Graffiti Wall

Representing Parent and Carer Views and those that support families with SEND across Essex

Essex Family Forum

Spring Term Report

January – April 2022

Concept of the Graffiti wall

The Graffiti Wall was set up to provide parents and carers 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 are invited to share their views.

Data gathered at in-person events or via email is updated, where consent has been provided.

The data gathered is anonymised and presented termly to the SEND Partnership Board, from whom we require specific feedback on this data that we can share with our Family Champions and with the SEND families in Essex we represent.

Collection of Data

63 Discounted Entries
2 Southend
2 Thurrock
59 provided no feedback

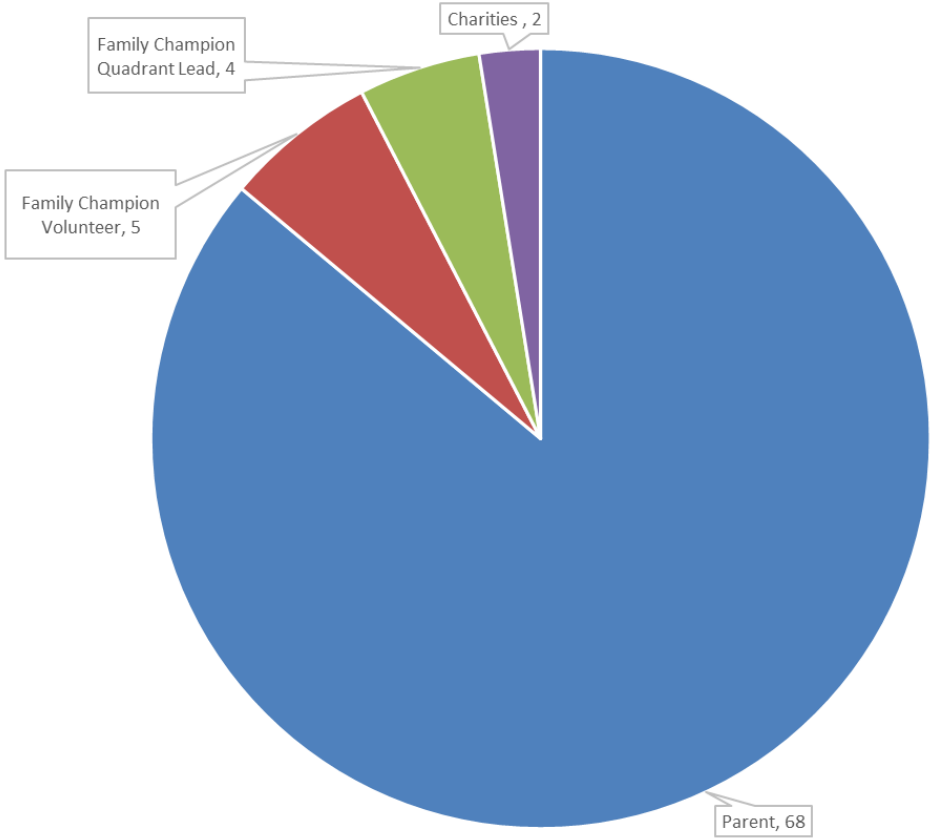
Valid Entries

Out of 143 overall entries, we had 79 valid entries, with the majority being provided by Parents.

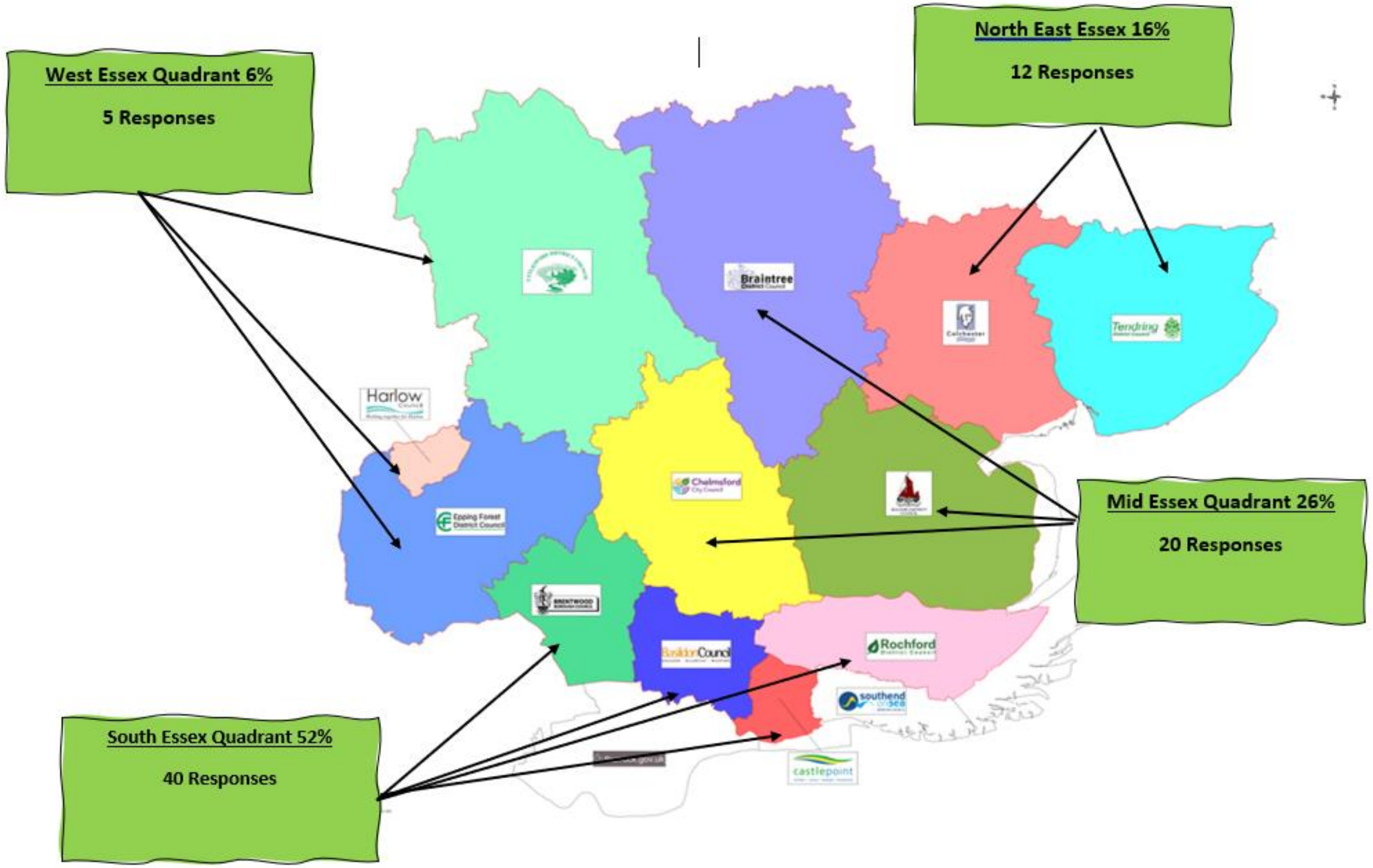
Family Champion Volunteers will often provide information of their own experiences and indicate "Parent"

It should be noted that our Annual Impact survey ran during the Spring Term and as such we anticipated lower engagement via the Graffiti Wall as a result

Type of Participant.



Responses by Area



West Essex Quadrant 6%

5 Responses

North East Essex 16%

12 Responses

Mid Essex Quadrant 26%

20 Responses

South Essex Quadrant 52%

40 Responses

Excludes responses by Charities

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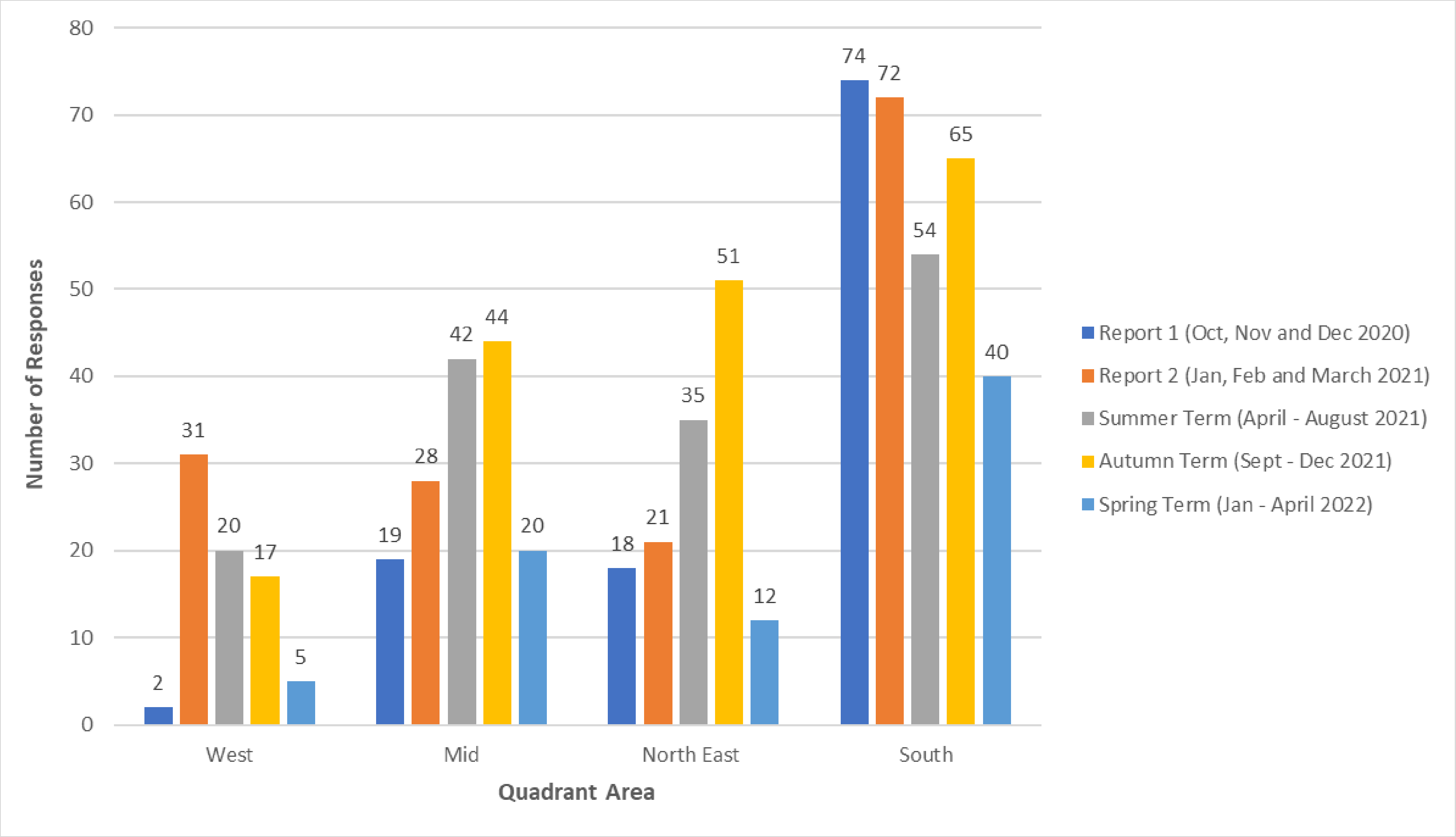
Responses by Area



Comparison of valid entries per Graffiti Wall report by quadrant

Excludes responses by Charities

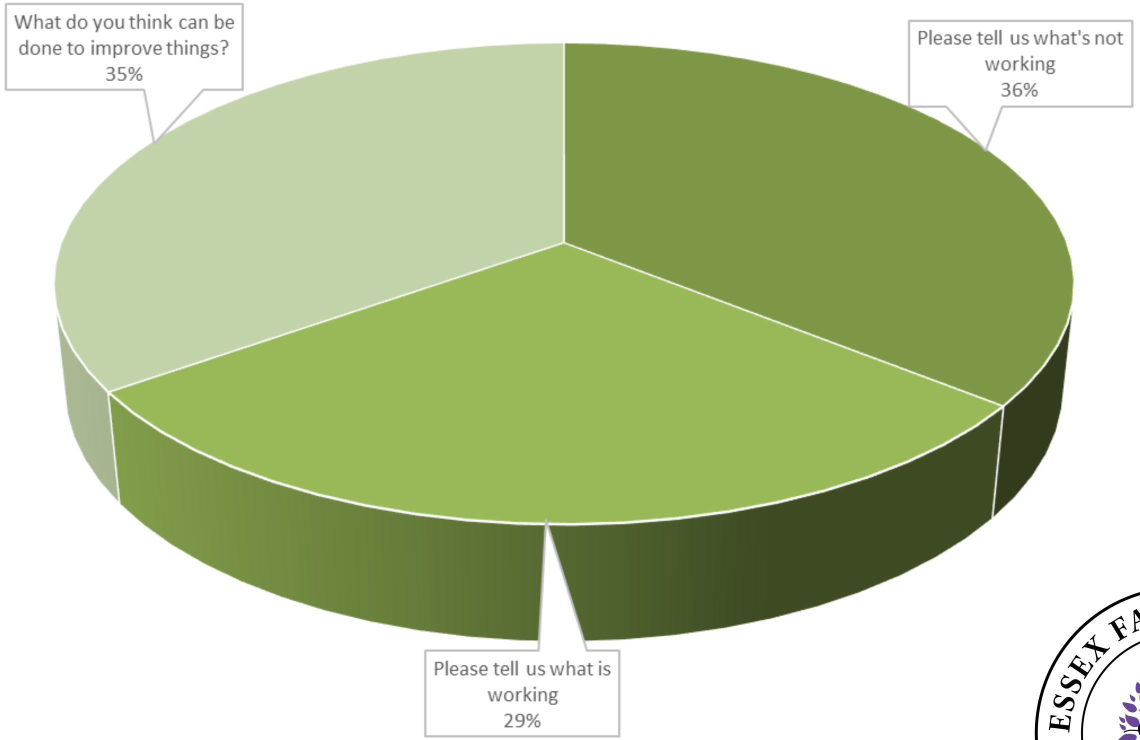
Category Breakdown and Type of Feedback

We asked parents and carers to categorise the area for which they were providing feedback from pre-existing themes. A total of 207 comments were provided across all themes, excluding comments that came from support groups or charities, which are counted separately .

We ask 3 key questions

1. **What's not working?** We recognise that it's important to parents and carers to be able to tell us what is not working for them and to provide us with details of their experience.
2. **What is working?** It's equally important to understand what is working, so that we can learn from best practice. It also highlights that what may not work for one family, may work for another.
3. **What can be done to improve things?** This is key. This allows us to be able to represent the services and provisions that parents and carers would like to see.

Participants have the option to provide a response on one, two or all three questions in relation to their selected area of feedback.



Transparency of Comments

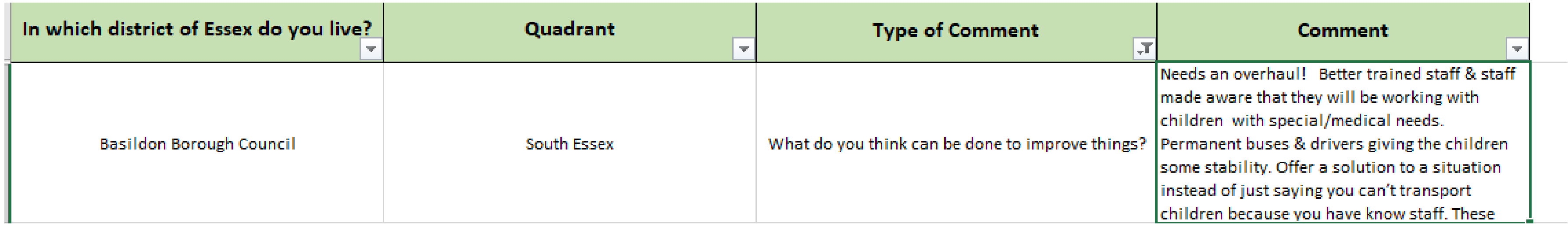
The report provides key issues raised by families over a variety of categories of feedback, however, we understand that not all key issues raised may apply to all areas of Essex; with the landscape of one Local Authority and three Integrated Care Boards (ICBs)* and a variety of commissioned providers, it's important to be transparent over the geographic area of the key themes as reported by families.

Whilst we have always offered the full anonoymised data (which included named provisions and professionals) so that each area can review their own data, following feedback from the boards and meetings in which the data is presented, we felt it was appropriate to ensure that ALL the data was reflected within the report rather than highlights.

Therefore, within this report, each category has key themes highlighted, a selection of comments and within the slides an embedded spreadsheet which lists all comments made for that specific category. The spreadsheet details the District and Quadrant (or ICB Footprint on Diagnosis) of Essex and comments provided with the data for the 3 key questions:

1. What do you think can be done to improve things?
2. Please tell us what is working
3. Please tell us what's not working

We hope that this will enable more localised discussions regarding key themes of feedback from Families.

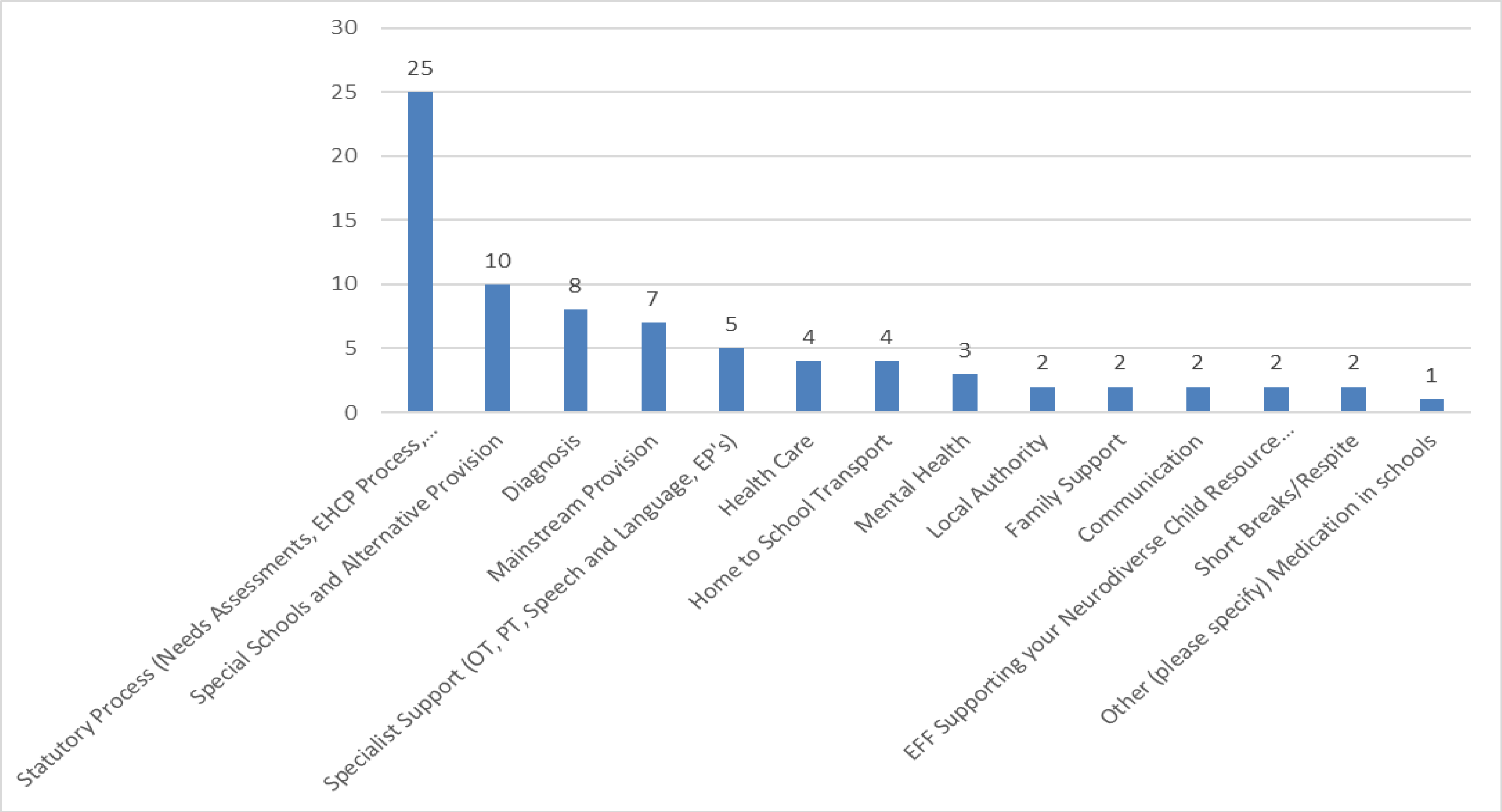


In which district of Essex do you live?	Quadrant	Type of Comment	Comment
Basildon Borough Council	South Essex	What do you think can be done to improve things?	Needs an overhaul! Better trained staff & staff made aware that they will be working with children with special/medical needs. Permanent buses & drivers giving the children some stability. Offer a solution to a situation instead of just saying you can't transport children because you have know staff. These

*We note that the data was collated, prior to the creation of ICBs whilst the Five Clinical Commissioning Groups (CCGs) were in operation

Category of Feedback

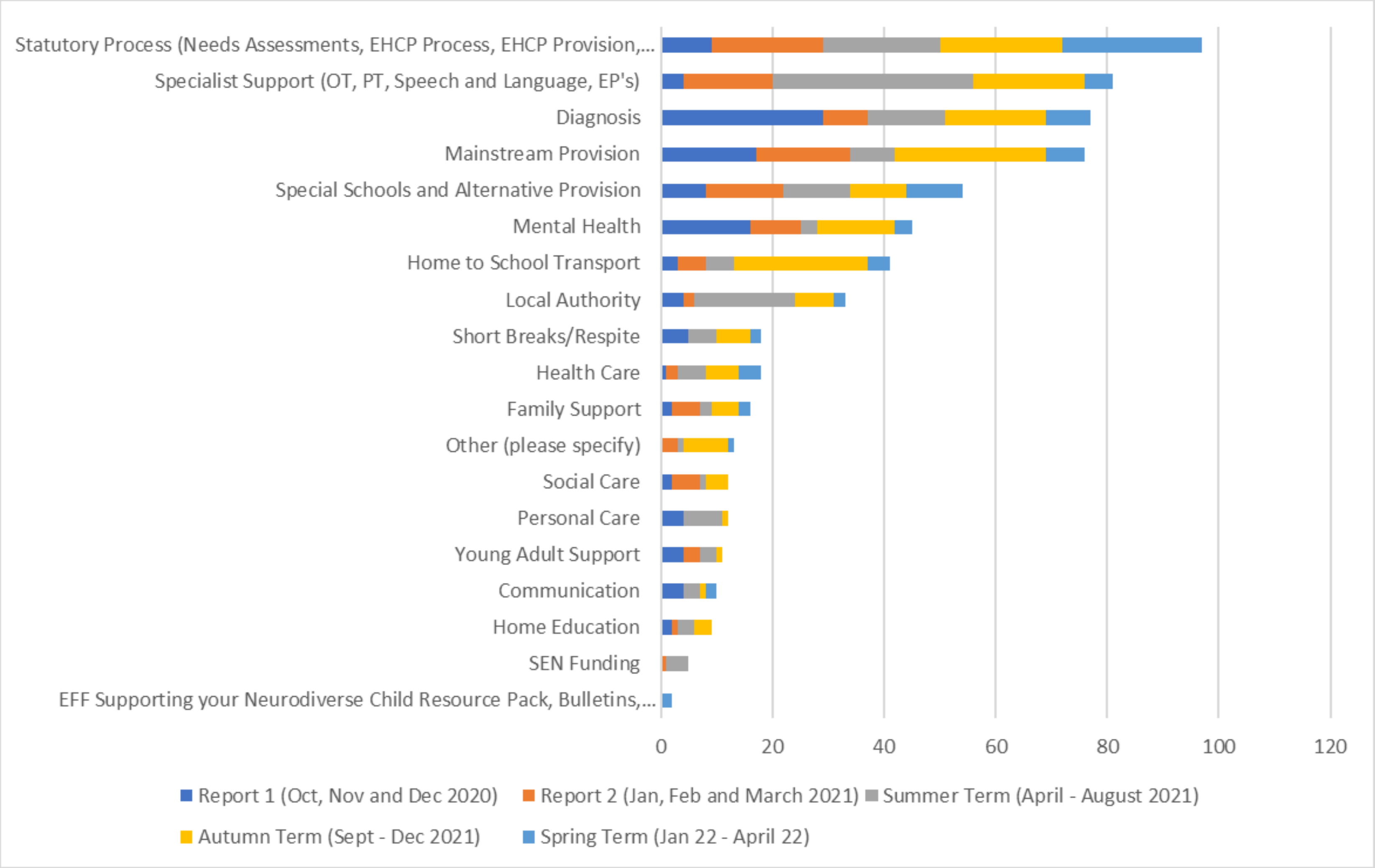
Summer Term only



This shows the feedback we received broken down by category for this period of reporting

Category of Feedback

Report Comparison

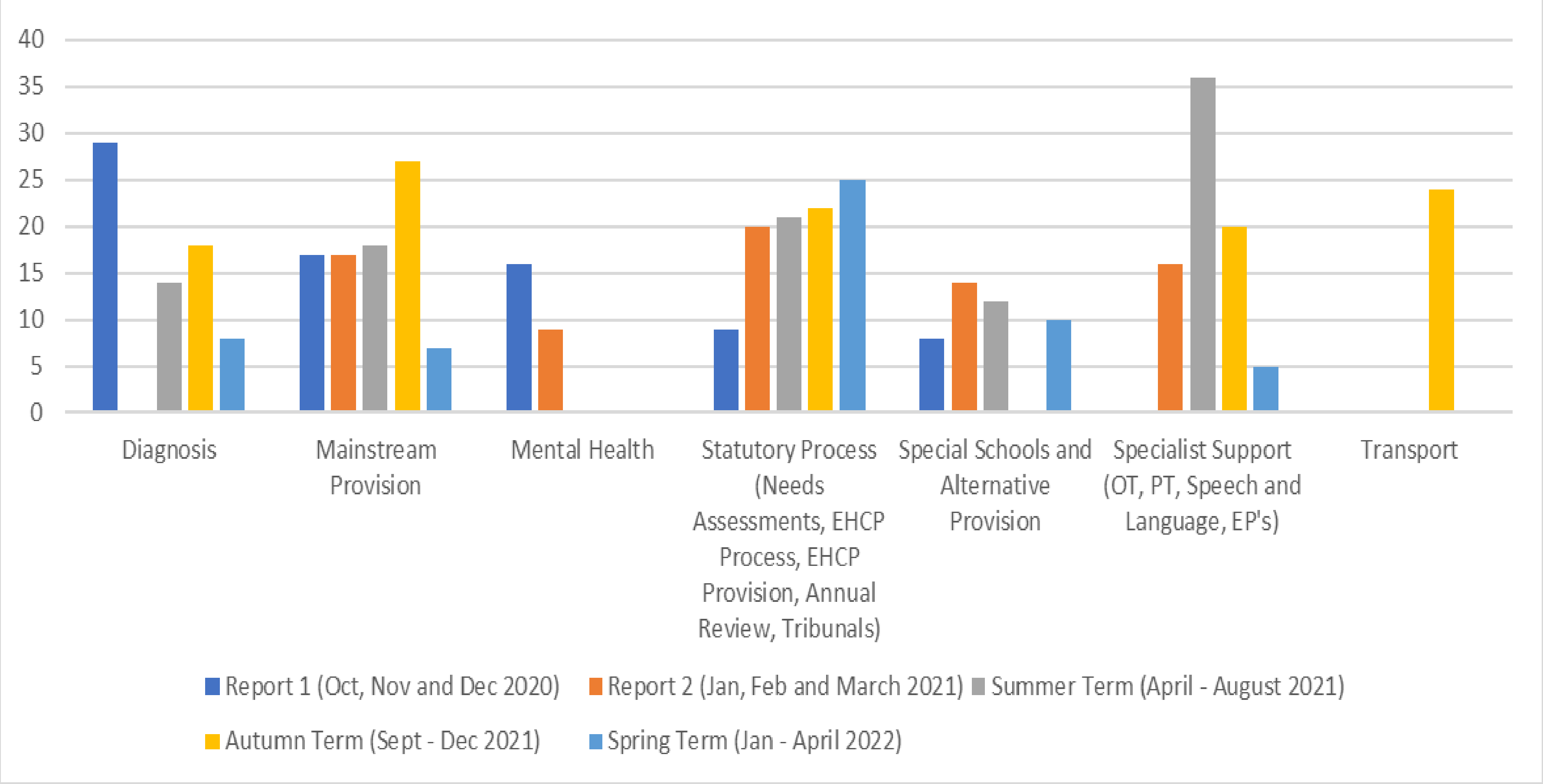


Key themes remain with the amount of feedback provided by category, with the top 5 overall areas being:

1. Statutory Process (Needs Assessments, EHCP Process, EHCP Provision, Annual Review, Tribunals)
2. Specialist Support (OT, PT, Speech and Language, EPs)
3. Mainstream Provision
4. Diagnosis
5. Special Schools and Alternative Provision

We can see how the top five fluctuates across each report on the following slide

Analysis of Top Five Categories



These figures show the top five areas of feedback over the 4 Graffiti Wall reports. Where there is no data that does not mean no data was received, simply that it did not feature within the ***top five categories*** of feedback for that report.

Mainstream Provision and Statutory Process remain consistent featuring in top areas of feedback across all four reports.

Home to School Transport featured in the Autumn Term report, which reflects feedback for the start of the academic year.

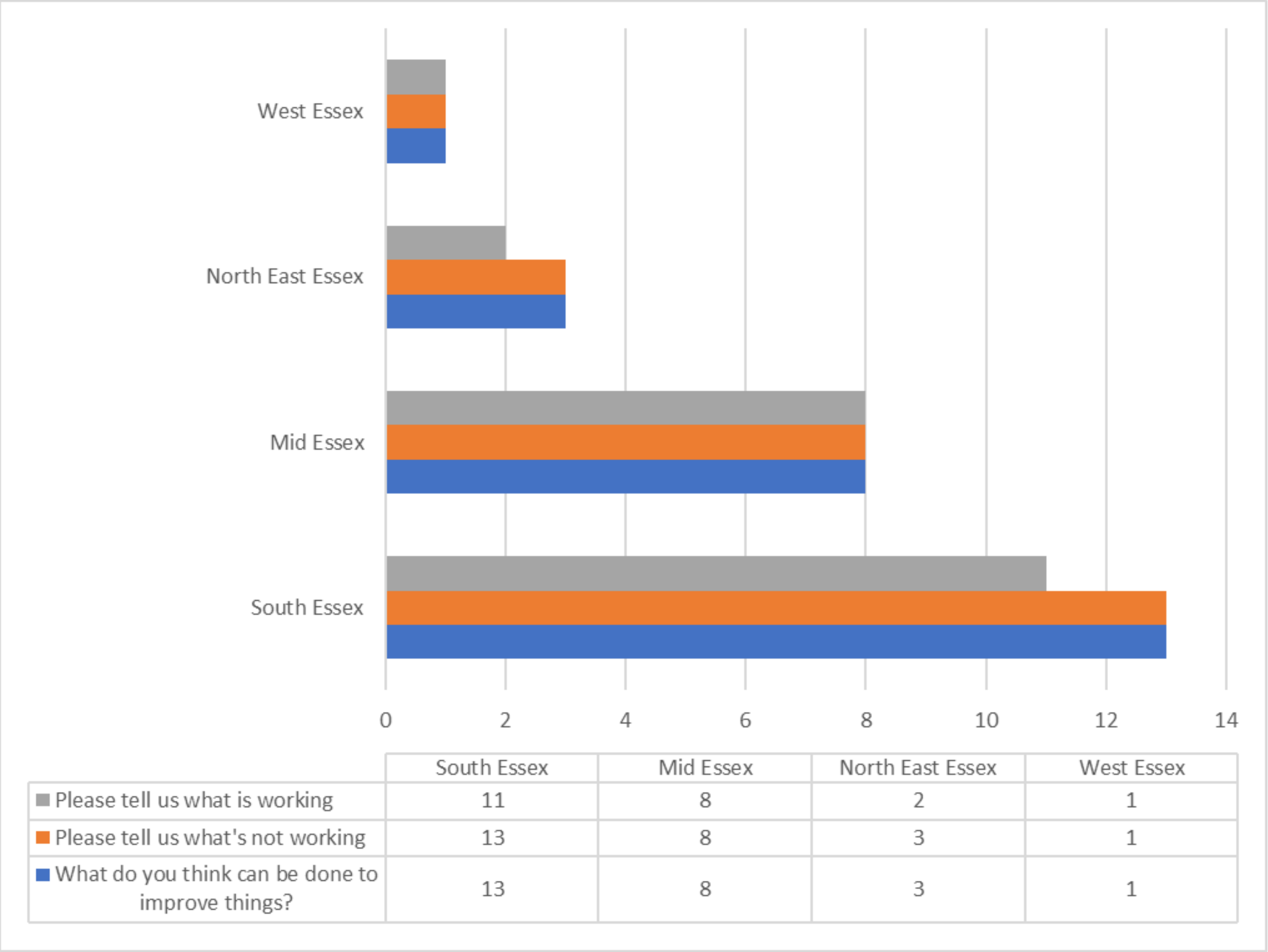
There was a targeted approach for therapy feedback in the Summer Term which account for the increase in comments.

The neurodevelopment survey ran during the Summer Term, so we anticipated a lower number of participants for this period

Our Annual Impact Survey ran during the Spring Term, so we anticipated that engagement through the Graffiti Wall would be lower.

Statutory Process

(Needs Assessments, EHCP Process, EHCP Provision, Annual Review, Tribunals)



	South Essex	Mid Essex	North East Essex	West Essex
⬜ Please tell us what is working	11	8	2	1
🟧 Please tell us what's not working	13	8	3	1
🟦 What do you think can be done to improve things?	13	8	3	1

We received a total of 72 comments to our key questions, from a total of 25 participants. Of those, *some* participants indicated the type of support that they were in receipt of.

- 21 indicated that they had an EHCP
    - 2 of these respondents also indicated that they were also Receiving support from Children's Social Care Services or in the process of being referred to Children's Services
- 3 Indicated that they had a One Plan of which 1 indicated they were also going through Needs Assessments

We have highlighted some key areas of feedback on the following slides.

For all anonymised comments received on the Statutory Process, please see the embedded document.

Microsoft Excel
Worksheet

Statutory Process – Key Themes

Please tell us what's not working	Please tell us what is working	What do you think can be done to improve things?
1. Annual Reviews • Not taking place/issued within statutory time frames • Post 16 – advised EHCP will cease for college • EHCP not shared with education setting 2. Education Health Care (EHC) Needs Assessment Process / EHC Process • Lack of EPs impacting on deadlines • Banding concerns • Issues with amendments to draft • Delays / not adhering to deadlines • Refusal to assess due to age (early years) • School not compiling with request for information 3. Accountably • Lack of accountability over complaints 4. Communication • Lack of communication • No response to e-mails	1. Support and Advice • School supportive 2. Specific Teams • Helpful and kind SEND team • Speech and Language 3. Negative Feedback provided in this section • Nothing (15 comments)	1. Communication and Transparency 2. Improved provision for those academically able 3. Statutory Processes • Adhere to time scales • Meet Legal Obligations (stop gatekeeping) • Allow 0-25 applications 4. For health to make decisions on provision 5. System needs to be properly funded 6. Specialist Teachers – Inclusion Partners are not the same 7. Work on behalf of the Children and families

Statutory Process – What is not working ?

Annual EHCP review keeps getting cancelled due to no-one available to represent from health and discuss/agree new provision. No annual review now for 3 years!

School SEN has advised that Essex are planning to end EHCP’s if/when they leave school at 16 & EHCP will not be supported post 16 if go to college!

Lack of communication. Send ops read my emails but haven't replied since beginning of February. They have finalised ehcp changing from agreed draft

Not being allowed to submit an EHCP application before your child turns 3y, even when they have significant complex needs which will definitely require EHCP. We are now in the stressful stage of not having EHCP drafted or finalised but having to apply for schools because our child was born in August.

My son had an annual review of his EHCP last January and in the summer a draft (extensively amended) EHCP was finally received (none of section f was specific or quantified). I responded. And now, a year after annual review, we have still not received the final draft of the EHCP and none of the recommended provisions have been implemented. They have now cancelled the annual review for this year as there is no EHCP to review

XXXX School are refusing to provide professionals reports in advance of annual reviews to all parents

The process has taken far too long that schools are being consulted on an out of date EHCP

No reviews- be first one , no post 16 advice , no views from School

Statutory Process -What is working?

Nothing. I cannot say any of the process has been dealt with in a satisfactory way.

We had speech and language which was helpful and have since been signed off but been able to keep in contact to find out where we are in terms of seeing someone and able to give good advice when needed

My daughters school is very supportive but they don’t have the funds and support to help her from ECC.

Nothing. The decision making process is corrupt in my opinions of many parents in my area

Nothing

Nothing is working quite as it should be. Gaps are being plugged (after a fashion, they aren't really adequate) but still no provision for over 2 years

Helpful and kind people on the EHCP/SEND team

Not much 😂

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Statutory Process – What can be done to improve things?

Allowing EHCP applications to be considered from 0-25 as they are intended, or at least from 2y, so that the process can be completed before having to look around and apply for schools for the youngest school starters

If school hasn't responded after 2 weeks for send ops to chase school and alert family so they can intervene. Communication process isn't working

Having a health representative who can make decisions or a process it can go through to agree new provision

1. Better provision for academically able disabled children whose needs can't be met in mainstream school. LEA, Statutory Assessment and other stakeholders *must* come to accept that there is a significant minority of disabled children who won't thrive in mainstream.

“

Communication

more transparency. legal guidelines followed.

Staff that work on behalf of the children and parents and don't just act as a barrier. Line management systems that work well.

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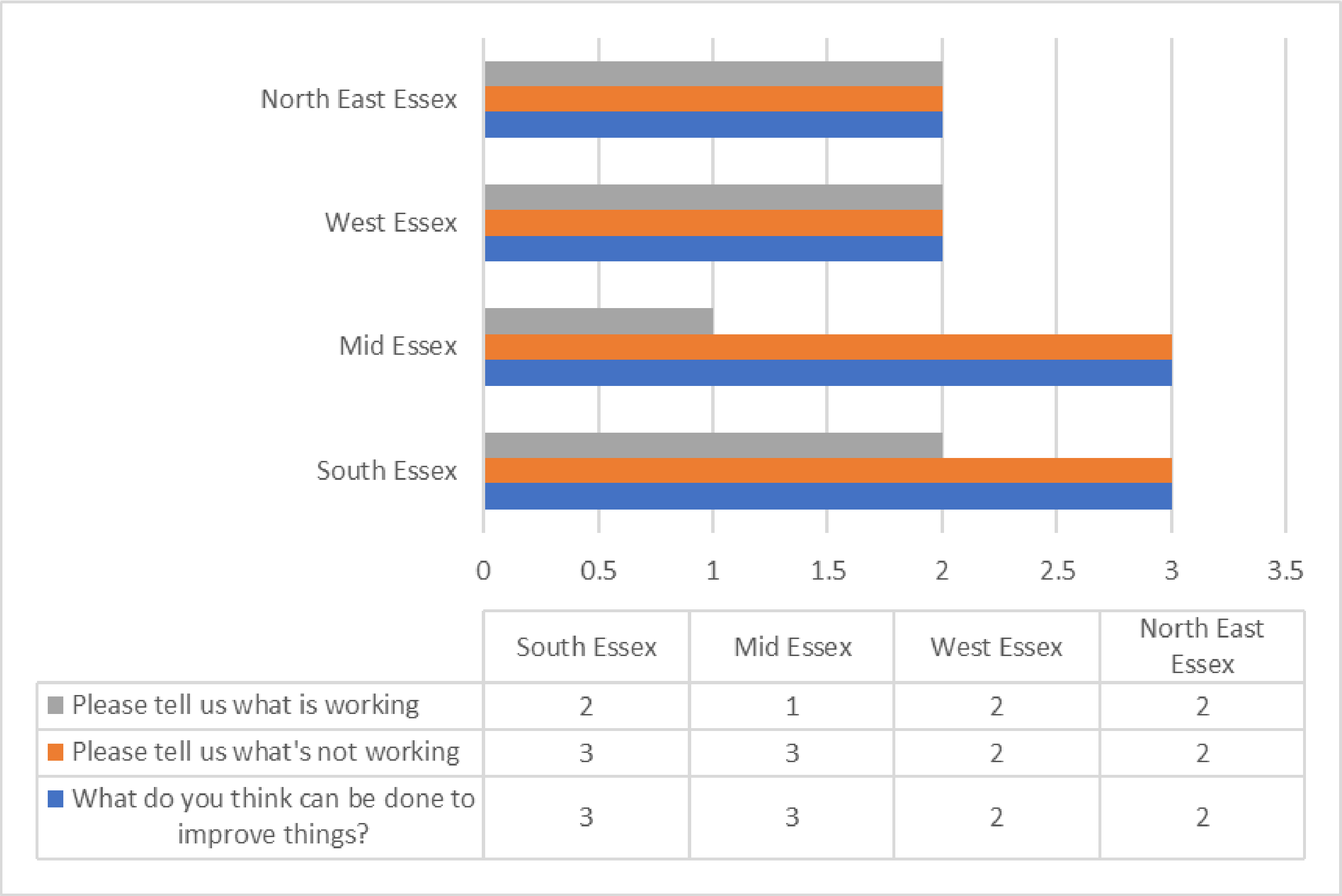
Special Schools and Alternative Provision



	South Essex	Mid Essex	West Essex	North East Essex
■ Please tell us what is working	2	1	2	2
🟧 Please tell us what's not working	3	3	2	2
🟦 What do you think can be done to improve things?	3	3	2	2

We received a total of 27 comments to our key questions, from a total of 10 participants

We have highlighted some key areas of feedback on the following slides.

For all anonymised comments received on Home to School Transport, please see the embedded document.

Microsoft Excel Worksheet

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Special Schools and Alternative Provision– Key Themes

Please tell us what's not working	Please tell us what is working	What do you think can be done to improve things?
1. Lack of SEND schools in Uttlesford (West) Malden (Mid) 2. Lack of SEMH Schools in South Essex 3. Long Travel time 4. No placement 5. Schools oversubscribed 6. Access to suitable provision	1. Supportive school 2. Better than mainstream – but not good 3. Paid for advocacy 4. Nothing	1. More schools 2. Access to suitable provision that meet need

“

Special Schools and Alternative Provision– What is not working ?

My child has no school place at all, and ECC cannot provide him with one. You cannot view most of the special schools in the area (even now covid regulations have been relaxed) ECC do not return calls, and just ignore you instead of sorting things out.

My son has adhd, is waiting to be assessed for autism but has been denied SEMh units because he is waiting to be assessed for autism and now he has been denied a special school catering for SEMh becusse he has an Ehcp. He is being failed and his mental health is suffering because he is unable to get the right support for his SEMh needs

My child's MLD school is massively oversubscribed. It's no longer working as a special school. It's too crowded with too few staff.

Where is the provision for neurodivergent children who are capable of qualifications across the board but find mainstream overwhelming? There is such provision out of county and we shouldn't need to look out of county

My son is academic, autistic and has SEMH areas of need. There are NO special schools in South Quadrant to meet his need. The 3 local ones are all for children with cognitive issues. He would have no peers. How can this be possible. How is this need not been understood. It's inconceivable that he is expected to travel 55 mins each way just to receive education. He can't do that. It's too far for him, anxiety provoking and he doesn't like being in the car for prolonged periods and will become unregulated due to the demand level. If this was the scenario for mainstream, families would be in uproar but because it's for a minority it's somehow acceptable ??? Can you please raise this with Essex and ask how they will addressing this gap.

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Special Schools and Alternative Provision– What is working?

It's still better than mainstream, but not good, just better than a completely awful option.

My autism advocate- although I pay for that

His school are supportive and are trying their best to put things in place but there are so many loop holes and criteria to meet that he does not meet and therefore been made to be on a reduced time table

Nothing

Nothing. Absolutely nothing.

“

Special Schools and Alternative Provision–What can be done to improve things?

We urgently need a SEN school in Uttlesford for autistic children with moderate difficulties

Another MLD school in Tendring or Colchester.

There is an urgent need for more special school provisions. All special schools in my area are full. There is also a huge gap for MLD schools with high level sensory support, they just do not exist. ECC are not improving this situation and it is getting worse by the day.

Build a SEN school

Ensure children with SEMh and waiting to be assessed for autism are allowed in the SEMh units like phoenix. It should not matter what their diagnosis is! If they have difficulties with SEMh and this type of unit is for that then they should be allowed in

Open appropriate provision. Ensure EHCPs are fit for purpose with smart targets and clear outline of provision expectation

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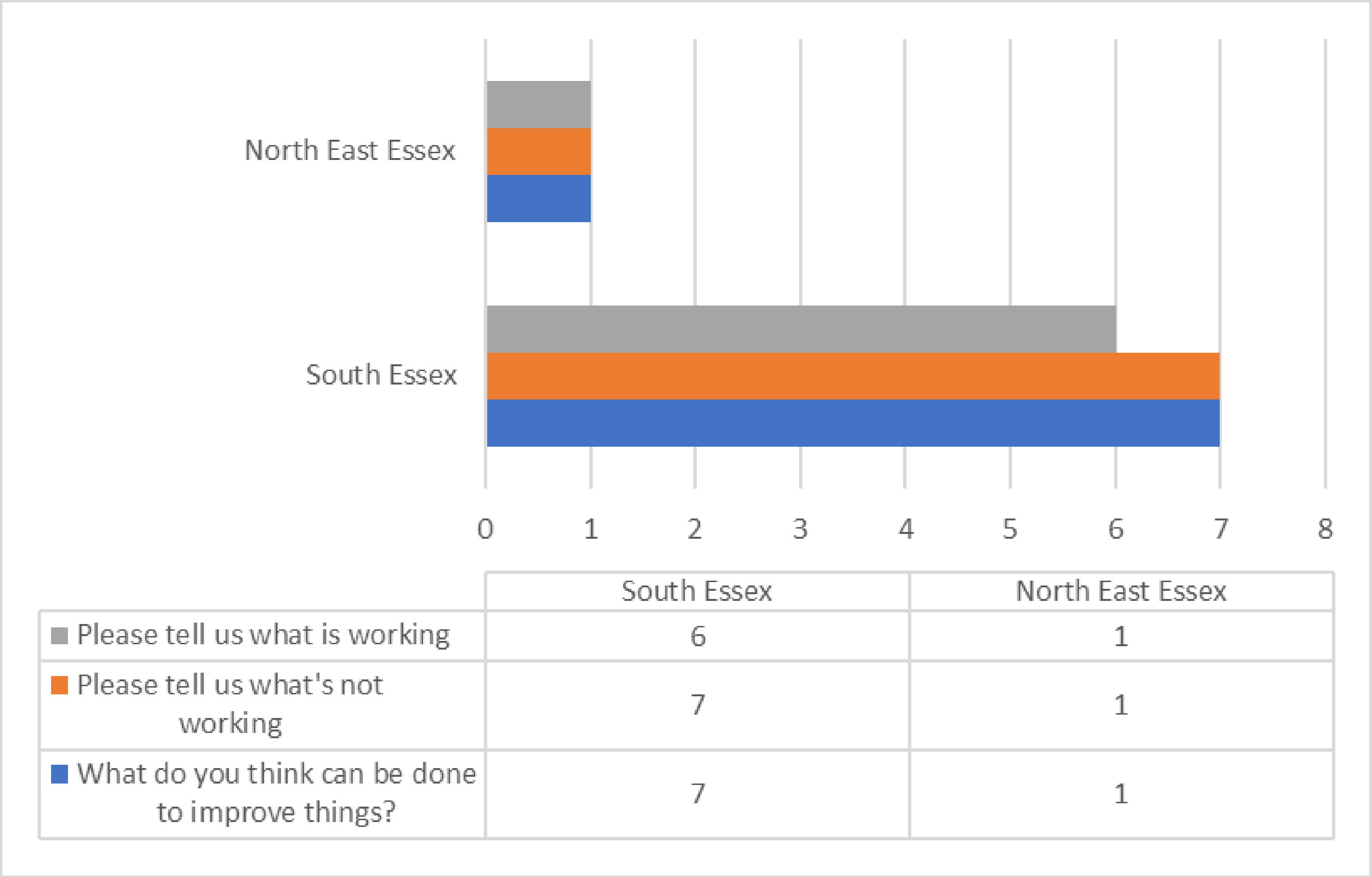
Diagnosis



	South Essex	North East Essex
■ Please tell us what is working	6	1
🟧 Please tell us what's not working	7	1
🟦 What do you think can be done to improve things?	7	1

We received a total of 23 comments to our key questions, from a total of 8 participants.

We have highlighted some key areas of feedback on the following slides.

For all anonymised comments received on the Statutory Process, please see the embedded document.

Microsoft Excel Worksheet

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Diagnosis – Key Themes

Please tell us what's not working	Please tell us what is working	What do you think can be done to improve things?
1. Advice and Support • Advocacy services unable to accept due to backlog • No support post diagnosis 2. Waiting Times • Long wait for diagnosis • Appointments • lack of communication 3. School Support • Lack of Understanding 4. Communication between professionals 5. Outdated and generic assessment forms	1. Charities 2. Good Locum 3. School help 4. Receives paperwork 5. Nothing	1. Communication 1. Improved communication 2. Keep in touch 3. Listen to Parents 4. Updates on waiting times 2. An online portal 3. Advice and Support post diagnosis 4. Stop parent blaming

“

Diagnosis -What is not working ?

All of it. The wait times for assessments are far too long and then half the time the professionals and or schools are in denial there is a problem, often making the parents feel guilty busy saying its them when it's not their fault. Often leaving them to not get on with it without any support and then penalising the parents

My little girl has just been diagnosed with autism. We were a bit shocked but I couldn't believe we weren't given anything to help from the doctor. My friend showed me your book which I am going to order but wanted to be able to speak more to the doctor about it. I don't know what to do or to expect. My friend has enough problems of her own and I don't want to keep troubling her.

Communication of waiting times - having to chase to find out if paperwork is being processed and how long the wait may be. Getting responses to emails. Outdated generic initial assessment form which appears to relate to the more known asd signs seen in boys rather than more hidden signs

Not once had a reply to an email. Had a 2 year wait for appointment first one was cancelled and rescheduled for 2 months later with no reasons. Appointment felt rushed and u left none the wiser and was told told follow up would be made in 6 months. I haven't heard anything and it's been 5 months

Doctor wanted to refer, XXXXX rejected referral, had to go through health visitor adding delay. Almost 12 months went past, no communication. Rang up to find the paediatrician had left, no one was following up on the case. They then got us seen privately and assessment was very quick. So communication, communication communication!

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Diagnosis -What is working?

I received some questionnaires!

Private practice seems to be resolving issues quickly. Locum very good.

Not got beyond waiting for an initial appointment so have no information on areas that might be working

Snap is helpful for advice and counselling other than that nothing

“

Nothing

Nothing yet

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Diagnosis – What can be done to improve things?

Better communication, no-one is touching base over a 12 month wait or checking things are OK and not getting worse.

Give more help to parents when an autism diagnosis is given

To beable to see, speak to professionals have appointments. Not years appart.

Online portal with clear up to date waiting times, easy option to request cancellation appointments, prompt responses to emails (or actually getting responses at all)

More timely acknowledgement to indicate wait times would take some of the stress out of the limbo situation we are in

COMMUNICATE!!

Everything from wait times, schools paying more attention and being more willing to help parents. Professionals to stop blaming parents and acknowledge the child has issues that need addressing correctly.

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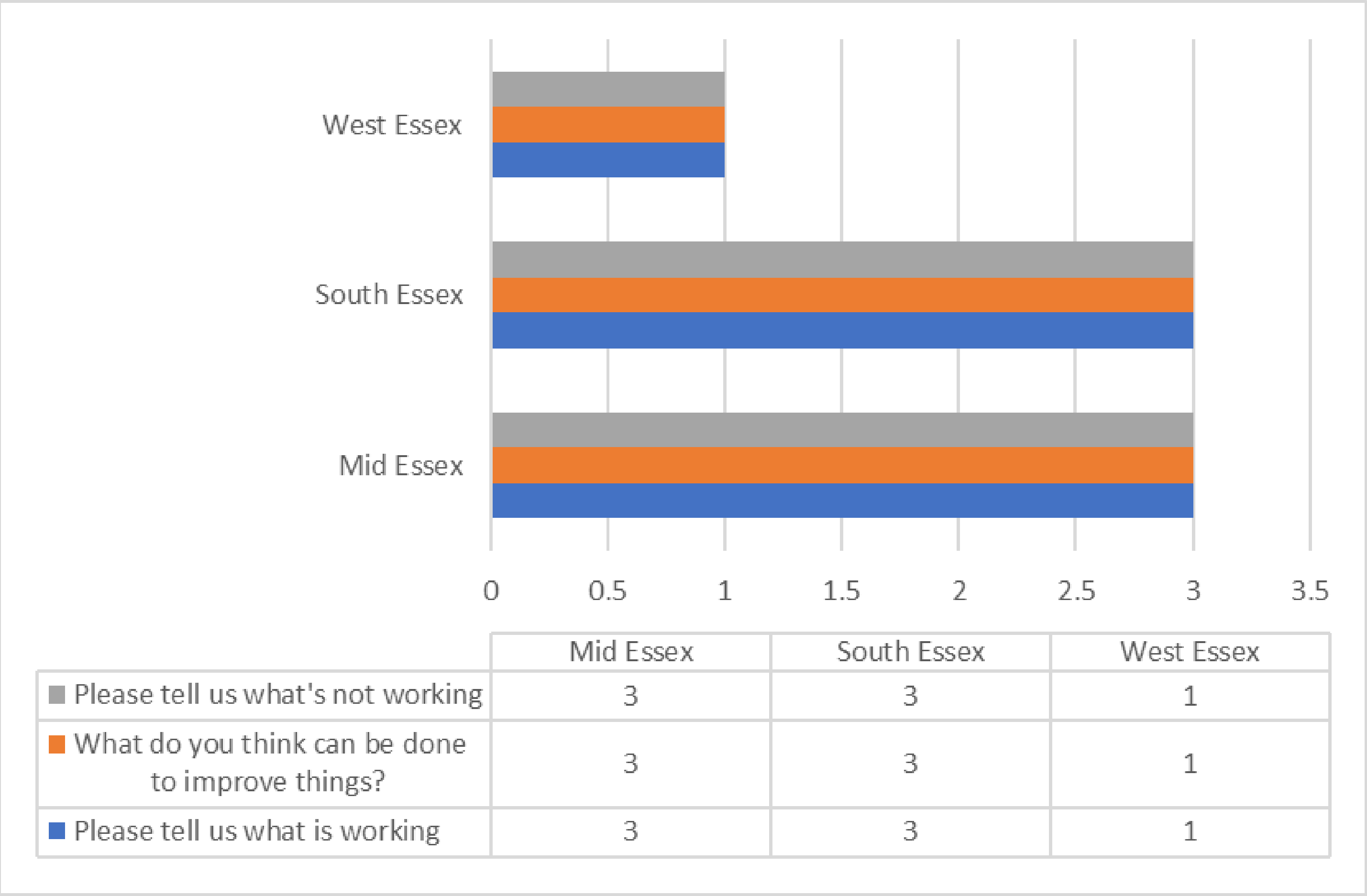
Mainstream Provision



	Mid Essex	South Essex	West Essex
■ Please tell us what's not working	3	3	1
■ What do you think can be done to improve things?	3	3	1
■ Please tell us what is working	3	3	1

We received a total of 21 comments to our key questions, from a total of 7 participants. The type of support reported was:

- 3 EHCP
- 3 SEN Support
- 1 Teacher of the Deaf

We have highlighted some key areas of feedback on the following slides.

For all anonymised comments received on Mainstream Provision, please see the embedded document.

Microsoft Excel Worksheet

Mainstream Provision – Key Themes

Please tell us what's not working	1. Please tell us what is working	What do you think can be done to improve things?
1. Mental Health/ Attendance • Parent asked for letters from GP/EMWHs regarding attendance • GP refusing to refer for support 2. Sencos Unhelpful 3. One plans not being followed 4. Uniform policy • Lack of Provision • Academically able • SEMH • For Girls 1. Social Services support scaled back (Parent reports post adoption) 2. Needs not being met • Lack of understanding and awareness • No adjustments made 3. NO support post Diagnosis in school	1. Supportive school/teachers that understands needs 2. Nothing	1. Monitoring system to ensure one plans are adhered to 2. Attendance team to follow statutory guidance 3. Professionals that advocate for children 4. Funding 5. I don’t know anymore 6. Training for professionals 7. Listen to parents 8. Follow EHCP

Mainstream Provision – What is not working ?

Mainstream school is not geared up to support SEN children . The structure and uniform is too rigid and there is not enough therapeutic support or understanding of SEN and the associated anxiety . Then extra pressure is applied in terms of attendance and parents are being threatened with court and fines for having SEN children who feel unable to attend . There is not enough special needs provision , especially not for girls who are high functioning , masking and needing SEMH provision. Diagnosis - diagnosis services are taking way too long and there is not sufficient provision , especially in areas such as FASD despite the NICE guidelines changing . Mental Health - Referrals being refused even by GP's and signposted to charities which cannot give the provision needed . Social services - support for previously looked after children appears to be scaled back , especially in terms of multi disciplinary services which a large proportion of adopted children need .

Poor level of teacher awareness to children with SEN Poor level of knowledge at senco level ECHP provision not being provided which in turn has an effect on my child's mental health - not wanting to go into school , saying they are scared of their teacher. School is too hard and scary

Attendance team asking for GP to specify period of time child should be out of school for and stated this is required before alternative education can be provided. Child out of school since 21feb22. Explained child referred to EWMHS 3 times but they suggest further play therapy despite child receiving 2 years through snap. Only other professional involved is our GP who was very reluctant to write a letter but states the responsibility is with EWMHS to provide support. For now, no support for education for child. Letter sent using NFIS template to request authorising of attendance without further medical support and to remove barriers for child to receive education.

XXX infant school appear to not like SEN children as they make no adjustments or allowances to support SEN children. All children are forced to eat school dinners even with sensory needs. The previous SENCO would fob off parents and tell them what she thought they wanted to hear. She referred to herself as *"language removed" to* staff. I believe she is a SENCO at another school in the Trust. They were told in the July before he started in September that he was sick most days but it was under investigation. He is always fine afterwards but they would send him home for 48 hours and deny him an education. Every time this happened, nobody mentioned he needed a letter from the doctors until I snapped as I was fed up with it. For over a year no one thought to mention that if he had a doctors ketter then he could stay in school. They even watched him choke on a yoghurt as it had bits in it and then he vomited. He was sent home for 48 hours even though he told them he was only sick because of the bits.

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Mainstream Provision – What is working ?

Nothing for us at the moment , we are just spinning around in circles trying to access support and being penalised for non attendance as our child cannot get the help needed at school or from the relevant services .

He has changed schools and is flourishing. The SENCO at XXXX Academy is the opposite to what I experienced at XXXX Infants. The same day that he joined, the teacher of the deaf was contacted and she saw him asap. He only gets sent home if he has a temperature whn he has been sick now so he is in school most of the time.

Nothing

The chid's classroom teacher was very helpful but limited to what they can do given they have a whole class to look after.

Having more support

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Mainstream Provision – What can be done to improve things?

Have people in a role that want to be in and excel in. Have someone that actual advocates for the children and pushes things forward for them.

I just don’t know anymore

Attendance team to follow statutory guidance and where there is strong evidence of family working with school to support child, but SEN creates barriers to attendance, absence to be authorised whilst EHCNA is carried out and alternative provision provided without unnecessary delays. Stop asking families to provide evidence from professionals they can’t access.

More funding and better provision of all services . Fully support adopted and looked after children with therapeutic help and diagnosis . Provide SEN and trauma perceptive training to all school staff and employ sufficient SEN staff to provide LSA support in class , make sure all schools have trained pastoral staff and sensory areas for breaks . More specialist SEN units attached to schools and Montessori style schools where children can have more autonomy over their learning . Teach skills that are relevant to life rather than the traditional curriculum. Remove uniform codes as too many schools refuse to make reasonable adjustments for sensory needs .

A monitoring system to ensure the oneplan is adhered to

Sen needs to be more supportive & all teachers need sen training in all schools as they fob u off

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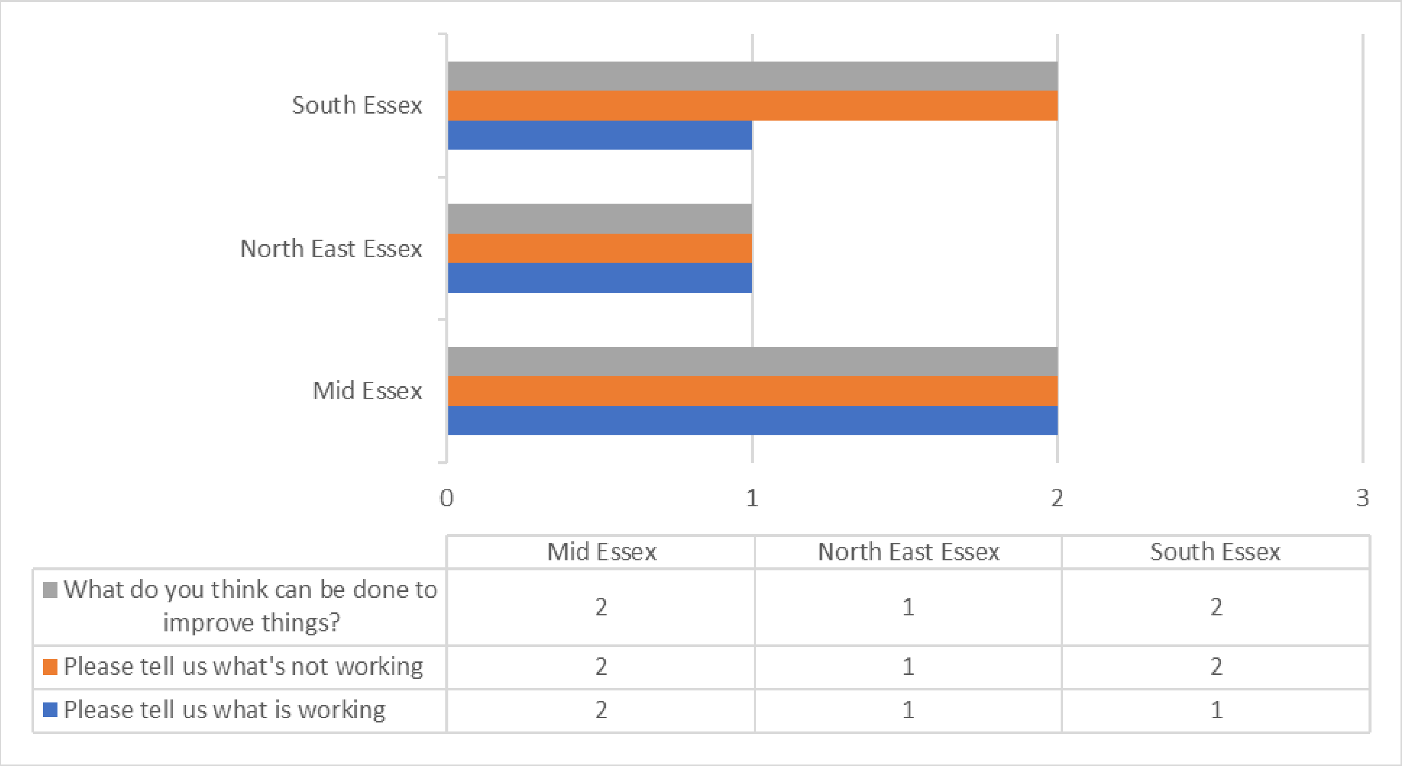
Specialist Support

(OT, PT, Speech and Language, EP's)



	Mid Essex	North East Essex	South Essex
■ What do you think can be done to improve things?	2	1	2
🟧 Please tell us what's not working	2	1	2
🟦 Please tell us what is working	2	1	1

We received a total of 14 Comments to our key questions, from a total of 5 participants. Of those 2 indicated that they had an EHCP.

We have highlighted some key areas of feedback on the following slides.

For all anonymised comments received on the Statutory Process, please see the embedded document.

Microsoft Excel Worksheet

Essex Family Forum
making a difference

Specialist Support – Key Themes

Please tell us what's not working	Please tell us what is working	What do you think can be done to improve things?
1. Waiting list times 2. Lack of understanding 3. EHCP provision not received 4. Lack of working with parents 5. Lack of support impact on family (neurodiverse parents)	1. Caring professionals 2. Nothing 3. System is broken 4. Good beginnings course	1. Improved communication between professionals 2. Joined up approach 3. Upskill parents and carers with strategies 4. For school to follow recommendations 5. Stop hiding behind covid 6. Employ more professionals

“

Essex Family Forum
making a difference

Specialist Support -What is not working ?

Speech Therapy Reports/Care Plans contain lots of information about what the therapists should do with schools - little or no mention of working with the parents who are the primary care givers and are less likely to have previous experience of speech therapy strategies/interventions and could do with more guidance and support.

My son was given a set amount of time with a ot written into his EHCP which he hasnt received

I have a (soon to be) 4 year old waiting on Autism-ADHD diagnosis, and on the list for SLT for about a year now. Being Autistic myself, having a pre-verbal child that cannot speak, while his needs are continuously growing is confusing, frustrating, stressful and ultimately harmful for the whole of my family.

Lack of care an attention for younger children that have issues. Being discharged following a video appointment is not acceptable because they behave differently in the home to an official appointment

Specialist Support -What is working?

I am so impressed by the caring nature of the ot and physio at the XXXXX - senior physio and OT . They appear to genuinely care and my child responded so well to them . It felt so good to be have an appointment with someone that genuinely enjoyed working with children and want to make a difference

The system for children with disabilities are broken and children with needs are being lost in the system

Nothing. Nothing because it's all virtual. So of course children won't participate with home distractions

We are attending Good Beginnings, which is interesting and very helpful. However, I feel that we are in need of some Professional help, as carrying all the burden of helping my child to understand and speak, while I cannot understand what he is thinking or feeling, is becoming unbearable.

ESSEX FAMILY FORUM
MAKING A DIFFERENCE

Specialist Support – What can be done to improve things?

Departments need to communicate better, more information on disabilities and help for parents with regards to agencies that are available to help

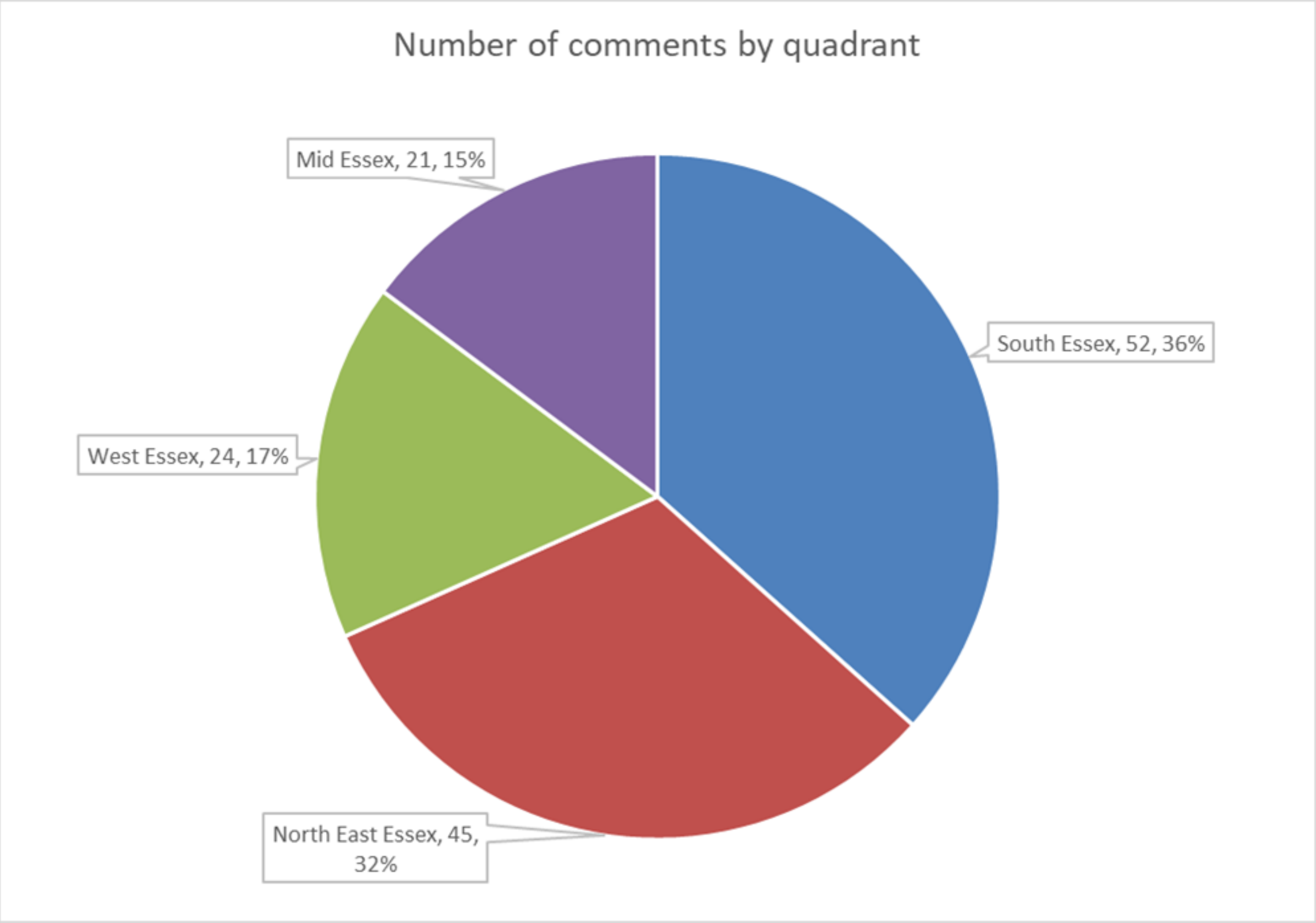
it would have been nice for them to stick to their recommendation of a meeting with the school

Stop hiding behind covid

Implement a fully joined-up approach and include the primary care givers for the child - spend more time upskilling parent/carers with strategies - demonstrate activities, provide links to useful resources. The child then stands a better chance of progressing and improving the quality of their interactions with their peers.

Maybe employ more professionals?

Remaining Categories



We received a further 22 responses, which provided a total of 50 comments of the over the remaining categories.

The number of comments per category is shown on the next slide.

The comments are embedded here and can be filtered by

- ✓ Quadrant
- ✓ District
- ✓ Type of comment
- ✓ Category of comments

Microsoft Excel Worksheet

Remaining Categories

Remaining Categories	Please tell us what's not working	Please tell us what is working	What do you think can be done to improve things?
Home to School Transport	4	2	4
Health Care	2	2	3
Mental Health	3	2	1
Communication	2	2	2
Local Authority	2	1	2
Short Breaks/Respite	2	1	2
Family Support	2	1	2
EFF Supporting your Neurodiverse Child Resource Pack, Bulletins, Leaflets and Newsletters	1	2	1
Other (please specify) Medication in schools	1	1	0

“

ESSEX FAMILY FORUM

MAKING A DIFFERENCE

Remaining Categories – Key Themes

Category	Please tell us what's not working	Please tell us what is working	What do you think can be done to improve things?
Home to School Transport	• Taxi Late • Lack of communication • No access – had to sign waiver • Issue with access on part time timetable • CYP Suspended. no reason/no contact	• Drivers and PA • Nothing	• Improve communication with parents • Improve communication between transport team and send ops • Support parents by funding
Health Care	• Insufficient care in A&E • CYP with MH long term patient on a children's wards. Inappropriate environment and impacted on care of others	• Outstanding care from named professionals in Basildon Hospital • Consultant speaking directly to CYP rather than through parents	• Improve wording on letters • Direct access to hospital wards • Appropriate facilities for MH inpatients
Mental Health	• Access to EWMHs • Sectioning CYP no warning to parents	• Local charity • Nothing	• Listen to CYP and Parents • Person centred approach
Communication	• Lack of information on support and provision • Lack of communication	• Coffee mornings • Nothing	• Awareness on support • Follow recommendations • Acknowledge e-mails and respond
Local Authority	• Lack of communication • No acknowledgement of e-mails/letters • Unsuitable provision/Funding	• It's a constant battle	• Communicate with parents • More support • Correct provision • Awareness and understanding of CYP need and abilities

ESSEX FAMILY FORUM
MAKING A DIFFERENCE

Remaining Categories – Key Themes

Category	**Please tell us what's not working**	**Please tell us what is working**	**What do you think can be done to improve things?**
Short Breaks/Respite	• Provision not suitable for complex needs • Additional costs for 1:1 • Being told going to work is respite	• Found a new provision that will accept child	• Inclusive holiday clubs • Care more for parents and carers
Family Support	• All support is in the day, impacts on parents who work • Aggressive child and no support, rejected from EWMHs	• Nothing	• Support families that need it • Provide support outside of normal working hours
EFF Supporting your Neurodiverse Child Resource Pack, Bulletins, Leaflets and Newsletters	• Wasn't given a copy by professional when started journey	• Lovely to have a book rather than be online • Enjoying talking about with other parents	
Other (please specify) Medication in schools	• School not supportive, not stored securely, not given at same time as required	• Maze and Families InFocus	

“

Remaining - What is not working ?

Transport
Why is it that no one responds to emails or phone calls anymore? My daughter has been suspended from her transport over 2 weeks ago and i have not been contacted to tell me why or when it will be resumed? Feeling frustrated 😫

Communication
Being informed of support/services we feel we are not made aware to get help when needed + know information that will support us, family my son.

“

Local Authority
There is almost no communication from the local authority. No acknowledgment of letters/emails sent to them. No one answering phones. To try and find information about your child's case/allocation of school is almost impossible. Your child's rights to education: There are no schools in this area for children with ASD, that are not severe or mainstream. Support: No list of resources or organisations that can help with meeting our child's needs.

Health Care
Autistic child with numerous other health issues should have direct access to childrens ward agreed when poorly. Records had not been updated and when he was taken to a and e was not fast tracked and instead had to wait in a and e for 5 hours whilst in a lot of pain - during this time he had sensory overload and it took several hours for him to be able to calm down nice on the ward - I'm additional to the physical problems for which he had been admitted

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MAKING A DIFFERENCE

Remaining - What is not working ?

Short Breaks/Respite

My daughter had a trail at kids camp before the last summer holidays they said great book her in which I did then 2 weeks before emailed to say they couldn't meet her needs so I was left at the last minute stuck. Driving my son there and my daughter to different friends who luckily stepped in. It wasn't good they couldn't be together. Then they said XXX needed 1:1 and were charging £120 a day for 1:1 plus the fees on top which I couldn't pay I found a charity who kindly funded 5 days for me which as you can imagine isn't enough for the year. Then I had her booked in for Easter and 3 weeks in advance told me they didn't have a 1:1 for the 1st week but could do the second I had booked my annual leave already for it and have to book at least 7 weeks in advance for my clinics at work so it left me completely stuck again. I have luckily found a much smaller provider I am now trying for both children in Easter and if it goes well I will use them in the summer. It's very stressful being let down at the last minute and trying to find funding when there should be adequate provision in place already for children with additional needs in the holidays so parents can work.

Mental Health

Contacted by family of 16 year old who have been told too old for ewmhs and too young for adult mental health services. Family not sure where to turn

EFF Supporting your Neurodiverse Child Resource Pack, Bulletins, Leaflets and Newsletters

I was given a copy of the neurodiverse child book today at a support group in wickford. The book is really brilliant. But I don't understand why my doctor hasn't given theirs to me ages ago.   I needed this information when my son was starting to have difficulties.

Remaining - What is not working ?

Other – Medication in schools

Sharing on behalf a parent who shared their negative experience with regards to medication at school (ADHD medication). *She didn't feel school were very supportive of daughter issues/anxiety about taking medication and sort of brushed it aside expecting her to just take the medication. *Medication (controlled drug) was not kept in office and locked away? like it should have been but kept in the class in the teachers desk which was not locked. *Medication was one tablet that needed to be broken into two half in the morning at home and half at school. School wanted full strip of tablets (unbroken) and broke them at school, but were breaking them into smaller piece which meant parent was concerned teacher didn't know how much child was being given. *Tablets were not given at same time each day *Child was given tablet in class in front of other children and not in private which was adding to distress anxiety about taking medication *Parent concerned over risk re where it was stored, in class where other children could access/tamper with it. Parent spoke to pediatrician who said it is a controlled drug and legally has to be stored correctly parent informed school who didn't no and didn't communicate with parent that they had changed this. *Parent also concerned about lack of staff training, the teacher didn't know what the medication was concerned the teacher didn't know how much she was giving the child due the the way the tablet was broken and also concerned they didn't know what to look for re side effects etc. *Parent moved to coming to school to administer medication themselves but the school were not very supportive about this

Family Support

Nothing is working. My nine year son has ADHD, ASD and epilepsy and he's in utter crisis and incredibly violent towards me, my husband and his little sister. We have never had ANY support other than medication from the paediatrician. EWHMS have rejected him four times on the grounds that "It's behavioural" despite it clearly saying on their website they help children with emotional and behavioural difficulties.

Remaining - What is working?

Short Breaks/Respite
hopefully I have found a new provision but will only know when we have trialled it.

Communication
These coffee mornings + parent chats would be great.

“

Local Authority
I'm working! Incredibly hard to find a metaphorical ladder to climb out of the hole myself and my children are being continously thrown down. I feel like I'm constantly battling the system to get my children what they are and should be entitled to. More support, correct provision, better understanding of Autism from staff, adequately trained staff who have appropriate expectations and knowledge of SEN needs, up to date documents, funding, outside agencies being more accessible, (my son hasn't seen an EP since he was 4!) The LA said that an EP and IP woukd be visiting him but after the Annual Review the IP hasbt been in touch and I've not seen the EP at all. It's not good enough.

Mental Health
Nothing is working so far.

Transport
Drivers and PA

ESSEX FAMILY FORUM
MAKING A DIFFERENCE

Remaining - What is working?

Health Care
my son had a dental appointment with oral consultant and at every point of the appointment the consultant made sure he was talking to my son in a way that worked for him, using easy words and confirming that he had understood, double checking with me. When it came to the consent form, he made it as easy as he could to ensure my son understood, rather than just asking me. I was really impressed. .

Other – Medication in schools
Parent mentioned that she was in touch with FIF and was very positive about XXX and also is attending MAZE

Transport
Drivers and PA

EFF Supporting your Neurodiverse Child Resource Pack, Bulletins, Leaflets and Newsletters
A lovely physical resource, so much is online it's nice to see a book

Family Support
Nothing.

Mental Health
Nothing is working so far.

ESSEX FAMILY FORUM
MAKING A DIFFERENCE

Remaining – What can be done to improve things?

Transport
Link education access team Process to send ops to ascertain at the start of the transport process if there is a need for a part time timetable and how that will be supported

Mental Health
Professionals to LISTEN to children AND parents. Take note and make the changes 100% and properly according to the child's needs. Not a 'one size fits all' strategy for neuro diverse children.

Communication
Awareness on support.

Local Authority
Communicate with parents

Short Breaks/Respite
Take inclusion off of holiday clubs which aren't actually inclusive! Provide proper provision for children with SEN needs for holiday clubs and provide information to parents of where this can be found.

Health Care
not a lot in this instance, except when the copy letter came through that had been sent to my sons dentist, it said that my son suffered from autism and learning disabilities. When my son is admitted for his oral surgery I will point out to the consultant that my son doesn't suffer at all :)

Family Support
Help families that need it. A self indulgent teenage girl feeling "anxious" because someone didn't like her selfies should not take priority over a family in crisis! Sorry but it's true. My son needs help and we need help to help him. I even referred him to social services because I was so worried that his sister was in danger and they did nothing!

ESSEX FAMILY FORUM
MAKING A DIFFERENCE

Support Services, Organisations and Charities

Over the spring term we held workshops with support services, organisations, and charities; collating their views on the work conducted through the written statement of action in preparation for the re-visit in May. Their views on all key areas were duly reported upon via our Impact Statement, a copy of which can be found ***here*****.**

That said we still had some detailed feedback from two charities.

Please tell us what's not working	Please tell us what is working	What do you think can be done to improve things?

• CYP unable to access EWMHS
• Other MH provisions, don't accept children under 8, or state that they are at capacity
• Services via FIF Xrra Flyer are mostly online and are not appropriate for CYP with SEND
• The process of seeking help for CYP with MH is complicated due to number of services and varying criteria.
• families are struggling to which is appropriate to their family without extensive time spent researching
• EWMHS signpost to local charities without any support
• Families requesting support for School anxiety and unable to attend school due to anxiety increasing
• Many families report school lack of understanding for CYP who Mask
	• Some families under Brentwood are reporting that they are being seen quicker
	• Some schools are doing a good job making reasonable adjustments and supporting the CYP
		• Clear criteria for Mental Health services and provision which, parents (and those that support them) can easily navigate in one area. Details to include:
		  • funded or requires donation or attracts a fee,
		  • Details of the type of service or provision for example is it counselling or coaching,
		  • Location of service or provision
		  • What "area" of Essex families must live in to be granted access
		  • Who can apply – for example, self referral, GP, School etc.
		  • Duration of offered service or provision
		• Training in schools to understand the differences in CYP with ASD
		• ASD Specialist teachers should be brought back to support schools

Next Steps and Feedback to our Families

Essex Family Forum will present this data to the SEND Partnership Board which is made up of Education, Health and Social Care decision makers. Essex Family Forum also sits on this board and represents parent and carer views. This data will also be shared with other key SEND Workstreams across Essex, the Eastern Region of Parent Carer Forums (ERPCF) and the National Network of Parent Carer Forums (NNPCF) to influence changes regionally and nationally. We will also share the data with our families via our website and social media.

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. Issues continue to be raised in meetings throughout the year to support change and resolve where possible.

Whilst we at Essex Family Forum, can tell you how this data is used, we recognise the need for improved feedback, from Essex County Council, and Health Providers to be provided to the parents and carers who kindly share their stories, as well as the wider community within Essex. We are pleased to confirm this has been acknowledged by the SEND Partnership Board and we are now working on a process to formalise this. We hope to share details of this very soon!

The named provisions, professionals, and education settings will be made available to the relevant boards and workstream meetings where appropriate. Every effort will be made to ensure that data will still be anonymised to ensure any names of children, young people, parents and carers provided in the comments are removed.

Essex Family Forum will continue to gather parents' and carers' experiences along with understanding the key issues families are reporting from the support groups, organisations and charities that support families via our Virtual Graffiti Wall, through our Family Champion Quadrant Leads, and Volunteer Family Champions. We present this data on a termly basis.

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.