

Cumbria Family Carer Focus Group

6 November 2018



This report summarises the second family carer focus group held as part of the Cumbria Early Intervention Pilot for **children with learning disabilities or autism and behaviours described as challenging**. It was organised by Jacqui Shurlock (The Challenging Behaviour Foundation) and Debbie Austin. (Family Carer). Thank you to all the family carers and professionals who attended and shared their experiences and views.

Attendees:

Family Carers: Leone Edwards, Dawn Esty-Meehan, Lisa Heppleston, Stuart Heppleston, Tracey Benson-Naylor, Emma Crabtree, Charlotte Wight, Debbie Austin, Vicky Threlkeld, Kerry Howarth, Sally Crosby, Sharon Seddon, Susan Rhind, Lisa Hickey, Wendy Askew, Shirley Murphy (Cumbria Parent Carer Forum)

Service representatives: Jo Wilcox (Community Learning Disability Team), Lynne Jones (CCG), Helen Leader (SENDIASS), Jacqui Shurlock (The Challenging Behaviour Foundation)

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1. Information for families

There were a number of presentations during the day to let families know about the early intervention pilot and about organisations which may be able to offer them support.

Challenging behaviour

Jacqui Shurlock explained the work of the national charity the Challenging Behaviour Foundation (CBF). The mission of the CBF is to improve understanding of challenging behaviour, empower families with information and support, and lead the improvement of services and opportunities for people with severe learning disabilities who display challenging behaviour. See www.challengingbehaviour.org.uk

Jacqui also explained national work the CBF has led around early intervention (see www.pavingtheway.works for more information.) Jacqui was asked whether early intervention just meant early years and she explained that it includes a focus on the early years but is about intervening early when a child starts to display behaviours that challenge, regardless of how old they are. As an approach it is not limited to younger children.

Cumbria early intervention pilot

Lynne Jones explained the Cumbria Early Intervention Pilot and the training available to families through the pilot. All three training opportunities have been co-developed with families working alongside professionals.

- **Early Positive Approaches to Support (E-Pats)** training is for families of children age 0-5 with a learning disability, autism or developmental delay who may be at risk of displaying behaviours described as challenging. It is delivered by a professional and a family carer co-trainer working together. The E-Pats training for this pilot has all taken place now.
- **Positive Behaviour Support (PBS)** training helps a family carer and a member of staff who supports their child to work alongside each other to understand the reasons for their child's behaviour and develop a behaviour support plan. It will be held at one or two schools in Cumbria (locations not yet confirmed). Families who are interested should contact lynne.jones15@nhs.net.
- **Resilience Training** uses a mindfulness approach to help families cope with the stresses and strains of caring for a child with a learning disability or autism whose behaviour is described as challenging. Families who are interested should contact lynne.jones15@nhs.net.

Family carer perspective

Debbie Austin gave a family carer perspective on positive behaviour support (PBS) and the early intervention pilot, including her role as a co-facilitator of the E-Pats training and the PBS training. Debbie explained the huge difference that using a PBS approach has made to her daughter and to family life. She described it as "just a way of life" For example, Debbie explained how PBS has

helped with everyday tasks which could otherwise prove impossible, such as administering a nasal spray.

Debbie only found out about the early intervention pilot via her professional role, rather than as a family carer and explained how she wants to see change which means families are aware of the information and services which can make a difference to them and are able to get their child's needs met effectively.

Children's Community Learning Disability and Behaviour Support Service

Jo Wilcox explained the role of the service: to provide support to understand and meet the health needs of children with learning disabilities, global developmental delay and autism .

The service does this by:

- **Group based parent programmes and workshops to support understanding of child's needs.**
- **Facilitating peer-to-peer support**
- **Advice and information**
- **Subsequent to this for some families the service provides targeted individualised health interventions.**

Jo explained that they are commissioned to work with children and young people with learning disabilities up to the age of 18 but can only provide targeted individualised health interventions to children up to the age of 11 with autism where there is no learning disability. There was discussion about how valuable this support is but how disappointing for many families that with children over the age of 11 they were not eligible for further support.

The group wanted to make sure this point was fed back, especially as for some young people behaviours that challenge do not start to become significant until puberty onwards. It was pointed out that the broader definition of early intervention (intervening early when behaviours become apparent) would be more useful for families. Jo had sympathy with this perspective but explained that difficult choices had been made about where to target the limited resources the team had available.

For more information contact childrenslearningdisability@cumbria.nhs.uk

webpage <https://www.cumbriapartnership.nhs.uk/childrens-ld>

South Cumbria (Barrow and Millom South Lakes) 01229 40469

East Cumbria (Carlisle and Eden) 01228 603195

West Cumbria (Allerdale and Copeland) 01900 705081

Referrals can be made by parents or professionals.

The Cumbria Special Educational Needs and Disabilities Information Advice and Support Service (SEND IASS)

Helen Leader explained that the SEND IASS services offers impartial and confidential support to parents and carers of children with special educational needs or disabilities (SEND) and also to young people with SEND. For example, help with education, health and care plans (EHCPs), support with case work, dispute resolution and advice on information and support available. Helen explained some of the challenges the service faces, including financial cuts combined with increasing demand for support which means that staff do not always have enough capacity. In addition, there are some cases where children are not getting the health funding they need via Children's Continuing

Healthcare. Please contact Helen direct with any feedback about the service. If you need support, details of co-ordinators are below and Helen's slides are attached at the end of this note.

Carlisle Area:

Tracey O'Roarty - T: 07825 088031 - Email: tracey.oroarty@cumbria.gov.uk

Penrith and Kendal Area:

Emma Stephenson - T:07769 935446 - Email: Emma.stephenson@cumbria.gov.uk

Copeland, Coniston and Ambleside:

Sally Godfrey - Tel: 07795 110940 - Email: sally.godfrey@cumbria.gov.uk

Allerdale Area :

Susan Eastwood - Tel: 07824 408922 - Email: susan.eastwood@cumbria.gov.uk

Barrow, Ulverston and Grange Area:

Celia Jones - Tel: 01229 407439 - Email: celia.jones@cumbria.gov.uk

Cumbria Parent Carer Forum

Shirley Murphy explained that Parent Carer Forums are representative local groups of parents and carers of children and young people with disabilities who work alongside local authorities, education, health and other service providers to ensure the services they plan, commission, deliver and monitor meet the needs of children and families. Shirley chairs a constituted group of parents/carers/grandparents/foster carers in Cumbria who have children with disabilities and/or special educational needs.

See www.cumbriaparentcarerforum.org.uk

Shirley explained that the forum is not as active in the South of Cumbria as they would like it to be and that they need more members and representatives from the South. Please get in touch with Shirley if you are interested in this: hello@cumbriaparentcarerforum.org.uk

During the course of the focus group there was also discussion about the importance of the Forum representing the views of families whose children challenge and suggestions for how this group might be better represented to local services and decision makers.

2. Ideas for change and improvement from families

The previous family carer focus group highlighted serious concerns from families about unmet needs and services that were not working for them or which they were not even aware of. The aim of this session was to explore in more detail some ideas for change, stemming from the previous group and from today's discussion.

Reaching families with information

One of the key issues identified at both focus groups was that families struggle to find out what support is available for them in Cumbria and how to access it. We asked families to list the best ways of getting in touch with them in order to share information, so we can use the list to circulate the survey that will go to families as part of the early intervention project. We also asked families to tell us which professionals it would be helpful to get information from. The lists are at Annex 1.

ACTION: Most families used Facebook to get information and Wendy Askew offered to set up a Cumbria families positive behaviour support (challenging behaviour) forum on Facebook for this group of family carers. It was suggested that every professional should have information for what is available in order to pass on to parents.

Hearing the voice of families of children who challenge.

Families of children with learning disabilities or autism whose behaviours challenge are too often isolated and it is difficult for their voices to be heard.

Some suggestions for how to address this included:

- We need to increase the visibility of the Cumbria Parent Carer Forum in Kendal/Barrow. The Forum is the voice of parents to decision makers so this group must be represented.
- Going into schools to promote the parent carer forum
- Promote PBS , training opportunities and other information via the new facebook group
- Parent Carer Forum to pick up key issues from the new facebook group and feed these back to services - need to know which services to link with (Cumbria wide)

ACTION: Parent Carer forum to consider/take forward the four actions above.

- Having a family carer from Cumbria on the early intervention pilot steering group
- Funding a group of families to take forward some action to address issues identified

ACTION: Early Intervention Pilot Steering Group to consider/take forward

Understanding and addressing unmet needs

- Debbie Austin identified a form developed by Kings College to record levels of unmet need. Could this be used by services in Cumbria to quantify the issue and inform commissioners and decision makers? **ACTION:** Early Intervention Pilot Steering Group to discuss and share with relevant groups.
- The previous focus group listed some gaps – families wanted to see more focus groups to find out what’s going on in more detail
- Issues which came up in this focus group, in addition to those identified previously, were:
 - GAP post 11 for those with autism and no learning disability. How many missing out? Adolescence. Exacerbated by late diagnosis, EI when needed, not by age.
 - Families feel excluded by the autism, assessment (MAAT) process; how can this be addressed?
 - Dismissal of parents concerns, judgements on parenting
 - Border issues with Lancashire – different provision and info on each side of the border, lack of understanding among schools of the other county.
- The Children with Disabilities sub group was identified as the forum which needs to understand the issues families have shared. Families suggested some ways they might be able to do this:
 - Physically – group of parents to attend
 - Report of the focus groups– to be read out or signed by parents
 - Videos – visual explanation of gaps relating to life situations

ACTION: CBF to explore with SENDIASS and Parent Carer Forum how to arrange this.

- Families also suggested issues could be raised more widely, through:
 - Petitions- through media- raising the profile, so it becomes public knowledge
 - MPs
 - Via Parent Carer Forum/SENDIASS
 - At other strategic multi-agency meetings

Family Vision of Support

Families discussed what “Utopia” would look like, if they and their children had all the support they needed. The vision included:

Information

- Navigator role – person employed in each district
- A phone number to speak to a navigator who can direct you to the right support – paid job, several people
- A directory that brings together all agencies and healthcare professionals

Support

- “Portage” style support lifelong
- No age restriction for support
- Continuing and dynamic support specific to the changing needs of the child – opt out not in
- Physical hub to meet other families and professionals
- All year round service provision (including holiday clubs)
- Passport for all at hospital (help children via a virtual visit, virtual film of departments)

Welcoming attitude and understanding of support needed rather than dismissal of family concerns over behaviour

- User friendly referral service also for family/siblings
- One easy referral form, not asking for lots of data eg GP postcode
- Would be good not to have trust issues with services- it’s hard to trust people as everything feels like there is a financial agenda
- Hidden disability awareness scheme
- Cumbria to acknowledge or provide support for PDA

ACTION: CBF to explore whether we can develop a graphically illustrated version of the Cumbria vision, combined with “what works” from the previous focus group note. This would be a useful summary to share.

3. Actions agreed

ACTION	WHO?	WHEN?
1. We need to increase the visibility of the Cumbria Parent Carer Forum in Kendal/Barrow. The Forum is the voice of parents to decision makers so this group must be represented.	Shirley Murphy, Parent Carer Forum	We have 2 disability information days planned for January & February 2019 in Kendal & Barrow.
2. Explore suggestion of going into schools to promote the parent carer forum	Shirley Murphy, Parent Carer Forum	We will look into this in January by approaching schools and attend parents days
3. Promote PBS, training opportunities and other information to families via a new Cumbria families PBS facebook group	Wendy Askew, Parent Carer Forum	
4. Parent Carer Forum to pick up key issues from the new facebook group and feed these back to services - need to know which services to link with (Cumbria wide)	Wendy Askew, Parent Carer Forum	
5. Have a family carer from Cumbria on the early intervention pilot steering group	Lynne Jones to add to agenda for discussion at Early Intervention Steering group	
6. Fund a group of families to take forward some action to address issues identified	Lynne Jones to add to agenda for discussion at Early Intervention Steering group	
7. Debbie Austin identified a form developed by Kings College to record levels of unmet need. Could this be used by services in Cumbria to quantify the issue and inform commissioners and decision makers?	Lynne Jones to add to agenda for discussion at Early Intervention Steering group	
8. Families to share issues identified with the Children with Disabilities sub group once we have survey results from a wider group of families in Cumbria	Jacqui Shurlock (CBF) to explore with Helen Leader (SENDIASS) and Shirley Murphy (Parent Carer Forum) how to arrange this.	

9. Explore whether we can develop a graphically illustrated version of the Cumbria vision, combined with “what works” from the previous focus group note. This would be a useful summary to share.	Jacqui Shurlock (CBF)	
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Annex 1

How to get in touch with families directly?

- Facebook
- Twitter
- App
- Parentmail (schools use it to communicate to families)
- Person (trained/knowledgeable) at front of supermarket who you can talk to if your child has additional needs
- Inform SAT, SALT, Ed Psych, Paediatrician, so info can be passed on to parents
- Parent videos directing other parents to services
- Increased visibility of parent carer forum
- Every professional at every visit asks and check that the parent knows about DLA, Parent Carer forum and local offer and supports access
- Newsletter
- Database of all TC cohort of children
- Shirley Gilpin, family support worker, Kendal area
- NAS Jackie Bell furness@nas.org.uk
- Sally Percival, South lakes Autism and Aspergers group
- SENDIASS FaceBook page
- South Lakes special needs facebook page
- Nicola Brockbank – Family Autism Support worker, Furness area
- Cumbria parent carer forum cumbriaparentcarerforum.org.uk
- Autism Support Allerdale and Copeland facebook page www.asaac.co.uk
- Through School
- Children's LD team childrenslearningdisability@cumbria.nhs.uk and <https://www.cumbriapartnership.nhs.uk/childrens-ld>
- Lancs border schools where children from Cumbria go to school
- Cumbria Local Offer

How to get in touch with families via professionals?

- School nurseries
- Health Visitors
- Early bird courses – NAS, Jackie Bell, Furness@nas.org.uk
- Facebook forums (Furness Parents and Carers Disability Forum, Furness Parents and Carers Support group, Special needs parents, South Lakes)
- Barnardos/Portage
- Community Paediatricians
- SENCOs
- Social Workers
- SENDIASS
- Parent Carer Forum