

Knowing Works®

From teens to adults

Views and experiences

Preparing young people with special educational needs and disabilities for adulthood

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About Knowing Works CIC

Knowing Works is a large-membership social enterprise working to independently include people's lived experience in the shape and design of businesses, services, and strategies across sectors.

Over a decade of development in…

engagement, partnerships & collaborations, research, communication, service evaluation and authentic co-production. We deliver projects with an understanding of the challenges faced by those who commission us, bringing to the fore lived experience and compelling evidence, that changes minds and brings about sustainable change.



Almost 200,000 experiences analysed



Tens of thousands of people engaged in communities



Demonstrable impacts for commissioners, providers & the public



A catalogue of published insights



Valued partnerships across sectors

Introduction

It is vital that all children and young people get support and guidance to prepare them for becoming an adult. Getting help at the right time and in the right ways helps young people to reach their full potential and to lead a fulfilling life.

Understanding the perspectives of young people and local families is critical to developing the best and most supportive culture in Suffolk within which young people with SEND can grow, develop and thrive. That is why Suffolk County Council asked Knowing Works CIC to engage people about how well young people with SEND are being prepared for their adulthood.

The research was commissioned by Suffolk County Council on behalf of the Local Area Partnership (LAP) for SEND in Suffolk. It aims to support organisations and services like schools, colleges, Suffolk County Council, and the NHS to work on a plan for how young people can be supported locally now, and into the future. Specifically, the findings will inform the development of Preparing for Adulthood Strategy.

The research has considered people's views across several key topic areas associated with preparing for adulthood, including:

- The choices young people with SEND have about their education and getting ready for the working world.
- Support for young people w5th SEND to transition into adult health and social care.
- How young people with SEND learn life skills, like managing money, cooking and cleaning.
- How young people with SEND gain independence to get around or do things in life without support.
- The support young people with SEND get to connect with others and find friends in local communities.

For more information about the project, please contact **info@knowingworks.co.uk**.

Approach

People participated in two anonymous surveys as part of this research between January 2026 and March 2026.

- Young people aged 13 – 20 could fill in a survey online. The survey was also available in easy read (printed and digital formats). Three older young people (up to 22) also filled in the form. Their responses are included alongside the others.
- Parents, carers, and guardians could fill in a survey online.

The Knowing Works team were available to support people to participate across these methods or provide other formats and ways to share views as required. Other communication support (e.g., British Sign Language interpretation) was also available.

All surveys were hosted on SmartSurvey (a popular UK-based survey hosting service).

Communication and reach

The opportunity to participate was shared widely by Knowing Works, Suffolk County Council, and local partners. A communications package was created to support people in sharing news of the project across platforms and in physical spaces. Resources included posters, flyers, social media content, and more.

More than **400** page views have been recorded across web content associated with the project on the Healthwatch Suffolk website. People may also have accessed survey links directly from social media and promotion by partners.

Interpreting the data

When interpreting the data in this report, it's important to keep the following in mind:



A snapshot in time – Survey and web form data reflects the views of respondents at a specific moment. It can highlight patterns, relationships, and associations, but cannot conclude one factor directly influences another.

> ***Example:*** If large numbers of young people report they have an EHCP, and don't attend any groups in school or college, this shows the two issues often occur together and may be linked, but it does not confirm that having an EHCP is the reason for not attending these activities.



Small numbers need caution – Findings from small groups, or small differences in numbers, should be interpreted carefully.

Example: If only a few students from a particular demographic respond, their results may not represent the wider population. Similarly, small differences in responses between groups (e.g., different gender identities) may be meaningful or simply due to chance.

The findings may not be transferrable to other contexts – A survey sample only ever represents the specific group of individuals who responded.

> ***Example:*** The results should be used in combination with other literature and expert opinion to inform policy aimed at supporting young peoples with SEND. A single survey cannot cover all available contexts (e.g., different types of school or every available pathway). Instead, results should be used as an indicator and supported by other data.

Evaluation & learning from the method

In addition to the survey findings, this project also offered an opportunity for learning about the best means and methods to engage with young people with SEND and their families. Some key reflections are shared below:

1. **The development of research and engagement work with children and young people with SEND takes time:** Knowing Works would recommend that future similar projects are conducted over at least 6 – 9 months, or even up to a year. The key benefits of this increased timeframe would be time to work in co-production with young people and families on the survey content and more time to work with local partners, including schools and colleges to promote it.

2. **Some areas of PFA strategy would benefit from more targeted engagement:** Health transitions, in particular, was difficult to ask about in a broad public survey, due to the many different services young people could be accessing and mixed stages of transition. Some young people's answers were unclear in their understanding of the questions around health transition. The Knowing Works team recommends that future work around health and social care transitions uses more targeted communication, contacting young people and families with direct experience of transition to ask them to participate in research around this specific issue.

3. **Future surveys could engage young people up to age 25** - The survey for young people was intended to capture experiences from young people up to the age of 20. Knowing Works invited young people aged 21 and above to take part in a case study interview reflecting on their experiences. Although this opportunity was extensively promoted alongside the surveys, there was very low take up from young people. Reflecting on this, the Knowing Works team would recommend that future survey work around PFA could include young people up to 25. In fact, some young people above the age of 21 responded to the survey, even though it was targeted at 20 and below. Their responses are included in the analysis. Because young people aged up to 25 with SEND may still be supported in FE provision, including them in a single method would make the communications simpler, and could increase participation amongst this cohort.

Results

Summary and Key Learning



Summary and key learning

In total, 144 young people with SEND (aged 13 – 20), and 139 parents, carers and guardians took part in a survey in February 2026. Key insights included:

- **Young people and families must be included in plans and review meetings.** Relatively few parents (30%) said their child had a 'Preparing for Adulthood (PFA)' plan, despite most having an EHCP. This may suggest parents are not aware of their child's plan, or the plans are not being completed. Similarly, only 68% of young people with an EHCP had joined in meetings about this each year.

- **Young people want support to develop skills for employment, but the right support and opportunities need to be available**. The types of support young people wanted included how to succeed in job interviews, how to write a CV and work experience or volunteering. The completion of vocational profiles may offer a structured approach for most, yet the take up of them has been low. Despite this, almost half wanted more information about completing one. Young people who had completed a vocational profile, or who said they had been spoken to about their choices were much more likely to feel they had enough help to think about their future. Those with an EHCP were also much more likely to indicate this. Finally, some parents felt there needed to be more supported employment opportunities for their child, as well as better information about transitioning into employment.

- **Support for transitions in education is variable and parents often did not feel supported.** Most young people were given good information and support regarding education and employment. However, this finding may reflect that older respondents (a larger cohort within the sample) were more likely to say they received support around future education or employment options. Conversely, parents were often negative about the support their child received around education or employment. Key themes included a feeling that there was no support available for their young person, issues with communication or involvement in meetings and plans, poor information and signposting and gaps in provision, such as being recommended settings unable to support their child's needs.

Summary and key learning

- **People sometimes experienced gaps in support, and issues with communication when they moved to adult health and social care services.** Comments included that parents had disagreed with how their child's needs were assessed and decisions that lead to an end to support on transition. As such, systems must develop plans that avoid 'cliff edge' withdrawal of support. Services should help people understand what will happen when their support changes and how they can manage. Those who had already transitioned often suggested it happened too quickly with little notice about what to expect. In addition, young people who will transition in the future often did not know what would happen or felt they were not given the information they needed.

- **Early discussions and support around independence may ease anxieties.** Some parents described their child's anxieties about independence because they could not foresee an independent future for themselves. Most young people expressed a level of worry about it too. This was most evident amongst those aged under 16 – perhaps reflecting reduced concern among older age groups already making independent choices. Furthermore, young people who said that they had enough help to think about their options for future education or work were less likely to be worried about independence. The most common things young people said they wanted support with to become more independent were confidence, looking after money, and looking after themselves at home.

- **Around half who had travel training said it increased their confidence.** These findings may indicate a need to review the effectiveness of travel training provision. There was also relatively limited take up of travel training amongst the sample. Future engagement could aim to understand whether this reflects gaps in provision, lack of clarity about eligibility, or an informed choice.

Summary and key learning

- **Most young people did not participate in organised clubs or groups. However, many (78%) maintained social connections informally, by meeting friends outside of school.** This may suggest that PFA planning should account for the informal networks young people participate in, as well as more structured opportunities to socialise. 'Lack of confidence' and 'not wanting' to join in were the two main reasons both parents and young people gave for not attending clubs or groups. Some young people may be more likely to face barriers to socialise than others. For example, young people who were worried about becoming independent in the future, and those who said they did not have other opportunities to meet friends outside of school were also more likely to say they faced barriers participating in community groups.

- **Final reflections from the Knowing Works team:**

1. All four key PFA domains are related. For example, health and wellbeing or education and employment can impact opportunities to build independence or participate in the community.

2. The critical consideration is therefore getting early and adequate support in place across all PFA domains. Young people need opportunities to prepare for adulthood provided in ways that suit their needs and they can understand.

3. It is important to continue to engage young people and families in identifying the most suitable methods for this to happen, embracing co-production wherever possible to ensure support is fit for purpose.

Results

Survey – young people (aged 13+)



Demographic summary

169 young people with Special Educational Needs and Disabilities (SEND) took part in February and March 2026.

- **Age:** Most respondents were aged between 16 and 19. However, there were a range of responses from young people aged 13 – 20. **Three** young people aged 21 or over responded.

- **School year: 45%** of the whole sample (**57**) were in school years 12 and 13. A quarter, (**41/26%**) did not know which school year they were in. Most who did not know their school year were 17 and over and in further education.

The age profile of the sample should be considered when interpreting the results of the survey. Older age groups are somewhat over-represented in the data compared to younger age groups.

- **Gender: 62%** (**100**) were male, **35%** (**57**) were female and **3%** (**5**) preferred to describe their gender another way. These included 'non-binary', "demi girl", and 'She/He/They'.

Age	%	Count
13	6%	10
14	10%	16
15	11%	18
16	14%	24
17	23%	39
18	14%	23
19	13%	22
20	8%	13
21	1%	1
22	1%	2

Gender	%	Count
Male	62%	100
Female	35%	57
Other	3%	5

Demographic summary

- **Education and training:** Most young people who responded were in further education (99/60%). A total of 16% (27) were at special school, and 8% (14) were in mainstream school. A small number were home educated (4/2%), not in education, training or work (5/3%), in sixth form (5/3%) or in an alternative provision (1/1%).

Like the age profile, the fact many young people who responded were in further education should be considered when interpreting the results of the survey.

- **Other responses:** Eight free text 'other' responses included:
  - "Work experience"
  - "Supported Learning in College setting"
  - "Pathway to independence"
  - "Professional driver scheme"
  - "Specialist Sixth Form"
  - "Supported Learning"

Education or training	%	Count
Further education or college	60%	99
Special school	16%	27
Mainstream school	8%	14
Other	5%	8
Not in education, training or work	3%	5
Sixth form	3%	5
Educated at home	2%	4
Supported internship	2%	3
Alternative provision	1%	1

Pre- and post-16 stage analysis

Age has an important influence over participant responses.

Throughout the report and analysis, young peoples' responses and their age is considered across two stages of transition:

1. **Pre-16 –** Including young people aged 16 and below who are in mainstream school, special school, alternative provision or educated at home and;
2. **Post- 16 -** Young people aged 16 and up in college, sixth form, not in education training or work and free text 'other' responses.

The results are considered in this way because:

- Splitting the data by education stage is more relevant to a young persons' experience than age alone. For example, a young person aged 16 who is still in school will have a different experience of support than a young person aged 16 in college.
- Sample sizes too small to make useful comparisons between smaller groups (e.g., education setting/type, or age in years).

Please refer to the table for more detail.

Age breakdown: pre and post-16 transition stage

	Pre-16 Stage		Post-16 Stage	
Age	**%**	**Count**	**%**	**Count**
13	21%	10	0%	0
14	34%	16	0%	0
15	38%	18	0%	0
16	6%	3	17%	20
17	0%	0	33%	39
18	0%	0	19%	23
19	0%	0	18%	22
20	0%	0	11%	13
21	0%	0	1%	1
22	0%	0	2%	2

Special Educational Needs and Disabilities

The most common self-reported special educational needs and disabilities reported by young people are shown below. 157 answered the question in total.

- Autism (54%/85)
- Mental health and wellbeing (30%/47)
- Learning disability (28%/44)
- Learning difficulty (25%/39)
- ADHD (23%/36)
- Physical disability (15%/24)
- Visual impairment (4%/7)
- D/deaf or hard of hearing (1%/1)

Three young people said they did not have any special educational needs. However, all three indicated they received SEND support in some way. One had an EHCP, was supported by a social worker or social care and one attended special school.

Eleven young people provided written alternative responses. They included:

- "I am suspected of disabilities, but have not been diagnosed"
- "I don't know"
- "Global Development Delay"
- "Brain injury [and] hypermobility sensory processing disorder"
- "Selective mutism"
- "Epilepsy"
- "Prayda Willi syndrome"
- "Tourettes"
- "Chromosome deletion disorder / FAST"



Other data sources

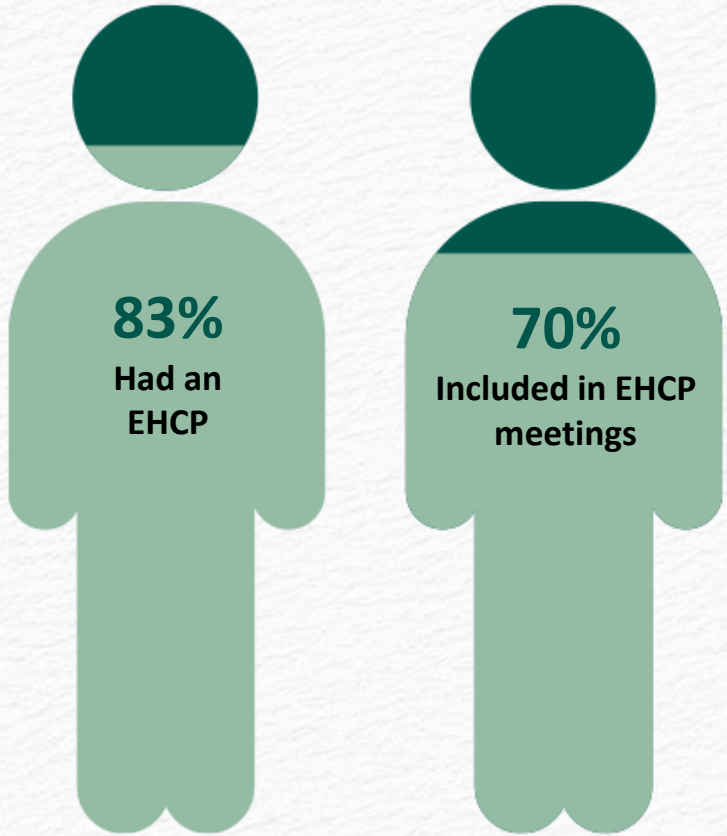
Data from the Department of Education (published locally by Suffolk's Public Health and Communities Team) indicated top needs across all ages as:

- Speech, language and communication (20.8%/4,139)
- Social, emotional and mental health (19.7%/3,923)
- Autism (15.4%/3,067)
- Specific learning difficulty (14.5%/2,894)
- Moderate learning difficulty (8.9%/1,766)

Education, Health, and Care Plans (EHCPs)

Most respondents had an EHCP (83%, 140) - 10% (17) did not, and 7% (11) did not know.

- Of those with an EHCP, **70%** (**96**) had joined meetings about their EHCP each year. **Nineteen** (**14%**) had not been included and **22** (**16%**) did not know.
- Young people who had transitioned to post-16 were slightly more likely to have an EHCP than their peers. Of those at the post-16 stage, **89%** (**107**) had an EHCP. In comparison, **68% (32)** of those at the pre-16 stage had an EHCP.
- Of those who had an EHCP, those in the post-16 category were slightly less likely to say they joined meetings about their EHCP each year (**68%, 71**) compared to **78%** (**25**) for young people in pre-16 provision.



How many young people have an EHCP in Suffolk?

A local needs assessment for SEND by Suffolk's Public Health and Communities team estimated that in 2024/25, **5.4%** of all school aged children had an EHC plan. In addition, an estimated **14.3%** of school aged children were receiving SEN support without having an EHCP (2025, Healthy Suffolk, page 8).

Education & employment

Young people



Future education & employment

Young people were asked about how well prepared they felt for education, employment or training in the future. This included whether they felt they had enough help to think about their next steps into education, training, or work, and whether they understood how their choices might link to future goals.

- Most (**75%, 126**) understood how their choices about education, training or work linked to their future goals.
- Nearly three-quarters (**73%, 122**) said someone had spoken to them about their options for education, training or work in the future.
- Most (**60%, 101**) felt they had enough help to think about their next steps into education, training or work. However, **20%** (**33**) did not get enough help, and one in five people (**20%/33**) did not know.

Understood how choices link to goals	%	Count
Yes	75%	126
No	11%	18
I don't know	14%	23

Someone had spoken to them about the future	%	Count
Yes	73%	122
No	15%	25
I don't know	12%	20

Felt they had enough help	%	Count
Yes	60%	101
No	20%	33
I don't know	20%	33

Completing a vocational profile

A vocational profile is a personalised document detailing an individual's skills, interests, work preferences, and support needs to help them find suitable employment. It acts as a person-centered tool, often used for young people with SEND (Special Educational Needs and Disabilities) or job seekers, to match abilities with job roles.

We asked young people if they had been encouraged to complete a vocational profile to support them in exploring future education, training, or employment.

- Most young people had not completed a vocational profile. Only **18%** (**28**) had completed one.
- Approaching half of respondents (**43%/65**) had not completed one, and **39%** (**59**) did not know.

Although most young people felt someone had spoken to them about their future (**73%**), less felt they had received enough help to consider their next steps (**60%**).

This data, coupled with a low awareness of vocational profiles amongst our sample, suggests the potential for more young people with SEND to be engaged in this type of personalised approach to goal setting. However, it may not be suited to every individual's needs and should be tailored accordingly.

Less than one in five young people had completed a vocational profile.



Who is most likely to be positive about support for transitions in education?

- Students who said that they had been spoken to about their choices for education or training or work were much more likely to also say that they had enough help to think about their future (**71%/ 87** compared to **48%/ 12**).
- Those who had completed a vocational profile were also much more likely to say that they'd had enough help to think about their future (**71%/20** compared to **49%/32**).
- Young people with an EHCP were also much more likely to say that they had had enough help to think about their next steps in education or employment (**63%, 88** compared to **50%, 8**). However, this comparison should be treated with caution due to small sample sizes.
- Young people who had transitioned to post 16 were more likely to be positive about their support for education and employment. They were more likely to feel they had enough help (**66%, 78** post 16 compared to **47%, 22** pre-16) and to understand how their choices impact their future (**82%, 97** post-16 compared to **60%, 28** pre-16).

Had enough help and transition stage				
	Pre-16 Stage		Post-16 Stage	
Had enough help?	%	Count	%	Count
Yes	66%	78	47%	22
No	13%	15	38%	18
I don't know	22%	26	15%	7

Young people with an EHCP in place, those who had been spoken to about their choices in education, training or work, and those who had completed a vocational profile were all amongst the most likely respondents to feel they had enough help to think about their future.

Support for transitions and education provider

There were differences in whether young people felt they had enough help to think about their next steps into education, training or work and the type of provision they were in. Please treat these findings with caution due to low sample sizes.

- **70%** of students in further education college (**69**) said that they had enough help to think about their next steps.
- **52%** of students in special school (**14**) said that they had enough help to think about their next steps.
- **50%** per cent of students in mainstream school (**7**) said that they had enough help to think about their next steps.
- **40%** in sixth form (**2**) said they had enough help to think about their next steps.
- **All three** students on a supported internship said that they had enough help to think about their next steps.

Had enough help and education type		
	%	Count
Further education or college	70%	69
Special school	52%	14
Mainstream school	50%	7
Supported internship	100%	3
Other	29%	2
Not in education, training or work	40%	2
Sixth form	40%	2
Educated at home	25%	1
Alternative provision	0%	0

Focus on: NEET young people

- Two of five had enough help to think about next steps.
- Three of five said someone had spoken to them about their future education or employment options.
- Three of five understood how their choices impacted their future.

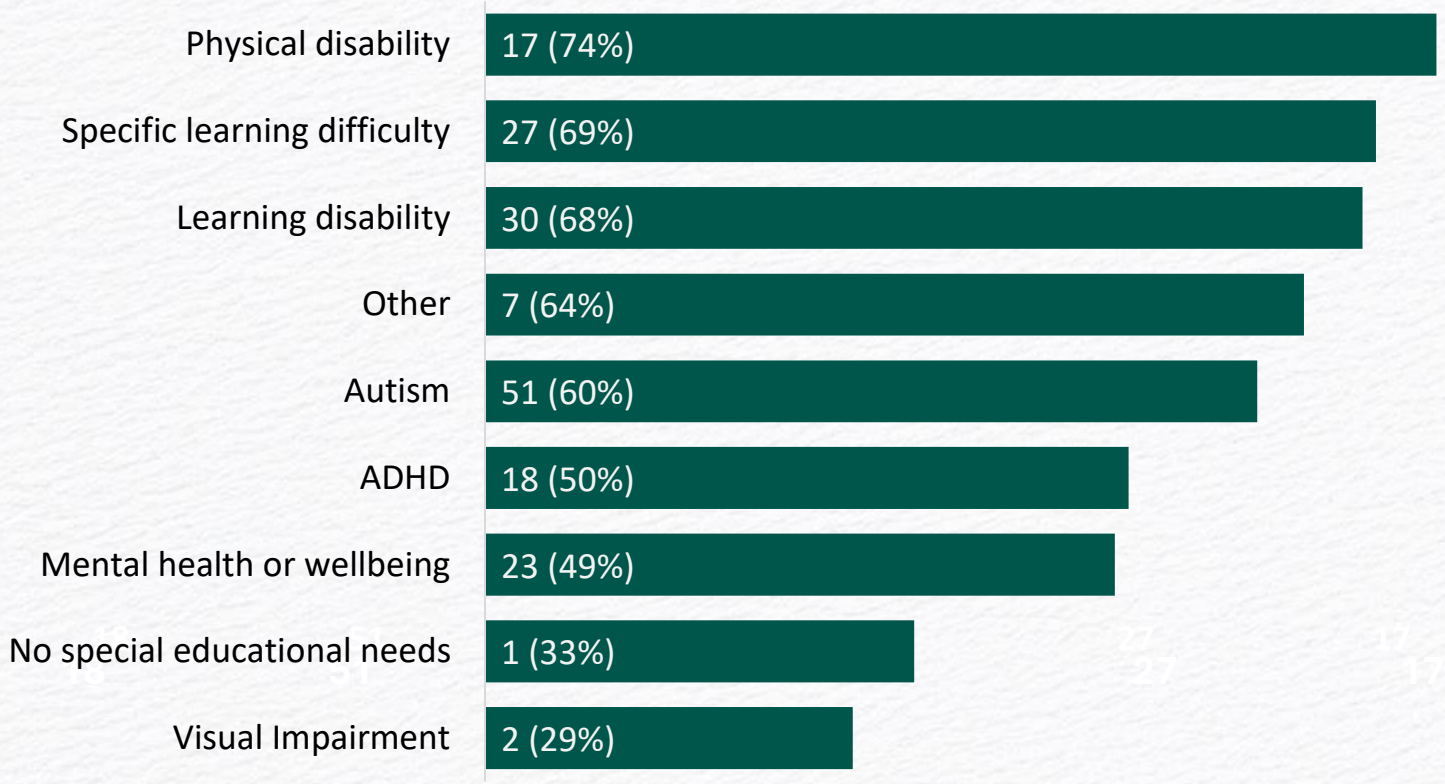
Focus on: Home educated young people

- One of four had enough help to think about next steps.
- One of four said someone had spoken to them about their future education or employment options.
- Two of four understood how their choices impacted their future.

Do young people with SEN needs feel supported?

There were some differences in whether young people felt they had enough help to think about your next steps into education, training or work and their additional support needs.

- Young people with a physical disability were the most likely to say they had enough help to think about their next steps (**74%, 17**).
- Young people with mental health or wellbeing needs often said that they did not have enough help to think about their next steps (**49%, 23**).
- It is not clear from the survey why there might be differences in how much help young people with a range of SEN needs feel they receive. Furthermore, the findings from some groups should be treated with caution due to small sample sizes.

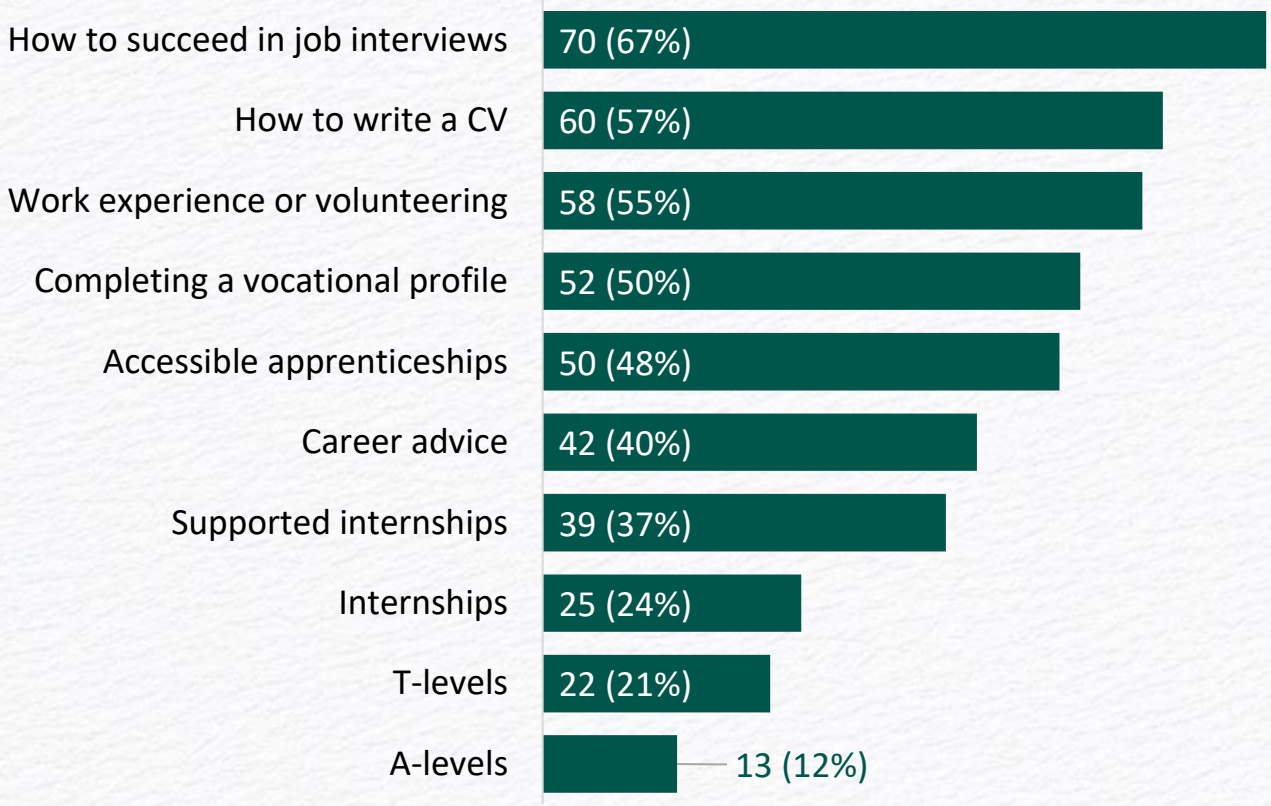


% felt they had enough help to think about future education, training, or work

Information to prepare for the future

Young people were asked what information could help them prepare for work or education the future. They could choose from the options in the table.

- Information about careers was popular, for example, how to succeed in job interviews (**67%, 70**), how to write a CV (**57%, 60**) or opportunities for work experience or volunteering (**55%, 58**).
- Completing a vocational profile was also popular (**50%, 58**). This may have been a popular choice because a previous question asked if they had completed one. Accessible apprenticeships was also a common choice (**48%, 50**).
- The least popular options were information about A-levels (**12%, 13**), and T-levels (**21%, 22**). This may be because most of the people who responded were aged 16 and up and already in further education.



% - information wanted to prepare for the future.

Information needs – education, training & work

There were slight differences in the information needs of young people pre- and post-16 -transition.

- Young people at the pre-16 stage were slightly more likely to want information about succeeding in job interviews (**74%, 23**) or how to write CVs (**52%, 16**).
- Young people in the pre-16 stage were more likely to want information about work experience (**71%, 22**). They were also much more likely to want information about A-levels (**23%, 7**) or T-levels (**52%, 13**), which may reflect the fact the post 16 group has already made this transition.

The responses can also be split to show the top choices for those who had not had enough help to think about their next steps:

- Information about accessible apprenticeships (**70%, 16**)
- Work experience (**65%, 15**)
- Completing a vocational profile (**61%, 14**).

Those who said they had enough help to think about their next steps were more likely to want information about how to succeed in job interviews (**71%, 44**) and work experience or volunteering (**56%, 35**).



Free text responses – young people's views on transitions in education and employment

Young people, aged 16 and above, were asked (in a free text question) to tell us about the support they had received to prepare them for what they want to do next in education, training or work. 89 respondents left a comment.

Twenty-nine (33%) mentioned positive support from education providers.

Many young people described positive experiences of support from their education providers (tutors, lecturers, mentors, LSAs and intervention leads) including help with applying for next courses, guidance on university and apprenticeships, and help to access work experience.

Thirteen (15%) commented about general support they had received.

References included that young people had received support to plan their future (such as discussions, meetings, or help understanding career pathways) but did not specify who provided this support. One said they had been to view universities.

Twelve (13%) described negative or no support experiences.

Comments mentioned receiving 'no support', or described negative experiences linked to a lack of support. One young person felt 'abandoned', while another described feeling 'confused' about what they may be able to do in the future. One respondent felt advice and support offered to them did not fit with their individual needs or aspirations.

> **I've received help from various staff members in my college, it is largely in part thanks to them that I am now able to proceed with my next course. They arranged an early interview and are working towards helping me find work experience which is required for my next course.**

“My parents, tutors and friends help keep me focused on my goals and keep my grounded but also remind me if I am wrong or congratulate me if I am right. I currently get the support I need whether home or college.”

Ten (11%) described careers support they had received.

Respondents specifically referenced support from a careers leader or having had a careers meeting. Many of these young people appear to be in college. One said they were receiving support at work. One additional respondent highlighted the role of a social worker in helping them secure their current college course.

Six (7%) mentioned future plans, but not any support received.

Comments simply outlined intended next steps but did not indicate whether the young person had received any support in making those decisions.

Seven (8%) described support received from parents.

Respondents indicated they had only received support from their parents, while others spoke about how their parents had supported them to understand information about universities, UCAS points and offering ideas.

Five (6%) comments mentioned annual reviews of EHCPs.

Comments specifically mentioned annual reviews of an EHCP.

Two (2%) comments mentioned having good support networks.

Comments described good support networks with family, friends and teachers working together to help them achieve their goals.

Three (3%) comments indicated indecision.

Comments suggested these young people did not know what their future plans were.

Two (2%) comments described receipt of individual support.

Comments described having received specific individual support to help them prepare for the future. This included support with college subjects (e.g., maths & English), daily living skills (e.g., kitchen or knife skills), and building confidence.

"…When the previous pathway to Independence and Volunteering ended, I was told I would need to leave college - there was NO assistance from college, the local authority or Jobcentre Plus to help find opportunities with Disability Friendly Employers… "

“I'm currently working an online course, so I haven't been helped directly. However, we have done work which relates to our future career choices as a way for our tutors to gain a better understanding of what we want. The college itself (Suffolk New) offers a lot of support, so I know that I'll have access to even more help once I transition into an in-person course.”

“I haven’t had anyone that had spoken to me, and I am very confused about what I am able to do in the future.”

“Haven't needed any. I know what I want to do next.”

“I've had help with my english and spelling and help with kitchen / knife skills and some help in kitchen theory.”

“At my college, I have had someone at my careers area ask me what universities I would like to do and any potential courses I could apply for. I have my parents that help me understand what some of the uni course requirements mean (such as what are UCAS points). My lecturers have speakers from universities such as Essex and people doing careers talks.”

“I have had discussions about the different career paths and what I would like to do. I have also been told about the benefits of each career path.”

Health & social care

Young people



Health transitions

Young people were asked whether they had transitioned from children's to adult health and social care services, or whether they would in the future.

- **44% (57)** did not need any ongoing support from health or social care services.
- **40% (52)** said they would transition to adult services in the future.
- **16% (20)** had already transitioned to adult services.

Young people who had already transitioned, or who would in the future, were asked which services they used. 41 answered the question.

- The most common services used were mental health services **(36%, 17)**, autism services **(34%, 16)** and ADHD services **(32%, 15)**
- A total of **28% (13)** used support from a social worker or social care.
- It was less common for young people to say they accessed physiotherapy or occupational therapy.

The seven free text "Other" responses included 'Music therapy', 'Rehabilitation', 'NHS', and 'Type one diabetes', "global delay", and "cardiology".

Health transition stage	%	Count
I do not need ongoing support from health or social care services	44%	57
I will move to adult health or social care services in the future	40%	52
I have already moved to adult health or social care services	16%	20

Health or care services used	%	Count
Mental health support	36%	17
Autism services	34%	16
ADHD services	32%	15
Social Care or Worker	28%	13
Physiotherapy	19%	9
Occupational therapy	17%	8
Other	15%	7

Age and transition stage

When comparing the transition data by age:

- Some young people in younger age groups said they had already moved to adult services. For example, **two** young people aged 13 and **one** young person age 14 said they had already moved to adult health and social care services.

- In addition, some young people in older age groups said that they would move to adult health services in the future. **Five** young people aged 18, **six** young people aged 19, and **four** young people aged 20 said that they would move to adult services in the future.

These comparisons are highlighted in the table.

It was unclear whether these young people had fully understood questions about transition or what a transition to adult health services meant for them. Of the **15** young people over 18 who said they would transition in the future, **nine** did not know what would change. In their free text comments, several appeared unsure how to answer. A couple implied that they had made a transition, but without much detail.

This lack of clarity on how young people have understood the questions about transitions should be kept in mind when interpreting the data. Knowing Works would recommend further research and engagement is carried out around transitions using a more targeted methodology and communications.

Age and transition stage				
	Already transitioned		Will transition in the future	
	%	Count	%	Count
13	25%	2	25%	2
14	8%	1	42%	5
15	0%	0	36%	5
16	0%	0	42%	8
17	8%	2	68%	17
18	28%	5	28%	5
19	18%	3	35%	6
20	31%	4	31%	4

Involvement in health transitions

We asked young people whether they knew what would change when they moved from children's to adult services.

- **Of those who had already transitioned**: About three quarters (**70%, 14**) knew what would change before they moved. Four said no and two said they didn't know.
- **Of those moving to adult services in the future**: Only **27%** (**14**) knew what would change when they transitioned. **Fifteen (29%)** said no and **43%** (**22**) said they didn't not know.

Respondents were also asked whether they had been given information about the move from children's to adult's services.

- **Of those who had already transitioned: Six** (**30%**) were not given any information. **Seven** (**35%**) were given some information, and **seven** said they were given all the information they needed (**35%**).
- **Of those moving in the future**: Around two thirds (**63%, 32**) had been given no information about the change. **Twelve** were given some (**24%**), and **seven** said they had been given all the information they needed (**14%**).

Respondents were also asked if they felt listened to and understood around their move between services. Eleven answered the question.

- **Of those who had already transitioned:** Most felt listened to or included 'A little' (**55%, 11**) or 'Completely' (**30%, 6**). **One** said "Not at all" and **two** did not know.
- **Of those moving in the future**: **Nine** (**17%**) felt 'Completely' included, **18** (**35%**) said 'A little', and **eight** (**15%**) said 'Not at all'. **Seventeen** said 'I don't know' (**33%**).

Not given any or just some information about transition



Young people did not always feel they were given information about moving between services.

Service breakdown

Comparing these findings across the services young people were using is unlikely to be reliable due to small samples for each service. However, some highlights from this data are shown below.

- **53%** (**nine**) who used mental health services knew what would change.
- **38%** (**five**) who used social care or a social worker knew what would change.
- **25%** (**four**) who used autism services knew what would change.

Similarly, it is difficult to determine how much information young people received about transitioning between services by the services they were using due to low sample sizes.

- **38%** (**5**) who used social care or social work services had not been given any information.
- **67%** (**10**) who used ADHD services you were not given any information.
- **50%** (**8**) who used autism services were not given any information.
- **47%** (**8**) who used mental health services were not given any information.

Knowing what would change		
	%	Count
Occupational therapy	63%	5
Mental health support	53%	9
Physiotherapy	44%	4
Social Care or Worker	38%	5
ADHD services	33%	5
Autism services	25%	4

Not given information about transition		
	%	Count
ADHD services	67%	10
Autism services	50%	8
Mental health support	47%	8
Physiotherapy	44%	4
Social Care or Worker	38%	5
Occupational therapy	25%	2

Free text responses – young people's views on transitions in health and social care

Young people aged 16 and above who had already transitioned from children's to adult services were asked to tell us about their experience in a free text question. There were 35 responses.

Fifteen (43%) were positive comments.

Several respondents left general comments such as 'it was alright', 'good' 'or 'easy process'. One person mentioned that they had 'felt supported' through the transition, while two further respondents highlighted the support they had received from nurses/healthcare professionals as they moved to adult services. One person commented that 'It seemed like the same as before, honestly I didn't know that I have changed to adult services'. A couple said that it had "stayed the same". One positive comment said, "*the people at adult services were really nice and helped me through it*."

Six (17%) comments were negative.

Comments included that the transition had happened too quickly, there had been a lack of information about the change, and that the move to adult services meant a loss of continuity of care. One person said they had felt terrified when they had been placed on an adult ward. One said their experience of transition was "confusing".

Fifteen (43%) respondents were not sure how to answer.

Six people were unsure about how to respond to the question, leaving comments such as 'I don't know', 'I don't understand what this means', 'I'm not too sure' and one respondent said 'I'm unsure how to describe it'. **Five** further respondents left general comments, not specific to the transition into adult health and care services, which again may indicate that people did not fully understand the question.

Free text responses – young people's views on transitions in health and social care

Young people aged 16 and above who had already transitioned from children's to adult services were asked to tell us about their experience in a free text question. There were 35 responses. Some of their comments are shown below.

- "I feel like the change happened in the blink of an eye without my consent and I didn't like it very much."
- "The nurse from the children's ADHD service was helpful and said about the transfer to adult ADHD service."
- "I was little nervous that I was going into adult healthcare services , but when I met the healthcare professional I was less nervous."
- "Moving of children to adult services feels like I have more responsibility to handle the services by myself then having my parents to do it for me."
- "It was terrible I was put in an adult ward and was terrified I really struggled with the harsh transition."
- "It was an easy change as I had all the information I needed to feel safe and supported."



Independence

Young people



Becoming independent

Young people were asked how worried they felt about becoming more independent in the future.

They were given the following definition of independence:

> **"Becoming more independent means doing more things on your own, for example looking after your own money, or cooking and cleaning. You might also travel and get around without help from someone else. Being completely independent means being able to live and do things on your own without other people helping you."**

- More than half were either 'A little worried' (**44%/63**) or 'Very worried' (**17%/25**) about becoming more independent.
- **28%** (**41**) were not worried about becoming more independent in the future and **10%** (**15**) were already completely independent.
- Those who had transitioned to post-16 were less likely to be becoming more independent than young people who had not made this transition (see table on the right).

Worried about becoming more independent	%	Count
I am very worried	17%	25
I am a little worried	44%	63
I am not worried at all	28%	41
I am already completely independent	10%	15

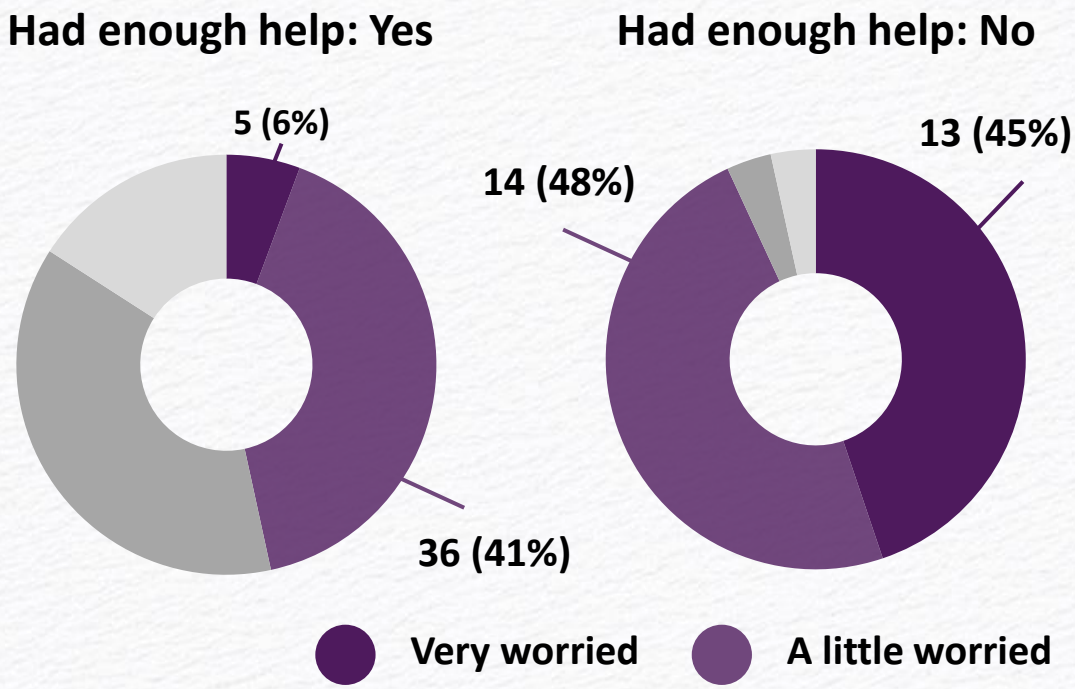
Worries about independence and age group				
	Pre-16		Post-16	
	%	Count	%	Count
I am very worried	36%	9	64%	16
I am a little worried	39%	24	61%	38
I am not worried at all	17%	7	83%	34
I am already completely independent	13%	2	87%	13

Who is worried about becoming independent?

- Young people who felt they had not had enough help to think about their next steps in education or employment (**93%, 27**) were more likely to feel worried than their peers about becoming more independent in the future.

- Similarly, those who had not been spoken to about their future education or employment were more likely to be 'worried' or 'very worried' about becoming more independent in their future (**75%, 15**).

This may suggest that getting early support around education and employment can help to improve how worried young people are about becoming more independent. Note that these factors could both be influenced by the age of the young person.



Focus on: NEET young people

- Three of five were a little worried about becoming more independent.
- Two were not worried at all.

Focus on: Home educated young people

- Two of four home schooled young people were a little worried about becoming more independent.
- One was very worried.
- One was not worried at all.

Support to become more independent

Young people were also asked what could help them to be more independent.

The most popular choices were:

- Increased confidence (**53%, 72**)
- Learning about looking after money (**42%, 58**)
- Learning how to look after themselves at home (**36%, 50**).

23 (**17%**) said they were already 'Completely independent'.

Five gave a free text "other" response. These included:

> "Having a career to build on."
>
> "Lessening the time of using online entertainment services."
>
> "Helping tying my shoe laces."
>
> "I am independent but do have support in college and at home from parents and PA."



% - support wanted to become more independent

“I need support in the community and travel, and in and around the home from my family or support worker. I have been practicing my independence skills in college for the last few years - I am not yet able to count money or tell the time, I would not be able to plan or take a journey on my own.”
(Completed with support from a parent)

Support to become more independent

Young people who were worried about becoming more independent in the future were most likely to indicate a desire for information across categories, including:

- More confidence (**67%, 57**)
- Information about how to look after money (**54%, 46**)
- Information about how to look after themselves at home (**45%, 38**).
- Support from staff or family (**25%, 21**).

Young people who were not worried or already completely independent were less likely to select any of the options overall. Confidence (**29%, 15**), money (**23%, 12**) and looking after themselves at home (**23%, 12**) were still the most popular choices.

Young people who had transitioned to post 16 selected similar choices to those who were still in school or similar pre-16 provision. They were more likely to say they were already independent (**19%, 19** compared to **8%, 3**) and were slightly less likely to want information about managing money (**39%, 38**, compared to **53%, 20**).

Support wanted and worries about independence				
	A little or very worried		Not worried or independent	
Support wanted	%	Count	%	Count
More confidence	67%	57	29%	15
Learning about looking after money (such as paying for things by yourself or saving money)	54%	46	23%	12
Learning about looking after yourself at home (cooking, cleaning, or washing)	45%	38	23%	12
Using communication tools to ask for help	38%	32	8%	4
Practice staying away from home	34%	29	17%	9
Learning about how to stay safe online	28%	24	15%	8
More support from staff or family	25%	21	10%	5
I don't know	16%	14	21%	11
Other	6%	5	0%	0
I am already completely independent	5%	4	37%	19

Top five responses

Travel Training

Young people were asked whether they had received travel training, and if so, whether it helped them to feel more confident.

- **52 (36%)** had received travel training.
- **45 (31%)** had not received travel training.
- **37 (26%)** did not want travel training.
- **Eleven** did not know.

- Young people who had already transitioned to post-16 provision were much more likely to say they did not want travel training (**32%, 33** compared to **10%, 4** of young people in the pre-16 stage). Both groups were about equally as likely to have received travel training (**33%** and **40%** respectively).

- There was not a large variation in the proportion of young people who had accessed travel training across most special educational needs and disabilities. However, those with a mental health or wellbeing need were the least likely to have accessed travel training (**17%, 7**).

Travel confidence

Of 52 young people who took part in travel training, **63%** said it had helped their confidence and **18% (9)** felt it had not.

Ten did not know.

63%



Had travel training and transition stage				
	Pre-16		Post-16	
	%	Count	%	Count
Yes	40%	17	33%	34
No	40%	17	27%	28
No, and I don't want it	10%	4	32%	33
I don't know	10%	4	7%	7

Community & friendships

Young people



Students attending schools & colleges

Young people who were attending school, special school, college or sixth form were asked:

1. Whether they had chances to meet friends face-to-face outside of school or college
2. Whether they took part in any clubs or groups in school or college.

- Nearly one in five young people (**18%/22**) felt they did not have chances to meet friends outside of school or college.
- Nearly three quarters of students (**74%, 86**) said they did not take part in any clubs or groups in school or college.
- Just **11%** (**13**) took part in lunchtime or after school clubs and **nine** (**8%**) attended a student council.
- A total of **six** free text 'other' responses included spending time with friends, helping around the school, choir, and "EDI society".

Meeting friends

Most young people (**76%**) said they had opportunities to meet friends outside of school or college. Some (**18%**) did not feel this way.

76%



Taking part in groups in school	%	Count
None	74%	86
Lunchtime or after school clubs	11%	13
Student Council	8%	9
Other	5%	6
Hobby clubs	3%	4

Who engages with their school community?

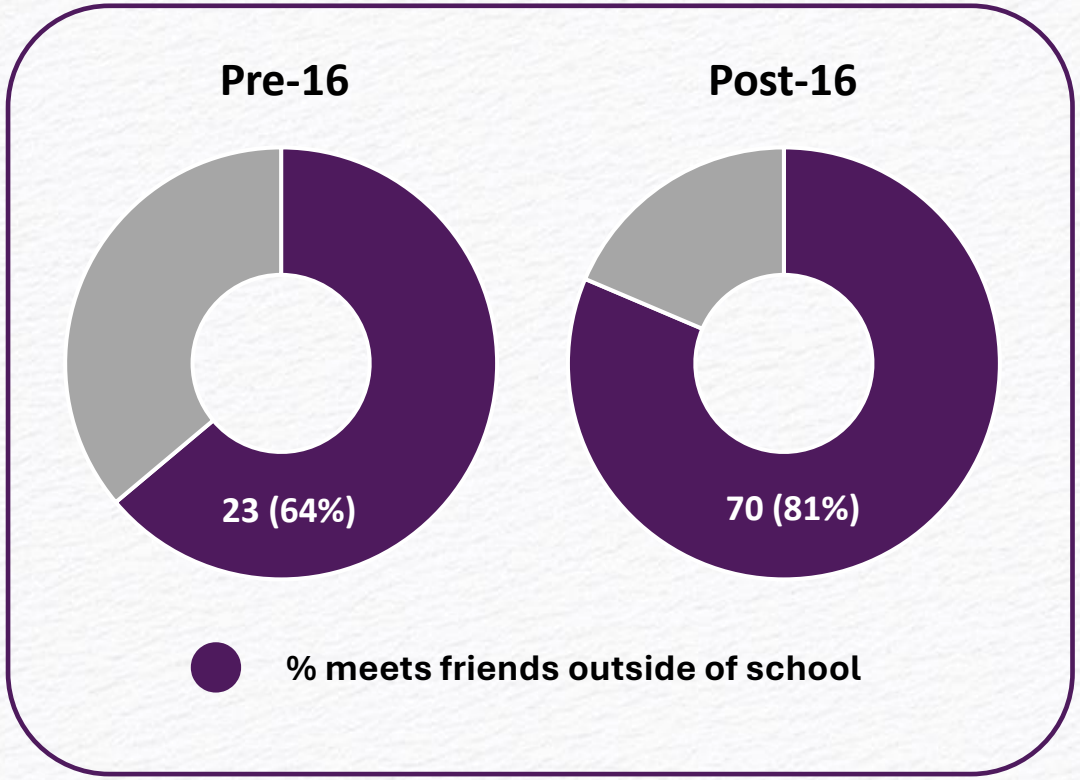
- Young people who had transitioned to post 16 provision (**81%, 70**) were more likely to say they had opportunities to meet friends outside of school or college than those who had not transitioned (**64%, 23**).

- Young people who had not yet transitioned to post-16 provision were much more likely to attend groups at school or college. Half (**51%/18**) in pre-16 provision did not take part in any groups at school, compared to **84%** (**68**) of those who were post-16.

- Young people who were already independent or not worried about their future were more likely to say they had opportunities to meet friends outside of school or college.

    - Most (**93%/14**) who were already completely independent had opportunities to meet friends outside of school or college.
    - Young people who were 'very worried' about becoming more independent in the future were the most likely to say that they did not have opportunities to meet friends outside of school or college (**50%, 9**).

- Male and female students were similarly likely to have opportunities to meet friends outside of school (**77%/ 58**) and (**72%/ 28**) respectively.



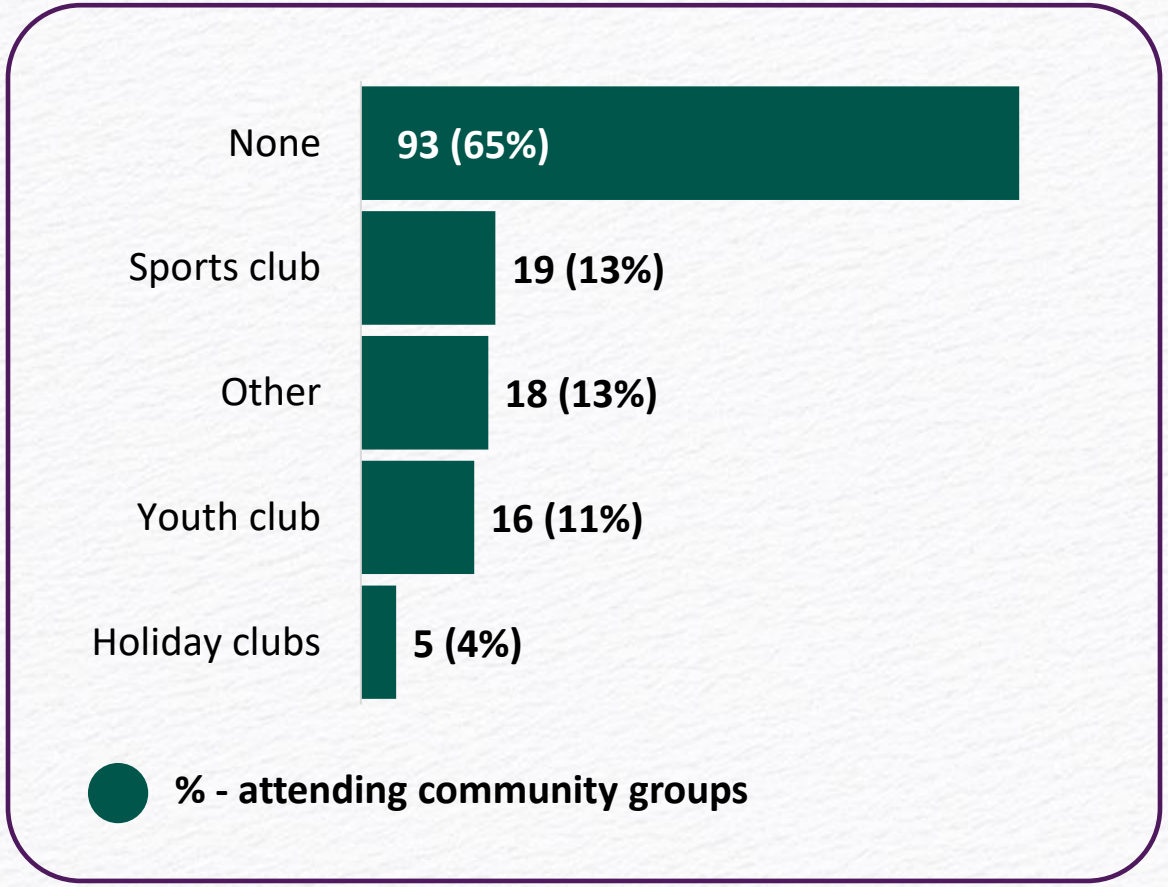
In the community

Young people were asked whether they took part in clubs or groups in their community. They were also asked about what may stop them from taking part in groups.

- **93** (**65%**) did not take part in any clubs or groups.
- **19** (**13%**) attended a sports club, **11%** (**16**) attended a youth club, and **4%** (**5**) attended holiday clubs.

Eighteen gave a free-text 'other' response. These included:

- "Bell ringing"
- "Church group"
- "I hang out with my friends or play with my friends"
- "I work and do horse riding"
- "I go to a gym sometimes with my Dad if that counts."
- "Men's football team and two local darts team."
- "Horse riding and scouts"
- "Suffolk Army Cadet Force"
- "Climbing club"
- "Singing at college"



What barriers are there to taking part in groups?

- Almost half did not take part in groups or activities because they did not want to (**49%, 50**) . Other frequent choices were not feeling confident (**35%, 36**) and not knowing what was available nearby (**29%, 30**). Having no one to go with (**27%, 28**) was also a common response.

- Issues with groups not meeting young people's needs, costing too much, or transport were less common.

Twelve free-text responses reflected similar themes, including feeling there were no groups they wanted to take part in, they would struggle to leave the house, or they would not feel safe.

Reasons for not taking part in clubs or groups	%	Count
Don't want to	49%	50
Don't feel confident to join in	35%	36
I don't know what is available near me	29%	30
No one to go with	27%	28
Costs too much	19%	19
Transport	14%	14
Do not meet my needs	13%	13
Other	12%	12

- "I really struggle to leave the house."
- "Because I might not feel safe."
- "Haven't heard of any that interest me yet."
- "There's nothing I would enjoy/I don't feel like I'd fit in with what there might be"
- "Too much course work to do."
- "Accessibility"
- "No one I know is there and I would rather hang out with a group I know than random strangers."
- "Not a fan of the core topic/subject."
- "Social and apprehensive anxiety."
- "I have a good circle of friends and I'm always very busy with life."
- "My local area doesn't have the best sport clubs for my age."

Who engages with the wider community?

- Female respondents were slightly less likely to join community groups (**73%/33** took part in no groups, compared to **64% (56)** of male respondents.
- Young people in pre- (**61%**) and post-16 (**67%**) provision were similarly likely to join groups. Furthermore, their top reasons for not attending were similar.
- Those who did not have opportunities to meet friends outside of school or college often did not know what groups were available (**63%, 10**) did not feel confident to join (**56%, nine**) or had no one to go with (**56%, 9**).
- Those who had opportunities to meet friends most often did not want to attend groups (**60%, 40**) and were less likely to select barriers.
- Young people who were worried about becoming independent in the future were also more likely to say they faced barriers joining in with community groups. They were:
  - Less confident to join in community groups
  - Less likely to know what's available near them
  - Less likely to have someone to go with
  - More likely to say community groups did not meet their needs
  - More likely to say that transport was a barrier.

Meeting friends and barriers				
	Has opportunities to meet friends outside school or college? **No**		Has opportunities to meet friends outside school or college? **Yes**	
	%	Count	%	Count
I don't know what is available near me	63%	10	19%	13
Don't feel confident to join	56%	9	22%	15
No one to go with	56%	9	12%	8
Don't want to	31%	5	60%	40
Transport	31%	5	9%	6
Costs too much	25%	4	15%	10
Do not meet my needs	25%	4	7%	5
Other	13%	2	10%	7

Results

Parents, carers, and guardians



Demographic summary

A total of 177 responses were received from parents, carers, and guardians in February and March 2026. This group will be collectively referred to as 'parents' herein.

- **Age:** The majority of the responses in the parents survey were about a child in the younger age range. **69%** of parents answered about a child between the ages of **13 and 16.**

- **School year:** Most who responded to the question asking about which school year their child was in said they were in Year **9 – 11.**

Age of young person	%	Count
13	20%	35
16	19%	33
15	16%	29
14	14%	25
18	10%	17
17	7%	13
19	7%	13
20 or above	6%	11

Year of young person	%	Count
Year 9	24%	39
Year 10	17%	27
Year 11	22%	36
Year 12	10%	16
Year 13	12%	20
I don't know	15%	25

Education type

Parents were asked to say what type of education, training or employment their child or young person was currently attending.

- The most common response was that their child attends mainstream school (**30%, 50**), followed by specialist school (**21%, 35**). Parents less commonly said their child attended sixth form, were on a supported internship or were home educated.

- **9% (16)** were not in education, employment or training.

- **7% (12)** were in EOTAS.

Free- text "other" types of provision parents mentioned were:

- Lapwing (5)
- Three parents said that their child was in mainstream school but currently unable to attend due to their needs not being met.
- Specialist provision within a mainstream college (two)
- Two mentioned receiving private tutoring, one of which said that they had found this because no college could support their child's needs.
- Private school (one)
- Green Light Trust (one)
- CF Education (one)

Young person education type	%	Count
Mainstream school	30%	50
Specialist school	21%	35
Other	10%	17
Not in education, employment or training	9%	16
Education Otherwise Than At School	7%	12
Mainstream college	7%	11
Specialist college	6%	10
Alternative provision	5%	8
Specialist unit in a mainstream school	2%	4
Educated at home	2%	3
Sixth form	1%	2
Supported internship	1%	1

Child or young person's needs

Parents were asked about their child or young person's primary areas of special educational need.

The most common special educational needs reported by parents were:

- Autism (**64%, 113**)
- Mental health and wellbeing (**52%, 91**)
- Learning disability (**36%, 63**)
- ADHD (**31%, 55**)
- Learning difficulty (**23%, 41**)

Parents were also asked to describe their child or young person's main areas of special educational need to align with the categories in the SEND code of practice.

Most parents categorised their child's area of need as social, emotional and mental health needs (**90%/157**) or communication and interaction (**82%/143**).

'Other' needs identified included 'executive function difficulties', 'chronic fatigue syndrome (CFS)', 'chromosome disorder', 'selective mutism', 'pathological demand avoidance (PDA)', 'global development delay (GDD)', and 'epilepsy'.

Young person primary need	%	Count
Autism	64%	113
Mental health	52%	91
Learning disability	36%	63
ADHD	31%	55
Learning difficulty	23%	41
Other	15%	27
Physical disability	15%	26
D/deaf or hard of hearing	3%	5
Visual impairment	3%	5

SEND code of practice need	%	Count
Social, emotional and mental health	90%	157
Communication and interaction	82%	143
Cognition and learning	70%	122
Sensory or physical needs	64%	112
None of the above	1%	1

Education & employment

Parent responses



Education, Health, and Care Plans (EHCPs)

Parents were asked whether their young person had an education, health and care plan or were receiving SEND support.

- **Most** (**84%/147**) parents said their child or young person had an education health and care plan, whilst **7%** (**12**) said their young person was receiving SEN support.
- **2%** (**4**) said they were in the process of being assessed for an EHCP.
- **6%** (**11**) said 'none of the above'.

Parents whose child had an EHCP were asked whether they also had a Preparing for Adulthood plan.

- **34%** (**49**) said their child did have a Preparing for Adulthood plan.
- **35%** (**51**) said their child did not have a Preparing for Adulthood plan.
- **31%** of parents (**45**) did not know.

Young people with an Education, Health and Care Plan (EHCP) must have a review in Year 9 that leads to a 'Preparing for Adulthood (PfA) plan' reviewed and updated annually.

EHCP status	%	No.
Has an EHCP	84%	147
Received SEN support	7%	12
None of the above	6%	11
Applied for assessment	2%	4
I don't know	1%	1

PfA plans

A third of parents said their child did not have a Preparing for Adulthood (PfA) plan and **31%** did not know.



Post 16 education & training options

Parents were asked how well informed they felt about education, training or employment options available to young people after they turn 16.

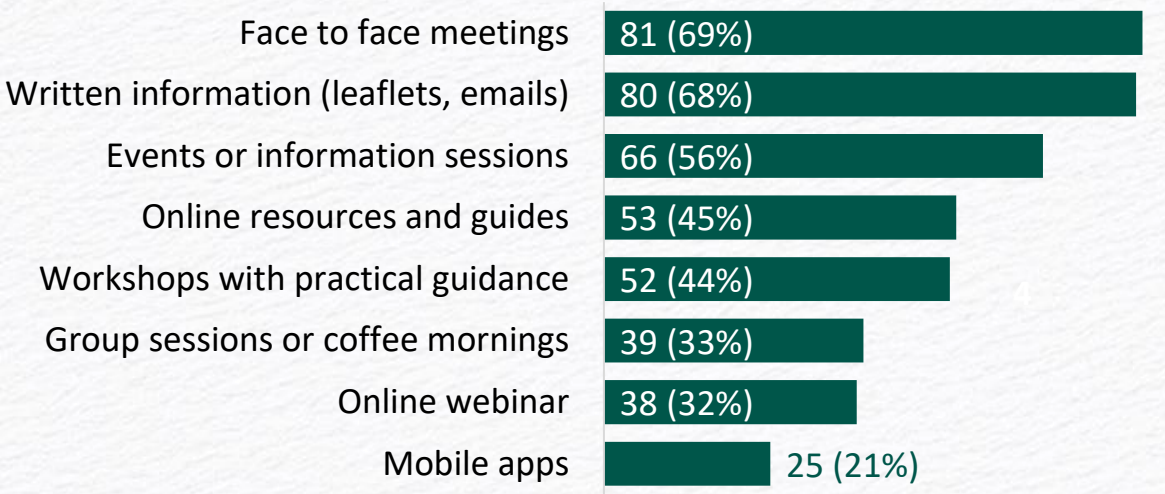
- Most parents did not feel well informed (**62%/74**). Only **7%** (**8**) felt well informed about their child's post 16 options.

They were also asked how they would like to receive information about post-16 options and preparing for adulthood.

- The most popular ways to receive more information were in a face-to-face meetings (**69%/81**) and written information like leaflets or emails (**68%, 80**). This may suggest parents would prefer personalised information and advice about their child's options.

- Overall, the findings reflect that communication should use a variety of different methods for it to be effective, and that people like to receive and engage with information in different ways. Exclusion of any one method may limit reach.

How informed are you about post 16 options?	%	Count
I don't feel informed	62%	74
I feel somewhat informed	27%	32
I feel well informed	7%	8
I don't know	5%	6



% - wanting information about post-16 options and PFA

Free text responses – parents views on transitions and support for education and employment

Parents were asked in a free text question how they felt about the support their child or young person has received when moving from education into further training or work. There were 113 responses. Key themes are shown below.

Thirty-six parents (31%) felt there has been little or no support for them or their child generally.

Comments included that there was 'no support' or support was not available to meet their child's needs. Examples included having an EHCP refused for a child with ADHD, feeling "let down", saying help was not given "freely", or that there was no plan for their child to transition. One parent "faced nothing but barriers".

Twenty-five (22%) were positive about support. The large majority related to good or personalised support from schools or colleges.

Positive comments mostly related to circumstances where children had received effective one-to–one or tailored support from a school, college or education provider. This included receiving good SEND support in school, support from a teaching assistant, help to prepare for transition from special school, or getting one-to-one support at college. Four comments were specifically positive about their experience of Lapwing Education. One was positive about their experience of the CHRIS team and two were positive about the processing times or team who handled their child's ECHP.

> *"The support given by school last year was excellent; any questions or problems I had, I knew I could take to them and they would help. I was fully involved in planning the next step in her education and was given plenty of advice and information. College has been very supportive of my daughter's needs since starting there in September, and are always willing to help with any issues which arise."*

“There hasn't been any support. My son hasn't been able to access education for more than 8 years.

“This is the first academic year a suitable provision has been appropriately funded, and it's too little, too late. He's had no education since he was in Year 3. How can he skip eight school years and be ready to move from education to work or training? Barriers - Local authority making parents jump through hoops for things to go to endless 'panels' that say no to everything anyway. Late diagnosing of life impacting conditions and disabilities.”



Continued…

Twenty-three (20%) described issues with communication and involvement.

Comments explored difficulties with communication or accessing support from the local authority. These included comments that reviews or meetings had been ineffective or unhelpful because people were not provided support to meet their needs. Some referenced a lack of support from family services or contact from their caseworker. Others felt they needed to re-tell their story or explain their child's needs to multiple professionals or services. This theme also included more general comments from parents about communication, such as needing to 'beg', 'fight' or 'battle' for support for their child.

Twenty-one parents (18%) highlighted poor information or signposting to support or information about what to expect when transitioning to post-16 provision or employment.

Comments about a lack of information often related to those about receiving little support generally. Parents found it difficult to find information about where to get help for their young person, or what their options were as they transitioned in work or education. Some had not received much or any information from their school or elsewhere about support they would receive moving forward.

Twenty (17%) said there was a lack of options or that it was difficult to find the right provision for young people with SEND at age 16.

Some respondents highlighted a gap in provision when young people with special educational needs and disabilities left school. Some parents described being told that they should contact mainstream colleges that subsequently told them they would be unable to support their young person's needs. Some just said there were 'no options' or that options were 'limited'.

> *"– In order to even access the bare minimum at an Alternative Provision for my son I had to write a lengthy, stern email to our local MP, Educational MP and the Governing board for the school because the [local authority] stopped replying to my emails and stopped returning my calls, with no explanation and no apology..." –*

“Support for our child with ADHD traits is minimal in secondary school. We have teachers who do not understand ADHD… They punish our child when they use a fidget or doodle book, even though that is in their pupil passport. They concentrate on behaviour and praise them when they are quiet…. It’s never about the child’s needs, only the schools academic needs.”

Sixteen (14%) highlighted other gaps in school- aged provision or that their child had been left without education.

In addition to gaps in post-16 support, some parents highlighted gaps in other areas of education. These relayed a feeling that their child's needs were “between mainstream and specialist” education, or that schools could not meet their child’s needs. In some cases, parents said their child had been left without appropriate education. This was mentioned in **five** comments and ranged between six months and eight years of not having an appropriate placement for their child. Others said their child’s needs were ‘between’ mainstream and specialist provision, leaving them unclear about which providers they could access.

Fifteen (13%) mentioned poor support from schools or colleges for young people with SEND, including not understanding their child’s needs or adaptations not being met.

A common theme was references to challenges with mainstream schools and colleges not meeting their child’s needs. Examples of these comments included that their child’s school or college did not communicate with them to manage issues before they became a disciplinary issue or that their child was seen as ‘naughty’ or ‘disruptive’, rather than receiving the support they needed. A couple felt their child’s school did not follow their EHCP, or that adaptations had not been made for their child.

Fifteen (13%) were uncertain or fearful for the future.

Parents often reflected on similar feelings of ‘fear’ or ‘uncertainty’ about their child's future. Some of these comments related to the uncertainty around transition specifically, for example how their needs will be met, or succeeding in exams. Others reflected a broader concern that their child might be left without support as they transitioned to adulthood.

“My child has been too anxious to allow education staff to undertake any work with her regarding her future, such as Preparing for Adulthood.

“It has not been accessible to her. Just the mention of it has triggered anxiety and depression. We do not really have a plan for her future as she does not know what she will be able to do considering her disabilities and fluctuating health. She does not know how to plan for the future because of this and so avoids thinking about it as much as possible. There does not seem to be many options available to her, so she is continuing with 1:1 tutoring in the home via her EHCP for now.”

“He has applied for a level 1 course… if he gets accepted I don't know what SEN support he would get. If he doesn't get a place, I don't know how to support him looking for employment. I do not feel he is ready to work and don't know if there is support for someone like him who has a mild learning disability. One of his main obstacles is his processing time. All tasks, even routine daily tasks, take him significantly longer than others. How would he be supported in a job?”

Eleven (9%) said that there was a lack of careers advice or work opportunities available for young people with SEND.

Some parents felt that there was poor information or support about how their young person could transition into employment. A couple said that they felt like they had to “figure it out for themselves”. However, some highlighted a broader issue, that there was a lack of accessible or flexible work opportunities for their young person to transition into. For example, one said that they did not feel their young person was ready for employment. Another said that their young person had spent over a year seeking work but had been unsuccessful.

Eleven (9%) mentioned issues with EHCPs impacting the support that their child received or their transitions.

Common issues with EHCPs included general comments about delays, or that delays in processing the plan made it difficult to know what provision their young person could access. For example, a couple said this made it difficult for them to choose a college. A couple noted that although their child had an EHCP, it was not updated. Finally, two said they had faced challenges getting an EHCP or that their EHCP resulted in what they felt was an inappropriate placement.

Finally, five (4%) mentioned PFA plans in their response.

While these comments did not necessarily reflect a single theme, they were considered because the focus of the research is on the provision of support to prepare for adulthood. These comments included:

- One said there was a “lack of timely planning” and that their “young person did not have a Moving into Adulthood plan in place six weeks before leaving their specialist setting. This was largely due to delays by the Local Authority in holding an Annual Review during an ongoing tribunal process”. They also felt that the preparing to adulthood plan did not feel “meaningful or collaborative”.

- Another gave similar feedback, noting that the annual nature of the preparing for adulthood plan means it is not proactive or responsive because “it is not looked at again until the next year”.

- One said they were not aware their child had a preparing for adulthood plan, and another said they had no representation at their annual review.

- Finally, one said that although they had filled in a PFA plan, they did not receive any information about their child's options at 16 or 19.

> *“In practice, the “Moving into Adulthood” plans themselves have not felt meaningful or collaborative. They are typically written by a teaching assistant shortly before the Annual Review meeting based on a short conversation with the young person… Earlier planning, and plans that are regularly reviewed and followed through would significantly improve the process of preparing young people with SEND for adulthood.”*

"I wish every young person in Suffolk receives the support that my young person does. We have an active representation from the local authority at the annual review. We take an active part in amendments after the annual review we are listened to first and foremost, our young persons aspirations are always considered… I am supporting them and working with the local authority and the college as a team and this is working well."

"Moving my child for mainstream to a specialist set up was instrumental for him to succeed on his GCSEs. What worked well for him was to move from a 30+ pupil set up to an eight-pupil group… With the help of trained staff that were able to move away from the narrative of him being "naughty" and "disruptive" and made him feel supported and understood he managed to flourish."

"His current provision at Lapwing is the first time we are starting to see progress in slow steps and they are actually listening to his needs and helping him slowly develop towards integrating into social settings"

"The school are amazing with my child, they help when ever there is help needed. They are also very helpful to both parents if we ever have any concerns or need help understanding anything. Our child is looking forward to their future and they feel safe knowing they have staff and people to talk to if they have any worries or issues."

"My child is now in a mainstream high school that does have a "hub" and support with a place to go to when he has a sensory overload. School has been very supportive, and my child has developed well. We have regular contact with the SEND Support at the school and feel they and the school are working together to help."

"The EHCP application was quicker then we expected, the whole team who processed this was amazing and very supportive."

“Schools say they will support by making a plan for college once we know which college can support needs but EHCP is held up with L.A. My child doesn’t really know what she wants to do in the future, and the future frightens her.”

“Suffolk County Council not finalising the EHCP with in the legal time has had a massive impact on my son and family . Leaving him not knowing where he will be going to in September is having a massive effect to his mental health.”

“I feel there is nothing else [to] support. Recently done a 10 minutes post 14 Teams. All I got was go and look at colleges. I have been told by who I have contacted they will say no because my child has severe learning disabilities not moderate. So who can meet his needs at post 16? He cannot stay at his special needs school cos they don’t have a sixth form… you can stay until 19 but he has not been offered.”

“No support available for education transitions just bog-standard careers advice which is no good for SEND children who've missed education or are behind peers academically and need to catch up... Huge gap here! Very difficult to find a way for my post 16 child to do GCSEs and no support from SCC.

“It has been very challenging and not straight forward I have had to do everything for my daughter alone… My daughter’s aspirations are not taken into account at all. In fact, she has no voice and she is perfectly capable of saying what she wants. We have had no representation at annual review or adult plan.”

“I’ve not had any help or guidance. My son is 18 soon and I’m having to find everything out on my own. He definitely did not have any preparation as he was left without a school place from year 9-11. He has been terribly failed by the system. There needs to be better support and help and guidance for planning and preparing for adulthood.”

“The transition reviews often feel like administrative formalities rather than genuine life planning…

If my child isn’t going to a standard college course, the options on the table are often non-existent… I feel let down by the lack of meaningful work opportunities… I see many young adults stuck on a merry-go-round of "life skills" courses at college.

They do Level 1, then another Level 1, simply because there is no supported job to go to…. It feels like unless I personally find an employer and convince them to hire my child, it won't happen.”



Health and social care

Parent responses



Getting long-term support from services

Parents were asked whether their child receives long-term support from the NHS or social care.

- **35% (61)** reported that their child does receive long-term support
- **65% (112)** reported their child does not receive this support.

Parents whose children were receiving ongoing support were asked whether their child had already transitioned to adult services or was expected to in the future.

- **56% (95)** did not know. The fact that many parents did not know whether their child would move to adult services may reflect that the sample was mostly of parents of younger children.
- **12% (21)** reported that their child had already moved to adult services.
- **32% (55)** said their child will move to adult services in the future

Knowledge of transitions

35% of parents said their child received long term support from health or social care services. However, **56%** did not know whether their child would transition to adult services in the future.

56%



Have they transitioned to adult services?	%	Count
They will move to adult services in the future	32%	55
They have already moved to adult services	12%	21
I don't know	56%	95

Qualitative responses

Parents were asked about transitions form children's to adult health and social care services. Those who had not transitioned yet were asked about their experience of planning for transition. There were 30 responses.

Twenty parents mentioned a poor experience. These are considered according to the stage of transition below.

- **Ten parents said their child had already moved to adult services.** They described challenges in social care, including gaps in support following transition. Others mentioned difficulties with communication or feeling involved. For example, **one** person received no preparation before transition, and another said adult services did not join their transition meetings. Comments did not always state services people were using but described similar themes like being left with 'no support' or that transition caused 'significant stress'. One specifically referred to transition in NHS services. They said, "There was no transition, with some services stopping due to them not being provided within adult services".

- **Twelve parents said their child will move to adult services in the future. C**omments indicated that people did not feel supported or had not received information about what transition would mean. Some described feeling "in limbo" or explained they were concerned therapies or services would end, such as support from CAMHS, respite care, or paediatric therapy. **One** person highlighted that social care would not pay for transport or day care between the ages of 16 and 18.

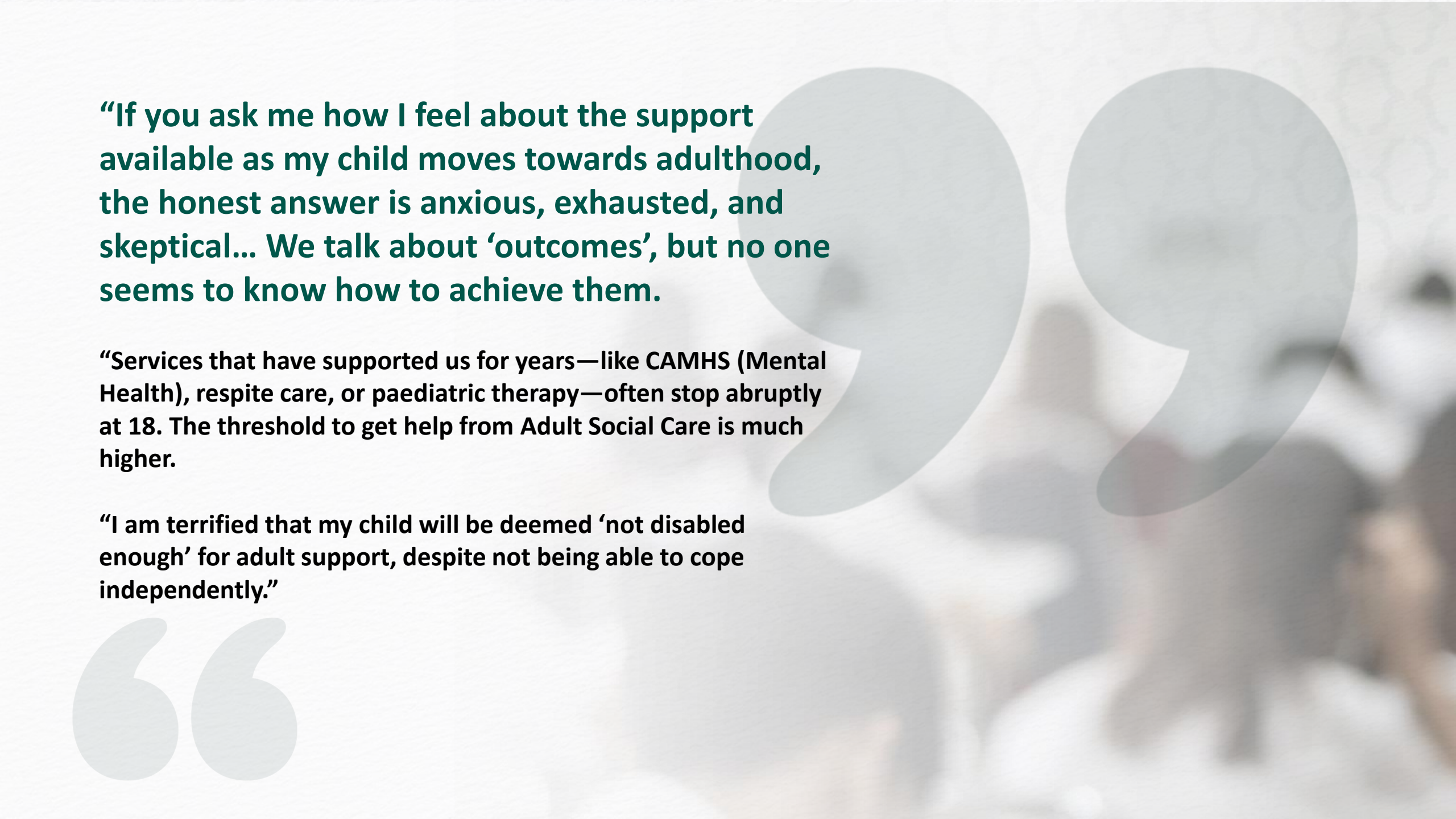
- **Three people did not know whether their young person would transition in the future.** Their comments included that they had received no information or support, they did not know what local provision there was to transition into, and that autism services would no longer support them because they were over 18.

> *"There was no support. During transition meetings, adult services declined to join. When our young person transitioned out of education into an appropriate provision, adult services attempted to stop this and 'explore other provisions'. Our young person needs a transition that is supported over months not a few sessions."*

“If you ask me how I feel about the support available as my child moves towards adulthood, the honest answer is anxious, exhausted, and skeptical… We talk about ‘outcomes’, but no one seems to know how to achieve them.

“Services that have supported us for years—like CAMHS (Mental Health), respite care, or paediatric therapy—often stop abruptly at 18. The threshold to get help from Adult Social Care is much higher.

“I am terrified that my child will be deemed ‘not disabled enough’ for adult support, despite not being able to cope independently.”



Two parents offered a mixed view of their experience of support for health and care transitions.

One person felt their child's transition was 'poorly handled', saying they had three different reviews and had to explain their circumstances each time. However, they were also positive about some of the support they received from their child's social worker, noting they had been 'amazing and did their best to get it all sorted'. Another parent said NHS annual health checks were helpful for their child but experienced a lack of support from social care.

Two parents were entirely positive about transitions in health and social care.

One comment indicated the family had always had support from the children's team at Suffolk Council. They noted that their daughter had always been listened to and asked for their opinion. Their comment is shown on the next slide. Another said they were "currently on Step Down", or in the process of moving to adult services. They were positive, saying information was provided when they asked.

"My child has clear social care needs due to disabilities and care expertise. CYP social care support has been tokenistic or non-existent. Social care staff have no apparent training or appreciation for the needs of a learning disabled child and blamed him and me when we reached crisis point. The transition to adult social care didn't happen and, post 18 he still has no social care support or care plan despite clear need. Throughout, social care have ignored our views and produced 'assessments' to their own template. The one-size fits all approach. I am his sole carer, and there is no backup plan. Should I die or become incapacitated, the young man will have no support whatsoever. The Council know this but don't care."

“Support from SCC children’s team has always been provided when asked for, and we are currently in the Step Down process and moving over to Adult Services.

“My daughter has always been asked her opinion, which, in her own way she has given, been listened to and interpreted as best as possible.”



Community & Independence

Parent responses



Activities in the community

Parents were asked whether their young person takes part in activities or groups in their local community.

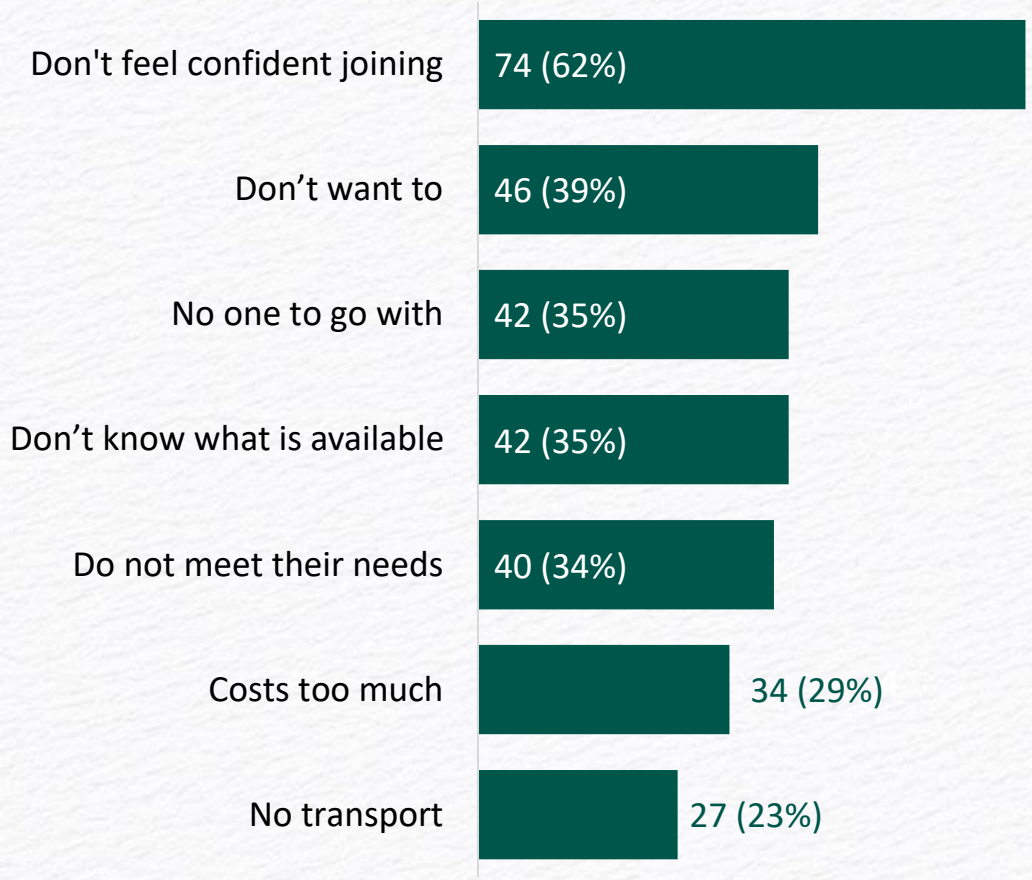
- **23%** (**40**) said their child participated in community activities or groups, while **76%** (**131**) said their child did not. One did not know.

Parents were also asked what stops their child or young person from taking part in groups or activities.

- The most common response was their child does not feel confident joining (**62%/74**). This was followed by their child not wanting to take part (**39%/46**), their child not having anyone to go with (**35%/42**), or not knowing what is available nearby (**35%/42**).

- Parents also offered other free-text responses as follows:

  - Anxiety (five)
  - Difficulties socialising or feeling that they did not fit in (four)
  - Sensory needs or becoming overstimulated (three)
  - Their individual communication needs (three)
  - That there is nothing available near them (three)
  - Or that they live in residential care (two)



% - barriers to participating in community groups

Accessing support

Parents were asked whether they had accessed support from any of the organisations listed in the table to the right.

- The services parents had accessed most were SENDIASS (**75%/77**), Local SEND offer (**51%/52**), and Suffolk Family Carers (**49%/50**).

- A total of 33 parents left a free text response. They included:

  - PACT [Parents and Carers Together] (5)
  - IPSEA [Independent Provider of Special Education Advice] (4)
  - SOS!SEN (2)
  - Special Needs Jungle (1)
  - Local MP (1)
  - Activities Unlimited (1)
  - Autism and ADHD (1)
  - Lapwing (1)
  - Private psychology (1)
  - SEND Compass (1)
  - Suffolk Family Carers (1)
  - Zest (1)
  - Not Fine in School (1)

Services accessed	%	Count
SENDIASS	75%	77
Local SEND offer	51%	52
Suffolk Family Carers	49%	50
ACE Anglia	3%	3
Scope	2%	2
Sensing Change	2%	2
Suffolk User Forum	2%	2



My Health, Our Future results

Introduction

My Health, Our Future (MHoF) is a unique research programme that explores the physical and mental wellbeing of children and young people.

Since 2015, the MHoF programme has offered yearly insights into the wellbeing of young people in Suffolk. The data has supported schools, colleges, and integrated care systems to improve support for children and young people, make decisions about services, attract funding for local support, and inform strategies around young people's health and wellbeing.

The programme has recorded **nearly 75,000** responses from young people on topics like bullying, body image, anxiety, and many others. Topics in the survey may vary according to co-production with local young people and professionals, which helps to ensure the findings remain relevant and supports maximum impact from sharing the data. Some aspects of the survey remain consistent across years.

This section presents findings from phase nine of the MHoF programme and specifically the responses from young people who self-identified as having special educational needs and disabilities.



2,053

responses were from students with SEND (21%). This compares to 21% (1,765) in 2024 and 16% (2,120) in 2023.

These young people self-selected statements from a list that included ‘I have autism, Asperger’s syndrome or ASD’, ‘I have ADHD’, ‘I have a sensory disability’, ‘I have a physical disability’, and ‘I have special educational needs’.

Year after year, MHoF data has shown that students with SEND are considerably more likely to experience lower levels of wellbeing.



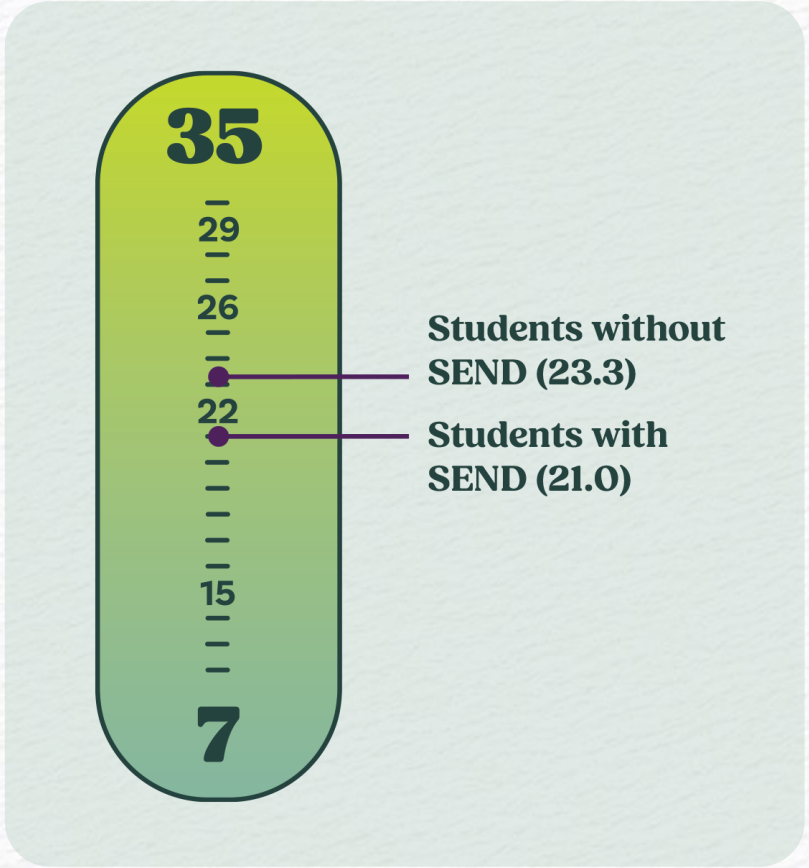
Wellbeing (SWEMWBS)

Overall wellbeing was measured using the Short Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS).

The SWEMWBS asks students to respond to seven statements about their wellbeing. Responses are combined to give a score between seven and 35, where a lower score indicates lower wellbeing.

Out of **9,717** students surveyed, **21% (2,053)** were identified as having special educational needs (SEND).

- The average wellbeing score for young people in Suffolk is **22.8**.
- The whole-sample average wellbeing score is the same as recorded in 2024 and follows the lowest recorded levels in 2020 and 2021 after the COVID-19 pandemic.
- Students with SEND reported lower average wellbeing **(21.0)** compared to students without SEND **(23.3).**



Personal Wellbeing Scale

The Office of National Statistics (ONS) Personal Wellbeing Measure (PWB) asks people to rate their wellbeing across four questions.

Each question is scored from zero to ten. The first three questions assess life satisfaction, feelings that the things done in life are worthwhile, and happiness. Responses are grouped into the following categories:

- 0 to 4: Low
- 5 to 6: Medium
- 7 to 8: High
- 9 to 10: Very high

The fourth question relates to anxiety, which is categorised differently to reflect that higher anxiety is associated with lower personal wellbeing. The scores are grouped as follows:

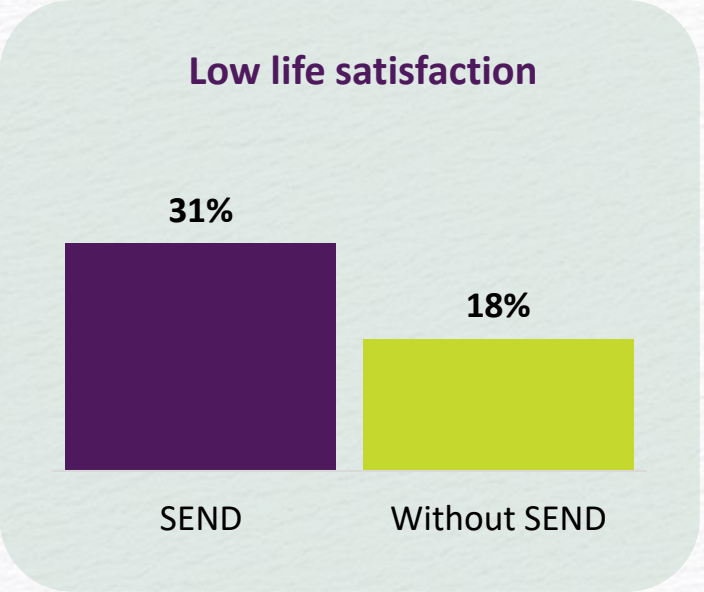
- 0 to 1: Very low
- 2 to 3: Low
- 4 to 5: Medium
- 6 to 10: High

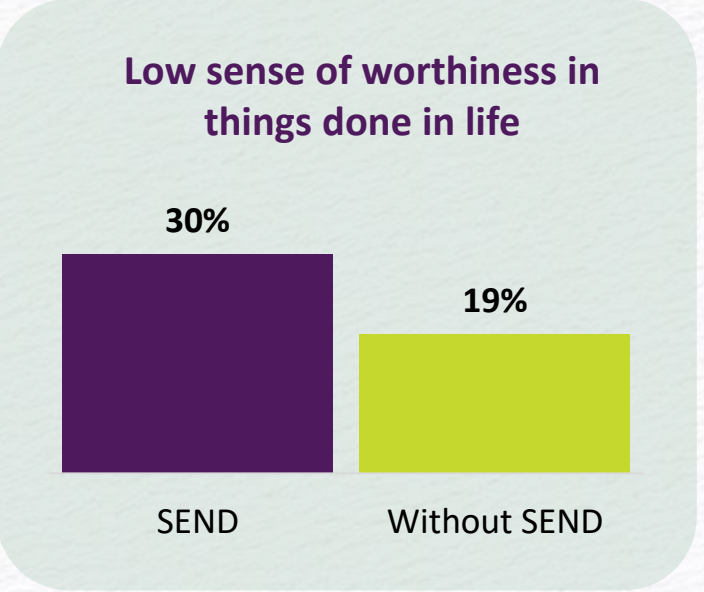
More details are available on the ONS website: here.

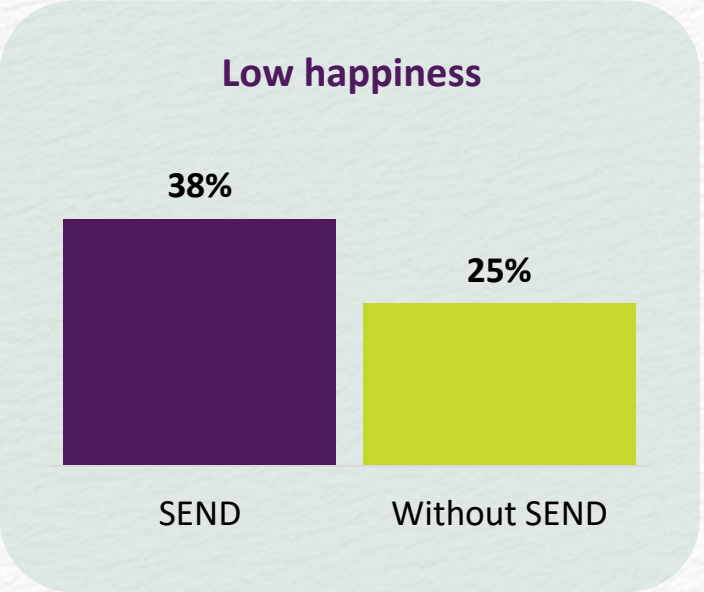
Note: Comparison should be treated with caution due to differences in sample sizes.

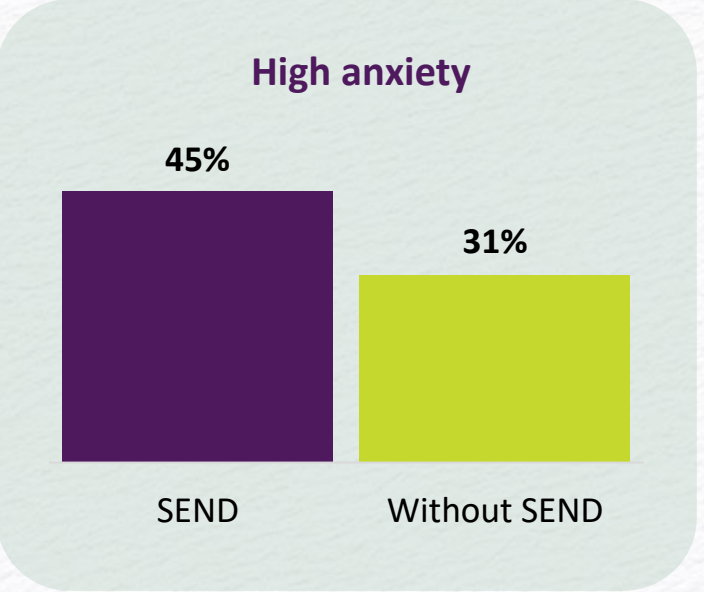
Students with SEND:

- **Had lower levels of life satisfaction:** Students with SEND reported lower life satisfaction than students without SEND.
- **Were less likely to indicate things they do are worthwhile:** Students with SEND reported a lower sense that things they do in life are worthwhile, compared to their peers. Almost a third measured low for this category.
- **Reported lower levels of happiness:** Students with SEND were more likely to report low happiness scores than their peers. This was true of nearly two in five students with SEND.
- **Indicated higher levels of anxiety:** Approaching half of students with SEND reported high anxiety levels.









Control over future

Feeling in control helps us feel safe and secure. Autonomy, which means being able to make your own decisions without interference from others, is connected to better mental health and greater motivation (The Positive Psychology People, 2023).

We asked students about how much control they felt they had over shaping their futures.

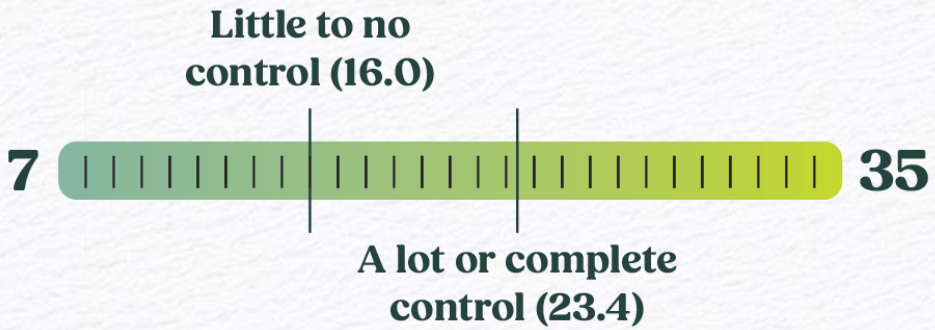
- Students with SEND were less likely to feel in control of their future compared to their peers without SEND. Half **(50%)** reported having a lot or complete control, compared to **62%** of students without SEND.
- Students with SEND were more likely to report little to no control over their futures **(17% vs 10%).**
- Students' sense of control over their future is closely linked to their wellbeing. SEND students who reported having a lot or complete control had much higher wellbeing scores **(23.4)** compared to those who felt they had little to no control **(16.0).**

	With SEND	Without SEND
A lot/Complete control	50% (905)	62% (4,184)
Little/ No Control	17% (301)	10% (650)

A lot or complete control over future



Students with SEND who felt they had little to no control over their future had much lower average wellbeing scores.



Concerns about the future

Future Concerns (Year 9+)

- SEND students in Year 9 and above were asked what concerns they had about the future.

- The most common concern was finding a suitable job **(66%).** This was followed by gaining the skills needed for their chosen career **(55%)** and being able to afford accommodation **(55%).**

Preparation for the Future

- Most students with SEND felt at least somewhat prepared for the future by their school or college **(61%).** However, only **24%** felt very prepared, while **15%** reported feeling not prepared at all.

- Students identified practical support as the most helpful for improving how prepared they feel for their future. Advice on managing money **(53%)** and life skills **(49%)** were most popular options.

- This was followed by better access to internships and work experience **(44%)** and more information about colleges, university, and careers **(42%).**

	%	Count
Finding a suitable job or stable job	66%	741
Gaining skills or qualifications for a career	55%	619
Meeting academic requirements or performance expectations in higher education or the workplace	51%	577
Adjusting to new social environments (Uni/Work)	45%	508
Managing financial pressures or debt	48%	537
Being able to afford stable accommodation	55%	622
I am not worried about my future	13%	145

	%	Count
Information re colleges, university & careers	42%	476
Better access to internships and work experience	44%	500
Training in life skills	49%	559
Advice on managing money	53%	596
Access to mental health support	35%	397
Regular one to ones	24%	276
Support to build confidence	33%	371

Careers

Careers Interest

- When asked about potential career paths, SEND students showed relatively low interest in a career in the NHS **(27%/295)** and in health and social care **(28%/304).**

Transition Confidence (Under Year 9)

- Students under Year 9 were asked how confident they felt about transitioning year groups. The largest proportion felt neutral **(42%),** while only **25%** felt confident or very confident and **33%** felt very worried or somewhat worried.

- The support students felt would help improve their confidence with transitioning was more information about new subjects or how existing subjects will change **(28%)** and advice on future career paths and how GCSE choices might affect them **(28%).**

- This was followed by access to mental health support or wellbeing support **(25%)** and support to build confidence and manage worries about the transition **(23%).**

	%	Count
Assemblies or talks to explain what to expect in the next year group	22%	147
Information about new subjects or how existing subjects will change	28%	189
Support or opportunities to make new friends	18%	123
Advice on future career paths and how GCSE choices might affect them	28%	185
Support to manage my workload	20%	133
Opportunities to talk to or be mentored by older students	13%	90
Access to mental health support or wellbeing support	25%	167
Regular one to ones with mentors or teachers	22%	148
Support to build confidence and mange worries about the transition	23%	153

Thank you for reading this report

This report has been produced to support the ongoing development and implementation of children and young people's mental health and emotional wellbeing support in Suffolk. It will be shared widely with people and services responsible for the delivery of services and strategy, including with schools, colleges, the NHS and Suffolk County Council.

Knowing Works is a social enterprise delivering insights to include people in shaping projects and services that help them. For more information about our services, please visit **www.knowingworks.co.uk** or reach out to our team at **info@knowingworks.co.uk**.

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