
FVP Annual Survey 2022 – 2023 Comparison Report

Results from 22-23
Survey with
comparison across
results 2018 to 2023

Parent Representatives

Annual Survey (2022 – 2023) and Data Comparison with 2018 to 2023 Results

Introduction

This report will follow a format introduced in the last two reporting periods whereby a brief analysis of the full current year Annual SEND Survey will be presented alongside where feasible a comparison of results from previous surveys 18/19 through to 22/23.

As with the previous comparison reports any results will be broken down in to several categories; Children and Young People (CYP) Needs and Education; Identification of Need; Understanding of Needs; Support and Review; Information; Social Care and Transitions; Carers Support.

The surveys compared are from the OFSTED/ CQC SEND Inspection Readiness and SEND & Parent Carer Support 18/19. In 19/20 a combination the questions in both the surveys were amalgamated and used to create the 19/20 End of Year Survey and the subsequent surveys, presented on an annual basis. Any comparison will be to identify basic trends and no conclusions will be drawn. A true comparison is not possible as all data sets are from anonymized surveys. The categories of questions from the annual survey fit with well Preparing for Adulthood, Early Help and Early Support, Joint Planning and Commissioning (individual inclusion as well as strategic involvement).

Some changes have been made over time to enable a base line to be developed of parent carer views across a range of areas (see categories above). Where possible the questions have been amended/ added to link in with themes that were listed as areas for concern in Peterborough's Local Area SEND CQC/ OFSTED Inspection report and the subsequent Written Statement of Action (WSOA).

It should be noted that this year there does appear to be a shift in how parent carers (known throughout this report as respondents) were experiencing and reporting their experience of SEND services from a negative to a positive position. This year reporting period is also unique in relation to the number of overall respondents compared to previous years; achieved through a more concerted effort by all parties (including LA and Health) to share the survey widely with parent carers known to them.

Children and Young People (CYP) Details (Needs/ Age/ Ethnicity/ Education)

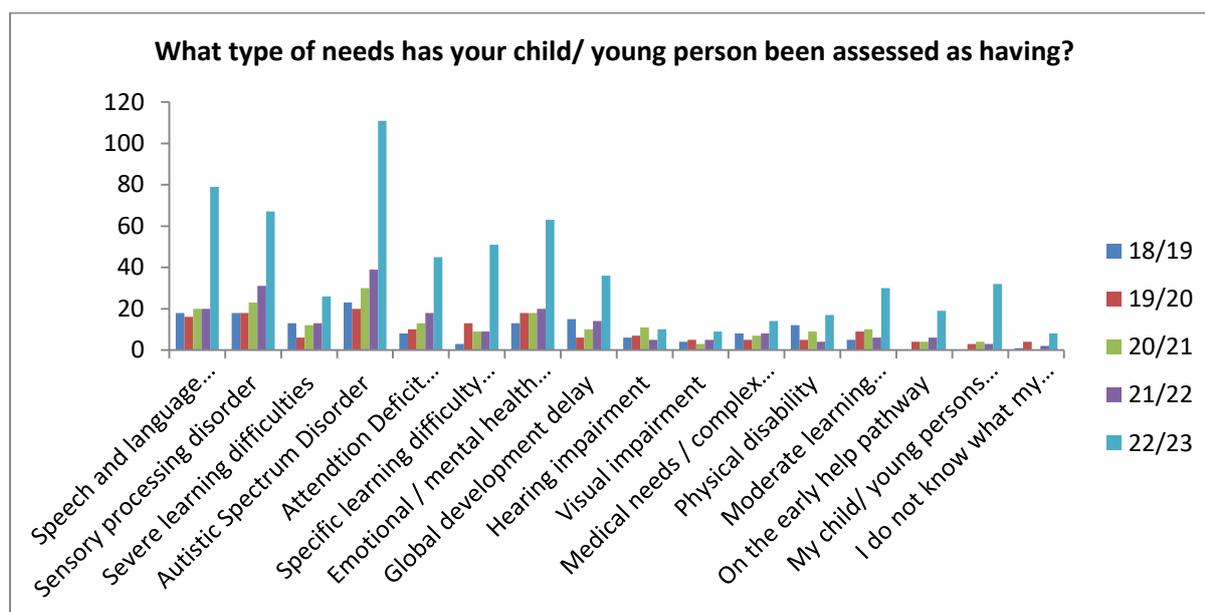


Fig 1. Areas of CYP need as identified by parent carers

Other areas self-reported over and above the categories provided for the parent carers (known from now as respondents) were:

1. FASD
2. Downs Syndrome
3. Visual perception
4. 22.11.2Q Deletion syndrome /Di George's
5. Torretts, mixed depressive and anxiety disorder , seizure / absent type episodes being investigated
6. Chromosome Deletion
7. Significant early years trauma
8. Down syndrome
9. Sensory processing
10. My child didn't speak very good
11. Anxiety
12. Scoliosis
13. ARFID
14. Genetic disorder

Across all reporting periods the most frequently reported area of need was ASD. It is also important to note that as per the trend noticed previously there continues to be an increase in respondents self-reporting having children/ young people (CYP) with a much broader range of needs engaging especially sensory impairment, physical disabilities and complex health needs.

An area of need/ educational inclusion that was mentioned in the inspection report and WSoA related to the use of part-time timetables by various educational settings. This is an area that has been explored across all reporting periods as well.

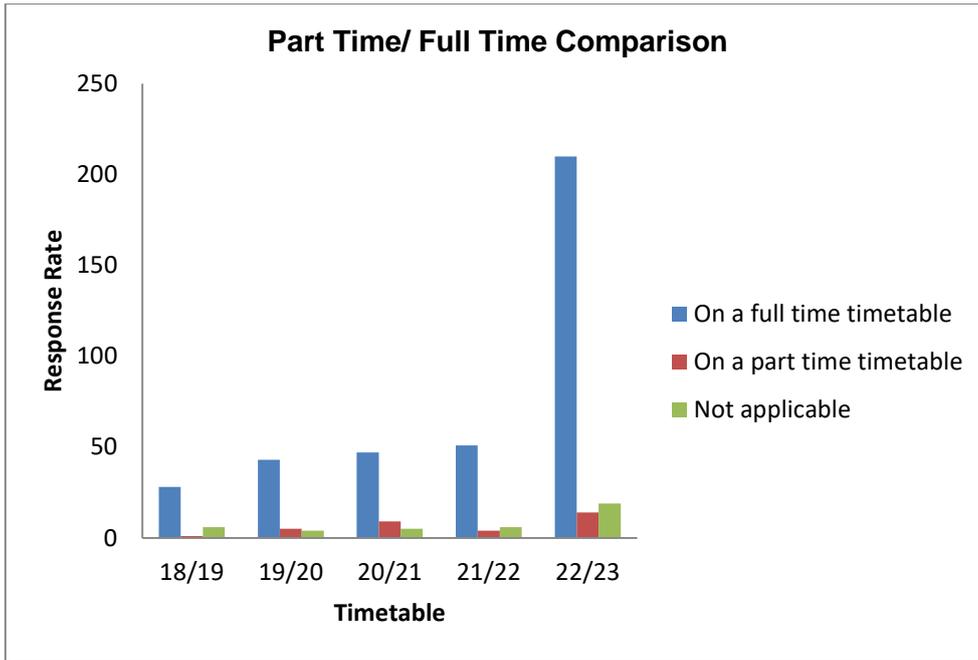


Fig. 2 Educational Inclusion

It would appear from fig.2 that in 22/23 there was an increase in parent carers reporting having their children on part-time timetables compared to previous years, but it should be noted the cohort of respondents was much higher so in comparison to previous years was lower as a percentage of the overall total. This may be related to the work conducted by Peterborough City Council (PCC) to reduce the use of part-time timetables which were identified as a concern in the Area Wide SEND Inspection of 2019. This could be seen to demonstrate the work carried out by PCC to reduce part time timetables as part of their Written Statement of Action (WSOA)

A brief comparison was completed of the ages ranges of the children and young persons (CYP) being reported by the respondents to the latest survey and the previous year's survey. There appears to have again been a slight shift in the respondents who were completing the survey. There was an increase in the number of children in the age range 5-10, 11-15 and then 19-25.

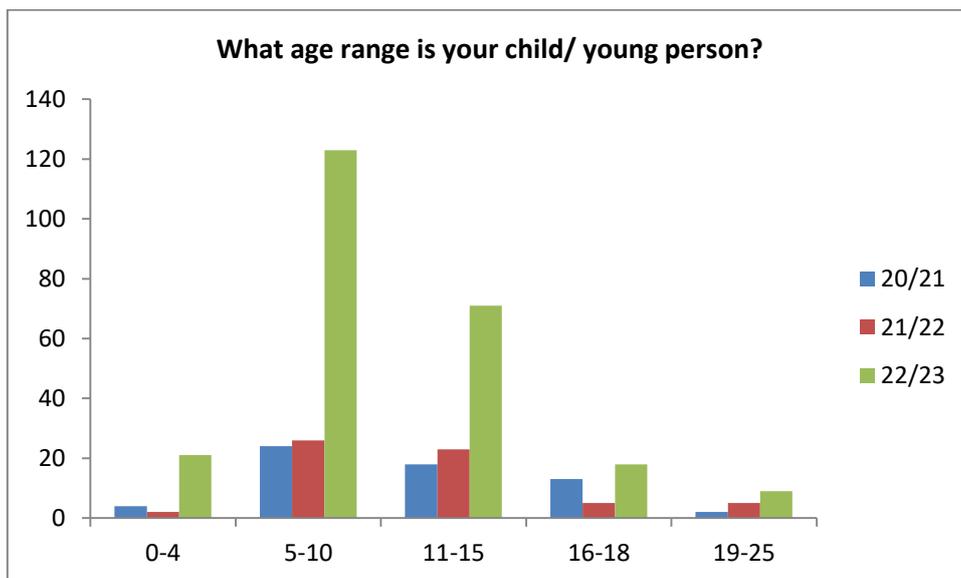


Fig. 3 CYP Age Ranges (20/21 & 22/23 Annual Surveys)

Having parents whose CYP are young completing the survey may have affected the results as from comparisons to be discussed it is clear that in some areas there is an overall increase in positive reporting over time.

This year's survey also saw small increases in engagement from seldom heard parent carers; although the predominant respondent still self-reports as "White British". The latest Census (2021) data shows an approximate split between White British at 60% and other ethnic groups at 40% of the overall population in Peterborough. For 22/23 the split is approximate 70% to 30% with 'White British being the higher percentage. This is relatively close to the latest census figures

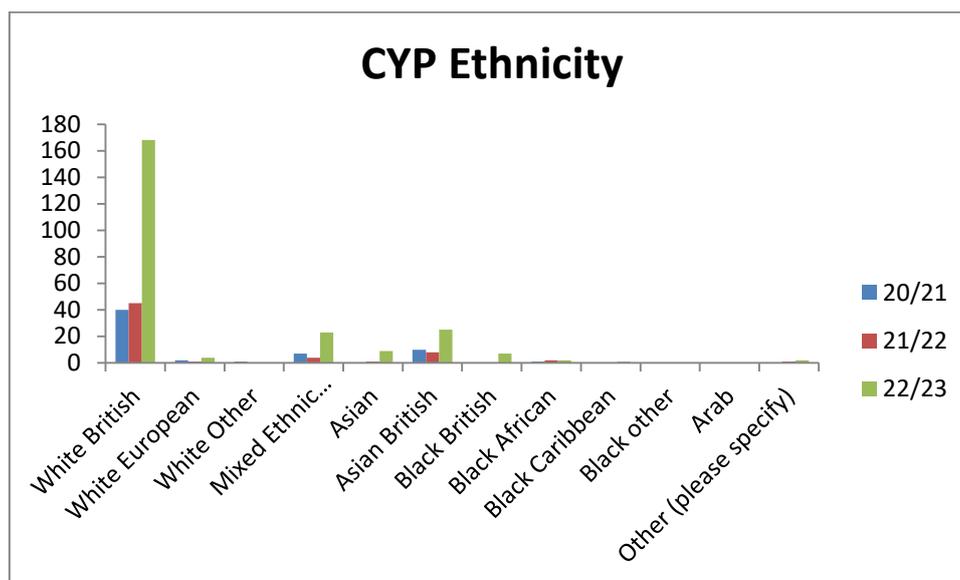


Fig. 4 CYP Ethnicity (21/23 Annual Survey)

Identification of Need

Identification of need looks at how parent carers feel their CYP needs have been identified across a range of areas including Education, Health and Social Care. There is also some focus in this report on the Early Help Pathway in relation to ASD/ ADHD.

One question in the Annual Survey asks respondents to select one of more statements from a series relating to the Early Help Pathway, as below:

1. I do not know what the Early Help Pathway is
2. I have not heard of the Early Help Pathway
3. I have had an Early Help Assessment
4. I am in the process of having an Early Help Assessment
5. I have been asked to attend a positive parenting course as part of my Early Help Assessment
6. I attended a positive parenting course as part my Early Help Assessment
7. My Child/ young person was referred for an ASD/ ADHD after my Early Help Assessment
8. I was referred for an Early help Assessment even though my child/ young person already has a diagnosis of ASD/ ADHD
9. I have been asked to attend a positive parent course even though my child/ young person has a diagnosis of ASD/ ADHD

10. My Child/ Young Person has been referred to CAMHs and I been asked to take a positive parenting course before they will be seen.
11. I would like to attend a positive parenting course but do not know what I need to do
12. I followed the early Help Pathway and my child/ young person now has a diagnosis of ASD/ ADHD
13. I have already attended a positive parenting course but I have been asked to attend another one
14. I have had a referral to CAMHs for my child/ young person turned down even though they have a diagnosis of ASD/ ADHD
15. I attended a positive parenting course and found it helpful
16. I attended a positive parenting course and it has not helped
17. I have not attended a positive parenting course as this does not apply to me/ my family
18. I attended a positive parenting course yet my child was refused a referral for ASD/ADHD diagnosis
19. Not Applicable
20. Other (please specify)

From Fig. 5 and Table 1 below it can be seen that there is across most areas what may be considered a slightly negative view/ experience of the Early Help Pathway, especially in relation to less positive outcomes from the respondent's perspective such as no diagnosis of ASD/ ADHD. There are still respondents reporting that they are being placed on the pathway or taking positive parenting programmes when they already have a CYP with a diagnosis and/ or are want to access CAMHs as opposed to a diagnosis.

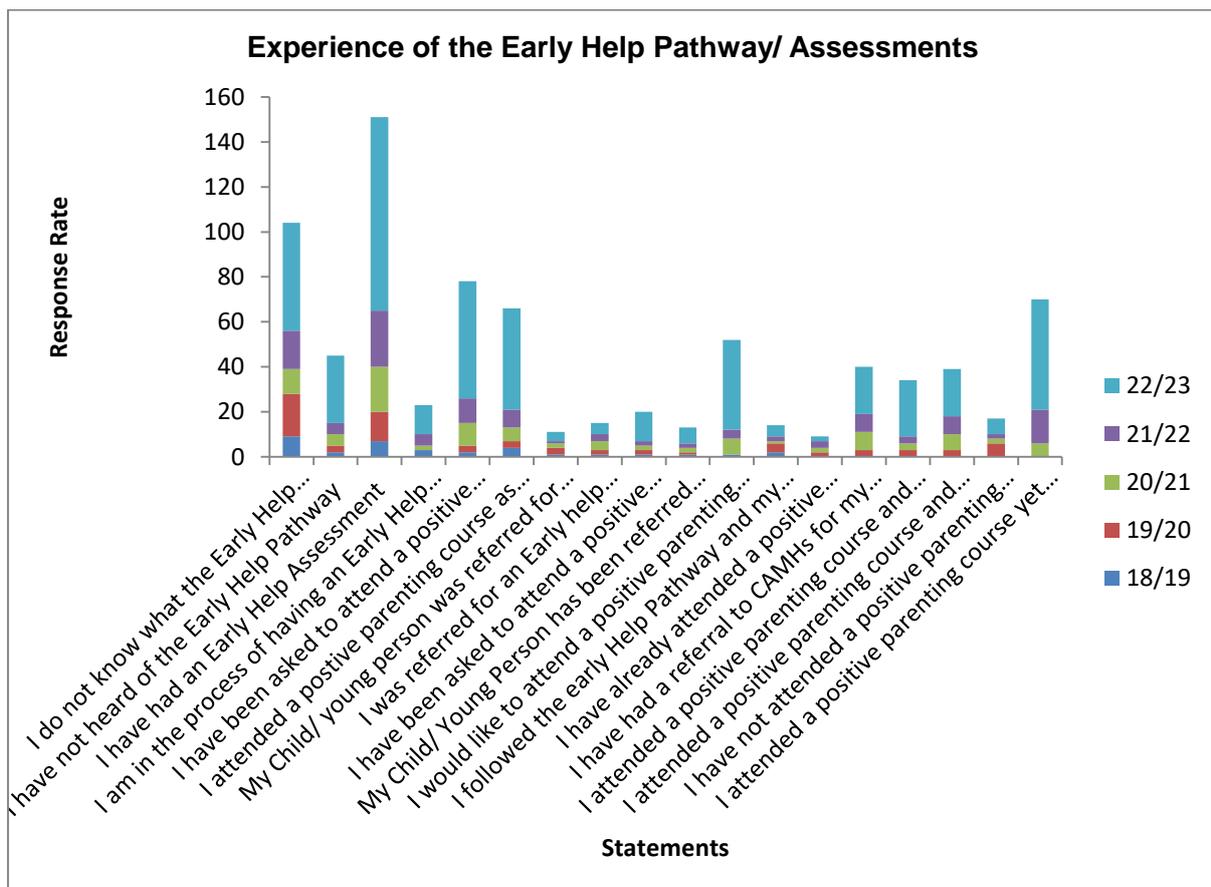


Fig.5 Early Help Pathway Understanding/ Experience

	18/19	19/20	20/21	21/22	22/23
I do not know what the Early Help Pathway is	9	19	11	17	48
I have not heard of the Early Help Pathway	2	3	5	5	30
I have had an Early Help Assessment	7	13	20	25	86
I am in the process of having an Early Help Assessment	3		2	5	13
I have been asked to attend a positive parenting course as part of my Early Help Assessment	2	3	10	11	52
I attended a positive parenting course as part of my Early Help Assessment	4	3	6	8	45
My Child/ young person was referred for an ASD/ ADHD after my Early Help Assessment	1	3	2	1	4
I was referred for an Early help Assessment even though my child/ young person already has a diagnosis of ASD/ ADHD	1	2	4	3	5
I have been asked to attend a positive parent course even though my child/ young person has a diagnosis of ASD/ ADHD	1	2	2	2	13
My Child/ Young Person has been referred to CAMHs and I been asked to take a positive parenting course before they will be seen.	1	1	2	2	7
I would like to attend a positive parenting course but do not know what I need to do	1	0	7	4	40
I followed the early Help Pathway and my child/ young person now has a diagnosis of ASD/ ADHD	2	4	1	2	5
I have already attended a positive parenting course but I have been asked to attend another one		2	2	3	2
I have had a referral to CAMHs for my child/ young person turned down even though they have a diagnosis of ASD/ ADHD		3	8	8	21
I attended a positive parenting course and found it helpful		3	3	3	25
I attended a positive parenting course and it has not helped		3	7	8	21
I have not attended a positive parenting course as this does not apply to me/ my family		6	2	2	7
I attended a positive parenting course yet my child was refused a referral for ASD/ADHD diagnosis		0	6	15	49

Table 1: Early Help Statements

For expansion on this question in relation to more detailed comments provided by parent carers see the 22/23 year annual survey report available from <https://familyvoice.org/participation-reports/>

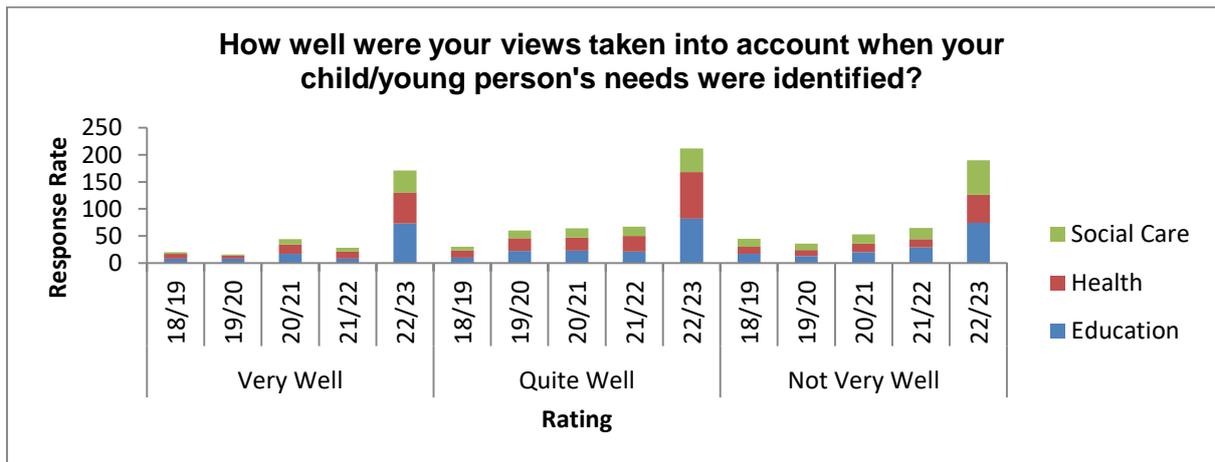


Fig. 6 Identification of Need by Education/ Health/ Social Care

Fig.6 above looks at how well respondents think their CYP needs have been identified by Education, Health and Social Care. It would appear from a cursory examination of the data that overall the decrease in positive reporting identified in 21/22 has reversed for 22/23. The responses were analysed further across Education, Health and Social Care separately, as can be seen in figures 7 to 9, where the data was grouped into positive (very well and quite well) and negative (not very well).

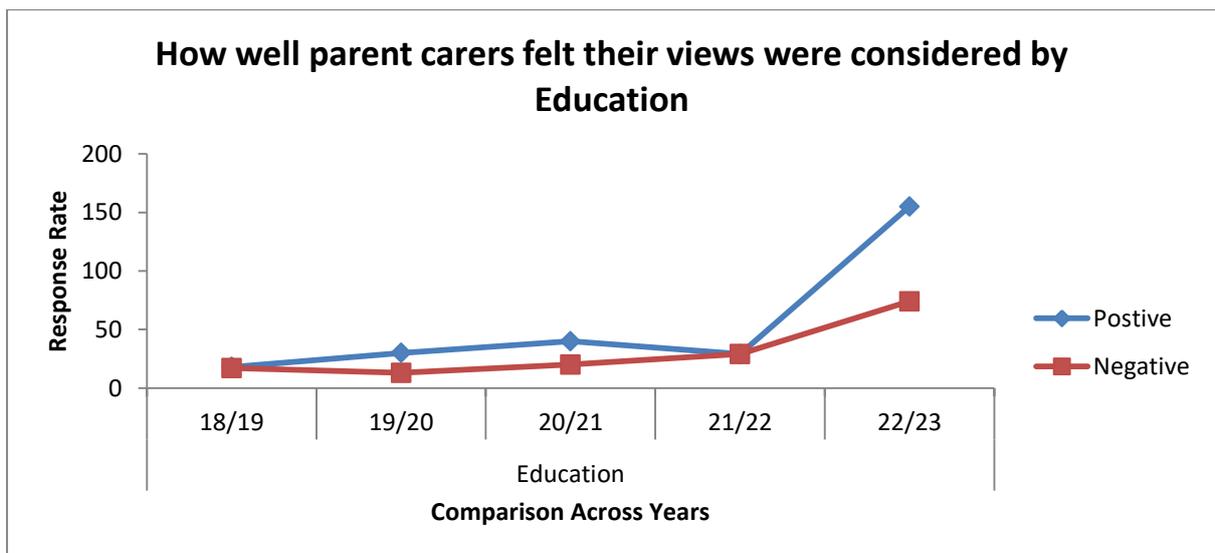


Fig. 7 Comparison 18/19 – 19/23 (Identification by Education)

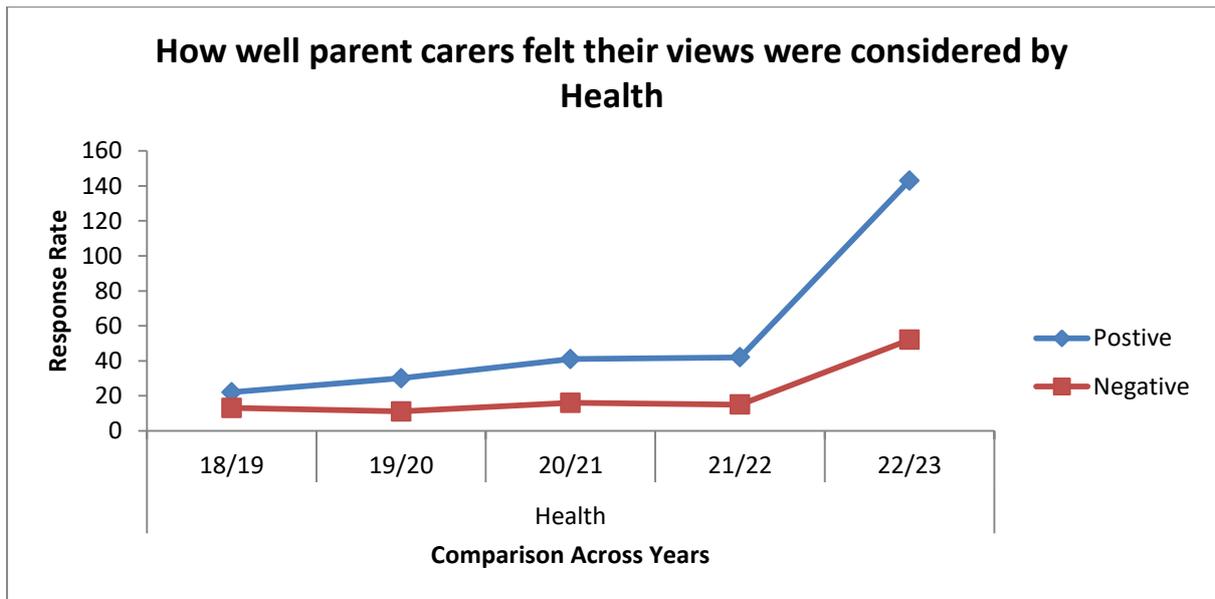


Fig. 8 Comparison 18/19 – 22/23 (Identification by Health)

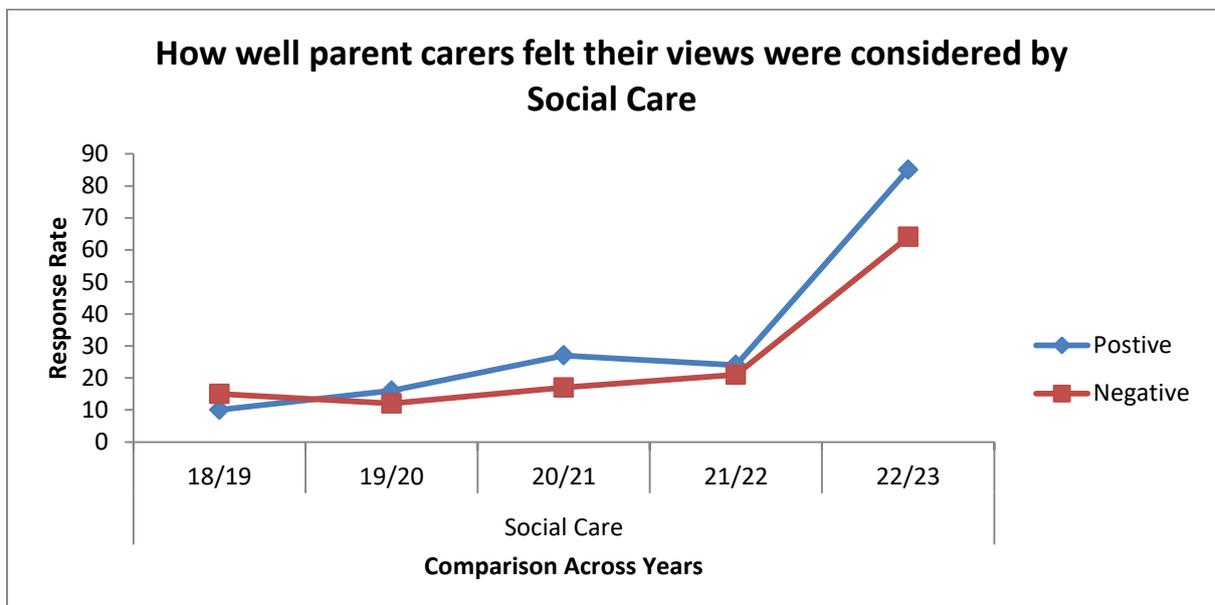


Fig. 9 Comparison 18/19 – 22/23 (Identification by Social Care)

Across all areas positive reporting increases and negative reporting decreases especially reversing the trend identified between between 20/21 and 21/22. It should also be noted that Social Care saw the highest number of respondents opting to choose 'Not Applicable'. This fits with anecdotal evidence that parent carers rate access to social care problematic.

Respondents were also asked how well their views were taken account of during the identification of need process and again there has been a move towards more positive views.

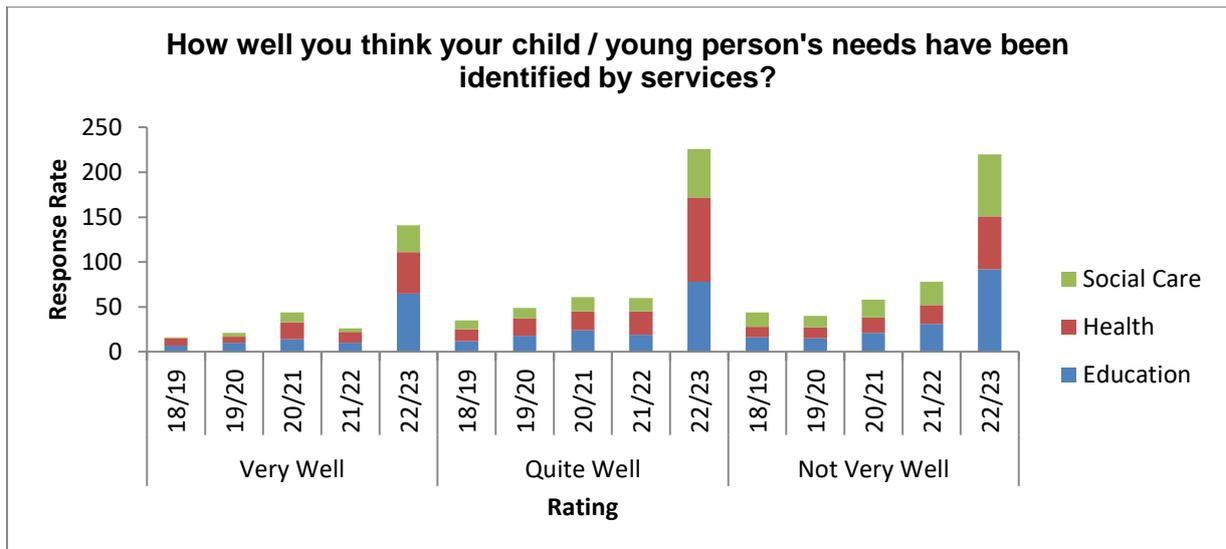


Fig. 10 Account of Parent Carer Views During Identification of Need

Fig.10 above shows the overall shift towards respondents feeling their views were better taken account of again reversing the trend in the previous years reporting period.

Figs. 11 to 13 below also demonstrate the increase in positive reporting more clearly. Again the responses were grouped to ascertain an overall picture of positive and negative experience.

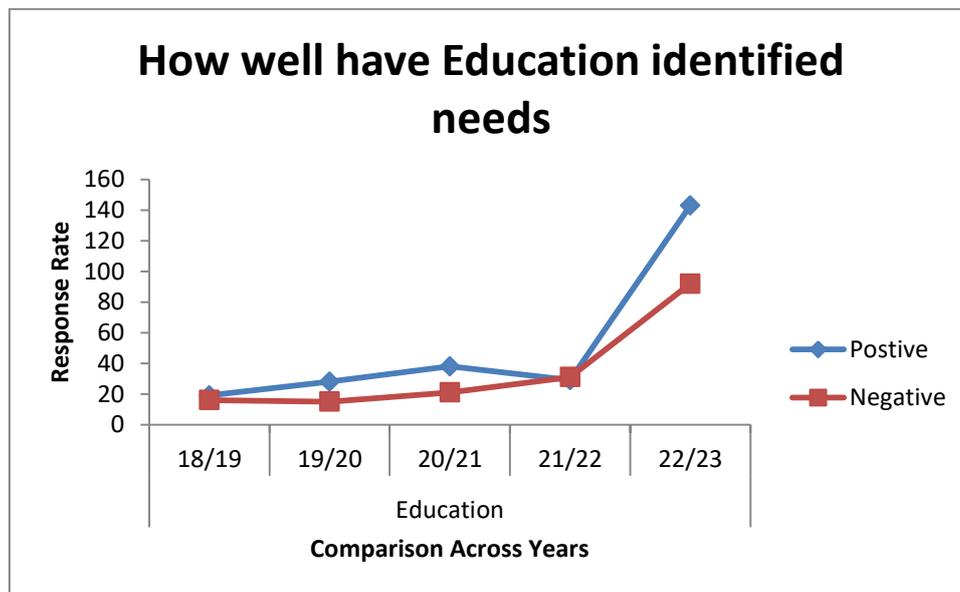


Fig. 11 Parents Views 18/19 to 22/23 (Education)

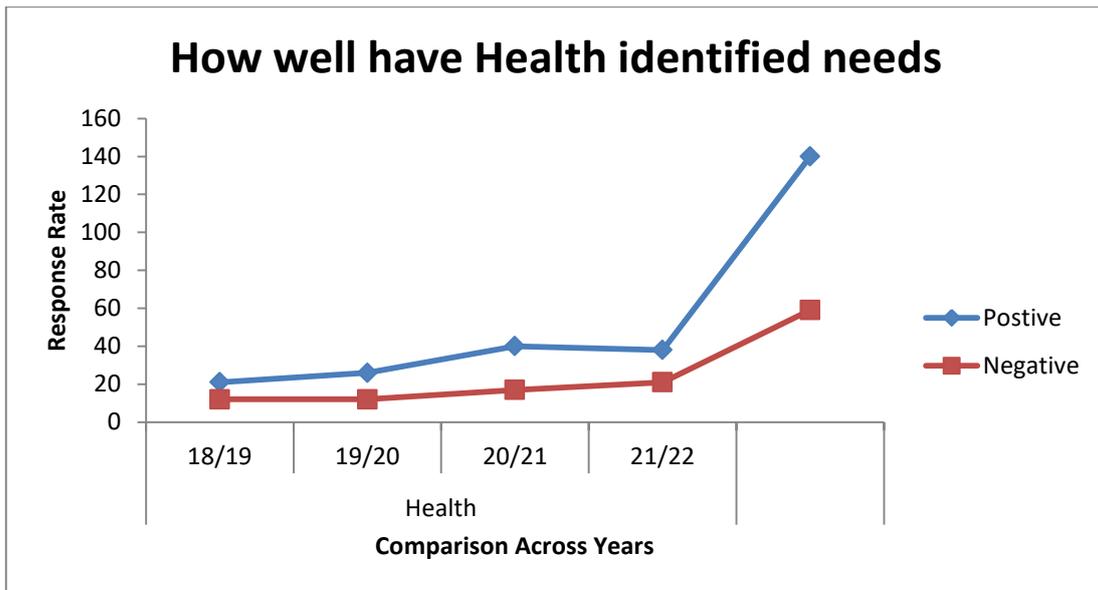


Fig. 12 Parents Views 18/19 to 22/23 (Health)

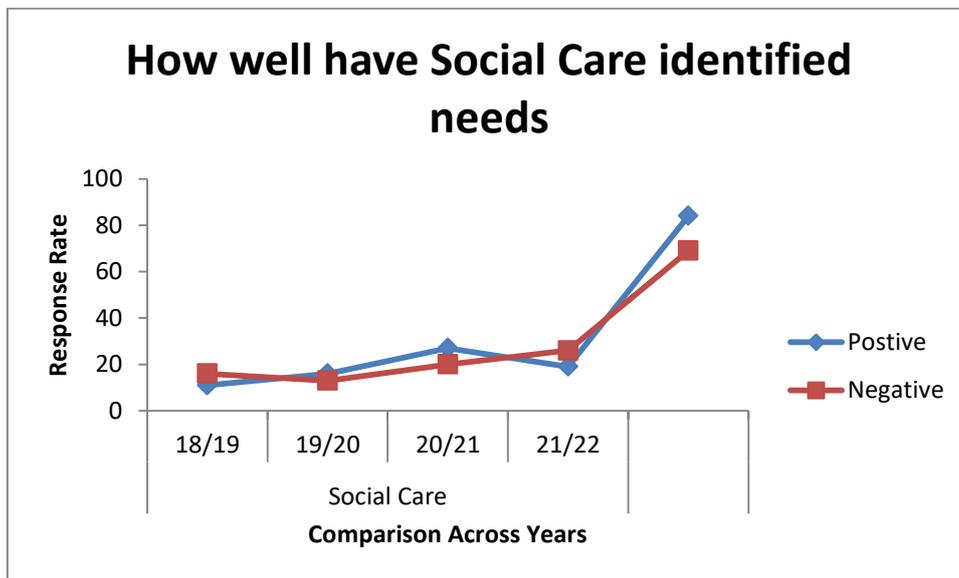


Fig. 13 Parents Views 18/19 to 22/23 (Social Care)

The change towards more positive reporting across the board could be down to a number of factors including; the cohort taking the survey, the changes strategically to improve SEND services and the increase in the number responding to the survey.

Understanding of Needs

Another area of focus is understanding of CYP needs by professionals and parents especially after identification. Overall the same trend towards a decrease in positive experience and increase in positive experience can be identified across all areas in relation to how respondents feel professionals understand their CYP needs.

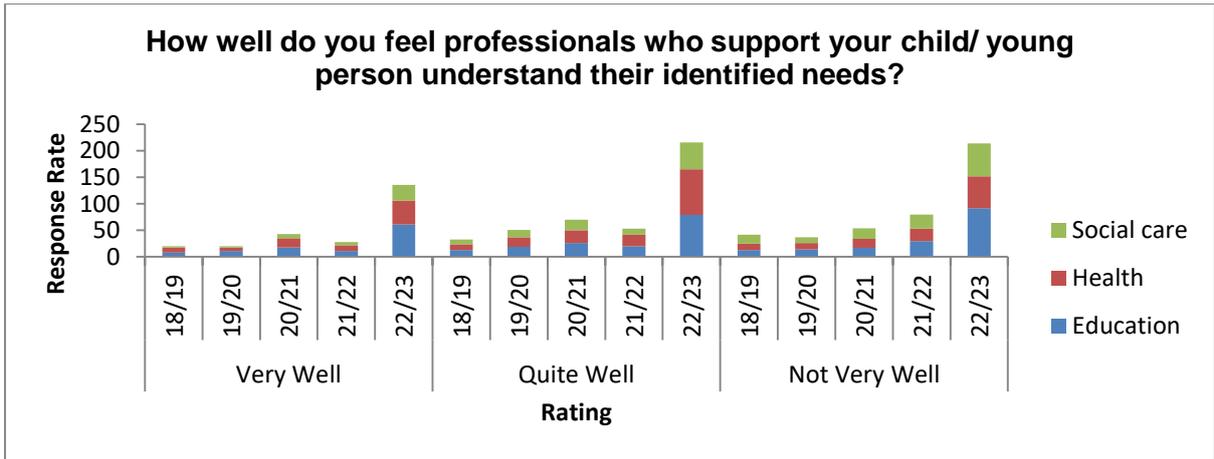


Fig.12 Professionals understanding of needs

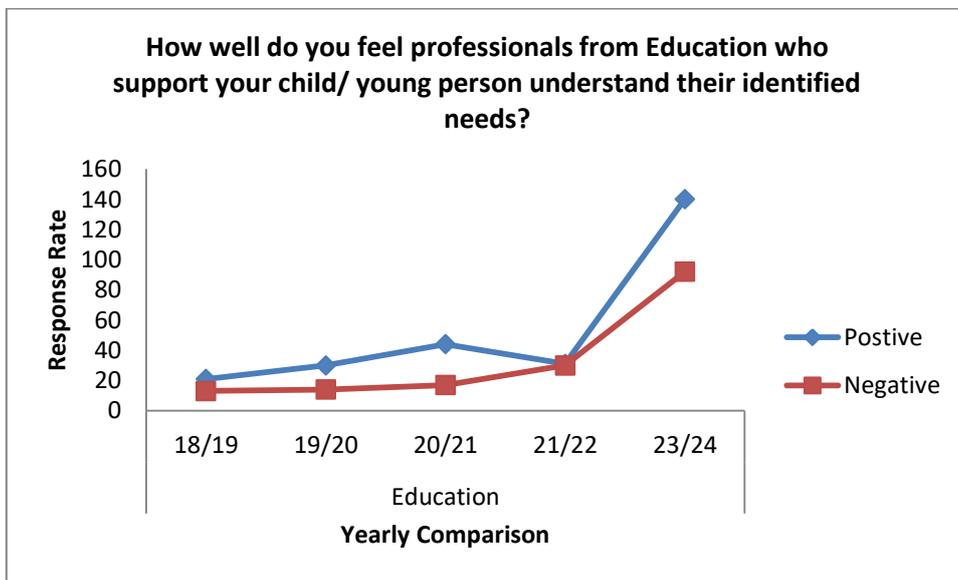


Fig.13 Professionals understanding of needs (Education)

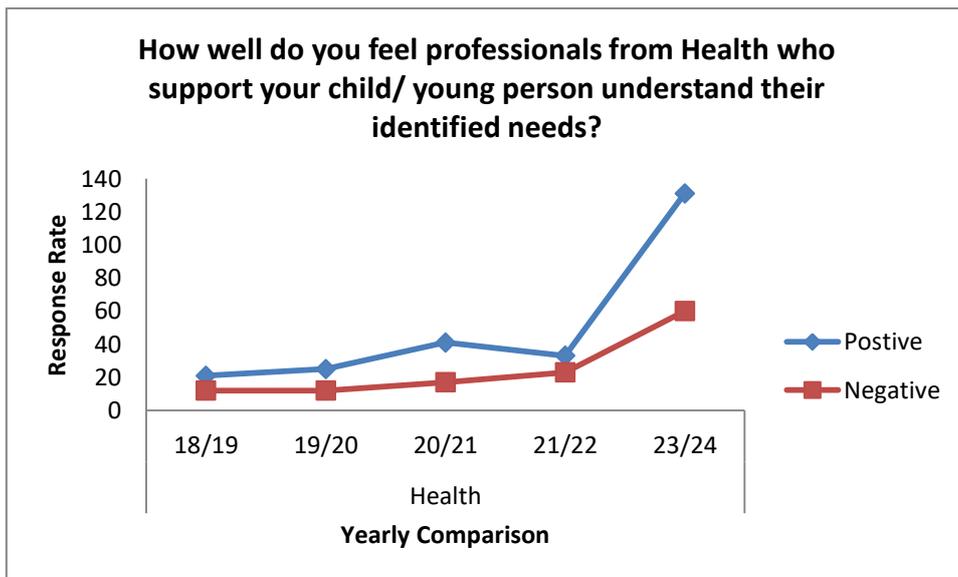


Fig.14 Professionals understanding of needs (Health)

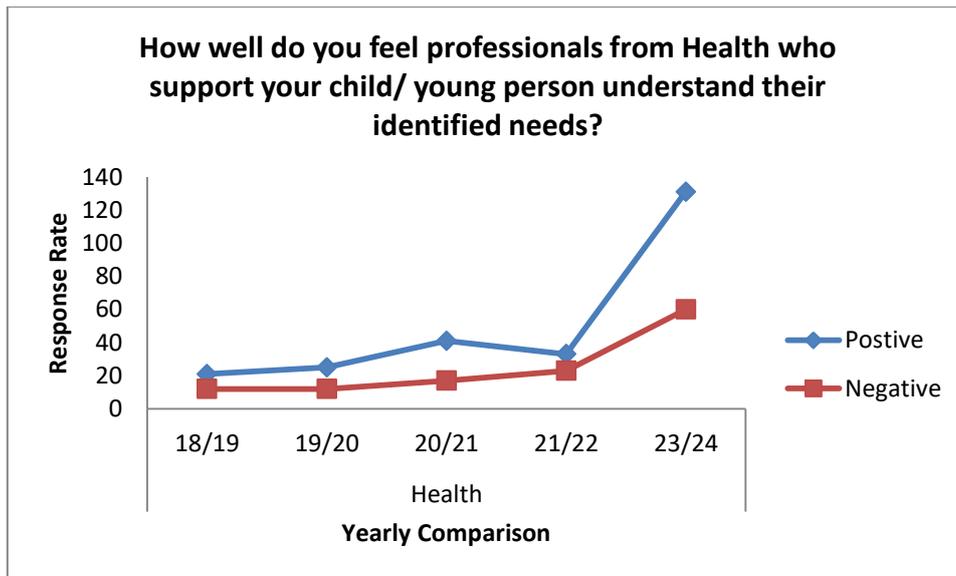


Fig.15 Professionals understanding of needs (Social Care)

A few parents provided comments further to their response to this question (see below). For a full view of all comments provided please read the full annual survey report referenced previously.

School has been amazing and supportive but again because school is a safe, structured place some children fall through the referral and assessment process, and school have to battle on behalf of the parent.

Apart from getting completely 'shafted' by the education system, we have been pretty much left to manage alone. Only help/info we ever got was from Little Miracles & Family Voice. Even the EHCP team went right over our heads....

*The school have been fantastic, understanding all ***** needs and helping me support her needs to how things happen outer the school environment*

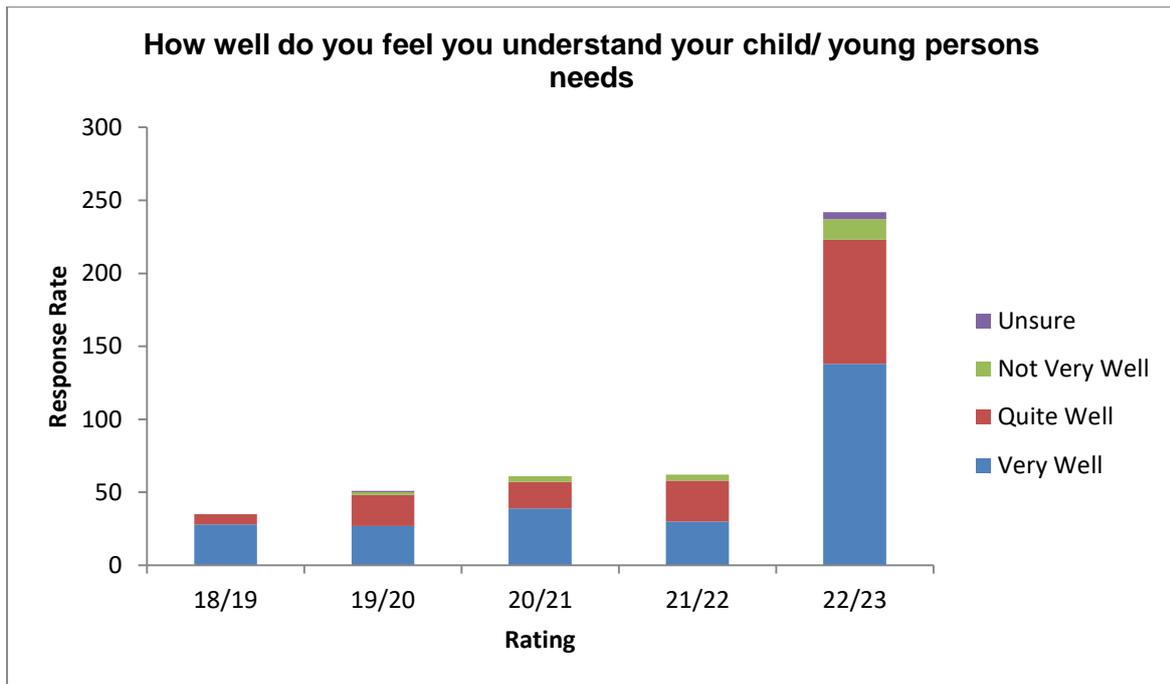


Fig.16 Respondents understanding of needs

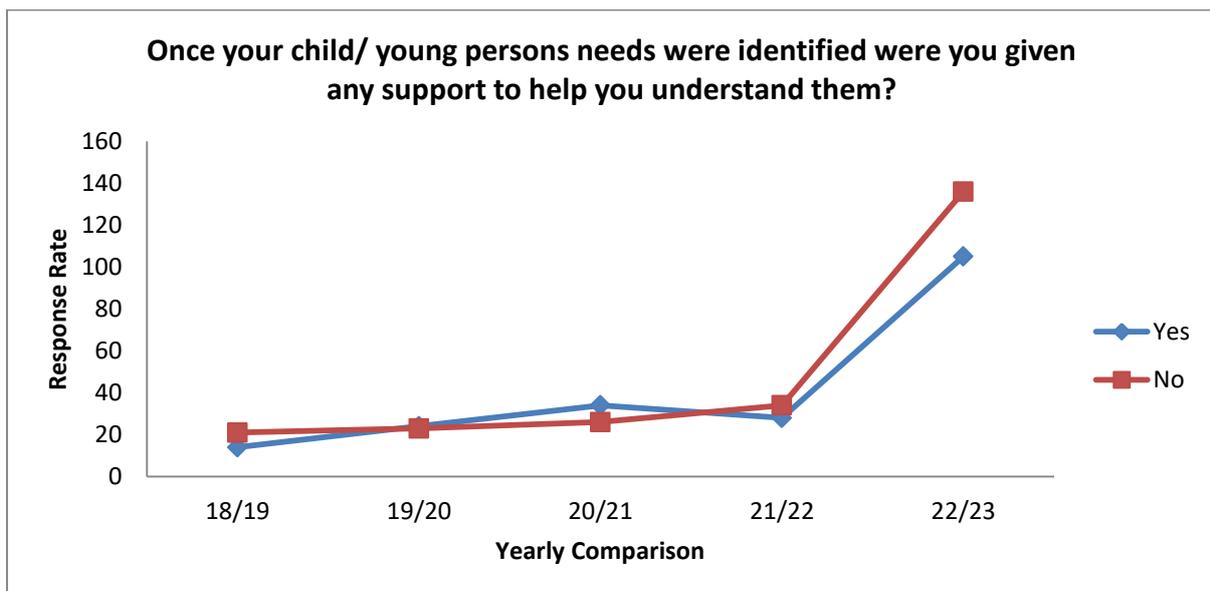


Fig. 17 Help to understand CYP needs

In this area the trend towards positive reporting drops off and moves towards more negative reporting.

Support and Review

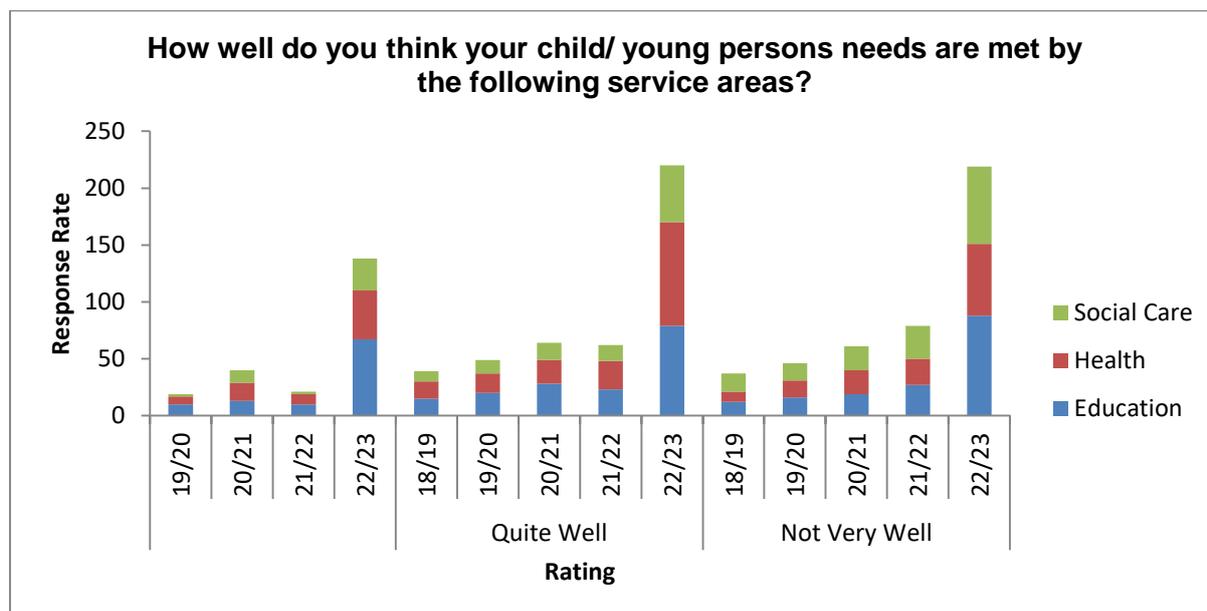


Fig. 18 how well services meet needs

Fig. 18 demonstrates the same trend with increases in positive reporting between 21/ 22 and 22 and 23. In this case how well CYP needs are being met. This is easier to demonstrate when looking at Education, Health and Social Care separately across 18/19 to 22/23 as shown in Fig 19 to 21.

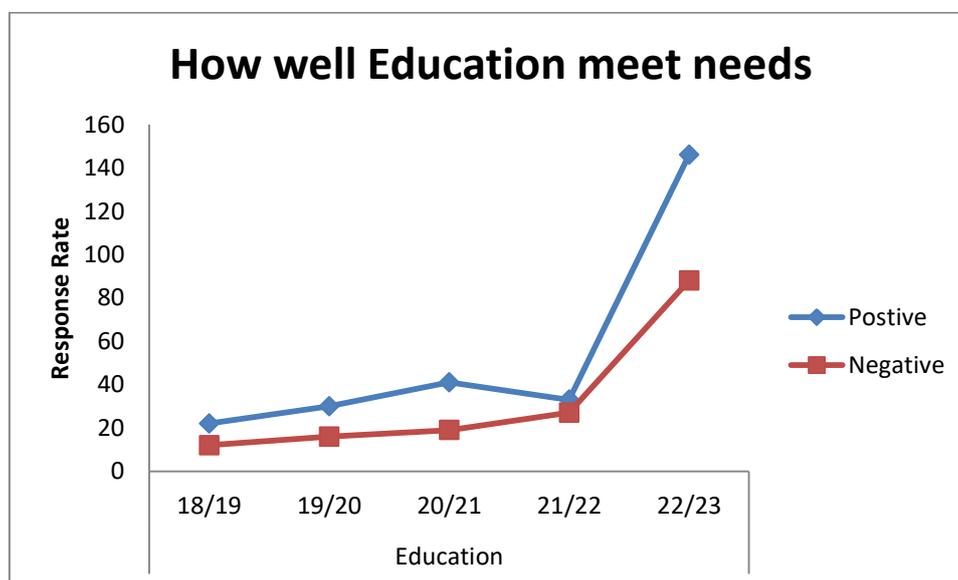


Fig.19 How well education meet CYP needs across years

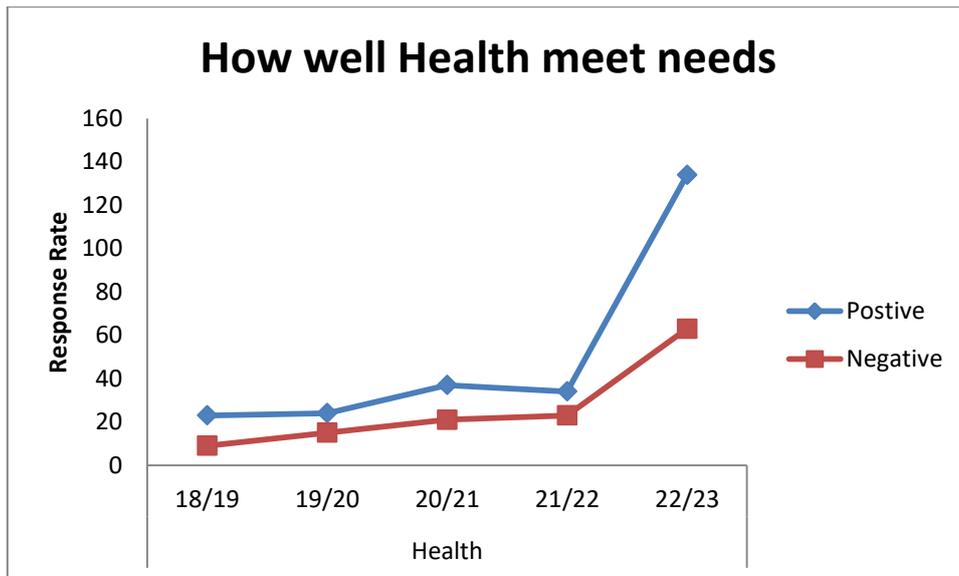


Fig.20 How well health meet CYP needs across years

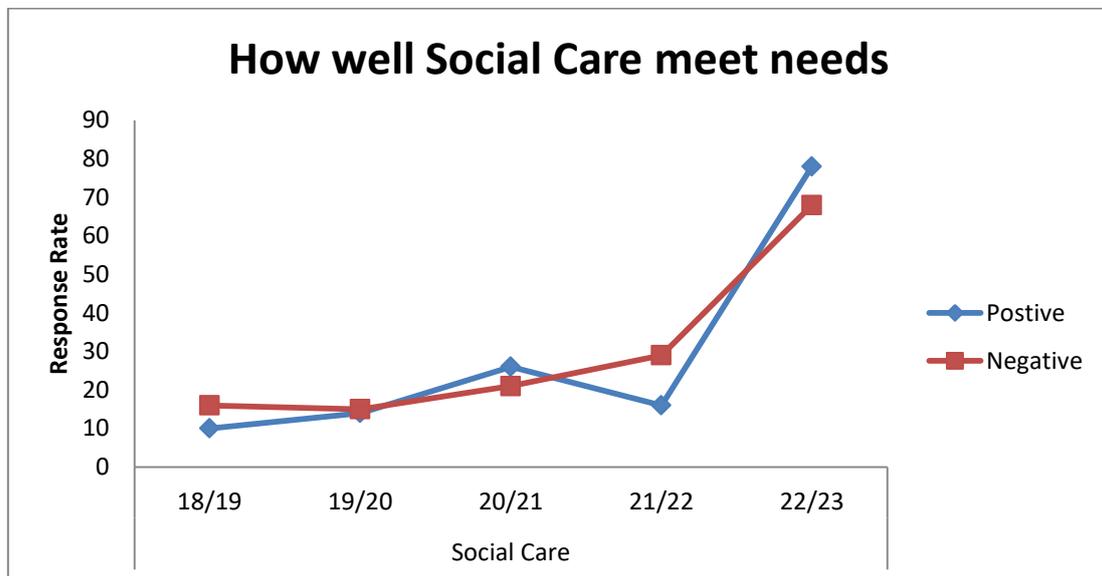


Fig.21 How well social care meet CYP needs across years

It should be noted that for social care although the trend towards more positive reporting exists the gap between positive and negative reporting is much smaller. This may be to less numbers accessing social care overall.

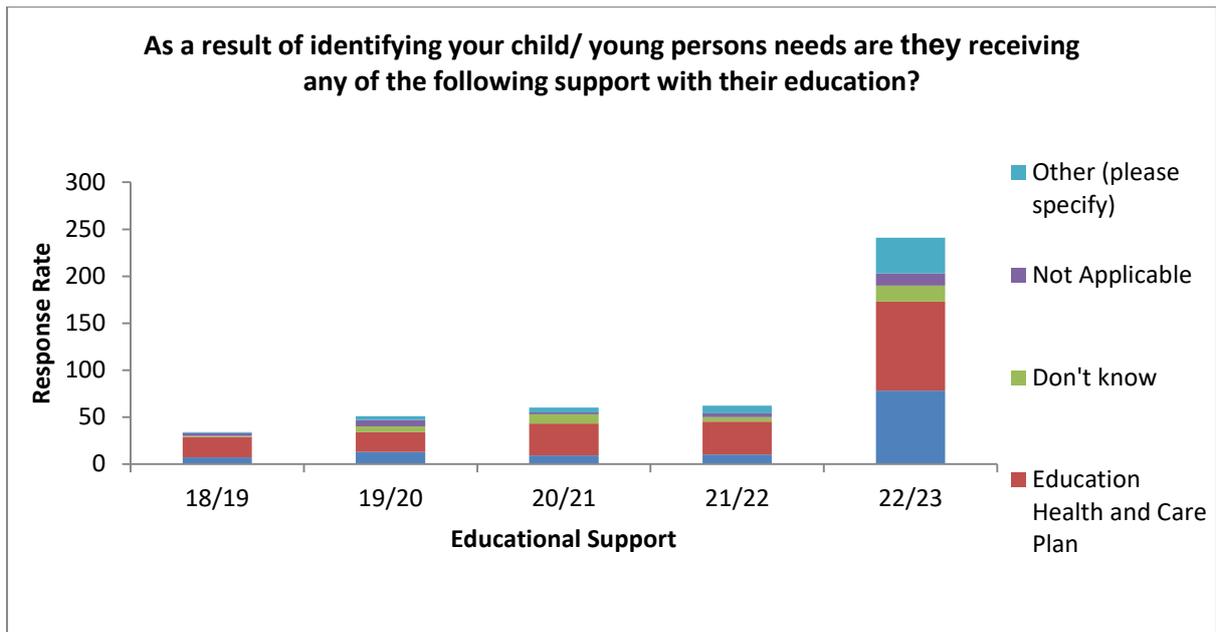


Fig. 22 Type of educational support

From fig. 22 the trend in increasing numbers stating their CYP receives support from an EHCp continues which matches local EHCp data and national trends.

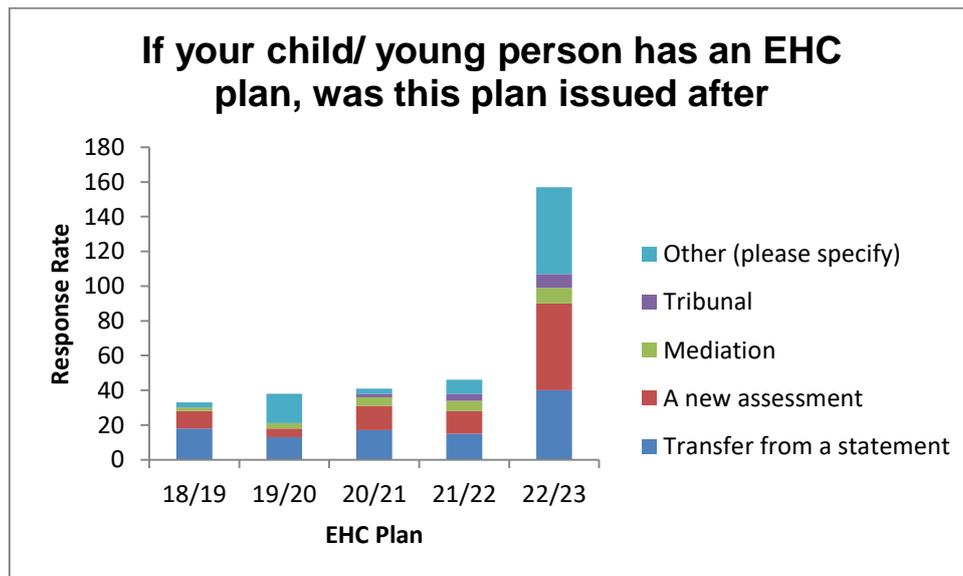


Fig.23 When was EHCp Issued

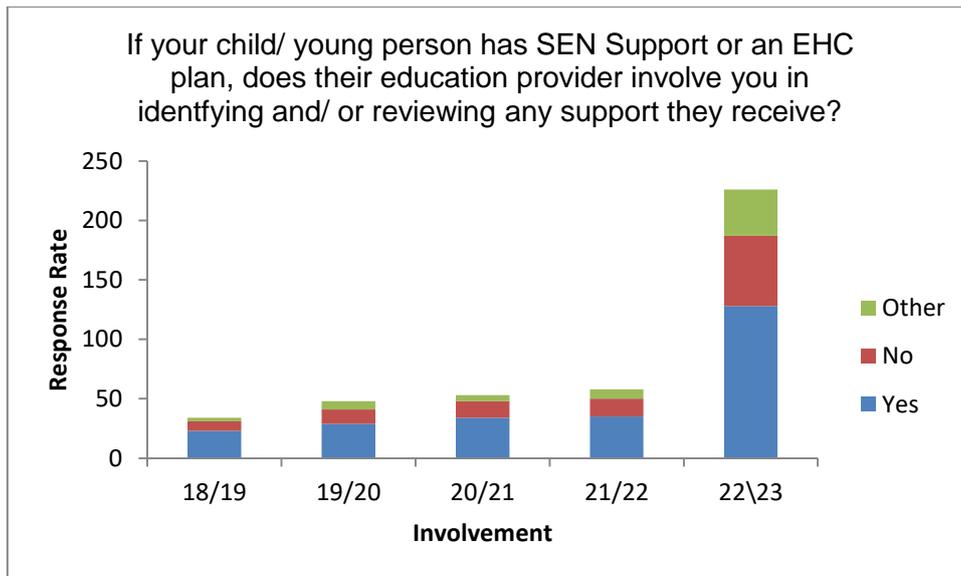


Fig. 24 Involvement in identifying and reviewing support

Further expansion on answers across all years shows that for some parent carers there is still a view that they are not involved actively in identifying and reviewing any support received via education in particular.

Every so often
Sometimes
Neither here or there not satisfied with support.
A little bit of information from things class teacher is doing with letter formation but other then that no other information from school
Only if I ask, they still don't fully understand he's needs. That's why he's on part time timetable.
In Year 4 it was the case, in year 5 so far no.
This is not applicable now as we took him out of school, but I found generally it wasn't worth the paper it was printed on for all the good it did. The schools will say they can cope with an autistic child, but in reality, all they seem interested in the extra 'funding' they get from having a special needs child.
I have a great working relationship with SEND support at the school.
Once per quarter plan meeting. Don't think it's sufficient.
An occasional email
Help is given, communication is very poor. I only feel the help is there due to a list of failures that are being made up for.
They do now, but I have had to fight for this every step of the way from year 5 to year 10
I get all of my support from her school which I cannot speak highly enough about.
I am only involved at yearly reviews, or when I feel there is a need to address his care with school. I receive no updates. Mainstream secondary is not for SEN children but spaces are non existent at specialist.
Only once a year, but not as often as it was stated in his plan
Only if I tell them something isn't working and at the annual review. Seems to be based on what the College can offer my son rather than what he's entitled to.
No I never get any updates any phone calls etc
not applicable
When she was attending the school

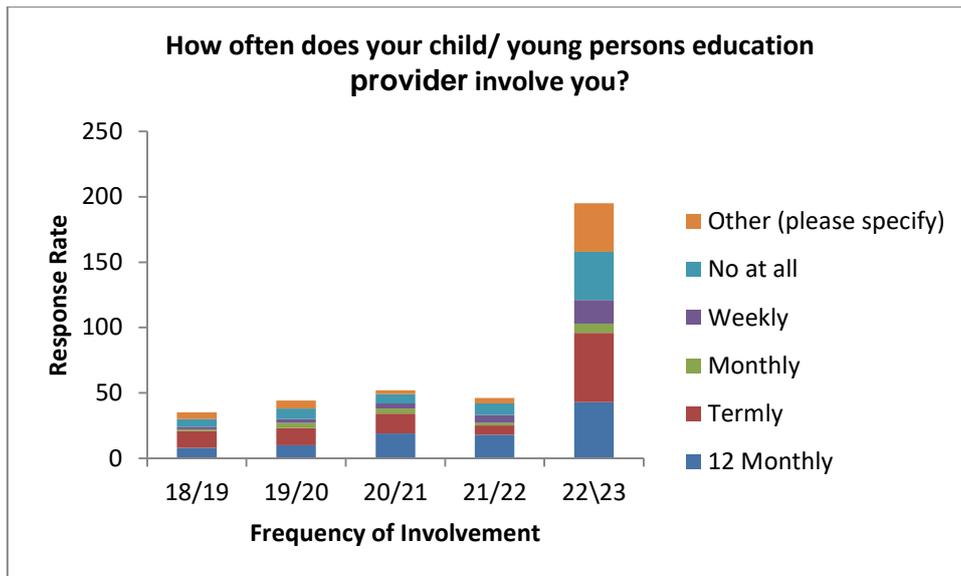


Fig. 25 When parent carers are involved

When they need to
I go into the school every time there is a problem
Noplan
Ad hoc
As and when required
Regular meeting when needed
Around 3 to 4 months
Reviewing to up he's timetable, as of when.
Plans are set out Termly but we will be notified of any amendments and kept up to date by school SENCO, we also get updates when collecting from school via TA's
I am notified every meeting or new plan involving my son
When there is an issue, when son is unsettled
Quarterly in year 4
As they see fit
When a need arises
Nothing unless we kick up a fuss
Reviewed when needed
Annually but also more frequently where requested
A couple of times a year
The help I got was from CAMHS buckinghamshire, not school.
The school involves me regularly
Since he started his new setting we only got to catchup with SENCO after I chased up asking for an update and that was Dec.
He does ring though i between the monthly taff meetings and I can ring him anytime I need to.
I am only involved at yearly reviews, or when I feel there is a need to address his care with school.
When I contact to query something.
12 monthly for EHCP review, but we often (about every 2 months depending on issues) request meetings to review the "on the ground" provision of what is actually going on in school as opposed to the theoretical provision of the EHCP.
When needed. They are great at communicating with me.
Professional meeting normally every six weeks as was on part time table

They don't really involve me I go about twice a year to ***** school and an open day for parents I want ***** to have therapy but unfortunately her father through the courts have stopped that what's not the schools fault but that's an ongoing issue in and out the courts
 I haven't heard anything from teachers regarding her education plan yet.

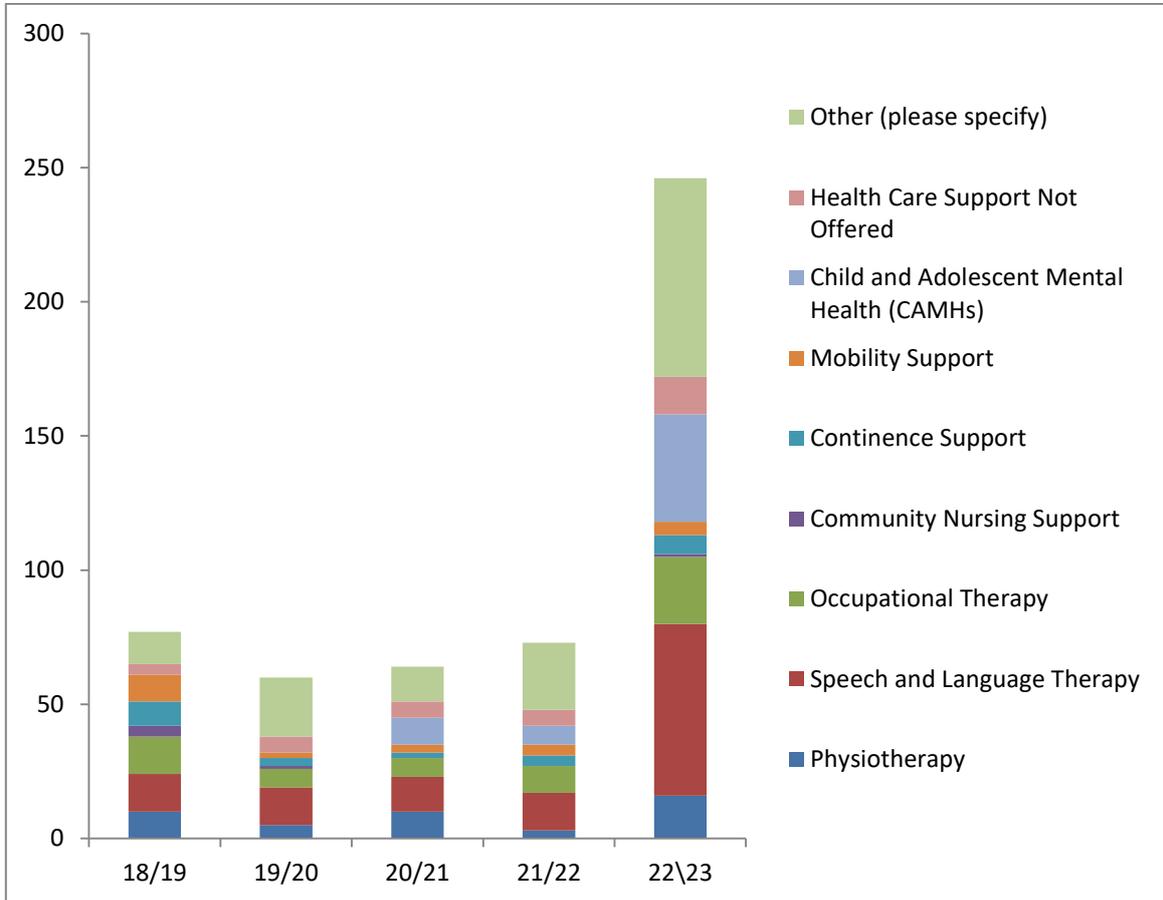


Fig. 26 Health service support

Further comments were elicited related to lengthy wait times, and lack of support from health services. Full details of the comments can be found in the yearly annual survey report mentioned elsewhere in this report.

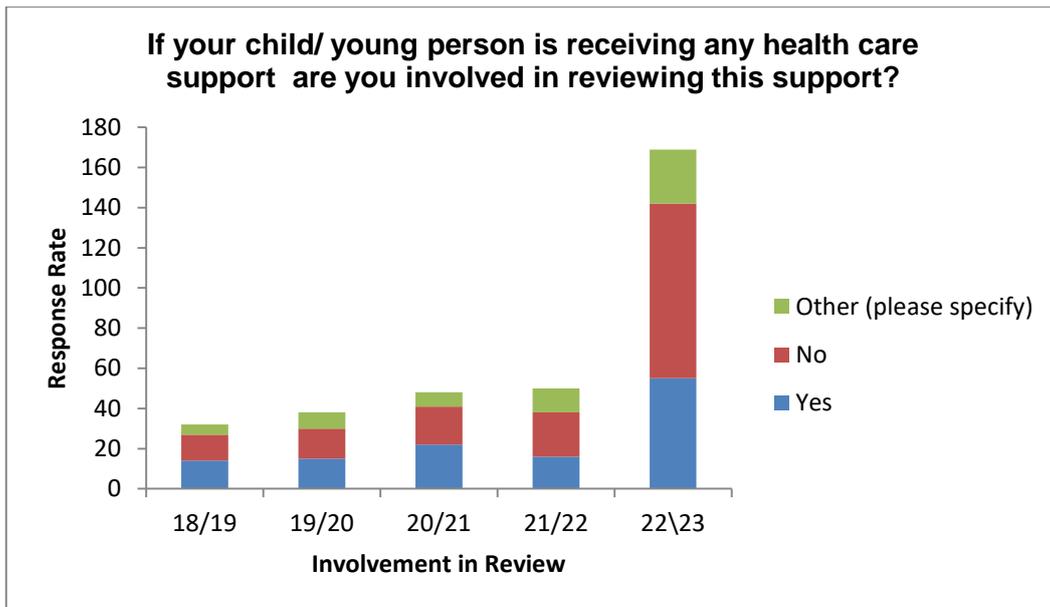


Fig. 27 Involvement in reviewing health support

Any comments defined under 'other' all relate to state either "Dont Know", "No Support" or "NA". What is clear from fig. 27 is that as there is again an increase in parents reporting negatively; in this case not being involved in reviewing the support available especially when compared to previous years. This also goes against the trend in this years survey results of positive reporting.

Follow on questions, from those mentioned and demonstrated in fig.18 to 27 which looked at parental involvement in reviewing support, looked at target setting, monitoring and support more generally. These will be discussed below.

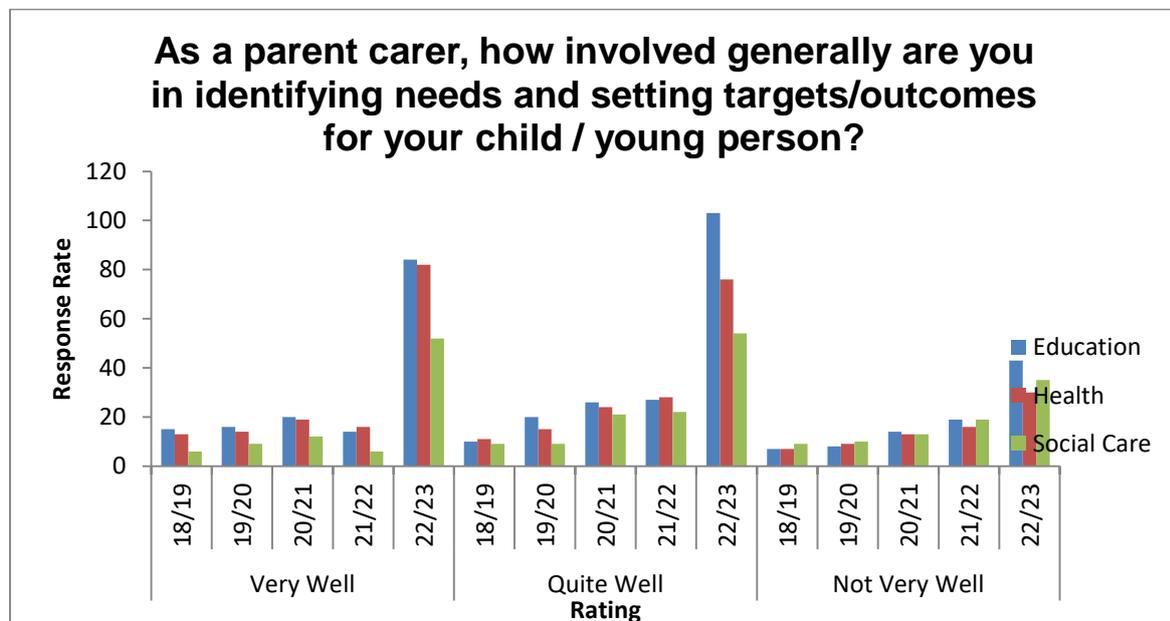


Fig. 28 Involvement in setting targets/ outcomes

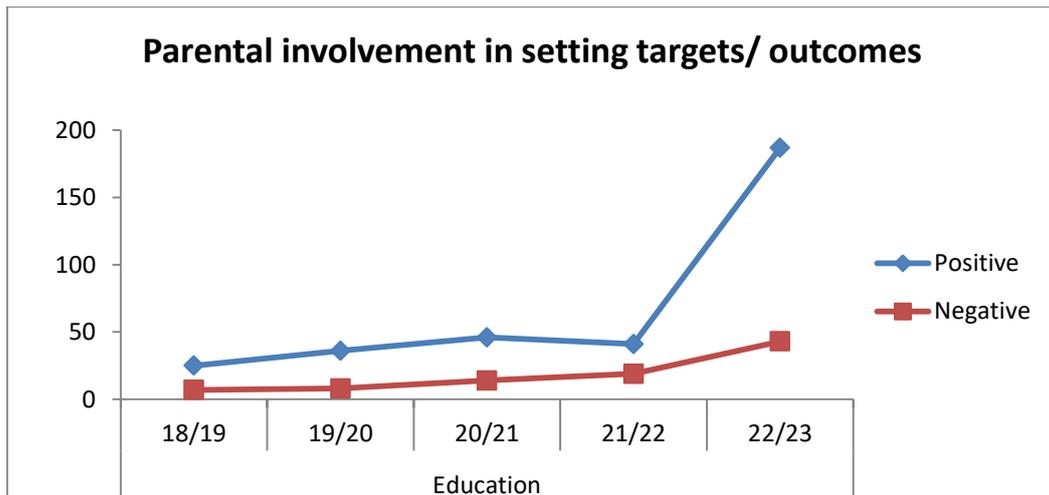


Fig. 29 Target Setting Education

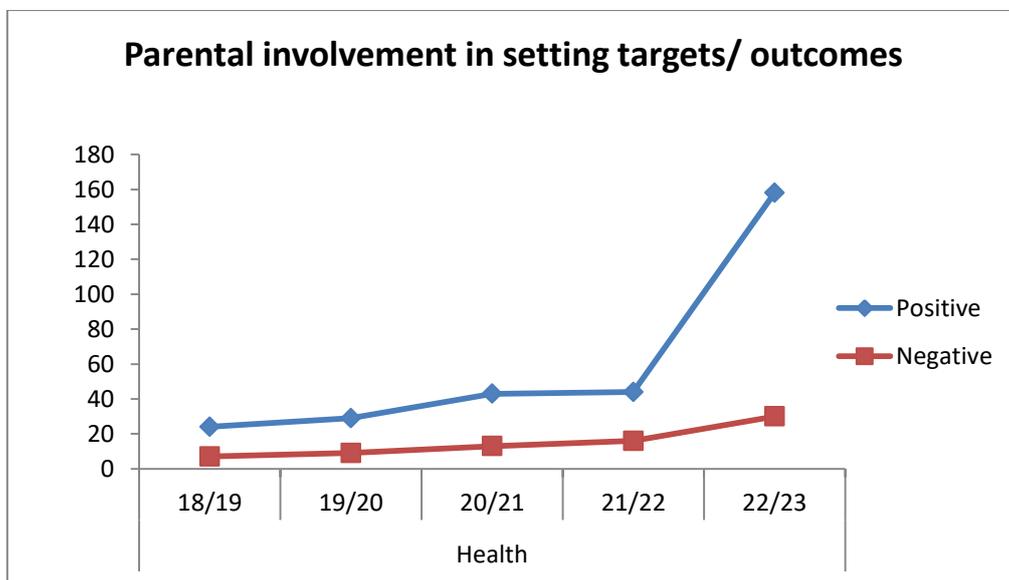


Fig. 30 Target Setting Health

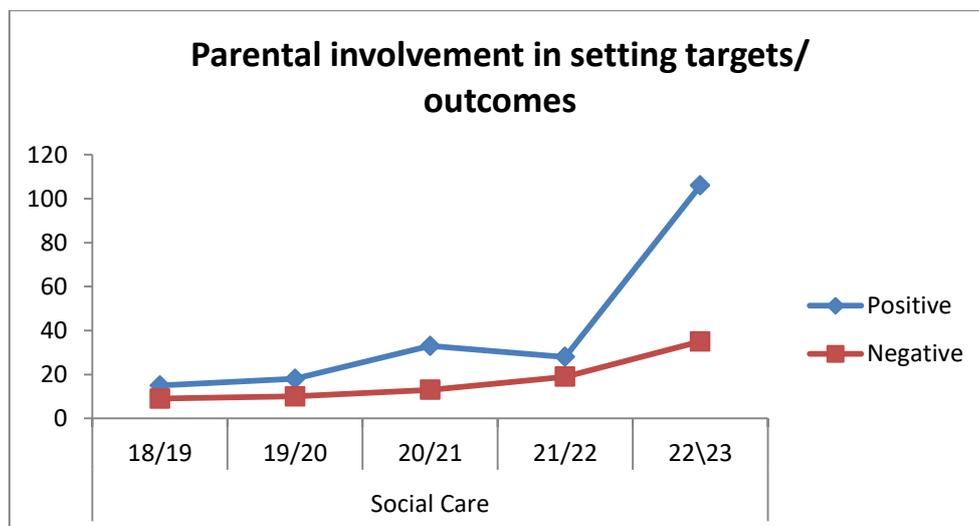


Fig. 31 Target Setting Health

Fig. 28 to 31 looking at Target setting again shows the same trend towards moving from an increase in negative reporting to a change towards reporting.

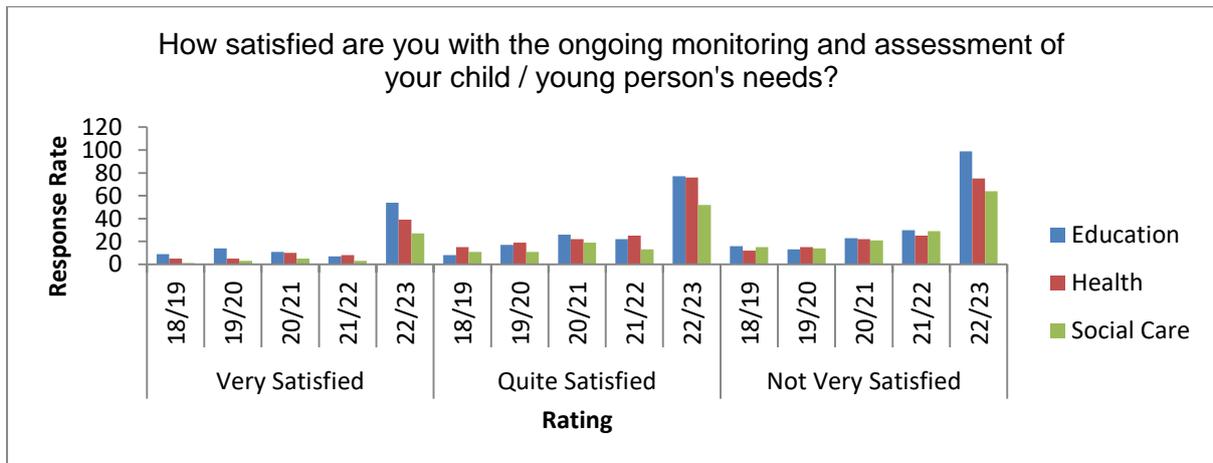


Fig. 32 Satisfaction levels around monitoring and assessment

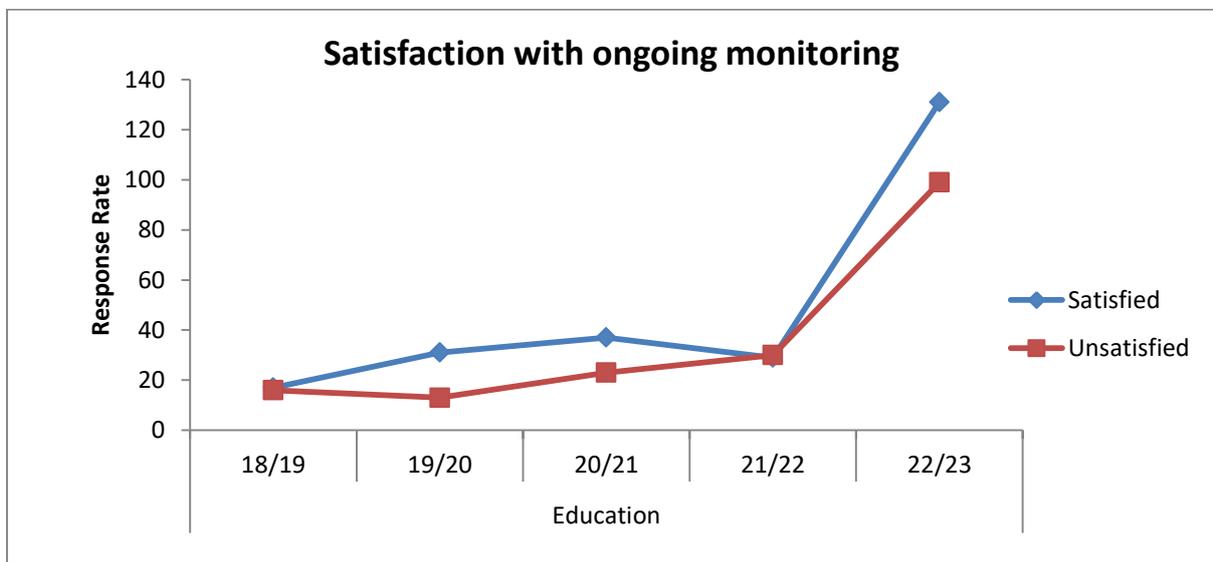


Fig. 33 Satisfaction in relation to monitoring of educational needs

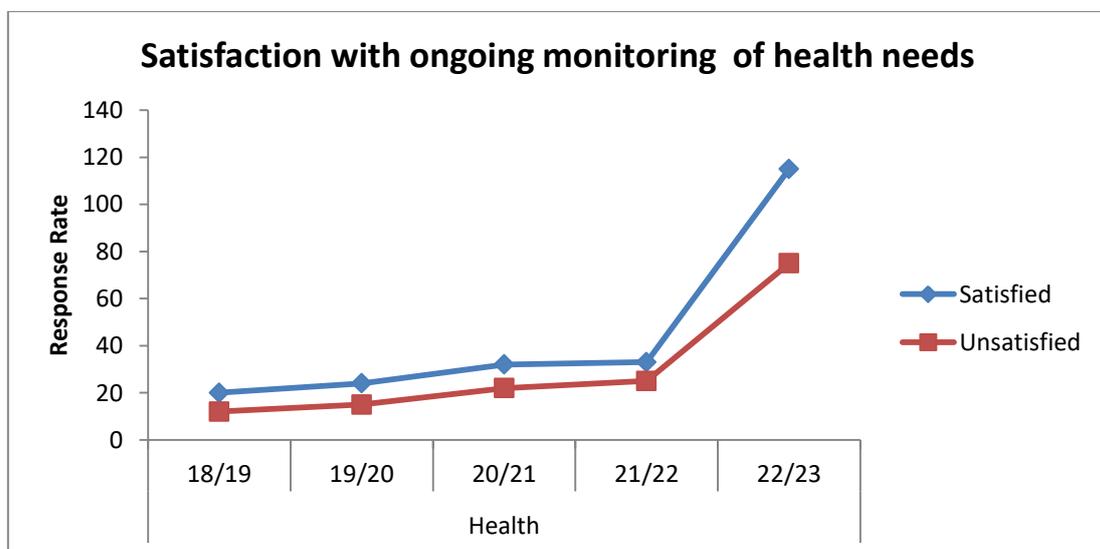


Fig. 34 Satisfaction in relation to monitoring of health needs

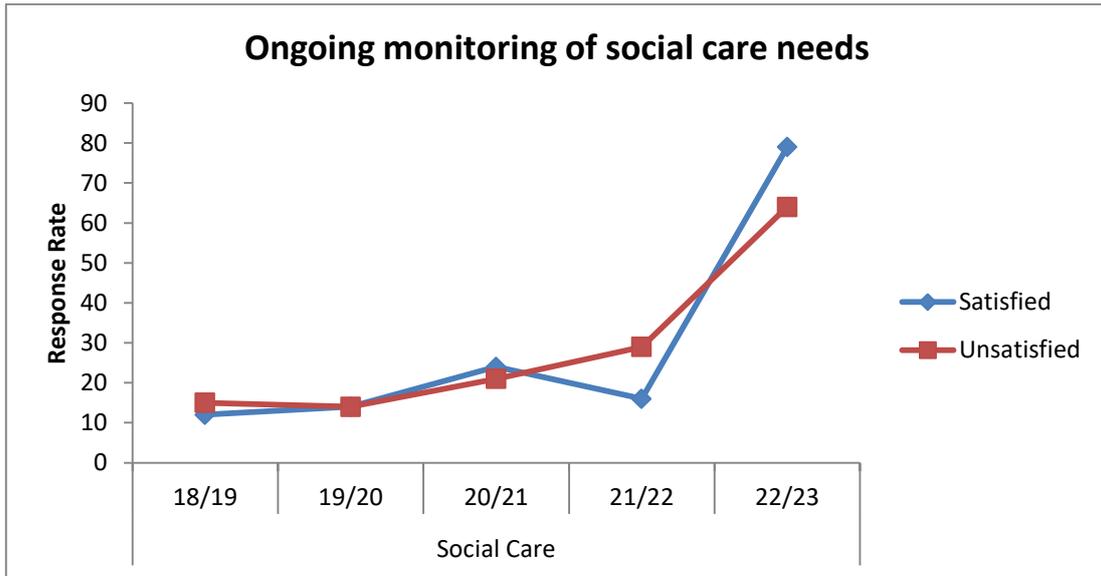


Fig. 35 Satisfaction in relation to monitoring of social care needs

The general trend follows through with satisfaction in relation to monitoring needs as demonstrated across Figs. 32 to 35.

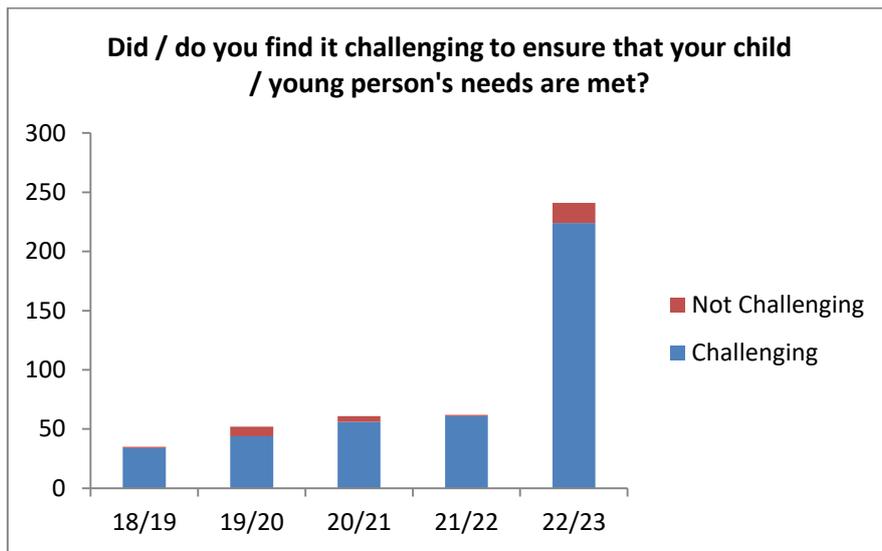


Fig. 36 Difficulty in ensuring CYP needs are met

Overall respondents also still report feeling that it is more challenging to ensure their CYP's needs are being met, which fits with a view in some areas that the system is more difficult to navigate and less geared towards meeting needs.

There is also an increase across the 5 year period of respondents reporting that services do not work well together (see fig. 37 below)

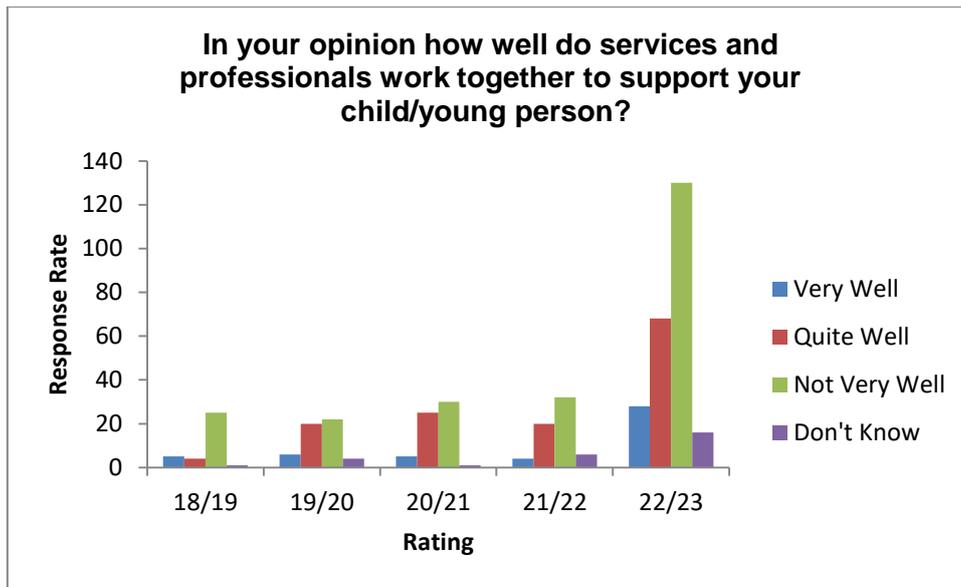


Fig. 37 Services working together.



Fig. 38 Overall ratings of how parent carers feel services help their CYP achieve good outcomes

When asked to rate how well services help CYP across four main factors; Educational progress, Leading a healthy life, Taking part in community services and Preparing for adulthood again the picture is more mixed; with PfA being reported slightly more negatively compared to the other areas.

General views were also sought in the annual survey around Educational and Health which elicited a very mixed response, with a move for this year towards waiting times being mentioned as a concern:

Educational Experiences 21/22	Educational Experiences 22/23
When she changed schools, and Covid started, we have not had much interaction with her instructors. Some of them seem to have no ASD awareness.	More awareness needs to be given about dyspraxia.
No support at home no clubs for sen children who r non verbal or apposite courses as cannot speck or wired or write no care needs	Some schools are amazing. But lack funding for staff to support. Then have to exclude or put child on part time
I struggled to answer some questions as i have 2 children in the same primary school	None

with ASD one i feel is very supported by SENCo and peers, teacher etc but i feel the other is supported but that i have had to push for this and feel more could be done to support him. Not entirely sure of what exactly but feel there must be something that could help with his emotional and mental health needs	
Slow at communicating no support at home don't take me seriously	I feel the school does not fully understand and support my child. They don't look at the bigger picture and unpick the behaviour they just put it down to bad behaviour and punish
Scandal of Post 16+ provision in Peterborough needs to be addressed. It is unlawful that there is no specialist provision for Autistic children when they leave Medeshamstede. Some children cannot access mainstream college. MHA needs to be post 16+ again	Educational provider is able to meet my child's needs well. We are approaching preparing for adulthood stage which is very worrisome.
Slow because of covid no help at home	She had a very bad experience in primary school as the teachers were untrained in SEN, and seemed to have little time or patience in dealing with them. Everything took far longer than it should - there was little support or reporting. I had to chase everything! It was dismal. Now she is in secondary school it is wonderful. The school supports her needs very well and communicate well with me. They get her the support when she needs it and treat her with respect. She is thriving there.
My son has just started secondary school and so far we had one meeting before Christmas. I'm expecting feedback by the end of this month relating to the issues my son has with the support provided	His school say they are going to do things to help and assist him but from what we are told this doesn't happen.
Since being at a specialist school ,my daughters needs are met	My child's educational provision has gone to shambles since a new Senco has been employed. The woman is a bully. Communication is non-existent apart from the last meeting when she shouted over my son and would not put a plan in place for my son's education.
I am happy	School do not communicate with me unless I make contact first
Doesn't get no support as a family even though we state we are struggling to meet his needs as we don't understand him and he can't maintain his emotions meaning he goes into melt down	My child attends a mainstream setting but this is with a huge amount of additional support from staff. The education is tailored for her level and her wishes and feelings are always taken into account by the setting.

	The classroom staff are outstanding in the care they provide for her. Other settings could learn a huge amount about this provision.
Primary school support was lacking. Secondary school support has so far (4 months) been awesome.	I have no support from the school about my sons needs. They haven't supported him with his dyslexia. He is supposed to have speech therapy at least 3 times a week. It took nearly half a term for them to do 3 sessions with him
City College provides excellent support for my daughter	I feel like he is overlooked a lot of the time by his school and the sen provision in place there.
Not in education anymore. However, when in education, we met many times with SEN in schools but the help was minimal at best	School failed older brother now doing nothing for son
I don't have a clue about his education and only have an annual review with one member of staff that's never met me or him!	Issues with my daughter have been raised/discussed and partially identified although not formally by the support team at her first and secondary schools
My son has only had 2 years full time secondary education and still needs high level support. We have requested that he stays at the independent specialist school for post 16 with day release to an outdoor education place- the following year he can transition to the outdoor place without the backing of school and look at a supported internship at peterborough- it sounds like a perfect plan but we are waiting to hear if the LA agree	No support given after diagnosis and how to apply for school
I'm waiting for his ehcp which haven't got yet.	The primary school has been very good and has supported my son since diagnosis. We have termly SEN meetings with the Senco to discuss targets to meet his needs.
it's shocking	The plan in place not specific to his needs he needs more one to one support he is not meeting any of his targets but resources are not available I've been told to support this
My boy has been in alternate education for almost 2 years and no plan has still been made to move him forward	I cannot fault the provision of education within a mainstream school for my daughter
My son had no education for 2 years after being excluded from a specialist autism school. My son is still not in the right provision & although has an EHCP there was only one person at his review that had never met me or him so knew nothing about his situation. no tutors or anyone from cahms or the LA attended	My son's school have ignored my concerns about my son's mental health for years. They refuse to assess for dyslexia due to funding and have only recently agreed to EHA for possible ADHD because I have been diagnosed as an adult
Its really hard to get the real help we need as ny daughter masks so much at school	Happy with current provision but limited choices of suitable schools for next

	transition.
<p>Since transferring from his mainstream setting to a special school, my son has been provided 1:1 outside of the classroom environment as apparently struggling. I've requested a review since the start of September to discuss the issues but they are yet to even respond. His previous provisions such as Weekly SALT and playtherapy have also ceased although included in his plan and were provided in the last school.</p> <p>They are also failing to push referrals needed through neurodevelopment yet are stating they are struggling and the setting will be unsuitable without him being medicated.</p>	<p>The system is outdated and staff in SEN positions are not supporting children in a way that the child feels supported or understood. Staff I have dealt with need more teaching</p>
Educational facility is not able to deal well with SEMH issues.	No issues at school
The school he attends doesn't support his emotional and social needs	Educationally she does well but I'm not convinced the school fully appreciate how much she masks other difficulties as these come out at home.
He is not happy in school	My son has had a provision map in place at school since 2017. This is updated termly usually after a meeting between his teacher, SENCO and I. He is identified as needing reading and writing intervention and is placed into small groups to assist with this.
Lack of specialist post 16 for autistic young people is a significant gap in PBO	I believe I receive all the help that I can receive, ***** have helped me well my child more than they actually can they have referred my child for as much help as they can and always include me as a parent in the process and in meetings.
	He gets bored in school needs a one to one full time at school
	My child neurological development still not been sorted still no diagnosis ask school for update but they have never got back to me thus has been going on since before covid started
	Despite multiple times my asking I am not kept in the loop with the school
	He attends **** ***** Nursery and they are currently in the process of completing his ECHP. We are applying to ***** school for a delayed place because he is too behind mentally to go to school this September
	<p>School are over run and can't provide the help the children need for each individual I have heard this from learning mentors within the school</p> <p>Also have been said my child needs dyslexia</p>

	<p>test (school have said they cannot provide this)</p> <p>Education physiologists (school have said they can't do this as too many children are waiting)</p> <p>Been reffered for play therapy 2 years go within the school still hasn't happened (waiting list too long)</p> <p>This are all things the hospital said my child needs but yet schools saying it can't been done due to waiting list funding and staffing</p>
	<p>The school has made an error as not dealing with he's needs, causing him to be unsettled. They are slowly trying more as they are aware of this. But it's far too gradually.</p>
	<p>Good</p>
	<p>Not sure</p>
	<p>**** ***** have offered exceptional support with needs, support has been second to none from all involved, a credit to the education ssystem.</p>
	<p>I am happy with the setting he attends but am quite appalled that we do not get to chose the hours he attends, due to his disabilitys which makes things very awkward for me and my family.</p>
	<p>Support on offer determined by staffing levels unfortunately this means that levels of support change with little notice with little consideration of impact on child.</p>
	<p>My son struggles in mainstream and the past 5 years have been very challenging. He's due to start secondary school this year and I worry constantly about how he's going to cope. I feel he would benefit from a specialist setting however I am consistently being told he wouldn't get a place without an EHCP and with the school refusing to support me on this.</p>
	<p>Not enough teachers/ TAs to adequately support child's needs. Teachers don't seem to have the time to do what's needed so it's left to me to try to gap fill and help more than most parents at home. This is typical of SEN families due to ever decreasing services and a real lack of understanding or resources to help.</p>
	<p>I don't feel I have been given any support or direction for my sons autism diagnosis. I would like his class teachers to know more about autism and get better understanding</p>

	My grandson would like to go to school, but a lack of provision to meet the criteria in his EHCP meant that I had no option but to refuse the placement.
	Sen in the school isn't very good and it's taken until year 6 to get started with proper provision when this all started in year 2
	The nsh need to diagnosis my child and not lie as told can't diagnosis my child as they would be unable to complete test
	They take into account what my son needs and try their best to help. Mainstream is still set up for a neurotypical person so he still has to mask all day but the school do everything they can to help him feel comfortable.
	I am happy with the work the school are putting in. I do hope that all adults involved in my child's class can be on the same page as SEND support. It sometimes feels like her needs are forgotten to some adults especially as we're awaiting assessments.
	My son hasn't been diagnosed but is SEN registered and the school have been terrible. He's always told off and loses play time daily as a punishment. Then send work home because he doesn't do it in class.
	Not getting help she needs from the school she needs testing for adhd and autism but we've been waiting since she was in preschool and had to reapply in September just to get help
	My child is not reaching his full potential due to lack of support. He started primary school very advanced for his age, but is slowly dropping. Whilst he still meets the levels required for the average child his age, he is not reaching his full potential. With the right support, he would fly, instead he spends every day dysregulated & at a disadvantage to his peers. He hates school, which wouldn't necessarily be the case if he didn't have so many unmet needs.
	We're very pleased with the school's offer, our daughter seems to be thriving and her teachers genuinely care about her.
	I know my child is capable of achieving more than he is currently and it's frustrating. His current teacher and TA are kind to him but I don't think teachers generally understand what he needs and I have had him start in a new class with a new teacher asking me the same question, "Has he had his hearing tested?" and as soon as the 1st one asked

	when he was 6 we got it checked out and it was fine so they hadn't passed the information on and it feels like you start all over again.
	Went without any form of education for weeks as not able to go to school
	Outside of school she has speech therapy
	Slightly disappointed with attendance letters following mental health concerns and bullying. Mental health should always be more important than attaining levels of attendance at times they need to be home being supported.
	Head teachers needs to not shout at children with learning needs. Need to learn how to talk to children with needs.
	Exams are a worry to me and the support through this as her needs are only just being recognised by the education system
	She was sent there as a cheap option rather than where her needs are best met. It's a good placement for some children but not able to meet my child's need
	We have to fight tooth and nail argue do everything. The school does nothing and put my child at risk and denies all. It's ridiculous, they are not professional, they do not communicate, they don't seem to understand safe guarding. I just want to give up
	I would like support with toilet training for my child there isn't enough support in this sector to
	I am contented and happy with my daughter's educational provision.
	Children in infant school needs to have the support as its far to late when they turn 13
	There are big discrepancies between the information the SEN support staff hold and how this is implemented to support young person in college. Very misunderstood on a course support level and needs are not fully recognised or supported appropriately.
	Within Primary care setting I can't thank the staff enough for their ongoing support, but it is frustrating trying to plan for Secondary school setting and ensuring transition and any needs will be met because the process for assessments has a narrow criteria that some children fall just outside of, but the school recognise this and try their utmost to push referrals.
	It has never been reviewed with me since starting secondary school in year 7.
	Lack of knowledge by teachers! Training and

	<p>education is needed for all staff. Why are we not alerting teachers to needs. Rather waiting for something to go wrong. Sadly even head teachers follow stereotypes for SEN, such as only boys getting ASD. Teach equality at all levels of society, especially to those who have such an influence on the next generation. Since moving to Peterborough I have heard many people talk of teachers bullying, never heard of this before my move - really sad. As we have experienced this by a girl who was new to school and already battling many barriers.</p>
	<p>I wish there was more communication as I have no idea what's going on.</p>
	<p>The education setting does not support children with SEND well, this was recently recorded in the latest OFSTED report where they 'required improvement' I have been through the school complaints procedure several times and got the LA involved, yet the school is still failing children with SEND in my opinion.</p>
	<p>As a result of me advocating for my daughter I was finally heard.....3 years later! How appalling is that, when I took my daughter to our primary health provider I was told oh you need the school as they know her better! I know my daughter! The secondary school is now onboard and finally after showing videos of my daughter at home melting down and self regulating I was heard my daughter was now seen!! How appalling is that having to secretly video your child so you can provide evidence you're not an over reactive mother!! And that your child is in crisis</p>
	<p>Additional SEN support provided and trying to gain extra help with an early years health plan.</p>
	<p>Since she started school, she has progressed a lot.</p>
	<p>Our child sometimes gets agitated when he is not happy which is highlighted on his EHC PLAN and the school is quite aware about this. However, there are occasions where we feel like the school has been suspending him on the basis of aggressiveness when we know that they don't have adequate resources such as teaching staff at times. This feels unfair to our child as every child has a right to full education regardless of their circumstances.</p>
	<p>As all schools the SENCO and provisions are over stretched for the amount of children needing their support or help.</p>

	***** have been fantastic with my son. Everyone is amazing with him all through the school including the office staff. They always give him time, listen to him and support him. I could have put him in a better school.
	Mainstream secondary is not a place of Autistic children, even with a EHC - lack of understanding, funding etc means SEN children are always second rate citizens
	I think sometimes the teachers of different subjects need to be aware that he does have problems ticks and concentration is hit and miss and the telling offs and detentions upset him and cause him distress and he can't help these things
	The school have offered additional support despite not having a diagnosis yet
	He isn't getting an education they do what they can to keep him in nurture room or suspend him.
	Information was not shared with all teachers only ones that I spoke with or emailed. New teachers starting were not given the info . Not all teachers had a good understanding of spld. According to my child post 16 have not offered any support for her SEN . Emails still sent with reams of writing, no spaced paragraph, no friendly font or changing background colour of page. Lap top not given until the second year of college. Despite this being a reasonable adjustment at school.
	My child is academically able and masks at school. This means that some adults dismiss her needs and I have to constantly fight for them to be recognised. Some members of staff said I wouldn't get an EHCP because she is too bright but I said this wasn't how they worked. SENCOS are either not clued up or being fooled by the LA as they have been lied to so many times. Everything about my child's support has been fought for.
	The provision is very variable in quality and understanding, depending on the person doing the providing; we have experienced a range from excellent to downright incompetent
	I need support with his next steps from College and a structured pathway how my son can be supported. It's a full time job trying to find what he's entitled and

	comparing entitlement to what's actually being offered.
	<p>***** have been absolutely fantastic in supporting my daughter. When she was at primary school, she was bullied by teachers and misunderstood. It was a struggle to get her to attend.</p> <p>In secondary school, she is so well supported and she loves school. She is doing well academically and socially, and has made such a transformation. I know the school has more resources as it is larger but the teachers seem more understanding of difference and that is their ethos.</p>
	<p>I found it very difficult to get the preschool to listen to my concerns regarding possible autism despite having three other children diagnosed.</p> <p>They don't understand her health needs very well at all.</p>
	The SENCO did not put support in place but CAMHS contacted the learning mentor who put the recommendations in place immediately
	My son is working at a high level, he struggles socially but school aren't interested as he's achieving very well
	I don't no
	Had to be removed from school due to lack of staff training and support or provision
	Concerned that current ***** provision will now stop unexpectedly at the end of this academic year but no provision yet in place for next year and I am being left to sort it.
	NHS reports are extremally poor and are written to fit local policy and not based on child's needs.
	Some teachers not listen and change things in EHPC even if you tell them you want them keep in and child was on part Time February to July as the teacher child was with Couldn't cope with child's needs but been full time from July as new teacher can cope with child's Not all staff in special needs school are Train to work with special needs children which I feel they should be all trying to work on a special needs school
	I don't think they do enough to understand that she has ADHD the teachers realy don't care

	not applicable
	.
	Meetings as and when I require them. Communicate a lot via email.
	Seems to be a long wait for specialist school been off since July 2022
	The school knows of my daughter's needs speech problems mental health problems everything seems to start off very positive but then it just all disappears and that goes with the help to
	***** is struggling in school yet because of her meltdowns. Plus she is Autistic so she comes home crying every other day. Whenever I ask teachers they said oh she was fine. I am quite confused.
	***** is struggling in school yet because of her meltdowns. Plus she is Autistic so she comes home crying every other day. Whenever I ask teachers they said oh she was fine. I am quite confused.
	I feel that the school does not really care that she has ADHD, they just tell her to get on with it, she does not get any help

Table 1: Educational Support

Health Experience 21/22	Health Experience 22/23
We are not offered support despite requesting it multiple times	You get a diagnosis then you're just left. My other son has autism and it's exactly the same with him.
I have always found health services great for xxxxx,his had his condition since Birth and been a learning curve for us all	Transition into adulthood services is difficult, I still do not know a clear pathway and what will happen once we lose our current paediatricians and other therapists
I used to have a family support worker for autism and she was brilliant but cut backs to budget through council funding meant her time was terminated. I would like to see these services offered again even if that support is done through zoom/teams etc i feel it would be beneficial to many parents and carers who like myself can often feel isolated and alone in coping with the needs of SEN children.	Mental health support is poor - direct you to a website which I can do by myself.
Don't take me seriously no support at home no follow up assessment	It took them a while to diagnose his problems but wasn't really offered much help or support. I was just told to keep an eye on him
NHS SaLT do not assess accurately based on child's needs, but on their local resources.	Our daughter has a paediatrician that has not seen her for years we have referred ourselves to addenbrookes to a specialist clinic for 22q deletion.
A struggle since moving here.	My sons most recent Camhs dr has been excellent in understanding my son, his needs

	and working with us.
Health services are good	His speech therapy lady is amazing. Keeps me up to date. She goes in every month. And she helped me address the school on their lack of support with his speech
We use school nurse and get nappies no problems	I have had no issue with health services.
He was under camhs but since age 14 we haven't heard anything from them	Health services are non-existent
I feel not enough help is out there my son is in year 4 currently working at year 1. Was in year 2 last year and they jumped him up to year 4 as he got to be in his cohort by year 6 but this is unfair as he clearly has needs and having to fight for everything he needs an assessment for his adhd but it's like banging head against brick wall.	CAMH, had previous bad experience with older sibling. Unwilling to engage with them again.
shocking	Paediatrician has been great that's it
We don't hear from camhs	I feel like we have not been given the support we desperately need.
No help services and no help with housing	These are often a struggle and luckily I can navigate the system somewhat as I work within the NHS. As a previous looked after - now adopted - child, you do often feel that post adoption support is non-existent.
NHS salt and OT significantly underweight in PBO- do not accurately assess child's needs but rather dictated by their local policy and preference on what resource to allocate	Health tend to write recommendations and only have further involvement when schools re refer.
	Gp have always seen xxxxxx when requested but very reluctant to give antibiotics, spoke with consultant now taking antibiotics 3 times weekly for low immune
	My son has eczema and asthma. Apart from access to his GP we have no other health service input.
	N/A
	It's been a long road. You don't get any help until they are diagnosed which is bad. The nursery have been amazing and we would have been lost without them
	No one listens, or if I do have appointments. They say to try strategies, which I do but sometimes don't help. But then they still close referral saying to keep it up and theirs nothing else they can do
	With most of the nhs, the services are too busy and not enough staff. I feel that once a child has been diagnosed, there is not a lot of help at all.
	Health visitor has been cooperative
	Health services are very slow. Things have increased maybe to this happening.
	My doctors surgery are brilliant any time I

	need to see them they are available. They have been very understanding of my sons needs
	Appointment wait times are ridiculous!
	Physio is few and far between. Not often enough reviews. Orthotics has long waiting list and not enough options- plastic, rigid are not always suitable
	Unfortunately I don't feel I know how the different assessments link. I want to know what I have access to as a parent.
	My grandson has expressed a need to talk to someone about issues he has, but we have yet to find some support.
	I've been waiting 16 months for a course for parenting help with sensory processing disorder and I've still not heard anything
	It's a waste of time
	Although a very long wait it was a relief to get a diagnoses. The person who assessed my child understood him very well and she knew exactly where we were coming from. We have however found other than parenting courses there doesn't seem to be any support or advice if your child seems to be coping OK in mainstream. I have spent a long time educating myself and looking up resources to understand autism better. It would have been very helpful to be told trusted sources with accurate info I could use early in the process. I feel like I've had to find everything myself. I don't mind I'd do anything to help my child but whilst trying to help a distressed child, work, raise other children etc it would have been helpful if someone could have pointed us in the right direction because waiting until diagnoses and then parenting courses after that took years and we needed to research and put things in place much sooner.
	Not applicable
	Don't know what support they provide after the diagnosis.
	The more we wait the less we can tell what's wrong with my child because the school isn't taking it seriously
	Absolute shambles/waste of time
	All fine. Support given and apts given promptly when needed
	Cambs have been helpful
	Health services are a battle and then you feel left to deal with day to day.
	She doesn't have any health needs
	I would like my child to be referred and

	assessed by the paediatrician but it's not happening
	N/A
	My son was Told he'd always need monitoring like his older sibling this has not been the case. I have tried and failed to get help and support
	Very little knowledge available on ARFID or support from any health services.
	Poor. Where's the support???
	Wait times are to long and regularly unable to see our GP, being told their are no appointments available. Most days you cannot even get through on the phone. Parenting courses have been useless and often we have known more than those running the course as was the case with the latest one for ASD! It has frustrated us that professionals always try to educate parents following a diagnosis, but no one ever tells the child what their diagnosis means for them or helps them come to terms with it.
	Our gp was useless passing the buck to school or to 111 option 2 if on crisis as we cannot do anything. The system is broken that's how I feel, it's as though we need to trust education to make clinical recommendations.....this is one of the most challenging things we have ever gone through as a family.
	Doctors will not progress request for pediatric support and have passed this back to the school to progress through relevant channels which is frustrating
	None existent at the moment - again not impressed.
	The health visitor sally leech was really good and got the paperwork done very swiftly and my son was on the early help pathway quickly.
	Overall tbh since diagnosis at 2 to now health care and support has always been non existent. As for school secondary mainstream for Autistic children should be banned.
	ENT consultant agrees my child needs his tonsils and adenoids out but we have been waiting years for this operation! This could help my child in areas such as speech, behaviour and sleep.

	Once a diagnosis is given you do not get offered any health care support. It might be listed as a recommendation but it's up to schools to refer and if they don't you don't get anywhere. Once again you have to argue with school staff to get them to do things.
	Our child's diagnosis of FASD from the FASD specialist centre xxxxxx was crucial to being able to access the necessary education and health care; without that clinical diagnosis, we would still be stuck on the pathway to try to access help.
	Speech and language therapist's visit to the school is not frequent enough to have an impact on the child. Occupational therapy was identified as a requirement however the service was not provided until it was raised as a concerning during EHC plan discussion.
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	We needed help for my daughter in 2000 with mental health and it took until 2021 to get her support as she wasn't considered a priority. She suffered so much that year that I do believe it was traumatic as it still affects her now and her trust in the health system.
	CAMHS was brilliant, very through and henwas seen very quickly for a mental health assessment
	I've had no input from any services since my yp was 14 & echp has no updated medical info from age 9!
	not applicable
	Healios support has been a very long wait. She has had her pre assessment and they wish to support and want the neurodevelopment team to look into her needs further.

	I wish it was easier to talk to a doctor or a healthcare assistant within a decent time frame
	She is under camhs for her ADHD medication, and has therapy for her anxiety

Table 2: Health Support

Generally from the number of responses provided, waiting times for health are viewed as an issue health and there are far more negative than positive views. For education, views are also more negative than positive and appear in some areas to be linked to setting specific provision and support, with PfA again appearing as an area of concern.

Information

A common theme across all areas and one that is looked at briefly in the annual surveys relates specifically to information. This is a theme that appears to crop up in most surveys and data gathering conducted by FVP and has been mentioned in all Topics of Importance produced so far.

This area goes against the positive reporting trend continues with a decrease in positive experience and an increase in negative reporting more negatively. See fig. 39 as a clear example of this trend change.

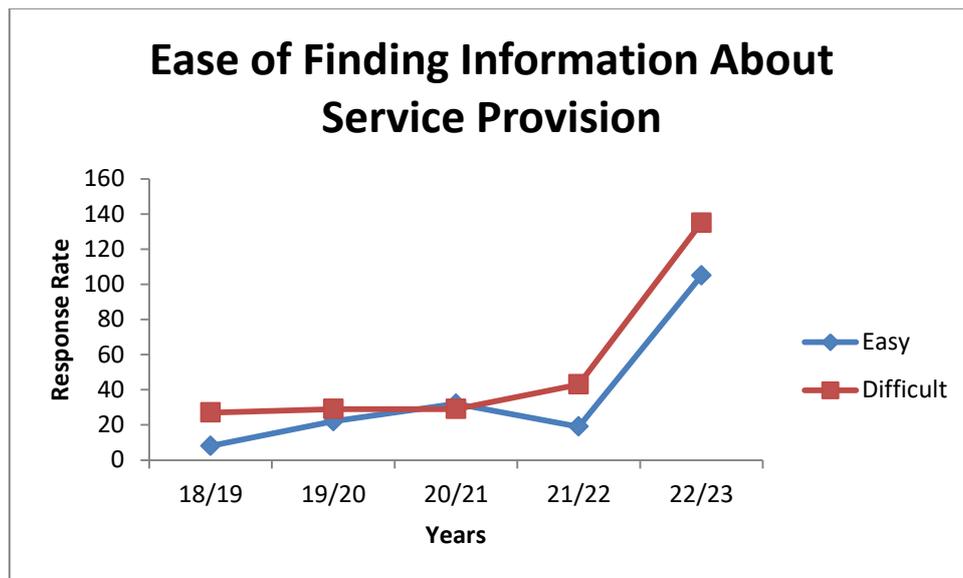


Fig. 39 Ease of finding information

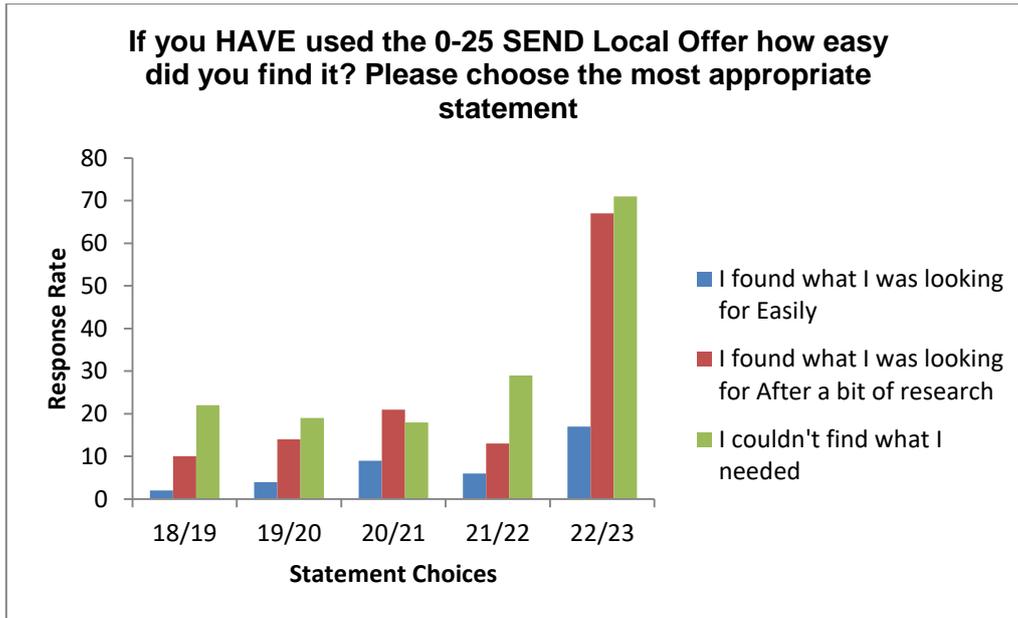


Fig. 40 Ease of using Local Offer

This area is a bit more mixed and if the more positive views are combined and compared with the negative views overall 56% report more positively for 22/23.

Further to this respondents were gain asked to provide a general overview of how they feel SEND has changed from 2015 onwards. Some comments are below:

Positive , he is getting what he needs.

The LA who support the family where very helpful and pushed the school. If it wasn't for them I feel I still be fighting for help.

Young person leaving college, unsupported, lacking in independence and unable to provide basic care for themselves. They are on PIP but do not qualify for social care. I found an app that would benefit them but social care will not fund and neither will education.

I have no idea what the 0-25 send local is so I wouldn't know where to start. The whole service is shocking and unless you fight and push your just left to get on with it alone.

Very disappointed that the approach is for children to fail first before support is offered.

What experience still waiting all teachers that are supposed to be involved don't know anything

Found Send to be very poor, until Feb 2022, had to hire a professional to get assessments with SALT, OT, TRAUMA COUNSELLING. They found hom to be ASD, DYSPRAXIC DYSLEXIC AND ADHD., The Senco at mainstream school, failed to assess him, and he was kept at the same level until Yr 5.. taking many classes with yr1 and reception, failure to follow EHCP and no 1:1 support until threatened with Ofsted and Legal proceedings. He was bullied so badly and actually hospitalised by a particular pupil, despite letters emails and calls to School, and their failure to act upon it.

There was far more negative than positive reporting when respondents were asked for their general views. The negative appears to centre on a lack of support, a sense of being 'not listened to' and lack of knowledge or awareness of what is available which relates to perceived lack of information.

Social Care and Transitions

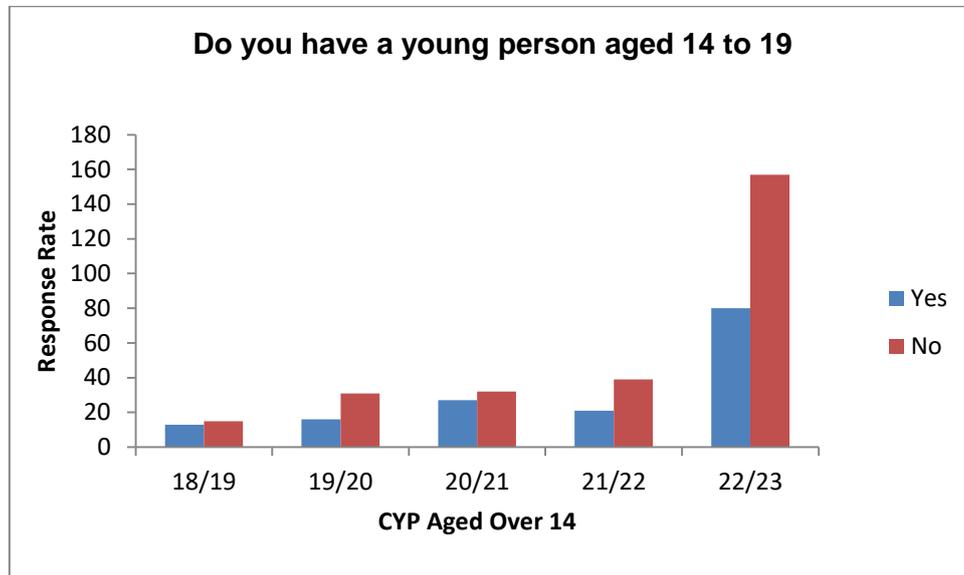


Fig 41 Number of CYP aged 14 to 19

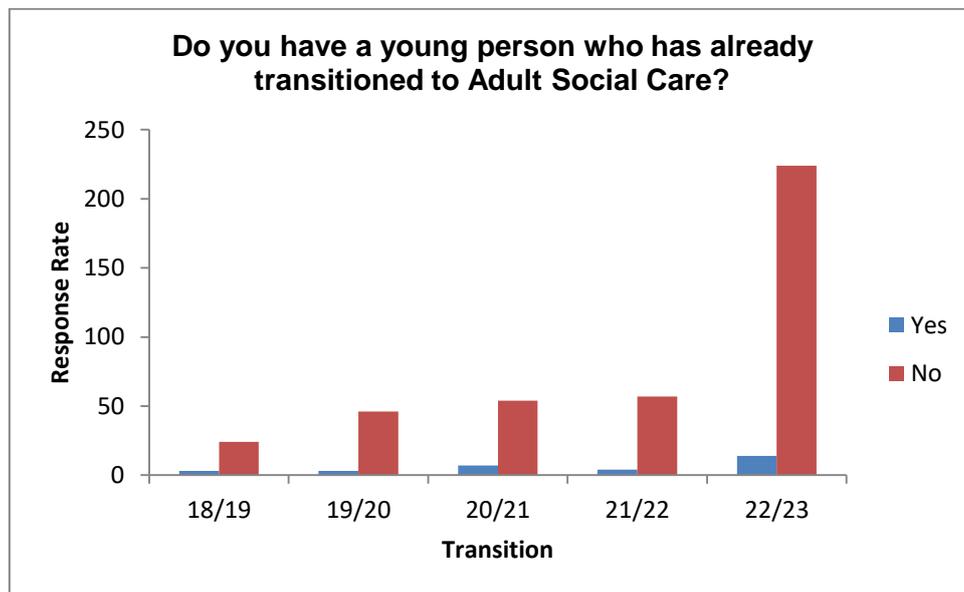


Fig. 42 Number of CYP who have transitioned to Adult Social Care

Figs. 41 and 42 show a slight increase in numbers who fall under Preparing for Adulthood (PfA) and an increase in numbers who have not transitioned yet which fits with the change in age range of CYP of those completing the survey for 22/23 as mentioned in first section of this report.

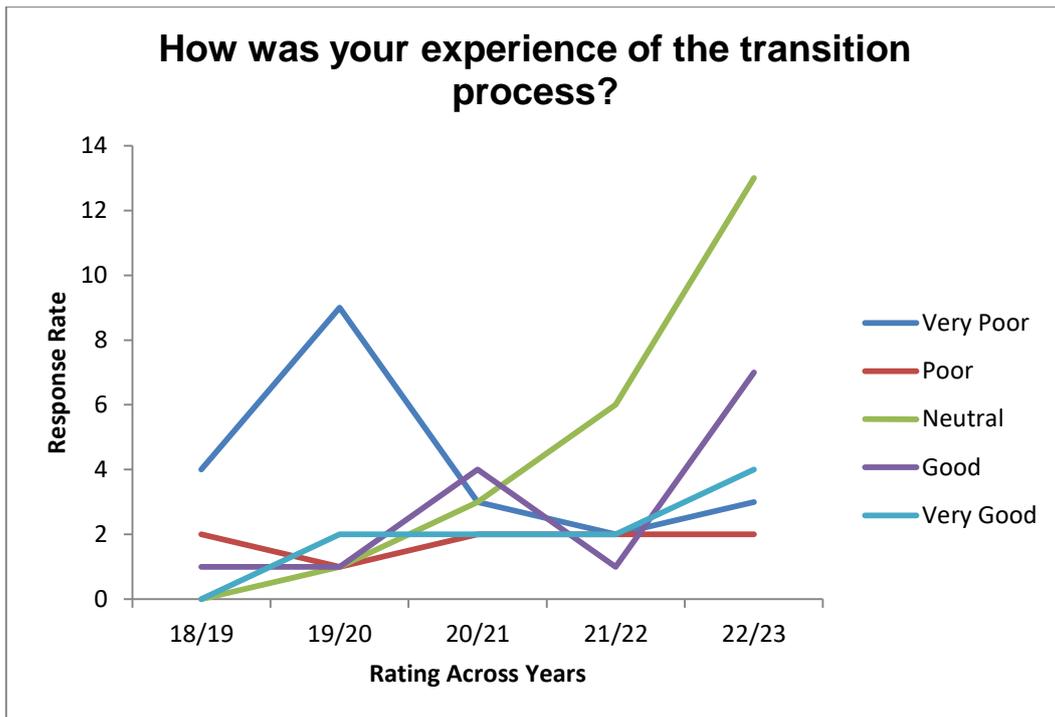


Fig. 43 Transition Experience

There has been a slight increase in the numbers reporting positively regards their CYP transition to adulthood. Respondents were able also provided a rating on what information was provided to support the transition and what support was provided to understand the process. This is shown in Fig. 44 and 45.

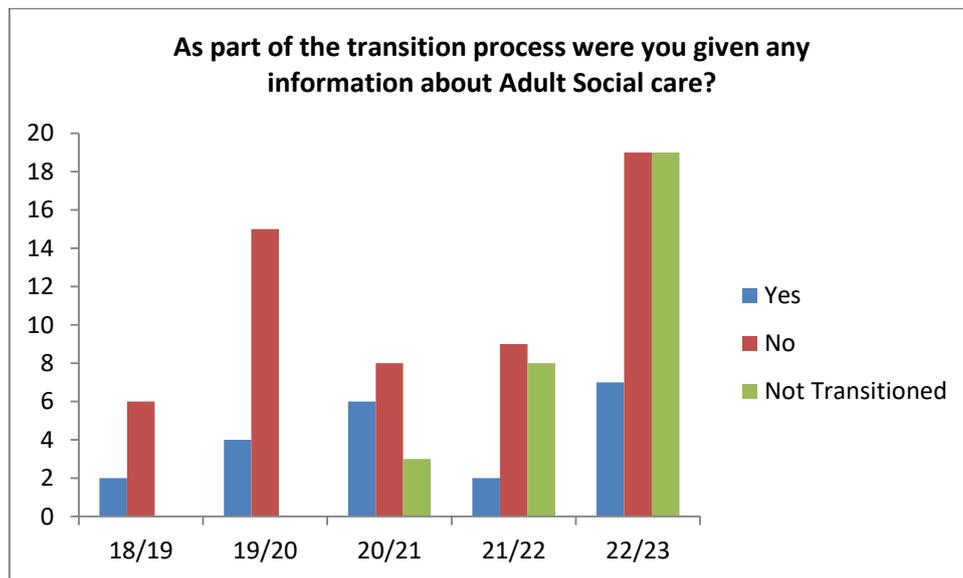


Fig. 44 Information provided regards Adult Social Care

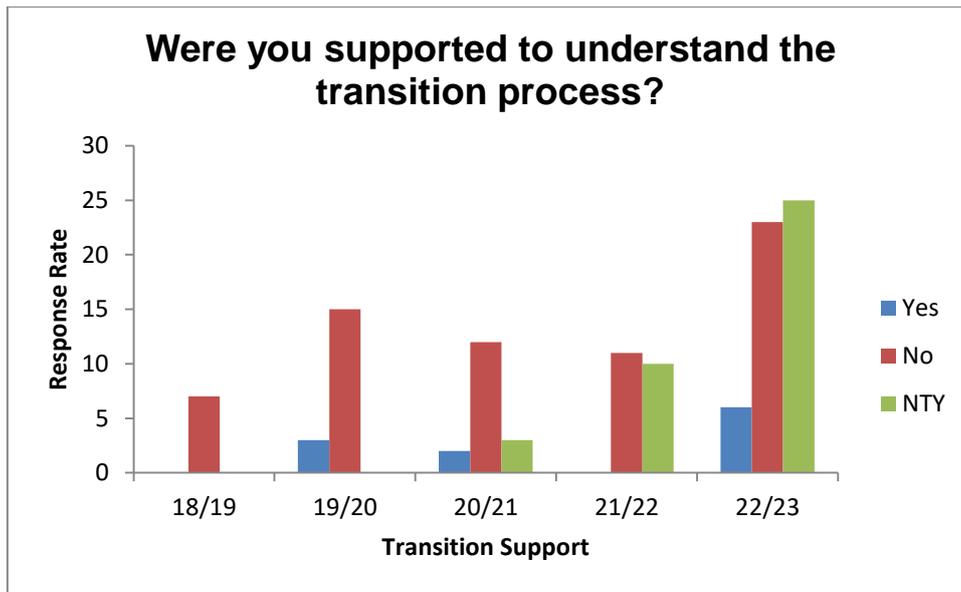


Fig. 45 Support to understand the transition process

From these two areas it would appear that overall support was not provided and there was a lack of information. Overall again there is more negativity, especially in relation to information or lack thereof.

Finally in the area of social care respondents were asked to rate overall the children's and adult social care offers as shown in Fig. 46 and 47.

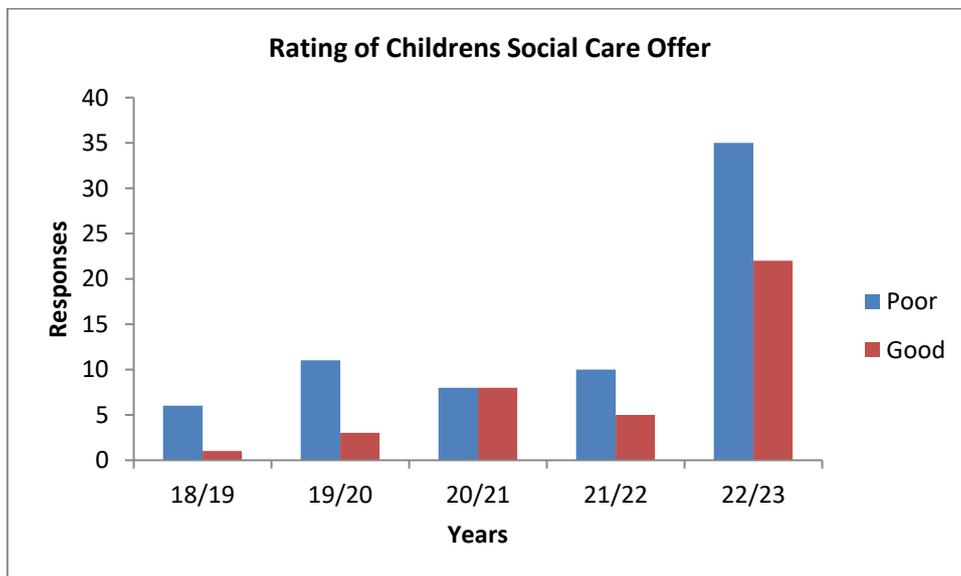


Fig. 46 Children's social Care Offer

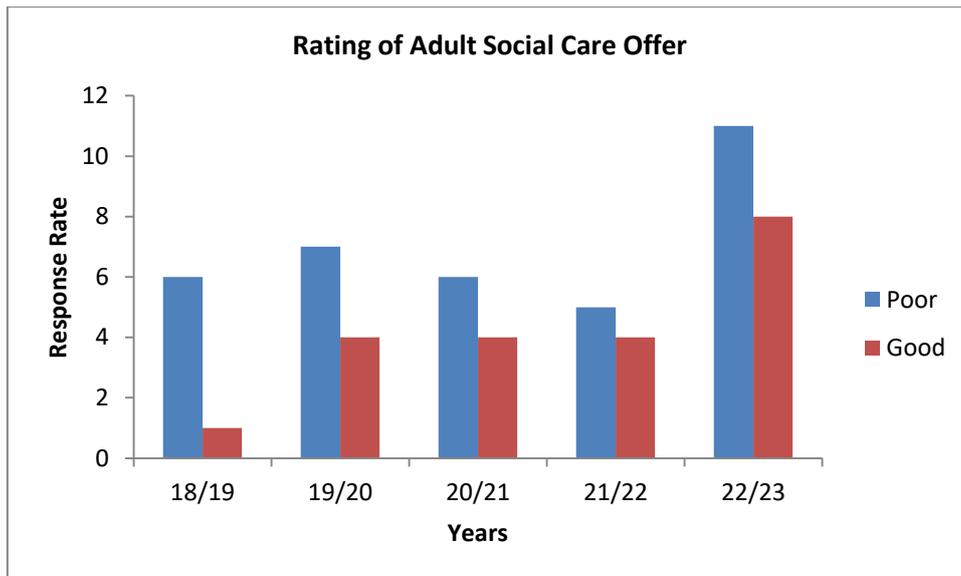


Fig 47 Adults Social Care Offer

Generally ratings of the offer for social care are poor across both childrens and adults.

When asked to provide more general views the following comments were shared:

Pretty non existent

Not enough social workers. Totally impacts on children. Wellbeing and trust. Transition at 18 to many being put in large foyers. Being exploited. Due to lack of support. Drugs/criminality

Post adoption support from Social Services is hopelessly inadequate - we are abandoned to have to work things out for ourselves. Any engagement with Social Services requires re-assessment, even though they know the history and issues - this is a waste of time and resource - it should be automatic.

Excellent Social Worker (from another authority)
Poor Cambridgeshire and Peterborough social workers. Poor experience of disability panel, clearly no interested in providing support. Make it as difficult as possible to seek support in the hope that you will give up...and this is made extremely obvious!

Ambition for my daughter from carers could be higher. Coordination between services piecemeal. General administration poor

Carers Support

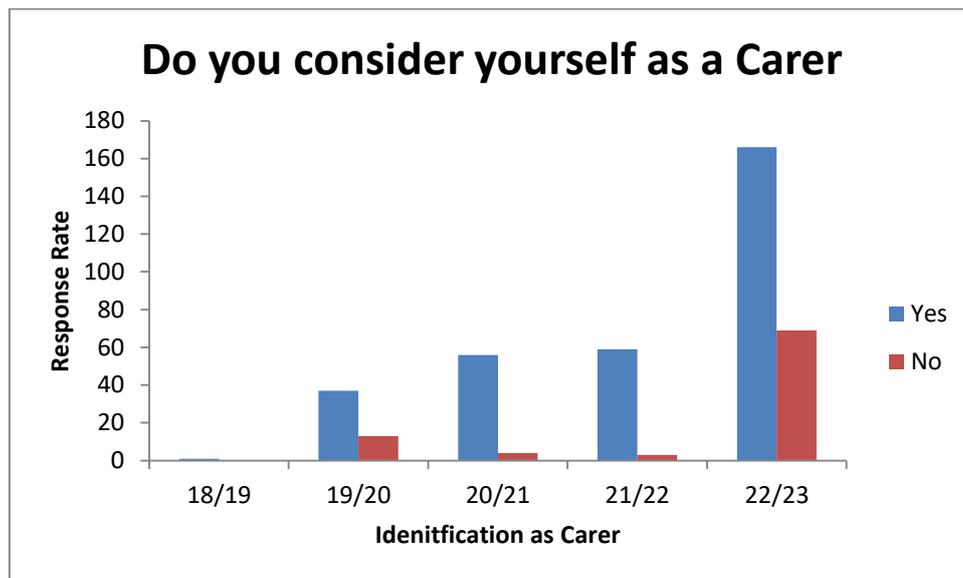


Fig. 48 Self Recognition as a Parent Carer

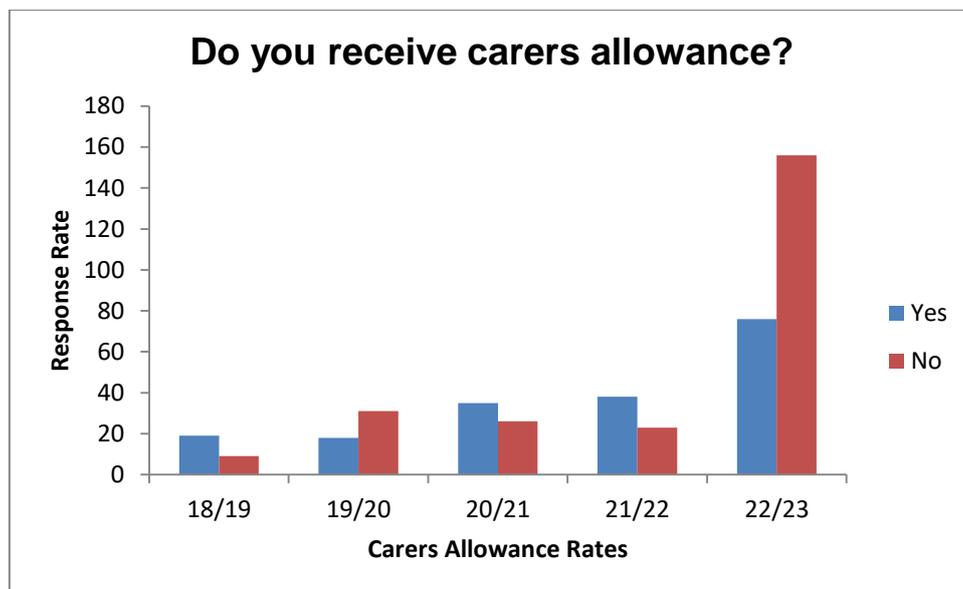


Fig. 49 Receipt of Carers Allowance

From Fig. 48 and 49 it can be seen that there has been a shift in how parent carers view themselves with a clear increase across the years. There has been a marked shift between years however of those who consider themselves carer and yet don't receive carers allowance.

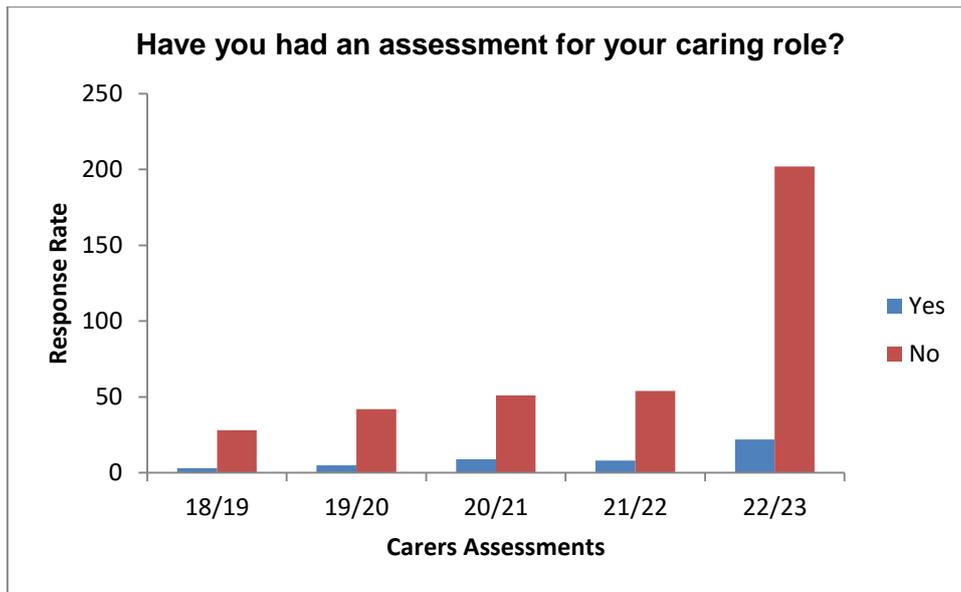


Fig. 50 Carers Assessments

From Fig. 50 it can also be seen that numbers of those reporting that they have not had a carers assessment has also increased across all four years. This all may point towards something in relation to recognition as a carer more generally.

Following on from these respondents were asked to state whether they felt having a caring responsibility impacted on their ability to socialize and work as well as their wellbeing. Across Fig. 51 to 53 more respondents stated yes as opposed to no.

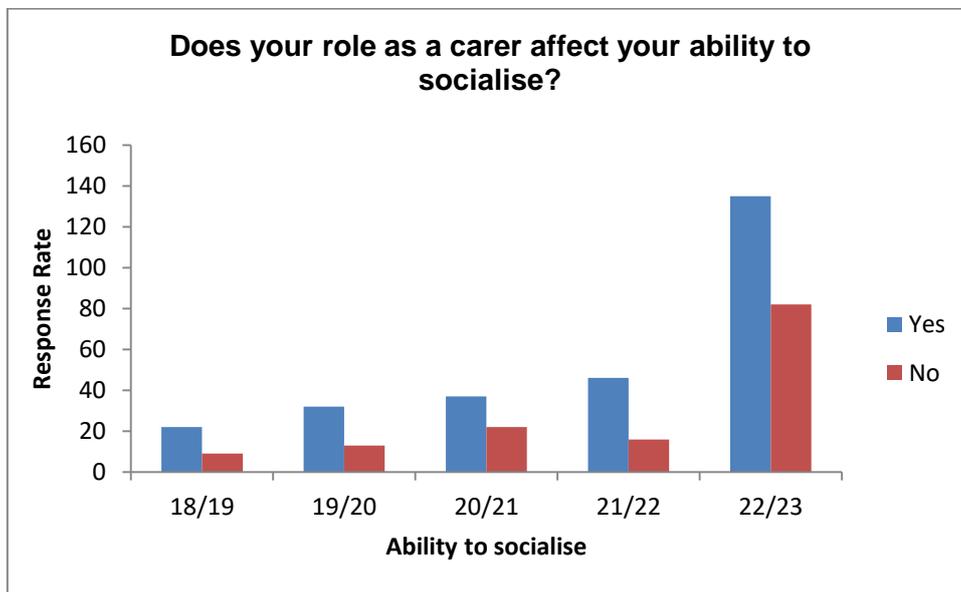


Fig. 51 Impact on socializing

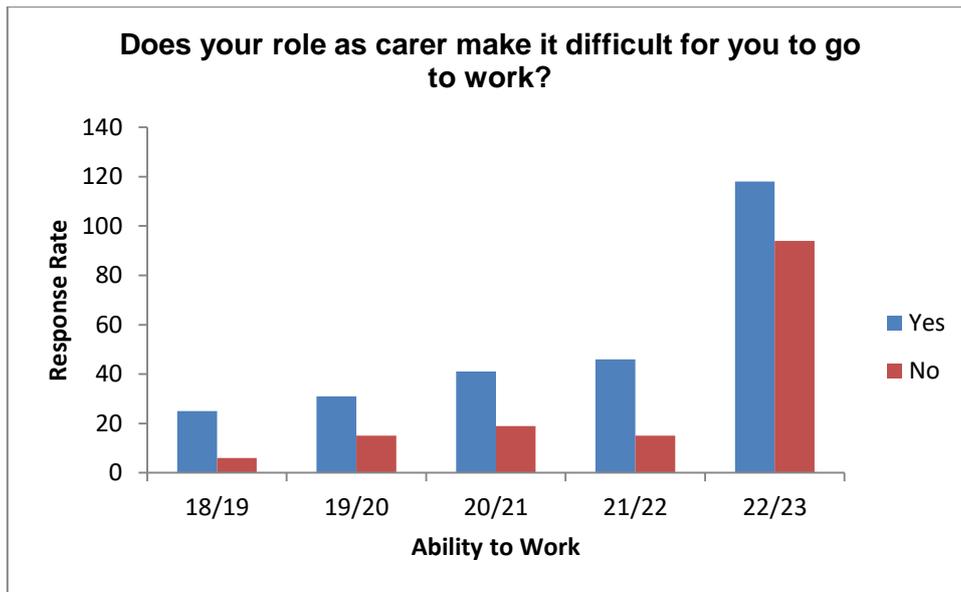


Fig. 52 Impact on work

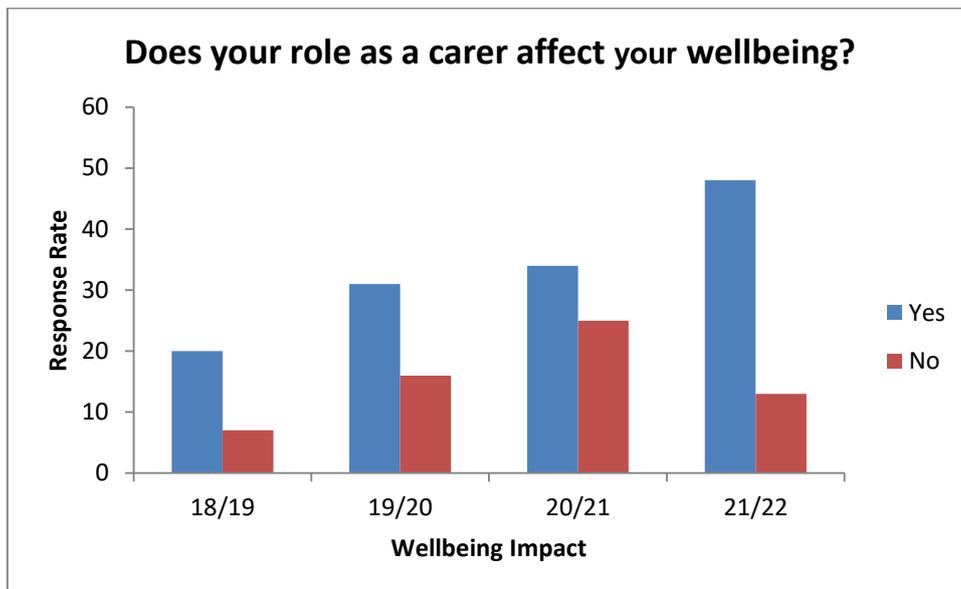


Fig. 53 Impact on wellbeing

The final part of the annual survey for 22/23 also provided the opportunity for comments relating to overall experience of SEND services and suggestions for improvement.

Please use this space to provide any other information you feel is relevant regarding your experiences with Peterborough SEN services across Education, Health and Social Care

- *Parents need support*
- *"Constant battle for accessibility.*
- *Long waiting lists."*
- *Have to work but juggling caring for 2 send children has led to burnout. I don't get benefits, I've always worked but struggle to find understanding employers.*
- *Once my child got into a special school her well-being improved. Large groups at Circles provides her with the best support, she is now able to socialize, make friends*

and have fun away from me, which gives her a bit more independence. I greatly appreciate this and cannot praise them enough!

- *I would like to see more support for my son before he gets too far behind in school and it's too late for him in the big wide world*
- *I just wish I had regular contact as I need to see how he is progressing, and need to know what I can do to help. I also would like to discuss his sensory issues I feel he may possibly have*
- *"Cannot fault the education side of things. We have been extremely fortunate with nursery and school.*
- *Health, Social Care, SEND, Disability service is terrible. Couldn't get any worse."*
- *Very disappointing.*
- *Sen support is poor. There is no access to professional help. You cannot get a GP appointment let alone help with SEN child.*
- *the entire process from request to granting of the EHCP was a complete nightmare and unfit for purpose. the community nurse team started collecting evidence and putting interventions in place but when it came to application all that work was ignored and the process had to start again. it was clear from a very early age and pre covid that our son would need additional support at every stage through to education and there just wasn't the protocol in place to start this process early enough and it was left up to the nurseries, us as parents and later the school to drive for the EHCP, without the school's intervention our son would still be fighting for his EHCP and losing even further time.*
- *School has been great*
- *I do not feel supported. I feel alone in the on going daily battles I have with my child.*
- *More positive experience with my youngest child aged 5.*
- *Am disabled my self so can't work but I support one of my children who's 14 and xxxx but my older daughters helps me as she's my young carea*
- *My son despite everything and his clear needs outlined by myself and the school has yet to be assessed after multiple attempts by the school*
- *We have had one appointment with a child psychologist and that's it. We've had one email from OT and that's it. If it wasn't for the nursery we would have really struggled. We are still waiting for speech therapy*
- *I am waiting to hear back, so far experience has been good*
- *Satisfied*
- *We felt that the SEN services were prompt to act and follow the protocol and guidance with regards to timeline very well.*
- *We recently with the help of the school requested an ASD/ADHD assessment, we submitted to the requirements, parenting course and all of the requested data from school, all of which took considerable time from all parties, we received a letter from Younited which denied this request for a reason very basically explained in the letter, whilst we understood the decision we wanted to discuss further as we felt there was clarity needed in their judgement, both us as guardians and the school were unable to contact anyone from the department, we tried many, many times without success.*
- *Q44 it doesn't affect me going to work but the carers allowance allows me to work school hours so I can be there in the mornings and evenings and school holidays when my son needs support.*
- *My biggest issue has been with education, which as far as I am concerned is diabolical. We live in a rural area and my grandson is desperate to go to school to 'make friends'. But in my opinion, the people at the schools just do 'lip service' and tell you what they think you need to hear; but in reality, they haven't got a clue how to manage autistic children. And don't even get me started on the 'special needs' schools. Getting a place in them is harder than winning the lottery.....!!!! And it doesn't help when Send are insisting your child remains in mainstream education because he's 'high functioning'. He may be smart, but emotionally he struggles and*

so has many problems, which led to 'meltdowns' and me having to collect him from school.

- *I'm a single parent with two children. My eldest has learning difficulties and anger issues. She has major meltdowns that affect me and my youngest. When she has a meltdown she is incredibly cross and often violent. It's difficult to help her calm down. There is so much about her behaviour and learning g issues that cause a lot of stress and worry and lack of sleep. It's so stressful and worrisome when we do t have any answers and the wait is too long to get the assessments needed to help my child.*
- *"This survey is difficult to fill in and I adandoned it half way through. I don't know what these questions mean, I don't know what you want to know.*
- *Autism and adhd are hereditary neurotypes, I believe that I am autistic and have adhd, these forms are not friendly. Please keep this in mind when working with the parents of SEN children. "*
- *His foundation teacher, who was and still is the Senco teacher, recognised he may have adhd or autism and didn't inform us. It could have helped with his education and how we were managing at the time as a family if we had been notified of her suspicion, at the time he was just labelled a naughty child and has suffered because of this. Thankfully his great Aunt, who has worked as a Senco teacher identified he was in the autism spectrum and this meant we bought it up with the school but even then the same teacher said there was no point getting him assessed because we weren't going to get any help, which has not been the case, he is very well supported emotionally by his current teacher and TA and his last teacher as well, so he is happier now but my concern is his capabilities educationally aren't coming to fruition and on paper he won't be represented as capable as he is of understanding subjects.*
- *Referral wait times are too long when you do get seen they fob you off*
- *Schools need to be more proactive in supporting with mental health and not penalising parents for it. Also preparing for adulthood should mean if a parent needs to collect 2 mind after collection time (traffic from work) a 15yr old mature student should be allowed to stand and wait for the parent and not be sent a bill. Making them wait inside isn't preparing them for adult hood. Child has phone and soon I will be in full time work needing child some days to get bus to me. I know I'll have arguments with school over this but being in year 10 going into year 11 dependent on child's individual needs, schools should accommodate better then they are*
- *Sen services have been good its the schools that need to understand more. Head teachers at all schools need to understand alot more not just senco.*
- *Services and referrals work well, am awaiting a diagnosis and my daughter is in year 9. Once she reached secondary school it was only once her behaviour changed as she struggled more that it was noticed, i had first took her to a pediatrician at 3 years old. Early help was opened as i was diagnosed with a brain condition to help support my daughter, it wasnt opened up for my daughter. Luckily it was opened and in place so when these issues become more apparent to teachers it was an easier process. The parenting course i found helpful in some ways, but didnt teach me anything new, just a different way of looking at things. If a child is presenting issues, this is just wasted time as the child is left waiting further in their journey*
- *They need to listen to every parent not only the ones that shout*
- *I feel we as parents have to research and sign post ourselves. Send Ned to be more involved and supportive ! Check in on families who are struggling or vulnerable and many parents are not aware of send services so raise awareness that there is help out there if needed*
- *I appreciate all the services across, please keep it up.*
- *My mental health is affected due to my daughters struggles*
- *"Transition to adulthood is a minefield. Professionals in children's services really didn't understand the process or what was available themselves so couldn't give*

clear information on how the transition things would work. This caused a lot of anxiety over a period of 2-3 years.

- *My child is off frequently ! So have to be home*
- *Sendiass was amazing so supportive quick to respond and give sound information. Schools are appalling, lack of trained teachers who are aware of sen needs however subtle. Doctors are just as poor telling me completing a form for referral for my daughter would take too much time and I must go to the school ad they know my child, then to say all services are too backed up due to covid and waiting times are terrible!*
- *God but they take time to establish some of the care plans for children. There are also other needs such speech and language therapy which the child needs but Peterborough SEN do not support that.*
- *The teams as with any other areas in public sector are too stretched to have time to be involved in every child care. Which means when it comes to reviews there minds are always somewhere else and prob don't even know your child name.*
- *Family Voice are brilliant. Very supportive in pointing me in the right direction.*
- *Early help is supposed to be a family based support yet we have to go through the motions every time, with a parental diagnosis of autism and ADHD and three of my four children diagnosed with autism it should be easier to access an assessment for number four.*
- *Not good.*
- *My daughter now lives in supported living so impact on my life now less than it was although I still consider myself one of her carers and still need to support her in raising the ambition of her carers, sorting out administration and ensure join up between services improves.*
- *Extremely challenging with no support for me. I feel very isolated. I work part time but have to have lots of unplanned time off due to my daughter's needs. I am often late for work and have therefore been issued a written warning which as put more added pressure on my mental health.*
- *I haven't applied for carer's Allowance yet. Yes my daughter's condition affected me in my way, in my physical and mental health both ways.*

Please use this space to suggest any changes you think need to be made to Peterborough SEN services across Education, Health and Social Care

- *More support and more guidance is needed*
- *Transition to adulthood - there needs to be one! Social care need to be involved with my 20 year old, she needs supported living, she can't do things for herself.*
- *Transitioning into adulthood is still unclear and gives me a lot of anxiety. Although Educational offer is clear on the Local Offer, the rest is still very murky. I am worried that once she goes to college or stops education I will have to leave my job because my daughter needs a lot of care and support. This will have an adverse impact on my own mental health as well as our family's finances.*
- *We need more support as parents to make choices for our young people and the help and support for there transport because the bus pass allowed them to get on the bus 9.30 and they have to go to education in time and how the college if they provide lunch and how safe it is to leave him there for the first time*
- *Give more support where needed to children and there parents.*
- *Communication with parents*
- *Staff at schools to be better trained on conditions such as asd to help more children cope better and be better understood.*
- *Stop using a one size fits all approach and treat child, young people and parents and carers with respect and as individuals.*
- *More respite services would be good*

- *Employing more people so that there is more support given to family's with diagnosis and not an EHCP.*
- *real interviews need to be done with children and their parents as a 1st course of action, an actual trained human reviewing the child in their current setting will flag up a high percentage of children that just need to be waived through and put in the queue to get the EHCP assessed & written. for example you don't need 3 years and 20 forms to tell that a child who is non-verbal and supposed to have started school 3 months previous is going to need additional help, it should be a formality not an assault course to get this through to an EHCP decision. also, next time please get someone professional to design the survey, if a section being filled out or skipped is dependant on how you answered a previous question then that needs to be build in to the flow of the questions, i.e. "you don't consider yourself a carer" is no then tell them to skip the next 20 questions.*
- *Better communications regarding special schools and how to apply*
- *I believe children should have more access to resources regarding mental health.*
- *"My 5 year old is happy at school and we have so far had a positive experience. I am concerned about the transition to his next school as so far none really give me a good feeling.*
- *My 20 year old is leaving college under prepared, ill equipped for working life. She does not have the skills to access work and yet does not qualify for social care. I work, parent other children and am studying as well as caring for my young adult. I think carers are hugely underestimated. More help should be available for my eldest to support her. The amount of work we do to help her is unrealistic, still needing social stories/scripts aged 20 for new scenarios/experiences. She can't make phone calls without support. It's ridiculous that as an adult she will be unsupported."*
- *More research when you leave the hospital and more support groups advised as unless you go looking you don't find*
- *Professionals should talk to parents directly when assessments are directly linked to home situations.*
- *Yeah. DO.YOUR.JOB*
- *Parents need to be made aware of all resources that are available and appointed a key helper so they have someone to turn to when things are difficult. Some people have never experienced autism or similar conditions before and have no idea what to do in certain circumstances. If we didn't have a helpful nursery I don't know what we would have done*
- *Communication needs to be improve between parent and the school and listening to each other to support the child best, and not telling parents things can't be done due to funding or the waiting list is too long so we won't bother*
- *Accept referrals don't make everything a battle, when us parents are already fighting for support from wherever we can get it from*
- *Satisfied*
- *"We feel if SEN services can take initiative to include self defensive skills such as karate or some kind of martial art to SEN kids who are able to be physically participate as this will help them to feel protected and also help in many ways.*
- *If we as parents if SEN kids want to train our kids with extra activities such as piano or roller skating for my child it is very difficult to find as no one is trained to so or we are not able find that information. Also, after school facilities for the SEN kids that can help working mothers. We don't know how to get these information."*
- *The ability to be able to contact a department would be helpful, we appreciate these departments are very busy but often time can be saved if requirements are dealt with at instigation.*
- *Different Peterborough health/help services need to communicate more with other workers. To provide the right information.*

- *More investment in support for young people so that they achieve positive outcomes. Waiting for children to fail is unacceptable. Early intervention has been proven to result in better outcomes for children. Peterborough SEN services are very disappointing!*
- *You need to make services easier to access and re look at your specialist settings criteria. Many autistic children are struggling in mainstream. Every day is a challenge for my son and I feel he would thrive if he was around children similar to himself and teachers understood his needs.*
- *Earlier identification.*
- *I think parents should have access to a hub and that links schools and council. I feel there needs to be a bridge between services and schools. schools also need to train staff better to understand the needs of autistic children.*
- *If the possibility of new special needs schools is not an option, then PROPER training of some teachers to deal with autistic children, not just saying they can cope, and then not being able to cope. At the end of the day it's our children who suffer.*
- *Faster process and follow up on the care that is needed*
- *I think everyone would agree that it takes a very long time to get help or diagnoses, too long. Our health visitor started to question autism at his 12 month check and actively started to pursue that line of thought at 18 months. He was not diagnosed until age 7 and all we have had in terms of support is a generalised parenting course called triple p that was not even designed for SEN children. We realise the pandemic has really impacted our experience but we have sourced all help and coping strategies/ information ourselves spending hours combing through books, podcasts and websites to try to help not only understand more about our child's autistic brain but to be able to help him in a world that is set up for neurotypical people. We could not have waited all that time for the parents of Autistic children course we are now booked onto (which is oversubscribed and even though offered a place in Jan it was full before we could even get onto it so we are waiting until March)*
- *I think the biggest change would be the waiting times for help. My child's school put her issues down to laziness for years and refused to listen to my concerns. Now we are going into the 5th year at primary school still without any answers to what's wrong. It's been 2 years that the school have registered there's difficulties and we're still waiting to be assessed.*
- *The meeting should be more frequent*
- *See above*
- *The parents should be informed if there's a suspicion of autism by the teachers and the parents shouldn't be put off having their child assessed, and all teachers should have a general understanding of how to deal with SEN children. For ex. The deputy head shouted at my child and he doesn't respond well to that we caused him to have a meltdown and tear the classroom apart.*
- *For once put yourselves in our shoes the struggle is real until you don't see it from our point of view changes will never succeed*
- *Quicker results*
- *"Easier support for parents with teens who have mental health/ behavioural needs.*
- *I have called police multiple times about meltdowns at school and taken over 2 years to finally get a social care assessment started"*
- *As above*
- *More monitoring and consistency with primary and secondary ensuring schools are all following the same guidelines*
- *More training to notice adhd in girls in primary school*
- *"Better training for staff.*
- *Better understanding of the needs of the young people and families. Stop trying to use a one size fits all aproach"*

- *It would be great if they visited schools more with parents so they would be able to support and help parents with send who are not knowledgeable in this process.*
- *Thank you 🙏🙏*
- *More joined up working between children's and adult services. Meaningful co-production where more than lip service is paid to experiences and struggles. A better appreciation of 'invisible disabilities' and more inclusion earlier on with 0-25 team, especially in the lead up to transition.*
- *"Improvement in picking up problems & acting faster. To sign post help ASAP.*
- *For the EHCP pathway to be easier & more accessible "*
- *Early intervention saves money and prevents all sorts of later problems. Invest in young local people, and you will get that invest back and more!*
- *SEN Services in schools needs massively improving.*
- *Better accessible Information for parents and carers, better forums for parents to question schools/health providers actions or lack of without them taking offence or trying to cover up their negligence. Better pathways for children who mask or are not the a typical stereo type for the disorder.....things need to change now! Better access to assessments before leaving primary to ensure we have things in place in secondary so we are able to have more positive outcomes as young adults for better transitions into adulthood. Ensuring focus is not just for educational purposes as a child who has social skills communication skills has confidence in themselves to attempt jobs will still have a chance to get educated later in their life! As a parent I want my daughter to be comfortable in herself to know she does not have to meet all the so called peer targets in education but just do her best! What is so concerning is who is advocating for those who are unable to understand or navigate this ridiculous maze we call education/healthcare!*
- *Peterborough SEN should increase their support requirements*
- *The ehcp assessment really needs looking into too many children falling through the net. I also think more information needs to be given out and explain what services can help and what they do. I had to find a family support worker myself through Bernardo's. I would have been nice to feel supported after my son had his diagnosis as I felt alone and I was so scared. I was professionally a carer in the community before having to stop working for my children. Too many appointments.*
- *Employ 10 more xxxx as she is the one member of staff who takes the time to answer your calls, emails, help etc. Cannot praise her enough*
- *More access to advice. I am new to this and knowing who to speak to or where to go is the hardest part so far.*
- *"Universal access to parenting programme prior to early help.*
- *Access to therapeutic parenting programmes and attachment pathway locally.*
- *For young people to be able to attend any hospital /consultant in the UK for diagnosis or treatment and not be turned down on grounds of funding*
- *Multi agency parents drop in service , advice and signposting. "*
- *I think that the staff who get employed to organised EHCP's need to know the law in regards to when they need to assess. They also need to be fully aware of what should and shouldn't be written in an EHCP. They should listen to staff and parents to ensure that the provision is written carefully. If they do not have enough information about certain areas they should actually use the assessment period to get professionals in rather than making up targets themselves. They need to actually put exactly what children need and not what they think.*
- *There needs to be a much more cohesive approach; the system is too fragmented and much time/resource is wasted by having to try to access triage pathways etc and having to discuss the same things over and over again with different agencies. There is also a "it's not our problem" mentality from each agency, trying to pass the responsibility onto one of the other agencies e.g. Education to Health, Health to Education and Social Care etc.*

- *SEN support should be for all children with a diagnosis, the experience I have had is that my children are all academically very capable and appear to be coping but have significant difficulty with social and especially emotional health. There is no support available for this. My eldest child has started secondary school unable to have a conversation with an adult and therefore unable to ask for help. Schools and preschools need better training in identifying SEN and what support they can give to children who struggle in these areas not just those who are struggling academically.*
- *they need to help in arranging child need instead of only focused on documentation .*
- *Better coordination between education and social care, greater proactively by social care services*
- *Senco need help to inform teachers of a special needs child, always a challenge for parents, even worse in secondary school my daughter struggled so much and still does.*
- *Once your yp reaches a certain age a parent carer should have help with stepping into adulthood housing etc*
- *Help needs to be more readily available and a quicker, easier process needs to be made. I have been battling for 5 years for help and things are still the same as they were if not worse.*
- *The waiting time for appointments and assessments and time to complete amended care plans*
- *Should have easy access for people in need. It's a struggle to find the help first of all then it's a challenge to get that help on time.*

General Conclusions

It is important to note, no attempt is being made to draw specific conclusions from the data, only to show a snapshot of views and experiences currently compared to previously. As all data is anonymized it is not possible to establish if the same parent carers have taken the survey across years. It is possible to identify some basic trends, such as a move towards more satisfaction with the SEND system currently compared to a decrease that was seen across previous years.

A general review of the comparative data presented in this report and the comments provided where respondents have expanded on their answers still point towards three broad areas of concern despite overall more positive reporting:

1. Lack of support
2. Lack of involvement
3. Difficulty in finding Information

Preparing for Adulthood (PfA), is still an area parents are more mixed about although it seems as if some improvements/ changes are being felt more positively. Negativity is still more obvious in relation to community provision and adult life.

Way Forwards

It may be worth considering looking at some further Topics of Importance (ToI), based on the trends identified in this report. Evidence for these, could be formulated from further small surveys, Facebook Discussions and Polls, Case Studies and Focus Groups. Potential ToI are:

- Communication and Information – Wider than LO
- Wider Support/ What is Wanted