



Parents are your
Superpower!

The Cumbria Early
Intervention Pilot.

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Parent/Carer.

Challenging
BEHAVIOUR
Foundation



making a difference
the lives of people
with learning disabilities

Coproduction in action.

- ▶ How did I get here today?
- ▶ The Cumbria Early Intervention pilot with the CBF and Tizard Centre as national experts.
- ▶ Challenging Behaviour Foundation advocated for funding to pay families properly for their input.
- ▶ The following presentation has been fully coproduced. I have been paid to write and present it.
- ▶ The results of the pilot could be a piece of pioneering work of national relevance.
- ▶ Ambitious. An opportunity not to be wasted.
- ▶ We have things to ask! Action is needed!

HELP !



Behaviours that challenge.

- ▶ Children and young people with learning disabilities are more likely to display behaviours that challenge in comparison to their peers. From very young ages.
- ▶ It is their best way of getting their needs met, they do not have the communication or social skills for this to happen in another way.
- ▶ This increases the risk of the following poor outcomes for the child and young person and their families.
- ▶ Physical health, including diagnostic overshadowing and misdiagnosis.
- ▶ Mental health including diagnostic overshadowing and misdiagnosis.
- ▶ Isolation/social exclusion.
- ▶ Institutionalisation.
- ▶ Poverty.

The cost of not getting it right.

- ▶ **£250,000** to place one child as an inpatient in an assessment and treatment unit. (2014)
- ▶ 2017 Dame Christine Lenehan's report found 6146 children boarding in residential schools and colleges costing **£500** million per year.
- ▶ Residential schools are often far from home.
- ▶ **£379,000**: Annual average cost for an adult who displays severely challenging behaviour.
- ▶ The human cost is even greater. Lost opportunities for full enriched family life for the child and parents.
- ▶ This is in *addition* to the financial and emotional costs associated with disability when behaviour is not a concern.



OPPORTUNITY →
← FAILURE



Lucy.
Our story
of
success.



Lucy's strengths

- ▶ Sense of humour and love of slapstick.
- ▶ Resilience
- ▶ A brilliant memory
- ▶ Musical
- ▶ Self reliance
- ▶ Determination
- ▶ Apart from a very serious illness at 18 months old, good health.



Challenges that Lucy's disability brings.

- ▶ A severe learning disability.
- ▶ High levels of anxiety.
- ▶ A concrete understanding of the world.
- ▶ Very limited danger awareness.
- ▶ Communication skills that require support of people who know her well, especially in social situations.
- ▶ Fine motor skills that require support eg. dressing, toileting.
- ▶ In social settings Lucy will sometimes use behavior to communicate her needs.



A PBS success story. With luck and good timing.

Introduced to Positive Behavioural Support early. Though could have been earlier.

5 days of training from Tizard Centre.

3 days training from CBF.

Friends and colleagues who work in the field.

A personal interest.

It all fell into place recently, Lucy has well managed needs and doesn't often need to use behaviours to express herself.

Lucy has increased confidence in us, as parents, to provide the support she needs. She can tolerate, even enjoy, situations she previously found impossible.



Beth's story.
“Tumbling
through the
system”

The Cumbria Early Intervention Pilot

Part 1. A collaborative approach.

E-Pats Early Positive Approaches to Support. An 8 week course co delivered by a parent carer and a professional. Both paid and trained to deliver the entire course content.

Positive Behavioural Support training from the CBF. Delivered by a trained professional and a paid parent/carer. Both trained together to deliver the course. Families and practitioners receive 2 days of training.

Day 1 family carers and paid carers are trained separately, but the content is the same. Day 2 they come together for the training to move forwards together.

Resilience workshops which will take place soon. With the intention of using family carers as trainers.



Families are your superpower.

Part 2. Views and experiences.

- ▶ Organised, facilitated and coproduced by the Challenging Behaviour Foundation.
- ▶ 1: Focus group June 2018, a small group of parents from across the county came together, in their spare time, to try to improve things for themselves and future families.
- ▶ 2: A larger focus group November 2018. With the same willingness from parents.*
- ▶ 3: Family/carer survey to try to reach wider and further.
- ▶ All families that came together shared similar experiences.

- ▶ **Many solutions were found quickly and easily.**
- ▶ *Challenging Behaviour Support Cumbria Facebook page was set up on that day by a parent and has 312 members.

What works well in Cumbria? Family viewpoint.

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- ▶ Increase in number of children's learning disability nurses. Fantastic support when people know about them.
 - ▶ SENDIASS service when people know about it.
 - ▶ Max card when people know about it.
 - ▶ There are many skilled practitioners across education, health and social care . These relationships, when they are positive, are valued by families. Not all families have had good experiences though.
 - ▶ Self referral to Carlisle springboard.
 - ▶ Family led voluntary support groups, Facebook groups, filling some of the gaps.
 - ▶ **The national pilot for early intervention must not be wasted.**



Problems as identified by family carers. It's like a lottery!

- ▶ Parents report finding out about relevant support and services by word of mouth, by luck or by accident. Or not at all. Some parents arrived at the CBF course upset as they had found out about it by word of mouth.
- ▶ Families were too often unaware of Parent Carer forum (South especially), Transforming care, PBS, the SEND reforms and the Local Offer adding that the local offer page is not easy to use.
- ▶ Support isn't **offered** when it is needed, it has to be fought for; perpetuating a lack of trust between services and their users. Or parents only access support if they ask the right question. (Episodes of care is applied variably)



Problems continued.

- ▶ When services are not available eg due to staffing, the issue stops there. Lack of reporting of unmet need; increasing as service providers become used to cuts.
- ▶ Lack of specific services. In particular, Paediatric support, mental health support, SALT.
- ▶ Parents are denied the opportunity to be an expert on panels when decisions are being made about their child. (For diagnosis of autism, application for social care etc.)
- ▶ Systemic challenges eg accessing social care assessment via safeguarding hub. This prevents parents asking for help.
- ▶ EHCP's are used as ieps not a way to plan integrated support to families.



And...

- ▶ Who and where are the families? Is it known who needs support? The low response rate (38 families) to the survey supports the issue that families are not being reached.
 - ▶ Across the board there is a gross lack of understanding about learning disability and autism. Especially understanding that behaviours are an expression of need.
 - ▶ Over the years there has been a lot of well intentioned work but no cohesion, no pathway. Ultimately little action.
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In short

- ▶ Interventions are not reaching enough families *in time* because it is not known who and where we are.
- ▶ Families in need do not know who to ask, and what to ask for.
- ▶ They are often not believed when they do.



Solutions summary.

- ▶ A commitment from commissioners to address the issues highlighted in the focus groups and survey.
- ▶ A joined up system of support for children with learning disabilities and autism between education, health and social care with no age barriers. Make the EHCP work.
- ▶ A commitment to valuing parents as partners and creating paid roles within services; recognizing that parents, as experts by experience, bring a clarity of vision to services that only they can bring.
- ▶ A commitment to meeting the needs of this small often hard to reach group of people, with the understanding that by meeting those needs, many needs of the wider community will be met. Whereas the converse is not true.
- ▶ The right support and information at the right time. (Including crisis support.)
- ▶ This pilot to become permanently funded. Courses and co production.

We need you use your superpower. Co-production.



- ▶ Allow the work that has begun to continue, fund a specific co production group for Cumbria families of children with learning disabilities and autism whose behaviours challenge.
- ▶ Commit to valuing parents as **paid** partners. Roles recognizing that parents, as experts by experience, bring a clarity of vision to services that only they can bring.
- ▶ Employ parents as **experts by experience** as colleagues in Learning Disability and Autism Teams. Following on from the success of co-facilitation of E-pats and CBF courses
- ▶ Ensure increased visibility and efficacy of the Parent Carer Forum. Accessible to all, available to all.
- ▶ Commission (pay) parents to be on the transforming care steering group.



We need you to know who and where we are.

- ▶ Collect meaningful data to know who and where families are so that targeted and focused support can be commissioned.
- ▶ By establishing and **maintaining** a data base to ensure no family slips through the net. Use schools and nursery settings as a starting point. EHCP's are too late. The learning disability register is hard to find, voluntary and not clear.
- ▶ End the word of mouth lottery to accessing support.



We need you to provide easy access to the support that is available.

- ▶ Develop a Cumbria wide pathway for children with Learning disabilities and autism in co production with families.
- ▶ To include the continuation of the early intervention courses.
- ▶ Commission paid navigator roles (see Frome model) in local hubs to guide families through the complex and fragmented systems for health, education and social care. One phone number for referral to any service. The navigation hub keeps up to date with the ever changing environment, families don't have to. **This will allow an accurate reporting of unmet need back to commissioners.**
- ▶ Employ key workers for families where needed. In line with NHS long term plan.



We need you to address the inequalities of provision in health and social care

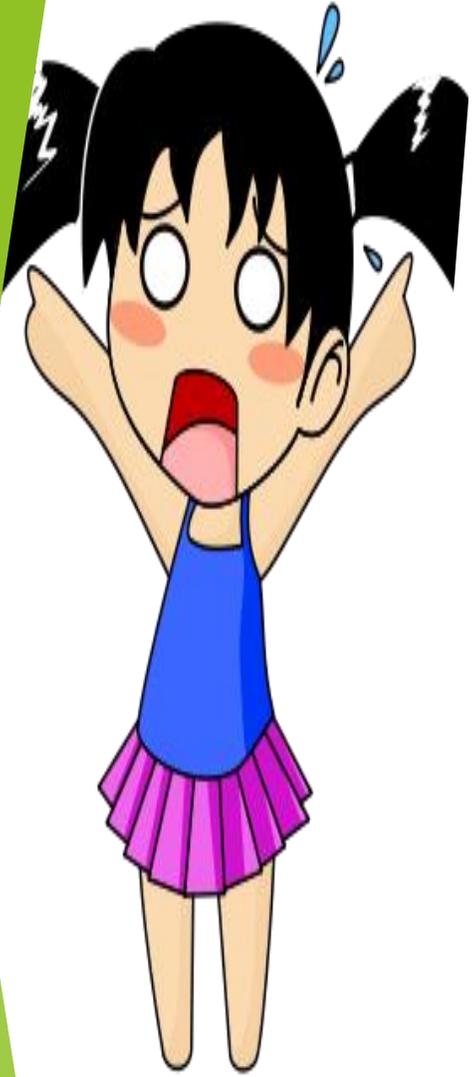
Urgently improve the unmet health and social care needs of children with learning disabilities and autism in Cumbria.

All families at the first focus group had at least one shocking experience of dismissive attitudes towards the needs of their children.

End the one size fits all approach of Episodes of care by reviewing people with long term needs, (in line with the NHS long term plan). The EHCP does not do this effectively.

Provide lifelong support, no age discrimination, no cliff edge at transition.

HELP !



We need **everyone** to understand that behaviour is a communication of unmet need(s).

Continue to provide training for families.

Provide training into schools, respite settings, to health professionals and social care staff. For everyone that supports families.

PBS Competencies.

The background features a white central area with a large, stylized question mark in blue and purple on the left. To the right, there are several overlapping green geometric shapes in various shades, creating a modern, abstract design.

Questions and discussion!

Thank you.

Frome article.

https://www.theguardian.com/commentisfree/2018/feb/21/town-cure-illness-community-frome-somerset-isolation?CMP=share_btn_link