East Sussex Parent Carer Forum (ESPCF) engagement report: The neurodevelopmental pathway

Report published December 2023

Summary

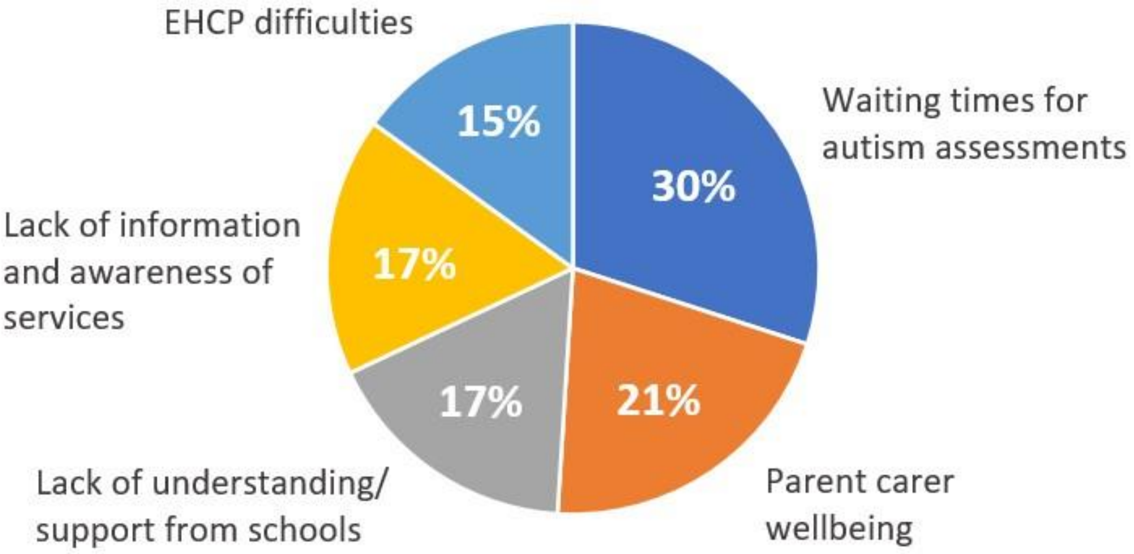
This report details the work carried out by the ESPCF engagement workers hearing from families about the information, advice, and support they need if their child or young person is on the neurodevelopmental pathway.

The 'pathway' is the different steps of the process from when something is first flagged right through to post-diagnosis support. It also includes those children and young people who are assessed but do not get a diagnosis.

Neurodevelopmental conditions included in the pathway are: autism, ADHD, foetal alcohol spectrum disorder (FASD), learning disabilities / developmental delay, social communication concerns, sensory processing disorders, tics/Tourette Syndrome.

Our report covers the period July 2022 to June 2023, plus a short update for the more recent months of July to November 2023.

The **main themes** which emerged from the engagement sessions with parent carers for the period of July 2022 to June 2023:



Key statistics for the period July 2022 to June 2023

- Number of parent carers who attended events: 186
- Number of practitioners who attended events: 65
- Total number of people engaged with at events: 251
- Total number of events: 44

Our recommendations

Waiting times for autism assessments

- Families need to be kept in the loop during the long waiting period.
- Readily available access to information and signposting.
- Schools need to make sure there is clear and helpful information on the support available for those with additional needs, whether a child has a diagnosis or not.

Parent carer wellbeing

- Recognising that while caring for a child or young person with SEND (special educational needs & disabilities) may bring its challenges, it is the system that wears parent carers down.
- The urgent need for overnight respite provision still needs to be resolved.
- Proper recognition and funding for experts by experience.

Lack of information/awareness of services

- Readily available, straightforward, and basic guidance and information in all nurseries and for all childminders.
- More work to find out from parent carers what would help them find the information they need when searching the Local Offer website.
- Practitioners who have contact with SEND families to have basic knowledge (as a minimum) on where parent carers can access information.
- Support for families and carers less able to navigate and access SEND provision.

Lack of understanding/support from schools

- Teachers who take on the SENCO role need to have completed initial training on SEND before they take on the role and should be required to start the qualification within (say) three months of taking up the role.
- SENCOs need to have the skills and the authority to train and/disseminate good practice to other school staff.

- SENCOs 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.
- Schools need to operate with a firm but fair behaviour policy, where there is flexibility and consideration of reasonable adjustments.
- There needs to be improved training and understanding within education providing a 'whole school approach' towards children and young people who have additional needs.

EHCP difficulties

- Changes need to happen more quickly – lost years in childhood cannot be recouped.
- The system needs to be less complex, but in the meantime parent carers need help to understand the process. It would help if SENCOs had consistent information and experience of how to apply for EHCPs.
- Improved transparency and accountability. This includes complaints that don't appear to go anywhere or change practice/make any positive difference.

Background

Back in June 2022, ESPCF welcomed Serene and Karen who joined the team as engagement workers to ensure the involvement of parent carers in shaping the support service, run by the charity Amaze, for families with children and young people on the neurodevelopmental pathway.

You can read more about the Amaze NDP Family Training and Navigation Service as well as the ESPCF update in November 2022 which explains how parent carers have been involved.

ESPCF has been working alongside the Amaze NDP Family Training and Navigation Service for over a year now and Serene and Karen have been busy getting out and about to hear directly from parent carers about the type of support and information that needs to be available. This report shows the information that was provided to the funding commissioner for the 12-month period July 2022 to June 2023.

The feedback highlights the themes captured by the engagement workers from events, visits to providers, community centres, parent carer groups/coffee mornings, and online focus groups.

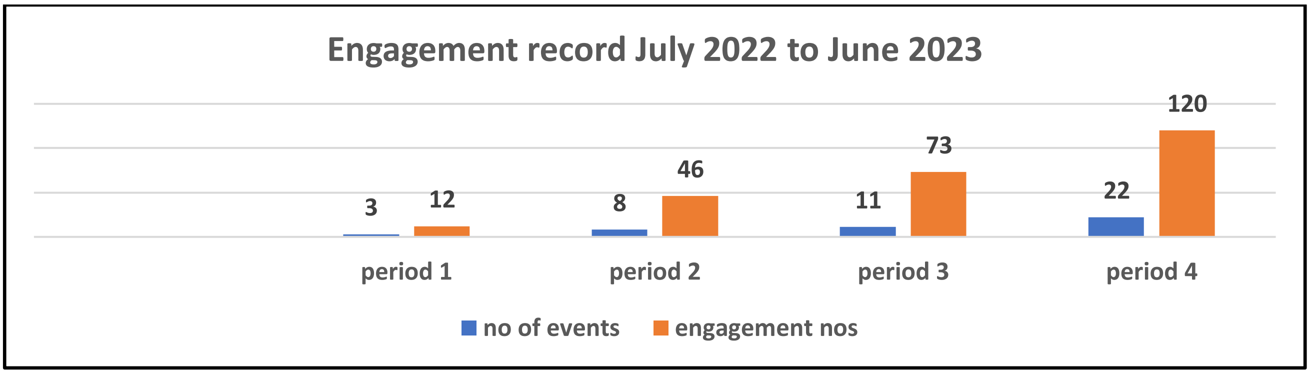
The report also looks at the feedback from parent carers in regard to training needs. This includes the survey that ran from 22nd June 2022 to 12th July 2022 which analysed the feedback from **70** respondents who represented **100** children and young people.

Finally, the report has a very brief update on the engagement workers activities since July 2023.

Engagement with parent carers and practitioners - July 2022 to June 2023

During the twelve-month period, Serene and Karen engaged with a total of **251 parent carers and practitioners at 44 events (186 parent carers and 65 practitioners).**

As the year progressed, the number of events grew, and the promotion and awareness of upcoming events resulted in substantial increases for each three-month period.



Feedback one year on – what are parent carers telling us?

At the events over the last year, ESPCF has engaged with 186 parent carers who have told us about their experiences, and their feedback has shown a number of clear themes.

Themes from parent carer feedback	
Waiting times for autism assessments	30%
Parent carer wellbeing	21%
Lack of information and awareness of services	17%
Lack of understanding/support from schools	17%
EHCP difficulties	15%

The numbers here refer to the issue reported to be most important to each parent carer we spoke to. It is important to note that there is considerable overlap between the themes.
It should also be noted that as we attended multiple ‘Small Beginnings’ sessions at Family Hubs, a significant number of parent carers we spoke to have children who are pre-school age. We are collating our wider feedback across all sources and hope to publish a broader report in early 2024.

1. Waiting times for autism assessment

Feedback and impact

- This is the most widespread problem for families and is already well-documented and known about. The East Sussex JSNA review in 2021 found that: ***'There are significant waiting times for many health services which impacts on severity of need'.*** In response, the East Sussex SEND strategy 2022 – 2025 identifies ***'Reduced waiting times across different health and wellbeing services'*** **as a key success measure.** The East Sussex Local Offer states: ***Assessment and diagnosis of autism can include a long wait. It can take years to obtain an assessment in East Sussex.***
- The majority of parent carers have **no information** on the length of time they will have to wait. Due to the high number of referrals, the Sussex Partnership NHS Foundation Trust website states *'We are therefore not in the position to respond to questions or queries regarding appointments or the waiting list'.*
- The long wait often means having to **re-do long forms** as circumstances will inevitably change over such prolonged periods of time.
- In the meantime, children and young people (CYP) and their families are not getting the support they need. The National Health Service website acknowledges the importance of a diagnosis for autism:

  > For parents and children, a diagnosis can help you:
  > - understand your child's needs and how you can help your child
  > - get advice about support for your child at school
  > - get support for parents and carers of autistic people, such as financial benefits
  > - understand that your child is not just being "naughty" or "difficult"

- The long wait for a potential diagnosis can have a significant impact on the majority of families in this situation. In recent years there have been several studies that have highlighted the harm that can be brought on by a delayed diagnosis.

  A British Medical Association report in 2019 stated ***'The potential impacts of a delayed diagnosis on a child's development are alarming and conversely the benefits of an early diagnosis are wide-ranging'.***

  Similarly an article in the Journal of Child Psychology and Psychiatry in November 2022 concludes ***'Late-diagnosed autistic children often have high levels of mental health and social difficulties prior to their autism diagnosis, and tend to develop even more severe problems as they enter adolescence'.***

- On a day-to-day basis the impact of waiting for a diagnosis can mean:
  - Delayed access to early intervention or prevention services.
  - Lack of appropriate support in school; reduced timetables; not attending school.
  - Not understanding, and therefore not knowing, how to support the child/young person with their view of the world.
  - CYP masking (usually at school) which is not properly acknowledged/supported, often leaving them feeling overwhelmed and drained, causing meltdowns or shutdowns at home.
  - Financial pressures: parents having to reduce hours or leave their employment to care for their CYP; not able to claim disability benefits; paying for private assessments.

What needs to change

- While the urgent action needed is for waiting times to reduce we know this will take a long time. In the meantime there are things that would help families manage the wait.

  - Families need to be **kept in the loop during the long waiting period**. A system of sending 'keeping in touch' letters every six months should now be in place but feedback indicates this is inconsistent. (one parent suggested a log-in system for families on the waiting list to check their progress and view assessments)
  - **Readily available access to information and signposting**. The Amaze Navigation service provides this, so it is vital that:
    - i) awareness is promoted as much as possible and
    - ii) the service is adequately funded to meet the ever-increasing demands. Making sure parent carers are aware of SENDIASS and the Local Offer. The latter has a 'Pre-Autism Pathway' document which has a great deal of information and signposting. However, it is 38 pages long and may be quite daunting for 'new' parent carers.
  - Schools need to make sure there is clear and helpful information on the support available for those with additional needs, whether a child has a diagnosis or not. Parent carers should be informed about **detailed assessments of need** and how '*the purpose of identification is to work out what action the school needs to take, not to fit a pupil into a category*' (SEND Code of Practice).

2. Parent carer wellbeing

Feedback and impact

- There is a great deal of feedback to show that many parent carers of neurodivergent children feel utterly exhausted. As above, there may be a long wait to gain a formal recognition of their child's additional needs but even then, obtaining the support that they need is rarely straightforward. Parent carers have described how this effects their wellbeing:

  - **Feeling absolutely exhausted**. We hear this more than any other comment on how parent carers feel. Many CYP require constant support (especially if they are not attending school) and parent carers regularly use words such as 'fight,' 'battle', 'struggle' in reference to their attempts to access support and provision.
  - **Feeling isolated**; experiencing discrimination and stigma; family and friends not comprehending what it means to have a CYP with additional needs; the community not understanding if CYP display 'different' and/or aggressive behaviours.
  - **Losing a sense of 'self-identity';** life being completely dominated by the parent carer role.
  - Having **less free time**, not able to enjoy a social life; frequently not enough time to rest and relax.
  - The **financial effect** has already been mentioned, and this is often due to a parent carer having to either reduce their working hours, or in many cases, stop working all together. This may well have a detrimental effect on the parent carers **sense of worth and self-esteem** and a gradual loss of confidence.

- The vast majority of these factor will be experienced by all parent carers and they are **not short-lived**. The long-term effects and the exhaustion can gradually erode resilience which can lead to wellbeing and mental health problems, and in some cases a family breakdown. In order to prevent these types of crises it is essential to look after the wellbeing of parent carers.

What needs to change

- The majority of the changes needed are system related and are addressed within other areas. (Such as access to information and services; EHCPs; school support etc.) It is absolutely crucial to recognise that while caring for a CYP with SEND may bring its challenges, it is the system that wears parent carers down. While the points below can help, they are **supporting the effects and not dealing with the cause.**

  - **Short breaks and respite**. There has been recent work and some improvement in relation to the availability of short breaks but there is still a long way to go, and there is still an **urgent need for overnight respite provision** which is almost non-existent in East Sussex.
  - Being **listened to and respected by those working in services**. Working together **with** parent carers and involving them in processes.
  - **Emotional support** can make a significant difference to a person's wellbeing and help them to stay resilient. Organisations such as Holding Space are few and far between and not adequately funded.
  - **Connecting with other parent carers** is one of the most valued support systems available. However it is becoming more and more difficult to find parent carer volunteers as too many are themselves exhausted. There needs to be proper **recognition and funding for experts by experience** who can spare a little time to provide peer support. This would also help with their own sense of worth and wellbeing.

3. Lack of information and awareness of services

Feedback and impact

- From the events over the last year, it has become clear that there are many parent carers who have **no idea where to go for information, advice and support**. They are not aware of the Local Offer or of SENDIASS – probably the two most important places for parent carers to be aware of ASAP.
- It has been additionally concerning that many of the **practitioners also lack knowledge** and have been very keen to find out more about what is available for families – hence the engagement workers have delivered information sessions at two 'learning lunches' for more than 30 health visitors.
- The lack of advice and information causes **additional avoidable stress** and is often the first point at which parent carers start to become frustrated and weary.

What needs to change

- There needs to be some straightforward and **basic information in all nurseries and for all childminders**. Parent carers may have concerns about their child's development at an early age and having readily available guidance can make a significant positive difference.
- Although the Local Offer has improved some parent carers still find it complicated and confusing. We need to do 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 CYP with SEND and their families should (at the very least) have some basic knowledge on where parent carers can **access information**.
- There needs to be **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.) There is some work already underway as part of the SEND strategy implementation plan.

4. Lack of understanding/support from schools

Feedback and impact

- We have heard from parent carers about the **positive difference a good SENCO can make**. Unfortunately, there is too much feedback where this isn't the case. Some SENCOs do not seem to have the expertise required to be guiding and supporting CYP with SEND and their families. Other feedback is that even a SENCO who has appropriate knowledge may have little time. Most SENCOs are teaching as well as coordinating, and many seem to struggle to communicate with parent carers in a timely fashion.

- CYP with SEND are more likely to be excluded from school. The most recent government statistics for 2021/22 show that the proportion of **exclusions accounted for by pupils with SEND for permanent exclusions is 45% and for fixed period exclusions 43%.** According to the DfE data, the biggest increase in reasons for exclusion is ‘persistent disruptive behaviour’**. Exclusions are underpinned by the school behaviour policy and the whole school ethos.**
- **Zero tolerance behaviour policies** are not supportive of CYP with SEND who may struggle to communicate their needs. Any expectation of behaviour must take account of children’s individual **needs** and how these needs (whether met or unmet) might affect their behaviour. Schools/staff **should not assume that all behaviour is deliberate** or within a child’s control, and then sanction them for making ‘poor choices’.

What needs to change

- Currently a SENCO can take up the position **without any specific training or qualification** with the requirement to complete the National Award for Special Educational Needs Coordination within three years of appointment. Parent carers have told us of examples of SENCOs who do not complete the award and leave the role shortly before the 3-year deadline. Teachers who take on the SENCO role need to have completed initial training on SEND **before** they take on the role, and should be required to start the qualification within (say) three months of taking up the role
- SENCOs need to have the **skills and the authority** to train and/disseminate good practice to other school staff.
- SENCOs 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 everyone understands their own responsibilities in supporting CYP with SEND.
- Schools need to operate with a **firm but fair behaviour policy**, where there is flexibility and consideration of reasonable adjustments.
- Schools must be committed to inclusion. There needs to be improved training and understanding within education providing a ‘**whole school approach’** towards CYP who have additional needs.

5. EHCP difficulties

Feedback and impact

- Feedback from parent carers over the last year corresponds to the feedback in the East Sussex JSNA review that for some families ***‘the EHCP process of assessment and allocation is not working effectively or fairly’***

- The JSNA also notes that East Sussex has the 3rd highest refusals to assess and high tribunals that rule in favour of parents, so it would seem clear that decision making is flawed.
- Parent Carers have told us:
    - It should be recognised that **a request for an EHC assessment is a request for help**
    - Some schools show a reluctance to refer for assessment; parents carers feel they are discouraged from starting the process
    - Applying for an **ECHP is a complex process**
    - Parent carers are not being involved enough to help build the picture of need / provide wrap around support in school and at home
    - When EHCPs were introduced, they were intended to be child-focussed, but that's not been the reality. **Parent carers feel failed by the system.**
    - There is a difference between what the LA thinks is available in mainstream schools and the reality of what is actually available in schools.
    - Many schools do not understand their responsibilities under the law and the SEND Code of Practice.

What needs to change

- The JSNA recommendation is very clear:
  Address identified issues relating to parent/carer experience, and communication of, current EHCP processes to make them more accessible, transparent and ***less complex to navigate****. This should include addressing the view amongst some parent/carers that an EHCP is the only route to support, as well as ensuring that the information on the Local Offer and communications from Assessment and Planning and SENDIASS are clear and support parent/carers through the process. The outcome should be that council criteria, processes and systems are no longer perceived as a barrier to support.*
  Some of this work is in process as part of the SEND strategy implementation plan.

- Changes need to happen more quickly – **childhood / education doesn't last very long** and the months and years lost through not receiving the right support at the right time cannot be recouped
- The system needs to be less complex, but in the meantime parent carers **need help to understand the process**. It would help if SENCOs had consistent information and experience of how to apply for EHCPs .
- There needs to be improved **transparency and accountability**. This includes complaints that don't appear to go anywhere or change practice/make any positive difference.

Family training

- The Amaze family training service has already delivered a number of much needed training sessions.
- The following feedback is from the survey that ran from 22nd June to 12th July 2022 and from the 251 parent carers and practitioners at 44 events over the last year.

General comments

  - There needs to be better promotion of training. Many parent carers were unaware of the courses available from CLASS, East Sussex, and Amaze. There needs to be a single point listing all courses and times. This is currently under development, being led by the Amaze family training service.
  - Parent carers need to know that training courses will not criticise their parenting skills, and the course content and the facilitator need to be sensitive to this when providing advice.
  - Training courses need to be available at varying times, including evenings. It would also be very beneficial to have training via webinars that can be accessed at a time to suit the individual.

Types of courses requested

  - Understanding the EHCP process; preparing for associated meetings
  - Support with behaviour that challenges in the home – both understanding and preventing, as well as how to physically support to prevent harm to the CYP and others.
  - Beginner's guide: Types of additional need; support available and how to access; **also** how to explain CYP needs and behaviour to family and friends etc.
  - Sensory processing – understanding what this means for CYP and how to support.
  - Supporting CYP with communication, including non-verbal.
  - Parent carer wellbeing and resilience.

Update from July 2023 to present

- Serene and Karen have continued to be out and about at various venues and events engaging with almost 150 parent carers in the last five months.
- Visiting children's centres (now called family hubs), in particular the Small Beginnings groups, has been useful as an opportunity to meet with parent carers who have very young children and are just starting to learn about SEND.

- Foodbanks have also proved to be beneficial for sharing information with families who might not otherwise be aware of services and provision or know where to look for information.
- The feedback has not changed from the themes already highlighted, with the most significant still being waiting times, lack of needs being met in schools, and battling with a complex system to try and get support.