

Graffiti Wall Report



Spring Term 20223

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

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We don't just wait for our termly report; we continue to use the "live", unpublished data so that we can address "hot" topics as they arise, such as Home-to-School Transport at the beginning of the academic year.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

The Feedback and Co-Ordination 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

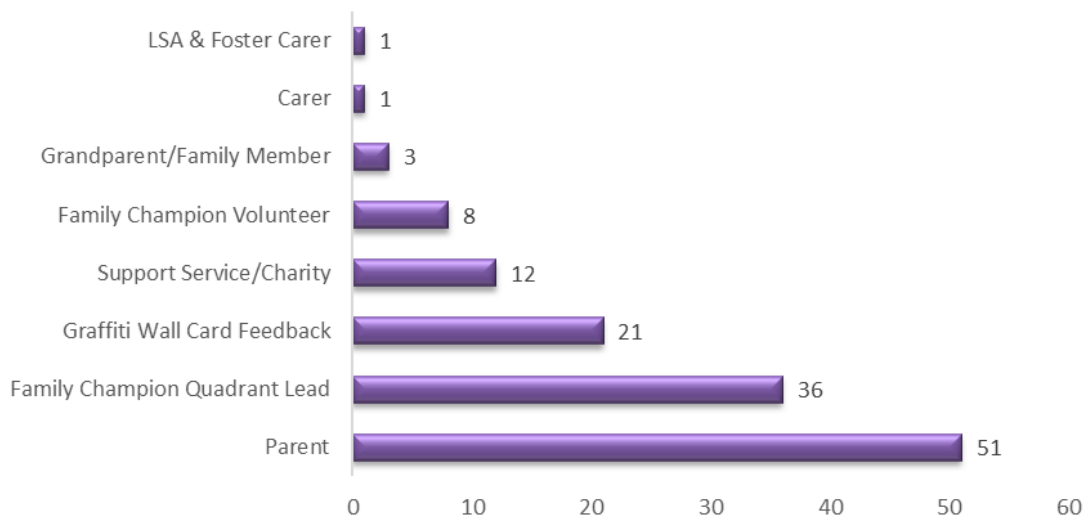
The Feedback Co-ordination and Oversight Group will share the report with Senior SEND Leaders and ensure that your views feed into the SEND improvement work across Essex. They will provide a written response to each termly Graffiti Wall Report outlining where improvement work is already underway and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



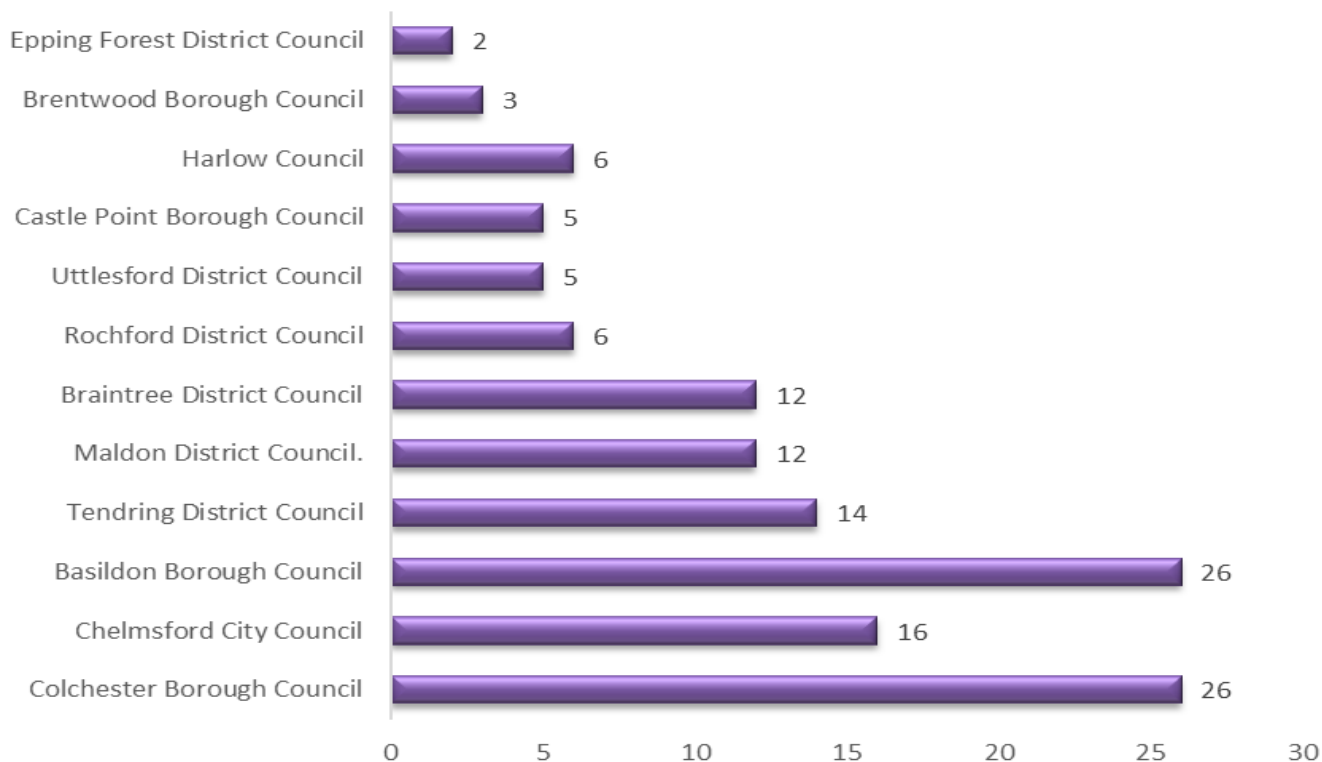
Some facts and Figures

Respondent - Source of Feedback



We had a total of 113 valid entries. It should be noted that our annual survey was also open in this period

Response via Geographic Location



North East Essex 40, Mid Essex 40, South Essex 40, West Essex 13



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 parent's own journey and life experiences of supporting their child or young person.

The headings are the overriding theme self-selected by the person providing the feedback. The feedback however is reviewed in detail and cross referenced and reported on across all categories. For instance, whilst only 10 respondents selected the overriding category "Finding Support and Information", approximately 35 respondents actually provided feedback that is reported within that category.

Overriding Category	Number of Valid Entries
Finding Support and Information.	10
SEND Support for Children and Young People in Early Years, Schools and Colleges.	28
Needs Assessments and Education Health and Care Plans.	14
Annual Reviews.	3
Education Settings.	7
SEND Transport.	2
Therapy for Children and Young People	5
Social Emotional and Mental Health (SEMH) needs.	7
Attendance and Anxiety.	8
Autism and ADHD diagnosis and support.	22
Short Breaks clubs and activities	14
Home Education/ Education other than at school	2
Other	11

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.

Comments¹ 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.

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:

- Finding the right support and information is hard – but when you access it's good
- There are several organisations that provide valuable support to children, young people and their families.
- There is a lack of awareness of how to access information and support.

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

"If you can get access to local groups like the Maze, they have amazing support + help available but as a working parent this can be difficult".

"Lack of career support. Lack of awareness of support/groups"

"Sendiass and Myotas have been amazing in their support during this difficult time".

"The parents that have made contact with us need the support of higher-level services that we don't have the capacity to deliver, but they are being told to contact us by those higher-level services."

"Once aware - charities that support such as FIF (help with EHCP application)"

"Education - More information for parents when they start school on what is available. It is so hard to find what services and if a leaflet or book is freely available when you enter the system."

"Family Support: you have to find everything yourselves".

"PDA society - having lots of resources online".

"The services and support including and after school clubs at SNAP".

"I was referred to the Maze group by a family support worker from Colchester 360. This support was invaluable".

"MAZE & FIF have always provided me with very good advice when needed - previously attended FIF Saturday activity club which was great".

"Autism Anglia have been amazing XXX is a fantastic support as is XXX from the Multi Schools Council".

"Maze Parent program is our most positive experience so far."



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:

- The quality of one planning is variable.
- Professionals need to develop their understanding of masking and its impact on children and young people.
- Professional support can be variable. Some professionals would benefit from additional training or that professional experts are consulted if needed
- Families are still reporting variable experiences with reasonable adjustments being provided in schools.
- Huge inconsistencies around support being provided in settings was reported, although it was noted there were also positive examples around culture and ethics, and we are seeking to understand and learn from these settings.

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

"His one plan isn't reviewed very often. We are only offered formal meeting 1 x a year. Provision that is promised isn't always delivered (consistently)"

"Schools need to be better educated on special needs. Support needs to be the same whatever LSA a child receives. Schools need to think out of the box and not work by textbooks. More individual support needed."

"SENCO at sons' school is very proactive & takes a trauma informed approach."

"We used to have Specialist teacher Team, which bridged the gap between school and home. We were allocated a 'key worker' so they know the CYP from the start of the journey and they continue regular visits. It has been a great loss since this service has stopped."

"Child with pica not being adequately supported at school He eats his tie and gets the threads stuck in his teeth and throat. Parent has requested a reasonable adjustment of no tie because of concerns over his safety but this has been declined by the school "

"One planning at school - very difficult to get a good, detailed plan and understanding of what specific support is provided for my child. Regularly have to seek support for this from FIF/MAZE."



School have been very supportive”.

“Asking for a one plan, but school refused. head of year just says naughty - but on waiting list for diagnosis and needs support, after complaining got an appointment with senco - but it was cancelled as I drove into the school minutes before.”

“My son’s school is mainstream, a small village school with a total of around 80 children. This environment has been the best possible place for my 2 youngest and they are thriving. The school has a high number of SEN students who do well.”



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):

- The roles and responsibilities of the tribunal team are not clear, and job roles that include “support” within title, perhaps do not aid understanding for parents.
- Tribunals wait times continue to be a concern.
- Delays in EHCP process impact on suitable school placements/ CYP out of school
- Delays in securing an Educational Psychologist assessment, impacting and delay the EHCP process.
- Communication continues to be a concern.
- Refusing to assess a child when a child has SEN.

We have included some quotes received by families:

“I’ve been appealing my daughters EHCP for nearly 2 years now. It’s been by far the most gruelling and horrific experience of our lives with our daughter and has led to me suffering a breakdown and having to have counselling. We’ve had zero support from the local authority throughout this process.”

“There is such a delay for an Educational Psychologist to complete the assessment. I have asked if an external EP will be sourced as it is known there are delays with the assessment process, but no answer. Please source out EP’S so children are not delayed in assessments and impacted on getting the help and support they require based on their needs”.

“The delay is ruining my daughter’s chance of a placement for sep23. She has been out of school since feb22, and her mainstream have acknowledged they can’t meet need.”

“SEND ops do not answer phone calls or emails”.

“Inclusion partners are good & Ep’s when you can get one!!”

“Communication in a timely manner isn’t always possible but communication should be happening at some point and there is no acknowledgement that they are outright ignoring families like mine”.

² EHCPs



Annual Reviews

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

- Families report that the annual reviews do not always happen in accordance with statutory guidance.
- Families are waiting too long for amended plans to be finalised.
- Annual reviews are not always referencing professionals involved with the child or young person, and as such not reflective of current needs.

We have included some quotes received by families:

“AR conducted in Nov (which was conducted after a several requests as stated was unable to do due to capacity)”

“Still do not have a EHCP plan following an AR which is reflective of current needs”.

“We are in our 2nd academic year of EOTAS. We have had our Personal Budget agreed and paid out for both academic years however we haven’t had a finalised EHCP during that time. We have had annual reviews that I have instigated but then waited 6 months or more for a draft plan. Due to me not agreeing the draft it has been dragged out until the next annual review is due and the cycle has started again.”



Education Settings

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

- Parents report that obtaining a school placement that meets their child or young person's needs is challenging and can be overwhelming.
- There is a lack of specialist school placements.
- Some settings are meeting their child or young person's needs.
- Post 16 College learning opportunities need to be considered so that the CYP is part of the community and their needs met as outlined in their EHCP.

We have included some quotes received by families:

"My child is out of school, and I have been feeling absolutely overwhelmed by all the meetings I need to attend with school who say they can't meet his needs. I was advised to contact families in focus for help, but they haven't even bothered to answer my calls. I can't find details of anyone else who might be able to help me "

"Now has a place at Southview school and goes every Thursday with her Mum for a session until she starts full time in September - is really loving going".

"Putting my child into a special needs school really helped him with education and life skills. he can now read; spell talk and a lot more".

"Have greater consideration for the implications of the segregation of Extended Learning pupils and main college population. Explore opportunities for integration and collaboration between the two different student populations. Work with the families of students to create a more personalised learning programme approach - these are students with EHCPs after all so their outcomes and provision should be personalised. Do more activities outside of the classroom, develop their independence. Find a better way to 'package' the requirement to continue to study Maths and English for students who are unlikely to ever achieve a level 2 qualification."

"Thriftwood have told me they're not suitable for my son going forward (he's year 8 and started last year). Columbus have now officially rejected XXX as too able - his levels are a 3 which won't be compatible with their offering. He's officially not SLD but not MLD either 🤔 So guess what.... Essex have to pay for an independent school AT 90k A YEAR!!!!!! Seriously that such an atrocious use of public funds I'm enraged! So we now have Luxborough, Towers and Doucecroft that be Essex are consulting with."



SEND Transport

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

- Families report variable experiences with their allocated drivers and passenger assistants.
- Travel training was found to be positive experience for young person.
- Parents feel that communication could improve and be provided in a timelier fashion regarding amending routes, drivers, and passenger assistants.
- Agreed transport not provided.
- Transport for Post 16 contract changes impacting on children and young people accessing provisions.

We have included some quotes received by families:

"The drivers (and PAs when we had one) were amazing".

"Positive experience with travel training for son. Son was previously at Churchill School in Haverhill and would be taken by Taxi. With the support of a travel trainer (ECC & Secondary school transport) son has been able to access public transport and use to get to and from school. Travel trainer was really good".

"Transport company getting rid of required PAs, changing routes with no notice, changing buses and drivers. Children are basically treated like cargo. Lack of communication from both transport company and ECC transport both to our family and to each other. Complete abdication of responsibility from both transport company and ECC and families are left with the massive impact of their cost cutting decisions."

"The school buses never turn up - there's been times my son hasn't been picked up by Kinect - they just don't turn up - that my son has been at home for nearly a week without leaving".

"Lily Rose Day Provision in Chelmsford have reported that there have been changes made to the transport provision for the young people that attend. UgoBus have been commissioned by ECC to provide transport to the young adults attending the provision who are unable to travel independently and have an assessed need for transport. UgoBus advised Lily Rose Day Provision on 10th January that, with immediate effect, they would be withdrawing their services to collect young people from the social club evenings and during the holiday provision as they are not commissioned to do this. They stated they would be contacted the next of kin for all involved to advise them to this needed to be arranged and funded privately. This, effectively, gave families 48 hours' notice to arrange alternative transport, and has caused distress and disruption for them and their vulnerable young adults. UgoBus and ECC's Passenger Transport are refusing to move on this - which breaches guidelines which states that where there is an assessed transport need that covers travel to and from day service provision but also for social activities. If ECC haven't commissioned the right contract to UgoBus they still have a statutory responsibility to provide transport - this should not be funded by the families."



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:

- Wait times are long, but once accessed therapists are helpful and supportive.
- The recommendation and use of private sensory assessments is unclear.
- The information surrounding NHS sensory diagnosis and provision is not clear.
- Families want improved communication about how to access provision, what support can be provided and information on the progress of their child or young person.

We have included some quotes received by families:

"OT support has been brilliant (but accessed privately)"

"Waiting lists for assessments and any support, e.g. OT, Paediatrician EHCP procedure feels long and slow."

"Spoke to several parents regarding CYP sensory needs they were asking about a NHS diagnosis - I explained we do a Sensory course in NEE and to ask GP to refer to it. Also recommended some good books to empower parents to understand needs"

"OT - although the wait was 2 years - it has been very valuable".

"Paediatrician at primary care told me to go to maze course after diagnosis, did maze course - advised to get sensory assessment, school won't accept as its private and paediatrician said SPD is not diagnosable so would not of recommended getting one..... "

"Post-op services for young people with CP was non-existent - No physio! I have to provide equipment that isn't funded - walkers AFO's these aren't cheap! Respite options are dire"

"S&L Signed off, but did not get sessions as per his EHCP"

"Difficult to get hold of therapists at all - why are they not at the Roadshows??"

"We are not in regular contact with SALT at school (special school)"

"Unclear of the process to access additional therapy for my child"



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:

- Families report that accessing support and understanding of children's mental health in schools is variable, but when accessed can be successful and professionals are helpful.
- Professionals are unaware of resources that can support families such as the "supporting your neurodiverse child" resource.
- SET CAMHS courses are positive experience for some, but others, they feel they do not provide sufficient support.
- Once discharged, there is not an easy route back into CAMHS if needs change.
- Wait times to access support such as CAMHS continues to be a concern for families.

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

"I requested some wellbeing support for my daughter (ADHD) who was beginning to struggle. I was told the primary school didn't have anyone to provide this and no pastoral care."

"Make sure the link to the ND pack is shared at the start of the course and even before that. The ladies delivering the course we're totally unaware of its existence until I shared link to it on EFF website. They were then extremely positive about the resource when we returned the next week and they had chance to read - they raised its use on future courses, etc with their management structure as were so surprised it had not been referenced to them before".

"Good delivery of PAG course by SET CAMHS. Course leaders are knowledgeable and tailor the session to the attendees. One of the people delivering the course also assessed my son and I did feel that she "got" the situation and was knowledgeable".

"In schools they have LSA to talk with the kids and that helps my son in school".



"My 9-year-old son has extreme anxiety and the GP referred him to EWMHS but they discharged him without even meeting him. They just "signposted" us instead. My son needed to be seen face to face and have someone listen to him and us as a family".

"Self-referred to SET CAMHS as GP and paediatrician said they could not prescribe anxiety medication to my son who is 14. He was already known to the service although discharged as was too unwell to engage and what was being offered was inappropriate for his ND needs. He is now asking for help in the form of medication and because he was discharged, we have to start the process again. It has been 10 weeks since the acknowledgement of receiving referral and I have heard nothing. Meanwhile he will be becoming too unwell to engage again".

A organisation which held support group session around supporting emotional well-being and had a discussion around therapy reported "4 parents stated that 6-12 week a of support (as offered by camhs and kids inspire) is insufficient to provide sustainable support for their children and that they need to build a relationship with their therapist and that longer term support is required."

"Booked a private assessment and am attending this week. This should not have to be the case when i child is begging for help".



Attendance and Anxiety

(Emotionally based school avoidance)

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

- Private attendance companies are used by schools, and they are not understanding or productive.
- Some schools are requesting proof that child or young person is unable to attend, which GPs will not provide.
- Families report feeling blamed for their child or young person being unable to attend school.
- Families report that support from schools is variable, with some supporting up to a point, and some who are not providing the appropriate support to families at all.

We have included some quotes received by families:

"Attendance officer. Had a meeting because diagnosed autistic daughter has too much time off. Awful meeting where spoke over me constantly, said we all have issues, and no excuse was good enough reason for not going to school".

"The school are happy to talk and understand her issues etc. But if attendance drops below a certain percent, it is handed over to outside agency".

"Threats with social care now my child is unable to attend school- no justification as to if this is child protection, children with disabilities. Feel oldest is so severely affected i.e., MH and blame being put onto us as a family rather than acknowledging school impact".

"School is not working with us or putting barriers in place to support my child who is out of school. They are not following LA guidance and recommendations. My child has now lost complete trust in them and is now refusing to attend after what she felt like was "tricked into staying school" and not letting her leave as agreed when I (Mum) handed her over in the morning. Matter has now been escalated to send ops as at crisis and placement is breaking down. being contacted by a private attendance company"

"Communication- no early intervention even though have been asking for support since September 2022".

"Help for children in schools for mental health provisions when a child is anxious, school refusing and medically unfit to attend, you are forced as parents to make them attend and go into an environment where they don't feel safe".



Autism and ADHD diagnosis and support

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

- Families report that waiting times for appointments and assessments for Autism and ADHD are too long.
- Referral acknowledgement and wait times are not effectively communicated to families.
- Families are unclear what their journey will look like leading up to and following a diagnosis.
- Families report that there is no support whilst waiting for appointment/assessment/following a diagnosis.
- Standardised questionnaires can mean if a child masks in schools they can be a barrier for a referral onto a pathway for assessment.

We have included some quotes received by families:

"More awareness for GPs with differences between boys and girls"

"ADHD & Autism referrals are simply too long. We've been waiting 2 years and still nothing. Resorted to private diagnosis @ £4K just to ensure our daughter gets the help she needs. It's not OK to make a young child wait so long."

"After diagnosis, apart from a couple of follow ups, he's been left. He is nearly 15 and I'm worried about adulthood, jobs etc".

"Diagnosis: Just given a leaflet!!"

"Following on from diagnosis - handed a leaflet and no follow-on care - As a parent left feeling lost not sure how to support my own child, having to actively search for support and information".

"Please give feedback from time to time on where we are on the waiting list to manage our expectations. Have you forgotten us? It's a constant worry that we have been forgotten or missed off the list".

"Lighthouse centre refusing to see my son as he masks in school so the questionnaires between home and school didn't show enough. Do they not understand about masking? It will only last for so long and then when it all falls apart, we will have to start this process all over again, whilst in crisis. In this day and age, a questionnaire from school shouldn't be a barrier, as parents we know our children".



“Parent who is herself autistic and has complex mental health needs was told paperwork for her sons ASD assessment had been lost so she needs a new referral with wait time of 2 years. (She has already been waiting 18 months). Son is 12 and self-harming with increasingly violent and challenging behaviour. School confirms that they see ASD traits and have requested support from camhs - he is waiting for assessment from them too. Single parent is now facing giving up work to support her son, but DLA declined upon first application because of lack of evidence without diagnosis. Parent does not have the capability to challenge the lengthy waiting times and needs urgent support”.

“Now awaiting assessment of youngest child who was referred by Busy Bees Nursery in Gt Notley over a year ago and I have not heard a thing since in terms of update from the service he has been referred to”.



Short Breaks

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

- Families reported mixed views regarding the newly commissioned short breaks offer, and the providers who were awarded the contracts.
- Families raised concerns that specific provisions were not awarded funding under the new contract.
- The Max Card and tickets for days out, are valued by families.
- Families state that the lack of suitable and affordable provision impacts on their ability to remain in employment.

We have included some quotes received by families:

"Giving my grandson no choice as the only thing he can go to in his area now will be Butterflies - this doesn't seem fair, and they say this was to give families more choice."

"Days out tickets - we had free tickets to go to the zoo last year and it was a wonderful family day out which we really appreciated. The respite was needed after a very stressful year of diagnosis, appointments, surgery and start of rehabilitation. Having some of the cost for the day reduced meant taking my partner and other son not a strain on us and we were able to reconnect as a family and have a very enjoyable day making fun memories".

"I think the max card is a wonderful idea, I don't know who is responsible for managing this but an overview of the websites content, making sure the offers are still valid with the various companies and a map view of the offers available would help greatly"?

"Holiday clubs need to be affordable for young people needing 1:1 Hoisting and changing places don't exist at holiday clubs".

"The new tender has only being award to 1 provider in each quadrant and they will be providing activities not respite/holiday clubs. The other providers will now have to increase prices and will be unaffordable to most".

"Share, Mushroom and BOSP have been a lifeline to us and my son will be very isolated without them and My Husband and I will not be able to continue with or current jobs"

"My son attends Butterflies Club, and it has been a lifeline to us, he keeps routine during school holidays and they've they have gently pushed his boundaries of comfort zones to be able to enjoy activities that we never dreamt of possible for him."



“There is absolutely zero after school/holiday clubs in Chelmsford that accommodate for SEN children that attend Specialist School education (e.g. Columbus) thus making it absolutely impossible to find employment or maintain employment. Many, including myself, have had to give up working due to the lack of provision”.

Home Education/ Education other than at school (EOTAS)

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

- Families report varied experiences of EOTAS provision being provided as per their child or young person’s EHCP.

We have included some quotes received by families:

“SEND team do not respond at all. Do not provide provision that is specified in an EHCP Do not provide an education to my child. Do not provide any of the EOTAS package they should be. Have not provided personal budget within the statutory deadlines.”

“Pleased EOTAS was agreed, with appropriate provision”.

“We are in our 2nd academic year of EOTAS. We have had our Personal Budget agreed and paid out for both academic years however we haven’t had a finalised EHCP during that time. We have had annual reviews that I have instigated but then waited 6 months or more for a draft plan. Due to me not agreeing the draft it has been dragged out until the next annual review is due and the cycle has started again.”



Other

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

- Good Quality Day Provision for Post 16's
- Families report that professionals do not always work together to support the child or young person, and as a result do not take a holistic view of the child or young person's needs.
- Some families report that they do not feel listened to, supported and that in some cases are blamed for the child or young person's behaviour/needs.
- GOSH have an app to support communication with families, which is beneficial.
- Improved support for adoptive families is needed.
- Positive experience with ECL/Employment support
- Support to access affordable childcare
- Access to dentists

We have included some quotes received by families:

"I just want to highlight what a wonderful provision Lily Rose Day Provision is for young adults. As a fairly new enterprise they are still developing their provision, but every expansion of their offer is aspirational for the young people in their care. My son is thriving!!"

"No connection / poor communication between the different professionals involved in a child's care making it hard for them to see the big picture about a child and overall needs to help prioritise them. Post code lottery - if you live in Mid Essex, you are at a disadvantage".

"CAF CASS, social workers and school SENCO don't listen, value or respect a parent's voice. Blame parents for all issues in school/issues must have come from home. No collaborative working"

"My GOSH (Great Ormond St app). Excellent way of keeping track of all appointments, medications, assessments, communications. Makes it easy to communicate with the hospital. There should be 1 central version of this used by ALL hospitals, professionals, specialists, GPs etc etc to record all referrals, appointments, assessments, diagnosis, test results, letters sent, communications sent by ALL and then summary of the child's overall needs. This will be accessible by ALL the professionals involved in child's care so they can see overall big picture about child, and it can assist them to join the dots when making a diagnosis. The service is too disconnected. Parents have to keep track of so many things and keep repeating the same info to different professionals - it wastes so much time."



"Where is the help? Where is the support? Why does my social worker a senior practitioner always email me back telling me it's not her job to help me when I'm struggling?!?! There's been times in the last 2 months I have no food. No gas. No nappies - not all shops do size 8/10"

In relation to support for children and young people who are adopted a Parent/Carer stated "I truly believe all adopted children should have access to a comprehensive educational psychologist assessment as part of placement planning. This would remove so many delays for families in securing diagnoses and provision from day one".

"Social care won't support parents to work with direct payment but yet there isn't a childcare provision you can pay for like a 'mainstream' child can access for working parents. It quite honestly astounds me that we are just expected to live on benefits".

"I need help he needs to see a dentist".

"I just want to say how brilliant the employment team at ECL are. They have been supporting my 20-year-old son since October. Nothing is rushed and it's a really personalised approach."

"Social Services should also have access so they can see all involved in child's care. This will avoid vulnerable children slipping through the net and being lost in the system".

"I come from a place where my son was under the care of the local children's centre. He would have had access to their services until he was 18-25. ESSEX NEEDS CHILDRENS CENTRES. They are available sources of care and information. Early intervention was also promoted, which I have noticed is not necessarily the case here. My youngest missed development checks, etc as it was impossible to get an appointment with a health visitor".



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.

