

Bedford Borough Parent Carer Forum Outcomes Report 2023

February 2024



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 2023, 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 2023 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.

We received 656 responses of which 589 contained relevant data (522 in 2022 and 543 in 2021). In addition, there were 1439 comments. A sample of comments are reproduced in this report to offer a qualitative analysis and the give a direct voice to the views of parent-carers. Quotes are presented verbatim, with no editing.

Summary Results

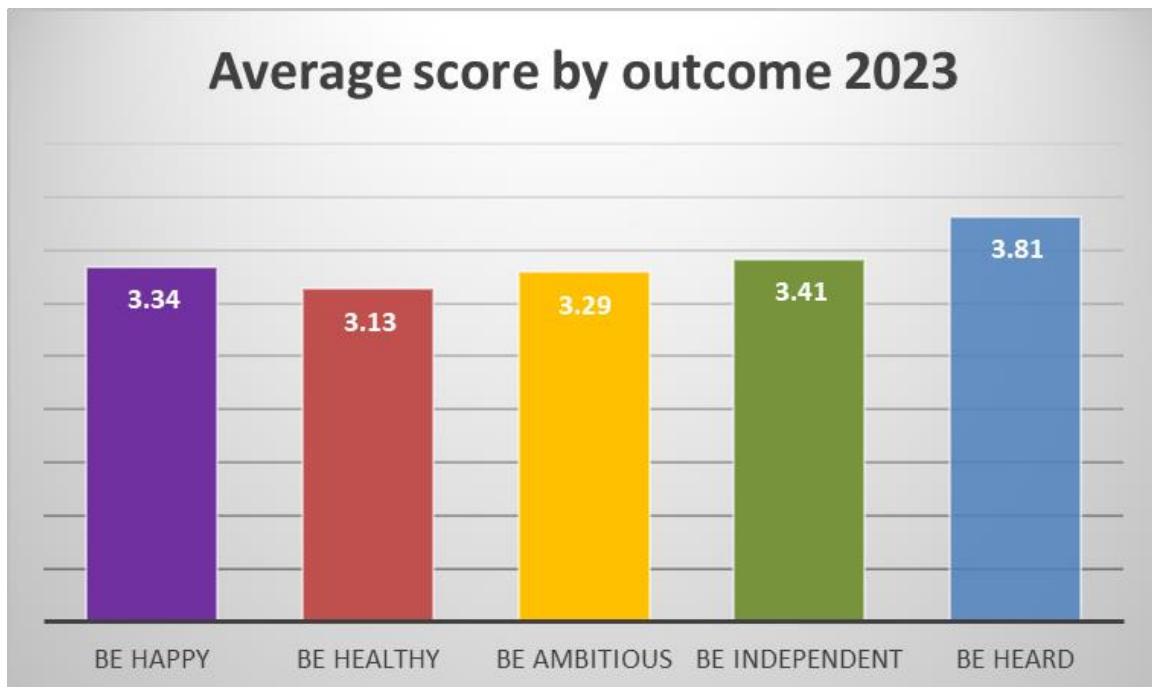
In absolute terms we are still not meeting the needs of children and young people with SEND well enough. The average score has fallen slightly year on year. Over the last 5 years, we have seen a notable improvement in the experience of families.

Average score
3.41
(out of 5)

The average score across all questions in our survey was 3.41. This is the same as last year and small fall from 2021 (2021:3.53)

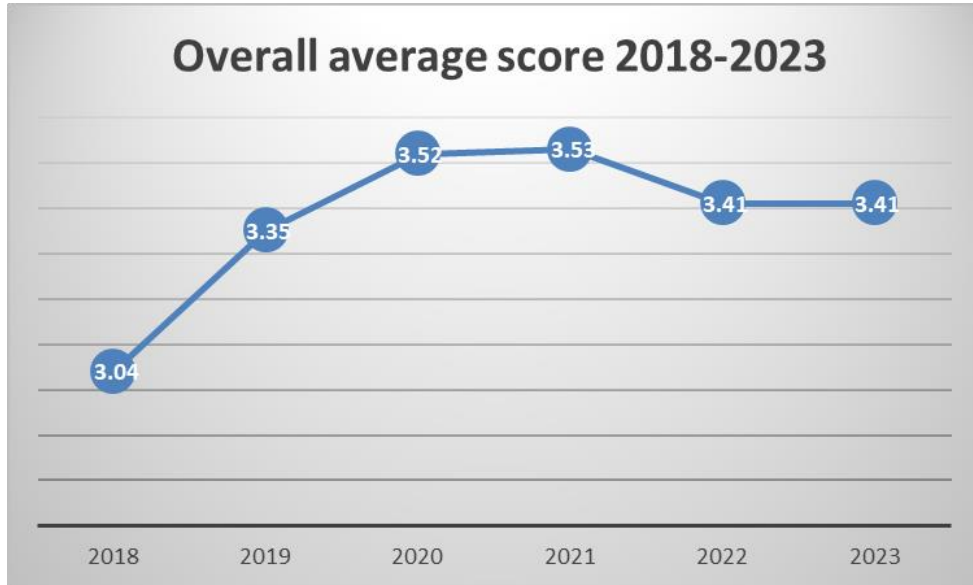
This means that the needs of children and young people with SEND are only being adequately met at best. This falls short of our stated ambition that needs should be being well met (a target score of 4 or more). Given that the questions were based on the United Nations Convention on the Right of the Child, 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:

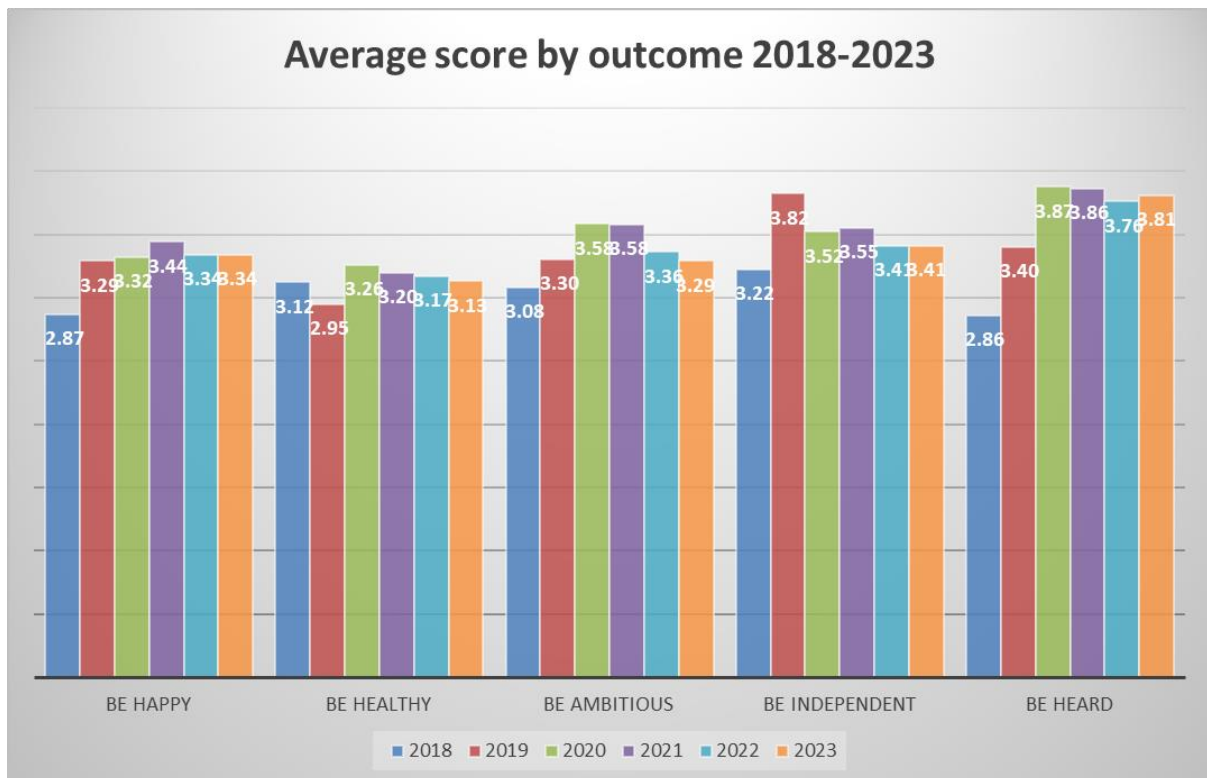


There has been a small fall in the overall average score year on year but the six year trend still shows an improvement

The average score in 2023 was 3.41 In our first survey in 2018, the average score was 3.04.



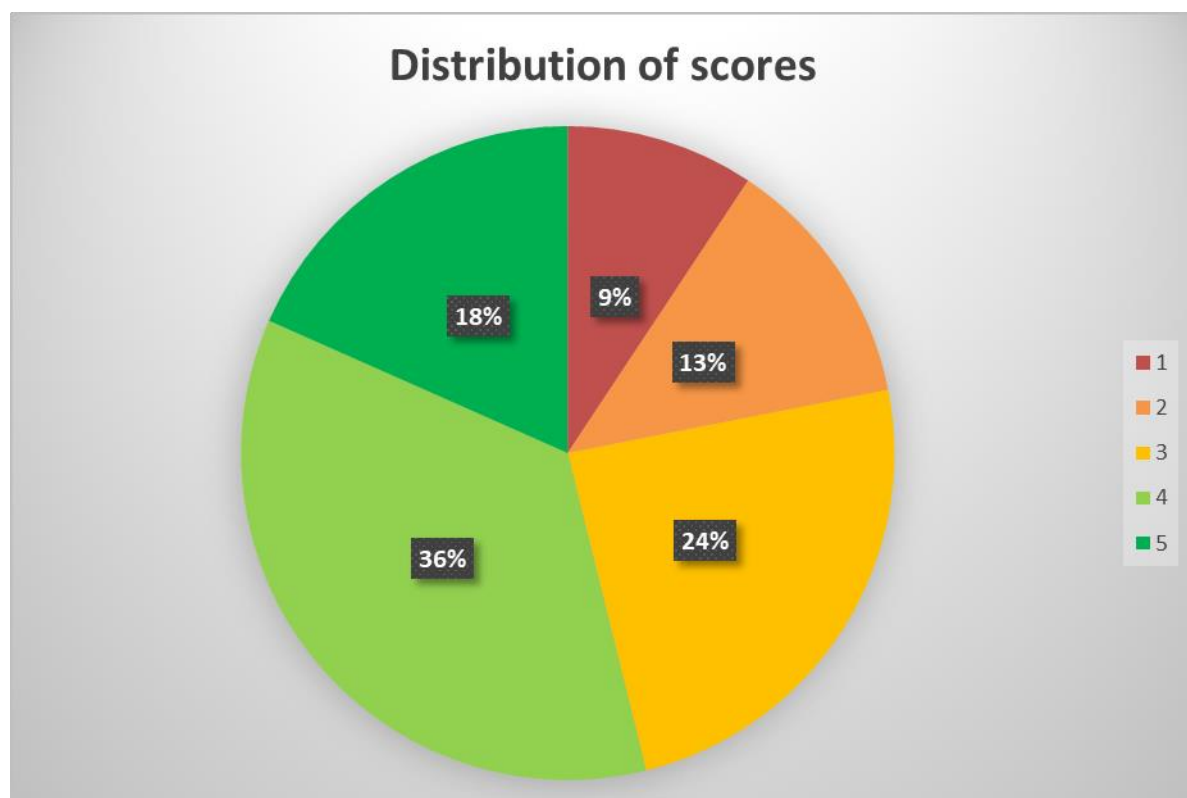
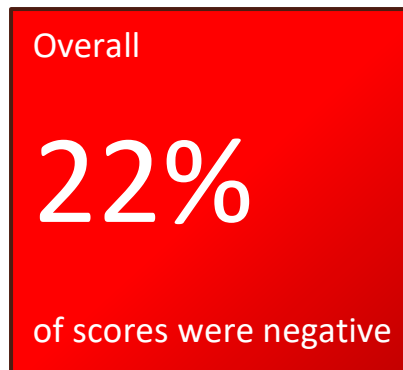
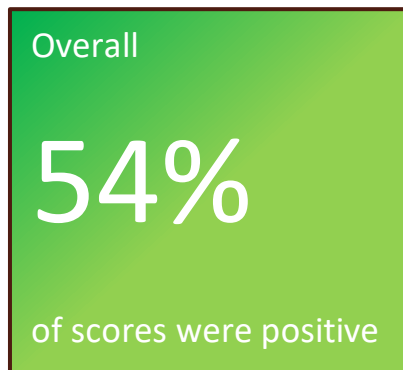
Generally, the average of individual outcome scores has improved since 2018 although all scores show a deterioration between 2021 and 2023



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, 54% (2022:54%) of all responses were positive (scores of 4 or 5) whilst 22% (2022: 21%) were negative (scores of 1 or 2). This is a ratio of approximately 2.45:1 positive to negative.

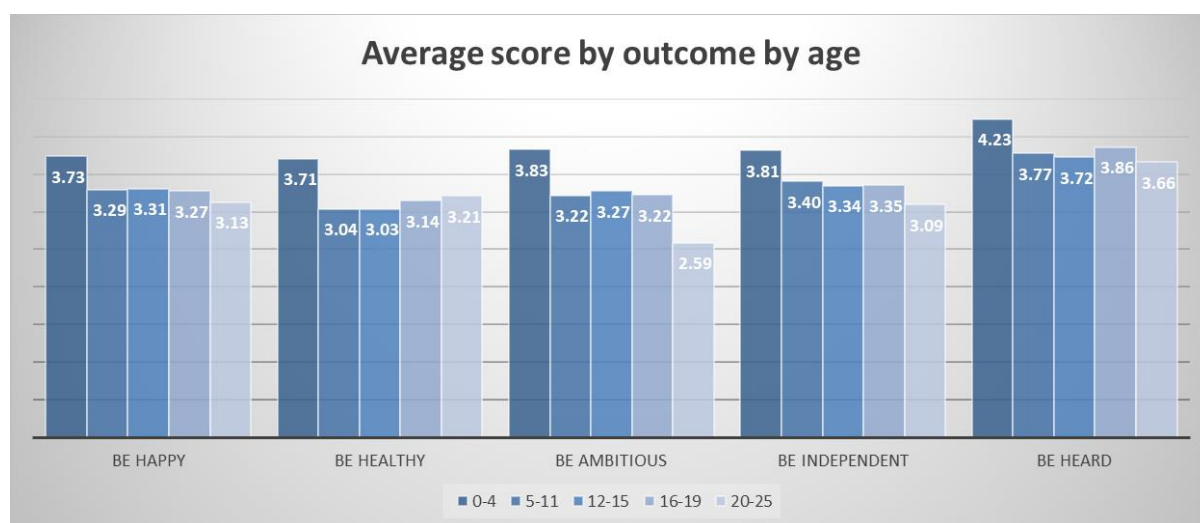
The largest category of scores was 4 with 36% of answers.



Commentary

1. Young people who are in the 20-25 age group have notably lower scores in some key areas that those of school and pre-school age.

The 20-25 age group scores consistently lower than other age groups across all but one outcome. Whilst this trend is clear, it should be caveated by stating that there were relative few respondents in this category (3%). However, this also correlates with anecdotal feedback given the parent carer forum.



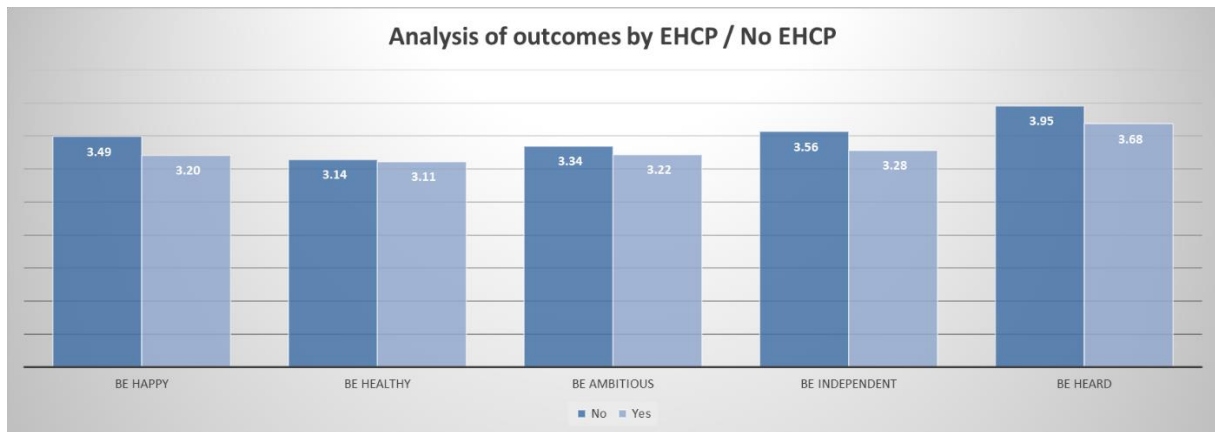
There are three key areas in which young people in the 20-25 age group score significantly lower than other age groups across the survey. These are:

- **Be Happy** - The 20-25 age group report that they do not have good access to organised groups
- They feel that everyone is less **ambitious** for their future with scores for all three be ambitious questions being notably lower than those at school or pre-school
- In **Be Independent** there are two areas in which the 20-25 age group score lower than other ages:
 - In their ability to live independently
 - And in community participation

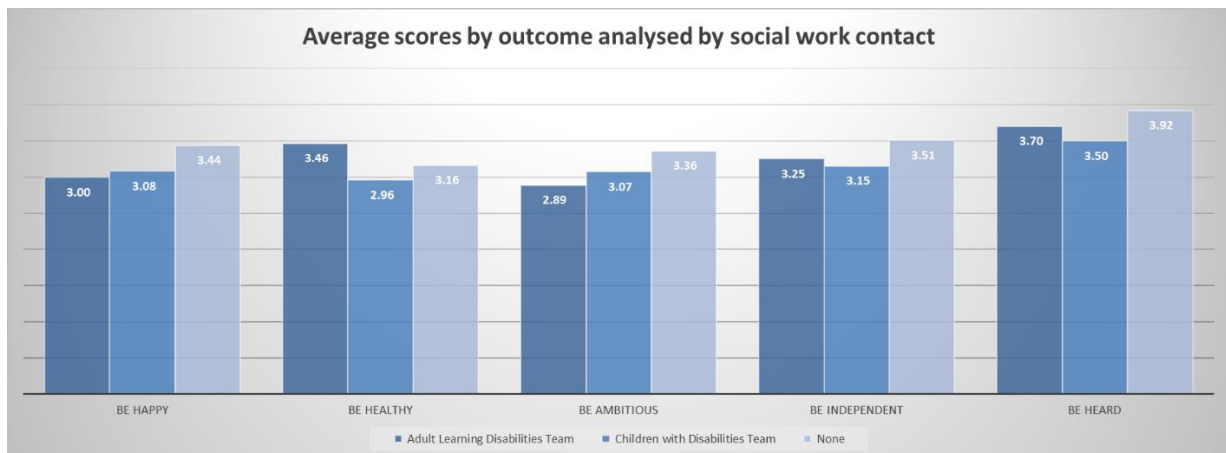
Recommendation: *The new SEND action plan must have a focus on the 20-25 age group. In particular, the council and ICB should ensure that there are enough activities, clubs and groups for young people with SEND to attend, a clear strategy for independent living in the community and a community wide focus on greater inclusion. Perhaps most importantly, services must be clear about how they are to be ambitious for the future of young adults with SEND.*

2. Children with more complex needs (as indicated by those that have an EHCP, are attending a special school and who have a social worker) have lower scores in areas of community inclusion than those with less complex needs

Across a number of measures, children with more complex needs score lower than their peers. For every outcome, the average score for those with EHCPs is lower than for those with SEND but no EHCP.



Similarly, those known to social care for their disability score lower than those without a social worker in all but one category.



Note: for those with an EHCP, there is a strong variation in experiences between special and mainstream schools – this is covered point 3 below.

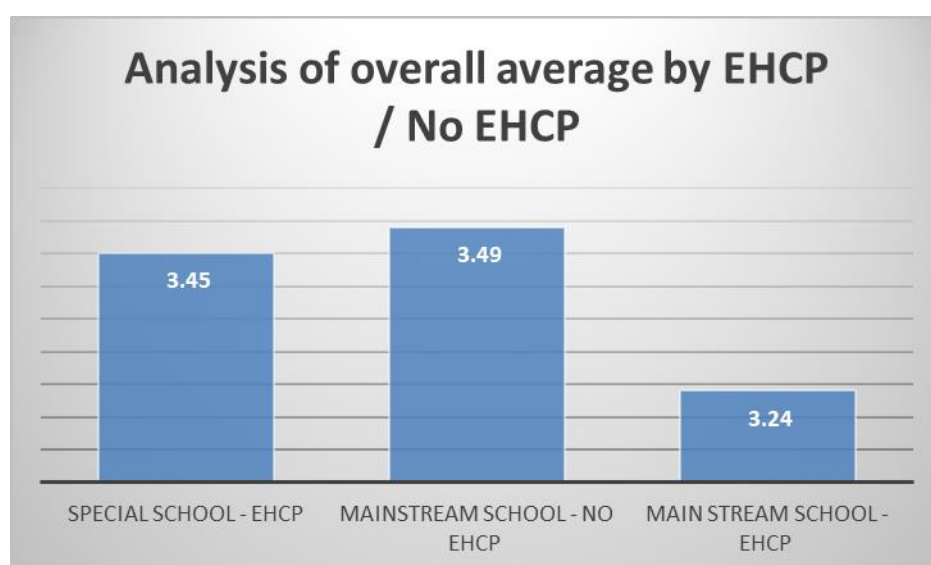
There are several drivers for these differences:

- **Be Happy** – those with EHCPs and social workers report it is more difficult to find the right organised groups and they find it more difficult to access leisure activities.
- **Be independent** – those respondents whose CYP have an EHCP scored lower across all of the be independent questions. The most marked difference here was in their opportunity to participate fully in their community.

Recommendation – the new SEND strategy should coproduce and commission activities and groups that will give children with complex needs more opportunities to attend organised groups and participate in their community (e.g. leisure activities, cinema). The comments also indicate that many respondents think very highly of many of the local charities and community groups (e.g. SSG) and so these organisations may provide a means to improve service delivery in these areas through careful and targeted commissioning.

3. Children with EHCPs in mainstream schools have lower scores across several key areas that indicate concerns with their educational experience.

There is a marked difference between those children and young people in a mainstream setting with an EHCP and those who have no EHCP in a mainstream setting and those who attend special schools.



The key areas that drive this difference are:

- **Be Healthy** – there is a significant difference in all three be healthy questions between those with an EHCP in mainstream schools than all other respondents. Parent carers do not feel as if services support their CYP to live a healthy life, to access the right health services and get help quickly when they need it.
- **Be Ambitious** – children in mainstream schools have a lower score when asked whether they have access to the right education. The comments indicate that many parent carers feel that the curriculum is not differentiated enough for CYP with an EHCP and they do not get the support they need in the school setting.
- **Be Heard** – parent carers of CYP in mainstream schools with and EHCP feel as if they are less respected to participate in decision making about their children. Comments indicate that many parents feel the views of practitioners carry more weight than the views of the family.

Note – this difference in experience may also explain the increase in demand for special school places – where families report better experiences for those with an EHCP.

Note – see also the comments on bullying below in point 5.

Recommendation: The new SEND strategy must have a clear approach for CYP in mainstream schools to improve the quality of inclusion. In particular, a means of accessing and navigating complex and scarce (see point 4 below) healthcare services (for example, the coordination function provided by special school nurses). The strategy should also explore how mainstream schools can be supported to improve the quality of teaching and learning support for CYP with EHCPs. This must improve measures to improve the quality of coproduction.

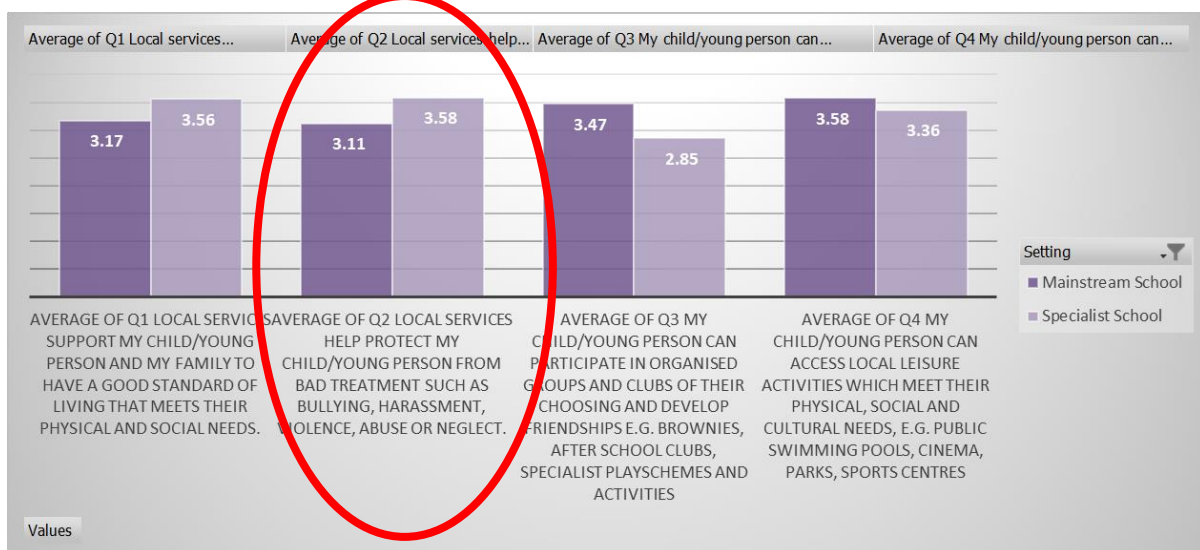
4. Access to appropriate health services and being able to access medical services quickly remain a major concern for parent carers.

The two questions about being able to access the right services and being able to get medical help quickly scored very lowly (an average of 3.10 and 3.05 respectively) in the whole survey. There is good local (and national) awareness of the issues facing children’s health services both in elective and community based care. In particular, paediatricians and mental health services have been highlighted in the comments as being of particular concern. Interestingly, in previous years speech and language services were also identified as a concern in the comments. This year, SALT has less emphasis.

Recommendation: The ICB and community care providers should review their community and elective paediatric service recovery plans in light of these comments and ensure they are fully integrated into the new SEND strategy being developed.

5. There are still many reports of bullying of children with special needs, especially for those attending mainstream schools.

The scores about the question of whether local services help protect children and keep them safe (including from bullying), reflects this difference.



This is consistent with previous years. However, the nature of the comments have changed in the last year, In previous years, respondents noted that children were being bullied and discriminated against by other children – this has remained the same although the number of comments on this issue has possibly decreased. However, in previous years there were also comments that schools and authorities did little to protect children who were being bullied. In addition, there were also some comments about bullying and discrimination from schools themselves. Although there were some comments of this nature, there were far fewer.

Recommendation: Bedford Borough should promote a culture of zero tolerance of bullying of children with SEND. They should consider:

- ***involving the Local Area Designated Officer for Safeguarding in bullying concerns where appropriate***
- ***re-running the legal training for schools previously offered with a focus on equalities duties***
- ***gathering data for reports of bullying in schools***
- ***informing parents of the most effective ways to seek redress in these cases – led by Bedford Borough Parent Carer Forum.***

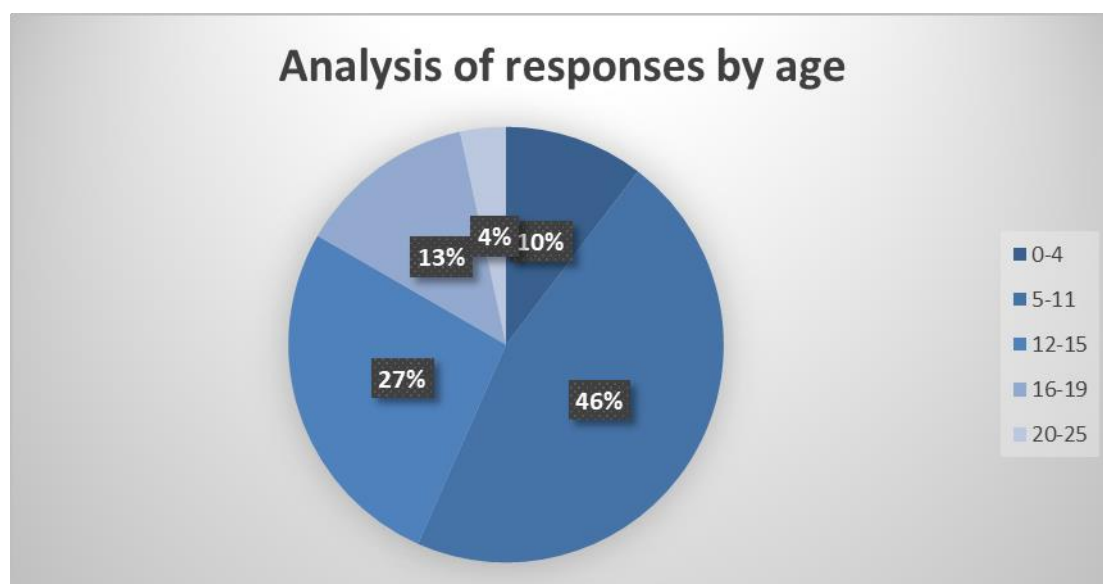
Analysis by age, setting and EHCP / no EHCP

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) which qualifies any conclusions we can draw from this age group. The age distribution of respondents is similar to previous years.

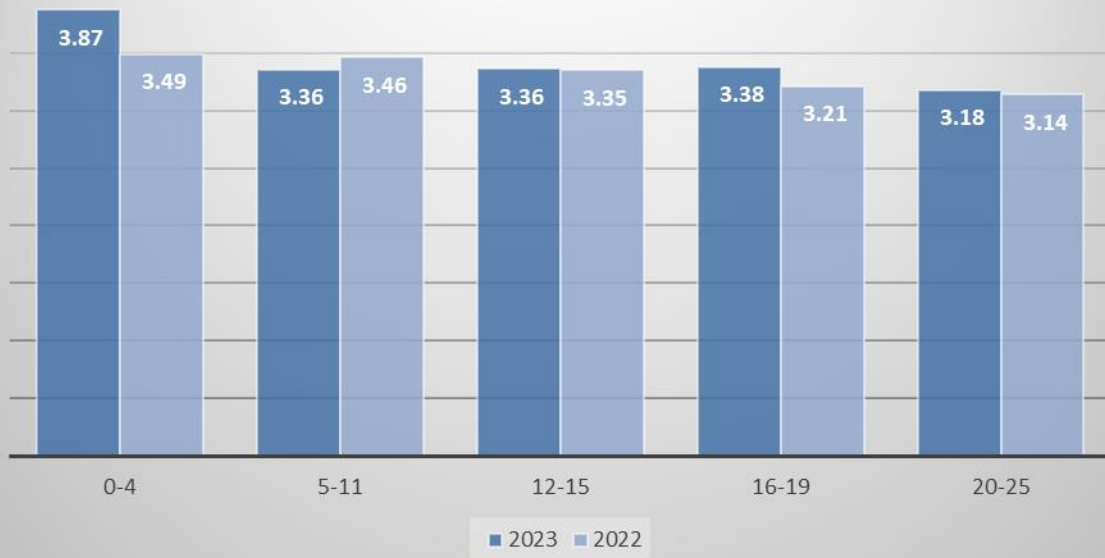
Age range	Number of responses	Percentage
0-4	61	10%
5-11	272	46%
12-15	157	27%
16-19	78	13%
20-25	20	3%
Grand Total	588	

Note: there was one blank response



Analysis of the overall average mark by age shows that the 0-5 age group have the highest average score (3.87) which gradually declines as children and young people age with the 20-25 age group having the lowest average score of 3.18. This is consistent with the trends from previous years (2021 being an exception which showed the 16-19 age group with the lowest scores). There are improvements in two age ranges (0-4 and 16-19) but these are countered by a fall in the more numerous 5-11 age group.

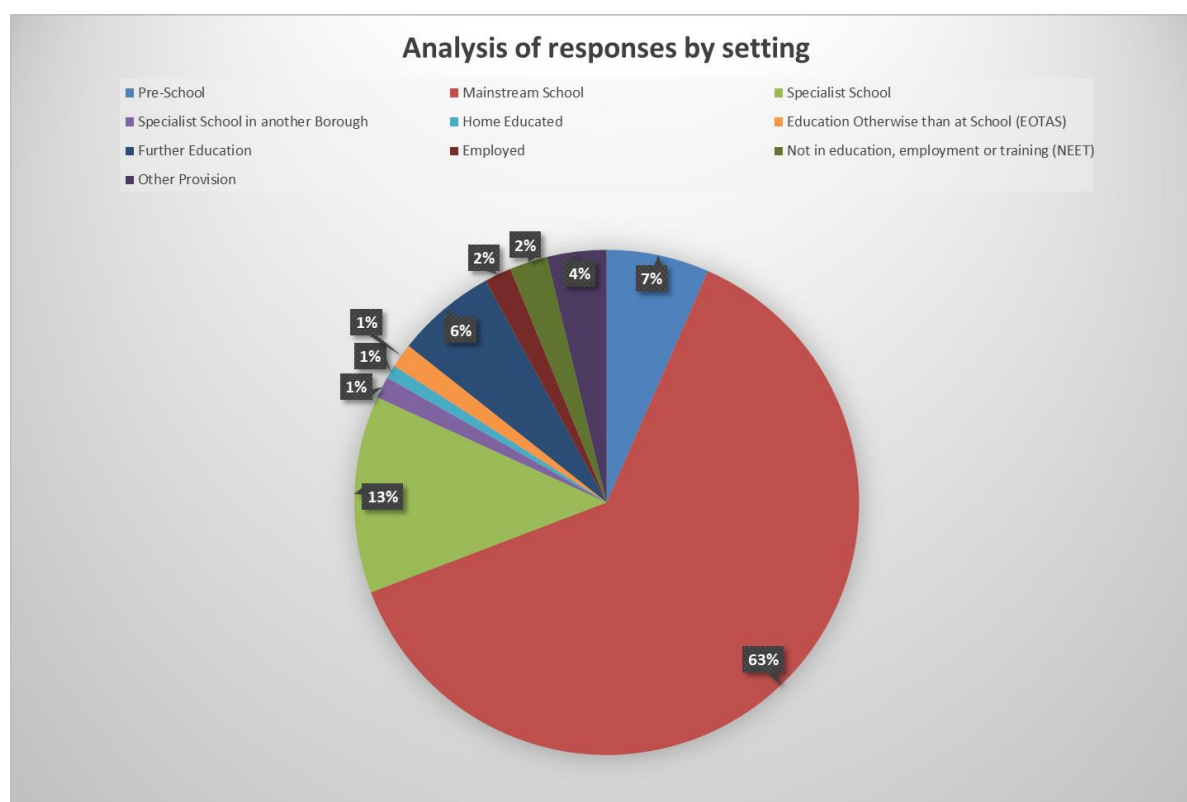
Overall average by age range 2022-2023



By setting

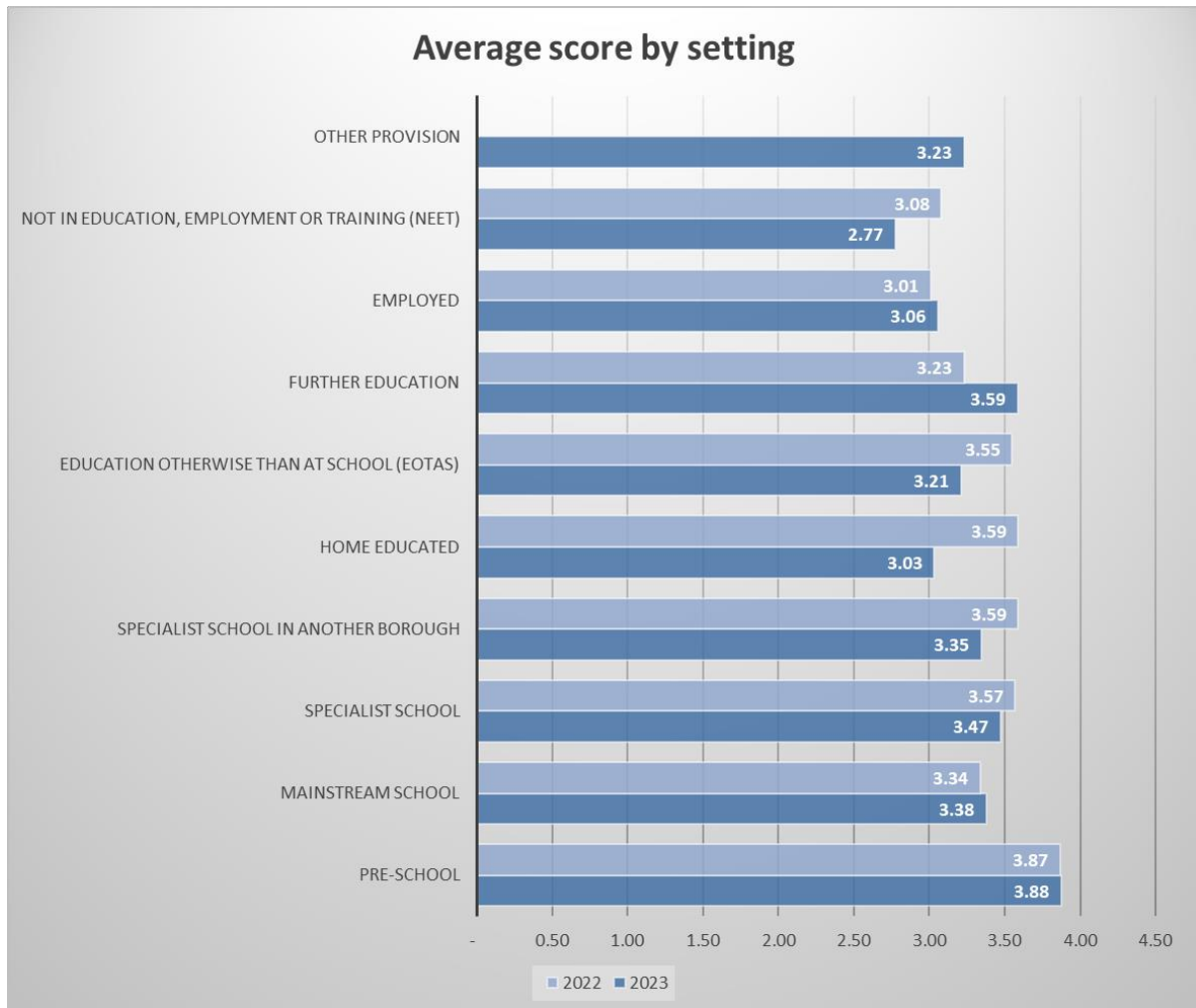
There were a range of responses from across different “settings” ranging from pre-school to employment and NEET. The majority of our respondents were of school age (79%)

Setting	Number	Percentage
Pre-School	38	7%
Mainstream School	362	63%
Specialist School	73	13%
Specialist School in another Borough	8	1%
Home Educated	5	1%
Education Otherwise than at School (EOTAS)	9	2%
Further Education	37	6%
Employed	10	2%
Not in education, employment or training (NEET)	14	2%
Other Provision	22	4%
Total	578	



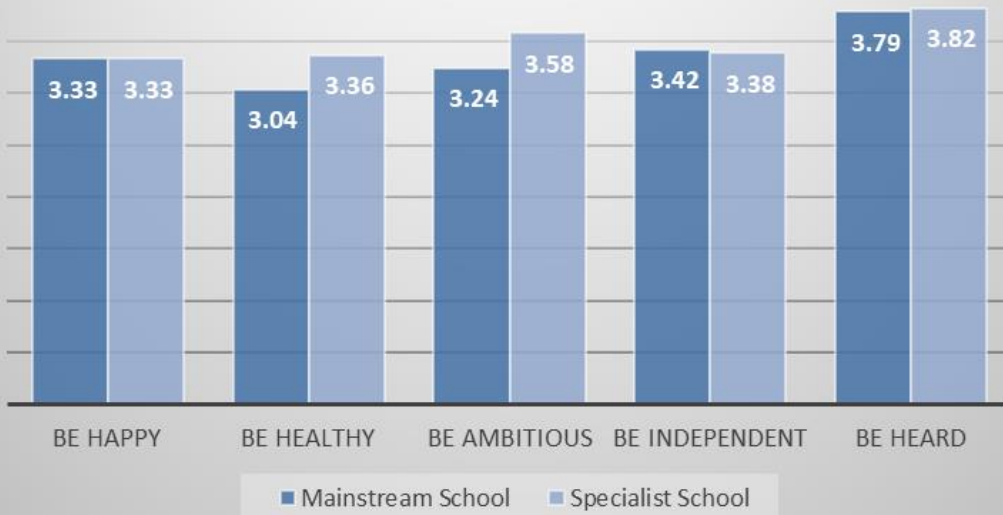
There is a clear difference between the average scores of children and young people in mainstream schools (3.38) and specialist schools inside the borough (3.47). This is a smaller difference than last year and comes as a result of a deterioration in the scores for those in specialist settings (a fall of 0.1) and a small improvement in mainstream schools (an increase of 0.04). 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 (3.88) and those who have left education have the lowest scores (Employed 3.06, NEET 2.77 and Further Education 3.23).



There are two outcomes where children in mainstream setting score significantly lower than those in specialist settings: Be healthy (0.32 difference) and be ambitious (0.34 difference).

Comparison of scores between mainstream and specialist settings



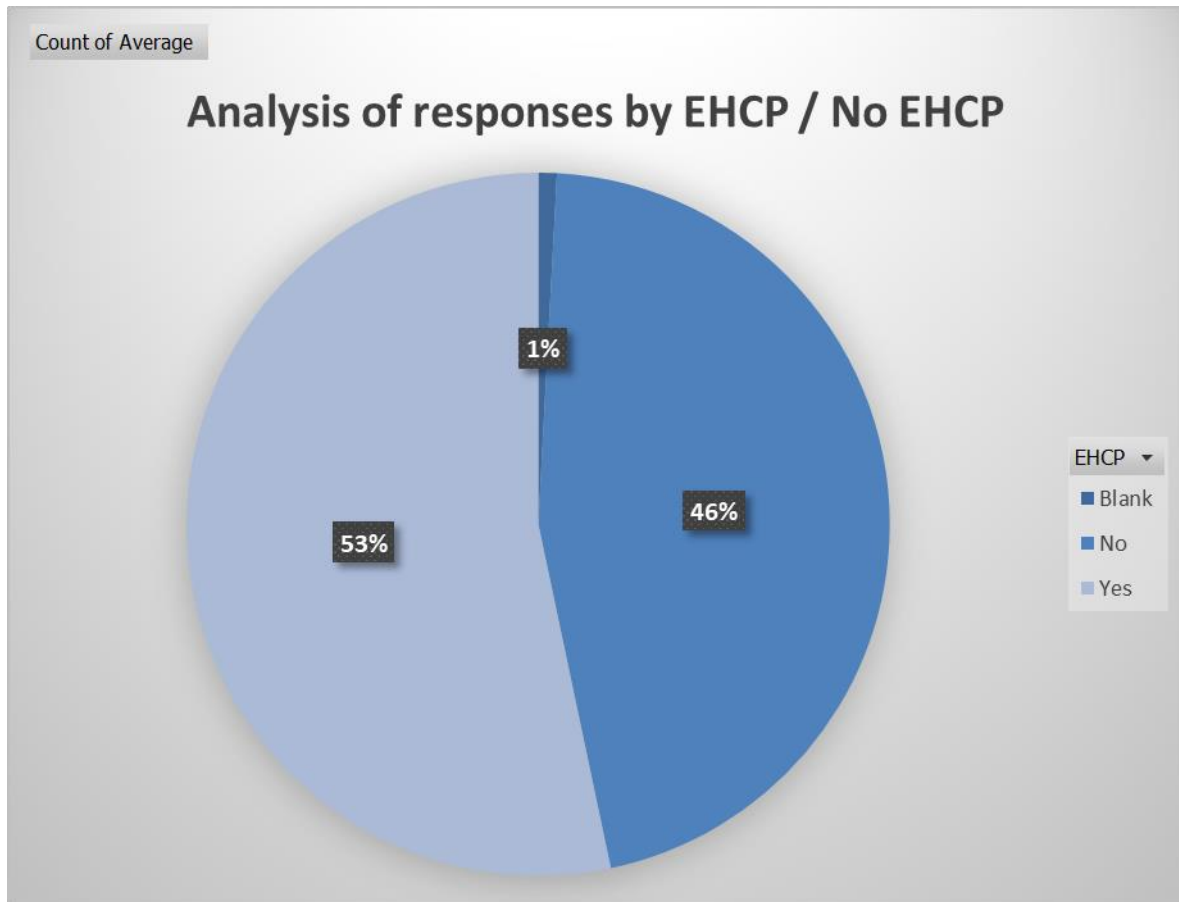
The experiences of CYP in mainstream schools have improved in each individual outcome year on year with the Be ambitious (0.16) and Be heard (0.1) outcomes improving the most.

Mainstream schools 2022-23 - comparison by outcome

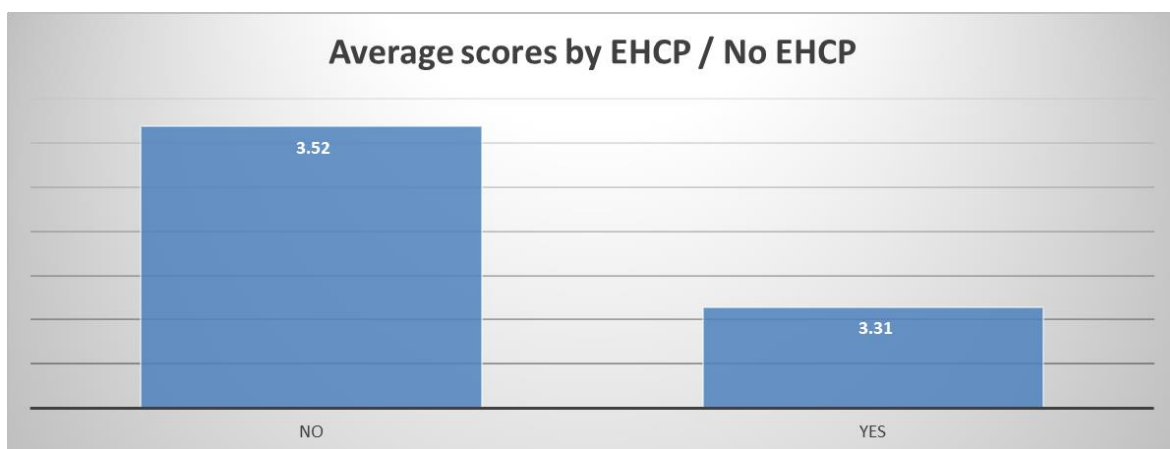


By EHCP / no EHCP

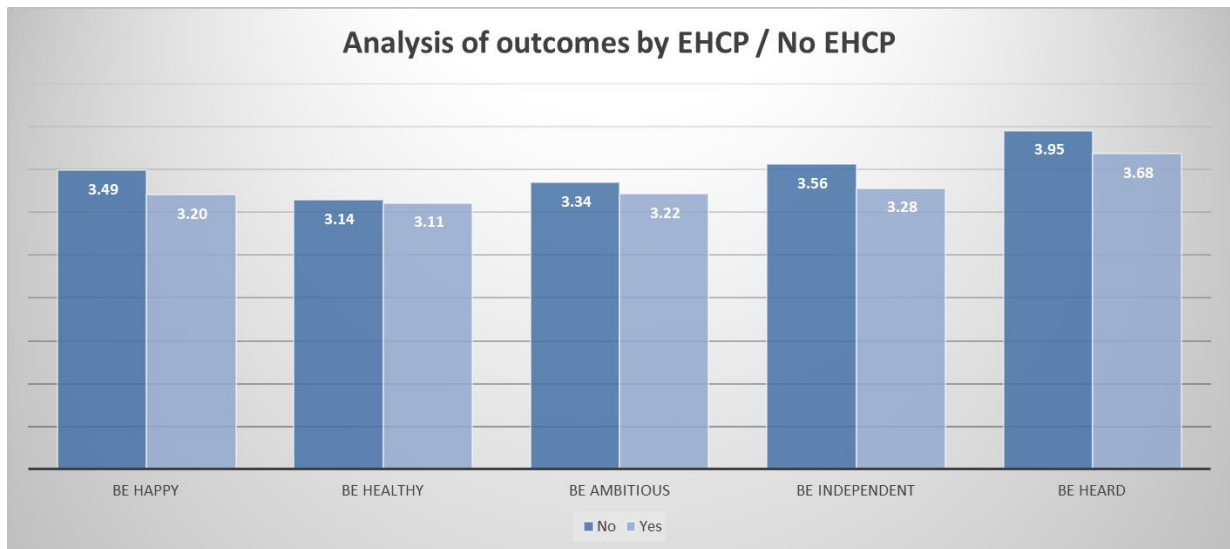
There is a good split of responses between those who have EHCPs and those who do not. With 53% having an EHCP and 46% not (1% responded N/A).



There was a notable difference between the scores for those with an EHCP and those without an EHCP. This is consistent with 2022 but a change from years before this when there was no material difference between those with and without an EHCP. In 2023, those without an EHCP scored higher 0.21 points on average.



This difference was distributed between all of the outcomes but was most marked in the Be Happy (0.29), Be Ambitious (0.12), Be Independent (0.28) and Be Heard (0.27) outcomes.



Analysis of individual scores

The individual scores that differed the most are consistently those which relate to community inclusion. The three items that showed a difference of greater than 0.3 points were:

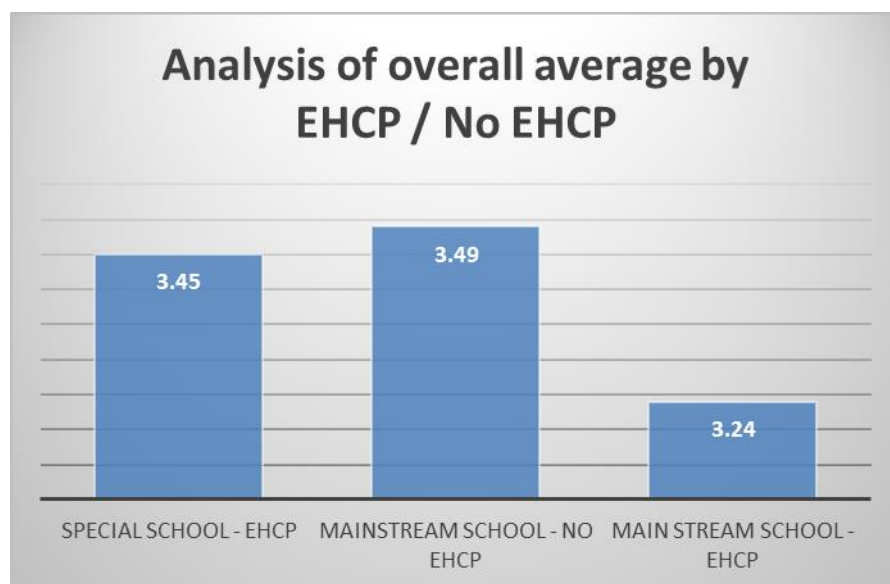
- My child/young person can participate in organised groups and clubs of their choosing and develop friendships e.g. Brownies, After School Clubs, Specialist Playschemes and Activities - 0.65 points difference
- My child/young person can access local leisure activities which meet their physical, social and cultural needs, e.g. Public Swimming Pools, Cinema, Parks, Sports Centres – 0.43 points difference
- My child/young person is provided with the right opportunities to participate fully in their community – 0.41 difference.

This is consistent with last year when the same three questions reported the biggest gaps.

Analysis by Setting and EHCP / NO EHCP

Bringing together the two analyses of setting and EHCP and no EHCP shows a picture that is consistent with the messages of the two previous sections.

Children with an EHCP in mainstream schools report significantly worse scores than those with no EHCP in a mainstream school and those in a special school.



The drivers for the differences in mainstream schools between those with EHCPs and those without are consistent with the wider EHCP / non EHCP community outlined above (i.e. community inclusion). In addition, there is a significant difference in other Be Heard categories most notably:

- My CYPs best interests are always the top priority in decisions about them (0.41 difference between mainstream EHCP and no EHCP)
- My CYP is supported to express their views on anything that affects them (0.4 difference)

When compared to CYP with EHCPs in special schools, there are three additional questions in which there are large adverse differences for CYP with EHCPs in mainstream schools

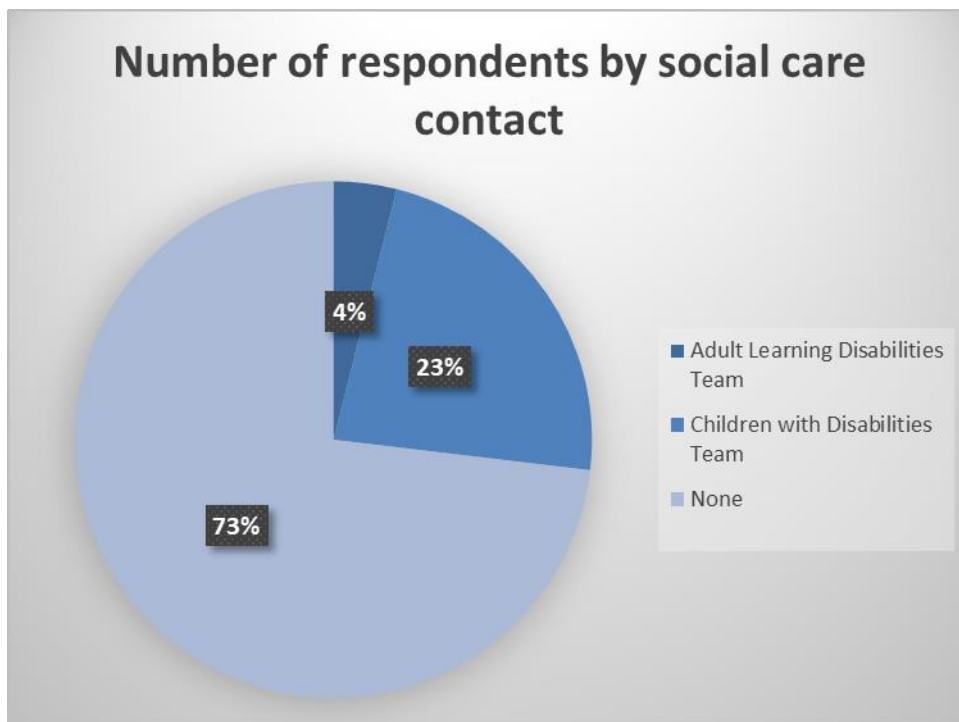
- My child/young person has access to appropriate education (including those that are home educated) – 0.68 difference
- Local services help protect my child/young person from bad treatment such as bullying, harassment, violence, abuse or neglect (0.54 gap)
- My child/young person has access to the medical services that they need (including mental health) (0.47 difference)

By social work status

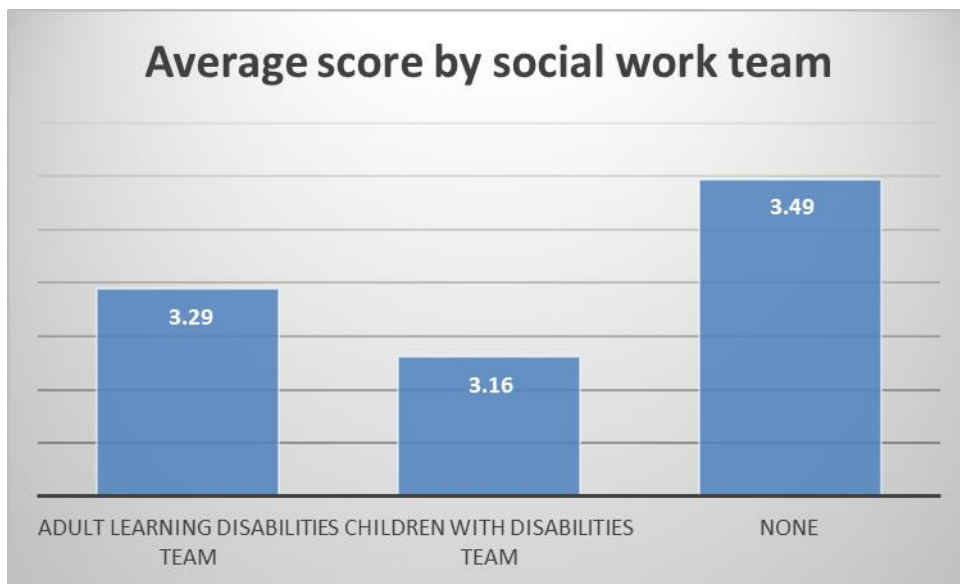
For the first time we asked respondents to share whether they had a social worker and identify which team the social worker came from.

Social work status	Number	Percentage
Adult Learning Disabilities Team	23	4%
Children with Disabilities Team	134	23%
None	427	73%
Total	584	

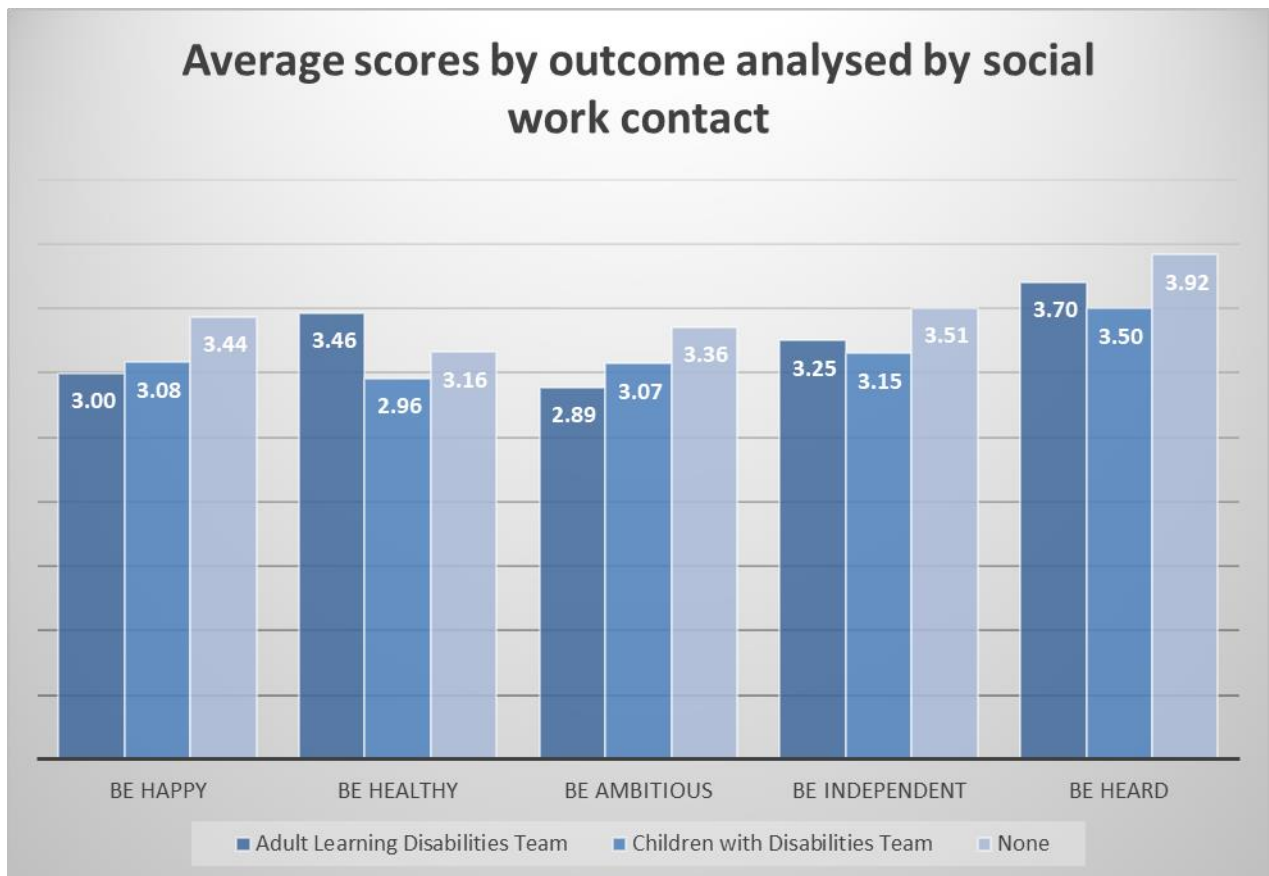
The number of respondents with contact with the ALD was relatively small and so any analysis of this group must be caveated as representative of a small sample size.



There was a difference in average overall scores based on the social work status of respondents:



When analysed further by outcome, the scores show a familiar pattern, consistent with the findings of the EHPC / No EHCP analysis. Those children with social workers from the CWD team scored lower marks in the Be Happy and Be Independent outcomes. In addition, they scored lower marks against the Be Heard category as well.



For the Be Happy and Be Independent categories, the main drivers were identical to those for the children and young people with EHCPs:

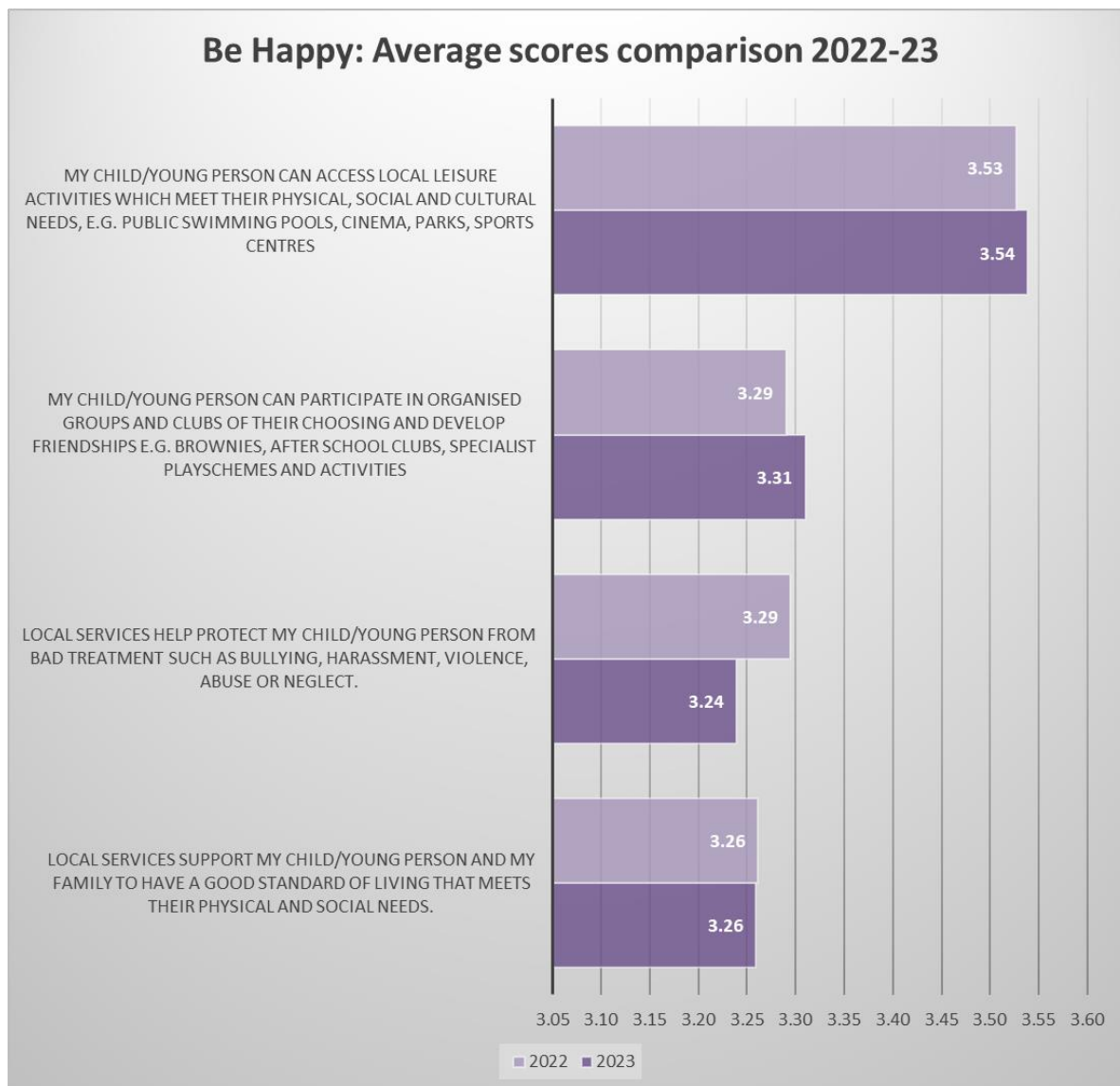
- My child/young person can participate in organised groups and clubs of their choosing and develop friendships e.g. Brownies, After School Clubs, Specialist Playschemes and Activities - 0.57 points difference
- My child/young person can access local leisure activities which meet their physical, social and cultural needs, e.g. Public Swimming Pools, Cinema, Parks, Sports Centres – 0.57 points difference
- My child/young person is provided with the right opportunities to participate fully in their community – 0.46 difference.

In addition, there were differences of over 0.3 in the following Be Heard scores as week:

- My child/young person's best interests are always the top priority in decisions about them – 0.61 difference
- My child/young person is supported to express their views about anything that affects them (this could include your decisions as a parent) – 0.47 difference

Be Happy

The average score for parent-carers in this category was 3.34. This is identical to last year. It is more in line with previous surveys which recorded scores in a similar region. Our first survey in 2018 recorded an average score of 2.87 for Be Happy.



There was very little movement in any of the average individual scores year on year. Two scores improved slightly, another stayed the same whilst the question around protection from bad treatment showed a drop of 0.05.

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 and young people with a 0.60 fall in average marks between preschool children and the 20-25 age group. This is broadly consistent with previous years.

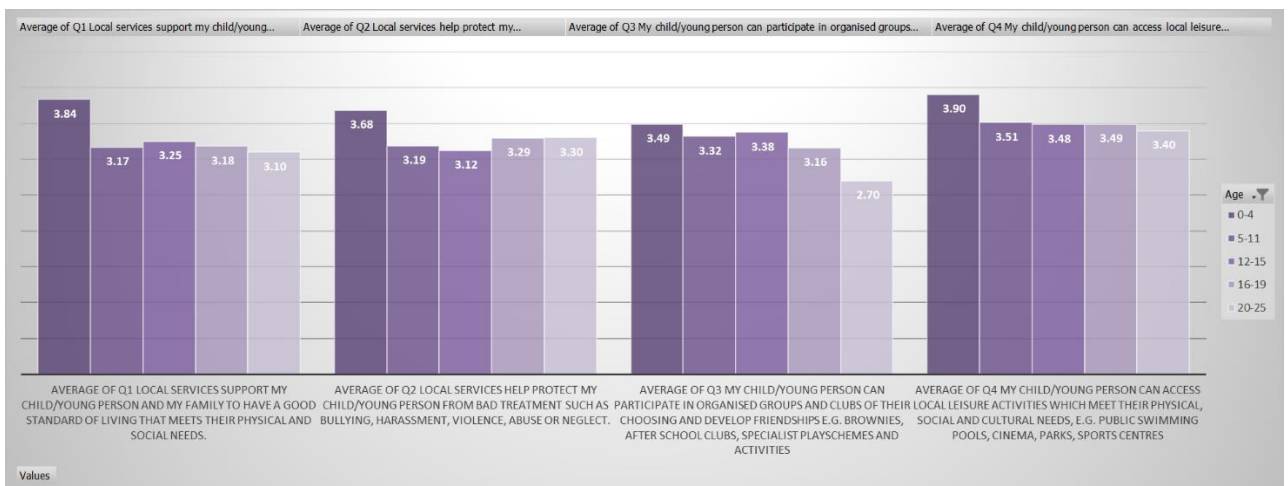


Access to organised groups and community based activities is highlighted as an issue across a number of dimensions

Age - Younger children find it easier to access organised and community based activities, whilst the 20-24 age group report many problems

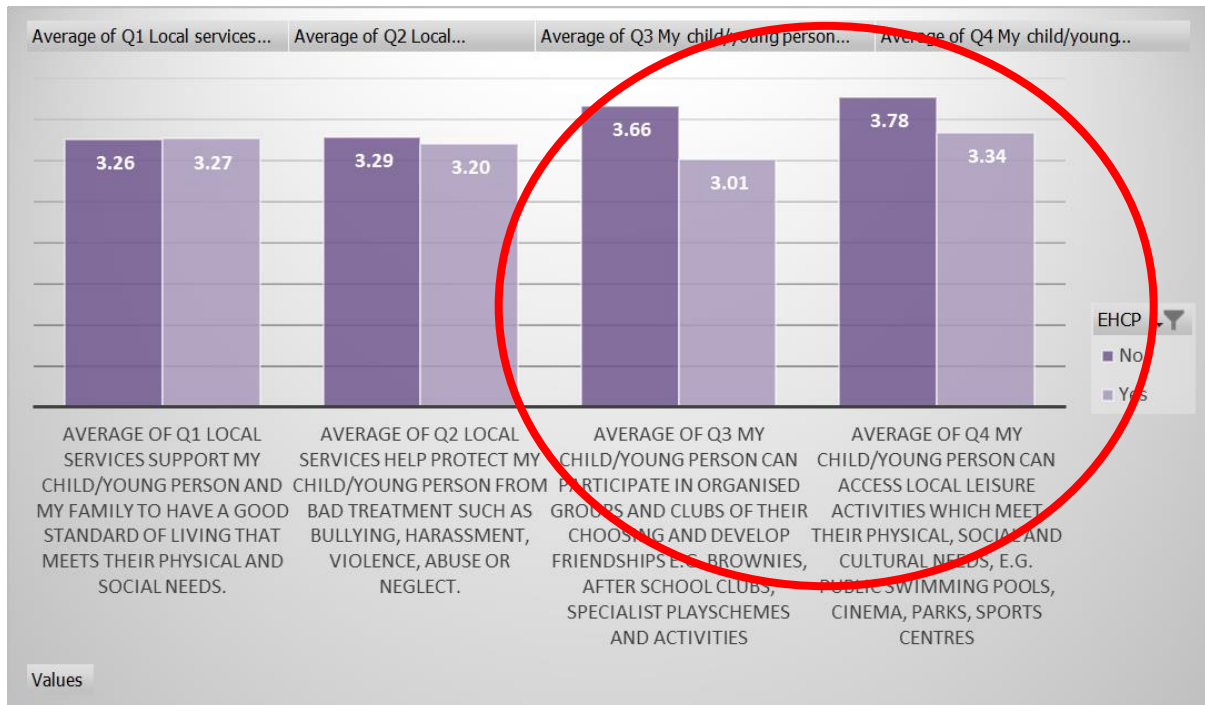
Many of the comments show the availability of clubs and activities or the inclusivity of activities driving lower scores for school age and post school children. There were few comments of this nature for pre-school age children which suggests that smaller children are more likely to be welcomed into universal clubs and activities in the community.

Analysing individual scores by age also provides insight into a driver of the poorer scores for the 20-24 age group. There is a significant drop in the question about the availability of organised groups for young people in their early twenties with a drop of 0.46 between those aged 16-19 and those aged 20-24.

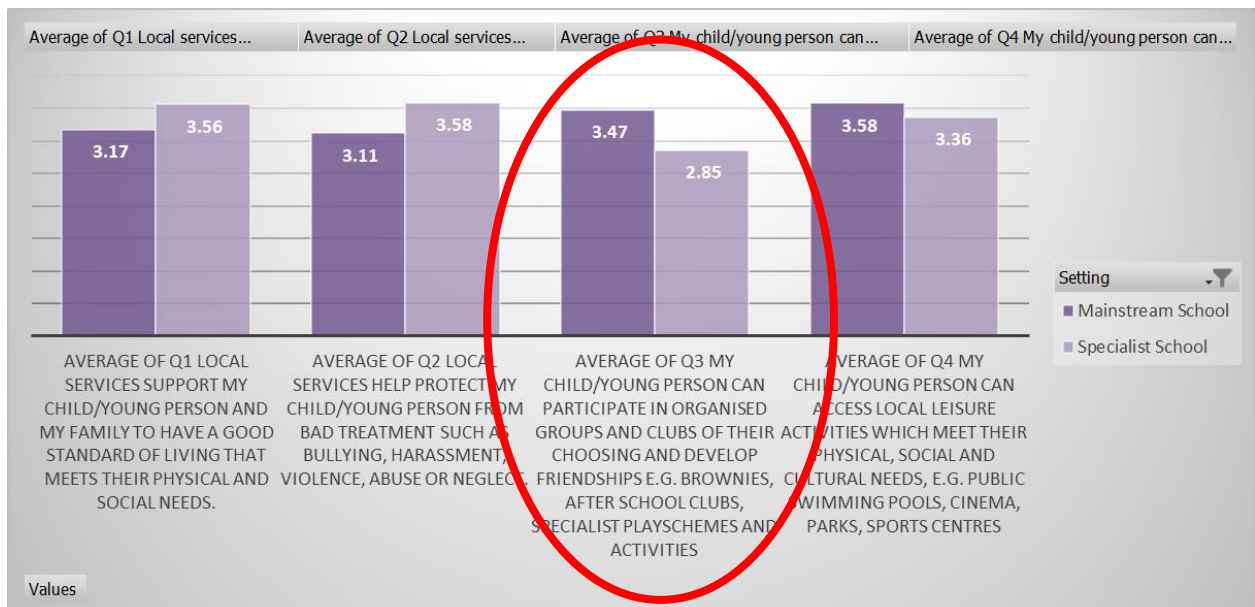


Those with more complex needs also report greater difficulty in accessing organised groups, clubs or community based activities.

Families of CYP with EHCPs show significant differences in their answers to questions 3 and 4 on the survey showing gaps of 0.65 and 0.44 respectively.



Likewise, those in specialist school settings report a large gap on Q3 about access to organised groups with a gap of 0.62 between those in mainstream schools.



The comments identify a number of themes and underlying causes for this:

There are not enough specialist clubs, groups and activities for children and young people with complex needs, especially as they enter adulthood.

Not enough social activities available for young adults with complex needs

I have searched, and searched and searched for suitable groups for my daughter - and there are NONE locally.

Not enough available for young people after leaving school & college

There isn't enough social activities for any range for people with learning disabilities. There isn't enough that meet the needs of children in parks groups and it requires a lot of improvement for children or adults to still be included

Even when I was signposted to SSG activities, they required me to fill in a form, and then suggested that they were unable to meet the needs of my child safely. Not sure where I go from here?

None that meet her needs and understand her disabilities. Cause increase in anxiety. Only thing that has been accessible is riding for the disabled but the waiting lists are long so unable to attend

Very little provision for adults with SLD and complex needs.

Again, no provision available for young adults with SLD who would still enjoy these activities.

Not enough Sen activities for complex needs

Not enough activities for my send son

Not enough SEN options at suitable times

Very little in Beds Borough except for play parks for those with PMLD / severe learning challenges/ delay

Many do not consider universal services and groups inclusive enough. Many reported either being rejected or asked to leave such activities or an environment unsuitable to neuro-diverse CYP.

Consistently denied being able to join mainstream clubs

My child was stopped doing after school activities as it was explained she doesn't join in and they have to chase her about, although she loved it. And yet there are other children not even participating and doing what they want, I did raise this concern she was being discriminated against

Our gorgeous girl has tried so many mainstream clubs where she gets asked to leave but also doesn't feel she fits in the special clubs

Swimming, Pools, Cinema and sport centres all represent large areas with lots of people and loudness. My son is unable to sit still for any length of time, cannot be confined to an area and doesn't interact with people.

Both my children are autistic and like quieter activities and groups. We went to the swimming but unfortunately There was an older boy who liked to talk to people and it frightened my two and we haven't been able to access this since.

My son has epilepsy and these are triggered by noises and his surroundings. He doesn't enjoy the cinema now either. It would need to be a hydrotherapy pool rather than a public swimming pool too.

Struggles due to these places being generally too busy causing high anxiety.

Unfortunately, even though local leisure facilities are legally disabled accessible, this rarely means the facilities are sufficient for my Complex child. This usually comes in the form of lack of suitable hoisting and changing facilities.

Fusion are impossible to book a carers ticket on line for swimming pools. Was able to access ssg swimming one school holiday but as no ehcp, unable to access again

We can go swimming but only when it's quiet.No 1 to 1 swimming sessions offered at preferred pool.CEA card good.

There are no groups suitable. My daughter joined a few, but was asked to leave/ they wasn't suitable

Many families identified the lack of support for those with SEND or complex needs as being a barrier to them attending many activities – the need for an adult to be present means that SEND children cannot access some activities.

As my child needs 1:1 support and constant engagement, there are few to no services that provide that level of care and support

He can only access activities with support, what's available either isn't adequately supported or I attend to help and it's not something that interests him.

The clubs that are available are often not accessible without support from parent

There is no support for my child to do this, we have been discouraged to ask for a personal allowance.

I don't feel these are suitable for my child as they do not offer additional support

My child can only access specialist playschemes as no universal clubs or groups can meet her complex needs, and have never been able to make sufficient adjustments to enable her to attend.

As my child needs 1:1 support and constant engagement, there are few to no services that provide that level of care and support

Cost was raised as a concern by some parent carers

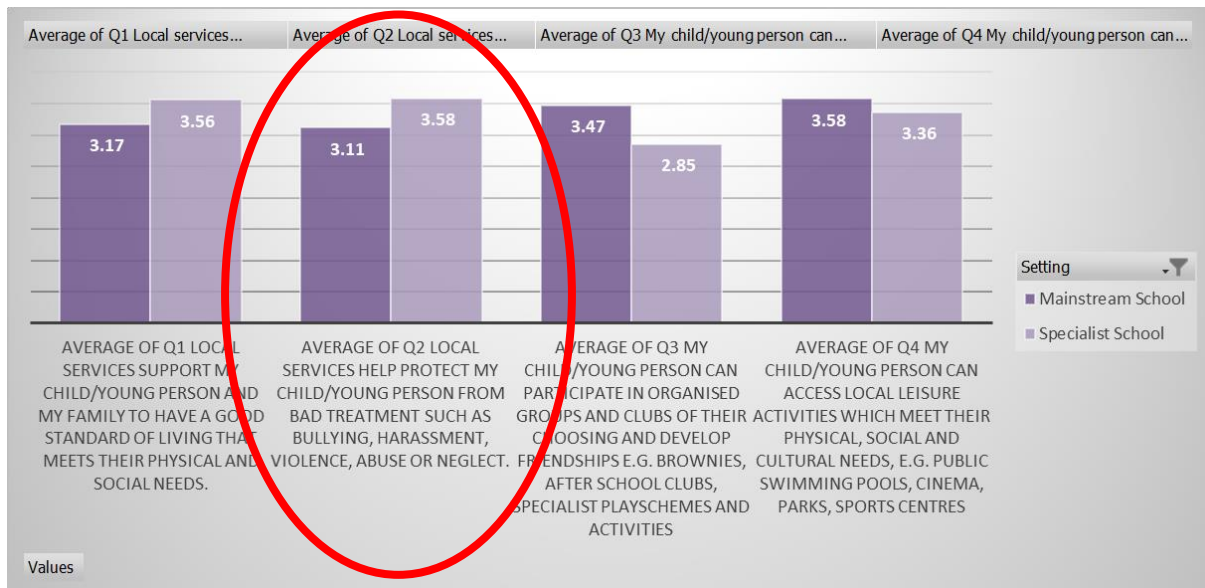
Although these services are expensive to access.

He could but again time and out of our price range

School won't allow my child to participate in after school club due to funding as she needs full support, therefore we have to pay private for 1-1 which cost more than any other child due to a disability.

Bullying is a major concern raised by a very large number of families.

There is a worrying increase in the 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 0.47 points between those attending mainstream and special schools. This is a slight improvement on last year when the gap was 0.5.



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

In a change from previous years, there were fewer comments that stated that schools had not taken bullying seriously or that schools and staff themselves were responsible for the bullying. This is different from previous years.

Bullying happens at school and therefore young person will not go out anywhere socially. Feels too vulnerable. No access to local services

Child has been assaulted and cyber bullied, police took so long faffing about not doing anything it ran out of time to bring a case so they dropped the case. Another incident of online grooming by an adult to my child, reported 2 months ago and still waiting for contact from the police and the promised counselling.

My child feels more intimidated than protected. Harassment and bullying aren't just playground issues; they're real problems that the local services seem to blissfully ignore.

My daughter has suffered bullying since year 4 and is now year 9 and it only seems to have just stopped, even though we have been in contact/ communication with both primary and secondary schools.

Have contacted the LA re bullying in school, as well as school dealing with it- no help. Parents need to use national helplines for support and find support themselves.

My son is being bullying at school and treated bad

They were bullied at school but no measures were taken to stop it.

Tried local park after lockdown, picked on and now he won't go back

When I reported that my son had disclosed being a victim of online grooming within an online gaming forum, neither the police or Early Help Team were able to offer practical assistance to identify nor investigate the incident that is still negatively impacting him to this day.

I feel parents are penalised for reporting and bring up any concerns related to bullying or just any playground 2ments a child has . When their paren are their advocates we are looked and and labelled immediately mentally unstable. An their first hand approach is we need to see therapist. For PTSD. Because we raised concern to the school.

There were many calls for increased training and awareness of SEND amongst school staff and providers of universal services

EHC needs assessment turned down in October 2023. School staff do not seen adequately trained to support our son who had an ASC diagnosis in June

Not enough awareness on disability. Make it easy for disabled to be targeted. those who choose to hurt anyone with a disability doesn't receive harsh enough punishment for the behaviour.

I believe schools should educate from early on re SEN, everyone being different, use neuro diverse language

School have moved our son to a quiet area & then integrate into mainstream lessons where staff are not trained

Social community awareness and safe place in bedford are needed

I haven't seen anything in place that would help explain my child disability to others, so that bullying etc doesn't happen. In fact, they generally know him and accept he's different. Not understanding or helping him make friends.

Access available, but support for social needs often not adequate (e.g. I suspect staff aren't trained to notice or how to respond)

There was a lot of praise for the services provided by the local charities and SSG

Activities do not seem to be available to young people with severe learning difficulties and need 121 support. Everything is based on physical age. Charity places for playscheme / Saturday clubs are hard limited. BDCPS are the only place we know our child's needs will be met.

Everything on the local offer is based on physical age and very little is appropriate for my non verbal son who is globally delayed and will need support for any activities. Other events are the wrong time of day, as in too late in the day. We have access to BDCPS which we found ourselves - they are brilliant!

PMLD or children with severe learning difficulties / development delay / non verbal are not able to attend many organised groups except for very specialised charities/ support which is hard to get into

We rely heavily on specific charities for this

Living it up are great. Fusion gym sessions also good

Only groups/services/clubs under Autism Beds, SSG, Mencap,

Signposted to Brave theater group at The Place theater by social prescribers, best thing we ever did.

Specialist groups such as play schemes and afterschool sport - yes. Still working on Brownies - there isn't a group in Bedford Borough.

Love the playschemes and SSG activities

SSG Youth club, AB Youth Club, cooking this summer. Lots to do

Family Swim and sensory room great

Sensory room, family swim have been great

Likewise, summer activities received positive comments

There is lots on offer and during the holiday times which is so good as it helps break the holiday up

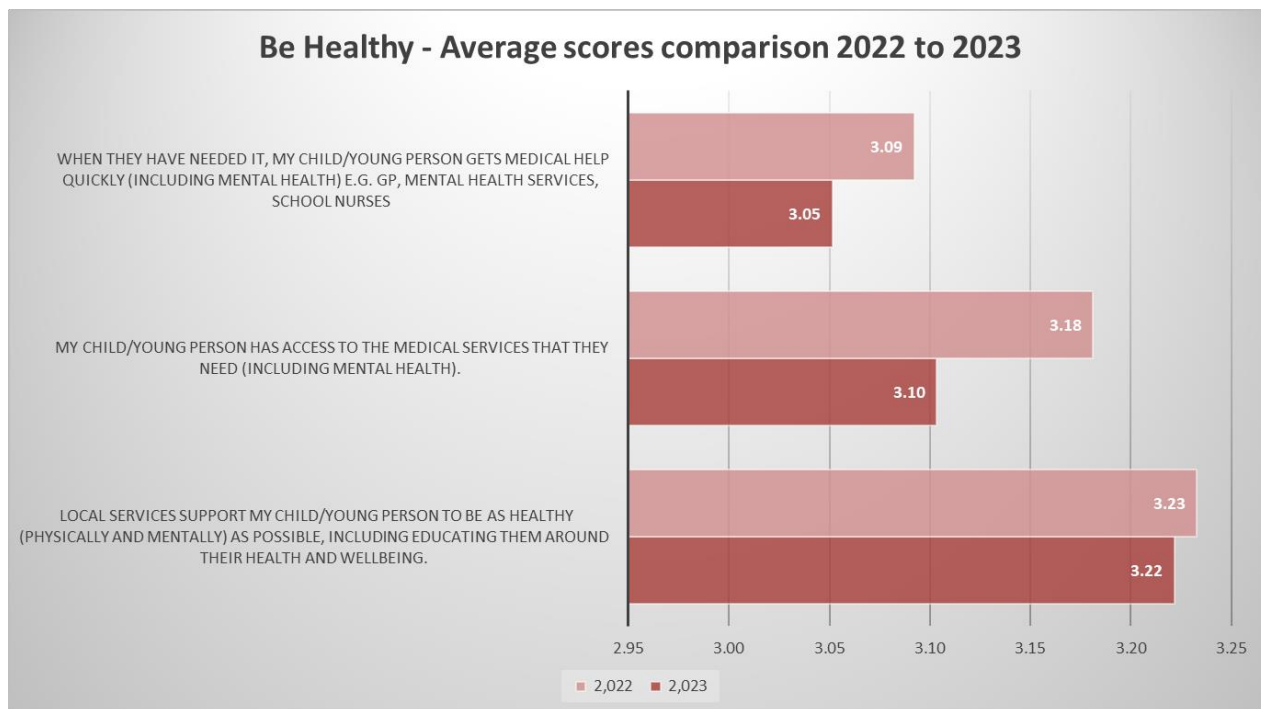
Holiday club only for us. As it is only affordable otherwise the Disabilities allowance will not be used fairly for the child. £50+ is the cost depends on how many days

Summer of SEND has been great. Tried lots of new stuff this year

Good work done to playgrounds accessibility wise. Not aware of many cultural events open to my son

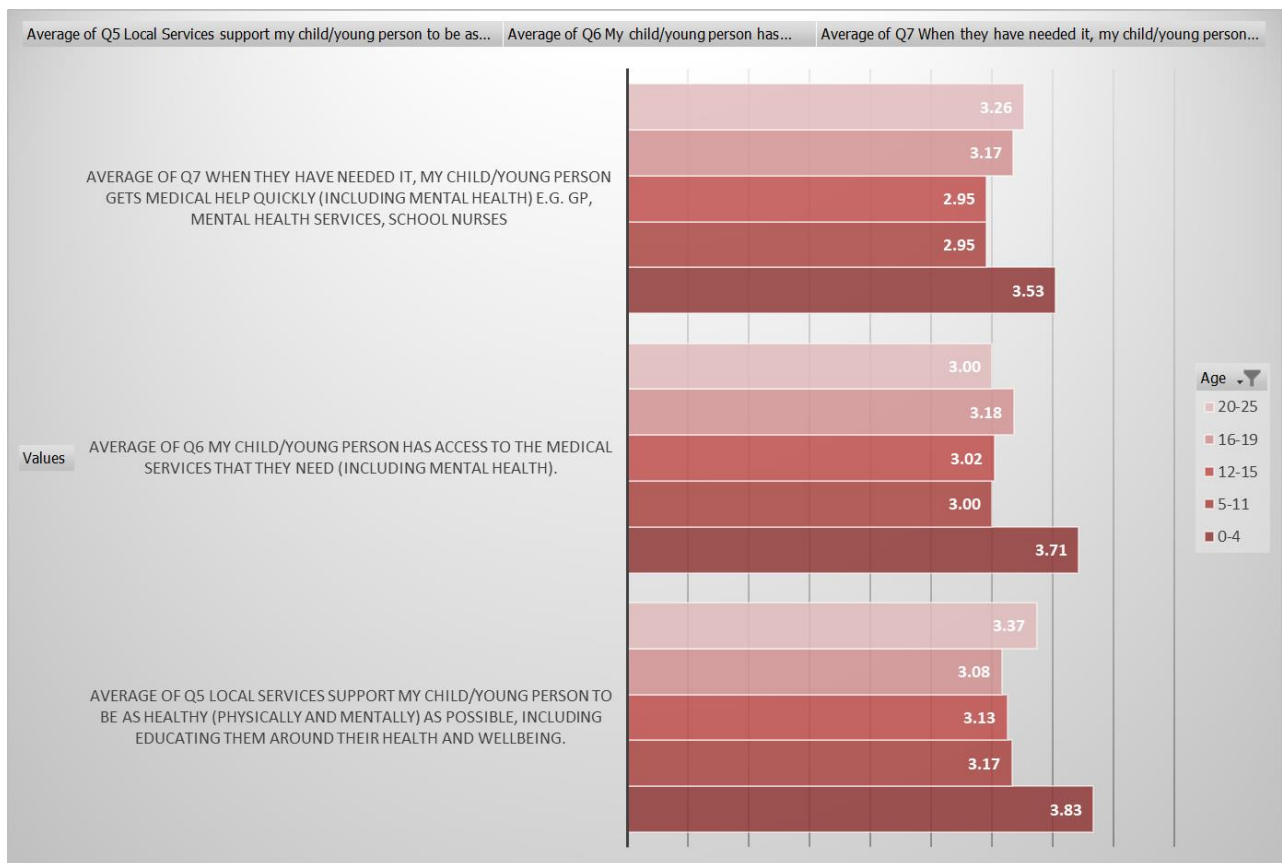
Be Healthy

There was a slight decrease in the average Be Healthy score year on year which was 3.13 this year. In 2022 the average score was 3.17 whereas it was 3.20 the previous year. Consistent with previous years, this was the lowest scoring outcome.



Each of the three questions saw a small fall in scores. The largest fall was 0.08 in access to medical services.

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. Unusually, the 20-25 age group was not consistently the worst scoring which suggests that the transition to adult services for medical support is not as difficult as the transition to adulthood in other areas.



There were a large number of negative comments about mental health services and paediatricians.

Families report that mental health services were difficult to access with criteria that were hard to meet, had long waiting times and that communication was poor. There were also reports that CYP with complex needs and multiple diagnoses were being turned away by mental health services.

The threshold for support from CAMHS for a child who is self harming and identifies as transgender is too high, too blinkered and too long. The assessment process does not take into account that they may not feel able to tell their story (not want to again and again) and then flip back into a "ready for school" mode. The wait is too long for support and I fear blinkered rather than open minded, suggesting we could be at risk of heading down the Tavistock route of difficulties around transgender. It left no other option than for our family to resort to private psychotherapy sessions which have been helpful but unaffordable for many.

Lack of support locally for mental health. They have previously accessed CAMHS and individual staff were very helpful to me, but type of support was not sufficiently adapted for autism, so they will now not engage with talking therapies again. Waiting list for CHUMS took 15 months, by which point impact of CAMHS meant they would not access it.

No mental health support

The support services needed are refused on a regular basis. Impossible to get to camhs. Mental health not supported. Physical health supported by specialist gym but not affordable for parents long term:

Getting mental health support has been incredibly hard, wait times are very long and communication within Camhs is not always great.

My son has been struggling with his mental health for a while but doesn't seem to get much support for it.

Access to support for sensory difficulties is non-existent. CAMHS is impossible to access, not sure who would meet the criteria unless in severe crisis!

All mental health keep trying my 7 year old down saying he has to many issues going on ! So can't support him!

As mentioned previously CAMHS have let us down despite self harm and mental health the triage process seems to be only activated by actual harm, children need support way before this happens whether through online services or drop ins.

Camhs been waiting 1 Yr keep refusing

CAMHS have not got the capacity to support and too much reliance on voluntary services instead

Camhs, consistently refuse referrals. Specialist nursing teams have hugely lengthy waiting times, so appointments are few and far between and difficult to contact between appointments. Sleep service appointments constantly need to chase. Paediatricians huge waiting lists. Parents remain Isolated and unsupported!

Camhs just not getting back to us. No support.

CAMHS - The need to go through a lengthy triage and possibly a waiting period is unacceptable especially when Self Harm is happening, yes there is always A&E but it shouldn't get to the point of an 'emergency'

CAMHS and specialist nursing team have not been able to offer my son any support despite him telling me that he wants to die

CAMHS could not help even after two referrals his asd seemed to get the way of them actively supporting him.

Long waiting times, fobbed off on many occasions and CAMHS is a joke as their practitioners don't have autistic training therapies (not commissioned) so we were discharged.

My child has had no support from the mental health team as they do t know where she 'fits'. Her school has paid privately for someone to come in to help her and others.

My son went through a stage of self harming and no service helped him throughout this time.

The physical health system is great but there is zero mental health services for him

The wait for mental health services is too long, then when you get the support it is too short.

Neurodiverse young people need time to develop a rapport with the individual before they will start to open up

With regard to paediatricians, the themes here were long waiting times, poor communication and a lack of follow up when promised.

Paediatrician not got a appointment for my son's diagnosis. Over a year now

Paediatrician, appointments are always we will see you in 6months and year and half later still waiting.

Paeds...been waiting since Jan 2022 for appt at the CDC

CAHMS, Occupational Therapy and the worst is paediatricians!

Very, very, very difficult to access paediatricians or any NHS services

On a positive note and in contrast to previous years, there were far fewer negative comments about speech and language services. However, this should be treated with caution – this represents the absence of a negative. There were not positive comments in this regard.

The lowest single average score in the whole survey was about access to health services quickly when needed.

The average score here was 3.05. This was supported by a lot of comments. The services mentioned most frequently were mental health and paediatricians.

In times of crisis, the support available is far from sufficient. We've struggled to find immediate help when situations escalate, which is deeply concerning.

Access to medical services is laughable. We've been stuck on waiting lists forever, and the communication is atrocious.

Been waiting from april last year for a adhd assessment. Doc said there is no help until assessment. To support in meantime with mental health or education.

Currently have 3 separate referrals for CDC - one over a year old and have not been seen. Only specialist we have seen is by going private.

My son has been on the waiting list for a diognosis for over a year now. Still waiting for a speech referral since 2021

Extremely hard to get any appointments and the waiting list and after care of cdc once diagnosed is nothing

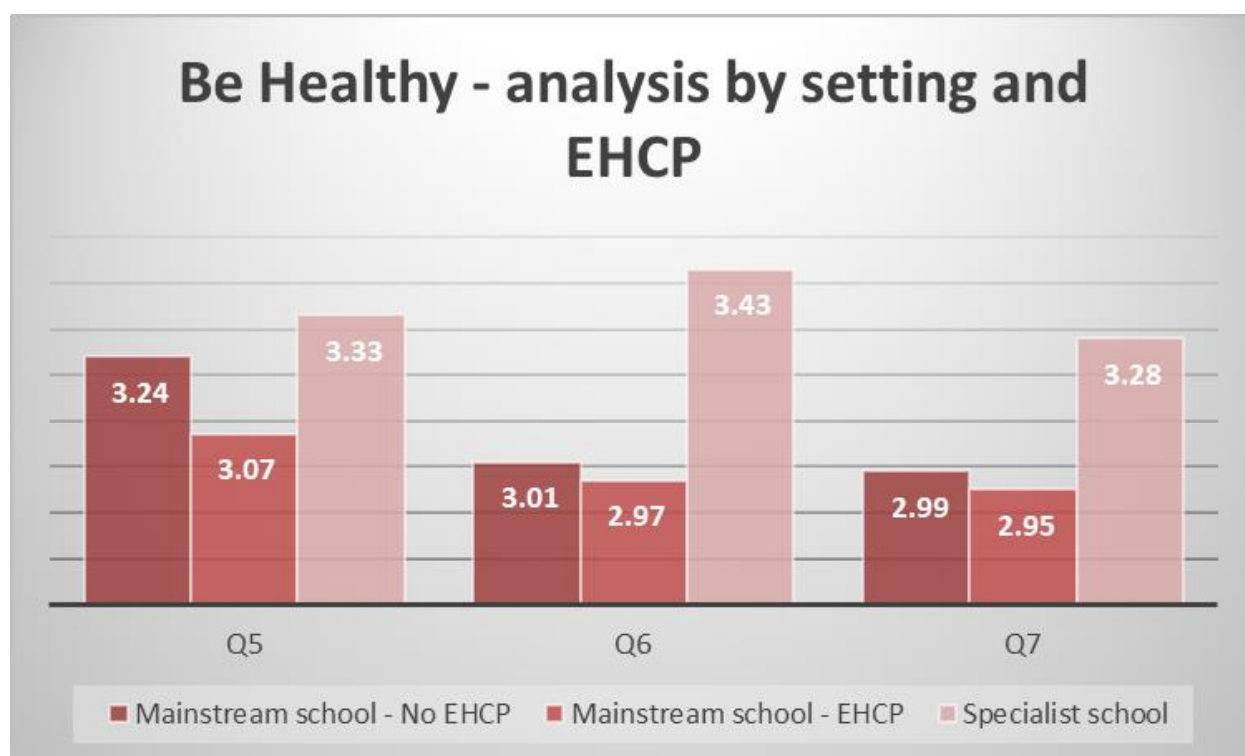
Extremely long waiting list

Been waiting from april last year for a adhd assessment. Doc said there is no help until assessment. To support in meantime with mental health or education.

Children in mainstream schools with an EHCP scored significantly lower than their peers in special schools and those in mainstream schools without an EHCP

The gap between those in special schools and those in mainstream schools was pronounced across all three Be Healthy questions. The biggest differences came in the questions about access to health services with those in special schools scoring 0.46 and 0.42 higher than those in mainstream setting with and without an EHCP respectively. When it came to speed of access to health services, those in special schools scored 0.33 and 0.29 better than those in mainstream setting with and without an EHCP respectively.

This is a dramatic difference and suggests that the health needs of children with EHCPs in mainstream schools are not being met as effectively or co-ordinated as effectively as they need to be.



Many respondents criticised communication from health providers.

Parent carers commented on poor communication where they were not kept up to date or informed of decisions, a lack of guidance and transparency pathways and health services.

The lack of clear communication is horrendous. We're always left guessing about what's happening with our case. It's a total lack of respect and transparency. You're failing our children and families!

Communication from the NHS and LA has been poor. We're often left in the dark about changes or updates in services, which affects our ability to plan our child's care.

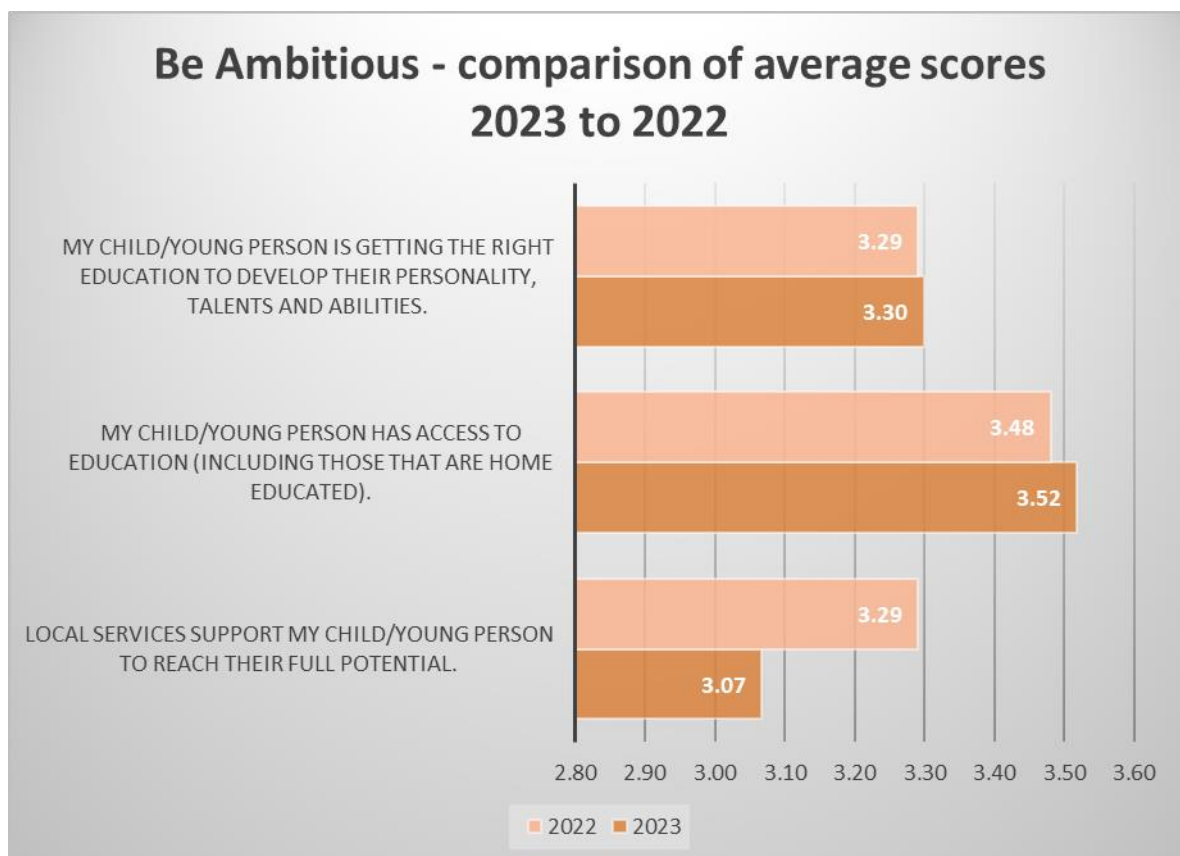
Navigating the referral process has been a nightmare. There's little to no guidance on how to proceed, and when there is some info on the Local Offer it's usually out-of-date, leaving us feeling lost and frustrated.

Pathways are so vague and opaque. Kind of needs your SENCO to be want to help. Everything seems like too much hassle.

Communication from the NHS and LA has been poor. We're often left in the dark about changes or updates in services, which affects our ability to plan our child's care.

Be Ambitious

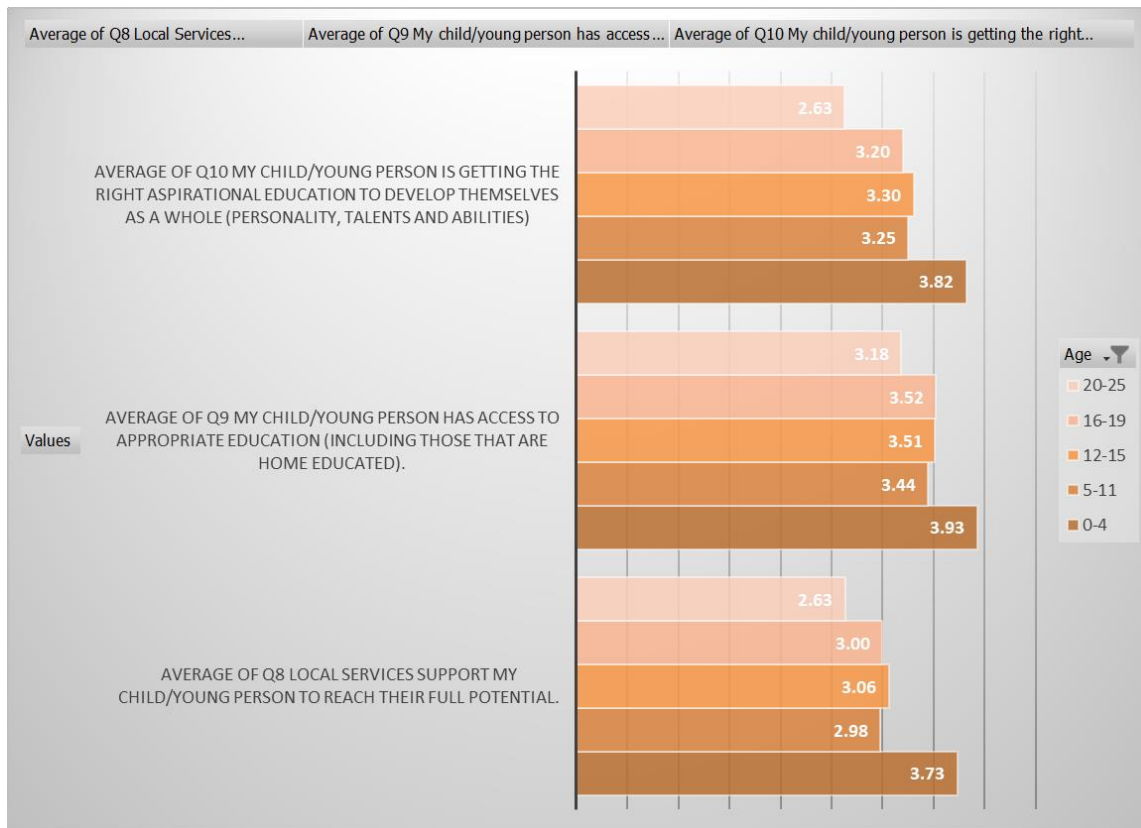
The average score for this category was 3.29 which is a fall of 0.07 on the previous year (3.36). There was little change in the questions about access to education and access to education that develops their talents and abilities. The question about levels of support for local services fell by 0.22 points to 3.07.



There is a significant difference in Be Ambitious scores between pre- school and post school

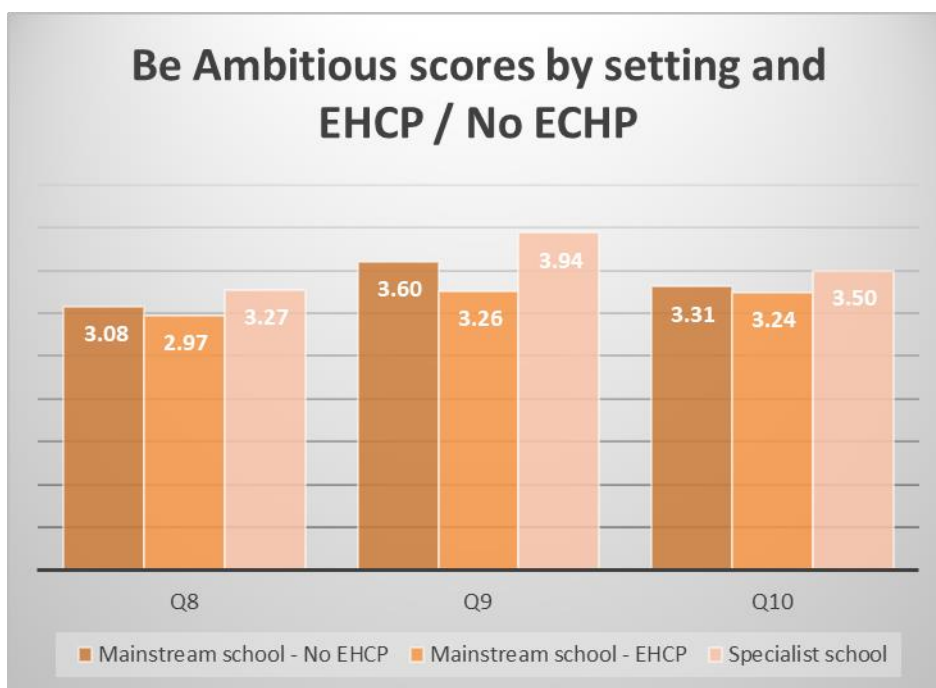
Analysis of the age profile for this question shows a similar pattern with parent carers being more pleased with the Be Ambitious scores and again we see a significant drop off in the scores for each question once the young people leave the school system.

For two questions, the difference between pre-school children and young adults who have left the school system, was particularly marked. Access the aspirational education dropped by 1.19 marks and support from local services dropped by 1.1 marks.



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

Children in mainstream schools with an EHCP scored significantly worse than those without an EHCP and those in specialist schools.



Across all three questions, children in mainstream schools with an EHCP got the lowest average score. Likewise those with EHCPs in special schools received the highest mark.

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 quality of specialised teaching, differentiated curriculums and reasonable adjustments.

My child is capable academically, so is largely left to fend for himself. He is not encouraged or motivated to be ambitious at all, and if anything, is helped back by the lack of challenge and lack of acknowledgment of his capabilities.

Potential is far too academically focused with not enough in school support of proper sport and arts at a decent level. These things are just as important especially for neurodivergent children.

School is one size fits all so no access to practical subjects which my neuro diverse child excellent at but too much emphasis on classroom based lessons which he hates

I think there is more that they can offer, like smaller groups and more help for parents. Its very hard when you feel you are on your own, no additional family structure and no one to share the burden/strategise coping with.

Child is academically able but struggles to engage due to sensory needs in school - there seems to be an attitude that because they are autistic, they shouldn't have high expectations for GCSEs.

Current provision has staff who aren't confident in working with complex needs and this is impacting on my son's ability to learn and thrive in the setting due to being constantly unsettled.

No promoting individuality. All the focus is on math and english which is too advance for my daughter so pointless

She is expected to conform to the expectations of the school

Again not enough 1-1s that are trained properly

Education not well rounded enough too academically focused not enough adequate sport and arts education

It very much feels as though autistic children are expected to fit into the limited provisions offered and there is a complete lack of understanding of the significant difference between an ASC experience of mainstream primary school and secondary school

Focus at school is still quite focussed on academic achievements

If in mainstream they are forced to go through the standard KS curriculum with very little or limited support. KS4 may have a little more choice but core subjects are still forced and required even if child has very little chance of gaining a grade in them. More foundation, life skills and alternatives to GCSE and A-levels need to be available.

Many people commented that they felt special school was the right place for their child, but they could not secure a place.

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.

Both of my children want to be in school, but the LA there are no spaces in suitable provisions for their year group.

I think there are real gaps around provision for autistic children that do not have additional learning difficulties

Waiting for specialist school, there no spaces , going to tribunal

My child needs a sen school.....

The special schools are oversubscribed. 100s are educated out of borough. Our children get dumped in mainstream, with supposed additional support. School are so stretched the money never really ends up benefiting our children.

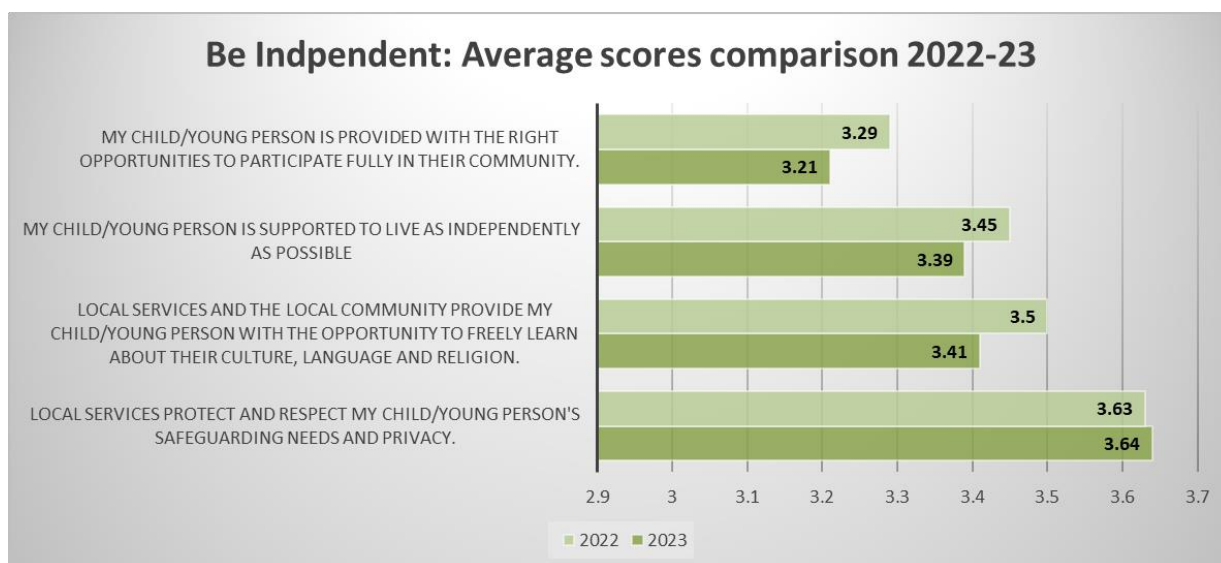
Waiting for a place in specialist school, whilst coping with a mainstream place, this is putting a huge strain on whole family

No spaces in the SEN schools

Be independent

The average score for this outcome was 3.41. This is very similar to the score last year which was 3.47 but shows a small (0.06) point fall.

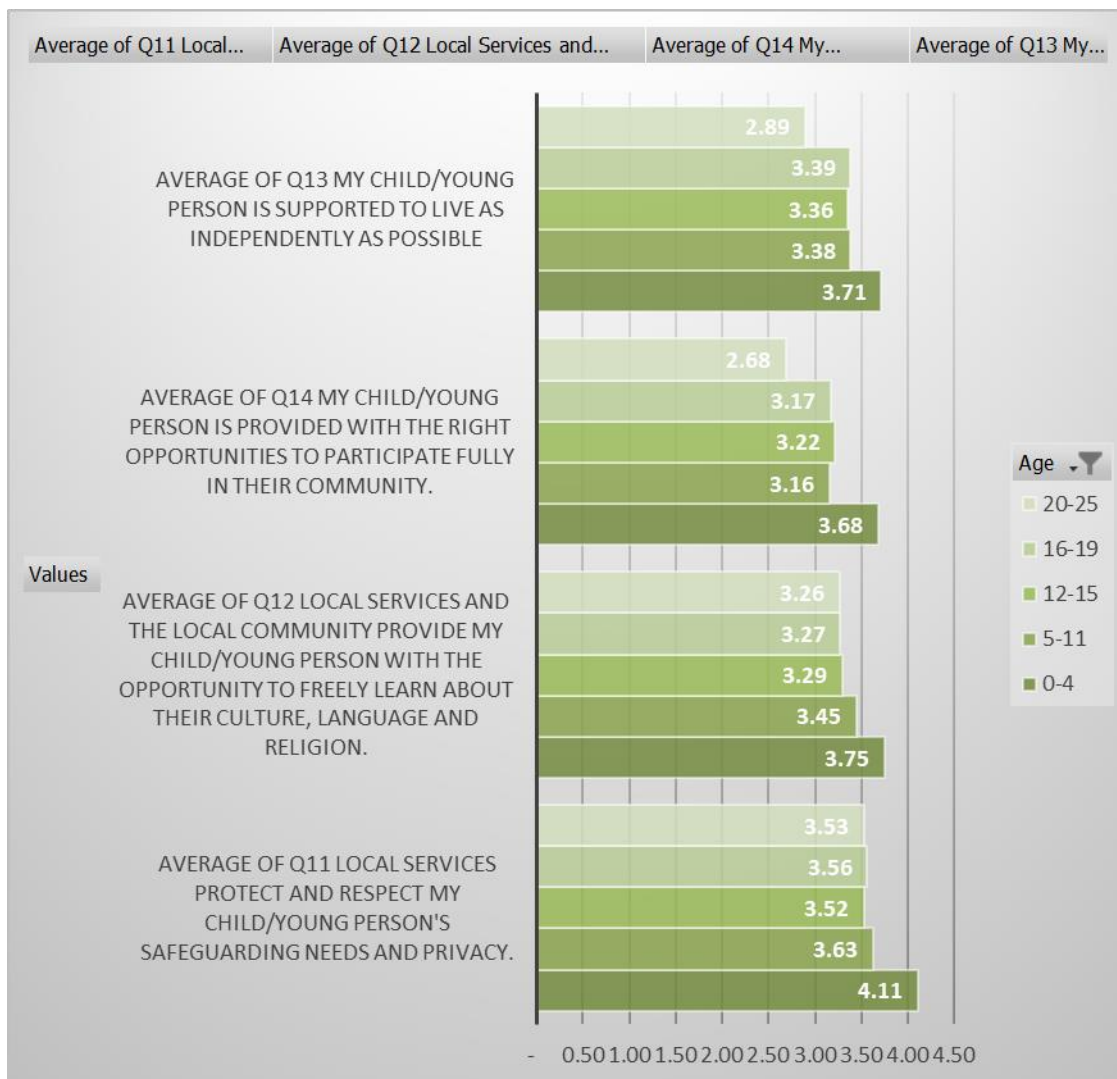
The individual question scores were also very similar year on year with three of the four scores showing a small fall. The question about privacy showed a marginal improvement. However, none of the moves year on year were significant with no move more than 0.09.



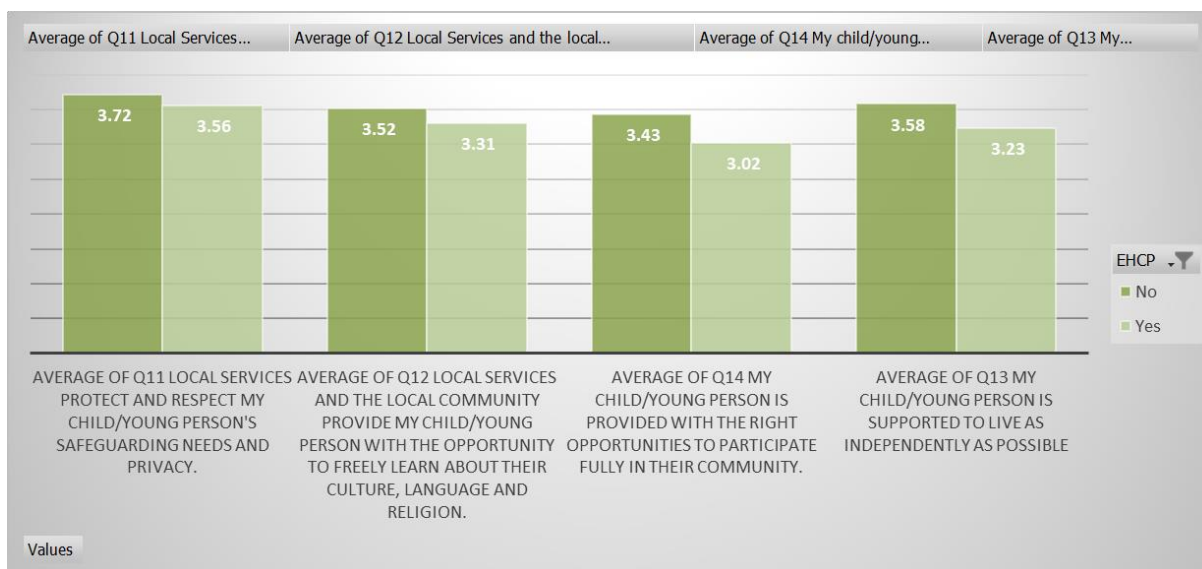
Similar to other outcomes, there was a clear pattern where the youngest respondents reported the highest scores across all questions, whilst the oldest reported the lowest scores. There is no clear pattern of scores based on age. The difference between oldest and youngest was significant, with one score (opportunities to participate in their community) showing a full one mark difference.

For two of the scores (privacy and learning about their language and culture), there was no significant difference between those in education and the 20-25 age group. However, for two scores (independent living and opportunities in the community) there was a further drop between those up to the age of 19 and the 20-25 age range.

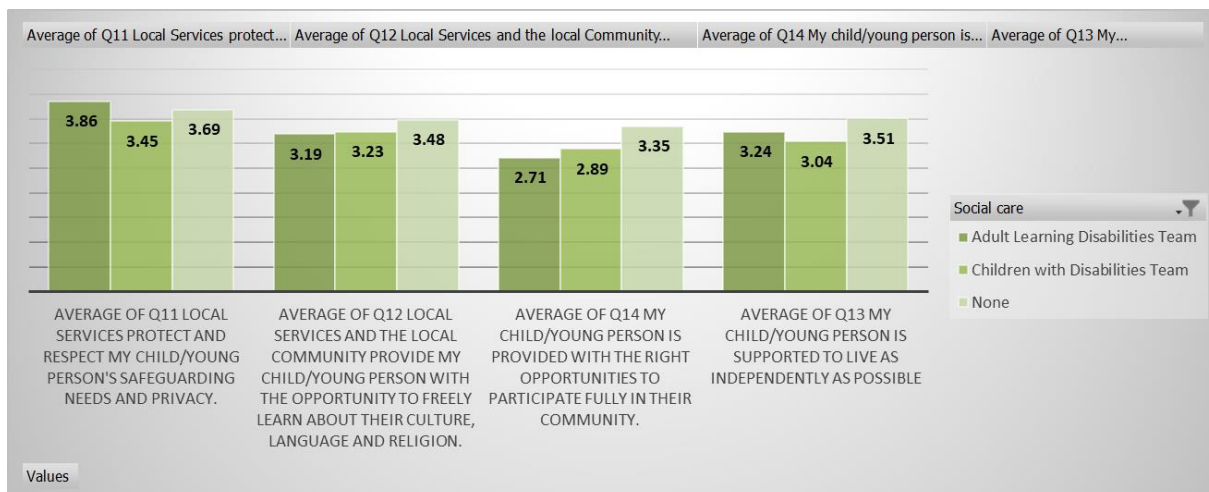
This is supported by comments which indicate many respondents identified issues with independent living and access to the community.



There is a small difference between scores for CYP with an EHCP compared to those with no EHCP. For all of the questions, CYP with EHCPs score lower than those without demonstrating that those with greater recognised needs are finding it more difficult to be independent in the community.



There is no clear pattern of scores dependent upon the social work status of respondents. However, the lowest single score is in the opportunities to participate in the community with all children and young people who have access to social work scoring below 3. This may suggest an area of development for the social care teams in Bedford Borough.



Many families described problems in accessing activities that would support greater independence for their children and young people.

Due to delays in equipment, independence is not applicable to my child.

no contact to see how she is doing in this respect as a 20 yr old. As she has limited capacity to work, she wont be able to support herself with independent accommodation

No lessons covering life skills such as money handling, budgeting, insurance, loans etc

Relaying on parents until average age of 25

The fact that transition into adulthood is so difficult and traumatic for many families, shows that appropriate support during childhood years has not been provided to ensure a child's level of independence increases as they approach adulthood.

There were lots of comments that the only way that CYP could access independence was through the involvement of parents, family and friends

We teach them life skills.

By me his Foster Carer

Yes by myself, myself finding activities arranging and paying for them. Cinema, swimming, sporting activities

yes, by us as a family.

Only because we as parents provide them - nothing from social services. We are not well off though, so it depends on finances

I am the only source currently teaching my child to become independent.

Only from us personally as parents, we can teach lifeskills in the home to a point but I would like to see more support from the LA etc for things beyond that. For example as my children get older I would like to see them freely travel into town or for appointments etc, however to plan and execute this we need a reliable bus service which we do not have.

This seems to be left to the parents/carers

Many parents-carers responded that there was very little available to support their CYP to access activities in the community.

No LGBT community to speak of here, no pride celebration, no access to BSL in school or in any events or activities other than those funded by the local deaf community.

My child has no support outside of our family.

Leisure activities for adults with SLD and complex needs are severely lacking.

My child is invisible to the community. Just keep inside, out of everyone's way. That is the vibe.

No involvement in the wider community unless we visit town

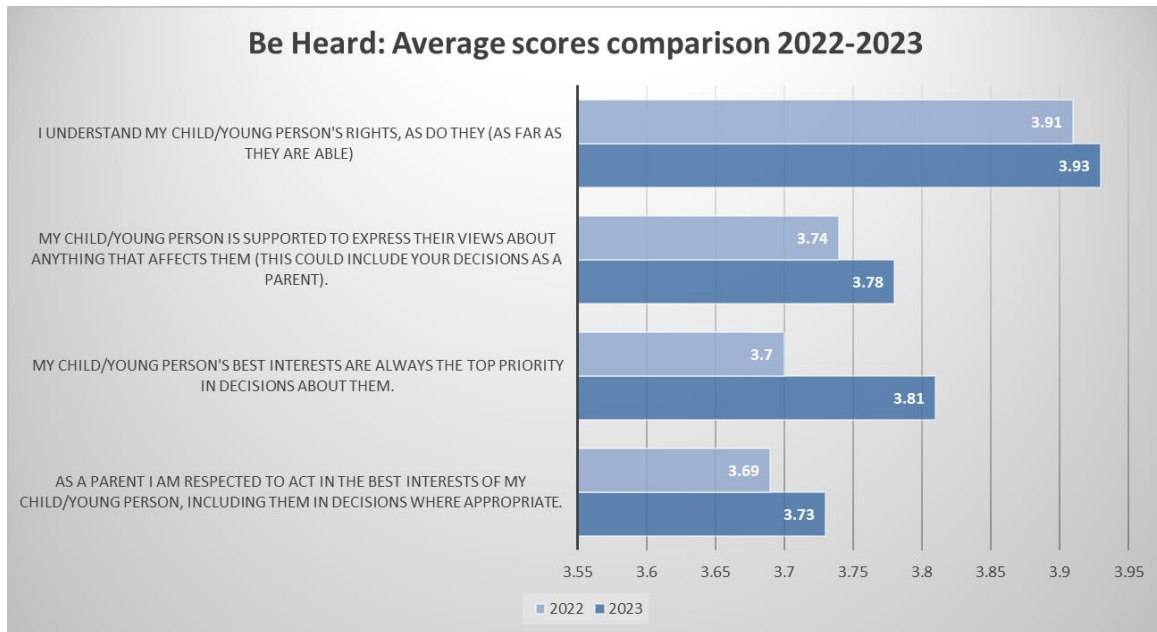
Right opportunities to participate in the community are a fantasy. They don't provide anything that genuinely helps my child engage with the community.

Very little activities for autistic children

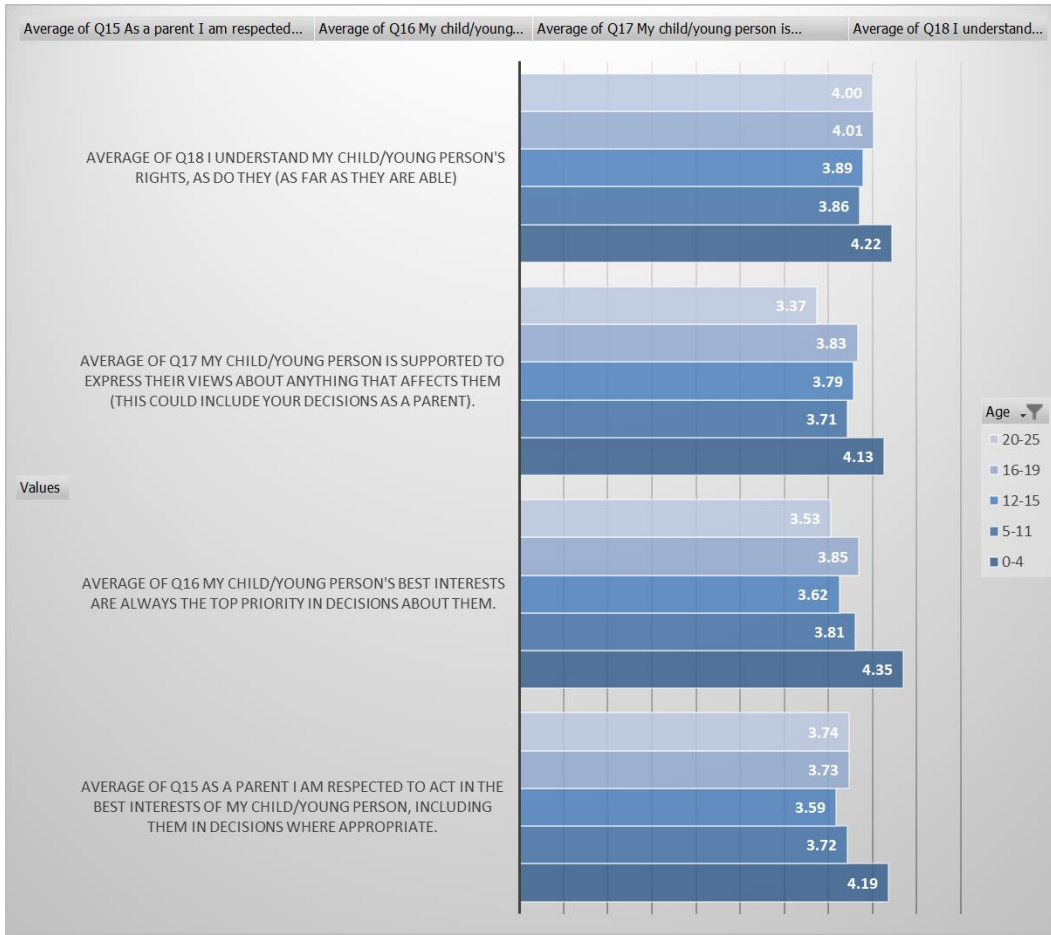
Be Heard

The average score for this category was 3.81 which was a small improvement on last year's score of 3.76.

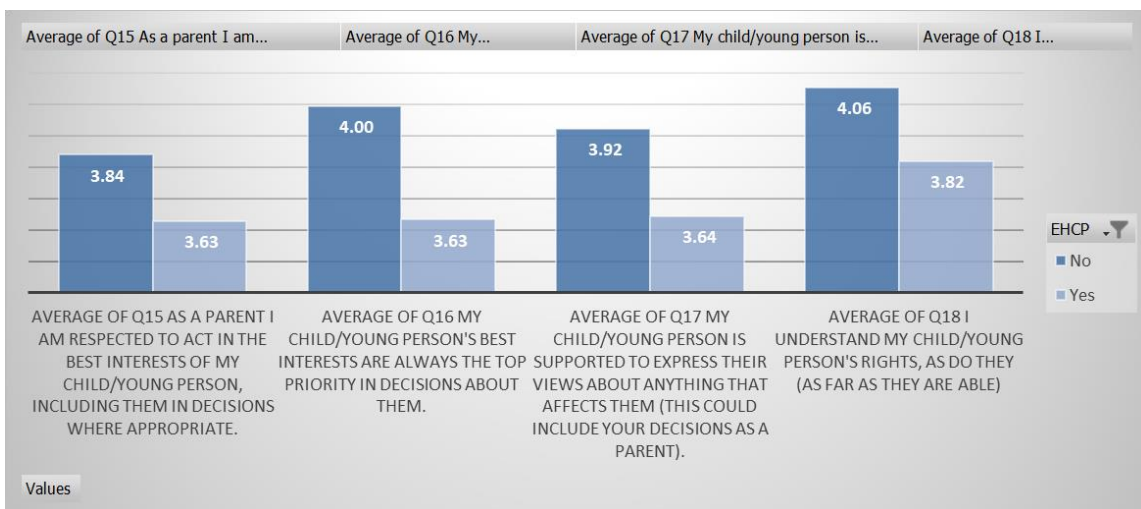
There was a modest increase in scores all questions, the most significant rise was that in the question about the young person's interests being the top priority in decisions about them which rose by 0.11 points to 3.81.



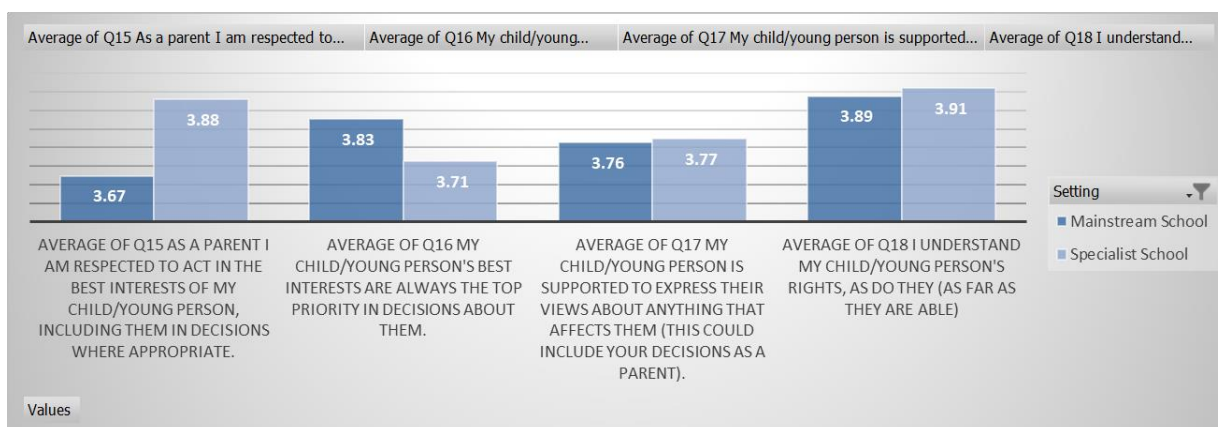
The age profile of scores shows that, like all the other outcomes, those with the youngest children scored the most highly. There was no clear pattern of deterioration for young people over the age of 20 as in some other outcomes where it was consistently the lowest score. The only major drop off was in the question about how well young people are able to express their views which did see a fall in the 20 and over age group.



The Be Heard scores analysed by EHCP / No EHCP, show that respondents whose CYP had an EHCP feel they are heard less well than those that did not have an EHCP. There were significant differences between those with an EHCP and no EHCP ranging from 0.37 (whether a CYPs interests are the top priority in decision making) to 0.21 for parents being respected to act in the best interests of their CYP.



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 they are significantly less respected to act in the best interests of their CYP where the gap is 0.21 points (the same gap was higher at 0.41 points last year). For the question of whether decisions are always in the best interests of their CYP- those in mainstream schools scored 0.12 higher than those in specialist settings. This is reversal from the scores last year.



Many families used the language of a fight when describing their experiences to access services for their child. This has been a consistent theme over the 6 surveys we have conducted, but this theme was more pronounced this year than in recent surveys.

Decisions have been made in the past that went against my wishes and were completely detrimental to my child's health.

I always act in the best interest of my child, it falls on deaf ears I'm often faced with what looks like a personal issue, no one seems to want to help they all just make my life hell

I have had to fight to be heard as a voice for my child

Every interaction has felt like a battle (mainly with education). I have had to continuously escalate to get a response. I have come away feeling like a nuisance and unheard.

I have to fight to be listened too

I often remind professionals that despite all the talking, there remains a child without an education. I still get no answers, occasionally a sorry. It is not good enough. Complaints are upheld but no action happens. Parents should not have to be driven into the ground for nothing. You fight, you complain, you 'win' and still nothing changes for the child.

There are many parents who do not believe that they are heard and that the quality of coproduction with them and their child is poor. Many parents do not feel as if they or their child is listened to with the views of practitioners taking priority.

I feel like the school and other organisations have more input than myself and their point of view count more. I'd like to be listened to more, as I feel not heard a lot of the time and over ruled in affect about my child

I feel powerless, excluded and not listened to. Getting any support is a battle. People are pushed to go private all the time

Schools and teachers generally never ask for feedback from students

Many families believe that resources are more important than the best interests of their child when making decisions about them. There was a mixture of anger and understanding about this in comments

It's all about budgets and box-ticking, not what's best for my child. Top priority seems to be saving pennies, not supporting my child. 'Best interests' doesn't seem to factor into the equation.

Money, money, money. If my child's best interests coincide with what is convenient or cheap, then maybe they will act.

That's the biggest lie. They put bureaucracy and cost-cutting above the needs of our children.

Funding and resources are the top priority and THEN my son's best interests

Funding, resources, waiting lists or professionals time, their enthusiasm to actually help strongly determine effect priorities when making decisions.

Sadly we have so often felt that the availability of budget is top priority in making decisions about them, especially when it comes to the council going to assess a child for an EHCP

I get the impression agencies involved try, but always limited by resources

I think there is still a resource/finance issue - if there are no SALT practitioners working in the job, then it doesn't matter what the EHC plans says.

Sadly budgets are part of every decision

Unfortunately I believe money comes into place so this isn't always the case

There were many comments identifying a theme of “parent blaming”

Parent blame is rife. The parents voice is the weakest at the table..if it is even heard.

Parent blame is rife. If you voice concerns they are dismissed and invalidated

While trying to get a diagnosis I was not listened to at all and even blamed for their "bad behaviour"

Parents need to shout loudly to be heard but once the ball gets rolling we seem to be seen very negatively and dismissed as 'anxious', or 'pushy', 'overbearing' 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”

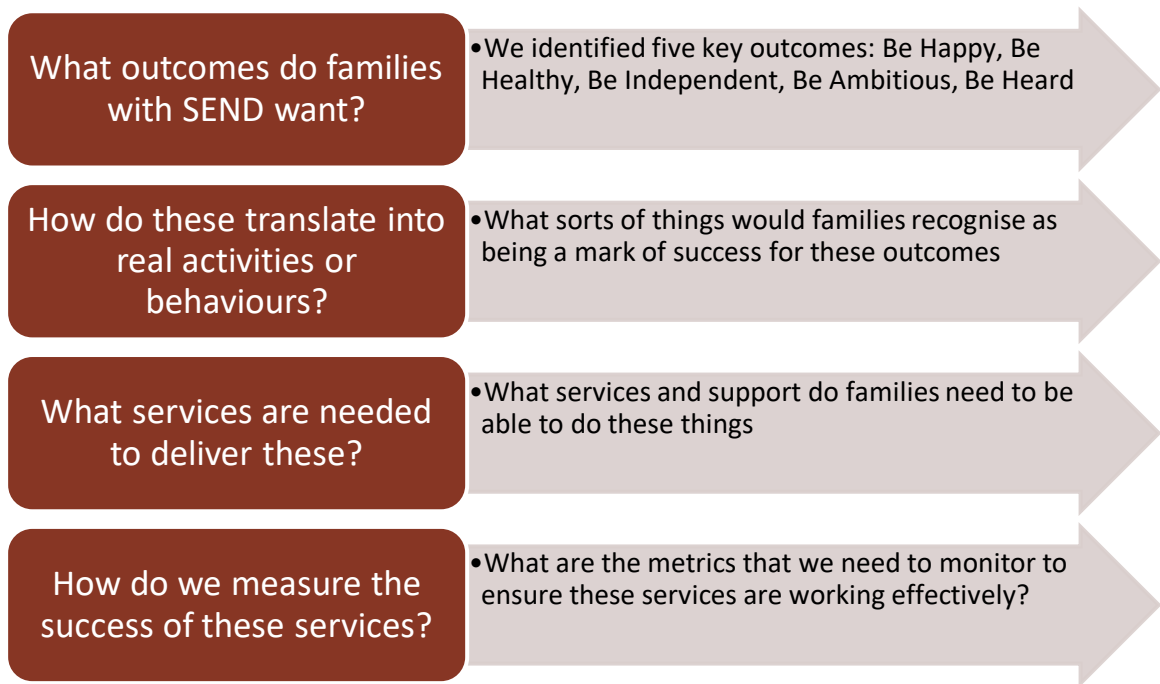
Outcomes framework

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.



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.