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# FVP Annual Survey 2021 – 2022 Comparison Report

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Results from 21-22  
Survey with  
comparison across  
results 2018 to 2022

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Parent Representatives

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## **Annual Survey (2012 – 2022) and Data Comparison with 2018 to 2022 Results**

### **Introduction**

This report will follow a format introduced in the last reporting period (2020 -2021) whereby a brief analysis of the full Annual SEND Survey for 2021 – 2022 will be presented alongside where feasible a comparison of results from previous surveys 18/19 through to 20/21.

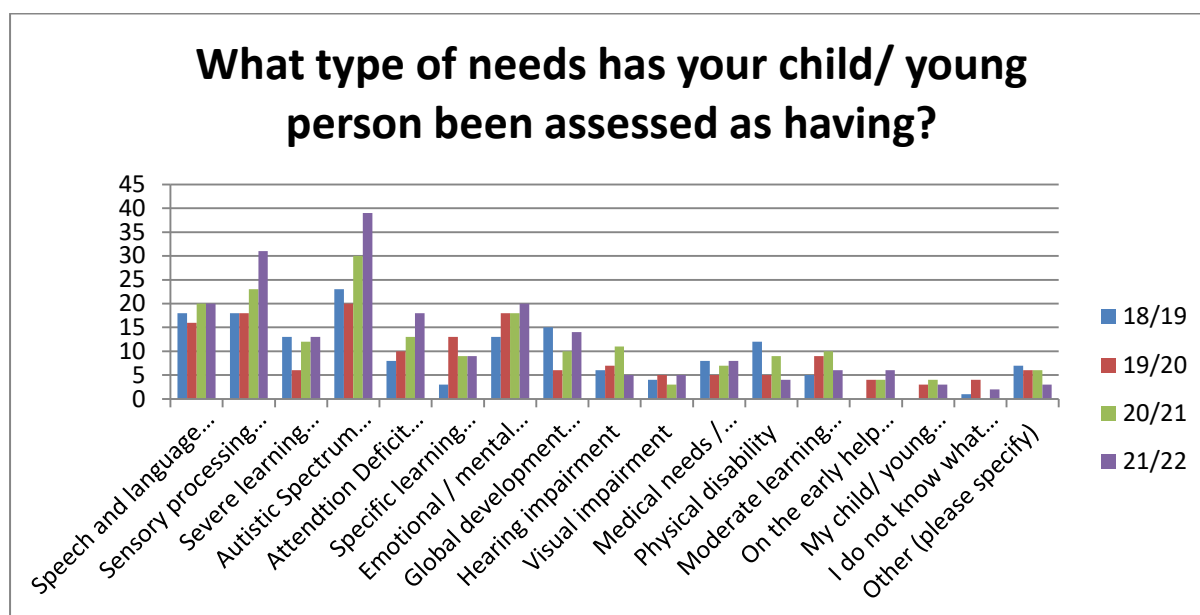
As with the previous comparison reports any results will be broken down in to several categories; Children and Young People (CYP) Needs and Education; Identification of Need; Understanding of Needs; Support and Review; Information; Social Care and Transitions; Carers Support.

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 was hoped in previous reports that over time there may be 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 report will detail a different story, when looking at views from data sets across the years.

It should also be noted that although the Global Pandemic linked to the virus COVID 19 (C-19) has moved on, and the country is now in the position of learning to live with C-19 the survey was completed based on the period 21/22 which still saw periods of lock down and change to SEND services to accommodate. During this time services have been stretched due to staff sickness, and COVID restrictions at varying levels.



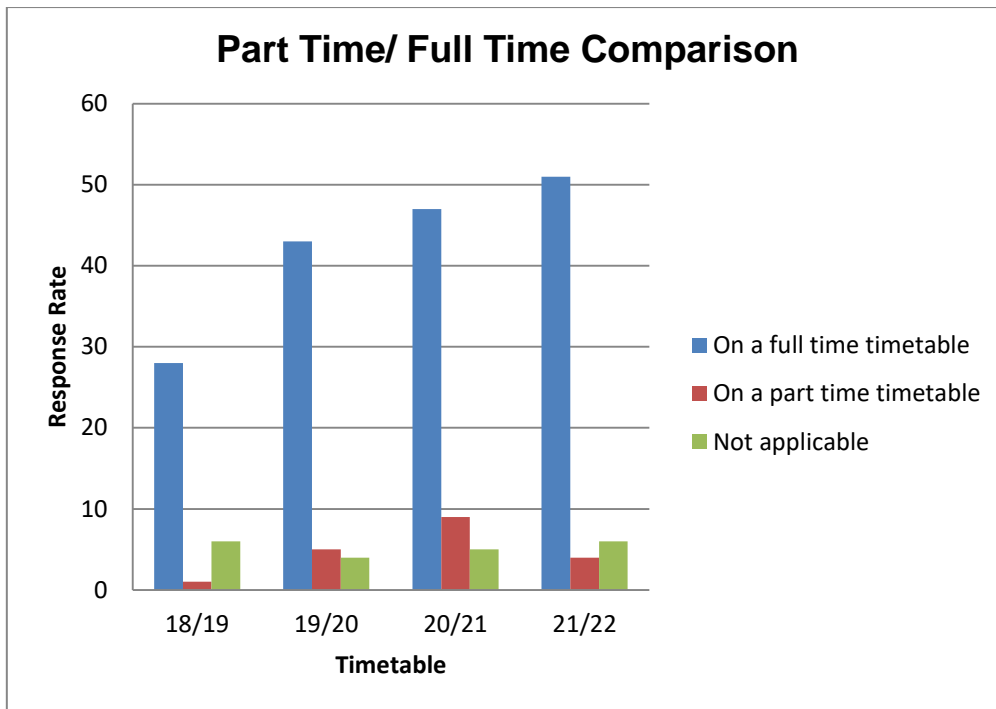
**Fig 1. Areas of CYP need as identified by parent carers**

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

1. Golden-har Syndrome
2. Down syndrome
3. Wiedemann-Steiner Syndrome

Across all reporting periods the most frequently reported area of need was ASD. It is also important to note that for 21/22 as with 20/21 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.

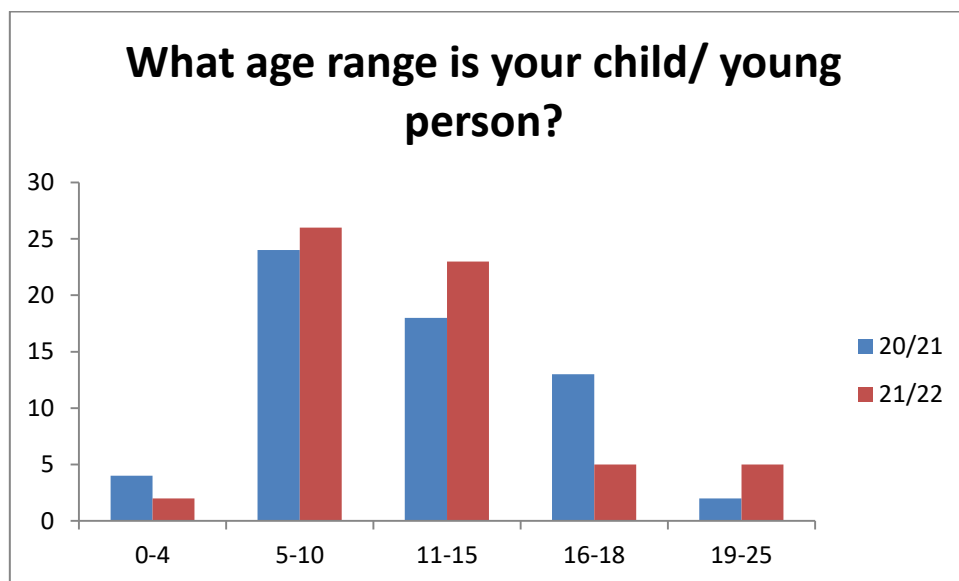
An area of need/ educational inclusion that was mentioned in the inspection report and WSoA related to the use of part-time timetables by various educational settings. This is an area that has been explored across all reporting periods as well.



**Fig. 2 Educational Inclusion**

It would appear from fig.2 that in 201/22 there was a decrease in parent carers reporting having their children on part-time timetables. 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. In the subsequent WSoA PCC worked on reducing their usage.

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 7 21/22 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 a slight 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".

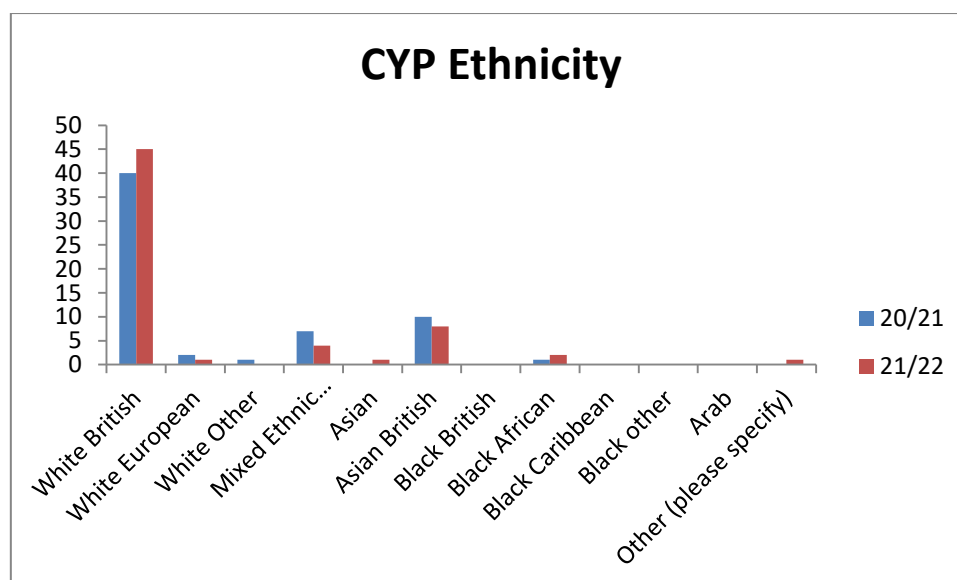


Fig. 4 CYP Ethnicity (20/21 Annual Survey)

### 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.

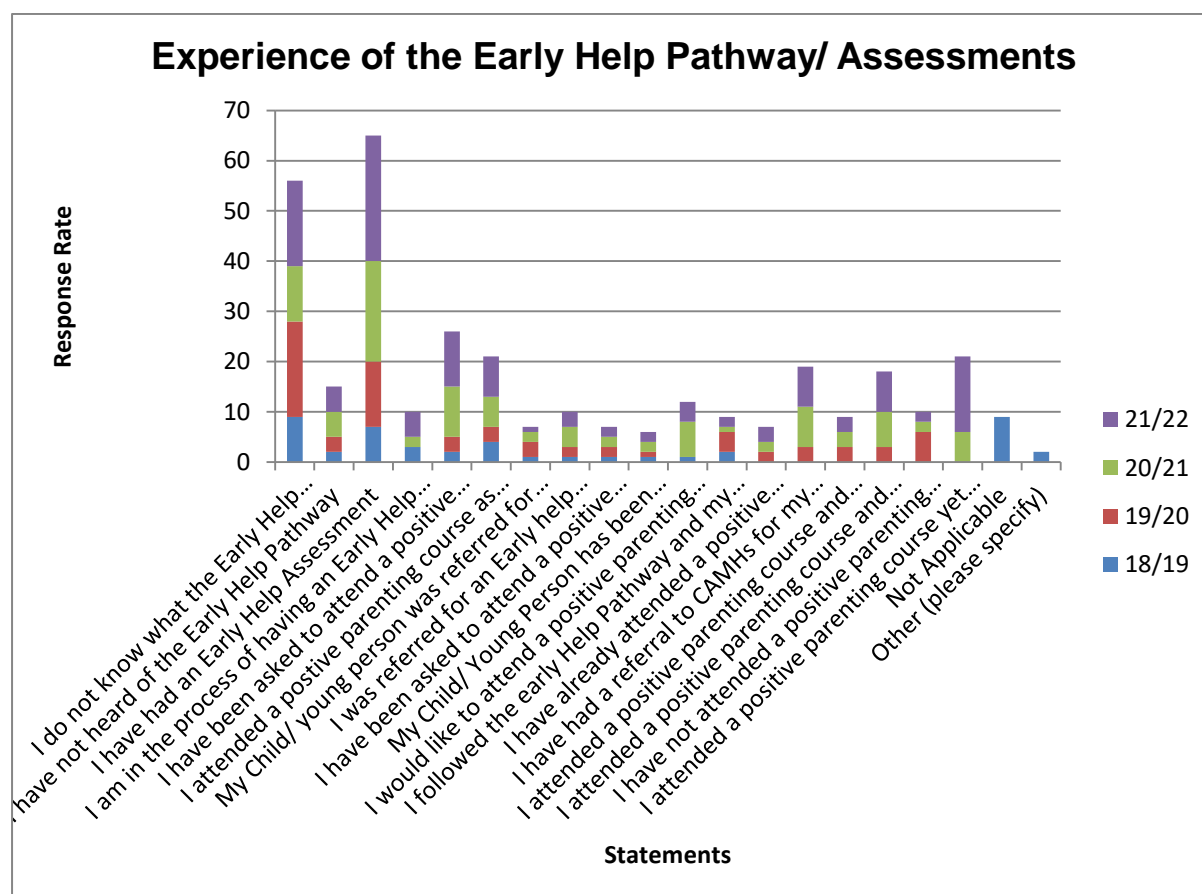


Fig.5 Early Help Pathway Understanding/ Experience

	18/19	19/20	20/21	21/22
My Child/ young person was referred for an ASD/ ADHD after my Early Help Assessment	1	3	2	1
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
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
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
I followed the early Help Pathway and my child/ young person now has a diagnosis of ASD/ ADHD	2	4	1	2
I have already attended a positive parenting course but I have been asked to attend another one		2	2	3
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
I attended a positive parenting course yet my child was refused a referral for ASD/ADHD diagnosis		0	6	15

**Table 1: Early Help Statements**

Further to this, some respondents provided further clarification to their choices:

Early help pathway is great but very long waiting time to wait

too lengthy process, training courses were great but 1 year too late

Recently just applied again to try get a adhd assessment. Already have a ASD diagnosis

Every time I mentioned it to an Educator I felt unsupported. Either they made me think they would do one and didn't or there wasn't enough time to get one done or they couldn't be bothered. The help needed was mainly around educational needs. EHP wasn't available until she was in further education.

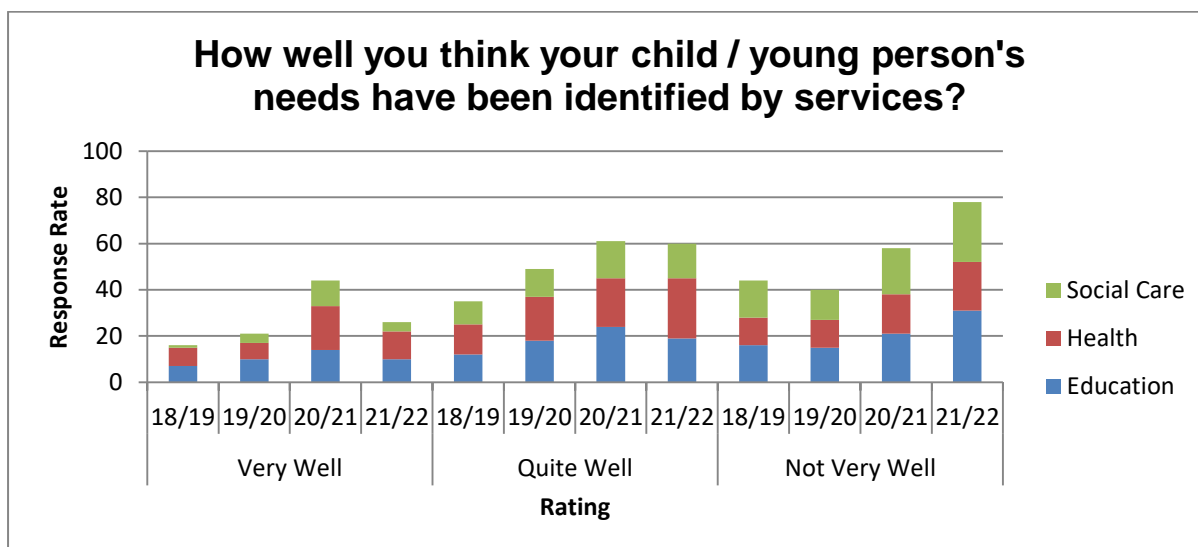
For one of my children it was great. Another one, however, haven't received any help and other than a latter saying thank you for your recent application (few months ago) I haven't yet heard anything yet.

I was told I had to do a course prior to diagnosis. I was told after the course, a diagnosis would be made, but it wasn't true. It was pointless, irrelevant and led nowhere. A panel refused any further steps to diagnosis. (Child is now diagnosed ADHD in the severe level, Autistic and with a language disorder, he's also in a special school )

Too long to get onto. Help provided was 1-2 years too late

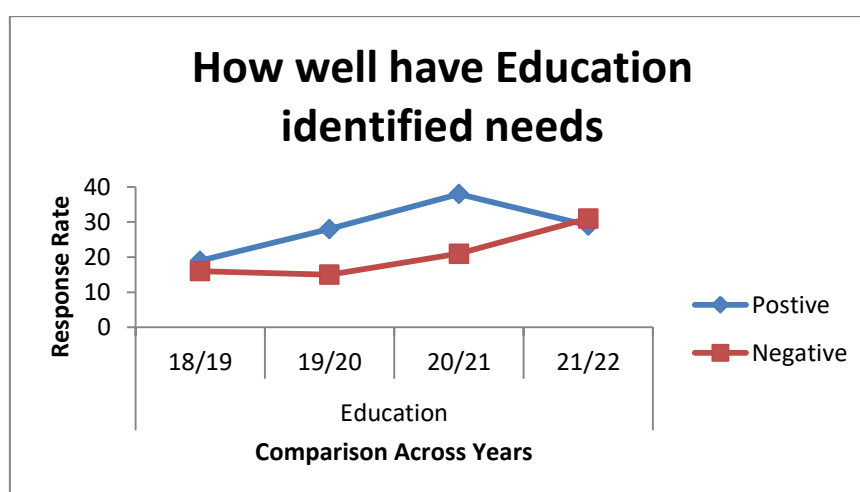
I was refused early help and any help not enough disabled child school said

It is not very good as professionals don't transfer it to other child when they need it it is always based on individual child not family needs



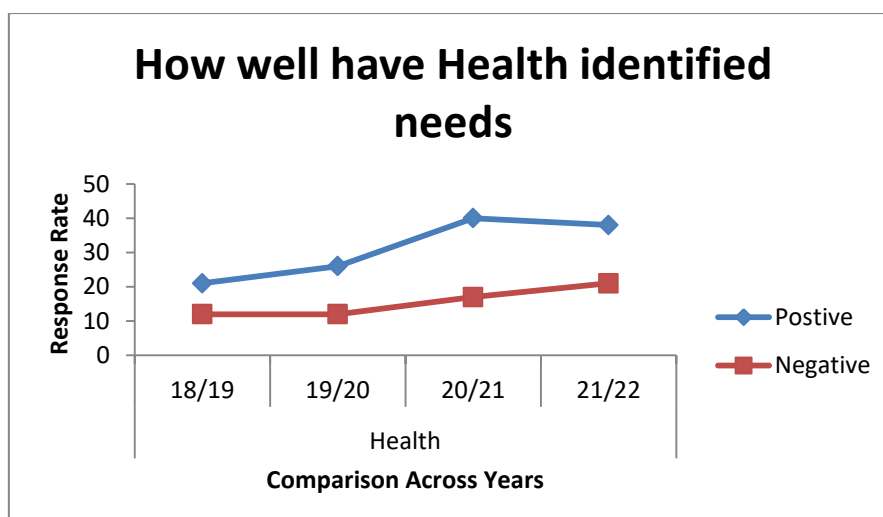
**Fig. 6 Identification of Need by Education/ Health/ Social Care**

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 increase in positive reporting identified in 20/21 has dropped in 21/22. 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).

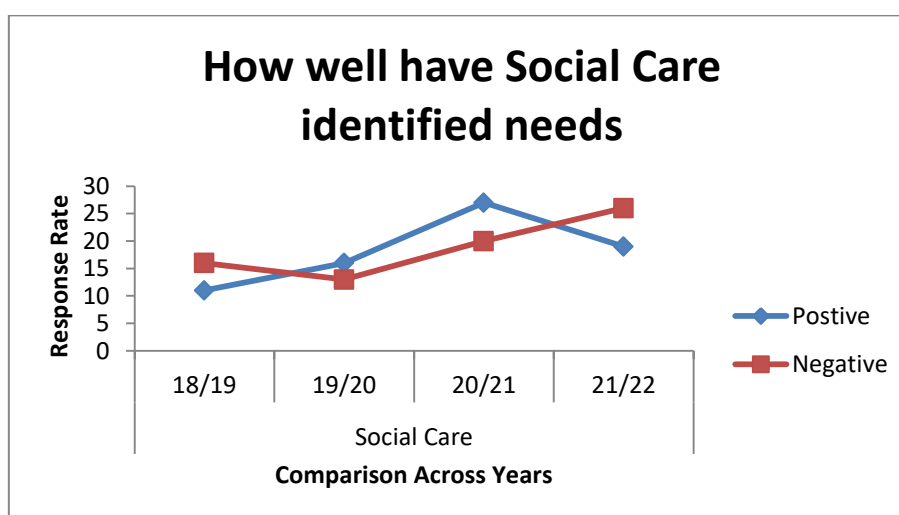


**Fig. 7 Comparison 18/19 – 19/22 (Identification by Education)**





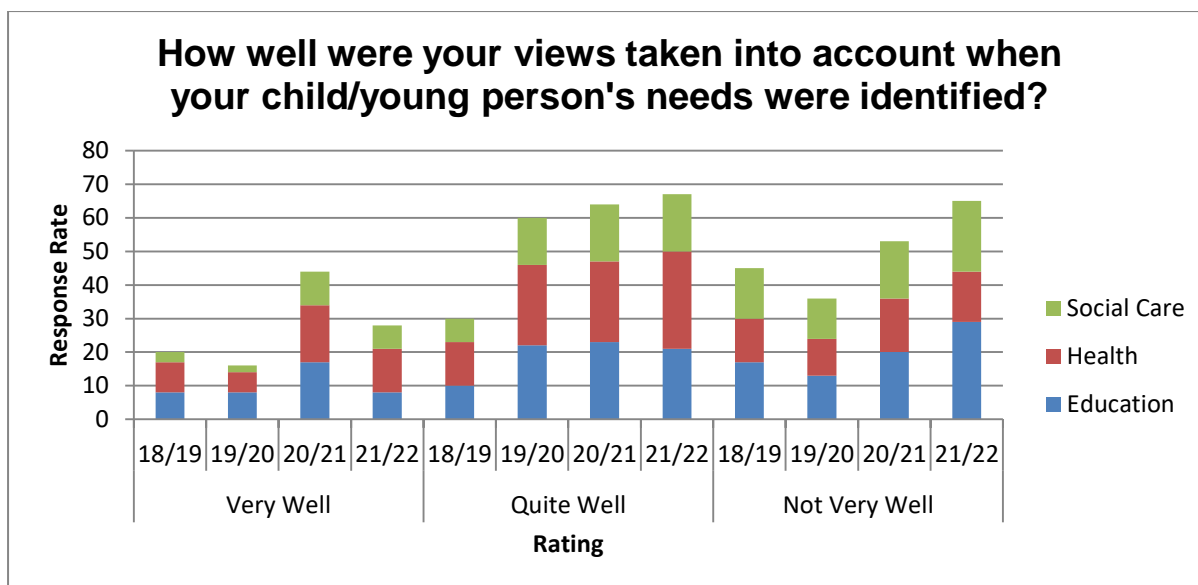
**Fig. 8 Comparison 18/19 – 19/22 (Identification by Health)**



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

Across all areas negative reporting increases and positive reporting decreases especially between 20/21 and 21/22, with Social Care seeing the most marked change. 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.

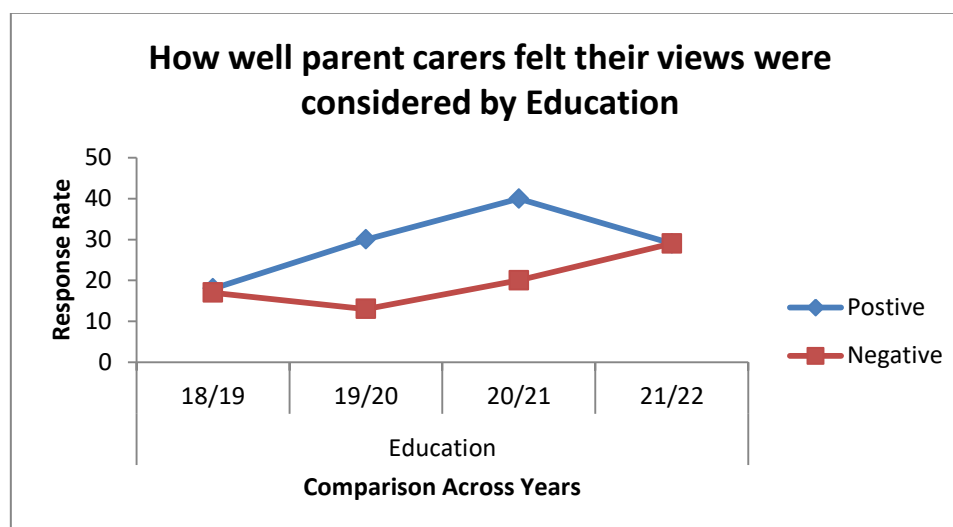
Respondents were also asked how well their views were taken account of during the identification of need process and again there has been a move towards more negative views.



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

Fig.10 above shows the overall shift towards respondents feeling their views were not taken account of so well, especially between 20/21 and 21/22.

Figs. 11 to 13 below also demonstrate the decrease 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 21/22 (Education)**

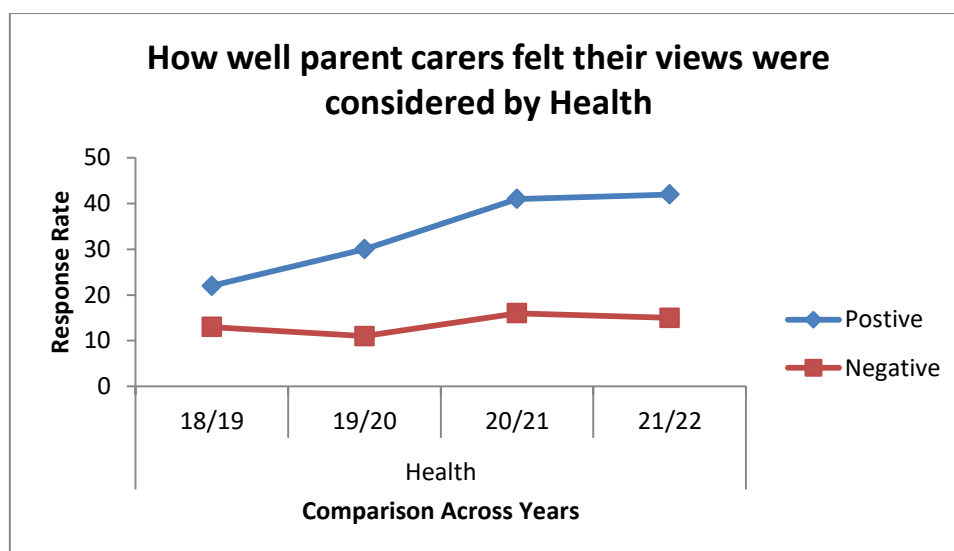


Fig. 12 Parents Views 18/19 to 21/22 (Health)

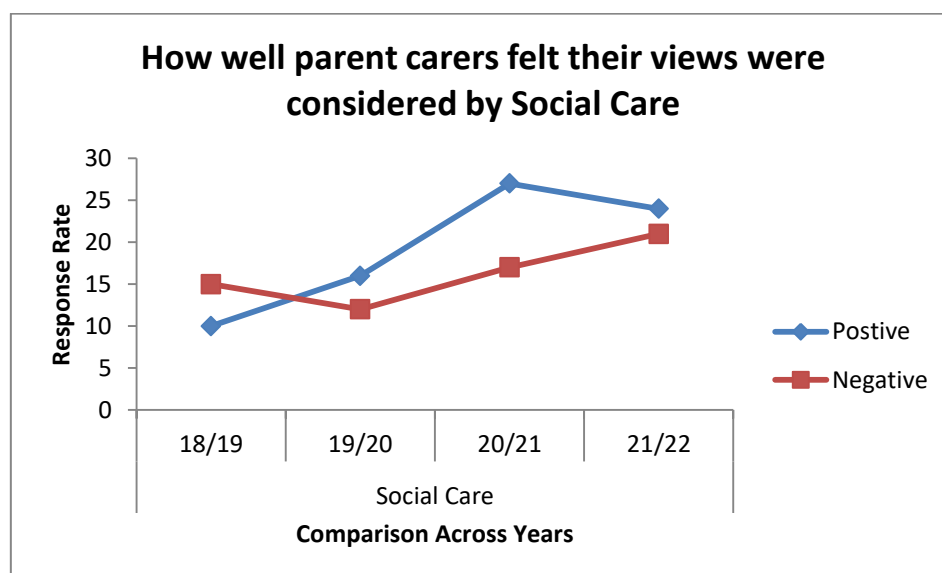


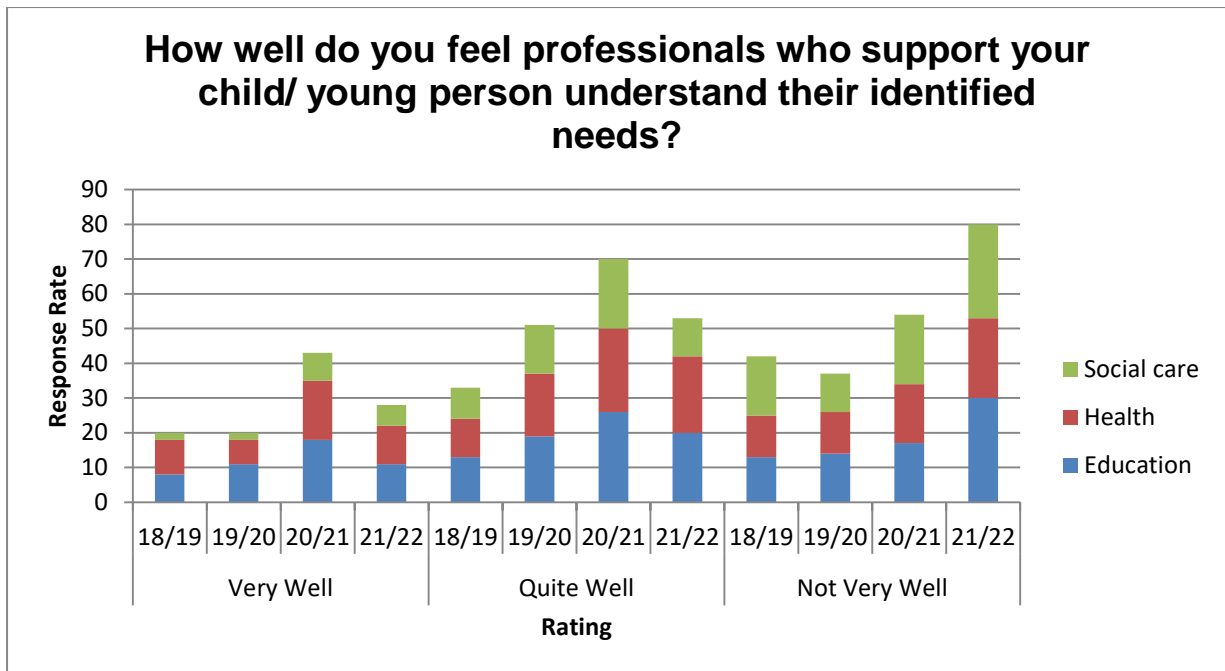
Fig. 13 Parents Views 18/19 to 21/22 (Social Care)

Overall across identification of needs social care is either rated poorly or in the main listed as not applicable. Health sees the least negative reporting in terms of both identification of needs and views considered during the identification process.

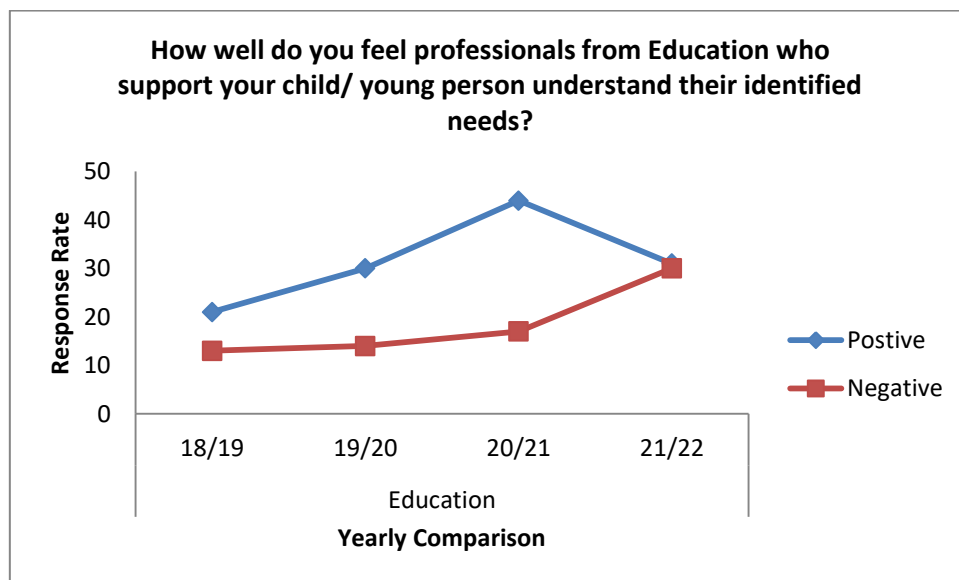
The above may be as a result of impact of C-19 on services relating to SEND.

### Understanding of Needs

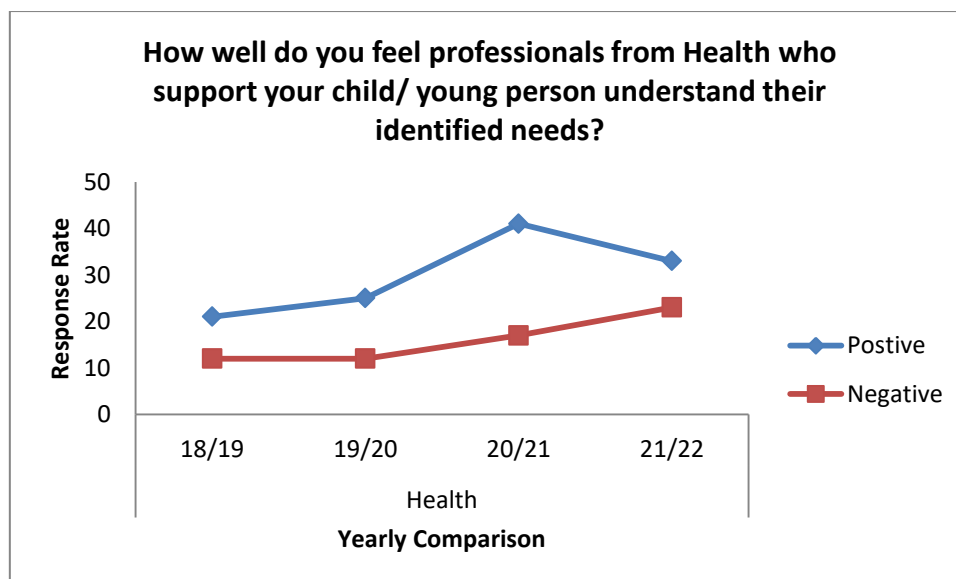
Another area of focus is understanding of CYP needs by professionals and parents especially after identification. Overall the same trend towards a decrease in positive experience and increase in negative experience can be identified across all areas in relation to how respondents feel professionals understand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



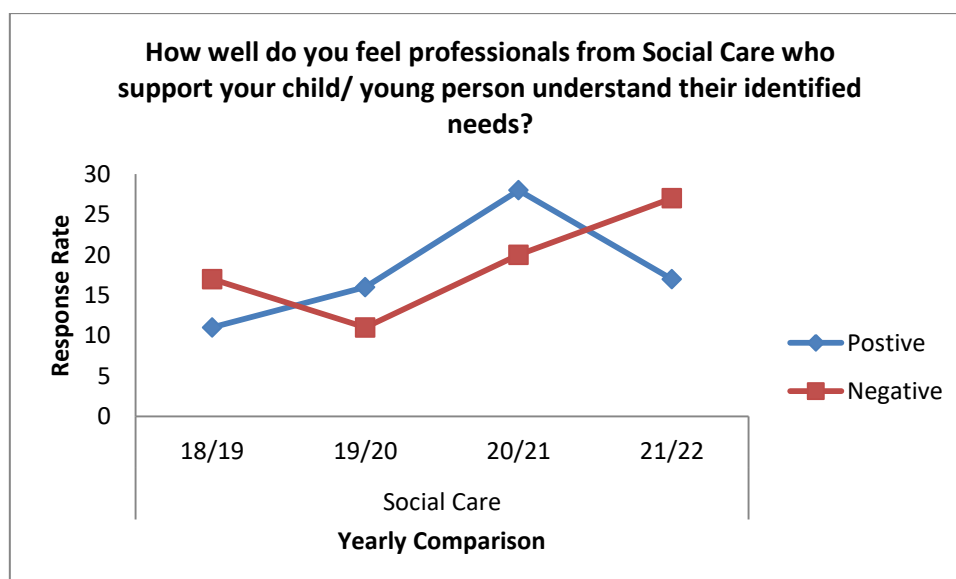
**Fig.12 Professionals understanding of needs**



**Fig.13 Professionals understanding of needs (Education)**



**Fig.14 Professionals understanding of needs (Health)**



**Fig.15 Professionals understanding of needs (Social Care)**

Three parents provided comments further to their response to this question.

*I think more understanding of how anxiety and mental health can impact on children with ASD and how they struggle to communicate their feelings and emotions and that they need support to regulate these emotions and how to problem solve to get a better outcome of a situation that are uncomfortable with.*

*NHS SaLT assessed needs based on local resources available rather than comply with CFA2014 or SEN COP. Needs were not accurately assessed*

*No help whatsoever*

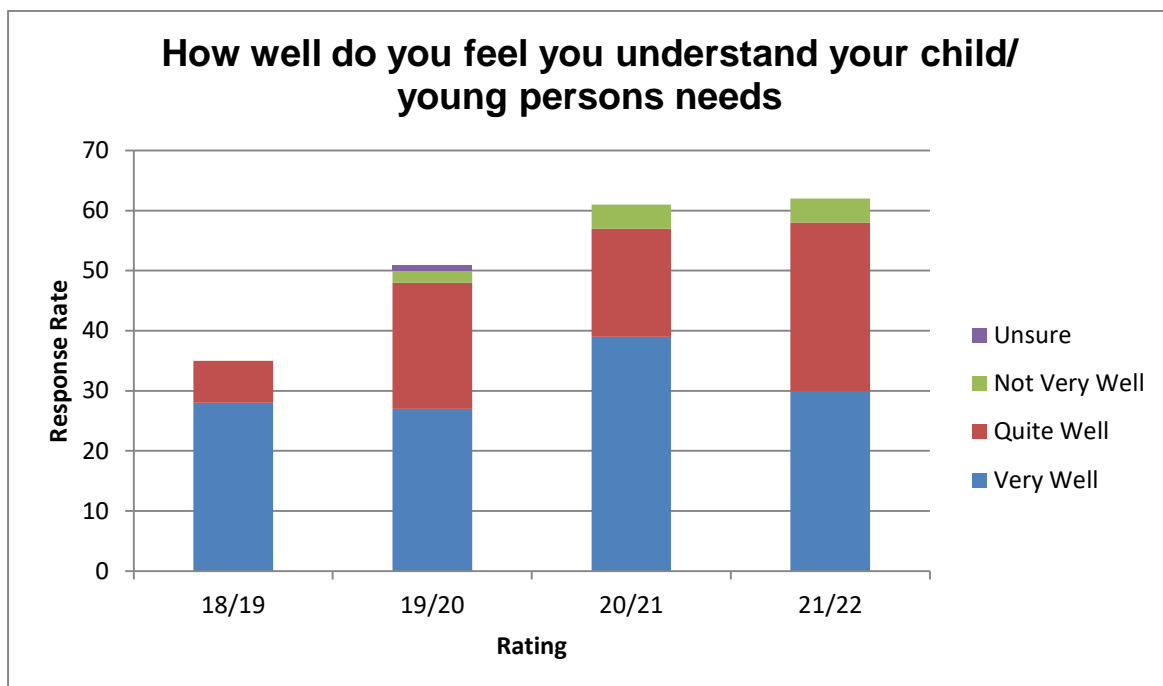


Fig.16 Respondents understanding of needs

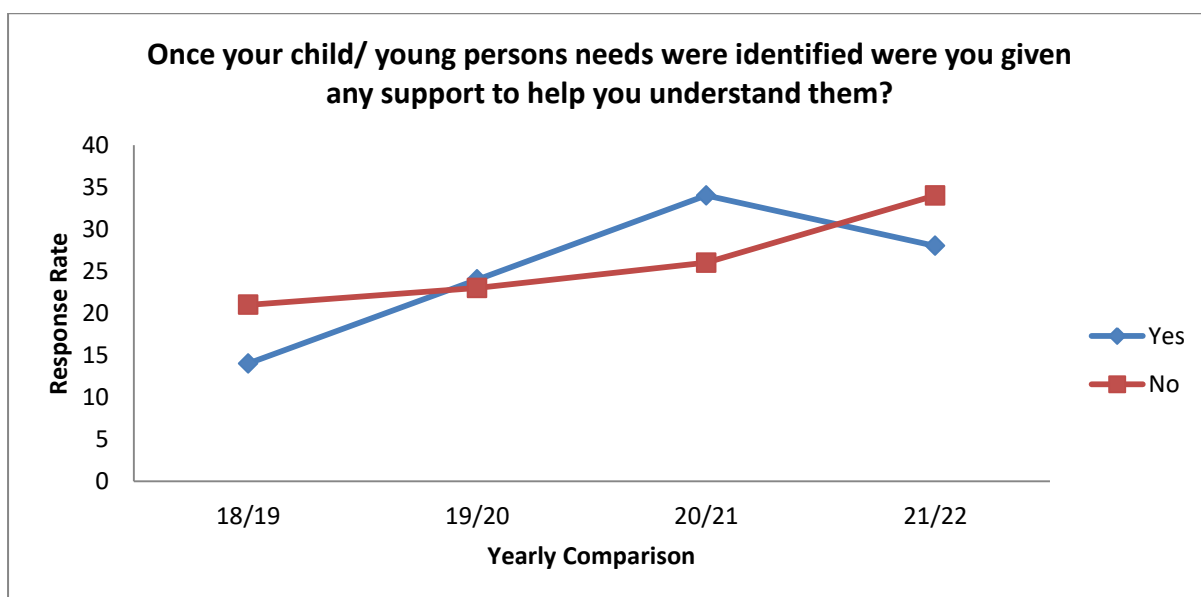


Fig. 17 Help to understand CYP needs

As with all areas so far satisfaction/ positivity has decreased and dissatisfaction/ negativity has increased. This trend relates in particular to 20/21 to 21/22, prior to this there had been a steady increase in more positive reporting.

## Support and Review

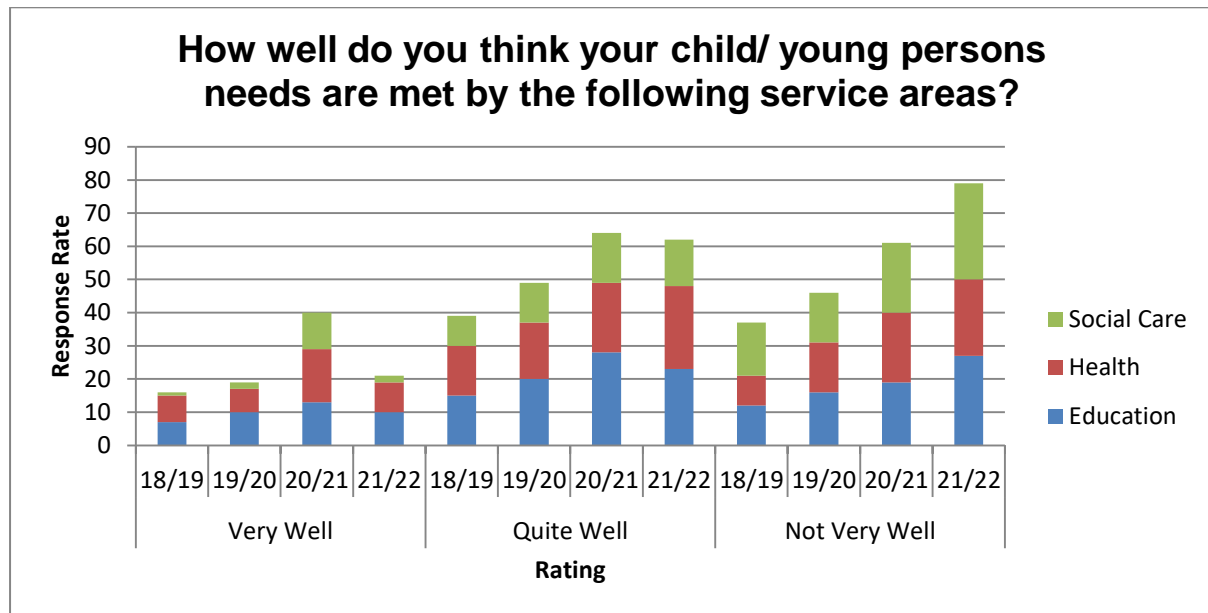


Fig. 18 how well services meet needs

Fig. 18 demonstrates the same trend with increases in positive reporting 2018 to 2021 and then a decrease between 21 and 22. 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 21/21 as shown in Fig 19 to 21.

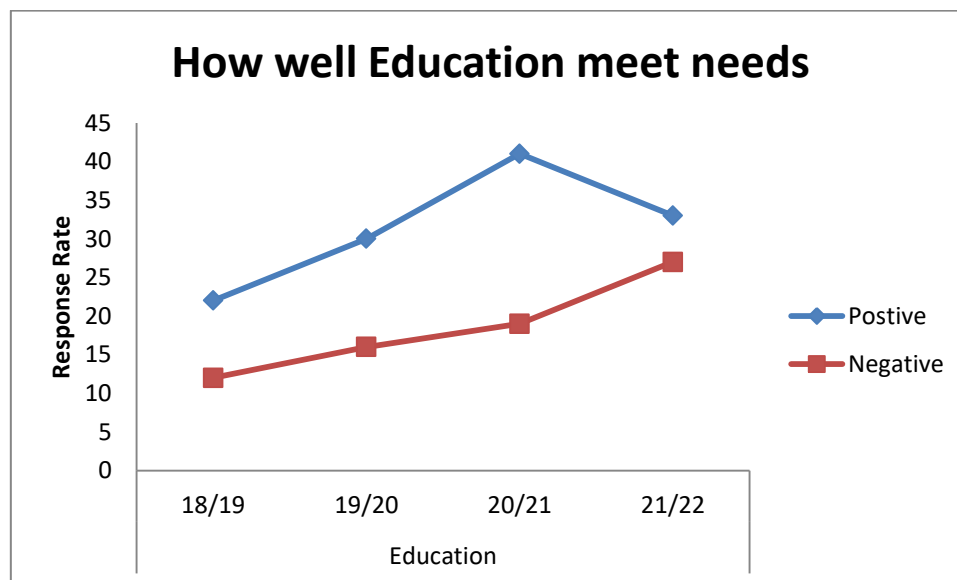
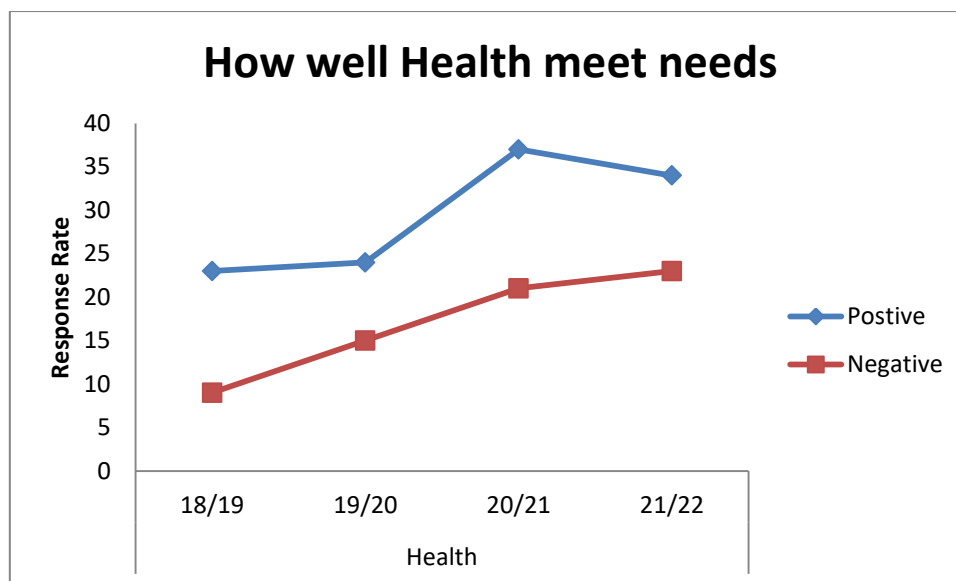
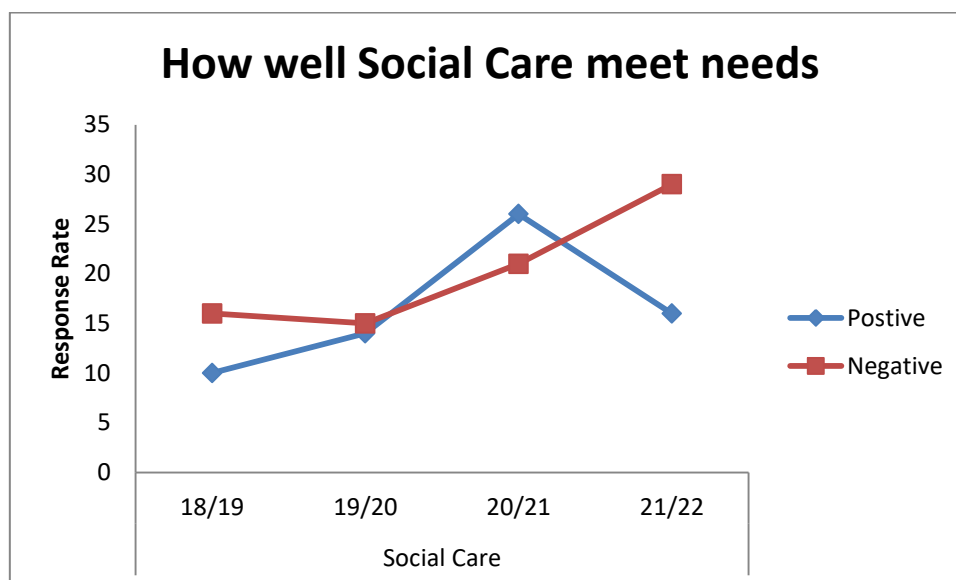


Fig.19 How well education meet CYP needs across years



**Fig.20 How well health meet CYP needs across years**

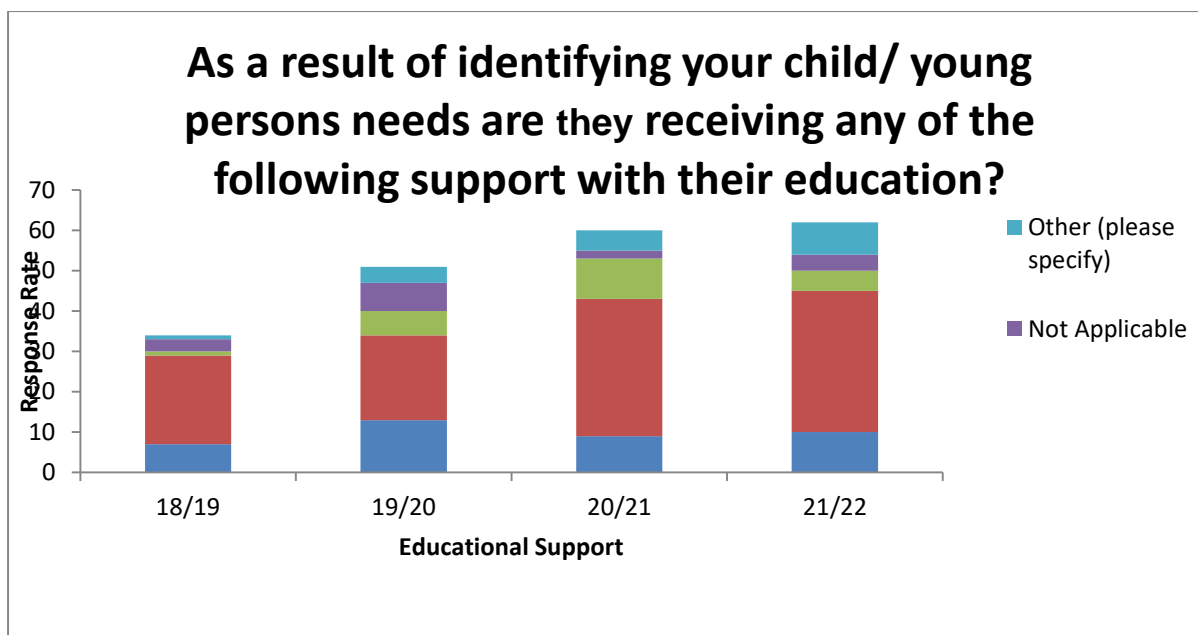


**Fig.21 How well social care meet CYP needs across years**

It may be that as already mentioned above that this trend may be linked to the survey taking place after extended periods of lock down, learning to live with C-19 and changes to how services are delivered as a result.

Across all areas Social Care fares worst in terms of how it is viewed across all areas from understanding of needs though to support, although it is also the area with the highest number of respondents selecting 'not applicable'. The numbers receiving or accessing social care are much lower than for Education and Health.





**Fig. 22 Type of educational support**

#### 20/21 Other Comments

- Does not have a plan
- no senco at the school or she would be
- None the sendco is also no help at all
- On paper she receives SEN support. In reality no adjustments are made, there is little understanding and knowledge of SPLD and Auditory processing dyslexia let alone how to actually support her to learn.
- Support for attending hospital appointments and 1:1 time with teachers.

#### 21/22 Other Comments

- ongoing assessment, just completed triple p parenting course.
- Nothing as school have no issue as he doesnt talk or communicate in school apprenently this is normal....
- er fighting still for this help!!
- Currently applying for ehcp
- Not receiving any help or ehcp
- Delayed again and no help
- Application for EHCP has been submitted

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. The comments also match an anecdotal view locally that it is difficult to get help for a CYP via an EHCp. It could be seen that fig. 23 further validates this position. Especially when noting the growing trend in receiving an EHCp after tribunal or mediation based on the responses.

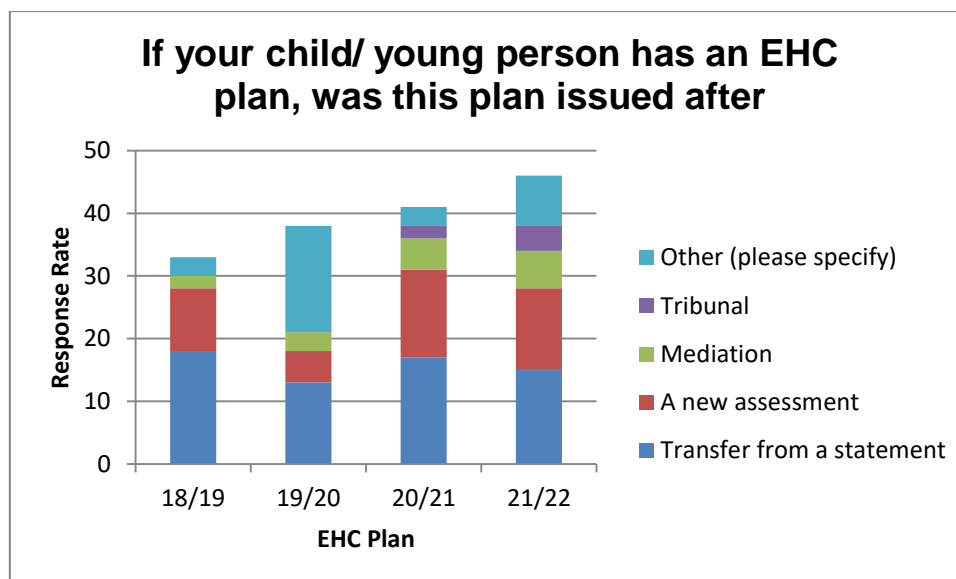


Fig.23 When was EHCp Issued

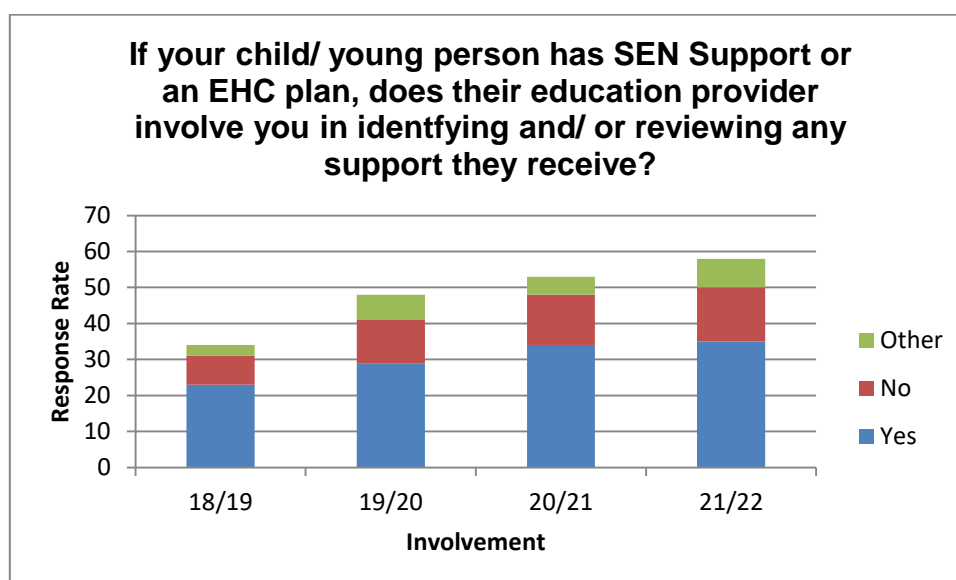


Fig. 24 Involvement in identifying and reviewing support

#### Views in 2019

- Only been at school for 5 weeks
- I have to be in contact with them for it to happen. It is not a two way process. The school feels threatened and does not welcome my opinion or views as a parent
- Schools couldn't cope, although they said they could, thus my child was traumatised by the education process. I had no option but to home educate

#### Views in 2020

- Only met in December, no further contact made, several emails and messages left by myself, no response
- Periodically, would like more often
- They are supposed to, but have refused to give specific feedback on how outcomes are being supported and reviewed.

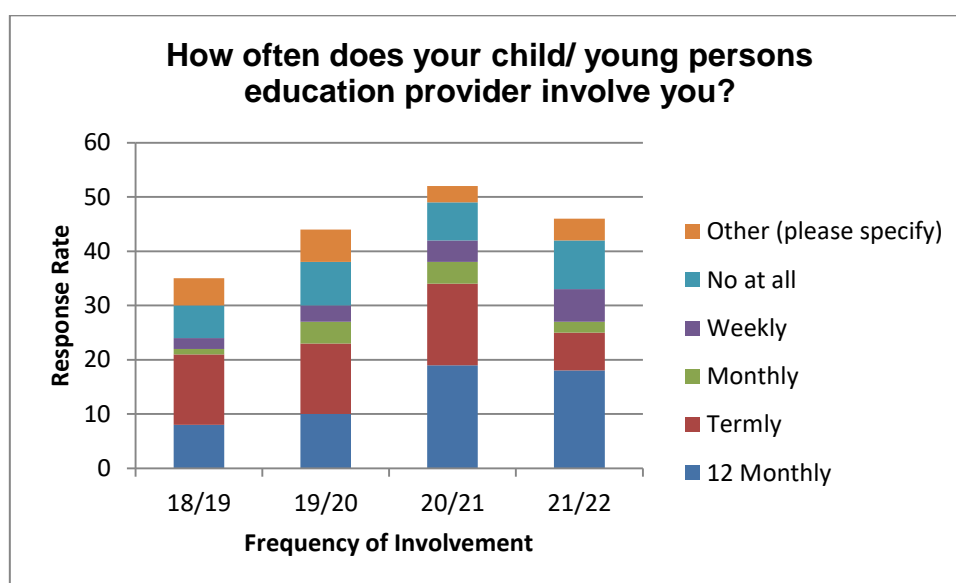
### Views in 2021

- Involved but my views aren't acted on
- At the beginning of the course yes, since then there has been no correspondence about ' how' she is learning.
- Very limited
- The support person from the SEND team is good but I have requested information from the actual course tutor consistently since September and have received nothing.

### Views 2022

- Recently issued
- The secondary school has not been forthcoming in providing feedback and information in general
- Not applicable anymore
- Yes they do
- Unsure as currently not attending we are awaiting a tutor until a new Placement has been found
- His previous mainstream school were fantastic.....since transferring to an academy special school I gave little to no involvement

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.



**Fig. 25 When parent carers are involved**

### Views in 2019

- I am regularly contacted via email by my daughter's duties if they have any concerns. And also termly reviews are held.
- Only been at school for 5 weeks
- When ever necessary
- It varies depending on the issues that arise. It is very inconsistent and communication can be abrupt and intimidating

- No involvement from LEA anymore, since I was forced to take my child out of school, it's like they don't want to know.

#### Views in 2010

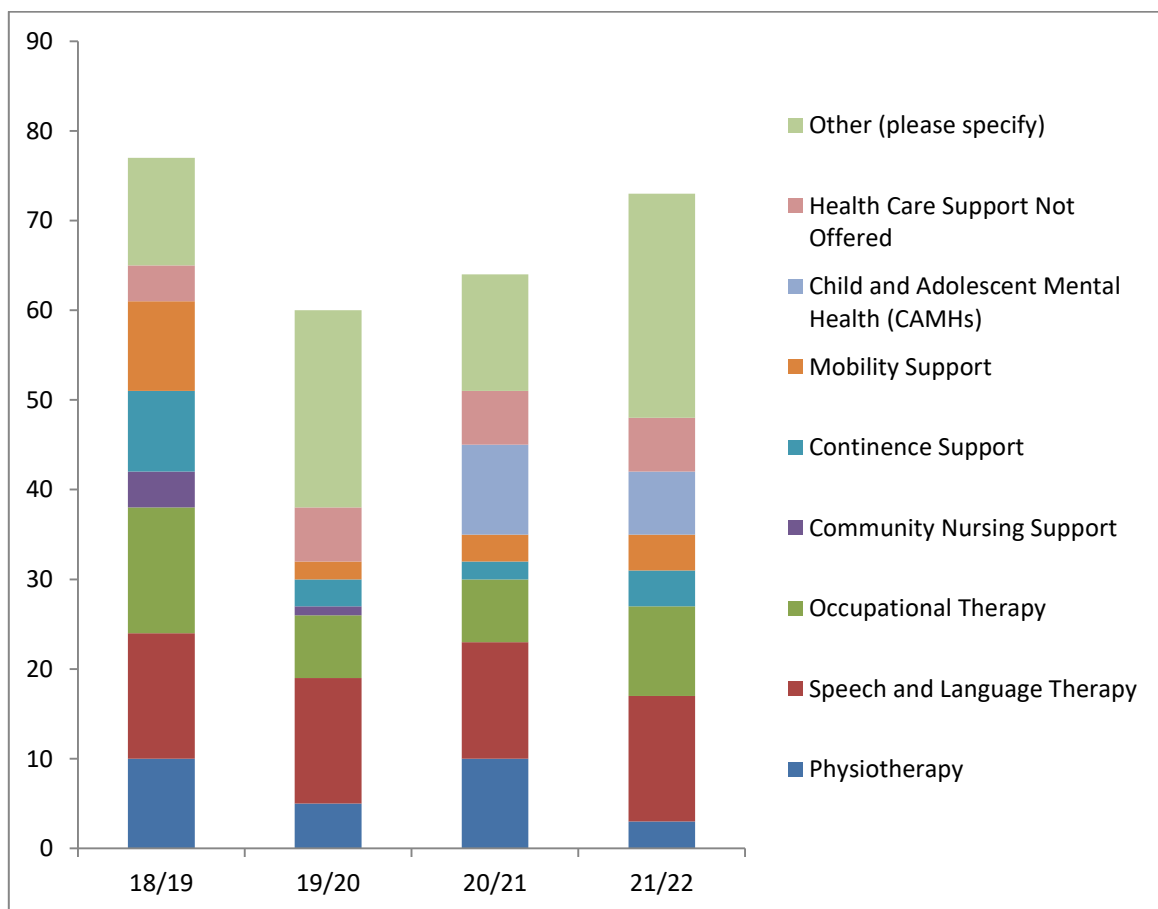
- As required via phone or email
- annually while at school till July 2019 - not sure now at College
- At least half termly but more if necessary.

#### Views in 2021

- Direct contact as necessary, monthly I think not covid
- No
- Maybe every 2 years when we have a annual review

#### Views in 2022

- Dont hear from our sendco
- I don't hear from them I don't know anything about his education now his 17
- Previous mainstream would involve me on a need to know basis which was daily. Current school does not inform me



**Fig. 26 Health service support**

### Views in 2019

- Physio to be arranged. Annual hearing reviews and regular input to her syndrome.
- Not Applicable
- Pay for private SALT nothing through NHS
- None offered
- CBT therapy
- No
- CAMHS referrals have been made to OT but waiting. Received help from AAT
- All been stopped after moving school for some reason
- These are provided by school- not Nhs or local services
- Ptsd treatment but have waited a whole year after diagnosis
- He doesn't need any of the above services
- Keep Referring but keep getting a letter back saying no continually fighting for the services your child needs

### Views in 2020

- Counselling through CHUMS
- My son receives no help
- NHS salt woeful provision. Follow local policy not meeting child needs.
- Has had help with speech and ot in the past
- Visual impairment support. Dexterity support
- SLT due to start again soon after break of c8 years
- Only physio provided
- my child attends the ent department only
- We fought for PIP and they get the higher rate in both components
- Dietician, pediatrician
- Not yet diagnosed
- No help at all, not even an education
- Support with maths English

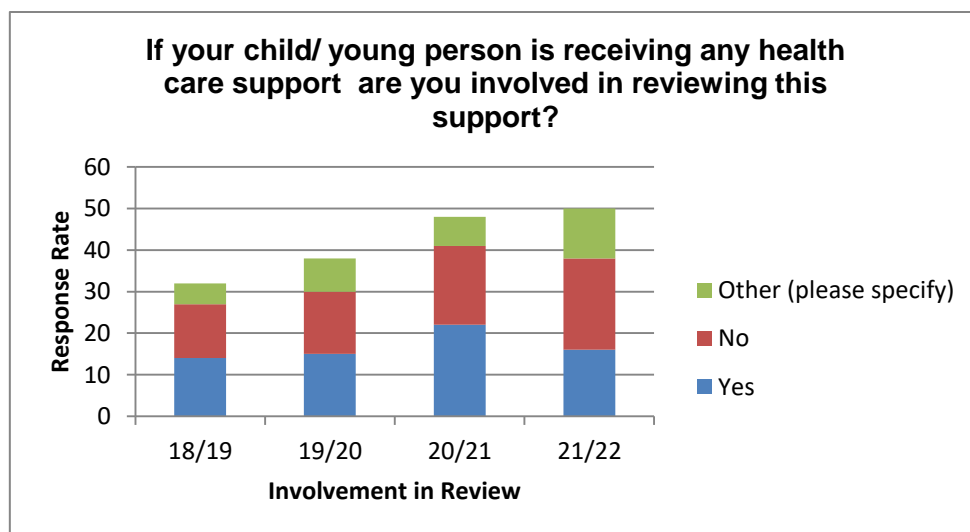
### Views in 2021

- Ok
- No support
- No support
- Applied to cambhs but they too busy with covid victims
- VI support link with College.
- "Hearing impairment
- Orthotics
- Private Salt and OT"
- none applicable
- No help
- None
- Has been identified as requiring SLT but this has stopped due to Covid 19
- Mental health and adhd / asperges team

- Cancelling at college every week
- Referred to paediatrics and given support for eyes.

#### Views in 2022

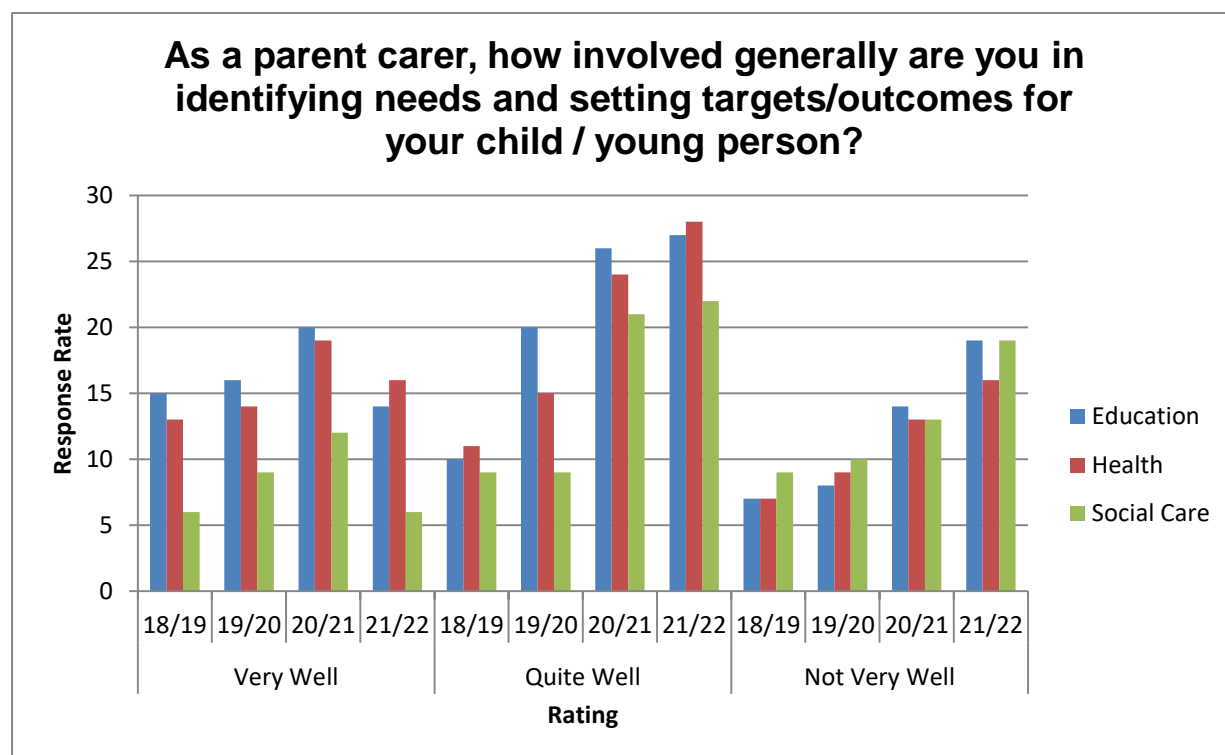
- N/A, though the school did give her a few weeks of mental health phone calls last year.
- Only at school
- "No used to have speech therapy for a short duration but this has not been reviewed.
- Would love my son so receive mental health support for his severe anxiety?"
- Targeted support with his learning
- Not since first diagnosed
- Should have it but has been spoke about need to chase
- Not applicable anymore
- We dont receive any help and no speech and language therapy has been mentioned at all, he used to recieve speech and language therapy at his old school but dont know about here. I need to ask.
- No support - refused assessment for diagnosis 11 times despite a detailed ND report pointing towards ADHD
- Early help but now diss continue as they feel don't need it anymore
- In school support
- No support
- Reccomendations by EP, OT
- He is supposed to be having SALT but not currently receiving this. The special school was chosen as he requires weekly support and they had an on-site SALT...I discovered after his transfer there, that they had fired her due to finances.
- Physiotherapy, speech and language therapy as well as occupational therapy has stopped since covid
- A referral for younited has been accepted
- No help offered no support nobody cares
- Told school should be doing it by CAMHS. BUT ARENT.



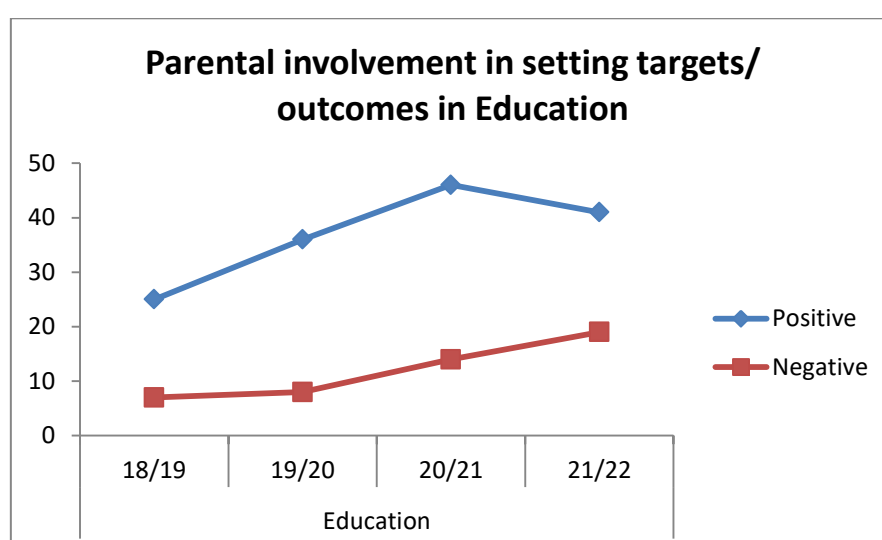
**Fig. 27 Involvement in reviewing health support**

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 comparing 20/21 with 21/22.

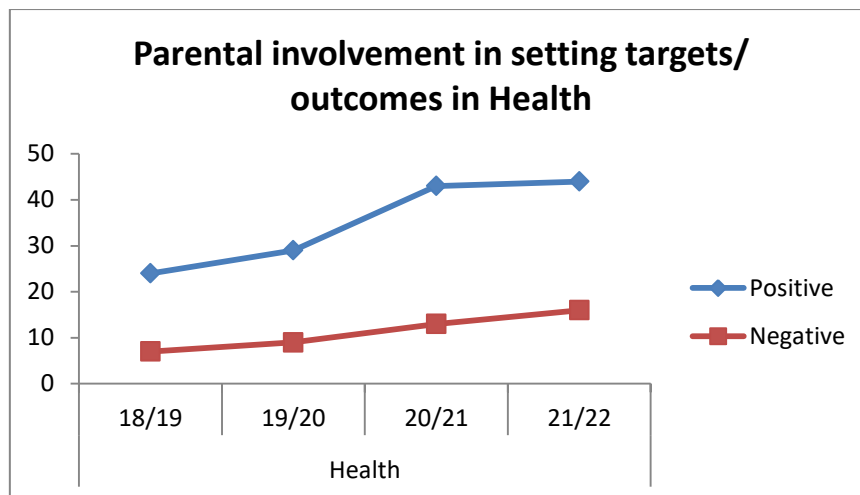
Follow on questions, from those mentioned and demonstrated in fig.18 to 27 which looked at parental involvement in reviewing support, looked at target setting, monitoring and support more generally. These will be discussed below.



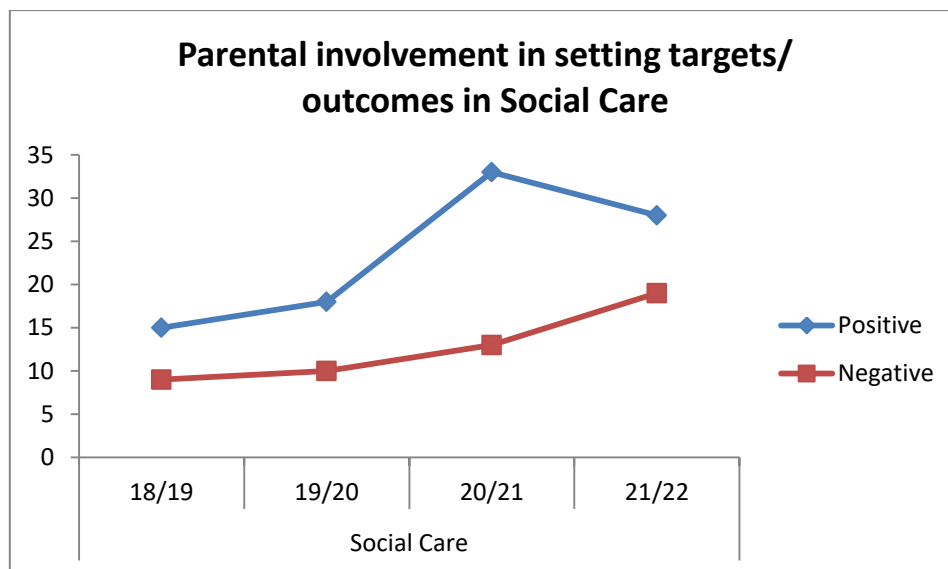
**Fig. 28 Involvement in setting targets/ outcomes**



**Fig. 29 Target Setting Education**

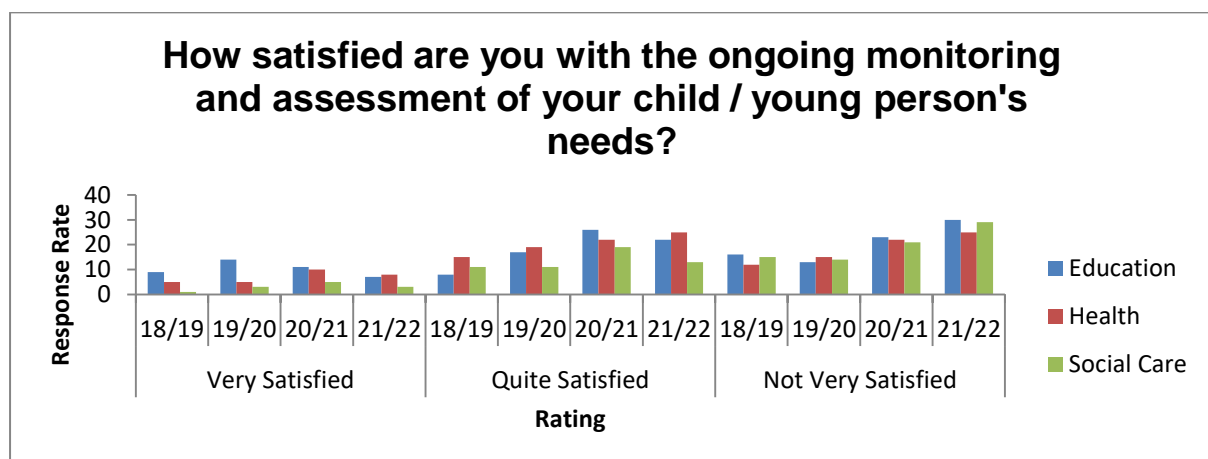


**Fig. 30 Target Setting Health**



**Fig. 31 Target Setting Health**

Fig. 28 to 31 looking at Target setting again show the same trend towards moving from an increase in positive reporting to a change towards negative reporting. This is apparent between 20/21 and 21/22.



**Fig. 32 Satisfaction levels around monitoring and assessment**



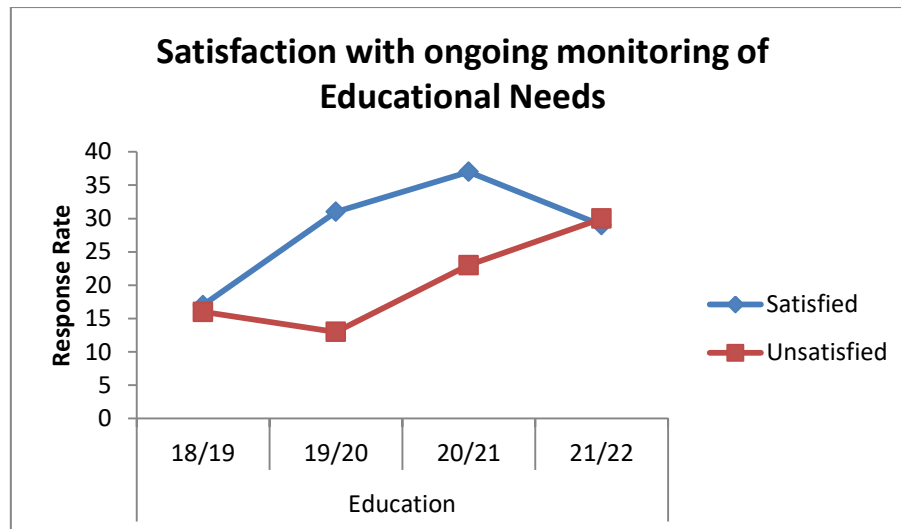


Fig. 33 Satisfaction in relation to monitoring of educational needs

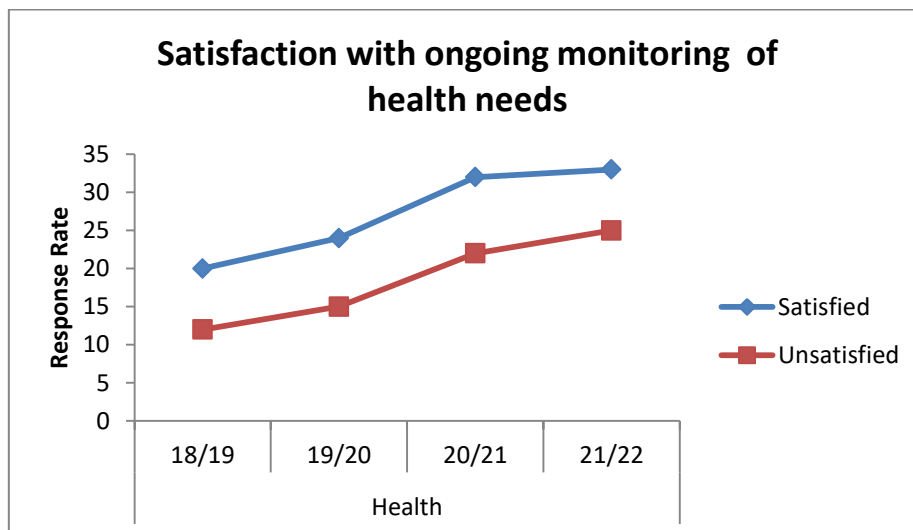


Fig. 34 Satisfaction in relation to monitoring of health needs

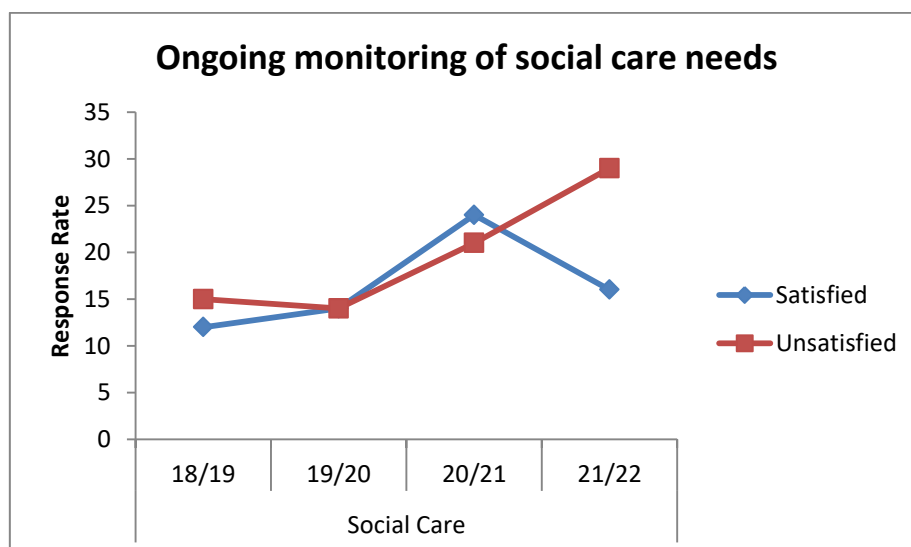


Fig. 35 Satisfaction in relation to monitoring of social care needs

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

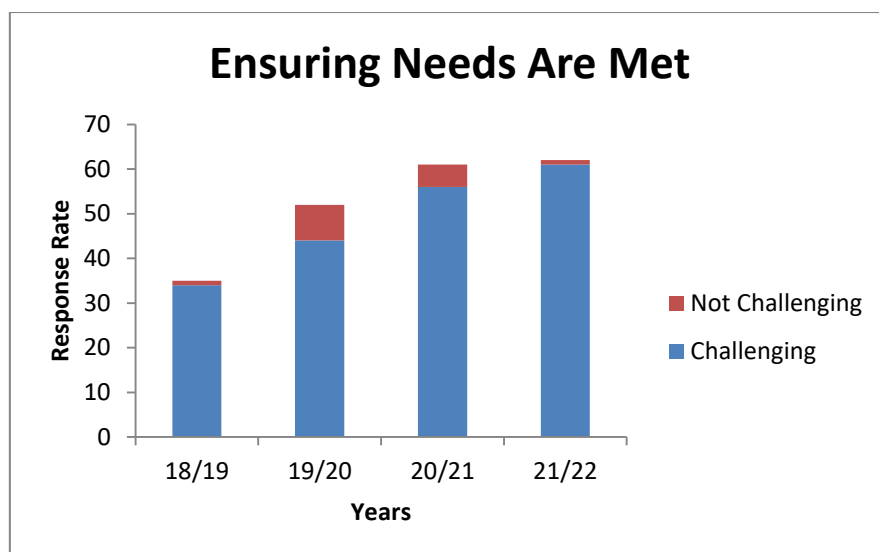


Fig. 36 Difficulty in ensuring CYP needs are met

Overall respondents also 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 a marked increase in this view between 19/20 and 21/22.

There is also an increase across the 4 year period of respondents reporting that services do not work well together (see fig. 37 below)

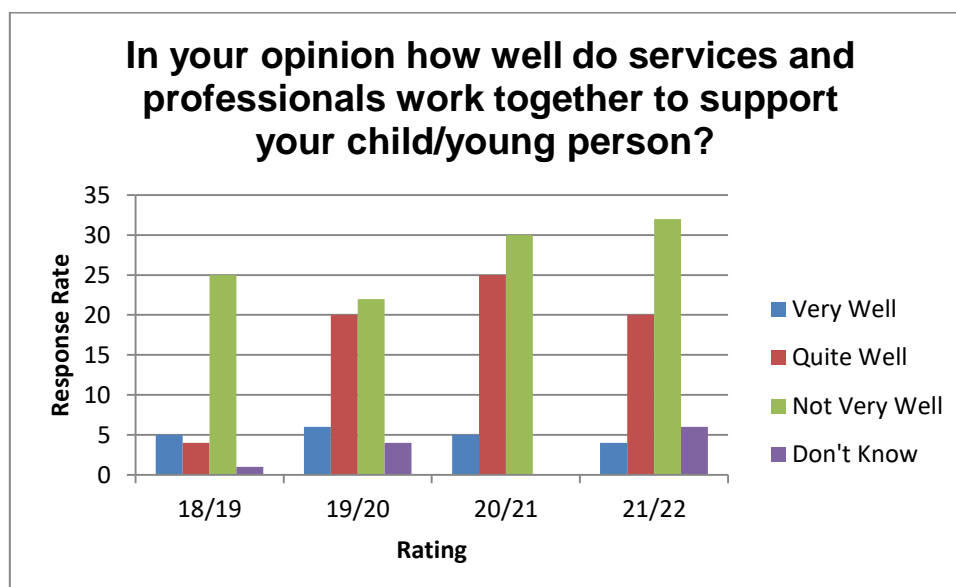
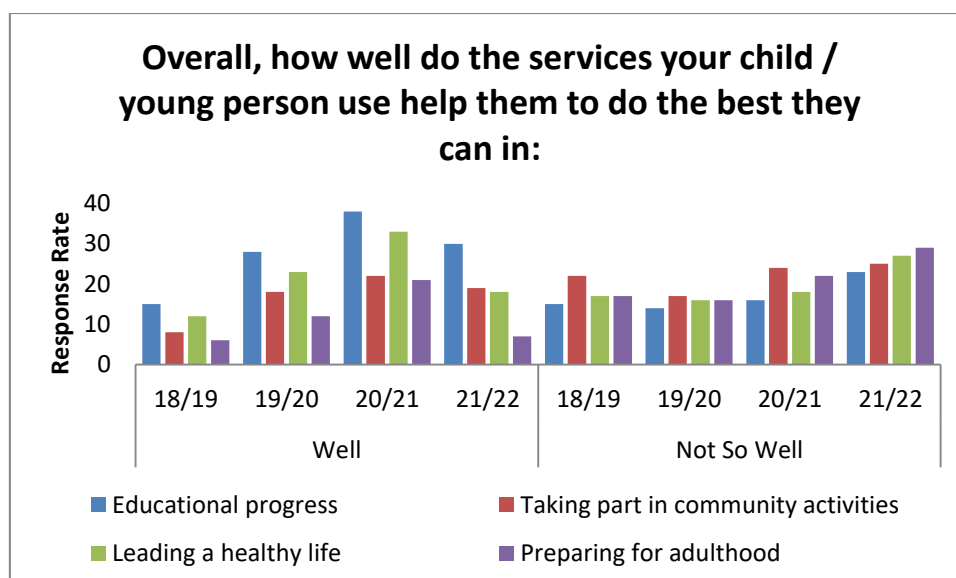


Fig. 37 Services working together.



**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 trend of a move from positive to negative reporting continues. In this area it looks as if Preparing for adulthood is viewed most negatively.

General views were also sought in the annual survey around Educational and Health which elicited a very mixed response, with again C-19 being mentioned as an area of impact on services:

<b>Educational Experiences 20/21</b>	<b>Educational Experiences 21/22</b>
Only have communication after panel meetings, and awaiting referral to get diagnoses	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.
Been difficult to establish a routine due to covid	No support at home no clubs for sen children who r non verbal or apposite courses as cannot speak or write no care needs
Always told school she didn't understand maths but they didn't believe me. even though we proved that she has Dyscalculia	I struggled to answer some questions as i have 2 children in the same primary school 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
im fighting the school regularly to recognise her needs but getting nowhere	Slow at communicating no support at home don't take me seriously
College very slow to accommodate my son's needs. Early days yet and hindered by Covid but I'm not impressed.	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

My son has autism and spd and is left at school to get on with things he has no help given	Slow because of covid no help at home
Not happy that since being excluded from a specialist school he has only received part time education and even now at post 16 it's only 2 days a week	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
Pulled out due to disregard for medical and asd needs	Since being at a specialist school ,my daughters needs are met
"There has been promise of a lap top yet none has been given."	I am happy
I get a weekly update from TA and have good communication with school	Doesnt get no support as a family even though we state we are struggling to meet his needs as we dont understand him and he cant maintain his emotions meaning he goes into melt down
My daughter attends College 2 days a week but this is the maximum provision available.	Primary school support was lacking.  Secondary school support has so far (4 months) been awesome.
She is in year 2 of her course and i will start enquiring about next steps on her return in January. It is not immediately obvious	City College provides excellent support for my daughter
I get a weekly update from TA and have good communication with school	Not in education anymore.  However, when in education, we met many times with SEN in schools but the help was minimal at best
My daughter is 4 years behind her learning age. She has learning and physical disabilities relating to two rare degenerative diseases that were diagnosed through genetic testing in March	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!
Not always listened too	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
We have been fighting for additional support for the past 7 years. We have finally gone to First Tier Tribunal, and the therapists engaged by the LA are identifying 'significant and wide ranging needs' and 'clinical' need across a number of areas.	I'm waiting for his ehcp which haven't got yet.
I am pleased with how he has settled but he was sent home on the last day of term due to sensory overload meltdown and I'm worried	it's shocking

about the new term and how they will deal with his behaviour/needs.	
Sons SENCO is brilliant, the teachers are great and have done so well with all the covid changes	My boy has been in alternate education for almost 2 years and no plan has still been made to move him forward
	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 CAMHS or the LA attended
	It's really hard to get the real help we need as my daughter masks so much at school
	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.  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.
	Educational facility is not able to deal well with SEMH issues.
	The school he attends doesn't support his emotional and social needs
	He is not happy in school
	Lack of specialist post 16 for autistic young people is a significant gap in PBO

**Table 1: Educational Support**

<b>Health Experience 20/21</b>	<b>Health Experience 21/22</b>
Need to see specialists for behaviour and also physical disability	We are not offered support despite requesting it multiple times
Inadequate provision for mental health issues that aren't life threatening	I have always found health services great for xxxxx, he has had his condition since birth and been a learning curve for us all
After my son was diagnosed I had a support worker and she was brilliant. She helped me to identify my son's needs as I didn't have a very good understanding of autism at the time. She helped me to identify triggers and positive parenting skills and I can't thank her enough for her support. I was very sad when she had to leave working with the family due	I used to have a family support worker for autism and she was brilliant but cut back 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

to cut backs in social support. I think this support is vital as like me many people out there won't have an understanding of autism until they are guided and supported. Having a child with additional needs is hard enough but if we don't have that support in place then it makes it even harder. When I recieved the support I had noticeable changes in my sons behaviour and i was able to help support him more. Happy mummy happy son. He still had meltdowns of course and temper tantrums like any child but I was more able to deal with it.	isolated and alone in coping with the needs of SEN children.
VI contact very helpful. Moorfields Hospital is very professional.	Don't take me seriously no support at home no follow up assessment
We are under st Mary's and pch adult service now and its amazing the difference from children's service that was lacking badly	NHS SaLT do not assess accurately based on child's needs, but on their local resources.
I took my daughter for a hearing test which she passed. An auditory processing assessment was refused due to cost. GP explained that assessments only available out of county, was told to ask school. School refused . No diagnosis.	A struggle since moving here.
Difficult to get helpful insight into menstruation issues	Health services are good
Not interested in general and keen to discharge her. Even though it is a life time condition that has no cure currently	We use school nurse and get nappies no problems
Very frustrating	He was under camhs but since age 14 we haven't heard anything from them
Taken a LONG time to get support, still chasing our tails to get the right team to speak to us.	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.
We have requested support for SEMH over a number of years but this had come to nothing so far.	shocking
Salt was stopped due to covid and now he is in school I get no communication from his SALT and I would like ideas to do at home and have always insisted I am included. Seems I have been phased out now he is in school, this isn't helpful to him.	We don't hear from camhs
GP refused umpteen times to refer for diagnosis. Neurodevelopment team refused 3 times now over the years to assess despite private assessment which identifies possible ADHD and suggested local diagnosis.	No help services and no help with housing
Need to see specialists for behaviour anf	NHS salt and OT significantly underweight in

also physical disability	PBO- do not accurately assess child's needs but rather dictated by their local policy and preference on what resource to allocate
Inadequate provision for mental health issues that aren't life threatening	
After my son was diagnosed I had a support worker and she was brilliant. She helped me to identify my sons needs as I didn't have a very good understanding of autism at the time. She helped me to identify triggers and positive parenting skills and I can't thank her enough for her support. I was very sad when she had to leave working with the family due to cut backs in social support. I think this support is vital as like me many people out there won't have an understanding of autism until they are guided and supported. Having a child with additional needs is hard enough but if we don't have that support in place then it makes it even harder. When I recieved the support I had noticeable changes in my sons behaviour and i was able to help support him more. Happy mummy happy son. He still had meltdowns of course and temper tantrums like any child but I was more able to deal with it.	

**Table 2: Health Support**

Generally from the number of responses provided, access to health provision and CAMHs are viewed far more negatively than positively across both years (20/21 and 21/22) being compared. Waiting times, assessments and how needs are viewed seem to be the main areas of concern. 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.

As with all reporting thus far the trend continues with a decrease in positive experience and an increase I negative experience, in this case in relation to finding information. See fig. 39 as a clear example of this trend.

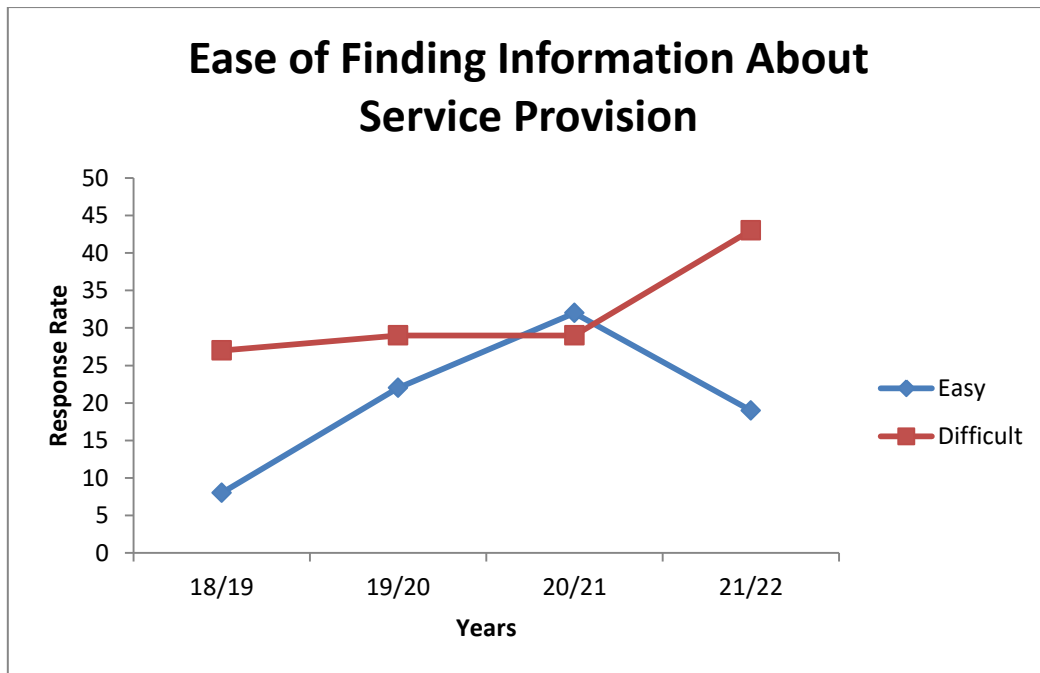


Fig. 39 Ease of finding information

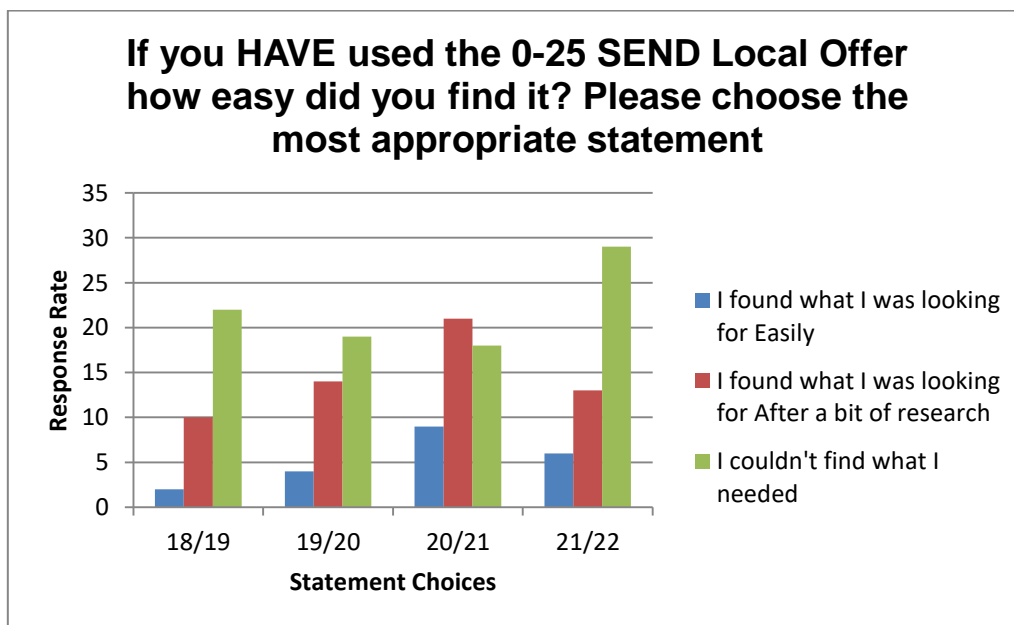


Fig. 40 Ease of using Local Offer

Again respondents are reporting more difficulty rather than less in finding information especially when comparing data between 20/21 and 20/22 which shows there seems to have been a shift in either the cohort responding to the surveys and/ or how people are feeling about and experiencing SEND more generally. The main factor worth noting is that the last two surveys have been completed during a period of intense upheaval for families locally and society more generally due to COVID, and this may be contributing to how people are responding.

Further to this respondents were asked to provide a general overview of how they feel SEND has changed from 2015 onwards.



It is easier now but still a bit daunting

Post 16 autism specialist provision is a scandal.

Very positive and supportive. Explanations are given with clarity and they are always willing to challenge the school if required

I don't know what the local offer is. my son was excluded from a special school and we had to fight the LA for 2 years to get him a place in college

I have been fighting for my boy who is now 9 to be assessed since year one

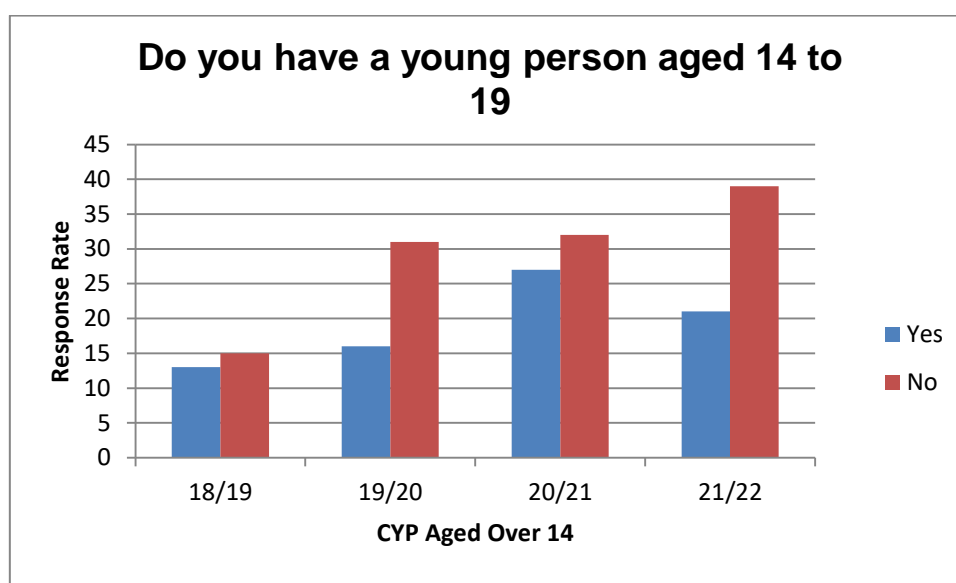
rubbish hard work judgement

I don't know what the local offer means. we were under camhs but it .....out & we don't receive support from anyone. My son has been given a .....year from college after he didn't attend because he broke his hand and needed two lots of surgery & metal plates in his hand. Was given a drs note but still threatened with exclusion although his on a sports course

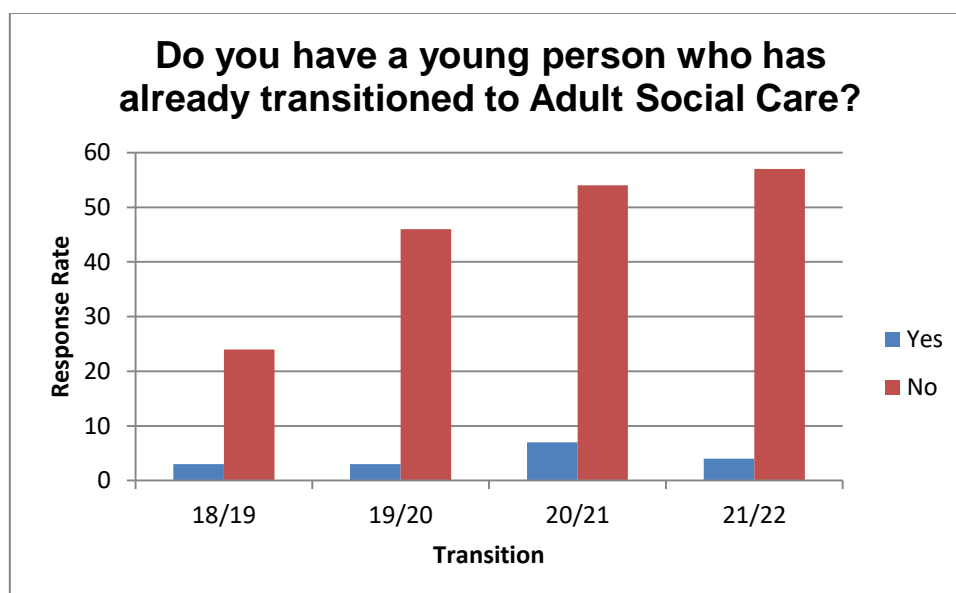
Really hard to get hold of anyone. Really struggled to understand and become familiar with the process. Found no one could meet the needs of my child so no help could be received

No help for our child even with ehc plan

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 lack of information.



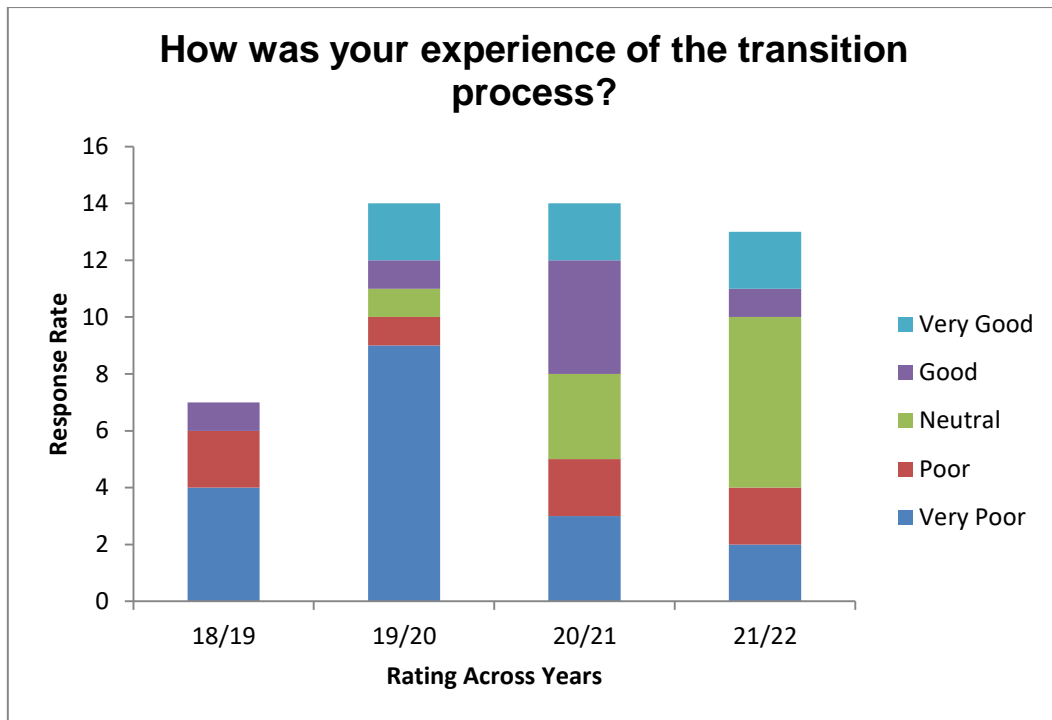
**Fig 41 Number of CYP aged 14 to 19**



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

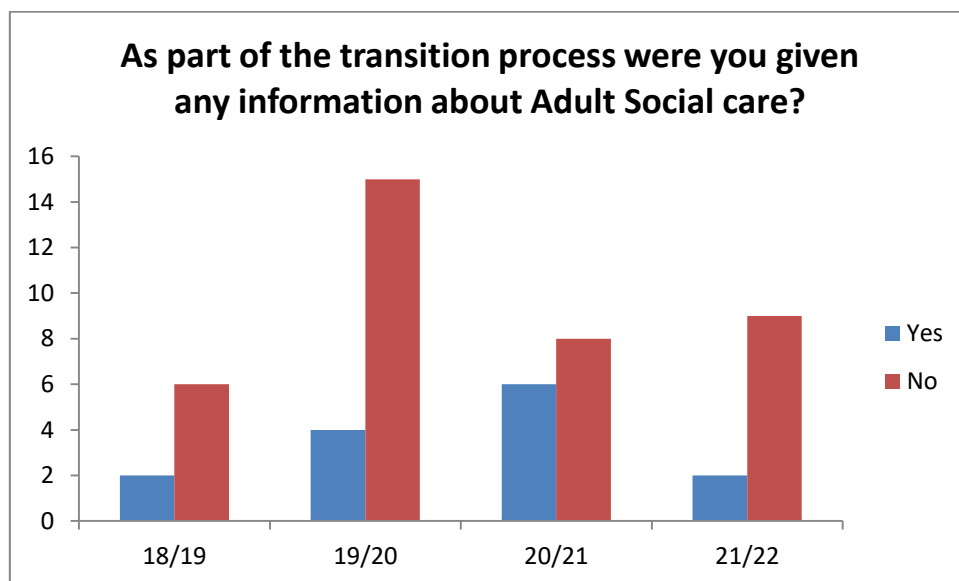
Figs. 41 and 42 show a decrease in numbers who fall under Preparing for Adulthood (PfA) and an increase in numbers who have not transitioned yet which fits with the change in age range of CYP of those completing the survey for 21/22 as mentioned in first section of this report.

A comparison across years is a little more problematic for this question, due the increase in numbers of overall respondents who have CYP who are not yet preparing for adulthood, and also the lower numbers who access social care more generally. Of those who have answered there has been an increase in choosing 'neutral' as an option. There has also been an overall decrease in the number choosing either 'good' or 'very good' to rate their experience in this area.

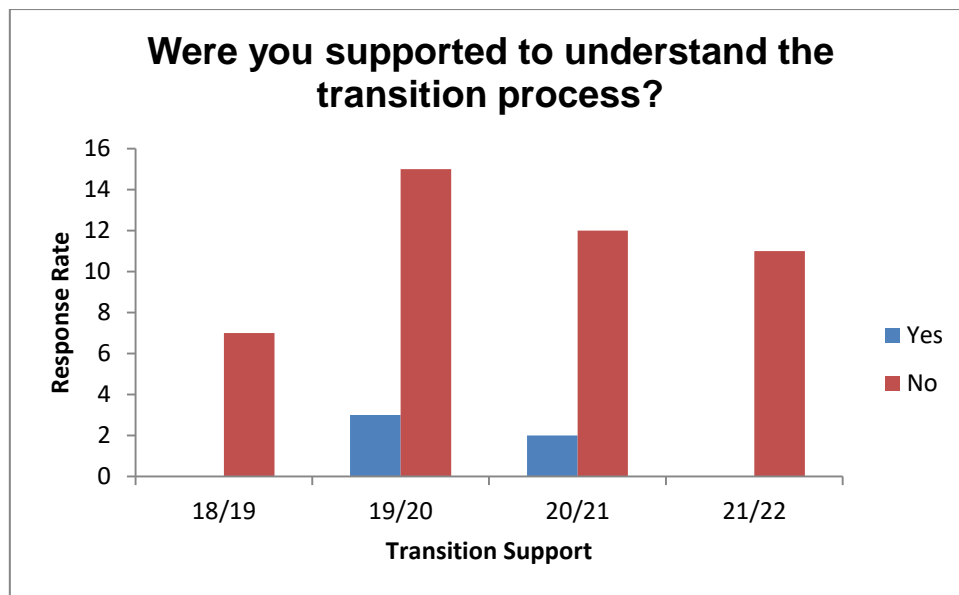


**Fig. 43 Transition Experience**

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.



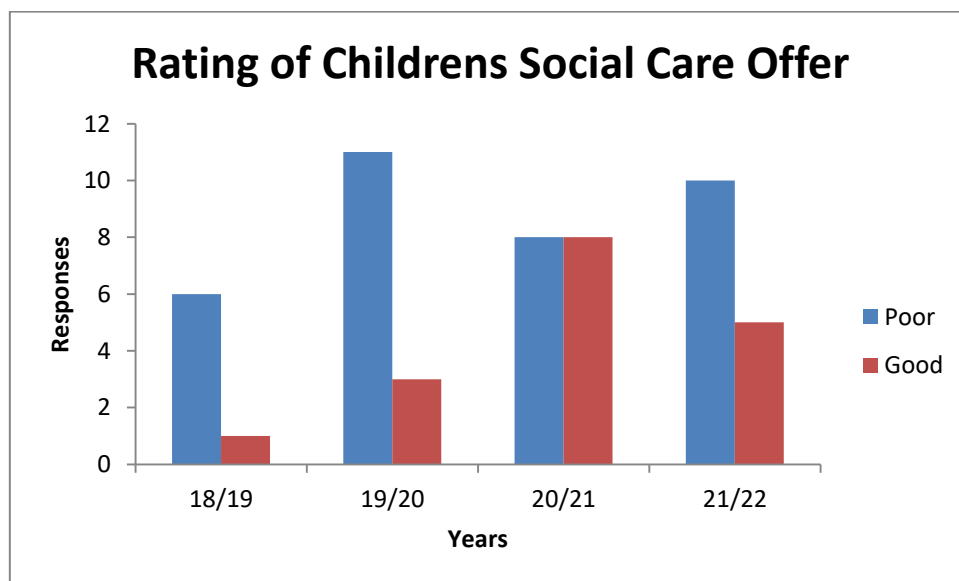
**Fig. 44 Information provided regards Adult Social Care**



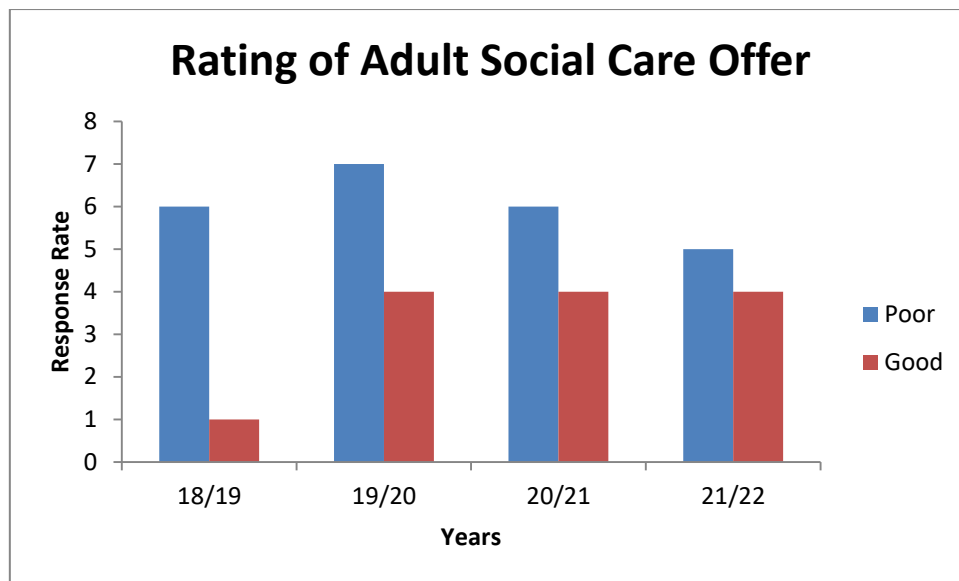
**Fig. 45 Support to understand the transition process**

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 ask to provide more general views the following comments were shared:

Slow to act no support  
no follow ups  
assessments

My daughter is generally well supported in independent living except for support with healthy eating and consequently she has put on a lot of weight since moving in 18 months ago. I have raised this many times and the point is acknowledged but minimal action taken

The child used in this survey is not under social care. I do have an older child who is...due to a brain tumour at 15 and resulting in life changing disabilities and needs. Child social care was fantastic.....as soon as he came of age however, the resources and help stopped with one phone-call after another and we were lost in the system straight away. I had to fight for adult social care independently and the help received now is very poor.

Social services do not take your whole family into consideration and how it effects everyone's life. You're just left drowning and no one really cares. If you do ask for more help you are made feeling guilty and inadequate.

We have 4 children with Additional needs and have never been offered any help from social care

## Carers Support

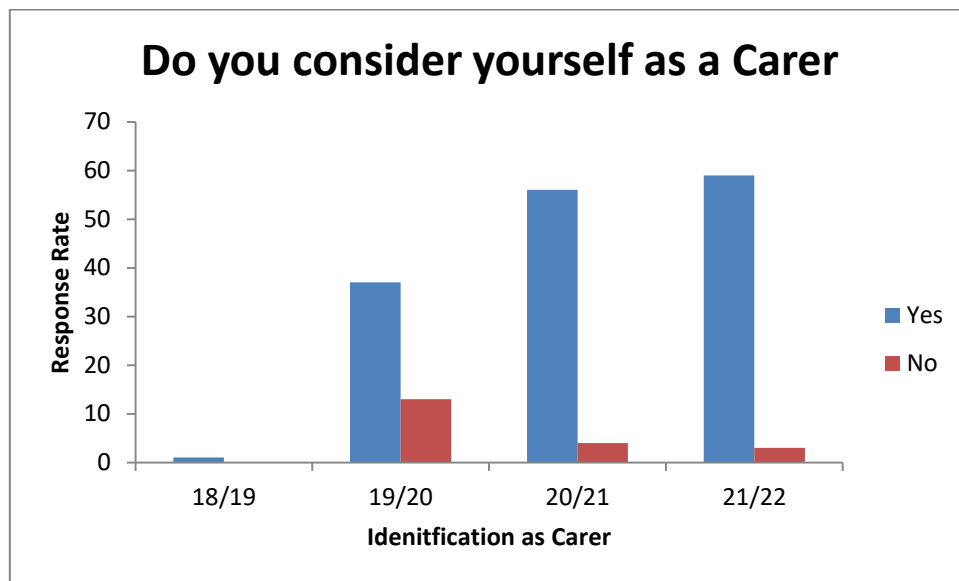


Fig. 48 Self Recognition as a Parent Carer

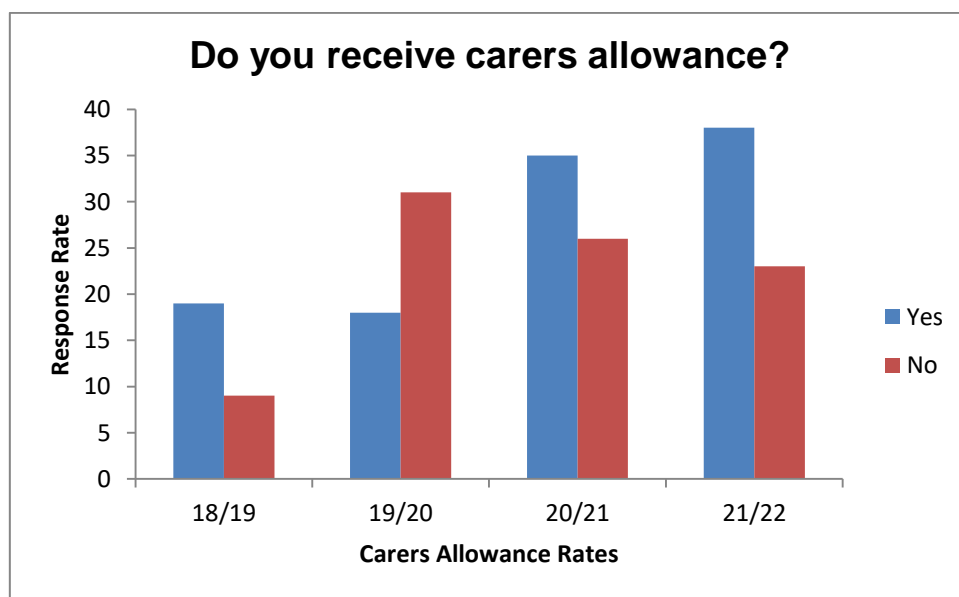


Fig. 49 Receipt of Carers Allowance

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 also been an increase in respondents stating that they claim carers allowance.

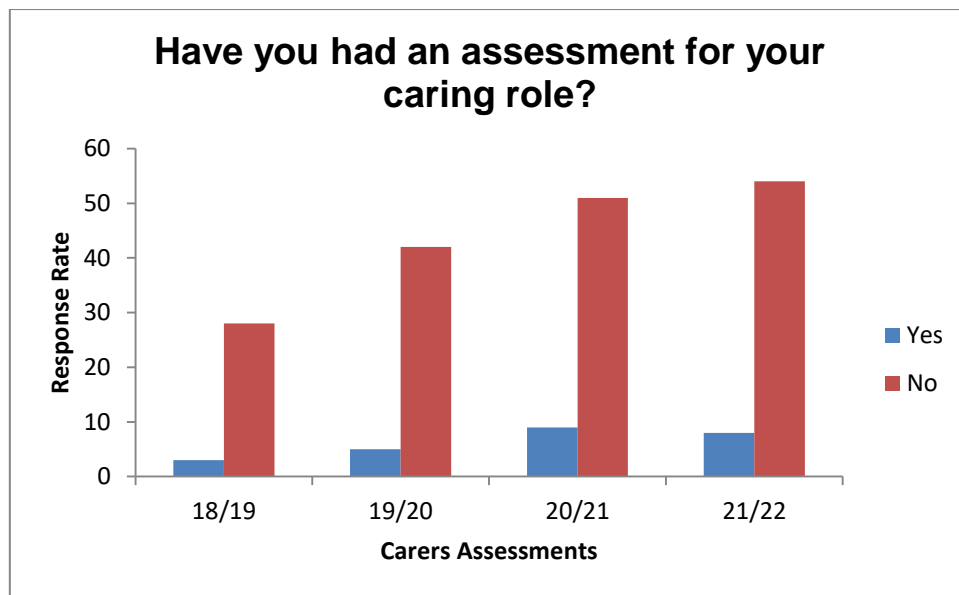


Fig. 50 Carers Assessments

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.

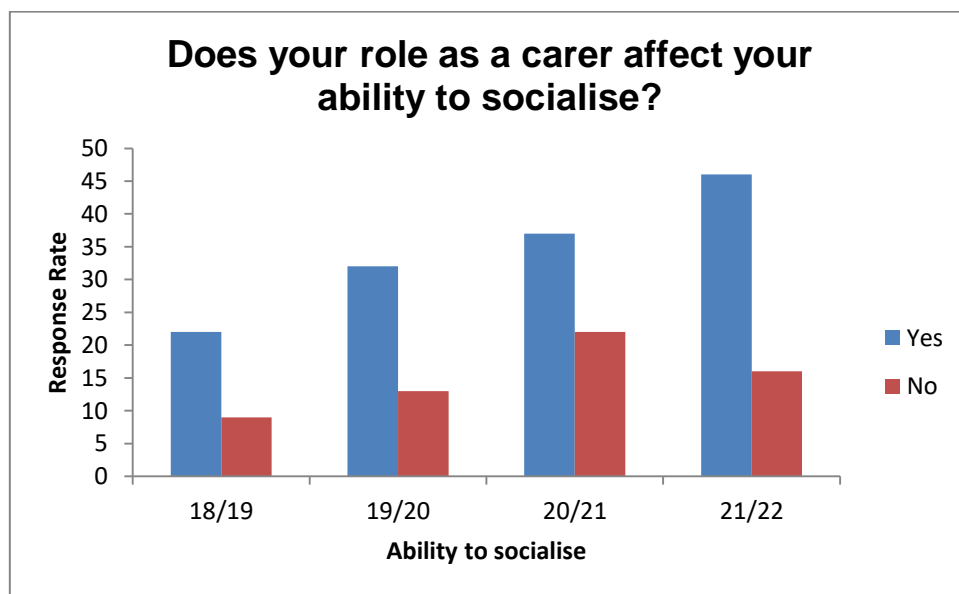


Fig. 51 Impact on socializing

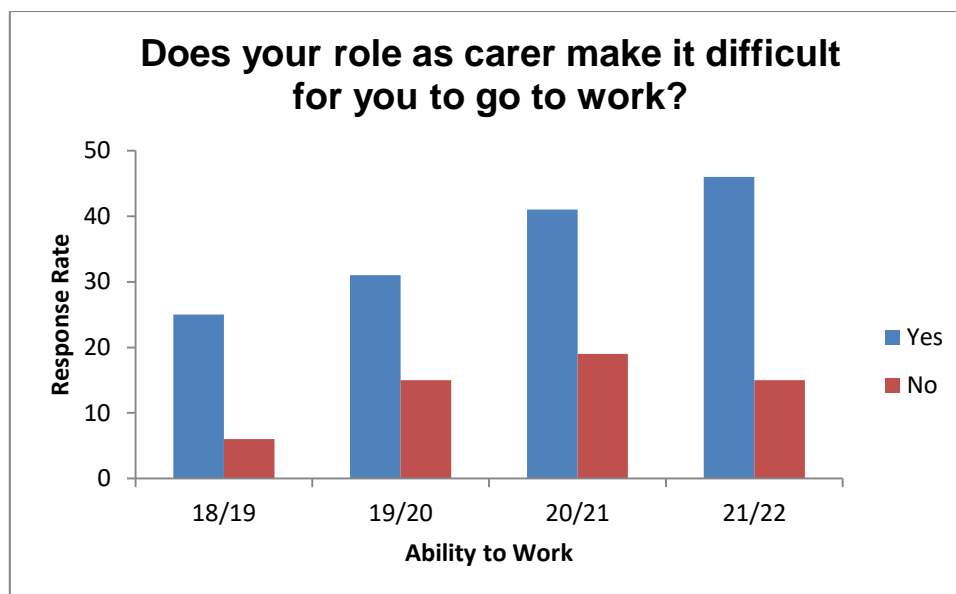


Fig. 52 Impact on work

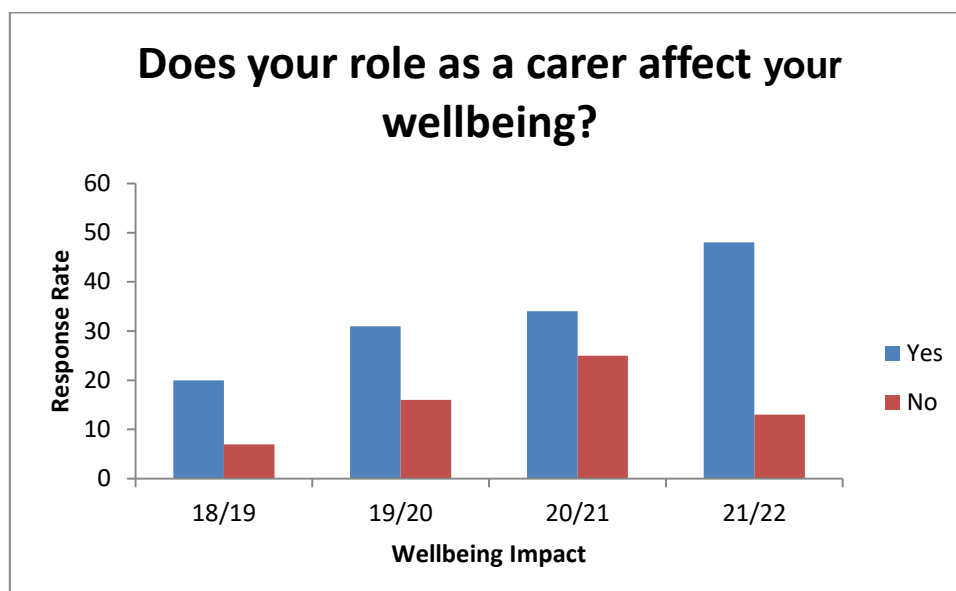


Fig. 53 Impact on wellbeing

The final part of the annual survey for 21/22 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**

- *Some school SEN support is dire unfortunately. Leadership teams are dismissive and discriminatory.*
- *Told xxxx doesn't fit the criteria as they feel he isn't ill enough to leave family unit at age 8 yrs old*
- *Affects my well-being in terms of that it can be challenging but parenting a child is challenging regardless of SEN or not i guess it's just a little trickier sometimes but we get by.*



- No one experienced to look after my kids in holidays no clubs for non-verbal children no care needs so no where to go
- Post 16 specialist autistic provision needs urgent investment. MHA should be extended to include 16+ as it used to be.
- Slow at getting things done
- I struggled with getting nappies, im short this month because they wont cover the cost when i sent invoices to ..... they were the cheapest that week so he's short. Gave up arguing almost straight away. Diagnosed with depression again. No help for people like me who live with someone. Son becoming for aggressive at home, broke my teeth head-butting me but because i live with someone no free dental so walked around for months in pain until my dad paid for me to go. No care and no support for someone in my position. I get no downtime from my son except when he is at school and that's if he stays.
- We received ehcp.
- Its gets lonely but my son needs my full on care and 1 on 1 attention
- "Long road to diagnosis then no support given.
- Was lied to by SEN in secondary education.
- Felt I didn't have enough personal information to apply for EHP as a parent /carer but Educators gave the impression they would help but couldn't be bothered as it was a long process"
- I get told no alot so i gave up looking or asking.
- Nobody works together
- it's draining and gets you no where
- The sen service have been very supportive recently regarding finding a new placement for my son
- I am unable to work as I have 3 children with needs. (Two with autism/adhd, one disabled with cancer) I obviously only get Carers allowance one child which is hard. I also have to be the taxi PA for the two ASD children for school as the Local Authority were unable to meet their needs for transport and would be in breach of their EHCP. There are no clubs at their special school to allow me to return to work and their needs are too high to be able to use private childcare.
- It is easier to get help for a child with complex needs in the early days. However if you have a child with SEMH the help is non existent and you're left trying your best to keep your child alive whilst completely ignoring your own life, needs and help. Social Care is awful, social workers change constantly and no one really cares about how you're coping as a family etc.
- Carers assessment refused our disabled child sharing bedroom with sister no one cares
- Medeshamstede Academy needs to revert to post 16 provision as this is a significant gap

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

- Early parental involvement in designing and reviewing services. Not as an afterthought or tick box exercise.
- Social care needs to meet the needs of families who have disabled children
- More emotional and mental health support for SEN children in a mainstream school. Guidance for them to help talk about their feelings and express this. Could be something like art therapy where they can draw their emotions to help label them and having someone to talk to like a counsellor type person. Someone who can check in with them regularly to see how they are doing as children with SEN can mask things and it can come out when they get home but this is not helpful in dealing with the problem there and then in the present when it is happening.

- *More quick response s to change updates more clubs for sen children to go*
- *More activities for non verbal children has no support for holidays or no people to look after my kids at clubs as cannot look after themselves not trained*
- *I dont know what they are as far as i know there is no services that are of help people in my position.*
- *Can be bit fast*
- *C/yp with UNcomplex /hidden disabilities/needs should be given the same chance to apply for and receive help and support and this didn't feel it was*
- *"Make respite for single parents with no help easier to access. When you get £67 per week carers allowance and have bills and a severely impaired child to care for i cant afford 10 per hour which equates to hundreds for a night off.... only ten more years old soul destroying headbutts, biting and scratching till hes eligible for some kind of overnight stays somewhere.*
- *Every questionnaire goes on about working... i care for my son 24/7, we are looking at reducing his hours because he is tired and done and keeps hurting me because hes moody. My mental health is deteriorating, i tried to find somewhere that does gym memberships for carers appears its not a thing because physically im not strong and my son is getting big. Its all great with people saying they worry about me because hes going to seriously hurt me when hes older and im small and weak but that doesn't help me. I care for him, he has everything he needs, im a brilliant mum but sometimes a little help, or being able to do something for myself that isnt getting shopping, cleaning and all the noise done before he gets home would be nice.*
- *I dont know much but some kind of health ans wellbeing provision would be good be it gym or swimming so carers can clear there heads but there is nothing. I dont want to have to take medication for depression again but its looking like the path ill have to visit again. "*
- *Drs,college tutors need to work together.As turning up at a review with someone that's never met your son or yourself is pointless.*
- *listen and help stop saying NO!!*
- *I think all services need to work a lot closer together.Once a child is under camhs parents should be advised of every bit of support they can get & where to access support.*
- *"Support for parents who do wish to work and need to work. Better understanding of what's written in the EHCP for needs when it comes to council transport. It shocks me that so much is placed on the schools to fulfil careplans and to ensure staff are trained and qualified... but it suddenly doesn't matter when it comes to transport. They are basically suggesting the child has no need between point A and B and an unqualified taxi staff member is adequate to understand and safely look after a child with complex issues only professionals are able to cater for.*
- *Time scales for referrals and seeking help are also really poor and are confusing to parents who do not understand how the system works. "*
- *For an ehcp to be a basic human right of the person with sen, to have a ehcp has part of the diagnosis*
- *Give some help to parents? Give some free swimming free activities help with housing it is hopeless living here*
- *Medeshamstede Academy needs to revert to post 16 provision as this is a significant gap*

## 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 less satisfaction with the SEND system currently compared to an increase 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 point towards three broad areas of concerns:

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

There is also a growing sense that parental mental wellbeing is being impacted more often than not and worryingly some reporting of CYP aggression against their parent carers. There is interplay amongst the various areas of SEND (Education, Health and Social Care) and wider community support/ provision.

Preparing for Adulthood (PfA), is an area that would benefit from further exploration, as this is viewed most negatively based on the survey results. This is especially in relation to the 'social care offer' and wider 'community provision'.

## 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:

- SEND Communication - LO
- Parent Carer Resilience
- PfA – Young Person to Adult Domestic Violence
- PfA - Wider Support/ What is Wanted