Essex Family Forum

Family Impact Survey 2023

Full Report

Date of Report: 23rd May 2023

Survey conducted:

1st February 2023 – 12th March 2023

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Introduction

This is our third Annual Family Impact Survey. Our previous surveys were conducted in October 2020 and February 2022. The results of our previous surveys can be found on our website, alongside the responses from Essex County Council and Health partners.

We have expanded the scope of this Annual Survey each year by adding additional questions and sections. We have based these on the most prevalent feedback we have received from families through our virtual Graffiti Wall and our Family Champion network.

The primary aim of our first Family Impact Survey was to provide some baseline data on parent/carer experience in Essex based on the Areas of Weakness identified in the OFSTED/CQC Local Area SEND Inspection of 2019. The OFSTED/CQC Inspectors' revisit in May 2022 deemed that the local area had made sufficient progress. You can read our response to the result of the revisit here.

The aim of our survey now is to compare the data from the responses this year to those received in the two previous surveys, as well as present the data for the new sections. This enables us, and the wider system, to measure where there has been any impact of the SEND improvement work that is being undertaken across Essex. It also highlights where families' experiences are still challenging and the issues that, therefore, need more focus systemwide.

Methodology

- Survey period: 1st February 2023 to 12th March 2023
- 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.
- The survey was promoted via Essex Family Forum social media, our Family Champion Network, connected support groups and through MailChimp to our members. We also circulated to our various contacts at Essex County Council and the Clinical Commissioning Groups for onward circulation via their communication channels. This year we collected data from the same link, rather than separate links for our members and wider circulation.
- There are a number of sections where we repeated the same questions as in our previous surveys in order that we could accurately compare the data year on year.
- We were able to filter the data for various sections in our survey. For the purposes of this report, we have "time-stamped" some of the experiences reported by families. These are mainly in regard to the Education Health and Care plan process (including Annual Reviews) and referral pathway for Neurodiverse conditions. This is to ensure we are reporting on the **current** experiences of families and not reporting on historical experience.
- New Sections added for 2023:
    - Pre-School Children
    - Social Care
    - Mental Health Support
- Sections that were renamed and significantly amended:
    - Home Education, Education Other than At School and/or Unable to Attend School (previously, Home Education)

Number of Participants

There were 932 participants who started our survey.

We used one link for the survey this year. However, that has meant that we have been unable to track where participants received details of the link for the survey.

9 participants did not consent for their anonymized responses to be used and shared. These participants were not directed to the survey itself, but a separate page which explained how data would be anonymized in more detail. They were invited to contact our "your voice" email with feedback if they still did not wish to participate.

Therefore, there were **923** valid entries.

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 that answered that particular question.

There was a significant increase in the number of participants this year. We received 638 valid entries to our 2020 survey and 517 valid entries for 2022.

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 static.

There are slight differences in the gender and ethnicity responses, but predominantly the responses are in relation to white, male children.

There is little change in the percentages of the age range of children/young people.

Parents – 96%

Male child
64% (-3%)

Age of Child
Primary - 48% (+2%)
Secondary - 33% (+1%)

Ethnicity
White British **- 89%**
(-5% 2022 survey,
= 2020 survey)

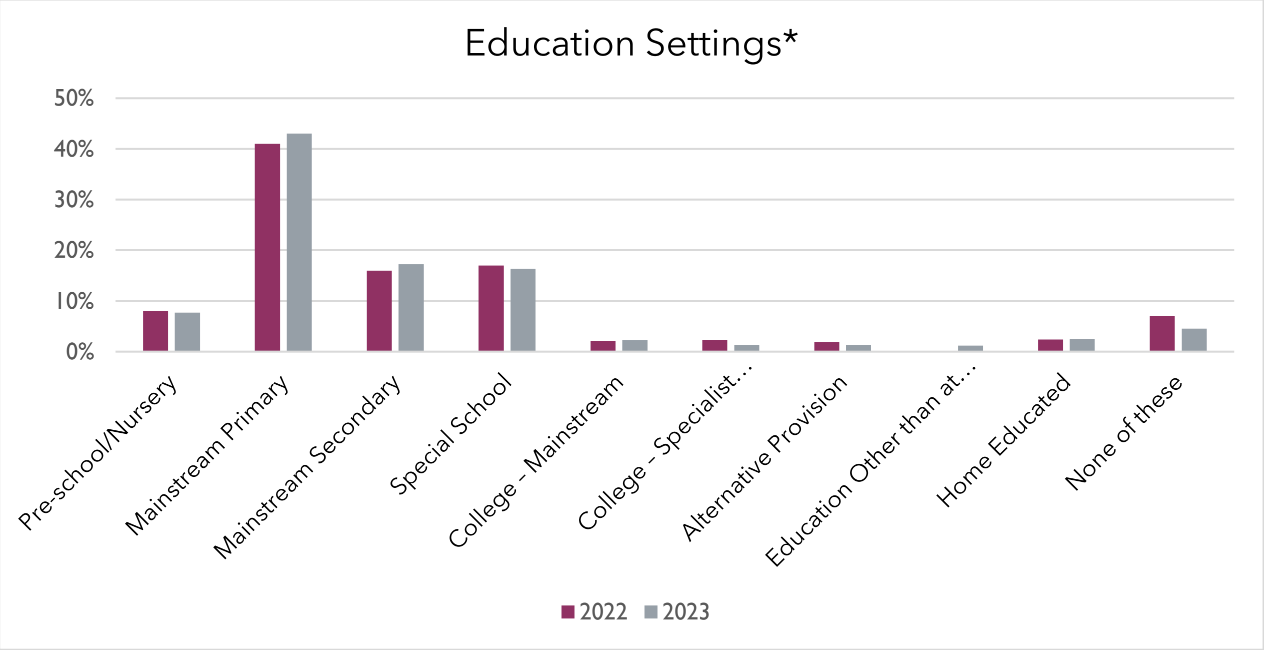
Responses by Area

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
Estimated % of overall population*	20%	26%	31%	23%
Local Council	Harlow, Epping, Uttlesford	Chelmsford, Maldon, Braintree	Basildon, Brentwood, Rochford	Colchester, Tendring
% of survey respondents per area	**15%**	**32%**	**32%**	**20%**
% difference with 2022 survey	(+4%)	(+2%)	(-8%)	(+5%)

*Essex Joint Strategic Needs Assessment 2019

Education Settings



**There was one additional category added this year, Education Other than At School, 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*

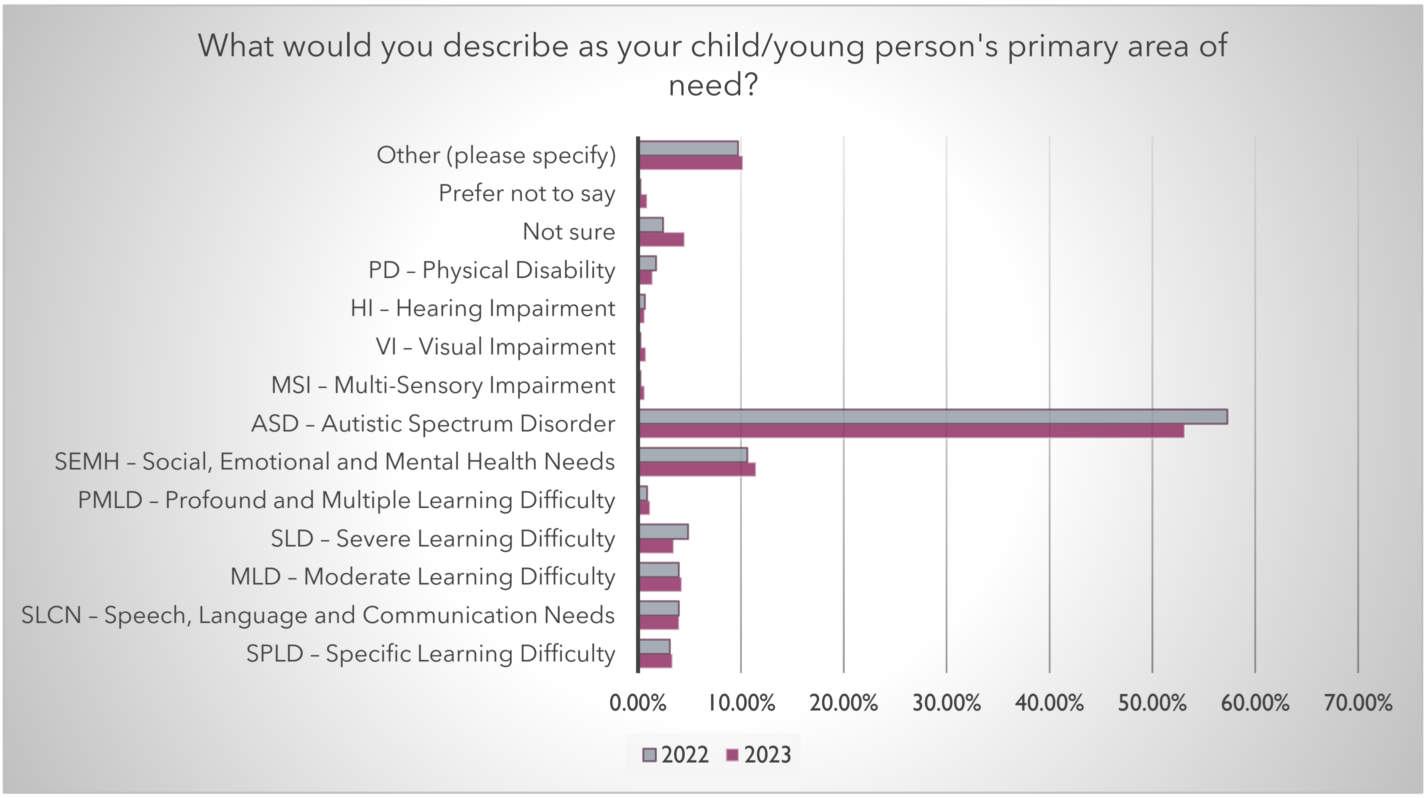
**The proportion of parent/carers who home educate through no other option is 3 times higher than those that do so as a lifestyle choice.*

- Settings where the total was under 2% were:
  - Specialist hub – Primary
  - Specialist hub – Secondary
  - Virtual School

  - 5 young people are in employment, but none were stated as studying at University

- The percentage of participants whose child/young person was not in school, employment or training has slightly reduced.
- The biggest proportion of those are compulsory age children, either on roll at a mainstream school or special school but not able to attend, waiting a placement or there is no suitable placement.
- The next biggest proportion were young people unable to access Post 16 provision, training or employment.

Identification of Need



As in previous years the category of need reflects the options available to schools on the School Census returns.

These responses reflect the **parent/carer** opinion of their child/young person's primary need as 67% of participants are unaware of the school census entry for their child/young person.

There was only one significant change between the data for 2022 and 2023. The number who state they are unsure of their child/young person's primary need has doubled. This is a small proportion overall.

The majority of those participants who selected 'Other' have stated that their child/young person's needs are complex and difficult to identify just one as a **primary need**. The second highest responses in this category indicated ADHD as a primary need.

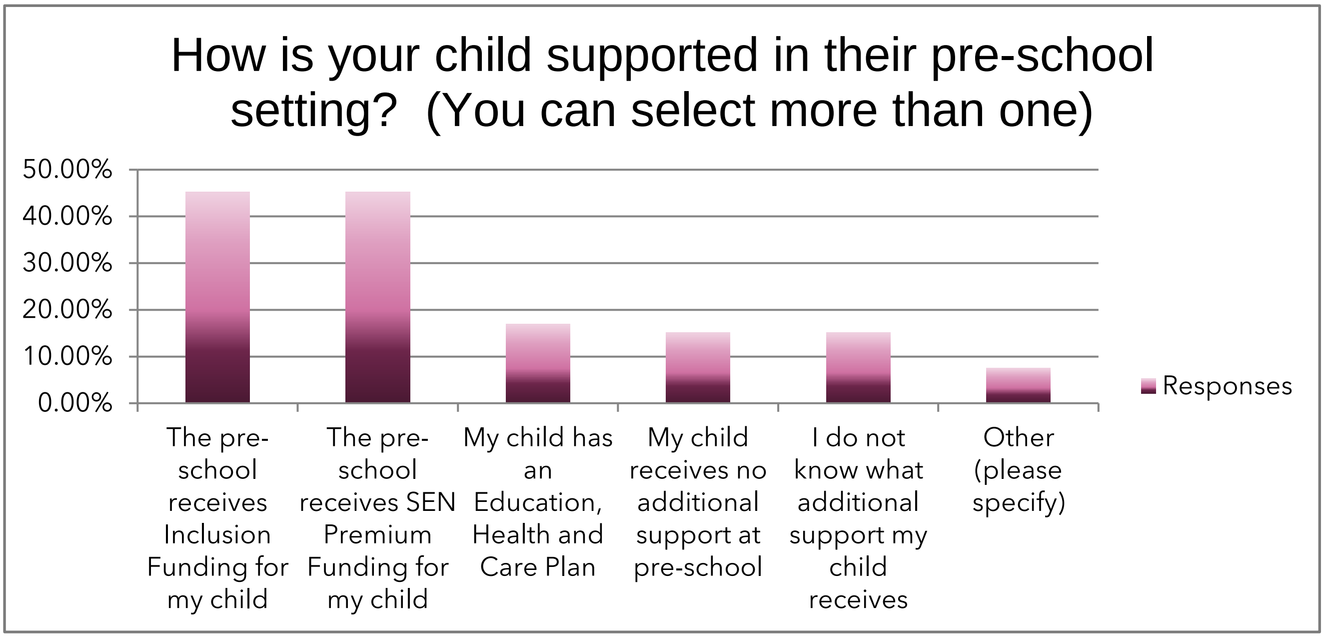
Who raises the initial concerns and who families talk to:

Respondents were allowed to select more than one option, but in the vast majority of cases (77%) parent/carers raised the initial concerns regarding their child/young's development/progress. Pre-Schools, Health visitors, Class Teachers as well as Family and Friends also raise the initial discussions.

Parent/carers initially speak to their Health Visitor in 29% of cases.

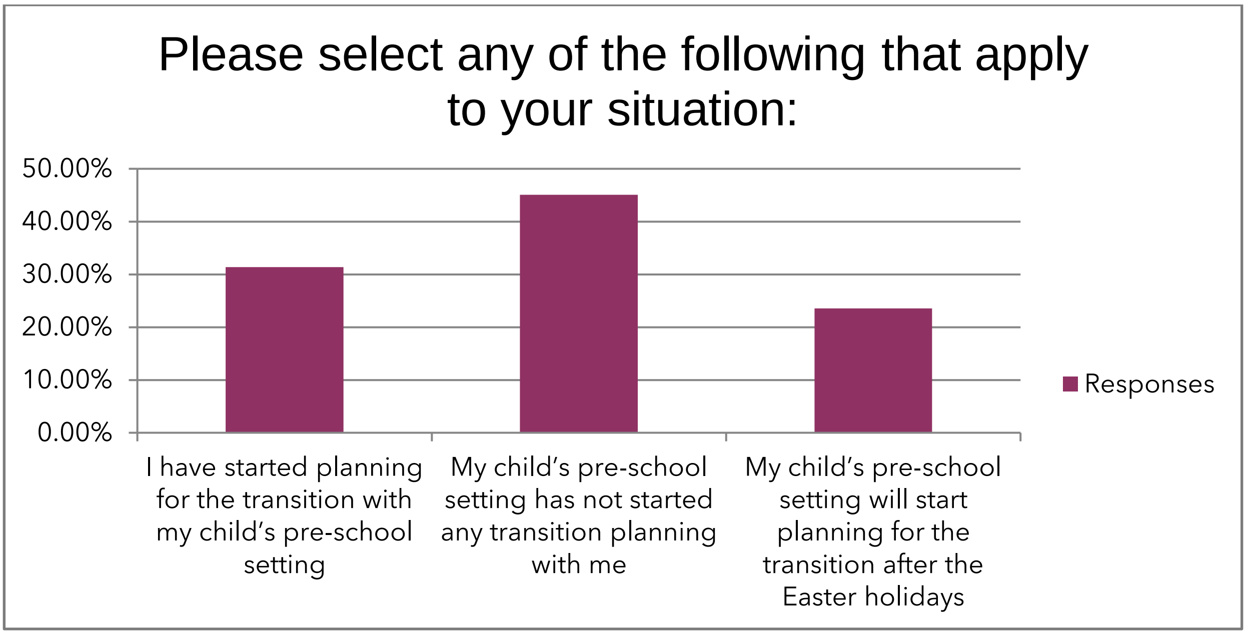
Pre-School Age Children

This was a new section added this year so there is no previous comparable data and represents less than 10% of all respondents. One of the main areas of feedback we receive through our networks is around access to additional funding for Pre-school settings. We wanted to understand the level of support and funding that parent/carers feel their child/young person receives in their Pre-school setting.



68% of respondents state their child will be starting school in September 2023.

We asked parent/carers about the transition planning arrangements with their Pre-school setting. More than half of settings have already started transition planning or will do so in the Summer term.



Statutory Processes – Education Health and Care Plan (EHCP) Needs Assessments

Participants requesting a Needs Assessment

59% have made a Needs Assessment request

63% did so as a mutual decision with education setting

Reasons Needs Assessments not requested

These were at similar levels to previous years.

16%
well supported at SEN Support

15%
gathering evidence to apply

19%
Other reasons*

26%
discouraged to apply by setting

22%
No knowledge of EHCPs or Unsure of Process

*We had 89 comments given for 'other reasons'. These were a mixture of the message being given by schools to not apply (for various reasons such as not having a diagnosis), and that parent/carers felt that their child/young person's needs should be able to be met at SEN Support or with reasonable adjustments. However, the tone of a number of comments implied that needs are not actually being met at universal and targeted levels.

> Trying to get school to meet needs under ordinarily available. This is not proving hugely successful so may need to move to requesting EHC so we can get a more detailed identification of the help he needs

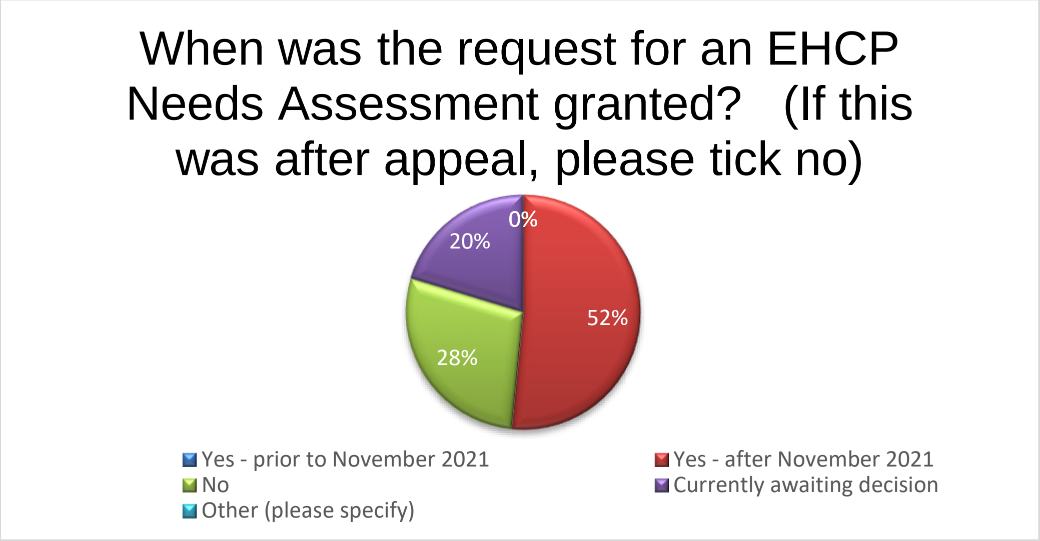
> Not a lot of understanding, spoke to school and they advise against as she doesn't qualify

> My son SHOULD have been well supported on SEN Support or, more accurately, with reasonable adjustments!

Statutory Processes – Education Health and Care Plan (EHCP)

Needs Assessments (continued)

The remaining questions in this section relate to Needs Assessments requested after November 2021. This is so we are capturing the **current** experience for families and can compare with previous years.



Refusal to Assess

The percentage of Needs Assessments that were refused has increased by 8%, and those waiting for a decision has increased by 7%.

The two main reasons for Refusal to Assess remains to be:

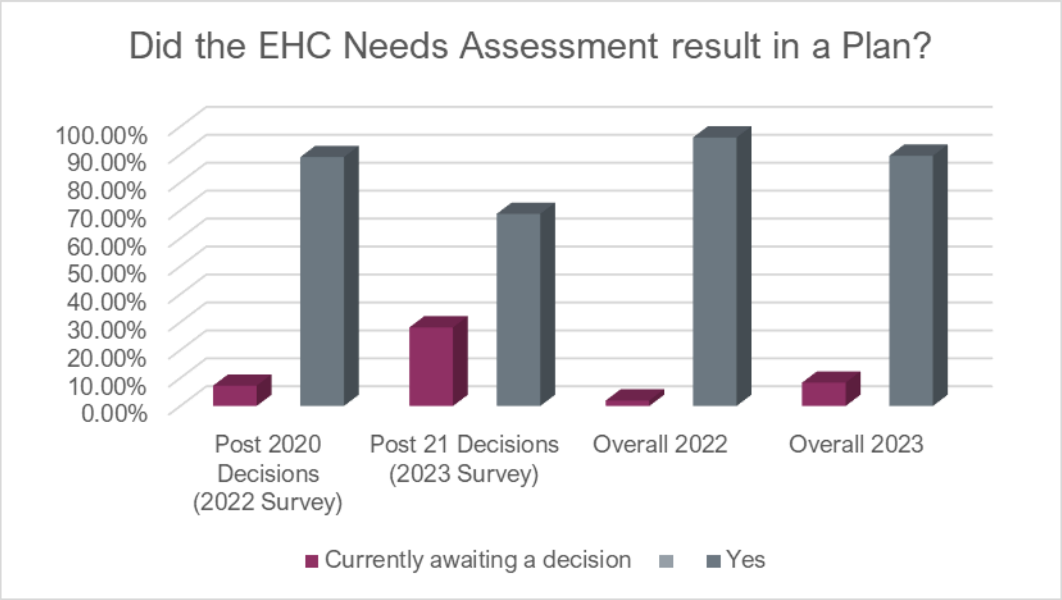
- Needs can be met at SEN Support/One Planning
- Insufficient evidence/reports received. Some comments received indicated that evidence and reports were sent, but not considered by SEND Operations team.

There was a slight increase in the number of families that are offered a Way Forward meeting following a refusal to assess decision. However, it still means that nearly 60% of families are not. These meetings can be really helpful for families to understand why the local authority reached this decision. It's an opportunity for everyone (family, school and the LA) to discuss what additional support can be put in place without the need for an EHC Plan and, perhaps, avoiding the stressful outcome of a formal appeal to the SEND Tribunal.

Statutory Process – Decision to issue an Education Health and Care Plan (EHCP)

As stated at the beginning of this section (Statutory Process) we have been able to filter our data to show families' experiences of the decision making process since 2021. In our survey last year, we could filter the data in the same way, but excluded decisions made prior to 2020, when the new process for Needs Assessments was implemented by Essex County Council.

In this year's survey, there is a large increase in the number of families still waiting for a decision on whether to issue a Plan, from just 7% to 28%. There were 29 comments relating to delays and lack of resource/capacity within ECC SEND teams, with several citing delays in obtaining Educational Psychologist advice.

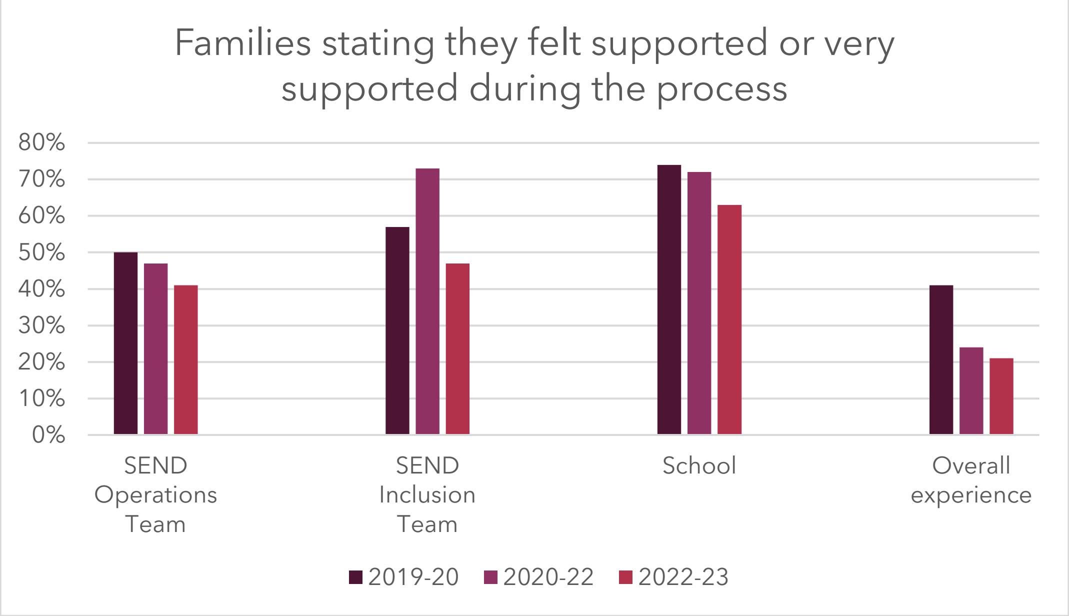


65% of families say they were offered an Outcomes meeting. This would suggest that a significant minority – 35% - were not offered one. However, in the comments section, some families indicated they were offered an Outcomes meeting but decided not to accept. We may change this question next year to include the option of 'Offered but declined' to give a more accurate picture.

There were some participants who stated they found the Outcomes meetings useful but, unfortunately, their child/young person's education setting has not implemented the support that was agreed.

Statutory Process – Support received

Since our first survey was conducted in 2020, there does appear to be a downward trend overall in how supported families are feeling by all teams involved in the Statutory EHCP Process. Given the comments mentioning delays in obtaining EP advice, perhaps it is unsurprising that there is a corresponding, significant, reduction in how supported families feel by the Inclusion team.



Following a larger drop last year, the downward trend for overall experience also continued with the majority of families **(79%)** stating their overall experience of the process is just OK or Poor.

Overall, there were 239 comments to this section, with 102 relating to Post 2021 experiences, with only 4 positive comments.

The comments section highlights the many reasons why families find the EHCP process so challenging. Families feel they are going through a process they really don't understand and don't feel they are given the tools to access the right information and support. They are also extremely frustrated by the delays and lack of communication with the ECC SEND teams.

Statutory Process - Support received (continued)

every single element. support guidance communication timeframes and especially the cost cutting impacting them to delay at every turn and at the cost of a vulnerable childs emotional mental and physical wellbeing . legal timeframes MUST be adhered to

If deadlines were met, if useful updates were given rather than "as soon as we can", if SEND Operations ever picked up the phone, if they told us that our case worker had left.

Actually being listened to, rather than being treated as though my child was just a statistic.

Meeting legal timeframes instead of dismissing them saying how busy you are. They're legally binding, not a choice!

Very delayed initially due to EP shortage and now during consultation period.

explanation of what an EHCP really is and how you can also apply yourself and support with how to do so.

More knowledgeable EHC team, rather than feeling we had to read up on everything and be driving the process for the best outcome for our child.

More guidance in what is needed. It's hard to find and no support is given when filling these in

Every aspect of the experience was poor. The entire process was stressful beyond words and still continues to be. The level of service was shocking at every turn and the whole system needs an overhaul

The whole process was a positive one, I was kept informed, listened to and timescales were kept to

Firstly it's a ridiculous system where you child has to fail at the setting to build up evidence. Secondly even when we had "enough" evidence the 20 week timeline was not met for various reasons including lack of EPs. School is generally awful and felt like they were trying to set up their case to exclude him during the process so they could say they couldn't meet his needs.

Statutory Process – Appeals and Tribunals

We only asked about Appeals and Tribunals for two specific circumstances – Refusal to Assess and Refusal to Issue a Plan.

51%

of participants did not appeal the Local Authority's decision (when relevant)

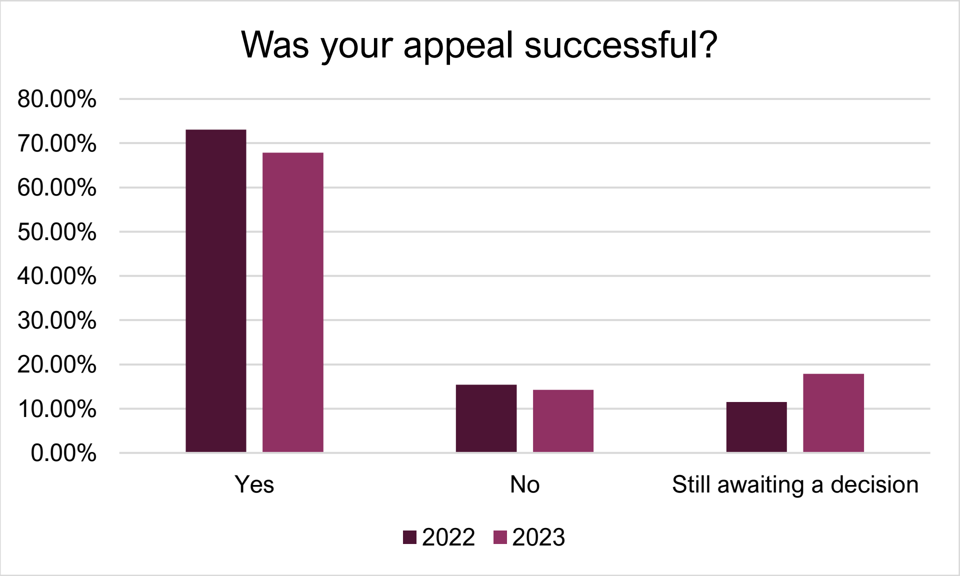
43%

appealed a Refusal to Assess

5%

appealed- Refusal to Issue a Plan

There was a slight reduction in the number of appeals, and a small rise in those awaiting a decision.



There has been no change in the percentage of successful appeals and, based on the comments received, the themes were similar to previous years:

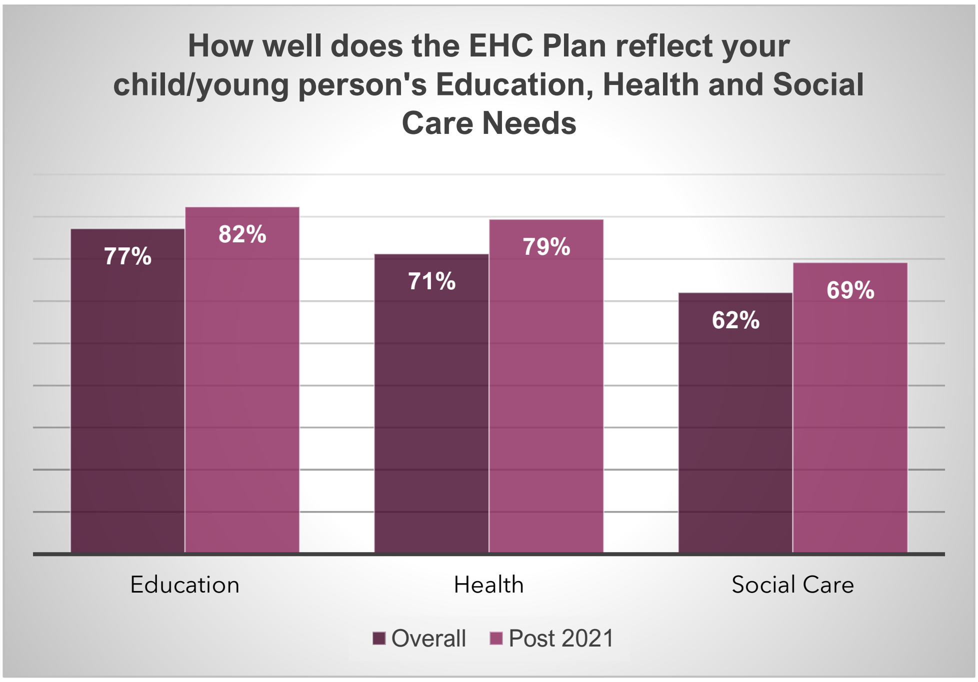
- LA conceding prior to the hearing
- Schools not meeting needs at SEN Support
- Child not in school (waiting placement or unable to attend)
- ECC SEND teams not using documentation sent with original requests for assessments

We received no data for tribunals themselves, although there are comments that referenced Tribunal rulings. Sadly, there were comments where families state they found the appeal process so stressful they are too tired to continue to ‘fight’.

Some of the more worrying comments received were in relation to decisions being based on

- child/young person having no diagnosis;
- academic ability overriding the impact of Social, Emotional and Mental Health needs.

Education, Health and Care Plans - Needs



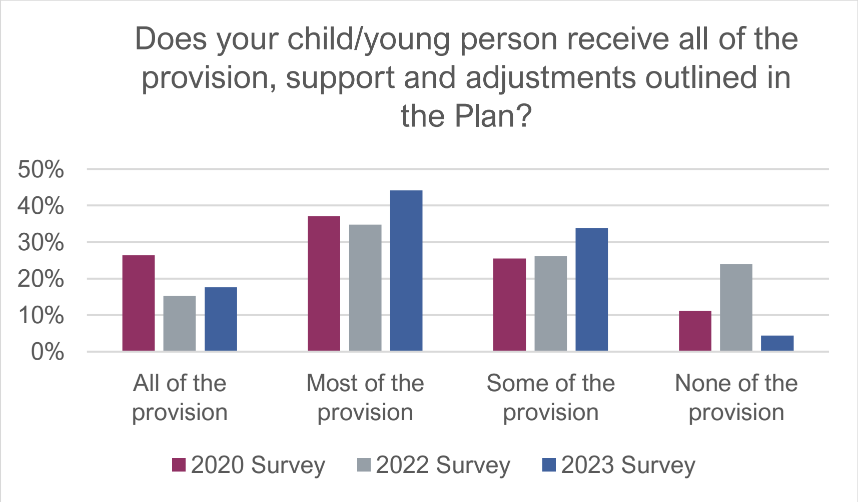
Comparison with 2022 Survey Data (overall):

Education:	+3%
Health:	+18%
Social Care:	+19%

For parent/carers whose child/young person's plan was issued earlier than 2021, one of their main concerns is that plans are not being updated to reflect their child/young person's changing needs.

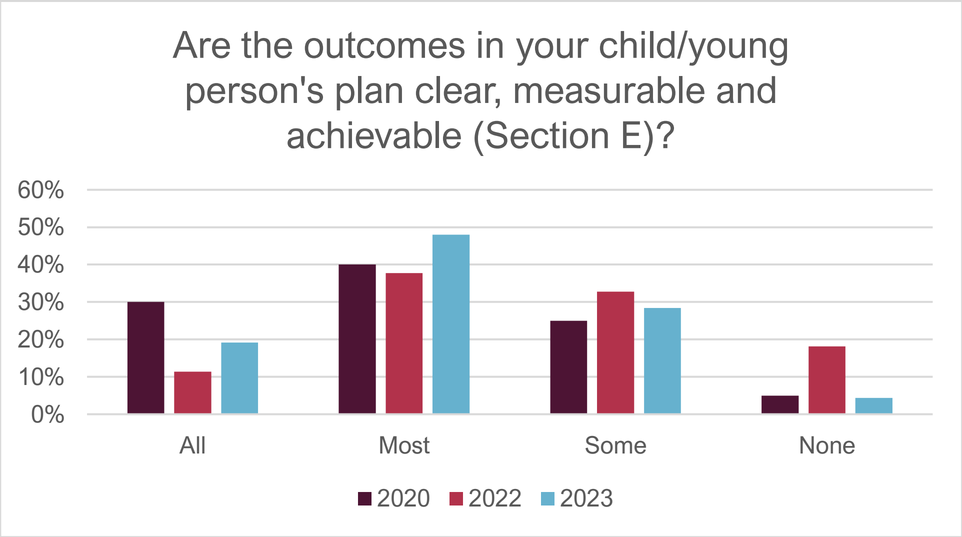
Education, Health and Care Plans - Provision

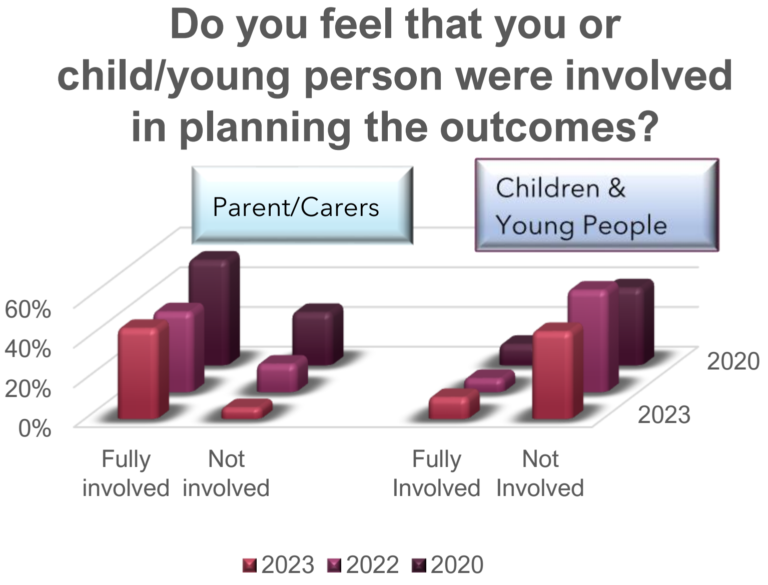
It is pleasing that less parent/carers are reporting their child/young person receives none of their provision and there is a corresponding rise in those that receive all, most or some of the provision outlined in their EHC Plan.



However, despite this improvement, it still means that **82%** of children and young people are not receiving **all** of the provision which they are legally entitled to. The impact on children/young people of provision not being implemented is highlighted throughout the comments we received. Unlike last year, parents and carers of children/young people whose first EHC Plan was issued prior to 2021 are reporting higher levels of confidence that the provision is being delivered, although only 23% report all of the provision is received.

Education Health and Care Plans - Outcomes





There was a marked difference in the comments we received from parent/carers with newly issued plans and those whose plans were issued prior to 2021. The concerns relating to newer plans were focused more on the process for planning outcomes, rather than how well they were written. – which was the main theme from comments on older plans.

Education Health and Care Plans (continued)

I don’t really know much about it all to be honest.

Social care needs are not included and I don’t have the energy to fight

A good EHCP on paper. Though school are not meeting the recommendations and I’ve had to go back and fight them and employ an external teacher privately funded to keep them on plan.

Had to chase up and complain re: inadequate therapy support not being provided, which was then implemented.

Aim higher! E.g. in speech outcomes vs just communicating with PECS/

… very woolly vague descriptors regarding level of provision - eg level of supervision and training of adults eg Makaton

her needs are identified, but schools can be creative about how they meet these and I find I have to keep tabs as things can slip without consistent monitoring

Yes she should of had 8 direct hours of speech last year and has received nothing

My school go above and beyond what is in the plan, I feel the teachers could be supported better

Annual Reviews – Statutory Timescales

We know that parents have been reporting significant delays relating to Annual Review decisions and timescales for amended EHC Plans. We amended some of the questions to this section this year to reflect this feedback. Therefore, we cannot make a direct comparison with last year's data for some questions, but can provide a general overview of how families' experiences compare.

-19%

The number of families who were invited to their child/young person's Annual Review at least 2 weeks prior to the meeting has reduced significantly from 85% to 66%.

This year we asked families whether they received a decision from the Local Authority within 6 weeks of the Annual Review Meeting date. In 2022 the timescale we used was 4 weeks from Annual Review, with 35% of families reporting receiving a decision within those 4 weeks.

25% received a decision within 6 weeks

63% are still awaiting a decision or the decision took longer than 6 weeks

71 comments

- 7 reports of **never** receiving a decision letter following previous Annual Reviews
- Delays range 7.5 weeks to 3 years.

50% of Annual Review decisions did not require any amendments to be made.

8% received a decision to cease the EHC Plan

94% of those parent/carers disagreed with the decision

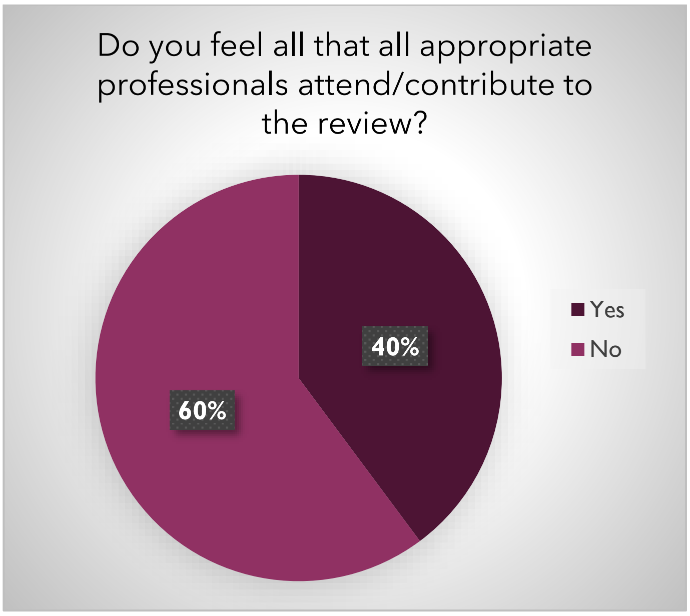
Annual Reviews – Statutory Timescales

Amended Plans:

44% of families report receiving the amended plan within 12 weeks of the Annual Review meeting.

The remaining 56% report waiting from 16.5 weeks to over 12 months for an amended plan.

Annual Reviews – Annual Review Experience



67%

of parents report being fully involved or involved in planning outcomes

22%

Report their child/young person are involved or fully involved

These figures have remained pretty static since 2022 and 2020.

We received 102 comments relating to the Annual Review experience of families, the most predominant themes were delays in response times/issuing amendments, professionals not contributing and poorly conducted Annual Reviews by settings.

Understanding it's relevance. Having the reports sent two weeks prior not the night before. It's a language thing. People take it for granted, but when you're working within the profession you have terms and references layfolk aren't totally comprehending.

Better provision needs to be made for the young person to be directly involved in the decision making

Having the reports sent two weeks prior not the night before.

A response from the LA would be helpful. Also n professionals attended. So it was just me and his teacher/senco.

His annual review has comments from a teacher that left over 1 year ago. Wrong child's name on some of the report. Comments about me that are wrong

Actually do an annual review

Information was not supplied in advance, some professionals involved did not attend. The meeting focused on reviewing the One Plan rather than the EHCP

School excellent but then stalls at SEND Ops with lack of communication. Health are not bought into the EHCP process & do not want to engage in anything out of standard basic care

Home to School SEND Transport

Home to School SEND Transport is always a 'hot topic' and never more than this year. There seems to have been unprecedented driver and Passenger Assistant (PA) shortages and disruptions to journeys for many children and young people. Some of the comments received do reflect the impact of those disruptions.

65% affected by disruptions caused by driver and PA shortages

Questions on Home to School SEND Transport were only open to participants whose child/young person has an Education, Health and Care Plan. Again, the majority of families are not in receipt of transport and, of those, 69% say they do not need transport.

A small proportion of participants said that their child/young person no longer needed transport or that they now travel independently. Only 5% said they applied and were told they were not eligible. Approximately 1/5th stated they did not apply as they had **already** been told they were not eligible, which is similar to 2022.

21% did not apply for SEND Transport as they had already been told they were not eligible

The main reasons participants were not eligible for transport were:

- It was not the nearest suitable school
- Family live within statutory walking distance

The children/young people of the families who were told they were not eligible for transport before applying attended mainstream schools or colleges. One family mentioned their two nearest schools said they could not meet their child's needs and would not agree to be named on the EHCP. There were two comments regarding being asked to sign a disclaimer. With regard to walking distance, comments indicate that parent/carers do not feel there is any consideration given to whether their child can walk safely to school, or even the route with a wheelchair. One family believed they were not eligible because their young person is 16 and there were two comments about not knowing how to apply.

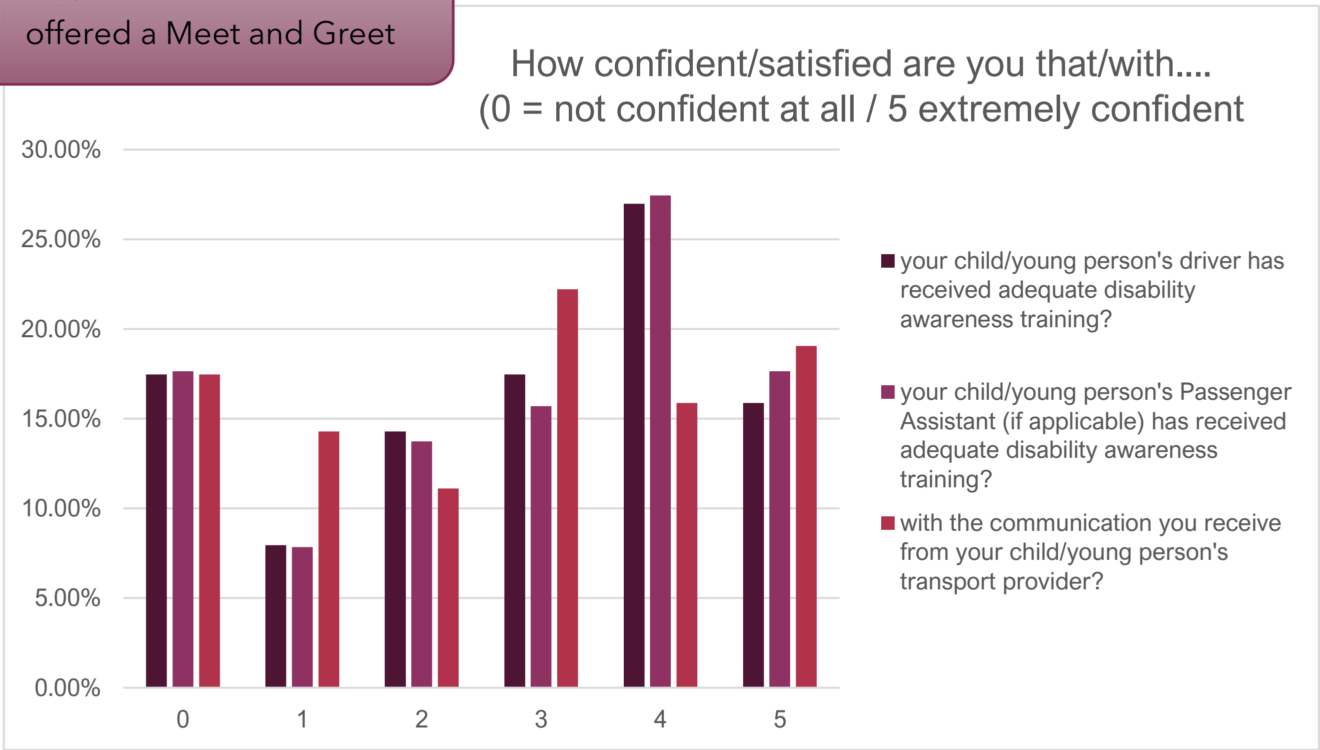
Methods of Travel:
81% - Shared vehicle
10% - Personal Tax
9% Mileage Allowance

I have to push my child in a special needs wheelchair for 45 mins to get to school as they cannot walk that far a distance. Because it is only a short distance as the crow flies we are not eligible for transport so the office staff have said.

I applied because my daughter struggles so much with walking to school! Although she doesn't have a physical disability she does have adhd,autism, anxiety and spd. It's not safe walking to school when she's having a meltdown. Even though it's only a 30mins walk it actually takes her 45 mins most days and on bad days it's taken us 2 hours where she's having a meltdown and running of into and near roads

There were similar levels of confidence with the disability awareness training for drivers and PAs with 2022. The satisfaction with the communication with the transport provider also remained fairly static. A number of parents mentioned the positive relationships with individual drivers and PAs but highlighted the difficulties that the frequent changes and journey disruptions have had.

48% of families were not offered a Meet and Greet



We received 75 comments regarding transport.

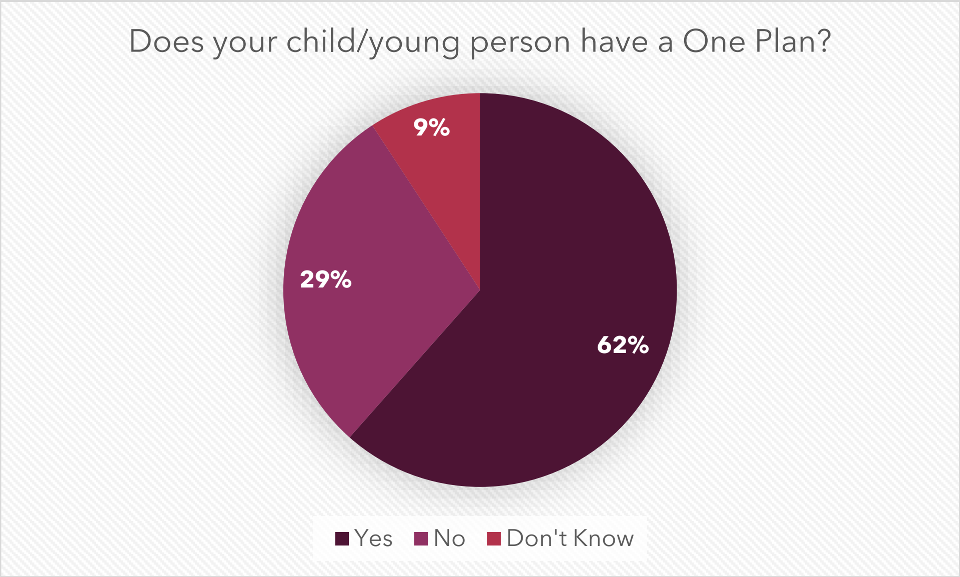
Absolutely fantastic driver and chaperone

Shocking, 5 different drivers since September this year

Drivers and PA'S don't seem to last any longer than 4 or 5mths. Routes are frequently changed and that worries the kids. …… Drivers and Pa's are all lovely, just wish the admin side was more helpful and organised.

The transport has been very hit and miss over the years. We have had many different drivers and PA's. This are changed at a moments notice, routes are changed and pupils on the bus are frequently different. This can cause distress and upset to the child and can really unsettle them.

SEN Support / One Planning



2022 – 66% had a one Plan / 24% did not / 10% unsure

Children and Young People with EHC Plans

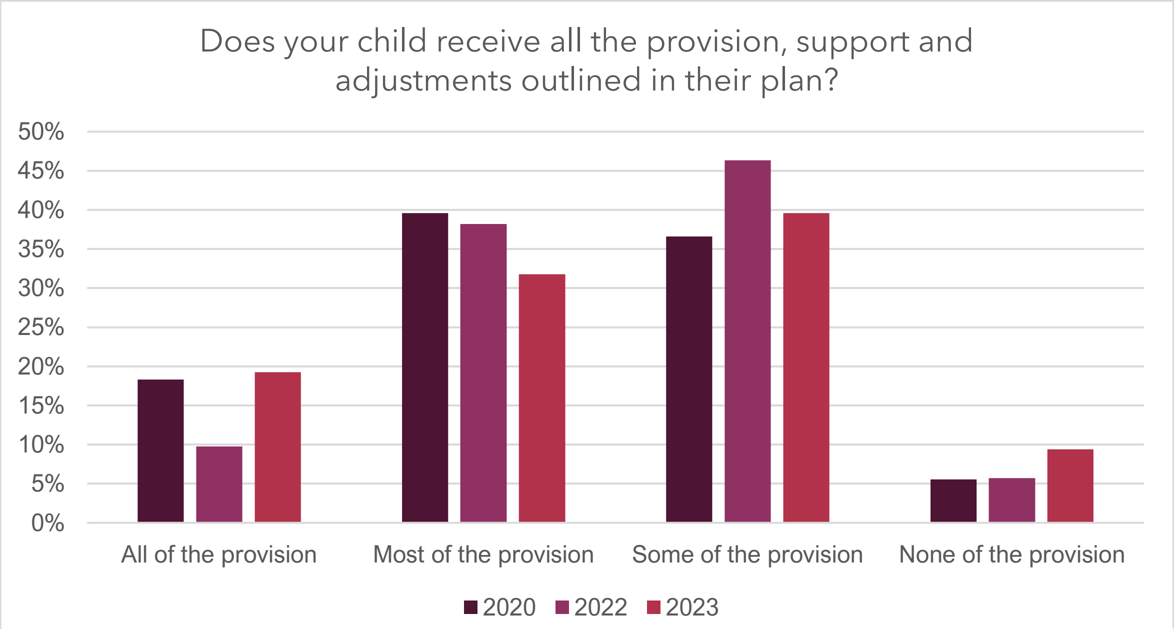
58% (-5%)
also have a One Plan
of those
30%
are only reviewed annually

17% (-7%)
are unsure whether their child/young person also has a One Plan

Question	**Response**	**Difference (%)** **2022**
One Plan accurately reflects child/young person's needs	**62%**	+7%
Understand well/very well the provision, support and adjustments described in the plan	**73%**	+1%
All or most outcomes are clear, measurable and achievable	53%	+4%
I/We were involved/fully involved in planning the outcomes^	**57%**	+1%
My child/young person was involved/full involved in planning their outcomes	**32%**	+10%
My child/young person's plan is reviewed termly	**58%**	-1%
No advice/contribution is sought, or I do not know whether advice contribution is sought from health care professionals involved#	**74%**	+6%

^10% lower than in 2020.

#overall increase of 15% since 2020.



There were 15 positive comments and some of these gave examples of best practice being adopted by the individual schools.

217
Comments
(+44%)

Main themes arising from Comments

Settings not working co-productively with parent/carers

Child/Young Person's Needs not being met or acknowledged by Settings

Poor One Planning practice, Plans not being followed or the agreed provision being put in place

Lack of knowledge/training by setting staff

Lack of information and support for families

Lack of capacity and resources within setting

My child receives no sen support as no matter how hard I try they will not acknowledge mental health is a sen need so now child is unable to attend school

Very much driven by what school see and deem appropriate. Often agreed upon strategies are changed with little to no warning and before being given a chance to work.

Listen to parents and take the whole picture into consideration

Only been introduced recently but has been a positive and helpful tool

Schools not demanding diagnosis of a 'condition' before engaging in One Planning

Daughter is really struggling and the school don't seem to be doing enough due to lack of funding and too many sen children in her class

We wasnt involved in the set up of a one plan, we were shown it on parents evening, i hadn't realised there was one in place, or when it was initially set up, or explained about it before hand.

Initially I was told what the One Plan was (in nursery) I did not appreciate that it would continue to primary school I thought it was something the nursery was doing to be proactive. I wasn't aware of what a "good" One Plan should look like and the involvement I (as a parent) could have in it.

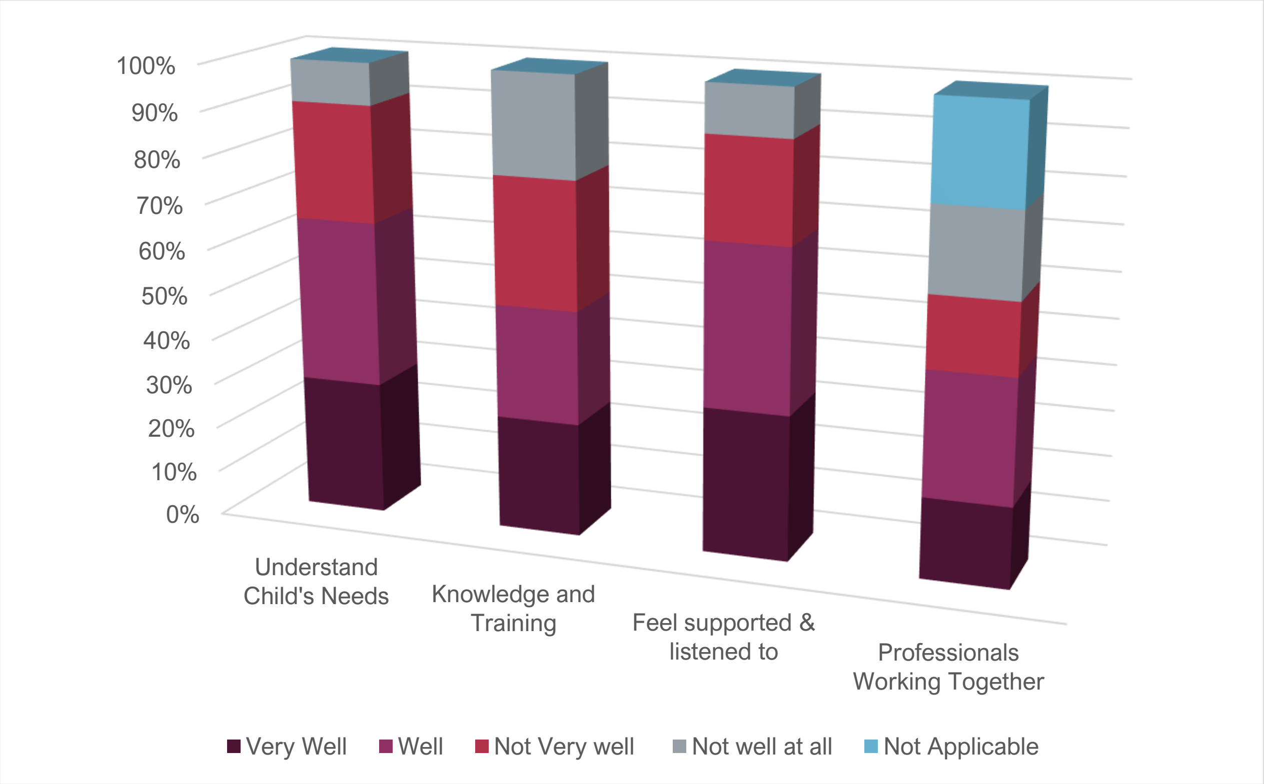
The school have been fabulous and we have worked collaboratively to share experiences, knowledge and ideas of how to support our child

Communication and Support with Educational Settings

There was very little difference in the figures between the current survey and 2022. The majority of parents and carers feel their child/young person's setting have a good understanding of their child's needs and they feel supported and listened to. However, for a third of families this is not the case.

Approximately half of the parents and carers responding are confident in the knowledge and training of the staff in their child/young person's setting but that does mean the reverse for the remaining half.

For one fifth of children and young people there were no other professionals involved with their child or young person who has special educational needs.



Communication and Support with Educational Settings (continued)

We received 138 comments regarding communication and support with education settings.
The four themes that occurred most frequently were, in order:

- Lack of communication with and poor working together between settings and parents and carers
- Training needs of setting staff
- Professionals and settings not working well together and/or communicating well
- Positive relationships between parent/carers and settings

There were also a number of comments relating to:

- Settings not implementing professionals' recommendations
- Lack of staff / funding to deliver provision
- Poor communication between staff **within** the settings themselves

We have excellent communication, I'm very happy with my setting

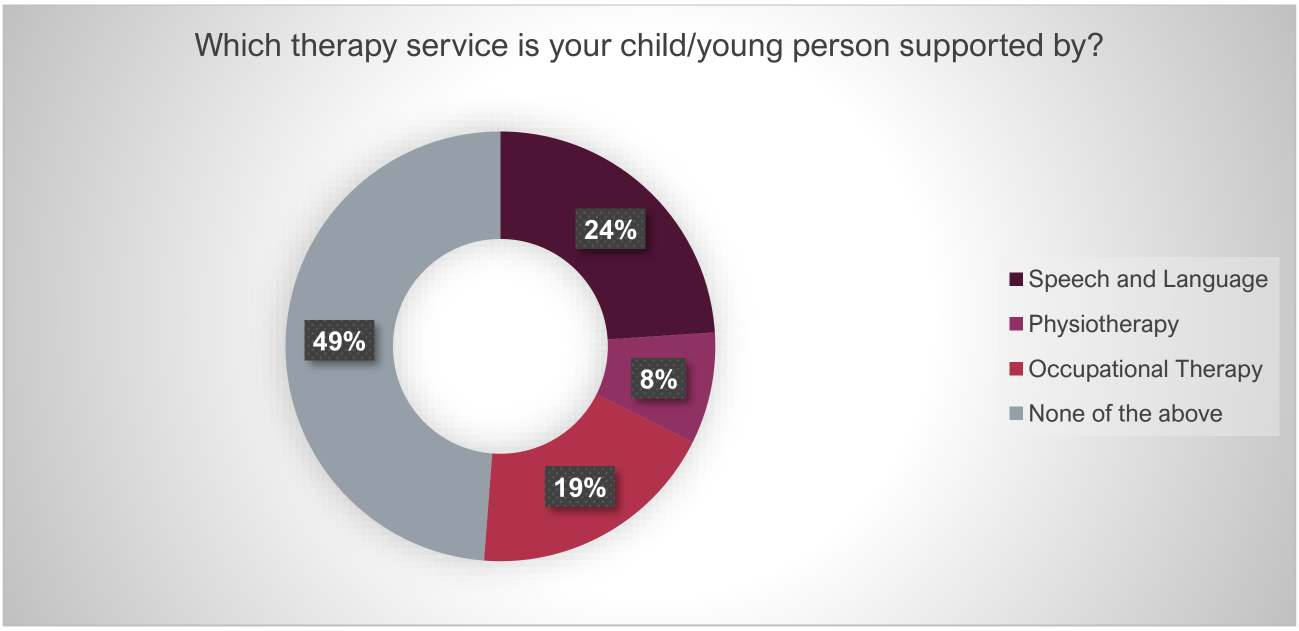
The school is great but therapists aren't communicating with them

Since September there has been talk about setting up a official plan in place. This has been happened. There was talk about sensory and brain breaks. However as there are no supporting staff in the year, there is no one to carry this out with my son.

Reading the reports that are sent by specialists. Regular meetings with senco and class teacher

Empathy, listening skills, more skilled staff, termly one plans, where staff don't make out as if the parent is the issue, willingness to work in partnership, understanding that the parent is the expert on the child - especially when the child masks their needs.

Therapy Services



2022 Survey

Therapy Services support:

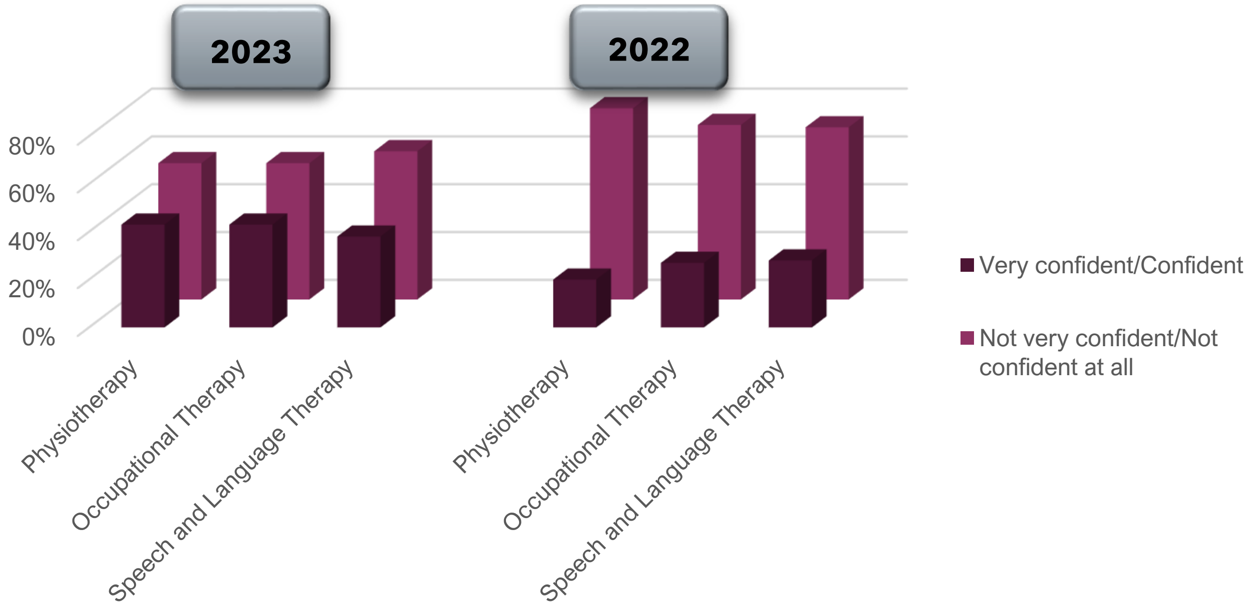
Speech & Language	**31%**
Physiotherapy	**10%**
Occupational Therapy	**26%**

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.

18% of respondents not currently receiving therapy services are on a waiting list, reduced from 30% in 2022.

The number of families, not on a waiting list, that have been discharged from a therapy service remains at 50%.

How confident are you that you receive the right information to support and make informed choices about your child/young person's therapy needs ?



We have been able to exclude the number of families who are not currently receiving any therapy support. This graph shows that families feel more confident overall in supporting their children/young people and more able to make informed choices. This may be explained, in part, due to the increasing likelihood that there are now more face to face/in-person interactions rather than online.

- However, there were 342 comments relating to therapy support (an increase of 56%) and the overwhelming majority were highlighting parental concerns. 39 comments related to Mental Health support/therapy.
- 30 comments were positive. However, 30% of those also highlighted an inconsistency in experiences across the different therapy services. For example, whilst a family might receive positive experience with Occupational Therapy, their experience of Speech & Language may have been less positive. Some comments relayed a feeling that the service had deteriorated so their most recent experiences were less positive.
- Nearly 1/3rd reported they felt the support received from therapy services was insufficient in meeting their child/young person needs.
- 11% of comments related to families paying for private therapy, either due to their lack of confidence in the NHS* therapy offer or not receiving any therapy from NHS services

(including having been discharged). Two comments related to schools stating they did not have funds to continue deliver provision*, so parents needed to pay for a private therapist to deliver provision. _*This also included therapy provision in an EHC Plan._

- Parent/Carers reported their child/young person being discharged without sufficient support being received/delivered in 10% of cases.
- Long waiting lists were also mentioned in 8% of all comments.
- Poor communication between therapy services and families was reported in 9% of cases; especially when therapists were delivering provision in schools.

> Deaf therapist can't hear my son and he couldn't hear her as deaf himself and she always wears a mask so he can't lip read.

> We weren't given occupational therapy, we had to pay privately for it as it was hugely beneficial. The speech therapy was brilliant til he was handed over to core, then it became less reliable. Physio was amazing.

> He sees the school SALT occasionally but i have no idea how frequently.

> Speech therapy was in erratic blocks- they did not provide work to do at home and struggled with my child's attention issues and developmental levels

> OT is only when requested for Review and SALT is virtually non existent and a private therapist employed by family has had to guide the school!!!

> My daughter was discharged from speech therapy as they said there's nothing they can do since she is non-verbal.
>
> Physical therapy has been cut without prior consultation and I am not sure who to turn to, to have this re-instated.

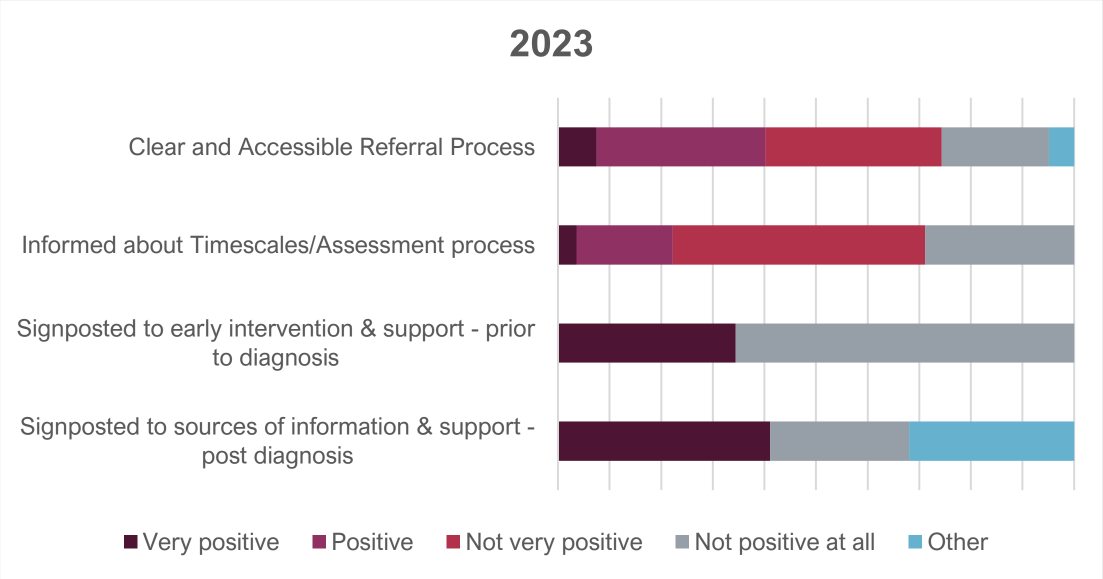
> Excellent OT who treated *{child's name removed}* with respect and helped with her Co-ordination and restricted diet

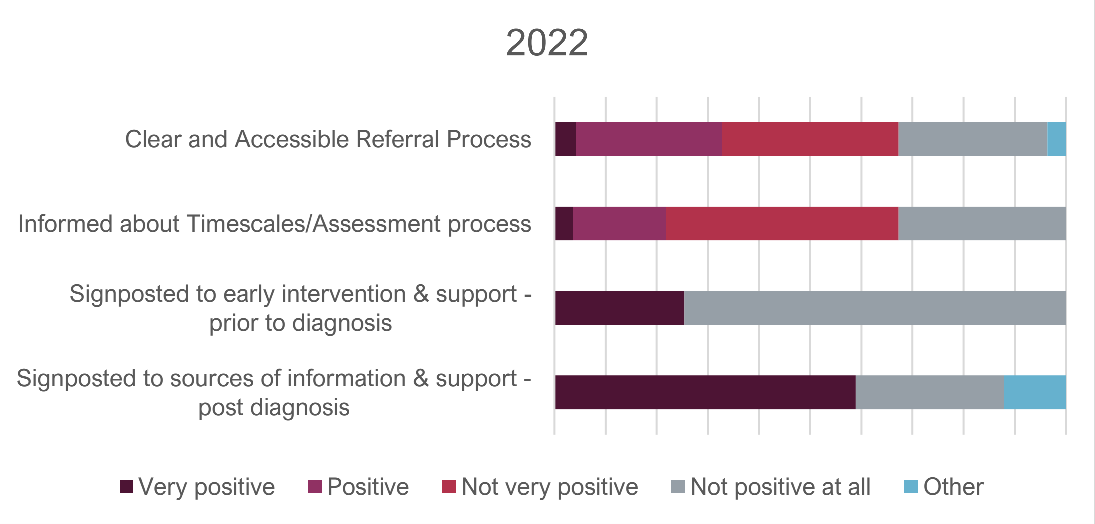
> My son had input from OT plus SALT in school. Both excellent.

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 2020.

Please note that the 2022 data, where shown for comparison purposes, includes children and young people who were referred in 2019.





73% of those referred received a diagnosis

(72% - 2022)

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

We received 190 comments from participants whose child/young person was referred for an assessment of a neurodiverse condition after 2020.

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. (33% of comments)

- A lack of information and support available whilst waiting for assessment. (30%)

- Lack of support and information after receiving their child/young person's diagnosis. (22%)

- Difficulties in the referral process (17%) – which could be further split into the following categories:

    - Lack of understanding in starting the referral process by GPs and settings
    - Completion of questionnaires by settings (resulting in delays & re-referrals being required in some cases)
    - Bouncing around services
    - Administration issues (confusion over when referrals made, accidentally being removed from waiting list, etc)

There were 24 positive comments; the majority of which were in respect of feeling supported by health professionals during the assessment itself. 7 comments related to waiting times for assessment being quicker than expected.

18 families reported seeking a private diagnosis due to the long waiting times.

We were given a diagnosis of ADHD & some leaflets. Then 2 weeks after a diagnosis of ASD & received a report in the post but no further information. We had a phone call a year later to see how things were going. If it wasn't for the fact that I work in this area we would have been left feeling very alone and confused and isolated by the whole experience.

Need more flexible open quieter appointments ie dogs allowed, Saturdays, relaxed masks, less surgery looking place

we had an amazing paediatrician. Covid made a longer waiting list however had a video assessment at Cadu. Felt quite supported all the way through.

We had to wait as pandemic.

We have had a long battle and was taken off list by mistake first of all then told nothing wrong .

Still waiting for other assessment been like running a marathon.

Not for the faint hearted

We have an amazing health visitor and she did lots of referrals and provided support but after that its like your lost in an abyss waiting to hear anything back.

Yes she has autism. Goodbye

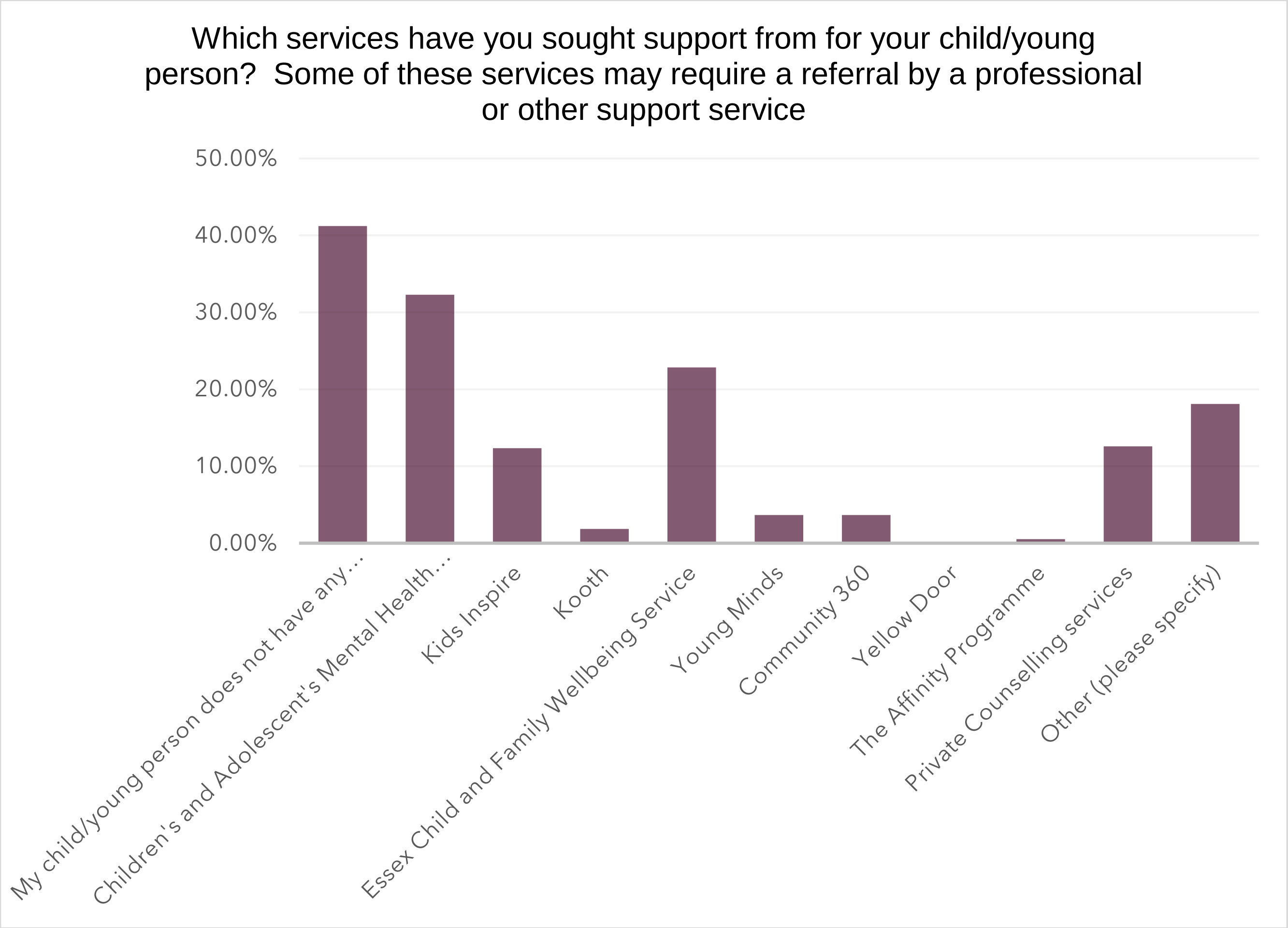
The worry while you wait, am I as a parent doing enough, am I doing everything I should be doing? Is my child suffering as a result? that weighs heavy on me as a parent and the struggles my child faces have a huge impact on him and also the rest of the familiy.

Positive - this time I was given details of resources I could access to support during the waiting process (Supporting your neurodiverse child resource pack) details of support groups. I was told I would be contacted this time to indicate how long I would be waiting...although I haven't been contacted yet and that was 5 months ago

Mental Health Support

This is a new section for 2023 so there is no comparable data with previous years.

Participants who stated their child/young person does not have any mental health support needs, were taken to the next section of the survey. The remaining participants were able to select multiple options for mental health services they have sought support from.


Which services have you sought support from for your child/young person? Some of these services may require a referral by a professional or other support service

What happened after referral?

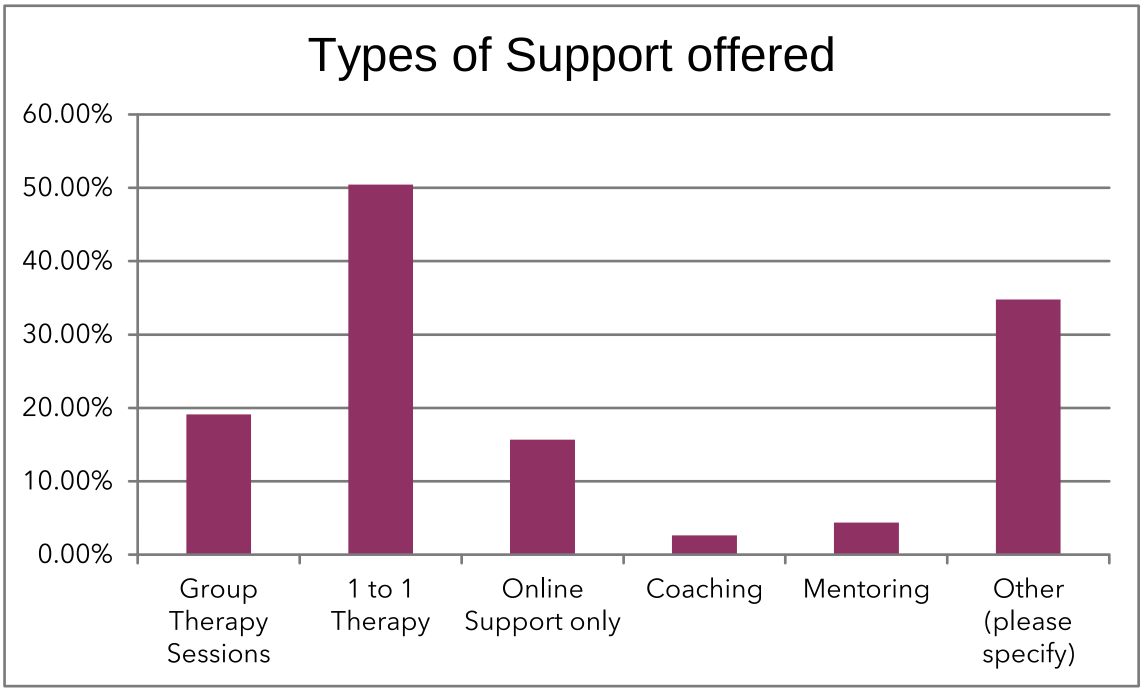
42% did not receive any support

76% were not signposted to other support services

13% are awaiting a decision

Mental Health Support (continued)

45% of families received support from mental health support services



We received 134 individual comments relating to the therapy support received and the impact of the therapy. We received a further 145 comments relating to Mental Health support experiences generally.

Some families told us that the impact of mental health support received led to improvement in their child/young person's mental health and ability to regulate their emotions. Many families felt that the number of sessions offered and delivered were not sufficient to make a lasting difference, with a number of families having to re-refer several times because of mental health decline. The type of therapy offered was not always felt to be suitable for individual children, or parenting courses were offered instead. There were a significant number of comments relating to long delays in accessing support, with children and young people being turned away from more than one service. Parent/carers have turned to private counselling in order to ensure their child/young person receives the mental health support they need. Some therapy services would not provide mental health support where the child/young person was also neurodivergent. A number of respondents mentioned a lack of understanding of neurodivergent conditions. There was one particularly worrying comment, where the therapist is quoted as saying to the child ""well we are all a little bit ASD aren't we".

Dire. Don't have the energy to expand upon that, sorry.

It helped them with self confidence, raised their self esteem and made them feel good.

Home Education, Unable to Attend and Education Other than At School (EOTAS)

This section was previously called Home Education. We have changed the title to be more reflective of the families whose children/young people are not regularly attending an education setting. 85% of respondents to this section indicated that their child/young person is in education, training or education, the remaining 139 respondents answered as follows:

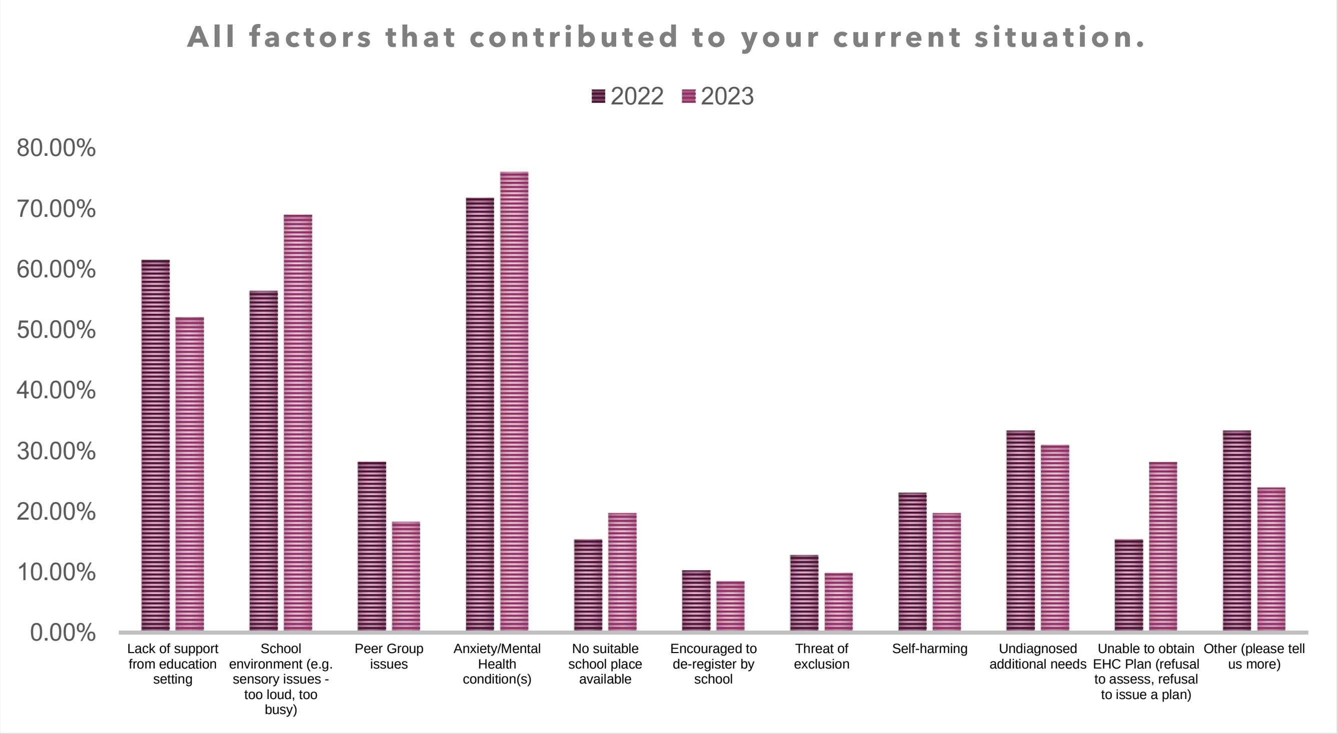
4%	Educated at home as a lifestyle choice
10%	Educated at home after breakdown in education placement
12%	EOTAS arrangement with an EHCP
9%	Unable to attend and there are alternative arrangements in place
21%	Unable to attend and there are **no** alternative arrangements in place
43%	Other**

The themes of the comments in Other**:

- Attending part time
  – a number of those have no provision or work set for the time not in school;
  - several comments not able to access classroom
- Unable to attend regularly / Setting unable to meet needs
- No placement
- Alternative provision taking a long time to implement
- Attending school leading to declining mental health
- Lack of Post 16/Post 19 options (incl. traineeships/apprenticeships) for young people without EHCPs

Home Education, Unable to Attend and Education Other than At School (EOTAS) - continued

We asked families the factors that had contributed to their current situation; this is what they told us (participants were able to select more than one category). The biggest rises were in parent/carers stating the school environment itself is a barrier (a 13% increase) and a 15% increase in participants stating the inability to obtain or be assessed for an EHC Plan is a contributing factor. The themes in the 'Other' comments are mainly concerned with lack of support from the education setting and health needs (both mental and physical).


All factors that contributed to your current situation.

Types of setting children/young people last attended:

38%
Mainstream Primary
(= 2022)

36%
Mainstream Secondary
(-8%)

7%
Special School
(-1%)

6%
Pre-School/ Nursery
(+6%)

6%
Mainstream College
(+1%)

68% are still on roll at their education setting

63% have received no support from statutory services

Home Education, Unable to Attend and Education Other than At School (EOTAS) - continued

Where families did receive support from statutory services there were, in some cases, more than one team involved:

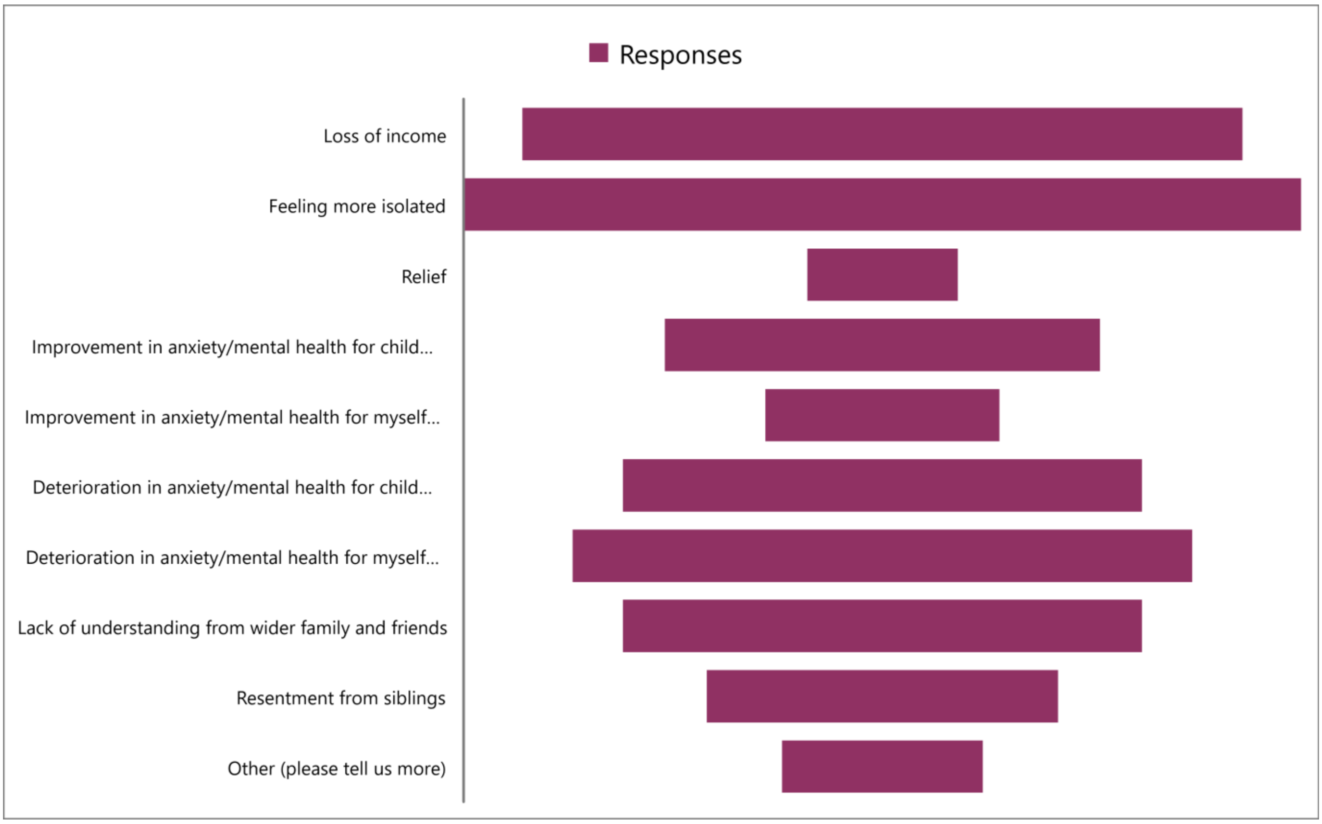
- SEND Operations (13%)
- Engagement Facilitator (8%)
- Team around the Family Support Officer (6%)
- Inclusion Partner (5%)
- Education Access (5%)
- Attendance Specialist (2%)

Providing Medical Evidence

For those families who are asked to provide medical evidence of their child/young person's absence, around half experience difficulty in obtaining written evidence from health professionals or having evidence accepted.

Impact on Family Life

The responses about the impact on family life were, on the whole, more negative to those received last year. This is possibly due to the remit of this section extending beyond those that have taken the decision to home educate their child/young person.



Home Education, Unable to Attend and Education Other than At School (EOTAS) - continued

92% of families state they receive no information or advice about home education from statutory services once their child is no longer attending school.

NB: Size of section reflects proportion of overall responses

Home Education, Unable to Attend and Education Other than At School (EOTAS) - continued

Words can not describe how hard it is. How emotional, how draining. Somedays you have it in you to fight others you don't. I am patronised, not listened to, blamed and been threatened with fines. It impacts everything

Pressure to meet needs with no social care support or respite causing physical conditions to be exacerbated and unable to get well due to lack of support, time to arrange appointments or do admin work

It's hell, trying to negotiate everything and being pushed from pillar to post,

Sometimes anxiety seems better but motivation is low and she is not seeing anybody which increases her anxiety when she does. It's almost like a vicious circle

Very stressful, lack of understanding from school. Advocating for our daughter is very time consuming, I am spending so much time reading legislation and guidelines, etc to make sure I am doing my best for my daughter and it feels like everything is made difficult to make you give up. I have resigned from my job so I can focus on my daughter and family.

Son's MH is better being at home but this is a long journey to get better now

This has been one of the most difficult experiences I have ever been through. It has affected every aspect of my life, my other 2 children's life and my Son's life. ……. It is exhausting and all consuming and it takes away the fun and happiness I should be experiencing whilst bringing up my three children.

Seizures easier to manage and feeding regime

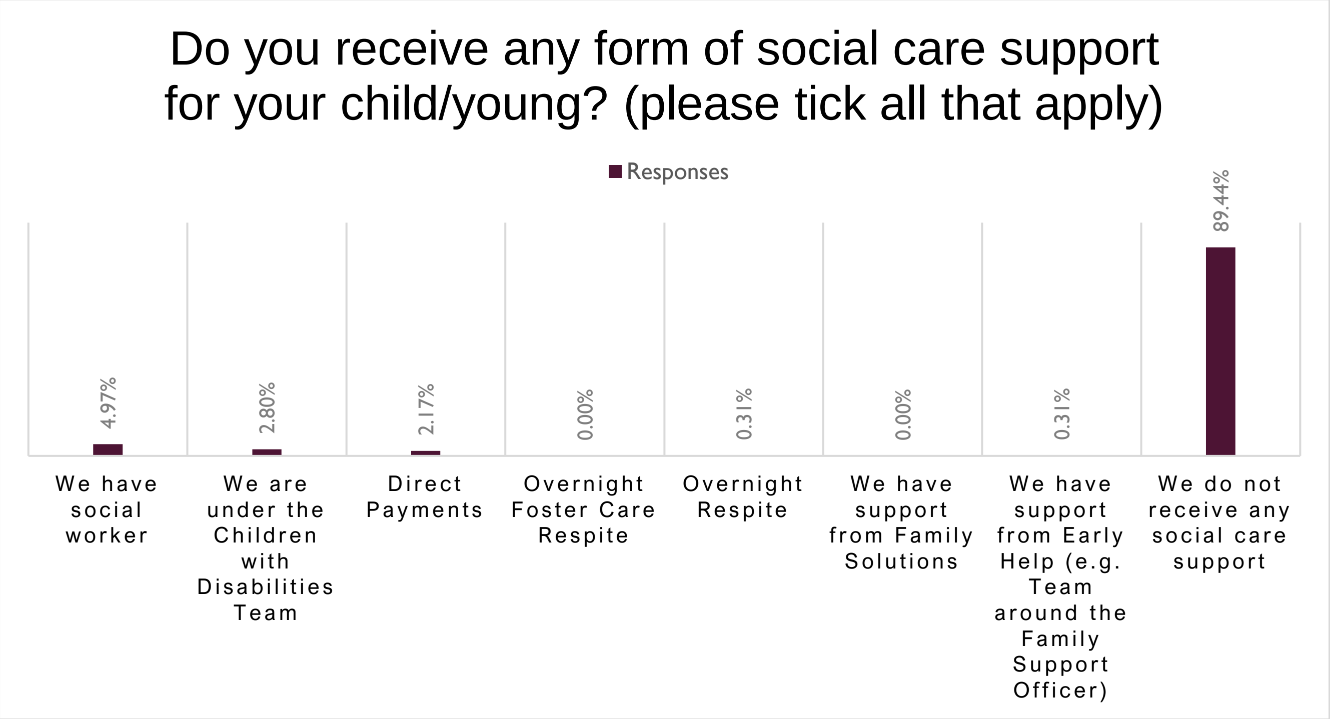
Its just to draining to even begin to explain.

Impact on his self esteem. Frustration that no one will be flexible to support his learning needs.

Having grandson at home with us has limited what we are able to do

Social Care Support

This was a new section added for this year. There are over 11,000 children and young people in Essex with needs sufficiently complex to require an Education Health and Care Plans. The most frequent feedback we receive from parents and carers about Social Care support is around difficulty in accessing social care services beyond the Shortbreaks Clubs and Activities offer.


Do you receive any form of social care support for your child/young? (please tick all that apply)

Of those not in receipt of social care support:

11% applied for social care assessment

28% awaiting an assessment

72% did not meet the critiera for assessment

67% were not informed of the criteria needed for assessment

55% were not signposted to other sources of support

Social Care Support (continued)

For those that were unable to obtain support or waiting for assessment – we asked what type of support they had **hoped** would be available. There were two main reasons that families told us:

- Advice and support with managing challenging behaviour;
- Respite due to their child/young person’s sleep issues and challenging behaviour.

Some families mentioned that they had been in receipt of support for short-term periods only and one family said they had been unaware they had been discharged from the service they had been receiving.

A number of families indicated they wanted advice and support to help with implementing better support strategies at school (suggesting needs are not being met in the education settings).

I'm unaware of the support they offer I'm just hoping for something

Families in receipt of Social Care support

We asked what was working well about the social care support families receive:

- Direct Payments (when managed by family)
- Overnight respite

The things that families told us could be improved were:

- Direct Payment provider/administrator
- Frequency/length of meetings with social workers
- Assessments for equipment (waiting times, planning for future needs)

Sources of Information and Support – Local Offer and SENDIASS

47% of parent/carers who responded to this section were aware of SENDIASS service.

of those **48%** have used the Helpline

of those **68%** found it easy/very easy to contact the Helpline

of those **63%** found the information provided to be useful/very useful

of those **31%** have used the Website

of those **89%** found it easy / very easy to contact the Helpline

of those **73%** found the information provided to be useful/very useful

54% of parent/carers who responded to this section were aware of Local Offer

of those **47%** have used the new Local Offer website

Of those **66%** found it Easy or Very Easy to use

of those **54%** were able to find the information they needed

of those **92%** said the information was up to datae, relevant and useful

We received 79 comments relating to parent/carers' experience of the new Local Offer website.

31 related to parent/carers not finding the site to be particularly user-friendly or easy to navigate.

28 were not specifically about the website, but about accessing support generally and services they need for their child/young person not being available.

There were 20 comments relating to information not being on the Local Offer and included some reflecting that information previously available had been removed since the update.

Other Sources of Information and Support

We asked families who or what are their main sources of support. There was the option to select all that apply These remained largely unchanged, with family and friends being a main support for 50% of respondents. Online/Social media support groups saw a 20% drop in being a main source of support, but are still the third highest category at 40%. This may, in part, be due to parent/carers having more opportunities to meet others in person over the last year than in the previous two years.

14% of parent/carers selected the 'Other' category and were invited to comment. Some of those named organisations or teams would have fallen in one of the categories listed. However, 33% who selected 'Other' said they had no source of support (or none other than their child/young person's education setting).

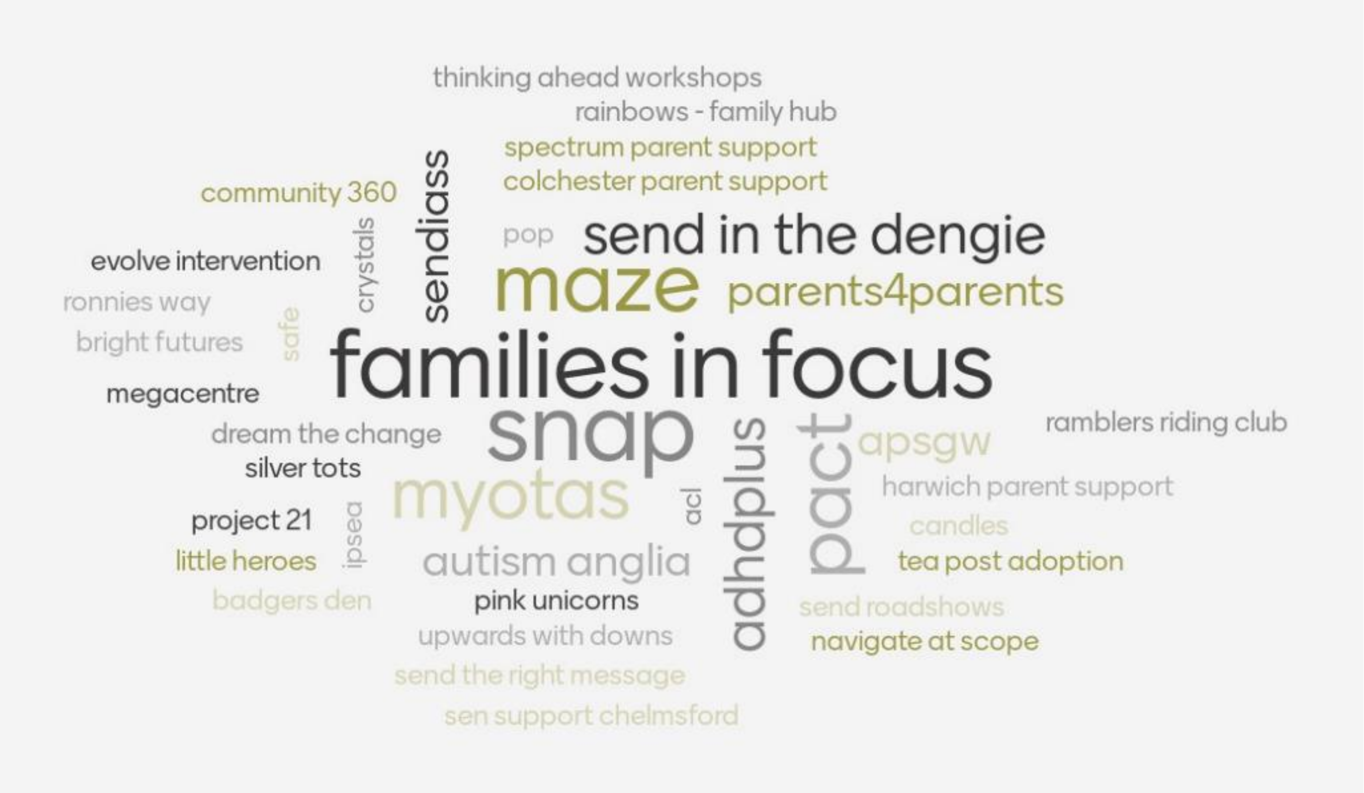
Other Sources of Information and Support – Support Groups

We asked parents and carers which parent/carer support groups they used. 45% of respondents said they contacted Families in Focus for advice and/or support. As they offer support to parents and carers throughout the entire county, it is, perhaps, not surprising. SNAP was the group as the second highest source of advice and support, with MAZE, MyOTAS and PACT being next in the top five support groups that parent/carers contact.

We received 110 individual comments regarding the various Support Groups and Charities throughout Essex that support children, young people and their parents and carers and it is clear from those comments what a valuable lifeline they are.

We received some comments from parent/carers who stated they were unaware of any of the support groups listed – with one parent/carer commenting that the list in our survey is very helpful and they will now be contacting some of the groups from this.

Along with the categories that were available to select in our survey, parent/carers shared the groups and organisations that have supported them, and we have combined the lists in to the graphic below. (*There were, additionally, a number of online (mainly Facebook) groups mentioned but we have kept the graphic to mainly groups that offer some element of face to face advice/support/activities.)*



Conclusion

This has been the biggest survey we have conducted, to date, both in terms of the number of participants and sections within the survey.

There are always two elements to our survey. The first is the quantitative data; the percentages and proportions of responses to specific questions and comparing with the previous year(s) data.

The other element is the 'qualitative' data we collect; the themes that we are able to gather from the individual comments sections to the survey. We fully acknowledge that participants are more likely to comment when things are not working well, but the sheer volume of comments alone does seem to suggest that families are finding their current situation (whatever that may be) particularly challenging. The content of those comments outlines what parent/carers feel are the factors contributing to the challenges and how they are impacting on their child/young person and the rest of their family.

Communication

Ineffective and delayed communication has consistently been one of the main areas of frustration for parent/carers responding to our surveys. The data clearly suggests that this is not improving. Unfortunately, the capacity and funding constraints that are being experienced by all public, voluntary and charitable sectors appears to be worsening this existing problem. As the Parent Carer Forum, we are concerned that this has led to higher levels of distrust with statutory services being expressed by respondents to this year's survey. Families should not be left feeling that barriers are deliberately being put in place to prevent their child/young person accessing the support they need. At a time when resources are stretched, it is far more beneficial for services and practitioners to work ***more*** co-productively with families to achieve the desired, positive outcomes for children and young people they are supporting.

One particular comment seemed to sum up that parent/carers appreciate the efforts of individual practitioners but are acutely aware of the challenges services themselves are facing.

> The only positive thing is the people as individuals that I have spoken to from all the various professions across health and social care have all been caring and understanding as individuals, and have all shared their view that the system is completely broken, but none have been able to offer a joined up or seamless / integrated support to us as a family

Statutory Processes – Needs Assessments, Education Health & Care Plans and Annual Reviews

There has been marked increase in the delays to statutory timescales for all aspects of the EHC Plan process from needs assessments to annual reviews. The Local Authority has a clear statutory duty to meet certain timescales throughout the EHCP and Annual Review process. These timescales are there to ensure that children and young people are receiving the right support at the right time. If statutory timescales continue to be consistently breached in the way they are now, it is reasonable for Local Authority to expect a rise in complaints that end up being escalated to the Local Government Ombudsman.

As mentioned earlier, it is even more imperative that good communication channels are maintained with families when they are experiencing excessive delays in decisions and issuing documentation. We would like to see Way Forward and Outcomes meetings being offered with far more consistency and frequency. EHC Plans need to be reviewed and updated on a timely basis to reflect the current needs of children and young people and corresponding changes provision required to meet those needs. For this to be achievable, the SEND teams need to have sufficient staffing capacity to meet the demands of their service. The impact of not able to meet demand to do this is clear from this comment:

> Essex/ case worker failed to meet the deadline for May 2022. And was made officially end of October 2022 so we have been left without a school

Parent/carer confidence in the quality of newly issued plans has risen – but too few children and young people receive all of the provision outlined in their Education Health and Care Plans. We would also like to see closer monitoring of whether provision is being delivered, especially at Annual Reviews. Again, there is a statutory duty on the Local Authority to do so.

One Planning/SEN Support in Education settings

The downward trend in children and young people with a One Plan has continued. Where there is a One Plan, a significant number of parent/carers reported that they do not feel they are involved or allowed to contribute effectively. Parents and carers are reporting that schools are not recognising or acknowledging their child's needs – especially when they are academically able or do not display the dysregulation in their education setting that they do at home. These issues are of particular concern given that there is a growing number of children/young people who are experiencing significant anxiety around attending school. We feel there is a need for targeted awareness training of these particular issues for educational settings.

Identification of Needs

This links very clearly with some of the issues described in the section above. Whilst Essex school census figures are now more in line with national averages, they very clearly do not match parent/carer's opinions of their child/young person's primary need. We know that this issue is not limited to Essex, but we would like to see ongoing work expanded to look further into these discrepancies.

Therapies

10% of families say they have paid privately for therapy assessments and/or ongoing therapy provision because of long delays in accessing NHS and statutory provision. We are aware that there are real capacity pressures within the NHS services nationally, not just in Essex. However, we are troubled at the increase in comments relating to families feeling they need to engage the services of private therapists because of long waiting lists and/or a lack of confidence in the quality of therapy provision offered by NHS providers. We hope that, in the long term, the 'Balanced System' being introduced across therapy provision in Essex will impact more positively on children and young people receiving timely support at the level they require. However, this new way of working is yet to be implemented and the impact for children, young people and their families will not be felt for some time. It is imperative that this work moves forward at pace. We will also be seeking to understand what measures can be put in place to ensure that families feel supported in the meantime.

Neurodevelopment Conditions – waiting times, assessments, pre- and post-diagnostic support.

Whilst waiting times continue to be an issue for many families, the lack of information and support whilst waiting is of equal frustration. Families are then disappointed with the level of support offered to their child/young person once a diagnosis is received because there has been very little information shared with them about what they can expect at that stage. We are continuing to work with the NHS Integrated Care Boards and NHS providers on the information and support that families have told us they need during this process. You can find out more about what we are working towards on our website.

Home to School SEND Transport

Less families have reported being asked to sign a disclaimer, but over 20% are still reporting they are informed they are not eligible for Home to School transport without first applying. It is hard to see how this could be the case, so we would like to see work being undertaken to understand this process.

There is an inconsistency across providers with regard to their disability awareness training for drivers and PAs. We will be working with the Transport and SEND teams, along with the Multi-Schools Council, to develop a better standard of training.

Home Education, EOTAS and Unable to Attend

The vast majority of children and young people are still on roll at their education setting, but most have not received any support from statutory services. From the comments received it would appear that the settings themselves are unsure of who or which teams they could be seeking support from. We would like to see settings be more informed and proactive in supporting children/young people and their families when needs first arise.

Mental Health Support

Families report being turned away from services and a high proportion of those are not being signposted to other services or sources of support. It would be helpful for individual services criteria to be easily accessible for families, so they are more likely to be contacting the appropriate service for their child/young person as well as better signposting between services.

Social Care

Parent/carers are requesting assessments from Social Care for two main reasons: respite, and support/strategies for managing their child's behaviour/dysregulation (including in their education setting). If an assessment is not granted, half of our respondents say they were not signposted to other sources of support. We would like to see this improved – especially where there are issues with their education setting and teams within ECC that are able to support with those types of challenges.

Sources of Information and Support

One of the most consistent messages from parents and carers throughout this survey and our previous surveys has been related to accessing quality information, support and guidance at various points along their journey. Many families told us they would prefer to speak to a person to help them navigate the various processes and services they need to access for their children and young people. There were some parents and carers that said they preferred to research information themselves. Our survey shows that approximately half of all parents and carers are still not aware of the statutory support and information services such as the Local Offer and SENDIASS.

There was one comment that highlighted why needing support to be able to access information can be particularly necessary for parents and carers of children and young people with SEND.

> My ability to access the fragmented system and track all of the various conversations, contact points and questionnaires and deadlines is severely impacted by my own ADHD too!

Next Steps

The responsibility for providing a response to the survey findings will lie with the Family Feedback Coordination and Oversight Group (COG) and this report will be shared widely with SEND service providers throughout Essex. We have made various recommendations in our Conclusion and will work collaboratively with the members of the Family Feedback COG to ensure that the findings feed into the SEND improvement work across Essex.

Where there is no specific ongoing work identified, the Family Feedback COG will share the survey results with the appropriate teams. There will be an expectation that those teams will provide a response to the Family Feedback COG, outlining measures that will be considered to address the issues raised.

Progress against ongoing improvement work and any additional measures will be monitored and regular communication updates will be provided for families, via Essex Family Forum and members of the Family Feedback COG.

As the Parent Carer Forum for Essex, we want to assure our families that we will continue to provide robust challenge to ensure that SEND services remain focused on improving the lived experiences of families.