



**Gloucestershire Parent Carer Forum**

**PARENT CARER  
SURVEY FEEDBACK  
APR 22- MAR 23**

- 01.** Introduction (pg 2)
- 02.** Summary of findings (pg 3 - 4)
- 03.** Detailed findings from the survey (pg 4)
- 04.** Who parent carers are (pg 4 - 6)
- 05.** Support for children with additional needs (pg 6 - 16)
- 06.** Conclusion (pg 16)

Gloucestershire Parent Carer Forum (GPCF) encourages parent carers to sign up to the Forum and to complete an anonymous survey at the time of joining. During the period between April 2022 - March 2023, the total number of parent carers signing up to the GPCF was 201. The number that went on to complete the survey was 126. The survey asks for information about parent carers and their family situation as well as information about their child(ren) with additional needs, level of support and services accessed as well as issues and challenges with accessing support or services. Below is a summary of the main findings of the survey followed by a more detailed report of the findings for each question in the survey.

During the period between April 2022 and March 2023, **201 parent carers signed up with the Forum**. Just under half of families reside in the Gloucester area whilst a quarter of families reside in the more rural areas of the county. **126 parent carers** completed the survey. Parent carers are predominantly aged between 36-44 (44%). Just under a quarter are aged between 26-35 and 46-55. 13% of parent carers come from very low-income families. Just under a **third of parent carers** were having to **manage their own condition** as well as their child(ren)'s.

### Educational Setting - Total No of Children 179

Most families had children that were in mainstream primary at the time of the survey (**41% 75**) with the second highest proportion in specialist settings (**16% 28**). **According to the survey, 28 children had no school placement**. This figure includes two children who were being home educated because of not having a school placement.

### Educational Support - Total responses 165

Just over a third of children were supported by an Educational and Health Care Plan (**EHCP 61**) and just over a quarter were on **My Plan+ (43)**, followed by **My Plan (31)** with just under a fifth **17% (28) of children had no support**. This figure links back to the previous figure of those children with no school placement.

### Financial Support – Total responses 165

Just under **half (72)** of families receive **no financial support** for their children, whilst **44% (64)** of families receive some form of **Disability Living Allowance (DLA)**. This equates to our finding above that more children are primary age and/or below the age 16 cut off for PIP.

### Conditions – Total responses 126

Parent Carers reported **448 conditions for 179 children – average 2.5 conditions per child**.

The top three conditions reported by parent carers for their children were **Autistic Spectrum Condition and/or Pathological Demand Avoidance (ASC/PDA)**, followed by **Mental Health** issues and **Processing difficulties** including **Sensory Processing**. **Two thirds (79)** of parent carers reported that their children had at least **three co-occurring conditions**. When we considered the figures, we found that **Anxiety** was highly likely to co-occur with an **ASC/PDA** presentation and that there was a high likelihood of **Anxiety** co-occurring with **ASC/PDA** and **ADHD/ADD**.

It is clear from these figures that most parent carers are supporting children with multiple and complex needs and Neurodivergent conditions predominate. It is of concern therefore, that nearly half (72) of families reported receiving no financial support, 17% (28) had no educational support and 28 children had no school placement.

### Accessing Statutory and Community Services – Total Responses 204

We asked parent carers what statutory and community services they had accessed or were currently accessing. Over a **quarter (54)** of parent carers report accessing **no services**. **21% (43)** reported accessing **Health and Assessment** services. The latter finding is unsurprising given the number of children with complex multiple needs relating to neurodivergent conditions and mental health. It is concerning that rather more parents are not accessing any services.

### Barriers to Accessing Services – Total Responses 173

The final question asks parent carers to tell us about the issues and challenges that they are facing. The top three reported issues in order of importance were:

1. **lack of support from services including lack of provision,**
2. **challenges accessing medical and mental healthcare services,**
3. **challenges relating to Education.**

**Lack of support relates closely to problems identified within Health and Education. The top three issues account for 68% of issues and challenges raised.**

## 3. DETAILED FINDINGS FROM THE SURVEY

The remainder of the report considers parent carers responses in more detail and provides a breakdown of the figures (in percentages and actual numbers) with graphs for each question of the survey. Where relevant, we have included responses from parent carers, in their own words, to help interpret the figures.

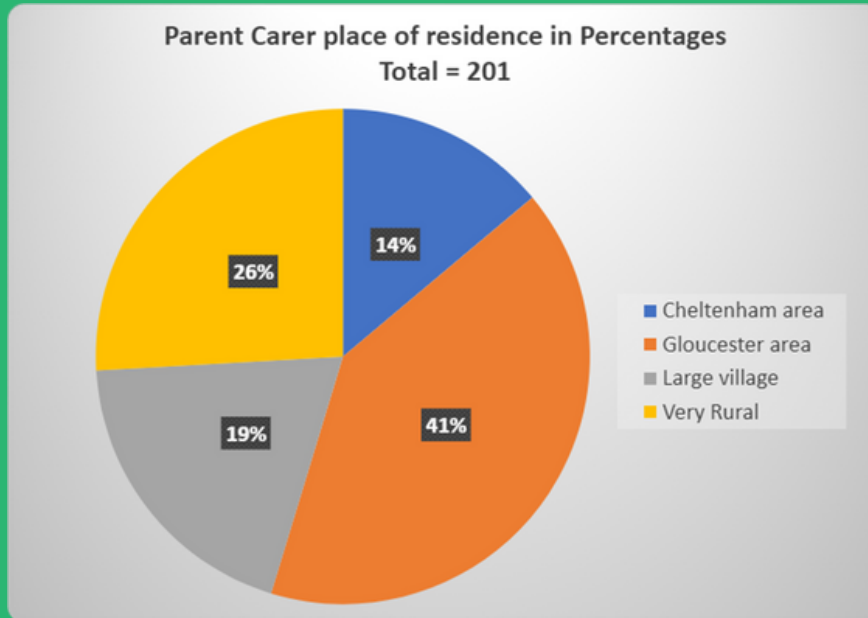
**The report below shows that parent carers are telling us that their greatest challenges relate to lack of support, and lack of provision of services, especially those related to Health and Education.**

## 4. WHO ARE OUR PARENT CARERS?

The Forum collected the following information about parent carers and their family situation: where our members live in Gloucestershire, age of parent carer completing the survey, parent carer background information and whether the parent carer had a health condition or additional need.

## 4.1 Where do parent carer families live in Gloucestershire?

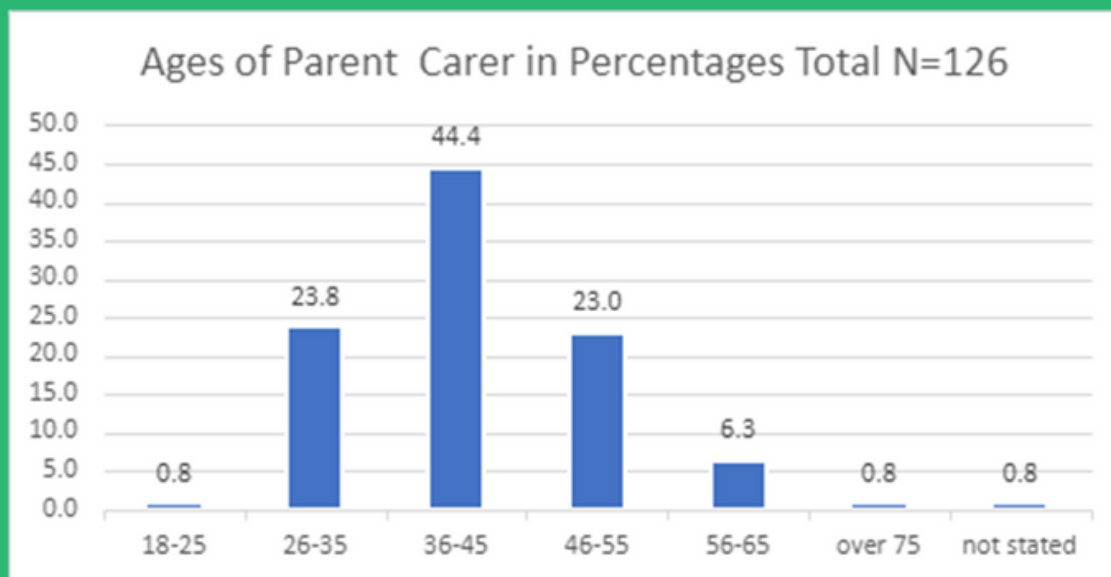
Qu: Postcode



A total of 201 parent carer families signed up as members of the forum during the year. Our families are located throughout the county with just under half of all families living in the *Gloucester* area - 41% (82). Just over a quarter of families 26% (52) live in *Very Rural* areas such as Staunton, Stow-on-the-Wold, Bourton, Blockley, as well as towns and villages around the Forest of Dean. A fifth of families 19% (39) live in *Large Villages* or small towns such as - Cirencester, Tewkesbury, Stroud, Fairford. The remainder of families 14% (28) live in an around the *Cheltenham* area.

## 4.2 Age of Parent Carers

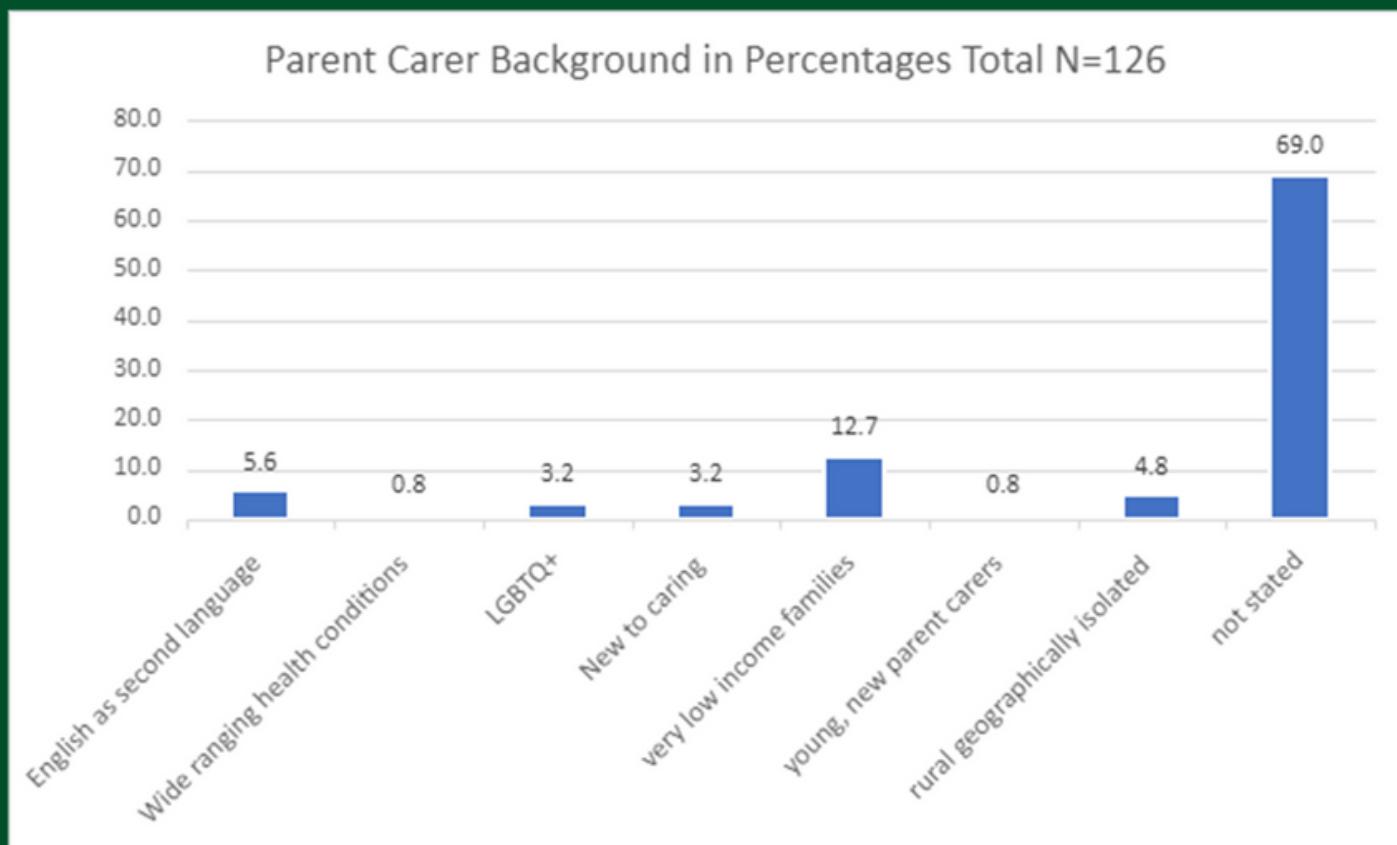
Qu: Your age now



Many parent carers are in the 36-45 age range 44% (56). Just under a quarter of parent carers are in either 26-35 age range 24% (30) or the 46-55 age range 23% (29). Only 6% (8) of parent carers are in the 56-65 category.

### 4.3 Parent Carer background information

Qu: Additional Background Information - please tick any you identify as being part of



The survey gave options about parental background which are listed on the graph above. Just under a third of the 126 parent carers answered this section 31% (39). 12.7% (16) of parent carers reported being from *very low-income families*, 5.6% (7) had *English as a second language*, 4.8% (6) were from *rural geographically isolated areas* and 3.2% (4) were LGBTQ+ and 3.2% (4) were *New to caring*, . Less than 1% (1) reported having *Wide ranging health conditions* of their own and less than 1% (1) were *young, new parent carers*.

### 4.4 Parent carers' health and other conditions

QU: Do you have any impairments or conditions and consider yourself to be a disabled person?

The issue of health and other conditions was pursued further, and more parent carers answered this section. In total just under a third of parent carers reported having at least one condition (31% of 126).

Of the 137 conditions reported, they included: *Chronic Pain, ME, Fibromyalgia* - 5.1% (7), *Autism/ADHD* - 6.6% (9), *Dyslexia/Dyspraxia* - 3.6% (5), *Vision/Hearing impairment* 2.2% (3), *Mental Health condition* 5.8% (8), *Other Medical condition* - 5.1% (7). Under *Other Medical*, parent carers reported dealing with cancer, long covid, autoimmune, epilepsy, skin and hypermobility conditions.

One parent carer tells us about the impact of their own health condition in trying to care for their child: *Services are too far away from where we live. I can't drive because of my epilepsy so my child cannot attend certain events.*

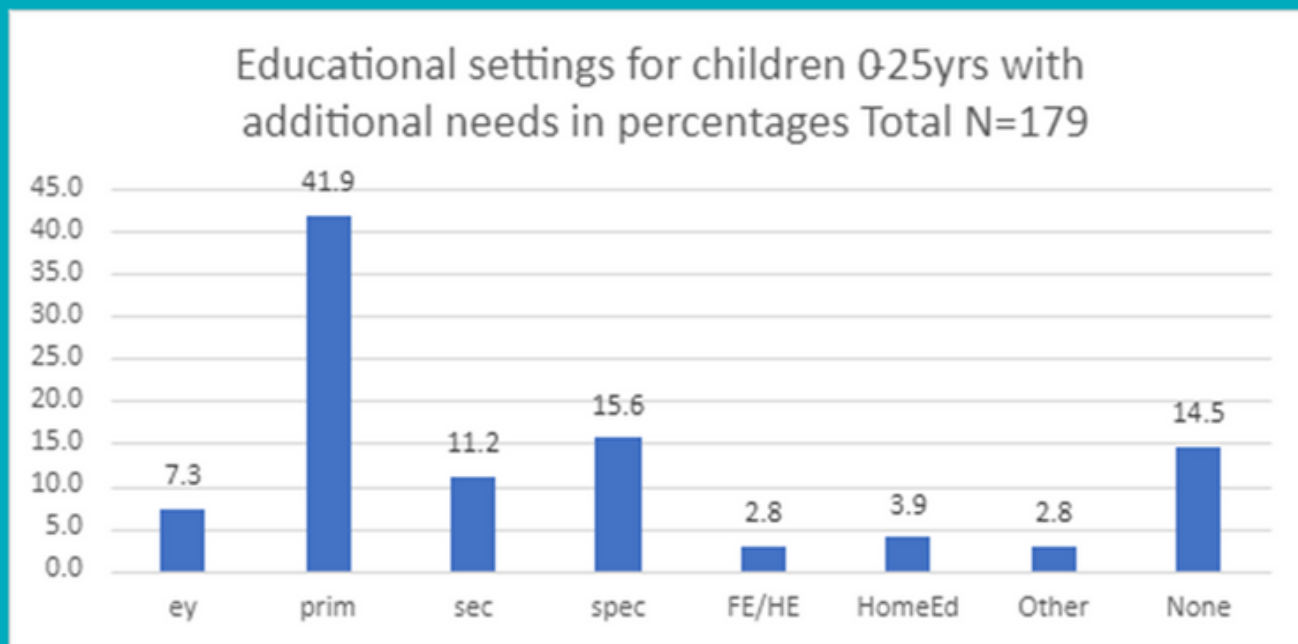
## 5. SUPPORT FOR CHILDREN WITH ADDITIONAL NEEDS

Parent carers told us about the children they care for: their condition(s) or impairment(s), their educational setting(s), their level of SEND support and the benefits that they were able to claim. Parent carers also reported on what services and benefits they were able to access and what issues and challenges they still faced, including difficulties accessing services they felt they needed.

Survey responses reveal that many families signing up with GPCF have more than one child with additional needs and that many children had multiple and complex conditions.

### 5.1 Educational Setting of the child(ren)

Qu: What type of education setting do your child(ren) attend?



Families reported on the educational setting of 179 children with additional needs. This tells us that several families have more than one child with additional needs in addition to children without additional needs. Many children are in mainstream primary education 42% (75). 16% (28) of children are in special education. It is concerning that 15% (26) of children are not in any kind of education *None*. The total is 28 because two families were forced to home educate because their child did not have a school placement.

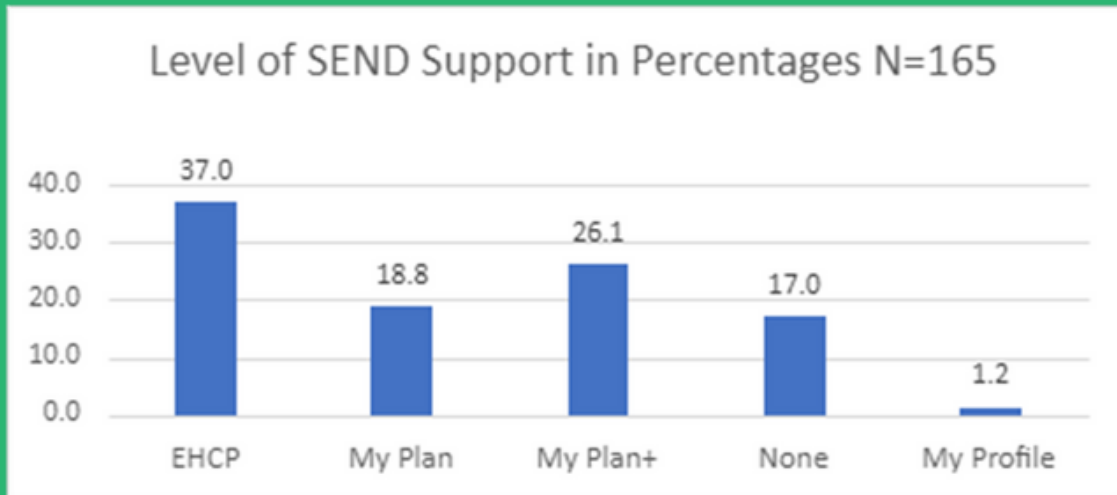
For example, one parent carer comments:

*We are struggling with home educating our child, but are not yet able to find a school that is suitable.*

11% (20) of children are in secondary school *sec*. The remaining categories are all less than 10% and include: early years - *ey* 7% (13), Home Educated - *HomeEd* 4% (7), *FE/HE* 3% (5), and *Other* 3% (5). The other category includes hospital, private or residential education.

## 5.2 Level of SEND support

QU: What level of SEND support does your child(ren) have?



The types of support accessed from most to least are *EHCP* 37% (61), *My Plan+* 26% (43), *My Plan* 19% (31), *None* 17% (28), *My Profile* 1.2% (2). Comparing this graph and the *Educational Setting* (5.1.) graph, it is probable that the children receiving no educational support are those who have no school placement. These families are likely to be the most vulnerable, the least supported and with the least access to services. As such, they should be a priority for services providers.

Two parent carers describe their child's conditions and tells us how long they have been out of school:

Conditions: *Autistic Spectrum Condition, Pathological Demand Avoidance, Anxiety, Depression*

Comment: *No education for 2.5yrs. No sign of any engagement with any professionals. No desire to re-enter 'normal' life at all, especially not school. Missing out on so much, should have been Y10.*

Conditions: *ASC, Anxiety, Attachment Disorder, Learning Impairment*

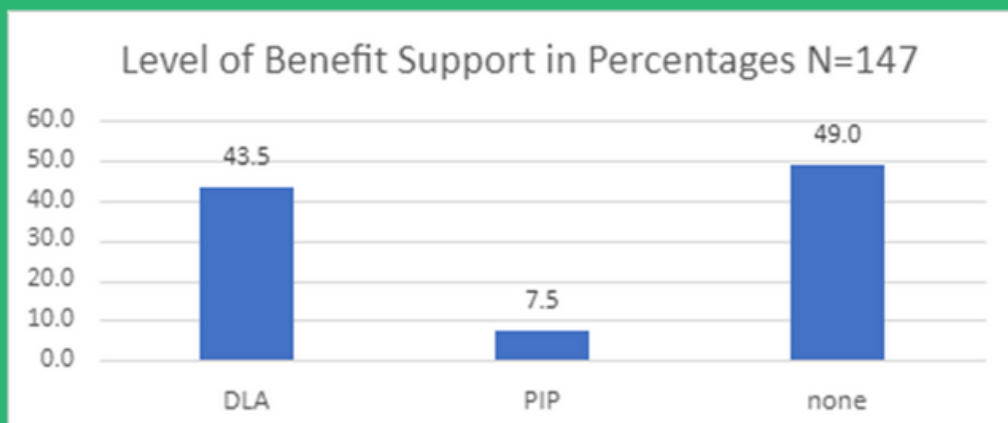
Comment: *His school placement at a specialist school has broken down and he has been out of school for a year with no progress at finding a new one.*

Parent carer of three children with additional needs:

*The local authority have been very difficult and don't seem to care that my son is out of education.*

## 5.3 Level of financial Support

QU: Do you receive Care Support, if so at what level?



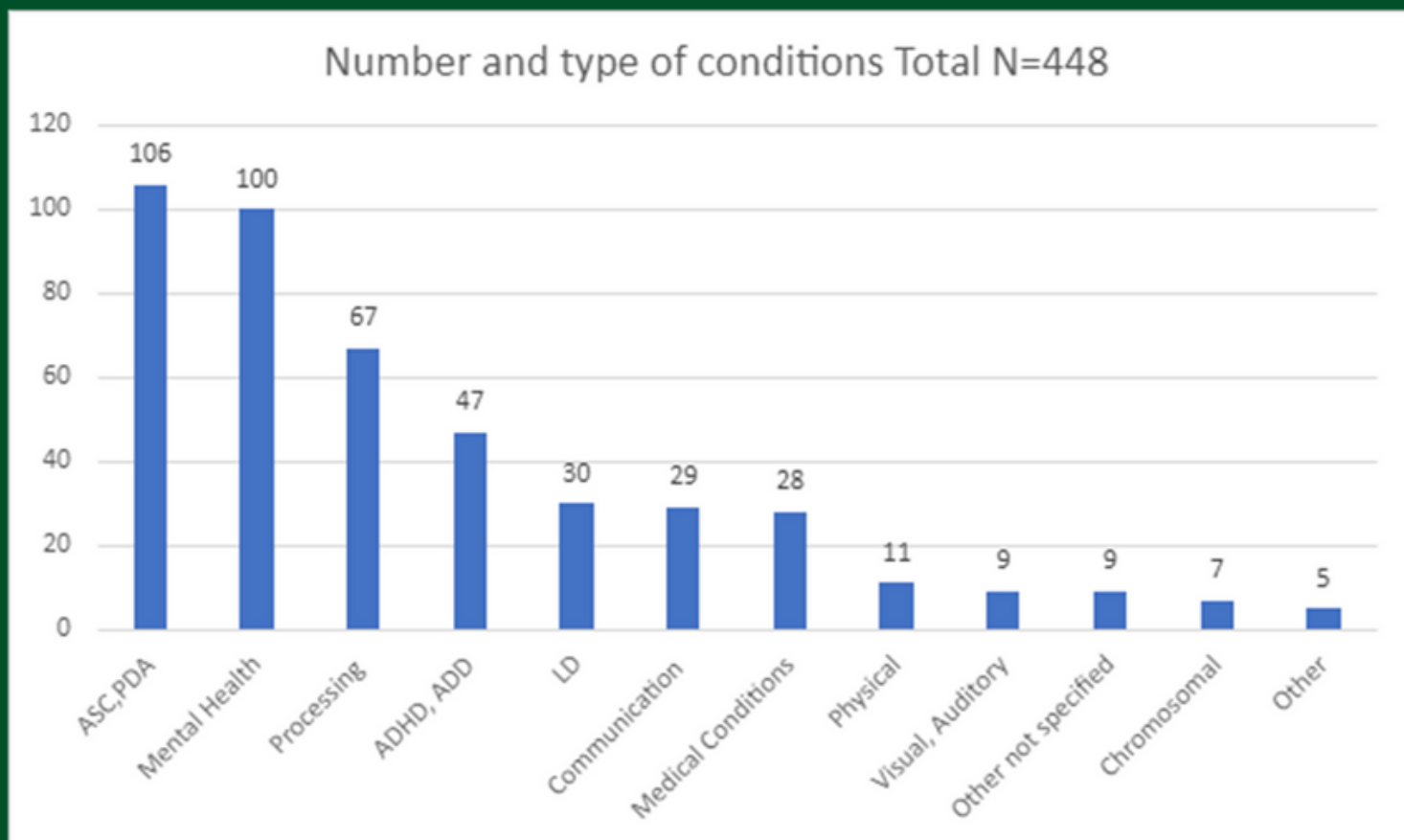


Of the total of 147 responses about financial support, just under half reported that their children had no financial support - *none* 49% (72). 44% (64) of children had some form of *DLA* benefit. 7.5% (11) of children had some form of *PIP* payment. Most children were below the 16yr age for *PIP*, hence the low number for this benefit. However, it is of concern that 49% (72) reported no financial support, which suggests that families may face barriers towards accessing financial support.

## 5.4 Types of conditions reported for children with additional needs

**QU: What is your child's/children's conditions/impairments/additional needs?**

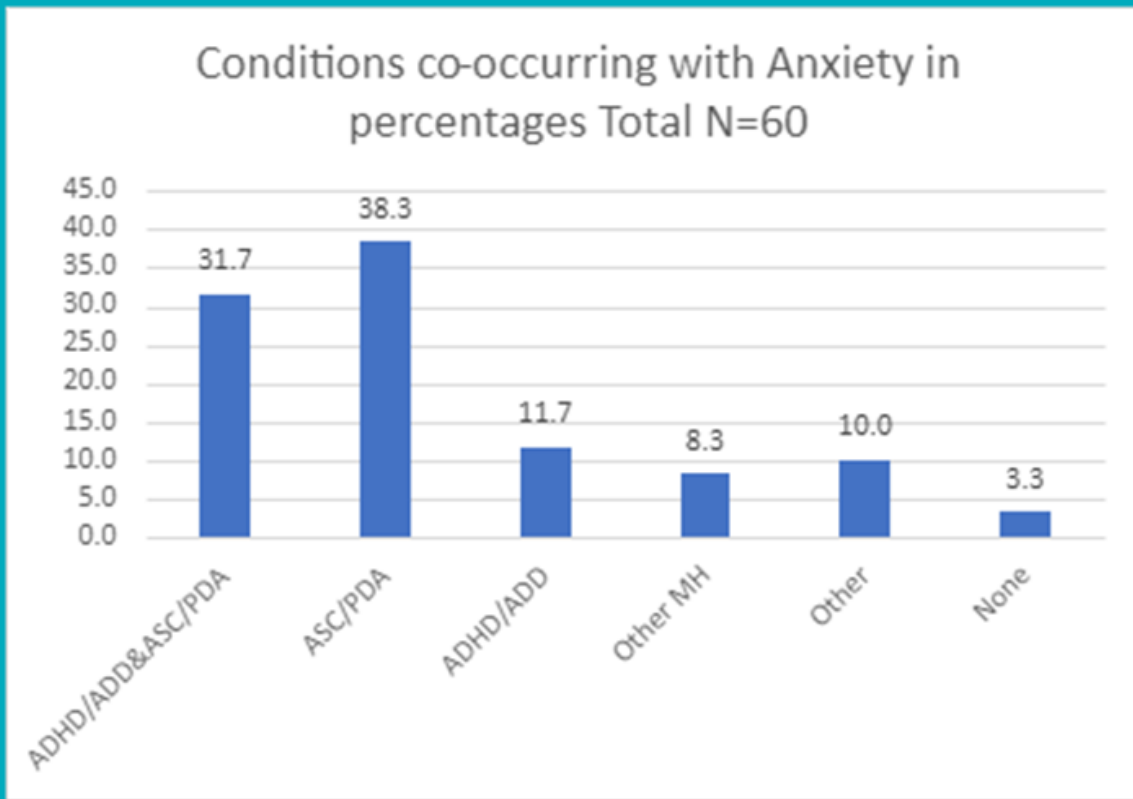
**QU: Does your child/children have any other physical or mental health condition?**



A total of 448 conditions were reported for 179 children (5.1. Educational Settings graph above). This suggests that many children present with more than one condition and/or multiple complex conditions. The conditions have been summarised into the categories shown in the graph above taking into account parent carers' own descriptions of the conditions. Parent carers report 106 instances of children having an Autistic Spectrum condition and/or Pathological Demand Avoidant condition – *ASC,PDA*. 24% of all conditions came under this category. This number was closely followed by the number of *Mental Health* conditions 100 (22%) of all conditions. The main mental health presentations in order of occurrence are anxiety - 60, attachment disorder 10, depression - 9. Processing difficulties represented 67 conditions (15%), of which 33 were due to sensory processing difficulties. *ADHD,ADD* accounted for 47 conditions (10.5%). The remaining categories have an occurrence rate of less than 10% and include: Learning Difficulties *LD*, ranging from mild-severe and including profound, multiple and complex - 30 (7%), *Communication difficulties* - 29 (7%), and *Medical Conditions*, including epilepsy - 28 (6%). Finally, those conditions representing less than 3% of the total number of conditions described by parent carers are *Physical*, including Cerebral Palsy 11, *Visual/Auditory* - 9, *Other not specified* - 9, *Chromosomal* - 7 and finally, *Other* - 5.

The above figures indicate that a significant number of children have co-occurring conditions, i.e., 448 conditions for 179 children. From graph 5.4.1. below, it is clear that a child with anxiety is more likely to have ASC,PDA or ADHD,ADD and that a high proportion of children will have all three Anxiety, ASC,PDA and ADHD,ADD.

### 5.4.1 Which conditions co-occur with Anxiety?



The graph analyses a total of 60 reported instances of **anxiety**. Of those 60, 38% (23) of instances are when anxiety co-occurs with *ASC,PDA* versus 12% (7) with *ADHD,ADD* or 8% (5) for *Other* mental health conditions. However, there is a high proportion of co-occurrence between anxiety, *ASC,PDA* and *ADHD,ADD* at 32% (19). By contrast, it is rare for Anxiety to occur alone - None - 3% (2).

**The overwhelming majority of instances involve co-occurrence between anxiety and ASC,PDA and/or ADHD,ADD without learning disability. These instances account for 82% of all cases. In addition, there are multiple complex co-occurrences with the conditions discussed above and other conditions including: other mental health conditions, processing difficulties, learning disabilities and physical/medical conditions.**

#### Parents Carers' comments on how anxiety impacts their children's lives:

*Accessing support for General Anxiety Disorder - it doesn't seem to be recognised as an issue.*

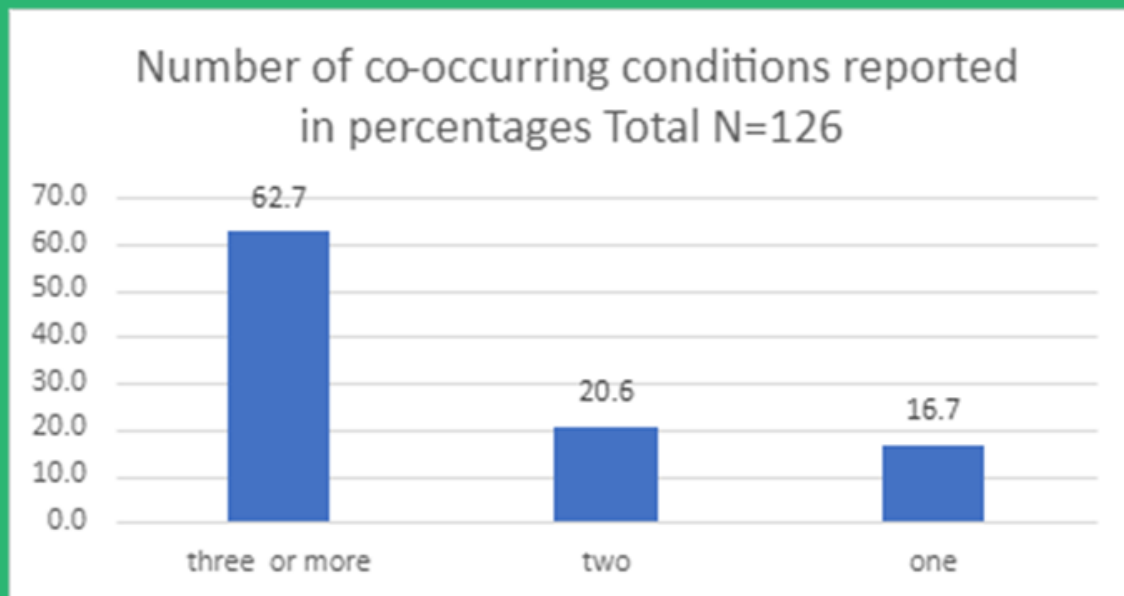
*Unable to leave the house to attend school.*

*There is no help for my daughter and her anxiety.*

*My sons anxiety stops him from being able to take part in activities and he is missing on things which his peers can do without a second thought.*

*Daughters anxiety restricting where we can go.*

## 5.4.2 Number of co-occurring conditions



This graph shows the number conditions that parent carers reported for their children. Most families are reporting children with three or more conditions 63% (79), followed by two or more conditions 21% (26), and finally one condition was reported for 17% (21) of families.

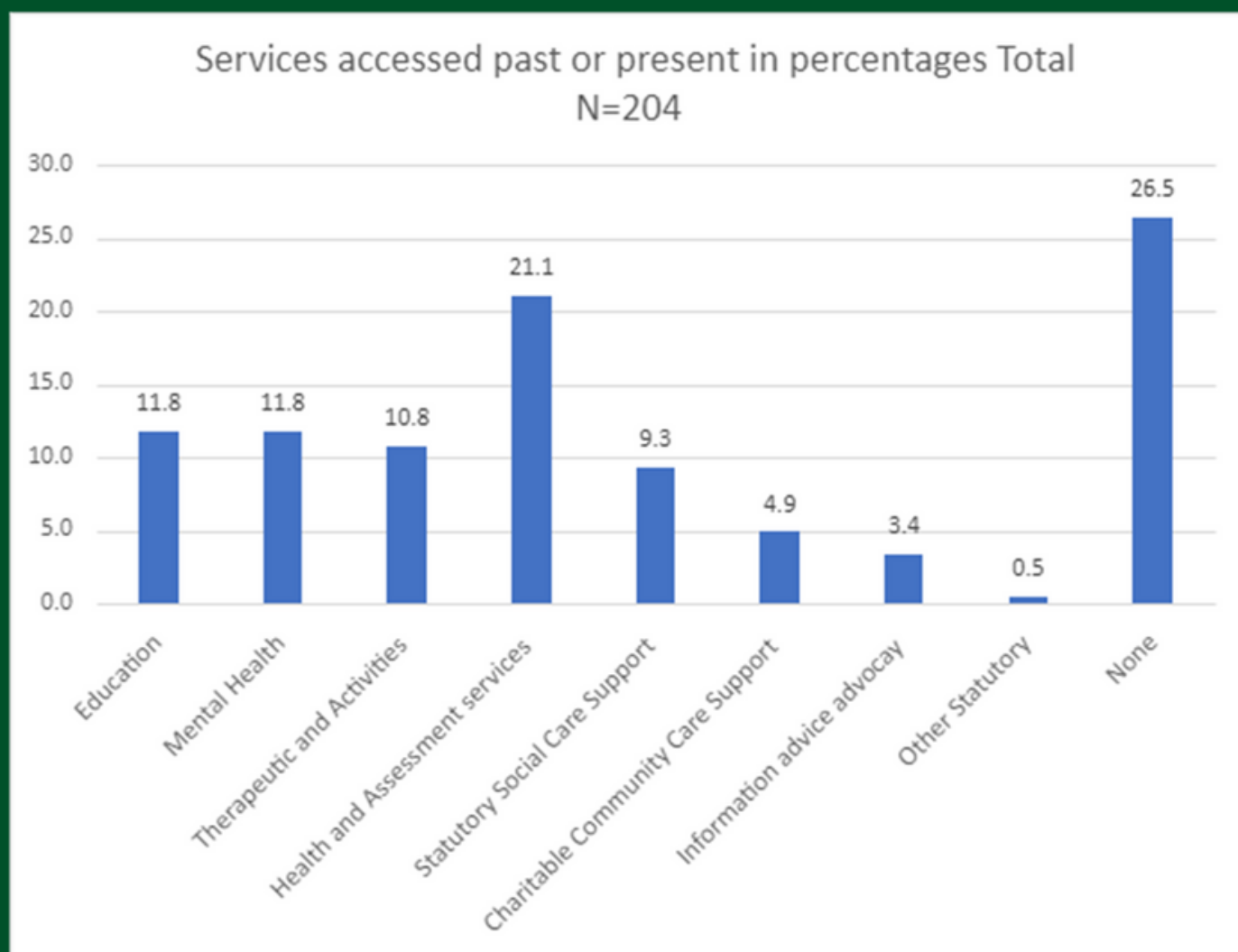
Families have told us that they support children who have multiple and complex conditions and challenges. A high proportion include those children who are neurodivergent and who are also highly likely to suffer from a mental health condition, in particular Anxiety. However, not all neurodivergent children are reported to have a mental health condition. **Families have also told us that their children are most likely to have at least three co-occurring conditions and therefore have complex presentations that are more likely to need specialist support and understanding.**

**It is particularly concerning, therefore, that half of our families report receiving no financial support and very worrying indeed that slightly more than 15% of children are not in any kind of education nor receiving the support that comes through education.**

We now explore in more depth what support and services families report that they have been able to access in the past or are currently accessing. We also have asked parents to explain what issues and challenges they are facing with regards to support and services.

## 5.5 Services accessed by parent carers

Qu: What services do you currently access or have accessed in the past?



Parent carers reported in their own words which services they were currently accessing at the time of the survey, or which services they had accessed in the past. The services were grouped into categories, and these are summarised in the graph above. The top figure of 27% (54) - *None*, represents those parent carers who were not able to access any services. This figure is of concern given the number of children reported as having multiple and complex conditions.

After *None*, the top services accessed, related to Health and Assessment services 21% (43). The greatest demand for support is from speech and language therapy (15), occupational therapy (11) and physiotherapy (8).

12% (24) of all services accessed were in *Education*. The most used were the Advisory Teaching Service (8), Educational Psychology (4), inclusion team (3). Parent carers also accessed in-school services such as art and play therapy and other specialist school services (4) or school nurse, pastoral care or counselling (3).

12% (24) of all services accessed were *Mental Health* services. The Child and Adolescent Mental Health Service (CAMHS) was the most in demand (13) followed by Teens in Crisis (5). Parent carers have received services from private or NHS psychiatrists (2) and clinical psychologists (4).

11% (22) of services fall within Therapeutic and Activities and relate to services outside of a school setting. These included Allsorts (6), private therapies - art, play, music (6), animal therapies - equine, Riding for the Disabled, Greenwood (5). Others used SEN specific stay and play and the Chamwell centre (3). Finally, CBT was used (2).

9% (19) of services accessed were from Statutory Social Care Support. These included social care (4), Community Learning Disability Team and DCYPS (5), Family Support - TAF, Families First, Family Support Worker (4), Early Years (3) and finally Holiday Activities and Food (HAF) and the Youth service (1).

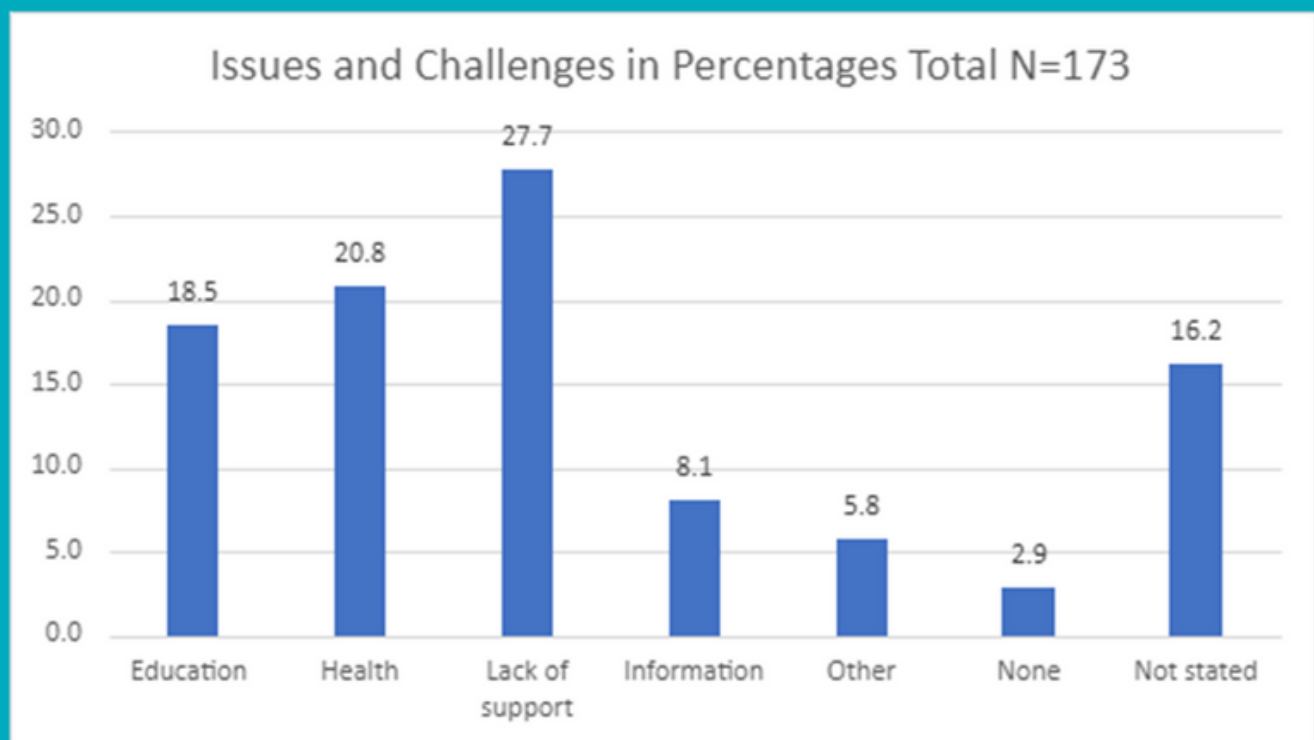
5% (10) of services accessed came from *Charitable and Community Care Support*. There was no one service that stood out as being used by parent carers, but the Carers Hub was mentioned twice, and the following groups were mentioned once - Gloucestershire Autism Support, Cotswolds Down Syndrome Support, Glo-active, Caring For Communities, Glos Young Carers, Early Help Barnardo's, Post adoption support and Scope Learning Disability.

3% (7) of services related to information, advice or advocacy including SENDIASS (5), Family Information Service (1), Glos Parent Carer Forum (1).

1% (1) used other statutory services - the police.

## 5.6 Issues and challenges facing parent carers

Qu: What issues do you currently face regarding services?



Parent carers reported in their own words which services they experienced issues or challenges. A total of 173 responses were grouped together into categories and the above graph represents a summary of the responses according to the main themes that emerged. There were 81% (140) of reported instances of challenges or issues raised by parent carers. The remainder did not answer the question 16.2% (28) or reported *None* 2.9% (5).

The top three issues and challenges that parent carers identified were related to *Lack of support* or provision 28% (48), *Health* 21% (36) and *Education* 19% (32).

Within the *Lack of support* category, parent carers reported lack of support or provision of services in general (27), 4 specified lack of services post 16 yrs. and to transition to adulthood, 2 mentioned lack of support to find a suitable Personal Assistant. Parent carers reported lack of service provision specifically (9). Some reported that systems were either unfit for purpose or that they were impossible to navigate, and these were a barrier to finding the right support (6).

From the graph above, many of the services needed by parent carers are within Health and Education.

### **Parent Carer comments regarding lack of support**

*Lack of support. No one wants to listen or help.*

*Being left alone with no support and no check ins from any services.*

### **Parent Carer comments regarding post 16 transition**

*Post 16 transition - Knowing what is available for Adults who have transitioned from children's services without the continuation to adult services for 25 year olds and over.*

*Our daughter is 20 and really we feel in the dark about what sort of support is available next and importantly after 25. We would really like our daughter to have some sort of independent life.*

*Feel as though we've hit a brick wall as no other services offered/continued/involved. Very concerned about transition to adulthood which isn't far away.*

Within medical and mental healthcare services Health, most issues related to long wait times to access services and long assessment waiting times (23). Parent carers also reported difficulty gaining access to healthcare services and having referrals refused (13).

### **Parent Carer comments regarding waiting times:**

*Waiting lists are long and it feels like being passed between agencies with no-one taking responsibility to help. I have been seeking support for at least 4 years and keep getting fobbed off. I am struggling to find the energy to fight all the time.*

*Trying to get her assessed for an autism diagnosis, waiting 18 months and counting since the referral, now they are saying she has started school and will have to join a new list.*

*Accessing formal Autism diagnosis quickly enough to gain access to services whilst daughter is still in school (currently year 9).*

*The wait for a paediatrician appointment is about 3-5 years so we have been forced to pay out thousands to get my children support!*

*Long waiting appointments for Paediatrics*

*The waiting list for occupational therapy is long*

### **Difficulties accessing Healthcare support and assessment**

*Unable to get referrals accepted for help with mental health, anxiety and support for my daughters day to day struggles. OT SALT CAMHS etc*

*Referrals to Glos Paeds for my youngest have been rejected twice due to 'not enough evidence from school' despite the struggles she has when home and in other settings. I deferred her so she attended an extra year at preschool. She masks at school and her current teacher (a retired SENCO's daughter) has put many helpful strategies in place to help her navigate day to day.*

*The NHS have been awful at providing support!!!*

*Trying to access a autism assessment but nhs has refused.*

*Struggling to access through NHS*

Within Education, most issues arose relating to problems with schools. Parent carers reported that either schools could not meet their child's needs, or that they did not understand their child's needs or that they were unsupportive (17). 7 reported that they had been refused an assessment for EHCP or were having problems due to long wait times. 6 reported that their child could not access school at all and were not in school, and 2 reported having problems with school transport.

### **Parent Carer comments:**

*Refusal of primary school to engage and actively obstructive regarding diagnosis. ADHD/autism*

*I'm struggling to access any help for my son that needs lots of extra support at school but doesn't act out/be naughty in the classroom for the teacher so doesn't to them seem like a problem but I then at home get lots of issues/meltdowns and all the anxiety he's holding in at school. Also he shows lots of signs of asd or adhd at home and to us when he's out but he masks so well that no one else sees it other than family.*

*The fact she masks at school so they don't understand what it like at home*

*While everything is based on school decisions and actions, progress for support is slow.*

*They are not issuing us an EHCP even though all professionals are stating that he needs one We had to fight for school transport, which has been granted but not implemented... yet*

*EHCP application for my child has just been declined. We plan to appeal.*

16% (28) of the responses were left blank Not stated. 8% (14) commented on problems of accessing appropriate or quality information. Under Other issues reported 6% (10), 2 included lack of overnight respite, 2 for housing issues and 2 reported their child being excluded from nursery provision. Problems with social services was reported once.

*I'm new to the area so knowing what is available esp. in the forest.*

*Trying to find something for my son to do in the daytime. Groups/activities that he can attend locally.*

*finding things locally he can do independently of us*

## 6. CONCLUSION

A total of **201** parent carers signed up with the forum between April 2022 - March 2023. **Over half completed our survey (126)**. They told us about their family situation. Many parent carers have caring responsibility for more than one child with additional needs. Many reported that their child had multiple complex co-occurring conditions. The most frequently named conditions were related to **ASC,PDA** which in turn had a high rate of co-occurrence with **ADHD,ADD** and **Mental Health**, in particular **Anxiety**.

**The most in-demand services are within Healthcare including Mental Health, and Education.** Parent Carers reported facing several barriers within these areas, including very long wait times for assessment but also lack of support within these services as well as a lack of understanding and recognition of their child's day to day struggles. A significant number of parent carers voiced concerns around receiving no support. Many of these parent carers are having to support children with complex and multiple conditions and report being unable to access specialist understanding, support or help. Of most concern were the number of parent carers reporting that their child could not access a school at all.

**We feel that an honest conversation is needed with parent carers related to the issues and challenges facing Health and Education services and that parent carers feel listened to in conversations with professionals. In addition, training for mainstream schools is needed to deal with some of the more complex presentations and finally, there is an urgent need to address the numbers of children with no school placement due to unmet needs and/or lack of recognition of their needs.**