

Graffiti Wall

Representing Parental Views on SEND across Essex

Essex Family Forum

May 2021



Concept of the Graffiti wall

A new virtual way of working

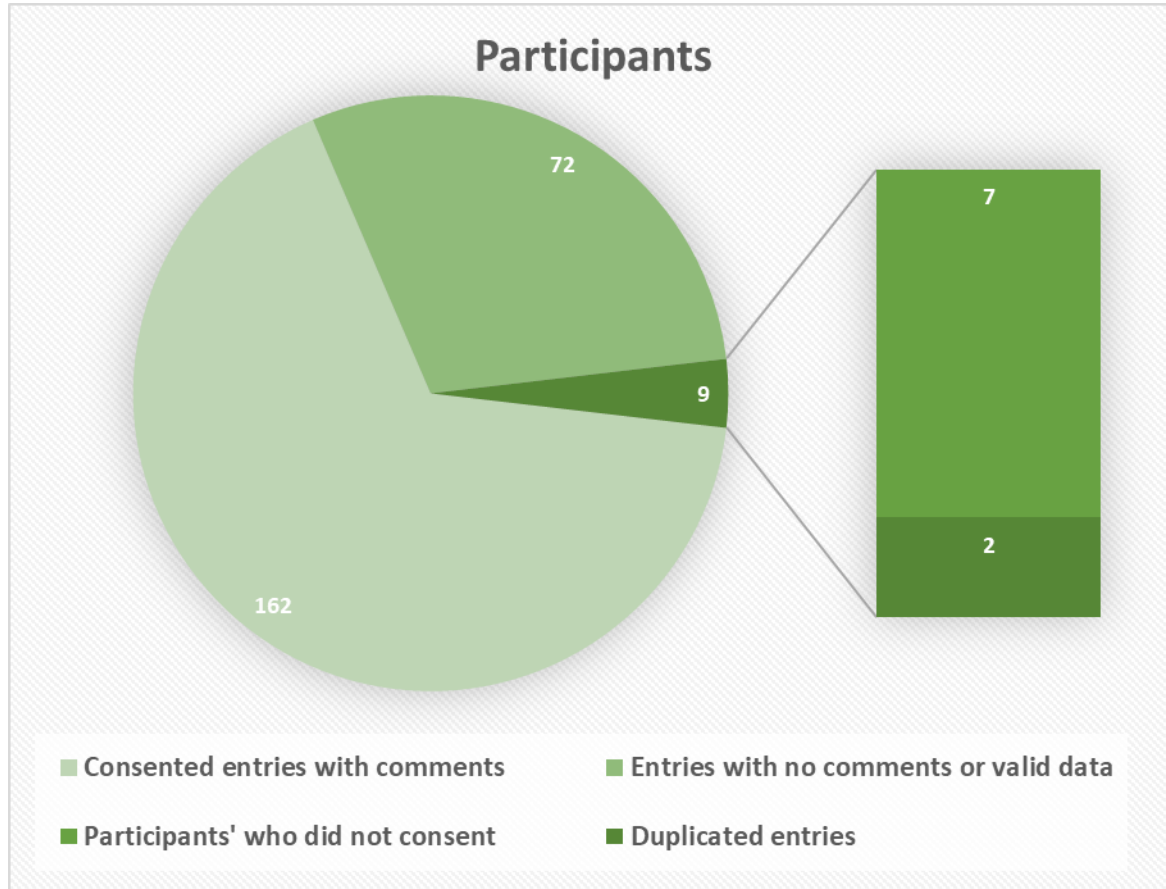
The Graffiti Wall was set up to provide parents with a continuous opportunity to tell us their experiences on SEND Services in Essex. We previously visited and hosted coffee mornings, events, met with parents and asked our Family Champions to collate views of the families they knew.

This is not currently possible so we have embraced the new virtual world of working and created an online tool for parents to tell us what life is like for them, what works, what doesn't, and how can it be improved. 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.

The data gathered is anonymised and presented quarterly 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.



Consent and Participants

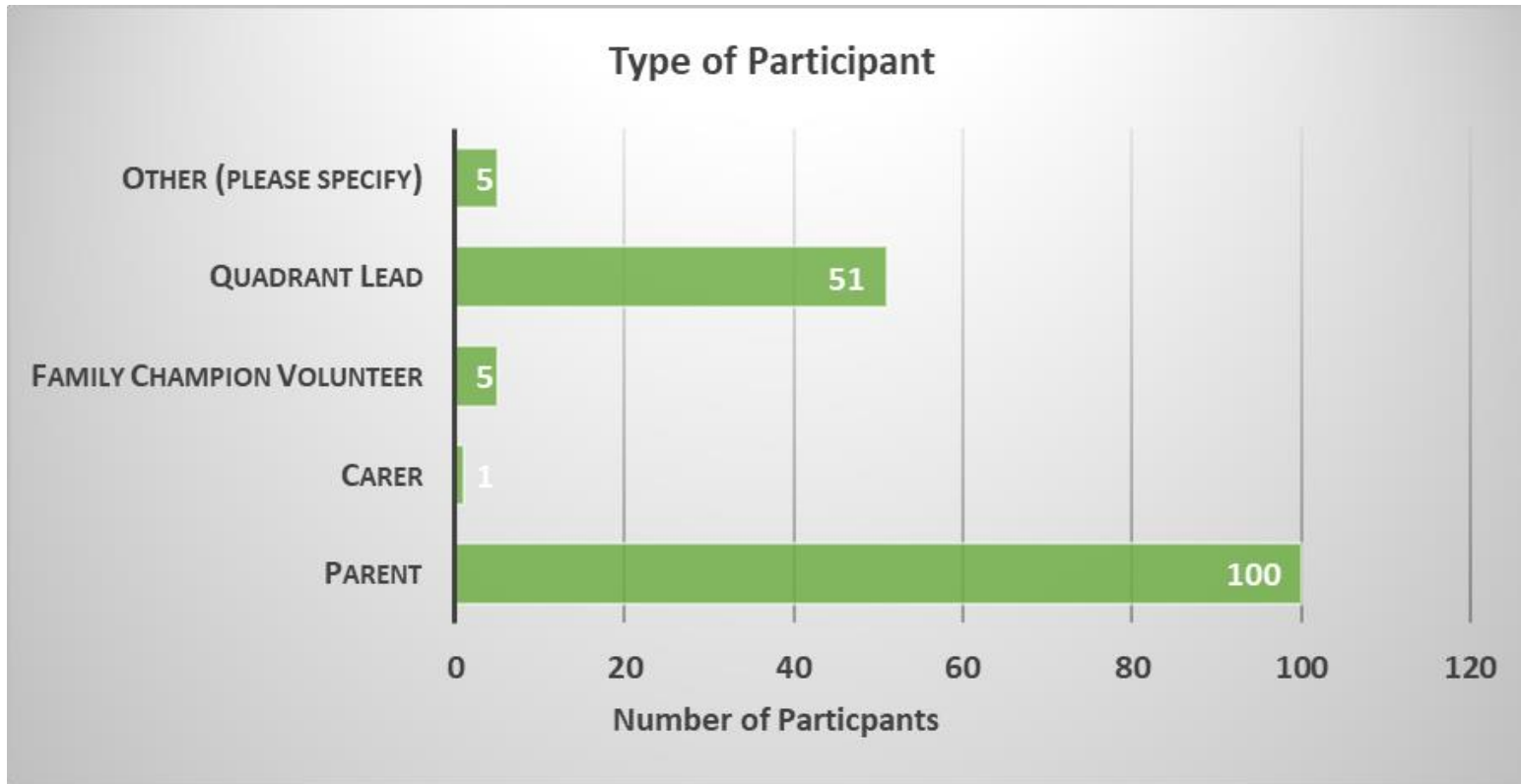


This Survey was open from 1st January to 31st March 2021

We had 243 Participants that clicked and proceeded through the survey, with 162 consented entries with comments.

This report will provide details on the 162 consented entries with comments and statistics used throughout this report will be based on this figure

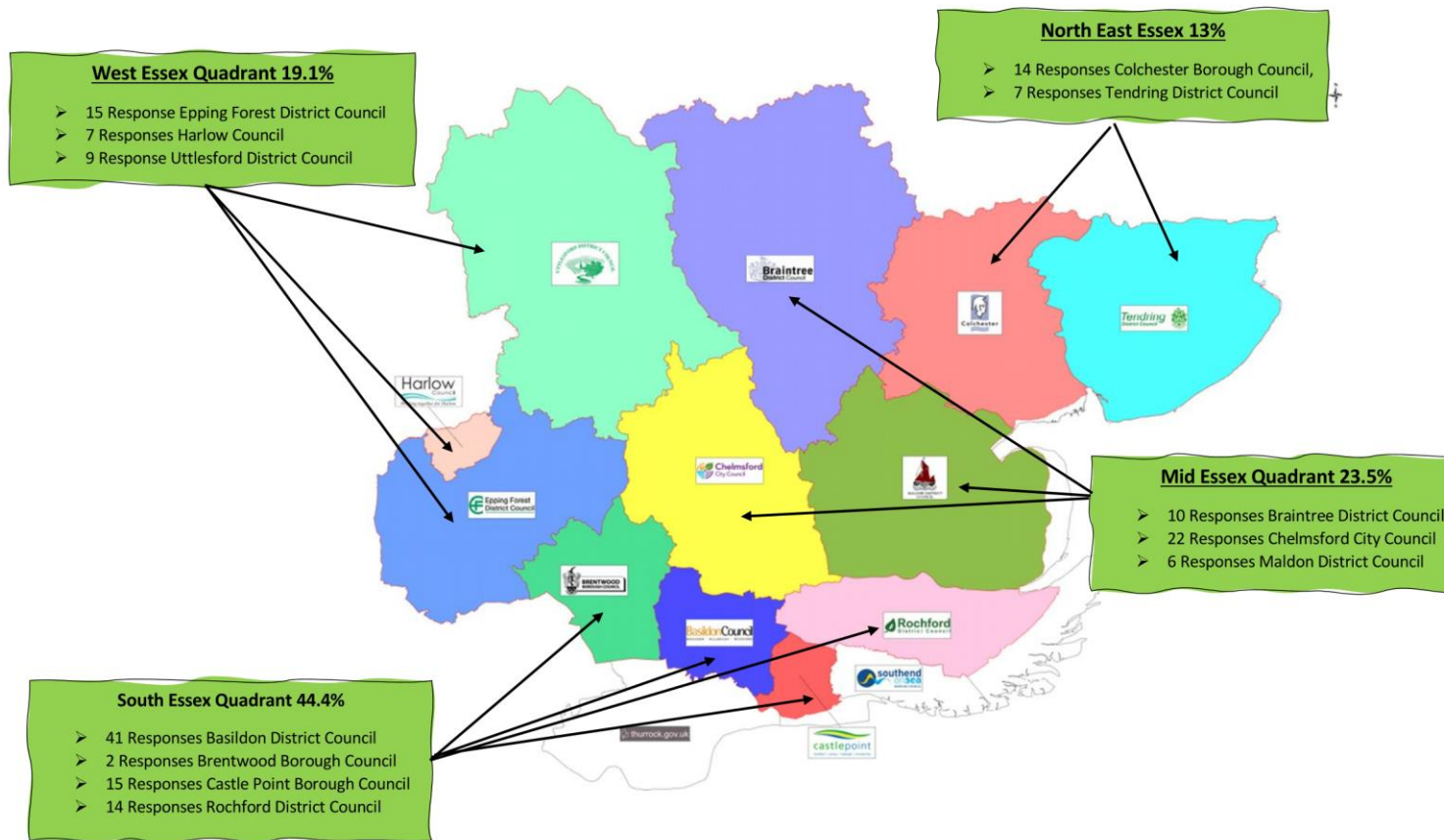
Consent and Participants



The “Other” Category included:

- 3 Professionals
- 1 Grandparent
- 1 Parent Support

Responses by Area



Observations

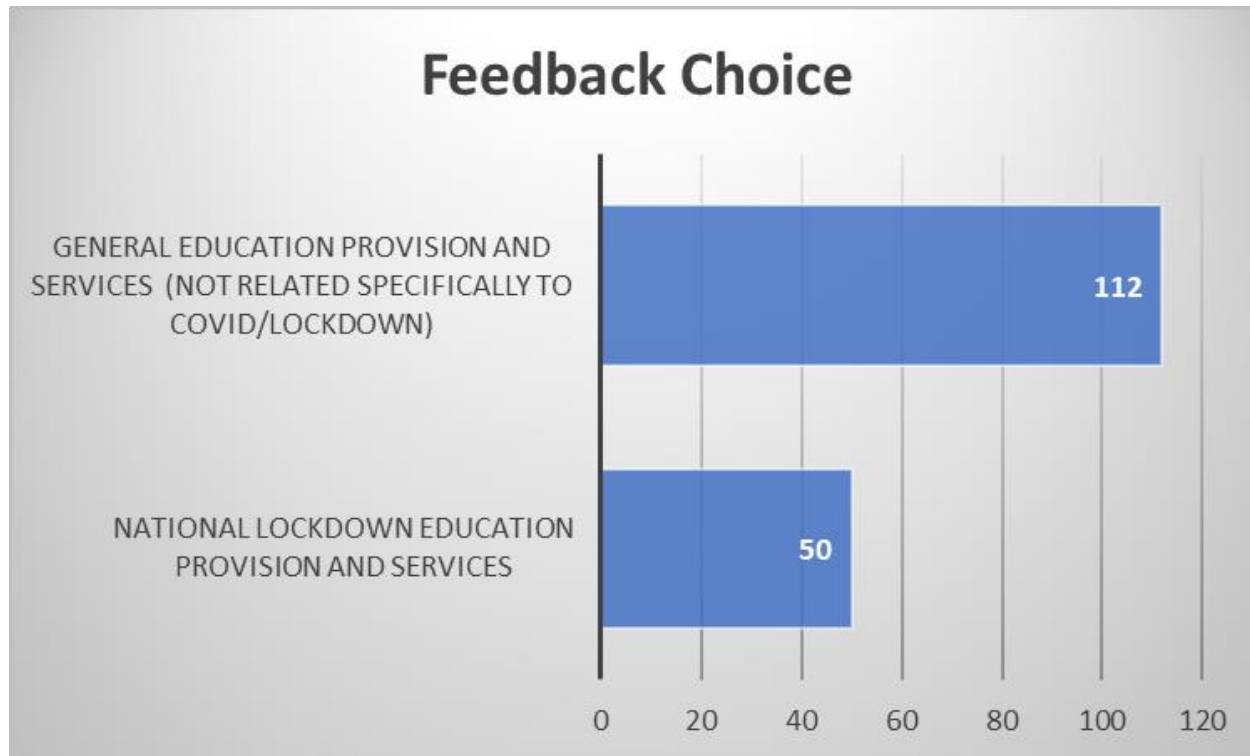
West represented 1.8% of feedback last quarter, with only 2 responses. We have significantly improved our reach within this quadrant.

Mid represented 16.8% of feedback last quarter with 19 responses, whilst this now has increased to 28 responses.

North East's percentage has decreased from 15.9% however, has an increased number of comments with 21 this quarter from 18 last quarter.

Whilst South's percentage has reduced from 65.5% last quarter, the number of comments was consistent with 74 last quarter and 72 this quarter. The drop merely represents increased feedback throughout the rest of Essex.

Feedback Categories



As this Graffiti Wall was open during the third National Lockdown, we amended the wall to provide feedback specific to Lockdown provision and added 7 specific questions relating to Lockdown provision.

Those Parents that selected General Education Provision and Services (not related specifically to COVID/Lockdown) were directed though to our “standard” Graffiti Wall.

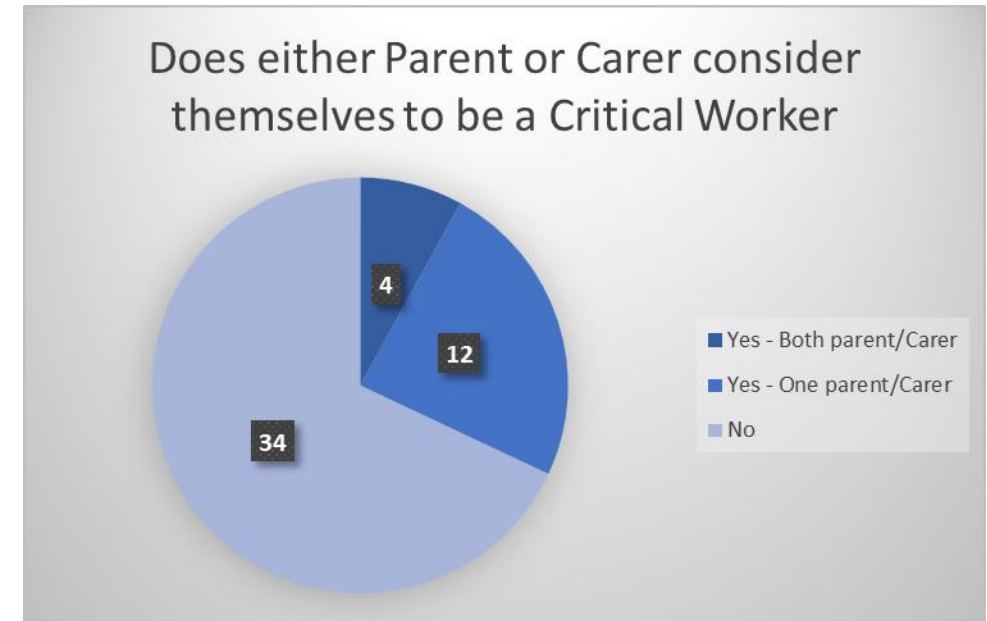
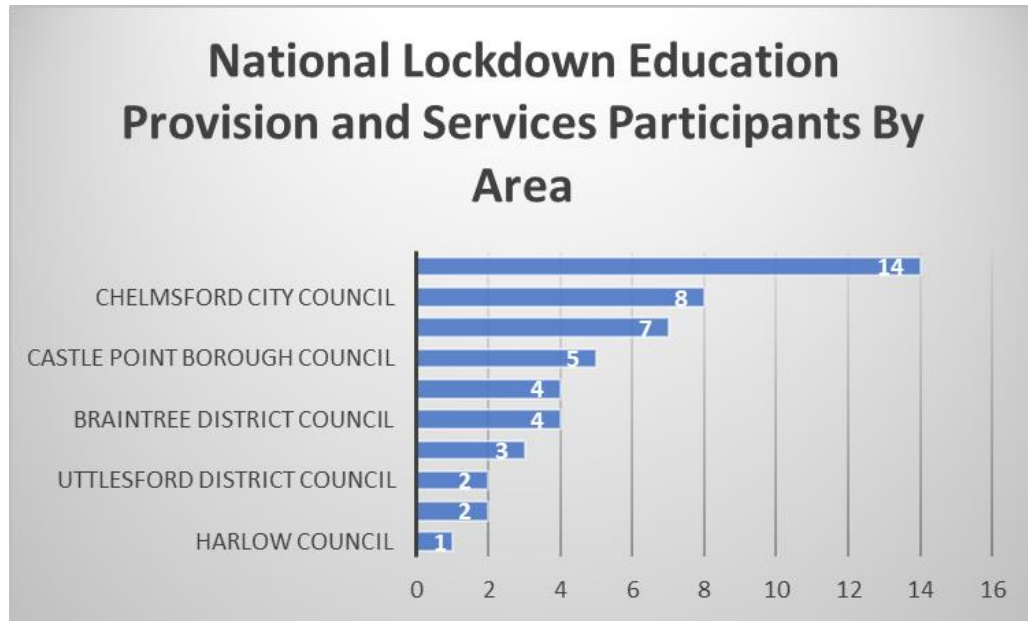
National
Lockdown
Education
Provision
and services

The following slides relate
to feedback provided
through the above
category



National Lockdown Participant Information

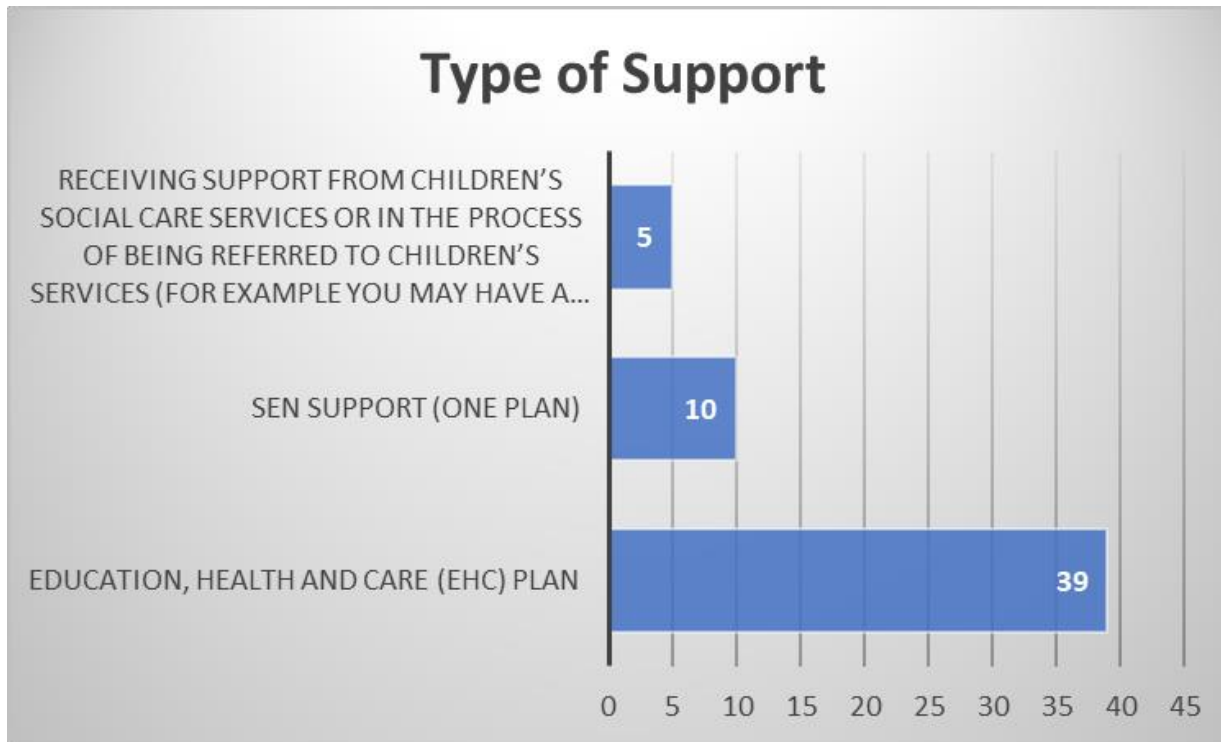
This provides some details on the demographic of those families that provided information within this section



National Lockdown

Type of Support

We asked Parents what type of support their child, young person or family was in receipt of.



Participants also mentioned:

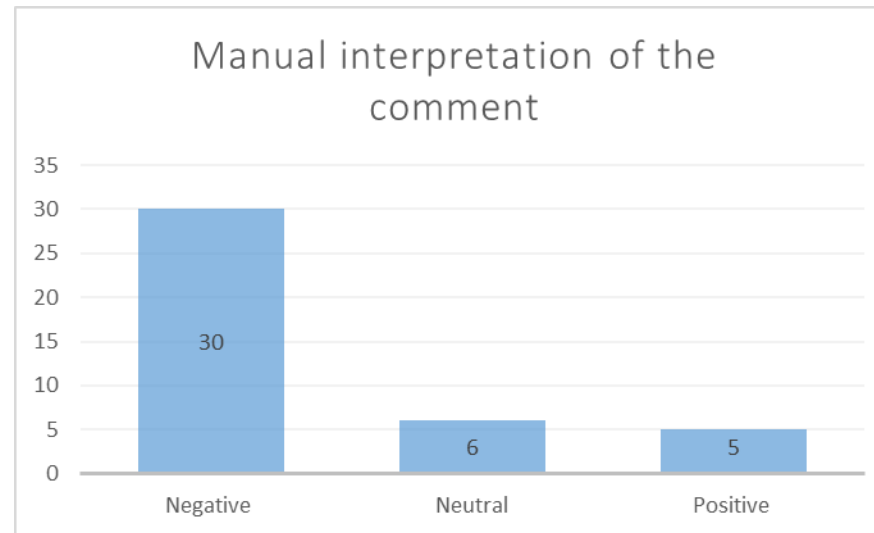
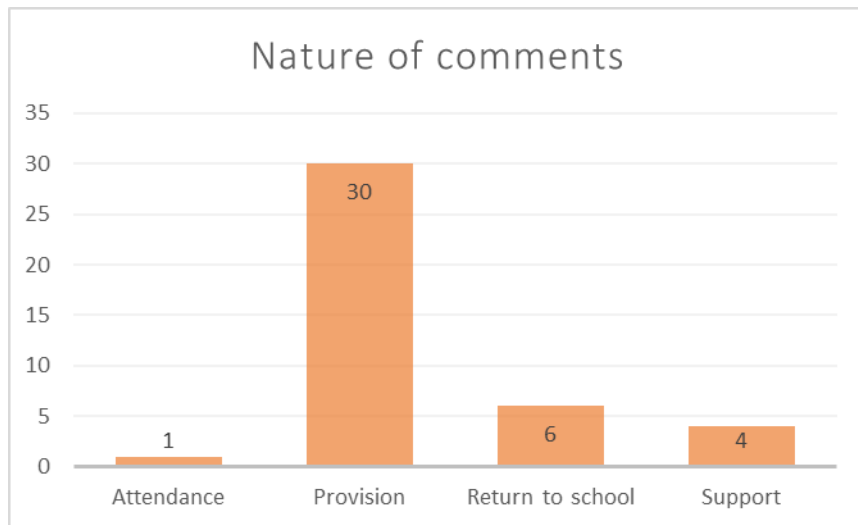
- ADHD Support+
- SENDIASS
- EWMHs
- Being assessed for EHCP
- Occupational Health and Physiotherapy support
- JADES pathway
- And two responses indicated paying for private support

Participants were able to tick all boxes that applied. Where a parent has ticked EHCP and one plan, we have reported statistics on the EHCP only.

National Lockdown Education Provision and Services - Feedback

We asked families to provide any comments they had regarding Education Provision

41 Parents provided feedback



Provision comments includes; access to school places, differentiation of work and virtual offer.

National Lockdown Education Provision and Services – Feedback

My key worker status and my 10 year old's needs have led his PMLD school to offer him full time face to face teaching. The teaching staff are doing a good job in extremely difficult circumstances and I'm hugely grateful to them. Credit must also go to the school administrators for the robust infection prevention measures they've taken for an environment where using masks isn't possible

The work being sent through has been differentiated and is great but the live group lessons are hard because my daughter is so far behind. I want her to feel socially included though so perhaps there could be less demanding live lessons.

absolutely rubbish support. Expected to keep a danger seeking child with huge anxiety and no awareness of danger safe whilst working full time with no support. Paediatrician ignored when warned ECC of Deteriorating mental health. Ed Psyc recommendations ignored. ECC and ****school name removed**** let down 200 pupils

We felt completely abandoned during lockdown. Very little help, we had weekly phone calls from the Senco from January and some sheets sent to us from the school but otherwise we're on our own to deal with our son, his education and all his problems.

A selection of some of the comments provided

Positive comments

Neutral Comments

Negative Comments

My son has ASD and ADHD and struggles in his mainstream class environment. He struggles to concentrate and focus and he struggles with personal relationships. During this last lockdown he has been working virtually at home (secondary school pupil) and has really enjoyed learning virtually. He has engaged fully in his learning and has produced some great work. I am worried that this will all be lost when he goes back to a classroom environment again

School very supportive. Good home learning provisions through lockdown, but were flexible and understanding for my two SEND children.

My son was forgotten about during the first few months of lock down. He was not provided any provision or tutoring . He has a full EHCP.

My son has an EHCP but is not in school as the changes to everything would be too distressing. His teacher is wonderful and adapting work as best she can, but there is a lot. I have asked the school if his LSA could support him virtually regularly with the work and they have agreed. I think that a child's EHCP money is there for that child and it could be used during this time to support children individually even if it is virtually or with equipment at home etc.

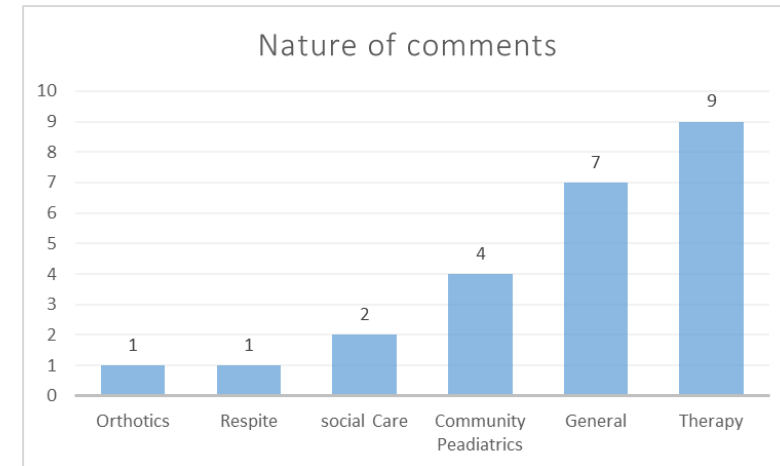
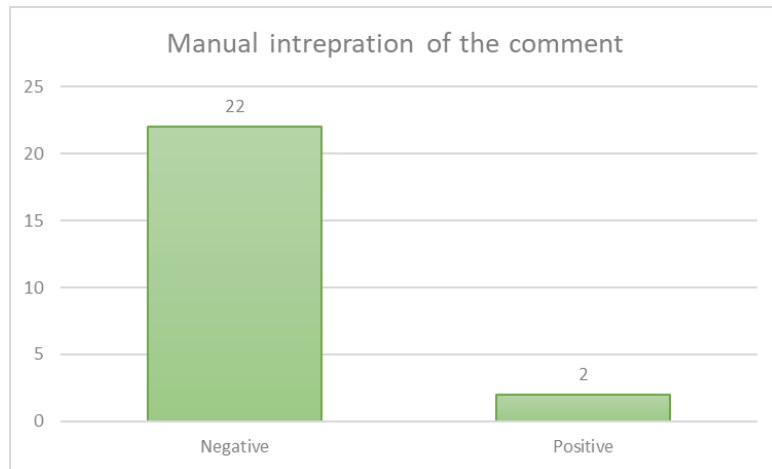
What will be in place to support children return to school for those children who haven't been able to engage in home learning and who are medically vulnerable

Still not much differentiation in work. Also no recognition that the child has learning support in every lesson plus extra one to one sessions, sensory breaks etc

The offering across different schools is very inconsistent - some are using teams, some google, some videos - some teachers seem completely disengaged and others are just winging it. Has anyone asked for feedback on what is working the best? Whatever it is , Training should then be provided and all schools should be adopting that approach. It seems that whoever shouts the loudest gets the help. Some parents just don't have any shout left in them.

National Lockdown Health and Social Care- Feedback

We asked Families to provide any comments they had regarding Health and Social Care
24 Parents provided feedback.



We also invited comments on vaccinations. Some families commented on routine vaccinations, whilst others focused on the intended COVID vaccination.

Comments regarding COVID vaccinations were mainly focused on the confusion over carer entitlement. This was an issue we raised on behalf of parents to our colleagues in Health and the Local Authority

I am a carer for my daughter with ASD - 'I asked my GP surgery about this (vaccine for carers) and they didnt know anything about it'

National Lockdown Health and Social Care- Feedback

A selection of some of the comments provided

My son is X years old, non verbal autistic and attends XXX school. Last year we were lucky enough to work with the CLDS team and CAYPS to help with our sons many challenges, most notably his behavioural and sensory challenges. Whilst all the recommendations of the CLDS and CAYPS have been adopted and have made an impact, it was acknowledged in line with my own concerns that he needs an urgent ADHD assessment as it is felt this is possibly his biggest barrier at the present time. Despite repeated referrals, chasers by the CLDS lead, School and his SW, the response from **Service provider name removed ** has been poor at best. They just keep telling us he is on a waiting list but refuse to elaborate on where he is on that list or how long we can expect to wait for an appointment. On Friday, several months after the referral and paperwork had been returned we received a pro forma letter telling us that due to COVID the paediatric team was operating differently, he is on a waiting list (which we knew) and again no indication of timeframes etc. Since the referrals were made in June, we have now been discharged from both CLDS and CAYPS in December. My son's mental health and stability continue to deteriorate, behaviours are escalating to crisis point again and with no end in sight, we are left not knowing what to do for the best. If we go to seek private assessment (which we can I'll afford atm given the current crisis) chances are the LA etc will ignore the outcomes if we send them because (a) it's private and (b) they seem reluctant to make changes to ehcps these days 😊. We will have to go down this route though as we cannot stand to see our son struggle when he actually possibly needs meds/adapted support in place to make his life more manageable.

Positive comments

Neutral Comments

Negative Comments

The ECC Short Break Respite Service has continued to offer us overnight breaks largely in line with our pre-COVID provision and respite centre staff have been very supportive, helping my youngster make developmental progress despite his elevated anxiety through the lockdowns.

No support provided despite my son being a shielding child and a Sen child been turned down again for support from social care

Speech and language being delivered virtually, a method in which my asd daughter does not engage. This provision is limited enough without being delivered in a way she will not engage with

My daughter hasn't been getting any of her provisions in her ehcp and I'm starting judicial review because of this, she has been failed massively

GOSH recommended to have CAHMS for our son back in November. We chased up the referral with GP who chased it up and said we were on a waiting list to see the paediatrician to be put on the waiting list for CAHMS. It is mid-March and we are still waiting for the paediatric appointment. We have been trying to get help from social services for over a year and we finally managed to get support after 3 referrals by family psychologist, 2 self referrals and 1 by police, 1 by school nurse/hospital A/E. our son is now on the child in need list and are hoping for help with his behaviour but are losing hope in the system

Good communication from NHS re Orthoptics. Happy to delay appt until cases eased and called when they said they would to arrange a new appointment. Staff were brilliant at Clacton Hospital.

My son has been waiting to be seen by paediatric services for an ADHD assessment since last summer. Despite professionals from CLDS/social care highlighting the urgency of this referral and the impact on my son, we have been ignored. The service won't engage, we have no idea where he is on the waiting list or how long the wait will be. It's dreadful.



National Lockdown SEND Transport and Other Feedback

Five families provided feedback on SEND Transport of which only one was themed as negative. 15 Further “additional” comments were made.

We have had some previous issues with the central team of the current provider, *name removed*, but nothing recently and our driver and PA have always been brilliant, and very understanding.

SEN Transport

I find it incredible the sustain that ***Service provider name removed*** has shown the professionals including our SW throughout this process, it's resistance to impart any info on the process and give any indication of likely wait times despite the reiterated urgency. I readily understand that COVID has turned everyone's world upside down but the lack of service is putting our kids at greater risk longer term and creating situations which could and should be dealt with better.

Additional comment

I think Essex county council have been really helpful, as during lockdown I have been receiving paperwork for school place and transport for going up to secondary school.

My sons school is where a little improvement could be made if a lockdown happens again. Rather than the headteacher posing in the paper 📰. Classes happened virtually, so I would have thought interventions or even check-ins could have happened.

Additional comment – split into two parts

Name removed company are an awful company so many negative experiences that I removed my son from transport no struggle to get him to school, no support available

SEN Transport

I would like the family as a whole more involved and listened too, as well as more support for parents from an early age, not just after diagnosis or once the behaviour is too serious to ignore. Prevention rather than cure. Listen more to parents they know their child. I only saw a health visitors a handful of times when he was a baby then nothing. I was on my own. Some support from children centers but only because I went looking for it myself and knocked on every door possible. There is not enough help or information or help out there.

Additional Comment

Think there is a long way to go before services and decisions feel fully coproductive. School is very good. Local Authority, social care and NHS need to improve.

Additional Comment

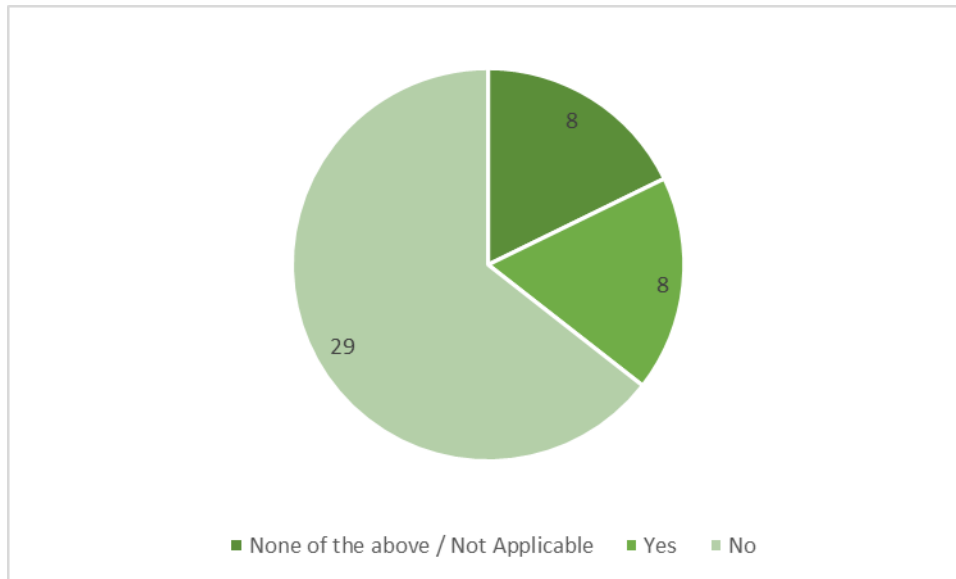
I'm sick of fighting for my daughter since September 2019

Additional Comment



National Lockdown Decision Making

We asked if families felt that decisions made about your child or young person's provision have/are being made co-productively (your views being heard and considered) with you and your child or young person (where appropriate)



Of the 45 people who responded to this question only **8 families** felt that they were included in the decision-making process of their child or young person's provision.

This was a theme which we highlighted in our two COVID specific surveys in the summer of 2020.

General
Education
provision
and services

The following slides relate
to feedback provided
through the above
category



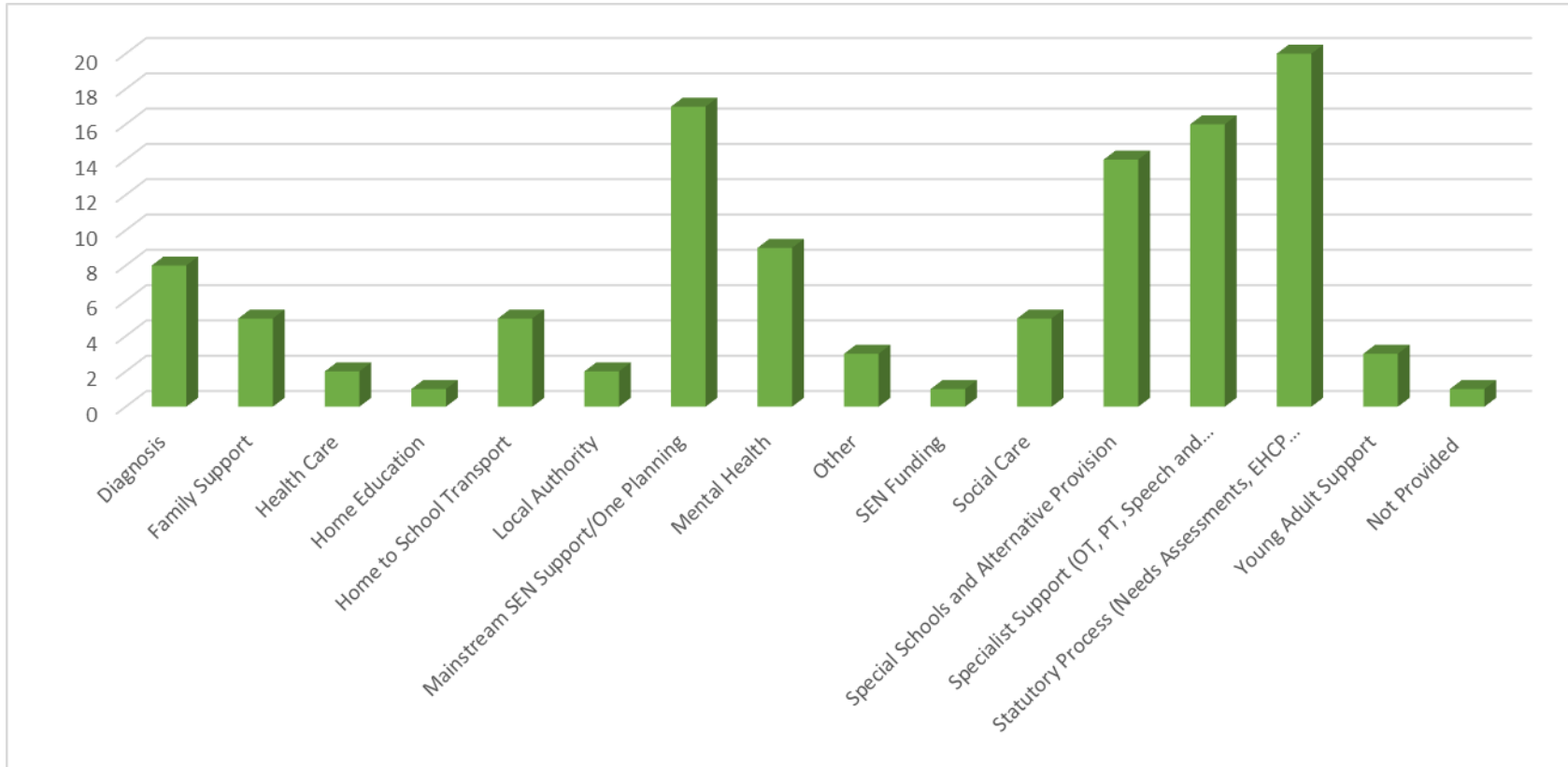
Category Breakdown

We asked Parents to categorise the area that they were providing feedback on, a list of which is provided below. A breakdown of this data set is shown on the next slide.

Special Schools and Alternative Provision	Social Care
Mainstream SEN Support/One Planning	Personal Care
Home Education	Health Care
Communication	Diagnosis
SEND Funding	Specialist Support (OT, PT, Speech and Language, EP's)
Home to School Transport	Family Support
Short Breaks/Respite	Local Authority
Mental Health	Young Adult Support
Statutory Process (Needs Assessments, EHCP Process, EHCP Provision, Annual Review, Tribunals)	Other

Category of Feedback

This shows the feedback we received broken down by category

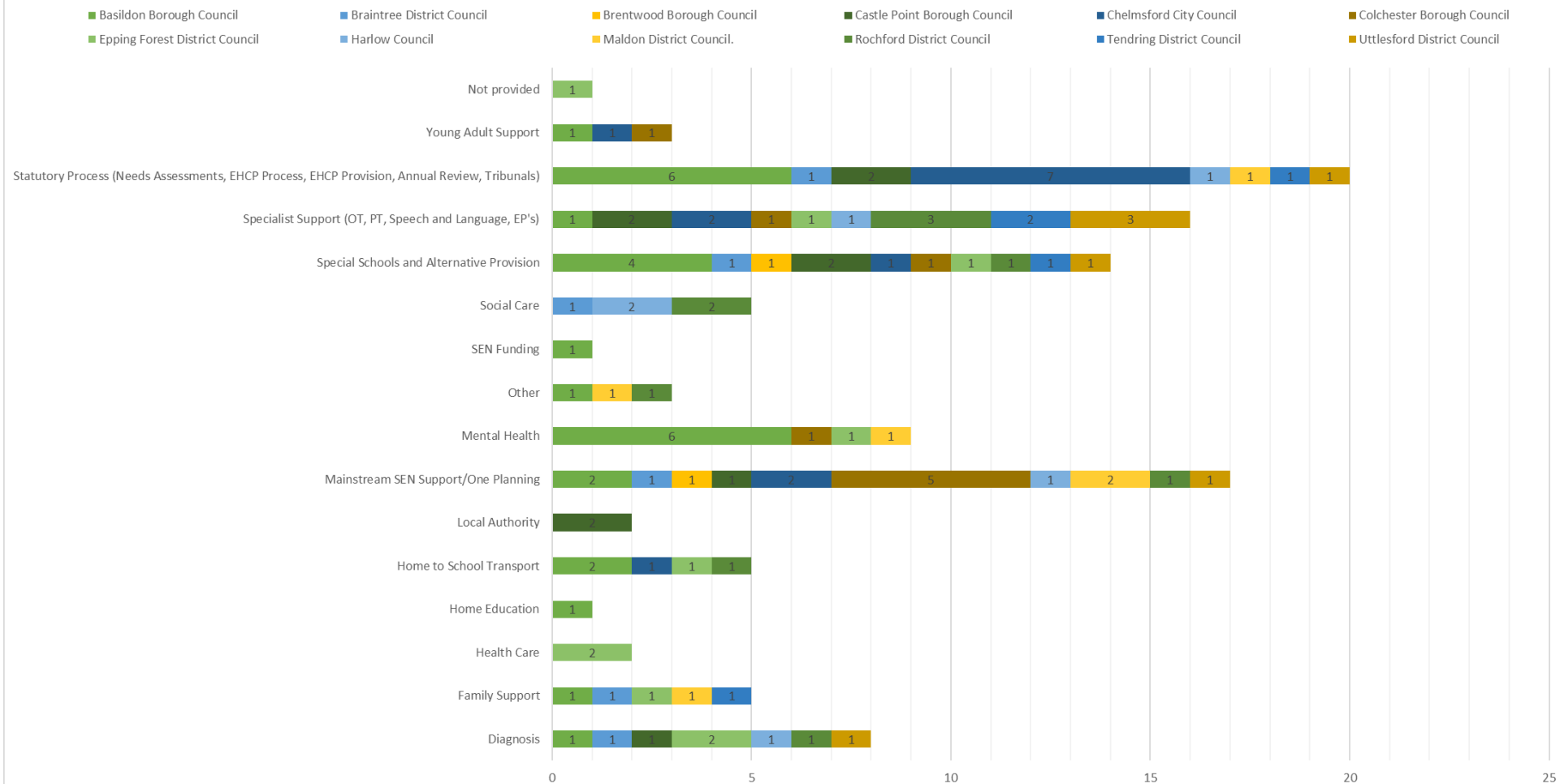


The biggest areas of feedback are:

- Statutory Process (Needs Assessments, EHCP Process, EHCP Provision, Annual Review, Tribunals)
- Mainstream SEN Support/One Planning
- Specialist Support (OT, PT, Speech and Language, EP's)
- Special Schools and Alternative Provision.

Category of Feedback

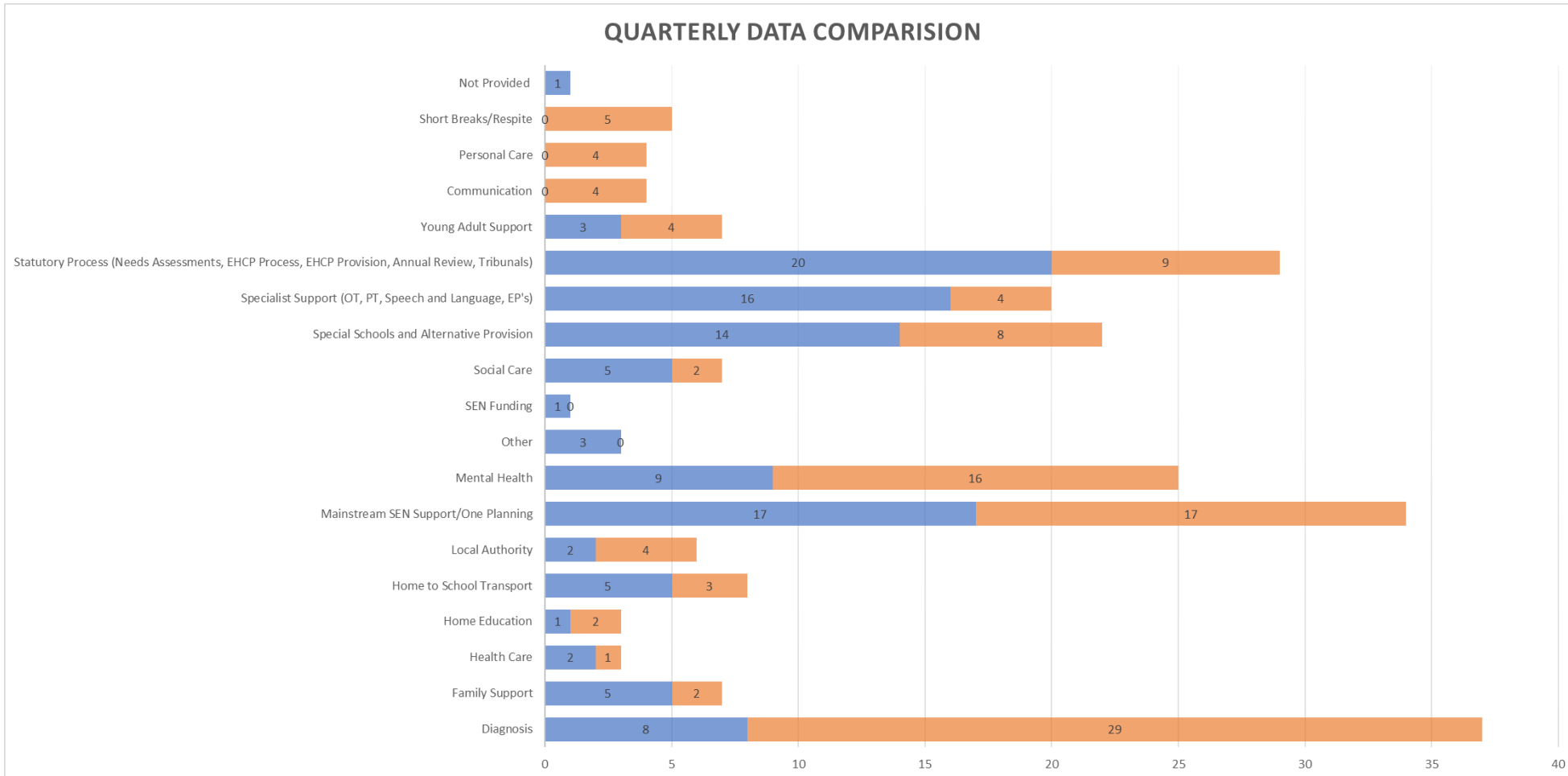
Comments by Category and District



This shows the category of feedback broken as provided by district



Category of Feedback



Quarter 1 Feedback

Quarter 2 Feedback



Analysis of Categories

There has been a significant shift in the category of feedback, we have highlighted key changes:

Increase of Feedback:

- Statutory Process (Needs Assessments, EHCP Process, EHCP Provision, Annual Review, Tribunals) has risen from 9 respondents to 20
- Specialist Support (OT, PT, Speech and Language, EP's) has risen from 4 respondents to 16
- Special Schools and Alternative Provision has risen from 8 respondents to 14

Mainstream SEN Support/One Planning has remained consistent with 17 respondents each quarter

Decrease of Feedback:

- Mental Health feedback decreased from 16 to 9 respondents
- Diagnosis shows the biggest fluctuation from 29 respondents to 8



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

What **is not** working?

- No suitable provision for those unable to cope in mainstream, but not MLD
- Annual Reviews/ Updated EHCP paperwork
- Lack of training of “system” parents and professionals
- EHCNA process
- No School named on EHCP
- Lack of communication from Send Ops teams
- LA not following SEN Code of Practice

I have still not had anything from SEND Ops Team despite continual chasing - Annual Review was in Sept and we have requested a change of school for next Sept (Castle Point Borough Council)

The LA not following the sen code of practice and removing information from needs assessment before going to panel. Not wanting to work with parents and not having a child centred approach (Uttlesford District Council)

Essex is known to have a backlog of work and so they refuse needs assessments to buy themselves more time, however this disadvantages the child- they also repeatedly fail to meet the legal deadlines throughout the process (Chelmsford City Council)

My son has an EHCP but no placement and his case keeps getting left behind. I can't appeal because there is no school named. No school seems to want him and I feel like a ping pong ball being bounced around with no place to go and no-one to help me consistently through the process. (Basildon Borough Council)

It takes far too long and my daughter probably won't get any help as she is "high functioning" but requires support to stay on task. (Tendring District Council)

Lack of training the SENCO's in schools, (they themselves have little knowledge of the process), parents unaware of process, I've had to pay privately for a therapy report to support EHCP transition review. This was completed in October 2020 and I only received the draft amendment of the EHCP 4 weeks ago - as did the nominated secondary school. The EHCP was wholly incorrect and hadn't been amended since inception, despite annual reviews and a very thorough transition review last year. Therapy requirements missing. Asked to sign a transport waiver despite it being our closest school. (Chelmsford City Council)

What **is** working?

- Nothing
- School Annual Review Process
- Communication
- SENDIASS/ Third Party Support

Everyone was in agreement at the Annual Review about what was best for my son (Castle Point Borough Council)

SENDIASS have been brilliant in supporting the process, without them my child would have continued to be failed (Chelmsford City Council)

Nothing here at all. How many years have ECC known about my son? It has been stated in his annual review every year that he is struggling in mainstream. Why has no provision been made for boys like him? (Braintree District Council)

Initial letter sent in a timely manner (Uttlesford District Council)

School annual review process (Chelmsford City Council)

Nothing. EHCP process slow, arduous and disjointed. (Chelmsford City Council)

He got his EHCP finalised in June and that process was good as we had outside support and lots of evidence. (Just no school on it!!) (Basildon Borough Council)

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

What *can be done* to Improve things?

- Create more Hubs/Fund for “HF” ASD provision
- Meet statutory timeframes
- Streamlined process
- Communication

More streamlined service

(Tendring District Council)

Stop moving staff around the LA and if a child has an EHCP but no school named there needs to be a system for them to be picked up on and not left behind for the parent to chase all the time. The LA should contact parents periodically to touch base with the situation as part of the course. I wait months for contact and then have to call them. More initiative and consistency on their part. And stop dropping jobs and funding for this area in education. We need more help with provisions, not less. More funding for SEN please.
(Basildon Borough Council)

Either schools set up for HF ASD children, or a hub in each secondary mainstream where these children can do online learning, rather like the current home learning, and access the other children for other, less academic lessons

(Braintree District Council)

There are too many people involved in the process and nobody knows what the right arm is doing. School hold annual review and send off paperwork to county, but schools don't know what county do with the paperwork or what is needed. It appears I am responsible for arranging input from OT or other professional services. In particular, the most recent annual review for secondary transition was incredibly difficult as local services refused to engage and I therefore had to pay privately for a physiotherapist report. This was provided to the school but not sent off to county because they didn't know it was required?! Then someone from county is supposed to re-write the report based on the notes made at review (someone who has never met the child). At some point someone somewhere refuses/agrees to new outcomes etc, but it's not clear who and then eventually a draft copy is sent out. I would suggest this process is not fit for purpose. A friend has had to go to tribunal because county has failed to update the EHCP to LESSEN the outcomes..that means the child needs less support or significantly different support than contained in the EHCP because it hasn't been updated in 6 years despite the annual reviews.

(Chelmsford City Council)

Need to improve communication from SEND Ops Team - timeliness & way of communicating. Parents should not have to chase everything.

(Castle Point Borough Council)

Work with parents and follow the Sen code of practice

(Uttlesford District Council)

Actually care about the child and their needs rather than having the overriding factor always being about saving money, stop placing parents under additional stress having to fight for basic support for their child when the needs have been identified
(Chelmsford City Council)

EHCP documents need to be updated yearly

(Chelmsford City Council)

Mainstream SEN Support Feedback

What **is not** working?

- Lack of understanding and support for CYP needs from School
- One plan – not collaborative
- Communication
- Provision not being delivered/strategies not being followed

*child showing high anxiety and not well enough for school. school insisting on note from GP to confirm absence. GP states that sick note should not be required. Parent suffering additional stress because of lack of clarity
(Basildon Borough Council)*

*School are still pushing trying to keep (boy 9) in class for learning despite his EHCP outlining his aural sensory issues, parent saying he can't cope and writing on his behalf in his "communication book". He's flown out of class a few times towards end of last week. Friday teacher still echoing same goal. I'm giving them today to see if attitude will adjust otherwise parent will pull him out. He was crying that the class is too loud for him. They see he has coped for small amounts of time and jump to "he can cope all of the time" conclusion. His coke bottle is now fizzing away.
(Basildon Borough Council)*

*Numerous conversations with school about daughter not receiving provision in EHCP, getting no where, dont know what to do next.
(Harlow Council)*

One planning - plan doesn't reflect a child's needs. - hadn't read a report provided in November ahead of one planning meeting in Dec and again in January so recommendations not included in the plan (or discussed) The meeting was 10 mins with the teacher and Senco - so I couldn't even discuss the recommendations provided. Again the meeting was focusing on the action and the do - rather than the "review" (Colchester Borough Council)

What **is** working?

- Understanding of needs
- Small class (covid)
- Strategies put in place
- Families in Focus support
- One Plan meetings

*We are a supportive family and are working together to support my daughter. We actively 'wonder' with her about her anxieties and explore these with her. We make it known that it is ok to not feel ok and that making mistakes is ok. My daughter is an amazing girl who goes from strength to strength every day.
(Chelmsford City Council)*

*Class LSA very supportive and "gets" my child - this makes such a HUGE difference. Class LSA provided really good support and social story for the daughter starting her period. LSA good communicator One plan stripped right back (at my request) Transition into school managed well with a specific routine Communication book detailing her day - this aids us at home to have positive conversations about their school day to reinforce daily achievements
(Colchester Borough Council)*

*For us, not a great deal at the moment.
(Uttlesford District Council)*

*The independent autism specialist input brought in by school.
(Rochford District Council)*

*Families in Focus are supporting us. We are finally able to ask the questions and they are slowly starting to listen and answer.
(Colchester Borough Council)*

Mainstream SEN Support Feedback

What *can be done* to improve things?

- Appropriate support and recommendations followed
- Parents to feel listened to and believed
- Training and understanding of needs
- Improved one planning

School taking on board their own independent professionals advise...

(Rochford District Council)

More staff to cope with SEN children Training for management in SEN . Compassion / change of attitude One plan targets should be made enforceable

(Castle Point Borough Council)

Send one plan documentation ahead of meetings Continue with current efforts of support and levels of communication

(Colchesterr Borough Council)

A better understanding of anxiety, dyslexic needs Differentiate work (spellings/home school work remote learning) read reports ahead of meeting so can have a productive discussion rather than not Both Dec and Jan one plans - simply agreed to (so we could actually have a plan!) with both times saying let's revisit this when we have reviewed the report provided.
(Colchester Borough Council)

Schools need to prove they have put strategies in place, not just written a report to sat they have.
(Uttlesford District Council)

A set format for one planning. More training in school on sensory needs. My son was called disgusting for trying to meet a Sensory need by a member of staff. She, clearly lacks understanding.
(Colchester Borough Council)

clear guidance of who to speak to if your having problems with school meeting needs of EHCP.
(Harlow Council)

As parents, we were made to feel that our concerns for our daughter were our fault. We were made to feel to 'blame' for her anxiety and mutism and during our consultation with EWMHS, were clearly told that the practitioner disagreed with paediatrician (which left us confused). No support has ever been offered to us since this initial consultation. School are very reluctant and don't see my daughters difficulties as an issue. She is compliant, well behaved and quiet.

(Chelmsford City Council)

Feel belived and that my child feels safe and not a problem when an issue arises

(Maldon District Council)

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

What **is not** working?

- Sensory Provision
- Access to services
- Provision for selective mutism
- Hourly Provision in EHCP covering report writing
- Regular appointments

No sensory specific support, Sen schools should have regular OT sensory training and be involved with specific children to help support their needs as they often are missed as a trigger for behaviour or child suffers in silence, even when it's specifically mentioned in an EHCP the child isn't receiving or sensory support as staff do not understand the effect it has in children
(Rochford District Council)

My son has for a long time been a selective mute, would not answer questions in school, ask for help or speak up. This was also true outside of the classroom. We had no support for this, school said SLT not necessary and he would speak when he wants to. He was under EWMHS but they didn't address this either
(Castle Point Borough Council)

There isn't any specialist support in the community so you have to get a place in a special school and then they don't get any qualifications.
(Tendring District Council)

SLT told us the 15 hrs specified in my daughters EHCP were not just face to face hrs but included report writing, paperwork etc which we didn't know. They also stopped inviting me to appointments in school, when I previously attended. This was before covid restrictions.
(Harlow Council)

Minimal appointments for a child with a disability, our physiotherapist left and we have not been reassigned a new one as far as we are aware and we currently do not have any follow up appointments.
(Colchester Borough Council)

What **is** working?

- Equipment provision
- Nothing
- Self referral
- Contact
- Transition to SALT

The transition to salt was very easy however he was discharged from them quiet quickly when the changes came in around clusters in Essex
(Tendring District Council)

All OT professionals I have met through the service, and I have now met a few have been both professional and caring. An insight in to fine and gross motor difficulties and what can be put in place to help. It is too limited still, but what was provided is helpful.
(Rochford District Council)

Nothing. Communication with children's services is almost impossible.
(Chelmsford City Council)

Equipment provision
(Chelmsford City Council)

School self referral for KS4 needs to the Epping Forest team has been successful and their support has been excellent. However, this support should have been in place for these children years before they ended up in Alternative Provision.
(Epping Forest School)

Being able to schedule a call eventually
(Uttlesford District Council)

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

What *can be done* to improve things?

- Regular and appropriate access
- Joined up working
- Sensory needs training for support staff
- Investment
- Suitable educational provision
- Communication

*Selective mutism to be considered as a Special Educational Need and provision be made accordingly, with support for families.
(Castle Point Borough Council)*

*Communication about what is happening with the service and how they are trying to accommodate for another physiotherapist. I understand some staff have been redeployed but many parents feel their children have been forgotten.
(Colchester Borough Council)*

*Should stop trying to fit MLD children to SLD provisions instead providing more funding to increase provisions in each sector. That option demeans the children and LEA cannot adopt a 'this will do' approach towards children with special needs.
(Basildon Borough Council)*

*A stream lined transition with dedicated teams to pick up new children coming in to the areas and sign posting where to go from there.
(Tendring District Council)*

*All children living with a life long disability should have access to the therapy needed to help them thrive. Clearly there is either an issue with funding, the way the funds are managed or simply incompetence.
(Chelmsford City Council)*

*These professionals should be given the time to provide 121s, true therapies and frequent follow ups in person. Please employ more professionals and ensure the processes are not that time consuming for the therapists and at the other end, in the life of a child that requires professional support
(Uttlesford District Council)*

*OT sensory training for all staff who support Sen children to make them aware that many behaviours are actually unrecognised sensory needs
(Rochford District Council)*

*Joined up CCGs - stay within current services where possible until can be transferred. Better communication with families on this process.
(Castle Point Borough Council)*

*Well you could start by actually providing regular hands on therapy for children. Unless you can provide it regularly, you may as well not do it at all and put the money into other areas. You're achieving nothing for our kids, with the service how it currently is
(Chelmsford City Council)*

Special Schools Feedback

What **is not** working?

- Communication
- Lack of suitable provision (Special and Hubs)
- Training in family support required
- TAC meetings should be used
- Blanket offer rather than follow individual EHCP
- Lack of SALT

There are no suitable school provision for my year 4 autistic son who is academically able but struggles hugely with anxiety and emotional regulation. Currently is in mainstream as unable to identify a more appropriate placement in our locality. All seem geared towards learning difficulties or semh with nothing that fits my child. Endeavour have said during an informal chat that he would not suit their provision due to his behavioral and emotional needs and milwards hub has closed or is closing. Even send ops said they were not aware of a suitable placement in our vicinity. Tragically he has now pretty much had it with school and is refusing to engage and attend. This is due to unmet needs. He has no social interaction with his peers as they think very differently to him and the gap in his social skills development and theirs is only widening. He hates school so much that he says he doesnt want to be alive anymore yet there is nowhere else for him. I could attempt to homeschool but I cannot give him everything he would get from school. However, if his mental health continues to deteriorate due to an inappropriate school placement I have no choice. Sadly he will suffer either way and that just doesnt seem right. He has the right to an education like any other child. He didnt choose to be autistic!
(Epping Forest District Council)

*What is being done to update training in SEN schools to follow individual EHCPs rather than have a blanket support/policy because that 'has always worked' for them. Especially because children now have more complex issues (rather than one learning difficulty) - for withren withMLD in a SEN school
(Castle Point Borough Council)*

*Lack of specific autism provision. Lack of speech and language therapy.
(Uttlesford District Council)*

*Approved for semh provision in March 2020. 1 year on and still no consultations sent out. They have agreed to independent provision but won't reply to emails and failed to attend cin meeting to answer what is happening.
(Basildon Borough Council)*

*It took almost 2 years to secure a place for my son. This means that he only has 2 years of his secondary education left. Rather than allowing him time to catch up with his education and allowing him an additional year of secondary education to gain some kind of end qualifications, he is having to make do with what's left of his final two years. This has significantly reduced his ability to achieve any end qualifications.
(Tendring District Council)*

What **is** working?

- Not a lot
- Happy Child
- Supportive
- Agreed without tribunal

*My daughter seems happy to go.
(Uttlesford District Council)*

*Independent provision agreed without need for tribunal as lea have advised no semh provision for girls in essex
(Basildon Borough Council)*

*Not a lot
(Basildon Borough Council)*

*The school that he is now placed in are supporting him really well and he is very happy.
(Tendring District Council)*

Special Schools Feedback

What *can be done* to improve things?

- Deliver provision as per EHCP
- Make the services such as OT, SALT accessible
- Communication
- Statutory process
- Suitable Provision

The process of getting an EHCP and an accompanying school placement needs to be quicker and the Local Authority need to be honest with parents rather than with holding services and deliberately misleading parents.
(Tendring District Council)

Need to have service level agreements and then stick to them. Resource adequately until you can stick to them.
(Chelmsford City Council)

More personalised therapy and interaction from other services such as OT
(Basildon Borough Council)

LA should have more provision for children like my son. I appreciate that everything was geared towards integrating children with additional needs into mainstream provision but it is not working for us, nor has it been working for a number of years. Private sen schools can offer this so why cant the local authority??
(Epping Forest District Council)

**School name removed* have been amazing so far*
(Basildon Borough Council)

Deliver the 1:1 support for a start!
(Braintree District Council)

Put in SLT urgently. Put in OT's. Make the services accessible.
(Basildon Borough Council)

Respond to emails attend meetings but most of all when you undertake to do something actually do it.
(Basildon Borough Council)

Provision of more SEN schools. LA stop wasting money employing barristers to represent them at tribunal and utilise that money to fund more spaces
(Basildon Borough Council)

Mental Health Feedback



What *is not* working?

- Lack of support
- EWMHS not fit for purpose
- Needs too complex for lower tier services and refused support from EWMHS
- Lack of information about services
- Bounced between, schools, GP, EWMHS, Charities and no one accepts CYP

EWMHS are not fit for purpose. Refused to offer any support beyond a generic CBT course and just parent blamed for child's difficulties. Disgusting
(Basildon Borough Council)

Teenage child with anxiety and depression struggling at school. School who felt child's needs were too complex and that they needed specialist input, so advised parents to ask GP for referral to EWMHS - EWMHS refused to accept the referral and said that school should be supporting the child.
(Basildon Borough Council)

My daughter is in severe school refusal. EWMHS simply told me there are thousands of children who feel the same, and to go to a local charity for counselling. The GP say they can't do anything because she won't engage. We are stuck.
(Epping Forest District Council)

child with asd referred to ewmhs 4 times but they just signposted other services to help and discharged child each time. eventually given 10 sessions with kids inspire which were useful but child needed many more. child is now angry and feels abandoned. the gp advised family counselling is needed but ewmhs have advised that nothing is available.
(Basildon Borough Council)

What *is* working?

- Nothing
- Telephone assessor
- School

Nothing!
(Colchester Borough Council)
(Epping Forest District Council)
(Maldon District Council.)

The Ewmhs service is awful. We have had four years of stress while our child has been under Ewmhs. They did not listen to us at any point and spent more time trying to blame us for our child's condition than they did trying to help us solve the issues. We saw a different person every time, they had never read the notes and we had to repeat ourselves again and again and again. At 6, our daughter was placed in groups that were inappropriate for her age and stage of development (with 10/11 year olds), and when we raised concerns that the groups weren't appropriate we were labelled as 'anxious parents' and not offered any alternative. In desperation after three years we paid thousands of pounds for private assessments and she was diagnosed with adhd and anxiety disorder. A very clear treatment pathway was recommended for her and we returned to the nhs with this. We received no help whatsoever and we're told that as she had been diagnosed with adhd (and subsequently ASD) it was 'just the way she was' and they wouldn't/couldn't offer anything, never mind the suggested treatment pathway as recommended in her private assessment. There is no mental health support for children with adhd/ASD. Why? They are entitled to mental health support just the same as neurotypical children. They should really have better support due to their vulnerability to mental health conditions. Why is it ok to discriminate against our children because of their conditions? I just don't understand. Where do we go for support? (Colchester Borough Council)

The senior school have been on the ball and supportive. The telephone assessor was very good.
(Basildon Borough Council)

Mental Health Feedback



What *can be done* to improve things?

- Overhaul the service
- Qualified staff
- Support in timely manor
- Tell it once approach
- Clear pathway/treatment plan
- Increased understanding for school refusal

A clear treatment pathway for children with autism/adhd, that takes account of their condition and often high anxiety. Early intervention is key. Our children shouldn't have to develop very severe mental health conditions before they can access treatment. I would also like to see a single allocated worker that walks with a family through the whole process. We were so sick of having to tell our story again and again. No one read the notes or spoke to each other and we felt totally worthless
(Colchester Borough Council)

More qualified staff to be able to cope properly with demand for these services in a timely manner in order to avoid situations worsening to self harm and suicide attempts
(Basildon Borough Council)

Overhaul the service. Contact families who have been discharged or refused support for their experiences
(Maldon District Council.)

A greater understanding of the causes of school refusal, take blame away, support the parents who are in pain watching their child suffer so badly and then have to cope with the pressure from schools to get their child to attend, increase budgets and teams to provide the help needed. Have a greater offering for alternatives to mainstream education, especially for those with a social anxiety where secondary school is too big and overwhelming.
(Epping Forest District Council)

Diagnosis Feedback

What **is not** working?

- Waiting times
- Lack of support
- Communication
- Post code lottery

*My daughter is almost 12. Still not able to get a multi disciplinary assessment even after going to my local MP
(Castle Point Borough Council)*

*We have been put on the Jades pathway and were told someone would contact us and give support while awaiting diagnosis and we have heard nothing. We don't know what we should be doing or how to help our son.
(Harlow Council)*

*In A and E a psychiatric doctor told us my son as ASD,ADHD and Extreme anxiety. Even with this we are still waiting for a diagnosis because they say he needs to go through process that can take over a year!
(Epping Forest District Council)*

*After a year of having an assessment still no outcome or any feedback or commutation after numerous calls made and calls promised back
(Rochford District Council)*

What **is** working?

- Communication
- Nothing
- OT Assessment
- Contact
- Transition to SALT

*Acknowledgment of the assessment request was provided in a timely manner
(Uttlesford District Council)*

*Nothing im stuck in limbo with not knowing where to go or who to talk to about it
(Rochford District Council)*

*Being told to wait for an assessment no less than 18 months. It's heartbreaking enough to wait that long and not getting the support needed until then
(Uttlesford District Council)*

*I've been trying to access assessments and a formal diagnosis for my son for six years now. He was under a paediatrician from two and he turns eight next week. He has only just began to grasp reading and can barely write. It has taken the school a while to agree to an EHCP and when the wheels were put in motion we went into lock down which has inevitably delayed everything. I feel as though he has been left to fall in between the gaps and fall further and further behind his peers. I feel resentful he has no diagnosis or ECHP despite all his problems.. it really seems to be a postcode lottery as to what help you get. If he did have this help he could have possibly been in school during Covid but instead he's just been at home with me falling further behind as without the routine and structure of school he refuses to learn anything. Life is not good for me either. He refuses to go out.. when he does go out he constantly moans at me and gets angry.. even going to get basic supplies is a challenge. I'm a single mum and life isn't easy.. some days I feel furious at the system!! I don't think it's likely he'll get his Jades assessment anytime in the near future now due to general waiting lists and Covid.
(Epping Forest District Council)*

*The OT assessment helped tremendously.. AnnaLyn at St Margaret's has been an amazing support. We also saw a physio which was equally as supportive and helpful. These services are great, it's the assessment process and school support that lets it all down
(Epping Forest District Council)*

*Good services when they become available.
(Braintree District Council)*

Diagnosis Feedback

What *can be done* to improve things?

- Deliver provision as per EHCP
- Make the services such as OT, SALT accessible
- Communication
- Statutory process
- Suitable Provision

*Waiting times
(Braintree District Council)*

*There need to be more paediatric centres with adequate staff and enough funding and referrals should not be refused over and over
(Castle Point Borough Council)*

*Provide at least 121 sessions to support an individual until an assessment initiates and not just giving guidance and websites the family has to go through and try to implement things when our roles are to support our child and we are not health professionals and could implement the suggestions incorrectly
(Uttlesford District Council)*

*More appointments and more multidisciplinary interventions. I dont understand why when a psychiatrist has diagnosed we how to still go through another long winded process
(Epping Forest District Council)*

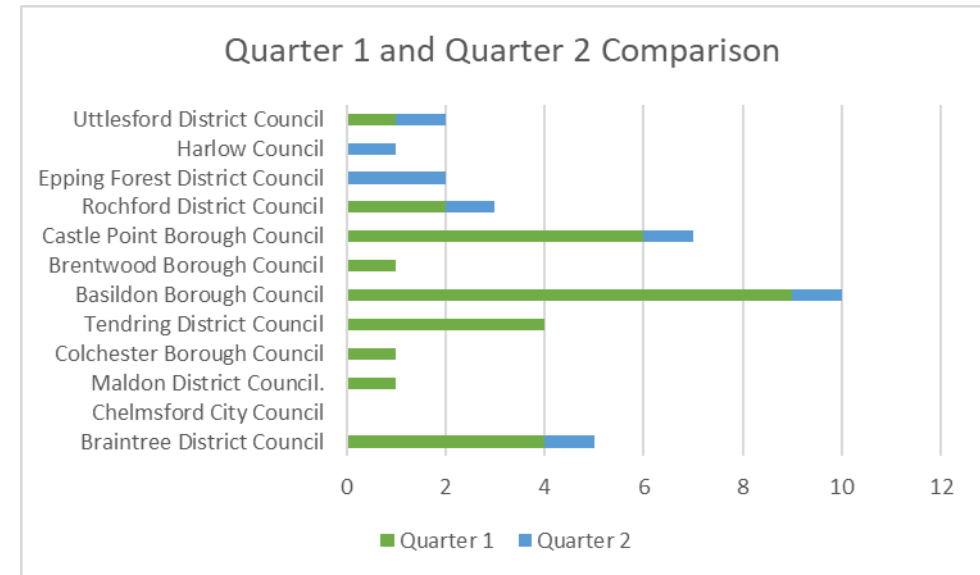
*Quicker assessment process.. more support from schools and the can't do attitude towards parents wanting EHCP needs to improve. More support for parents
(Epping Forest District Council)*

*contact and support whilst waiting for diagnosis
(Harlow Council)*

*Everything especially communication
(Rochford District Council)*

There has been a significant shift in both the amount and geographical location of feedback

From 29 respondents in quarter 1 to 8 in quarter 2



Other Feedback

(to include Family Support Health Care, Home Education, Home to School Transport, Local Authority, SEN Funding, Social Care, Young Adult Support)

What *is not* working?

- Lack of a joined-up approach
- Turnover of social workers
- Lack of focus on Preparing for Adulthood /Post – 16 options
- Changes in staff (SEND Transport)
- Lack of understanding of SEND Behaviours on SEND Transport
- Communication from SEND Operations
- Lack of family support
- Lack of SEN funding within Early Years
- Support for difficult behaviour
- Social Care assessments
- SEND Transport Refusal
- Social Care support
- Listened to – BAME Community
- Lack of support for Tics and Tourette's

*Families that need support with CYP challenging behaviour cannot access the great support from SC behaviour teams because referrals need to be made by a Social Worker and they dont meet criteria for CWD team so cannot get a SW.
(Harlow Council)*

*No clear pathway or local provision for Tics and Tourette's syndrome There are currently only 3 centres in the UK that can fully help children with TS and those who require a proper assessment for the condition. These centres are based in: · Sheffield Children's Hospital (who are no longer accepting referrals for children with TS due to capacity issues) · Great Ormand Street Children's Hospital London · St *child name removed*s Hospital in London There are no NICE Guidelines for Tourette's Syndrome. (Colchester Borough Council)*

*Pre-school SEN funding does not sufficiently support nurseries well enough. As a result, preschoolers, with SEN, do not have their needs met and are not able to have the same education as their peers.
(Basildon Borough Council)*

It has taken a long time for my daughter to be diagnosed with ADHD, in fact it was only around a month ago. She is 18. The GP finally referred her, then she got has a video consultation with a doctor where she spent an hour talking and she diagnosed her with ADHD and general anxiety. Straight away she put her on medication, and now my daughter has to fill a form in each week with weight, blood pressure and any side effects she feels. The issue I have is yes she is 18 but she is younger than her years. The doctor won't talk to me, my daughter isn't sure if she feels any different and she forgets the meds or she forgets to eat so then won't take the meds (although overall she has done well). She has been left to just take these medications but with no support, where can she go for support? Can she can get any financial help (because that's another issue she can't get a little job because her anxiety is suffering, she struggles socially). I feel we have waited for this diagnosis for a long time and now we have it we are left with it. (Colchester Borough Council)

*Social care system. Social workers change like the wind. Question for you - do your socials have SEND children? If not why are you expecting them to understand our situation. Unless you live it, you don't understand it. Criteria of get help. What is it? Who are the panel that make decisions on our life's.? Why do you always have to be reactive to situations when being proactive is better for all.
(Braintree District Council)*

*Lack of communication from SEND Operations Team. They do not reply to emails despite chasing and escalation.
(Castle Point Borough Council)*

*My 9 year old son with ASC behaviour had become violent during lockdown including extreme OCD which he has always had. His dad pushed to get a referral from the GP to EWMHS, EWMHS send a generic letter turning him down for an appointment. This is unacceptable, families shouldn't have to struggle alone in crisis.
(Rochford District Council)*

Other Feedback

(to include Family Support Health Care, Home Education, Home to School Transport, Local Authority, SEN Funding, Social Care, Young Adult Support)

What *is* working?

- SENCOs
- Parent support groups
- Nothing
- Correct absence code
- Short Breaks Clubs
- Specific Special Schools
- Specific Transport Provider
- Transport Education Awards Team
- Paying for Private support

*The occasional good senco and the existence of parent support groups
(Maldon District Council.)*

*Nothing! Because we have to go through ever hoop, climb ever mountain etc to get thereg.
(Braintree District Council)*

*My son as mentioned is very dependent, the one to one help he gets in college is brilliant. I just wish he had the help to not need one to one anymore.
(Chelmsford City Council)*

*Nothing, atm School agrees to correct absence code
(Rochford District Council)*

***Name removed**the transport provider, are great. They are helpful and try to be as accommodating as they can with any queries.
(Basildon Borough Council)*

*For the first time ever - I am amazed by ECC Transport Education Awards!!! Emailed about a pro-rata refund for the Spring term's Post 16 Transport - got a phone call telling me I don't need to pay for the summer term because of the disruption. Fantastic
(Basildon Borough Council).*

*Paying for private support.
(Basildon Borough Council)*

*There's nothing to work as there are no family support services
(Tendring District Council)*

*My son's school * name removed* is a fantastic support, as well as *Name removed* club in Hockley, the staff are well trained and empathetic to disabilities.
(Rochford District Council)*

*The senco at **Name removed** primary school, and her team, are brilliant. They use the funding from the ehcp plan to great effect. The SALT from ** Servive provider name removed ** is also very good. Dr S**Name removed** from CDAC also supportive re medication and referrals where necessary.
(Epping Forest District Council)*

*The school is amazing for my son. We couldn't be happier. It was a fight to get in but worth it.
(Epping Forest District Council)*

Other Feedback

(to include Family Support Health Care, Home Education, Home to School Transport, Local Authority, SEN Funding, Social Care, Young Adult Support)

What *can be done* to improve things?

- Consistent provision across all geographic locations
- Follow law and guidance
- Lower criteria for CWDT
- Early Family Support
- Specialist teaching support
- Communication
- Listen to Families
- Improved respite
- Provide appropriate support
- Improved signposting and information to navigate the system

*For ECC to stop acting unlawfully.
(Basildon Borough Council)*

*Lower the criteria for Sen kids to receive support under CWDT to include complex cases
(Rochford District Council)*

Stop neglecting the Dengie area Stop neglecting post 16 options One of my children travels 50 miles to school as there's no suitable provision closer. There needs to be some options for those who fall between mainstream and MLD etc Stop wasting money on services that add nothing, like preparing for adulthood (Maldon District Council.)

*Give back the early family support you ditched . Being back specialist teachers and thier supporting staff
(Tendring District Council)*

Provide in home expertise and support/breaks. (Epping Forest District Council)

*Action speak louder than words!
(Braintree District Council)*

The only thing I would say is that ECC could have changed their standard letter when requesting payment for the Summer term - realise some Post 16 students will have been attending school during the lockdown so couldn't have granted refunds to everyone, but it did not mention the possibility at all. (SEND Transport) (Basildon Borough Council)

They need to stop saying no! Those paid to help us, hinder us. I have to do the research, find out what help there is, spend hours of my week complaining, emailing, begging, calling... signposted to completely unsuitable services who are confused when I tell them I was told to ring them. Placated with phone calls from people higher up who just take longer and use more words... to ultimately still say no. I dread to think how must it costs the tax payer. All these man hours spent saying no to people instead of helping them. Not to mention the legal fees once parents eventually have to take that route. Imagine the services that could've been funded with that money. The help SEND CYP could have. Also education, health, and care need to talk to each other. They need to be aware of who offers what and who is responsible for what. Stop passing the buck. And let SEND CYP have a personal budget to fund services that can only be accessed privately. Let them have direct payments. That is what they are there for. Like SaLT and OT, the NHS does not provide that kind of help to autistic teenagers! (Chelmsford City Council)

*Families need to be taken seriously and not turned away when they reach out for help. Respite is needed for families that have little support as it can be impossible to leave children with disabilities with child minders or even other family members.
(Rochford District Council)*

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 quarterly 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 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.