

Graffiti Wall Report



Autumn Term 2022

Representing the voices of Parents and Carers of - and those that support with - children and young people aged 0-25 with special educational needs or disabilities.



Essex Family Forum

February 2023

What is the Graffiti Wall?



The Graffiti Wall was set up to provide parents with a continuous opportunity to tell us their experiences on SEND Services in Essex.

Our virtual Graffiti Wall is located on our website and the link is regularly shared through our social media platforms, Family Champion Leads, and our Family Champions. All parents and carers of children with SEND aged 0-25 and those who represent them, are invited to share their views.



As well as our virtual Graffiti Wall, we also gather feedback from those with lived experience in person at coffee mornings and events using our Graffiti Wall Feedback cards. We also gather information via our dedicated Family Champion Hub on Facebook and through social media and e-mail where consent has been provided.



Why tell us?

We need to hear the voices of parents and carers with lived experience and those that support them. This is so we know what is working well and what is not working so well. By understanding what is working and what is not working for children, young people and their families, it helps us represent your views and experiences. It allows us to influence and inform the provision and services used by our children, young people, and their families.

We don't just wait for our termly report; we continue to use the "live", unpublished data so that we can address "hot" topics as they arise, such as Home-to-School Transport at the beginning of the academic year.

We then use the experiences shared with us when we work with Essex County Council (Education and Social Care) and Essex Health Care Partners to influence and inform the provision and services used by our children, young people and their families.

Who do you work for?

Essex family forum works *with, not for*, Essex County Council (Education and Social Care) and Essex Health Care Partners.

Essex Family Forum is part of the National Network of Parent Carer Forums (NNPCF) and the Eastern Region of Parent Carer Forums (ERPCF). This means your views not only contribute to the work we do in Essex but also to regional and national discussions and developments relating to SEND.

You can find out more on our website:

<https://essexfamilyforum.org/about>



How does Feedback work?

There is now a group of senior leaders from Essex County Council's Education and Social Care Teams and Essex Health Care Partners that meet regularly to review all feedback received from families. The responsibility of this group is to identify issues that may be a consequence of a short-term problem that can be addressed and resolved fairly quickly. The representatives in the group are well-placed to know whether there is already improvement work ongoing to address more systemic issues that are highlighted by the feedback. They can also make decisions on whether additional improvement work needs to be considered as a result. The findings from these reviews will be shared with our families.



Some facts and Figures

Mid Essex	
Chelmsford City Council	17
Maldon District Council.	16
Braintree District Council	11
Total	44
North East Essex	
Colchester Borough Council	12
Tendring District Council	10
Total	22
South Essex	
Basildon Borough Council	11
Castle Point Borough Council	6
Brentwood Borough Council	4
Rochford District Council	3
Total	24
West Essex	
Harlow Council	8
Uttlesford District Council	6
Epping Forest District Council	5
Total	19

We ask parents and carers to tell us what their main area of feedback is regarding.

We often find many areas overlap and comments will be about more than one category.

That's why we then review each comment in detail and draw out all the themes.

Main Category of Feedback	Number of Entries
Mainstream Education Provision	28
Needs Assessments, Education Psychologists, EHCP Process, EHCP Provision, Annual Reviews, Tribunals, SEND Operations Team (Statutory Process)	21
Diagnosis (Referral process, waiting times, Assessments and Outcomes)	15
Family Support (Early Intervention support access, Support Groups, Charities)	10
Mental Health Support Services and Provision	7
Home to School Transport	6
Short Breaks/Respite/Holiday Clubs	6
Special Schools and Alternative Provision	4
Health Care (GPs/Health Visitors/Hospital provision)	4
Therapy Provision (Occupational therapy , Physiotherapy and speech and language therapy)	3
Social Care Provision	2
Equipment (Physical and Medical Equipment such as Hoists, chairs, frames)	1
Home Education/Education other than at school (EOTAS)	1
Other: All of it	1



Themes

Often when families share their life experiences, it can involve many different aspects of their journey. It can involve the support that their child or young person receives in school to a health diagnosis that they may receive, such as Autism.

It can also involve the parents own journey and life experiences of supporting their child or young person.

We have looked at all the comments and drawn-out key areas:

- Finding Support and Information.
- SEND Support for Children and Young People in Early Years/Schools and Collages.
- Needs Assessments and Education Health and Care Plans.
- Annual Reviews.
- Education Settings.
- SEND Transport.
- Therapy for Children and Young People
- Social Emotional and Mental Health (SEMH) needs.
- Attendance and Anxiety.
- Autism and ADHD diagnosis and support.
- Other.

Within the key areas we have summarised comments in overarching statements drawn from the feedback.

It is not possible to include all comments and issued raised in detail within this report, but all comments have been anonymised and provided to Essex County Council and health care partners for full consideration, alongside this report. We will also use all the feedback gathered in our on-going conversations to influence improvements for all children, young people and their families.

Comments¹ that are included that have been randomly selected, to support the overriding statements. Some of the comments published, may be extracts of a larger more detailed comments that cover several areas.

The following pages outline what families are telling us.

¹ Comments have been subjected to spelling checks, but otherwise verbatim.



Finding Support and Information

The following key areas are what families are telling us about finding and accessing support and information:

- The local offer is useful.
- There are some great charities, organisation that provide support.
- Families reported that some organisations do not have the capacity to provide the required support for example, out of area, unable to attend meetings with parents, delays in communication.
- Families reported that some professionals can say conflicting things which can cause confusion.
- Essex Family Forum/ Supporting your Neurodiverse child book by EFF/MYOATS/STRM.
- Navigating home life, social situations can be stressful.
- Parents and carers own needs can impact on their ability to support their child or young person.
- Navigating the system to find and access the right support can be complicated.
- Access to the right support can vary depending on where families live.
- Professional support can vary across the system.

We have included some quotes received by families:

"PACT are great - They have emailed me & offer great support".

"SENDIASS are not attending school meeting and supporting parents as a shift in staff".

"Parent has a 3-year-old with needs but not getting any support. Finding everything confusing and different professionals say different things. The health visitor was supposed to do a home visit but didn't even turn up."

"Essex forum leading a supportive way in their book and in person. Real people with real experience of SEN children".

"We try one thing thinking it works and then trying it again and it doesn't".

"I am a parent with undiagnosed ADHD. The long waiting lists for assessment are impacting my ability to cope every day. Because I haven't received any support, I have been unable to support my child (ASD, ADHD, PDA) in the way I would like to e.g. creating monthly social stories, organising the house, regular reading etc."

"I feel we are jumping through hoops to obtain access to needs. It's very hard to set aside time for all the online seminars etc, and after completing I'm still not able to access the support. My child is on multiple waiting lists and has been for years!!"



"I think a timeline, guide or checklist would be useful for parents to know that they have contacted the available support, sourced resources and applied for financial aid."

"SNAP provision stating full to us. They are prioritising Billericay/Brentwood/Basildon families. Dengie family effectively turned away as a result."

"There are many professionals who genuinely care and are helpful. Often those that have personal experience".



SEND Support for Children and Young People in Early Years, Schools and Colleges

The following key areas are what families are telling us about SEND support for children and young people in Early Years, Schools and Colleges:

- SEND support within mainstreams school vary in the quality and amount of support they offer to children and young people. Needs are not always understood, such as behaviour, dyslexia, masking, or ASD in girls.
- The quality of one planning is variable, with some families being told their child or young person does not need a plan.
- Some parents report that Elective Home Education (EHE) has been suggested by schools, or parents are having to do so, but not by choice.
- Private reports are not always accepted by schools.
- Communication with schools can vary.

We have included some quotes received by families:

“A new SENCO has taken over in my son's school over the summer and removed the provision in his one plan, saying we will see how it goes! The new teacher didn't even know there was a previous one plan.”

“Communication with parents not listened to, blocked, kept from addressing issues for over a month, issue with one plan not being implemented washed over in meeting, had to fight to get it mentioned on the agenda. Still nothing has changed, teachers are not supporting my child as per the one plan. Both teacher and assistant are not supporting or listening to my child. In fact, my child complains she is not comfortable around both of them”.

“School has supported us in crisis situation. Head teacher and SENCo have been in regular contact and kept me updated. School are recognising son's needs and trying their best not to exacerbate dysregulation. Great partnership working between school and me as a parent.”

“We have experience of both really good SENCO's and not so good!”.



"Training for all school staff to recognise ASD and ADHD particularly in girls".

"They don't even invite me to one planning meeting anymore just sent it home to sign".

A charity reported: "seen an increase in the amount of EHCNA requests that I am receiving, some of this I feel is down to poor one planning".

"Child in Yr6, struggling to attend school on the wait list for lighthouse. Been told doesn't need a one plan, but is so anxious it is a barrier to learning and affecting attendance. Meeting held with head and attendance officer, no plan of how to support attendance just told has to improve or will be fined. No IP included and suggested EHE, even when parent said is unable to EHE as unwell herself and a carer for other relatives was still given an action in minutes of meeting to explore the possibility of EHE and discuss at next meeting."

"My daughter had such severe TIC episodes that I ended up in hospital twice, they diagnosed with Tourette's and that was it. I had to push for more info, and it took 6 months for a referral to GOSH who then also diagnosed ASD and helped with support for the TICS. Her school could no longer have her there, because he TICS cause safeguarding issues, they paid for GP and consultant letter to back up a referral for medical tuition and we still have not had it. I am being forced to home educate."

"Private assessments do not seem to be recognized by schools. We spent 1,000 + on diagnosis from an educational psychologist only to be told it wasn't recognized by Essex CC."

"The schools are not keeping evidence of what help the child is receiving. They are not telling the parents of that help or struggles the children need. It takes too long to actually speak to anyone who can give the child the right help they need. You have to constantly fight the school to action anything".

"Emails from a staff member on how her day is going"



Needs Assessments and Education Health and Care Plans²

The following key areas are what families are telling us about Needs Assessments and Education Health and Care Plans (EHCPs):

- Some families report that the process to apply EHCNA is variable and can be confusing.
- *Interactions with SEND ops can be variable for families:*
- *Parents report that statutory timelines for the EHCP process are not always adhered to.*
- *Parents report that the quality and timeliness of information provided impacts the both the EHCP plan and the process.*
- *Families report that provision is not always followed or put in place in a timely fashion:*
- Charities are reporting in long delays for Tribunal hearings, which is impacting on school placement and provision.

We have included some quotes received by families:

“The process of applying for an EHC /one plan as a parent was easy to follow and all parties in getting help was great”.

“EHC Process very confusing. Trying to understand the process as to obtaining a specialist provision.”

A charity reported that “Lots of parents being refused EHC needs assessments, and this decision is generally overturned within a few weeks of submitting an appeal”.

“Information booklet at start of EHCP journey to explain how it works and what goes into it. Information booklet re types of SEN schools available - Where they are/What needs/What ages”.

“Send operations! Thy ignore calls and emails, provide incorrect information, miss legal deadlines and delay access to provision granted in EHCP”.

“Thanks to (professionals name removed) from the South Essex send ops team for understanding and support of a very challenging period for my daughter and inviting input from all of those working with her to develop appropriate solutions It has really helped to have the same case worker involved over an extended period to learn from previous and recurring difficulties “

“The timeline for EHCP after request is now over 28 weeks”.

² EHCPs



"I was impressed with the LA fir contacting me to say they had not had paperwork returned from college months after the review. The person who contacted me (Professional name removed) was helpful and supportive. This has allowed an EHCP to be issued in spite if not having college paperwork. Unfortunately, it has not lead to EHCP being adopted and I am still unable to reach anyone at college"

"Lack of specific up to date reports from SLT for sons assessment, so SEND ops say they can't make the plan more specific."

"Non- involvement of health professionals in the process"

"We have been waiting since mid a July to be allocated an EP as part of EHCNA. We are now over the 20-week deadline and still my daughter hasn't been seen by an EP. She supposedly was allocated an EP 3 weeks ago and we or the school are yet to hear when she is going to consult her assessment. My daughter has had a detailed and thorough EP assessment done 6 months ago and the LA are not prepared to make their decision one whether to issue a plan or not based on that evidence and schools' evidence".

"The LA requested paperwork from school and gave two weeks to reply. However, her case was taken to panel before the two-week deadline and before the paperwork was received, it was of course instantly refused."

"EHCP finally issued more than 6 months ago but section F provision still not in place. Raised with SEND Ops and formal complaints sent. All dismissed. LA acknowledge lack of provision but still taking no action."

"During covid some of my sons EHCP provision was reduced, I understood this, but it doesn't seem to have been increased again and school dodge my questions."

"Daughter's school have been implementing their sections in EHCP".

"Tribunal cases are taking a year to get to a hearing".



Annual Reviews

The following key areas are what families are telling us about Needs Assessments and Education Health and Care Plans (EHCPs):

- That annual reviews do not always happen in accordance with statutory guidance.
- Annual reviews are not always reflecting professionals involved with the child or young person.

We have included some quotes received by families:

Charity reports that's "annual review process is taking months (sometimes over a year)"

Our annual review was done back in November 2021 after chasing my son OT sessions it came to light, they had even processed is annual review we got it back July 2022

"I asked that CAMHs who my daughter is under and in receipt of therapy - to be asked for advice on 3 different occasions. It's the day before and it has not happened. I have now arranged a meeting with CAMHs for January to discuss what additional support she may need, but this is now outside of the AR I also asked if the attendance team could attend/provide some advice, as daughter is not in school and they attended the TAF meeting in the summer. I was told the attendance team do not get involved in the AR so no. I also asked if we could seek input from the IP - again at TAF and as not in school - was told no, I challenged and they said would look into. I am now advised they are unable to attend, but I do question if they have actually been asked, as I know CAMHs have not been "



Education Settings

The following key areas are what families are telling us about education settings:

- Families report a lack of specialist school placements.
- Choosing the right education provision for your child or young person can be confusing and difficult.
- Parents can feel unsupported and it a challenging process to arrange provision for a child or young person who is unable to attend school.
- Some settings are meeting their child or young person's needs.

We have included some quotes received by families:

"SEN Schools are over capacity, there should be more special education settings with children with needs are being turned away because children with more additional needs are more 'worthy' of space".

"No SEN school places and nothing for children who are more in the moderate bracket and where mainstream school is not suitable either."

"A parent reported to (name removed) that she was trying to view Primary schools at the moment, so that she could make her choice in January. Her son has an autism diagnosis but no EHCP yet. She had been to Open Days but wanted to speak to the Head/SENCo to find out their SEN ethos and get a feel for whether they could meet her son's needs. When she asked 2 of the schools for appointments to do this, she was told that wasn't possible - they were "too busy" to be able to give individual appointments. They said if she applied for and was awarded a place at their school, they would have an in-depth conversation then - which defeats the point!!!! This parent was very confused and had no idea how to go about making the decision".

"Parents should clearly be told the process of applying for a SEN school during EHCP process, how it works, what panels are etc."

"Educational settings suitable for girls with autism- especially those on the higher end of the spectrum. Forcing square pegs into round holes comes to mind."

"The hub is a supportive and safe environment. The SENCo is like "a very low paid lawyer" in my sons' words".

"An allocated caseworker who proactively works with the family to set up a package - this hasn't been suggested to me (EOTAS) and everything is being done piecemeal".

"My 11-year-old daughter hasn't attended school since Jan 2022, due to severe anxiety. She has autism and suspected ADHD. The Education Access team finally provided a robot for her to attend lessons at her primary school, but it didn't become available until the final week of term of Year 6..... Her EHCP was finalised in July 2022".



"There's no proactivity here and I am the one doing all the research and running about - in the meantime my daughter has no education, and no social interaction other than with me, her dad and Nan and is becoming increasingly isolated and anxious. I don't understand why this is being left to me to push and plan and sort out when I have no education experience at all, and I have a younger child also displaying anxiety and refusing to attend school".

"Allow for alternative solutions such as home education, quality virtual schooling or schools targeted towards teenage girls on the higher end of the autism spectrum."



SEND Transport

The following key areas are what families are telling us about SEND Transport:

- Parents report different experiences with drivers and passenger assistants.
- Some parents report that the journey time for their child or young person is too long.
- Parents feel that communication could improve and be provided in a timelier fashion.
- Parents feel that the local school is not always the most suitable and are disappointed that this impacts on transport eligibility.

We have included some quotes received by families:

"The crew have no real idea when it comes to Sen and the terms and phrases they use are quite frankly disgusting. Transport is provided by 24/7 who claim they provide SEN training but it's evident that the training isn't sufficient. I also feel that they should be divided with details of the children in their care so that they can best plan how to support them. When I mentioned how awful the crew were to the school, they school made it clear who they have nothing to do with transport".

"Driver is excellent, communicates really well, goes out of way to ensure my son is comfortable in his journey eg. plays his music requests".

"Sometimes the cover staff are not fully advised of changes/needs".

"My daughter goes to a school in Chelmsford. We tried to use the transport for her, but we were told she would have to leave at 6.50 for an 8.40 start. The same travel time coming home. We felt this was too long a day for her. Kinect are the travel providers, and we live in Burnham".

"Transport for specialist school provision just turned up out of the blue to introduce themselves. We should have been informed so we could prepare CYP and make sure we were in!!!".

"We need details of transport weeks before school starts, not a few days, or even worse on the day. It causes unnecessary stress for families every year".

"My sister had made arrangements with them, they change the route twice, after not showing up for a week, then last week on Friday they informed Me at drop off, their routes were changing again, and we would have new, (not, no-one) drivers and companions".

"My son is starting a mainstream school with a autism hub as you know & I have to pay for the bus because I didn't choose the local school but the reason I didn't choose that school was they didn't have a SENCO at the time & the SENCO who was looking after the school didn't even call me back when I call up to speak to him. I feel that my son should get a free travel or at least lay on the school".



Therapy for Children and Young People

(Speech and Language, Physiotherapy and Occupational Therapy)

The following key areas are what families are telling us therapy for Children and Young People:

- Therapists are helpful and supportive.
- Families want access to early interventions.
- Families want specified provision in reports regarding their child's needs, to support the correct provision being specified in EHC Plans.

We have included some quotes received by families:

"Physio team supporting my daughter and doing her annual CPIP assessment are so lovely and helpful. Really knowledgeable and great interpersonal skills with both parent and child. Physio even paid me a compliment on what we are doing as a family to support daughter's condition - this is rare a professional does this! - but it means so much!"

"Early intervention is key; however, we are approaching a year since referral and we have had no intervention treatment provided. One initial assessment with a speech & language therapist and 2 online presentations do not cut it."

"Long waiting time. Daughter's orthotics have been hurting and rubbing sores. Asked for an appointment to review/recast back on early August 2022. Still waiting for an appointment and now in December! No more clinics being booked yet, so cannot even be offered an appointment for some time on the future!"

"Lack of specific up to date reports from SLT for sons' assessment, so SEND ops say they can't make the plan more specific."



Social Emotional and Mental Health (SEMH) needs

The following key areas are what families are telling us regarding Children and Young People social, emotional mental health (SEMH) needs:

- Support and understanding of children's mental health in schools is variable.
- Parents report that support accessed is successful and professionals are helpful.
- That routes to access the right support is confusing and parents report that they are often "bounced around the system" whilst trying to secure support for their child or young person.
- Parents report that access to the right support and or diagnosis for certain conditions is lacking within Essex, in particular for those with eating disorders and Oppositional defiant disorder (ODD)
- That delays in children and young people accessing the right support means their mental health deteriorates.
- Parents believe that the CAMHs service is underfunded and understaffed. Parents also report that there is a lack of understanding of children and young people's needs, with further training needed.
- Some parents report that they are funding therapy privately due to long wait times.

We have included some quotes received by families:

"Secondary mainstream schools and the impact attending a school that cannot meet needs has on a child- the school trauma they encounter from an early age when no one understands them"

"The school have been very understanding and supportive".

"My child needs understanding of her school-based anxiety as she's not diagnosed but I suspect ASD and ADHD, but she masks at school. They just see her as quiet and overly anxious. Why is there no awareness of girls masking in schools, the paediatrician she was under, and every school has not realised she is masking every day, it's having a massive detrimental effect on her mental health."

Charity reports that there is a "real lack of support for those with complex mental health needs and then struggling with the result of those such as self-harming, being groomed, social isolation (spending all day in their rooms) and eating disorders."



"Offered a 6 week self-esteem group session with HRCG via CAMHS. The ladies running it are really great and my daughter, whilst was not happy at going and had meltdowns over going, came out happy each session and last week was session 3 and she went in happy with no meltdown and she was proud of herself for that. She really likes (Professionals name removed), who is one of the ladies that run it. (Professionals name removed), always touches base with me afterwards to let me know how she got on in the session and tells my daughters how great she was. Ladies running the course arranged for the new keyworker to contact me. She phoned me within a few days, and we chatted about how things are and arranged a meeting once the self-esteem course has finished to discuss next steps".

"Am being 'bounced' around for a referral. Behaviours of son is not displayed in school setting. Asked to refer to GP - GP referred to CAMHS. CDC said lack of information on form. Referred back to school nurse - Feels like going round in circles. Just need some support for Son as difficult to get into school & hides under duvet as soon as he gets home".

"Referral process has been painfully slow. Each time there is an appointment it is months of waiting time for feedback and written reports and a follow up appointment. CAMHS triage and just refer you in for "self-referral" to alternative services. The onus is constantly on us to ask, follow up, press for info. No one wants to listen. It's like parental observations count for nothing."

"To get my child further assessed and helped has been going on now this whole year. She is as diagnosed with ADHD at the age of 5 privately as NHS wouldn't see her, she now needs to be assessed for ODD and on the waitlist for over 1 year for autism and still battling to actually see someone. NHS provide don't assess ODD, her paediatrician doesn't deal with ODD and camhs won't even see her even after a school letter was done. As a parent you ask for help and keep getting pushed back and nowhere to turn to?"

"Supporting a family whose daughter has been diagnosed by camhs with anorexia. No therapy is being offered; she is on the waiting list to receive counselling with no expectation given of when she might be seen. no actual help or positive suggestions are being made. They are providing very strict weight related targets which are proving unachievable (e.g. IBMI needs to go from 80% to 95% before she can resume activities that she enjoys- Parents disagree with what they are being told to do because it is making her mental health worse and she is now showing other signs of depression. Support is needed now to understand and support the deeper reasons behind the eating disorder".

"My daughter (15) was first seen by the crisis team at Colchester Hospital in Nov 2021. She was not referred to CAMHS despite there being an obvious MH need. I asked the GP to refer & she was seen by CAMHS in Feb 22. Because she was offered some counselling in school CAMHS wanted to end their involvement. Oct 22 - My daughter has finally started to see a MH worker through CAMHS. Her MH has significantly deteriorated in this time, and she is struggling to engage. GP referred to paediatrics for ASD in March. We are still waiting to hear if we will be offered an appointment. Her education is suffering as she is now struggling to engage at school."

"CAHMS. Understaffed, undertrained, and underfunded "

"A private psychiatrist has been sought due to CAMHS long waiting list."



Attendance and Anxiety

(Emotionally based school avoidance)

The following key areas are what families are telling us regarding Children and Young People social, emotional mental health (SEMH) needs:

- Knowledge, understanding and support from schools can vary when a child or young person is unable to attend school.
- Long wait times for mental health support or an ASD diagnosis, can increase the amount time a child or young person is out of education.
- Some parents report that they have to pay GP for letters regarding child or young person's mental health.

We have included some quotes received by families:

"Astounding compassion from school staff. We are incredibly lucky. But we shouldn't have to rely on luck for our daughter to feel safe in school".

"School should be following supportive procedures, a one plan, asking for support from IP and ways to support attendance. EHE (Elected Home Education) should not be mentioned".

A charity shared the following experience from one of their parents: "Many families reporting CYP not being able to attend school and instead of support are being threatened with fines. There is also a number that are not being supported in school to meet their needs and then being excluded due to their behaviour."

A charity shared the following experience from one of their parents "Child in Yr6, struggling to attend school on the wait list for lighthouse. Been told doesn't need a one plan but is so anxious it is a barrier to learning and affecting attendance. Meeting held with head and attendance officer, no plan of how to support attendance just told has to improve or will be fined. No IP included and suggested EHE, even when parent said is unable to EHE as unwell herself and a carer for other relatives was still given an action in minutes of meeting to explore the possibility of EHE and discuss at next meeting".

"My son (Year 3) has been unable to attend school full time since Sept 2022 due to a blood and sick phobia. He has been managing on average about an hour of school a day. A private psychiatrist has been sought due to CAMHS long waiting list. He is awaiting therapy privately. We are waiting for Education Access support whilst he is barely able to attend. School have been very supportive but can't do any more. I have a letter from the GP confirming his inability to attend that I had to pay for. I feel that I have had to do all of this myself with no support from any services".



Autism and ADHD diagnosis and support

The following key areas are what families are telling us regarding Autism and ADHD diagnosis and support:

- Wait times are long and are dependent on where you live.
- Route for referrals not always clear.
- Parents feel that the advice and support given is whilst awaiting an ASD or ADHD diagnosis is variable and free access depends on where you live.
- Parents feel that communication needs to improve, with a specific need to receive an acknowledgement of referral/acceptance on to the pathway.
- Professional support is variable.

We have included some quotes received by families:

"Am being 'bounced' around for a referral. Behaviours of son is not displayed in school setting. Asked to refer to GP - GP referred to CAMHS. CDC said lack of information on form. Referred back to school nurse - Feels like going round in circles."

"Waiting times are long to see paediatrician, but the team seem to be trying their hardest".

"We had an excessively long wait for an ASD assessment in Chelmsford (2.5 years). At the same time Colchester's waiting list was much shorter."

"I have a 13-month-old showing signs of ASD. I have a 5-year-old that was diagnosed at 2 years, so I can notice similar traits in 13-month-old. I am just being told I have to wait until she is 2 years old before they will even assess her. I know the waits are really long, so she will most likely be starting school before I get any proper help/support".

"A recent ADOS report received from Paediatrician had reference to PARC Essex on it - signposting to PARC for support - and PARC has now closed".

"Charity reported "Braintree based family - child diagnosed ASD and diagnosing paediatrician signposted (North East Essex) charity - when parent (single mum) contacted them for support she was advised to attend a course at a cost of £80 which she could not afford".

*"The Neurodevelopmental Pathway Coordinator that helped me was able to support me through the support available. Giving me information at a pace I could deal with so I wasn't overwhelmed. She helped me to complain effectively where I felt support was lacking and referred me to a **sensory workshop** that*



helped me understand my sons needs better. I really like that I can re-refer myself at any time if I need further support.”

“NHS well done on all of your services and improvements made as I feel we are maybe one of the first to benefit from these new supports now in place”.

Report from a Family Champion Lead who attended a coffee morning “Three parents were just going through the diagnosis process with their preschool children, and one parent had just received a diagnosis. All 4 parents reported that they didn't know where to go for support or to meet other families - the family that had received a diagnosis thought this would open doors to lots of help, but this hadn't happened. They all felt at a loss to know where to go. They were really happy with the ND packs that I gave to them and said that really helped”.

“After diagnosis there seems to be a general trend of being left to fend for ourselves and a lack of support and information. Don't know what we were entitled to or how to access”.

“Lack of clarity around JADES pathway. School applied in July 2022 and to date I have received nothing. I made numerous calls to the jade's team and eventually got through to someone who said she was accepted onto the pathway in August 2022 but to date I have received nothing to say this and if I didn't call weekly for months would know nothing at all”

“Long wait time, no communication. No appointment dates”.

“Then diagnostic report took over 4 months to arrive. No further support offered.”

“Communication to parents to say acceptance on the pathway with detail of what the pathway consists of”.

Lighthouse centre- I have 2 children with ADHD and on medication. One of them has access to the fabulous ADHD nurse who is in regular contact. The other does not, and I have no idea why!

“ I felt for the first time like I had been seen and heard after years of being told I must be doing something wrong for my daughter to have such extreme meltdowns”.

Paediatrician (name removed) was very thorough. Took the time to fully understand the situation and fully consider diagnosis. Impressed that he took his time and asked to review in a few months to gather further evidence. Was very good at acknowledging and validating my concerns as a parent even though said he needed more evidence to diagnose. To wait longer was frustrating, but to know he was taking the matter seriously and keen to make the right diagnosis for a life-long condition was reassuring and much appreciated.

“Other professionals inputting into diagnostics (e.g., teachers and teaching staff) would benefit from stronger general knowledge of neurodiverse conditions and the differences in presentations between males and females. I feel had there been this awareness we would have potentially saved a further 4-6 months waiting for diagnosis. They clearly saw the behaviours in unstructured times (e.g., lack of organisation, poor attention, constantly chatting, etc), but did not realise that it was indicative of my daughter's ADHD, of which she has been diagnosed.”



Short Breaks

The following key areas are what families are telling us regarding Short Breaks:

- Parents shared their views on the new short breaks contract.
- Access to suitable clubs and activities can vary depending on where a child or young person lives.

We have included some quotes received by families:

"I've just seen the announcement for the new short breaks offer and my mind is blown that the award-winning SNAP charity have received no funding! They're the only provision who offer zoom options to their sessions, to support extremely vulnerable children who are too poorly to leave their homes. It's the only provision we can access regardless of our daughter's state of health".

The short breaks team help me understand what's available and are very friendly. I saw on Facebook some families were angry because SNAP didn't get funding. There are loads of other clubs available, but it can take a bit of encouragement to try them. The short breaks team reassured me when parc closed and I never thought my son could go to some of the clubs he has been going to. Art have been amazing! I think other parents should be more willing to try out different options even though it's hard and I talk from experience!!".

"No activities put on in the area for SEND children the providers are always saying they don't have the right trained staff, or your child isn't of low income or free school meals. So as SEND parent in this area we are supposed to just carry on while other areas get clubs, respite."

"This summer there wasn't a single regular club that caters for over level 2 SEN in the whole of mid Essex. Maldon and the Dengie have many SEN children that are being let down and not provided for. Parents of SEN children over level 2 are the ones that need support and respite the most and have been failed".



Other

The following key areas are what families are telling us regarding other key areas as highlighted below:

We have included some quotes received by families:

➤ **Health Care – Dentist/GP/Health Visitors**

“Dental services, I still struggle to find a suitable service to treat my son's teeth. I am not alone from our group looking for a dental clinic that would help a child with special needs. Our dental service keep checking my child's teeth up without any further support, we've been waiting for the Community dental services for more than a year now, we went to a private clinic paid £70 for a consultation just to learn that the inhalation sedation would not work for him due to the fact that he avoids breathing through the inhaling equipment but uses his mouth to breath. I was referred to another private clinic that located near London, I need to arrange a transport to get there and I'm not sure when they have appointments for and you can imagine costs as it's a private clinic”.

“Awareness of SEND parent carer experiences. The GP made our visit memorable and positive because of his bedside manner and empathy. What he offers was one of a range of reasonable choices, but he managed to do it and connect with my son enough to gather his views as well, which was exceptional.”

“There are no specialist health visitors in the area and nobody to signpost you to the appropriate help for disabled children. This makes us feel lost and alone. There is also no hydrotherapy available in the area and this is desperately needed to help children like ours to develop physically.”

➤ **Equipment Leaflet**

“You asked if folks had seen the document about specialist equipment. We have a safety bed and seating but have not seen the document.”

➤ **Social Care**

“My son is 20 years old, and we have had the most positive experience with the Learning Disability Team from Adult Social Care. There was a significant delay in the referral to the right team, but once they were involved, things have moved swiftly. The Social Worker (professional's name removed) was excellent. She was able to build a really good rapport with my son on that first visit. He has significant speech and language difficulties, and she adapted her level of conversation so that he was able to fully participate in the discussions. She picked up when he was uncomfortable with support she was suggesting, and came up with alternative options, so that he could make autonomous decisions about his support. She also realised when my son was starting to disengage and asked his permission to carry on the conversation with me “.



“Son is 14, nonverbal, with autism. Violent and not very continent. 13-year-old with cerebral palsy, and a 5 year old. We cannot go out together due to my son's behaviour. Violence at home means the younger children are suffering, locks on their doors to stop him accessing. Social care have said we don't qualify for help, and GP offered me anti-depressants”.

“I cannot leave my house on my own with my two children as it is dangerous. This means in the summer holidays I have to pay a carer to come with me so we can have a day out. I feel there should be easier access to free care from social care departments”.

➤ **Employment**

“ECC seem to be doing well at reaching out further afield e.g. I run a small business and have received support from the targeted employment team to get young people with neurodiversity into work. I am very lucky my child's school seem to support him although we still have some issues to overcome”.

➤ **Events**

“I attended the online learning event run by ECC. It was such a positive step. Lots of helpful sessions and run in the evening too. And recorded so more parents can watch them. Showed a real desire to support parents. Thank you”.

“Events such as todays (30/09/22 Ofsted and CQC Re-visit Parent/Carer Engagement Event) - Parents/carers need to build trust in system again so better attend. Is Apathy due to feeling it may make no difference?”.

➤ **Funding**

“Increase of government funding at school level to help train SENCO positions, deliver support to mainstream schooling students and their parents”.



Disclaimer

The information and comments presented in this report are the views of the survey respondents and in no way, express or implied, should be construed to represent the views of Essex Family Forum CIC.

Essex Family Forum's purpose is established under the legal requirements of the Children and Families Act 2014. We therefore have a duty to faithfully relay the views and experiences of parents and carers of children and young people with SEND aged 0 – 25 years with regard to the services they use.

Essex Family Forum aims to work co-productively with services to improve the users' experiences and to recognise good practices. Essex Family Forum accepts no legal liability for the personal accounts, views, or opinions that survey respondents shared.

