



Parent carer survey 2023-24

Report of findings



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Introduction

This report shows the results of the parent carer survey carried out by East Sussex Parent Carer Forum (ESPCF), which ran from October 2023 to January 2024, with a total of 235 responses. It is an opportunity for ESPCF to measure families' experiences of local special educational needs and disabilities (SEND) services and support. It sits alongside the snapshot data ESPCF collects in termly temperature check polls, the results of which show that many families do not feel the right support is in place.

The questions in the survey were based around those used in the 2021 survey of parent carers as part of East Sussex's SEND joint strategic needs assessment (JSNA), which was co-produced with ESPCF. **It is now three years since that report, and it is important to understand and record the more recent and ongoing experiences of families.**

The results of the JSNA can be found in the [Comprehensive Needs Assessment 2021](#) which identified a number of areas for improvement.

This ESPCF report also looks at the results from [ESPCF's East Sussex 'temperature checks'](#). These are four to six quick questions for parents and carers of children and young people with SEND in East Sussex to express their overall feelings about how things are going. The temperature checks have been carried out five times so far between June 2022 and Sept 2023. While they are not designed to provide *detailed* feedback, they do track changes over time, and demonstrate to the local authority, health, or other services whether the overall feeling is that things are getting better, worse, or staying the same.

For families reading this report, and leaders, commissioners, and service providers working hard across the SEND system, it will be a challenging read. Many of the issues identified are not unique to East Sussex and relate to broader national policy and lack of funding for SEND provision.

It is hoped that this report is a useful exercise in tracking what has changed, what hasn't changed, and where resources need to be targeted in the future. ESPCF is committed to working with East Sussex County Council, NHS Sussex, and other partners to continue to represent the experiences of families and strive for improvement.

Thank you to all the parent carers who completed the survey and the temperature checks and have provided valuable feedback for this report.

Summary of key findings

The overall message throughout the parent carer survey and the five temperature checks is that most of the families who responded are not receiving the SEND support and/or provision that their children and young people need, or are entitled to, as set out in the Children and Families Act 2014 and the SEND Code of Practice.

The most common message from parent carers is the continuing and exhausting battle they face with processes and services and the need to fight the system for their child or young person's needs to be met. All of the survey findings align with the feedback ESPCF gathers in a variety of ways in its ongoing day-to-day work.

"For the last 7 years I have had to fight for everything! The whole process from ESBAS, EHCP, schools, ISEND and TLP is long and complicated and constantly feeling let down and forgotten. My son's needs were never met and he was not given a fair access to education. I felt he became a nuisance they'd rather ignore. Now I'm left unsupported with a young adult who has been let down by an underfunded system. These children are being let down and forgotten."

It is almost ten years since the [SEND Code of Practice](#) provided statutory guidance on duties, policies, and procedures to ensure that children and young people with SEND would be able to:

...lead happy and fulfilled lives... For children and young people this means that their experiences will be of a system which is less confrontational and more efficient. SEND Code of Practice, P11

However, this is most certainly not the experience of the majority of families who responded to the ESPCF survey and temperature checks.

Over 50% of survey respondents said their child or young person's needs are **not well supported or not at all supported**

The average across all five temperature checks shows **rates of 'dissatisfaction' and 'very dissatisfied'** at: education 72%, health 65%, social care 66%

“Some experiences are positive, but overall, I have to say I’m extremely dissatisfied. I’m exhausted from continually fighting the system whilst trying to balance with caring for and meeting my son’s needs. I’m exhausted, my mental health is at an all-time low and have very little quality of life myself. I feel increasingly isolated and if it weren’t for very supportive colleagues and other SEN parents for advice and moral support, I don’t want to think where I would be right now.”

“It is a huge amount of work and stress for families already having to manage children with challenging needs. It feels like a series of hurdles to see how long you can keep fighting and like a flowchart process rather than looking holistically at a child’s needs and what’s best for them.”

“My child needs a specialist school place (parental, school and professional opinions). We are having to appeal to the SEND tribunal. In the meantime, my child will miss another year of education. We have asked for interim support and been refused. The LA is derelict in its duty to ensure that the provision in my child’s EHCP is being delivered.”

This was also highlighted three years ago in the [SEND Joint Strategic Needs Assessment \(JSNA\)](#), which commented on the feedback from parent carers:

The consultation with parent carers had highlighted that the current system of SEND provision is not seen to be working effectively to meet the needs of children and young people with SEND. SEND Comprehensive Needs Assessment, P119

The summary below highlights the most common issues **as described by the parent carers who provided feedback in our survey and our temperature checks**. These are reported here as key themes - intentionally so that this information is accessible and not too lengthy to read. The percentage responses can be seen in the full data in ‘survey results’ which underpin these thematic findings. Positive feedback is also included later in the report, as it is important to recognise where this is happening and the impact it can have for families.

The system

- Systems are complicated; information is either lacking, difficult to find, or overwhelming and confusing, and services and professionals are not working together. Parent carers want greater clarity and openness about navigating the system.
- Securing an EHCP is frequently a struggle which can take years to resolve. This is well known within the parent carer SEND community, and applications are therefore generally not made lightly and only pursued when a child or young person's needs are not being met.
- The view remains, as identified by the JSNA, that:
In line with national views, the EHCP assessment and application processes are perceived to be too lengthy and complex, lacking honesty and transparency, and generally a huge struggle for those trying to navigate them. There is a strong view among families that the Council process itself presents a significant barrier to support. SEND Comprehensive Needs Assessment, P145.
- The battles that families face are not short-lived, but can regularly last several years. This has a detrimental effect on the mental health and wellbeing of parent carers, which also places further additional demand and stress onto the system. It is not uncommon for needs to escalate, or a child or young person to be partly or fully out of education while the right support is being sought.
- A significant part of the battle is that parent carers' views are not listened to or respected, with decisions being made either without consultation or with a disregard for the parent carer view. Within the survey and the temperature checks are many references to 'parent blaming'.

Identifying needs

Education

- School staff, including SENCOs, are not being adequately trained to recognise special educational needs (SEN), especially where the child or young person is masking.
- Parent carers feel dismissed, not heard, and not taken seriously. This can lead to delays in the child or young person's needs being identified, sometimes to the extent that the child or young person is not appropriately supported at school or college, leading to unelected home education (where a family feels they have no choice but to home educate their child or young person).
- There are delays, lack of information, and lack of support around the EHCP process, and EHCPs and annual reviews are often not accurate in fully identifying need.

Health

- There are long waiting lists for CAMHS and the continuing lack of a diagnosis results in needs not being identified. The long waiting lists for assessment and diagnosis for neurodevelopmental conditions and mental health support are having a huge impact on families. It commonly means a child or young person is not receiving the right support at school and as a result is attending only part-time or not at all.
- There is a lack of communication and information on how long the wait is likely to be. A system of 'keeping in touch' letters was instigated some time ago, but an [ESPCF poll in 2024](#) showed that only 14% of respondents had received these letters.
- Access to assessments for speech and language therapy and occupational therapy is difficult.
- There is a lack of clarity about whether private assessments are accepted. Parent carers report that they have no choice but to explore and fund independent assessments in order to secure support for their child or young person during the long wait.

Social Care

- The stark finding from the survey and temperature checks shows that there has been no change from the findings of the JSNA three years ago:
High referral thresholds/criteria for health and respite services limit available support. SEND Comprehensive Needs Assessment, P9
- Social care involvement in EHC needs assessments and plans is not always sufficient.
- Carers assessments are difficult to access.

Supporting needs

Education

- SEN support in schools is inadequate. This is due to needs not being identified and/or acknowledged, a lack of resources, or a lack of skilled staff. This often results in parents requesting EHC needs assessments, and the consequent wait may result in the child or young person being partly or fully out of education.
- Even when an EHCP has been secured, the provision is not always put into place.
- School staff are not adequately trained, particularly in relation to neurodivergent children and young people, and schools and staff are often not neuro-affirming.
- Reasonable adjustments are not always applied to practices or embedded within school policies.

Health

- There is an increasing lack of mental health support and services, even when a child or young person is in crisis.

- There is a lack of support for children and young people who are autistic and/or have ADHD who are experiencing mental health problems. Parents report that mental health support teams (MHSTs) that operate in some schools are not always able to offer expert support to neurodivergent children and young people.
- There has been a significant reduction in therapeutic support, such as occupational therapists, and speech and language therapists.
- There is dissatisfaction following diagnosis from CAMHS due to a lack of follow-up information and support.

Social care

- For the few families who meet the high threshold/criteria for overnight respite there is still a shortage of provision.
- There are families in crisis where the child or young person has complex needs but does not meet the narrow 'severe learning disability' criteria.
- Short breaks have significantly increased which is positive but there is insufficient provision; services are not set up and/or staffed to support those with complex needs so do not provide a break for parent carers.
- Where direct payments are allocated, there is a shortage of appropriately trained personal assistants.

What is working well

- When referring to what is working well, several of the feedback comments refer to an individual that has made a significant difference - sometimes a teacher or a SENCO. In a couple of cases a particular school is acknowledged as working well.
- The charity Amaze which provides advice and support (including SENDIASS) is frequently mentioned.
- CLASS (Communication, Learning, and Autism Support Service) and CLASS+ (supporting families where a child or young person is autistic) are mentioned several times. However, there is sometimes a caveat that the service does not have enough influence with schools or supporting EHCP content.
- Parent carers frequently refer to the understanding and advice they receive from other parent carers and appreciate the powerful benefits of peer support.

Survey results

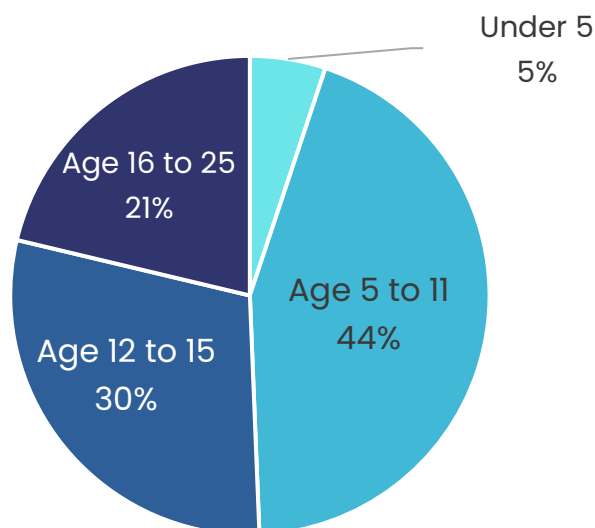
Who completed the survey

What is your child or young person's primary additional need or disability?

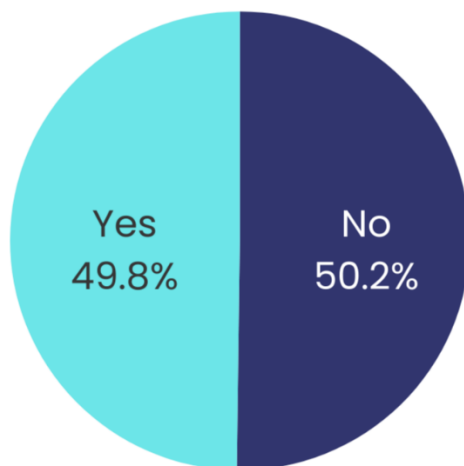
ASC	79	33.6%
ASC with PDA	35	14.9%
ASC and ADHD	34	14.5%
ADHD	20	8.5%
Other	18	7.6%
Learning disability or difficulty	12	5.1%
Dyslexia	7	3.0%
Speech, language and communication needs	7	3.0%
Down's Syndrome	5	2.1%
Social, emotional and mental health	5	2.1%
Cerebral Palsy	4	1.7%
Epilepsy	3	1.3%
Hearing impairment	2	0.9%
Physical disability	2	0.9%
Profound / multiple learning disability	1	0.4%
Visual impairment	1	0.4%

The 18 'other' responses to this question were made up of waiting for assessment or diagnosis; multiple and/or complex needs, and rare syndromes.

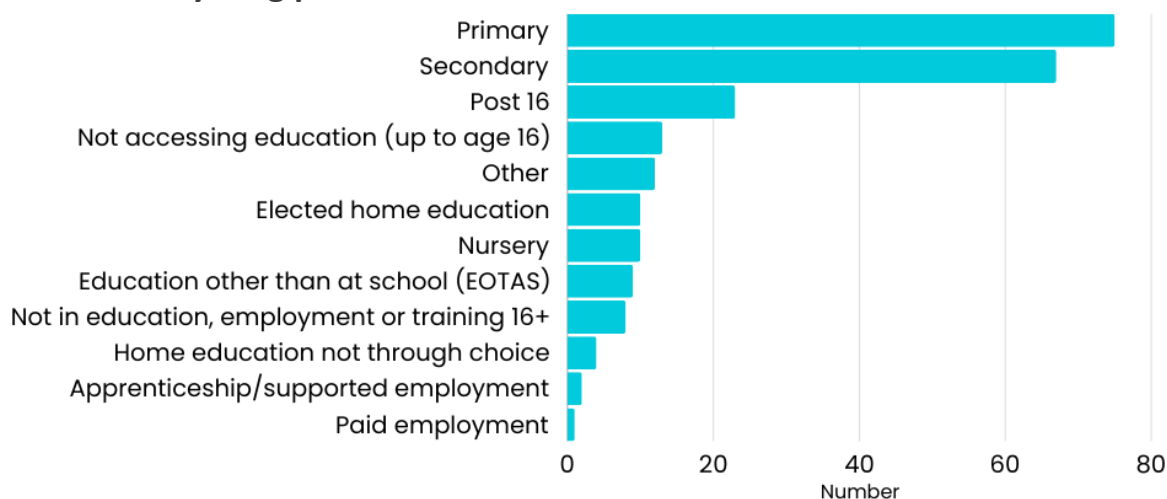
How old is your child or young person?



Does your child or young person have an EHCP (education, health, and care plan)?



Which of these best describes the education/employment/training phase of your child or young person?



Primary	76	32.1%
Secondary	67	28.6%
Post 16/further education	23	9.8%
Not accessing education (up to age 16)	13	5.6%
Other	12	5.1%
Elected home education	10	4.3%
Nursery	10	4.3%
Education other than at school (EOTAS)	9	3.8%
Not in education, employment, or training 16+	8	3.4%
Home education not through choice	4	1.7%
Apprenticeship/supported employment	2	0.9%
Paid employment	1	0.4%

SEND services, support, and provision in East Sussex

Question 10: Thinking about SEND services, support, and provision in East Sussex, is there anything that you feel is working particularly well in supporting your family's needs? 205 responses.

Is anything working particularly well?



"Absolutely not. You have to constantly fight for the bare minimum and it's the most difficult journey you'll ever be on."

"School has been fantastic! CAMHS are readily accessible and fully supportive of the whole family."

There were many different services named as examples of what is working well. The services that had multiple responses are below:

Services working well



"Provision within the specialist school has been really great and our daughter is now enjoying school and making friends."

"Spectrum is fantastic but a shame it's only 6 weeks."

"The secondary school has put in place a SENCO that does recognise our child's needs and is very supportive."

I feel we have been pretty much ignored by all services apart from Amaze who have been really proactive, supportive, and helpful.”

“We were well supported over the past year by ESBAS and CLASS, however there was little that they could do for our child.”

Question 11: Thinking about SEND services, support, and provision in East Sussex, is there anything that you feel is not working particularly well in supporting your family’s needs? 222 responses.

Various services were named; below are the most common:

Services not working well

School 77	CITES/ therapy 18	CAMHS 14
		SENCO 10

“Lack of CITES provision, time taken to obtain essential equipment, time to access vital services, lack of resources, lack of holiday provision, constant administration, lack of communication, the list is endless.”

“The whole process takes far too long. The waitlist to get a reply from CAMHS just for a referral is over a year. The wait for a diagnosis is 3-4 years. In that time there is no support or help for parents or the children. Trying to get considered for a diagnosis as a girl is also just impossible.”

“SENCOs in schools are not full time and spread very thinly across a few schools so support is not enough for the amount of children needing support.”

“There is no secondary school that meets my daughter's needs. We have had to compromise massively and now do a 12 mile a day round trip to an unsuitable school which was the best of a bad bunch.”

Question 12: Are there any services that you are aware of that you would like to access but are not? Please give details below. It would be helpful to know which services and what barriers you have faced/are facing when trying to access them.

Various services were cited that respondents have not been able to access or access adequately. The most the common are: **CAMHS (32 responses), CITES (20 responses), and respite/short breaks (18 responses).**

“Apparently my son is too severe to access support. Social services and CAHMS have provided zero support. I am stuck with coping on my own.”

“Single working parent with 2 children with SEN, one very complex. Respite support would be welcomed. Don't meet threshold for help from Children's Services.”

“Speech and language. Referral turned down 3 times even though not speaking at nearly 4. No real reason given for refusal.”

Question 13: How well do you feel your child or young person's needs are being correctly identified?

And

Question 15: How well do you feel your child or young person's needs are being appropriately supported?

Both questions received 235 responses and the results are shown on the next page (page 14), side by side for comparison, by sector.

Education

How well are your child or young person's needs being correctly identified?



How well are your child or young person's needs appropriately supported?



Health

How well are your child or young person's needs being correctly identified?



How well are your child or young person's needs appropriately supported?



Social care

How well are your child or young person's needs being correctly identified?



How well are your child or young person's needs appropriately supported?



Question 14 and question 16 asked for any additional information to question 13 and question 15 respectively.

Question 14: How well do you feel your child or young person's needs are being correctly identified – additional information. 121 responses.

Only **2** of the respondents these stated that needs have been correctly identified. The remaining **119** talked about the services that had not supported the correct identification of need, and the reasons surrounding this. The responses that referenced the system noted the continuing need to battle, the need to acquire private/independent support or assessments, and where needs had been identified this was due to the parent carer being proactive and constantly chasing.

Most common services not identifying need:

Education: 31%

System: 26%

Mental health/CAMHS: 21%

CITES: 3%

"I would like to add that where needs are being correctly identified, it has only been as a result of me being extremely proactive and chasing, plus with the supporting evidence of independent reports that I have privately commissioned and I have still had to quote the law at times."

"Mental Health services never tried to engage successfully with my son, so his full needs were never identified. I had to research and diagnose them myself."

"If we had answered this 18 months ago, I would have said that education was "not at all". Our daughter masked all through primary and as she was not disruptive in school was totally overlooked. By the time she was in year 5 (mainstream) she was only working at year 1 level and school were still not able to truly identify and meet her needs. Once she was moved to specialist school this all changed."

Question 16: How well do you feel your child or young person's needs are being appropriately supported – additional information. 84 responses.

These responses are too varied to categorise. Within the 84 responses there were only **2** that acknowledged needs were being supported. There were **5** responses that noted efforts were being made but with restrictions or with needs being met due to private resources.

Examples below:

“Education only working well due to judicial reviews and tribunal.
Previously appalling.”

“I feel school has done the most they can with resources/staff but are limited and have to make tough decisions, which unfortunately have been unfair on my son. On a personal level, since needs have been acknowledged, the senco particularly works very hard and obviously cares.”

The remaining **77** responses provided varied reasons as to why needs are not being supported:

“Our son is in crisis. We are in crisis. We are on a waiting for CAMHS LD FISS. Our only safety plan is to call 999.”

“My child has been failed by education. He should not be in a mainstream [school] due to high difficulties in transitions and education itself. My child’s mental health state is being affected due to this.”

“We have no support since deregistering him from school. We are waiting on CAMHS waiting list. Apart from that I very much feel that I've been left to deal with it all on my own.”

“I realised that I – me, the parent – was the only person who was going to appropriately support my child – as I have always done and continue to do. Absolutely NO support – we have up.”

“I don’t feel the EHCP annual review process actually is effective in meeting my child’s needs and provision takes months to agree and put in place.”

Question 17: While your child or young person's needs were being identified, did you feel that:

What you said made a difference



You were kept informed



You were able to influence decisions



What you wanted to happen did happen



Your child or young person's views were taken into account



Question 18: Please use the text box below to add any additional information about your answers to question 17. 91 responses.

This question asked for more detail about experiences during the process of identifying needs. There were only **3** positive responses, with **2** of them citing an individual/school as the reason:

“The school is very nurturing. They listened to your views and your child’s.”

“During the EHCP process the Assessment and Planning Officer was extremely helpful. She was reliable, reasonable and kind. This made a huge difference during what is a stressful time.”

Two responses were mixed as in the example below:

“Very mixed experiences. I felt listened to and what I said mattered at all times when speaking to professionals, but this did not translate into reports/provision, particularly within the EHCNA. I think all staff care and want to do the best for the child and family but are restricted by finances/staff/policies within broken systems. I think staff are as broken as parents. I feel broken and I consider myself an educated competent parent with legal knowledge. My child is broken. He is seven years old. I am scared for his future.”

There were a few responses that acknowledged an eventual positive outcome but noted how difficult the process was:

“We eventually did get what we felt was needed but we had to go to appeal, pay for private assessments and battle/challenge poorly worded EHCP for a few years.”

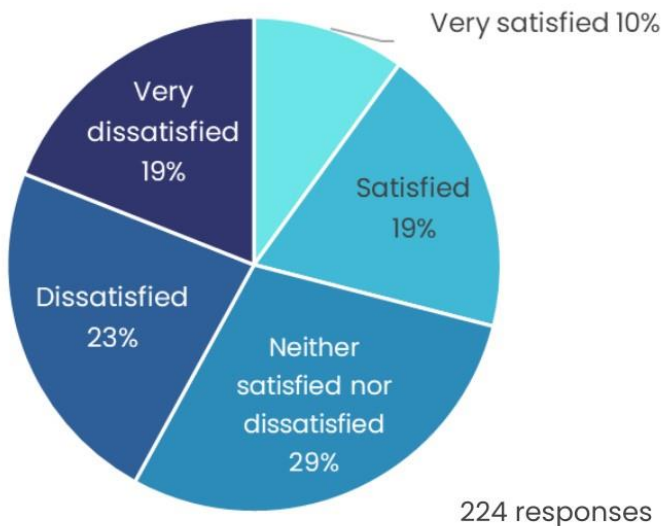
“What we wanted to happen has happened, but it has come at great cost and been the most challenging and unnecessarily devastating time due to lack of resources, provision, and proper support. It will take us years to recover both mentally and financially.”

The majority of responses had not felt listened to or kept informed:

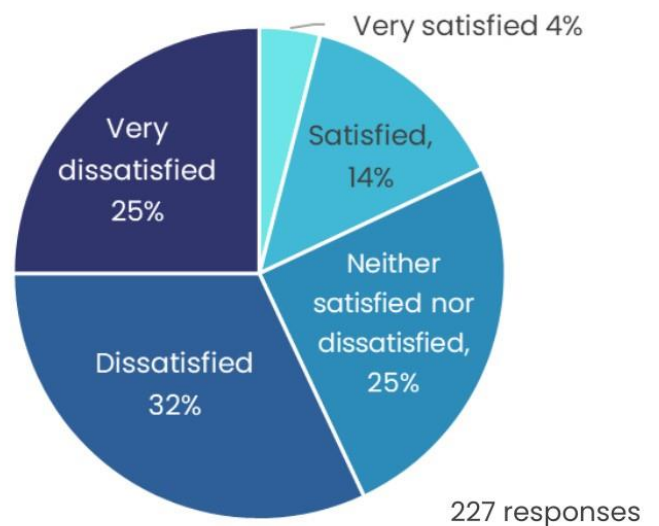
“It has taken a huge amount of effort to ensure that our voices are heard. ESCC were particularly resistant and took the most effort to persuade. Once we had overcome the barrier that ESCC presented, it was much easier to make meaningful progress.”

Question 19: How satisfied are you with:

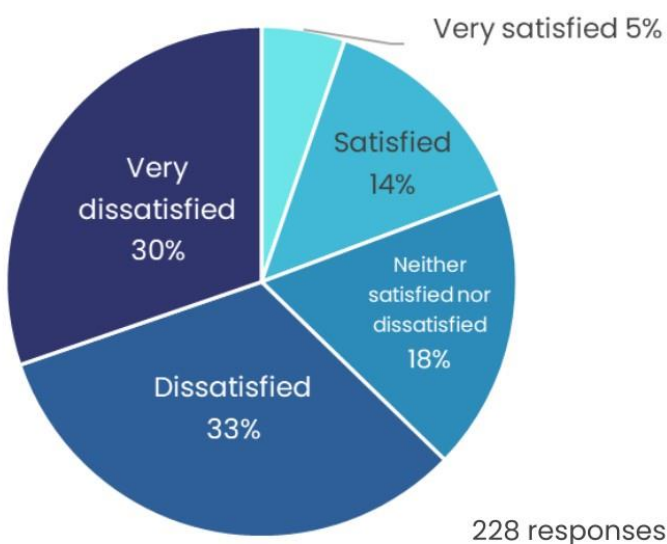
Assessment of need



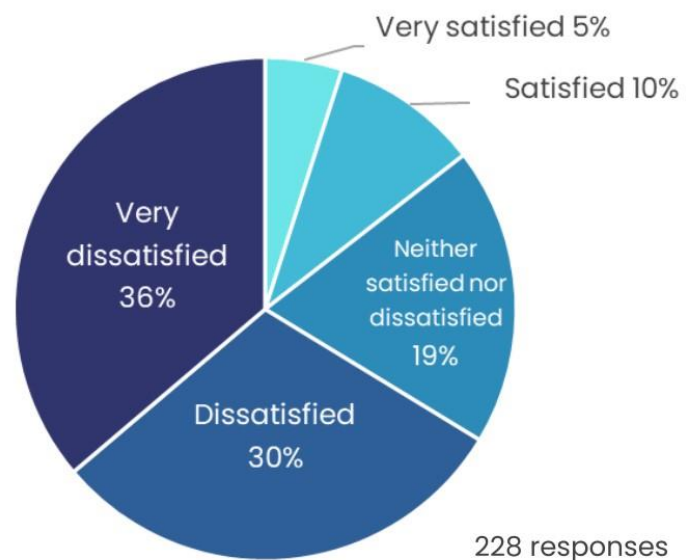
Information provided about SEND provision



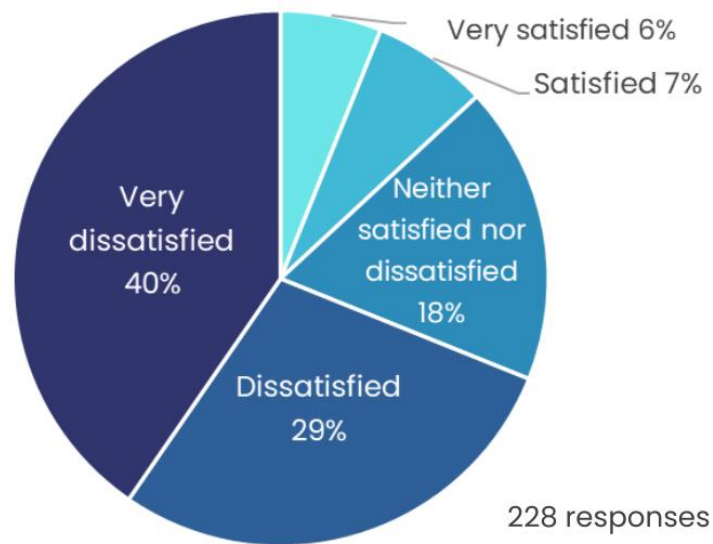
Monitoring child or young person's needs



Information provided about child or young person's rights



The way in which professionals work together



Question 20: Please use the text box below to add any additional information about your answers to question 19. 91 responses.

Of the **91** responses covering the five areas in question 19, **20%** made reference to their experiences about professionals and services not working together:

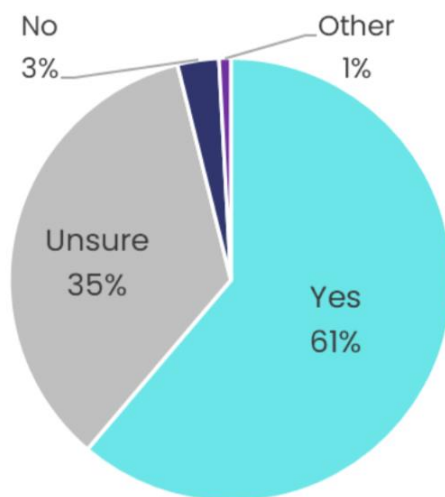
“No-one works together. When we did have a social worker, CAMHS never attended any meetings, even when they were on a child protection plan. Everything is very disjointed and relies on the already very overwhelmed parent to chase and communicate between services.”

13% of the responses commented on the lack of information:

“The professionals assessing our child were generally good... However, the exception and the weak link was ESCC whose reticence meant that support and information was non-existent. We have carried out a lot of research ourselves and sought the help of a professional advocate to speed up the progress of the SEN appeal and to add legal weight to our evidence and concerns.”

Question 21: In addition to existing service provision, is there any other kind of support that isn't in place currently that you think would be helpful to support you or your child or young person's needs? 232 responses.

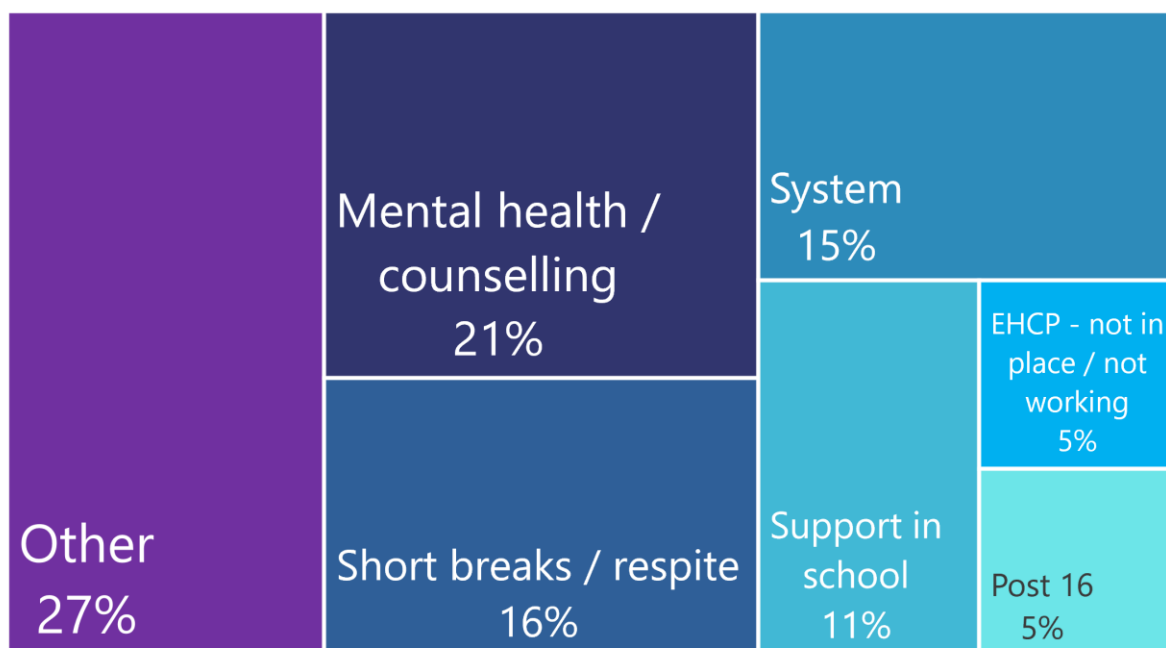
Is there any support not in place that would be helpful?



Question 22: Please use the text box below to add any further information about your answer to question 21. 145 responses.

These responses identified support that would be helpful but is not adequately available within existing provision. The chart below indicates common responses.

Support that would be helpful



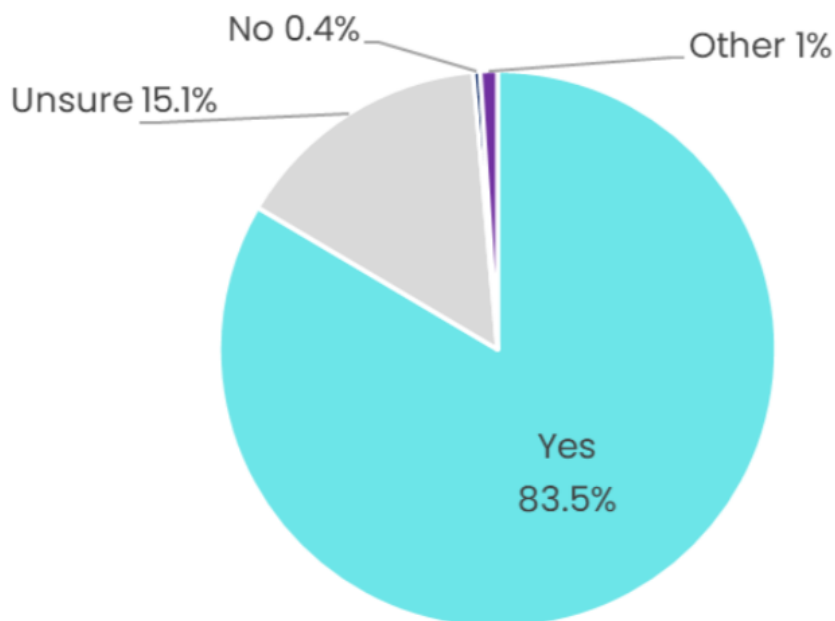
“Children's and young people's counselling services – particularly for neurodivergent children who require a different understanding and approach.”

“Support with getting some respite. Both me & husband work full time & with such high needs it's exhausting. Clubs I have to attend with my child as he requires 1:1 due to flight risk.”

“We need support as parents in navigating the Byzantium systems... We all don't have the pockets, mental ability and strength.”

Question 23: Thinking about SEND provision in the county, is there anything that you think should be done differently in the future to improve provision and better meet the needs of your family? 225 responses.

Could anything be done to improve provision?



Question 24: Please use the text box below to add any further information about your answer to question 23. 172 responses.

The responses were varied but it was possible to group *most* under three main categories:

System: 105 responses

Communication: 42 responses

Funding: 22 responses

“A supportive and understanding process from the outset of identifying your child has special needs. Not constantly having to knock down the brick walls put in place. I feel very much we were constantly being pushed to electively home educate. We were able to afford to pay for the help we needed to keep our son safe. My fear is what has happened to all the families who could not sustain the fight as we did.”

“Professionals and organisations please, please stop treating us families and children like we are your enemy.”

“Listen to the family and child. Treat all children as individuals and give them the help that’s needed for them to be an equal member of society.”

“More support for parents who self-fund private education when child not coping in mainstream; a contribution towards fees would be far, far cheaper than a LA funded specialist placement.”

Question 25: Are there any other comments or suggestions you’d like to share about your family’s experience of SEND provision in East Sussex? 116 responses.

An overwhelming majority of **76%** gave additional information about the system and the exhausting need to battle against processes in an attempt to ensure their child or young person’s needs are met.

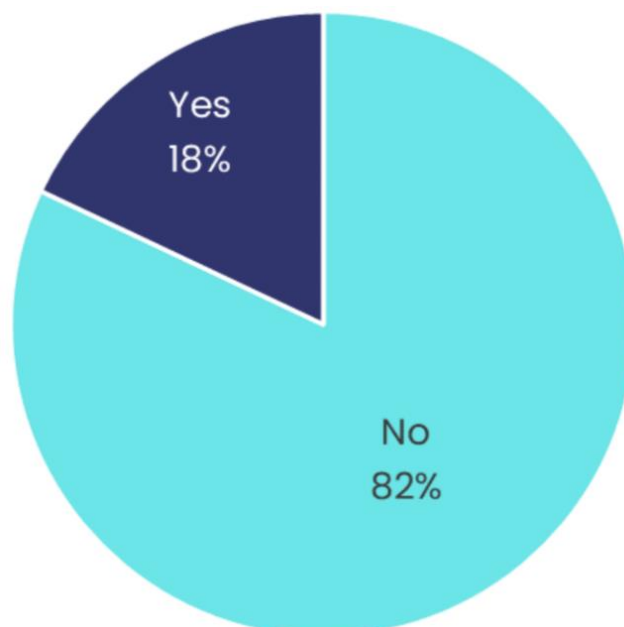
“It is a huge amount of work and stress for families already having to manage children with challenging needs. It feels like a series of hurdles to see how long you can keep fighting and like a flowchart process rather than looking holistically at a child’s needs and what’s best for them.”

"It's been horrendous. Has broken us and we are still fighting 5 years on.... Even the appeal process is being ignored by ESCC and had to raise with judicial team to decide how to proceed when we have just started appeal process. None of this should be needed and evidence should be used correctly, not forcing parents to spend £1000's to prove what is already known to fight an unfair battle all the while your child loses their childhood and chances in life diminish due to the discrimination and thoughtfulness of those involved. There needs to be some repercussions/fines for every incorrect action taken, any deliberate misinformation given and a direct link for parents to raise concerns/referrals where schools do not support. Again, LAs should have more authority over schools where no EHCP in place."

This survey also asked **three questions intended to learn more about children and young people's voice**, including understanding potential barriers to engagement, as detailed below. Local services are working to increase engagement with young people and ensure that their voices are being heard. This is in terms of both strategic work feeding into relevant services (in a similar way to ESPCF representing parent carer voice to services), and the individual voice of the young person, for example in their EHCP.

Question 26: Have you, or has your child or young person, heard about opportunities for them to get involved/share their views, and if so, what have you or they heard about? 189 responses

Heard about opportunities for child or young person involvement or share views



There were varied responses for the 18% who said yes:

Yes	10
CYP would not attend/unclear if heard about opportunities	9
Views sought for EHCP review	7
Had fed back views via ESPCF	4
Hospital Questionnaire	2
Advert in town	1
Views sought at Milbrook wheelchair services	1

Question 27: Have there been any barriers or reasons why your child or young person has not been able to or not wanted to get involved? 162 responses.

Unaware of any opportunities	66
CYP would not want to or would not be able to participate	62
CYP has lost trust and would not feel listened to	18
Barriers with access such as time and place	10
Unsure or N/A	6

Question 28: Is there anything that might make a difference to your child or young person being able to share their views? It would help to hear about things they may find would make it easier, or things that may make it more difficult. For example, if they were supported by you or another family member/trusted friend, a teacher, an advocate, or someone to represent them directly. 134 responses.

Of the **134** responses, **60** replied that the right support would be needed for their child or young person to be able to share their views. This could be parent or family support, a trusted adult or an advocate.

17 respondents commented that a lack of trust and a belief that they would not be listened to prevented their child or young person presenting their views.

9 respondents suggested acquiring views via questionnaires or other online methods that would allow the child/young person to express their views anonymously.

“Send my kids a questionnaire and they will fill it in. Let them give their views in a Zoom Conference without using their full name: their generation is conscious about digital footprint and may not want to be the Face of Autism etc in the future.”

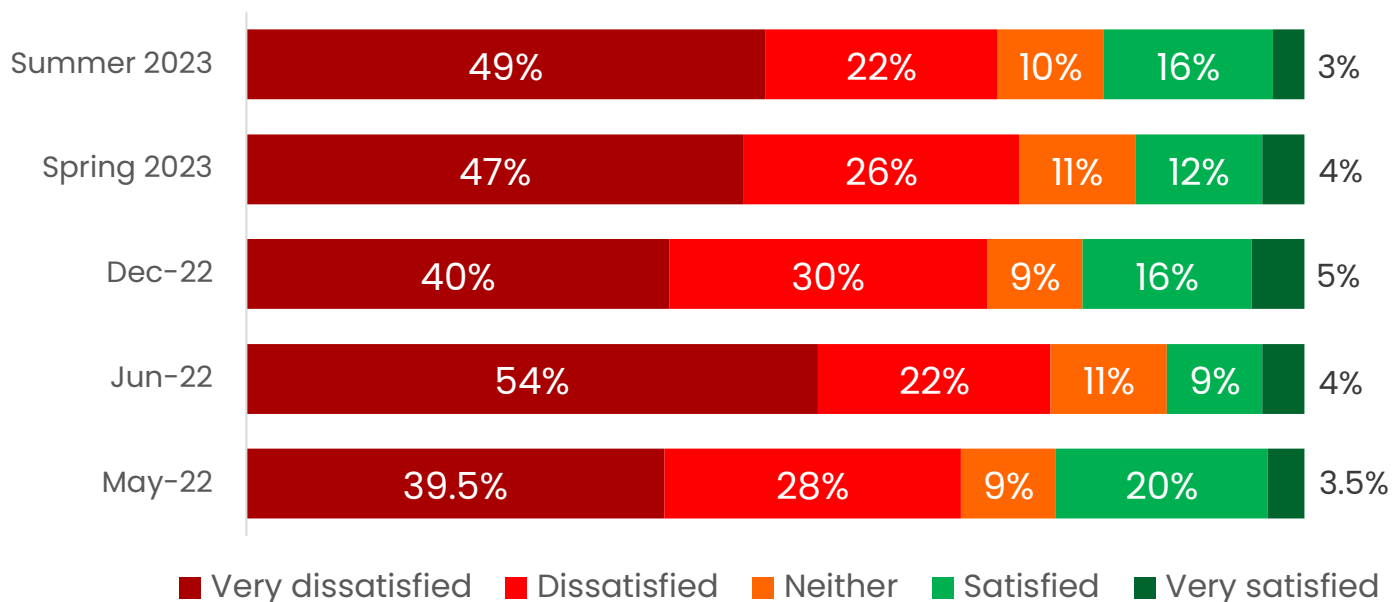
“Support from a trusted individual. Having the option to engage either online, in person or by phone. Apps are always welcome especially for teenagers to engage.”

“Giving them something in terms of SEND support so they can have a view would be a great start given my son believes nobody cares because he is not smart enough.”

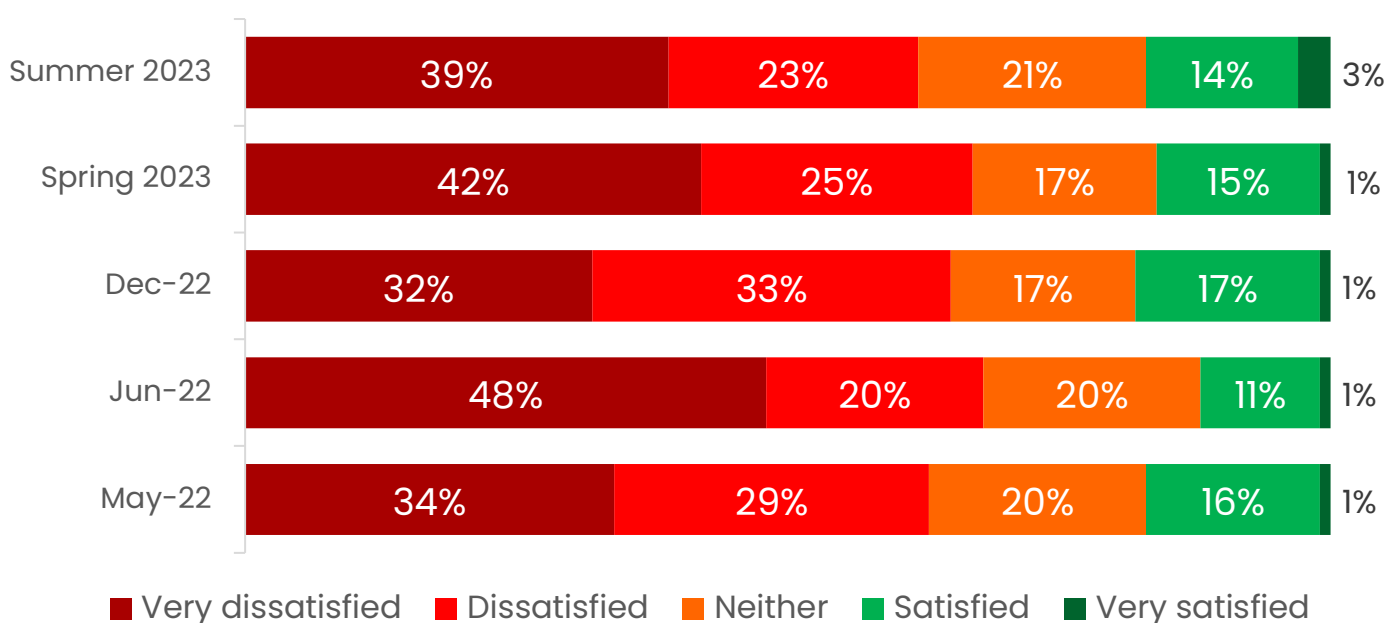
ESPCF temperature checks: results

Questions 1: Overall, how do you feel at the moment about the support and/or services for your child/young person with SEND in East Sussex in the three main areas of education, health, and social care?

Education



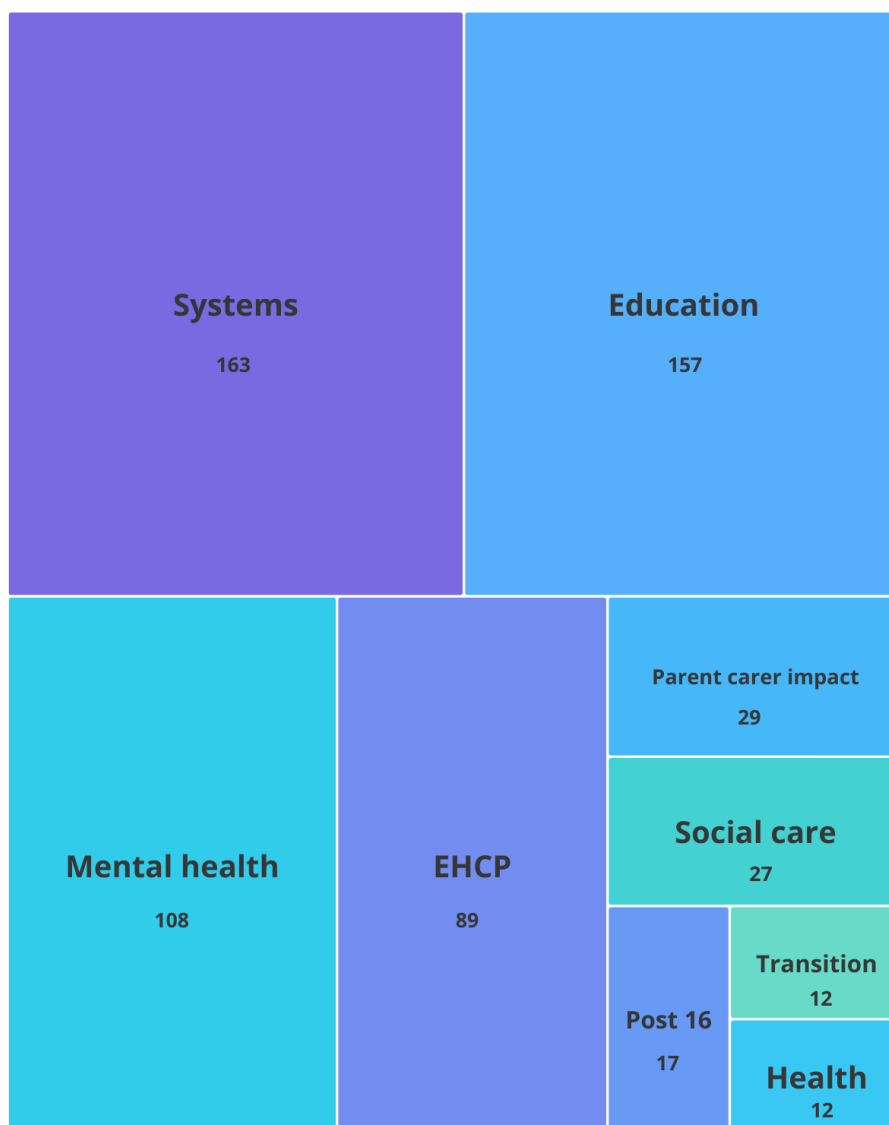
Health



Question 3: Is there anything else, good or bad, that you'd like to tell us about at the moment?

The five temperature checks which ran from May 2022 to July (summer) 2023 provided **614** comments which described the problems parent carers have been experiencing.

Categories of problems/issues described by parent carers in temperature checks



Numbers show the total comments for each category

There were also **30** comments that provided some positive feedback. These are included in full because it's important to recognise where there is good practice and the impact that it can have for families:

Amazing nursery.

Both of my boys are now well supported in school which I am extremely appreciative of, having had a number of traumatic experiences in the past. Having a good SENCO is always good!

My child is supported well at the moment but the extra help available seems to tail off as kids get older and I am concerned for the future.
However, with other issues, and providing extra support for my son, the school have been brilliant! It's just the lack of communication from the teacher that has really caused issues.
My son finally got his school move during summer term to new school and senco support in new school is amazing and so on point where as old school was non existent.
Plumpton and dv8 are both working well for my children.
I've put dissatisfied for education because that's overall but there is one teacher who has been amazing because I think her son is autistic so she gets it a bit better.
My son is supported by an amazing teacher. That he will lose next September.
His E Learning with TLP is BRILLIANT. the service is fabulous and has been great for my son. The teachers are kind and gentle with my fragile son and they have really helped his confidence grow. Please pass this on to ESCC because I wish other send departments had their attitude.
ISEND have been amazing stepping in and helping my children thrive.
An excellent EHCP process.
Good support from ISEND to get special school placement.
My APO is giving me hope.
Daughter (6) received review from CLASS , which is incredible.
Class have been more helpful than any other services although even they are a bit textbook and school staff should already know the basic things they are saying.
ESBAS anxiety 1-1 keyworker has been great, but her time has come to an end before the next step is fully in place sadly.
Our Ed Psych, OT, and ESBAS anxiety specialist have all been amazing support.
Class and class plus are brilliant!
Really pleased SEND kids are now included in HAF summer programme.
CAMHS have been superb .
CAMHS nurse is productive.
We have just been awarded some direct payments for my learning disabled little boy which will be so amazing and helpful to all our family.
GP, college, groups in Bexhill are great.
Millbrook have been really helpful with my son's wheelchair when it broke they were really quick to sort it and really helpful and easy to deal with.
Health has been good with my daughter's epilepsy.
Eggtooth project and education futures trust are amazing.
Good - Amaze Charity have been the biggest and best support for me so far.
Love the work you (ESPCF) do, to give parents a voice in helping improve local services.
ESPCF has been amazing support thankyou to you all.
You're (ESPCF) doing a brilliant job. Thank you so much.

The final words in this report come from East Sussex parent carers:

“We've felt really alone for years when trying to get help and the only people who have been helpful are other parents, not the people being paid thousands and thousands of pounds but without actually helping. Other parents I speak to are all saying it's really bad out there too and we're all desperate for something before our kids are adults and even more forgotten about.”

“It's been horrendous. Traumatic. Poor. Years of let down and fighting. Had to leave my career to support son. From year 2 onwards, even with EHCP, provision was poor and experiences horrendous. Finally, year 9 it is good, and my children are being supported.”

“So often, if parents fight, we are seen as troublesome. I think the county council lose sight of the fact that all we want is for our children to be supported with their SEN in order for them to meet their full potential.”

Glossary of acronyms

ADHD	Attention deficit hyperactivity disorder
APO	Assessment and planning officer
ASC	Autistic spectrum condition
CAMHS	Child and adolescent mental health services
CITES	Children's integrated therapy and equipment service
CLASS	Communication, learning, and autism support service
CLASS+	Communication, learning, and autism support service
CYP	Children and young people
EBSA	Emotionally based school avoidance
EHC NA	Education, health, and care plan needs assessment
EHCP	Education, health, and care plan
EOTAS	Education otherwise than at school
EP/ED PSYCH	Educational psychologist
ESBAS	Education support, behaviour and attendance service
ESCC	East Sussex County Council
ESPCF	East Sussex Parent Carer Forum
HAF	Holiday activity fund
ISEND	Inclusion, special educational needs and disabilities, now called Education East Sussex
JSNA	Joint strategic needs assessment
LA	Local authority
OT	Occupational therapist
PDA	Pathological demand avoidance
SaLT	Speech and language therapist
SEN	Special educational needs
SENCO	Special educational needs co-ordinator
SEND	Special educational needs and disabilities
SENDIASS	Special educational needs and disabilities information and advice and support services
TLP	Teaching and learning provision