

# Graffiti Wall

Representing Parental Views on SEND across Essex

Essex Family Forum

Summer Term

April 2022 – August 2022



# 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.

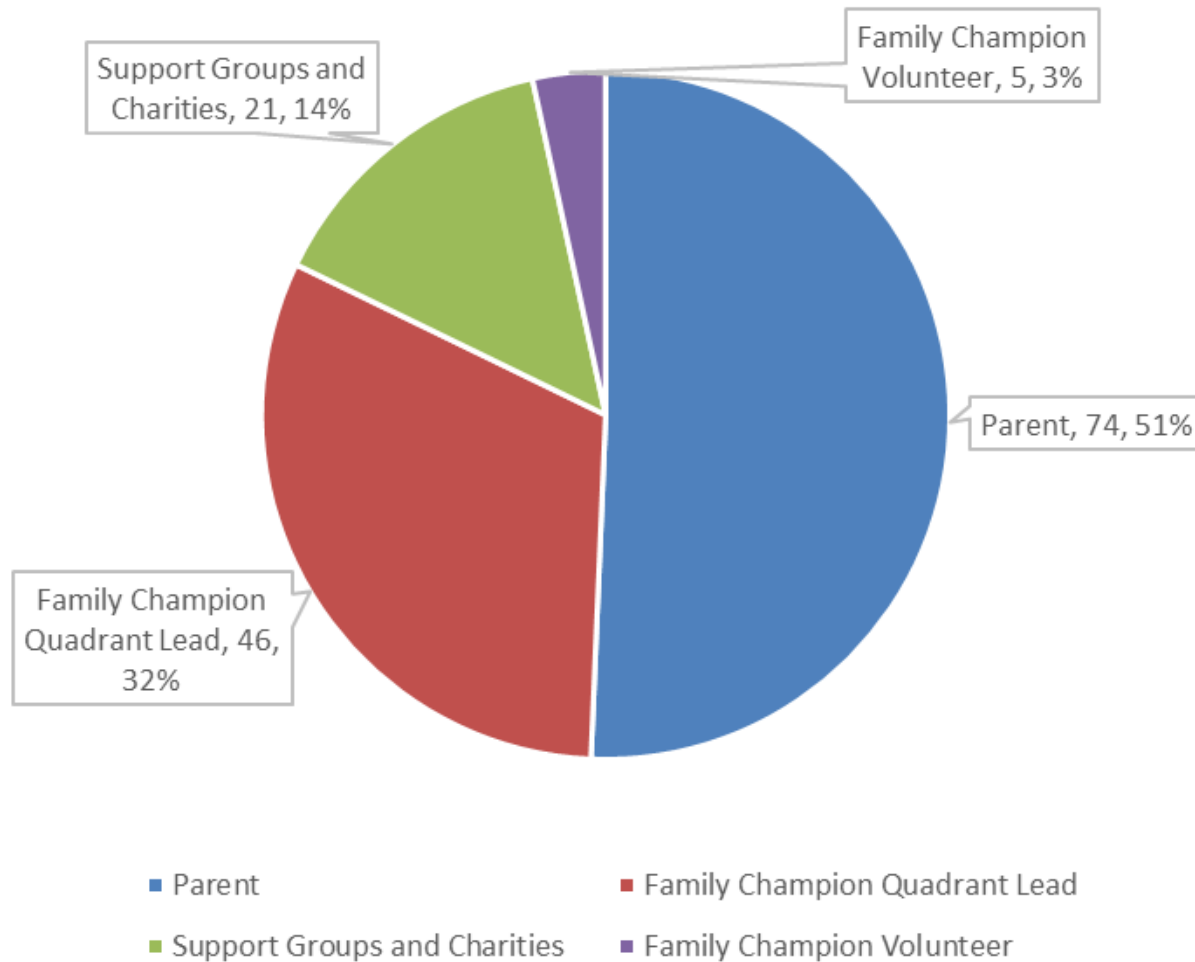
Our virtual Graffiti Wall is located on our website and the link is regularly shared through our social media platforms, Family Champion Leads, and our Family Champions. All parents and carers of children with SEND aged 0-25 are invited to share their views.

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, from whom we require specific feedback on this data that we can share with our Family Champions and with the SEND families in Essex we represent.



# Collection of Data



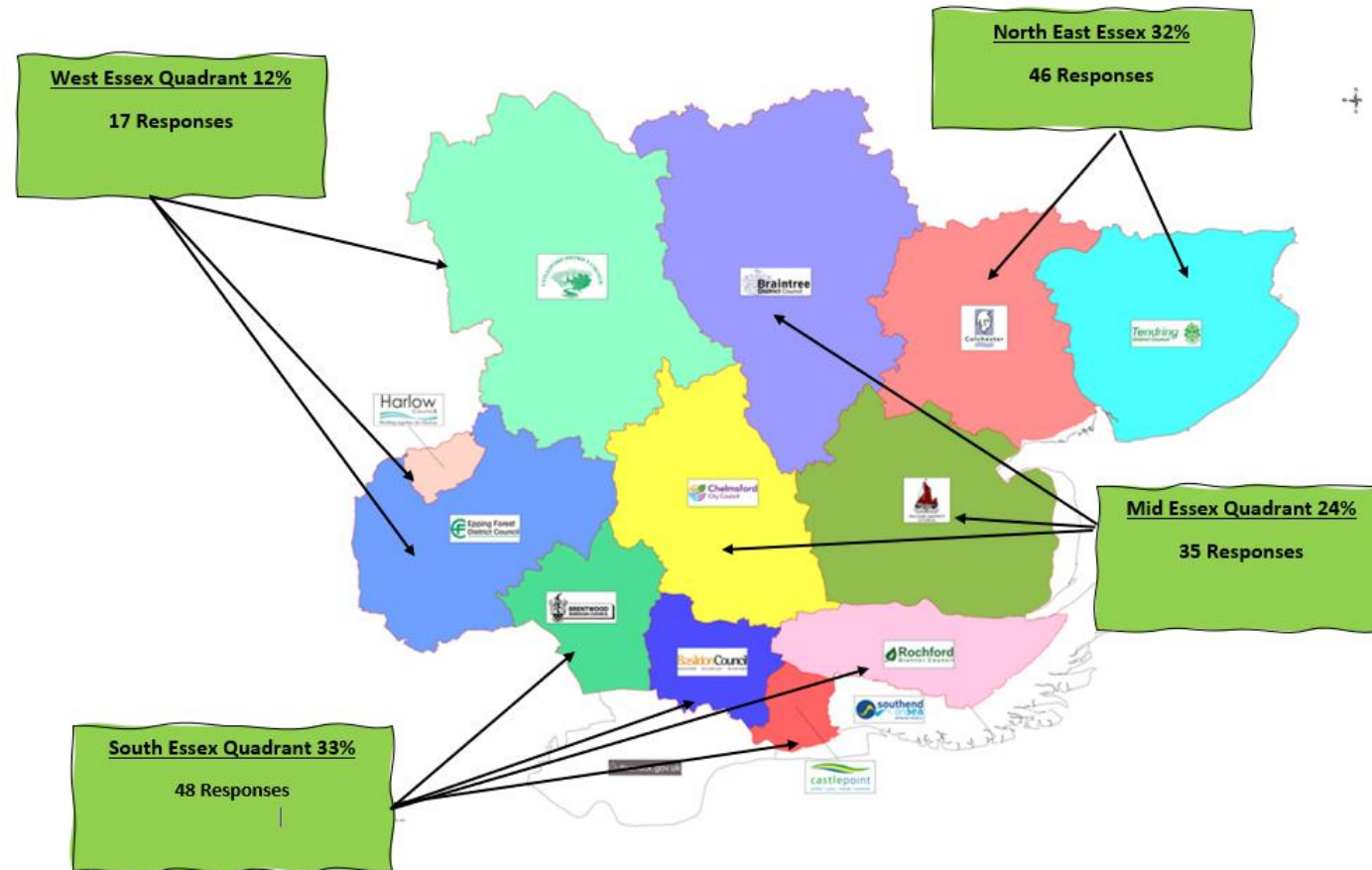
## Valid Entries

Out of 232 overall entries, we had 146 valid entries

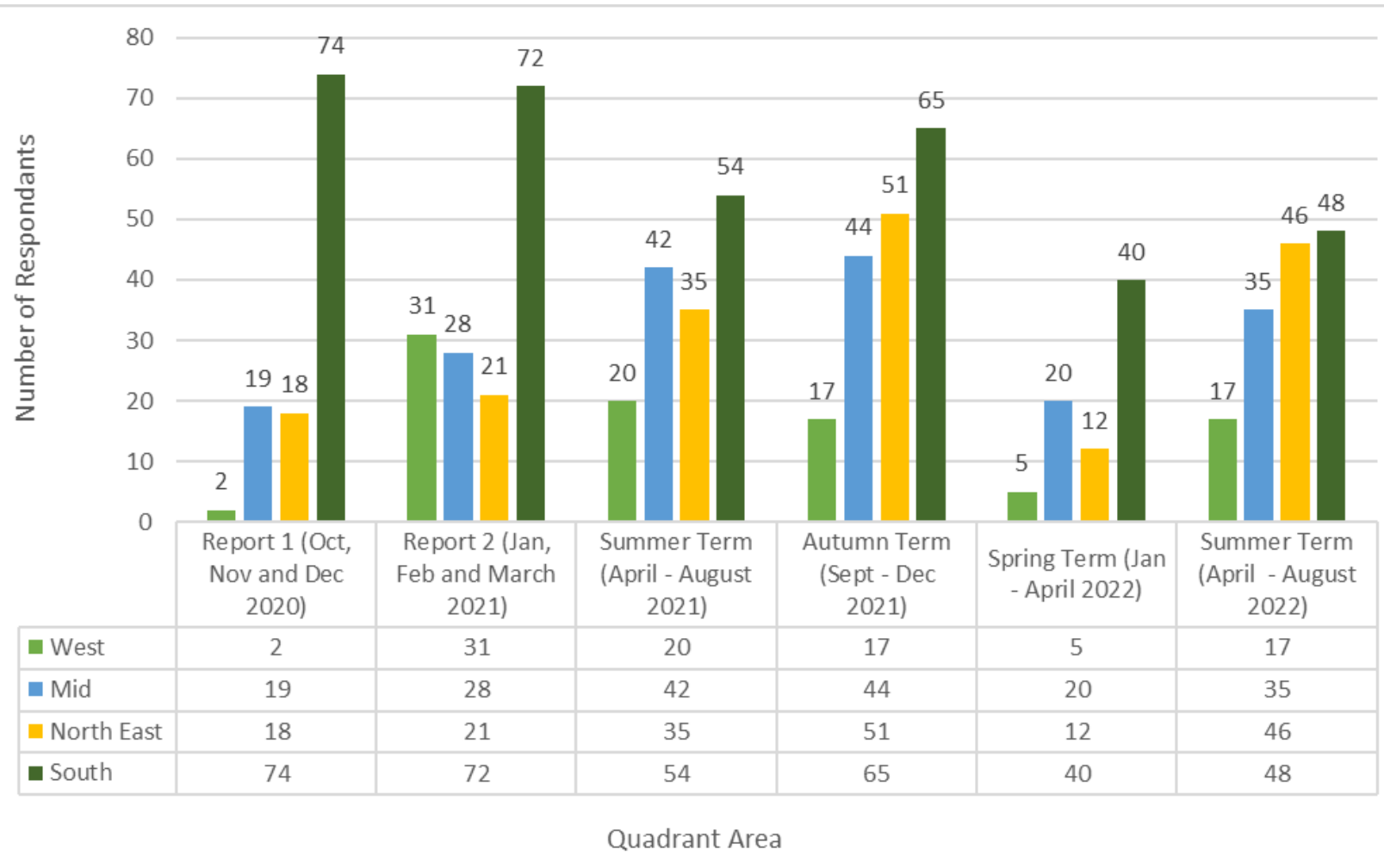
Entries are shown broken down by number of valid entries and by percentage.



# Responses by Area



# Responses by Area



Comparison of valid entries per Graffiti Wall Report by quadrant





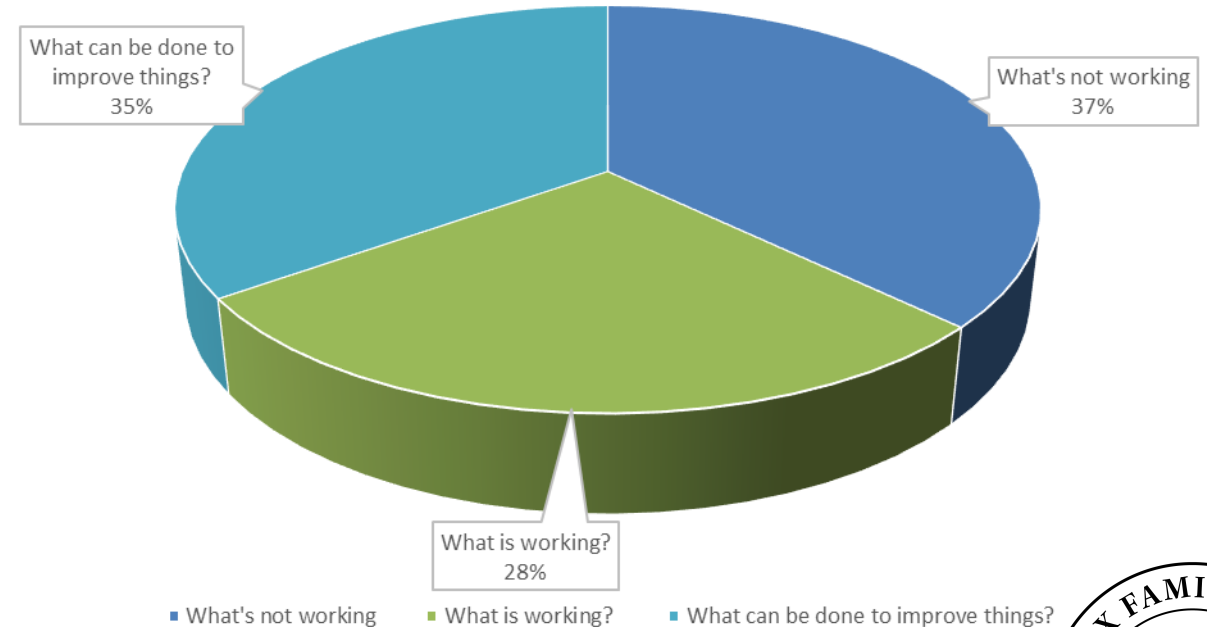
# Category Breakdown and Type of Feedback

We asked parents to categorise the area for which they were providing feedback from pre-existing themes. A total of 385 comments were provided across all themes.

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. It should be noted of the 108 comments we received, 34 were considered negative. For example, *"Nothing. The entire system is broken"*.
- 3. What can be done to improve things?** This is key. This allows us to be able to represent the services and provisions that parents and carers would like to see.

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



# Category of Feedback

Summer Term only

Parents and carers, support groups and charities can select the categories that most applies.

As part of our review of the data we have reviewed the selected category and amend where appropriate to ensure all comments are reflected in the correct category. This is to ease the data being reviewed within the appropriate Co-ordination & Oversight Groups (COGs).

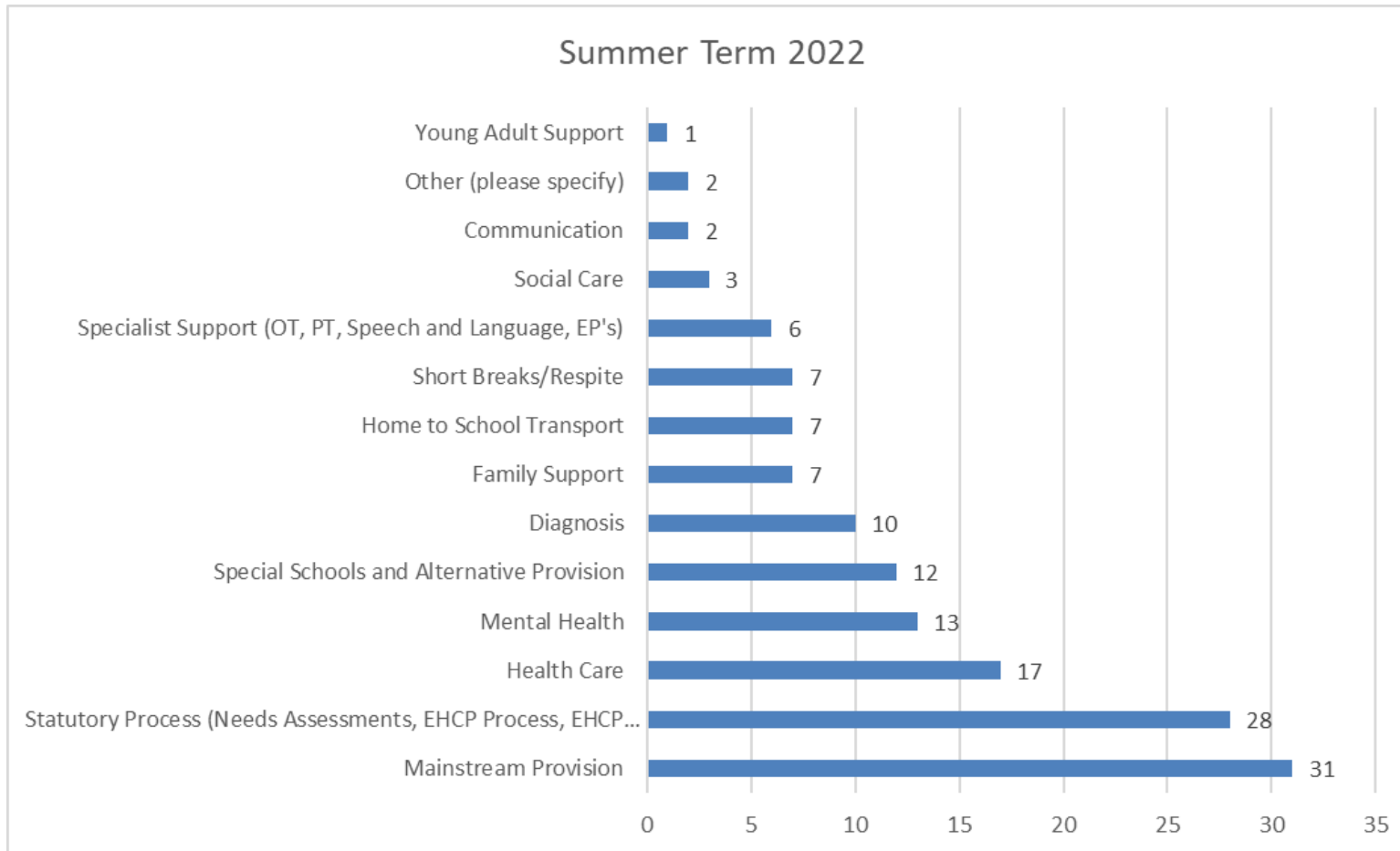
Many of the comments amended are where “other (Please specify)” has been selected.

We also for this report added a category for “Ofsted and the Care Quality Commission (CQC) re-visit of Essex County Council May 2022” which for the purposes as previously stated have also been amended.



# Category of Feedback

Summer Term only



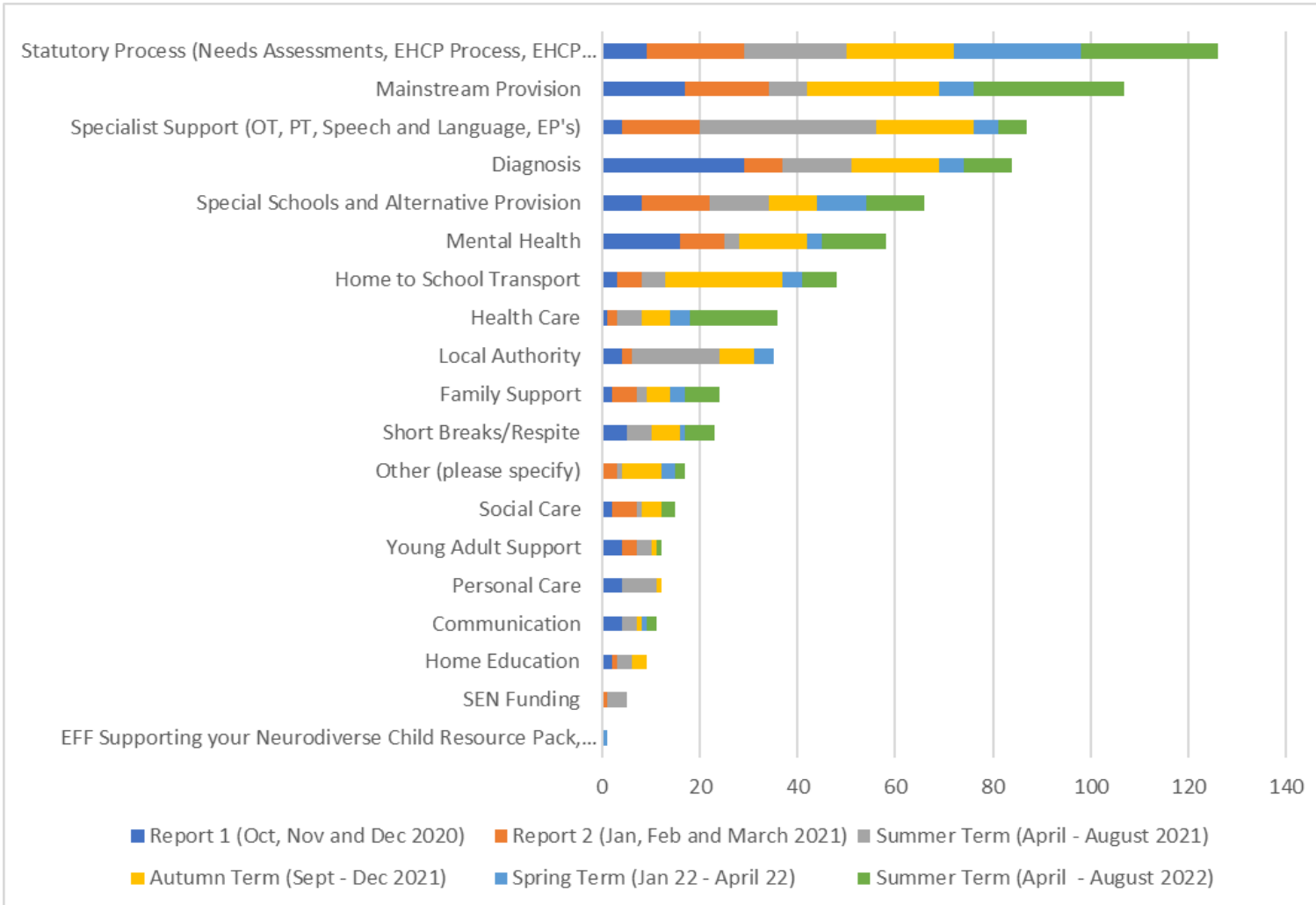
This shows the feedback we received broken down by category for this period of reporting





# Category of Feedback

## Report Comparison



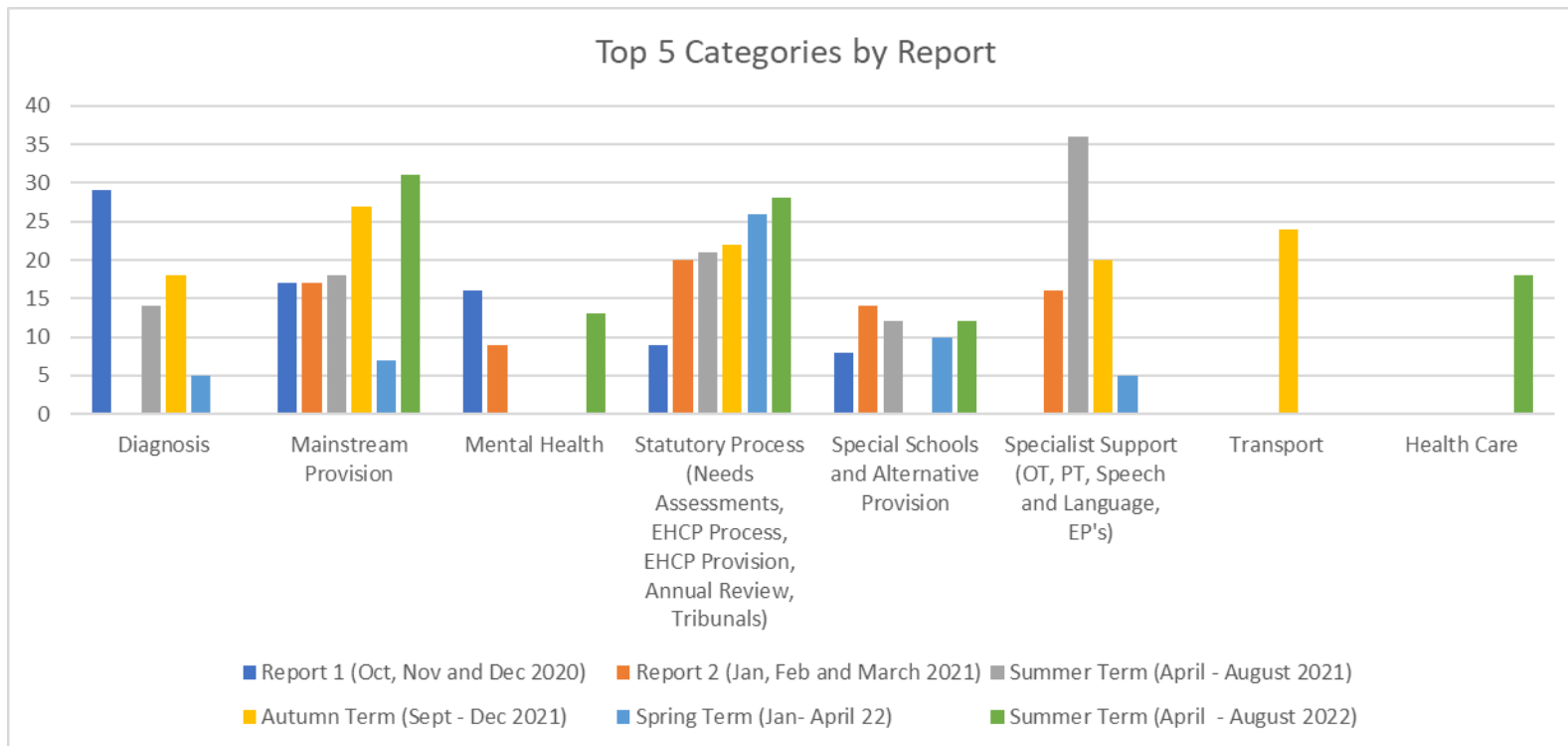
Key themes remain with the amount of feedback provided by category, with the top 5 overall areas being:

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

We can see how the top 5 fluctuates across each report on the following slide



# Analysis of Top 5 Categories



These figures show the top 5 areas of feedback over the 4 Graffiti Wall Reports. Where this is no data that does not mean no data was received, simply that it did not feature within the **top 5 categories** of feedback for that report.

Mainstream Provision and Statutory Process remain consistent featuring in top areas of feedback across all 6 reports.

Home to School Transport saw an increase and we believe this can be attributed to the start of a new academic year with new providers for several special school routes, and one provider who shares the Graffiti wall link within their newsletter. We also held a workshop with SENTAS.

There was a targeted approach for therapy feedback in the Summer Term 2021 which account for the increase in comments.

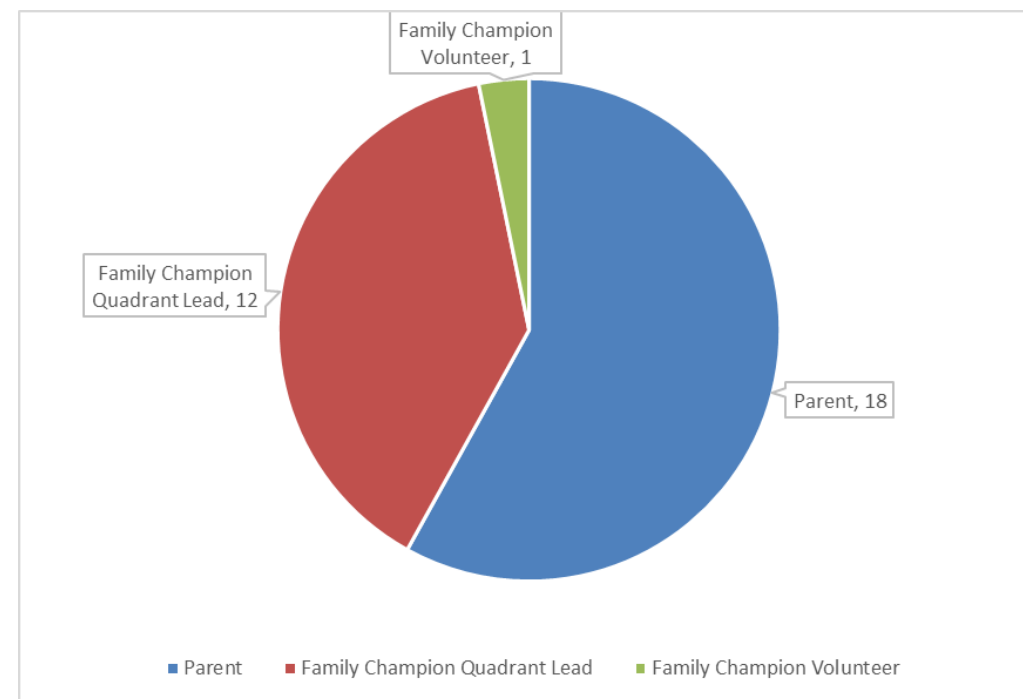
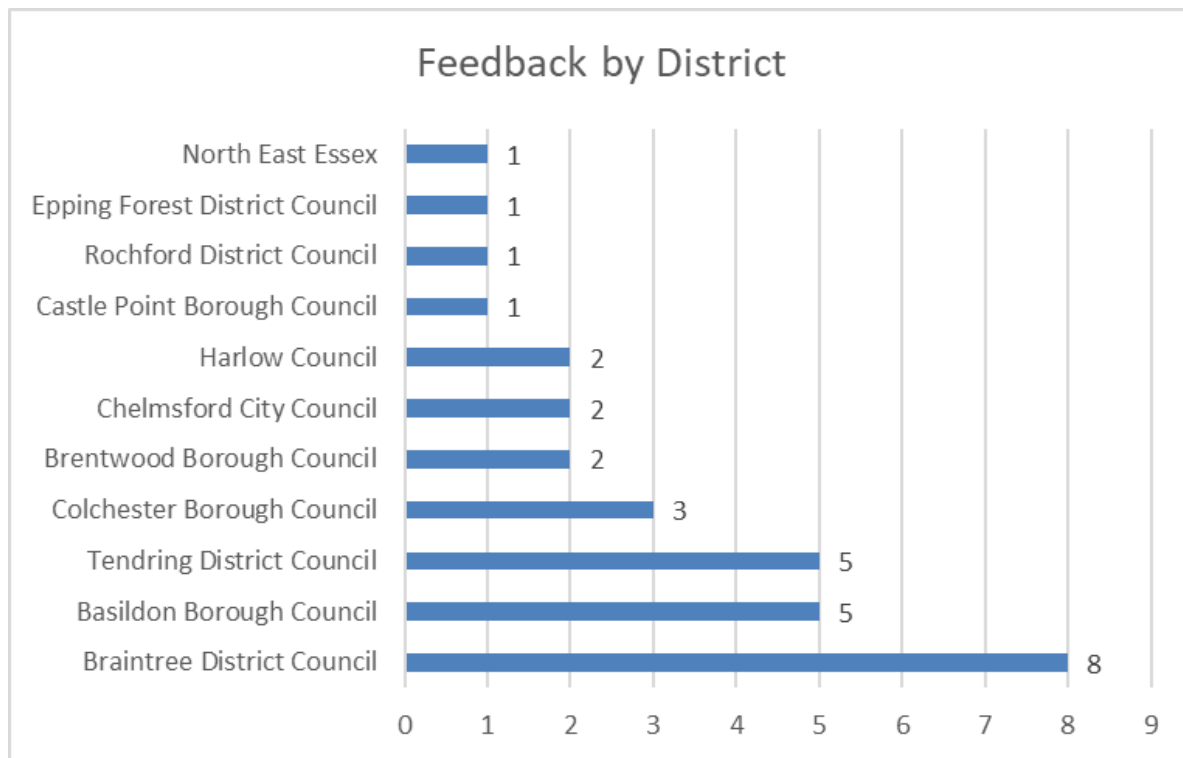
The neurodevelopment survey ran during the summer term, so we anticipated a lower number of participants for this period

Health Care reflects an increased amount of feedback around Health Care Provision for children with Down Syndrome.



# Mainstream

A total of 31 responses were received for this category.



Types of support their CYP received was indicated as follows:  
9 EHCP  
15 SEN Support

Details of 12 education settings were provided.

# Mainstream – What Is Not Working

- Poor Identification/Understanding of Need
- Access to Early Years Provision
- Poor Sen Support – Early Years/ Primary
- Access to Post 16 Education
- Sensory difficulties and School Uniform
- Communication
- Lack of support/knowledge around EHCP process
- EHCP Provision not being delivered (1:2:1)
- Lack of differentiation of work
- Inflexible lunch policy
- Not supporting behavioural difficulties/punitive behaviour points
- Unable to access school due to mental health and lack of support.
- Inadequate transition to Year 7
- CYP not being able to take part in school life
- Poor quality one plans
- Lack of understanding ADHD/ASD (in girls)
- Parents not feeling heard

*“My child is being sent home too regularly and when they are, it is often without work to complete.”*

*“Working alongside my school, I feel my child is very overlooked and don't feel like my voice is heard or taken seriously.”*

*“There are no positive strategies put in place.”*

*“School using 1-2-1 support staff to support the whole class, while not having experience or proper training.”*

*“My daughter's anxiety is really high and she is not able to attend school. She refuses to leave the house and is not engaging with us a family. this impact on her sister who is not able to do activities outside the house due to her sister reluctance to leave the house. Secondary school very reluctant to provide additional transition meetings, to meet to discuss provision (EHCP in place ) and whilst state they offer reasonable endeavors - refused to make any amendments on school uniform (expect would allow black boots, rather than shoes) or homework”*

*“School advise ECHP is only guidance and they are the professionals they decide what recommendations need to be done although provision is to follow a programme as advised by a therapist School not providing provisions One year down the line school saying they can't do certain things and a provision on the ECHP recommended by EP unreasonable . When this could have been all stated at outcomes meeting”*



# Mainstream – What Is Working

- Schools appear supportive
- Specific settings reported positively
- Needs are met
- Improved communication
- Schools and teachers doing their best with limited resources and fundings
- Personalised approach with non-attendance
- Reasonable endeavours around school uniform
- Good SENCO
- Nothing
- Supporting behavioural needs.
- Working in smaller groups
- Transition

*“XXX nursery in XX has been amazing. They have never seen my sons difficulties and have been so positive about finding ways to help him.”*

*“Primary School (XXX) are amazing at meeting her sensory needs.”*

*“The school are generally appearing supportive and sympathetic*

*“Mostly, communication with school is better. The children are more understanding of my child’s Tourette’s now “*

*“Helping to reduce stress and anxiety. Ignoring the behaviour and assuming is communication because of an earlier problem. Working in smaller groups (sometimes) at school.”*

*“School gave 1-1 support for my son and his life has improved at school sumountably but they have had to take from their budget due to not enough funding. (OT - Son needed more help and due to changes in NHS at the time he was only offered one appointment although OT therapist said he needed to be seen regularly. ”*

*“Very little. Only when we have made complaints have things started to improve.”*

*“Current school is great, support is great.”*



# Mainstream – What can be done to improve things?

- Training in mainstream on SEND/MH/Girls/Masking/Sensory
- Safe spaces within school
- Multidisciplinary teams for under 5's
- Improved signposting to services, provision and funding for parents
- Provide SEN Support Post 16 at specific settings
- Sensory Provision
- Accountability of delivered EHCP provision
- Inclusive schools
- Alternative provision when CYP can't access school
- Improve transitions
- Offer reasonable endeavours
- Communication
- Teaching Assistants in all classes

*“Sensory provision on the NHS. Teacher training to include SEND.”*

*“System should be proactive in supporting Sen children and help them to thrive in mainstream. Not simply intervene when they fall behind and are in an even worse position.”*

*“Schools more inclusive of neuro divergent children”*

*“The school need a better understanding of ADHD and how children mask it. They also need to provide a safe environment for children to speak up if they don't feel OK. A documented process to follow in terms of the SEN register and One planning would be helpful.”*

*“Better cpd for staff”*

*“Each child under 5s needs someone who can pull together all the different people who help care for that child. The nursery needs a clear plan. Parents should not be seeking out the help their child is entitled to. HELP SHOULD BE OFFERED all the help and services and funding should be clearly communicated to the nursery. As soon as a child is identified as having difficulties the nursery should be made aware of any and all help and support that can be available.”*

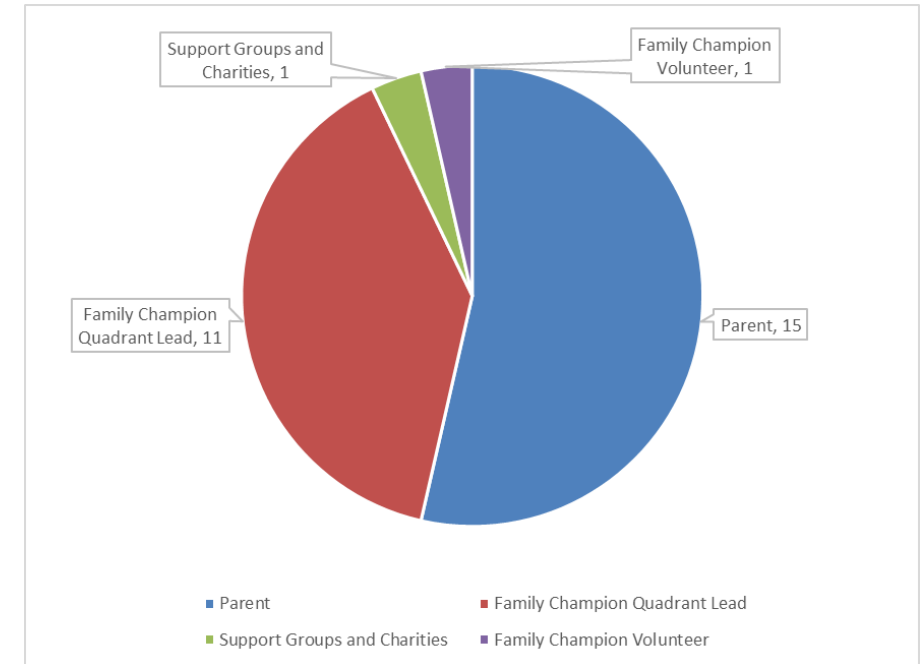
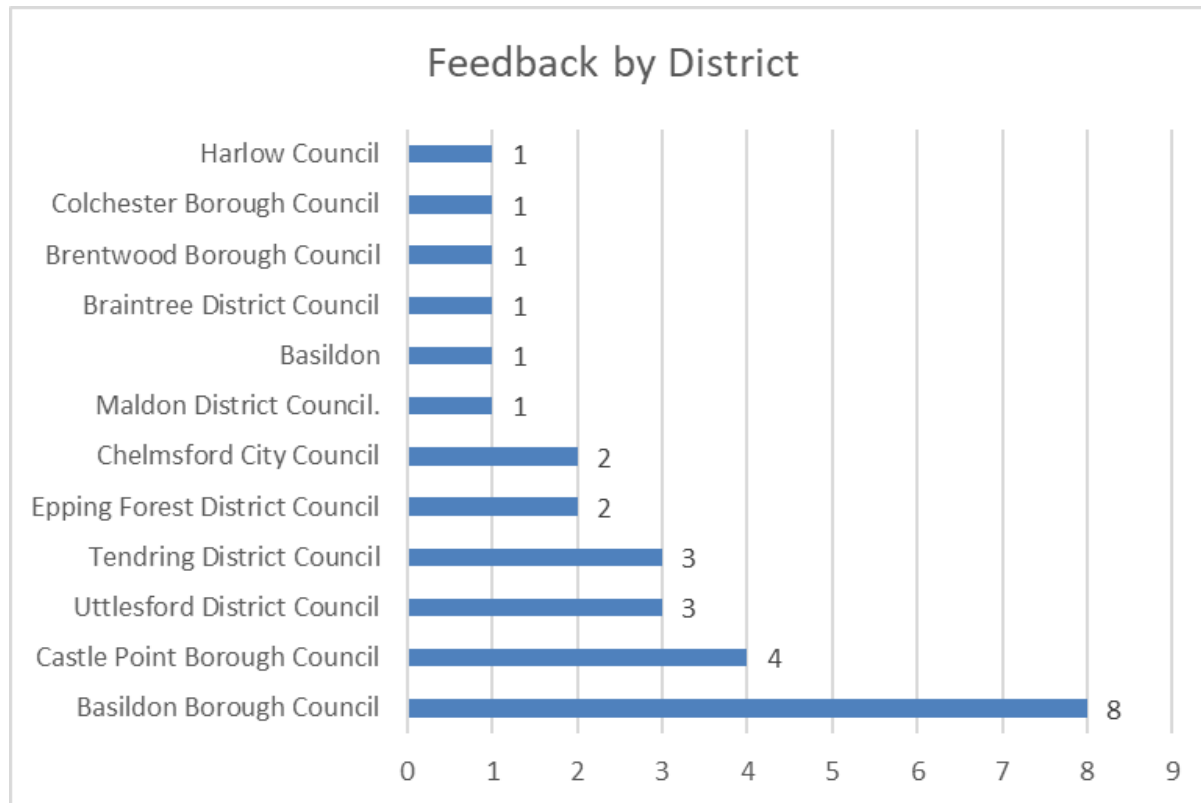




# Statutory Process

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

A total of 28 responses were received for this category.



Types of support their CYP received was indicated as follows:

- ✓ 16 EHCP
- ✓ 13 SEN Support
- ✓ IPRA Funding
- ✓ Specialist Teacher/Ed Psych/OT/Physio/ SLT/Medical Consultant

Details of 7 settings/services or providers were provided.



# Statutory Process – What Is Not Working

- Poor communication with SEND Ops Teams
- Delays with finalising EHCP
- Delays in finding suitable provision
- Delays with Annual Review
- Delays with staff storages and annual leave being cited as reasons
- Lost or using out of date reports
- EHCP provision not delivered
- Poor post 16 extended learning provision at mainstream college
- Delays impacting future placements
- Refusal to assess
- EHCP conditional based on agreeing to self fund transport
- Process of medical evidence is not co-ordinated with health
- Lack of support to apply for an EHCP
- CYP in provisions which don't meet needs
- Timescales not clear
- Ed Psych not observing CYP
- No support

*“So many delays in getting my son’s EHCP put in place. Very little help and support from the LA and then more delays in finding a suitable provision. No urgency or support for a teen whose time in education is ticking away.”*

*“School lacking in communication towards an EHCP assessment.”*

*“ have received my child's EHCP, on condition that I agree to pay current and future travel costs. I've not actually requested money toward travel and I can't see into the future!”*

*“timeframe for amended draft EHCP after annual review. 46 weeks since annual review and no finalised plan. We have had another AR since without having previous plan finalised, appalling. “*

*“Families are frustrated with getting little response from SEND Ops. Rarely answer the phone. Email's sometimes are not answered & untimely if they are. SEND Ops have 'lost' professional reports & fail to keep to deadlines. When have had meeting, they use records/information which is out of date.”*

*“Absence of Key Sen Ops staff in last week of summer holidays and beginning of school term meant that processes not completed in time for children to transition to new placement at the beginning of the school year with a negative effect on the child.”*

*“schools and sencos don't want to apply based on LA unlawful criteria. They dont tell parents they can apply themselves”.*



# Statutory Process – What Is Working

- Good Therapists – enabling re-engaging with school
- Nothing unless pushed for
- Parents understanding of the SEN Code of Practice
- Supportive/Good professionals
- Specific Education settings
- Lack of accountability of schools
- Support and advice from PCF and Charities
- Nothing

*“Using the SEN code of practice to refer to for support”*

*“Inclusion officer very supportive”*

*“EHCP process not fit for purpose Support from LA or ability to hold schools to account non-existent”*

*“The educational psychologist was extremely good.”*

*“The EHCP system is currently reviewing our case. The secretary has been brilliant (name removed)”*

*“In terms of the LA? Literally nothing. The only time things happen is when wither I or the school push for things to be done.”*

*“Well all our council tax has gone up so it must be benefitting someone somewhere ?”*

*“Support from PCF and charities, they have provided important and relevant information.”*

*“Primary school are supportive with his needs”*



# Statutory Process – What can be done to improve things

- Increased capacity within SEND Operations
- Better training and awareness
- Early intervention
- Accountability
- Increased support from Schools
- Ensure appropriate cover for SEND Ops during key times
- Improve communication
- Follow legislation and guidance
- Empower parents and carers
- Provide clear information about the EHCP Process

*“The LA should be held legally accountable for its failures.”*

*“More support from school to get the correct entitlement to their Education”.*

*“Follow due process and guidance, Essex policy does not trump law”*

*“Knowledge to parents.”*

*“Clearer information about the EHCP process for future parents to access it.”*

*“LA needs more funding and more people. We need more people who actually understand the needs of our young people. Things need to be put in place sooner; not when the child is broken from having to try everything first. It becomes much harder to ‘fix’ things if we don’t address the issues straight away.”*

*“COMMUNICATION - schools and settings are not effectively communicating with their SEND families - talk to us, make us part of your community. CAPACITY - properly fund and resource your teams with enough people to actually provide effective support to your families. Families get frustrated and upset and because they feel unsupported they end up ranting and taking it out on the people who are trying to help but can't do so effectively because there is not enough of them. And then they leave because who wants to be in that position? It's a vicious circle “*



# Health Care

The Majority of feedback within the *Health Care Category* was provided by a North East Essex Charity called *Candles – Down Syndrome Support Group* through our Family Champion Lead.

Comments provided are at times provided as a complete narrative over a period of time and so we have taken each comment and drawn out the main points of:

- What is working
- What is not working
- What can be done to improve things.

It should be noted that as well as health care issues, mainstream provision and high-quality teaching strategies were also raised.

“Mainstream schools seem to be struggling with children with DS. XXXX experience of school is more like baby sitting club rather than education and learning. What seems to be happening is that they struggle with them and instead of finding an answer to meet their needs in that setting they say to parents "we think they'd be better in a special school" why??? What would be any different there? Lower expectations?? There needs to be a shift on mindset....what can we try to help..... who can we get in to support .....not simply... its not working he needs a special setting” (quote adapted – with extracts taken from a longer statement)

Aside from the feedback from Candles, we received for two further comments relating to health care, one from Braintree and one from Basildon, which are also included in this section.



# Health Care – What Is Not Working

- Delay in medical support after moving into Essex
- Difficult to navigate
- No support for ARFID
- Inequitable access to health care due to Down Syndrome diagnosis
- Access to services feels like a tick box exercises and provision is not quality.
- Feeding/Breastfeeding Support
- The use of language:
  - At scans
  - In respect of terminations
  - Viability of pregnancy
  - Teaching opportunities
  - Medical appointments/Interactions

*"I had a doctor ask if some students could come in and learn about down syndrome, something along those lines. I didn't mind that in theory, so gave consent but he ended up pointing out features of XXXX's like his eyes and how they were different and he also talked about health problems children with down syndrome tend to have"*

*"when I left I thought that was not only a very insensitive way to be teaching but also I'm a tired anxious mum, new to the diagnosis for my son so more than anything I didn't need to hear those extra potential issues in that particular moment."*

*"So you've decided you're keeping baby?" It was really unsettling you'd never ask that in a typical pregnancy.....it just puts doubt in your mind. They even asked us this at 32 weeks which was just insulting"*

*"Basically, saying their health problem is "a downs thing" and failing to treat them as they would someone else. E.g. a 2 year old typical child would get lots of intensive physio if they couldn't walk. But a child with DS doesn't get intensive physio "because it's normal for DS"*

*"Meanwhile my husband was spoken to by the lady or her team again and said to him 'If you don't want him we can find somewhere for him to go"*

*"Going round the houses with support for eating disorder ARFID. Referred to GOSH who then referred to EWHMS who will not help until daughter is 8 (she is just 6)"*



# Health Care – What Is Working

- Support from short break providers
- Initial appointment access
- Positive feedback for:
  - Community nurse
  - Community paediatrics
  - Dietitian
  - OT
  - PT
  - Health Visitors
  - Colchester NICU
  - Addenbrookes
  - Specialist Teacher
  - Breastfeeding Team
  - Midwives
- Sensitive use of language in appointments
- Support Groups (Candles)

*“My high risk screening 1 in 43 (from standard blood tests) was handled very sensitively I thought. She asked me how I felt and if I was happy to continue with pregnancy and that was that never mentioned again.”*

*“Care at (Hospital name removed) and back at (Hospital name removed) NICU was fantastic for me, staff made a lot of time for me, talked to me, listened and really understood how challenging it was initially when XXXX was born.”*

*“The specialist teachers, and our quite frankly awesome health visitor, (name removed ) were our only real support. Without them fighting our corner, and this group of mums, I'd probably have gone insane.”*

*“We are getting the initial appointment but no support or therapy received.”*

*“We had the most loveliest specialist health visitor who was really reassuring and lovely and explained a lot to us and put us in touch with services etc. I just wish she could have been with us through the pregnancy as I really spent most of the time anxious and in fear and with nobody to reassure me. It wasn't really enjoyable and was quite a lonely time.”*

# Health Care – What can be done to improve things?

- Celebrate the life of a child with Down Syndrome
- Seamless transition of care when move
- Meetings and workshops with consideration to minorities and those for whom English is second language
- Eating disorder support for under 8's
- Promote pre natal peer to peer support
- Support for school age CYP with Down Syndrome
- Clear Information and support for CYP with Down Syndrome
- Positive 2 year check
- Holistic approach
- Joined up approach – tell it once
- Community Nurse support link to GP
- Parent workshops for CYP with Down Syndrome
- Health Visitors should be aware of DS Growth Chart for baby weigh-ins
- Correct use of Language
- A dedicated pathway for CYP with Down Syndrome from pre-birth.

*“Please celebrate the life of a child who happens to have down syndrome. They are someone’s child. Please be mindful of this at all times and talk respectfully about the child. Please don’t bog parents down with negativity or what if scenarios”.*

*“When typing up a report, don't list DS as a "problem" Ds is not a 'problem', it's a diagnosis “*

*“regular meetings and workshops, particularly for minorities as most have a language barrier.”*

*“The care is not very holistic, it seems departments are separate and you have to repeat things.”*

*“The birth of children with DS needs to be celebrated and the mum needs to be made to feel as they do with the birth of any other child”*

*“Use correct language, not a Downs child, a ‘child with Down Syndrome!”*

*“The care should be seamless all is NHS so it shouldn't take waiting 2 years because she has to be seen by Essex”*

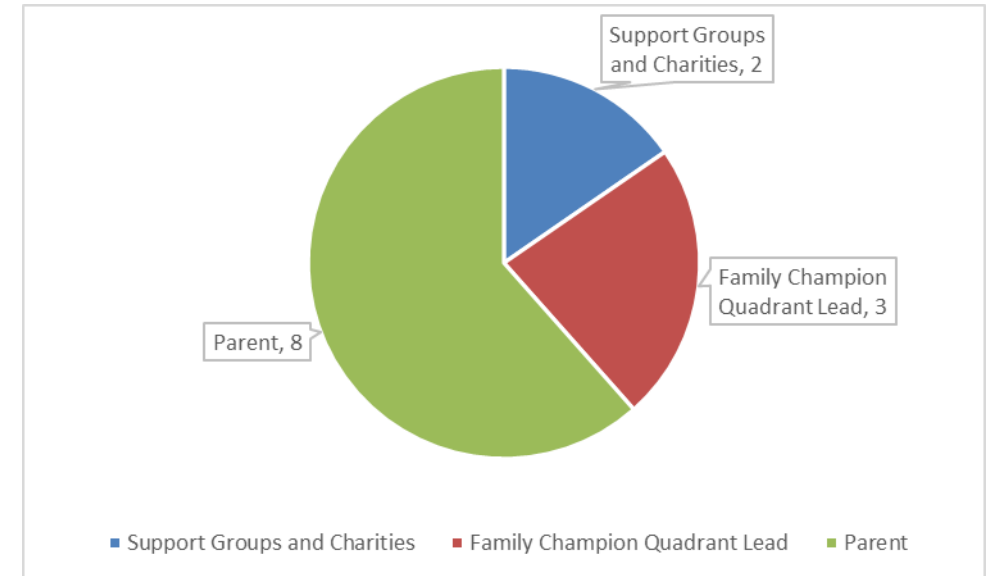
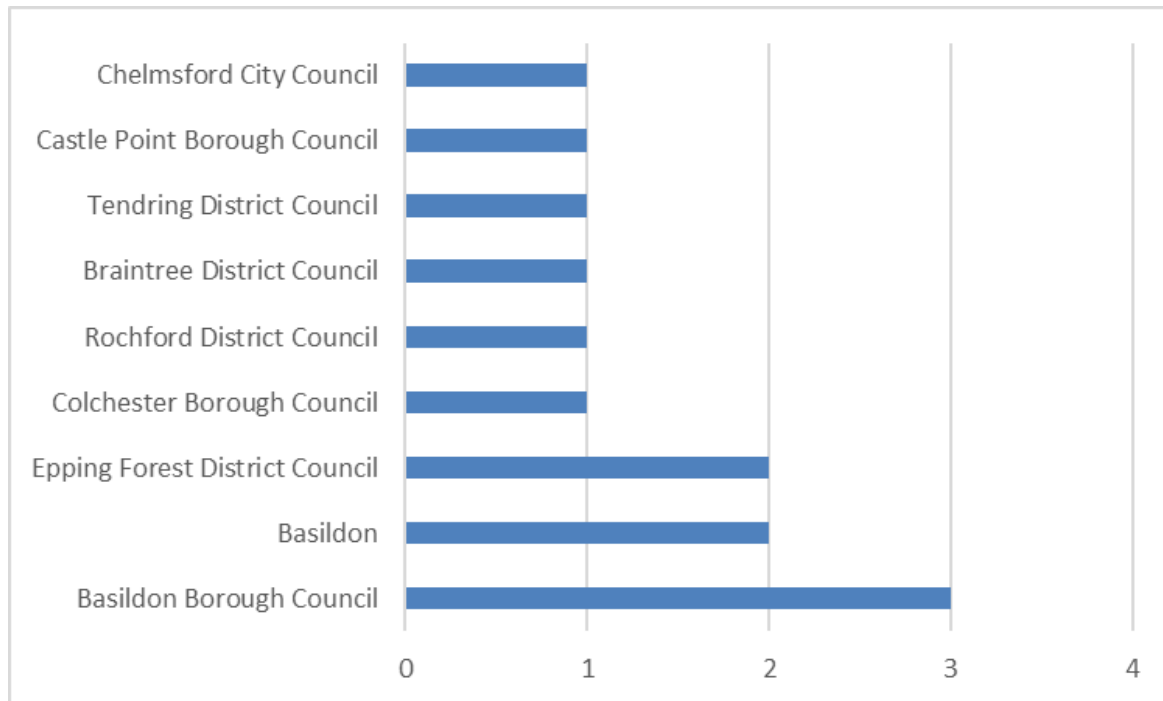
*“Support for under 8 year old's with diagnosed eating disorders.”*

*XXX has his 2 year review soon and it made me think maybe we should have an alternative one or some kind of progress chart or record we can fill in? Even if its like a memory record or something, I know people could do that themselves anyway but rather than us just feel like our kids are potentially falling short of the mainstream one, it would be nice to have something legitimate where we can focus on what our children have learnt and the progress they have made.*

*“I was introduced to a new mum with a baby with Down syndrome to talk to and I called her we talked and then I met her and her family it was actually XXXX with XXXX that was the best experience I could of had before the birth”*

# Mental Health

A total of 13 responses were received for this category.



Types of support their CYP received was indicated as follows:

- ✓ 4 EHCP
- ✓ 4 SEN Support
- ✓ 1 Children's social care services (or being referred)
- ✓ 1 School nursing team, asthma and allergy nursing team.

5 Respondents named services.

# Mental Health– What is Not Working?

- Impact of transition on Anxiety/Mental Health
- Impact of access to education
- Access to support
  - Lack of capacity within some charities
  - Waiting Times (even in private sector due to capacity)
  - Access to suitable provision/ CAMHS
  - Lack of face-to-face support
  - Lack of understanding
  - Education settings
  - CAMHS – lack of understanding
  - Inappropriate use of language
- Inconsistent care/ appointments cancelled
- Discharged when support still needed
- No intervention support for Eating disorders only diagnosis

*“Due to lack of understanding in my daughter's school, her mental health has been majorly affected and she is constantly in trouble as she is treated like a non SEND child”*

*“Ewmhs in general. Staff do not understand complex ND mental health. Not commissioned for school anxiety associated with Disability. Staff continually use FII and perplexing presentation to close file and discredit parents.”*

*“Total lack of support - no access to face to face assessments. Decisions are made over the phone with little attention paid to the history of the case or recommendations from other services involved. Help is offered but they cannot say who by, what it will look like and when it will happen.”*

*“Lack of understanding of language during an assessment appointment. The lady (who was lovely) was chatting to my daughters and in an attempt to emphasize with her said "well we are all a little bit autistic aren't we" it was at this moment my daughters pulled her hood up and got up and said i am ready to leave. once we left the session my daughter said that when they lady said that, it showed she didn't understand autism or her feelings and what was going on in her head and that annoyed her, and that if everyone was a little bit autistic, autism wouldn't exist.”*

*“Absolutely no support for mental health. Camhs are not fit for purpose. Cherrypicking all they will help. My son was left on a waiting list for six months we had to pay for a private psychiatrist as he needed urgent help. It's a national disgrace”*

*“My 16yr old daughter has missed a year at school due to severe social anxiety. She's been on the EWMHS waiting list for 11 mths, still hasn't seen a counsellor! Now she's having seizures that could be caused by stress, still no counsellor!!”*



# Mental Health– What is Working?

- Nothing
- Accepted to the service
- Regular check up calls
- Team around the family meeting

*Nothing*

*“Unfortunately for this family, nothing at the moment. We are helping them to find charity services who can support during this time of crisis”*

*“EWMHS is not fit for purpose!”*

*Nothing*

*“The fact we got accepted to the service!!!! the regular check up calls and when having a few issues with new school - a call to the school and follow up e-mail with outcomes to me”*

*“The Team Around the Family at school and with health services has been good, however those in the team only have limited capacity to refer and to influence the outcomes of decisions.”*

*“Not much right now.”*

*Not a lot! Weight has stabilised and medication from psychiatrist helped*





# Mental Health– What can be done to improve things?

- Increase capacity
- Fund Charities
- Commission services for ND/SEND
- Improve access to early interventions
- Suitable provision (Group workshops are not suitable for all)
- Teacher training to support SEND
- Provide 1 to 1 sessions
- Face to face sessions
- Training in the use of appropriate language
- Prioritise children not able to access education due to mental health
- Children and young people should be assessed not discharged post referral
- Listen to parents
- Therapies and interventions for eating disorders
- Clear signposting for support and advice
- Training/support for parents and carers

*“Children seen within 3mths of referral, sooner if they are not in school or it is affecting their physical health”*

*“If a child has been referred to (provider name removed), then an assessment should take place instead of discharging them and signposting to local charities.”*

*“Parents listened to more and that the case is seen on its individual merits and not compared to other cases that they deem to be worse or more at risk. Increased funding for mental health services. Less time to wait for help. Face to face appointments rather than phone appointments.”*

*“Provision of therapies and interventions to young people with eating disorders, which is also suitable for ND young people. Clear signposting and training for parents to support their seriously ill children.”*

*“Increased capacity at funded services (eg sendiass ) or paying other charities to provide these services. Or having more professional support available during school holidays.”*

*“More immediate support & access to proper mental health care for children. Group anxiety workshops are not suitable help”*

*“Teachers need more training on different SEND children and support”*

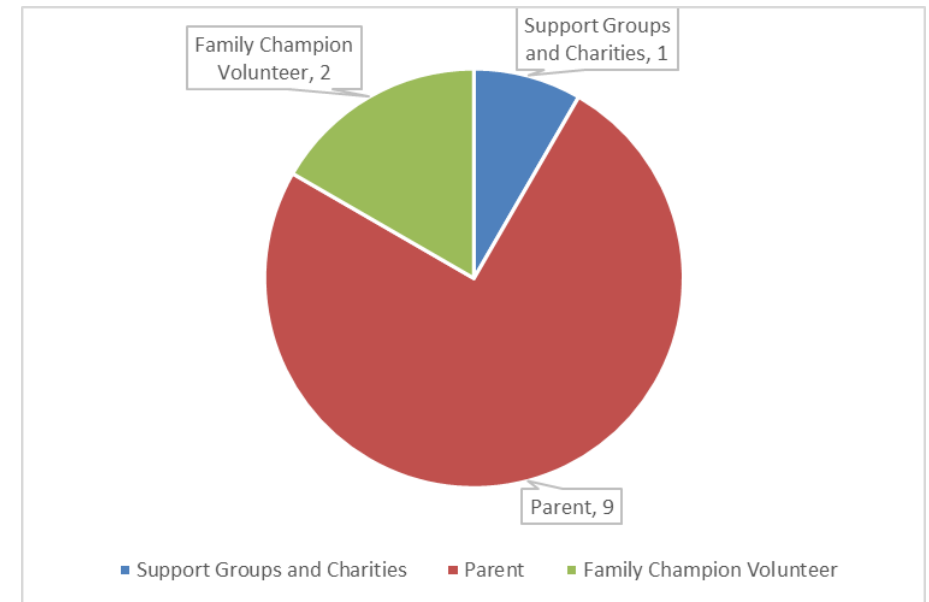
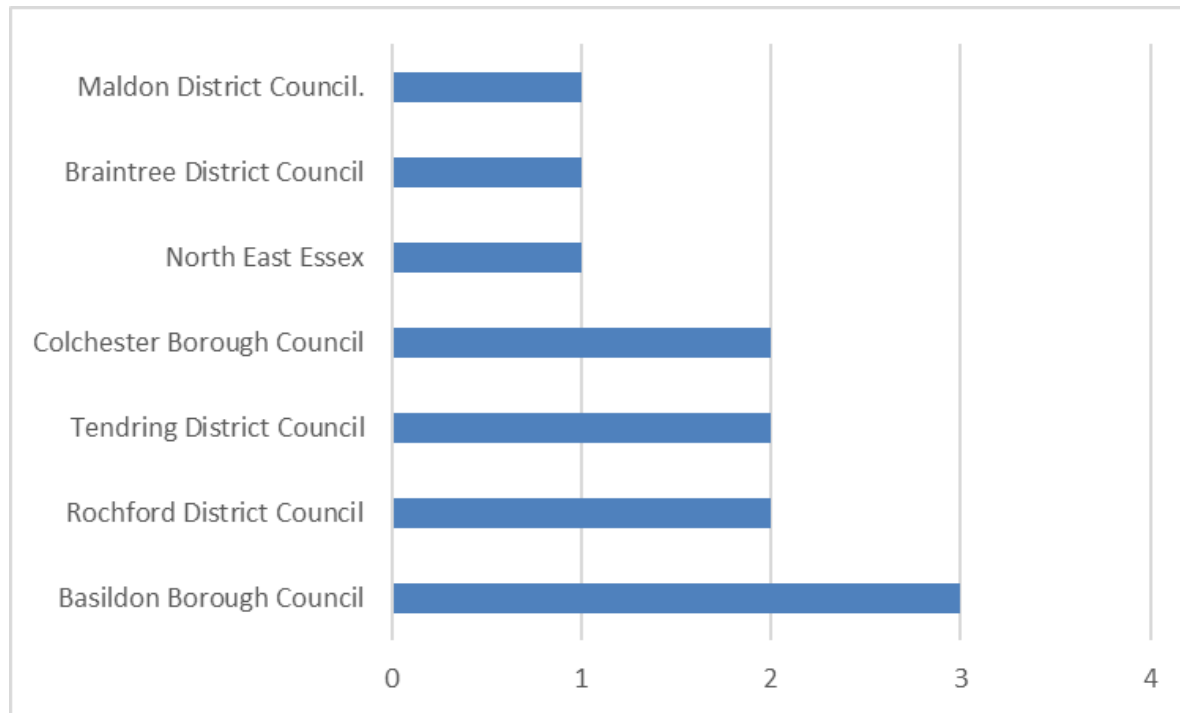
*“Commission specialist mental health service for ND and SEND “*





# Special Schools and Alternative Provision

A total of 12 responses were received for this category.



Types of support their CYP received was indicated as follows:

- ✓ 8 EHCP
- ✓ 2 SEN Support
- ✓ 3 Children's social care services (or being referred)
- ✓ 2 respondents indicated that whilst they had an EHCP in place they were not receiving the provision within it.

5 Respondents named services/settings

# Special Schools and Alternative Provision – What is Working?

- Covid impact on schools
- No school place
- EOTAS not provided when needed
- Delays in securing placements
- Communication
  - Lack of communication (schools)
  - Lack of empathy
  - Parents not listened to
  - Calls/e-mails not responded to (SEND – Ops)
- Private assessments ignored
- Banding concerns
- School Support for application process
- Distance children need to travel to access suitable provision
- Schools not supporting diagnosis process
- Inadequate support in schools – reduced timetables/expelled
- Interactions with Police
- Schools not adhering to statutory guidance for annual reviews
- In appropriate care and activities in school
- Inadequate provision for
  - autistic girls
  - CYP moderate Cerebral Palsy
  - CYP with mobility needs
- Training for cerebral palsy needs to be improved

*“The police do very little and as he has ADHD he is seen to be naughty. His life appears to be over at 13 due to the bad decisions he is now making. However, if we had been supported to get the appropriate diagnosis when he was younger, I would have been able to properly adapt my parenting so he would listen,”*  
(Quote extracted from a longer narrative)

*School will not provide reports in advance of annual reviews and do not adhere to statutory requirements School refused to carry out a near miss investigation after a danger seeking child with severe learning disabilities was forgotten and came out of the toilet to discover his class empty and all children and staff had left for the day School introduced dive sticks to a danger seeking child who is attracted to deep open water, encouraging him to sink to the bottom to retrieve the dive stick. He cannot swim and this has placed his life at risk. They then cut his swimming lessons from weekly throughout the year to only for one term each year. He continues to dive in water. If he drowns, this will be due to the negligence of the school Provisions are being erased from all childrens ehcps at the recommendation of the school since the arrival of the new head (some only months after tribunal rulings)*

*The provision for autistic girls is woeful. Despite being exceptionally bright my autistic daughter cannot cope with the school environment and I feel helpless as I see her teenage year’s slipping away. She wants to be happy, she wants to be “normal”. She wants to be able to cope with mainstream school. So what is the alternative? Nothing. She is too bright and able for Special Education Provisions, home education is being attacked by government policy and virtual learning is out of reach financially. Meanwhile a gifted child with so much potential is being discarded. This is not only cruel but it is immoral.*

*“A number of parents reported the closure of (school name removed). It was suggested that the school was closed 20+ days out of a month before Easter. The closure was due to positive covid tests (staff and children). (Reported by local charity)”*

*“I have been trying to get my child moved from a (Location removed) School to one closer to home. all SEN schools are oversubscribed, meaning my daughter has to leave at 7:30 a.m every morning just to get to school. The SEN school system needs looking at, there just isnt the right amount of provision for our children. In my experience since moving to this borough last year, not a lot has been working! I have hit brick walls constantly and have had to become THAT parent... from school transport to moving schools.. to peadiatrician having over 6 month waiting list to be seen. still not seen...”*



# Special Schools and Alternative Provision – What Is Working?

- Charities activities for children and young people are well attended
- Charities/Agencies/peer to peer support
- Nothing
  - Unable to secure placement
  - System is broken
  - Special schools are at capacity
  - Teachers and LSA
- Settings working hard to meet need
- Child/Young person is happy at setting

*“Special schools are working hard to meet needs of our young people”*

*“At the moment nothing with trying to get a secondary placement”*

*“(Charity name removed) activities are going well. They are well attended and well received by families.”*

*“Teachers and LSA staff are fabulous”*

*“The Facebook communities and charities that support local families going through this endless battle with Local Authorities”*

*“Nothing. The entire system is broken”*

*“I wish I knew.. things are probably working. but the pace is snail like”*

*“I have been supported well by some agencies.”*

*“Nothing at all. The system is not working and all special schools are full to capacity.”*

*“Son is happy at (school name removed)”*



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

- Respond to calls/e-mails/complaints
- Listen/Work with parents and carer
- EOTAS packages and support for those out of school
- EHCP to be written in house
- Improve the quality of EHCPs
- Social Care assessments to be conducted
- Improve teachings on the completion of diagnostic questionnaires, and for doctors to be mindful its only view-point.
- Training to better equip settings on behavioural needs
- Schools' compliance with Annual Reviews
- Invest in storage of school places
- Stop changing categories of needs on plans.
- Improve training and provision for children and young people with moderate Cerebral Palsy
- Online communication tools for schools

*“There needs to be a shake up somewhere. I wish I knew where to begin. but our kids are the ones that are suffering here. its a constant battle, constant phone calls.. chasing chasing.. trying to find the correct people to contact it's mind numbing.. We needs more SEN schools or larger capacities”*

*“Increase funding so provisions aren't cut  
Ensure school investigate incidents  
Ensure compliance with SEND code of practice by school re annual reviews”*

*“School name removed should have some sort of online communication like School name removed”*

*“Stop changing categories of needs on plans and have a plan for investing in schools to address the shortage of places”*

*“Actually respond to emails and calls - work with the parent not against - take parent views into account - provide all SEND families with a SEND child a social care assessment as part of the process and provide the help when it is needed. - ensure EHCPs are written to an adequate standard by a case worker who knows the family - respond to complaints about SEND - be contactable - work towards the legal timescales - do not outsource writing of EHCPs - provide an adequate support and EOTAS package to all children out of school as required by law Work on opening new/more special schools as a priority Ensure schools allow viewing and cooperate with parents Conduct EHCP reviews when requested Update parents on each panel outcome Use professionals private reports Don't ignore parents Ensure regular contact with families with children out of school”*



# Diagnosis

What is not working	What is Working	What can be done to improve things?
<ul style="list-style-type: none"> <li>➤ Health and Education not communicating</li> <li>➤ Peads referral rejected suggesting seek EP support, but school advise wont see individual children.</li> <li>➤ Process is overwhelming</li> <li>➤ Professionals dismiss concerns</li> <li>➤ Waiting times</li> <li>➤ Trauma delays cause for CYP</li> <li>➤ Miscommunication</li> <li>➤ Lack of advice and support whilst waiting</li> <li>➤ Lack of advice and support post diagnosis</li> <li>➤ Parental blame</li> <li>➤ Private sensory OT report – school not read</li> </ul>	<ul style="list-style-type: none"> <li>➤ Nothing</li> <li>➤ Support from School</li> <li>➤ Peer to Peer Support</li> <li>➤ Understanding professionals</li> <li>➤ Child and Family Wellbeing service</li> <li>➤ Private sensory report in-dept</li> <li>➤ PACT</li> </ul>	<ul style="list-style-type: none"> <li>➤ Better understanding of the process and waiting times</li> <li>➤ Communication</li> <li>➤ Confirm receipt of the referral</li> <li>➤ Listen to parents concerns</li> <li>➤ Improved consultant support</li> <li>➤ Improved understanding of sensory processing</li> <li>➤ Keeping in touch whilst waiting</li> <li>➤ Agency's working together</li> <li>➤ Advise and support</li> </ul>

*“From first voicing our concerns to the diagnosis we found a lot of miscommunication, assumptions and blame, lack of support and long waiting periods.”*

*“school really helpful.”*

*“All professionals need to be on the same page. A clear timeline and timescale of the diagnosis process. Support groups should be made available before the diagnosis not just after. All concerns should be taken seriously and no parent should be made to feel it is there fault a child has SEN”*

10 responses



# Family Support

What is not working	What is Working	What can be done to improve things?
<ul style="list-style-type: none"> <li>➤ Managing child's needs</li> <li>➤ Lack of advice and support for parents</li> <li>➤ Insufficient resources on therapies etc</li> <li>➤ Sensory needs</li> <li>➤ Child's needs being met by school</li> </ul>	<ul style="list-style-type: none"> <li>➤ SENCO</li> <li>➤ School - But issues with Masking</li> <li>➤ Charities, EFF</li> <li>➤ ADHD Nurse</li> </ul>	<ul style="list-style-type: none"> <li>➤ Improved support</li> <li>➤ Conversations, feedback, informing parents</li> <li>➤ Easy access to information</li> <li>➤ Links and videos to access at home</li> <li>➤ Considering type of provision child attends.</li> <li>➤ Accountability</li> </ul>

*“Sensory side of things we really struggle with”*

*“ADHD nurse - every 6 months enjoy all the workshops and parent programs so far.”*

*“Parent training, Easy access to information on services.”*

*“Nothing. Nothing is working. What family support?! There was none, except to push our family to breaking point through the diagnosis/EHCP / education system process. A shambles”*

*“Charity groups, Family Forum been so helpful for me .”*

*“Easier steps to find the help we need e.g. links & videos to watch at home. help with own research without a professional diagnosis.”*





# Transport

What is not working	What is Working	What can be done to improve things?
<ul style="list-style-type: none"> <li>➤ Communication from provider</li> <li>➤ Late allocations cited as reason for delay in communication</li> <li>➤ Delayed meet and greets</li> <li>➤ Lack of diagnosis impacting on ability to access SEND Transport</li> <li>➤ Short notice cancelation and failing to transport child to school and respite</li> <li>➤ Inadequate remuneration for transport costs when provider fails to transport child</li> <li>➤ Inaccurate information regarding PAs being present on journey.</li> <li>➤ Unfriendly PAs</li> </ul>	<ul style="list-style-type: none"> <li>➤ Drivers and PAs are amazing</li> <li>➤ Driver communication</li> <li>➤ Driver supports child</li> <li>➤ Nothing</li> </ul>	<ul style="list-style-type: none"> <li>➤ Our of hours communication – particularly for those with early pick-ups</li> <li>➤ Improved communication</li> <li>➤ Allow time for changes</li> <li>➤ Provider who cares about wellbeing of disabled children</li> </ul>

*“Had a phone call at 330pm from (Provider name removed) to say they forgot my son’s driver was on leave and they had no one to pick him up from school”*

*“Our driver is brilliant, has a whole playlist ready for my son when he gets on the bus. Goes out of his way to make my son feel comfortable on transport.”*

*“Transport company need to start communicating with both families and staff on transport. Allow time for families to ensure children are ready for changes”*

# Short Breaks/Respite

What is not working	What is Working	What can be done to improve things?
<ul style="list-style-type: none"> <li>➤ Access/lack of respite</li> <li>➤ Concerns around new tender process</li> <li>➤ Lack of activities in specific areas/ accessible by public transport</li> <li>➤ Lack of provision for complex needs or pre—school children (parc closed)</li> <li>➤ No help unless you have a diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>➤ Short breaks Max Card</li> <li>➤ Short breaks days out</li> <li>➤ Sunflower lanyard</li> <li>➤ Parents staying on the ball</li> <li>➤ Wheelchair service</li> <li>➤ Surgical appliances at hospital</li> <li>➤ Short breaks team in relation to Parc closure.</li> </ul>	<ul style="list-style-type: none"> <li>➤ Review short breaks tender</li> <li>➤ Wider publication of activities</li> <li>➤ Access in specific areas</li> <li>➤ Provide information and advice</li> <li>➤ Forethought and transparency around PARC Closure</li> <li>➤ Provide access pre-diagnosis</li> <li>➤ Praise for Short Breaks Team around Parc Closure</li> </ul>

*“A single mum of two boys of additional needs. I find some of the help out there isn’t always on the table for parents like myself. You have to make so many phone calls explain time and time again I’m struggling with NO RESPITE.”*

*“Many existing services that provide superb crisis prevention work..”*

*“Make the service inclusive for families needing support before an official diagnosis has been made.”*

*“I came on here to tell you that the short breaks team were really helpful after parc closed. You could tell they wanted to make sure families were supported even though it was hard they managed to get summer holidays sorted before they started in less than a month. I was called in the evening so they were working late to reassure me. Art have also been really good and it's great some staff were able to get work with them.”*

7 responses



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

What is not working	What is Working	What can be done to improve things?
<ul style="list-style-type: none"> <li>➤ Lack of support post SLT assessments</li> <li>➤ Lots of SLT assessments but little constructive support over 2 years to ASD/Development delay Diagnosis</li> <li>➤ Lack of EP's</li> <li>➤ Unable to access SEND Psychotherapist</li> <li>➤ Communication                             <ul style="list-style-type: none"> <li>➤ Chasing reports</li> <li>➤ Chasing appointments</li> <li>➤ No one returning phone calls</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>➤ Good Beginnings course</li> <li>➤ Early Communication skills group</li> <li>➤ Good OT – home and school visit helped</li> <li>➤ Good PT</li> <li>➤ Good Orthotics department</li> <li>➤ Struggle to see something positive</li> <li>➤ SEND Psychotherapist</li> <li>➤ Having a named contact</li> </ul>	<ul style="list-style-type: none"> <li>➤ Improved organisation/assessment so children access early intervention when younger post COVID</li> <li>➤ Happy with support received</li> <li>➤ More Eps</li> <li>➤ More SLTs</li> <li>➤ Improve/offer SLT in schools (LSA and teachers lack specialist knowledge)</li> <li>➤ Improve communication</li> <li>➤ Another SEND Psychotherapist</li> <li>➤ Bigger Budge/more staff</li> </ul>

*“The Good Beginnings programme was the most efficient, informative, educational and helpful course I have attended in the past two years, amongst dozens of other courses, books and piles of information.”*

*“There needs to be more Eps. More slt with ability to diagnosis conditions but also provide slt sessions within school environments on a regular basis like weekly or monthly either in single or group sessions. Or give options of therapy sessions on weekly/monthly basis. Children do not currently have access to support where the teachers and school lack specialist knowledge to support the children who sen. Perhaps additional training in a variety of sen for teachers should be an option . So they are able to support the assessments made by the slts and eps. Others things that could be improved include. Time frames of assessments should be followed strictly . ”*

*“We waited for 26wks following an OT referral. Called a couple of times to enquire and nobody returned the calls. Eventually received support after putting in 2 complaints. We are also on the waiting list for a paediatrician appointment and have been waiting for 26wks. Only found out the referral had been accepted when I emailed to ask after not hearing anything. Have now been told there is still another 4-5mth wait for appointment.”*

6 responses



# Social Care, Communication, Young Adult Support and Other

What is not working	What is Working	What can be done to improve things?
<ul style="list-style-type: none"> <li>➤ Access to find information is hard</li> <li>➤ Education hard to access</li> <li>➤ EHCP Support</li> <li>➤ Communication between Paediatrics and parents</li> <li>➤ Variation of SEND support varies between settings</li> <li>➤ Lack of specialist places</li> <li>➤ Need real help – not parent classes</li> <li>➤ Lack of social care support (LAC and non LAC)</li> <li>➤ Accessing provision/ remote location</li> <li>➤ Poor Accommodation impacting on health needs</li> <li>➤ Impact on family life</li> <li>➤ Poor PFA support/ Poor progression fair for SEND CYP -</li> </ul>	<ul style="list-style-type: none"> <li>➤ Homelife</li> <li>➤ The Maze Group</li> <li>➤ School SEND Team/School</li> <li>➤ Approach and care SLT</li> <li>➤ SENDIASS have made improvements since 2019 inspection</li> <li>➤ Dream and The Change</li> <li>➤ Voluntary sector services – only ones to help</li> <li>➤ Supportive out of school clubs</li> <li>➤ That CYP will be leaving a provision</li> </ul>	<ul style="list-style-type: none"> <li>➤ Easier access to SEND Facilities</li> <li>➤ Advocates to help with schools</li> <li>➤ EHCP support to appeal</li> <li>➤ Improve communication with parents</li> <li>➤ Meet/Assess CYP before decline social care support</li> <li>➤ Co-produce SEND college progression fairs with families – find out what they want and need</li> <li>➤ Clear procedure for CYP who have school anxiety</li> <li>➤ Increase specialist school capacity</li> <li>➤ Hoping Ordinarily available will improve with inconsistencies of support in mainstream</li> <li>➤ Improve one planning</li> </ul>

## Responses:

- 3 Social Care
- 2 Communication
- 2 Other
- 1 Young Adult Support



# Social Care, Communication. Young Adult Support and Other

*"My son is non verbal and has autism. He is 14 years old. I have called several times to try and get help through social care services to access some help with taking him out. We are always told that he doesn't qualify for help. I have two other children age 13 and 5 years old. My 13 year old has cerebral palsy. We can not go out as a family!"*

*"SENDIASS have made improvements related to the feedback from the original inspection"*

*"A clear procedure for children who have school anxiety. Special schools need more funding to increase capacity / more schools need to be created. Hopefully the Ordinarily Available offer will help with inconsistencies in SEN support in mainstream, but more can be done around One Planning and use for targeted support."*

*"Voluntary sector- they are the only realty services that have helped us!"*

*"Out of school clubs all been wonderfully supportive."*

*"Sending correspondence and any information to parents in the first instance."*

*"Communication between paediatrics and parents. I feel as though, as parents, we come second to school. Poor"*

*"Support in mainstream is not working needs specialist placement. Need support from Social Care as looked after child, but not getting it."*

*"I have just been to the Progression Fair at (Education setting name removed) with my young person who attends their Extended Learning Provision. I am so angry at how this was put together - I'm struggling not to rant. the majority of exhibitors were in the sportshall - that had been all dressed for the occasion - looked all very professional. For the Extended Learning students - their exhibitors were separate and shoved in a small squash court - so only room for about half a dozen, one of which was (Education setting name removed) own supported internship programme - and two exhibitors that hadn't turned up. There wasn't anyone from the PfA team (or not that they were obvious) There was no dressing/staging in there - just a handful of rickety tables!! Really looked like the poor relation. I get the busy atmosphere of the main hall could have been considered to be too overwhelming but they were still taken round in their tutor groups anyway so that contradicts that theory! It made me feel that the young people attending the Extended Learning provision are not seen as full and valued members of the college community. Just absolutely appalled that they could think this was in any way acceptable"*

*"Earlier intervention better resources in The voluntary sector"*

*"It's less than 2 months until the college year finishes."*

*"Being told over the phone that he doesn't qualify is not good enough. We would love someone to come out and assess our son's needs and meet him" (Social Care)*





# Next Steps and Feedback to our Families

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

We continue to use the “live”, unpublished data so that we can address “Hot” topics as they arise, such as Home-to-School Transport at the beginning of the academic year. Issues continue to be raised in meetings throughout the year to support change and resolve where possible.

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

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

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





# Disclaimer

The information and comments presented in this report are the views of the survey respondents and in no way, express or implied, should be construed to represent the views of Essex Family Forum CIC.

Essex Family Forum's purpose is established under the legal requirements of the Children and Families Act 2014. We therefore have a duty to faithfully relay the views and experiences of parents and carers of children and young people with SEND aged 0 – 25 years with regard to the services they use.

Essex Family Forum aims to work co-productively with services to improve the users' experiences and to recognise good practices. Essex Family Forum accepts no legal liability for the personal accounts, views, or opinions that survey respondents shared.

