

Graffiti Wall Report



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We don't just wait for our termly report; we continue to use the "live", unpublished data so that we can address "hot" topics as they arise, such as Home-to-School Transport at the beginning of the academic year.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

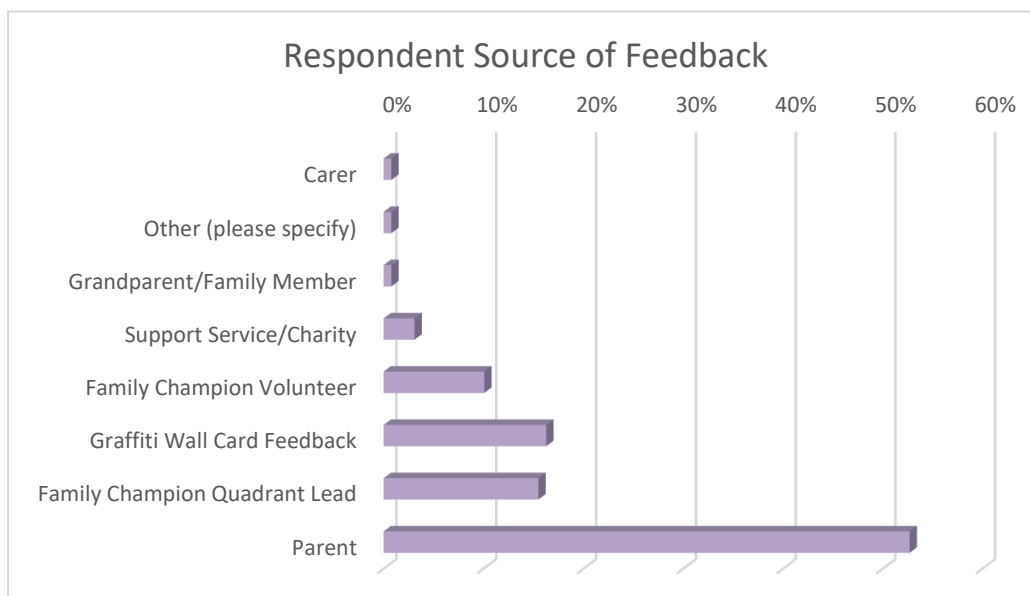
Step Four- Responding to feedback

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.

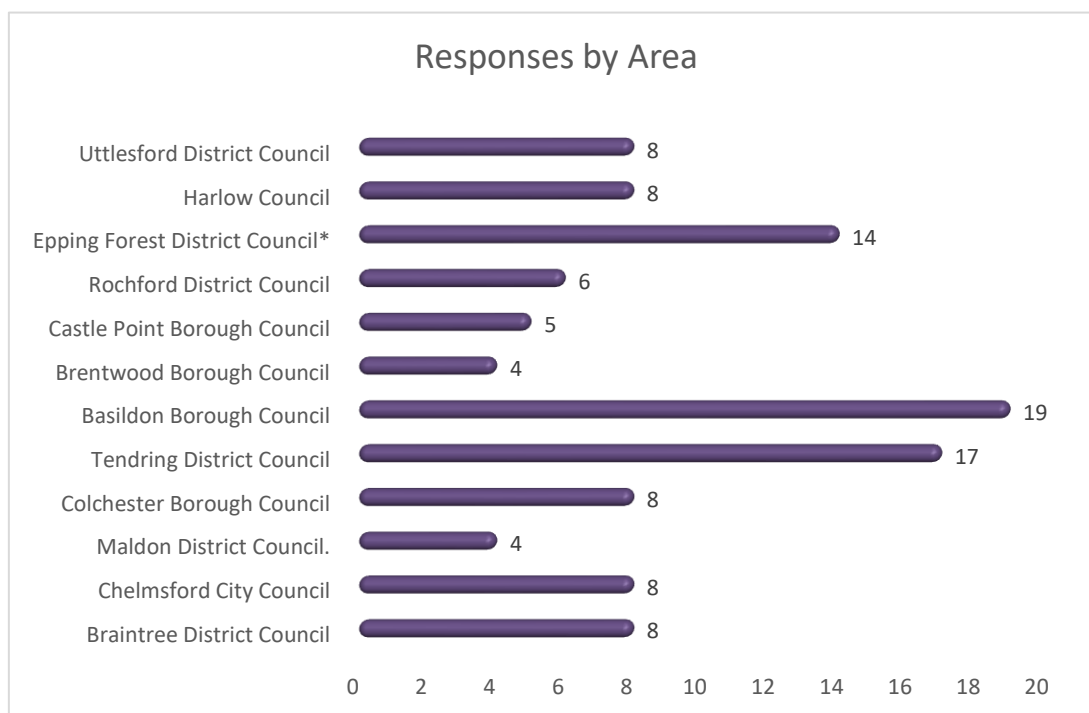
Did you know we share your views regionally with the Eastern Region of Parent Carer Forums and Nationally with the Network of Parent Carer Forums? To find out more about the parent carer voice beyond Essex see our website: <https://essexfamilyforum.org/about>



Some facts and Figures



We had a total of 110 valid entries.



* includes data relating to all areas of West Essex (Epping, Uttlesford & Harlow) from Support Groups

ICB Footprint	No.
Mid & South Essex	55
North East Essex and Suffolk	25
Hertfordshire and West Essex	30



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 themes that can be self-selected by the person providing the feedback. The feedback is reviewed in detail and cross-referenced and reported on across the categories. For instance, there was one entry under SEND support and that will be reported under the "Other – Shortbreaks" category.

Categories of Feedback	No of Responses
Finding Support and Information	19
SEND Support for Children and Young People in Early Years/Schools and Colleges.	29
Needs Assessments and Education Health and Care Plans	10
Annual Reviews	1
Education Settings	13
Home Education/Education other than at school (EOTAS)	1
SEND Transport	0
Therapy for Children and Young People (Occupational, Physiotherapy and Speech and Language Therapy)	2
Social Emotional and Mental Health (SEMH) needs.	11
Attendance and Anxiety (Emotionally based school avoidance)	1
Autism and ADHD diagnosis and support	7
Other (please specify)	
Shortbreaks	9
Commissioned Charities	1
Lighthouse Centre	3
Health Services	1
Keyworker Support	1
Wheelchair Services	1
Total	110

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.



Finding Support and Information

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

- Support received from charities is good.
- It is difficult to find support and information, or referrals to the right services, in areas that are geographically isolated
- There is a lack of awareness of how to access information and support at the time you need it.

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

"A number of families in the Great Wakering area say they often feel stuck finding info and services because services automatically refer them to Southend based services, due to Southend address, they feel out of the loop with support from Essex, roadshows etc."

"I speak to a lot of families struggling with Autistic/ADHD children, and not knowing how to support them at home as well as how to get the right help at school"

"I feel by completing my understanding autism course, I had more knowledge which helped me understand the process of getting my son diagnosed, my son's school have been very supportive and I feel early intervention with regards to support before a diagnosis should be given more."

"I went to a coffee morning at Wat Tyler and found out about about the SEND Roadshow. I got a lot of good advice especially MYOTAS."

"It would be amazing if there was a local charity or provision for making home gardens accessible - Our garden is on 2 levels and my daughter who is a wheelchair user cannot access the upper part"

"The SEND Roadshow was invaluable.....in the end someone listened and I've been proven right about everything I've been trying to get someone to listen to."

"I don't feel parents are supported enough to understand EHCP's or one planning reviews. I'm agreeing with professionals because I'm not sure of what I need to do or say."



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:

- Year 6 to Year 7 transitions arrangements for SEN children are not always well planned.
- A lack of early intervention and appropriate support being put in place in education settings, a number of these comments also referred to long waiting times for Neurodevelopmental assessments. *For example: families being told that certain support cannot be given without a diagnosis or an Education Health and Care Plan (EHCP)*
- Long delays in conducting EHCP Needs Assessments affecting the level of support available to children and young people in their education setting
- Support Groups are reporting on increasing numbers of children unable to attend school and/or parents de-registering their children from school due to unmet needs
- Staffing capacity issues and funding constraints within settings impacting on the level of support that can be provided

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

"I supported a parent at a meeting with a local senior school. They had concerns and had made a list of what to discuss. The Senco started the conversation and mentioned all the concerns and offered solutions, even before the parent spoke. It was a very positive, supportive conversation."

"I have a child in Year 2 of mainstream school, they cannot meet his needs, currently waiting for diagnosis / EHCP. My son still needs nappies and because personal care is not on his EHCP, they do not have provision to change his nappy, so he comes home in the one I send him in!!"

"Transitioning Year 6-7To much all at once e.g. had the taster day then the same evening the welcome meeting. My son was too overwhelmed by the end of the school day to attend the welcome meeting and missed the opportunity meet teachers and other students. "

"...when asked about passport to leave the room if overwhelmed, we were told can only get with an EHCP."

"New school fantastic, regular meetings and communications, one plan in place"



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 in obtaining Needs Assessments
- Provision missing in Education Health and Care Plans or not being delivered
- Cessation of Education Health and Care Plans impacting progress at Post 16 provisions

We have included some quotes received by families:

“My daughters EHCP final is a at 50 weeks, with no placement and no communication until last Friday”

“EP report was missing provision (where needs were already reported) and lacking specificity in some areas. Asked for a meeting from October 2022 to March 2023.”

“The complaints process works to get a response from professionals who otherwise ignore emails”

“Don’t take support away without realising how this will affect young people especially at transition. You don’t know what their needs will be in a new setting.”

“My daughter has 15 hours of Speech and Language Therapy on her EHCP, last year she received 1 hr, this year so far she’s received 2 hrs. Each time I chase it the answer is “we just don’t have the staff” in fact their staff turn over is very high. Often we’ve been allotted a new therapist but they have left before they’ve even seen my daughter”

¹ EHCPs



Education Settings

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

- Good communication and a collaborative approach between parent/carers and schools makes families feel supported

We have included some quotes received by families:

*"(*school name*) very helpful, enjoyable for my child. Staff are supportive."*

"Communication is absolutely essential, as is recording and sharing communications. It is pointless having a great SENCo-parent relationship if the information leaves the office..... All communications need to be recorded and stored somewhere. It may not make sense then, but a little thing makes part of a bigger picture. And all staff need to know what's going on"

*"(*school name*) supportive school. In general years 1, 2 and 3 have been positive."*

"Some schools have adopted a more therapeutic approach and incorporated things like meditation/yoga into the timetable"

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:

- Physical environment of clinic waiting area isn't suitable.
- Unclear pathways / referral processes to the correct support
- Delays in accessing support from CAMHS and escalation in mental health needs
- Neurodivergent conditions being a barrier to support

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

"If you are in crisis there is a 2-3 month wait!"

"4 families have advised us that they have been declined for support from Kids Inspire because their child is neurodivergent."

"Extremely long wait for individual therapy at CAMHS for my child despite it being deemed urgent."

".....it has been decided 'that symptoms appear to be within the context of their ASD diagnosis' so psychiatric interventions are not currently being considered."

"My son, aged 10, is not sleeping, threatening to use a knife, high anxiety. At CAMHS appointment, adviser said "How do you know he will go through with using the knife?" Only saw my son for 2.5 minutes, after that he sat in the hall with lego while I spoke to the adviser. She discharged him there and then saying it was all down to his ASD and he "looked fine" sitting in the hall with Lego".

"My daughter was assessed by camhs after 6 month wait. They diagnosed ocd and anxiety. BecUse she is autistic and has high anxiety they said group therapy not appropriate and apparently no other options available so she was discharged and we have been left with no help for a serious mental health issue"



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.
- Families feel there is lack of a clear process around monitoring and reviewing medication
- 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.

We have included some quotes received by families:

"A support worker to reach out to parents once discharged from paediatrician. We as a family would of been greatly appreciative of support a actual person to be able to go through a actual best next step for our child/family. although the list of charities is helpful, it is overwhelming and hard to navigate whats appropriate for your childs/ familys needs. "

"ASD referral 3 years ago - still waiting. Zero parent support until now. School do not share SEND info or groups info. Kept in the dark with whats available"

"I mentioned to Health visitor concerns regarding ASD for my 2 year old in 2020. I was told they were too young. In 2021 we had a check up from health visitor, and they told me off for not caring for my child, they said I should have chased up and need to get my child into nursery so can get help with speech and language. We started the process for ASD assessment, took just over 2 years and now they have been diagnosed. May 2023. If HV had listened to me in first place, this could have been put into place sooner."

"Adhd medication. We have not had an appointment yet that has not had to be chased. Dose titration is happening on a 6-8 month basis. It is only because i am monitoring child's blood pressure, weight and height that these checks are happening at all and we only seem to get follow up appointments due to chasing. Last appointment, wasn't even an appointment, just a call out of the blue. Yes pleased we got a call but what if i had missed that call? How much longer would we have waited? How is this safe? How does this not put at risk a child's whole life outcomes?"



Short Breaks

The following is the only theme from the comments received regarding Shortbreaks:

- Families reported mixed views regarding the newly commissioned short breaks offer, and the providers who were awarded the contracts.

We have included some quotes received by families:

“The new services that have been funded DO NOT support severe disabilities and the ONE place that does would not have made the new hoop jumps for funding and I’m so disappointed as it’s our only source of respite available, there should be an additional funding pot to cover severe disabilities as they need care ALOT more than most.”

“My daughter attended Butterflies for a while in 2021 and it just was not suitable for her and she didn’t enjoy it. I was not happy when they were announced shortbreaks provider for my area. However we went to a meet and greet and we discussed her complex needs and how she doesn’t like structure or busy places. We were steered towards certain sessions and activities. She attended a taster session and got on ok and has been attending a lot of sessions since. She seems to be really enjoying it and comes home happy each time. She has a one to one each session and has been to Club sessions where it is much more relaxed in the sessions she attends and she has been on 2 trips so far.”

“My son attends Butterflies clubs. He loves the activities that they offer. I find their programme well thought through with a wide variety of activities my son can access. It’s the only place that I never worry sending him, and where he says he has friends. Their provision over the summer holidays means that myself and my husband can keep working where we would not otherwise be able to find childcare. Their weekend activities mean I can spend some one to one time with my daughter. AMAZING organisation that makes a huge difference to my family. “

“Short Breaks in South doesn’t seem to have anything suitable for us. The choice seems to be big halls with multi-activities or whole day trips out for over 15s. It does not cater for higher need with behavioural difficulties.”

“My son is 15 years of age and has quadriplegic cerebral palsy as well as a number of other complex conditions. He is unable to sit or stand and is totally reliant on his wheelchair and personal assistants to support him in accessing all aspects of daily life. He (until recently) was a regular user of the Discovery Club at Columbus school, where they had all of the appropriate facilities to support his personal care needs in a safe and wheelchair accessible environment. To my knowledge none of the new service providers have the necessary on-site facilities to cater for his needs (makeshift rooms and mats are being offered as a solution). It is great that there are a number of community excursions on offer, but most places do not have the changing places facilities, so this also prevents him from attending days out in the community. He has gone from being able to enjoy holiday clubs and experiences with his peers to nothing, which is incredibly disheartening on a number of levels. Young people with his high level of need do not seem to have been accounted for with the new short break services.”



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, we were unable to theme the comments so are reporting them as they were given:

➤ Annual Reviews

Nothing is working. I feel like I'm in a packed room screaming at the top of my lungs yet everyone is ignoring me. We are desperate for a resolution to our daughters case but at every point the LA are blocking it. We make compromises but the LA put nothing on the table in return. We are so far backed into a corner there is no option of giving up because there's nothing on offer to give up and accept. It now feels like the LA are pushing us towards deregistering.

➤ Therapies

*"My son is at ** independent special who have their on site therapy team who review my son termly and their yearly report is included in his Annual review. He was also evaluated by their speech and language team who found multiple areas of need (which I had highlighted when I requested an EHC NA) requiring 1:1 weekly intervention. The NHS SLT found no issues. The level of assessment through an EHC NA isn't the same high standard as special schools."*

➤ Attendance and Anxiety

"My child has severe anxiety due to bullying at school. We told the school his mental health was deteriorating and now he is unable to go to school or interact as he previously did at home."

➤ Keyworker service

"Spoke to a parent who MSE child has a CeTR and they have a keyworker. Keyworker had less experience than the family so wasn't able to really identify with what they are going through. Also not flexible enough to provide any meaningful help. For example can't drive the child to places, can't do physical activities with the child to give parent respite."

➤ Equipment

"We have been looking for some time now for a reasonably priced hydrotherapy pool. We have been lucky to have been able to use littlw havens I'm the past but unfortunately it has been out of order since before covid - the only close pool is the hamelin Trust which was subsidised for a time by ECC but at £25 for 45 minutes swimming it is just out of our reach. Could the subsidy be considered again?? Hydro is so freeing for our son who is a full time power chair user and is his favourite thing to do. Community pools are always far too cold."

"I initially began discussions about a manual wheelchair for my son in January of 2022 with his OT at the Lighthouse. There were some discrepancies where the referral was not received and then eventually had a visit in May of 2022 for first assessment. A second visit with a wheelchair to assess suitability happened in the summer holidays (I can't remember the date). A manual wheelchair was



ordered thereafter. We are now in July of 2023 and we still have not heard anything further. I have telephoned several times and around May managed to arrange to collect a chair cushion which had been ordered at the same time to use in an existing chair (this has not been reviewed for suitability at all). When I have managed to speak to a staff member I have been advised that there is only 1 OT who works at WCS covering paediatric patients who only works 1-2 days a week otherwise it is only an OT assistant taking the day to day queries and calls. It has been suggested that delays in manufacturing has been the problem. My son has a neuromuscular condition and the community is very small so there are many if us nationally that keep in touch and it seems that "manufacturing delays" are not a national issue in the way I have been told as other areas are certainly not experiencing the delays that we have been.. Coincidentally, I have attended a few SSIF events and have met other parents who have shared that they too are experiencing severe delays in Southend. I spoke with a mum last week whose 3 year old who is unable to sit up or walk is currently still using a regular stroller in which her child is not safe because they have been waiting over a year for a specialist stroller. I'm very concerned that my son and many others it seems are being failed locally by WCS and are being left without a means of getting around or even leaving the house."

➤ **Accessibility**

"There are no playgrounds local to us with accessible equipment for wheelchair users – I would like to be able to visit a playground with my daughter."

"Our garden is on 2 levels and my daughter who is a wheelchair user cannot access the upper part - It would be amazing if there was a local charity or provision for making home gardens accessible."

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.

