

Graffiti Wall

Representing Parental Views on SEND across Essex

Essex Family Forum

Summer Term

April – August 2021



Concept of 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 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, of whom we require to provide 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

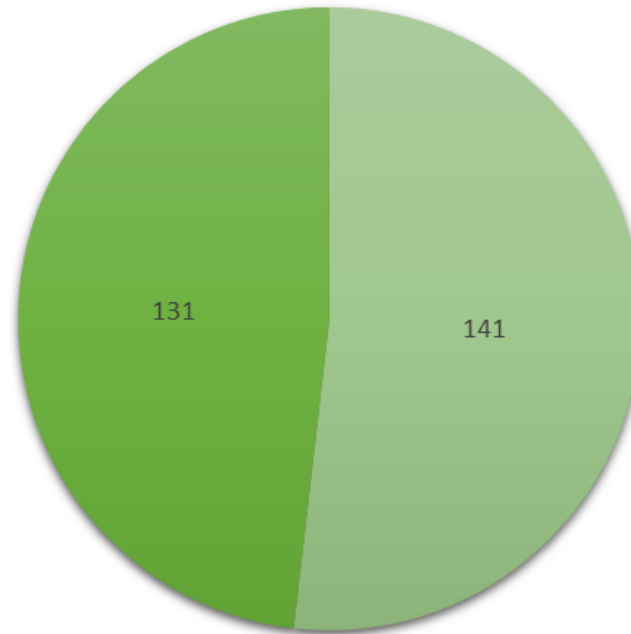
327 Participants accessed the survey in total.

287 Participants provided feedback.

272 Responses to the Survey, collected via two sources.

Better Communication CIC Website.

Essex County Council, Southend Borough Council and the NHS Clinical Commissioning Groups across Essex and Southend commissioned Better Communication CIC, to review children's therapies including speech and language therapy, occupational therapy and physiotherapy. Essex Family Forum was asked to collate feedback from Parents and Carers who come under Essex Council. Our Graffiti wall was embedded on to their website for parent and carers to contribute to this project.



Essex Family Forum Website.

The survey is embedded in our website and the link is shared through our social media channels, MailChimp to our members and through our Family Champion Quadrant Leads and Volunteers



Collection of Data

327 Participants accessed the survey in total.

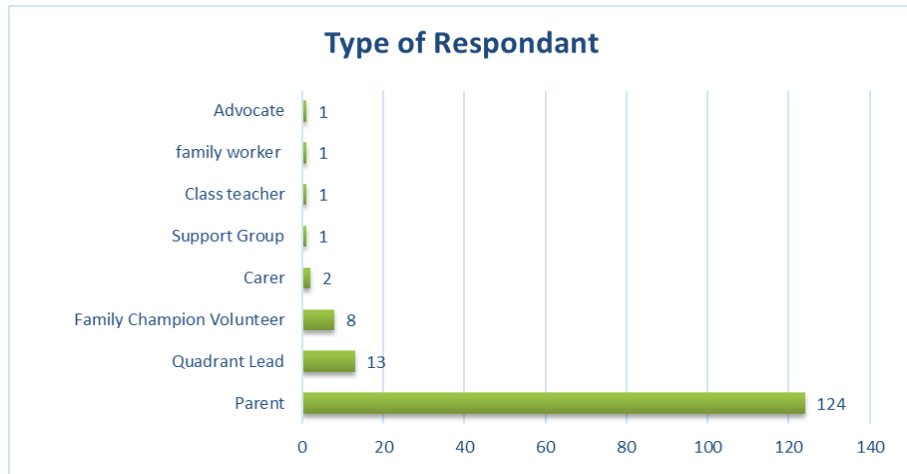
287 Participants provided feedback.

Participant Information

Of the 272 entries, 121 entries were deemed to be “invalid”. These entries were where consent was provided but no further details.

Many of the invalid entries were though the link on Better Communications, so we assume this would be where professionals may have viewed the survey as they explored the balance system webpage.

This means we had 151 valid entries



Type of Participant.

Most of our responses came directly from parents.

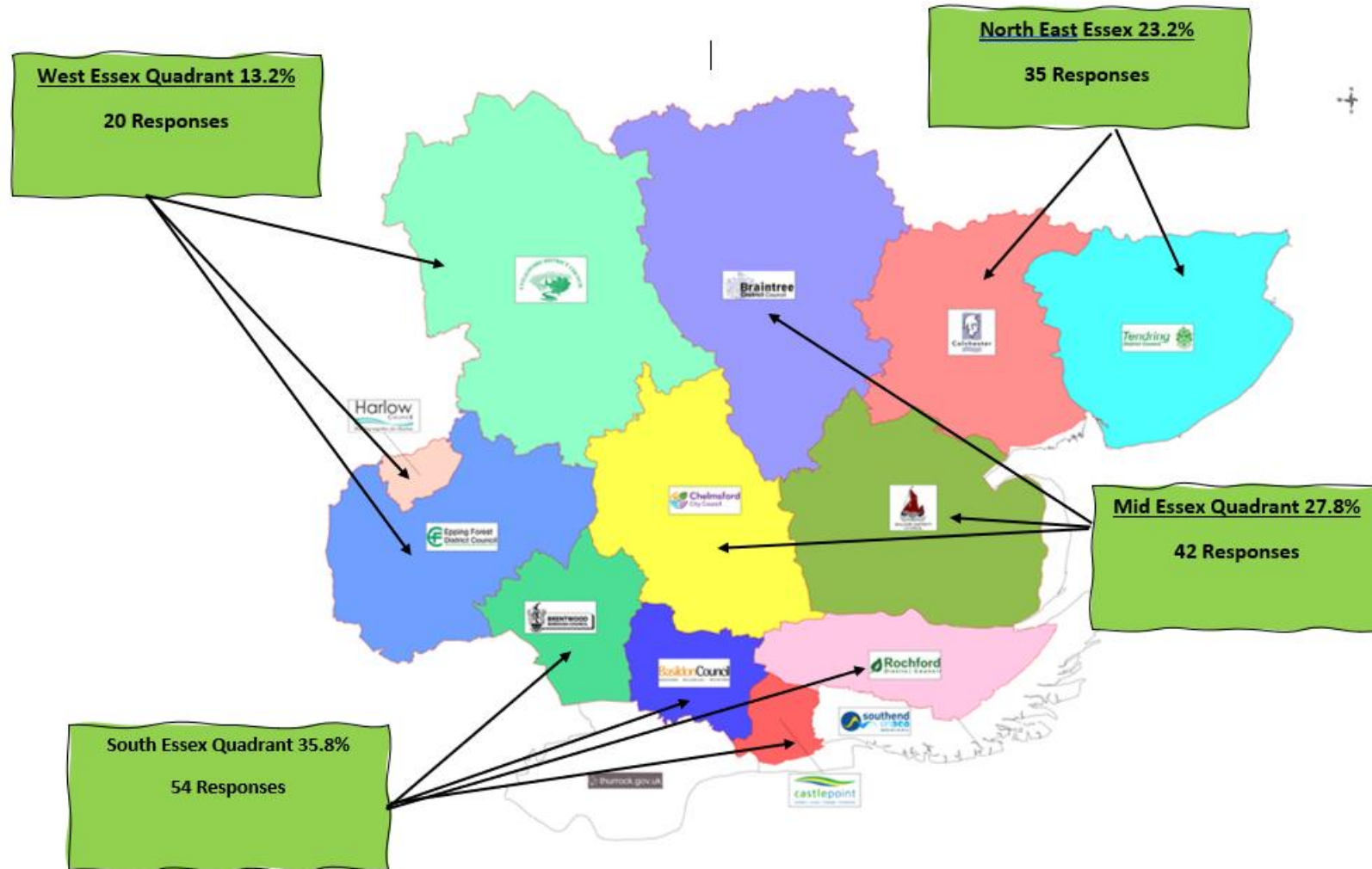
- Quadrant Leads are Essex Family Forum appointed roles.
- Family Champions are volunteers. They will often add entries as “parents” providing details of their own personal feedback.

Where “parent” and another category was ticked for example “Carer ”we used “Parent” to categorise the response

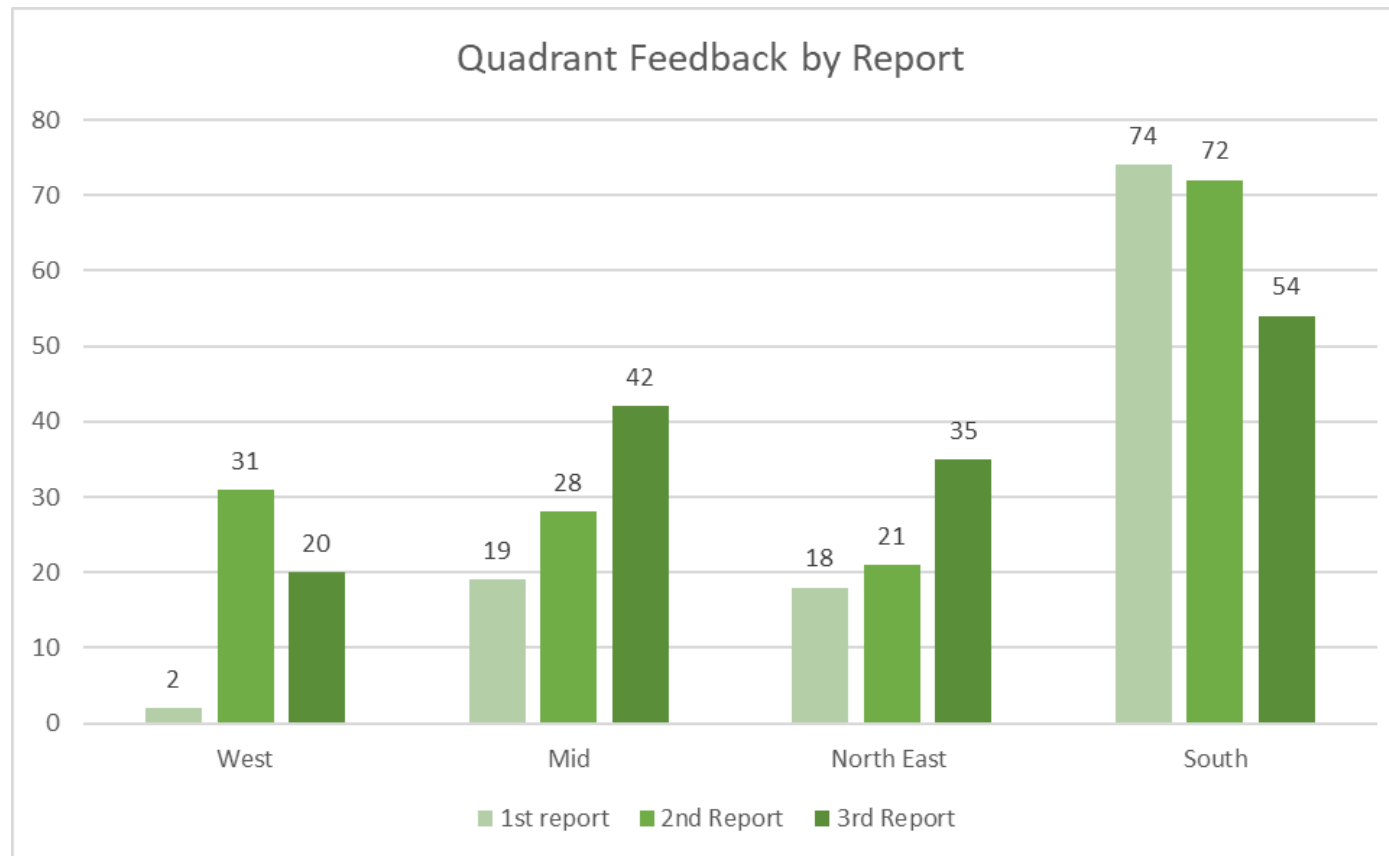
Data Variation on number of participants

Participants have the option to “skip” some questions. This means the number of participants varies across the survey. We therefore will report the number of participants for each data set.

Responses by Area



Responses by Area



Comparison of valid entries per Graffiti Wall Report by quadrant

1st Report – October, November and December 2020

2nd Report – January, February, March 2021

3rd Report – Summer Term (April – August 2021)

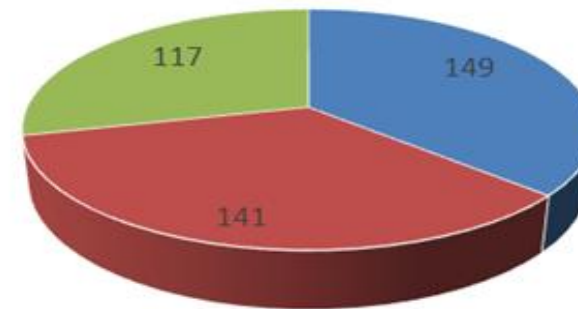
Category Breakdown and Type of Feedback

We asked Parents to categorise the area that they were providing feedback for from pre-existing themes. A total of 407 comments were provided by the 151 valid participants.

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.

Number of Comments



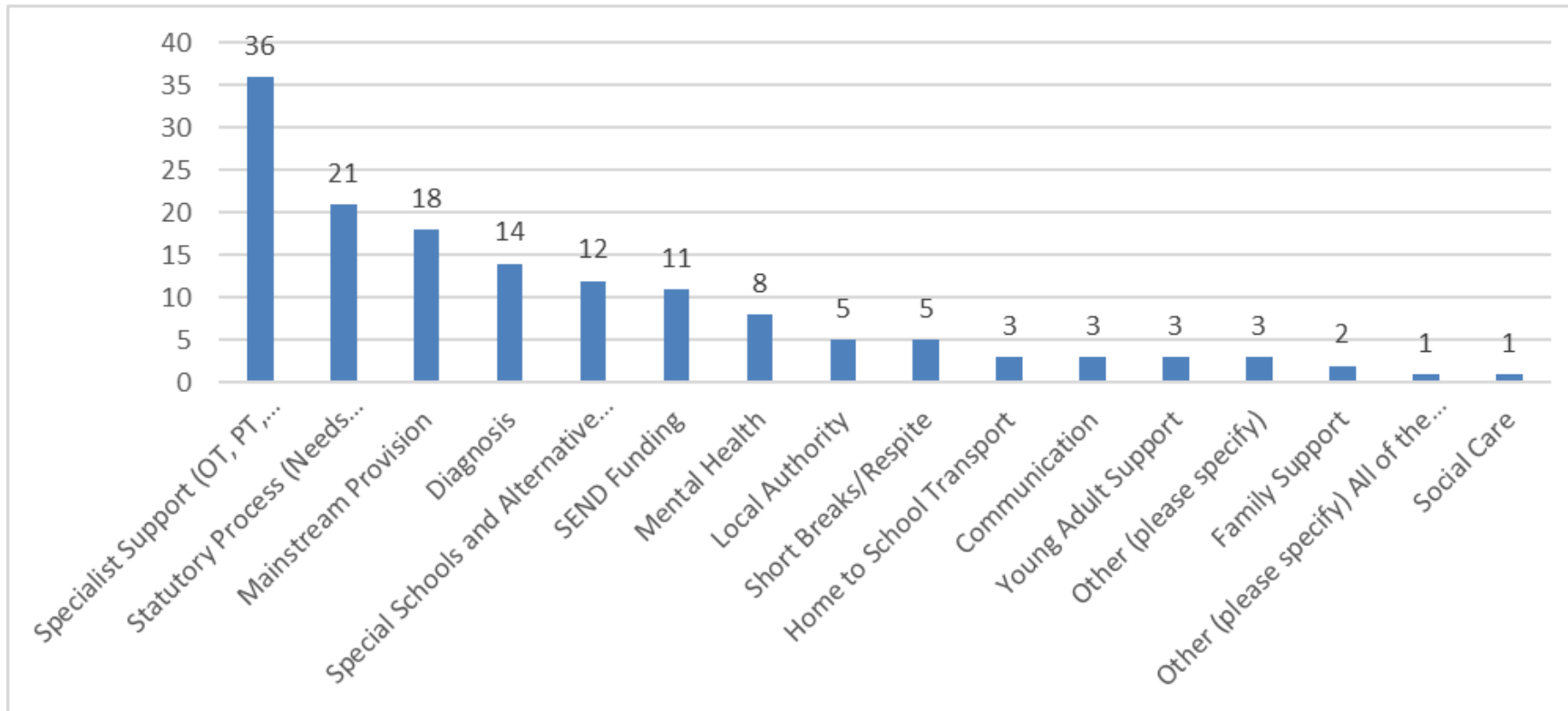
- Please tell us what's not working
- What do you think can be done to improve things?
- Please tell us what is working

Participants have the option to provide a response on 1, 2 or all 3 questions in relation to their selected area of feedback.

Category of Feedback

Summer Term only

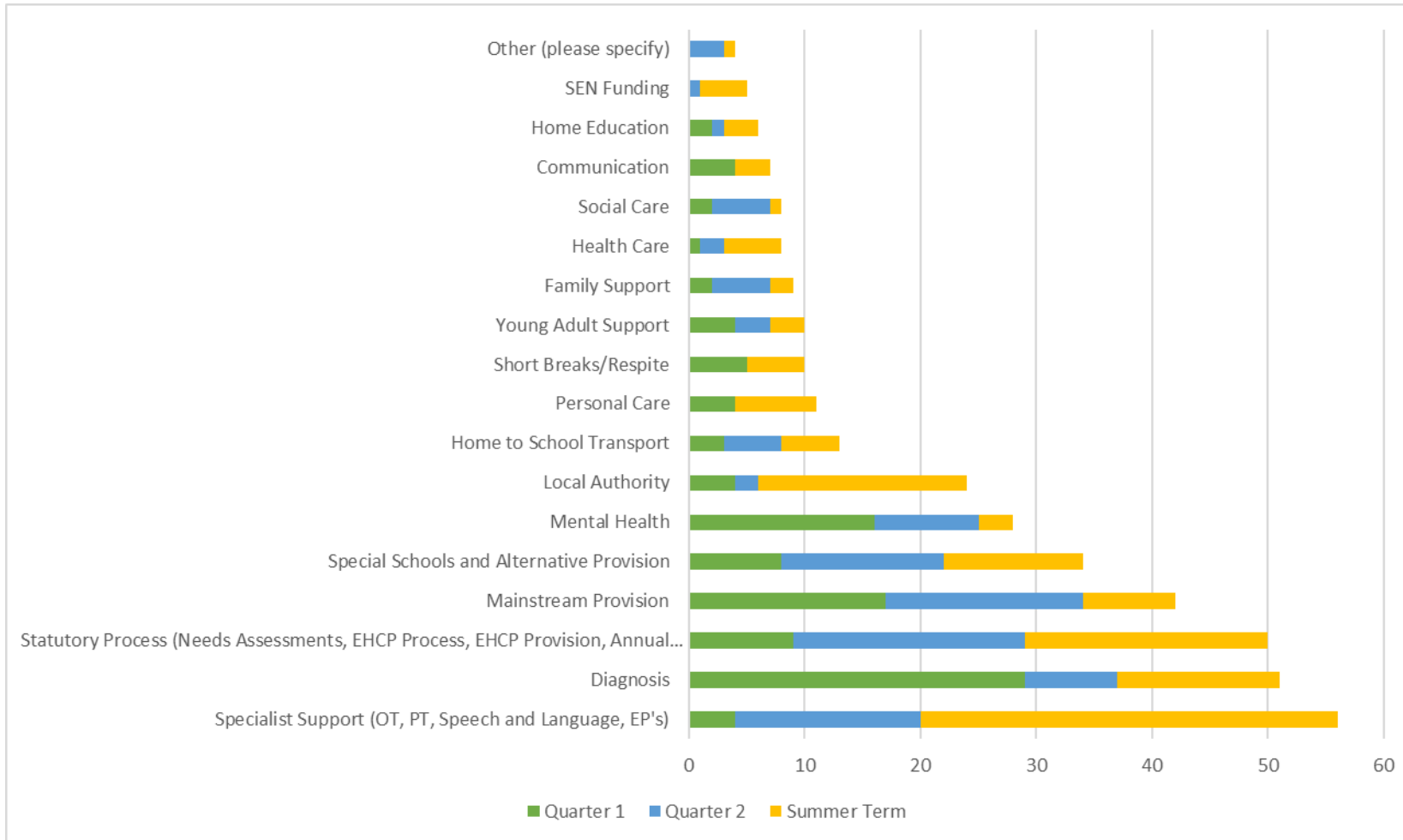
This shows the feedback we received broken down by category for this period of reporting



Given the targeted approach to requesting therapy feedback during this period, it is not surprising that this is the category with the largest amount of feedback.

It should also be noted that our Neurodevelopment Survey also ran throughout July and August, and so we expected a drop in the number of participants reporting on diagnosis.

Category of Feedback Report Comparison



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

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

Analysis of Categories

These figures show the top 5 areas of feedback over the last 3 reports.

Quarter 1 (Oct, Nov and Dec 2020)	
Diagnosis	29
Mainstream Provision	17
Mental Health	16
Statutory Process (Needs Assessments, EHCP Process, EHCP Provision, Annual Review, Tribunals)	9
Special Schools and Alternative Provision	8
Quarter 2 (Jan, Feb and March 2021)	
Statutory Process (Needs Assessments, EHCP Process, EHCP Provision, Annual Review, Tribunals)	20
Mainstream Provision	17
Specialist Support (OT, PT, Speech and Language, EP's)	16
Special Schools and Alternative Provision	14
Mental Health	9
Summer Term (April - August 2021)	
Specialist Support (OT, PT, Speech and Language, EP's)	36
Statutory Process (Needs Assessments, EHCP Process, EHCP Provision, Annual Review, Tribunals)	21
Mainstream Provision	18
Diagnosis	14
Special Schools and Alternative Provision	12

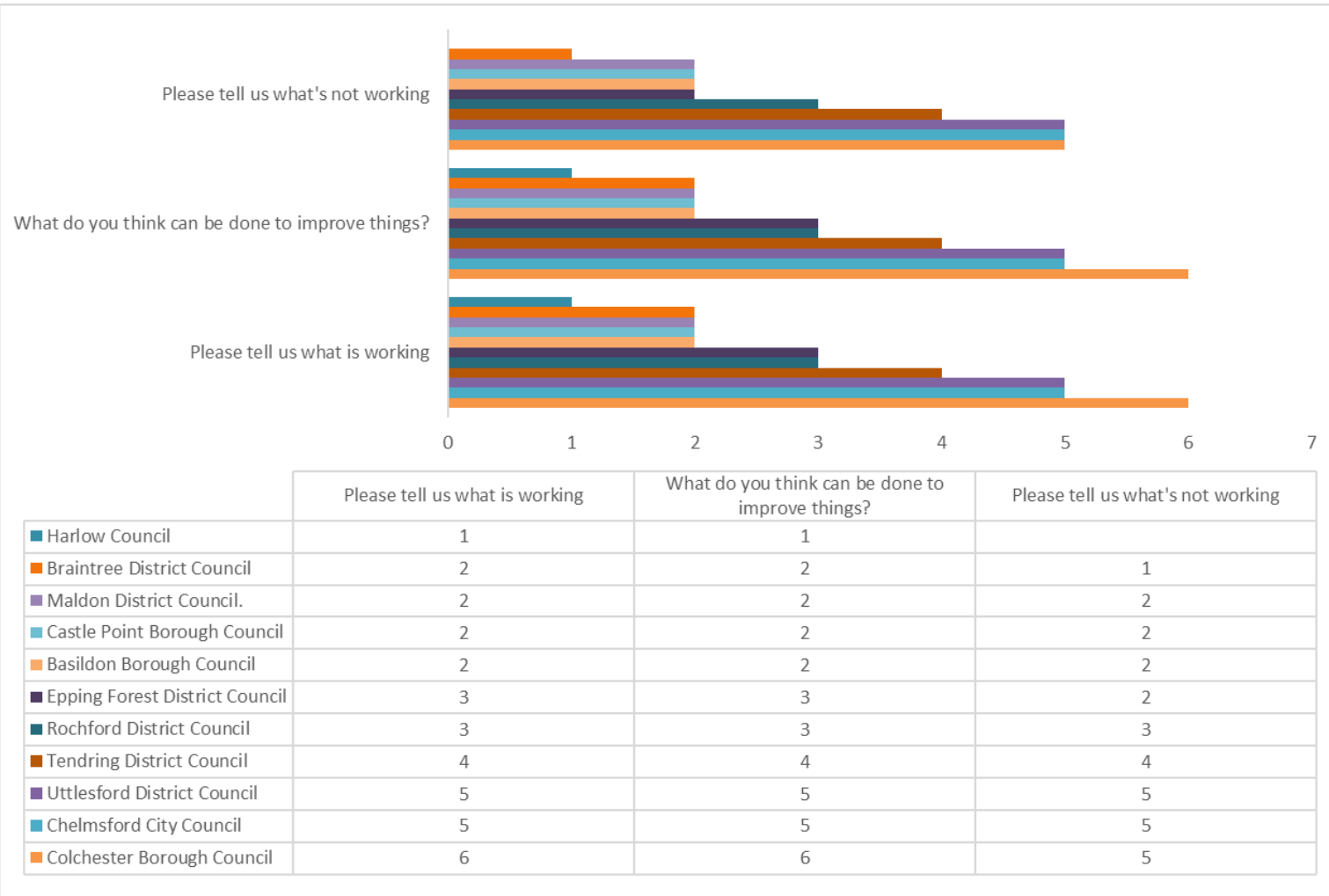
This shows that main areas of feedback remain consistent.

As stated earlier in the report, there was a targeted approach for therapy feedback and will account for the increase in comments.

Diagnosis dipped in quarter two to position 6, with 8 comments, as stated due to the neurodevelopment survey running during the summer term, we anticipated a lower number of participants in this category for this report.

Mental Health, dropped within the summer term to position 7, with 8 comments.

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



We received a total of 105 responses to our key questions, from a total of 32 participants

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

It should be noted that 16 responses out of the 32 that responded to “what is working” stated that they felt nothing was working.

No responses were received from the Brentwood area



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

What is working

- Nothing/Not Much
- Private assessments
- School SALT
- LA Commissioned Therapists
- Parent Dedication
- School Support
- Therapists/Team Members

Nothing really... very disappointing that all seems to be down to a postcode lottery or who's shouting the loudest
Uttlesford District Council

The LA commissioning independent therapists
Maldon District Council

I'm delighted with our SALT: she's approachable kind and I have confidence in her. She makes sessions fun and engaging.
Castle Point Borough Council

OT kept in touch during lockdown on phone, very quick to provide any equipment we needed with a follow up call a week after to see how its going, (would be better to see them in person though.)
Colchester Borough Council

Nothing has worked for our family
Braintree District Council

The speech therapists that have worked with my child have been very good and are also friendly
And supportive.
Chelmsford City Council

Her school have been the only place we have been find support, real care and some guidance. But because is a main stream school they don't have all the access to SEND - they are doing the best They Can and I can see their commitment to support my daughter.
Basildon Borough Council

private funded assessments.
Colchester Borough Council

Functional needs are assessed
Epping Forest District Council

Reviews with ADHD nurse – *Team member name removed*. Lovely demeanour. Very patient and professional. Takes things at my son's pace and explains everything to him and me along the way.
Tendring District Council

School SALT
Rochford District Council

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

What is Not Working

- Denied access to provision
- Delays following referral
- Referrals not received
- Long wait times
- Lack of Provision for Non-Verbal Children
- Frequency of Provision
- Lack of provision for Deaf children
- Provision ceasing
- Lack of Communication
- School capacity to provide SALT
- Constant fight
- Sensory Provision
- Forced to go private
- Poor support throughout COVID
- Complicated system to navigate

My biggest issue is everything is complicated. It would be great if there were simplified information on the website so anyone can follow it - like a basic follow chart. A lot of what my son gets is only because I know to ask for it.
Tendring District Council

No regular speech therapy being delivered. Parents have to fight to access therapy for their children
No face to face appointments
A lack of specialised/trained speech therapists to work with deaf children
Chelmsford City Council

Not enough or regular support
Braintree District Council

Such long wait times, everyone talks about early intervention but my child is starting school and has no support with SLT so we have had to go privately.
Harlow Council

"My daughter was diagnosed with ASD at 3 years 8 months. She is now 5 years old and we did not receive the speech therapy sessions that were promised. I completely understand the COVID situation. However for us it is even worse, more isolation than ever and not support for any therapy, OT, ST. If NHS is not able to help at least should be guiding and supporting families that are already identified and more information to other families that are experiencing a harder time. It's known that the earlier the support and interventions with kids the better outcomes and we feel we haven't been receiving the right support."
Basildon Borough Council

Lack of communication and involvement, especially from speech and language. Once every 18 months isn't enough and even when they join in a 1:1 meeting they looked disinterested and didn't contribute
Colchester Borough Council

Frequency: 30 mins every 2 weeks is not enough for a pre school child with significant SAL delays. 30 mins a week for a school age child is just enough to make steady progress, but not to make inroads into closing the gap between them and their peers.
Castle Point Borough Council

Been discharged when still issues, possible issues identified and not followed through with referrals
Uttlesford District Council

Referrals take too long
Maldon District Council

Zoom calls for deaf patients!!
Rochford District Council

Sensory needs are not being assessed thoroughly and their therapeutic provision in schools is not happening. Sensory needs are often very significant, particularly to those with an ASD diagnosis and yet this area is often not properly assessed. This impacts on a child's ability to access all areas of education.
Epping Forest District Council

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

What Can be done to Improve things?

- Right support at the right time
- Early Intervention
- Parental support and Guidance
- Communication
- More Staff
- Access via school, without an EHCP
- Listen to Families
- Stop the battle/fight
- Better funding
- Constant/regular/frequent appointments
- Joint working across Health and Education
- Sensory OT's
- Face to Face Provision
- Face to Face for Deaf Children
- Holistic approach to Multiple Therapies
- Training for professionals

Make therapies and sessions available via schools without the need for an ehcp
Chelmsford City Council

Less wait time
more support in
early years.
Harlow Council

Better communication
Braintree District Council

More specialist
teachers
More specialist
asd schools
More access to
services such as
salt, OT and an EP
*Uttlesford District
Council*

Need to look at the burden on the family of multiple therapy requirements, we see OT, PHYSIO, SALT, continence, ophthalmology. If we religiously did all that was expected of us we wouldn't get time to parent and enjoy our child. A more holistic and realistic approach is required.
Rochford District Council

Have trained sensory OTs who are able to assess childrens needs and provide sensory diets or therapy as required.
Epping Forest District Council

Accept that most appointments need to be face to face
Better communication - *Provide* just didn't respond
Maldon District Council

Provide something!
Tendring District Council

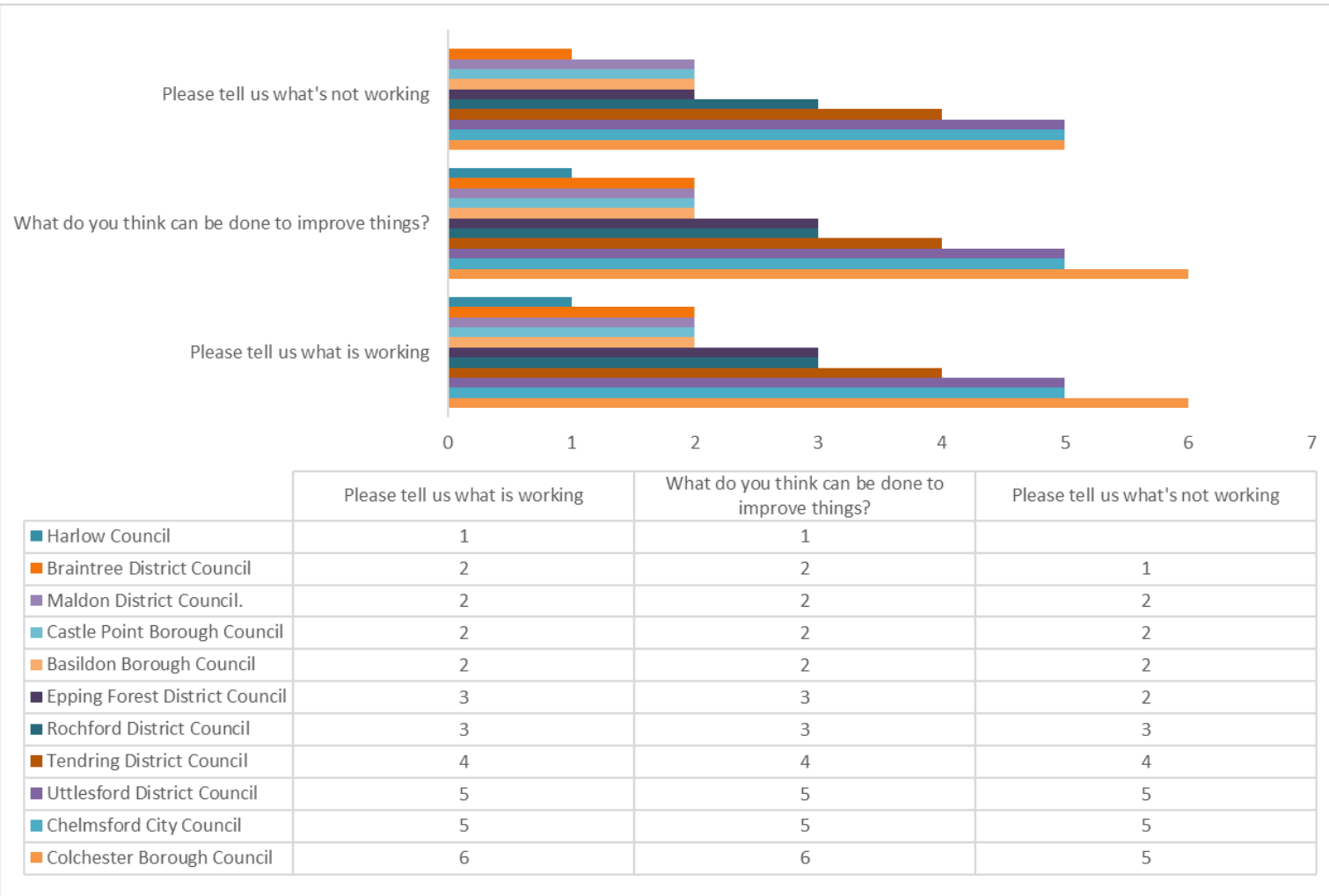
The local authority do not seem to work with health. EHCP's should be for education and health yet it has been a struggle to have the right access to therapy. Departments need to communicate better, the LA need to put in place therapies that are recommended by NHS and private therapists and make sure yearly reports are gathered for the EHCP annual review.
Colchester Borough Council

More and easier access earlier to close the gap pre school. School age where language and speech are still a year or more delayed: two or three sessions per week minimum. Not being understood has such a negative effect on mental health and the child's enjoyment of the classroom.
Castle Point Borough Council

Making sure that non verbal children are prioritised at a young age rather than waiting for them to start school. Focus on early intervention programmes
Basildon Borough Council

Statutory Process

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



We received a total of 53 responses to our key questions, from a total 21 participants

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

It should be noted that 6 responses of out the 15 that responded to “what is working” stated that they felt nothing was working.

No responses were received from the Brentwood area



Statutory Process

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

What is working

- Nothing
- Placement
- Supportive setting
- Support Groups
- Provision
- Helpful professionals

Some of the provisions in the EHCP are working well.
Colchester Borough Council

Have extra help in an incorrect setting. Only agreed because we will argue against mainstream again for secondary school.
Tendring District Council

Approved for independent semh provision without us needing to request
Basildon Borough Council

Now that I have actually spoken with (name removed - Case worker), she has been very helpful and has, hopefully, made more progress in one day than has been achieved in the last few months!
Basildon Borough Council

Nothing at all in the case of parent communication!
Braintree District Council

At the moment - nothing!
Basildon Borough Council

Parent joined local support group and found it helpful to discuss with parents who have been through EHCP assessment process
Castle Point Borough Council

professionals support from other agencies
Rochford District Council

I wish as a parent I could say there was something working. As a professional my experience is different. That shouldn't be a positive.
Colchester Borough Council

Laindon PRU very supportive and able to help autistic school refusers
Basildon Borough Council

The school have offered a tour and did talk about their offer.
Colchester Borough Council

Statutory Process

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

What is Not Working

- Needs assessment processes
- Naming a setting - Communication and consent
- One Planning
- Provision not supportive of Needs Assessment
- Annual Review – Delay in providing updated EHCP
- Annual Review – Delay in naming Provision at Transition
- Provision named in plan
- Suitable Placements

Laptop was identified as useful equipment for my daughter. Applied for one via personal budget but LA declined and said it wasn't needed. We purchased a laptop out of daughters DLA money and it's a shared resource between school and home. School are happy for it to be used. During tribunal process for Section B F & I of EHCP LA queried why we had requested to include interventions using 'personal laptop'. Was advised not to include the word personal as that will put the responsibility back on the LA to provide one. So frustrating when we have just paid out!
Tendring District Council

Autistic child in year 5 needs additional support at school. School have agreed to commence one planning process but told parent that 3 rounds of one planning are required before they can apply for EHCP. She challenged the school on this point but they said they had been told this by SEND Ops. Parent is looking at secondary schools as they need to apply this autumn. She has been told by secondary school that they will need EHCP to be in place for them to provide the help that she believes her son will need. Parent feeling overwhelmed because secondary schools saying the need for EHCP is urgent but current school saying timescales are not achievable. Parent had looked on local offer to try and find out how to apply herself but couldn't find the information.

Castle Point

It is August, my son is due to start at the Extended Learning Provision at Chelmsford College in September, BUT we have still not received his draft EHCP plan naming the new provision. We live in South Essex but my son attended Thriftwood College which is Mid. The college was extremely late in getting the Annual Review paperwork to ECC and went way beyond the statutory timescales as they didn't send the Annual Review paperwork to ECC until after the Easter Holidays, over 6 months after the Annual Review took place. I have called the SEND Ops Team several times since late May. Whilst my calls have been answered every time, it isn't clear whether my messages for our caseworker (*Team member name removed*) have been forwarded as today was the first time she has returned my call. She has had to track down the paperwork, which has not yet been forwarded to the South team by the Mid SEND Operations Team/PfA Team. She informed me all the paperwork from Thriftwood is sent to the Mid teams initially. I'd like to know whose desk it has been sitting on for the last 4 months, gathering dust! Chelmsford College has not even been consulted officially by SEND Ops yet, let alone commencing drafting a revised EHC Plan - 4 weeks before the new term and a new provision!!!! Fortunately, his place at Chelmsford has been agreed, outside of this statutory process, and he has had a tour and has received his enrolment letter. A monumental catalogue of errors by all parties (except the family). I am debating whether to lodge a complaint with the Local Government Ombudsman because this so unacceptable. PLEASE DO BETTER!

Basildon Borough Council

Secondary school more interested in the banding of my child's EHCP than the provision within it. In initial conversations, made it clear full uniform expected despite sensory needs and EHCP referencing difficulty in wearing full uniform.
Colchester Borough Council

So frustrated: EHCP AR held in November - still nothing from LA. A school was named and we don't even know the outcome of the discussions. My child is so anxious not knowing where they are going post 16 they are unable to engage with school and their GCSE replacement assessments
Basildon Borough Council

child has does not have appropriate education to meet her needs. LA are struggling to identify. Mainstream have had no support for LA
Rochford District Council

Statutory Process

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

What can be done to improve things?

- Adhere to Statutory timescales/processes
- Improved communication
- Suitable provision for those academically able
- Suitable SEMH Provision
- Improved Transition process (schools and SEND Ops)
- Listen to Parents
- Improve funding/Staffing levels
- Regular Ofsted inspections

It is clear that Thriftwood College need to implement a more efficient process around completing the Annual Review paperwork. I know it was an unprecedented scenario this year, but I still don't see why it would cause a 6 month delay in preparing Annual Review paperwork. ECC SEND Operations teams clearly need to introduce a monitoring system for Annual Reviews. Surely, if there was such a system, they would not have allowed Thriftwood College to delay submitting crucial transition year Annual Review reports way beyond the expected timescales. And seemingly, there is no monitoring or logging of paperwork received, otherwise my son's AR report would not have sat on someone's desk for 4 months with nothing being actioned!

Basildon Borough Council

More funding into EHCP processes to increase staffing levels to make the process faster Cases should be graded and more urgent cases fast tracked More regular updates onto your place in the queue/estimated timescales
Rochford District Council

Staff training about the needs of autistic girls. Clarity about complaints process - make sure this can be easily searched

Brentwood Borough Council

Better communication with parents about why they're not able to help. Assessing All children with a diagnosis of SEN and not making a rash decision on paper.

Colchester Borough Council

Better provision for SEN children who are academically able. Everyone that understands Autism will know that the academic achievements will only happen if the whole framework is set up to make the right learning environment that suits the autistic child. If that is not set up correctly, every day will be one of anxiety and emotional episodes and crisis, where learning does not happen - yet frustrations, upset - and in my sons case - self harm - will!

Braintree District Council

Communication, working with parents, Ofsted inspections of schools - ours is 14 years out if date we have had 3 head teachers and school is NOT outstanding

Tendring District Council

meet the needs of the child
Rochford District Council

Adhere to Statutory time frames, communicate with parents.

Colchester Borough Council

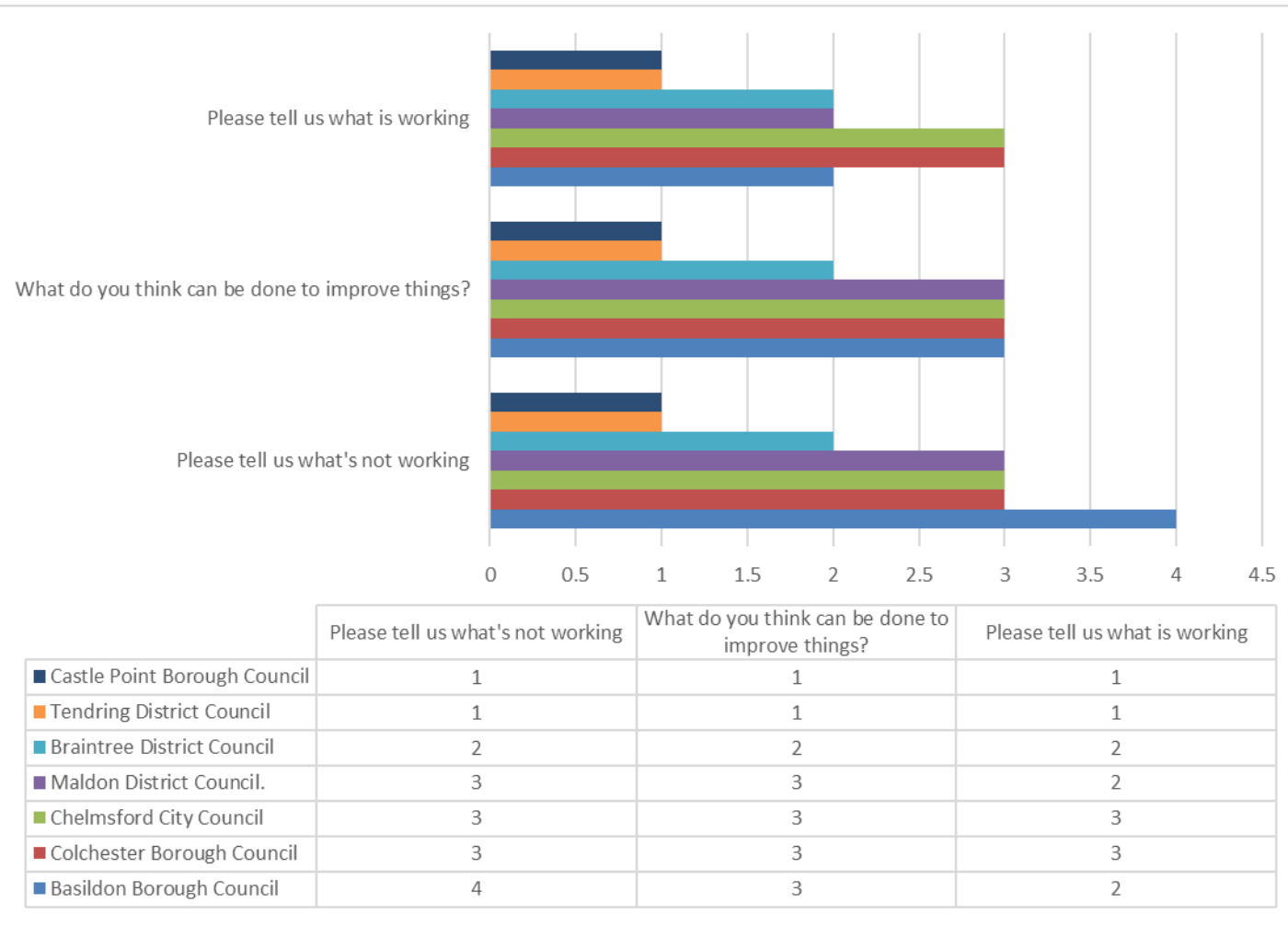
Communicate. More semh provision particularly for girls

Basildon Borough Council

Listen more in-depth to parents, take us more seriously. Make the waiting times less!

Uttlesford District Council

Mainstream Provision



We received a total of 47 responses to our key questions, from a total 18 participants

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

No responses were received from Harlow, Epping Forest, Uttlesford, Rochford and Brentwood.

Mainstream Provision

What is working

- Nothing – Constant Battle
- Supportive setting
- Professional's approach
- Provision
- Homeschool
- Parents listened to
- Timely meeting

Meetings agreed in a timely fashion when a meeting is requested. Parents input listened to and noted.

Chelmsford City Council

The LSA is amazing with him, he trusts her and they are great together.

Chelmsford City Council

School set up a Monday Morning Munchies club. Starts minutes before school and they get breakfast. The club appears to be for those children who struggle with the transition into school. For the second week, my daughter has woken up got dressed (herself!!!!), and has been excited to go into school. Such a small change, but really effective to transition from weekend to school. Made a difference to my morning!

Colchester Borough Council

Homeschool as his anxieties have lessened but he needs to be with children.

Maldon District Council.

I have no idea. In my experience as a SEN parent you have to constantly prove your kid is disabled enough to get the bare minimum of assistance. And even that's not enough for the child to thrive, just enough to see them potter along

Tendring District Council

Nothing from school. I paid privately for a child psychiatrist to assess her last Summer, and he confirmed her ASD diagnosis, diagnosed Tourette's and social anxiety. Since then she has been prescribed Sertraline which hasn't worked, her dose has been doubled as of last week. I hope it has some effect in reducing her anxiety to the point where she's able to leave the house. The Trustlinks course I am hopeful will give her confidence that she is not alone and other children are going through similar experiences to her. It is a much more supportive and inclusive and relaxed environment for her

Chelmsford City Council

EHCP and provision for this in mainstream school.

Braintree District Council

Inclusive classroom practice

Castle Point Borough Council

Nothing!

Colchester Borough Council

The services are helpful once in place.

Braintree District Council

“ Shout out to (professional Name removed) the Senco at beauchamps school in wickford. She works tirelessly for all children with additional needs and has a deep understand of autism and mental health issues. She is supporting my son so positively during a really difficult period in his life. She demonstrates flexibility, understanding, compassion and excellent communication skills to listen to us as parents and keep us up to date with what is going on. She is making a really positive difference.

Basildon Borough Council

Mainstream Provision

What is Not Working

- Lack of support before diagnosis
- Constant fight for provision and support
- Poor Communication
- Provision via plan not provided
- Lack of support from professionals/schools
- Not listening/supporting parents
- Having to seek private diagnoses (dyslexia)
- Lack of understanding of needs
- Curriculum not meeting need
- Senco independence
- No suitable placements for “middle” children

More awareness of disabilities and parents concerns without belittling them.
Castle Point Borough Council

A lot! Despite fighting for (and finally obtaining) an EHCP for my son (something the school never supported), I feel like I'm still having to fight to get him the help he so clearly needs at school.
Maldon District Council.

A child in year 6 not given extra support until a diagnosis was received and passed on to the school. Now no extra support for transition from primary school
Basildon Borough Council

There is a very frustrating lack of school placements for the ‘middle’ kids. It seems to be that either your child is severely disabled and you get a SEN school, but if your child has a few struggles then they’re expected to function in mainstream.
Tendring District Council

The wait times can be long and this can hinder early intervention for some children.
Braintree District Council

My daughter has one plan in place. she received a recent diagnosis. It was suggested we review the plan as "her needs will have changed now we have the diagnosis". Given one plans should be needs led, there should be no need to review her level of need. That said I think that the sentiment of reviewing it as there has been a change was welcome.
Colchester Borough Council

Lack of communication from senco. Teachers not reading one plan or knowing child’s diagnosis. little understanding of child’s needs or no safe place for child to regulate. School not identifying child’s need or supporting EHCP process. teachers approach to learning. Teachers lack of training and understanding of a child with special needs. No sensory spaces, sensory equipment provided is removed. No involvement from inclusion team when child and family desperately need support. Sensory overload and anxiety causing impulsive behaviour which is not managed, consent negative feedback on a daily basis with punishments for the child. Ticking, fidgeting or hand flapping results in child being removed from lesson. School refusal. No life skill lessons. social communication difficulties and no support with peers. Lunch and breaks. To be honest nothing in a mainstream secondary school is working for my child.

Colchester Borough Council

Very little understanding of autism, particularly in girls. And the requirements around that. Very little support. Support only given if you are very pushy. And then it seems to be just for show, to say that something has been tried. No real communication within departments of the child’s needs.

Chelmsford City Council



Mainstream Provision

What can be done to improve things?

- Be Empathic and Kind
- Support based on need not diagnosis
- Share best practice
- Signpost parents
- Support/Listen to parents
- Recognise changing of needs
- Appropriate SEND training
- Listen to /Include Child
- Appropriate funding

I feel that although the school are now saying they'll be led by me, that they then try to move the goalposts. I don't feel as a parent I know where to turn a lot of the time for information/options/support. At no point have school signposted me to any organisation that could offer guidance or information on what our options are. They clearly are not able to meet her needs as things stand, and I believe that she has been traumatised by the years of enforced school attendance/masking/meltdowns cycle. She is now at the point where she doesn't want to go to any school and struggles to leave home which is her safe place, even when there is something she really wants to go to or someone she wants to see. She is isolated and her friendships have suffered and are hanging by a thread. I would like there to be clear information given from which parents can then seek help or take actions to support their children

Chelmsford City Council

Funding. It all comes down to money. Stop spending money holding all these pointless meetings and put that money towards what the children actually need. It's impossible to see therapists without being on the edge of sanity first. A child needs to be suicidal before they can see CAHMS or a play therapist. Why are Occupation Therapists like gold dust around here? And that's only if you meet the very very strict criteria. And even if you do see one, it's for the very bare minimum before they have to move onto the next person. I am a single mother, only able to work part time due to my child's needs and yet I've had to find the money from thin air just to see a private occupational therapist. It's ridiculous

Tendring District Council

Be empathetic and kind. Be careful on the use of vocabulary which can often offend parents

Castle Point Borough Council

to include my daughter (i have asked this term for her to be included) previous meetings done via teams, so appreciate the difficulty but they did manage to include my other daughter in hers.

Colchester Borough Council

Schools should recognise that support is based on need not diagnosis.

Basildon Borough Council

Training of all staff and teachers on autism , particularly in girls. More listening to what the child actually has to say, and their needs.

Chelmsford City Council

More training for all school staff in schools, educate them about difficulties family's face when children have disabilities, mental health problems. Learn from parent support groups, what it's really like.

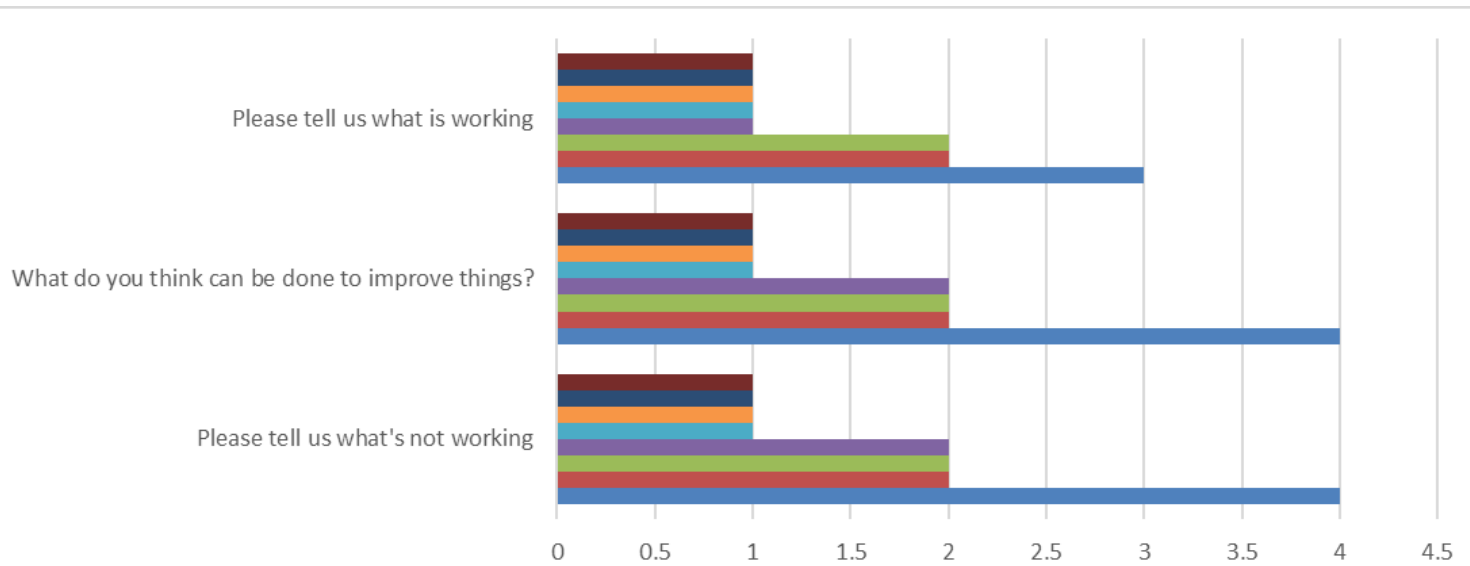
Maldon District Council.

There needs to be a more coherent application for parents. With less waiting times and where you don't have to apply to each service separately.

Braintree District Council



Diagnosis



	Please tell us what's not working	What do you think can be done to improve things?	Please tell us what is working
■ Basildon Borough Council	1	1	1
■ Colchester Borough Council	1	1	1
■ Rochford District Council	1	1	1
■ Uttlesford District Council	1	1	1
■ Harlow Council	2	2	1
■ Chelmsford City Council	2	2	2
■ Castle Point Borough Council	2	2	2
■ Braintree District Council	4	4	3

We received a total of 40 responses to our key questions, from a total 14 participants

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

No responses were received from Colchester, Epping Forest, Maldon and Brentwood

Diagnosis

What is working

- Nothing
- GP referral
- Support Services
- Improved diagnostic process
- Lorna Wing
- Local Charities

On 23rd October 2020 my daughter age 9 was referred to community paediatrics to be investigated for ASD. This in itself was great as firstly she is a girl, and we often hear of the “battle” to get a diagnosis for a girl and secondly we only asked for a referral to OT/PT as she had pains in her legs from walking on tip toes. The GP was great, reviewed her history asked us lots of questions and asked if I would be happy to be referred as she thought she may have ASD. We have had a few telephone consultants and questionnaires for ASD then ADHD done and yesterday our first face to face appointment we were given a diagnosis of ADHD. I will also say the Doctor yesterday took the time to explain about support in schools and gave leaflets about ADHD and a handout about support in the classroom and I was pleased to say he spoke to my daughter as well and listened to what she said she had to say. Personally I wasn't expecting a diagnosis yesterday, so it was a welcome surprise, though not entirely unexpected. Given we had been through the pathway previously with my older daughter, and discharged end of last year (with a blue card) I found the process much quicker than in 2017 which was when she was officially diagnosed and was given more information this time round. also pleased to say that the Diagnosis letter came within a few days of the appointment, previously it was a long wait, possibly 6-8 weeks.
Colchester Borough Council

Haven't found anything to be “working”
Uttlesford District Council

Nothing
Castle Point Borough Council

I can not comment on this as still on the waiting list for an assessment on the JADES pathway
Harlow Council

Lorna Wing Mina Essex
Autism Local Charities
Rochford District Council

The mAze group advice, parenting group and support on phone email who actually care and have first hand experience Families in focus offering ideas advice and supporting family on calls with schools and knowing the legal jargon that schools differ on and change to suit them and some DONT know
Chelmsford City Council

It's not
Castle Point Borough Council

My girl's coping mechanisms
Braintree District Council

Nothing
Basildon Borough Council

I can honestly say that we haven't received any help. Communication is very poor. It's just wait to hear from us. The provide help centre is very helpful when you get through and are able to update you.
Braintree District Council

The gp did the referral quickly
Braintree District Council



Diagnosis

What is Not Working

- Waiting Times
- Jades Care Plan
- Not listening to parent concerns
- Lighthouse
- Lack of Support
- Lack of diagnosis impacts on provision
- Impact on Parents Mental Health

The waiting time for an assessment for a diagnosis on the JADES pathway is horrific. To leave families approximately 2 years waiting for a diagnosis when measures to help could be in place is not fair on the child or family.
Harlow Council

Been waiting for daughter's referral from Lighthouse Centre since Jan'20. Had appointment in Sept'20 that was cancelled, then they cancelled the referral. After complaint they re-referred and still waiting. Only communication has been letter saying no appointments at the moment. Now had to go private.
Castle Point Borough Council

Dont listen to mum if another parent doesn't see it! Common autistic mask trait! Rely on school in mainstream again when not experienced only minor traits that are not picked up ! When significant traits suddenly appear a second wait of over a year to see another community paediatrician after first one made excuses about it being anger, or separation or hormones age etc Pathways not clear, support not quick enough and months go by fighting for support and advice and no actual help in mean time No one believes you yet mum knows best!!!
Chelmsford City Council

We waited several years for diagnosis, paediatrician appointment after appointment which my girl hated going to. Then diagnosis, then discharged. No further support, no further care. I've been depressed and hopeless ever since.
Braintree District Council

Can't get answer to phone/emails at Lighthouse Centre. Trying to get ASD referral but they are refusing. Can't get right support at school since no diagnosis, daughter now dropped out of school
Castle Point Borough Council

We need to help young children with potential autistic spectrum disorders, who are left on waiting lists for over 2 years (even longer now due to Covid) These poor children are being left in their own heads not understanding what is going on. Being branded by family, schools & doctors as "naughty" "disruptive" or "just pushing the boundaries". I am so sick of hearing about early intervention, helping children's mental health & getting the right support before things get out of hand. When in fact in reality the help & support is not there, parents/Carers are at breaking point with no where to turn. Being told they don't meet the criteria & to call someone else. Call who, who can actually help!? I have been there & it is a very dark place, thankfully I had my parents to help a little. I am now on antidepressants but that still doesn't help my child or all the other children. I have been fighting for help for my son for over 4 years, we have just been told that it is likely he has high functioning Autism spectrum disorder, this is not a formal diagnosis & we are still on the waiting list. When the doctor told me I cried, normally you are not happy when someone tells you there is something wrong with your child but on this occasion I was over the moon. Spent most of the next day on cloud 9, I was right that my son was not pushing the boundaries, it wasn't our parenting skills, it was in fact that the world was different for him & he was struggling & all the blood, sweat & tears had been for something. Why are children left on a waiting list for that long, surely the quicker we work out what is going on the quicker we can help these children. I am really not very good at writing things down but I hope this give you a little insight into what is happening in the real world & what I know is there is no one making a stand for these children. Things need to change now, they need help.
Uttlesford District Council

Whilst on Jades pathway you are supposed to receive a care plan in reality this is just links to websites while you are waiting. So as a parent you have to wade through it and try and source what you need.
Harlow Council

The wait for diagnosis is not acceptable Those who cannot afford a private diagnosis are forced to wait years for a diagnosis assessment Lighthouse centre
Rochford District Council

Given wrong diagnosis
Basildon Borough Council

Diagnosis

What can be done to improve things?

- Improved wait times
- Early Intervention opportunities
- Support/Clubs activities for Children and Young People
- Improved communication
- Quick Triage/Fast Tracked where appropriate
- Support while waiting
- Effective signposting
- Appropriate support at school WITHOUT diagnosis
- Family Support

Get more people who can diagnose children to stop them falling further behind and start working through the list. It feels as if Essex do not have SEN as a priority or care about children awaiting a SEN diagnosis and making their lives harder when there is no need.
Harlow Council

More communication, triage appointments quickly to find out the main issues to see if any can be removed from list, or fast tracked, or if you can be referred for any help or provision while you are waiting
Braintree District Council

Autism assessments and therapy needs to be provided quickly. Countless studies show how early intervention is so important. The provision in Chelmsford is failing and is simply negligent. - There needs to be more local offerings in terms of clubs, schools, after school clubs, activities etc for all ages, especially for younger children and older adults are particularly lacking.
Chelmsford City Council

Better communication/admin at Lighthouse Centre. Waiting times too long.
Castle Point Borough Council

sign posting to more local services rather than national ones.
Colchester Borough Council

More funding Increase the number of diagnostic centres in Essex that can be used so there is an alternative to Lighthouse Centre
Rochford District Council

Proper practical family support on how to deal with behaviours, get support in school, tips and tricks to try etc
Harlow Council

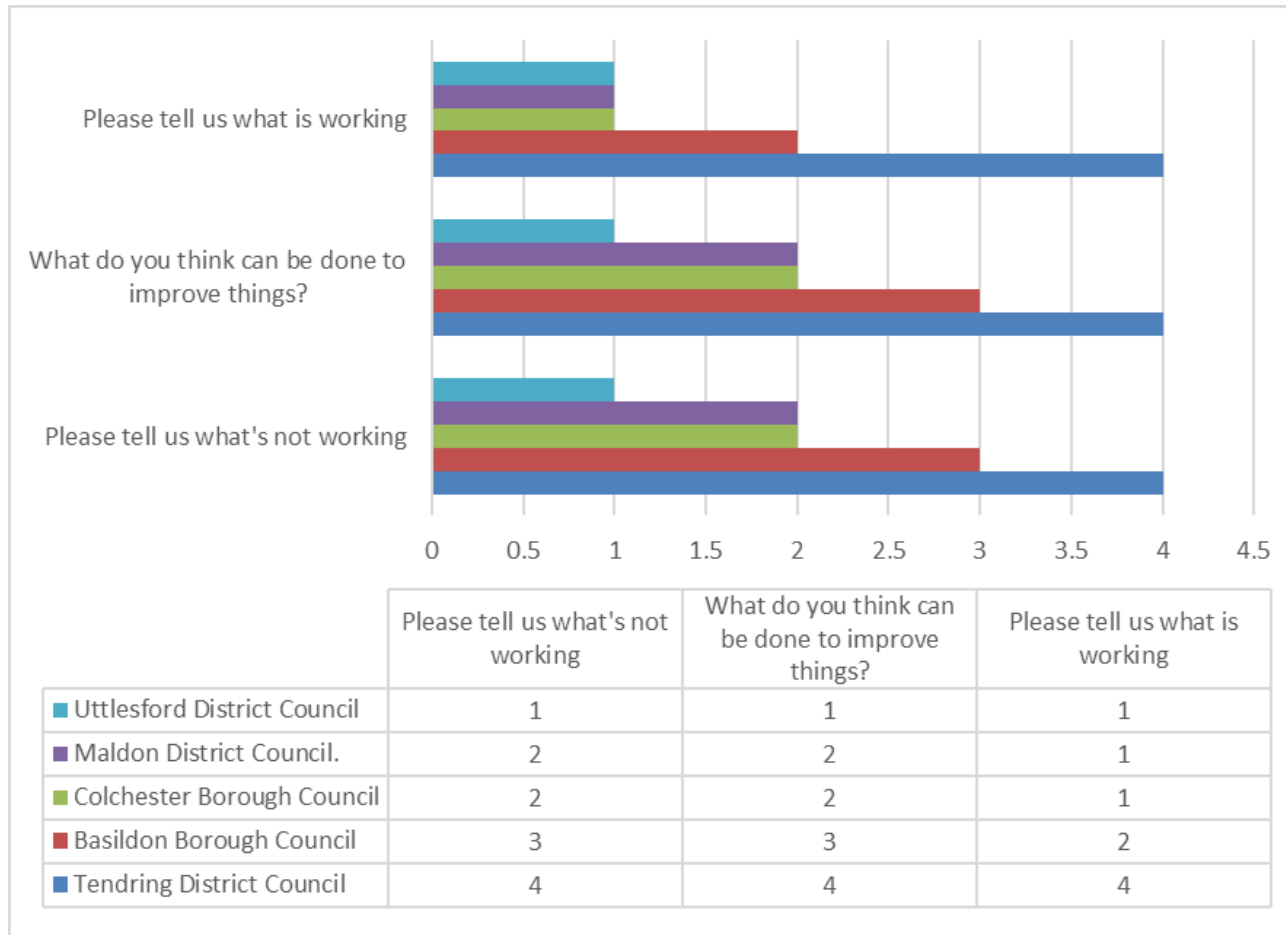
Not treating everybody like a number
Braintree District Council

Listen to parents and explain advice
Basildon Borough Council

Lighthouse Centre not fit for purpose. Paediatricians that don't believe in "labels", communication non existent. Shouldn't need diagnosis for help at school but that's the reality
Castle Point Borough Council



Special Schools and Alternative Provision



We received a total of 33 responses to our key questions, from a total 12 participants

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

No responses were received from Harlow, Uttlesford, Chelmsford, Braintree, Castle Point, Rochford and Brentwood

Special Schools and Alternative Provision

What is working

- Child Thriving
- Child achieving their potential
- Good Headteacher
- Nothing working
- Long Fight
- Has a placement
- Lack of support

Not a lot there's no support in any areas just left to get on with it.
Maldon District Council.

Not much
Send operations can challenge special schools but never do
Colchester Borough Council

My child, despite a long school day including an hour and a half commute each way, is achieving at or close to their academic potential.
Tendring District Council

Nothing!
Basildon Borough Council

When in the right provision you just know as the child thrives
Uttlesford District Council

We have a great headteacher at current school. Nothing else is working. She is also beyond fed up.
Tendring District Council

My child has placement
Basildon Borough Council

Nothing for us is working everything is a fight a long long fight
Tendring District Council

Special Schools and Alternative Provision

What is not working

- Unable to secure a placement
- Communication with SEND ops
- Not enough special schools
- Lack of consultation with low banding
- Specified provision not been followed as per EHCP
- Lack of provision for those who are academically able with SEMH/Complex needs
- Travel time
- Professional recommend Special provision but Local Authority name Mainstream
- Lack of joint working between health and education

Why is it not acceptable for abled body children to have to commute an hour to school (recent response to mainstream children not getting a place locally) but for children with less stainer, concentration, disabilities an often lower immune systems, an hour commute is the only option they have and seems to be acceptable?
Maldon District Council.

Not enough support for early years and when a child doesn't meet specialist school requirements but doesn't cope in mainstream no inbetween. No support for challenging behaviour
Tendring District Council

There is no provision within the area, for bright academically able students with additional education needs. The SEN school my child attends is on the Suffolk Cambridgeshire border. SEN schools are not held to the same standards as mainstream schools and so do not use data that comes with a student from year 6 SAT scores to map outcomes or measure value added. The additional therapies and specialists within school settings are limited in time and length, and do not communicate the diagnostics within the teams teaching and supporting students. The accommodations and understanding of behaviour caused by neurology and mental health issues is lacking and not conjoined. Tendring District Council

Send ups ignore emails, fail to attend meetings and don't return calls.
Basildon Borough Council

My child is at a mainstream school and I have been trying to transfer him to a special school. I have sent several emails but have not had any real help.
Basildon Borough Council

There isn't enough special schools. The special school do not and will not accept consultations with low banding/funding only high which means top funding, then leaving children out of school for months missing childhood memories, socialisation, fun and daily routine in return affecting their mental health! The way special schools are accessed needs to be reviewed as children have to wait 3 weeks every time a consultation is sent for a yes we will accept you or no you don't fit here! Very unfair the council should take control and put each child where they have identified needs. Instead children are going unnoticed and forgotten. What is the point of an EHCP if it's not even adhered to as a legal document? The child's needs aren't being met at home either! Failing kids for the future.
Colchester Borough Council

Why is it so hard to get the right provision for a child? And when it's found it's still hard to get the funding. It seems unless you're prepared to appeal etc you're very often given the wrong provision which then sets the child up to fail.
Uttlesford District Council

Special Schools and Alternative Provision

What can be done to improve things?

- Communication
- Honesty and transparency
- Increased provision / placements/ hubs
- Reviewing banding/admissions process
- Reduce travel times
- Increased support with challenging behaviors
- More support in early years
- Investment
- Training

There isn't enough provision in Essex for Higher functioning children my sons iq is high but social and communication is low so it's hard to find any support for him as his iq needs to be lower.
Uttlesford District Council

More support for early years in challenging behaviour and having peer groups. More clubs and activities for Sen children to access
Tendring District Council

More cooperation/communication with parents. Dont lie to parents about applications. Carry out promises
Basildon Borough Council

LA need to be honest Communication needs to improve Documents should not be "lost" If assessments are needed they should be done The lawyers at the LA need to know the law and the tribunal process. It was embarrassing but I knew more about how the process worked and the law than the LA'S legal person and I am not legally trained. Everyone (I.e. then LA)should read the paperwork on the child. Basic information was not even read There needs to be more mld school places
Tendring District Council

SEND children should not have to commute further than 30 mins to get to school.
Maldon District Council.

Scrap the process of how admissions and banding funding is done
Colchester Borough Council

Parent wants better communication from the school.
Colchester Borough Council

A lot, more schools for Sen, more hubs, more support services etc
Maldon District Council.

They need to invest money in educating teachers and funding. They need to build more specialist schools. Our children are being left behind
Tendring District Council



SEND Funding

What can be done to improve things?

- Communication
- Transparency
- Funding of Private schools
- Get things in place quickly

Better communication, as the LA do not respond to emails or calls. Transparency wrt the EP funding banding recommendation, which has been requested repeatedly but not provided.
Uttlesford District Council

Change the funding to private schools OR there needs to be changes so that the school has to contribute and doesn't leave the parent with a huge shortfall they cant pay.
Rochford District Council

More funding
Basildon Borough Council

	Please tell us what's not working	What do you think can be done to improve things?	Please tell us what is working
■ Colchester Borough Council	1	1	
■ Chelmsford City Council	1		1
■ Harlow Council	1	1	1
■ Braintree District Council	1	1	1
■ Maldon District Council.	1	1	1
■ Rochford District Council	1	1	1
■ Uttlesford District Council	2	2	2
■ Basildon Borough Council	3	3	1

What is working

- IPRA Funding
- EHCP Funding
- Nothing – child non attendee

My little boy is actually really well supported in school. Just not getting all the provision he should be.
Braintree District Council

IPRA emergency fund has helped reduce what we have to pay.
Rochford District Council

Nothing at the moment as she is a non attendee
Uttlesford District Council

We have an EHCP written, but it cannot be implemented as currently no funding is agreed
Uttlesford District Council

What is not working

- Provision delivered based on banding provided, not what plan outlines
- Short fall with private settings
- LA refusing to fund EHCP correctly
- Funding for equipment
- Early Years funding is not adequate

EHCP issued and banding awarded. EHCP appealed and substantial additional provision added. Banding not amended. SENCO said additional funds would be needed. SENCO changed and no additional funds asked for. Provision now being decided based on funding band not provision specified in plan.
Braintree District Council

The LA are refusing to provide the school with the funding necessary to implement my child's EHCP.
Uttlesford District Council

SEND funding does not work when child is in private school. Has left a short fall of £2000 per term that I need to find and pay myself OR pull my child out.
Rochford District Council

Mental Health

What can be done to improve things?

- Streamlined quicker referrals
- Training in schools
- Better Communication
- Improve wait times
- Provide dedicated teenage service
- Improve transition between children and adult services
- GP Prescribing Medication

There should be a teenage age service for children with leaning difficulties, which is totally separate to adult services
Basildon Borough Council

Give the teachers nand head teachers 100% more training so they can understand
Basildon Borough Council

GP prescribing medication for under 18. More people in CAMHS, more psychiatrists, different therapies than just CBT.
Chelmsford City Council

	What do you think can be done to improve things?	Please tell us what's not working	Please tell us what is working
■ Chelmsford City Council	1	1	1
■ Tendring District Council	1	1	1
■ Braintree District Council	2	2	2
■ Basildon Borough Council	4	4	2

when apprcaching 18 years old and under the children mental health doctors due to additional needs with EHCP and is not in mainstream education due to extra needs, transtion to adult mental health needs to be supported very differently. Triage didnt understand our child, this made our son very distressed, the service needed even know what they could do to carry on the support his already having. the services needs to change. our young adults don't change over night of there 18th birthdays. Basildon Borough Council

To get more help at a faster rate
Tendring District Council

Tranistion from childrens mental health the adult mental health
Basildon Borough Council

Long waiting times, only therapy offered CBT, ASD assesment 2 years waiting list, resistance to medicate severely depressed and anxious and suicidal teenager as under 18. No beds in psychiatric hospitals.
Chelmsford City Council

My daughter's paediatrician told me on last week that she recommended that my daughter should see a therapist for her crippling anxiety, phobias, sensory issues, poor self esteem and OCD. The paediatrician is apparently not able to refer her, and I was advised to contact The Emotional Wellbeing Service, which I did. They told me they would email me a questionnaire to fill in to see if they thought she was bad enough to get their assistance. I have not yet received the questionnaire. I was also told to call Basildon Mind to see if they could offer counselling. I did but was told that waiting lists were so long that I should look into doing it privately. Basildon Borough Council

The schools do not understand the effect of trauma on a childs mental health. Teachers including head teachers need more training to be able to understand and help the children in mainstream schools
Basildon Borough Council

What is working

- EWMHs
- Nothing
- Homeschool

Nothing.
Chelmsford City Council

Tutor. For homeschooling
Tendring District Council

Ewmes counselling service is an excellent service for kids with trauma
Basildon Borough Council

Support from children mental health; it's taken over a year to feel he can talk and now his got they used to new buildings abs people again
Basildon Borough Council

My paediatrician has been brilliant and very understanding of my daughters needs. She put me in touch with ewhms.
Braintree District Council

Remaining Categories

(Local Authority, Short Breaks/Respite, Home to school transport, Communication, Young Adult Support, Family Support, Social Care)

What is working

- Provision for 19 +
- Support Services and charities
- Parents!
- Nothing
- Professional Support
- Private provision
- Virtual Appointments

Have seen some improvement in the way transport provider communicates - at least trying to be parent friendly
Castle Point Borough Council
Home to School Transport

I'm there for my kids
Rochford District Council
Family Support

Good 19+ provision is available
Basildon Borough Council
Young Adult Support

Nothing
Rochford District Council
Local Authority

Help and advice from one charity called ministry of parenting although couldn't do much they did take the time to speak to me. SNAP have given me some hope after speaking to them today
Colchester Borough Council
Young Adult Support

Nothing. Went private for everything.
Chelmsford City Council
Short Breaks/Respite

Nothing
Chelmsford City Council
Home to School Transport

The option of virtual appointments has relieved a lot of stress of travelling anxiety to my young person and has meant we can attend even if she is unwell or unable to travel.

Tendring District Council
Communication

Support from social worker & child in need assessment. Support from OT.
Basildon Borough Council
Local Authority

Remaining Categories

(Local Authority, Short Breaks/Respite, Home to school transport, Communication, Young Adult Support, Family Support, Social Care)

What is not working

- Lack of provision for 18 +
- Transitions for SEND Transport
- COVID recovery plans
- Lack of short break provision for Early Years
- Funding for equipment
- Social Care assessment
- Lack of clubs and activities
- Lack of suitable home to school transport
- Criteria for CWDR Social Worker to high
- Send Ops under resourced
- Lack of respite
- The System
- Lack of joint working
- Needs of parents not considered in COVID

Coming up with and Putting into place recovery plans for SEN children especially those who could not engage with online learning and those already struggling in school. Covid has made it worse. ECC take to long to make suitable decisions and there are many gaps in services for SEN children especially MLD children. There's no social care support either. There needs to be a joint up approach between school parent and social care to many children are fallen though the gaps.

Rochford District Council
Local Authority

Children at SEN school told by current taxi drivers in mid June that transport provision will change from September 2021 from 24/7 to Connect. As at 5/7 parents have still not been told what is happening. Parents spoke to headteacher who said he was unable to comment. Family champion reports that numerous parents and children are anxious about the change and feel angry that they haven't been formally told what is happening and it is making children anxious. Transitions should have commenced already but still no one really knows what is happening.

Basildon Borough Council
Home to School Transport

Can't seem to find many places that actually support 18+ newly diagnosed people and families
Colchester Borough Council
Young Adult Support

I keep getting email about activities for SEN children at weekends or school holidays, but there is nothing for early years children before they reach school age.

Harlow Council
Short Breaks/Respite

The criteria for having a CWDT social worker is way to high it's left a massive gap in service between them and family solutions/early help support. Families need practical support and access to direct payments to buy in the support they need yet they can't get this because the criteria for a social worker is way to high leaving vulnerable families struggling in crisis

Rochford District Council
Social Care

The role of parent carer isn't valued, the needs of carers throughout this pandemic haven't been recognised, factored into planning or met in anyway.

Rochford District Council
Family Support

LA refused to fund a Self care toilet for my 13 year old disabled son, despite the OT & Social Worker writing to the LA Grants dept to support the need. Reason was due to already being approved a grant for downstairs wetroom & bedroom to maximum amount. (incl standard toilet) However the cost already goes over the maximum grant level and specialist toilet is a further £3700, which we've been told to self fund, or wait until the current grant is paid out & reapply for another grant to take out the newly installed standard toilet with a specialist toilet!!! Totally balmy!! After significantly challenging the council & threatening legal action they provisionally agreed a top up discretionary grant, however this comes with a condition of a charge against our home indefinitely and must be repaid in full either on sale or death. There is no end to this & therefore it is an indefinite interest free loan!

Basildon Borough Council
Local Authority



Remaining Categories

(Local Authority, Short Breaks/Respite, Home to school transport, Communication, Young Adult Support, Family Support, Social Care)

What do you think can be done to improve things?

- Young Adult Support
- Better transport assessments
- Training for transport
- Commination – be transparent
- Constancy across quadrants
- Improve Schools ability to sign post
- Listen to parents
- Right Support and the Right Time
- Holiday clubs and respite
- Training for professionals

The LA need to work closer with specialist health OT/social care, and budgets reviewed for individual child cases. Social care health can provide a hoist above a maximum grant but LA can't provide a specialist toilet! Words fail me & the needs of my child are not at the heart of these decisions
Basildon Borough Council
Local Authority

Actually have support for young adults, instead of saying birth to 25 years and then not actually implementing this. My daughter got diagnosed at 18 and then left to it
Colchester Borough Council
Young Adult Support

Improve school knowledge on what support can be accessed improve referral times improve communication with parents and schools. be consistent with how policies are being implemented with in each quadrants because it appears in practise the threshold for support for CWDT in north Essex is less then south Essex meaning children in the north of Essex receive care but if they lived in south Essex they would not meet threshold.
Rochford District Council
Local Authority

Provide holiday or weekend club in Harlow
Short Breaks/Respite

After 19+ still provide specialist SEND services, named OT and physio etc
Basildon Borough Council
Young Adult Support

Better training of transport staff so they are better equipped to deal with situations as they arise
Castle Point Borough Council
Home to School Transport

The SEN team need legal training. It's not ok for them to say and so things that are not inline with the Children and Families Act as well as the SEND code of Practice.
Basildon Borough Council
Local Authority

I've got an idea! How about the Preparing for Adulthood team work with the Short Breaks team to produce a programme that works for teenagers?
Tendring District Council
Short Breaks/Respite

Better assessment to ensure safe travel provided regardless of nearest suitable school. Nearest suitable school should include how the child would travel to school.
Chelmsford City Council
Home to School Transport

Improve communication between families, schools and LA. Listen to families and be open and honest
Rochford District Council
Local Authority

Next Steps

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.

Essex Family Forum will continue to gather parents' experiences via our Virtual Graffiti Wall through our Family Champion Quadrant Leads and Volunteer Family Champions and present this data on a termly basis.

Essex Family Forum will continue to use this data to represent parent and carer voices to influence change to SEND provision and services in Essex.

The anonymised hard copy data will be made available to the SEND Partnership Board if requested.

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.