



The Cumbria Early Intervention Project

Independent
Evaluation

Berni Graham
May 2020

Contents

Executive summary.....	5
1. Introduction and background	9
2. The Evaluation	12
3. Overview of the Cumbria Early Intervention Project (CEIP).....	14
4. The CEIP constituent programmes	16
A. Early Positive Approaches to Support (E-PATs)	18
Feedback provided by participants	20
Key enablers identified	24
Key challenges identified	24
Recommendations emerging.....	25
B. Positive Behaviour Support workshops for families and schools	26
PBS training for CEIP	28
Key enablers identified	31
Key challenges identified	32
Feedback from and reported outcomes for participants and children	35
Recommendations emerging.....	37
C. Resilience workshops.....	38
Background and ethos	38
Key challenges identified	41
Feedback from participants	42
Recommendations emerging.....	44
D. Cumbria strategic development work.....	45
Identifying families' needs in Cumbria.....	46
Co-producing strategic reviews and priority recommendations for Cumbria.....	49
Disseminating the key strategic messages.....	50
Key enablers found	52
Key challenges found	52
Recommendations emerging.....	52
5. Discussion and key learning points emerging.....	53
Appendices	57

Terms and abbreviations used in this report¹

Autistic Spectrum Disorder: is shortened to ‘**ASD**’ for convenience. The National Autistic Society describes Autism as ‘a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them’².

Learning disability: According to Mencap, ‘A *learning disability is a reduced intellectual ability and difficulty with everyday activities, for example household tasks, socialising or managing money, which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people.*’³ Like all conditions the term, ‘learning disability’, includes an enormous range of abilities, comes in many forms and is highly individual.

‘**Behaviour that challenges**’ is the term adopted in this report, but occasionally ‘**challenging behaviour**’ is used if it fits more easily in the sentence. Behaviour that challenges is not limited to people with learning disabilities or ASD, but might be more enduring and potentially harmful for children and young people if not addressed in the best way. Children and young people ‘*often behave in a way which challenges those caring for them (for example, screaming, crying or refusing to do as they are asked) when they are unable to explain their needs or emotions. This is usually a phase which children grow out of as they develop new skills. It is harder for children with learning disabilities to develop the communication and social skills which other children use to get them what they want and need. This may mean that their behaviours are more challenging, and they are unlikely to “grow out” of those behaviours on their own, without skilled support to get their needs met in a different way*’⁴. It is not a diagnosis, not least because it is an individual’s response to a context and is communicating a need which is not being met’⁵.

‘**Family carer**’ is used to encompass parents, grandparents, siblings and others who are closely involved in looking after a child or young person with ASD and/or learning disability.

‘**Early Intervention**’ The [Early Intervention Foundation \(EIF\)](#) describes early intervention as ‘*a means of identifying and providing effective early support to children and young people who are at risk of poor outcomes. Effective early intervention works to prevent problems occurring, or to tackle them head-on, before they get worse. Early intervention can take different forms ... Early intervention works to reduce the risk factors and increase the protective factors in a child’s life.*’⁶

Positive behavioural support (PBS) is an evidence-based approach approved by the NHS, NICE, the CQC and others. It aims to improve a person’s quality of life by helping professionals and family carers to understand the reasons and contexts which can lie behind a behaviour, and to focus on what the person is trying to communicate. The [PBS academy](#) describe PBS as a ‘*multicomponent framework for developing an understanding of behaviour that challenges. It is based on the assessment of the broad social, physical and individual context in which the behaviour occurs, and uses this information to develop a range of evidence-based support. The overall goal is to enhance the person’s quality of life, thus reducing the likelihood of challenging behaviour occurring in the first place*’⁷.

Abbreviations used.

Abbreviations are kept to a minimum, but are sometimes useful. The most common ones used are:

ASD - Autistic spectrum disorder – see brief explanation above

CBF - the [Challenging Behaviour Foundation](#)

CCG – the NHS Clinical Commissioning Group

E-PaTS - Early Positive Approaches to Support. A programme in this pilot and explained below.

PBS - Positive Behavioural Support — see explanation above

RMS - [Royal Mencap Society](#), which is the UK-wide Mencap body.

[Carlisle Mencap](#), provided nearly all the Mencap input to this pilot. Carlisle Mencap supports families and provides services across Cumbria and is semi-autonomous of RMS.

Acknowledgements

Thanks to everyone who participated in this evaluation and all the project partners. Special thanks to the family carers who contributed their time generously and enthusiastically; the steering group who conceived of and got this project off the ground; and to the CEIP coordinator, Lynne Jones, who managed to keep the pilot on track and support the steering group and the evaluation on top of the demanding regional workforce development work.

Berni Graham, independent researcher and evaluator, www.grahamresearch.co.uk

¹ Decades of research, development and expertise have gone into these issues, definitions and programmes. Excuse any shorthand only used to limit the length of the report. References provide more detailed and contextualised explanations.

² <https://www.autism.org.uk/about/what-is.aspx>, accessed 4/5/2020

³ <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>;

⁴ <https://pavingtheway.works/why-this-project-is-needed/what-is-a-learning-disability-what-is-challenging-behaviour/>

⁵ <https://www.challengingbehaviour.org.uk/understanding-behaviour/understanding-behaviour.html>

And from NICE- <https://www.nice.org.uk/guidance/ng11/resources/challenging-behaviour-and-learning-disabilities-prevention-and-interventions-for-people-with-learning-disabilities-whose-behaviour-challenges-1837266392005>

⁶ www.eif.org.uk February 2020

⁷ <http://pbsacademy.org.uk/>

Executive summary

This is an independent evaluation of the Cumbria Early Intervention Project (CEIP), which aimed to support children with learning disabilities and / or autistic spectrum disorder (ASD) who display behaviour that challenges and also support the carers and professionals who look after them.

CEIP was spear-headed, developed and delivered by a diverse group of statutory, academic and voluntary agencies, and a group of family carers. Agencies included different branches of the NHS, the Challenging Behaviour Foundation, Carlisle Mencap, the Royal Mencap society (RMS), Northumbria University and the Tizard Centre at Kent University. Each party brought extensive specialist expertise to the table as well as enthusiasm to see early intervention rooted in practice. Many of the project partners had previously developed programmes which they felt could be highly preventative if applied early enough in a child's life or before behavioural patterns took root.

At the time the Transforming Care agenda was being introduced in Cumbria, although mainly focussed on adults, not children. This group saw an opportunity to build on and develop their discrete programmes as a joint early intervention approach and test their combined effectiveness for children with ASD and / or learning disabilities whose behaviours challenge.

The pilot ran over 2018-19 and set out to identify key learning points around processes and potential effectiveness in Cumbria, and assess any benefits of providing a group of linked programmes for the same families. The pilot comprised four main strands:

- **Early Positive Approaches to Support (E-PATs)** was aimed at families with children aged 0 to 5. E-PATs workshops were delivered in 6 locations across Cumbria by local facilitators from Carlisle Mencap, the Community Learning Disability nursing team and four family carers, all trained by the Tizard Centre. In total 31 family carers attended. Each course comprised eight, two and half hour sessions.
- **Positive Behaviour Support (PBS)** workshops targeted family carers and professionals with a focus on school-aged children. These workshops were also jointly delivered by family carers and professionals. In this pilot, two sets of PBS workshops were delivered to 46 family carers and professionals. Each attended two full-days training to develop their understanding and practice around PBS. The first day was solely for family carers or professionals alone, and on the second day they came together to develop a joint plan for individual children.
- **Resilience workshops** aimed to support the family carers and targeted those who had already attended E-PATs or PBS workshops. Four family carers participated in five, half-day, workshops. Sessions were designed to be relaxed and discursive. They focused on the family carer's mental and physical well-being through the use of mindfulness and reflective practice.
- **Co-produced strategy development.** In the fourth strand, family carers reviewed data from a Cumbria-wide survey, official policies and reports, to develop priority recommendations to improve early intervention and support services for children with learning disabilities and ASD whose behaviours challenge and their families. Two family carers undertook disseminating the key messages, including speaking at meeting and producing videos.

Co-production by family carers

Valuing the input of family carers was a key ethos of CEIP and reflected in every intervention. EPAtS, PBS and Resilience had each been developed in close collaboration with family carers and followed a model of cascading knowledge and skills. Cumbrian family carers and professionals were trained in how to co-facilitate courses for this programme and in the future. This promoted a wider dissemination and implementation of these approaches, while also ensuring that the perspectives of family carers were included in each programme and session.

Family carers were similarly closely involved in all stages of the strategy work. The two focus groups were planned and developed by a family carer and a CBF professional; and a group of family carers analysed the current situation in Cumbria for children with learning disabilities and/or ASD and their families, and recommended improvements. Two family carers were recruited to disseminate the key strategic messages from families to policy leads in the county. A small amount of funding was made available for some of the family carers' training and strategic work. Family carers appreciated this and felt it reflected a degree of respect for their expertise as well as their time, input and commitment to improving Cumbria services.

Overall enablers

- The pilot brought a focus on early intervention to existing policies, such as the Transforming Care agenda. CEIP complemented other initiatives and service gaps, in an innovative way.
- The CEIP stakeholders shared a wealth of specialist knowledge and reputations in this field. Each provided different realms of expertise, spheres of influence, authority and networks.
- E-PAtS, PBS and the Resilience workshops came with an evidence base and developed programmes. PBS also had some official endorsement (e.g. from the NHS, NICE and the DfE).
- The steering group and the family carer co-producers brought immense enthusiasm and good will, which helped kick-start the project and maintain momentum. Substantial amounts of input and time were provided without payment.
- Many partners already had good working relationships with each other.
- The model of training local professionals and family carers to deliver each of these programmes enhances the potential for their long-term delivery and to be embedded into local services. There is now a small pool of trained family carers and professionals to draw on.
- The Community Learning Disability nursing team deserve particular credit for their considerable support to the development and roll-out of the project. Staff were trained to facilitate the EPAtS and resilience programmes, creating a substantial body of expertise in the team. Moreover, these programmes were incorporated into the team's suite of parenting programmes, enhancing the range of services on offer to families.
- This team and Carlisle Mencap proved essential in promoting the programmes, and establishing trust with and boosting the recruitment of families.
- Indeed, the Community Learning Disability nursing team and Carlisle Mencap continued to deliver additional E-PAtS after the official pilot finished and both organisations have shown clear drive and commitment to make these programmes part of local services going forward.
- The experience of the Challenging Behaviour Foundation (CBF) and the efforts of a small number of local parents proved essential in recruiting other parents to the co-production work, connecting with more isolated families and reaching beyond existing parent groups.

- Family carers responded enthusiastically to invitations to co-produce and to be trained as joint programme facilitators.
- Costs were kept to the bare minimum. Most partners contributed their expertise, the programmes and time for free and some partners helped fund the pilot, or supported projects to access funding, not least Cumbria and North Cumbria CCG and Public Health England and Health Education England.
- There was no attendance fee for families participating in any of the three programmes.

Key Challenges

- During the pilot, the NHS Clinical Commissioning Groups and NHS trusts were reorganised, and split into North and South Cumbria. This directly affected the Community Learning Disability nursing team (which was split) and the commissioning of services, and created questions over who would financially support the involvement of family carers to co-deliver courses and other co-production initiatives and take the work forward.
- Key agencies were missing from the table, not least education and children's social care.
- Delivery of the PBS and resilience workshops were substantially delayed for different reasons.
- Recruiting schools proved much more complicated and slower than anticipated. This was found to be attributable to misunderstandings around 'PBS'; possible misconceptions that PBS was already being followed; difficulties matching schools' timeframes and workflows, and inadequate project time capacity to engage with schools and secure commitment.
- Attendance at the resilience workshops was lower than desired, which limits the learning that can be derived from this part of the pilot.
- Cumbria's geography, localism, public transport, road network and associated travelling time and costs created challenges for programme delivery and recruitment. These generated many additional considerations around the optimum location of services and ensuring accessibility.
- Reaching families in different parts of the county and gaining their interest and trust was found to require substantial time and input.
- CEIP lacked sufficient administrative, coordinator and development time to follow up on leads, recruit more agencies (e.g. education and children's services) to the steering group, or develop a communication strategy.

Key learning points

The immediate outcomes and positive feedback from family carer and professionals indicates the potential of these programmes, individually and combined, to meet local needs.

A clear outcome of the pilot was the growth of mutual acknowledgement and respect between professionals and family carers. The findings show that family carers did not want '*yet another parenting programme*' or to be talked down to, or to be treated as deficient in their parenting skills. The pilot demonstrated that family carers have lots to contribute in terms of developing policy and strategy, as well as the willingness and skills to run workshops and share best practice approaches with other families and professionals. More than anything, they want to be respected as partners in the care of their child.

At the same time, it cannot be presumed that family carers can afford to provide lots of time for free. As well as reimbursement for loss of earnings, travel, childcare and other essential associated costs, family carers' need to be paid for their input.

On-going recruitment is essential to ensure that co-production with family carers and groups of family carers remain fresh, representative and to avoid placing too much onus on a few individuals.

The CBF survey data along with the strategy work point to many gaps in health, early years, education and other services for children with learning disabilities and/or ASD in Cumbria, all compounded by poor diagnostic pathways and coordination. Too many families had been unable to access a diagnosis, or occupational therapy, or an education, health and care plan, or see a paediatrician.

There is a lack of reliable data on the numbers of children and young people in Cumbria who have learning disabilities and/or ASD, let alone those in that group who have behaviours which challenge.

The EPAtS and PBS programmes and CEIP as a whole were based on Positive Behaviour Support. The participating family carers and professionals found these workshops invigorating, pertinent and helpful. Unfortunately, many interpretations of 'PBS' were said to exist. Some bore little resemblance to the PBS approach advocated by the CEIP. The findings show that what CBF, Tizard and other relevant agencies mean by 'PBS' needs to be communicated more effectively and widely to achieve a common understanding.

A programme like this, especially in an area where partners, relevant agencies and families are geographically dispersed and meeting in person is so difficult, would benefit from developing a communication strategy from the outset and improving this iteratively.

Fortunately, in this pilot most of the partners already knew each other and brought considerable experience, influence and their own networks. At the same time, while using existing contacts proved valuable, this approach also brought inherent limitations. Some key players remained missing from the table, not least education and children's social care, and although family carers were given a strategic role, there were no families carers in the steering group, despite this being proposed at the start.

Coordinating a diverse programme like this requires a paid coordinator and administrator to address multiple challenges in a timely way, develop works pathways, strategies and systems, and engage all the relevant potential partners. Two part-time posts would probably be adequate, as long as periodic peaks and troughs can be accommodated.

The access barriers posed by Cumbria's geography and infrastructure, on top of family carers' caring responsibilities and schedules, indicated that programmes need to be brought to families in order to ensure accessibility and acknowledge. As was learnt in this pilot, this may mean running more numerous, if smaller, sessions around the county.

1. Introduction and background

This Chapter provides a brief contextual background for the Cumbria Early Intervention Pilot project (CEIP). It includes an overview of issues and services for children with learning disabilities and/or ASD and their family carers, which the pilot aimed to address. Estimates on the numbers of children and young people in the county are provided. However accurate data is difficult to obtain and thus any figures are considered to be underestimates. The Ofsted and the CQC report in March 2019 found many shortcomings in the county's policies and services for children and young people with special educational needs and disabilities, which the NHS, education authority and the county council have pledged to address. The chapter also sets out the evaluation aims and methods.

Over recent years the provision of care for people with a learning disability and/or autistic spectrum disorder (ASD) has received increased attention, unfortunately mainly because of scandals and professional malpractice, exposed in cases such as Winterbourne View⁸ and Whorlton Hall, Durham⁹. These brought a long overdue focus on services for this group of disabled people. They also boosted the efforts of charities and professionals who had been pressing for improved care and resources for decades; not least the provision of adequate family and community based services to avoid using institutional care, which was far from home and often with multiple restrictions.

Many problems are noted to be commonly experienced by children and young people with learning disabilities and/or ASD whose behaviour challenges, including misdiagnosis, social exclusion, institutionalisation, physical harm, deprivation, abuse, ineffective interventions and generally poor outcomes¹⁰. Unless directly addressed, issues can continue into adulthood and are often associated with mental health problems in childhood and adulthood¹¹. Moreover, primary care givers, typically mothers, are more likely than other parents to experience mental health difficulties on account of their caring role.

Children with learning disabilities and/or ASD are known to be more vulnerable to developing behaviours that challenge than their peers. Hastings et al. (2013)¹² found that behaviour is best understood in relation to context and that contextual aspects can also maintain and perpetrate any behaviours which challenge.

'First, challenging behaviours are defined in terms of their social effects. Second, vulnerability factors for challenging behaviour include some biological factors, but mainly psycho-social risks relating to the life situation and inequalities experienced by people with developmental disabilities. Third, social contextual processes are primarily responsible for maintaining challenging behaviours.'

At the same time, behaviours that challenge have been shown to be amenable to intervention, reducing or preventing the potential negative outcomes listed above. Ideally intervention needs to be

⁸ <https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf>

⁹ <https://www.communitycare.co.uk/2019/05/23/reaction-panorama-programme-abuse-learning-disability-hospital/>

¹⁰ CBF (2014) Early Intervention for Children with Learning Disabilities whose behaviours challenge

¹¹ Bowring et al (2019), Prevalence of Challenging Behaviour in Adults with Intellectual Disabilities, Correlates, and Association with Mental Health

¹² (PDF) A conceptual framework for understanding why challenging behaviours occur in people with developmental disabilities. P1. <https://www.researchgate.net/publication/263527512s> [accessed Apr 06 2020].

pursued early enough once behaviour manifests. Unfortunately, early intervention has not been funded adequately over the years in the UK nor pursued wholeheartedly and instead funding has been perversely weighted towards responding to crises, or providing institutional care when care in the community breaks down¹³. Early intervention has the potential to reduce the need for more costly, late interventions.

While the Department of Health and Social Care currently advocates early intervention, progress has been quite slow, piecemeal and far from standardised across the country. Over 2015-16 the Department funded CBF and the Council for Disabled Children (CDC) to examine the evidence around early intervention for children and young people who have learning disabilities and/or ASD and behaviours which challenge. Their review found that early intervention brought many benefits for parents and children, and overall concluded that positive behavioural support (PBS) represented ‘*the most effective evidence-based approach to supporting people*’ with learning disabilities and behaviours that challenge but also noted that the use of PBS in England ‘*was limited*’¹⁴. In her 2017 review, Lenehan¹⁵ identified several distinct official agendas pertaining to people with learning disabilities, not least Transforming Care¹⁶; Integrated Personalised Commissioning and Budgets; and the Children and Young People’s Mental Health Transformation Programme. Her review found that no single department or agency held overall responsibility for the wellbeing of people with learning disabilities or ASD, and concluded that this lack of coordination had contributed to recent failings and serious incidents. She advocated a model of care that included wrap-around support and universal adoption of PBS, and providing PBS in a consistent way. Hastings et al. (2013) summarise the definition of PBS as a ‘broad approach’ which needs to be grounded in its underlying theoretical conceptual framework. In other words, if attempts are made to implement it without that conceptual framework, it may not actually be PBS.

Cumbria Ofsted and CQC inspection 2019

In March 2019 Ofsted and the Care Quality Commission (CQC) found Cumbria’s Special Education Needs and Disability (SEND) policies, services and practice severely wanting on many fronts¹⁷. Although they noted some promising exceptions, they criticised poor, multi-agency working, limited ambition, inadequate consultation with family carers, inadequate information on the Local Offer and marked inconsistencies and variations across services and locations. They highlighted particular problems experienced by children with ASD in accessing support, leading to avoidable crises.

‘Overall, there is a lack of joint working between health, care and education. Leaders across the partnership have not collaborated to plan, commission and deliver services for children and young people with SEND. Although there are promising examples that indicate a potential sea-change in this area, the joint commissioning of services remains rare. Many parents and carers have lost faith and trust in the local area. Although they are understanding of the local area’s situation and financial limitations, they feel as though they must battle to gain access to the services that their children require.’

¹³ Gore, N. et al (2014) Early intervention for children with learning disabilities: making use of what we know.

¹⁴ <https://www.ncb.org.uk/sites/default/files/field/attachment/early%20intervention%20meet%20the%20needs%20of%20learning%20disabled%20children.pdf>

¹⁵ Lenehan, C. (2017) *These are our Children*. London: Department of Health and Council for Disabled Children

¹⁶ <https://www.england.nhs.uk/learning-disabilities/care/>

¹⁷ <https://files.ofsted.gov.uk/v1/file/50079132>, ‘p2-3

The county council, NHS and the Cumbria Parent Carer Forum responded with a joint Written Statement of Action¹⁸. This accepted the findings of the inspection and set out remedial steps, including establishing six thematic groups and involving family carers in each. Children and young people with learning disabilities get a brief mention and are promised increased GP health checks. Those with ASD were included in the group to get improved social, emotional and mental health support. However, there was no direct mention of extra support for children whose behaviour challenges.

Estimated numbers of Children with a Learning disability and/or ASD in Cumbria

It is difficult to provide accurate data on the number of people in England or the UK who have learning disabilities and/or ASD, let alone the sub-groups of those whose behaviour is challenging. For example, official estimates range from 180,000, or approximately 2.5%, of school-age children in England to have a 'moderate', 'severe' or 'profound' learning disability¹⁹; and 286,000 children and young people under 18, or roughly 2-3% of the general population²⁰. Available official statistics are often based on the identification of learning disability by state schools, and are thus considered underestimations for several reasons. For instance they rely on identification by professionals using formal assessments; the educational sector criteria often omit children who have no diagnosis (yet); and they exclude children not in mainstream schools, such as children under five, those attending special schools or residential special schools outside the county, children educated at home (more common among children with ASD), and those excluded from school because of behaviours that challenge. The RMS estimates that in the UK there are 351,000 children aged 0 to 17 with learning disabilities, out of a total of 1.5 million adults and children with learning disabilities²¹. Quoting 2007 NHS data, the National Autistic Society estimates there to be 700,000 children and adults with ASD in the UK, or more than 1 in every 100 people²². Meanwhile, NHS England quotes research which estimated that the number of children under 18 in England who display behaviour which challenges to be 40,000 in 2014²³

In Cumbria precise figures on the number of children with learning disabilities or ASD are equally difficult to ascertain, and any figures available are considered underestimates. The Cumbria County Council's Joint Needs Assessment on Learning Disability and ASD for 2017, estimated that 4,176 Cumbrian pupils aged 3 to 18, attending mainstream nurseries or schools, had a learning disability; that 1060 children aged 0 to 18 had ASD; and that 1,675 people with learning disabilities and/or ASD of all ages are in contact with Cumbria's Learning Disability and Autism services²⁴. As well as diagnoses and behaviour that challenges, other data is needed to inform policies and practice, such as who gets what educational provision, the numbers living at home or in other accommodation, housing and care needs. The Dynamic Risk or 'Support' registers may help provide useful data on high level needs in the county, such as the numbers of people with learning disabilities and/ or ASD who are at high risk of

¹⁸https://content.govdelivery.com/attachments/UKCCC/2019/08/22/file_attachments/1270814/Cumbria%20SEND%20WSO%20for%20submission%2021.8.19.pdf

¹⁹https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf

²⁰ <https://www.england.nhs.uk/wp-content/uploads/2017/02/model-service-spec-2017.pdf>

²¹ <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability>

²² <https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx>

²³ <https://www.england.nhs.uk/wp-content/uploads/2017/02/model-service-spec-2017.pdf>

²⁴ <https://www.cumbria.gov.uk/eLibrary/Content/Internet/536/671/4674/17217/17220/4311291159.pdf>

being admitted into hospital or long term residential arrangement²⁵. In Spring 2020, the Dynamic Risk Registers for North and South Cumbria had five and ten children and young people respectively, considered to be at that level of risk.

Services of children with Learning Disability and/or ASD in Cumbria

Cumbria hosts a wide range services for children with learning disabilities and ASD. In parallel with this pilot Cumbria was developing services under the Transforming Care agenda, although this mainly involved training staff in adult services. In addition to the adult work, Cumbria²⁶ and the North East NHS was selected for NHS Accelerator work^{27,28} to improve understanding of ASD in the region. This aimed to support families, by focusing on schools and family carer co-production. While this overlapped a bit with CEIP themes, it was only developed in the North East, and so did not directly affect the CEIP.

2. The Evaluation

As this was an innovative set of programmes and collaboration, the CEIP commissioned an independent evaluation to help identify key learning points, outcomes and the potential for this model to be developed or rolled out more widely. As constituent initiatives, e.g. E-PaT and PBS, had an evidence base and/or had been evaluated elsewhere, this evaluation focused mainly on their application in this context, and what if any added value was derived from the multi-agency approach and what learning emerged from the joint planning, delivery and Cumbrian context.

Key evaluation questions

- How effective are the processes and systems involve?
- To what extent have other priority aims and objectives been achieved? For example, how has the programme impacted on local commissioners and other key agencies and on workforce skills, understanding, knowledge and practice?
- How have family carers been involved? To what extent has the input from family carers' influenced service design, planning, and delivery?
- What are family carers' views on their participation and what do they make to ensure their involvement is maximised and meaningful?
- What are the benefits of having an overarching coordinated partnership approach and what indications emerge around the model's scope to provide an effective early intervention approach?
- What are the key enablers and challenges and what learning emerges to enhance programme development and implementation, and scale it up across Cumbria or elsewhere?

²⁵ <https://www.england.nhs.uk/wp-content/uploads/2017/02/model-service-spec-2017.pdf>, p13

²⁶ And later the North Cumbria CCG

²⁷ [https://www.contact.org.uk/news-and-blogs/accelerator-programme-evaluation-report-published-\(1\)/](https://www.contact.org.uk/news-and-blogs/accelerator-programme-evaluation-report-published-(1)/)

²⁸ <https://northcumbriaccg.nhs.uk/your-health/learning-disability-and-autism>
<https://www.challengingbehaviour.org.uk/learning-disability-assets/evidenceseminartransformingcareforchildrenjuly18.pdf>

Evaluation approach and methodology

In keeping with the dynamic nature of the pilot, the evaluation had to be highly iterative and respond to developments in how the project was delivered. The first years' evaluation was formative and focused on processes in order to provide helpful insights and support the Steering Group and further programme development. A presentation based on the findings was presented to the CEIP Steering Group in December 2018 and used as a basis to discuss medium-term plans and overall strategy.

This final evaluation retains a focus on processes as these provide valuable learning both for partner agencies and other organisations, aiming to replicate or build on this model. It also explores all the available data around outcomes for families, participating agencies and others, as well as overarching themes emerging from this multi-stranded and multi-agency pilot.

Evaluation methods

The evaluation used a mixed methodology to suit contexts and capture a range of perspectives. The CEIP partner agencies monitored and evaluated their own programmes to different extents. The data provided from these and documentary analysis have been incorporated into this final evaluation report and supplemented by primary data collection, including one to one and group interviews and focus groups. Combining primary and secondary qualitative, quantitative and monitoring data enabled data triangulation, with the aim of maximising its reliability. Table 1 below sets out the methods and number of evaluation participants per year and method. All qualitative interviews and focus groups were analysed using the Framework approach²⁹, which enables a systematic qualitative analysis by theme, sub-theme and by case.

Table 1: Evaluation methods and numbers

Method	Numbers Year 1	Numbers Year 2
Primary data collected		
• Qualitative telephone interviews with CEIP key stakeholders	10	3
• Qualitative interviews with family carers	2	0
• Focus group with family carers who had attended programmes	n/a	3
• Interviews with Parent Facilitators	1	2
• Focus group with project partners in Steering Group	10	7
• Qualitative telephone interviews with school leaders	0	1
Analysis of data collected by CEIP partners		
• Monitoring data from each programme	varied	varied
• E-PaTS feedback data year 1 and validated measures	10	12
• Feedback from participants from PBS workshops	n/a	36
• Resilience workshops pre and post measures completed by participants	4	4
• Direct Feedback from participants at Resilience workshops	4	4
• CBF scoping survey across Cumbria	38	n/a
• Feedback from and interviews with family carers about strategic co-production	25	2

²⁹ Ritchie, J and Spencer, L, (1994), Qualitative Data Analysis for Applied Policy Research, in Analysing Qualitative Data, edited by Alan Bryman and Robert G. Burgess pp. 173 – 194, Taylor and Francis Books Ltd.

3. Overview of the Cumbria Early Intervention Project (CEIP)

This chapter explains the CEIP aims, delivery model and collaboration among partners who formed the steering group. It then provides a summary overview, followed by a more detailed explanation, of each of the four constituent programmes (E-PATs, PBS, Resilience and the strategic work) and the extensive family carer involvement. Each subsection contains a description of each programme, who attended, feedback provided, key enablers and challenges identified, any outcomes reported to date and recommendations made per programme.

Aims and vision

The CEIP grew out of conversations among learning disability experts, mainly working in Cumbria and the North East, and was quickly developed into a pilot programme. From the start it aimed to provide an innovative suite of programmes, drawing on the key partners' expertise, to promote early intervention in the context of behaviours that challenge and fill a gap in provision. CEIP built on the Challenging Behaviour Foundation's (CBF) mantra: to provide the right support in the right place at the right time. Hence in this pilot, 'early' meant both early in age, as well as early in terms of when the behaviour starts to emerge. The aim was to prevent challenging behaviour becoming an embedded default for an individual, their family, or institutions such as schools, and in turn avert issues that might otherwise ensue.

'Without intervention, behaviours that challenge often continue into adulthood, presenting further difficulties for individuals, families and services. Often there is a crisis management approach which is costly for the individual, their family and local areas, and yet delivers poor outcomes'³⁰

Effectively the CEIP served as a small pilot adjunct to the region's extensive Transforming Care training programme, in recognition of the need to focus on early stages and ages, as the former was primarily directed at the care of adults with learning disabilities. This evaluation developed the logic model in Figure 1, based on underpinning tenets listed below, which were provided by the project partners.

Fig 1: CEIP Logic model around communication and behaviour



³⁰ 'The Proposal for an STP based Learning Disability and/or autism early intervention and prevention proposal' from project partners, Autumn 2017

- Behaviour that challenges occurs in a context and is often a response to that context.
- Behaviour is primarily a form of communication, possibly deriving from the person's desire to control what is going on in their lives;
- It is typically an expression of a need, or a response to an unmet need³¹;
- Such a behavioural response is amenable to intervention;
- If people with learning disabilities, their family carers and professionals learn effective ways to communicate, the person with a learning disability does not have to resort to other behaviour to be 'heard'.

The CEIP multi-agency planning and delivery model

CEIP was coordinated by a multi-agency Steering Group of professionals, from the NHS, charities and academia, working in the learning disability field and supported by the NHS North Cumbria Clinical Commissioning Group (CCG).

A launch event for the pilot in January 2018 attracted 47 professionals from a range of sectors and four family carers. As well as the eventual steering group members, attendees included many NHS professionals, Cumbria's children's, education, early years services and Special Educational Needs Coordinators (SENCOs), residential care and school settings, the Local Government Association and charities such as Barnardo's, Mencap and the Challenging Behaviour Foundation. The largely professional participants identified a substantial list of difficulties and gaps in Cumbria's services for children with learning disabilities and/or ASD. These related to Educational Health and Care Planning; various aspects of education, including the shortage of specialist nursery provision; coordination across health, local authority and other professionals; getting a diagnosis or specialist support, mental health support for children and young people, or respite care breaks; poor information sharing and coordination across health professionals; and few opportunities for families to provide mutual support. Moreover, the lack of data to help understand the number of relevant children in Cumbria and their needs was felt to undermine service planning.

A Steering Group for CEIP was formed in early 2018, bringing together lead personnel from³²:

- NHS partners from Cumbria and the North East, including the Cumbria CCG³³, the Cumbria Children's Community Learning Disability nursing team³⁴ Northumberland Tyne and Wear NHS Foundation Trust³⁵ and the Transforming Care Partnership;
- The Challenging Behaviour Foundation;
- Carlisle Mencap; and
- Learning disability experts from Northumbria University and the Tizard Centre, Kent University.

The Challenging Behaviour Foundation was set up by a family carer to ensure other families get the information, support and training they need, including around Positive Behavioural support and to ensure that the perspectives of people with severe learning disabilities and their families are heard by

³¹ <https://www.challengingbehaviour.org.uk/understanding-behaviour/communication-sheet.html>

³² See appendix for full list of CEIP Strategy group members

³³ Over the course of the pilot the Cumbria CCG was restructured, and names changed.

³⁴ Short title used in rest of this report Children's Community Learning Disability nursing team

³⁵ Who moved to Northumbria university during the lifetime of this pilot

decision makers. They and Carlisle Mencap brought substantial experience of engaging with families and delivering responsive services in the community for people with learning disabilities and ASD and their family carers. At the time of set up, the Tizard Centre was already planning a random controlled trial (RCT) to test the effectiveness of their E-PaTS programme. The Cumbria project provided a further two sites for this RCT. At the same time, Northumbria University were testing resilience workshops for family carers of adults who had learning disabilities. This was adapted to test its usefulness for family carers of children with learning disabilities.

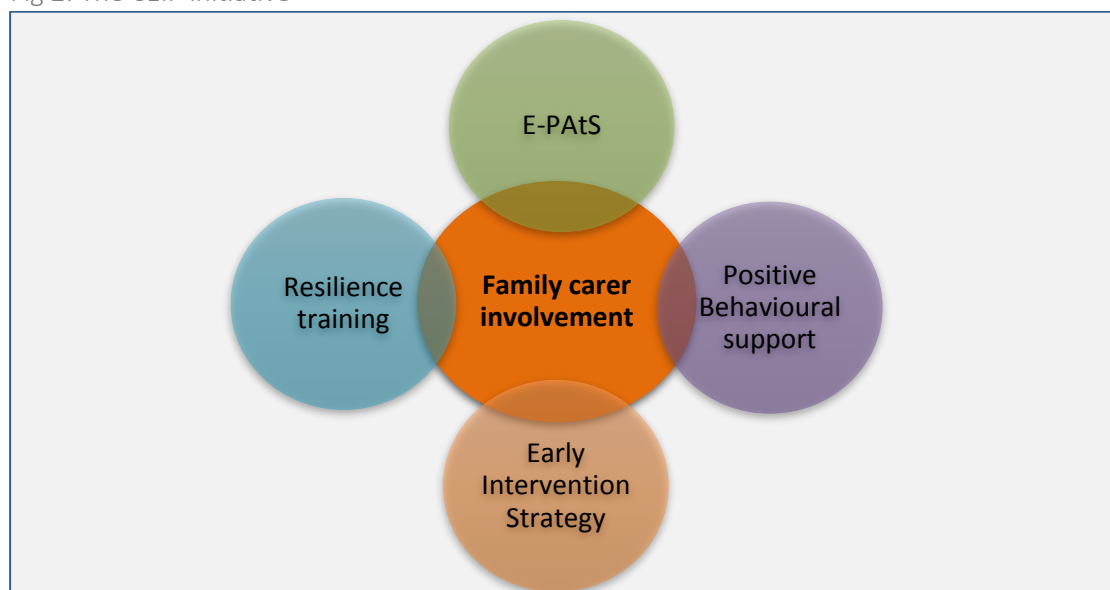
The Steering Group met approximately every six weeks, normally remotely using tele-conferencing. The work of this disparate group was coordinated by the Strategic Workforce Development Manager. She was based in the North East and Cumbria Transforming Care Partnership, which formed part of the North East and North Cumbria Transforming Care initiative funded by the CCGs, which aimed to increase staff skills, knowledge and competency in relation to PBS in the region. However, this transforming care training and development work focused on adult services. CEIP had no administration support which meant that each agency was responsible for their own, but the Coordinator arranged and noted meetings and executed various action points between meetings.

This evaluation did not undertake an analysis of costs or value for money. However, it was noted that the costs of venues and childcare for participants' children, which were originally omitted, were essential for projects like this.

4. The CEIP constituent programmes

Overall, the CEIP piloted five initiatives. Three early intervention programmes were delivered directly to family carers. These aimed to improve the wellbeing and quality of life of the respective children as well as those of their primary family carers, and in turn benefit the whole family. The family carer involvement and strategic work were aimed at improving longer-term service development in the county. Figure 2 below represents CEIP and its constituent programmes diagrammatically.

Fig 2: The CEIP initiative



Three of the five programmes consisted of a series of workshops:

- A. Early Positive Approaches to Support (E-PaTS), for children aged 5 and under;
- B. Positive Behaviour Support (PBS) for school-age children; and
- C. Resilience training – for family carers with children of any age.

In addition:

- D. Co-production. A local needs analysis was undertaken, which fed into a co-produced early intervention strategy and recommendations for Cumbria, in respect of children with learning disabilities and/or ASD. In addition, each individual programme, and the pilot as a whole, placed a strong emphasis on family-carer involvement.

As can be seen in Table 2, each intervention had its own target group and underpinning research, which informed its design, development and delivery. By trialling the programme in the Cumbrian context with families with young children, CEIP enabled the partner agencies to identify any adjustments required. It was hoped that families might gain additional value from programmes being linked and mutually promoted, for example by attending two or three programmes consecutively.

Table 2: Summary of each CEIP programme

Name	Short name	Brief description	Developed by	Delivered to	In CEIP delivered by
Early Positive Approaches to Support	E-PaTS	8 weekly, 2.5, hour sessions, providing information, skills & techniques	Tizard Centre, University of Kent	Family carers with a child aged 5 and under, who had ASD, or a Learning Disability, or no diagnosis.	One family-carer trainer and one professional
Positive Behavioural Support	PBS	3, day-long, sessions, focussed on understanding a specific child's communication and	Challenging Behaviour Foundation (CBF)	Family carers and key staff at the child's school, or in a short-breaks setting.	A CBF professional and one family-carer trainer

		behaviour. Staff and families work together to develop a practical behaviour support plan			
Resilience Training	n/a	5 half-day sessions focused on family carers' own mental & physical wellbeing	Northumbria University and NTW NHS Foundation Trust	Family carers looking after a child with challenging behaviour, plus ASD, and/or a Learning Disability.	Two Professionals
Strategy development	n/a	Co-produced research and recommendations for Cumbria policy and practice on early intervention for LD and ASD	The Challenging Behaviour Foundation	Developed by family carers who later disseminated it to NHS & other agencies. Supported by CBF	CBF and family-carers

The following sections explore each of the three programmes delivered, namely: E-PaTS, PBS and Resilience and the Strategy Development, before going on to examine the model of involving family carers in CEIP. Each section describes the programme's aims, delivery methods, available data on the numbers and demographics of those attending; any feedback from participants and any outcomes reported.

A. Early Positive Approaches to Support (E-PaTS)

Programme description

E-PaTS is a course of eight, two and half hour, sessions, providing information, skills and advice to family carers, with children aged 0 to 5 who have a diagnosis of learning disability and/or ASD. However, as diagnosis can take some time for very young children, it is also available for families where there has been no diagnosis yet, as soon as significant developmental differences are noticed. E-PaTS had previously been trialled in Leeds and Belfast.

Based on a Positive Behavioural Support model and developed iteratively over the previous six years with CBF, RMS and others. The course aims to build family carers' resilience, wellbeing, knowledge and skills and in so doing help the child's quality of life, wellbeing and development and reduce the risk of behaviour that challenges.

Normally run weekly, individual sessions cover: accessing services and support; family carers' emotional well-being; supporting their child's sleep, communication and skill development; and developing positive approaches to behaviours that challenge.

Each session is participative, interactive and provides time for group discussion and for each person to share their own experiences and reflect on how the content might apply in their situation. The course emphasises that the family carer is the expert when it comes to their child. Sessions are

supported by training materials and other resources, previously co-produced by E-PATs with family carers and professionals. Normally, the family carers have an informal meeting with one of the facilitators before the course to help decide if E-PATs is right for them at that time.

The training is jointly facilitated by a professional and a family carer, each trained by the Tizard Centre. The family carer input is essential as they share their lived experiences, plus insights and tips on how the E-PATs approach applied in their own situation and other families they know.

An essential feature of E-PATs is cascading the knowledge by recruiting and training local professionals and family carers to deliver the course. In Spring 2018 the Tizard Centre provided a five-day facilitator training course to four Cumbrian family carers³⁶, six staff from the Cumbrian NHS Community Learning Disability and Behaviour Support Team and one Carlisle Mencap staff member. Tizard reported that this was the first time they had trained NHS staff, as previously all the professional facilitators had been drawn from voluntary and charitable organisations (VCS). Cumbria's Children's Learning Disability Nursing team engaged whole-heartedly with E-PATs and provided all bar one of the professional co-facilitators during the pilot, although it did not receive any additional funding for this work. The team also incorporated E-PATs into their core suite of programmes for families. However, delivery in the future will rely on securing funding for the family carer facilitation fees.

The original budget covered the costs of Tizard's train-the-trainer training of professionals and family carers, their initial supervision of the new trainers and the family carer's training fees up to September 2018. Carlisle Mencap applied to Public Health England for funding to provide the creche, venue and associated facilities which proved essential in enabling family carers to attend. These costs had not been originally budgeted for. On the basis of learning from the first two courses, additional creche time was factored in for subsequent courses to give family carers time to ensure their children were settled before the workshops started.

After the two initial courses, Carlisle Mencap successfully applied for further funding to jointly deliver two more E-PATs courses with the Community Learning Disability nursing team in Barrow and Kendal in 2019. Since the pilot ended, Carlisle Mencap secured further funding from the Morecambe Bay CCG for the delivery of five programmes in the south of the county, in partnership with the Community Learning Disability nursing team. At the time of writing these are planned to run up to June 2021.

Recruiting families to E-PATs

Publicity was undertaken in different ways, but the course took longer than anticipated to get off the ground. In the first two courses, participants were recruited by Carlisle Mencap, mainly because of the design of the E-PATs RCT. Carlisle Mencap's expertise, contacts and other infrastructure support were said to have been invaluable in securing training venues, engaging families and getting the workshops off the ground. All subsequent E-PATs courses in Cumbria were recruited by both Carlisle Mencap and the Children's Learning Disability Nursing team. Carlisle Mencap's promoted these through their service users and well-established networks and the Children's Learning Disability Nursing team then included E-PATs as part of their core service to families.

³⁶ Two more applied, but as training places were limited, only four were selected although all were eligible.

Organisers reported that attendance was only possible by locating the training in different parts of the county, given distances, travel and childcare costs and other logistical obstacles which would have otherwise prevented families from attending.

As E-PaTS is not designed to be a self-selecting programme, in practice publicity and recruitment had to combined with careful targeting and selection, along with briefing and preparing family carers. For example, even if the course suited the child and their family, the precise timing was not necessarily appropriate for their needs. The selection process required time and substantial communication in advance of the course and was found to be best done in person. Some families told the learning disability nurse that they were declining E-PaTS, as they preferred to wait for the team's NAS EarlyBird programme, which also ran in the county. This was because they had already heard about this it had a good reputation and it was recommended for pre-school children with a new diagnosis of ASD. During recruitment, family carers were asked to commit to the whole programme, as it is not designed for people dipping in and out. Families sometimes found this difficult to balance with caring responsibilities. Two families in the Barrow course who commenced E-PaTS could not continue because of various external pressures in their lives. Table 3 details the numbers attending each set of workshops. Most were mothers, but some fathers and grandparents also attended. Sometimes two family members attended in respect of one child. The majority of the participants were White.

Table 3: Cumbria E-PaTS course locations delivery and attendance

Start date of each course	Location	Delivered by	Number of family carers who started*	Number of family carers who completed*
June 2018	Ulverston	Learning Disability Team & a family carer	5	5
	Carlisle	Learning Disability Team & a family carer	6	4
September 2018	Workington	Learning Disability Team & a family carer	5	5
	Penrith	Carlisle Mencap & a family carer	5	5
May 2019	Barrow	Learning Disability Team & a family Carer	9	6
	Kendal	Learning Disability Team & a family Carer	8	6
Total			38	31

*Often more than one family carer attended in respect of a certain child

Feedback provided by participants

The first two courses in Ulverston and Carlisle formed part of the larger pilot directly delivered and evaluated by the Tizard Centre. In these two settings, validated quantitative tools (GO4KIDDS Brief

Adaptive Behaviour Scale, the Checklist of Challenging Behaviour and the Everyday Parenting Scale³⁷) were completed by nine of the 11 participating family carers before the course. Four completed these afterwards. In addition, Tizard conducted qualitative face-to-face interviews with six family carers.

The Tizard Centre reported that insufficient quantitative data was collected to be useful. Disaggregated data for Cumbria was not available. However, the Tizard Centre shared the interim findings of its qualitative interviews conducted with all the UK E-PaTS trial participants ($n=35$), before and after they attended E-PaTS, which included data from the Cumbrian participants. Although their specific data could not be extracted, the overall pattern of findings were said to be broadly similar.

These interviews found that participants' children had a range of diagnosed and undiagnosed conditions. Some had multiple diagnoses, and many had additional physical or sensory disabilities. Prior to the E-PaTS course, family carers reported feeling lonely, isolated, guilty and deficient in their parenting, hopeless, and worried about the future, but presumed that they just had to get on with it. After the workshops, these family carers reported they felt more knowledgeable, more able to identify their child's needs, say the 'unsayable' and express difficult emotions, and had a better understanding of what services were available and how to access these, such as speech and language therapy. They also reported feeling better in themselves emotionally and recognised the need to look after themselves, as well as their child.

These findings were echoed in the feedback from the subsequent courses delivered by the Children's Community Learning Disability nursing team and Carlisle Mencap. Written feedback collected from 16 of these participants was totally enthusiastic and positive. Family carers reported that the programme had met their needs, was informative and enjoyable and that they had gained a better understanding of why behaviours occurred. They praised the course content and delivery, felt they had gained new information, insights, frameworks and techniques and that it had helped them emotionally. Many expressed gratitude. In some cases, families reported a reduction in some of the challenging behaviours experienced previously and a step down in statutory support. Many had recommended the course to others.

The post training feedback forms asked these 16 participants to score how helpful they found the course, the input of the family carer trainers, the acquisition of new information and ideas, the resources shared, and if they or their child had experienced any benefits. All sixteen scored the different aspects of the course as highly as possible. Their additional written comments were extremely positive. A sample are provided here:

'I have learnt a lot and don't feel as alone dealing with things and I'm a lot more confident in dealing with behaviours now'

'Superb course. I would keep coming back until I was forcibly removed'

'I have really enjoyed the course and taken a lot from it. So many of the ideas and studying given have literally been life changing for us and we have come on so much with [child] and as a family. The [professional and family carer] trainers have been

³⁷ Dunst & Masiello, 2002

fantastic and delivered the course to a high standard. Thank you.'

I have really enjoyed the course. It has helped us in our family life. And I can support my children in their struggles and tricky times'

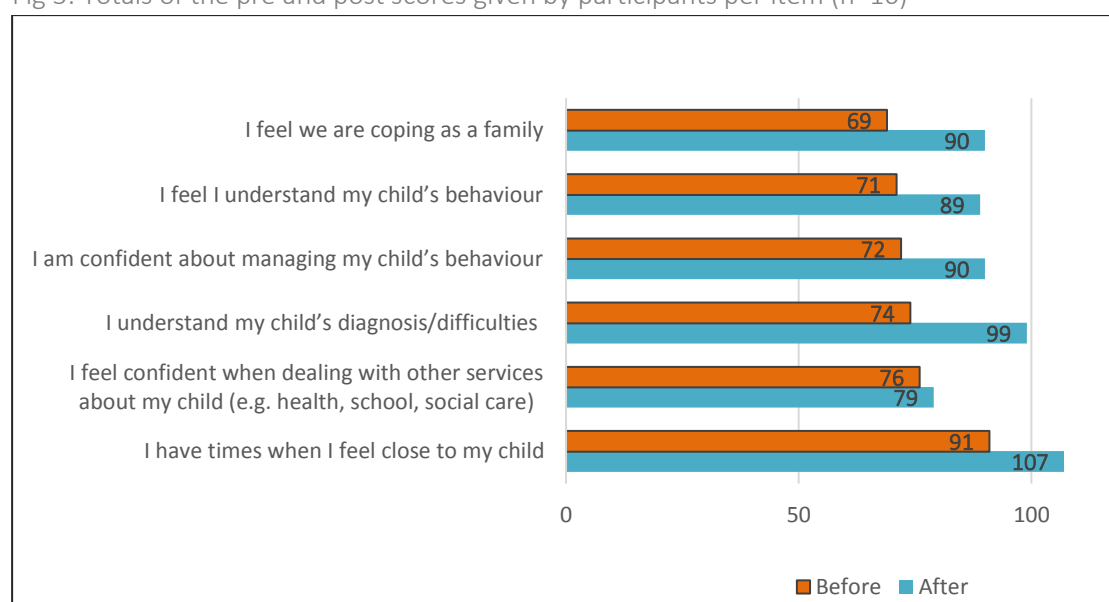
'we have prevented some behaviours with strategies from the course and I learnt how to put me first'

'... it can be emotional dealing with your child's issues, but the environment of the course was very safe'

'Having a creche facility was essential. The relaxed open atmosphere you created made it easy to share experiences and connect with other parents. It helps to be in touch with parents who know what you are going through'

In addition, the Children's Community Learning Disability nursing team asked these 16 family carers to answer a set of questions, both before and after the Barrow and Kendal workshops, to help assess what improvements if any the workshops had made to their lives. These questions were extracted from other validated tools. The questions posed aimed to explore their feelings and confidence levels on a scale of zero to 10, where zero was the lowest score and 10 the highest possible. Twelve family carers completed these. The numbers are too low to draw any statistically reliable conclusions. However, the evaluator aggregated and compared the pre and post course scores given by all 12 respondents per question, to extract any indication of trends. As can be seen in Figure 3 below, quite a positive picture emerges. Overall, family carers reported improvements in understanding and managing diagnoses, behaviour and feeling more able to cope and closer to their children. Notably, the smallest amount of change related to family carers' confidence in dealing with services.

Fig 3: Totals of the pre and post scores given by participants per item (n=16)



Professionals working with families had observed '*huge improvements for families*' and reported that the '*parents comments we have had has been phenomenal from this course*'.

In the family carers' focus group run by the evaluator, the family carers were equally enthusiastic about E-PaTS and felt they had gained lots from participating. They particularly appreciated having a space to share their experiences, felt a huge relief that these were accepted and had gained insights from other parents in similar situations. Often in nurseries and schools their child was the only child displaying certain behaviours, which aggravated their sense of being alone. Effectively they had been trying to make sense of and essentially diagnose their child's condition, before many professionals accepted there was a condition. Their sense of frustration and isolation was aggravated if their children only displayed challenging behaviour at home. Attending E-PaTS and being with others in similar situations had helped overcome a previous hopelessness, especially when professionals did not accept there was anything amiss and in effect had blamed the parents for their child's behaviour.

'[Child] masks a lot. We get very different behaviour [at home] than at school, ... So, it's been very interesting for us to speak to other people that have similar children that do similar things ... E-PaTS was what we needed ... to understand [their behaviours] ... Some of those people on E-PaTS had more experience, they had other children. That's a really good part... And you start thinking you know what, I am not imagining this.'

Family carer at focus group

'I thought autism was kids that don't talk, but [child] is really, really clever. So, to me it was "they can't be autistic, that's rubbish ... [child] just needs to sleep" ... I had the school SENCo say to me "We need to look at how you discipline [child] at home because [they're] fine here, so the relationship completely broke down with the school.... The second we left those school gates it was an absolute nightmare and I got to the point where it was 'It must be me, because the school tell me it's me'

Family carer at focus group

In all forms of feedback, participants appreciated the input from the family carer co-facilitators and felt this helped embed the key messages as well as establish trust.

'It's really good to get a parent's' perspective'

Written post course feedback from participant

'Legitimacy and authenticity, if you haven't lived it, you don't have a clue. Having someone that is in the trenches... you pay more attention to someone who has been through it'

Interview Feedback to E-PaTS research conducted by Tizard

'what you bring is that trust ... parents trust parents at the end of the day ... they know that you've lived it and you are living it. And when you are saying about sleep, and you are saying "I know what it's like", I just think parents trust you. [It] takes away that thing of parents being put on a parenting course. No one likes to be told "you are going on the parenting course" because they feel... that they need to be told by a professional what to do better ... when you meet parents who struggle to access services, you can be a useful kind of bridge to gap for families. ... they just want to talk to you a little bit more'

Family carer facilitator interviewee

A peer support group had been established by families in one area. They continued to meet up after E-PaTS finished, often in each other's homes, together with the children. The family co-facilitator reported meeting this group and was able to reinforce some of the course points, such as on sleep.

'...they were so much more confident. Was lovely to see them all supporting one another and the children interacting. They now have an online support chat group going on and plans for regular meet ups. '

Family carer co-facilitator

Attending the course had also prompted families to avail of benefits and services they were not previously aware of, or presumed they were ineligible for.

"I can honestly say the E-PATS course has been so worth it. Jigsaw pieces are slowly slotting into place"

Family carer comment on social media

Key enablers identified

- CEIP benefited from being able to apply an established model which had been iteratively developed and improved over previous years.
- All parties were really enthusiastic about E-PaTS. It was seen to fill a gap in providing an early intervention service.
- Family carers reported that they had been crying out for something like this for years, that most parenting programmes did not cater for them or their children.
- Setting the threshold for admittance to the course deliberately low, made E-PaTS very accessible. For example, no precise diagnosis is necessary.
- Funding from Public Health England, the CCG and input and support in kind from Carlisle Mencap, the Children's Learning Disability Nursing team and the CEIP Coordinator all proved invaluable.
- Quality is controlled as only those trained directly by Tizard can deliver E-PaTS.
- In time, the Tizard 'brand' combined with the E-PaTS RCT if favourable, may help publicise the course and encourage GPs and other professionals to refer families to the programme.
- Continuity was provided by the Children's Learning Disability Nursing team and Carlisle Mencap.
- Employing family carers as joint facilitators enabled them to share their practical tips and lived experiences. In Cumbria they proposed useful amendments to E-PaTS.

Key challenges identified

- Recruitment took more time than initially expected and many access barriers emerged.
- Where to site training sessions emerged as a distinct issue in Cumbria. Travelling distances, limited public transport and other infrastructure factors plus the associated costs, time and childcare combined with a growing acceptance that people preferred, or indeed might only access, services in their own locality. For example, it proved unrealistic to expect people from Barrow to travel to Kendal, let alone Penrith or Carlisle, or vice versa.
- Planning, setting up the workshops and addressing logistical issues required a period of intense communication and joint planning, which had not been originally factored in.

- Communication was also challenged by geography. Moreover, some family carers did not have mobile phones and/or could not deal with large amounts of forms and documentation.
- At the same time the training groups required high enough numbers to generate a group dynamic as well as consistent attendance.
- For some agencies and professionals this was their first time working with a different sector, e.g. the NHS, or university research project, or VCS agency. Some teething troubles emerged.
- During the pilot the Cumbria CCG and Community Learning Disability nursing team were split North and South, which affected funding and complicated delivery.
- Professionals delivering courses were said to sometimes find it difficult to hear the criticisms families gave of their services and colleagues.

Recommendations emerging

- There is an appetite for more E-PaTS courses and across different parts of the county to maximise access.
- It seems sensible and most cost-effective to employ the numerous trained staff and family carers facilitators to build on this pilot and deliver more courses.
- Training content and skills may need to be kept updated.
- Running E-PaTS course regularly and as part of the standard services on offer would enable families to access a course when challenging behaviour first emerges, changes or escalates, and to get refreshers.
- Diverse methods are required to successfully recruit family carers, including local networks and trusted social media networks. Printed and other media need to follow accessibility guidelines. Word of mouth and family-to-family recruitment was noted to work well.
- E-PaTS could be recommended in EHCPs and by health visitors and GPs.
- Person-to-person explanation is essential. Adequate time needs to be allocated to explain E-PaTS, clarify mutual expectations and ensure it is appropriate for that family at that time.
- VCS and statutory agencies work to different time scales, priorities and structures which need to be factored into multi-agency collaboration.
- In this pilot, examples were given where misconceptions that E-PaTS would be '*just another parenting course*' lecturing parents on parenting skills, had to be corrected. This distinction may be useful to promote in other areas, as it is possible that more parents, like those in Cumbria might feel '*that they didn't need to be told how to be a parent*'.

B. Positive Behaviour Support workshops for families and schools

Programme Description

'Positive Behaviour Support' (PBS) is a well-established approach, officially approved by the NHS³⁸, NICE³⁹, the CQC⁴⁰ and other bodies to improve a person's quality of life and prevent or minimise behaviours that challenge. PBS has numerous essential and interlinked components aimed to help professionals and family carers understand the reasons and contexts which lie behind behaviour that challenges. PBS sets out to prevent the need for challenging behaviour and focusses on what unmet support needs are being communicated.

PBS rejects the notion behaviour can be changed by using aversive or restrictive interventions. Instead, PBS seeks to understand behaviours that challenge. It promotes the idea that it is communicating an unmet need and it is for those supporting an individual to try to understand this message, contexts and triggers and seek alternatives ways for the person to get what they want, often by teaching new or alternative skills.

The CBF brought a well-established PBS training model to, and ran two courses for, the CEIP, attended by 40 family carers and professionals. This course had been co-produced with family carers and formally evaluated by the Tizard centre. It was jointly delivered by a family carer and a professional to family carers and professionals, centring on co-creating a behaviour support plan for the children they support. This support plan contains both proactive and reactive strategies that are consistently followed by all involved in the person's support.

Feedback was very positive. Several enablers and challenges were identified.

Background

Positive Behaviour Support (PBS) has been in development for many years, building on the work of the Tizard Centre and others (Gore, et al., 2013)⁴¹. The [PBS Academy](#) provide extensive details⁴². It is officially endorsed by the NHS, NICE, and the CQC. Nonetheless, members of the CEIP Steering Group and others told this evaluation that PBS was not well known or followed across the country and that restrictive practices were still common.

The ten essential elements of PBS are set out in Table 4 and grouped under three overarching themes: values, theory/evidence base, and process. In 2015 a group of specialist agencies developed a framework of competencies necessary to deliver PBS at different levels⁴³ *'in an effort to 'bring together the fundamental elements of PBS in a way that could usefully inform future service, policy and*

³⁸ https://www.england.nhs.uk/atlas_case_study/positive-behavioural-support-at-the-non-profit-social-enterprise-pbs4/

³⁹ <https://www.nice.org.uk/guidance/ng11>

⁴⁰ https://www.cqc.org.uk/sites/default/files/20180705_900824_briefguide-positive_behaviour_support_for_people_with_behaviours_that_challenge_v4.pdf

⁴¹ Gore, N.J., McGill, P., Toogood, S., Allen, D., Hughes, J.C., Baker, P., Hastings, R.P., Noone, S.J. & Denne, L.D. (2013). Definition and scope for positive behavioural support. *International Journal of Positive Behavioural Support*, 3 (2), 14-2

⁴² <http://pbsacademy.org.uk/>

⁴³ <https://www.skillsforcare.org.uk/Document-library/Skills/People-whose-behaviour-challenges/Positive-Behavioural-Support-Competence-Framework.pdf>

research developments in the UK' (p5). Background and guidance on PBS can be found on the CBF and PBS academy websites^{44, 45}. PBS is described as a multi-component framework, within a set of values and processes, to help understand behaviour that challenges. It is not a single therapeutic approach, treatment or philosophy as such, as it encompasses the broad social and physical context in which the behaviour occurs. It is stressed that the effective implementation of PBS necessitates the combined use of all of the ten elements.

Table 4: Key Components of PBS from PBS Competence Framework 2015

Values	1. Prevention and reduction of challenging behaviour occurs within the context of increased quality of life, inclusion, participation, and the defence and support of valued social roles
	2. Constructional approaches to intervention design build stakeholder skills and opportunities and reject aversive and restrictive practice
	3. Stakeholder participation informs, implements and validates assessment and intervention practices
Theory and evidence base	4. An understanding that challenging behaviour develops to serve important functions for people
	5. The primary use of constructional principles and procedures from behaviour analysis to assess and support behaviour change
	6. The secondary use of other complementary, evidence-based approaches to support behaviour change at multiple levels of a system
Process	7. A data-driven approach to decision making at every stage
	8. Functional assessment to inform function-based intervention
	9. Multicomponent interventions to change behaviour (proactively) and manage behaviour
	10. Implementation support, monitoring and evaluation of interventions over the long term

The overall aim of PBS is to increase quality of life. It is underpinned by a strong values base, including an acceptance that all behaviours happen for a reason and that prevention requires focusing on what support the person needs. It promotes the idea that behaviour that challenges is the communication of an unmet need. Most fundamentally, PBS rejects punishment. Instead it looks at the triggers to behaviour that challenges, seeks to understand them and the message communicated and to find alternative ways for the person to get what they want, often by teaching new or alternative skills. PBS works on an individual level, while also examining the system, contexts, processes and routines around the child and their needs and wants. It does this by co-producing a support plan that contains both proactive and reactive strategies, with the aim that these are then followed consistently by everyone involved in the child's support. The PBS workshops are aimed at families of children with a severe learning disability. According to [CBF](#) this includes children who have little or no speech; find it very difficult to learn new skills; need support with daily activities such as dressing, washing, eating and keeping safe; have difficulties with social skills; and are expected to need life-long support.

⁴⁴ <https://www.challengingbehaviour.org.uk/information/information-sheets-and-dvds/positive-behaviour-support.html>

⁴⁵ <http://pbsacademy.org.uk/>

PBS aims to help family carers and support professionals to look at the antecedents to the behaviour and explore what someone is trying to communicate through that behaviour (often because of a lack of appropriate communication skills); to avoid punishing people for their behaviour; and instead to develop interventions which enhance quality of life outcomes for the individual and their family carers.

PBS was already an approved approach for the North East and Cumbria region, which had been selected as one of NHS England's five fast-track areas, as part of Transforming Care agenda. However, this focused mainly on adults and a 2016 scoping study around regional staff needs in relation to PBS recommended a focus on family carers and children⁴⁶.

PBS training for CEIP

The information included here is based on data collected by the Challenging Behaviour Foundation (CBF), CEIP steering group minutes and from the evaluator's in-depth interviews, focus groups and other discussions with family carers and CBF staff.

The PBS training developed by CBF is based on research and best practice examples and delivered across the UK for many years⁴⁷. It aims to help families and professional participants understand challenging behaviour, its causes, triggers and link with communication and to support behavioural change. Participants are encouraged to develop effective communication strategies, positive behavioural alternatives and effective partnership working around the child.

As well as enhancing understanding, the course aims to help family carers and professionals understand their respective roles, pressures and needs in supporting more positive behaviour. As well as a framework, the workshop aims to provide encouragement and improve participants' confidence about improving matters. The input from other family carers who have faced similar challenges was reported to be particularly encouraging for the family carers attending.

The desired learning outcomes included:

- Understanding the reasons behind challenging behaviour
- Identifying strategies to prevent and reduce challenging behaviour
- Where and how to access ongoing support
- Gaining practical communication strategies
- Improving partnership working between families and professionals

Essential features to the CBF PBS model included:

- Local family carers with lived experience of challenging behaviour are trained alongside professionals to jointly deliver the course. Courses are co-facilitated by a family carer and a CBF trainer or other professional.

⁴⁶ <http://www.pbsnec.co.uk/wp-content/uploads/2017/01/PBS-report-16-Aug-final-version.pdf>

⁴⁷ <https://www.challengingbehaviour.org.uk/workshops/pbs-workshops/what-the-workshops-offer.html>

- The employment of family-carer facilitators is aimed to bring the course theory and materials to life, by sharing their own lived experiences, help establish rapport with family-carer participants and overcome potential alienation or anxieties on their part.
- As well as the general principles, the workshops seek to help the family carers and professionals explore how to apply it to the children they are looking after.
- Sessions are intended to help respective family carers or professionals identify pertinent issues, communication and behavioural patterns around an individual child.
- Family carers attend the first session; professionals the second; and in the third they work together to share insights and perspectives and jointly develop a positive behaviour support plan that everyone agreed to and could follow.
- Delivering the first day in separate groups is designed to help family carers be more open and be frank about their experiences, as well as appreciate that they are not alone and that others might be going through the same and have similar reactions.
- The joint second day is intended to inform and strengthen partnership work.
- The time lapse between the first and second workshops is intended to enable attendees a chance to reflect on and implement learning points from the first day.
- Each 'day' runs from 10 am to 2.30 to allow for using transport and school runs.

Most of the topics covered in the workshops are outlined in Table 5. On the joint training day, the family-carers and professionals are expected to collaborate to create support plans for the relevant children. The Antecedent-Behaviour-Consequence (ABC) tool is used to describe the behaviour, help build an understanding around why the behaviour is occurring and inform planning.

Table 5: Positive behavioural support training content

Understanding Challenging Behaviour includes:	Supporting Behaviour Change includes:
<ul style="list-style-type: none"> • What is challenging behaviour • The impact of challenging behaviour • Why do people challenge • Context and environment • Purposes (functions) of behaviour • Reinforcement • Setting events and triggers • Sensory issues in autism • Recording Antecedent-Behaviour-Consequence (ABC) • A story of success 	<ul style="list-style-type: none"> • Arousal curve • Positive behaviour support • Proactive and reactive strategies • How to prevent challenging behaviour • How to stop behaviour escalating • How to respond to behaviour safely • What to do after an incident • Individual planning and behaviour support plans • Working in partnership

Setting up and planning the PBS training in Cumbria

CBF trained family carers to jointly facilitate a set of workshops alongside a CBF professional, to benefit school-aged children. It was planned that approximately 20 family carers and 20 school staff, drawn from both special and mainstream schools, would be trained. As recruiting these numbers from any one school was not considered feasible, efforts were made to recruit staff from a number of special and mainstream schools across the county, with one school hosting the workshops.

To this end, efforts were made to get buy in at a county level from the council's education department and several special and mainstream schools were approached, starting with a special school in the south of the county, which had already expressed interest. However, for various reasons, it took considerable time to get the PBS workshops off the ground and the numerous challenges encountered are discussed below. In the end, the first set of workshops ran over June-July 2019, in a special school in Kendal. This caters for children and young people aged 3 to 19, who mainly have moderate and severe learning disabilities, although some have highly complex needs. The second set of workshops was delivered over September-October 2019, in a respite centre in Carlisle. Both sets were open to family carers and professionals from other schools in the area.

Attendance at the PBS workshops

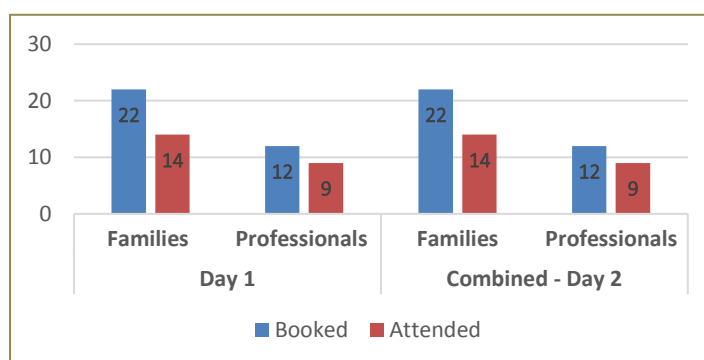
A total of 61 family carers and professionals booked to attend the courses, much higher than the numbers originally anticipated. However, there was some attrition (15 or 25%): out of those who booked, 46 attended the first days and 40 the combined days. The charts below illustrate the numbers attending each course. In Kendal numbers were maintained over each day, but in Carlisle fewer families attended the second day.

In the main, the reasons given for non-attendance were considered quite reasonable, such as attending a funeral, hospital appointments, illness, and staff shortages. One family did not attend their second day because they found that the first workshop did not offer anything new for them due to the complexity of their child's needs. However, in some cases no reasons were provided, or apologies sent. On the Carlisle course, most attendees left early on the second day, which proved quite disruptive. While trainers understood that family members could be called away to meet the needs of their child, they found it more disconcerting when staff left early. No data is available on why this happened.

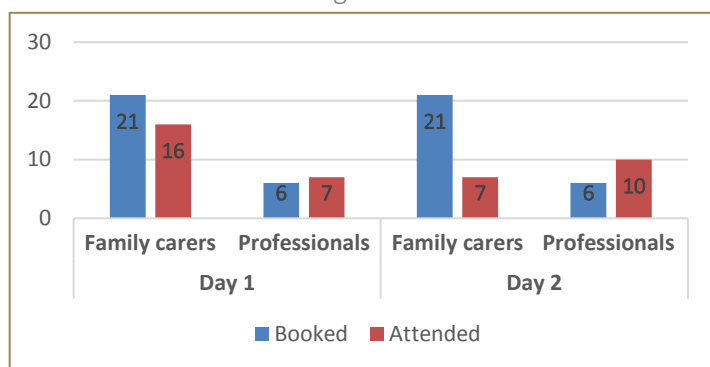
Attendance Kendal training - summer 2019

- Of the 22 family carers who had booked, 14 attended on both days.
- Out of the 12 professionals who had booked, 9 attended both days;

The children, family carers and professionals were from different schools.



Attendance Carlisle training - Autumn 2019



- Out of the 21 family carers who booked, 16 attended the first day;
- Seven professionals attended their first day, one more than the 6 who booked;
- Out of the 21 family carers who booked the combined day, only 7 attended; but 10 professionals attended rather than the 6 who had booked.

Number of children represented

Sometimes more than one family member attended in respect of a child and individual professionals were commonly working with more than one child. For instance, in the Carlisle group, the family carers discussed 12 children, while the professionals were working with 25 children, some of whom were the children of the family carers. Data is not available on the number of children focused on in the Kendal workshop.

Key enablers identified

- CEIP benefited from the fact that the PBS approach already had official endorsement, and was being promoted across the county; and being able to trial the CBF's well-developed PBS programme in the Cumbrian context.
- CBF managed all bookings once people expressed an interest.
- As with the other CEIP workshops, it was provided free to schools and families.
- The special school was particularly welcoming of this opportunity and keen to try out new approaches with support staff, families and pupils. They said they were always looking for training and new ways to do things.
- The family carer facilitator was critical in attracting family carers to the school sessions, building on a parent support group already running at one school.
- The CBF facilitators felt that the school workshop benefitted enormously from the fact that staff and families already know each other and the children. Existing relationships facilitated developing a joint strategy and minimised the need to explain a child's behavioural patterns.
- In the Kendal course, the input from the Community Learning Disability nursing team was felt to be extremely useful. They outlined local services and shared their contact details. (There was no information on why they were not invited to attend the Carlisle workshops).
- The family carer facilitators commented that although the courses were carefully planned and largely scripted, no two courses were the same as they responded to the needs of participants. This allowed them ample scope to add their personal insights and experiences.
- The input from the family carer facilitators proved particularly valuable when family carer participants were describing a behaviour which they thought only pertained to their child. Here the family carer facilitator could relate how their own or another child they knew did something similar, and how they had come to recognise the 'triggers' for behaviour escalating.

- The school felt the training was broad and deep enough to enable everyone to ‘*get out of it what you needed*’ and that it provided an excellent framework for staff to learn to reflect on what was being communicated through behaviour. They felt the workshops would prove useful for both new and for long-term staff, especially practical aspects to apply the knowledge learnt

‘... We were talking ... about the subtleties of [behaviour escalating] and I said “oh, my son does these movements and stuff like that... so then I know he is starting to get stressed”. It just takes a few little triggers... it is just little things like that ’

Family carer facilitator

Key challenges identified

The challenges emerging fell into three main categories: misconceptions around PBS, project capacity and course design. These and some other factors all affected recruitment.

‘Schools ... reacted in very different ways ... Another school was interested, but they did not see the CBF program as fitting their needs or plans at that time ... saw themselves at different points of the journey. One of them had very specific ideas ...of where they were at and what they were delivering ... [the CBF training] wasn't probably going to give them what they wanted at that point ... Whereas the other school was like “Yes, let’s have a go”’

CEIP Coordinator

Misconceptions around ‘PBS’ and identified need

- Misconceptions of what ‘*Positive Behavioural Support*’ comprises created significant barriers to recruitment and on the ground, ‘PBS’ was said to encompass a wide breadth of interpretations and applications. Interviewees considered many of these to be a far cry from the models and the meaning approved by NICE, CQC, NHS, CBF and others. Unfortunately, these misapprehensions were believed to have resulted in schools and other institutions declining the CBF PBS workshops, because they felt they already knew enough about and applied PBS and therefore complained that they were being asked ‘*to suck eggs*’.

‘Oh yeah, PBS we do that anyway.’

CEIP Coordinator

Interviewees had observed that many professionals and institutions, whilst believing they used PBS, were actually employing a punishment model.

‘They are telling me they are using PBS. Absolutely not! Special schools I am talking about ... So, there was a point where something was said in the workshop and the [other facilitator] said “I am going to play devil’s advocate here and suggest that what you are using is punishment”. And they went: “Oh yeah, I suppose. I haven't thought of it like that”. So training is really, really, really, needed.’

Family carer facilitator

An example was given of a mainstream school which was trying its best to apply PBS but had no formal input on this and so was floundering. In the end, the child's parent had shared their knowledge of PBS and the tactics they used at home, all of which the school found very useful.

'... when the parent spoke to the school about what they were dealing with and she said "Well I would just do this" and the school said "Oh we hadn't thought of that".

Family carer facilitator

For interviewees this illustrated how schools often felt they knew PBS better than they did and how they rarely considered looking to parents for solutions. As a result, in these and possibly other cases, the children received two very different approaches and arrived home distressed, because punishment was being used, although the family carers believed that the school used PBS.

As a corollary of this, serious concerns were expressed around the monitoring or assessment of schools' application of PBS. It was unknown if Ofsted inspections were detailed or expert enough to judge this.

'... I was just thrilled that [the school] knew the word 'Behaviour Support Plan'. Actually, when you learn more you realise there are good behaviour support plans and really, really, poor behaviour support plans. Schools need a lot more support to actually write a good support plan ... I don't think the schools know they are not using PBS. But they think they are.... And actually, who is evaluating? When schools are saying "We know PBS" who is evaluating that?

Family carer facilitator

Project capacity and lack of a clear communication and engagement strategies

- Inadequate project capacity may also account for not addressing misapprehensions of PBS. Although the coordinator and another partner had many meetings with headteachers, Cumbria's education department and headteachers from special schools and SENCOs and SENDIAss attended the launch event. It was felt that more communication was needed to gain sufficient traction and insight that CEIP offered something new. This might have helped achieve a mutual understanding of PBS. To be fair, the inaccurate conceptions of PBS did not emerge in meetings, mainly came to light during the workshops and was said to be common across the country. In other words, it was not easy to anticipate.
- CEIP lacked an overarching communication, engagement or development strategy to liaise and deepen understanding at a strategic and system levels. The findings indicate that the project relied heavily on a snowball technique and developing and exploiting the steering group members' existing networks and contacts. This proved useful, but also limited.
- The proportion of academies in Cumbria presents an additional communication challenge, as these and/or their parent organisation may need to be approached individually.
- CEIP succeeded in establishing some strong links with individual services and professionals but focused mainly on testing delivery at a service, practitioner and family level. While this was valuable in assessing the courses' viability, it did not test how to spread awareness of PBS more widely. Arguably, securing interest and understanding among Cumbria's key strategic leaders may have helped develop a more accurate and consistent concept of what does and does not

constitute 'PBS'. Ideally this could then have been cascaded to all the county's educational institutions, underpinned a systemic change as well as buy in to the CBF programme.

- Inadequate project coordinator time also meant that there was insufficient time to explore with CBF if the programme could be amended in any way to respond to the emerging diverse needs of different schools, or to gather direct feedback from school and other participating agencies for example on any improvements they felt were needed in the processes or content.

Recruitment challenges

- Getting these workshops off the ground took much more time and effort than originally anticipated. The limited local project capacity impacted the number of requests for the training and resulted in less than desired engagement with individual schools to promote and explain the training in detail. This is likely to have contributed to a loss of momentum. In comparison, the concomitant adult transforming care programme, benefited from two years of engagement and communication work before training commenced. This was felt to have created excitement and interest in that programme, as well as familiarity with the principles and content.
- Apart from the hosting the special school which had been interested from the start, getting other schools, agencies and participants on board required much more input than anticipated. Several early expressions of interest did not materialise, and occasionally other obstacles to attendance arose for the schools which had previously expressed an interest.
- It became evident that recruiting schools required a bespoke and individualised approach, and more time than CEIP originally envisaged. This had not been factored in, possibly because of the absence of any education sector input on the steering group and insufficient project time, combined with the lack of any pertinent leverage e.g. from the DfE, or the Local Education Authority (LEA) and the proportion of academies in Cumbria.
- As mentioned above, some schools declined because they felt quite confident in their knowledge and application of PBS. This exemplified in practical terms the conflict between the DfE emphasis on managing, and zero tolerance around, behaviour and the NHS guidance.
- More time and work was needed to factor in schools' priorities and annual timetables and familiarise them with the workshops. This included considering timings which fitted schools' priorities, such as exam periods and Ofsted inspection, and options for a school to release large numbers of staff, including paying for teaching staff cover. Overall, the PBS offer was felt to lack sufficient advantages to compete with other pressures facing schools.
- As found in E-PAtS, 'a Cumbrian factor' emerged, linked to geography, localism, transport and time. This particularly affected attendance at the Carlisle sessions, which therefore could not attract families or professionals from the west or south of the county.
- Arranging dates with the Carlisle respite centre required a substantial lead-in time, to enable transport and alternative care arrangements to be set up.
- For various reasons, the normal eight week lead in time for participants, designed to give them time to prepare mentally and practically, e.g. to arrange alternative care, was not feasible in this pilot. This was reported to have affected participants' preparedness for the course and made them look more last minute than they actually were.
- The Carlisle workshops, delivered in a community setting, were said to lack some of the advantages evident in the school setting: especially not being able to generate the same group dynamic among families and professionals who already knew each other and the children.

- As a result, it proved harder to ensure a match the professionals and families in the Carlisle course and so, the joint, second, day was not as collaborative. Some families and professionals had to work alone to write plans, which was more difficult for families and meant a vital aspect of the collaborative strategy planning was missing.

Feedback from and reported outcomes for participants and children

Two family carers were trained to deliver the programme and were very pleased with the knowledge and skills they gained and which they shared with other family carers.

Feedback from attendees and school heads

Written feedback was collected from participants through a feedback form administered by CBF at the end of each training day. Feedback was also obtained from the headteacher at the special school which hosted one set of training and from family carers in the focus groups and interviews.

The feedback was overwhelmingly positive. Family carers reported enjoying gaining new insight and information and sharing the same training as professionals. They felt that having the first day together with other family carers helped them identify and then later present their experiences and observations to the professionals in a coherent and effective way.

Employing family carers as joint trainers was very well received and their own stories were enjoyed. Professionals commented that the family carer trainers' input made the sessions feel '*more real and relevant*' and that their narratives worked much better than '*made-up*' case examples. For families attending the way the family carer facilitators shared their experiences and provided information proved much more effective and was much less threatening, or top-down.

'It's not another professional standing up in front of families and telling them "what you have to do is this" and "what you should not do is that"

Family carer written feedback

Some aspects were described as particularly useful, including analysing the reasons behind challenging behaviour; understanding the interaction between communication and challenging behaviour; the discussion and sharing of experiences; colour-coding and charting behaviour; and the interaction and collaboration with professionals.

Professionals were very positive about the training, reporting they had learnt a great deal and would have welcomed more. They appreciated having the opportunity to share ideas and experiences with colleagues and families, the small groups and interactive nature of the sessions, getting stimulation, the opportunity to reflect on existing practice and understand the family carers' perspectives. The special school felt that the PBS model fitted the school's approach, and although staff were already quite experienced, they gained fresh ideas. The course was said to help them overcome a tendency to get '*a bit stale*' and served as a reminder to explore the antecedents and what was being communicated through behaviour. The training prompted staff to revise strategies for individual children, where matters had become stuck in a rut '*rather than, oh they're being badly behaved again*'. In their written feedback professionals described the workshop as "*informative*", "*fun*" and

“upbeat”. In contrast to existing training and strategies around needs and behaviour, the CBF course was said to give them a more positive focus and greater emphasis around communication, working with families and understanding more about what happens at home and providing children with autonomy and choices.

Both family carers and schools felt that sharing each other’s perspectives shed new light and depth on issues and strengthened planning. The school reported that this joint method generated more robust plans, and so they aimed to undertake it more often, but said it was not possible in every case as it would be too costly to implement wholesale.

‘It isn’t the norm. It’s becoming more and more the norm. To try to make that happen constantly would be a challenge, but the course showed us the importance of doing this’

Senior school staff

Professionals and family carers enjoyed having the opportunity to discuss experiences and matters with each other. For family carers this proved *‘really effective and reassuring’*. Family carers were said to have gained a much better understanding of the child’s behaviour in different settings and staff benefitted from understanding more about the home dynamic. Most notably, the professionals were said to have gained a deeper understanding of the pressures faced by families, including the fact that family carers get no *‘time off’ to recover*, whilst for them there were always other staff around to share the responsibility and pressure. Sleep was a prime example of this, especially where professionals had not been aware of how little the child slept or how much they disrupted the sleep of the rest of the family. The intense and unremitting nature of looking after someone and dealing with challenging behaviour 24 hours a day, seven days a week and being *‘always on’* was brought home to professionals. As a result, they had a better appreciation of why family carers often arrived at appointments or school tired and worn out. Conversely, family carers gained an understanding of the contexts in which staff work, for example, that they may be dealing with 10 to 12 children with challenging behaviour at any one time.

The learning situation and tasks required were said to have helped equalise the relationships between the professionals and family carers. Moreover, rather than the former being the instructor, both parties had an equal role in creating plans.

“we are all one team together, not them lecturing us”

Family carer in written feedback

CBF received lots of positive feedback from family carers who said they felt the course had made a substantial change to their lives and that they had changed everything they did at home *‘No longer see child as ‘naughty’ and ‘the child has improved immensely’*. Another family carer said they had used the course information to reflect on their own understanding of and interaction with their child and had modified the reactions of all family members and the whole home environment too.

Observations by trainers and organisers

CBF described the school-based workshop in the Kendal school as one of the best they had ever run. This was largely attributed to the fact that staff and families already knew each other well, collaborated very enthusiastically and as a result were more able to create plans for the future. The experience and skills of the trainers helped build mutual understanding of practical scenarios, by analysing real life incidents, including one which had occurred on the day of the training, to explore potential options to do things differently, communication and contingency planning by families and settings. Trainers observed an improved understanding between the family carers and professionals of each other's stresses and pressures, which further enhanced their collaboration.

Recommendations emerging

- Continue the same training model as it appears effective on the whole, but also explore developing add-ons or variations for children with very complex needs.
- Embedding this approach in Cumbria is key to sustainability. This requires training up local professionals as well as more family carers as trainers, similar to what was done under E-PaTS, or increasing the CBF's capacity to deliver it in the region.
- Low numbers and highly localised delivery may be the best fit for the Cumbria context. If so, planning, budgets and training offer need to match this reality.
- Courses need to be run regularly, to make it easier for families and staff to access, especially if challenging behaviour emerges, changes or escalates, and to get refreshers.
- PBS could be recommended in EHCPs and by GPs and other professionals.
- Exploration is needed around how to assess how well PBS is actually applied e.g. in schools. This will involve the LEA, Ofsted and relevant national bodies.
- The NHS, NICE, CBF and other official PBS interpretations and guidance need to be discussed with the DfE, Cumbria LEA and Academy bodies to resolve the potential conflict with approaches to maintaining school discipline, and to help limit school exclusions. The response to the SEND OFSTED inspection could provide a platform for this.
- An engagement and communication strategy is needed in Cumbria to share the potential benefits of the programme for children and families, e.g. across SENCOs, SENDIAss and GPs.
- Work with education professionals and schools to explore persuasive selling points to attract schools and any variations required for specialist settings.
- Make PBS a core element of teacher training and continuous professional development.
- Provide explanations about local services, as done and appreciated in Kendal.
- Allow as much lead-in time as possible. Ideally start planning six to 12 months in advance.
- Explore methods to maximise the 'match' between family carers and professionals to enable discussions around the same child. Recruiting the family carers first might help.
- Work to encourage people to turn up on Day 2 and stay to the end of the session.
- Participants would have liked more time to explore the 'amber' strategies.

C. Resilience workshops

Programme summary

The resilience workshops were the third programme on offer to family carers. Like E-PAtS and PBS, this programme had an evidence base established over many years, although this was the first time the programme was delivered to professionals or family carers looking after children with learning disabilities or ASD. Previous programmes were delivered to those looking after adults.

In line with the other two programmes, the resilience workshop model was based on cascading learning. One family carer and 13 nurses from the Community Learning Disability team attended an introduction to core principles of mindfulness and acceptance workshop over the summer of 2019. Although they were not involved in co-facilitating the autumn workshops, two of the community nurses observed the full delivery of the five session programme with the expectation that they would deliver it in the future.

The family carer and some of these nurses were previously trained to deliver E-PAtS and the family carer had delivered the PBS workshops also.

Background and ethos

The resilience workshops focused on the well-being of family carers of people with learning disabilities, with a particular emphasis on their mental well-being. This programme was developed from participatory health research, led by Northumbria University, which trialled mindfulness and self-care interventions with carers of adults with learning disabilities. This study found that the approach could improve 'long-standing response behaviours and build personal resilience and improve mental health'⁴⁸.

The CEIP resilience programme was founded on a set of principles developed from research and previous trials:

- Family carers commonly play the most critical role in looking after people with learning disabilities.
- At the same time, family carers' lives are stressful, because of their complex, often multiple, and unrelenting caring responsibilities. Many family carers provide unpaid care to more than one person and over many years or decades.
- Family carers are commonly isolated and receive little or no support from statutory or other services.
- All these factors test family carers' resilience, and in the long run can undermine their mental and physical health. For example, a 2019 survey of carers ($n=8000$), undertaken by Carers UK,

⁴⁸Cook, T., Noone, S., and Thomson, M. (2019) *Mindfulness-based practices with family carers of adults with learning disability and behaviour that challenges in the UK: Participatory health research*; in Health Expectations June 2019: <https://onlinelibrary.wiley.com/doi/epdf/10.1111/hex.12914>

found that the majority of carers put the care needs of others before their own needs⁴⁹. In a 2018 UK survey (n=6828), 72% of the carers who responded reported suffering mental ill-health, and 61% reported physical ill-health, resulting from their caring roles⁵⁰.

As well as helping to shape the course content and delivery, family carers participating in the earlier research programme identified four key indicators of success. These were analysed in an attempt to identify the main negative processes that led to problems which the workshops had helped resolve.

- **Positive behavioural change.** This suggested that an indicative problem for carers might be a behavioural repertoire, which in turn limited their positive experiences and enjoyment of life.
- **Awareness of physical responses, both physiological and emotional.** This suggested a restricted ability to monitor and attend to their internal states.
- **Enhanced reflection skills,** such as taking a step back, observing their own thinking and reactions. This was felt to imply that carers may tend to become entangled in negative thinking.
- **Feeling calmer.** This was felt to indicate that carers had high levels of arousal and distress prior to the course, and that they were less cognisant of positive experiences.

The CEIP Resilience workshops

The essential elements of this research programme were translated to the Cumbrian pilot: with the only difference being that in CEIP the family carers attending the workshops looked after children and young people with learning disabilities, rather than adults. The workshops were based on the principles of mindfulness, acceptance and commitment therapy (ACT), with a participatory emphasis to support family carers to identify their own priorities and sources of resilience. In other words, although some ideas and techniques were taught by the workshop leaders, there was an emphasis on personal reflection and encouraging family carers to generate solutions which suited their own contexts and lives. This approach had been found to be particularly effective in the study on those caring for adults with learning disabilities.

The course attempted to demonstrate how normal it was as a human to become distressed. It encouraged participants explore how this might manifest for them, aiming to help participants reflect on common experiences. For example, the programme shared a list of the negative emotions commonly felt by family carers, including: stupidity, anxiety, fear, embarrassment, confusion, anger, sadness, failure, overwhelmed / dread, useless, frustration, disbelief, alarming and nerve-wracking, distressed, powerless, annoyed, blame and shame at own disgust. The programme illustrated how all carers can easily become resigned, resentful or bitter, but nonetheless not ask for support.

The principles of a 'resilient' carer were agreed to include: the ability to detach oneself and not take someone else's behaviour personally; maintaining a sense of humour; staying aware of the tender moments in the day; being psychologically flexible and not expecting to be always in control; to be in the moment; looking for the positive parts of being a caregiver; and respecting and looking after their own needs.⁵¹ The family carers undertook a number of practical exercises: for example one which

⁴⁹ <https://www.carersuk.org/news-and-campaigns/state-of-caring-survey-2020>

⁵⁰ https://www.carersweek.org/images/Resources/CW18_Research_Report.pdf

⁵¹ From slides shared by the course developers

helped them clarify what was most important in their lives. Another helped them practice mindfulness techniques that they could use at times when they felt stressed.

Recruitment and attendance

The workshops were targeted at family carers who had previously attended the E-PAtS and/or the PBS training. This was intended to help them get the most from the whole pilot, and conversely help CEIP assess the benefits, if any, of having a combined suite of programmes to offer family carers. Delivery was delayed to the autumn of 2019 for several reasons, not least the programme's readiness, conflicting time pressures of facilitators, time to clarify if research ethical clearance was required for this pilot, the need to follow the PBS workshops and challenges in recruiting participants. In the end most attendees were recruited in the south of the county, from the previous E-PAtS and PBS workshops and some additional family carers were recruited by the Cumbria Learning Disability Teams.

Six family carers signed up to the course, along with two nurses from the Cumbria Learning Disability Nursing Team, who were learning how to run the course in the future. Out of these six family carers, four completed the programme. One of the two people who dropped out said they did so because they found groups too challenging. Another couple hoped to attend together, and one of them attended the first day, but in the end neither could attend due to other demands.

The facilitators were struck by the amount of stress the family carers experienced and that they chiefly came to get help to deal with that stress, although they had not previously identified the need to look after themselves as such.

'I had some idea that it [was] for my own mental health obviously, but I didn't really know how it was going to be ... it had followed from the E-PAtS, there is a section on looking after yourselves. That made sense to me in terms of what that's something I should be doing...'

Family carer in focus group

'... at the time we were going through a hell with [child] so I was kind of fixed on "I need to help for [child]". I guess I still didn't believe you need to look after yourself first ... The E-PAtS benefited [child] massively, but I feel the resilience course was where I really listened to me... about me. [before] I was losing the will to live...'

Family carer in focus group

Content and delivery

The course comprised five, three-hour, sessions delivered every fortnight over September to November 2019. The sessions were deliberately spaced to provide participants with sufficient opportunity to apply what they had learnt, reflect on any barriers to doing so and discuss these in the subsequent session, if desired. Participant numbers are kept to a maximum of eight to ensure everyone gets as much as possible from each session.

Table 6 sets out the main topics covered each day. Training was not didactic, in that the facilitators aimed to explore the topics in a discursive and conversational way, to respect and build on family carers' own experiences, contexts and knowledge. The focus was on helping participants identify their own thinking patterns and stress reactions, rather than presenting an 'expert' to teach a set of 'facts'. The course placed a large emphasis on self-respect and self-care, mindfulness, breathing and grounding / centring techniques. The delivery style was deliberately kept low key and conversational, to make sessions as relaxed and accessible as possible. The second and subsequent workshops included time to review lessons learnt and any impact felt.

Table 6: Topics covered in each session

Session 1	<ul style="list-style-type: none"> • Normalising human experience of distress using large body board and discussion • Establish rational and preparation for mindfulness practice • Introduce first two steps of the three-step breathing space
Session 2	<ul style="list-style-type: none"> • Learning to slow down and notice (eating meditation). • Introduce values clarification with values cards. • Three step breathing space.
Session 3	<ul style="list-style-type: none"> • Repeat values clarification with bullseye to establish importance and commitment. • Explore the things that hold us back and the cost of a life lived on auto – pilot. • Three step breathing space.
Session 4	<ul style="list-style-type: none"> • Understanding how we can respond without thinking and how we get trapped in our psychological experience. • Explore patterns of responding. • Over-coping barriers to living a valued life. • Longer, three-step, breathing space, exploration of practice in the real world. • Option of doing walking meditation.
Session 5	<ul style="list-style-type: none"> • Reflections and review of previous 5 weeks • Celebrate success • Meditation.

Key challenges identified

- Naming the programme. 'Resilience' now seems to have stuck and is a more accessible and slightly more self-evident name than FABPos, which stands for Family Based Positive Support.
- Recruitment arguably suffered from the need to wait until the PBS training had taken place and the facilitators' conflicting time demands. The associated delay in setting dates undermined promotion.

Feedback from participants

Verbal feedback

Everyone at the final session talked about how they had found the group helpful and enjoyable and found being part of a group useful in itself mainly because this provided an opportunity to appreciate that other people had experiences similar to their own, and also experienced distress like them.

Participants welcomed receiving some simple, practical ideas of how to be mindful. They particularly appreciated the emphasis on the importance of prioritising what was important in life and in turn making sure they gave enough time to the things that matter most.

Self-completed pre and post course quantitative measures from participants

Before the start and at the end of the last workshop participants were invited to answer a set of question in the measures listed below. These are all validated tools used to assess issues such as psychological well-being and values. Each of these tools contain several domains and numerous questions and an individual's responses translate into a set numerical score. To that extent they enable a snapshot of a person's thinking, and in this case helped indicate if there had been any change over the course of the workshops. The four tools used were:

- **The Believability about Anxious Thoughts Questionnaire (BAFT)**.⁵² This assesses someone's tendency to or buy into their own negative thinking. BAFT provides a single score that denotes how much a person believes anxious thoughts to be true. The higher the score the more someone believes their anxious thoughts. The data in the CEIP pilot suggests a promising reduction in this score, in line with the intention of the course to enable participants to disentangle themselves from worrying and troublesome thinking.
- **The General Health Questionnaire (GHQ)**⁵³ is a key psychometric tool, used to measure general psychological well-being. The higher the score, the poorer the well-being. The results here show reduced scores after the workshops.
- **The Mindfulness Attention Scale (MAAS)**⁵⁴ helps measure someone's capacity to be mindful. This gives an average score that indicates how aware someone is of what is happening to them. Therefore, a higher score indicates greater awareness.
- **The Valued Living Questionnaire (VLQ)**⁵⁵ is a different type of measure to the three above. It provides a qualitative record of how each person judges, from a list of common values, what is most important to them at that time. They are asked to rank how they value 10 areas of their lives on a scale of 1–10, and then indicate how important they treated this issue in practice over the previous week. Therefore, any change in scores may mean very different things to each person. If they have expanded their range of values, they may have a higher score when they repeat the questionnaire. Alternatively, they may have a lower score, but this may reflect that they have focused more time on a smaller number of options. As a result, each person's scores must be viewed individually.

⁵² <https://www.ncbi.nlm.nih.gov/pubmed/22486595>

⁵³ <https://academic.oup.com/occmed/article/57/1/79/1557723>

⁵⁴ [https://ggsc.berkeley.edu/images/uploads/The_Mindful_Attention_Awareness_Scale_Trait_\(1\).pdf](https://ggsc.berkeley.edu/images/uploads/The_Mindful_Attention_Awareness_Scale_Trait_(1).pdf)

⁵⁵ <https://www.div12.org/wp-content/uploads/2015/06/Valued-Living-Questionnaire.pdf>

Table 7: Pre and post self-completion measures by family carer participants (n=4)

Pre and post scores given by each person								
	BAFT-1 before	BAFT-2 after	GHQ-1 Pre	GHQ-2 Post	MAAS- 1 -Pre	MAAS- 2-post	VLQ-1 Pre	VLQ-2 Post
Person 1	106	78	24	17	1.9	2.06	47	59
Person 2	69	60	15	8	2.9	3.8	85	75
Person 3	72	73	17	14	3.2	3	65	63
Person 4	86	58	33	1	1.3	4.3	41	67

Overall, the post-workshop results suggest some improvement: there was some reduction in belief in negative thinking patterns; a decrease in self-reported poor health; and some increase in being mindful. But the trends are not consistent per participant, or in all measures for each individual.

Moreover, the results given in Table 7 have to be viewed with extreme caution and are indicative at best. For a start the available data is too limited to enable any meaningful analysis, as only four family carers completed both the pre and post measures. Moreover, the immediate feedback was possibly affected by the feelgood factor of attending the course. We do not know if, or how long, any positive change continued, or to what extent. There is also a risk of 'confirmation bias', in that respondents sometimes feel they should give responses which seemed the most desirable to the facilitators.

Feedback derived through interviews and focus groups with family carers

- Family carers liked the fact that these workshops focused on them (for a change), not on the children.
- The input on prioritising what matters most and the insights around the tensions over control hit home for many. They said that this had helped them prioritise their own needs, allow themselves to take a break, see the need to pace themselves over a lifetime of caring and to value and invest in their relationships with their partner.
- The resilience work fitted in well with the previous E-PaTS and PBS training, which the focus group family carers had attended. The other two courses had provided insights and remedies centred around the child, their communication and behaviour, whereas the resilience workshops gave the family carers time to focus on what they were doing and thinking and the impact that had on their current approach to caring and life.
- Family carers and staff said they had benefitted from the grounding, mindfulness and breathing techniques and said they continued to pursue these. Staff and their own needs.

Feedback from the facilitators

The facilitators observed that the group delivered on many levels. Despite the amount of stress experienced by the participants the sessions succeeded in providing ideas and methods which helped reduce their minimise stress.

Recommendations emerging

- This small pilot indicates that resilience workshops were worthwhile to develop in combination with E-PAtS and/or the PBS programmes and that both family carers and staff can benefit.
- Given the stress experienced by these family carers and the body of evidence which exists on the negative impact of caring on family carers' physical and mental well-being, it was felt that mechanisms were needed to maintain any gains and to support family carers to continue to apply the learning over the longer term, and help deal with new challenges.

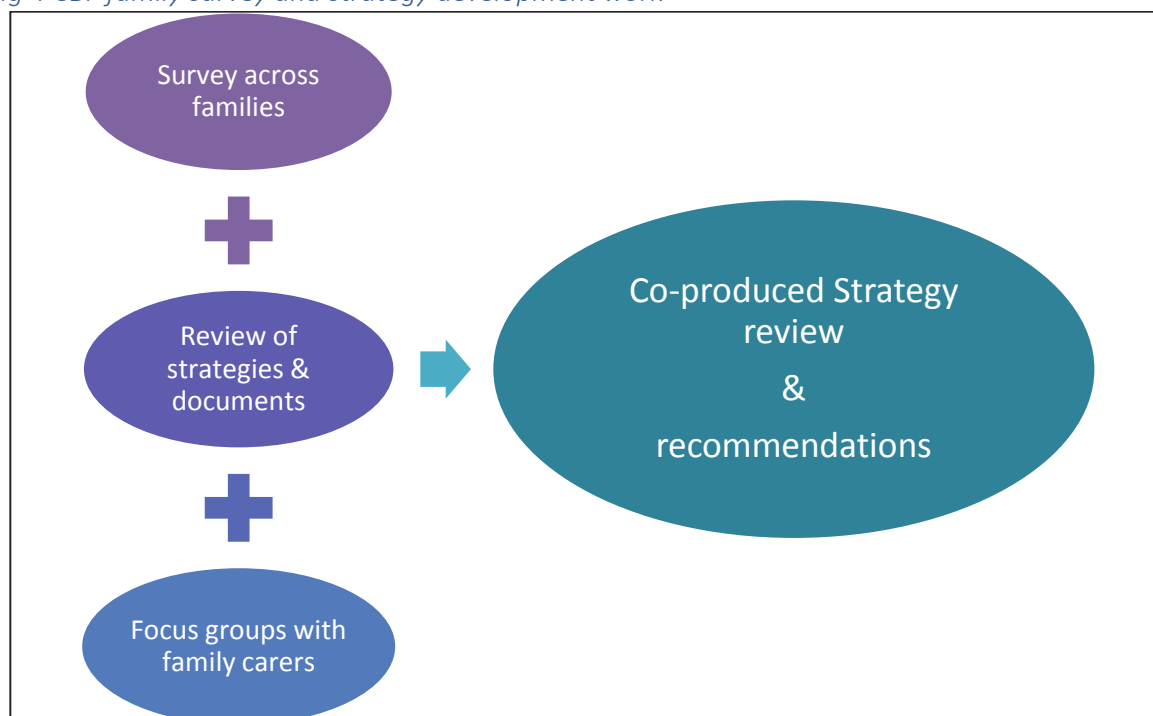
D. Cumbria strategic development work

The fourth CEIP strand investigated the priorities and needs of children with learning disabilities and/or ASD and their family carers, assessed how well these were addressed by current strategy plans and set out strategic ideas to improve matters for this commonly overlooked group. This work was led by CBF, with family carers firmly involved throughout. Family carers led many aspects of this work and disseminated the final key messages.

This work entailed:

- A targeted survey of families in Cumbria to help ascertain the numbers of children with learning disabilities and ASD who display behaviour that challenges and to identify awareness of services and priority needs.
- A desk based review by CBF of relevant local and national strategies.
- Priority setting, through two focus groups with family carers to discuss relevant issues and needs in Cumbria
- The findings from all three exercises were translated into a strategic report, a presentation and video to be shared with local boards, decision makers, families and online.

Fig 4 CBF family survey and strategy development work



Identifying families' needs in Cumbria

a) CBF survey of families

CBF designed and disseminated an online survey to improve information on the numbers of children and young people in the county who had learning disabilities and/or ASD; the sub-group of those who had behaviour which challenged and to help ascertain children's and carer's priority needs and access to services.

The survey included questions on the child's diagnosis if any, communication skills and behaviour, any impact of this on the family and how well their school managed any behaviour that challenged; sources of support family carers were aware of and used, including any health or social care services; the carer's information needs and preferred methods for receiving information; and their awareness of SEND reforms, Transforming Care and the Parent Carer Forum.

The survey ran from December 2018 to February 2019 and was disseminated through various agencies and networks, including Carlisle Mencap, the CEIP Steering Group, The Cumbria Special Needs Group, the Cumbria Parent Carer Forum, the Cumbria CBF Facebook group and parents who attended the focus groups. Everyone was encouraged to share it further. A total of 38 responses were received. It emerged later that another similar survey was running at the same time, which might have affected the response rate⁵⁶. The response rate is too low to help estimate the incidence of learning disabilities and/or ASD and challenging behaviour in the county, but the data provided about around families' awareness of services and priorities was interesting.

Other data on the numbers of children and young people with learning disabilities in Cumbria

Other sources were examined to try to ascertain the potential numbers of children and young people who have learning disabilities and/or ASD in Cumbria. But this proved quite challenging. Few statutory or voluntary agencies publish this information. Relevant data is not defined or recorded in a uniform way, or collated in a central place, and so health, social care and educational bodies hold different figures, if any. Often children do not get a diagnosis or have to wait many years to get one. GPs are not required to record autism; and learning disability or autism might not be the only, or the primary, diagnosis used on medical records. The numbers experiencing challenging behaviour are even more difficult to estimate, not least because of variable definitions and recording.

The Cumbria County Council's 2017 Joint Strategic Needs Assessment (JSNA)⁵⁷ provides limited data on learning disability and ASD in the county. The authors acknowledge that true rates are likely to be higher, largely because of the issues above combined with under-identification/ reporting and difficulty in separating data on children and young people from older groups. The JSNA reports the following statistics:

- 2,614 people of all ages are recorded on GP Registers to have learning disabilities (0.5% of all GP patients);
- An estimated 1060 children and young people aged 0 to 18 have autism;

⁵⁶ Transforming Care survey of families across Cumbria and the North East, which ran at the same time as the CBF survey, received 200 responses. Only four came from families in Cumbria.

⁵⁷ Cumbria CC (2017) Learning Disabilities and Autistic Spectrum Disorder Joint Strategic Needs Assessment (JSNA)

- 4,176 of pupils aged 3-18 are known to have a 'learning difficulty' assessed as a 'special educational need' (SEND). This is a wider category than, but includes those with, learning disabilities and/or ASD; and
- 1,675 people of all ages are in contact with Cumbria's Learning Disability and Autism services.

The National Autistic Society estimates that one in 100 people of all ages are on the autistic spectrum⁵⁸. If applied to Cumbria's population of (498,888⁵⁹), that would yield a figure of 4988 adults and children, or 948 children and young people aged 0 to 17, a lower estimate than the JSNA⁶⁰.

The JSNA also notes an *'increase in complexity of the young people transitioning from children's services, in particular people with multiple disabilities and others whose behaviour presents challenges'* (P5). It reports that people with learning disabilities tend to have much poorer health experiences and outcomes and higher mortality rates than those without.

Needs and issues identified by the survey

The survey results need to be read with caution, given the response rate (38) and the difficulty in assessing the representativeness of respondents. As in many surveys, there may have been a potential bias toward families who were already in networks, or in touch with services and families whose children had ASD. However, even if we cannot reliably estimate how accurately the percentages reflect the views of all relevant families in Cumbria, the issues raised are nonetheless informative and chime with other data, not least from the family carer focus groups. The headline findings are presented in Table 8.

Table 8: Headlines from the CBF family survey 2019

<ul style="list-style-type: none"> • Thirty families (80%) reported that their child had a diagnosis of autism; 11 (28%) a 'learning disability' and (10) 25% a 'severe learning disability'. Many children had two or more diagnoses. For example, 70% of those who had a diagnosis of learning disability also had a diagnosis of ASD. • Over half the families (20/ 53%) reported that their child displayed behaviour that challenged every day, and a further 11 (30%) said this happened at least once a week. • 14 (38%) children did not use verbal communication as their main form of communication. • Three-quarters (28/75%) of respondents said they needed more information about how they should support a child who displays challenging behaviour and about useful services. • Thirty (80%) had an EHC plan for their child and most were happy with education provision. • Over half (22/58%) had tried to access social care support; half of these had succeeded; but few were happy with the services provided. • Half (19) had not been able to access Paediatric care for their child and just under half said they did not know how to get a referral to access appropriate health support. • Over one-third (13/35%) reported being unable to access mental health support. • A similar proportion had tried but failed to access occupational therapy services (12/32%) • Half (19) were unaware of how to get a referral to health services for their child if needed. • The majority were aware of the Local Offer, the Parent Carer Forum and SENDIASS, but 30 (80%) were unaware of Transforming Care.

⁵⁸ <https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx>

⁵⁹ <https://www.cumbriaobservatory.org.uk/population/>

⁶⁰ <https://www.cumbriaobservatory.org.uk/population/>

b) Focus groups with family carers

Two focus groups with family carers from across Cumbria were convened by CBF to discuss relevant families' views on the main challenges, needs and priorities in Cumbria. These took place in June and November 2018 and attracted nine and 16 family carers respectively, including a representative from the Cumbria Parents Carers' Forum.

All the family carers were keen to be involved in co-producing a more effective way forward for children whose behaviours challenge and to reach and help other families of children with learning disabilities or autism. Most were completely new to the topic and being engaged in co-producing policy solutions and had not heard of the Cumbria Parent Carer Forum before attending the meeting.

As well as the CBF convenor, professionals from the Community Learning Disability Service Team and the Cumbria Special Educational Needs and Disabilities Information Advice and Support Service (SEND IASS) attended the first meeting to explain their services.

The family carers identified what they felt currently worked well in Cumbria. This included the recently expanded Community Learning Disability nursing team, Carlisle Springboard, especially being able to self-refer, carer led support groups, the discount card (Max). SENDIASS and EHCP were also praised, once family carers managed to access them.

However, on the whole, these family carers painted a picture of patchy services in the county, poor information about their entitlements, barriers to accessing available services, staff shortages and experiencing negative or insensitive attitudes when they tried to access a service. It was found that families were often not aware of, or did not know how to access, the specialist learning disability nursing team, a care assessment for their child, disability living allowance, a carer's assessment for themselves and did not know that young people with learning disabilities aged 14 or older are entitled to an annual GP health check.



The family carers were particularly exercised by the difficulties in securing a diagnosis for their child and accessing health services, echoing the survey findings. They were highly aware that their disabled children often did not receive the healthcare they were entitled to or needed, for example from health visitors, paediatricians, physiotherapy, speech and language and occupational therapy. Many health problems went undiagnosed and untreated for long periods of time. Nonetheless families' efforts to get their child's needs assessed were often frustrated. Getting their needs reviewed and updated, or securing appropriate services was just as hard. It was reported that professionals tended to presume that another service was supporting the child, for example, the two-year old check by health visitors sometimes did not happen for this reason.

Family carers felt strongly that the current concept of "Episodes of Care" was an inappropriate model for children with lifelong conditions, known to be at high risk of poor health and social outcomes, and that they needed continuity of care. Their poor experiences, and having to be the proactive party in drawing their child's health needs to the attention of health professionals, were also at odds with national research, guidance and best practice about support for children with learning disabilities,

which recommends regular monitoring and health checks. Unfortunately, it fits with the general picture of people with learning disabilities' experience of unequal access to health services and inferior health outcomes in the short and long-term. Unmet health needs are also a known trigger for behaviours that challenge and can lead at times to crises, which have to be dealt with by the mental health system.



Most of these family carers had not previously been aware of positive behavioural support and felt their views on services were rarely sought. However, the CBF focus groups and co-production approach engendered a great deal of enthusiasm and families demonstrated that they had lots of constructive insights and suggestions to offer.

After the second focus group, families agreed to set up a Facebook group "*Cumbria Challenging Behaviour*". Over 200 families joined in the first 48 hours. This was seen to reflect family carers' appetite for information and networking if the format is right.

Families at the CBF focus groups suggested many ways to reach more families. Clearly, much more needs to be done to ensure that families of this vulnerable group are involved and able to inform decision making.

Co-producing strategic reviews and priority recommendations for Cumbria

Using the findings from the survey and from CBF's initial review of national and local strategies, the two focus groups co-produced a set of strategic recommendations to fit the Cumbrian context. This work was undertaken before Ofsted and CQC inspected SEND services in Cumbria and before the response to that that was written. However, the latter specially referred to the need to engage family carers more universally in planning.

The CBF review⁶¹ of national and Cumbrian strategy documents was partly prompted by research which clearly established the link between children with learning disabilities and/or ASD whose behaviours challenge and poor outcomes. These include social exclusion, physical harm, abuse, misdiagnosis, institutionalisation and deprivation. Their parents have also been found to be at high risk of physical and mental ill-health, both due to the extra challenges they face in their 24/7 caring role, and the lack of support or services available for their children.

This review found '*no shortage of documents and plans which set out how the health care and wellbeing of Cumbria citizens should be improved*'. However, the review did not find '*much focus on children with learning disabilities and autism within plans for children's services and rare to find much content about children in documents related to learning disabilities. However, a trawl of local strategic documents demonstrated that, if implemented successfully, Cumbria's ambitions could make a significant difference to children with learning disabilities or autism whose behaviours challenge.*' (P6). The documents accessed are listed in Appendix 1.

⁶¹ CBF (2019) The future in Cumbria for children and young people with learning disabilities whose behaviours challenge

Strategic recommendations developed with family carers

From this review the family carers developed a set of recommendations for local leaders to help reduce the likelihood of disproportionate poor outcomes for children and their families, which themselves come at a human, service and ultimately financial cost. For example, the family carers identified ways to minimise out-of-area residential and Tier 4 CAMHS placements, improve service integration and address many of the requirements made in the 2019 SEND area inspection⁶². This had found the county's SEND provision wanting, especially in relation to pupil's emotional health and wellbeing and particularly those with ASD.

Family carers' priority recommendations included:

- i. Collect meaningful data on the number of children with a learning disability or autism whose behaviours challenge. Use this evidence to make informed commissioning decisions.
- ii. Develop a Cumbria-wide pathway for children with learning disabilities and/or ASD and for the children with the most complex needs, in co-production with families. This would help families be aware of and access the right services in the right place at the right time. This could be modelled on existing pathways for other long-term conditions, such as asthma.
- iii. Driven by a Lead Commissioner (recommended by NICE guidelines⁶³) this could include:
 - A key-worker role, in line with the NHS *Long term Plan*⁶⁴
 - Commitment to roll out the Early Intervention approach pioneered by the CEIP and increasing awareness in mainstream schools, under *Transforming Care* accelerator site.
 - A 'network of hubs' to provide information and support on challenging behaviour in each of the three Cumbria areas.
 - Local crisis support, in line with the model recommended in the NHS *Long Term Plan*. This could build on the expertise of services which are already highly valued by families, such as the Community Learning Disability Team and the respite support provided by Carlisle Mencap and Westhouse.
 - Clarity on the roles of different agencies and how they should work together
- iv. Take urgent action to address unmet health needs.
- v. Families suggested initiating a system to log unmet needs, for example, when they are told there is a long waiting list to see a physiotherapist, to ensure this data is collected and reviewed by commissioners. This would meet a priority in the NHS *Long term Plan*.
- vi. Fund and support a specific co-production group(s) for Cumbria families of children with learning disabilities and/or ASD and whose behaviours challenge, potentially operating alongside the *Parent Carer Forum*. This recommendation could help to address a concern flagged up in the recent *SEND Area Inspection* to improve on the "limited involvement of children, young people and families in the co-production of services, resources and support."

Disseminating the key strategic messages

The CEIP was keen to continue and build on the co-production with families and ensure the issues raised by families were heard in the right places. It also seemed important to demonstrate the worth and benefits of working with and valuing families as partners, paying them for their work and

⁶² Joint local area SEND inspection in Cumbria, May 2019. <https://files.api.ofsted.gov.uk/v1/file/50079132>

⁶³ Learning Disability and behaviour that challenges: service design and delivery <https://www.nice.org.uk/guidance/ng93>

⁶⁴ The NHS Long Term Plan. January 2019. <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan-june-2019.pdf>

sustaining the energy and progress already made. Using a small budget (£2,000), the CBF invited competitive bids and selected two family carers to take this work forward. This final stage included:

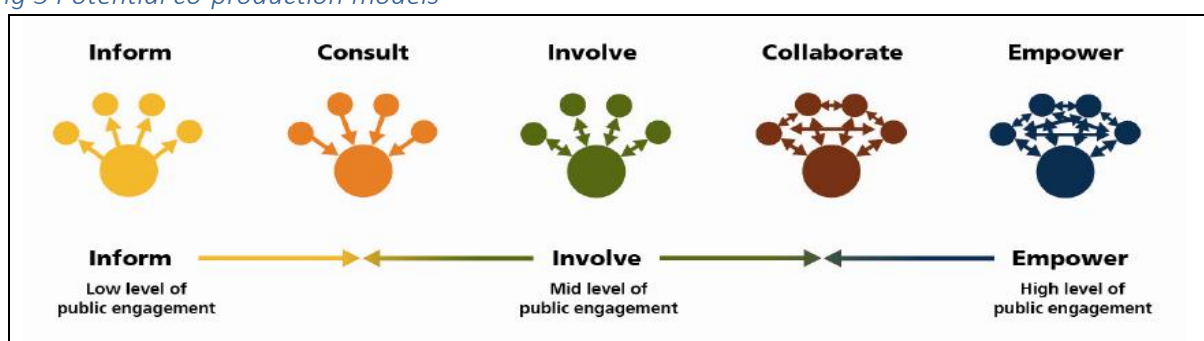
- Turning the findings and recommendations into an accessible presentation and videos which could be easily shared in person, at presentations and meetings and online.
- Sharing the key findings and recommendations with local decision makers and families. Over late 2019 and early 2020 the two family carers made presentations to:
 - The North Cumbria Steering Group for people with a Learning Disability and/or Autism,
 - Cumbria's Head of SEND commissioning,
 - The Transforming Care Board in Durham,
 - Cumbria SEND working group on emotional health and wellbeing,
 - Cumbria SEND working group on co-production,
 - Cumbria Parent Carer Forum, and
 - The SEND Working Group on Co-production.

These presentations were reported to have been very well received, especially the positive suggestions on how to improve services. However, the family carer sometimes found on arrival that the meeting's purpose had not been explained fully; decision-making was opaque; or the presentation time had been cut without notice, despite a lengthy journey. At the time of writing no further funding for family carer involvement had been identified or offered, e.g. to continue to deliver workshops, or disseminate key messages, or participate in strategy development.

Models of co-production

Figure 5 sets out the range of potential ways family carers can be involved, distinguishing involvement from merely informing people or a policy. Participation / involvement needs to be beneficial as well as proportionate, focused and efficient, as family carers lead busy lives and deal with multiple demands. So different types and extents of participation may suit people at different times in their lives. Involve⁶⁵ and Social Care Institute for Excellence⁶⁶ provide expert guidance on involvement. The CEIP model was collaborative and proved quite empowering.

Fig 5 Potential co-production models⁶⁷



⁶⁵ <https://www.involve.org.uk/>

⁶⁶ <https://www.scie.org.uk/publications/guides/guide51/>

⁶⁷ <http://www.bangthetable.com/what-is-community-engagement/>⁶⁷

Key enablers found

- This work tapped into a huge appetite among family carers in Cumbria for co-production.
- The approach and methods adopted reached and engaged a group of families who previously had little or no contact with other bodies generally expected to represent the views and needs of family carers, such as the Cumbria Parent Carer Forum.
- Family carers provided well-informed, constructive, observations and suggestions to improve services, rooted in their lived experience.
- CEIP benefitted greatly from the CBF collaborative flexible approach to involvement, which proved highly effective.
- The family carers said they really enjoyed the role, being treated as equals to professionals and having their experience valued, as well as being paid and having travel costs covered.

Key challenges found

- Though appreciated, the funding for co-production in groups and the dissemination work was limited, which curtailed its scope, development or continuation.
- Often professionals at the dissemination events did not appear to appreciate the effort and time the family carers put into developing these idea and presentations, and the allotted times to present was cut at the last minute, without notice.
- This gave family carers the impression that their input was not really valued or a priority.
- To date a small, if energetic, number of family carers have pursued this work. Maintaining engagement in co-production and keeping this representative is a well-known challenge.

Recommendations emerging

- To gain traction the momentum and recommendations made by family carers above need to be pursued with as many kept agencies and fora in Cumbria as possible, including Transforming Care, the NHS, education, children's service and other key policy makers.
- The need for accurate data on the numbers of children and young people and their situations and needs cannot be overstated and is essential to the development of adequate services.
- Improved information sharing and collaboration is necessary at ground level, especially across primary care providers (e.g. midwives, GPs, health visitors, early years ...), mainstream and other schools and VCS agencies working in this field.
- Better communication, referrals, coordination and pathways could potentially help new parents and those dealing with changing needs and/or a new diagnosis.
- Continuous reflection is necessary to ensure a wide range of family carers are given a voice and that groups do not become stagnant either in composition or focus.
- In recognition of Cumbria's geography, travel considerations, caring responsibilities and other access barriers, developing fora at district/locality levels might maximise engagement.
- The model of co-production developed in Cumbria was effective in attracting new people, fresh and positive ideas and generating a head of steam to improve services. Supporting this model of family carer involvement and co-produced early intervention strategies for children whose behaviours challenge would be a positive project legacy, but needs coordination and funding to be to be maintained, strengthened and established.

5. Discussion and key learning points emerging

CEIP was shown to be effective in synchronising and trialling three innovative early intervention programmes for children whose behaviours challenge, alongside strategic and other forms of co-production with their families. Although the total number of participating families was relatively low, the project generated substantial learning around needs, demand, processes and engagement specific to the Cumbria context.

The findings show that the E-PATs, PBS and Resilience workshops were well conceived and received. Family carers and professionals welcomed the insights, knowledge, understanding and techniques. But even more important to family carers was the recognition of the relentless pressures they lived with, respect for their vital role and expertise, acceptance of their children's needs and behaviour and the focus on enhancing the child's well-being, and the partnership approach to finding workable and personalised solutions. The programmes proved complimentary, as was originally envisioned. Family carers appreciated the refreshing focus on their own needs provided by the resilience workshops, alongside support to understand and meet their children's needs through E-PATs or PBS.

The immediate outcomes reported are encouraging, albeit analysis is limited by the low numbers, especially in the resilience workshops. Nonetheless the overwhelmingly positive feedback from family carers, as well as professionals, points to these programmes meeting previously unmet needs and doing so in a way which was acceptable to family carers and maintained their engagement.

Strong messages emerged. These included that parents were tired of being offered nothing or poorly coordinated services, or being held responsible for their child's behaviour, or of professionals not taking that behaviour seriously, or being considered deficient parents. Previous negative (and possibly widespread) experiences can present a barrier to engagement in programmes like these, but luckily were sufficiently overcome in this pilot. They also point to the need to build trust and establish a relationship over time with potential family carers, before expecting them to attend a '*yet another parenting*' programme and the need to treat them as partners and experts in relation to their child rather than standing in judgement.

The individual programmes harnessed the experiences and energy of family carers to co-deliver workshops and other work, and the CBF strategic work exemplified their skills and insight in identifying current gaps in service provision and generating a suite of remedial solutions.

Family carers relished these opportunities. They particularly appreciated being respected for their expertise and the opportunity to share what they had learnt so far with other families. Being paid to jointly facilitate courses in a professional manner augmented their sense of being taken seriously at last. Overall, the model developed in this pilot could, if co-produced and rolled out widely, help meet many of the SEND shortcomings found by Ofsted and CQC.

Key Learning points emerging

- The **project benefitted from the previous applications and testing** of the E-PaT, PBS and Resilience programmes, including established delivery methods, target groups and expertise.
- **Involving family carers** proved critical to this project and arguably provided even more benefits than had been anticipated. The CBF model of co-production was found to be appropriate. The model was flexible and iterative enough to enable this group of busy family carers shape a level and type of input which was appropriate for their available time and capacity. Arguably this pilot has demonstrated **two models of worthwhile and effective family care involvement** which could be usefully applied to developing learning disability and other services across Cumbria: training and employing family carers to jointly deliver courses; and involving them to shape policy. The standard of the joint facilitation, strategy work and dissemination by family carers is testament to the worthwhileness of this method.
- The **professional coordination** and support provided by CBF staff proved essential and family-carer participation is unlikely to have developed so well without initial experienced facilitation.
- CEIP benefited immensely from the enthusiasm, skills and insights brought by **a fresh group of family carers**, new to consultations and involvement. The findings clearly point to the need to develop methods to continually recruit new family carers, keep groups fresh, ensure diversity and that those who are less often heard are included and provide opportunities for meaningful engagement. Otherwise, there is a real risk of over-relying on a few parents and of carer groups losing their edge and potential representativeness. Moreover, volunteers' circumstances change and their scope to provide free input cannot be presumed over the long-term.
- It was evident that the **family carers went the extra mile** and more to contribute all they could. There is a high risk that family carers may become disheartened if their efforts come to nothing, or policy makers do not show a willingness to listen or respond to the points being made, which would only build on their frustrations over the years of not being heard.
- As well as training family carers to co-facilitate courses alongside professionals, **it proved vital to pay** them a proper fee as joint facilitators and reimburse travel and other expenses.

'That's critically important. We are valued... we would approach it professionally anyway, but it gives that expectation that you'll deliver a professional course at a professional level.'

Family carer facilitator

- **Those attending the courses appreciated hearing from the family carer co-facilitators**, as it made the teaching more real to their lives. They clearly trusted someone talking from their own lived experience. Overall, this was believed to have helped maintain families' engagement.
- Goodwill and enthusiasm reinforced the **collaboration across the various project partners**, especially as most meetings had to be conducted remotely due to geographical distances and the

lack of budget to enable meeting in person. Everyone was generous in contributing their time on top of existing stressful and busy schedules, bolstered to some extent at least by previous working relationships and mutual respect. This was fuelled by their passion for early intervention and their respective projects. Each party brought different expert knowledge, reach to families and access to more diverse funding streams. Partnering with VCS agencies and their skills and networks, in this case CBF and Carlisle Mencap, proved crucial. Their expertise, flexibility and responsiveness helped the project get off the ground more quickly, provided infrastructure such as training premises and childcare, assisted in reaching and engaging families and facilitated co-production. Equally the process proved that it takes time to learn each other's priorities, timescales and *modus operandi*.

- A small number of family carers and staff from the Community Learning Disability nursing team were **trained to delivery PBS, E-PaT and Resilience courses**, which enabled their continuation of these workshops in the county in the future and for these courses to be embedded into the services on offer to families.
- **Costs** were kept as low as possible in this pilot. Many partner agencies provided substantial in-kind support and used their own budgets e.g. to deliver training. Going forward, budgets need to accommodate the costs of publicity, childcare, room hire, family carer co-facilitators' fees, travel and administration.
- Trainers will need **refresher training and input over time to maintain standards and consistency** and ensure they keep up to date. Over time new professionals and family carers will need to be recruited and trained.
- Ideally if the three programmes were **embedded in Cumbria's local offer** and run frequently enough, this would maximise their accessibility.
- **A budget is needed for administration, coordination and to support partners to contribute more time to planning.** Lack of funding aggravated partners' limited availability and competing workloads and contributed to project slippage, some missed opportunities to engage other agencies and arguably a lack of development of the partnership itself. Possibly as a result the steering group remained heavily NHS focused and had no representatives from the LEA, SEND, or Children's Service, nor any family carers. No budget had been factored in for contingencies or new costs emerging, but luckily Public Health England funded the creche, once it was recognised that this was essential. Possibly the limited infrastructure contributed to some original aspirations not being pursued. *'some nice ideas fell by the wayside'*. One of these was the development of a pathway plan for children whose behaviours challenge.
- A programme like this, aiming for cultural and practice changes **needs a communication strategy** from the outset. Relying on existing networks is inherently limited. More effort is always needed to recruit a comprehensive range of agencies who work with children with learning disabilities over their life-course, rather than sticking to existing sectoral and professional relationships. Working with the geography if Cumbria emerged as a key factor to successful delivery and relevant to any future programme in Cumbria or elsewhere. In order to ensure attendance and

accessibility for relevant families, the programmes need to be brought to them rather than the other way around. This implies running numerous if smaller sessions around the county.

- **For families, location proved to key to engagement as was building trust and taking time to establish a relationship**, before expecting people to attend a programme. Endorsement by other parents and the joint facilitation by family carers also served to boost attendance. By all accounts everything has to be quite localised in Cumbria as communities are quite discrete and disparate. In turn this would address the immense travel, childcare and associated considerations, but possibly means small numbers at each course.
- **Recruiting schools and family carers** was shown to be an art in itself. Schools require a bespoke and early approach, but also need to be convinced of the need to prioritise this programme over multiple other pressures. LEA's decreasing governance, amidst schools' academisation, adds a further hurdle and point to the need to also approach schools individually.
- School's participation in '**Positive Behavioural Support**' (PBS) workshops requires a shared understanding of PBS. Unfortunately, this evaluation found that the term had multiple, conflicting, meanings and forms of application, which undermined the recruitment of schools. DfE endorsement of the NHS and NICE approach to PBS would help secure some leverage with schools, and help address misconceptions that they are already applying PBS.
- **Families' descriptions** of how they were routinely side-lined, ridiculed or even blamed for their children's behaviour, ignored by health, education and other services and effectively refused their entitlements to support plans or services, exemplified the capriciousness of current services. Many had had to navigate their way through complex systems and jargon and find their own solutions. Or none. The isolation imposed by their caring responsibilities was aggravated by the effort and time required to research potential diagnoses, press for referrals, undergo multiple disparate or overlapping assessments, and if lucky get professionals '*to see what I see*'. But this relied on learning how to present their child's needs in professional jargon, or 'luck'. CEIP programmes came as a huge relief, not just because of the focus on communication and behaviour, but also for showing respect for family carers and recognising their needs.
- The **strategy and recommendations** developed by the family carers offer sensible ideas for taking this work forward and improving the lot of children and young people whose behaviours challenge. These largely build on existing national and local policies and so do not require reinventing the wheel. Moreover, the three programmes piloted and the model of family carer involvement could feed into the recommendations around pathways of care.

Appendices

Appendix 1: Documents used by CBF as part of the CEIP strategy review and referred to in report

- Cumbria Children and Young People's Plan (2016-19)
- Cumbria Early Help Strategy (2016-21)
- Cumbria Transformation Plan (2015-20) and 2018 refresh
- Cumbria Health and Wellbeing Strategy (2016-19)
- Scoping the workforce development needs of health and social care providers delivering Positive Behavioural Support for those with Learning Disabilities across the North East and Cumbria: A report of a collaborative action research project conducted October 2015-July 2016 Commissioned by Health Education England North on behalf of NHS England North East & Cumbria For the Workforce Development Task & Finish group of Transforming Care Programme (2016)
- Healthier Lancashire and South Cumbria Sustainability and Transformation Plan 2016/17-2020/21
- West North & East Cumbria Sustainability and Transformation Plan 2016-2021
- NE and Cumbria Transforming Care Community Model for people with Learning Disabilities and / or Autism
- NHS Cumbria CCG Transforming Care Programme Learning Disabilities (2016)
- DH Winterbourne View Review: Concordat: Programme of Action
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213217/Concordat.pdf
- Building the Right Support. <https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>
- Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. <https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf>
- Developing support and services for children and young people with a learning disability, autism or both. <https://www.england.nhs.uk/wp-content/uploads/2017/09/developing-support-services-children-young-people-with-learning-disability-1.pdf>
- Reducing Restrictive Intervention of Children and Young People. The Challenging Behaviour Foundation and PABSS (2019) <https://www.challengingbehaviour.org.uk/learning-disability-assets/reducingrestrictiveinterventionofchildrenandyoungpeoplereport.pdf> 23
- No Safe Place: Restraint and Seclusion in Scotland's Schools. Children and Young People's Commissioner Scotland (2019). <https://www.cypcs.org.uk/ufiles/No-Safe-Place.pdf>
- Developing support and services for children and young people with a learning disability, autism or both. NHS England and Local Government Association <https://www.england.nhs.uk/wp-content/uploads/2017/09/developing-support-services-children-young-people-with-learning-disability-1.pdf>
- Learning Disability and behaviour that challenges: service design and delivery
<https://www.nice.org.uk/guidance/ng93>
- Joint local area SEND inspection in Cumbria, May 2019. <https://files.api.ofsted.gov.uk/v1/file/50079132>
- DH (2012). *Transforming Care: A national response to Winterbourne View Hospital* [Online]. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf.

Segregation in Mental Health wards for children and young people and in wards for people with a learning disability or autism. CQC, May 2019.

https://www.cqc.org.uk/sites/default/files/20190626_rssinterimreport_full.pdf

‘Far Less Than They Deserve’: Children with learning disabilities or autism living in mental health hospitals. Children’s Commissioner, May 2019. <https://www.childrenscommissioner.gov.uk/wp-content/uploads/2019/05/CCO-far-less-than-they-deserve-2019.pdf>

‘Investigation into learning disabilities services run by major NHS contractor after police brought in over abuse of patients.’ The Independent, 10th May 2019. <https://www.independent.co.uk/news/health/care-home-abuse-care-learning-disability-cygnnet-whorlton-hall-durham-cqc-a8908081.html>

The NHS Long Term Plan. January 2019. <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan-june-2019.pdf>

NICE Learning Disability: Behaviour That Challenges Quality Standard (updated 2019)
<https://www.nice.org.uk/guidance/qs101>

Emerson E., & Einfeld S. (2011). *Challenging Behaviour* (3rd ed.). Cambridge University Press, Cambridge: UK.

Families Special Interest Research Group of IASSIDD (2014). Families Supporting a Child with Intellectual or Developmental Disabilities: The Current State of Knowledge. *Journal of Applied Research in Intellectual Disabilities*, 27, 420–430.

McGill, P. (2008). Residential Schools for Children with Learning Disabilities in England: Recent Research and Issues for Future Provision. *Tizard Learning Disability Review*, 13(4), 4-12.

Hastings, R. P., Allen, D., Baker, P., Gore, N. J., Hughes, J. C., McGill, P., ... & Toogood, S. (2013). A conceptual framework for understanding why challenging behaviours occur in people with developmental disabilities. *International Journal of Positive Behavioural Support*, 3(2), 5-13.

Hastings, R. P., & Beck, A. (2004). Practitioner review: Stress intervention for parents of children with intellectual disabilities. *Journal of Child Psychology and Psychiatry*, 45(8), 1338-1349.

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47(4-5), 217-230.

Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *Journal Information*, 107(6).

Hastings, R. P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual and Developmental Disability*, 27(3), 149-160

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50(3), 172-183.

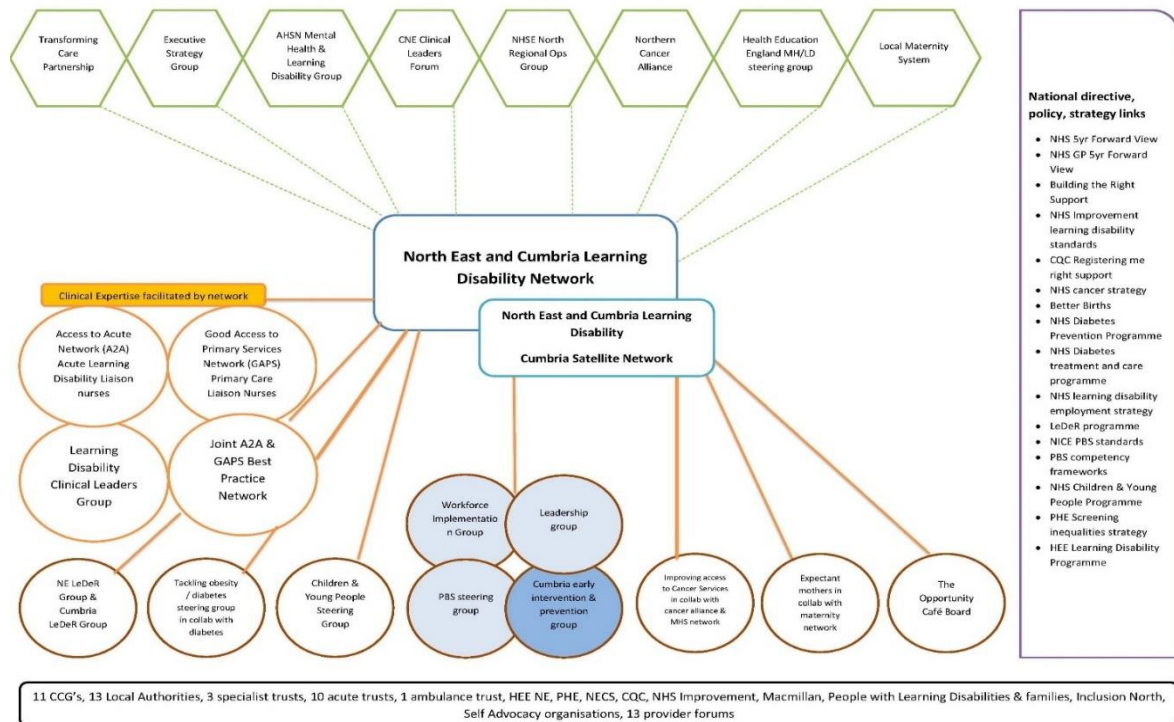
Naylor, A., & Prescott, P. (2004). Invisible children? The need for support groups for siblings of disabled children. *British Journal of Special Education*, 31(4), 199-206.

Neece, C. L., Blacher, J., & Baker, B. L. (2010). Impact on siblings of children with intellectual disability: The role of child behavior problems. *Journal Information*, 115(4).

Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior problems: a transactional relationship across time. *American journal on intellectual and developmental disabilities*, 117(1), 48-66.

The Challenging Behaviour Foundation. (2014) Early Intervention for children with learning disabilities whose behaviour challenges. <https://www.challengingbehaviour.org.uk/learning-disability-files/Briefing-Paper.pdf>

Appendix 2: Diagrammatic plan of Cumbria NHS learning disability work- is this correct



Appendix 3: E-PAtS Publicity leaflet Barrow – 2019

Are you a family caregiver for a child who has a learning disability, global developmental delay or
Autism aged 0-5?

Diagnosis is not necessary

Then you might be interested in attending

Early Positive Approaches to Support (E-PAtS)

E-PAtS is an 8 session group that provides sensitive support and information for families in the early years. All groups are facilitated by a trained family caregiver and professional and cover:

- Accessing services and supports
- Emotional wellbeing and resilience for caregivers
- Supporting sleep for children
- Supporting communication
- Supporting skills development
- Positive approaches to behaviours that challenge

In E-PAtS **you are always the EXPERT on your child**. You will have the opportunity to work alongside other families to build on ways to support yourself, your child and family. **You will never be judged or told what to do**

Meet with a facilitator week commencing 15th April 2019 – to be arranged when convenient for you and your family

The following sessions will be held at Bram Longstaff nursery, Barrow
with crèche facilities for your child

Week 1 – 25th April 2019 09:30- meet at the crèche for a 10:00 start – 12:30

Week 2 – 2nd May 2019 10:00-12:30

Week 3 – 9th May 2019 10:00-12:30

Week 4 – 16th May 2019 10:00-12:30

Week 5 – 23rd May 2019 10:00-12:30

Week 6 – 30th May 2019 10:00-12:30

Week 7 – 6th June 2019 10:00-12:30

Week 8 – 13th June 2019 10:00-12:30

If you would like to find out more about how you can take part, or have any concerns about the time or dates please contact

Nicola for an initial chat or to request further information pack (01229 404693)



TIZARD
University of Kent



NHS
Cumbria Partnership
NHS Foundation Trust

Copyright © 2012 Tizard Centre, University of