

Essex Family Forum

Family Impact Survey 2024

**Report on Neurodevelopment Assessments –
including Referrals, Waiting Times, Support
and Information**



Date of Report: June 2024

Survey conducted:

1st February 2024 – 17th March 2024

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Introduction

This is our fourth Annual Family Impact Survey. We have expanded the scope of the survey each year by adding additional questions to existing sections and adding new sections. We have based these on the most consistent themes from the feedback we have received from families in all the forms we receive it. (e.g. our Family Champion network, virtual Graffiti Wall, Local Offer Roadshows, coffee mornings).

The aim of our survey is to detail parent/carer experiences in trying to secure the right support at the right time for their children/young people at the time they need it. We are then able to compare the current situation with what families have told us in our previous surveys. We are then able to identify where there has been any improvement in those experiences and where families are still finding it challenging to obtain the right support for their child/young person.

The results of our previous surveys can be found on our [website](#). It has been challenging to obtain a timely response on the findings from our previous surveys from the relevant teams and services across education, health and social care. We have, therefore, decided to separate the findings from this year's survey into specific reports for each section of the survey as follows:

- Education, Health and Care Plans - Statutory Processes including Needs Assessments, Annual Reviews and Appeals and Tribunals
- Neurodevelopment Conditions Assessments - Referrals, Waiting Times, Pre and Post Diagnostic Support and Information
- SEN Support, One Planning, Communication and Support with Education Settings
- Home to School SEND Transport
- Home Education, Unable to Attend and Education Other than at School (EOTAS)
- Therapies
- Mental Health Support
- Social Care and Shortbreaks Clubs & Activities
- Preparing for Adulthood
- Sources of Information and Support

This report concentrates on families' experiences of assessments for Neurodevelopmental conditions, including the referral process, waiting times and the support and information they are provided with whilst waiting and after assessment.

Methodology

- Survey period: 1st February 2024 to 17th March 2024.
- The survey was conducted via Survey Monkey and designed with both qualitative and quantitative questions. Throughout this report, we have included samples of the verbatim comments received from families.
- The survey was conducted via Survey Monkey and designed with both qualitative and quantitative questions. Throughout this report, we have included samples of the verbatim comments received from families. We have removed any personal or potentially identifying information from those comments such as individual names, settings and service providers.
- The names of settings and service providers will be available, upon request by Essex County Council (ECC) or the Integrated Care Boards (ICBs) but will only be provided in terms of the 'theme' within which they were mentioned. They will not be attributed to any specific comment - in line with the collection of data policy as outlined in the previous bullet point.
- The survey was promoted via Essex Family Forum social media, our Family Champion Network, connected support groups and through Email Octopus to our members. We also circulated to our various contacts at Essex County Council and the Integrated Care Boards for onward circulation via their communication channels. We used separate links this year so we can identify where the survey received the greatest engagement. We are delighted that those sent via our membership and Family Champion Network counted for over half of all the responses, with social media counting for one third of the overall responses. 87 parent/carers received their link via their child/young person's education setting.

Number of Participants

There were **1240** valid entries for the survey this year, as all participants who started our survey gave consent for their anonymized responses to be used and shared.

Participants were directed to sections of the survey via “skip logic” based responses they gave. They were also able to skip certain questions if they did not wish to provide a response. Therefore, participants only completed sections that were relevant to them and did not need to answer every question within the survey. The responses shown are based on the numbers of participants that answered that particular question.

The number of families completing our survey is increasing each year. In 2020 we received 638 valid entries, 517 in 2022 and 923 in 2023.

Disclaimer

The information and comments presented in this report and appendices 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.

General Information

The number of participants who are parents has remained fairly static. *A number of participants who selected 'Other' stated their parental status (Mother or Father).

Based on our previous surveys in 2020, 2022 and 2023, there is no significant difference in the gender of children/young people, or in the age ranges of] children/young people. The percentage difference between 2023 and 2024 is shown in brackets

Our survey respondents were predominantly white British. This is at a higher proportion than the general population of Essex according to the latest census figures (2021).

Parent

95% (-1%)*

Male child

62% (-2%)

Ethnicity

White British - **90%**
(2021 Census Data = 86%)

Age of Child / Young Person

Early Years - 10% (=)

Primary - 45% (-3%)

Secondary - 34% (+1%)

Post 16 - 7% (+1%)

Post 19 - 4% (+1%)

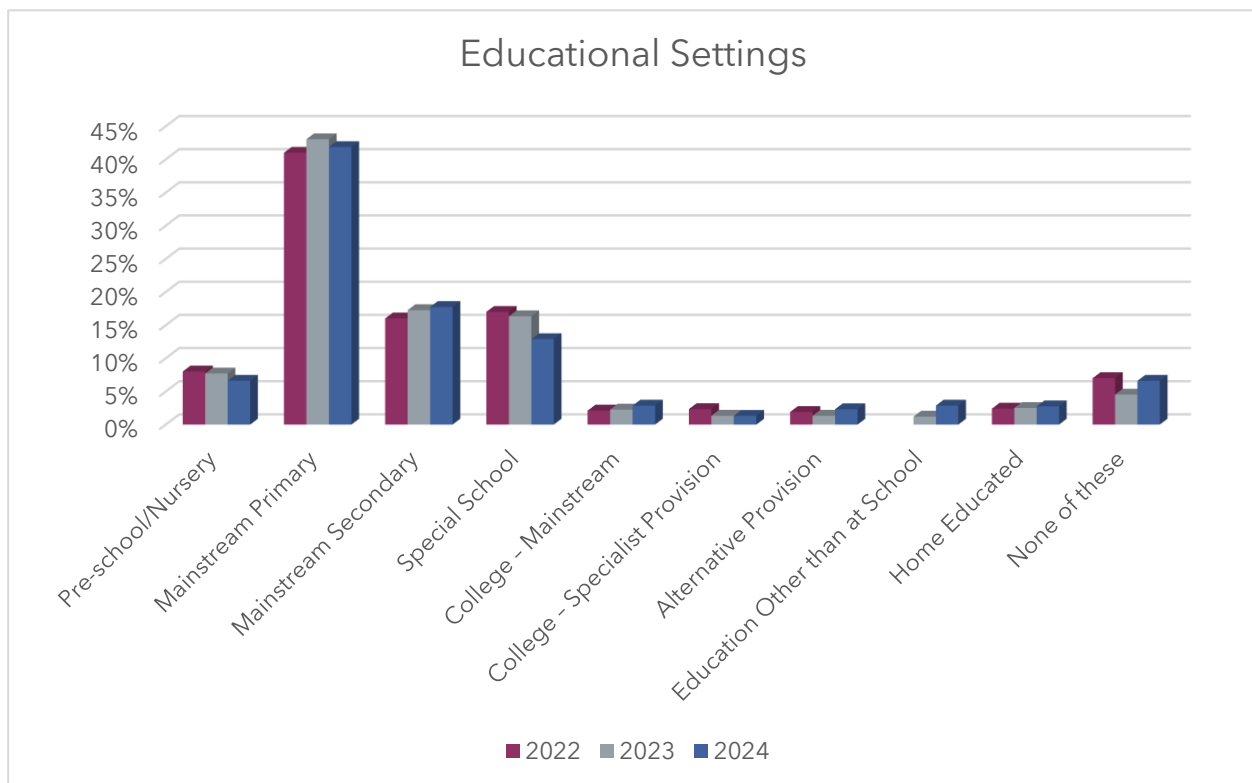
Responses by Area

We ask our survey respondents to indicate which area of Essex they live in as Essex is divided, administratively, into these four quadrant areas. We can also identify the local NHS Integrated Care Board that will be responsible for providing health services. By asking this question we can compare how reflective of the population, by area, our survey participants are. We are also able to filter our data to highlight the experiences of SEND families in each of the areas and compare the similarities and differences.

Area	West Essex	Mid Essex	South Essex	North East Essex
% of overall population*	21%	27%	29%	23%
Local Council	Harlow, Epping, Uttlesford	Chelmsford, Maldon, Braintree	Basildon, Brentwood, Rochford	Colchester, Tendring
% of survey respondents per area	20%	28%	27%	28%
% difference with 2023 survey	(+5%)	(-4%)	(-5%)	(+8%)

*Office for National Statistics - Census 2021

Education Settings



- Education Other than At School - 2023 was the first year it was included so there is no corresponding data for 2022.
- The option for Home Education was split further into 2 categories:
 - ◆ Home Education as a lifestyle choice
 - ◆ Home Education through no other option*

*The proportion of parent/carers who home educate through no other option is 4 times higher than those that do so as a lifestyle choice.

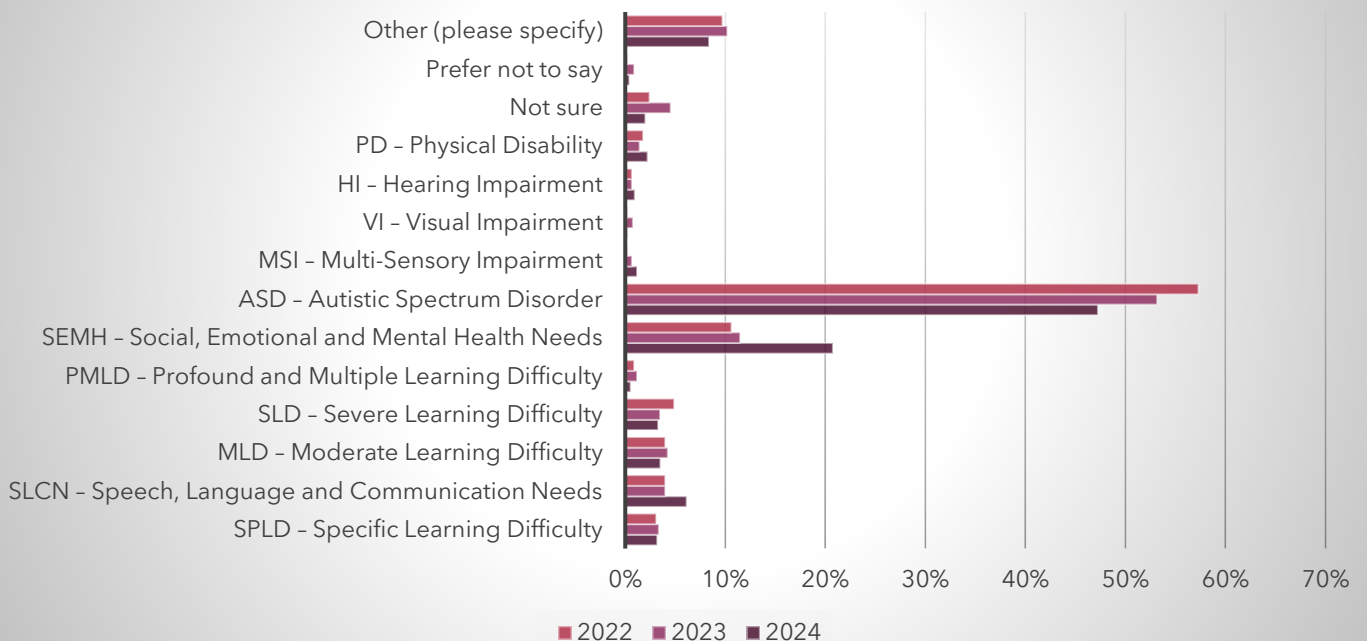
- Settings where the total was under 1% were:
 - ◆ Specialist hub - Primary
 - ◆ Specialist hub - Secondary
 - ◆ Virtual School
 - ◆ University (4 people stated their young person is studying at university)
 - ◆ Apprenticeship/Internship/Work based training
- This year, none of the respondents said their young people were in employment.
- The percentage of participants whose child/young person was not in school, employment or training slightly increased, but they have remained fairly static over the last three years.
 - ◆ As in previous years, the biggest proportion of those are compulsory age children, either on roll at a mainstream school or special school but not able to attend, awaiting a placement or there is no suitable placement.
 - ◆ The next biggest proportion are still young people unable to access Post 16 or Post 19 provision, training or employment.

Identification of Needs

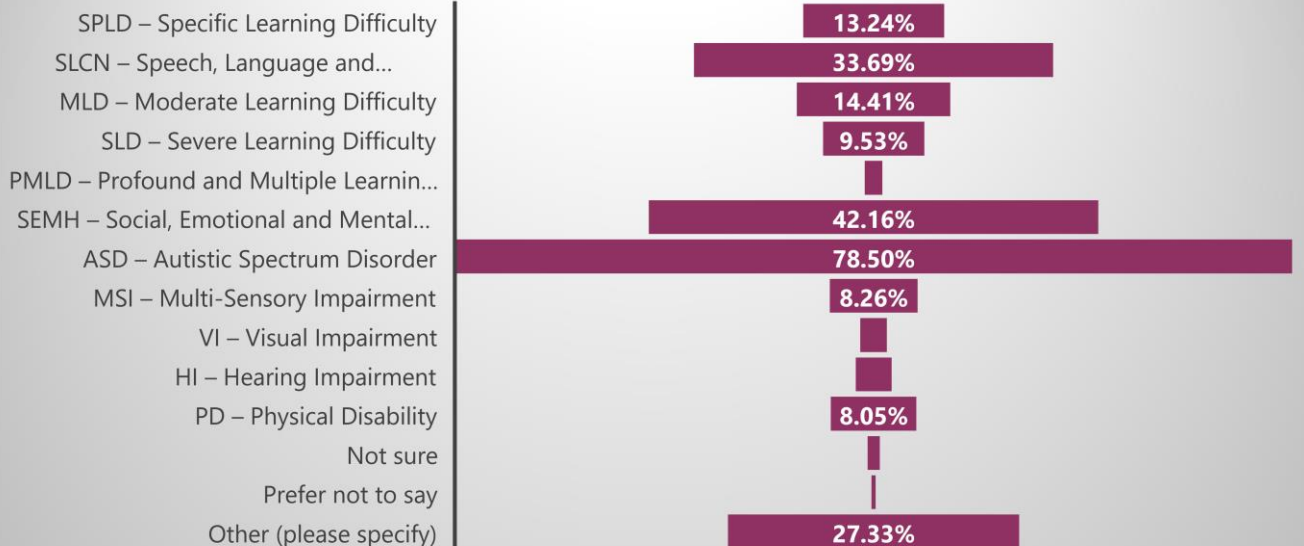
In each of our previous surveys, many parent/carers have indicated that their child/young person's needs are too complex and interlinked to pinpoint which is their primary need. Historically, we have asked this question to ensure there is correlation between parent/carer views and that of the education settings, using the options available in the school census returns.

This year we added an additional question so that parent/carers had the opportunity to provide details of **all** their child/young person's needs. (Therefore, the overall percentages will total more than 100%)

What would you describe as your child's primary area of need?



Child/Young Person's Needs (All)



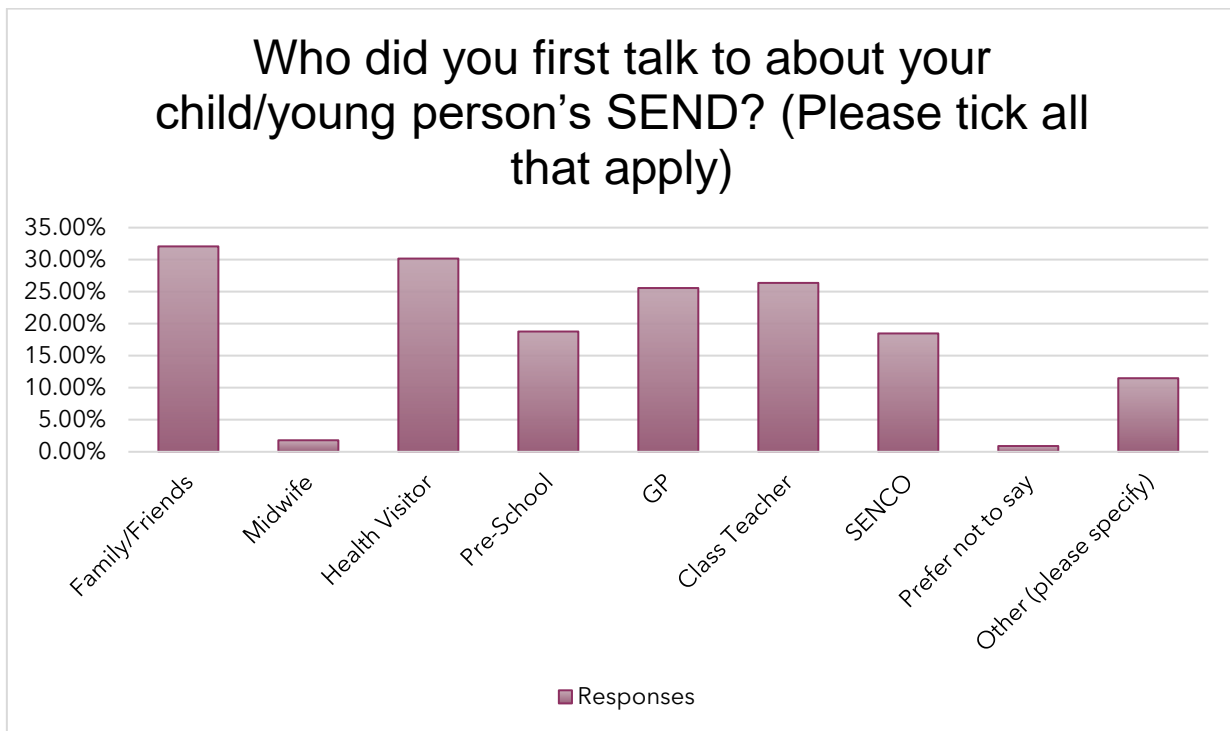
When describing all the needs of their child/young person the percentages categories increased significantly, compared to just the primary need selected. Where parent/carers selected other, the vast majority listed ADHD, either on it's own or with other needs described. This accounted for 16% of the overall total. The second most common need listed in the 'Other' category was sensory processing difficulties - again on it's own or with other needs. Some parent/carers listed needs such dyslexia and dyspraxia within the 'Other' category. It is our understanding that these would fall under the Specific Learning Dfficulty category when completing the school census.

62% of parents are unaware of the school census entry for their child/young person.

Who raises the initial concerns and who families talk to:

As in previous years, parent/carers are raising the initial concerns about their child's development/progress in the vast majority of cases (85%). Pre-Schools, Health visitors, Class Teachers as well as Family and Friends most commonly also raise initial concerns.

There is little change from previous years when it comes to who parent/carers first approach with their concern, (respondents could select more than one choice):



There were a wide range of practitioners specified under the 'Other' option, the largest being speech and language therapists (including private therapists), paediatricians and school staff (such as Headteachers and Pastoral Support).

Neurodevelopmental Conditions - Waiting Times, Assessments, Pre and Post diagnostic support

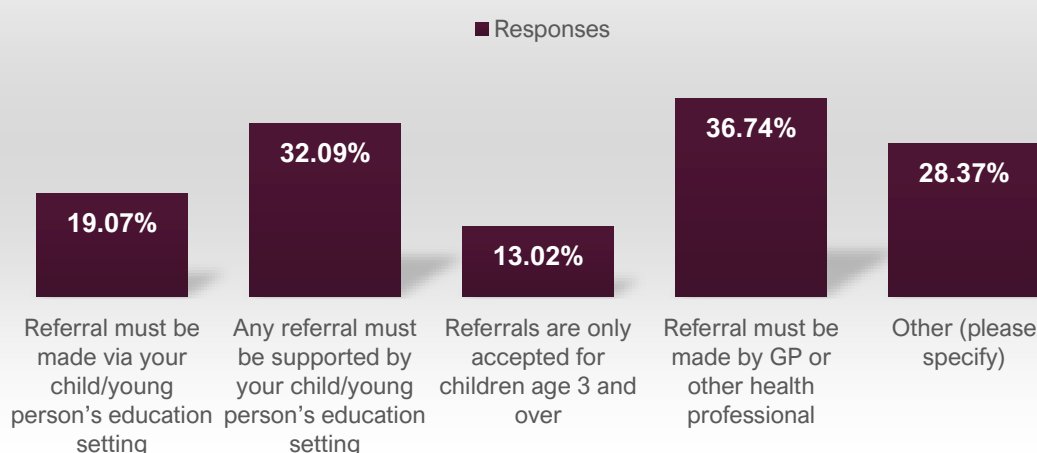
For the purposes of this report, we have filtered the data to exclude responses for any child/young person referred for assessment prior to 2021.

Please note that the 2023 data, where shown for comparison purposes, includes children and young people who were referred from 2020 onwards.

We added new questions this year and slightly changed the format of some existing questions to reflect the feedback we have been receiving from parent/carers and from discussions we have had in various strategic meetings about the Neurodevelopment assessment pathways in Essex.

Following updated operational guidance¹ on the autism pathway being issued by NICE (*National Institute for Clinical Excellence*) in 2023, parent/carers have been reporting some inconsistencies and conflicting advice about the referral process. We asked the following question to understand where the barriers to being referred are perceived to be. This is the overall picture, taking all areas of Essex into account.

Have you experienced any barriers to the referral process from any practitioner or professional? Please tick all that apply

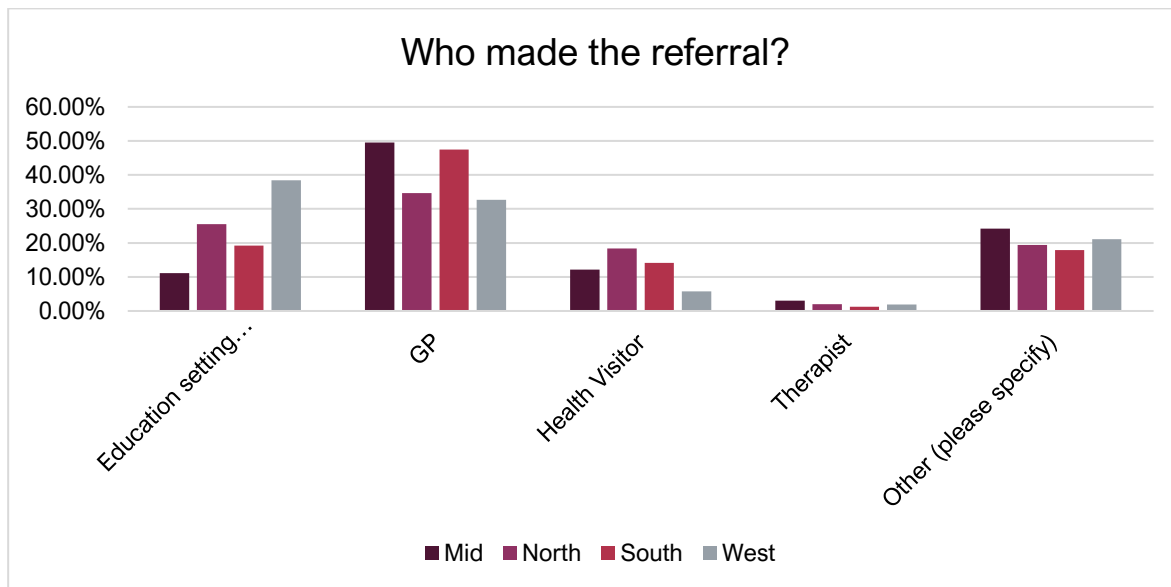


Parent/carers in South Essex are most likely to receive conflicting advice about the referral process - with 43% being advised that the referrals must be supported by their child/young person's education setting and 39% being informed that the GP must make the referral. More parent/carers in Mid (15%) and North Essex (18%) report being told that referrals are only accepted for children aged 3 years and over. In West Essex this figure is 8%.

¹ [NICE guidance](#)

Neurodevelopmental Conditions - Waiting Times, Assessments, Pre and Post diagnostic support (continued)

There is also some disparity in who does make the referral, based on where you live. Overall, 42% of referrals were made by the GP but is as high as 49% in Mid and only 33% in West.



The comments in the regarding referrals in the 'Other' category predominantly mentioned paediatricians making the referral (suggesting that these children/young people have fairly complex needs). In West Essex, the most common response in 'Other' was that the parent made the referral.

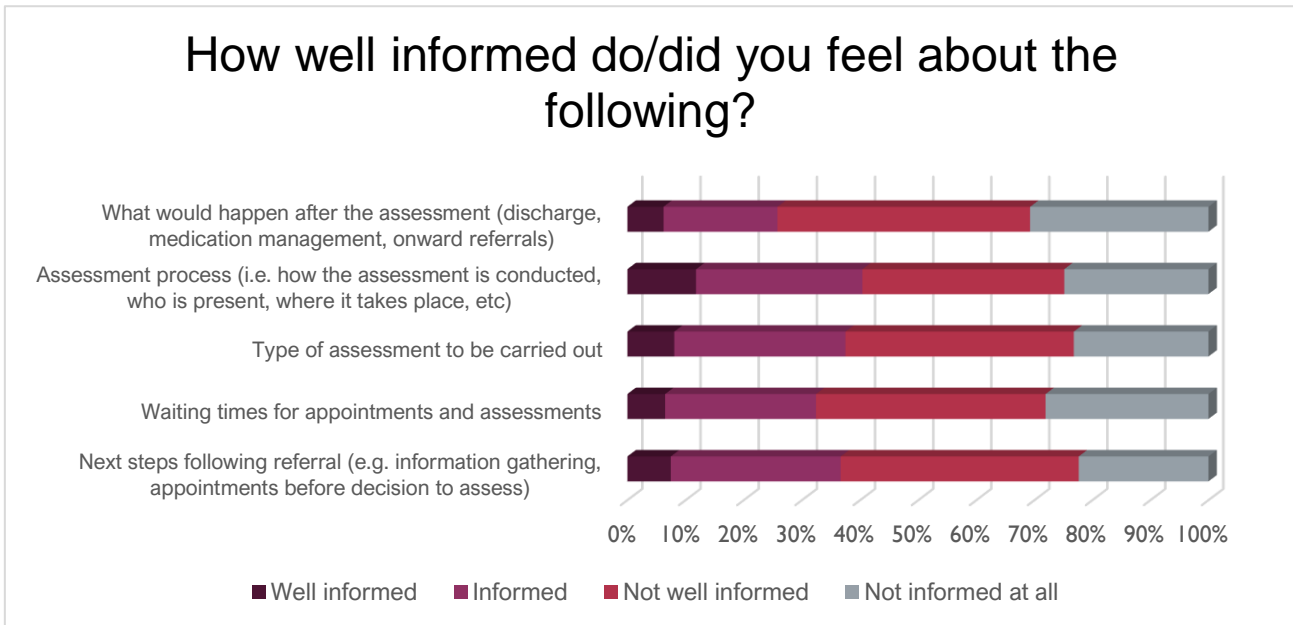
Referrals made by GPs was the most common route, overall. However, respondents highlighted that this was not always straightforward, with parent/carers having to be persistent with repeated visits before a referral was made.

Where parent/carers were able to give a free text answer about their experience of the referral process, comments included respondents stating that once the GP or health professional made a referral, there were delays by the child/young person's education setting in returning the forms that they were required to be complete, especially where they were unsure a referral for assessment was necessary. Respondents also report being bounced between services, particularly when living close to the boundary for different NHS providers.

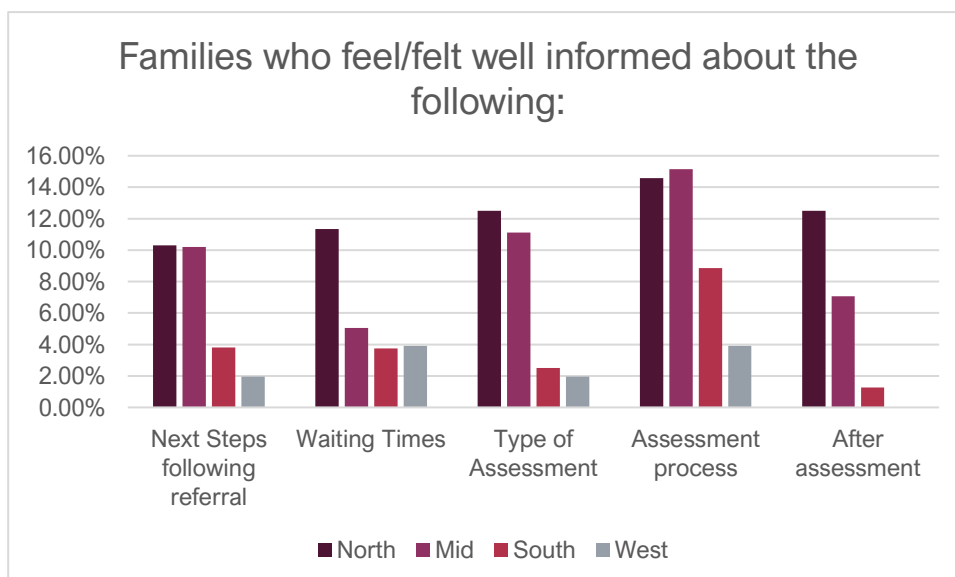
Neurodevelopmental Conditions - Waiting Times, Assessments, Pre and Post diagnostic support (continued)

We have often heard from families that they do not know what to expect once a referral is made for a Neurodevelopmental (ND) Assessment. There is a clear expectation in the NICE guidance referenced earlier in this report that information on what to expect throughout the pathway should be clear and accessible.

This year we asked parent/carers about their confidence in understanding certain aspects of the assessment pathway for ND conditions. The graphic below shows the overall picture for all areas of Essex.

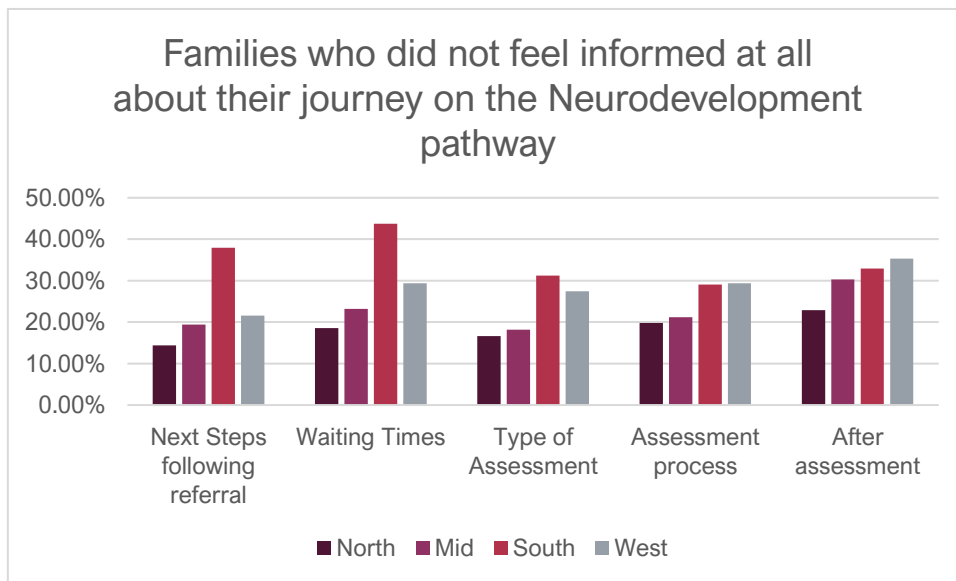


We can then break this down into each individual area; this first graphic just concentrates on parent/carers who told us they feel well informed about their journey on the ND pathway. Overall families in North Essex say they feel the most informed. Very few families in West and South feel well informed, with no families in West Essex saying they felt well informed about what would happen after the assessment had taken place.

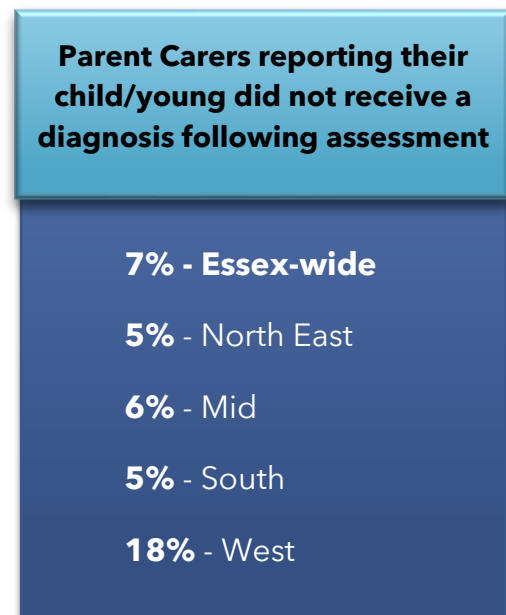
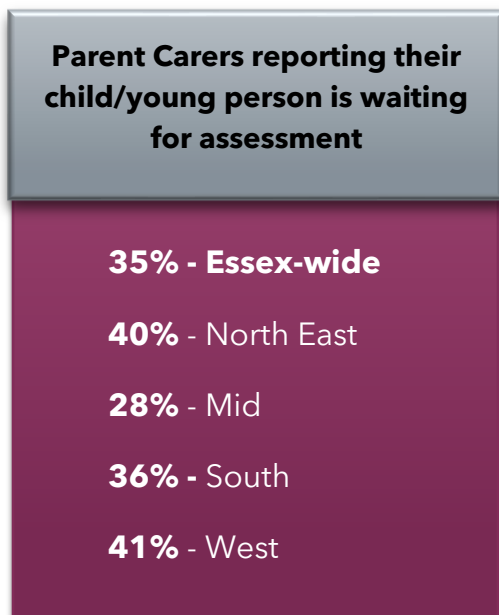


Neurodevelopmental Conditions - Waiting Times, Assessments, Pre and Post diagnostic support (continued)

This next graph concentrates on the proportion of families who did not feel informed at all about their journey.



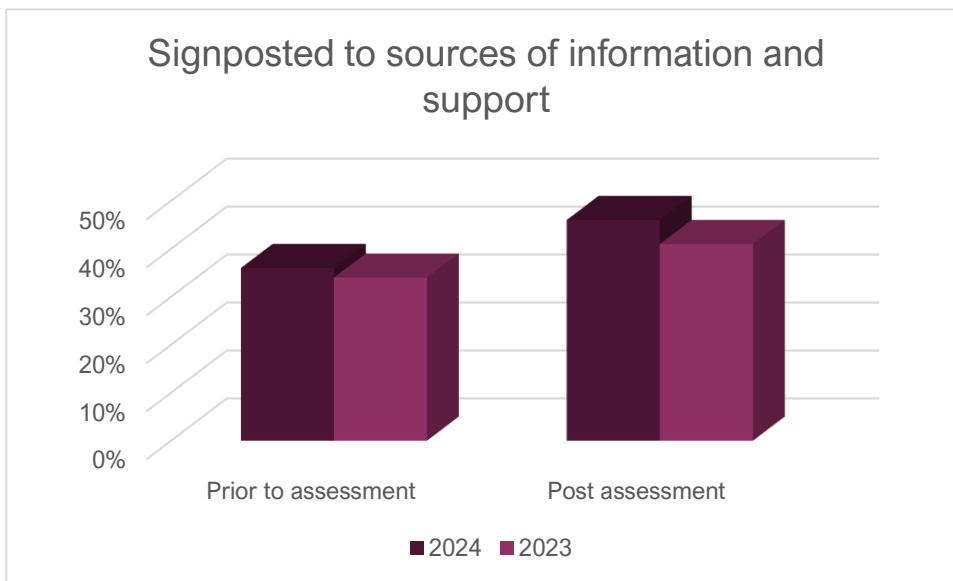
Of those that have been referred for an ND assessment since 2021 just over a third of respondents said that their child/young person is still waiting for assessment.



Neurodevelopmental Conditions - Waiting Times, Assessments, Pre and Post diagnostic support (continued)

Feedback we receive outside this survey is clear that families are still reporting that they do not feel that they do not receive a lot of information about support services and organisations either whilst waiting for assessment or following an assessment taking place.

However, there is a slight increase in parent/carers who report they were signposted to services and organisations that could provide support and information both prior to and post assessment. There is very little difference in the percentages across each individual area of Essex for signposting to services and organisations whilst waiting for assessment (prior to diagnosis). There are differences in how parent/carers view being signposted to sources of information and support post assessment in the various areas of Essex.



% of parent/carers who were signposted post assessment per area

North East - **47%**

Mid - **35%**

South - **52%**

West - **71%**

Parent/Carers were asked to rate the level of support they were signposted to for themselves and their child/young person. However, there are very few questions in our survey where participants are 'forced' to provide a response and only a small percentage (23%) of those eligible to answer chose to do so. On a scale of 1-5 (1=poor/5=excellent), 15% parent/carers rated the support excellent, 43% rated it poor, with the remaining 42% spread across the middle scores.

For the first time we also asked if children/young people were signposted to sources of information and support for themselves - just under 1/3 said they were. However, only 5% of parent/carers rated the support offered for children and young people as excellent.

Neurodevelopmental Conditions - Waiting Times, Assessments, Pre and Post diagnostic support (continued)

We received 85 comments from participants whose child/young person was referred for an assessment of a neurodiverse condition after 2021. They were split evenly across North, Mid, South and West Essex.

The majority of comments related to more than one area of the assessment process (from referrals to post-diagnosis). The main themes arising from the comments were closely linked to the questions asked in this section and related to:

- Long waiting lists and periods between appointments along with a lack of information about the length of expected waiting times.
- A lack of information and support available whilst waiting for assessment.
- Lack of support and information after receiving their child/young person's diagnosis. 36% of comments were parent/carers saying they wish for follow up or direct referrals to support

The positive comments (10% of total) mainly reflected feeling supported by health professionals during the assessment itself and there were several comments praising voluntary sector organisations which supported families through the process and post diagnosis, specifically Maze in the north and SNAP in the south of Essex.

Neurodevelopmental Conditions - Waiting Times, Assessments, Pre and Post diagnostic support (continued)

Being handed leaflets and left to get on with it doesn't give parents any sense of understanding or empowerment. We feel lost in a world that's different to the one we were in before the appointment. We need a check in afterwards, we need to be given positive information. Often we leave in a state of shell shock, feeling frightened of the world for our children. **Make it so it doesn't feel like this.**

We had to wait 18 months for the assessment. I had to escalate and complain a couple of times to even get any feedback about what was happening.

The assessment itself was really good. Through. Person-centred. Loads of examples given/ shared of how inattentive ADHD shows up. Diagnosis given and clear information about what to do if we wanted to consider medication which we did follow up on. The written report came out quickly too which was a great help and a relief after waiting such a long time. As a parent I didn't feel there was much support

We received a photocopied leaflet with details of charities about which we already knew. More targeted/dynamic support post diagnosis would be beneficial.

The professionals we encountered were great I can't fault their attitude towards my son and us as parents. We didn't feel dismissed at any point. The only thing I would say was a negative was the amount of time we had to wait for assessment and also once we had the diagnosis we were sent on our way with a piece of paper with groups and charities that could help us and then discharged from the service and told to wait for written diagnosis which could be up to 4 weeks wait.

as a parent with dyslexia having someone to talk to would have been so much more helpful than a list of websites.

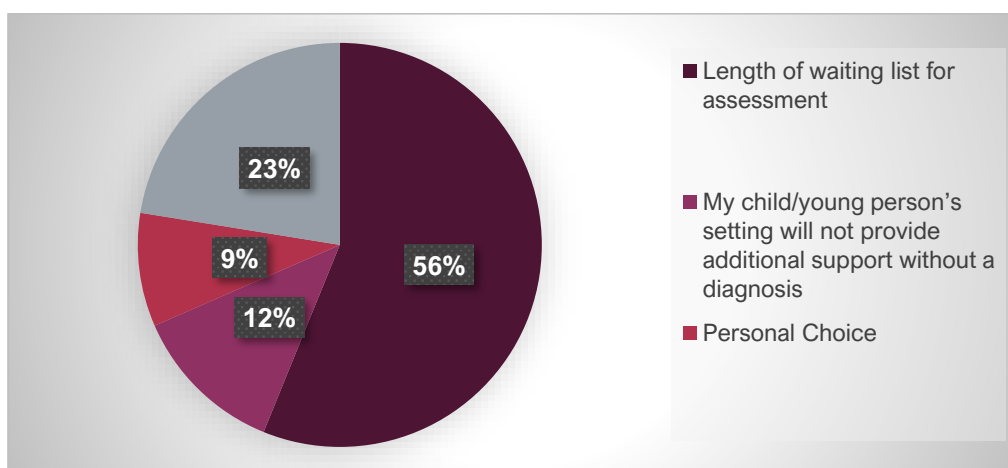
We waited for assessment 2 years. On the day the process was explained. it was clinical and bland. Support offered was websites and teenager clubs too far too travel for us. 12 weeks post assessment awaiting report, school is keen to see report and so is therapist.

Those parent/carers whose child/young person were referred for an ND assessment prior to 2021 were given the opportunity to share their experiences in the form of a free text box. It would appear from their comments that very little has changed in the last 10 years. This is an extract from a parent comment based their experience in 2014.

"All the professionals we encountered were lovely, kind and warm there was no wrap around support, meaningful signposting to services or aftercare."

Private Assessments for Neurodevelopmental Conditions

Another common theme of feedback we receive is that parent/carers will seek a private assessment of neurodevelopment conditions for their child/young person. The way a private assessment is arranged can be through different means such as the NHS Right to Choose, workplace private healthcare or families paying private clinicians themselves. We have heard, anecdotally, of parent/carers taking out pay-day loans in order to be able to afford to pay privately. 120 parent/carers responded to the question why they sought a private assessment for their child/young person. The responses were fairly evenly split across the areas of Essex. Parent/carers in Mid Essex were most likely have sought a private diagnosis, parent/carers in South and North were least likely. The reasons given for seeking a private assessment are outlined below, and the main reason is due to the length of waiting times for assessment:



The main themes from the comments in the 'Other' category related to:

- assessment of Sensory needs (which parent/carers do not believe is sufficient under NHS services)
- assessments for conditions such as Dyslexia and Tourette's syndrome
- to obtain the right support for their child/young person - whether in their education setting or from wider services
- some families mentioned difficulty in progressing beyond the triage stage under the NHS referral process.

93%
were very satisfied or satisfied with the outcome of the assessment

80%
received a positive diagnosis

30%
experienced difficulty with having the outcome accepted by education settings*

*One parent was told "A professional paid by myself could say anything I wanted them to."

Neurodevelopment Conditions - Conclusion and Next Steps

Long waiting times for assessments are still a concern for many parent and carers, and the main contributing factor to seeking a private assessment for their child/young person's neurodivergent needs.

Only 12% of parent/carers say they felt well informed about the assessment itself and how it would be conducted. Less than 10% of parent/carers reported feeling well informed about the referral process for assessment, support available whilst waiting or what happens after assessment in terms of additional support given. Not understanding what support is or should be available whilst waiting for assessment is also a contributing factor in a parent/carer's decision to pay for a private assessment.

Where parent/carers have accessed support, they have not rated the quality of that support particularly highly.

Next Steps

As members of the Neurodevelopment Strategic Partnership (NSP) (which included representatives from the Integrated Care Boards and Essex County Council) we developed specific outcome measures relating to the advice and information that should be made available to families who are referred on the Neurodevelopment (ND) pathway. These outcomes were developed in response to a parent/carer survey conducted in 2021 and from sessions we hosted with parent/carers and support groups.

We also spoke to parents and carers again, in February and March 2023, to ask them what they felt quality advice and information looked like for families referred to the ND pathway. This feedback was shared with the NSP with aim of seeking improvements the information and support available.

We repeatedly asked the NSP to work towards these outcomes within their ICBs. The Partnership meeting ceased at the end of March 2024, a decision we supported due to the lack of progress towards the outcomes.

The feedback in this year's survey very clearly reinforces the message from Parent/Carers about the advice, guidance and information they would like to be available throughout the Neurodevelopment Assessment Pathway. It is disappointing that, despite Essex Family Forum providing continuous feedback on key issues and championing for change, the same issues continue being raised by families. We firmly believe that by parents and carers understanding what the diagnostic pathway will look like and by providing the right support at the right time, families will feel more supported and the outcomes for children and young people will improve.

Therefore, we urge the NHS Integrated Care Boards and their providers to focus on achieving the four outcomes as co-produced with families, specifically focusing on:

- Reviewing commissioned support and services to which families are signposted.
- Improving the quality of communication with families about:
 - The “Referral pathway”, including the referral process, is depicted in a clear and accessible way and is widely and easily available to view on the ICB and NHS provider websites. The Essex Local Offer should be provided with the appropriate links to this information by the ICB and/or NHS Providers and that these links are regularly reviewed and kept up to date.
 - Support available whilst waiting for assessment
 - Clear indication of the likely waiting time for appointments and assessment and keeping in touch correspondence at regular intervals
 - Clear explanation of the next steps following assessment, such as discharge or ongoing care, including the advice and support that is available

We also ask that they do so as a co-productive approach with us, Essex Family Forum, and our parent/carers.

Previous surveys and parent/carer feedback on Neurodevelopment Assessment Pathways:

[NDD Survey 2021](#)

[Outcomes Measures 2022](#)

[Advice and Guidance Feedback 2023](#)