

Graffiti Wall

Representing Parental Views on SEND across Essex

Essex Family Forum

February 2021



Concept of the Graffiti wall

A new virtual way of working

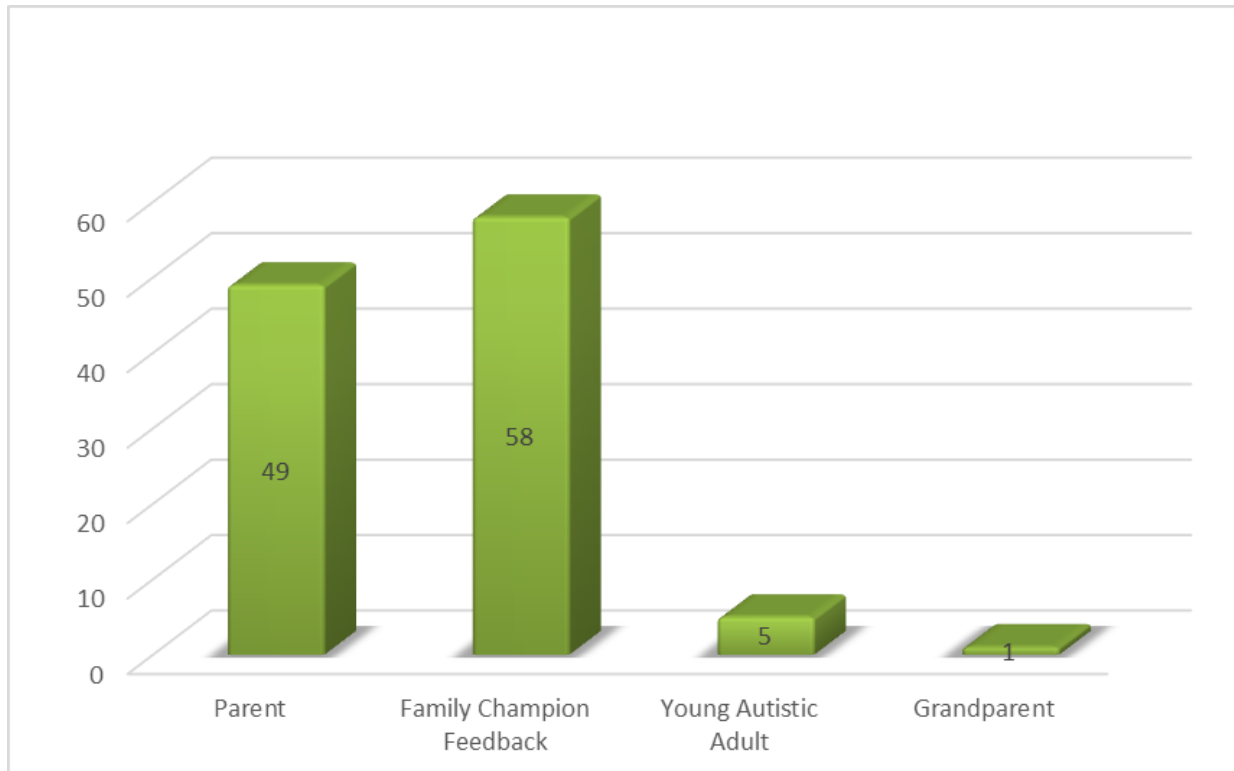
The Graffiti wall was set up to provide parents with a continuous opportunity to tell us their experiences on SEND Services in Essex. We previously visited and hosted coffee mornings, events, met with parents and asked our Family Champions to collate views of the families they knew.

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, 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 0-25 are invited to share their views.

The data gathered is anonymised and presented quarterly to the SEND Improvement 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



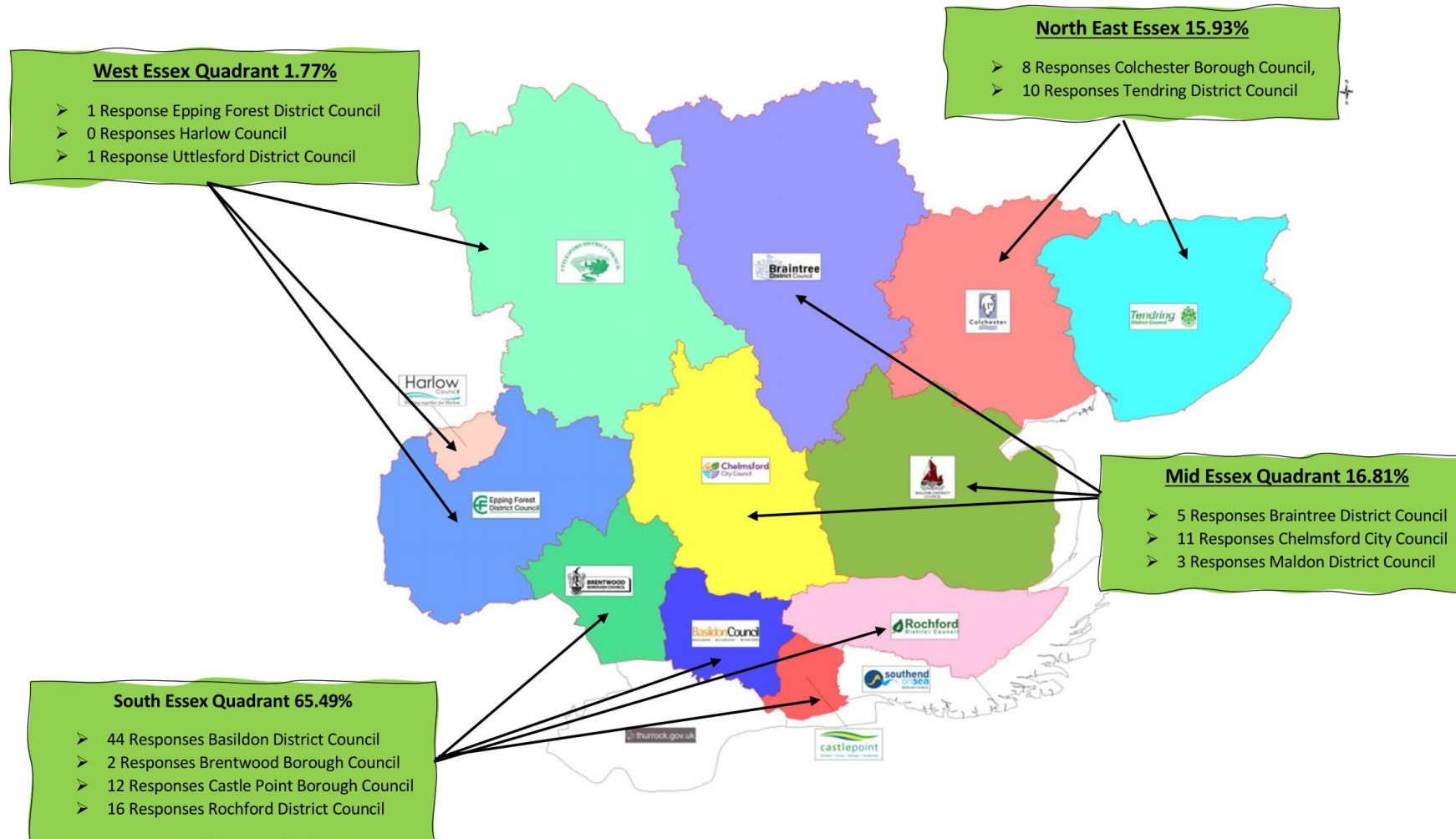
A total of 116 people provided feedback between 09th October 2020 and 31st December 2021.

- 97.4% (113) of participants consented to sharing their experiences
- 2.6% (3) of participants did not consent to sharing their data being used and therefore it has been excluded

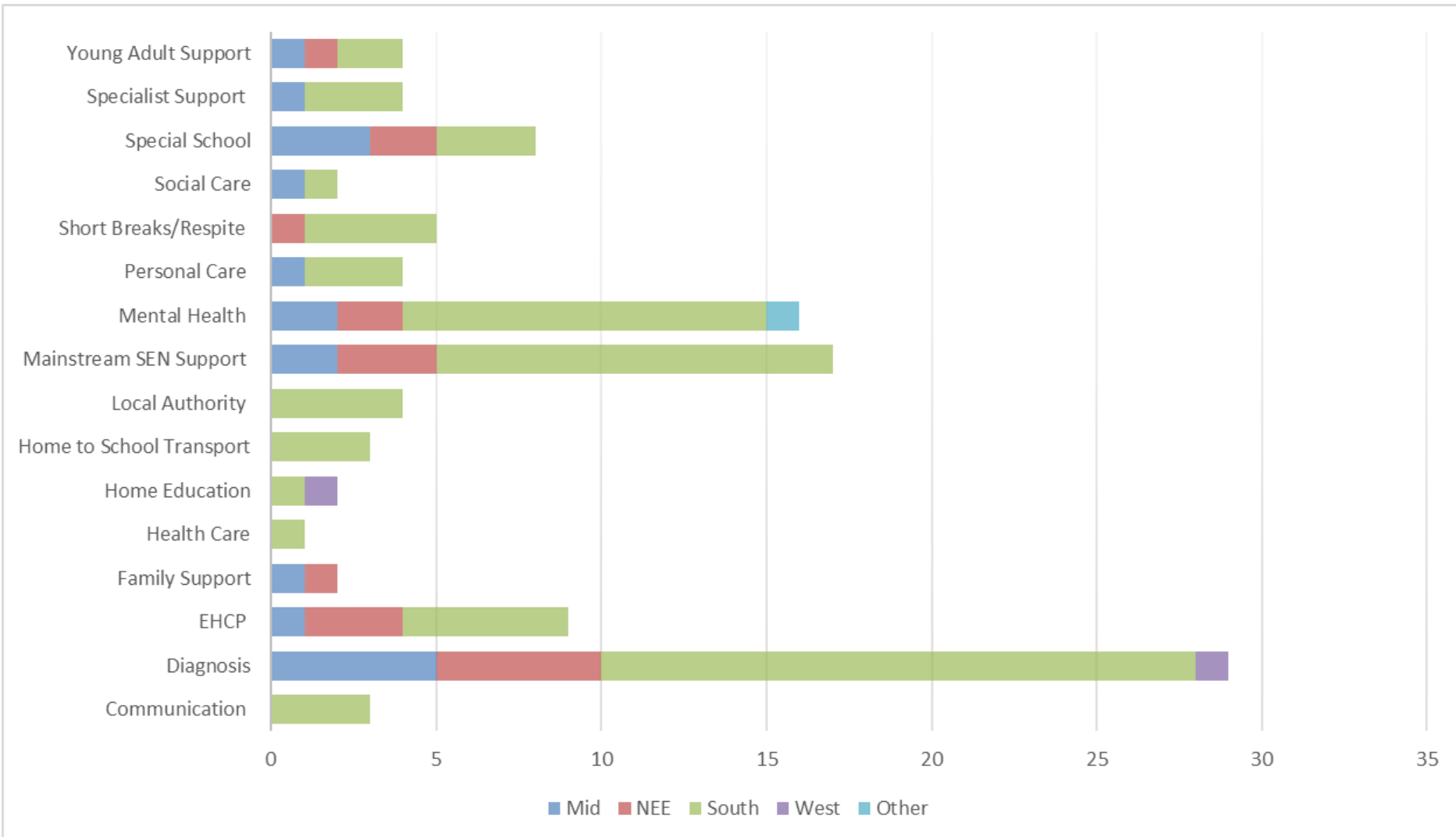
A Breakdown of Participants is shown. It should be noted that the 'Family Champion' feedback includes feedback provided to us via:

- EWMHs Engagement Events which we hosted,
- our network of Family Champions
- our Family Champion Quadrant leads

Responses by Area



Category of Feedback by Quadrant



We asked Parents to categorise the area that they were providing feedback on.

A full breakdown of categories is provided overleaf.

Category Breakdown

Special Schools	Gaps in specialist provision, ASD hubs
Mainstream SEN Support	Teacher and SENCO training, Academy school accountability, consistent mainstream provision, One Planning
Home Education	Help with home schooling and in getting back to school
Communication	All education providers and services
SEN Funding	Funding formula, banding, ring-fencing
EHCP	Needs Assessment, EHCP process, ability to obtain, plan quality and Annual Reviews
Home to School Transport	Needs Assessment, EHCP process, ability to obtain, plan quality and Annual Reviews
Short Breaks/Respite	Access to clubs, holiday care, overnight respite
Mental Health	Access to help in schools, EWMHS
Social Care	Access to Social Care, support provided, Direct Payments, Personal Budgets
Personal Care	Continence service, staff training, feeding, mobility and equipment
Health Care	Training of GPs, Dentists etc., access to Paediatricians and other Consultants, specialist health visitors
Diagnosis	Referrals, Waiting lists
Specialist Support	Access to SLTs, OTs, EP's
Family Support	Pre & post diagnosis support, support groups, training courses, SENDIASS, one point of contact, charities
Local Authority	Local Offer, inter-connection between services incl. NHS services
Young Adult Support	Preparing for adulthood, Transition to adult services, options available for SEN post education
Other	

Engagement

The Graffiti Wall was launched directly after our first annual survey had closed. We fully expected this to impact on the number of parents who would then re-engage and update their views on the Graffiti Wall shortly thereafter.

Essex Family Forum appointed four Family Champion Leads to guide parental engagement in each of the quadrants in September 2020. Their roles includes:

- Increasing the number of Volunteer Family Champions in each quadrant
- Engaging and building relationships with local support groups and provision

Whilst our Family Champion Leads are building on existing relationships with support groups, family champions and provision, we also recognise the challenges we, as a forum, face due to the ongoing restrictions and national lockdowns as a result of the current pandemic.

- The increased pressures of home-schooling and loss of respite facilities, family support clubs and activities are impacting heavily on families being able to engage in a meaningful way.
- Establishing strong links to education settings has and continues to be a challenge due to current pressures of the pandemic.
- Many coffee mornings and SEND parent events have stopped due to the restrictions in place, and virtual attendance of those that do run are lower than when face to face (for example our recent EWMHs Virtual Engagements) which makes establishing relationships with parents and carers difficult.

Diagnosis Feedback

What is not working

- Pre and post diagnosis information is inconsistent and poor.
- Pathways are not transparent. No information on what to expect, assessments, waiting times
- Poor communication/ Parents not listened to or feel dismissed by professionals
- Long waiting times
- Lack of diagnosis is a barrier to access other services such as short breaks and appropriate support in schools,
- Schools not supportive of parents pursuing an assessment.
- Lack of mental health support whilst waiting for an assessment,
- Moving between CCGs effects wait times and access to services,
- Children who are Home Educated experience this as a barrier to diagnoses as school input is required,
- Lack of knowledge and inconsistencies from professionals (GP/Health Visitors/Paediatricians)
- No pathway for a Dyslexia diagnoses
- No diagnoses for sensory processing or Pathological demand
- Referred out of area
- Lighthouse Centre
- Recognition ASD presents differently in Girls

Not being able to transfer between councils whilst on the diagnostic pathway (south to mid area) We received an appointment after 18 months wait, but this was cancelled when they realised we had moved and we were moved to the bottom of the waiting list in the new area.

What is working

- Good GP support
- Moulsham Grange arranged a peer support group
- Lorna Wing
- Local charities and organisations providing workshops and information

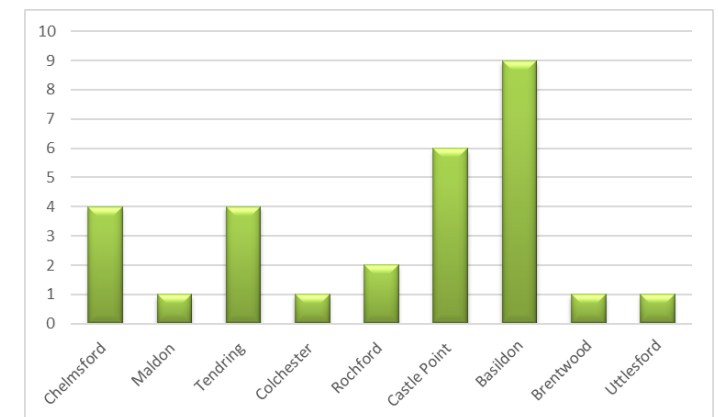
What can be done to improve things

- Improved local offer
- Specific guidance on diagnosis
- Clear pathways between services
- Improved communication
- Improved waiting times

Clear explanation of the process and what to expect. Regular and empathetic communication Provision of a support and information pack to be given when diagnosis is given

Went to GP to request physio and came away with a referral for ASD. GP was amazing

Feedback by district



Mainstream SEN Support Feedback

What is not working

- Generic one plan/ paper exercise
- No Support
- No training or support for parents
- Transition support
- Schools don't support diagnoses
- Funding
- Lack of understanding
- Lack of training (sencos/teachers/headteachers etc)
- Bullying not being addressed by school due to SEN
- Reduced/No access to services due to lockdown (School risk assessment not letting in professionals eg: EP's)
- No support for those on SEN Support during lockdown
- No suitable provision for HF ASD

My son's senco called me and was so patronising and made me feel like I had failed as a parent. I was so upset after the call. She had no sympathy and lacked understanding on ASD.

What is working

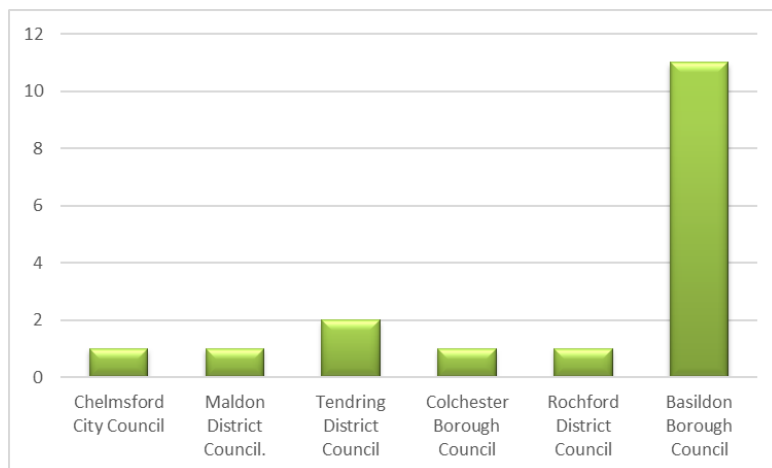
- Positive feedback
- Good Sencos
- Strategies put in place
- Family Support
- Online meetings

I received a telephone call today from a class teacher to say how much she enjoys having my child with SEN in her English class. Communication with schools is almost exclusively talking about problems, and it was truly wonderful to have someone take the time to feedback something positive. Her positive attitude is probably a lot of the reasons why her class is a positive experience for my child! Be great if more teachers could look for the positives and share them with parents

What can be done to Improve things

- Tailored support to meet child's needs
- Communication between parents and school
- Transparency
- One planning workshops for parents and schools
- Schools to list to Health advice
- Increased support for those on SEN Support in Lockdowns
- Transition Information/process

Communication between school and parents. Consistent SEN provision and more transparency

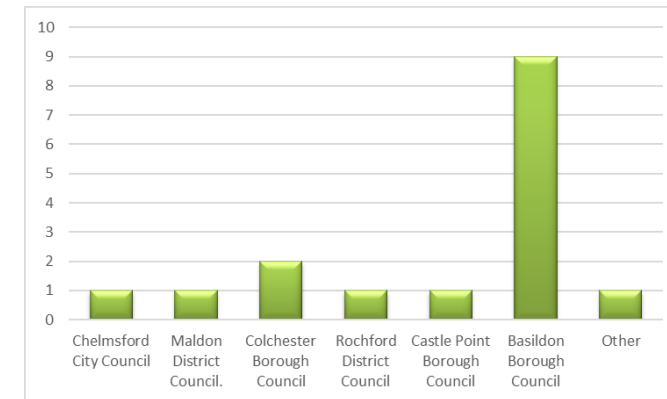
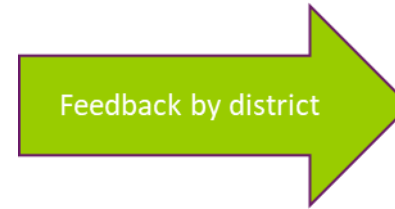


Feedback by district

Mental Health Feedback

What is not working

- Long waiting times
- Mental Health/Anxiety affects school attendance
- The number of appointments offered not sufficient to create bond and work with child with SEND
- Some charities don't accept children with EHCPs
- The referral route into some charities service and the cost is unclear
- Crisis line referred to an on-line self-referral link and told to read lengthy documents – not great when in crisis
- EMWHS won't accept children with ASD
- Low tier interventions won't accept self-referral as needs to complex (EWMHS won't accept either)
- No clear support for ASD co-morbid disorders such as eating disorders
- Inappropriate support offered for children with SEND
- No immediate support at crisis points (suicide attempts/self-harm)



What can be done to improve things

- Supporting children with ASD
- Improved communication parents and schools
- Improved targeted support

My recommendations are for more parent and young person support, more positive activities for young people (eg wilderness project, yoga, social activities). Opportunities for young people to express themselves in a manner that suits THEM. More training for schools.

EWMHs - my daughter was refused access even though she said we wanted to be dead, she couldn't be in this world any longer, it was too noisy and too busy for her and she just wanted to leave this world. She was self-harming by picking at her skin until she had sores all over her arms and legs. Community peads (who she was under due to ASD) recommend a self-referral to EWMHs. Typically, she was happy at the appointment, but her speech had regressed and was babbling like a baby (she was 8). Was told nothing they could do as she had ASD and it was part of the course with ASD. Also, i was told that I should explain what being dead actually means, if I did and she understood that she probably wouldn't say such silly things... (she was 8 with ASD and was not able to communicate with more than a baby babble...) Lockdown came and all the sores went as did the anxiety. In the lead up to school, she refused to leave the house, barely her bedroom for weeks. She now school refuses and the behavior of skin picking is starting again. she came out of school with a paperclip stretched out and had used it to scratch and mark her arm.... school didn't see the issue.. Advice from a local offer said she was above their grade for support and i see no point in trying EWMHs again.... so what to do now?

What is working

- Not Much
- Psychiatrist Support
- School support

The senior school have been on the ball and supportive. The telephone assessor was very good.



EHCP Feedback

What is not working

- Needs Assessment refused
- Had to go to tribunal
- Annual Review poor
- Lack of communication
- Not SMART (Specific, measurable, attainable, realistic and timely)
- Waiting times/time scales not adhered to
- Send ops team not supportive

What is working

- Nothing
- Educational psychologist and S&L assessment reports were good

Educational psychologist and S&L assessment reports were good

What can be done to Improve things

- More funding
- Training
- Follow the law
- SMART plans
- Meet deadlines/work to time scales

A governing body that is responsible for making sure the local authority do not continuously get away with not abiding by the SEND code of practice. Professional bodies within the local authority continuously provide unlawful information because they either do not know the legislation correctly or they do but choose to ignore it!

The whole process. Refused needs assessment x 3 but then got awarded ehcp after appeal. Argued that banding wasn't sufficient to pay for all needs...ongoing. Annual review appalling. LA didn't come, took 8 weeks to respond, removed 2/3 of need...we await appeal. The system is designed to break parents who are already at breaking point.



Feedback by district

Special Schools Feedback

What is not working

- Gap in provision for children who are academically able, but due to SEMH can't function in mainstream
- Not meeting academic needs
- Guidance on what constitutes Moderate (MLD) or Severe (SLD) learning disabilities
- Guidance on admission for specialist provision
- MLD school used Applied behavioural analysis (ABA) - there is no alternative
- Not using teaching methods as stated in EHCP, instead relying on outdated methods
- Leadership Team

What can be done to Improve things

- Autism Hubs
- A greater focus on provision for those who are academically able
- Fact sheets to aid understanding of MLD and SLD
- Fact sheet to understand levels of support at specialist provision schools
- Professional guidance who understands the child and their journey
- Improved communication between schools and parents
- Improved implementation of EHCP provision

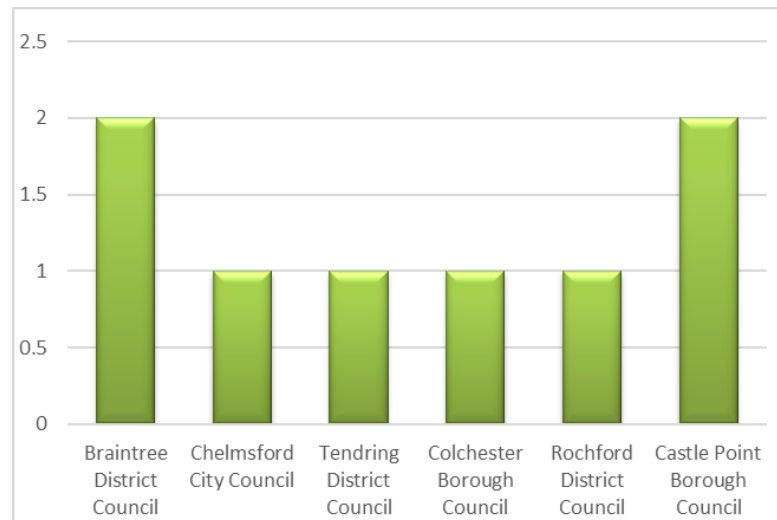
Better communication with parents and better implementation of EHCP

Smaller classes, calm environment, less pressure, support for social skills

What is working

- Peer Support
- Environment (smaller classes, calm)
- Teaching Staff

There is a lack of guidance on which type of specialist school to send a child to - when we moved my daughter from mainstream to specialist provision, no one gave us guidance on whether she was moderate or severe. Neither schools would comment, SEND Ops wouldn't comment and we had no idea. Eventually SEND Ops said moderate as she was "able to learn". She went to Thriftwood, who are wonderful but within a year they were saying they couldn't meet her needs and needed an SLD school. More upheaval for a child when all it needed was someone to take ownership



Other Feedback

Young Adult Support, Specialist Support, Social Care, Short Breaks/Respite, Personal Care, Local Authority, Home to School Transport, Home Education, Health Care, Family Support and communication

What is not working

- More support for those with challenging behaviours
- Transition/Young adult support/ transition to adult services
- Access to exam centres with understanding of SEND (Home ED)
- Lack of support/No go to person
- Moving between CCGs and dropping from services/back to bottom of waiting list
- Communication
- Access to services during COVID (Wheelchair/Hydrotherapy/respice/hospice care/therapies)
- Training for transport teams
- Online/Zoom remote teaching
- Transport not observing bubbles or social distancing

No constituency in approach. It's depends on your social worker on the assistance you get. No communication. We have to fight for everything. Treated as low life. We have to tell them everything, exposing are vulnerabilities to what end ! It's begging

Despite having an EHCP Essex county council ignore all responsibility to ensue I receive support. Haven't heard from them for over 18 months. They go out of there way not to support. EHCP means nothing

What is working

- Nothing
- Social Worker support
- Transport – permanent driver and bigger bus for Social Distancing
- Dream the Change provided support during COVID

What can be done to Improve things

- Improve outreach support – support groups/workshops
- Use SEND schools to host exams for home Ed
- Provide a go to person
- Improved communication
- Pathway agreements between CCG's
- Follow Law/Guidance
- Trained and knowledgeable Professionals
- Improved Preparing for Adulthood services

Our social worker was very supportive during the transition from college to supported living.

It's just not working at present but what would work would be a one point of contact for parents Who could act as lead professional or coordinator

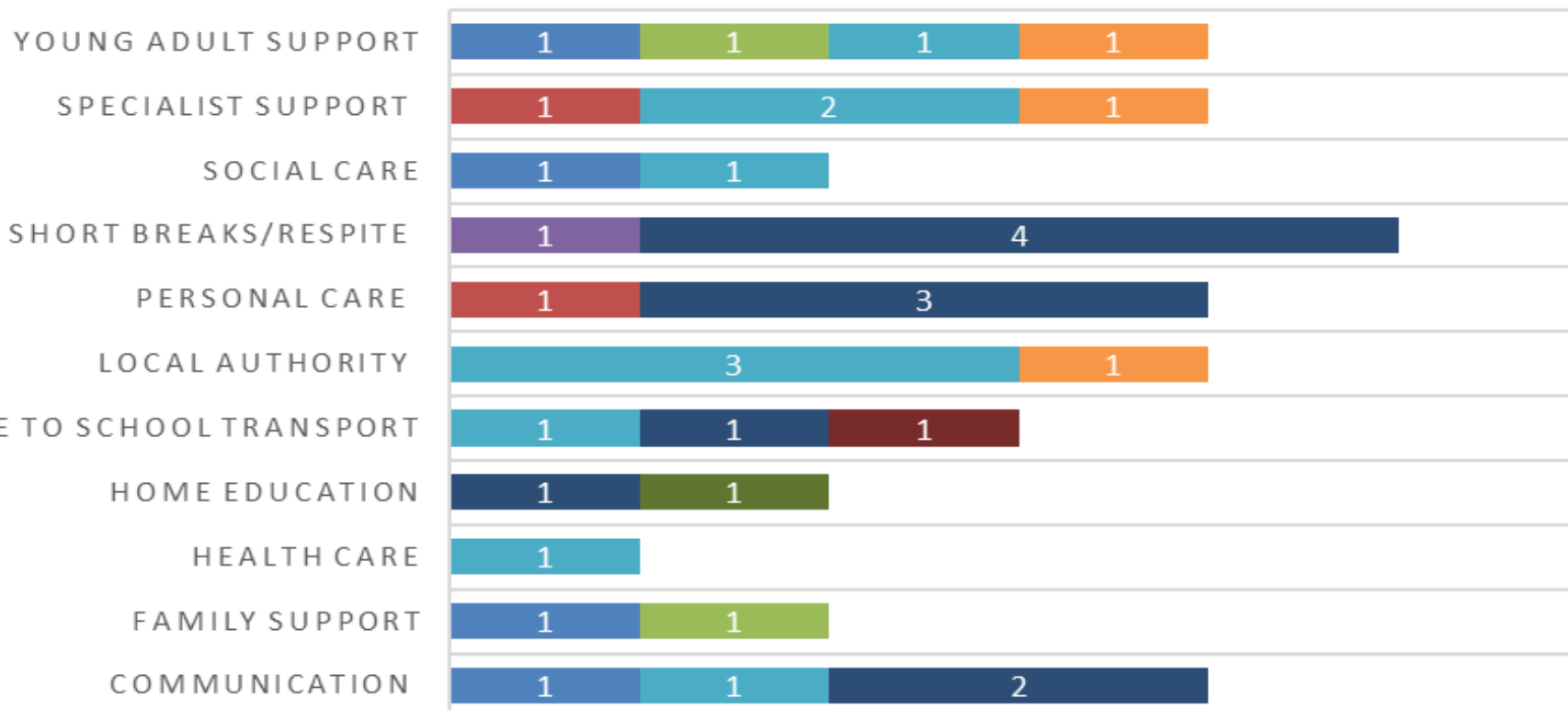
A "go to" person for early help, transition stages etc. who can follow your families journey

A pathway/agreement between CCGs that the child can continue with therapy under one CCG until can be picked up by the new CCG

Other Feedback

Young Adult Support, Specialist Support, Social Care, Short Breaks/Respite, Personal Care, Local Authority, Home to School Transport, Home Education, Health Care, Family Support and communication

- Braintree District Council ■ Chelmsford City Council ■ Tendring District Council
- Colchester Borough Council ■ Rochford District Council ■ Castle Point Borough Council
- Basildon Borough Council ■ Brentwood Borough Council ■ Epping Forest District Council



Next Steps

Essex Family Forum will present this data to the SEND Improvement Board. The SEND improvement board was set up in response to the weaknesses identified in the SEND Area Local Inspection that was carried out 30th September – 4th October 2019.

Essex Family Forum's response to this inspection can be found here: <https://essexfamilyforum.org/ofsted-and-cqc-local-authority-inspection/>

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

Essex Family Forum will continue to gather parents experience via our Virtual Graffiti wall through our Family Champion Quadrant Leads and Volunteer Family Champions and present this data on a quarterly basis, with the next being produced in April 2021.

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

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.