

Essex Family Forum

Family Impact Survey 2024

Report on Preparing for Adulthood



Date of Report: February 2025

Survey conducted:

1st February 2024 - 17th March 2024

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Introduction

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

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

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

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

This report focusses on Preparing for Adulthood.

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. 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 on 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%)

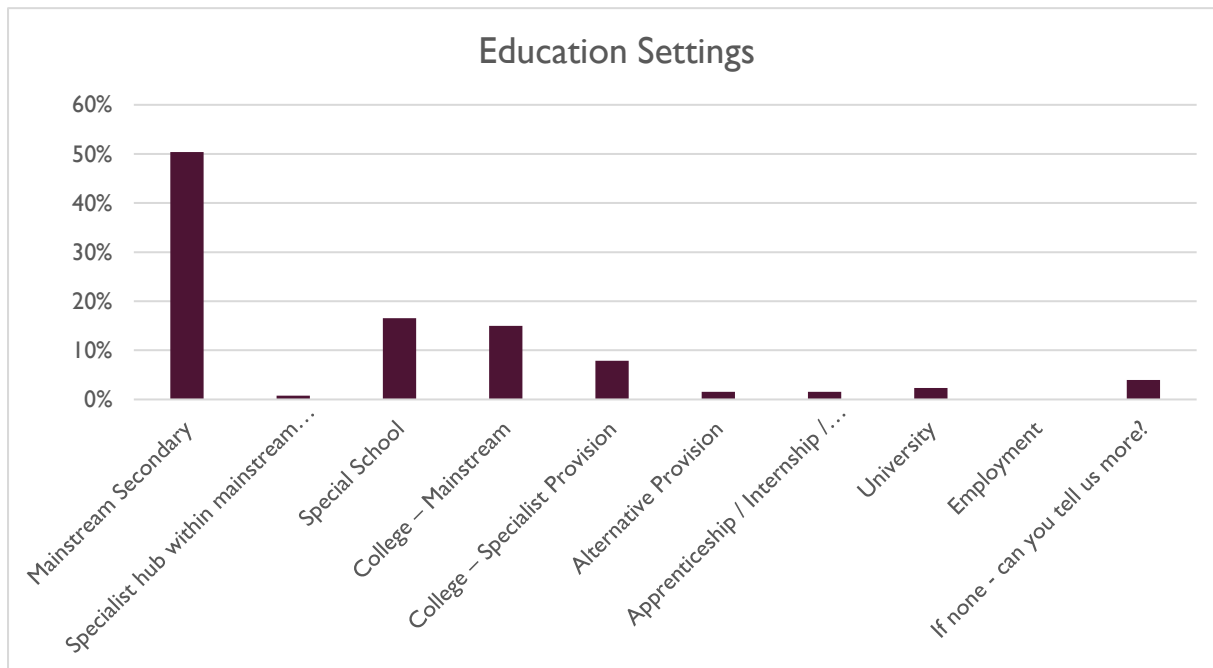
Post 16 - 7% (+1%)

Post 19 - 4% (+1%)

Preparing for Adulthood

This was the first year where we included specific questions relating to Preparing for Adulthood. The questions we asked were to gain a general overview of how confident parent/carers feel about making informed decisions about their young person's future beyond statutory education.

The questions in the Preparing for Adulthood section of the survey were answered by 127 parent/carers who stated their child/young person was in Year 9 or above. Unfortunately, due to an error in the skip logic, these questions were not open to those whose young people have not been able to attend their education setting, have an EOTAS package or who are home educated. However, we are including information shared by these families within this report where we feel it is relevant



- **None of the respondents said their young people were in employment.**
- When looking at the overall data for those whose child/young person was not in school, employment or training the percentages have slightly increased, but 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, waiting for 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.**

For young people who are not attending an education setting on a full-time basis:

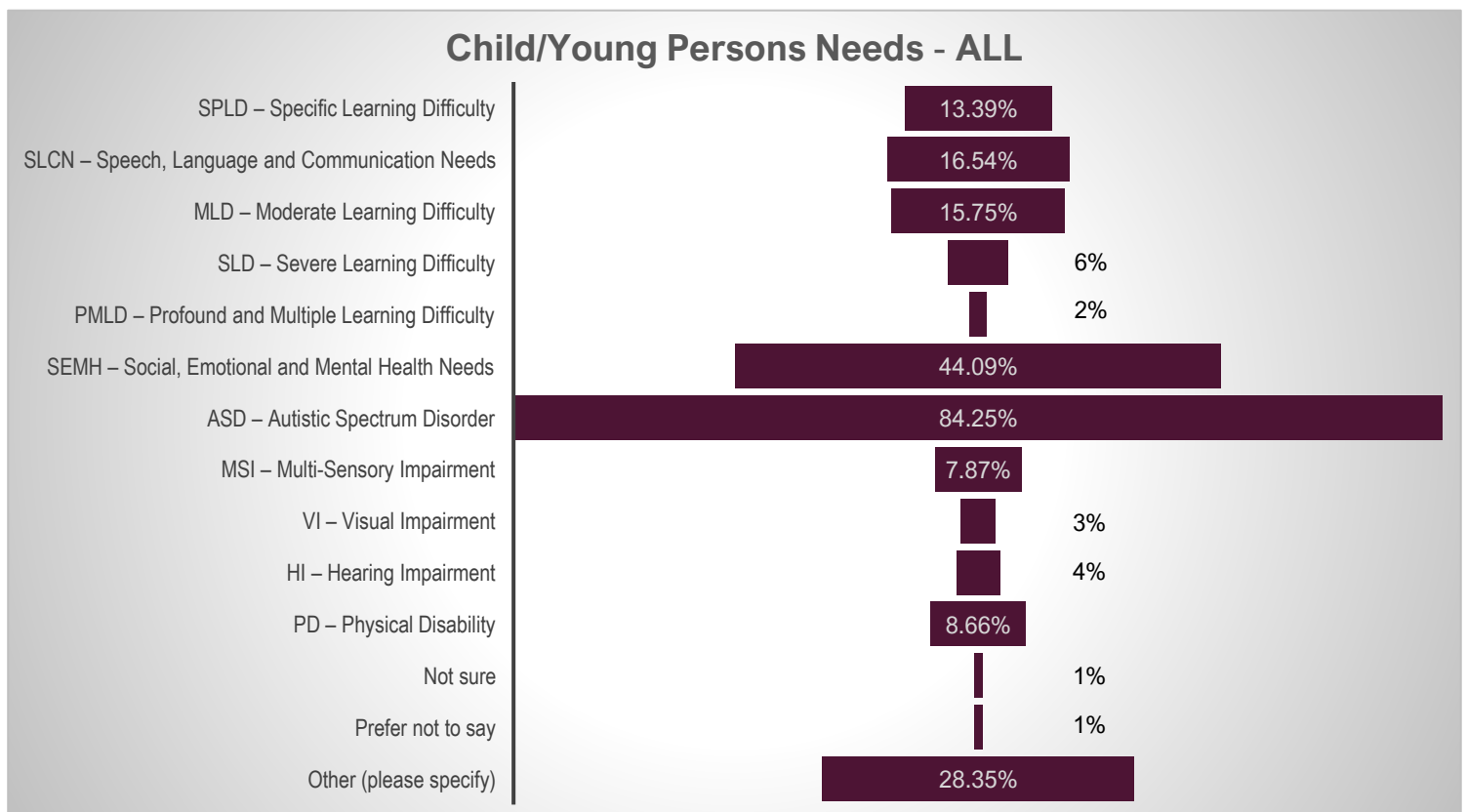
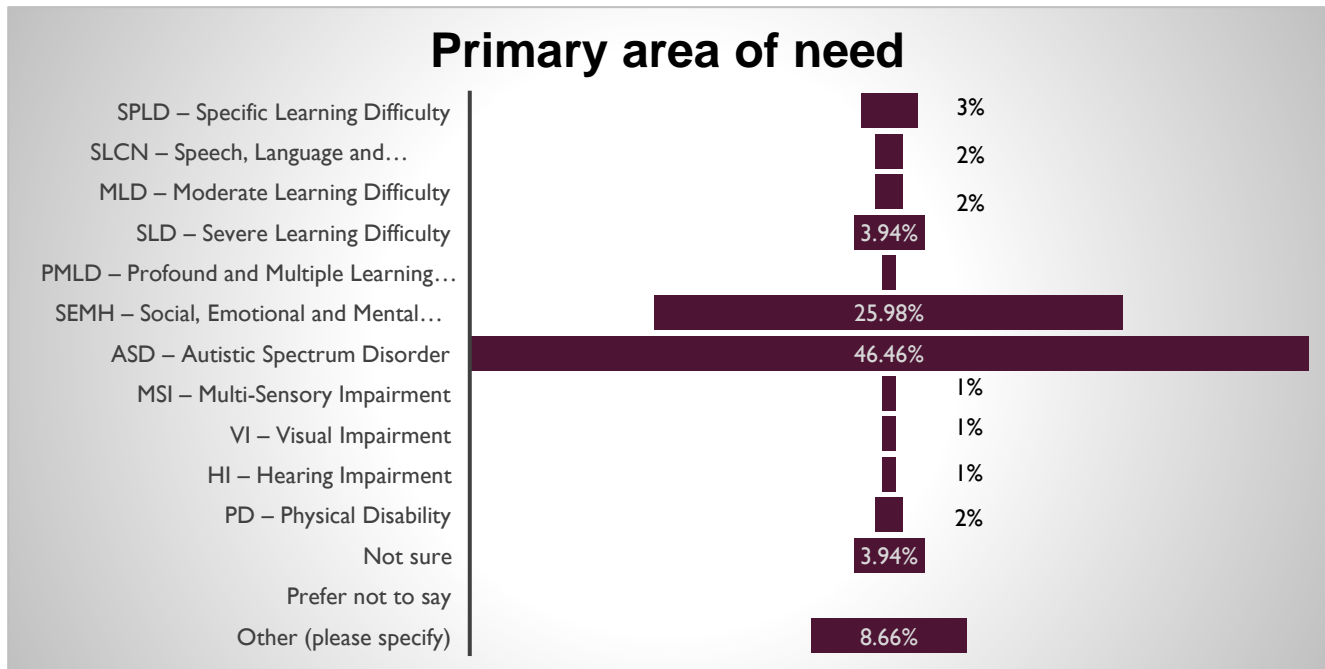
60% are still on roll at their education setting

69% have received no support from statutory services

Identification of Needs

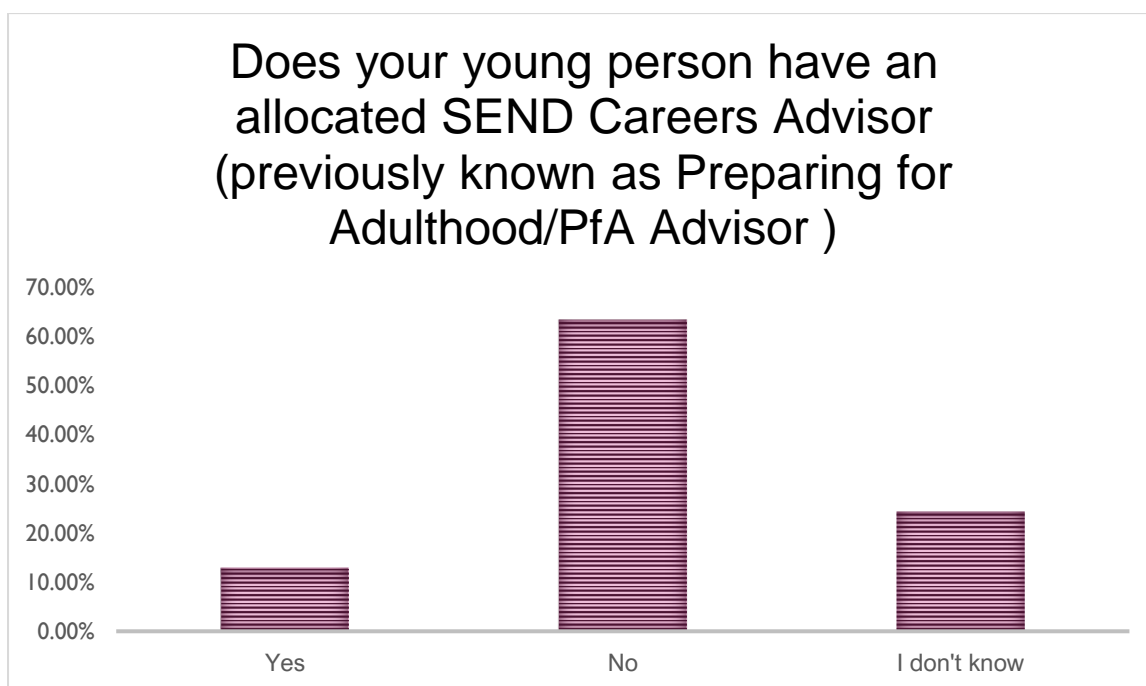
In each of our previous surveys, many parent/carers have indicated that their child/young person's needs are too complex and interlinked to pinpoint which is their primary need. This year we added an additional question so that parent/carers had the opportunity to provide details of **all** their child/young person's needs. (Therefore, the overall percentages will total more than 100%)

This data has been filtered to those in Year 9 and above. The only significant difference in the needs of young people in Year 9 and above is with Speech and Language Communication difficulties - the figure is half of the level described in the overall data, whether by primary need or all needs.



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 18% of the total for this section (+2% higher than the overall data). The 'Other' needs listed needs listed included: dyslexia, dyspraxia, tics and tourettes, Downs Syndrome, global development delay, emotional needs and anxiety, obsessive compulsive disorder and sensory processing difficulties .

Support & Information



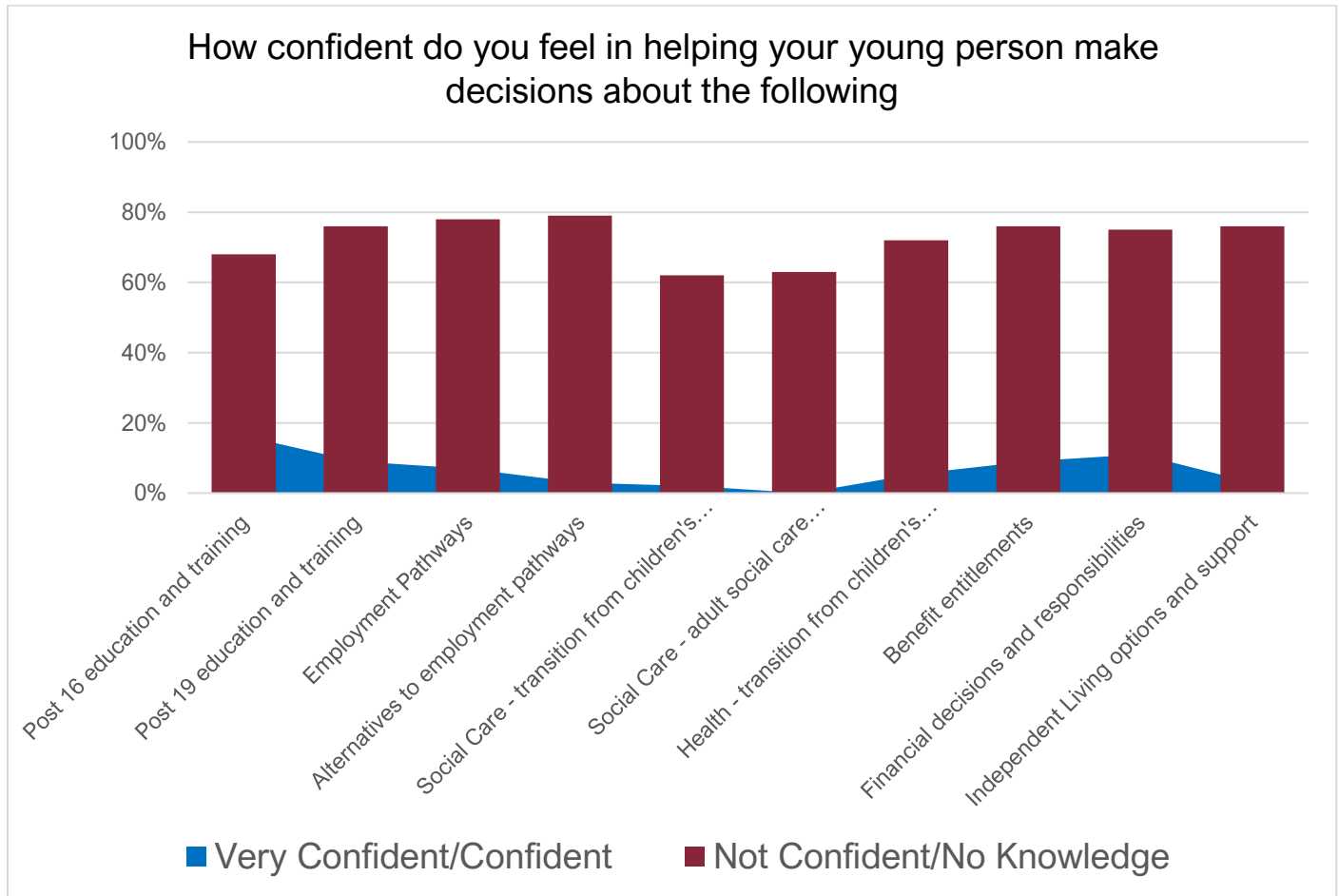
100% of those who responded Yes to this question have an Education, Health & Care Plan (EHCP) - with half attending a special school and 12% at a mainstream secondary.

76% who answered NO have an EHCP (more than half of these attend a mainstream secondary, 7% at a special school, all of those that are not currently in education, training or employment (with the exception of those respondents who were inadvertently excluded from this section).

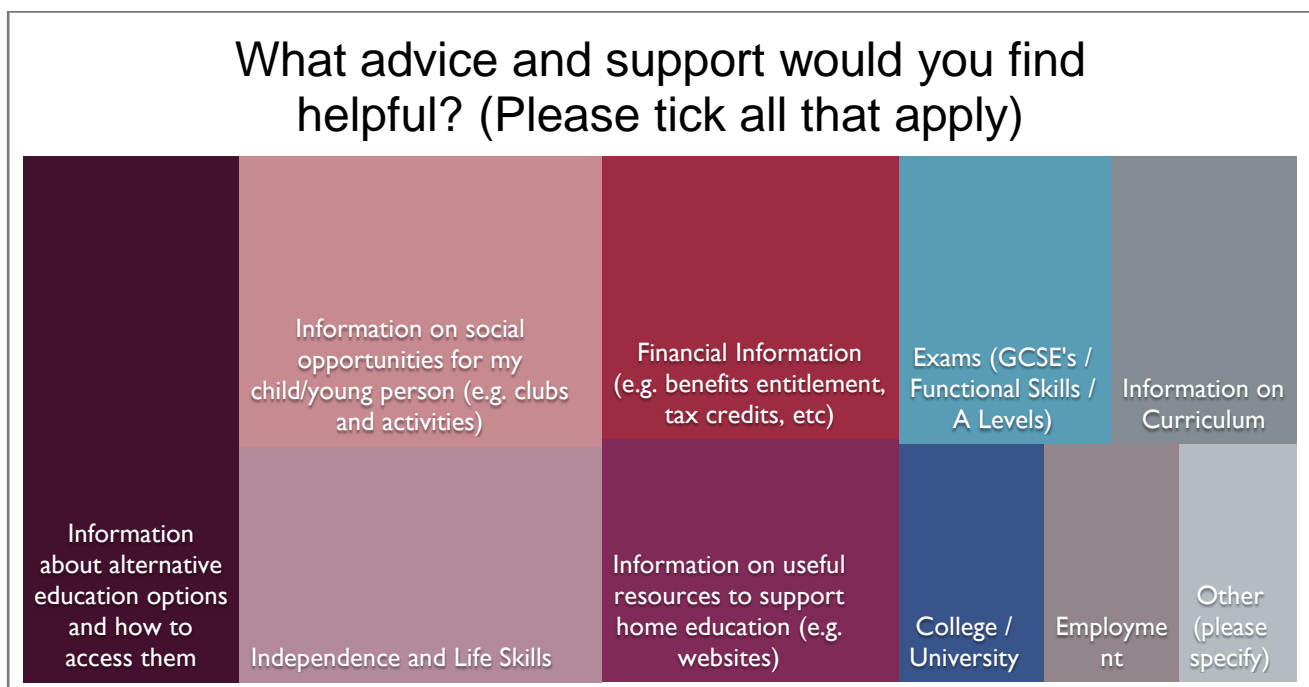
90% of those who do not know if they have a SEND Careers adviser have an EHCP. 40% attend a mainstream secondary, 20% special school, and 12% special college.

Support & Information (continued)

The majority of parent/carers reported very low levels of confidence in supporting their young person to make decisions about their support beyond statutory school age.



The parent/carers of children and young people not attending an education setting have previously told us the information and support that they feel would be useful.



Support & Information (continued)

We received 75 individual comments to this section. 69 of which related to families not feeling they have sufficient advice or support in making decisions regarding their young person's future from Post16 and beyond. The majority of the comments were parents stating that they are having to or have had to find out the information they need by themselves and the difficulties they have had in doing that. Several comments highlighted that parent/carers feel there are a lack of clear pathways for Post 16 and Post 19 options. One parent expressed frustration that the education setting did not support their young person's high aspirations.

I've never heard of a SEND Careers Advisor. I have put 'not confident' as I am now having to investigate all of these things myself....
And I don't feel there is any reliable, accessible place to go to talk all this through, to know what her rights are, what's is available and what to expect along the way.

With our recent experience with college there can be an enormous gap between what the organisation says they provide and the reality of accessing these services. Doesn't feel they have sought any input from Parents or Parents with children with additional needs.

This is an area that I could not receive any help with because my child did not have an EHCP, every avenue I reached out to was shut down.

Very poor transition in mental health, still waiting for adult services to pick up, discharged from child services 3 months ago.

My child was CIN but they closed 6 months before application to adult social care could be made, so having to start from scratch again. Still waiting for an adult assessment.

The support from the university has been excellent from the beginning even before the formal diagnosis.

She will be leaving education in June 2025 and I'd like to find out now about options available for independent living but have to wait until Jan 2025 which doesn't give very much time to plan. It would be better to be able to research options now so we are able to support her to make the best decisions available to her nearer the time.

No support at all. The adulthood part of EHCP has been a joke. My child was dropped soon as he left education. With no plan or support

Learning Disability Healthchecks

Young people with a Learning Disability aged 14 and over are entitled to Annual Healthcheck with their GP surgery. Therefore, we included some basic questions to find out whether families are aware of this entitlement and their experience of them when they are carried out.



14%

Have been invited for their Annual Health Check

We received 63 comments regarding Annual Health checks. The main themes of the comments were:

- unaware of LD Healthchecks
- young people not invited for their annual health check
- GPs unaware of LD Healthchecks
- Positive experiences of the healthchecks that do take place

It was good - comprehensive & thorough, giving her the time and space to ask questions. It was addressed to her, not to me, which was excellent too

It took a while for the GP to understand about annual health checks, but now my child is called regularly and the appointment is carried out gently and as non intrusive as possible by a lovely paramedic at the surgery. She always listens to my input as mum, also.

Recently had their first GP health check. Went well, but they do need to have proper weighing facilities for someone in a wheelchair. Prescription that was needed, was done straightaway. All in all good service

I have spoken to GP about it, but they were not aware of Learning Disability Register or Annual Health Checks

I have no idea what these are!

Conclusion and Next Steps

Preparing for Adulthood

As stated this was the first year this section was included in our survey. The aim was to gather a general overview of parent/carer confidence in making decisions about their young person's future. The overwhelming theme from the responses we received is about the information and advice available to families about the next steps for their young people. Parent/Carers concerns extend beyond education and future employment. They do not feel there is a co-ordinated approach to ensuring that young people and their families are equipped with the right knowledge to make informed decisions, even for those with Education Health & Care Plans.

Next Steps

There is a significant project being undertaken by the Local Offer team to improve the information that is available for young people and to ensure that it is available in formats that are accessible to young people. We have been involved with this project since the beginning and will continue to do so.

We have recently established a regular meeting with ECC's Preparing for Adulthood SEND Strategy Lead. This feedback will be central to our discussions.

We will also be submitting this report to other relevant teams in education, health and social care.

Annual Healthchecks

An Annual Health Check should be available to anyone with a learning disability from the age of 14 who is on their GP learning disability register. It is clear from the responses to the questions in our survey that there is a significant lack of awareness about the learning disability register and health checks. Therefore, we are concerned that the majority of young people that are eligible for Annual Healthchecks are missing out.

Next Steps

We know there is a focus on monitoring the numbers of Learning Disability Healthchecks being undertaken in all areas of Essex. We will be taking this information to local area teams involved in this work, and to the Integrated Care Boards to discuss how awareness amongst families and GPs can be raised.