The Essex Alliance
Working together to represent the parents and carers of Southend, Essex and Thurrock

Transforming Care

Voluntary, Charity, and Support Organisations Event – October 2024

Parent and Carer Event – November 2024

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Transforming Care Information Event

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Event Overview

We hosted two events in collaboration with the Learning Disability and Autism Health Equalities Team, working on behalf of the three Integrated Care Boards (ICBs) and local authorities across Southend, Essex, and Thurrock (SET), alongside The Essex Alliance, which represents the three appointed Parent Carer Forums.

The Essex Alliance Team

- **First Event:**
  Attended by representatives from 19 voluntary sector organisations, charities, and local groups across the SET Essex footprint. These organisations provide support to autistic children, young people, with and without a learning disability, and their families.
- **Second Event:**
  Approximately 45 parents and carers participated, with CAMHS also present to raise awareness of their services.

Transforming Care Information Event

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Key Aims of the Events

1. **Raise Awareness:**
   Provide an overview of the Local Transforming Care Programme, focusing on improving health and care services for CYP aged 0-25 with autism and/or learning disabilities.

2. **Information Sharing:**
   Ensure local organizations and families are equipped with the essential information to navigate and access support services effectively.

3. Introduce and Explain Services:
Highlight new and existing services available for CYP with autism and learning disabilities, including:

1. Dynamic Support Register (DSR).
2. Care and Education Treatment Reviews (C(E)TRs).
3. All Age Autism Outreach Service.
4. Keyworker Service.

Challenges and Opportunities in Engagement

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- The session for the Voluntary and Charities sector aimed to equip participants with knowledge to help them provide accurate information to families.
- It was noted that not all organisations in attendance had direct engagement with families or CYP who had accessed services commissioned by the LD/A Health Equalities Team, nor were they always aware of the wider programme of support available.
- Many attendees found the session informative and said it would help them better signpost families and understand the support they may be accessing—improving how they work with those families.
- In the session with families, most had not accessed Transforming Care services, though many had CYP with mental health needs. This reflects our understanding that families often do not engage in participation during times of crisis. At such points, they are focused on seeking immediate, targeted support rather than contributing to wider system feedback.
- As a Parent Carer Forum, our role is to gather lived experience and amplify the collective voice—not to provide direct support or advocacy. We often connect with families after a crisis or when they are struggling to access services. This is why we value the insights of organisations in the voluntary and charity sector, who often support families during these critical moments.
- Many families choose not to share their experiences during or after a crisis due to concerns about the impact on their child's care. Reflecting on those experiences can also be traumatic, and some prefer to move on rather than revisit them. As a result, Parent Carer Forums often find it difficult to engage families who have been through Transforming Care—especially compared to parents navigating processes like obtaining an EHCP.

Gathering Feedback

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As part of these events, we took the opportunity to collect feedback on the experiences of both Parents, Carers, and the organisations that support them.

We structured the feedback around three key questions:

1. What is working well?
2. What is not working well?
3. What can be done to improve things?

The majority of the feedback focused on **what is not working well.** This aligns with the ongoing national "crisis" in SEND, as highlighted in key reports such as:

- **Children's Commissioner:** *Waiting times for assessment and support for autism, ADHD, and other neurodevelopmental conditions.*
- **National Audit Office:** *Support for children and young people with special educational needs.*
- **Isos Partnership:** *Towards an effective and financially sustainable approach to SEND.*

While our primary aim was to gather feedback specific to the Transforming Care agenda, the responses offered a broader perspective, shedding light on systemic issues across the entire system.

This presentation also reflects these wider concerns.

Understanding Family Perspectives: Why It Matters

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Turning Challenges into Opportunities

We acknowledge that hearing feedback from families can be difficult. Learning about systemic gaps, failures, or challenges may evoke feelings of guilt, frustration, or even defensiveness in professionals who are working hard within the constraints of the system. Feedback, while directed at the system as a whole, can sometimes feel personal to those striving to make a difference.

However, feedback from lived experience is **invaluable for driving meaningful change**. By embracing these perspectives, we can turn challenges into opportunities for improvement.

Understanding Family Perspectives: Why It Matters

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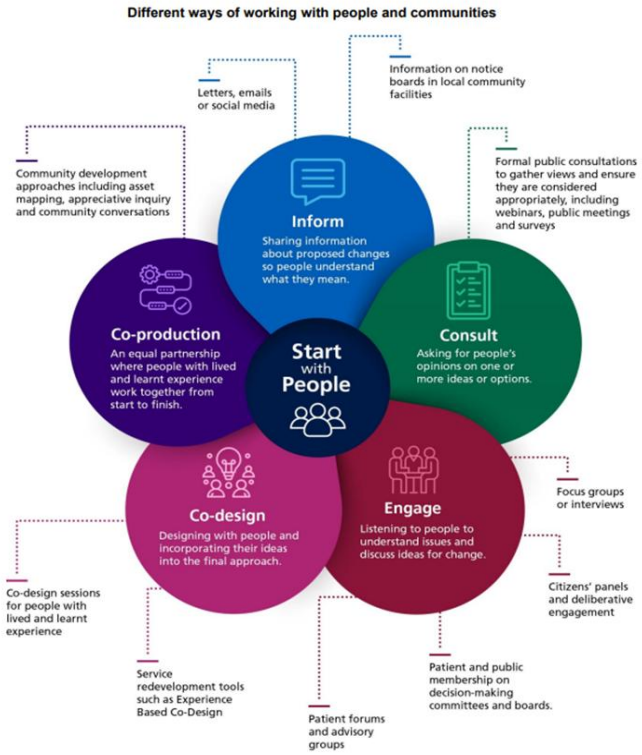
Why Listening to Families Matters

1. **Families Are Experts by Experience**
    1. Families and their supporters have first-hand knowledge of the challenges and gaps in the system and understand their impact on daily life.
    2. Their lived experiences provide insights that professionals may overlook, offering a deeper understanding of what needs to change.
2. **Practical, Real-World Solutions**
    1. Considering families' perspectives ensures solutions are practical, relevant, and aligned with real-world needs.
    2. Feedback from lived experience helps create services that work better for the people they are meant to support.
3. **Building Trust and Collaboration**
    1. Actively listening to families demonstrates respect and fosters trust between service users and professionals.
    2. This collaboration strengthens partnerships and creates shared ownership of solutions.
4. **Inclusive and Equitable Solutions**
    1. When families' voices shape the design of services, the solutions are co-produced rather than imposed.
    2. This approach leads to more inclusive, equitable outcomes that truly reflect the needs of those affected.



Working in Partnership with People and Communities: statutory guidance (NHS England 2022) https://www.england.nhs.uk/wp-content/uploads/2022/07/B1762-guidance-on-working-in-partnership-with-people-and-communities.pdf

Discussions on Transforming Care

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Many valuable discussions throughout the day were not fully captured in the "post-it notes" feedback. However, these insights were conveyed through meaningful discussions during the presentations, with the key points summarized below:

Access to the Dynamic Support Register (DSR)
Concerns were raised that access to the Dynamic Support Register (DSR) is overly restrictive. The high threshold prevents some children, young people (CYP), and their families from accessing critical support.
It is unclear what level of need a CYP must have to be included on the DSR. The term "at risk" is often interpreted differently by professionals across services—and by families—which leads to inconsistency and confusion.
Although the DSR is technically just a list, it acts as a gateway to vital support services.

Challenges with Diagnosis-Led Provision
•Families cannot access the DSR or keyworker support without a confirmed diagnosis.
•This creates delays and gaps in care during critical periods.
•Long waiting lists highlight the need for non-diagnosis-led support.
•CYP who self-identifying are excluded from services.

Discussions on Transforming Care

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- Keyworker – Those that had experience of the service or who had supported families, said it was invaluable.
- There was confusion if the keyworker service was a clinical service or not.
- The voice of the CYP or Families should be listened/valued more in CETRs.
- Professional Attendance at CETRs: examples that schools did not attend and this impacts on the recommendations and support.
- Limited engagement from Education/SEND Operations and EHCP are not updated to reflect changing need when a CYP is in crisis/CETRs
- Recommendations and actions from CETRs are not always carried out
- Some families were unsure if their CYP were still on the DSR/ reported unclear communication about changing levels of need.
- Queries were raised over the difference of AOS and Keyworker, with it being difficult to understand the difference (post explanations)
- Lack of good quality information which explains access and services.

Discussions on Transforming Care

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Gap Between Universal and Targeted Services with Specialist Services

- Parents and those that support them report significant gaps between universal, targeted and specialist services, reporting that their children, young people, and some families are often inadequately supported until they reach a crisis point.
- Interventions at this stage often require more intensive support, which can lead to poorer outcomes

Inadequate Mental Health Support for Neurodiverse Individuals

- Many participants felt that Child and Adolescent Mental Health Services (CAMHS) do not provide adequate support for neurodiverse children and young people.
- Families want to understand the difference of autism and a Mental Health Need. This should be clear for families, so they can seek and access the right support.
- Mental health concerns are often dismissed as being "autism" rather than mental health, leaving no dedicated clinical services to address autism-specific needs.
- The Autism Outreach Service was recognised as a positive initiative; however, its capacity has been overwhelmed by demand. Since our events, the service has ceased accepting new referrals as of December, only months after its launch*.
- As a result, mental health challenges often escalate to crisis points.

**This information is correct at the time of writing. Please verify the current status directly with the service or with the Health Equalities Team*

Key Systemic Challenges

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Based on the comments made from both Parents, Charities and the voluntary sector under the theme of “what is not working” there seems to be 4 overarching challenges.

1. Disjointedness between services.
2. Poor Communication with families
3. Long waiting times for EHCP, CAMHS, and autism assessments.
4. Over-reliance on (at times inappropriate) signposting instead of direct support.
5. Complex referral and eligibility criteria, compounded by limited early help offers.

Key Challenges – Specific Areas

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Transition and Post-School Support
- Lack of preparation for transitions to adulthood.
- Gaps in mental health support during and after transition.
- Differences between children and adult social services.

Educational Support Gaps
- Inadequate support in mainstream schools for SEND.
- Lack of specialized school spaces.
- EHCP not being effectively implemented or respected.
- Stigma and punitive policies around attendance.

Challenges with Mental Health Services
- CAMHS inefficiencies and limited engagement with neurodivergent children.
- Limited options for non-CBT therapies.
- Over-reliance on group-based approaches.

Supporting Parents and Carers
- Insufficient respite care for Parents.
- Lack of training and clear communication from professionals.
- Overwhelming reliance on parents to coordinate services.
- Over-reliance on signposting instead of direct support.

Impact on Children Young people and their Families

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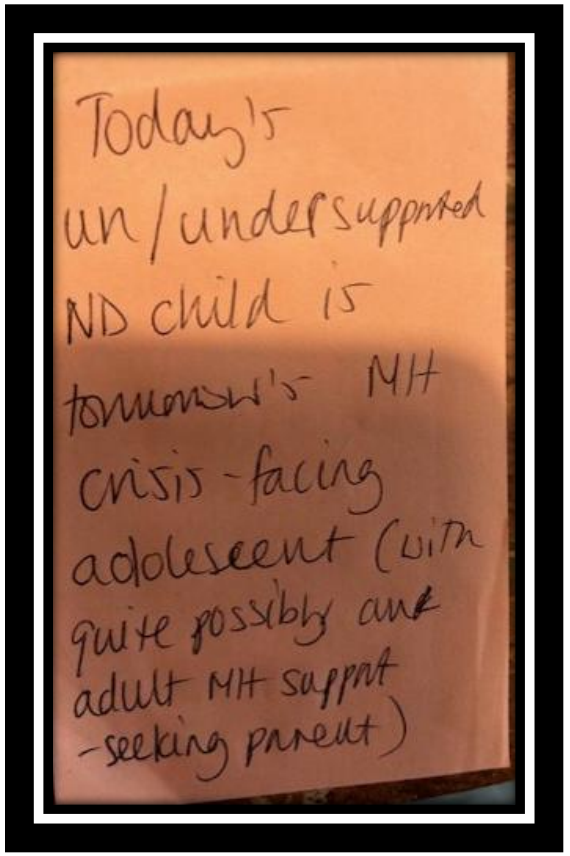
1. Families report feeling unheard, overwhelmed by information, and lacking respite.
2. Insufficient help for parents, with increased crisis risk
3. Limited PA support.
4. Difficulties obtaining accurate diagnoses; criteria are often too restrictive.
5. Lack of support for co-occurring conditions within mental health provisions.
6. Poor CAMHS to adult service transitions; services often discontinue without adequate follow-up.
7. Lack of appropriate educational settings means many children are not effectively supported in mainstream schools.
8. Emotional and financial strain on families.
9. Missed educational and developmental opportunities for children.
10. Trauma from repetitive and inefficient communication processes.



"Today's un/under supported ND Child is tomorrow's Mental Health Crisis facing adolescent"

Key Themes of Success

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Based on the comments made from both Parents, charities and the voluntary sector under the theme of “what is working well ” there seems is less data to analyze but it was clear that some areas are working well.

Many parents at the second event commented at both the event and via the feedback that the information session offered was valued and families asked for more to be hosted, particularly with a focus on Mental Health and earlier intervention.

Key Successes – Specific Areas

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Peer and Community Engagement and support
- Peer support and parent networks are effective.
- SEND clubs and third-sector services are valued.
- Charities and community groups offer consistent support.
- Information sessions such as hosted event

Professional Support and Services
- Approachable adult social care teams in Essex County Council.
- Trusted and practical support from keyworkers.

Schools and Education
- Some schools are going above and beyond with inclusion partners.
- Improved communication and better-educated schools.
- Positive engagement with families and young people.

Innovative Services and Opportunities
- Lovely day opportunities and events for young people.
- Positive impact of the "Supporting Your Neurodivergent Child" resource pack.

Key Themes of Improvement

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Feedback from parents, charities, and the voluntary sector under the theme of “What can be done to improve this” offered fewer individual data points for analysis but revealed several overriding themes:

Key Themes Identified

1.Addressing Systemic Gaps in Support

1. Bridging gaps in services to provide seamless and effective support for families.

2.Enhancing Collaboration, Communication, and Accessibility

1. Promoting better coordination among services to ensure clear, consistent, and accessible communication.

3.Focusing on Long-Term, Holistic Solutions

1. Developing sustainable, comprehensive approaches to address the diverse and evolving needs of SEND children, young people, and their families.

In reviewing these themes for improvement, we have expanded our recommendations based on the overarching feedback shared by families and their supporters. These recommendations aim to reflect the priorities expressed and drive meaningful change within the system

What Can Be Done to Improve Support for SEND Families

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Prioritising Early Intervention for Mental Health Support

- Provide services to support children before they reach a crisis point.
- Emphasize early intervention as a form of prevention for mental health needs.
- Ensure access to services for cases where CAMHS cannot meet the required needs.
- Clearly define the distinction between "autism" needs and "mental health" needs.
- Identify gaps in services to ensure commissioned provisions adequately address the needs of individuals seeking support for autism and/or mental health challenges.
- Establish dedicated and appropriately resourced autism and neurodivergent support services (including support for ADHD and those awaiting a diagnosis), that do not require eligibility through the Dynamic Support Register (DSR).
- Develop a clear understanding and process for those on waiting lists who, due to the lack of a diagnosis, would otherwise be able to register on the DSR and gain access to keyworkers.

Communication and Awareness

- Better communication between professionals and earlier sharing of information.
- Create easy-to-navigate diagrams outlining starting points and pathways in the SEND system.
- Help parents understand available support services and navigate the system by improving the accessibility of published criteria.
- Provide effective signposting by creating resources that are clear and do not place an administrative burden on parents and carers to access support.
- Enable direct referrals to alternative services

What Can Be Done to Improve Support for SEND Families

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Post-16 and Transition

- Clear pathways for children aged 16+ and support for college information.
- Continuation of support after school, especially for those transitioning to adulthood.
- Improved collaboration between children's and adult services for realistic transition pathways.

Respite and Long-Term Care

- Addressing the need for respite care for parents, particularly for those with family members young adults.
- Replacing lost services like Southend Carers with equivalent support.
- Offering longer-term care solutions for neurodivergent individuals.

Education and Training

- Schools to receive better training to support neurodivergent children.
- Resources for mainstream schools to support SEND children not eligible for specialist schools.
- Focusing on reducing dysregulation by meeting needs in schools to prevent issues at home.
- Learning and replicating successful strategies from schools excelling in SEN support.

EHCP Improvements

- EHCPs to include better integration of health and care services.
- Improved transparency in addressing EHCP backlog and prioritization process.

Strengthening Partnerships

- Improved collaboration with local charities and organisations and faith based organisations
- Improve understanding of local services to better support children, young people, and their families effectively.

Conclusion

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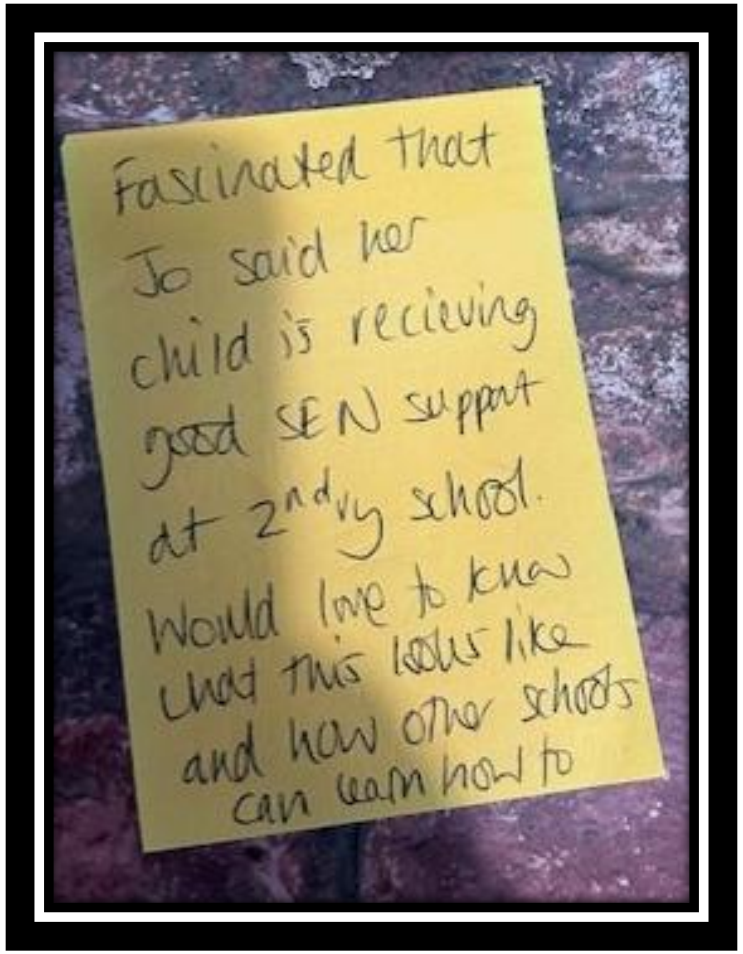
- The growing demand for Special Educational Needs and Disabilities (SEND) services in England, combined with inadequate funding, has created a widespread perception among parents that eligibility criteria are becoming increasingly strict, with significant gaps across universal, targeted, and specialist provision. Long waiting lists, unmet needs in mainstream education, and unclear pathways to support continue to exacerbate these systemic challenges.
- This creates a funnel effect for children and young people (CYP), where families report having to wait until reaching a point of crisis before receiving support—such as access to a keyworker. Many families and organisations who attended our events expressed frustration that the support shared was often "gatekept" at such a high threshold that those in need could not access it.
- It is essential that families have access to clear, high-quality information that helps them understand the nature of their child's needs, including the distinction between autism and mental health, and how the support available differs accordingly. Families would benefit from information that links the services offered under Transforming Care, clearly outlining their purpose, the processes involved, and the roles of the professionals working alongside CYP and their families. This would support greater clarity and confidence for both families and those supporting them.
- From our events, case studies, and conversations during coffee mornings and HCRG keyworker sessions, it is clear many parents believe that Transforming Care involvement could have been avoided if their child’s needs had been met earlier. As a system, we must do better in understanding the lived experiences of CYP who access Transforming Care. These insights should be used to inform commissioning decisions across universal and targeted services, helping to break down barriers to early support.
- The Essex Alliance, together with the parents, carers, and organisations it represents, urges the system to prioritise early identification of needs and timely, appropriate support. By doing so, we can prevent escalating needs and reduce the reliance on costly, crisis-driven interventions.

Keyworker service really helpful for families (practical support) at the most difficult times



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North
Tribunals that are stopped just before date to be heard, in favour of parents.
So much Stress!!!

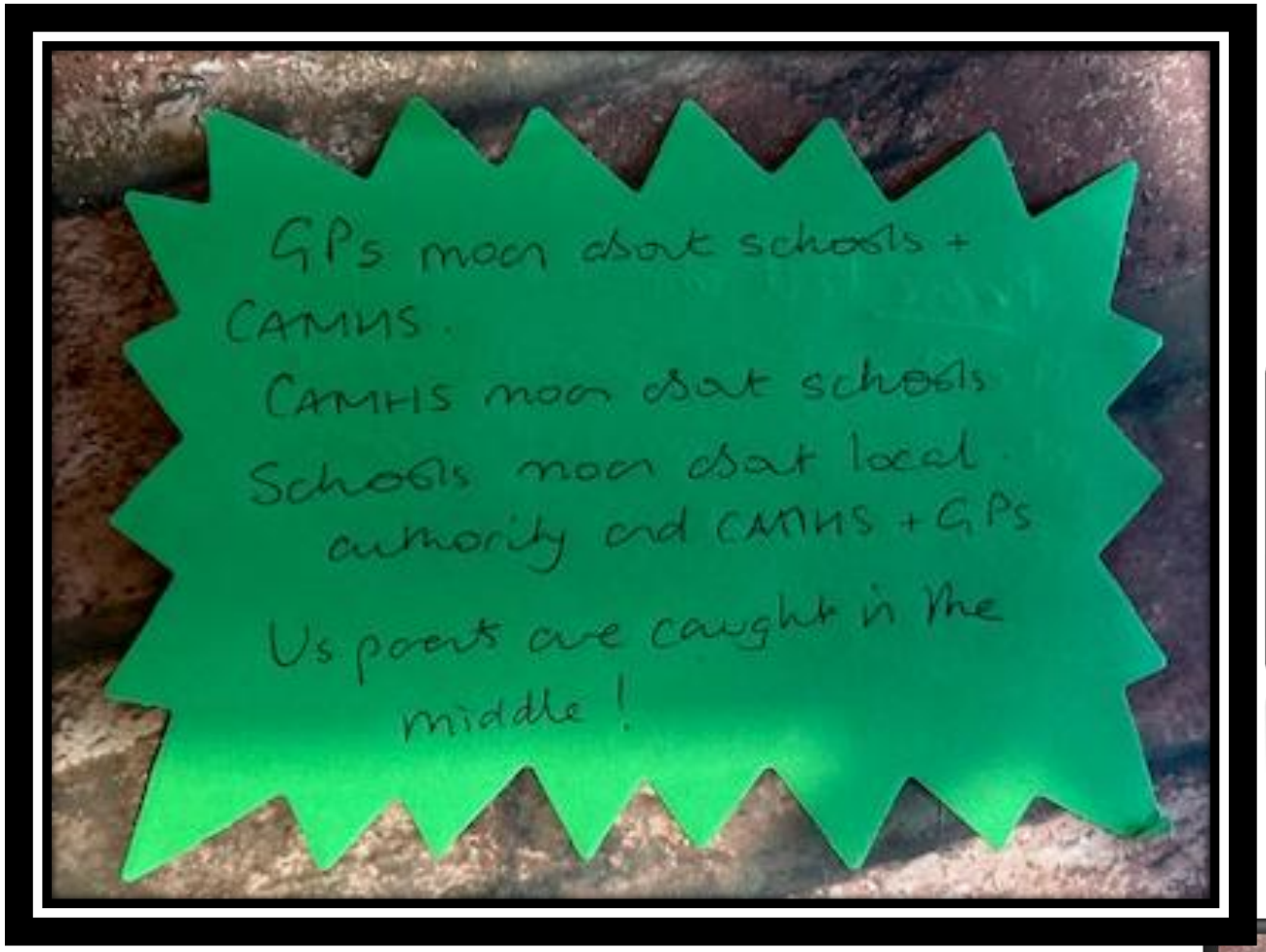
Support on College info for 16+ Kids

Referal process for support is longwinded.
SOUTHEND

Help parents navigate the system or even know where to start and how to find out more.

Help continuing after school. My son had been offered some help in year 11 but was refused some services due to nearly finishing. We have not received any communication/help since he finished

Need support for sensory needs, particularly feeding



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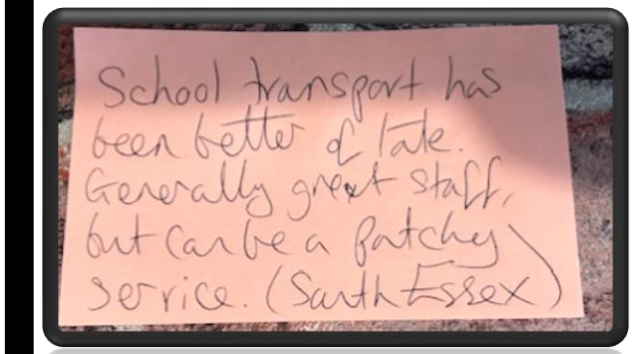
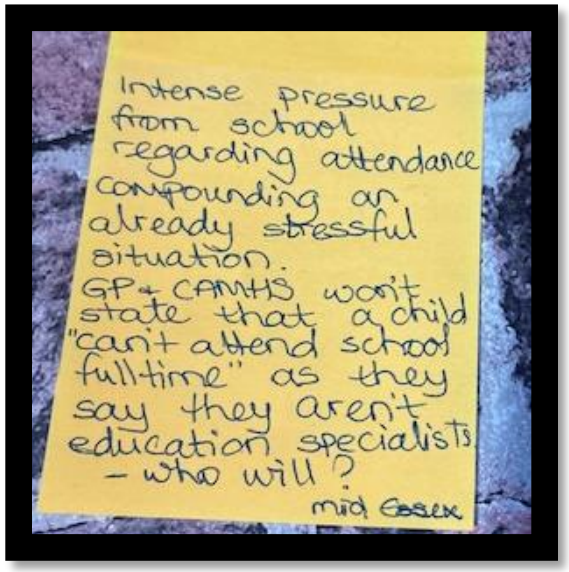
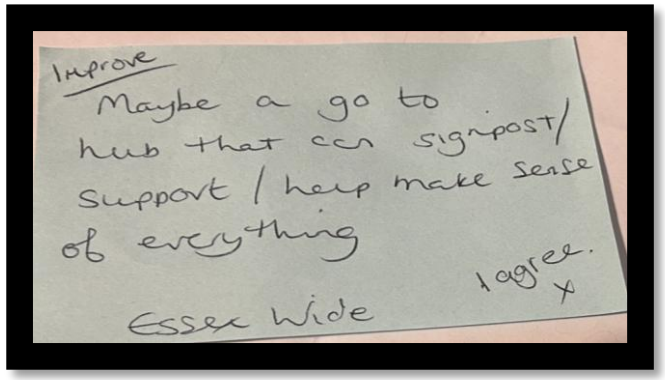
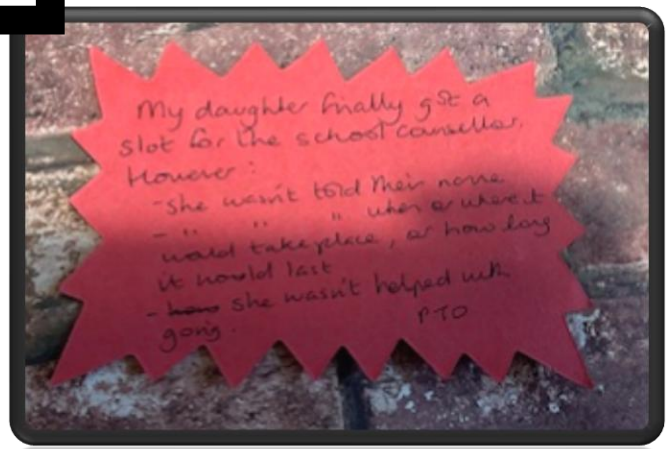
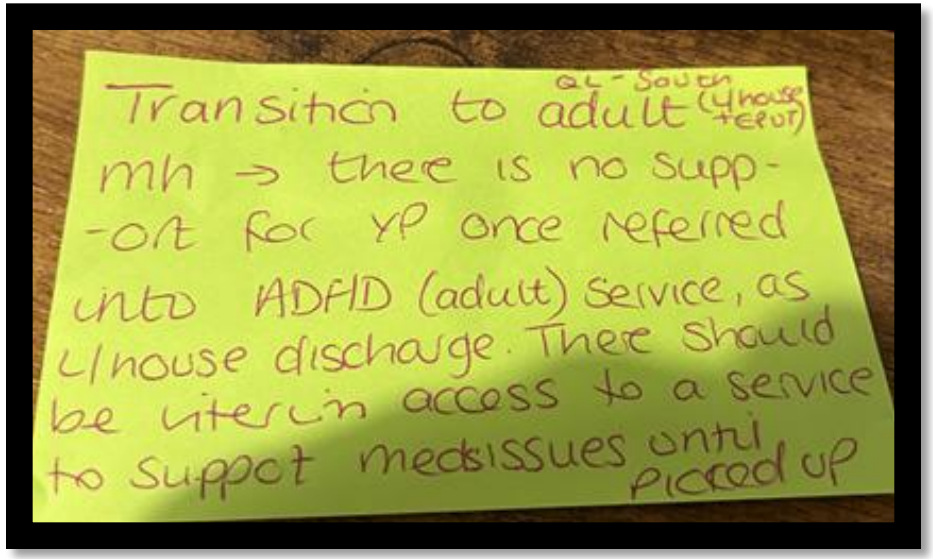


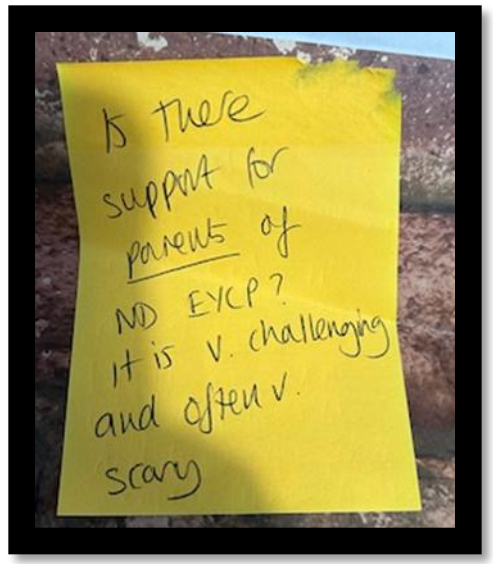


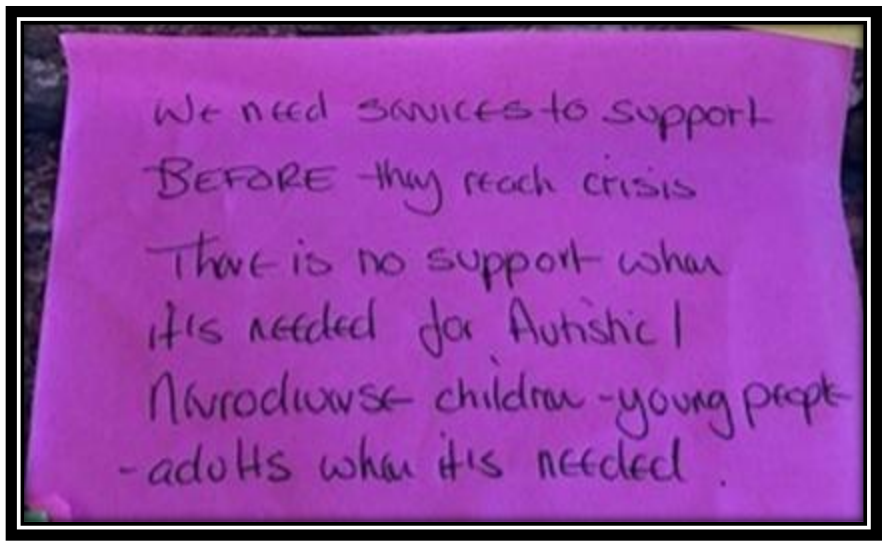






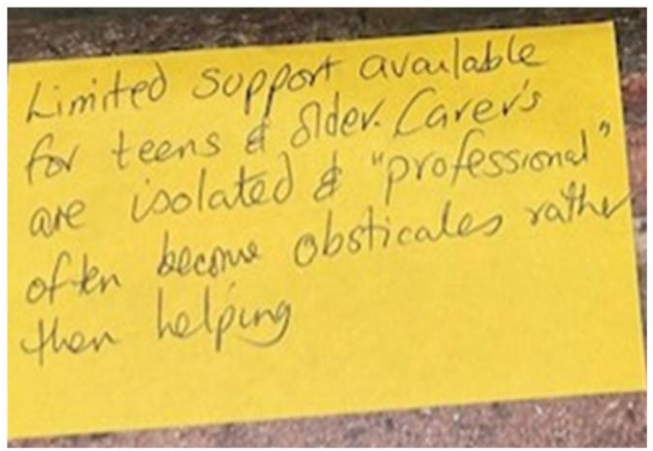
Waiting times slowly going down





Working ! Boredom

peer support



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