



**Communication while on  
autism, ADHD, and  
mental health support  
waiting lists**

**Poll results**



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## Summary

It is well known that the waiting lists for autism and ADHD assessments, and for mental health support, for children and young people in East Sussex are considerably lengthy. This is a national issue, and there are a number of contributing factors, including funding and workforce. However, ESPCF frequently hears from families who are frustrated, overwhelmed, and bewildered by the lack of communication and support while they are waiting.

**ESPCF believes that there are solutions which can be implemented locally to go at least some way to improving families' experiences.**

On multiple occasions in meetings and workstreams, ESPCF heard that 'keeping in touch' letters were being sent every six months to families on CAMHS (child and adolescent mental health services) waiting lists. But this did not match parent carer feedback to the forum. It was therefore important to understand the extent of the issue, and to have a better idea of how many families were in fact receiving these letters, as well as to hear from parent carers about what would be most helpful to them during these long waits.

This report sets out the results from ESPCF's poll asking parents and carers in East Sussex about the amount and type of communication received while their child or young person is awaiting assessment from CAMHS for autism (for those aged 11 to 18) and/or ADHD (attention deficit hyperactivity disorder), and/or mental health support.

It also asked about those children on the waiting list with the Child Development Clinic, run by East Sussex Healthcare Trust (ESHT), for autism assessments for children under eleven years old. This was included to build a more complete picture of experiences and to understand what support would be most helpful while waiting across all services.

The poll ran from February 2024 to March 2024 and **194** people responded.

**Thank you so much to everyone who took the time to answer the questions and share your experiences and suggestions.**

## Next steps

### 'Keeping in touch' letters

ESPCF has raised its findings, detailed below, about the number of parent carers not receiving 'keeping in touch' letters with CAMHS leads, and the issue has been acknowledged. ESPCF has also been told that some **IT/system issues have been identified, and that processes are currently being reviewed** in order to ensure that 'keeping in touch' letters are sent out regularly to all families who should receive them.

ESPCF also understands that work has just started within NHS Sussex to improve information and advice for parent carers while they are waiting for a referral or an assessment for neurodevelopmental services. ESPCF has been asked to be involved in this work to help ensure the content is as helpful and accessible as possible for families.

ESPCF represents East Sussex families in a pan-Sussex co-production group chaired by the CAMHS neurodevelopmental pathway lead. The group's remit includes reviewing communications, so hopefully this will be an opportunity to ensure the letters are as helpful for families as possible.

The [monthly CAMHS parent carer participation group](#) is also a useful avenue for parent carers to speak directly to CAMHS leads to feed into this process.

## Transparency about waiting times

The findings from the poll demonstrate that greater transparency and communication about the length of waiting times is a priority for parent carers. While the difficulties of providing exact timescales are understood, **ESPCF recommends that factual information should be provided to parent carers while waiting, such as stating the month and year that children being seen that month joined the waiting list.** This should be alongside improved communication about the different factors affecting waiting times, and what is being done locally to try to address this.

## Key findings

- **Almost three quarters (74%)** of respondents have a child or young person who has been on a waiting list for **more than one year.**

*“Waiting lists are horrendously long, impacting the child’s needs for correct support.”*

*“We have been on the waiting list a very long time. We have had no communication from CAMHS apart from saying we had passed the first test and are now on the waiting list.”*

- **Almost one third (31%)** of respondents said that their child or young person has been on a waiting list for **more than two years.**

*“I keep being told not to call as appointments are assessed by need. We will be allocated an appointment as soon as they have one available. 5 years we have been waiting.”*

*“My son has been on the ADHD waiting list for over 3 years. Very little support or information. I know why some parents give up as it’s so hard to get help.”*

- **55 respondents (30%)** said they were either **not certain if their child or young person was on a waiting list** (either assuming they were because they’d been referred, or were still unsure), or they only knew because they had proactively got in touch with the service to check.

*“I ended up emailing CAMHS to get confirmation as I’d heard nothing from them after 9 months of paperwork being sent in.”*

*“For ADHD the school sent paperwork, so I assume we’re on the list but we haven’t had anything confirming anything, so I suppose I’m actually not sure. It’s been over a year now.”*

- Of those on a **CAMHS waiting list, 86% had not received a ‘keeping in touch’** letter which ESPCF had been told were supposed to be sent out every six months.

*“I have not had any keeping in touch letters and I’ve had to chase numerous times. It would be nice to know where abouts on the waiting list and also a rough estimate of how much longer to wait. We were told 6 months nearly 4 years ago and still waiting...”*

*“I was told people would keep in touch during the 2 years wait but we are 10 months in and haven’t heard a thing.”*

- Of the 14% who *had* received a letter, **83% said it was unhelpful.**

*“No, it was not helpful, it named websites to look at. Had already done extensive research before child was referred. The letters are a waste of paper. How about highlight how long you are likely to wait, how about providing a date if it’s in 2-or-3 years’ time? Otherwise, what’s the point in saying it’s at least a 2 year wait, probably longer.”*

*“We have received 1 letter in 20 months and the letter provided no useful information.”*

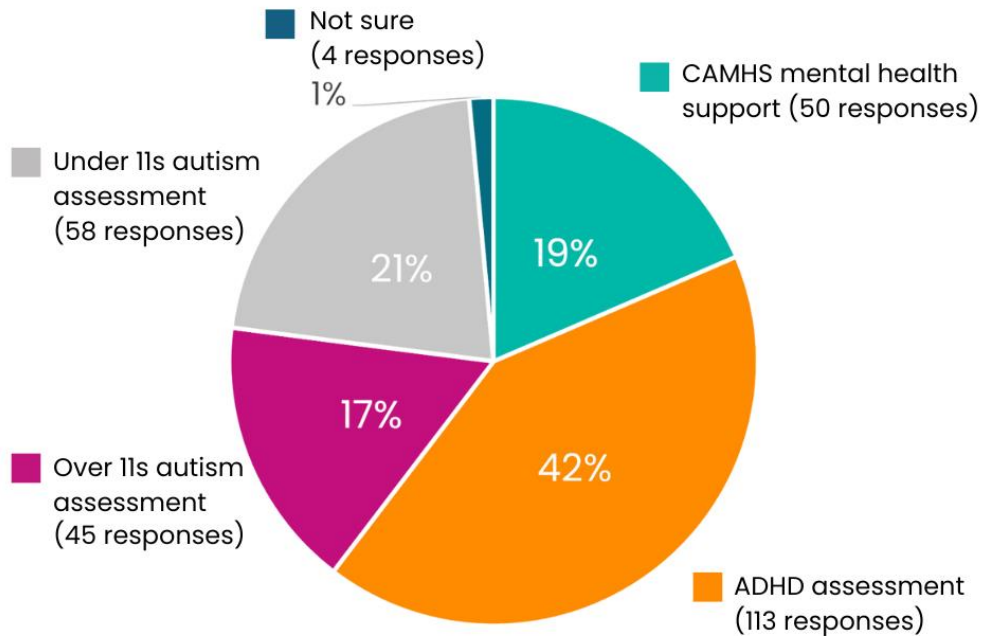
- In terms of what would be most helpful while on the waiting list, **85%** of those who responded said **knowing how much longer they had to wait** would be most helpful.

*“We need accurate information about where we are on the list and how much longer there is to wait. A letter saying they can’t answer any questions about waiting times and with generic information is not very helpful.”*

## Poll results

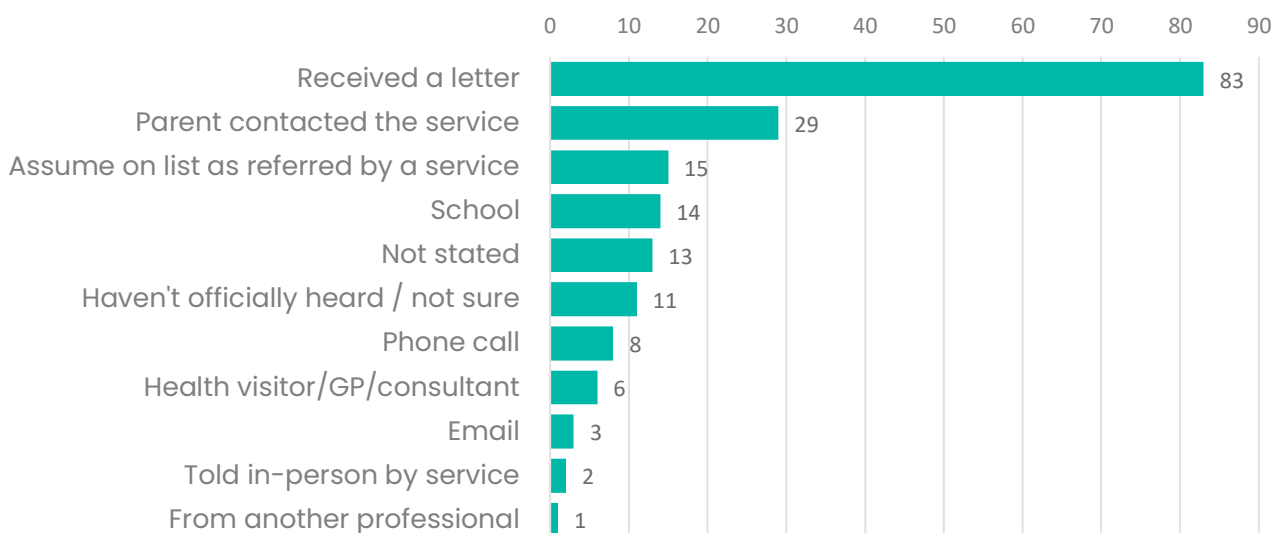
### Question 1: Which waiting list is your child or young person on?

Respondents were able to select more than one category which is why the total number of responses to this question (270) exceeds the total number of people who completed the survey (194). Percentages have been rounded up/down.



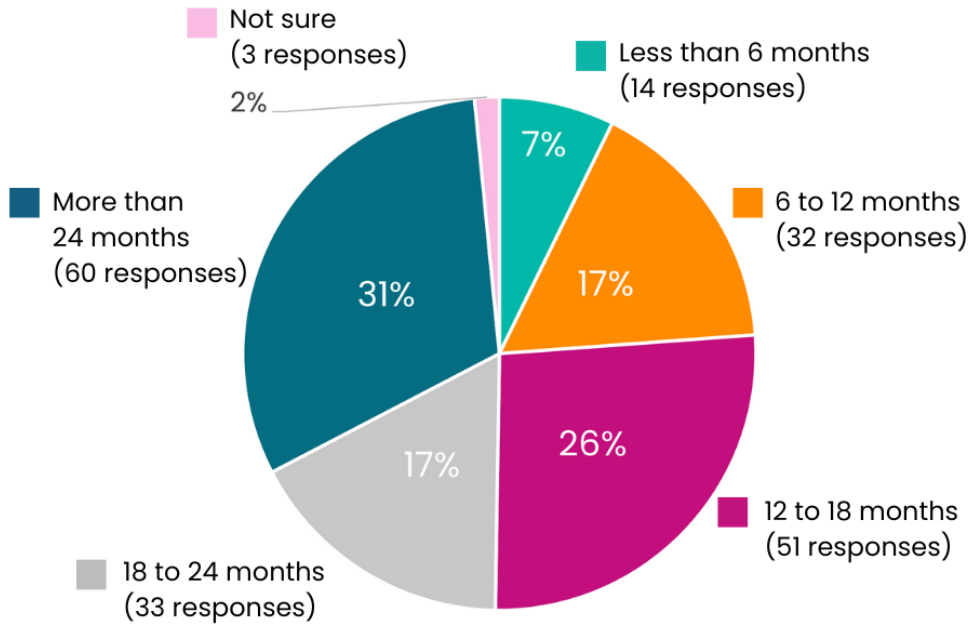
### Question 2: How did you know your child or young person is/was on the waiting list? (185 responses)

This question was asked because feedback to ESPCF shows that some parent carers are not sure if their child has even been referred or accepted onto a waiting list. As the poll findings show, it is not all that uncommon for parent carers to have to proactively get in touch with the service to find out this information. This is not helpful for parents, and it also puts additional pressure on services.



### Question 3: How long has your child or young person been on the waiting list?

(193 responses) Percentages have been rounded up/down.

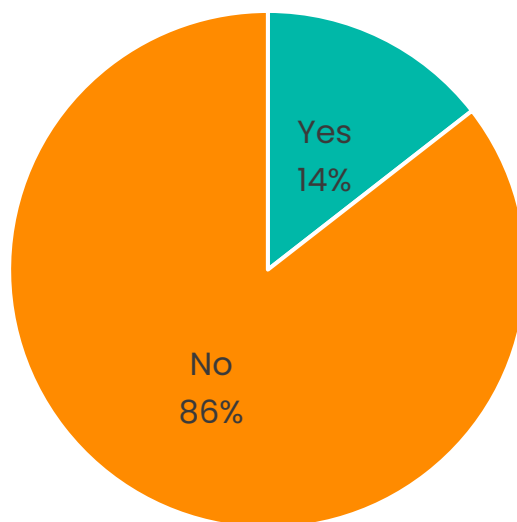


### Question 4: Have you received any 'keeping in touch' letters?

(152 responses)

The results in this question show the responses from those who have a child or young person on a **waiting list under CAMHS**, i.e. CAMHS mental health support, ADHD assessment, and over 11s autism assessment, and have been on the list for more than 6 months (which is when 'keeping in touch' letters should be sent out). It **doesn't include** those who are on a waiting list for **under 11s autism assessment**, as this sits outside CAMHS and does not send the letters.

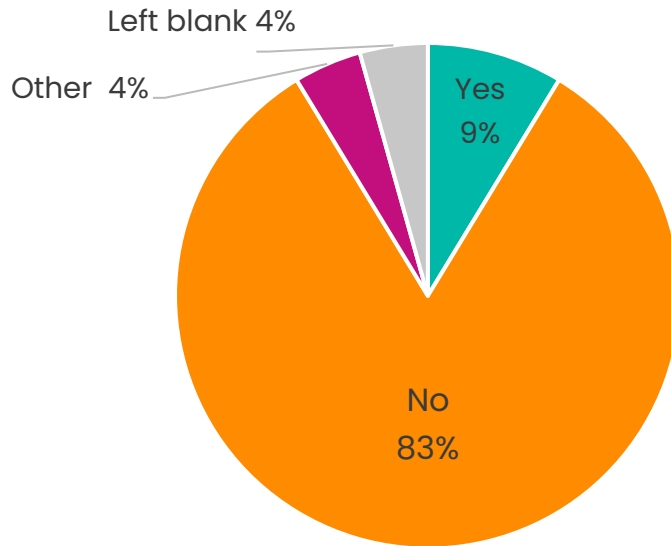
Have you received a keeping in touch letter?



**Question 5: If you have had a keeping in touch letter, did you find it helpful?**

As with the question 4, these results show the responses from parent carers who have a child or young person on a CAMHS waiting list for more than six months.

Did you find the keeping in touch letter helpful?



Of the **23** respondents who said they had received a keeping in touch letter, **2** found it helpful, **19** found it unhelpful, there was **1** blank entry, and **1** who said neither yes nor no (other).

**Question 5 also asked for suggestions about what information is, or would be, most helpful for you while you are waiting for assessments/services.**

There were **40** responses which included **suggestions** for what would be most helpful. Some individual responses contained more than one suggestion.





- **85%** (34 comments) said that **knowing how much longer there is to wait** would be most helpful. Openness and transparency about waiting list times were identified as being very important, and even if there wasn't good news to share, i.e. being told the wait is still lengthy, parent carers still valued being kept informed and updated.

*“It would be helpful to know if the wait has got any longer or shorter, I appreciate they can't give an exact date but a rough idea would be helpful.”*

*“Confirmation of being on the waiting list and how much longer it will be approximately. I'd like them to explain why it's so long and what they are doing to try and get our kids seen sooner and how we can get in touch with questions at the moment or what to do if things have got worse since the referral and information needs to be updated.”*

- **37.5%** (15 comments) said that knowing **what interim support is available** while waiting would be helpful. Within these comments, there were several mentions of the importance of up-to-date information on where to get help or advice, and there was an emphasis on practical support, for example schools knowing what provision and support to put in place, and information for parent carers about in-person events such as coffee mornings or clubs for their child or young person – not just being signposted to a website.

*“Advice on interim support available that is up to date, as I was signposted to services that are at capacity and not accepting new referrals, and to others that were irrelevant.”*

- **10%** (4 comments) said **providing contact details** of who parent carers can get in touch with is important, particularly if situations are deteriorating and families don't know where to turn.

*“Contact details would be helpful as well. If things get worse, what do we do?”*

- **10% (4 comments)** said just **knowing that they and their child hadn't been forgotten** was important.

*“A letter just letting us know we haven't been forgotten...”*

*Note: many of the 40 responses contained more than one comment, which is why the total percentage number is more than 100.*

## Question 6: Is there anything else you would like to tell us?

(130 responses)

The responses to this question can be grouped into the themes set out in the table on the next page. Again, some responses contained more than one comment or suggestion.



Impact of lengthy waiting lists: **63** comments

*“The waiting time is ridiculous, and I have been told by CAMHS that it's likely my daughter will have finished secondary school before being assessed. This means she's not getting the support with either her autism or mental health which breaks my heart as she desperately wants a career working with children with disabilities but it's looking likely she will not get the entry grades she needs due to lack of support. CAMHS say that even though she is on the pathway to being screened the school should treat her and support her as if she had autism but in reality, the school doesn't as they always say to me, ‘but she has no diagnosis’.”*

Poor or no communication while waiting: **50** comments

*“I called 10 times in 2 months. Not a single call back.”*

*“No communication at all from CDC re autism assessment. Nothing, not even an email. I can't be sure she is even on the list. They don't accept phone calls so you can't even check.”*

Lack of support from services: **23** comments

*“Graded / tiered packages of care mean that we spend longer on waiting lists and accessing support that is ineffective as it isn't meeting need and therefore wasting time of CAMHS and the young person (and usually meaning their difficulties get worse in the meantime).”*

Seeking/paying for external support: **5** comments

*“At the point of now starting the process to go private, a £4,000 assessment for ADHD and autism for my son. The stress this has caused on top of an already challenging situation!”*

The **20** comments which have been categorised as ‘other’ include the following issues:

- Child or young person has been out of education for a sustained period of time.
- Worry about what happens when young person transitions to adult services.

- Impact of working fulltime on parent carers' ability to contact services during the week.
- Referrals from GP and special school turned down.
- Impact of delays on the whole family.
- One response praised ADCAMHS (adopted children's and adolescent mental health services) and how valuable this specialist understanding was.