

# **Weekly Snapshot from EFF**

### Week ending- 12/10/25

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:

#### Easier Access to Post-16 Education and Employment Events

There has been lots of feedback over the last year from families telling us it's hard to find out about post-16 events until it's too late, and that event information is often scattered or hard to find.

## We did:

In response to the feedback we have shared at our monthly meeting with the PFA/Targeted Employment team, they have created a new interactive calendar using Page Tiger: Targeted Employment Events Calendar

This termly-updated calendar brings together post-16 education and employment opportunities in one place, making it easier for families to plan ahead.

A flyer is due shortly, and we'll share it as soon as it's available.

#### \*\*Update\*\* MyCareBridge (MCB)

Since MyCareBridge launched, families have shared a wide range of feedback with us through events and the graffiti wall—from App and website glitches to missing information and faulty save functions and hard to find resources. Some parents struggled to use the portal due to lack of data or devices, and many felt unsupported when completing forms. There were concerns about the lack of user guide for families and the need for a video guide was identified to help those with literacy difficulties access the guide that was created for families.

More recently, families told us the app felt helpful at first, but once their child was placed on the waiting list, it became unclear what was happening. The portal appeared to close to them, taking away access to the At our monthly meeting this week, we were pleased to finally get confirmation that the feedback we raised from families over the past year has now either, been or in the process of being resolved including differences between the App and website which we feel may have been contributing the differing save experiences that parents had recently told us about.

The team have also made progress on supporting families facing digital exclusion, digital literacy barriers, and those without settled accommodation, where access to devices or stable internet may be limited. Several charities and organisations are now involved, with the portal team providing training on MyCareBridge. Signposting information to these services will follow once everything is in place.



resource section and preventing families with literacy difficulties from seeing new guidance on how to use it when that information became available.

Some haven't been sure why they'd been referred, and felt unsure where to go for support with autism or ADHD or what the assessment process is.

The video guide to the portal is nearly ready—just waiting on the voiceover.

In response, to the more recent feedback we've received we've asked for a standard document to be added to the resource section across the platform, explaining what the portal is, what the autism assessment involves, and where to find support.

The Supporting Your Neurodivergent Child book has now been uploaded as a standalone resource and should be easier to find. This means that those referred remotely by Health Visitor teams will be able to access the book, which families have told us they felt they missed out on.

The team are working to restore access to the portal for those accepted onto the waiting list.

Education and health staff will be reminded, via this term's webinars, that they must ensure parents understand the process, the reason for referral, and where to find support.

We will continue to request updates on any outstanding issues we have raised. Please continue to share your experience with MyCareBridge. You can find our Graffiti Wall for feedback here Feedback Wall | Essex Family Forum

### In other news.....

New Volunteer for West Essex – Stacey met with Chloe, who is keen to get involved
with Essex Family Forum as a volunteer. We're delighted to welcome her on board! Our
volunteers play a vital role in helping us capture as many family voices as possible,
ensuring that we can shape and improve services for children and young people across
Essex. If you'd like to learn more about how you can get involved, visit our website;
https://essexfamilyforum.org/get-involved/family-champion



- **Preparing for Adulthood (PFA) Meeting** Kate and Ange met with the PFA team last week for their monthly feedback and update session. The team were pleased to share two new resources, which reflect ongoing feedback from families and aim to support smoother transitions into adulthood for young people. These were:
  - o **Interactive Events Calendar**: Now live and ready to support families in planning and accessing opportunities. *See the link above*.
  - Post-16 Guide: Currently undergoing final checks, with hopes to publish by the end of the year. This will be a guide for both families and professionals to ensure consistency in information for young people and families.
- STOMP STAMP Oversight Group Kate and Stacey attended the bi-monthly STOMP STAMP meeting last week, which brings together professionals and parent carer forums to improve medication safety. We received updates on the STAMP report and reviewed the SET LeDeR Annual Report. The group discussed psychotropic medication and how it's currently prescribed, monitored, and safely reduced and that families need clearer communication and support, particularly when medication is being deprescribed and the expectations around how long the medication will be used for need to be addressed when starting medication. Essex Carers Network are working with King's College Hospital to improve practice to ensure families are informed and supported.

#### **STOMP STAMP Abbreviations:**

- **STOMP** Stopping Over-Medication of People with a learning disability, autism or both
- STAMP Supporting Treatment and Appropriate Medication in Paediatrics
- LeDeR Learning from Deaths Review Programme
- **SET** Southend, Essex and Thurrock
- Next Steps. Targeted Employment event Kate, Claire and Ruth, our new Mid Quadrant Lead, attended the Next Steps event in Chelmsford last week, speaking with families about post-16 support, access to ADHD medication, and what's available around employment and training. Many were unsure what help is out there, especially without an EHCP. These are familiar concerns, and we're currently looking over a document that the Preparing for Adulthood team has written, in collaboration with various teams and organisations, shaped by feedback we've shared and that they've gathered through their own channels. We hope it will help address some of the gaps in knowledge and give families clearer information about their options.
- MyCareBridge Forum Kate and Claire attended this month's MyCareBridge forum, joined by new Quadrant Leads Ruth (Mid) and Carly (South). We were pleased to hear that the majority of concerns raised by families and ourselves over the past year have now been resolved, you can read more about this in 'You Said, We Did' above. We also raised the issue of ongoing misinformation around the need for three terms of One Planning before a referral can be made, which is not the case. The team confirmed they



will continue to address this in school webinars and will ensure that health staff are made aware via GP bulletins, the intranet and in their Time to Learn sessions.

• The Lighthouse Centre Parent, Carer and Young People's Forum - Kate and Carly (South Quadrant Lead) attended this week's forum. The parent link was down, but Lighthouse have committed to fixing it before December's meeting.

Kate raised concerns about ADHD medication shortages, shared care delays, and the lack of support for 18–21 year olds who were previously under their care. Lighthouse advised:

- To safeguard children already receiving medication, they have been prioritised within the service. This change has contributed to longer wait times for those seeking assessment and medication.
- The loss of the ADHD Service and the prescribing nurses has reduced followup capacity and has contributed to service delays.
- GP hubs in Castle Point & Rochford are being prioritised, but transfers to GP federations are delayed due to the three-month contact requirement, which is also affecting waiting lists.
- Prescription Requests, families should request prescriptions at least two
  weeks in advance and re-request prescriptions as soon as the current one is
  collected.
- o If your child is 14+, has already done their research and is considering ADHD medication, they can ask to start this at their appointment. Due to currently issues around ADHD prescribing and shared care, choosing to go away and think about it currently means joining a waiting list of at least six months, possibly longer, before treatment can begin. This can mean they're not seen in time to start medication before key transitions like exams, college, or leaving children's services to go adult services, where there may be a further wait to be seen.
- o If your child isn't ready, it's definitely okay to hold off starting medication. There's no pressure to decide quickly, taking time to think it through is often the right choice for many young people, and it's important not to rush. The advice above is simply for those who've already had those conversations and feel ready to begin, but may not realise there could be a wait and later wish they'd asked to start medication sooner.
- For those aged 18+ Current ICB guidance suggests that they could contact their previous prescriber for prescriptions whilst transitioning to adult services. Kate asked if the Lighthouse Centre could support previous patients in this way, and the Centre confirmed that sadly this isn't something they can currently offer to those previously under their care. There are conversation happening on how to support these young people.



- Claire & Ruth attended the monthly SET Therapies Delivery Group for Mid Essex. We
  heard from the professionals involved that all schools in Mid Essex now have a link
  therapist for Speech & Language. The group are now including Early Years professionals
  to bring the Balanced System to that cohort. Have you receive communication from
  your school with details of your Link Therapist? Let us know on our Graffiti Wall, link
  below (Sarah can you put the link into the GW pls)
- Claire & Ruth attended the Mid Essex SEND Joint Working Group on Wednesday. We
  heard updates from SEND Operations on how they are communicating with schools
  about Annual Reviews due. We also heard updates from the Multi Schools Council, and
  the Essex Children and Family Wellbeing Service. We highlighted the main issues we are
  hearing at the moment from families, including SEND Home to School Transport.
- On Thursday, Claire & Ruth attended the Mid Essex Startwell Group which is attended by professionals working with children under 5 and their families. There are a series of Roadshows over Mid Essex starting from next week for families with children either starting school or pre school to meet with professionals and ask questions. Our Essex Family Forum Facebook page has details of the times and venues.

### News from the region.....

• Childhood vaccines and the winter Flu vaccine rollout – We have been asked to share the following information. "Public Health Commissioning in East of England NHS has been requesting the support of the ERPCF to widen the uptake of Vaccinations (both childhood vaccines and the winter Flu vaccine rollout). Public Health have developed a very quick (7 minute) survey for Parent carers to complete to give Public Health a better insight into why some SEND children & Young people do not get vaccinated. Once they know the wider issues - they can start to address them. The link to the survey is: <a href="https://forms.office.com/e/aQLaGPXpfe">https://forms.office.com/e/aQLaGPXpfe</a>

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.