We have evaluated the new 'triage' role within the Family Support Team. This role is the first point of contact for families looking for support by telephone and email, answering general enquiries or prioritising and escalating queries to the family support caseworkers. Trustees have agreed to continue this administrator role as part of the Family Support Service, to work more efficiently and freeing up family caseworker time for those who need more in-depth specialist input.

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We have continued to respond to a high number of families coming to us with complex situations requiring significant support and casework. During the year we have supported 58 requests for individual support requiring casework, supporting families with a range of issues including managing specific behaviours, accessing services and support to meet their relative's needs and maintaining contact with family members in care. Most significantly, this work supports families through times of change and transition, such as moving from child to adult services or moving between services. Sadly, these situations often relate to safeguarding issues, lack of appropriate support, poor placements or placement breakdowns and unrecognised health concerns. Families approaching us with these multiple complex issues often require intensive casework over a long period. The average period of support is six months with some families returning over many years for further support as new issues emerge.

> **"It's been .... really and truly a lifeline, having that contact, having that friendly person to talk to, who's like in your corner, who totally gets everything, (it) has been a real source of strength ... that's been a big life-changing experience for us.**
>
> **- Family Carer**

We remain grateful for the support of our Legal Panel whose members, providing input on a voluntary basis, have played a vital role in enabling families to access legal advice and support to take appropriate action. During the year we have referred a number of families to the panel. They received the specialist legal support required to take their issues forward or were given support specific to their circumstances. (see page 21 for further information about the work of the Legal Panel)

> **"The CBF are always on my side – they make you see it's possible, you can do it! ... (they) give you such a good feeling of empowerment.**
>
> **- Family Carer**

We have a network of 37 volunteers who help support families across the country and share their experiences with local families and key professional groups. We have provided equipment and software licences to ensure their work with families can continue virtually. Our 'carer catch-ups' continue to provide peer-to-peer support in an informal and relaxed setting and these have been positively received and will continue as part of our range of flexible support offers to family carers.

> **"To be in touch virtually, it's quite nice to be part of a community where parents have actually experienced such extreme situations that normally otherwise you wouldn't ever find yourself saying this out loud to anybody, because they wouldn't know what you were saying! This is almost like your own tribe, like everyone gets each other and you can just reach out to someone who's actually aware of all your challenges.**
>
> **- Family Carer**

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Listening Ear calls

We now support two committed family carers who offer listening ear calls to our families. These telephone calls lasting one hour offer a chance for the family carer to talk about their feelings without the fear of judgement. The active listening approach is not solution focussed like our family support calls, so the caller will feel no pressure to take action to resolve the issues that they have discussed if they do not feel able to.

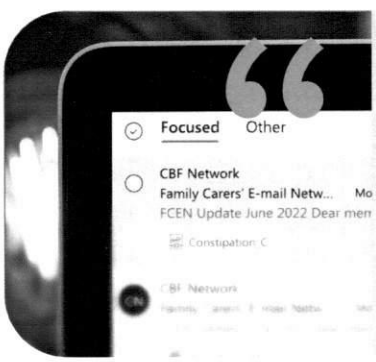


It's that validation: you're not on your own, what you're saying is making sense. It's not even something you can speak to a friend about, because your friend really doesn't understand, because they're not living it! But when you have that Listening Ear, it's someone who knows exactly what you're saying, you don't have to explain it, you don't have to justify, it's invaluable just to keep yourself sane, to keep your humanity, to carry on believing in yourself.

– Family Carer

Email Networks

Our family carer email network now has around 470 members and continues to be regularly used. This forum enables families to ask one another questions, share solutions and seek support around issues impacting their daily life, support package or relative's behaviour that might be described as challenging. This peer-to-peer support is valued by our members for its emotional and practical support and encouragement through lived experience. Families can also ask our Professional Panel questions via our professional email network, a network of over 1200 practitioners from across the health, education and social care sectors who also use this forum to share information, learning and asking their peers questions to support their work and disseminate good practice.



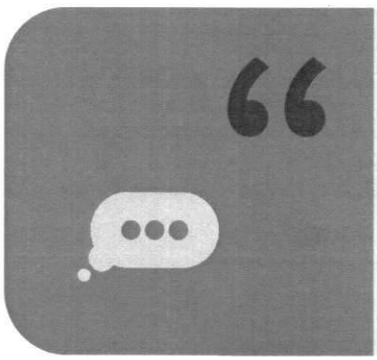
I love this network, and the Challenging Behaviour Foundation. My son has autism, but that isn't really a problem to me! It's the behaviours that challenge that I want advice and guidance with, and this network is perfect. It is really encouraging to hear from parents whose children are now in their 20s and 30s and the parents are now real pros at this.

– Family Carer

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The CBF Family Forum (Facebook group)

This year, we set up a social media-based peer support network run via Facebook Groups. This enables family carers to support each other in 'real time'. Currently the group has 240 members and membership is limited to individuals with a relative with severe learning disabilities to ensure that the group is an understanding and empathetic forum. Membership applications are approved, and posts monitored for safeguarding concerns, by five volunteer family carer Local Champions supported by CBF.



If I cough it triggers my son into a meltdown. This was 8.30am! And he's been crying all day! I'm new to the group, it's nice to talk to people who know how hard it is. All quiet now, so I'm going for a cuppa at the front door and look at the trees for a few minutes!

– Group Member

Helpline Collaboration

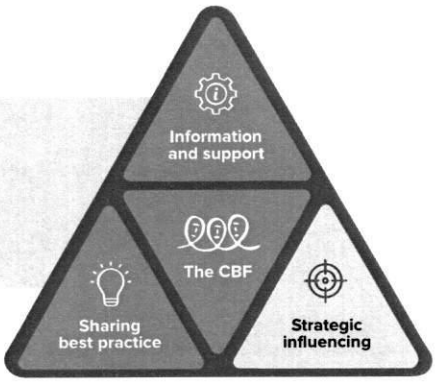
This year, in response to our understanding that families often get passed to several helplines and charities before they find the right one for them, we launched the Helpline Collaboration. We invited Mencap, the National Autistic Society, Contact and Cerebra to join us. Meetings happen once a month via Teams, and we share information about each of our services, identify common issues coming to us from families and provide peer support to each other which is especially appreciated by those who attend.



I've only come along to a couple of meetings so far, but they've been an excellent forum for sharing experiences and discussing ideas, so many thanks to you all at CBF for organising them.

–Helpline Collaboration member

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Achievements and Performance
Strategic Influencing

As a small organisation we can achieve much more by specifically informing and encouraging individuals and organisations in positions of power and influence to raise their understanding and awareness of the issues individuals and families face, and to influence their activity. We aim to promote collaboration to drive progress.

The three strands of our work are inextricably linked and closely aligned. In practice our family carer experiences steer our influencing work. We continue to raise concerns and challenges to a range of senior individuals and organisations both at a local level and nationally where individuals' human rights are being breached.

Numerous challenges have been made to officials questioning investment in models of support that conflict with national policy and best practice which are in direct opposition to the aims of the Transforming Care policy and Building the Right Support programme.

> **"They (the CBF) relayed the experience of families quite vividly, with examples to illustrate how the regulations were impacting people – their direct experiences – which was very helpful, really powerful.**
>
> **- Senior official, NHSE**

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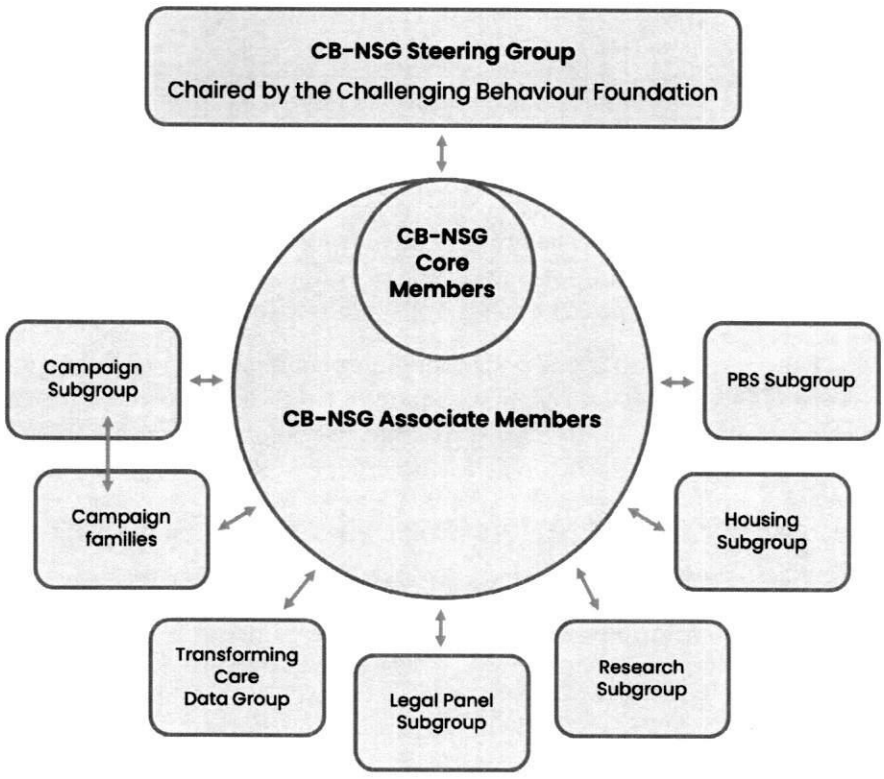
Challenging Behaviour National Strategy Group (CB-NSG)

We are very grateful to the Esmee Fairbairn Foundation for their continued support and funding towards the National Strategy Group and its work. The CB-NSG includes representatives from professional bodies, networks, charities and the government alongside family carers, people with learning disabilities and researchers. It is based on the principle that if all the individuals and organisations who have a role to play in supporting this group work together in a coherent and coordinated way it will deliver better outcomes.

There are currently over 90 core CB-NSG members who have significant knowledge and expertise, and a senior level role in supporting and delivering services to people with learning disabilities, and over 600 associate members who commit to working following the values and principles of the Challenging Behaviour Charter.

The group also has six sub-groups (two new groups have been formed this year) made up of members, and co-ordinated by the CBF:

- Campaigns (including campaign families)
- Legal Panel
- Positive Behaviour Support
- Transforming Care Data
- Research
- Housing



From February 2021 it is a requirement that all CB-NSG members have signed up to the Challenging Behaviour Charter, a co-produced rights and action framework to deliver the right support in the right place at the right time. Two CB-NSG meetings, with multi-stakeholder members, have taken place this year, both virtually.

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The first meeting focused on making all parts of the system work together to enable people with learning disabilities to get the right support, which was entitled 'Are we ALL ready?'.

> **I found the discussion really stimulating and informative, as always! You have built up an amazing network of supporters over the years, I'm always impressed by the range of people who turn up, not least all the family-carers.**
>
> **– Professional, CB NSG attendee**

A range of presentations were delivered, including from a family carer on how their experiences illustrate the need for all parts of the system to work together; a professor of law from Leeds University on how people with learning disabilities and their families face multiple, interconnected issues which are not currently well co-ordinated; and the Family Network Manager (a family carer) from MENCAP who presented and discussed the Winterbourne Families Report, 'Tea, Smiles and Empty Promises'. Actions from the workshops included having a shared meaning of good practice, following a proactive rather than reactive approach to solving problems, and improving opportunities for families to link up with each other.

The second meeting of the year focused on using best practice to influence and drive change. The meeting began with a presentation from a family carer on the Building the Right Support action plan, and another from a psychiatrist on changes in the delivery of Health and Care– Integrated Care Systems and provider collaboratives.

> **Keep doing what you are doing, bringing people together and sharing what's working and what's not working.**
>
> **- Anonymous**

We continue to be very grateful for support from the National Lottery Community Fund. Their funding has enabled us to take forward several actions identified at CB-NSG meetings.

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Campaigns Sub-group (including Campaign Families)

CB-NSG members meet regularly to share information about policy and practice and agree campaigning priorities, including aligning with and supporting activities by other individuals and organisations.

Over the past year the Campaign Families group have provided input to the draft 'Building The Right Support' action plan and other key consultations. To mark 10 years since BBC Panorama exposed abuse at Winterbourne View hospital in May 2021, a group of families whose relatives were at Winterbourne View published 'Tea, Smiles and Empty Promises' reflecting on the lack of progress in transforming care and setting out their calls for action.

The Campaign Families will be meeting in summer 2022 to review the long-awaited Building The Right Support Action Plan and consider and agree campaigning priorities for the group. The Campaign Families, along with other families supported by CBF and Mencap will also provide input to the consultation on proposed reforms to the Human Rights Act and the introduction of Liberty Protection Safeguards.

Legal Panel Sub-group

Several years ago, we established, and we continue to maintain, a legal panel consisting of specialist lawyers and barristers who provide pro-bono information and support to families who contact our family support service. The aim is to ensure free initial access to timely specialist legal advice.

We continued to take forward the strategic legal work identified by our legal panel and built on our collaborative working relationship with key experts in the legal field. We recruited more partners to promote a joined-up approach to enable easier access for families to legal support and information, as we are mindful of the reluctance of many families to instruct lawyers fearing it results in an adversarial approach. The work of this panel increased significantly due to the coronavirus restrictions with regular (fortnightly) meetings of the panel and new lawyers and barristers requesting to join the panel. A series of legal Frequently Asked Questions (FAQ's) submitted by families were developed and shared widely.

> **"Thank you all so much. The eviction notice has been rescinded and they are working to review his care plan! I can't believe it and am so happy. On behalf of my son and myself thank you all so much for your valued advice and experience. I am so grateful people like you exist. Wonderful.**
>
> **- (Family carer feedback about a recent legal panel referral)**

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In September 2021, alongside and in partnership with Legal Panel meetings, the CBF brought together a diverse group of attendees and held the third legal strategy meeting, to discuss a range of strategic legal issues. The meeting included discussions of assessment of need and parent carer blame, providing legal support to individuals in inadequate rated CQC services, legislative reform (Mental Health Act and Mental Capacity Act) and minimising the trauma families experience in the legal system. Attendees worked collaboratively to identify actions which can be taken forward to improve outcomes for families across these topics. A number of actions were identified to inform and develop a legal strategy.

Over the last year, the Legal Panel has continued supporting families with covid related legal enquiries. They met regularly ensuring that families had access to timely support on urgent issues. Questions received by CBF Family Support are triaged and allocated to panel members, with responses uploaded as FAQs on our website so they are widely shared and available:

bit.ly/ourCOVID-19resources

The legal panel members have also been taking on increasing non-covid related questions from families as we move out of the pandemic, and panel members have worked together to consider and address key areas of legal challenge both related to the inequalities for people with learning disabilities which have arisen during the pandemic and the ongoing inequalities due to failures in Transforming Care.

Positive Behaviour Support Sub-group

Work is still being undertaken to re-orientate the PBS Subgroup as a collaborative Research subgroup. This group will link together some key research initiatives with CB-NSG member involvement including the PBS academy, Sharland Foundation Development Disabilities ABA Research and Impact Network (SF-DDARIN) and the Tizard Centre.

Transforming Care Data Set Sub-group

The group has focused on requesting data and/or clarification from NHS England and the Care Quality Commission (CQC), particularly regarding unit characteristics, a regional breakdown of patients currently receiving inpatient care who do not need it according to their care plan, along with further details about individuals working towards discharge.

The data group has had multiple discussions with NHS learning disability policy leads and NHS Digital to better understand and utilise the Assuring Transformation and Mental Health Services Data Sets and progress toward Transforming Care targets.

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Reducing Restrictive Interventions and Safeguarding Children (RRISC)

The Reducing Restrictive Interventions and Safeguarding Children (RRISC) group have continued to meet. In June 2021, the CBF and Positive and Active Behaviour Support Scotland (PABSS) published a report and data supplement looking at restrictive interventions in schools during the pandemic in 2020. At the June 2021 RRISC meeting, a member from Institute of Health Visiting premiered an animation as part of their 'Understanding Behaviour' project inspired by the RRISC reports. The animation, which aims to work with families to reduce restrictive practice, has now been published and received positive feedback.

The External Support Group (ESG)

The External Support Group (ESG) brings together a number of individuals with significant practical experience in supporting people with complex needs in community settings, including developing individualised packages of support and maintaining that support to provide good outcomes for individuals. Areas of expertise in the group include experience in clinical/medical practice; commissioning; inspection and regulation; research and evidence; advocacy; the third sector and family support.

Over the last year, the ESG has continued to refine and develop and deliver the approach, building on the learning. A "Proof of Concept" report has been compiled, and a number of processes have been developed (for example a recruitment process for new members joining the group). The work of the ESG has been shared in various fora, and an animation has been co-produced to explain the approach on a dedicated webpage on the CBF site External Support Group (ESG) - Challenging Behaviour Foundation

Information has been collected regarding the support delivered, the outcomes achieved, and the cost savings made. This information will be presented to senior leaders in the field over the next few months.

STOMP/STAMP

The STOMP (Stopping Over-Medication of People with a Learning Disability, Autism or Both) STAMP (Supporting Treatment and Appropriate Medication in Paediatrics) programmes are initiatives within NHS England to try to address the issues around medication. We have been raising these issues for many years due to the impact on the families we support, including meetings with several senior government officials. Three influential reports were then published which led to the STOMP/STAMP programme.

The STOMP/ STAMP work has been less prominent this year, and we plan to review what impact the pandemic has had and what we can do to build on previous work with NHSE and other partners to drive forward positive change in this area.

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Trauma Support

Building on previous work with the Tizard Centre and Respond, commissioned by NHSE, we have worked with families to co-produce a powerful awareness raising resource about the trauma caused to families by their interaction with "the system" as they try to get support for their family members.

Although the final report from the initial work has yet to be published by NHSE, two peer reviewed journal articles have been published about the findings from the project, helping to raise awareness of the issues.

The awareness raising resource has been completed and was co-produced through every stage - from agreeing what the resource was, to content and how messages were included, and points made. It consists of 4 short films featuring families sharing their experiences, along with graphics to illustrate key points. These are shown in sequence in a workshop, co-facilitated by a professional and a family carer. The workshops were piloted with NHSE staff, and the feedback has been overwhelmingly positive.

> **"Co-production is an authentic commitment to working 'with' families and valuing their expertise equitably, alongside that of professionals - something that CBF have embedded within the heart of all their work.**
>
> **- Family carer**

The family carer steering group and the participants in the film have set out key principles about the use of the resource and plans are being developed to secure funding to deliver the workshops to a wider audience (across education, health and social care). This includes recruiting, training and supporting family carers as co-facilitators to ensure there is capacity to meet demand. We hope to secure funding to take this work forward next year, and to explore opportunities to further raise awareness including the potential to produce a documentary.

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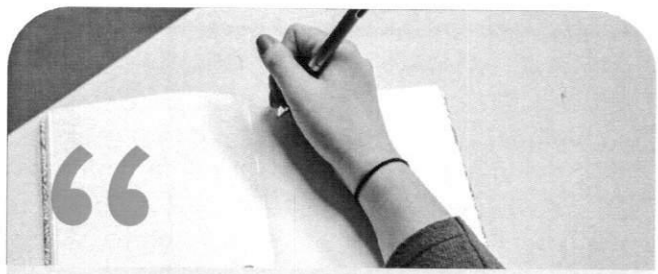
Internships at the CBF

This year we have again been able to offer 3 internships at the CBF. We have now had 29 paid internships since 2011 covering Family Support, Policy, Research and Communications. Each internship is for one year and provides valuable experience in learning disability, working with a range of professionals in the field and gives insight into the experience of family carers.



The internship at the CBF is an amazing opportunity for new graduates and gives a unique introduction to working in the learning disability field. I have learnt a huge amount in my time here and the internship has provided me with the opportunity to work with some truly inspiration people. The CBF team are welcoming, friendly, and always happy to help. I would definitely recommend this internship to anyone interested in a career in this field.

– CBF Intern



The knowledge I have gained and experiences I have had during my internship at the CBF have been invaluable and I am so grateful. The whole team are amazingly kind and will ensure that you gain as much as possible during your time with them.

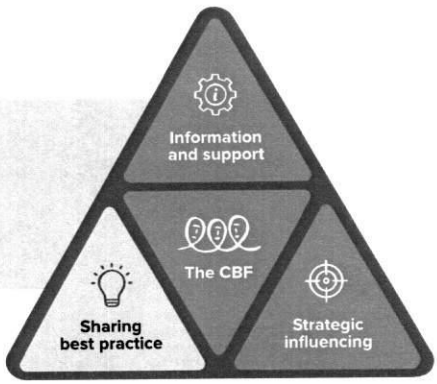
– CBF Intern

Previous CBF interns have gone on to:

- Policy and communications roles in the voluntary and public sector
- Practitioner roles such as: social work, learning disability and mental health nursing and special needs teaching
- Further study at Masters and PhD level in related fields

Initial discussions have taken place exploring development of the internships, and we hope to further develop this with partners going forward.

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Achievements and Performance
Sharing best practice

The principle of sharing and actively promoting best practice runs through all aspects of our work. We share and promote best practice through our family support work, including casework and resources, and our national influencing work. This includes disseminating information via the CB-NSG, its core and associate members, our family carer and professional email networks as well as our specific networks e.g., Paving the Way network that focusses on children and young people. We are invited by researchers to contribute to a range of research projects which vary from recruiting members to advisory or reference groups to leading Public and Patient Involvement (PPI) facilitating focus groups with family carers to ensure their input to the research and its dissemination.

Workshops

Our current workshops are now being delivered successfully online and this continues to create new opportunities for remote delivery and increased accessibility for some.

Positive Behaviour Support Workshops: During the year we delivered 47 workshops to family carers and a wide range of professionals. These virtual workshops bring family carers and professional support staff together to develop a shared language and understanding around developing and co-producing a positive behaviour support plan for the person they are supporting.

> **"I have learnt so much and with this knowledge and hearing the experiences from the participants, made me feel not alone. Everyone is going through the same ups and downs with our challenging behaviour loved ones.**
>
> **– Family Carer**

In response to demand, we have co-produced a specific workshop on Pica, a behaviour involving eating inedible objects. A core group of family carer and professional trainers have co-produced and will co-deliver this new content which has been piloted and will be available in the coming year.

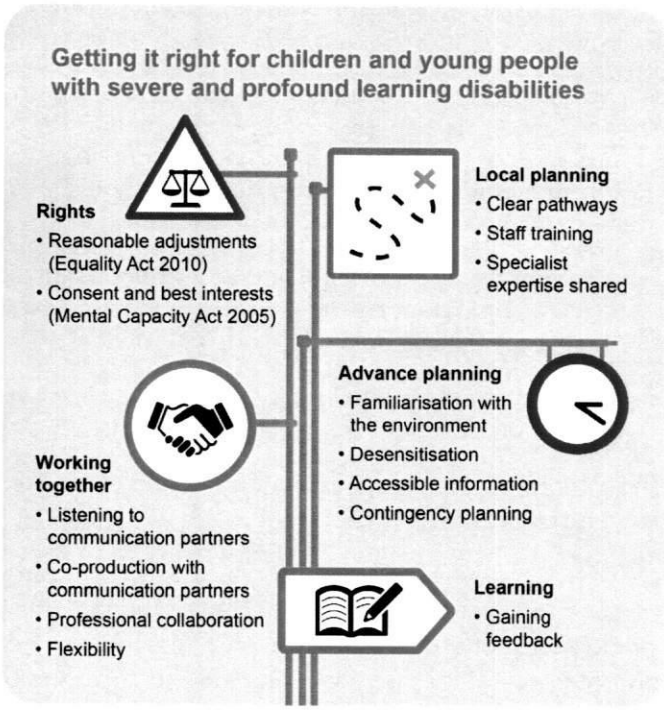
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In addition, we are co-producing a workshop on working in partnership with families, called "Whole Family Approaches", in response to experiences from families we support as well as other "parent blame" evidence. We will pilot and refine this workshop, so it is available in the coming year.

Alongside this we will seek funding to refine the Trauma workshop (see page 24) and recruit and support new trainers to deliver this, to increase our workshop offer and range on topics that families have identified as important.

Direct Engagement – hearing the views and experiences of children and young people with learning disabilities and complex communication challenges

Building on our successful 'Seldom Heard Voices' project (report provided to NHS England but not published) and in recognition of the need to get better at seeking the views of children, young people and adults with learning disabilities and more complex communication challenges, we have been working with the Office of the Chief Dental Officer, and the Tizard Centre at the University of Kent this year to gather the views of children and young people with severe learning disabilities and profound and multiple learning disabilities and their families on access to dental, hearing and sight care. A focus group and survey of family carers were conducted, followed by direct engagement with three young people.



A summary of the findings of the OCDO report

Across the direct engagement with children and young people with severe or profound and multiple learning disabilities and the focus group and survey of family carers, we found that advance planning, reasonable adjustments and clear local pathways were essential to enable equitable access to dental, hearing and sight checks.

We are expecting NHS England to publish the findings from the project and have been informed that this process is underway.

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Advocacy

We have been working as part of the NHS England major review of advocacy for people with learning disabilities and/or who are autistic, who are or have been inpatients in mental health services in England. Our work has been informed and directed by family carers who are members of our project advisory group.

As part of this work, we have investigated family carers' experiences of advocates provided to their adult relatives with learning disabilities and/or who are autistic, whilst they were or are in inpatient units, as well as their experiences acting as advocates themselves. The project comprised three stages of research – a focus group, online questionnaire and desktop research – which generated several clear themes:

- Charities, support organisations, project partners, and family carers have different views on what advocacy is and what advocates should do.
- We know what good advocacy looks like. Good advocacy is long-term involvement from a truly independent advocate, who understands a person's communication, needs, and preferences, who is willing and able to challenge decisions and involves those who know the individual, and their communication, best.
- Based on the information collected from families, adults with learning disabilities and/or who are autistic, in mental health, learning disability or autism specialist hospitals or in ATUs too often receive inconsistent or ineffective advocacy, which fails to fulfil the role set out in the Mental Health Act Code of Practice.
- Data indicates that advocacy is organised in ways that are not person-centered, long-term or holistic, but instead are crisis led, issue-based and short-term.

The interim report for the project has been submitted and we are awaiting feedback from NHS England.

We are also developing an online Advocacy support and information resource for family carers who act as advocates for their relatives. This is currently being finalised and will include a list of organisations we have researched and collated that provide support to parent carers of adult inpatients and the community in their roles as advocates.

In addition to the National Advocacy Project, we are working with two regions (The North West and the North East; Yorkshire and Humber) on a Regional Advocacy project. We have worked with the local partners to devise a plan that will have the greatest impact, be sustainable and will link into the National Advocacy project. This work will be supported by a paid family carer and aims to produce a flexible and practical online advocacy resource which can also be printed out and sent as a hard copy.

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Getting It Right Project

Using funding from The National Lottery Community Fund for a three-year project working across England, we built on our previous work and experience of local area and national strategic work. In the first year of the project, we worked with West Sussex. In the second year we have been working with the Black Country. We have gathered the views of Black Country family carers through an online survey and have planned two virtual focus groups for May 2022. We also provided virtual positive behaviour support training to local family carers. A Black Country stakeholder engagement event is planned for June 2022 to bring together local professionals, third sector organisations and family carers to share the findings from the project and identify short and long-term actions to take forward. In the Black Country the focus of the project has been on transition, including young people up to the age of 25.

All activities in the Black Country have been delivered virtually due to COVID-19. Rising COVID-19 cases in winter 2021 and resulting reduced capacity for engagement in the project from professionals and families meant the focus groups and stakeholder engagement event planned for December 2021 and January 2022 had to be postponed.

Camden have been recruited as the local area for year 3 of the project, to start in April 2022. We held an initial meeting with Camden in November 2021 to begin discussing possible aims and outcomes for the project in Camden. Learning from our experience in the Black Country, we began engagement with Camden family carers in December 2021, raising awareness of the project and opportunities for involvement.

This project continues to provide an opportunity to increase our reach through additional capacity for communications and sharing best practice.

Keyworker Project

The CBF was included within a successful bid by Wolverhampton and the Black Country to form part of their 18-month keyworker pilot. Our role is to act as a critical friend on the steering group and to lead a peer support strand of work. This work will continue into 2022/23 with a focus on the evaluation of the peer support strand of work.

Input to Research Projects

In line with our aim of sharing family lived experiences and building evidence to inform our strategic influencing work, we have continued to support and shape a variety of research applications and funded projects with a wide range of academics and researchers. We have continued to provide input to steering and advisory groups and supported paid family carer participation in consultations and focus groups, including translating research findings into practice. During the year we have supported a number of research projects in this way covering diverse areas including: how to best identify children at risk of developing challenging behaviour, testing adapted therapies for

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post-traumatic stress disorder in people with a learning disability, developing training for families and understanding of withdrawal programmes to support the prevention of over-medication of people with a learning disability, and a range of projects looking at the gaps in evidence for service development and delivery and the engagement of carers in the research process.

We continue to encourage and support families to contribute to consultations and calls for evidence so that their experience and views are heard and included in any response that the CBF submits. We have responded to a range of consultations/calls for evidence with input from families to highlight the issues for children, young people and adults with severe learning disabilities whose behaviour challenges and their families.

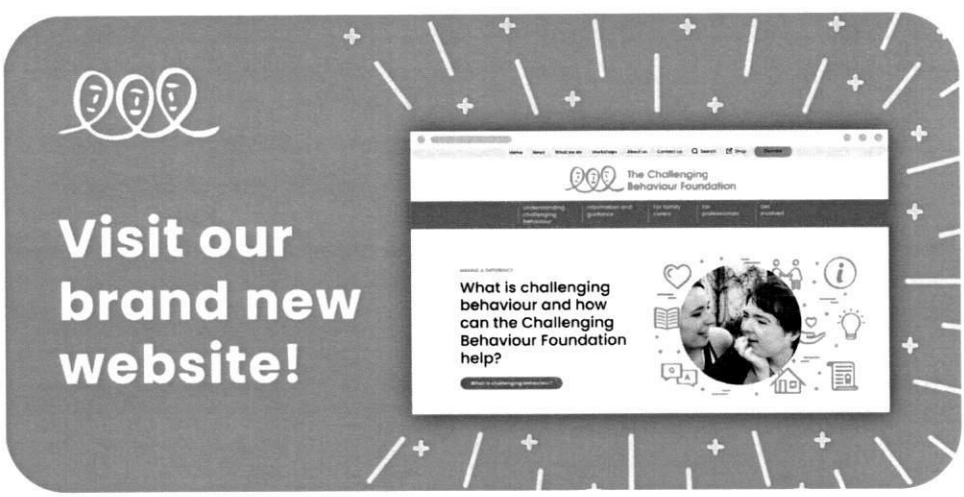
MindEd

We have continued to support the Health Education England mental health e-learning platform, MindEd with developing learning disability training for health and social care professionals. Following a survey of family carers by the CBF in Spring 2019, MindEd received funding to produce a set of six e-learning sessions on STOMP (Stopping over medication of people with a learning disability, autism or both). Funding from Health Education England was agreed for a further 4 sessions to be developed by MindEd in May 2021. We have supported a group of 8 family carers as co-authors who have worked with professionals to develop the e-learning sessions. The first 6 sessions are scheduled to go live in May 2022, and the additional 4 sessions in summer 2022.

New Website (www.challengingbehaviour.org.uk)

The National Lottery Community Fund enabled us to develop a new website as part of the Getting It Right Project, to reach more families and provide them with practical information and support. The new website was launched in May 2021 and is easier to access on mobile phones and tablets as well as laptops and is a more user friendly and accessible website.

Families were key partners throughout the website's design process to ensure it meets their needs, and all CBF resources were reviewed to ensure they are up to date. The new site includes new resources and video clips filmed by family carers, and new stories and photos as well as an online shop for professionals to purchase resources (which are free to family carers).



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> **I saw your new website yesterday for the first time and think it looks really fantastic! I know what a lot of hard work it will have been for everyone getting it to his point, but it really is brilliant- well done to everyone involved.**
>
> **- Professional**

We will implement our plan for reviewing, updating and further developing the website and its content over the coming year, incorporating feedback gathered.

Newsletter

We produced 3 electronic newsletters during the year with 2 of the editions also being sent out to around 3000 people in hard copy per edition to ensure families throughout the UK without digital access were not left out.


Challenge

Winter 2020 Registered charity no. 1060714

The Challenging Behaviour Foundation

Your rights during difficult times

To read online, please see: http://bit.ly/CBFNewsletters

What's in this newsletter?

Welcome to the latest CBF newsletter

As we approach the winter months the national pandemic arrangements are ever changing and continuing to affect everyone's daily lives. Living with uncertainty is difficult at any time, especially when you support a family member with a severe learning disability whose behaviour challenges. I know from my own experience with my son that as a family we have had to learn to respond swiftly to unexpected changes and new challenges, but Covid-19 has introduced a whole new layer of unpredictability. This newsletter contains a range of information we hope will be practical and helpful, from joining online Carer Catch-ups with other families in similar situations who understand, to managing risk – in ways that activities can still take place, but with reasonable adjustments to manage and minimise the risk.

We know from all of our work with families that feeling isolated and alone is common - and that it is hard to find information that is practical and tailored to the needs of families supporting children and adults with severe learning disabilities whose behaviour challenges. The current pandemic has made life more complicated for everyone and increased concerns and worries about our relatives. One family carer shares her experiences on page 8, and this newsletter contains information about a range of ways we hope to help with this. There are reminders about our helpline support and new online resources, as well as summaries of information for families who do not use the internet and who may be feeling even more isolated as more and more contacts, groups and information are provided online. Although all CBF staff are working from home currently, we can still post resources and information to families so do ring us if you need hard copies.

These are difficult times – do get in touch for information or support.

Vivien Cooper
Family carer and CEO of the CBF

Resources in this issue

Positive risk taking: maintaining quality of life during the pandemic	3-3
How the pandemic has impacted the health of people with learning disabilities	4-5
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Activity ideas for children or adults with severe learning disabilities	9-10
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Workshops and training, Frontline Families	15
Thank you	16

All the resources featured in this newsletter (and more) are available on our website: www.challengingbehaviour.org.uk/

New website coming soon!

Also look out for our new website coming soon, funded through our 3 year project with the National Lottery Community Fund.

We are currently working very hard to get a brand new website up and running. There will be a new design to make finding information easier and improvements to accessibility.

This includes improving how we share resources so you can get the information you need more quickly.

Who are the CBF? We are a charity supporting families of children, young people and adults with severe learning disabilities whose behaviour challenges.

1

The Summer 2021 edition focussed on communicating and connecting, and the impact of the pandemic. It included information on adapting to things being different and finding new ways of connecting with people. Along with this 16-page newsletter, we also took the opportunity to send out the following information:

- Quick read challenging behaviour guide (new resource) – giving tips and strategies to help families during a period of new or increased challenging behaviour
- Challenging Behaviour Charter – setting out the rights of children, young people and adults who are perceived as challenging and the action that needs to take place
- Wellbeing Information Sheet (new resource) – information on family carer wellbeing and resilience
- Making it Happen Information Sheet - positively managing risk for children and adults with severe learning disabilities (new resource)
- Medication pathway flyer – information for families of people with learning disabilities, autism or both who are prescribed psychotropic medication

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In the Autumn 2021 edition we celebrated families and their varied and sometimes challenging roles, and the differences they are making to their relatives' quality of life. Navigating the complex education, health and social care systems to access the right support and services can be exhausting and frustrating – but enabling their relative to be happy and to enjoy life is hugely rewarding and a cause for celebration.

We will continue to seek funding and partnership opportunities for hard copies of our newsletters to be sent out in the future.

Social Media

We continue to use our social media platforms to share good practice information and practical resources. All our social media platforms have all seen an increase in followers this year allowing us to reach more people.

Looking back over the year

This year has seen a combination of continuation of ongoing work and support as well as new projects, all encompassed within our three core strands of work (support and information, strategic influencing and sharing best practice) - and all with lived experience and co-production at the core. As a small team with limited resources, we have to work efficiently, flexibly and effectively, ensuring that we always focus on outcomes and impact. We have many years of experience that inform all our activities and approach.

We know that the change we want to see for everyone will not happen quickly - and that it will only be achieved by persistence and working collaboratively. We will continue to champion and independently advocate for the rights of individuals and their families to be upheld, and for investment in early intervention and community support and services to ensure the system delivers what it needs to - the right support in the right place at the right time.

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Financial review

Financial position

Incoming resources for the year amounted to £610,424 (£595,267 in 2020/21) and resources expended were £516,484 (£507,520 in 2020/21), giving net income of £93,940 (£87,747 in 2020/21). 38 per cent of incoming resources from charitable activities arose from earned income for one-off consultancy and other services, offsetting a reduction in grant income, which was boosted in the previous year by emergency Covid funding. Unrestricted net income of £86,430 reflects continuing tight budget management, cost reductions due to some activities being temporarily delivered online, and the use of the core staff team to undertake project work wherever possible, reducing the need to deploy additional external resources.

The support of trusts and foundations remains vital in enabling us to carry out work to increase the CBF's impact while helping to maintain its financial viability. We would like to extend our grateful thanks to all supporters who have enabled us to achieve this. The receipt of a 3-year grant from the National Lottery Community Fund enables us to raise awareness of our evidence-based approach much more effectively. We wish to thank the Esmee Fairbairn Foundation for supporting our policy and influencing work, and the Sobell Foundation, the Dulverton Trust and Colyer-Fergusson Charitable Trust for supporting our family support service. Thanks are also due to Garfield Weston Foundation, Pears Family Charitable Foundation and several smaller foundations for supporting core costs.

Looking ahead, it is clear that the funding environment is becoming more challenging than ever. Most paid work is ad hoc, unpredictable and fluctuates in volume, while grant funding is one-off or relatively short term and subject to fierce competition. In the light of this, the Trustees continue to scrutinise regular forward projections, review closely the financial performance of individual projects and identify pre-emptively any funding gaps and the actions needed to address them.

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Reserves policy

The Trustees have reviewed the key risks across the organisation and have set a target of holding closure costs plus nine months running costs in free reserves (unrestricted funds) to ensure the charity is in a stable position to:

1. Fulfil notice periods, statutory redundancy and meet all other obligations and liabilities in event of closure of the charity
2. Provide effective staffing to seek alternative funding and support the development of alternative forms of support for families in need of long-term casework in the event of a downturn in income or closure (we typically provide casework support to families for a period of 6 months – 3 years)
3. Enable the organisation to respond to unforeseen external challenges such an increase in demand similar to that experienced due to covid restrictions.

In determining the reserves strategy, the Trustees have taken a holistic and strategic approach to carefully consider the reasons for maintaining reserves as well as the logistics of utilising them. This includes consideration of the external factors that may affect reserves such as demands on capacity and the high competition for and relatively short-term nature of grant funding, which forms a large part of the charity's income, and often involves a long lead time to secure.

We also maintain these reserves to remain sufficiently flexible to respond to any opportunities that may arise at short notice for us to influence national policy on behalf of our beneficiaries. Decision to use the reserves in this manner is at the discretion of the Trustees taking into account the charities financial position to balance any risks to its sustainability.

Free reserves amounted to £447,134 at 31 January 2022, representing almost nine months of running costs, after taking account of estimated closure costs, based on predicted expenditure for 2022/23.

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Our Plans for the coming year

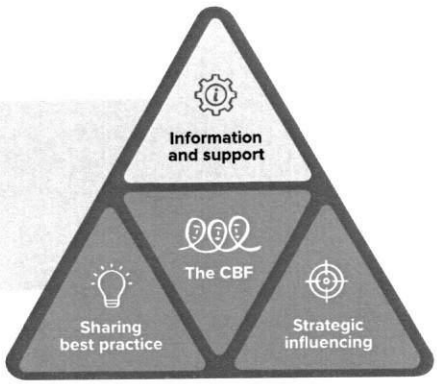
Whilst compiling this report, we have continued to live through a pandemic and the COVID-19 restrictions and the inevitable and significant impact on our work and its delivery. Uncertainties beyond our control remain as the lockdowns and restrictions are relaxed and re-imposed according to new variants, vaccinations and Government responses. Our planned phased return to the CBF office for our staff was impacted by new restrictions, but implemented when guidance allowed, with an interim hybrid arrangement for some roles which we will review going forward.

We plan to recruit 2 interns in the coming year - funding has been secured and these roles have proved effective and good value for money, but we have no plans to increase our core staff team. Our core aim of making society inclusive and the statutory support systems work effectively for children and adults with severe learning disabilities whose behaviour challenges and their families remains, and shapes all our work and plans. Our ultimate aim as an organisation is not to be needed because the 'system' works, although we know this is a long term aim and in the interim we need to sustain our work. If and when more capacity is required, we intend to utilise consultants who have been through our core training, to enable flexibility without long term financial commitment, unless there are new opportunities for funding fixed term posts which arise for project work we want to take forward.

We anticipate that additional funding challenges will emerge as the pandemic costs are repaid. Trustees are mindful of potential future financial risks and plan accordingly, including building reserves and investment in additional fundraising capacity.

Our core aim remains to ensure that "the system" and society enable individuals with severe learning disabilities, and their families, to receive the right support in the right place at the right time. Our approach and all our work is carefully planned and thought through with regular reviews to consider outcomes and impact, and in the coming year we will continue to focus on our three key interconnected areas of work (information and support, strategic influencing and sharing best practice). Our many years of experience have informed and refined our work and how it is delivered to achieve impact and good outcomes. The change we want to see is significant and takes time. Although we are acutely aware of the urgency and are ambitious and impatient for change, we are realistic regarding our capacity, the inertia and resistance to change within the system, and the need and investment required to work collaboratively.

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Future plans
Information and support

We plan to continue to ensure our specialist family support and information service is maintained, continues to be family centred and provides high quality independent expertise and advocacy for families in need. The families we support are often in very complex situations, navigating through disjointed education, health and care systems, and experiencing marginalisation, "parent blame" and exclusion. Families clearly describe "the fight" for the support and services their relatives need, and their experiences of discrimination and basic human rights being ignored.

A key challenge in the coming year will be to ensure children, young people and adults with a learning disability who display behaviour that challenges and their family carers, are supported through COVID-19 "recovery" and the restrictions imposed during the pandemic are removed to enable a return to accessing support and services that meet their needs. There is strong evidence that individuals with learning disabilities and their families have been disproportionately impacted by the pandemic. This will add an additional layer of challenge, complexity, and concern to their daily lives. We are mindful that demand for our support remains high, so this will require us to continue to manage our capacity and skills within the team efficiently, including through our triage arrangements, providing support in even more complex situations, and developing new resources and online forms of support and information.

Funds generously provided by The Lloyds Bank Foundation, The Sobell Foundation, the Dulverton Trust and Garfield Weston Foundation for our family support helpline and casework are vital to enable this work to continue, and some multi-year funding is coming to an end. We will prioritise seeking further funding to ensure we can maintain and develop the support and information we provide for families who are often in crisis.

We will continue our new peer support Facebook group to offer families the option of different forms of peer interaction and communications. This will run alongside the existing 'Family Carer Email Network' to cater for the differently-technologically-suited groups of families who benefit from having access to online interaction and peer support. In addition, subject to funding, we will continue to offer a telephone "listening ear" service to provide trained and supported peer support to those who cannot access or prefer not to use our online support networks.

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As an extension of our Carers Catch Up fortnightly online support group, we will deliver Carers Catch Up Plus. A well-being activity such as mindfulness and crafting will be followed by an opportunity to speak informally with other family carers. We hope that this will encourage a new group of families to access our Carers Catch Up alongside those who already attend.

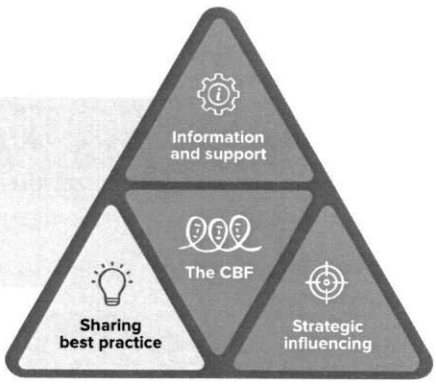
We will review the diversity of the families who use the CBF's information and support service and work to increase inclusion for a broad range of families, particularly those from 'hard to reach' communities. We will continue to send paper newsletters (subject to identifying funding) and information resources to families who do not use the internet or who request hard copies of resources.

We will further improve relationships with other family support organisations and charities that run helplines by leading the co-ordination of regular meetings which has proved highly beneficial, providing peer support, problem solving and opportunities for joint working. This helpline collaborative has enabled efficient signposting to others when appropriate and helps us to identify any gaps in support. We will continue to facilitate this group and to identify joint working opportunities as well as any new members to join the group.

Family experiences of trauma will continue to be an important area of work for the CBF. The trauma awareness resource co-produced with families and developed in collaboration with Respond and the Tizard Centre has been finalised and plans for wider dissemination and strategic influencing will be taken forward.

Our family support and information service takes a lifelong approach and we will consider how we target families in particular situations to increase our impact.

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Future plans
Sharing best practice

Our new website launched in Spring 2021, and we will continue to monitor and evaluate its use, with a planned timetable for updating both written and visual content on it incorporating feedback and in partnership with families. We aim to invest in ensuring that our website and database work efficiently together, and that we increase and widen our reach.

The views and experiences of children and adults with severe learning disabilities are often disregarded as they are unable to attend or use traditional methods such as focus groups or surveys – but it is important that we adapt our approach to enable their views to be captured. We will therefore continue to develop our work on engagement with children, young people and adults with complex needs, working with other leaders in this field, to find innovative ways to seek their views, and to demonstrate that it is possible to consult with them in a meaningful way. At the same time, we will take every opportunity, in our own work and the work of other organisations, to ensure that families of children, young people and adults with complex needs can share their lived experience to drive forward change.

Promotion of early intervention approaches, both in terms of support in early childhood as well as early support with emerging challenging behaviour at any age, will remain a key feature in all three strands of our work - information and support, sharing best practice and strategic influencing. We will continue to collate and present evidence of the positive benefits of early intervention, and work with researchers and academics to achieve this. This is particularly important as we emerge from the pandemic and there may be a tendency to cut existing early intervention services or not invest in them where needed. We plan to work with researchers to publish an Early Intervention report collating the evidence presented at the 2021 early intervention seminar, and to further promote investment in families and availability of timely specialist support.

We will work with researchers to investigate opportunities for formal evaluation of our PBS workshops, and other research initiatives will be pursued, both with academic partners and through our CBF/ Tizard Family Carer research group, to further build the evidence base. In partnership with a range of other individuals and organisations we will work to develop a national learning disability research strategy.

We will continue to review, refine, and co-produce the topics and co-delivery method of our training workshops, aiming to have a blended approach to capture the benefits of

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both in person workshops and online delivery. We will pilot our newly developed 'Whole Family Approaches' and PICA (eating inedible objects) workshops, recruiting, training and supporting family carer and professional co-trainers to jointly deliver the sessions.

Family experiences of trauma will continue to be an important area of work for the CBF. Working in co-production with the family carers involved in the production of the Trauma Awareness films, produced in partnership with Respond and the Tizard Centre, we will refine the workshop materials using the 4 chapters of the film already produced and ensuring the original wishes of the families for the use of the footage is retained. In addition, we will develop and take forward plans with family carers to recruit and train new trainers and target key workforce groups for this awareness raising work, as well as exploring other opportunities to highlight the issues and plans for wider dissemination and strategic influencing will be taken forward.

Building on our national and regional advocacy work, we will promote the need for accessible, robust and independent advocacy for individuals and families. We will complete the online advocacy resource and develop a dissemination plan to share it widely.

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Future plans
Strategic influencing

We are ever mindful that we operate in the wider context of the learning disability, carer, social care, education, health and voluntary sectors. Developing and maintaining relationships with others with similar related aims to the CBF will increase our collective impact and our collaborative, solution focussed, and evidence-based approach will continue.

Working collaboratively takes longer and requires skilled management to build trust and focus on shared aims and objectives rather than differences of opinion, but we believe we can achieve more by working together and, by using this co-production approach, can deliver better outcomes.

Our influencing agenda will of course continue to be responsive to the changing political circumstances and challenges that arise. Constant reorganisations and changes in education, care and health systems and key post holders continue to pose challenges through lack of continuity, delays, and inertia.

We remain committed to continue to challenge the failure of the Transforming Care agenda.

We have long called for a cross Government approach, which was initially rejected but now adopted, and we will continue to monitor whether this results in any action that makes a difference and keeps this on the national and local agenda. This work has the potential for a very significant impact for our client group and specific multi-year funding support to pursue this work from Esmee Fairbairn is enabling this vital long-term work to progress. There is no "quick fix" solution - it requires strategic patience, commitment and determination.

We will continue to bring together a diverse range of stakeholders, through our CB-NSG members and associates, and work in partnership to identify ways to drive forward the change needed, developing workable initiatives that build on past experience and existing knowledge, and delivering a solution focussed approach.

We will build on, and expand the External Support Group (ESG), a CBF led initiative, bringing together a group of senior experienced clinicians and professionals to provide support to local teams who are supporting individuals. Utilising funding for "proof of concept" we will test, refine and evaluate the model in one area and consider how to further develop and expand the model.

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We continue our local strategic input work as part of a 3-year project funded by the National Lottery Community Fund. We will be completing work with the Black Country and partnering with Camden for the third and final year of the project.



Our work targeting professionals who work with families, increasing their awareness of need and the issues families face, will continue. We will continue our work with the keyworker pilot, in particular looking at the evaluation of the peer support model, and work with other professions who support families of children.

We are planning to continue the strategic legal work identified by our legal panel members and the individuals and organisations who have participated in our legal strategy meetings so far. We will continue to promote a joined-up approach to enable easier and timely access for families to legal support and information, and to ensure best use of limited resources. This work, linked to the CBF Legal Panel work may require seeking additional specialist capacity to drive this forward.

Our work on reducing the use of restrictive interventions will continue, via the RRISC (Reducing Restrictive Interventions and Safeguarding Children) group, and other initiatives such as the NHS England STOMP and STAMP programmes, which aim to address the inappropriate medication of individuals with learning disabilities. The RRISC group plan to update the name of the group and the terminology used to ensure it reflects the group's goal to eliminate inappropriate restrictive practices.

All parts of the system need to work well for children, young people and adults with severe learning disabilities whose behaviour challenges - including the regulators. We will continue to press for robust regulation, inspections, monitoring and data collection, and challenge the registration of new services which do not fit the model of increasing good quality local community support.

Joined up working

In the coming year we will continue to progress our work in all three key areas, regularly reviewing our activities and their impact. As a small team with limited capacity and resources, we are ever mindful of the need to target our efforts carefully and influence those in positions of power who can make change happen, and who have a wider reach and more resources. Our work is wide-ranging because it reflects the multiple issues and systems that families have to negotiate and contend with, and we know that there are

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many areas of work that need to be taken forward concurrently. All elements of our work and projects are interconnected, we work proactively but are also able to respond quickly to opportunities and needs as they arise - as evidenced in our response to the pandemic and having sufficient reserves is a key enabler in this respect.

We know there will be significant challenges ahead - both in terms of the needs of the families we support, and the financial challenges we will face as a small charity to secure funds for our work. We will take all the necessary steps we can to ensure we are able to continue our much-needed work, making a difference to the lives of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families.

COVID-19

The COVID-19 pandemic has continued to have a significant impact on the CBF and families we support, and we do not know how this will develop going forward. We have learned to be creative in our delivery of support and projects to ensure they continue with as little disruption as possible. Staff and volunteers are transitioning back to the office and a hybrid working model is being trialled. Although remote (and hybrid) working has posed a range of additional challenges and issues, including ensuring that we are all connected and with good communication and peer support mechanisms, all staff have responded positively and adapted to the challenges and opportunities this brings.

Some positive opportunities emerged from the enforced "work from home" rules which we will continue to incorporate into our working practices going forward:

- The use of virtual meetings enabled people to join groups who would otherwise not be able to attend, for example due to caring responsibilities or location, to engage with a range of areas of our work.
- It has been possible for CBF to have representation at a range of virtual meetings which if in person we would not have been able to attend due to prohibitive travel cost or time constraints. Members of our family support team have also been able to join some virtual meetings with families and professionals as part of our complex casework support. Families have reported that they have found this valuable and beneficial.
- Family carers have been involved in providing peer to peer support through video 'carers catch-ups' or trained and supported to provide listening ear telephone calls. These catch-up calls are not limited to working hours and can be during the day or in the evening or weekends to suit the participants.
- All our training workshops were adapted to be delivered online which has enabled us to deliver training to families and paid support staff throughout the UK. This has reduced costs and increased engagement, although we know that some of the networking opportunities and "informal connections" made at in person events have been lost. We intend to offer both face to face and online workshops in the future.

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- All our DVD/Video resources were moved online so they could be viewed for free from our website during the pandemic. Although this will reduce a source of income for the charity, we will continue to keep them available on our website and free to watch so the information can be accessed by more people who can benefit from the information.

These new ways of working will be incorporated as we move out of the pandemic, and we are looking into hybrid models of delivery. We are however very mindful of the "digital divide" and that not all families have access to online resources or technology. We will therefore continue to strive to ensure our information and support is available to all and in a range of formats.

Throughout the COVID-19 challenges and the difficulties they have presented to everyone, the small CBF staff team has continued to progress work in all 3 key areas, increasing our information and support service, increasing sharing best practice and continuing our strategic influencing work. Evaluation and feedback from varied sources continue to confirm that we are making a difference.

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Structure, governance and management

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

Recruitment and appointment of new Trustees

Trustee skills are reviewed annually to ensure the board has the range of skills and experience required. We had a detailed review of trustee skills, facilitated by an external consultant, during the year. Any gaps in specific skills are identified and addressed through training or pro bono consultancy input or through the recruitment of new members to the Trustee Board. This year, we have appointed two new Trustees through this process.

We are currently reviewing how our network of Trustee Advisors are supported, involved, and contribute to the CBF and will implement new arrangements following the review.

Organisational structure

The Trustees, who are directors for the purpose of company law and Trustees for the purpose of charity law, who served during the year and up to the date of this report are set out on the following page. Members of the charitable company guarantee to contribute an amount not exceeding £10 to the assets of the charitable company in the event of winding up.

Day to day management of the charity's activities is delegated by the Trustees to the Chief Executive Officer. The Trustee Board meets quarterly to review achievements and performance, finances and future plans.

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Risk management

The Trustees have a duty to identify and review the risks to which the charity is exposed, including ensuring appropriate controls are in place to provide reasonable assurance against fraud and error.

The Trustees have put in place a risk management strategy, comprising an annual review of the risks the charity may face, the establishment of systems and procedures to mitigate risks identified, and the implementation of procedures designed to minimise any potential impact on the charity should any of these risks materialise. The work has identified a potential reduction in funding, together with inflationary pressures on salary levels as major risks in the light of the difficult financial environment following the COVID-19 crisis. The regular updating and review of financial projections and tight budget management are key elements in the management of these risks. Attention has also been focussed on non-financial area such as reputational risk and suitable mitigating actions put in place, while the pandemic has highlighted the importance of ensuring that the CBF is in a position to respond to national or international-scale incidents that lie beyond our control.

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Reference and administrative details

Registered Company number

3307407 (England and Wales)

Registered Charity number

1060714

Registered office

c/o The Old Courthouse
New Road Avenue
Chatham
Kent
ME4 6BE

Trustees

Dr D Allen (Appointed July 2022)
Ms S Cooper
Mrs V A Cooper (Resigned July 2022)
Mrs D C Cutler (Retired April 2021)
Mr J Dodd
Ms A K Giles
Dr N J Gore
Ms D E Lightfoot (Chair)
Mrs C Million
Mr A Rook (Appointed July 2022)

Company Secretary

Mrs C Million

Auditors

Xeinadin Audit Ltd
Becket House
36 Old Jewry
London
EC2R 8DD

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Statement of trustees responsibilities

The trustees (who are also the directors of The Challenging Behaviour Foundation for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to;

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.
In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditors are unaware; and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

AUDITORS
The auditors, Xeinadin Audit Ltd (via Calcutt Matthews Ltd), will be proposed at the forthcoming Annual General Meeting.

Approved by the order of the board of trustees on 31/08/2022 and signed on its behalf by:

Mrs C MILLION - Trustee/ Company Secretary

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The Challenging Behaviour Foundation

Report of the independent auditors

to the members of The Challenging Behaviour Foundation

Opinion

We have audited the financial statements of The Challenging Behaviour Foundation (the 'charitable company') for the year ended 31 January 2022 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 January 2022 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

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Conclusions relating to going concern

We In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Report of the Trustees has been prepared in accordance with applicable legal requirements.

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Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Trustees.

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

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Our objectives in performing the audit are to identify and assess the risk of material misstatement in the financial statements due to fraud or error and to obtain sufficient audit evidence to support this. We also evaluate and respond to the risk of material misstatements.

Audit procedures performed by the engagement team included:

- Gaining an extensive knowledge of the entity and environment
- Obtaining a sufficient understanding of the internal environment, including control systems in place for the detection and prevention of fraud.
- Evaluating said systems to determine whether they are operating to a satisfactory level and are providing the right level of control and authorisation within the entity.
- Understanding the entity's current activities, assets and liabilities and comparing these to the entity's charitable objectives and aims.
- Discussions with management and those charged with governance as to any known or suspected instances of non-compliance with laws and regulations, including fraud.
- Reading minutes of meetings of those charged with governance and comparing these to what is reflected in the statutory accounts.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Nicholas Hume FCA

Nicholas Hume FCA (Senior Statutory Auditor)
for and on behalf of Xeinadin Audit Ltd
Becket House,
36 Old Jewry
London,
EC2R 8DD

Date: 29/9/22.

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Statement of financial activities

for the Year Ended 31 January 2022

	Notes	Unrestricted funds £	Restricted funds £	31.1.22 Total funds £	31.1.21 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	26,694	-	26,694	26,602
Charitable activities	5				
Information and Support		73,435	129,265	202,700	45,648
National Influencing		-	171,291	171,291	6,829
Core Funding		207,455	-	207,455	514,398
Other trading activities	3	2,138	-	2,138	1,363
Investment income	4	146	-	146	427
Total		**309,868**	**300,556**	**610,424**	**595,267**
EXPENDITURE ON					
Raising funds	6	19,587	-	19,587	17,801
Charitable activities	7				
Information and Support		40,894	126,471	167,365	136,318
National Influencing		-	153,886	153,886	17,239
Core Funding		162,957	12,689	175,646	336,162
Total		**223,438**	**293,046**	**516,484**	**507,520**
NET INCOME		**86,430**	**7,510**	**93,940**	**87,747**
RECONCILIATION OF FUNDS					
Total funds brought forward		**360,704**	**115,792**	**476,496**	**388,749**
TOTAL FUNDS CARRIED FORWARD		**447,134**	**123,302**	**570,436**	**476,496**

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Balance sheet
31 January 2022

	Notes	Unrestricted funds £	Restricted funds £	31.1.22 Total funds £	31.1.21 Total funds £
FIXED ASSETS					
Tangible assets	13	-	-	-	6
CURRENT ASSETS					
Debtors	14	46,249	-	46,249	88,775
Cash at bank		469,856	145,717	615,573	658,438
		516,105	145,717	661,822	747,213
CREDITORS					
Amounts falling due within one year	15	(68,969)	(22,417)	(91,386)	(270,723)
NET CURRENT ASSETS		**447,134**	**123,302**	**570,436**	**476,490**
TOTAL ASSETS LESS CURRENT LIABILITIES		**447,134**	**123,302**	**570,436**	**476,496**
NET ASSETS		**447,134**	**123,302**	**570,436**	**476,496**
FUNDS	16				
Unrestricted funds				447,136	360,704
Restricted funds				123,300	115,792
TOTAL FUNDS				**570,436**	**476,496**

The financial statements were approved by the Board of Trustees and authorised for issue on 31/08/2022 and were signed on its behalf by:

Mrs C Million - Trustee

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Cash flow statement
for the Year Ended 31 January 2022

	Notes	31.1.22 £	31.1.21 £
Cash flows from operating activities			
Cash generated from operations	1	(41,888)	209,396
Other expense		6	-
Gift Aid		(1,129)	(1,500)
Net cash (used in)/provided by operating activities		(43,011)	207,896
Cash flows from investing activities			
Interest received		146	427
Net cash provided by investing activities		146	427
Change in cash and cash equivalents in the reporting period		**(42,865)**	**208,323**
Cash and cash equivalents at the beginning of the reporting period		**658,438**	**450,115**
Cash and cash equivalents at the end of the reporting period		**615,573**	**658,438**

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Notes to the cash flow statement
for the Year Ended 31 January 2022

1. RECONCILIATION OF NET INCOME TO NET CASH FLOW FROM OPERATING ACTIVITIES

	31.1.22	31.1.21
	£	£
Net income for the reporting period (as per the Statement of Financial Activities)	93,940	87,747
Adjustments for:		
Depreciation charges	-	182
Interest received	(146)	(427)
Decrease/(increase) in debtors	43,655	(19,284)
(Decrease)/increase in creditors	(179,337)	141,178
Net cash provided by operations	(41,888)	209,396

2. ANALYSIS OF CHANGES IN NET FUNDS

	At 1.2.21	Cash flow	At 31.1.22
	£	£	£
Net cash			
Cash at bank	658,438	(42,865)	615,573
	658,438	(42,865)	615,573
Total	658,438	(42,865)	615,573

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Notes to the financial statement

for the Year Ended 31 January 2022

1. ACCOUNTING POLICIES

Basis of preparing the financial statements
The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

- Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity

- Designated funds are unrestricted funds earmarked by the Trustees for particular purposes.

- Restricted funds are subject to restrictions on their expenditure imposed by the donor or through the terms of an appeal.

Income
All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure
Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Allocation and apportionment of costs
Support costs are allocated pro rata to staff numbers involved with each charitable activity.

Tangible fixed assets
Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Plant and machinery - 20% on cost
Fixtures and fittings - 33% on cost

Taxation
The charity is exempt from corporation tax on its charitable activities.

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1. ACCOUNTING POLICIES - continued

Fund accounting
Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Pension costs and other post-retirement benefits
The charitable company operates a defined contribution pension scheme. Contributions payable to the charitable company's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

2. DONATIONS AND LEGACIES

	31.1.22	31.1.21
	£	£
Donations	25,565	25,102
Gift aid	1,129	1,500
	26,694	26,602

3. OTHER TRADING ACTIVITIES

	31.1.22	31.1.21
	£	£
Fundraising events	940	626
Sales and earned income	1,198	737
	2,138	1,363

4. INVESTMENT INCOME

	31.1.22	31.1.21
	£	£
Deposit account interest	146	427

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5. INCOME FROM CHARITABLE ACTIVITIES

	Information and Support	National Influencing	Core Funding	31.1.22 Total activities	31.1.21 Total activities
	£	£	£	£	£
Grants	129,265	171,291	58,606	359,162	475,716
Contract and Other Non Grant Income	73,435	-	148,849	222,284	91,159
	202,700	171,291	207,455	581,446	566,875

Grants received, included in the above, are as follows:	31.1.22	31.1.21
	£	£
Colyer-Fergusson Charitable Trust	2,483	-
The Sobell Foundation	16,667	12,500
Garfield Weston Foundation	25,000	25,000
The National Lottery Community Fund - COVID	-	18,853
Department of Health and Social Care (DHSC) Covid Recovery	41,378	228,396
The Stonewall Park Charitable Trust	1,000	500
The Sir James Roll Charitable Trust	1,000	1,000
The Esmee Fairbairn Foundation	40,000	20,000
Lloyds Bank Foundation	-	12,566
The University of Warwick	5,500	-
Baily Thomas Charitable Fund	-	20,000
National Lottery Community Fund	131,291	104,069
Lloyds Bank Foundation - COVID	18,737	12,832
Esmee Fairbairn - COVID	-	20,000
The Steele Charitable Trust	20,000	-
The Dulverton Trust	30,000	-
Pears Family Charitable Foundation	25,000	-
The Paypal Giving Fund UK	356	-
The Grace Trust	750	-
	359,162	475,716

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6. RAISING FUNDS

Raising donations and legacies

	31.1.22	31.1.21
	£	£
Staff costs	17,000	17,000
Fundraising	346	120
	17,346	17,120

Other trading activities

	31.1.22	31.1.21
	£	£
Bad debts	2,241	681
Aggregate amounts	19,587	17,801

7. CHARITABLE ACTIVITIES COSTS

	Direct Costs	Support costs (see note 8)	Totals
	£	£	£
Information and Support	167,365	-	167,365
National Influencing	153,886	-	153,886
Core Funding	170,325	5,321	175,646
	491,576	5,321	496,897

8. SUPPORT COSTS

	Governance costs
	£
Core Funding	5,321

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9. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	31.1.22	31.1.21
	£	£
Auditors' remuneration	1,856	2,117
Depreciation - owned assets	6	182

10. TRUSTEES' REMUNERATION AND BENEFITS

Vivien Cooper was employed full time as Chief Executive Officer with the express permission of the Charity Commission in recognition of her unique skills and experience. She is enrolled in a work-place pension scheme for her role as Chief Executive Officer. Vivien Cooper retired as a Trustee in July 2022.

Audrey Giles, a Trustee, received £1,116 for managing a project that required her specific skillset and knowledge, not for her role as a trustee.

No Trustee or any person related to the charity had any personal interest in any contract or Trustee transaction entered into by the charity during the year other than as disclosed above.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 January 2022 nor for the year ended 31 January 2021.

11. STAFF COSTS

No employee was paid over £60,000 in the year.

The average monthly number of employees during the year was as follows:

	2022	2021
Information, Support & Training	6.5	7
National Influencing Work	8	7.45
Total	14.5	14.45

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12. INTANGIBLE FIXED ASSETS

Net income/(expenditure) is stated after charging/(crediting):

	Database
	£
COST	
At 1 February 2021	9,853
Disposals	(9,853)
At 31 January 2022	-
AMORTISATION	
At 1 February 2021	9,853
Eliminated on disposal	(9,853)
At 31 January 2022	-
NET BOOK VALUE	
At 31 January 2022	-
At 31 January 2021	-

13. TANGIBLE FIXED ASSETS

	Plant and machinery	Fixtures and fittings	Computer equipment	Totals
	£	£	£	£
COST				
At 1 February 2021 and 31 January 2022	8,161	1,258	5,075	14,494
DEPRECIATION				
At 1 February 2021	8,161	1,258	5,069	14,488
Charge for year	-	-	6	6
At 31 January 2022	8,161	1,258	5,075	14,494
NET BOOK VALUE				
At 31 January 2022	-	-	-	-
At 31 January 2021	-	-	6	6

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14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.1.22	31.1.21
	£	£
Trade debtors	34,397	81,919
Other debtors	3,013	-
Gift Aid reclaimable	7,985	6,856
Prepayments	854	-
	46,249	88,775

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.1.22	31.1.21
	£	£
Trade creditors	4,851	113,436
Social security and other taxes	4,826	4,700
VAT	8,271	-
Funds held for other organisations	15,423	15,423
Accruals and deferred income	58,015	137,164
	91,386	270,723

Funds held for other organisations £15,422 (2021: £15,422) represents monies held by the charity where it is working with other charities on joint projects. At 31 January 2021 these are as follows:

Learning Disability Senate	£12,840
Employment Dissemination	£2,582

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16. MOVEMENT IN FUNDS

	At 1.2.21	Net movement in funds	At 31.1.22
	£	£	£
Unrestricted funds			
Core Funding	346,040	101,051	447,091
Training Designated Fund	14,664	(14,619)	45
	360,704	86,432	447,136
Restricted funds			
The Esmee Fairbairn Foundation	5,138	4,750	9,888
The National Lottery Community Fund	32,788	6,350	39,138
The Lloyds Bank Foundation	2,712	(2,712)	-
Baily Thomas Charitable Fund	20,000	(20,000)	-
CB-NSG	4,305	(90)	4,215
SHIEC	3,572	-	3,572
Peoples Postcode Trust	4,227	(2,050)	2,177
Rrisc	978	-	978
Asquith Legacy	3,689	(490)	3,199
National Lottery People's Project	35,999	(3,349)	32,650
Lloyds Bank Foundation Covid Fund	2,384	(2,384)	-
Colyer-Ferguson Charitable Trust	-	2,483	2,483
Steele Charitable Trust	-	20,000	20,000
The Dulverton Trust	-	5,000	5,000
	115,792	7,508	123,300
TOTAL FUNDS	476,496	93,940	570,436

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16. MOVEMENT IN FUNDS

Net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
Core Funding	277,705	(176,654)	101,051
Training Designated Fund	32,164	(46,783)	(14,619)
	309,869	(223,437)	86,432
Restricted funds			
The Esmee Fairbairn Foundation	40,000	(35,250)	4,750
The National Lottery Community Fund	131,290	(124,940)	6,350
The Lloyds Bank Foundation	18,738	(21,450)	(2,712)
Baily Thomas Charitable Fund	-	(20,000)	(20,000)
CB-NSG	-	(90)	(90)
The Sobell Foundation	16,666	(16,666)	-
Peoples Postcode Trust	-	(2,050)	(2,050)
Asquith Legacy	-	(490)	(490)
National Lottery People's Project	-	(3,349)	(3,349)
DHSC - Covid Recovery	41,378	(41,378)	-
Lloyds Bank Foundation Covid Fund	-	(2,384)	(2,384)
Colyer-Ferguson Charitable Trust	2,483	-	2,483
Steele Charitable Trust	20,000		20,000
The Dulverton Trust	30,000	(25,000)	5,000
	300,555	(293,047)	7,508
TOTAL FUNDS	610,424	(516,484)	93,940

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16. MOVEMENT IN FUNDS

Comparatives for movement in funds

	At 1.2.20	Net movement in funds	At 31.1.21
	£	£	£
Unrestricted funds			
Core Funding	230,795	90,880	321,675
Training Designated Fund	45,917	(6,888)	39,029
	276,712	83,992	360,704
Restricted funds			
The Esmee Fairbairn Foundation	1,243	3,895	5,138
The National Lottery Community Fund	42,083	(9,295)	32,788
The Lloyds Bank Foundation	1,121	1,591	2,712
Baily Thomas Charitable Fund	-	20,000	20,000
CB-NSG	4,305	-	4,305
SHIEC	3,572	-	3,572
Peoples Postcode Trust	4,227	-	4,227
Rrisc	978	-	978
Asquith Legacy	13,963	(10,274)	3,689
National Lottery People's Project	40,545	(4,546)	35,999
Lloyds Bank Foundation Covid Fund	-	2,384	2,384
	112,037	3,755	115,792
TOTAL FUNDS	388,749	87,747	476,496

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16. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
Core Funding	158,297	(67,417)	90,880
Training Designated Fund	7,751	(14,639)	(6,888)
	166,048	(82,056)	83,992
Restricted funds			
The Esmee Fairbairn Foundation	20,002	(16,107)	3,895
The National Lottery Community Fund	97,883	(107,178)	(9,295)
The Lloyds Bank Foundation	12,565	(10,974)	1,591
Baily Thomas Charitable Fund	20,000	-	20,000
The Sobell Foundation	12,500	(12,500)	-
Asquith Legacy	1	(10,275)	(10,274)
National Lottery People's Project	(1)	(4,545)	(4,546)
National Lottery Community Fund Emergency Covid-19	25,041	(25,041)	-
DHSC - Covid Recovery	10,600	(10,600)	-
Government Emergency Funding to Charities Package (DHSC)	217,796	(217,796)	-
Lloyds Bank Foundation Covid Fund	12,832	(10,448)	2,384
	429,219	(425,464)	3,755
TOTAL FUNDS	595,267	(507,520)	87,747

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16. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined position is as follows:

	At 1.2.20	Net movement in funds	At 1.2.22
	£	£	£
Unrestricted funds			
Core Funding	230,795	191,931	422,726
Training Designated Fund	45,917	(21,507)	24,410
	276,712	170,424	447,136
Restricted funds			
The Esmee Fairbairn Foundation	1,243	8,645	9,888
The National Lottery Community Fund	42,083	(2,945)	39,138
The Lloyds Bank Foundation	1,121	(1,121)	-
CB-NSG	4,305	(90)	4,215
SHIEC	3,572	-	3,572
Peoples Postcode Trust	4,227	(2,050)	2,177
Rrisc	978	-	978
Asquith Legacy	13,963	(10,764)	3,199
National Lottery People's Project	40,545	(7,895)	32,650
Colyer-Ferguson Charitable Trust	-	2,483	2,483
Steele Charitable Trust	-	20,000	20,000
The Dulverton Trust	-	5,000	5,000
	112,037	11,263	123,300
TOTAL FUNDS	388,749	181,687	570,436

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16. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
Core Funding	436,002	(244,071)	191,931
Training Designated Fund	39,915	(61,422)	(21,507)
	475,917	(305,493)	170,424
Restricted funds			
The Esmee Fairbairn Foundation	60,002	(51,357)	8,645
The National Lottery Community Fund	229,173	(232,118)	(2,945)
The Lloyds Bank Foundation	31,303	(32,424)	(1,121)
Baily Thomas Charitable Fund	20,000	(20,000)	-
CB-NSG	-	(90)	(90)
The Sobell Foundation	29,166	(29,166)	-
Peoples Postcode Trust	-	(2,050)	(2,050)
Asquith Legacy	1	(10,765)	(10,764)
National Lottery People's Project	(1)	(7,894)	(7,895)
National Lottery Community Fund Emergency Covid-19	25,041	(25,041)	-
DHSC - Covid Recovery	51,978	(51,978)	-
Government Emergency Funding to Charities Package (DHSC)	217,796	(217,796)	-
Lloyds Bank Foundation Covid Fund	12,832	(12,832)	-
Colyer-Ferguson Charitable Trust	2,483	-	2,483
Steele Charitable Trust	20,000	-	20,000
The Dulverton Trust	30,000	(25,000)	5,000
	729,774	(718,511)	11,263
TOTAL FUNDS	1,205,691	(1,024,004)	181,687

The Training Designated Fund represents funds set aside by the Trustees to invest in the CBF's capacity to deliver training and help diversify the charity's income.

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17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 January 2022.

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THE CHALLENGING BEHAVIOUR FOUNDATION

England & Wales - Charity number 1060714

Accounts

Annual Report
2020–2021

The Challenging Behaviour Foundation



The Challenging Behaviour Foundation

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Foreword from our Chair

Diane Lightfoot



The Challenging Behaviour Foundation (CBF) was set up by the parent of a child with severe learning disabilities who displayed a range of behaviours described as challenging who struggled to find out about and obtain the right support in the right place at the right time. **It is this key aim - to make "the system" work and deliver good outcomes for children, young people, adults, and their families - that continues to drive all our activities.**

2020 was an exceptional year with unprecedented and unforeseen challenges for all. For the CBF, this meant an increase in our workloads due to the disproportionately high impact of the pandemic on the lives of disabled children, young people, adults, and their families. At the same time, we had to confront the organisational changes required to enable our staff team and volunteers to work remotely in line with government requirements.

I am pleased to report that the CBF rose to the challenges and continued to provide much needed support, information and advocacy and this is a tribute to the CBF's commitment and ability to react rapidly and flexibly to changing needs.

The pandemic has further highlighted the significant challenges and inequalities that families with children and adults with severe learning disabilities whose behaviour may challenge face - and when the system shuts down, it is families who provide a safety net and continue to support their relatives.

The individuals that we support require significant care and support, structured activities and typically find managing change difficult. The pandemic resulted in some services closing, altering their provision, and/ or adapting how their support was delivered. This resulted in routines being disrupted and ordinary activities being significantly restricted.

There were many families who had to take on the responsibility to find creative ways to support their relatives to maintain a quality of life often with little or no external support and at significant cost to their own wellbeing.



The Challenging Behaviour Foundation

We know that many families we support feel very isolated and find it difficult to source practical information. This increased during the pandemic with generic guidance issued, usually online only, creating a digital divide and leaving people without tailored information specific to their situations.

Working with and listening to families, the CBF team prioritised developing, producing, and sharing practical information for families as well as increasing capacity in our helpline. In addition, we continued our policy work to ensure that Government officials understood the challenges being faced by families of children and adults with severe learning disabilities whose behaviour may challenge and the need for targeted information, support and adjustment to the pandemic restrictions.

We would like to extend our thanks to everyone who offered support, volunteered and helped in various ways, and who continue to do so. It has been an excellent example of teamwork, flexibility and creativity and we will build on this momentum going forward. We know the impact has been significant and the recovery will present its own challenges over the years to come.

We are also very grateful to our existing funders for their understanding, support, and flexibility during this time as our planned work priorities and projects had to be adjusted.



The CBF team consists of 8 full time and 7 part time staff, including 3 full time Internships, a team of volunteers, a Board of Trustees and number of Trustee advisors. Sincere thanks to them all for their work over the last year and their commitment going forward. There is still much to do and we will continue to target our limited resources to the areas of greatest impact to ensure that children and adults with severe learning disabilities whose behaviour may challenge and their families get the right support in the right place at the right time.

Thank you to everyone who has made a difference.

Diane Lightfoot

Diane Lightfoot, Chair of Trustees

> **We just want to express our immense gratitude to the CBF for all the support and information updates to us all during this very difficult coronavirus lockdown.**
>
> **Since I forwarded the updated government guidance to my son's care provider he has been out for an outing to a local nature reserve to exercise feed the swans and took a flask of coffee which is one of his great joys. It is a small thing but it has lifted his spirits greatly.**
>
> **– Family Carer**

Report of the Trustees

For the year ended 31 January 2021

The Trustees who are also the directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 January 2021. The Trustees have adopted the provisions of the Statement of Recommended Practice (SORP) 'Accounting and Reporting by Charities' issued in 2015.

Objectives and activities

Objectives and aims

The Challenging Behaviour Foundation (CBF) exists to improve the quality of life of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families.

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

Our mission is to make a difference to the lives of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families by: -

- Championing their rights
- Ensuring timely information and support
- Raising awareness and understanding
- Promoting and sharing best practice

We are the **only** UK charity **focussed specifically** on the needs of children, young people and adults with a severe learning disability whose behaviours may challenge, their families and those who care for them.

The NHS estimates that there are between 30,000 and 35,000 people in the UK who have a severe learning disability and are at risk of developing challenging behaviours. A person with a severe learning disability will have little or no speech, find it difficult to learn new skills and need ongoing support to carry out daily activities such as washing and dressing. Challenging behaviour has a **formal definition** and is a term used to refer to a variety of behaviours which some people with a learning disability may display. These behaviours vary and include aggression, eating inedible objects, severe self-injury or significant obsessive repetition, typically putting the safety of the person or others at risk and/or restricting their access to ordinary life opportunities.





Without appropriate support, children, young people and adults with severe learning disabilities whose behaviour may challenge find themselves at greater risk of poor healthcare, poor life prospects and at greater risk of abuse. Families often find themselves isolated from their local community, unsupported by local services and separated from their relatives.

Our work focuses on family-led carer support and adopts a Positive Behaviour Support (PBS) approach. PBS is a well-evidenced approach and aims to understand behaviour and its functions for the individual. Through providing tailored support, tools and strategies to overcome the communication barriers, the sensory or other needs of the individual, and by teaching alternative skills, PBS aims to give people the ability to overcome challenges, exercise control and choice and live happily, supported in their local community.

As the only UK charity focussed specifically on the needs of this group, our objectives are to ensure that with good support each individual can live a happy, active life in their community with access to healthcare, employment, leisure and education, as well as a fulfilling family life. Our focus is enabling children, young people and adults to exercise their rights to participate in ordinary life opportunities through a proper understanding of their behaviour and access to appropriate support.

To meet these objectives, we have prioritised three interconnected main areas of need: **'information and support'**, **'strategic influencing'** and **'sharing best practice'**, as described below in more detail. More information about the work of the charity can be found at:

www.challengingbehaviour.org.uk





Information and Support

We offer a free, confidential and expert telephone support and casework service. We run email and local peer-to-peer support networks, provide Positive Behaviour Support (PBS) training workshops and a comprehensive library of information guides and resources. All of this aims to equip family and professional carers to understand behaviour that may be described as challenging and empower them to access good quality support. We have worked with families to co-produce a range of training workshops for families, unpaid carers and professionals around PBS, specific behaviours, communication etc. This models a collaborative and consistent approach to supporting individuals with evidence-based strategies, grounded in lived experience. These are delivered jointly by family carers and PBS trainers.

In addition to helping families better understand their relative's behaviour and secure better support and services, we are also concerned with a carer's own welfare and the services and support available to them. Family carers of people with learning disabilities often face significant challenges including being listened to by those providing and commissioning care and support. There are barriers to accessing relevant information and legal advice in order to effectively address the issues they and their relative are facing. The CBF addresses these issues through our unique longer-term casework, where we can support families through complex situations over many months.



Strategic Influencing

Our family support work, and families' lived experience, informs all our strategic influencing and policy work in a complex system, which spans child and adult policy and practice, education, health and social care, regulators and professional bodies. We believe that most can be achieved by working together. We established and chair the influential 'Challenging Behaviour - National Strategy Group' (CB-NSG), a unique multi-stakeholder group whose members include family carers, senior representatives from health, education and social care, government departments, regulators, service providers, clinicians and researchers. The CB-NSG meets regularly to share learning and take forward key projects to increase the evidence base, inform and influence government policy and develop and share best practice around supporting individuals with severe learning disabilities whose behaviour challenges.

We promote and highlight the need for an early intervention approach, to work with, and invest in families as valued partners, and with full and meaningful co-production. In partnership with others, we work to find ways to seek the views and input of children, young people and adults with the most complex needs and share and promote their engagement.

We work collaboratively across the sector to highlight the need to co-ordinate fragmented support and services so that they deliver good outcomes for the people they exist to support. We have developed positive relationships with researchers to amplify the voice of families of individuals with severe learning disabilities in research, and support families to input to national policy making and service development, to push forward the agenda for better local provision, with enhanced skills and training for support workers and paid carers.



Sharing best practice

Best practice provides evidence that it is entirely possible to deliver the right support in the right place at the right time. Sharing, modelling and actively promoting best practice on the ground runs through all our work. We do this through our family support casework and resources, strategic influencing work and family carer and professional email networks, as well as through specific projects involving local authorities, government departments and other partners.

We believe it is crucial that our three strands of work are interconnected and inform each other. For example, what families tell us when asking for support is fed into our strategic influencing work to ensure the lived experiences of families are reflected accurately in projects we input to, and that learning from all stakeholders is shared to improve experiences and understanding for all.

In planning and reviewing the charity's activities to meet these objectives, the Trustees have taken account of the Charity Commission's guidance on **public benefit**. The CBF delivers public benefit by providing information and support to families and professionals caring for and supporting children, young people and adults with severe learning disabilities whose behaviour challenges. All our information and support is provided free of charge to family carers. We also work to improve the understanding of challenging behaviour amongst professionals and the wider public, helping others to provide better services and more opportunities.

Achievements and Performance

> **Supporting parents of children who display 'challenging behaviour', this is one of the most impressive small charities in the country.**
>
> **– Paul Streets, Chief Executive Lloyds Bank Foundation**

The impact of the COVID-19 pandemic

The onset of the pandemic and subsequent restrictions required the whole team to move to remote working at pace. The whole CBF staff team, including Trustees and volunteers, worked hard to respond to the changing situation quickly and efficiently, ensuring that our services could continue to be delivered with minimal disruption to families who needed our support.

The families we support are a marginalised community facing numerous barriers, often isolated within their local community with little opportunity to connect with their peers. The pandemic has exacerbated an already complex environment for our client group. This meant we needed to maintain our existing support as well as respond to the increase in contact with our family support service. We also developed new and specifically tailored resources about the changing emergency measures.

We are very grateful to our current grant funders for their additional financial support and flexibility around existing projects which enabled us to swiftly adapt to the new arrangements and increased demand, enabling us to re-prioritise and re-arrange delivery of our work.

In addition, we were able to secure emergency COVID-19 funding, working collaboratively with other voluntary sector partners to respond to the increased challenges faced by children, young people and adults, and their families during the pandemic.

The pandemic has highlighted the existing inequalities within society, including within this marginalised client group, this includes inequalities in access to online resources and information. We have therefore prioritised ensuring that hard copies of information and newsletters have been proactively posted to families and have encouraged other organisations to do the same.



> I felt hugely supported for the hospital appointments being made and brought forward. To be heard and understood for the need of an OT Assessment for adaptations to bathroom and creating safe space at home for the vulnerable young person who has challenging behaviours.
>
> **– Family Carer**

Information and support

When the first lockdown was announced in March, CBF staff focussed on developing and providing information resources for families to help them in all aspects of the new normal. This included information on how to navigate through the new restrictions as well as practical activities to enable them to cope with the closure of their usual support and services. We have now developed dedicated webpages for COVID-19 information with 20 new information sheets/ guides and 18 legal FAQ's which have received positive feedback from families and professionals.

We have also produced information covering the subsequent lockdowns, restrictions and guidance, for example 'wearing a facemask' and 'returning to school'. We anticipate the need for further resource development and updates as guidance changes and lockdown eases.

During the pandemic, significant work was undertaken to ensure all of our resources were as accessible as possible including making our DVD resources available online. In addition, 3 printed newsletters have been produced and posted to provide relevant, practical, and accessible information about the pandemic specifically tailored to our client group.

Emergency funding allowed us to temporarily increase our capacity in family support as there had been a significant increase in numbers and complexities of enquiries. Our family support service has responded to 1219 queries through our support line, email and website this year which is a 59% increase. We had 27k resources downloaded from our website which is an increase of 74%. The large amount of information available on our website ensures that the families we support have 24-hour access to information around the key issues that impact on their lives. Our family carer review panel and professional volunteers help us to review and update our resources, to ensure they are current and helpful.



I love this network, and the CBF. What a gift! My son has autism, but that isn't really a problem to me! It's the behaviours that challenge that I want advice and guidance with and this network is perfect. It is really encouraging to hear from parents whose children are now in their 20s and 30s and the parents are now real pros at this.

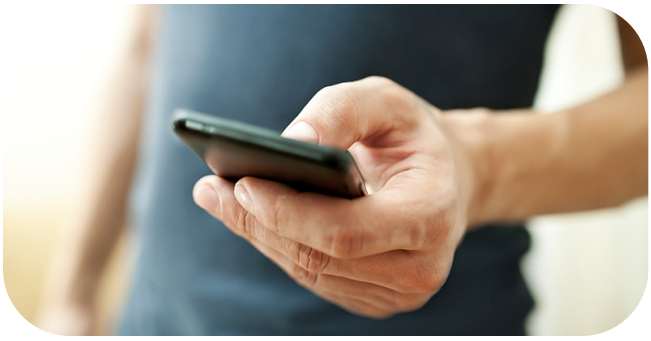
– Family Carer



As a parent I have found your organisation invaluable in offering the sort of help parents need. You understand the challenges parents face and the lifelong uphill struggle to improve the lives of our children and adults with Severe Learning Disabilities.

Huge thanks.

– Family Carer



As part of our response to the pandemic, we have been piloting a new 'triage' role within the Family Support Team. This role is the first point of contact for families looking for support by telephone and email, answering general enquiries or prioritising and escalating queries to the family support caseworkers. This role has been very successful during the pandemic with the increase in enquiries to the team and we have secured funding for a further year.

56 requests
Number of requests for individual support requiring casework

6 months
Average number of months supporting families with casework

We have continued to respond to a high number of families coming to us with complex situations requiring significant support and casework. During the year we have supported 56 requests for individual support requiring casework. We support families with a range of issues including managing specific behaviours, accessing services and support to meet their relative's needs and maintaining contact with family members in care. Most significantly, this work supports families through times of change and transition, such as moving from child to adult services or moving between services. Sadly, these situations often relate to safeguarding issues, lack of appropriate support, poor placements or placement breakdowns and unrecognised health concerns. Families approaching us with these multiple complex issues often require intensive casework over a long period. The average period of support is six months with some families returning over many years for further support as new issues emerge.

> **Many thanks to CBF for comprehensive answers to many questions. Not sure how we shall get through the unprecedented times, but it's good to know we have allies and friends who understand and live out our predicaments.**
>
> **- Family carer**



We are most grateful for the support of our Legal Panel whose members, providing input on a voluntary basis, have played a vital role in enabling families to access legal advice and support to take appropriate action. During the year we have referred a number of families to the panel. They received the specialist legal support required to take their issues forward or were given support specific to their circumstances. See page 20 for further information about the work of the Legal Panel.

With the support of Lloyds Bank Foundation, we have recruited and trained seven new Local Champions. We now have a network of 37 volunteers who help support families across the country and share their experiences with local families and key professional groups. Due to the pandemic, we have equipped Local Champions with IT equipment and licences to ensure their work with families can continue virtually. We have set up 'carer catch-ups' to provide peer-to-peer support in an informal and relaxed setting and these have been positively received and will continue as part of our range of flexible support offers to family carers.

LOCAL CHAMPIONS

37 volunteers

Number of Local Champion Volunteers

400 family carer members

Number of family carer members who have joined our email network

Our email network now has around 400 family carer members and has been used frequently during the pandemic. This forum enables families to ask one another questions and seek support around issues impacting their daily life, support package or relative's behaviour that might be described as challenging. This peer-to-peer support is valued by our members for its emotional and practical support and encouragement through lived experience. Families also can ask questions via our professional email network, a network of over 520 practitioners from across the health, education and social care sectors who also use this forum to share information, learning and asking their peers questions to support their work and disseminate good practice.

Quick Response Behaviour Chats

The COVID-19 pandemic saw a significant increase in families contacting us with concerns around changes in their family members behaviour. We had offers of support from various professionals who wanted to volunteer their time and expertise to help support families at this time so as part of our response, we set up a new, quick response support service called 'behaviour chats'.



We co-developed and co-produced a practical and comprehensive 8-page quick read challenging behaviour guide giving tips and strategies to help family carers care for their family member during a period of new or increased challenging behaviour. This guide is a resource to quickly provide positive behaviour information to families whilst they wait to attend a behaviour chat or speak with a family support worker. The guide is available online and could be posted to families individually. We sent out over 4300 guides with our newsletter to families and professionals and shared with over 10,000 people on social media. This guide will remain on our website for anyone to access Quick Read Challenging Behaviour Guide.

Quick Reach Challenging Behaviour Guide



We recruited volunteer experts (qualified professionals) who offered to help CBF support families during the pandemic and gave up their time to attend the behaviour clinics for free. We joined the behaviour specialists with a (CBF) trained family carer and developed a model of support which was an hour long zoom call with a follow up call from CBF. We set up a robust online process for booking behaviour specialists and trained family carers to appropriate virtual clinics offered at a range of days and times to make it easier for participating family carers to attend. We developed database functionality to facilitate the booking process and created new webforms for family carers who can access online. We worked with families to ensure they are familiar with the technology to access the chat, so they do not waste time with IT issues during the call with the clinicians. Follow up calls enabled individual support and further exploration of concerns, signposting and a friendly "ear".

"

Thanks for yesterday and the information sent, we found it very helpful.

– Family carer

Thank you so much it was good to talk with everyone.

– Family carer

Thank you so much for all your support and advice.

– Family carer

Common themes from the sessions

- Family carers are magnificent – strong, capable, articulate, resilient and caring.
- Families are isolated – geographically and emotionally.
- Blamed for the challenging behaviour their child, young person, or adult displays – either told poor parents or this doesn't happen in school.
- Lack of partnership working between specialist schools and families – consistency not there, lack of understanding from school staff about home environment, transition and families living 24/7 with the additional difficulties of raising a family, maintaining relationships, siblings and working.
- Considerable reduction in usual services during COVID crisis – either withdrawn or reduced significantly. Families having to cope on their own.
- CAMHS, CLDT stating they could not help as the person's challenging behaviour too difficult for them.
- Lack of awareness of right for every child over 14 with a learning disability to have an annual health check.
- Lack of awareness of Carers Assessment.

Families have been grateful for the lifeline these sessions have thrown them – to talk, share, not be judged, access peer support and be signposted to appropriate services.

> **"After your phone call yesterday, I was in a much better place and felt confident and strong to start fighting for my Son and what was right. Also, the documents, which I am still reading through, gave me energy to continue.**
>
> **- Family carer**

We have collaborated with a range of organisations to provide information and resources to families, including working with Learning disability England on a Learning Disability Nurse resources information sheet. In addition, we set up a collaborative initiative of Frontline Families working with other grass roots, family carer led groups to co-ordinate a range of options available to families.



Online workshops

Workshops

Early last year, it was clear that face to face workshops were not going to be possible or practical. We therefore postponed any booked workshops and worked to develop and adapt the content to be delivered on a virtual platform. Workshops are now being delivered successfully online and this has created new opportunities for remote delivery and increased accessibility for some. During the year we delivered 18 workshops to family carers and a wide range of professionals. These virtual workshops bring family carers and professional support staff together to develop a shared language and understanding around developing and co-producing a positive behaviour support plan for the person they are supporting.

In response to demand, we have co-produced a specific workshop on Pica, a behaviour involving eating inedible objects. A core group of family carer and professional trainers have co-produced and will co-deliver this new content which has been piloted and will be available in the coming year.

Strategic Influencing

As a small organisation we can achieve much more by specifically informing and encouraging individuals and organisations in positions of power and influence to raise their understanding and awareness of the issues individuals and families face, and to influence their activity. We aim to promote collaboration to drive progress.

The three strands of our work are inextricably linked and closely aligned. In practice our family carer experiences steer our influencing work. For example, sadly, we continue to be contacted by families experiencing ongoing abuse impacting people with a learning disability, also highlighted in several high-profile media investigations. We continue to raise concerns and challenges to a range of senior individuals and organisations both at a local level and nationally.

We have also raised numerous challenges to officials asking why there is investment in models of support that conflict with national policy and best practice and are in direct opposition to the aims of the Transforming Care programme. We continue to highlight the plans to build a new large institution for people with a learning disability on a remote site and funded by Government, as we see this as a significant threat to the reduction in dependency on hospital services rather than investing in community support.

> **“Some of the most thoughtful and evidence based work I have seen has originated from or been heavily influenced by CBF, I hope you realise just how much you have helped achieve in this space.**
>
> **– Senior National Stakeholder**

Challenging Behaviour National Strategy Group (CB-NSG)

We are very grateful to the Esmee Fairbairn Foundation for their continued support and funding towards the National Strategy Group and its work. The CB-NSG includes representatives from professional bodies, networks, charities and the government alongside family carers, people with LD and researchers. It is based on the principle that if all the individuals and organisations who have a role to play in supporting this group work together in a coherent and coordinated way it will deliver better outcomes.



90 core members

and 600 associate members

There are currently over 90 core CB-NSG members who have significant knowledge and expertise, and a senior level role in supporting and delivering services to people with LD and over 600 associate members who commit to working following the values and principles of the Challenging Behaviour Charter. The group also has four sub-groups made up of members and co-ordinated by the CBF:

- Campaigns
- Legal Panel
- Positive Behaviour Support
- Transforming Care Data Set

Two CB-NSG meetings, with multi-stakeholder members, have taken place this year, one face to face early in the year, and one virtually. CB-NSG members have all signed up to the Challenging Behaviour Charter, a co-produced rights and action framework to deliver the right support in the right place at the right time. The first meeting focussed on good outcomes for people with learning disabilities entitled 'Good Outcomes – Good Life'. One attendee wrote on their evaluation form:

> **"I expected the day to be informative. But I was not prepared for how important it was for me personally as a family carer to feel so supported and heard. Great, Moved.**
>
> **– Family Carer**

A range of presentations were delivered, including from a family carer on the support package she has developed for her son, a senior official from the Department of Health and Social Care on Transforming Care figures; and the Director of Transforming Care from NHS England who updated the group on progress towards the development of regional expertise since the last meeting. Actions from the workshops included bringing together support workers and family carers in partnership to deliver good outcomes for people with learning disabilities and autistic people and identifying essential changes to the Mental Health Act to avoid its inappropriate use.

The second meeting of the year focussed on delivering good outcomes for people with learning disabilities in a post COVID-19 'new normal'. The meeting was delivered virtually considering the impact of the pandemic and what should and should not be taken forward to retain any positive changes in the 'new normal'. The meeting began with a pre-recorded presentation from a family carer sharing their lived experience, and throughout the day presentations were delivered on various topics, including; Trauma, the External Support Group specialist input to local areas, Medication and training for regulators in Positive Behaviour Support for their inspectors.

We continue to be very grateful for support from the National Lottery Community Fund. Their funding has enabled us to take forward several actions identified at CB-NSG meetings. This includes linking up support workers and family carers to work in partnership, overcome barriers and improve outcomes for individuals with learning disabilities. The funding was also used for designing and facilitating consultation opportunities from a range of stakeholders for the formal Mental Health Act White Paper consultation as this is an important opportunity to achieve a much needed legislative change.

> **"Just a quick note to give you and the team a pat on the back. They say you should do something scary every day and I bet trying to do your conference by zoom was scary. You probably had enough scariness to last you all month but I thought it went really well and I found the day very instructive.**
>
> **– Professional**

Campaigns Sub-group

Over the last year, the Campaign subgroup's work has closely aligned with the Data Group, raising awareness of issues including the rate of COVID-19 deaths among people with learning disabilities, challenging unfair restrictions and prioritisation for the vaccine. The campaign subgroup will help co-ordinate top-line views and key calls for several consultations and inquiries in 2021 including the Mental Health Act White paper and an inquiry by the Health and Social Care Committee (HSCC) into the treatment of people who are autistic and/or have learning disabilities. It will also begin work preparing for the 10-year anniversary of Winterbourne View which is on 31st May 2021, working to support a group of families whose relatives were at Winterbourne View Hospital, with plans to publish a report of family's stories and create a video.

Campaign Families

Over the past year the Campaign families played a crucial part in all the work outlined above. It is hoped they will continue to share their lived experiences and learning from these in the upcoming year which will inform the work on the Mental Health Act White paper and the HSCC inquiry. They, along with other CBF and Mencap families will work together to plan and input to the campaign work on the 10-year anniversary of the Winterbourne abuse scandal.

Legal Panel Sub-group

Several years ago, we established, and we continue to maintain, a legal panel consisting of specialist lawyers and barristers who provide pro-bono information and support to families who contact our family support service. The aim is to ensure free initial access to timely specialist legal advice.

We continued to take forward the strategic legal work identified by our legal panel and built on our collaborative working relationship with key experts in the legal field. We recruited more partners to promote a joined-up approach to enable easier access for families to legal support and information, as we are mindful of the reluctance of many families to instruct lawyers fearing it results in an adversarial approach. The work of this panel increased significantly due to the coronavirus restrictions with regular (fortnightly) meetings of the panel and new lawyers and barristers requesting to join the panel. A series of legal Frequently Asked Questions (FAQ's) submitted by families were developed and shared widely.

In November 2020 the CBF held the second legal strategy meeting, building on the meeting held in September 2019 to discuss a range of strategic legal issues with a diverse group of attendees. The meeting discussed the Mental Health Act, the Care Act, and the legal panel, to identify where collaborative action could be launched to improve outcomes for families across these topics. A number of actions were identified to inform and develop a legal strategy.

It was identified during this meeting that families do not have access to a single, accessible space within which they can find a range of legal resources and information. As a result, the CBF recruited a volunteer who has helped to compile a 'legal resources directory', with input by panel members. This directory is being prepared for publication on the new CBF website and will be updated regularly.

Over the course of the pandemic, the legal panel increased their support to families. They met regularly ensuring that families had access to timely support on urgent issues. Questions received by CBF Family Support are triaged and allocated to panel members, with responses uploaded as FAQs on our website so they are widely shared and available:

Visit our COVID-19 resources

In addition, panel members have worked together to consider and address key areas of legal challenge both related to the inequalities for people with learning disabilities which have arisen during the pandemic and the ongoing inequalities due to failures in Transforming Care.

"

Thanks for the CBF guidance and help over COVID - brilliant stuff!

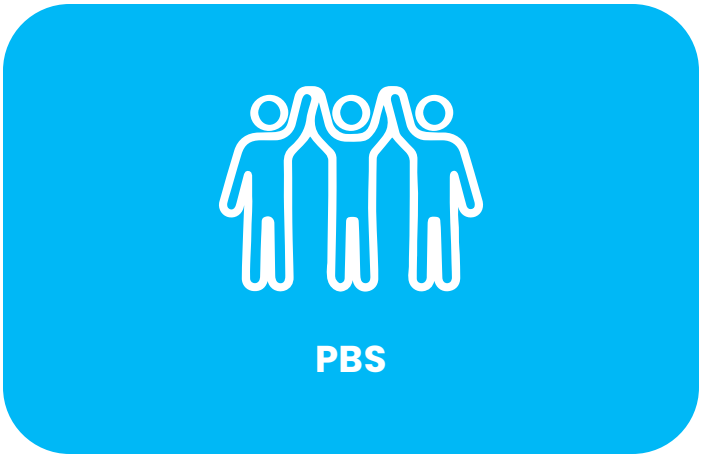
– Professional

I have found all your resources and advice really useful during lockdown and passed on many of them to my sons residential home.

– Family carer

It does highlight how difficult the situation is and I have forwarded the advice to the school in question, many thanks, wonderful service.

– Professional



Positive Behaviour Support Sub-group

Work is being undertaken to re-orientate the PBS Subgroup as a collaborative Research subgroup. This group will link together some key research initiatives with CB-NSG member involvement including the PBS academy, SF-DDARIN and the Tizard Centre.

Transforming Care Data Set Sub-group

The group has focussed on the health inequalities exposed by the pandemic including contributing to the research advocating for people with learning disabilities to be added to the vaccination priority list. It will continue to monitor this issue and the uptake of the vaccine by people with learning disabilities.

Group members have also continued to look at the wider issues in the Transforming Care data, particularly focusing on data around restrictive practices and further breakdown of the data for local areas. The data group submitted a collective response to the Assuring Transformation data set consultation and aims to make links with key stakeholders to highlight gaps in data collection and analysis and work with them to address this.

New Normal

The sudden changes to support and services enforced during the pandemic provided potential opportunities to deliver support and services differently and more flexibly. The CBF initiated discussions with others about capturing the learning for how those changes impacted on this client group to provide evidence of changes that were positive and could be maintained within a "new normal". The CBF collaborated with The Tizard Centre (University of Kent) and SF-DDARIN (an academic research network) on a 'New Normal' project gathering information about the impact of the COVID-19 pandemic on individuals with severe learning disabilities and their families. The project has had two strands. As part of the first strand, a series of interviews with family carers were carried out based on a methodology developed between CBF and the Tizard Centre. Ethical approval from the Tizard Centre has been gained, meaning the findings can eventually be submitted for academic publication contributing to our evidence-based practice work.

As part of strand two, CBF investigated the challenges that families and organisations faced throughout the pandemic. Identifying how services, support and work practices have been adapted to meet these challenges, and which adaptations or innovations should be carried forward, will be included as recommendations of best practice and shared widely. Findings from a survey of family carers and professionals and from workshops held at the CB-NSG meeting have been written up into reports including recommendations to ensure support and services for children, young people and adults with severe learning disabilities and their families are improved going forward. The reports are receiving final input from CB-NSG Steering Group members and will be published in early 2021.



Seldom Heard Project

The views and experiences of children and adults with severe learning disabilities are often disregarded as they are unable to attend or use traditional methods such as focus groups or surveys – but it is important that we adapt our approach to enable their views to be captured. In recognition of the need to get better at seeking the views of children and adults with learning disabilities and more complex communication challenges, NHS England has funded the Seldom Heard project which builds on existing good practice around listening to and involving people with severe and profound learning disabilities. The initial plan, pre COVID-19, was for our researchers to visit individuals where they live to get to know them and seek their views and perspectives in person, using the emerging methodology set out in "Stop, Look and Listen to Me".

The project is being led by CBF in partnership with the Tizard Centre, University of Kent and supported by an active advisory group of family carers and organisations. Our shared aim is to take on board the views of those who are seldom heard, with the ambition that one day they will be routinely heard by all those who have an impact on their lives.

The project began in early 2020, just before the COVID-19 pandemic, so the original plan to engage directly with 14 individuals where they live had to be significantly revised to be delivered remotely. The advisory group agreed that the best way to do this would be by working with "communication partners" – family carers or staff members who know the individual well and can work in partnership with our researchers to find new ways to seek views, building on what they already have in place. Significant changes were therefore made to the delivery methodology to ensure the project outcomes were achieved. The findings and recommendations will be available later in 2021.

We will continue to develop our work on engagement with children, young people and adults with complex needs to find innovative ways to seek their views, and to demonstrate that it is possible to consult with them in a meaningful way. At the same time, we will take every opportunity, in our own work and the work of other organisations, to ensure that families of children, young people and adults with complex needs can share their lived experience to drive forward change.

Learning Disability Nursing Project

In February 2020, the CBF was commissioned to produce a report sharing family carers' experiences of learning disability (LD) nursing including good and poor practice examples and providing recommendations for future working. We recruited a family carer advisory group and co-produced a survey of family carer's experiences of LD nursing. We also held workshops with family carers which found families lack awareness of how an LD nurse could help them, and that - if better informed – could result in utilising them as a resource for improved outcomes when accessing healthcare services.

In December 2020, the CBF presented at the Annual Learning Disability Nursing Symposium, co-delivering a presentation with a family carer on the CBF's LD Nursing resource, created as a result of the project.

We will now collect case studies of where and when LD nursing has made a real difference to families and co-develop a training package for LD nurses based around these examples of action by LD nurses impacting on outcomes.

Reducing Restrictive Interventions and Safeguarding Children (RRISC)

The Reducing Restrictive Interventions and Safeguarding Children (RRISC) group have continued to meet. In February 2020 the CBF and Positive and Active Behaviour Support Scotland (PABSS) launched a joint report at an event hosted by Baroness Hollins at the House of Lords. This updated the 2019 report sharing family carers' accounts of their children's experiences of restrictive intervention. At the event attendees including RRISC group members, law firms, national charities, education and health representatives made pledges to reduce restrictive intervention through specific actions.

The group met again virtually in September 2020. An official from the Department for Education joined the meeting to hear views on the behaviour content of Government Guidance during the COVID-19 pandemic. It was agreed that a survey of families' experiences of education and restrictive interventions in the pandemic should be conducted. We designed and shared two surveys, one for families and one for schools, to gather evidence about restrictive interventions in schools, during the first lockdown and when all children returned in the autumn term. The results were analysed and presented at the January 2021 RRISC meeting and will be written into a full report which will be available later in the year.

Institute of Health Visiting Project

Health Visitors provide early support to families of children with disabilities, and it is important that they are well informed about the functions of behaviour and its impact.

As a direct result of the RRISC report (see previous section), the CBF was approached by the Institute of Health Visiting (iHV) to partner in a project which aims to safeguard the rights of young children with disabilities to appropriate care, using the least restrictive approach, raising awareness for health visitors to promote best practice with families.

We are on the project steering group and were commissioned to conduct a survey and focus group of family carers as part of this work. 113 family carers responded to the online survey, followed by a virtual focus group. The findings and recommendations of both were presented to the steering group and written up into two full reports ready for publishing later this year. The findings and recommendations from the reports and the workshop will inform the development of training materials and resources, including an animation, PBS training, a parent carer account of the early years, and presentations on trauma, restrictive interventions and challenging behaviour. These will be shared in a series of workshops for Health Visitors later this year.

The External Support Group (ESG)

The CBF has worked hard to try to influence the Transforming Care programme and activities- but this has not been as successful as hoped. Therefore, a different approach has been initiated - recruiting a group of senior clinicians and professionals with significant expertise - and asking them to identify actions that will make a difference. This group, the External Support Group (ESG) brings together a number of individuals with significant practical experience in supporting people with complex needs in community settings, including developing individualised packages of support and maintaining that support to provide good outcomes for individuals. Areas of expertise in the group include experience in clinical/ medical practice; commissioning; inspection and regulation; research and evidence; advocacy; the third sector; family support. The ESG members worked together (unfunded) to develop a model of support that was evidence based and outcomes focussed. The ESG will work with local areas to help improve the quality of life and care provision for individuals inappropriately 'stuck' in hospital placements as well as influence systematic change and improve practice in the long term. This approach was carefully designed to improve the lives of individuals and provide supportive input and expertise to local teams as well as identifying and addressing issues within the system that are barriers to driving change.

Three members of the group have been providing local support to an area at the urgent request of NHS England. Though the group was not designed to intervene at crisis point, it was agreed that their help would be valuable in this instance, and it was also an opportunity for the group to test some features of its model. We hope to secure funding to test out the model of support through "proof of concept" funding and are exploring this through various channels.

STOMP/STAMP

The STOMP (Stopping Over-Medication of People with a Learning Disability, Autism or Both) STAMP (Supporting Treatment and Appropriate Medication in Paediatrics) programmes are initiatives within NHS England to try to address the issues around medication. We have been raising these issues for many years due to the impact on the families we support, including meetings with several senior government officials. Three influential reports were then published which led to the STOMP/STAMP programme.

We received funding from NHS England for a project called "STOMP- The Next Steps", to assess what progress has been made in the implementation of STOMP/STAMP and what needs to be done to ensure full adoption of the programme, including a review of all the current materials and resources available and development and delivery of a promotion and dissemination plan. Workshops with family carers were held in February and followed by a STOMP presentation (delivered by a family carer) and group discussion at the October 2020 CB-NSG.

Over the year we have also been working in collaboration with MindEd, who are producing 6 e-learning sessions on STOMP in a project beginning now and finishing at the end of this year. These resources are being developed with input from family carers recruited and facilitated by the CBF (see page 28).

Trauma Support

The CBF was commissioned, in partnership with Respond, The Tizard Centre, and Three Cs to look at the need for trauma support for the family carers of children and adults with learning disabilities and/or autism. The CBF set up an advisory group of family carers with lived experience to co-design a survey to gather the views and experiences of family carers and to input into the whole project (which was made up of three interconnected strands of work).

The co-produced report of the findings from the CBF survey (strand 1 of the project) is called 'Broken': The psychological trauma suffered by family carers of children and adults with autism and/ or a learning disability and the support required. The CBF report contains three key recommendations for education, health and social care, and other professional learning disability bodies: 1) do not traumatize families in the first place; 2) when trauma happens there needs to be a pathway to support in place; and 3) act now to help the families who have already been traumatised and will have an immediate need due to the pandemic. This report was shared with CB-NSG members in October 2020 and is published on the CBF website.

The report of the whole project has been finalised and is awaiting sign off. In the meantime, we have been commissioned to work with the collaborative partners again to undertake a follow-up piece of work using our initial findings to develop trauma training resources for a range of stakeholders including commissioners and NHS England LD Regional Leads. This is due to be completed in 2021.

Internships at the CBF

This year we have been able to offer 3 internships at the CBF. We have now had 26 paid internships since 2011 covering Family Support, Policy, Research and Communications. Each internship is for one year and provides valuable experience in learning disability, working with a range of professionals in the field and gives insight into the experience of family carers.

> **If you have an interest in a dynamic, fast paced, exciting internship then do it. It's an incredibly supportive, kind and generous team, they will help you maximise your time here.**
>
> **- CBF intern**

Previous CBF interns have gone on to:

- Policy and communications roles in the voluntary and public sector
- Practitioner roles such as: social work, learning disability and mental health nursing and special needs teaching
- Further study at Masters and PhD level in related fields

Sharing Best Practice

The principle of sharing and actively promoting best practice runs through all aspects of our work. We share and promote best practice through our family support work, including casework and resources, and our national influencing work, including disseminating information via the CB-NSG, its core and associate members, our family carer and professional email networks as well as our specific networks e.g. Paving the Way network that focusses on children and young people.



We are invited by researchers to contribute to a range of research projects which vary from recruiting members to advisory or reference groups to Public and Patient Involvement (PPI) led facilitating focus groups with family carers to gather their input to the research and its dissemination.

Getting It Right Project

Using funding from The National Lottery Community Fund for a three-year project working across England, we built on our previous work and experience of local area and national strategic work. This year we worked with West Sussex to gather the views of families of children and young people with learning disabilities on existing local support and services and their hopes for the future. We also provided virtual positive behaviour support training to local family carers. In December we brought West Sussex professionals, third sector organisations and families together to reflect on the project findings and identify short and long-term actions to improve support for children and young people with learning disabilities and their families going forward.

The COVID-19 pandemic and lockdown meant we had to adjust the format and timing of activities delivered in West Sussex. Families attended two in-person focus groups before March, but then steering group meetings, positive behaviour support training and the stakeholder engagement event were held virtually. This made engagement easier for some families (no travel/ reduced time commitment) but technology and 'zoom fatigue' also created a barrier to access/ engagement for others.

The Black Country has been recruited to partner with us in year 2 where the focus will be on transition, including young people up to the age of 25. The West Sussex local steering group are preparing to share learning from year 1 with the Black Country and more widely at the next Challenging Behaviour National Strategy Group meeting in May 2021.

This project provides an opportunity to increase our reach through additional capacity for communications and sharing best practice.

Input to Research Projects

In line with our aim of sharing family lived experiences and building up evidence to inform our strategic influencing work, we have continued to support and shape a variety of research applications and funded projects with a wide range of academics and researchers. We have provided input to steering and advisory groups and supported paid family carer participation in consultation and focus groups, including translating research findings into practice. During the year we have supported a number of research projects in this way covering diverse areas including: how to best identify children at risk of developing challenging behaviour, testing adapted therapies for post-traumatic stress disorder in people with a learning disability, developing training for families and understanding of withdrawal programmes to support the prevention of over-medication of people with a learning disability, and a range of projects looking at the gaps in evidence for service development and delivery and the engagement of carers in the research process.

We continue to encourage and support families to contribute to consultations and calls for evidence so that their experience and views are heard and included in any response that the CBF submits. We have responded to a range of consultations/calls for evidence with input from families to highlight the issues for children, young people and adults with severe learning disabilities whose behaviour challenges and their families.

Tizard/ CBF Family Carer Research Alliance

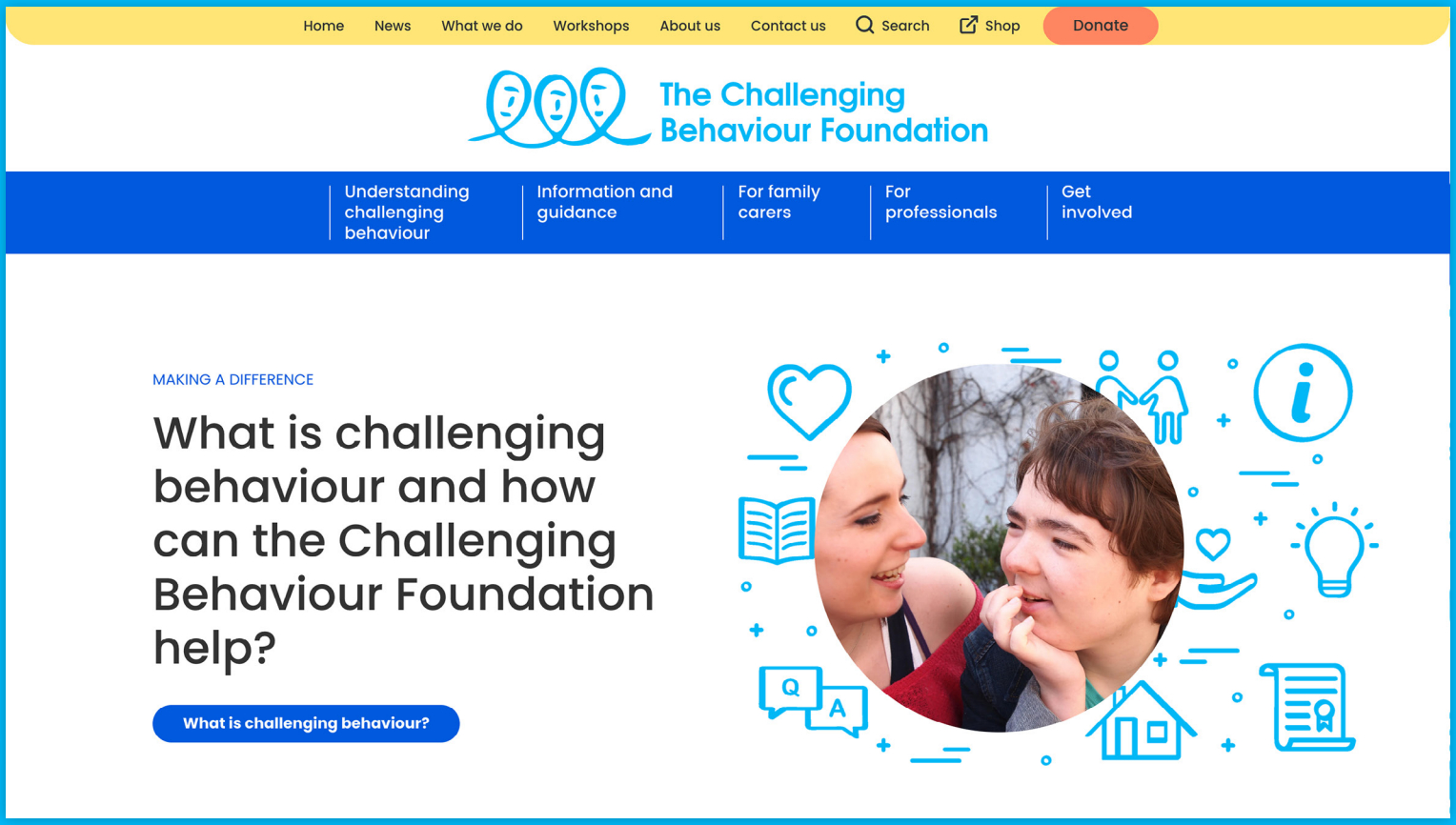
The Tizard/ CBF Family Carer Research Alliance is a group of family carers and researchers working together to increase and improve co-production in research. Activities have included a workshop at the CB-NSG where a promotional video was launched. A workshop was led by members of the group to gain input to the work of the alliance. Other work included discussions with Project Artworks in Sussex about future research and engaging with the Research Alliance group.

The research alliance has selected 5 recent research publications and summarized them in an accessible format for family carers. The first research newsletter is in its final stages of review and publication is planned for this year.

Due to the pandemic, and the subsequent increase on their family caring responsibilities, the group has paused this work. We are exploring funding options to enable it to continue.

MindEd

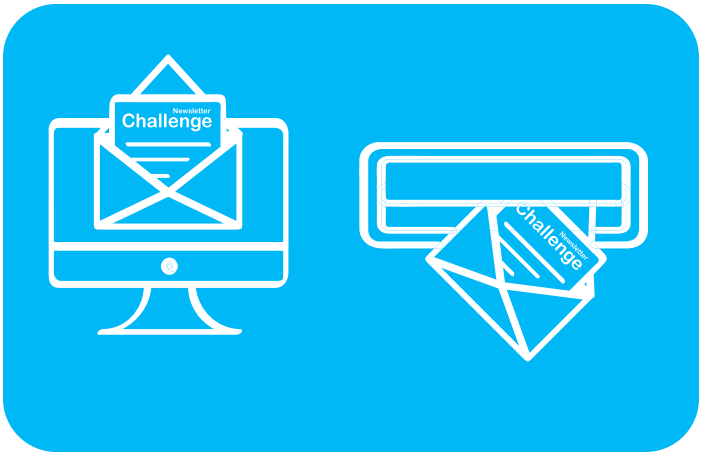
We have continued to support the Health Education England mental health e-learning platform, MindEd with developing learning disability training for health and social care professionals. Following a survey of family carers by the CBF in Spring 2019, MindEd received funding to produce a set of six e-learning sessions on STOMP. We have supported 6 family carers as co-authors who have worked with professionals to develop the e-learning sessions, scheduled to go live in June 2021.



New Website

We are very grateful to the National Lottery Community Fund who have enabled us to develop a new website as part of the Getting It Right Project, to reach more families and provide them with practical information and support. Developing a new website requires a significant allocation of time and resource to ensure that it is constructed in a way that is useful and accessible. We set up an advisory group including family carers and professionals to oversee and steer the whole process to ensure the website would be both practical and useful. All CBF material was reviewed prior to being transferred to the new site. The new website will be more accessible and include updated information with more videos and visual content to help engage people further. The new website was launched late Spring 2021.

Visit www.challengingbehaviour.org.uk



Newsletter

We continued to produce 3 electronic newsletters during the year. We applied for and were successful in securing emergency funding during the pandemic to also produce hard copies to ensure families without access to the internet or printed copies were not left out. These editions were focussed on support during the pandemic. We will continue to seek funding and partnership opportunities for hard copies to be sent out in the future.


Challenge
Winter 2020 Registered charity no. 1060714
The Challenging Behaviour Foundation
Your rights during difficult times
To read online, please see: http://bit.ly/CBFNewsletters
What's in this newsletter?

> Thank you for your continued hard copies of your newsletter, which you have regularly sent out to me over several years. As a nurse for people who have a learning disability, I have continued to be very impressed by the material that you print and make available and for the enormous support you give and campaigning you do for people with learning disabilities and their families.
>
> Thank you. It really does help people to feel better supported and informed, including those who work in this field and ultimately to make a massive difference to people's lives.
>
> **– Learning Disability Nurse**

Social Media

We continue to use our social media platforms to share good practice information and practical resources. All our social media platforms have all seen an increase in followers this year allowing us to reach more people.



Our plans for the coming year

Whilst compiling this report, we have been living through a pandemic and the COVID-19 restrictions which has had a significant impact, and which is covered separately below.

The pandemic has inevitably impacted our planned work and its delivery, and there remain some uncertainties beyond our control as we emerge from the lockdowns and restrictions. When Government guidance allows, we will plan a phased return to the CBF office for our staff. We plan to recruit 3 interns in the coming year- funding has been secured and these roles have proved effective and good value for money.

We have no plans to increase our core staff team – if and when more capacity is required we intend to utilise consultants who have been through our core training, to enable flexibility without long term financial commitment - we anticipate that funding challenges will emerge as the pandemic costs are repaid. Trustees are mindful of potential future financial risks and plan accordingly, including building reserves and investment in additional fundraising capacity.

Our core aim is to ensure that "the system" and society enable individuals with severe learning disabilities, and their families, to receive the right support in the right place at the right time. Our approach and all of our work is carefully planned and thought through with regular reviews, and in the coming year we will continue to focus on our three key interconnected areas of work (information and support, strategic influencing and sharing best practice).



Information and support

We plan to continue to ensure our family support and information service is maintained and provides high quality independent expertise and advocacy for families in need. The families we support are often in very complex situations, navigating through a complex education health and care system, and they experience marginalisation and exclusion. Families clearly describe "the fight" for the support and services they need, and their experiences of discrimination and basic human rights being ignored.



A key challenge in the coming year will be to ensure children and adults with a learning disability who display behaviour that challenges and their family carers, are supported through the impacts of COVID-19 and the restrictions imposed as a result. This will add an additional layer of challenge, complexity and concern to their daily lives. We are planning now for our response for this group who are likely to be adversely impacted. We are mindful that demand for our support is already high, so this will require increasing our capacity, providing support in even more complex situations and developing new resources and online forms of support and information.

The new Triage Officer role will be evaluated to assess its impact on the efficient running of the family support service and making best use of our experienced caseworker's time and expertise. Funds generously provided by The Lloyds Bank Foundation, The Sobell Foundation and Garfield Weston Foundation for our family support helpline and casework are vital to enable this work to continue, and some multi-year funding is coming to an end. We will prioritise seeking further funding to ensure we can maintain and develop the support and information we provide for families who are often in crisis.

We will explore setting up a new peer support 'Facebook' group to offer families the option of different forms of peer interaction and communications. This will run alongside the existing 'Family Carer Email Network' to cater for the differently-technologically-suited groups of families who would both benefit from having access to online interaction and peer support. While the Family Carer Email Network works well for many families, a feedback survey we produced found that many in the network felt they would benefit from having access to a convenient and active Facebook group. Such a group will also bring some benefits for the CBF – such as easy dissemination of polls – however it will operate largely separate from the CBF, being run by family carer volunteer moderators (trained and supported by CBF).



We will review the diversity of the families who use the CBF's information and support service and work to increase inclusion for a broad range of families, particularly those from 'hard to reach' communities. We will continue to send paper newsletters (subject to identifying funding) and information resources to families who do not use the internet or who request hard copies of resources and we will pilot a telephone "listening ear" service to provide trained and supported peer support to those who cannot access or prefer not to use our online support networks.

We will build on and invest in existing relationships with other family support organisations and charities that run helplines to lead the co-ordination of work through regular meetings, peer support, problem solving and opportunities for joint working.

This will enable efficient signposting to others when appropriate and to identify any gaps in support. We will continue to support the National Autistic Society who have started a new casework support service to share our learning and experience gained over the last 20+ years.

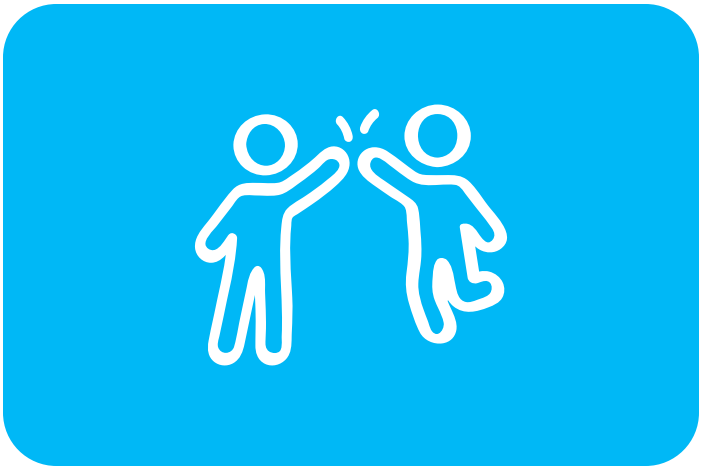
Family experiences of trauma will continue to be an area of work for the CBF. The trauma awareness resources co-produced with families and developed in collaboration with Respond and the Tizard Centre will be finalised and disseminated.

We will review the delivery method of all our training workshops, aiming to have a blended approach to capture the benefits of both in person workshops and online delivery.

Sharing best practice

Our new website will be launched in Spring 2021- and we will monitor and evaluate its use, with a planned timetable for updating material on it. We aim to ensure that our website and database work efficiently together, and that we increase and widen our reach.

The views and experiences of children and adults with severe learning disabilities are often disregarded as they are unable to attend or use traditional methods such as focus groups or surveys – but it is important that we adapt our approach to enable their views to be captured. We will therefore continue to develop our work on engagement with children, young people and adults with complex needs to find innovative ways to seek their views, and to demonstrate that it is possible to consult with them in a meaningful way. At the same time, we will take every opportunity, in our own work and the work of other organisations, to ensure that families of children, young people and adults with complex needs can share their lived experience to drive forward change.





Promotion of early intervention approaches, both in terms of support in early childhood as well as early support with emerging challenging behaviour at any age, will remain a key feature in all three strands of our work- information and support, sharing best practice and strategic influencing. We will continue to collate and present evidence of the positive benefits of early intervention, and work with researchers and academics to achieve this. This is particularly important as we emerge from the pandemic and there may be a tendency to cut existing early intervention services or not invest in them where needed. We plan to work with researchers to collate research evidence to make the case for investment in this area, including the economic case, and to hold a seminar to present information to senior policymakers in summer 2021.

We will work with researchers to investigate opportunities for formal evaluation of our PBS workshops, and other research initiatives will be pursued, both with academic partners and through our CBF/ Tizard Family Carer Research Alliance, to further build the evidence base.

Strategic influencing

Our influencing agenda will of course continue to be responsive to the changing political circumstances and challenges that arise. We remain committed to continue to challenge the failure of the Transforming Care agenda and to ensure that a cross Government approach is developed that keeps this on the national and local agenda for action. This work has the potential for a very significant impact for our client group and specific multi-year funding support to pursue this work from Esmee Fairbairn is enabling this vital long-term work to progress. There is no "quick fix" solution - it requires strategic patience, commitment and determination. We will continue to bring together a diverse range of stakeholders, through our CB-NSG members and associates, and work in partnership to identify ways to drive forward the change needed, developing workable initiatives that build on past experience and existing knowledge, and delivering a solution focussed approach. Working collaboratively takes longer and requires skilled management to build trust and focus on shared aims and objectives rather than differences of opinion, but we believe we can achieve more by working together and, by using this co-production approach, can deliver better outcomes.

One example of this is the External Support Group (ESG), a CBF led initiative, bringing together a group of senior experienced clinicians and professionals to provide support to local teams who are supporting individuals. We will apply for funding for "proof of concept" and will test and evaluate the model in one area, and consider how to further develop and expand the model.

We continue our local strategic input work as part of a 3 year project funded by the National Lottery Community Fund and will be partnering with the Black Country in year 2.

Our work targeting professionals who work with families, increasing their awareness of need and the issues families face, will continue. We will build on our work with Health Visitors, continue our work with the Keyworker Project (see below), and work with other professions who support families of children.

We are planning to continue the strategic legal work identified by our legal panel members and the individuals and organisations who have participated in our legal strategy meetings so far. We will continue to promote a joined-up approach to enable easier and timely access for families to legal support and information, and to ensure best use of limited resources. This work, linked to the CBF Legal Panel work may require seeking additional specialist capacity to drive this forward.



Keyworker Project

The CBF was included within a successful bid by Wolverhampton and the Black Country to form part of their 18-month keyworker pilot. Our role is to act as a critical friend on the steering group and to lead a peer support strand of work. Work planning to develop the role of the peer workers in Black Country has begun and will carry on into 2021/2022.



Our work on reducing the use of restrictive interventions will continue, via the RRISC (Reducing Restrictive Interventions and Safeguarding Children) group, and other initiatives such as the NHS England STOMP and STAMP programmes, which aim to address the inappropriate medication of individuals with learning disabilities. All parts of the system need to work well for children, young people and adults with severe learning disabilities whose behaviour challenges - including the regulators. We will continue to press for robust regulation, inspections, monitoring and data collection, and challenge the registration of new services which do not fit the model of increasing good quality local community support.

In the coming year we will continue to progress our work in all three key areas, regularly reviewing our activities and their impact. As a small team with limited capacity and resources, we are ever mindful of the need to target our efforts carefully and influence those in positions of power who can make change happen, and who have a wider reach and more resources. We know that there are many areas of work that need to be taken forward concurrently. All elements of our work and projects are interconnected, we work proactively but are also able to respond quickly to opportunities and needs as they arise - as evidenced in our response to the pandemic.

We know there will be significant challenges ahead - both in terms of the needs of the families we support, and the financial challenges we will face as a small charity to secure funds for our work. We will take all the necessary steps we can to ensure we are able to continue our much-needed work, making a difference to the lives of children, young people and adults with severe learning disabilities whose behaviour challenges, and their families.

COVID-19

The COVID-19 pandemic continues to have a significant impact on the CBF and families we support. We have learned to be creative in our delivery of support and projects to ensure they continue with as little disruption as possible. All staff and volunteers are still working remotely, and although this has posed a range of additional challenges and issues, including ensuring that we are all connected and with good communication and peer support mechanisms, all staff have responded positively and adapted to the challenges and opportunities this brings.

Some positive opportunities have emerged from the enforced "work from home" rules:

- Although we are not currently able to carry out face to face meetings and focus groups, the use of virtual meetings has enabled people to join groups who would otherwise not be able to attend, for example due to caring responsibilities or location, to engage with a range of areas of our work.
- In addition, members of our family support team have been able to join some virtual meetings with families and professionals as part of our complex casework support. Families have reported that they have found this valuable and beneficial.
- Family carers have been involved in providing peer to peer support through video 'carers catch-ups' or trained and supported to provide listening ear telephone calls. These catch-up calls are not limited to working hours and can be during the day or in the evening or weekends to suit the participants.
- We have adapted our direct engagement model (in the Seldon Heard Voices work) to support family members to act as 'Communication Partners' to help find the views of children and adults with complex communications needs.
- We have adapted all our training workshops to be delivered online which has enabled us to deliver training to families and paid support staff throughout the UK. This has reduced costs and increased engagement.
- We have moved all our DVD/Video resources online so they can be viewed for free from our website.
- Staff have swiftly increased their knowledge in technology!

We will continue to develop these new ways of working and we are looking into hybrid models of delivery once the restrictions lift.

It is a tribute to the whole CBF staff team that throughout the ongoing COVID-19 challenges, we have continued our work in all 3 key areas, increasing our information and support service, increasing sharing best practice and continuing our strategic influencing work.

Financial review

Financial position

Incoming resources for the year amounted to £595,267 (£437,695 in 2019/20) and resources expended were £507,520 (£322,359 in 2019/20), giving net income of £87,747 (£115,336 in 2019/20). The increase in incoming resources was mainly due to one-off COVID-19-related grants to cover the increased demand for our services during the pandemic. This was partly offset by the deferral of income relating to specific projects, which were postponed with the agreement of the relevant funders in the light of the exceptional circumstances. The unrestricted net income of £83,992 reflects principally the flexible use of our core staff team to undertake project work wherever possible, including in relation to the pandemic, reducing the need to deploy additional external resources.

The support of trusts and foundations remains vital in enabling us to carry out work to increase the CBF's impact while helping to maintain its financial viability. We would like to extend our grateful thanks to all supporters who have enabled us to achieve this. The receipt of a three-year grant from the National Lottery Community Fund enables us to promulgate our evidence-based approach much more effectively. We wish to thank the Esmee Fairbairn Foundation for supporting our policy and influencing work, and the Sobell Foundation and the Lloyds Bank Foundation for supporting our family support service. Thanks are also due to Garfield Weston Foundation, the Baily Thomas Charitable Fund and several smaller foundations for supporting our core costs. In addition, we are a deeply grateful to the Department of Health and Social Care, the National Lottery Community Fund and the Esmee Fairbairn Foundation for providing emergency Covid funding during 2020/21.

In the longer term we expect the funding environment to become more challenging than ever. Most paid work is ad hoc, unpredictable and fluctuates in volume, while grant funding is one-off or relatively short term and subject to fierce competition, exacerbated by the effects of the pandemic. A combination of tight budget management, close review of the financial performance of individual projects, and the focussing of fundraising effort to address specific funding gaps has enabled us to build up our reserves towards our target over the last few years. However, a number of significant existing multi-year grants will end over the short to medium term, resulting in the rapid depletion of reserves unless they can be replaced in the near future.

Reserves policy

In determining the reserves strategy, the Trustees take a holistic and strategic approach and carefully consider the reasons for maintaining reserves as well as the logistics of utilising them. This includes consideration of the external factors that may affect reserves such as demands on capacity and the relatively short-term nature of grant funding, which forms a large part of the charity's income and often involves a long lead time to secure. We also need to ensure that the charity can meet its liabilities in the event of a significant downturn in income.

In addition, the reserves target takes into account the need for continuity in the provision of information and support to family carers who often experience complex situations which can last for several months, along with ensuring our strategy work remains embedded at a local and national level despite fluctuations in funding levels. Reserves also enable us to remain sufficiently flexible to respond to any opportunities that may arise at short notice for us to influence national policy on behalf of our beneficiaries.

In the light of these circumstances, the Trustees have set a target to hold twelve months of running costs in free reserves (unrestricted funds). Free reserves amounted to £360,704 at 31 January 2021, representing 8.7 months of running costs, based on predicted expenditure for 2021/22.

The Challenging Behaviour Foundation

Structure, governance and management

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

Risk management

The Trustees have a duty to identify and review the risks to which the charity is exposed, including ensuring appropriate controls are in place to provide reasonable assurance against fraud and error. The Trustees have put in place a risk management strategy, comprising an annual review of the risks the charity may face, the establishment of systems and procedures to mitigate risks identified, and the implementation of procedures designed to minimise any potential impact on the charity should any of these risks materialise. The work has identified financial sustainability as a major risk in the light of the difficult funding environment. The regular updating and review of financial projections and tight budget management are key elements in the management of this risk. Attention has also been focussed on non-financial risks such as reputational risk and suitable mitigating actions put in place, while the current COVID-19 crisis has highlighted the importance of ensuring that the CBF is in a position to respond to national or international-scale incidents that lie beyond our control.

Organisational structure

The Trustees, who are directors for the purpose of company law and Trustees for the purpose of charity law, who served during the year and up to the date of this report are set out on the following page. Members of the charitable company guarantee to contribute an amount not exceeding £10 to the assets of the charitable company in the event of winding up.

Day to day management of the charity's activities is delegated by the Trustees to the Chief Executive Officer. The Trustee Board meets quarterly to review achievements and performance, finances and future plans.

Recruitment and appointment of new Trustees

In seeking to ensure that the needs of individuals with severe learning disabilities and challenging behaviour are being met through the charity, a network of contacts with both personal and professional experience of the issues involved have been recruited to advise the Trustee Board, and to enhance the potential pool of Trustees. Trustee skills are reviewed annually to determine any training needs, and should specific skills be identified which would require the recruitment of new or replacement members to the Trustee Board, individuals from the advisory network may be approached to offer themselves for election.

By invitation Advisers may attend Board meetings to offer input and to further their knowledge of the CBF, thus providing both a recruitment and a training path for new Trustees.

The Challenging Behaviour Foundation

Reference and administrative details

Registered Company number

3307407 (England and Wales)

Registered Charity number

1060714

Registered office

c/o The Old Courthouse
New Road Avenue
Chatham
Kent
ME4 6BE

Trustees

Ms S Cooper
Mrs V A Cooper
Mrs D C Cutler (Retired – 17.10.2020)
Mr J Dodd
Ms A K Giles
Dr N J Gore
Ms D E Lightfoot
Mrs C Million

Company Secretary

Mrs C Million

Auditors

Calcutt Matthews Ltd
Chartered Accountants and Statutory Auditors
19 North Street
Ashford
Kent
TN24 8LF

Statement of trustees responsibilities

The trustees (who are also the directors of The Challenging Behaviour Foundation for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditors are unaware; and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

AUDITORS

The auditors, Calcutt Matthews, will be proposed for re-appointment at the forthcoming Annual General Meeting.

Approved by the order of the board of trustees on 23rd October 2021 and signed on its behalf by:



Mrs V A COOPER - Trustee

The Challenging Behaviour Foundation

Report of the independent auditors

to the members of The Challenging Behaviour Foundation

Opinion

We have audited the financial statements of The Challenging Behaviour Foundation (the 'charitable company') for the year ended 31 January 2021 which comprise the Statement of Financial Activities, the Balance Sheet and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 January 2021 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Report of the Trustees has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Trustees.

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the Statement of Trustees Responsibilities, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements. A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

N M Hume (Senior Statutory Auditor)

for and on behalf of Calcutt Matthews WBZ Ltd
Chartered Accountants and Statutory Auditors
19 North Street
Ashford
Kent

Date: 25 October 2021

The Challenging Behaviour Foundation

Statement of financial activities

for the Year Ended 31 January 2021

	Notes	Unrestricted funds £	Restricted funds £	31.1.21 Total funds £	31.1.20 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	26,599	3	26,602	50,809
Charitable activities	5				
Information and Support		7,750	37,898	45,648	185,929
National Influencing		-	6,829	6,829	129,514
Core Funding		129,909	384,489	514,398	68,442
Other trading activities	3	1,363	-	1,363	2,570
Investment income	4	427	-	427	431
Total		**166,048**	**429,219**	**595,267**	**437,695**
EXPENDITURE ON					
Raising funds	6	17,726	75	17,801	21,968
Charitable activities	7				
Information and Support		38,369	97,949	136,318	139,158
National Influencing		1,224	16,015	17,239	160,260
Core Funding		24,737	311,425	336,162	973
Total		**82,056**	**425,464**	**507,520**	**322,359**
NET INCOME		**83,992**	**3,755**	**87,747**	**115,336**
RECONCILIATION OF FUNDS					
Total funds brought forward		**276,712**	**112,037**	**388,749**	**273,413**
TOTAL FUNDS CARRIED FORWARD		**360,704**	**115,792**	**476,496**	**388,749**

Balance sheet

31 January 2021

	Notes	Unrestricted funds £	Restricted funds £	31.1.21 Total funds £	31.1.20 Total funds £
FIXED ASSETS					
Tangible assets	13	6	-	6	188
CURRENT ASSETS					
Debtors	14	88,775	-	88,775	54,820
Cash at bank		432,227	226,211	658,438	450,115
		521,002	226,211	747,213	504,935
CREDITORS					
Amounts falling due within one year	15	(160,304)	(110,419)	(270,723)	(116,374)
NET CURRENT ASSETS		**360,698**	**115,792**	**476,490**	**388,561**
TOTAL ASSETS LESS CURRENT LIABILITIES		**360,704**	**115,792**	**476,496**	**388,749**
NET ASSETS		**360,704**	**115,792**	**476,496**	**388,749**
FUNDS	16				
Unrestricted funds				**360,704**	**276,712**
Restricted funds				**115,792**	**112,037**
TOTAL FUNDS				**476,496**	**388,749**

The financial statements were approved by the Board of Trustees and authorised for issue on 23rd October 2021 and were signed on its behalf by:

V Cooper

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Mrs V A Cooper - Trustee

Cash flow statement

for the Year Ended 31 January 2021

	Notes	31.1.21 £	31.1.20 £
Cash flows from operating activities			
Cash generated from operations	1	209,396	141,553
Gift Aid		(1,500)	(1,417)
Net cash provided by operating activities		207,896	140,136
Cash flows from investing activities			
Interest received		427	431
Net cash provided by investing activities		427	431
Change in cash and cash equivalents in the reporting period		**208,323**	**140,567**
Cash and cash equivalents at the beginning of the reporting period		**450,115**	**309,548**
Cash and cash equivalents at the end of the reporting period		**658,438**	**450,115**

The Challenging Behaviour Foundation

Notes to the cash flow statement

for the Year Ended 31 January 2021

1. RECONCILIATION OF NET INCOME TO NET CASH FLOW FROM OPERATING ACTIVITIES

	31.1.21	31.1.20
	£	£
Net income for the reporting period (as per the Statement of Financial Activities)	87,747	115,336
Adjustments for:		
Depreciation charges	182	182
Interest received	(427)	(431)
Increase in debtors	(19,284)	(8,512)
Increase in creditors	141,178	34,978
Net cash provided by operations	209,396	141,553

2. ANALYSIS OF CHANGES IN NET FUNDS

	At 1.2.20	Cash flow	At 31.1.21
	£	£	£
Net cash			
Cash at bank	450,115	208,323	658,438
	450,115	208,323	658,438
Total	450,115	208,323	658,438

The Challenging Behaviour Foundation

Notes to the financial statement

for the Year Ended 31 January 2021

1. ACCOUNTING POLICIES

Basis of preparing the financial statements
The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

- Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity

- Designated funds are unrestricted funds earmarked by the Trustees for particular purposes.

- Restricted funds are subject to restrictions on their expenditure imposed by the donor or through the terms of an appeal.

Income
All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure
Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Allocation and apportionment of costs
Support costs are allocated pro rata to staff numbers involved with each charitable activity.

Tangible fixed assets
Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Plant and machinery - 20% on cost
Fixtures and fittings - 33% on cost

Taxation
The charity is exempt from corporation tax on its charitable activities.

1. ACCOUNTING POLICIES - continued

Fund accounting
Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Pension costs and other post-retirement benefits
The charitable company operates a defined contribution pension scheme. Contributions payable to the charitable company's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

2. DONATIONS AND LEGACIES

	31.1.21	31.1.20
	£	£
Donations	25,102	45,892
Gift aid	1,500	1,417
Grants	-	3,500
	26,602	50,809

Grants received, included in the above, are as follows:

	31.1.21	31.1.20
	£	£
David Solomon Trust	-	1,000
Three Monkies Trust	-	2,500
	-	3,500

3. OTHER TRADING ACTIVITIES

	31.1.21	31.1.20
	£	£
Fundraising events	626	1,738
Sales and earned income	737	832
	1,363	2,570

4. INVESTMENT INCOME

	31.1.21	31.1.20
	£	£
Deposit account interest	427	431

5. INCOME FROM CHARITABLE ACTIVITIES

	Information and Support	National Influencing	Core Funding	31.1.21 Total activities	31.1.20 Total activities
	£	£	£	£	£
Grants	37,898	6,829	430,989	475,716	243,713
Contract and Other Non Grant Income	7,750	-	83,409	91,159	140,172
	45,648	6,829	514,398	566,875	383,885

Grants received, included in the above, are as follows:

	31.1.21	31.1.20
	£	£
The Sobell Foundation	12,500	25,000
Garfield Weston Foundation	25,000	25,000
The National Lottery Community Fund - COVID	18,853	79,029
Department of Health and Social Care (DHSC)	228,396	-
The Stonewall Park Charitable Trust	500	-
The Sir James Roll Charitable Trust	1,000	-
The Esmee Fairbairn Foundation	20,000	40,000
Lloyds Bank Foundation	12,566	24,684
Baily Thomas Charitable Fund	20,000	-
National Lottery People's Project	-	50,000
National Lottery Community Fund	104,069	-
Lloyds Bank Foundation COVID Fund	12,832	-
Esmee Fairbairn (Emergency COVID Grant)	20,000	-
	475,716	243,713

6. RAISING FUNDS

Raising donations and legacies

	31.1.21	31.1.20
	£	£
Staff costs	17,000	17,000
Fundraising	120	1,092
	17,120	18,092

Other trading activities

	31.1.21	31.1.20
	£	£
Bad debts	681	3,876
Aggregate amounts	17,801	21,968

7. CHARITABLE ACTIVITIES COSTS

	Direct Costs	Support costs (see note 8)	Totals
	£	£	£
Information and Support	132,439	3,879	136,318
National Influencing	17,239	-	17,239
Core Funding	333,807	2,355	336,162
	483,485	6,234	489,719

8. SUPPORT COSTS

	Governance costs
	£
Information and Support	3,879
Core Funding	2,355
	6,234

9. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	31.1.21	31.1.20
	£	£
Auditors' remuneration	2,117	2,023
Depreciation - owned assets	182	182

10. TRUSTEES' REMUNERATION AND BENEFITS

Vivien Cooper was employed full time as Chief Executive Officer with the express permission of the Charity Commission in recognition of her unique skills and experience.

No Trustee or any person related to the charity had any personal interest in any contract or Trustee transaction entered into by the charity during the year other than as disclosed above.

Vivien Cooper is enrolled in a workplace pension scheme for her role as Chief Executive Officer.

Trustees' expenses

	31.1.21	31.1.20
	£	£
Trustees' expenses	-	47

11. STAFF COSTS

No employee was paid over £60,000 in the year.

The average monthly number of employees during the year was as follows:

	2021	2020
Information, Support & Training	4.73	3.9
National Influencing Work	6.33	4.35
Total	11.06	8.25

12. INTANGIBLE FIXED ASSETS

Net income/(expenditure) is stated after charging/(crediting):

	Database
	£
COST	
At 1 February 2020 and 31 January 2021	9,853
AMORTISATION	
At 1 February 2020 and 31 January 2021	9,853
NET BOOK VALUE	
At 31 January 2021	
At 31 January 2020	

13. TANGIBLE FIXED ASSETS

	Plant and machinery	Fixtures and fittings	Computer equipment	Totals
	£	£	£	£
COST				
At 1 February 2020 and 31 January 2021	8,161	1,258	5,075	14,494
DEPRECIATION				
At 1 February 2020	8,161	1,258	4,887	14,306
Charge for year	-	-	182	182
At 31 January 2021	8,161	1,258	5,069	14,488
NET BOOK VALUE				
At 31 January 2021	-	-	6	6
At 31 January 2020	-	-	188	188

14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.1.21	31.1.20
	£	£
Trade debtors	81,919	48,078
Gift Aid reclaimable	6,856	5,356
Prepayments	-	1,386
	88,775	54,820

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.1.21	31.1.20
	£	£
Trade creditors	113,436	5,750
Social security and other taxes	4,700	4,562
Funds held for other organisations	15,423	15,474
Accruals and deferred income	137,164	90,588
	270,723	116,374

Funds held for other organisations £15,422 (2020: £15,474) represents monies held by the charity where it is working with other charities on joint projects. At 31 January 2021 these are as follows:

Learning Disability Senate	£12,840
Employment Dissemination	£2,582

16. MOVEMENT IN FUNDS

	At 1.2.20 £	Net movement in funds £	At 31.1.21 £
Unrestricted funds			
Core Funding	230,795	90,880	321,675
Training Designated Fund	45,917	(6,888)	39,029
	276,712	83,992	360,704
Restricted funds			
The Esmee Fairbairn Foundation	1,243	3,895	5,138
The National Lottery Community Fund	42,083	(9,295)	32,788
The Lloyds Bank Foundation	1,121	1,591	2,712
Baily Thomas Charitable Fund	-	20,000	20,000
CB-NSG	4,305	-	4,305
SHIEC	3,572	-	3,572
Peoples Postcode Trust	4,227	-	4,227
Rrisc	978	-	978
Asquith Legacy	13,963	(10,274)	3,689
National Lottery People's Project	40,545	(4,546)	35,999
Lloyds Bank Foundation Covid Fund	-	2,384	2,384
	112,037	3,755	115,792
TOTAL FUNDS	388,749	87,747	476,496

16. MOVEMENT IN FUNDS

Net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
Core Funding	158,297	(67,417)	90,880
Training Designated Fund	7,751	(14,639)	(6,888)
	166,048	(82,056)	83,992
Restricted funds			
The Esmee Fairbairn Foundation	20,002	(16,107)	3,895
The National Lottery Community Fund	97,883	(107,178)	(9,295)
The Lloyds Bank Foundation	12,565	(10,974)	1,591
Baily Thomas Charitable Fund	20,000	-	20,000
The Sobell Foundation	12,500	(12,500)	-
Asquith Legacy	1	(10,275)	(10,274)
National Lottery People's Project	(1)	(4,545)	(4,546)
National Lottery Community Fund Emergency Covid-19	25,041	(25,041)	-
Covid Resource (DHSC)	10,600	(10,600)	-
Government Emergency Funding to Charities Package (DHSC)	217,796	(217,796)	-
Lloyds Bank Foundation Covid Fund	12,832	(10,448)	2,384
	429,219	(425,464)	3,755
TOTAL FUNDS	595,267	(507,520)	87,747

16. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1.2.19	Net movement in funds	At 31.1.20
	£	£	£
Unrestricted funds			
Core Funding	221,686	9,109	230,795
Training Designated Fund	19,246	26,671	45,917
	240,932	35,780	276,712
Restricted funds			
The Esmee Fairbairn Foundation	4,684	(3,441)	1,243
The National Lottery Community Fund	3,377	38,706	42,083
The Lloyds Bank Foundation	1,682	(561)	1,121
CB-NSG	4,305	-	4,305
SHIEC	3,572	-	3,572
Peoples Postcode Trust	14,861	(10,634)	4,227
Rrisc	-	978	978
Asquith Legacy	-	13,963	13,963
National Lottery People's Project	-	40,545	40,545
	32,481	79,556	112,037
TOTAL FUNDS	273,413	115,336	388,749

16. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
Core Funding	118,458	(109,349)	9,109
Training Designated Fund	79,521	(52,850)	26,671
	197,979	(162,199)	35,780
Restricted funds			
The Esmee Fairbairn Foundation	40,001	(43,442)	(3,441)
The National Lottery Community Fund	79,030	(40,324)	38,706
The Lloyds Bank Foundation	24,684	(25,245)	(561)
The Sobell Foundation	25,000	(25,000)	-
Peoples Postcode Trust	-	(10,634)	(10,634)
Rrisc	1,001	(23)	978
Asquith Legacy	20,000	(6,037)	13,963
National Lottery People's Project	50,000	(9,455)	40,545
	239,716	(160,160)	79,556
TOTAL FUNDS	437,695	(322,359)	115,336

16. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined position is as follows:

	At 1.2.19	Net movement in funds	At 1.2.21
	£	£	£
Unrestricted funds			
Core Funding	221,686	99,989	321,675
Training Designated Fund	19,246	19,783	39,029
	240,932	119,772	360,704
Restricted funds			
The Esmee Fairbairn Foundation	4,684	454	5,138
The National Lottery Community Fund	3,377	29,411	32,788
The Lloyds Bank Foundation	1,682	1,030	2,712
Baily Thomas Charitable Fund	-	20,000	20,000
CB-NSG	4,305	-	4,305
SHIEC	3,572	-	3,572
Peoples Postcode Trust	14,861	(10,634)	4,227
Rrisc	-	978	978
Asquith Legacy	-	3,689	3,689
National Lottery People's Project	-	35,999	35,999
Lloyds Bank Foundation Covid Fund	-	2,384	2,384
	32,481	83,311	115,792
TOTAL FUNDS	273,413	203,083	476,496

16. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
Core Funding	276,755	(176,766)	99,989
Training Designated Fund	87,272	(67,489)	19,783
	364,027	(244,255)	119,772
Restricted funds			
The Esmee Fairbairn Foundation	60,003	(59,549)	454
The National Lottery Community Fund	176,913	(147,502)	29,411
The Lloyds Bank Foundation	37,249	(36,219)	1,030
Baily Thomas Charitable Fund	20,000	-	20,000
The Sobell Foundation	37,500	(37,500)	-
Peoples Postcode Trust	-	(10,634)	(10,634)
Rrisc	1,001	(23)	978
Asquith Legacy	20,001	(16,312)	3,689
National Lottery People's Project	49,999	(14,000)	35,999
National Lottery Community Fund Emergency Covid-19	25,041	(25,041)	-
Covid Resource (DHSC)	10,600	(10,600)	-
Government Emergency Funding to Charities Package (DHSC)	217,796	(217,796)	-
Lloyds Bank Foundation Covid Fund	12,832	(10,448)	2,384
	668,935	(585,624)	83,311
TOTAL FUNDS	1,032,962	(829,879)	203,083

The Training Designated Fund represents funds set aside by the Trustees to invest in the CBF's capacity to deliver training and help diversify the charity's income.

17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 January 2021.