



Health Based Surveys Report

This reports details
in one place the data
and findings from a
series of small scale
health services
surveys

Family Voice Peterborough

Introduction

In a move away from previous reports which detail surveys separately it has been decided in this instance to detail three surveys together due to how they all relate to disability/ health services broadly. The surveys cover Continence, Therapies (Physiotherapy, Speech & Language Therapy and Occupational Therapy), Wheelchair Services and Sensory Impairment.

The surveys were completed by a diverse range of parent carers, with some completing more than one survey. Although responses were anonymous some details were sufficiently similar to detail where they were from the same respondent. Duplicated details were removed from the section that follows relating to participants and their children/ young persons (CYP) needs. There are also a small but growing number of parent carers from different ethnic back grounds now completing surveys than at the start of the financial year when data was first recorded.

The results are mixed in terms of service experience and in the case of sensory impairment general understanding. There is a general low level of satisfaction and parent carers report difficulty in accessing services in particular.

Respondents

A total of 46 parent carers took part in at least one of the three surveys.

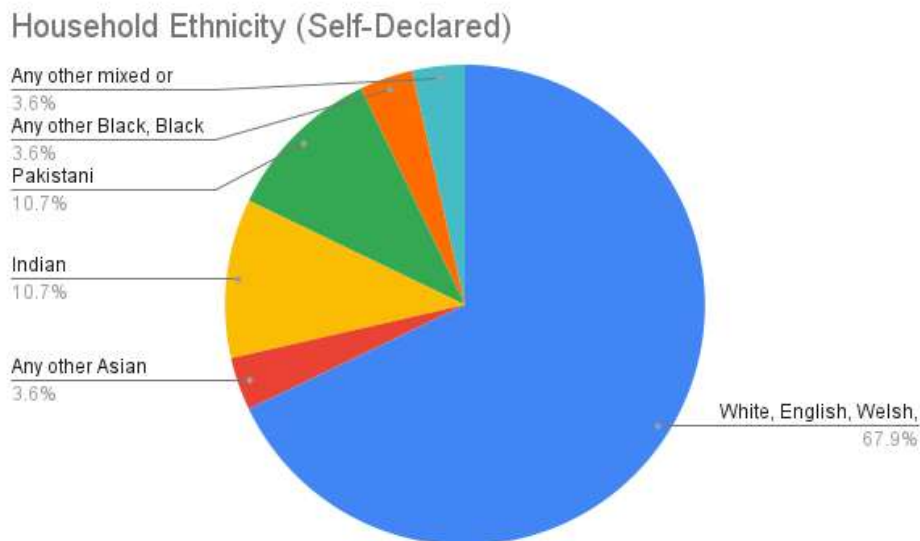


Fig.1 Self-Declared Household Ethnicity

From Fig.1 it can be seen that approximately a third of respondents at 32.1 % are from ethnic backgrounds other than White British. This is an increase on previous surveys.

Where declared it was possible to establish that 43% of the parent carers who responded were either married or cohabiting and 22% were in single parent households. All of those who responded stated that they were either on benefits alone or in work benefits with the primary benefit being Universal Credit. Also 15% stated that they themselves or another adult in the household had a health need or disability.

CYP ages, Gender, Areas of Need

Several households have more than one CYP with needs as seen in Fig.2 and the most frequent age range is 16-20 followed by 11-15 and 0-5 (fig. 3). More households have CYP declared as male at 51.4% (fig. 4).

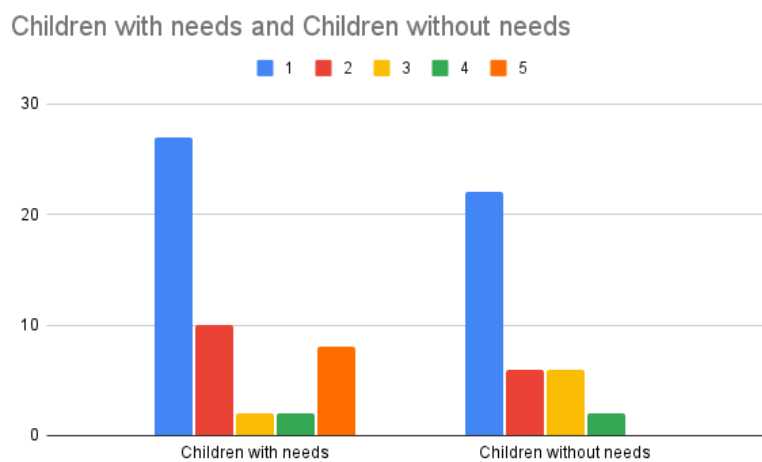


Fig. 2 CYP with/ without needs

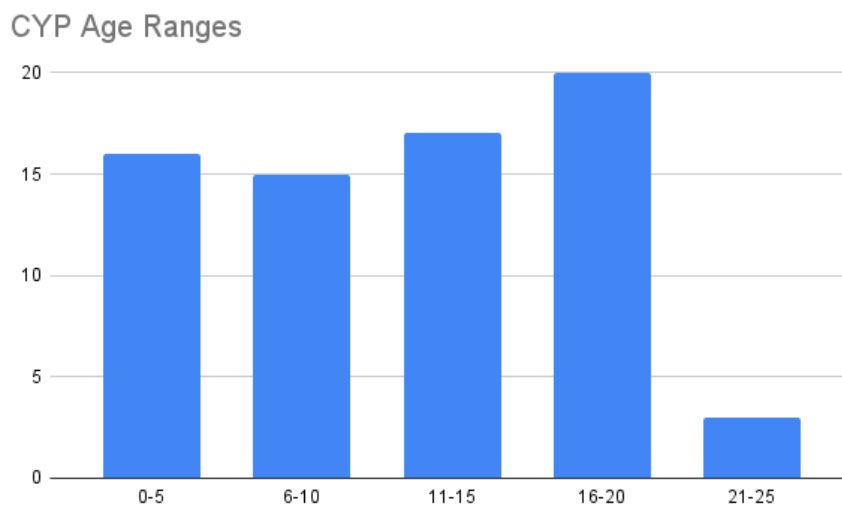


Fig.3 CYP Age Ranges

CYP Gender

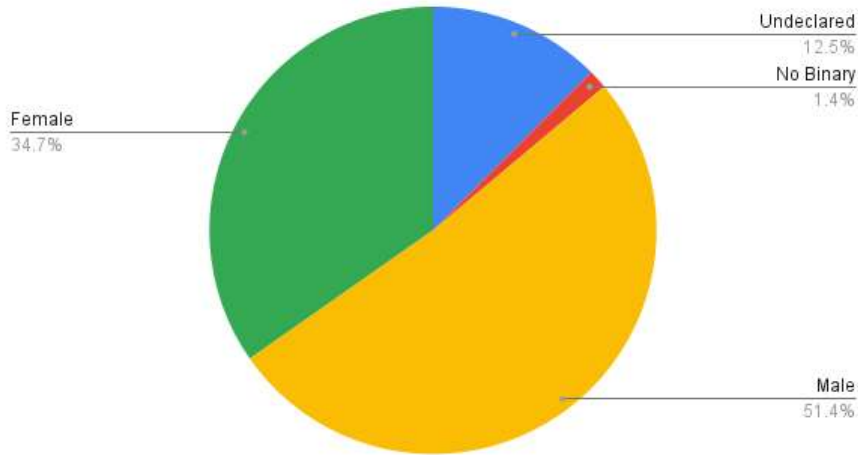


Fig.4 CYP Gender

CYP Needs include as recorded by respondents; ASD, ADHD, Visual Impairment, Hearing Impairment, Down Syndrome, Anxiety, Complex Health including use of catheterisation as an example, physical disabilities, Arthrogyryposis, Epilepsy, Arthritis, hereditary spherocytosis, Learning Disability and behavioural needs. As in previous surveys the most frequent declared need is ASD.

Surveys

Continence Services

The first survey conducted that relates to health services/ needs was around 'continence services' also referred to as 'toileting'. Many parent carers when talking about having a CYP who is in need of 'toileting support' often use the phrase 'continence' as opposed to 'toileting'. This may be linked to generally using 'special needs' language when raising a CYP with needs.

Have you visited your GP or spoken to any other health professional about your concerns regarding your child's toileting issues?

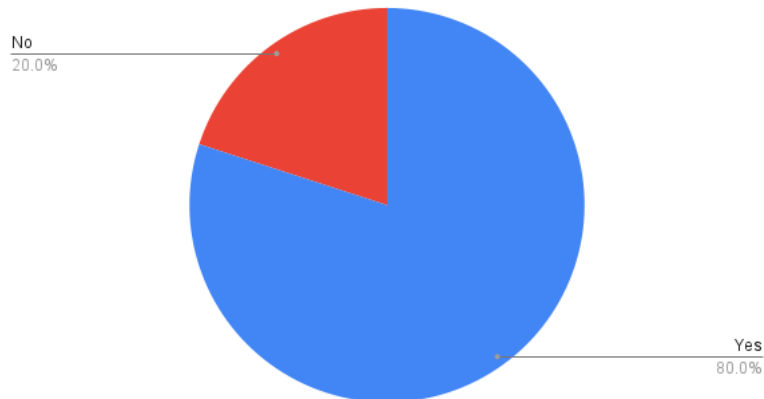


Fig. 5 Raising 'Toileting' Concerns

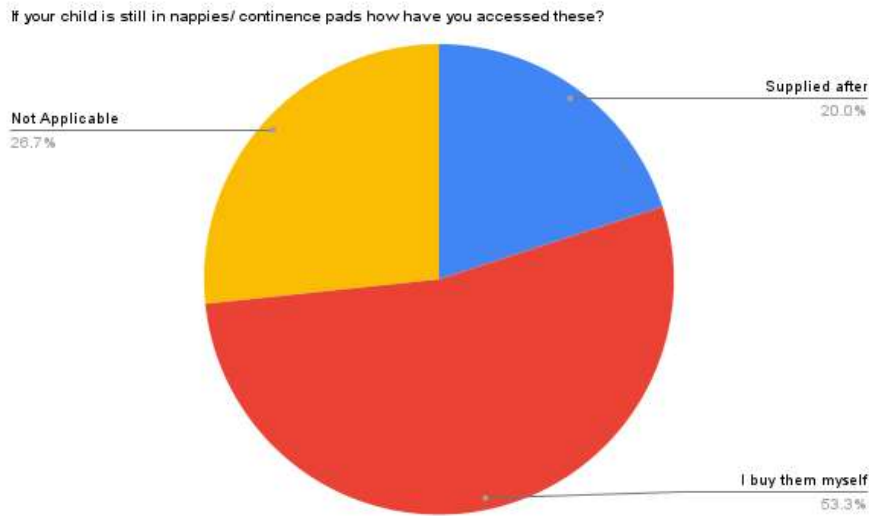


Fig. 6 Sourcing Continence Pads

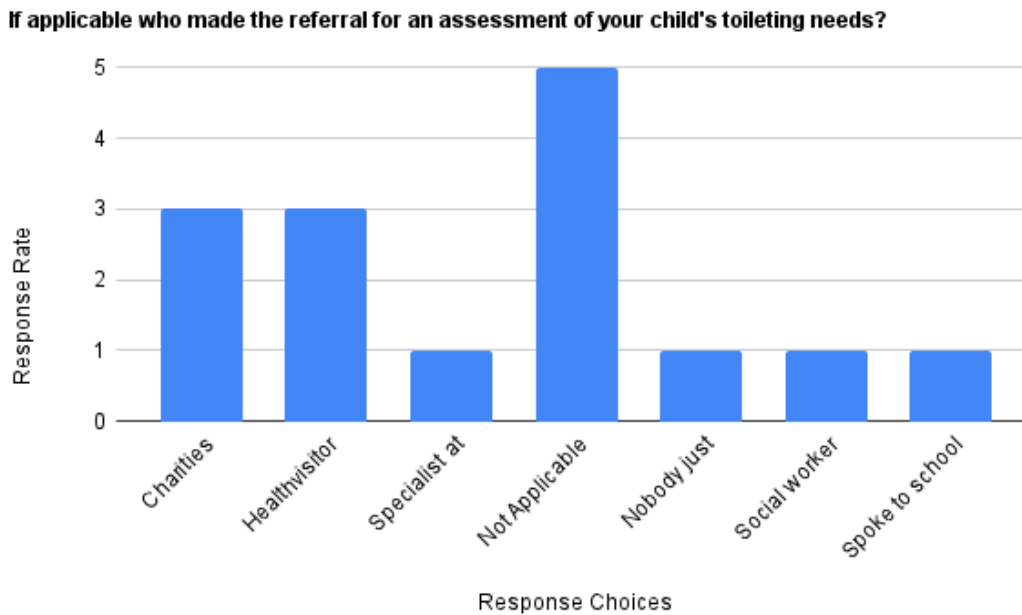


Fig. 7 Referral Routes

Although parent carers were asked about whether they felt their CYP needed a referral for assessment of need the question remained unanswered. From Fig. 7 it can be seen in some cases that referrals were sought but the number is low. Fig. 6 shows that a number of CYP are sourcing their own continence pads/ nappies which may be related to low referral routes, or parent carers for any range of reasons not being referred or seeking a referral. It is not possible to ascertain the reason, only to show that there is a need parent carers are seeking to address themselves.

If applicable are the number of pads/products per day enough?

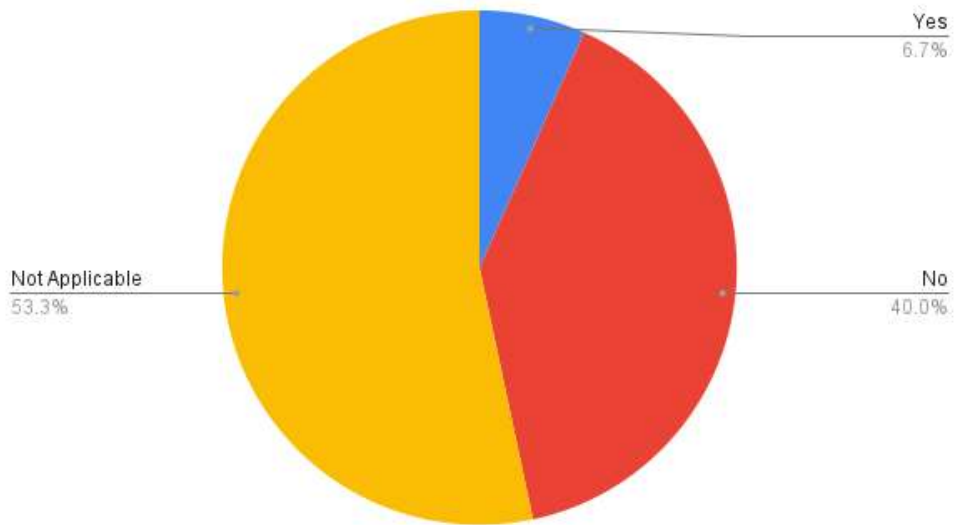


Fig. 8 Number of Pads Suitability

Is the process of ordering/reviewing your order easy?

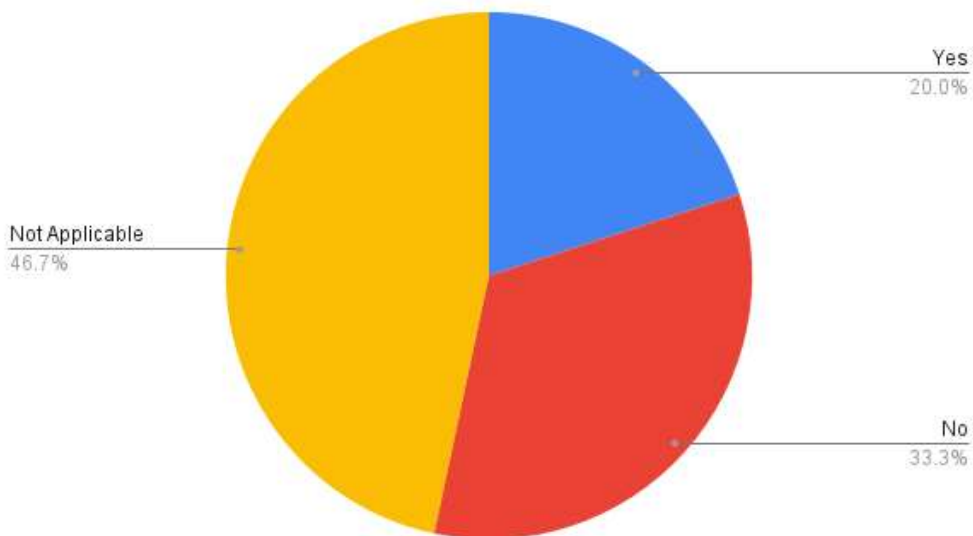


Fig. 9 Ease of service use

For those accessing support for example through the provision of pads feedback is not positive. In general as seen in Fig.8 and 9 the ease of ordering pads and reviewing any order is seen as difficult, and the number of pads supplied is viewed negatively. Pad rationing is something that has been raised anecdotally by parent carers previously as a concern. When removing those who selected not applicable as shown in fig.8 it leaves over 85% stating that the number of pads supplied is insufficient.

Do you have any suggestions or comments on the service?

- *It would be so much easier if gp didn't pass to school nurse then school nurse back to gp*
- *Wholesale review . It is simply not fit for purpose.*
- *Should be better signposted and accessible - I had no idea about this*
- *I didn't know the service existed, Nurse practitioner at local GP didn't know and told me when my son lost control of his bowels due to ongoing gastrontiritus, I was told I had to re-train my son because he was no longer aware of his need to use the toilet, and would mess his under pants, up to 5 times a day. I have bought the incontinence pads myself to help recently as for months I have been washing multiple times a day since February/March 2022. I'm still working with this, some days my son can say he needs the toilet, other days not.*
- *My 6.5 year old is still wetting at night and GP won't help till she turns 8 and I'm struggling*
- *Son is toilet training, have a lot of accidents so need to be near a toilet at all times as he doesn't have skills to tell us he needs to go and we read his body language*
- *I spoke to my GP who said go to my school nurse & nurse sent me back to GP*
- *Terrible service. Had to unnecessarily fight and no support to help transition to toilet training pants.*

Of those who chose at the end of the survey to provide any further information no-one had anything positive to say. Two statements show there may also be some confusion as to who can make referrals/ support CYP with needs relating to 'toileting'.

More support may be required with informing families as to how to get support, as well as supporting practionners to know and understand any service provision pathways.

Sensory Services

The Sensory Services survey was based on a series of open ended questions that were useful in showing there may a difference in understanding of what 'sensory impairment' means between the general public/ services and parent carers especially those who have a CYP with ASD. For the parent carers who completed the survey were the primary CYP need it can be seen that 'sensory impairment' has been seen as synonymous with 'sensory processing'. This was not necessarily the intended outcome of the survey, but it is still useful to see. The survey also showed that there is a general parental concern over accessing the community more broadly as well as receiving any support to manage need related to any perceived sensory processing difficulties.

What do you think sensory impairment means?

- *Overloaded of sensory, or the opposite needs lots of input*
- *not normal ability to smell touch or taste*
- *Disability to include any of the senses*
- *Lack of sight hearing taste need to squash squeeze sensory overload*
- *Someone with difficulty hearing/ seeing or other sensory needs such as autism, can also be communication difficulties non verbal, sensory seeking*
- *Struggles with sight, sound, taste, smell, touch etc in there everyday life*
- *It involves the 5 senses*
- *Meaning such as hearing, no verbal*
- *Touching certain things/hearing/seeing*
- *This is a senses impairment ie deaf, blind, visual impairment*
- *Additional needs mental or physical with difficulty processing things*
- *Multiple Physical and / or Neural Pathway Errors / Deficits that result in disability and / or physical and / or Emotional distresses.*

What specific sensory needs does your child/young person have?

- *Noise, places, non grounding, over reacting,*
- *Sensitive to noise, touch is very hard and will self harm*
- *One of my children has sensory toys throughout the day & gets over stimulated so has to take breaks in quiet places ie leaves sch early so not to be flustered around other children & noise*
- *Hearing impairments, sensory seeking, non verbal*
- *Sensory processing and sensory overload*
- *Light, smell, hearing*
- *Hearing lost*
- *20yr old has Processing, Cognitive and Neurological abnormalities that cause Significant delays to and / or impairment of and /or to speech, ability to learn and relearn, delayed processing of visual and auditory stimuli intermittently, dysfunctional memory, limited ability to develop lifeskills and social skills, seizures of currently Unknown origins, Severe Emotional disturbances and Inability to regulate Emotions, No unsolicited touching rule, body temperature and heart rate and at times significant bowel reactions (IBS) that have been seen to be linked to his ASD and DCD particularly. The list expands and contracts dependent on input environmentally and so forth. 19yr old has a lack of Self Regulating abilities, limited life skills and ability to implement what is learned, delayed and at time selective (Pronounced behavioural disturbances) hearing and sight. Some mild to moderate memory / cognition issues, Mild IBS but nevertheless upsetting to him symptoms associated with his inability to self-regulate. At times Pronounced social and food related sensory impairment that negatively impact mental and sometimes physical wellbeing. 14yr old male has Distinct and Significant Neurological damage that has resulted in his subsequent diagnoses. This impacts his ability to Self regulate emotionally and physically that include Profound Bowel , nerves*

throughout left side of his body significantly impaired and stomach issues. He has no Colon, part of lower stomach resected, less than 20cm of small bowel remaining and Significant Disease level remaining in what is left. He comes under Neuro-Divergent / FND and DND umbrellas. Gets visual and auditory disturbances at times and has severely damaged nerves on the left side of his body particularly which appear similar to a stroke when presenting with the usual symptoms he's had with relation to this since development antenatally and birth. He manages to mobilise fairly well in warmer weather. Joints are Enlarged so seize up in winter months. All three boys become significantly distressed regularly from a variety of usual and unusual input factors. All three are still to undergo further Multidisciplinary assessments and gain supports and resources access.

- *My child is deaf so she has hearing aids*
- *Sensory seeking but can also be hypersensitive*

What services across the community/ education/ health are you aware of that are available for you and your child/young person?

1. family voice little miracles caring together
2. 0-25 disabled children, early help , adoptive services
3. Extra help in school
4. Just finding out now
5. To look for his education needs
6. I'm aware of multiple. Although their Accessibility, Availability, Service Inclusivity and Performance vary wildly. There is no consistency to any of the services really and I have been working with, for and alongside relevant parties to address these Profound Service issues we face in Peterborough, Nationally and Globally.
7. Deaf teacher, audiologist, charities
8. Learning about the local offer through family voice

What barriers or difficulties have you experienced in terms of accessing community services?

- *We don't get help*
- *making it accessible to all*
- *Knowing what's available*
- *People don't understand when my child has sensory overload & tend to judge so don't others censing help.*
- *Not much communication, ppl in our community don't tend to be open about disabilities*
- *Not knowing where to go*
- *Inconsistent and out of date information on the city Council website that links us to All relevant local resources. The Google search for relevant parties also needs amending by said parties to only include Current, relevant and Easy Read resource information and access. NHS is in the process of addresses all*

services including their digital services (I am involved in relevant capacities aforementioned in this form). We need to form a Families and Communities led Liaison and Networking service, that Links All relevant services, charities, organisations and governing and Independent Oversight and works alongside and or within the current Sustainable Combined Authorities and Services strategy plans. I have already started the Initial Human Resource Intense and Physical Time Intense work to Develop my suggestion. My Networks are expanding steadily. So tbc.

What support if any have community services provided to make accessing them easier

- *leaders listening*
- *No but have just started looking*
- *Getting in touch with 0-25 disability team*
- *Only now and again that they do autism hour in shops or banks*
- *With the exception of NHS, FVP, Caring Together and the expected Good Practice of services like Trussel trust, local communities cafes and hubs and CKH I am at a loss to add any further services that are making consistent and concerted efforts regarding Inclusivity and Accessibility for service users. I tend to research Everyone and Everything and then make relevant signposts and referrals to services / resources to general*
- *public and to people within all of my Networks or that contact me in crisis.*
- *Family voice sign posted which made few thing easier*

What type of community services would you and your child/young person like access to?

1. inclusive sports
2. Access to play days where you feel welcome
3. Family activities, breaks - things for young carers, help with education and learning also sports clubs
4. More support to be able to leave the house and to attend education.
5. Going on holiday in the UK and support to keep his mental health good to stay focus
6. For the autism hour to be at a reasonable time, like in the morning
7. Clubs, day activity
8. Regular Specialised community educational opportunities on All relevant Public Health and SEND / Neuro-Divergent information and training. With a focus on Community Sustainability practices that include Self Management to minimise the long term impact of and upon services for disabled people and families and to promote lifelong learning, independence and well managed wellbeing and empower the communities engaging in these programs (e.g. an American charity called Mindspring Health Alliance Org and their Active and Internationally popular and relevant delivery of services and training with

relation to service delivery and other relevant areas)That can and will cater to those needing additional physical and or emotional / practical mentoring. LDE and many others have some fantastic ideas about Community development and engagement. Also see Young Minds and relevant National Disabled Children and Young People Council works.

9. Just any help or support for deaf children
10. Help with educational and physical learning resources also help within the home to make life easier

What are your child/young persons' view's on community services?

- *N/A son doesn't understand these things*
- *My child loves community services*
- *Unsure*
- *They are Brilliant its great to have that support and know you aren't alone*
- *Not great unfortunately. I try to advocate for Community engagement for services and put into practice whatever I express an opinion on / interest in / on. Children and families need more Role Models that are Relatable,consistent and a regular face within the community because they live and work within it. For this reason I put an emphasis on time spent in and on Communities support and volunteer and engagement works / projects.*

In an ideal situation what would you like to access in the community?

1. Dance drama music art
2. Swimming
3. Sensory play
4. Be able to have access to big sky or activity world without any questions being asked
5. Support worker and places to take them
6. Free High grade education to all, Complete NHS and affordable Private healthcare / Dentistry care, more Hydrotherapy pools space (Peterborough has huge need), 2 day a week free access to community high quality gym and classes / equipment (sustainable CoOp style loyalty membership for those who wish to access whenever they can). Small donations / fee requests for other services should definitely be looked into as evidence globally of success with Circular services & Economies models. HassellGroup-Scorecard.
7. Deaf children groups
8. Respite, days out for family, and for young carers (siblings)

What barriers or difficulties have your experienced in terms of accessing education?

1. not inclusive
2. It's a long process

3. Threat of exclusion if I don't sign a form to say my child can be assessed by Mental health
4. Very limited - hard to get Sen tutors and sports clubs and when you do it's very expensive
5. A lot of talk and paperwork but never no real hands on support.

What support if any have education services (educational setting/ the LA) provided to make accessing easier

1. ability to apply for ehcp
2. School is great but difficult finding g approp comm based activities
3. LA nothing. School have been great giving my child full time 1:1
4. By working with the child as a team and giving support and information

What support would like to see offered to make accessing education easier?

1. more training around send needs
2. Mailing list to ppl cith special needs child with what is available locally
3. No threat of exclusion
4. Guidance about best clubs, groups to compliment education
5. Support worker/mentor to help my son's to feel able to attend school and college
6. More activities in the community
7. Early health care plan
8. Help and guidance with form filling and what resources are available - sometimes we don't know what we're looking for
9. More information available in understandable language and someone to go to

Generally the survey responses point to:

1. Differing understanding of what is meant by 'sensory impairment' and confusion with 'sensory processing'.
2. A sense of a lack of support in managing the needs of CYP with SEND.
3. A lack of understanding in the community about what SEND means and how this impacts on the CYP and their family.
4. A need amongst SEND families for more leisure and sport based community provision that is SEND aware.

It is interesting to note in this survey that although respite/ short breaks/ leisure were not the topic being looked into they were still mentioned by those who took the survey. This matches other small scale surveys conducted by FVP that have highlighted these areas as something families are seeking.

Therapies (SALT/ OT/ Physio) and Wheelchair Services

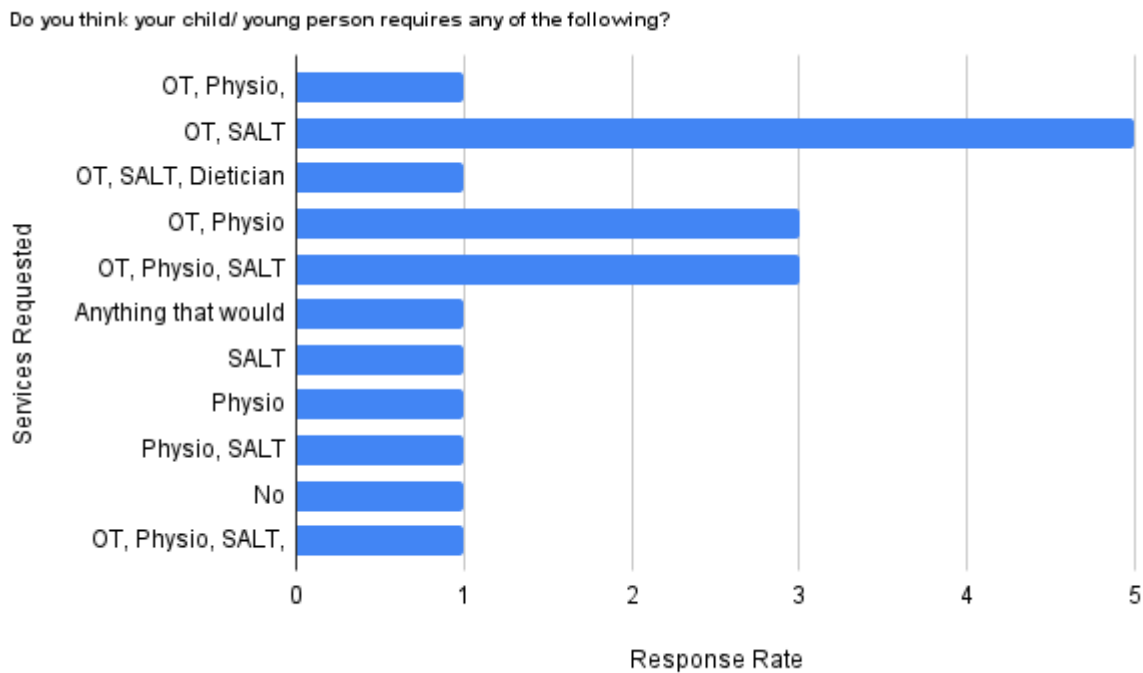


Fig.10 Do CYP need therapeutic support?

If you feel you should have had to access any of the services listed in the previous questions and have not been able to do so please tell us a bit more about this.

- *Gets harder once they leave school*
- *We are currently on the waiting list for each service, we have just had our first SALT appointment after waiting since April. Yet to see OT or dietician and have had just one round of intervention with the psychologist. Everything takes months to access and it feels like a constant battle.*
- *Waiting for OT assessment to be finalised then hopefully more future further support*
- *Occupational therapy gate kept, first have to complete online activities then refer if necessary. Time is a huge factor! SLT never even discussed.*
- *Just way too frustrating trying to speak to any professional s or to get gp apt*
- *Saw occupational therapy who said she needed skeletal physio within 2 weeks and still haven't heard after 7 months*
- *Finding it hard to chase them and still in waiting list*

Fig.10 and the subsequent question highlight how parent carers feel their CYP have needs that would benefit from therapeutic support across a range of areas.

Therapies Accessed

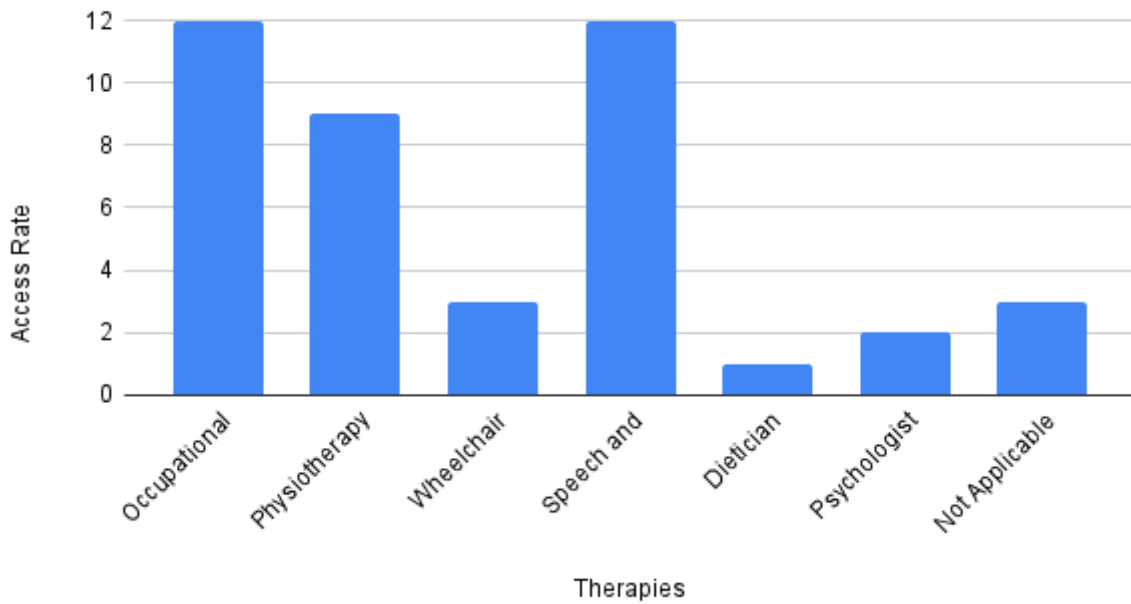


Fig. 11 what therapies are being accessed.

If you have accessed any therapies/ wheelchair services who referred you?

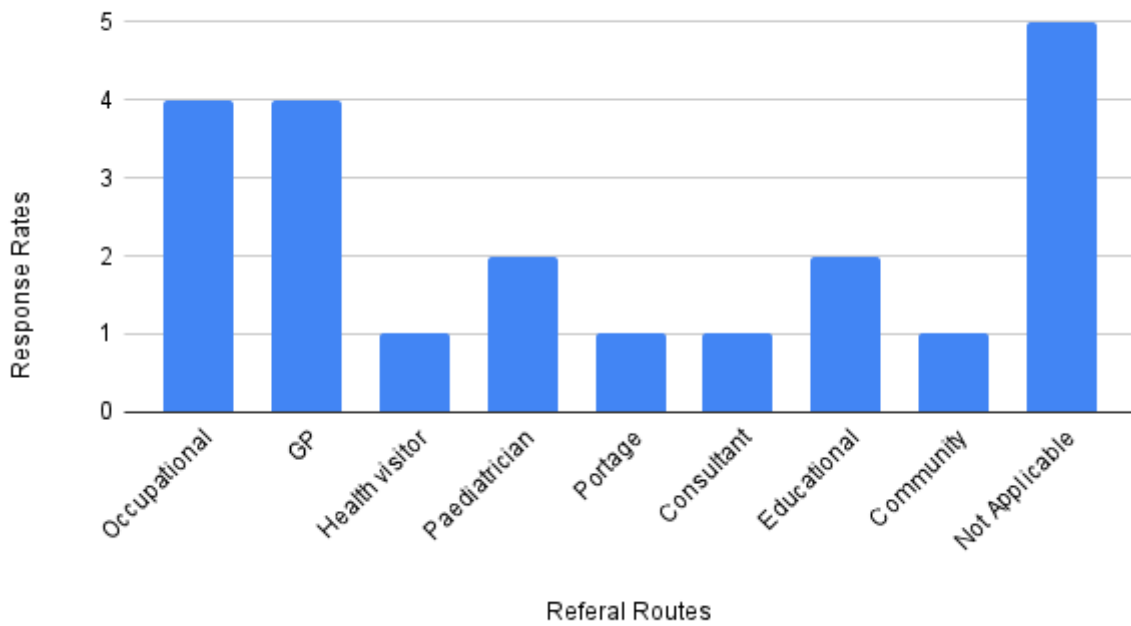


Fig.12 Referrals in to therapy services

OT, Physio, SALT and Wheelchairs Ratings

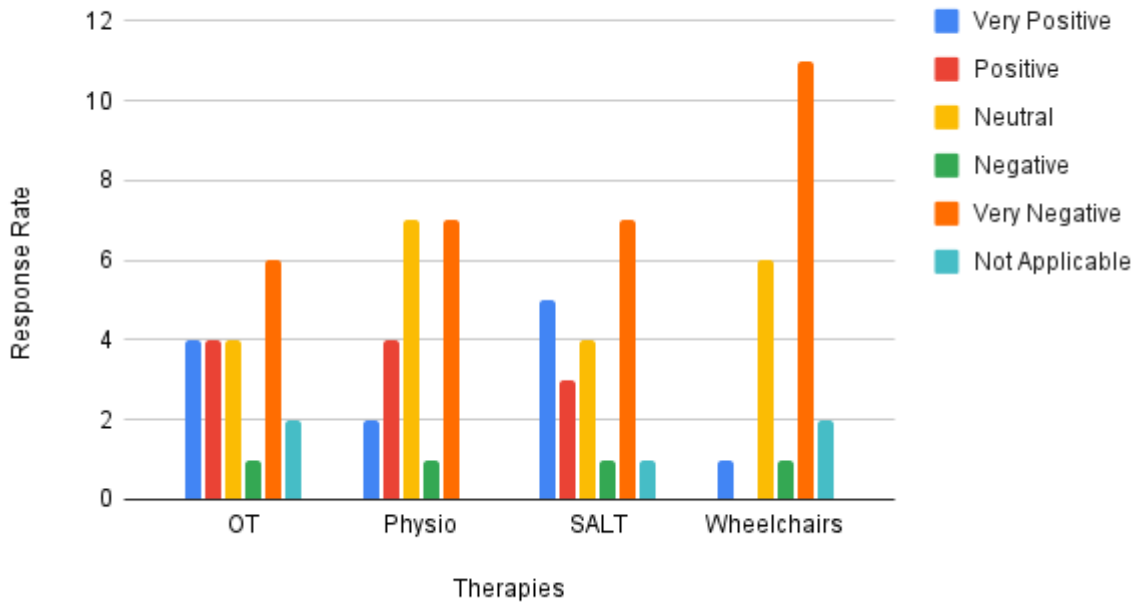


Fig.13 Overall Service Ratings

In a general assessment of access to therapies and overall assessment of the service as a whole feedback is somewhat negative. This can be seen across fig.11 to 13. Numbers accessing services are low, referral in is mixed and more parents view the services negatively when accessing them.

Wheelchairs

Please select the statement that best fits your child/young persons mobility needs

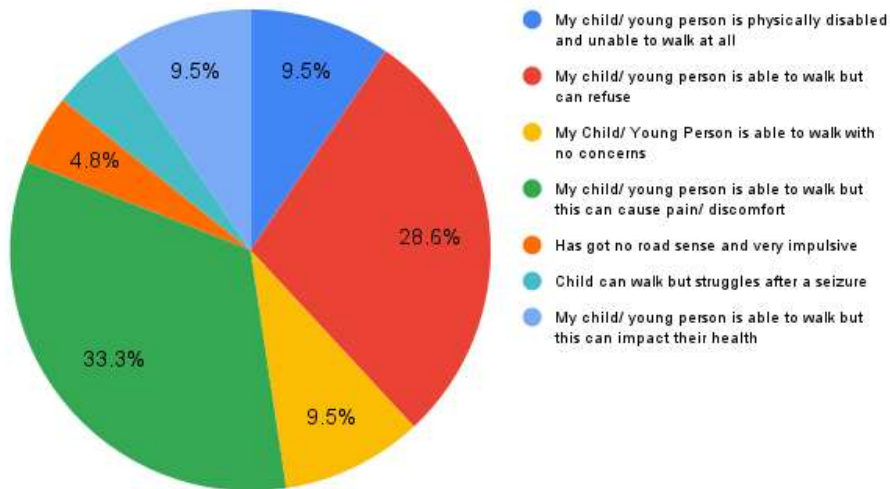


Fig.14 Parent Carer views of CYP mobility needs

If you feel your child has mobility needs please explain more about them
<i>Unable to weightbear</i>
<i>My child will refuse to walk if he doesn't want to. He is easily overwhelmed by his surroundings and/or alarmed by noises (ie a car horn) which then causes refusal or meltdowns.</i>
<i>My child is too large to carry and so requires a specialist pushchair due to height/weight.</i>
<i>My child has no sense of danger and needs to be supervised at all times. He is delayed in his mobility, unable to walk up or down a single step unaided at this point for example.</i>
<i>1 leg is shorter than the other and walks with a slight limp</i>
<i>Can have several bumps falls per day get unbalance and says legs are paining hurts to get up to walk discomfort will go into pushchair struggles with end off the day stairs getting to bed can refusal to walk and need carrying supporting</i>
<i>My child is very hyperactive and does not have any road sense and can be very impulsive and run out in roads</i>
<i>Has had tendons lengthened but needs operation agian</i>
<i>She has sensory issues with her legs. She has complaining leg pain alot. She is not been able to walk at all. School asked for buggy aswell for her</i>
<i>My child is very delayed in development and cannot walk for long periods or climb steps. Not able to hop/jump like peers</i>
<i>He walks with a gape</i>
<i>She struggles with walking and running, her movements are very rigid</i>
<i>Arthritis in all joints</i>
<i>Exercise causes low sugars</i>

In a slight move away from previous surveys and Facebook Polls questions were asked in a different way to establish what parent carers considered as mobility needs and what they felt was the reason for their CYP mobility needs. In other small scale assessments it was not clear where a CYP could not walk or had other reasons why mobility may be difficult including factors such as refusing to walk. Fig.14 and the following table of wider comments show that being unable to walk was in the minority for reasons attributed to mobility concerns. No conclusions are being drawn from this, as it only provides a snapshot view of what is a concern for a range of parent carers.

Following on from this parent carers were asked if they had spoken to their GP or another professional about their concerns and subsequently whether their CYP had been offered an assessment of their needs (Fig.15 and 16). It can be seen that although a high percentage had raised concerns the majority stated that their CYP had not been offered an assessment of needs. This may be a cause of concern to

parent carers who have previously reported anecdotally that their concerns are not listened to.

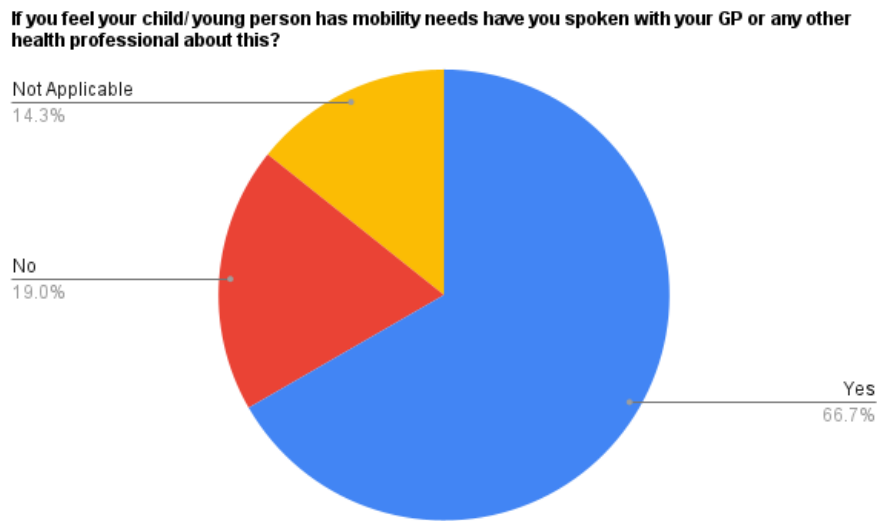


Fig.15 Seeking support for CYP mobility needs

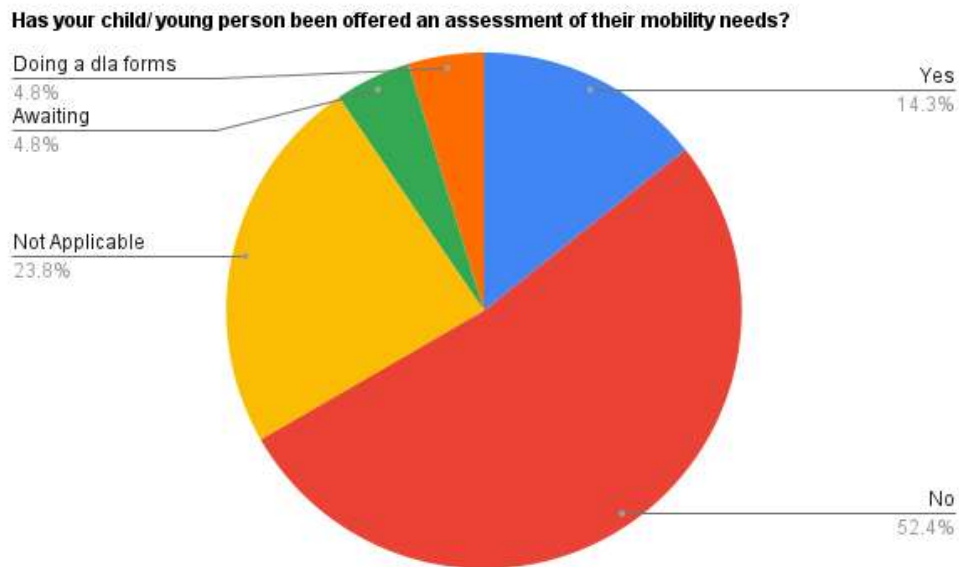


Fig.16 Assessments of CYP mobility needs

The above begs the question 'how can it be decided whether someone has needs without an assessment of needs?' Following on from this parents were also asked if they used a wheelchair/ buggy for their CYP how they secured it. Fig. 17 shows that if you discount the not applicable responses over half of the remaining parent carers at 70% purchased something themselves. Only 20% had a wheelchair supplied.

If you have a wheelchair/ buggy for your child/ young person did you?

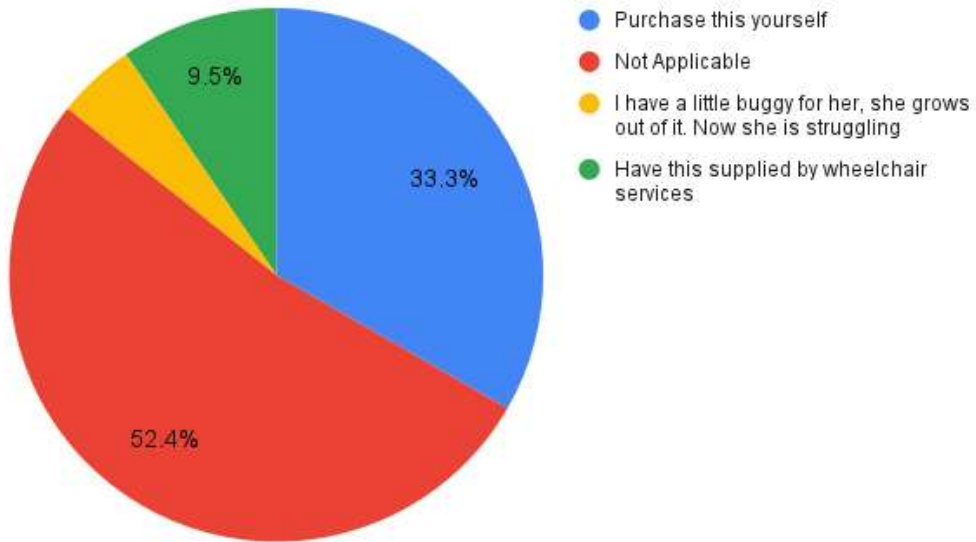


Fig. 17 Solutions to managing CYP mobility needs

Wheelchair Services Ratings

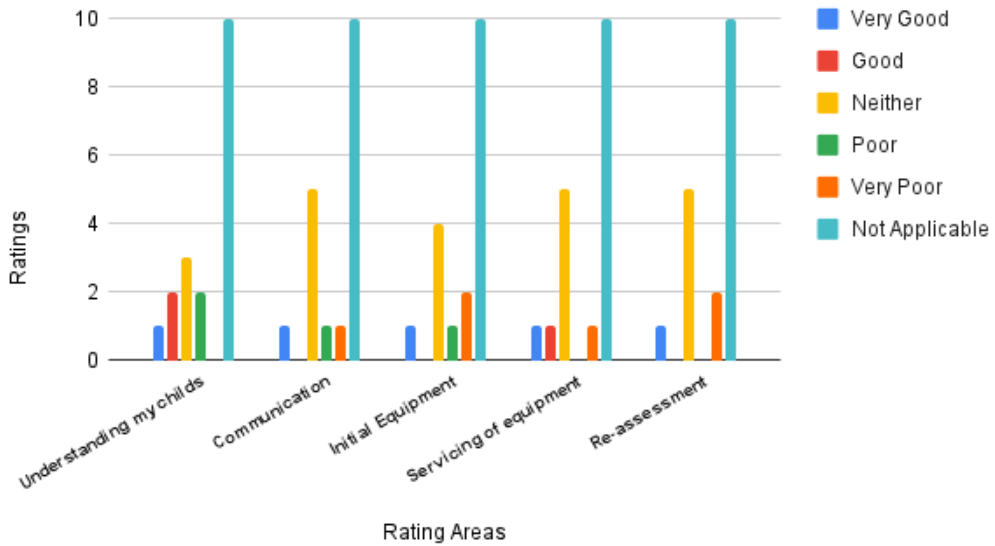


Fig.18 Over ratings of wheelchair services

Occupational Therapy

Do you think that your child/young person requires help from Occupational Therapist?

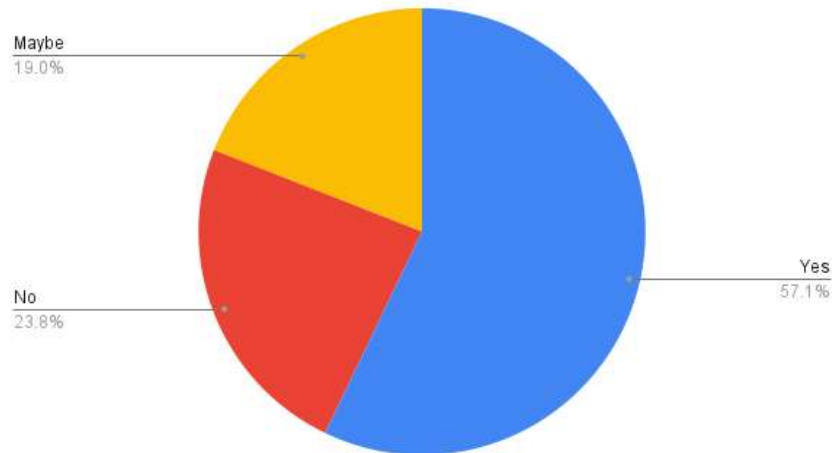


Fig.19 Parents views on whether OT is required

Were you able to access any support from Occupational Therapy services?

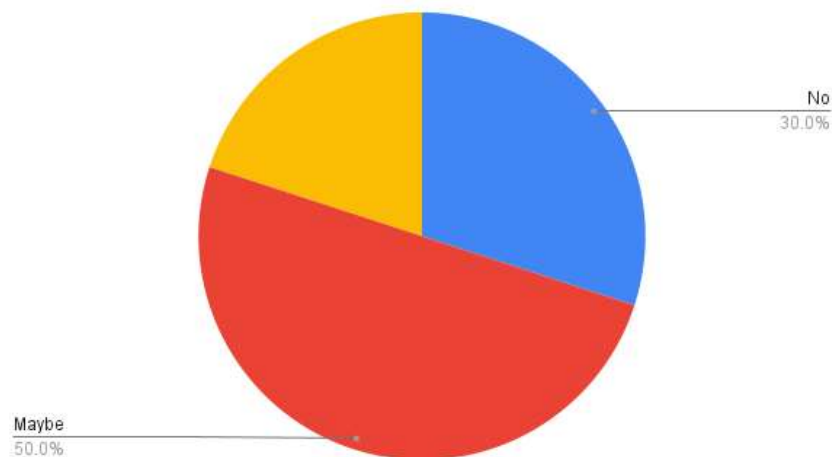


Fig.20 Accessing OT services

From fig.19 and 20 it can be seen that parents feeling their CYP should have access to OT support is high but this is not matched by actual access which is low. Further work would need to be conducted to unpick this and see if it could be established why.

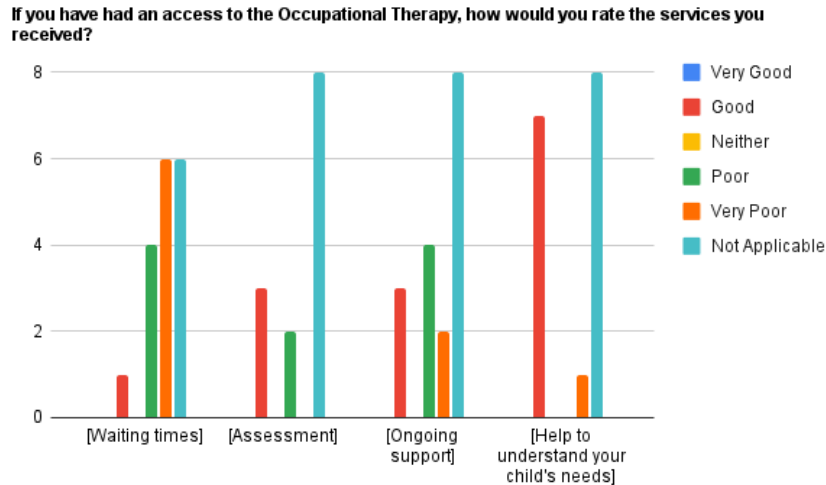


Fig.20 OT ratings by parent carers

Is there anything else you would like to tell us more about the service?
Far too limited OT support, Rush to discharge
My child is still on the waiting list for OT and has been since April. He needs this intervention more than any other I feel and this wait is very disappointing. He has massive challenges to all his senses and needs support.
It's very confusing and unnecessarily complicated

From fig. 20 and open ended comments from parent carers for a few views are not positive in relation accessing OT, especially in relation to waiting times and ongoing support.

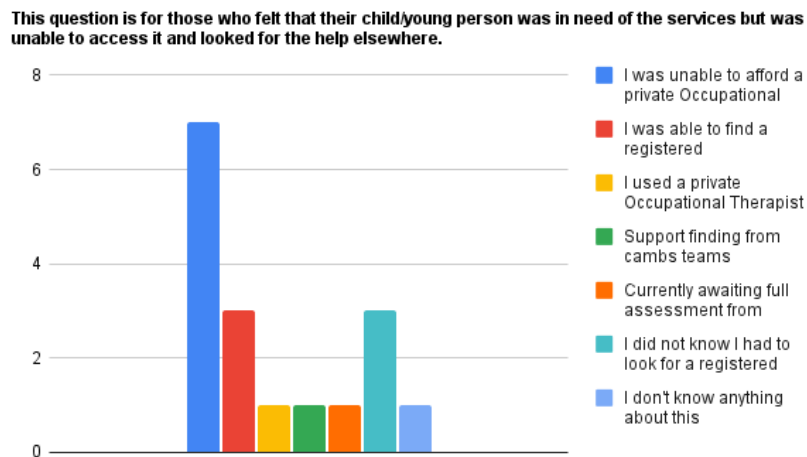


Fig.21 Views of parent carers who have not accessed OT

There are also a number of parents who have been seeking OT support privately. One area of concern is that some parents did not realise that therapists should be registered/ accredited.

SALT

Please choose which of those statements are most applicable to your child/young person

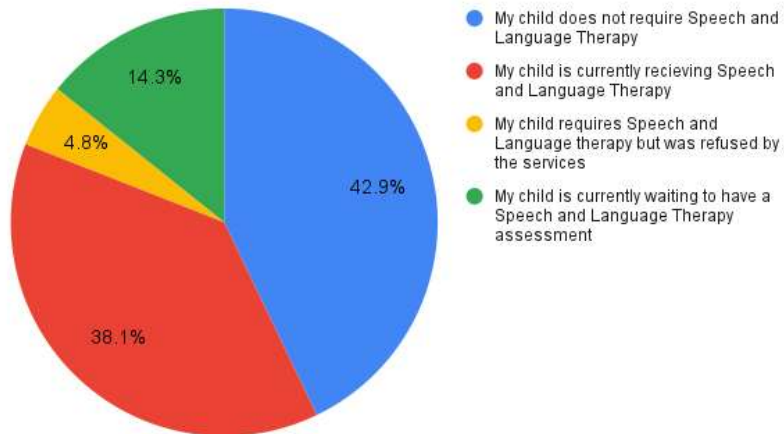


Fig.22 Parents views on whether SALT is required for their CYP

If your child/young person is currently receiving or was recently discharged from the services, how would you rate your experience?

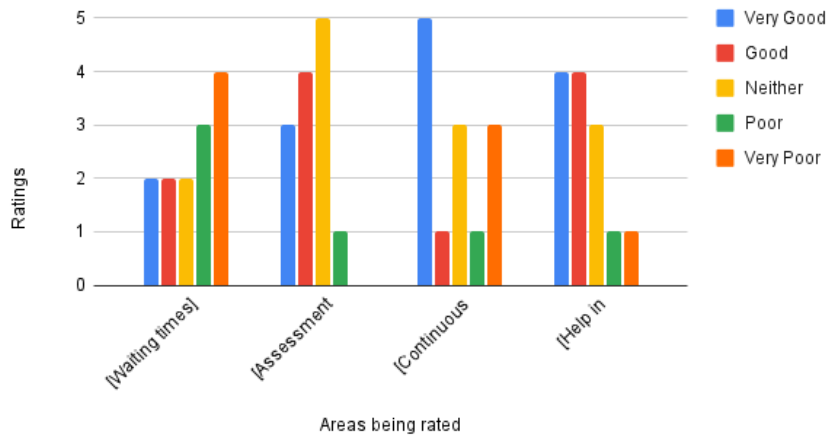


Fig.23 Parent carer ratings of SALT

Please use this section if your child/young person was unable to receive the support you feel they need and you had to find help elsewhere.

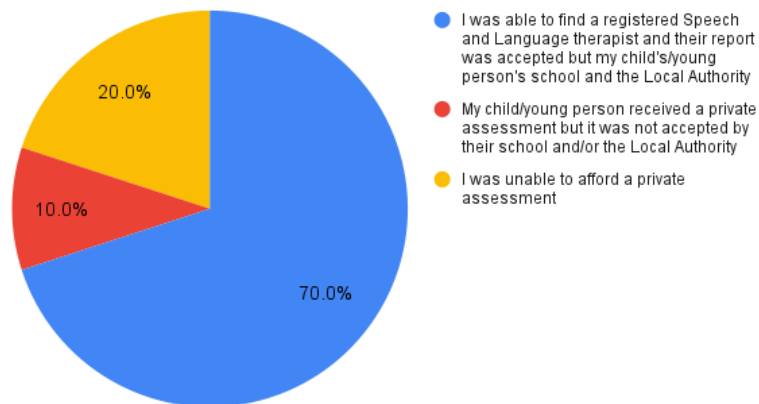


Fig. 24 Parent carer use of private therapists

Please use this section if you want us to tell anything else about the Speech and Language Therapy.

Extremely poor in Peterborough. Very limited support then discharged. No ongoing support.

My son is non verbal and shows no understanding of any language, including his name. We need SALT and waited approx 20 weeks from referral to first appointment.

Excellent service

From fig.22 to 24 and the open ended comments in the table above it would seem overall that SALT is viewed fairly positively from assessment to support. Also unlike the responses to OT private assessments more parents reported that the SALT private assessments they sought were accepted by the local authority in assessment decisions.

PHYSIO

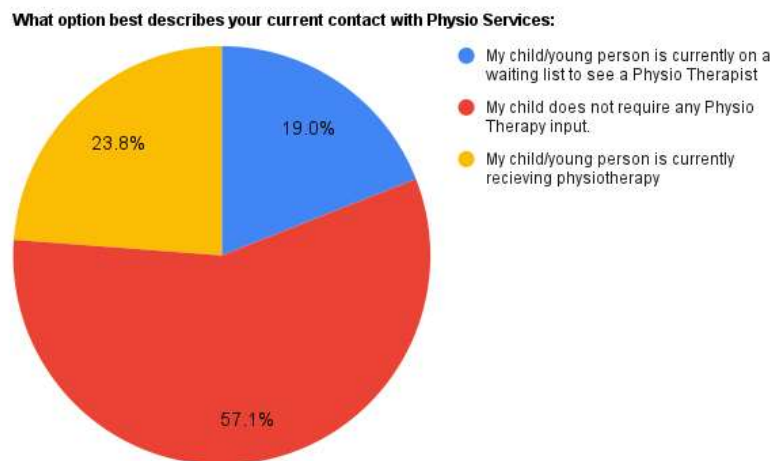


Fig.25 Contact with Physio Services

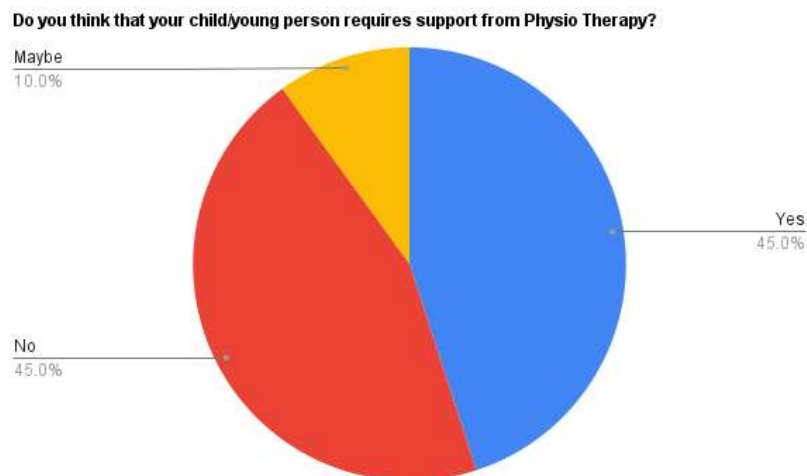


Fig. 26 Parent carers views on whether physio services are required for their CYP

Were you able to access the help that you think your child/young person needs?

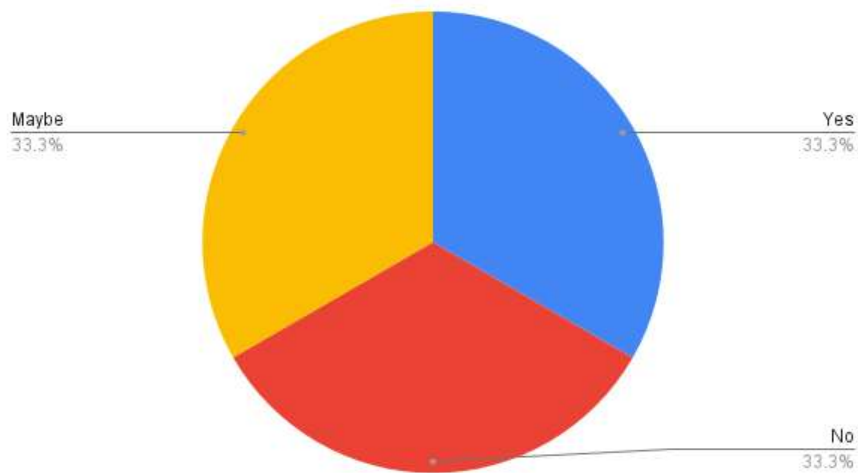


Fig. 27 Accessing Physio services

How would you rate the following aspects of physio services

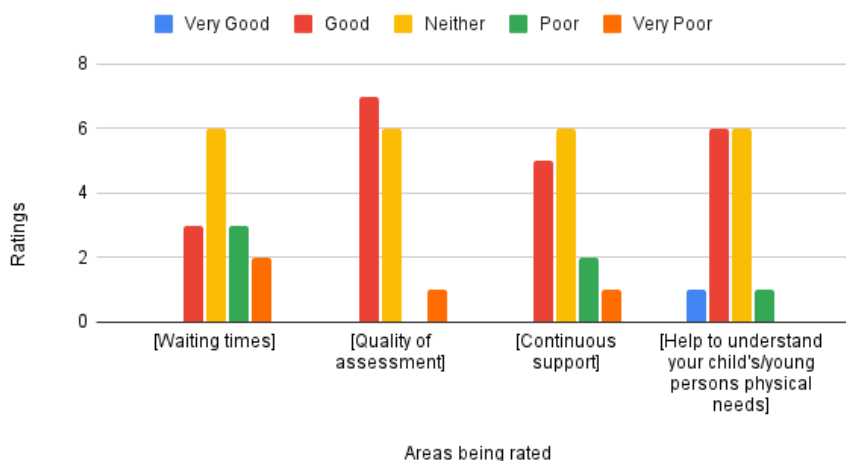


Fig. 28 Ratings of physio services

Ratings overall are most positive for physio and as a service area it is one that the least number of parent carers felt was required for their CYP (see fig. 25 to 28). Waiting times was the area to receive the most negative ratings, compared to other areas.

Reflections

The surveys in the report are only intended to give a snap shot of current views and experiences, as such no real conclusions can be drawn from the results. Simply a review of the results has been presented with views on why parent carers may be feeling the way they do.

Overall views tend to be most negative in relation to gaining access to health based services, with many more parent carers feeling their CYP need such services

compared to the number actually receiving services. This leads to a high level of dissatisfaction amongst parent carers in general. There is least negativity about SALT compared to other health based services.

Recommendations

- Further exploratory work looking at why parents feel their CYP need access to the health services
- Look to hold focus groups to gather more in depth insight to how services are viewed and also provide details around eligibility.