

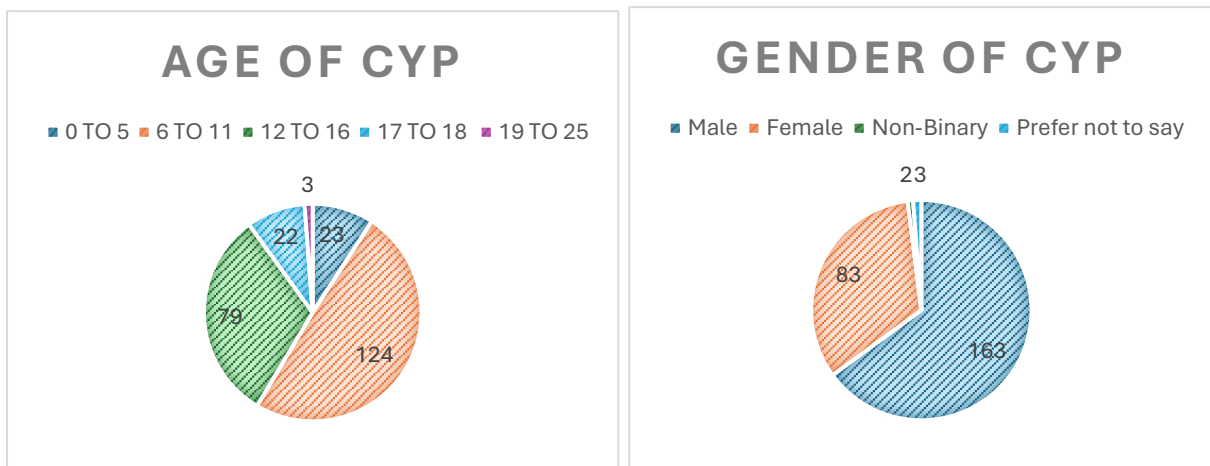


'giving a voice to parents & carers of children & young people (0-25) with additional needs'

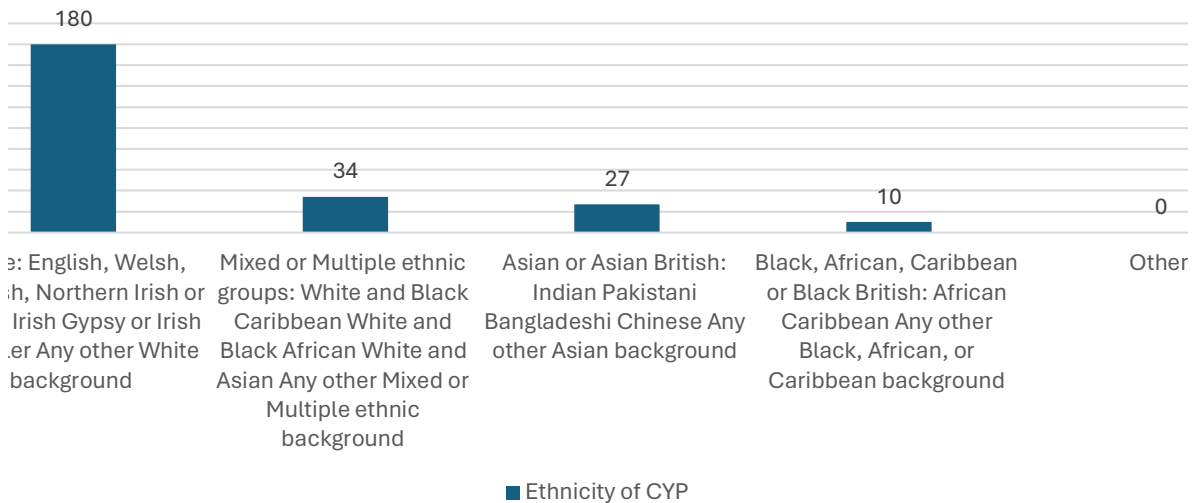
AUTISM SURVEY REPORT – APRIL 2024. – 251 Responses

Our questionnaire about Autism was launched at the end of January 2024 and closed at the start of April 2024. The themes raised in this report mirror those in our Annual Report 2022/23 and also the Preparation For Adulthood Report for Thematic Review 2024.

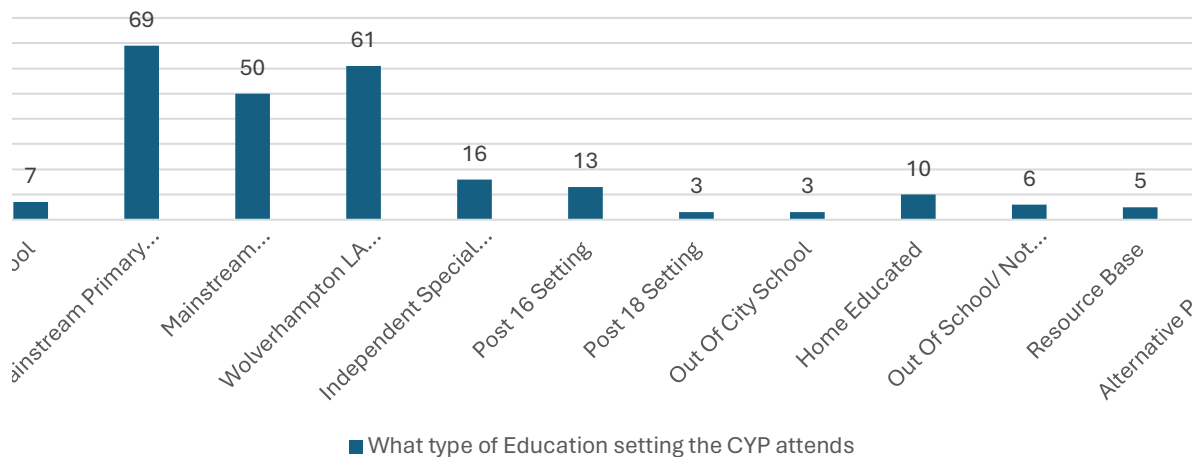
“I try my best for my children, they are my world but like many families, at times things are difficult because of their autism & sensory needs. Life can become tough & help should be there but it's not always.”



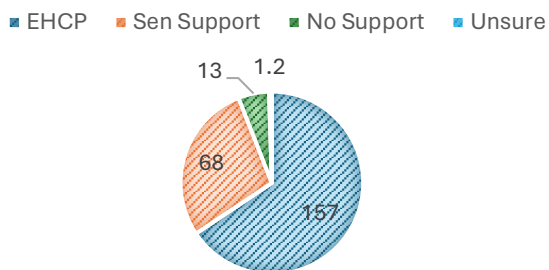
Ethnicity of CYP



What type of Education setting the CYP attends

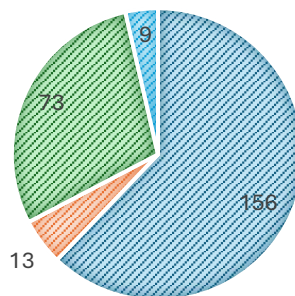


DOES YOUR CYP HAVE THE FOLLOWING IN SCHOOL:

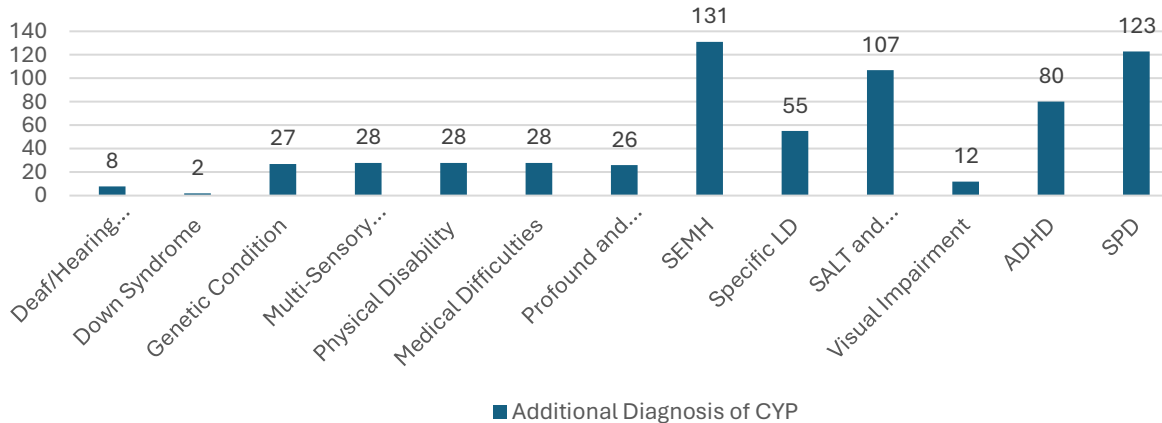


DOES CYP HAVE A DIAGNOSIS OF ASC

■ Yes ■ No ■ On Pathway ■ Don't know how to access

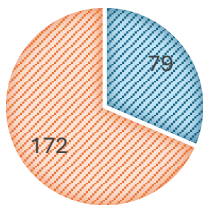


Additional Diagnosis of CYP



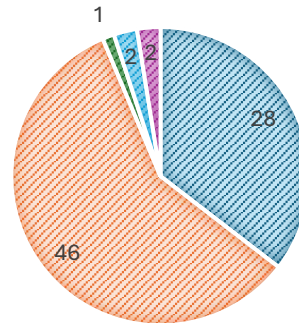
DO YOU HAVE MORE THAN 1 CYP WITH ASC/ON PATHWAY

■ Yes ■ No ■



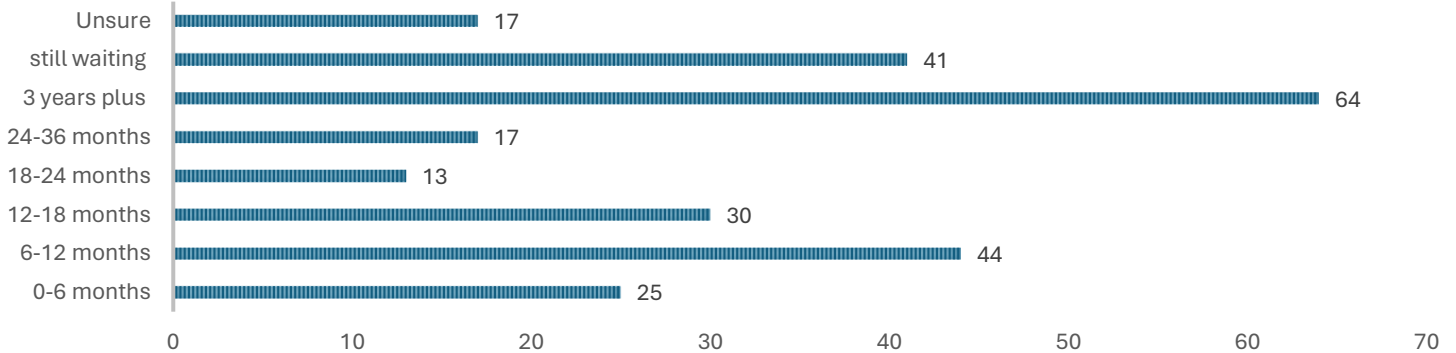
HOW MANY ADDITIONAL CYP IN FAMILY WITH ASC

■ 1 Additional ■ 2 Additional ■ 3 Additional
■ 4 Additional ■ 5 Additional



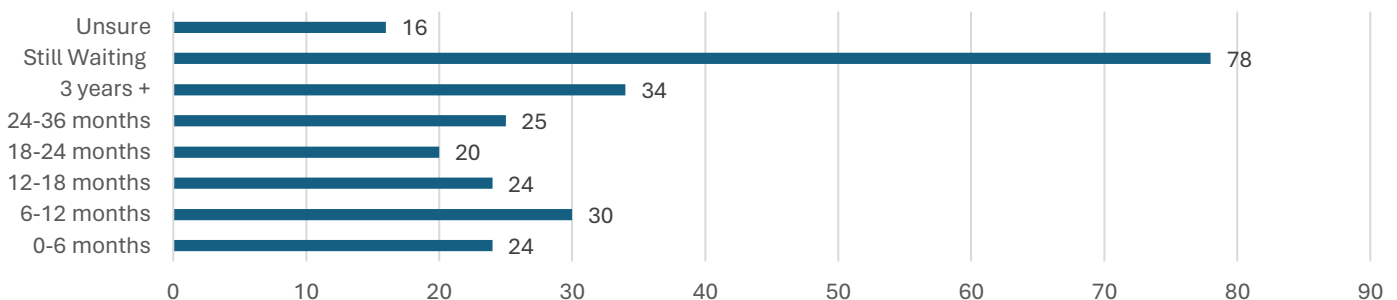
HOW LONG IT TOOK FOR CYP TO BE REFERRED FOR AN ASC DIAGNOSIS

■ How long it took for CYP to be referred for an ASC Diagnosis



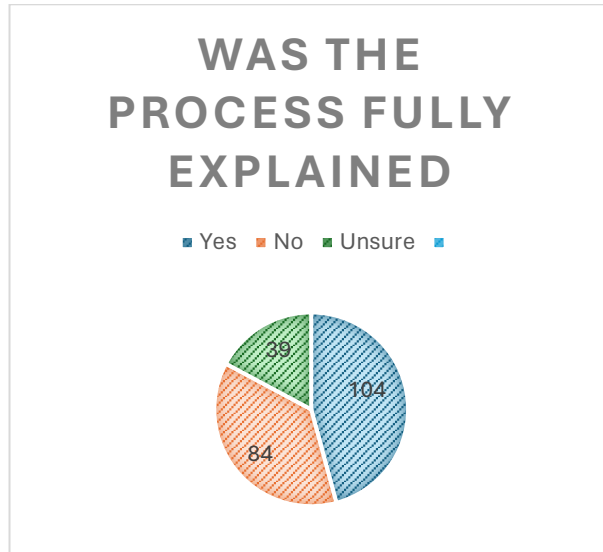
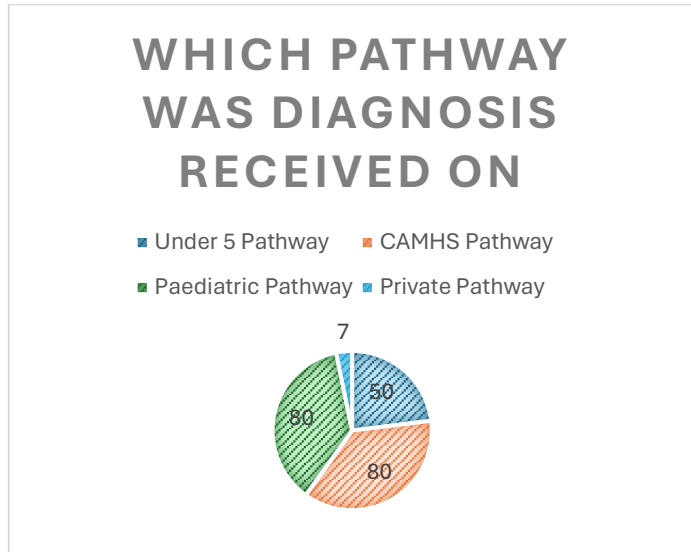
How long CYP was on the pathway before receiving an Autism Spectrum Condition (ASC) Diagnostic Decision?

■ How long CYP was on the pathway before receiving an Autism Spectrum Condition (ASC) Diagnostic Decision?



For those with a diagnosis, only 58 from 173 CYP were diagnosed post 2021.

Those still waiting for diagnosis - 14 have been waiting 12-18 months (mainly Paediatric Pathway); 20 have been waiting 2-3 years (mainly CAMHS Pathway); 7 have been waiting 3-4 years (mainly Paediatric Pathway) 1 has been waiting for 5 years, 1 for 6 years and 2 for 7 years (all paediatric pathway) Others are unsure.

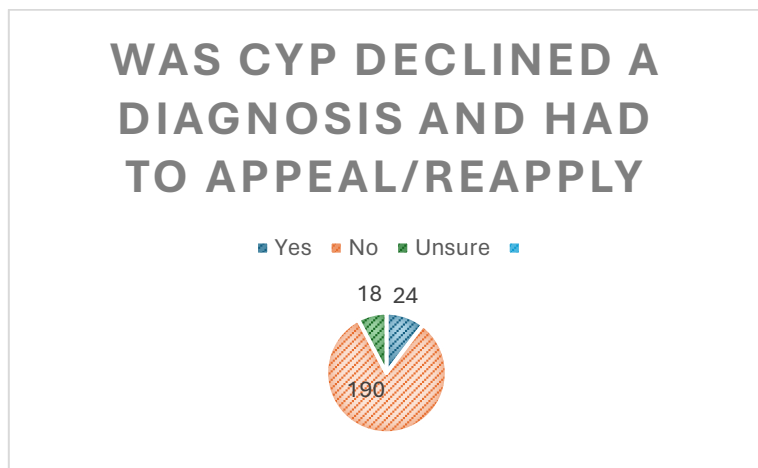


The families that used a Private Pathway did so because:

- NHS waiting lists were too long and that there was an element of parent blaming.
- Adoption Support Fund paid for the Private Diagnosis.

However, only 1 of these families reported that the private diagnosis was accepted by professionals – Families were told that their Private Diagnosis didn't fit criteria and were made to go through the NHS process anyway (To which an ASC diagnosis was received); 1 family specified that CAMHS wouldn't accept the private diagnosis, 1 family specified that LA wouldn't accept the diagnosis and 1 family specified that the Under 5 team specified that Wolverhampton wouldn't accept the diagnosis. 1 of the families stated that CAMHS had to ratify the private diagnosis.

Only 1 family stated they were advised on "The right to choose" **There is little knowledge of right to choose it was only as a friend told me that a was able To go through that pathway. I then had issues as they kept referring to the wrong right to choose provider"**.



From this 24 CYP declined at 1st Panel, 20 of these CYP received an ASC diagnosis at a further panel. (15 on 2nd panel and 5 on 3rd panel).

HOW EASY WAS IT TO ACCESS THE PATHWAY FOR AN AUTISM SPECTRUM CONDITION DIAGNOSIS?

On a scale of 1-10 how easy was it to access the pathway to be considered for an Autism Spectrum Condition Diagnosis (1 being very difficult and 10 being very easy) **4.31 average**



HOW EASY WAS THE WHOLE PROCESS OF GETTING A DIAGNOSIS OF AUTISM SPECTRUM CONDITION?

On a scale of 1-10 how easy was the whole process of getting a diagnosis of Autism Spectrum Condition (1 being very difficult and 10 being very easy) **4.18 average**



When broken down into individual Pathways –
Under 5s average for ease of process is 8.184
CAMHS average for ease of access is 3.43
Paediatric average for ease of access is 4.15

SATISFACTION RATINGS FOR SUPPORT FOR PRE/DURING AND POST DIAGNOSIS SUPPORT.

On a scale of 1-10 please rate the **Pre - Diagnosis** support (1 being Terrible and 10 being Excellent)

3.78 average



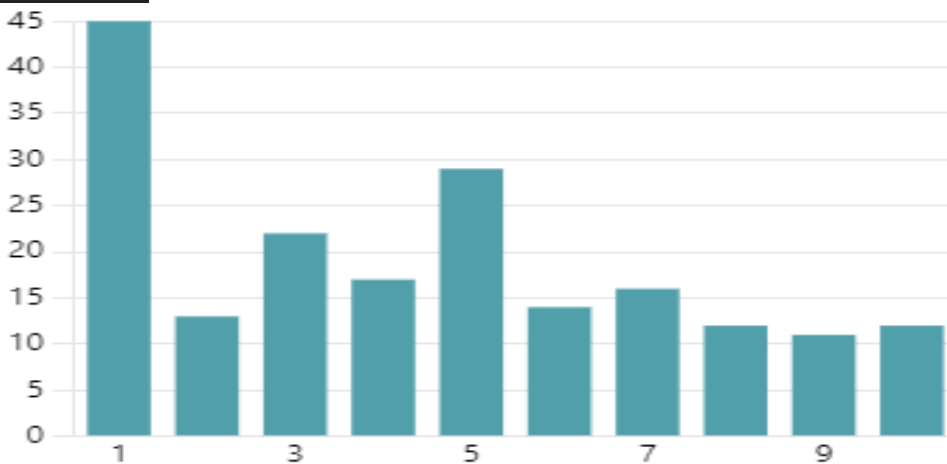
On a scale of 1-10 please rate the **During Process Support** (1 being Terrible and 10 being Excellent)

4.22 average



On a scale of 1-10 please rate the **Post- Diagnosis Support** (1 being Terrible and 10 being Excellent)

4.51 average



126 Families stated they received NO support whilst on the ASC pathway, 24 were unsure and 79 Families stated they did receive support whilst on the ASC Pathway.

What is clear from these responses is that those families that accessed the pathway through Early Years have received a very different support package to those outside of Early Years. Mention is given to several workers in particular, that a **KeyWorker** is fundamental in offering support to families and helping them navigate the varying systems, including therapy, behavioural and help in school. Keyworkers in SNEYS work with schools and therapists as well as Educational Psychology to ensure the process is smooth.

“Key worker with SNEYS. If we needed it, she made it happen. Very different experience to our previous son who was on the over 5 pathway. That took 5 years. What a joke that was too”.

Outside of SNEYS for families whose children enter via a different pathway- School can also be a source of support, but it seems this is generally once Outreach has been involved. Reflexions were also mentioned by 1 family.

“We were assigned a caseworker eventually after getting outreach involved. The caseworker was very supportive but the whole process took 7 years!”

“Support was a 10 until they went to school. Teachers do their best but they are not keyworkers. Mainstream teachers are even less qualified to act in place of a properly trained and knowledgeable keyworker”.

The Gem Centre has been mentioned as a source of support for 22 families only – 9 of which via Paediatricians, 8 via CAMHS and other mentions to Inspire, Autism Pathway and an Autism Course provided by the Gem.

Unfortunately, 25 parents took this opportunity to advise no support from services, that leaflets they were sent were not helpful and that some therapy provided wasn't appropriate and left the CYP/Family feeling more isolated. Others took the opportunity to advise they found online support groups useful, websites and their own research.

Others advise that Community Groups and Support Groups in Wolverhampton are a great source of support. This shows that Peer support offering families the opportunity to do things together with those in similar situations is a great resource for families.

“School have been good. Outreach parent workshops. Community groups like Voice 4 parents, Hugglepets and Sassy Sensory putting on support groups/holiday activities etc. “

Only 66 families stated they received regular calls and communication from a keyworker whilst they were on an ASC Pathway, 14 were unsure and 149 received no communication at all.

51 Families stated they received support after diagnosis, 87 stated they received no support, and for 86 families this is currently not applicable, either because they are still waiting for an ASC panel decision or within an appeal process, remaining families were a mix of maybe and unsure (which to a degree indicates that if they did receive support, it wasn't memorable). Again, Responses were mirrored when asked about support offered after diagnosis, those families that accessed the pathway through Early Years have received a very different support package to those outside of Early Years with more families feeling that they got access to more support/voluntary and charitable groups once a diagnosis was received. Those who already had a Keyworker or support from SNEYS continued with that support.

Some families accessed Outreach, and courses ran by Outreach and Tettenhall Wood School including Early Bird and Teen Life. However, these are described as a bit problematic for those families that work as times/dates of courses weren't always accessible to working Parent Carers.

Worryingly,

- 8 Parent Carers stated that it was only once their CYP received a diagnosis they actually received support from school/ Keyworkers and Educational Psychology to access an EHCP, Support in School and also support in getting their CYP into a specialist school setting.
- 6 Parent Carers stated that it was only once their CYP received a diagnosis they actually received help from CAMHS with sleeping medication and counselling.
- 9 Parent Carers stated that it was only once their CYP received a diagnosis they received a Pack/Leaflets or further information regarding Autism and support available to them

“The private Educational Psychologist I used to be amazing and so helpful and supportive. But prior to this I did not feel supported by The Gem Centre”

“Saw a paediatrician by mistake. Was part of the autism assessment but he was already diagnosed privately but she accepted the diagnosis. D as he was helpful and gave me a list of support groups and self-information places”.

Only 12 families from 251 responses felt that there is enough support for families with an autistic CYP, numerous things that could help support families or would have better-supported families:

Communication – A better explanation of the ASC Pathway, with regular contact whilst on the pathway that updates on where families are in the process, how long they will be waiting, what’s actually happening and what will be done next. Families felt it would be good to have a contact name and a number of a practitioner that they could ask questions of as/when needed as well as well as where to get help during and post-diagnosis. A keyworker would help with this aspect as families report feeling forgotten and not able to navigate the complexity of Health, Education and Care systems, someone to simply “check in” as well as being able to explain test results/ reports that have been written and what this means for CYP and their families.

This should also include information on what Autism is and what it means, How to get what your CYP needs and information on obtaining a private diagnosis (and the implications of this). Further information about financial support including Grants/Funding and DLA, and Impact on Welfare benefits was also requested as a form of support.

“regular updates on what's actually happening while I'm still awaiting and what waiting times I am looking at, took over 35 weeks for a CAMHS to then be told yes she has several signs and with school backing your now on another list to wait to see a paediatric for a full diagnosis although GP/ school staff and nurse and audiologist and other members from the gem centre have stated she had ADHD just need to wait for another person to confirm.”

“After 5, keyworkers are still a necessity and not school teacher unless a specific role. Support from services continuing especially if in a special school not used as an excuse to discharge. Staff are teachers, not therapists. Parents must be taught their rights and what a good EHCP should include”.

Workshops/Classes/Training – Support is needed on how best to support an Autistic CYP and families feel they should be given various options of theoretical/research materials, practical workshops and therapy sessions (Individual for the CYP, Individual for Parent Carer/ Siblings and/or Group therapy sessions as appropriate. Practical workshops and support identified include;

- Emotional Support /SEMH Support and how to help a CYP when emotionally dysregulated including coping with anxiety, and suicidal thoughts and helping CYP to understand themselves as well as information around Parental Mental Health ;
- Behavioural Support/ practical tips and skills for all, including explaining and helping with meltdowns and managing crisis/ intervention support and strategies;
- Tips on adapting Parenting Techniques and Strategies that can help

- OT/ SALT Therapies to help with Sensory Processing Disorder, Toileting/Incontinence, Eating/sleeping etc
- Communication Equipment / Communication boards/ how to facilitate communication between families (V4P did run a series of sessions on this that families found really useful).
- Sensory Equipment to be on loan as this is expensive and not accessible for all families, especially in the early stages of trying to find strategies/equipment that might help;
- Practical help on helping CYP to be independent and able to best prepare for adulthood to include practical support with Personal Care/ Finances/ Travel training/ transition services/decision-making skills and confidence building.

“Help with coping with moving to adulthood and what comes after school, and finances”.

“Parents and carers just require direction from the professionals When the support is given, sometimes it can be too late as family relationships break down and can cause an impact on their lives”.

“I think more understanding of the condition, workshops and strategies”.

Joint Working/Understanding – What is clear through qualitative responses to the survey is that throughout the entire process, there needs to be a better working relationship between ALL involved in the CYP Care, including Education (School/ Outreach/ Educational Psychology) Care (CAMHS/ Therapy Services, School Nurses, GP and Hospital) and Social Care (Respite/Carers Assessment and Carers Team for Carers Conversation).

Just under half (112 families) stated they felt supported by Education staff but 90 families felt that the formal ASC diagnosis was required to access school support.

“It’s a lonely process, very long and very stressful for all. My child does not know who to be so copies a lot of people. Had a real fight for mainstream support and had a battle with LA to get better provision. She had to get to crisis point with self-harm and anxiety-related tics before anyone took us seriously. Parents are not believed by professionals”.

Only 13 CYP from 132 of 14+years with an ASC Diagnosis has been offered a Health Check from their GP. Some families mentioned that they didn’t realise CYP was eligible but others stated that when they asked at their GP surgery the surgery refused to offer the Health Check and some practices were not aware of Annual Health Checks, Parent Carers feel that there is an element of gatekeeping by receptionists and that ASC isn’t an automatic diagnosis to receive the check.

“It was a tick box exercise and we were only offered a DNACPR – it was during COVID and they labelled my son as having a Learning Disability Incorrectly – not offered one or had one since.”

“GP’s need more awareness and training. The health visiting team need to do referrals when they promise as this delayed us as they didn’t send it off so had to wait until she was 5. Was meant to be done at 2. The GP was unable to refer until she turned 5.”

Triangulation of these services are missing and when Parent Carers were asked if there was anything further, they wanted to tell us about support, most responses included an element of this being missing.

As with all V4P Surveys recently, Parents mentioned that there is no thought from services on the impact having a diagnosed/suspected Autistic CYP has on the family and when discussing support, many stated they needed help with their own mental health and can be made to feel like they are wrong or at fault as well as not being believed. Support is hit and miss and easily denied as a CYP might be seen as more capable and it is only once a CYP hits an absolute Crisis point that any form of support is offered.

There needs to be a joined-up approach to what support is open to Parent Carers – this should be extended to Siblings. Parents do not feel heard and feel they are the communication link between services.

“It has been a constant struggle over many years. Autism drains parents of energy and time just due to the extra daily support needs of the child. From that depleted state we then have to fight for every bit of external support. This situation has not improved over the years, it has worsened”.

“It has been relentless and respite would have helped but I was declined. Support for son understanding diagnosis. Support with school refusal”.

“His diagnosis meant academically capable so was refused all support. Consequence he ended up with poor mental health and anxiety resulting in suicide attempts”.

“there needs to be more contact between CAHMS and the LA regarding children and their diagnosis (with permission from parents) it always seems that we are chasing the LA to sort out information that they could contact CAMHS for directly - Guidance about what to ask for in school as school was clueless and wanted me to guide them”.

“There isn't a great deal of support for children or parents whilst awaiting diagnosis ,They don't ever meet the child the diagnosis is based purely on paperwork only and even then they will blame anything else other than give a diagnosis this has been a constant battle of 11 yrs. for my son despite every male in my family being autistic and every professional who meets him says he's autistic yet the panel who have never met my son will blame anything other than autism firstly he was too young bring him back when he's older if he still has traits we will diagnose him so I brought him back older and with more traits and then they blamed covid for his traits so he's currently awaiting yet again another panel hopefully third time lucky I get little to no support for my son”.

“Education staff need to listen to parents more. The gas lighting and parent blaming needs to stop. Dismissing parents' concerns is damaging to children's mental health and my son has trauma because of the lack of support despite my begging for help. The only time we got any support and things started happening was when my son was no longer able to attend school. Had he been supported and had I been listened to, he would not have missed 14 months of education whilst I fought for him to be in the correct setting. Waiting lists for Camhs and the panel are too long”.

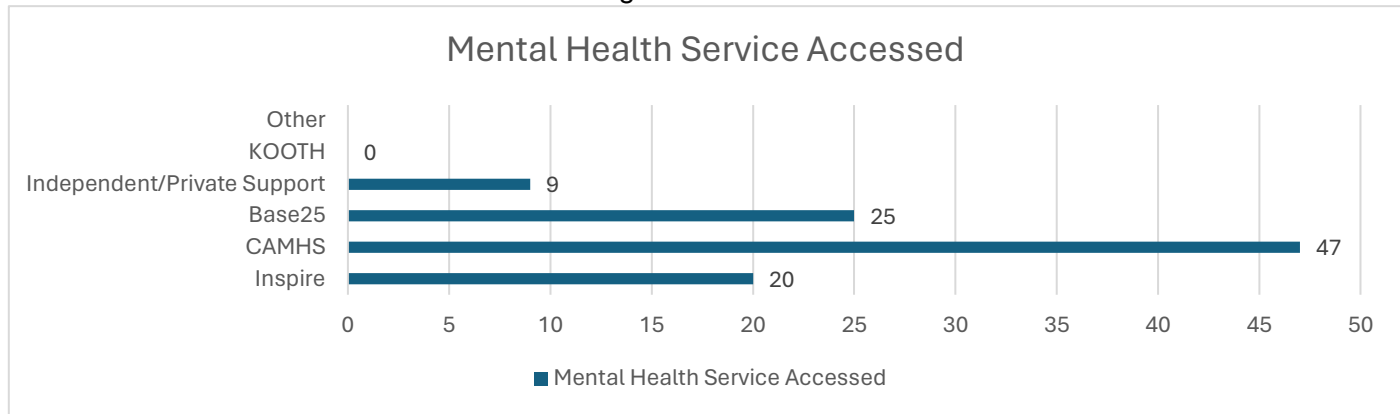
Leisure/Respite – Families report that there is a greater need for accessible leisure and in particular Respite Care for them and their CYP – This has been brought up in many reports via V4P over the last few years – Access to any form of respite is difficult and providers aren't adequately trained to provide what is needed to help support Autistic CYP in the main. CYP are isolated from society and struggle to integrate. Further understanding and promotion of Personal Budgets would help this.

“There are no respite centres or local residential settings that are good. When your child is bigger and two to one no one wants to take them so the ones who need support most are left. There needs to be more facilities locally for the more challenging children”

“To have more social occasions my child/teenager can go to, he wants to isolate himself (he wears a hoodie and Crocs with social occasions he has been bullied because of his dress) loves V4P as he can be himself, I think V4P has done some fantastic social occasions for the children but quickly get booked up and it would be lovely if they had the funding to do more Thank you so much Voice for Parents”

ASC and Mental health Services

102 CYP have either accessed or are accessing Mental Health Services



From these, 71 families felt that their CYP actually needed to access Mental Health services. Following this we asked how Parent Carers felt the diagnostic process had impacted their CYP Mental Health. Again, those CYP that were diagnosed quite early all stated that they felt that there was no impact at all on their CYP as they were too young to understand and/or knew no difference so had a general acceptance of themselves growing up.

106 families (from 173 that responded) stated that the process had a negative impact on their CYPs mental Health. They explained that their CYPs struggled to understand themselves and their emotions, struggled to feel safe and settled and had quite extreme Social Anxiety. It is felt that due to lack of support whilst on Pathways, Mental Health deteriorates quickly for the CYP whilst waiting for a diagnosis and that this had a massive impact especially socially and at school which furthered the feelings of isolation.

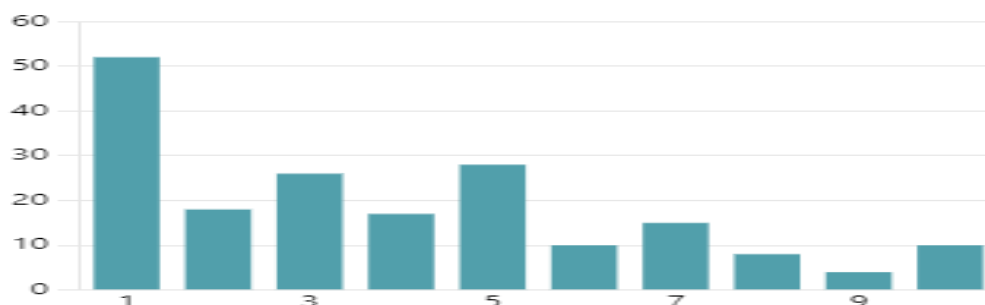
“Awful she is struggling so much we can't get help just told to wait don't know what service to go to she's questioning life and all doors fully shut”

“My son has a bright cheery outlook on life and tries not to let things get him down but he often feels left out and asks why he gets singled out & picked on for being different”

“It impacted my child in a significant manner that affected his access to the right school to support his needs. He was stuck in a tiny room with a TA every day as that mainstream primary didn't know how else to support him. He never got to be in the classroom to mix with other pupils. This affected him socially and emotionally. He ended up regressing in speech and was selectively mute for a year”.

“It has affected my daughter massively regarding school in which I went down the route of homeschooling for 3 years. I got no support from school what so ever. If my daughter would have had a diagnosis then maybe she would have had the help she deserved and not feel lonely in an education setting where she doesn't understand when other children are making fun of her and teachers not understanding her needs, even when told”.

If applicable, how suitable do you think mental health services are for CYP with autism? (1 being awful and 10 being excellent) – **3.93 Average**



HOW CAN MENTAL HEALTH SERVICES WORK BETTER

Parent Carers feel that Communication and Training on ASC for Mental Health Providers. is key. It is felt that there is no real continuity of care and that if there was a true understanding in general around Autism, professionals would be aware that 1 style of offering support isn't the answer and that a much more collaborative approach between professionals, CYP and families is required. Many Parent Carers felt that if they were just listened to or included in sessions or feedback (particularly being included in regards to BASE 25) that the Therapies would be much more productive, less damaging for a CYP and a better use of time. It is felt that an offer of 6 sessions is simply not enough for a CYP with ASC to feel settled with professionals and be able to be open to the therapy offered. It is felt that most adjustments needed should be classed as Reasonable Adjustment – One Size doesn't fit all.

“Spend time getting to know the child. Having the same workers and not changing them all the time”.

“My son is traumatised due to the lack of support and what they have put him through. He is now a shadow of his former self. Even attending appointments is traumatising for him now”.

“Camhs is reactive instead of proactive and I strongly believe this is why they are unable to keep up. Too many children have been allowed to get to crisis point and the services aren't there for them”

This is particularly problematic because access to the services isn't easy in the first place and waiting lists are long. There is appetite from many, for Family Sessions before trying a more tailored approach – Parent Carers suggest that it is only by knowing a CYP can mental Health support do what it needs to in supporting families.

“My daughter is 9 years old and DELIBERATELY OVERDOSED due to being ignored by professionals and still hasn't received any support”.

“MHS do not know how to support a child in real life. They are teaching standard strategies that young people just won't use day to day. Young people are peer led, device reliant and services are outdated.”

“A 6-week block at base 25 is not helpful. It takes that long to start to build a relationship and trust. And then the block is over”.

“I would like someone to call and let me know what is happening, they took her base 25 counselling from her without reason when it was helping. they give help for 8 sessions then because the counsellor couldn't take her attitude/personality she said she didn't want to see her again. Great help that.- Who do I contact?”

Parent Carers do not believe all services for Mental Health are clear on their offer and that rather than “squabbling in house over who does what” and passing families between services, there needs to be a proper clarity on if CAMHS really can't see a CYP “because they are Autistic (as reported by far too many parents in this survey), that it should be decided “WHO CAN?” – and that this has to be looked at seriously by commissioning as services like Kooth and some degree lower level counselling services are also not responding to the need for many Autistic CYP.

“All added up to suicidal thoughts and depression. Camhs refused support because he is autistic”

“My child's mental health has been severely affected by the process as he now has PTSD based around school attendance. We have recently been told that there are no therapy services that CAMHS can offer him”

“Needs to be a pathway so young people don't get excluded automatically by camhs once they are diagnosed as Autistic.”

The crisis line / team doesn't appear to be effective in a way that Parent Carers feel is supportive and useful and several Parent Carers feel that the entire system including pathway and triage by Mental Health Services needs overhauling – “get it right for Autism, it will be right for a bigger majority of SEND CYP”. Again, this was a major part of feedback in V4P Annual Report 2023/23 and 12 months on – nothing seems to have progressed.

“Contacted the crisis line when my son was saying he wanted to kill himself. 3 days to get a response. How is that of any use? I don't want to take him to A&E, that's more trauma in itself”.

“Have an actual crisis team. My family were in crisis and the most they could offer me was an appointment that was 3 weeks away. That's after my daughter wasn't sleeping at night and having meltdowns 24/7”

“Therapies for autistic children. My son has been under the psychiatrist for 2 years and has not received a minute of therapy, only medication. Better access and support from the crisis team. For e.g. I called the crisis line because my son was self-harming and I was told to “speak to him in a calm voice” and when I took him to A&E the crisis team were unavailable as they only work in the hospital between 8am and 8pm. The adult crisis team is 24 hour and this should be the same for children. Most of my sons worst episodes have been at night”.

9 CYP in the survey have been admitted as an inpatient due to Mental Health, all 9 were allocated a Keyworker but only 2 have stated that the CETR process was followed.

Understanding the importance and Impact... Parent Carer Comments on what happens when its not right

“It has taken 10 years to get my son on the pathway. He has been told by several different people along his journey that he is showing signs of ASC but because of his other diagnosis' he hasn't clearly ticked the correct boxes due to overlap of conditions, this has prevented him from getting the help & support needed”

“Any form of help..we had nothing I had to give up my career...she was at burnout and had been masking for many years we now know..it was picked up from her diabetes support worker following a diagnosis of Type 1 diabetes. We had no support from school. I was refused support from Early Help and struggled with her mental health .. I had to get a private assessment for her, an EHCP has never been done despite her attending the Orchard Centre, I had no help to get her to and from despite being told school was paying for taxis which never happened..despite being told I would be sorted..I'm now in debt and we've spent since September with her struggling to settle in post 16 education so now I'm really struggling financially. I don't have any family who can provide respite and her dad isn't on the scene in any capacity to provide any level of care.”

“We had no support during the very long wait for a diagnosis. The treatment by his secondary school was disgraceful. No support whatsoever. There should have been support in school from the moment ASC was considered. There was no support after diagnosis. Just a diagnosis letter and told to self-refer to base 25. It took the whole 5 years of secondary school to get a diagnosis. My sons actually came through in his first year of college. I am shocked and appalled at the total lack of any autism resources in Wolverhampton.”

“It's a lonely process, very long and very stressful for all. My child does not know who to be so copies a lot of people. Had a real fight for support in mainstream and had a battle with LA to get better provision. She had to get to crisis point with self-harm and anxiety related tics before anyone took us seriously. Parents are not believed by professionals”

“I waited almost 4 years for it to go to panel and they declined and said it was down to trauma then covid came and I had no support at all on how to appeal or what to do was told numerous of times I would have a call back which I didn't receive then to appeal the decision I had to have evidence from a professional if

they disagreed with the decision which due to covid I was unable to get any help with I am now back waiting to be told my daughter needs therapy before they can put her on the waiting list to go to panel in which there is also a waiting list for therapy my daughters journey started at the age of 7 she is 16 this year!"

"We have all become extremely withdrawn. We constantly have to decline invitations or change plans and this can make you unpopular with society when they do not understand the impact our daughter and her conditions have on our life. We feel isolated and physically shattered. Our finances are in a terrible state always replacing things that aren't auditable or trying to have the right food options available. We feel like we only live a small portion of the life that we had before."

"It was a steep learning curve and we had no idea about anything. How to support them, what help existed or where to find information. It was very lonely and has affected every part of our lives, from every day things to family holidays and activities"

"We are stressed and worried most of the time, it has been very frustrating not being listened to by GP's and not knowing what is going on, what will happen and what the actual pathway is! I still don't know what 'the pathway' is! At Our paediatrician appointment the doctor said "I'm sending him straight to panel for autism" she then gave me a very blurry printed leaflet with 'autism spectrum condition information' on which said 'your child has been referred to the autism spectrum condition pathway, this may take a while to be seen by panel' and that was it. Apart from the same thing in multiple languages. I had to ask another parent what 'panel' means and I'm assuming the 'pathway' just means the waiting list for it. It is very difficult to manage my sons needs when no one can 'see' physical issues and doesn't really listen to what I say about him. School haven't given him any support since nursery until now. He struggles with anger, movement, strength, understanding, speech and more and yet he is been made out to be 'naughty' instead and punished which is very wrong. I have never felt so much stress and upset and frustration, our son is adopted and expected to have more support and info because of this, but we have had none. It has impacted my own depression and anxiety making it worse, I struggle to cope with basic things some days, I never feel rested and always feel on edge and tense. Adoption is hard enough. My mood and ability (or lack of) impacts my other children and my relationship with my husband, being stressed and agitated bit also upset and sad."

1 Thing that is Working well.....

When asked what one thing is working well for their Autistic CYP – Parent Carers have explained that family and their own relationship with their CYP works well as they can best understand how to support their family and put the appropriate support in place, providing exactly what their CYP needs.

When support is in place, CYP can understand and accept themselves and this in turn helps them all round, socially, emotionally and allows them to build in confidence and independence.

"Being able to talk to us about anything that's on his mind and knowing we are his safe space."

"He's informed of his diagnosis and he understands himself better to why he acts and feels the way he does and why he thinks the way he does"

"Knowing that when she has a meltdown, after her physically outbursts and temper she will be able to calmly sit down and talk to either parents or draw with us, or do something with the family to ease her hurting without fear or punishments."

"I don't feel that my son has changed much but I feel that learning about Autism has helped me to be a better parent so we don't have as many meltdowns, shutdowns, stimming and I can deal with it much better"

It is also clear that when professional services are properly in place and understand a CYP, the whole experience in school is better and engaging. When schools work with Parent Carers to support needs, things improve for all. When support is offered, it makes a massive difference to families lives.

“I have now given him ear defenders and picture exchange cards to use in school, the ear defenders seem to be working and helping him to stay calmer and not as overwhelmed by people and noise. Also, he has a new senco at school who seems to be actually doing things to help! Finally!”

“The provision he currently attends is brilliant for his needs. The school recognises that my child cannot cope in a classroom (within the SEND unit) so has been put into a very small group of 4 other children and gets educated that way (The Orchard Centre-Lawnswood Campus)”

“Her feeling heard by professionals not always being challenged and having the understanding from school. Talking and embracing them being unique as parents.”

“the communication board provided by Voice4 Parents - this has helped my son and family . Support groups like V4P helps us a lot with info etc”

“All support received in any fashion is received with thanks and gratitude that someone cares enough to make the effort to make a difference”.

“Outreach worker support.. without her support and understanding, I don't know what I would do!”

“Voice4parents is the only service that has listened to my voice, I feel supported by them and I know I can turn to them for advice and guidance.”

“Having a great SNEYS key worker”

“started a specialist in September and is thriving in school. The support within the school has made a huge difference”.

RECOMMENDATIONS

- Keyworker to support the entire process from referral – like a TAC Process – where the family are supported emotionally, and practically, given the correct information at the correct time and kept informed regularly in a way they can understand
- If a diagnosis isn't appropriate – support still needs to be offered for issues displayed/reported so that families aren't left with nothing. This needs to be followed up to make sure support is working for that individual and their family
- Need to address that Parent Carers have the “right to choose” in regards to diagnostic pathway i.e., Private pathway options. Better information regarding pathways in an easy read format
- When working on communication, a tool needs to be in place that informs Parent Carers about the Diagnosis process, where they are in that process, realistic timescales and regular check-ins. Maybe consider a form of Accessible Portal where families can log in to see these details for themselves.
- If giving Leaflets/ Useful Information Guide – this needs to be given to ALL families in a timely manner, results from the Survey show it's really hit and miss what information is given to families and the approach isn't consistent. Understanding of Autism is also required across all professionals.
- Support within school/ Access to EHCP or Specialist Educational Provision SHOULD NOT be based upon a diagnosis, so further work around the Graduated Response is required to ensure the Process IS NOT reliant on diagnosis.
- Support via issuing Medication or accessing therapy/ workshops etc shouldn't be reliant on diagnosis and would be best offered at the earliest stage to help with understanding of traits/behaviours/problems rather than letting them continue and develop.
- To consider how to work better with GP Practices to ensure Annual Health Checks are carried out – This would provide an element of support within itself from a health perspective.

- In line with data for GPs to provide Annual Health checks – GPs need to correlate this data to also offer Parent Carers the same Health Check as it's reported this doesn't happen at present - Again providing an element of support.
- Requirement for Training GPs on all things ASC – Explaining Pathways, How to refer, Support that is on offer to Families etc.
- To consider how to develop a better support package with Other professionals including Education, Social Care and Carers Support to better understand the needs of Autistic CYP and their families. This needs to include training on ASC along with reasonable adjustments/practical suggestions on how to implement change in class as well as guidance on listening to a parent carer concern rather than “Parent Blaming” – This could initially be something to discover within the Local PINS Projects.
- When a family is known to Education and/or Health Services as having/potentially having a CYP with SEND, a referral to the Carers Team is needed and a Carers Conversation should always be carried out. This should also be considered for Siblings as Young Carers – A whole family approach.
- To consider how to utilise and promote Health Personal Budgets / Personal Budgets to particularly help with isolation and Social Needs.
- RESPITE CARE provision and activities are lacking. Actively need to work with Social Care and Leisure providers / Joint Commissioning plans on how to be more inclusive for CYP with ASC and that provision is adequate.
- To consider how to develop relationships and help fund Community/Voluntary Groups and Charities/ Leisure Providers (including HAF) to understand the needs of Autistic CYP to help them become valuable members of society and to be able to access activities/social groups.
- Better methods of streamlining ASC Pathway/ Diagnosis timeline whilst increasing access to CAMHS/Mental Health Therapy for CYP with Autism.
- Access to Mental Health Services needs to be made easier and professionals require better training in Autism. The introduction of more family sessions before trying a more tailored 1:1 approach.
- If CAMHS are not the correct service for CYP with Autism – commissioning to fund an appropriate service.
- Crisis Line/ Crisis Team to have a clearer offer and timelier service that includes a 24-hour offer and not an 8-8 offer. Consider better accessibility via a chatline to talk to someone/email/text/app for those CYP who find it difficult to talk.
- A Keyworker that is specifically for the CYP to help navigate ALL transitions (life/education/care) and ensure choices are supported with achievable goals.
- Recommendations in PFA report 2024 are to be read in conjunction with this report.
- Recommendations in V4P Annual Report 2022/23 are to be read in conjunction with this report.
- EHCP's need to be considered once an Autism diagnosis has been made that the EHCP reflects the needs, outcomes and provisions needed...so the diagnosis does not become a “so what?” This also needs to be considered at Annual reviews especially how Autism can effect the CYP social care needs in particular. Social care needs to reflect this more widely in EHCP's. We need a process embedded where this is flagged with social care so needs assessments take place as a priority
- Pre, during and post-diagnosis support needs to be addressed again. There appears to be no consistent approach as families report varying experiences. This support needs to be proactive and followed up to make sure that it is having a positive impact. Ideas on what this support looks like and what Parent Carers feel would be most useful is clearly documented in the main body of the report.