

Cumberland SEND Partnership Annual Survey Report

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Background

The Cumberland SEND Partnership annual surveys were approved by the Cumberland SEND and Alternative Provision Partnership in October 2024.

The surveys were the first annual surveys from the Partnership since both Cumberland Council and the Cumberland SEND and Alternative Provision Partnership were established following Local Government Reorganisation taking place in Cumbria in April 2023.

The surveys were conducted to understand parents/ carers and children/ young people's views of SEND services and processes in the Cumberland area; to understand what was working well, and what could be improved.

Methodology

Two surveys were conducted, one for parents and carers, one for children and young people with SEND. Both surveys were open for responses between Monday 20th January and Friday 7th March.

The surveys were both purposefully kept under 20 questions to maximize completed submissions and ensure there was limited survey fatigue. Both surveys were co-produced, with the parent/ carer survey being co-produced with SENDAC and other parent/ carers in the community, and the children and young people survey being co-produced with Unique Voices, a group for children and young people with SEND that is supported by Cumberland Council. While coproducing the survey, SENDAC assisted with ensuring our language was easy to understand and that acronyms when used were explained, and jargon was avoided.

For the parent/ carer survey, several theme areas were identified to enquire on. These were EHCPs, education, health, and social care. Each themed area had a mix of quantitative and qualitative questioning to ensure data could be gathered on each area, with an opportunity for parents to leave written and more detailed responses on each area.

The surveys were produced on Microsoft Forms due to the alternative platform available (Citizen Space) having limited accessibility.

Both surveys were promoted online via the Cumberland SEND Partnership communication channels and a full communications plan was produced to promote the survey and encourage responses.

This included being distributed to schools to promote. The communications plan highlighted risks and mitigations, including that SENDAC, Cumbria's parent/carers forum, had conducted their own parent-carer survey in late 2024.

No printed copies of this survey were distributed, but this has been recorded as a recommendation for future surveys to ensure equity of access.

Response Rates

A total of 155 parent/ carers completed the parent/ carer SEND Annual Survey and a total of 35 children and young people completed the children/ young people survey. Due to the small percentage of response rates compared to the figures of children and young people with SEND currently living in Cumberland, we cannot take this response rate to be statistically representative of the views of parents/ carers and children/ young people with SEND in Cumberland.

At the end of this survey report there will be recommendations for future surveys to encourage response rates.

Analysis and Reporting

This report presents the findings from the two surveys. Firstly, the results of the parent/carers survey and then the results of the children's/young person's survey.

As this is the first survey conducted by the Cumberland SEND Partnership since its establishment, this survey will be used as a benchmark for comparisons against future surveys to show any changes, improvements, or deteriorations in performance. Due to this, we have not compared the results of this survey and data gathered to previous surveys conducted, as the Partnership and Local Authority are newly established.

Please note that some percentages may vary due to the use of matrix questions throughout the survey, which some respondents may have skipped certain statements within that matrix, altering the base size for that specific statement.

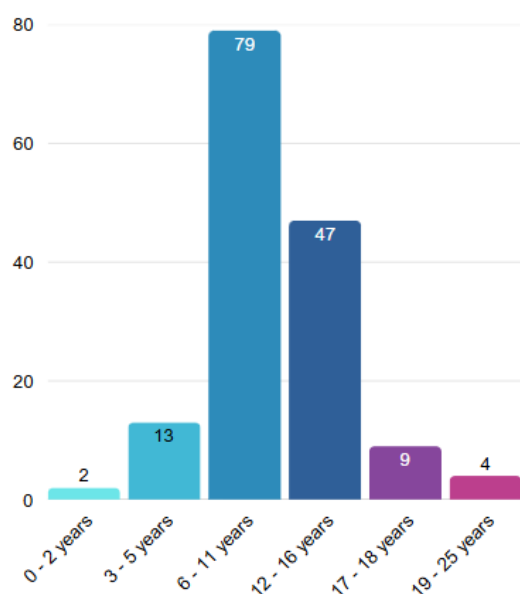
Please also note that throughout this report we have highlighted selected qualitative responses under key themes. Some qualitative responses have not been included in this report due to identifying information, or due to similarity with other responses. All qualitative responses submitted to this survey have been included in another version of this report that has been circulated to the Cumberland SEND and Alternative Provision Partnership Board.

Parent/ Carer Survey Data

Respondent Profiles and key variables

Questions were initially asked to establish respondent profiles, including age, gender, area of Cumberland, and need.

Age of child/ young person (base size: 155)



Parents/ carers with children aged between 6 – 11 and 12 – 16 accounted for 81% of respondents, **meaning at least 81% of respondents had children at compulsory education age at the time of the survey.**

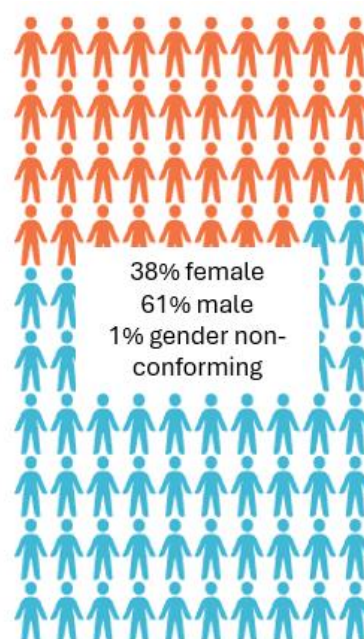
Gender/ Gender identity (base size: 155):

38% of respondents selected their child/ young person was female.

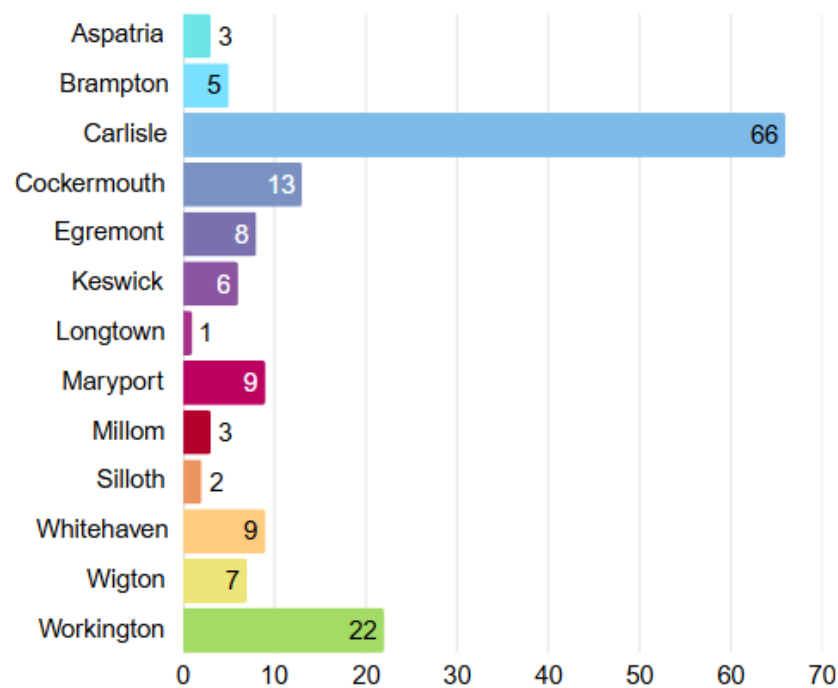
61% of respondents selected their child/ young person was male.

1% of respondents selected their child/ young person was gender non-conforming.

1 respondent selected 'other' and stated they had two children with SEND, one male and one female.



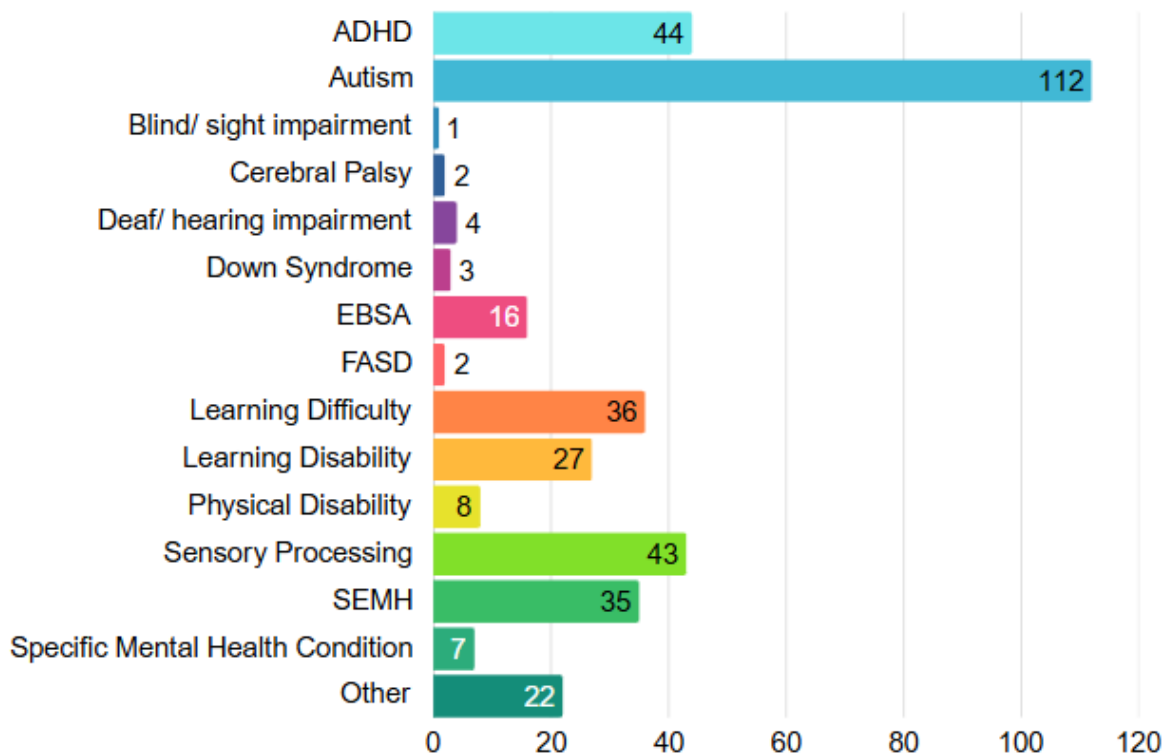
Nearest town/ city (base size 154):



This was asked to establish the nearest locations where children/ young people are more likely to access services or attend education settings. All towns/ cities listed had some representation from survey respondents, with the smallest response rate being from Longtown (1), and the largest being Carlisle (66).

42.8% of respondents selected Carlisle as their nearest town/ city.

Primary and other needs (select as many as apply- base size 154):



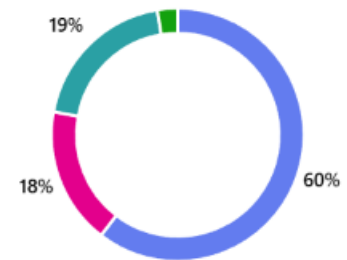
Respondents could select more than one primary need. 362 needs were selected overall from 154 respondents.

Autism presented as the highest primary need, with 72% of the 154 respondents selecting this as a primary need.

The 22 respondents who selected 'other' responses included: hypermobility, PDA (pathological demand avoidance), anxiety, delayed development, Jacobsen Syndrome, Epilepsy, ARFID (Avoidant/ restrictive food intake disorder), DLD (developmental language delay), Tourette's Syndrome, selective mutism, and those awaiting assessment.

Support in place (base size: 154):

● My child/ young person has an Education, Health and Care Plan (EHCP)	93
● My child/ young person receives SEN Support	27
● My child/ young person has no support/ plan in place	30
● I don't know/ not sure	0
● Other	4



60% of respondents selected their child has an EHCP in place (93).

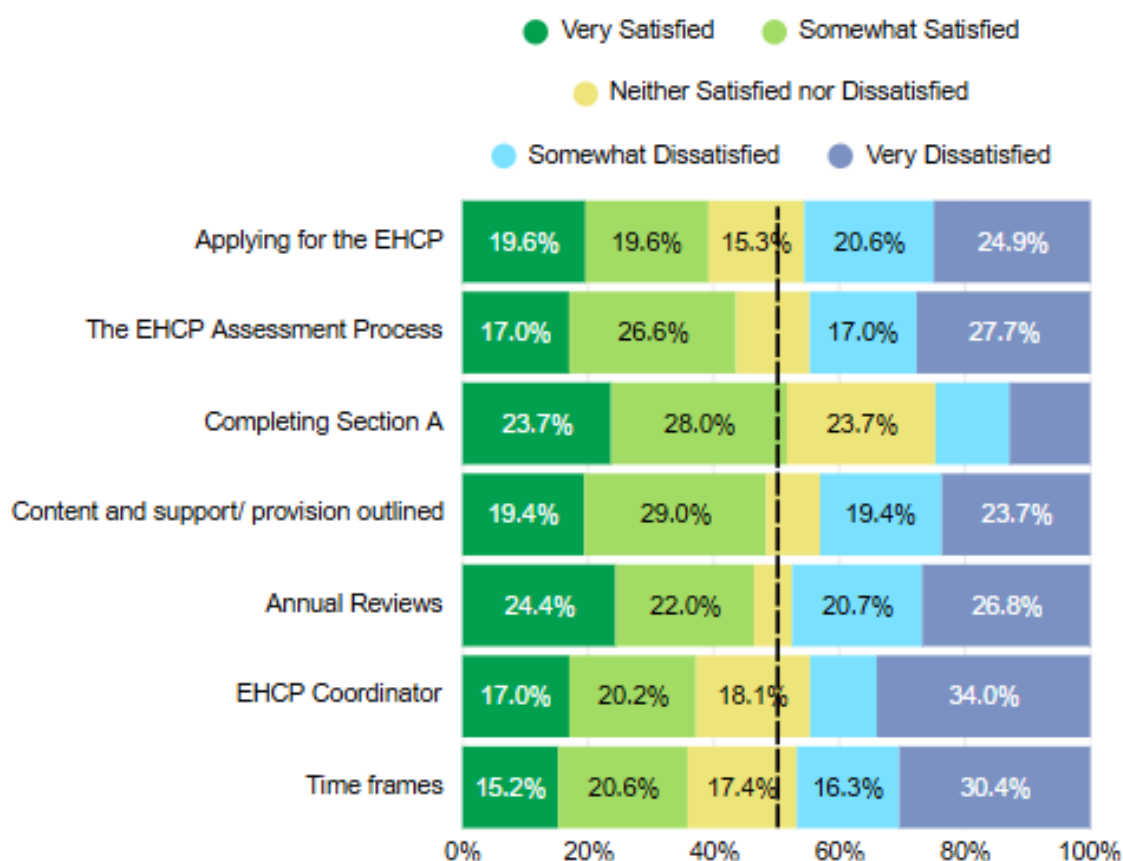
4 respondents who selected 'other' responses included: EHCP ceased, still on waiting list.

Those who responded that their child had an EHCP were taken to a separate page to answer questions on their experiences with the EHCP and the process of applying for it. Those who responded that their child did not have an EHCP were taken to alternative questions.

3036 children and young people in Cumberland have an EHCP as of May 2025, meaning this number is not statistically significant and is not representative of the population.

EHCP themed (Education, Health and Care Plan)

EHCP Matrix questioning (base size: 94):





A full response breakdown is available on the next page.

Please note the figure above has removed N/A answers, meaning percentages in this graphic may differ from that on the results breakdown table, as the base size varies between statements.

Key statistics/ themes:

Responses to these questions overall are very mixed.

For every statement however, over 50% of respondents selected either 'very satisfied', 'somewhat satisfied', or 'neither satisfied nor dissatisfied' (this does not include respondents who selected N/A).

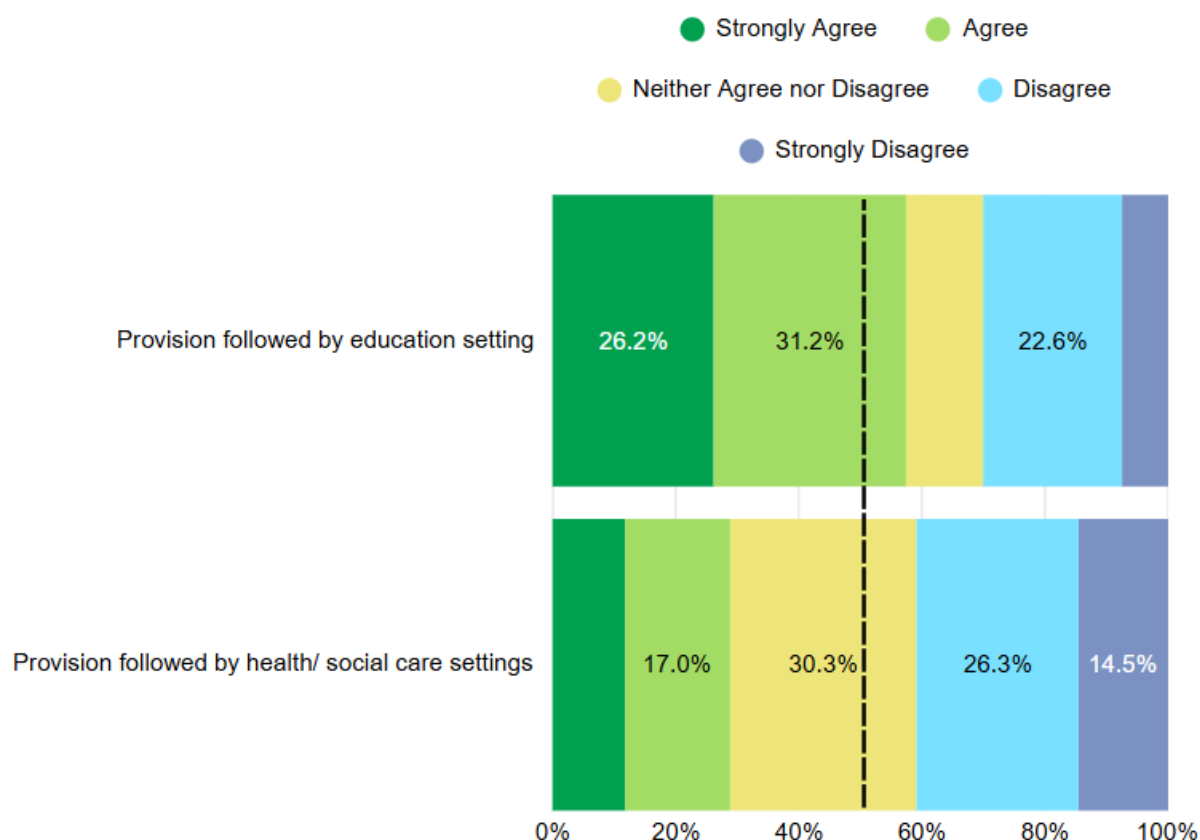
	The highest proportion of 'very dissatisfied' was selected in relation to EHCP Coordinators .		The highest proportion of 'very satisfied' was selected in relation to Completing section A .
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Response Breakdown:

Most selected answers highlighted green. Second most selected answer highlighted yellow.

	Very Satisfied	Somewhat Satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Very dissatisfied	N/A (excluded from scoring)
Applying for the EHCP	19.4% (18)	19.4% (18)	15.1% (14)	20.4% (19)	24.7% (23)	1.1% (1)
The EHCP Assessment Process	17% (16)	26.6% (25)	11.7% (11)	17% (16)	27.7% (26)	
Completing Section A	23.7% (22)	28% (26)	23.7% (22)	11.8% (11)	12.9% (12)	
The content and support/ provision outlined in your child/ young person's EHCP	19.4% (18)	29% (27)	8.6% (8)	19.4% (18)	23.7% (22)	
Your child/ young person's EHCP Annual Review	21.3% (20)	19.1% (18)	5.3% (5)	18.1% (17)	23.4% (22)	12.8% (12)
Your child/ young person's EHCP Coordinator	17% (16)	20.2% (19)	18.1% (17)	10.6% (10)	34% (32)	
The time frames around applying for your child/ young person's EHCP/ annual reviews	14.9% (14)	20.2% (19)	17% (16)	16% (15)	29.8% (28)	2.1% (2)

Provision and support in EHCP adhered to (base size: 94):



A full response breakdown is available below.

Please note the figure above has removed N/A answers, meaning percentages in this graphic may differ from that on the results breakdown table, as the base size varies between statements.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
The provision/ support outlined in my child/ young person's EHCP is followed by their education setting	22.3% (21)	26.6% (25)	10.6% (10)	14.9% (14)	19.1% (18)	6.4% (6)
The provision outlines in my child/ young person's EHCP is followed by wider health/ social care settings	9.6% (9)	13.8% (13)	24.5% (23)	19.1% (18)	21.3% (20)	11.7% (11)

48.9% of respondents selected either 'strongly agree' or 'agree' that the provision outlined in their child/ young person's EHCP setting was adhered to in their education setting.

Qualitative EHCP question:

(please provide any further comments on your answers given above):

This question was left open-ended to allow parents/ carers to talk about the areas of the EHCP that mattered most to them, and to avoid asking too many qualitative questions on the same subject.

A full list of responses given to this question is in Appendix 1.

54 respondents gave a response to this question.

Selected key themes of qualitative responses:

- **Lack of support for parents/ carers:**

“Help is given too late parents are not listened to and very little support out there for the parent and young person.”

“I begged for support in applying for an EHCP for my daughter and was told time and time again 'children who need them aren't getting them, so she won't get one'.”

“Find whole process is harder than needs to be. It isn't sympathetic to the families and harder to get support. Forms and reviews are very impersonal.”

- **Misinformation and lack of knowledgeable professionals:**

“Parents are left feeling like they are the problem, there are not enough knowledgeable professionals to assess and it feels a negative experience for child and parent.”

“The information in her EHCP is outdated, incorrect and inconsistent in its implementation. Section A was omitted even though it was completed and submitted to school.”

“Overwhelming, over complicated and the LA make you feel like a criminal for asking for help! Quick to provide sanctions to family for missed deadlines however, not even an apology for completely missing their time frames! Incompetent coordinators - ridiculous how many times questions couldn't be answered and had to await phone calls from more senior staff.”

“Absolutely disgusting. Coordinators consistently lie all the time, deliberately gaslighting parents into believing they don't follow statutory timescales and duties.”

- **Staff Changes:**

“I have no idea who my son's EHCP coordinator is as I've not seen one or heard from one for years.”

“Our child has had a number of EHCP Coordinators and we never get told.”

“Very poor communication from EHCP coordinator and not clear at time who it was.”

- **Positive feedback:**

“The support my daughter, siblings and family receive from the primary school is fantastic.”

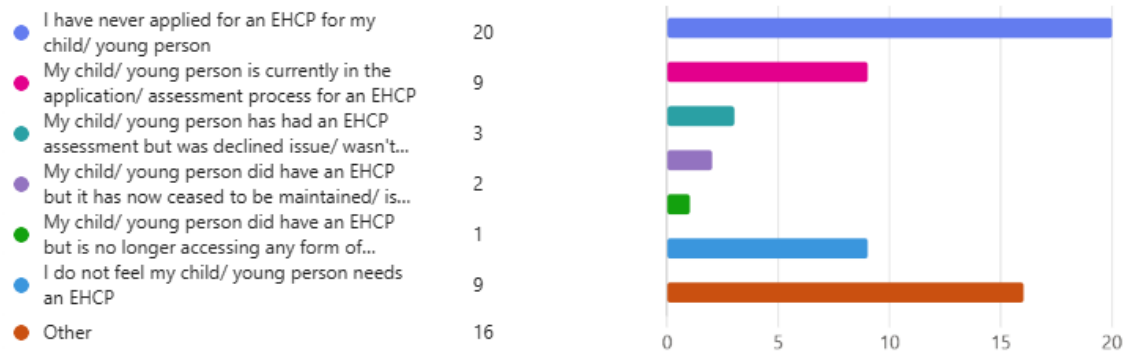
“School is fantastic, but I had to fight tooth & nail to get her in- All Saints in Cockermouth, a fantastic example of how integrated SEND settings work in mainstream schools.”

“Millom school provide my son with the highest standard of care/ learning brilliant school for send school.”

“Without early encouragement from our nursery setting, we wouldn’t have known about EHCPs, and they really supported us in our initial application...”

Children/ young people with no EHCP (Education, Health and Care Plan)

Respondents who selected their child did not currently have an EHCP were brought to the below question (base size: 60)



Clarification for titles above:

I have never applied for an EHCP for my child/ young person	20
My child/ young person is currently in the application/ assessment process for an EHCP	9
My child/ young person has had an EHCP assessment but was declined issue/ wasn't agreed to	3
My child/ young person did have an EHCP but it has now ceased to be maintained/ is no longer in place	2
My child/ young person did have an EHCP but is no longer accessing any form of education	1
I do not feel my child/ young person needs an EHCP	9
Other	16

Those who selected 'other' responses included; is not allowed to have an EHCP, not applied but feel they need, no plan in place but told one is needed, no diagnosis, lack of support from school, awaiting EP input, in progress of assessment, school feel needs can be met.

Qualitative no EHCP question:

(please provide any further comments on your answers given above):

This question was left open-ended to allow parents/ carers to talk about what mattered most to them, and to avoid asking too many qualitative questions on the same subject.

31 respondents gave a response to this question.

Key themes:

- **Lack of support from school/ professionals:**

"My child's school do not support applying for an EHCP and instead sit her with another child who has support."

"Absolute nightmare trying to get support for my child. School is unsupportive, the SEND team are unhelpful and condescending. Everything is a fight."

"Having major issues getting the school to co-operate and recognise there is any need due to masking. School official line "not seeing anything of concern". Not listening to parents with regards to negative impact of school environment and no reasonable adjustments. Child on verge of Autistic burnout with pressure of year 11 yet school unfazed."

"School say they have to jump through lots of hoops before he can get the plan."

"I put a parental application for EHCP in and was successful as schools would not help. School then got a new SENCO who decided she would go ahead and cancel it despite my concerns. She did so, support was withdrawn, my son failed his GCSEs and is now at college still struggling with no support but having to be in education."

- **Do not feel need to apply for one:**

"Never needed to apply for one always felt we got the support he required in schools he attended."

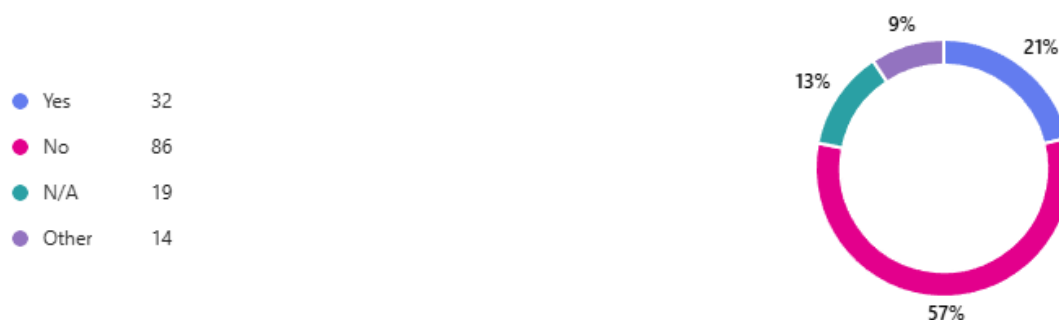
"At present the school she attends have put in place certain accommodations which mean she is able access education."

Health themed

Respondents were asked, if their child/ young person has or is in the process of receiving a diagnosis, did they feel they waited an appropriate amount of time for appointments/ to speak with health care professionals (base size: 151).

Note: Cumberland is currently served by two ICBs (North East and North Cumbria and South Cumbria and Lancashire).

Unfortunately, only 3 respondents selected they were from areas served by the South Cumbria ICB, so it was decided comparing the data would not provide any useful or actionable analysis.



Of the 14 respondents who selected 'other', the majority stated they ended up going private for a diagnosis, or are still waiting for a diagnosis.

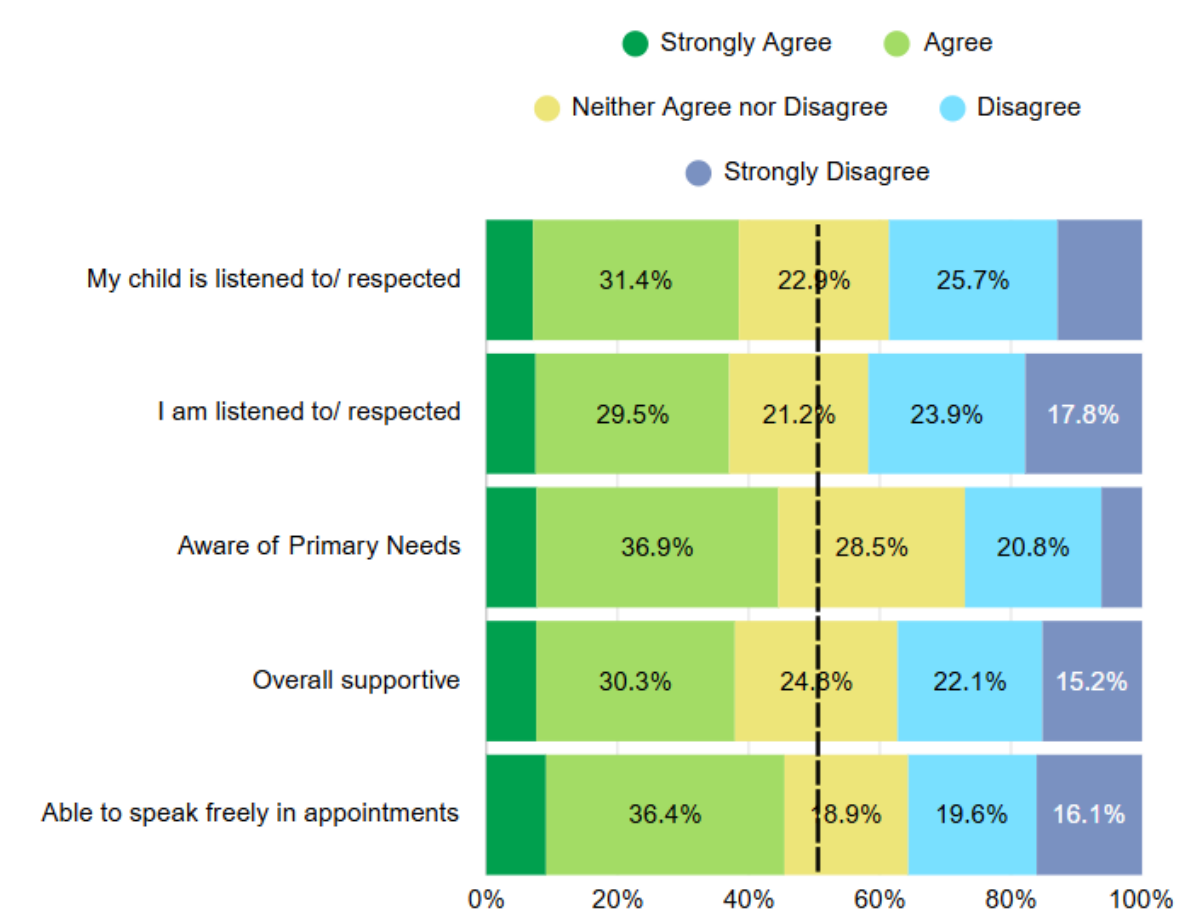
Adjusted results from removal of 'N/A' or 'Other' results' (base: 118).

72.8% of respondents selected 'No.'

27.2% of respondents selected 'Yes.'

51 respondents out of the 118 who answered 'yes', or 'no' were from Carlisle. Of these 51 respondents 80% selected 'no' (41), and 20% selected 'yes' (10).



Health Matrix questioning (base size: 152):



Response Breakdown:

A full response breakdown is available on the next page.

Please note the figure above has removed N/A answers, meaning percentages in this graphic may differ from that on the results breakdown table, as the base size varies between statements.

	Highest levels of ‘strongly disagree’ were in ‘I am listened to and respected by health professionals.’		Highest levels of ‘agree’ were in ‘Aware of primary needs’ . ‘Strongly agree’ received very similar response rate across all questions.
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Most selected answers highlighted green. Second most selected answer highlighted yellow.

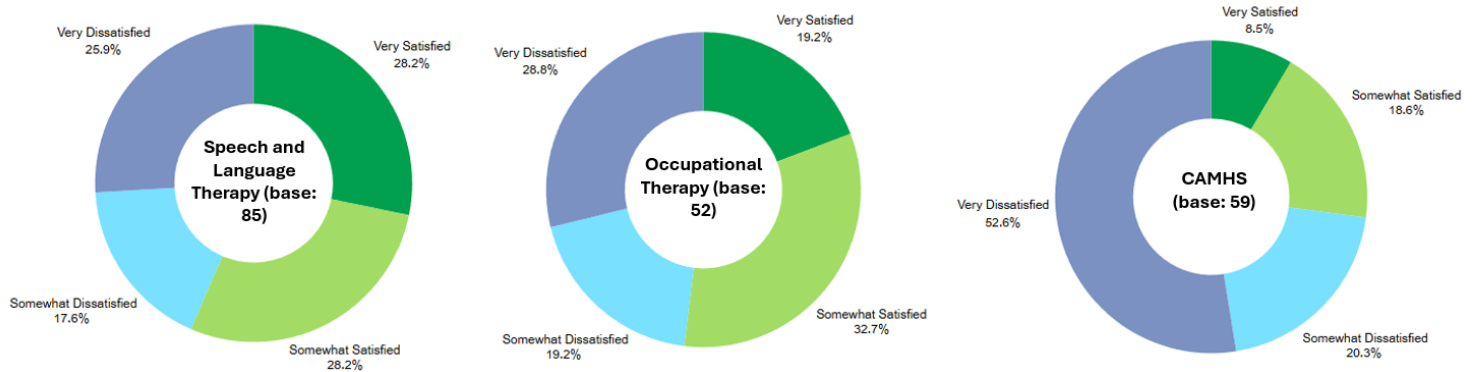
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
My child/ young person is listened to and respected by health professionals	6.6% (10)	29.1% (44)	21.2% (32)	23.8% (36)	11.9% (18)	7.3% (11)
I am listened to and respected by health professionals	7.2% (11)	28.3% (43)	20.4% (31)	22.4% (35)	17.1% (26)	4.6% (7)
Health professionals are aware of my child's primary needs	6.6% (10)	31.6% (48)	24.3% (37)	17.8% (27)	14.5% (22)	5.3% (8)
Health professionals are overall supportive	7.2% (11)	28.9% (44)	23.7% (36)	21.1% (32)	14.5% (22)	4.6% (7)
I feel that in appointments I am able to discuss my child's needs or any worries I have openly	8.6% (13)	34.2% (52)	17.8% (27)	18.4% (28)	15.1% (23)	5.9% (9)

The last question in this matrix was suggested by a parent/ carer, who said that in her experience health care professionals would often discuss her son in a negative light in front of her. Approx 43% of respondents stated they felt they could discuss their child openly with health practitioners.

Responses for this matrix were again mixed, with 'strongly agree' receiving consistently the lowest response rates. However, 'agree' was the most selected answer for all statements, with the proportion of respondents selecting 'agree' being just under a third for all responses, except for the statement related to feeling they could discuss their child openly, which was slightly over a third.

For all statements the positive/ neutral responses equated to over 50%.

Specific services matrix questions (base size: 151):



A full response breakdown is available below.

Please note the figure above has removed N/A answers, meaning percentages in this graphic may differ from that on the results breakdown table, as the base size varies between statements.

Response Breakdown:

Most selected answers highlighted green. Second most selected answer highlighted yellow (excluding N/A). Please note some matrix questions were left blank; base size may vary slightly.

	N/A	Very Satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied	Declined Service
Speech and Language Therapy	38.9% (58)	16.1% (24)	16.1% (24)	10.1% (15)	14.8% (22)	4% (6)
Occupational Therapy	56.8% (84)	6.8% (10)	11.5% (17)	6.8% (10)	10.1% (15)	8.1% (12)
CAMHS	48.6% (72)	3.4% (5)	7.4% (11)	8.1% (12)	20.9% (31)	11.5% (17)

Qualitative Health question:

(please provide any further comments on your answers given above):

This question was left open-ended to allow parents/ carers to talk about what mattered most to them, and to avoid asking too many qualitative questions on the same subject.

76 respondents gave a response to this question.

Key themes and selected responses:

CAMHS:

"Phone conversations during COVID with CAHMS (waste of time) St Joseph's Catholic School did a better job of getting my son the support he needed with a counseling service that they paid into."

"CAMHS don't provide any help or support just ask a few questions and send you on your way with no solution or advice."

"My son is very aggressive, and I am scared when he is angry, and I rang CAMHS for help but they said they can't help till he gets an appointment, but it could be another 2 years."

"CAMHS made my child significantly worse and discharged her as she had no mental health needs. She was at the time self-harming and had depression."

"My child was self-harming. I was told CAMHS would only see her if she was suicidal."

"CAMHS stated they could not work with my child as they wouldn't engage."

"The service provided by CAMHS is amazing if you can get through the door. My son had 2 yrs of counselling after a suicide attempt due to undiagnosed ASD their support was fantastic and really helped him learn about himself. "

Occupational Therapy:

"My child has significant delays including gross and fine motor skills. He was declined for OT because 'he is too delayed to help' He has been referred two times. Once in 2020 and again in 2023. Declined both times for the same reason."

"As she wasn't expressing pain with her movement physio declined to see her having never meet her, she was born with a turned in foot at birth."

Speech and Language Therapy:

"Declined salt treatment, despite having received private assessment and treatment in pru and agreed it would be added to EHCP."

"Very long wait for S&L in ASD diagnosis, but professional was excellent when we saw her."

“My child is non verbal and speech and language were beyond useless. Not interested and withdrawn from the service. Private speech therapist suggested using AAC device, which speech and language would not fund because they weren't sure whether he could use it. School funded it and he is using it wonderfully.”

Difficulty talking openly due to child being present:

“Paediatric appointments are always with my child in the room which makes it difficult to talk openly about their struggles.”

“How can you have a sensitive conversation about your child and talk about difficult things you don't want them to hear if you're having to have appointments with your child present?”

“My child has been in the same room during appointments with paediatrician where I am expecting to talk about her struggles. It isn't conducive to good mental health for either of us and means I often held back on telling doctors the full extent of problems.”

Lack of Support/ Clarity:

“You seek help from any professional and then they bombard you with the same questions on paperwork, the same lengthy questionnaires to fill in going back to pregnancy before they'll help that you've filled in a million times to everyone else, it drowns you. You ask for help after hitting rock bottom and they still make things harder. No one listens because they are too busy to give you the time you need. You are rushed in and out and interrupted as you speak because they don't have time. You end up feeling like you can't get help from anyone.”

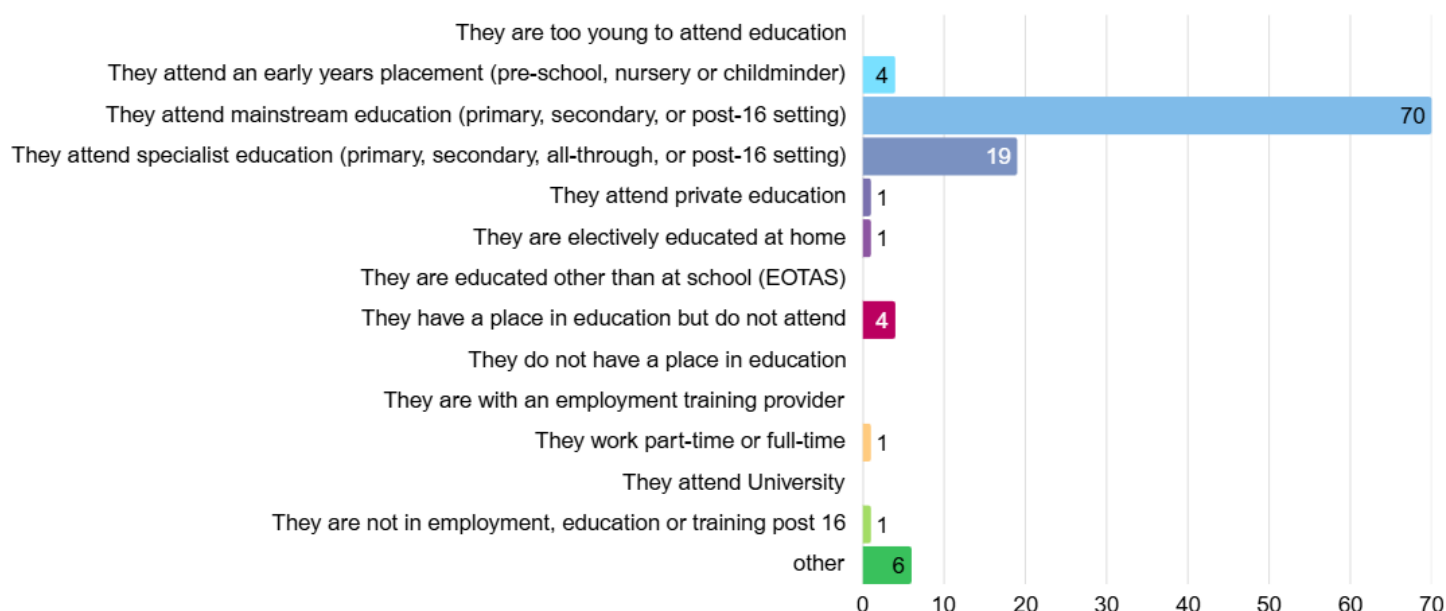
“No support or guidance at all for parents and unless you want to medicate your child there is little support. The amount of time for diagnosis is ridiculous.”

“My child hardly gets any support and it is not clear what is available.”

“School have been the only people who have helped us at all No professional help offered very lonely.”

Education themed

Education setting (base size: 151):

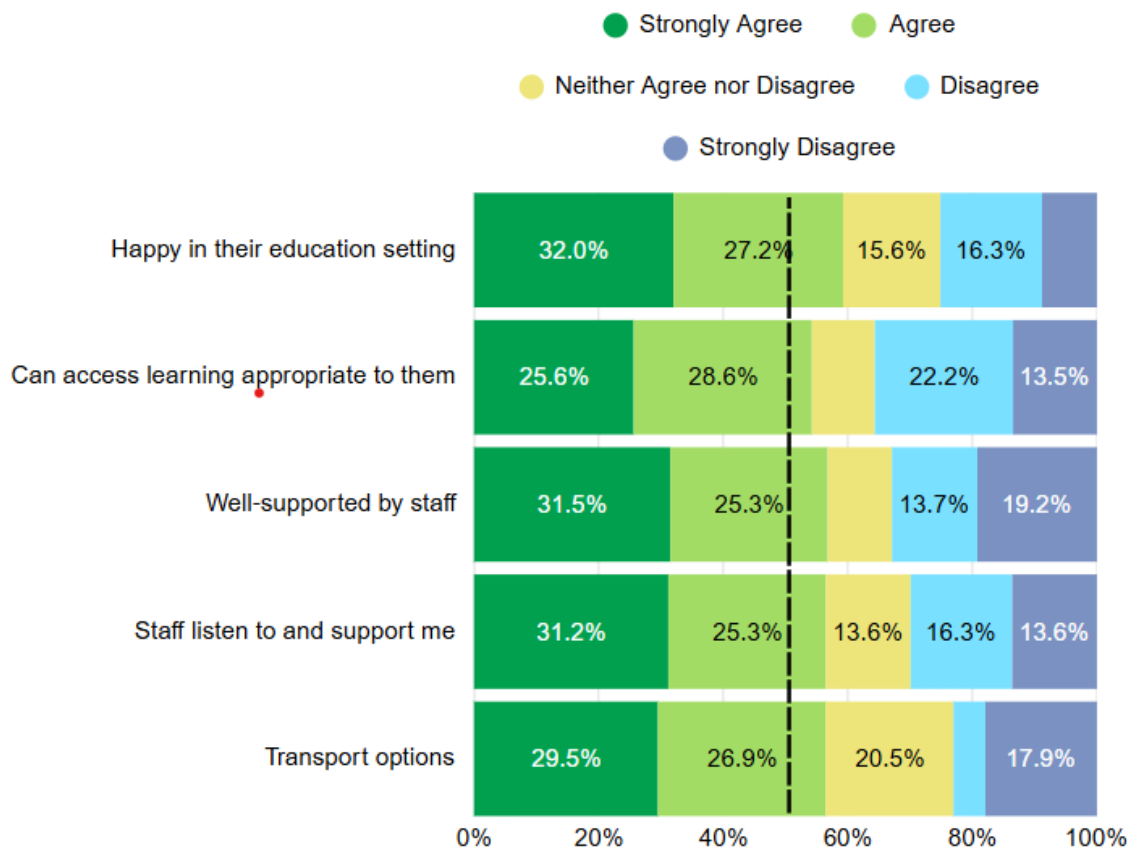


Results breakdown (base 151):

They attend an early years placement (such as a pre-school, nursery or childminder)	5
They attend mainstream education (primary, secondary, or post-16 setting)	101
They attend specialist education (special primary, secondary, post-16 setting)	23
They attend private education	1
They are electively educated at home	2
They are educated other than at school (EOTAS)	3
They have a place in education but do not attend	6
They work part-time or full time	1
They are not in employment, education training post-16	1
Other	8

Of the respondents who selected 'other', responses included; college, excluded from special school, flexible school arrangement, and attends a day centre.

Education matrix question (base size: 153):



A full response breakdown is available on the next page.

Please note the figure above has removed N/A answers, meaning percentages in this graphic may differ from that on the results breakdown table, as the base size varies between statements.

Overall selected findings:

For all statements provided as part of the matrix, the most selected answer was 'strongly agree' with the exception of 'My child/ young person can access learning appropriate to them and their development level at their current education setting', for which the most commonly selected answer was 'agree.'

Response Breakdown:

Most selected answers highlighted green. Second most selected answer highlighted yellow.

Please note some matrix questions were left blank; base size may vary slightly and impact percentages.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
My child/ young person is happy in their current education setting	30.7% (47)	26.1% (40)	15% (23)	15.7% (24)	8.5% (13)	3.9% (6)
My child/ young person can access learning appropriate to them and their development level at their current education setting	25% (38)	27% (41)	9.9% (15)	21.7% (33)	13.2% (20)	3.3% (5)
My child/ young person is well-supported by staff at their current education setting	30.3% (46)	24.3% (37)	9.9% (15)	13.2% (20)	18.4% (28)	3.9% (6)
I feel staff at my child/ young person's education setting listen to and support me with any concerns I have	30.1% (46)	24.2% (37)	13.1% (20)	15.7% (24)	13.1% (20)	3.9% (6)
I am satisfied with my child/ young person's transport options to and from their education setting	15% (23)	13.1% (21)	10.5% (16)	2.6% (4)	9.2% (14)	49.7% (76)

	The highest proportion of 'strongly disagree' was selected in relation to 'My child/ young person is well-supported by staff at their current education setting'.		The highest proportion of 'very satisfied' was selected in relation to 'My child/ young person is happy in their current education setting.'
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Mainstream Education Qualitative Question

(please provide any further comments on your answers given above):

This question was left open-ended to allow parents/ carers to talk about what mattered most to them, and to avoid asking too many qualitative questions on the same subject.

42 respondents gave a response to this question.

- **Positive feedback for schools:**

"If it wasn't for my sons school, I would have had a breakdown by now. They have supported us in more ways than the 'system' ever has."

"Now we have something in place the school are very supportive and now my daughter is getting the additional support she needs."

"School are providing support above EHCP to allow ensure child can access the school environment."

"All Saints school in Cockermouth is fantastic, but there are only 2 places per yr group! More like them are needed."

- **School do their best within their means:**

"My child is listened to and supported well by the pastoral staff who have a much better understand of her needs, but many teachers are not equipped in their understanding of how her needs present and how to work effectively with her."

"The school do their best with the resources they have trying to support with the universal offer provisions however they seek to push independence on her she's demonstrably not been able to cope with in the past."

"Caldew school have always shown care and support but are stretched to meet the mental health and wellbeing needs when they are masked/internalised by students."

"Staff helpful at school but not getting the help she needs as doesn't yet have EHCP."

"The school are good trying to support my daughter, but they are limited because of the delay in waiting for her diagnosis."

- **School is not supportive/ lack empathy**

"School have been very dismissive of my child's needs, and it is only through the personal determination of a teaching assistant we are receiving any support. Senco has a lack of understanding of autism in girls and support is unreliable at best."

“School gaslight me and don’t believe anything I tell them about my child.”

“Westlakes just didn't care. The SENCo would do nothing unless teachers raised a concern - he didn't listen to us”

- **Lack of training/ awareness from staff:**

“Lack of staff training and awareness in practice of SEN needs. Lack of school support in SEN education and duty of care disappointing. Children with SEND who are not working to age KS are expected to do the same work as others, even though the school setting is aware they can't do it.”

“We discuss my child in education and agree a plan, then the school record a completely different plan and record something completely different. None of which supports my child but it makes the school look like they are ticking boxes.”

Specialist Education Qualitative Question

(please provide any further comments on your answers given above):

This question was left open-ended to allow parents/ carers to talk about what mattered most to them, and to avoid asking too many qualitative questions on the same subject.

Key themes:

- **Positive feedback for setting**

“The current setting my child attends are fantastic, he enjoys it, is happy to go and our family are heard and supported.”

“My child's school is amazing. The place at this school would not have been possible without a huge stressful battle with the LA as they tried to discourage us from applying.”

- **Concerns about school capacity/ staff**

“The school is the right place but it was an unnecessary fight to get the place she absolutely needs and they are so short staffed that you do not feel you get as much support or information about our children as we should. My child is non verbal and cannot tell me how their day is or what they've been doing but the school staff and TAs are so understaffed that they can't take the time to tell us either. You are left not knowing what is going on.”

“The school don’t follow his EHCP, the staff are nice but undertrained. I have had several meetings with the school about my concerns and each time, I’ve been ignored and everything has carried on the same. They also have a ‘we know best approach’ when they don’t.”

“School have one agenda, and it’s to following their own. Not the child’s provisions set out in the EHCP.”

“The school are so lovely with My son but I feel the class size is too big for him as the school is over subscribed, he gets very overwhelmed easily with the noise etc. and spends a lot of time outside the classroom to regulate, i worry he’s missing out on a lot of learning with always having to be taken out.”

“My son is happy at Mayfield, but he was not allowed to go up to the secondary setting last year as there were no extra places if this happens again, he may regress.”

- **Concerns/ complaints about transport:**

“Transport is a joke, constant changes!! Stop coal care a joke... 6 LD social workers in 2 years. Whole system is underfunded, under educated and staff worn out and spread far too thinly!”

“I have written strongly disagree because the transport options are awful. My child is on the bus for over an hour with severe sensory processing needs and he only lives 20 minutes away.”

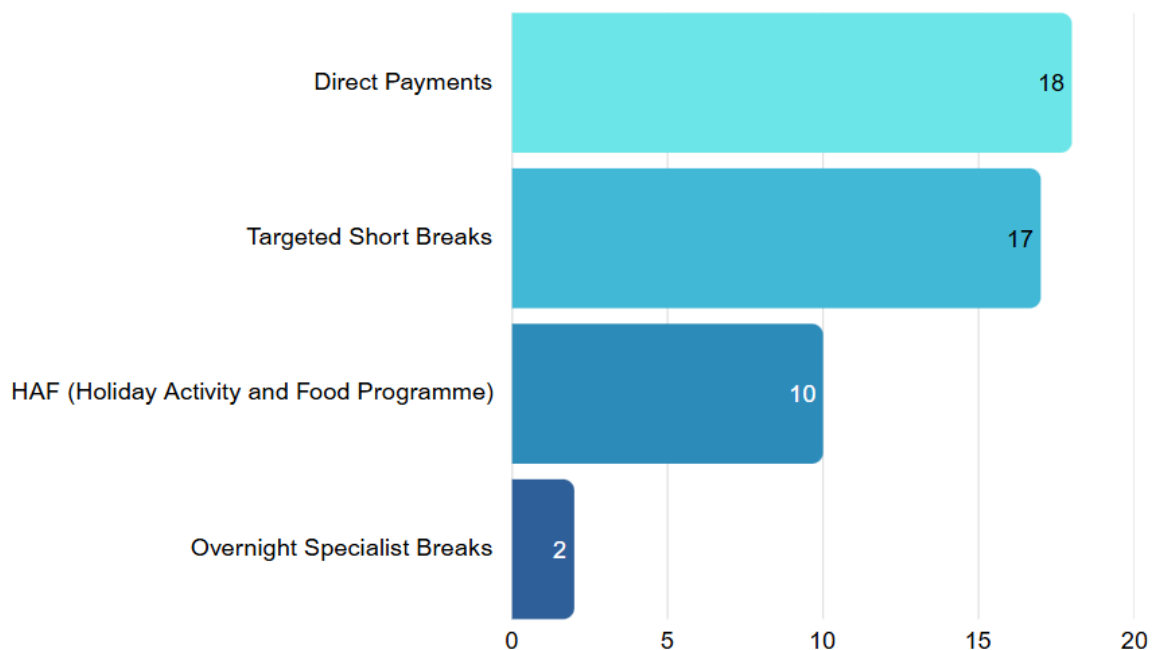
“Transport was awful! Had to take my son off a few years ago, just didn’t want to get on anymore as if he was terrified, screamed all the way to school, used to love it until Hobens took over, heard lots of negative comments about Hobens at the time, lots of children had to be taken off.”

“I drive my son to school and receive parental mileage. I know the legislation, so get all 4 legs reimbursed, but was lied to by the transport team before they realised I knew what I was talking about.”

Social Care themed

When asked what social care provisions or services their child or young person accessed the responses were as follows (base size: 155). Please note, only 22 respondents selected their child/ young person accessed any form of social care. This equates to 14.2% of total respondents.

The numbers below equate to 47, however some respondents selected more than one answer.



When asked to rate the service/s they accessed, the average score was 4.3 out of a possible 10.

Those who accessed Direct Payments alone (5 respondents) rated this on average as a 6 out of 10.

Those who accessed Targeted Short Breaks alone (6 respondents) rated this on average as a 2.3 out of 10.

Those who accessed HAF alone (2 respondents) rated this on average as 8.5 out of 10.

Social Care Qualitative Question

(please provide any further comments on your answers given above):

This question was left open-ended to allow parents/ carers to talk about what mattered most to them, and to avoid asking too many qualitative questions on the same subject.

11 respondents gave a response to this question.

Key themes:

- **Not aware of social care available:**

"I have never been given any information from the LA on options for direct payments, short breaks etc."

"We are never offered any if these things, which proves my point of lack of support for SEN children and families."

"Wasn't aware anything was available to us."

"I was not even aware that I could access such provisions."

"Nobody has spoken to us about support with social care."

- **Cannot access offer**

"Targeted short breaks are only focused on autistic children, there's absolutely nothing for physically and medically disabled children."

"No short breaks are running anymore so my child doesn't get to go."

"We were told we weren't eligible for social care as daughter doesn't have a learning disability. Seems wholly unfair. She still has vast needs."

"There has been a total lack of TSB provision in Copeland."

"Have not been able to access any targeted short breaks since I was informed my child was entitled to them. No information available at all or any explanation on how this works."

- **Struggles with suitable care (direct payments)**

"We get direct payments but we've had to reduce our hours to pay staff more because no one wants to work for a child with complex needs for minimum wage so we had to reduce the hours we get respite to pay a higher wage meaning we don't get the break we should be getting and you refused to give me more hours despite asking for help. We also have to find staff ourselves which isn't easy so even when we have hours we can't use until we find staff. We cannot use the targeted short breaks because they are only for children with low/moderate needs so if your child cannot toilet or feed themselves they cannot access the hours offered so the parents who are struggling with profound children don't get any help at all and overnight respite is only for children over 8 years and the waiting list is years long to even be given a place so yet again no help."

"Can't find people to do the direct payment work, "specialist" care services have staff with very little knowledge, constant changes, there is no room for overnight respite as not enough places or staff, there is nothing to support families with children with complex needs during school holidays, only mild needs can be met, yet it's the families with the complex needs that are desperate for the help and support!!"

- **Positive feedback**

"The only ones we have ever used have been Grace Little Centre, the staff care for the children and know them well. In particular, Jonathan and Megan have really understood all the little quirks and issues our neurodivergent children have and ensure that they have their needs met."

“My son thrives at short breaks, there’s only a small number of people that go, I feel he gets more from it than school because less noise hence joins in with activity’s as happy! I can relax knowing I won’t get a phone call, it really is the perfect break for us and him 😊.” (Note – provider has since not bid for Short Breaks contract and currently no longer offers service.)

“My son used HAF in the oval centre for the whole of summer and they were fantastic with him. Oval centre staff are very supportive and are able to help him a lot.”

Other Qualitative Feedback

A final qualitative question was asked to end the survey:

Do you have any final thoughts/ comments for us?

There were 80 responses to this question, varying widely in theme.

- **Feeling let down:**

“Services are very very bad and my child has been let down at every level.”

“I have absolutely no confidence in Cumberland Council and their ability to meet my child's needs.”

“Social support non existent in Cumbria. My son has been failed massively. Complaints put in but ignored. Next step is legal action. Massive impact on my own mental health people in these departments should be held accountable.”

“One of the overwhelming feelings I have had through this process is the lack of help, advice or information I have been given. We go through the steps and processes, with no idea whatsoever what they may lead to. The majority of information we have received has been from other parents.”

“I am personally very upset by the whole process, but because I don’t shout I’m not heard.”

- **Suggestions:**

“Schools and LA need to have more knowledge and compassion and believe parents and respect them rather than blame them for child attendance issues.”

“There’s not enough support for those going EBSA. Parents are often made to feel like it’s their fault. There’s not enough alternative provisions for those who are unable to attend school. EOTAS is amazing but always feels precarious, like it will be removed from us and my child will be forced back to a setting.”

“Someone needs to be looking specifically at how Send is handled in some of the local secondary schools - particularly academies. In our situation I have been quoted “we won’t put any assistance in place to support M until we have a diagnosis in case we are doing it wrong” and “we won’t apply for an EHCP unless there is a significant learning difficulty”. This is just the tip of the iceberg.”

“Please talk to parents better. We are not stupid, we want what is best for our children. Don't force families to go through the trauma of tribunal to get an education like any other child. If you can't offer what the family wants/needs, work with them and COMMUNICATE properly to find another answer. Just saying 'no' is not good enough.”

“We feel there should be more autism training in school, especially autism in girls. We have found it can be ignored and dismissed because the struggles and behaviours aren't overt and don't cause a disruption in the classroom.”

“Please provide diagnosis for dyslexia through schools. These children needs that extra time but aren't eligible unless they have the formal diagnosis. This is unaffordable for the many.”

“All health care professionals school staff and anyone that deals with children should have more information about Fasd. “

“More consideration for children with physical disabilities rather than just tagging it on. Always feels like those children with physical disabilities are an after thought to those with autism and/or ADHD”

“More suitable changing places needed, especially in town centres. Stop forgetting about physically and medically disabled children. New play parks that are being built are not accessible.”

- **Positive feedback on survey**

“Great survey. Well done for doing this.”

Child/ young person Survey Data

There were 33 total responses to the children/ young people survey.

A full communications plan, including asking schools to complete the survey as part of the form time was carried out, however this appears to only have been followed in one instance.

This survey was co-produced with young people from Unique Voices.

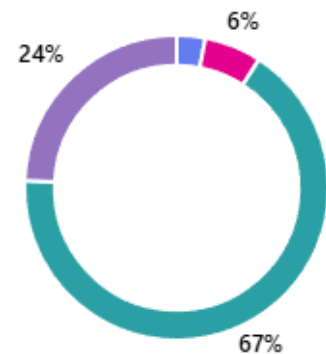
Respondent Profiles and key variables

Age (base size: 33):

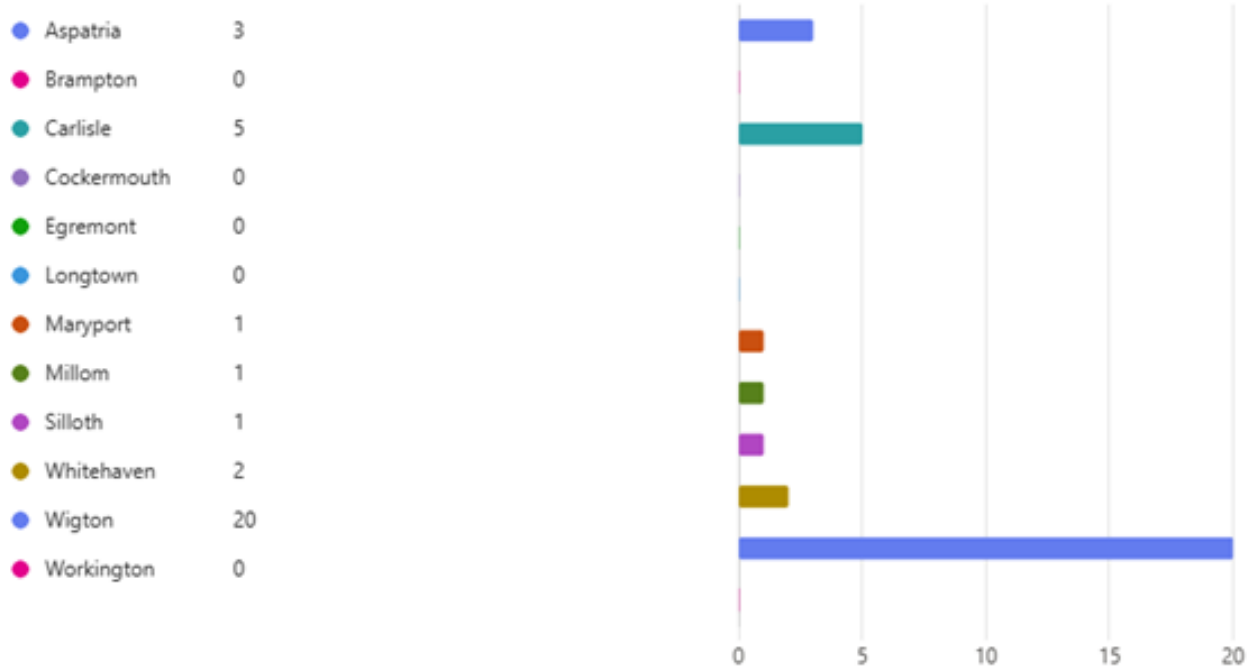
67% of respondents were aged between 11 – 15.

There were no respondents aged between 19 – 25.

● 0 - 5	1
● 6 - 10	2
● 11 - 15	22
● 16 - 18	8
● 19 - 25	0



Nearest town/ city:



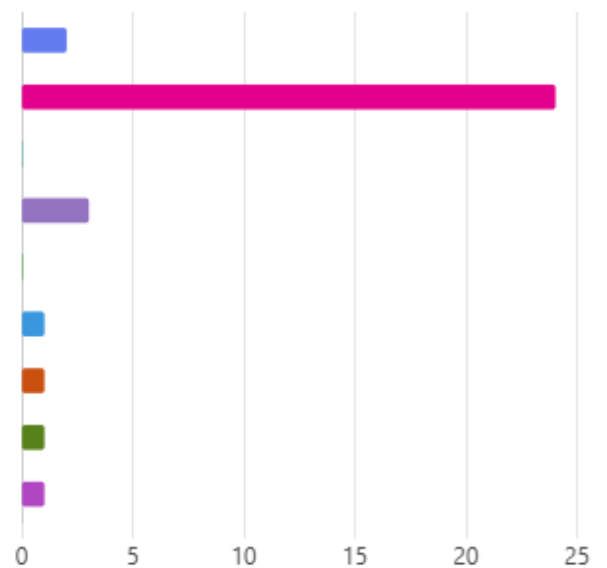
60.6% of respondents selected their nearest town/ city to be 'Wigton', suggesting a school in Wigton encouraged children to complete this survey. Unfortunately, this was not replicated by any other education settings, as the second highest response rate was from Carlisle, with 5 respondents.

Education questions

It has been noted that between the parent/ carer survey and the child/ young people survey there is a lack of consistency between education settings listed, with RP and AP not listed as part of the parent/ carer survey. This is something that will be rectified in future surveys.

72.7% of respondents selected they attended a secondary school – none of the respondents selected they attended a special school, showing limited engagement in the survey from our special schools.

Primary school	2
Secondary school	24
Special School	0
College/ Sixth Form	3
Home educated	0
Resource Provision	1
Alternative Provision	1
I don't go to school or an education setting	1
Other	1



Respondents were asked a number of questions about their experiences at their education setting (base size: 32).

They were given 'Yes', 'No', or 'sometimes' to choose from.

Yes No Sometimes

I like to learn

I have friends

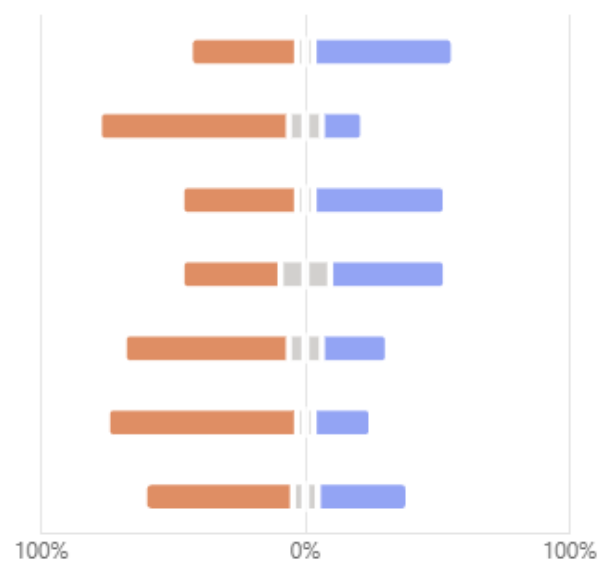
I feel happy often

I feel calm often

I feel supported

I know who I can ask for help

Teachers know how to support me



A full response break down is below:

	Yes	Sometimes	No
I like to learn	40.6% (13)	53.1% (17)	6.3% (2)
I have friends	71.9% (23)	15.6% (5)	12.5% (4)
I feel happy often	43.8% (14)	50% (16)	6.3% (2)
I feel calm often	37.5% (12)	43.8% (14)	18.8% (6)
I feel supported	62.5% (20)	25% (8)	12.5% (4)
I know who I can ask for help	71.9% (23)	21.9% (7)	6.3% (2)
Teachers know how to support me	56.3% (18)	34.4% (11)	9.4% (3)

For all questions, the most commonly chosen response was 'yes' or 'sometimes'.

The highest proportion of respondents selected 'yes' related to having friends, and knowing who they could ask for help.

The highest proportion of respondents selected 'no' related to feeling calm often.

Qualitative education question

Respondents were asked: is there anything else you'd like to tell us about your school/ education setting?

There were 16 responses to this question. 5 said 'No'.

- **Positive responses:**

"I have a Key Worker at school who helps me."

"I like swimming and cooking."

"My favourite subject is Food Tech."

"My favourite subjects are Spanish, Computing, Science and Maths."

"I want to go to Sixth Form after Year 11."

"There is really good food at my school."

"The food is good."

"Eden education is much better for me because it is less stressful."

- **Negative responses:**

“They think they know what's best, even when it makes me shutdown, then when I have a meltdown they suspend me and never look at the teacher that caused the problem.”

“It feels like a prison.”

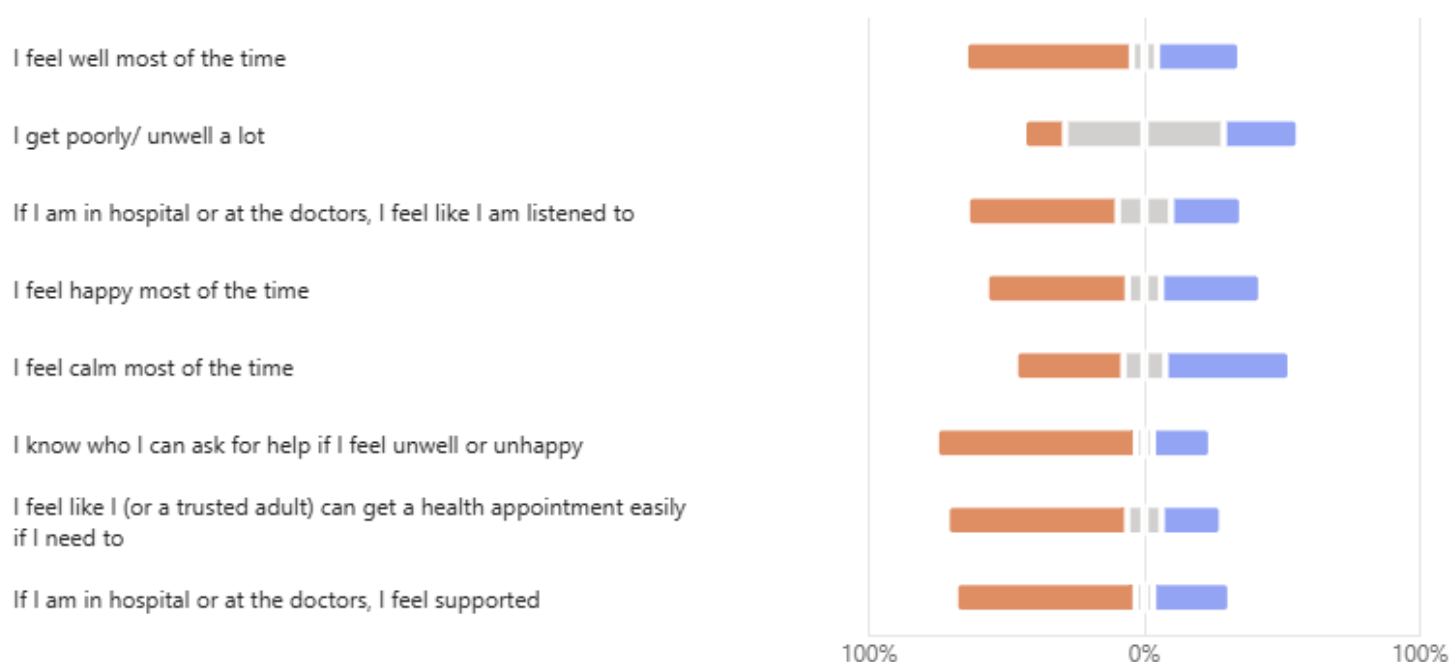
“I am in employment as education was too stressful for me.”

Health questions

Respondents were asked a number of questions about their experiences with their health of in health settings (base size: 33).

They were given 'Yes', 'No', or 'sometimes' to choose from.

● Yes ● No ● Sometimes



A full response break down is below:

	Yes	Sometimes	No
I feel well most of the time	60.6%	30.3%	9.1%
I get poorly/ unwell a lot	15.2%	27.3%	57.6%
If I am in hospital or at the doctors, I feel like I am listened to	54.8%	25.8%	19.4%
I feel happy most of the time	51.5%	36.4%	12.1%
I feel calm most of the time	39.4%	45.5%	15.2%
I know who I can ask for help if I feel unwell or unhappy	72.7%	21.2%	6.1%
I feel like I (or a trusted adult) can get a health appointment easily if I need to	65.6%	21.9%	12.5%
If I am in hospital or at the doctors, I feel supported	65.6%	28.1%	6.3%

Qualitative Health question

Respondents were asked: is there anything else you'd like to tell us about health and feeling well?

There were 8 responses to this question. 4 said 'No'.

"The dentists doesn't listen, and waits until the hole is big before helping even tho I told them it was there ages ago."

"I felt unsupported when I have needed to access healthcare."

"I don't get ill a lot."

"I liked being in hospital the nurses were kind and funny."

Preparing for Adulthood questions

Respondents were asked if they were over 14, and if they knew about the following things (base size: 18).

They were given 'Yes', 'No', or 'a little bit' to choose from.

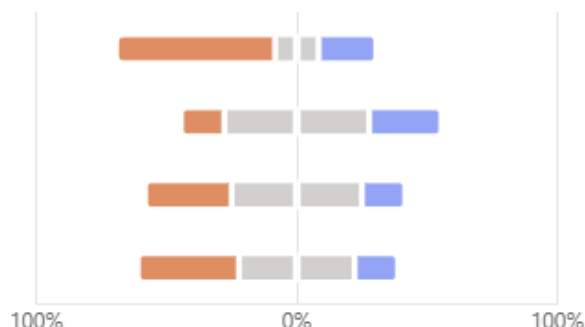
● Yes ● No ● A little bit

I know who can help me plan for the future

I know what support I will get when I am an adult

I know who can support me for college or work when I am an adult

I know who can support me with living options when I am an adult



	Yes	No	A little bit
I know who can help me plan for the future	61.1% (11)	16.7% (3)	22.2% (4)
I know what support I will get when I am an adult	16.7% (3)	55.6% (10)	27.8% (5)
I know who can support me for college or work when I am an adult	33.3% (6)	50% (9)	16.7% (3)
I know who can support me with living options when I am an adult	38.9% (7)	44.4% (8)	16.7% (3)

8 respondents for this question selected they were aged 16 – 18, 10 respondents selected they were aged 11 – 15.

Some data trends were present between these age groups, particularly that the 11 – 15 age bracket feel more supported in preparing for adulthood than the 16 – 18 age bracket:

When asked “I know who can help me plan for the future” 80% (8) of those who were aged 11 – 15 selected ‘Yes’, with 20% (2) selecting ‘No’.

When asked the same question, 50% (4) of those aged 16 – 18 selected ‘A little bit’, 37.5% (3) selected ‘Yes’ and 12.5% (1) selected ‘No’.

When asked “I know what support I will get when I am an adult”, 87.5% of respondents aged between 16 – 18 selected ‘No’.

When asked “I know who can support me for college or work when I am an adult”, 62.5% (5) of respondents aged between 16 – 18 selected ‘No’, with the rest selecting ‘A little bit’.

Qualitative Preparing for Adulthood Questions

Respondents were asked: is there anything else you'd like to tell us about health and feeling well?

There were 7 responses to this question. 3 said 'No'.

"I'm not sure about the future because my grades keep getting worse and they won't listen, even though I've finally got a EHCP plan now."

"I feel unsupported now, so I'm scared for the future."

"I think I want to go to Sixth Form at my current school when I have finished my GCSEs."

"I want to run a gift shop in the future."

Other Qualitative Feedback

A final qualitative question was asked to end the survey:

Is there anything else you would like to tell us today?

There were 10 responses to this question. 5 of these said 'No.'

"I feel like my school has made me a target for bullies as they haven't dealt with them when I've gone to tell them. They pick on me because they enjoy trying to get me to react to them. I just want them to leave me alone. I feel like my school has made things harder for me."

"I feel like I am quite an advanced person; I know things and how to work things."

"SEND support in schools needs to be better. EHCP constantly declined when there's enough evidence for one just so the council can save money. took it to mediation and decision got overturned before the mediation meeting so it was clear that there was enough evidence for me to have an EHCP assessment originally. caused my mental health to be awful and i still can't access the support i need in school because of waiting for an EHCP assessment."

"I wish it was all easier because my mam isn't very well and always doing stuff for me."

"I like Godzilla and gravity falls (tv show). I also like Fortnite."

Recommendations for future survey activities

There have been several lessons learned as part of this process:

- Trust and faith is currently a Partnership Priority and is being built with parents/ carers to ensure their feedback is acted upon. In future it is hoped there will be a larger response rate

to this survey to ensure data can be compared and contrasted and improvements can be seen.

- The co-production process of writing the survey should be more in-depth, with a steering group and further input from the parent/carers forum to ensure the right questions are being asked both to parents and children/ young people.
- Key focus areas need to be discussed in future to ensure the right questions are being asked for specific services/ areas. This survey will serve as a benchmark.
- Partnership leaders, particularly in health and social care, should have a larger input into their sections of the survey going forward to ensure actionable results.
- Specifics around naming education setting need to be considered going forward, as the data provided in this survey is very mixed, even when grouped by nearest town/ city.
- Consistency across respondent profiles needs to be built, such as ensuring education settings are the same across all surveys.
- Accessibility and equity of access need to be considered going forward, including printed surveys being available and considering the survey format.

If you have any suggestions for our future surveys, or would like to be involved in writing our next Partnership survey, please email our Communications and Engagement Officer, Steph at stephanie.campbell@cumbria.gov.uk