

Pinpoint's Mid Year Survey Report

October 2024



Summary Headlines

There has been a particularly low uptake to this survey with only 37 responses received across the 10.5 weeks that the survey was open (we extended the deadline due to the low uptake and made an extra effort to encourage people to complete the survey!). We are aware of other system surveys being carried out by individuals at a similar time and have not had the same level of engagement from professionals to advertise the survey as before. We also did not offer a prize giveaway on this occasion which often helps to encourage responses. Overall, the low impact would seem though to be symptomatic of low parental resilience and anecdotally, we hear that parents are frustrated that although they offer their voice regularly, they do not recognise any tangible change to on the ground services that results.

Of those who did respond, we might characterise approximately $\frac{2}{3}$ to $\frac{3}{4}$ as being unhappy with their experiences which is a rise from the survey in April 2024. There are concerns about the messages we are hearing from those who do not report satisfaction with their experiences of the SEND system in Cambridgeshire. The free text comments demonstrate high levels of dissatisfaction across the board but it is important to embed this in the context that as a forum we are more likely to hear from those for whom things are not working smoothly.

We continue to hear predominantly from parents and carers of school age children and a few whose children are age 0-4 years. This supports the work that we know Cambridgeshire are keen to achieve to identify needs of children and young people earlier and to get them the right support at the right time. However, it is concerning that even those who are early on their journey appear to be struggling to get the needs of their children met. Those who have young people in the Preparing for Adulthood stages are overwhelmingly negative about their experiences. This sits within the context that the majority of parents and carers that we hear from have young people who attend mainstream settings and we know that Preparing for Adulthood is not working well for that cohort.

The survey results offer an opportunity to look at what quick wins can be taken to support parental resilience and to help children and young people to get their needs met earlier in their journey. We know that those in the system are working hard to address these concerns which will not be a surprise to any of them. We also know that there are systemic flaws which are being exacerbated by an extreme lack of capacity.

The issues raised by the survey have already been raised by Pinpoint over the last 12 months and are well known to the Local Authority and Health – there are no surprises and the areas identified by Pinpoint and this survey have been agreed as priorities: compliance, Preparing for Adulthood/transitions and improving SEN Support.

Key messages

Free text commentary predominantly reflects frustrations and disappointments – it is rare that we get positive feedback from this section of the survey.

Statutory Assessment team communication and compliance with timescales continue to be a concern with parent carers using words such as battle and fight.

Preparing for Adulthood continues to cause concern in terms of those cliff edge finishes for young people.

Parent carers are concerned about the siloed working of professionals and systems meaning that they regularly have to explain their situation repeatedly.

There is cause for concern about a lack of social care support for children and young people with SEND.

Waiting times for Education Health and Care Needs Assessments, diagnostic assessments and mental health support are too long and there is a lack of support for those who are waiting, often without communication about how long the wait might be.

Many parent carers are seeking private support but this creates a divide for those who have the means to be able to do this, and those who do not.

Parental resilience is exceptionally low with parents talking about burnout in themselves as well as their children and young people. This raises concerns about their ability to be able to continue in their caring role and the additional pressure that this has the potential to add to an already struggling system.

Review by questions

- Parental confidence about their engagement has decreased since April 2024, with some parents stating that they were not asked for their views, even in statutory processes.

Over half of the parent carers who responded are confident that they do understand their child's needs well, but 40% reported that they do not feel confident about this. Alongside this, 75% of parent carers state that they have not been given any help to understand their child's needs.

Alarming, over half of parent carers that responded do not feel that professionals working with their child or young person have a good understanding of their needs.

94% of those responding told us that it is challenging to get their child or young person's needs met.

- Too many (we hear from) only get needs met by recourse to a dispute.

9.5% of those who responded report that EHCP's were only issued after a tribunal. Whilst nobody selected that their dispute had been settled at mediation.

47% of those we heard from have an Education, Health and Care Plan in place for their child or young person suggesting that things are difficult for families even with this high level of support in place.

- The legal requirements are either poorly understood and inconsistently implemented or are unknown and non-compliant in some cases.

Nearly half report that they had no involvement in SEND processes and nearly 70% are not

satisfied with the ongoing monitoring and assessment of their children's needs.

- There remains work to be done to ensure all services are considered to perform well and work together around the family.

Nearly $\frac{3}{4}$ of parent carers are dissatisfied with how well services work together.

Around half of the respondents told us that they are unhappy with the service they receive from education, with around $\frac{2}{3}$ of respondents being unhappy with the service that they receive from health. Nearly $\frac{3}{4}$ of respondents were negative about the support that they receive from social care. We should caveat this by saying that approximately 50% responded 'other' to the social care satisfaction question so may not be in receipt of social care services, however, there are still 35% of respondents who said that they are unhappy.

40% of those we heard from told us that their child is only accessing education part time or not at all.

- 55% of people we heard from have had a positive experience with searching for information on the SEND information hub (Local Offer) however, 26% of people told us that they have never heard of it.
- 57% of respondents told us that their children and young people do not feel included in out of school activities with concerns such as a lack of variety of clubs outside of sporting activities and a lack of appropriate support in clubs being cited.
- · Preparing for Adulthood remains a priority – it's not universally known by the target group and what is known does not fully reflect an offer beyond that of education.

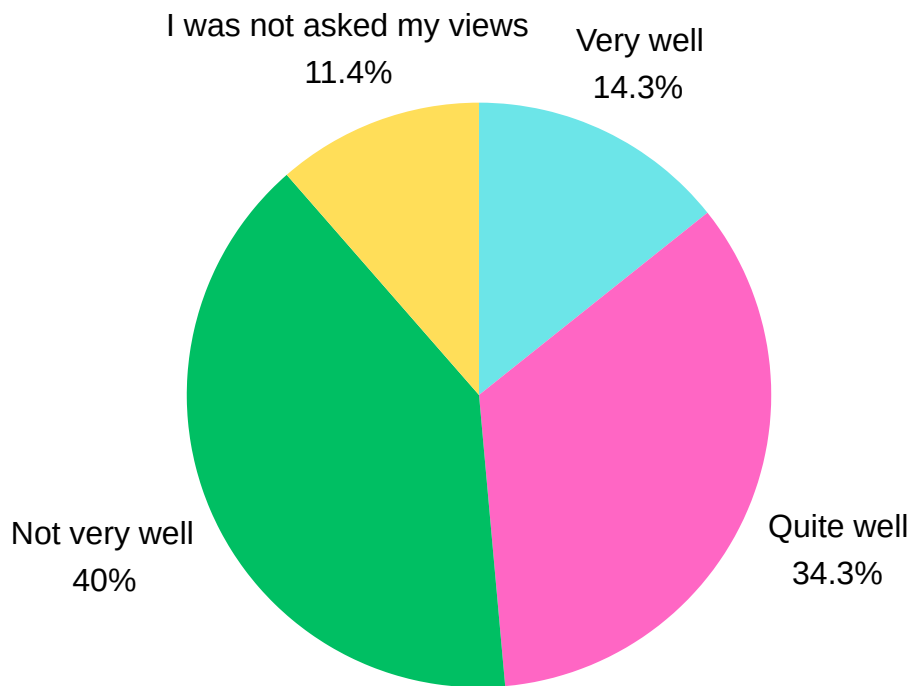
78 % of those we heard from reported a negative experience at age 14+ and 100% of those we heard from told us that their experience at 18+ was negative and they were not well informed or not informed at all.

We only heard from people that they had information in Preparing for Adulthood about education options and not in other areas.

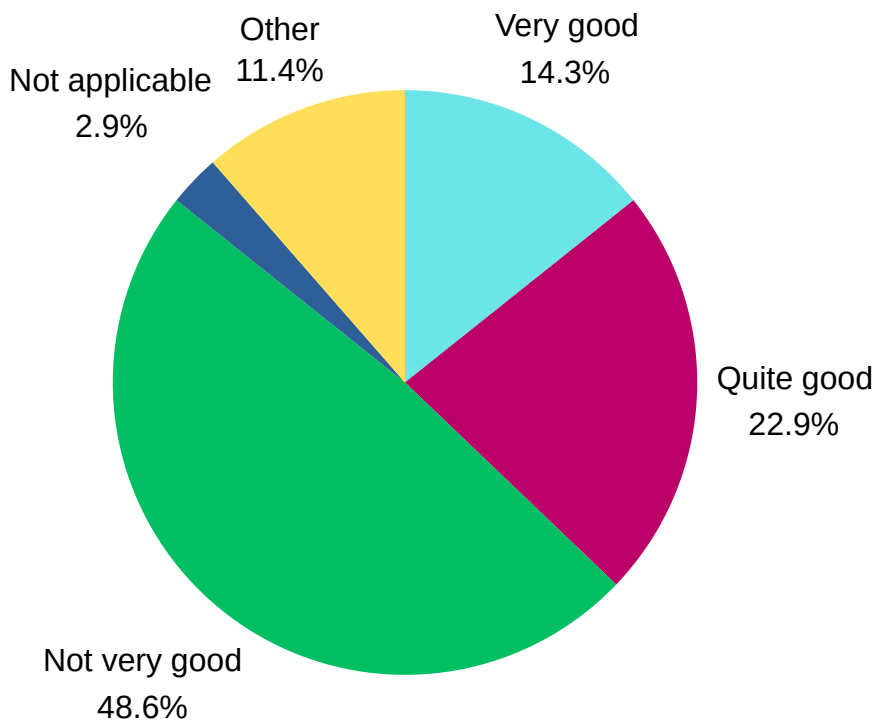
100% of respondents told us that their experience of social care at age 18+ was negative.

Question responses

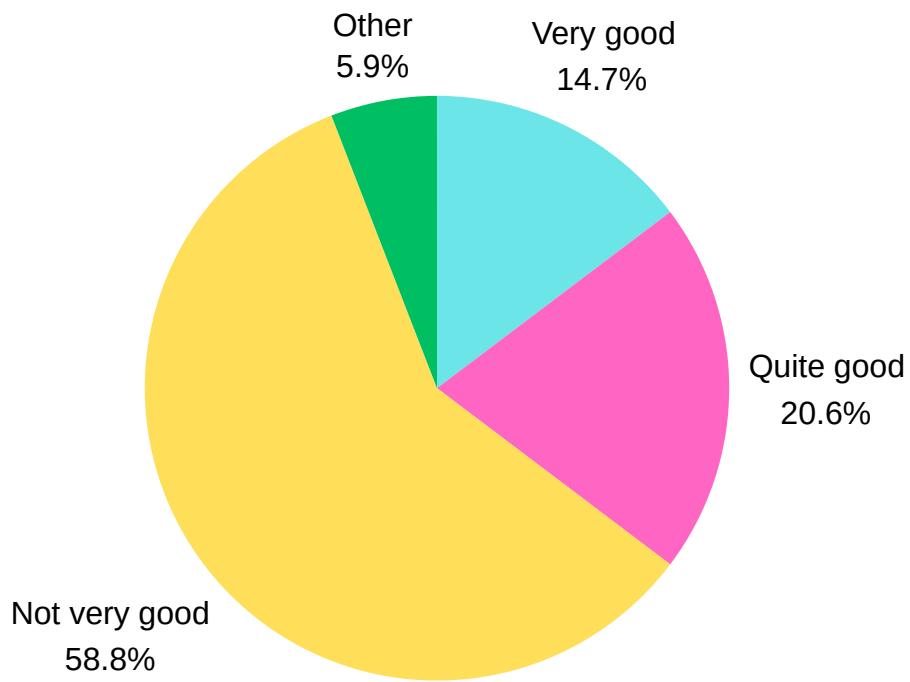
Please tell us how well your views were taken into account to support your child/young person when your child/young person's needs were identified?



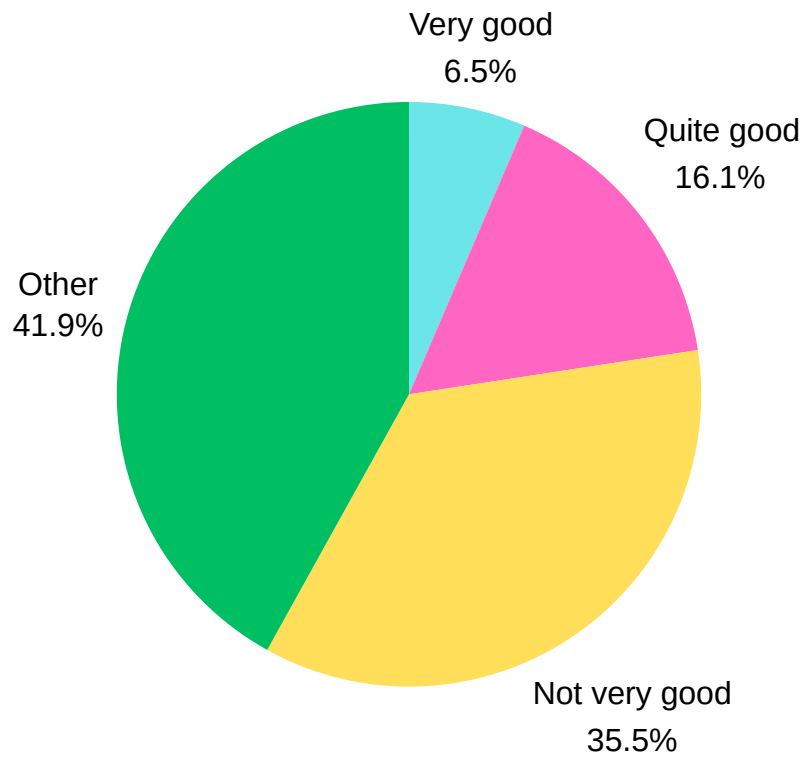
Please rate the support you have received from education services



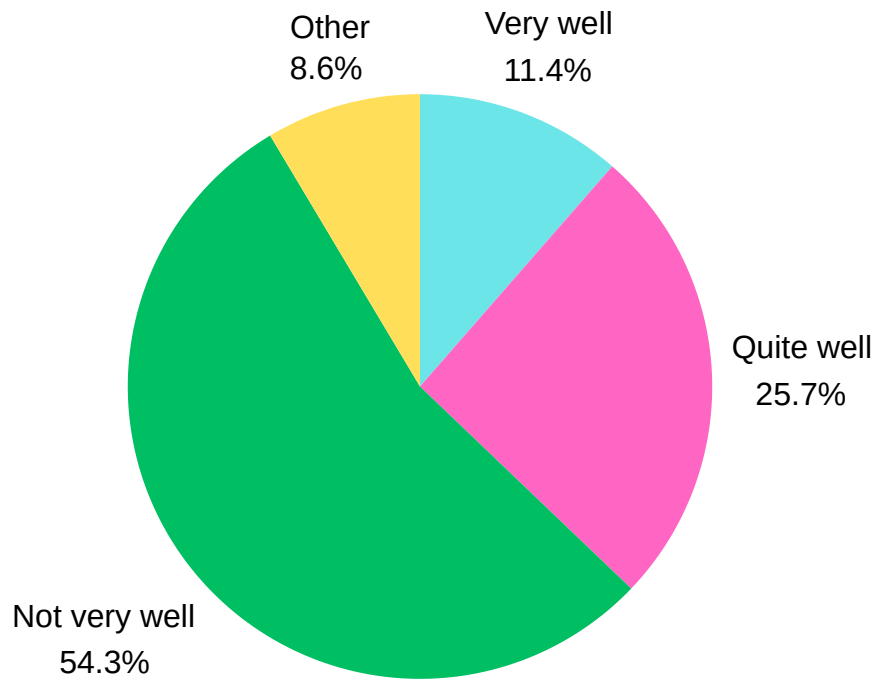
Please rate the support you have received from health services



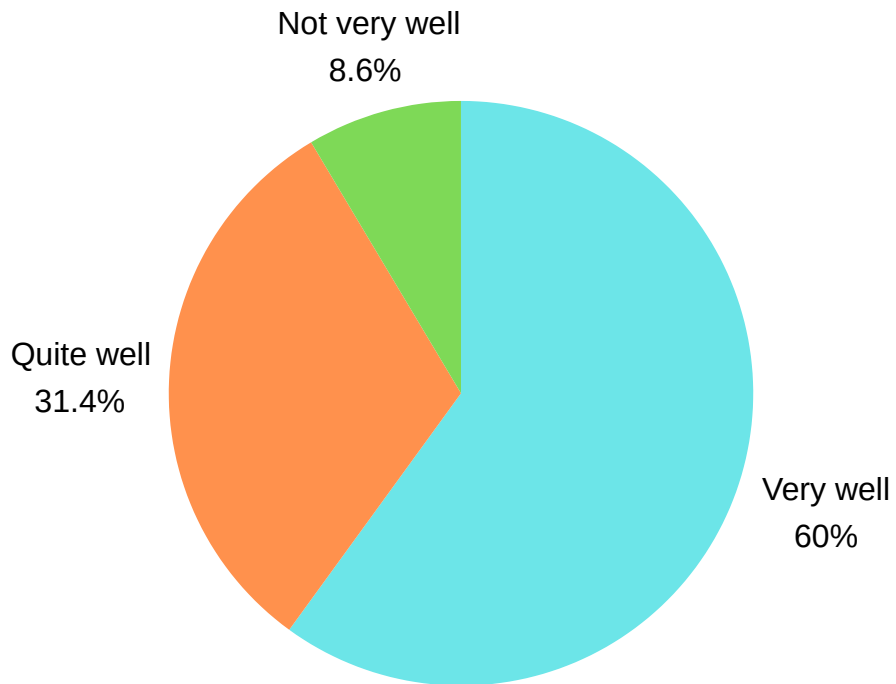
Please rate the support you have received from social services



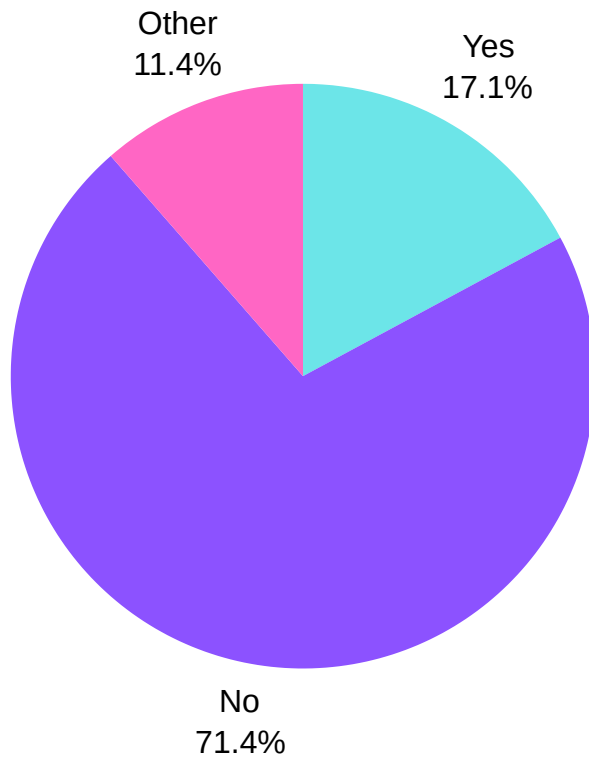
How well do you feel professionals who support your child/young person understand their identified needs?



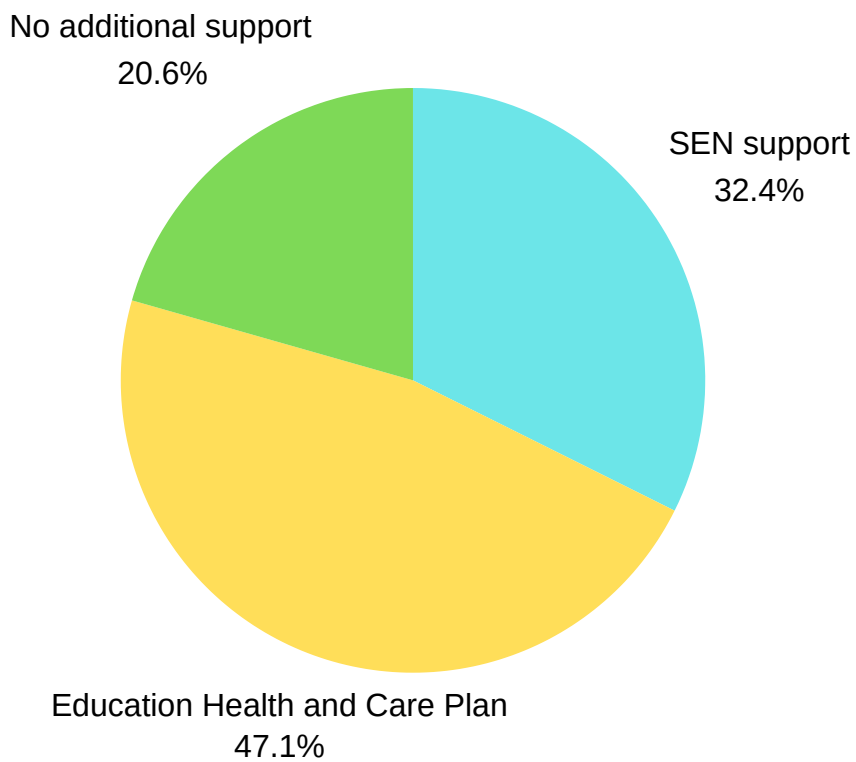
How well do you feel you understand your child/young person's needs?



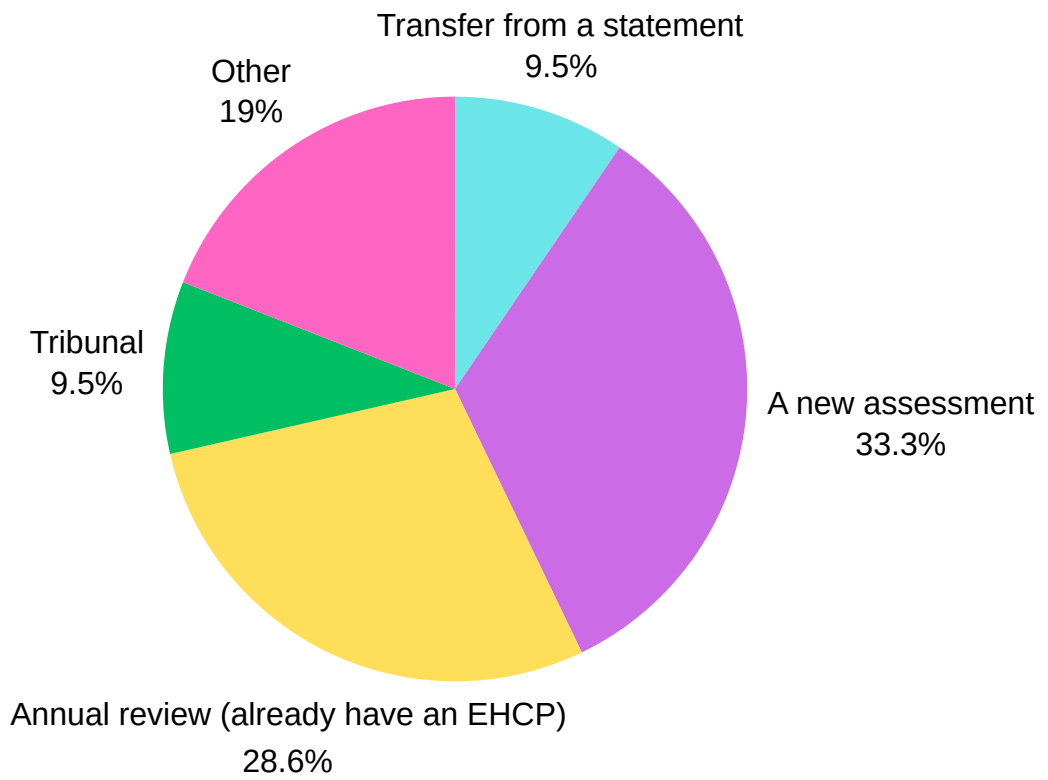
Once your child/young person's needs were identified, were you given any support to help you understand them?



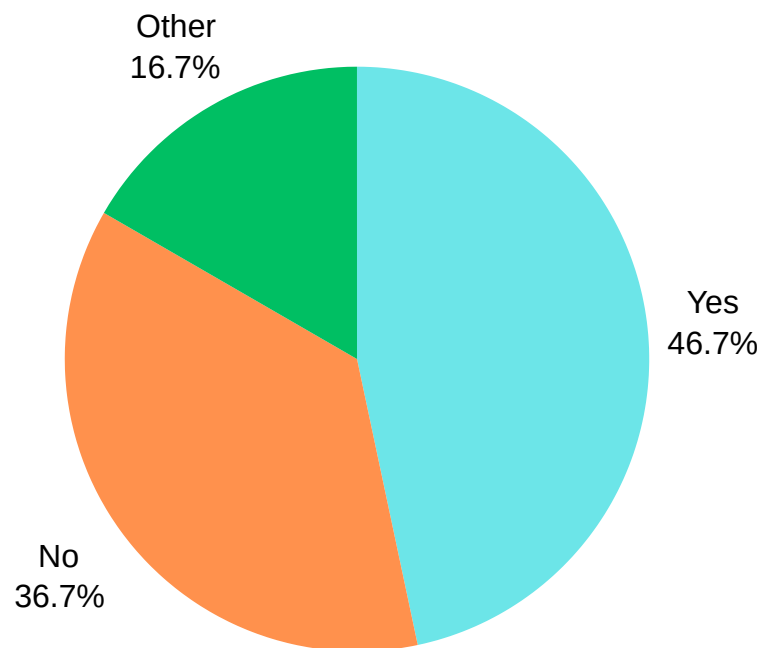
As a result of identifying your child/young person's needs, are they receiving any of the following support with their education?



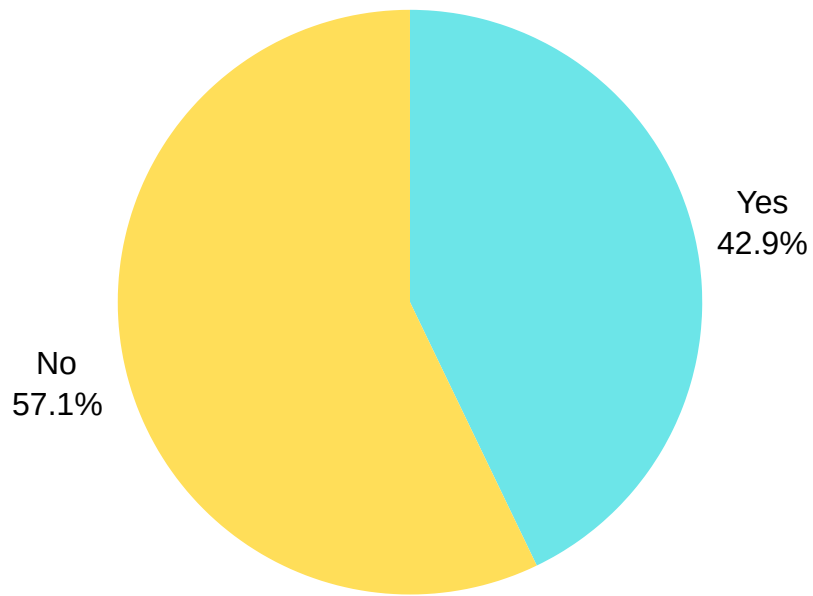
If your child/young person has ECH Plan, was the Plan issued after:



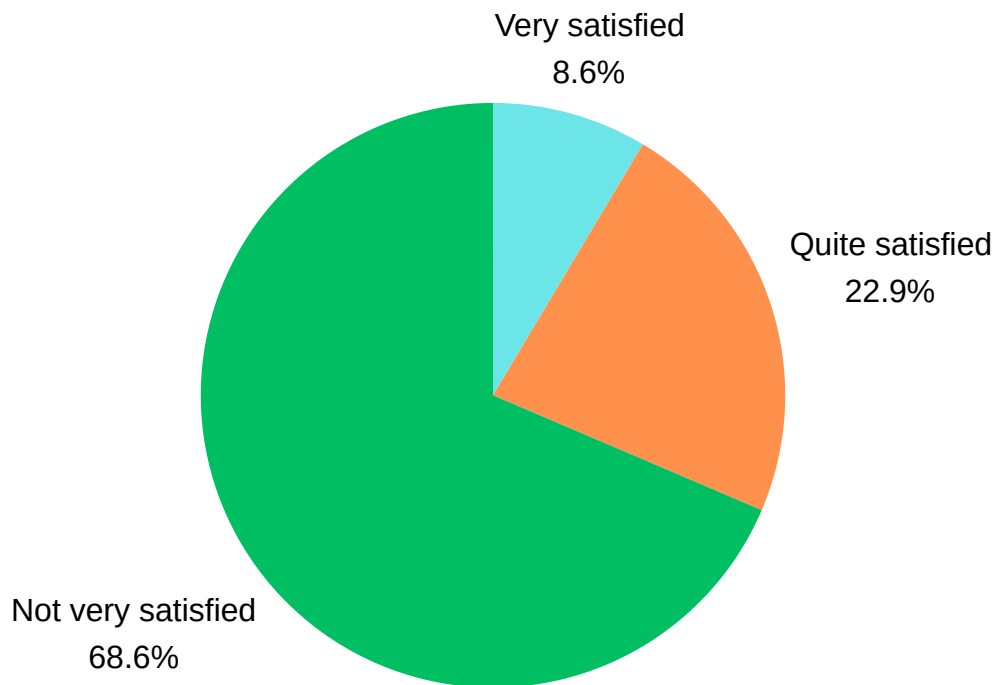
If your child/young person has SEN Support or an EHC Plan, does their education provider involve you in identifying and/or reviewing any support they receive?



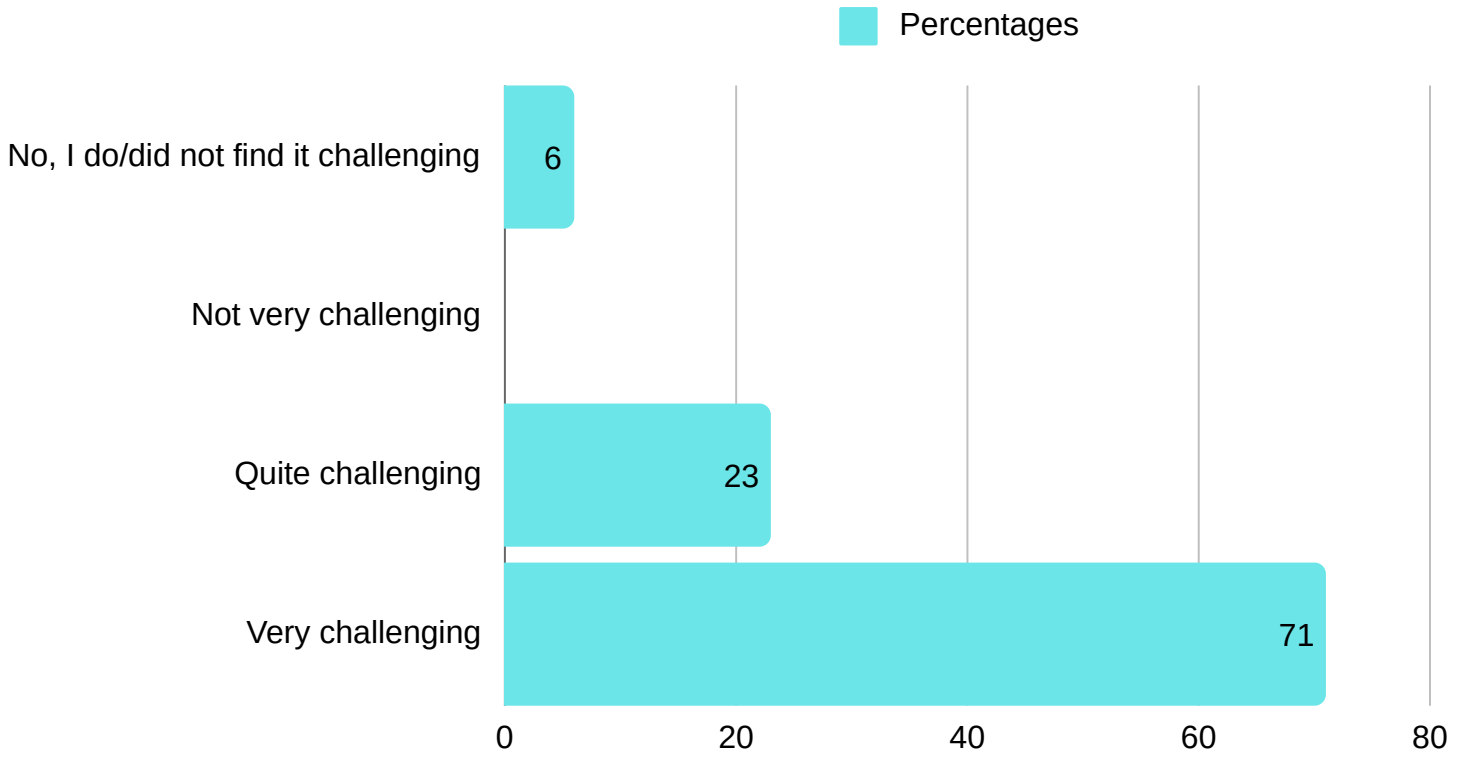
Does your child / young person feel included in out-of-school activities with their peers?



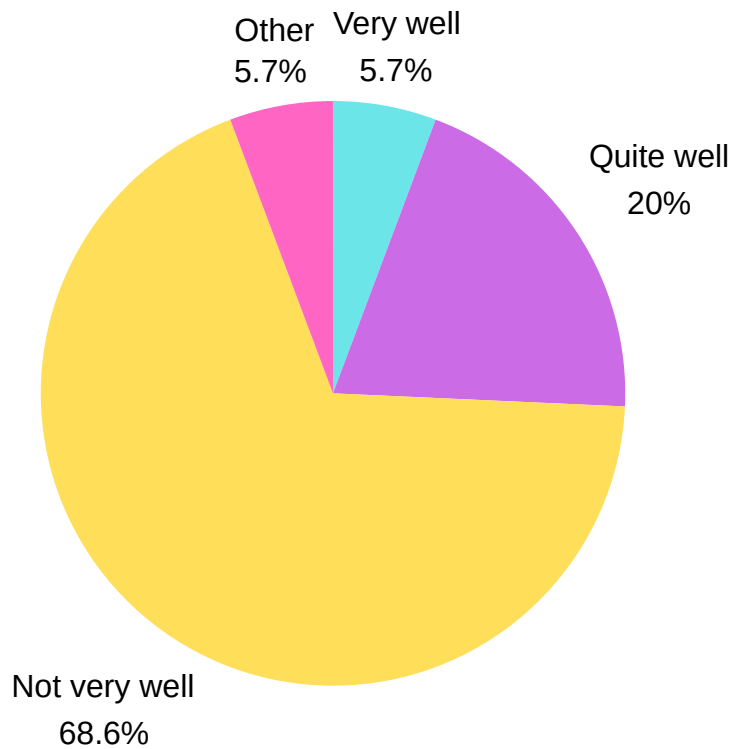
How satisfied are you with the ongoing monitoring and assessment of your child/young person's needs?



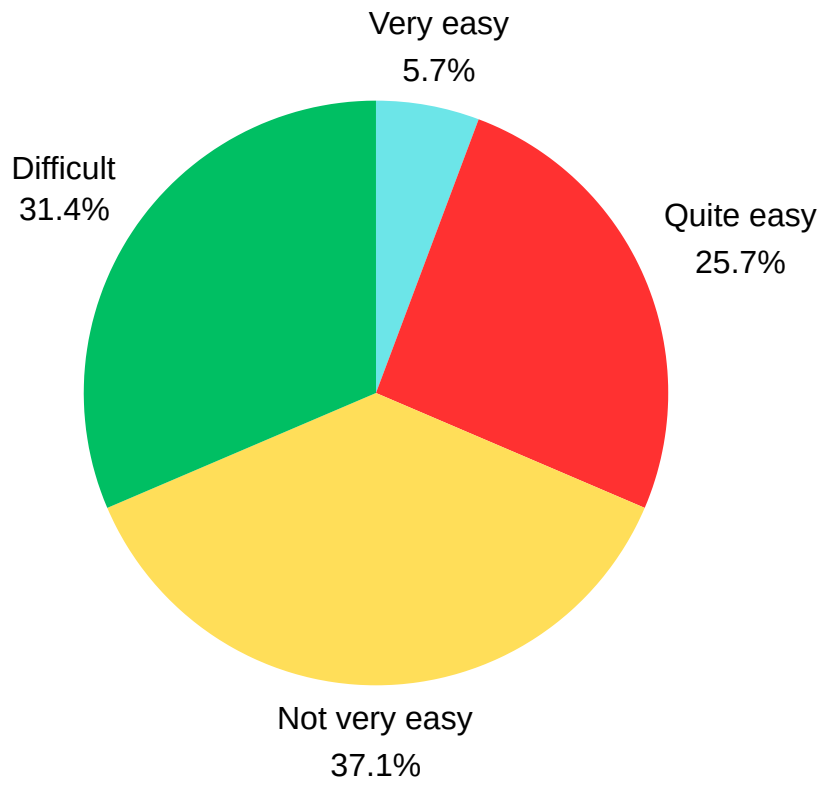
Did/do you find it challenging to ensure that your child/young person's needs are met?



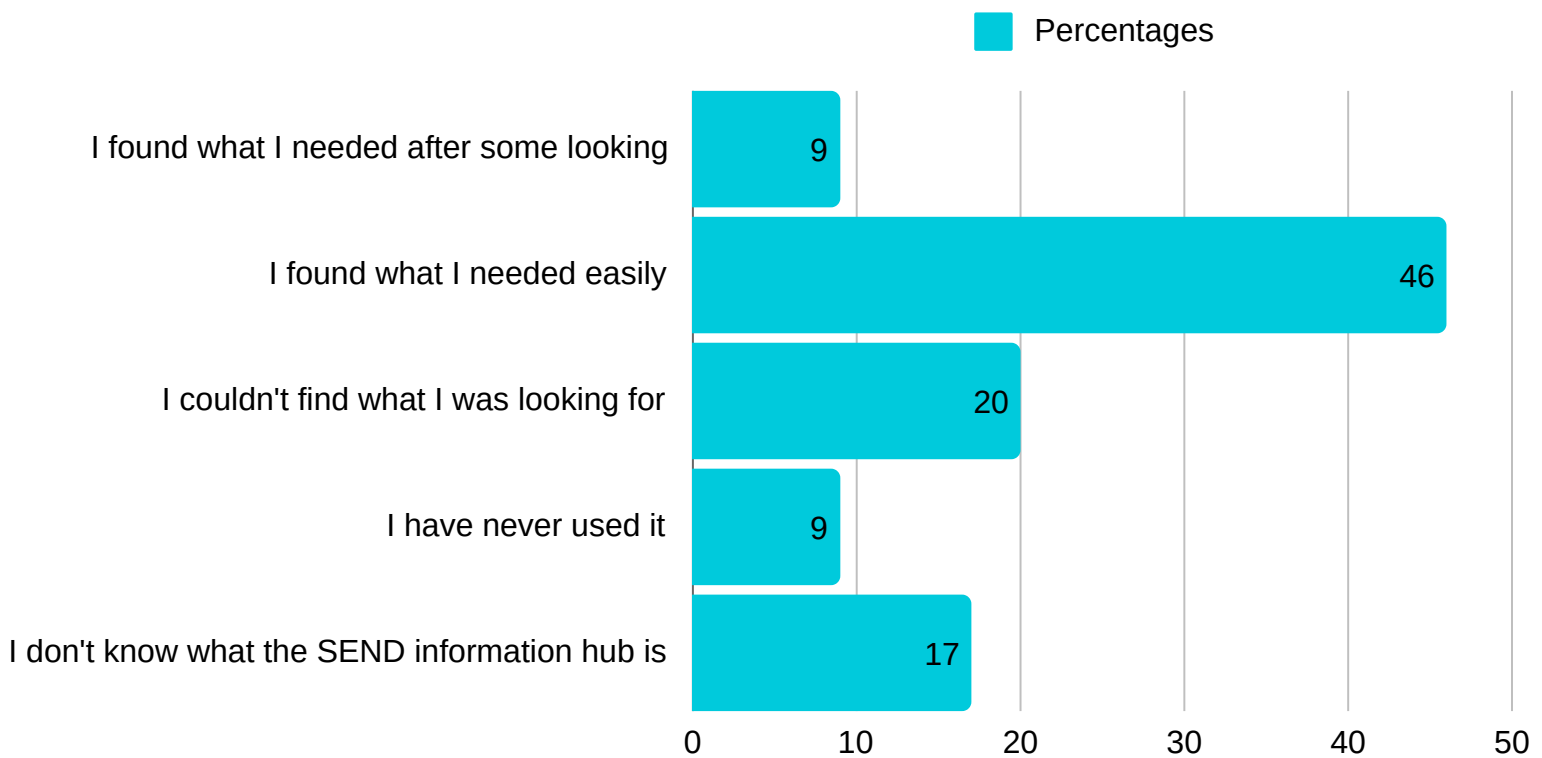
In your opinion, how well do services and professionals work together to support your child/young person?



How easy do you find it to get information about what services are available and what they do?

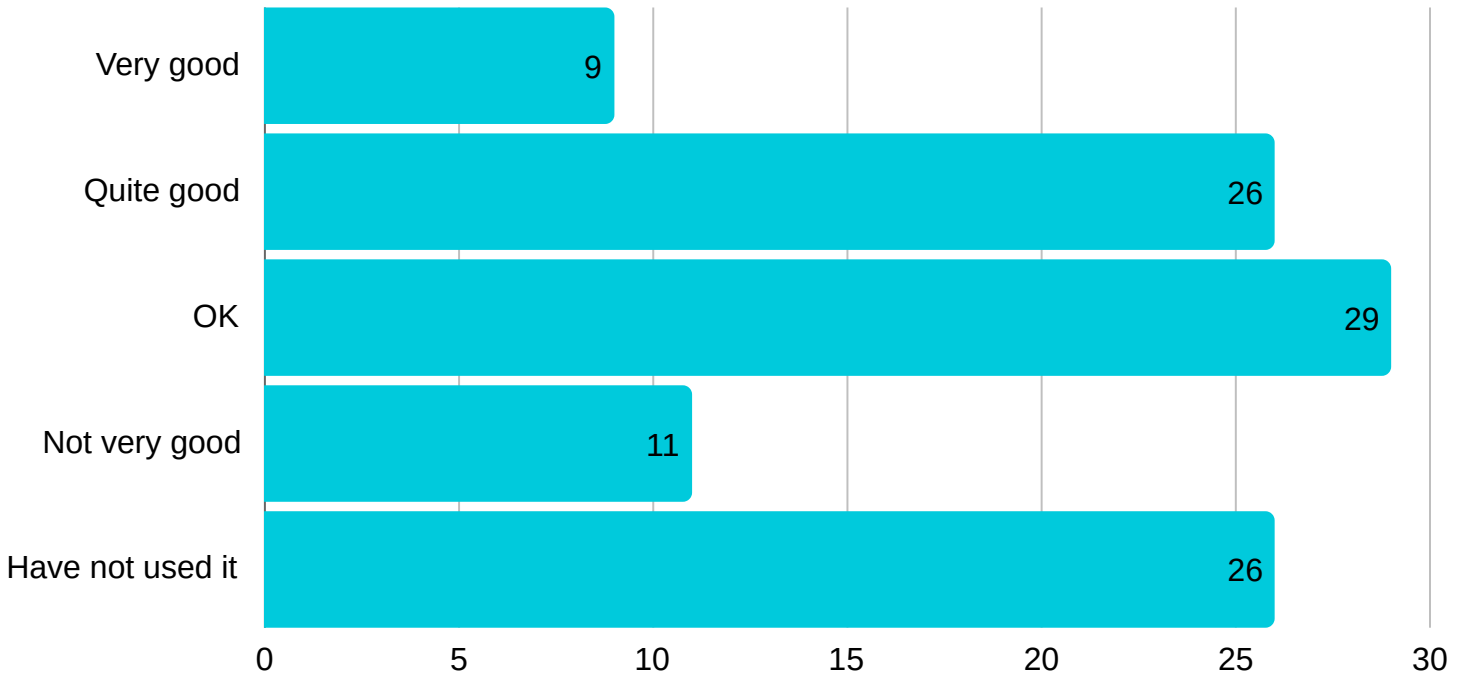


If you have used the 0-25 SEND Information Hub (Local Offer), how easy was it to navigate? Please choose the most appropriate statement.



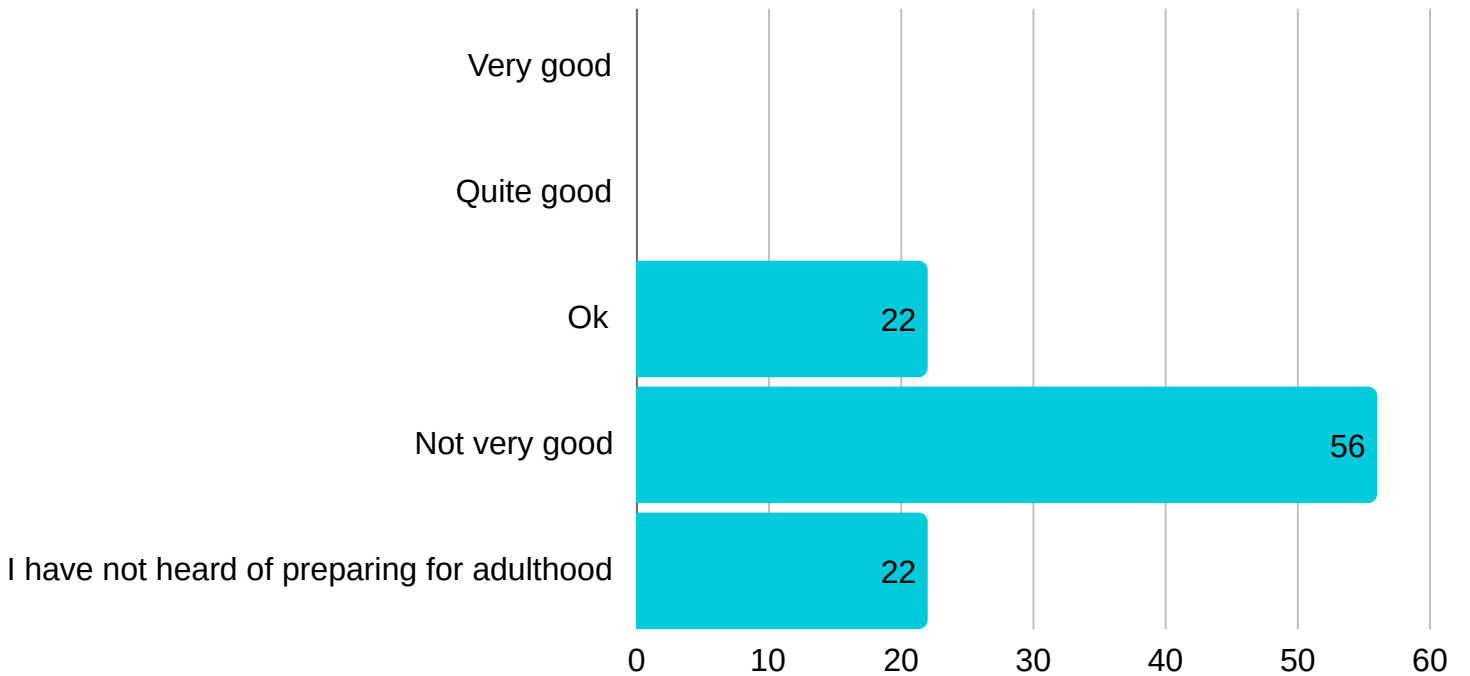
If you've used the SEND Information Hub (Local Offer), how would you rate the information?

■ Percentages

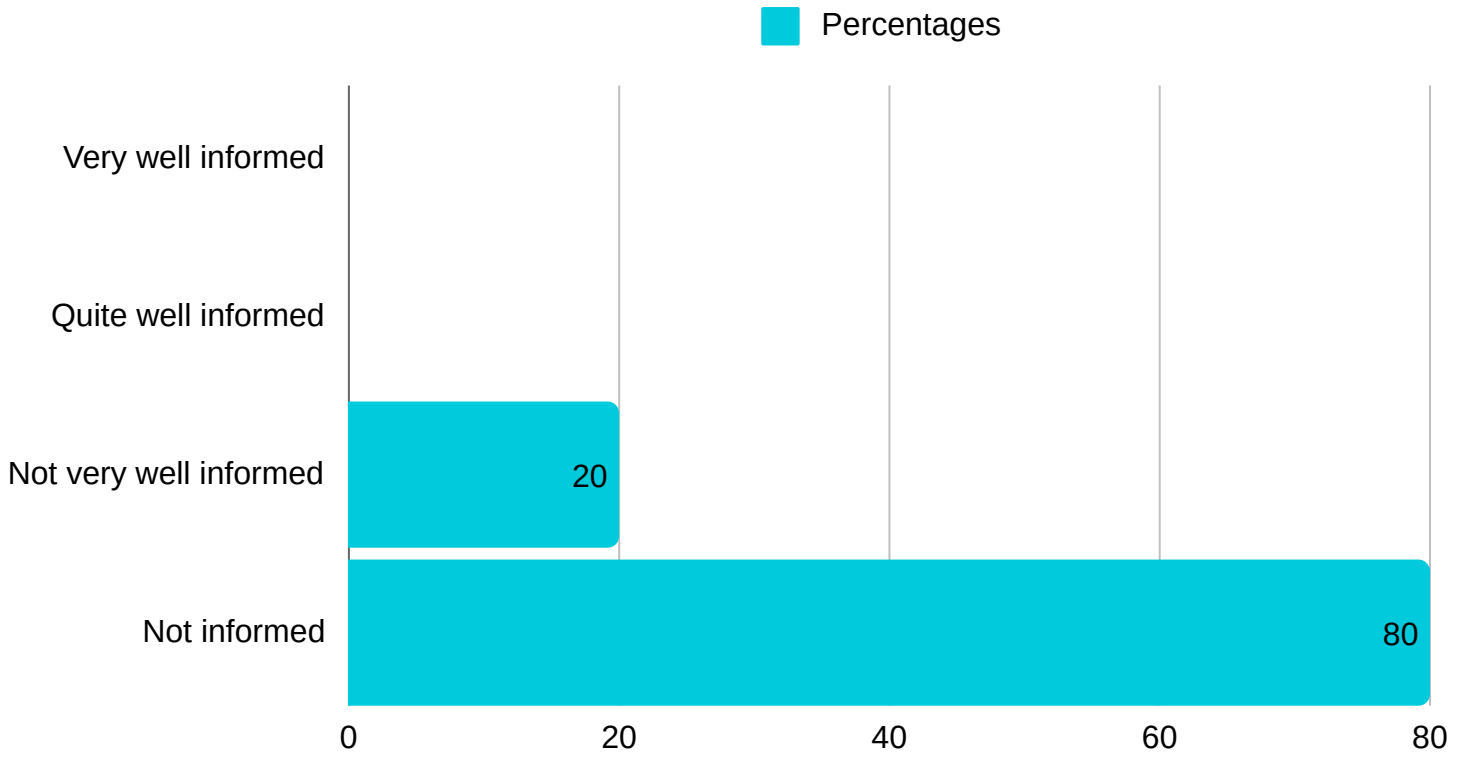


If your young person is older than 14, what has been your experience of the support for Preparing for Adulthood?

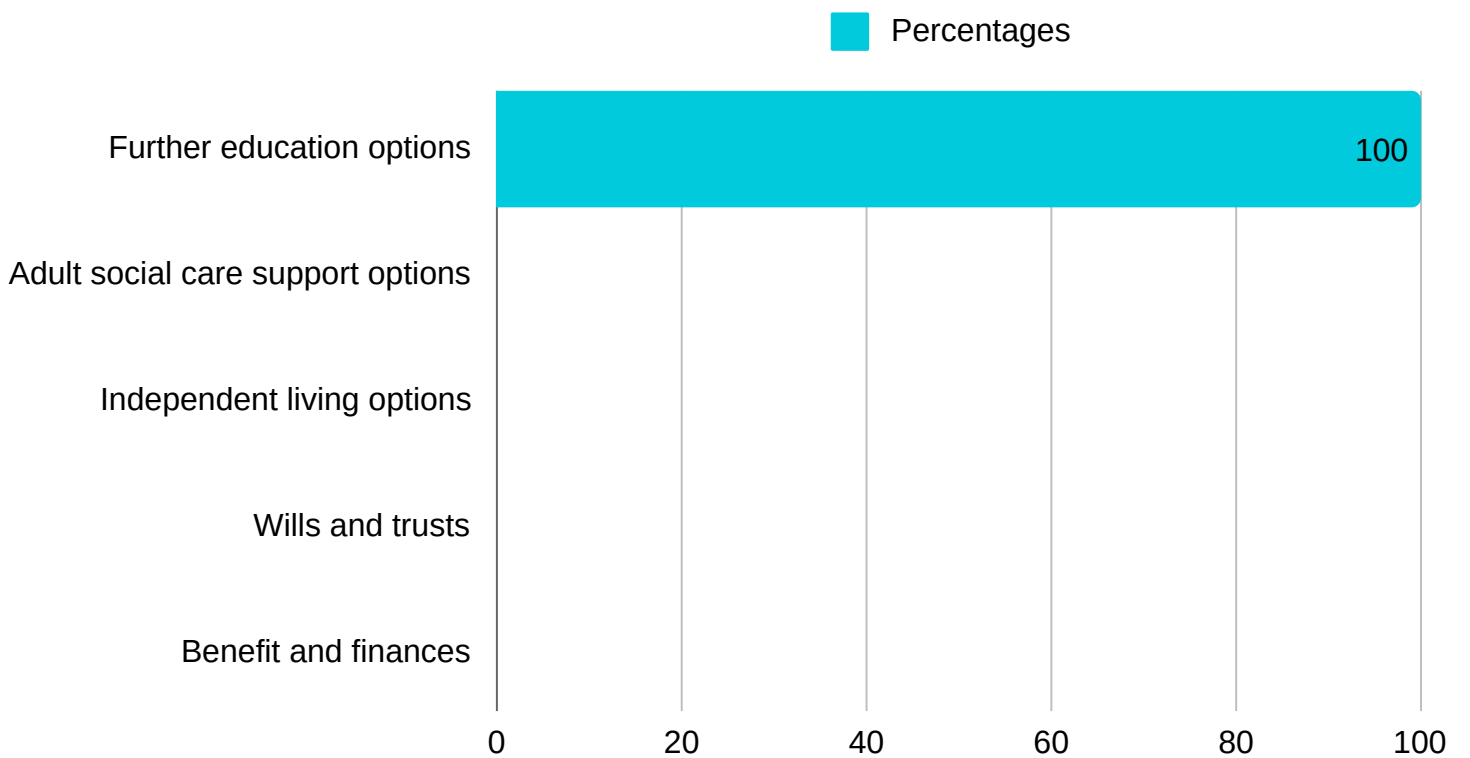
■ Percentages



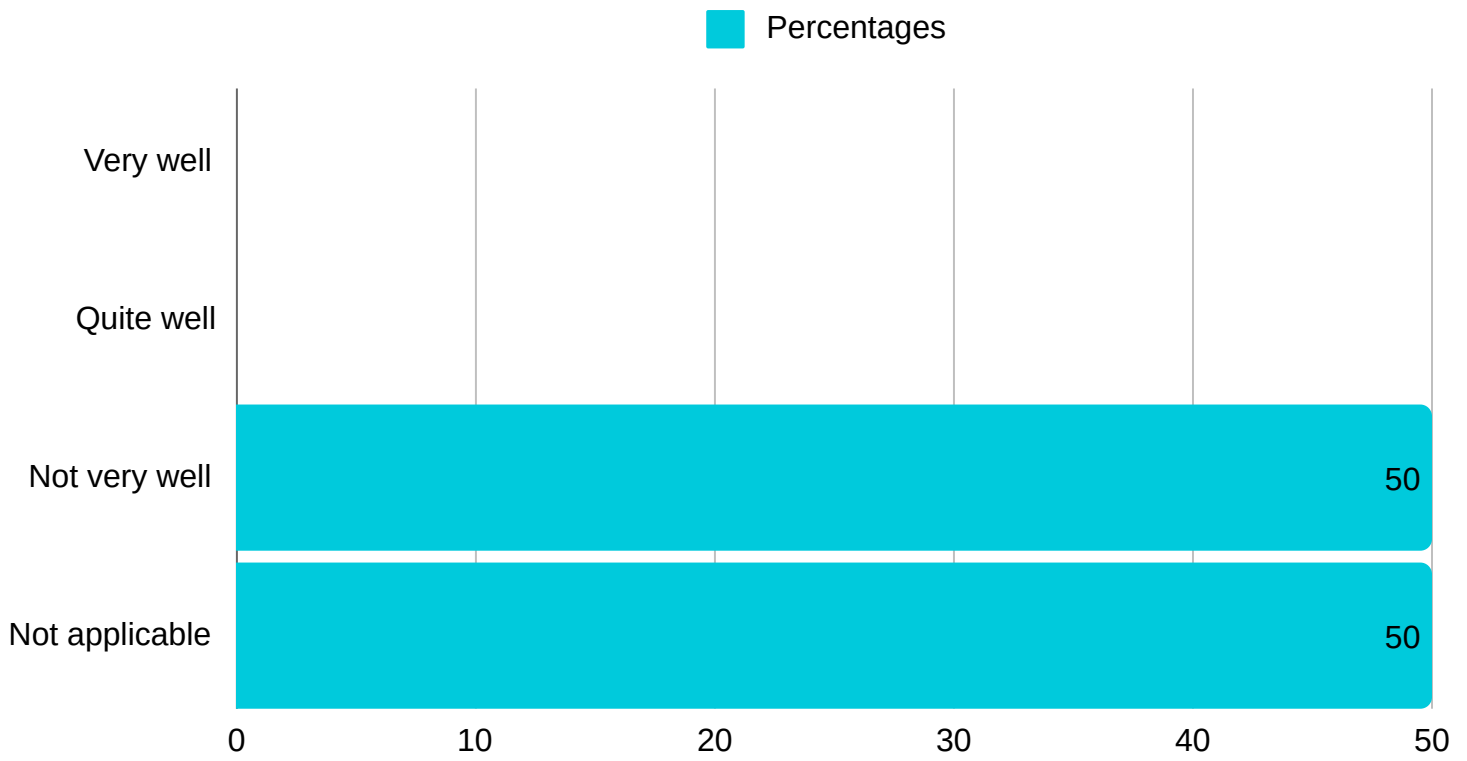
If you have a young person over 18 years old, how well-informed do you feel about how you can support them?



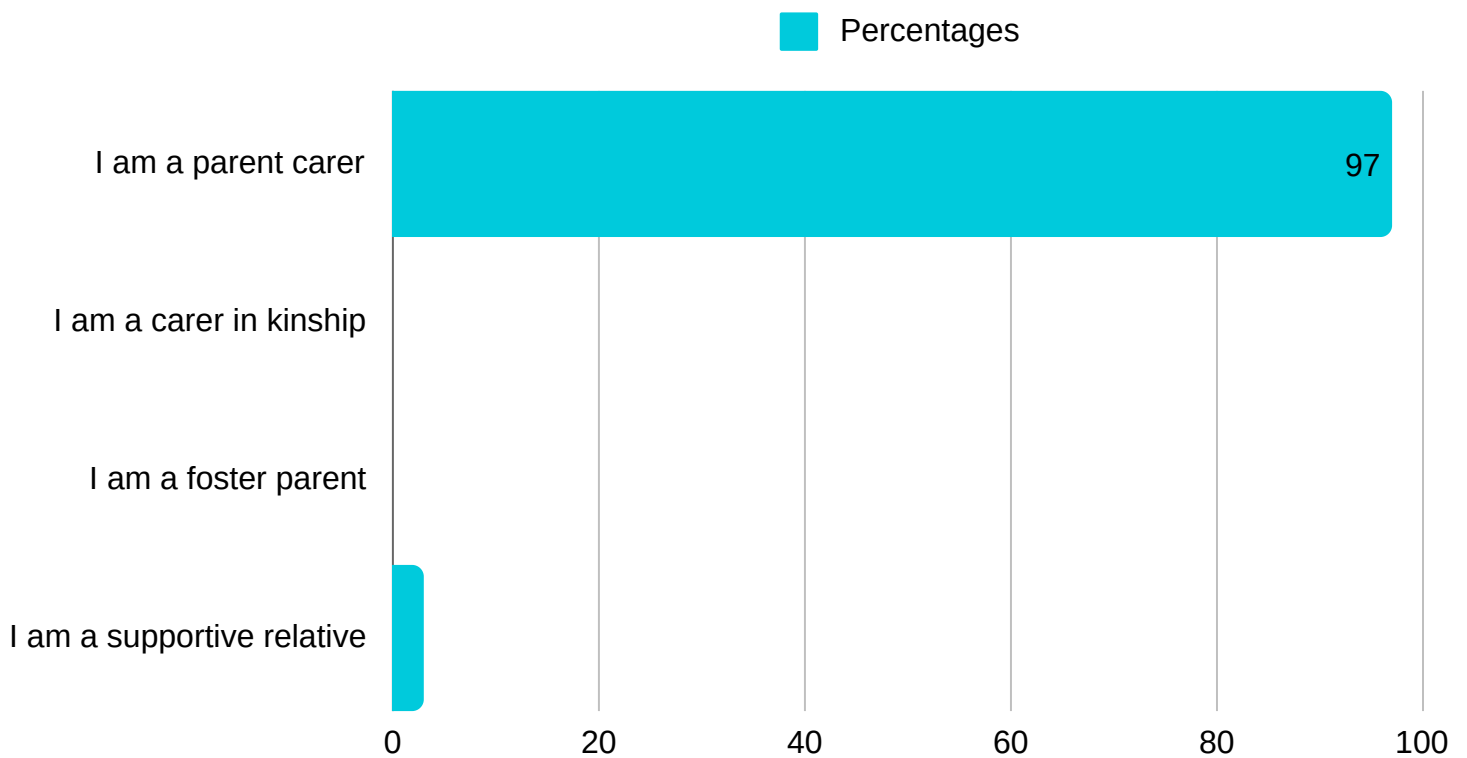
If your young person is 16 and older, have you/they received information on the following:



If your young person is older than 18, how well supported are they by Adult Social Care?



Which of these best describes your role?



We asked what would make a difference for your child or young person to feel more included in out of school activities

Opportunities for non sporty small group gatherings.

There is no out of school activities through school this would be really helpful to my daughter who struggles with change. We were given a list of inclusive out of school activities but everywhere we called they said she would struggle to join in and basically put me off her joining. This means she does nothing out of school and we get no rest bite.

Decent friends! He's been badly bullied- severe- school's approach/ lack of action, means he does not give the issues the severity it requires and still believes they are his friends- they only approach him when they want something from him. even to gaslight him that it's his fault for their poor behaviours. the answer would be in finding decent, understanding, morally and emotionally intelligent true friends.

Smaller Groups. More variety of clubs

There are no activities !

Too young at the moment.

There need to be options for non sporty children that are neurodivergent. We tried beavers but he couldn't cope. There needs to be proper options with leaders trained in neurodivergence to support our children.

Joining other groups, such as little miracles, CamRare etc.

No friends , no opportunities!

Clubs and societies aimed at children with extra needs

He would say yes, however socialising outside of school is very limited due to needs. He attends an Aspire youth club but had to stop attending Scouting at the end of cubs level as the next group up were not going to offer the support needed. He attends a computing club intermittently according to how well he is coping that week.

No, constantly gets called names, told he is too slow, picked on etc

Most out of school activities are sports/physical related which he doesn't enjoy because of his dyspraxia

They do feel included but I have needed to push as a parent.

CAF funding continuing beyond April 2025.

Help to join in in a way she understands and also not putting barriers in her way. Such as choir she has echolalia so can mimic any song perfectly and has perfect hearing for notes and instruments but she's been told she can't join in till next year

Other children with a similar presentation of complex need/hidden disabilities

Some of the free text comments

It has been very hard to get my son the help he needs. I'm still on the waiting list to get him tested. I've not really received any support while waiting.

Social Care are a very weak link.

IT Service good once we got an appointment, had to wait four months after OT assessment.

CAHMS assessment is not fit for purpose, does not follow NICE guidelines and only parents able to go private can help their desperate children

It's been terrible. I had to fight for 3 years to get an EHCP, then had to fight to get her into a SEN school only to be told she should never have gone to mainstream. She is currently going through puberty and I've asked for support but I can't even get someone to call me back. I've got Short Breaks Funding but can't use the part for activities as no one will take her. She and us are at breaking point.

Pinpoint has been the only consistently useful organisation supporting us in our SEND journey! Still no appropriate mental health support two years after agreeing to a referral to YOUNited/CAMHS. EHCNA is well over the 20 week limit. Two years out of school due to EBSA, but still no Alternative Provision. School blaming daughter's poor mental health on family (i.e. safeguarding referral to Social Work due to suicidal ideation) rather than on the chronic failures to meet statutory duties of Education, Health, and LA. Failure of NHS to promptly assess parents for autism, ADHD, etc. also negatively impacting on ability to cope effectively with the demands of battling The System. Professionals too often feel like they are just going through the motions, ticking boxes, but not actually committed enough to see the whole picture and find real solutions. School consistently ignores polite, reasonable requests for information, even after chase-ups. Utterly sick of having to meet yet another new professional, impose the stress of a stranger in the home on our daughter, and struggle to get them to understand our daughter's needs instead of judging us. I've set my baseline expectation of public services to zero: if they do not actively harm us, then I consider that a win of sorts, and have no expectation that any other benefit will arise. In other words, we are on our own as far as supporting our daughter - our role is simply to protect her from harm from public services. We're actively considering emigrating in the hope of finding proper support in a new country.

I am close to burnout, am off work now, the stress of my job, coupled with so many plates spinning- I have 3 YP's ASD spectrum, I cannot even focus on getting the ehc off the ground, Sendiass have been very helpful, although this part is down to me, I just feel so exhausted all the time.

The battle continues with every new school year. You start right at the beginning fighting to get things in place again that took months to get in place the previous year. As a result we got back to not wanting to attend school faster than ever before. I really wish services would talk to each other and come up with a better plan than just passing families from pillar to post. I am losing faith in all three services, which is a really scary place to be when you know your child desperately needs help.

Possibly the most stressful element of my life for the past 5 years. 4 years parent blaming. RTC diagnosis within 8 weeks after years of being fobbed off. I hate having to deal with the LA because the double standard are ridiculous. I am on week 30 after Ehcp review. Yet when I receive the draft I get 15 days to respond! It causes tension and resentment. We have to jump. They barely have to acknowledge us.

Lack of training amongst staff and no help available

Support for 18+ diabolical and nonexistent!

It has been a struggle, it is only because he is in a brilliant secondary school that care and support SEN children that some of my answers were positive as they do deserve to be praised. As for health, mental health and other services there is no help or consistency. I have given up trying to get help and so has the school.

We have mainly used private services for our child who has Down's Syndrome. The NHS offer has been minimal. Until the EHCNA we had almost no contact with the LA. Our independent Portage Worker told us about Disability Social Care, no one else mentioned it either before or during the EHCNA. We are appealing the EHCP and have a Tribunal date.

Severe lack of understanding within school. Feels impossible to get EHCPNA even though it has been agreed

A battle. No cohesion. Have to constantly repeat the answers to the same questions with different professionals. Due to NHS threshold being too high we ended up having to get a private assessment where he got a diagnosis of a condition it was obvious he had

The battle to get the right provision for our son is extremely challenging and hugely stressful and is now coming too late as we are expected to apply for secondary schools this month but he absolutely could not attend a mainstream secondary. EHCP applications is in very early stages. We don't feel listened to, we feel dismissed as anxious parents despite stacks of evidence to the contrary. Most importantly we know we won't get what our son needs without a huge battle with the local authority which will last considerably longer than it should and take a huge toll on us as his parents and carers. We feel the local authority are only interested in reducing the Sen support available due to budget constraints. Costs should never come in to these decisions it should purely be about what are in the best interests of the child and it sadly never is.

I originally did a parental EHCP application when my son was in primary school. The school did not approach me and said he had to be badly behaved to get support.... He was 4 years academically below where he should be so I did the application and luckily it was agreed a needs assessment was needed. Since my son has moved to secondary school with the EHCP in place they have been amazing and my son is no longer anxious about school.

We feel we have been let down. Our child's mental health has suffered and so has mine.

Always feel lost, CCC website said 1 thing but when it comes down to action, it is completely the opposite, such as EBSA, all these info and toolkits suggesting what to do and how to work together with school etc. School ignore the facts and guidelines, leaving parents confused and frustrated. Parents and SEN children shouldn't be suffering because the broken of the system.

No support via SS no named SW nothing since before Covid which was when she transitioned to adult services . So she missed out completely on all transitions . I dread what the future holds for her .

Just a pile of leaflets given after diagnosis, no advice or help. Wrongly advised by LA specialist teacher 5 years ago that diagnosis should come before EHCP. Only seen the SAT team once and no

advice given. Don't know what I can ask for or what I can request to be put on EHCP. Only found out about a tech assessment by chance but would have helped years ago. Waiting lists are just too long and everybody I know is stuck waiting with no access to medication (eg if suspected ADHD, can't get melatonin if suspect neurodiverse but no diagnosis etc), no information about how long waiting lists are, transport appeals not being touched. When contact is actually made with professionals they are generally really helpful and explain things but they are all overworked and burning out and so there is no consistency. Communication needs to be better and for people to be told approximately how long waiting lists are or what to expect.

Lack of support or information known out there is very poor before diagnosis

Some initial good meetings when EBSA started but person the disappeared and no one else told us what's going on.

The SEND Information needs to be easier to navigate. It took me ages to find information about applying for an EHCP. Maybe test with some parents how they search things? Schools need to be better at Assess Plan Do. Staff should all have training in autism in girls, to avoid statements from headteachers like 'decompressing is a trendy word for having a break' or assumptions that anxiety for autistic is something that can be treated separately to adjustments being made in school. The what time for EHCNA and ASD assessments needs to reduce.

Horrified to hear that CAF is to be stopped in April 2025. I'm trying to choose a school and return to work but my child cannot attend an after school club without a 1:1 as they have in nursery. Hoping that Pinpoint will join with parents in the campaign to persuade the LA to reconsider this decision.

We need more support for needs not just post diagnostic results listen to parents and schools and support them you don't need a piece of paper telling you you know what you already know

Please educate services on hidden disabilities/SEN so we don't have to

About the respondents

Location

Fenland 6%

East Cambridgeshire 14%

South Cambridgeshire 34%

Huntingdonshire 31%

Cambridge City 14%

Gender of child

Male 57%

Female 40%

Non-binary 0%

Prefer not to say 3%

Age of child

0-4 years 6%

5-10 years 51%

11-15 years 31%

16-18 years 3%

19-25 years 9%

25+ years 0%

Ethnicity

White British 80%

White European 0%

White Gypsy or Irish Traveller 0%

White Other 9%

Mixed Ethnic Background 6%

Asian 0%

Asian British 0%

Black British 0%

Black African 0%

Black Other 0%

Arab 0%

Prefer not to say 3%

Other 3%

Current placement by school/institution

Nursery / Pre-school 6%

Mainstream Primary 37%

Mainstream Secondary 26%

Special School 3%

Cabin or other provision within a school 0%

Pupil Referral Unit 0%

Independent School 0%

Independent Special School 3%

Alternative provision 9%

Out of County placement 3%

Elective Home Educated 6%

Out of school/ not receiving education 3%

Hospital School 0%

Further / Post 16 Institution 6%

Finished Education 0%

Timetabled provision

Full time timetable 58%

Part time timetable 21%

Not in school 21%

Need ranked by times reported by those completing the survey

Autistic spectrum condition/disorder (ASC/ASD) 20%

Social and Emotional Mental Health needs 15%

Attention Deficit Hyperactivity Disorder/Attention Deficit Disorder (ADHD/ADD) 12%

Specific learning difficulties e.g. dyslexia, dyspraxia, dyscalculia, dysgraphia 11%

Sensory processing disorder 10%

Speech and language impairment 7%

Global Developmental Delay 5%

My child/young person's needs have not yet been identified 4%

Moderate learning difficulties 4%

Hearing Impairment 3%

Physical disability 3%

On the early help pathway 3%

Medical needs / Complex health needs 2%

Severe learning difficulties 2%

Visual Impairment 1%