

Graffiti Wall Report



Autumn Term 2023

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

October 2023

What is the Graffiti Wall?



The Graffiti Wall was set up to provide parents with a continuous opportunity to share 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 such as local charities and support groups, are invited to share their views.



This report now incorporates **all** the feedback we have received during the given term. 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 needs to be improved. 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We don't just wait for our termly report; we continue to use the "live", unpublished data so that we can address "hot" topics as they arise.

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>



National Network of Parent Carer Forums
'Our Strength Is Our Shared Experience'

How does Feedback work?

The Family Feedback Co-ordination and Oversight Group (COG) is a group of senior leaders from Essex County Council's Education and Social Care Teams and Essex Health Care Partners. The Feedback COG meets regularly to review all feedback received from families (Step 3).

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 process is explained in the infographic below. Findings from these reviews will be shared with our families (Step 4).

How YOUR views help shape SEND services and provision



Step One- Parents/carers share their views

Parents and carers can share their views with our Family Champions, in person at events or coffee mornings, by e-mail and social media. Views can also be shared through our virtual Graffiti Wall, on our website, where we also welcome views from support groups and charities.

Step Two- Representing your views

We continually review what you are telling us and share your experiences in meetings and through discussions with SEND services. We aim to ensure they drive the right changes to help improve SEND provision for Essex families.

Step Three- Collaborative Review and Report

Each term, the Feedback Co-ordination and Oversight Group, which includes Essex Family Forum and key representatives across Health, Education and Social Care, undertakes a collaborative review and analysis of all the anonymised feedback. Essex Family Forum then produce a written report, highlighting the key themes for families, identifying short and longer term issues that need to be addressed and where there are opportunities for learning throughout the system.

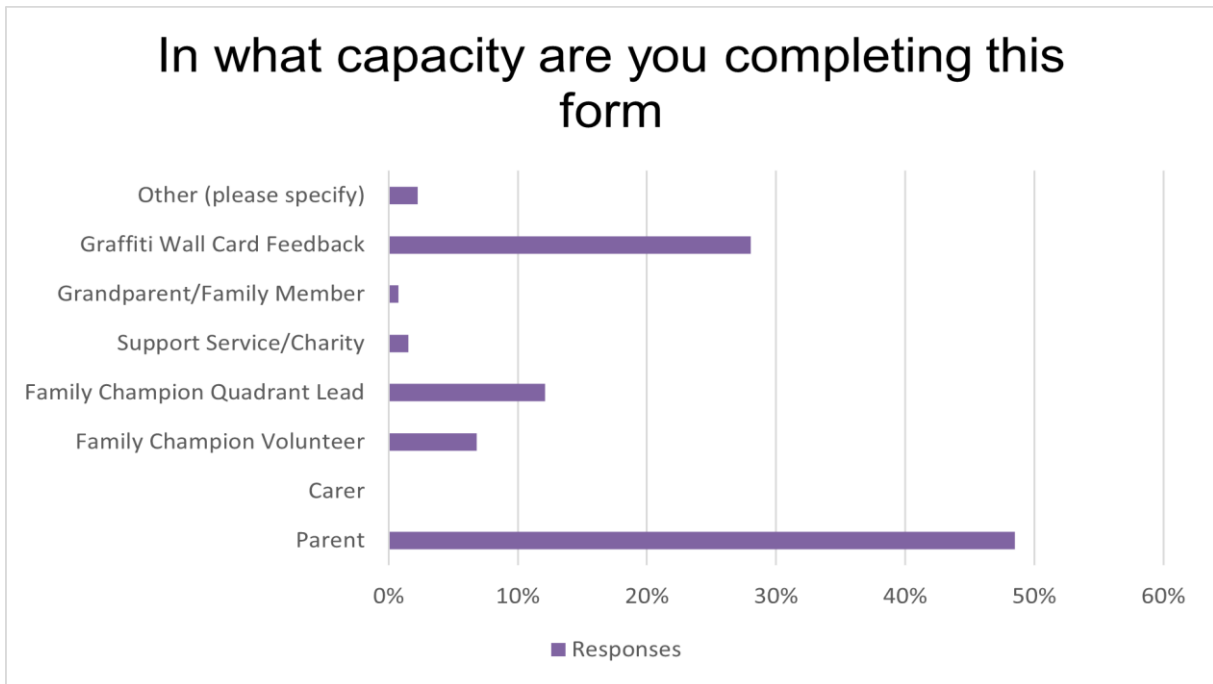
Step Four- Responding to feedback

The Feedback Co-ordination and Oversight Group will share the report with Senior SEND Leaders and ensure that your views feed into the SEND improvement work across Essex. They will provide a written response to each termly Graffiti Wall Report outlining where improvement work is already underway and whether there is additional action that needs to be considered.

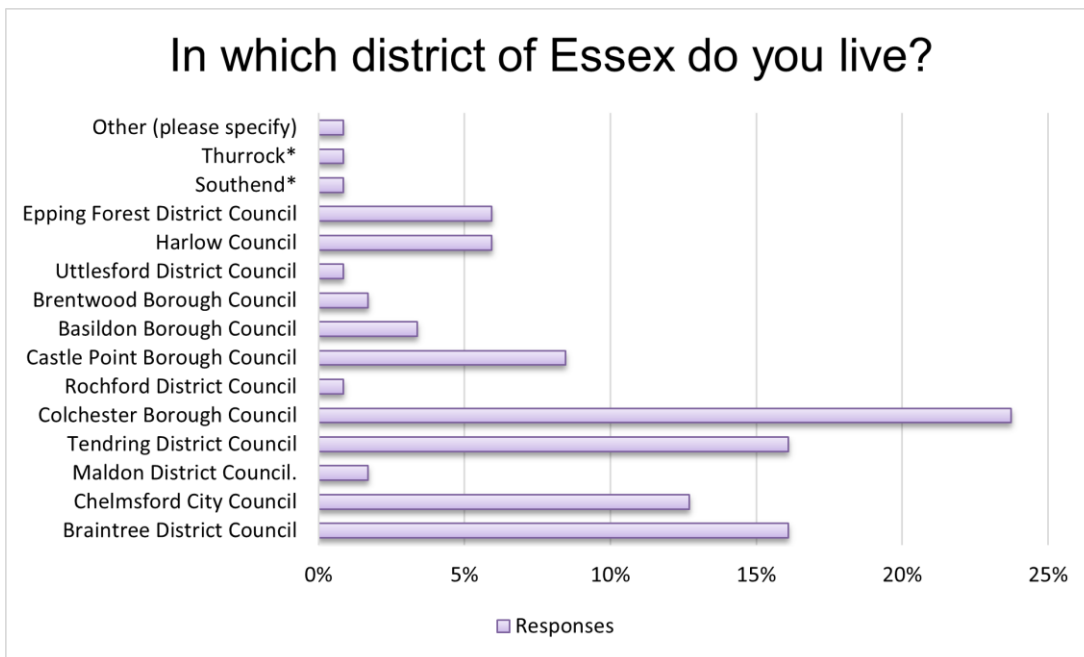
Did you know we share your views regionally with the Eastern Region of Parent Carer Forums and Nationally with the Network of Parent Carer Forums? To find out more about the parent carer voice beyond Essex see our website: <https://essexfamilyforum.org/about>



Some Facts and Figures (Graffiti Wall only)



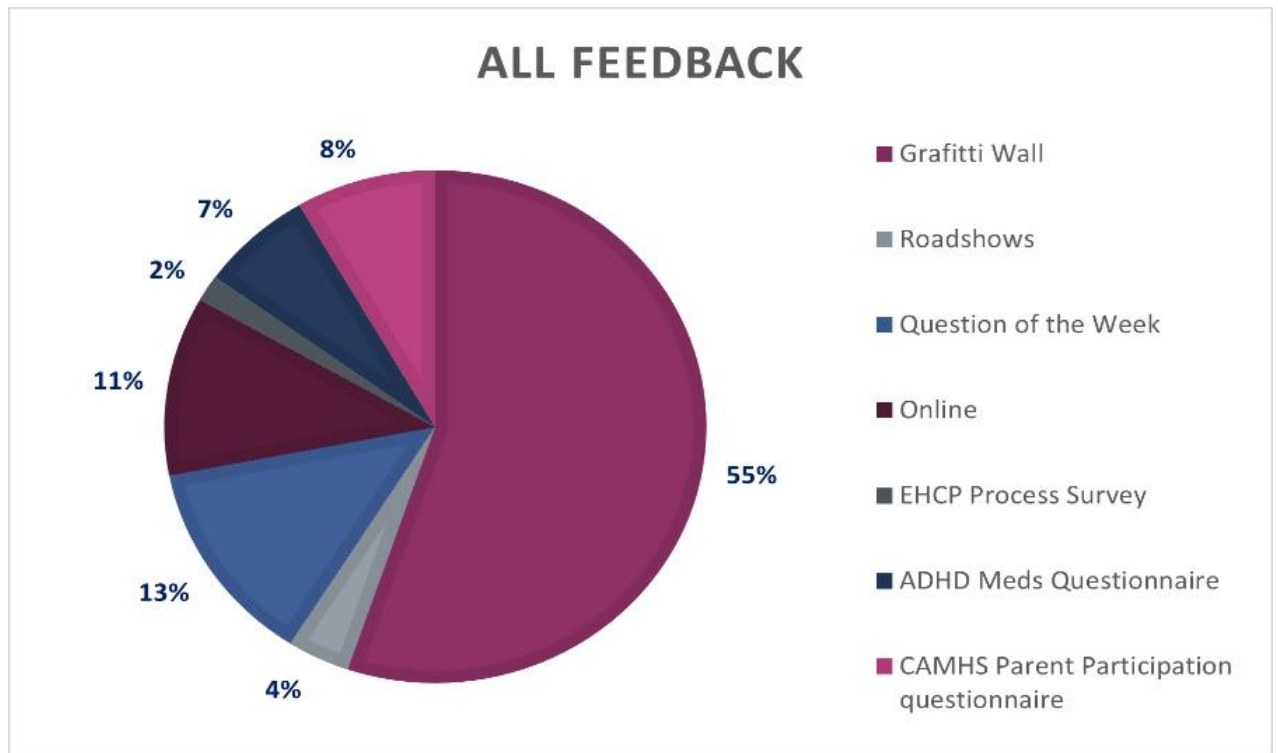
**Respondents were redirected to the Parent Carer Forums for their own areas and no data was collected*



14 people declined to provide a response to this question.

ICB Footprint	No.
Mid & South Essex	53
North East Essex and Suffolk	47
Hertfordshire and West Essex	15

Sources of Feedback



Themes of Feedback

The headings are the categories that can be self-selected by the person providing the feedback on our Graffiti Wall. The feedback is reviewed in detail and cross-referenced and reported on across the categories.

This report now contains information from all our feedback channels, including mini surveys on specific issues. 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 parent's own journey and life experiences of supporting their child or young person. Where feedback has been received outside of the Graffiti Wall, we have attributed the information to the Graffiti Wall category that most closely matches the themes of the comments/discussions.

Discussions that were had with parent/carers outside of the Graffiti Wall were:

- Assessments for Neurodiverse conditions (including referral process, waiting times and pre & post information and support)
- Access to health checks for young people aged 14+ with a Learning Disability
- EHCP Process (including Needs Assessments Requests, Refusal to Assess)
- Alternative Provisions and Transport
- ADHD Medication Shortage
- CAMHS – Parent Participation (what works)

Categories of all Feedback received in the Autumn Term 2023	No of Responses
Finding Support and Information	23
SEND Support for Children and Young People in Early Years/Schools and Colleges.	18
Needs Assessments and Education Health and Care Plans	24
Annual Reviews	3
Education Settings#	20
Home Education/Education other than at school (EOTAS)	6
SEND Transport	7
Therapy for Children and Young People (Occupational, Physiotherapy and Speech and Language Therapy)	13
Social Emotional and Mental Health (SEMH) needs.	21
Attendance and Anxiety (Emotionally based school avoidance)	4
Autism and ADHD diagnosis and support	31
Social Care	1
Young Adult Support	2
Shortbreaks	1
Other ~	8
<i>Below are listed the biggest responses to "Other"category</i>	
ADHD Medication Shortage	32
Health Care	7
Total	221

The majority of these comments are related to the support received in schools and settings.

~ We received comments about single specific issues which are detailed further in the report.

It is not possible to include all comments and issues 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.

Comments that are included have been randomly selected to support the overriding statements. Some of the comments published may be extracts of a larger more detailed comment.

Finding Support and Information

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

- A need for improved communication across all sectors (whether that is for families to be kept updated on waiting list/assessment timescales, or just feeling heard and valued)
- There is a lack of awareness of how to access information and support at the time you need it. This does not just apply to parents and carers but a lack of awareness by professionals is also reported.
- In-person events, such as parent support group coffee mornings and the SEND/Local Offer Roadshows are highly valued by families
- Parent/carers feel empowered by parent workshops
- Parent/carers feel supported by Advocacy and Navigation services

We have included some quotes received by families and organisations who support families:

"Parents rely on professionals to advise but often it is left to the parent. We need to look up and research at times when we are already struggling to cope."

"Families in Focus are consistently excellent at providing support"

"Long waiting times without updates (seeking diagnosis) and no information on support. No information on getting support at school, especially in regards to One Plans.No support for school avoidance - only the threat of a fine for absence."

"Home life us all understanding what's happening to our family , extended family not understanding. Going out as a family".

"Overwhelming information available - That said once you can navigate it there is help out there."

"Maze coffee mornings allow you to hear and see more support available."

"Psychology in Schools Childhood Neurodiversity Parent Workshops - Excellent resource for parents."

"More family support Teachers being more educated in SEN children and supporting families. Family counselling Respite. Being listened to."

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

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

- An improvement in SEND training and knowledge for teaching and support staff in education settings.
- Punitive behaviour and attendance policies in education settings; linked to a lack of understanding of children and young people's SEND needs.
- Lack of One Planning or poor One Planning.
- Families would like a more holistic approach and focus on family support.
- Support and advocacy services are invaluable but are struggling to provide timely support due to high levels of demand

We have included some quotes received by families and organisations who support families:

School - attendance company sending threatening letter. Inappropriate comments from the attendance company, no matter the diagnosis there is no excuse for not attending school. They need SEN training. School are trying to go against agreed adjustments/ these are not being followed through.

Family support - where?? I'm exhausted. Diagnosis takes so long. Needs assessment - so hard to get one. Mainstream provision - schools are struggling with lack of funds, large classes and this impacts on children with SEND.

Positive reports from families using Families in Focus and SENDIASS - but also saying that hard to get timely advice as so in demand.

How do schools decide what is QFT/OA and what necessitates a One Plan? It varies hugely by school.

My son is diagnosed with ADHD and dyslexia. He struggles hugely with executive function skills, especially time management and organisation, and he can be impulsive. He gets constant detentions every week for being late, forgetting homework and forgetting detentions, which then leads to further sanctions.

Needs Assessments and Education Health and Care Plans¹

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

- Delays to the EHCP Needs Assessment Process and the effect that has on the child/young person's education and well being
- Lack of understanding of masking in schools leading to refusal to assess decisions (due to lack of evidence from setting)
- Lack of communication during the process*
- Lack of information for parent/carers to understand the process*
- Inconsistencies with Way Forward meetings

We have included some quotes received by families:

"The hold ups are not new and seem to be getting worst. Is there a plan or strategy to get out of this hole instead of just fighting fires. There needs to be considerable resource to clear the back log and a better system put in place moving forward so this doesn't reoccur."

"A single person, a single point of contact someone who could be the conductor to the orchestra of services and provisions. Someone who knows the system and can guide parents and carers through the labyrinth. Act as a coordinator and liaison to make sure everyone is singing from the same hymn sheet. Right now the system is fragmented and complicated. There needs to be a single place where all the information is accessible to all the people within that child's care. One plan training across nurseries and schools each year every year!"

"My daughter was refused an EHCP assessment. I called the Local Authority to ask for a way forward meeting (the advice from SENDIASS) but they told me they no longer do these and haven't done them for a while. We have mediation Monday"

"The way forward meeting helped in terms of school understanding I knew his rights and put more in place but made no difference to getting the plan."

* This is the example received of a totally positive experience and shows the impact that timely communication and responding to queries can make. (The respondent did highlight that calls need to be answered when the team is busy):

*" We were given multiple opportunities to review and make amendments, working hand in hand with **** (name removed), who is fantastic at her job and showed empathy, understanding and diligence throughout. We felt the final EHCP reflected our child's needs very well. **** was in regular communication with me, and took the time to answer every single one of my (multiple) questions throughout the process. She showed genuine care and empathy for our family and worked hard to ensure all parties involved in the creation of the EHCP were satisfied with its contents. She is a credit to the team and I feel comfort in knowing she will be looking after us for the next year."*

¹ EHCPs

Therapy for Children and Young People (Speech and Language, Physiotherapy and Occupational Therapy)

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

- Face to face appointments are felt to be more beneficial than being directed to information on a website
- Lack of follow-up care following initial appointment
- Speech Therapy provision delivered virtually is benefitting some children and young people.

We have included some quotes received by families:

"You tell me! Not sure how you can dismiss a child who scores in the 1st percentile. If kids in the 1st percentile don't need OT, then who exactly does?!"

"All they sent us was 28 double-sided pages of exercises, for him to do daily. It just made me laugh. Getting my son to do his teeth each day is a mission, let alone 28 pages of exercises. I felt like they told me he was really behind, sent a load of overwhelming exercises, and then said "OK bye!" Really disappointed."

"Lack of SLT for Pre-school and advice with next steps. "

"Referrals for occupational therapy. Paediatrician wanted my son to be seen by OT and put in a referral. We were then sent a letter sending up to a website with information and it was left up to us as parents to decide if our child still needed to be seen..... Also I am not more qualified than a paediatrician. If she want my son seen by OT, he should be seen. I cannot say whether me watching some videos on a website is enough that he no longer needs an OT referral."

"One of the OTs was much better with him and had a better manner. She seemed to respond more to my son when he was upset, and understood that pushing him wouldn't actually help the process. She could also see when he was getting tired etc."

"It's fantastic for kids who can engage with it. I expect for some kids with more complex communication needs it might be more difficult but otherwise it's been absolutely game changing."

Social Emotional and Mental Health (SEMH) needs

The following key areas are what families are telling us regarding Children and Young People's social, emotional, mental health (SEMH) needs. We also ran a short survey this term asking parent/carers what they felt would work for parent participation groups being proposed by the Child and Adolescent Mental Health Service (CAMHS):

- A high level of disillusionment with support offered by CAMHS was expressed by some families
- Being informed of what changes are being implemented as a result of feedback is felt to be important

We have included some quotes received by families and organisations who support families:

"If you are asking for valuable time from parents/carers then they will need to know it is taken seriously and will make a difference."

"Some assurances that the feedback provided will actually be taken into consideration and effect objectives and outcomes."

"Having others with lived experience or from different support groups/specialists to support."

"To be able to have an follow up update to see if what is shared/discussed has reached the specific people who are in a position to receive/review constructive feedback and implement change where possible."

Home Education/Education other than at school (EOTAS)

There was one dominant theme with what families are telling us regarding Home Education, Education other than at School (EOTAS). We have also included comments about Alternative Provision as it is sometimes unclear whether these are part of EOTAS arrangements.

- It is difficult to find the right information and support – whether that is related to finding out what range of options are available to families with EOTAS packages (e.g. transport arrangements) or how to access additional support services whilst home educating (e.g. emotional wellbeing)

We have included some quotes received by families and organisations who support families:

“The case for EOTAS went to panel on Tuesday - they have just come back to say they want to consult with Thriftwood & the Hawthorns - both special schools for children who are not academically able! Surely this is a waste of everyone’s time, and delays my daughter getting the very valuable therapy that she needs?”

“I've home educated for 5 years and it works but we need more advice on mental health situations at home, i.e. anxiety, mild self harm (hitting self) anger management.”

“Offered AP, but no transport, I dont drive so child cant attend as unable to cope with public transport. This needs to be considered”

“We have just been awarded EOTAS, haven't received a draft of it yet but provision has been in place for a year. The LA have never mentioned support with mileage, my daughter would never get on transport so this wasn't an option”

“I was actually offered transport for my son’s alternative provision. But I turned it down as he wouldn’t go on transport. I think if the LA source the alternative provision they must provide transport? But I’m not 100% sure”

“We had an EOTAS package for 3 years and never had any support with transport. It was never mentioned to us as an option. We live in Basildon area”

Attendance and Anxiety

The following key areas are what families are telling us regarding Attendance and the underlying Anxiety about attending education settings

- Parent/Carers not knowing where to get support and advice
- Inconsistency in the flexibility of approach and level of support given in education settings to support children and young people unable to attend due to anxiety

We have included some quotes received by families and organisations who support families:

“My sons previous school were not able to provide proper support for my son's anxiety. The anxiety was caused by bullying, which the school did not deal with properly. This turned into anxiety. I was in contact with the wellbeing teacher, who constantly didn't keep to her promises and let my son down, when she had promised to meet my son to reassure him and help with his anxiety. This led to my son suffering from such bad anxiety that he started to refuse to go to school. I believe the wellbeing teacher and the lack of caring caused my sons anxiety to spiral out of control. This lack of support from the school led to me removing him and sending him to a new school, who have been amazing. “

“Unplanned welfare checks inside the home. When plans were already in place for this to happen at a planned time - caused a lot of distress as daughter off school due to school based anxiety. LA need to make it clear if you can pay privately for EP assessment. Shouldn't need a doctors note to be off school for mental health.”

“We have seen a huge rise in the number of children who are unable to attend school due to their anxiety, particularly at secondary school. Schools seemed to show empathy and understanding short term (particularly over September) but after a couple of weeks many are reverting back to putting additional stress on the young person and parents, with talk of fines and court action. The Let's Talk... We Miss You guidance doesn't seem to be embedded and few schools are offering long term adjustments to support the young person to access education.”

“Parents feel isolated and under threat when their child is experiencing emotional based school avoidance. They are unsure of their rights and where to go to get support with this. There is a lack of awareness of what choices they have and where they can get support and information.”

“Support from Families in Focus and SENDIASS at school meetings has been invaluable for many families when they have been able to access this. Support from an Engagement Facilitator has also worked really well for some families, however we rarely hear of this being offered by schools.”

Autism and ADHD diagnosis and support

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

- Waiting times for appointments and assessments for Autism and ADHD are too long and that there is a lack of communication during the waiting period.
- There is little or no support whilst waiting for an appointment/assessment, or following a diagnosis.
- Unclear process for referrals of children under 3 years old or available support until referral can be accepted.
- Level of support offered dependent on where a family lives.
- Delays in issuing reports following diagnosis

We have included some quotes received by families:

"The wait time for an autism assessment is so long it damages a child's chances of early intervention. Wait times are not communicated you are just told that they are very long. We have been given an estimate of 2-3 years for the whole process."

"The support we were signposted to via the maze group is wonderful but most of the courses are only funded if you live in a certain part of Essex, otherwise you have to fund help yourself."

"Applied July 22 letter to say accepted Dec 22 with a call in Dec 22 with long wait times. Asked a question that they could not answer so said they would call back, never did. No communication since."

"Stuck in a vicious circle of anxiety, lack of academic progress which is now affecting physical well being and school attendance. CAMHS won't open. Correct diagnosis is needed but still waiting time approx 6 months (referred in Dec 22) for first appointment. No communication as to timescales."

"After diagnosis, there is no check in from professionals"

"No updates unless I call. One of my sons took 2 years and I'm still waiting for his full report from Feb. My other son has been waiting since Oct 21 and I was told he won't be seen this year!"

Other - Health:

The following are what families are telling us regarding 'Other' key areas for Health. Due to the low number of responses received for these areas individually, we were unable to theme the comments so are reporting them as they were given:

➤ Hospital Appointments

My son was recently referred to Southend hospital for an ECG and then a 24hour ECG. This is done in the heart and chest clinic which is not a specific children's service. My son is ASD and when I rang up to find out more information to prepare him I was told that I could ask any questions on the day. This is not helpful and I had to resort to googling videos of the procedure to show my son, whilst explaining that it wasn't the same place, staff and may not be done in the same way. The staff in the clinic were very helpful and understanding. A simple social story/ video on the hospital website/link sent in appointment letter for any departments that carry out assessments tests on children, but are not set up with play workers etc. This could really improve anxiety and make experiences go a lot smoother for families.

➤ GP

First visit to the GP to ask for support with regards to my daughters sensory issues resulted in the GP telling me that my daughter is just being naughty and that there is nothing in this borough to support me. Only on my second visit I found support and referral. It seemed that the first GP has no idea of SEN. In one conversation he even told me he doesn't believe in them. Perhaps some GPs need training. This would have given me earlier support.

My daughters surgery (Castle Gardens) has a health and wellbeing hub she has been referred to. We have had one successful session and due for second appointment. They spent 1 hour one to one then they rang me and asked further questions for 40 mins excellent.

I think having to explain a situation to a receptionist and again to a secretary and again to a GP over the phone is quite exhausting and time consuming. It would be great if GP surgeries had a direct contact for mental health concerns for those under 18 so you're not going round the houses before you might be lucky enough to get an appointment.

➤ Referrals – Sensory

The referral letter from paediatric team from NHS gave link to Neurodevelopmental Pathway which has been very helpful in terms of resources and putting me in touch with the Maze group. I wish I got in touch sooner.

➤ Hospital Passports

(what is working) 'Passports' to use in hospital for Children with additional needs. Not everyone knows these are available. They do not always help. for example, A&E it isn't noted anywhere that child has needs and the department that helps is only Mon-Friday 9-5. Needs to be more accessible."

➤ Annual Health Checks

*I have successfully registered my child and they are called for an annual check. It's actually a lovely paramedic at our local surgery, who does the checks. I had to ask for my child to go on the list and then **explain the NHS procedures to the surgery**, but once they'd got it, it's gone smoothly since.*

Son had first last year at 21, this years due shortly and inquired today as having our covids and was told be shortly nurse is working through the list It's very important to get these appointments, my son has asc aspergers, a more recent dx of a muscular dystrophy and has Crmo, son has to have yearly ecg so this is a good check up before his neurology and rheumatology appointments that are coming up again. Peace of mind for what needs checking and good for picking up on things should they arise.

➤ **Referrals - Tourettes and Tics**

I have two sons who have tics along with other neurodiverse issues. They have both asked for support with their tics and so I have tried to start the process of diagnosis. I have had to start the process for an ADHD diagnosis as I have been told there is no support in the county for tics. I know both my boys should be diagnosed with a tic disorder and I would like the opportunity to seek one of the three therapeutic options for them, however, I know this is going to be a fight. We need to do better for those who have a need for tic support, regardless of any comorbid conditions they may or may not have. The route to assessment is also far too long. Waiting times need to be brought back under control.

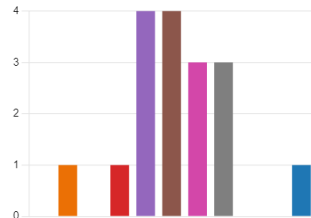
Other – ADHD Medication Shortage:

We are outlining the results of the short survey we ran in December 2023:

2. Please tell us where in Essex you live by selecting your district or borough council below.
This question is important as there are 3 separate NHS Integrated Care Boards in Essex

[More Details](#)

Basildon	0
Braintree	1
Brentwood	0
Castlepoint and Rochford	1
Chelmsford	4
Colchester	4
Epping	3
Harlow	3
Maldon	0
Tendring	0
Uttlesford	1



Are you experiencing any difficulty with obtaining your child/young person's ADHD medication:

[More Details](#) [Insights](#)

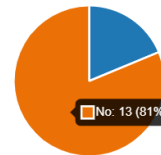
Yes	16
No	1



Has your pharmacy been able to offer helpful advice?

[More Details](#) [Insights](#)

Yes	3
No	13
Not applicable	0



5. Have you had any discussion about whether an alternative medication would be suitable for your child/young person?

[More Details](#) [Insights](#)

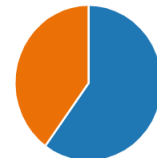
Yes	10
No	6
Not Applicable	0



3. We would like to understand how education settings are working with children, young people and their families at this time.

[More Details](#) [Insights](#)

I have discussed the medication...	9
I have not discussed the medica...	6



6. Have you been able to contact your child's/young person's prescribing clinicians to discuss an alternative prescription, if needed?

[More Details](#) [Insights](#)

Yes	11
No	4
Not applicable	1



9. Please select the option which best reflects your current situation:

[More Details](#) [Insights](#)

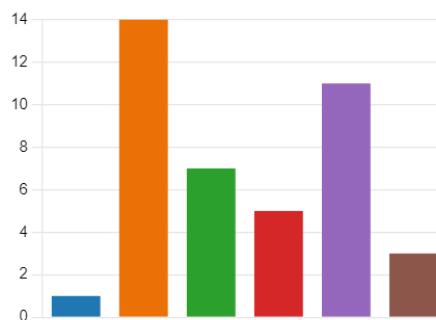
We feel well supported by my c...	8
We do not feel well supported b...	6
My child/young person is not at...	2



7. Please tell us more about the impact this is having on your child/young person

[More Details](#)

They have experienced little or ...	1
Increased Dysregulation (e.g. m...	14
Sleep Disturbance	7
Attendance difficulties	5
Increased difficulty in education...	11
Other	3



The following are what families are telling us regarding the ADHD Medication Shortage and the impact this is having. Just over half of the comments are from our Graffiti Wall:

- *No communication from anywhere unless I have reached out myself first.*
- *We were switched a month ago, and it didn't really help; when I had a call with the nurse, they had already spoken to the pharmacy, who has managed to find a new dose of the meds he preferred, so we have switched and are hoping for the best. The initial change was horrible and has affected our family massively. We have had no monitoring or blood pressure checks.*
- *My child was left with no medication since August and no communication. We were not contacted until I rang in August and I knew nothing about the supply issue. By then, my child I had had no ADHD medication for two months. We recently had a meds review and were not given any advice for alternatives, exercise or diet. We have now switched from Strattera to Intiniv but have had no guidance, advice, or medication log to support this titration.*
- *We've not been able to get Guanfacine for months... it just isn't available, and there is been no alternative offered. We are waiting until the supply issue is resolved.*
- *I have had a whole week of chasing back from Queensway surgery and the Lighthouse, the Lighthouse not answering emails at all to ringing for 2 days. I was getting very worried as my boy was down to his last 2 tablets. I am still waiting for a callback.*
- *When my son had a med review the nurse checked with our local pharmacy if his meds would be available and could not have been more helpful. The pharmacy has not been great, but I have been able to get his meds.*
- *I went to get my son's prescription today to be told nowhere has it, and the lighthouse centre knows that and shouldn't have given it to me. Asked for advice here after trying to source some - have found somewhere that has his medication in stock but only in 10mg and 20mg, not the 30mg capsules he has and they have said I need to contact the lighthouse centre for a new script stating 10mg and 20mg · On top of this, the lighthouse centre just said they're aware and apologise and have given me a telephone medication review at the very end of November to find an alternative, leaving my son potentially without medication for just over 2 weeks if I cannot get any more! · I couldn't get hold of the lighthouse and had to stop the medication. Lighthouse said to restart. Got 1mg and 3mg. 2 mg out of stock. We can't progress onto 2 as the pharmacy can't get it, so we've had to stop again! My poor baby had just gotten over the side effects, and now we're waiting on an appt; I have been told the earliest is in 6 weeks.*
- *We haven't been able to get our medication, so we have now been prescribed another tablet to try. Lighthouse did contact me very fast, and we have a review phone call booked.*
- *My grandson is still waiting for an appointment with Lighthouse to get his medication changed he is now not on anything at all.*
- *Ridiculous situation. Being told to track your own meds down*
- *We've been having problems getting my son's ADHD medication for approximately a year. We've had all sorts of different brand names but I'm told it's the same medication. I told the paediatrician last time we had a medication review, but he said it was the first he'd heard about medication supply problems. My chemist and the GP work well on getting something for us.*
- *We are struggling with ADHD meds. All keep being unavailable, which is a nightmare. The doctors have been rubbish. The chemist has been helpful, but it is not great when your child behaves so differently without meds and can't shut down to sleep. It's very hard for my children, who are stable and then suddenly are all unbalanced again. She is now refusing school.*
- *My son has been suspended from school due to not being able to get a medication review and has no medication.*
- *Went to collect my son's Xaggitin to be told they don't know when they will be receiving more stock. My son has none left so now waiting to call the Lighthouse first thing*
- *I was not informed about the shortage of medication for my son until I experienced it. The Lighthouse team was unhelpful and I had to constantly follow up with them, but to no avail. I was told that my son would have to undergo a medication review to see if there was an alternative medication available for him. However, I had to wait for 3 weeks to be informed that there was no need to switch his medication and that everyone was experiencing the same shortage. Overall, it was a terrible experience.*
- *This is the second time in a year we have had trouble getting my sons ELVANSE20. This is so upsetting as it means he comes off it (he has a heart condition so cannot easily be switched). This sees his difficulties rapidly increase, when we finally get meds he then deteriorates again as he has to get used to taking them again. He*

has just started at special school so this is the last thing we need. Can't get hold of Dr's and a script when you get it expires after 28 days, so if not fulfilled have to go back! Only get 30 days per prescription so it's a constant worry! They are controlled drugs which doesn't help as can't stockpile.

- *There is no alternative to his medication and despite discussions with the school he is still in trouble almost every day for being disruptive and unable to focus. His learning is severely impacted.*
- *It's so frustrating and has a huge impact on the whole family. This is the second time we have an unplanned break in medication. We were unable to obtain any in the summer, just prior to my son moving to his new school(secured by the tribunal process). This meant he spent the summer without meds which increased his anxiety and saw a deterioration in behaviours. When he started the meds again, he was further affected. He was back on them a few months and we have the same scenario again. This is complicated further by his heart defects which means drs are reluctant to swap meds and also by the fact that they decrease his appetite. They couldn't just up the dose.*
- *It is really frustrating that prescriptions only last 28 days and if they are not filled expire and have to be requested again. This always requires extensive conversations as to why a new script is needed so early. One months supply is also the norm which means the price blew reoccurs with regularity and given the controlled status of the meds we can't hold a month in hand. I have written to my MP but have not recieved any replies.*
- *This is children's lives that are being effected, school placements that hang in the balance and as usual parents and carers that have the impact and no control over the solution.*
- *We are lucky as a family to have the support of the learning disabilities support team, many won't have this and will struggle without additional support and guidance. Reasonable adjustments in any setting will be so important and need additional understanding. How has this not been seen or addressed as a serious medical failure for our children and young people.*
- *We have so far manged to plan any medicine gaps so he has enough for school. That has then had a knock on effect on weekends and we have not been able to go out. We've had a lot of issues with the pharmacy and getting hold of people in Provide to tweak prescriptions for melatonin. Communication with the pharmacy has been appauling, and that alone has left us without meds, and this was a big chain one. It's caused so much stress and taken days to chase.*
- *Increased periods of dysregulation as we have needed to vary the dose spending on Supply (with advice from paediatrician). Stress levels and having to call multiple pharmacies in a 20mile radius to find medication 'on the shelf' as it couldn't be ordered from the wholesaler.*
- *Secondary school need to listen to parents regarding adhd. They have no knowledge or not interested.*
- *Has A levels pending this year it is very worrying!*
- *I have found it extremely stressful and difficult to get my daughter the medication she needs to function day to day*
- *There has been no communication about this situation with parents from anybody. I had to contact the paediatrician myself and was told that there was no real solution, there was no alternative that could be used, and now my son has had no medication for months which has affected his ability to be able to regulate, learn, access the curriculum and it has affected his wellbeing and his happiness. Also now, we have been told that if this situation ever resolves, he will now have to be put back on very slowly to get his body used to it, like going back to the beginning again with all the side effects.*
- *Temporary exclusion from school*

My son was diagnosed with ADHD by Provide Wellbeing. He was prescribed Concerta XL. We paid for the first prescription, and the following prescriptions were prescribed by the NHS. Now, 5 months later, the doctors are saying they need a joint protocol, and they are unable to prescribe until he has had a medication review. This has meant my son has no medication left and it has been abruptly stopped for over a week.

Other areas of Feedback:

The following are what families are telling us regarding other key areas as highlighted below. Due to the low number of responses received for these areas individually, we were unable to theme the comments so are reporting them as they were given:

➤ Shortbreaks

We have experienced a lack of SEND clubs and respite during half terms and holidays. We can only rely on Mistley Kids Club depending on their availability to provide 1:1 support for our child.

➤ Annual Reviews

People (SEND OPs) don't reply to emails or keep us updated ETAs or dates.

The school does their part, and then the LA completely fails to do theirs. NO health input at all, despite conditions apart from learning challenges.

I have two kids with echp's they need help with coordination, muscle strength and core stability but have nothing written into their plans! Should this be under health?

➤ Blue Badge Application

"Read information given and respond to the actual issues raised - treat us like people. Make the process transparent and caveat that you can tick 'no' on the DLA high rate mobility question if you want to be considered under alternative criteria. Perhaps just reword the question: "If you receive the higher rate mobility component of DLA or PIP do you want to be considered for a blue badge under the automatic entitlement criteria?" YES - go through automatic process questions NO - go through alternative criteria questions This is a simple fix and not rocket science!!!!"

➤ Social Care

After hitting rock bottom as a family due to DD refusing to go to school we made a referral into social care for support. It took 3 weeks for us to receive a response from them which was a short letter saying we don't meet criteria and to try a TAF meeting with no further information. We are now left not knowing where to go or what to do

➤ Young Adult Support – Targeted Employment

I contacted targeted employment as the college couldn't meet sons new EHCP needs yet she attended Harlow one of her linked colleges and discussed it and informed on what it meant and son interviewed and started college this week. STANSTEAD COLLEGE, LSA is amazing. First time in 3 years son is back in education. Roadshow introduced me to the right people, education people explained PFA and contacted advisor as hadn't got one before.

There was a role advertised on the Targeted Opportunities Board - when my son expressed an interest in June we were told the role was still under development & they wanted to see who would apply first(?????). We've chased up the Targeted Employment team and the response was that there had been some funding issues so role hasn't been developed yet and they'll let us know when ready to recruit. Very disappointing - please don't advertise positions that aren't actually available or ready to recruit. It's not helpful and difficult for a young person with autism and a learning disability to understand.

➤ **Young Adult Support**

How it is assumed a SEND student (especially with high support needs) will not go to university, so there is very little information on how to navigate getting the support needed. Mainly I believe the Preparing for Adulthood advisors (FKA IAGs) should have the knowledge to prepare parents/carers and students for how to get the support. This should also be on Local Offer and SENDIASS should know too. Being told "Just get DSA it pays for everything" is not enough and not true! Support funding and provision comes from three sources Reasonable adjustments are provided by the HEP (Higher Education Provider). Technology, like Technology Enabled Care and equipment, plus things like BSL translators is DSA (Disabled Students Allowance. Personal care is social services. I am a big researcher and even I did not know this, until I actually read the entire DSA guidance documents meant for assessors! As a result my autistic son has had a very stressful exhausting start to uni. He needs one to one support at all times, has had this in school and college for 14 years. Uni are supposed to pay for this, I am still arguing this (equality act... etc). Surprisingly social services have stepped up to fund this, despite acknowledging it is not actually their remit. His support assistant started yesterday. Had I known this a year ago, this would've all been sorted by the time he started. Uni was his only option. Targeted employment opportunities are limited and not really for people with academic qualifications and hopes, day centres... he has no learning disability at all despite high support needs. I would like to see that university is mentioned always as an option for all SEND students, because it is, if you know how to get the support in place.

➤ **SEND Transport**

Our son is moving from one specialist school to another this term and had particular needs from school transport that were well known previously.....but the information wasn't passed over to the new transport provider by ECC. The vehicle is not adequate however it's up to me to contact ECC Transport to ask for authorisation for an alternative. I phoned the number shown on the ECC website and was told they couldn't help, I would have to email. The automated response said I should receive a full response within 2 weeks although this could be longer due to it being such a busy time of year. We also had to arrange a new Crelling harness with the new provider as the previous provider refused to allow this to be handed to us so it could transfer with our son. The replacement has still not arrived with the new provider. This is a waste of tax payer's money as the previous provider (27x7) also retained our son's smaller harness when he outgrew it. Information regarding special transport arrangements should be handed over by ECC Transport to providers and families at the earliest opportunity. It is a waste of time and therefore resources otherwise and causes stress to children and families which could be completely avoided.

No chaperone in transport- 2 v distressed children, first day of term... poor driver... email says 10 working days response, but only found out 8 working days before term started that there was no support.

➤ **Support for ethnic minority groups**

The ability to get ethnic minority into activities and also how to ensure or enhance their ability to accept and understand autism. Groups like Dream the Change are good. Maze also very good. These two ensure parents are informed on the way forward to reduce marginalization in terms of cultural differences. Education/training Meeting with cultural groups/religion More in spreading the word and reassurance that they will not be judged.

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.

