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**REGISTERED CHARITY NUMBER: 1060714**

**REPORT OF THE TRUSTEES AND  
AUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 JANUARY 2017  
FOR  
THE CHALLENGING BEHAVIOUR FOUNDATION**

THE CHALLENGING BEHAVIOUR FOUNDATION

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for the Year Ended 31 January 2017

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This year has continued to see an increase in the number of families and professionals who contact the Challenging Behaviour Foundation (CBF) for specialist information, support and resources. As a user-led organisation, over 75% of our staff, volunteers, steering and reference group members are family carers of individuals with severe learning disabilities and behaviours described as challenging. This ensures that all our work is based on lived experience and is outcome focused in areas that will make the greatest difference to the lives of one of the most marginalised and vulnerable groups in our society and makes us uniquely placed to focus on their needs.

Our approach, combining holistic, practical information and support to empower families to get the right support, in the right place, at the right time, with working at a strategic influencing level, has an impact at both an individual and national level. This was evidenced, for example, by the National Audit Office inviting us to join their advisory group for the follow-up investigation into the national 'Transforming Care Programme' and supporting families through high-profile legal cases including telling their stories in national media to highlight the impact of inadequate and poor support.

With limited resources, it is essential that we work efficiently and collaboratively and we continue to encourage and support our network of family carer volunteers across the country to provide peer-to-peer support, information online, by post, over the phone and through attending events, reaching more families than ever before.

Our investment in early intervention and prevention work has had an impact nationally and locally with the Transforming Care Programme establishing a Children and Young People Delivery Group to drive the change needed in this area. This new focus is a significant step forward and we will continue to share our expertise in this area as a member of this group.

Our Family Support Service has seen an increase in the number of families supporting relatives in very complex situations which require a level of expertise, knowledge and support not available elsewhere. Families are regularly signposted to us from large national charities that recognise our specialist knowledge in this area. Our regular evaluation processes confirm that families value the consistently high standard of practical and emotional support we provide.

We proactively encourage partnership working whilst retaining our independence and focus, as we believe that more can be achieved by working together. We adopt a co-production approach to all our work. We know that good support for individuals with severe learning disabilities and behaviours described as challenging requires all parts of the education, health and social care system (children and adults) to work in a co-ordinated way. One of our most significant achievements in this area is the creation of the Challenging Behaviour - National Strategy Group (CB-NSG) which the CBF still runs. It meets bi-annually to drive change and continues to be an authoritative well-attended, vibrant and influential group, bringing together senior-level, multi-stakeholder members from diverse parts of the system including government, regulators, researchers, service providers, clinicians, commissioners, people with learning disabilities families and other relevant charities to co-produce action plans and share best practice.

Despite the increase in demand for our work, the CBF is, in common with many other organisations in our sector, facing an increasingly tough funding environment. Government funding continues to reduce while we are witnessing greatly increased competition for Trust and Foundation grants. This has necessitated a review of all our expenditure, resulting in a decision to restructure the core staff team in the summer of 2017, in order to reduce costs and secure the longer term sustainability of the charity, while enabling us to continue to deliver excellent outcomes.

This has been another year when an incredible amount has been achieved with limited resources and a lot of hard work by our staff, trainers, and volunteers across the UK, who continue to go "above and beyond" to support families and effect change nationally. I would again like to extend my thanks to all of those staff, volunteers, supporters, funders and families who make the work of the charity so far reaching and powerful. It is more important than ever that this marginalised group at risk of poor support and abuse are given access to the specialist support and expertise that we provide - and empowered so they do not remain unseen and unheard.

**Diana Cutler**  
Chair of Trustees

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 2017. The Trustees have adopted the provisions of the Statement of Recommended Practice (SORP) 'Accounting and Reporting by Charities' issued in 2015.

## OBJECTIVES AND ACTIVITIES

Challenging behaviour is a term used to describe a range of behaviours which some children and adults with learning disabilities may display. Behaviours can vary and include aggression, eating inedible objects, severe self-injury or obsessive repetition - these behaviours typically put the safety of the person or others at risk and/or restrict their access to ordinary life opportunities. There is always a reason for challenging behaviour and for change to happen it is essential to understand what the reasons are.

A child or adult 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. 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.

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 relative. As the only UK charity focused on the needs of this group, we aim 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 people to exercise their rights to participate in ordinary life opportunities through proper understanding of their behaviour and access to appropriate support.

The purpose of the CBF is to relieve the suffering and distress of individuals with severe learning disabilities whose behaviour is described as challenging. In planning and reviewing the charity's activities in order to meet this objective, 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 who display behaviour described as challenging. 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.

To meet these objectives we have prioritised three 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](http://www.challengingbehaviour.org.uk).

### Information and Support

Our small family support team provides **telephone, email and individual case support** to families of children, young people and adults with severe learning disabilities who display behaviour described as challenging. We produce and



regularly update a range of **information resources** including information sheets, DVDs and newsletters. In addition, we facilitate **email networks** for family carers and professionals to share experiences, best practice and information. We also operate a **family linking scheme** to deliver peer-to-peer support for families and we train and support family carers as local champion volunteers to reach more families and provide information within local communities. We have worked with families to co-produce Positive Behaviour Support training **workshops** for families, unpaid carers and professionals around supporting behaviour change which models a collaborative and consistent approach to supporting individuals. These are delivered jointly by family carer and Positive Behaviour Support trainers and

have been independently evaluated positively by the Tizard Centre, University of Kent.

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 being listened to by those providing and commissioning care and support for their relative, and have difficulty accessing relevant information and legal advice in order to effectively address the issues they and their relative are facing. Those who support people with learning disabilities are "not always equipped to recognise the need for legal assistance or how to access a service", and "reported difficulties in getting specialist advice about those aspects of the law that are particularly relevant to people with learning disabilities, such as community care, welfare rights and public law".

### **Strategic Influencing**

Adopting a strategic approach to the issues individuals and their families face has the potential to deliver far-reaching impact and better outcomes for significantly more families and individuals than working in isolation. We are committed to proactively influencing others to achieve the changes needed to ensure that children and adults with severe learning disabilities who display behaviour described as challenging, and their families, get the right support in the right place at the right time. Good support for this group of individuals is dependent on health, education and social care and those working within these systems understanding the needs of this group of marginalised people and working efficiently in a co-ordinated way to meet those needs.

We are committed to the principle that more can be achieved by working together and therefore invest in developing and maintaining relationships with individuals, organisations and bodies who have a role to play in supporting individuals and their families as well as co-ordinating and utilising opportunities, sharing evidence-based practice and positively influencing those in positions of power or influence to drive change. We do this through various means.



The **Challenging Behaviour - National Strategy Group (CB-NSG)** which we established in 2008 plays an important role in ensuring that all parts of the system are aware of the needs of this group of individuals and how to support them and work together to deliver good outcomes. This unique multi-stakeholder group, working at a senior level with over 70 core members, meets twice a year to share best practice, identify opportunities for collaborative working, create action plans and deliver on the outcomes. The collective and diverse perspectives and experiences of this group which covers all areas of health, education and social care, with researchers, service providers, regulators, commissioners family carers and individuals with a learning disability amongst its members, enable creative, joined-up and workable solutions to meet the needs of children, young people and adults with learning disabilities who display behaviours described as challenging.

We co-chair a **campaign sub-group** on the CB-NSG alongside the learning disability charity Mencap, focused particularly on highlighting the needs of the children, young people and adults with learning disabilities who are inappropriately stuck in hospital settings in order to ensure the Government delivers on its Transforming Care promises for this group of individuals. This work has successfully ensured that there is still a spotlight on the need to transform care after the abuse at Winterbourne View Hospital was exposed in 2011.

The Department of Health funded **Early Intervention Project** provided an excellent opportunity to highlight the benefits of evidence-based early intervention for children with severe learning disabilities and their families, reducing the need for crisis interventions and residential placements, and improving outcomes. Similarly our support for three **Integrated Personal Commissioning** sites provides an opportunity to demonstrate the effectiveness of a coordinated approach.

We participate in a range of **work with other stakeholders** including researchers, Government departments, regulators, health and social care bodies and other relevant charities, groups and networks, either through staff members or a family carer supported by us. This may take many different forms, such as membership of steering groups, responding to consultations, projects and consultancy, and speaking at events or running workshops or focus groups.

### Sharing Best Practice

In order to meet the needs of children, young people and adults with severe learning disabilities who display behaviour described as challenging and their families, it is essential to get the right information to the right people at the right time. We know that there is a body of evidence-based knowledge and good practice, but we also know that this is not uniformly available and delivered.

We work to ensure information is available and accessible by sharing and promoting best practice with a range of stakeholders through our family information and support networks and resources, along with our strategic influencing work.



## ACHIEVEMENT AND PERFORMANCE

Over the past year, we have made progress in all three identified areas of need.

### Information and Support

#### **Family Support**

The family support service responded to 1,458 enquiries during 2016/17, supporting 250 families. Families whose relatives were at risk of abuse or stuck inappropriately in an inpatient service and subjected to inappropriate restrictive practices such as over-medication and prone restraint were prioritised for long-term support.

25% of all enquiries identified safeguarding issues for people with learning disabilities and we made 25 safeguarding alerts to local authorities in 2016/17 in addition to supporting other family carers to do so themselves. Families reported instances of suspected physical abuse, sexual abuse, financial abuse and neglect in care homes, supported living services and inpatient units.

*"How do I explain or ever put a price on what it meant to have someone to hold your hand and truly understand you when you are going through the darkest of experiences? What I discovered was they (the CBF) enabled me to grow in confidence with the information they provided us. Our strength was reinforced by knowing a charity with great integrity believed our family struggles and were not daunted by the magnitude of the problem but helped us find solutions. They sourced endless credible resources to assist me to effectively challenge abusive practices. Important strategies such as Positive Behaviour Support Courses and Person Centred Plans were introduced to me via CBF which has in turn helped to make a huge difference to the quality of my son's life and a huge reduction of behaviour that challenges."*

**Parent**

As a result of the difficulties accessing support, families describe a negative impact on their wellbeing, describing feelings of depression, anxiety and hopelessness.

*"Because the services and systems are not equipped or specialised enough no one understood. This led to family breakdown, isolation, regression in social and mental wellbeing"*

**Parent**

The individual telephone and email support we provide continues to be valued by families, as do our information resources, Positive Behaviour Support workshops and peer support networks.

*"There are so many awful things happening to people with a learning disability and their families. I can't thank you enough so far for your patience and your support through an incredibly difficult period. Without the CBF to turn to for invaluable advice and family support I can imagine how parents struggle to cope."*

**Parent**

*"We would very much like to thank you for all the help and support you have provided this year. You have been truly amazing and we wouldn't have been able to do it without you. You helped us prevent [our son] from being sectioned and for that we are truly grateful so thank you so very much."*

**Family carer**

To increase accessibility this year, we introduced a telephone interpretation service, to enable callers who speak English as a second language to access the Family Support Service via an interpreter.

As planned, two full-time interns (recent graduates) have assisted the family support workers including running the peer support networks and organising volunteer activities. The interns update information resources and contribute to new resources as well as delivering project work.

As part of our ongoing review of our activities, we have begun to scope developing a volunteer "expert advisor" role, and plan to pilot this next year. In addition, this year we have established a **legal panel** to assist families to access appropriate and timely legal support. The legal panel comprises solicitors from three legal firms, two barristers, a psychiatrist and representatives from the charities CBF, Mencap and the National Autistic Society. A referral process has been agreed with lawyers and we have worked with Mencap and the National Autistic Society to identify areas for law reform that would strengthen the rights of individuals with learning disabilities and behaviour that challenges and their families. Learning gained from our family support work about the common barriers families face has contributed to this review. The legal panel work will inform our future policy, campaigns and influencing work, and we plan to develop the panel and evaluate the outcomes and impact next year if we can secure funding to do so.

### **Information Resources**

Family carers and professionals rely on us to supply up-to-date and relevant information about challenging behaviour and related topics. We have planned, reviewed and updated a range of information resources this year. During 2016/17 we created and published several new information resources to cover gaps in the information available about issues relating to challenging behaviour. We have established a family carer 'review panel' to input to the whole process of producing a new resource, from commenting on initial ideas for content to giving feedback on final drafts. A plan has been developed to produce resources specifically for siblings of people who display challenging behaviour, who have different information needs from parents, in collaboration with the charity SIBS.

We aim to increase our reach to families and professionals who support them. Our Challenge newsletter continues to provide information, support and a means of sharing experiences for family carers and professionals. We planned to transition over to an electronic version of the newsletter in 2017 and this year has seen a steady increase in the number of people subscribing to the electronic version. Our newsletter includes direct information and support to families, shares good practice and provides more platforms for different family and professional experiences. We share information through different mechanisms and have increased the number of visitors to our website and followers on social media.

We have established a network of Local Champions, volunteering around the country to represent the charity and share information with families and professionals. Local Champions have attended conferences and events to raise awareness of the work of the CBF and distribute information resources. Many involved volunteers giving a talk or presentation to family carers, professionals or students at university. The latter is an activity we are increasing, to enable students of psychology, social work and other courses to hear directly from a family carer what supporting someone with a severe learning disability is like.

### **Family Linking Scheme**

Family Link Volunteers have been supported to provide a listening ear and support to family carers, encouraging hope and confidence in their caring role. Supporting them through difficult times, Family Link Volunteers have been linked to families coping with a disabled child and a new baby, caring for an adult son with learning disabilities and cancer and also dealing with the death of an adult brother with learning disabilities.

### **Email Networks**

The growing Email Networks for family carers and professionals we facilitate continue to be valued by their members, enabling them to ask questions of their peers, and share experiences and information. We also provide a professional panel for family carers to ask questions requiring a professional response or technical information.

*"The network, and of course the CBF as a whole, is a great source of support and help. I've learned such a lot from reading responses to other people's questions as well as my own, including things I'd never thought of challenging or investigating before! It's also so helpful to know that other parents and carers are facing the same issues, feeling the same emotional pressures, etc. - to know that we are not alone in our struggles to do the best for our sons and daughters." **Member of the Family Carers' Email Network***

### **Workshops**

During the past year we have delivered 47 Positive Behaviour Support (PBS) workshops to a variety of organisations including NHS Foundation Trusts, Local Councils, Carers Groups and schools. We continue to work successfully with Gloucestershire County Council delivering workshops to family carers across the area and this year we were delighted to receive a contract to provide the workshops for a further three years. Additionally, Gloucestershire County Council received funding to enable us to deliver our workshops to Polish speakers using an interpreter and the feedback from this group was extremely positive.

We also received funding from Health Education England to deliver our 'working in partnership' PBS workshops to family carers and staff through their Clinical Commissioning Groups in their fast-track areas which ranged from Lancashire through to Cornwall.

Feedback from all the workshop attendees was very positive. Most of the attendees comment on the family carer co-trainer being involved and sharing their own lived experience as something they like best about the workshops. Also family carers commented that it is the realisation that they are not alone, but that others are going through similar experiences to them that is important! Almost all attendees reported that they would recommend our workshops to others.

*"Absolutely brilliant workshop, well put together, informative"*

**Family carer**

*"Fantastic trainers who listen and help guide you to resolve issues"*

**Professional**

*"Thank you for a very inspiring workshop - can't wait to try out the new ideas/strategies."*

**Family carer**

### **Strategic Influencing**

#### **Challenging Behaviour - National Strategy Group (CB-NSG)**

Steering group members have continued to meet regularly to plan the work of the group and the bi-annual national meetings. In March, the CB-NSG held its first meeting themed around 'Early Intervention and Prevention for Children, Young People and Adults'. This meeting featured workshops, speakers and a poster exhibition from a variety of professionals and family carers, and showcased learning from the Early Intervention Project run jointly by the CBF and the Council for Disabled Children.

The second CB-NSG meeting, entitled 'Making Sense Together', was held in partnership with the Learning Disability Professional Senate in October and featured presentations, workshops, modelling co-production and a session pulling together discussions from the day. Around 160 delegates attended including individuals with learning disabilities and family carers, as well as professionals representing health, social care and education. Feedback from both meetings was highly positive, with 93% of respondents across the Learning Disability Professional Senate and CB-NSG members saying that they would be interested in attending a similar event in the future. Actions from the CB-NSG meetings are taken forward and progress monitored and shared.

#### **CB-NSG Campaigns Subgroup**

The CB-NSG has a campaigns subgroup with multi-stakeholder members who develop and implement a campaign plan. A strategic planning day was organised to identify what had been successful so far, and to plan what the priorities were moving forward. Senior stakeholders attended and the event was opened by Norman Lamb MP, former Minister for Social care, who shared his insights on what drives change.

The particular focus for the subgroup involves working together with Mencap to support a group of families whose family members have direct experience of inpatient units, to campaign for change. This solution-focused group has provided valuable input to the assurance process for the Transforming Care Partnership plans. Activities in 2016/17 included supporting some of the families affected by the issues at Winterbourne View to write an open letter to the Prime Minister expressing their anger at the lack of progress since the Winterbourne View scandal, which was published in national media.

A local campaigns pack, "Making it Happen", developed in collaboration with Mencap and the National Autistic Society was launched in September to support local campaigners to ensure that NHS England's promise to make sure 35-50% of inpatient beds close, and the right support is built in the community by 2019, is fulfilled. This was accompanied by an easy-read version and an e action.

The campaign group was supported to meet the new Minister (the fourth Minister during this campaign) and a representative from the National Audit Office (NAO) to influence the political leadership of the Transforming Care Programme and input to the NAO report. The previous NAO and subsequent Public Accounts Committee (PAC) reports were pivotal in influencing NHS England to commit to a closure programme. Following this meeting we submitted a report to the NAO which included information from the meeting and the results of surveys to CB-NSG members and family carers.

#### **Early Intervention Project (EIP)**

Findings from the Early Intervention Project have influenced a number of key stakeholders to recognise the importance of effective support for children and their families, including the Learning Disability Professional Senate, which now includes children's representatives as core members, and the Transforming Care Programme, which officially recognised children as in scope for the programme in its publication Building the Right Support. We have established an email reference group to keep in touch with the new stakeholder contacts made through the Early Intervention Project. We have also influenced wider children's policy through links with the Children's Commissioner for England, the Department of Health, Department for Education, NHSE and membership of the children's Health Policy Influencing Group and the Council for Disabled Children.

The project has significantly informed both the commissioning of the **Lenehan Review** and its findings - this review was commissioned by the Department of Health to consider support for children with learning disabilities whose behaviours challenge. Dame Christine Lenehan (Director of the Council for Disabled Children) included all the learning from the EIP within her analysis and it has resulted in a second Lenehan review of residential special schools.

Although the funding for the EIP (now known as Paving the Way) has ended we have introduced mechanisms over the past year to ensure the learning and networks are sustained. The final evaluation of the project concluded that it had met all its objectives, successfully combined research evidence and lived experiences by families, been a trusted source of information and provided good value for money.

In March 2016 we launched a new website, [www.pavingtheway.works](http://www.pavingtheway.works), to bring together information and best practice around supporting children with learning disabilities whose behaviours challenge, and their families. It includes:

- Learning from families
- What works
- Why the project was needed
- Resources and links to further information

Whenever a new resource is launched we invite a guest blogger (family carer, professional or expert) to share a relevant story or perspective.

A review of the website confirmed around 35,000 views since its launch (almost 100 per day) and around 11,000 individuals using the site. The survey found that a majority of respondents found the site useful or very useful and easy to use. The site hosts the Paving The Way resources which include:

- **Two videos** launched at the CB-NSG meeting. Both show the experiences of young people. The first is about the restraint of children: the second is about loved ones who are stuck far away from their families in Assessment and Treatment Units (ATUs).
- A **downloadable leaflet and poster** developed in partnership with the Learning Disability Professional Senate, to raise awareness among professionals and staff who do not have expertise in learning disabilities and behaviours that challenge and also aimed at parents who need further support.
- A **Video** we produced, featuring artwork by a family carer (with her voiceover), recounting her and her son's experience of being "**lost in transition**".
- A new **Keeping in Touch with Home** report, developed in partnership with Mencap which has been widely welcomed. This resource was informed by small-scale research with family carers and aimed at commissioners and providers. It clarifies the legal duties for keeping children in touch with their families when living away from home and sets out best practice and case studies.
- A **Positive Behaviour Support (PBS) resource for families** developed in partnership with the PBS Academy. This is a set of practical resources enabling families to better understand how they might use PBS or learn more and how to judge whether a provider is using a PBS approach.
- A set of **tools to help develop local pathways for children with learning disabilities whose behaviours challenge**. This was the result of a piece of work commissioned by NHS England and developed in partnership with National Development Team for Inclusion (NDTi). It involved four site visits to Somerset, Gloucestershire, Leeds and Halton to speak to family carers, professionals and commissioners. The results were analysed and three resources produced:
  - o Why we need local pathways
  - o Legal duties and guidance
  - o Tools to help develop local pathways

Initially the plan was to produce a resource to be published by NHS England but they decided to write their own resource and to cross-reference the tools published by us and NDTi. As yet NHS England have not published their pathway resource.

Over the course of the Early Intervention Project we tried to consult children and young people about what good support looks like to them. We held a video competition and a focus group at a school, but felt this engagement did not go far enough in seeking the views of children with severe learning disabilities. We are therefore taking forward a direct engagement project, developing a methodology in partnership with the Tizard Centre, University of Kent. The methodology is now complete and 14 families have expressed interest in taking part. This will be progressed next year.

Strategically influencing others in relation to early intervention has been a priority and we have had a number of significant achievements:

- Ensuring the **Children's Commissioner** is aware of the issues for this group of children and young people. After an initial meeting she has followed up a number of actions and commitments, including a visit to an Assessment and Treatment Unit (ATU) with CBF, follow-up letters to the Minister and local commissioners, a recorded message for CB-NSG and a programme of visits to children in ATUs.
- Convincing the **Learning Disability Professional Senate** to expand their membership to include representatives who work with children. This has impacted on the agenda of the meetings which are now all-age discussions.

- Playing a key part in the greater focus on children within the **Transforming Care programme**, including the admission that not enough focus has been given to children to date.
- Informing the **Lenehan Review**, commissioned by the Department of Health to consider support for children with learning disabilities whose behaviours challenge. Dame Christine Lenahan (Director of the Council for Disabled Children) has included all the learning from the EIP within her analysis.

### **Integrated Personal Commissioning**

This year we have supported three sites piloting Integrated Personal Commissioning (IPC). The emerging IPC framework is characterised by shifts in the model of care and we have supported this process by providing Positive Behaviour Support workshops to staff and families and commenced initial work to develop family carer engagement in one area.

The packages of support we can offer to support organisations in working more closely with families caring for someone with a learning disability have been shared extensively over the year, with services across health and social care. There has been some interest from services in commissioning support from us and we are in the process of agreeing Positive Behaviour Support workshops with families and staff in two areas (Hertfordshire and Luton).

Although in theory the IPC approach to delivery is sound, in practice it has proved difficult and time consuming to negotiate with NHS England (NHSE) to deliver in the way the local sites have requested. We will continue to work with sites and NHSE to enable local areas to access our workshops and consultancy.

### **Other Influencing Work**

We have contributed to a number of consultations to ensure the needs of our client group are included and recorded, including:

- Submitting information on the formation of a new organisation, (Learning Disability England) via a consultation run by People First England and the Housing & Support Alliance
- Providing information to the "Shaping the Future" consultation by the Care Quality Commission (CQC).
- Submitting information on the impact of the Care Act for families of people with severe learning disabilities and wider issues via the "Care Act for carers: One year on Commission".
- Providing comments for Nottinghamshire County Council on their Transforming Care plans, entitled, "Transforming Care for People with Learning Disabilities and/or Autism who Display Behaviour that Challenges including those with a Mental Health Condition in Nottinghamshire".
- Submitting a joint Mencap/CBF consultation response to the CQC accountability hearing. Members of the Health Select Committee asked the CEO of CQC several questions from our submission during the course of the hearing.
- Responding to a consultation from National Institute for Health and Care Excellence (NICE) on their Mental Health Problems in People with Learning Disability Quality Standard. Our feedback was taken on board, specifying that health checks should be for young people (as well as adults) so it is now explicit that health checks (including mental health) should start at aged 13 years.
- Submitting information to the Law Commission's consultation on their Mental Capacity and Deprivation of Liberty project.

### **Sharing Best Practice**

The principle of sharing and promoting best practice runs through all aspects of our work. We are committed to sharing evidence-based best practice and therefore support a number of research projects through input to steering groups, including dissemination of findings to maximise impact. During the year we have contributed to:

1. A study of Positive Behaviour Support for adults with learning disability and challenging behaviour: Randomised Control Trial (RCT).

2. Goals and Outcomes for Intervention (GO-for-IT): Nick Gore (Tizard Centre, University of Kent) - 5 interlinked pieces of work: systematic review; child & family views project; outcome tool development; survey of PBS practices in children's services; PBS pathway intervention study.

3. Transition to adult social care from residential schools - Prof Peter McGill (Tizard centre, University of Kent).

4. Who's Challenging Who: (RCT) Prof Richard Hastings, University of Warwick.

5. What works in Family Based Support: Tina Cook - Northumbria University, Newcastle.

We have contributed to funding applications for the following research work:

- British Association of Childhood Disabilities (BACD): Prof Chris Oliver (University of Birmingham) - Identification of children at high risk of developing challenging behaviour - feasibility study
- Early Positive Approaches to Support (E-PATs) for families of young children with intellectual disability: Feasibility study - Prof Richard Hastings (University of Warwick)
- Parental impact on child wellbeing - development of a resource for families: Vasiliki Totsika (University of Warwick)

Our information and support work and our influencing work contribute to sharing best practice. We have developed, over many years, a range of networks enabling significant reach to a wide and diverse group of stakeholders, including families, clinicians, providers, voluntary organisations and groups, regulators, committees and boards, health, education and social care bodies and groups, researchers and academics and all the Transforming Care stakeholders. Our information is shared through these extensive networks, and with our newly developed database we have improved flexibility to target information very specifically to ensure it is relevant and appropriate to the recipient. Our staff and Local Champion volunteers regularly speak at local, regional and national events to share best practice with families and professionals.

We develop and produce a range of accessible, evidence-based and practical resources for families and professionals as well as working collaboratively with other organisations where additional specialist input is needed. We facilitate a family carer review panel which helps us co produce our resources, providing feedback to ensure our resources are useful and accessible, and all resources are disseminated through our extensive range of networks and via events and social media.

We co-produced, with family carers, our Positive Behaviour Support Training workshops. These are delivered by a Positive Behaviour Support trainer and a family carer co-trainer working together, modelling co production and partnership working. The workshops facilitate partnership working, to enable staff and families to work together to identify appropriate, individualised behaviour support strategies that can be used consistently across all settings. They provide a mechanism to share best practice, provide practical support and information to families and demonstrate by example the positive outcomes that can be achieved by working together.

The Challenging Behaviour - National Strategy Group (CB-NSG) is a network of stakeholders from different parts of the system. Core and associate members of the group receive and share regular updates and information.

### **Planned Activities for 2017/2018**

We carefully plan activities under our three key areas to achieve the greatest impact and deliver positive outcomes for children, young people and adults with severe learning disabilities who display behaviour described as challenging, and their families. The Board of Trustees, working with our small staff team, have reviewed our activities and agreed that the three interconnected areas of work are an effective approach that should continue. We aim to sustain and progress existing activities that deliver positive outcomes, and further develop areas where we have identified a need, subject to the availability of the necessary funding.

#### **Information and Support**

In the coming year we plan to continue the high standard of support provided by the Family Support Service, including telephone and email support, casework, the Email Networks and the Family Linking Scheme. We will enable the Family Carers' Email Network to become true peer support, by recruiting and training family carers as volunteer co-ordinators to run the network.

The CBF's range of information resources will be maintained and will continue to be sent free of charge to family carers around the UK. We aim to distribute more information resources to family carer groups, via post, email and using our Local Champions to visit the groups. We will produce a comprehensive guide to the use of psychotropic medication for families of people with learning disabilities, as a part of the national programme Stopping the Overuse of Medication for People with a learning disability and/or autism (STOMP), led by NHS England.

We will continue to seek funding to develop a group of 'expert advisors' to support families in complex situations, beginning with a small pilot.

Having prioritised the development of a legal panel in 2017, we wish to continue this work to ensure families benefit from timely legal advice and we will work in collaboration with others to strengthen the rights of people with a learning disability.

#### **Strategic Influencing**

We will continue to prioritise our strategic influencing work, building on our success in raising the profile of this group of individuals and their families at a local, regional and national level. This will include engaging with the Transforming Care Programme to ensure that greater progress is made, and continuing to work with other bodies that can provide national independent scrutiny. Our strategic influencing and policy work will continue to be informed by the experiences of the families who contact us for our support and information.

We will continue to support and resource the Challenging Behaviour - National Strategy Group, and support the campaign subgroup to implement its campaign plan to:

- Highlight the issues for people with learning disabilities who are stuck in inpatient units to the media, to ensure public support for the continuation of the Transforming Care programme of work.
- Support families to produce film clips highlighting the key issues to enable their voices to be heard on social media.
- Provide evidence to the National Audit Office and Public Accounts Committee to ensure that failings in the Transforming Care Programme are addressed.

We will retain our focus on early intervention and prevention, building on our successful work to date, making change happen for children and young people and their families, and linking and co-ordinating the opportunities of the Special Educational Needs and Disability (SEND) reforms and Transforming Care. We plan to:

- Publish at least one blog post a month on the Paving the Way site and remind people of the least visited resources to ensure families and professionals benefit from all the information available on the website.
- Conduct a survey of families to inform Child and Adolescent Mental Health Services (CAMHS) Tier 4 service specifications.
- Develop a new resource of best practice examples in engaging children and young people.
- Revise the PBS families' resource to make it easier for families to download and use the information.

- Promote and share our work at national conferences.
- Take forward a direct engagement project with children and young people.
- Publish a report of our direct engagement project and share with all Transforming Care Partnerships.
- Support an All-Party Parliamentary Group (APPG) focused on children with learning disabilities whose behaviours challenge.
- Influence the Department for Education review of best practice in the Early Years.

Respond to consultations/calls for evidence on:

- The Lenehan Review
- Residential Special schools
- CAMHS Tier 4
- High needs Funding
- Reducing Restrictive Interventions with Children
- Visiting guidance.

We will continue to engage with the Integrated Personal Commissioning programme to deliver PBS workshops to help local areas to support and empower family carers.

### **Sharing Best Practice**

It is essential to promote and enable the use of resources and share best practice to support and achieve change. We aim to:

- Revamp our website to make it mobile friendly and more accessible to a diverse range of users.
- Develop a short film of families' experiences to raise awareness amongst a range of stakeholders and encourage families to access our support.
- Continue to work with media organisations to highlight the issues this group of families face, expose poor practice and promote the need to ensure people have their basic human rights met.
- Work with researchers to gather evidence about the effectiveness of early intervention training packages available for families.
- Continue to promote and disseminate evidence-based practice through a range of means including speaking at conferences, contributing to articles in relevant publications and sharing information through our extensive networks.
- Continue to promote best practice through delivery of our workshops.

In order to achieve the plans described above, we need resources. Independent evaluation shows that we provide high quality work and good value for money. Securing adequate funding is, however, becoming increasingly challenging and thus our objectives for 2017/18 include increasing the volume of grant applications while at the same time diversifying income, particularly through growing the paid work we do.

## **FINANCIAL REVIEW**

### **Financial position**

As shown on page 19, incoming resources for the year amounted to £369,933 (£616,006 in 2015/16) and resources expended were £465,771 (£635,062 in 2015/16), giving net expenditure of resources of £95,838 (£19,056 in 2015/16). It should be noted that £47,701 of this total represents planned expenditure associated with restricted funding received and shown as income in 2015/16. The reduction in income reflects the ending of a three-year contract with the Care Quality Commission coupled with the completion during the year of several grant-funded projects.

In recognition of the challenging funding environment in which the charity operates, the Trustees have set up procedures to monitor the financial position, including forward projections and identification of actions needed, at least monthly. This has resulted in measures to reduce core costs, mainly through the restructure of the permanent staff team in summer 2017. This process has been very carefully managed with our priority being to sustain our family support and policy work and to ensure that we have a sound foundation on which to build so our activities can be increased when more funding is secured. We anticipate that in the meantime the excellent networks we have established over the years will enable access to additional resources flexibly as and when they are needed to deliver specific projects.

Growth in income from contracted and paid work is expected to be an important contributor towards the charity's future financial sustainability, with the provision of workshops, consultancy, research and policy work enabling us to progress our aims whilst delivering services to key partners. It will be essential to ensure that this work is self-sustaining as well as making a fair contribution to the charity's core costs. We intend to continue to carefully select opportunities to engage in work of this nature, ensuring it offers a good fit with our aims and objectives and does not overstretch the capacity of the team.

In the meantime we continue to rely on the support of trusts and foundations to support our staff and core costs. We would like to extend our grateful thanks to all supporters who have enabled us do so. In particular we wish to thank the Big Lottery Fund for supporting the development of our volunteer programme and extending our support networks, The Lloyds Foundation for supporting a full-time family support worker role, the Department of Health for supporting our Early Intervention Project, the Esmée Fairbairn Foundation for supporting our work on the Winterbourne View campaign and several other smaller foundations for supporting core costs.

### **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, as well as internal factors (contractual obligations and operational issues). The reserves target also 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 is embedded at a local and national level in the event of a downturn in income. 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.

The Trustees seek to hold six months of running costs in free reserves. Free reserves amounted to £176,435 at 31 January 2017, representing just below this target, based on predicted running costs for 2017/18.

## **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**

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 as observers and to offer input in order to further their knowledge of how the CBF is managed, thus providing both a recruitment and a training path for new 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 this 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

## **REFERENCE AND ADMINISTRATIVE DETAILS**

### **Registered Company number**

3307407 (England and Wales)

### **Registered Charity number**

1060714

### **Registered office**

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

### **Trustees**

Ms S Cooper	
Mrs V A Cooper	
Mr J Dodds	- appointed 26.4.16
Dr N J Gore	- appointed 16.7.16
Mr C Hawkins	
Ms D E Lightfoot	
Mr P McGill	- resigned 22.04.17
Mrs C Million	- appointed 21.1.17

### **Company Secretary**

Mrs V Cooper

**Auditors**

Calcutt Matthews  
Chartered Accountants and Registered Auditors  
19 North Street  
Ashford  
Kent  
TN24 8LF

**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 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 focused on non-financial risks such as reputational risk and suitable mitigating actions put in place.

**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 order of the board of trustees on ..... and signed on its behalf by:

.....  
Mrs Vivien Cooper - Trustee