East Sussex
Parent Carer Forum

Representing the views and experiences of SEND families in East Sussex

November 2024

Contents

About ESPCF

ESPCF is an independent parent carer-led organisation **representing the views and experiences of over 1,000 parent carers in East Sussex** about what life is like for their children and young people aged up to 25 with special educational needs and/or disabilities (SEND). **ESPCF's priorities are determined by the feedback it hears from parent carers**, and it works alongside education, health, and social care to try to bring about positive change in SEND support and provision.

This report sets out key information about ESPCF and summaries of the main themes and issues drawn from the 2,565 pieces of feedback it has received from parent carers, and feedback from partner groups and organisations and local communities.

How parent carers share their experiences

Parent carers share their views and experiences in a variety of ways, including:

- Focus groups
- Polls and surveys
- Coffee mornings
- Information sessions
- Social media, emails, and phone calls
- Membership form feedback
- School visits
- Engagement sessions in community venues, e.g. community centres, shopping centres, local events
- Consolidation of themes / needs with partner groups and organisations, including Amaze's SENDIASS, Parent Groups Befriending and NDP services, ImPACT support group, Holding Space, T21 Friends

How ESPCF represents those experiences

The lived experiences and views of parent carers are fed back to East Sussex County Council (ESCC) and NHS Sussex in a number of ways:

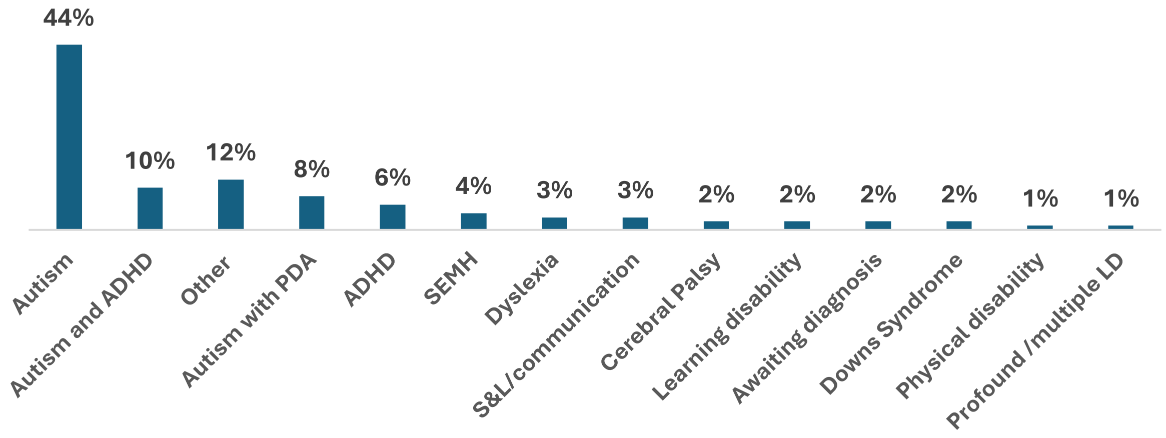
- Working directly with services as part of **operational workstreams**. ESPCF considers this to be the most effective way for parent carers to have their voices heard in a way that can make a real impact on the outcomes for families.
- Being part of and involved in the **strategic work** of ESCC and NHS Sussex. While these meetings do not deliver outcomes in the same way as operational groups, they are important discussions where parent carer feedback needs to be presented and where family voice should have an influence in strategic direction.

- **Engagement events and focus groups** attended by senior managers and practitioners, whether in person or online, are an effective way in which parent carer feedback can be shared and where direct, productive two-way conversations can be had. These events can also help to bridge the gap between families and professionals/practitioners. ESPCF would like to see more of these.
- Parent carer feedback is sometimes obtained through **specific surveys and polls** and on these occasions the feedback is collated into a report that is provided to the relevant service(s).
- ESPCF has on occasion fed back the experiences of parent carers and their families by way of a **position statement**. These have been created when ESPCF has wanted to convey that the perspective of parent carers differs from the viewpoint of the service(s) in question.
- The feedback of parent carers is sometimes sought for **documents or letters** which are being developed or are under review.
- ESPCF representatives are occasionally asked or request to be involved in **recruitment processes** (job description development, shortlisting, interview activities, and panels). This is usually for senior and/or strategic roles or those that have direct impact on co-production and/or service delivery where parent carer views are important.

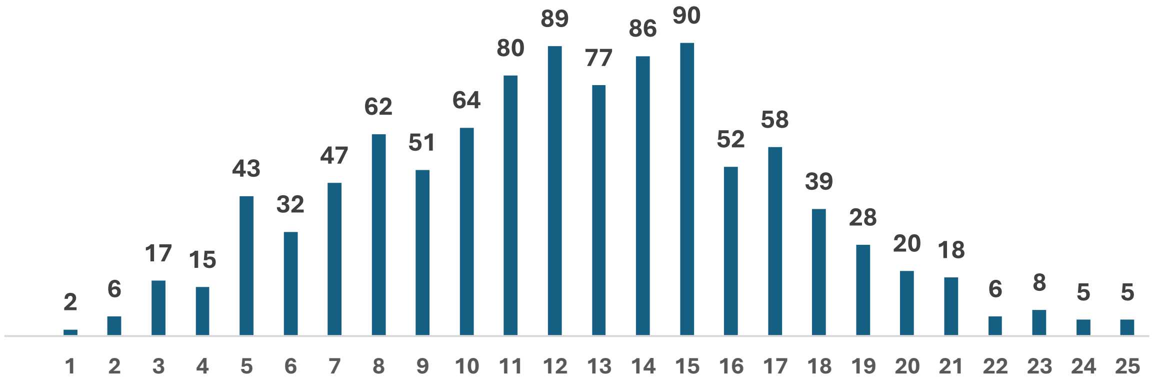
ESPCF membership data

- **1,040** parent carer members
- **68%** of members have children and young people with autism and associated conditions
- Remaining **32%** cover a wide spectrum of additional needs and disabilities
- **1,900** Facebook followers
- **977** members in its closed Facebook group

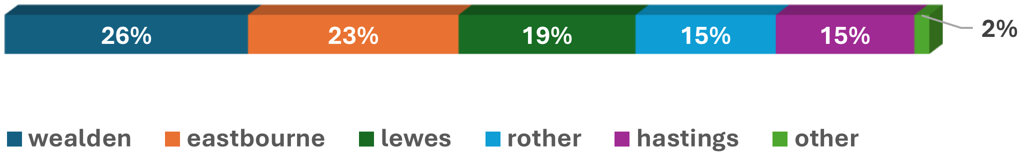
ESPCF membership by primary additional need ('other' category represents each of the conditions that are represented by less than ten families– such as spina bifida, obsessive compulsive disorder.)



ESPCF membership - ages of 1000 children and young people represented (not all members provide this data)



ESPCF membership by district ('other' category indicates families living out of county using East Sussex schools and/or other services)



Governance and structure

- Steering group of parent carers providing oversight and strategic direction, including representatives from local partner groups and organisations
- Currently 3 part-time staff working combined 63 hours per week - equivalent to 1.8 full-time staff
- 4 additional part-time staff working on specifically funded, time limited projects equivalent to 0.8 full-time staff
- 10 parent carer ESPCF representatives plus others who volunteer on ad-hoc basis
- Charitable status with back-office support and hosting provided by **Amaze**

Parent carer feedback

ESPCF was established in November 2019 and officially launched in January 2020. The Covid pandemic and subsequent lockdowns quickly became a priority, and the forum worked to support families through the pandemic. Parent carer feedback during this time was mostly relevant to the difficulties families faced coping with the pandemic.

In Sept 2021, ESPCF developed a system to collate the feedback from parent carers into the most prominent themes. This detailed feedback, which now spans more than three years, **reveals the areas which cause the most difficulties for families and shows that very little has changed in that time**. ESPCF acknowledges that East Sussex County Council (ESCC) has made changes and is working towards improving services, but **the feedback is a strong indicator that the struggles faced by some families have not eased since the 2021 Joint SEND Needs Assessment**.

ESPCF would like to stress that although it does not reach every family of a child or young person with SEND, some of whom may receive a good, adequate or possibly a bad service, the adverse feedback from over 1,000 members should be acknowledged as significant.

It is also important to recognise that the majority of ESPCF members face struggles that have a negative impact on the quality of life for their children/young people and their families and continue for many years. **It is ESPCF's role and responsibility to represent these experiences**, as per its mandate, and work in partnership with ESCC, health, and other partners to seek service improvements and development. This report catalogues these concerns for the purposes of the area SEND inspection in November 2024. It is ESPCF's hope and intention that the key themes do not come as a surprise to its partners, as they are issues that the forum has previously identified and fed into various meetings and workstreams. ESPCF is committed to continuing to work together with partners on the conclusions drawn from the SEND inspection and the implementation of emerging recommendations.

It is clear that lots of the negative experiences that this report conveys relate to a lack of resources within the system and immense pressure on services and staff. ESPCF does not repeat this throughout the report or seek to differentiate between what is system/resource determined or otherwise – it has to take this as a given and hope the feedback can be received with the knowledge that ESPCF understands the challenging context. As has been reflected in many a partnership meeting, **the challenging context can never become a reason for not listening to families' experiences**, however challenging they are to hear. ESPCF believes that these system pressures make it all the more important to work together with families affected by decisions to ensure that the limited funding, time, and workforce are deployed in ways that have the most impact to improve experiences and outcomes for children and young people.

ESPCF parent carer feedback

2,565 parent carer feedback comments have been collected and collated into themes from Sept 2021 – Aug 2024 sourced from a range of activities, including:

- **2,134** parent carers took part in **192** events and feedback requests Sept 2021 – Aug 2024
- **235** parent carers responded to ESPCF's parent carer survey with questions based on the 2021 JSNA
- **843** parent carers provided feedback to ESPCF 'temperature checks' Dec 2022 – Nov 2024
- **194** parent carers responded to a poll on autism, ADHD, and mental health waiting lists
- **69** parent carers responded to a poll on mental health support in schools

ESPCF also has a wider reach into the community, for example via partner groups and organisations supporting parent carers across East Sussex, as well as via several broader local-based groups on social media. Common themes, scope of issues, strength of feeling, or specific examples are noted, but the comments are generally not recorded in the same way as feedback submitted to the forum directly.

Feedback themes

ESPCF has received extensive feedback from parent carers, providing **2,565 comments**. The word 'comments' is used in this report to encompass the entire range of individual and group feedback submitted to the forum, which includes extensive, detailed emails, as well as shorter, more informal submissions.

These comments have been recorded by academic years:

2021/22 – 785 **2022/23 - 991** **2023/24 - 789**

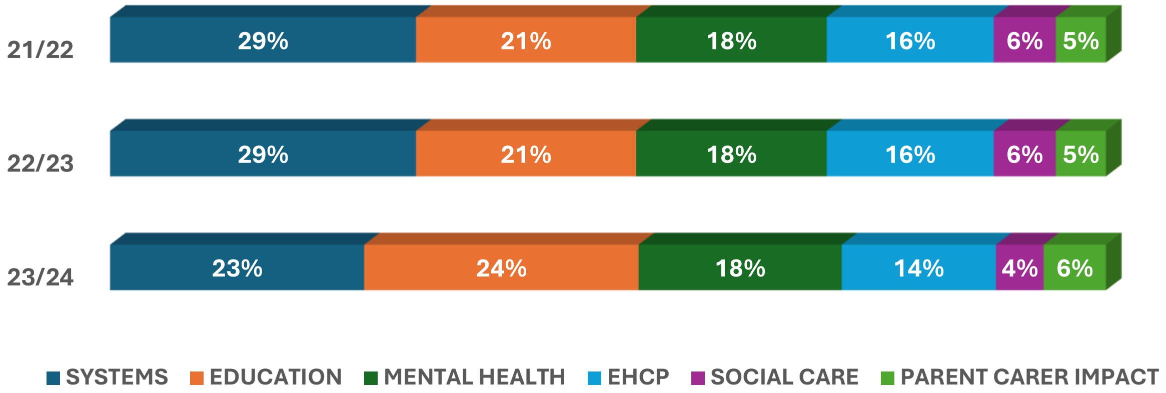
ESPCF has received a further **236 comments** collected during the months of September and October 2024. At this point the top six themes show a slight variation (see charts on page 10).

The data has been sorted into themes. These were selected in accordance with the topics within the feedback and then divided into sub-themes as shown in the chart below. It should be noted that these themes are not static and new sub themes are added when there is sufficient feedback to indicate issues.

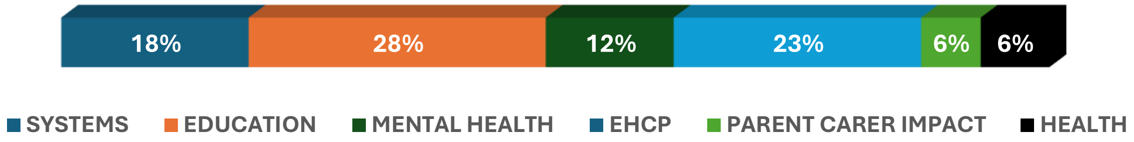
THEME	SUB-THEMES
SYSTEMS	Fight/battle with the system/complex system; disregard p/c view; difficulty finding info and advice; lack of support; finance before need of children and young people; lack of monitoring and accountability; lack of joined up working; diagnosis/assessment waiting time; communication
EDUCATION	Poor/no school support; poor staff/senco; P/T timetable; exclusion; home educated elected; Home educated needs not met; behaviour/reasonable adjustments
MENTAL HEALTH	CAMHS waiting times for MH/diagnosis; ND; Communication; Lack of support; School/EBSA;
EHCPs	Tribunals/appeals; communication; quality of plans; quality of assessment; refusal to assess; decision making; school/senco; social care; complex system; transport
SOCIAL CARE	Specialist respite; short breaks; assessments; adult social care
IMPACT ON PARENT CARERS	Health / wellbeing / Mental Health; finance / reducing or stopping work
HEALTH	Physical Heath; CITES; other
POST 16	NEET; Lack of support/provision
POSITIVE FEEDBACK	It has not been straightforward to divide this into themes, but feedback is documented to highlight services and provision that are repeatedly mentioned.
TRANSITION	Education - all phases; health children to adults; social care children to adults
EARLY YEARS	No sub-themes

Parent carer feedback top six themes September 2021 to August 2024

(The total does not add up to 100% because these charts do not include all the themes, only the top six.)



Parent Carer feedback top 6 themes Sept and Oct 2024



Positive feedback

It is important from the outset to acknowledge that there are many dedicated and knowledgeable staff and practitioners working hard to try to support children and young people with SEND and their families. Parent carers have shared the following examples:

"New school and senco support in new school is amazing."

"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!"

"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."

"Our Ed Psych , OT, and Esbas anxiety specialist have all been amazing support."

"Early Years Service are involved with my son at nursery who are fantastic."

"We have an amazing SENCO at school and the school itself are great, so we are lucky there."

"CLASS+ is brilliant."

"Small Beginnings group has been supportive and helpful."

"Enjoying attending the small beginnings group, getting helpful support and advice there."

CAMHS parent carer participation group

ESPCF works with the CAMHS participation team holding monthly sessions for parent carers to speak to CAMHS staff about the issues they are facing and to discuss ideas for improvements. Parent carers have commented on how much they value the opportunity to have these conversations, and while there are difficult messages being shared, and opportunities for progress or influence are not as anyone involved would like things to be, the openness and honesty from everyone is refreshing. It is something that should be replicated across other teams and departments as a model for how to keep conversations going and build relationships despite challenging circumstances.

Please see the *ESPCF co-production and involvement* document submitted alongside this report for additional examples of positive working.

The picture painted by this positive feedback, while very heartening to read, does also suggest that good practice is often the result of dedicated individuals rather than being embedded system-wide.

Battling the system

The most common feedback ESPCF has received since the forum was initiated in November 2019 has **not changed** and was noted in the JSNA in 2021:

*'There was consensus that **accessibility** of SEND services and support needs to be improved, with many citing the feeling of **having to 'fight'** to access SEND support'.*

The feedback ESPCF receives from parent carers describes the exhausting and ongoing battle they face with the system. These battles are not short-lived and commonly last several years.

It is clear that many families are not supported sufficiently to understand their rights. This situation has existed for too long and should be a priority action for ESCC and NHS Sussex.

Difficulty accessing support

ESPCF hears from many parent carers who are exhausted and overwhelmed. The key message is that while caring for a child/young person who has SEND may bring its challenges, it is **the system** that wears families down.

ESPCF has feedback from parent carers who note there is a **significant gap between what the law states as their rights and entitlements and what families experience**. Many parent carers comment about the lack of advice from ESCC on how to navigate the system to access appropriate provision for their child/young person and that the only way to get through the bureaucracy is if they themselves become experts on SEND legislation. This leaves children and young people's needs insufficiently or inaccurately identified for too long, so they don't receive the right support at the right time.

Disregarding of parent carer views

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. Parent carers are not given credit for their knowledge and in some cases are blamed for their child's behaviour, rather than the underlying needs been acknowledged.

This disregard for parent carers is especially important as so often the onus will be on parent carers who find they need to convince practitioners that their child/young person has needs that are not being met. The result is the continuous need to battle/fight the system.

Difficulty finding information and advice/complexity of system

Feedback indicates that the **ESCC system of how to seek support is far too complex and needs to be much more straightforward**. Systems are complicated; information is either lacking, difficult to find, or overwhelming and confusing. Parent carers want greater clarity and openness about navigating the system.

The long waiting lists within CAMHS for a diagnosis mean there is an urgent need for services to provide information and advice while families are on the waiting list, but parent carers regularly tell ESPCF that their calls are not returned and correspondence not answered. They comment on **being passed from pillar to post and talking to staff who themselves do not understand the system and cannot help them or signpost them elsewhere**. The information they are given is often out of date and at times parent carers have been guided to provision and services without being told they are no longer accepting new referrals, for example as happened recently with the sleep service.

The ND Family Support Service launched in November 2022 and run by the charity Amaze is providing an invaluable service for families with children with neurodevelopmental differences. However, it would need significantly more resources and increased capacity to meet the needs of all families who need this support. See Document 1 – NDP Report 22-23.

ESCC processes

The feedback from parent carers who stress their battles with the system have commented on some of the processes that hinder their access to support.

The **lack of joined up working across departments is a frequent complaint** with the result that families are required constantly to repeat the same information time and again. Not only is this frustrating for parent carers but also seen as wasting the time (and therefore finance) for the practitioners involved.

The **shortage of funding is well-known by families who are aware that this impedes ESCC in delivering its legal obligations**. However, parent carers say in their feedback to ESPCF that they feel there is a lack of honesty and transparency about finances which create a sense of mistrust.

Parent carers report a **lack of real monitoring and accountability within ESCC services**. When mistakes are made or systems do not work as they should there is little acknowledgement and in several cases, bad practice by named individuals has continued despite an acceptance of wrongdoing.

Lack of support

ESPCF regularly hears from parent carers about the lack of support, including insufficient or no support at all for families awaiting assessment/diagnosis. Children and young people are often **left to struggle at school while their needs are not being met**. Parent carers are left trying to cope with **increasingly difficult, stressful, and upsetting situations**. They often report feeling isolated, having to conduct their own research or rely on peer-to-peer help, while left in limbo.

Impact on parent carers

As already noted, parent carers repeatedly tell ESPCF that it is their battles with the ESCC system of education, health and social care that wear them down, with common descriptions of feeling **isolated, overwhelmed, exhausted and not knowing where to turn** for support.

There is significant data showing how common it is for parent carers having to **reduce their working hours or in many cases needing to give up employment all together**. There are examples of parent carers losing the businesses they have worked hard to create because the needs of their child/young person are not being supported.

This has serious financial implications for families which in turn places additional demands and pressure on the already stretched system of benefits. It doesn’t help that the process of applying for benefits are in themselves complicated and often entail yet more battles with the system.

As well as the financial implications, the effect of ‘fighting the system’ has an **enormous impact on the heath and wellbeing of parent carers and their families**. These long-term effects and exhaustion can gradually erode resilience leading to serious health problems for parent carers, and in some cases a family breakdown.

As reported in the JSNA in 2021 many families cited ‘*the feeling of* ***having to ‘fight’*** *to access SEND support’* and the feedback to ESPCF shows this has not improved. ESCC has a responsibility to make sure parent carers and young people are involved in the decisions that affect their lives; they need to be listened to and not disregarded and not left to battle against ESCC to access services.

There needs to be straightforward and basic information much more widely available in places such as GP surgeries, hospitals, nurseries and childminding services. Parent carers may have concerns about their child’s development at an early age and having readily available guidance can make a significant difference.

Although the Local Offer has improved many parent carers still find it complicated and confusing. There needs to be more work to find out from parent carers what would help them find the information they need.

All educational, health and social care practitioners who come into contact with children and young people with SEND and their families should have basic knowledge on where parent carers can access information, advice and support. The engagement work that ESPCF has done out in the community shows that many of practitioners have no knowledge of signposting for SEND services and support.

There needs to be improved support for families and carers less able to navigate and access SEND provision, particularly more vulnerable parent carers with barriers to accessing information (EAL, own learning needs, low confidence, digital poverty etc).

Mistakes need to be openly acknowledged, and lessons learned, with visible changes made where required, demonstrating greater accountability.

Parent carers need to be informed about delays and given as much information as possible. Comments show that a lack of resources is understood when the facts are provided.

Parent carers say…

“Everything is a fight - deferring a school place, accessing the right school, therapy, equipment, transport, EHCPs - a ghastly, complex and time-consuming process. It is a full-time job to fight for the rights of your child and although you hear everyone say that the parent has a voice and will be listened to - ultimately, everything comes down to money/funding. The fact that you have to be at breaking point to access a social care/continuing health care assessment is at its very root fundamentally flawed. Then you embark on an utterly harrowing six-month process.”

“As a parent it's hard not to suffer from ongoing depression as a result of caring for one's child whilst fighting for their support. Life mostly feels very bleak.”

“Although we are really satisfied with her school now she is at a school that is meeting her needs including her healthcare needs with doing physio etc we have had a really hard time over the years to fight and fight for things from the council and NHS. That has all been more hard and exhausting than looking after my daughter even with everything she needs doing for her. We're made to feel she's just a burden and drain on the public purse.”

“The system is broken, it’s so complex and stressful and as a parent you feel lost, with no unbiased support. Fighting for what your child legally deserves shouldn’t be so difficult.”

“Our family is in crisis but there is nowhere to go for help. We are battling for the right school. We are battling for mental health support. We are battling for an ADHD assessment in the hope that medication helps. We have no respite. I am broken by it all and I feel that the people who are meant to help us are instead crushing us even more.”

“We shouldn’t need to fight so hard for what our kids are entitled to.”

“I feel I’m like I’m at the bottom of a big mountain and I have to figure out where to start climbing.”

“It takes a long time to get support. It shouldn't depend on good luck of having a good teacher or Senco or TA.”

“Everything is a constant fight and battle. There’s not enough services out there at all. It’s exhausting. I feel constantly let down. And banging my head on a brick wall.”

“How on earth do people cope if they don’t know how to access, or what to access?”

An East Sussex parent carer writes from a mental health crisis unit about the personal impact of battling the system

“For the past 18 months, my 10-year-old child has been without suitable full-time education or support. That’s not just a statistic – it’s 18 months of providing round-the-clock care, with my husband and I tag-teaming 16+ hours daily, while trying to maintain jobs, a household, and some semblance of normality.

“I’m not just providing care – I’ve become a full-time advocate, legal researcher, case manager, and administrator. Every email, every form, every appeal falls on my shoulders.

“The cost has been enormous. Beyond the obvious financial strain of reduced hours and lost jobs, there’s a deeper toll. Marriages strain under the weight of constant crisis management. Mental health erodes from the relentless pressure. Physical health suffers when self-care becomes an unaffordable luxury. The system doesn’t just fail to support – it actively creates new challenges, new crises, new breaking points.

“Mental health professionals couldn’t comprehend how we’d been left to manage this alone for so long. They were horrified by the lack of education provision, the absence of respite care, the overwhelming administrative burden of fighting the system. Yet their horror, while validating, came too late—at the point of crisis, when prevention was long since possible.

“The mental health team was shocked by the education system’s failures. The education system points to mental health support that doesn’t exist. Social care remains conspicuously absent. And families like ours fall through the ever-widening gaps between these services.”

Support in schools

The second most common theme in the feedback ESPCF receives from parent carers is the lack of adequate support for children and young people with SEND in mainstream schools.

There is a strong indication within the feedback from parent carers and the data from ESCC that **SEN support is schools is inconsistent and repeatedly inadequate**. This feedback highlights how the top four feedback themes – systems, education, mental health, and EHCPs - interrelate:

- Additional needs not recognised or acknowledged by school
- Needs are not agreed without a formal diagnosis
- The long waiting lists mean significant delays in diagnosis
- Children and young people experience long delays in accessing and receiving mental health support
- When there is a lack of reasonable adjustments and a lack of mental health support, the incidents of EBSA and/or part-time timetables/exclusions increase
- Parent carers continually and consistently report how their views and experiences are not accepted and the knowledge they have about their own child/young person is disregarded. For many this is the beginning of a long battle to get the right support.
- The subsequent gaps in SEN support in schools results in the high number of applications for an EHC needs assessment. This application is the start of the long-lasting fight that parent carers report on the EHCP process, appeals and tribunals, and the quality and implementation of EHC plans.

Lack of support/trained staff

School staff, including SENCOs, are often **not adequately trained and skilled to support children and young people with SEND**. This is particularly so with those who are neurodivergent. The common trait of masking in autistic children and young people is not always acknowledged and complex needs (such as PDA) are not understood.

See Document 2 – PDA Position Statement

Parent carers relate the lack of support in schools and report that despite the requirement for any additional needs to be recognised and met there are still staff who inaccurately state a diagnosis is needed. ESPCF feedback has many examples of parent carer views and experiences being disregarded and even disputed. This refusal to acknowledge parent carer voice is the key reason that there are still high numbers of families needing to ‘fight’ the system.

Access to specialist support

Access to speech and language support, and occupational therapy support, from therapists in mainstream schools is very unlikely. This can lead to an EHCP being required to ensure appropriate support.

Support is increasingly given via school staff, who are not adequately trained or specialised in these areas.

See Document 3 – ESPCF interim report SALT support Nov 2024

Neurodivergent children and young people

The difficulties of **getting needs correctly identified, and getting the right support at the right time for neurodivergent children and young people is a significant issue in East Sussex**, and one which there has not been sufficient progress in addressing for several years.

There are **long waiting lists for neurodevelopmental assessments**, such as for autism or ADHD, and **progress on addressing this has also been limited**.

See Document 4 - ND Position Statement May 2024

There has been a lot of talk about developing a ‘needs led approach’ across Sussex. Whilst ESPCF supports the fact that needs should be met without needing to wait for a diagnosis first, it should actually already be the case that support is needs led. The word ‘diagnosis’ does not appear in Part 3 of the Children and Families Act 2014, which is the legal framework around support for children and young people with SEND. **It is therefore challenging to see a ‘needs led approach’ being presented as something new or revolutionary.**

There has been considerable time spent looking at various ND profiling tools, with the aim of adapting one for use in East Sussex. However, **ESPCF feels that looking at profiling tools without considering the wider context of the areas they are being used is not ideal** – such as the Portsmouth Profiling Tool, which is actually used as part of a wider approach to ND support in their city, not as a standalone tool.

ESPCF is pleased that some professionals recognised the limits and potential for harm instead of help from some of the tools considered.

Whilst a more positive, generally neuro-affirming profiling tool has been identified to be trialled, ESPCF as well as children and young people, have raised doubts as to whether this is the right place to focus time, attention and resources as the potential impact is dependent on school environments, staff knowledge, understanding and skills, all of which still require significant improvement to be consistent across all schools.

The PINS (Partnership for Inclusion of Neurodiversity in Schools) and Autism in Schools projects have potential to bring improvements in the trial schools, and hopefully wider learning. The right conversations need to happen to identify barriers to implementing improvements as there have already been worries raised by school staff about how they can make changes within the existing system constraints, despite their best of intentions to try.

Dyslexia

- Recent feedback from parent carers has reported **confusion - previously raised - over what support is available as children and young people with specific learning disabilities are not being recognised at school**. Parent carers have said they have no knowledge of a pathway to support these specific difficulties. Parent carers are either not told if any support is bring provided: *"The lack of communication about any additional help with dyslexia is non-existent."*
  Or note that the support is unsatisfactory, for example infrequent or poor use of laptops despite it being "*such an effective tool in helping the children achieve better results. This should surely be standard practice."*
- In June 2021 ESPCF representation was requested for a dyslexia working party that planned to re-visit and update the dyslexia identification pathway in East Sussex schools. Two workshops were held in early 2022 as an opportunity for parent carers to share their lived experience and views
- A number of suggestions were made by parent carers, some of which were taken forward for the work on preparing resources.
- The importance of a *diagnosis* was noted by all parent carers. This was not only about ensuring the right support but for other reasons such as helping friends and family to understand and validate their child or young person's difficulties, and to provide a formal 'explanation' to potential employers.
- Parent carers also noted that the media representation of dyslexia has significantly improved, providing many positive examples of people with dyslexia overcoming their difficulties and a reason for seeing the diagnosis as helpful.
- ESCC has taken the decision to use the term 'identification' of dyslexia instead of 'diagnosis' of dyslexia stating, 'It is believed that using the term 'identify' is likely to work better in helping to protect a child's fragile self-esteem.'

School exclusions and part-time timetables

The ESCC self-evaluation document recognises that attendance for pupils with SEND remains below the national average and that 'despite improvements in permanent exclusion rates for children with an EHC plan, suspensions and permanent exclusions for children with SEND remain a concern'.

Although the percentages fluctuate, the **top four feedback themes from parent carers over more than three years have remained consistent: complex systems, education, EHCPs and mental health**. The detailed comments from parent carers provide a compelling indication that these themes are interrelated and that in these situations the resulting poor support within schools can lead to part-time timetables, exclusions, and parent carers home educating because their children and young people's needs are not being met. At this stage some children and young people become disengaged and the return to education becomes even more difficult.

Alternative Provision (AP) is not considered or implemented in a timely way, such as being considered when a child is facing barriers to school attendance, multiple fixed-term exclusions, or at risk of permanent exclusion.

Lack of reasonable adjustments

ESPCF has heard from many parent carers who have experienced **zero-tolerance behaviour policies within schools with an assumption that behaviour is deliberate and in the control of the child/young person**. They are then sanctioned for making “poor choices”.

Any expectation of behaviour must take account of children’s individual needs and how these needs (whether met or unmet) might affect their behaviour. Parent carers regularly report that children and young people with SEND are being punished for breaking the rules. This is particularly common in schools where the rules about school uniform are strict and rigid with no allowance made for children who (for example) have sensory processing differences.

Some parent carers have reported that this intolerance has increased or even created difficulties for a child or young person’s mental health and wellbeing. There is also significant feedback that as a result of trauma at school, some children and young people have been diagnosed with PTSD, or experience suicidal ideation or attempts. This is particularly the case for neurodivergent children and young people.

All schools need staff who are able to understand and support neurodivergent children and young people thus providing a whole school approach. This is particularly so for SENCOs who should not take up the role without some initial training. The three years allocated for the SENCO qualification is too long and undervalues the needs of the children and young people requiring support.

SENCOs need to have the skills and the authority to train and/disseminate good practice to other school staff. They need to be given the time to complete the requirements of the role and schools need to value their SENCOs. Ideally, they should have a position within the Senior Leadership Team to ensure that all staff understand their own responsibilities in supporting children and young people with SEND.

There needs to be a clear pathway for children and young people to obtain mental health support to ensure that it does not become a barrier to learning. Around half of schools are without Mental Health Support Teams, and where children and young people are supported by MHSTs the support and approach need to be reflected in the classroom.

Schools need to operate with a firm but fair behaviour policy, where there is flexibility and consideration of reasonable adjustments.

Until such time as SEN support in schools meets the needs of children and young people, there will continue to be a high demand for EHCP NAs.

Parent carers say…

“My daughter is being discriminated against almost every single day by teachers and the senco, headmaster, everyone who doesn’t understand autism and expect sen kids to behave like there's nothing wrong with them. This is having a really bad effect on her mental health and on her education because she's spending so much time out of class. I've had to give up my job because I have to keep going in to school to settle her but they say they don't need to do more to help she just needs to make better choices. I don't know what to do.”

“My adopted son has a reading age of a 7-year-old, disengaged with education finally in yr 7 due to lack of dyslexia support. His mental health is rock bottom. 29 schools have said they can’t cater for need. We had to pay for every assessment to prove his needs as LEA and NHS spent ten years telling us he was fine, and it was our parenting that was at fault. He is now too complex for schooling?? He has FASD, ADHD, ASD and severe dyslexia.”

“School have only recently referred to child development now they have seen emotional regulation issues appearing, although I’ve been asking for support for 5 years. School support needs to be far better as I feel the issues for me and my son have now been worsened by the school disagreeing for so many years that he needs some extra support.”

“My son is being extremely let down and set up to fail in his current mainstream setting. He is now at risk of permanent exclusion. I try to call services and they either do not answer their phone or do not come back to me.”

“Not enough help and support in the classroom, the child wants to go to school but cannot get enough support to properly fully access the curriculum.”

“Finding school very difficult at the moment and resulting in significant challenging behaviour at home. I am trying to get EHCP for my daughter but her school is not helping much so feel very alone fighting this battle.”

“I feel the education system sets up neurodiverse children to fail with blanket behaviour policies, lack of understanding and tolerance.”

Mental health

Lack of support

Lack of support is the overwhelming issue facing many families where a child or young person is experiencing mental health challenges. Feedback shows that this is the case across the spectrum from mild to severe mental health challenges.

As set out in Document 5 – ESPCF's parent carer survey report:

- 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**. Parent carers 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.

See also:
Document 6 – ESPCF report on communication while on autism, ADHD, and mental health waiting lists
Document 7 – ESPCF report on support in school and college for children and young people with 'mild to moderate' mental health needs
Document 8 – ESPCF report on accessing mental health and social care
Document 9 – ESPCF report on NHS keyworker service for East Sussex

Parent carers report being **left to research and seek resources themselves** while in a state of limbo, on a waiting list, uncertain if and when any support will be offered and with no help in the meantime to prevent a deterioration in their child's mental health. They also cite being blamed and told the child's problems are due to behavioural issues and attention seeking.

Where support is available in schools, for example with a counsellor, the capacity does not meet the numbers in need and is subject to long waits.

And instances where mental health support does occur – and parent carer feedback includes some examples of dedicated professionals who have made a difference at critical points in their child's life – often the resources and capacity are not there to sustain it longer-term. There is a particular worry from parent carers about support received in primary school not being available once their child starts secondary school.

NDP transformation agendas have not focused at all on the acute end of the pathway. This means when the SEND (special educational needs and/or disabilities) communities across Sussex ask their parent carer forums what is happening to address the systemic failures in the system identified by inquests, such as that of Jessie Eastland Seares, there is no information to share and no reassurance that much-needed service development is happening.

See Document 10 – Jessie Eastland Seares inquest

Threshold for accessing support

Parent carers being told by mental health services that help cannot be provided until their child has actively tried to take their own life is extremely distressing. To wait until the worse-case scenario unfolds is, quite obviously, too late.

Appropriateness, timing, and suitability of support

When mental health support is provided, some families have reported inappropriate techniques or strategies, e.g. 'think happy thoughts', interventions that are all about breathing, or sessions that feel 'awkward or patronising' for the child, or overly formal.

See Document 7 – mild to moderate mental health needs.

Feedback flagged a gap in support groups for teenagers with mental health needs, and particularly for minorities.

Parent carers have **praised some of the support offered by school nurses**, but there is also concern from families about the short-term nature of the support (e.g. only six sessions) and what will happen once it finishes.

ESPCF were told by CAMHS that the **evidence base for the Stepped Care model they have introduced is weaker for neurodivergent children and young people**. Some parent carers have reported their child being discharged because they have not been able to engage with group support.

Transition to adult mental health services

Parent carer feedback indicates that the transition from CAMHS to adult mental health services for their young person is not smooth. Young people are not being given the tools and support needed to manage this significant adjustment and are therefore unprepared. As a result, the fight for support becomes even more challenging.

Support for autistic children and young people

Communication from CAMHS remains unclear as to if and how it offers mental health support to autistic children and young people. Whilst there is not a blanket policy stating they do not provide support for anxiety to autistic children and young people, in reality **CAMHS support is frequently denied on the basis that the child or young person's anxiety is as a result of their autism rather than a mental health concern**. This is an ongoing source of frustration for families, and also relates to parent carers' views being disregarded. Where parent carers have seen the changes in their child or young person over time as their anxiety has increased, this should be better acknowledged and families included in conversations around what is or isn't appropriate support. This has been highlighted in multiple sessions of the CAMHS Parent Carer Participation Group, but no progress has yet been made.

School environments and rigid policies can be particularly oppressive for neurodivergent children, which can lead to masking, or distressed behaviours, which can lead to poor mental health.

See Document 14 – ND mental health workshop

Lack of training

A recurring issue across many themes is insufficient training for school staff, and this is true for mental health support. Mental health needs don't fit into boxes – a child's individual needs need to be better understood and met – and teachers should receive adequate training to be equipped to help meet this need.

Parent carers say…

"I have pleaded with various people within CAHMS to speed up with the assessment because of the situation and his mental health. He has said he doesn't want to exist, hates his life, is useless, pathetic and life is torture. I am not getting anywhere and desperate for help and support. Having worked in a school as an INA and seen things first hand, I would like ALL teaching staff to be much more educated on mental health and SEN."

"No one (school, GP, SPOA, camhs) seems bothered about my son's mental health other than his current teacher. He has low self esteem and regularly says he wishes he was dead. We are struggling big time!"

"LA legislation surrounding mental health difficulties and neuro diversity is complicated. Stuck in a vortex of child unable to attend school due to anxiety and mental health difficulties, school/LA won't recognise private reports from psychotherapist but can't access CAMHS for 2 years. The LA and school feel that fining is the answer...."

"GPs do not know what to do with children like ours suffering anxiety/mental health. Children's Services don't want to know either, so where does it leave us? Paying for a private child psychology report is extremely expensive, starting around £1500 just for the report, and then there are the therapy sessions starting at approximately £50 but can be as much as £90 per session."

"Our GP referred to CAHMs due to my son self-harming during a meltdown and our concerns over his mental health but they immediately discharged him citing that there was nothing they could do due to him being autistic."

"It is a minefield, often I feel lost and not sure who can help or where I can reach out for help."

“Like many other parents we felt very much left to get on with it with no guidance on how to support our child navigate her mental health challenges.”

“After many, many years of fighting, ostensibly my son has been offered a creative group therapy as well as family therapy. Both of these are a 40-minute drive away, in school hours. So practically-speaking, I am supposed to pull one child from school twice a week and another child (for the family therapy) also from school weekly. The two children’s school are a half hour apart. As jaded as I am after all these years, it seems designed to fail before it even begins. And I’m supposed to keep a job with this too?”

“Overall, the ‘things’ put in place were ok (ELSA, sensory group, RAG cards, slightly later arrival, phased return, working outside the classroom etc), but the slow speed of intervention, how well/quickly we were listened to, the language used towards us/our child, and how we felt blamed instead of supported etc, made for a very miserable experience. Support is not just “things you do” but how you develop a real sense of partnership with a child and their family, and how you work together to solve problems and create a sense that they belong and are valued within the school community, for both child and parents. We feel that this point gets lost in discussions about reasons and interventions and staffing etc and should be more prominent in EBSA guidance for schools.”

“The delay in supporting my child and the opinion of LA workers going against professionals’ opinion and advice has meant my child will now never return to school. Their mental health got so low they wanted to unalive themselves. Yet CAMHS declined to support, and LA declined to support. Having been out from year 7 they should now be in year 10, but after two tribunals and three appeals, costing the public purse a ridiculous amount, we now have an EOTAS package, awarded through tribunal. Key elements of this are still not in place, causing other provisions to not be as accessible as they could be.

“As a result, and at further cost to the public purse, I had to close my business last year and my health was affected to the point where I now cannot work, relying on universal credit and am applying for PIP. My own debts including credit cards to fund assessments to counter someone's opinion are costing me £75 a month in interest alone. I am very close to losing our home which will mean I will also need housing benefit.

“The knock-on effect is horrendous. I was once independent. I know I am not alone in this. This could have been so much better if I’d have been believed.”

Emotionally based school avoidance (EBSA) / attendance

EBSA is intrinsically linked to mental health and school support issues - two of the themes that feature prominently in parent carer feedback to the forum. Lack of support in school for children who are struggling to cope can cause or exacerbate poor mental health leading to a downward spiral where school becomes a barrier.

Key issues

Parent carers feel blamed by school and services for their child not being able to go to school. They are not listened to and valued as experts on their child and the difference between their child not wanting to go to school and not being **able** to go to school is not acknowledged or understood. The focus is wrongly on changing child and parent behaviour rather than on improving the school culture and environment. Feedback reports that this is particularly so when a child or young person has PDA. The low demand requirement can wrongly be seen by school staff as poor parenting with no boundaries. It must be recognised that parent carers *are* the experts on their children. Their knowledge and experience should be valued. The child's voice must be at the heart of everything.

The **relationship between the school and the family** should not be understated. Having a trusted adult for the family to liaise with is paramount, and maintaining this link when the child is not attending is crucial if reintegration is to stand a chance of succeeding.

It is important for schools to be **flexible** and not undo work done during reintegration. For a child with EBSA to be back in school and then be penalised for minor infractions could potentially undo all the good work in helping them back to school.

School staff do not have sufficient training to be equipped to understand and support children who are at risk of EBSA. School staff should be able to recognise early signs that a child may be at risk of EBSA so that interventions can begin immediately to support that child and their family, and measures put in place before the child starts to disengage.

As mentioned earlier in this report, **attendance and behaviour policies are too rigid**, and do not allow for consideration of EBSA. Reasonable adjustments to these policies and practices does not always happen.

The term **'emotionally based school avoidance' is problematic**. Parent carers say the condition is more akin to school-based trauma as a result of unmet needs.

Despite a promising start during 2020 to 2022, **co-production with parent carers has not been maintained** – in fact, it has lessened dramatically. There is more detail on this in the ESPCF co-production document, but ESPCF is very concerned that if this situation doesn't change, then the hard work of the EBSA parent carer working group will have been in vain. Services need to include parent carers at the earliest opportunity to co-produce training and guidance for schools and services, and guidance and support for families. Unfortunately, **while writing this report, ESPCF became aware via ESCC social media of a new EBSA project seeking parent carer views of which ESPCF had not been made aware**, despite the availability of two knowledgeable EBSA parent carer reps.

Lack of provision for children unable to attend school (there is overlap between this issue and EBSA)

- Disputes over local authority (LA) duties as per Section 19 of the Education Act 1996, which states 'local authorities shall make arrangements for the provision of suitable education at school or otherwise than at school for those children of compulsory school age who, by reason of illness, exclusion from school or otherwise, may not for any period receive suitable education unless such arrangements are made for them.'
- Families get caught in the middle of LA and school each saying the other should be responsible for providing education when child unable to attend
- Often means child is left with no education, and can also affect their mental health and wellbeing, access to social activities.
- Interim Provision Service/Teaching and Learning Provision (TLP) has some more positive feedback for those able to access it, however the lack of access is an issue.
- Families cannot self-refer to TLP, and schools must have recorded absences as illness/medical on the school register. It can be very difficult for families to obtain sufficient medical evidence because of barriers and challenges in accessing other services. This is amplified for children and young people who do not yet have any formal identification of their SEND e.g. diagnosis or an EHCP.
- There is a lack of clarity around the criteria for TLP access, with some families being told their child must be receiving consultant level care.
- Provision is not always sufficient, such as only a small number of hours a week for a child or young person who would be able to access more.
- Provision is not always provided in a timely manner. A small number of parent carers have had to complain about this, including via the Local Government Ombudsman.

Parent carers say…

"My son has EBSA. There is no education and nothing for his mental health. The support is invisible. My son and us (his family) feel invisible to everyone in positions that are meant to help him."

“My daughter has been out of school for most of last year. Lots of local authority bods involved in meetings and still no action plan. For a child that needs consistency, forward planning, and safety, it’s totally useless.”

“My child is currently only spending 30 minutes a week at school. This is due to the school (mainstream) being unable to adequately support him with a 1-2-1 and therefore adequately safeguard.”

“I had to deregister my son from school due to unmet SEND needs and him experiencing autistic burnout which caused a mental health crisis. School were not supportive, even suggesting I drag him there in pyjamas. I’ve had to give up work to care for him. I feel very let down by the system.

“They say the school can meet needs. She’s not attended fully for three years. How are they meeting needs?!”

“Son is unable to access a school setting. Barriers to attendance: anxiety, trauma, lack of trust, poor mental health. Has been turned down for TLP and AP due to cost to LA. Have had to self-fund for private provision with huge impact personally and financially.”

“So angry, upset, frustrated! Everyone passing the buck, everyone stating lack of funding or all AP placements full, meanwhile, where does that leave my kid?”

“We have been telling our child’s school for over two years what needs to happen but it was just ignored and now we are in a situation where our child is missing huge amounts of school. This could have been prevented.”

See Document 11 – EBSA for me: an ESPCF member’s story

Education, health, & care plans (EHCPs)

Complex system

Overall, the EHCP system is overwhelming for families. The concerns are longstanding and well documented. The parent carer voice section of the 2021 SEND JSNA stated that although there were some examples of things working better, "the majority of comments relating to EHCPs were to note that the whole EHCP system was not seen to be working well to support people."

The JSNA also noted that 'There is a strong view among families that the Council process itself presents a significant barrier to support.'

Sadly, more recent feedback from parent carers indicates that these feelings are *increasing* rather than *improving*.

The overwhelm is amplified when statutory processes are not completely followed properly. It is very **difficult for families to find help and advice**, because the information available online for example will state what *should* be happening, however where things are not being done properly, parent carers have a challenge to work out how the information applies to their case, or which stage they are at and therefore what information is relevant to them.

It can be difficult to get support. The SENDIASS advice line is valued, but the service is not able to provide casework support that some families feel is so desperately needed, nor more in-depth help such as individual meeting preparation or attendance, drafting paperwork/forms, checking draft EHCPs.

"I wish more practical help were offered. Everything is left on the parent's shoulders. I do not know when to turn and where to begin."

"The East Sussex pathway puts the onus on the parents to beg for help and instantly disables the child and family from taking part in normal activities with the view we are asking too much of an overloaded system"

"The whole pathway approach is broken. Nothing is made easy for the children or parents who due to the conditions of their child already have additional pressures. The current process only adds to that pressure and therefore causes mental health issues which adds more pressure to the healthcare system. The approach to identifying an educational setting

took from November to September for us and to have so many schools say no is absolutely heart breaking as a parent, especially when these are schools you didn't want. Communication on the process is absolutely critical and when there isn't any it adds to the emotional stress."

"It makes my blood boil that they (children and young people) have to become overwhelmed and struggling in order to evidence the need for an EHCP or any other help for that matter just because they don't listen to parents."

"I wouldn't wish the stress of trying to ensure your child receives their right to an education, and to be believed about their struggles on my worst enemy. The pointless appeal systems for quality written EHCPs and adequate placements is unnecessary."

Communication, information, and transparency

Communication, proactive and accessible information, and transparency are problematic at all points of the process. This can start prior to the statutory process beginning, with **communication from schools being unclear and leaving families unsure what is going on**. There still appears to be a considerable amount of **misinformation or misunderstanding amongst SENCOs or other school staff** which is not in line with legislation. This is then passed on to parents and carers, adding to the confusion and overwhelm around the process. A common example of such misinformation is that an EHC needs assessment application cannot be made before the school has carried out three reviews of school-based support, or that they must have tried specific interventions for three terms.

Communication with ESCC assessment and planning officers is often very poor; it is not uncommon for parent carers to describe it as 'non-existent'. Parent carers have to chase officers for responses to emails or phone calls. Feedback gathered in November 2021 is still reflective of what ESPCF hears today.

See Document 12 – APO concerns

Families do not always know who their assessment and planning officer is, particularly when this has changed once or more during the process. This makes it difficult for families to know who their point of contact should be. Some parent carers have chased a response from their assessment and planning officer for weeks or months only to find out later they no longer work for ESCC.

No alternative point of contact is given to families who have statutory deadlines within a period when their assigned officer is on annual leave or off sick.

Parent carers are not routinely included in ESCC communications with schools during placement consultations. Families are not always made aware of which schools are being consulted, or of decisions or reasons that a school believes it can or cannot meet a child's needs.

There have been instances in which families have managed to have sight of consultation communications, sometimes only via a Subject Access Request, and have found that incomplete information has been shared with schools, so they were not able to provide a fully informed response.

Families often do not know where to go for information or advice, particularly for more in-depth support such as preparing for or attending meetings with school or services as SENDIASS are generally unable to provide this level of support.

“Our APO seems lovely so it’s nothing personal, but she is really hard to get hold of and when we are in touch it’s clear she is just the messenger. I actually feel quite sorry for her having to be the one to always give the bad news and even she seems surprised by the decisions being made.”

“I’ve lost count of the number of APOs we’ve had in this 20-week process which started about 116 weeks ago because of having to appeal twice so far. Some have started and left before I’ve even had another reply to an email.”

Refusal to assess

East Sussex data shows that adherence to statutory timescales for new EHCPs is better than in other areas. This data should be considered alongside other data sets, including refusal rates.

The Department for Education (DfE) data from May 2024 shows that East Sussex was considerably more likely to refuse an EHC needs assessment the previous year than other areas (41% refusal rate vs the national average of 24%). Where these decisions are appealed, **almost all decisions are found in favour of the parent carers**, whether via SENDIST judgements or decisions being changed and appeals conceded by the local authority. The appeals process can take quite some time, leaving the child or young person without appropriate support in the meantime for a significant amount of time.

Refusals are often felt to be a delay tactic, or a way to put parent carers off pursing support.

Whilst only a relatively small number of refusals to assess are challenged via the appeals process, it would be remiss to assume that families agree with the local authority’s decision in all other instances, or that the decision would not also be found in their favour were they to appeal.

Families report a multitude of reasons for not appealing, including but not limited to: not knowing anything about the process at the time; lack of time; despair; exhaustion and overwhelm as this often comes after battling with the system outside of the EHCP process for some time; cost or perceived cost; or the parent carers’ own needs.

Refusal to assess letters are usually very generic, making it difficult to know the specific reasons for the refusal. Letters tend to say that needs can be met in mainstream school without an EHCP - this creates distrust amongst the community, as it is felt this is said too freely, without a thorough, individual, child centred decision-making process, so families do not know when this in fact *should* be the case, or when an EHCP actually *is* required.

> *"It would be good for council to not refuse as a means of delay and to put people off"*

> "Currently fighting with the council and going through appeal. The process method in relation to appealing the EHCP decision as it does not think of the child who is in the same position for over a year which is very upsetting."

Quality of assessments

Assessments are not always thorough. Sometimes advice and information are obtained from **professionals who have not met the child**, instead having a telephone conversation with the parent carer.

Occupational therapy and speech and language therapy assessments in particular are not always carried out even when they are reasonably believed to be necessary.

Parent carers report feeling they need to **commission independent professional assessments** to ensure all of their child or young person's needs and required provision are fully and accurately identified. This can cause frustration and upset further down the line if recommendations from independent professionals are then not included or are removed from the draft or final plan.

There is **some positive feedback about the assessments and reports by ESCC Communication, Learning and Autism Support Service (CLASS)**, with the reports described as being detailed and accurately reflecting the child. However, even these internal services reports are not always included in the contents of the plan. ESPCF heard from a parent carer who is having to appeal sections B and F through the tribunal process in order to get recommendations from CLASS included in the EHCP.

Quality of plans

Provisions recommended in professional evidence is not always included in the EHCP. This is especially the case with information and recommendations contained in independent professional reports commissioned by parent carers, generally because of lack of access to ESCC/NHS services, or concerns about the quality of assessments and resulting reports.

Provision is not always specified and quantified as per legal requirements. Wording is either too vague, or there have been clauses added saying that the SENCO/school will review provision at a point outside of any formal review process, thus giving the family no right of appeal if provision was changed or withdrawn.

Parent carers views are not always listened to and valued.

Parent carers have had to go through the tribunals process to get wording agreed, causing further delays and adding cost for all parties, and additional stress and overwhelm for families.

"They just ignored about three quarters of everything recommended in various evidence. You can tell that they were trying to take out things that will cost extra money. They put a few bits back in when I made it clear I wasn't going to be asking for a special school which leads me to assume they were manipulating section F around their school choice not around [Name]."

"Our youngest has an EHCP at last but in reality, it's a useless paper exercise that has made no difference!"

Social Care

Social care sections D and H were previously often left blank, or when information was requested the response would simply be that the child was not known to the service. When ESCC started using the Invision 360 auditing tool this was highlighted as an issue. Some stock phrases were therefore developed which are used to satisfy the Invision 360 tool, instead of leaving sections blank.

However, although appearing as an improvement to processes in this audit process, this **does not bring any improvements for families**, as access to social care assessment and or support remains very difficult to get, and the standard stock phrases stating there are no social care needs is being used even when families are saying this is factually incorrect.

Heath needs

Health sections were often left blank, or now using stock phrases.

In a current case ESCC has removed all the diagnosis information, which has been there at every review, from Section C and has informed the parent that going forward medical needs will only be mentioned if they are 'very significant'. It is **not clear yet whether this is a one-off case of misinformation, or a policy direction**, nor is it clear who must rate the severity of medical needs, and how they are qualified to do so. There are concerns that removing this information affects schools making fully informed consultation responses.

Families have reported delays due to disagreements as to whether support constitutes health provision, or education provision, and therefore who must agree is and fund it.

Personal budgets

Lack of information given to parent carers, including where a personal budget may be appropriate.

Generic phrases have reportedly been put in section J (personal budgets) stating that personal budgets have been discussed with the family, despite this not necessarily having happened.

Families receiving personal budgets have reported having to chase payments. There have also been examples of successful provision being lost for this reason – tutors or therapists who have had to stop working with a child or young person due to being unable to afford the payment arrears. This is particularly upsetting for children or young people for whom change is very difficult, and/or those who need considerable time to build up a trusting relationship before being able to work with a new professional. ESPCF hopes the new brokerage team in ESCC should address this issue.

Direct payments, which some families would prefer, are challenging to get agreed and in place.

“Section J says ‘Personal budget was discussed with parent/carers’ but again it wasn’t discussed at all”

“Our APO has apparently never heard of personal budgets.”

Implementation

ESPCF is not aware of any formal processes or arrangements in which the local authority checks that provisions in EHCPs are secured in schools/settings. It frequently hears from families that the support that is meant to be in place is actually not happening. This is across a range of different provisions, including 1:1 support, speech and language or occupational therapy sessions, safe spaces, additional scaffolding around academic tasks.

Where provision lacks specificity and quantification, it makes it difficult to know what should actually be in place.

When provision is not happening, the advice from ESCC is for parent carers to contact their assessment and planning officer. However, communication with them is poor, as more fully outlined above.

A parent carer shared an example of their young person’s EHCP which names a placement they have never actually been able to attend. The college placement has been named in the plan for two years. The parent carer said they don’t know whether the college has received any funding for their child, whom the college has never even met.

“Where is the speech and language therapy and occupational therapy? Where are the reasonable adjustments from schools? Where is a senco who knows what they're doing? Where is the provision in EHCPs? Where has my APO gone? Where is CAMHS? Where on earth is social care? Where is anyone who cares? So let down.”

“I thought getting the EHCP would be the hardest part of the process but making sure that what is detailed in the plan is in place in school has been exhausting. The school is continuously short-staffed and this affects the support they are able to provide. The SENCO has several other roles to fulfil in the school and is not able to dedicate her time to SEN issues as she should. I worry that I am not clued up enough to know what should be happening as it is a complicated area and I am concerned, not only for my child, but for those children whose parents don't know their rights.”

Decision making

Parent carers feel removed from the decision-making process, with little opportunity to share their views.

Information about decision-making and panels is vague. A parent carer shared copies of emails between officers in which vagueness and not including too much information was being encouraged.

ESCC senior officers have repeatedly described decision-making as ‘robust’. Whilst this in itself would not necessarily be a problem, it is **important to ensure that ‘robust’ does not mean applying a higher threshold than the legal criteria**. The very high percentage of appealed decisions which are reversed, either by the tribunal, or by ESCC before the hearing date, would seem indicative of a flawed decision-making process rather than simply a ‘robust’ decision-making process.

“Provisions were taken out of the draft plan even though there was lots of clear evidence they were needed. When I asked why, they just said they didn’t think it was necessary but they had no evidence to back this up.”

“My son's education has been totally ruined all because some people sat in an office somewhere are trying to avoid paying for what he needs and instead used their money to make me go to court but then agreed at the last minute anyway but by that time it was too late and his mental health is so bad he can't go to any school at the moment and is not being given any alternative education. They have caused harm to my child.”

“We are currently appealing the LA's school decision for my son, it's a fight we shouldn't be having! He has an EHCP, is autistic, has severe global development delay, is pre verbal and has absolutely no danger awareness, but the LA in there infinite wisdom have decided that a mainstream school would be the best setting, even though 6 mainstream schools have said they are unable to meet my Son's needs, and two special schools have offered him a place, which the LA have dismissed. It is taking a massive emotional and financial toll on our family and we are exhausted with constantly having to fight for our Son's future. The system as a whole is completely broken!”

Tribunals/Appeals

Parent carers feel forced into appealing. They often have a wealth of evidence which feels like it has been ignored in the decision-making process, or certain needs or provisions removed or altered to fit a certain school.

Communication during appeals is poor. When appealing the contents of a plan some parent carers have been told that they cannot have any further discussions outside of the formal tribunal responses and evidence. This increases the adversarial nature of things and is not in the child’s best interests of resolving things earlier where possible, to enable to right support to be put in place at an earlier opportunity.

There is a feeling that the appeals process is used as a means of delay by the local authority. This is particularly felt by families in which their appeals are conceded by the local authority very late in the process before the hearing date, despite there being no additional evidence since previous decisions or responses.

Statutory deadlines are frequently missed.

"ESCC haven't complied with tribunal directions about the response and documents that should have been sent. Some documents haven't been sent and a lot of it is blank so I'm having to chase it and question things."

"I'm in the middle of a tribunal process appealing section F and I for change of placement. His needs have changed significantly which warrants specialist provision. We have had our parental preference reply to consultation stating they can meet need this but current school are still fighting stating they can meet need - I've provided lots of evidence to prove is not the case. We are also in the middle of phase transfer and I'm completely overwhelmed by the whole process at the moment."

"I applied for an EHC assessment in Nov 2020. I was refused by ESCC at every stage . ESCC carried out one assessment and refused to issue. I went to the SENDIST in July 2023 and the judgement issued in August 2023 was in my favour due to the lack of evidence from the LA . Despite the judgment the LA has failed to implement the plan due to lack of availability of teachers and they are taking a [lenient] approach about therapeutic support - OT / SALT / Therapy. My son is now in his third year out of school. He is isolated and his anxiety is severe. I have asked the GP / Paediatrician/ CITES and ND team for help. My son has received nothing."

"My son started an independent specialist school on Wednesday, and everything was agreed by consent over the holidays. It did however take many years of battling and lost education to get him out of mainstreams and he's 13 now. I appealed all 3 stages and won all of them without them getting to tribunal once. This was only because I was able to prove that no maintained schools were suitable along the way in 3 sets of consultations."

"When I got to tribunal told the Judge and Advisory Panel how emotionally exhausting this process was for parents. Especially when ESCC conceded at Tribunal - it didn't need to go that far. They agreed and held ESCC solicitor to account."

Annual Reviews

Timeliness of annual reviews has been problematic for several years. It has not been uncommon for ESPCF to hear from parent carers who have not had one year's annual review concluded before the next year's one is due.

It is not made clear to families that the annual review is more than just the AR meeting itself. Relevant information is not always gathered, or circulated two weeks prior to the meeting, as per the SEND Regulations/Code of Practice.

It is positive that ESCC have established a transitions teal within the EHCP assessment and planning department, and they are attending some annual reviews in key years. Whilst parent carer voice may have influenced this, it was not at the center of the development of the team/service. A valuable opportunity to ensure it was as helpful and effective as possible was missed. This could have included considering the scope of the team's involvement, and looking at how their role could support families before the meeting so they are well equipped and well informed for the process.

"They didn't even bother saying if they were going to amend/keep or discontinue this one, and haven't amended his EHCP despite recommendations and being asked to each year, his EHCP hasn't been touched since about 2020."

School/Setting

As outlined earlier, parent carers often have to battle the system within their child's school before even beginning the statutory EHCP process.

EHC needs assessment requests are not always requested by schools in a timely manner, for a multitude of reasons, including misinformation; pressures not to apply; limited time/capacity; not identifying or understanding underlying needs. This leads to delays in accurately identifying needs, and therefore also delays to getting the right support in place.

Previously ESPCF heard more positive feedback about ESCC Early Years teams supporting in applying for EHCPs. Whilst there is still some positive feedback about the early years team more generally, positive feedback in regards to help around EHCPs has lessened since the service changed their practice in this area.

"I'm currently going through the EHCP process it's utterly dehumanising to constantly have to prove your child's needs over and over again. It's also very frustrating as a parent you can spend ages collating evidence and giving reports from other professionals and for it all to be discounted on the word of school. The lack of understanding of autism among mainstream teaching staff is huge. Trying to get teachers to understand that autism isn't linear, abilities can vary day to day due to many factors and things such as masking doesn't mean a child is OK, it just means they don't feel safe enough to show you how they truly feel inside. So often teachers and support staff take external experiences and assume a child is "fine in school" rather than thinking about how the child's experience is and what they are feeling inside and just because they cannot see it, it doesn't mean it's not happening or valid!"

Transport

There have been instances where families have felt they have had to agree to transport their child to school themselves in order to get a placement agreed, despite maintaining that there is not a nearer or cheaper suitable school.

Communication is poor – families do not always know if transport has been arranged, or who will be collecting their child, particularly at the beginning of a new school year.

The statutory gap in 16-19 transport contributes to young people becoming NEET (not in education, employment or training) as they are unable to get to their placements.

There are often spikes in concerns in September – generally around the lack of communication about arrangements.

Since the beginning of this academic year concerns are building around proposed cuts to the home to school transport budget in 2025-26 and the impact on children and families. There has been a higher volume of concerns flagged regarding unsuitable arrangements being made. This includes additional children squeezed into taxis where there is not enough room to travel comfortably, which is particularly difficult for children with sensory differences. ESPCF has have been told this follows a direction from senior officers as part of a range of cost cutting measures across the county due to budgetary difficulties.
However, some families have described their child's transport arrangements as unsuitable and having a negative impact on their education once they arrive at school, which is not in line with case law in this area.

Home to school transport is covered in more detail in its own section below.

Social care

In the early part of 2022 ESPCF facilitated engagement events for parent carers to meet senior local authority staff. One of the themes was social care and ESPCF received **significant feedback from parent carers who had not been able to access any kind of social care support**.

See Document 13 – SEND engagement events 2022 parent carer feedback

In January 2024, ESPCF published a report on the East Sussex Single Point of Access (SPoA) and described the **difficulties families face in trying to access social care support**.

Document 8 – SPOA and access to services ESPCF report Jan 2024

ESPCF welcomes the improvements noted below that have taken place in the last year or two. However, there **remains a serious concern for the many families who have children and young people with complex needs and are not deemed eligible to receive any kind of social care support**.

Specialist/overnight respite

ESCC has acknowledged the severe lack of provision for families needing overnight respite. For many years the one dedicated respite service was used instead as a residential service. **ESPCF presented the feedback and struggles families were facing to the local authority and there have been some improvements.** One service is up and running providing some of the additional nights that are desperately needed. Two other homes have been renovated to provide respite and are waiting to be appropriately staffed.

This is a welcome improvement. However, there are **many families who are in dire need of respite in order for them to continue their caring roles** so the availability of provision against the demand must continue to be carefully monitored.

Short breaks

The engagement events in early 2022 highlighted the serious lack of short break activities available to children and young people with SEND. At one of these events the parent carers all agreed that their ordinary life for years and years has been the same as it has been for others during the Covid pandemic – restricted and regularly unable to go out.

In September 2022 the commissioning manager responsible for short breaks worked with ESPCF to seek the views of parent carers to find out what the gaps were and what services were most needed. Since then, the **amount of short breaks available have more than doubled. This has taken time and is still growing and developing but has been another welcome improvement.**

Feedback shows that there is **still a complete lack of activities suitable for children and young people with complex needs who cannot access universal or targeted services**.

Access

This is the **most pressing problem** in regard to social care as evidenced in the ESPCF SPoA report. There are many children and young people who have complex needs but **do not meet the very limited severe learning disability criteria of the Children's Disability Service**. Those who are not eligible are told to contact SPoA, but feedback to ESPCF shows that many families are not offered an assessment thus preventing access to support and provision.

The local authority SPoA webpage remains confusing and inappropriate for parent carers despite ESPCF requesting this to change. ESPCF parent carer feedback is varied on whether contacting SPoA has been useful, but even when it is, the criteria for support is high and there are gaps in services, leaving some families struggling and heading towards risk of breakdown.

Adult social care

Adult social care does not appear to offer an adequate and up to date service for SEND young people/young adults and their families. Provision is divided into autism and learning disability with no mention of support for those who are neurodivergent or have other additional needs.

The social care transition service is described as supporting *'young people with severe and enduring disabilities and their families through the process of moving from childhood to adulthood, and into Adult Services. Our main clients are those receiving a service from the Children's Disability Team'*. As noted above in relation to access, this transition service has already created a barrier with its similar eligibility criteria.

Parent carers have told ESPCF that this criteria is a real stumbling block with young people with SEND often seen as 'not disabled enough' and describing the move to adult social care as feeling like a cliff-edge with no formal crossover or handover.

The information on how to access social care support needs to be accessible, up to date and reflect the requirements of the Care Act. This includes the Single Point of Advice (SPoA) webpage which needs to be appropriate for members of the public beyond the information to report a concern.

The local authority needs to address the gap in social care support services for those children and young people who have highly complex needs and require specialist support but who do not meet the severe leaning disability criteria of the Children's Disability Service. The feedback to ESPCF shows that these families are not accessing help support and guidance via SPoA.

There needs to be a better understanding about the impact of a lack of resources and support and how the shortage of respite has for some families resulted in long term residential care for a young person. The whole family need to be considered to help them avoid exhaustion and breakdown.

Short break provision needs to be diverse and respond to the different needs of children and young people. Activities need full accessibility with a better understanding of personal care needs and availability of changing areas with hoists and changing tables.

Direct Payments need to be realistic and acknowledge that the salary for a Personal Assistant should reflect the skills required and the responsibility that comes with caring for vulnerable children and young people with complex needs

Parent carers say…

“Had respite but now closed. YP doesn’t sleep and needs constant support. Need time to get housework done, take a break and get energy back. Single parent with own health problems, essential to have a chance to recuperate and have enough energy to carry on caring role. Having no break makes health worse so constant vicious circle.”

“No nights off from caring for 10yrs. Despite very complex needs of children and young people, still almost impossible to get respite”

“Many years of waiting – family at risk so 6 weekly repetitive meetings where continually told no resources. Need more honesty”

“Her EHCP is not worth the paper it's written on and has never had social care included even though we are in desperate need of it. No one wants to take responsibility.”

“Frustrated that the lack of services social services has to offer doesn't seem to be being addressed”

“Social care has offered absolutely nothing appropriate even when we have been at breaking *point as a family”*

“We get told our home is unsafe for our disabled child (which we already know) but no financial support to change it. This means our son requires 1 to 1 support. We get promised respite but they carers are paid so little we can't recruit one.”

“Currently the criteria are very problematic. An assessment that considers the whole family impact of needing/not having access to respite would be helpful.”

“Direct Payments need to be more realistic – pay allocated for PAs is demoralising. It’s a specialist caring job for vulnerable children and young people and should be more than living wage. People can earn more in a supermarket with much less responsibility.”

“The criteria for support is too high when YP has very complex needs and requires constant support, but not eligible. It is really hard to access an initial assessment”

“There is a lack of day services for my daughter since she left school. Accessing adequate funding for her personal health budget has been a huge struggle and finding suitable carers to support her day to day, or funding for care during the night, is an ongoing challenge.”

Learning disabilities and physical health

Key issues

Parent carers report the following three main issues in relation to learning disabilities and physical health:

- **Respite** (see the section on social care for more information)
- **Holiday clubs/HAF (Holiday, Activities, and Food programme) not suitable** for child or young person's needs
- **Transition services post-education**, including social care packages and how to access them

Other key issues include:

- Direct payments: parent carers say these are **not fit for purpose**; a package may be awarded but personal assistants are impossible to find for children and young people with more complex needs.
- **Lack of information about housing options** post-18.

ESPCF attended a coffee morning at Chailey Heritage School where the focus was on transition to adult services for young people with complex neurodisabilities, particularly around Continuing Healthcare packages and funding. The following feedback was shared:

The Continuing Healthcare team are valued by families. Communication is good and the team are passionate and helpful.

The **importance of being familiar with the national framework** around Continuing Healthcare, particularly the criteria for the different levels of need in the Decision Support Tool.

The Continuing Healthcare assessments framework causes challenges, particularly the importance of **using the right language when describing care needs** so they're not underestimated or misinterpreted. This doesn't always come easily for families, or the schools, as there is an ethos of a strong culture of celebration of achievements and focusing on what the children and young people can do. An example was shared where a parent carer had referenced their young person 'riding their bike to school'. The assessor had assumed it meant the young person independently pedalled a standard bicycle down the road. In fact, this was part of a physiotherapy program with a team of support in place to help the young person pedal the specialist equipment.

The importance of evidence. This can be professional evidence such as from occupational therapists, physiotherapists, speech and language therapists, dieticians, daily handling records, etc. But it can also be keeping a diary of care needs at home to record those things that we often don't even realise we do because they are just a part of our everyday life.

Empowering parent carers to challenge decisions they don't agree with, whether formally appealing a decision, or along the way such during the assessment. Parent carers can also have professionals who work with their young person attend the assessment to give further evidence or clarification.

The **worry of being supported in the community** once a young person/young adult has left Chailey, or after age 25. One parent described feeling extremely daunted and fearful by leaving the confines of Chailey.

See Document 17 – Complex health needs case study

Post 16

Parent carer feedback to ESPCF shows a significant gap in the support provided for young people with SEND once they reach the age of 16 years. The move from secondary school to post-16 provision is a critical step for young people as they prepare for adulthood. The challenges experienced during this transition can lead to disengagement and negative long-term outcomes resulting in young people (NEET)

Lack of support/provision

- **EHCPs are often not updated** and **do not accurately reflect** the support a young person needs. This has resulted in colleges/provision offering a placement which then breaks down as needs cannot be met
- Parent carer experiences show there is **not enough focus on Preparing for Adulthood** at year 9 annual reviews. This is the time to ensure the needs for post 16 are highlighted and appropriate support is implemented. These reviews are rarely attended by an Assessment and Planning Officer, but parent carers say they are essential to ensure effective planning and to identify the young person's needs to support progress. ESPCF waits to see what the impact of the new team working on annual reviews/transitions will be.
- There is **little or even no alternative destination to college**. With inadequate planning many young people have no sense of what they are aiming for, so it is difficult to identify a progression route.
- There is extensive feedback on the **lack of mental health support** and as young people develop they will become more aware of their own 'condition'. Many young people will have difficulty planning, and thinking long-term can be a challenge causing great apprehension. Without the right support, this can increase anxiety and create low self-esteem and low aspirations.

Not in Education, Employment or Training (NEET)

- **ESCC are often not engaging soon enough** in planning for what happens to young people with SEND once they leave education, despite the Code of Practice requirements around transition-planning as an EHCP is ceased. The situation is exacerbated by a lack of social care services, supported employment services and specialist careers information, advice and guidance
- Some parent carers have young people **not accessing education but who are still on roll**. There is real concern at the lack of support for these young people and whether they are 'lost in the system' and therefore not identified as at risk of NEET. Parent carers note the lack of information, advice and guidance for young people who are NEET, home-educated or unable to attend school.

There needs to be a **stronger focus on preparing for adulthood** from the year 9 annual reviews. This is the time to ensure needs for post 16 are highlighted and appropriate support is implemented. Parent carers feel there should be a greater awareness that the annual review is more than just a meeting, with actions planned and monitored. ESPCF hopes the transitions team created within the ESCC assessment and planning department will address these areas for development. Current reports are inconsistent as to whether one of the team attends the annual review meeting.

There needs to be **more focus on independent living skills**. In particular, travel training could make a significant difference.

For those young people unable to attend/access school/colleges/provision there needs to be **more resources for home tutoring**. The funding allocated to a young person's needs or provided for a special school/college placement, stays in the system if the young person is not attending. This funding should be attached to the young person and where appropriate could support home tutoring.

Strong links are needed between employers and education providers to improve transition and to illustrate a wide range of employment opportunities.

Identification pre-16 of possible support and reasonable adjustments that may be needed in employment. This can allay fears that a young person will be expected to work without recognition of their additional needs.

Young people not accessing school/college need **appropriate information, advice, and guidance** on activities and interacting with others – social groups, outdoor activities, craft and vocational sessions. Charities offering such opportunities are not always well used.

Focus on independent living skills in preparation for adulthood from year 9 annual review, including transport, life skills, and mental health.

Early identification of young people without a career plan is needed so that interventions can be made to hold early annual reviews where necessary, so progression routes are clearly planned. More tailored support is needed than current services can provide to offer the level of bespoke and well-paced support young people and their families need, around understanding pathways, identifying aspirations and taking steps towards them.

Parent carers say…

"The post 16 cliff edge is awful as if getting help at school wasn't bad enough it's even worse now. My daughter is mostly just stuck at home now."

“Post 19? Forget it, EHCP may - on paper - be up to 25, case law may prove that it’s possible and appropriate, ESCC don’t even bother to attend the AR for this last transition phase. If you think you’re on your own at secondary transition, you’re in the wilderness for Post 16 *and 19”*

“There is a lack of day services for my daughter since she left school. Accessing adequate funding for her personal health budget has been a huge struggle and finding suitable carers to support her day to day, or funding for care during the night, is an ongoing challenge.”

“My 20yr old daughter’s EHCP has not been in place or reviewed since May 2022, she has mainstream college in section I, has never attended and no one has been in contact. How many others are there like us I wonder.”

“My older daughter is nearly 15 and we have no idea what she will be able to do once she's left school because friends she knows with autism who are already at college have been left to get on with it on their own and are struggling or dropped out.”

“There's no support for my children outside the age of 18, and very little in teenage years”

“Post school options are a scary thought. Colleges I've spoken to don't seem to offer much help so I really worry my daughter won't be able to fulfil her potential. She wants to do A Levels but is unlikely to cope emotionally (she is autistic and struggles socially).”

“In our case we have had to remove our child from *college name* and we are trying to explore options for the next year with very little support from county. Our APO didn't even turn up to the annual review despite us making her aware of the issues and her knowing that our daughter was being removed with our agreement.”

“School wouldn't put enough support in place for my child to be able to attend, as she doesn't yet have an autism diagnosis. She is now college aged and unable to attend as nothing will be put in place until she is already struggling. A cycle of struggle, guilt and shame constantly for my daughter and no help.”

Transition between educational phases

Transition is often a time of anxiety for children, young people and their families; a time of uncertainty which can be made even worse because educational placements have not been confirmed. Parent carers report that **support with transition is complex, confusing, hard to navigate and the consequences can make a vital difference as to whether a child/young person is able to remain in their educational placement**.

There are multiple educational transitions that most children and young people will experience:

- starting early years
- early years to primary school
- key stages within primary school (Early Years to Key stage 1; KS1 to KS2 and possibly moving between year groups)
- primary to secondary school
- secondary school to further education or work and preparing for adulthood

It is not unusual for a child/young person with SEND to experience more than the usual number of transitions when schools are not able to meet needs and parent carers go through the complex system of trying to source the right educational provision for their child/young person. The SEND Code of Practice 0 to 25 years states:

"SEN Support should include planning and preparation for transition, before a child moves into another setting or school. This can include a review of the SEN support being provided or the EHC plan. To support the transition, information should be shared by the current setting with the receiving setting or school. The current setting should agree with parents the information to be shared as part of this planning process."

Parent carer feedback reports that the **planning and preparation is sadly lacking** and describes how the struggles children and young people face with transition can result in a long-term negative impact and in some cases result in the child/young person becoming withdrawn or isolated and unable to sustain the placement.

In preparation for any transition, information should be shared through usual processes and paperwork, including EHCPs where relevant. However, information also needs to be gathered from parent carers directly to benefit from their insights and include sufficient detail for the setting to understand the child/young person's stage of learning and development, their likes, dislikes, who and what is important to them, their routines, and, importantly, how they communicate.

The needs of a child/young person with SEND will often require detailed planning if transition is to be successful but feedback highlights a number of areas that are regularly not taking place but could make an important and positive difference to the success of transition:

- transition preparation does not begin early enough; there needs to be time to establish good communication and to build a trusting relationship between home and the setting
- tours of new provision are not appropriately and reasonably adjusted for children and young people with SEND to be less overwhelming
- there is not enough opportunity to meet key staff and identify a trusted adult
- more and improved information about timetables are needed so any concerns can be raised
- information about breaks during the day and how individual needs can be supported where required need to be discussed and agreed

The processes involved in preparing for smooth transitions for children and young people with SEND are significant and dependent on the commitment of leaders and managers having a good understanding of what a good transition involves and recognising the potential serious impact on a child/young person when it goes wrong.

Parent carers say…

"I'm going through tribunal for EHCP sections B [special educational needs], F [special educational provision], and I [placement], we currently have no secondary school named at all. It all seems so backwards; my son needs extra time for transition and support however now his friends have all found out where they are going but because we are going through tribunal his journey to secondary school is already tainted and ruined in my eyes. So heartbreaking for him"

"We have no local authority involvement at annual review and horrific experience. [name] transitioned from primary school to secondary school as his first EHCP was being written, yet none of the plan was put in place, he was school refusing by the October half term and being home educated by Christmas while I went to tribunal."

"Secondary school admission process didn't exactly go to plan. Didn't get any of our three choices of mainstream despite me providing evidence of ASD/PDA profile and that she suffered a TBI at birth. I linked it heavily to her staying with her peer support group as this was vital for her to continue her good attendance and progress at school. We got given the local school which is graded inadequate and poor behaviour, teaching and bullying is evident and their SEND department was also quoted as being ineffective in their OFSTED report."

“The move to secondary school was awful. It's such a big change and there wasn't enough preparation or enough help now she's there and drowning.”

“Transition from primary to secondary. My child is only in year 5 but the local secondary does a short transition visit for yr 5 children in nearby primary schools. No thought of SEN had been planned into the visit which was a disappointment and a worry.”

“There was something for me about children with SEN not being thought about at every stage of transition and that is a gap.”

“My child is almost 16 and only just had contact re transition despite filling in form when child was 13yrs.”

Early years

ESPCF engagement workers heard about issues relating to early years provision and support during their work hearing from parent carers about support needed for families on the neurodevelopmental pathway.

Key issues

- Parent carers **do not know where to seek support or information** and feel lonely and isolated. They report a steep learning curve once they do manage to find information and say that navigating their way through pathways can be confusing and overwhelming.
- Early years **staff often do not know where best to refer families for support**. Staff reported not being aware of services such as SENDIASS and the NDP Family Support Service. Parent carers also said that nurseries and childminders need to be better informed about SEND.
- There is a **big gap** in support for pre-school children with SEND who are not in nursery and where the local authority early years service has ceased support.
- Parent carers **valued the support received at Small Beginnings sessions** and expressed a need for this to continue. They were worried about the gap in help and information once they no longer attended the sessions.
- ESPCF has heard positive feedback about the Early Years Service, but it understands that its **ways of working with parent carers / settings have changed** and ESPCF has not received sufficient feedback yet to assess the difference.
- **Transition into primary school was a recurring theme** with parent carers saying they received conflicting advice about whether to apply for an EHCP and were unable to find clear guidance on this. It also led to confusion about whether parent carers should be applying for their child to attend mainstream school or a specialist placement. Again, it was **difficult to find clear guidance** on this.
- Parent carers are **surprised that they do not have to seek a diagnosis** for their child in order to access support.
- **Little support** is in place once a referral to the child development clinic is made, and families feel abandoned.
- Families who **live further away** from the more populated coastal areas e.g. Eastbourne, Hastings, and Bexhill struggle to find local parent support groups to join.
- There are **long waiting lists for speech and language therapy (SALT) and physiotherapy**. Parent carers consider private assessment because they are worried about lengthy waiting lists and not having support in place ready for transition to primary school.

- Some parent support groups are **not able to accommodate young children** which makes it difficult for parent carers to attend as they need to sort out childcare.

Parent carers say…

Feedback noted by ESPCF from in-person sessions and events

- Would like a flow chart/ webinar/online course of what to do and when in the 12 months leading up to starting school for SEN children. This is not clear at the moment and results in parent carers not having the ability to visit special needs school as well as mainstream as often the EHCP has not been finalised in time.
- Was told by paediatrician to send to mainstream to show that the child couldn't cope/fail and then they might get considered for specialist placement.
- Parent with two deaf children feels well supported by health and community centre but feels unprepared with regards to preparing for applying to schools and letting them know what exact needs child will have.
- Families reported that once referrals had been made to Child development centre, no further input and felt 'abandoned' until they started the Small Beginnings group.
- One parent noted that ESPCF gave her more information today than she's got in over a year. Poor access to SALT with very limited sessions.
- All three parent carers at the session felt very unsupported outside of the Small Beginnings group; with school approaching, they had no idea how to prepare for obtaining support for their child.
- Transitions seemed to be a theme with children who would be going to school next year and whether or not an EHCP should be applied for- conflicting advice given by the local authority and nursery and no clear guidance to be found anywhere.
- Many parent carers reported feeling overwhelmed with professional and referrals and often did not know who they could contact to find out where the referral had been sent to.

Home to school transport

ESPCF has held meetings with the transport department at East Sussex County Council each year since 2020 to raise issues that it hears about from families. These meetings are usually at the request of ESPCF.

Key issues

- Communication with families
- Information and guidance for families
- Training for drivers and passenger assistants
- Contingency arrangements and contact details

At the end of **August and in early September 2024**, several issues regarding home-to-school transport for children with EHCPs were brought to ESPCF's attention by members and the wider parent carer community. The forum requested an urgent meeting with the transport department.

The underlying issues in almost all the concerns flagged to us stemmed from:

- **Changes to arrangements**: such as a different driver or passenger assistant (PA); the route and the number of other children in the vehicle; the vehicle itself e.g. changing from a car to a minibus.
- **Lack of timely communication**: families were not told in advance that there were changes being made to their arrangements, and instead received phone calls from taxi companies with very little notice, or in some instances received no communication at all before the beginning of term.

"Change to school transport with little consideration of our child's needs. Last minute change of driver and no contact before the first day of term."

There is a clear overlap between these two underlying issues. Many children with special educational needs and disabilities (SEND) struggle with changes, therefore clear and timely communication is vital.

"My son has ASD so needs preparing. Last year he had two taxi firms, four drivers and countless PAs. No notice of any changes. Every morning is full of anxiety about what time the taxi might arrive, who will be driving and if a new PA. Communication is poor and little if any consideration of children's needs."

Unfortunately, these issues are not new and are things that ESPCF has discussed with ESCC in previous years.

Transport updates highlighting the same or similar issues have been published on the ESPCF website or in its newsletter each year since 2020.

Further feedback and position statement

September 2024 home to school transport update

October 2023 home to school transport update

July 2023 home to school transport update

July 2022 home to school transport update

Document 15 - ESPCF home to school transport position statement July 2021

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East Sussex Parent Carer Forum