

# Getting It Right for children, young people and adults with severe learning disabilities and challenging behaviour

## West Sussex evaluation report

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## Introduction

The Challenging Behaviour Foundation (CBF) is a registered charity for children, young people and adults with severe learning disabilities and challenging behaviour, providing support and information to families and promoting evidence-based policy and practice. The charity successfully bid to National Lottery Community Fund to deliver the 'Getting It Right' (GIR) project over three years from September 2019, with the over-arching aim:

“As a result of our specialist training, input and information, our beneficiaries will receive the right support, in the right place and at the right time, from well informed professionals and staff so they can live a happier and more inclusive life in their community.”<sup>1</sup>

Three inter-related streams of work were proposed: strategic local input, strategic national policy work and sharing information and best practice. The Strategic Local Input strand builds on a pilot project in Cumbria<sup>2</sup> and involves:

“Work with one local authority area per year (three in total) to provide: Specialist, in-depth and strategic support; guidance and resources; and our PBS (positive behaviour support) training to 90 people (a mix of families and professionals). We will involve all relevant players in the area and aim to leave three local authorities with a strategic plan for the future and 700 families with a better support network. This work will build on our previous experience and knowledge of supporting local authorities and Clinical Commissioning Groups (CCGs) and linking health with social care, education and employment. The model can then be replicated around the UK.”<sup>3</sup>

West Sussex was chosen as the first Strategic Local Input area and is the focus of this evaluation report. The aims and objectives agreed with West Sussex partners were:

### Project Aim

As a result of our training, input and information, we hope our beneficiaries will receive the right support, in the right place and at the right time, from well informed professionals and staff so they can live a happier and more inclusive life in their community.

### Objectives

- 1 To provide specialist training and share best practice with families, professionals and commissioners in West Sussex
- 2 Support families, professionals and commissioners to develop meaningful plans for sustainable improvements in future support in West Sussex (including a self-fulfilling network reaching out further afield)

<sup>1</sup> CBF (April 2019) *Getting it right for children, young people and adults with severe learning disabilities and challenging behaviour: Proposal to the National Lottery Community Fund*

<sup>2</sup> See [www.challengingbehaviour.org.uk/driving-change/cumbriaearlyintervention.html](http://www.challengingbehaviour.org.uk/driving-change/cumbriaearlyintervention.html)

<sup>3</sup> From the funding application (as above, footnote 1).

- 3 To improve the resilience of families of children and young people with learning disabilities whose behaviour challenges, through improving networks and connections between families.

Source: GIR Local Area Project Plan for West Sussex (final version, shared February 2020)

## The evaluation

The grant included a small amount of funding for evaluation. A formative approach was agreed to support learning and improvement in each of the three local areas, working in partnership with the project manager and local leads to gather evidence of impact. Year One (in West Sussex) benefitted from the support of a Masters student in social research, enabling more in-depth research to be carried out. Key questions agreed for the evaluation were:

In the early stages of the project:

- i. What is our starting point? What are our key objectives (NB informed by parent-carers)? How are we going to make progress towards them?

Throughout the delivery phase:

- ii. Are we doing this as well as we could be? (to inform on-going improvements)

Towards the end of the delivery phase:

- iii. What difference is it making to our intended beneficiaries? (to assess outcomes)
- iv. What's worked well, what are the barriers/enablers to progress, how have we been able to move forward (process learning, to inform roll-out in other areas).

Source: West Sussex local evaluation plan (March 2020)

Key elements of the evaluation framework agreed were as follows:

1. A **logic model**<sup>4</sup> drafted by the project leads and refined by the West Sussex Steering Group to show how proposed inputs and activities lead to intended outputs and outcomes. This is shown in Annex A.

<sup>4</sup> <https://www.gov.uk/government/publications/evaluation-in-health-and-well-being-overview/introduction-to-logic-models>.

2. A detailed **online survey of parent-carers** to shine a light on families' experience of local services, their needs and gaps in provision.
3. Gathering **feedback and evidence of outcomes** for each element of the delivery plan (focus groups, PBS workshops, stakeholder events) through short questionnaires completed at the end of each event.
4. **Process learning** around the development and delivery of the programme throughout the project, largely through discussions between and with team members (for example, the evaluator attended most Steering Group meetings); and towards the end of the project, through semi-structured phone interviews with CBF and local partners.

An interim evaluation report in February 2021 was provided to enable the CBF to report to the National Lottery Community Fund on first year of Local Strategic Input. However, delays caused by the Covid-19 pandemic (described further in the next section) meant that CBF's strategic involvement in West Sussex had not yet concluded, in particular, the final Steering Group meeting (focused on action-planning and sustainability) had not taken place. Several elements of the evaluation evidence were outstanding. Since the interim report was written:

- The final Steering Group meeting took place on 24 March 2021. Actions flowing from the Stakeholder Event in December 2020 were discussed, to form the basis of an action plan, currently in development;
- Semi-structured interviews have been conducted with West Sussex partners;
- Learning from this project was shared in a joint presentation by the West Sussex Project Lead and the independent evaluator, at a workshop at the Challenging Behaviour National Strategy Group on 26 May 2021. This was attended by colleagues from each of the areas in which the CBF has provided Strategic Local Input: Cumbria (pilot project), West Sussex and the Black Country (the second GIR area), as well as interested academics, practitioners and family-carers.

At the time of writing (July 2021), some elements of the evaluation evidence are still outstanding. However, as the CBF's direct involvement in West Sussex has concluded and work in the Black Country is now underway, it is an appropriate time to draw a line under the first year's evaluation and to share learning to support progress in both areas.

## Limitations

There were delays and/or difficulties in collecting some of the evidence for the evaluation, which we reflect on later in this report (see 2.3: Gathering and sharing evidence). In particular:

- A detailed write-up of the survey of family-carers is awaited, although emerging findings were shared at the Stakeholder Event in December and had a clear influence on discussions there.

- No families responded to the online follow-up questionnaire to assess outcomes from the Behaviour Chats (virtual PBS workshops), one month after the training.

Another important limitation is that it is too early to assess impact in terms of local area change: while some actions have already been taken (described in Section 4), others will take many months to progress and significantly improved outcomes for families may require a sustained focus over several years. The evaluation reports on years 2 and 3 of the Getting It Right Local Strategic Input will provide an opportunity to revisit progress in West Sussex.

Given the timing of this report (coinciding with the early stages of work in the Black Country) and the evidence available, the main focus is therefore on 'process learning': reflecting on practical lessons around what worked and why in the project's delivery in West Sussex, difficulties encountered and room for improvement. We conclude with emerging evidence of outcomes and reflect on how the project partners could promote sustainable improvements for local families caring for someone with severe learning disabilities.

## Section 1: High level themes: what worked well and why?

### 1.1 Successful project delivery in spite of the challenges of Covid-19

“Thank you to everyone for being so flexible, it could have just not happened with Covid, that commitment is very much appreciated.” West Sussex Project Lead

“We kept going through Covid - strong leadership and commitment, tenacious in best possible way. Other things dropped by the wayside, but this didn't.” Clinical Lead, SPFT

Delivery of the GIR project in West Sussex largely coincided with the Covid-19 pandemic. The Steering Group first met in January 2020 and two family-carer focus groups were held in February/March, before a national ‘lockdown’<sup>5</sup> was announced on 23rd March 2020.

This had immediate practical implications for the project. Meeting in person was not possible, so the Steering Group had to meet virtually and the anticipated Stakeholder Events and Positive Behaviour Support workshops were put on hold.

Many of the project’s intended beneficiaries (families with a child or young person with severe learning disabilities and challenging behaviour) were ‘shielding’<sup>6</sup> to protect vulnerable family members, with children sent home from school (temporarily or for many months) and greatly reduced access to key services such as health therapies and CAMHS. The pressures on some families were immense, as shown by a survey of families with SEND in West Sussex by the charity, Reaching Families.<sup>7</sup>

Local services had to respond rapidly to the challenges created by the pandemic, with many health professionals redeployed in the Covid-19 response, schools closed and all but essential face-to-face service delivery halted.

In these extraordinary circumstances, the Steering Group (in March 2020) considered whether to postpone the project’s delivery and an extension of several months (to December 2020) was agreed with the National Lottery Community Fund. However, they decided to proceed with the survey of family-carers as a means of engaging isolated families and sign-posting them to support; this would also provide a richer evidence base for strategic planning, at such a time as the project could resume.

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<sup>5</sup> Extensive restrictions on social contact to reduce the spread of the virus, requiring people to stay at home, closing schools and many public services. <https://www.gov.uk/government/speeches/pm-address-to-the-nation-on-coronavirus-23-march-2020>

<sup>6</sup> A higher level of restrictions to avoid all social contact. <https://www.england.nhs.uk/coronavirus/publication/guidance-and-updates-for-gps-at-risk-patients/>

<sup>7</sup> Published in O’Hagan, B. and Kingdom, S. (2020), “Experiences of children with special educational needs and disabilities and their families in the United Kingdom during the coronavirus pandemic”, *Tizard Learning Disability Review*, Vol. 25 No. 4, pp. 229-235. <https://doi.org/10.1108/TLDR-09-2020-0025>

Over the next few months, as everyone adapted to working remotely, options for continuing with the programme's delivery became clearer. For example, CBF (nationally) adapted their PBS workshops to be delivered virtually as part of their response to the Pandemic, knowing that many families were struggling to cope unsupported with challenging behaviour in the lockdown. Building on this experience, in the Autumn, 'Behaviour Chats' were able to be offered to families in West Sussex, co-produced with and facilitated by local professionals, alongside CBF-trained family-carers.

The Stakeholder Event took place virtually in early December, sharing the key messages from the focus groups and emerging findings from the family-carer survey, before breaking into discussion groups to identify priorities and actions to improve outcomes for families.

The country was in a third national lockdown when the Steering Group last met, in late March 2021. This final meeting focused on action-planning informed by the Stakeholder event, and planning for a reflective workshop to share learning from the project at the Challenging Behaviour National Steering Group (CB-NSG) in May 2021.

Over the extended duration of the Project (an additional six months), the partners successfully adapted and delivered nearly everything that they had planned to do at the outset. Further detail on what this involved and learning around each element of the programme is provided in Section 3.

## 1.2 Local success factors: Effective steering group, key individuals, strong partnership working, shared vision and values, CBF 'added value'

West Sussex was the first of three areas which CBF are working with, through the Strategic Local Input strand of the Getting It Right (GIR) programme. The criteria for selecting these areas are not defined (based on a combination of 'warm' contacts and local knowledge), but objectively, many success factors (outlined in this short section) were in place in West Sussex, making it an excellent area in which to start an innovative three year local project of national ambition.

### Effective steering group

"The importance of the steering group and getting the right people on it is really vital - being able to see how well it worked, having all these disciplines around the table". West Sussex Project Lead

"The mapping, networking, getting everyone's buy-in at the start... that was really helpful. Some dropped away over time, but the key people were there at start and some really good things happened as a result." Clinical Lead, SPFT

An **effective Steering Group** was put together in the early months of the project, which included all the key local services, notably:

- West Sussex Parent-Carer Forum
- West Sussex County Council senior commissioners (all age services, SEND, PBS)
- Sussex Partnership NHS Foundation Trust (SPFT) - learning disability and neurodevelopmental services
- Children's social care (child disability teams)
- Children's residential services
- Transforming Care partnership
- Intensive Planning Team
- Special schools.

In spite of the pressures of the pandemic, attendance at meetings was good, although less consistent in the later stages as some partners (notably schools, social care, head of commissioning) struggled with timetabling 'clashes' and/or heavy demands on their time. The meetings benefitted from clear agenda, were well chaired and action-focused, with work undertaken efficiently between meetings.

Local partners interviewed for this evaluation were very positive about the value of the Steering Group but suggested a range of other services which they felt should have been more closely involved. This included, variously:

- Schools and social workers, as the key services in close contact with families; as noted above, they were in fact represented on the Steering Group but struggled to attend regularly
- Carers support organisations
- CYPRESS (enhanced support service for children and young people with learning disabilities and autism; also invited, but seldom able to attend)
- CAMHS (not involved). However, a Clinical Lead (Learning Disabilities) from SPFT always attended and tried to ensure that issues across the full age range were considered, including a focus on young adults (aged 18-25 years).

### Key individuals

The Project Lead in West Sussex, Marie Willan, and the Family-Carer Lead, Grainne Saunders, were generous with their time and showed great commitment to this project. For example, Marie phoned every family registered for the focus groups, explaining their purpose and encouraging them to attend. Grainne reached out to families and regularly shared families' feedback with the project leads, clearly articulating this perspective in discussions. Both these individuals made a major contribution to the success of the project.

The Project Lead was able to bring a valuable combination of expertise and strategic influence to the project, thanks to her dedicated role, leading for West Sussex County Council on Positive Behaviour Support Commissioning and with a professional background in PBS. The creation of her role (thought to be fairly



unusual) demonstrates the County Council's commitment to improving outcomes for people with behaviour described as challenging; a commitment shared by Sussex Partnership NHS Foundation Trust, who also commission PBS services across the County and were active partners in this project.

### **Strong partnership working**

Strong partnership working was evident throughout the project, between key West Sussex partners (notably, the County Council, Sussex Partnership NHS Foundation Trust (SPFT) and West Sussex Parent Carer Forum) and with CBF colleagues, with active problem-solving (e.g. how to proceed at each stage of the pandemic) and proactive sharing of expertise, resources and contacts.

Feedback from local partners suggested that this predated the project (for example, they would not hesitate to pick up the phone to discuss a problem with another service), but that relationships between key individuals were strengthened through the experience of collaborating on this project. Integral to this, and another key local success factor, was the strong and open relationship with the Parent Carer Forum.

"The relationship with the Parent Carer Forum is really good here, West Sussex approach their parent carers as experts." West Sussex Project Lead

### **A shared vision and values**

There was a strong alignment between the aims and values of the CBF (being put into practice through the GIR project) and the strategic aims, vision and values of the service leads in West Sussex. This was most clearly articulated by the CBF lead for the PBS workshops, interviewed for this evaluation:

"This has worked especially well because of a shared commitment ... all on board with the same shared aim .... (enabling) proper, effective co-production."

Co-producing a logic model in the early months of the project helped to reinforce a clear focus on outcomes for families, shared by all the partners:

"Thinking about outcomes from the start was really powerful - like the logic model, it's worth sharing this." West Sussex Project Lead

### **CBF 'added value'**

As well as local success factors described above, several partners in West Sussex described how the involvement of the CBF in their area helped to galvanise local partners around strategic aims of the project, adding momentum and a sense of strategic importance:

“It helped to get people on board, to get recognition and respect for the project” West Sussex Project Lead

“When energy was waning, things were well timed to keep it going – for example, Vivien (Cooper) joining a meeting really reset everyone and got it back on track!” Clinical Lead, SPFT

Local partners valued being able to draw on the experience of the pilot project in Cumbria through the CBF project leads, and colleagues in these two areas are now connected following the recent CB-NSG workshop. There was also much praise for efficient way in which CBF colleagues managed the project and the expertise they brought to it.

“Everything had quality and integrity - they did it well.” Family-Carer Lead

“It was well organised, led and steered. The administration and project leadership was helpful, well organised and diligent.” Clinical Lead, SPFT

### 1.3 A clear focus on families throughout

“Parent voice was very important and powerful in helping to steer the project; it was so integrated into the model from the start.” Clinical Lead, SPFT

Consistent with shared vision and values described above, the project’s target beneficiaries – families with a child or young person with a learning disability and challenging behaviours – were clearly in focus throughout the project.

Outcomes for families are central to the project’s logic model [Annex A], initially drafted by CBF and refined through several Steering Group discussions. Additions to the West Sussex delivery plan strengthened the family-carer voice beyond the approach proposed in the GIR funding application (which was already family-focused). Specifically:

- Two family-carer focus groups were held in February-March 2020 to help identify priorities for local families;
- A detailed survey of family-carers went out in August 2020.

The Steering Group repeatedly reflected on how to engage the right families and actively used their own networks and contacts to do so. As noted above, the Project Lead in West Sussex and the parent-carer representative were particularly proactive in this respect.

“They did a good job in reaching isolated families.” Family-Carer Lead

Much discussion and thought was devoted to ensuring that parents felt comfortable, safe and listened to, in each of the events (focus groups, PBS chats, stakeholder event). The Family-Carer Lead reflected positively on this:

“The CBF team were incredibly person-centred, welcoming, really kind, they really put parents at ease and that never changed. There was a sense of respect for families and warmth - they were very compassionate, empathetic and genuine. It felt really easy to trust them, it felt very safe for families in the workshops. People shared their stories freely because it felt safe and because these were people who were going to try to improve their lives.”

Nonetheless, several of the local partners – including those who themselves invested much effort on this front - wondered if they could have gone further in reaching out to the right families, especially the most isolated. An education partner suggested that schools could help more in this respect, since they already know families well and could offer a familiar environment. She suggested that schools could host some of the engagement events and deliver PBS training, which would have the added benefit of helping families to get to know each other and develop an informal support network.

#### **1.4 Continuous learning and improvement**

As the first GIR area and faced with the unprecedented challenges of the pandemic, the West Sussex Steering Group played an active role in shaping the delivery of project, developing approaches and resources which can be replicated (adapted as appropriate) in other areas. Although a broad plan existed, much of the detail was worked out between partners in West Sussex and CBF colleagues, and adapted in the context of the pandemic.

For example, West Sussex suggested two family focus groups instead of one, to make it easier for families across this large County to attend, and made funding available for this. Materials for the virtual Behaviour Chats were co-produced with West Sussex partners. Feedback and outcomes tools were refined in consultation with the independent evaluator and West Sussex partners; the Family-Carer Lead contributed much to these discussions.

A formative evaluation approach was agreed, with feedback gathered after each element of the project (i.e. focus groups, behaviour chats, stakeholder group), shared with the Steering Group and used to inform the next stage. For example, feedback from the first focus group, where one family (caring for a child with learning disabilities) felt dominated by another more vocal family (caring for a child with autism), led to more careful targeting and facilitation of the second focus group, yielding more positive feedback. A summary of learning from the focus groups was then discussed at the Steering Group and fed into the design of the survey and the Stakeholder Event.

## Section 2: What could be improved upon? (High level themes)

There are three high level issues which the programme leaders may wish to reflect on, based on the experience of delivering this project in West Sussex:

- 2.1 Project duration and sustainability
- 2.2 Maintaining a focus on the target group, while being supportive of other families facing similar challenges
- 2.3 Gathering and sharing evidence.

### 2.1 Project duration and sustainability

“It takes a long time for people to warm up, to understand what's happening and get engaged ... Maybe do more pre-engagement with partners... Perhaps do a bit more warm-up e.g. a pre-newsletter, short video ... to get people excited, prepared, so that when they arrive, we're all ready to go.” Family-Carer Lead

The National Lottery Community Fund application proposed strategic partnerships in three local areas, one per annum over the three-year funding period. High level agreement for the project in West Sussex was secured in October 2019 and the Steering Group first met in November 2019. It was anticipated that CBF's involvement would end around August 2020, with the second local area project beginning in September 2020. This represents an ambitious timetable, even without the challenges of the pandemic.

In practice, Local Area Strategic involvement by CBF in West Sussex continued for 18 months (September 2019 to March 2021), approximately six months longer than planned.

The West Sussex project plan anticipated that the project would culminate in co-producing a strategic plan and setting up new social networks to support local families. However, with competing demands on key individuals' time in early 2021 (which some felt were worst months of the pandemic), less time was able to be invested at this stage. A range of actions were agreed at the final Steering Group (late March 2021), informed by discussions at the Stakeholder Event.

The Project Lead in West Sussex is writing up learning from the project and an action plan, setting out short, medium and long-term goals. She plans to coordinate progress through their existing (recently revived) local Behaviour Support Network, which includes local commissioners, providers and family-carers.

Following a meeting with the Parent-Carer Forum, the CBF are recruiting a new local champion in West Sussex, 'nested' with the PCF to ensure that families with lived

experience of challenging behaviour are represented in strategic discussions. Further information on actions to date in West Sussex is provided in Section 4.

Meanwhile set-up work has been progressing in the second area (Wolverhampton and Black Country), with the first Behaviour Chats held in June 2021.

The set-up and concluding phases of local area strategic projects such as this are arguably critical to their success and sustainability, as the key periods when aims and outcomes are agreed, relationships are developed; and (towards the end) when strategic plans with clear actions assigned to individuals are put in place, and key messages shared to influence changes in commissioning, policy and practice.

Interviews with local partners suggest that on-going contact with the CBF project leads would be valuable in helping to sustain progress. There is also much appetite for developing a peer support network and actively sharing learning between local areas, building on the workshop at the Challenging Behaviour National Strategy Group (CB-NSG) in May 2021.

Outcomes and sustainability are considered further in Chapter 4.

## **2.2 Maintaining a focus on the target group, while being supportive of other families facing similar challenges**

“It was a difficult project to communicate, to identify the right families. But they were really inclusive, generous not to dismiss other voices.” Family-Carer Lead

The Challenging Behaviour Foundation describes itself as “the only UK charity specifically for children, young people and adults with severe learning disabilities and challenging behaviour” and these families are the focus of the Getting It Right project.

In the interviews conducted for this evaluation, the project leads reflected on the long-standing tension of trying to focus on their target beneficiaries as a priority, while being inclusive and supportive of others facing similar challenges, notably those with autism and challenging behaviour. These two groups overlap significantly and key policy agenda, such as Transforming Care, are concerned with both.

Experience suggests that the target group (those with severe learning disabilities) tend to be more isolated, less well ‘networked’ (i.e. connected to others in similar circumstances) and harder to engage than the more numerous group of families with autism.<sup>8</sup> In West Sussex, great efforts were made to reach out to the intended beneficiaries, with:

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<sup>8</sup> Perceptions of the project leads at CBF and West Sussex, consistent with discussion at the CB-NSG workshop in May 2021. We are not aware of research into the comparative needs and circumstances of these two groups.

- Members of the Steering Group using their networks and contacts to engage the target group of families;
- Flyers and posters for family-carer events highlighting learning disabilities and behaviour, rather than autism.

Nonetheless, families caring for a child or young person with autism were well represented in all the events, often outnumbering the target group of families. Why was this and does it matter? These questions were explored with local service leads, practitioners, academics and family-carers at the CB-NSG workshop in May 2021. Participants there suggested that:<sup>9</sup>

- Autism is more common than severe learning disabilities, so in simple numerical terms, there are more such families.<sup>10</sup>
- Higher take-up by families with ‘autism only’ likely reflects the gap in many areas in access to behaviour support and mental health services for this cohort. Local eligibility criteria often exclude children and young people with autism but no learning disability. Local leads in West Sussex are looking into this now.
- Families caring for someone with a severe learning disability may be more isolated and less well connected to support networks than those with autism, making them less likely to hear about the project and less likely to engage.

“There are no natural parent support groups for these families.” Family-Carer Lead

- Although the same services may be needed (e.g. PBS training), different strategies are likely to be appropriate. Families may be more comfortable sharing their experiences with others dealing with similar issues; the lived experience of a family whose child has a severe learning disability may be very different from that of a family whose child has high-functioning autism. It may therefore not be ideal to group these families together, in local workshops and engagement events.

The same tension can be expected in other areas, so this issue needs to be explored with local project leads, and strategies considered for reaching out to the target group of families and planning events. West Sussex colleagues interviewed for this evaluation suggested that schools, residential care, social workers (children’s disability team) and the PCF could all play a role in identifying and engaging these

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<sup>9</sup> This list reflects well informed people’s perceptions, but has not been corroborated with research evidence.

<sup>10</sup> However clear national data on prevalence are lacking. School Census data (January 2020) show that 11% of children with EHC plans had a primary need of ‘severe learning difficulty’, while almost three times as many 30% had an ‘autistic spectrum disorder’. DfE (May 2021) *Special educational needs and disability: an analysis and summary of data sources*.

families. Although great efforts were made to target families, the West Sussex Project Lead felt they could have gone even further:

"We could have done more to identify and define the cohort ... There are other families who with a little bit more thought we could've identified and approached way ahead, and encouraged them to be part of it, on a personal level."

It should be noted that experience in West Sussex suggests that targeting families caring for someone with a severe learning disability will not exclude those with autism only, who were well represented in all aspects of the project and whose views were clearly heard.

### 2.3 Gathering and sharing evidence

As discussed in the introduction, a formative approach to evaluation was adopted, developing a logic model at the outset (refined over time) and reflecting on the feedback from each event in Steering Group meetings, to see if and where there was room for improvement. The partners' committed approach to continuous learning and improvement (noted in section 1.4) was a clear strength of this project.

However, at the time of writing (July 2021) there remain some important gaps in the evidence generated. There is now some urgency to this, as the West Sussex Project Lead is still not able to pull together and disseminate all the learning from the project, to underpin the action plan she is developing.

#### Survey of family-carers

A **detailed online survey of family-carers** launched in August 2020 achieved an impressive response rate (N=98) in spite of the pressures of the pandemic. This was generously carried by a Masters research student on a voluntary basis.

Headline survey findings shared at the Stakeholder Event in December had a clear influence on discussions. The detailed analysis is still not available, but should provide valuable data to inform local strategic planning and is keenly awaited by local partners.

"The survey was powerful - it was a shocker! But it needs to be out there - what we learnt and what we did needs sharing." Clinical Lead, SPFT

The survey was adapted from a similar one developed for the Cumbria Early Intervention Project and could be repeated in the next two local areas. Consideration is needed as to who will lead and time/resource required to carry out this important element of the project.

## Outcomes from the PBS workshops

“It would be good to see feedback on behaviour workshops, we heard they went well, but what do we know about outcomes?” Clinical Lead, SPFT

A ‘before and after’ approach was developed to assess outcomes from the PBS workshops, based on evaluation forms already used by the CBF, with minor changes to align them with the outcomes agreed in West Sussex. Family-carers completed a short survey prior to the training and then were asked to answer identical questions a month later, so that comparisons could be made to assess impact.

Both surveys were online. The first was completed at the start of the workshop by 18 participants (out of a total of 29 people across the three workshops). Disappointingly, no responses were received to the second questionnaire, sent out by email approximately one month after the training.

Experience suggests that follow-up feedback tends to have a lower response rate than immediate feedback, and in this case, the request (and follow-up email) was made to families in January/February 2021, which to many felt like the ‘low point’ of the pandemic.

Discussions have been held with the PBS workshop lead at CBF to explore how more responses to the follow-up survey might be achieved in future. For example, at the CB-NSG workshop in May 2021, a family-carer (in the pilot area, Cumbria) who was passionate about the ‘utterly transformational’ value of the PBS training she had attended, said that she would welcome a follow-up session to reflect on progress and challenges. Such a session could help to embed positive outcomes for families and provide an opportunity to collect feedback.

A solution needs to be found to enable CBF and local partners to evaluate the effectiveness of virtual PBS chats, as compared to in-person training. This delivery method has already demonstrated its value in reaching more families in a cost effective way, but does it achieve equally positive outcomes?

## Building the evidence base nationally

The focus of this evaluation is on process learning i.e. understanding what works to inform the next stages of the Getting It Right project, as well as assessing outcomes in terms of impact on families and local area change.

Although there has been some delay in pulling together learning from family-carers in West Sussex, gathered through the focus groups and the survey, there should be a rich evidence base to support local area change.

The same range of evidence, capturing the voice and experiences of families caring for a child or young person with severe learning disabilities and behaviour described



as challenging, will be gathered in each of the three local area projects. Similar research was also conducted in Cumbria.<sup>11</sup>

Given the CBF's role as a national campaigning charity, there would be merit in building up a cumulative picture of family-carers' experiences across each of these four areas (and possibly others in future) so that it can be used to influence improvements in commissioning, policy and practice more widely. For example, are the issues and challenges experienced by families the same or different? What can we learn about what 'good looks like' from each of these local areas, in terms of co-production, early intervention, supporting family-carers, access to specialist behavioural support and so on?

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<sup>11</sup> <https://www.challengingbehaviour.org.uk/what-we-do/projects-and-research/early-years-and-early-intervention/cumbria-early-intervention-pilot/>

## Section 3: Learning around each element of the programme

This section summarises learning around each element of the programme, to inform its roll-out in other areas, considering:

- What changed? (from the approach initially proposed)
- What worked?
- What could be improved on?

### 3.1 Family focus groups

#### *What changed?*

The family-carer focus groups were not explicitly mentioned in the National Lottery Community Fund bid, but one focus group was proposed in the West Sussex project plan agreed with local partners. At the suggestion of local leads, two focus groups were organised, to make it easier for families to attend across this wide area. West Sussex met the additional costs, also providing venues and refreshments.

#### *What worked?*

- The focus groups were a valuable addition to the plan, ensuring family-carers views and experiences were heard from the early stages of the project. In all, 18 family-carers participated.
- The West Sussex Project Lead phoned all families who registered to explain the event and to help them to feel at ease in the workshop. She also attended the workshops and with the CBF project leads co-facilitating, was able to have quiet chats to explore individual concerns.
- Advice and support from the family-carer lead helped to engage target families and made them feel more confident to share their experiences in the focus group.
- Careful facilitation of the second focus group helped to ensure a more balanced discussion, with some less confident families speaking up more.
- Feedback on the second workshop was very positive. Extracts are shown below.

All 7 family-carers who completed feedback forms said they found it 'very enjoyable'. They enjoyed:

'Being listened to'  
'Learning about the CBF, PBS, strategies, structured conversations'  
'PBS strategies, vision, info'  
'Sharing experience with other carers. Well organised approach, collecting inputs in particular.'  
'Finding out about positive behaviour support'  
'Open and honest group discussions, lunch and refreshments'  
'Chat with other parents'

This overlaps a lot with what they found useful:

- ‘Learning. Listening to others’
- ‘PBS strategies’, ‘PBS’
- ‘Techniques for identifying reasons for behaviour’
- ‘Ideas/ groups from others’
- ‘Different types of strategies and gaps that need filling.’

#### *What could be improved on?*

- Feedback on the first workshop was mixed, but only 2 forms were collected. Response rates were improved by completing the evaluation forms just before the end of the next workshop.
- This group was dominated by one or two vocal individuals who were most concerned about services for children and young people with autism; another family with learning disabilities did not feel able to be heard, as reflected in the feedback:

“It was difficult at times for everyone’s voice to be heard. Some parent carers are very overbearing with their own journey which meant other parents could not voice their opinions and thoughts despite trying and at times even when they did put their hands up and started to share they were overtaken by the stronger voiced parents.”

This was taken into account in planning the next workshop; all 7 people providing feedback on that reported it was ‘very easy’ (4) or ‘easy’ (3) to share their thoughts and ideas.

## **3.2 Family-carer survey**

#### *What changed?*

In the West Sussex delivery plan, a survey to gather views from families and professionals was planned for launch at the Stakeholder Event in April 2020. This was not explicit in the initial plan (National Lottery Community Fund proposal), although a ‘baseline questionnaire’ of stakeholders was envisaged. The involvement (on a voluntary basis) of a Masters student in social research who also works for CBF enabled the survey to take place.

#### *What worked?*

- The family survey developed in the CBF Early Intervention Project in Cumbria was shortened and tailored to reflect West Sussex context; Steering Group members, especially the Family-Carer Lead, provided valuable advice.
- Proactive support was provided by Steering Group members, using their contacts and networks to reach families in target groups.
- Responses were received from 98 families in spite of the pressures of the pandemic, which is impressive, especially as it was a long survey. The

emerging messages provided a valuable basis for discussion at the Stakeholder Group in December 2020.

- As well as providing rich evidence on families' experiences of local services and pressures during the pandemic, the survey provided a vehicle for engaging with isolated families during lockdown and sign-posting them to advice and support.

#### *What could be improved on?*

- There were delays in sending out and writing up the survey, which was generously carried out on a voluntary basis, fitted in alongside work, study and other commitments during the pandemic.
- At the time of writing (June 2021) the detailed findings are keenly awaited by West Sussex project leads, who want to disseminate the learning with their action plan.
- Will other areas have the capacity to replicate this approach?

### **3.3 Behaviour chats**

#### *What changed?*

Three Positive Behaviour Support (PBS) workshops were planned for May-June 2020, for around 30 family-carers and the professionals who support their relatives in West Sussex. These were put on hold in the early months of the pandemic, then adapted to be delivered virtually to a total of 29 family-carers, in three workshops in the Autumn. The online training covered the same core content but was packaged as shorter, more informal 'Behaviour Chats', better suited to virtual delivery. Another important difference was that the training was delivered only to family-carers, not the professionals who support their relative.

#### *What worked?*

- Strong co-production between behaviour specialists in child and adult services, West Sussex County Council, Sussex Partnership NHS Foundation Trust and the CBF to tailor the workshop materials.
- Families recruited via Steering Group members' contacts and networks; professionals who were involved felt they had reached the right groups (consistent with information provided in the pre-training questionnaires – see Annex C)
- Facilitation by local professionals from the services families are familiar with, co-delivered with CBF-trained family-carers.
- The CBF PBS lead co-hosted the event and helped to ensure it ran smoothly e.g. managing transitions to chat rooms.
- At the suggestion of the West Sussex PBS lead, families were grouped by age of their child, to ensure some commonality of experience.
- Very positive feedback by all involved, especially as regards how well everyone worked together and how smoothly the workshops went: *"You would not have known we had not met each other before!"* (CBF PBS lead)

### *Not yet known*

- Online delivery may have succeeded in reaching families who would find it difficult to attend; worthy of further research.

### *What could be improved on?*

- The smallest workshop had 7 participants; discussion was reported to have flowed better with the larger groups (10-12 participants).
- Two of the experienced PBS trainers regretted that the virtual format does not lend itself to picking up on individual concerns or allow for a quiet chat in the margins of the meeting. They opened a 'chatroom' for parents to drop into, but it was not used.
- We lack robust evidence on outcomes, although informal feedback was very positive. Although 18 pre-training questionnaires were completed, no responses were received to the post-training online survey, sent out around one month later. This represents an important gap in the evidence base for this project, as discussed in section 2.3. Outcomes were expected to be more modest than in the full PBS training model,<sup>12</sup> reflecting the shorter online format.

## 3.4 Stakeholder Event

### *What changed?*

Two stakeholder events were envisaged: first, in the early months of the project to explore gaps in services and develop a vision; second, towards the end, to share learning and develop an action/delivery plan. The pandemic meant that only the second event took place, virtually (via Zoom) in December 2020.

### *What worked?*

- Opening presentations by CBF CEO Vivien Cooper and West Sussex Family-Carer Lead Grainne Saunders were very well received and helped to ensure clear focus in the discussion groups on improving outcomes for families. 9 participants completed feedback forms, of whom 6-7 rated these presentations as 'very useful' with the remainder finding them 'useful'.

“Vivien (Cooper)'s presentation was really powerful for families, being able to share that made families feel more comfortable coming forward about the problems they have.” School partner

- Initial findings from the family-carer survey had a clear impact on the group discussions.
- The discussion groups were all rated as 'very useful' or 'useful', with the most positive rating for the group on Valuing Families as Partners, facilitated by the Family-Carer Lead.

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<sup>12</sup> Previously evaluated, see Gore N. (July 2012) *Challenging Behaviour Training for Family Carers and Teaching-Staff: A Second Evaluation*, Tizard Centre University of Kent and the Challenging Behaviour Foundation

- Overall, the event was rated very positively, at between 8-10 (on a scale of 1-10, where 10 is excellent) by all those providing feedback.
- The delayed timing, towards the end of the project in West Sussex, allowed learning to be brought together and provided a valuable basis for action planning.
- The format and online delivery, including use of breakout rooms for discussion groups, worked well with only one participant reporting that they experienced technical difficulties. Example comments from the feedback forms:

Well organised and good pace.

A great virtual meeting. It was good to have breaks throughout.

The format was perfect. Really good to see what the agenda was to be at the beginning of the meeting and also the ability to pop off to do a job or two when I needed to and come back to the meeting.

#### *What could be improved upon?*

- The number of people attending (around 30, with some dipping out of the meeting at times) was lower than anticipated, although the event was widely publicised through local networks (professional and family-carer). Virtual delivery could have enabled many more participants; however it is possible that by December 2020 many families and professionals were suffering from 'pandemic fatigue'<sup>13</sup> and/or 'Zoom fatigue'. Suggestions for improvement from the feedback provided:
  - A wider range of professionals from across W. Sussex (beyond the Steering Group) should have been involved.
  - More families should have been involved; if the Stakeholder Event had been soon after the focus groups, as anticipated, this might have helped.
  - Some suggested that discussion groups should have been more balanced in terms of parent-carer and professional participation.

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<sup>13</sup> Informal terms used to describe the fact that many people grew increasingly weary of covid-19 restrictions and the additional pressures (caring and work related) arising from the pandemic; as well as the widespread use of videoconferencing using Zoom and similar packages.

## Section 4: Outcomes and sustainability

### Outcomes

At the time of writing (June 2021), it is too early to assess outcomes in an authoritative way. This section therefore reports on outcomes achieved to date and considers how all the partners involved in this project can build on the progress already made, to realise sustainable improvements for families caring for a child or young person with severe learning disabilities and behaviour described as challenging.

The evaluation framework sought to collect a range of evidence on outcomes, including feedback on each event, 'before and after' questionnaires to assess outcomes for families who attended the Behaviour Chats and semi-structured interviews with local partners after the last Steering Group. In the absence of robust outcomes data on the Behaviour chats (as discussed in Section 2.3), this section draws extensively on interviews with local partners, as well as evidence (such as Steering Group minutes) of actions already in progress or planned. The West Sussex Project Lead, Marie Willan, has kindly ensured that this information is up to date, at the time of writing (June 2021).

### Impact on families

Improving outcomes for families caring for a child or young person with severe learning disabilities and behaviour described as challenging was central to the logic model agreed by the Steering Group.

#### **Outcomes in the West Sussex Local Area Strategic Change logic model**

Key outcome: Families are more resilient.

- Families have the knowledge and confidence to use PBS techniques to understand reasons for challenging behaviour and to respond appropriately.
- Families who have been on PBS workshops find a reduction in the prevalence/ severity of challenging behaviour and positive changes to the whole family dynamic.
- Families feel well informed about useful services and support in West Sussex.
- Families are routinely involved as valued co-producers in developing and improving services and support.
- Families feel less isolated and better connected to local support networks.
- Professionals learn from families (through this project and beyond) and use learning to strengthen support and services they are offering.

(Full logic model shown in Annex A.)

Local stakeholders were very positive about the benefits for families engaged by the project – through the parent-carer forums, the Behaviour Chats and the Stakeholder Event – and feedback on these events (cited in section 3) was mostly very positive.

“It certainly benefited families that came to the workshops, who engaged in the behaviour support workshops, they were phenomenal. But these families don't have the capacity to share in the same way others might.” Family-Carer Lead

“We had really positive feedback from those families who engaged, I think they all took something away. The forums were helpful, the training was really powerful and hearing from Viv (Vivien Cooper, CBF) - that was really powerful. It helped point some families in the right direction, towards services they weren't aware of.” West Sussex Project Lead

As noted in section 1 (local success factors), West Sussex already had a good relationship with their parent-carer forum and local leads felt that this project strengthened this, in particular in respect of the target group of families.

“From the local point of view, it tells families we are listening, it supports our relationship with families.” West Sussex Project Lead

Another positive outcome for families, highlighted by the Family-Carer Lead, was improved awareness and understanding of challenging behaviours associated with learning disabilities:

“The project being here has removed a bit of the taboo around challenging behaviour - you know it's not your fault.” Family-Carer Lead

Further awareness-raising and information-sharing activities have been planned with the West Sussex Parent-Carer Forum (with information posted on FaceBook<sup>14</sup> and a 'Talking Heads' event scheduled), as well as follow-up activities such as PBS workshops to be delivered by local partners.

The Family-Carer Lead felt it was empowering for local families to be aware of the CBF as a national voice, advocating on their behalf and as a source of information and advice. In future, a CBF-trained Family Local Champion will be 'nested' within the West Sussex PCF, which should help to sustain the visibility of these families and facilitate the sharing of CBF information and resources with local families.

“There's more awareness of CBF, their phenomenal resources and confidence in speaking to families and advocating for families. Families are reassured that CBF are real campaigners and advocates for change...I think that will be a lasting legacy.”

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<sup>14</sup> <https://www.facebook.com/WestSussexParentCarerForum/>



## Impact on Local Services

### Local Offer

One action flowing from the Stakeholder Event and agreed at the last Steering Group, was to review the information published in the SEND Local Offer on challenging behaviour and specialist support services available locally. Local authorities are required to publish a Local Offer, to provide a clear overview of the range of support available for children, young people with SEND and their families.<sup>15</sup> This should help to improve the information available to parents and make it easier for them to navigate local services (and could build on the mapping of relevant services undertaken at the start of this project).

“I think the Local Offer will be improved and strengthened. (So) people will be more proactive, asking for help on this - they will now know that services exist.”

Family-Carer Lead

### Commissioning

The Project Lead in West Sussex is responsible for PBS commissioning by the County Council; PBS is also commissioned by Sussex Partnership NHS Foundation Trust. She is now working on plans to extend PBS training, including for schools, the (social care) Children with Disabilities Team and direct training for parents. The Parent-Carer lead felt that it was particularly important that schools and social workers should be involved, as the key services that families are in regular contact with.

At the final Steering Group, the possibility of recruiting another behaviour specialist was discussed, to supplement capacity in the Intensive Planning Team and it is hoped to have someone in post by the Autumn; as well as building back up the multi-disciplinary ‘Positive Behaviour Support’ peer network (with parent-carer involvement) across West Sussex.

The experience of delivering the Behaviour Chats online could also enable them to reach more parents and practitioners more cost effectively, perhaps supplemented with occasional in-person training:

“Now we've done it (online training and events) and see that it can work. You miss out on those soft conversations, which are crucial - but you can do the training in shorter blasts, families don't have to travel, it's accessible to those with more caring responsibilities.” West Sussex Project Lead

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<sup>15</sup> This was a key element of the SEND reforms under the 2014 Children and Families Act (section 30).

The project also highlighted a gap in provision for young people with autism (without learning disabilities) and associated mental health needs, there is ongoing dialogue between partners about how this can be addressed.

The Clinical Lead from Sussex Partnership NHS Foundation Trust hoped that the project would influence future commissioning in a transformational way:

“I’m hoping it will influence commissioning, support things that were already in motion, being talked about... I hope we have the evidence base to support transformational commissioning for this group.” Clinical Lead, SPFT

## Sustainability

As noted in section 2.1, the pandemic contributed to delays in the project, with the result that there was little time left for co-producing an action plan, beyond the Stakeholder Event in December (where actions were proposed in the workshops) and the final Steering Group meeting, where people reflected on progress and discussed some of these actions.

There have also been long delays in sharing the detailed write-up of the survey of family-carers, generously carried out by a volunteer who has had many demands on her time.

To underpin future progress, the West Sussex Project Lead has committed to producing:

- an action plan setting out actions in the short, medium and long term; and
- a summary of learning from the project, which will draw extensively the survey findings. There is some urgency to this now, to sustain momentum beyond the official end of the project.

“We need a really well planned presentation in West Sussex to share this work, a really good integrated summary of what came out of this project ... We need to commit to clear, smart targets, things we can achieve and continuing the dialogue with families. We need a list of actions, outcomes and responsibility.” Clinical Lead, SPFT

Although the Steering Group will no longer meet, the (pre-existing but reinvigorated) West Sussex Behaviour Support network of professionals, with parent-carer representation, is expected to be the key forum for reviewing progress and planning next steps. A dedicated regular slot on the agenda and occasional input from the CBF project leads could help ensure the continued visibility of the project in West Sussex and provide some accountability to help sustain progress.

“There needs to be some reaching out between us to make sure it doesn't fall by the wayside.” Clinical Lead, SPFT

Local leads were positive about the potential and sustainability of the local strategic change process, but acknowledged that there remain some important gaps in services. Asked in the concluding interviews, if it would be sustainable, they answered:

"It absolutely will, because the right people know about it and are positive about it... the want is there." West Sussex Project Lead

"The commitment is there in West Sussex, but we need to consider the commissioning gaps shown by this project." Clinical Lead, SPFT

While the project lead strongly emphasised the importance of clarity of vision, shared values and partnership working, all of which have been strengthened by this project, the Family-Carer Lead highlighted the need for sustained investment to address gaps in provision:

"You need some proper investment in the area by the local authority or NHS/mental health providers. We need investment and specialist skills and knowledge. There's still not enough support and information for families around behaviour - parents need a lot of support, challenges change and evolve as children grow. We need a really specialist offer of support. There are no quick fixes."

Once the action plan and summary of learning from family-carers are ready, there also needs to be a programme of engagement with key decision-makers including the new head of SEND commissioning, service leads and elected members. CBF colleagues may be able to support this process, for example, with a letter from their CEO, Vivien Cooper and perhaps a presentation to local leaders.

Importantly, findings and planned actions need to be shared with local families whose views and experiences brought so much to the project, in the spirit of the principles of "Ask, Listen, Do."<sup>16</sup>

"Cabinet members, elected people, the Director of Children's Services - they need to notice this project, those people should have been engaged more and listening to how difficult it is for families - I'm not sure they have any idea!"  
Family-Carer Lead

Going forward, local partners were clear that continued contact with CBF, as well as with other areas taking forward a similar change agenda, would be valuable in helping to support progress.

"Having an open door, keeping in touch with CBF, being able to work collaboratively, to be partners going forward, will all help to sustain progress.

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<sup>16</sup> <https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/>

That contact (with CBF), that peer relationship (with other GIR areas) would be really powerful.” West Sussex Project Lead

There was clearly much appetite for sharing learning between the three areas involved to date (West Sussex, the Black Country, and the predecessor Early Intervention Project in Cumbria) at the workshop held at the Challenging Behaviour National Strategy Group (CB-NSG) on 26 May 2021. Those attending have since been connected by email. A dedicated section of the CBF website<sup>17</sup> will be used to share learning from the project with wider audiences. Consideration should be given as to what more is need to enable a ‘Community of Practice’ to develop around this ambitious project, to facilitate peer support and learning between the local areas directly involved and more widely.

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<sup>17</sup> <https://www.challengingbehaviour.org.uk/what-we-do/projects-and-research/support-and-services/getting-it-right/>

## Conclusions and recommendations

Overall, the experience in West Sussex, as the first of three GIR local strategic projects, has been very positive, in spite of the challenges of the Covid-19 pandemic. The project partners worked together effectively to deliver nearly all elements of the plan, learning at every stage and adapting continuously to the restrictions and extraordinary pressures of the pandemic. Strong partnership working was reinforced by the shared values, aims and commitment of all those involved in reaching out to the target group of families (with severe learning disabilities and challenging behaviour) and learning directly from them.

Delays and additional demands on people's time caused by the pandemic meant that there was limited time and capacity to support the concluding stage of the project, co-producing an action plan and a report to inform commissioning. At the time of writing, the detailed analysis from the survey of parent-carers is still outstanding.

Although CBF colleagues are now actively engaged in supporting the second GIR area, the Black Country, they should make themselves available to advise the West Sussex lead (in so far as wanted) in shaping the local action plan, disseminating learning from the project and influencing local decision makers.

Keeping in touch regularly over the coming months and years and facilitating the development of a peer support network and community of practice could do much to sustain momentum and support positive change for families, in West Sussex, the other GIR areas as well as more widely.

“It takes ages for things to change. I hope they'll keep in touch, keep the lines open.”

Family-Carer Lead

### Summary of key issues for consideration and recommendations from the evaluation

Section	Issues and recommendations	For consideration/ action by:
2.1	<p><b>Project duration &amp; sustainability</b></p> <p>Is one year long enough for a local area strategic change project of this ambition? Need to ensure sufficient time for set-up and concluding phases.</p> <p>On-going contact with the CBF project leads would be valuable in helping to sustain progress in West Sussex.</p>	<p>CBF project leads CBF finance/fund-raising</p> <p>CBF project leads</p>

Section	Issues and recommendations	For consideration/ action by:
	A peer support network/community of practice between all the local areas involved in the EI and GIR project would help to sustain progress, facilitating sharing, learning and peer support. What more is needed beyond GIR website and connecting people by email?	CBF project leads
2.2	<p><b>Maintaining a focus on the target group, while being supportive of other families</b></p> <p>Actively seek to engage families caring for a child or young person with severe learning disabilities at every stage of the project, through steering group contacts and key local services e.g. special schools, residential care, social workers (children’s disability team) and the parent-carer forum.</p>	Local project leads
2.3	<p><b>Gathering and sharing evidence</b></p> <p>How can the survey be resourced in the next 2 areas?</p> <p>How to improve the response rate to PBS Chat follow-up outcomes questionnaire? A follow-up chat might be beneficial to participants and allow for a quick questionnaire to be completed.</p> <p>Build up a cumulative picture of family-carers’ experiences and ‘what good looks like’ across each of these four areas to influence improvements in commissioning, policy and practice more widely.</p>	<p>CBF project leads Local project leads</p> <p>As above + evaluator</p> <p>CBF project leads</p>

## Annexes

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C	Analysis of pre-training questionnaires completed by family-carers attending ‘Behaviour Chats’ in October/November 2020	31

## Annex A: Logic model - Getting It Right in West Sussex 2019-2020

**CONTEXT:** In West Sussex, existing services need to be strengthened and the offer to families broadened. The CBF have experience and knowledge of supporting local authorities and CCGs and linking health with social care, education and employment. The delivery phase coincided with the coronavirus epidemic and ‘lockdown’, so some planned events had to be delivered online.

**AIMS AND OBJECTIVES:** Children and young people (0-25) with learning disabilities at risk of behaviours that challenge will receive the right support, in the right place and at the right time, from well informed professionals and staff so they can live a happier and more inclusive life in their community. (In this logic model ‘Families’ refers to families of children and young people with learning disabilities whose behaviour challenges.)

### INPUTS

#### *Specific project inputs*

National Lottery Community Funding  
GIR project time from staff at CBF and West Sussex

- Children and Young People’s Policy lead at the CBF
- Policy Officer at the CBF
- West Sussex project lead (PBS commissioning lead) and steering group

Independent evaluation

Financial input from W Sussex- travel and refreshments.

#### *Existing service provision in West Sussex*

Children’s Disability social work team/ Life Long Service; Early Help teams are SEND champions

PBS lead commissioner supporting Special Schools

Health challenging behaviour input through CYPRESS (under 18s). CLDT health and social care offer and access to Enhanced Support Service to cover 18-25s.

Quarterly behaviour support network meetings for providers and families

Special Schools have Team Around the School approach.

### PROCESSES

GIR steering group meetings

#### *To inform delivery plan:*

2 x family carer focus group (North and South)  
Stakeholder (professionals and family carers) event in West Sussex

Online survey of family carers and professionals about the service provision in W Sussex  
CBF write up findings in report and co-produce delivery plan for W Sussex.

#### *To develop families’ and professionals’ skills and confidence in PBS:*

1x 3 positive behaviour support workshops.

### OUTPUTS

Meaningful plans for sustainable improvements in support in West Sussex

Provision of specialist training and sharing of best practice with families, professionals, and commissioners in West Sussex.

New self-sustaining networks established to support families, informed by focus groups/survey.

Families have a space (in focus groups in the first instance and then virtually) to share their experiences/ feel listened to by services and each other.

Presentation on project findings by West Sussex colleagues at Challenging Behaviour -National Strategy Group Meeting.

### OUTCOMES

**KEY OUTCOME:** Families are more **resilient**.

Families have the knowledge and confidence to use PBS techniques to understand reasons for challenging behaviour and to respond appropriately.

Families who have been on PBS workshops find a reduction in the prevalence/ severity of challenging behaviour and positive changes to the whole family dynamic.

Families feel well informed about useful services and support in West Sussex.

Families are routinely involved as valued co-producers in developing and improving services and support.

Families feel less isolated and better connected to local support networks.

Professionals learn from families (through this project and beyond) and use learning to strengthen support and services they are offering.

## Annex B: Steering group - Getting It Right in West Sussex Project (at August 2020)

Name	Job Title	Organisation
Alison Nuttall	Head of Commissioning, All Age Services	West Sussex CC
Caroline Lees	Service manager for child disability teams	West Sussex CC
Catherine Scott	Deputy Director Quality for TCP & Safeguarding	Sussex CCGs
Debbie Buckwell	SEND Strategic Commissioning Lead	West Sussex CC
Ellie Rimmer	TCP Programme Support Officer	Sussex CCGs
Grainne Saunders	Family carer volunteer, West Sussex Parent Carer Forum	West Sussex Parent Carer Forum
Jacqui Shurlock	Children's Policy Lead	The CBF
Karin Fuchs	Consultant Clinical Psychologist	Sussex Partnership NHS Foundation Trust
Lianne Finch	Residential Manager	West Sussex CC
Lindsey Butterfield	Intensive Planning Team Co-ordinator	West Sussex CC
Marie Willan (West Sussex Project Lead)	Positive Behaviour Support Commissioning Lead	West Sussex CC
Mary Spence (CBF Project Manager)	Policy Officer	The CBF
Phillip Potter & deputy, Carrie-Anne Sillence	Special School Headteacher	Oak Grove College, West Sussex
Simon Rowe	Principal Clinical Psychologist	Sussex Partnership NHS Foundation Trust
Viki Baker	Clinical Director for Learning Disability and Neurodevelopmental services	Sussex Partnership NHS Foundation Trust
Viv Cooper	Chief Executive	The CBF



## **Annex C: Analysis of pre-training questionnaires completed by family-carers attending West Sussex 'Behaviour Chats' in October/November 2020**

Survey question, designed to allow 'before and after' comparisons to assess impact of the training: **Please rate the specific behaviour your relative has displayed in the past month. Please leave blank if this behaviour has not occurred in past month.**

Participants were asked to rate the types of behaviour listed below in terms of:

- Frequency (chart 1)
- Manageability (chart 2)
- Impact on family (chart 3)

**Types of challenging behaviour** (slightly abbreviated for ease of reference in the charts):

Aggression (e.g. hitting)

Self-Injury (e.g. head banging)

Destruction (e.g. throwing)

PICA behaviour (eating inedible objects)

Sexually inappropriate behaviour (such as undressing or masturbating in public areas)

Repetitive or self-stimulatory behaviour (e.g. rocking, jumping)

Ritualistic behaviour (e.g. closing/opening doors, hoarding)

Eating difficulties Eating problems which go beyond typical fussy eating (e.g. refusing to eat, will only eat foods of certain colour or type, regularly throwing food, refusing to sit to eat)

Toileting difficulties: Compliance with toilet training, fear of toileting, smearing/eating faeces

Verbal/vocal behaviours (e.g. Shouting, swearing, screaming)

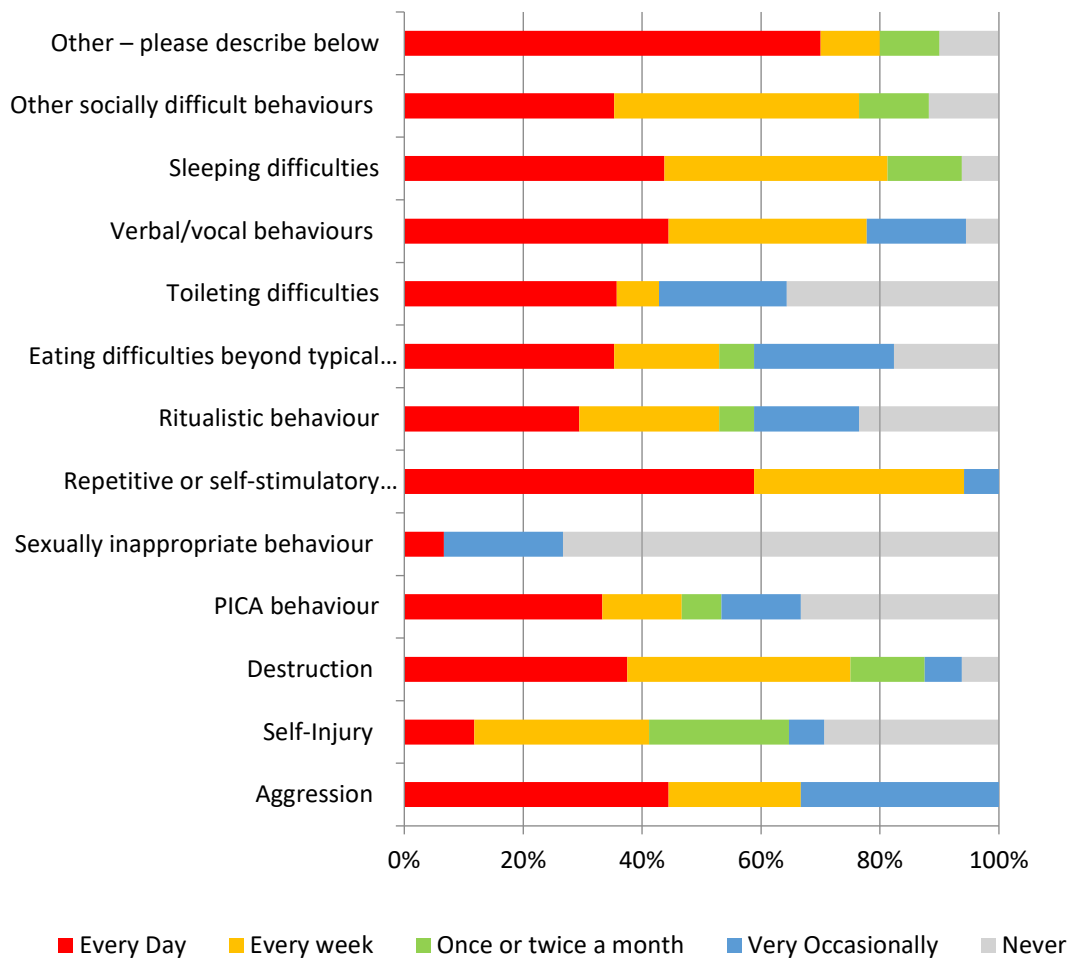
Sleeping difficulties: Struggling to rest or get to sleep (e.g. not napping during the day, not going to sleep at night, not staying in bed when put to bed, waking too early or too often)

Other socially difficult behaviours (e.g. spitting, refusing to move, stripping off, running away)

Other – please describe below

Results are shown in charts 1-3 (overleaf). Please note, the option of 'not relevant' has been omitted from the charts for ease of reference and because it was never selected.

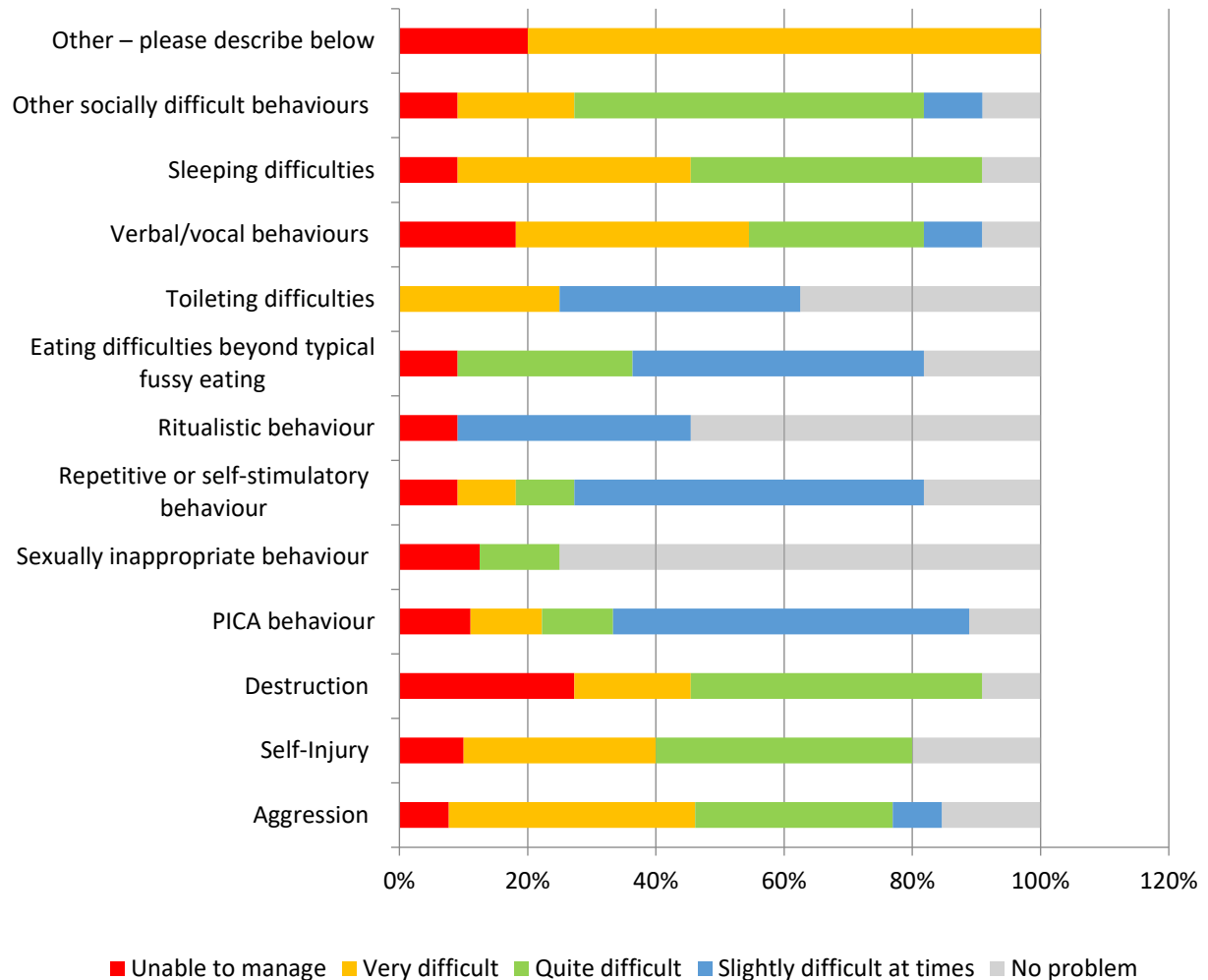
Chart 1: Frequency  
How often does your relative display this behaviour? (N=18)



**Other** (as described by family carers, N=9):

Will get out of situations by asking if I can get someone to sit with him and I go out  
 Anxiety  
 Laughing when someone gets hurt  
 OCD  
 Impulsivity, sudden aggression, risk to himself & others, property damage  
 Avoids, oppositional  
 Attachment issues, to Mum and reliance on the same teaching staff at school  
 Challenging EVERYTHING requested of him - will argue the sky is blue when in fact it might be raining.  
 Manipulative crying

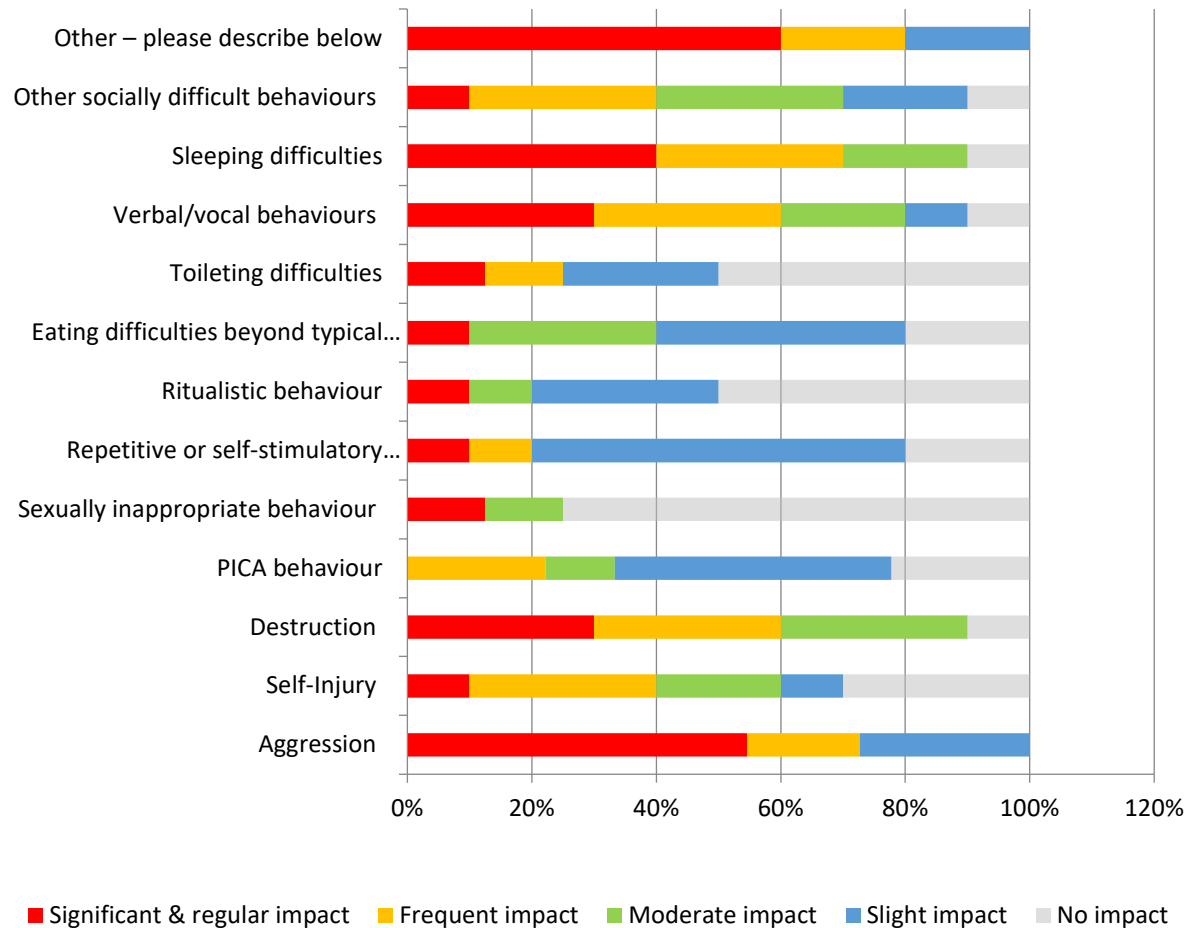
Chart 2: Manageability  
How difficult do you find this behaviour? (N=18)



**Other** (as described by family carers, N=9):

Will get out of situations by asking if I can get someone to sit with him and I go out  
 Anxiety  
 Laughing when someone gets hurt  
 OCD  
 Impulsivity, sudden aggression, risk to himself & others, property damage  
 Avoids, oppositional  
 Attachment issues, to Mum and reliance on the same teaching staff at school  
 Challenging EVERYTHING requested of him - will argue the sky is blue when in fact it might be raining.  
 Manipulative crying

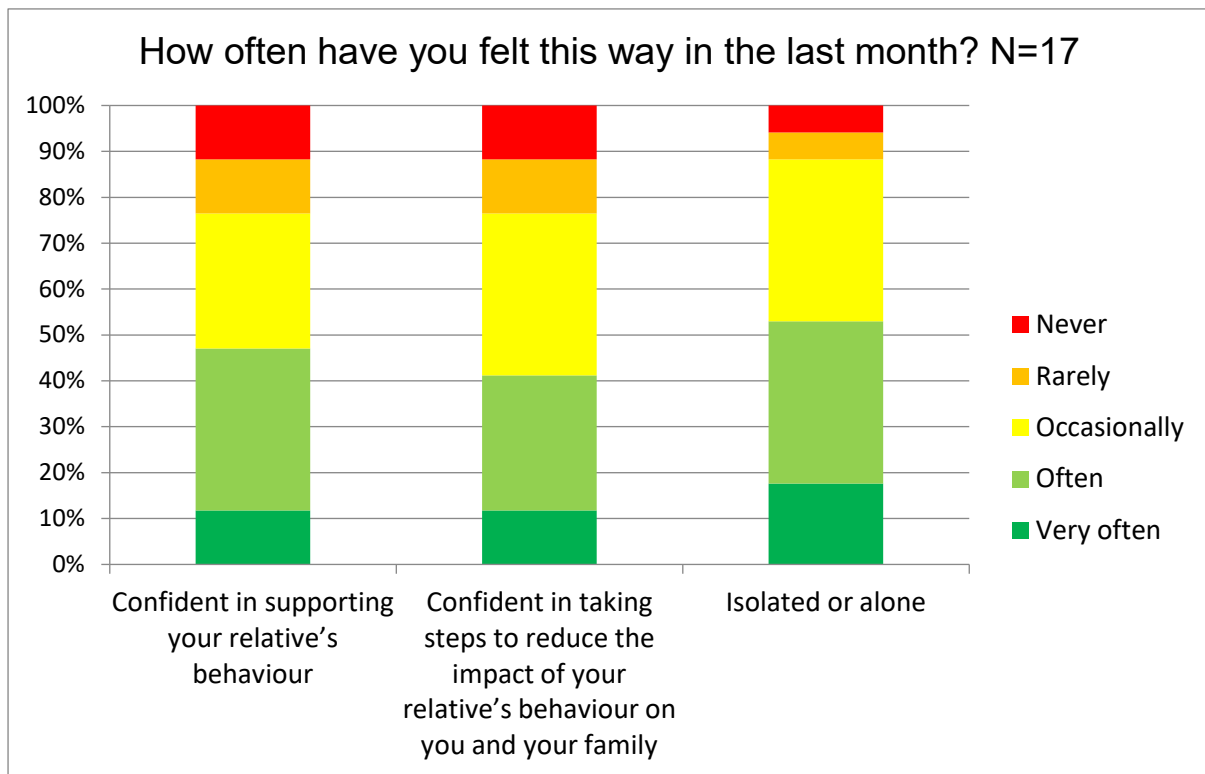
Chart 3: Impact  
What is the impact on you and your family? (N=18)



**Other** (as described by family carers, N=9):

Will get out of situations by asking if I can get someone to sit with him and I go out  
Anxiety  
Laughing when someone gets hurt  
OCD  
Impulsivity, sudden aggression, risk to himself & others, property damage  
Avoids, oppositional  
Attachment issues, to Mum and reliance on the same teaching staff at school  
Challenging EVERYTHING requested of him - will argue the sky is blue when in fact it might be raining.  
Manipulative crying

**Q3. Please rate how often you have felt the following in the past month:**



**Q4. How easy do you feel it is getting support for your relative?**

