Bedford Borough Parent Carer Forum Outcomes Report 2024

21 January 2025

Introduction

In response to the February 2018 joint Ofsted / Care Quality Commission local area Special Educational Needs and Disability (SEND) inspection, Bedford Borough Parent Carer Forum (BBPCF), undertook to create an “outcomes framework” that enables local leaders to better understand, prioritise, commission and deliver services that families of children and young people (CYP) with SEND need.

In order to benchmark lived experience of families, BBPCF undertook a series of workshops and conducted a survey between October and November 2018. This survey has been repeated annually since.

Our methodology

Between October and December 2024, we asked parent carers of CYP with SEND to complete a survey to capture their lived experiences in Bedford Borough. Participants were invited to complete 18 questions that cover five key outcomes for children and young people. These are for them to Be Happy, Be Healthy, Be Ambitious, Be independent and to Be Heard. These outcomes were developed in coproduction with our membership. The survey questions are based on the United Nations Convention on the Right of the Child.

The 2024 survey was based on the survey we conducted in previous years to ensure comparability. However, we did review the language of the survey to reflect comments from previous years with a view to making the questions more easily understood – the meaning of questions was not changed. No questions were added or removed. For a full list of questions see Appendix 2.

We asked respondents to identify the age, the education, training or work setting and status of their CYP, their social work status and whether they have an EHCP or not. In addition, we asked respondents to tell us whether their child or young person had undergone a transition between school settings or between children’s and adult health and social care settings. This year we also asked about the disability status of parent carers.

We received 711 valid responses (656 in 2023 and 522 in 2022). In addition, there were 1988 comments. A sample of comments are reproduced in this report to offer a qualitative analysis and give a direct voice to the views of parent-carers. Quotes are presented verbatim, with no editing.

Summary Results

In absolute terms we are still not meeting the needs of children and young people with SEND well enough. The average score has fallen slightly year on year. Over the last 7 years, we have seen a small improvement in the experience of families with improvements in 3 years and falls in 3 years (one year stayed the same).

Average score

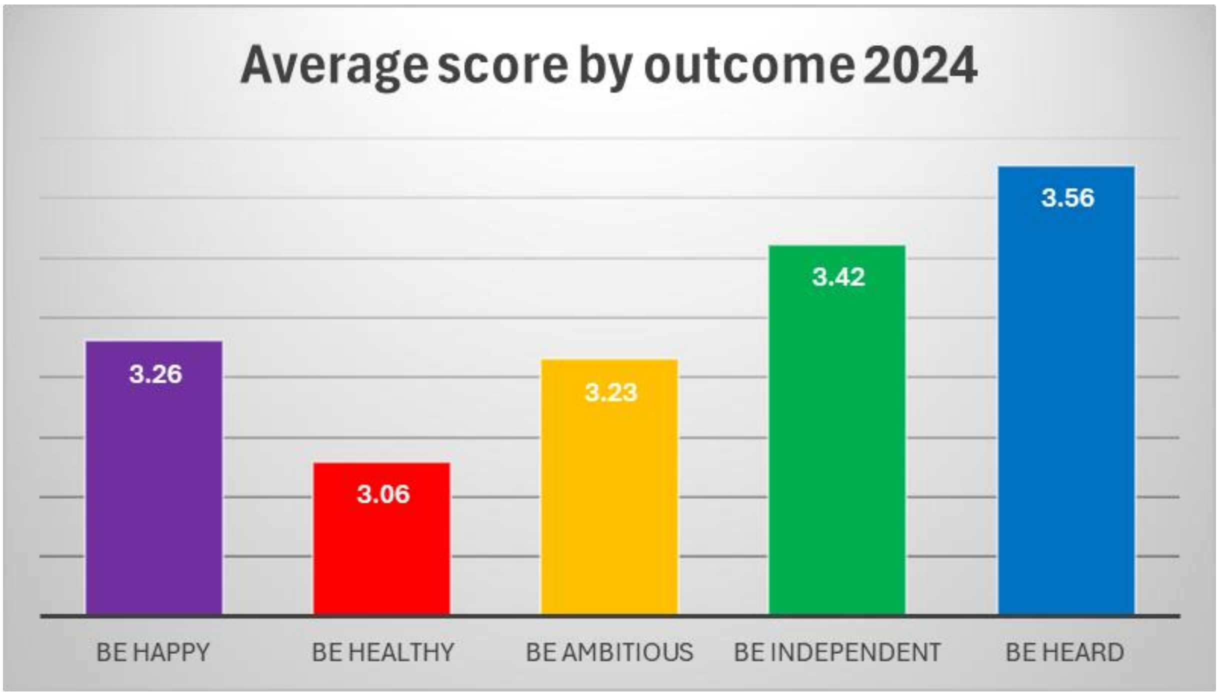
3.32

(out of 5)

The average score across all questions in our survey was 3.32. This is a small fall from last year and the previous year when the score was 3.41.

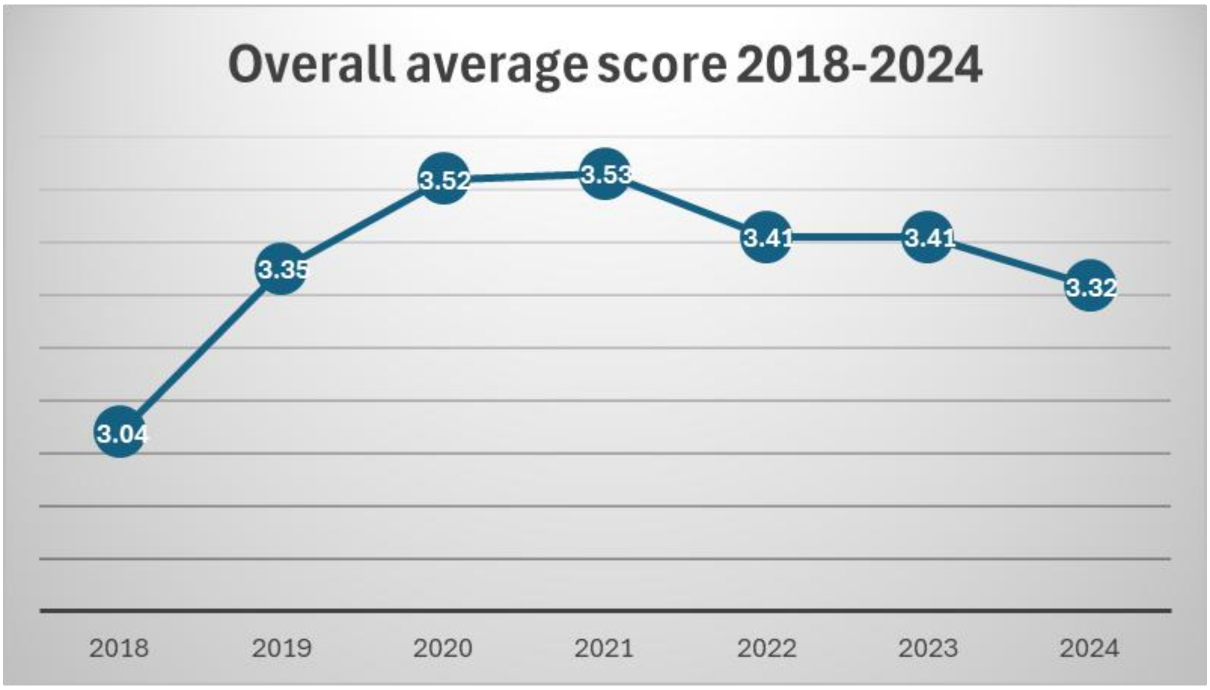
This means that the needs of children and young people with SEND are only being adequately met at best. This falls short of our stated ambition that needs should be being well met (a target score of 4 or more). Given that the questions were based on the United Nations Convention on the Right of the Child, we believe this to be an appropriate target based on a minimum level that families should be able to expect.

The average scores for each outcome were as follows:

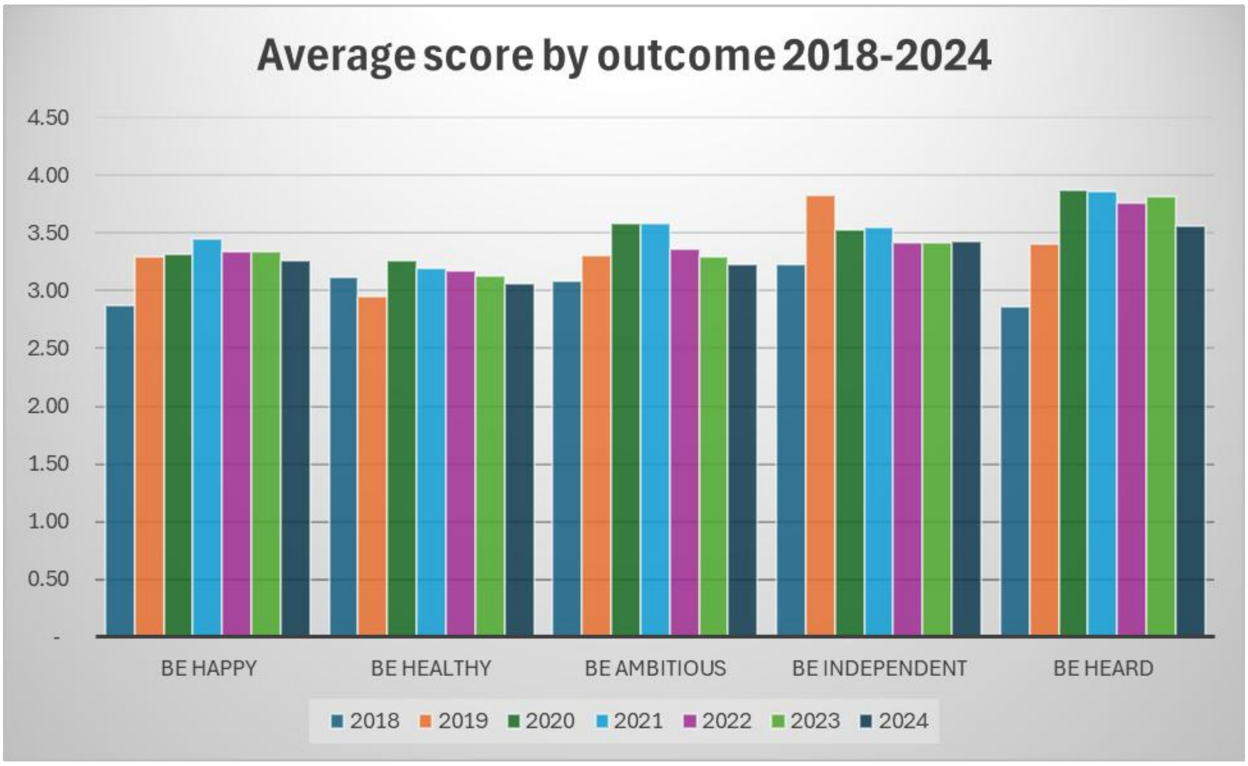


There has been a small fall in the overall average score year on year. After an initial rise, scores have declined over the last three years.

The average score in 2024 was 3.32 In our first survey in 2018, the average score was 3.04.



Generally, the average of individual outcome scores has improved since 2018 although all scores show a deterioration between 2021 and 2024



Despite the overall improvements in scores, the majority of the comments collected were negative but give a good indication of what needs to be done to continue to improve scores year on year.

Overall, 49% (2023:54%) of all responses were positive (scores of 4 or 5) whilst 23% (2023: 22%) were negative (scores of 1 or 2). This is a ratio of approximately 2:1 positive to negative.

The largest category of scores was 4 with 36% of answers.

Overall

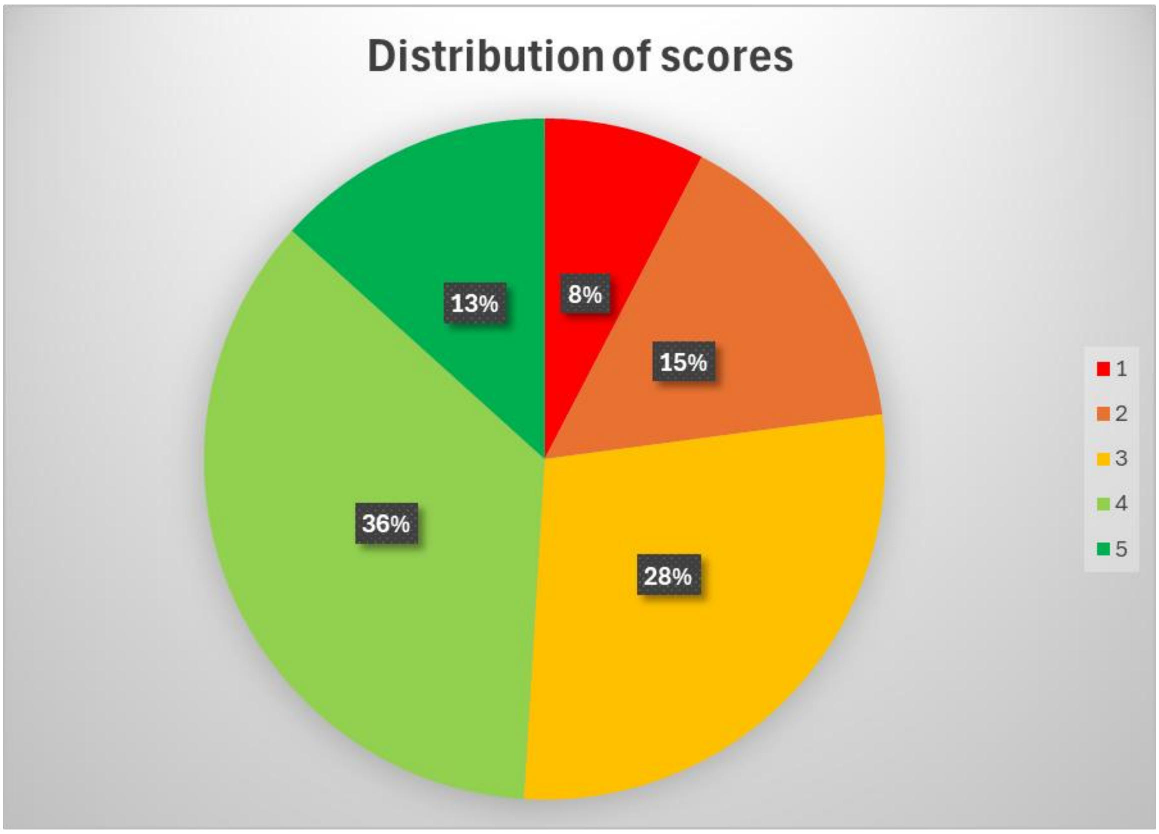
49%

of scores were positive

Overall

23%

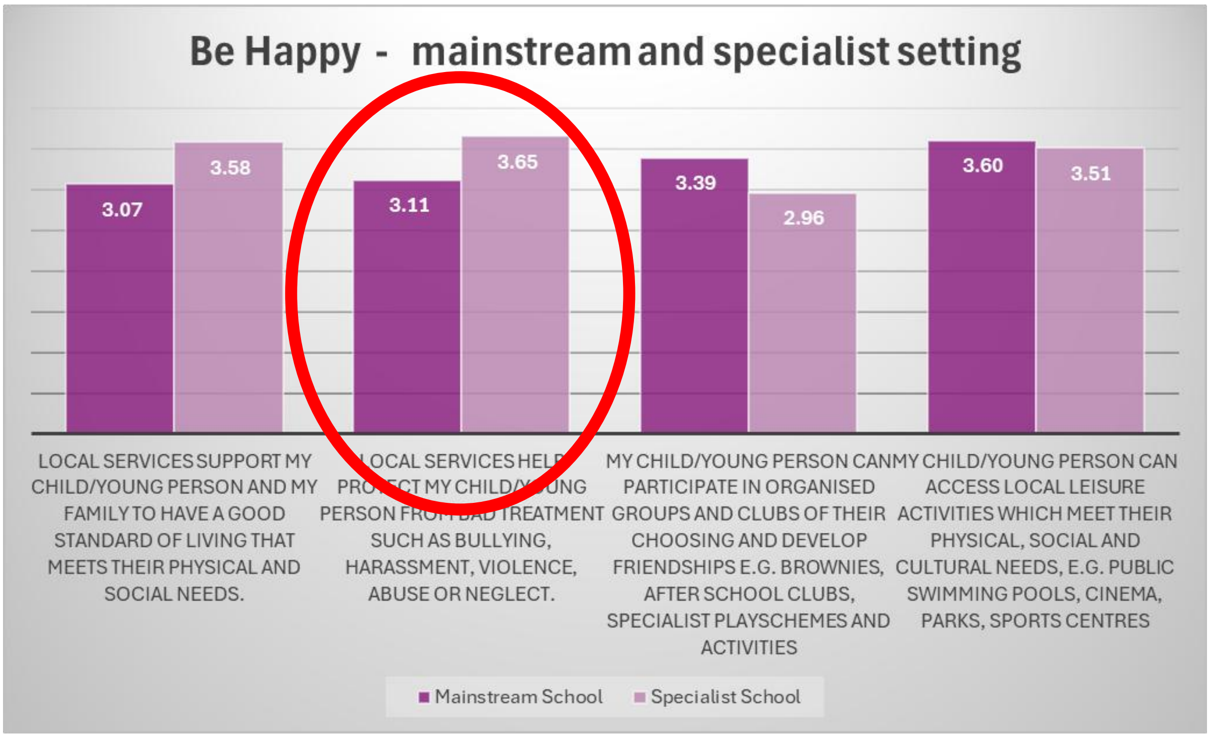
of scores were negative



Commentary

The experiences of children in mainstream schools are poorer than their peers in specialist settings. There are a number of reasons for this

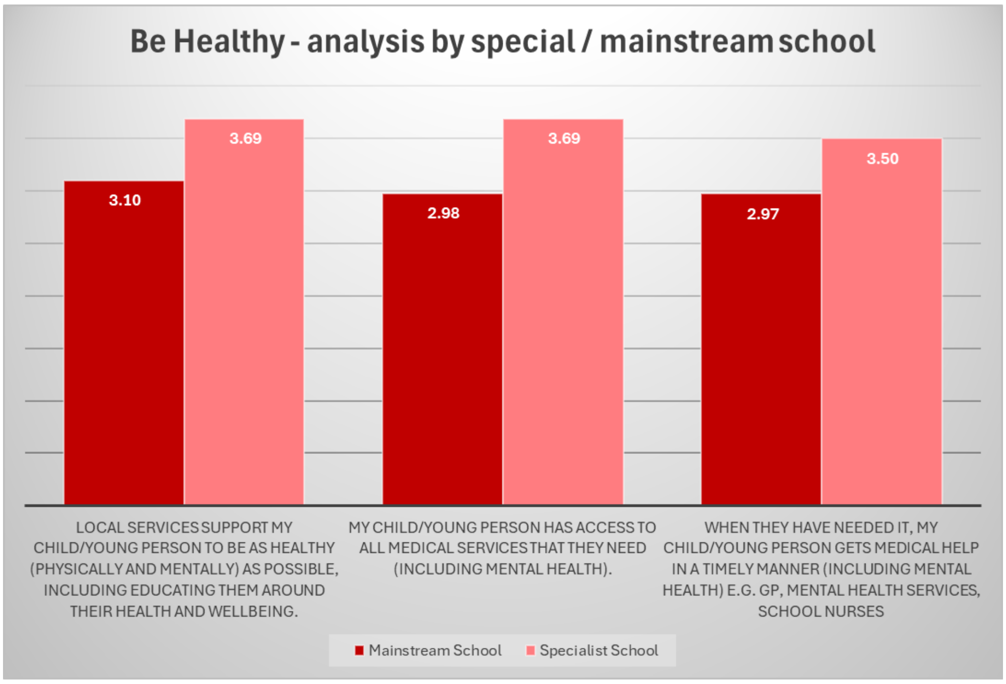
1. Bullying is a major concern raised by many parent carers for children in mainstream schools



The difference between mainstream and specialist schools for whether local services help to protect children is 0.54. This is further supported by comments (see Be Happy section). In addition, this is consistent with findings in previous years.

2. Children and Young People in mainstream schools report lower Be Healthy scores than those in specialist schools.

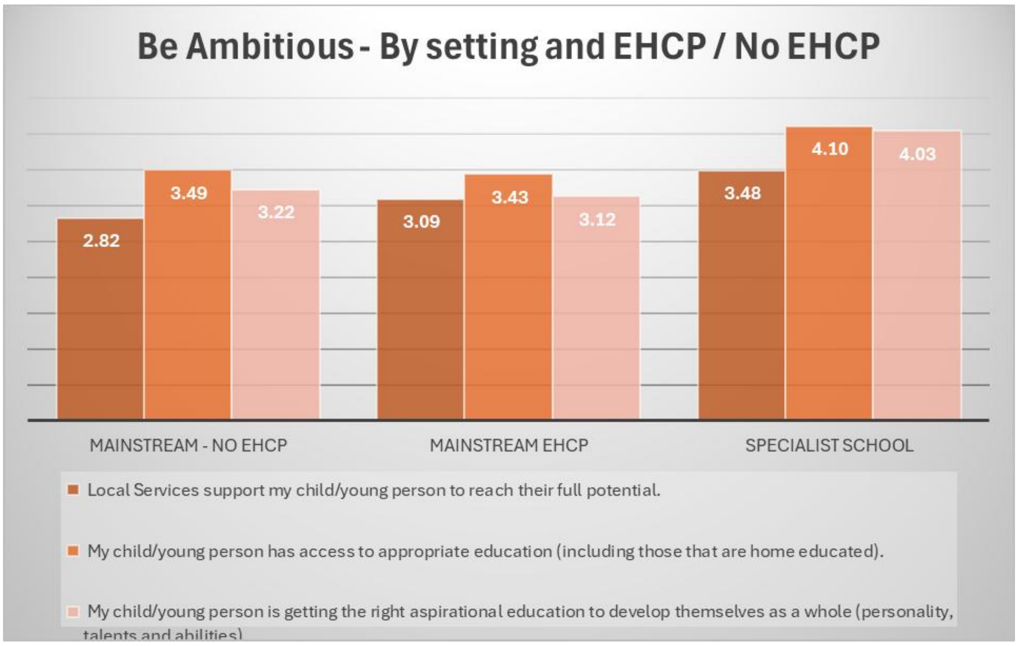
Special school scores were higher for all be Healthy questions. The difference is quite marked with gaps of 0.59, 0.7 and 0.53 for the three questions.



This is regardless of whether a CYP has an EHCP or not- the differences are driven by setting, not by EHCP status.

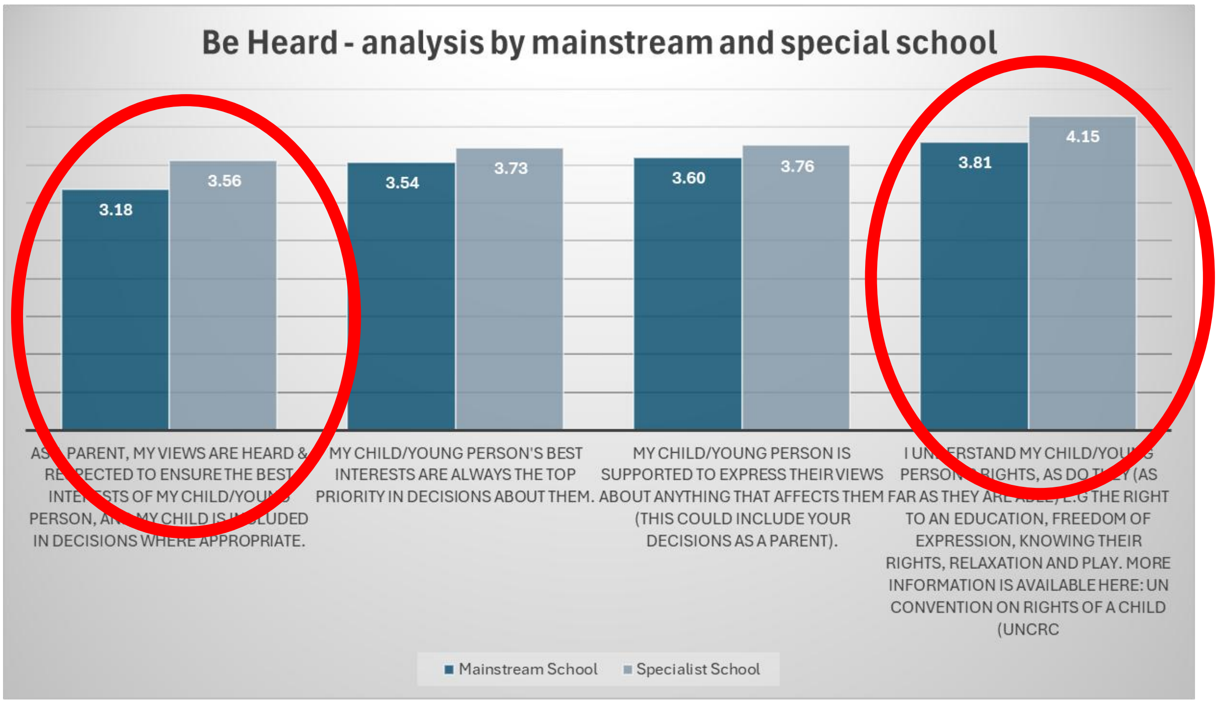
3. Families feel that mainstream schools are less ambitious for their CYP, especially for those that have an EHCP in mainstream settings.

There was a 0.91 point gap in the question about aspirational education for those in special schools compared to those with and EHCP in mainstream schools. This gap was 0.81 for those with no EHCP in mainstream settings.



4. Families of CYP in mainstream schools feel that they are not listened to as well as those in specialist settings

The analysis of those in mainstream schools compared to those in specialist settings shows a marked difference in two questions. Parent carers of children in mainstream schools believe their views are less respected than those in specialist settings and they also feel as if they are less aware of their rights.



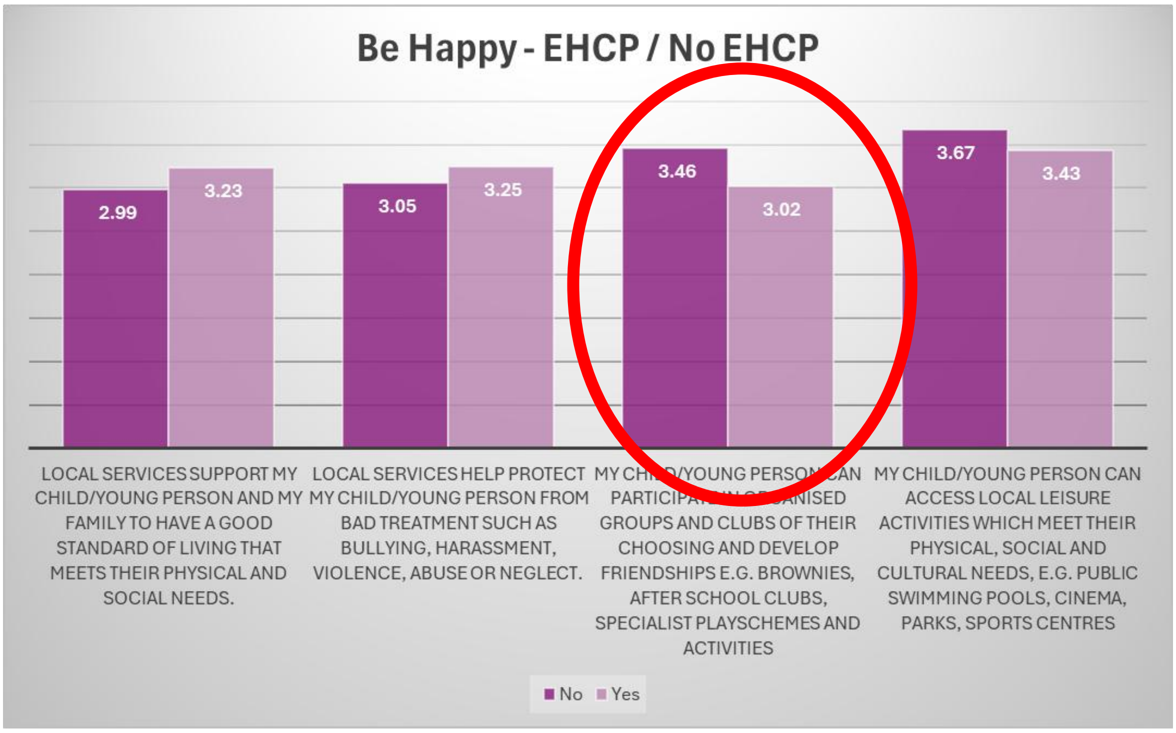
Recommendation: Convene working groups for families of children and young people in mainstream settings with SEND to ask the following questions:

- What can we do to reduce bullying in mainstream settings?
- How do we better support you with your health needs?
- What can be done to be more ambitious about your CYP and help them achieve their full potential
- What can we do to make sure that your voice is better heard?

These focus groups should be convened by Bedford Borough Parent Carer Forum and attended by representatives of the local authority, mainstream schools, special schools and health commissioners and providers.

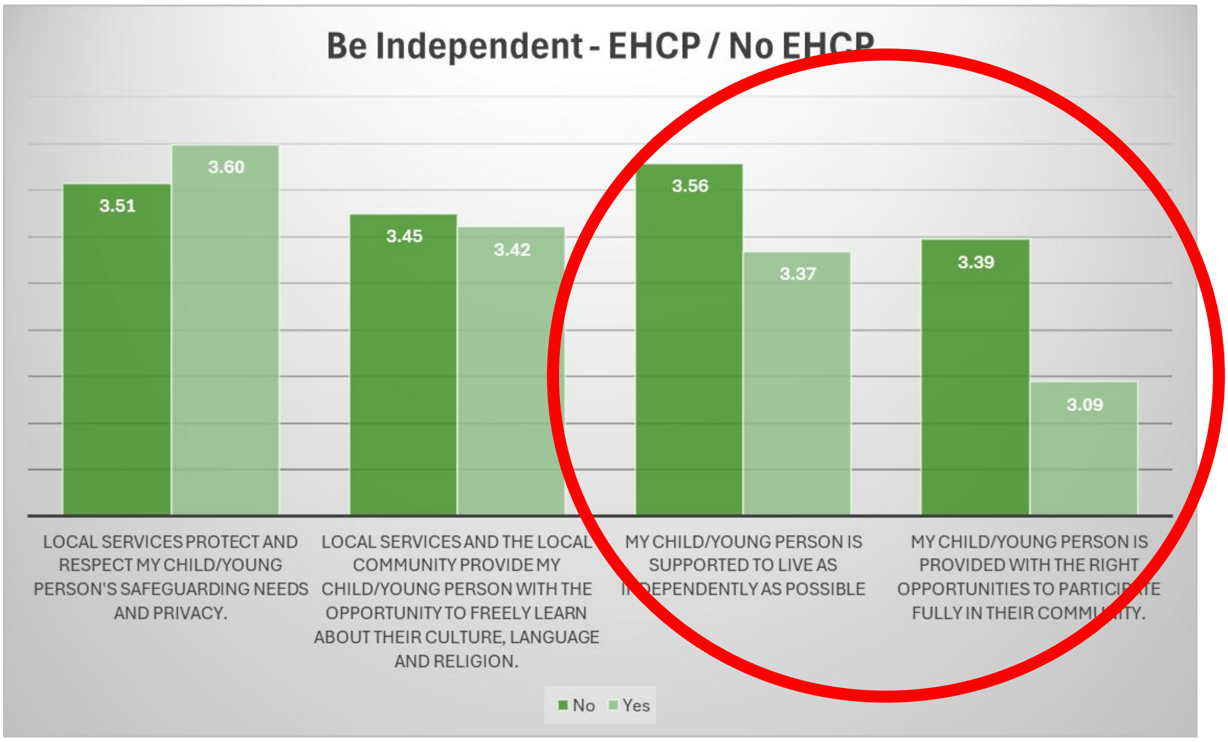
Parents of children and young people with more complex needs report difficulties accessing clubs and activities and report that they find community inclusion more challenging.

5. Those with EHCPs feel there are few clubs and organised activities for them



Families of CYP with EHCPs show significant differences in their answers to question 3 with a gap of 0.44 to those without an EHCP. This is mirrored in the comments from families that highlight difficulties for those with more complex needs to find clubs and activities for their CYP

6. Those with more complex needs find it more difficult to participate in the community and live independently



There is a difference between scores for CYP with an EHCP compared to those with no EHCP. The largest differences come in the scores for opportunities to participate in the community (0.31) and being allowed to live as independently as possible (0.19).

Recommendation: Convene working groups for families of children and young people with education health and care plans to explore what can be done to improve access to clubs and activities and how they might be better supported to participate in the community.

Comments highlight some of the barriers as being a lack of available clubs, poor knowledge of activities that are available, practical barriers such as transport and factors such as poverty and the cost of living.

Access to medical services

7. Access to health continues to be a major concern for families – in particular, they highlighted long waits for services and difficulties in meeting thresholds for treatment. Interestingly, in contrast to previous years, there were few comments about the quality of services for those who were receiving them.

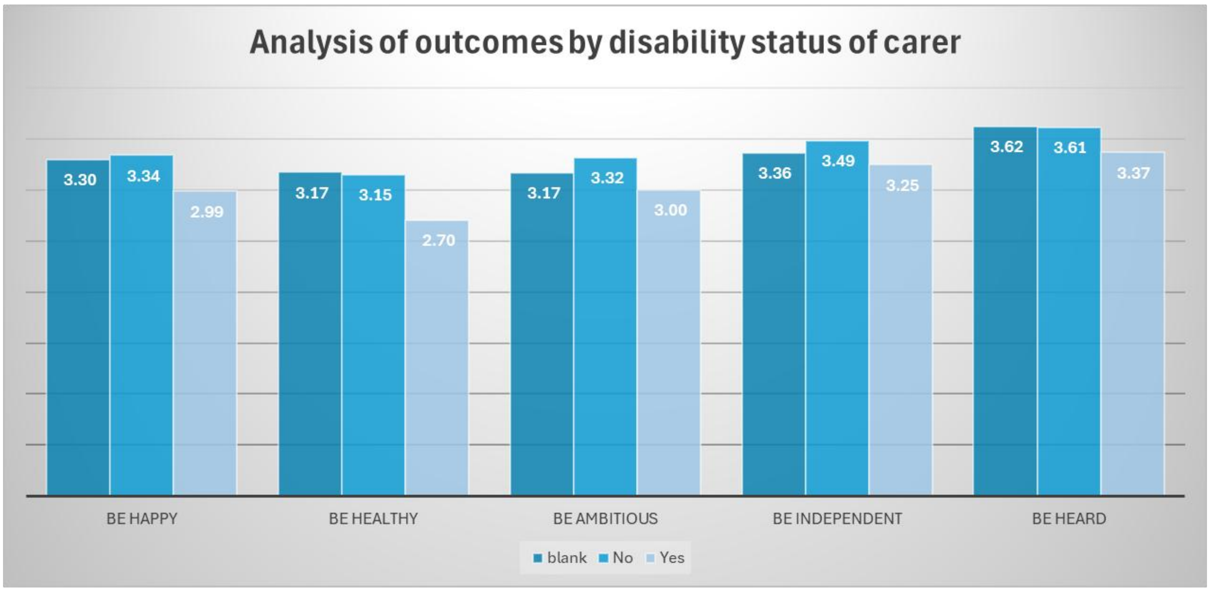
Two Be Healthy questions, about being able to access health services and being able to be seen promptly scored two of the three lowest overall scores in the survey (3.02 and 0.04 respectively). The comments shed light on this with frustrations over waiting times and difficulty getting appointments. There were more comments about these two questions than any others in the survey. However, for those receiving health services there were many positive comments particularly about CAMHS.

The challenges facing health services post-Covid are well understood and this is a clear priority locally and nationally.

Recommendation: Convene working groups for families of children and young people who do not meet criteria for health services or those who are currently waiting to explore what additional help and support would enable them to better support their children or young people and / or “wait well.”

Support for parent carers with a disability

8. **This year, our survey asked a question about the disability status of parent carers, not just children and young people. This reveals that parent carers who have a disability, have poorer outcomes across the board than those that do not.**



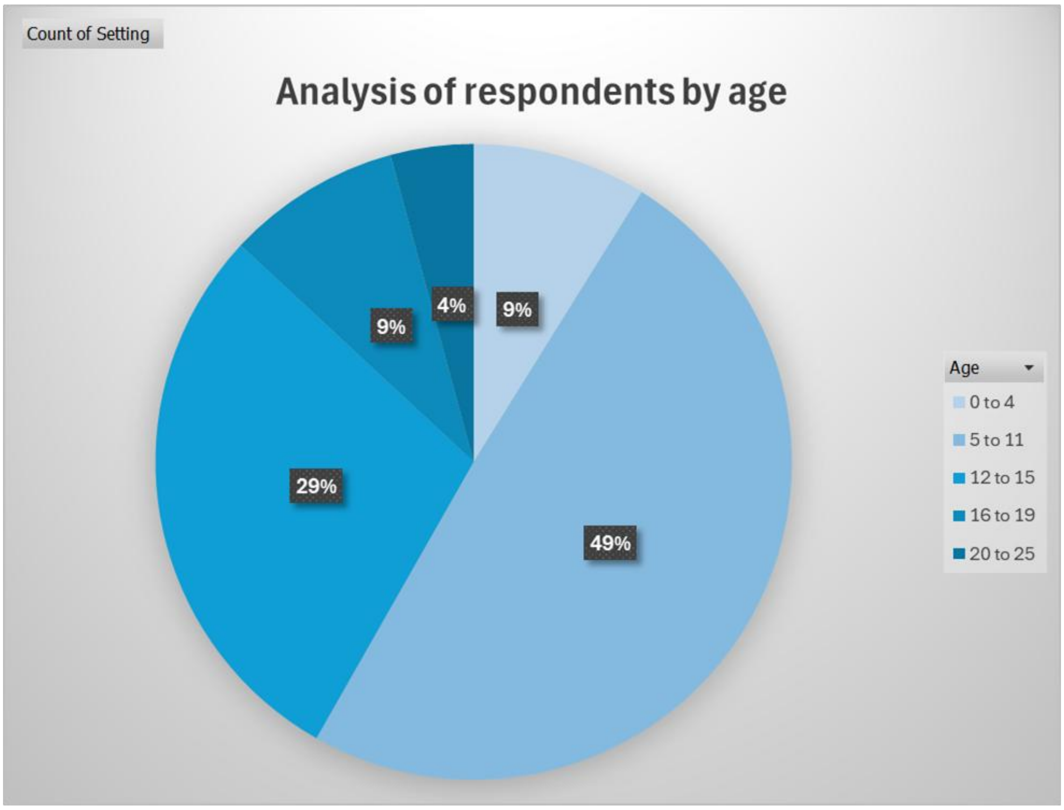
Recommendation: Consider providing additional support for parent carers with a disability to help them navigate a complex system and access the care that their family would benefit from. Consider "keyworking" services not just for CYP with additional needs but also parent carers with disabilities.

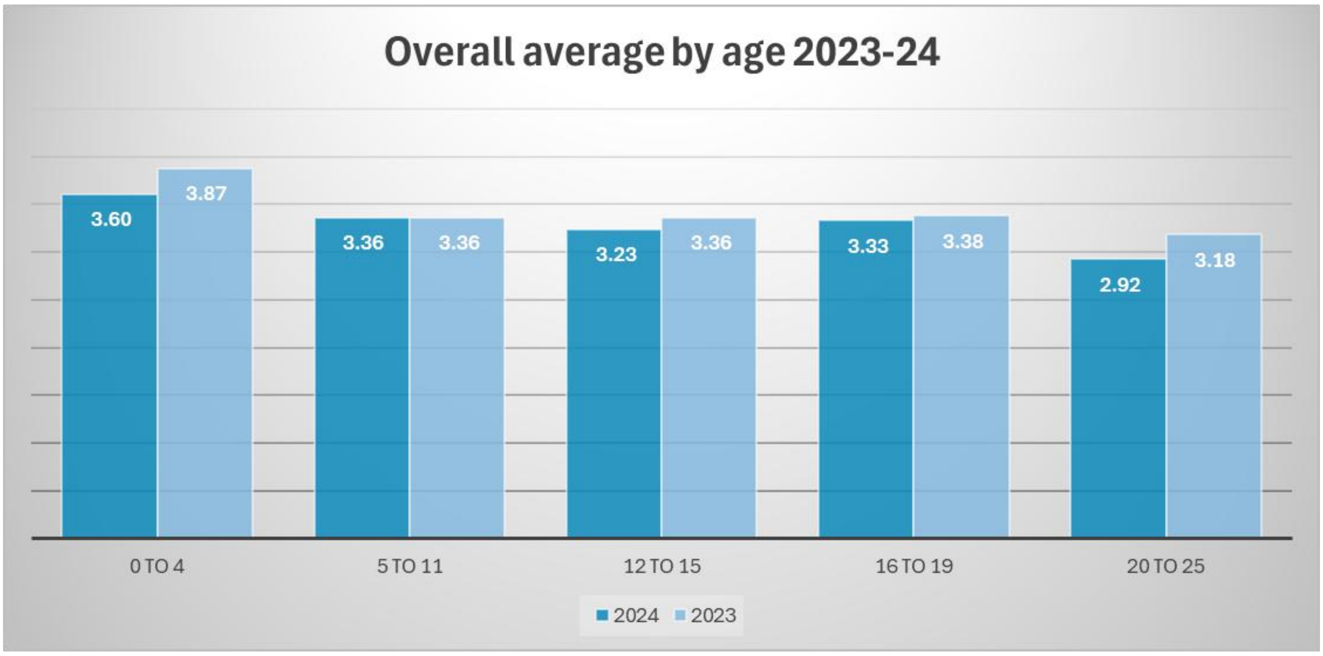
Analysis by age, setting, EHCP / no EHCP, social work status and disability of carer

By Age

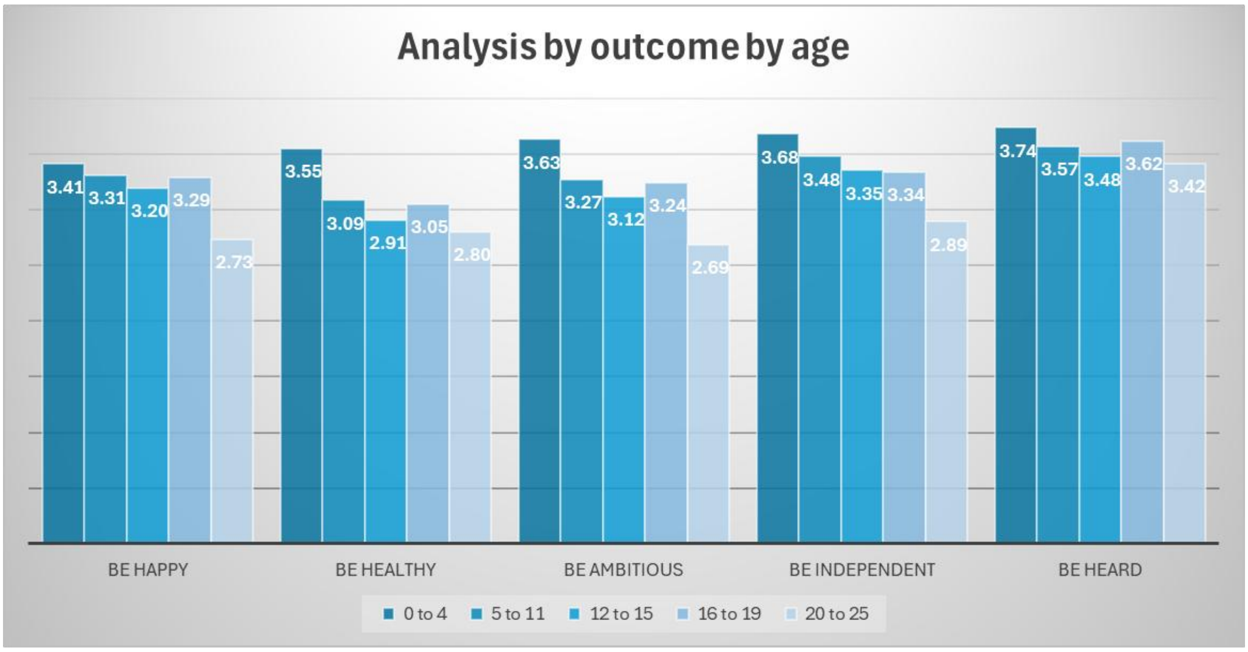
There was a reasonably good distribution of respondents up until school leaving age. Because there were relatively few respondents in the 20-25 (post education), this qualifies any conclusions we can draw from this age group. The age distribution of respondents is similar to previous years.

Row Labels	**Number**	**Percentage**
0 to 4	63	9%
5 to 11	351	49%
12 to 15	204	29%
16 to 19	63	9%
20 to 25	30	4%
Grand Total	**711**	





Analysis of the overall average mark by age shows that the 0-4 age group have the highest average score (3.60) which gradually declines as children and young people age with the 20-25 age group having the lowest average score of 2.92. This is consistent with the trends from previous years. All of the age groups showed a deterioration year on year with the exception of the 5-11 range which stayed the same.

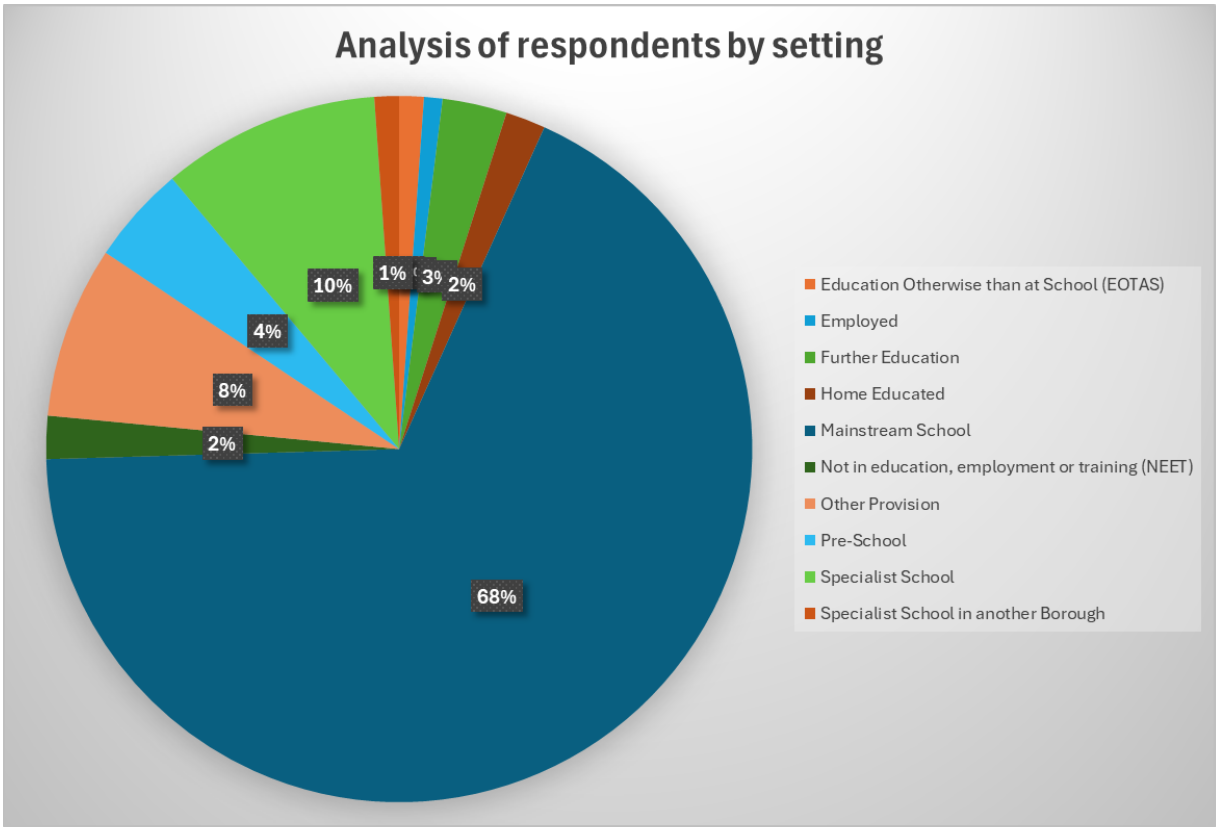


Analysis of outcome by age shows that for all outcomes, except Be Heard, there is a marked fall for the 20-25 age group. We treat these results with some caution given the relatively small number of responses in this category. Nevertheless, it is marked.

By setting

There were a range of responses from across different “settings” ranging from pre-school to employment and NEET. There was a representative range of settings with the majority of CYP attending a mainstream school. We had representation from those outside of school and education settings as well.

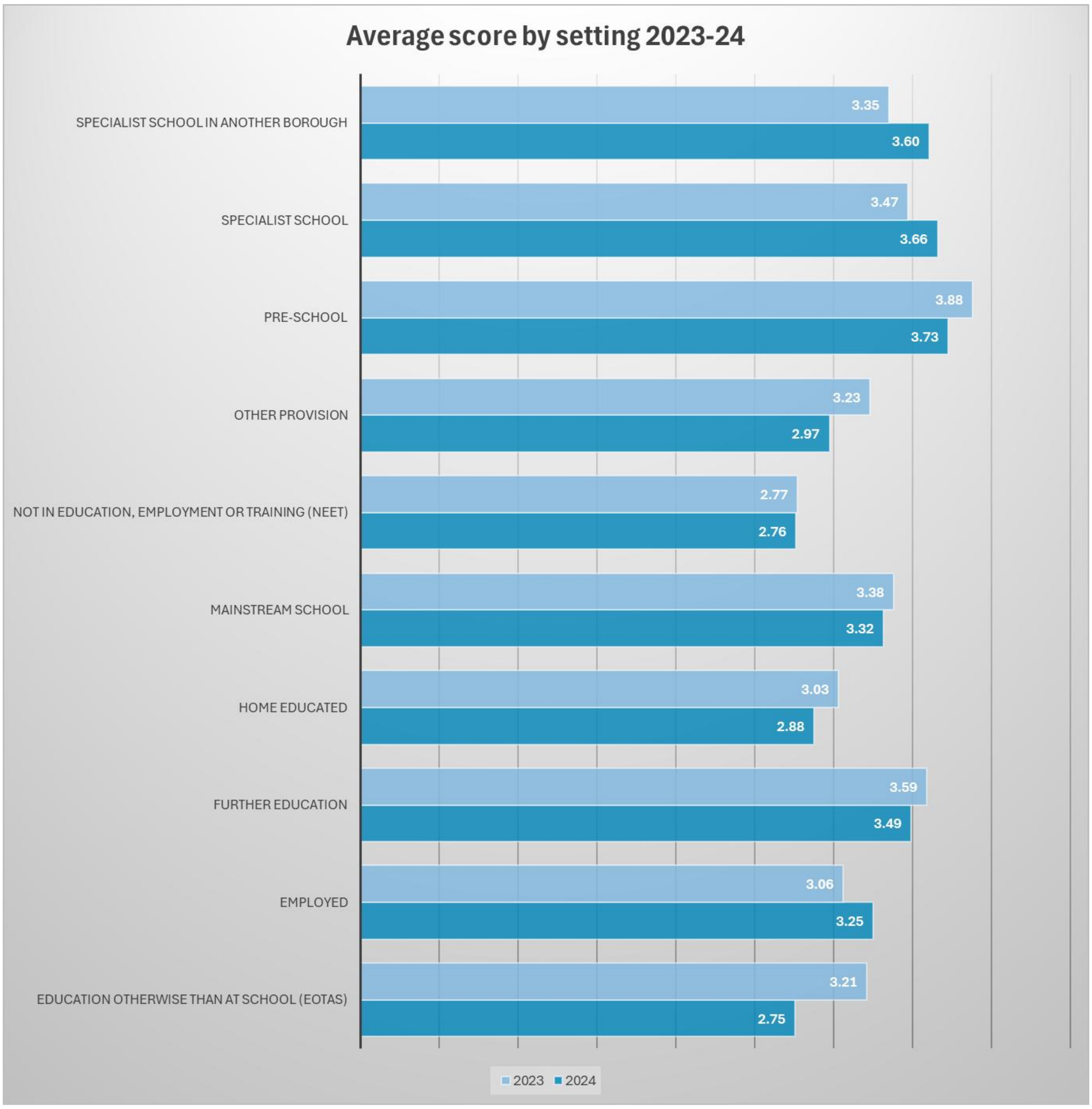
Setting	Number	Percentage
Education Otherwise than at School (EOTAS)	8	1%
Employed	6	1%
Further Education	21	3%
Home Educated	13	2%
Mainstream School	482	68%
Not in education, employment or training (NEET)	14	2%
Other Provision	56	8%
Pre-School	32	5%
Specialist School	71	10%
Specialist School in another Borough	8	1%
Total	**711**	

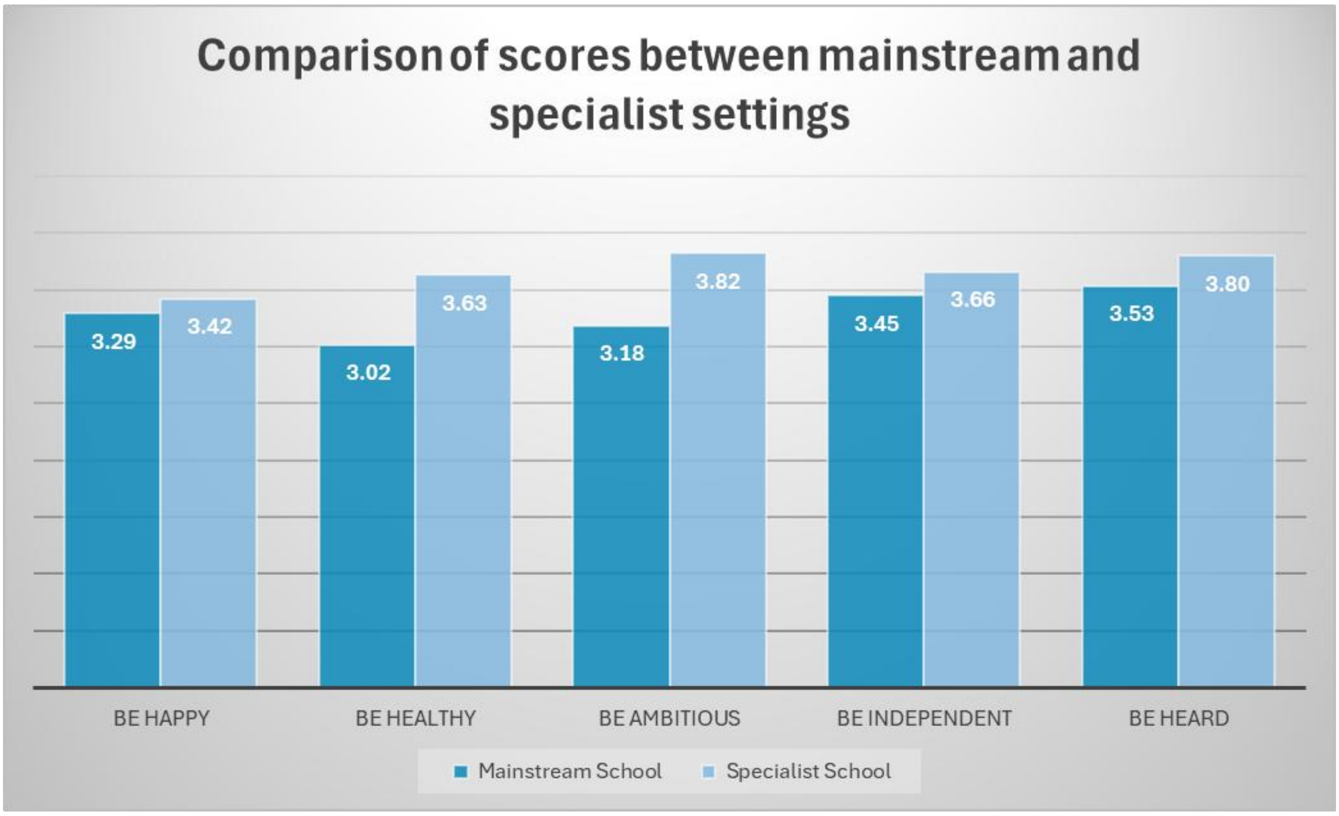


There is a clear difference between the average scores of children and young people in mainstream schools (3.32) and specialist schools inside the borough (3.60) of 0.28 points. This difference has grown in the last year (which was 0.07 points). In surveys prior to 2022 there has been no significant difference between specialist and mainstream settings.

Consistent with the findings of the age analysis, those in pre-school have the highest scores (3.73) and those outside of the education system (NEET 2.76, home educated 2.88 and EOTAS 2.75) had the worst overall experiences.

Only those CYP in specialist settings or in employment saw an improvement in scores year on year. All other scores deteriorated.

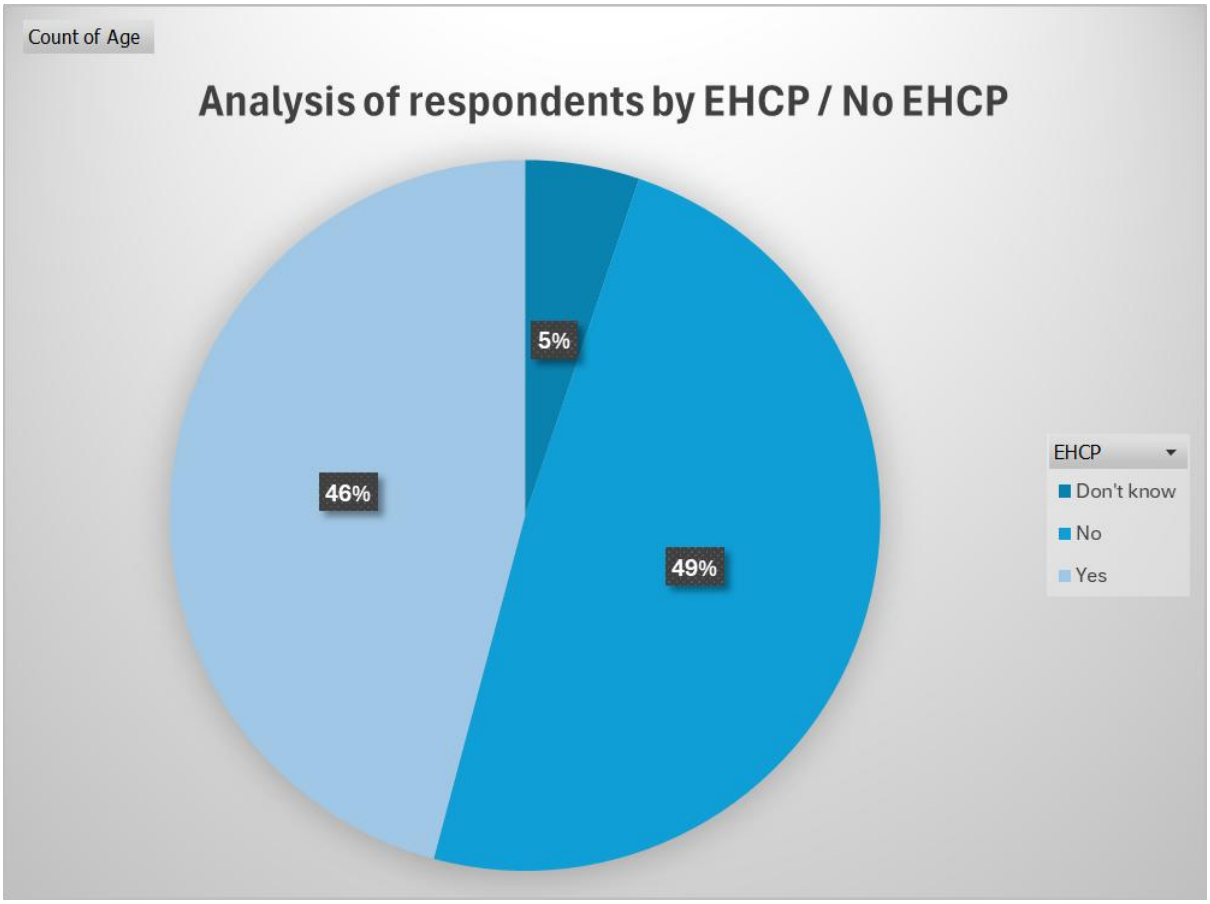




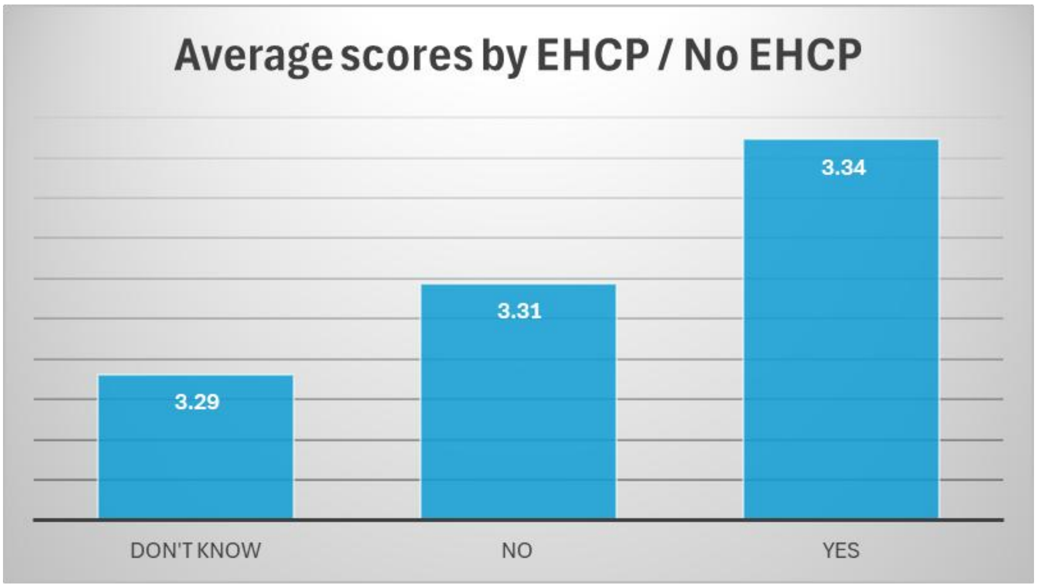
CYP in specialist settings scored higher than those in mainstream settings for all the outcomes. The most marked differences were in the Be Healthy (0.61 points) and the Be Ambitious (0.64 points) scores. These differences have increased significantly year on year (by 0.29 and 0.3 points respectively).

By EHCP / no EHCP

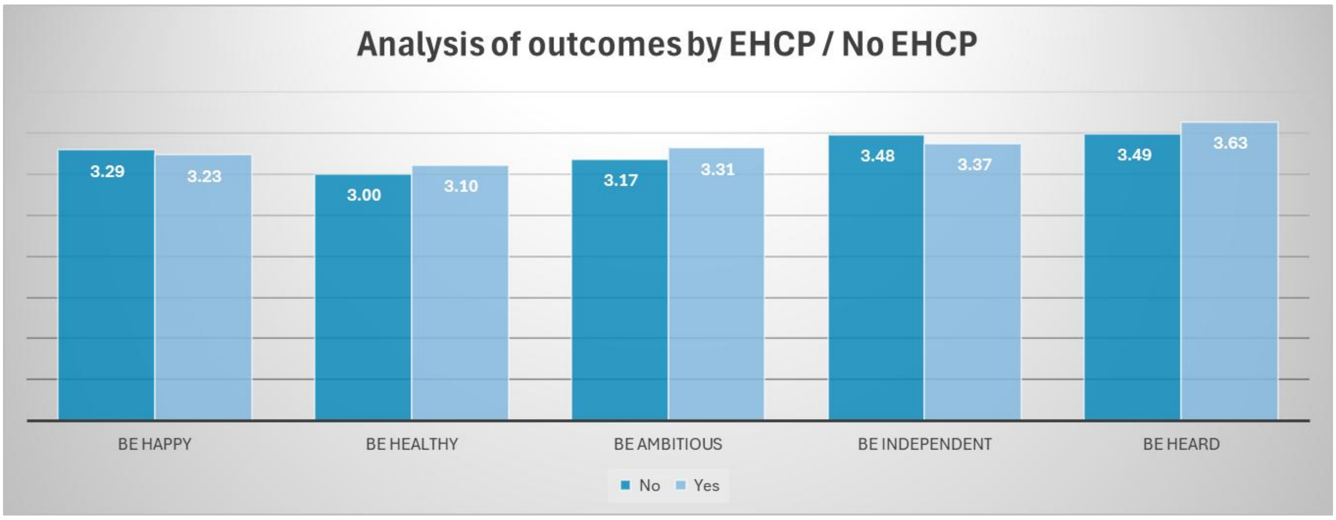
There is a good split of responses between those who have EHCPs and those who do not. With 46% having an EHCP and 49% not (5% responded don't know).



There was no notable difference between the scores for those with an EHCP and those without an EHCP. Last year there was a small difference of 0.21 with those without an EHCP scoring higher. The 2024 result is consistent with years prior to 2023 which saw no material difference between those with and without an EHCP.

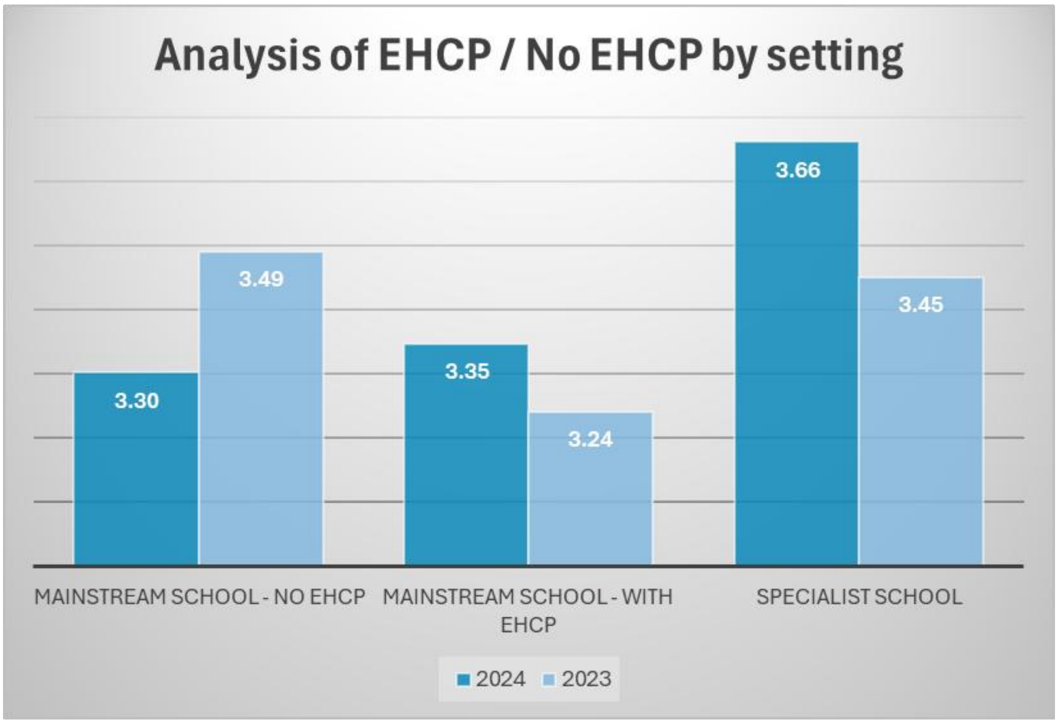


There were no large differences in individual outcomes between those with an EHCP and those without. Those without EHCPs were marginally happier and felt more independent but those with EHCPs felt better supported to be healthy, ambitious and heard.



Analysis by Setting and EHCP / No EHCP

There is no significant difference between the experiences of CYP in mainstream schools whether they have an EHCP or not this year (last year there was a 0.25 point difference). However, there is a clear difference between mainstream and specialist schools.

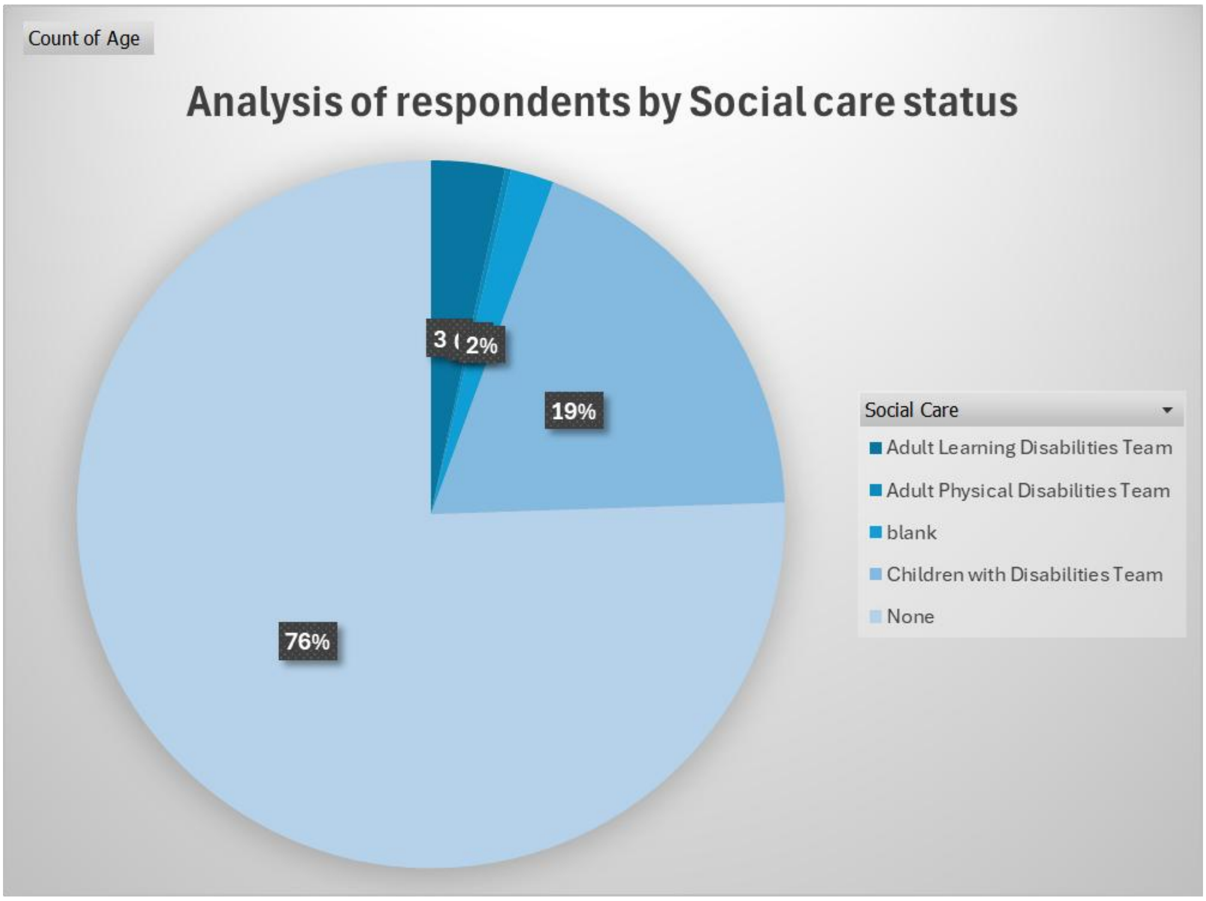


By social work status

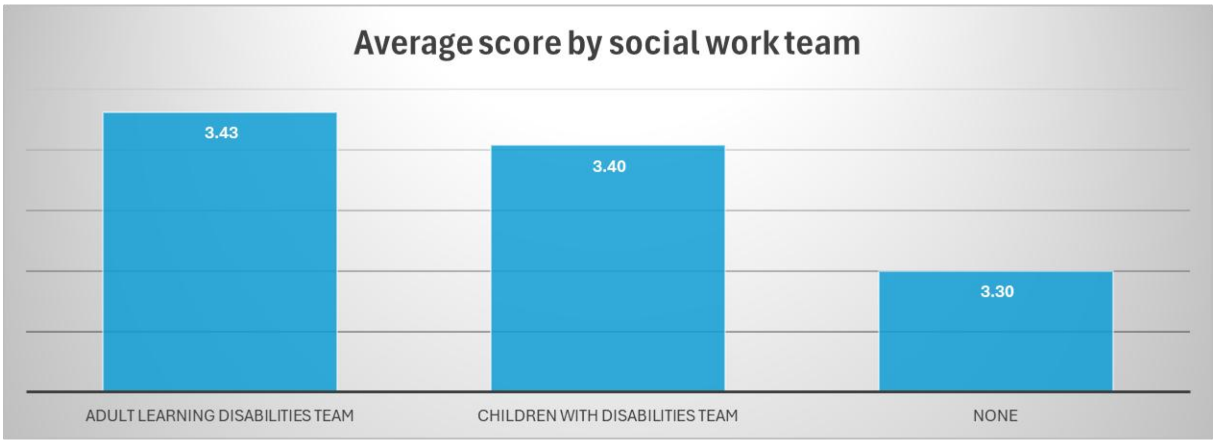
There is a good spread of respondents from a range of social work support.

Social Care Team	Number
Adult Learning Disabilities Team	24
Adult Physical Disabilities Team	2
blank	14
Children with Disabilities Team	134
None	537
Total	**711**

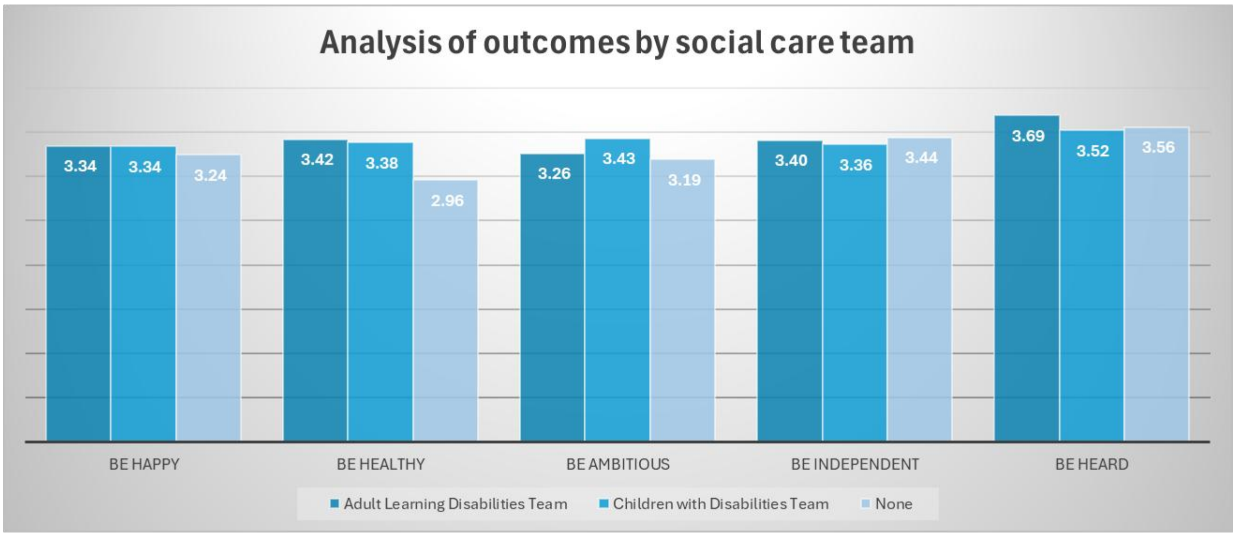
The number of respondents with contact with the adult teams was relatively small and so any analysis of this group must be caveated as representative of a small sample size.



There was a difference in average overall scores based on the social work status of respondents. Those with contact with the social care teams scored 0.1 points higher for the Children with Disabilities Team and 0.13 higher for the Adult Learning Disabilities Team compared to those that had no social care contact.



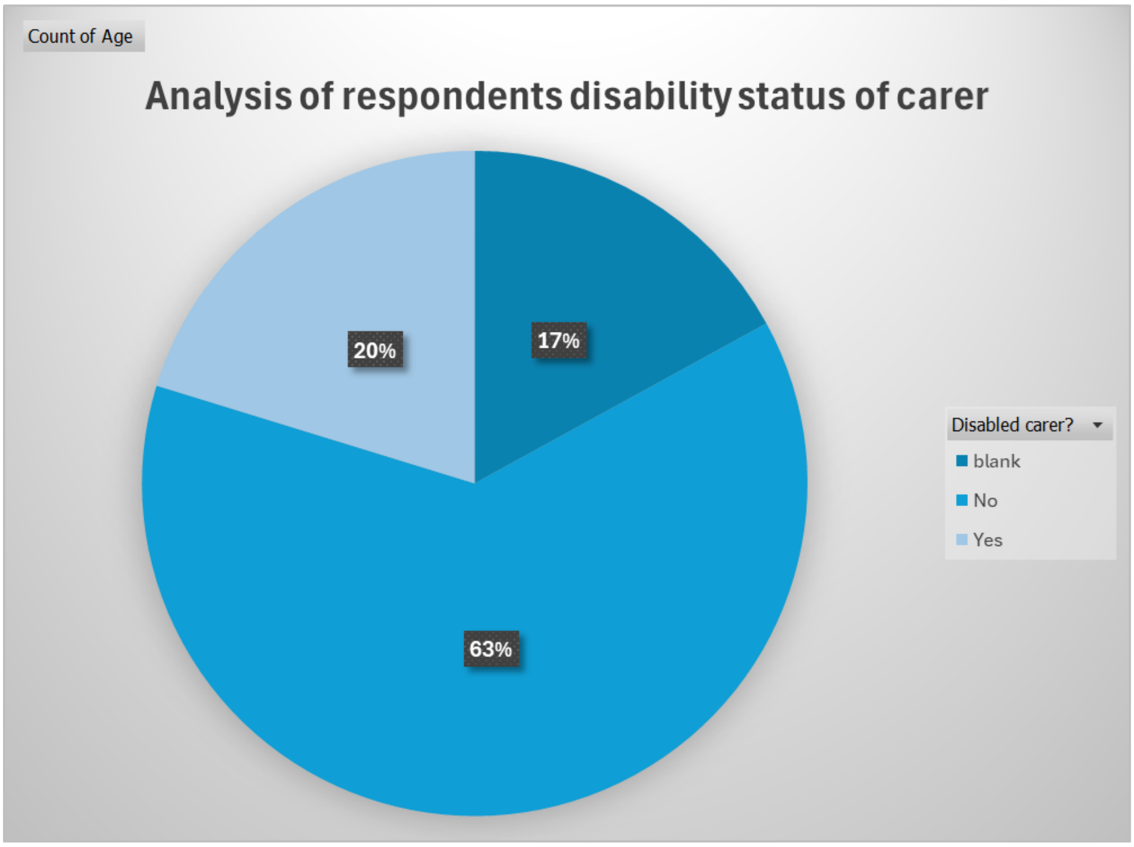
The biggest differences when analysed by outcome is that those with social care contact feel better supported to Be Healthy than those without. There was also a notable difference for those with the Children with Disabilities team for the Be Ambitious scores.



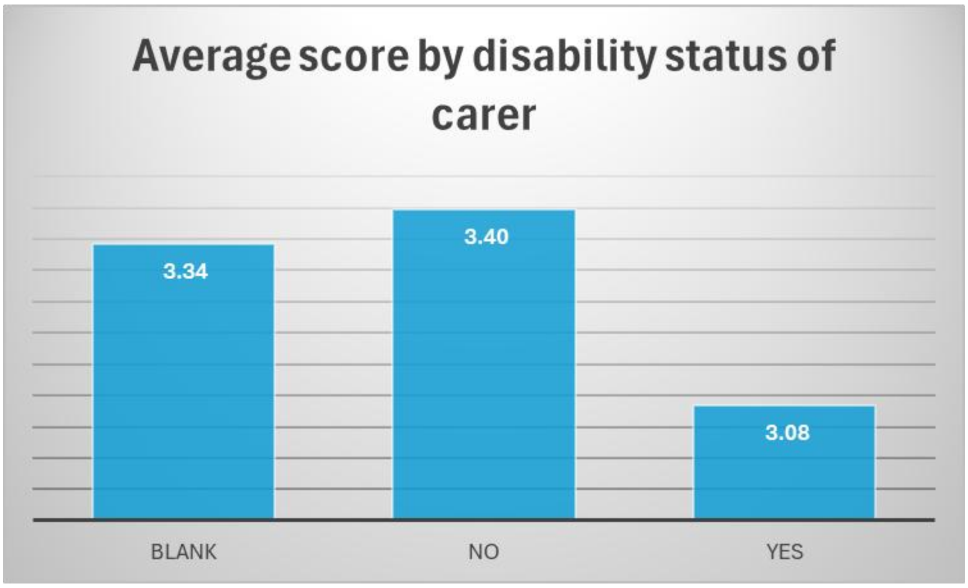
By disability status of carer

For the first year, we asked carers completing the survey to tell us if they, themselves had any disabilities. The majority of respondents shared these details:

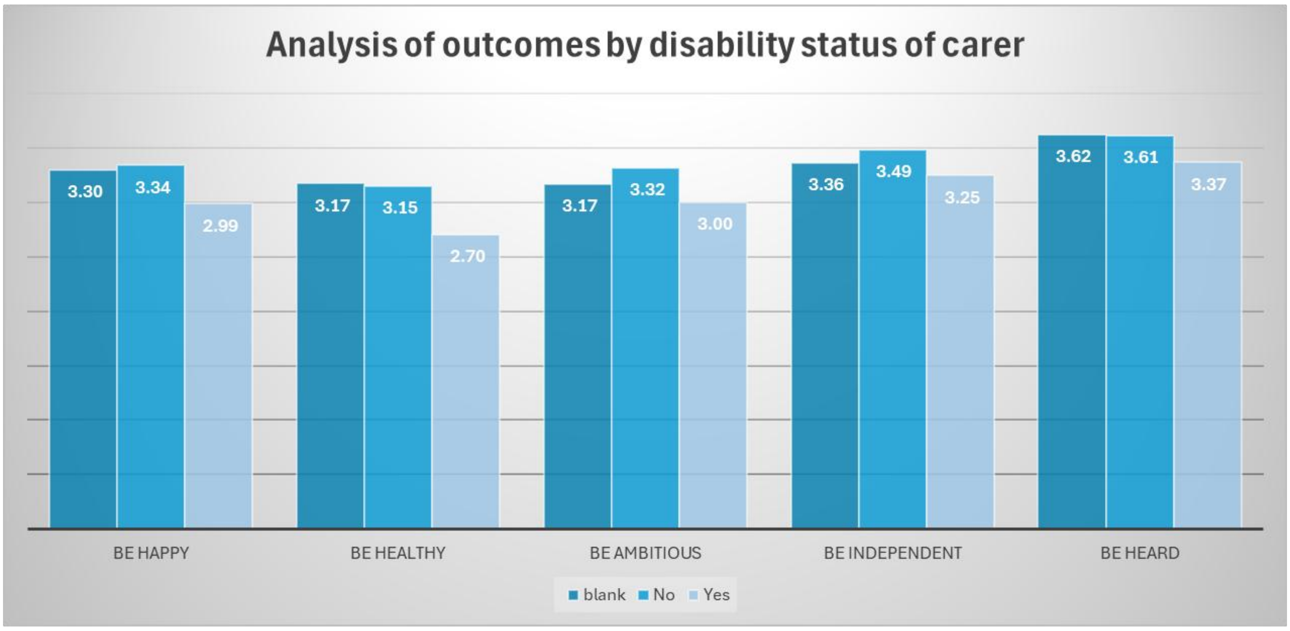
Disability of carers	**Number**
blank	121
No	446
Yes	144
Total	**711**



There was a significant difference in the experiences of children and young people for those whose parents declared a disability. Their average scores were 0.32 points lower.



All of the outcomes showed a clear negative difference for those with carers with a disability. An analysis of outcomes shows that the biggest differences come in the Be Happy (0.35), Be Healthy (0.45) and Be Ambitious (0.32) categories.



Be Happy

The average score for parent-carers in this category was 3.26 This represents a small fall from last year when it was 3.34. Our first survey in 2018 recorded an average score of 2.87 for Be Happy.

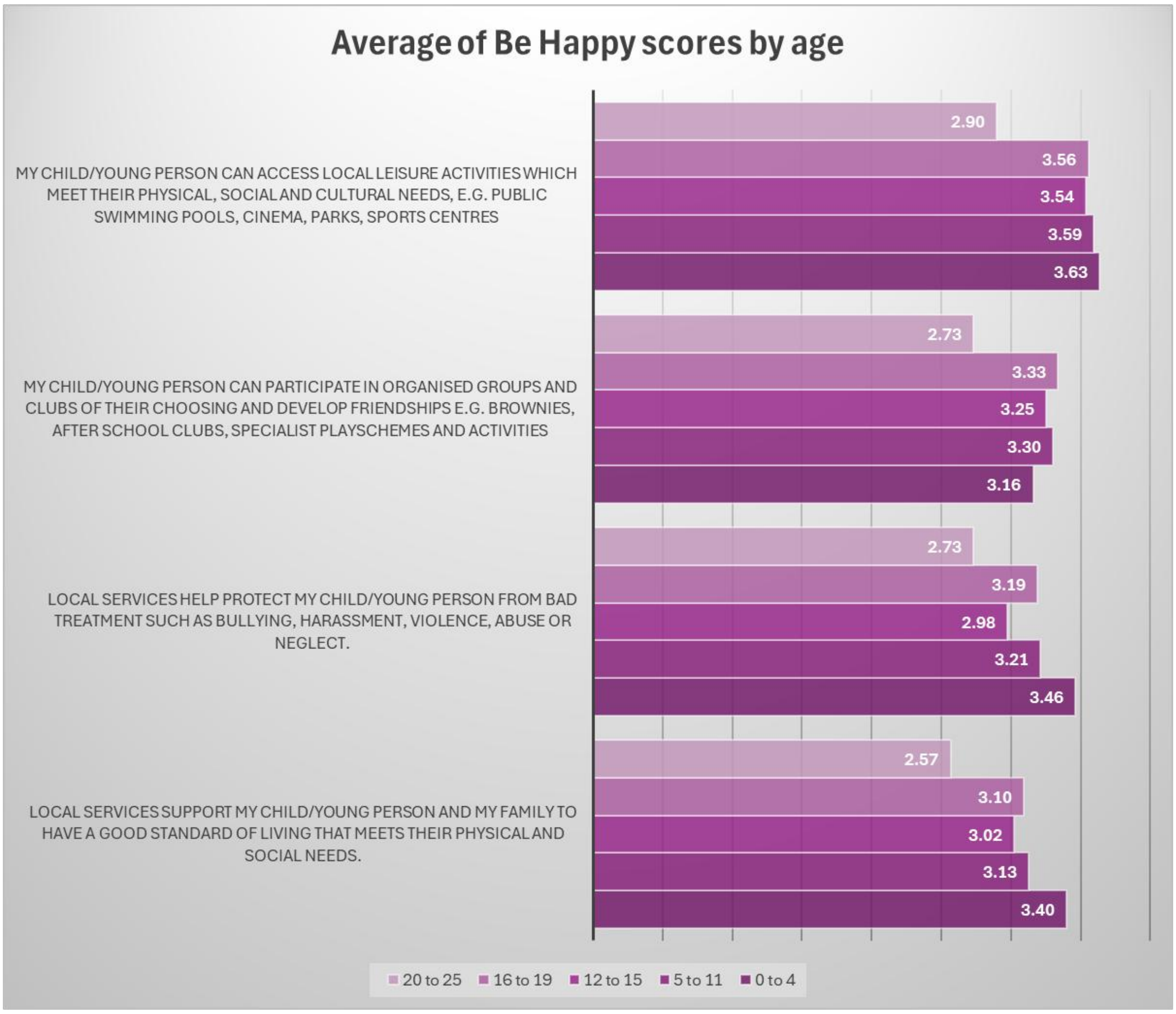
There was little movement in any of the average individual scores year on year. Three scores deteriorated and one improved very marginally.

Children and young people with SEND feel less happy the older they get

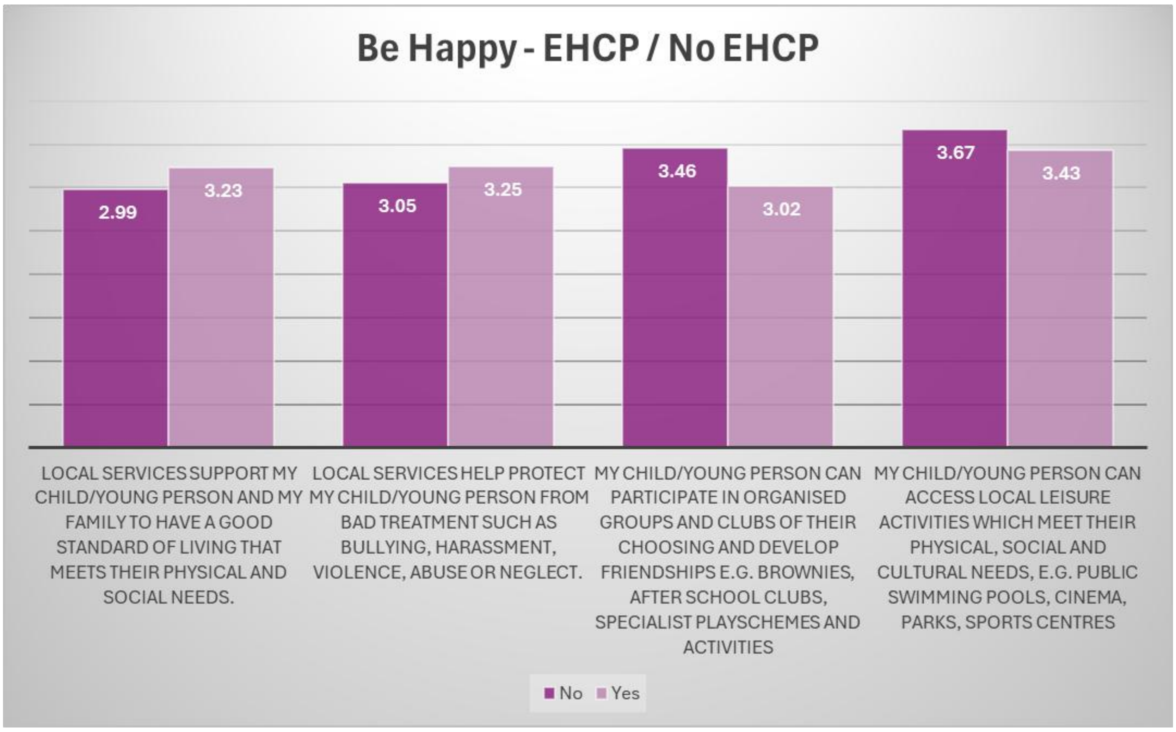
As a theme, analysis by age groups shows that families of younger children tend to feel happier than families with older children. With the exception of one question, the happiest age group is the youngest. The lowest scores are invariably for those in the oldest category 20-25 for all questions. However, the number of respondents in this category was relatively small.

There is a notable drop in the question about exposure to bad treatment including bullying for secondary school age children. This is picked up in the analysis of comments below.

There is more positive news for the 16-19 age groups which scores relatively better in all questions which is a change on previous years when there was no significant variation.



Those with EHCPs feel there are few clubs and organised activities for them



Families of CYP with EHCPs show significant differences in their answers to question 3 with a gap of 0.44 to those without an EHCP. This is mirrored in the comments from families that highlight difficulties for those with more complex needs to find clubs and activities for their CYP

Extra curriculum activities and clubs in my local area and after school I feel do not cater to Sen nor do they have the training or understanding for Sen children

He has special needs so he can't attend

My YP is unable to access groups independently or without support

No appropriate clubs for level of SEN child we have and Mencap charity declined child this summer.

Not able to based on medical grounds and what's on offer

school do not make any changes or amendments to after school clubs to allow his participation, he attends mencap club, and sometimes ssg saturdays, otherwise nothing

There are no regular clubs for kids with complex needs. The only one is Fun4all and itâ€™s so over subscribed he doesn’t get to go regularly which for a child with Autism who loves routine is another struggle.

Can only access groups if there is a carer or parent with him.

No where is able to provide a 121 for my son and I cant get a social worker because he's not diagnosed because they waiting list is another 4years

I don't feel there is enough support for my child to be at extra clubs or after school clubs incase she needs the one to one support or has a melt down and no one to help her

Comments indicate that this is to some extent about awareness of what is available, this could be improved through better signposting or communication

As mentioned in the previous question, I think we had contact from the 'children with disabilities team' when we first moved to Bedford but do not feel that we have been contacted by them since. Feel we would benefit from their support.

Don't feel like there is help out there, forever battling for advice and help.

Feel very let down with all services SEND related at present. Not exactly sure how their need ls are met as communication is extremely poor from school. No other outside services offered.

I know of no groups or activities for my child

Where families do attend activities, there was praise, for example:

The only initiatives for our family's standard of living are run by Autism Bedfordshire and BBPCF. The AB Summer Scheme has changed our lives, and the webinars and events run by BBPCF. Socially and physically, local services do nothing for my autistic child. The school don't run any clubs which are suitable for my child after school or in the holidays.

I am not sure what services there are to support. The main support we have received is through the school and Autism Bedfordshire.

I only know about the support from school and how the LA/BBC support interacts with them. I don't have any personal/family support outside of school. However I do have support from local charities.

Autism Bedfordshire was the best support. Care and understanding was incredible.

Mencap is great but wish it could run though other holidays not just summer. It's hard to find specific specalist clubs that are close by or have any space or if u have multiple children with send that they can all attend due to them often being different ages at different times or days

In addition, cost of living and practical considerations (e.g. being able to transport CYP to clubs) were raised as barriers to participation:

Everything cost to much and I don't get benefits

I do not have any money to take my children and I do not drive.

My child does not participate in anything because I cannot afford it and I receive no state support.

Cost and transport are an issue. Hard to access activities that are supportive of kids with ADHD.

I do not drive and public transport is minimal, getting somewhere will take too long. If transport was provided, this would help.

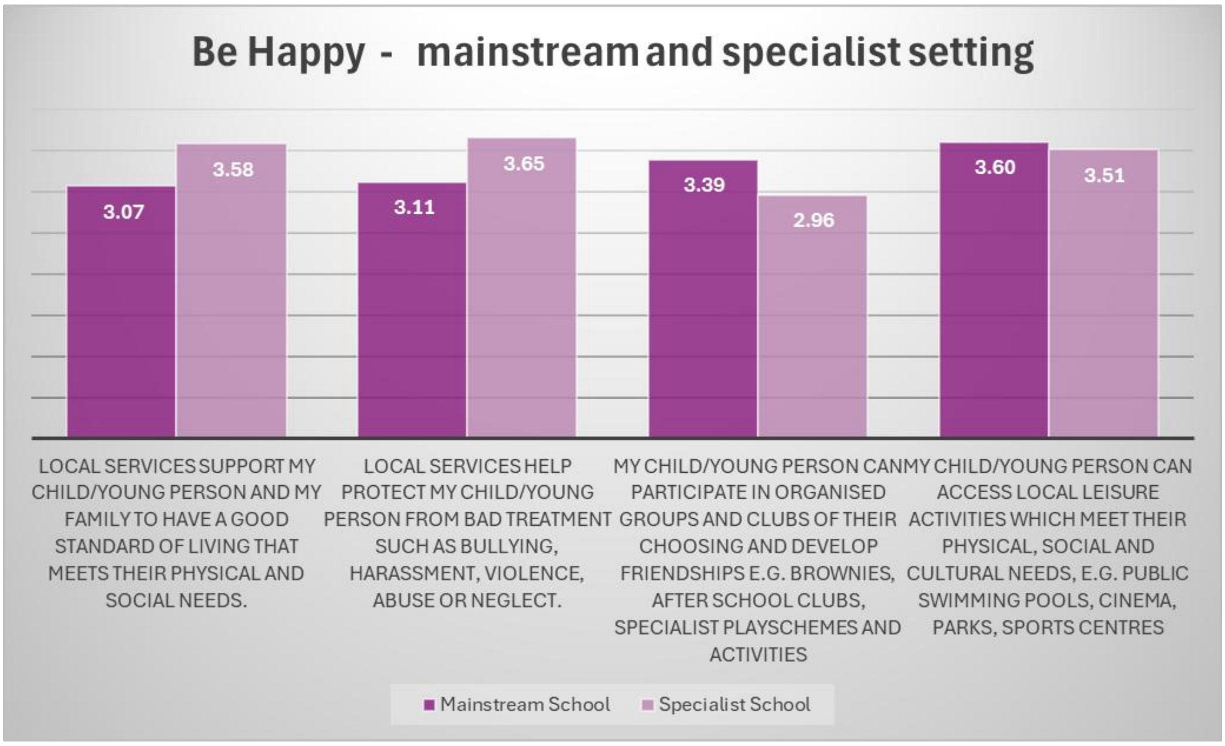
It is really hard to get to children activities without transport and there is no help with transport. It is especially hard to access activities if you have more than one child with special needs. Public transport does not work with my children's needs.

He can access these but can not do so without my support. As a teenager he wants to do things but I worry for his safety and how he will react when under pressure.

Too expensive to travel there as dont drive . So cant do local activities

Bullying is a major concern raised by a very large number of families, particularly in mainstream, secondary school.

Consistent with prior years, there are a large number of comments that speak about bullying. Detailed analysis of the data shows that there is a significant gap between the scores for local services help protect my child / young person from bad treatment for those attending mainstream and special schools with a gap of over 0.54 points between those attending mainstream and special schools. This is a deterioration on last year when the gap was 0.47.



The age range analysis above, shows this difference is most marked in the 11-15 age group (secondary school).

This is supported by a large number of comments drawing attention to bullying, largely in mainstream settings.

Bullying is not dealt with appropriately, nor adequately at school.

He's being bullied regularly

I have been to the school many times and nothing stops the bullying

My child gets hurt and gets picked on. He always the one who gets told off. I do not feel the school understand.

My childs been placed into the wrong school setting which opens her up to bullying and puts her in situations that could be normal for a child without needs but dangerous for a child who has needs and doesn't understand danger or are unable to read social situations

My daughter gets bullied all the time at school

My daughter has suffer bullying in 2 schools which caused immense anxiety

My son is going through a tough time at school with bullying and anxiety however nothing seems to be being done

That raised several complaints of bully by teachers and students which are brushed under the carpet. My child is exploited by other students and nothing happens

Bullying occurs in school and always has. Neuro divergent children stand out and are not supported enough. The school system is broken and something needs to be done as the children are being failed

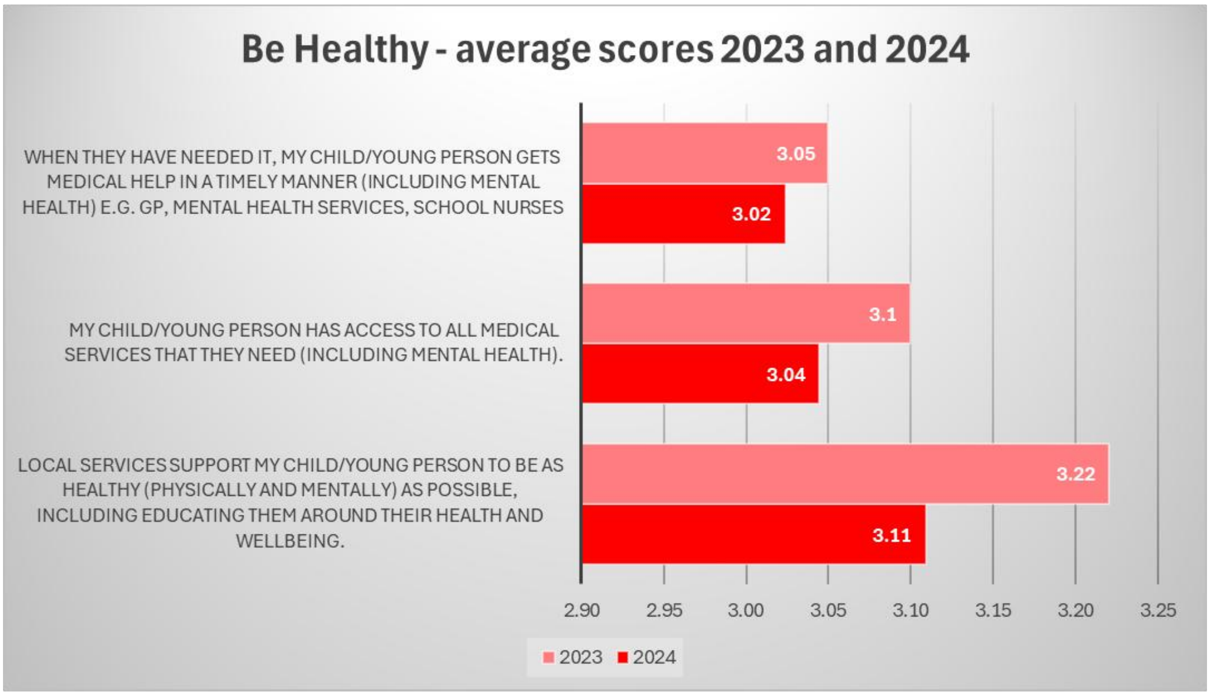
have called the bullying service at the LA once - useless, told me to call school, who were not helping and were the reason I called the LA for advice. some great national resources and free online webinars though

Those in mainstream school feel less well supported to have a good standard of living that meets their physical and social needs.

The same analysis shows that those in mainstream school feel less well supported to have a good standard of living than those with an EHCP with a difference of 0.51.

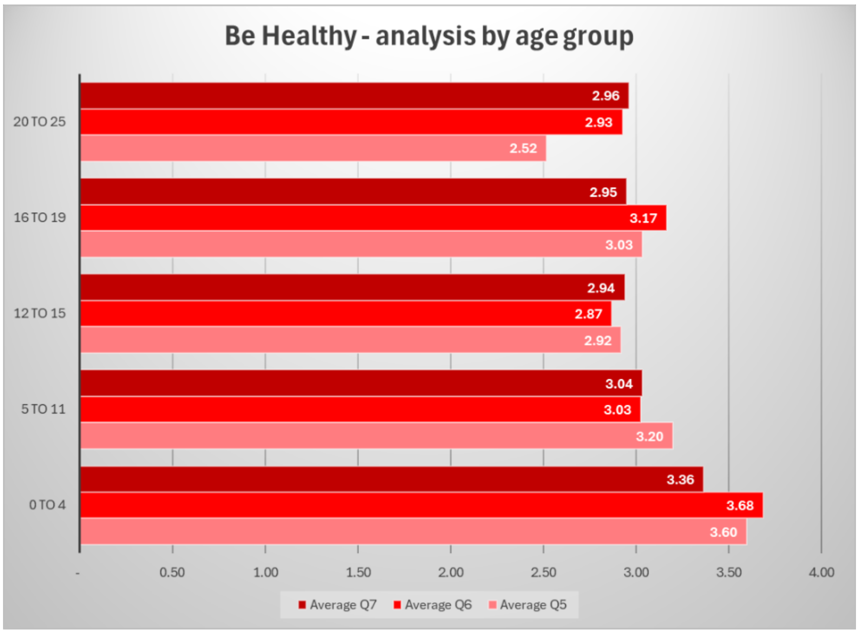
Be Healthy

There was a slight decrease in the average Be Healthy score year on year which was 3.06 this year. In 2022 the average score was 3.13. Consistent with previous years, this was the lowest scoring outcome.



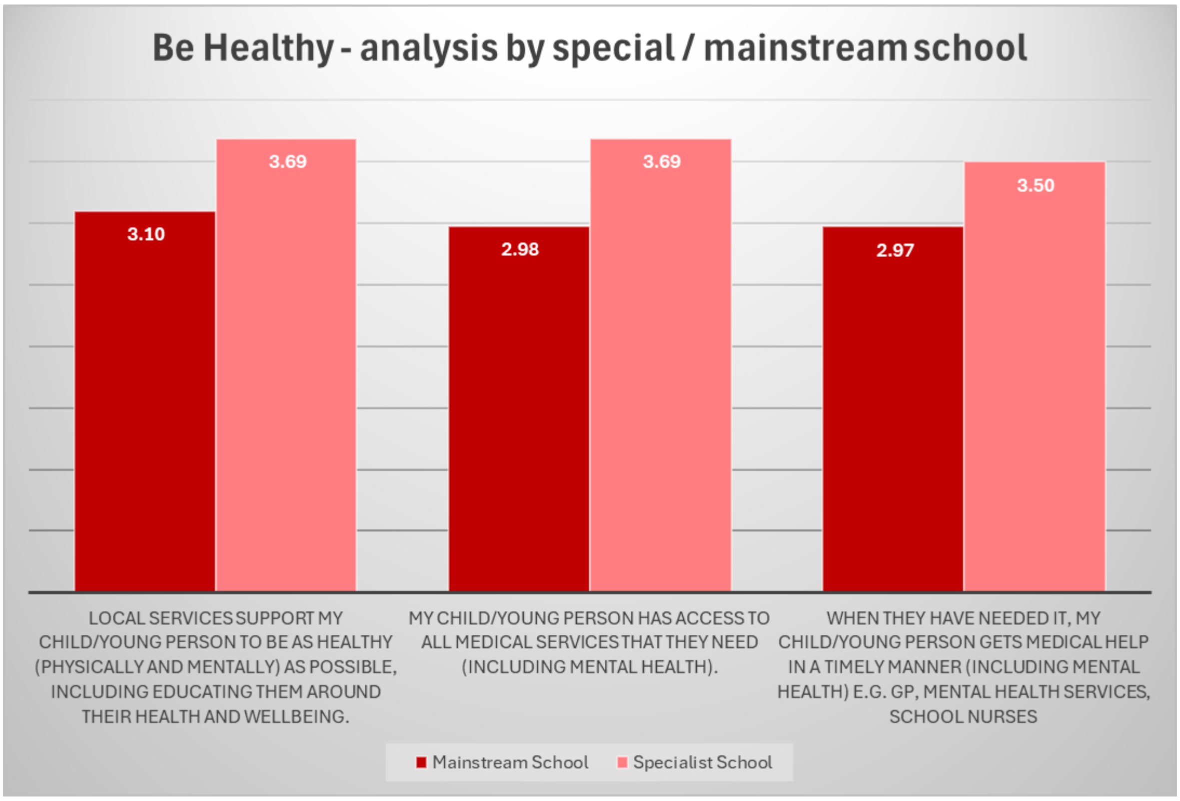
Each of the three questions saw a small fall in scores.

There was no clear pattern in the scores broken down by age group. The best scores came in the 0-4 age range with all other age ranges recording similar scores.

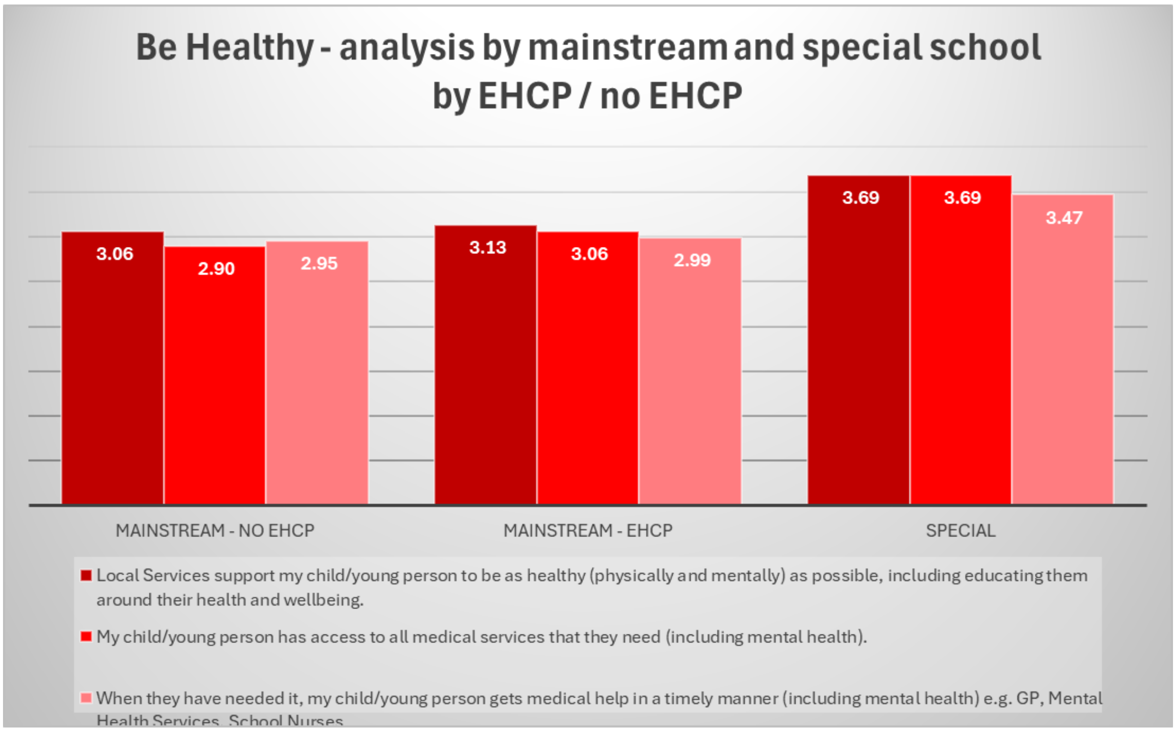


Those in special schools felt that their medical needs were being better met than those in mainstream schools.

Special school scores were higher for all be Healthy questions. The difference is quite marked with gaps of 0.59, 0.7 and 0.53 for the three questions.



The following chart shows that the key difference is school environment, not whether a CYP has an EHCP or not. Clearly, the holistic support provided by special schools makes a difference to family experiences.



There were a large number of comments about long waiting times for health services to explain low scores:

The question on access to health services when needed was the lowest Be Healthy score at 3.02.

We have waited a considerable amount of time (5 months+) for CAMHs to complete assessments. We are still waiting for them to help with guidance

Our waiting lists are far to long for diagnoses for send and physical health children wait years to receive support it many areas

Services for mental wellbeing are far too limited, with massive waiting lists.

Could I get an appointment for a neurologist when my son developed epilepsy, no.

Im waiting on the GP to referr me to the 0-19 incontinence team this is my second time asking, I'm also waiting on a dietician

Just rejoined paediatrician waiting list for another 2 year wait.

CAMHS has been very limited. There are long waiting lists for everything else.

He is on the waiting list to be diagnosed with Autism and he will be 2 years before he will be seen.

Waiting list for CAMHS way too long

2 year waits for a paediatrician is shocking

How? When there is such a huge waiting list!!!!

No clear contact   Takes weeks to talk to people and then leading to crisis

Within this, there were a large number of comments about access to GPs

When he gets sick I take him to the local GP but the appointments take over 2 weeks.

Drs in Queen's Park surgery are hard to get hold of. Really hard to get appointments from GP surgery, I had to go to hospital for my children because i was not given an appointment and their health got worse. A health nurse has been trying to help me a with my son to get him to take medication, but I have not seen by a pediatrician or specialist.

GPs not willing to refer to therapy team/CAHMS or to a paediatrician. GP knowledge of SEND and related services is poor

No we call an ambulance when needed - GP / village medical centre constantly voices that they support >10,000 patients and will not give appointments

It's is really hard to get GP appointments, and impossible to get on the same day. Other appointments have long waiting lists.

Getting GP appointments is near impossible unless you can use a crystal ball and know you are ill a month in advance.

CAMHS Services divide opinion

There were a large number of negative comments about not meeting thresholds for CAMHS services, services not being available or long waits.

Unable to get support through CAMHS as he does not meet the threshold. He will be far worse before they give help. Had support from the dietary/exercise programme but again it was not run by staff who were familiar with SEN needs. Would like to add some physical exercise, such as a gym to his EHCP, to channel his physical energy but not aware of anywhere we can do this. Gyms just do not want 13 year old boys with their Mum there!

We have waited a considerable amount of time (5 months+) for CAMHs to complete assessments. We are still waiting for them to help with guidance

Camhs - 5 referrals before being accepted, only because of being put on CP due to child's needs not being met. Still not providing support after over a year of being on their books

Rejected by CHUMS and CAMHS many times, even in crisis

Rejected from CAMHS,   Waiting lists are too long - wait for 16+ months for urgent surgery

Turned away from all mental health saying has to complex needs in multiple areas, so have no where to turn.   Trying to find out how to get support from certain teams or even knowing they exist is hard such as continence or behaviour or OT

We were rejected from CAMHS despite self harming and suicidal ideation because we werenâ€™t high enough risk.

Getting a GP appointment is hard going, when CAMHS were needed she was declined any support

My child has had suicidal thoughts and expressed them several times over this year. CAMHS didn't have anything to do with it- when asked, the threshold wasn't met for their intervention. They've referred to another scheme, "Life Hacks" but it has been months with no support nor help from them yet.

It was only after an attempted suicide that my child's mental health was taken seriously

However, there were many very positive comments from CAMHS users who scored 4s and 5s. Often, these comments were non-specific – they just say CAMHS or CHUMS (20 examples) - these comments have not been reproduced here.

CAMHS are a great support but unfortunately the wait time can be long

My son was being seen by CAMHS and they supported him with his emotions.

I really like the CAMHS NDT Team. I appreciate it’s hard and long wait for us parents and more importantly the kids. However, they have supported us so much and be such a positive influence on my son.

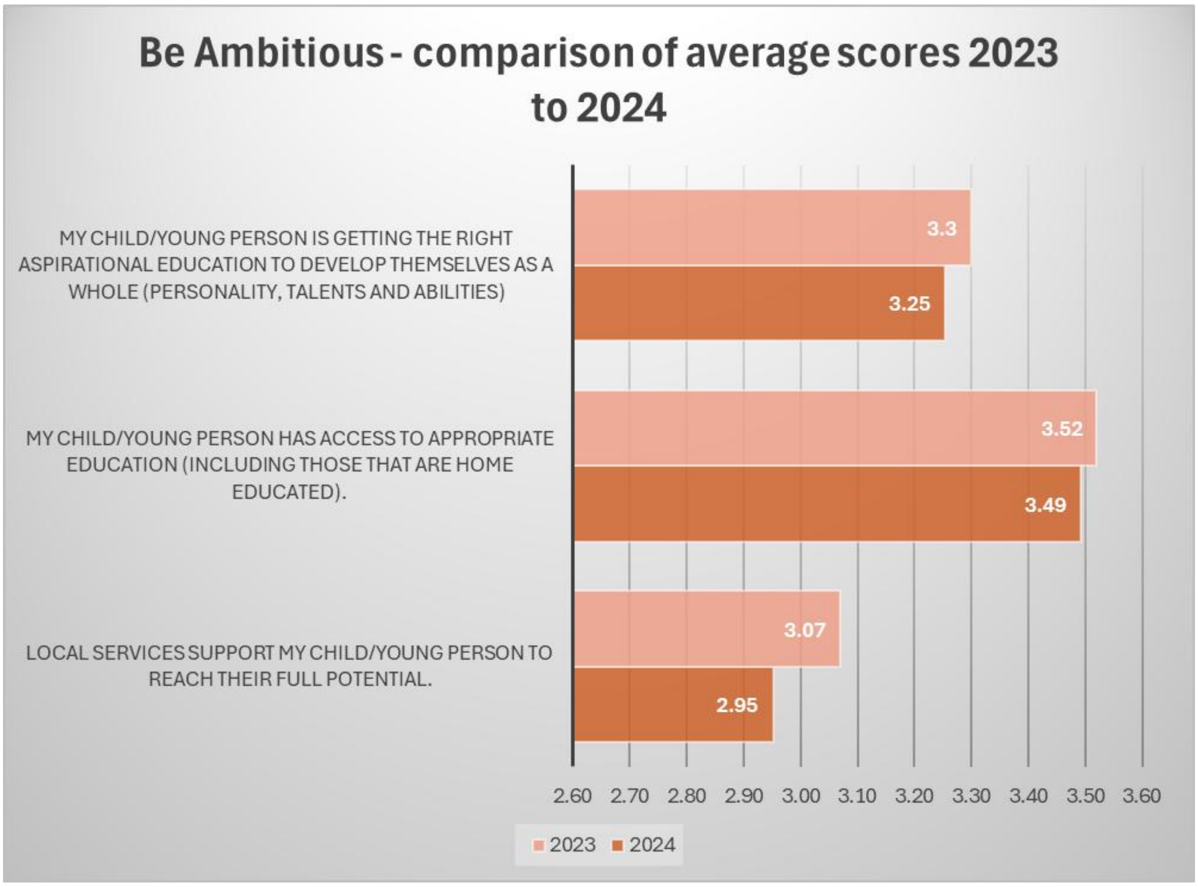
We have used CAMHS a couple of times

Have used CAMHS to support my child with play therapy sessions.

Cahms have been fantastic just wish they could have sessions

Be Ambitious

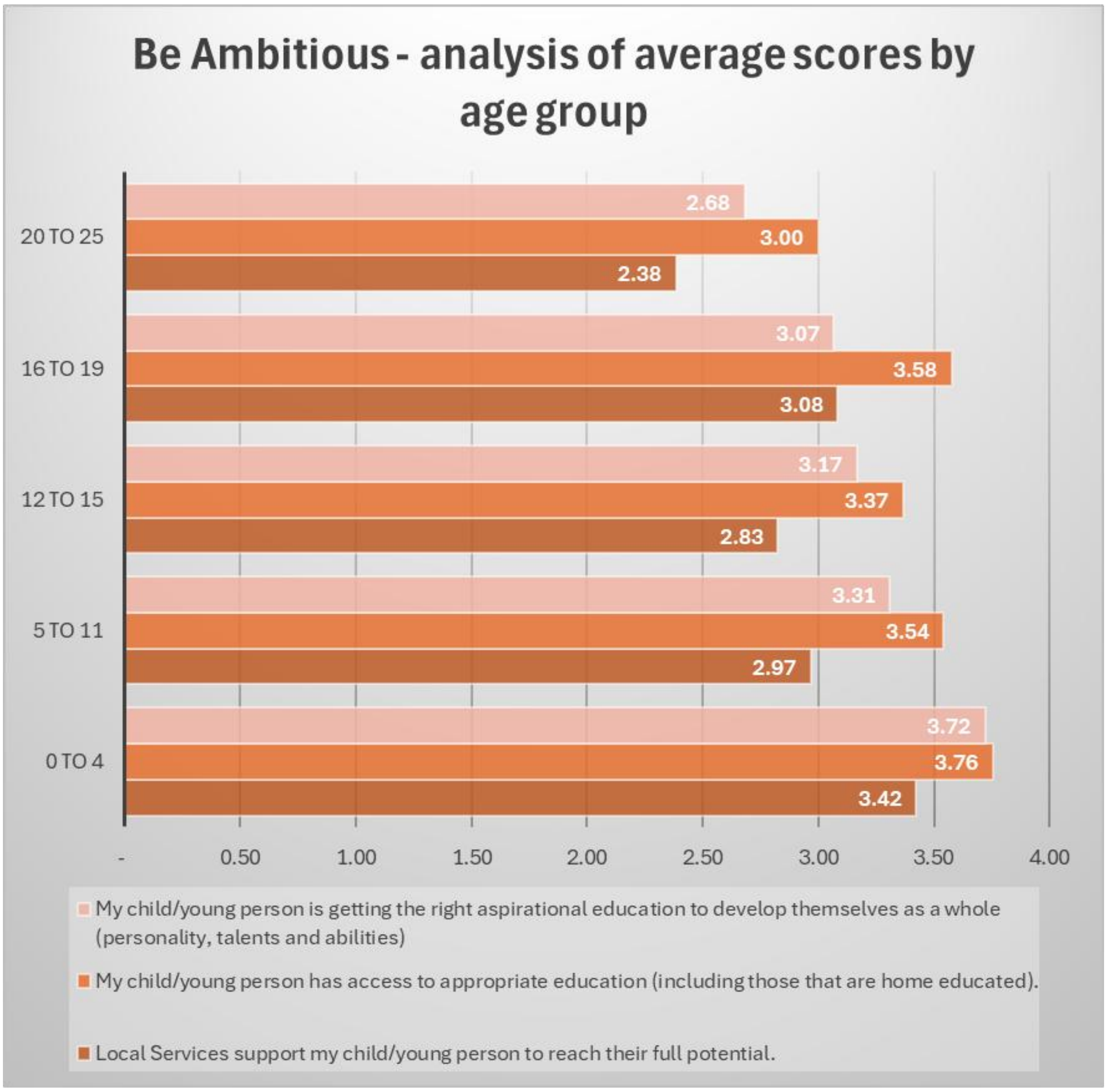
The average score for this category was 3.23 which is a fall of 0.06 on the previous year (3.29). All of the scores show a modest year on year decrease. The Be Ambitious outcomes showed a wide variation with the question about supporting CYP to reach their full potential scoring the lowest average score across the whole survey.



There is a significant difference in Be Ambitious scores between school age CYP and post school

Analysis of the age profile for this question shows a similar pattern with parent carers being more pleased with the Be Ambitious scores and again we see a significant drop off in the scores for each question once the young people leave the school system.

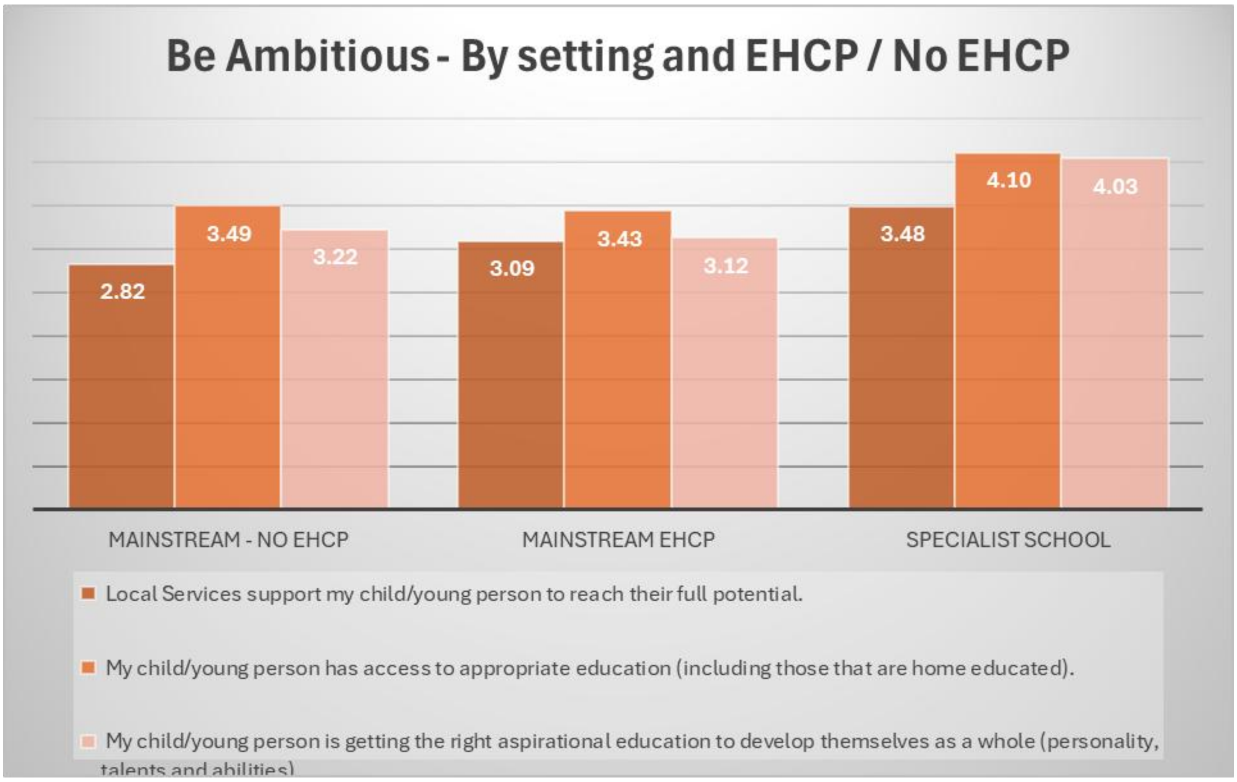
Those who are aged 20-25 feel as if the local area gives them very little support to meet their full potential with a score of only 2.38. This was the lowest age-based score across the whole survey.



Scores for children of school age remained largely consistent across age groups.

Children in mainstream schools scored significantly worse than those in Specialist settings

There was a small difference between those with EHCPs and no EHCP in mainstream settings but the most marked difference was between mainstream and specialist settings.



The comments shed some light on this. Many respondents did not feel that the right adjustments were being made for their children with EHCPs who attended mainstream schools. They commented on the availability of specialist resources, a lack of a holistic approach and too narrow an academic approach. Access to specialist resources outside of the school setting (most notably health and EPs) was mentioned by many.

Waiting on the cdc is like being in limbo as the school can only do so much and help without an official diagnosis they have done an EP for us

While the school offers a nurturing environment and some support, I feel that additional involvement from local services could help my child reach their full potential. More targeted support around social skills and managing peer relationships would be beneficial in fostering a positive, supportive experience for my child and those around them.

I have not had any contact from anyone outside of the school setting, even though he is on the SEN register. Heâ€™s dyslexic, undiagnosed because thereâ€™s no money in the Borough to spend on a diagnosis.

The school have been helpful but health has been inaccessible.

Reduced timetable 2 hrs /day however TAF has determined needs cannot be met in current mainstream provision. SEMH or SEN provision required

Due to mental health needs my child cannot access a full and broad education. They will not even leave the home currently.

My son is an Einstein but he is being missed completely because he doesn't fit into a box and no one has the time to support him and his needs

Lincroft is focussed on punishment not encouragement

Inflexible school system. My child is behind and school refuses to relieve the pressure and let her redo previous year. Insurmountable task for her to catch up one whole year of GCSE as she missed yr 9 at that school/they have different exam boards/done other topics, while issues are ongoing. She should be given time to settle into new school/get familiar with teachers/students, ... be in a better place mentally.

School only focuses on educational side

Unfortunately I feel more could be done with more funding and more staff.

Too few spaces in specialist school provisions, too many children in inappropriate educational settings. Few options for good quality adult support services

There is no funding or services to provide the help me and my child need

Unfortunately I feel more could be done with more funding and more staff.

Many people commented that they could not get into a school, or that the right school place was not available for them.

The comments support the analysis of the scores that show that many parent carers believe that mainstream school is not appropriate for children with more complex needs and / or those who have an EHCP. There were many comments about trying to get into special schools, long waits and a lack of places.

It took 6 months for my child to have a school place when he wasn't able to return to mainstream

Meets all criteria for the grange except they are fully physically able and advanced in p.e?! So stuck at mainstream where even with an ehcp they're struggling so much.

My childs in the wrong school setting with no support no point in having an ehcp because they don't use it or follow it

Not in school, on school roll, school do not seem bothered - I have to push for everything, medical school/hospital education a referral has been made after I made the point LAs duty to offer education and now they have been making excuses even though evidence provided

Not in the right setting as is"not bad enough" for SEN school but mainstream isn't the right fit either. There's nothing out there for children who inbetween.

There were many comments praising the approach of individual schools, approaches and teachers

They do their best but are limited

School helps him to reach his full potential

Lincroft School ARC provision led by Mr Barry was pivotal in my child being able to achieve their potential with their GCSEs - this was down to his excellent approaches to working with young autistic teenagers.

The school do amazing with encouraging and easily accessible sites for extra work.

The school is great but again the is only one SENCO which is not enough for the volume of neuro diverse children.

Love St John's School

Putnoe primary school has been fantastic in helping support my son who has ADHD

his current teacher is taking his time and is able to get the best out of him whereas before he was seen as a naughty child - talking too much not being able to sit still and focus -

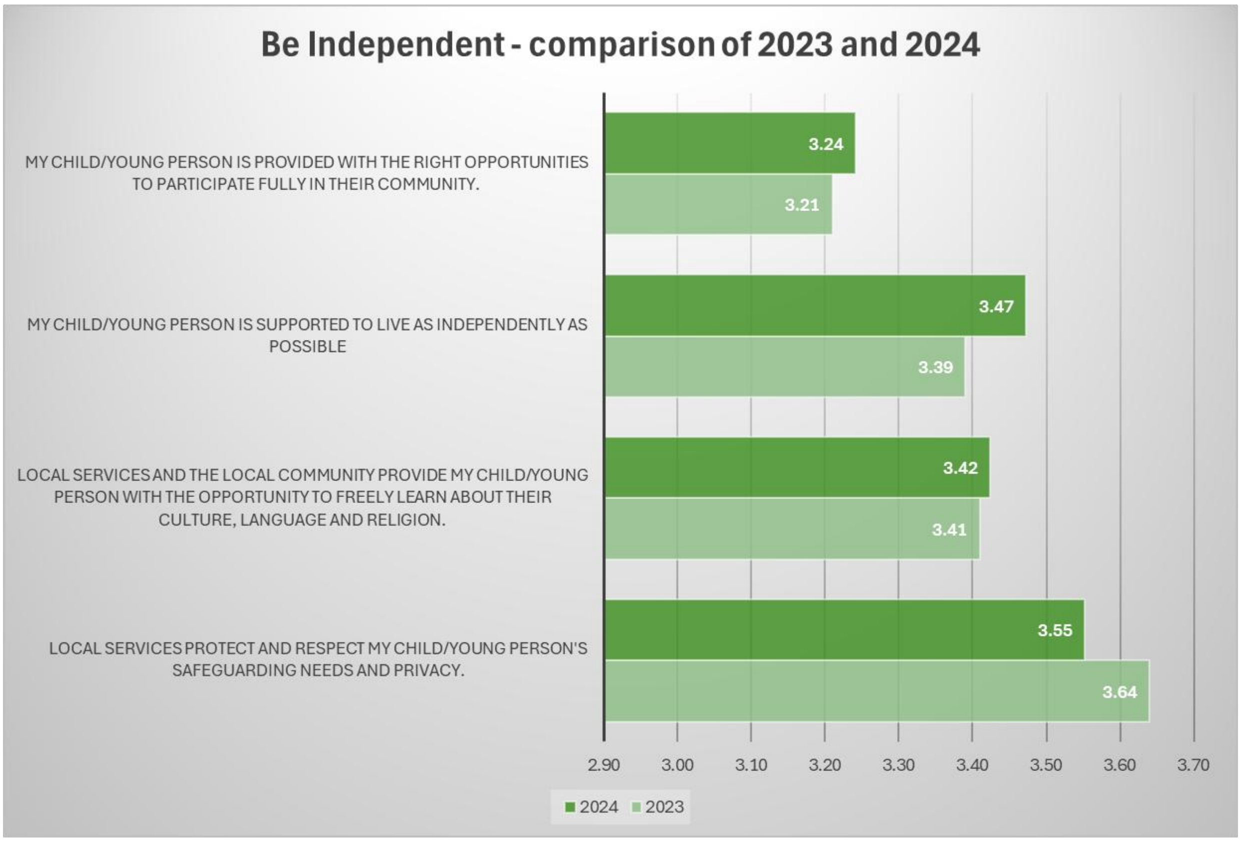
Her school have been fantastic workimg with her and me to help her confidence is re building since going to secondary

Great support from teachers and his learning mentors

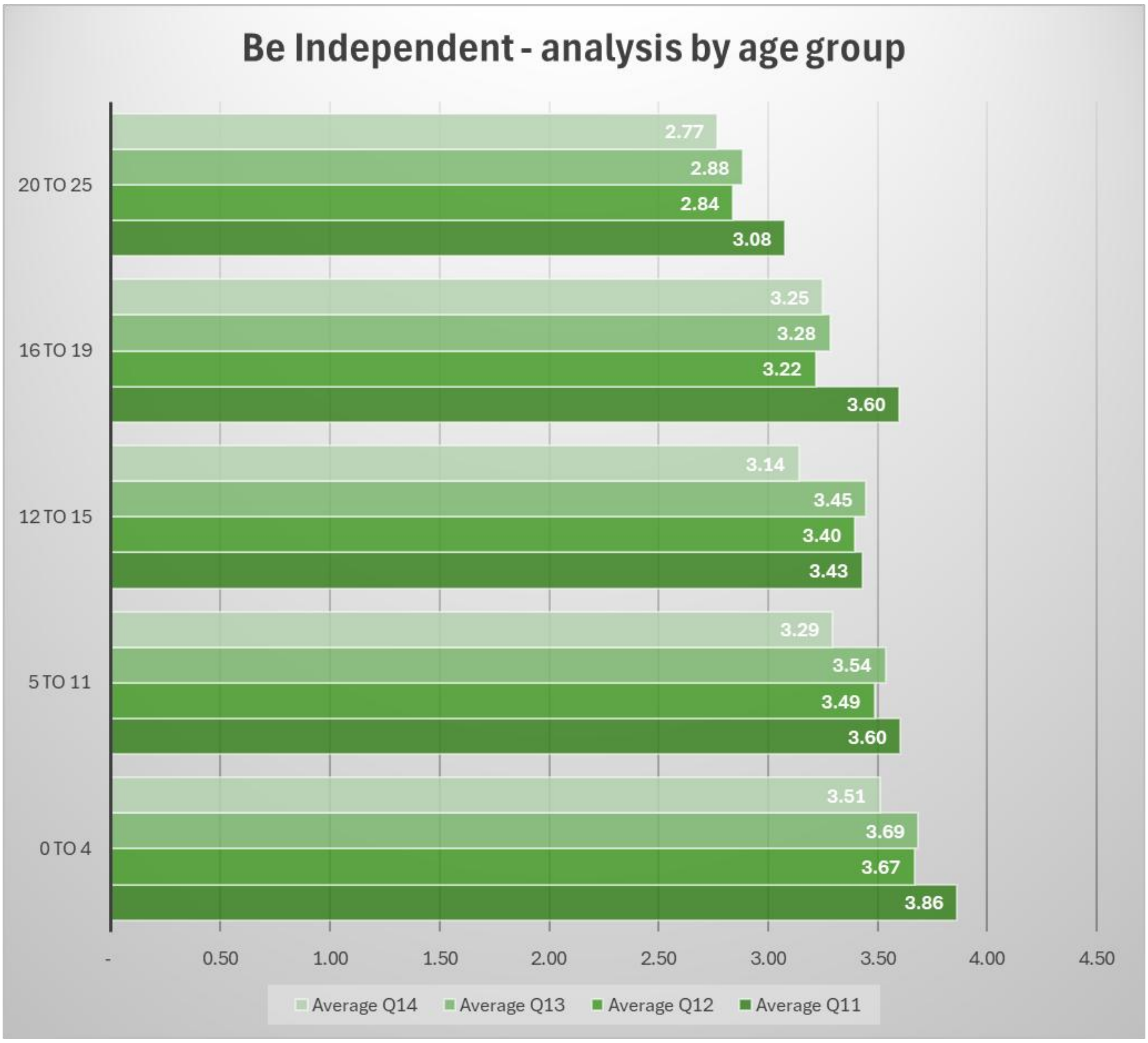
Be independent

The average score for this outcome was 3.42. This is very similar to the score last year which was 3.41 but shows a small (0.01) point fall.

The individual question scores were also very similar year on year with three of the four scores showing a small improvement and one question regarding privacy and safeguarding showing a marginal deterioration. However, none of the moves year on year were significant with no move more than 0.09.

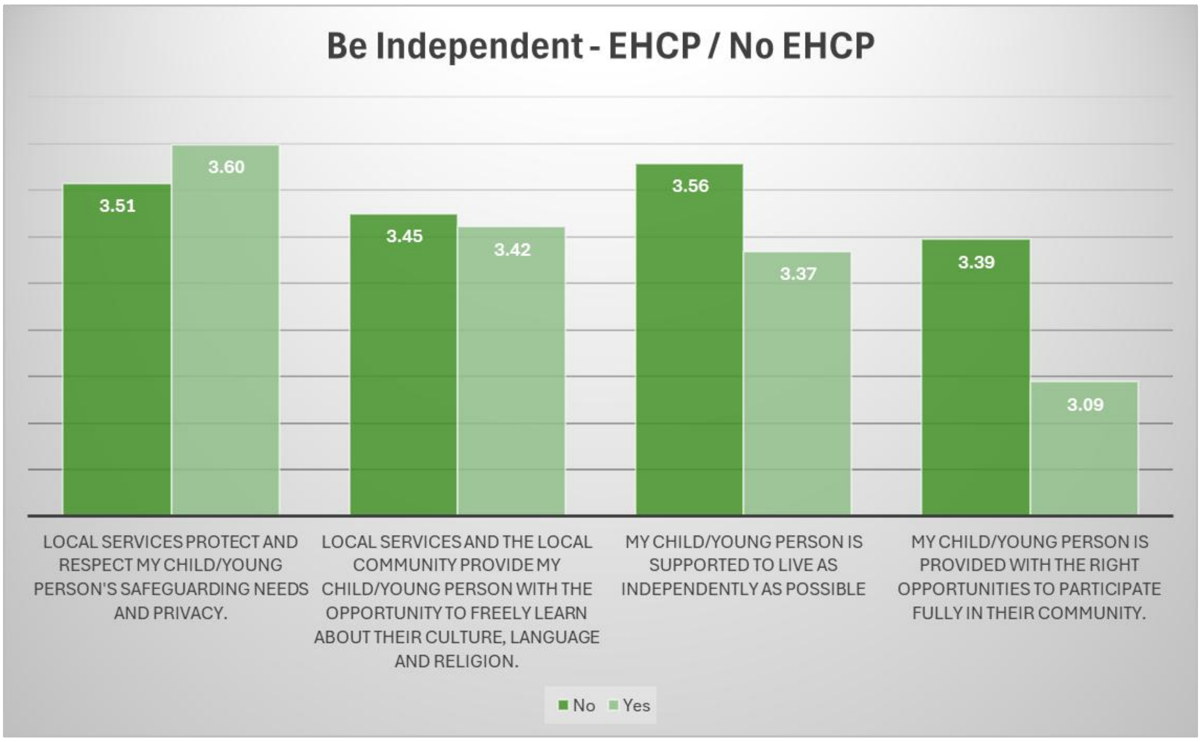


Similar to other outcomes, there was a clear pattern where the youngest respondents reported the highest scores across all questions, whilst the oldest reported the lowest scores. The difference between oldest and youngest was significant



For all of the scores, there was a significant difference between those in education and the 20-25 age group. This suggests that many families find the “cliff edge” of leaving education challenging.

Those with more complex needs find it more difficult to participate in the community and live independently



There is a difference between scores for CYP with an EHCP compared to those with no EHCP. The largest differences come in the scores for opportunities to participate in the community (0.31) and being allowed to live as independently as possible (0.19).

This is suppoprted by comments explaining low scores in these areas

My support stopped at 16. This left me totally alone and I felt scared and helpless.

Needs supported housing, but told this is unavailable due to him not being registered as SEND, even though he should be and technically is.

Need an increase in life skills v academic success

Severely physically disabled my severely physically disabled and come medically complex child is currently in transition, and I think there is still a huge emphasis on parent carers providing unpaid Care for they're disabled adult child, Which we feel does not promote independence.

All care needs met by family due to high level of needs.

He isn't provided with any opportunities that are right for him. I tyhink this is because local services just don't understand his needs and don't take time to leatn and understand him, his disability or his needs

I am not aware of any opportunity for my child to participate in our community. Opportunities are limited by their ability to leave the house, and activities or events within their interests.

Apart from Mencap playscheme for three weeks in the summer, which is heavily over subscribed there is no club or place for my child in the school holidays. There is also no weekly club he can go to as the one run by ssg is so oversubscribed he can only go 4/10 sessions.

Feel there could be more specialist focus for autism in clubs such as cubs, swimming lessons etc

Families cited a lack of information about the types of services and support that may be available.

Bedford Borough Council provides many opportunities for children in the area & there are many organisations around who help, such as BBPCF, Carers in Bedfordshire

Activities put on by the BPCF are outstanding and really help my son access the community

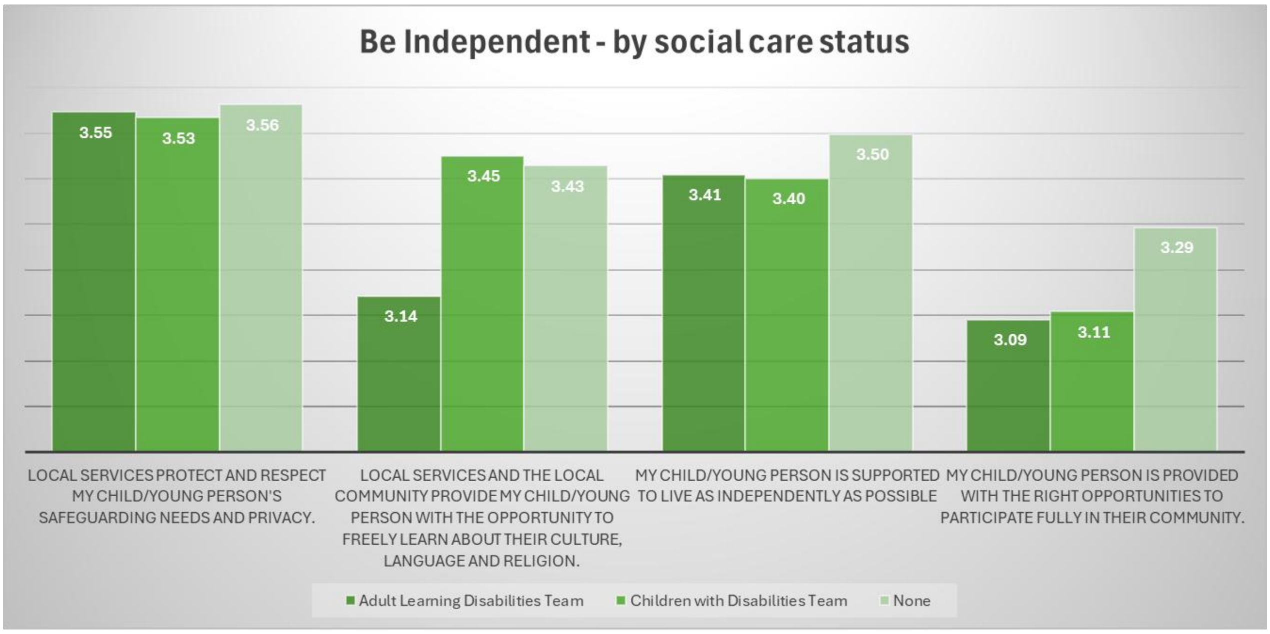
Not sure

Not sure what those opportunities are

Nothing for SEND children aged 7

I recently moved in the area and don't know about opportunities

There were some differences in scores based on the social care status of respondents



Consistent with the EHCP analysis above, those with a social worker (either from the adult or children’s teams) found it more challenging to participate in their community.

Also, those with the adult disabilities team noted a significant difference in being able to learn about their own culture, language and religion.

For the first time, there were some comments of this nature

I feel that local services do not understand out cultures

There is no service for African cultural education. We have to seek out community which means leaving the area to connect with others.

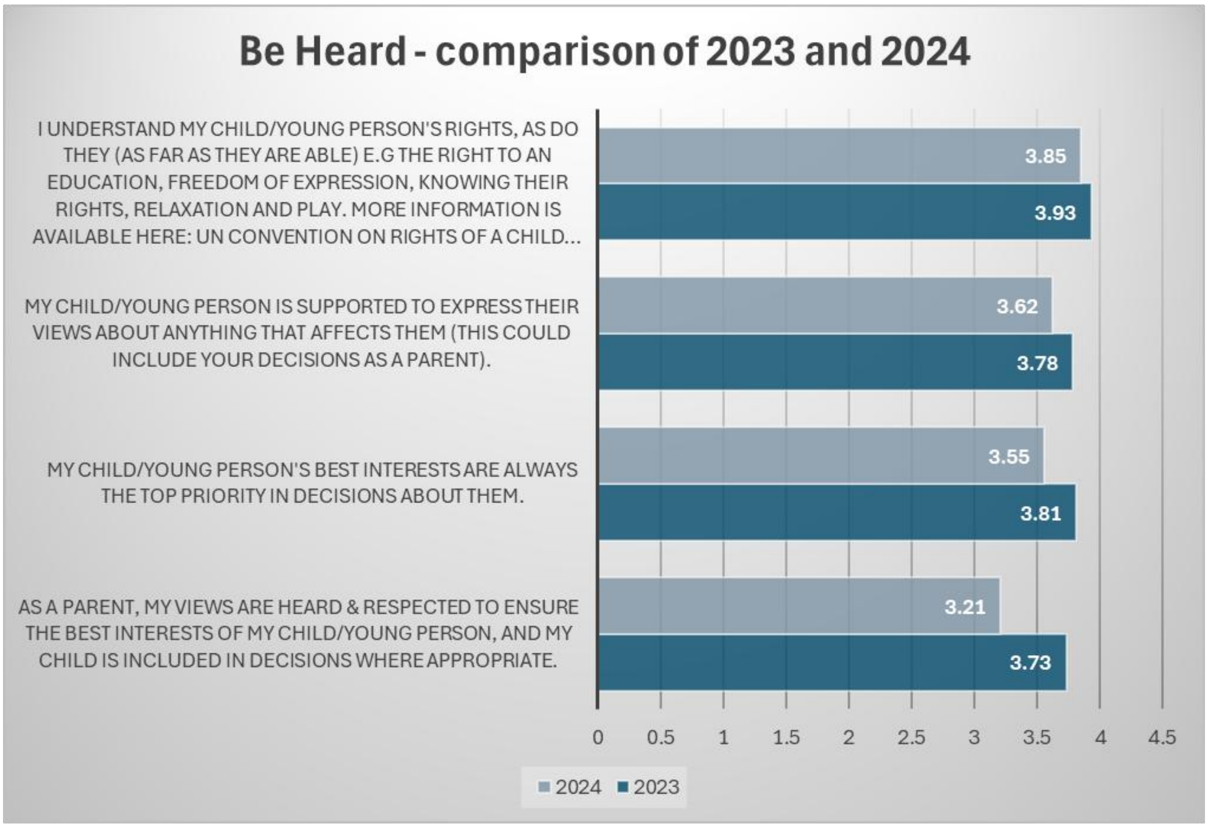
Mainstream in Bedford is severely lacking diversity and cultural teaching/learning/awareness

I feel some people do not understand my child and we feel unwelcomed.

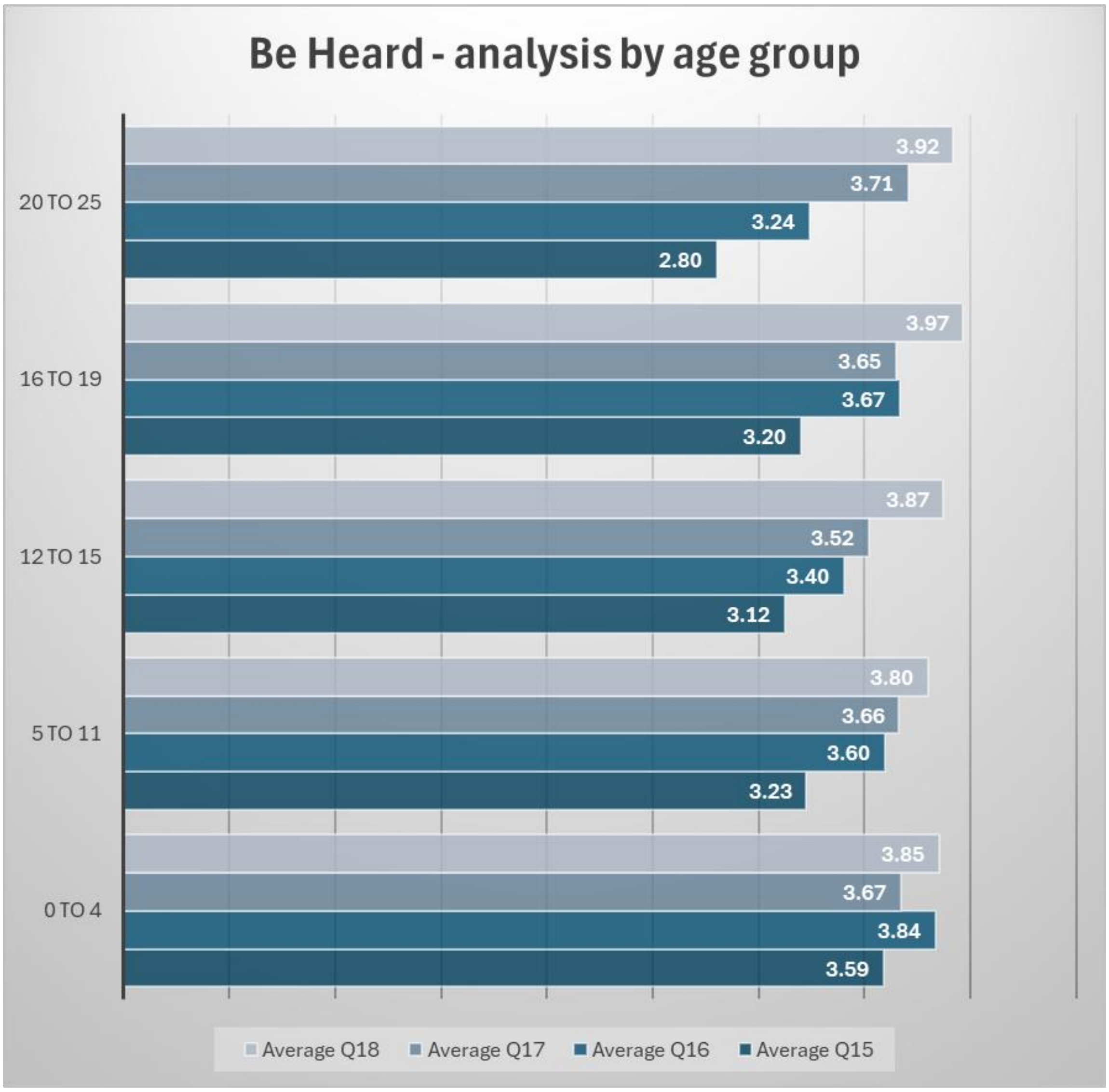
Be Heard

The average score for this category was 3.56 which was a fall on last year's score of 3.81.

There were drops in all the scores, however, the most significant fall was in the question about parental views being respected where there was a large drop of 0.52. In previous years, this has been a "bell weather" score – significant movements in this score often indicate the state of the whole survey.

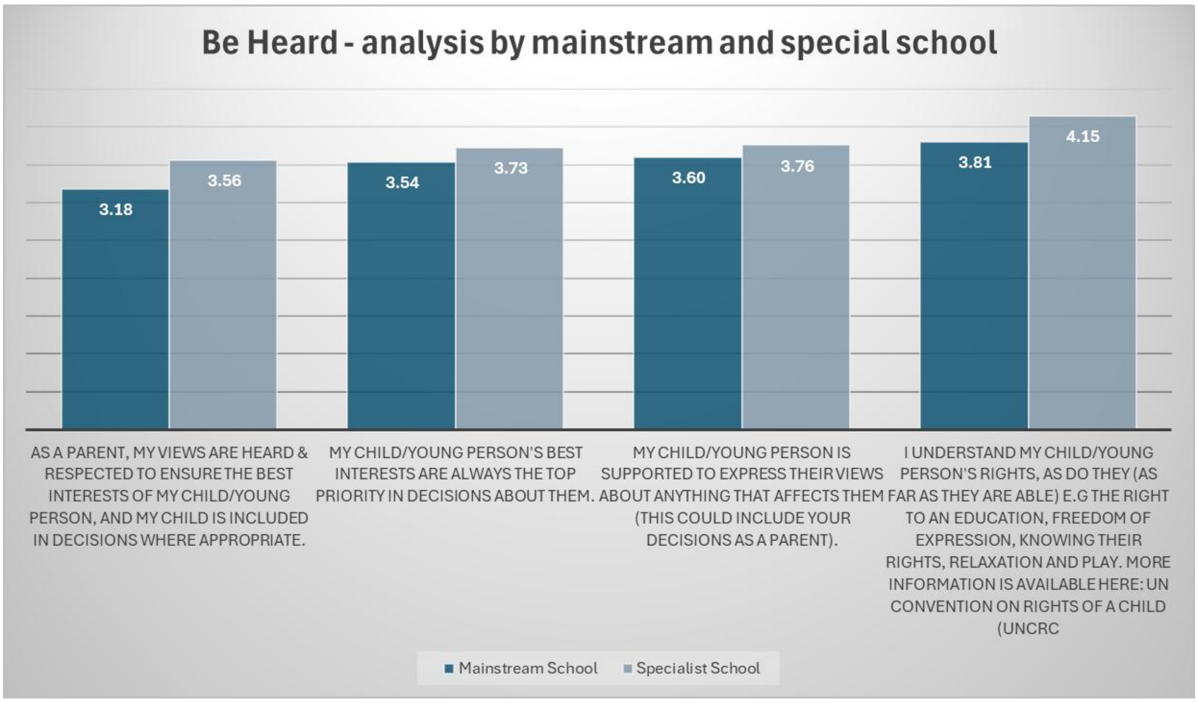


The age profile shows that for two of the outcomes (understanding rights and support for CYP to express their views) there was only a small variation across the age groups. However, for two of the other scores, there was a noted deterioration as CYP got older – in these cases fewer people believe that their children's best interests are the top priority and that they are listened to as parent carers. These scores saw falls of 0.6 and 0.79 between the youngest and the oldest age groups.



Parent carers of CYP in mainstream settings feel less well heard than those in special schools

The analysis of those in mainstream schools compared to those in specialist settings shows a marked difference in two questions. Parent carers of children in mainstream schools believe their views are less respected than those in specialist settings and they also feel as if they are less aware of their rights.



Comments support these scores

even after complaining to bedford college group they have not wanted to meet with us. I had to ask for a meeting with her teachers. Send allocated worker at the college was terrible. I have recently felt heard by the local authority, but it remains to be seen as to whether they support us to get her the right educational facility. We were given no appropriate options, I am having to insitigate everything.

her reception teacher was very dismissive, even when medical professional was saying the same as I. I am also in the teaching community and it is a statement that has gone around that the headteacher of my daughters school said "adhd is an excuse for bad behaviour".

My sons school has not been supportive of his needs.

Always having to battle and fight for them especially in school so there needs are met

for two years in a row we raised the likelihood of him being ADHD in school meetings, it took a very long time to be taken seriously by the school. He had a change of teacher partway through year two, and she recognised this in him, allowing us to set up a meeting with the SENCO.

Often treated by school as if we are deliberately not conforming to high expectations. That we don't understand what the issues are

Only issues with the school, when suggested what works at home for my child nothing put in place to support him

Schools do not listen. Do not care about mental health

However, there were also many comments that showed that some parent carers do feel as if they are listened to and many comments praised the interactions with schools.

Her teachers also respond to what is needed for my child.

Yes - went to school and had to discuss and issue I had when my stone received a red card - one the discussion was over the red card was cancelled

At school we work well alongside teachers/SEND etc

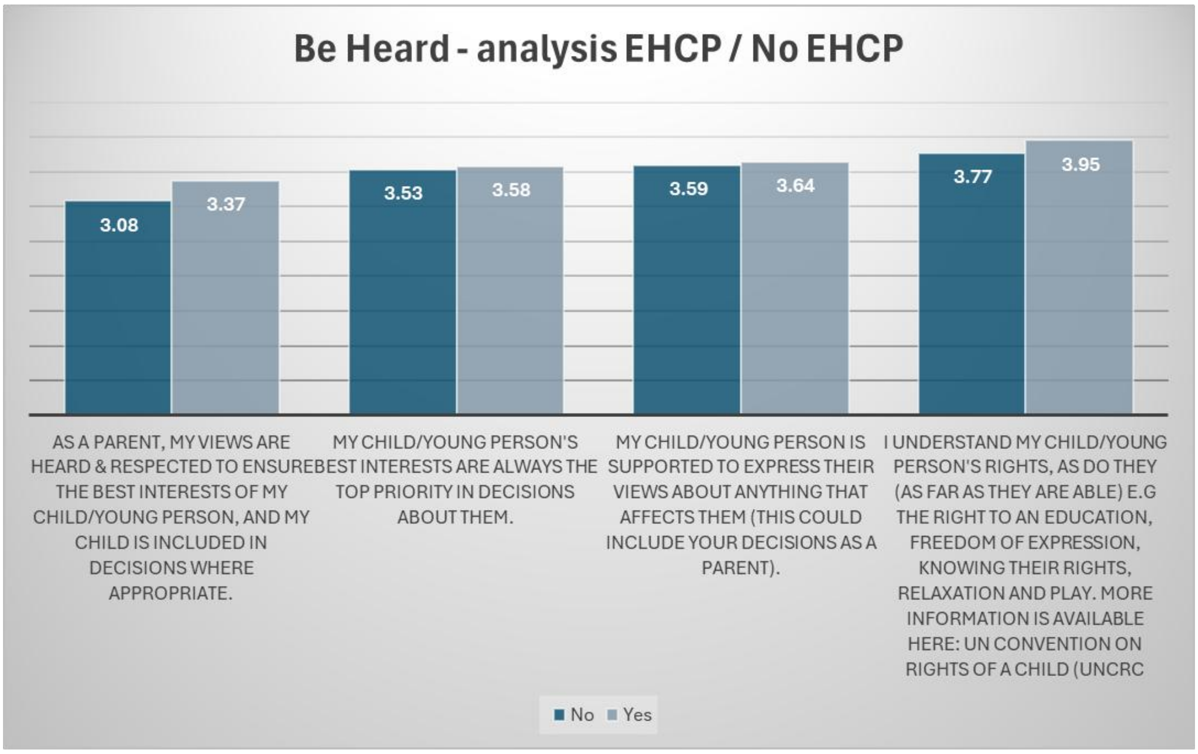
yes if I have any concerns I will contact the SENCO at the school and she is wonderful - fully listens to my concerns can be anything not even relation to school or education and they will help

I was included all the way throughout the EHCP process and again there are annual surveys, asking parents to review services.

Now they're in a good setting yes finally heard and acted upon.

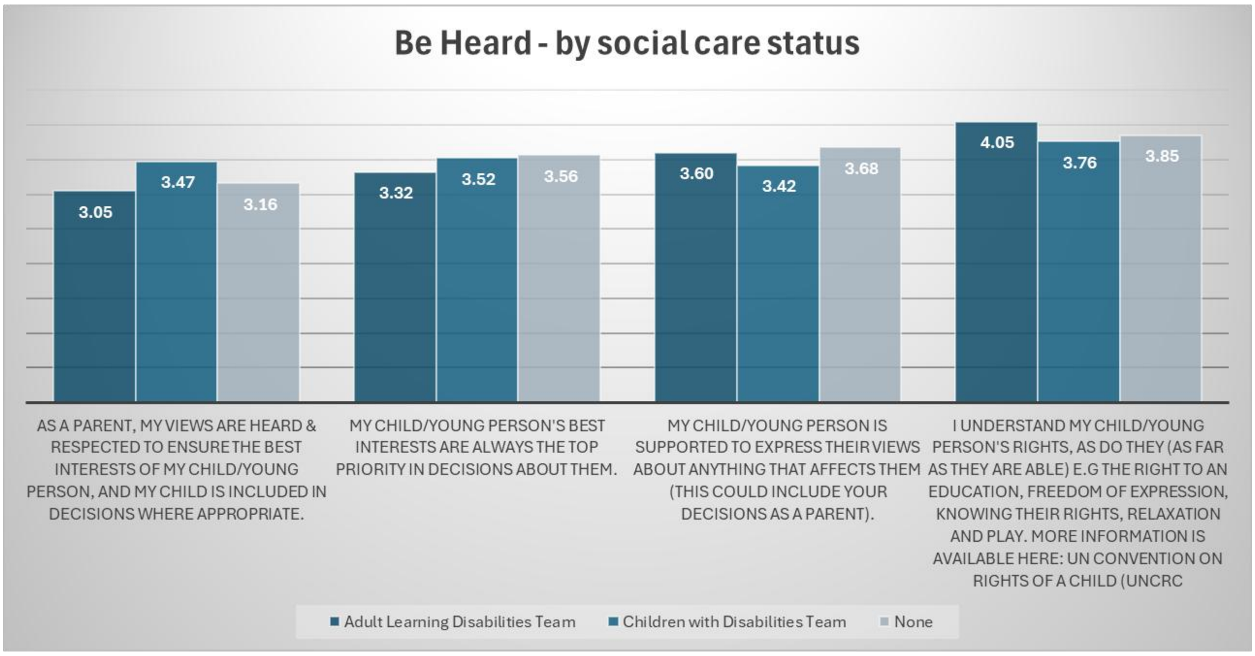
Those with EHCPs feel better heard than those without

The analysis between EHCPs and no EHCPs does not show large differences across any question but parent carers of CYP with EHCPs do feel better heard than those without. The biggest difference is on parental views being respected with a difference of 0.31.



There are no significant differences in the experience of being heard based on social care status

There are no significant differences between the Be Heard scores by social care stats. Of interest though, is that it is clear that as CYP transition parental views are considered less and young people are supported to express their views.



Comments reveal the frustrations of not being listened to – by both parents and when they feel their CYP is not heard

Comments from parents

I am not listened too - our views are not heard - all that is heard is how much things cost

I consistently feel like I am not listened to, I have been talking about my daughter's mental health for over two years. The school only listened once I had paid for a report from her therapist basically saying the same things I have. Emails are consistently ignored by the school. I feel like I am going around in circles. I am trying to be positive, to inform, to understand their perspective, but it feels hopeless.

I feel I am not listened to properly and I have to chase professionals

I feel professionals talk over me and make decisions which benefit the la or funding

I have to fight to be heard. Everything is a battle.

Never. Seen as the difficult parent for asking anything. Child is totally misunderstood.

No one is listening to me. I'm mentally and physically exhausted. Everyone gives up on the first time and I'm the one continually picking my up the pieces.

And those about children and young people, many of whom could do with additional support to be heard.

he cannot speak so he cannot express his views

My daughter is rarely given opportunity to communicate in a way that is suitable for her

They have communication differences and are often not given the correct time or opportunity to express themselves in a way that meets their needs or checked that they have been understood. People interpret things in their own way leading to gross misunderstandings and upset for my child

He isn't consulted very much and his social preferences and needs aren't really considered

I feel that my child is not listened to. It is difficult for me to tell them what my child needs as I do not speak the language.

My child struggles to inform others of their thoughts and only on certain occasions has she received support to express herself

He refuses to speak or attend meetings

rbearing' etc

Appendix 1: Background

In February 2018 the Ofsted and Care Quality Commission joint inspectorate conducted a Local Area Special Educational Needs Inspection (LA Inspection) of Bedford Borough to judge the effectiveness of the area in implementing the special educational needs and disability (SEND) reforms as set out in the Children and Families Act 2014.

The inspection found significant weaknesses that resulted in a written statement of action (WSOA).

The first of the significant concerns raised stated that:

"There are no co-ordinated priorities, strategies or accountabilities between the services to ensure that joint commissioning is undertaken effectively."

In the body of the letter, inspectors stated

"Leaders do not have a mutual understanding of their overarching priorities as a team of services or of their approach to holding one another to account for the implementation of the reforms. Leaders' plans to tackle the significant weaknesses in the provision do not include jointly agreed health education and social care priorities. Leaders equally do not have a mutual understanding of how they are measuring the difference that they are making to the outcomes for children and young people who have SEND"

Outcomes framework

In response to this Bedford Borough Parent Carer Forum undertook a project to create an outcomes framework.

This will enable leaders to:

- understand what parents and carers of children and young people with SEND need to improve their lives.
- highlight the services that are needed to deliver this
- create shared priorities for services and commissioning
- identify and measure the metrics to measure the effectiveness of those services in delivering the impact that families want to see.

The outcomes framework is best understood as a theory of change logic model.

What outcomes do families with SEND want?	•We identified five key outcomes: Be Happy, Be Healthy, Be Independent, Be Ambitious, Be Heard
How do these translate into real activities or behaviours?	•What sorts of things would families recognise as being a mark of success for these outcomes
What services are needed to deliver these?	•What services and support do families need to be able to do these things
How do we measure the success of these services?	•What are the metrics that we need to monitor to ensure these services are working effectively?

Local area inspection revisit 2020

In February 2020, Ofsted and the Care Quality Commission revisited Bedford Borough to assess what progress had been made in addressing the areas of weakness identified in the 2018 inspection.

They assessed that sufficient progress had been made against all five areas of weakness previously identified. They stated that:

“Area leaders are tackling the failings identified in March 2018, with unflinching honesty and integrity. The Director of Children’s Services (DCS) and chief nurse have been integral in leading a sea change in culture at the highest levels in both the local authority and Bedfordshire Clinical Commissioning Group (BCCG). From their previously disjointed approach, leaders are now a cohesive area team that challenges and supports its members. As a result, area leaders are tackling systematically and effectively the significant weaknesses identified at the initial inspection. “

“The Parent Carer Forum (PCF) has made an influential contribution to the area’s leadership and governance. Its members are active voices, who gather the views of families. The PCF champions the rights of families where there is still work to do for children and young people with SEND.”

The role of the outcomes framework in understanding the experiences of families was explicitly noted:

“Leaders’ SEND joint strategic needs assessment and outcomes framework is informing a strategic and systematic approach to joint commissioning. Leaders are proactive in seeking new opportunities to jointly commission services and provisions for children and young people with SEND. “

Appendix 2: Survey questions

What age range is your child/young person?
What type of Educational Setting does your child/young person attend?
Does your child/young person have an Education, Health and Care Plan (EHCP)
Is your child/young person currently open to the Children with Disabilities Team or Adult Learning Disabilities Team
Local services support my child/young person and my family to have a good standard of living that meets their physical and social needs.
Local services help protect my child/young person from bad treatment such as bullying, harassment, violence, abuse or neglect.
My child/young person can participate in organised groups and clubs of their choosing and develop friendships e.g. Brownies, After School Clubs, Specialist Playschemes and Activities
My child/young person can access local leisure activities which meet their physical, social and cultural needs, e.g. Public Swimming Pools, Cinema, Parks, Sports Centres
Local Services support my child/young person to be as healthy (physically and mentally) as possible, including educating them around their health and wellbeing.
My child/young person has access to the medical services that they need (including mental health).
When they have needed it, my child/young person gets medical help quickly (including mental health) e.g. GP, Mental Health Services, School Nurses
Local Services support my child/young person to reach their full potential.
My child/young person has access to appropriate education (including those that are home educated).
My child/young person is getting the right aspirational education to develop themselves as a whole (personality, talents and abilities)
Local Services protect and respect my child/young person's safeguarding needs and privacy.
Local Services and the local Community provide my child/young person with the opportunity to freely learn about their culture, language and religion.
My child/young person is supported to live as independently as possible
My child/young person is provided with the right opportunities to participate fully in their community.
As a parent I am respected to act in the best interests of my child/young person, including them in decisions where appropriate.
My child/young person's best interests are always the top priority in decisions about them.
My child/young person is supported to express their views about anything that affects them (this could include your decisions as a parent).
I understand my child/young person's rights, as do they (as far as they are able)
If your child/young person has had a significant change to their education setting/placement within the last year has there been adequate planning, preparation and support from local services.
If your child transitioned from the Children with Disabilities Team to Adult Services within the last year did you find the process worked well? (was it started in a timely manner? were you kept informed?)
If your child transitioned from Children's to Adult's Health Services within the last year did you feel that you had appropriate support?

Appendix 3: Bedford Borough Parent Carer Forum

A parent carer forum is a group of parents and carers of disabled children who work with local authorities, education, health and other providers to make sure the services they plan and deliver meet the needs of disabled children and families

The Bedford Borough Parent Carer Forum was formally launched in February 2014 but has functioned with a steering committee since May 2013. We have approximately 1600 members covering all areas of SEND.

Our objectives are:

- to be the strategic, consultative and collaborative body within Bedford Borough representing families of children with special educational needs and disabilities, providing a liaison point for Statutory and Voluntary Agencies within Bedford Borough.
- to work co-operatively with local service providers and commissioners to enhance and develop the range and quality of services provided for all children in Bedford Borough with special educational needs and disabilities.
- to consult with, inform and train our membership in order to be an independent, parent carer-led body that determines and acts upon the priorities of its members.