FEBRUARY 23, 2024

COURAGEOUS CONVERSATION IN ESSEX
SUMMARY REPORT & CONSIDERATIONS

VERSION 1.4

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On behalf of the Eastern Region SEND Partnership

COURAGEOUS CONVERSATIONS

1. SHORT REPORT FOLLOWING THE COURAGEOUS CONVERSATION IN ESSEX

1.1 INTRODUCTION AND BACKGROUND

This short report summarises the main findings of the Courageous Conversation that took place in Essex in February 2024.

1.2 DATE OF FIELDWORK:

6th February 2024

1.3 THE COURAGEOUS CONVERSATION TEAM:

Michael Bateman:	Assistant Director, SEND Strategic Improvement and Partnerships, Norfolk County Council
Lisa Belton:	National Representative, National Network of Parent Carer Forums C.I.C.
Katy Blessett:	SAT Strategic Manager, Cambridgeshire County Council
Lou Williams:	Independent Consultant and formerly Director of Children's Services

1.4 AREA OF FOCUS FOR THE COURAGEOUS CONVERSATION:

The areas of focus in this conversation were:

- How are delays in diagnostic pathways and Education, Health and Care needs assessments impacting on children, young people and their families?
- What can be done to better support those 'waiting' in the diagnostic pathway and/or EHC needs assessment process to mitigate delays?

1.5 THE COURAGEOUS CONVERSATION APPROACH

The approach to the courageous conversation is for an initial discussion to take place with the authority and partners to agree an area of focus. The peer team is then assembled, and is provided with a range of written background information relevant to the focus.

The peer team spends a full day on site discussing the theme in depth with a range of key stakeholders. A short feedback session concludes the day.

A brief summary report is then provided; this remains the property of the local authority hosting the courageous conversation. It is, however, recommended that the findings are shared with local partners as appropriate.

The aim is for all local authorities and their partners in the Eastern Region to participate in a courageous conversation by March 2025.

General themes from these conversations will be shared with the region in order to support mutual learning and the development of best practice.

2. KEY THEMES FROM THE CONVERSATION

2.1 GENERAL OBSERVATIONS

Essex is a large county where partnership arrangements are complex. Three Integrated Care Boards have overarching responsibility for the commissioning of health services from five provider organisations. Two of the ICBs have responsibilities for populations that cross local authority boundaries [one into Suffolk and another into Hertfordshire]. This presents additional challenges for the ICBs concerned in seeking to avoid different systems developing across their footprints and in ensuring that access to provision is equitable across the populations served.

Despite this complicated landscape, there is great commitment and passion shown by all those working in and leading the systems to ensure that children and young people of Essex are able to achieve the best possible outcomes.

Partners have worked hard to develop strategic approaches to identifying and meeting need across Essex. They have set their priorities for change and transformation to align with the areas identified by parents and carers through the Essex Family Forum as being of greatest concern, as well as to relevant best practice guidance such as that relating to autism diagnosis and support pathway. Good progress has been made in relation to the sharing of datasets, meaning that strategic leaders have transparent oversight of performance including areas of challenge across the county area.

Essex Family Forum is clearly very highly regarded, not only by parents but also by those working in schools, the local authority and health services. There is a strong commitment to co-production across the County, and input from parents and carers is clearly valued.

In our meetings with stakeholders, despite best efforts, almost all talked about a continuing inconsistency of response to the needs of children, young people and their parents and carers across the county. These inconsistencies could be found in relation to the experience of children and their parents and carers while awaiting a neurodiversity assessment as well as in the extent to which schools and settings responded to need through the making of reasonable adjustments and ordinarily available provision.

There was a sense that while much had been achieved at a strategic level, these changes had yet to be felt in concrete ways by children and their parents and carers in delivering improvements in areas such as the quality of communication about their progress along diagnostic or assessment pathways.

2.2 PRINCIPAL CONSIDERATIONS

It is suggested that the council and partners consider:

- Establishing commonality of vision across the County, by establishing minimum standards of expectations in terms of things like communication and information provided for parents waiting for neurological assessments;
- This information to include signposting for support, arrangements for keeping in touch, clarity about ordinarily available provision in schools and settings and around access to support and provision based on need rather than diagnosis;
- Reviewing access to training for staff and others working in settings to improve their confidence in supporting neurodiverse children and young people;
- There are always likely to be variations in commissioning activity across the County, given the complex partner arrangements and differences in population. This notwithstanding, we thought that consideration could be given to reviewing existing commissioning arrangements and identifying areas where joint procurement activities could take place;
- Some commissioning arrangements will always be short-term because of funding arrangements, but we heard that there was more potential to ensure that such arrangements leave an on-going legacy after they cease;
- There are some similar things to consider in respect of supporting children and young people waiting for an Education, Health and Care plan needs assessment as there are for those waiting diagnostic assessment;
- Providing greater clarity about the Ordinarily Available offer, for example, while also offer greater contact with families who are waiting, and considering seeking opportunities to enable greater personal contact through the process;
- Adopting approaches such as these will have resource implications but these are likely to be worthwhile if they help to build trust for parents and carers;
- Reviewing the templates used for communicating with parents and carers may also be worthwhile, ensuing that these are clear and offer strength-based messages and information;
- We thought that consideration should be given to segmenting the waiting population, and agreeing priority groups as well as reviewing arrangements for those newly waiting. Such changes would require consultation, of course;
- The schools we spoke to valued their Inclusion Partner, but also spoke of needing better access to practical advice and support. We wondered whether the role of the Inclusion Partner was sufficiently clear to all, and whether there was a need for this to be reviewed;
- Finally, we thought that the governance arrangements that have developed in Essex are complex and would suggest a review of these, with a view to slimming down the number of boards and seeking to clarify lines of accountability.

3. HOW ARE DELAYS IN DIAGNOSTIC PATHWAYS AND EDUCATION, HEALTH AND CARE NEEDS ASSESSMENTS IMPACTING ON CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES?

3.1 GENERAL OBSERVATIONS

Prior to the fieldwork day, the Essex Family Forum developed and collated responses from two questionnaires. The first explored the impact of delays in neurological assessments, while the second explored the impact of delays of Education, Health and Care plan needs assessments on children, young people and their families.

The responses provided a detailed account of the impact of these delays. For some children and young people, the cumulative impact of delays had resulted in them being out of school or on heavily reduced timetables. Being out of education in this way has a profound impact on the child or young person, while for many families, the knock-on impact was a parent no longer being able to work as well as a build-up of mental and emotional difficulties affecting the whole family.

One of the primary frustrations expressed by parents and carers was the lack of communication in either process. Strategically, partners have agreed that those waiting for an ASD or ADHD assessment should be ‘waiting well’. This means that parents and carers should have clarity about likely wait times, understand the pathway and the various stages, receive regular updates and be able to discuss their current circumstances.

It is clear from parent feedback that this is not yet consistently happening. Representatives of schools in Essex had not heard of this approach, suggesting that it is not yet consistently understood by front-facing settings.

Those waiting for Education, Health and Care plan needs assessments to be completed expressed similar frustrations with delays and with the lack of communication. Particularly stressful for families was when the needs assessment was remaining outstanding as key transition points for their children were approaching, or where their child was no longer accessing education or was on a very reduced timetable.

The school representatives we spoke to were very committed to mitigating the impact of neurodiversity on children’s experiences and learning in their schools. One in particular had adopted an approach whereby all teaching was inclusive of the needs of neurodiversity children, arguing that there would always be a number of children in classes not yet identified as being neurodiverse or awaiting assessment, and that adopting this approach was potentially beneficial to all children in the class and certainly could not cause harm.

This is not yet the experience of all children and parents, however. Feedback through the Family Forum was that many schools continued to say that reasonable adjustments could only be put in place when children had a diagnosis, an Education, Health and Care plan, or both. The representatives of the schools we spoke to discussed being aware of a number of schools and settings that did not adopt the same inclusive approaches as they were.

4. WHAT CAN BE DONE TO BETTER SUPPORT THOSE ‘WAITING’ IN THE DIAGNOSTIC PATHWAY AND/OR EHC NEEDS ASSESSMENT PROCESS TO MITIGATE DELAYS?

It was apparent from all the stakeholder meetings the team conducted that there is a strong desire to improve the experience of children, young people and their families affected by delays in the diagnostic pathway and/or the Education, Health and Care plan needs assessment process.

4.1. SUPPORTING CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES THROUGH THE DIAGNOSTIC PROCESS

Data shared with the courageous conversation team illustrated the long waits that the majority of children and young people face before a neurodiversity assessment is undertaken. There are a number of factors behind these waits, which include:

- Shortages of appropriately qualified practitioners;
- A growing overall child population;
- An increasing proportion of children and young people with complex presentations, and who require additional clinical time for assessments to be completed.

The ICBs each have different neurodiversity pathways. All are impacted by resource pressures and pressure to meet competing priorities. There is acknowledgment that waiting times are longer than anyone would wish for are likely to remain a feature for some time.

The partnership is committed to supporting children, young people and their families to ‘wait well’ and has taken steps to define what this means such as keeping families informed of their progress, and ensuring that access to support services are not diagnosis-dependent wherever possible.

The experience at the front-line is that these commitments are not yet translating into the experience of children, young people and their families. None of the schools we met with had heard of the approach.

Parent and carer representatives, the schools and settings and practitioners we met all continued to talk of inconsistencies in practice and communication across the County.

4.2. CONSIDERATIONS: CLARIFYING THE SUPPORT AVAILABLE TO CHILDREN, YOUNG PEOPLE AND FAMILIES WAITING FOR NEUROLOGICAL ASSESSMENT

Agree a pan-Essex shared vision and values

The first consideration we are suggesting is for the partnership in Essex to agree a clearly articulated and co-produced pan-Essex statement of values that sets out:

- The principle that wherever possible, access to services and support is not dependent on a diagnosis;
- That support for children and young people in schools and settings is similarly not dependent on a diagnosis and that reasonable adjustments should be made for children and young people, giving examples of what this means;

- That initial letters to parents and carers should set out in plain language information about the Essex-wide approach, including:
    - The above points about accessibility of services without a diagnosis;
    - That support for children waiting includes in schools and settings through the Ordinarily Available offer;
    - Arrangements for keeping parents notified of progress;
    - Including sources of advice and support to parents, and reassurance that they cannot do harm by adopting parenting techniques aligned to parenting neurologically diverse children and young people;
    - Consideration to producing bitesize video clips and similar on areas such as eating and sleeping and including links to such resources.
- These initial letters should then also include clear information about the pathway for children and young people in the area of Essex where they are living, recognising the reality that this will vary between ICB area. This should include arrangements for informing about changes of circumstances and needs and local advice and support forums.

Parents and carers and some schools questioned whether there was a need for a single neurodiversity pathway for children and young people, as opposed to separate ones for ASD and ADHD.

All communication and resources need to be co-produced with parents and cares. Links to the Essex Family Form and MyOTAS produced 'Supporting your Neurodiverse child' should also be included.

North East London Foundation Trust publishes a wide range of advice and details about support on its website: https://www.nelft.nhs.uk/support-for-your-child-while-waiting-for-assessment/

Agencies and services have a shared responsibility to ensure that messages about diagnosis and access to support and services is widely understood. We heard from parents, health staff and schools that some schools will say that parents need a diagnosis before their child can access support, for example. Providing clear advice to parents about provision and accessibility will help them to challenge message such as these.

This approach could also be used in helping to manage parental expectations about the impact of a diagnosis; that for many/most, ordinarily available support and services should be offering effective help and support for children and young people. A diagnosis will not usually result in significant changes in the support needed, but might well suggest some helpful fine-tuning to ensure that the support provided enables children to derive maximum benefit.

Taking these steps would go a long way to addressing parental concerns about continuing lack of clarity about process and sources of support while assessments are awaited. They are in line with the strategic priorities and have the potential to be realised relatively quickly.

4.3. CONSIDERATION OF TRAINING AND AWARENESS RAISING FOR PRACTITIONERS AND SETTINGS

We heard that some practitioners in some settings can also feel de-skilled and anxious when supporting neurologically diverse children and young people but who do not yet have a diagnosis. There may be value in considering ways of supporting practitioners to also feel confident that they can do no harm in adopting the same approaches as they already use with children and young people with a formal diagnosis.

Colleagues from schools made the point that their learning support assistants are some of the most valuable resources they have in supporting children and young people in learning. They suggested whether more training and support could be made directly accessible to them, as opposed to being via the SENCO. The view was that this would make them feel more valued as practitioners and be more efficient for schools.

4.4. COMMISSIONING ACTIVITY

We heard that each individual ICB commissions a variety of support services and that many of these are well regarded. We also heard from parents and carers that the range of commissioned services, the short-term nature of some of these, and the variation in arrangements across the County resulted in some confusion and inconsistency.

It is suggested that the ICBs and local authority review existing commissioning arrangements, plot end dates and consider extending ones where there is a potential to bring end-dates together so that joint procurement activities can be considered. This will not be possible in all circumstances, but might go some way to addressing the concerns about lack of consistency across the County.

More work could also be completed on ensuring that the learning and outcomes delivered by commissioning arrangements are captured and evaluated. Short-term funding streams make it inevitable that there will be some short-term commissioning arrangements, but value can be added by ensuring that the commissioning agreements require there to be a legacy, whether that be a product or a support resource that can continue to be accessed after the end of the contract.

We heard how parents and cares particularly value peer support and the value of many voluntary and community sector organisations. This support is not cost-free, of course, and commissioning arrangements need to prioritise resources towards sources of support that are most valued by parents and carers.

It may also be possible to develop some joint commissioning approaches with the County Council at some point in the future.

4.5 CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES WAITING FOR EDUCATION, HEALTH AND CARE PLANS

The scope of the focus of this conversation did not include exploring the reasons why delays for the Education, Health and Care plan needs assessment process have increased in Essex, although key underlying issues include a shortage of educational psychologist time and growing demand. Some demand is being driven by recommendations from practitioners working with children and families that an Education, Health and Care plan will help their child access provision and support within schools.

Numbers waiting more than 30 weeks for a needs assessment are significant and increasing, with over 680 waiting for this length of time as of December 2023. Action to address waiting times is, however, starting to demonstrate some progress for the smaller numbers waiting for 52 weeks or more. Most recent data is that only around 1% of plans are being issued within 20 weeks.

Reducing waiting times is a clear priority for the local authority. There is an equal priority that doing so does not lead to a reduction in the quality of the plans being issued, which is welcome.

The parents we spoke to were clear that part of the impact of the delay was in accessing tailored support for their children in schools. The schools that we met were very conscious of their roles and responsibility to support children and young people through ordinarily available provision, but agreed with parents that this was inconsistent and very much depended on the inclusiveness of the school concerned.

Parents talked of the difficulties of obtaining clear timeframes for how long it would be for the needs assessment to be completed, with officers being unwilling or unable to commit to this. Some talked about struggling to make contact for updates on progress. Strikingly, the feedback from one parent who was told of a 40-week wait was very positive because they thought that the person with whom they spoke gave them lots of advice on steps to take in the meantime and they felt they had a clear timeframe, even if not one that was ideal.

4.6. CONSIDERATIONS FOR IMPROVING THE SUPPORT AVAILABLE TO CHILDREN WHILE THEY WAIT FOR THE NEEDS ASSESSMENT TO BE COMPLETED

Ordinarily available provision

As noted above, there is inconsistency among schools across Essex about ease of access to ordinarily available provision, with parents often repeating that some schools are insistent that accessing support provision is reliant on an Education, Health and Care plan.

It is suggested that initial communication with parents is reviewed, and that it includes specific information on the types of reasonable adjustments and the range of ordinarily available provision available to children and young people. This would enable parents to be in a stronger position when talking to schools about support and adjustments for their child.

As with the comments about communication regarding diagnostic assessments above, this initial letter should also include links to useful resources, including the ‘Supporting Your Neurodiverse Child’ published by Essex Family Forum and MyOTAS.

Improving communication and introducing personal contact where possible

Some forums for promoting communication are very highly valued by parents and carers. These included the SEND roadshows, which were highly praised for the quality of information ad opportunities for support the provide.

As noted above, one of the very clear concerns from parents [as well as schools] in respect of the Education, Health and Care plan process was the difficulty in obtaining clear information about likely timescales. This was further exacerbated if timescales changed, but those changes were not communicated.

Trust is an important element in building confidence for parents and schools that support for children and young people will be forthcoming. Once trust is lost, it is very difficult to rebuild, contributing to a higher proportion of parents and carers feeling that they have to fight in order to obtain the support their children need.

Improving the quality of the initial contact and building in a system that means that parents are proactively contacted for a regular update of progress would help to build and maintain trust. This would require some additional resource, either in assessment team or within early help services. The latter is worth considering since it would provide an opportunity for the discussion to include other areas of support that might be available.

A number of areas have found that this additional resource is a worthwhile investment as it builds trust and can help to avoid difficulties further along the process.

As part of this process, it is worth reviewing other standard communication templates to make sure that they are as clear and strengths-based as possible. Schools told us, for example, that letters to parents notifying them of a refusal to assess could be phrased much more positively. They could, for example, say that it is good news that their child can be supported through ordinarily available provision at their school, and that this means avoiding the inflexibility and intrusive processes related to provision of support through an Education, Health and Care plan. Including links to useful information and providing concrete examples of the support available would also be helpful.

Parents raised the issue of confusion around use of private Educational Psychology assessment. Some understood that these were never accepted, while others thought that they were accepted if completed in line with NICE guidance. There are clearly issues to consider including the extent to which allowing such assessments has an impact on equality of access and the extent to which they may identify ‘nice to have’ as well as provision that is needed. Some parents struggle to understand why the authority will not accept privately funded educational psychology assessments, given the capacity issues. Some clarity would be appreciated.

Considering segmenting the current waiting population

Some parents talked about the impact of waiting for an Education, Health and Care plan needs assessment including that their child was out of school, or that parents had needed to give up work because their child was on a reduced timetable. Others were particularly stressed about the prospect of transition from early years’ settings into reception or from primary to secondary.

We understood that the waiting list is not currently prioritised. It may be worth considering seeking to prioritise those who are waiting and who fall into these categories. It may also be worth thinking about differentially managing waiting times for those who are already waiting and those who are starting the process.

The Council is planning to bring additional resources to tackle the current waiting list, which is positive. There are clearly questions of fairness and equity to balance here, but simply deploying that resource on tackling the existing waiting list in the same way as currently runs the risk of making only very slow improvements over an extended timeframe for all those awaiting a needs assessment. It offers limited opportunity to develop a new and improved relationship with those who are new to the process from the start, while leaving some groups of parents who are already waiting and for whom impact on their child is most significant in limbo.

It is therefore suggested that the authority works with parent carer forums and schools and settings on how it might segment the population of children waiting in order to bring swifter impact for those facing the greatest challenges, while also supporting the building of better relationships from the beginning with those new to the process.

Supporting schools and settings to support children and young people with neurodiverse needs

The schools we spoke to were all striving to do the best for their children and students. They too felt that communication could be better, and that it would help if they could be included in communications relating the waiting well process above and the Education, Health and Care plan needs assessment process.

Some SENCOs felt that they were quite dependent on what they had found out from others about support that is available, as opposed to feeling that there is a central point to which they can refer to for support and guidance.

Schools and settings were aware of the arrangements to allocate additional funding in advance of the needs assessment being completed and were appreciative of that. They were particularly positive about their inclusion partners, describing them as being often the most accessible and helpful contact for help and support.

Nevertheless, one said ‘I feel on my own; I have an extremely good inclusion partner but would value more specialist advice from an EP at times. If I am struggling with a child, and have used the strategies I am familiar with in school and they do not work, where do I go?’

This comment struck a chord with others present, who agreed that prompt access to practical advice and support was lacking and would be of great benefit.

These comments about knowledge being dependent on who you know and a perceived lack of access to timely advice and support made us question whether the role of the inclusion partner needed some clarification as they would seem on the face of it to have important roles to play in this area.

Schools also said that on occasion they could hear that there was capacity in some of the Enhanced Provisions, sighting examples of discovering that there had recently been some vacancies in GROW enhanced provisions. We wondered how well links were operating between all schools those with enhanced provisions and special schools, and whether these could be improved.

In the longer term, we wondered whether consideration could be given to delegating some additional funding to clusters of schools, with access to this being through agreement of schools within the cluster. Norfolk has found that this approach, in the past, had brought benefits as schools have offered peer challenge and support around inclusion and what should be available through the ordinarily available offer and are currently moving to a revised model to achieve this outcome. Nottinghamshire have a long-standing arrangement of ‘families of schools’ allocating funding between them and organising training and this could be a good source of information for Essex to consider.

Partnership for Inclusion Neurodiversity in Schools

We heard that Essex Family Forum, the authority and health partners are discussing whether the PINS programme is something that can be developed locally to improve inclusion, build parent-school relationships and upskill staff in participating schools. Without having the detail in relation to critical factors including funding arrangements, it is positive that this is being explored and has the potential to deliver impact for children and young people.

5. GOVERNANCE ARRANGEMENTS

Essex is characterised by very complex partnership arrangements, as described elsewhere. It is one of the largest local authority areas in the country both in terms of geography and population. It is also an area that includes very diverse communities with differing needs, levels of deprivation and opportunity, with populations spread across large urban centres, smaller market towns and relatively rural areas.

Perhaps in part because of this reality, complex governance arrangements have developed, which can result in a dilution of accountability. We heard how similar issues can be discussed in a number of different groups, often including a number of the same people.

We would suggest that partners review governance arrangements and seek to reduce the number of boards/partnership meetings, while establishing a clear line of governance to a single strategic board.

We would also suggest reviewing some of the report templates including highlight reporting to ensure that this focuses on impact for children, young people and their families, with less consideration to reporting system progress.

CONCLUDING REMARKS

There is a great deal to be positive about in Essex. There is a high level of energy and commitment across the partnership, from strategic leaders to practitioners. The parent-carer voice is strong and there are some great resources available to support parents, carers, young people and children. There is a good and productive relationship between parent carer forums and the authority, ICBs, schools and settings and a commitment to co-production at all levels.

Considerable work has been done in developing the strategic vision, informed through co-production, and in sharing data and discussing strengths and challenges openly across the partnership.

Despite this, we also heard considerable frustration about continuing inconsistencies of experience by children, young people, their parents and carers across the County, and about a lack of tangible impact of strategic activity on the ground.

We were impressed by the passion and commitment of all we spoke to and of their readiness to think and act differently in order to achieve that consistent and tangible impact for children, young people and their families. Now is perhaps a good time to revisit the priority areas, and distinguish what will be achieved in the near, medium and long terms.

In complex systems, sometimes focusing on an issue of shared priority – such as the waiting well process described in section 4.2 above – can bring swifter impact and provide tangible evidence of things moving, changing and improving. This in turn brings additional confidence in tackling other challenges and delivering the improvements in the experiences of and outcomes for children, young people and their families that all are so committed to achieving.

Lou Williams

February 2024