Neurodevelopment Survey

Representing Parental Views on SEND across Essex

Essex Family Forum

2021

Contents

Background

This survey was undertaken in relation to a weakness identified in Joint Commissioning in the Written Statement of Action following the Local Area SEND Inspection in Essex in October 2019. It stated:

"Weaknesses in commissioning and strategic oversight have resulted in unwarranted variation, gaps in provision and unacceptable waiting times before needs are assessed and addressed. In some areas the waiting time for autism assessments can be as long as 18 to 24 months and post-diagnosis support is not effective, which is not compliant with NICE guidelines"

Essex Family Forum conducted this survey in partnership with the ASD ADHD Subgroup and the Joint Commissioning Group, which is made up of key representatives across Education, Health, Social Care and Essex Family Forum.

This survey will focus on the parent and carer feedback on Neurodevelopmental pathways of the following Clinical Commissioning Groups (CCGs): North East Essex, Mid Essex, Castle Point and Rochford, West Essex and Basildon and Brentwood.

Parent and carer feedback is a fundamental part of the improvement journey that is being undertaken in Essex.

It's hoped that by providing the views and experiences of the families, it will help the Joint Commissioning Group to better understand families' experiences and will inform the provision of future services, meaning improved outcomes of children and young people and their families going forward.

Click here to view the Written statement of Action.

Survey Details

The survey was open from 30th July to 30th September. It should be noted that a further 18 respondents accessed the survey in October and their responses have been included.

The survey was promoted via Essex Family Forum social media and through MailChimp to our members

We also requested that the survey was shared via education settings, the Essex Local Offer and through the aforementioned Clinical Commissioning Groups social media.

Whilst Essex County Council shared the details in their weekly newsletter to our schools, our families reported that their education settings did not share the survey with them, which was disappointing.

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Data Considerations

2021 Referral Data

We have included data for referrals made in 2021.

It should be noted that we would expect the number of respondents to be lower as the survey was open from 30th July to 30th September 2021 and then closed. Therefore, we are not comparing whole year data.

This should be considered when comparing data year on year.

Year of Referral data

This question was not a forced answer question, meaning that participants could skip this question. This means that data provided by year of referral may not include all responses to that specific question.

Covid – 19

This survey represents experiences that would have occurred throughout the Covid-19 Pandemic.

Essex Family Forum is aware that during this time, due to national lockdowns and re re-deployment within health services, appointments were delayed and face to face appointments were not always possible, which no doubt has impacted on some of the families who responded to our survey.
However, as a parent carer forum, we have a duty to accurately reflect the experiences provided to us by the families we represent. We do not distinguish within this report those experiences which may have been impacted by Covid-19.

Comments

All comments included within the report are provided verbatim. We have made every effort to anonymise comments. Professional details, such as named professionals and education settings names can be made available to the CCGs or ECC, if requested.

Acronyms and Terminology

Acroynm	
CCG	Clinical Commissioning Group
EFF	Essex Family Forum
ECC	Essex County Council
CYP	Child or Young Person
SALT or S&L	Speech and Language Therapy
PT	Physiotherapist
OT	Occupational Therapist
EWMHs	Emotional Wellbeing and Mental Health services (also known as CAMHs)

Geographical Coverage

Throughout this report we will refer to specific areas. This following table explains which districts, fall under which CCG's or which "Quadrant" of Essex within ECC.

Area	Includes the following local authority districts	Clinical Commissioning Group (CCG)	Essex County Council (ECC) Quadrant
North East Essex	Colchester and Tendring	NHS North East Essex Clinical Commissioning Group	North East Essex Quadrant
Mid Essex	Chelmsford, Maldon and Braintree	Mid Essex Clinical Commissioning Group	Mid Essex Quadrant
Basildon and Brentwood	Basildon and Brentwood	NHS Basildon and Brentwood Clinical Commissioning Group	South Essex Quadrant
Castle Point and Rochford	Castle Point and Rochford	Castle Point and Rochford Clinical Commissioning Group	South Essex Quadrant
West Essex	Uttlesford, Harlow and Epping Forest	West Essex Clinical Commissioning Group	West Essex Quadrant

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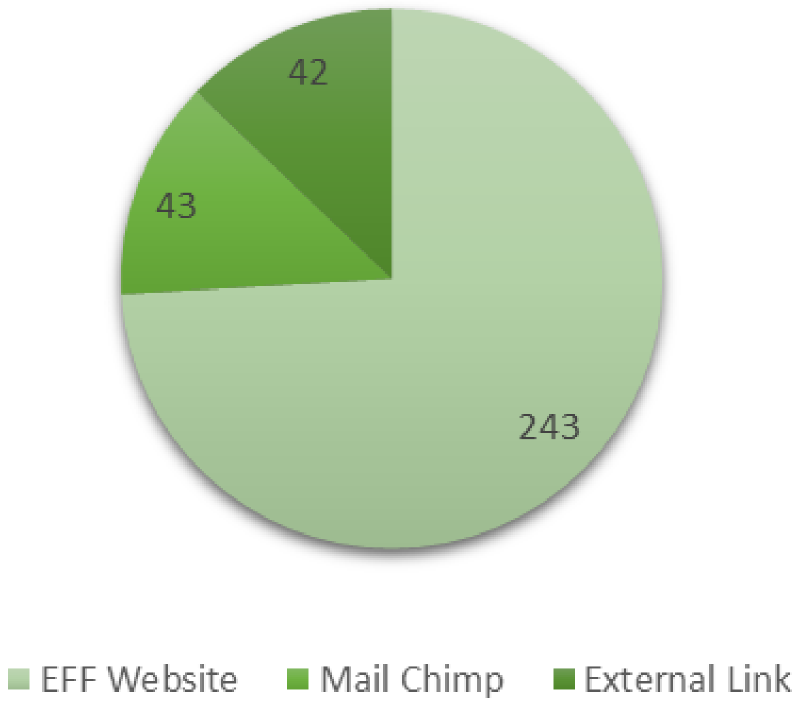
Number of Participants

We created several links for distribution to enable us to gain a better insight of how our families accessed our survey.

1. EFF Website – This link was accessed via our website and the same link shared via social media. Where our post was shared, such as by the Essex Local Offer, the respondents would show as accessing via this link
2. MailChimp – This link was e-mailed to our members
3. External Link – This link was provided in a flyer and to our external partners for sharing. It contained a weblink and a QR code for ease of access.



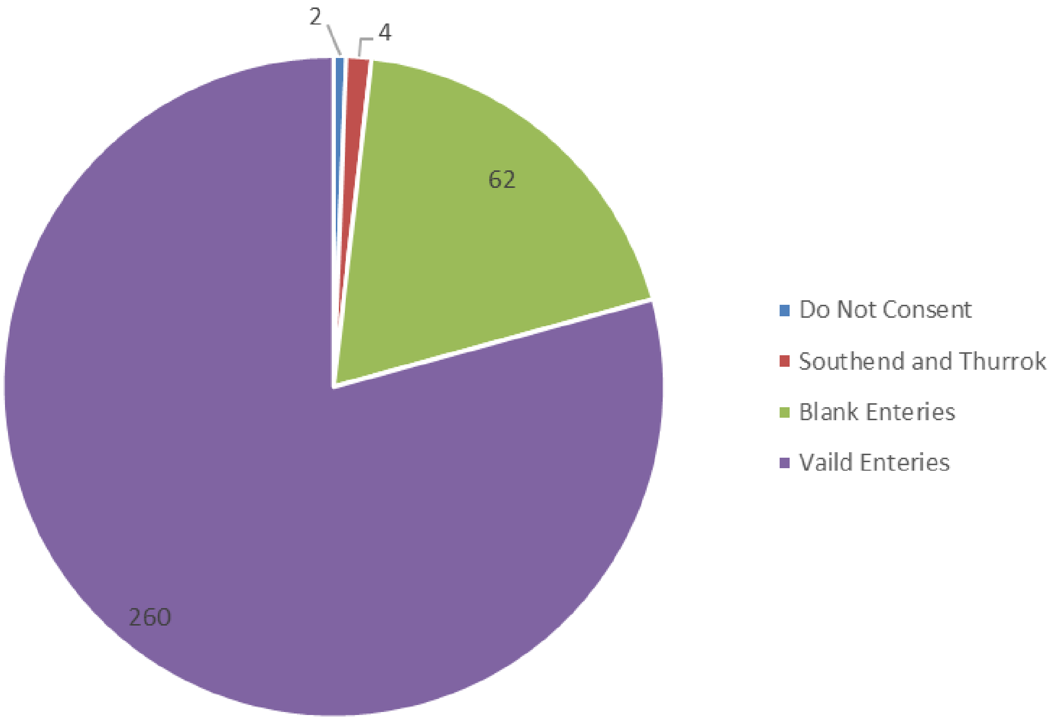
Response By Link

We had a total of 328 participants access the survey.

- 2 participants did not consent
- 4 Participants were from South and Thurrock and as such we did not collect their responses
- 62 Entries were blank so discounted.

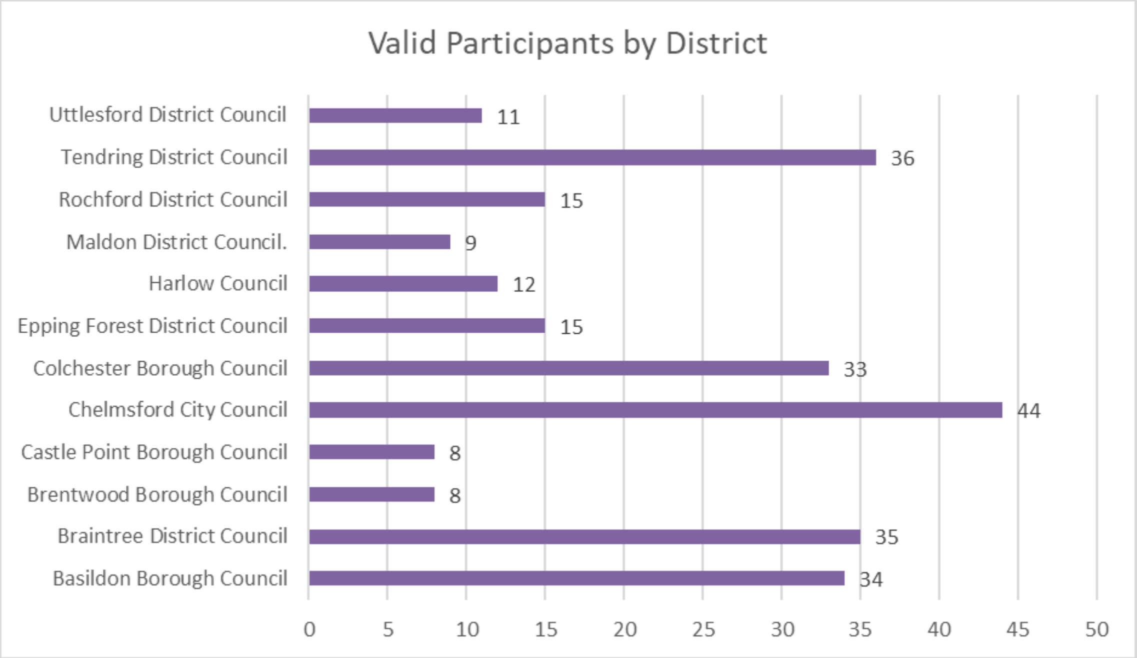
This means we had 260 valid entries

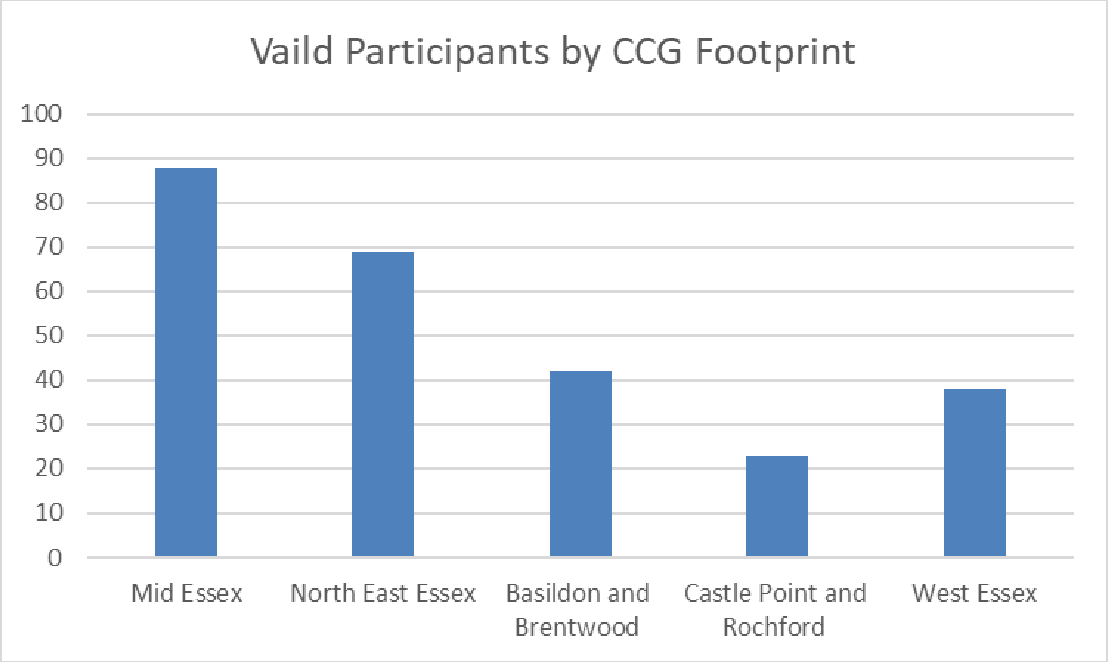
Participants were directed through the survey via logic based on their answers. Participants were also allowed to “skip” questions if they did not want to answer a specific question. Therefore, responses will be shown based on the numbers that answered the question



Geographic demographic of Participants

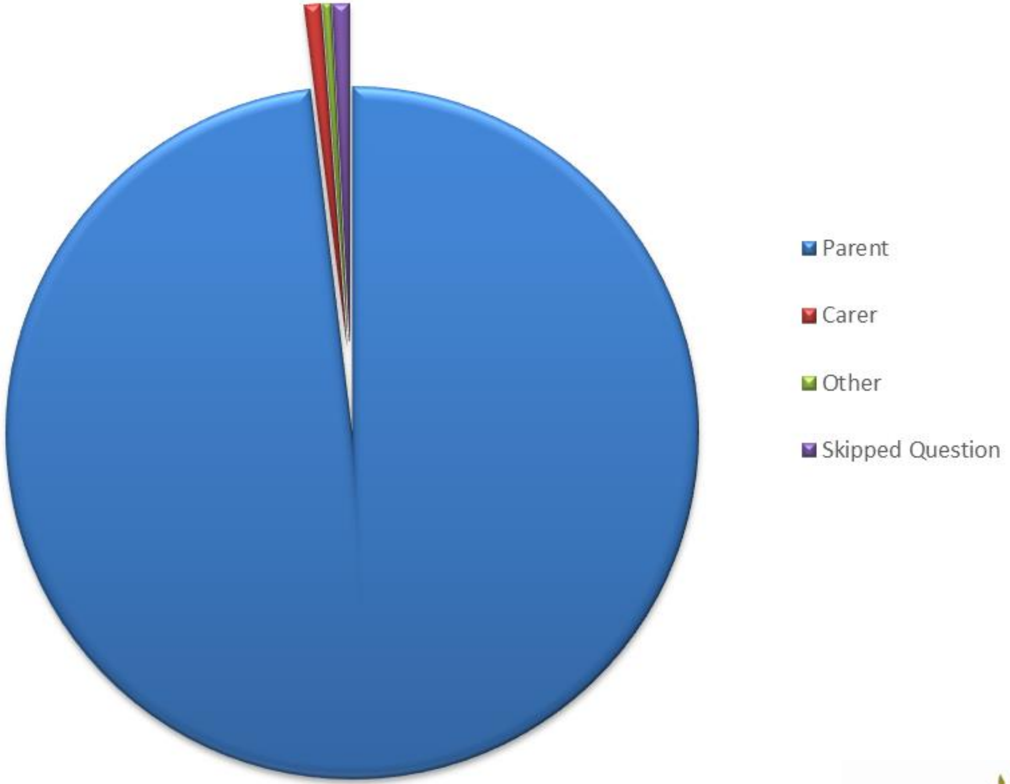
The tables below show the participants broken down by District and by CCG Footprint.
Where possible, throughout the survey, the data has been grouped from districts to CCG footprint.





Type of Participants

- 255 of the participants identified as a parent. 6 identified as a carer and parent, so for the purposes of this survey we have chosen to include them in the “Parent” Category.
- 2 Carers
- 2 Skipped the question
- 1 Other – identified themselves as a supporter.



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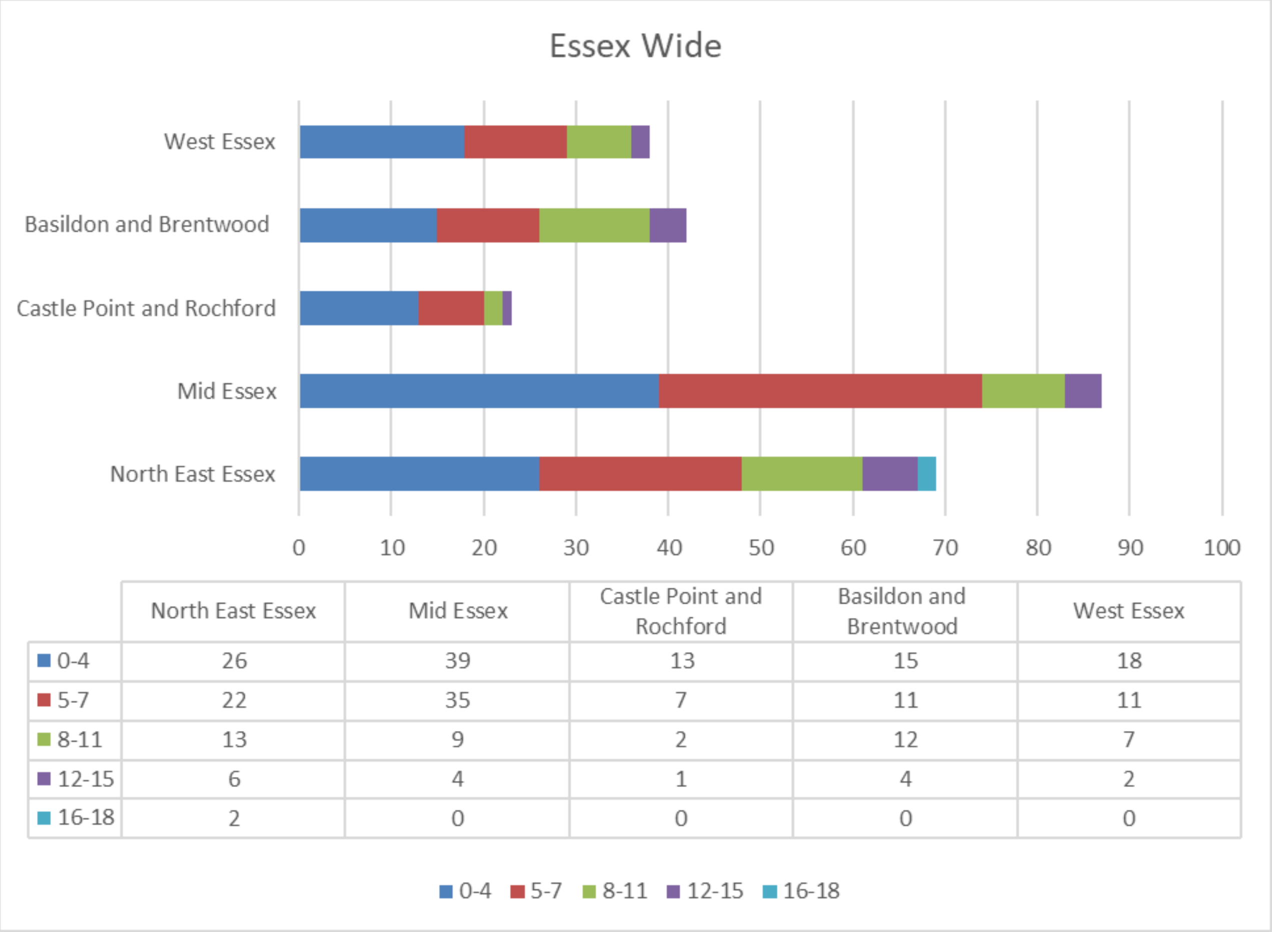
Age of Child or Young Person

We asked participants “How old was your child or young person when they were referred to the pathway?”



	North East Essex	Mid Essex	Castle Point and Rochford	Basildon and Brentwood	West Essex
🟦 0-4	26	39	13	15	18
🟥 5-7	22	35	7	11	11
🟩 8-11	13	9	2	12	7
🟪 12-15	6	4	1	4	2
🟦 16-18	2	0	0	0	0

Most referrals occurred within the early years with the second largest area being within the primary school age co-hort.

It is acknowledged that historically there was a gap in provision for 16-18 year olds, so we are not surprised to see a low uptake in this area

We received no feedback from Young People aged 19-25

Why is that ??

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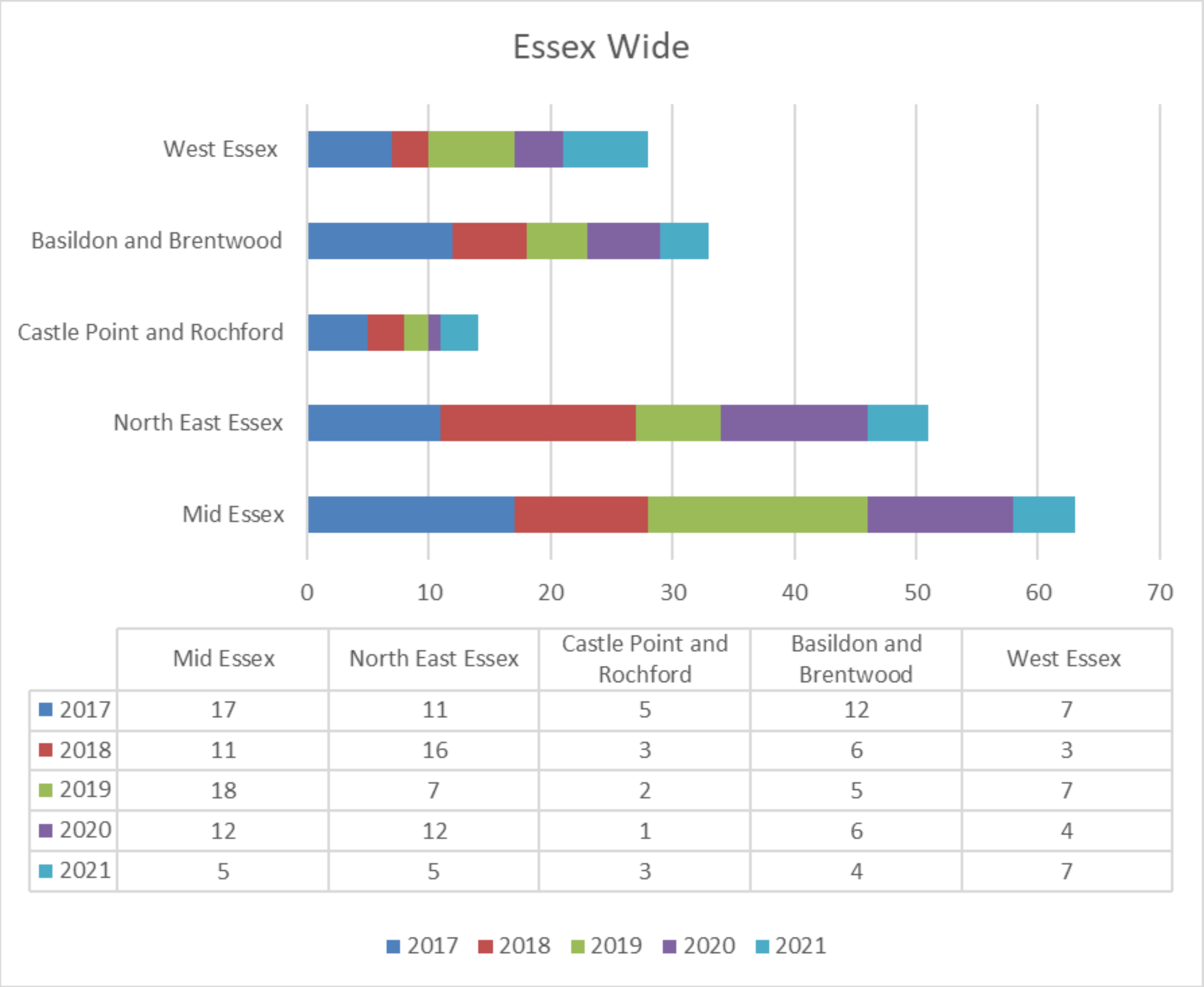
Year of Referral

We asked participants “Approximately what year was your CYP referred to the pathway?”



	Mid Essex	North East Essex	Castle Point and Rochford	Basildon and Brentwood	West Essex
🟦 2017	17	11	5	12	7
🟥 2018	11	16	3	6	3
🟩 2019	18	7	2	5	7
🟪 2020	12	12	1	6	4
🟦 2021	5	5	3	4	7

It is important for us to understand the approximate year the referral occurred so we can understand which time period their experiences relate to.

AS this report progresses, where possible, we have broken down feedback by the year of referral.

As changes are made to improve the ASD ADHD pathways across Essex, we hope to see, in further surveys, the changes are impacting on families' experiences in a positive way.

However, this was not a “forced” option question, which meant that participants were able to skip. It was felt by forcing a response and the respondents being unsure, it could have prevented them completing the remainder of the survey.

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Year of Referral

We asked participants “Approximately what year was your CYP referred to the pathway?”

We had 71 respondents that did not indicate a year of referral from the provided choices and selected “other”. As you can see from the comments, many of these participants were referred prior.

Where the data is specifically looking at 2017 to 2021, their responses have not been included.

Comment Provided	Number of Participants
1998	1
2004	2
2006	2
2007	2
2008	2
2009	3
2010	2
2011	6
2012	6
2013	5
2014	14
2015	10
2016	10
2001/2	1
2005/6	1
2015/2016	1
Although still waiting for someone to acknowledge!	1
Still waiting	1
Too long so we went privately	1

CCG Foot Print	Total number of Participants
Mid Essex	24
North East Essex	17
Castle Point and Rochford	9
Basildon and Brentwood	11
West Essex	10
Total	71

The data and detail that the respondents have provided is invaluable and as such we have provided a breakdown of these specific cases, by each CCG, for review for questions 1-30. Questions 31-33 are included within the report as indicated.

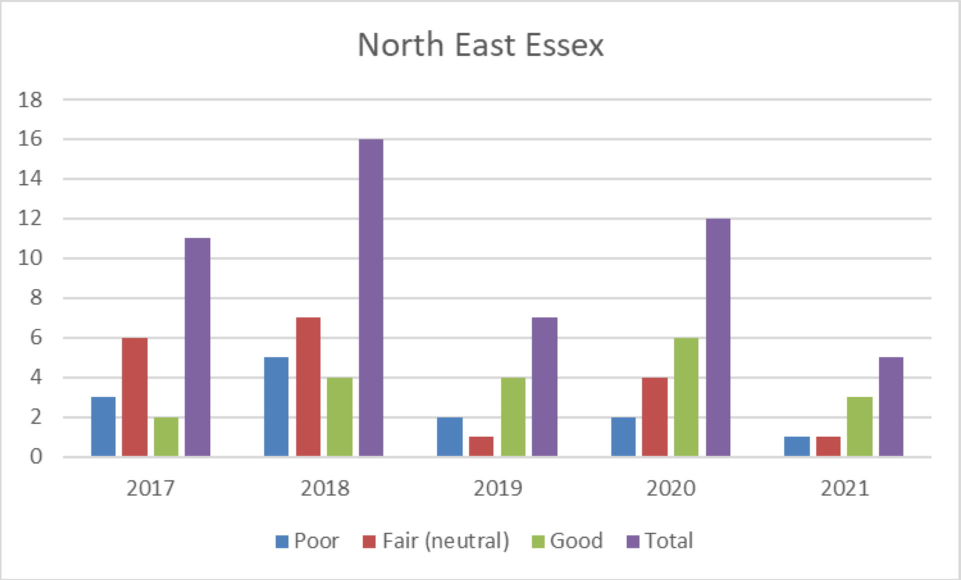
Microsoft Excel Worksheet

Referral Experience – By Time Period and CCG

We asked Participants “How do you rate your experience on being referred to the pathway (via GP/School/Therapist)?”

We have broken down the responses by time period and by the CCG footprint. The attached document gives comments provided by respondents broken down by year of Referral and by CCG footprint

Microsoft Excel Worksheet



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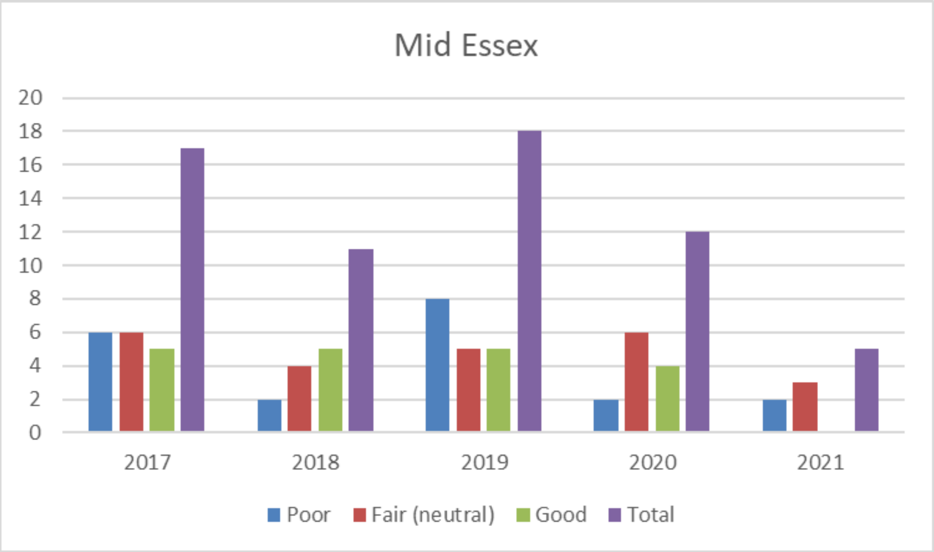
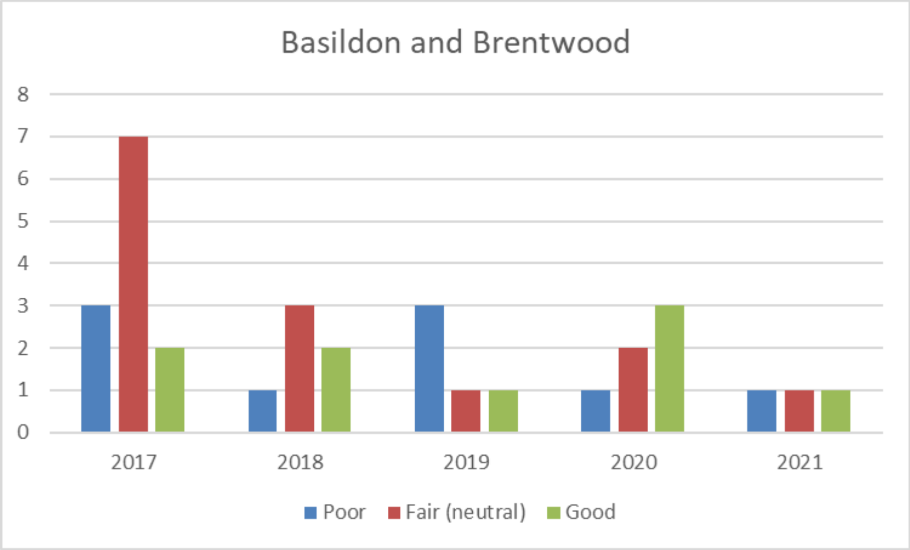
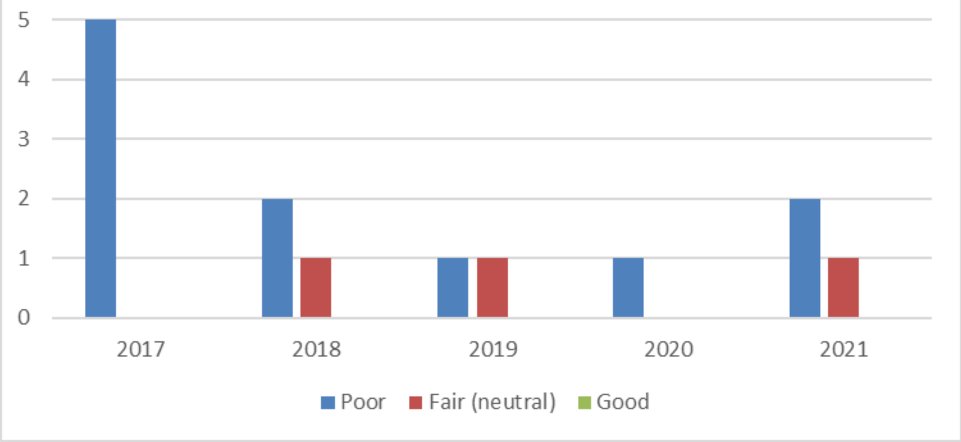
Referral Experience – By Time Period and CCG

We asked Participants “How do rate your experience on being referred to the pathway (via GP/School/Therapist)?”







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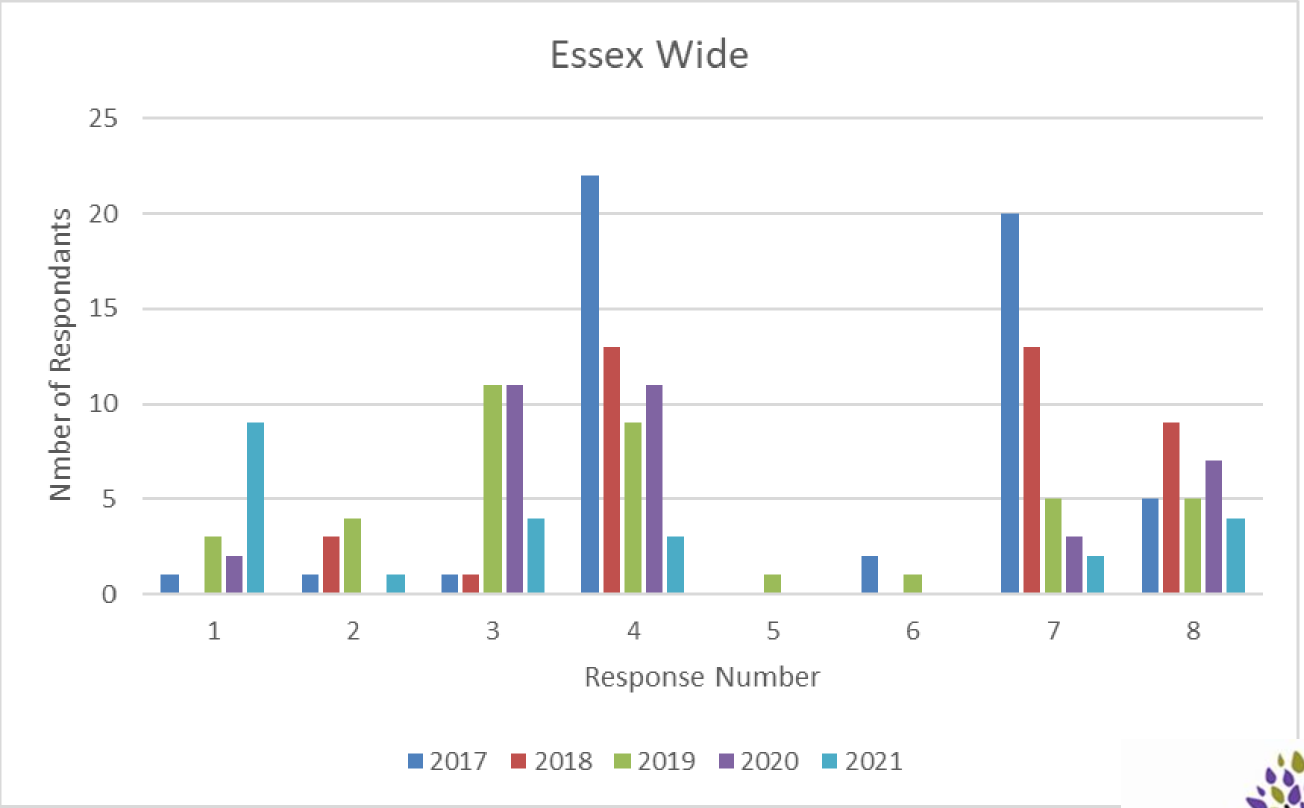
Current Status

We asked participants “What is your current status with Community Paediatrics (or similar)?"

Response Legend	
1	Awaiting the first appointment
2	Currently being reviewed. For example: Questionnaires sent to schools / awaiting follow up appointment.
3	Community Pediatrics have agreed to an assessment (ADOS/BOSA/Qb Test) and we are on the waiting list
4	Diagnosis has been made, we have periodic reviews.
5	Discharged - Child or Young Person did not meet the threshold for a Neurodevelopmental assessment (eg: ADOS/BOSA)
6	Discharged - A Neurodevelopmental diagnosis was not given following a Neurodevelopmental assessment (eg: ADOS/BOSA)
7	Discharged - A Neurodevelopmental diagnosis was given following a Neurodevelopmental assessment (for example ASD/ADHD)
8	Other (please specify)



We received total of 31 comments, which you can see on the embedded document, along with a breakdown of the status by CCG

Microsoft Excel Worksheet

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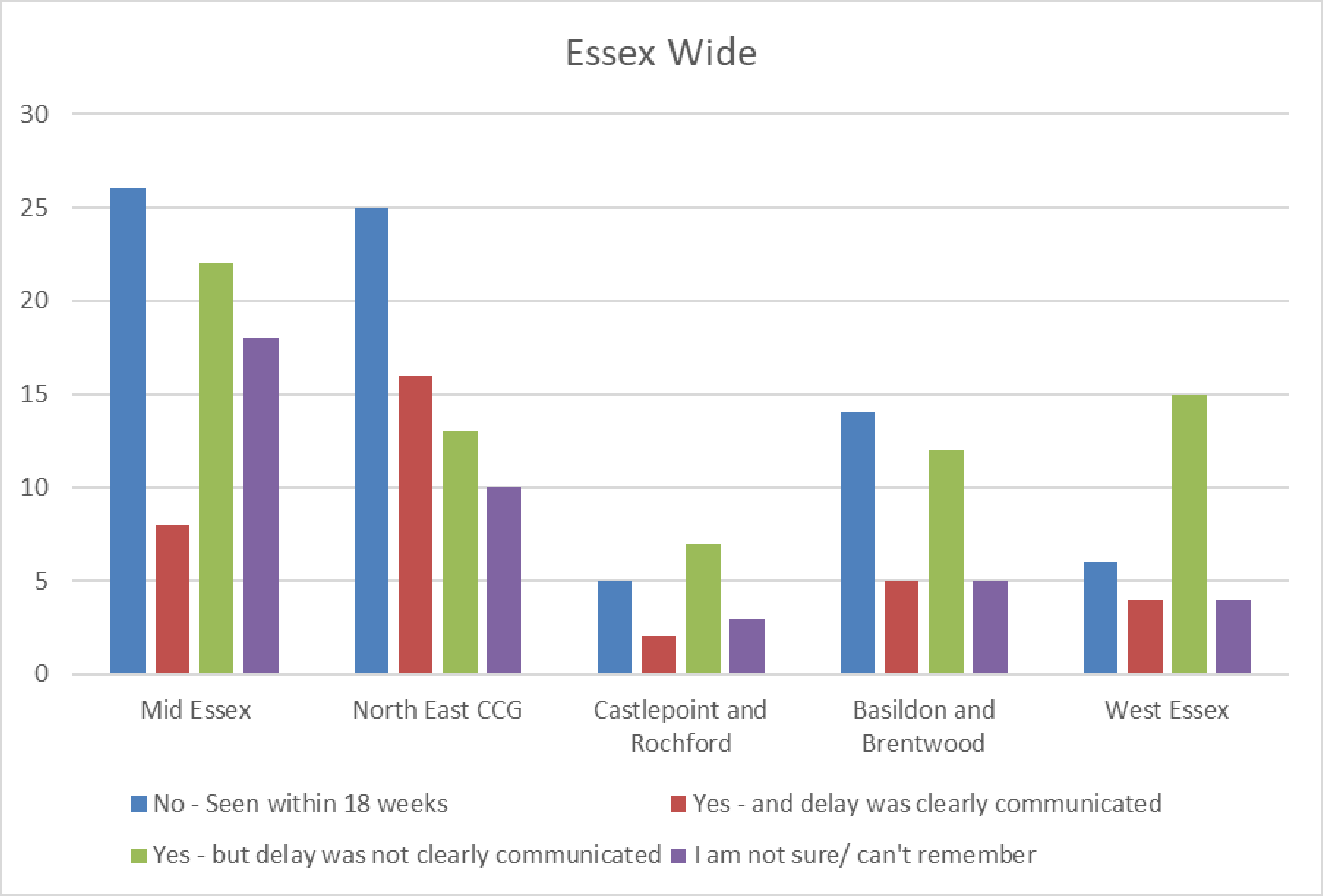
First Appointment Delays

We asked Participants “Did you experience any delays/long wait times for your first appointment? Delays are considered to be over 18 weeks (approximately 4 1/2 months) as per NICE Guidance.”



First Appointment Delays

The responses show a mixed response in terms of communication surrounding delays. The data shows of those who responded, that the number of respondents reporting that delays were not clearly communicated have dropped since 2017. However, we also see the number of respondents reporting that delays were communicated also drop.

This could partly be attributed to the fact that here is a variation of number of referrals per year, so we would expect lower response rates for each question asked and given the time of the survey being taken in 2021. Its arguable that many respondents who were referred in 2021 would have not exceeded the 18 weeks time frame and, as such, experiences in 2021 is not truly reflective.

We have further broken down this data by CCG, which can be located on the embedded attachment.

We have also included comments provided by respondents, which provide both negative and positive feedback.

Year	Number of respondents
2017	49
2018	36
2019	32
2020	30
2021	11
Total	**158**

Microsoft Excel Worksheet

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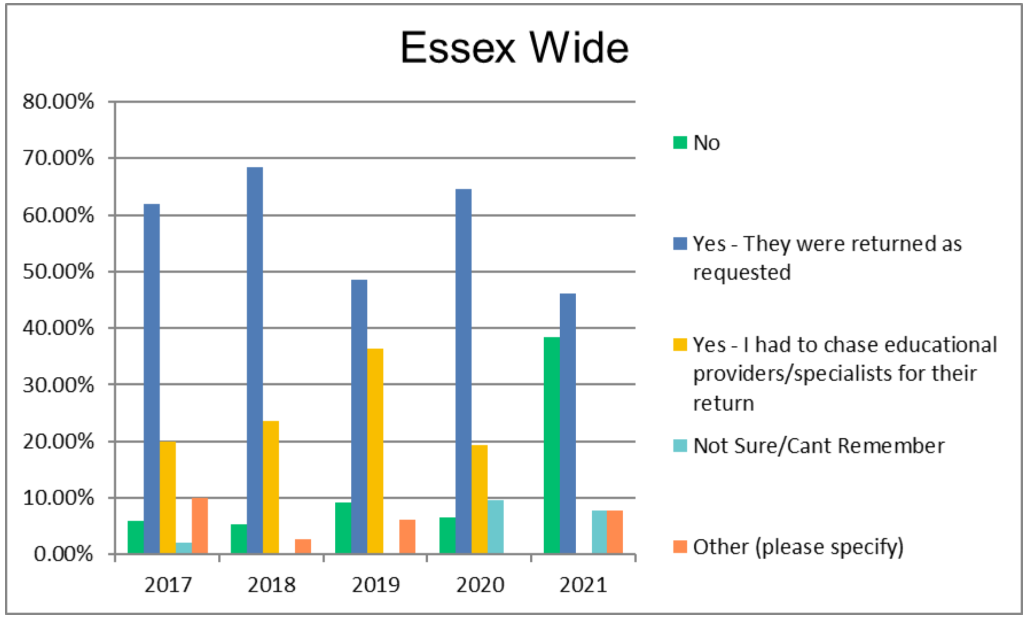
Questionnaires and Information

We asked Participants “Were questionnaires and information on your child or young person requested from educational providers or other specialists?”



Overall:

60% Report that the questionnaires were returned

22% Report that they had to chase for their return

“Other” comments are provided below

Year of Refferal	Comment
2017	But has taken5 yees to get this far!
2017	Home educated - provided
2017	I had to chase the school because they didn’t want to complete the Connor form
2017	On second referral questionnaires from school were requested. School didn’t receive them until day before our initial appointment, paediatrician only saw them for first time in our appointment
2017	Yes but was during transition from Primary to Secondary
2018	Yes. School failed to return them despite several chasers from paediatrics and myself. When forms were returned they were simply marked as no issues at school despite numerous things reported in home-school book (school deemed as rude / lazy rather than asd)
2019	The ADHD Nurse specialist had to chase ***remove*** School on several occasions - it was during the pandemic but she was frustrated.
2019	Yes but ADHD nurse had to chase, repeatedly
2021	I requested school did a q

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Assessment

We asked Participants "Have you been offered or had an assessment (eg: ADOS, BOSA, Qb Test)?"

When reviewing the 6 participants who advised that their child did not meet the threshold.
One parent reported:

"I was told my child could not be diagnosed with adhd as they are home educated!!!"

For those respondents who indicated that they had been offered an assessment we asked further questions to gain a better understanding of their experience

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Assessments

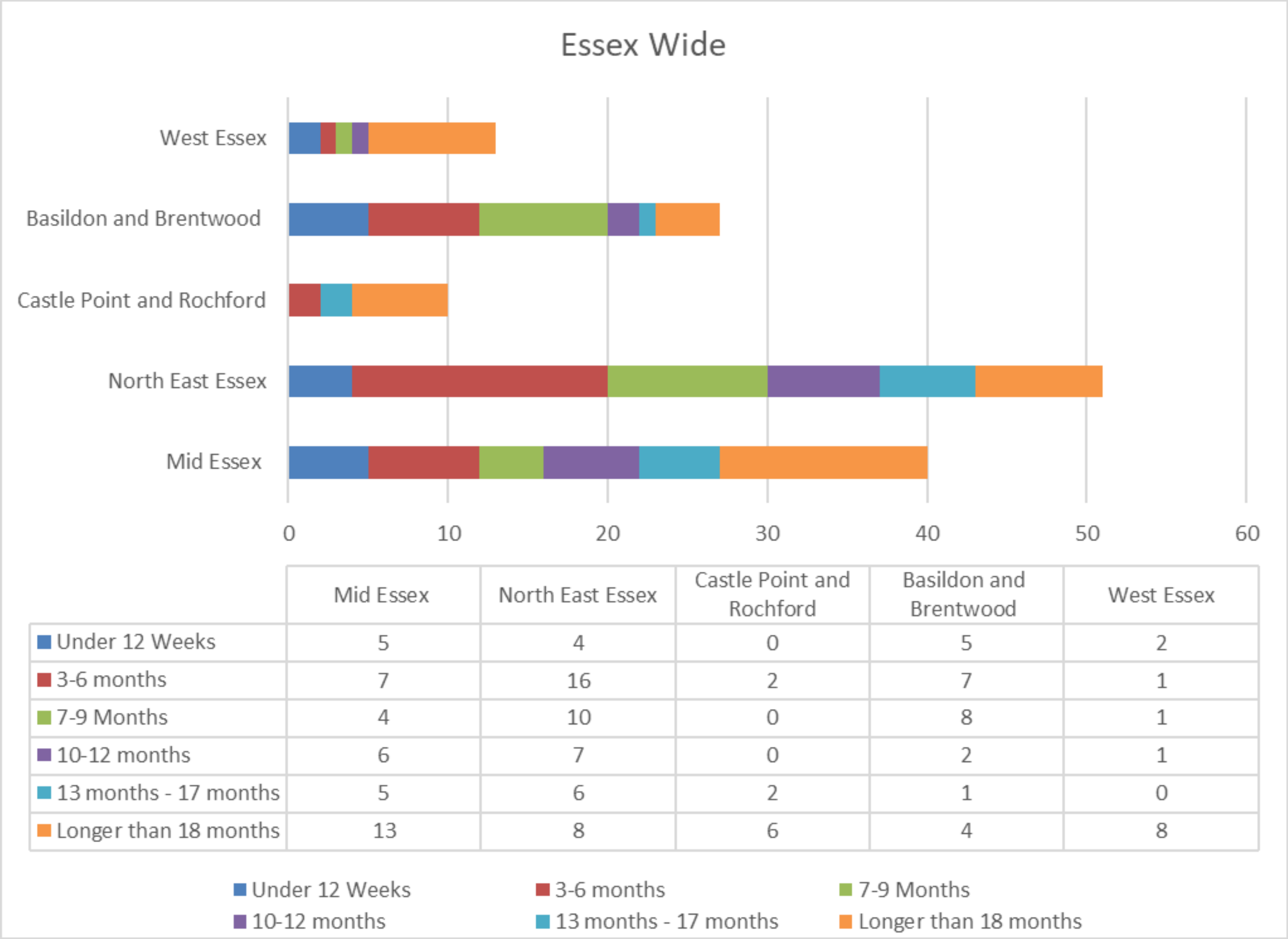
79% (178) of the respondents indicated that they were offered an assessment with 18% (41) of respondents stating that it had not been discussed at all. 3% (6) report that their child was did not meet the threshold for assessment. It was disappointing to note that the reason given for not meeting the threshold for one parent was that the child is home educated. That said, it is to be expected that not all CYP will meet the need for threshold and we welcome the fact the numbers reported were low.

A further analysis of the data shows that 73% (30) of those respondents where assessment has not yet been discussed are still under community paediatrics, while the remainder have been discharged. Therefore, we must assume that the CYP needs are still being viewed and/or monitored.

3 respondents who were discharged state the reason for discharge was not explained to them and 8 respondents state they were not provided with any details to re-access the service should their CYP needs change. Whilst small in overall numbers, Essex Family Forum firmly believes that all parent and carers should clearly understand the reason for discharge from their service and how to re-access should their CYP needs change.

Assessment Wait

We asked Participants “Approximately how long did you have to wait for your assessment? (From the point a decision to assess was made, not the initial referral to community paediatrics)”



	Mid Essex	North East Essex	Castle Point and Rochford	Basildon and Brentwood	West Essex
Under 12 Weeks	5	4	0	5	2
3-6 months	7	16	2	7	1
7-9 Months	4	10	0	8	1
10-12 months	6	7	0	2	1
13 months - 17 months	5	6	2	1	0
Longer than 18 months	13	8	6	4	8

It is important to note, when looking at the results, the varying number of respondents for each CCG

Assessments

When we look at the statistics for the wait for the assessment there is reported variation within each CCG. Overall, 65% of respondents stated that they waited over 7 months for an assessment which clearly exceeds the NICE Guidance.

When we look at the data for the specific years the percentage waiting *over 7 months* for assessment is shown below:
2017 - 78%
2018 – 55%
2019 – 75%
2020 – 60%

Furthermore 28% (39) respondents in total indicated that they waited over 18 months.

When we look at these 39 respondents and look at the advice and support, they received, it is disappointing:
71% reported that they were ***not*** signposted for advice at point of referral.
51% report that they were ***not*** signposted for support by community paediatrics.
29% report that they were ***not*** signposted for support at the outcome of assessment.
32% report they were ***not*** signposted for support at the point of discharge.

It is disappointing that not only are parents experiencing inadequate wait times, but - more importantly - they are not being signposted by professionals for the appropriate support whilst they are waiting and even following assessment and discharge.

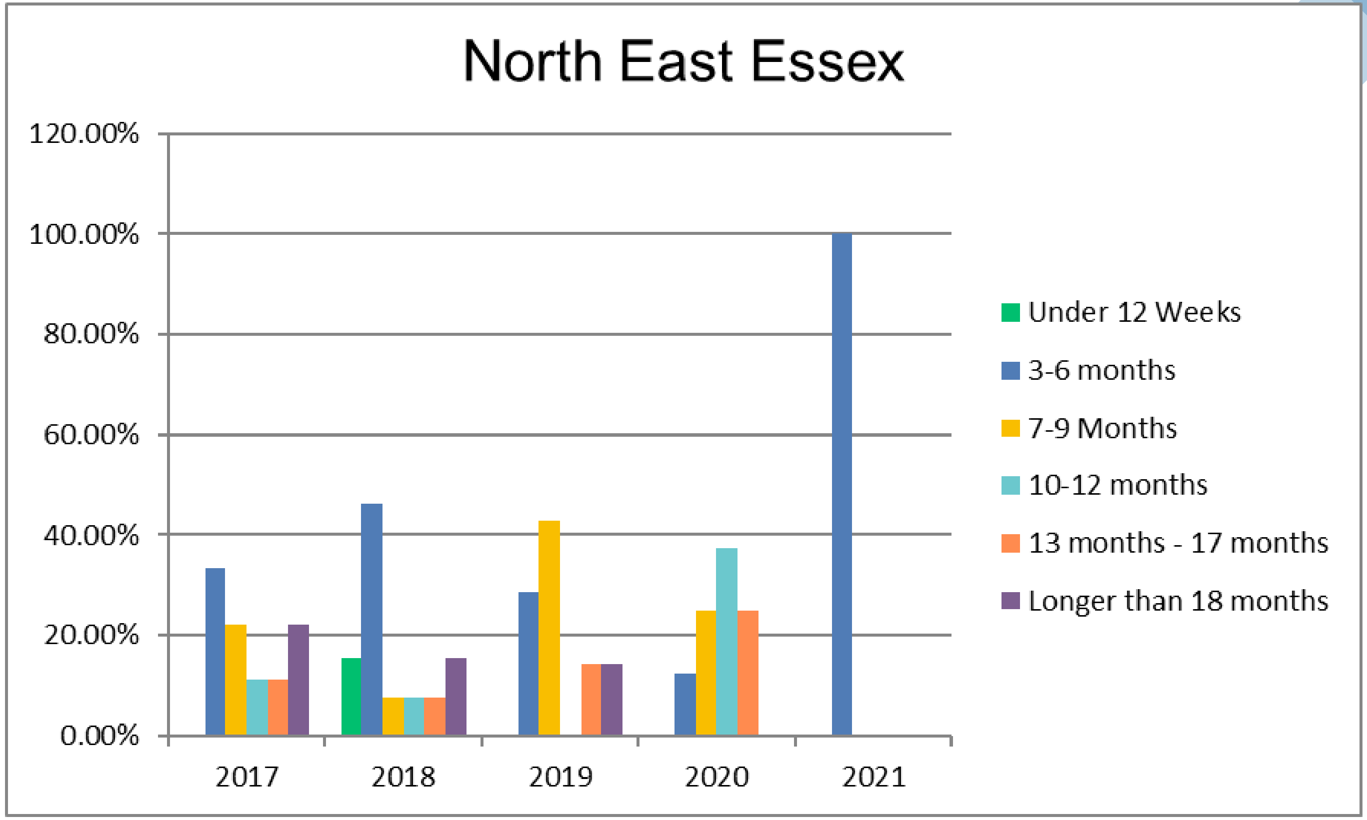
A breakdown of wait times per CCG footprint follows.

Assessment Wait

We received 38 responses for North East Essex confirming they had received an assessment

We received a further 5 comments from those who state that they had yet to have an assessment.

2017	Again, I couldn't say for certain how long the wait was, but it was longer than I had expected compared to previous experiences.
2018	Diagnosis was made by Dr on day as ados was not needed and my son was to neurology delayed to cope with ados assessment
2020	7 months
2020	Since March 2020
2021	Still waiting 7 months

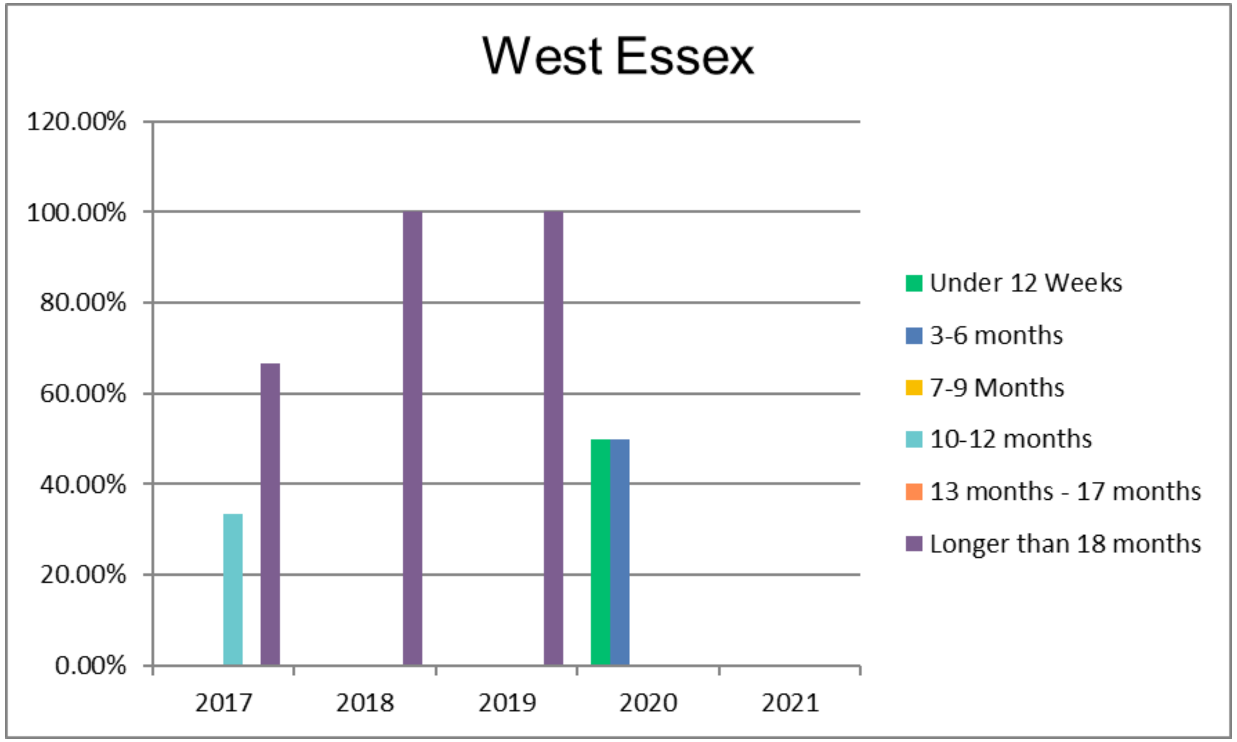


Assessment Wait

We received 7 responses for West Essex confirming they had received an assessment

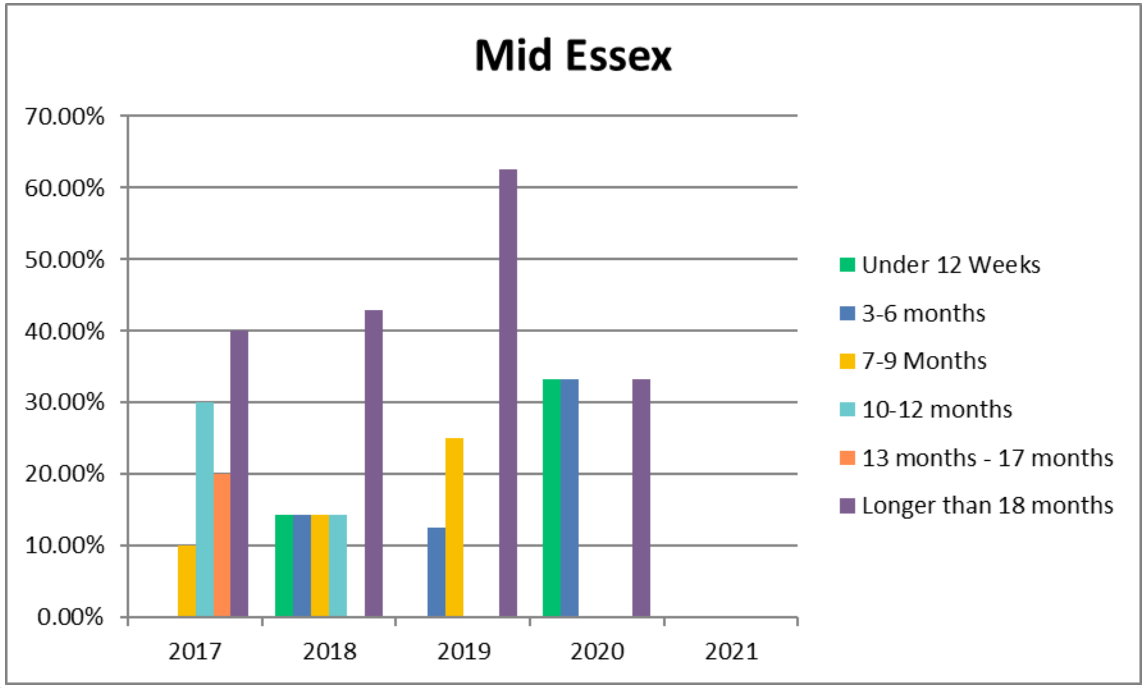
We received a further 6 comments from those who state that they had yet to have an assessment

2017	We went private due to long wait of over two years
2019	Have been waiting for about 6 months so far
2019	Just under 18 months
2019	Been waiting since Sept 2020
2020	Assessment completed by the community paediatrician during the very 1st appointment as dr had enough evidence
2021	4 months



Assessment Wait

We received 28 responses for Mid Essex confirming they had received an assessment



We received a further 17 comments from those who state that they had yet to have an assessment

2017	4 years went private
2017	First paediatrician was not willing to diagnose as school didn't agree, changed paediatrician then got a diagnosis - was a year with the first one
2018	We have been awaiting since May this year
2019	12 months +
2019	19 months
2019	2 years
2019	20 months
2019	Been waiting since Aug 2019
2019	due to covid
2019	It's been 2 years since initial referral
2019	Still waiting we we told December last year but covid has put everything back still waiting been waiting september 2019
2019	We are currently just at 18 months. Really hoping for an assessment soon as child is now going into year 1 of school and really needs this assessment
2020	12 weeks
2020	Have been waiting 3 months so far
2020	Since January 2020.
2020	We have currently been waiting 2 months. I have been told the waiting list is about 2 years long. I contacted the service to ask several questions regarding certain tools being better for diagnosing girls, other support available & private services, but never received a reply. I had to chase up to confirm that the completed acceptance of referral to this stage had been made.
2021	Two weeks but told it will be about 18 months

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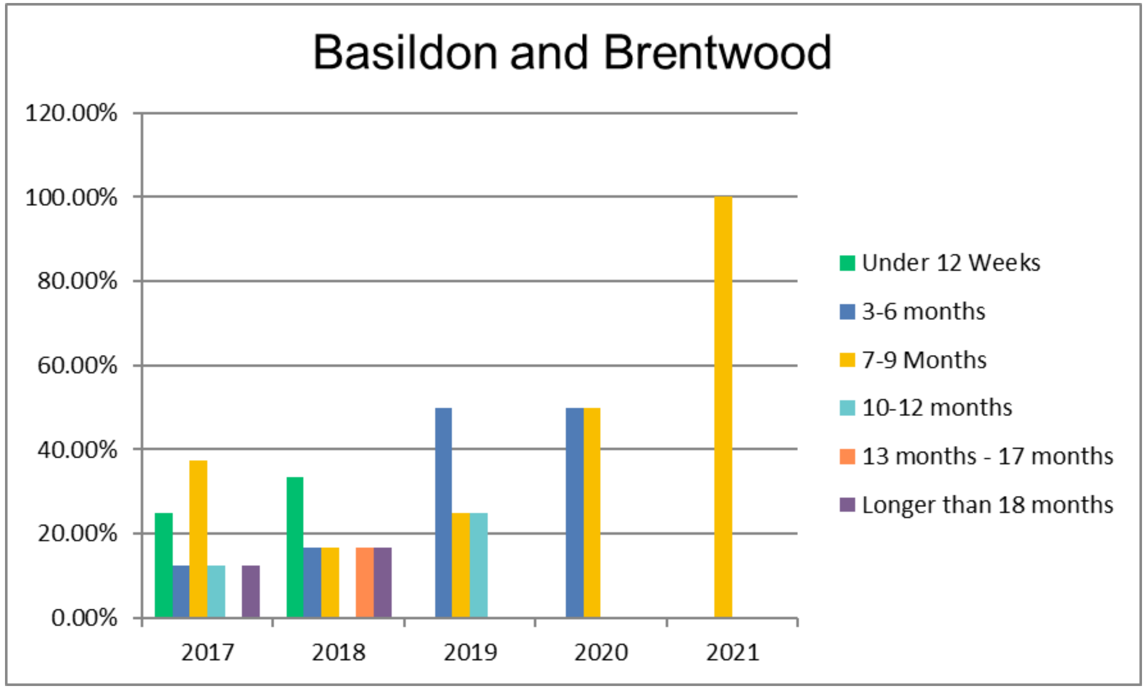
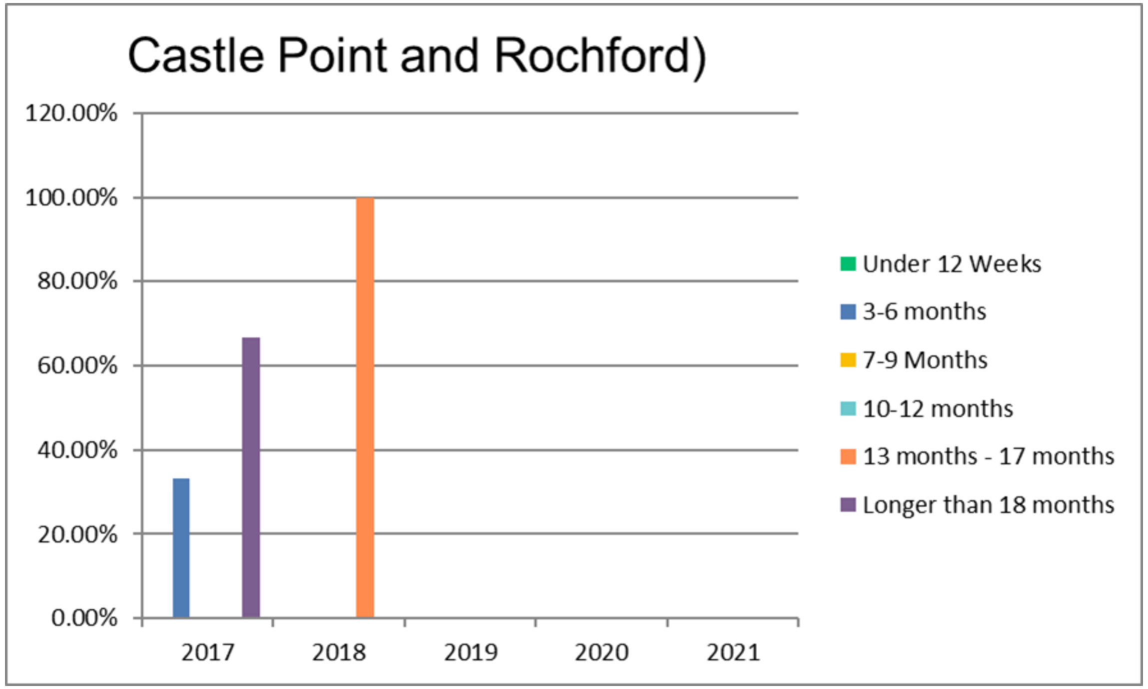
Assessment Wait

We received 21 responses for Basildon and Brentwood confirming they had received an assessment

We received 5 responses for Castle Point and Rochford confirming they had received an assessment





We received one further comment from a person who states that they had yet to have an assessment

“3 months, not yet been properly referred “

We received no comments for Castle Point and Rochford

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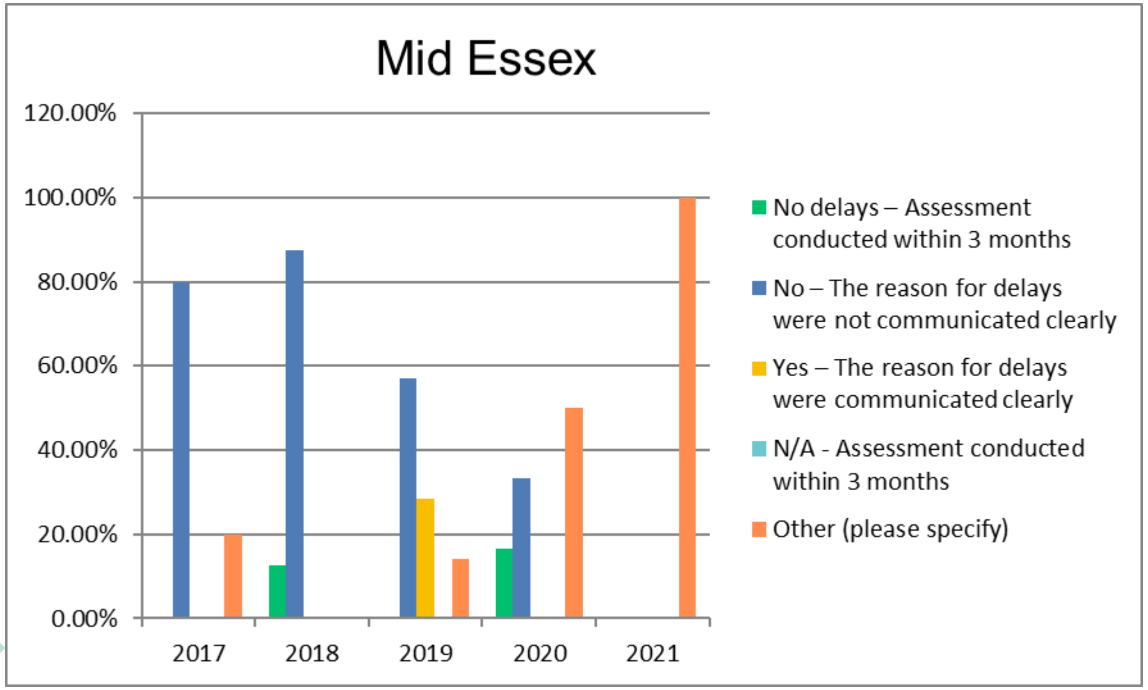
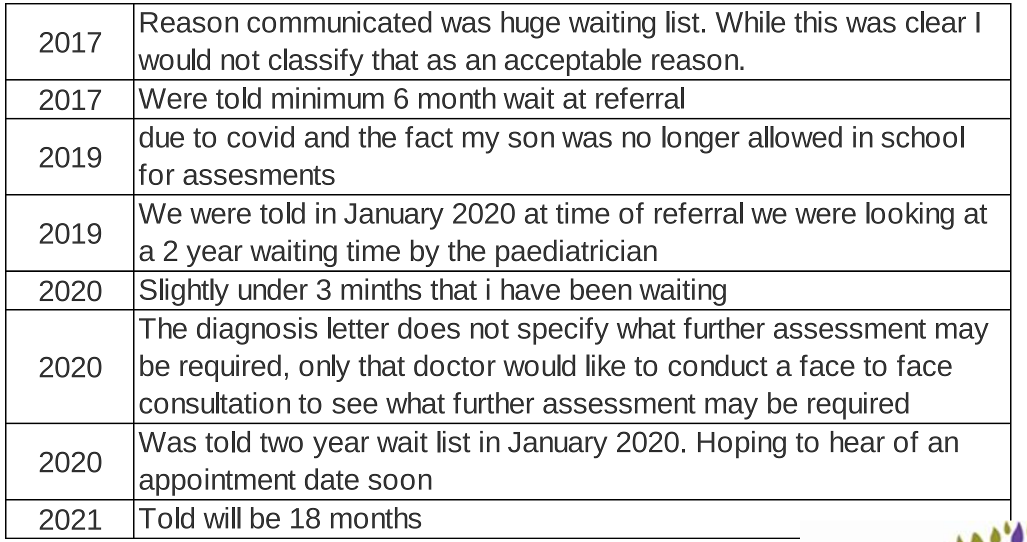
Assessment Delays

We asked "If the wait for assessment was/has been over 3 months, was the reason for the delay for assessment communicated with you?(NICE guidance states ‘Start the autism diagnostic assessment within 3 months of the referral to the autism team'. This is considered to be the date it was agreed an assessment, such as the ADOS is required)"

We had 39 respondents and 87 comments under “other”.

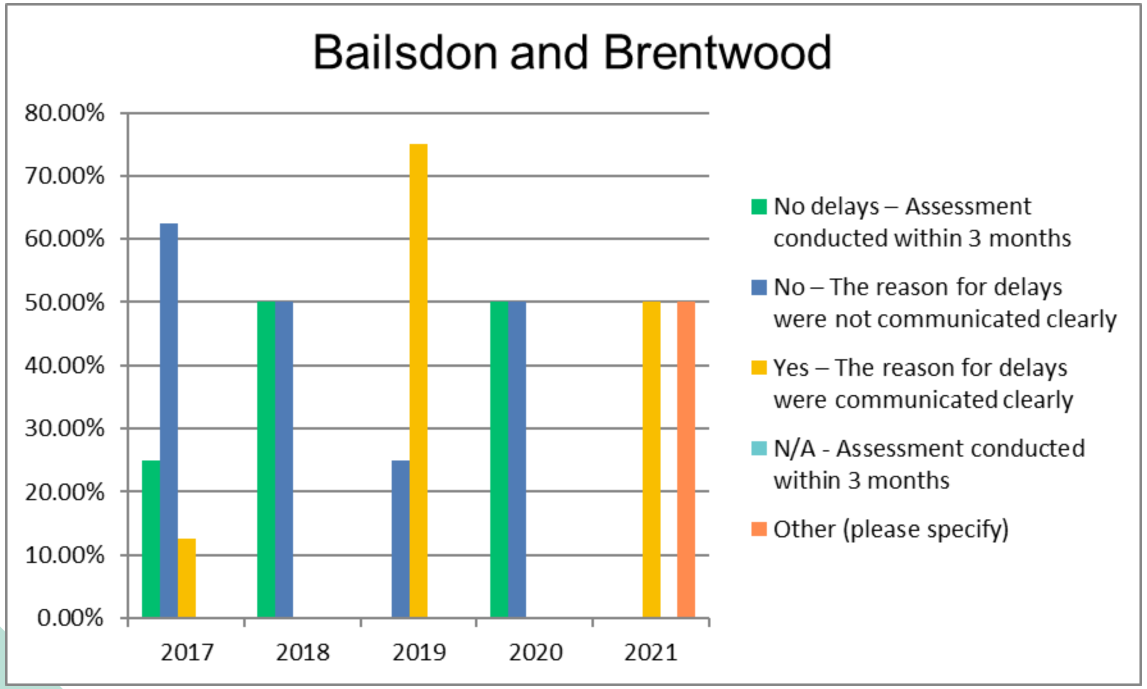




2017	Reason communicated was huge waiting list. While this was clear I would not classify that as an acceptable reason.
2017	Were told minimum 6 month wait at referral
2019	due to covid and the fact my son was no longer allowed in school for assesments
2019	We were told in January 2020 at time of referral we were looking at a 2 year waiting time by the paediatrician
2020	Slightly under 3 minths that i have been waiting
2020	The diagnosis letter does not specify what further assessment may be required, only that doctor would like to conduct a face to face consultation to see what further assessment may be required
2020	Was told two year wait list in January 2020. Hoping to hear of an appointment date soon
2021	Told will be 18 months

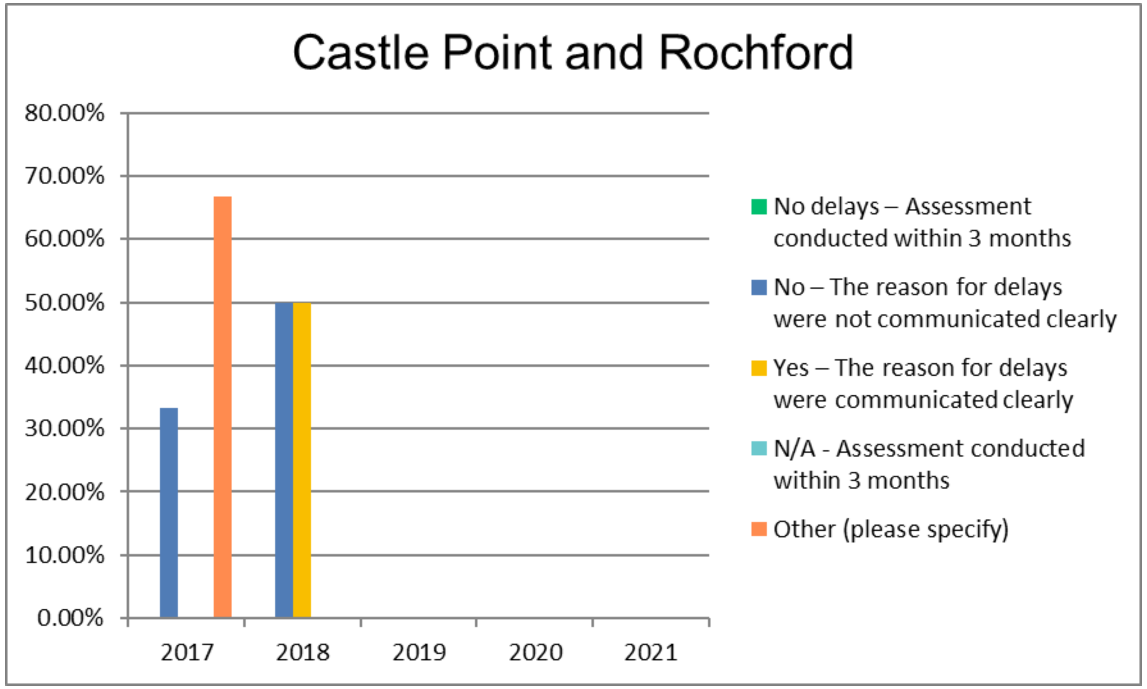
Assessment Delays

22 Responses and 1 comment provided for “other”



2021	Three month delay to even be referred

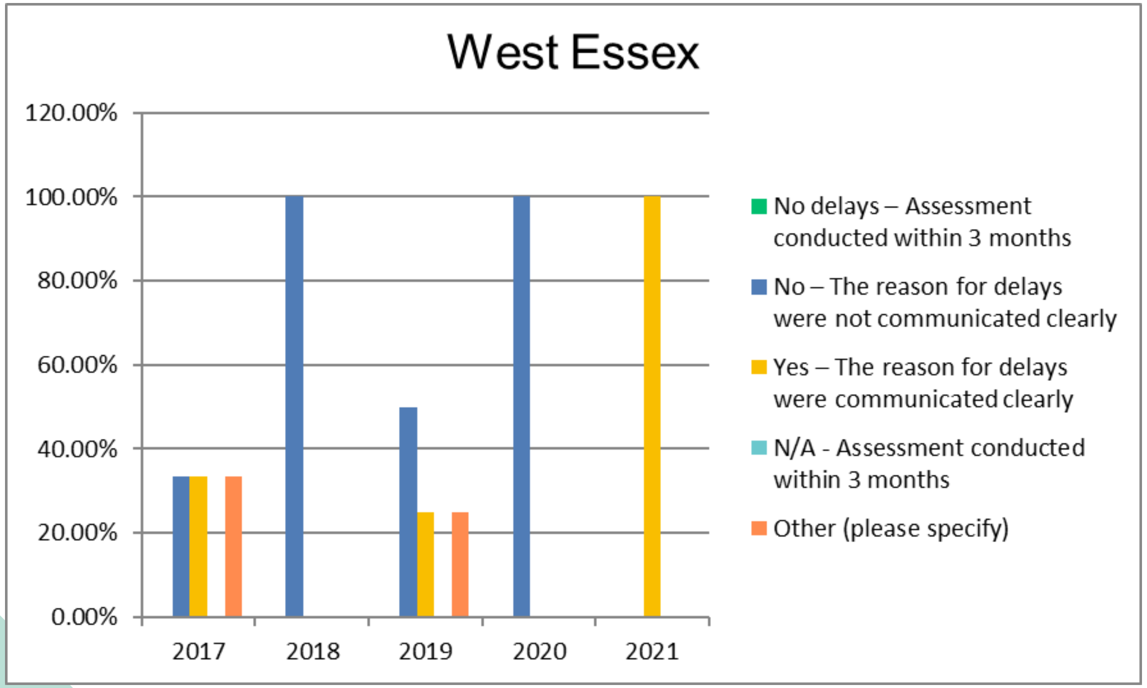
2017	Had to constantly chase up and ended up woth complaint and chasing CCG constantly for 3yrs
2017	Due to covid along with lack of paediatric consultants at the lighthouse I had to chase myself with the CCG directly to get our referral picked up and sent to central referral service in order to get an appointment. The lighthouse centre was giving out false information about the referral process



5 Responses and 2 comments provided for “other”

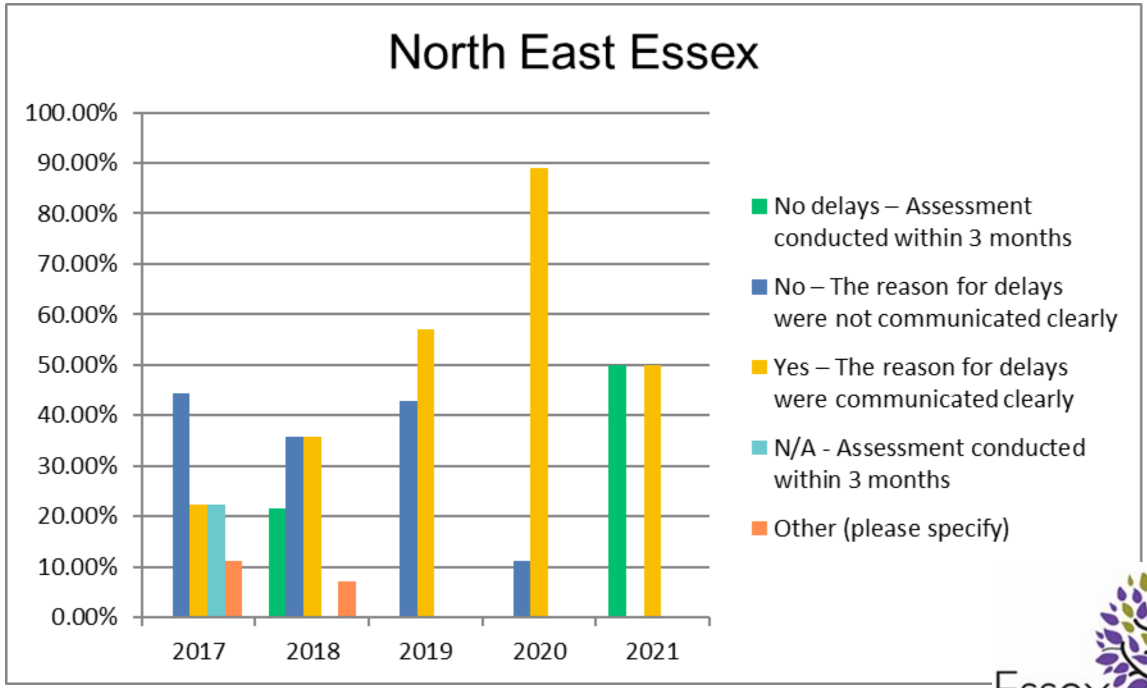
Assessment Delays

11 Responses and 2 comments provided for “other”



2017	Delays due to short staffing in CDC
2017	Haven’t been assessed yet

2017	Process took six months - when paediatrician agreed to assess, we were placed on ADOS list (told this was 18mths - 2yr list) but when we returned for 2nd appointment at the 6 month mark, we had assessment and diagnosis of Sensory Processing Disorder, Educational Psychologist report and input and report from the Specialist teaching team and therefore given an ASD diagnosis without needing ADOS
2018	Diagnosis with out ados as multidisciplinary assessments already completed including private O.T



41 Responses and 2 comments provided for “other”

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Assessments Delays

Out of 163 respondents to this question, 24 respondents reported that assessment occurred within 3 months.
74 respondents (45%) reported that the delay in assessment was not communicated, compared to 42 respondents who said it was.

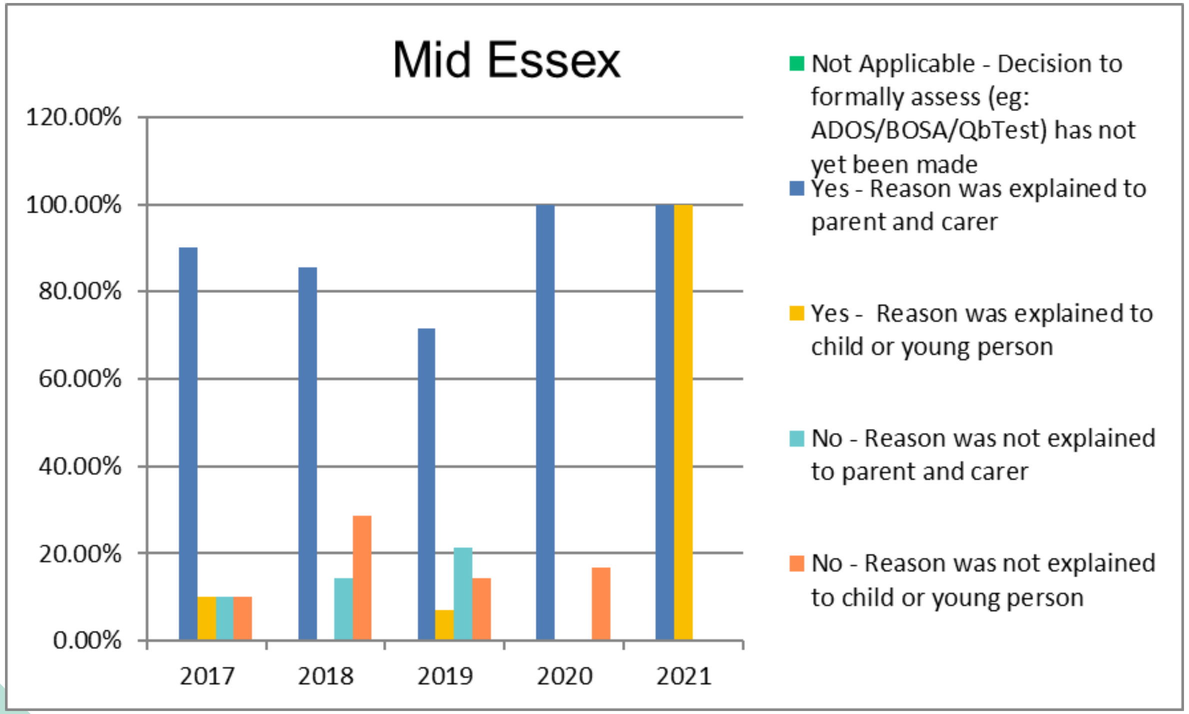
It is clear that there is variation across the CCGs, which in part is due to the variation of respondents from each CCG.

In an ideal world, families would not experience any delays and would been seen within NICE guidance time frames, however we appreciate that this may not always be possible. Therefore, Essex Family Forum firmly believes that written communication should reflect approximate wait times and that regular updates should be provided. We also feel that it's important that families understand who to contact should their CYP needs change whilst waiting for an assessment to ensure that those who are waiting are waiting safely.

We would strongly advocate for regular communication whilst waiting, which outlines what families can do if CYP needs change and re-confirm signposting for support.

Reason for Assessment

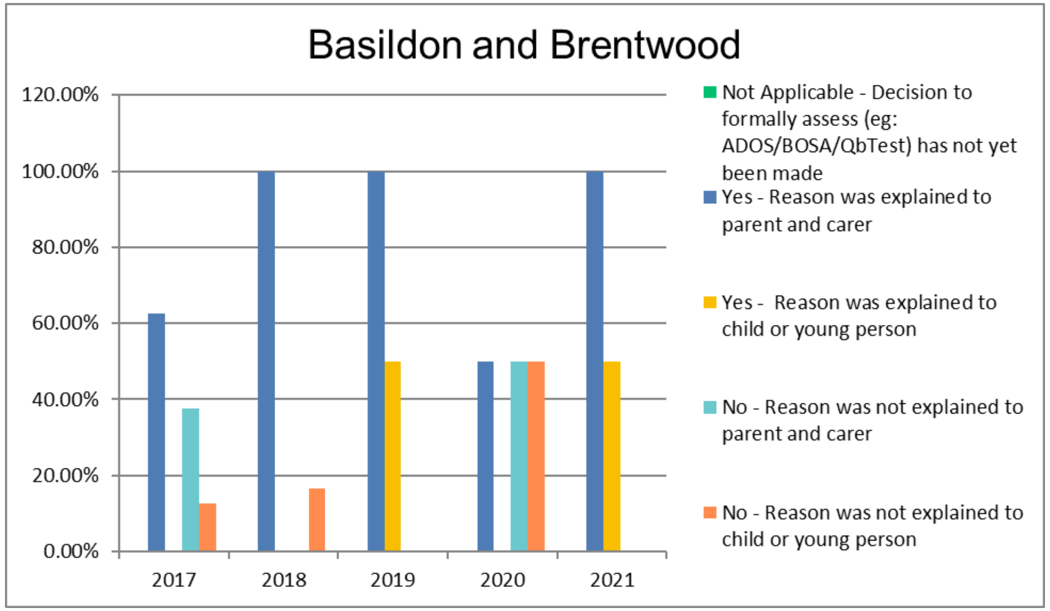
We asked Participants “Was the reason an assessment was needed clearly explained?(tick all statements that apply)”



2018	No, it was me that insisted an assessment was needed
2018	She was young and I don't think would have understood so that's fine by me.
2019	Due to covid
2019	Covid
2019	Great doctor. Very thorough assessment by paediatrician as to why Son was being referred for an ASD assessment and conversation with myself (parent)
2020	My child had left the consultation at this point after becoming agitated at the treatment discussion so it was agree I would explain it to him

38 respondents provided feedback and 6 provided additional information

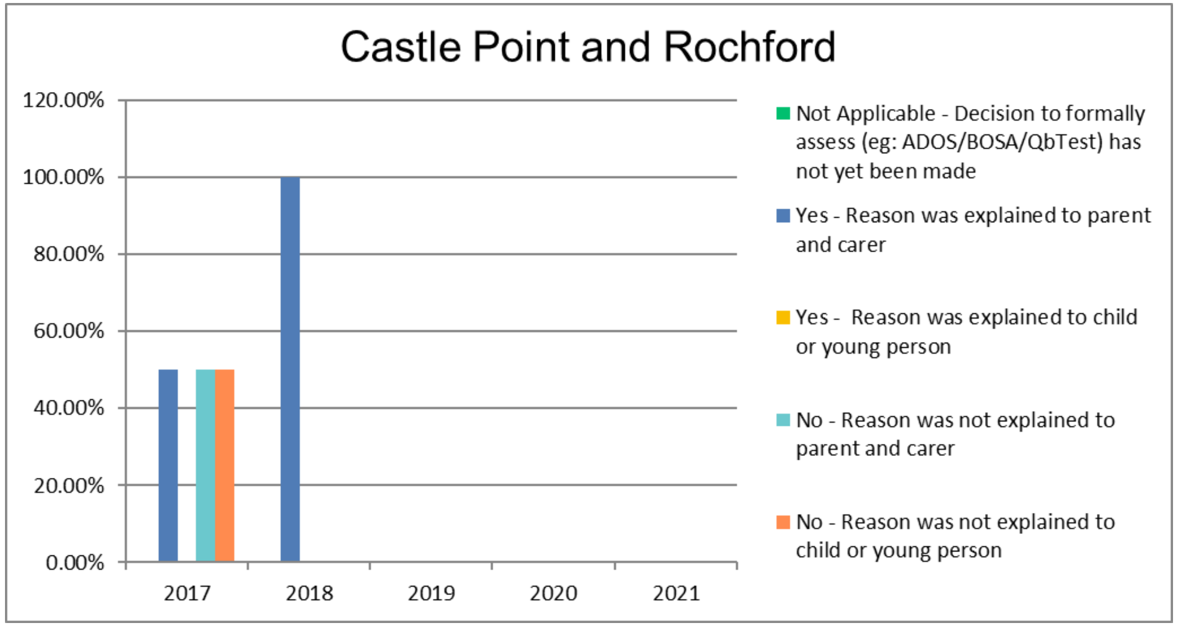
Reason for Assessment



22 respondents provided feedback and 2 provided additional information

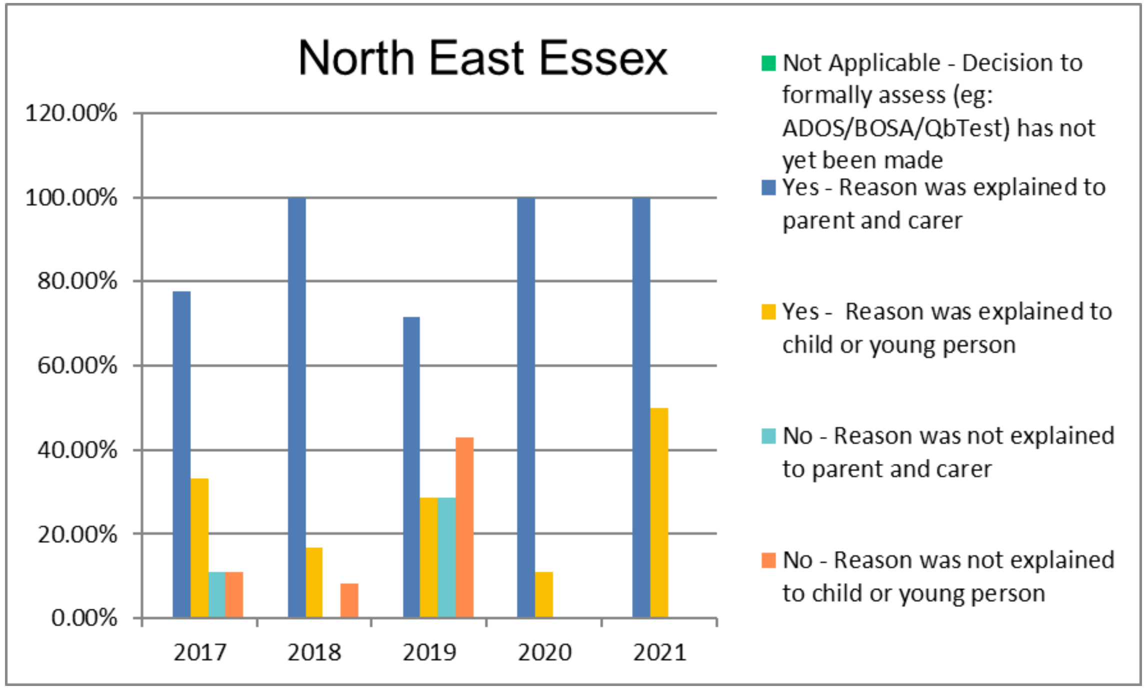
2017	My son was offered a ASD test because the school wouldn't agree with the ADHD suggested diagnosis
2020	We haven't been told anything.

4 respondents provided feedback and 1 provided additional information



2017	I had to fight for the assessment referal

Reason for Assessment

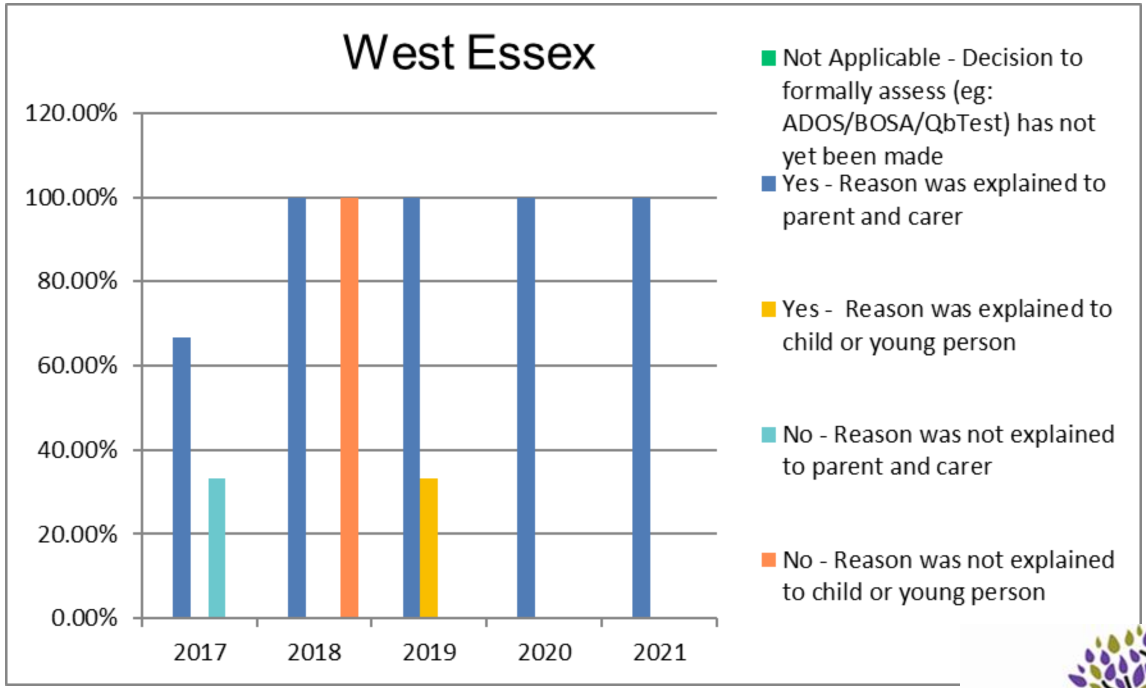


39 respondents provided feedback and 1 provided additional information

2018	What difference an ados would have on diagnosis was not explained.

10 respondents provided feedback and 1 provided additional information

2019	Haven't been assessed yet



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Reason for Assessment

Essex Family Forum recognises that explaining the assessment to a CYP may not always be *appropriate* or *possible* and, after consideration, we accept that the question did not perhaps reflect this. However, we do believe that where it is *appropriate* CYP should be kept informed and involved in decisions about their care and that communication tools such as social/communication stories can and should be used and that families should be supported to have those conversations where needed.

However, it is positive to see that many parents and carers report that the CYP was included in the discussions around assessment. The data shows that it is variable across each of the CCG footprints, but we accept that our phraseology of the question did not perhaps support the findings.

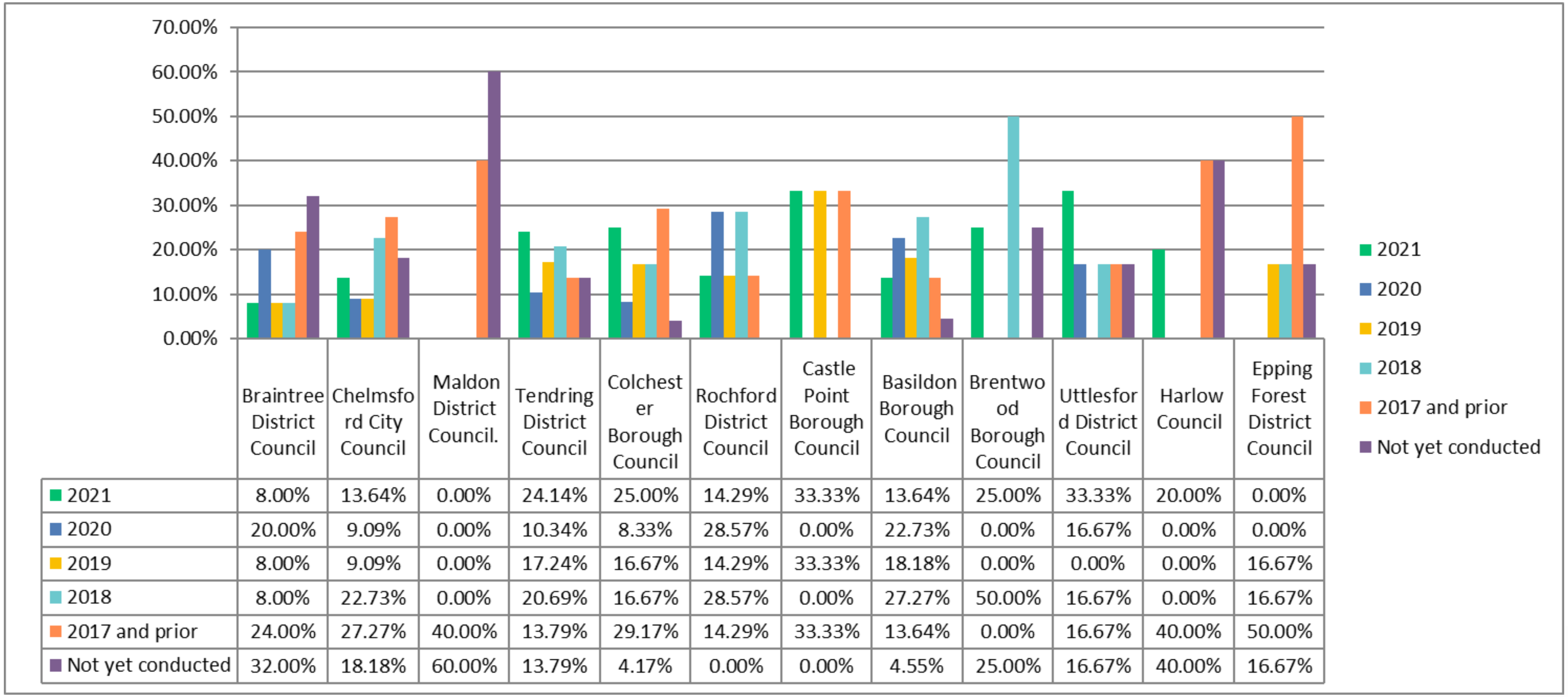
Whilst it is disappointing that 13% (23) parents report reasons for assessment was not explained, it is very positive that 82% (130) parents overall reported that that the reason for assessment was explained. When we looked at some of the comments of the 130 parents and carers many report that there needs to be improved communication, reduced waiting times and better understanding in schools. There was however some positive comments, such as “ Our paediatrician is amazing and she is the reason why my son is now getting the support for his ADHD” and “I was seen by Dr ***Removed*** and found him very helpful, during initial assessment he was very professional and answered any questions”

When we look further at those who say the assessment process was not explained we can see that 41% of those reported that they were not confident in the health professional's ability to assess their CYP and a further 32% reported that they did not feel that the health professional listened to their views.

One parent wrote that *“‘I’m always to sacred to ask any of them for help”* another wrote *”More explanation on point of receiving diagnosis. I felt I was told asd and adhd and then completely abandoned. I was handed a leaflet for a charity I can’t remember which one I never looked it. I wish they would have explained a little what of what a diagnosis could mean and told properly where to get help. I thinks follow up after the appointment would be amazing because it’s very hard to process emotionally a diagnosis and take on any information about where to get help and support”*

Year of Assessment

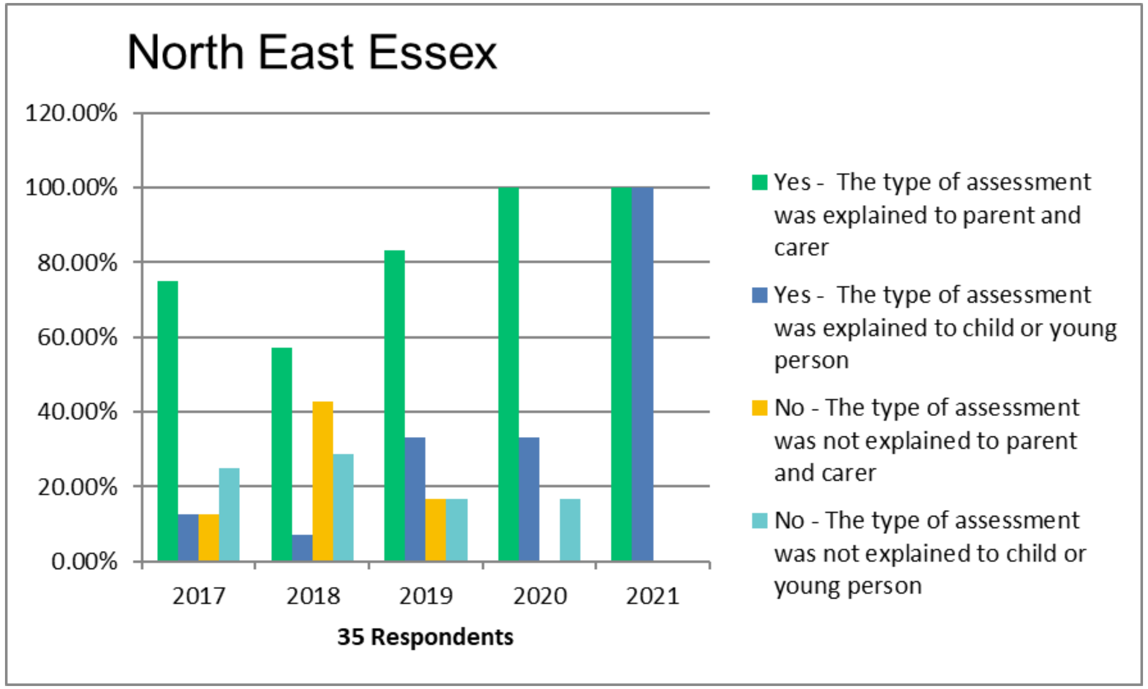
We asked participants “What year was your child or young persons assessment conducted?”

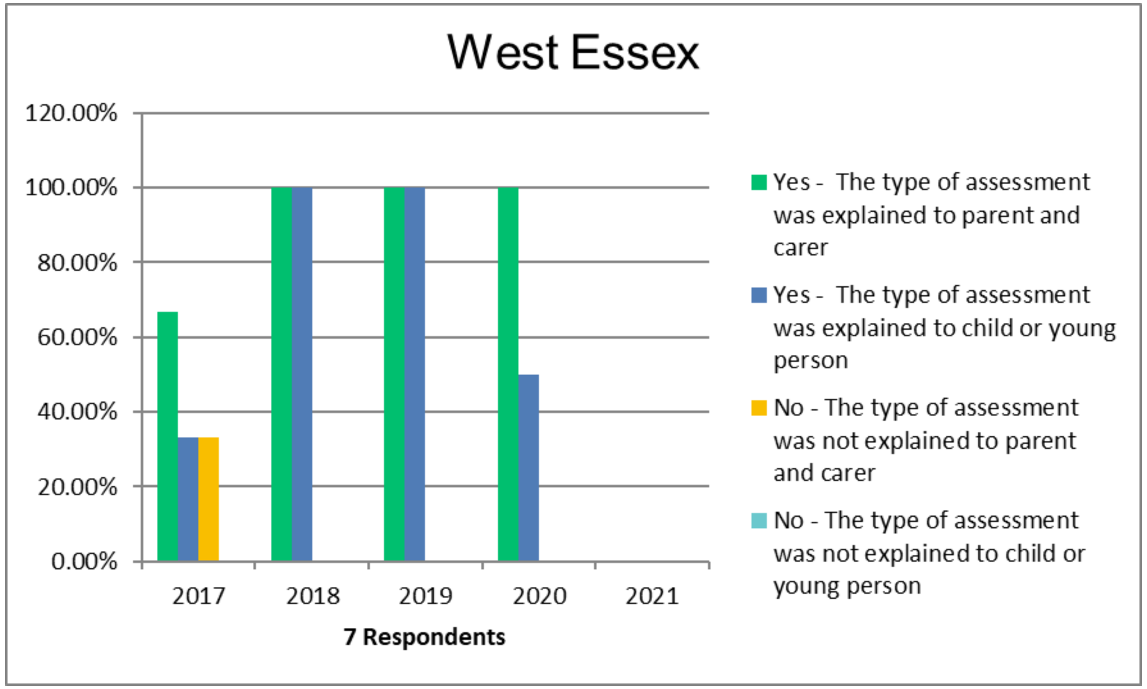


	Braintree District Council	Chelmsford City Council	Maldon District Council.	Tendring District Council	Colchester Borough Council	Rochford District Council	Castle Point Borough Council	Basildon Borough Council	Brentwood Borough Council	Uttlesford District Council	Harlow Council	Epping Forest District Council
2021	8.00%	13.64%	0.00%	24.14%	25.00%	14.29%	33.33%	13.64%	25.00%	33.33%	20.00%	0.00%
2020	20.00%	9.09%	0.00%	10.34%	8.33%	28.57%	0.00%	22.73%	0.00%	16.67%	0.00%	0.00%
2019	8.00%	9.09%	0.00%	17.24%	16.67%	14.29%	33.33%	18.18%	0.00%	0.00%	0.00%	16.67%
2018	8.00%	22.73%	0.00%	20.69%	16.67%	28.57%	0.00%	27.27%	50.00%	16.67%	0.00%	16.67%
2017 and prior	24.00%	27.27%	40.00%	13.79%	29.17%	14.29%	33.33%	13.64%	0.00%	16.67%	40.00%	50.00%
Not yet conducted	32.00%	18.18%	60.00%	13.79%	4.17%	0.00%	0.00%	4.55%	25.00%	16.67%	40.00%	16.67%

Type of Assessment

We asked participants “Was the type of assessment (for example ADOS) clearly explained? (tick all statements that apply)”





Essex Family Forum
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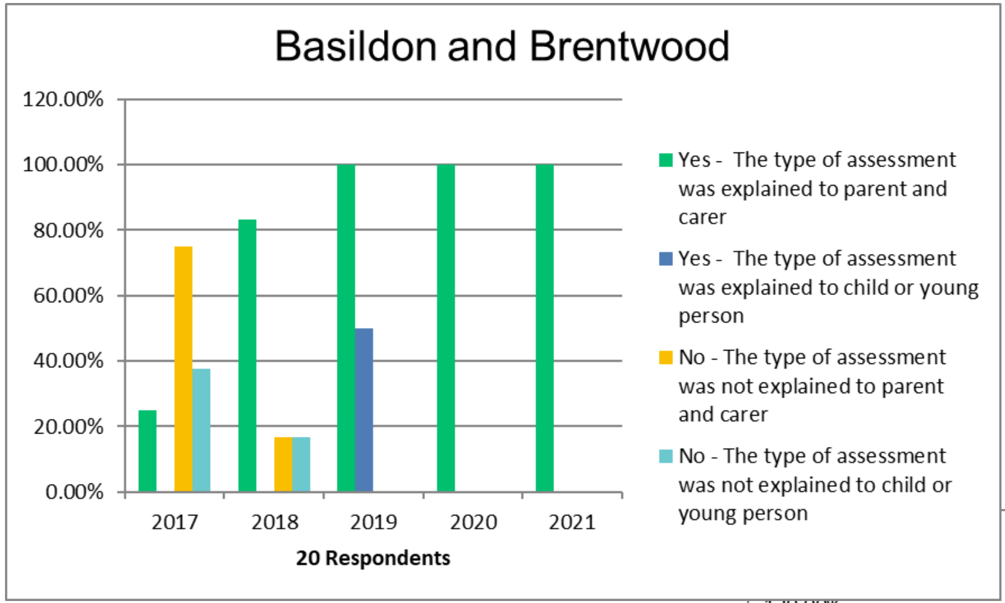
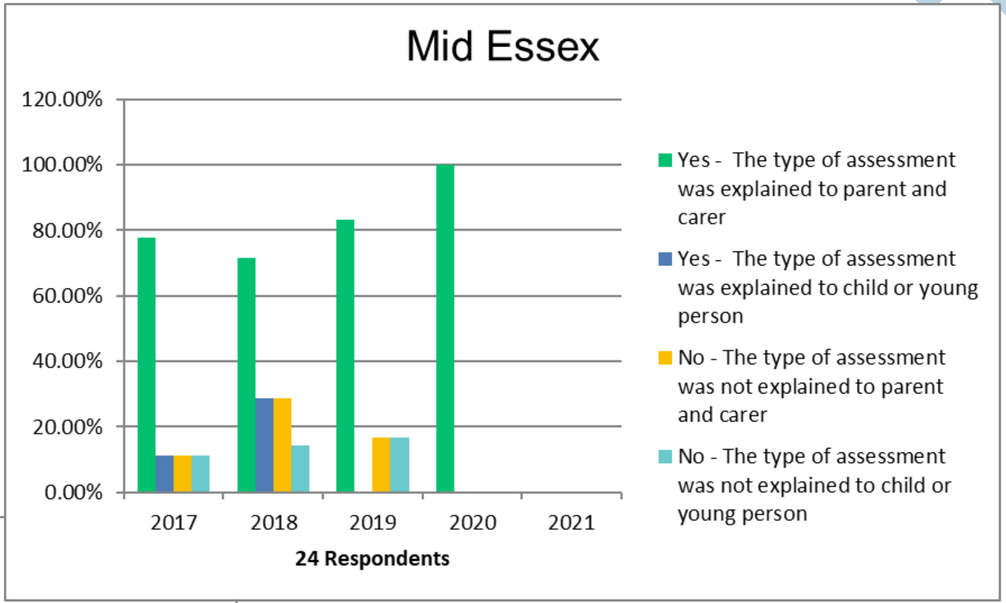
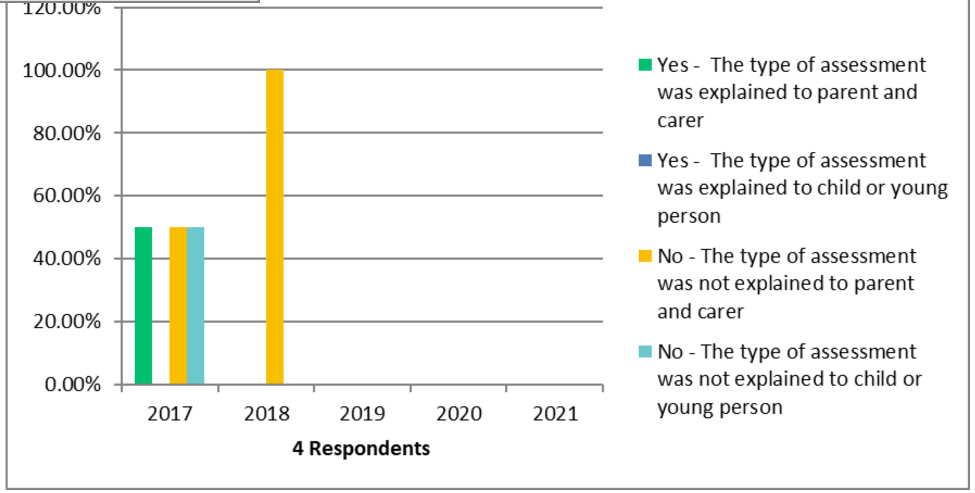
Type of Assessment

We asked participants “Was the type of assessment (for example ADOS) clearly explained? (tick all statements that apply)”







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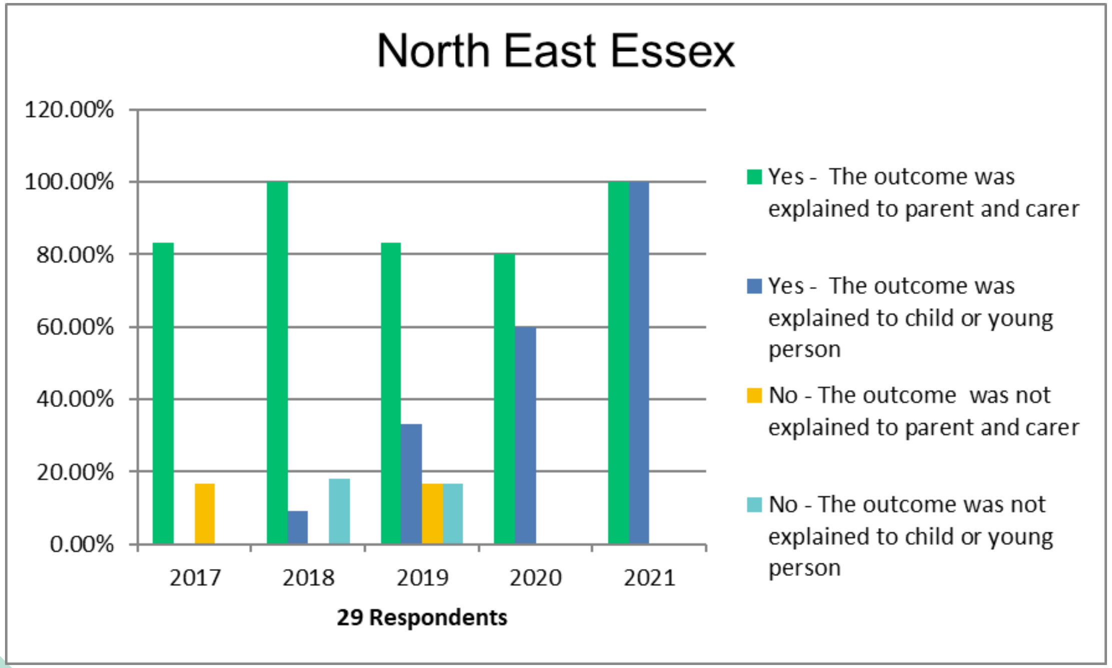
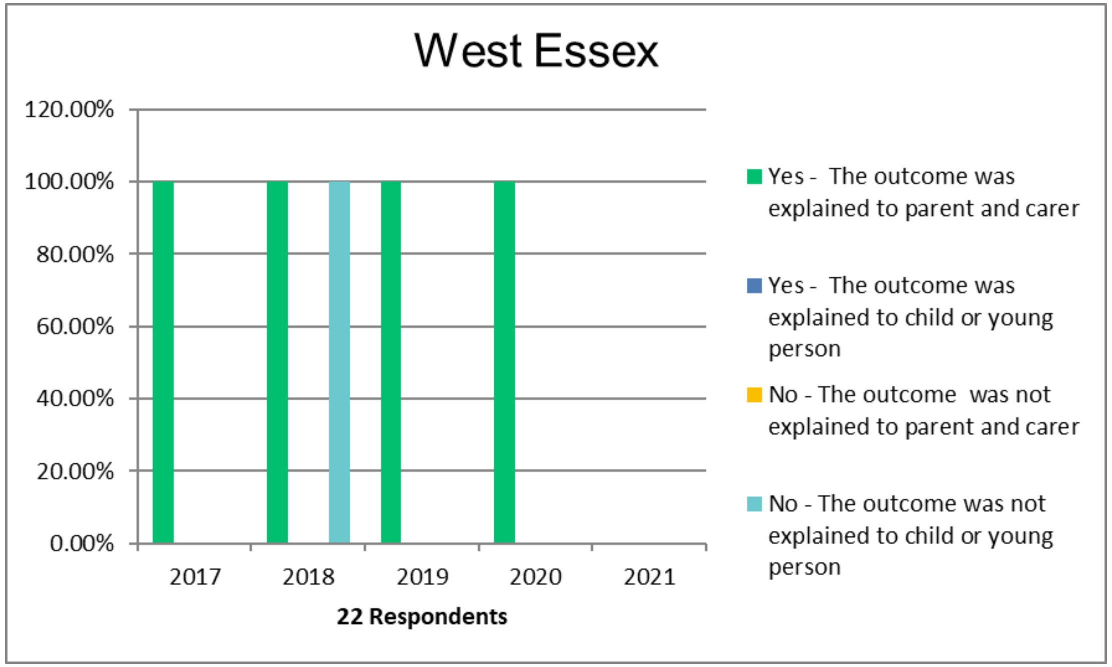
Outcome of Assessment

We asked participants “Was the outcome of the assessment clearly explained?(tick all statements that apply)”





Essex Family Forum
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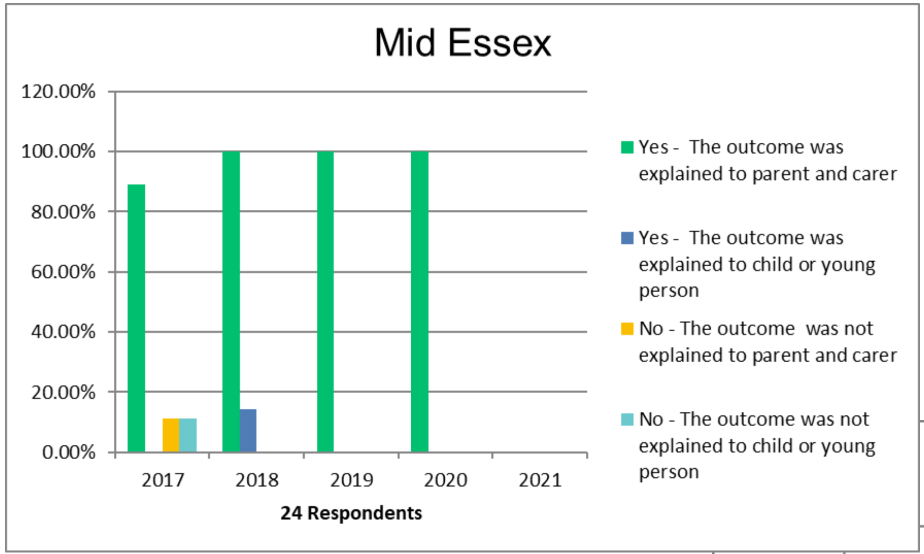
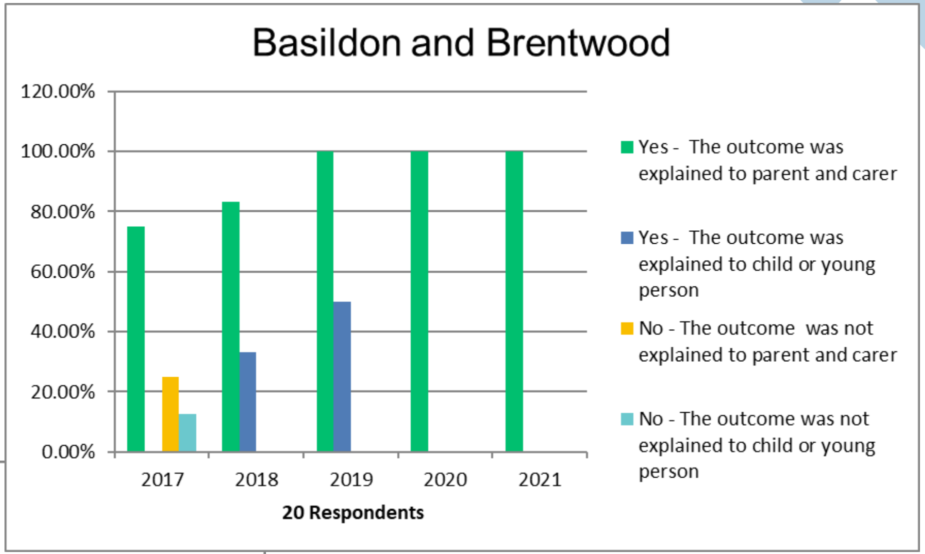
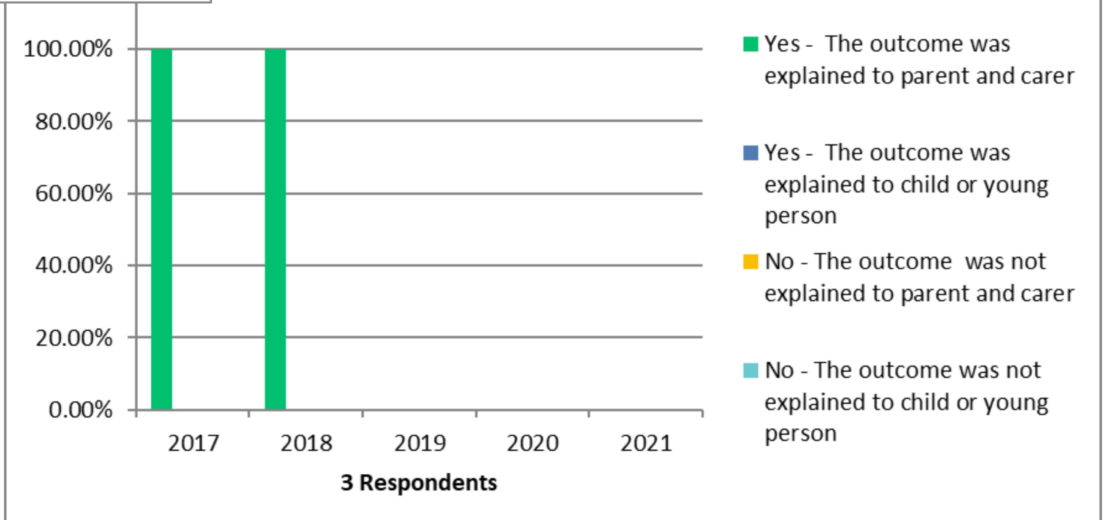
Outcome of Assessment

We asked participants “Was the outcome of the assessment clearly explained?(tick all statements that apply)”





Castle Point and Rochford



Type of Assessment and Outcome

Again, Essex Family Forum recognises that explaining the type and outcome of the assessment to a CYP may not always be *appropriate* or *possible*, and, after consideration, we accept that the question did not perhaps reflect this. However, we do believe that where it is *appropriate* CYP should be kept informed and involved in decisions about their care and that communication tools such as social/communication stories can and should be used and that families should be supported to have those conversations where needed.

However, it is positive to see that many parents and carers report that the CYP was included in the discussions around the type of assessment and the outcome of the assessment. The data shows that it is variable across each of the CCG footprints, but we accept that our phraseology of the question did not perhaps enable us to reflect an accurate picture of those who participated.

73 % of parents state that the type of assessment was clearly explained. On reflection and addressing one of the responses, what does “clearly explained mean”; it was the intention to understand not only the type of assessment the CYP would undertake but also the details of how that assessment would take place. We know that many parents and carers are aware of the type of assessment, but lack clarity on what will happen at the assessment and how the assessment will be carried out. We know that CYP and the parents and carers will often attribute this to increased anxiety, as was also reported by one of the respondents *“I had to seek further clarification as initial explanation wasn't clear and our anxiety was high*”. Our phraseology of this question is, therefore, ambiguous. Whilst we can be confident in saying the majority of parents and carers are advised of the type of assessment, we cannot be confident that the same number of parents understand how the assessment will be conducted and therefore provided with all the information that meets both their needs as well as the CYP needs.

92% of parents and carers report that the outcome of the assessment was explained. That said, some of the comments reflect that it was explained but not clear. “But not clearly - I didn’t really understand what I was being told”, “It was explained but not very clearly, however I done a lot of my own research and study on ASD so have a good understanding “. One respondent suggested that a copy of the report was not made available despite asking. The issue here is two-fold: yes, parents are being told the outcome, but we didn’t seek the opportunity to ask if that outcome was *understood.* It's key that that not only the outcome of the assessment is understood but the needs of the CYP. We know that Neurodiversity is an umbrella spectrum and each person has strengths and challenges that are often identified within the assessment process. To ensure that parents and carers, along with educational settings, can support a CYP effectively, it's paramount that their CYP needs are clearly identified and explained, beyond that of a simple diagnostic label.

The comments for both type and outcome of the assessment can be found on the embedded attachment.

Microsoft Excel Worksheet

Advice and Support

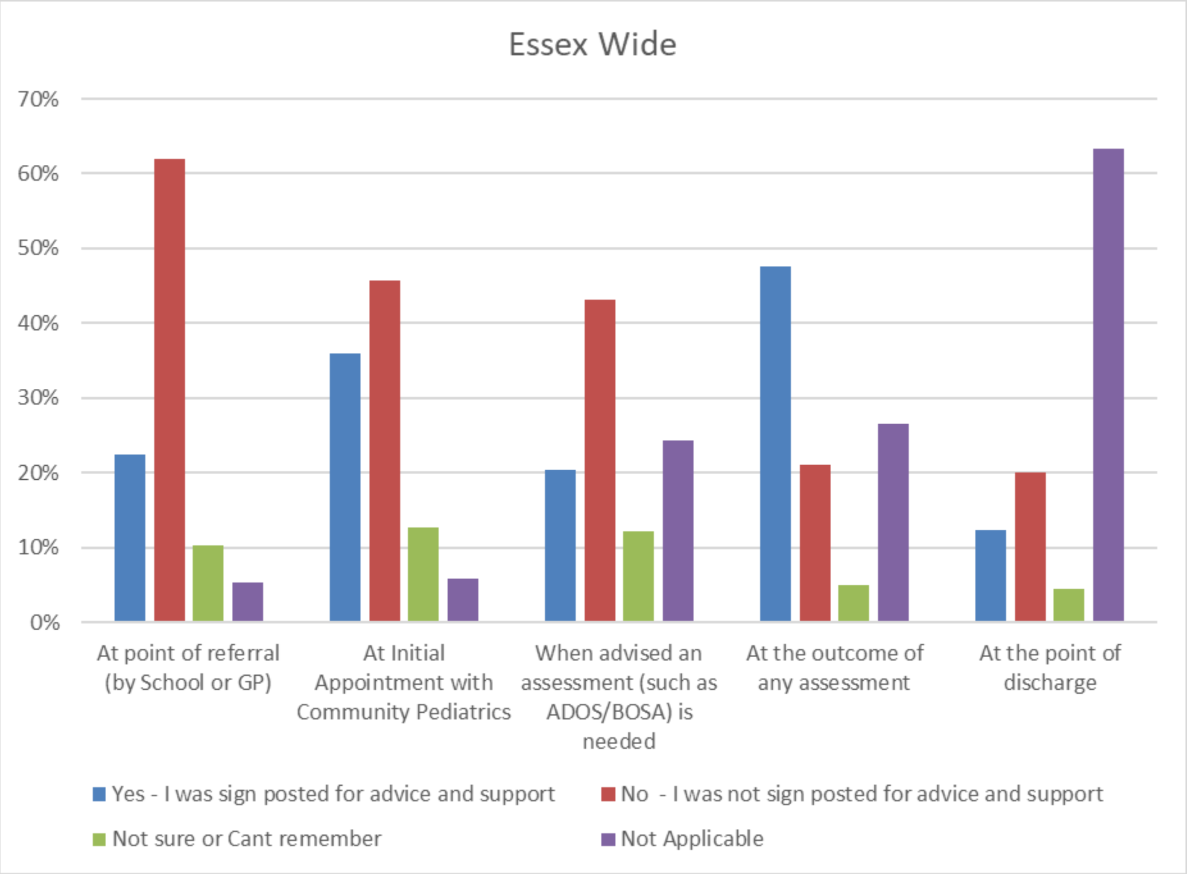
We asked Participants “Were you referred or signposted to another service for advice or support at:

- At point of referral (by School or GP)
- At Initial Appointment with Community Pediatrics
- When advised an assessment (such as ADOS/BOSA) is needed
- At the outcome of any assessment
- At the point of discharge

We had a total of 206 respondents provide feedback.

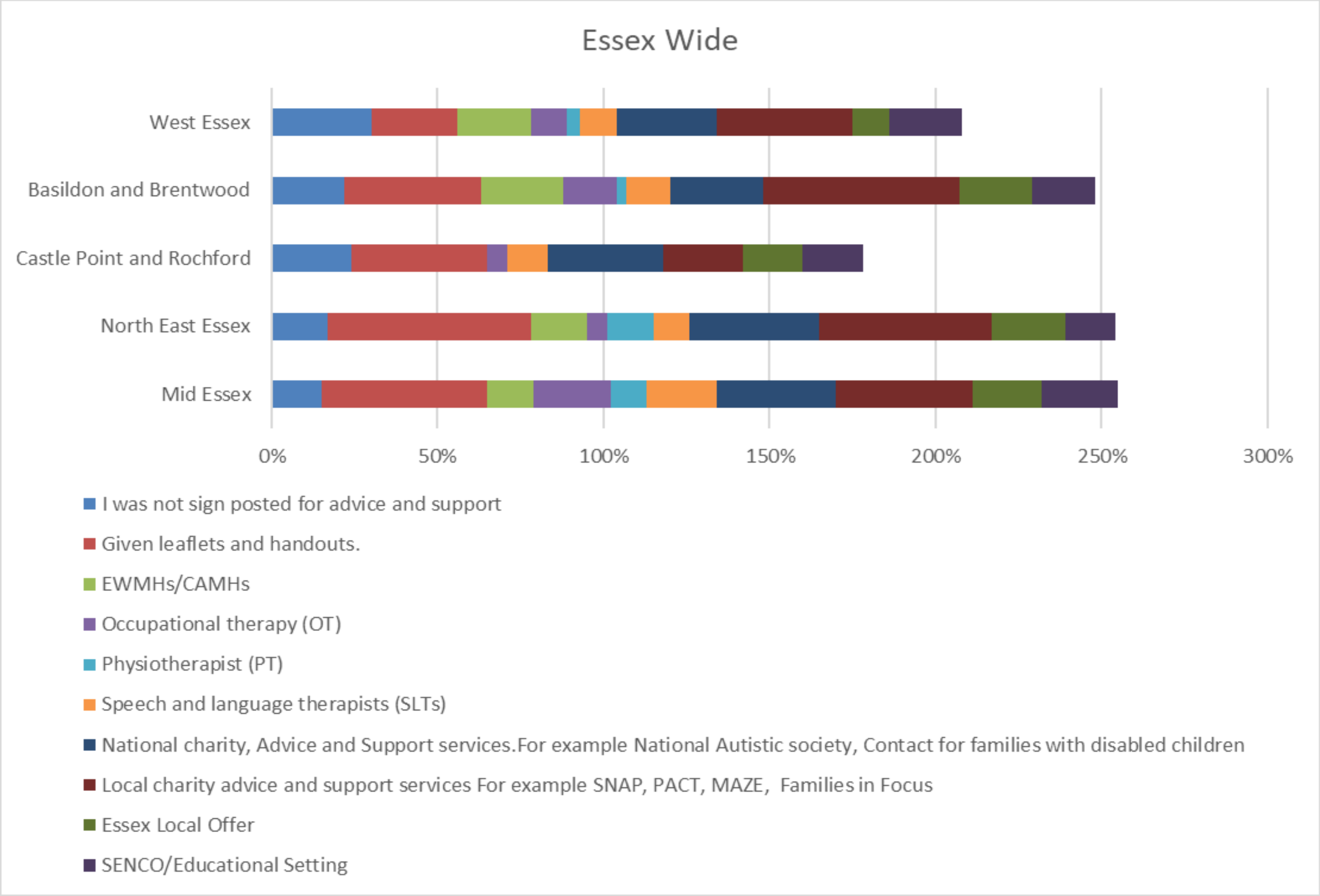
The data can be found broken down by year and CCG Footprint in the embedded document

Microsoft Excel Worksheet



Advice and Support

We Asked Participants “If you were signposted for Advice and Support, please tick all that apply”



We had 198 respondents

We would expect specialist provision to be low, as not all CYP will require specialist provision.

Top 3 were:

Leaflets and Handouts 47%
Local Charities 45%
National Charities 35%

It is noted that only 20% of respondents say that they were signposted to the Local Offer

Advice and Support

We asked Participants “Is there a particular organisation/ service/course/professional/support group or resource that has been particularly useful?”

Local Charities and organisations such as SNAP Charity, Families InFocus (Essex) and The Maze Group, prove the most “***useful***” support to parents.

Attached shows:
Tab 1: Raw Comments
Tab 2: Tally of Mentions

Microsoft Excel Worksheet

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Advice and Support

47% of parents reported that they received leaflets and handouts and this reinforces the need for good quality and accessibility for such information. We hope that the new publication *"Supporting Your Neurodiverse Child"* a guide written for parents by parents by Essex Family Forum with parents from Send the Right Message Southend, Takiwatanga Support Services alongside professionals from across Health, Education and Social Care will be made available to all families via community paedatrics as they start their journey.

There is also a huge reliance on parents and carers to seek support through local charities, with 45% of respondents reporting that they had engaged in seeking their own support. The top 5 reported charities and support organisations were:

1. SNAP Charity, based in Brentwood, was praised by many parents across all CCG footprints not just within the Basildon and Brentwood Footprint.
2. The report shows that Families InFocus reaches parents and carers across all Footprints.
3. The Maze Group was praised by parents primarily in North East Essex, however a few parents from the MID Essex CCG also highlight them as offering support.
4. Takiwatanga is reported by many families mostly within the Basildon and Brentwood CCG Footprint
5. PACT for Autism, the charity based in Harlow, reported by families mostly within the West Essex CCG Footprint

It was very positive to see so many different groups and charities mentioned within the section, that have clearly made a difference not only to the families that have participated in this survey, but (we are confident) also many more.

Advice and Support

Parenting Courses
We asked parents is there was any specific courses that they found useful and the 3 that stood out were:

1. Good Beginning Course. 11 respondents indicated this, being a course offered through Essex County Council, aimed at those in early years.

2. Moving on together course was also mentioned by 3 respondents but it was also reported that this is no longer running.

3. The Maze Group Parenting course was also mentioned by 15 respondents and has been highlighted in the previous slide. However, no differentiation between the support offer/coffee morning and courses The Maze Group offer has been drawn from the comments.

Other courses, that obtained a mention were IPSEA courses, Sensory courses and a Southend SENDIASS Course.

Local Offer

Only 20 % of respondents report that they were signposted to the Essex Local Offer for advice and support. And Only 1 respondent indicated that it has been "particularly useful".

Given the local offer has a statutory duty to provide information for children and young people with special educational needs and disabilities (SEND) and their parents/carers within the Local Authority footprint, it is disappointing that so few are recommending it as a resource for parents. That said, we fully acknowledge the commitment from the local area to improve this under-utilised resource for parents and carers and we continue to be involved and support this key piece of work.

Advice and Support

Statutory services and provision

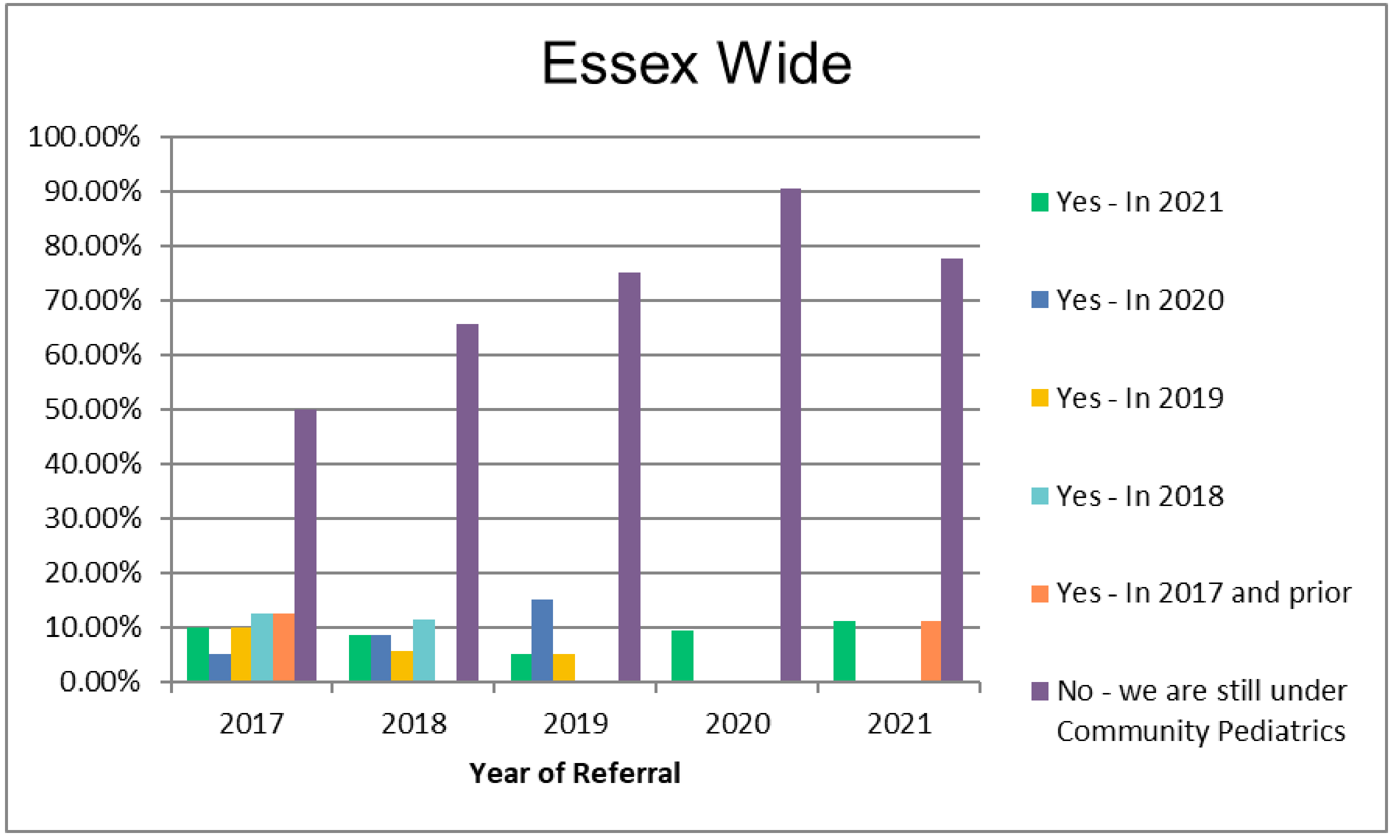
EWMHs, Occupational Therapists, Physiotherapists and Speech and Language therapists, SENCos/Education setting were all indicated as provision that parents and carers were signposted to. When reflecting on the numbers of these referrals, it's important to note that these services are deemed to be specialist provision and many CYP needs may not meet the threshold for referral.

However, as we can see, many of the CYP referred to the pathway are of school age or would be in an early years setting, yet only 18% parents and carers reported that they were signposted to their Senco/Educational Setting. We appreciate that the question was not specific to state clearly that the signposting should come from community paediatrics, so it could simply be that many responses include the signposting in general, which we know Senco/Educational Settings, of course. do. However, only 8 respondents indicated that the Senco/named educational setting had “been particularly useful”.

SENDIASS were mentioned by 6 respondents as an organisation that had “been particularly useful” alongside Community Paediatricians by 5 respondents.

Discharge

We asked participants “Have you been discharged from Community Paediatrics? If so, approximately what year?”



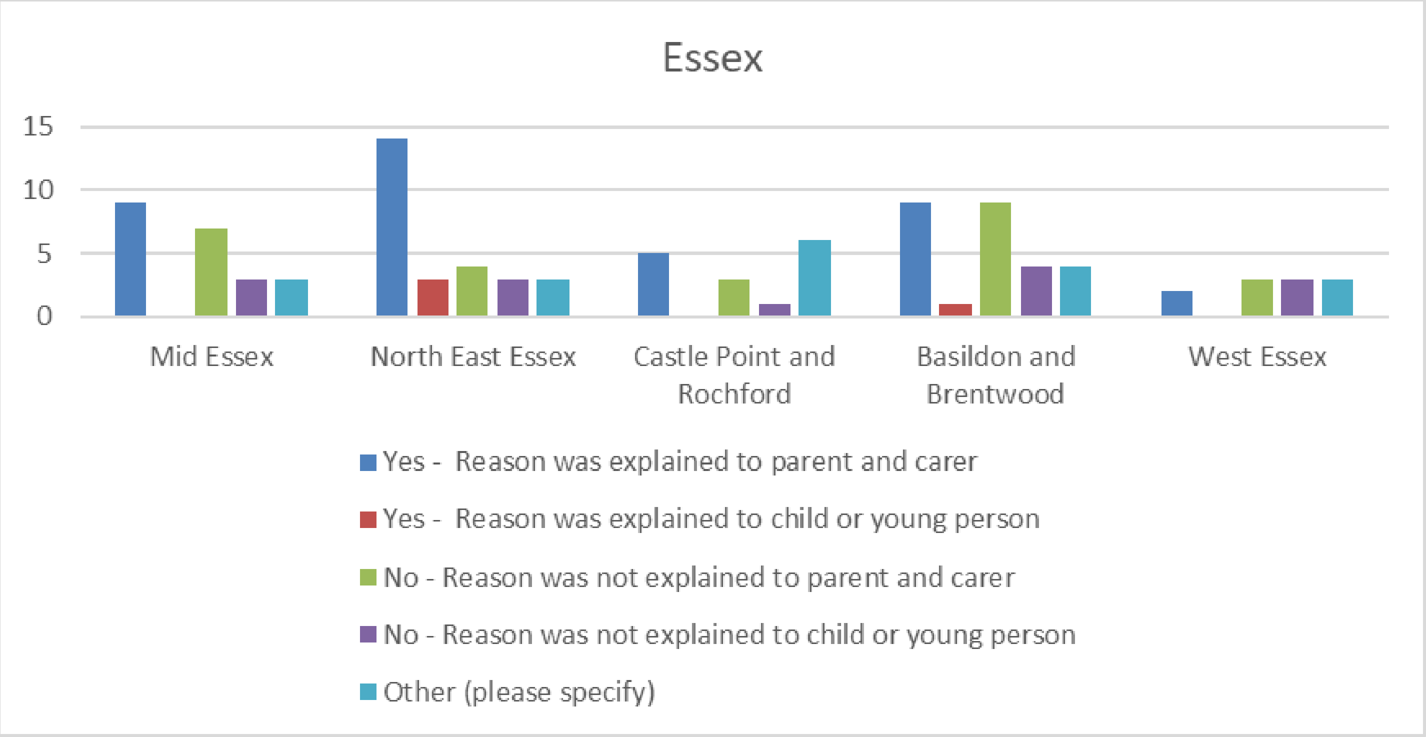
59% of the respondents, indicated that they are still under community paediatrics

The data has been broken down by CCG footprint in the embedded attachment.

Microsoft Excel Worksheet

Discharge

We asked participants “Was the reason for your child or young person being discharged from community Paediatrics clearly explained to you?”



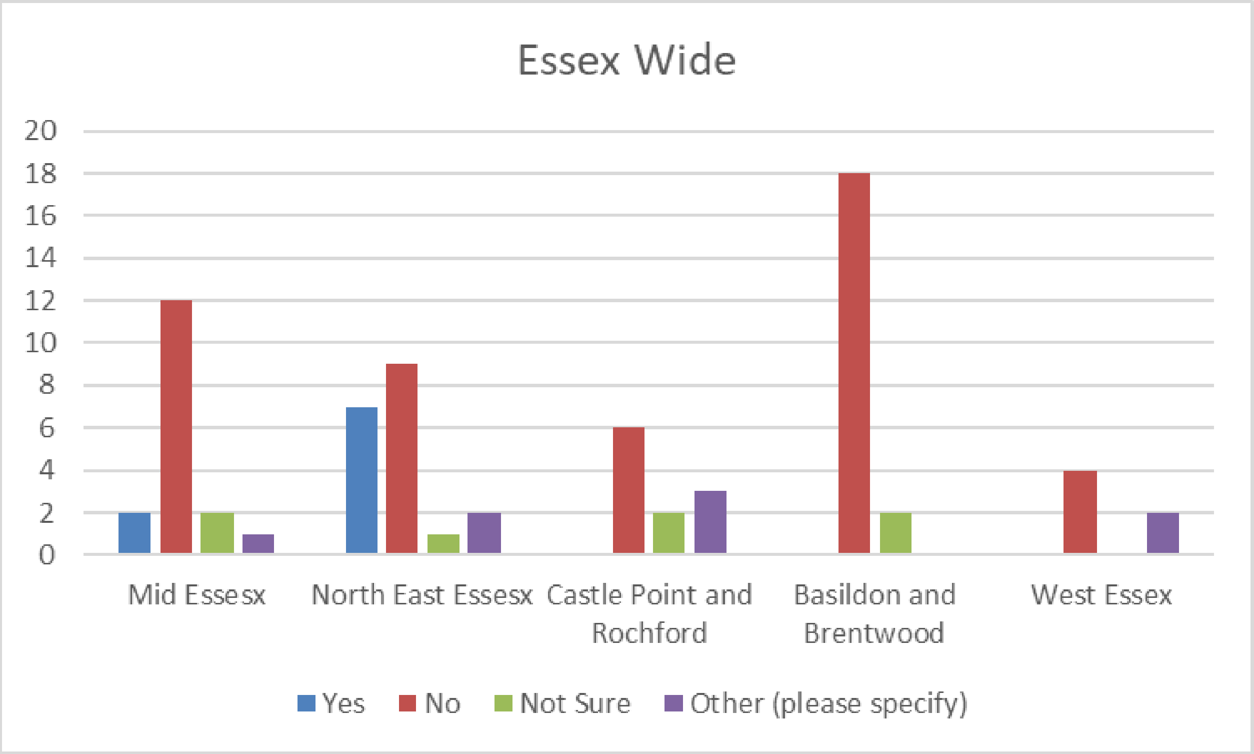
65 Responses

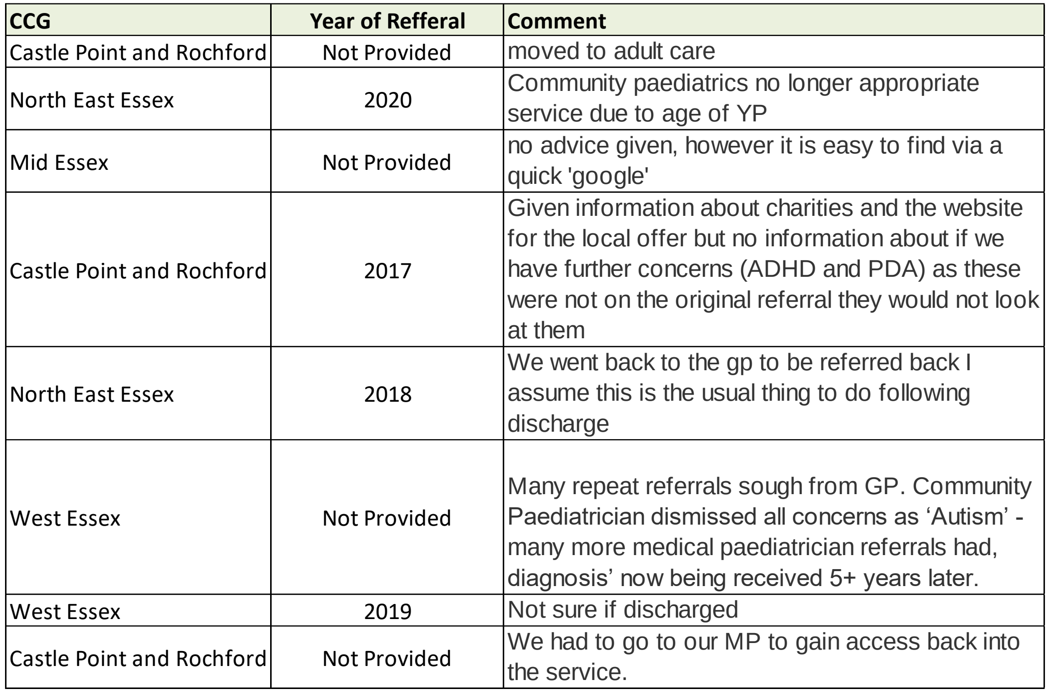
We also received 19 comments. Comments suggest a sense of frustration and confusion from some respondents

Microsoft Excel Worksheet

Discharge

We asked participants “Were you given advice on easy access back into the service should your child or young person's needs change? (This could be a blue card, letter leaflet, conversation)”





CCG	Year of Refferal	Comment
Castle Point and Rochford	Not Provided	moved to adult care
North East Essex	2020	Community paediatrics no longer appropriate service due to age of YP
Mid Essex	Not Provided	no advice given, however it is easy to find via a quick 'google'
Castle Point and Rochford	2017	Given information about charities and the website for the local offer but no information about if we have further concerns (ADHD and PDA) as these were not on the original referral they would not look at them
North East Essex	2018	We went back to the gp to be referred back I assume this is the usual thing to do following discharge
West Essex	Not Provided	Many repeat referrals sough from GP. Community Paediatrician dismissed all concerns as ‘Autism’ - many more medical paediatrician referrals had, diagnosis’ now being received 5+ years later.
West Essex	2019	Not sure if discharged
Castle Point and Rochford	Not Provided	We had to go to our MP to gain access back into the service.

17 Responses and 8 comments for “other”

Discharge

Over 106 respondents indicated that they were still under community pediatrics.

Again, Essex Family Forum recognises that explaining the discharge from community pediatrics to a CYP may not always be *appropriate* or *possible* and after consideration, we accept that the question did not perhaps reflect this. However, as previously stated, we do believe that where it is *appropriate* CYP should be kept informed and involved in decisions about their care. It was, therefore, positive that some respondents (4) indicated that such conversations took place.

67% (49) of respondents who reported they had been discharged, reported they were not told how to re-access the service. To provide such information is reassuring for parents and it doesn't feel that the *"door is shut"* . What was concerning, was the number of parents and carers, 26, who state the reason for discharge was not explained. When the data for these parents were reviewed, it was clear that communication was a thread of their overall experience.

"They separated us during the assessment. My son was only 7 and shy. The psychologist took him into another room to talk to him. He was nervous. When she presented her findings she was extremely rude and dehumanised my son. It broke my heart"

"We was not told we would be discharged. So when I believed we was due a 2 year review I reached out to the paediatrician to ask for an earlier appointment as we was struggling with my daughters anger we was told we could not be seen. We was told we had to go back to our GP and request a new referral. This is extremely disappointing"

"We felt as though the diagnosis was given then the door shut & locked behind us as we walked out the door. There was mention of a course about Autism being available but it had a 6 month waiting list. We enrolled for the course but we're never offered a place, I followed up a few times via the Health visitor but I never heard back about a place on the course"

There were some positive comments.

"Dr Name removed was really lovely and understood that the school were not supportive and even called the school to get them to support my child as she could see how unsupportive they were being"

"Everyone we met was friendly, hardworking and committed"

Moving

We have previously identified moving across CCG Footprints as a concern for some parents. When reviewing this with providers, it was also reported that not being provided with updated address, GP details and Education setting details can also cause delays. We are pleased that services are working hard to address concerns and putting in place processes for improved transfer of care. Essex Family Forum is working hard to improve the information on the local offer to support parent and carers with a "checklist" and information and advice regarding moving when their CYP is under health provision.

Therefore, we asked participants "After your initial referral to community paediatrics, have you moved between Clinical Commission Groups (CCG's)?For example from Colchester in North East Essex to Harlow in West Essex, or perhaps from another county into Essex. If so, what was your experience?"

We had a total of 7 respondents indicate that they had moved, providing the following comments:

Moved in 2018 and took untill 2021 for assessment to complete

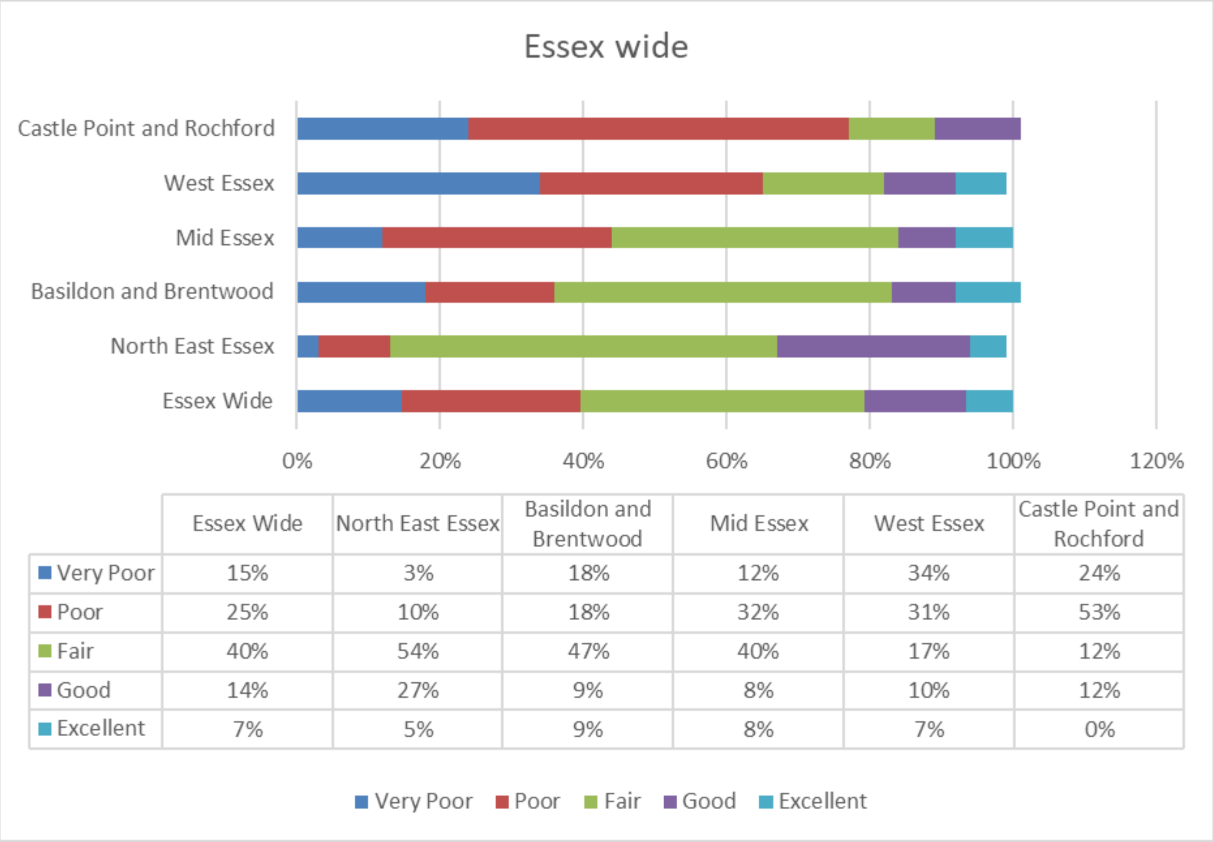
- *I did but not with local hosp as daughter was under a different hosp so all at same hosp .due to local hosp saying daughter to old to go down pathway at 11 even tho was referred multiple times*
- *transfered to GOSH*
- *I contacted oriot to my child turning 5 that moving would not be practical due to lack of transport*
- *We moved from North to Mid while awaiting the ASD assessment, we were given the option to continue the process in North which we chose to do for various reasons. This went seemlessly.*
- *Still awaiting contact after 4 months!*
- *Moved but still under the same community peads*

A further comment surrounding moving was also provided in the additional comments questions

- *Better communication, information from the start of the pathway. A central point of contact to help families through the process. Not being dropped from all waiting lists/services when moved between CCGs*

Communication

We asked Participants “How do you rate your experience of the communication received?”



	Essex Wide	North East Essex	Basildon and Brentwood	Mid Essex	West Essex	Castle Point and Rochford
Very Poor	15%	3%	18%	12%	34%	24%
Poor	25%	10%	18%	32%	31%	53%
Fair	40%	54%	47%	40%	17%	12%
Good	14%	27%	9%	8%	10%	12%
Excellent	7%	5%	9%	8%	7%	0%

- 40% of respondents reported communication was “fair”.
- 40% of respondents indicated communication was “poor” or “very poor”.
- Only 20% of respondents report communication was of a “good "or “excellent” standard.

CCG Footprint	Total Number of Participants	Weighted Average
Essex Wide	212	2.73
North East Essex	59	3.20
Basildon and Brentwood	34	2.74
Mid Essex	73	2.68
West Essex	29	2.24
Castle Point and Rochford	17	2.12

Year of Referral	Total Number of Participants	Weighted Average
2017	42	2.48
2018	33	2.97
2019	34	2.91
2020	30	2.92
2021	19	2.32

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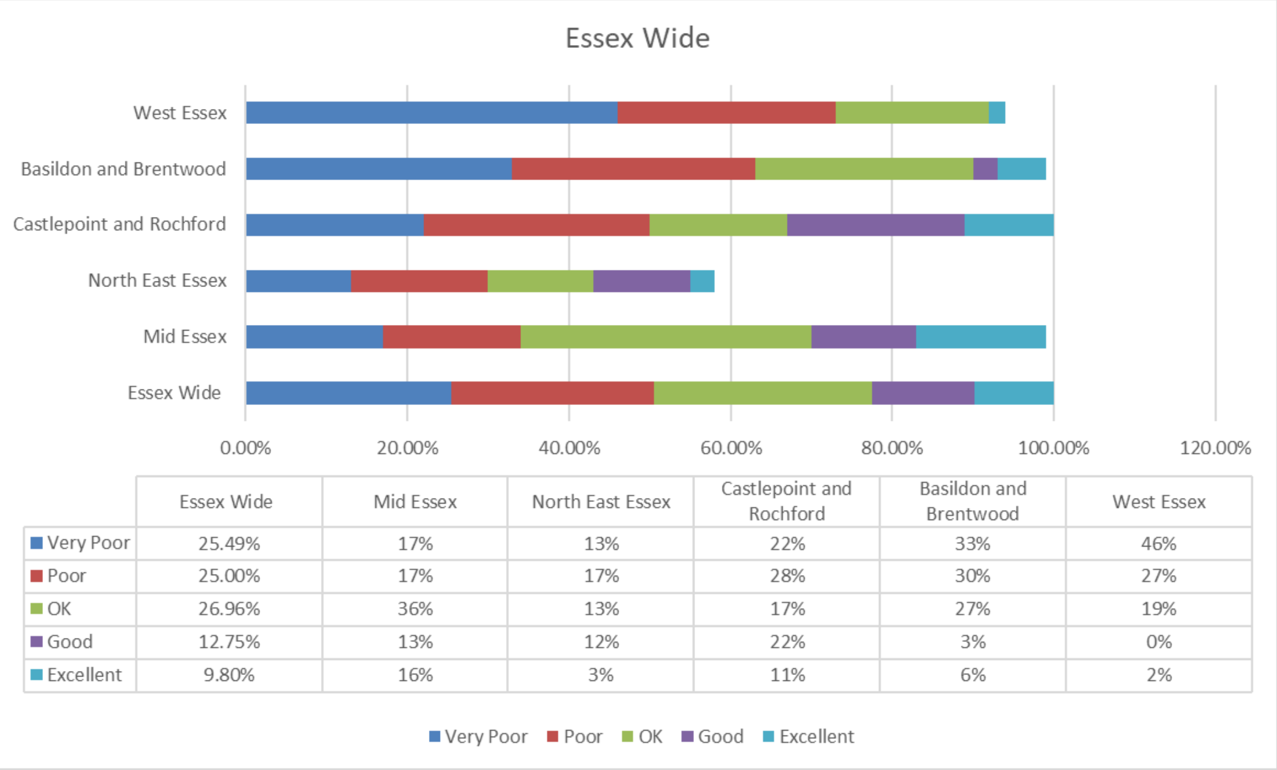
Joint Working

We asked Participants “How well do you believe that the professionals involved in the care of your child, (for example, SENCO, school, therapist, or social worker) worked together and communicated to support you and your child or young person?”



	Essex Wide	Mid Essex	North East Essex	Castlepoint and Rochford	Basildon and Brentwood	West Essex
■ Very Poor	25.49%	17%	13%	22%	33%	46%
■ Poor	25.00%	17%	17%	28%	30%	27%
■ OK	26.96%	36%	13%	17%	27%	19%
■ Good	12.75%	13%	12%	22%	3%	0%
■ Excellent	9.80%	16%	3%	11%	6%	2%

CCG Footprint	Total Number of Participants	Weighted Average
Essex Wide	204	2.56
Mid Essex	69	2.93
Castle Point and Rochford	18	2.72
North East Essex	58	2.57
Basildon and Brentwood	33	2.18
West Essex	26	1.96

Year of Referral	Total Number of Participants	Weighted Average
2017	41	2.34
2018	32	2.59
2019	32	2.53
2020	26	2.81
2021	19	2.63

- 27% of respondents reported joint working was “ok”.
- 50% of respondents indicated joint working was “poor” or “very poor”.
- Only 23% of respondents report joint working was of a “good "or “excellent” standard.

28 comments were received of mixed reviews. They can be located on the embedded document broken down by year of referral and CCG footprint

Microsoft Excel Worksheet

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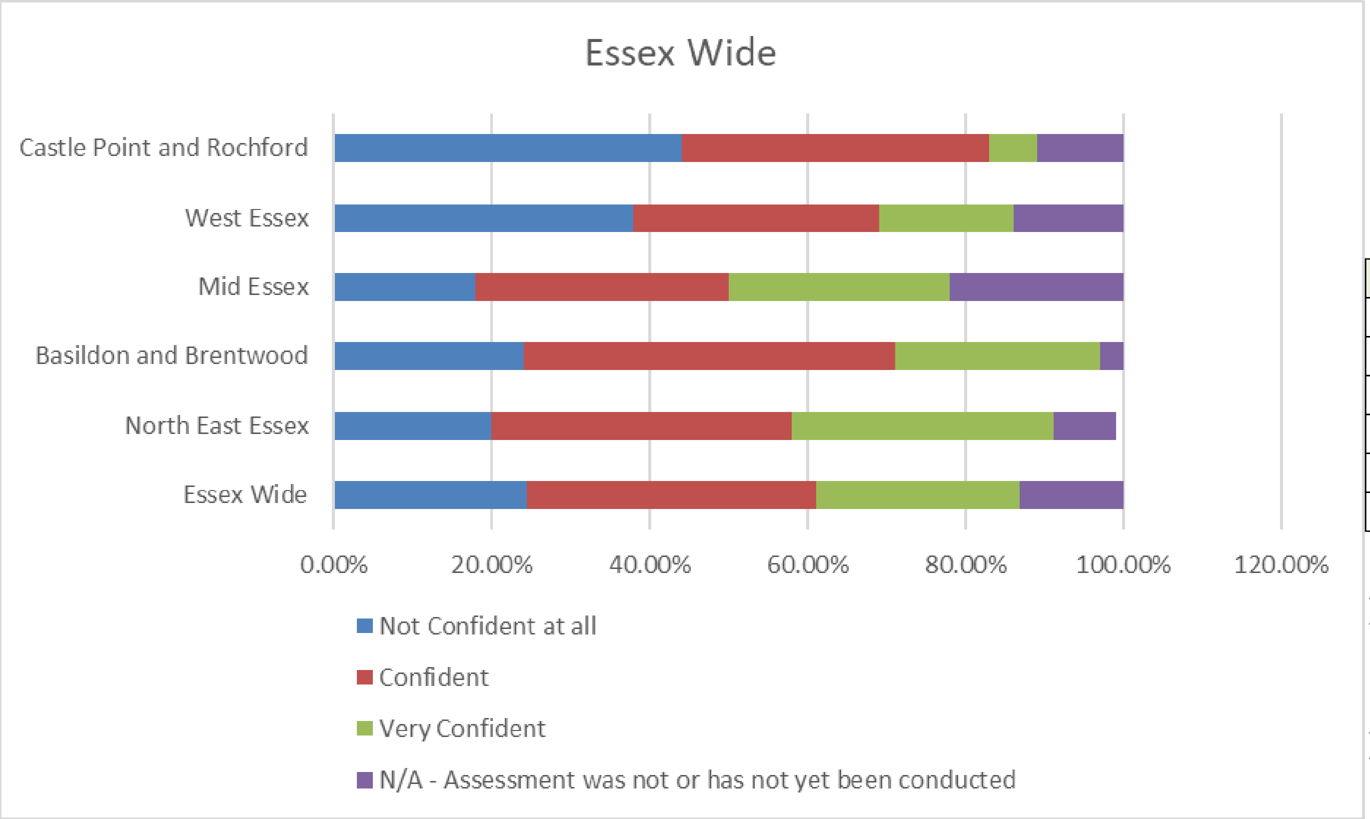
Confidence of Health Professional

We asked Participants "What was your level of confidence in the health professional's ability to fully assess your child or young person?"



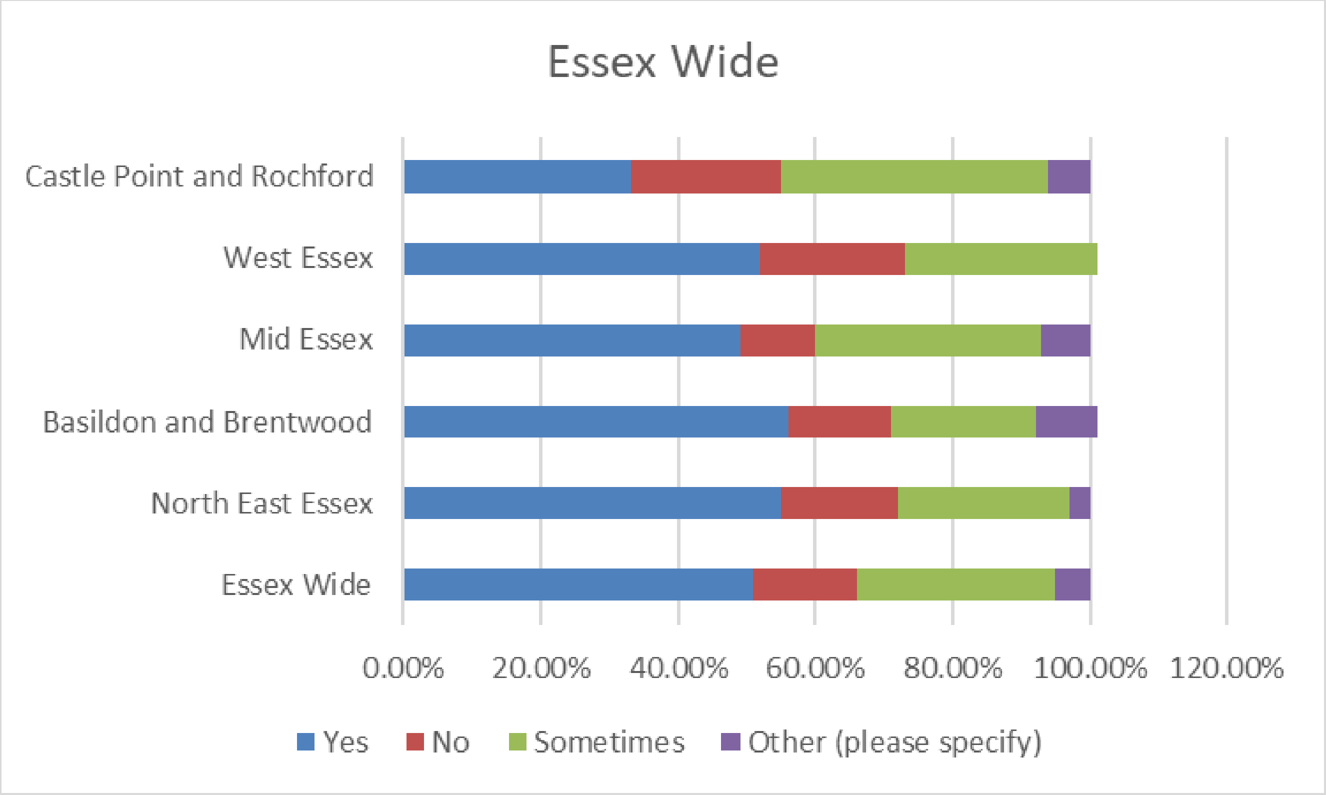
Year of Referral	Total Number of Participants	Weighted Average
2017	42	1.95
2018	33	2.09
2019	34	2.04
2020	29	2.1
2021	19	1.67

CCG Footprint	Total Number of Participants	Weighted Average
Essex Wide	213	2.02
North East Essex	60	2.15
Mid Essex	72	2.13
Basildon and Brentwood	34	2.03
West Essex	29	1.76
Castle Point and Rochford	18	1.56

- 26 % of respondents reported that they were not confident at all
- 70 % of respondents reported that they were confident or very confident

Listening

We asked Participants “Did you feel that the health professionals listened to your views?



Year of Referral	Total Number of Participants
2017	42
2018	33
2019	34
2020	30
2021	19

CCG Footprint	Total Number of Participants
North East Essex	60
Basildon and Brentwood	34
Mid Essex	73
West Essex	29
Castle Point and Rochford	18
Essex Wide	214

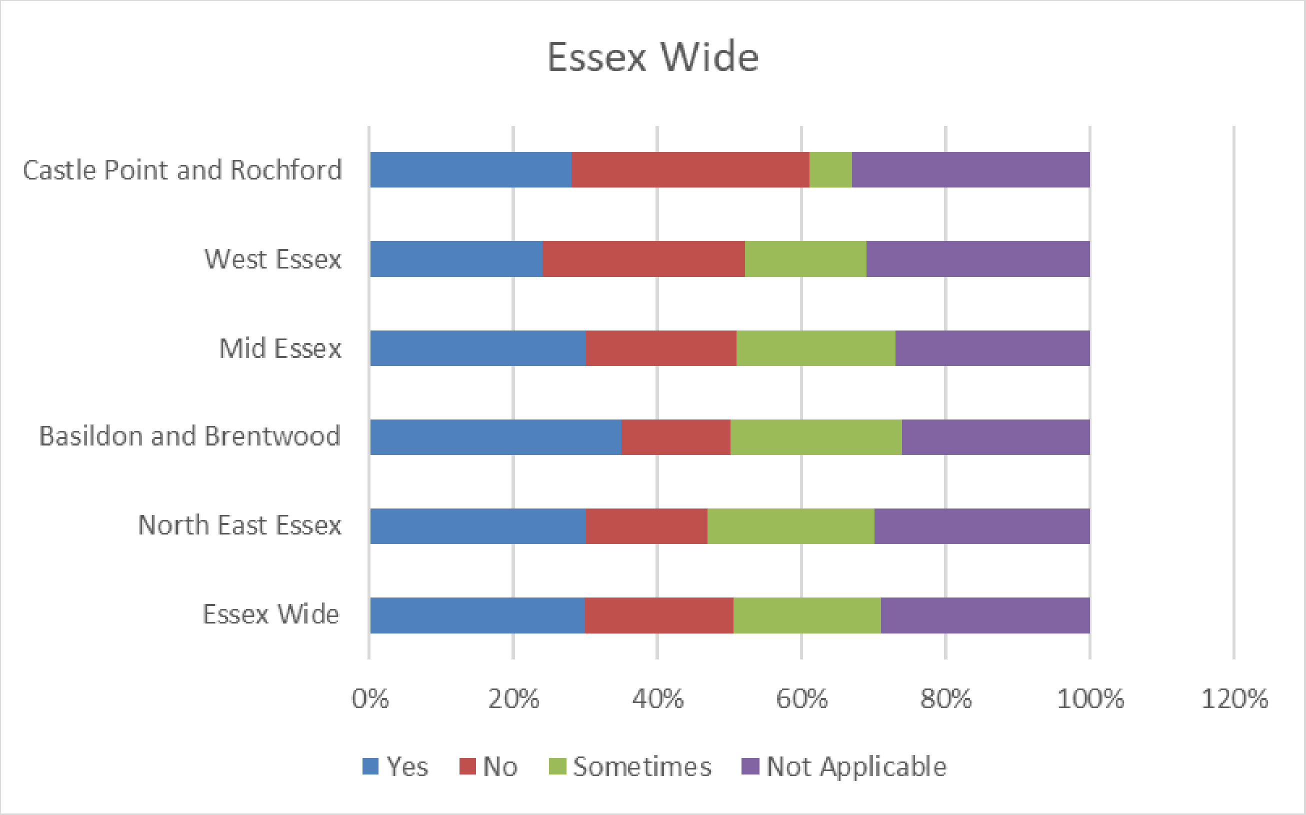
- ➢ Only 51% of respondents reported they felt their views were listened to.
- ➢ 29 % reported sometimes
- ➢ 15 % reported that they felt their views were not listened to.

9 Comments were received, which are listed by year of referral and CCG footprint in the embedded document

Microsoft Excel Worksheet

Listening

We asked Participants “Did you feel that the health professionals listened to your child’s or young person’s views?"



Year of Referral	Total Number of Participants
2017	42
2018	33
2019	34
2020	30
2021	19

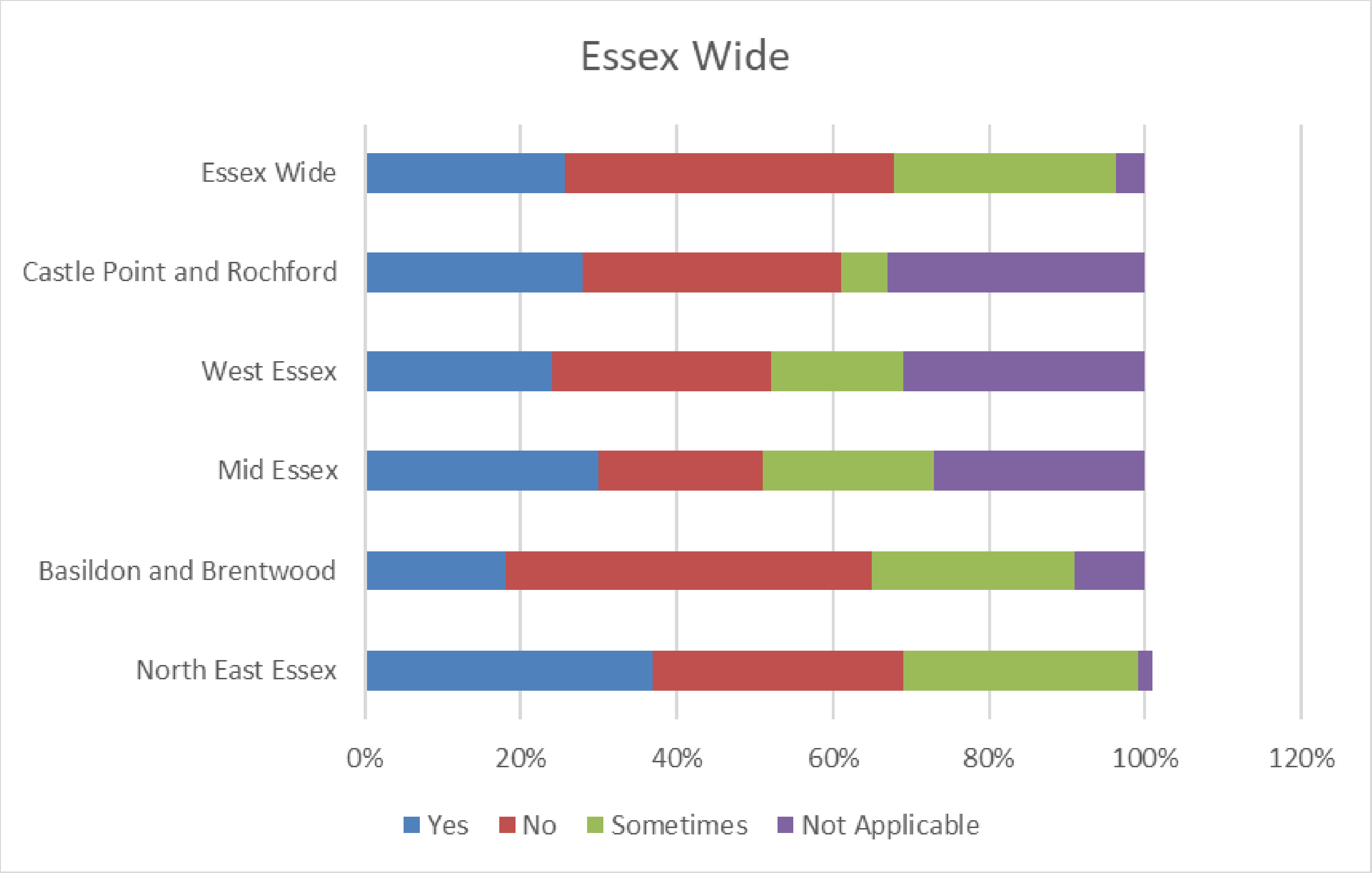
CCG Footprint	Total Number of Participants
North East Essex	2014
Basildon and Brentwood	60
Mid Essex	34
West Essex	43
Castle Point and Rochford	29
Essex Wide	18

Here, we did provide the option of not applicable, which 29% of respondents reported.

21 % still reported no. Positively, 30% did reported yes and 21% reported sometimes

Personalised Care

We asked Participants “Did you feel the service received so far provided a personalised approach to the care of your child?"



Year of Referral	Total Number of Participants
2017	42
2018	33
2019	34
2020	30
2021	19

CCG Footprint	Total Number of Participants
North East Essex	2014
Basildon and Brentwood	60
Mid Essex	34
West Essex	43
Castle Point and Rochford	29
Essex Wide	18

26% reported Yes
29% reported sometimes
42% reported no
4% stating not applicable

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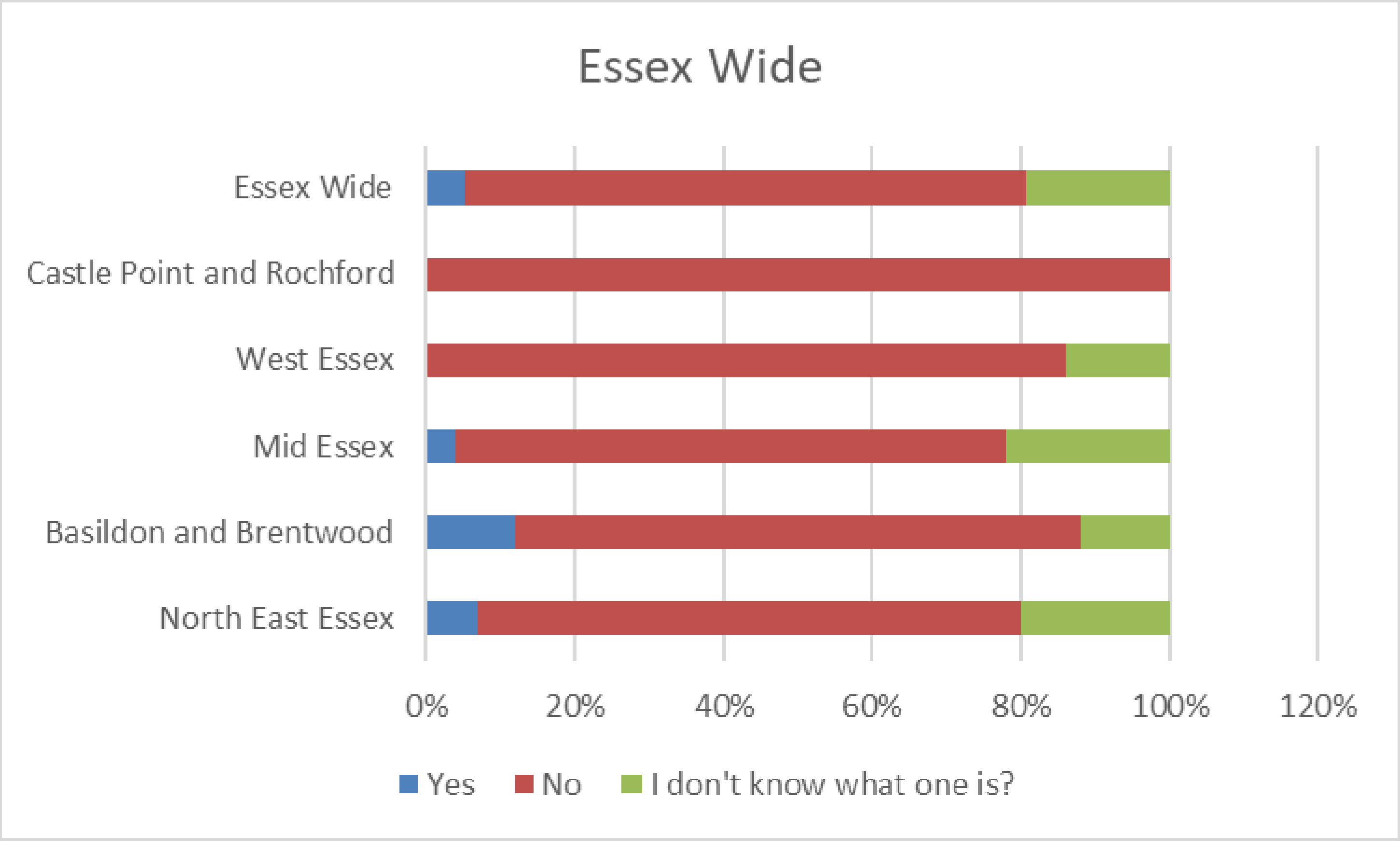
Health Budget

We asked Participants “Did anyone speak to you about a personal health budget/plan?"



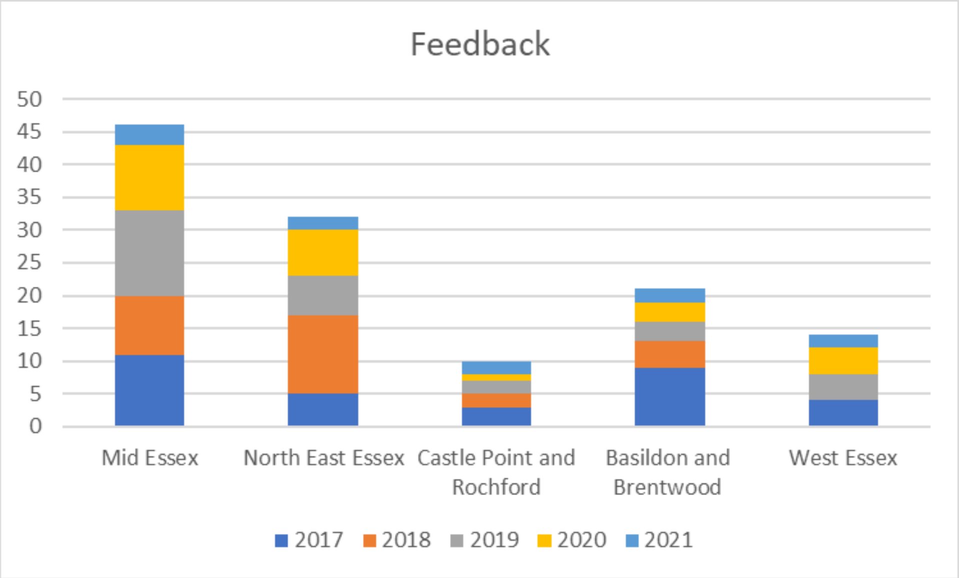
Year of Referral	Total Number of Participants
2017	42
2018	33
2019	34
2020	30
2021	19

CCG Footprint	Total Number of Participants
North East Essex	2014
Basildon and Brentwood	60
Mid Essex	34
West Essex	43
Castle Point and Rochford	29
Essex Wide	18

It is important to note that this question, whilst significant, doesn’t reflect if a personal budget/plan would be appropriate in these families / CYP circumstances. Therefore, to draw conclusions from the findings would not be appropriate. However, it is positive to see that some families reported having such discussions.

What can be done to improve the experience?

We asked participants “What do you feel could be done to have improved you and your child or young person's experience?”



A breakdown of all feedback provided by year of referral and CCG footprint is included in the embedded attachment.

The spreadsheet also included a further 39 comments from participants who did not indicate year of referral

Microsoft Excel Worksheet

When we looked at the type of feedback provided, we interpreted it into 4 main categories:

1. Improve wait times
2. Positive experience
3. Support
   - *Improve schools' knowledge of the assessment process*
   - *Provide aftercare post diagnosis*
   - *Better support from other agencies such as EWMHs/OT/PT*
   - *Provide strategies*
   - *Support and understanding from GP*
   - *Improve school support*
   - *Improve schools' knowledge on girls/masking*
   - *Schools to accept and recognise diagnosis*

4. Communication
   - *Improve communication*
   - *Listen to parents*
   - *Clear explanation of the process*
   - *Share completed questionnaires with parents*
   - *Improve quality of information on letters*
   - *Improve resources and leaflets provided at appointments*
   - *Improve communication with schools*
   - *Improved joint working between professionals*
   - *Don’t discuss CYP in front of CYP*
   - *Include CYP in conversations*

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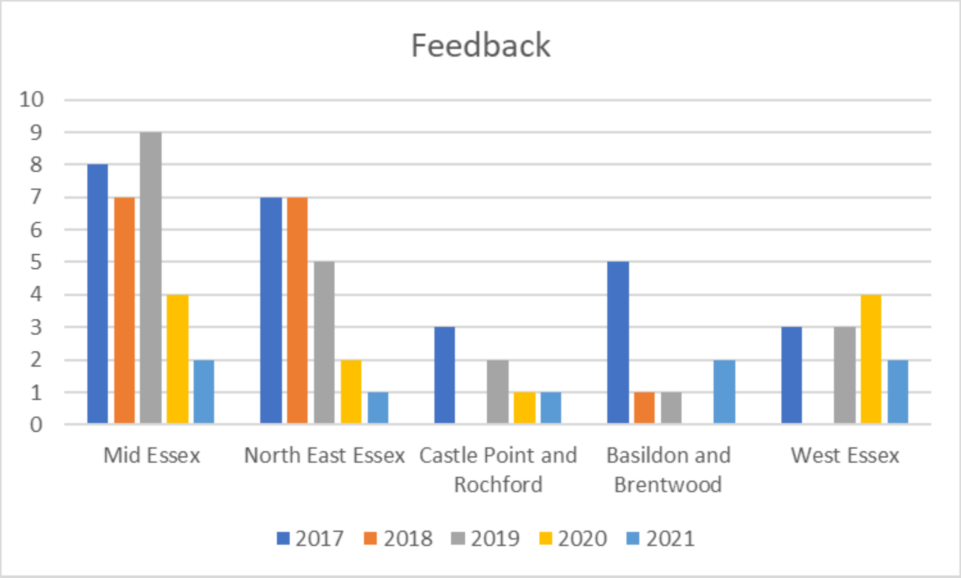
Additional Comments

We asked participants “Do you have any additional comments relating to your experience?”.



A breakdown of all feedback provided by year of referral and CCG footprint is included in the embedded attachment.
The spreadsheet also included a further 29 comments from participants who did not indicate year of referral

Microsoft Excel Worksheet

When we looked at the type of feedback provided, we interpreted it into 5 main categories:

1. Provision/Process:
    - *Health and Education Provision is under funded/under resourced*
    - *Positive feedback for specific health professionals*
    - *Poor support schools/sencos/CAMHs*
    - *Lack of Provision – Sensory and attachment needs*
    - *Lack of understanding of Masking*
    - *Wait Times*
    - *Inadequate access to SALT*
2. Diagnosis
    - *Barrier for Provision*
3. Communication
    - *Poor communication for wait times/ between services and schools*
    - *Using stereotypical assumptions for ASD*
    - *Need to listen to parents more*
    - *Engaged with CYP*
    - *Professionals need to engage appropriately with CYP*
4. Support
    - *Lack/No/Fight for Support*
    - *School/professionals provided good support*
5. Feelings
    - *Feelings of being forgotten, frustrated, traumatised, let down, stressful, impact on mental health, lost faith in system reported*

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Final Thoughts

The data is comprehensive and certainly tells the story for those parents and carers who shared their experience. Some families have reported a positive experience and, sadly, many parents have reported difficulties. We have summarised some sections throughout the report, however we would like to re-emphiase several key areas as our overriding final thoughts.

- **Waiting Lists**

We firmly believe that accurate data needs to be maintained in each area regarding waiting times, which we know is being established, but we think it's important to understand if that data is reflective of families’ experience.

We also believe it's important to make clear to families when placed on a waiting list, what the expected wait time will be. We understand that it can be a long journey for some families: it can be following investigations over several appointments, or as some parents have indicated, a sit and wait approach is sometimes taken before a CYP is then put forward for formal assessment. This means the length of time under community paediatrics can be over many years. But, it is concerning that some families report they are waiting several years for a diagnosis.

Final Thoughts

- **Navigation and Signposting**

The Local Offer is not being utilised to its full potential, as few families are reporting that they are signposted to it. The Local Offer needs to contain accurate details of the pathways and, in each local area, who to contact with any queries. We know that support offers differ across the CCG, so it's important that The Local Offer clearly reflects what support is available locally and how it can be accessed.

It's important that as work is carried out on the Local Offer, that not only is the Local Offer promoted to families, but it is promoted to the professionals that refer and support families.

Effective signposting needs to be at the point of referral, support by community paediatrics, at outcome of assessment and at point of discharge. As well as the Local Offer this should include information such as:
- “Supporting Your Neurodiverse Child” Information Packs, any commissioned offer of support along with local support groups and courses such as “Good Beginnings”.

Information should be included in correspondence, not solely reliant on a conversation in an appointment. Appointments can be stressful and contain a lot of information, which can at times be emotive, difficult to hear and hard to process. This could mean that some information is understandably not retained. Therefore, to have that information provided on an appointment letter, or a letter regarding the outcome of the appointment could easily improve the families experience in this regard.

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Final Thoughts

➢ Communication

Communication is the golden thread which runs through the entire report. Only 20% of respondents report communication was of a “good "or “excellent” standard.
Verbal proactive communication within community paediatric needs to be given at each stage of the process including:

- Where there are delays in first appointment or assessment
- Reasons for assessment or otherwise
- Reason for discharge and how to navigate back into the service

It's is also clear that parents and carers want to feel heard with only 51% of respondents reporting they felt their views were listened to.

➢ Education and Joint Working

Whilst this survey's aim was to review the health provision, it is clear that families have reported the impact on provision within education impacts on the family’s overall experience. Families are still reporting that a lack of a diagnosis is a barrier for appropriate support and there is still a reported lack of understanding of CYP needs or that health recommendations are not followed. Furthermore, 50% of families reported that joint working was “poor” or “very poor”. This highlights the need for a system wide approach to support the CYP and their family throughout the diagnostic process.

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Next Steps

Essex Family Forum (EFF) will present this data to the ASD ADHD Sub Group and the Joint Commission Board within Essex. Essex Family Forum also sits on this board and represents parent and carer views.

EFF will formally ask the ASD ADHD Sub Group and the Joint Commission Board for a response, which can be shared with parents regarding the findings of this report and confirm what steps are currently being taken to improve parent and carer, child and young people's experience.

We also intend to highlight the concerns that were raised around education support and joint working to Essex County Council.

It is our intention to repeat the survey after a minimum period of 12 months. It is our hope that those families referred to the pathway from 2021 onwards will reflect an improved experience.

This data may 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 via our website and social media.

Essex Family Forum will continue to gather parents' experiences via our Virtual Graffiti wall through our Family Champion Quadrant Leads and Volunteer Family Champions and present this data on a quarterly basis.

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.

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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.