

Topic of Importance – health inequalities (send families)

There is much data and reporting on health inequalities for different groups of people. There has been more focus on such inequalities and associated research during and after the pandemic known as COVID 19 (C-19), but those with SEND appear not to be reported on as much

Cambridgeshire and Peterborough's Health Inequalities Strategy July 2020 only mentions disability once in particular in relation to learning disability *"In Cambridgeshire and Peterborough there are 3,955 people on the learning disability Quality Outcomes Framework register 25 . Learning disabilities affect health in different ways. A review of the literature found higher levels of epilepsy, coronary heart disease, respiratory disease, diabetes, chronic pain, visual and hearing impairments and mental health problems in those with learning difficulties"*(Cambridgeshire and Peterborough Health Inequalities Strategy, July 2020, V2.1, p25).

NHS England explain further about these inequalities and which groups are most likely to be impacted <https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/what-are-healthcare-inequalities/>. Again disabilities (SEND) does not get a proper mention. The Disabled Childrens Partnership have been conducting wide scale research into this area in particular and have been impressing upon Central Government and NHS England to recognise this and put in appropriate planning and support especially through their #LeftInLockdown Campaign <https://disabledchildrenspartnership.org.uk/leftinlockdown/> Special Needs Jungle in their analysis of this research state on their website *"DCP surveys also showed that over 70% of disabled children have been unable to access pre-pandemic levels of therapies and health services. Ultimately, as opportunities to manage conditions were lost, nearly three-quarters of disabled children have seen their development at managing their condition regress.*

We are not through this. A huge backlog in services and assessments remain, creating a ticking time bomb of unmet need. The longer these delays last, the worse the situation gets." <https://www.specialneedsjungle.com/government-reduce-inequalities-disabled-childrens-health-care/>

Locally at Family Voice Peterborough (FVP) we have been picking up more and more anecdotal data detailing SEND household concerns relating to health service waiting times and access. It is unclear whether this relates specifically to SEND broadly or more specifically CYP who are Neurodiverse and their parent carers. Further to this we have also had conversations with parent carers who feel that some areas of need are being 'forgotten' and that there is an over focus on 'neurodiversity' by health commissioners which could be evidenced depending on how the wording within Cambridgeshire and Peterborough's Integrated System Five Year plan is interpreted.

What are parents telling us?

Through a range of sources but primarily sign-posting conversations and comments provided via the 'Your Say' form we use to gather general information on SEND services parent carers are reporting concerns relating to:

1. Waiting times
2. Lack of SEND awareness in General Practice and Emergency Departments in particular.
3. Not being listened by health practionners
4. Lack of reasonable adjustments being made during health appointments.

Where we get our evidence from

Evidence has been gathered from signposting conversations and completion of a form called ‘Your Say’ which enables parents to say what is working well, and what could be better across Health, Education and Care.

The first survey completed was reported on in September 2023 and looked at Health Appointments in relation to waiting times and ease of securing them; the second survey in November 2023 looked at Health Inequalities and Accessing support while at A&E.

Between both surveys over 50 parent carers had a chance to participate. Some basic demographics for the households who responded are below:

Health Appointments

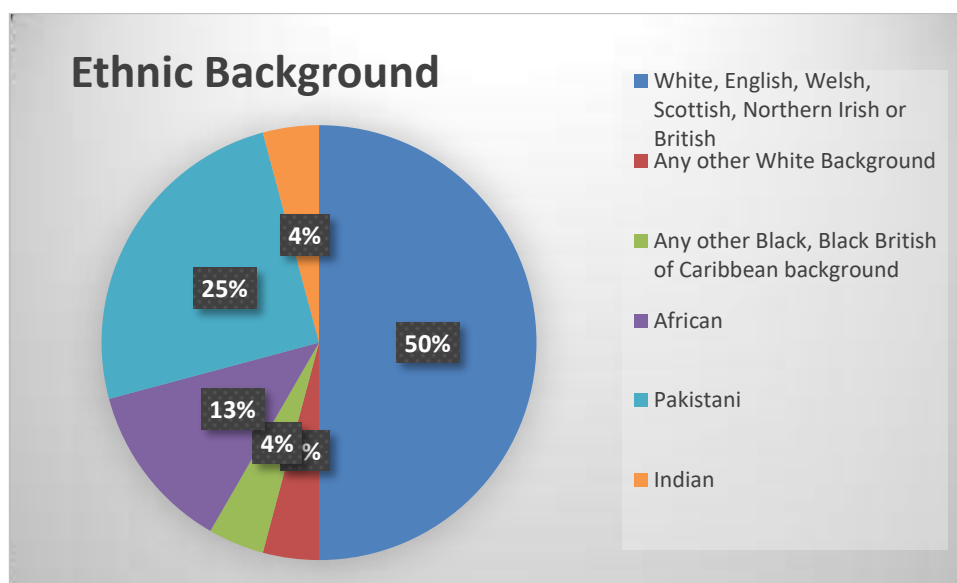


Figure 1 shows the respondent's Ethnic Background

Respondents have also provided more details about their wider household, including needs, economic and marital status:

4 people living in the house, Mother has heart needs, unemployed ,daughter still in school asthma and anaemia
Single
Single, Epilepsy ,stay at home mum, partially deaf
Single parent , unemployed, full time, carer, chronic pain, ADHD
Disabled single kidney disease
Married housewife, part time work for husband
single African
Single
Married foster carers 3 siblings
Low income family
Pakistani
Married, adults hearing
I have a child with autism
Married I have fibromyalgia and arthritis unemployed

Some of the determinants listed above can have an impact on how families access the services available to their children/young people. Many households have adults who have needs themselves and there is evidence of families experiencing economic difficulties which could impact on whether the parents feel able to engage positively with other services. Financial strains can also impact on the way families are able to access wider services, for example appointment time availability etc.

We asked the respondents how many Children and Young people with SEND they have per household:

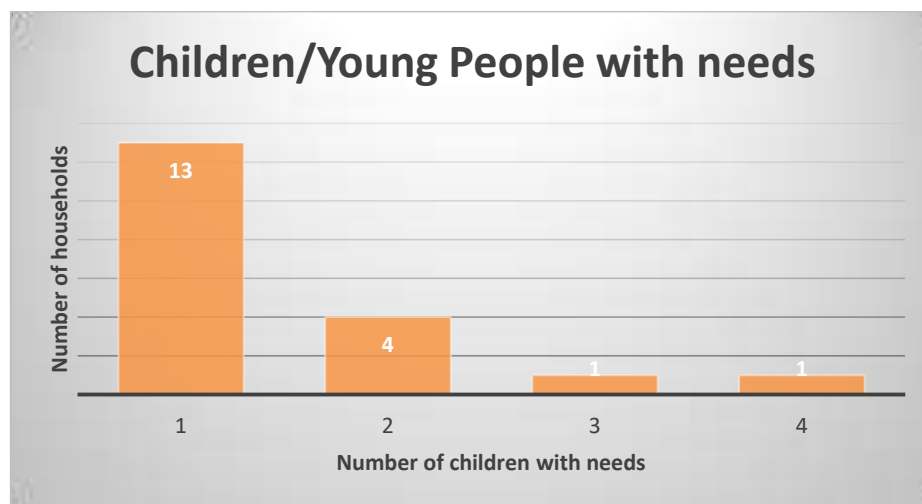


Figure 2 shows CYP with SEND per Household

Figure 2 demonstrates that 31.58% of households are caring for more than 1 child with SEND leading to these families facing multiple extra pressures associated with caring for a disabled child.

Some of the parent carers also provided about the need their children/young people have:

Male 16 LD ADHD
Girl 8 Autism
4 Male Autism
Autism ADHD SPD Male
9 female dyslexia ADHD
7 F LD
Male autism adhd tourettes 11,9,6
Male age 10. Female 11
9 Male - Down's syndrome and additional developmental delays
Autism/5/male
9 female deaf, 6 male deaf
Autism
(Boy) has Autism 6yrs male

Health Inequalities

From those who took the survey and provided details it can be seen that 70% self-declared as ‘White, English, Welsh, Scottish, Northern Irish or British’ and the other 30% from a mix of other ethnic groupings. The Ethnicity categories are based on those used in the Census.

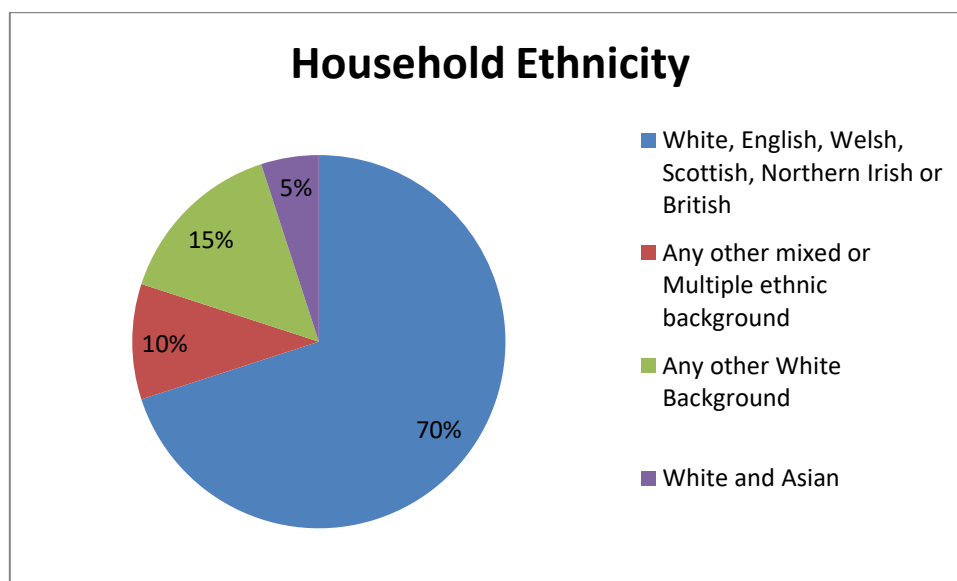


Fig.1 Household Ethnicity

Further to asking respondents to report on their ethnicity they were also asked to provide wider household information if they felt comfortable to do so. These questions are always optional so numbers of responses can be a bit lower. Where information was provided broadly speaking the majority had at least one parent/ adult with a health need and/ or disability at 67%, the majority were surviving on out of work benefits and a minority by a

small margin classed themselves as single parent households at 42% (see fig. 2 and 3 respectively).

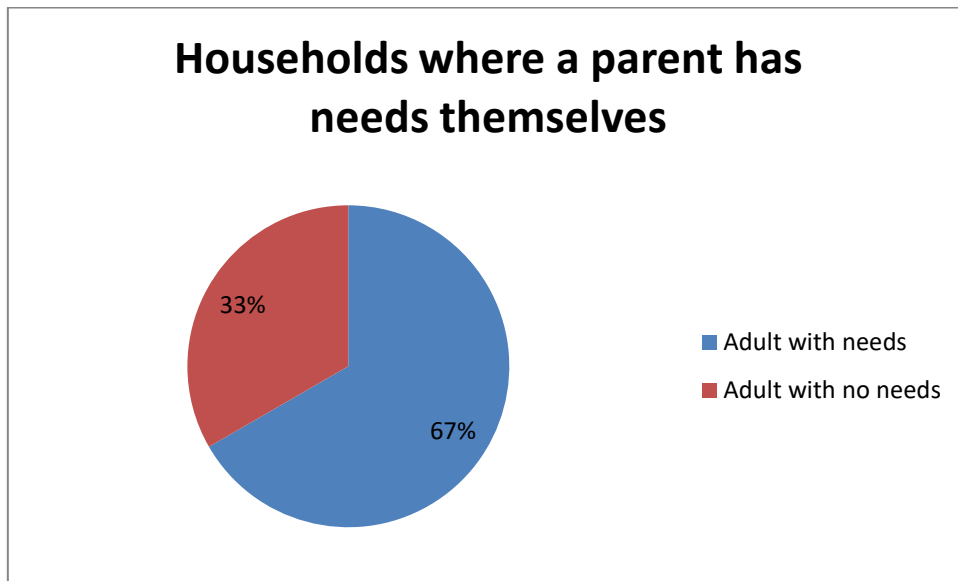


Fig. 2 Parent Carers with and without needs percentages

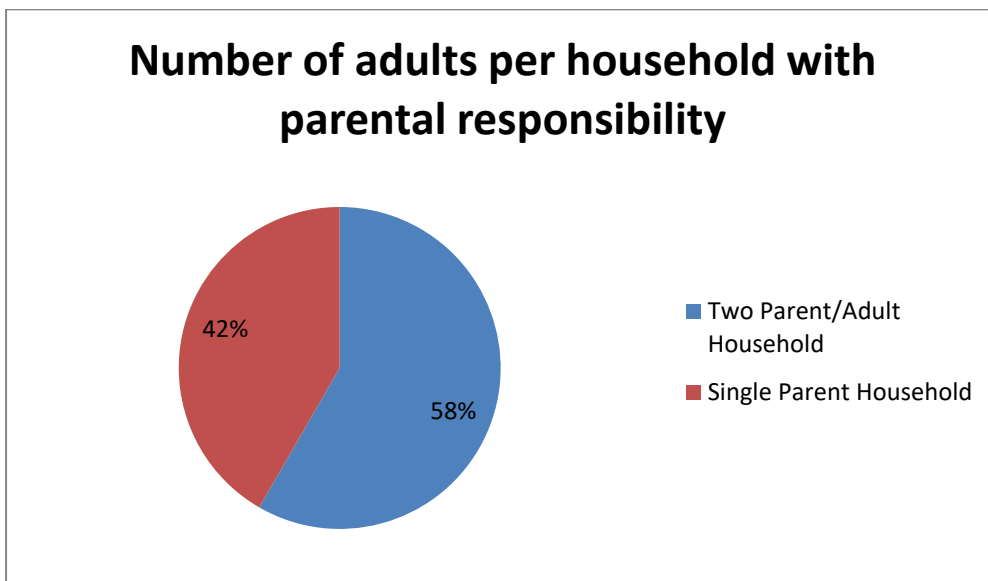


Fig. 3 Household Adult Make-Up

It is clear from the above information that most households have complicating factors that may impact on their lives in multiple ways.

Parent Carers were asked to state your child/ young person with SEND needs/ age/ gender. The details of which are as follows (again this question was optional):

5 yrs 11yrs and 19 yrs all male
Male 19 autism adhd tourettes

Down's syndrome, 15, female
Age 7, male
Adhd epilepsy 12 male
9 year old ASD 18 year old selective, mutism 20 year old anxiety and depression and ASD
ASD, 10, male / ASD, 8, male / ASD, 4, male
3yr 4m male
7, Female with global developmental delay, low muscle tone.
7 years Male Deaf , Blind , Peg fed , OSA requiring BIPAP, Epilepsy, GDD, Wheelchair bound.
Female age 6 Profound developmental needs complex medical problems Trisomy 9m
Asd dyspraxia and dyslexia 13 M
Daughter born with spina bifida
9 Male ADHD/Autism, suspected, 3 Male ADHD/Autism suspected, 14 Male ADHD/Autism suspected
Autism ADHD
Daughter autistic, diabetes type 1, ARFID
5 yrs old Male Autism and ADHD
1 year old boy Autistic spectrum disorder

Table1: CYP Data

It can be seen that areas of need are broad, with the predominant one being ASD at just over 58%.

From data provided in relation to how many children/ young people (CYP) with and without needs per household it should also be noted that there was 1 household had 8 children without needs and 5 with. 32% of households (fig. 4) had children with needs only and 35% (fig. 5) had more than one CYP with needs. The average number of CYP with SEND per household is 1.7.

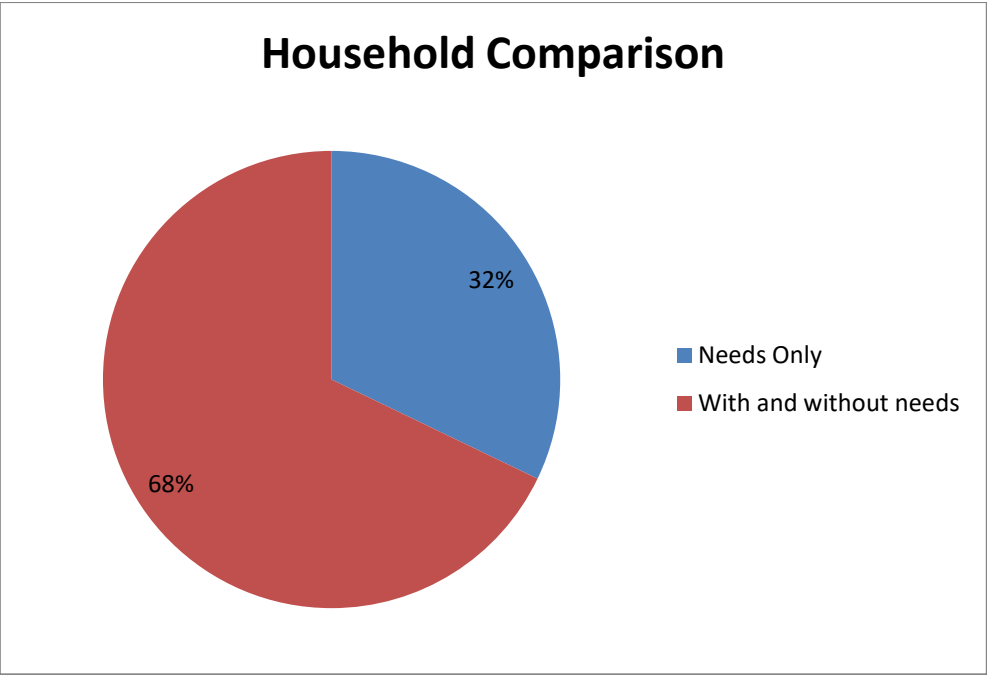


Fig. 4 SEND of CYP

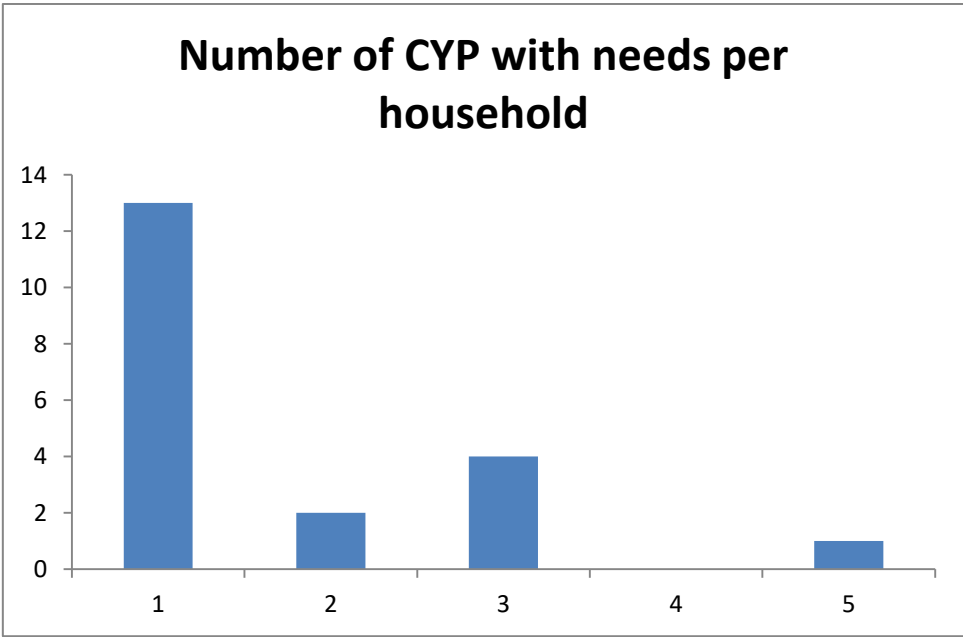


Fig. 5 Number of CYP with SEND per household

Many households have multiple caring responsibilities which can further impact on accessing services.

Both reports can be accessed via FVP's website www.familyvoice.org

Further to this parent carers provided the following feedback regards health on the 'Your Say' Form:

Your Child/Young persons Age, Gender and Area of Need	Do you have any positive feedback to share about Health Care	Do you have any neutral or negative feedback to share about Health Care
17,15,14,4 2 female and 2 male adhd and autism	Always been helpful in giving advice and writing reports where they can from assessing individual needs of child young person	None
Age 7 male, diagnosed ASD, ARFID and Dyslexia. High anxiety, awaiting ADHD assessment	The dietitians team based in Cambridge are fantastic. Our GP surgery - Wansford are fantastic.	Long waiting lists for assessments and support. Having to chase everything and fight for what your child needs. So many hoops parents have to jump through to even see a paedatrian it is exhausting. No ARFID pathway in Cambridgeshire.
18 female fnd(functional neurological disorder.) Non epileptic seizures. Sensory issues. Need 24hr supervision	Left to deal with everything on my own	Left to deal with everything on my own
11 male Sensory issues		
Also Care full time for disabled husband		
11, female, sensory/ASD/adhd/mental health	Good communication and efficient when you do get appointments	Slow process as lots of people on waiting lists.
4/ female/Autism and development delay	No	Parents are not supported enough to get the right help and the waiting lists are very long
Casey Harrison girl autism	Mostly quickly get appointments and reviews with the doctors regularly	
13, male , austism spectrum disorder	Hospital appointment are accessible for us , for example for physiotherapy he waited only 3 weeks from referral date .	Some doctors don't listen , but I think it all depend on personality .
has golden-har syndrome	Always been happy with health care	No
male 21 arthrogryposis, shay male 15 asd and mental health conditions, laila female 14 mental health, female 2 development delay	Occupational therapists are fantastic while children are school age, when they leave education and become adults its a different ballgame!	No
12 boy autism	No	Yes mental health help is a joke no help for our son. All he has is online

		calls for self harm.
16- ASD- female 5- ASD- male 2 - No diagnosis	Very pleased with GP services.	Other services such as CAHMS very poor.
13 F ASD/Language Disorder 11 M ASD/Moderate Learning Disability	Not applicable	No
9 year old Male with adhd 10	No The doctor always struggles because he cant communicate so we end up being sent to hospital most times.	Long waiting lists Doctors are not massively trained in autism
18 autisma	Once you have their support, it makes such a difference.	Getting someone to listen and help is not easy. You have to grow thick skin, and never give up.
10, F. Autism: PDA profile, generalised anxiety, OCD.	Psychiatrist and psychologist do their best to engage our daughter.	Needed to submit a complaint to pals to get anywhere.
28 female Down's syndrome	No	Although annual health checks appointments are made the follow up are not always followed through
6 years old,male, autistic 6years old, male, autistic	No	still waiting for ... to be diagnosed. ... gets his diagnosis and that was it - you are left to yourself.
5 yrs old, female,Autistic	Not at the moment	Appointment should be given bit quicker. Health care system is very slow.
Age 20, Female, with ADHD and Autism. Needs some living support and supportive education provision.	No	Health care very limited. No regular visitations or significant support

18 Asd and intellectual disability	My positive is that my daughter was diagnosed at the age of 5. So has meant some support started at that point with her needs.	Would say that it's sad to know that the NHS still believe schools over parents and had meant for my daughter that the intellectual disability was not accepted by the professionals until I had battled a year for an educational psychologist and this proved no cognition change six years after being assessed from beginning of primary school. Same with ADHD. I was kept on a waiting list for 10 years, to then only be told that even though my daughter showed it in the QB test, the school however stated that as long as there is routine her attention is ok and just about manageable. Since being in post 16, the routine that special school gave her has somewhat disappeared and has had my daughter and still now going back to behaviours we saw back in primary due to inconsistency and complacency in post 16
Male 19 ADHD ASD TOURETTES	No we've had no involvement since age 14	We've struggled accessing health care & even places like hospital with such long wait in A& E he was still expected to wait & because he couldn't handle the wait he would walk out of appointments and then get discharged as a no show
10 male ASD	Special needs dentist is fantastic	N/a
13yrs, female, anxiety, depression, lung condition	Good health support	Took time to get it initiated
12, male, asd adhd	no	school nurse sent out flu and vaccine consent forms. filled in and returned, school nurse arrived early, did NOT read forms, just assumed it was a yes. its a good job my child refused on the day as we did not consent. who checks? this could have been a deadly decision.
14 female ADHD/Autism	Yes sometimes	Sometimes feels like a battle for your child.

26, male with autism	Accessing annual health check	Difficulty accessing GP service
24, male with autism, learning disability and epilepsy	Accessing annual health check and epilepsy reviews	Difficulty accessing GP services
16 female global developmental delay	No	They don't really know what's wrong with my daughter even though she's on end of life they think she doesn't meet repaite for health needs
Global delay	Free	Delays and not take seriously
19yrs male 11 yrs male and 5 yrs male autism and behaviour	Can get appointments quick	Need to speak to a person not very quick to get back to u no dentists for children with send should be a priority
Kaizer Malik Sayed (9) male	Health care is difficult to access at the moment but appricate all the help they do	Long wait times and issues with contacting gp
Age 7, Male, Diagnosed ARFID, Dyslexia, ASD. High anxiety, awaiting ADHD assessment	General paediatrics team are great	Why isn't there an ARFID pathway in Peterborough, my grandson has a diagnosis but no support, my daughter has to pay privately for this

Some suggested reasonable experiences from Parent Carers:

Extra time taken
More communication and updates on wait times, option of quiet place to sit as very loud
If the young person want an parent or carer to talk for them they should allow it due to the disability of selective mutism
Quiet waiting area, listening to parents about what their child is / isn't able to do.
Appointments straight after lunch/breaks so there is not a backlog wait from other patients. Being given a quiet space to wait without other people helps to some degree vs busy waiting rooms. Additional time taken to gain an examination
At some point we will need a hoist when on the ward and i am not sure if this will be easily available.
Availability of hoist to get him out of the chair
Art therapy as they promised
Taking time exploring what is happening, separate rooms are available on intensive care, not pushing on eating ARFID

How have FVP responded

The survey reports and further evidence of concerns relating to health have been presented to both PCC and Health Leads and this ToI has been produced as a way of linking all information together. Information has also been gathered into monthly highlight reports and presented back to various boards.

Where FVP have shared this talking point

1. FVP Website
2. FVP Social Media Channels
3. FVP E-News
4. Peterborough City Council and Cambridgeshire & Peterborough Integrated Care System Decision Makers

Next Steps and Areas for Consideration

1. For FVP to conduct an awareness raising campaign with parent carers about registering with their GP as a Carer, finding out more plus asking about LD health checks and making use of Health Passports.
2. For PCC/ Health to consider working with frontline health partners to recognise the importance of the views of the parent carer and where applicable young person and helping them to recognise tools such as health passports.
3. For front line health providers to recognise what reasonable adjustments could be made that would improve the experiences of SEND families.

Timescales

1. For PCC/ Health to respond within three months of issue of this ToI
2. For this ToI to be published on the SEND Information Hub (Local Offer) within one month of the issue of this ToI