

Cumbria Family Carer Focus Group

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This is a note of a focus group held with nine family carers from across the region of Cumbria who have children with learning disabilities or autism whose behaviours are sometimes described as challenging.

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The focus group was organised by Jacqui Shurlock from the Challenging Behaviour Foundation, in partnership with Debbie Austin, family carer, and supported by Lynn Jones, Strategic Workforce Development Manager, Positive Behavioural Support, North East and Cumbria Transforming Care Partnership. It formed part of the Cumbria Early Intervention Pilot.

Jacqui updated families on national work around early intervention for this group and Lynne and Debbie explained the pilot project. Family carers were then asked for their views and experiences of support and services in Cumbria.

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A VISION FOR OUR CHILDREN ♥

OUR CHILDREN Should have the same opportunities & experiences as other children

OUR CHILDREN Are trying to tell us things

OUR CHILDREN Should be valued, should be understood, feel safe & secure

A SUMMARY OF MESSAGES FROM FAMILY CARERS OF CHILDREN WITH LEARNING DISABILITIES WHO'S BEHAVIOURS CHALLENGE

AT EVERY AGE OUR CHILDREN NEED:

- 1 A keyworker to help us through the system
- 2 Everyone to use Positive Behavioural Support pro-actively
- 3 Proper Reasonable adjustments to ensure access to healthcare & community

AT EVERY STAGE WE NEED:

Information & training so we understand causes of behaviour & how to support change

Support for the practical difficulties we face (support from parents/professionals)

WHEN THEY ARE LITTLE (0-5)

- Early identification by experts!
- The right information & support, at the right time, in a form that is right for us

WHEN THEY ARE AT SCHOOL (5-16)

- Schools/services to work with us
- Local schools to rise to the challenge of supporting our children
- Professionals to help us access local mainstream & specialist support

AS OUR CHILDREN GROW UP (14-25)

- A keyworker, one-stop-shop for planning & delivery
- Appropriate housing options
- Activities - real choice including positive risk
- Lifelong learning
- Skilled support workers/carers

BETTER OUTCOMES FOR CHILDREN, FAMILIES & COMMUNITIES

WE NEED GOVERNMENT, LOCAL AUTHORITIES & HEALTH TO:

Show that you value disabled children

Think & talk about people not processes

- ★ Have a named Challenging Behaviour Co-ordinator
- ★ Deliver long-term planning & clear pathways
- ★ Employ keyworkers

- ★ Commission Positive Behavioural Support
- ★ Include specialist support within the "Local Offer" to respond to needs identified in Education, Health & Care Plans

- ★ Ensure access to responsive schools near home which work with parents to provide effective education

- ★ Develop a national strategy
- ★ Ensure a joined up approach

National families' vision of early intervention (CBF 2014)

What works well in Cumbria at present?

Families summarised the things that work well in Cumbria.

- Increase in children's learning disability nurses and the support they offer
- Carlisle Springboard – the fact that families can self-refer
- Photos/tools families have developed to share child and family journeys so professionals get to know children as individuals (eg photo album, communication passport)
- Own (family carer led) support groups
- Having EHCP workers (when they are skilled)
- SENDIASS (when people know about them and can access their help)
- Professionals who know the child and family well, have a relationship and a history
- The Max card, giving discounts and access to community activities for families of disabled children (when people know about it!)
- Good practitioners (examples shared were of good learning disability nurses, community nurses and health visitors, but this was not a universal experience)

What could be improved?

Communication/information provided to families: Most families were unaware of what support is available and had found out about particular services or forms of support by accident – by speaking to another parent or meeting someone through their work, for example. Some were unaware of key services available in the region, including the learning disability nursing team, and the Parent Carer Forum. Some families had never heard of the local offer and others found it unhelpful. Most parents were unaware of national guidance on best practice in support for children with learning disabilities and autism. Most were unaware of Positive Behaviour Support. Families reported a lack of systematic information sharing about what would be useful for them. It is no one's job to tell them what is available and what might help. When they sought advice from key professionals such as GPs, Paediatricians, schools, those professionals were also unaware of other support on offer in Cumbria.

Culture and attitudes of staff and services: All families at the workshop had at least one shocking experience of dismissive attitudes towards the needs of their children, some many more. For example,

- it was seen as acceptable for a child to be out of education for seven and a half months – families compared this to the reaction they would get if a typically developing child were out of school for this long.
- Adaptations required to the home of one young man took 11 years to be approved and completed
- A young man who is registered blind was seen by a health professional who did not read his notes and asked him to draw something on a piece of paper
- Health professionals talking about children/their behaviour/things likely to distress them while they are present and not making arrangements to be able to have a private frank discussion with parents
- It was a common occurrence for families to be told they could not get support from key services, including paediatrics, SLT, incontinence service because there was no one in post.

Families were not being told how this unmet need would be addressed or whether it was reported upward to commissioners and service leads.

- Parents felt they were often disbelieved or blamed for their child's behaviour

Families explained they would like to see more openness and transparency. They understand that services are stretched but their children have a right to have their needs met. Is it acceptable to say "we don't have this service/staff member" and just expect families to live with unmet need?

Support for families to know and get what they are entitled to. For example:

- Families all knew they were entitled to DLA but some were not able to complete the form and were not given support to do so. Those who had found support to complete DLA forms got this from the CAB or from Mencap Carlisle but not everyone knew this support was available.
- Most families were not aware that GPs are contracted to provide annual health checks for people with learning disabilities age 14 and over.
- Some families were not aware of the learning disability nursing team
- Families were not all aware they were entitled to a Social Care Assessment under the Children Act (1989) or a carers assessment.
- Even where families knew specific forms of support were available they did not know how to get referred to those services, whether they could self refer or who could help them to access the service.

The role of Primary Health Care. Most families had not had the Health Visitor check when their child was two years old although they knew typically developing children had received this. One family was told "well you don't need a Health Visitor now, you'll be getting all the support for disabled children." Another parent had contacted a Health Visitor asking for support and had no reply for six months. Families explained that this reflects a perception among generic health professionals that they can step back and hand over to specialists, when in fact no such specialist steps in to support families. Instead they are left to try and find the right sorts of support by themselves, which often happens by accident. GPs were generally unaware of where to refer children with learning disabilities and autism and had little understanding of challenging behaviour. Families explained that their disabled children often did not receive the healthcare they needed with many health problems going undiagnosed and untreated for long periods of time.

Team around the Child. Families were not clear whether this model still exists in Cumbria. Some had previously had a Team Around the Child and it was felt that this more co-ordinated approach is helpful.

Developmental support for children. Families explained that there used to be a blue developmental file to complete, which is no longer used. They did not want the same system reinstated but explained that it would be helpful to have some help to encourage good development and to know how best to support their children as babies onwards; especially at points of key developmental change. This would be particularly useful now Portage is much more limited and unavailable in some part of Cumbria.

MAAT (multi-agency assessment team) meetings for diagnosis of ADHD/autism. When cases are “borderline” families explained that people have to wait another 18 months. There is no input from parents and no input from other relevant professionals eg SLT.

What is missing/what doesn't work?

Good Healthcare. Families were clear that the lack of expertise among GPs and Health Visitors about learning disability, autism and challenging behaviour made it difficult for their children to access good healthcare. Combined with the difficulties in accessing support from a Paediatrician (see below) families felt this was putting children's health at risk and undoubtedly having an impact on behaviour as well. An example was given of a five year old child with a severe learning disability who had severely enlarged tonsils; she had twice suffered sepsis due to tonsillitis, she has no paediatrician, has not been fast tracked to ENT and until the age of five no one had looked in her mouth.

Continuity of care and support vs Episodes of Care. Learning disabilities and autism are lifelong conditions. However, families explained that there is no continuity of care and support. There has been a shift towards “Episodes of Care”. If done properly, families understood that one episode should lead on to another – for example a disabled child may be supported for speech, then another issue addressed. However, this is not what happens in practice. A specific issue is dealt with and then the individual is discharged. Families explained that this model may work for something which can be addressed fully with one intervention over a fixed period of time (eg, a broken arm). However, families were clear it is entirely inappropriate as a model of care for vulnerable children; known to be at risk of poor health and social outcomes when they have don't have the right support in place (eg Paediatrics, SLT, physiotherapy, OT) to review their health and development. Families explained that sometimes, once discharged from the care of a particular service, they do not know how to get referred back in when a problem arises. Even if they do know, the onus is then on the parent to spot problems or issues, rather than having regular reviews in place. This approach is entirely at odds with national research, guidance and best practice about support for children with learning disabilities. It relies on parents spotting issues rather than regular reviews and professionals having a preventative role in supporting good health and wellbeing.

Positive Behaviour Support (PBS). Positive Behaviour Support was not something families had been aware of unless they were part of the early intervention pilot or had been supported by one of the learning disability nurses. It was not an approach used by schools and families had not been offered information on or training in PBS.

Empowerment of families/co-production. Families appreciated the opportunity offered by this focus group to share their experiences and views on how support could be improved. Families stated that co-production with families was not common and that services, including schools, were generally bad at consulting families and working in partnership with them. The majority of families present were not aware before this meeting of the Parent Carer Forum and its role in developing a co-production strategy and were keen to be involved in future co-production opportunities.

Care co-ordination/keyworking. There is no professional role in place to support families to access the support they are entitled to and to navigate a complex system. That system is not joined up or

co-ordinated. Families were clear that their best route to find out what support was on offer was word of mouth from other families or simply by chance.

Paediatrics Most families present found it difficult to access a Paediatrician for their child, including those with complex health needs. Families were being told that there was a lack of Paediatricians but not told what was being done to address this or how their child's health needs can be met in an alternative way. One parent who tried to access the Paediatric service in Barrow was told she had to go to Kendal; but there was no service in Kendal. Families were extremely concerned about this situation.

Speech and language therapy Most families present had difficulty accessing speech and language support for their children, including children who had no speech and had already started school.

Equipment and adaptations The wheelchair service is currently based in Preston; a long way for families. There are satellite services in Kendal and Barrow but they are in a room with no hoist. One family had waited many years for agreed adaptations to their home.

Portage Portage is available in some areas but not others and is no longer what families used to understand as a Portage service as it is time limited. One family carer was told that as she was receiving Portage for her child they would not need OT.

Incontinence Team Families were not sure if there is still an incontinence team available in the South Lakes area.

Transition to adulthood Families felt it was particularly difficult to get health input to decisions about transition to adulthood.

Social work Families explained that the only route in to Social Care is via the safeguarding pathway. This does not feel appropriate to families who have disabled children. In addition, thresholds are so high that most families are not able to access any support from social care. It is difficult to access short breaks or support. One family carer explained that her friend was only able to access Social Care support by stating that she was in crisis and likely to harm herself or her children. Without this level of need families were clear there was no support from Social Care. Those who did receive social care input were told overnight respite in their own home was no longer available. If families want home respite overnight they have to save up their daytime hours. However, going to a respite centre is often difficult for children with significant needs or behaviours that challenge.

CAMHs Families experienced similarly high thresholds when trying to get support from CAMHs. There was no sense of early help to maintain wellbeing.

Physiotherapy Families explained they were not able to access physiotherapy for their children. They were either paying privately or not receiving any input from Physio.

Barriers/challenges

Families noted some of the barriers and challenges to better support. There was general agreement that there are ways to overcome all these barriers if there is commitment to do so.

- Families don't know what is available to access, don't know what questions to ask. This is made more difficult by:
 - Professional jargon/different terminology across services
 - The need for re-referral
 - Hoops to jump through to get support (eg Social Care)
 - Battling – not being believed about children's needs
 - Lack of understanding about learning disability/autism/challenging behaviour
- Geography of Cumbria. Both the rurality of the region but also the fact that there are different services available in different part of Cumbria, plus
 - North and south Cumbria have different CCGs
 - West and South lakes often miss out on services. Barrow and Kendal are far apart. Barrow and Ulverston often have services but this does not cover Kendal.
- No comprehensive disabled children's register in Cumbria to enable families to all get the right information and be put in touch with forms of support and other families.

What would make a difference?

Families were clear that some changes could be made fairly quickly and cost effectively which would make a real and immediate difference to children and families.

- **Information packs for families.** Families stated that the SEND local offer is not effective for families of children with learning disabilities or autism whose behaviours challenge and does not help them find what they need. They wanted to see very clear packs of information for this group of children, giving key information, explaining what is available in Cumbria (and nationally) in terms of support and clarifying for families what they and their children are entitled to. Families thought it might make sense to develop packs or directories of services relevant for different ages (0-5, 5-14, 14-25) and to ensure that families are given these at key points eg birth (where a child has a genetic condition), diagnosis and key developmental points eg starting school, year 9 review). Families thought it would be helpful to have a diagram showing all the different teams and services in Cumbria offering relevant services and support. Ideally there should also be a contact number for each and someone able to give overall signposting advice.
- **Develop a network** (email or social media) across Cumbria of families of children with learning disabilities/autism and behaviours described as challenging. This could be a network within the parent-carer forum, allowing information specific to this group to be shared more effectively and enabling families to be involved in co-production opportunities. Families identified the biggest challenge as locating the families and felt it would be helpful to have posters/information in key locations such as GP surgeries, schools, support groups with families and professionals in those settings able to identify people and link them to the network as appropriate.

- **Hubs in each locality.** In addition to the virtual network it was suggested that there could be monthly drop in sessions in different areas of Cumbria where professionals and support groups could be available to talk to families. The hubs could hold the directory of services and help people to access relevant support where re-referral is needed. This could link to the new app under development.

Families also suggested some changes they would like services to take forward to address some of the issues raised at this workshop.

- **Effective use of the 2.5 year health check.** Health Visitors should understand the key risk factors associated with learning disability/autism/challenging behaviour and should be able to share the information packs and signpost families to the learning disability team or other relevant support. It should not be acceptable to assume disabled children no longer need Health Visitor input.
- **Introduction of a family co-ordinator role** or key worker role to help families understand and access the support they are entitled to and to offer practical and emotional support. There are a number of ways this could be implemented. It might be a professional, or it could be a volunteer family carer (with the right infrastructure, training, supervision and support). This role could help to address the issue of no-one giving continuous support over time. Families could have a reminder email (eg on a child's birthday each year) of what they are able to access and to see if they need any help/reviews/assessments.
- **A system for services to record unmet need.** For example when families are told "you can't see a SLT/Paediatrician/OT/Physio etc as there is no one in post or a long waiting list" there should be a way to capture and record that so commissioners have clear data about the impact on families in order to consider how to address those unmet needs.

Co-production/partnership working with families

There was unanimous support from the 9 families present for the following:

- Offering families training alongside staff (the approach used in CBF PBS training)
- Employing family carers as co-trainers (as in E-Pats and the CBF PBS Training)
- At least one (ideally two) family carers to sit on early intervention pilot steering group
- Families of children who challenge to be represented in the co-production strategy led by the Parent Carer Forum
- Establishment of a family carer strategic group focussed on championing and driving forward early intervention for children with learning disabilities or autism
- Family carer representation within communities of practice
- Awareness raising for commissioners of family carer perspectives – training/co-production

All family carers present were keen to have continued involvement in the Early Intervention pilot and were interested in helping to shape and take forward the suggestions in the "what would make a difference" section.