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# ASD Needs Survey

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November 2019

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Family Voice Parent  
Representatives

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## **Background**

This survey has been created in response to parent carers telling us via face to face participation that their children and young people with Autism Spectrum Disorder experience many co occurring difficulties which they are not being supported to manage. Initially, Family Voice Peterborough ran a poll within a closed Facebook group specifically for Peterborough parent carers: "Family Voice Peterborough SEND Participation." The poll was responded to by a total of 26 individual parent carers, with the predominant need disclosed as being difficulties with eating, followed by toileting difficulties and lastly mobility.

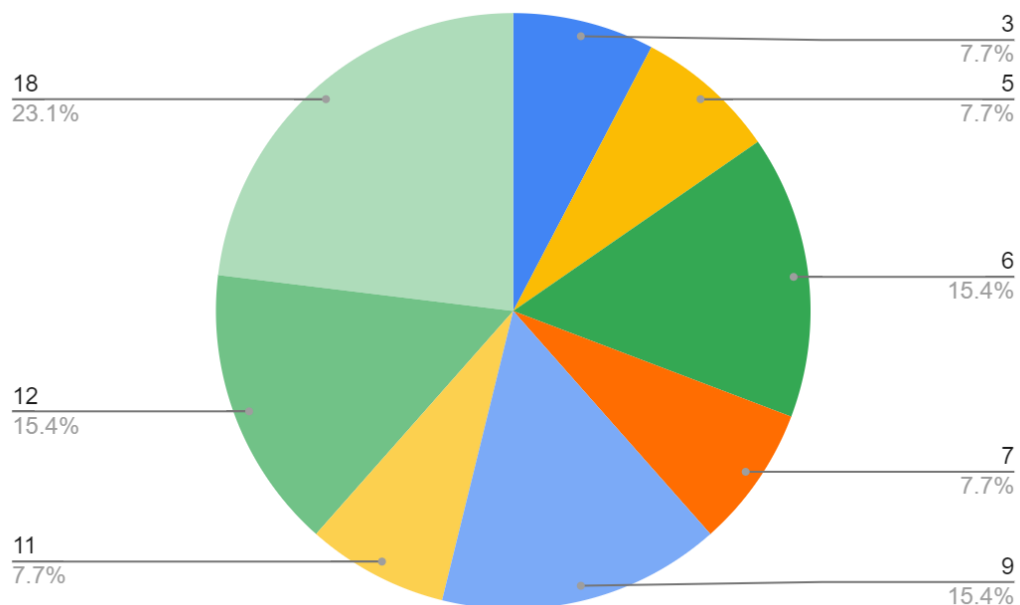
<b>Eating</b>	<b>Toileting</b>	<b>Mobility</b>
20	16	11

**Fig . 1 Responses to Facebook Poll entitled: "Does your ASD Child/Young Person experience issues with:"**

In order to further explore the specifics of the difficulties and levels of support being received, a short survey was drafted and circulated, the results of which are explored within this report.

## **Population:**

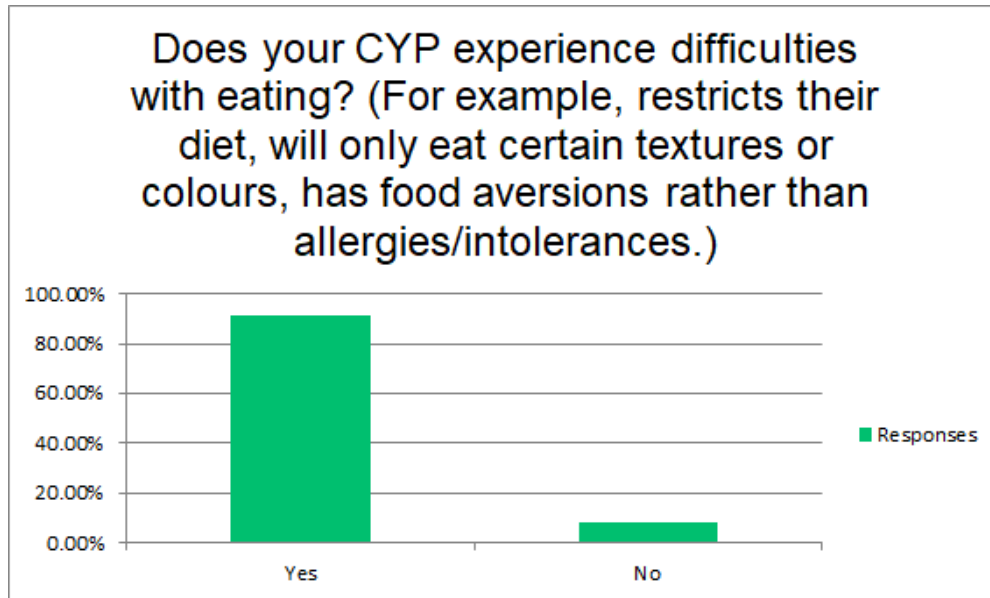
This Survey was completed by a total of 14 Parent Carers, all of whom have a child or young person with a diagnosis of Autism Spectrum Disorder (ASD). It is designed as a snapshot view on the sensory, toileting and mobility needs associated with the ASD diagnosis. The Children and Young people represented are from a wide range of ages, from 3 years to 18 years as broken down below.



**Fig. 2 Ages of Children and Young People Represented**

Of the Children and young people represented, 9 were declared to be male, and 3 female. The National Autistic Society estimates that the national ratio of male's to female's with autism is 3:1<sup>1</sup> - which correlates to the responses given in this survey.

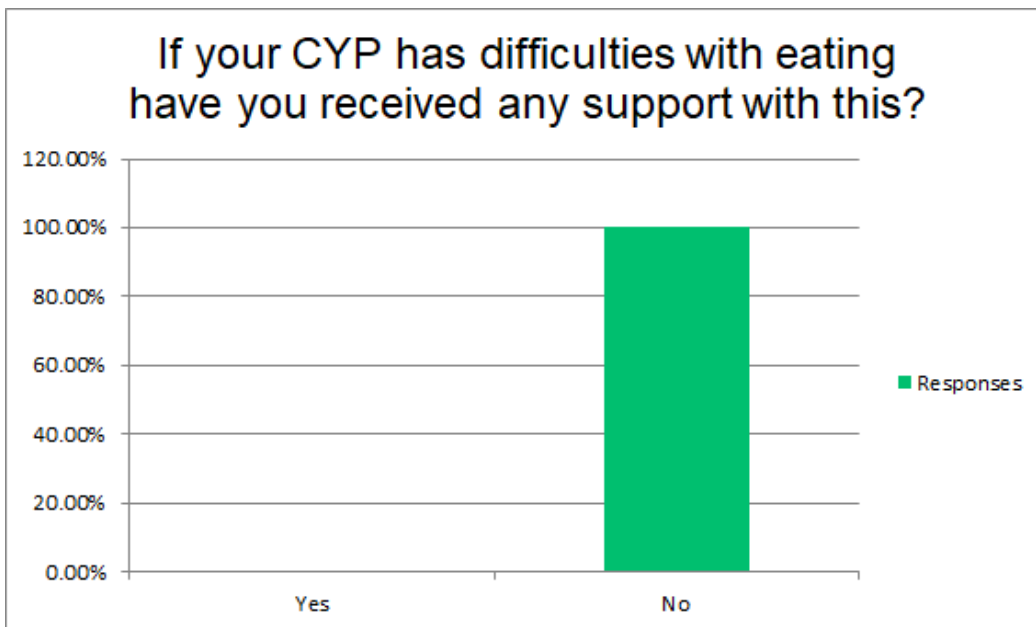
### **Breakdown of ASD Specific Questions**



**Fig. 3 Declared difficulties with eating**

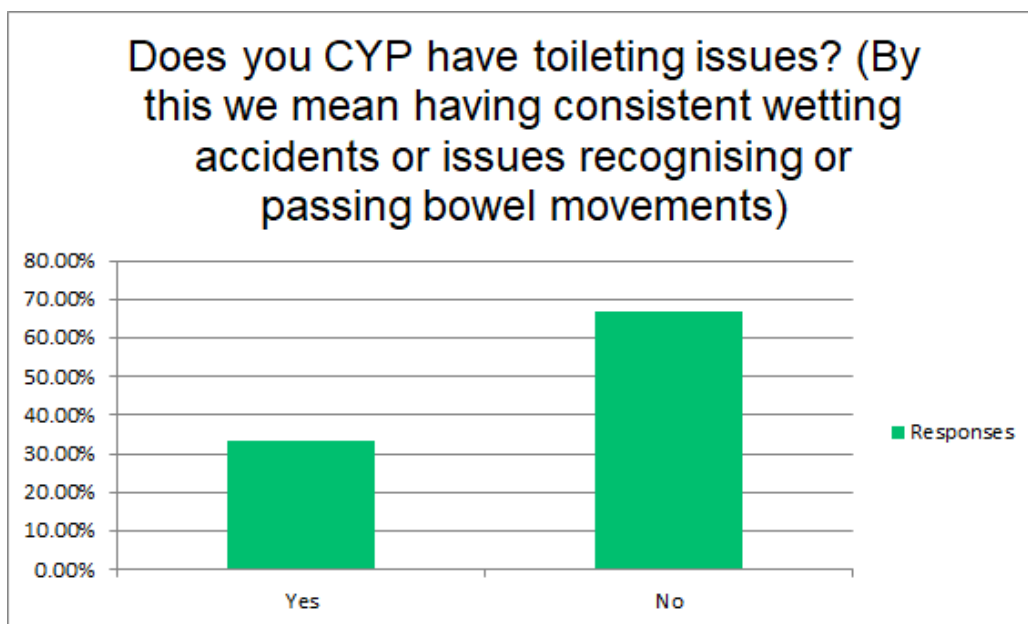
The first question of the survey asks parents whether or not their child or young person experienced difficulties with eating - specifically looking at sensory issues relating to taste, texture and colour as opposed to any intolerances or allergies. Of those responding, a total of 11 individuals declared that their child or young person did experience difficulties, with 1 responding in the negative and 2 choosing to skip the question.

<sup>1</sup> <https://www.autism.org.uk/about/what-is/gender.aspx>



**Fig. 3 Support received by parent carers relating to eating difficulties**

All of the parent carers who responded to the previous question declared that they had not received any support to manage their child or young person's difficulties with eating.



**Fig. 4 Declared difficulties with toileting**

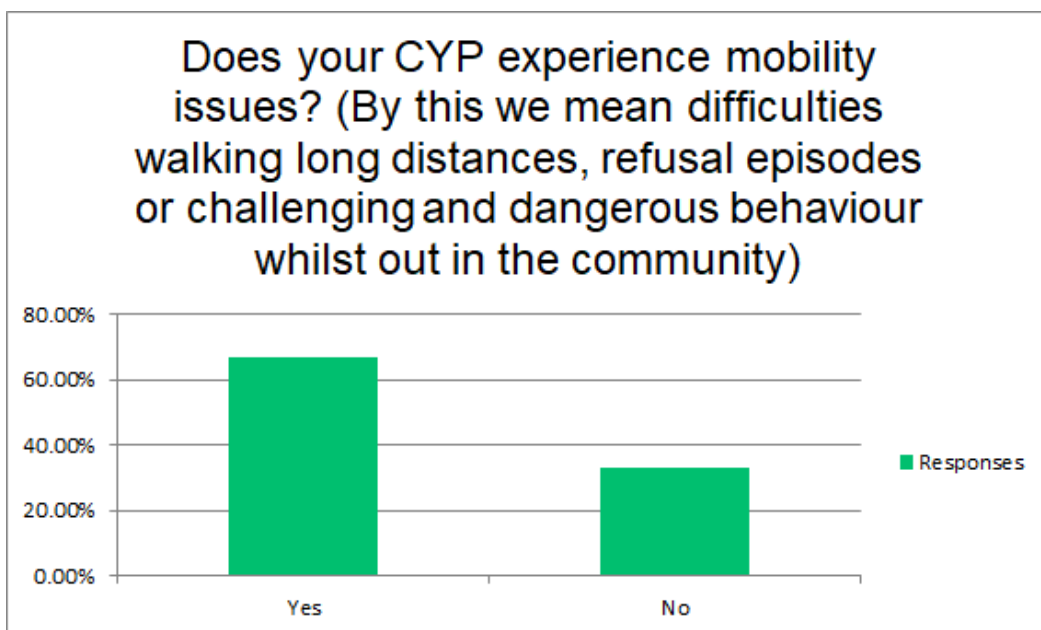
Of the respondents to this question, 4 individuals declared that their child or young person has toileting issues. The breakdown of specific support received with this is broken down below:

Age of Child/Young Person	Support Received	Own Solutions Sought
5	Healthy child team and	Purchasing Pull-Ups from

	school nursing team, then told to go to GP for additional support but not been able to get an appointment	Supermarket
12	Support through the community nurse team which was fantastic	None
18	None	Fight with school regarding when she needs to go to the toilet - told no, only at break times
9	Referral to urology and given medication but no referral to incontinence clinic so have no pads. Also have no behavioural support to toilet train.	Purchasing Pull-Ups from Supermarket

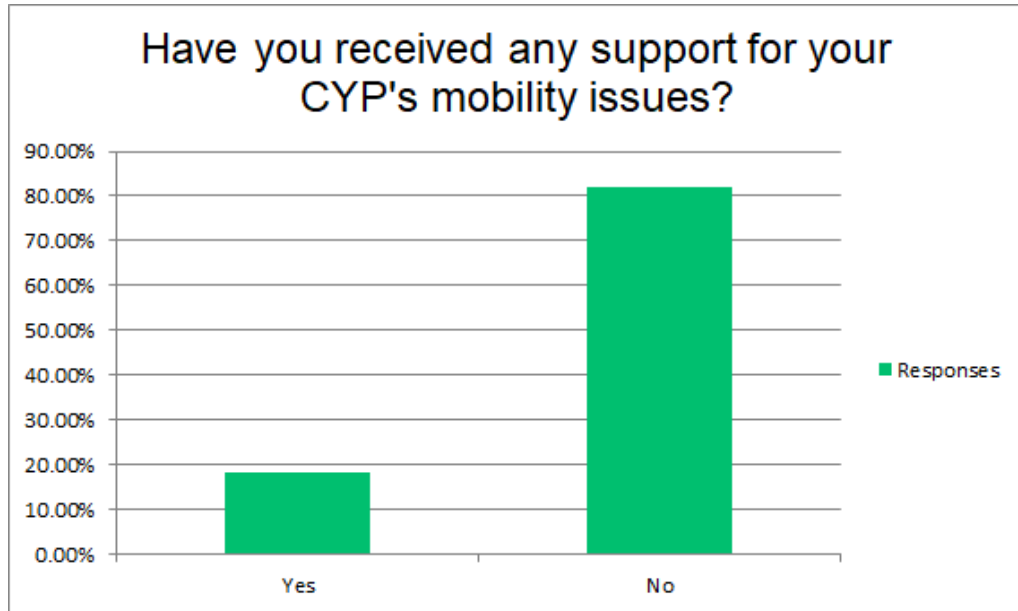
**Fig. 5 Declared support received with toileting issues**

As displayed above, there is a wide range of ages of children and young people represented within the survey who have additional toileting needs, from as young as 5 to as old as 18. Two out of the four parent carers are needing to purchase pull-ups from the supermarket as a way of managing the need as they are not able to access pads from medical services. One parent carer has detailed the struggle they are having with their educational setting to get reasonable adjustments made so that their daughter can use the toilets when she needs to, as opposed to only at break times, and has thus far been unsuccessful.



**Fig. 6 Declared difficulties with mobility**

A total of eight out of twelve parent carers have declared that their child or young person experiences issues with mobility. This question relates not only to physical difficulties with walking but also associated danger awareness concerns, and the refusal to leave the house.



**Fig. 7 Support received by parent carers regarding mobility**

When asked, only two of the responding parent carers declared they had received any support with their child or young person's mobility issues. The support declared by parent carers was:

*“Received support which was very good up to age 5 which was very good from early years psychologist. Now asking for advice gets the offer of a parenting course”*

*“low. Rate mobility”*

While it is encouraging to see that one parent carer has declared that they received a high level of support for their preschool age child, it appears that any available support tapers off once a child reaches school age, with the only available support being the lower rate mobility payment. This has left the majority of parents seeking and financing their own solutions in order to keep their children and young people safe outside of the home. The solutions sought were declared as being:

Respondents	Solutions Sought
1	Encouraging
2	Wrist link

3	We did have a special needs pushchair but now he refuses to use.
4	Reins for both my son's 3 and 5. Going to apply for blue badge soon.
5	We use a pushchair and don't go anywhere where walking is required
6	no
7	learning traffic light
8	bought a maclaren major.

**Fig. 8 Solutions sought by parent carers for mobility issues**

The most common answers relate to continuing to use pushchairs or reigns for young people beyond the age range they are intended for. These solutions, whilst making going outside manageable for the parent carers, do nothing to address the underlying causes nor provide any support for the child or young person to overcome their issues with mobility.

The final question of the survey asked the respondents to detail any additional comments on how they thought services could be improved to support autistic children and their families. The responses were varied, and touched on a number of topics not specifically covered within the survey which as such gives a valuable insight into parent carer opinion on all services they feel are needed in order to support a young person with Autism Spectrum Disorder.

Respondents	Responses
1	Listen to parent more than schools
2	Support for transition to being an adult and how to think about a job
3	Use clear and simple list of services. We haven't got time to read 100s of leaflets and search through what is available where ( different help and support given in different areas ... Whittlesey/Peterborough)
4	Na

5	I feel the introduction of the blue badge with help families with children with ASD enormously however the wider community do not tend to see the hidden disabilities.  The symbol on the blue badge I feel should reflect that not all disabilities are those in a wheelchair.
6	like like to know what qualifies for the 0_25 group as we don't fit the criteria and would like to have some kind of respite care to give me a break,I would like a break,he hasn't been to school since October so I am responding single for him 24/7,. IAM 75and he is 11.
7	understand daily issue by council, schools
8	when you ask for help people just look at you and there is nowhere for them to send you or you just get past from pillow to post
9	we need support with these issues in the form of appointments, follow-ups, workshops and support groups.

**Fig. 9 Additional comments on how services could be improved to meet the needs of autistic children and their families**

One of the overarching concerns declared by parent carers here is that they do not feel listened to or understood, be that within schools, social care services or within the council as a whole. There is a feeling that the systems and services are too complicated, and poorly understood.

### **Summary**

The underlying theme running throughout the responses to this survey show that parent carers do not feel like they are receiving adequate support in order to manage their child or young person's needs associated with Autism Spectrum Disorder.

There is a declared gap in support for those suffering with eating issues, with no examples of support received being offered. Support with toileting difficulties is inconsistent - where help is received via the community nurse team this is reported to be very good, but the majority of respondents declared the support they received was either non-existent or not long term and as such have had to resort to purchasing their own pull ups with no guidance for managing the underlying cause of the incontinence. Mobility Support has been declared to be adequate for preschool age children, but then non-existent for school age children. This has left parent carers managing the symptoms of the child or young person's behaviour via



pushchairs or reigns, but without support to treat the underlying issues and work towards improving mobility.