
Health Inequalities

Snapshot of whether
SEND households
experience
inequalities in health
access

FVP Team November 2023

Introduction

This is one of a series of small scale surveys that FVP has carried out over the past two years looking at how local SEND families experience health. The most recent survey although only small scale demonstrated that SEND families experience real issues simply trying to access appointments and overwhelmingly reported negatively about their experiences. The numbers in previous surveys and this one although small do point to a current situation where those who respond have in the main negative lived experiences in relation to health.

This survey looked more specifically at health appointments, being listened to and reasonable adjustments to see if SEND families may face any potential inequalities. It was felt at that once accessing the health sector views would be more positive, but the responses did not match this.

Respondents

Household Ethnicity

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.

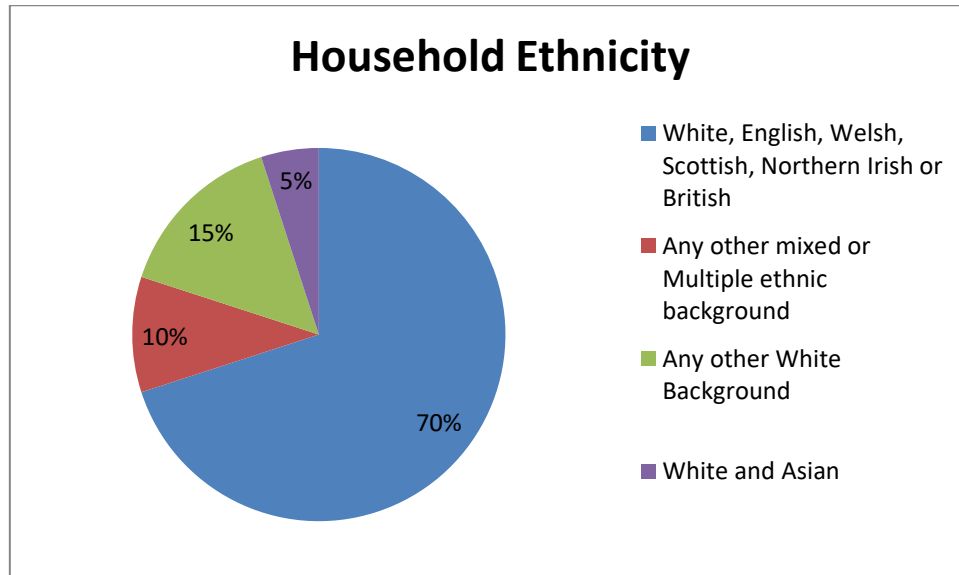


Fig.1 Household Ethnicity

Household Information

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).

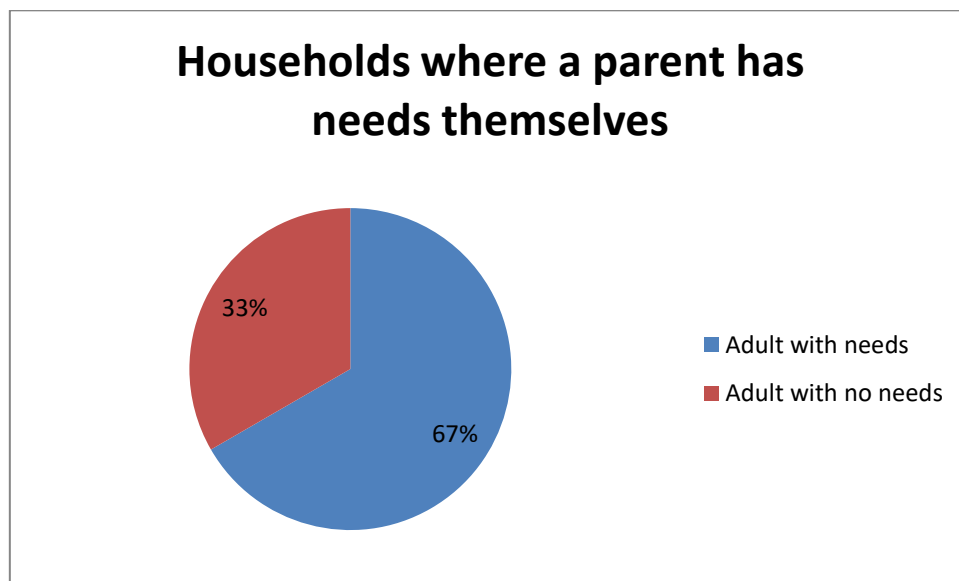


Fig. 2 Parent Carers with and without needs percentages

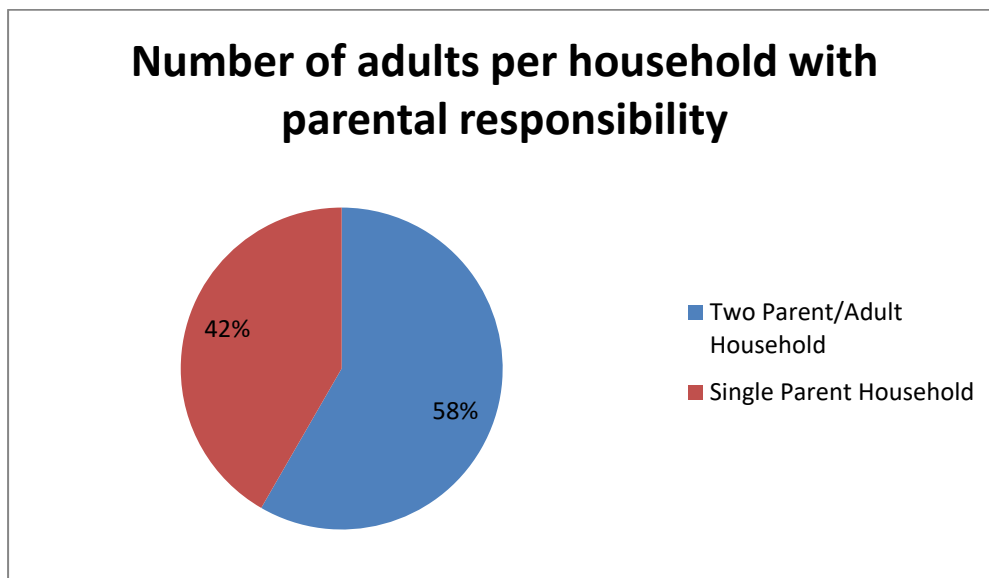


Fig. 3 Household Adult Make-Up

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

CYP Needs

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.

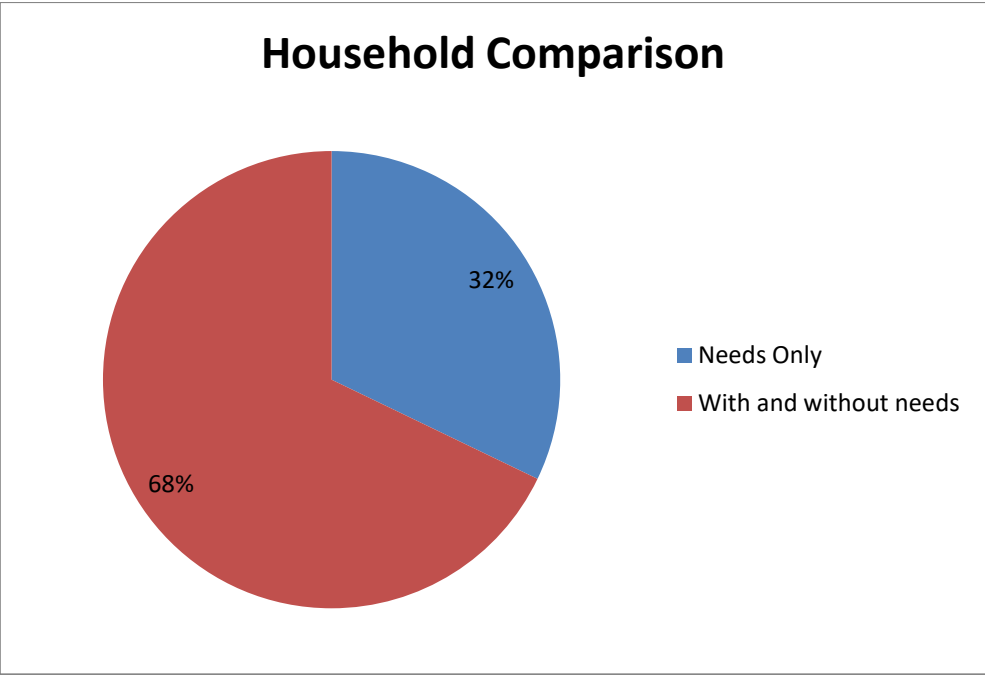


Fig. 4 SEND of CYP

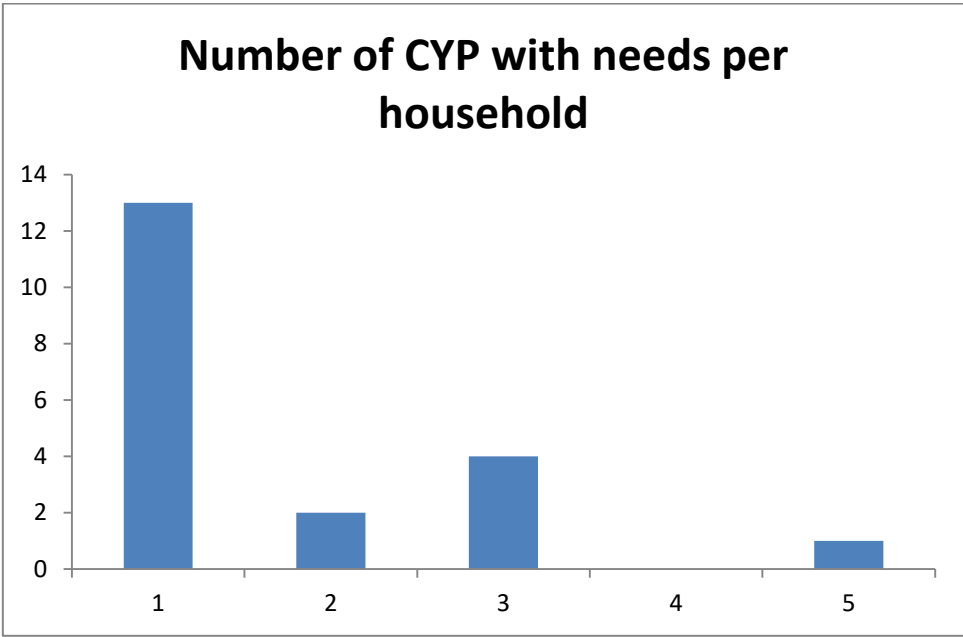


Fig. 5 Number of CYP with SEND per household

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

Health Survey Responses

The survey was broken down in to a number of areas, all of which are detailed as follows. Sections cover; Access, Reasonable Adjustments, Parental Views, A&E Visits, Admission & Discharge, Overall Outcomes and What Difference has been made as a result of health involvement.

Health Services Access

Which services did you access for your child/young person?	Following from the past question, please use this space to tell us a bit more about your experiences?	
	Working Well	Even Better If
GP	Friendly	
Hospital	N/A	
Hospital	Quite happy.. Adjustments made, pathway to adulthood used	
In the last 12 months we have accessed GP, Hospital, community paed, OT, physio, dietetics, Amazon children's ward, rainforest outpatients and hospital		Experience in A&E terrible, autistic child left for four hours with fractured ankle, had to ask for an ice pack and pain relief. Amazon ward too long wait and no updates given on wait time. Rainforest outpatients great. OT, physio, dietetics no real concerns except how desperate they are from mental health teams.
Hospital	N/a	
GP		Doctor wasn't any good
Multiple: GP, A&E, speech and Language		It was absolutely horrific. We had a trip to A&E at Peterborough and the staff treated my child disgracefully, with no accommodations made for his SEND. He had to wait lying on the floor, next to teenage girls discussing their self harm.
Several of the above		Practitioners are generally quite good with our son however we have had experiences were they've not even tried to examine him due to his additional needs.
Hospital	No Problems	
GP, Hospital, wheelchair services, Occupational Therapy, Physio Therapy , Dietetics, Other health professional ,Dentist.		No problems except for Wheelchair service. Being not fit for purpose. Slow to answer the phone with a long wait for appts and even longer wait for a new wheelchair. Rude staff on the phone with no updates.
Gp, community paediatric services,wheelchair services, occupational therapy, physio therapy, dietetics, other helth professional, rainforest outpatients, addenbrooks long term vent clinic	N/A	
Mental health services		Waiting times for assessments are

		ridiculous.
Mental health services		Video therapy that does not help
GP	N/A	
GP		A year and 3 month for a new wheelchair
GP	N/a	
Mental health services		Very long being seen
Hospital	Hospital visit for diagnosis diabetes type 1 everyone tried to be gentle with my daughter sometimes it required educating first about her eating disorder and sensory needs	
GP		Getting a GP appointment is very hard more so if you want face to face when we visit the hospital we had to wait 6 hours to be seen
GP	N/a	
Speech and Language Therapy		SALTS are very knowledgeable and informative once you get them into the setting. The problem is the constant chasing to get them to visit the setting . As with most services as a parent you have to be very resilient and persevere

Table 2: General Health Service Access

Experiences of accessing health services has been varied based on the responses of parent carers to the survey. No one service comes out ahead of any other but two stand out areas for negative experiences are GP services and A&E.

The more services accessed the more varied the experience, which is shows that complexity of need can lead to more complex experiences. Waiting times also appear to be a concern, with reports of waits taking too long.

Reasonable Adjustments

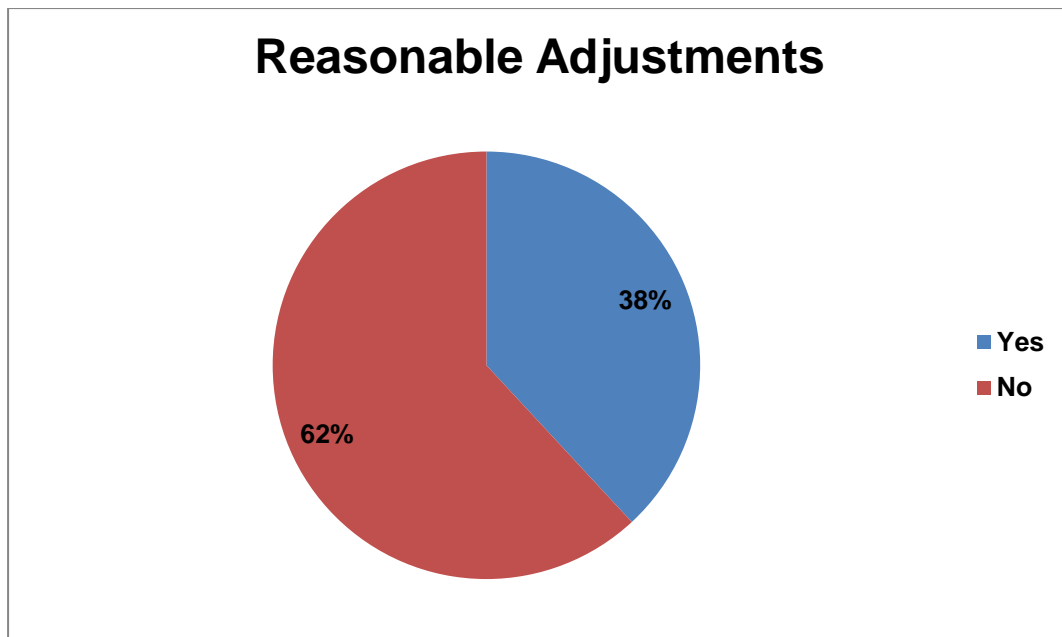
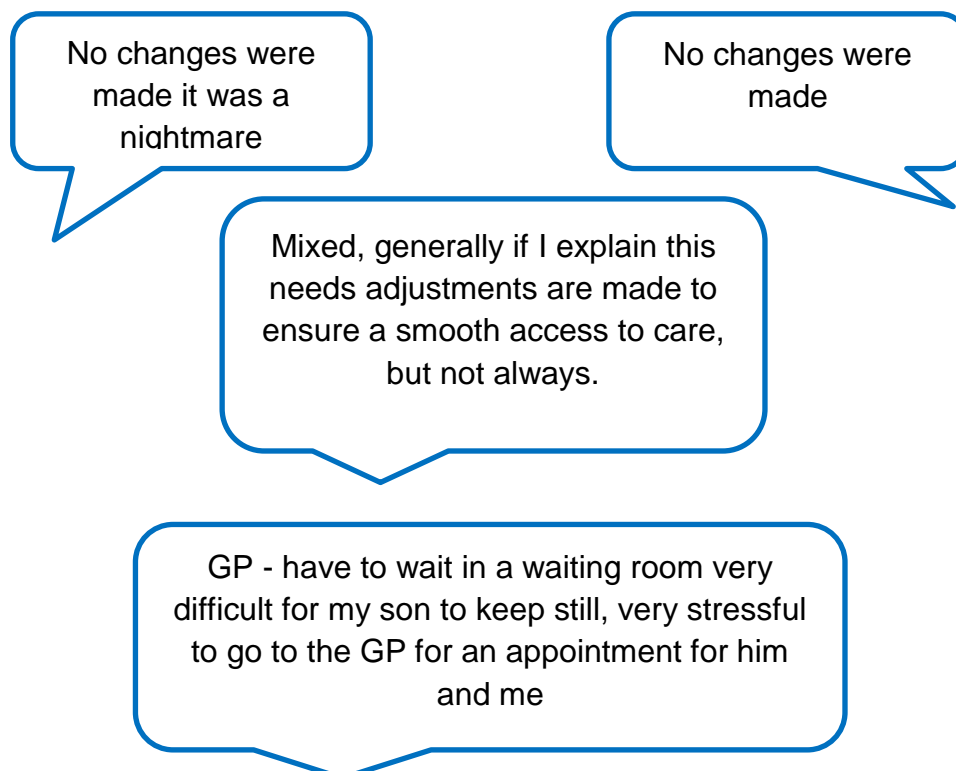


Fig. 6 Reasonable adjustments made for CYP with SEND

Further to asking parent carers to report on general health services access experiences they were also asked in any reasonable adjustments were made. Worryingly the majority at 62% stated that no reasonable adjustments were made.

Some parents said:



Following on from the last question some parents reported on what reasonable adjustments were made and in none were made what they felt should have been adjusted to help their CYP.

Tell us a bit more about any changes that were made, if any. If none were made please tell us what you would have liked to have been changed/adjusted.
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

Table 3: Reasonable Adjustment Suggestions

Parents reported wanting; extra time to be factored in, being listened to and having a quiet space as three of the main reasonable adjustments they felt would help. All three suggestions would be relatively simple to implement and should have little cost implications to health providers.

Parental Views

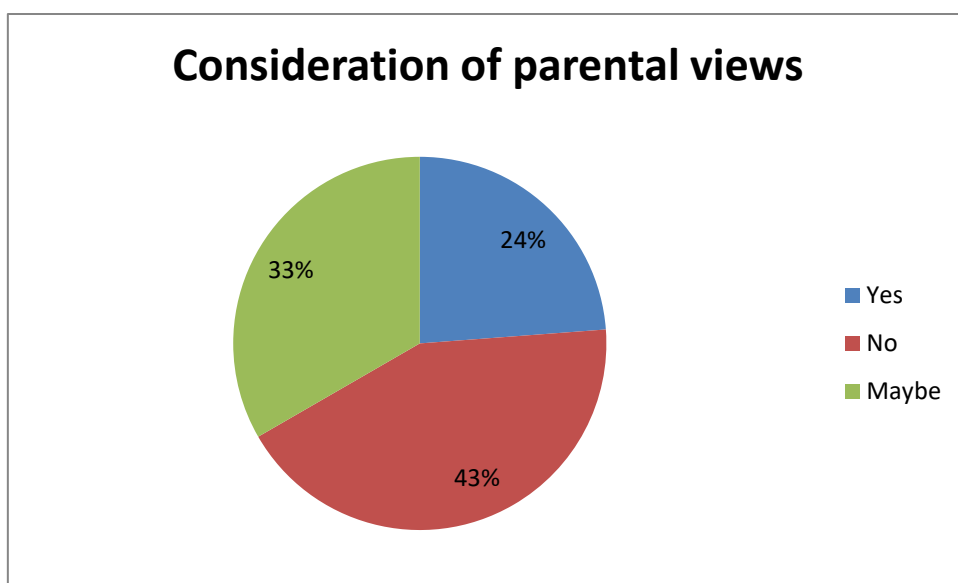


Fig. 7 Consideration of Parental Views

The idea of listening to parent carers was explored too and it is important to note it was considered by parent carers to be a reasonable adjustment that could be made by health providers.

The majority of parent carers at 43% reported not being listened to by health providers (see fig. 7 above). It is not ideal that such a large proportion at 33% reported feeling that 'may' have been listened to.

Some parents expanded on their experiences:

My concerns were recorded, but then not accessible to other healthcare services.

Did let talk so young person just left doctors

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

We have sometimes been dismissed.

Not educated to deal with special needs children

A&E Attendance

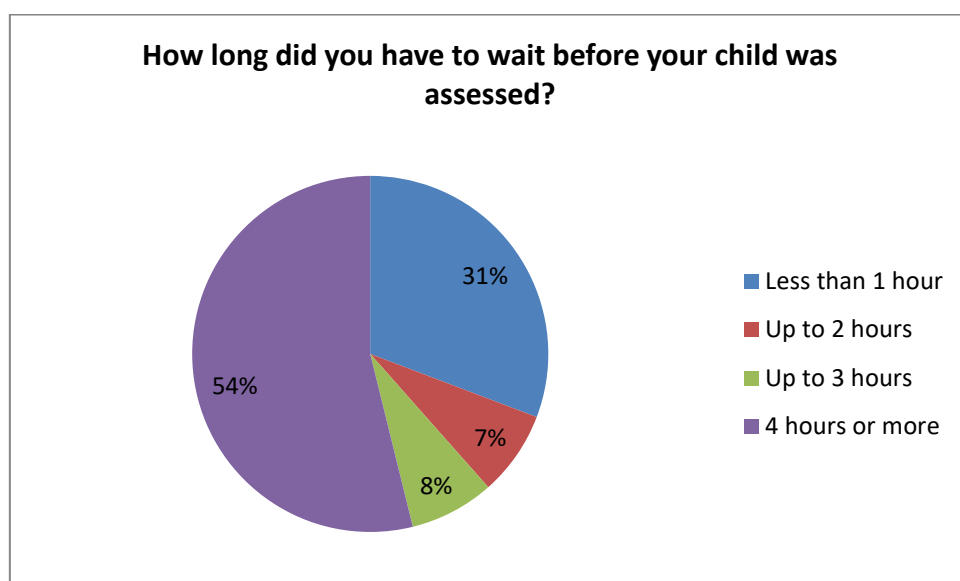


Fig. 8 A&E Waiting Times

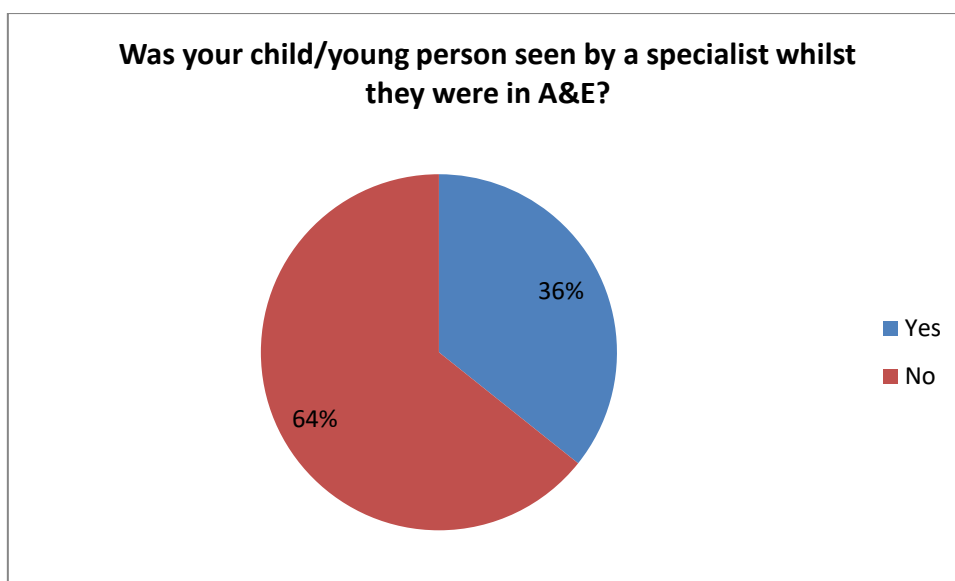


Fig. 9 Access to specialists in A&E

Fig. 8 and 9 point towards a less positive view of A&E visits for the parent carers with waiting times for the majority at 54% being over 4 hours and only 36% seeing a specialist for the CYP's needs.

How were your child/young person's needs taken into account by the person(s) who they had contact with?	
Working Well	Even Better If
I think they were taken in to account.	No as such a long wait
Slightly	No consideration for needs and no reasonable adjustments, communication was terrible
The nurses were empathetic	No
They took seriously her being autistic and needing things to be done slow and calm and quiet unfortunately initially she require urgent medical intervention and this part was a traumatic experience	They weren't. It was disgusting.
	Mixed, some clinicians took needs in to account some disregarding this
	Not autism friendly
	Was not at all

Table 4: Needs Being Considered

Experiences being less positive are further demonstrated by the comments made regarding whether CYP needs were taken into consideration during any A&E visits.

It should be noted here that for some of those who responded they did have a supportive experience with nursing staff being considered empathetic and considerate of needs.

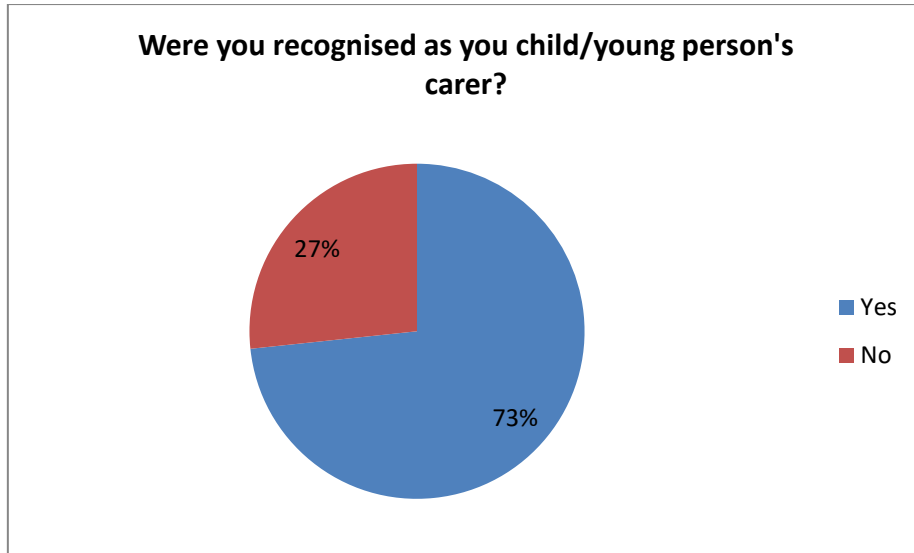


Fig. 10 Percentage of Parents recognised as Carers

An interesting point to note here (fig. 10) is that a clear majority at 73% of parents felt they were recognised as carers, which is at odds of the sense from parent carers more generally that they do not feel listened to when accessing health services more generally.

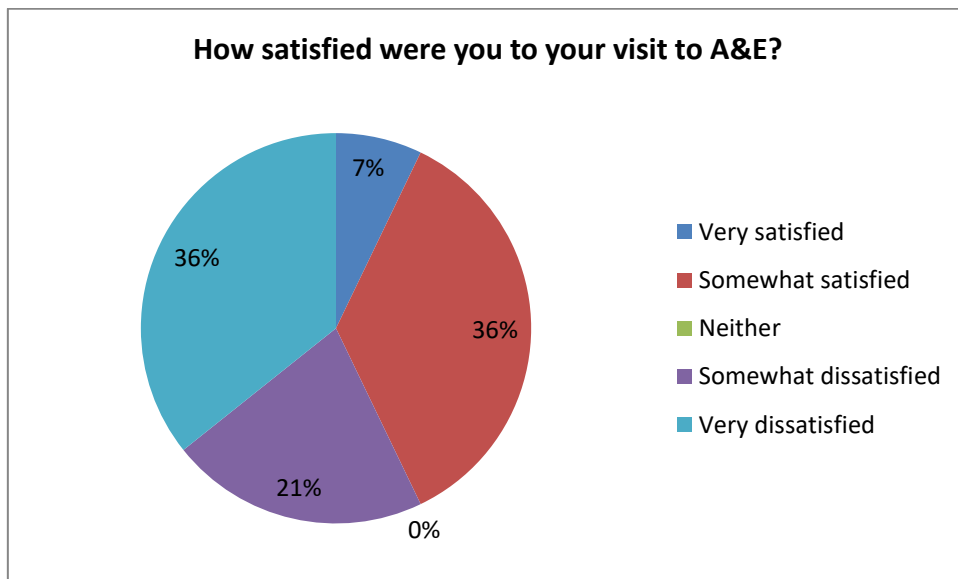


Fig. 11 A&E Satisfaction Ratings

Overall satisfaction is poor with the majority choosing options relating to dissatisfaction at 57%.

Admission and Discharge

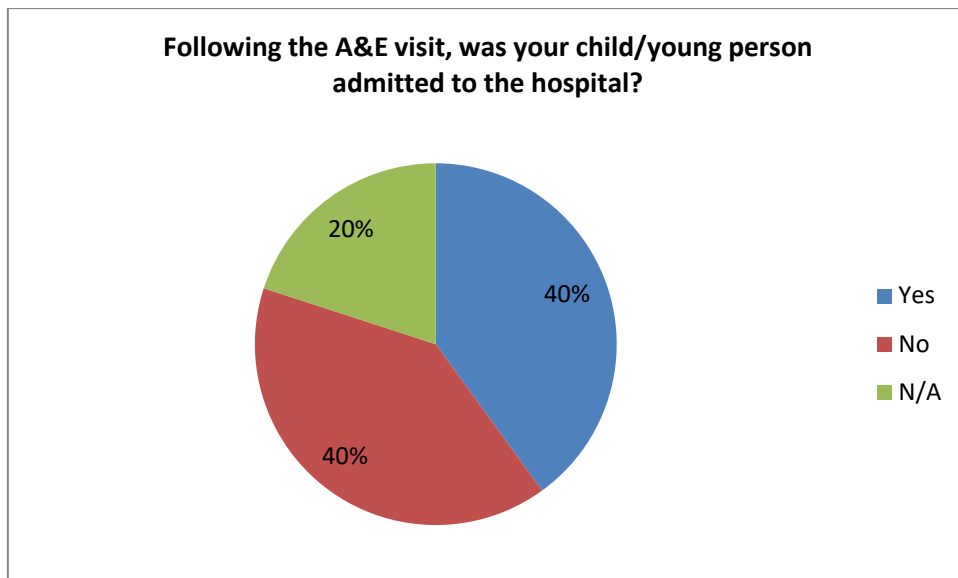


Fig. 12 Hospital Admissions

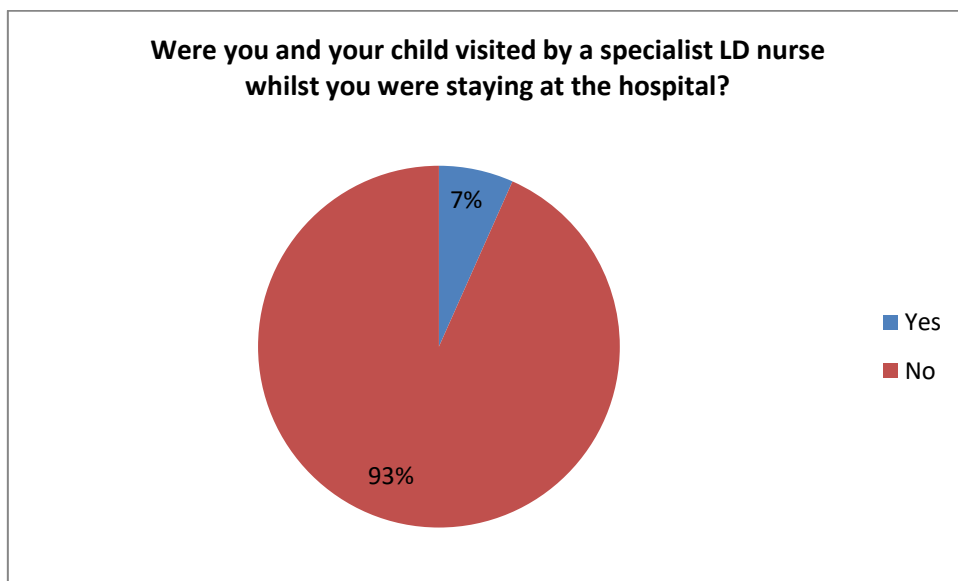


Fig. 13 LD Nurse Support

Where 40% of those who attended A&E (fig. 12) with their CYP with SEND reported admission to the hospital for further treatment only 7% reported contact with the LD nursing team (fig. 13).

It is not possible to ascertain why this may be but it would fit with parent carers feeling not listened to, a lack of reasonable adjustments being made and low reporting of consideration of CYP needs.

Parent carers were also asked for any further comment regards their visits to A&E and any resultant admissions. Generally reporting was more negative than positive. (table 5 below)

Tell us a little bit more about your experience about the A&E visit and/or hospital admission.	
Working Well	Even Better If
Hospital admission in hinchbrook..great care given	No additional needs were taken into consideration
Our experience in A&E was ok.	A&E is terrible try to avoid it if I can and wait for a separate minor injuries to open
Planned admission - good experience.	It was horrendous, see above.
	Given a quiet room to wait but also told to vacate and sit with other patients and parents due to someone else needing the room more. Also asked for just one parent to be present when it requires both parents to assist in medical examinations and treatment such as blood tests which he doesn't tolerate.
	It was not the best
	Just a horrible time

Table 5: General Views

Following your child/young person's hospital admission, how did you find the discharge process, if applicable?	
Working Well	Even Better If
Fine	
Ok	Awful. We discharged ourselves after we were told he'd need to wait 2 hours for some pain relief because he can't swallow meds and it apparently requires two nurses to administer a pessary (when I can do it quite easily by myself).
Easy	Slow, lots of waiting due to lack of doctors.
Bit slow .. but generally very comprehensive	Long wait
	Quite long and uncertain but it was due to Joanna being too unwell so we had to wait and we were struggling with it as she thought she would go home
	Very long winded

Table 6: Views of Discharge.

The final question in this part of the survey looked at how parent carers experienced any discharge from hospital and as with previous responses they tended to be more

negative than positive. Waiting times appear to be the main area of concern resulting in negative experiences.

Overall Outcomes

What was the overall outcome from your child/young person's contact with the health services?
Yes furthers surgery from a break, with metal rods which then led to arthritis diagnosis
Another admission in future
Follow up appointment or huge waiting list
Received a diagnosis but was no a good experience
None
Discharged.
Discharged without follow up.
To be seen by Epilepsy Nurse in a few months & discharged.
It is a regular admission for sleep study.
Waiting lists are too long
Still doing the therapy
We are still going through a diagnosis process but its a very frustrating process we feel like we are going in circles without being any further forward
Still awaiting diagnosis very slow
Diabetes type 1 diagnosis , follow up care, practically 24/7 on the phone, by email, in the clinic if needed
Waiting for a follow up appointment

Table 7: Overall health access outcomes

Difference Made

What difference, if any, has accessing health services made to you and your child/ young person with SEND?
Quiet time done after school
Not sure... we have consistently received great care
Caused heightened anxiety and distress
Hard as not all are very understanding
A massively negative one. It's made it much harder to access care, which obviously places my child at greater risk.
Concerned raised due to recurrent fevers, told likely due to lockdowns and lack of exposure however later found iron and immune deficiency
Kept him well
Resulted in no sen placement due to waiting times for diagnosis.
No difference does not help us at all
A huge difference but more help and support is always needed not only with my children but also with my own mental health and well-being.
Nice to like talk to likeminded people

Table 8: Difference made as a result of contact with health services.

In a slightly different approach to previous surveys two new questions were asked; what if any outcomes were achieved and what difference the services had made for the families. The results to which were variable; outcomes for some meant diagnosis or more appointments whereas difference made meant increased anxiety and concern for others.

General Views

Overall parental experience of health services is mixed, with a trend towards being more negative than positive. Common themes are needs not being recognised/ supported, an inconsistency in reasonable adjustments being made and parents being recognised as carers but their views not necessarily being considered.

From this survey and others conducted it appears that parent carers may have lived experience of inequalities in health service access relating to their caring role and their CYP's SEND needs. The inequalities relating to SEND are broad and not need specific.

Previous conversations with parent carers have shown that simply caring for a CYP with SEND can be stressful enough and often comes with anxiety; to have this exacerbated by lack of support, understanding and awareness of the CYP's SEND when accessing health services creates undue extra pressure and stress. For parent carers to report that accessing health services has created extra anxiety and stress in relation what difference has been made is concerning.

Next Steps

This is the second survey FVP have conducted regards Health Access and also follows on from various concerns being raised during sign-posting sessions with parent carers. It is felt that a couple of recommendations should be made:

1. FVP to put all relevant information into a Topic of Importance (ToI).
2. FVP to raise concerns more formally via the ToI with Health and LA professionals.