

Responses to request on info for Violent and Challenging Behaviour (VCB) Support

Overview

Following our last WG2 meeting where we reviewed the SEND survey analysis it was decided that we needed more information about what was meant by parents when they said there was a requirement for 'More services to meet the needs of children with anger, social and emotional difficulties'. I volunteered to ask the question of parents in the various social media support groups around Cumbria for SEND parents. I received 62 responses, and the feedback is broken down as follows:

Geographical Area

Allerdale	8
Barrow	5
Carlisle	13
Copeland	9
Eden	11
South Lakes	5
Not stated	11

Age

Early years 0-4	3
Infants 5-7	12
Juniors 8-11	12
Secondary 12-17	18
18 Plus	7
Not stated	10

Gender

Male	41
Female	12
Not stated	9

Diagnosis (many gave more than one diagnosis so the total exceeds 62)

Autism	40
ADHD	7
OCD	3
ODD	1
SEMH	1
PDA	2
Dyspraxia	3
Dyslexia	2
Learning Disability	17
Downs syndrome	2
Selective Mute	2
Not stated	6

Detailed Feedback

The feedback from parents was wide and varied, but there were several themes that came up again and again, along with some ideas of how to improve the services for children and their families. When asking for this feedback I promised parents anonymity, and that in return I would feedback to them a summary of our discussions and any outcomes going forwards.

Significant themes

- Access to CAMHS is extremely difficult. Many children had referrals refused. Many children had one or two sessions only before being discharged, despite the problems not being resolved. Several responses said that CAMHS didn't understand the need to work at creating a relationship with the child over time in order to get the child to engage.
- Access to services is often not possible for children with Autism but no learning disability. This came up over and over again, with more than one parent stating that theirs were 'forgotten children'.
- In a number of responses, CAMHS offered meds as a first resort, and discharged with no follow up or alternative when families refused.
- 53 of the 62 responses mentioned a Parent Blaming culture from education and other services. Parenting courses are offered but they are often for neurotypical kids – which are of limited help for those with SEND.
- There are no services specifically for SEND and VCB despite it being a big area of need.
- Many parents felt that there is a systemic problem of professionals seeing children with VCB as naughty – as one parent put it 'they are too busy dealing with his anger to care why he is angry'. The 'root cause' is never sought out or dealt with so the VCB remains.
- Parents feel Transition from Children's to Adult services is poor and too early – why not 25 for SEND? There are no specialist services for VCB in adult services either.
- Several responses complained that Education, Health and Social Care don't work together, and as a result parents and children go round in circles to try and access help.
- Several responses said that they either couldn't get a community Pediatrician appointment, or that they were supposed to be seen yearly (or 6 monthly) but hadn't had an appointment for a long time, in some cases not for a number of years.
- Of the 55 respondents who said whether they were currently accessing services to help with VCB, 41 said they currently had no support or services involved.
- 17 responses said they had not asked for specific help, or had hesitated asking for help with their child's VCB because they were ashamed and felt they would be blamed or that Social services would become involved. Some said they were unaware it was a recognized problem and that they could seek help.

- 7 respondents stated their child had been excluded from school because of VCB and that they felt it wasn't dealt with appropriately.
- One parent sent me distressing video of their child exhibiting VCB due to anxiety. The parent said she felt alone and abandoned during COVID. (I put her in touch with the SEND Covid helpline)
- One parent detailed a child's suicide and felt strongly that lack of any help or support for VCB was a major contributor to their child taking their own life.

Suggestions from parents to improve services

- Easier access to CAMHS, and appropriately trained staff who know that engagement takes time
- CAMHS stop offering meds as first resort and don't discharge without alternative when meds refused
- Better transition to adult services – CAMHS and other services should go to age 25 for SEND
- Lots of parents suggested more appropriate schools or school places – school is a big trigger of anxiety as it is often not appropriate for Autistic and other neurodiverse kids, so VCB results. Many parents feel if the school is right for the child then VCB will reduce as a result.
- A dedicated team for VCB within the SEND system where people can go for help and support without blame or judgment
- Better support for SEND children (and their families) who are expelled from school
- Better access to support for children with autism but no learning disability
- More and better trained pediatricians
- Easier access to respite and a better understanding of VCB effect on the family and siblings
- Need a dedicated ASD service across Health, Education and Social care
- Two parents mentioned they use the Ross Green Explosive Child Method to help their children.
- One parent said the Nurture group previously used at the Guilford Centre for younger children had been very helpful.

Things parent say work well

- Learning disability nurses – they say we need many, many more!
- The new Autism academy – several parents praised their approach and said more spaces/schools like this across the county are needed
- Meds work well for some families
- Respite services work well for most who can access them