

Essex Family Forum

Family Impact Survey 2024

Report on Therapy Provision in Essex



Date of Report: July 2024

Survey conducted:

1st February 2024 – 17th March 2024

Contents

Introduction.....	2
Methodology	3
Number of Participants.....	4
Disclaimer.....	4
General Information.....	5
Responses by Area.....	6
Education Settings	7
Identification of Needs	8
Therapy Services	10
Therapy Services (continued)	12
Therapy Services (continued)	13
Therapy Services (continued)	14
Therapy Services (continued)	15
Therapy Services (continued)	16
Therapies - Conclusion and Next Steps	19



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 Therapy services in Essex, specifically to support Speech & Language/Communication, Physiotherapy and Occupational Therapy needs.

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%)

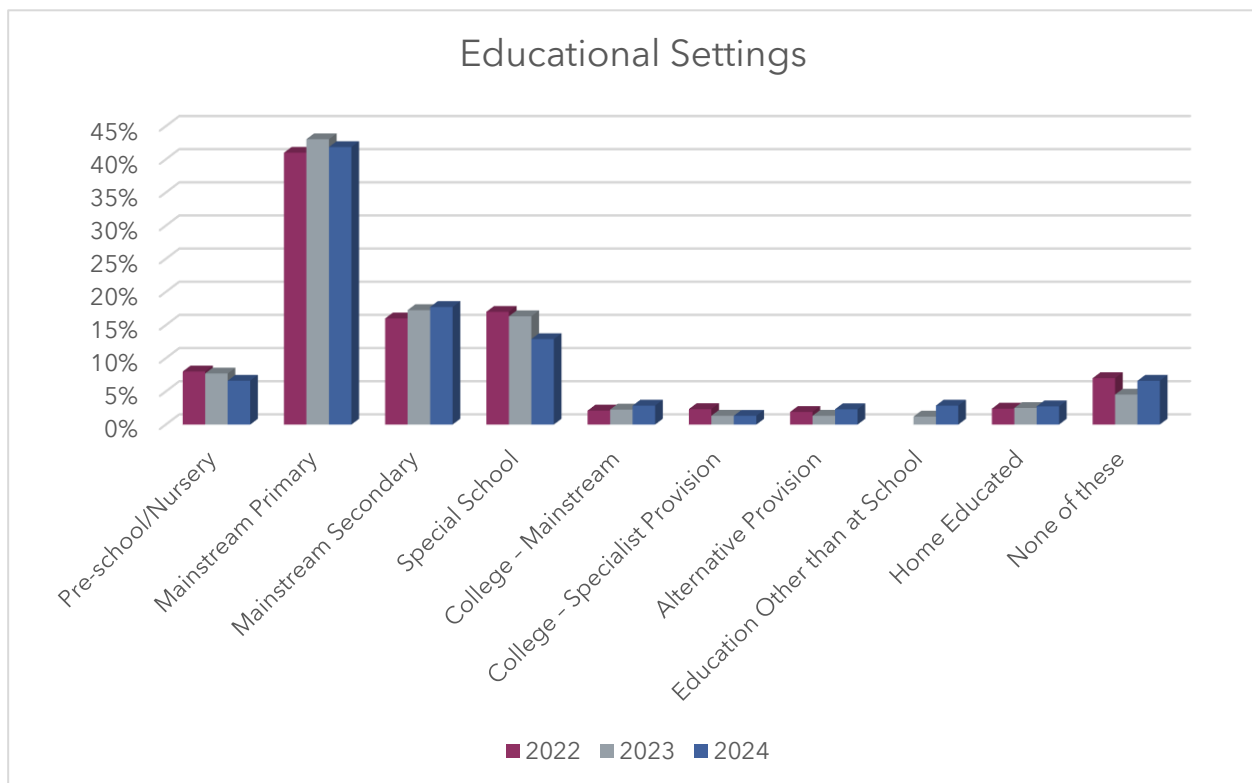
Responses by Area

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.*

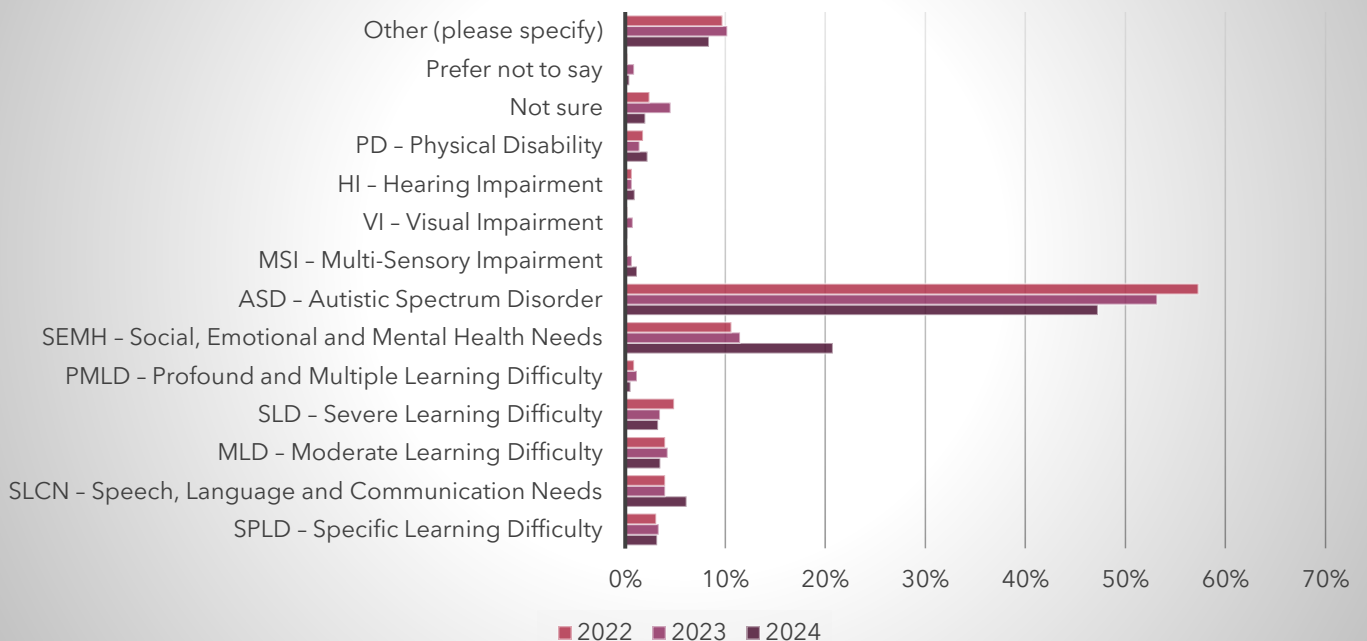
- Settings where the total was under 1% were:
 - ◆ Specialist hub - Primary
 - ◆ Specialist hub - Secondary
 - ◆ Virtual School
 - ◆ University (4 people stated their young person is studying at university)
 - ◆ Apprenticeship/Internship/Work based training
- This year, none of the respondents said their 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

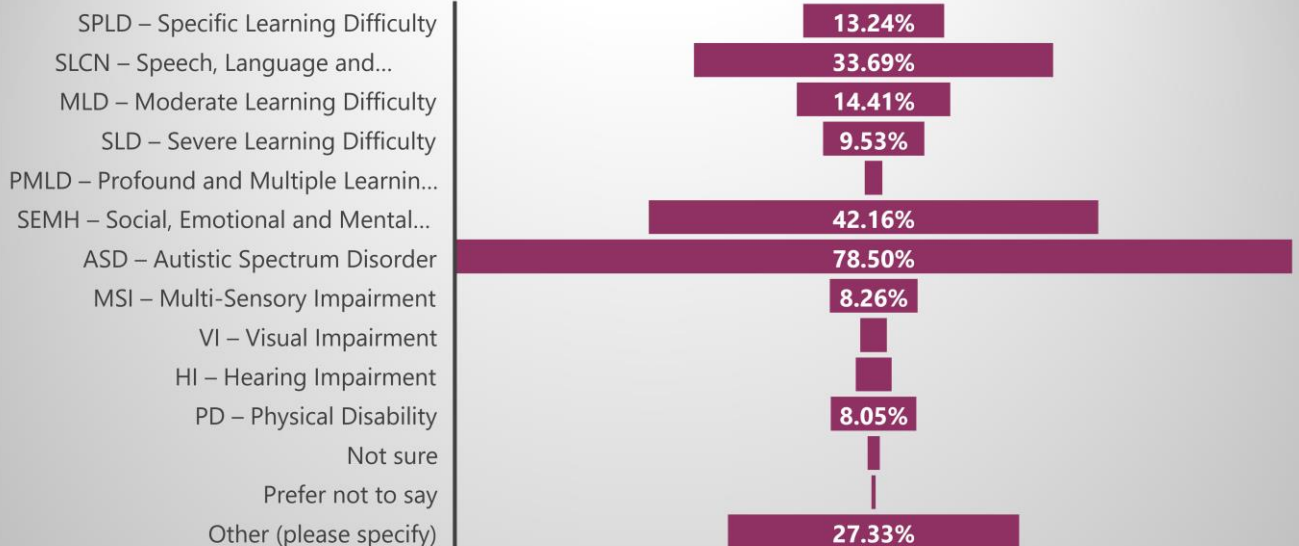
In each of our previous surveys, many parent/carers have indicated that their child/young person's needs are too complex and interlinked to pinpoint which is their primary need. Historically, we have asked this question to ensure there is correlation between parent/carer views and that of the education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



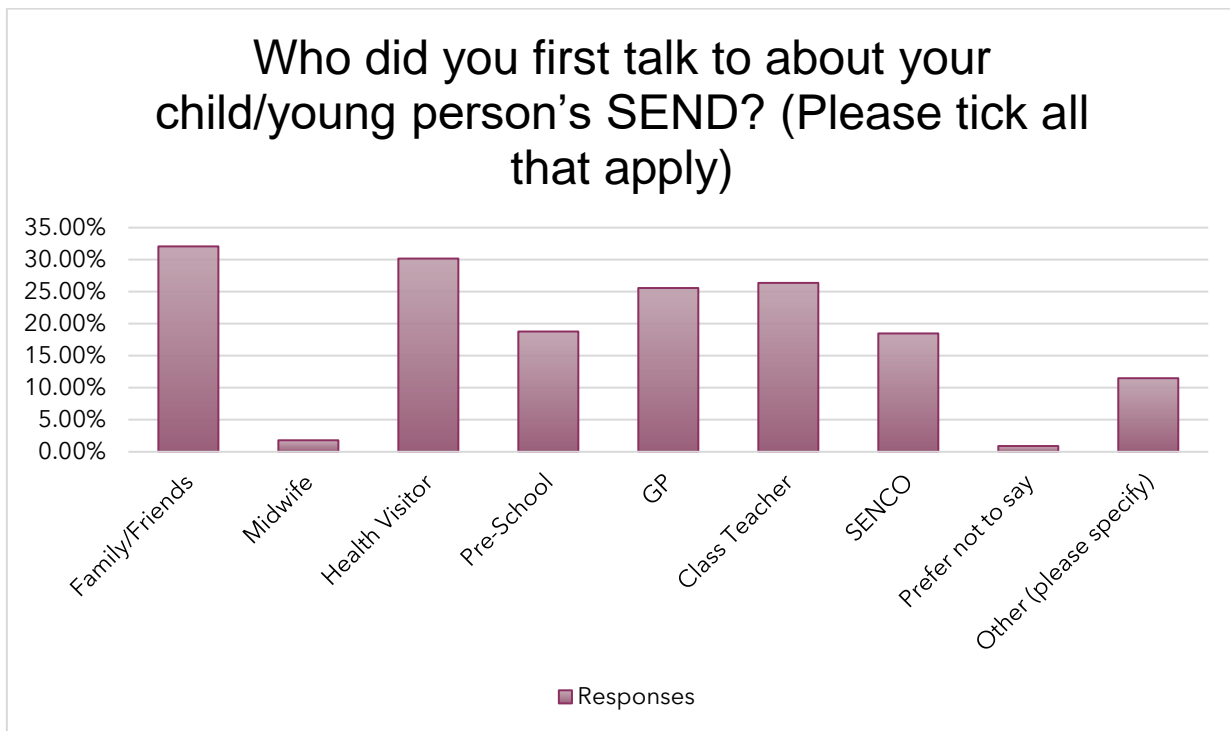
When describing **all** the needs of their child/young person the percentages categories increased significantly, compared to just the primary need selected. Where parent/carers selected other, the vast majority listed ADHD, either on it's own or with other needs described. This accounted for 16% of 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):

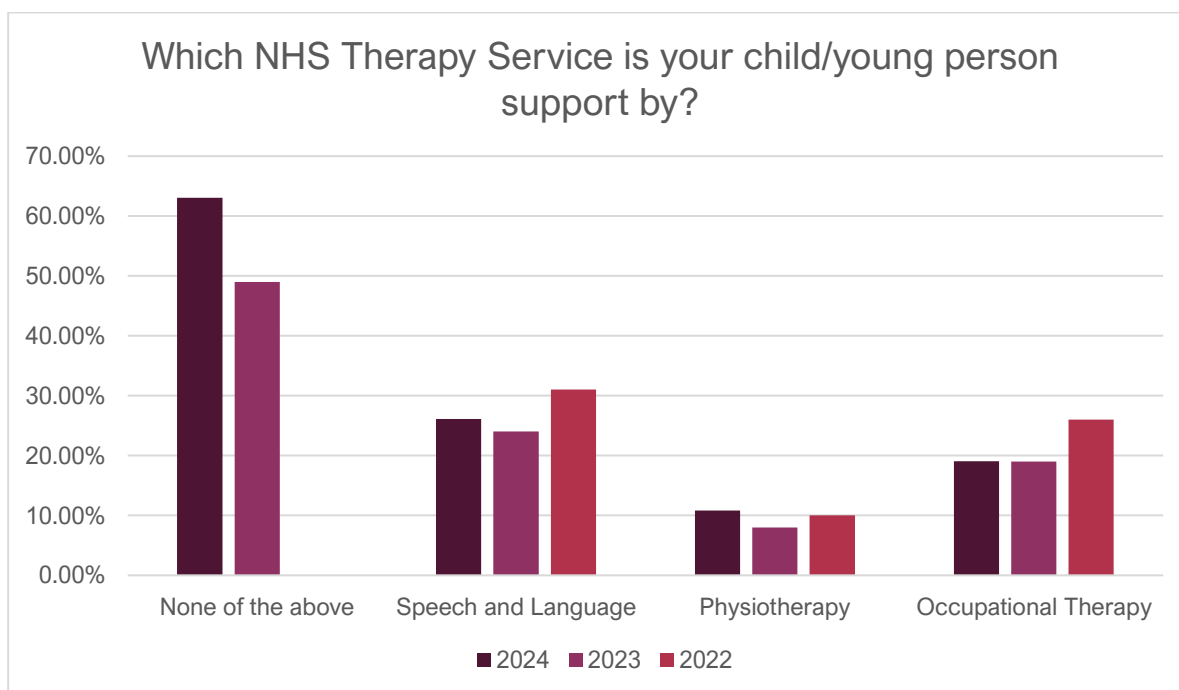


There were a wide range of practitioners specified under the 'Other' option, the largest being speech and language therapists (including private therapists), paediatricians and school staff (such as Headteachers and Pastoral Support).

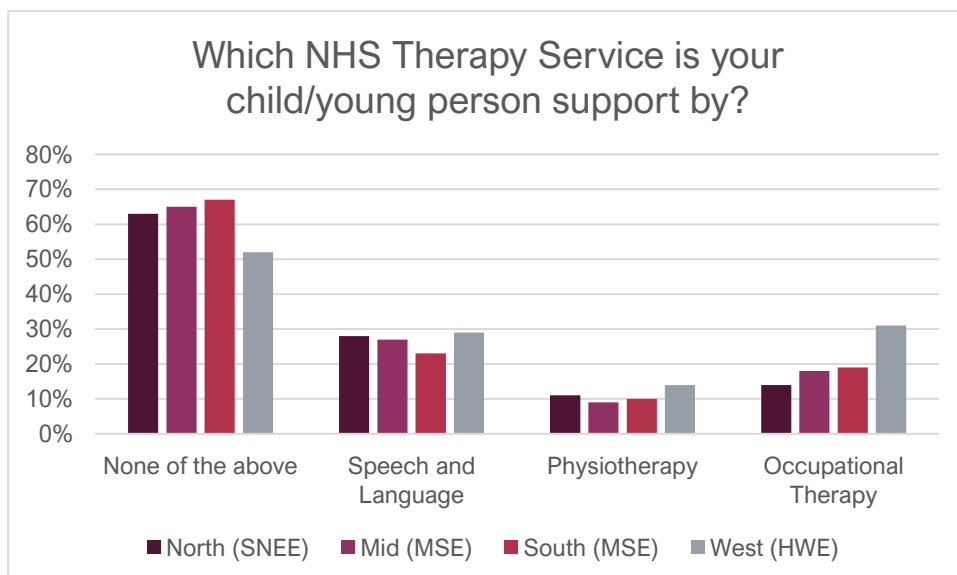
Therapy Services

Therapy services support was a new section in our 2022 survey and included an 'Other' category. The majority of participants indicated that the 'other' therapy their child/young person received (or tried to access) were mental health services. This is now a separate section in our survey and so we removed the 'other' category from this question.

There are a number of families whose children/young people are receiving therapy provision from more than one service and, therefore, the totals will be more than 100%.



This year we have further broken these responses into the four areas of Essex - which stretch across the 3 Integrated Care Boards of Suffolk & North East Essex (SNEE), Mid & South Essex (MSE) and Hertfordshire & West Essex (HWE) and their providers.



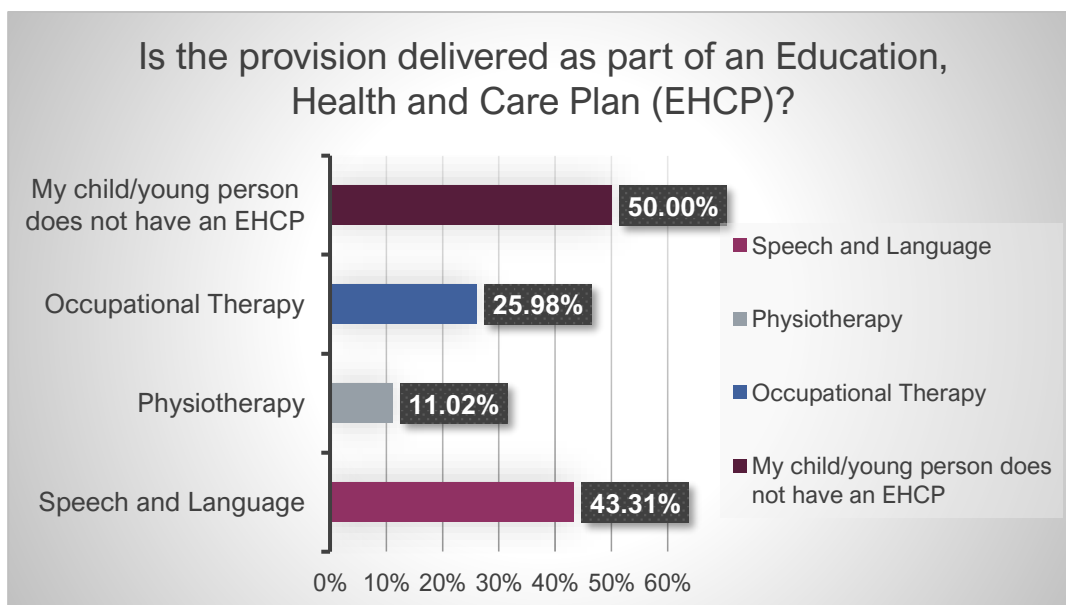
Respondents who answered 'None':

18% are on a waiting list for therapy services

50% have been discharged from a therapy service

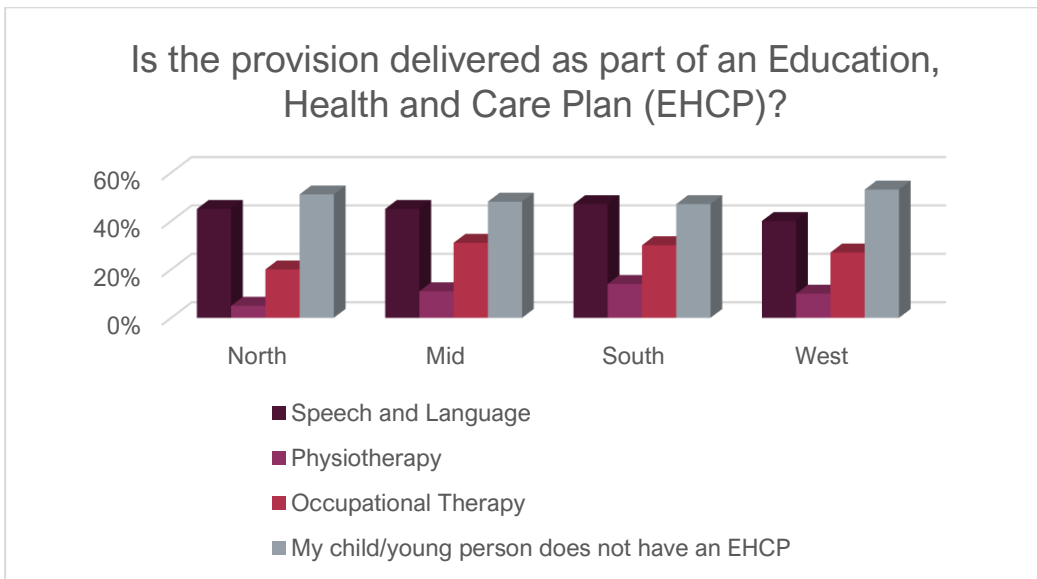
These figures have remained static since last year. There is no more than a 5% difference across the different areas in Essex. You are most likely to be on a waiting list in North East Essex (22%) and in Mid Essex are more likely to have been discharged from therapy services (53%).

Another new question we added this year was whether therapy provision was delivered through an Education, Health and Care Plan. 50% stated their child/young person did not have an education health and care. The remaining 50% responded as outlined in the graph below - the total will not equal 100% as some children/young people are supported by more than therapy service.

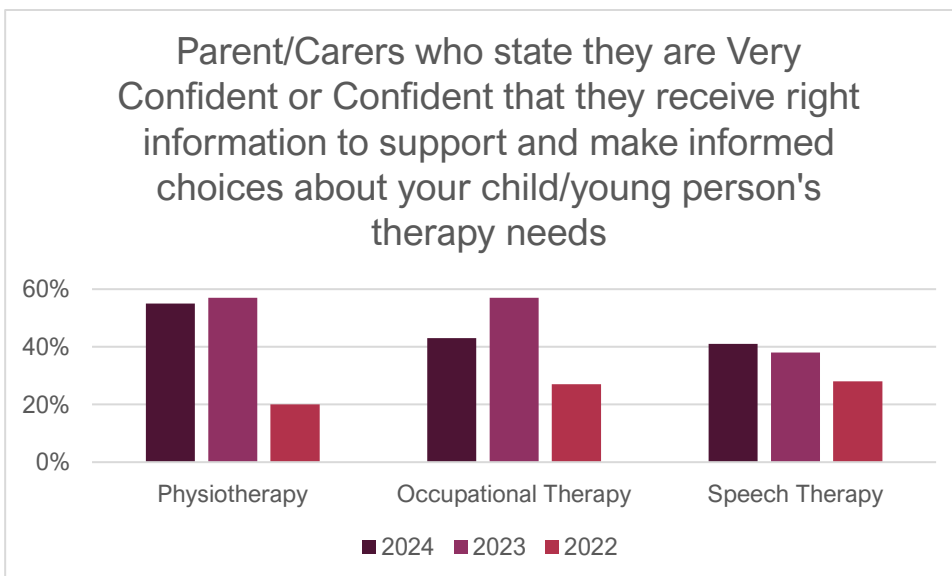


When these figures were broken down across the areas of Essex, there was some disparity in respect of the percentages receiving Physiotherapy and Occupational Therapy provision in their EHCP, as highlighted in the graph on the following page. However, we accept that this may purely be reflective of the needs of the population in the local areas but would welcome a comparison with local ICB data sources.

Therapy Services (continued)



Approximately half of all children and young people receiving therapy provision do not have an Education, Health and Care Plan and so are receiving their therapy from core services.



The proportion of parent/carers report they are Confident or Very Confident that they receive the right information to support and make informed decisions is similar across the areas of Essex. Speech and Language Therapy continues to be the area where parent/carers are least confident, wherever they live. However, Mid Essex parent/carers report higher levels of confidence for Occupational Therapy (51%) and Speech & Language Therapy (49%) than other areas and North Essex parent/carers report the highest levels of confidence in the information they receive in regard to their child/young person's physiotherapy needs (62%).

Whether a child/young person is supported in their education setting through an Education, Health and Care plan or through One Planning at SEN Support level, it is important that appropriate support is based on the most recent recommendations of the professionals supporting that child/young person, including any therapy professionals.

EHCP Annual Reviews

51%

Feel that all appropriate professionals contribute to their child/young persons Annual Review

One Plan Reviews

32%

Feel that all appropriate professionals contribute to their child/young persons One Plan reviews

Only **29%** of parent/carers believe that their child/young person is receiving all of the education provision in their plan. As therapy provision is most likely to be included in Section F (Education Provision) of an EHC Plan, it can be assumed that this percentage includes therapy provision. Approximately 10% of parent/carers do not believe their child/young person receives any of their provision.

For those supported through One Plans, only **14%** of parent/carers believe that their child/young person is receiving all of the provision outlined in their plan. As approximately half of our respondents whose child/young person is supported by a therapy service, this percentage is likely to include therapy provision. 7.5% of parent/carers do not believe their child/young person receives any of their provision.

1/5 of children/young person with SEND are reported to only be supported by their education setting with no other professionals providing advice or support regarding the child/young person's special educational needs

In the EHCP section of our survey the majority of comments were relating to the delivery of provision, with parent/carers reporting they receive little communication about how provision is implemented in their setting or, in a significant number of cases, that settings are unable to deliver the provision in the plan. There were similar themes relating to provision in the SEND Support/One Planning section of our survey, including Professionals and settings not working well together and/or communicating well.

Online Therapy

We know that there is an increase in an online offer for therapy provision and so we asked some general questions in relation to the positives and challenges to receiving therapy online.

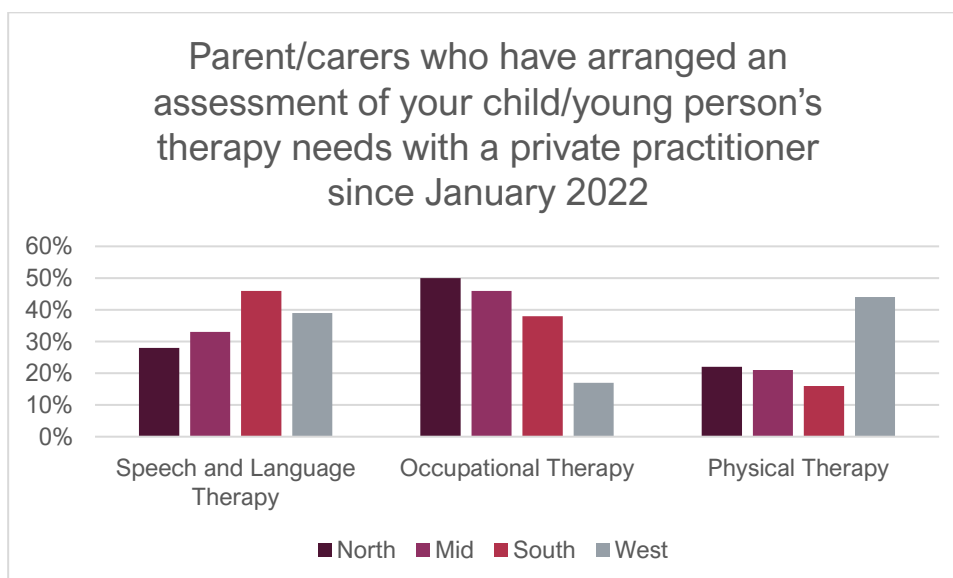
- 51 parent/carers said that their child/young person received online therapy provision.
- 18 parent/carers said that being able to receive therapy provision in the home is a positive experience and felt that they had an improved understanding of the strategies as they were able to be present
- 11 parent/carers said their child/young person was more relaxed receiving therapy online

We received 43 comments relating to the challenges of online therapy provision - with the majority stating that their child/young person struggles to engage with the online format. One parent reported that they need support to access online services which is rarely available.

Private Therapy Assessments and Provision

In last year's survey we were surprised that a number of families reported self-funding a private practitioner to deliver therapy provision outlined in their child/young person's EHCP. So this year we introduced some questions on private therapy assessments and provision.

It is important to note that the vast majority of parent/carers have not sought private assessment or therapy provision for their child/young person's needs. 99 parent/carers told us that they had sought a private assessment, and we have been able to filter their responses by therapy type and area.



Proportion who have then received therapy provision from a private practitioner:

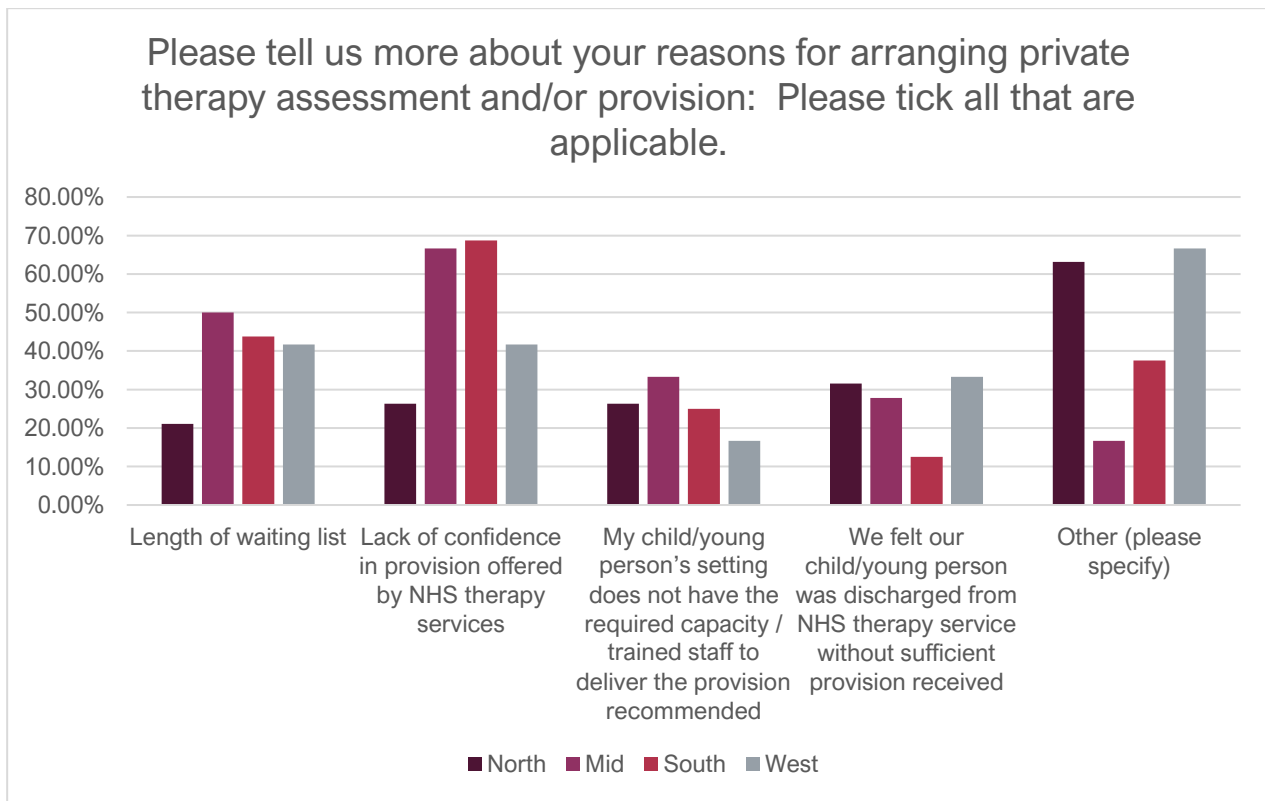
North - **50%**

Mid - **76%**

South - **68%**

West - **78%**

Therapy Services (continued)



The reasons for seeking private assessments and/or provision that parent/carers gave in the 'other' category were overwhelmingly due to a belief that the NHS provision offered was not sufficient to meet the needs of their children/young people. The majority of North Essex parents expressed concerns over NHS provision for sensory processing needs. There was at least one comment from Parent/Carers in each of the areas of Mid, South and West Essex saying that they engaged a private therapist as their child/young person's EHCP provision was not being delivered as outlined in their plan.

We received 482 comments relating to therapy support.

65 were in relation to mental health needs and will be included our report on the mental health section of our survey.

20 comments were positive and highlighted where services are working well, although 4 comments also highlighted inconsistencies in experiences with different therapy services. For example:

"S&L therapy is so infrequent that it is of very little use to us or our daughter....."

"OT has been more helpful because the therapists are more accessible and offer very child focused advice. They were also helpful in the transition between nursery and school and offered support to the school as well as to our family."

Therapy Services (continued)

The remaining most common themes, in order of the highest frequency, were:

- Discharged with insufficient support or strategies being provided – some participants reported that the therapy was being discharged or delegated to the school who then failed to deliver the provision needed
- Insufficient support or strategies being provided by the therapy service
- Issues with referrals, including parent/carers who are unaware of how to request a referral or who they need to speak to. One parent/carer reported that their child had been discharged by speech and language therapy, but new needs had emerged, and the school advised that they were unable to re-refer into the service.
- 36 comments related to parent/carers engaging private therapists – there were 2 main reasons cited for this
 - Provision offered under NHS therapy was not felt to be sufficient to meet the needs of child/young person
 - Long waiting lists meant that child/young person was not receiving early intervention they need

Several parent/carers mentioned the cost of private therapy provision, with 2 parent/carers reporting they could no longer afford to continue.

There were 4 comments relating to settings paying to engage private therapists

- Long waiting lists
- 18 comments specifically referred to EHCP provision not being delivered by settings or providers
- 2 parent/carers reported that their young person's therapy provision had ceased once their education ceased and there was no advice or onward referrals to adult services.

A selection of comments relating to these themes are included below and on the following pages.

Waiting for SALT, incorrectly informed that SALT don't cover selective mutism, so we've lost out on nearly 18 months where he could have received therapy and support.

SALT - prior to attending special school with onsite SALT provision our son was on the high pathway for support in NE Essex - the therapy received was very good, included home and nursery visits

School has to provide private as never seen by NHS because of waiting list and availability

Occupational therapy for specialist desk, computer, writing aids. Occupational Therapy were very good. School made things difficult

What "professionals"?
Honestly, are any left or providing any assistance any more? Everything is delegated to the educational setting.

OT- through provide, was observed once for 20 mins in his mainstream, That OT then called me saying she was leaving and would pass us onto her replacement. Never heard anything again! I chased a few times with no luck, then stopped bothering as I knew he would be joining a SEN school and have access to OT

Awful. Not delivered spent 7 months emailing send ops, provide, complaining to MP who has complained to head of Essex county council.

March 2024 received a voicemail from provide no name left or number to call back and told they wouldn't deliver salt in spring term. Will try in the summer. Appalling that's 2 whole terms of therapy missed. Still don't recall they are to provide OT too.

Useless.

Have requested personal budget to arrange myself

Provide are meant to be providing an hour per month according to ehcp. In 6 months they have visited for 40 minutes.

Speech therapist are very expensive as they know there is such a long waiting list in NHS. I feel the few we have tried are more interested in money and pushing old practices.

OT- i am attending a parental sensory course- its very useful

SALT- poor provision from the start, not fit for purpose- 3 group sessions that were too far away and not appropriate for my child's needs

I have never been offered any therapy for my child and don't know what is available

It has taken nearly 18 months to get anything in writing from the OT for a support plan despite numerous visits. We were then discharged from the service despite very little progress being made by my child.

I have had to fight very hard for NHS speech and language therapy too but am now happy with the level my child is receiving.

My daughter..... was offered 6 sessions of OT and saw the SAL therapist in school 2 or three times. We were not involved in any of these sessions as they were all offered in school. We received a photocopied piece of A4 paper with the exercises OT had given her and had no communication with SALT - As parents we felt let down by this It would have been positive to have been included in discussions with both services so we could have supported more at home.

What actually happened is that my child was on the waiting list for so long, that when we were finally contacted, they had turned 18 and were no longer eligible. Nothing else was offered.

SLT, Physio and OT providers very professional, helpful and available. Takes time to organise and get appointments, but people on ground superb service.

He was discharged from NHS SALT in Oct 2022 and NHS SALT wrote to LA and asked them to commission through education as they could not provide what my son needs. We have been waiting for this since Oct 2022 and he still has nothing, despite and LGSCO finding in our favour and awarding compensation for over a year of missed provision.

The OT who sees my daughter through NHS therapies, at times, has been terrible at providing reports, at times providing none at all. I've had to really push for reports to go in for the EHCP.

I have to find SLT for my daughter as the nhs would no longer fund her after a review in Reception.

We are supposed to have speech therapy, but we don't not even in school as far as I'm aware

We believe our son needs both OT and SALT assessments and therapy but whenever we have asked about these the school have not supported us to apply. I had hoped we might have an OT assessment as part of the EHCNA but it was not offered and when I asked I was laughed at due to the wait time

The school was told they must engage the speech therapy every 3 months to remain on their books, the school maintain they did this and the salt say they did not and discharged us. We are now on a waiting list. Our son's needs are great so this is a very frustrating situation to be in. We don't know if it's the school or salt at fault. We are in the dark but have no authority. Our son is losing valuable input

2 speech And language appointments and discharged as told non verbal so no point in having therapy

My child was having speech therapy for a speech developmental delay. They went to {name of setting removed} school so he worked with a specialist speech and language LSA there and saw the speech therapist during nursery sessions.

{child's name removed} is supposed to have SLT and OT input at her special school but this is not happening. I have been told that priorities are given to new students and the therapist for her age is on maternity leave

Our initial contact with any health care professional who recognised our son's struggles was an OT who was amazing! Just the recognition that there was something more and not just 'bad parenting' was a huge weight lifted. We also had the hugely helpful sensory needs online workshop which then helped us to develop our sons 'making sense of my senses' which we have been able to share with school, childminder, and grandparents and extracurricular activities (e.g Beaver scouts) which has made a huge difference to adult's understanding of our sons needs.

Therapies - Conclusion and Next Steps

One of our primary concerns is the significant proportion of parent/carers who are reporting that they do not feel their child/young person is receiving sufficient support from NHS therapy services to meet the needs of their child/young person or that they are discharged without receiving the support they need. These are also cited as main reasons that families engage the services of private practitioners (not always successfully), along with long waiting lists for NHS therapy assessments and/or provision - which results in the chance for early intervention and support being significantly delayed.

It is extremely concerning that parents and carers have reported that the therapy provision in their child/young person's EHCP is not being delivered, either by the provider or the education setting they attend. From the comments we received it is clear that this also includes where the therapy provision has been delegated to special schools to support children and young people with, perhaps, the most complex needs. Where there are recruitment and retention issues within the special schools therapy teams, a high proportion of children attending those special schools will, therefore, be affected and not receiving the provision they need at the time they need it.

Even fewer parent/carers of children and young people who receive targeted SEND Support through One Plans, believe that they receive all the provision in their plans, including therapy provision.

We have concerns that these particular issues could impact the successful implementation of the Balanced System approach to therapy provision.

Chapter 2 of the NHS Long Term Plan focusses on prevention and health inequalities. One of the key principles of the SEND Code of Practice is the early identification of children and young people's needs and early intervention to support them. If children and young people are not receiving the right support at the right time (ie early intervention) this makes the likelihood of reaching the goals set out in both sets of guidance -unachievable. More importantly, it will negatively impact the long-term outcomes for children and young people in Essex.

There is clearly a need for improved communication with parents and carers about their child/young person's therapy needs and provision. For example; some therapy provision is being delivered through an online provider service, or via instructional videos. For some families, this works well; however, for others it does not. This is where effective channels of communication are imperative to ensure that the way that therapy provision is offered is suitable for the individual children/young people it is meant to support.

Next Steps:

We will be sharing our findings with senior leaders throughout Essex County Council and within the Integrated Care Boards (ICBs) and their providers via the Therapies Delivery Partnership. This partnership is responsible for the delivery of the Children's Therapies Transformation Programme (including the implementation of the Balance System approach to therapy provision). We feel this is the most appropriate channel for discussions to take place to address the issues raised by families in our survey.