
SEND In Peterborough & Annual Survey Comparison Report

An analysis of how families are experiencing SEND across Peterborough based on annual survey comparison data and other sources of information.

Parent Representatives

Executive Summary

The purpose of this report is to inform all parties with an interest in SEND of the feedback that parent carers have given Family Voice Peterborough (FVP) over the past six years with a particular emphasis on their lived experiences of changes in the SEND system over the past 12 months. FVP's hope is that SEND system leaders will affect positive change that enables parents carers to have better outcomes for themselves and their families.

The information has been collated from a number of sources over the past six years, that FVP has gathered from parents and Carers including the annual survey that takes place yearly.

In 23/24 FVP have engaged with 345 known individuals and an additional 351 have taken part in anonymized surveys. From the numbers that have engaged with FVP from the 1st April 2023 to the time of this report, there has been an increase in engagement particular from seldom heard groups.

The Data Clearly demonstrates there is much more strain in the SEND system and comments from respondents are mixed this year with a general move to more negative reporting.

From all the data reviewed most of which has been presented in the full report there are a number of broad themes coming through:

1. Parental blame – for example being seen as a burden, drain on resources, negative and part of the problem, being made to do parenting courses that are not appropriate to SEND, parenting courses make parents feel they are at fault.
2. Lack of support – managing benefit changes, applying for an EHCNA, mental health management to name a few, support after diagnosis
3. Lack of involvement in decision making, support planning and areas of EHCp outcome monitoring.
4. Difficulty in finding Information – you don't know, what you don't know!
5. Lengthy waiting times - Waiting too long for access to assessments and access to therapies and other forms of support once assessed.
6. Preparing for Adulthood – Not knowing what entitlement may be for access to services, having to self-refer to the 0-25 team, lack of access to transitions officers, impact of benefit changes, '5' day offer and other matters.

The Report suggests ways forward and makes recommendations based on parental request on types of support they would value

FVP would ask that the following recommendations be taken under consideration:

- SEND Communication be considered as a priority for strategic leaders, with a refocus on the SEND Strategy and Action Plan.
- key support initiatives be delivered by the LA/ Health
 - Face to Face befriending (Peer to peer support)
 - Benefits Advice and Support (DLA to PIP)
 - Independent Support (EHCp process)
 - SEND Navigators (support) to find information to help parent carers
 - Development of a resource for new SEND households (Welcome to Your SEND Journey)

- Ongoing opportunities for parent carers to shared their lived experiences directly strategic leaders
- A group to be set up for various group leaders to work with FVP to bring forward the lived experience of the SEND community
- Look at how third sector groups, and front line SEND charities can be funded or supported to gain funding to work directly in providing parent carers with support

Purpose

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Where the basic format of this report will follow previous formats there will also be some changes in that the core results from the survey conducted for 2023 to 2024 will be reported on alongside some comparative data. Where feasible comparisons will be drawn across all surveys conducted annually since 2018. The report will also draw on other sources of information and data FVP have gathered over the past financial year all of which point towards a far more negative SEND experience for local families.

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 and Resilience.

In 19/20 previous separate surveys were amalgamated and some original questions plus a set of new questions were used to create the End of Year Survey in its current format. 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 well with Preparing for Adulthood, Early Help and Early Support, Joint Planning and Commissioning (individual inclusion as well as strategic involvement and services working together).

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, the subsequent Written Statement of Action (WSOA) and ongoing Accelerated Progress Plan Work.

Annual Survey Respondents

The results from respondents are very mixed this year and there is a general move to more negative reporting. The survey being reported on runs from 1st of January to 31st January each year, and any response rates are related to this time period each year. The number of respondents is also variable from approximately 35 in 2018 to 249 in 2023 and now for this year down to 188 (2024). Last year there was a concerted coordinated effort by a number of LA/ Health officers to help increase reach, but this year the coordination has not occurred to the same extent. The respondents are from a range of households with many parent carers also having their own needs

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

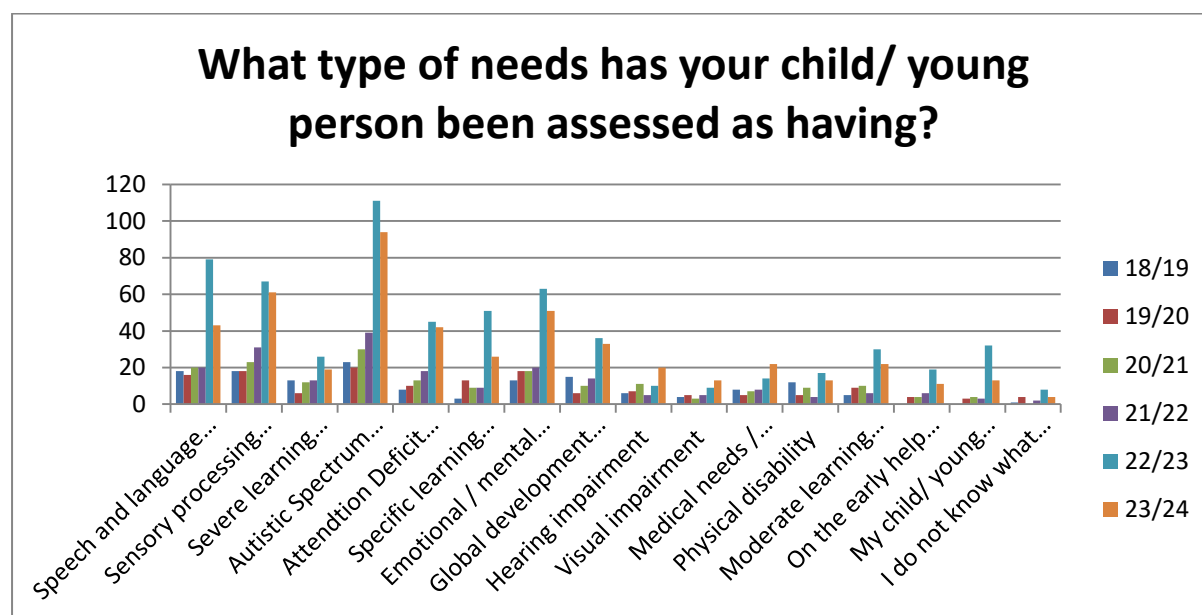


Fig 1. Areas of CYP need as identified by parent carers

In 22/23 and 23/24 the following have been listed under the 'Other' option with conditions such as ARFID being mentioned for the first time.

2022 to 2023	2023 to 2024
FASD	ARFID eating disorder , diabetes type 1
Downs Syndrome	Down Syndrome
Visual perception	Attachment issues
22.11.2Q Deletion syndrome /Di George's	learning difficulty , but would not class as severe
Tourettes, mixed depressive and anxiety disorder , seizure / absent type episodes being investigated	Anxiety
Chromosome Deletion	JIA
Significant early years trauma	Rare genetic condition – microduplication 3p26.3
Down syndrome	Acquired brain injury
Sensory processing	N/A
My child didn't speak very good	leukaemia
Anxiety	Eating Disorder – ARFID
Scoliosis	FASD
ARFID	ARFID – eating disorder
Genetic disorder	Downs Syndrome

Table 1: List of Conditions

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. In this survey and other sources ARFID is also being reported more.

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.

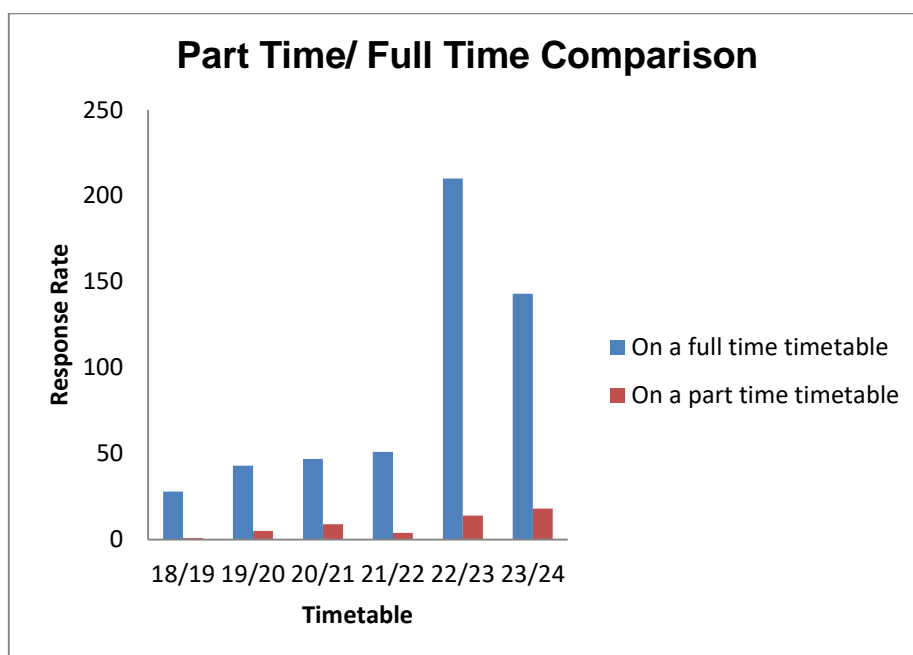


Fig. 2 Educational Inclusion

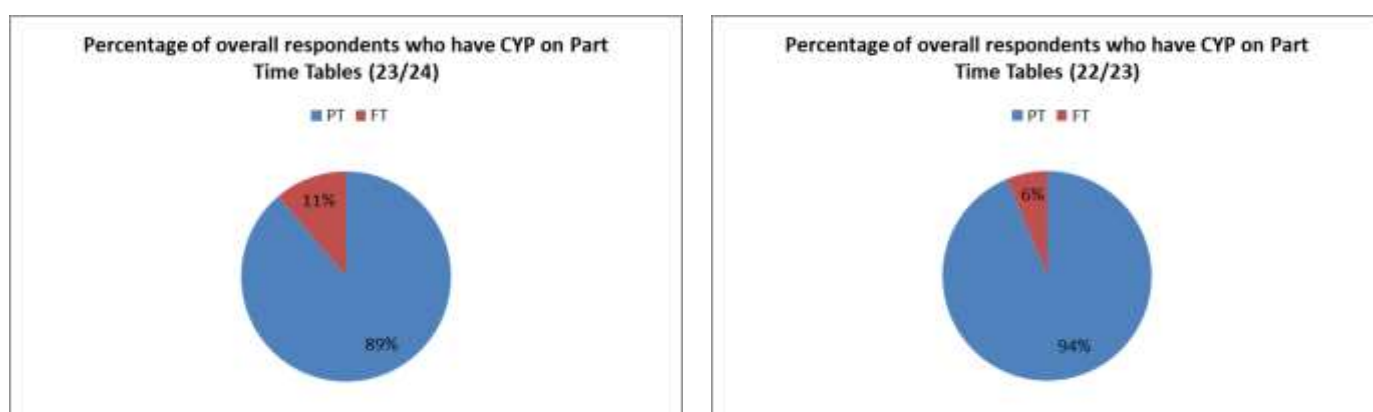


Fig. 3 Comparison of CYP in Part Time Education 2023 and 2024

It would appear from fig.2 that in 22/23 and in 23/24 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. However looking at the percentage of those on part-time timetables as part of the overall total across each year separately then it can be seen that more children are in education part time in 23/24 than previous years.

Previously it had been reported that the changing rates in a reduction of part-time timetables may be due to efforts by PCC to reduce the number of part time timetables as part of their Written Statement of Action (WSoA) work. The data this year however is showing a shift towards more part-time timetabling despite the work conducted previously. This may be reflective of a national trend which the PCF are picking up from anecdotal data being shared in various online sources.

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 are large increases in CYP being reported as being between 5-10 and 11-15. Also between the 22/23 survey and 23/24 there has been an increase in respondents with CYP in the 19-25 age range.

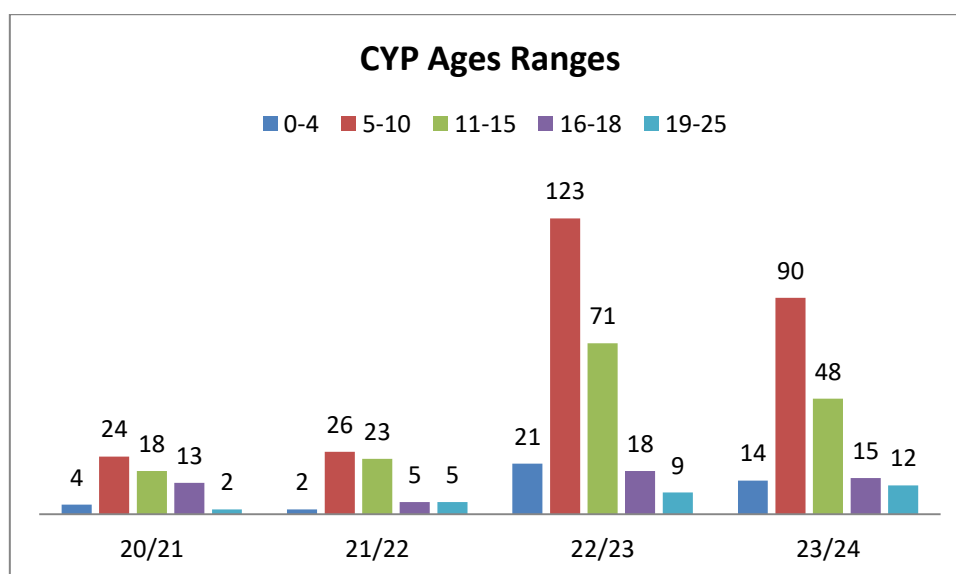


Fig. 4 CYP Age Ranges (20/21 to 23/24 Annual Surveys)

Having parents whose CYP are older 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 decrease in positive reporting over time especially in areas relating to PfA.

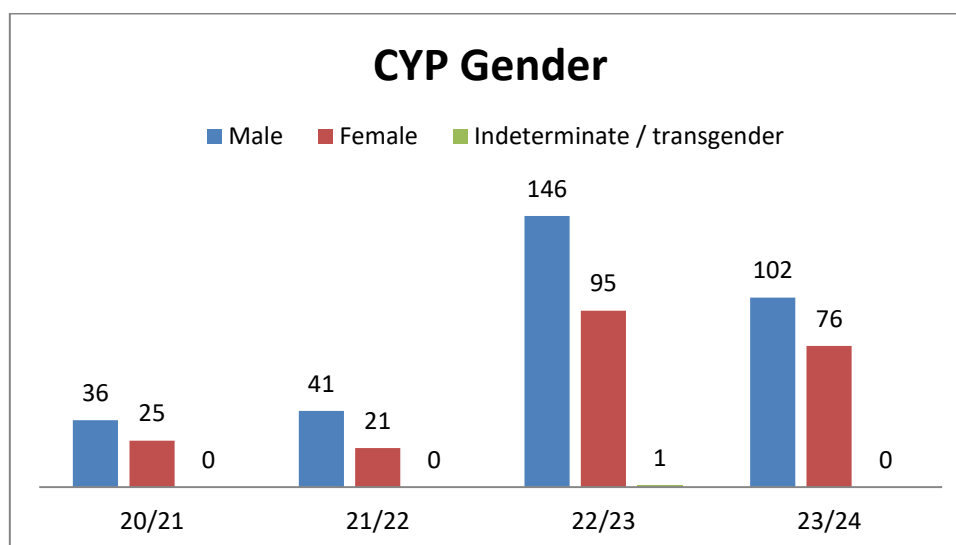


Fig. 5 CYP Gender

Overall across all years the majority of respondents are more likely to have CYP declared as 'Male' with needs.

This year's survey also demonstrates a continued increase in engagement from seldom heard parent carers from 2020 to 2024 (see fig.6); 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 23/24 the split is approximate 72% to 28% with 'White British being the higher percentage. This is relatively close to the latest census figures

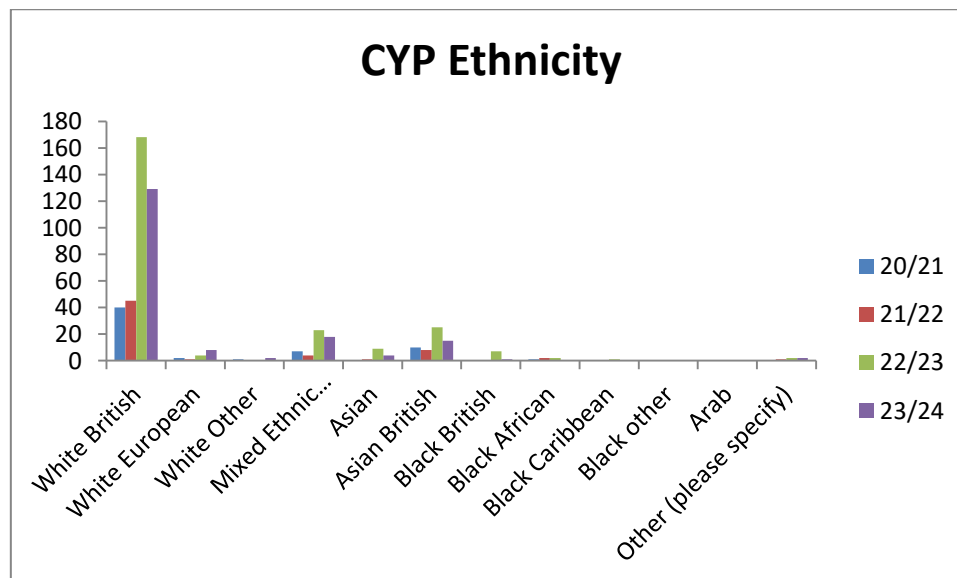


Fig. 6 CYP Ethnicity (20/21 to 23/24 Annual Survey)

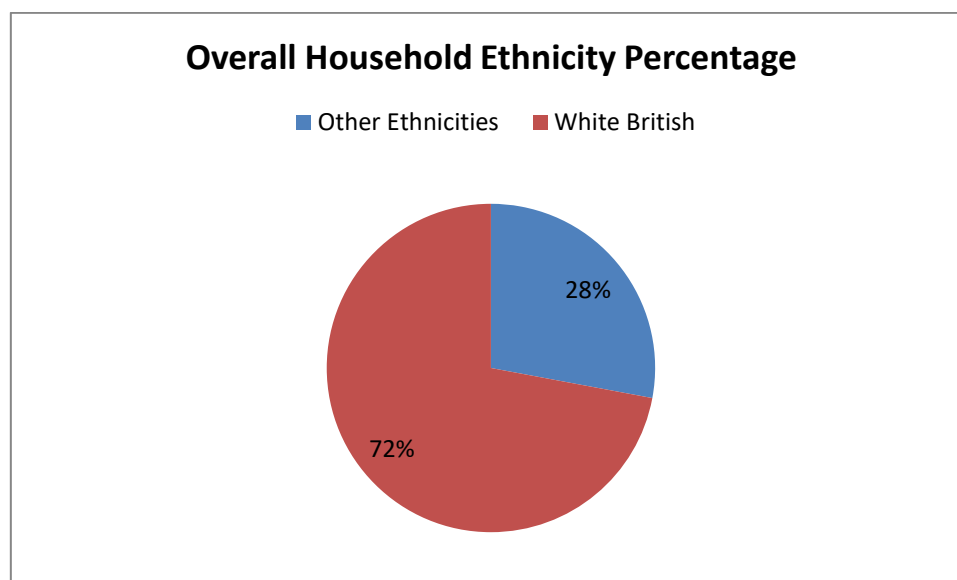


Fig.7 Overall percentage of household ethnicity

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 or 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. 7 and Table 2 & 3 below it can be seen that there is across most areas what may be considered a 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 take part in parenting courses that it is felt are not relevant to the needs of their CYP. 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.

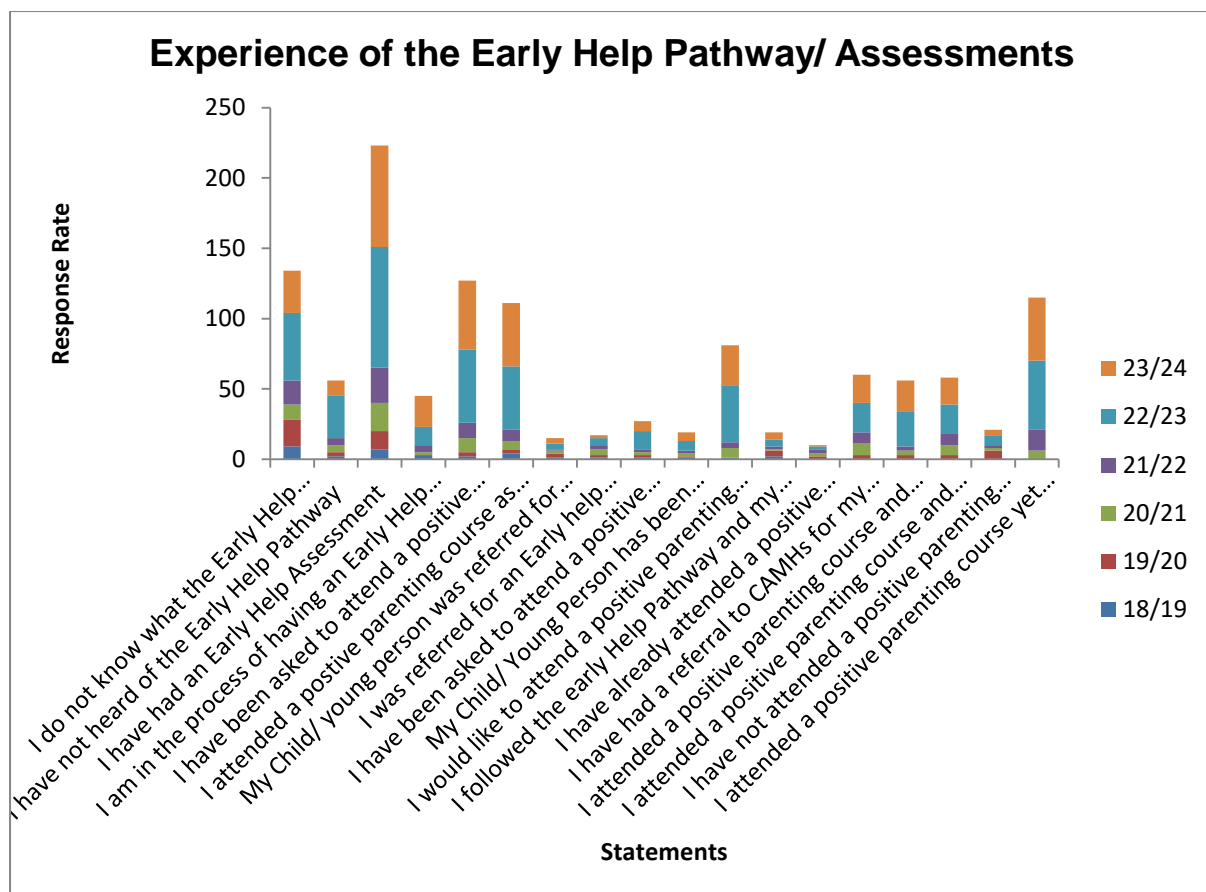


Fig.8 Early Help Pathway Understanding/ Experience

	18/19	19/20	20/21	21/22	22/23	23/24
I do not know what the Early Help Pathway is	9	19	11	17	48	30
I have not heard of the Early Help Pathway	2	3	5	5	30	11
I have had an Early Help Assessment	7	13	20	25	86	72
I am in the process of having an Early Help Assessment	3		2	5	13	22
I have been asked to attend a positive parenting course as part of my Early Help Assessment	2	3	10	11	52	49
I attended a positive parenting course as part my Early Help Assessment	4	3	6	8	45	45
My Child/ young person was referred for an ASD/ ADHD after my Early Help Assessment	1	3	2	1	4	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	2
I have been asked to attend a positive parent course even though my child/ young person has a	1	2	2	2	13	7

diagnosis of ASD/ ADHD

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 6

I would like to attend a positive parenting course but do not know what I need to do

1 0 7 4 40 29

I followed the early Help Pathway and my child/ young person now has a diagnosis of ASD/ ADHD

2 4 1 2 5 5

I have already attended a positive parenting course but I have been asked to attend another one

2 2 3 2 1

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 20

I attended a positive parenting course and found it helpful

3 3 3 25 22

I attended a positive parenting course and it has not helped

3 7 8 21 19

I have not attended a positive parenting course as this does not apply to me/ my family

6 2 2 7 4

I attended a positive parenting course yet my child was refused a referral for ASD/ADHD diagnosis

0 6 15 49 45

Table 2: Early Help Statements

Working Well	Even Better If	Other
I learnt to keep calm	Parenting course was generic on how to communicate with a baby - this was not relevant to our family as we know how to communicate with babies. I wanted something tailored to my son's needs.	I never was offered anything to do with early help pathway
Early Help pathway team was quite helpful. They referred my daughter to quite a few places where we got help. Thankful to them.	Very long process, school didn't agree with me and fought it. Now going through same with my youngest and school blocking pathway	To be more accessible for working parents
Early Help pathway team was quite helpful. They referred my daughter to quite a few places where we got help. Thankful to them.	Aimed at toddler age children. Many of the strategies were things tried when my child was 2/3. There were some little nuggets but I wouldn't say it made the parenting course valuable. I don't know what else early help is apart from the parenting course and a tickbox exercise to diagnosis.	Attachment and parenting course post adoption services
Good	My child was 9 years old when I attended the positive parenting course. As it was during lockdown the course was online. Having an older child with ASD I learned more from parenting him than the course. The course was much more suited to preschool age children.	We were provided early bird after diagnosis

<p>Early help and healthvisitors have always been amazing! I can't thank them enough for all their help over the years with my 2 younger asd children.</p> <p>And it helps to show me how to deal with his problems he had a lot of difficulties with different types of problems eating listen and can't sit for long and behaviour problems but I see how to deal with the problems and issues I get support for him so I work with the teachers and staff with any issues as parents</p> <p>Our daughter has been very well supported</p>	<p>My child has been on the early help pathway since 2020. It's a slow long process and is dependent on professionals knowing the pathway and their understanding is essential to avoid long delays. All professionals should be trained on the pathway and know who to contact to progress.</p> <p>My son went down the pathway for adhd/asd. We were told he dis not have adhd after the qb test and there would be no way he has asd as he has friendship groups, he now has a diagnosis of ASD. Since starting secondary school we receive much more support and now have an ehcp in place.</p>	<p>Currently waiting for support from xxxx</p> <p>Working with the cambs team currently have a case worker key worker for ongoing support</p>
	<p>Very long process</p> <p>It is very lengthy process</p>	<p>Currently going throughout process</p> <p>My daughter is awaiting referral for diagnosis and was turned down by camh. Is currently home educated as the school she was offered has advised it's on hold due to needed a fair access panel meeting</p> <p>Still waiting after 3 and half years for an ECHP to be started with my daughter in mainstream primary school</p>
<p>My son was put towards the Early Help Pathway in 2016. ***** was diagnosed with ASD in 2017. The pathway was useful as it helped draw out the main issues followed by parenting courses and health visitor visits before going to panel to be referred towards assessment.</p>	<p>Long process, then unnecessary parenting course (not aimed for children with SEN). While waiting to be referred to CAMHs, my child has is now got high anxiety, traumatized from school, ASD , SPD. The waiting time/list is long, once accept for assessment. Unnecessary processes, constant knock backs and more paperwork. From beginning our journey to get assessed, was 7yrs, not acceptable, these kids are suffering and need early intervention and support. There's only so much a parent can do, school and professional need to recognise accept referrals quicker, as being left causes high anxiety and trauma, and much more mental health issues..</p> <p>Takes a long time. Until your child has a diagnosis there isn't much help.</p>	
<p>The early help pathway are very good. I have another child on the pathway. This time waiting lists are a lot longer.</p>		<p>For my son to get his EHCP had to attend the parenting course and early help the process look about 2 years as first EHCP was refused I did a</p>

I was asked to do the positive parenting course but provided evidence of doing similar courses voluntarily in previous years and other courses relating to autism/ADHD so it was waived

It is a very long process for parents to go through to get help for their child, and to get a diagnosis for them.

Although we managed to get him diagnosed and on the road to the right support, it is a very long, drawn out process that takes its toll both mentally and physically on the parent. It feels as if you are constantly having to jump through hoops, to fight for help every step of the way and constantly having to prove the needs of your child at every step. It can feel like a very lonely path to walk. Even after diagnosis accessing the support is again long winded, very long waiting lists and more fighting. I wish this process was easier to navigate and you got support along the way, even if that support was just a quick check in now and again to see how you are and if you have any questions etc it would have felt like somebody was there in your corner. However all that being said I honestly can't fault any of the professionals that we saw along the way

Positive when opened but once closed due to ASD referral no contact or support while waiting

Apart from arranging assessments, I'm not sure what they do. No actual 'help' was given.

I had to attend the positive parenting twice, once for deaf issues, and once before CAMHS referral I did feel this was an insult to my parenting and once was enough.

SENDS course so I knew the laws and rights which got my son his EHCP because the council was NOT meeting his needs

I have completed a positive parenting course and had Early Help previously. Early Help has since been opened up again. We are awaiting appointments for ASD/ADHD and some support for mental health.

Not sure if I had an early help assessment, I filled in a form, attended parent course to go down the neuro development assessment pathway

More needs to be done for mental health.

Finding that children that are compliant within a school setting but have struggles outside of that environment fall into a 'referrals void' making the process for assessments and referral acceptance less likely.

I did an EPP course. Not sure if same thing?

I feel the parenting course, was unhelpful as these was everything I was doing. I knew my son was autistic and going on a course for Sen children would have been more helpful

My child was rejected for early help due to being a previously looked after child and receiving external psychological input from AdoptionPlus although that is not medically or professionally recognised in terms of diagnosis and assessments

Somethings are very repetitive and I feel if a child had an EHA some years ago (2yrs) a parent shouldn't have to start from the beginning to complete another, even if it was closed, it should still be kept on the system so it can just be updated with new information and re send

Went for a meeting with school back in September - already done the positive parenting course and then I've heard absolutely nothing from anyone. It's so long winded all I want is some

Support and appointment to help my daughter who I suspect has ASD want her supported earlier rather than later so having to wait years isn't good enough.

The Teen Triple P course I had to do before my child was even allowed on the pathway for ASD diagnosis was frankly offensive and of no help whatsoever for those with autistic children whether they are diagnosed or not. As a solo parent with no local support the course made me feel inferior to parents who have support. The strategies it wanted to be out in place exacerbated my child's anxiety, self harm and suicidal ideation. They were the wrong strategies for someone who is ASD with anxiety and depression and did more harm than good.

It takes too long, my health was a concern so my doctor got involved as well as the primary school, it took nearly 3 years to get my daughter diagnosed for ADHD she is now under CAMHS

It is out of date and it takes too long for it to be authorised by target support.

My child was added to the early help pathway twice and within week he was removed with no help from the service

Total lack of services available and very long waiting lists

I have a meeting tomorrow to start the EHA process

It seems like a robust system but the wait times can be disconcerting and cause anxiety.

Diagnosed before Early help came in

Had an assessment 3 months ago. Haven't heard anything at all moving forward.

We are currently going through this process now and the information collated on my child will be shared with a panel soon.

I have no idea what Early Help pathway is unless you are referring to ECHP? Information above is not really clear to me.

I have not had any response from them since it was sent through last year. I have been put

The positive parenting course had a lot of irrelevant information for example having a safe environment, putting bleach away etc.

I have been asked to do the parenting course but i work and can't get time off to go, i haven't been offered any other option.

Don't think it is applicable to do when my son is not really naughty he is the opposite to being quite and won't ask for help with autistic traits and can't write

Still waiting for my EHA which I have school consent for in September

I found the parenting course, triple p, outdated.

Especially the use of time outs for sensory overwhelm and subsequent meltdowns.

Early help pathway is a shambles. The delays in getting a child or young person assessed so they can get the proper support is nothing short of harmful. I see no harm in parenting courses etc during the wait but parents are forced to jump through hoops to get their child assessed. You also can't parent the autism, adhd or any other needs the child misfit have, can't be parented away. All too often parents are made to feel like they are to blame or at fault for their child's challenges. The child is left to suffer and the parent feels like a failure or that they are under the microscope or like a circus animal that needs to do as they are told in order to achieve the end goal. It's demeaning and not fit for purpose.

Please ensure that pathways are relevant to family and not a one size fits all approach. EG parenting courses not being appropriate or relevant to Adopters and/ or previously looked after children.

I found the parenting course to be unhelpful as the majority of things spoken about I already did as a parent. It made me feel inadequate and made me question whether what my child was going through was my fault, hence having to attend a parenting course. I think it could be named something else and cover topics that would be helpful for those seeking ASD diagnosis, eg more on challenging behaviour, sensory needs etc.

Lengthy set backs for referral for diagnosis although parenting course I have completed twice as my elder son has diagnosed autism, always keep getting rejections for further info 3rd time now Being assistant heads in our jobs and working with several young people with different needs, the parenting course was not overly useful and the refusal for neuro referral lacking school evidence was dismissed quickly even though it was clear we had concerns related to home and not school.

Early help pathway isn't really Lear in itself I didn't find much help at all, done parenting course twice still waiting on adhd referral, also they have said need educational physiologist but school have said this can't been as too many children
Not useful , they just allocated special school but not considered my suggestion of speech therapy .
Totally unnecessary to push parents onto a course years after it is relevant, and also upon 2nd diagnosis.

It takes far too long it took 3 years to get my daughter diagnosed with ADHD and anxiety
Both children been put on the pathway.. both have appointments for CSA but that's all the help we've been given.

Early help was stopped at mainstream school, without my knowledge, we removed him from this school due to bullying and him being hospitalised
We are still waiting for assessments. My child has a referral to the the child's development clinic in Peterborough but it's a 6-12 month wait for an appointment.

In my child's case, the school were pretty certain the outcome would be an ASD diagnosis & that a parenting course wouldn't benefit us. My partner had to take time off work unpaid & we didn't gain a single thing from the course, as not only had I already researched everything we were taught, it was too generic & a lot didn't really apply to my ASD child.

My husband and I have gone through the Triple P course and have been to a meeting at hospital with our child and have been told we will have to wait approx 1 year before he's seen again to do a further assessment to try and determine if he is adhd or high functioning autistic.

I don't think this is relevant for someone with mild dyslexia

A long process. My daughter was referred whilst in primary school, it wasn't until she had outside counselling from young peoples counselling that the referral for adhd was pushed. The process has taken too long and didn't send my daughter for an assesment until she was 13

Too little or insignificant. This was our experience with EHP

Everything was perfect up until ***** decided not to refer my child to a specialist

I am booked on a ASD and ADHD course (March and April) by CAMHS that I have yet to attend. My daughter has had 1 CAMHS appointment locally, as we relocated from Buckinghamshire (August).
We have had no further appointments, and the first did not go well.

I think this whole process is so long and prevents

children getting the diagnosis they need earlier. Issues were raised with school when my daughter was in year 1. The next parenting course was not starting until the October of year 2, so nothing was done. I then had to complete the 12 weeks

Of parenting before the Early help was opened. As my daughter was threatening to kill herself at the age of 7, we didn't have to complete the 6 weeks of embedding the parenting, but this was supposed to be done. Once panel decided we needed an appointment with the paediatrician we then went through the various pathways but didn't get the diagnosis until July when she was in year 3! School kept apologising that I had to attend the parenting course. I think there should be some way of bypassing this is school and parents agree that there could be neurological reasons for a child's behaviour.

As a family we were told early help would help in getting support for both my children but nothing was forthcoming other than an online triple p course aimed at toddler/preschool age my daughter was 10 at the time.

Table 3: Early Help Pathway Feedback

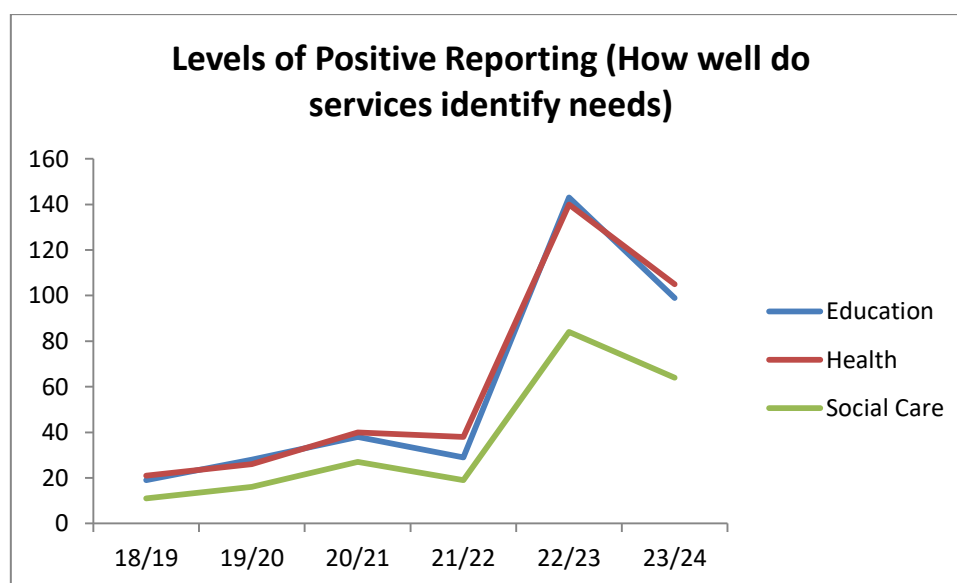


Fig. 9 Identification of Need by Education/ Health/ Social Care

Fig.9 above looks at how well respondents think their CYP needs have been identified by Education, Health and Social Care across the past few years. It would appear from a cursory examination of the data that overall there is a decrease in positive reporting identified from 22/23 to 23/24. When looking at the data in isolation from the last survey there is a slightly different picture in that where social care is viewed positively or negatively at the same level in respect of identification of needs across Education and Health a higher percentage of respondents in 23/24 report more negatively in relation to whether needs were identified well or not. (see fig. 10 and 11)

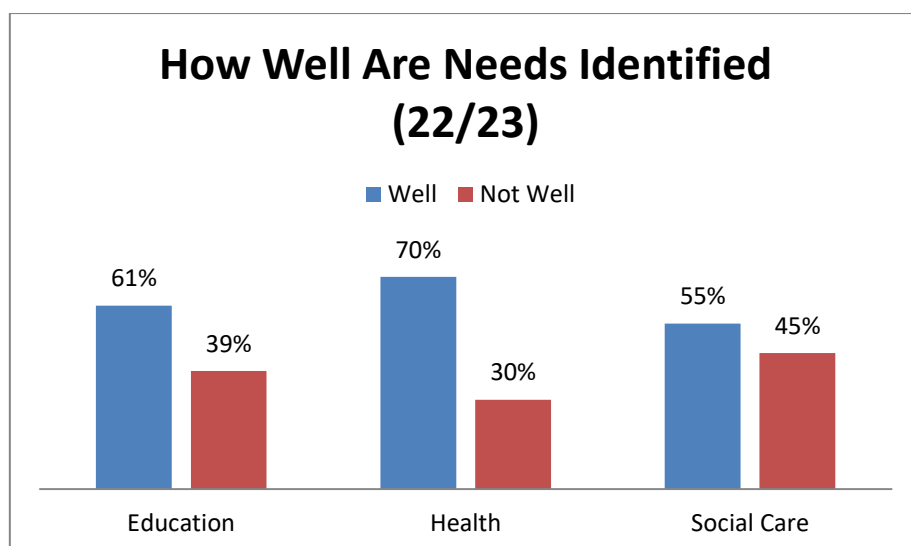


Fig. 10 How well are needs identified 22/23 results only

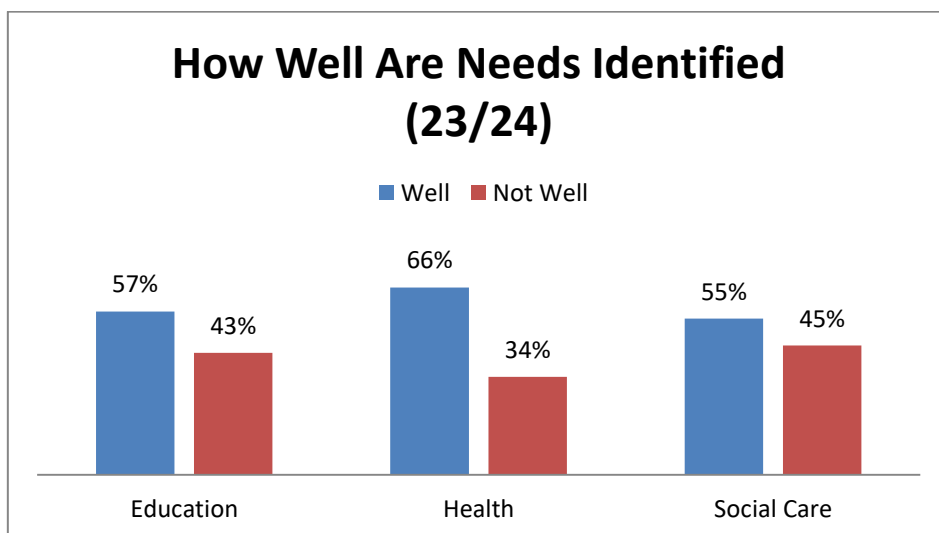


Fig. 11 How well are needs identified 23/24 results only

Further to looking at how well needs were identified parent carers were asked how well their views were taken into account as part of the process of identifying any needs.

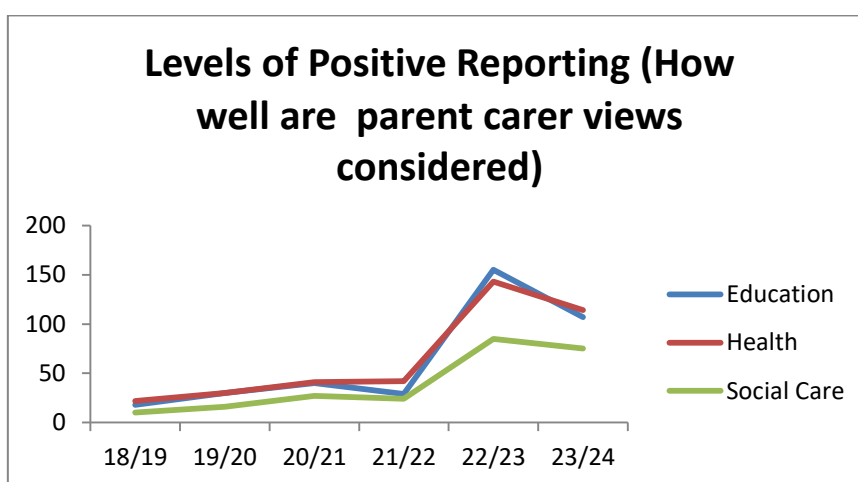


Fig. 12 Account of Parent Carer Views During Identification of Need

Fig.12 above shows a drop in respondents feeling their views were better taken account of well, which could viewed as drop in positive reporting.

This perspective from that parent carers that their views are not being accounted for has also been reported previously in a survey report and associated Topic of Importance (ToI) focusing on health inequalities. Previously 43% of parent carers reported not being listened to with one reporting:

I told them he couldn't take meds orally, but the nurse pinned him down, shouted at him, and tried to force him. He gagged and spat it all over her before she admitted defeat and we were left with nothing. He now screams at the mere mention of the word "hospital".

This also although not specifically about identification of need does still show that parent carer views can be disregarded by professionals.

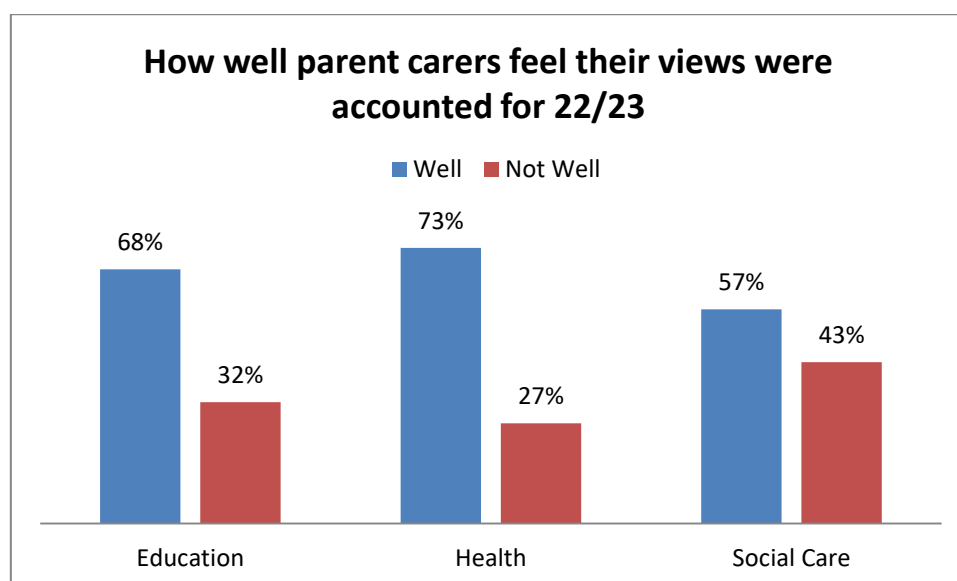


Fig 13 parent views being accounted for in 22/23

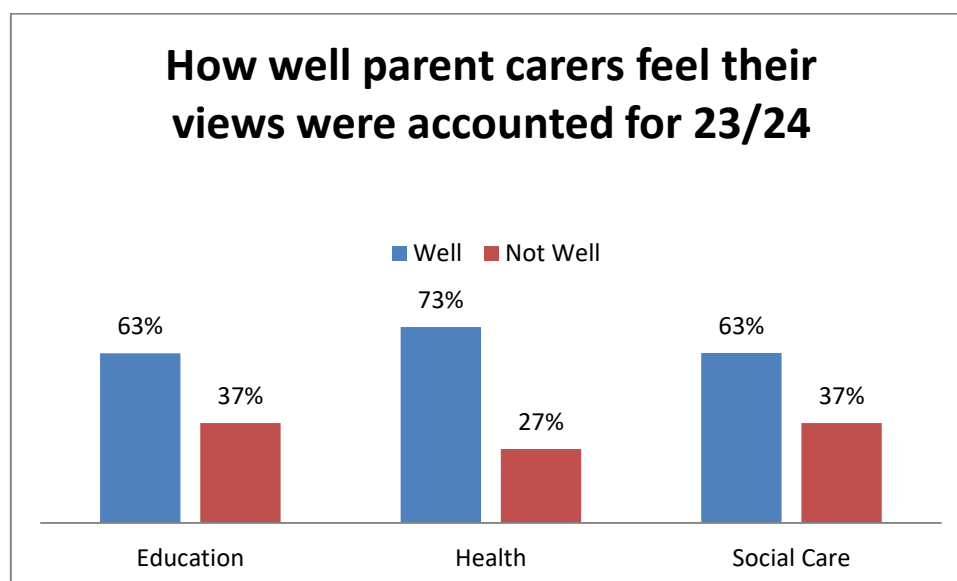


Fig 14 parent views being accounted for in 23/24

When viewing the survey data from a different direction and looking at the same question but for 22/23 and 23/24 separately it would appear that the increase in viewing this area negatively is specific to education.

Understanding of Needs

Another area of focus relates to 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.

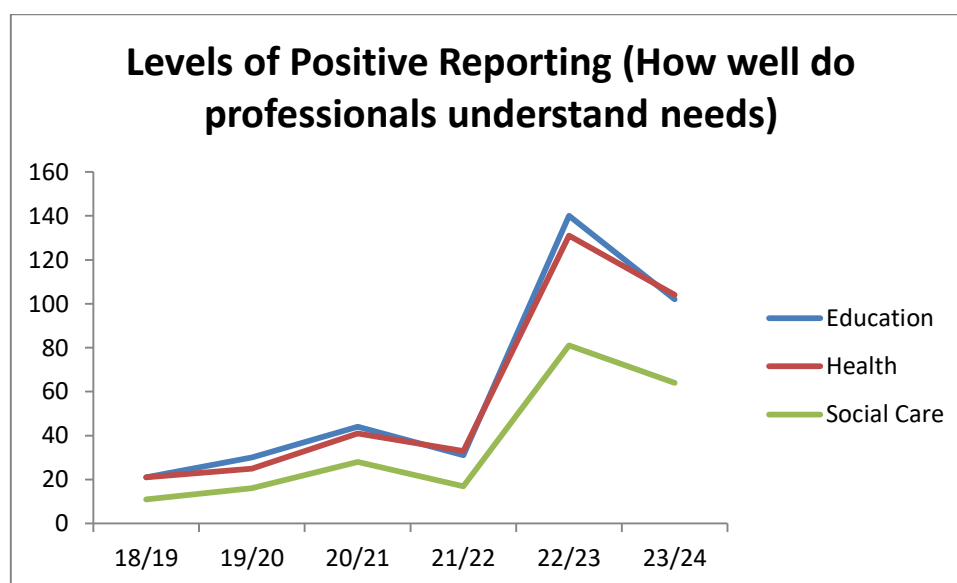


Fig.15 Professionals understanding of needs

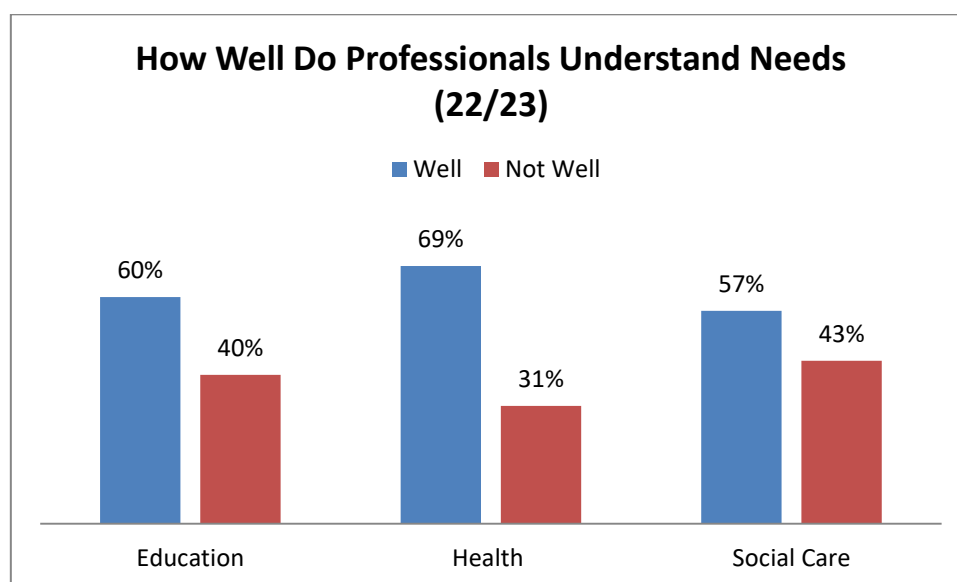


Fig.16 Professionals understanding of needs 22/23

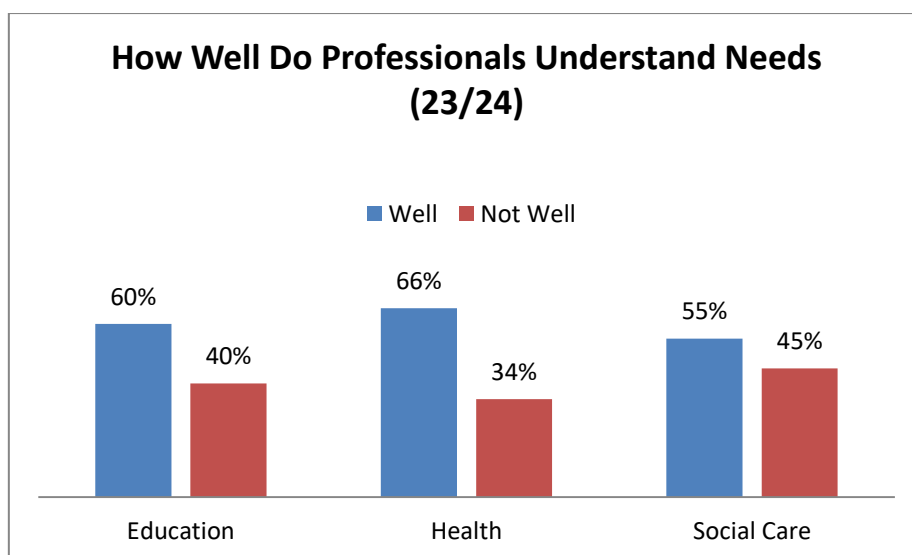


Fig.17 Professionals understanding of needs 23/24

A few parents provided comments further to their response to this question (see table 4 below). Generally respondents were more likely to provide negative commentary with Health and Education raising more concerns.

Understanding of Needs		
Working Well	Even Better If	Other
Now he has been diagnosed. But there was not much support beforehand.	Early days since been diagnosed. Haven't really, accessing extra support. I'm still concerned about other unmet needs, which they say, ask falls down to ASD, so I'm not listened to hear.	Not sure what social care is
Teachers of the deaf and SEN always very understanding. General education setting teachers and support not as understanding	The professionals understand the need but are not willing to do anything about it. The services provided by LA and the community NHS team are awful to say the least. What is the point of identifying the child's need but not meeting these to ensure they progress? All 3 services are following a tick box exercise which is quite dangerous for children and leads to safeguarding concerns.	Any understanding that has been achieved has been because I have shouted loudest. Everything is a fight to get what my child has needed.
Post adoption social worker have a much better understanding of his needs	My son wasn't ready to leave school. But the was no help just pushed towards college. He's suffering really bad mentally.	Autism advisory teaching service are exceptional but school do not listen to their advice and actively avoid having their involvement. AATS need to have more powers to force schools to follow advice.
Now she is on specialist provision she is well understood	I feel that CAMHs clearly don't, or they are so lacking funds that they can't act on concerns. Despite recognising that he had significant problems, they discharged him and told me to go to adoption support (not sure what you do if he wasn't adopted); Adoption support could not offer the ongoing support he needs. Following a	Some teachers understood, others did not

	successful tribunal regarding my sons health and education needs, his education were dealt with appropriately, but CAMHs failed to follow the recommendations made by the tribunal, as a year later my son was again seen by CAMHs, once as an emergency, as his is threatening to kill himself and embarking on dangerous behaviour. This time, I have heard nothing from them since his appointment, which was 2 months ago. I struggle to see what their purpose is!	
	In my opinion it has been a long battle in education since my child was diagnosed when she was 7	
	Within school they are amazing with my son but the support from council and health care system isn't great it took 3 years for my son to get his diagnosis the council refused EHCP saying his education was not affected even tho my son was only at school 2 hours a day because he needed one to one support, just because a child is clever shouldn't affect them needing emotional or support	
	Schools need more help to understand Autism!! Training in schools are terrible. Even sencos are shocking!!	
	They just see her as a naughty child and since starting secondary her attends ce is on 20% because of fixed term exclusions	

Table 4: Views on whether services understand CYP needs

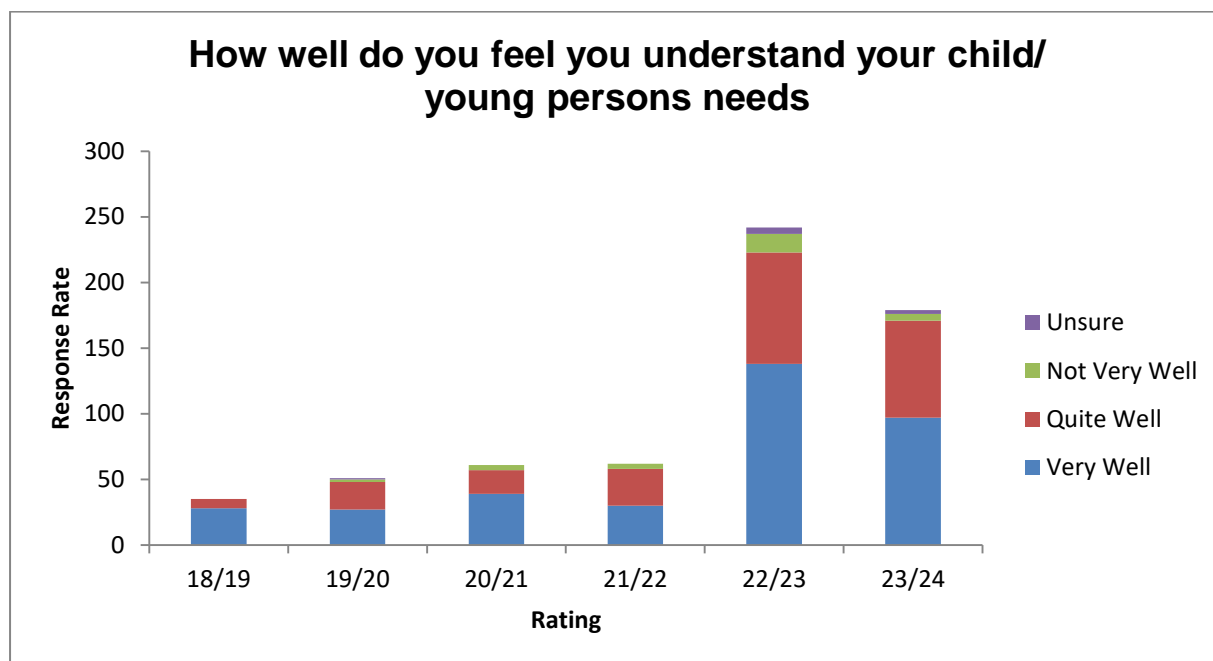


Fig.18 Respondents understanding of needs

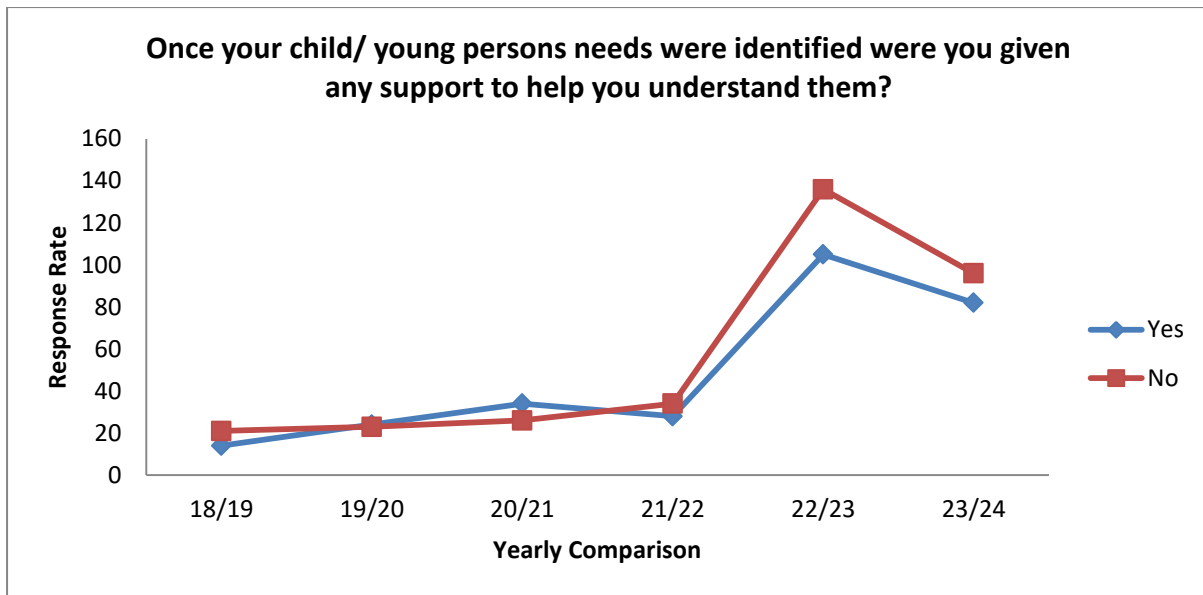


Fig. 19 Help to understand CYP needs

There has been a trend towards more negative reporting in respect of understanding CYP needs.

Support and Review

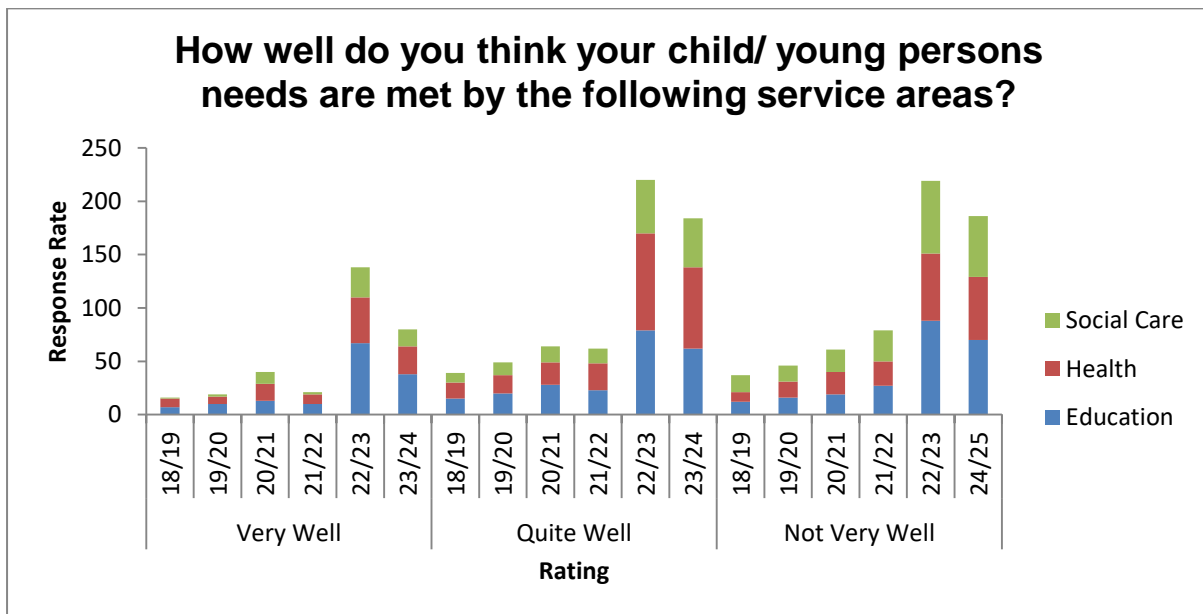


Fig. 20 how well services meet needs

Fig. 18 demonstrates the same trend with decreases in positive reporting between in 23/24, in respect of how well CYP needs are being met according to the respondents. This is easier to demonstrate when looking at Education, Health and Social Care separately across 18/19 to 22/24 as shown in Fig 19 to 21.

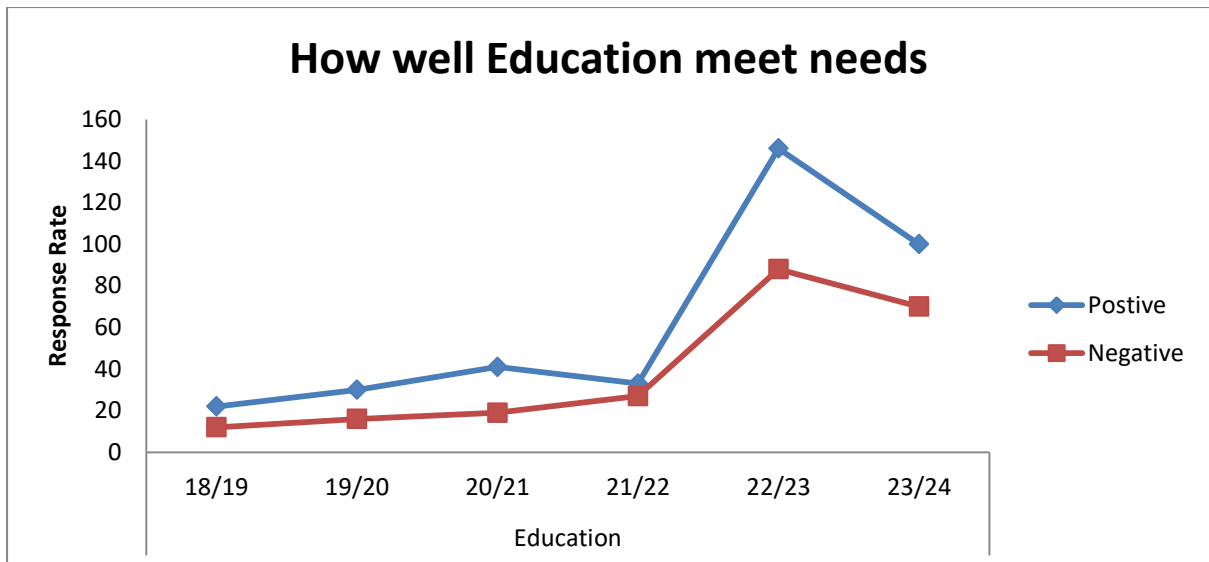


Fig.21 How well education meet CYP needs across years

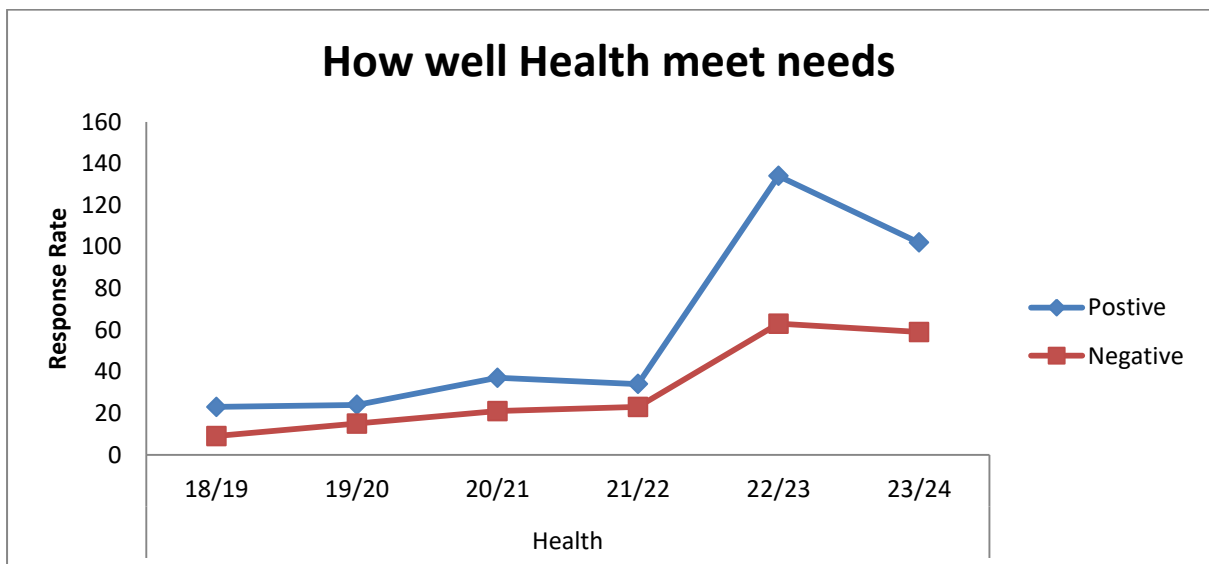


Fig.22 How well health meet CYP needs across years

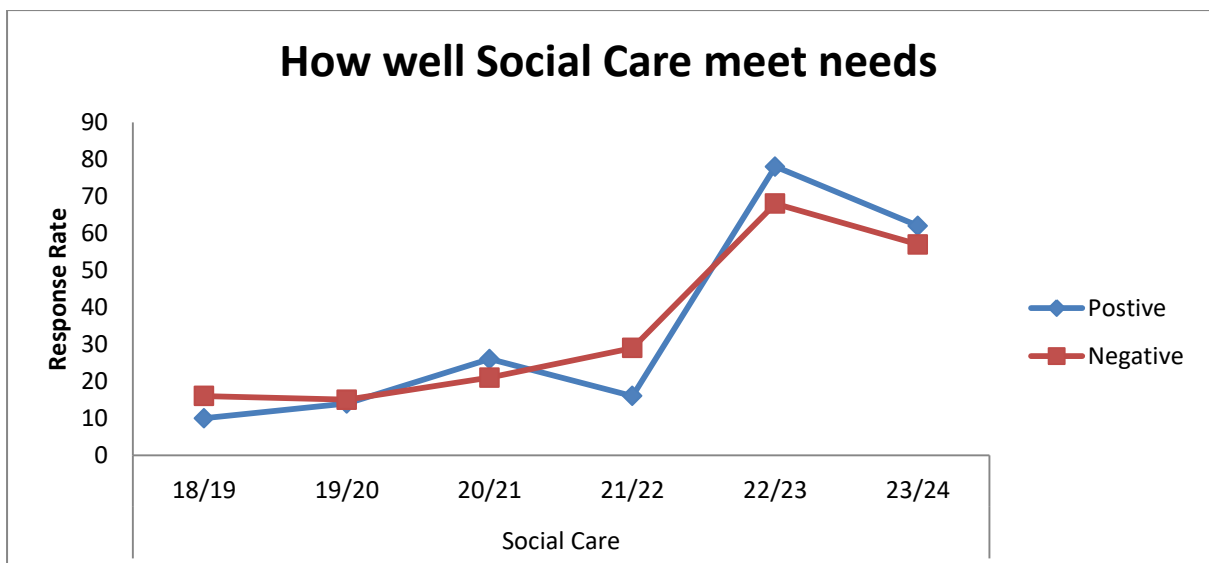


Fig.23 How well social care meet CYP needs across years

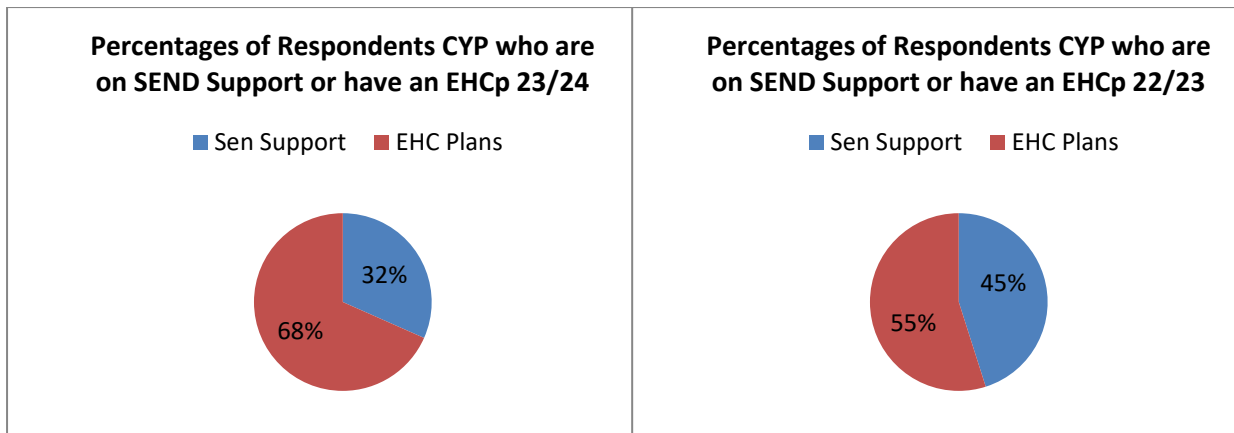


Fig. 24 Type of educational support

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.

Figs. 23 to 24 relate more specifically to how respondents feel they are included in their CYP's educational support.

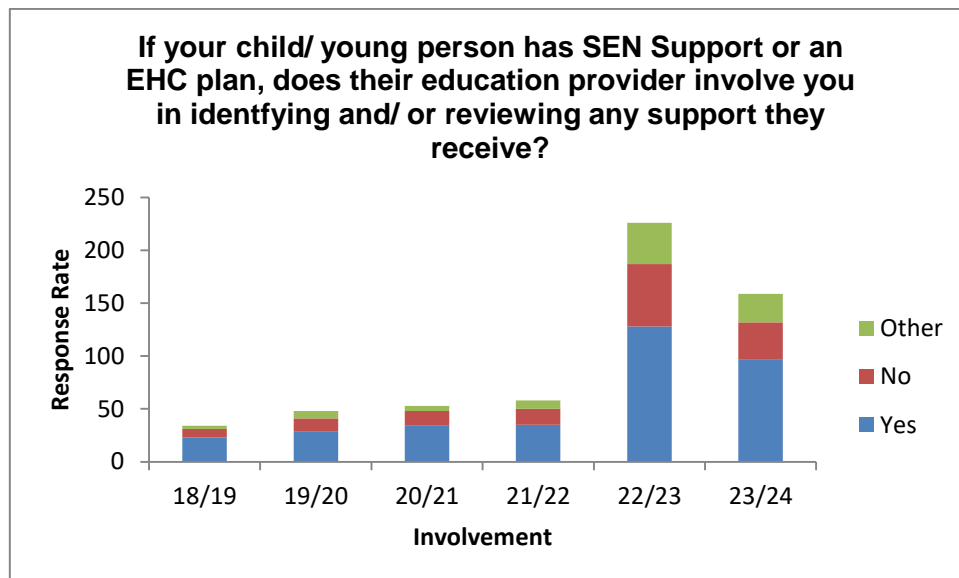


Fig. 25 Involvement in identifying and reviewing support

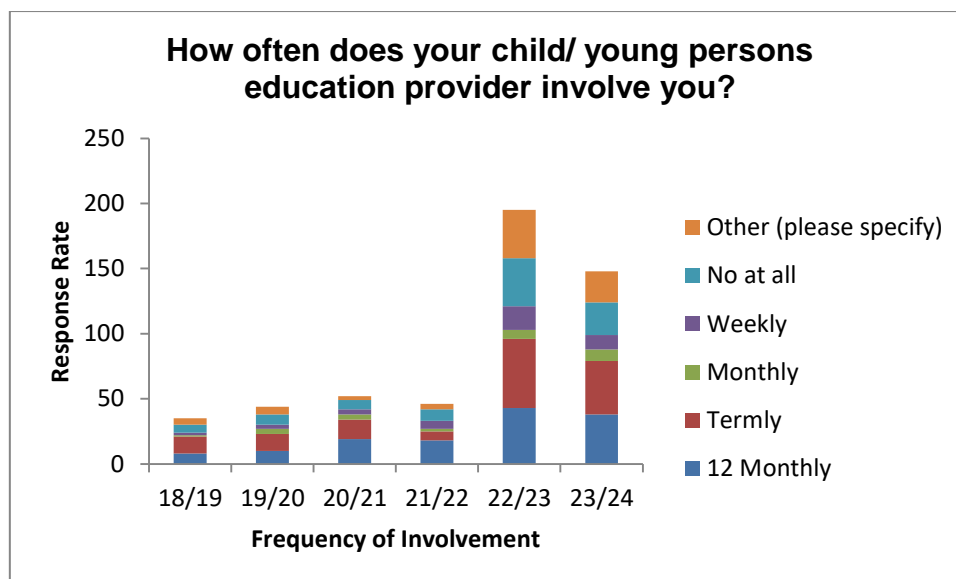


Fig. 26 When parent carers are involved

Further to involvement from education respondents were asked similar questions about health carer services as seen in figs. 25 and 26. Similar trends continue towards more negative reporting in 23/24 survey responses.

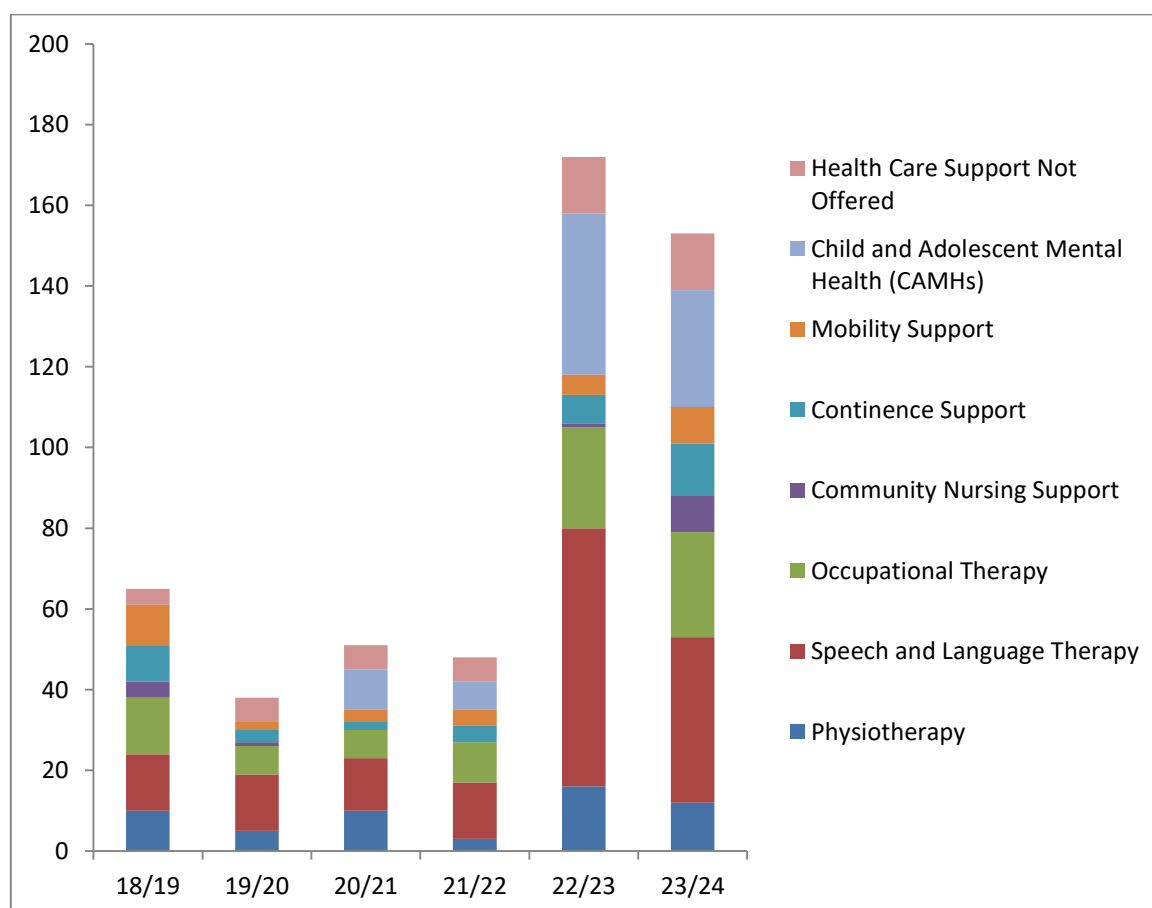


Fig. 27 Health service support

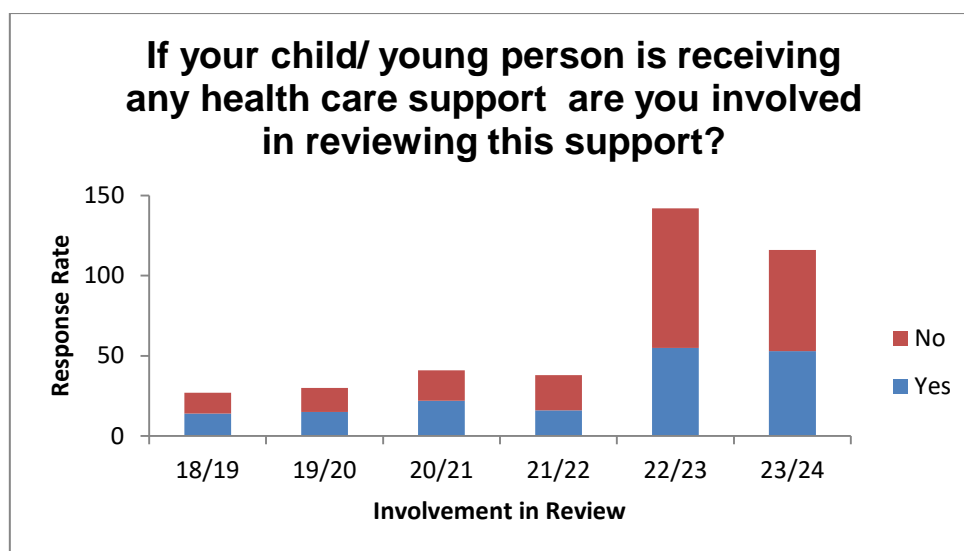


Fig. 28 Involvement in reviewing health support

Further to the above closed question responses parents were asked for supplementary commentary on how often they are included by education where they are and what types of health support their CYP may be receiving if not listed. This elicited the following comments, all of which point towards a system that does not work for everyone and leads to parental frustration around waiting times, being listened to and involved.

Level of involvement with education (comments)	Types of health support (comments)
it is me who sets up meetings	My child has OT needs, physio needs, and Speech & language needs. He also has severe multi-sensory impairment.
	However, OT had seen him once and then discharged him without ensuring the child is progressing (which they're not). Physio identified the child needed physiotherapy but refused because my child could walk and then told us to go privately. Speech & Language have never bothered to see him. My son has mobility needs but has not been seen by this team.
When I enquire or complain	Community nursing team are lovely though - they are the only ones from the whole of the community team that we see who have been fantastic with us.
As and when any changes happened	OT was recommended but no further support available.
	They have been on CAMHS waiting list for over 4 years, the most recent assessment towards the end of 2023 identified the need for 1:1 support rather than CBT and unsurprisingly has been put on another waiting list
Varies, only if they trying new strariges to engage my son back into school. Usually annual review for EHCP	APartly my son is too young for physiotherapy. They said they'll re-refer for SALT, but not done.

Daily

They took a box by putting a meeting in place but do not listen to parent's views or the child's views
every time there is a ccr, pep, or review of ehcp

Teacher gives me weekly update, but I am not involved with plans except at review. Meant to be yearly but tends to be once I kick up a fuss to get it done

Daily reports provided
We used to have termly meetings but have not had them in over a year now.
Every 3-4 months
No support at all

contact only ever takes place when we hassle the SEN rep when our son is struggling again.

Still waiting
I have to contact them

We get a sheet or sign, but that's it.
When they need to

As and when I contact

All the time.

On waiting lists for CAMHS doctor and therapist

SEN support at college
My son has recently been seen by CAMHS but we have never had any feedback from them.

My son recently started weekly therapy sessions at school, as has had mental health issues.

Through the gp now
Orthotics. My son has hyper mobility issues and has to wear orthotic splints to support his joints, posture and provides body awareness

No help discharged with no help
Awaiting ASD screening appointment and have a genetics appointment this month

Teacher of the Deaf
Been on waiting list for OT over a year.
Dietitian over 9 months, needs speech and language, not sure what's going on with that.

Declined for Early Help and CAMHS despite regular self harm due to 'previously looked after children are not able to be assessed by the current assessment system'

Awaiting CAMHS
On waiting list AGAIN for SALT

School were not welcoming of private SALT
Heard nothing yet
Waiting list for OT, SALT, physio been 2 yrs for some

No support other than the local SEN
As my child does not attend a school none of the services are involved in helping him
Still awaiting OT
Currently undertaking PACT
Hospital paediatric appointments

Annual check ups
Neurologist and specialist epilepsy doctor
He was referred but they currently don't act on it until it affects breathing. He has a pidgeon chest, ribs stick out more on one side.
Deaf CAMH
Waiting to complete parenting course to then go onto waiting list for CAMHS
Dietitian but this is due to come to an end

soon, no other support except an OT group
As everything - it's a waiting game! YEARS
in our case!

Table 5: Involvement Comments (Education and Health)

FVP have also gathered other commentary on how families are experiencing local Education, Health and Social Care services through face to face sessions and sign posting, with the parents saying:

'Good morning,

*My number is *** not sure why is not connecting. I am at work at the moment.
I really struggle at the moment my son was referred to Camhs last year for mental health assessment and at the meeting he was promised some art therapy but instead he got video therapy from Healios which was terrible for him and he struggled a lot with having it online. We were promised referral for ADHD but instead Camhs discharged him and that was it. He is 12 autistic and also self harming. I am thinking of calling our GP ask for help again but Camhs said they are not likely to accept another referral so not sure what to do.*

*My***** has DiGeorges syndrome and needs a further medical diagnosis for possible Autism as she is falling behind in key skills at school and needs additional support in class. We are currently in the Webster Stratton parenting program as we was told by school we need to complete this before an EP can be sourced.*

'Boy 8 yrs old, 5 yrs process/pathway please email me with advice on how to appeal, ASD assessment declined'

female - age 11 - school avoidance - sensory difficulties - mental health - social and emotional difficulties - on pathway for diagnosis of ASD/adhdAny break would be fantastic. This nightmare has been on going for months upon months. It has torn my family apart and I have lost my job of 17 years because of it. To see my daughter not coping with life is heartbreaking and it isn't fair on my young son to see and hear all of the difficulties she faces and causes.

Figs. 27 and 28 below focus on broader areas relating to how well the system involves parents in target setting and monitoring of support & needs/ outcomes with responses varied but pointing towards the impression that parents feel this is not going to well.

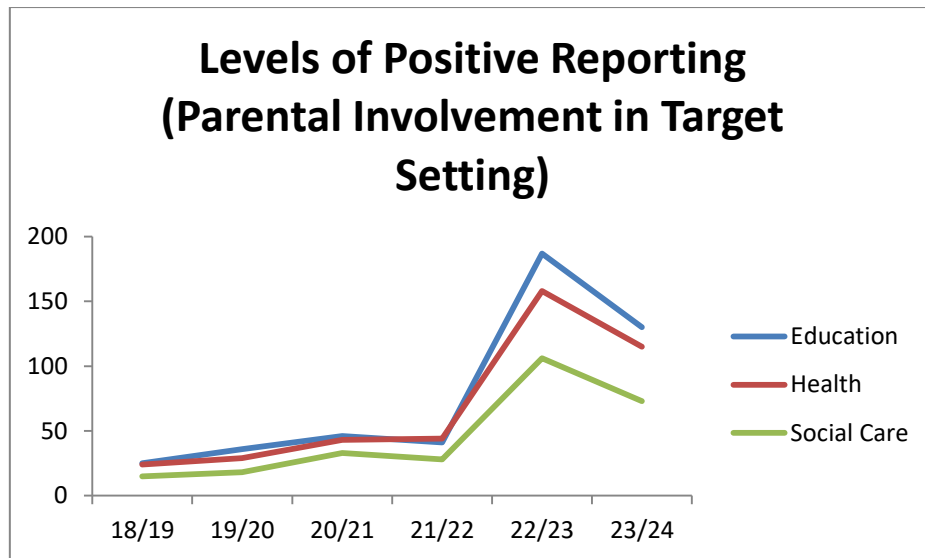


Fig. 29 Involvement in target setting

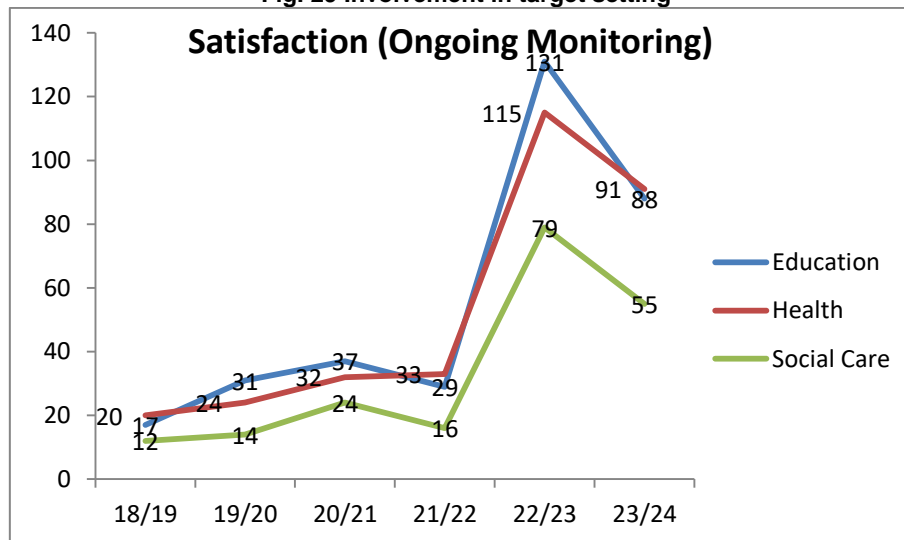


Fig. 30 satisfaction with ongoing monitoring

Figs. 29 and 30 also lean towards respondents reporting that the system is not doing well in relation to working together or helping CYP do well in achieving outcomes across four key areas.

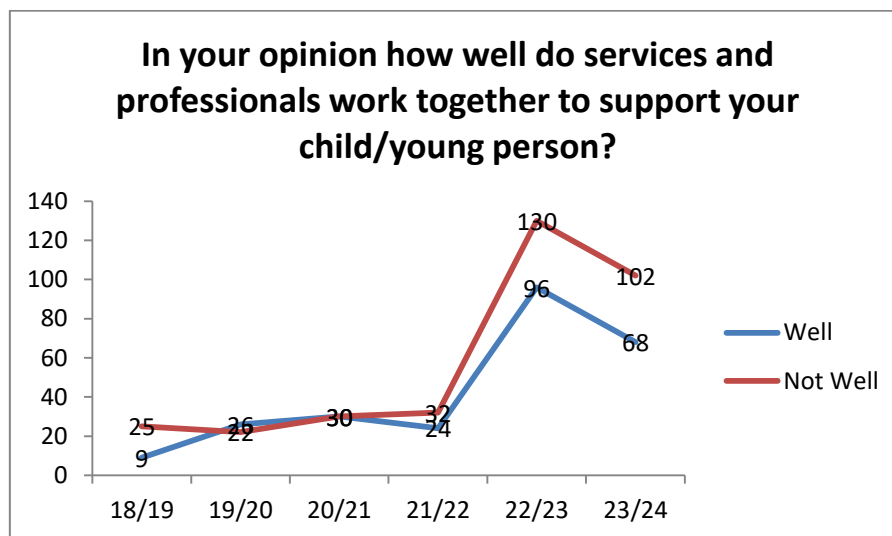


Fig. 31 views on how well services work together.

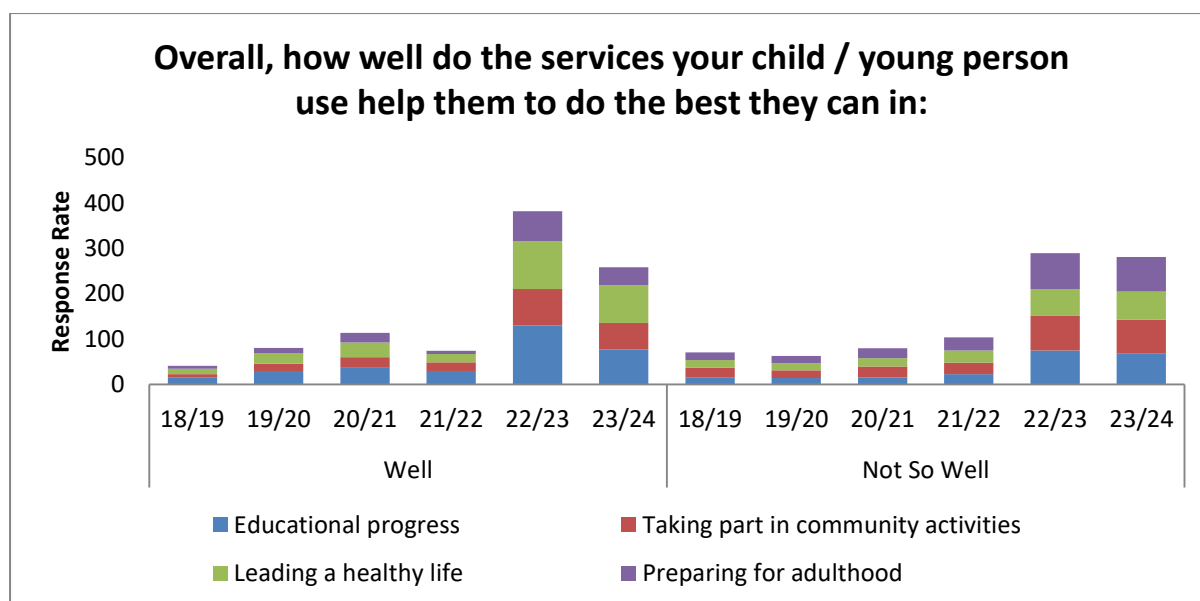


Fig.32 How well services help CYP achieve good outcomes

Please use the space below to provide any further details you have regards your child/ young persons educational provision.

The was no suitable provision for my child's needs so i had to decide to home educate my child
 We are currently going through a private assessment to speed up the process of identify the needs of our daughter, alongside the process within the educational system.
 I usually have to highlight issues to the school, and they are often accommodating but some things they won't make reasonable adjustments and they won't do an ehcp

His school is fabulous now and consult and work with us as parents to give Josh the best support. He is now thriving and happy.

Teaching staff are absolutely amazing with my child. Would like to see more SEN involvement/awareness generally within the school.
 In mainstream primary but we have secured placement at Marshfields for September 2024 intake. Mainstream no longer the right setting.

We're very fortunate to be part of a school with lots of understanding and allowance for my child's needs

Please use the space below to provide any further information regards your experiences relating to health services

No access to OT

 No offer of any sort of help for my daughter s mental health

 Health professionals have a lack of understanding of Down Syndrome, despite clear guidance on infections and low threshold for antibiotics.

 My son is on 6 waiting lists for different services. Early Help referral was completed in July but I do not feel it has achieved anything and nothing has changed in terms of services coming on board.

 Took years to get a diagnosis.

 Very difficult to access and lengthy waiting times. Also once accessible seems to be for the shortest time possible.

 Great team but under funded and short staffed so always a challenge to have regular

I worry about going to secondary school where these needs will not be met
I always feel as though I am prompting support and wish instead I was regularly updated on the support (if any) they receive.

GCSE are a worry but hoping after a meeting we will be more at ease.
They need to listen to parents

It's a very hard battle to get your child's needs met in school

Being that my son is in a SEMH school, I would of hoped they had better techniques to how to handle children with SEN. As they constantly give numerous exclusion, part time timetables (which they call bespoke). The only person they benefiting from techniques, is school, not the child.

very happy mostly with lime academy just needs to work on communication from management.

v happy with teachers of the blind and deaf

My daughter been on early help for nearly 4 years still waiting for school support to apply for an EHC plan

Get daily diary from tutor at college

I'm worried about my child's envisioning how he's going to struggle later in life
PCC has the money for children with SEN, but the managers sitting at the top who have been working with the council for years have zero understanding of anything. They will either bully parents or ignore them. They do not ensure a child is safeguarded at all times; if a child is fine at home hut the problem lies within the school or the

appointments.

I had to go back to go several times to instigate referrals and referrals. It's frustrating that notes are not shared or read.

No funding available for FASD diagnosis

Not listened too. I've had to learn alot myself, prior my son being diagnosed, to help him.

More funding is needed. They need to see and recognise the further help people with Sen require, rather than us telling and having to fight for everything.

very happy with physio, ot. happy to be back with peterborough CCN's.

if mobility support includes wheelchair services theyvare a joke and should be removed of their contract.

Community team at Child Development Centre (City care centre) are vile to say the least as they only do a tick box exercise. They are lovely people who cannot provide my child with the level if service he requires.

I am thankful for all what is but needs more attention face to face, not sending photos to Gp online. Disabled people want to be listened and received some peace of mind from doctors if needed. They may not understand that mommy sent a picture and doctor said "it's fine", they will trust the specialist sometimes more , than mother.

We had not help

GPs/drs don't necessarily understand the basics of autism or how ro deal with an autistic child.

LA, the everyone looks the other way including disability social workers - the entire system is not only corrupted but has been designed to ensure failure for all SEN children.

I am happy with our college. I don't know why it said please enter a comment. I have said everything

Lack of 121 support. I feel my child is left to her own devices after they complete bare minimum of the tasks set.

There is no help for children leaving school when they are not ready. They are pushed into college. My son is suffering mentally and has been on a waiting list for counselling for nearly 3 years.

We did not receive any help after diagnosis, asked couple of times for parental courses at school and family voice but they never came back to me about it

my son is expressing how he wants to end his life and embarking on dangerous behaviour. He has his two appointments with CAMHs, on 3 as an emergency, but despite this, we have heard nothing further from them or been offered help other than websites to look at.

Identifying diagnosis took a long time over a year, this was a very hard time.

Cahms have been helpful for my daughter, she has had help with her anxiety

Accessibility is terrible. Support never tends to include parents who have no child care so we can't go to meetings. Places are set in remote or inaccessible areas. When your child can't use public transport and the DLA drag their heels to provide mobility it makes getting anywhere impossible and you become house bound.

Seeing a therapist once every four to six months, I don't feel is conducive to actually helping them really progress. Someone on the spectrum needs regular visits to engage properly and feel comfortable. This is why things like the dentist are a nightmare. You are told "we can do some warm up appointments" then they are weeks/ months apart. It doesn't work. It feels like we are all being spoon fed a little help, to tick a box. Make information accessible to parents. It's hard for many to get online and do stuff like search for support. Provide one booklet with all of it in. So we have it at hand. GP Surgeries are a nightmare for my child.

Regardless of my endless reminders he needs a quiet space. We rarely get it, if we do I am told off by doctors. I have been told by receptionists they just can't do it as doctors have asked them not to provide me with one. My son ends up down the corridor, over stimulated, desperate to leave. By the time he is seen, he is generally unable to settle. It is clear children with autism do well when they are prepared for what's coming, using social stories and pictures. It

would be good if clinics etc had photos they could provide parents with, such as the waiting room, the room they will go in, the face of the doctor/nurse they will see. This would help reduce anxiety building up. And possibly make the appointment more successful. I also believe some sort of class for kids on the spectrum where they can rehearse such things would help. Like rehearsing going to the dentist and sitting in the chair. Anything to relieve anxiety and help the appointment be successful

My son is a residential school Monday to Friday.

After several appointments with speech therapy that did not seem beneficial to my child who is non verbal with limited understanding we were offered PACT which has been amazing

I feel there is hardly any provision for post 16 education/provision for complex needs & I do worry about his future
Excellent communication, always working together as a team to make home and school a happy safe place.

No help for mental health

The services we have received have all been extremely good but unfortunately time scales for waiting on appointments and then any form of support in the meantime has really made for a really hard impact on my daughter mental well being .

It is us that gets in contact with senco in school, they do not contact us

Camhs have supported child and family fantastically.

There is zero support, I get zero financial support. We are left isolated with nothing. For me Peterborough provides nothing

Our daughter suffers with constipation, which I believe is fairly common alongside autism. She has been prescribed meds for over 2 years now with no GP review.

Concerned for dyslexia

Audiology is brilliant. ENT has been a poor experience throughout. We had great support in lock down with OT exercises for vertigo.

My child has been assessed for ADHD and Autism. But we are still awaiting the results. I think the whole process takes far too long. It's been 5 years I've been chasing for assessments. I notified the school when my child was 6 years old. She's now 10 and only just had the assessments. Once school were on board and saw what I saw, they have been great. But it's a shame it's my child's last year in primary school and only just receiving help.

Waiting lists are far too long. We feel forgotten, still unsure when or if going to get seen. Kids need support as a matter of urgency. My son now has extremely high anxiety levels, on top of he's ASD ,due to a failing system, who. Left him so long to get seen, over 7yrs from when I showed my concerns. CAMHs kept saying they need more information (even though they had loads, and my son was excluded, regular exclusion all the time, also put into a behaviour school. All the school/other professional saw the

N/a

Ravensthorpe primary school have been lacking in all levels of knowledge and support with any sen care needed. Numerous meetings and complaints but a non consistent knowledge of sen and an inability to staff support has led to my child's mental health being affected by lack of support and consistency in care and communication is absolutely non existent. Child placed in mainstream. Could not cope and has been signed off by camhs. Still waiting 10 months for a specialist placement.

The staff at Orton Longueville Playgroup and then Orton wistow primary school have all been absolutely fantastic! We found there to be a massive difference between knowing about autism and understanding autism... The playgroup and the school both understand, and this means that our daughter is receiving the help and care that she needs to thrive within the setting.

We do receive quarterly reports on the support given in school, and regular update reports from teacher of the deaf visits.

Although we have a Teacher of the Deaf assigned, when choosing schools for my daughter we weren't given names of schools that were more suited for deaf children. We started my daughter at a mainstream school with no other deaf children and after reception did not feel the school gave the support she needed. We then found a mainstream school with a deaf hub which has far improved the education of my daughter and improved her social and self confidence in being around other children like her aswell as a school that is deaf aware and takes that into consideration in daily activities

Happy with school. Consistently disappointed by the LA

Our primary school, Castor said children only get EHCP if 2 years behind, no support for my deaf child. Had to constantly chase for Teacher of the

ASD however CAMHs kept wanting more proof, before going on they long waiting list. Kids mental state worsening due to this.

15 months over due an appointment to follow up in 3 months due to ear problems identified at 3 months but due to his situation appointments have not been regular enough to identify and action issues.

Very difficult to access and lengthy waiting times. Also once accessible seems to be for the shortest time possible.

Great team but under funded and short staffed so always a challenge to have regular appointments.

So needed to be seen in 3 months for a more accurate diagnosis - appointments repeatedly cancelled by NHS and 3-month follow up appointment due Nov 2022 is now scheduled for Feb 2024.

Ophthalmology have been excellent post adoption and he has had an operation that has improved his quality of life.

Our child requires help with SALT and continence support which we are struggling to obtain..

To long a wait it's just not good enough.

No help given nothing explained the systems is failing all special need children and their families

deaf support. AMVC have been brilliant this last term with their varying provision and our new teacher of the deaf is supportive

Only know how my son is doing, when he's dysregulated, then it's usually a exclusion. Which is a totally wrong, way of handle, as sends Sen children wrong messages. And then children get traumatised by school environment/teachers, because of lack of training for SEN children. Kids then become depressed, have anxiety problems, the list goes on. This is a very complex matter and should be looked into more intensely, to help Sen children not traumatized further.

It was a slow start but they are now really supportive

Due to the incompetence from the school due to multiple SEND officers and Family liaison officers it has taken 2 years to get my daughter to the place I am at now. She was identified as SEN since pre school, she is due to start secondary school this year and I feel the primary and the system have let my daughter down considerably. She is now on a waiting list for neurodevelopmental which is his knows how long, bearing in mind she saw a paediatrician back in 2020, where they said she would be seen again once she got to upper primary but I've had to go through the whole process once again, it takes too long especially as I've already been through this once before

EHCP not met not enough being done by school regarding occupational therapy or speech and language. Very disappointed with the system

My child's current education provision is wonderful. Its a shame she needs to travel for 50 minutes to get there.

My child's safety has been put at risk despite my desperate attempts to communicate his needs. We do not receive enough communication/evidence to feel satisfied that his ECHP is being met and recommended interventions take place as stated in the plan. Unfortunately help reduces as the child starts school as you loose the help from MDT but it is not sufficiently replaced through school. We are now 5 months into/ waiting on a new referral for SALT and when asking for help for toileting and hearing gp directs you back to school nurse - school say it's not their responsibility.

No provision put in place - left in the dark with no one updating me

They pass the blame onto school and vice versa

Impossible to get OT involvement to support my child's sensory and regulation needs

There is no specialised therapy for Autistic youth locally. The CBT offered by Camhs does not help autistic people.

The doctors review and never include us only when they have decided what to do.

Too many waiting lists and long waiting or being forgotten

Long waiting lists pointless appointments to be put on more waiting lists they need to listen to the schools more

I have tried to have my son referred to camhs, got told to do the parenting course again, then once completed I had 12 weeks before he could continue with the referral. Applied online for it to

Any accomodations have had to be fought for. School for a long time disregarded what I was saying. If they had listened my child's attendance would be far better than it is. Also staff need training on autism support for late diagnosed girls. They should all read the Autistic Girls Network White Paper: Autism, Girls and Keeping It All Inside.

Our EHCP was changed after it was agreed by all parties without our knowledge by the school and the LA. The LA told me to appeal it! It was lawful to change the plan without consulting us.

It's currently non existent. My daughter has been failed

The school do amazing which such little funding from the council but the council process needs improvement

Needs have not been met, taken 2 years for ant change to be made

My daughter struggles in school daily even with 1:1 support and things their trying

Battled with this school since Yr 1 my daughter is now in Yr 4 and not much further forward she's had assessments and outside professio also that says she is dyslexic and her school is saying that it's not a formal diagnosis ..their also traits of adhd and yet I've got to do a parenting course which is stupid as she just be solely assessed for this

She cuts her hair to harm herself with frustration of struggling so also mental health concerns

It's too lengthy to get these children the support they obviously need

Special needs care for child and their parents is shocking there is a lot off promises for help but no follow through on actually helping family's

I don't think they care

be rejected as I need to contact the start to start the whole process again.

Diagnosed and discharged in the same appointment. Waited 2 years for cygnets course.

The problems we have had have been with my child needing audiology help which we have had a lot of problems with, without this help my child is possibly stuck in limbo not being able to achieve what he could if they had helped adequately from the beginning

xxxhas orthotics for his flat foot however due to sensory needs he struggles to wear these

xxx also still see continence for bed time wetting

Been on waiting list for dietary services for 2 years. Given up hope of ever being seen by them. Speech and language wasn't very productive.

Awful for most part.

Auditory processing difficulties were identified but referral to GOSH refused by local commissioners. Difficulty went undiagnosed.

Long waiting lists, parental exhaustion from having to constantly fight for and chase up support for your child, no timely support

It would be nice to be more involved within the school activity days sports days ect

Educational setting actively avoids giving the child the support they require and using the funding to meet the child's needs.

I provide all the sensory equipment my child needs including chew toys.

Education setting doesn't like to communicate affectively with parents and actively excluded them from meetings to update risk reduction plans.

Flying under the radar, academically able and quiet, masking.

Secondary school not interested because he is academically achieving very well

Don't always understand child needs and put loads of demands on child than say we unable to meet needs even though it's a special needs school and they are meant to be trained to work with needs of child needs not help with staff not always trained to work with special needs children and don't have the qualifications to work in the schools been to appointments and have had to tell school how to teach as have teaching qualification myself

Education staff need to be trained in Autism to help them understand children's sensory needs and issues. Schools tell them to sit down and be quiet. If they don't then they tell them off!! This is encouraging children to mask and not be themselves causing anxiety problems.

My son can't write so he needs help with this think he has dyslexia, the school is not doing much to help. He currently goes to Ken Simpson.

My child's school is brilliant with him and we couldn't have asked for better

My son has no education provision at this time due to ongoing first tier education tribunal regarding contents of EHCP and placement being totally unsuitable due to cost

The SEN rep at school is ineffective and only ever does the minimum for our son's dyslexia. We have to chase and hassle to get any feedback or

provided following diagnosis.

Terrible. I have lost my job of 17 years due to my daughter's difficulties and I feel it is a never ending vicious circle! I feel so let down. It is and has effected my life and the people around me for too long with little to no support.

So far I feel listened to and supported

Physio is good .

My son has been refused referrals from the doctor as they said it's for the school to put in even with asking the last school for referrals they refused.

arrange any help for him. Most of his teachers do not even know he is dyslexic. It is disgusting how little effort they make. The entire school management team are more focused on the type of shoes that are worn than the quality of education provided especially for pupils with SLD. My son was in mainstream where they continuously failed to meet his needs his mental health really suffered his attendance went down to 70-80% and school was more concerned how it would effect there own outlook than supporting my son into being in school

Since my child went to secondary school, they have been exemplary in supporting her. I now realise how badly her primary school treated her. We have now had 2 governors meetings because of the amount of fixed term exclusions. She has no support in school and I have only just recently had contact with the Senco as I had to request a meeting

Not enough knowledge of SpLD amongst teachers. Focus is on protective interruptive behaviours instead of looking at cause.

The symptoms in school were ADHD however despite a dyslexia diagnosis this was never even mentioned

I was disappointed that my daughter's education terminated last summer after city college changed their entry requirements and Peterborough College were unable to provide a suitable placement beyond 1 day per week
NA

Very well given follow up to talk about his progress

I'm reception and is doing very well.

He hates it. Very emotional. Never wants to go find it overwhelming and demanding.

Very interested

I am happy with the new school they have already seen me a few times and also my son and he doesn't start yet. He will be on 1/2 days to get used to it as he struggles with change and transitions. They also have done a social story for him. I feel they already understand some of his needs and will do their best to meet them as much as possible.

I feel there is a massive skills gap with regard SEND, so much so that a TA had never heard of masking.

School are very good at listening but not good at implementing plans. Often I will ask for support for

my son i.e. sensory room and I am told that is only for children with an EHCP. Attendance is suffering due to needs not being met. The mental health team (or CAMHS) have completely let my child down. We have been battling difficulties for 5 YEARS now! I understand they are busy and Covid set people back but seriously! I feel like I am doing all the running around for the so called professionals and my daughter is just seen as a number. Had to home educate due to school failing to meet my child's needs
Na

I've had to chase college to make sure any reasonable adjustments have been put in place I have been homeschooling since easter and we have heard nothing from the local authority about education. He has been referred to camhs There is a lack of communication so I'm constantly guessing what going on which makes it harder to support at home. On average I see his actual teacher maybe once a week so have to barrage her with questions then I'm happy with the provision he is well supported

Table 6: Overall experiences of Health and Education

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.

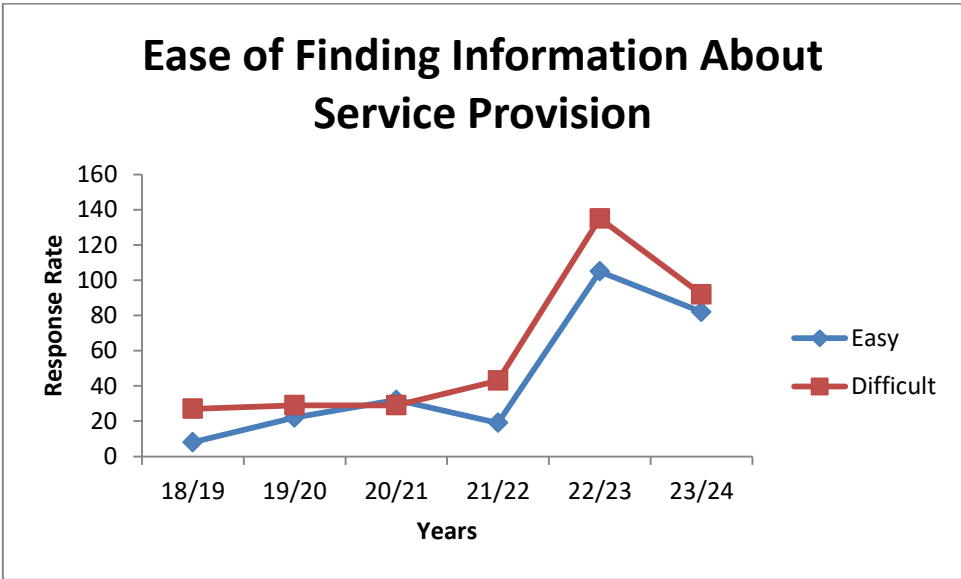


Fig. 33 Ease of finding information

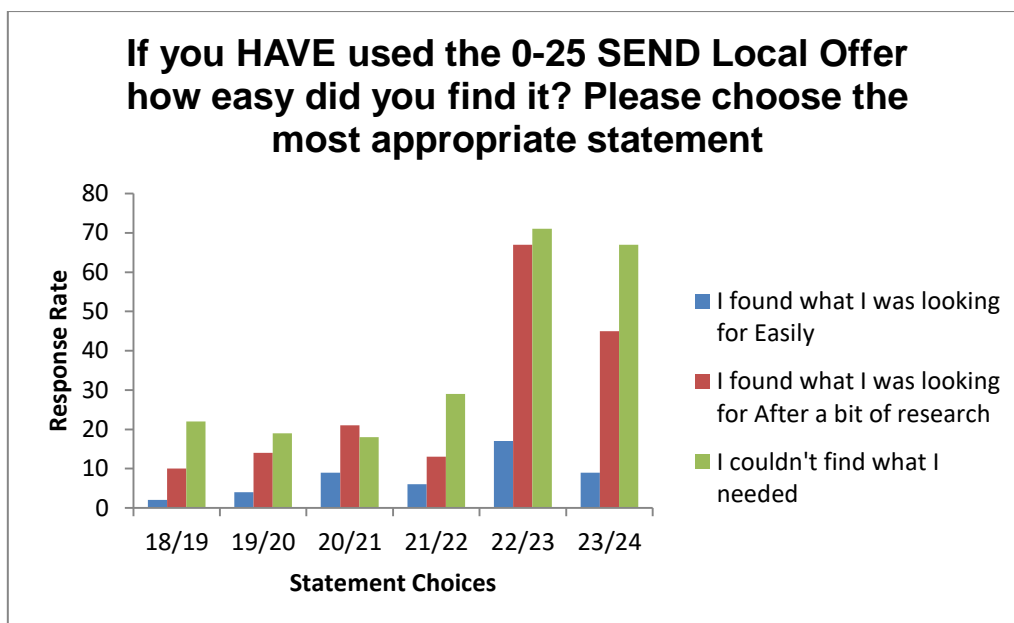


Fig. 34 Ease of using Local Offer

This area is a bit more mixed and if the more positive views are combined and compared with the negative views overall 44.63% report that were able to find information they required, which is down from 54.2% last year.

There does appear to be a trend towards parent carers experiencing some difficulty accessing information across a range of areas as further evidenced by the increasing number of parent carers seeking sign posting across a much broader range of areas.

Since April 1st 2023 up to an including 1st February 2024 FVP have received 170 sign posting contacts

Social Care and Preparing for Adulthood (PfA)

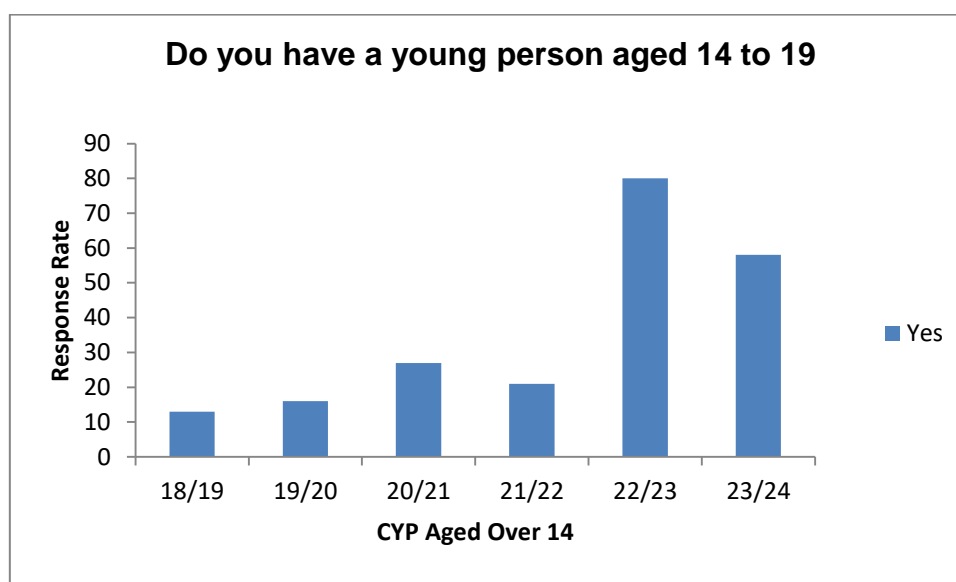


Fig 35 Number of CYP aged 14 to 19

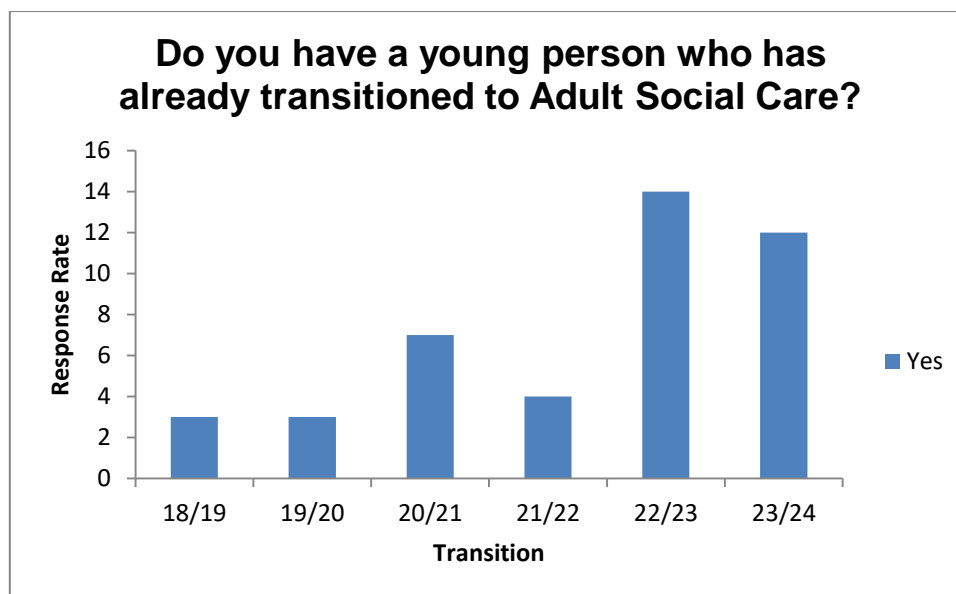


Fig. 36 Number of CYP who have transitioned to Adult Social Care

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

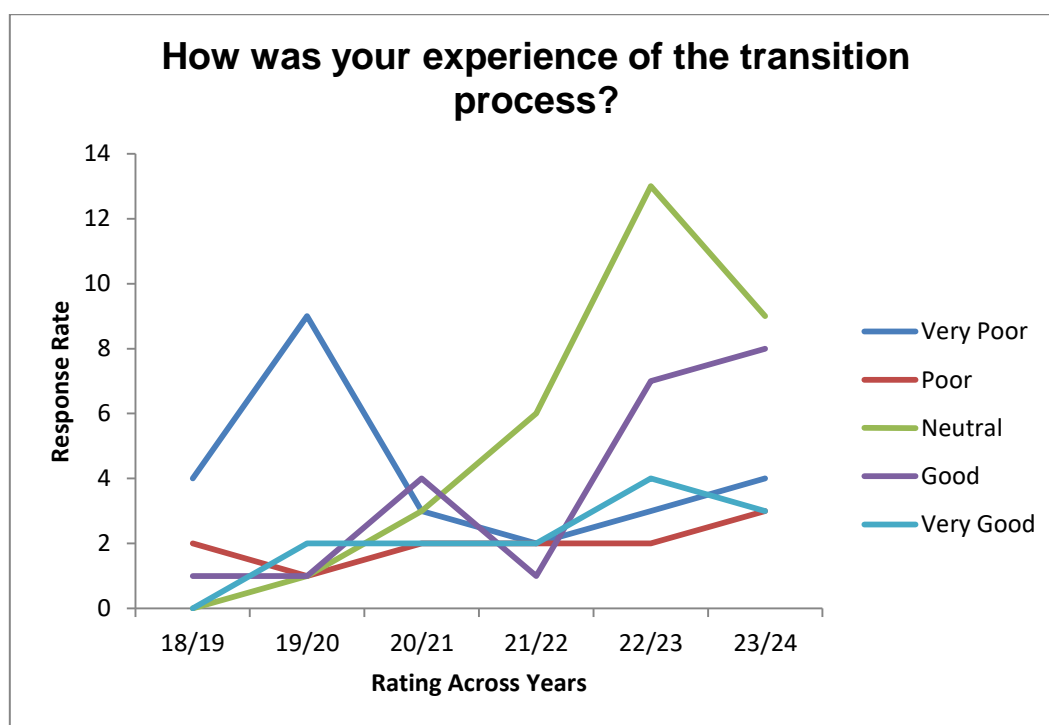
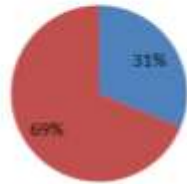


Fig. 37 Transition Experience

There has been a slight decrease in the numbers reporting positively regards their CYP transition to adulthood. When looking more closely at responses for 22/23 and 23/24 it can be seen there has been a slight increase in negative reporting especially in relation to the transition experience (see fig 36 below).

How was your experience of the transition process?
22/23

■ Poor ■ Good



How was your experience of the transition process?
23/24

■ Poor ■ Good

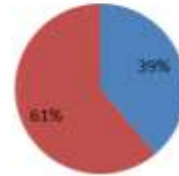


Fig. 38 Comparison across years of transition experience

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. 37 and 38.

As part of the transition process were you given any information about Adult Social care?

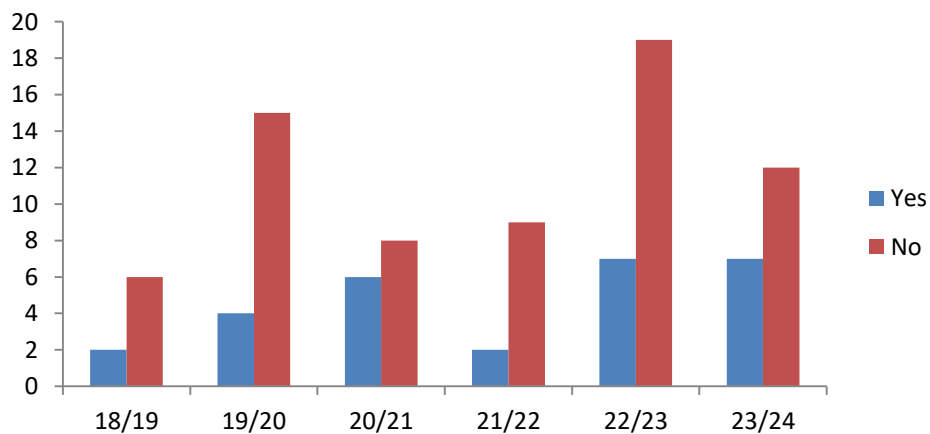


Fig. 39 Information provided regards Adult Social Care

Were you supported to understand the transition process?

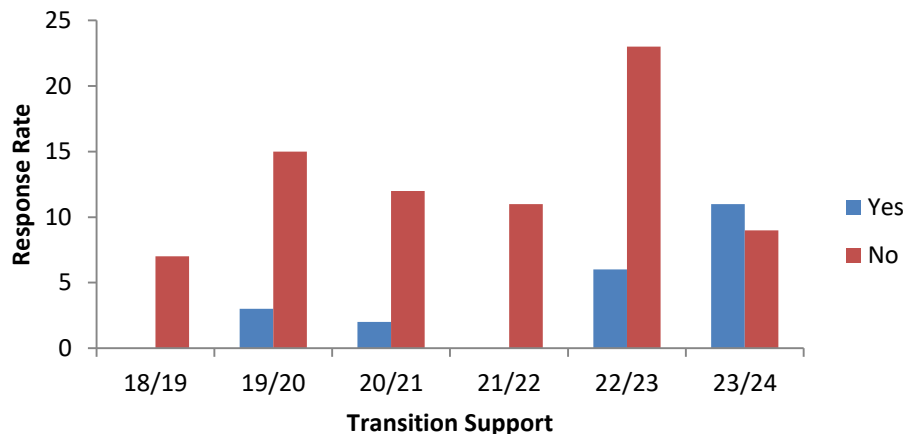


Fig. 40 Support to understand the transition process

Between 22/23 and 23/24 there was a 10% increase in positive reporting in relation to respondents receiving information as part of the transition process; this is also followed by a 34% increase in respondents reporting that they were supported to understand the process. This all goes against the overall trend towards negative reporting.

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. 39 and 40.

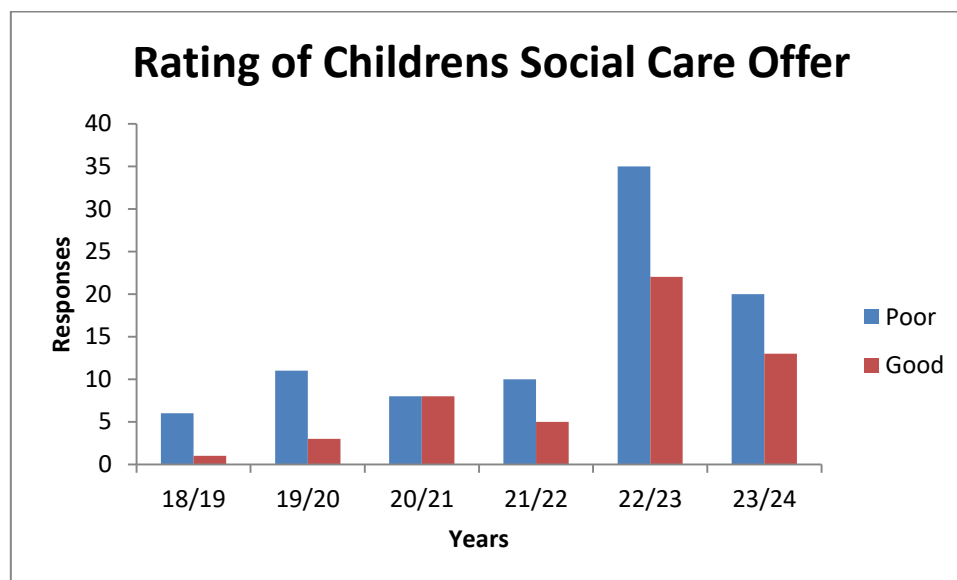


Fig. 41 Children's social Care Offer

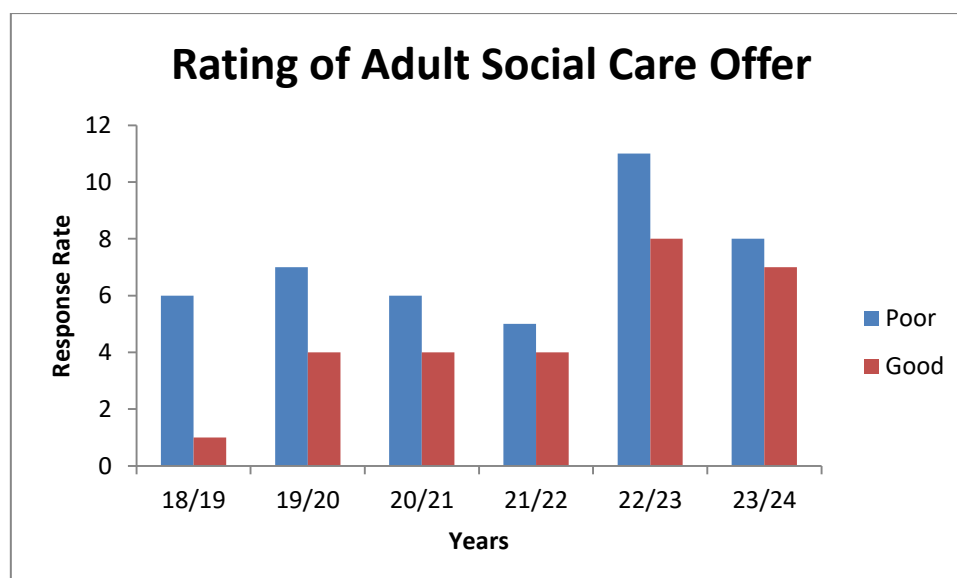


Fig 42 Adults Social Care Offer

Generally ratings of the offer for social care are more likely to be across both childrens and adults, however there was a 5% increase in respondents reporting the offer from adult services more positively in 23/24 compared to 22/23

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

Please use the space below to tell us anything else about your experience with childrens or adults social care

Sorry not sure what social care is?

Social care has never been offered to us even though my daughter absolutely qualifys.

Now having to research myself what steps we need to take to get rest bite.

Previously struggled to trust them as they let me and my son down when coming out of an abusive relationship and my sons dad hurting him, yet letting him have alone time with him due to the social worker leaving the organisation.

I feel they send you round in circles so that after 3 years my son is no further forward in receiving appropriate care. Every professional he is under says he requires this but panel/ social services keep putting up barriers. we have started process of complaint taking to tribunal.

Children's social care identifies most things in the assessment but do not actually provide the level if support needed. Everything is a tick box exercise with them. Our social worker fails to safeguard our child.

I feel children's social care needs to have a review. All u have experienced has always been a fight & still us. All I get TOLD the child is my responsibility till he's an adult- I hope that adult services is not as bad as children's have been in my experience. It really has affected my mental health & abilities to stay focused for my child & to alway choir my battles .

We have never heard anything since my daughter changed to adult care only that we see the go which is shocking as we can't access anything let alone see a doctor.

Don't get any

We were under disability social care due to our daughters outbursts in behaviours which could be quite dangerous. After a couple of months we were passed onto another social worker who never contacted us and our case was closed as we weren't bad enough. I then called and asked for help 2 years later when her outbursts became worse and more aggressive, and we had our third child on the way so we were concerned about her hurting the new baby as well as her little sister. After a relatively short phone call with someone from the team, she said 'you're doing most things right, I don't know what to suggest or how we can support you more so we won't be taking you on for support'. We were and still are disgusted.

On waiting list still have had no support, struggling as a family but no one cares

Unable to get any social care support.

Social worker very good and listens. Helpful, but so much red tape

Not eligible for restbite care, despite my son being in a 2 to 1 residential setting for a year he came home with no support

We didn't get any offer of help with transition to my now 19 year old.Last year I rang homeless support team as he wasn't safe living with us and was told as he doesn't have a social worker they would leave him on the streeet

My daughter lives in Peterborough, PE4 even though I have now moved. Supported living provides independence for us both but the standard of care should be higher especially with a healthy diet, exercise and social activities outside regular daycare.

Disability funding- took 7 months from making the application to actually receiving the funding.

Tried to get respite but they made it difficult. Wasn't allowed to use how would benefit us it was how they wanted or not at all so gave up with it.

Good care

We weren't offered anything from children's social care. My doctor put in a referral and when I spoke to them they said my children are too young. So we are on our own.

Table 7: Views on Social care

Other views gathered from seldom heard communities specifically in relation to PfA are shown below:

Tell us about your understanding and experience of Education.	Tell us about your understanding and experience of Employment and Getting a Job	Tell us about your understanding and experience of Health.	Tell us about your understanding and experience of Friends/ Relationships/ Communities	Tell us about your understanding and experience of Independent Living
My daughter 16yrs old . Has recently had dyslexia screening, she is struggling a lot in studies but still determined to study further for her future career. She has possible ADHD . She has not any educational plan settings for her yet.	She has no job experience but she is looking for part time volunteering.	Health experience is terrible at the moment. Doctors are not helpful.no	Friendship she is so important	
My child has ehcp and is on the track to archive the outcomes	I don't have experience with that yet but as far as I know my child want to continue education after his GCSEs	We haven't get any experience about health check yet for him	It's good to have network support.	He will be living with us at the moment . He is still young and law can change and support can change after few years so than we will be thinking when the time is right
Was to poorly to attend	No completely disable		Very good	No experience
My child don't have EHCP plan I have applied but it got rejected so now school is applying one	My goes to school		Good	No yet
We have had no information of what PFA is and what the Post 16 learning provision is. I would have thought authorities, Gp's or even the schools would at least let parents know when their child is about to reach PFA age and the parent/carer can start looking into options but parents are just left in the lurch. The 5 day offer is very misleading as just reading it parents have the impression that the child or young person will have a provision or education that covers 5 days a week. The title is very misleading and needs looking into	One of the toughest tasks we have had to face so far. Not much information about what is available with regards to support into employment	Gp's seem as if they are basically non existent so we haven't bothered much as everytime you want an appointment there isn't any. I have heard of the annual health checks but not from my Gp but through my own research Never been told about adult health services All that I know about my young adult I have researched myself. It would be very helpful to parents if LA or schools can run PFA sessions for parents when	My young person has never had/made friends. I don't think she knows any different anyway but if she had the opportunity to get support to know how to make friends that would help	I am quite scared about this topic as I have heard horror stories with adult social care charging for services that they are not providing especially in cases whereby there is little or no mental capacity and the young adult doesn't quite understand what is been explained to them. With the cost of having to apply for Deputyship, PA or LPA, some parent carers cannot afford it and thereby this results in the young person making decisions they fully do not understand or have no mental

		their child is about to start transitioning to adulthood.		capacity to deal with
He has EHCP but I feel there is not enough provision here in pboro	He does not have understanding or capability if this	Have heard but no one spoken to me about them	Not a lot	

Table 8: Views of PfA from seldom heard parent carers

Carers Support

This section has some addition, in relation to Parent Carer resilience as was as how parent carers are viewed and view themselves in relation to their caring role. There is a system wide tendency to see the parent in their parenting role as opposed to recognizing what they do as a carer over and above parenting. At times parents themselves do not realize they are caring as well as parenting. Fig.41 below demonstrates this and it is worth noting that for 23/24 18% of respondents did not view themselves as a carer. Further to this in 23/24 52% of respondents report not being in receipt of Carers Allowance.

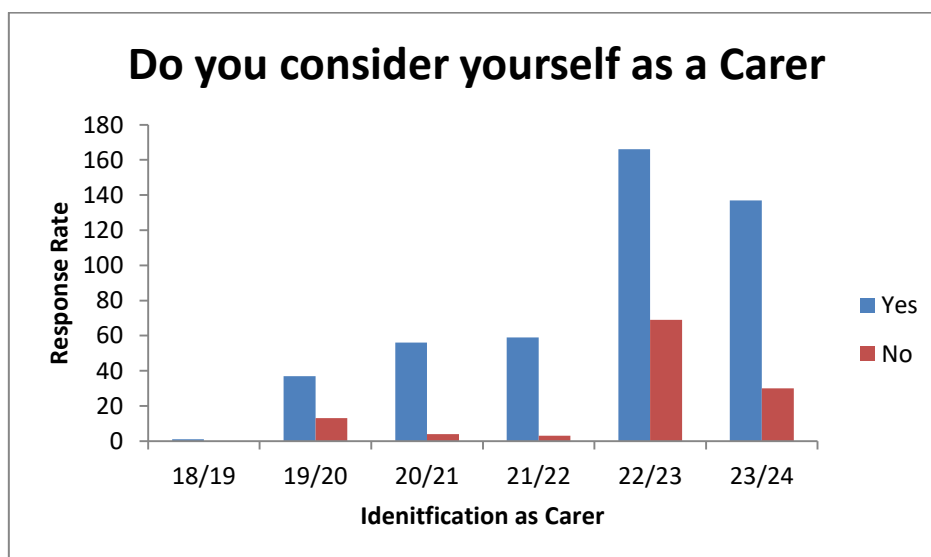


Fig. 43 Self Recognition as a Parent Carer

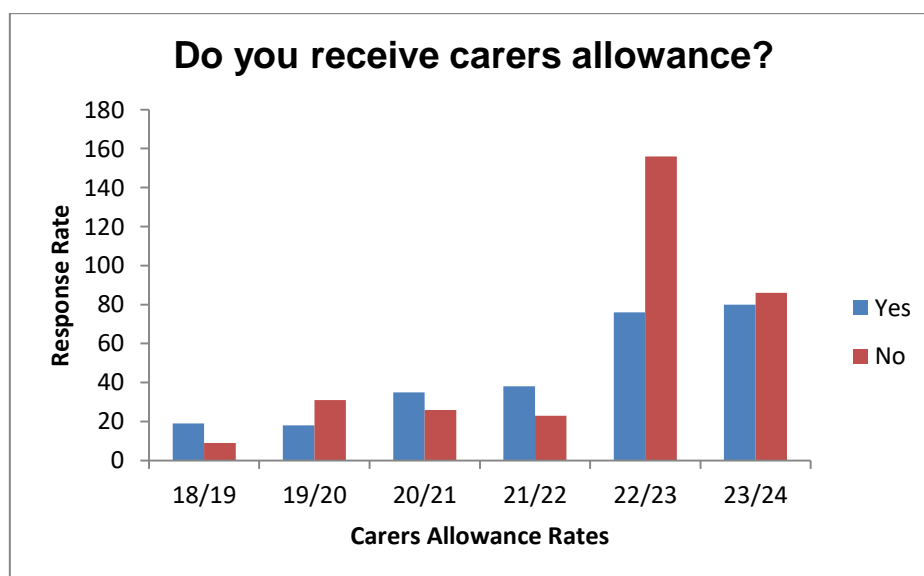


Fig. 44 Receipt of Carers Allowance

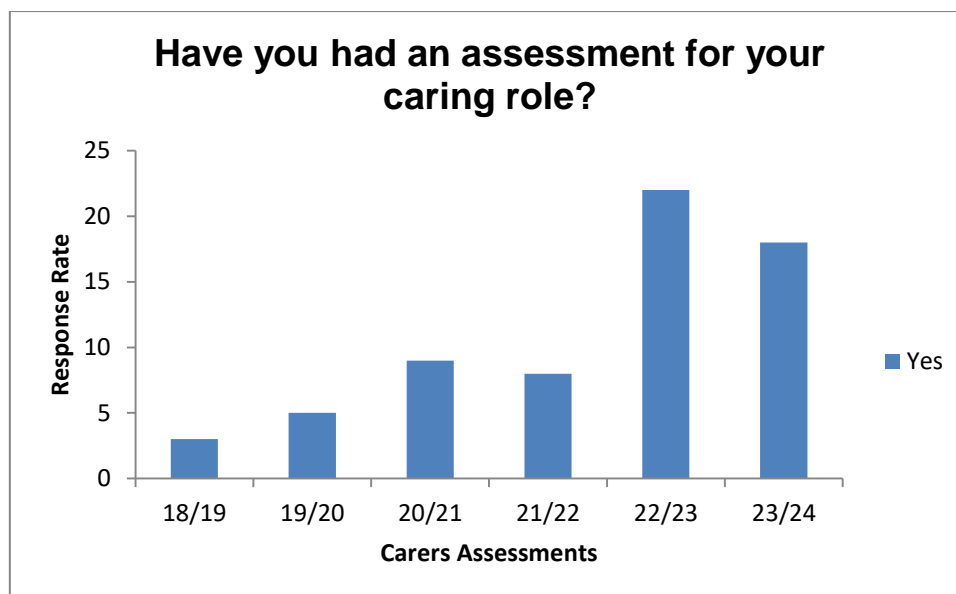


Fig. 45 Carers Assessments

From Fig. 43 it can also be seen that numbers of those reporting that they have not had a carers assessment has decreased between 22/23 and 23/24. This may point towards a concern 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. 44 to 46 more respondents stated yes as opposed to no.

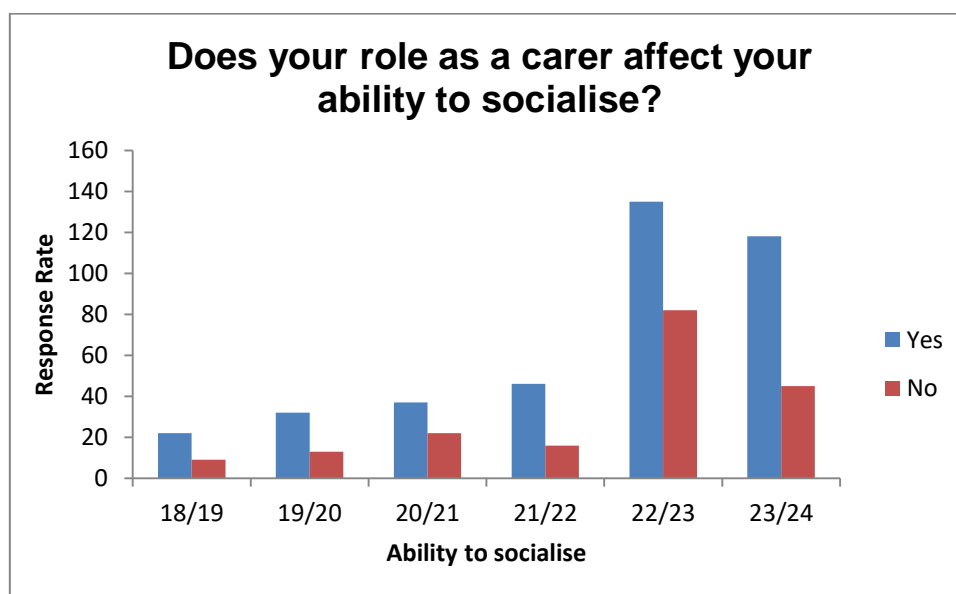


Fig. 46 Impact on socializing

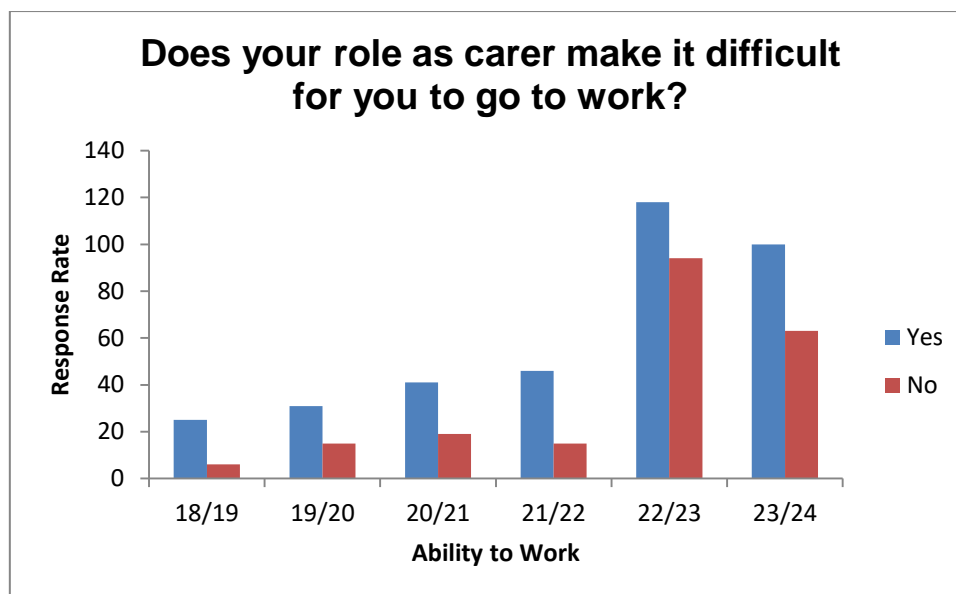


Fig. 47 Impact on work

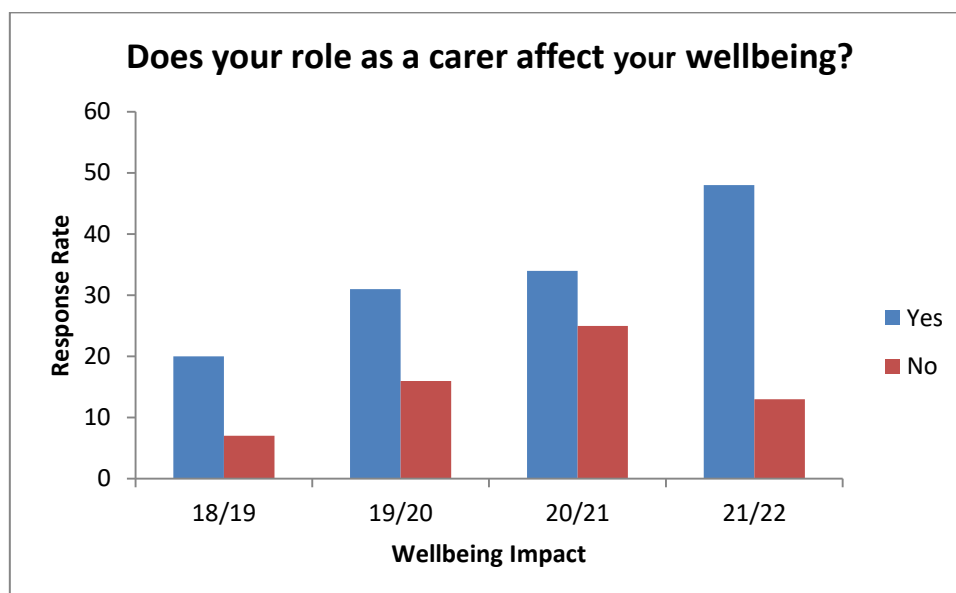


Fig. 48 Impact on wellbeing

Across all the questions relating to impact of being a carer all respondents reported as a Conversely to drop in numbers being recognized or recognizing themselves as carers there was an overall percentage increase between 22/23 and 23/24 of respondents reporting that caring was impacting a number of areas of their lives.

Percentage of respondents who feel caring impacts their lives		
	22/23	23/24
Socialise	62%	72%
Work	56%	61%
Wellbeing	61%	67%

Table 9: Percentage of respondents who feel caring has an impact

Throughout 23/24 FVP have also been gathering other commentary, survey responses and sign posting contact from parent carers all of which point towards a marked decrease in wellbeing and resilience.

Carers Support Survey

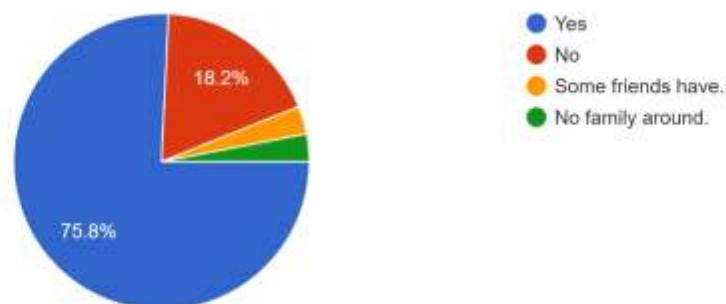
Our survey 'Carer Support' had 33 responses; majority of respondents stated that their child had a neurodivergent diagnosis with autism spectrum disorder being the most common condition. Themes identified from parent contact with the charity highlights accommodation, food poverty and social issues, such as poor housing conditions, relationships difficulties and risk of homelessness.

The issues raised were:

Future planning and worry.

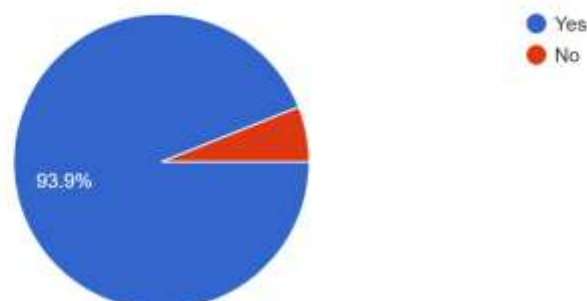
Since realizing your child/ young person has needs have you noticed changes in how family and friends treat you and your family?

33 responses



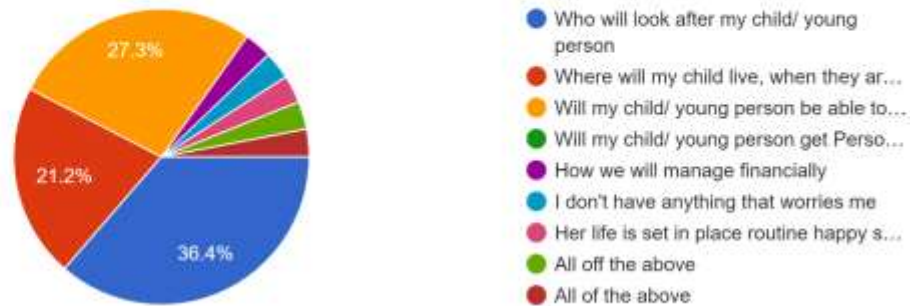
Do you worry about the future?

33 responses



What is it that worries you the most about the future?

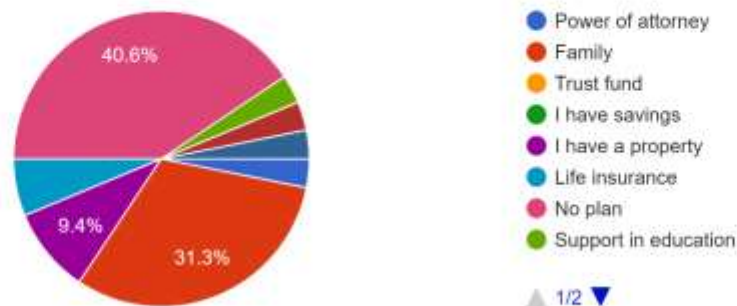
33 responses



Majority of the respondents stated that they had no real plans for the future.

What measures have you put in place to reduce this worry

32 responses

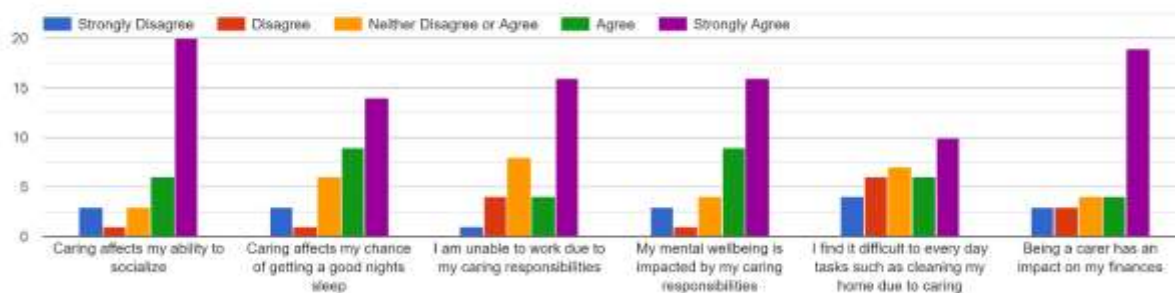


The psychological impact of parent caring on parental mental health is significant, respondents stated that their day to day parenting has caused isolation, stress, worry and anxiety.

- *"I worry a lot more, I am exhausted from needing to work to pay for his needs and activities and of course household bills, I don't sleep very well, I am less patient than I used to be, I no longer have any energy to do anything, everything from housework or taking my child out is like a chore. I also don't have time for my next older child, he has exam pressure and stress and spoke about not wanting to live recently due to school bullying, feeling a failure - so have been more tearful recently whilst I try to make more time for my older son."*
- *isolating*
- *all focus on SEND child and supporting their development*
- *Everyday life, holidays, where we can go and meltdowns, not wanting to go to school*

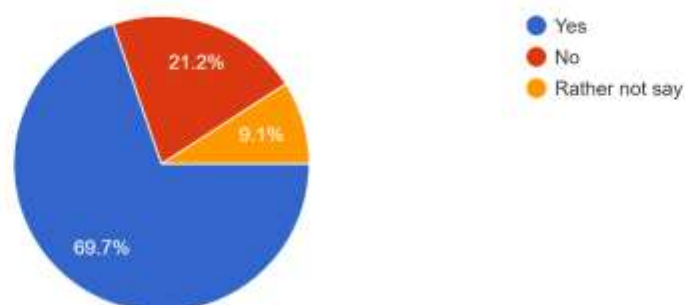
- *Well being not been able to work for 18 years and isolation, challenging but empowering at same time*
- *Stressing,*
- *Sometimes I feel lonely*
- *Makes me think about things differently*
- *I worry a lot more, I am exhausted from needing to work to pay for his needs and activities and of course household bills, I don't sleep very well, I am less patient than I used to be, I no longer have any energy to do anything, everything from housework or taking my child out is like a chore. I also don't have time for my next older child, he has exam pressure and stress and spoke about not wanting to live recently due to school bullying, feeling a failure - so have been more tearful recently whilst I try to make more time for my older son.*
- *Socially isolated exhausted mentally drained*
- *Depression, anxiety, feelings of isolation, left out, no life other than my sons needs*
- *Worried sad who will look after them*
- *Stress, ill health, worrying all the time and tired all the time*
- *Main thing is the worries for their future who will look after them if I die.*
- *I too have physical and mental health issues*
- *Mentally Physically exhausted*
- *It is exhausting and leaves little time for me to have to myself and withy other children.*
- *Extra stress, work issues, lack of support from family/friends*
- *Effects a lot*
- *I dont have alot of free time i have to do all her banking and checking of everything but its manageable*
- *Hits hard, you feel alone and feel that you are always judged*
- *Does not get time to myself*
- *It's a struggle and not much support*
- *Profoundly disadvantages me. Socially, economically, health wise...*
- *I don't have any childcare support around me. The childcare on offer is non existent for send children. What is on offer is unsuitable. Sorting childcare stresses me out when I am working. Carers allowance is a pittance. It means I can't have the career I want. Employer expectations do not consider caring for send children. The lack of support in general we get impacts us all. My 10 year old without needs suffers mentally. My 19 year old can't look after herself, there is nothing out there that helps her to achieve independence for young people who are reasonably intelligent. It is assumed intelligence and independence are linked when they are not. My 5 year old had to wait a year before getting an OT appointment which meant I had to give up my job to be able to support him.*
- *It affects every element of life. I cannot work. Emotionally and physically, it is very difficult. We have spent a lot building an annex to move my parents in for extra support*

Please read the following statements and rate how being carers affect you.



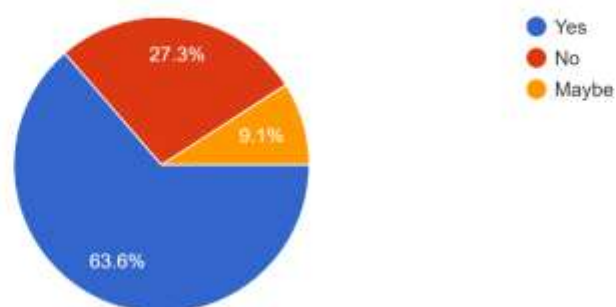
Have you experienced financial difficulties in the past 3 months?

33 responses



Are you aware of any other parent carers in you community?

33 responses



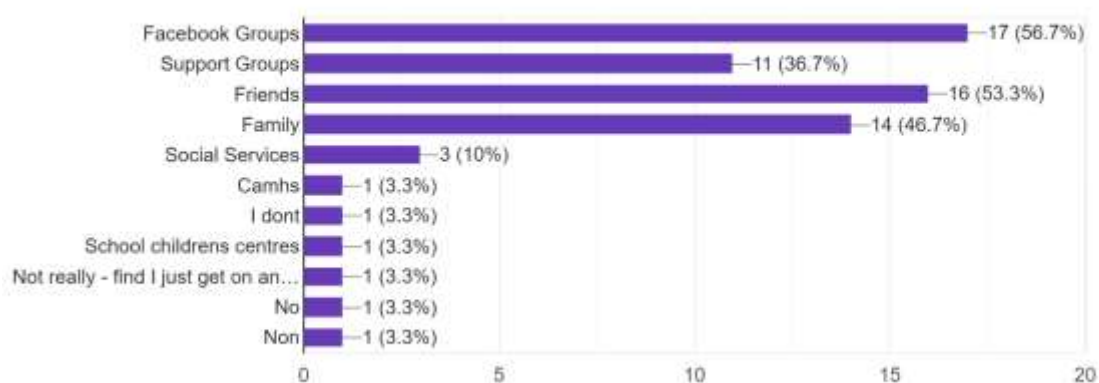
What additional support do you as a parent carer believe you may require?

- None
- help with understanding my sons needs
- More clubs for special needs
- Adulthood prepare

- *Friend circle ,community circle*
- *For my additional needs son to have somewhere to go, so I can have some rest and space to be with my older son.*
- *social events*
- *A break or some respite to allow my other children quality time*
- *Gave up asking.*
- *Help with legal aid information my rights*
- *Activity*
- *Clear Guidance as to what help is available*
- *A listening ear someone who can just listen to my worries.*
- *Hone calls papers benefits help I'm only one person*
- *Social*
- *A break so i can rest and regroup mentally*
- *Help outside of family, play groups etc where he can stay on his own.*
- *More money, better childcare, better support for my child.*
- *Just the usual friends with children who understand*
- *Get help go on holiday with the children and trips*
- *Unsure*
- *Support groups in Louth Lincolnshire*
- *Social support and financial*
- *Financial support; carer's allowance is means tested and at an appallingly low rate.*
- *Education*
- *Specialised childcare. Better benefits. Job flexibility.*
- *Better financial support. Holiday care for my disabled child and social groups for both myself as a carer and my son as a young carer*

Do use any of the following to access support currently?

30 responses



Overall, the survey results confirm that parent carer resilience is affected by the demands of caring for SEND children. Caring for a CYP with SEND and any associated demands on the parent have an impact on mental health, financial security, and social support. This includes employment and social interactions.

Although majority of the respondents reported that they have contact with other parents and that they use online social media to engage with other people they also reported that the

impact on their mental health is significant, particularly worry and anxiety regarding future planning.

The number of parents contacting the charity highlighting issues with accommodation, food poverty and isolation suggests that Parent carer resilience is compromised. Parent carer suggestions are in line with factors required for individuals to develop emotional resilience.

Limitations

The number of participants is small however the findings provide an overview or a snapshot of factors which effect parent carer resilience.

The information gathered can be used to develop targeted sessions for parents to develop a better understanding of how parent carer role is interlinked with parent carer burnout and therefore sessions can be used to help prevent carer burnout.

State of SEND – Parent Carer Perspective

As part of the annual survey presented to the local SEND community two questions enable the respondents to give fuller open answers as to how they are or have experienced SEND across Peterborough from Education through to Health. The responses have been overwhelming 'negative' with a number of themes cropping up that relate to lengthy waiting times, having a struggle accessing support, feeling anxious and at times overwhelmed, a sense of being 'blamed' and constantly 'fighting' for any support.

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
Everything is slow, always a fight and never enough information. People always leaving roles doesn't help.
Although I am not a carer, it's very difficult mentally to work full time and support a child with SEN because of finances and time it's mentally draining
<i>They helped me get my son into a mainstream school</i>
Involve the parents more and listen to what they have to say
As above. A parents SEMH, becomes a strain, when having to constantly fight for our children. Constant big/long paperwork to fill out.
there is not enough money to go round. not enough provision/ thought is given to out of school hours care for medically complex children eg no holiday club, after school club etc.
Care is given to one and not another as in not evenly distributed. I am continually astounded that social services especially dont think parents talk ti each other so wont know what is available. Had our sons 4 th EHCP and it was first time sw bothered to turn up.
The three services PCC provides are all awful!
Very poor, boring choice of services
Have struggled a lot with continence , fighting for pads as the have a limit per day, child is 16 Years old & still fighting for DFG - the family & hiw they live @ what us not going to make their life difficult us never listened to. The professionals ALWAYS know best. They are not living this life I feel things NEED to change where parents views need to be considered - THEY R THE ONES HAVING TO JUGGLE THEIR LIVES, with jobs, extra bills due to equipment etc m, extra expenses bcos of limit of continence products provided . No DFG - councils way or no way!!
<i>Been a positive experience</i>

I think the whole system needs looking at especially when they reach 18 you are left on your own to do everything no support or advice what so ever and the gps have no clue
Very long waiting
I don't know if this applies but I do feel strongly that a special needs school should hire teachers trained in special needs and not fresh out of teacher training for mainstream schools. My child's experience has been awful for special school education, partly due to this problem. Finalise my EHC plan and support people who are lone parents with zero support around them to get their child into the right setting. It's exhausting. I don't have enough hours in the day to sort it all, educate, chase adults about trying to get his EHC plan done. Therapy my child and do all the basic parenting stuff too. I get zero breaks. I am up most of the time until 3am and then woken up anytime from 5am. I feel everything is designed to make you give up asking for help. I don't get peterborough. My child gets zero funding yet I am expected to meet the requirements in his EHC plan. Yet a school gets funding. It isn't right. Information needs to be accessible and not just available online as not everyone can use the internet. Home education needs more support. People just feel abandoned. Access to useful resources that will support SEN children would be good.
I had to give up my job because my son isn't in school.
For us to have an appointment regularly with sen services or even on diagnosis to look at child's needs and what support entitled to. I have never had this. I don't really know if we have all support we should have
As above, please please please when parents show concerns please make the process much more quicker. Waiting lists are far too long.
We were repeatedly encouraged by the school to get an autism diagnosis as this was 'the best way to get an EHCP' despite our sons highest needs obviously being social mental and emotional conditions and disabilities, along with physical disadvantages and the autistic traits being less life impacting.
I am just disgusted with the time it is taking it not only affects my child but myself as well, I have been fighting for 9 years for my child
The LA never stick to the EHCP time frame always have to chase them.
Listen to the parents more allow parents to assist
I would have moved if it didn't affect other family members
Carers have no help or support in dealing or learning their children needs
There is no after school provision or wrap around care which affects my work and my ability to progress / choose a career I want. Restricted hours provided by Sen schools means parents/ carers get even less support than their mainstream counterparts.
More support needs to be given to parents of children with sen
The school have been good from the start. I can't fault them
Support for parents and children. We had an OT assessment and they provide support for a couple of weeks then discharge. I know nothing about sensory needs so I have had to do a lit of research. How is that considered support?
Like banging my head against a brick wall when it comes to education
My son has high needs due to autism he struggles to be in social situation and we have to leave he is easily triggered for.meltdown from smells crowds to change in routine
I'm not sure what the LA role is in SEN other than to help with the EHCP process.
My 11 year old is currently excluded still from before Christmas she is receiving no education
I remain actively involved in my daughter's care encouraging her carers to increase the quality of care. This has included making written complaints to PCC during the last 12 months. Particular concerns are diet, exercise and social engagement in evenings and weekends
Everything was excellent and the service and support was good
Hard and invasive.

Very good
Waiting lists are too long, additional funding needs to be provided to adequately resource services
Wait times are unreal. Mental health needs massive improvements and girls in particular, need to be supported more as masking plays a massive role in misdiagnoses'.
My experience with my son at school was diabolical regards to SEN. The education system failed him terribly.

Please use this space to tell us anything else regarding your experience with the SEND since the reforms started
I find I get more from charities who are specifically there for children or adults with Down Syndrome, they have so much more knowledge. I've lost trust in health professionals, which is a shame when my son is only 1 years old. They continue to let him down.
I am unclear what an Early Help assessment has achieved, as no more services have come on board due to 'waiting lists'.
I feel that a lot of the time it is left to us parents.
After diagnosis cahms just disappear. Have to find own support etc. Not sure what services you refer to in question 27
Our worse experience was 2018/2019 for annual EHCP review waited 11.5 months for revised plan with only 2 weeks to the next review, so that year nothing was implemented. Best experience securing Marshfields with no fight which was surprising.
I do not know about this Hub
the send team at the school are not encouraging him to work in lessons as they are not always there
It's been extremely difficult to get any information accepted
Same as above. Challenging, exhausting stressful, not listened to. Waiting times far to long
wheelchair services not fit for purpose.
NRS are very slow and for some reason couldnt possibly service all of your equipment on the same appointment (wasting my time and theirs and money)
Social OT needs to learn how to make appointments it is not fair to ask a child to have a whole day off school for a 15 min appt.
social services are rubbish
Not enough help and support in place for my daughter whom has mental health difficulties and eating disorders
For both my daughters it's been different, for one services have been fantastic for my other daughter has not been good at all
Communication barriers
SEND services are awful across social care, education and health. They all work together to ensure a child's needs are not met.
I have feel SEND have really deteriorated vastly & it sometimes is just a tuck box exercise - but not much is put in place for the child concerned
A long process to get the help your child needs
I rarely get replies. I haven't had support. I do not feel peterborough is a good place for families like myself. It is very isolating. I have been alone for over five years now. I don't feel listened to, I don't feel my son's development is important to anyone but myself. I don't feel part of any community and my son definitely doesn't feel apart of the community. That

breaks my heart. He should be able to access activities but due to transport we never get to go anywhere really. If I could move I would. But I feel stuck
The staff that we've been in contact with have all been brilliant. They've been thorough and keen to make sure that any diagnosis is correct. Being a girl made assessment more difficult, but the team made sure that they were able to see all aspects of her life and spent time in the playgroup setting to observe her in her usual environment. We know and trust in the diagnosis.
We have had very little support after our son's diagnosis of ASD. His needs are not significant, but we feel unequipped and uneducated about how to navigate the education system and how best to support him. We were invited to a parenting course after diagnosis, but by then he was too old for us to attend.
We have had good service and support, when we've had issues we've had the support to find solutions and resolve. I worry more for the future with things like accessing support in University what to expect when leaving the service etc.
My son who now has full time 1:1 funding refused assessment. Disgusted by the LA who hadn't read his information properly. Caused much unnecessary distress, during Covid. Overturned day before mediation meeting. EHCPs never within time frames, despite school fulfilling legal obligations regarding timings. Still waiting for new EHCP from review done in July 2023. This is much shorter than it has been previously.
My daughter was diagnosed deaf at 5 years old in 2017, initially unilateral mild now bilateral moderate severe, getting support from sensory support initially was a battle, we were then told as unilateral no teacher of the deaf, with more loss in hearing in second ear there was a battle to get teacher of the deaf support back. We had an mri but no appointment to explain properly the results. ENT have advised we need to see senior consultant each time but when we go we are giving a junior doctor who then doesn't understand the condition and last time the consultant was rude about us having an appointment with a junior doctor. Last appointment 14 months ago said review in 6 months.
If I hadn't been parent rep on CHSWG for a few years I would have no clue about anything. I am an educated parent, active member of Peterborough and district deaf children's society and I find getting provisions a battle particularly as my daughters hearing loss is progressive. New secondary school is supportive, they have given us ehcp form and now have to complete those.
Exhausting, stressful, not listened to. I know there's lack of funding. But SEN children need the right support as a matter of urgency. Trust my when I say, the longer left and not heard the child is suffering with everyday environments, especially school. Causing further mental health problems on top of whatever else is going on for them.
Everything feels like a challenge and the child suffers while adults defend themselves and don't work in partnership.
As a parent you have to fight for everything your child deserves. No one offers help or support until you are on your knees or the child has a problem at school. They should be offered support before this happens. EhCP are not followed by the school and the LA do not help.
I applied for an EHCP for my older daughter in 2018 and secured one. It is difficult and support is not easy for those not in education
It's been a long and painful journey haven't to point out everything that your child finds hard and having to put your child down or show their worst moments and long waiting lists to the school are underfunded and do amazing but it's not fair on the parents and teachers we fight for the rights to a education and a happy one but the councils just see it a burden very disappointing
Have been fighting to be heard, have contacted numerous members, caused stress on me and my family, have left my job but still a battle
Absolutely appalling through mainstream

The system is failing special needs children and their families
It would be good for a simple step by step guide of what to expect, how and where to get support, options available etc.
It is very challenging to navigate where to get help and support at times. When things get tricky again it's hard to get help.
No follow up of addh assessment after inconclusive result. Asd diagnosed after adhd assessment.
No recognition for pda diagnosis
Everything is a battle. Regardless at how known and clear your child's needs are.
A lot of my time is spent fighting the system for the support my child is entitled to and being anxious and stressed regarding how the school actively avoid following the EHCP.
More information on local clubs and groups would be good.
I feel the schools need to help more with diagnosis, my son had help in primary, ehp plans and when he then went to secondary school they just put it to one side.
The whole service is getting worse year on year with too many parent carers having to go to court and hire experts to fight, to get what their children need and are legally entitled to. Especially for 19-25
I found that any it was ignored by the SEN service when any criticism or complaint was made toward our son's school and the lack of help with his dyslexia. It came across as very 'old boys network' and everything was smoothed over or ignored despite many subject teachers not aparently knowing of my son's dyslexia and therefore not supporting him in class. There needs to be accountability but there is not.
Send services are alot more difficult to use now there just not enough support for families and children and we all suffer a d our children are being let down
It's been terrible for my 11 year old but easier for my older child who was diagnosed at a younger age
Our issues never even got to SEND services . It rarely went beyond the sendco I had to push for strategies to be trickled down to class teachers. And they are the staff that are issuing sanctions for behaviour they do not understand which leads to further sanctions and negative experience of education.
More training and awareness for teachers needed in all areas of SEN .
Special school (phoenix) and City College were supportive of my daughter until 2019 and 2023 respectively. Respite care vital. Peterborough College said they could support my daughter then decided at short notice that they could not. My daughter now lives in supported living in Peterborough. Care is adequate but diet remains quite limited and carers struggle to encourage engagement in social activities in down time ie evenings and weekends. I still need to push in both of these areas.
All services need to do a better job of working together to meet the needs of the child
The website is not user friendly

Julaybib Group

The following has kindly been provided by The Julaybib Group to detail the themes they are hearing from seldom heard parents locally:

- Schools postponing or/and not recognising that the child needs assessment. Not believing to the parent if the child behaves well and/or academically performing well. There were also cases where child had to fell behind academically in order school started to notice parents concerns.

- long waits for assessment and apparently according to Karen Chopping the parenting course was cancelled a year ago but SENCO's were not aware of that.
- Long waiting lists for speech therapy and occupational therapy for children resulting them being falling behind academically and socially
- Disability social workers are not being helpful especially for older children
- Schools are not following ehcps and not providing 1to1 for children who desperately needs it due to not enough funding or other resources
- No support for parent after diagnosis of autism/adhd or parents are not aware there's some support available
- Home occupational therapist are not taking into account family's need when providing home conversions for disabled children resulting families to fund themselves
- Wheelchair services are absolutely disgraceful. Every single family who had to use them has a complaint about them.
- Potential racism during the assessment process

".....I can safely say that unfortunately there is no actual help or support available to parents of SEND kids in Peterborough."

".....SENDias that they are just LA's tick box and very much in favour of schools rather than parent"

Data on Themes

Further work was conducted to sense check the themes coming through from the annual survey. The themes were put into a Facebook Poll and parents carers had the opportunity to vote on which ones mattered to them most. The poll had a reach of 130, and the votes were:

1. Parental blame – 5%
2. Lack of support – 9%
3. Lack of involvement in decision making, support planning and areas of EHCp outcome monitoring. – 9%
4. Difficulty in finding Information – 15%
5. Lengthy waiting times – 36%
6. Preparing for Adulthood – 8%
7. Not being offered therapies after diagnosis (Parental choice on FB only) – 18%

General Conclusions

Parent Carers are experiencing a system that is 'creaking under the strain' and have a sense that they are not valued by the SEND System. There is a lack of resources, funding and capacity to match an increasing need for assessment, support and services from families with often far more complex needs than is realized. This is demonstrated by the commentary from parent carers within this report and reporting by the parent rep team from their contact with services and settings. FVP reps are hearing from a number of different sources that the concerns from parent carers mentioned in this report are being mirrored by other services and organizations. FVP are also struggling to meet the need for sign posting support from parent carers and are exploring ways to manage capacity.

From all the data reviewed most of which has been presented in the full report there are a number of broad themes coming through:

7. Parental blame – for example being seen as a burden, drain on resources, negative and part of the problem, being made to do parenting courses that are not appropriate to SEND, parenting courses make parents feel they are at fault.
8. Lack of support –managing benefit changes, applying for an EHCNA, mental health management to name a few.
9. Lack of involvement in decision making, support planning and areas of EHCp outcome monitoring.
10. Difficulty in finding Information – you don't know, what you don't know!
11. Lengthy waiting times - Waiting too long for access to assessments and access to therapies and other forms of support once assessed.
12. Preparing for Adulthood – Not knowing what entitlement may be for access to services, having to self-refer to the 0-25 team, lack of access to transitions officers, impact of benefit changes, '5' day offer and other matters.

Way Forwards

FVP feel very strongly that the level of concern being raised by parent carers in the annual survey reported on here, through other groups and organisations such as The Julaybib Group and through the lived experience of parent carers speaking to FVP through sign posting at trips, activities and schools sessions need to be heard by Health and LA partners. Many of the issues raised are also being experienced on a daily basis by FVP's workforce, who often reports that services need to not just listen but hear what is being said. FVP would ask that the following recommendations be taken under consideration:

- SEND Communication be considered as a priority for strategic leaders, with a refocus on the SEND Strategy and Action Plan.
- key support initiatives be delivered by the LA/ Health
 - Face to Face befriending (Peer to peer support)
 - Benefits Advice and Support (DLA to PIP)
 - Independent Support (EHCp process)
 - SEND Navigators (support) to find information to help parent carers
 - Development of a resource for new SEND households (Welcome to Your SEND Journey)
- Ongoing opportunities for parent carers to shared their lived experiences directly strategic leaders
- A group to be set up for various group leaders to work with FVP to bring forward the lived experience of the SEND community
- Look at how third sector groups, and front line SEND charities can be funded or supported to gain funding to work directly in providing parent carers with support.

Other Reports

<https://familyvoice.org/toireports/>

<https://familyvoice.org/surveyreports/>

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