



Cumbria Parent Carer Forum

Report on the Feedback to a Cumbria Parent Carer Forum questionnaire to parents and carers in Cumbria regarding SEND provision in Cumbria – May 2018

Produced in conjunction with the Cumbria SEND Information, Advice and Support Service

Aims and objectives

Cumbria Parent Carer Forum (PCF) was seeking the opinions of parents and carers in Cumbria of SEND provision for their children and young people in terms of education, health and social care. They want to identify what the gaps in provision are and what the strengths and weaknesses are.

Methodology

In May 2018, the Chair of PCF and another steering group member worked with colleagues from health and the SEND Information, Advice and Support team to set up a questionnaire on Survey Monkey. The chair sent out an on-line link to this by email to 450 parents on the database throughout Cumbria. She also publicised the link on the PCF website and on the PCF Facebook page to reach as many parents and carers as possible. This questionnaire was open and available for parents to complete for several weeks and reminders sent out to parents to ensure as high an engagement rate as possible.

Analysis of feedback

Information from respondents

46 parents and carers responded to the questionnaire on line and gave their opinions to the 21 questions on a range of topics related to their experiences of SEND provision in Cumbria. They came from the following districts in Cumbria:

District	Percentage	Number
Barrow	23.91%	11
South Lakes	17.39%	8
Allerdale	15.22%	7
Copeland	21.74%	10
Carlisle	15.22%	7
Eden	6.52%	3
Total		46

Parents responded from all districts to the survey as demonstrated above. Parents indicated their children were: 33 male, 17 female 1 transgender. This mirrors the general rate of more boys having

SEND. 32 respondents stated they have 1 child with SEND, 13 have 2 children with SEND and 1 has 3 children with SEND.

This table shows the ages of the respondents' children/young people:

Age range	Respondents' children/young person
0-4	3
5-11	17
12-15	14
16-19	14
20-25	5

This table shows the primary diagnosis for the respondent' children/young people:

Primary Diagnosis for child/young person	Number
Autism	33
Deaf Hearing impaired	0
Down Syndrome	3
Moderate Learning Difficulties	6
Multisensory impairment	2
Physical disability	3
Physical and medical	5
Profound and multiple	5
Severe learning	11
Social emotional wellbeing	10
Specific learning difficulties	3
Speech and language and communication needs	9
Visual impairment	1

This table shows the education the respondents' children receive:

Nursery and preschool	3
Mainstream Primary	14
Mainstream Secondary	10
Special Schools	11
Out of County School	4
Further Education	3
Dual Placement Primary	0
Dual Placement Secondary	1
Alternative provision	2
Home School	1
Out of county further education	2
Out of school and not receiving education	2
Other please specify (hospital home tuition and specialist provision)	5

Satisfaction levels about the SEND provision in Cumbria (number of respondents)

Question	Very satisfied/satisfied	Dissatisfied/very dissatisfied	No opinion	Not applicable
7. How satisfied are you that you child/young person's needs have been identified by:				
Education	27	19	0	0
Health	20	21	1	4
Transport	13	8	2	23
Transition to adulthood	3	16	4	23

31 people left comments to this question. 7 people made positive comments about how good their child or young person's education is. The rest of the comments were negative including several which talked about the whole process taking a very long time:

"Transition to adult provision. What should have been a process since year 9 has turned into a 7 month process before his funding ends this July. It means rushed planning and decisions with no transition plan to follow, involving professionals who have not previously been involved with my son and do not know him well enough to make an accurate enough judgement of need. Plus, there is no straightforward directory of the choices available making decisions about the next step very difficult. Specialised provision which my son is assessed as needing just simply isn't there. In our opinion the transition process as it currently stands is poor."

"Home School transport do not recognise that some children's needs are so complex that specific training needs to be put in place to keep them safe."

"CAMHS is failing our children/young people and there is little or NO transition from children's to adults service."

"In the early years of school, behaviour was identified as negative but a disability or difficulty wasn't considered until I referred my child through the GP. The school only became supportive of this after the fact."

"The lack of alternate educational provision in this area is a disgrace. Where do children go who cannot cope with the demands of mainstream but who are not severe enough for a special school? There is no help or support and services ignore you or play 'pass the buck'."

8. How satisfied are you that you were asked about your views and listened to when your child or young person's needs were being identified?	Very satisfied/satisfied	Dissatisfied/very dissatisfied	No opinion	Not applicable
Education	23	23	0	0
Health	16	23	4	3
Transport	11	10	2	23
Transition to adulthood	1	17	5	23

Some of the negative and positive comments received from parents and carers:

“School, Ed Psych, Specialist Teacher all listen well but it then feels like a battle to get the LA to fund what everyone agrees the child needs.”

“Local schools did what they could. Social services have tried, however CAMHS have been appalling.”

“I am always fully informed about the education being received. The health service do an amazing job.”

“The GP took my concerns seriously and immediately made a referral to the paediatrician. Timely appointment with paediatrician but along gaps between seeing each specialist for the multi-agency diagnosis. I also find it ridiculous and counterproductive to hold ‘secret’ meetings to discuss potential diagnosis and needs without informing parents and offering them chance to attend. School mainly focused on behaviour without looking at underlying causes until prompted by referral. School did however support the diagnostic process and application for EHCP.”

“School have been very supportive and daughter has access to a behaviour support mentor, however, funding/changes in job description have meant that this isn't as readily available as it was in the beginning. Since NCDS have been involved from Newcastle, we feel a sense of relief that we are finally being understood, health-wise because they understand autism in girls. In Cumbria, there are no practitioners who specialise in this field, so many girls are getting misdiagnosed and having to seek second opinion from NCDS - then actually getting a diagnosis! I cannot say anything positive about CAHMS.”

“Professionals are still not educated in all things autism. It startles me how little they know.”

9. How satisfied are you with the ongoing monitoring and assessment of your child/young person’s provision, whether through the annual review of the EHC plan or review of SEND support in school?	Very satisfied/satisfied	Dissatisfied/very dissatisfied	No opinion	Not applicable
Education	20	20	3	3
Health	11	24	5	6
Transport	12	6	5	23
Transition to adulthood	3	15	6	21

23 comments were received for this question– 5 were very positive and said they had good support and monitoring in place at school. Several said agreed amendments were not made to the EHC plan and 3 said they had no reviews at all and others said they did not understand the review process. Some of the comments received:

“The health support is non-existent, the community paediatrician sees us around every 3 years for my son’s annual appointment!!”

"We have challenged the transition from statement to EHCP and have never been issued with a final version. The draft has been in place for 2 years, we feel it isn't precise enough in identifying his needs and have been told as far as the authority is concerned it is the final draft. Very unsatisfying."

"Home School transport is not taken into consideration in the EHCP. Only that it is required, but nothing specific to the needs of the child."

"EHCP review is good but timescales for saying if they will amend and then completing the amendments are missed by months."

"SEND team at social Services are very good. CAMHS bad."

"Hospital and Home Tuition have gone out of their way to try and help and support my daughter - they are a fantastic service. However, 5 hours of education is not enough and my daughter is basically being discriminated against because she cannot cope in a mainstream school environment. If I only sent her to school 5 hours a week I would be fined and hauled over the coals but it seems it is okay for the LEA to only offer this."

"No one from health or the LA ever attends the EHCP review (even the important transitional ones)."

10. Do you fully understand the annual review process?	Yes	No	No answer
	24	20	2

Several parents said they had not had a review of their child's provision and here are some of the other comments received about the annual review process:

"It's to give the young person time to process what they have been asked and to let their parent carers help them to understand."

"Has improved since social worker assigned to us. Previous years never anyone attended except school and Inspira representative."

"A LOT more guidance is needed. And there needs to be a separate form for children with profound and complex medical needs."

"Only because we are now 3 years in and I have educated myself on it (and it is difficult to get to grips with. Bearing in mind I have a master's degree the process really requires a course for parents so they have at least a chance of being able to navigate it successfully)."

11. Do the professionals involved in the annual review profess explain the process and what is happening?	Yes	No	No answer
	22	21	3

Some of the comments made are:

"School are very thorough"

"I'm always kept up to date with how she's doing at school any changes that have been made or needs made and how she's doing on a daily basis"

"We have TAF meetings but only school ever gets involved, despite their best efforts to invite CAMHS!"

12 If your child uses health services:	Very satisfied/satisfied	Dissatisfied/very dissatisfied	No opinion	Not applicable
Did they receive treatment in a timely way?	12	19	7	7
Did it meet your child's needs?	13	20	6	7
Did you get empathetic treatment?	15	17	6	8
Was it delivered by the right person from the start?	14	18	7	7
Did you know how to contact your health professional when the episode of care finished?	10	11	9	15

Some of the comments received:

"We only use ENT and dental support. Both have been fantastic and take into consideration our son's needs."

"CAMHS were totally inadequate; psychiatrists only interested in providing medication and never saw the same member of staff more than once."

"Just that no-one listened to me for four years until infant school. I suffered in silence."

"Contenance issues are passed around between the community nurses, OT and the continence team. You never know who to contact. Hypermobility has been diagnosed and then ignored. We haven't seen the paediatrician since diagnosis 3 years ago despite repeated requests."

"Limited access to paediatricians. Shortage in Cumbria long waiting lists. Little support when transferring to adult services."

"Great health support has been available for us."

"The service at CAMHS is quite poor. For the last 3 appointments it has been a different psychiatrist each time. The last (and by all accounts permanent psychiatrist) spent 20 minutes with us, increased her meds and sent us on our way. The two previous psychiatrists were really good but they were locus and were offered permanent positions elsewhere. Child paediatrics are another health service where appointments run at 8 months overdue and have very little to offer."

"S & L service not fit for purpose. There is a clear clinical need that is not being met. Staff not trained with correct knowledge to give the correct input the child needs. The child is suffering."

"Wheel chair services were better than other departments we have used."

“Doesn’t return calls or emails. Had to make complaint to get a response from consultant, one month after contacting.”

13. Do you have to repeat your story many times with professionals involved in your child’s care?	Yes	No	No answer
	41	4	1

Several respondents said they did not think professionals read the family’s notes before the meeting and that professionals did not share the notes when they needed to. Some of the comments were:

“Accessing the assessment unit at RLI, you have to repeat a very long-winded story 3 times! Once to a nurse, then a doctor, then a consultant. Can they not read the nurses notes?”

Health professionals not attending the early help meetings can be frustrating as the meetings are meant to limit repetition at appointments.”

“No professionals were interested in initiating an early help assessment. Discouraged from applying for EHCP.”

“You have to start again each time you see someone new. Sometimes you have to tell it all again even if you have seen that person before as they don’t seem to remember specifics.”

“All professionals should have access to a generic computer system.”

“Notes do not seem to be read, probably because they are very busy people.”

“Need a joined up approach for professionals. Repeat myself constantly.”

14. How well do you think your child/young person’s needs are met by the following service areas?	Very satisfied/satisfied	Dissatisfied/very dissatisfied	No opinion	Not applicable
Education	25	20	0	0
Health	16	24	2	4
Transport	13	6	4	23
Transition to adulthood	3	15	5	22

Some of the comments made:

“Education has been positive to date, especially considering the transition process from Junior to secondary but appears to be tailing off due to lack of school provision. We are relieved to be involved with the NCDS now and their process is much faster so we’re hopeful that soon everyone will be singing from the same hymn sheet so support in healthcare can happen.”

“Not enough autism training across the health and education.”

“Transport was great once it was done hybrid parental grant. It was nearly a disaster before when county suddenly gave us untrained escorts.”

“Health care is largely inaccessible and inconsistent.”

“Health is too hard to access so her needs are unmet in this area.”

“Lack of adult services in Barrow. Little choice. Services being cut. More pressure on families. Respite inadequate. 1 wheelchair accessible room to cover such a large area.”

“Needs definitely not being met at all”.

15. As a parent or carer, how satisfied are you that you are involved in setting targets/outcomes for your child/young person	Very satisfied/satisfied	Dissatisfied/very dissatisfied	No opinion	Not Applicable
Education	25	17	1	1
Health	14	24	3	5
Transport	9	5	6	25
Transition to adulthood	3	14	5	22

Some of the comments received:

“I would have liked annual or maybe every couple of years health checks done!”

“Education targets are set as a partnership, which works really well. We don’t have any health targets.”

“We have little say in these things.”

“Although the staff at HHTS are brilliant, they alone cannot provide for the targets and outcomes. They are only meant to be a temporary service not one which provides your child’s only long term education. There are many children in this situation and it is about time that this was recognised and services offered to try and help support the young people.”

“We haven’t really talked about where to go with my daughter as she gets older at school (but I mean through teenage years not adulthood!) and targets with Camhs have been totally unrealistic and unhelpful - I am so fed up of being asked to get her into a routine!!”

16. How well do services and professionals work together to support your child/young person	Very satisfied/satisfied	Dissatisfied/very dissatisfied	No opinion	Not applicable
	11	34	0	1

Some of the comments received:

“Children in out of county special schools...a constant fight as to whose responsibility they are. Services in Cumbria need to be transferrable to Lancashire Schools if that's where the child attends. Education, health and social care provision are still completely separate. Health and social care don't see the EHCP as something they should be involved in and don't turn up to meetings despite being invited. This is improving in social care but health still seem to see themselves as 'above' it.”

“They don't work together, dreadful communication between agencies but also involving parents”

“Can't get professionals to help with health issues (funding and staff resources) and very long waiting lists.”

“Very political.”

“Services need to start communicating with each other better it might even save some money, needs more joint working.”

“Multi agency working at all. Services very disjointed.”

“Professionals are working together better.”

“Deciding who funds adult care seems a bit of a mystery to them.”

“The school seems to be the only people who care about my child or family.”

13. How satisfied are you that your child/young person is supported in these areas?	Very satisfied/satisfied	Dissatisfied/very dissatisfied	No opinion	Not applicable
Educational Progress	27	18	0	1
Taking part in community activities	16	20	3	7
Leading a healthy life	22	18	2	4
Getting ready for adulthood	3	20	4	19
Short break activities	13	14	5	14
Overnight respite	6	12	5	23

Some of the comments received:

“Our respite has worked well, but as needing one-to-one care, social care not going well with all providers. Some appear to not like one-to-one clients or do not have sufficient staffing levels to provide it.”

“No suitable overnight respite for my 19 year old autistic son. Previously very good provision at Hart St which just disappeared on his 18th birthday. Any of the comments above that we are satisfied with are only because we challenged vigorously, the LA working against us not with us, to get the correct provision for our son. Concerns about transition to adulthood well documented above.”

“There is a lack of provision of short break activities for severely affected SEN CYP. Too often, overnight respite does not go ahead as planned because of LA use of emergency beds on a medium or long-term basis; this is a misuse of overnight respite facilities by the LA.”

“Direct payment works very well for us. At school our daughter has a fantastic TA and School are supportive and ambitious for her, tailoring the curriculum to adapt for her learning disabilities. We need help with her sensory processing issues as this impacts on her eating and therefore her health.”

“I don’t believe there are sufficient opportunities for young people with disabilities to access community services and activities. It is vague and difficult to apply for respite and short breaks and asking people to refer to the Safeguarding Hub to get an assessment is deliberately dissuasive. Incorrect, misleading information is also given when contacting the Hub about this and thresholds to receive this support are very high.”

“We have been very lucky to have access to young carers because I have a health condition which means my two children have to help with some of my care needs. They have been really supportive of both children and offer a port of call, as well as community activities. The school have also been proactive in getting my son funding to go on 2 separate residential trips so that he could have respite from his sister. My daughter occasionally gets to go on day trips with young carers but would not stay overnight with anyone.”

“More help with overnight respite.”

“West House are a joke. They have abandoned Millom AGAIN. Millom Parents and Carers Disability Group put on all the activities for children with disabilities in the area. They are self-funded. They do a brilliant job.”

“My child has only started getting respite after nearly two years of asking.”

14. How easy do you find it to get information about what services are available and what they do?	Very Easy/easy	Neither easy nor difficult	Very difficult/difficult	No opinion
	3	12	31	0

Some comments from respondents:

“The local offer website is cumbersome and difficult to navigate. The best source of information has been other parents and social media closed support groups (local ones).”

“Only because I am able to research on the internet.”

“Very hard to find out what is available to us and how to help our son.”

“CCC website is difficult to navigate and doesn’t always have up to date information.”

“Thank goodness for Facebook support groups and Contact a Family. Otherwise you have to search for the information but don't always know what to search for as we don't know what exists!”

“Once a child is given the diagnosis there's no more information. A lot I found out was from other parents it feels like you get left alone.”

19.	Yes	no
Have you heard of the 0-25 SEND Local Offer?	28	18

20. If you have used the 0-25 SEND Local Offer, how easily did you find information?	Very Easy/easy	Very difficult/difficult	No opinion
	0	17	25

Some comments on the local offer:

“Navigation around is poor and a dearth of services available in the county.”

“Not worthwhile using.”

“Heard of it but couldn't tell you what it is.”

It's too hard to navigate, and it isn't 'friendly'. When newly diagnosed I used it to try and find services but couldn't work out which ones I was allowed to access or would be suitable for us. Much of the contact info and links are out of date or broken.”

21. How satisfied are you with:	Very satisfied/satisfied	Very dissatisfied/dissatisfied	No opinion	Not applicable
Educational provision for young people who are 16+	7	11	9	19
For young people who are 19+	1	14	8	23

Comments

“19+ is being cut to 3 days for young people, my son needs to remain in education to continue learning to read and learn about money.”

“What Provision? The services in Cumbria suck across the board as far as 18+ is concerned.”

“Had to appeal against reduced hours at FE and also believe that government were backing education to the age of 25 why has this never been offered/discussed.”

“There is no residential 19+ provision in Cumbria. The 19+ day provision is now reduced by the new council policy saying it will only be given for 3 days a week which renders the provision ineffective; the only effective option now is out of county residential provision.”

“Told I cannot refer my son to targeted youth support without an Early Help assessment. There are no professionals involved currently to initiative one.”

“Little choice available in area.”

“Only really given one option Lakes college!”

“At 16 those at “mainstream” have a choice of two colleges and if they cannot cope with that what then are they meant to do? By law they have to stay in education or training but there is nothing out there to offer them. At 19+ there is the choice of Beaumont or Furness College. Furness College does not have the staff or provision to securely look out for young people with learning difficulties so you are only left with one option.”

“There needs to be more options for young people not just the bog-standard ones that are available.”

“3 days of education is not full time! Huge gaps in time to fill post 16.”

“I am dreading my son turning 19+ as there seems to be no provision for him at the moment.”

“Hope they keep the 5 days at Beaumont Barrow”

“Tell us what's available and how to get it funded. All we have had is a negative sounding letter saying young people only get 3 days. What a terrible reflection on how little they value our young people. Very disappointed.”

Summary

What are the strengths?

Some of the stronger points of the feedback were 27/46 of respondents were satisfied or very satisfied that their children’s needs had been identified for their education and there were some positive comments made. 25 respondents said that they were satisfied or very satisfied that their children’s needs were being met by Education. 25 of the respondents said they were satisfied or very satisfied that they were involved in setting targets and outcomes for their child or young person. 27 respondents felt that their child was supported in their educational progress and 22 said their child was supported in leading a healthy life. 28 respondents had heard of the local offer.

What are the weaknesses?

Transition to adulthood - parents have expressed some very low satisfaction rates; out of 46, only 1 to 3 people said they were satisfied or very satisfied in a range of questions about transition to adulthood for their children and young people.

Health – there were generally more people unsatisfied or very unsatisfied with their experiences with health through a range of questions. Only 12 were satisfied that treatment was received in a timely way,

only 13 said the treatment met their needs, 15 said they were treated empathetically and 14 said it was delivered by the right person from the start.

CAHMS – there were many negative comments about the CAHMS service throughout the replies to all questions from the parents and carers who replied to these questions. Several respondents felt that CAHMS was failing their children and young people.

41 parents and carers said they had to repeat their story many times and several respondents said they did not think professionals even read the family's notes before the meetings with families.

31 parents and carers thought it was difficult or very difficult to find out information about what services are available for their children and young people and what the services do. 17 thought the local offer was difficult or very difficult to find information on the local offer.

Partnership working – only 11 people felt satisfied or very satisfied with the way that services and professionals work together to support their children and young people.

Action going forward

This report will be distributed to relevant senior managers in Children's Services, Health, Adult Social Care, Transport teams and Schools and the Parent Carer Forum would like to ask all agencies and teams to respond to findings from parents and carers about their services.

Shirley Murphy, Chair/Cumbria Parent Carer Forum