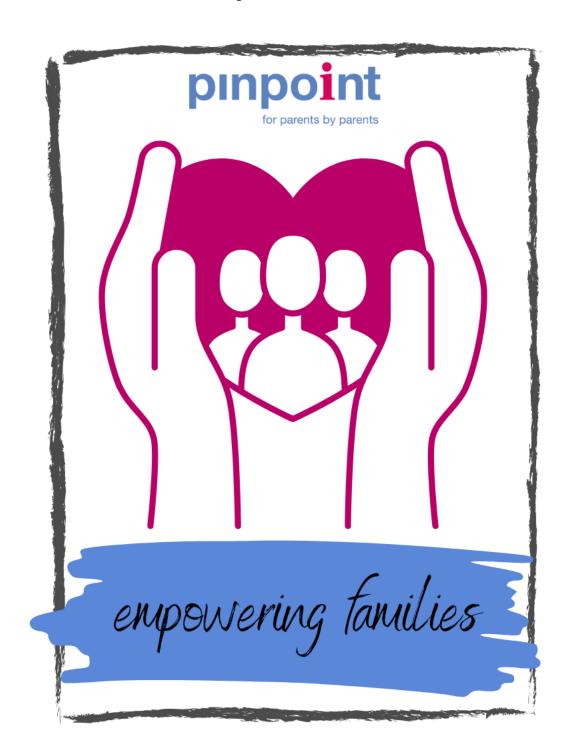
Pinpoint's Annual Survey Report April 2025



Summary Headlines

There remains a low uptake of our annual survey with only 49 responses despite offering 2 prizes as incentives to take part. There remains a low levels of engagement from professionals to advertise the survey. We do know that the Ofsted ASEND Inspection had an exceptionally high uptake of parental responses and our survey results still largely mirror those heard by Ofsted. We offer regular opportunities throughout the year for parents and carers to tell us what is working and not working and so, perhaps an annual survey is not a high priority for parents and carers who have already had their voices heard in other ways. We also hear that parents are frustrated that although they offer their voice regularly, they do not recognise any tangible change to on the ground services that results.

Of those who did respond, we mighty characterise approximately 1/2 to 2/3 as being unhappy with their experiences which is an improvement from the mid year survey in December 2024. There are concerns about the messages we are hearing from those who do not report satisfaction with their experiences of the SEND system in Cambridgeshire. The free text comments demonstrate high levels of dissatisfaction across the board but it is important to embed this in the context that as a forum we are more likely to hear from those for whom things are not working smoothly.

We continue to hear predominantly from parents and carers of school age children and a few whose children are in the early years and secondary school age brackets. This supports the work that we know Cambridgeshire are keen to achieve to identify needs of children and young people earlier and to get them the right support at the right time. However, it is concerning that even those who are early on their journey appear to be struggling to get the needs of their children met. Those who have young people in the Preparing for Adulthood stages are overwhelmingly negative about their experiences. This sits within the context that the majority of parents and carers that we hear from have young people who attend mainstream settings and we know that Preparing for Adulthood is not working well for that cohort.

The survey results offer an opportunity to look at what quick wins can be taken to support parental resilience and to help children and young people to get their needs met earlier in their journey. We know that those in the system are working hard to address these concerns which will not be a surprise to any of them. We also know that there are systemic flaws which are being exacerbated by an extreme lack of capacity.

The issues raised by the survey have already been raised by Pinpoint over the last 12 months and are well known to the Local Authority and Health – there are no surprises and the areas identified by Pinpoint and this survey have been agreed as priorities: compliance, Preparing for Adulthood/transitions and improving SEN Support.

Key messages

Free text commentary predominantly reflects frustrations and disappointments – it is rare that we get positive feedback from this section of the survey. The main themes here are a lack of available information, SAT team capacity and communication, CAMHS waiting times and lack of support, Emotionally Based School Non-Attendance, parent carers feeling isolated and blamed, and low resilience of parent carers.

Statutory Assessment team communication and compliance with timescales continue to be a concern with parent carers using words such as battle and fight.

Preparing for Adulthood continues to cause concern in terms of those cliff edge finishes for young people.

Parent carers are concerned about the siloed working of professionals and systems meaning that they regularly have to explain their situation repeatedly.

There is cause for concern about a lack of social care support for children and young people with SEND.

Waiting times for Education Health and Care Needs Assessments, diagnostic assessments and mental health support are too long and there is a lack of support for those who are waiting, often without communication about how long the wait might be.

Many parent carers are seeking private support but this creates a divide for those who have the means to be able to do this, and those who do not. Those who get a private diagnosis then face difficulties when this is deemed to need to be ratified before further help can be given.

Parental resilience is exceptionally low with parents talking about burnout in themselves as well as their children and young people. This raises concerns about their ability to be able to continue in their caring role and the additional pressure that this has the potential to add to an already struggling system.

Review by questions

• Parental confidence about their engagement has increased since December 2024, however 43% of parents still state that they were not adequately involved and 4% state they were not asked for their views at all, even in statutory processes.

94% of the parent carers who responded are confident that they do understand their child's needs well. However, approximately half of parent carers state that they have not been given any help to understand their child's needs.

Alarmingly, over half of parent carers that responded do not feel that professionals working with their child or young person have a good understanding of their needs.

Worryingly, 94% of those responding told us that it is challenging to get their child or young person's needs met.

- Far fewer compared to previous surveys have told us that they have had to rely on legal means in order to get needs met.
 - More than half of those we heard from have an Education, Health and Care Plan in place for their child or young person suggesting that things are difficult for families even with this high level of support in place.
- The legal requirements are either poorly understood and inconsistently implemented or are unknown and non-compliant in some cases.

just over 1/4 report that they had no involvement in SEND processes and more than hald are not satisfied with the ongoing monitoring and assessment of their children's needs.

 There remains work to be done to ensure all services are considered to perform well and work together around the family.

Nearly 2/3 of parent carers are dissatisfied with how well services work together.

Around half of the respondents told us that they are unhappy with the service they receive from education, with around half of respondents being unhappy with the service that they receive from health. Nearly 2/3 of respondents were negative about the support that they receive from social care.

42% of those we heard from told us that their child is only accessing education part time or not at all.

• 43% of people we heard from have had a positive experience with searching for information on the SEND information hub (Local Offer) however, 12% of people told us that they have never heard of it.

3/4 of respondents told us that it is not easy to get information that they need about their child's needs.

- 61% of respondents told us that their children and young people do not feel included in out of school activities with concerns such as a lack of variety of clubs outside of sporting activities and a lack of appropriate support in clubs being cited.
- Preparing for Adulthood remains a priority it's not universally known by the target group and what is known does not fully reflect an offer beyond that of education.

68 % of those we heard from reported a negative experience at age 14+ with 32% having not heard of Preparing for Adulthood. 3/4 of those we heard from told us that their experience at 18+ was negative and they were not well informed or not informed at all.

There does seem to be a better split of information across the Preparing for Adulthood areas than in previous years although numbers of respondent telling us that they had information about any area were low.

Only 1/4 of respondents told us that their experience of social care at age 18+ was positive.

Question responses

Please tell us how well your views were taken into account to support your child/young person when your child/young person's needs were identified?



Please rate the support you have received from education services

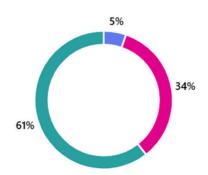


Please rate the support you have received from health services



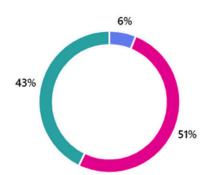
Please rate the support you have received from social services





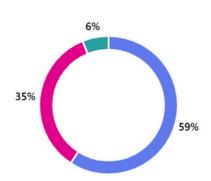
How well do you feel professionals who support your child/young person understand their identified needs?





How well do you feel you understand your child/young person's needs?





Once your child/young person's needs were identified, were you given any support to help you understand them?



As a result of identifying your child/young person's needs, are they receiving any of the following support with their education?

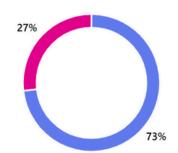


If your child/young person has ECH Plan, was the Plan issued after:



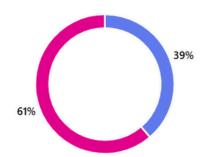
If your child/young person has SEN Support or an EHC Plan, does their education provider involve you in identifying and/or reviewing any support they receive?





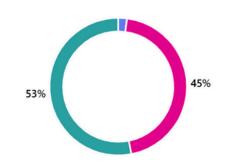
Does your child / young person feel included in out-of-school activities with their peers?



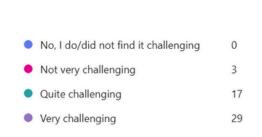


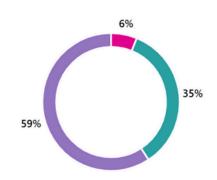
How satisfied are you with the ongoing monitoring and assessment of your child/young person's needs?





Did/do you find it challenging to ensure that your child/young person's needs are met?



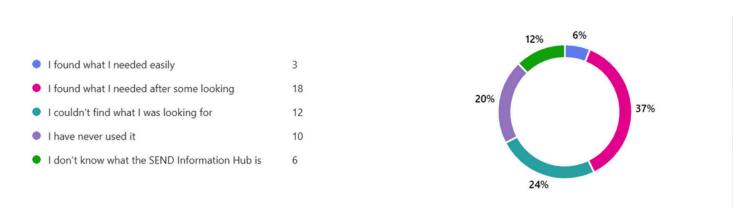




How easy do you find it to get information about what services are available and what they do?



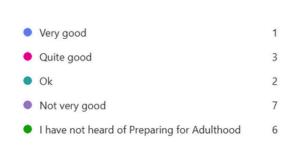
If you have used the 0-25 SEND Information Hub (Local Offer), how easy was it to navigate? Please choose the most appropriate statement.

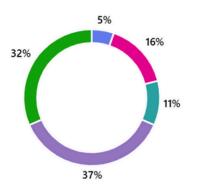


If you've used the SEND Information Hub (Local Offer), how would you rate the information?



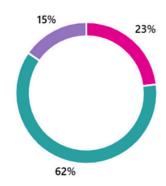
If your young person is older than 14, what has been your experience of the support for Preparing for Adulthood?





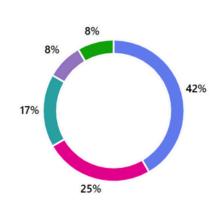
If you have a young person over 18 years old, how well-informed do you feel about how you can support them?





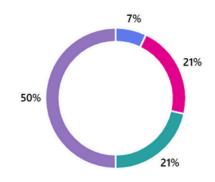
If your young person is 16 and older, have you/they received information on the following:



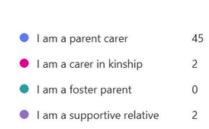


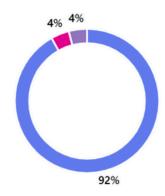
If your young person is older than 18, how well supported are they by Adult Social Care?





Which of these best describes your role?





We asked what would make a difference for your child or young person to feel more included in out of school activities

SEN help at clubs

More support in adult care legal stuff ID cards groups his own kind to make friends that are safe more support for non verbal people days out

To be included in any out of school activities people just take the mick out of his way of doing things

Has never been offered and would need a 1:1

Activities offered need to be accessible and of interest to children like my son. They're predominantly sport related or music

Do ASD people ever feel included in any group? If you were in a group of ducks would you feel included or slightly interested in watching these alien creatures? What would help you to fell more included in a group of ducks - nothing, because you are trying to mix oil and water. Silly question.

Actually having activities and venues that cater for her needs. Raised awareness with providers of such activities.

More home education groups

For this to change my child would need to change. Her transition to secondary was unsupported despite her diagnosis and my attempts to get support. Things disintegrated rapidly and the school didn't seem to know or care how to support a pupil with EMBSA, indeed they collaborated with another school in this opinion, by this time my daughter felt marginalised, different and hopeless. My elder son's experience was totally different but he had an EHCP prior to transition to the same Ofsted excellent rated secondary. This was because he had been difficult in primary school whereas my daughter was compliant and masking and we had all the problems.

In short then I don't think my daughter will recover - this happened virtually 3 years ago. However others have never apologised or accepted any responsibility and this hurts. On the plus side schools are now trying to support pupils like her more and trying to be more inclusive.

Has queried activies before and never been answered. Feels unsupported. Has no friends and gets picked on.

More activities available suitable for his needs.

Honestly, I don't know...maybe to actually be able to attend

Having clubs that meet my child's interests would help. It would also help if there were social clubs for children unable to attend school, my child would love to socialise with other children but does not have the opportunity.

No out - of - school activities at his school

He's not in school currently but when he was there were no out of school activities that he felt he could access as they were predominantly sport based and he has dyspraxia.

Hard to say but I think basic skills to try about self advocacy

More opportunity to take part in activities based around interests and needs

Having friends

My son requires 1:1 support and couldn't access any after school activities without this.

Staff that truly understand how to meet her needs (staff with neurodiverse family usually seem the best). Plenty of space around her (i.e. the opposite for feeling crowded). A table to herself (if relevant). Staff experienced in using PDA strategies, e.g. declarative language. Maximise choice in activities (e.g. in an art class, allow her to do her own thing even if the intention was for everyone to create an identical picture). Same staff every time (i.e. avoid high churn, frequent redeployments, etc.). Staff member assigned to discretely monitor and step-in to support her when necessary. Freedom to leave whenever she wants (to avoid feeling trapped). Safe place and activity (e.g. game console/YouTube) to escape to from noise and bustle to regulate when needed. Activities held elsewhere than at school (which triggers anxiety due to school-based trauma). Freedom to eat snacks from home when she wants to. Freedom to bring a transitional object (e.g. soft toy) without objections from staff. Presence of safe person (e.g. parent) for co-regulation (if safeguarding constraints allow). Full or partial reimbursement of fees if regular attendance proves impossible due to anxiety/unmet needs.

Support from mental health to lower his anxiety.

Children being taught about inclusivity and given sen child opportunities to join in more out school clubs

Sessions to deal with severe anxiety over being judged for being different

Providing individual needs and there are more adults who can support for the needs

Currently no provision in place

Some of the free text comments

Rubbish only people who've helped are pinpoint caring together Nessie and little miracles

My son is in residential setting and my worry is what happens when he's 16 as he has to leave that setting then and they want him to go into supported living. I know he will not cope with that . There is not much information out there for parents who have to put their children into residential placements . I really think there need to be some kind of parent support for this. I've had an mix experience with ssn services for my child but a positive with social services

been ok

We sent the LA a letter asking for an EHC Needs Assessment in November 2024. The SAT team sent us and school forms to complete and return by 19th December. We as parents completed our form and returned it with supporting information. School were working on completing their part. On 19th December we received a decision not to assess from the LA. They had gone to panel without the information from school! I chased the SAT team on the phone and by email weekly until finally in February they confirmed all the information would be resubmitted to panel. We received a decision on 14th February, almost 3 months after our letter requesting the assessment. Clearly the system needs reorganising. Staff in the SAT team even told me on the phone that 'everything takes forever here' and 'nothing is straightforward' I need to send them feedback about this but am now too busy focusing on going to mediation about the EHCNA plus the daily support my child needs ahead of SATs and secondary transition. We need the LA to better understand and empathise with the level of stress their incompetent systems cause us as parents. Thank you for everything you're doing on parents' behalf Pinpoint.

CAHMS does not follow NICE guidelines and is designed to put up hurdles and not help children when they need it

Poor experiences in school. I have raised them for 3 years. He was finally supported then after 8 days support was withdrawn without any consultation with myself. Disaster followed

CAMHS is a complete joke. We went through right to choose for assessment having been on the CAMHS waiting list for 4 years. Now been referred back to CAMHS for ADHD medication 8 months ago and had an appointment for a QB test which I had already advised my son would not be able to complete due to severe anxiety but the appointment was arranged anyway and he could not complete the assessment. We are now waiting for an appointment for a clinician but no timescale given so I assume by the time our 10 year old son actually is in a position to be prescribed medication that could change his life he'll be an adult and have to start the whole sorry performance all over. It's an utter disgrace!

15 years of stress, has effectively taught young person that all adults lie with impunity. If the young person can understand the EHCP they can identify when it is broken, they can understand when provision is withdrawn without notice, they can understand that people paid to support them are taking money under false pretences. We would have done better if the money wasted on non-support in independent school/transport/TAs/ed psychs/solicitors/tribunals/legal costs etc etc had been given to us to invest in a trust fund for his future.

Sen services need to work together and see undiagnosed children faster it shouldn't be unauthorised absence of your child struggles with school avoidance schools should be made to work with and surport partent/carers it should be what they choose to put in their policies they are not expiriaced enough with children with SEND they just make matters worst and parent/carers are pushed to breaking point rather then showing their support and helping they work against you

No support provided by them at all-feel very isolated and unsupported

I answered the latter questions using data from my adult son. Without a doubt not only is provision for all transitions erratic and individual dependent - ie staff at x and y dependent - support for adulthood is dire in schools, piecemeal from the LA. Schools do not see adulthood as their responsibility only really exams. You need to change the markers and the curriculum to get change here. There also needs to be loads more training. Lots of staff even in good schools do not fully understand SEN pupils and families and there is lots of blame that is spoken about- I work in education hence I know- but frequently I have to say nothing even when I feel outraged.

Our child is adopted and we fall through the gaps. When the child/ family is crisis the pre birth and early life trauma are not considered in the mix alongside mental health challenges and SEND. You can get support for one or other, but not a child centred response. We did a MASH referral as a family five months ago and despite everyone saying we need support and access to services we have received no extra support. Lots of focus on assessment after assessment but little no provision in place. Experienced disagreements between social care teams and CAMHS. SAT team have for the first time ever now engaged as specialist provision required. School proactive and supportive even though can no longer meet need. Police also helpful when called/ required. Lack of support means real risk of adoption placement breaking down.

Appalling

The waiting period for EHCP assessments is totally unacceptable. The knock on effects of lack of funding tor the school and full time support for my son are damaging to his education and social development.

Our children are both adopted and we have been really surprised at how challenging it has been to seek out support for them given their early childhood experiences which are well documented by social services.

EHCP Case worker rubbish. Gerald Maiden OT-Excellent, the only proffesional involved in our son's care who seems to have actually cared and helped him/us. A's school is incredible he is at T school and we are glad he attends here and happy with the support/input/advice/workshops we have done with pinpoint and the PINS project.

Health support - reasonable adjustments have been good from Addenbrookes Hospital and our GP. I think they have had neurodiversity training and access to specialist staff to support disabled patients, but CAMHS have not had this training and don't have access to support. CAMHS were not able to provide reasonable adjustments so my child was not able to access support. Our experience with CAMHS was distressing for both parents and child. Education - serious delays in the whole system have meant my child has had less than 2 weeks education over the space of 3 years - there are no consequences for the LA breaking the law on this. My child's needs were not accurately assessed so their EHCP does not describe their needs so there have been a series of inappropriate placements and the wrong support. Different teams do not communicate well with each other or learn from each other's expertise (eg CAMHS could learn a lot from OT about sensory regulation and from Addenbrookes and the GP service about supporting neurodivergent patients). The statutory assessment team rarely communicates at all and delays at all stages - these delays cause further damage to children's education and as such their needs are increased. Though I should add that our most recent case worker is good (we have had 4 in a year) she is just very overworked so she can't help as much as she would like. There is insufficient alternative provision available and the LA avoids providing it or delays so children as left for months without provision. We have been forced to source and fund alternative provision ourselves so that our child has some education. There seems to be a difference in what should be available and what actually is available. I go on pinpoint sessions which talk about what should be available but in reality that support for my children isn't there or at least isn't available to my family. It can be really frustrating being told that there is support and we can just never seem to get it no matter how hard we try. Everything is a battle and we are made to feel like we are in the wrong for asking for support for our child. The whole system is adversarial and getting support is exhausting - we have to regularly chase professionals, we fill in forms that are ignored and our child still has no support. It seems like nobody knows how to support our child and every team we work with just wants to hand our family to someone else. Overall I feel my child has been let down by the system, their future has been stolen.

I am an involved Grandma . It was a REAL battle for my don and his partner getting support initially with my their son meltdowning , self - harming

Camhs is utterly atrocious. Our son was referred 5 years ago for ASD assessment. We still had not heard anything at all last year so went through right to choose for ASD and adhd assessments. He was diagnosed AuDHD and referred back to camhs for titration for ADHD medication last July. We were told he'd have to do a QB test (which I advised he wouldn't be able to do due to severe anxiety but insisted on an appointment and he couldn't do the test), we would then see a clinician, we would be referred for a parenting course and discharged for 12 weeks before meds could be prescribed. No timescale has ever been given. We have now been waiting 8 months and heard nothing more. Our son has been assessed by a right to choose provider who holds an NHS contract and assessed inline with the gold standards. Despite this CAMHS who have shown themselves to be utterly appalling think the assessment and diagnoses need to be challenged by them and more red tape and further hurdles put in the way to make obtaining much needed medication for my son is made impossible. If someone has any other illness they are referred to a specialist and diagnosed and appropriate medication given within a few months. Why are we still FIGHTING to get him medication that could transform his life 5 years later with absolutely no end in sight. It is absolutely disgraceful, shameful and ruining children's like our sons lives!

Staff changes need communicating more and there work load needs to be less so they can fully support families

SAT was in complete disarray when my son had his post 16 transfer. I am dreading g having to deal with them again at the next transfer.

SCHOOL Except for 1 hr of one-to-one per week, Z. has more or less not attended school at all for 3 yrs now due to EBSA subsequent to chronically unmet SEND needs & bullying. Despite attempts to request it, LA has never provided any alternative education. School is still causing harm, e.g. by: * repeatedly failing to listen to my advice - instead, staff seem to assume "I know best". * repeatedly reporting safeguarding concerns to Social Work citing symptoms of ASD & anxiety as evidence of neglect & emotional abuse. * school forcing us every week to wake up Z. for a safeguarding home visit. Z. is currently suffering from a sleep disorder & so sleeps in the day & wakes at night. Sleep disruption caused by home visit is not good for physical & cognitive development or for health, & Z. reports visits make her more anxious. So-called safeguarding visits are, ironically, causing harm! * derolling would be best for Z's mental health, but unable to deroll for fear of disrupting EHCNA process. Why do we have to harm Z. through continued contact with the school that induced trauma in order to try to secure appropriate educational provision? Access & Inclusion mentioned seeking alternative education on medical needs grounds at the beginning of this academic year, but only in the last few weeks has there been any movement towards this. A professional was assigned to our family only to disappear after just a few weeks. So many professionals (20+) have come & gone in the last few years without much in the way of useful input, that we're all very jaded. EHCNA process is at 40+ wks! EP assessment was about 2 mths ago, but still no sign of draft EHCP, nor any updates (other than EP's report). It's 3 yrs since the SENDCo misinformed us a child needs to be academically 3 yrs behind for an EHCNA. At this rate, Z. will have left primary before she gets an EHCP & (perhaps) appropriate provision! NHS Giving no indication of CAMHS waiting list time is unreasonable: is it 1 mth or 3yrs? - stuck in limbo! Online scheduling own appointment would save time, effort & stress of to & fro with CAMHS' admin. CAMHS should send automatic updates quarterly via email/text. CAMHS does not provide enough info about the purpose of an appointment, the roles of staff, the length of the appt, what the building, meeting room, & staff look like (to help reduce anxiety). Initial appt (45 mins) was too short to explain all concerns. Having had appt, I regret waiting over a year for it - now have low confidence that CAMHS will provide useful input. A private provider (funded by grandparents) seems likely to be quicker, more effective, & potentially safer. Dentist ended NHS contract - no NHS dentist now! SOCIAL WORK SW should not show up on a SEND family's doorstep in response to a safeguarding referral unannounced! It's stressful for everyone, particularly an ASD child, & it's even worse if they carry trauma from previous encounters with SW. Engaging with an ASD family is not necessarily free of harm - it can trigger anxiety that can impact sleep etc. for days or weeks afterwards. SW, don't assume schools understand SEND! SUMMARY In our experience, public services are like a cargo-cult: staff tick-boxes but are not educated & resourced to provide effective support, & instead sometimes impose harms. Pinpoint has been the only consistently available, informative, trustworthy, & supportive beacon of hope! I wish 4 yrs ago when I (correctly) self-diagnosed Z. as having ASD & ADHD, the LA had simply said "Here's £50,000. For the next 6 yrs use this to buy whatever education or therapies you think will help. You're on your own now!". We have essentially been on our own anyway, eternally on a waiting list for one thing or another that all prove unsuitable, & without funds to take matters into our own hands. In the meantime, school & Social Work have traumatised Z. (and us), adding mental health issues on top of the challenges she already had due to ASD & ADHD.

My son has had a Statement/EHCP for the last 10 years. Nothing changes. I can remember 10 years ago being told there was a lot of staff absence which was why there was a delay in receiving a child's statement. For at least 4 years now, I don't receive a Final plan before the annual review the next year. I only got the draft this year because I said I was going to put in a complaint. There is no communication with parents. It's tiring. I can't go off sick. I have to keep going. I can cope with my children's behaviours but dealing with professionals on a daily basis is draining. Drastic changes are needed.

Poor

Needs more funding at schools.

My main experience has been with the school and it is not good at all. Pinpoint and SENDIASS have been very helpful though.

Absolutely shocking. Passed from pillar to post. Nobody is held to account for failing. Fortunately we have a great school

Impossible to get heard, needs not taken seriously until I was literally screaming. Local offer sessions I have attended have been a godsend, so informative and helpful. School now supporting more but has taken far too much shouting, still awaiting diagnosis

About the respondents

Location

Fenland 14%

East Cambridgeshire 24%

South Cambridgeshire 29%

Huntingdonshire 27%

Cambridge City 6%

Gender of child

Male 55%

Female 45%

Non-binary 0%

Prefer not to say 0%

Age of child

0-4 years 2%

5-10 years 55%

11-15 years 24%
16-18 years 6%
19-25 years 12%
25+ years 0%
Ethnicity
White British 90%
White European 0%
White Gypsy or Irish Traveller 0%
White Other 2%
Mixed Ethnic Background 4%
Asian 0%
Asian British 2%
Black British 0%
Black African 0%
Black Other 0%
Arab 0%
Prefer not to say 2%
Other 0%
Current placement by school/institution
Nursery / Pre-school 0%
Mainstream Primary 43%
Mainstream Secondary 14%
Special School 16%
Cabin or other provision within a school 4%
Pupil Referral Unit 0%
Independent School 0%
Independent Special School 2%

Alternative provision 6% Out of County placement 0% Elective Home Educated 2% Out of school/ not receiving education 6% Hospital School 0% Further / Post 16 Institution 4% Finished Education 0% **Timetabled provision** Full time timetable 65% Part time timetable 14% Not in school 20% Need ranked by times reported by those completing the survey Autistic spectrum condition/disorder (ASC/ASD) 23% Social and Emotional Mental Health needs 13% Attention Deficit Hyperactivity Disorder/Attention Deficit Disorder (ADHD/ADD) 10% Specific learning difficulties e.g. dyslexia, dyspraxia, dyscalculia, dysgraphia 8% Sensory processing disorder 13% Speech and language impairment 9% Global Developmental Delay 4% My child/young person's needs have not yet been identified 1% Moderate learning difficulties 4% Hearing Impairment 2% Physical disability 2% On the early help pathway 2% Medical needs / Complex health needs 2% Severe learning difficulties 5% Visual Impairment 2%

Fetal Alcohol Spectrum Disorder FASD 0%