



Weekly Snapshot from EFF

Week ending- 26/09/25

Essex Family Forum receives many comments through our online Graffiti Wall, at events and through our Family Champions. Although we are not able to address all of these through this snapshot, please be assured that all feedback is raised with services and issues that are shared repeatedly are being highlighted.

You said:	We did:
Inconsistencies in Support – Mid & South We've long heard concerns about inconsistent support for families across MSE, particularly during the often lengthy wait for a diagnosis. Services like The Lighthouse Centre are working hard to support families during this time, but there's a clear need to build on and replicate their efforts. Consistent, coordinated support across MSE is essential to help families "wait well" and feel supported.	In January, Kate & Claire presented to Commissioners and Paediatricians from the Mid & South East Integrated Care Board (MSE ICB) at Brentwood Community hospital. The presentation used quotes from families about their experiences of waiting for an autism/ADHD diagnosis, and after diagnosis, and what families want from this service. EFF has now been invited to attend a System Transformation Summit on 1st October to focus on what a needs-led approach could look like in MSE. This will include representatives from SEND services across the region, including Education and Social Care. We are very excited to be involved in something that could make such a positive difference to so many families.
Update Ordinarily available information for parents	We are now able to share information explaining what the Ordinarily available is - click here . See link for more info: Types of support your child can get at school Essex Local Offer
ADHD Medication – Mid Essex At the recent Mid Essex Roadshow in Braintree, we heard that families were struggling to get ADHD medication reviews at Halstead hospital as there was no paediatrician available.	We have checked with the Operations Lead for Provide who has confirmed that families in this situation can be referred by their GP to Provide for medication reviews, as long as the GP is in Mid Essex. They would be placed on the waiting list for an appointment.
Accessible Communications Parents are recognising neurodivergent traits in themselves, which can make accessing support feel overwhelming. Some feel they're	We've continued to work alongside services to improve how information is shared with families. When communications and information are co-produced with us, we're



<p>letting their child down, struggling to advocate in the way a neurotypical parent might. Families asked for clearer, ND-friendly materials such as plain English, audio and video options and easy-read guides that work for both parents and young people.</p>	<p>mindful to ensure they are clear and easily read. Everything on the Local Offer is provided in plain text so it can be read aloud by screen readers and supported by SENDIASS and charities. We were recently part of a working group that recommended all services update documents through a neurodivergent lens, to make them more accessible.</p>
<p>One Planning: Terminology and Documentation Variation Families and professionals raised concerns about inconsistent terminology and documentation across Essex. The same provision is often labelled differently between schools, making it harder to understand what support is in place and creating confusion when children move settings. There's a clear ask for shared language, templates, and examples to help ensure consistency and reduce uncertainty.</p>	<p>We had similar feedback earlier this year, which we shared with the relevant Quadrant Manager around terminology and documentation.</p> <p>We've now passed this latest feedback on to the team leading the rollout of Ordinarily Available provision, to explore whether anything could be done to support greater consistency across schools as part of the rollout. We've also looped in the Quadrant Manager again so they're aware this type of feedback is still coming through.</p>
<p>ADHD Shared Care – GP Communication Gaps Families are not receiving clear information about ADHD Shared Care changes from GP surgeries. Despite communications being written and made available by the Integrated Care Board (ICB), they are not consistently passed on with shared care agreements. Parents feel left in the dark and unsupported.</p>	<p>We have raised this through Integrated Neighbourhood Team (INT) channels to explore whether there are ways to improve how information is shared between the ICB, GP surgeries and families.</p>

In other news.....

- Representatives from Essex Family Forum attended the Parent Carer Support Group hosted by Essex County Council's SEND Navigation Team. Transport was a key topic, with many families reporting issues at the start of the academic year. As this appears to be a recurring problem, concerns are being escalated to prevent similar disruptions in future years. We'll share updates as soon as more information becomes available.

There was also discussion around Educational Psychologists (EPs), with many reportedly requesting to carry out assessments online. We were reassured that EPs, as



registered professionals, will only conduct remote assessments when appropriate. Parents have the right to decline a remote assessment, though opting for an in-person appointment may involve a longer wait due to limited availability of EPs offering face-to-face assessments. For details of upcoming Essex Local Offer roadshows, please visit the events page ([click here](#))

- Claire and Kate attended a national meeting this week held by the National Network of Parent Carer Forums (NNPCF) to discuss key issues ahead of the Government's forthcoming White Paper. Although there was not any new information to share at this stage, this was an important opportunity for us to give our views and insights. This will enable the NNPCF to shape their response and focus ongoing conversations with Government policy teams.
- Kate and Ange attended the South Joint Send Working Group last week. Issues discussed include insistence of diagnosis to access support in school, changes to the Family Impact Survey amongst other things.
- Kate had her informal Family Champion Volunteer catch-up on Monday at Human Kind Café in Billericay. It was a lovely opportunity to connect with Family Champions in south Essex, hear what's been going on for them, and share updates. If you're curious about becoming a Family Champion Volunteer, feel free to visit the *Be a Family Champion* page on our website: [Family Champion | Essex Family Forum](#)
- Kate attended the SET Therapies meeting for the south this week. The Balanced System continues to progress well across the south, with positive feedback on drop-ins, choose and book appointments, and duty/advice lines. Parent communications were discussed, with plans to share updates once available. A range of formats is being considered to support accessibility, including digital documents, printed flyers and short videos.
- Sarah attended the North East Essex Neurodevelopment Adult Partnership (NAP) Meeting this week representing SEND families up to the age of 25.
- EFF is aware that the Autism Central contract is moving to Anna Freud from 1st October, from National Autistic Society. You can visit the Autism Central website for further details (<https://www.autismcentral.org.uk/news/autism-central-update>). ECC has been running the East of England regional hub for 2 ½ years. We have been assured by ECC that the valuable support to parents will be continued, albeit in a slightly different guise. We hope to update you with further details next week.
- The management committee has been working especially hard in the past few weeks with the recruitment to a couple of vacant positions created by reorganisation and expansion of our team. We will introduce our new staff members, here, next week!



Please note: The Graffiti Wall and Snapshot is designed to give anonymised feedback and cannot be used to answer individual queries.

All EFF staff are part time and work on a flexible basis. If there are weeks when a quadrant does not appear represented in this snapshot, we are still working hard. Please bear this in mind.