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## Health Appointments survey report

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## Introduction

Family Voice Peterborough parent reps work closely with parent carers, Local Authority, Health Services and Third-Party Organisations in order to share parental experiences and help to improve the current services and provision for children with SEND. We also work regularly with SENCOs' through PCC conferences, SENCO forum, SEND training as well as directly through schools, having regular coffee mornings and signposting sessions.

Through regular contact with parent carers a number of key themes are cropping up with some parent carers reporting difficulties accessing Health Services. We have had a lot of anecdotal information that we were presenting at the relevant board meetings and were asked to conduct a survey and ask parent carers some specific questions in relation to the difficulties in accessing the Health Services. On 25<sup>th</sup> August 2023 we published a 'Health Appointments' survey to gather more information and to get a better understanding about the difficulties parent carers experience. We will be conducting further surveys and Facebook Polls to gain a better understanding about the everyday issues that parent carers, their children and young people experience.

The findings provide a basic snapshot of current lived experiences of 24 parent carers and are not intended to be used to make any assumptions about wider concerns/ issues/ needs of SEND households in relation accessing Health Services. However, the findings help us to understand the current lived experience from some household who have children with SEND.

## Respondents

We have had 24 people from across a wide range of backgrounds responding to our survey.

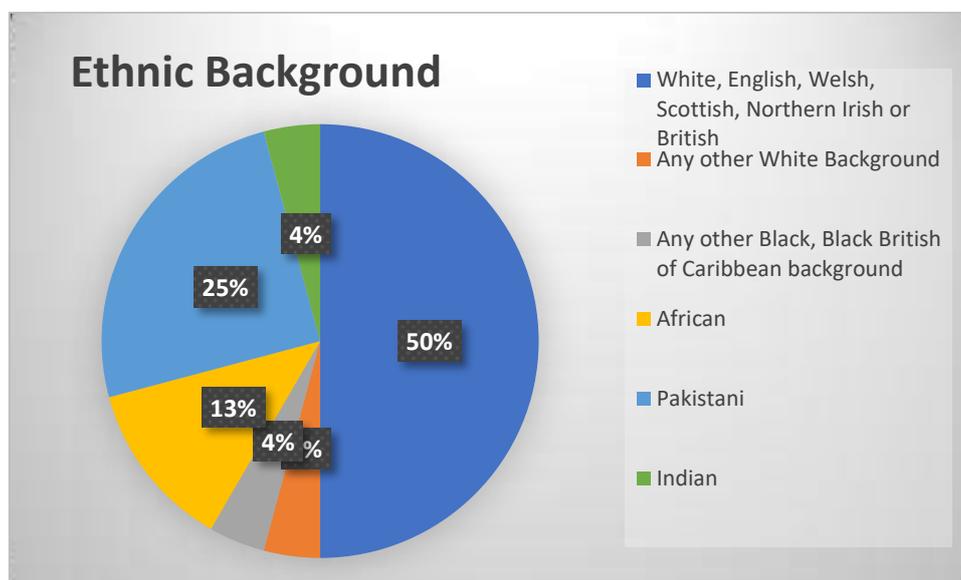


Figure 1 shows the respondent's Ethnic Background

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.

**Main Findings:**

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

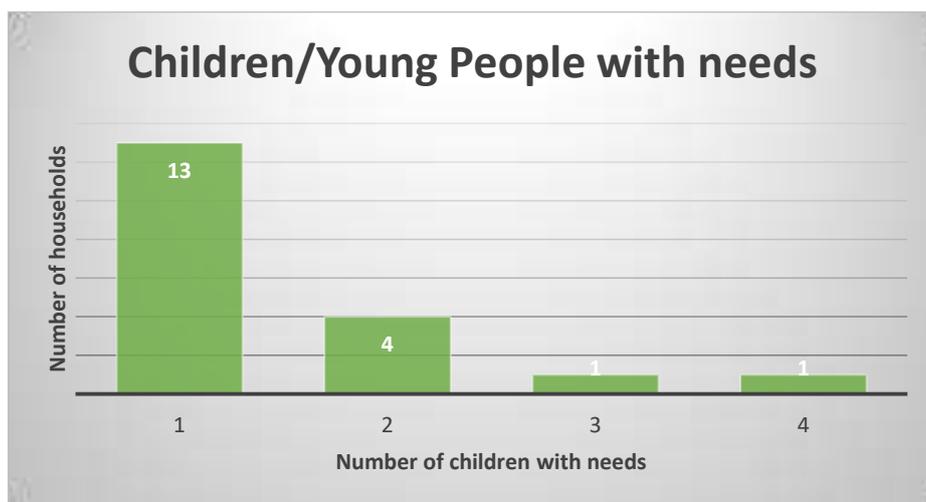


Figure 2 shows CYP with SEND per Household

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

We asked the respondents whether they have recently tried to access any Health Services for their Children/Young People:

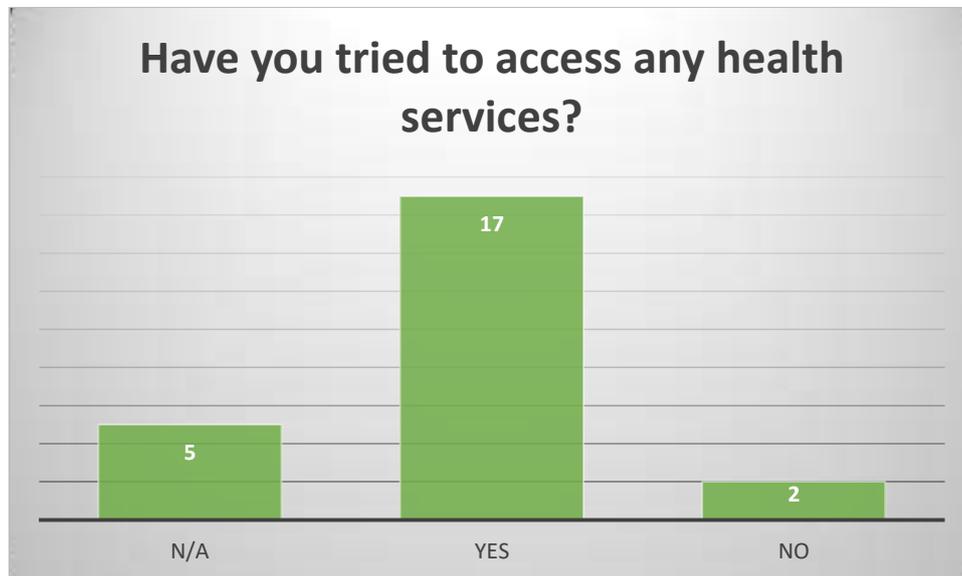


Figure 3 shows the number of families who tried to access health services.

For those who answered 'Yes' to the question above, we asked to provide a little bit more details about the type of services they needed to access. This is what the respondents told us:

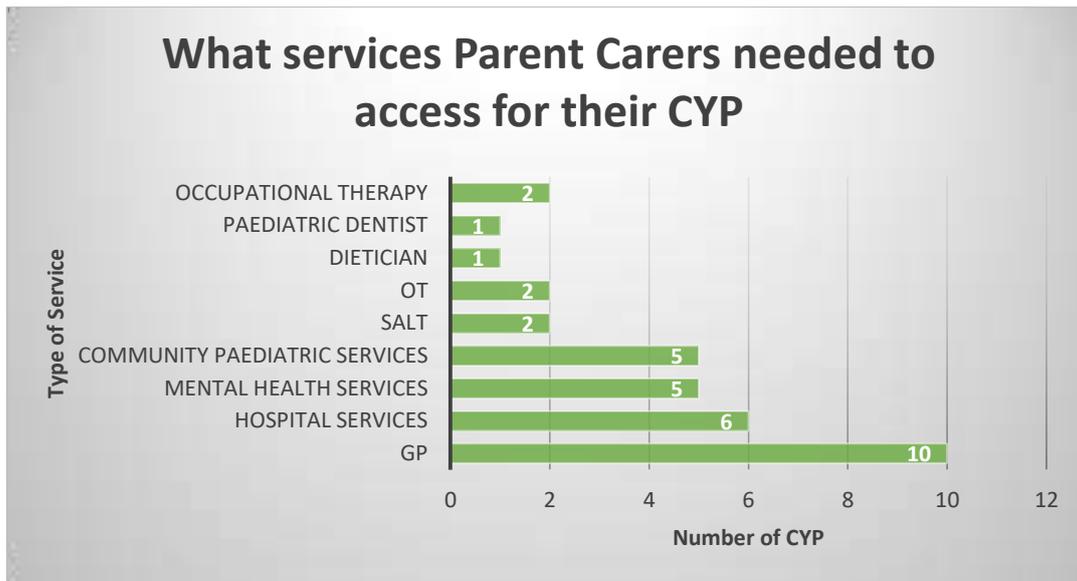


Figure 4 shows what services Parent Carers tried to access.

As you can see from the table above, parent carers wanted to access a very wide range of health services due to the different issues:

For medical check up for his liver
I need to access the dentist for my children as it is part of the most important thing in this country for children
paediatrics regular check ups were extremely good and flexible with times during the holidays very quick getting see and child outpatient were friendly and helpful
Alicia suffers with anxiety and LD
Due to his hypermobility
Bowel withholding
Ritual traits, anger
To check re autism ADHD
Asthma and medication
One child has not slept for more than 4/5 hours per night due to trauma
The other child has ptsd but we can't get appointments for ot for sensory issues
Hip pain
Annual Reviews
My son needs early help but unfortunately it's not happening at all , no one has time for us at all.
Send diagnosis teams along with paed's app
Both need to see ent consultant
Audiology needs
She had some issues regarding her health
For medication to help fight Infection

In order for us to gain a better understanding about the waiting times, we asked parent carers how long they had to wait for the appointment to come through:

1 month
1 week and under
Regular appointments now being seen next year
6 months
1 year
It has been over a year
3 months
1 week and under
Still not seen asthma nurse
I wasn't offered and appointment/still waiting to hear
It has been over a year
It has been over a year
3 months
It has been over a year
I wasn't offered and appointment/still waiting to hear
I wasn't offered and appointment/still waiting to hear
1 week and under
I had to contact 111
6 months

As you can see from the table above, a lot of the respondents had to wait for an extended periods of time for their appointment:

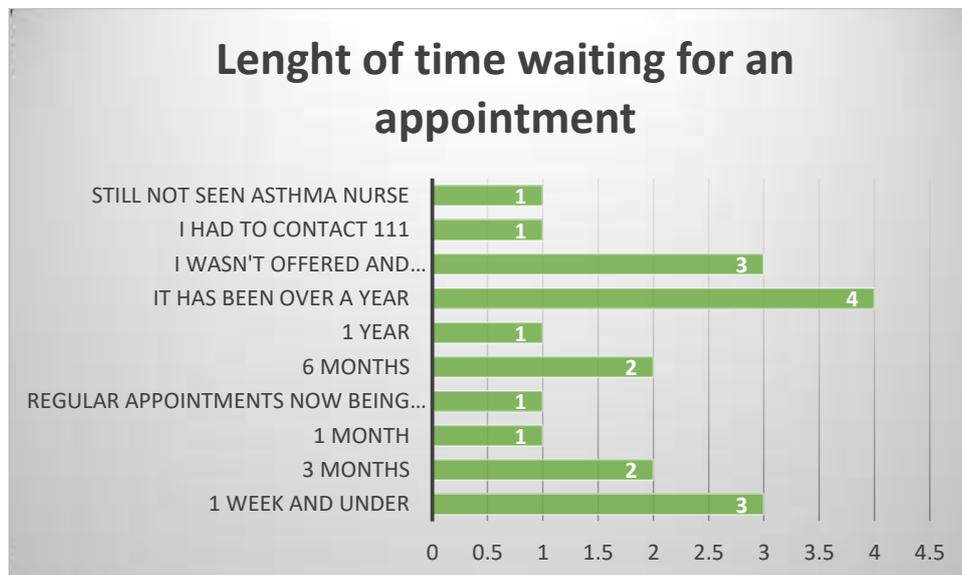


Figure 5 show long the respondents had to wait for the appointment their CYP needed.

We also asked the respondents about the impact the extended waiting times had on their Children/Young People as well as the rest of the family. This is what some of the parent carers told us:

Constant worry need advise from doctor how to go about safety
Bowel movements limited to 1 every 1-2 weeks big impact on Childs behaviour leads to violent aggressive outbursts
His out of breath
Child not sleeping
My son has been in terrible pain
Lots of delays regarding appointments
He is neglected by NHS, no support at all. He is missing out professional help. He is neglected emotionally, physically, mentally . Our family is coping as we can because we have no choice.
Still awaiting after nearly 6 months
So far waited 7 months , child regularly unable to wear hearing aids due to eczema. We are waiting for a softband BAHA assessment
It's hard to wait
Child really unwell
Yes long waiting time child left without support

Some of the respondents told us that even though they felt that their Child/Young Person needed an appointment but were not offered one, so we asked what actions parent carers took to resolve their issue:

Yes I cancelled my GP on numerous occasions
No kept trying to get an appointment but all was gone
Yes tried school and gp
Being referred to another hospital
Yes
I ve tried to get referred to different professionals but have been accused wanting too much . I should make my mind up apparently even though no one has seen us over the year. I ve been to private services instead.
Regularly contacting the hospital
Always told the waitlist is huge but will be next month then it doesn't happen
I went to chemist and tried different medications over the counter
Called 111
No choice but wait

As much as it is important to understand the difficulties that parent carers experience, we also want to hear about all the positive things. So we asked parent carers whether there was something else they wanted to tell us about health services. This is what the respondents told us:

Waited long periods for my daughters appointments and assessments which was difficult during covid and longer waits
Every service my child needs has a very long wait list making it hard to access help for him
Been waiting for the ADHD assessments since child was 2 (3yrs so far)
Our doctors surgery is quite fast it's a text service for appointment usually seen in about 4 days
No one seems to appear to see them once you mention trauma, they put it all down to trauma which is unfair
Delays on majority of apportionment needs - seen along time after requirements
Too long waiting time. In my opinion waiting more than a year is ridiculous. Especially with SEND children who need early help.
Waited 3 months for ears to be cleared of wax. By this time it was impacted
It's very difficult when you're child is sick and you don't get any help and the child is with special needs
Was told he needed to be seen within 2 hours after waiting 2 hrs for a phone call we couldn't get an out of hours appointment for another 5 hrs

Although not all of the respondents have had a good experience with the Health Services, one of them told us that *'Our doctors surgery is quite fast it's a text service for appointment usually seen in about 4 days'*.

Adults with Autism and/or Learning Disabilities are reported to have a much shorter life span. Annual Health Checks were introduced in order to end the health inequalities hence we thought it would be important to ask if, where applicable, parent carers are aware of them and whether they found them accessible.

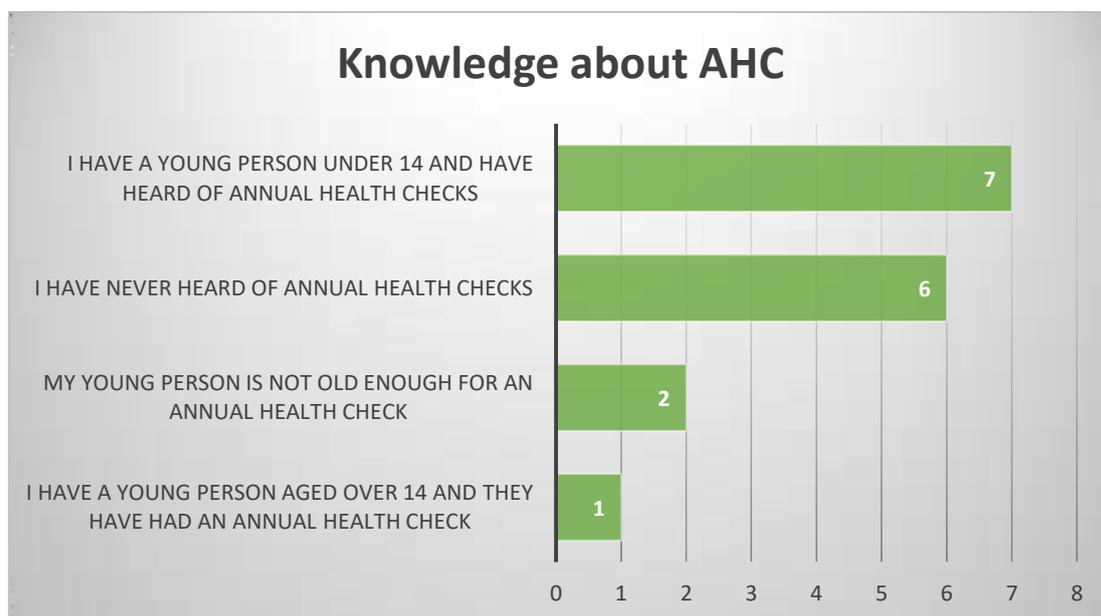


Figure 6 shows knowledge about Annual Health Checks

We also asked 'What difference, if any, has accessing health services and, if applicable, Annual Health Checks made to you and your child/ young person with SEND?' Most people opted not to answer this question, or answered 'none', but of those who did, the experience was not a positive one: *'A lot harder as it seems they're no longer classed as important appointments'*.

## **Recommendations:**

This is the first of a series of health surveys and Facebook Polls we have/will publish. Health plays a vital role into our everyday lives and we understand that for some people it might be more difficult to access Health services due to their needs and they may need more input in order to live healthy lives.

The answers to the survey above are rather worrying and it shows that Children and Young People often wait for prolonged periods of time for the needed appointments which can have an adverse effect on their everyday lives as well as their parent carers and the wider household. NHS England has published that *‘Based on 2018-19 data, males with a learning disability have a life expectancy at birth of 66 years. This is 14 years lower than for males in the general population. Based on 2018-19 data, females with a learning disability have a life expectancy of 67 years. This is 17 years lower than for females in the general population.’* Health services should be available to all people equally and learning needs should not impact on the average life span. Family Voice Peterborough will need to further investigate Access to Health Services for Children and Young People with SEND to find out whether it is the waiting times or also access to proper healthcare that is worrying for parent carers.

This report is a reflection of the respondents and we have made no judgements and formed no conclusions; however, it is vital to understand the lived experience of parent carers. This report will be presented to the relevant boards so that the parental experience is visible, and changes could be made to ease their difficulties.