
2022/2023 Annual Survey Report

Family Voice
Peterborough

Feb 2023

Introduction

Family Voice Peterborough (FVP) conduct an overarching survey annually looking at parent carer experiences of Special Educational Needs and Disability (SEND) services across Education, Health and Social Care within Peterborough Local Authority area. The 2022/2023 survey is intended to be a benchmark from which Peterborough can measure the efficacy of its Written Statement of Action created following Ofsted and CQC's joint SEND inspection of 2019. Parent Carers were asked to respond to a total of 44 questions, the responses to which are analysed below.

Population

The survey was completed by 244 parent carers, all of whom are Peterborough residents who care for a child or young person with SEND. Parent Carers are asked to give information on their children/young people, including their gender, age, ethnicity and area of need.

Sex/ Gender

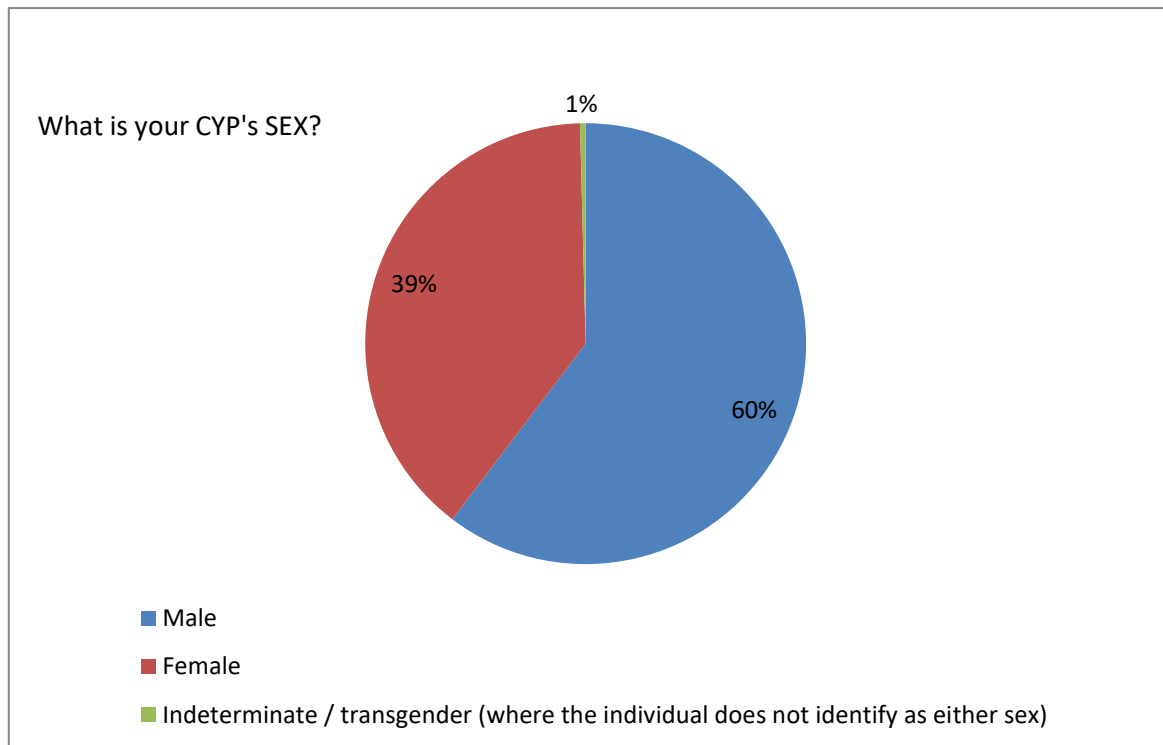


Fig. 1 Gender of Children/Young People Represented within survey responses

Age

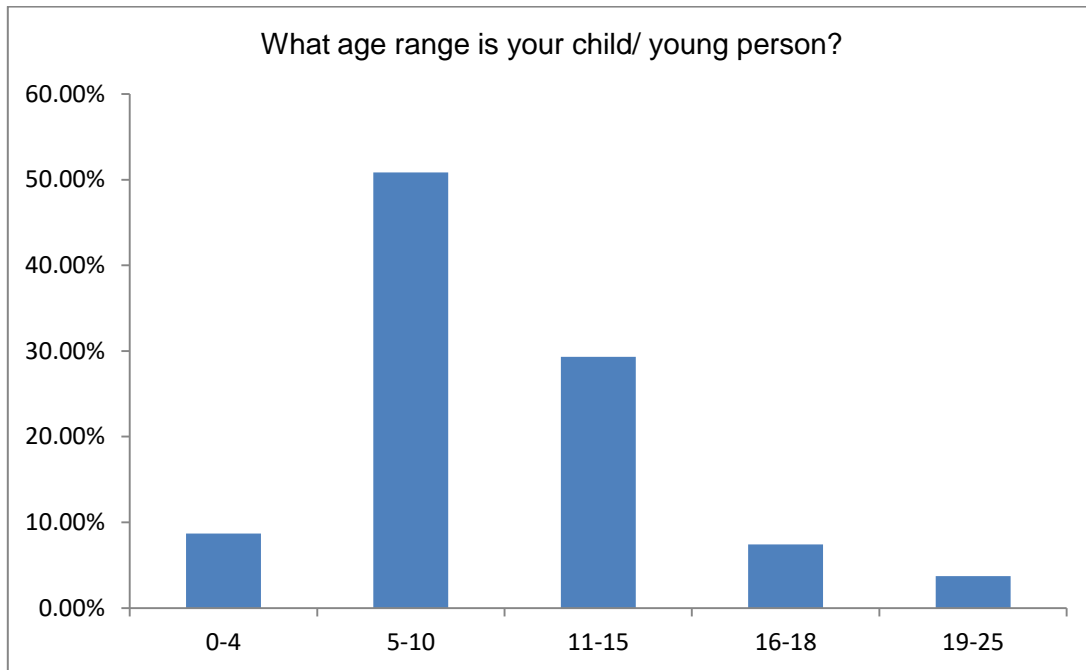


Fig. 2 Ages of children/young people represented within the survey

Ethnicity

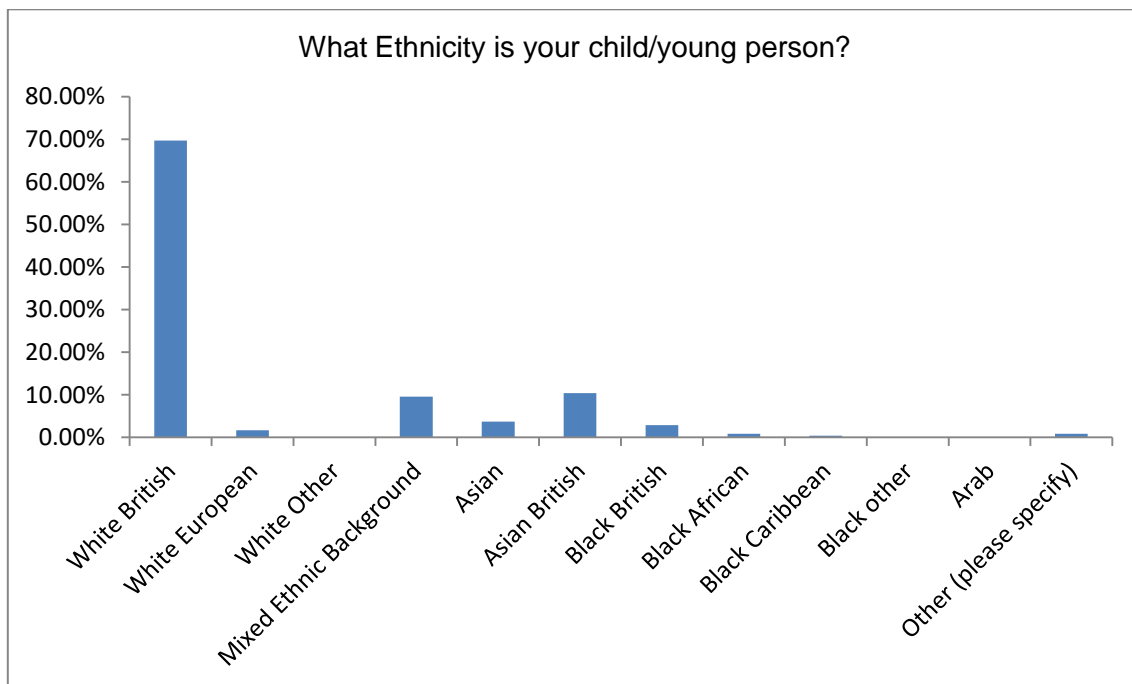


Fig. 3 Ethnicity of Children/Young People represented within the survey

As displayed above, children and young people represented within the survey responses come from a mix of genders and age ranges – the most common age range being 5-10 years. 69.71% of children and young people represented come from a White British ethnic background, while this figure seems high, census figures from the 2021 census show that 59.5% of the population across Peterborough come from a White British ethnic background, and as such 30% of survey respondents originating from an alternate ethnic heritage

highlights the success of outreach work completed by FVP in targeting and engaging Seldom Heard Communities.

Needs

Answer Choices	Responses
Speech and language impairment	79
Sensory processing disorder	67
Severe learning difficulties	26
Autistic Spectrum Disorder	111
Attention Deficit Hyperactivity Disorder/ Attention Deficit Disorder	45
Specific learning difficulty e.g. dyslexia, dyspraxia, dyscalculia, dysgraphia	51
Emotional / mental health needs	63
Global development delay	36
Hearing impairment	10
Visual impairment	9
Medical needs / complex health needs	14
Physical disability	17
Moderate learning difficulties	30
On the Early Help Pathway	19
My child/ young person's needs have not been identified yet	19
I do not know what my child/ young person's needs have been identified as	8
Other (please specify)	26
TOTAL	243

Fig. 4 Areas of Need of Children/young people represented within the survey

Parents were asked to declare their child/young person's area of need. These responses are displayed above; the "Other" responses were a combination of:

- FASD
- Downs Syndrome
- Visual perception
- Deletion syndrome /Di George's Tourette's
- Mixed depressive and anxiety disorders
- Chromosome Deletion
- Seizure/absent type episodes
- Anxiety
- Scoliosis
- Expressive language difficulties,
- Significant early years trauma
- ARFID

Autism Spectrum Disorder remains the predominant area of need amongst children and young people represented however there are also a large proportion of those with emotional and mental health needs as well as sensory processing disorders. Also

represented are varying levels of learning disabilities, in addition to sensory impairments and physical disabilities.

Educational Status

Answer Choices	Responses
Nursery/ Pre-school	11
Mainstream Primary	112
Mainstream Secondary	43
Special School	38
Pupil Referral Unit	0
Independent Special School	0
Home Educated	3
Out of County Placement	0
Academy Primary	5
Academy Secondary	8
Academy Special School	1
Out of School	0
Further Education/ Post 16 Institution	12
Finished Education	2
Other	8
Total	243

Fig. 5 Types of Educational Setting attended by children/young people represented

The Majority of children and young people represented attend a mainstream Primary or Secondary school within Peterborough, with 39 children/young people attending a specialist setting. This is in contrast to previous years, where the majority of respondents had children in specialist schools.

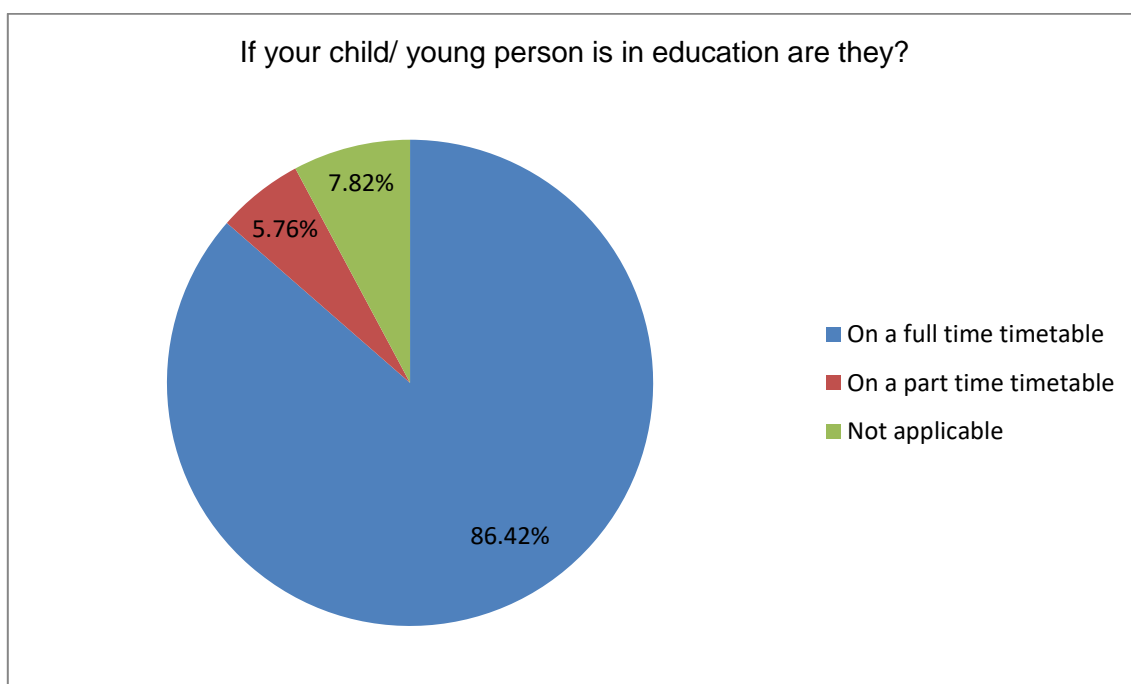


Fig. 6 Educational status of children and young people represented

Identification of Needs

Early identification of need and involvement in the process on an individual basis are key to improving the parent carer experience of SEND across Peterborough. This was also acknowledged in the Cambridgeshire and Peterborough SEND strategy 2019 – 2024.

The strategy has a focus on ensuring that “SEND is everybody’s business and not just the concern of the few.” The SEND strategy has three main priority areas, one of these being: “Identify and respond to needs early – a holistic and joined up early identification of, and graduated response to needs.” The strategy was co-produced by a range of professionals across Education, Health and Social Care as well as parent carers and children and young people with SEND.

Early Help

Parent carers were initially asked about their experiences with the Early Help Pathway.

Answer Choices	Responses
I attended a positive parenting course yet my child was refused a referral for ASD/ADHD diagnosis	7
My Child/ Young Person has been referred to CAMHs and I been asked to take a positive parenting course before they will be seen.	13
I was referred for an Early help Assessment even though my child/ young person already has a diagnosis of ASD/ ADHD	4
I have been asked to attend a positive parent course even though my child/ young person has a diagnosis of ASD/ ADHD	5
I have already attended a positive parenting course but I have been asked to attend another one	5
I have not heard of the Early Help Pathway	30
I have been asked to attend a positive parenting course as part of my Early Help Assessment	13
I attended a positive parenting course as part my Early Help Assessment	52
My Child/ young person was referred for an ASD/ ADHD after my Early Help Assessment	45
I have had a referral to CAMHs for my child/ young person turned down even though they have a diagnosis of ASD/ ADHD	2
I attended a positive parenting course and found it helpful	21
I attended a positive parenting course and it has not helped	25
I followed the early Help Pathway and my child/ young person now has a diagnosis of ASD/ ADHD	40
I have not attended a positive parenting course as this does not apply to me/ my family	21
I have had an Early Help Assessment	86
I do not know what the Early Help Pathway is	48
I would like to attend an Early Help Assessment but don't know what I need to do	7

Fig. 7 Respondent access to the Early Help Pathway

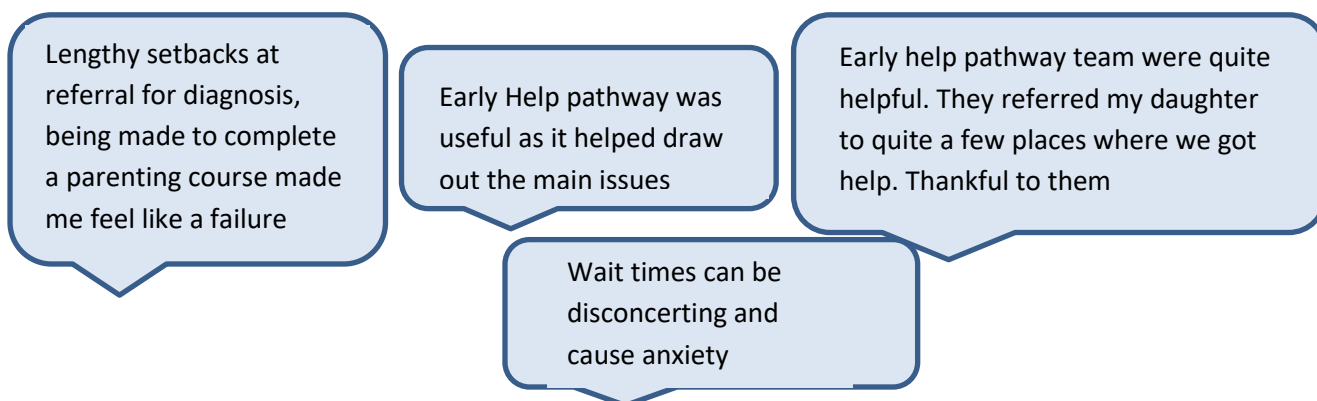


Fig. 8 Parental Feedback on the Early Help Pathway

Parents are reporting within the survey that there are long waiting times for support once on the Early Help Pathway and that there are practical issues with the delivery of support once an Early Help Assessment has been completed. Parents are telling FVP that in reality they often have to wait months, sometimes over a year to access the Parenting course, pushing the overall time to access a diagnosis as high as two years.

Working Well	Could Be Better
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	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.
Our daughter has been very well supported	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.
My son was put towards the Early Help Pathway in 2016. He 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.	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
We are currently going through this process now and the information collated on my child will be shared with a panel soon.	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 team was quite helpful. They referred my daughter to quite a few places where we got help. Thankful to them.	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
The early help pathway are very good. I have another child on the pathway. This time waiting lists are a lot longer.	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.
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	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
	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 don't think this is relevant for someone with mild dyslexia
	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.
	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.
	More needs to be done for mental health.
	I have took 2 triple p courses but it only early help at ***** school that have do anything yet.
	Early help was stopped at mainstream school, without my knowledge, we removed him from this school due to bullying and him being hospitalised
	Both children been put on the pathway.. both have appointments for CSA but that's all the help we've been given.
	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.
	It seems like a robust system but the wait times can be disconcerting and cause anxiety.
	Everything was perfect up until CAMH's 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.
	Had an assessment 3 months ago. Haven't heard anything at all moving forward.
	<p>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</p> <p>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.</p>

Fig. 9 Overall comments on experience of Early Help

Experience of identification

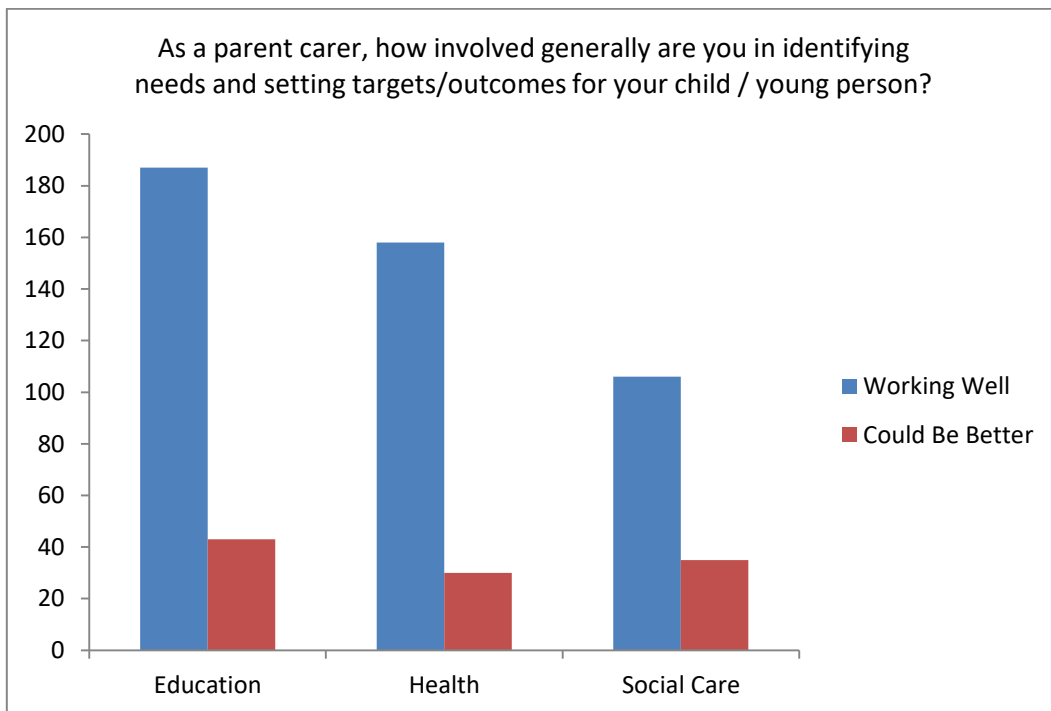


Fig. 10 Parental involvement in identifying needs and setting targets for their young people

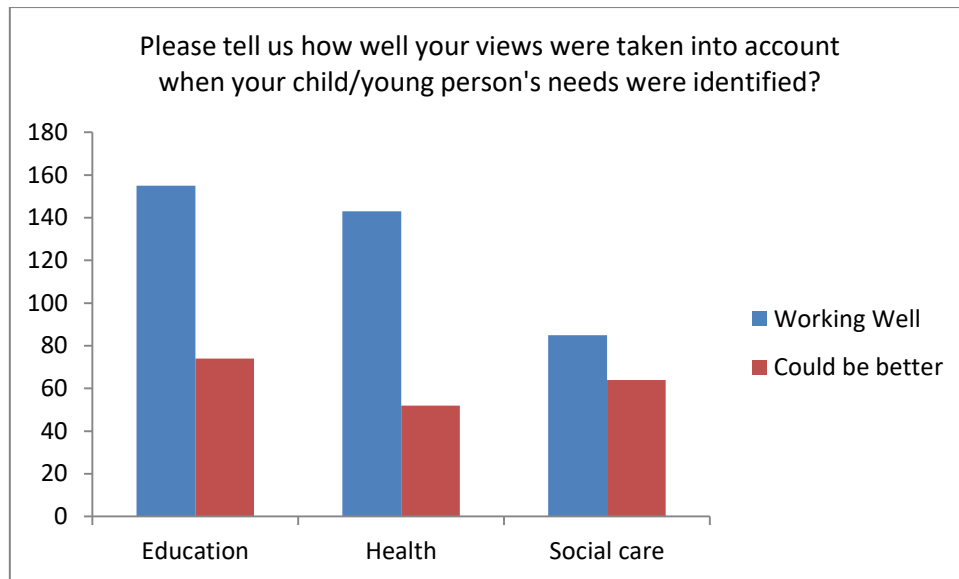


Fig. 11 Views accounted for during identification of needs

The 2015 SEN Code of Practice set out an increased emphasis on parent carer involvement in all areas relating to the identification and management of their child or young person's SEN. As we pass seven years post-SEND reforms one would expect that joint working and co-production would be well embedded into Peterborough's SEND system, and in general that data presented could be said to demonstrate improvements. In a continuance of previous annual survey data, Education is the area in which parent carers are reporting the most satisfaction with the way in which professionals seek their involvement in identifying needs and setting targets. This is potentially a result of Peterborough's ever growing SENCO Network:

*"The Peterborough **SENCO** Network is a network of the Special Educational Needs Co-ordinators (SENCOs) across the Peterborough area. The network exists to:*

- *Enable SENCOs and colleagues to support each other;*
- *Build better communication between early years settings, schools, colleges, the local authority and other professional services;*
- *Share good practice and solutions to common challenges.*

The SENCO network is led by a steering group with representatives from across the range of education settings in the Peterborough area, the Local Authority, and Family Voice Peterborough."

The SENCO Network is now in its seventh year of existence, with membership growing annually.

The area with the smallest difference between working well and not so well as displayed in the above graph is still Social Care, although the majority of responses said that this was not applicable to them/their families. There are fewer children with SEND accessing social care support or provision in relation to both education and health care. This is largely due to higher threshold to access the support, education and health care are more universal services. Parent carers also tell us that there is a remaining stigma around accessing social care support, with a general view that it is geared towards poor parenting, and young people in need as opposed to children with disabilities that require extra help and support

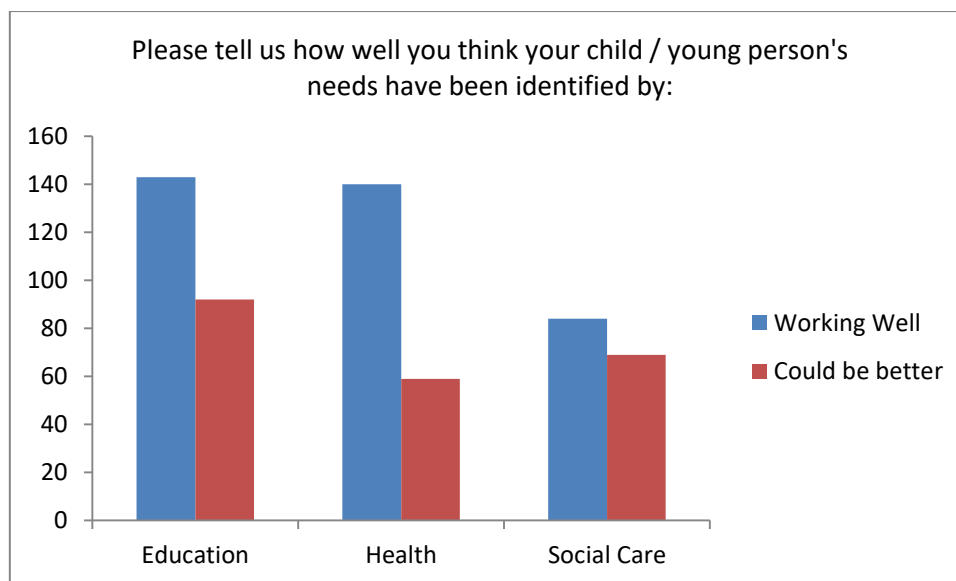


Fig. 12 respondent view on identification of need by services

	Very well/quite well	Not very well	N/A
Education	143	92	7
Health	140	59	41
Social Care	84	69	85

Fig. 13 Parental views on how well services have identified need in tabular form

As seen above, Education is the best performing area relating to positive views on identification of need – with the highest percentage of parents declaring the sector to identify needs either very, or quite well. However Education also has the highest percentage of parents who feel that needs are identified not very well. This contrast comes about due the volume of parents who declared the involvement of each sector to be not applicable – education is the crux of most families’ experiences with SEND, and as such education has the largest number of responses. Parent carers report to FVP that their experiences can be vastly different dependent on which educational setting their child/young person attends, regardless of this consistency is growing across all settings, and with the continued growth of membership of the SENCO Network this should continue to improve.

37% of agreed overall that all three areas fell within the “not very well” category, which demonstrates a shift towards more positive experiences overall. Peterborough’s Written Statement of Action, in response to the 2019 Ofsted and CQC Local Area SEND Inspection provides a response and plan to the following identified area of weakness:

“Joint planning, including commissioning and intervention are not sufficiently well established to make sure that all agencies and services play an active role in meeting the requirements of 2014 disability and special educational needs reforms.”

As such, Peterborough has a co-produced plan to improve experiences relating to services commissioned to meet needs locally. There is an expectation that year on year we will see an improvement in the positivity of responses to this particular question as demonstrated thus far (see FVP cross comparison report for fuller explanation).

Understanding of Needs

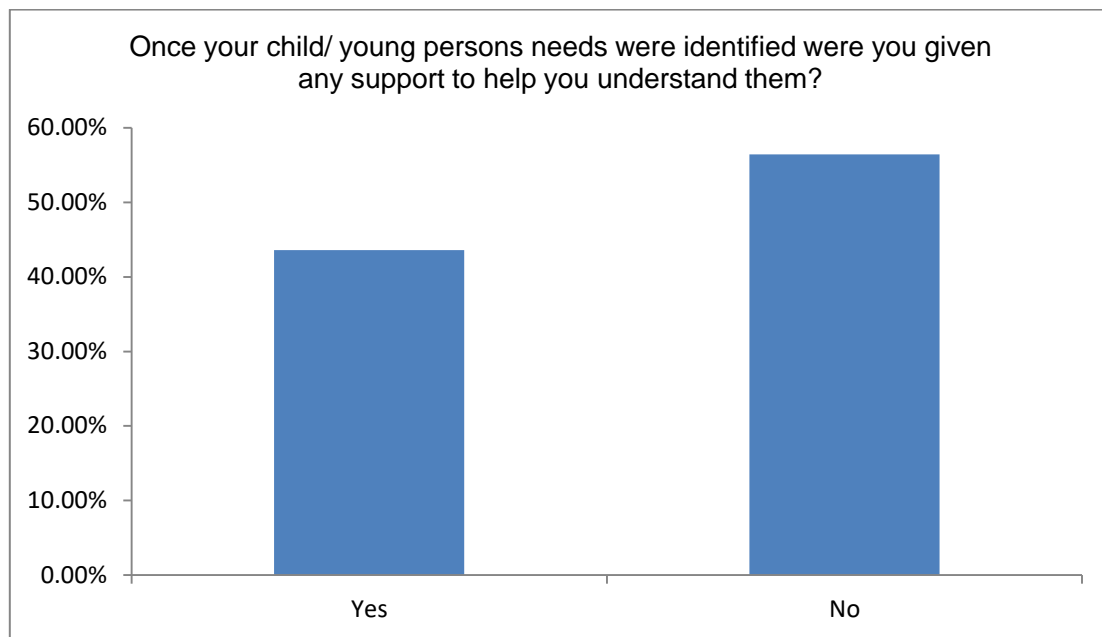


Fig. 14 Support given to parent carers to understand needs.

Responses relating to support given to understand needs are split with the majority (nearly 57%) of respondents declaring they were NOT given the support that they required. This may be indicative of the different needs declared by parent carers, and could represent the difference in experiences between parents of children with a primarily neurodevelopmental disorder as opposed to those who parent a child with more complex or physical needs.

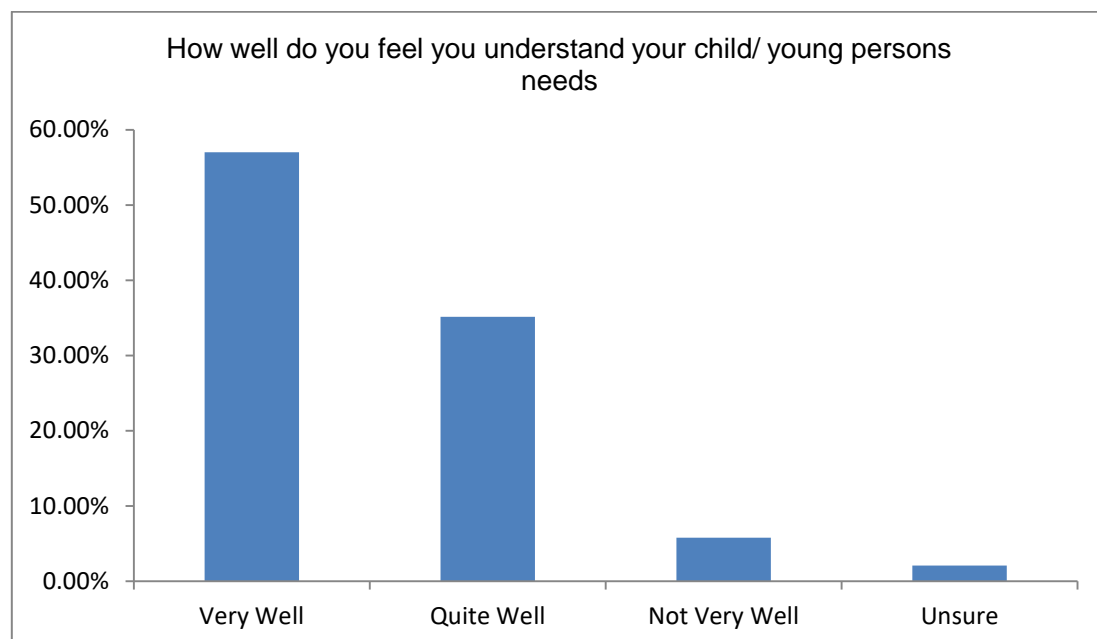


Fig. 15 How well respondents feel they understand their child's needs

Regardless of 57% of respondents feeling they were not given adequate support to understand their child or young person's needs, almost all parent carers responding felt that they now understand those needs either quite, or very well. This is in contrast to how

respondents felt that professionals supporting their children understood their needs, which is demonstrated below:

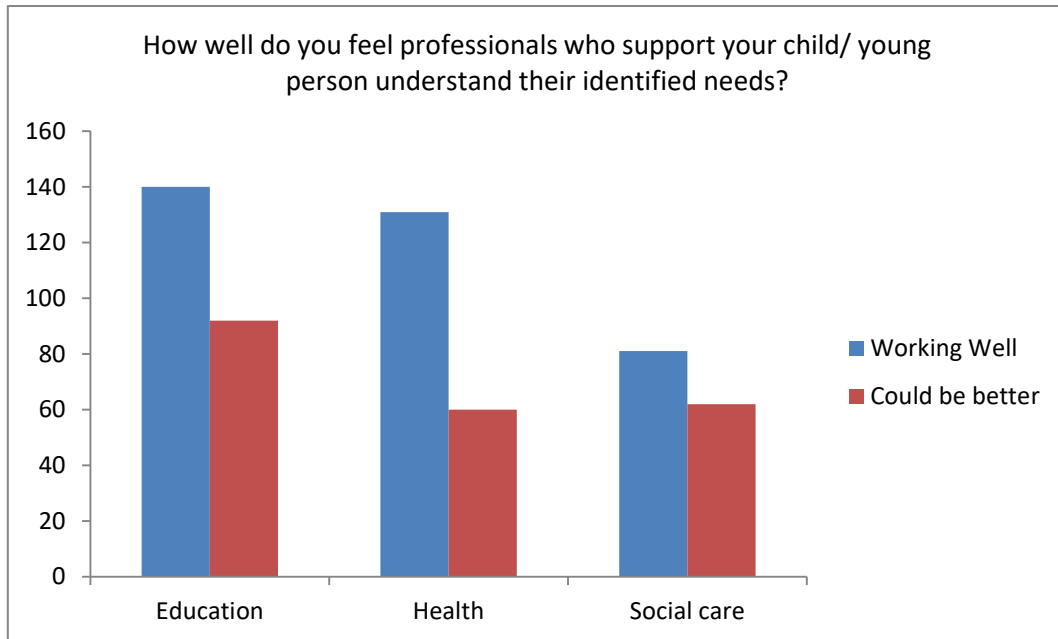


Fig. 16 respondent opinions on understanding of needs across services

Support of Needs

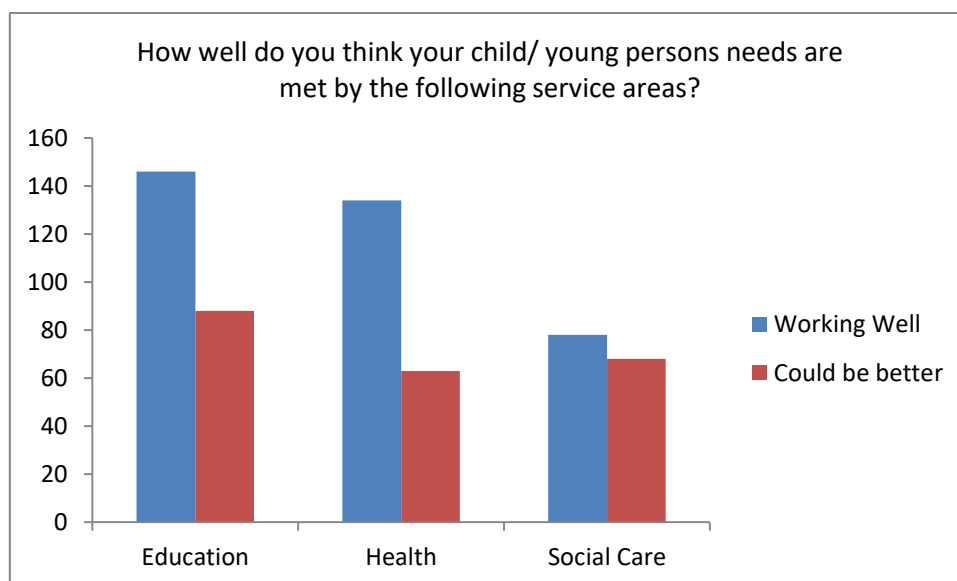


Fig. 17 data relating to meeting of needs across service areas

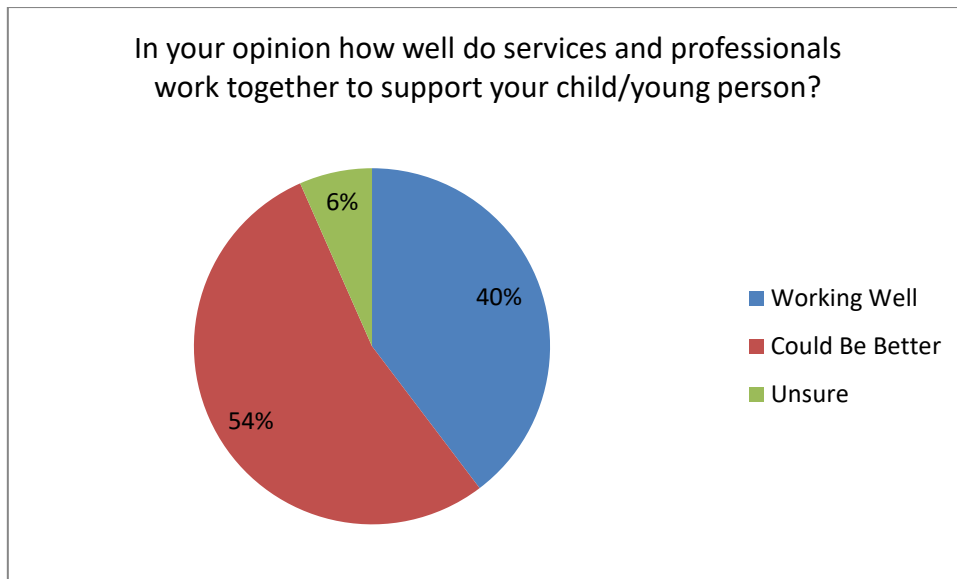


Fig. 18 Joint Working to Meet Needs

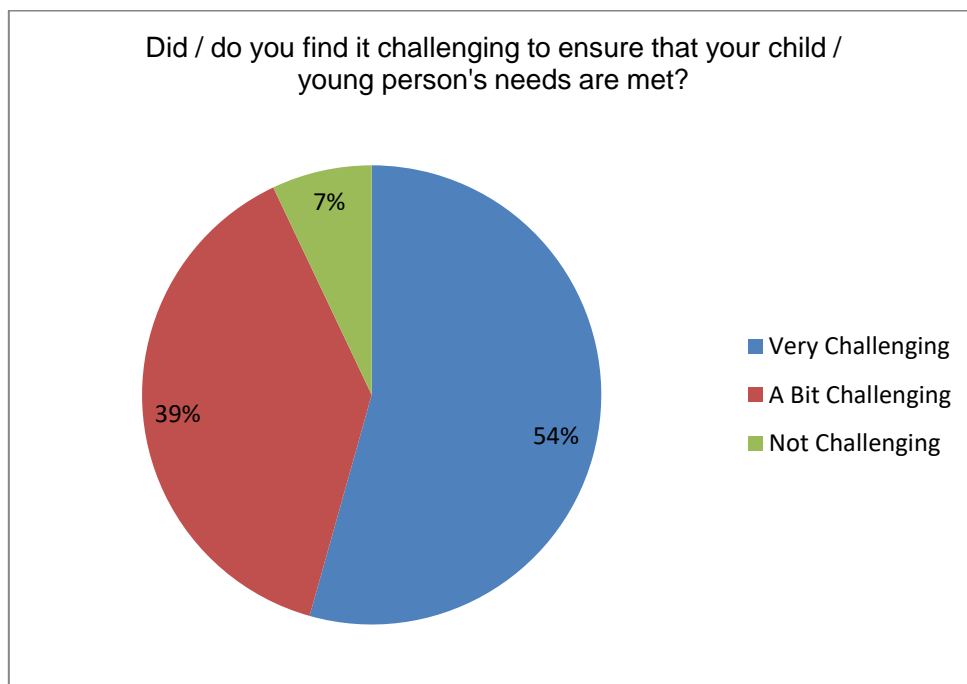


Fig. 19 Difficulty in have needs supported from parental perspective

Although overall parent carers feel that their CYP's needs are met by services as shown in fig.17 there are still areas for improvement and a sense that services could work better together (fig. 18 and 19). It still feels for parents that things are a 'battle' and this makes the task of caring more stressful which can impact on resilience.

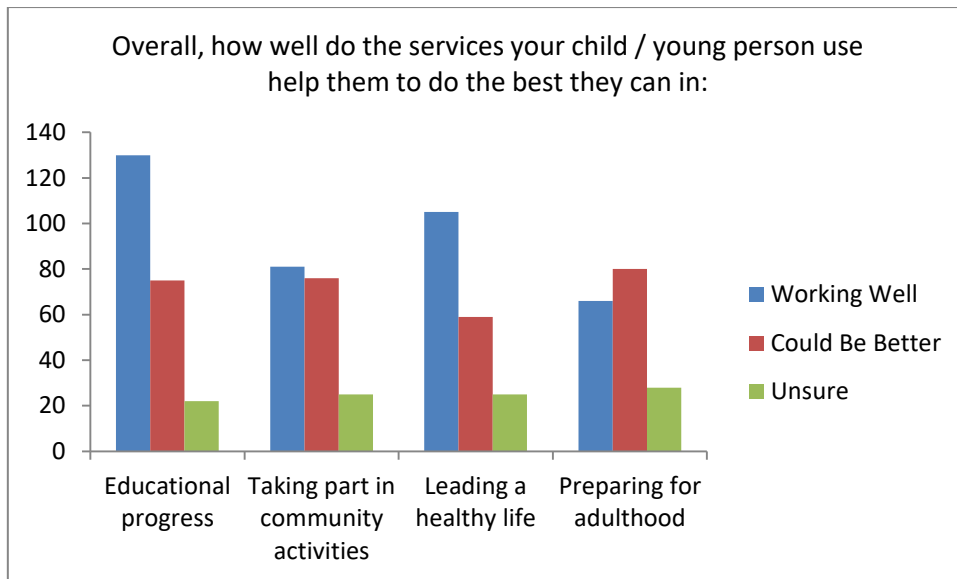


Fig. 20 Responses to “Overall, how well do the services your child / young person use help them to do the best they can in:”

When considering a more holistic approach to the needs of a child/young person, services’ enabling educational progress is the standout area for the highest levels of satisfaction in keeping with the other findings of this survey. The worst performing area is preparing for adulthood – another issue which was raised within the 2019 Ofsted inspection. There are currently numerous working groups in action attempting to improve experiences relating to the transition to adulthood, including those looking at independent living and employment.

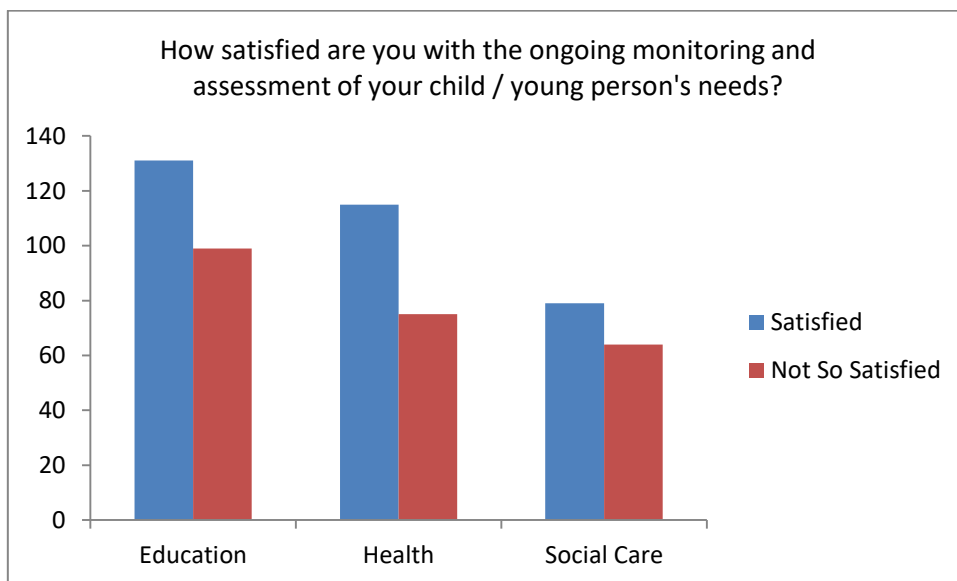


Fig. 21 Monitoring of needs

Working Well	Could Be Better
xxxxxxx xxxxx was excellent, but I think she has now retired.	Young person leaving college, unsupported, lacking in independence and unable to provide basic care for themselves. They are on PIP but do not qualify for social care. I found an app that would benefit them but social care will not fund and neither will education.
It was ok	Social care is a joke. No communication, constantly

	changing social workers, a lot simply cannot keep up who is who!
The support in primary school was not very consistent. Lots of chasing up with the school to make sure support was in place. Secondary school has been amazing so far, lots of communication and a meeting review meeting already	The service seems very inconsistent – some can get help, some can't. It took us 18 months to get our child help when she was suffering mentally. This was too long. The services don't seem to speak to each other or have very uncomplete notes. So frustrating to talk history at every appointment.
They are getting better.	I don't feel my son gets the help and support he requires at school.
Positive , he is getting what he needs.	I feel that my child hasn't had enough speech and language therapy since he has been under SEND, I haven't been updated of any progress or be given any help or information on what to do at home to help, I have been doing my own research and activities with him. I feel he has further needs with regard to sensory clothes issues but need to get help, but I don't have regular contact with the SEND teacher
Never needed to use , built up a group of other parents with children with ds and we all support each other	Not enough basic information and who to talk to if you have questions about your young person.
The LA who support the family where very helpful and pushed the school. If it wasn't for them I feel I still be fighting for help.	It's very isolating and we feel alone most of the time with zero support. You are given a diagnosis and then left to try and cope on your own. I thought there would be support post diagnosis and have been disappointed that there is none. Same with school, I am hoping there is more supper available when he goes to secondary school.
Thanks, well done	Tried to access Direct Payments scheme, has been made extremely difficult to access. Clearly no intention to help at all.
What is the local offer? Also it was primary school where I found it challenging to get the help not secondary school	What experience still waiting all teachers that are supposed to be involved don't know anything
It's been a very bumpy journey. I have been able to navigate the services due to my job role	Also have young person aged 20 who is under prepared for adulthood and very unsupported from services.
They are getting better.	I do not know what the SEND 0-25 local offer is?
My daughter was diagnosed with Autism Spectrum in last year March. Since then we are struggling to find best support for her, she has started school in September. School is trying to sort the support for her but it's too early to comment on the school's performance for me.	As a parent we are new to SEND in the past few months. I understand checks and processes are in place but it feels like many hoops to jump through and dismissal for assessment was done quickly and I think they would benefit from speaking with parents prior to decision making.

	I didn't know there was a place I've been here 2 years have one child with an ehcp but nothing been told to us about extra support
	It's a very hard long pathway . Professional/teachers. Don't believe theres a problem, or think it's a behaviour issues and nothing else. Lack of training which results in children and parents feeling lonely and stressed, down to no support or understanding. Very sad as a lot feel this has had an negative impact on my child.
	SEND helped me to secure a place at the local high school, but the senco teacher wouldn't confirm that my grandson would have a teaching assistant, and it was amid all the crazy covid times, which I knew my grandson would never cope with. So I had to withdraw the placement. And he's still stuck at home.
	Very disappointed that the approach is for children to fail first before support is offered.
	Found Send to be very poor, until Feb 2022, had to hire a professional to get assessments with SALT, OT, TRAUMA COUNSELLING. They found hom to be ASD, DYSPRAXIC DYSLEXIC AND ADHD., The Senco at mainstream school, failed to assess him, and he was kept at the same level until Yr 5.. taking many classes with yr1 and reception, failure to follow EHCP and no 1:1 support until threatened with Ofsted and Legal proceedings. He was bullied so badly and actually hospitalised by a particular pupil, despite letters emails and calls to School, and their failure to act upon it.
	I have no idea what the 0-25 send local is so I wouldn't know where to start. The whole service is shocking and unless you fight and push your just left to get on with it alone.
	Our child has difficulty using a toilet. He still uses a potty and is in ks2. We have found that because he doesn't need nappies and isn't incontinent there doesn't seem to be a service that knows how to help.
	It takes far too long, Not helpful
	I knew from year 1 there was a problem with maths which I kept pushing... wasn't looked into until year 5. A lot of wasted time which could have been dealt with better.
	Primary school there should have been more done, a lot feel its wasted my daughters education and self esteem.
	The waiting list for assessment and help is much too long to make any meaningful changes to a child when they need it most. We went via private assessment to enable my son better transition from primary to secondary school and despite having the assessment and sharing it with GP and school sharing it with SEND for "processing" we have not heard from them for 2 years.
	Send services are very disjointed and professional do not seem to talk to each other, it is also very difficult getting in touch with anyone and having questions / concerns address. Also waiting times are extremely long – we have not seen our paediatrician for about 18 months despite

	ringing for an appointment- I was told there were a lot of children to see and we would be seen when they could fit us in!
	It has been an ongoing struggle to get the level of need acknowledged and the right support in place. We are now finding issues which we asked for support with in the past coming to the fore, and feel if they had been dealt with when we raised concerns several years ago, many of the current struggles the young person has would have been avoided.
	Hahahahahaha! What send services??
	If you a lot research or speak to other parents the school will not identify anything or discuss with you unless your daughter is showing the most well known signs of certain learning disorders, if you suggest something you are waved off.
	To be quite honest I am disappointed with the services provided. Especially from the team that deal with EHCPS. They refuse to assess and state reasons relating to academic ability. You then ask for mediation and have strict dates you have to adhere to, but they then can't meet the dates themselves so everything is delayed. The staff lie to you and try to fob you off when you ask for further details to be included in EHC plans. The information given is limited and unless you do your research or complain you could easily be fobbed off and children's lives are impacted.
	Local Offer is very difficult to find and when you do find it it's written very academically so I struggle to understand what it's telling me.
	Could do a lot more and need to talk to teachers about children with special needs sometimes teachers don't have a clue
	SEND is concerned more on documenting child need, but not worried how this need can be addressed practicaly .

Fig. 22 Overall comments relating to SEND in Peterborough

As part of the survey parent carers are provided the opportunity to provide further information relating to SEND services overall, and at this point there are more responses that fit within a could be better approach. Parent carers are generally more likely to say where things are not working as opposed to working which may be why this response rate is higher. Although overall the experiences in relation to early identification, joint working and support of needs are more positive there is still room for improvement, with the biggest area of concern largely relating to communication and involvement.

Education Specific Responses

This section of the survey looks at the specific types of support that children and young people receive in education, and the way in which settings involve young people and their parents in determining and carrying out the required provision.

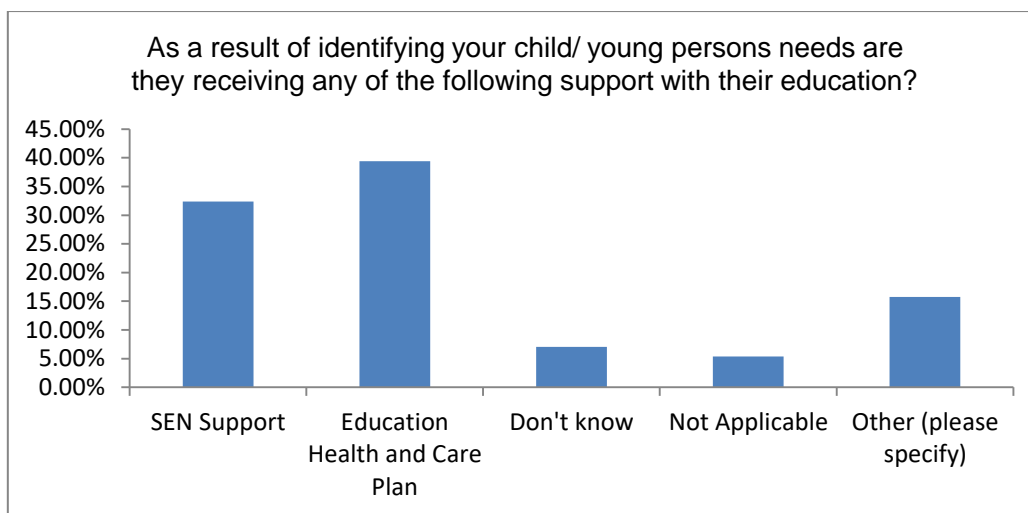


Fig. 23 types of support received in education

Of those surveyed, the majority of respondents' children or young people receive provision and support in accordance with an Education Health and Care Plan (EHCP). It is concerning to see that over 7% of respondents were unaware of the type of support that their child gets whilst in education, which highlights an underlying issue in joint working between settings and parents, along with a communication and information sharing short fall. Considering the high percentage of children and young people with an EHCP represented within the survey it is positive to note that the majority are schooled within a mainstream educational setting, indicating that settings are improving at meeting the needs of children and young people with SEND without the need for specialist provision.

Some teachers at the school are exceptional, others take no notice
I have been told they have SEN support however my child doesn't ever mention doing anything with SEN teachers regarding his speech
Ehcp refused
He receives sen support in school, but I feel and EHCP would have been more appropriate for him and would have helped with the transition we will soon be doing into secondary school. I am concerned he will be left and his needs not met when he goes to secondary.
No one form ***** has been in contact with me
The support for my child is poor and is left to struggle with her needs not met.
Extra Tuition paid by parents to help with specific needs
Waiting for response
SEN support as of now at her school but EHCP has been approved but yet to be finalized
Not been given any.
I have an EHCP, but as he doesn't attend school, I keep it going to help when the time comes to be able to enrol at college.
Still trying to get a ehcp
Still awaiting assessments and diagnosis so the school can only so so much without the answers.
At the meeting at the hospital we were told that because of our child's difficulty with concentration she believes the school are failing him as his grades have slipped from where he was with one of the teachers who was very attentive with his needs and as we've been told it will be another year before he's going to be assessed that's another year he's missing out information.
My daughter needs a EHCP, however it was declined. School promised to make this happen yet no action has been taken. As a result of her ASD and amazing masking skills, my

daughter looks almost fine in school. Yet she has meltdowns at home, and cause serious damage to me, my son and home. Therefore, a smooth transition is vital and an EHCP is needed. Not sure what you want to happen to give her the support she needs. Failure at every stage. Even her diagnosis was not easy. I recognised the symptoms and pushed the diagnosis, this took years to complete. I fear for parents with less knowledge or education who may not be able to take on the fight needed to get a diagnosis and help.
Im not too sure, I do know my child has one on one all day even for lunch
SEN and EHCP which I had to fight for - not impressed!
we pay for private counseling sessions in 10 weeks blocks for last 6 months
Sensory circuits
Despite a detailed EHCP and attending a special school, there is still an alarming lack of training and awareness of FASD with associated ADHD, and it's manifestations.
Will need support plans when she starts school in September
Not on SEN support in reception despite receiving support and targets in preschool
My child is achieving at a high level so school decided no support was needed and ignored the recommendations from CAMHS to give him thingsblike movement breaks and sensory circuits until a further assessment from CAMHS was done and recommendations were given again.
None despite asking
Removed from mainstream school
Applied for ehcp via little miracles waiting to hear back
**** will eventually be offering support virtually during school time where my child will be assisted by an adult at school.
Currently doing a path way form and waiting on speach therapy (referral was sent beginning of December)
My daughter is still on long waiting lists
She does not get much support from sen in her school, but they do listen about her anxiety

Fig. 24 Comments relating to educational support provision

The expanded comments as seen in fig.24 show again that communication and involvement are a concern, showing work is still required to really achieve participation and ultimately coproduction at an individual level.

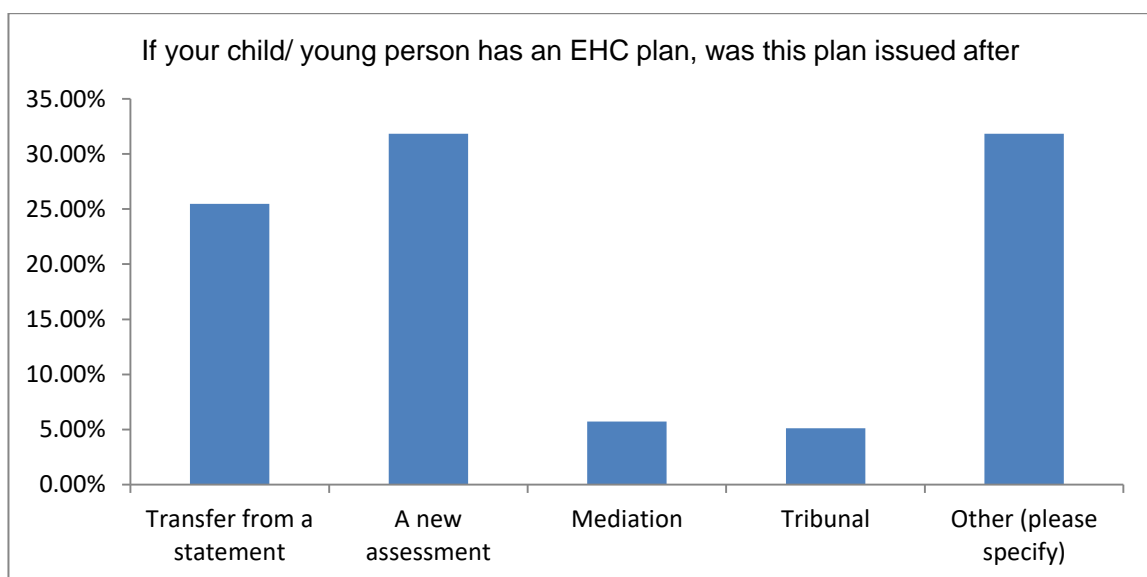


Fig.

25 Parental route to accessing an EHCP

The majority of EHCPs within the respondent group were issued a EHCP plan, after receiving a new assessment. Of the remaining, just over 25% transferred to a EHCP from a Statement of Need, just over 5% had a plan issued after a tribunal process and nearly 6% following mediation after the Local Authority refused to carry out a Needs Assessment. Outside of this survey, parents have been reporting to FVP that they are unsure of the process and requirements for applying for, and getting an EHCP – and that it often takes numerous attempts at requesting before the LA will carry out an assessment of need. This is also evident within the “other” response option to this particular survey question, examples of responses detailed below:

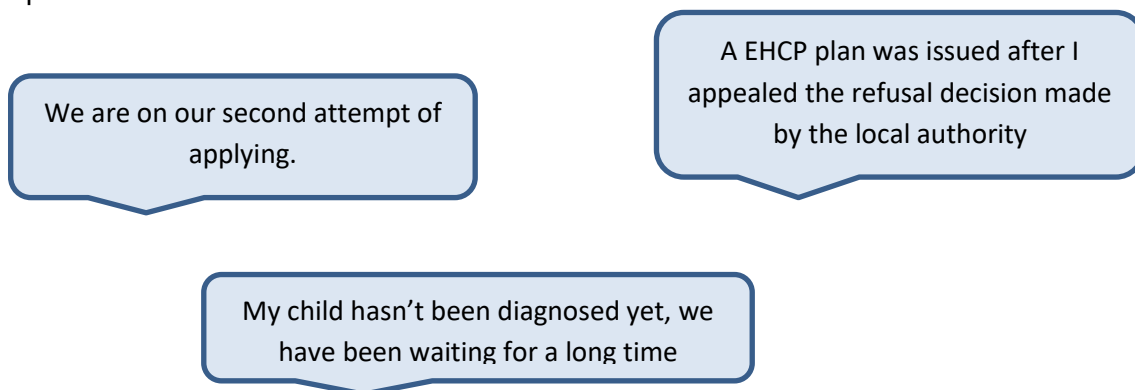


Fig 26 other responses to “if your child has an EHCP was this issued after:”

There is still a belief among a number of parent carers that an educational setting must apply for their child to have an EHCP Needs Assessment, and this is not something that they themselves can request. This is compounded with a lack of knowledge around the levels of support that an educational setting can provide within SEN support.

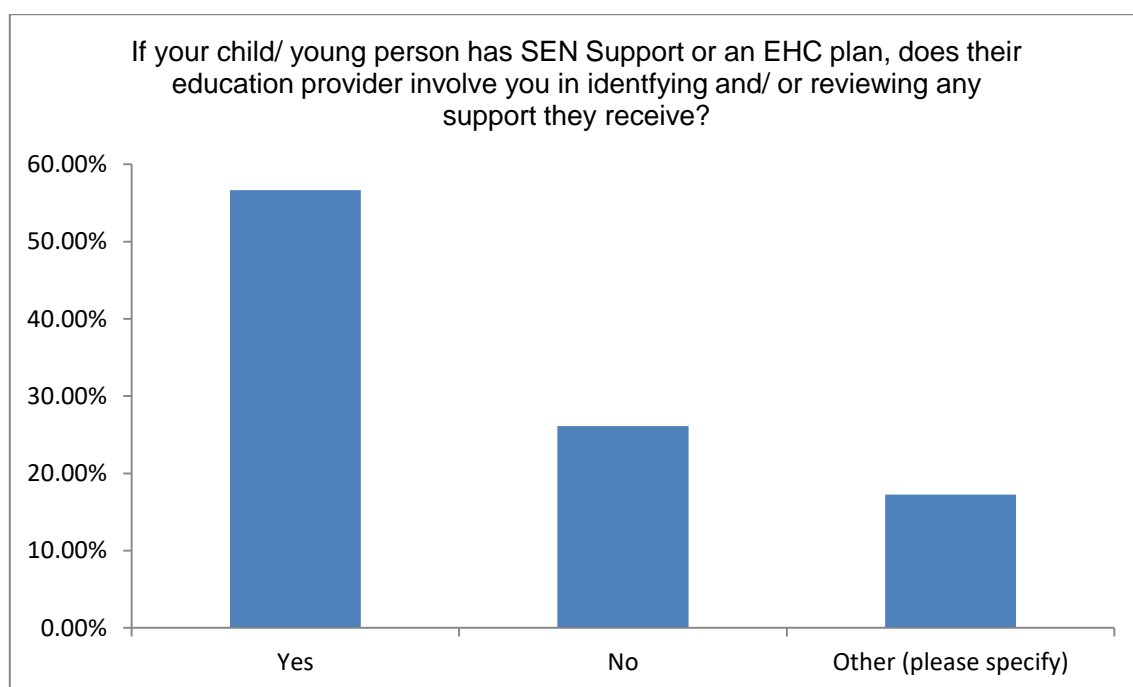


Fig. 27 parental involvement in educational support

There is a statutory duty set out in the SEN Code of Practice to consult with parent carers and young people when arranging and reviewing support within education to meet need.

While it is positive that nearly 60% of respondents agree that they are involved, over 26% have stated that they have no involvement at all.

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

Fig. 28 Expanded comments regards involvement I educational provision

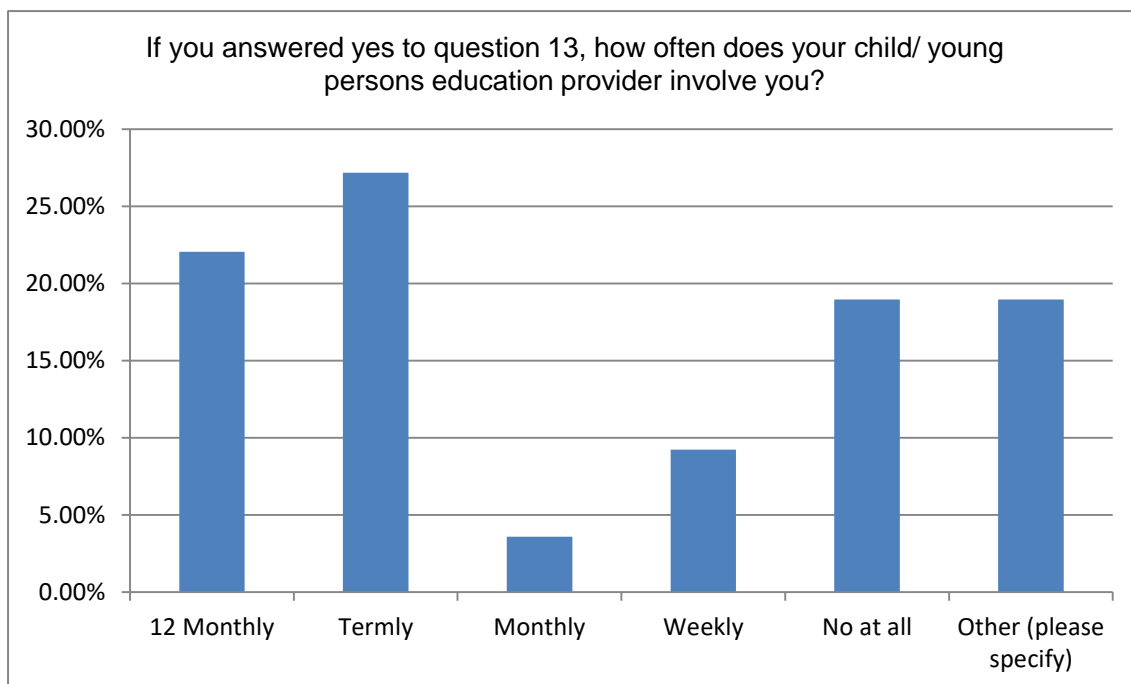


Fig. 29 frequency of parental involvement in SEND provision in settings

Each educational setting must publish a SEN Information Report, in which they must set out their arrangements for consulting with parent carers and young people on issues relating to SEN provision. As a minimum schools must arrange to involve parent carers annually – in line with the statutory requirement for EHCP annual reviews, however when considering the requirements of completing cycles of Assess Plan Do Review as set out within the SEN Code of Practice (CoP) it becomes evident that annually is not frequent enough to truly provide a child centred approach. The CoP recommends:

“Where a pupil is receiving SEN support, schools should talk to parents regularly to set clear outcomes and review progress towards them, discuss the activities and support that will help achieve them, and identify the responsibilities of the parent, the pupil and the school. Schools should meet parents at least three times each year.”

As displayed in Fig. 29 above, 40% of respondents are involved termly or more frequently in line with the recommendations set out in the CoP leaving 41% who are consulted less frequently. FVP will suggest that the sharing of best practice regarding consulting parent carers be a focus of the SENCO Network in the next academic year.

Further to the above questions and responses relating to educational experience at an individual level parent carers had the opportunity again to provide general comments/ views as below.

Working Well	Could Be Better	Other
Educational provider is able to meet my child's needs well. We are approaching preparing for adulthood stage which is very worrisome.		More awareness needs to be given about dyspraxia.
	Some schools are amazing. But lack funding for staff to support. Then have to exclude or put child on part	He gets bored in school needs a one to one full time at school

	time	
<p>She had a very bad experience in primary school as the teachers were untrained in SEN, and seemed to have little time or patience in dealing with them. Everything took far longer than it should - there was little support or reporting. I had to chase everything! It was dismal.</p> <p>Now she is in secondary school it is wonderful. The school supports her needs very well and communicate well with me. They get her the support when she needs it and treat her with respect. She is thriving there.</p>	<p>I feel the school does not fully understand and support my child. They don't look at the bigger picture and unpick the behaviour they just put it down to bad behaviour and punish</p>	<p>He attends **** ***** Nursery and they are currently in the process of completing his ECHP. We are applying to ***** school for a delayed place because he is too behind mentally to go to school this September</p>
<p>My child attends a mainstream setting but this is with a huge amount of additional support from staff. The education is tailored for her level and her wishes and feelings are always taken into account by the setting. The classroom staff are outstanding in the care they provide for her. Other settings could learn a huge amount about this provision.</p>	<p>His school say they are going to do things to help and assist him but from what we are told this doesn't happen.</p>	<p>School are over run and can't provide the help the children need for each individual I have heard this from learning mentors within the school</p> <p>Also have been said my child needs dyslexia test (school have said they cannot provide this)</p> <p>Education physiologists (school have said they can't do this as too many children are waiting)</p> <p>Been referred for play therapy 2 years ago within the school still hasn't happened (waiting list too long)</p> <p>This are all things the hospital said my child needs but yet schools saying it can't been done due to waiting list funding and staffing</p>
<p>Issues with my daughter have been raised/discussed and partially identified although not formally by the support team at her first and secondary schools</p>	<p>My child's educational provision has gone to shambles since a new Senco has been employed. The woman is a bully. Communication is non-existent apart from the last meeting when she shouted over my son and would not put a plan in place for my son's education.</p>	<p>The school has made an error as not dealing with his needs, causing him to be unsettled. They are slowly trying more as they are aware of this. But it's far too gradually.</p>
<p>The primary school has been very good and has supported</p>	<p>School do not communicate with me unless I make contact first</p>	<p>I am happy with the setting he attends but am quite</p>

<p>my son since diagnosis. We have termly SEN meetings with the Senco to discuss targets to meet his needs.</p>		<p>appalled that we do not get to chose the hours he attends, due to his disabilitys which makes things very awkward for me and my family.</p>
<p>I cannot fault the provision of education within a mainstream school for my daughter</p>	<p>I have no support from the school about my sons needs. They haven't supported him with his dyslexia. He is supposed to have speech therapy at least 3 times a week. It took nearly half a term for them to do 3 sessions with him</p>	<p>I don't feel I have been given any support or direction for my sons autism diagnosis. I would like his class teachers to know more about autism and get better understanding</p>
<p>Happy with current provision but limited choices of suitable schools for next transition.</p>	<p>I feel like he is overlooked a lot of the time by his school and the sen provision in place there.</p>	<p>I am happy with the work the school are putting in. I do hope that all adults involved in my child's class can be on the same page as SEND support. It sometimes feels like her needs are forgotten to some adults especially as we're awaiting assessments.</p>
<p>My son has had a provision map in place at school since 2017. This is updated termly usually after a meeting between his teacher, SENCO and I. He is identified as needing reading and writing intervention and is placed into small groups to adsist with this.</p>	<p>School failed older brother now doing nothing for son</p>	<p>Not getting help she needs from the school she needs testing for adhd and autism but we've been waiting since she was in preschool and had to reapply in September just to get help</p>
<p>I believe I receive all the help that I can receive, ***** have helped me well my child more than they actually can they have referred my child for as much help as they can and always include me as a parent in the process and in meetings.</p>	<p>The plan in place not specific to his needs he needs more one to one support he is not meeting any of his targets but resources are not available I've been told to support this</p>	<p>I know my child is capable of achieving more than he is currently and it's frustrating. His current teacher and TA are kind to him but I don't think teachers generally understand what he needs and I have had him start in a new class with a new teacher asking me the same question, "Has he had his hearing tested?" and as soon as the 1st one asked when he was 6 we got it checked out and it was fine so they hadn't passed the information on and it feels like you start all over again.</p>
<p>Good</p>	<p>My son's school have ignored my concerns about my son's mental health for years. They refuse to assess for dyslexia due to funding and have only recently agreed to EHA for possible ADHD because I have been</p>	<p>Exams are a worry to me and the support through this as her needs are only just being recognised by the education system</p>

	diagnosed as an adult	
**** ***** have offered exceptional support with needs, support has been second to none from all involved, a credit to the education system.	The system is outdated and staff in sen positions are not supporting children in a way that the child feels supported or understood. Staff I have dealt with need more teaching	Slightly disappointed with attendance letters following mental health concerns and bullying. Mental health should always be more important than attaining levels of attendance at times they need to be home being supported.
We're very pleased with the school's offer, our daughter seems to be thriving and her teachers genuinely care about her.	Educationally she does well but I'm not convinced the school fully appreciate how much she masks other difficulties as these come out at home.	Head teachers needs to not shout at children with learning needs. Need to learn how to talk to children with needs.
I am contented and happy with my daughter's educational provision.	I feel that the school does not really care that she has ADHD, they just tell her to get on with it, she does not get any help	She was sent there as a cheap option rather than where her needs are best met. It's a good placement for some children but not able to meet my child's need
***** have been fantastic with my son. Everyone is amazing with him all through the school including the office staff. They always give him time, listen to him and support him. I could have put	My child neurological development still not been sorted still no diagnosis ask school for update but they have never got back to me thus has been going on since before covid started	I would like support with toilet training for my child there isn't enough support in this sector to
***** have been absolutely fantastic in supporting my daughter. When she was at primary school, she was bullied by teachers and misunderstood. It was a struggle to get her to attend. In secondary school, she is so well supported and she loves school. She is doing well academically and socially, and has made such a transformation. I know the school has more resources as it is larger but the teachers seem more understanding of difference and that is their ethos.	Despite multiple times my asking I am not kept in the loop with the school	There are big discrepancies between the information the SEN support staff hold and how this is implemented to support young person in college. Very misunderstood on a course support level and needs are not fully recognised or supported appropriately.
The school have offered additional support despite not having a diagnosis yet	Support on offer determined by staffing levels unfortunately this means that levels of support change with little notice with little consideration of impact on child.	I wish there was more communication as I have no idea what's going on.
Meetings as and when I require them. Communicate a lot via	My son struggles in mainstream and the past 5 years have been very	Since she started school, she has progressed a lot.

email.	challenging. He's due to start secondary school this year and I worry constantly about how he's going to cope. I feel he would benefit from a specialist setting however I am consistently being told he wouldn't get a place without an EHCP and with the school refusing to support me on this.	
	Not enough teachers/ TAs to adequately support child's needs. Teachers don't seem to have the time to do what's needed so it's left to me to try to gap fill and help more than most parents at home. This is typical of SEN families due to ever decreasing services and a real lack of understanding or resources to help.	Within Primary care setting I can't thank the staff enough for their ongoing support, but it is frustrating trying to plan for Secondary school setting and ensuring transition and any needs will be met because the process for assessments has a narrow criteria that some children fall just outside of, but the school recognise this and try their utmost to push referrals.
	My grandson would like to go to school, but a lack of provision to meet the criteria in his EHCP meant that I had no option but to refuse the placement.	Additional sen support provided and trying to gain extra help with an early years health plan.
	The nsh need to diagnosis my child and not lie as told can't diagnosis my child as they would be unable to complete test	As all schools the SENCO and provisions are over stretched for the amount of children needing their support or help.
	They take into account what my son needs and try their best to help. Mainstream is still set up for a neurotypical person so he still has to mask all day but the school do everything they can to help him feel comfortable.	I need support with his next steps from College and a structured pathway how my son can be supported. It's a full time job trying to find what he's entitled and comparing entitlement to what's actually being offered.
	Sen in the school isn't very good and it's taken until year 6 to get started with proper provision when this all started in year 2	Concerned that current ***** provision will now stop unexpectedly at the end of this academic year but no provision yet in place for next year and I am being left to sort it.
	My son hasn't been diagnosed but is SEN registered and the school have been terrible. He's always told off and loses play time daily as a punishment. Then send work home because he doesn't do it in class.	
	My child is not reaching his full potential due to lack of support. He	

	<p>started primary school very advanced for his age, but is slowly dropping. Whilst he still meets the levels required for the average child his age, he is not reaching his full potential. With the right support, he would fly, instead he spends every day dysregulated & at a disadvantage to his peers. He hates school, which wouldn't necessarily be the case if he didn't have so many unmet needs.</p>	
	<p>We have to fight tooth and nail argue do everything. The school does nothing and put my child at risk and denies all. It's ridiculous, they are not professional, they do not communicate, they don't seem to understand safe guarding. I just want to give up</p>	
	<p>Lack of knowledge by teachers! Training and education is needed for all staff. Why are we not alerting teachers to needs. Rather waiting for something to go wrong. Sadly even head teachers follow stereotypes for SEN, such as only boys getting ASD. Teach equality at all levels of society, especially to those who have such an influence on the next generation. Since moving to Peterborough I have heard many people talk of teachers bullying, never heard of this before my move - really sad. As we have experienced this by a girl who was new to school and already battling many barriers.</p>	
	<p>The education setting does not support children with SEND well, this was recently recorded in the latest OFSTED report where they 'required improvement' I have been through the school complaints procedure several times and got the LA involved, yet the school is still failing children with SEND in my opinion.</p>	
	<p>As a result of me advocating for my daughter I was finally heard.....3 years later! How appalling is that, when I took my daughter to our primary health provider I was told oh you need the school as they know her better! I know my daughter! The secondary school is now onboard and finally after showing videos of my</p>	

	daughter at home melting down and self regulating I was heard my daughter was now seen!! How appalling is that having to secretly video your child so you can provide evidence you're not an over reactive mother!! And that your child is in crisis	
	Our child sometimes gets agitated when he is not happy which is highlighted on his EHC PLAN and the school is quite aware about this. However, there are occasions where we feel like the school has been suspending him on the basis of aggressiveness when we know that they don't have adequate resources such as teaching staff at times. This feels unfair to our child as every child has a right to full education regardless of their circumstances.	
	Mainstream secondary is not a place of Autistic children, even with a EHC - lack of understanding, funding etc means SEN children are always second rate citizens	
	I think sometimes the teachers of different subjects need to be aware that he does have problems ticks and concentration is hit and miss and the telling offs and detentions upset him and cause him distress and he can't help these things	
	He isn't getting an education they do what they can to keep him in nurture room or suspend him.	
	Information was not shared with all teachers only ones that I spoke with or emailed. New teachers starting were not given the info . Not all teachers had a good understanding of spld. According to my child post 16 have not offered any support for her SEN . Emails still sent with reams of writing, no spaced paragraph, no friendly font or changing background colour of page. Lap top not given until the second year of college. Despite this being a reasonable adjustment at school.	
	My child is academically able and masks at school. This means that some adults dismiss her needs and I have to constantly fight for them to be recognised. Some members of staff	

	<p>said I wouldn't get an EHCP because she is too bright but I said this wasn't how they worked. SENCOS are either not clued up or being fooled by the LA as they have been lied to so many times.</p> <p>Everything about my child's support has been fought for.</p>	
	<p>The provision is very variable in quality and understanding, depending on the person doing the providing; we have experienced a range from excellent to downright incompetent</p>	
	<p>I found it very difficult to get the preschool to listen to my concerns regarding possible autism despite having three other children diagnosed.</p> <p>They don't understand her health needs very well at all.</p>	
	<p>The SENCO did not put support in place but CAMHS contacted the learning mentor who put the recommendations in place immediately</p>	
	<p>My son is working at a high level, he struggles socially but school aren't interested as he's achieving very well</p>	
	<p>Had to be removed from school due to lack of staff training and support or provision</p>	
	<p>NHS reports are extremally poor and are written to fit local policy and not based on child's needs.</p>	
	<p>Some teachers not listen and change things in EHPC even if you tell them you want them keep in and child was on part Time February to July as the teacher child was with Couldn't cope with child's needs but been full time from July as new teacher can cope with child's Not all staff in special needs school are Train to work with special needs children which I feel they should be all trying to work on a special needs school</p>	
	<p>I don't think they do enough to understand that she has ADHD the teachers realy don't care</p>	
	<p>The school knows of my daughter's needs speech problems mental health problems everything seems to start off very positive but then it just all</p>	

	disappears and that goes with the help to	
	***** is struggling in school yet because of her meltdowns. Plus she is Autistic so she comes home crying every other day. Whenever I ask teachers they said oh she was fine. I am quite confused.	

Fig. 30 Overall educational experiences

Health Specific Responses

Answer Choices	Frequency
Physiotherapy	16
Speech and Language Therapy	64
Occupational Therapy	25
Community Nursing Support	1
Continence Support	7
Mobility Support	5
Child and Adolescent Mental Health (CAMHs)	40
Health Care Support Not Offered	14
Other (please specify)	74

Fig. 31 types of health care support accessed by respondents

Speech and Language Therapy is the most common type of support accessed by the children of respondents, with Occupational Therapy and CAMHs also accessed in a higher percentage of cases.

Working Well	Could Be Better	Other
They are under cahms I believe but not for mental health support they have had ados assessment and diagnoses and we are about to start the parenting course related directly to autism. We have already done the other parenting course at the beginning of the process.	OT and physio for a short period, then just left to own. I paid for him to have physio privately.	Waiting list for further assessment
Having a disability social care assessment currently	SALT support has been terrible. It only improved after I had to make a complaint about how poor the support has been.	Waiting for camhs referral
	He did receive SALT but that hasn't been done since covid. He has no support, and we do not either.	She was born with a medical condition which means we access support that way but not through her ADHD diagnosis.
	My child is non verbal with	Morning Sensory class

	sensory issues and GDD but school and myself receive no support from healthcare professionals.	
	My child has not had any support	Just filled in new dla for mobility support
	Have requested help with eating and also Camhs, had to complete survey and now got to wait 3 months to do a parent course I have already done, before they will even refer him for therapy.	Had a visit from mental health but signed him off to early help
	She has needs but not supported yet by the professionals listed above such as speech and language therapist and OT	Waiting list for therapy due to anxiety
	Nope, not been given any.	I'm past OT, apart from that nothing. Was told he would be re referred, but he hasn't. He is now under CAMHs due to me pushing.
	Awaiting mental health services for over 12 months!	Dietician, paediatrician, audiologist & ophthalmologist.
	The above are involved but haven't seen any support, to many delays	Waiting to hear from Speech and language
	None!!! Apparently speech & language cannot do anything more	They have in the past but not currently.
	Awaiting guided self help therapy which was auctioned in last September but an 18 week fir actual appointment which we still have not had!! Appalling waiting times	They had some continence support in the beginning but we manage it ourselves now
	Repeatedly requesting speech and language therapy but no response so considering going privately.	She was offered speech and language therapy but she is struggling with walking for long and complain for tiredness and legs pain. We are on a waiting list for physiotherapy.

	<p>Prior to the covid pandemic, she was having regular hospital appointments. Since then I've heard nothing from the hospital and have since contacted her GP to have these appointments re instated. I'm still waiting for a response both from the GP and the hospital to update me!</p>	
	<p>Was referered by GP for OT and M Health but both declined due to where our docs sit in terms of county vs our address. Counselling for Anxiety etc was declined as and I quote he wasn't suicidal!!!!</p>	
	<p>Apparently my child/family can have support but only when my home educated child returns to school!</p>	
	<p>She will access continence support at 4, she has a condition which means she has no bowel control. An OT referral was done months ago but haven't heard anything.</p>	
	<p>they have not arranged any therapy , I requested for speech therapy but not considered by them .</p>	
	<p>Help with healthy eating is piecemeal.</p>	
	<p>My daughter did receive speech therapy through zoom in the pandemic but unfortunately it had to come to an end as we didn't have the right equipment in you want you supposed to have more therapy but it never happened and again it seems to be on a waiting list</p>	
	<p>XXXX had some speech therapy through zoom through the pandemic but it stopped due to technical problems I just didn't have</p>	

	<p>the right equipment when she was in reception she was supposed to have more support never happened and now she's in year one again should have support in going to speech therapy but nothing has come about it the school knows about xxx anxiety problems due to domestic violence problems me and xxx left my now ex-husband it's not all the schools fault as my husband has put a stop to a lot of therapies and we're back and forward through court</p>	
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Fig. 32 Expanded comments about health experiences

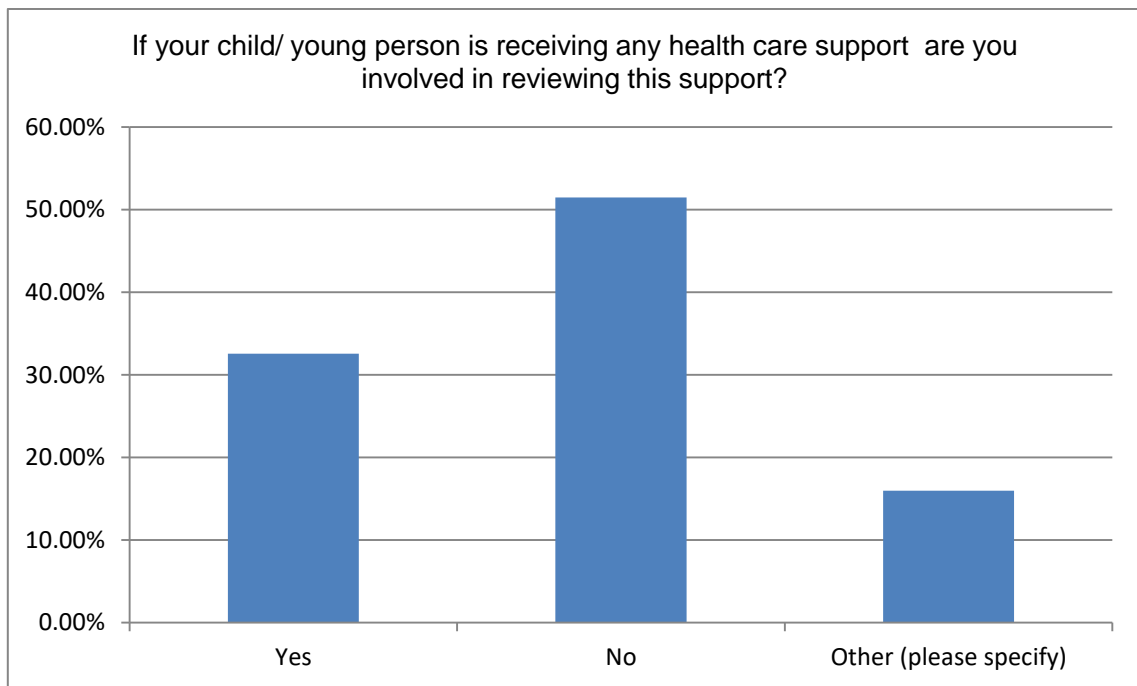


Fig. 33 levels of parental input in reviewing health care provision

There is an expectation that parent carers and young people will be involved in setting their health care targets, and reviewing the provision set out. Of those responded, just under 33% declared that they are involved and over 50% declared that they are not. Parent carers are reporting to FVP that they feel that there is not enough flexibility within Health Care provision, and therapists deliver set provision as opposed to provision which is individually tailored to meet need, this is reflected in the following comments provided on the survey, see fig. 32 above.

There are also concerns being raised from parent carers of pre-school children that have a speech delay and social communication needs, that they are unable to access SALT provision until after they have had a multi-disciplinary assessment as a part of the neurodevelopmental pathway. This is in direct contrast to the ethos of early intervention, and may prevent the right support being delivered at the right time.

These concerns are also mirrored in a small scale survey conducted into health therapies shared previously with strategic partners. <https://familyvoice.org/wp-content/uploads/files/SurveyReports/Health%20Based%20Surveys%20Report.pdf>

Again (see below) parent carers were asked to provide any final comments they felt are relevant to their experiences.

Working Well	Could Be Better	Other
My sons most recent Camhs dr has been excellent in understanding my son, his needs and working with us.	You get a diagnosis then you're just left. My other son has autism and it's exactly the same with him.	Transition into adulthood services is difficult, I still do not know a clear pathway and what will happen once we lose our current paediatricians and other therapists
His speech therapy lady is amazing. Keeps me up to date. She goes in every month. And she helped me address the school on their lack of support with his speech	Mental health support is poor - direct you to a website which I can do by myself.	Our daughter has a paediatrician that has not seen her for years we have referred ourselves to addenbrookes to a specialist clinic for 22q deletion.
I have had no issue with health services.	It took them a while to diagnose his problems but wasn't really offered much help or support. I was just told to keep an eye on him	Gp have always seen xxxxxx when requested but very reluctant to give antibiotics, spoke with consultant now taking antibiotics 3 times weekly for low immune
Paediatrician has been great that's it	Health services are non-existent	My son has eczema and asthma. Apart from access to his GP we have no other health service input.
Health visitor has been cooperative	CAMH, had previous bad experience with older sibling. Unwilling to engage with them again.	It's been a long road. You don't get any help until they are diagnosed which is bad. The nursery have been amazing and we would have been lost without them
My doctors surgery are brilliant any time I need to see them they are available. They have been very understanding of my sons needs	I feel like we have not been given the support we desperately need.	With most of the nhs, the services are too busy and not enough staff. I feel that once a child has been diagnosed, there is not a lot of help at all.
	These are often a struggle and luckily I can navigate the system somewhat as I work within the NHS. As a previous looked after -	Health services are very slow. Things have increased maybe to this happening.

	now adopted - child, you do often feel that post adoption support is non existent.	
Although a very long wait it was a relief to get a diagnoses.	Health tend to write recommendations and only have further involvement when schools re refer.	Unfortunately I don't feel I know how the different assessments link. I want to know what I have access to as a parent.
All fine. Support given and apts given promptly when needed	No one listens, or if I do have appointments. They say to try strategies, which I do but sometimes don't help. But then they still close referral saying to keep it up and theirs nothing else they can do	The person who assessed my child understood him very well and she knew exactly where we were coming from. We have however found other than parenting courses there doesn't seem to be any support or advice if your child seems to be coping OK in mainstream. I have spent a long time educating myself and looking up resources to understand autism better. It would have been very helpful to be told trusted sources with accurate info I could use early in the process. I feel like I've had to find everything myself. I don't mind I'd do anything to help my child but whilst trying to help a distressed child, work, raise other children etc it would have been helpful if someone could have pointed us in the right direction because waiting until diagnoses and then parenting courses after that took years and we needed to research and put things in place much sooner.
Cambs have been helpful	Appointment wait times are ridiculous!	Don't know what support they provide after the diagnosis.
CAMHS was brilliant, very through and henwas seen very quickly for a mental health assessment	Physio is few and far between. Not often enough reviews. Orthotics has long waiting list and not enough options- plastic, rigid are not always suitable	The more we wait the less we can tell what's wrong with my child because the school isn't taking it seriously
The health visitor was really good and got the paperwork done very swiftly and my son was on the early help pathway quickly.	My grandson has expressed a need to talk to someone about issues he has, but we have yet to find some support.	ENT consultant agrees my child needs his tonsils and adenoids out but we have been waiting years for this operation! This could help my child in areas such as speech, behaviour and sleep.
	I've been waiting 16 months for a	

	course for parenting help with sensory processing disorder and I've still not heard anything	
	Absolute shambles/waste of time	She is under camhs for her ADHD medication, and has therapy for her anxiety
	Health services are a battle and then you feel left to deal with day to day.	
	I would like my child to be referred and assessed by the paediatrician but it's not happening	
	My son was Told he'd always need monitoring like his older sibling this has not been the case. I have tried and failed to get help and support	
	Very little knowledge available on ARFID or support from any health services.	
	Poor. Where's the support???	
	<p>Wait times are to long and regularly unable to see our GP, being told their are no appointments available. Most days you cannot even get through on the phone.</p> <p>Parenting courses have been useless and often we have known more than those running the course as was the case with the latest one for ASD!</p> <p>It has frustrated us that professionals always try to educate parents following a diagnosis, but no one ever tells the child what their diagnosis means for them or helps them come to terms with it.</p>	
	Our gp was useless passing the buck to school or to 111 option 2 if on crisis as we cannot do anything. The system is broken that's how I feel, it's as though we need to trust education to make clinical recommendations.....this is one of the most challenging things we have ever gone through as a family.	
	Doctors will not progress request for pediatric support and have passed this back to the school to progress through relevant channels which is frustrating	
	None existent at the moment -	

	again not impressed.	
	Overall tbh since diagnosis at 2 to now health care and support has always been non existent. As for school secondary mainstream for Autistic children should be banned.	
	Once a diagnosis is given you do not get offered any health care support. It might be listed as a recommendation but it's up to schools to refer and if they don't you don't get anywhere. Once again you have to argue with school staff to get them to do things.	
	Our child's diagnosis of FASD from the FASD specialist centre xxxxxx was crucial to being able to access the necessary education and health care; without that clinical diagnosis, we would still be stuck on the pathway to try to access help.	
	Speech and language therapist's visit to the school is not frequent enough to have an impact on the child. Occupational therapy was identified as a requirement however the service was not provided until it was raised as a concern during EHC plan discussion.	
	We needed help for my daughter in 2000 with mental health and it took until 2021 to get her support as she wasn't considered a priority. She suffered so much that year that I do believe it was traumatic as it still affects her now and her trust in the health system.	
	I've had no input from any services since my yp was 14 & echp has no updated medical info from age 9!	
	*** support has been a very long wait. She has had her pre assessment and they wish to support and want the neurodevelopment team to look into her needs further.	
	I wish it was easier to talk to a doctor or a healthcare assistant within a decent time frame	

Fig. 34 Expanded comments regards health experiences

As with previous areas communication and involvement still remain a general concern and also accessing support early is for some families still not working, despite overall the general experiences of families working well.

Preparing for Adulthood

FVP have over the past year conducted a series of surveys pertaining to preparing for adulthood (PFA) leading to a Topic of Importance with corresponding response from PCC. These can be viewed here www.familyvoice.org/participation. They demonstrate that PFA remains a concern for families and that there is a drive from PCC to make improvements to the overall process.

Within this survey, parent carers were asked to specify if they had a young person aged 14-19, or one who had already transitioned to adult social care. They were also asked about specific aspects of any transition such as support, information provided and involvement.

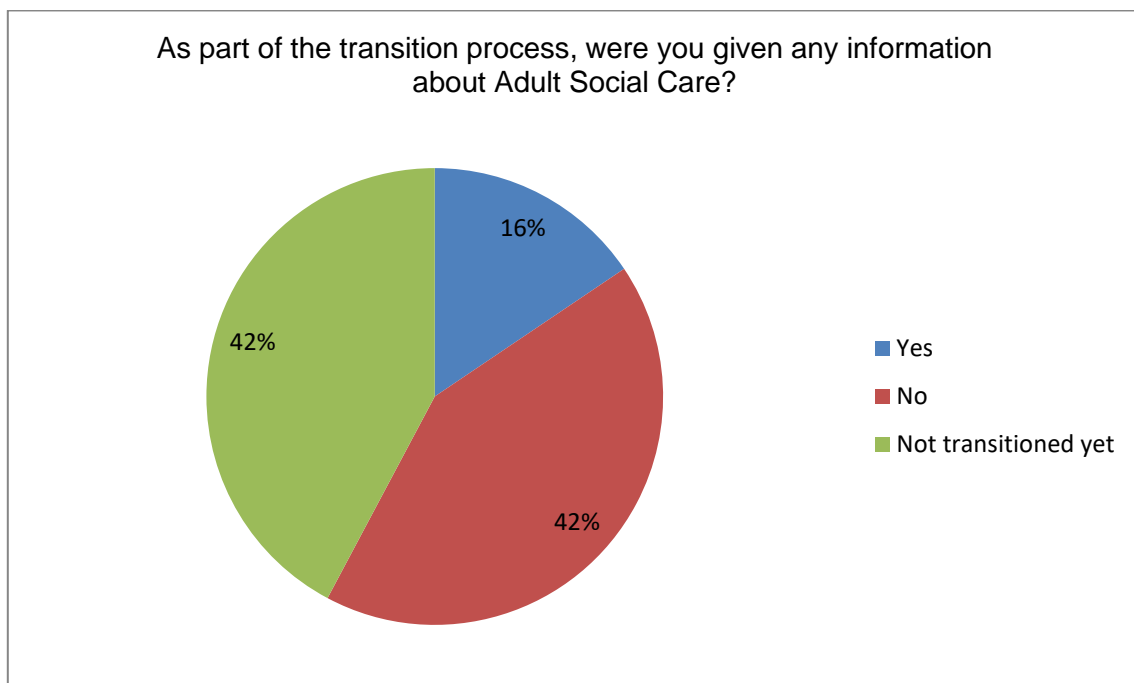


Fig. 35 Information given to parents regarding adult social care

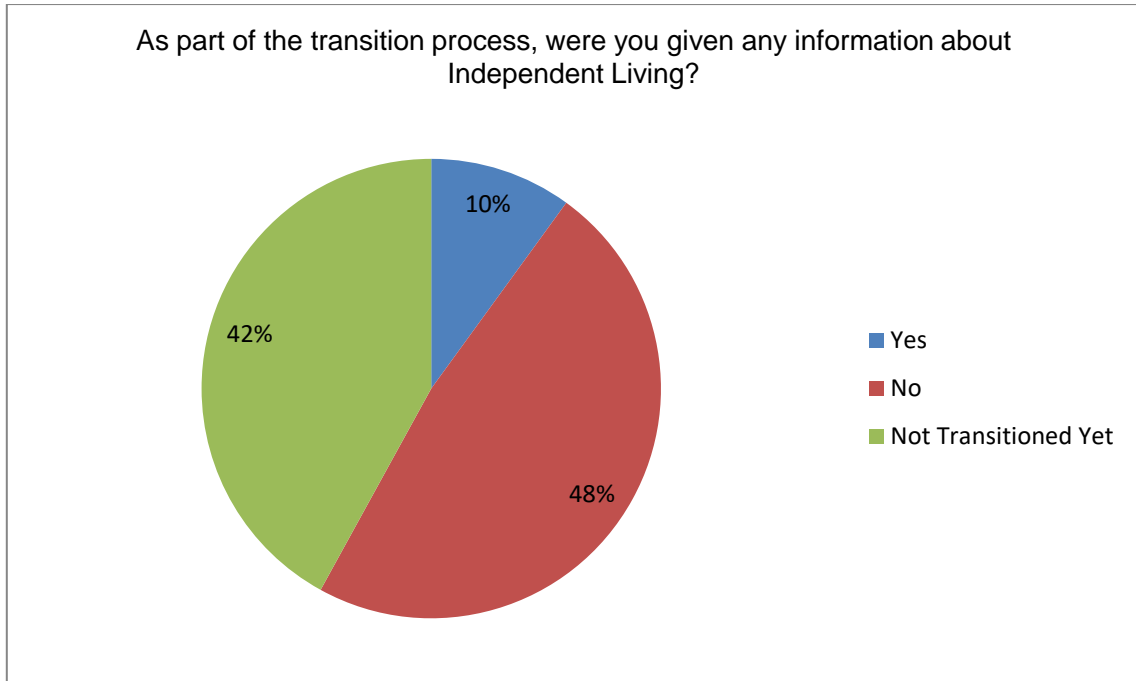


Fig. 36 Information given to parents regarding Independent Living

Of those responding, 42% received no information regarding adult social care or independent living as a part of the transition process. A lack of information can be a leading contributor in parental dissatisfaction regarding service provision – this is not just an issue within social care but across the board for SEN services. Peterborough Local Offer provides comprehensive information relating to all services, including a co-produced guide to transitioning to adulthood; however there are still lower levels of awareness around the existence of the Local Offer, which coupled with remaining search function issues which make the website less effective that it could be as a conduit for sharing information.

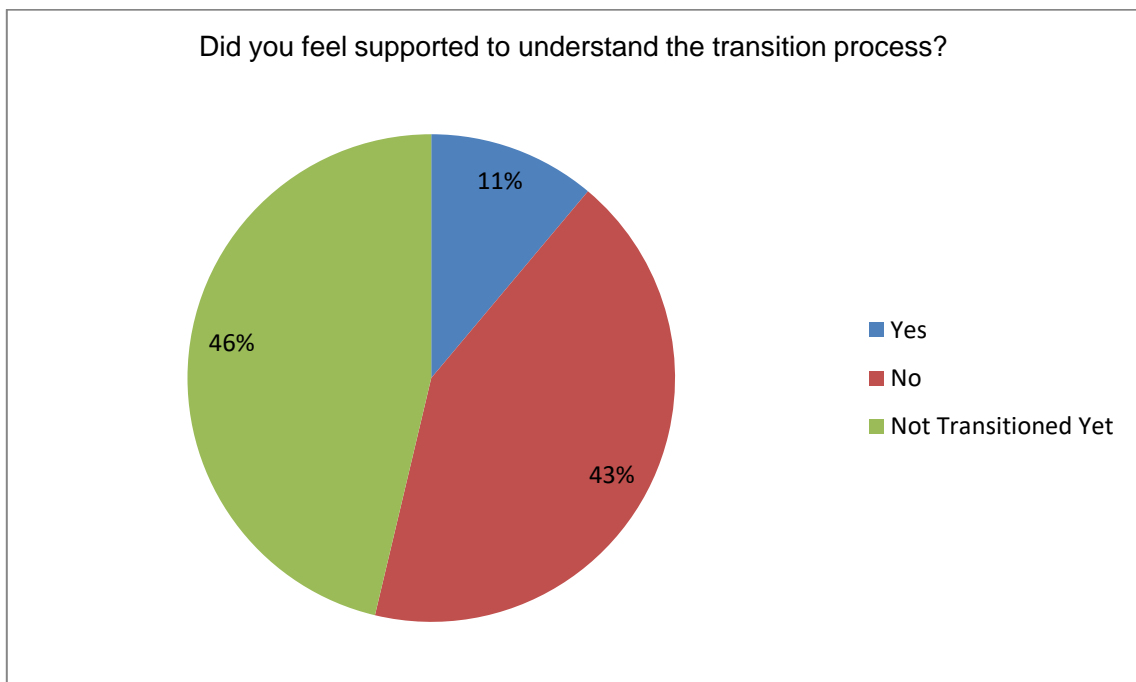


Fig. 37 Parental feelings of support to understand the transition to adulthood.

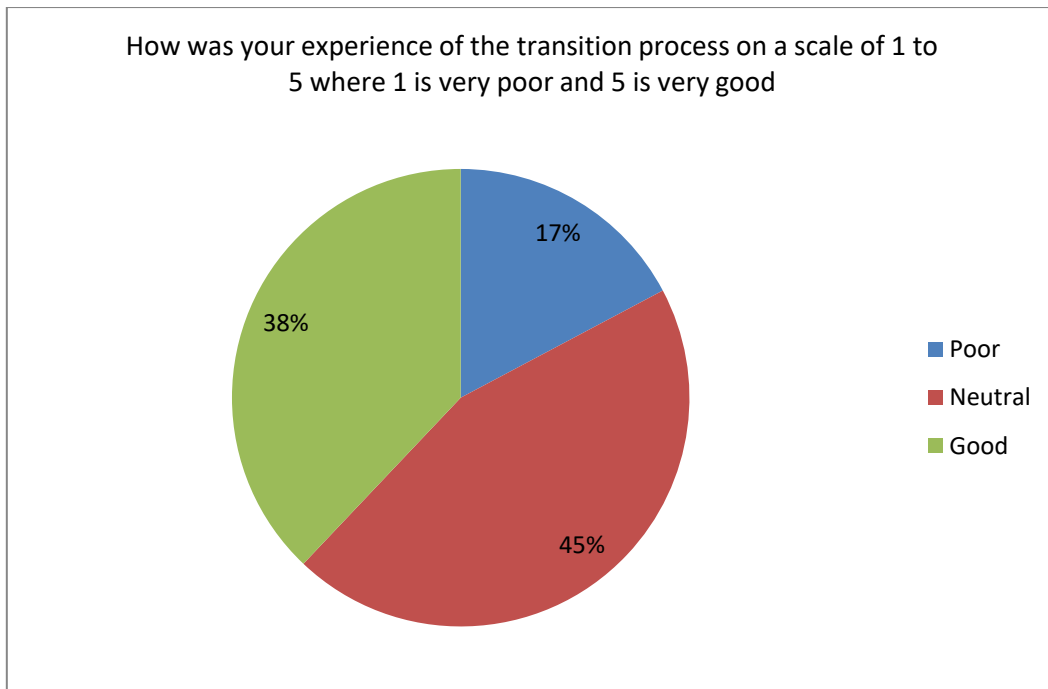


Fig. 38 Overall transition experience where applicable

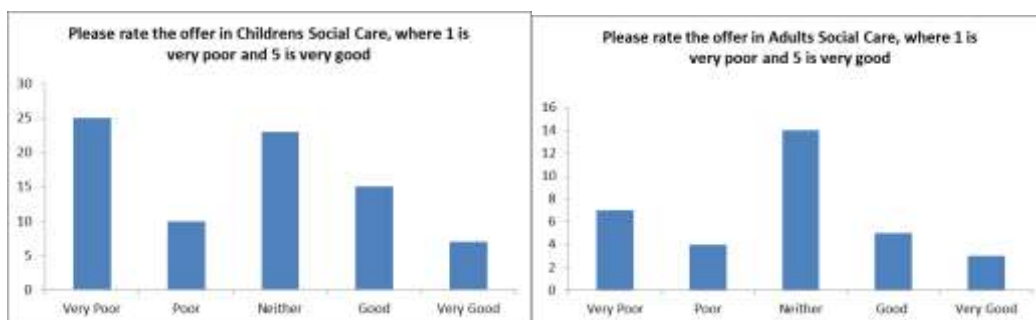


Fig. 39 average ratings of adult and children's social care by respondents

Social care remains an area of contention for parent carers. This is largely due to instability within the Peterborough social care team – with parents reporting social workers changing frequently, coupled with poor communication and information sharing. Average ratings out of 5 as displayed above show a medium level of satisfaction with both adult and children's social care.

“Not enough social workers. Totally impacts on children with their wellbeing and trust.”

“Post adoption support from Social Services is hopelessly inadequate – we are abandoned to work things out for ourselves.”

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

Fig. 40 Parental comments regarding social care

Information Sharing

Information sharing and communication is a golden thread which runs across all areas of SEND service practice in order to ensure success. The 2015 SEND Code of Practice States:

- 1.1 Section 19 of the Children and Families Act 2014 makes clear that local authorities, in carrying out their functions under the Act in relation to disabled children and young people and those with special educational needs (SEN), must have regard to:
- the views, wishes and feelings of the child or young person, and the child's parents
 - the importance of the child or young person, and the child's parents, participating as fully as possible in decisions, and being provided with the information and support necessary to enable participation in those decisions
 - the need to support the child or young person, and the child's parents, in order to facilitate the development of the child or young person and to help them achieve the best possible educational and other outcomes, preparing them effectively for adulthood

In order to comply with their statutory duty, Local Authorities must publish a co-produced Local Offer, containing all information pertaining to SEND services within their boundaries, as well as any information containing provision which may be relevant further afield. Peterborough has a well developed Local Offer website, which contains all required information, and yet parent carers are reporting that they still do not feel adequately informed.

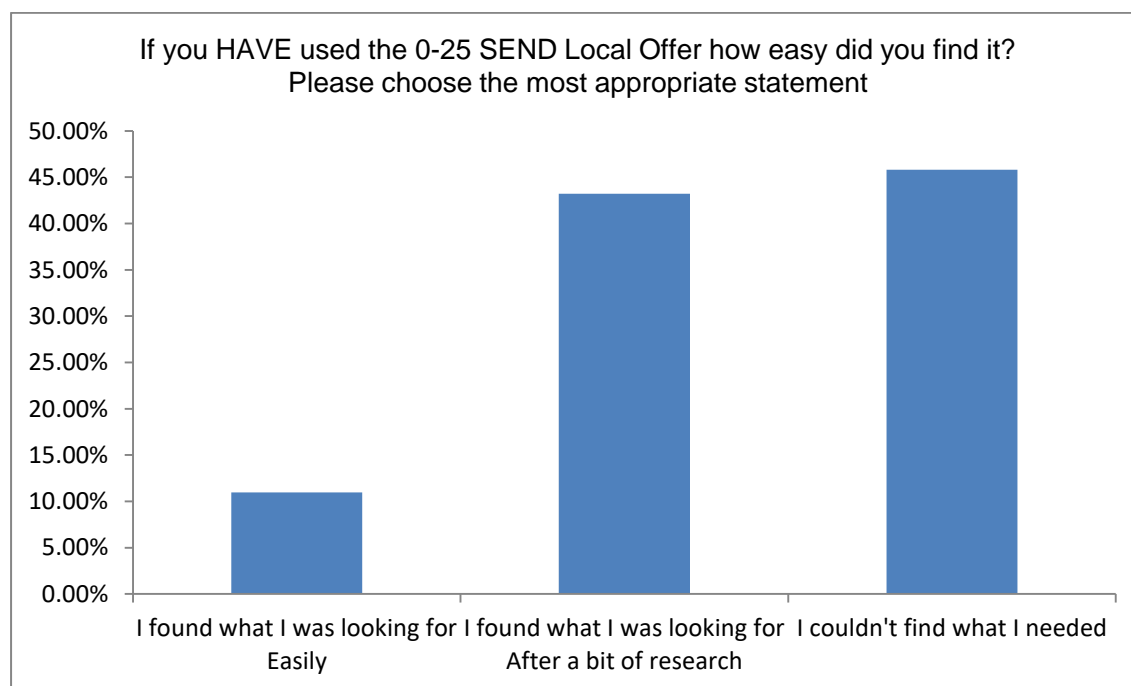


Fig. 41 Ease of access for information on the Local Offer

Within this survey, parents were asked to select the option which best fit their experience of using the Local Offer. Only 11% of respondents declared they found the Local Offer easy to use, and were able to easily find what they were looking for – with an additional 43% able to find information after researching further. Over 45% of respondents using the Local Offer

were not able to find the information they wanted at all. FVP have worked closely with Peterborough’s Local Offer team, to co-produce its layout and content: including two workshops for parents at their October annual conference – during which parents shared ideas on buzzwords that they would often search for when looking for information. Shortly before lockdown Peterborough also launched its new Local Offer post cards – hand-outs containing information on the website, along with useful contacts for parent carers.

FVP signposts all parent carers that they have contact with to the Local Offer website – taking information to all events and information stands, yet in almost all new contacts parent carers are reporting that they were unaware the Local Offer exists. You are able to read more information on Parental views on Information Sharing and communication, as well as the Local Offer in FVP’s Topics of Importance and Information Sharing and Communication specific survey report, both of which can be found at www.familyvoice.org/participation.

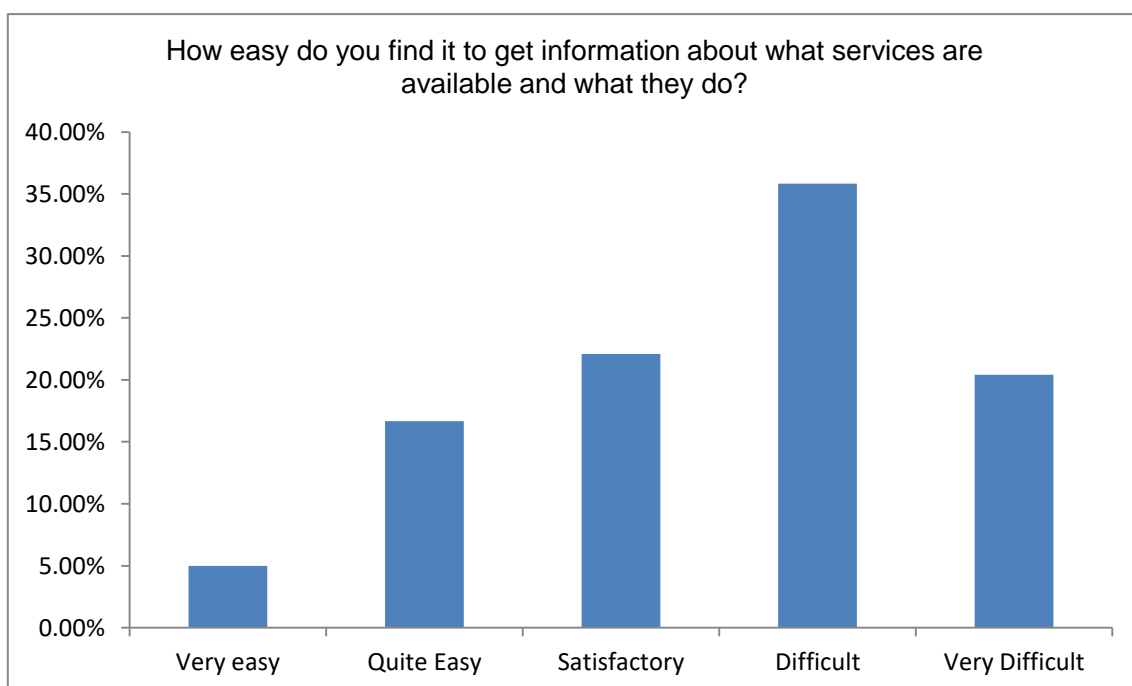


Fig. 42 parental ease of finding service information

Parent carers were asked to rate how easy they found it in general to get information about services and what they do. 56% of respondents declared they found this task either difficult, or very difficult. The reasons for this may be a mixture of lack of knowledge regarding the Local Offer, issues with ease of finding information on it, and an underlying lack of awareness of what services are available initially – it is difficult to find information on a service that you do not know exists.

FVP undertake an annual review of Peterborough maintained and academy educational settings’ SEN Information Reports; these reports must contain information on services that they work with in order to identify and meet children’s needs, as well as information regarding Peterborough Local Offer. The quality of these reports has improved exponentially over time, and they are becoming more and more detailed, however they lag behind in the area of co-production. FVP suggest involving parent carers annually in the process of reviewing the document in order to build better relationships between teaching staff and parents, and to raise awareness of the document and the information shared within.

The sharing of information can not only be a static process whereby parent carers independently research documents written by professionals – it must also be the backbone of all communication. Peterborough has one of England’s few integrated neurodevelopmental diagnostic pathways which is considered successful in that paediatric waiting times are relatively short, and parents are offered positive parenting courses before and after diagnosis.

Parent Carer Resilience

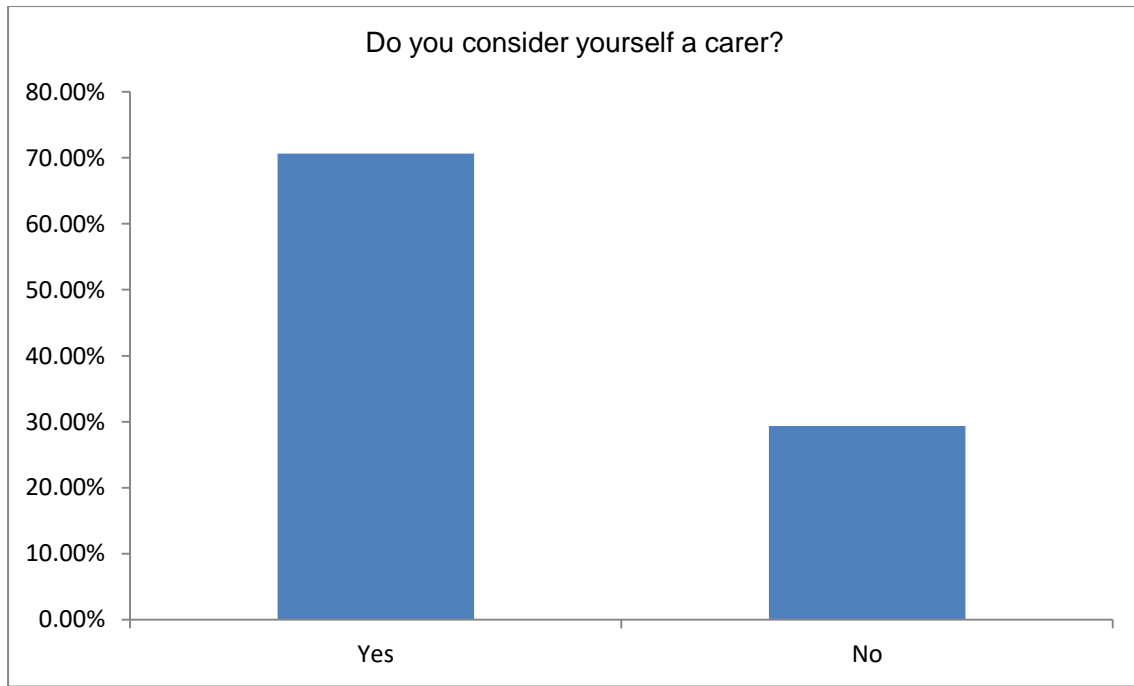


Fig. 43 Respondent views on their caring duties

Over 70% of parents responding consider themselves to be carers – providing support and care to their child or young person in excess of what would be usually expected from a parent. Carers UK estimate that unpaid family carers save the UK government almost £20k per year by carrying out their duties, the financial pressure of doing so can be crippling for a family, in addition to the effect it has on the carers wellbeing and ability to carry out tasks that many take for granted. Of those responding, only 32% were in receipt of Carers Allowance – a benefit which can be claimed if an individual spends more than 35 hours per week caring, and does not earn over £132 per week. Carers allowance for 2022- 2023 is set at £69.70 per week.

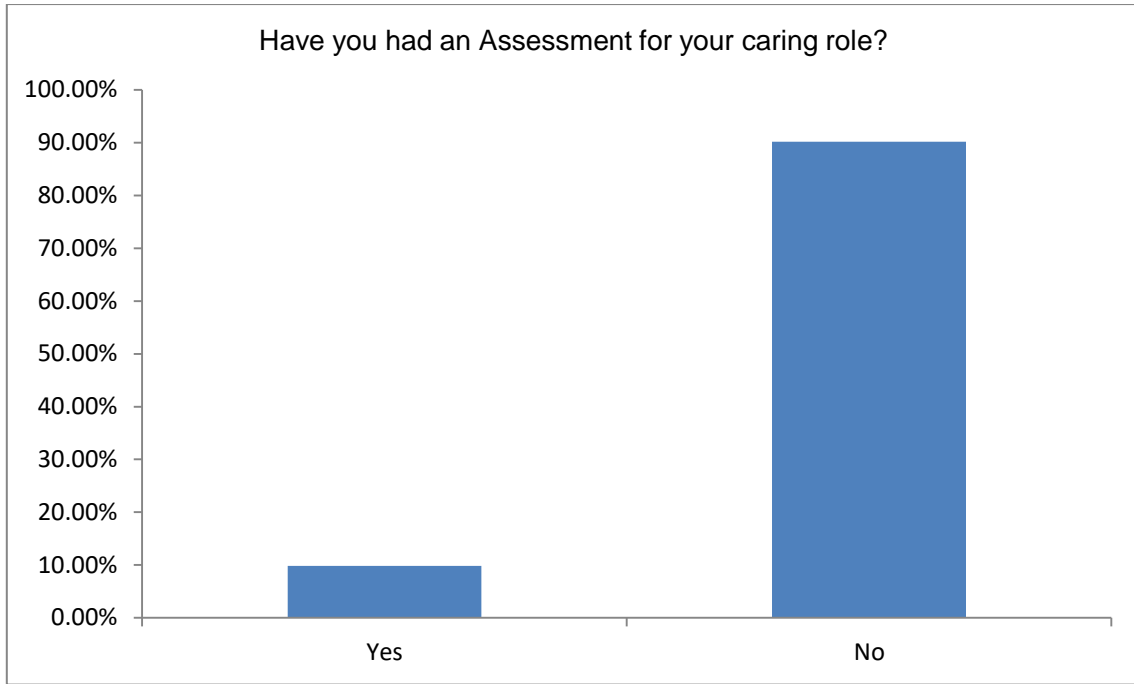


Fig. 4 assessments provided to respondents on their caring role

Regardless of the high levels of care provision being declared by respondents, almost 90% have had no assessment of their caring role, and as such will not be receiving any further support to carry this out.

Displayed below is respondent opinion on how their caring role affects their daily lives and wellbeing. 55% of parent carers surveyed declared their role affects their ability to find work, with 60% acknowledging that it has an impact on their wellbeing. Parent Carers report to FVP that they find it very difficult to find adequate affordable childcare for their young people, in order to find full time work, or indeed find any time to socialise as individuals, or carry out activities to support their own wellbeing.

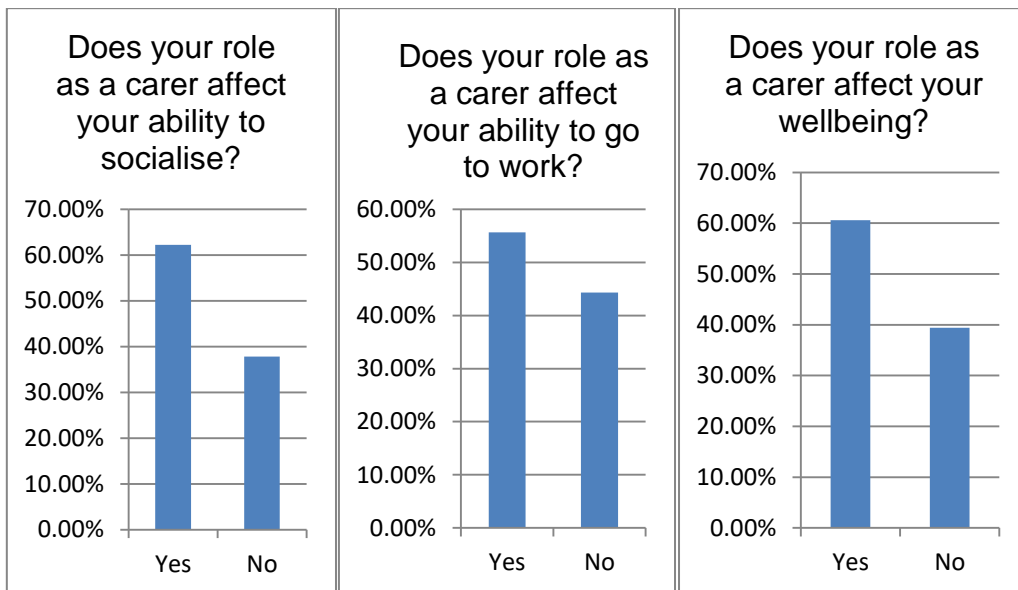


Fig. 45 respondent views on the effects of their caring role

Additional Parental Comments

This survey provided opportunities throughout for parents to provide more detailed answers on their views relating to SEND services. These have been interjected and included within this report. The final survey question asked for ideas on changes parents would like to see made to the SEND services in order to bring about positive change. The responses are displayed below:

Parents Recommendations/ Suggested/ Comments changes

More support and more guidance is needed
We need more support as parents to make choices for our young people and the help and support for there transport because the bus pass allowed them to get on the bus 9.30 and they have to go to education in time and how the college if they provide lunch and how safe it is to leave him there for the first time
Give more support where needed to children and there parents.
Communication with parents
Staff at schools to be better trained on conditions such as asd to help more children cope better and be better understood.
Stop using a one size fits all approach and treat child, young people and parents and carers with respect and as individuals.
Employing more people so that there is more support given to family's with diagnosis and not an EHCP.
real interviews need to be done with children and their parents as a 1st course of action, an actual trained human reviewing the child in their current setting will flag up a high percentage of children that just need to be waived through and put in the queue to get the EHCP assessed & written. for example you don't need 3 years and 20 forms to tell that a child who is non-verbal and supposed to have started school 3 months previous is going to need additional help, it should be a formality not an assault course to get this though to an ECHP decision. also, next time please get someone professional to design the survey, if a section being filled out or skipped is dependant on how you answered a previous question then that needs to be build in to the flow of the questions, i.e. "you don't consider yourself a carer" is no then tell them to skip the next 20 questions.
Better communications regarding special schools and how to apply
I believe children should have more access to resources regarding mental health.
More research when you leave the hospital and more support groups advistised as unless you go looking you don't find
Professionals should talk to parents directly when assessments are directly linked to home situations.
Parents need to be made aware of all resources that are available and appointed a key helper so they have someone to turn to when things are difficult. Some people have never experienced autism or similar conditions before and have no idea what to do in certain circumstances. If we didn't have a helpful nursery I don't know what we would have done
Communication needs to be improve between parent and the school and listening to each other to support the child best, and not telling parents things can't be done due to funding or the waiting list is too long so we won't bother
Accept referrals don't make everything a battle, when us parents are already fighting for support from wherever we can get it from
We feel if SEN services can take initiative to include self defensive skills such as karate or some kind of martial art to SEN kids who are able to be physically participate as this will help them to feel protected and also help in many ways.
If we as parents if SEN kids want to train our kids with extra activities such as piano or roller

<p>skating for my child it is very difficult to find as no one is trained to so or we are not able find that information. Also, after school facilities for the SEN kids that can help working mothers. We don't know how to get these information.</p>
<p>The ability to be able to contact a department would be helpful, we appreciate these departments are very busy but often time can be saved if requirements are dealt with at instigation.</p>
<p>Different Peterborough health/help services need to communicate more with other workers. To provide the right information.</p>
<p>More investment in support for young people so that they achieve positive outcomes. Waiting for children to fail is unacceptable. Early intervention has been proven to result in better outcomes for children. Peterborough SEN services are very disappointing!</p>
<p>You need to make services easier to access and re look at your specialist settings criteria. Many autistic children are struggling in mainstream. Every day is a challenge for my son and I feel he would thrive if he was around children similar to himself and teachers understood his needs.</p>
<p>Earlier identification.</p>
<p>I think parents should have access to a hub and that links schools and council. I feel there needs to be a bridge between services and schools. schools also need to train staff better to understand the needs of autistic children.</p>
<p>If the possibility of new special needs schools is not an option, then PROPER training of some teachers to deal with autistic children, not just saying they can cope, and then not being able to cope. At the end of the day it's our children who suffer.</p>
<p>Faster process and follow up on the care that is needed</p>
<p>I think the biggest change would be the waiting times for help. My child's school put her issues down to laziness for years and refused to listen to my concerns. Now we are going into the 5th year at primary school still without any answers to what's wrong. It's been 2 years that the school have registered there's difficulties and we're still waiting to be assessed.</p>
<p>The meeting should be more frequent</p>
<p>For once put yourselves in our shoes the struggle is real until you don't see it from our point of view changes will never succeed</p>
<p>Quicker results</p>
<p>Easier support for parents with teens who have mental health/ behavioural needs.</p>
<p>I have called police multiple times about meltdowns at school and taken over 2 years to finally get a social care assessment started</p>
<p>More monitoring and consistency with primary and secondary ensuring schools are all following the same guidelines</p>
<p>More training to notice adhd in girls in primary school</p>
<p>Better training for staff.</p>
<p>Better understanding of the needs of the young people and families. Stop trying to use a one size fits all aporoach</p>
<p>It would be great if they visited schools more with parents so they would be able to support and help parents with send who are not knowledgeable in this process.</p>
<p>More joined up working between children's and adult services. Meaningful co-production where more than lip service is paid to experiences and struggles. A better appreciation of 'invisible disabilities' and more inclusion earlier on with 0-25 team, especially in the lead up to transition.</p>
<p>Improvement in picking up problems & acting faster. To sign post help ASAP.</p>
<p>For the EHCP pathway to be easier & more accessible</p>
<p>Early intervention saves money and prevents all sorts of later problems. Invest in young local people, and you will get that invest back and more!</p>

SEN Services in schools needs massively improving.
Better accessible Information for parents and carers, better forums for parents to question schools/health providers actions or lack of without them taking offence or trying to cover up their negligence. Better pathways for children who mask or are not the a typical stereo type for the disorder.....things need to change now! Better access to assessments before leaving primary to ensure we have things in place in secondary so we are able to have more positive outcomes as young adults for better transitions into adulthood. Ensuring focus is not just for educational purposes as a child who has social skills communication skills has confidence in themselves to attempt jobs will still have a chance to get educated later in their life! As a parent I want my daughter to be comfortable in herself to know she does not have to meet all the so called peer targets in education but just do her best! What is so concerning is who is advocating for those who are unable to understand or navigate this ridiculous maze we call education/healthcare!
Peterborough SEN should increase their support requirements
The ehcp assessment really needs looking into too many children falling through the net. I also think more information needs to be given out and explain what services can help and what they do. I had to find a family support worker myself through Bernardo's. I would have been nice to feel supported after my son had his diagnosis as I felt alone and I was so scared. I was professionally a carer in the community before having to stop working for my children. Too many appointments.
Employ 10 more xxxx as she is the one member of staff who takes the time to answer your calls, emails, help etc. Cannot praise her enough
More access to advice. I am new to this and knowing who to speak to or where to go is the hardest part so far.
Universal access to parenting programme prior to early help. Access to therapeutic parenting programmes and attachment pathway locally. For young people to be able to attend any hospital /consultant in the UK for diagnosis or treatment and not be turned down on grounds of funding Multi agency parents drop in service , advice and signposting.
I think that the staff who get employed to organised EHCP's need to know the law in regards to when they need to assess. They also need to be fully aware of what should and shouldn't be written in an EHCP. They should listen to staff and parents to ensure that the provision is written carefully. If they do not have enough information about certain areas they should actually use the assessment period to get professionals in rather than making up targets themselves. They need to actually put exactly what children need and not what they think.
There needs to be a much more cohesive approach; the system is too fragmented and much time/resource is wasted by having to try to access triage pathways etc and having to discuss the same things over and over again with different agencies. There is also a "it's not our problem" mentality from each agency, trying to pass the responsibility onto one of the other agencies e.g. Education to Health, Health to Education and Social Care etc.
SEN Coordinators should listen to parents so the child's needs are captured and appropriate help and services are documented in the child's EHCP. Schools should be supported to hire more TAs to promote 121 support to children with special needs. No support outside educational setup is provided at the moment even though the service includes Health and Social care.
SEN Coordinators should listen to parents so the child's needs are captured and appropriate help and services are documented in the child's EHCP. Schools should be supported to hire more TAs to promote 121 support to children with special needs. No support outside educational setup is provided at the moment even though the service includes Health and Social care.
SEN support should be for all children with a diagnosis, the experience I have had is that my

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

Fig. 46 Final Parent Carer Responses

Final Comments

Overall there is a general move towards more positive experiences in relation to assessment of need, involvement in SEND services and support for those CYP with needs. However communication is in general still an area requiring improvement. More work is also needed to help parent carers know where to find information to navigate the world of SEND, which would decrease some stress.

SEND at a strategic level is working well, operationally for individual parent carers some work is still required to improve participation in particular. It also appears that more issues for families occur at setting or service specific levels as opposed to organisational levels in particular for PCC.