

Bedford Borough Parent Carer Forum Outcomes Report

February 2021



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 the lived experience of families, BBPCF undertook a series of workshops and conducted a survey between October and November 2018. The outputs of these workshops and survey were published as our “Review of outcomes for children and young people with SEND in Bedford Borough” in February 2019. For more details on the outcomes framework, see appendix 1.

We agreed that we would repeat this survey annually and this report is the second annual refresh of that initial survey.

Our methodology

Between October and December 2020, we asked parent carers of CYP with SEND to complete a survey to capture their lived experiences in Bedford Borough. The survey was only available online because of coronavirus restrictions Parents were able to add comments to each answer.

The 2020 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. There was no intention to change the meaning or intent of the questions. In 2019, we had added two questions in areas in the “Be Healthy” category where we felt we needed more information having learnt from the 2018 survey. These questions were coproduced with the local authority and the Clinical Commissioning Group (CCG). No questions were removed. For a full list of questions see Appendix 2.

The survey questions are based on the United Nations Convention on the Right of the Child.

The survey was completed by 556 respondents in 2020 (107 in 2019 and 151 in 2018). In addition there were 1080 comments made in 2020.

Summary Results

In absolute terms we are still not meeting the needs of children and young people with SEND well enough but the experience of families is improving.

The average score across all questions in our survey was 3.52.

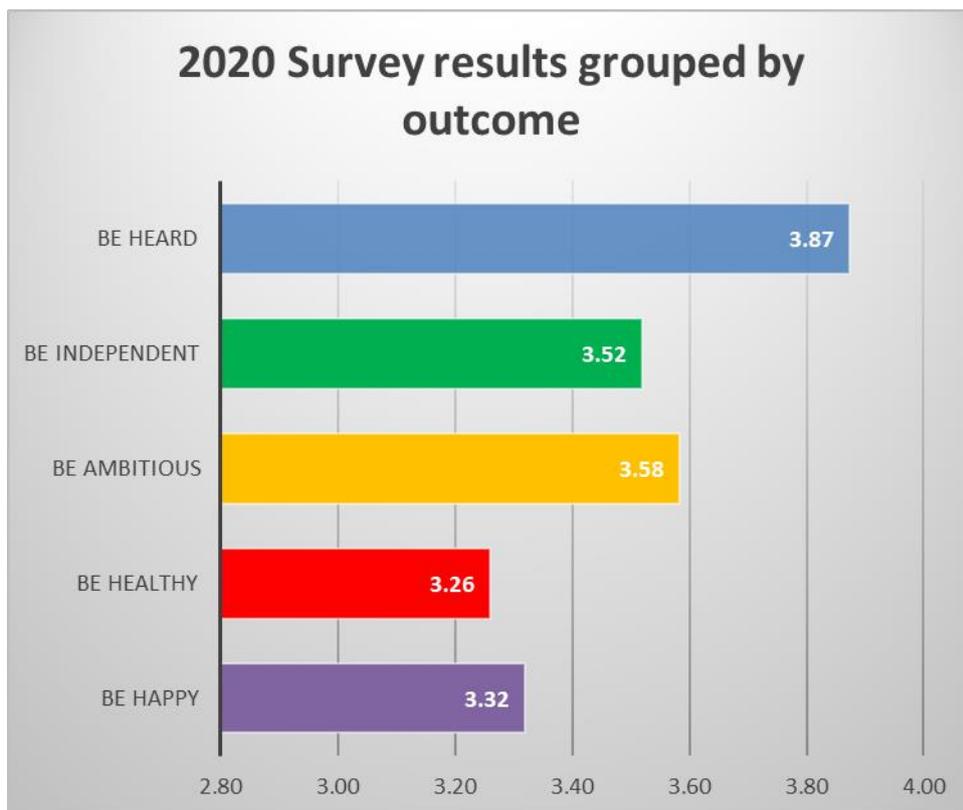
This means that the needs of children and young people with SEND are only being adequately met at best. This falls short of our stated ambition that needs should be being well met (a target score of 4 or more). Given that the questions were based on the United Nations Convention on the Right of the Child,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

Average score

3.52

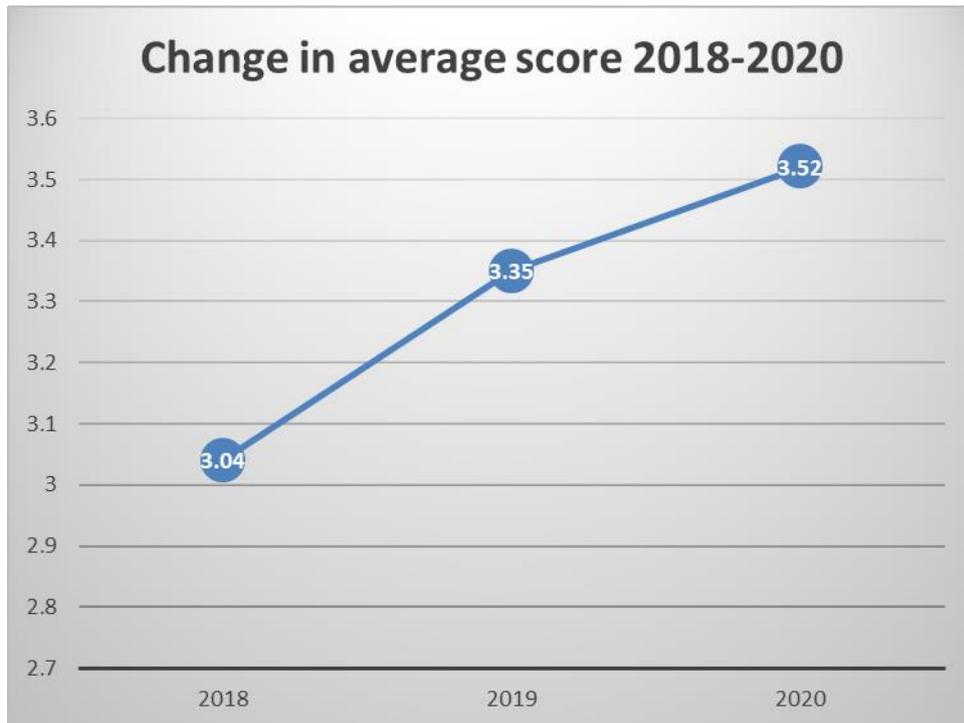
(out of 5)

The average scores for each outcome were as follows:

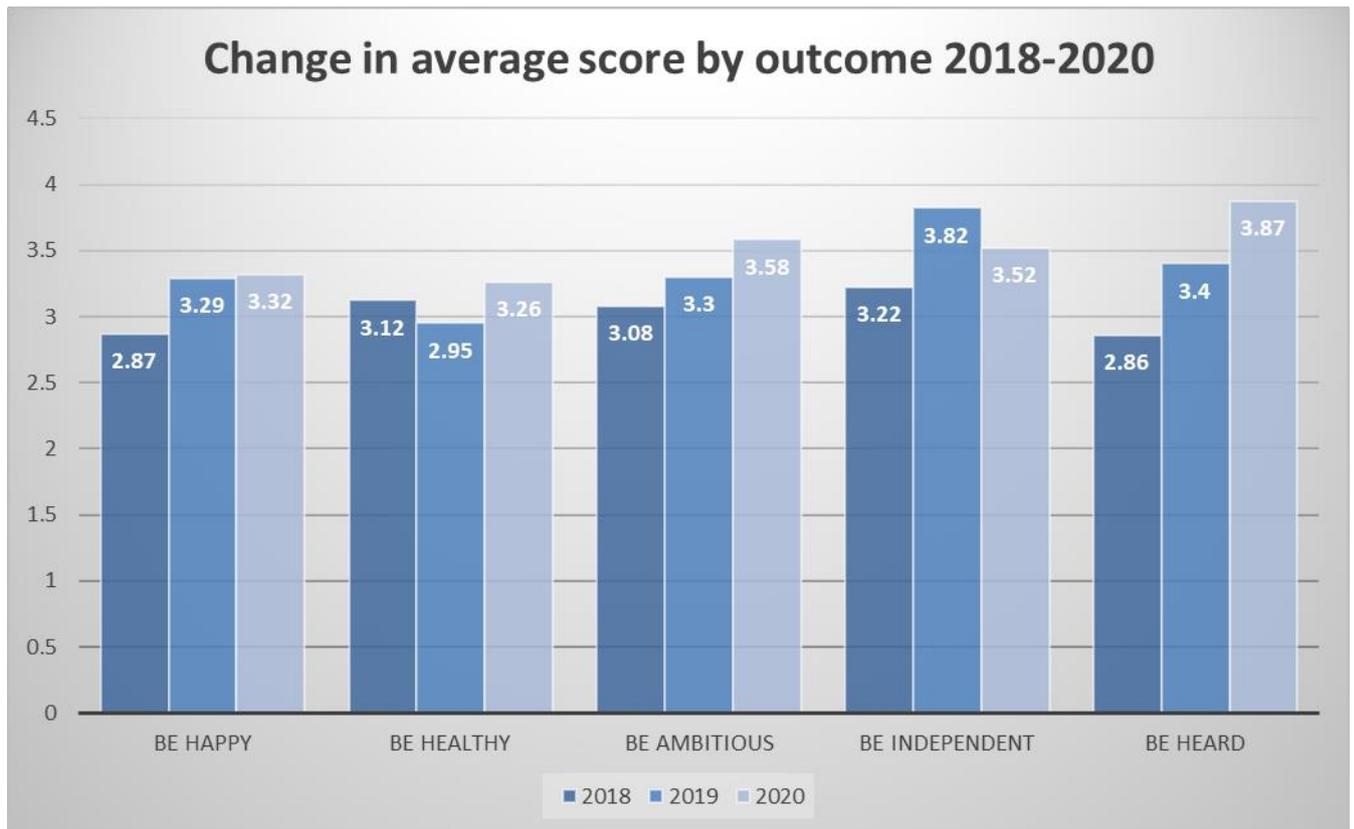


There has, however, been an improvement in scores in comparison to previous years, which evidences that some of the changes that have been made are having an impact.

The average score in 2020 was 3.52. This was an improvement in scores in comparison to the results in 2018 when the average score was 3.04 and from 2019 when the average score was 3.35. This represents an improvement of 0.17 year on year.

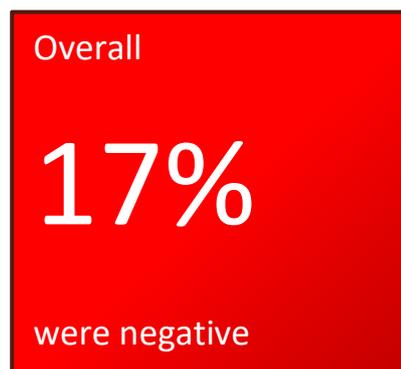


Generally, there was an improvement across all of the outcome areas with the exception of the “Be Independent” category which dropped slightly.



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, 61% of all responses were positive (scores of 4 or 5) whilst 17% were negative (scores of 1 or 2).



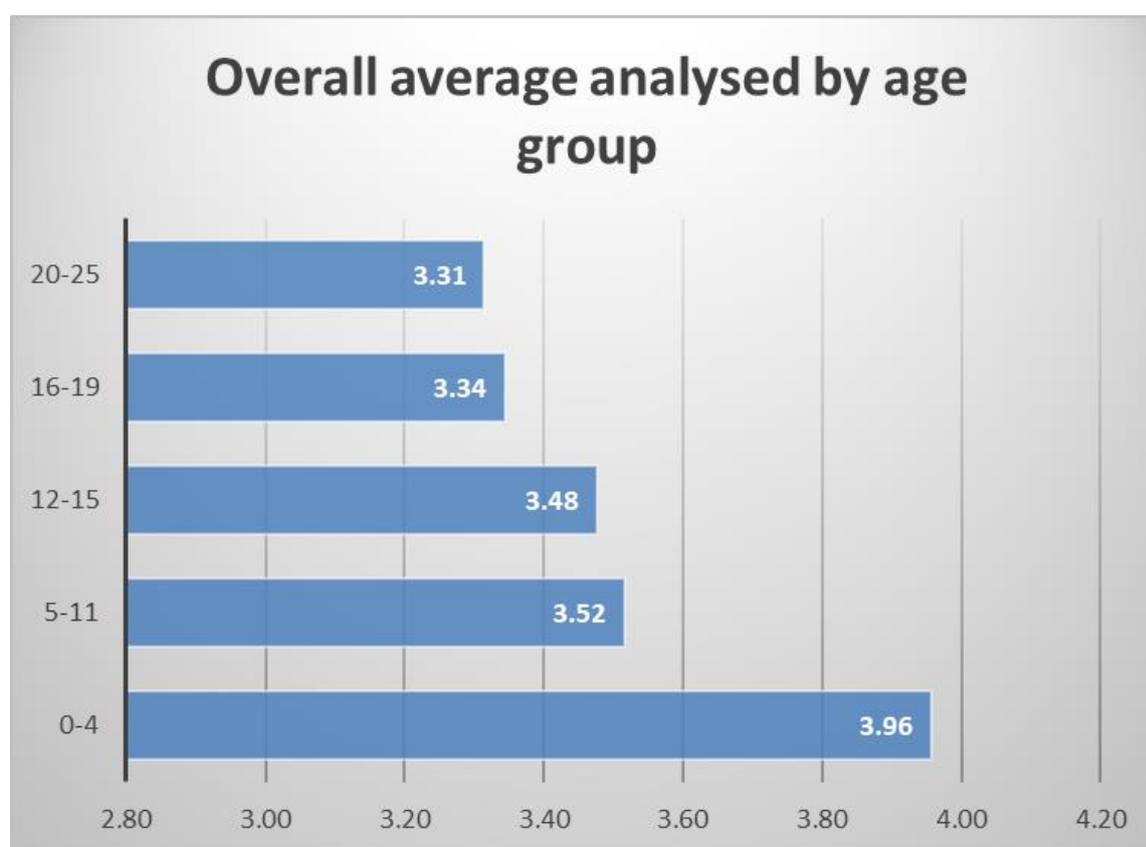
This marks a notable improvement from previous years when 50% and 38% of scores were positive (2019 and 2018 respectively) and 28% and 38% were negative. More respondents reported having a positive experience than last year (up by 11%) and fewer respondents reported having a negative experience (down by 11%). The number of neutral scores (3 out of 5) stayed the same at 22%.

Key Findings and Recommendations

There are some very clear messages about what the system must do to continue to improve the experiences of children and young people with SEND

1. Families are less satisfied the older their children get

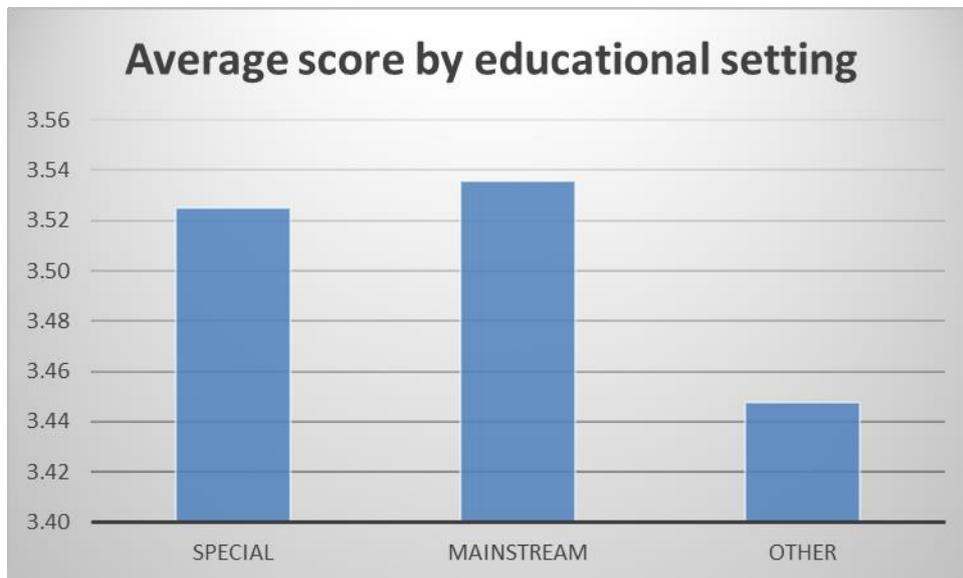
The average score for those in pre-school years (ages 0-4) was a healthy 3.96. However, by the time that young people with SEND have reached the 20-25 age range, this score has dropped to 3.31.



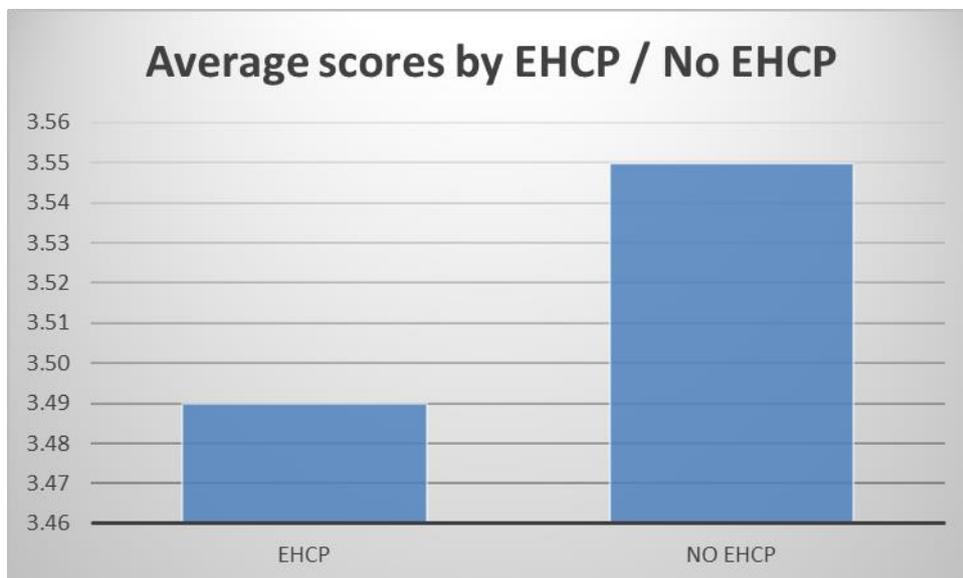
Comments reveal that the ambitions for children and young people with SEND are limited with many parents themselves having low aspirations and resigned to a poor quality of life for their children as they grow up.

The Borough should review its preparing for adulthood strategy in light of these findings to see what can be done to boost the opportunities, ambitions and outcomes for children and young people with SEND as they grow up.

2. There was no material difference between children and young people in mainstream and specialist settings and those with and without EHCPs



The average score for the 68 children in special schools was 3.53 compared to 3.54 for the 405 children in mainstream settings. This contradicts the anecdotal evidence that the parent carer forum hears – where typically there are a greater number of concerns and more troubling concerns from parents of children in mainstream settings.



The average score for the 241 children who had an EHCP was 3.49 compared to 3.55 for the 313 respondents who had no EHCP.

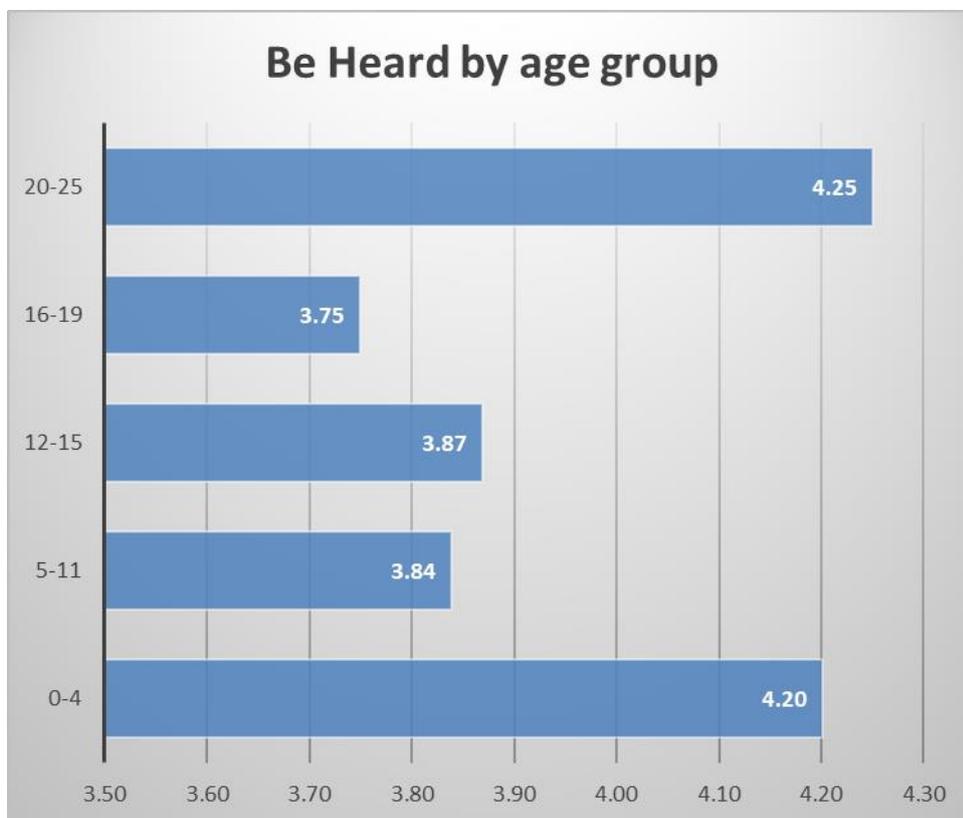
3. Families feel a lot more heard than they did two years ago but the scores for school age children are lagging behind those of pre-school and post-school age.

Since 2018, the be heard score has increased by a whole mark from 2.86 to 3.87.

This represents the work done in response to the written statement of action such as the coproduction charter and the regular interactions with parents by practitioners at formal and informal events.

Anecdotal evidence suggests that there is a correlation between the quality of coproduction with families and their satisfaction with the outcomes their children are achieving.

However, there is a marked difference in scores between those of school age and those who are pre and post school.



The local authority should continue to promote the principle of coproduction (including the coproduction charter) with schools in Bedford Borough to ensure that they are coproducing with families in the most effective way.

4. Getting access to the right support including EHCPs

Many comments still described the battles and challenges that parents felt they had in order to get the right educational support for children. Parents described not being listened to by professionals, being told that they were not eligible for support and long waits for help. The EHCP process attracted a number of negative comments with families feeling that it was inaccessible, hard to navigate and geared against them

5. There are concerns about the quality and quantity of educational provision for children and young people with ADHD and complex or high functioning ASD

Many of the comments in the be ambitious section highlight concerns parents have about the quality of provision for children with ADHD and with complex and high functioning autism. Parents felt that the understanding of ADHD was poor amongst teaching staff and SENCos. Many also highlighted the lack of places and specialist provision for those with complex and high functioning autism.

The local authority should explore additional ADHD awareness, support and skills training for teaching staff.

The development of the new specialist free school should include additional places and provision for children and young people with complex ASD.

6. Bullying is a real concern for families, particularly in mainstream schools

In comments, many parents reported that their child had been bullied. They were disappointed with the response from schools and school leaders and said that they did not feel that appropriate action was taken when they reported bullying or that their children were appropriately protected. This has clear implications for the wellbeing and outcomes for children including their mental health and their sense of belonging to a community.

BBPCF and the local authority should host a joint focus group or open meeting on the subject of bullying of children with SEND to ensure that they understand the experiences of families who have been bullied and the action that could be taken to address their issues.

7. Many families describe very lonely children and the need for more social and physical activities

Comments revealed some heart-breaking stories of loneliness – parents described children who had few or no friends who were desperate for more social interaction. Parents described a paucity of services that their children could access, that would welcome them and were able to meet their needs. As above, this clearly has an impact has clear impact on the wellbeing and outcomes for children including their mental health and their sense of belonging to a community.

We recommend that the local authority and CCG look at the social and physical activities that are available to children and young people with SEND. This should include the universal offer (e.g. more training for universal services providers on how they can welcome children with SEND) and commissioning of targeted services.

We recommend that the local authority and CCG organise focus groups to understand what is missing and how this can be commissioned.

8. There are very mixed experiences and opinions about mental health services

There was a huge disparity in comments about mental health services. There were many comments that were very complimentary describing effective early intervention, short wait times and satisfaction with services including CHUMs and CAMHS. However, just as many families reported long wait times, difficulties in accessing services, a lack of engagement from mental health services, and complex referral pathways.

9. Parents want more support to understanding their rights

There were many comments from parent-carers that they found the SEND system complex and confusing. Many stated that they did not know their rights and what they could reasonably expect as well as they thought they needed to. Many commented that they had taken it upon themselves to educate themselves about their rights whilst others said they looked to other parents to advise and inform them. Some complemented the work of the parent carer forum in helping develop their understanding.

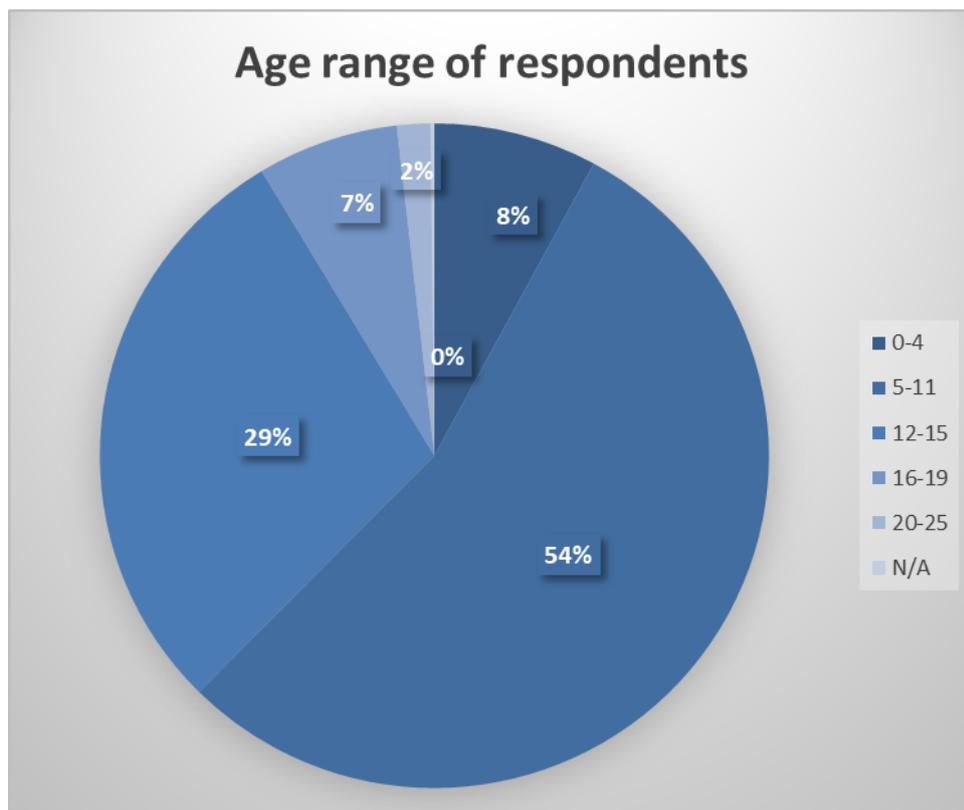
The local authority and CCG should continue to support the parent carer forum's work in informing parent carers about their rights in the SEND system – this may involve information and training on how to access services locally as well as the legal framework for SEND services.

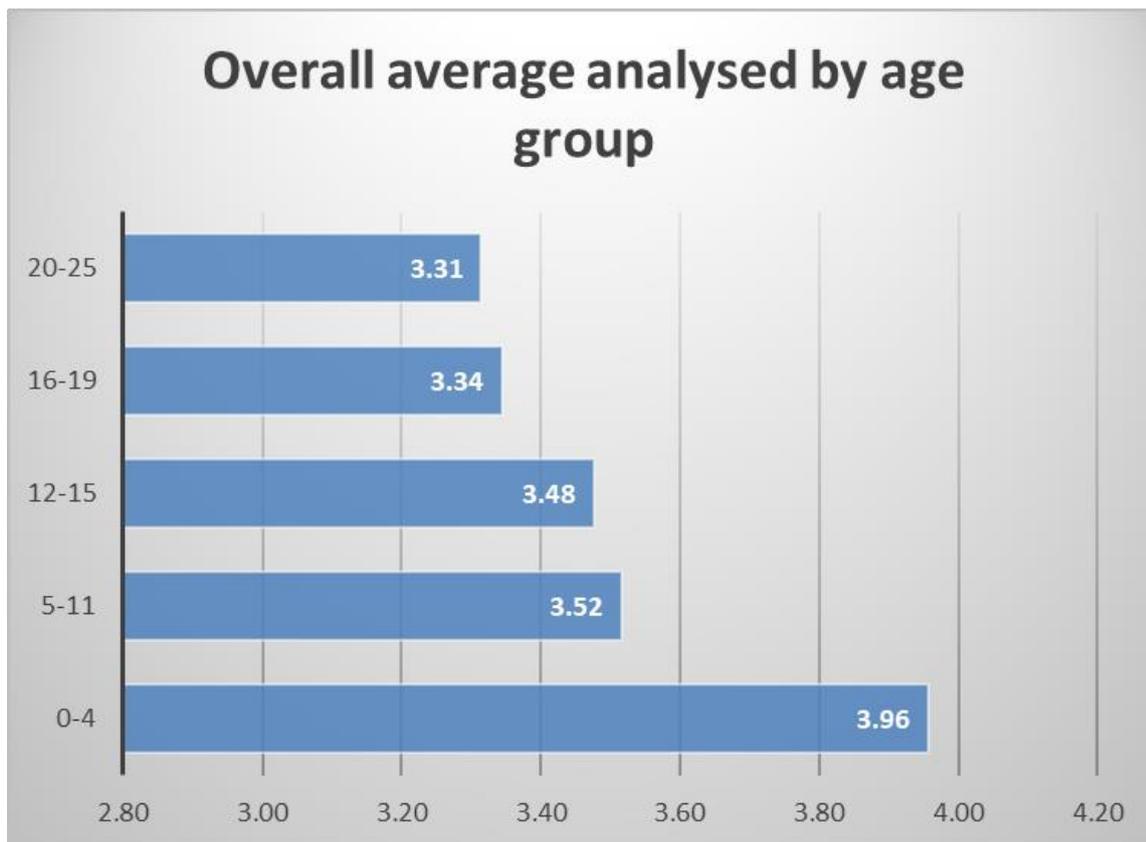
Analysis by age, setting and EHCP / no EHCP

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.

Age range	Number
0-4	44
5-11	303
12-15	161
16-19	38
20-25	9
N/A	1

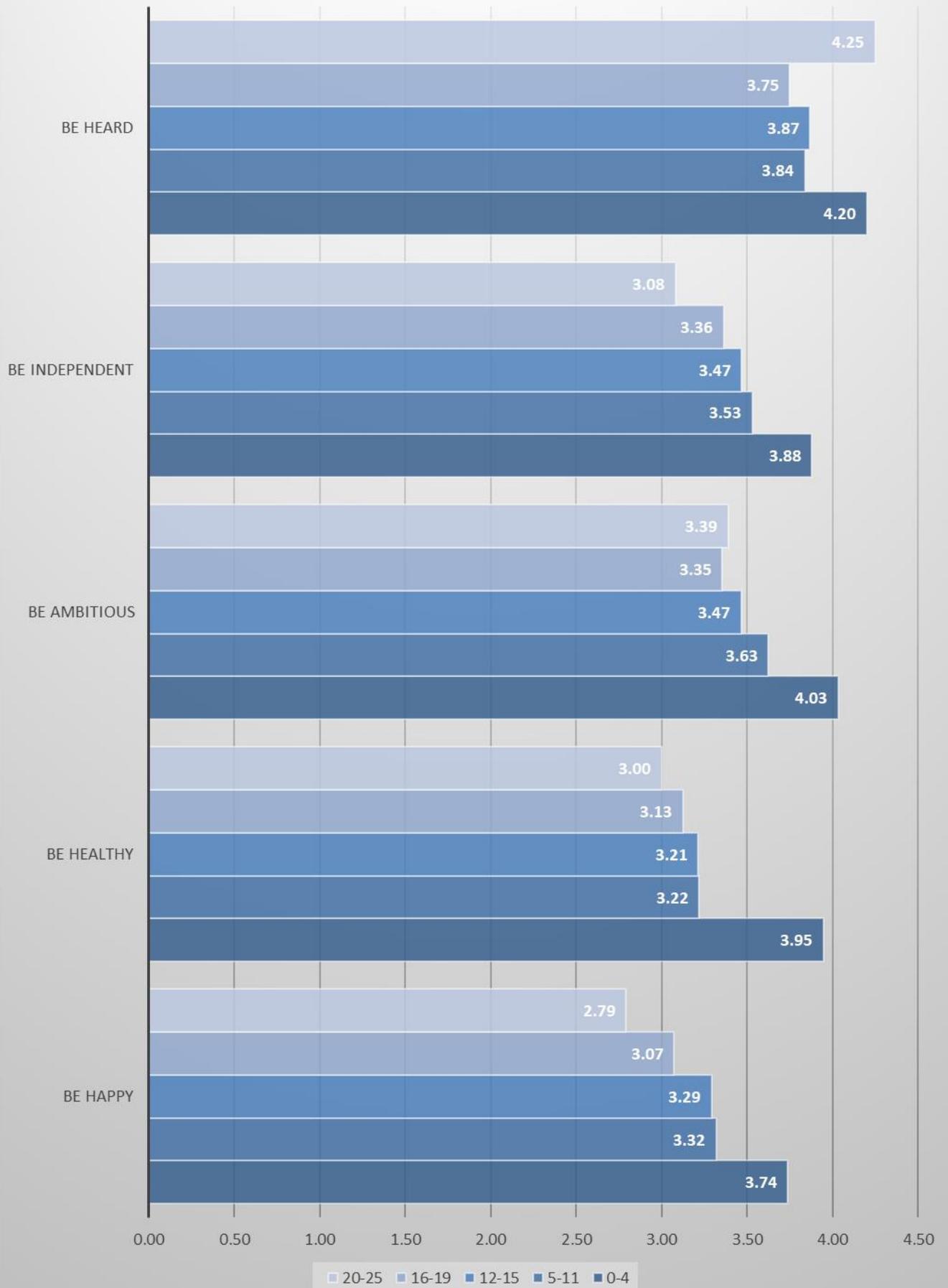




Analysis of the overall average mark by age shows a marked decline, the older our children and young people with SEND get. Whilst the average score was almost 4 for those of pre-school age, by the time they leave education it has dropped to 3.31.

When we look at averages across each outcome theme, we can see that there is a deterioration across all themes as children and young people get older. The exception to this is Be heard – pre school children and post education young people feel as they are heard significantly better than those of school / education age.

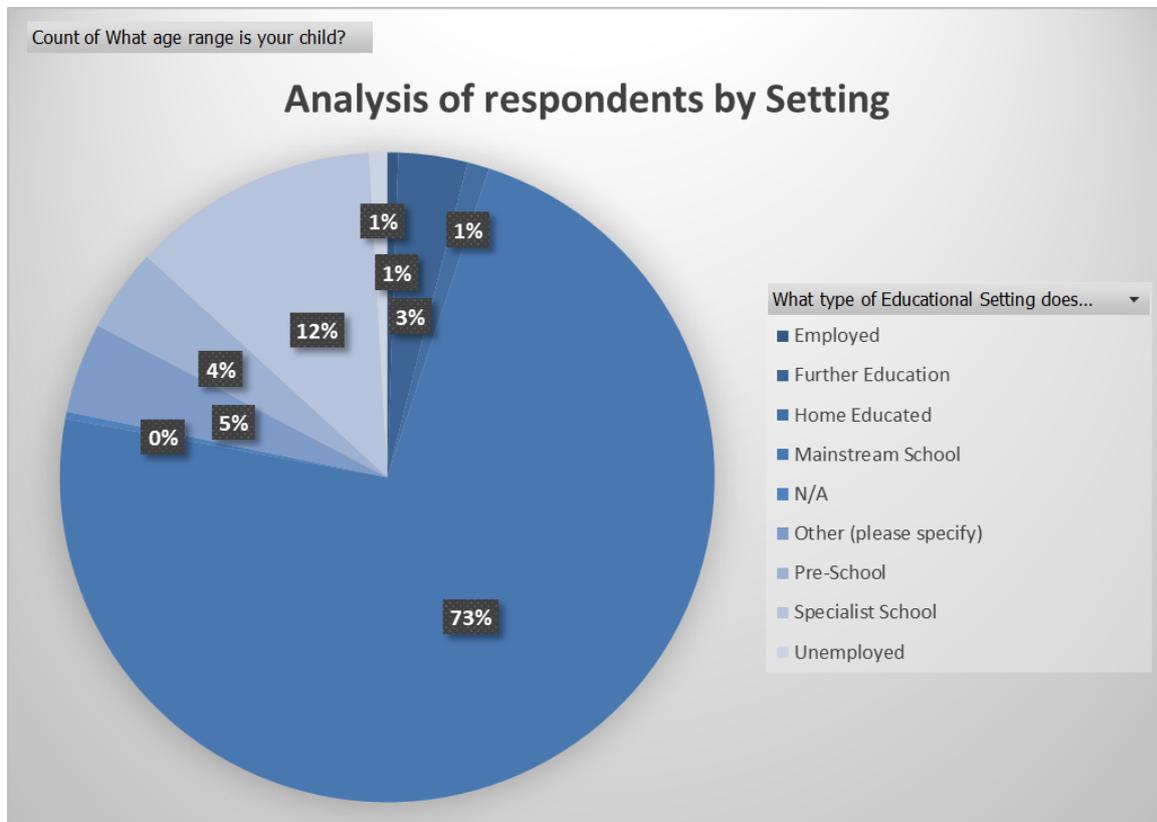
Analysis of outcomes by age group



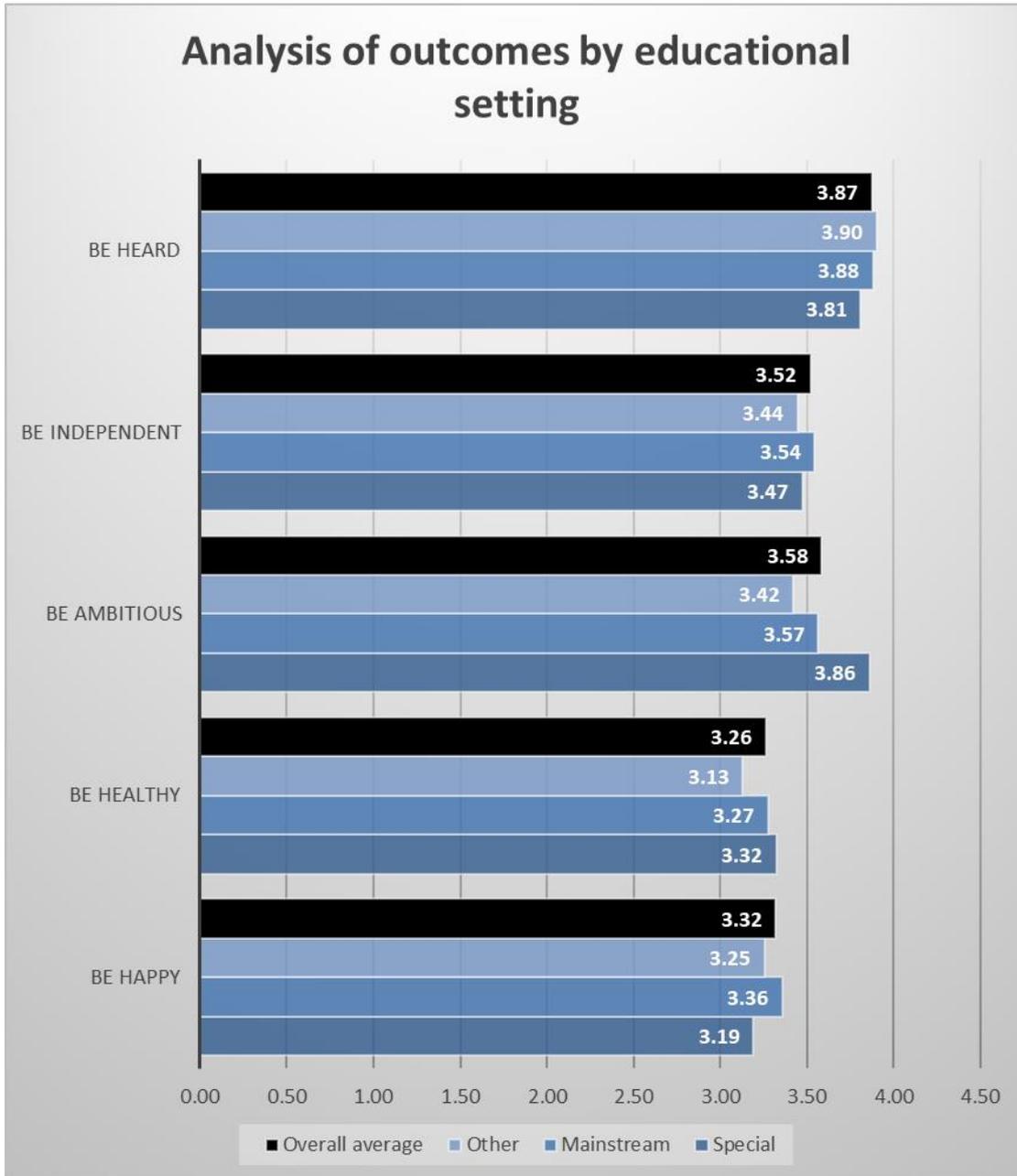
By setting

There were a range of responses from across different “settings” ranging from early years to employment and NEET. The majority of our respondents were of school age (73%)

Setting	Number
Employed	3
Further Education	19
Home Educated	6
Mainstream School	405
Other	27
Pre-School	23
Specialist School	68
Unemployed	5



There were sufficient respondents from mainstream and specialist educational settings to justify further analysis. However, we saw little significant variation in the differences in scores between children and young people in mainstream and specialist setting across any of the outcomes scores.



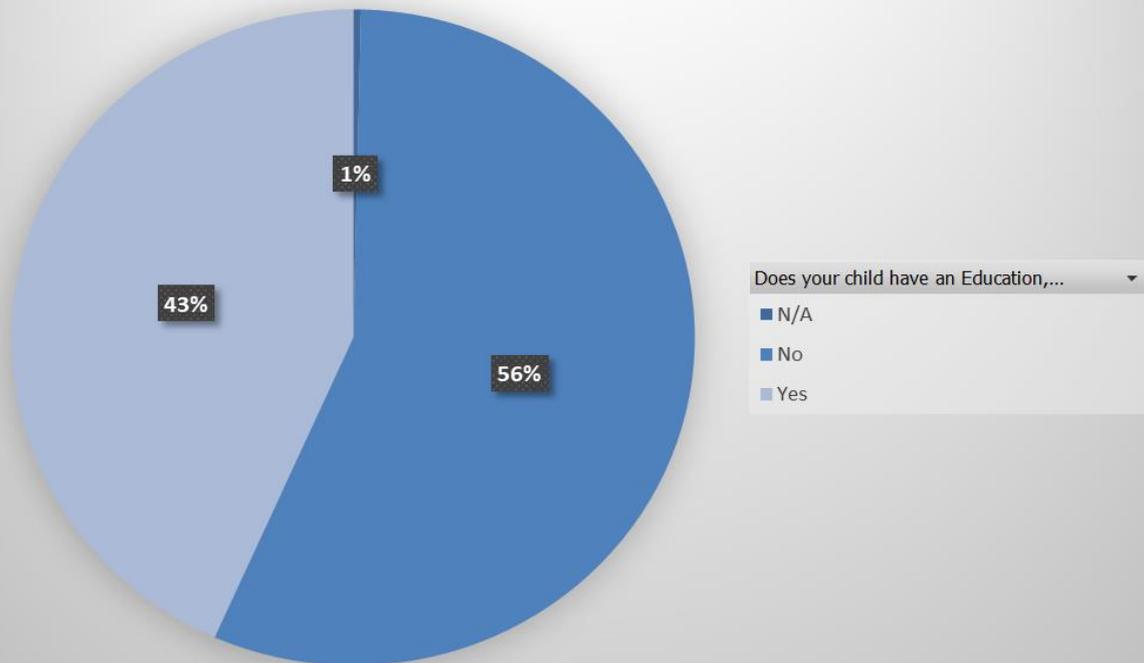
For details of each individual question, see Appendix 3.

By EHCP / no EHCP

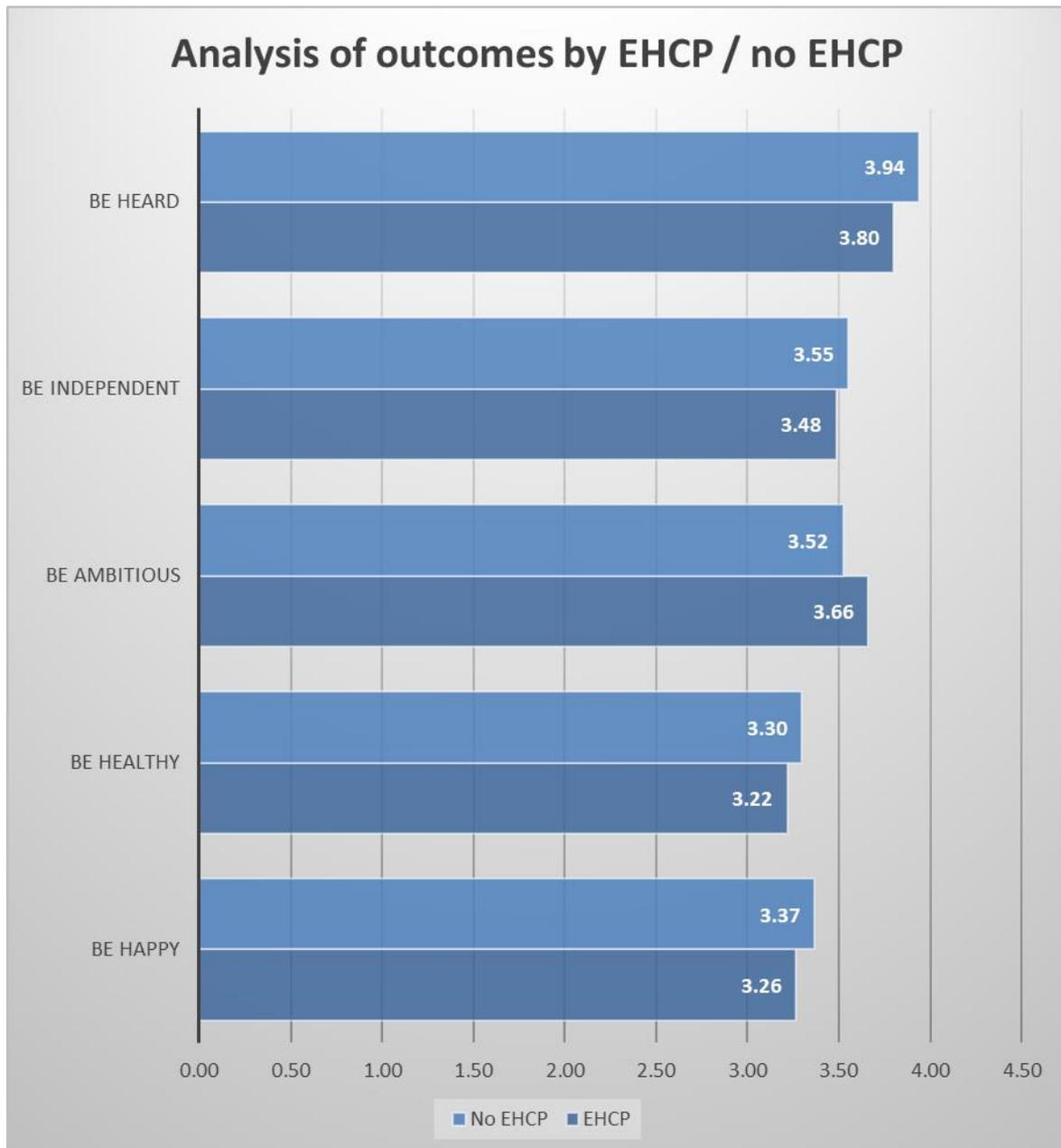
There is a good split of responses between those who have EHCPs and those who do not. With 43% having an EHCP and 56% not (1% responded N/A).

Count of What age range is your child?

Analysis of respondents by EHCP / No EHCP



Again, there was no significant variation in scores between those children and young people who have an EHCP and those who do not.

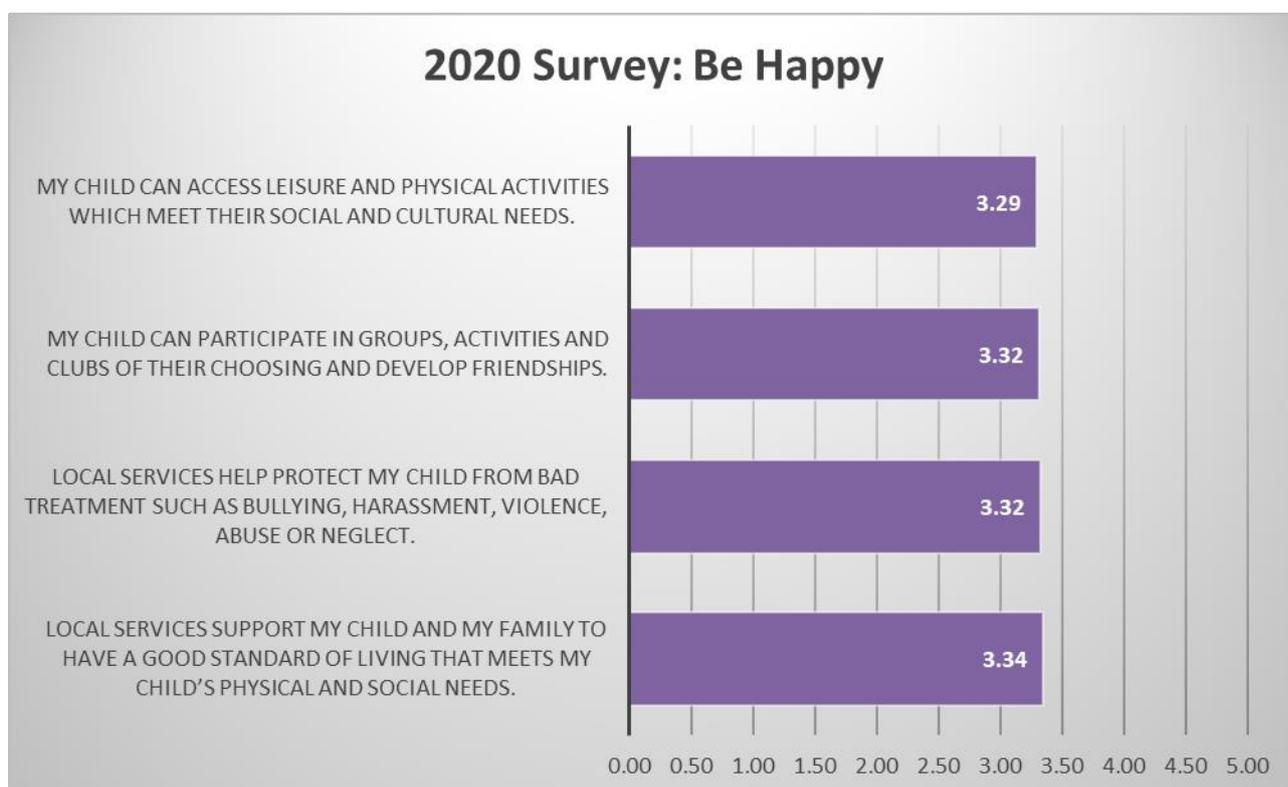


For a full analysis of EHCP / no EHCP responses by question see Appendix 3.

Be Happy

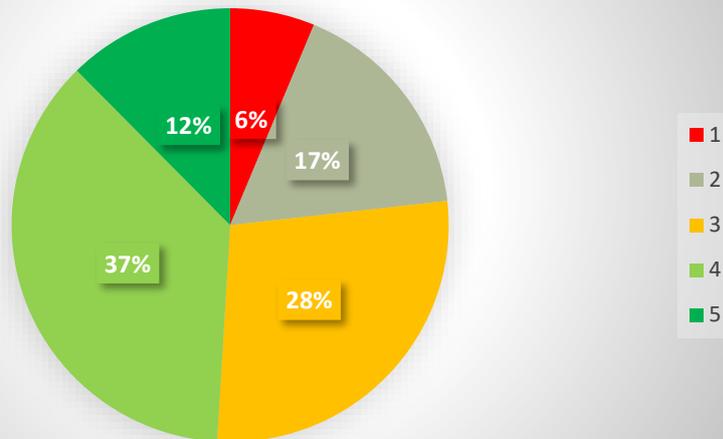
The average score for parent-carers in this category was 3.32. This represents a small decrease of 0.03 since last year.

However, this includes a clarification in the third question below which was previously phrased as: “Do you think your child is protected from bad treatment, violence, abuse and neglect?” Feedback from parents told us they were interpreting this question to mean were they (as parent carers) protecting their child from these harms which was not the intent of the question. If we exclude the impact of this change (i.e. take the average of the other 3 questions), then the average be happy score increases from 3.02 in 2019 to 3.32 in 2020. Both of these scores represent an improvement from our 2018 survey when this scored 2.87 – a 0.49 increase over 2 years



There has been a consistent improvement across all questions year on year with the biggest single jump coming in the final question around the standard of living which increased by 0.41.

Be Happy: Distribution of scores

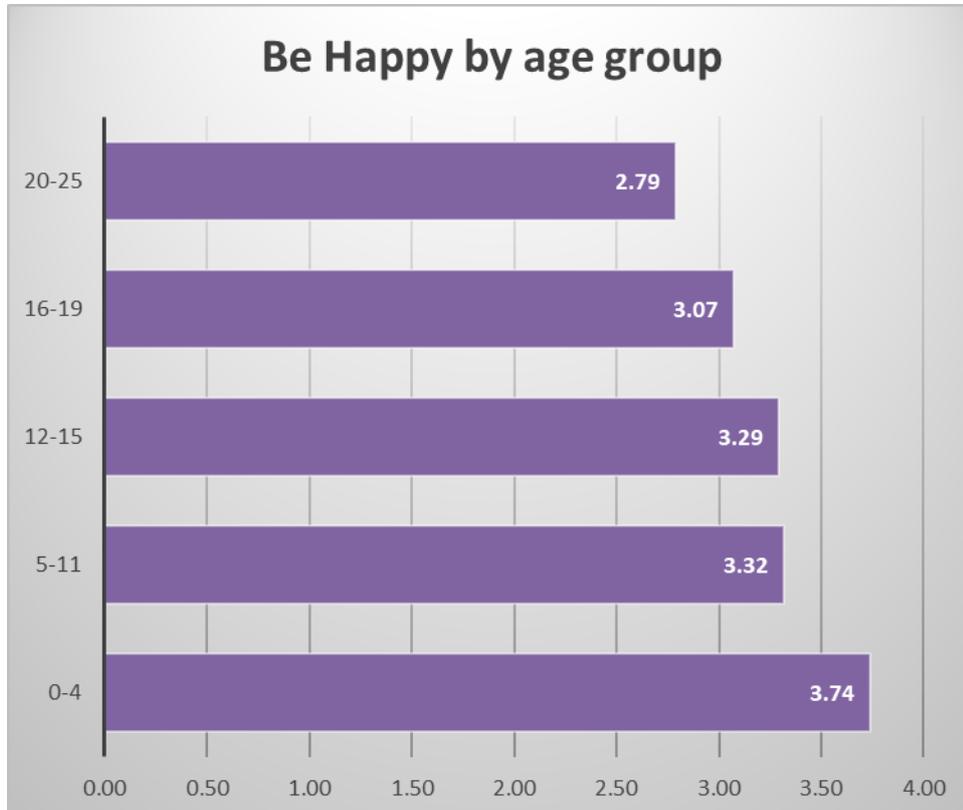


In this year's survey 49% of responses were positive and 23% were negative

This is an improvement from the 2019 results in which 47% of responses were positive and 28% were negative.

The average Be Happy score by age group shows that the older that children and young people with SEND get, the less happy they are with the fall of almost a whole mark between the 0-5 and 20-25 age groups:

Be Happy by age group



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

Time and time again, parents mentioned bullying. This is perhaps the single theme that received the most comments in our survey. The majority of bullying was happening in schools and in mainstream schools. Families described a lack of support, understanding and action from school teachers and leaders.

"My child need to be with similar peers, he is pointed at, mocked because he is in the wrong environment and school. Teacher are negative because of the pressure of having my child in a "normal" classroom"

"my son has been the victim of bullying and violence in school"

"He is told he is too sensitive or if the teacher didn't see it didn't happen"

"We have had a lot of issues around bullying that do not get dealt with by schools or further afield."

"Bullying at school was one reason we began home educating."

"My child has been bullied by parents of a school, so I had to move him to another school, due to lack of the Headteacher supporting my child properly."

"She's been hit, kicked in the back, coat ripped, school tie stolen, school bag ripped and more."

"In the third year of fighting for help to prevent my 9 year old child being bullied in school. The bullying has resulted in 2 hospital admissions."

Many families tell us that there are not enough social and physical activities for their children.

The comments frequently pointed out that there were very few or no social and physical activities that their child could easily access. Parents also raised concerns that universal services were not welcoming and did not make reasonable adjustments.

"I have increasingly found it difficult to find recreational activities for my child who has high anxiety. Been asking for help for 10 years. Beginning to think we're running out of time."

"There is not much around socially for kids to meet up"

"There is not a lot for my child to do either physically nor socially"

"No local groups available"

"My son has struggled to be part of groups as staff are unable to understand and meet his needs. I have had to take him out of swimming lessons"

"My son cannot do school sports activities as they cannot meet his needs so he is excluded"

"I haven't found any groups to take XXX in 11 years."

"Reasonable adjustments are not made often."

Many families do not know where to find more information about what is available for their children.

A large number of comments asked for better information about services.

"I'm not aware of many local services"

"There is no information about this that is forthcoming if there is anything at all."

"It's very hard to become aware of what services are available and then a challenge to access them."

There was an understanding of the impact of covid 19 on services

There were many comments about services not being available at the time of the survey. The closure of many facilities, clubs and activities that SEND families access is being keenly felt. However, this did not play through into the scoring – almost all of the comments that referenced Covid related closures gave a mark of 3, suggesting acceptance and understanding of the situation.

"Current conditions mean that all of these things have been cancelled."

"Covid has stopped all of this and causing detriment to mental health of many children"

"COVID-19 has meant my son cannot access any of the support he was previously accessing."

"Covid has stopped most things."

A large number of comments described very lonely children.

"There is never enough places/groups for my child to develop friendships"

"My child struggles to do this and particularly struggles to make friendships."

"Struggles with making friends. Is very much a loner."

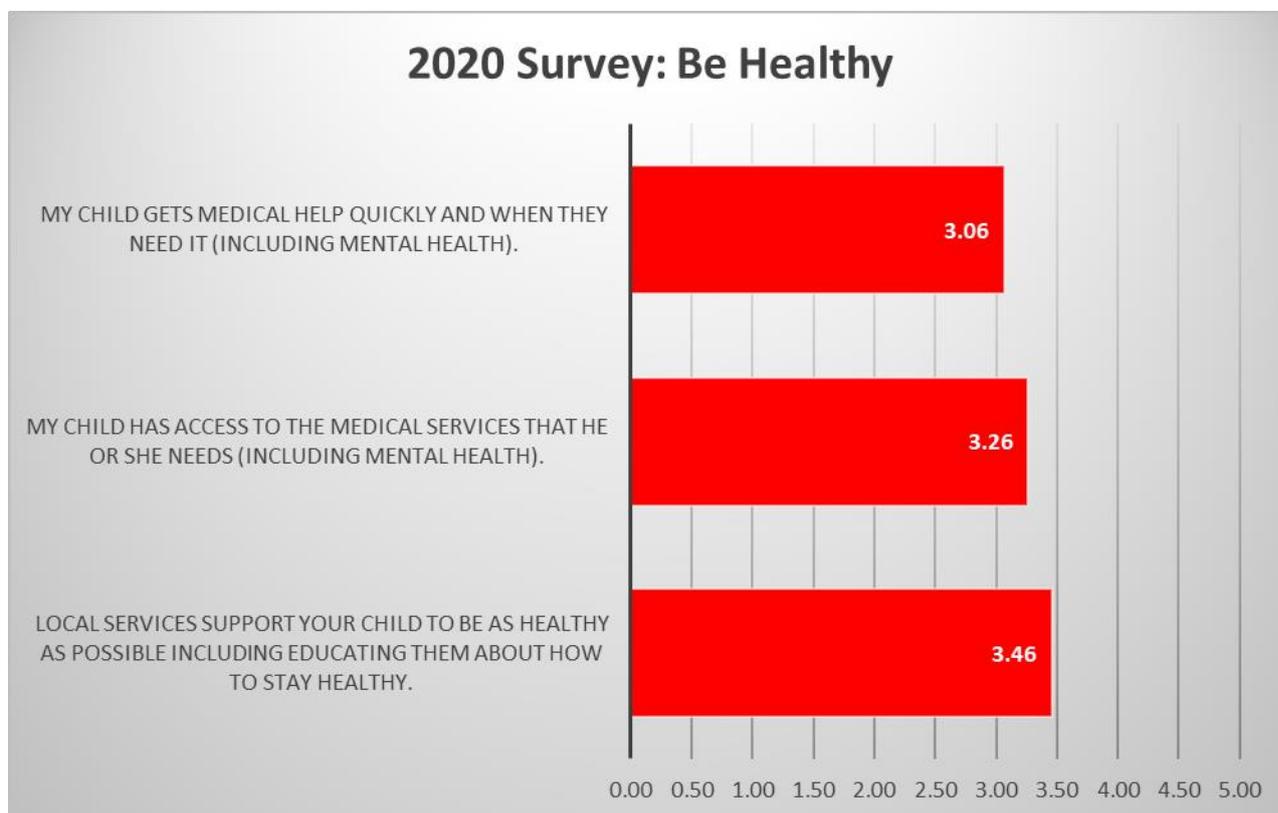
"Daughter struggles socially"

"My son does not have friend."

"Clubs won't accept any daughter or ask her to leave. She is desperate for a friend who is a girl that understands her."

Be Healthy

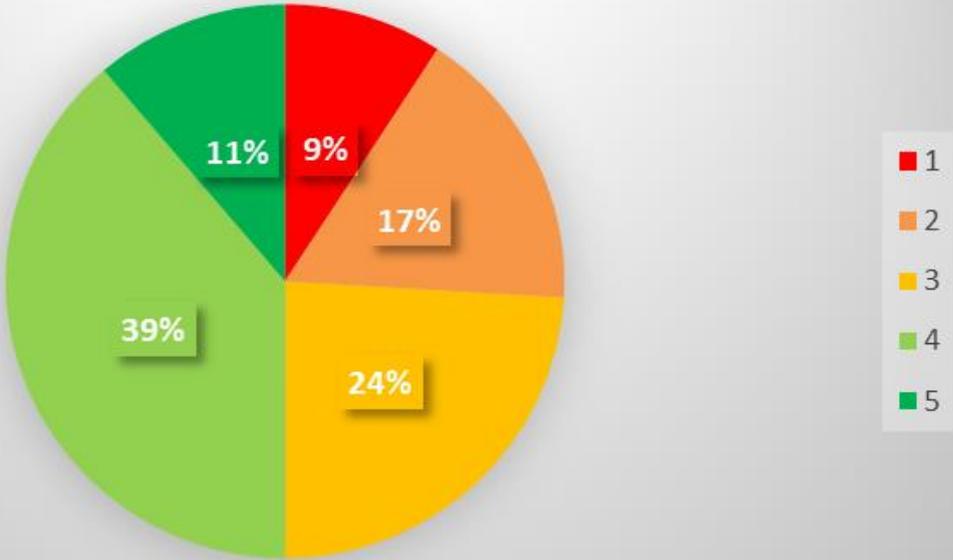
The average score for parent-carers in this category was 3.26. This is an improvement of 0.31 over the score in 2019.



There has been a steady improvement in all scores, in particular the first two questions above which improved by 0.56 and 0.46 respectively. The last question only improved slightly year on year by 0.09.

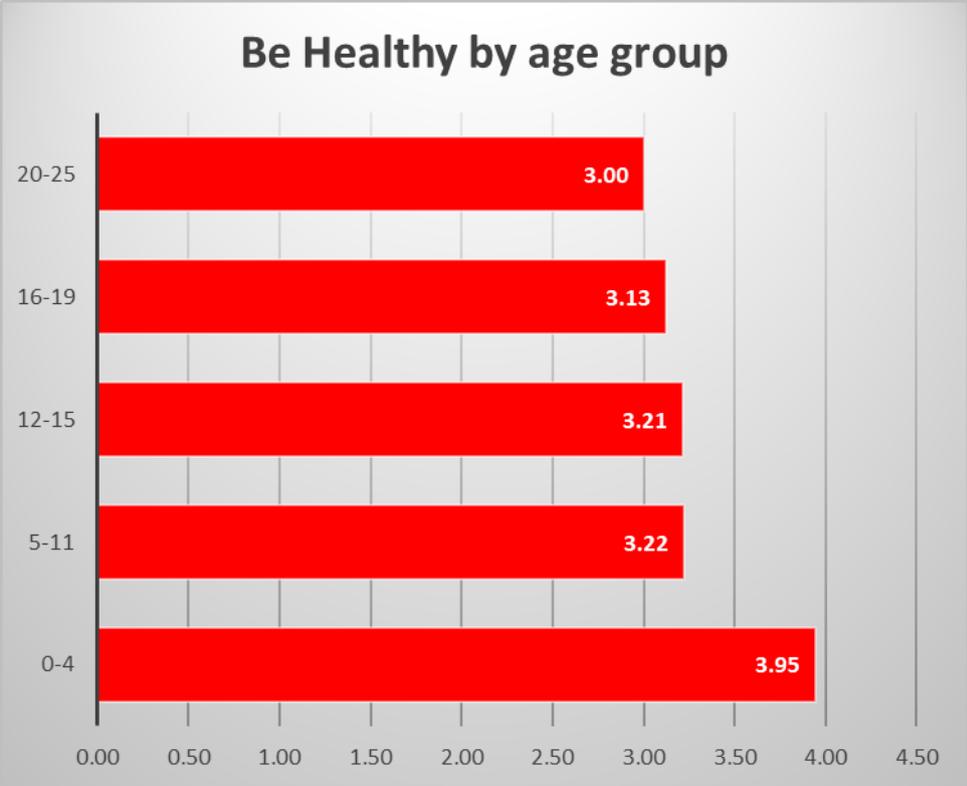
In this year's survey 50% of responses were positive (marked 4 or 5) and 26% of responses were negative. This is an improvement on last year when 36% were positive and 39% were negative.

Be Healthy: Distribution of scores



The age profile of scores shows that parent carers are less satisfied with the quality of health services, the older their children get. The average score of the 0-4 age group is 3.95 falling to 3.00 for 20-25 age group.

Be Healthy by age group



There was a lot of support for the work that schools do in educating children and young people to be healthy

Schools received a lot of positive comments about the work they do to support the physical health of children ranging from education about a healthy diet, the physical education to cooking classes.

“Always cooking at school.”

“This is only relevant to school.. my son has well-being sessions and lots of physical exercise and access to forest school.”

Mental health services split opinion.

There were many comments that were very positive about the CHUMS and CAMHS but there were just as many that were very critical. The key critical themes broke into three broad categories – that services were difficult to access and the CYP needed to be at breaking point before help was available, the waiting times were too long and that they did not help child with ASC.

A selection of the positive comments

“Have used CAMHS, quick response time and while they couldn’t help too much with the issue we were dealing with they were a fantastic support..”

“We were referred to chums and they were amazing.”

“CAMH- but it took a complete mental break down, self harming and severe hallucinations with admittance to hospital before FINALLY being believed on how severe my child was. My child had to fall too self humiliating and heartbreaking mentally ill levels before correct support was deemed accessible - time wise two and a half years of refused referrals. To have to wait for your child to physically want to die, before help was given and it took three years from their childhood so far. When it didn’t need to get so far. But once assigned a team at CAMH they have been excellent.”

There were also many more comments that were not descriptive but simply stated “CAMHS” or “CHUMS” next to a 4 or 5 mark

A selection of the negative comments

“Camhs will not help asc children”

“CAMHS not accessible as too busy.”

“CAMHS refuse to see anyone that isn't trying to kill themselves.”

“We were referred to CAMHS when he was suicidal. I was trained and told we were on a two day priority, after six weeks I had to pull strings at work to get him an appointment. The nurse then left without writing up her notes so nothing was done. Just given up.”

“Let down by CAMHS when daughter threatened to self harm, too much red tape even to get to triage stage. In a situation like that you just want advice and to talk to someone not be told you have to jump through several hoops first.”

“Ridiculous trying to access CAMHS.”

“We cannot access Camhs who tell us that my child's behaviour (running away, risk taking, threats to self harm or commit suicide) are solely behavioural due to his ADHD. There is no recognition that he may also have anxiety and depression and need skilled professional help. CDC have told us that these behaviours are best dealt with by CAMHS so we fall through the gaps.”

There were a lot of comments about long waits for services, most notably paediatricians

“Paediatrician services are slow you wait months and your not contacted they wait for you to book the appointment. Had to also wait 5 months for blood test results had to chase it up.”

“My last appointment with the Paediatrician was over a ago and we are supposed to attend 6 monthly reviews. We have no appointment booked in.”

“Was due an appointment with his paediatrician months ago, it was cancelled and I am still waiting a new appointment, I have asked the school nurses about it twice now.”

“Last appointment was supposed to be a 26 week follow up but took 18 months.”

There was also a consistent theme of comments about getting through to services, referral pathways being confusing and having to navigate a complex system and finding the “right door” before help was delivered.

“We see lots of poster and pathway but do they work in practice, no. please train the receptionist to be kind.”

“It's an absolute fight for anything. Even calling our GP last week took 149 attempts (I have the screenshot of the call log to prove this). “

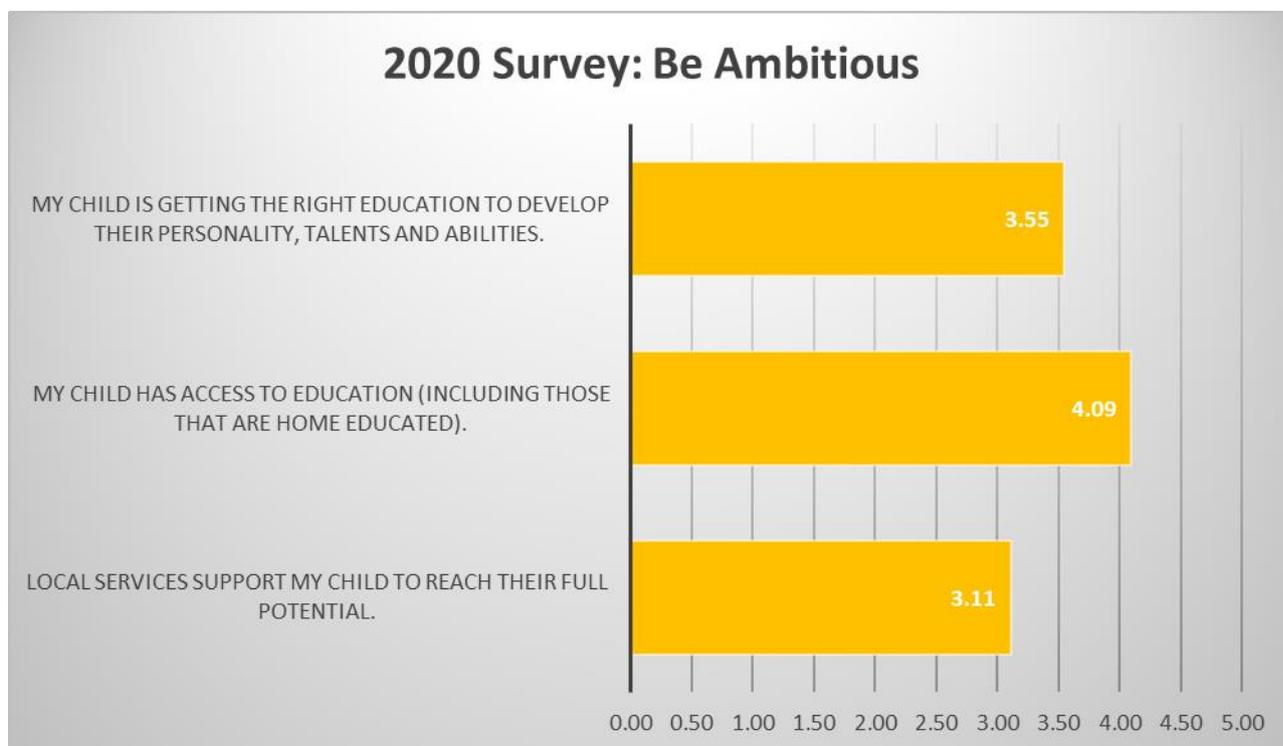
“Waited for weeks even though we were in crisis and then was passes from service to service and eventually no help.”

“I had to wait three months for an appointment at paediatrics and the. It got cancelled. I was then referred to the child development centre and they refused the referral.”

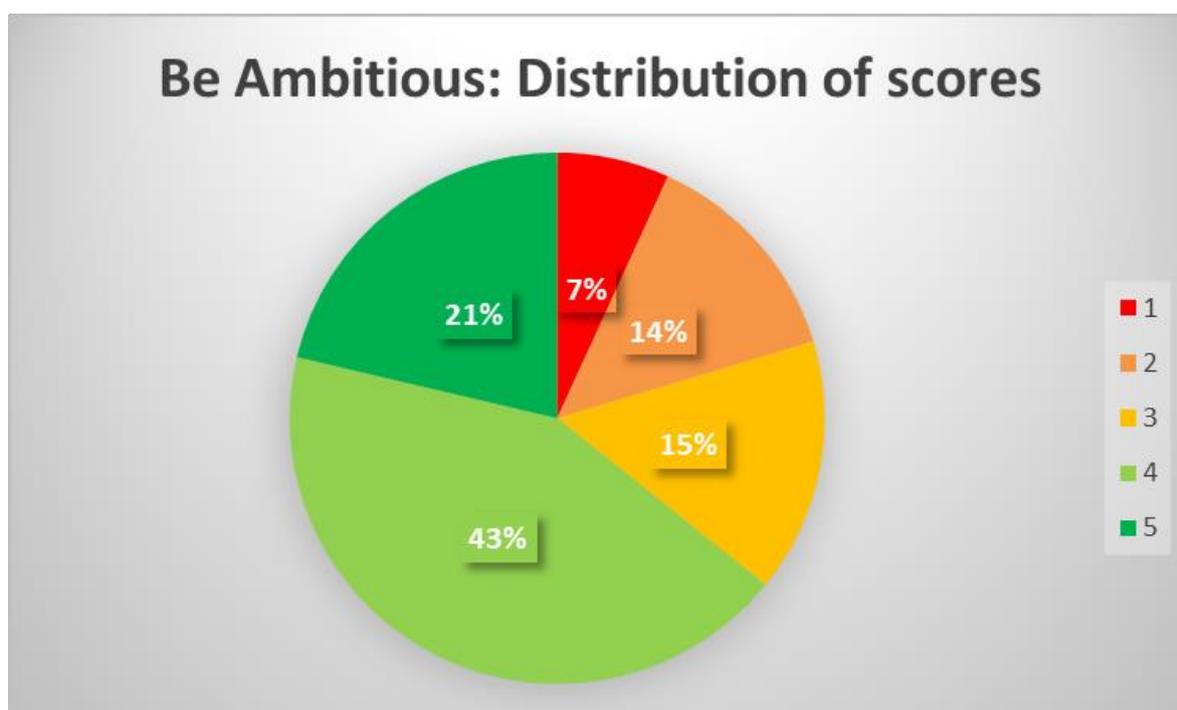
“Referrals can take years to get answered, and then potentially rejected because the process wasn't followed/was unknown the parent and sometimes even the referrer.”

Be Ambitious

The average score for parent-carers in this category was 3.58. In 2019 the average score was 3.30. This represents a 0.28 increase from the previous year.

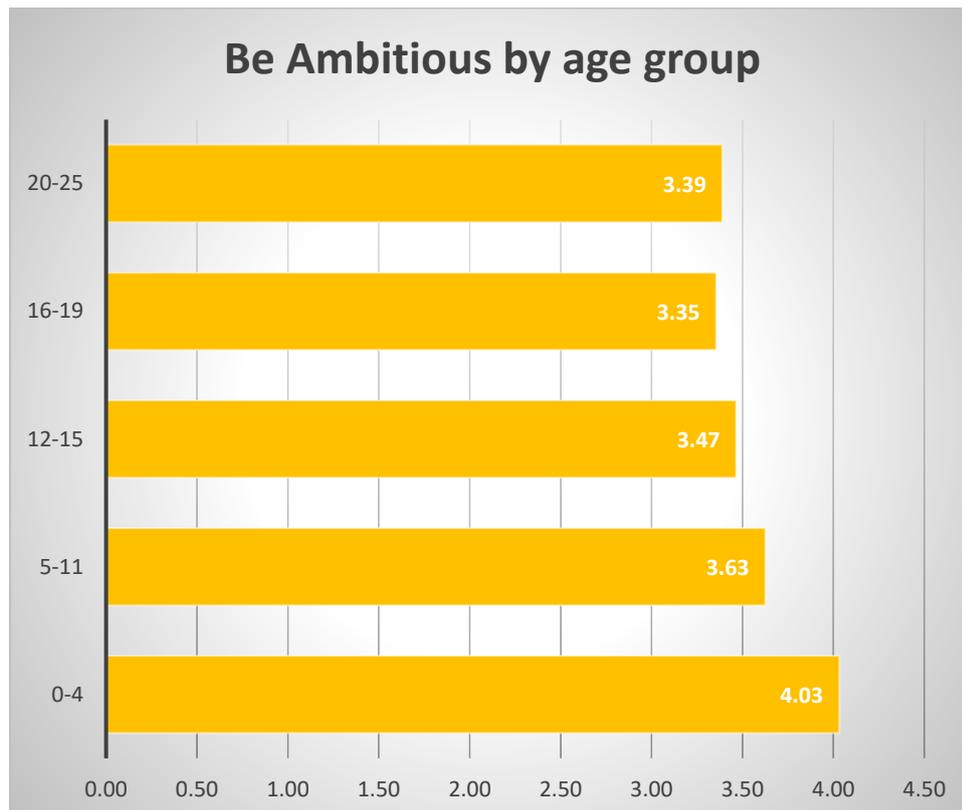


The overall distribution of scores was:



In this year's survey 64% of all responses were positive (grades 4 or 5) and 23% were negative (grades 1 or 2) . This represents an improvement of last year's scores when 61% of responses were positive and 17% were negative.

There was some variation in the scores based on ages The highest scores were for pre-school children and primary school age children. The scores increased again when young people reached the age 20-25.



Getting access to the right support including EHCPs

Many comments still described the battles and challenges that parents felt they had in order to get the right educational support for children. Parents described not being listened to by professionals, being told that they were not eligible for support and long waits for help. The EHCP process attracted a number of negative comments with families feeling that it was inaccessible, hard to navigate and geared against them.

“The gap between my child and their peers has continued to widen now up to 4 yrs in some areas due to the lack of support and despite the school and our best efforts.”

“We have been actively discouraged by one school from seeking support for our son, told that no one would see him, that he would never get an EHCP etc and have had to fight for every provision.”

“I have been asking for specialised support for a long time, it’s always a battle. We are in the process of applying for an EHCP.”

“My child was refused another EHCP last academic year based on her school attainment. That same school did not enter her for any GCSE's . I had to fight and threaten with legal action to get her into sixth form.”

“Absolutely not! Denying my child's needs when they're not even considering assessing them will not help him reach his full potential.”

“Cannot access support as blocked due to passing buck nobody doing referrals. Parents can't refer, health visitor can't refer, nursery don't know how so stuck.”

“My son has needed a EHCP for years and it just gets putting back each time so he is not supported.”

Education for complex / high functioning ASC and ADHD

We had many comments from three groups of parent – carers – those whose children had either complex autism, those with high functioning autism and those with ADHD. All three felt that there was not enough specialist knowledge, skills or provision and that their education was being compromised as a result.

“No opportunities for children with higher functioning autism “

“Unaware of local services for additional needs for neuro diverse children.”

“Lessons are taught and a neuro diverse student is expected to conform to those standards and be able to adapt/ learn in a set way.”

“Staff in mainstream education are not trained in supporting pupils with ADHD and ASD leaving a huge gap in provision.”

“Services don't know enough about ADHD to support it.”

“More training for teachers in helping a child with ADHD is needed.”

“I believe that some teachers either lack training in how to help a child with ADHD reach their full potential or are just not interested.”

“I feel he has been palmed off as a naughty, disobedient child rather than having the right support for a child with ADHD. More training needs to be given to teachers on how to develop those with additional needs.”

Praise for schools and educational settings

There were also many comments that praised the school settings that their children were in.

“The SENCO at my child's school has been instrumental in ensuring my child gets the support and education he needs.”

“Every day I am so proud about what he tells about school, what they been doing and how he feels.”

“Couldn't ask for more.”

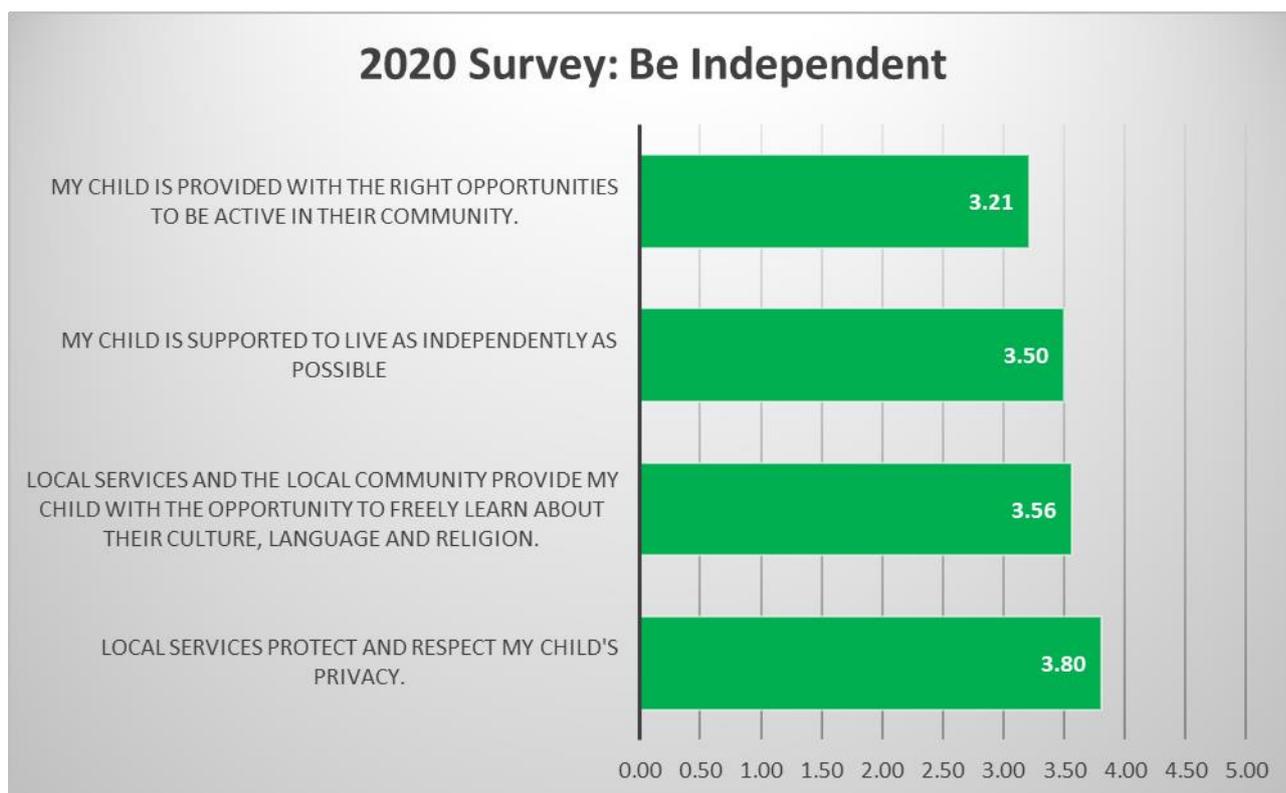
“School supports my daughter well.”

“The school have been amazing.”

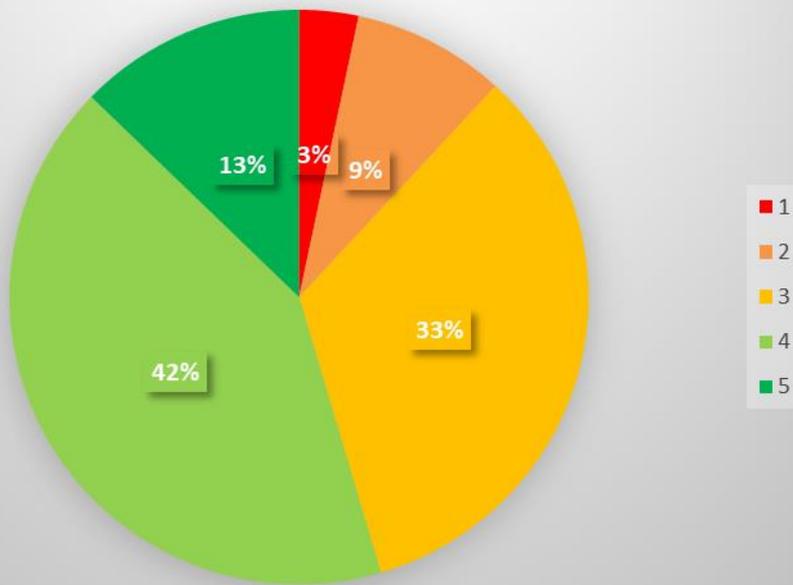
*“My 12 year old again is really supported in his learning even when he finds it tough in class.
My Child is in an amazing setting now and absolutely loves going to school.”*

Be independent

The average score for parent-carers in this category was 3.52. This is a fall from 3.82 last year. However, the two scores are not directly comparable because one question was split into two to clarify what was being asked and the wording of the questions was changed slightly to reflect that the influence of local services on independence was being measured rather than the role of family.



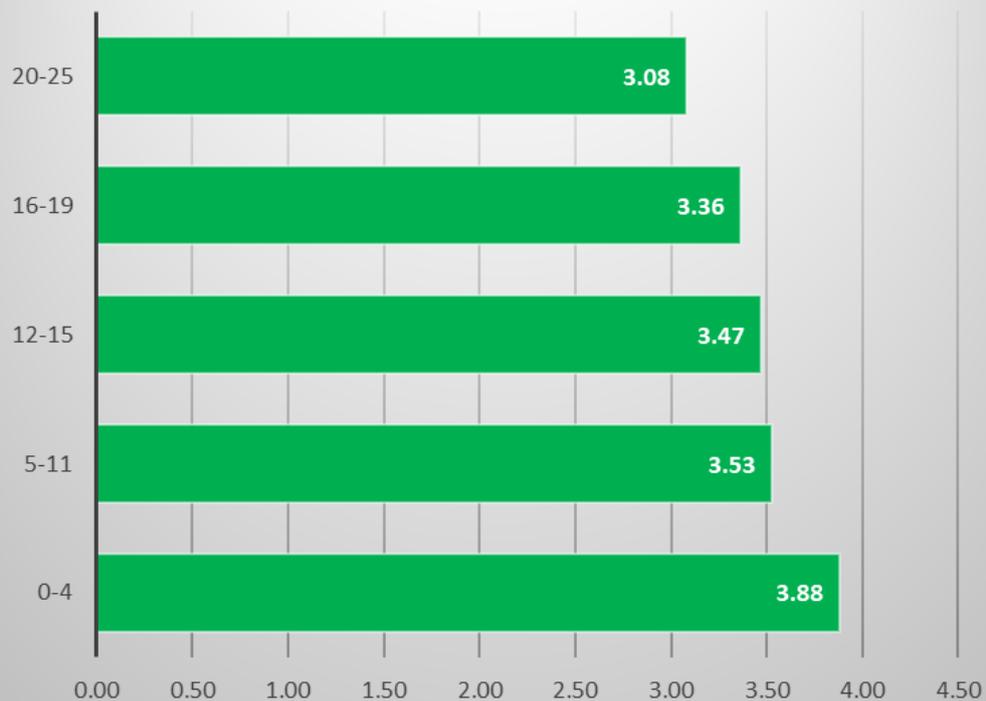
Be Independent: Distribution of scores



In this year's survey 55% of responses were positive and 12% negative. Last year 66% of responses were positive and 16% were negative.

In line with other outcomes, we see a deterioration in scores, the older that children and young people get with the average score dropping from 3.88 for the 0-4 age group to 3.08 for the 20-25s.

Be Independent by age group



Many families felt that the support and services to help their children get involved in the community were missing.

“What social opportunities do children with additional needs really have outside of school?”

“There are no opportunities available.”

“I provide opportunities for him, not local services.”

“Nothing for older children with mainstream SEND understanding.”

“There are very few opportunities I am aware of for my son to attend events in the local community due to his needs. “

“Minimal groups and opportunities in local area.”

“Difficult to access some community groups as they do not have the staff or training to support him.”

“There is no or very little choice for community groups or peer group social activity - especially post 18.”

“There is little available most opportunities are for Luton or central Bedfordshire children.”

Families were often very pessimistic about the future for their young people as they grow up.

Many reported that there were few if any opportunities for their children to meaningfully progress outside of education. Some went further and believed it was unrealistic to have any ambitions for their young people.

“I have little hope for their future as adults.”

“There is no opportunity for my child to live independently to a standard that is acceptable or caters for his needs.”

“She is in the age range for transitioning to adulthood, she would never cope living independent unless support is put in place to enable her to do this.”

“Services truly need to help support independents and see the benefits of this.”

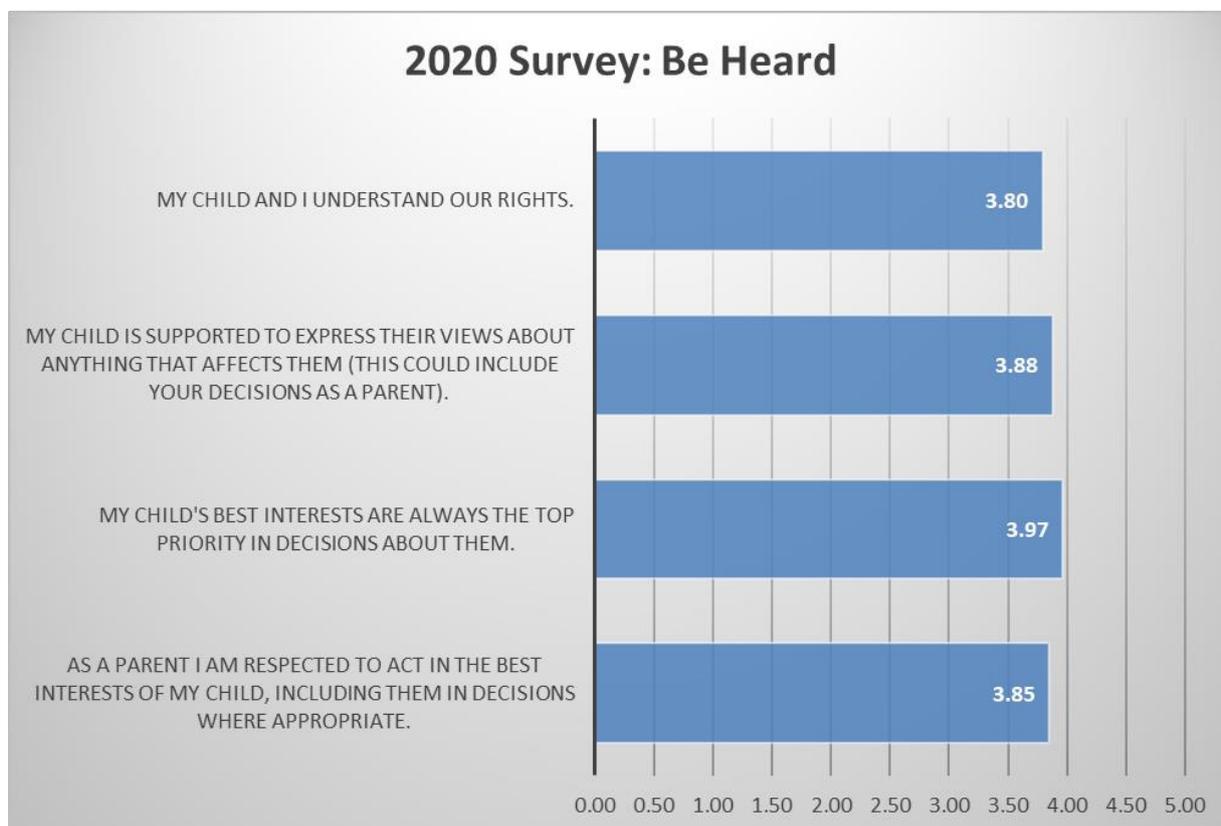
“My child can’t live independently compared to other children his age.”

“My sons disability is severe, he will never have any independence.”

“Irrelevant, she will not live independently.”

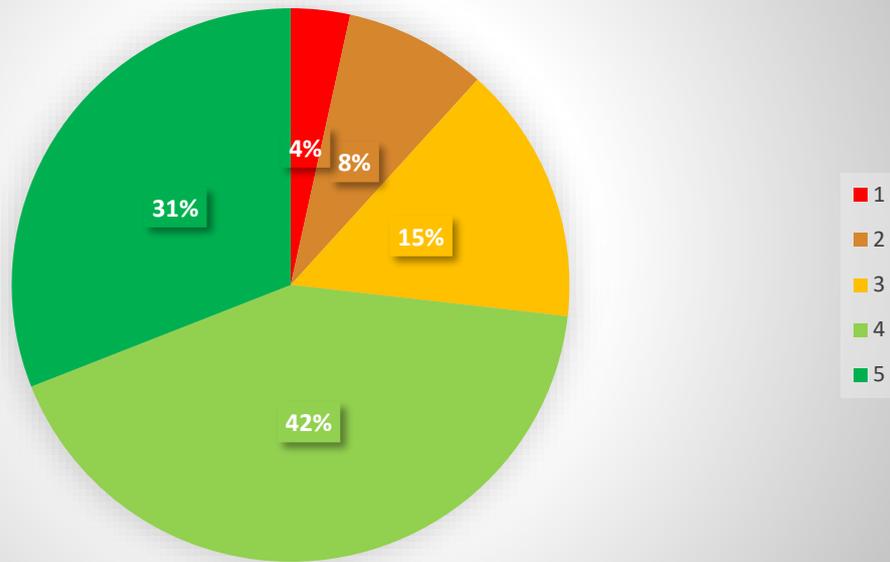
Be Heard

The average score for parent-carers in this category was 3.87. This represents a significant increase in scores since 2019 when the average mark was 3.40 which in turn had increased from 2.86 in 2018..



In 2018, the be heard score of 2.86 was the lowest average mark across all of the outcomes. The score in 2020 of 3.82 represents an increase of a whole mark over two years and the be heard average score is now the highest average outcome score.

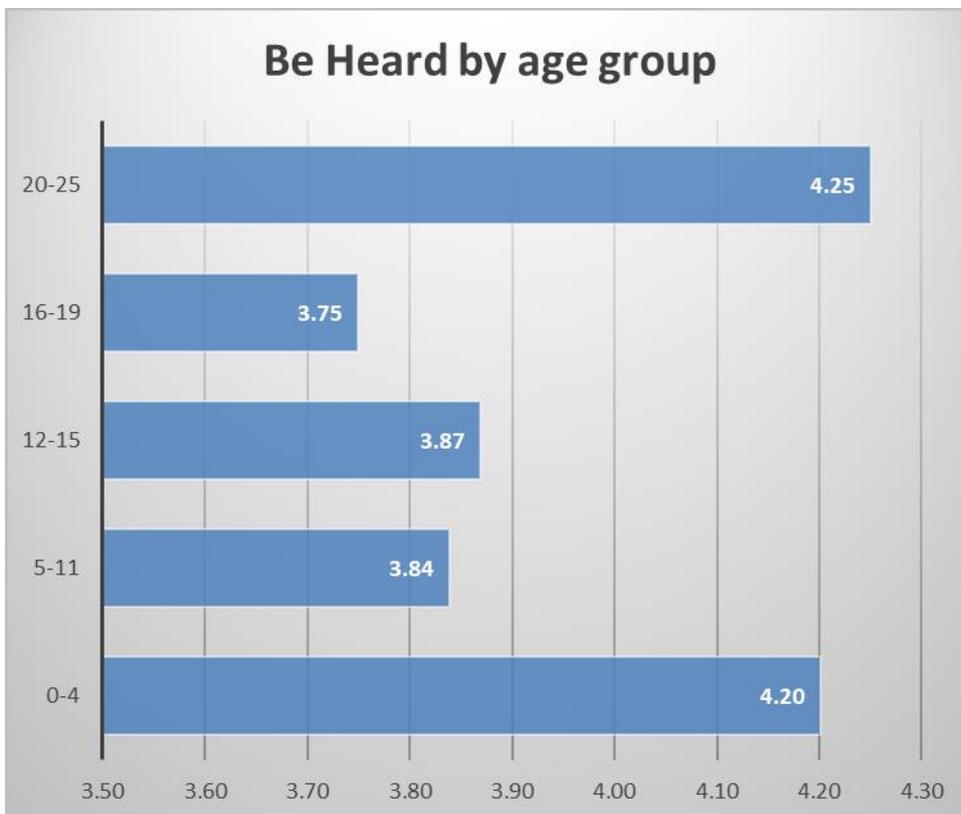
Be Heard: Distribution of scores



In this year's survey 73% (2019: 54%) of responses were positive and 12% (26%) were negative. This is further improvement from the 2018 results in which 34% of responses were positive and 44% were negative.

The age profile of the scores is significant:

Be Heard by age group



Parents feel as if they are better listened to in pre and post-school years. During school years they clearly feel that their opinions and those of their children are less significant.

Despite the improvements in scores there is a significant group of parents who do not believe they are listened to

The local area must ensure that it listens to all parents and young people – their voice is at the heart of the SEND legislation.

“Professionals never believe parents”

“It feels like I am expecting to know everything but not make any decision about my child.”

“No-one seems to listen to me or her and a lot of the issues could be dealt with and some situations could have been avoided if I was listened to over 2 years ago!!!!”

“Excluded from annual reviews. Views ignored.”

“I feel we have / are not being listened to in meetings with professionals when we discuss our child.”

“Yet we know them best and see them the most. We then don't get support we feel she needs because our views and decisions are listened to.”

“Parent treated unequally in conversations and decisions about child. “

Many families believe that resources are more important than the best interests of their child when making decisions about them

“I feel that the services we access always have another agenda; whether it be their lack of funding, strict procedures that the parent isn't aware of or are simply overwhelmed so they can't support every child in the way they would like.”

“Mostly about resource. “

“It is always about capacity, costs and if there is a person in the post.”

“Local services put their interests above the child.”

“Absolutely not. The LA decision make for their best interests. Not the child. I'm talking about my experience.”

“The top priority is always funding or resources available.”

“Budget budget, budget.”

Advocacy is very important to make sure that the voice of children is heard in decisions about them. Some parents feel that more support is needed to overcome the barriers that stop their child being heard.

"She feels no-one listens to her or supports her."

"No advocate available to her. Have requested this though."

"She is not able to express herself at school due to her anxiety."

"Again depends who is there."

"Attempts are made but for my son who has speech and language difficulties I think people give up too easily."

"He is non verbal."

Many parents reported that they did not adequately understand their rights and were asking for me help with this. Many also asked for help in ensuring that their young people understood their rights.

"I am learning, slowly but she has no idea what her rights are."

"Our son has little understanding."

"I am not very knowledgeable with this but still learning."

"Seems to be only when we specifically ask and only about the 'one' we mention."

"I don't have enough knowledge."

"The whole system is a minefield. We do not understand fully."

"I'm learning but don't believe we have full information/understanding."

"I'm learning slowly but don't fully understand all the processes."

"

"I am trying to educate myself about rights, what we can ask for, how the system works, etc. I feel I have to find all this out for myself as the information is not provided. Very confusing and exhausting."

"I don'tI am unsure of our rights as a parent of a child with additional needs."

"I would benefit from a fact sheet in regards to their rights across childhood."

"I do research and attend groups which I find very helpful and is where I get a lot of information. It is hard to find yourself - word of mouth is always easiest."

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”

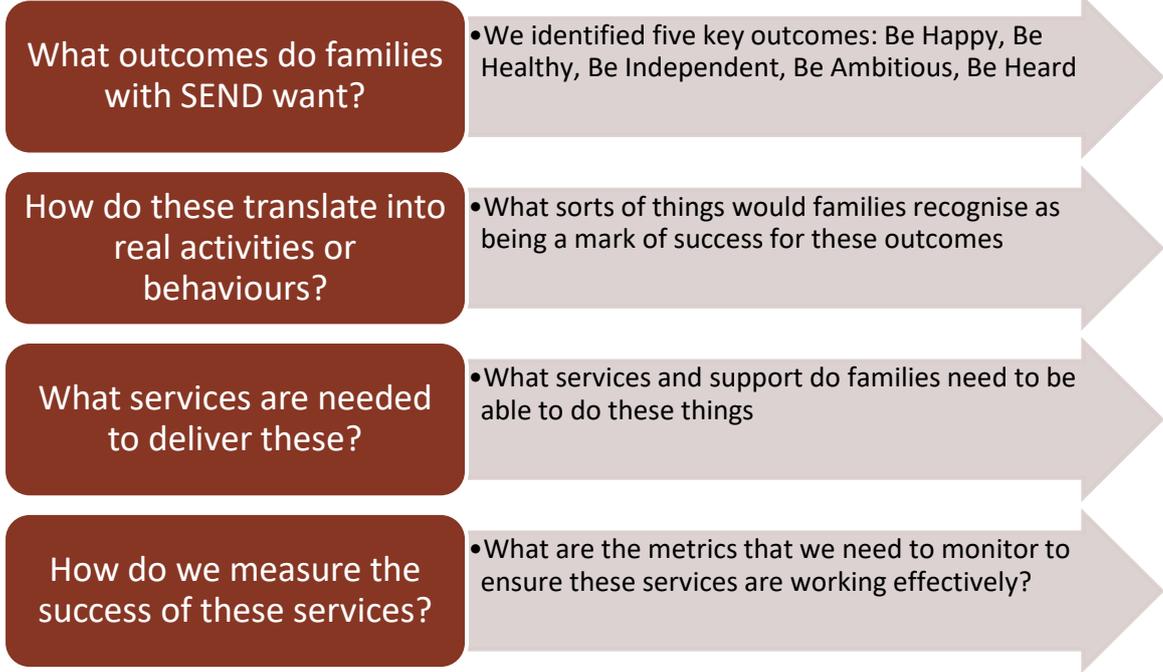
Outcomes framework

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 a best understood as a theory of change logic model.

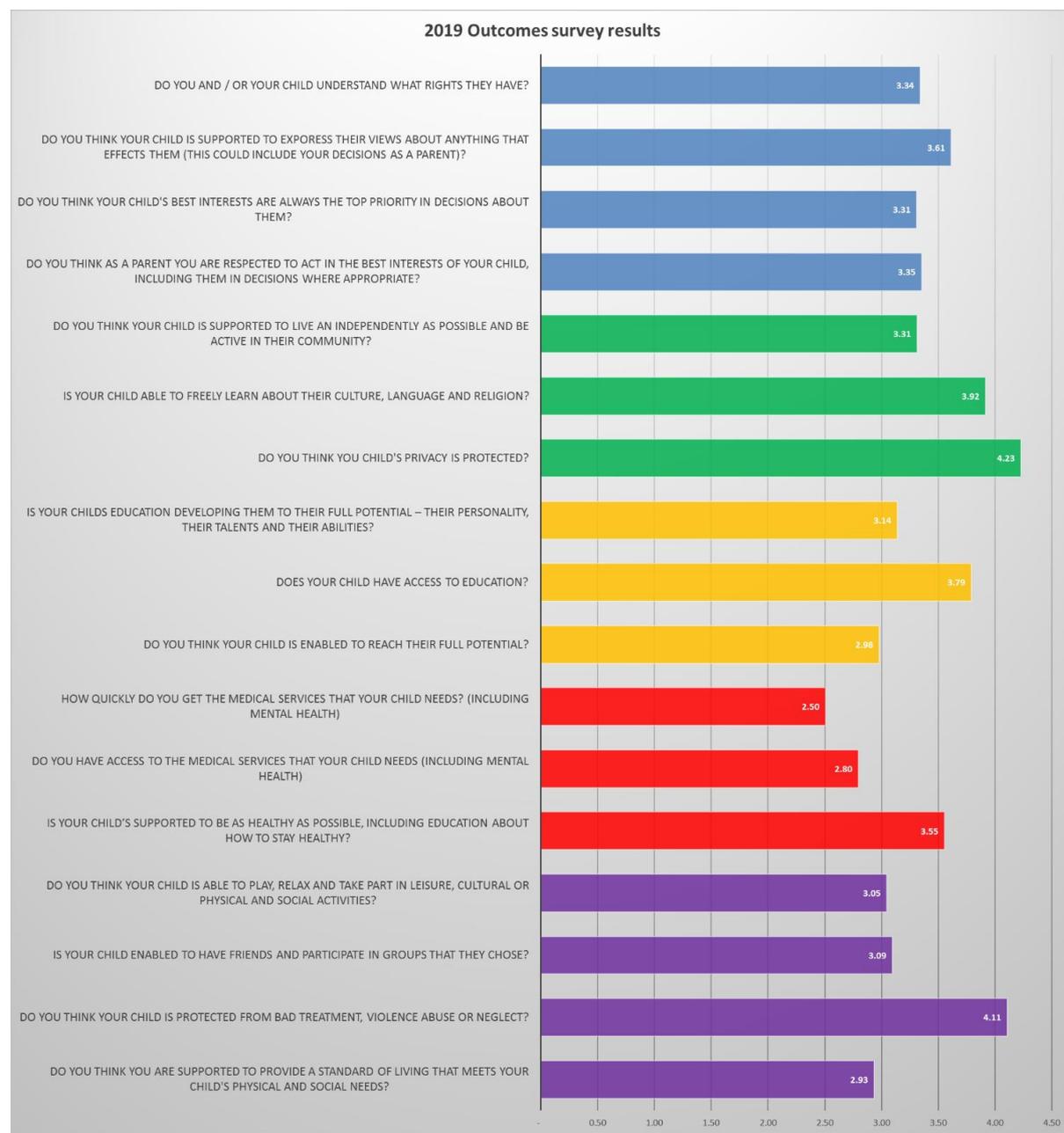


Appendix 2: Survey questions

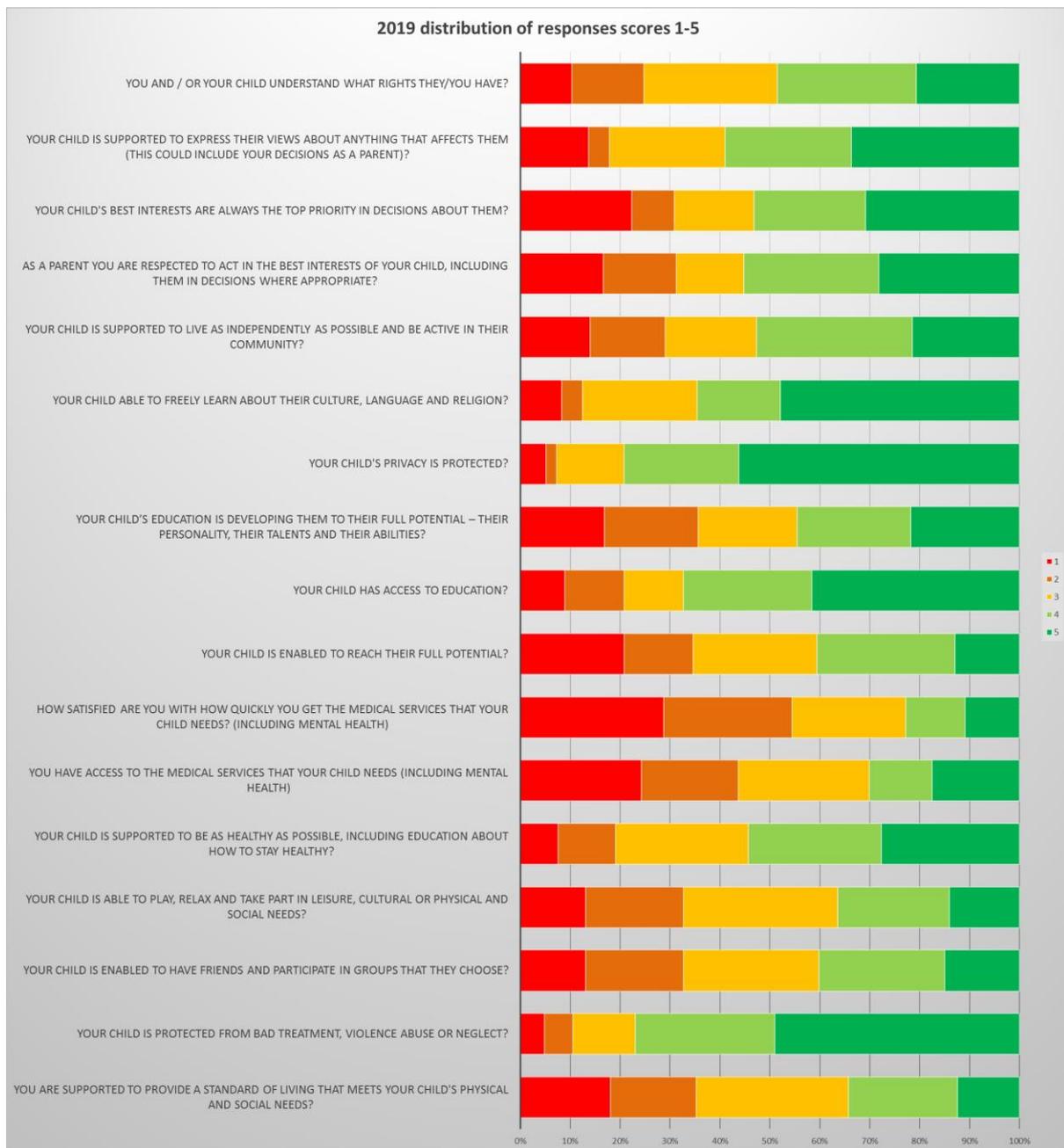
General	What age range is your child?	Response
General	What type of Educational Setting does your child attend?	Response
		Other (please specify)
General	Does your child have an Education, Health and Care Plan	Response
General	If you would like to be entered into the draw for a £50 Love Bedford Voucher please enter your email address below. All of your answers to this survey will still be completely	Open-Ended Response
Be Happy	Local services support my child and my family to have a good standard of living that meets my child's physical and	Response
Be Happy	Local services help protect my child from bad treatment such as bullying, harassment, violence, abuse or neglect.	Response
Be Happy	My child can participate in groups, activities and clubs of their choosing and develop friendships.	Response
Be Happy	My child can access leisure and physical activities which	Response
Be Healthy	Local Services support your child to be as healthy as possible including educating them about how to stay	Response
Be Healthy	My child has access to the medical services that he or	Response
Be Healthy	My child gets medical help quickly and when they need it	Response
Be Ambitious	Local Services support my child to reach their full	Response
Be Ambitious	My child has access to education (including those that	Response
Be Ambitious	My child is getting the right education to develop their	Response
Be independent	Local Services protect and respect my child's privacy.	Response
Be independent	Local Services and the local Community provide my child with the opportunity to freely learn about their culture,	Response
Be independent	My child is supported to live as independently as possible	Response
Be independent	My child is provided with the right opportunities to be	Response
Be Heard	As a parent I am respected to act in the best interests of my child, including them in decisions where appropriate.	Response
Be Heard	My child's best interests are always the top priority in	Response
Be Heard	My child is supported to express their views about anything that affects them (this could include your	Response
Be Heard	My child and I understand our rights.	Response
Covid 19	My child is back in school	Response
	If the answer is b or c above why is your child not in school full time? Please tick all that apply	a. I am worried about Covid 19 and I believe they are safer at home
		b. My child has been told to shield by their doctor
		c. Someone else in my household is shielding and my child is not attending school to keep them safe
		d. My child has not been offered the right school placement for them
		place
		f. I have decided to home educate because I think this works better for my child
		g. My child has been off-rolled
		h. My child has been excluded
		needs (e.g. if they need aerosol generating procedures like suction)
Covid 19	The transition back to school has been smooth for my	Response
Covid 19	The school has taken clear measures to make sure it is	Response
Covid 19	The communication from school, the council and the NHS was good and helped my child return to school.	Response
Covid 19	My child and family got the support we needed to help my	Response
Covid 19	Is your child getting any extra support since returning to	Response
Transport	Does your child use school transport?	Response
Transport	If you answered 'yes' to question 29, to what extent do you agree with this statement? 'My child feels safe on	Response
Services	Is your child and family getting all of the services they	Response
School	My child feels safe at school.	Response

Appendix 3: Detailed Survey Results

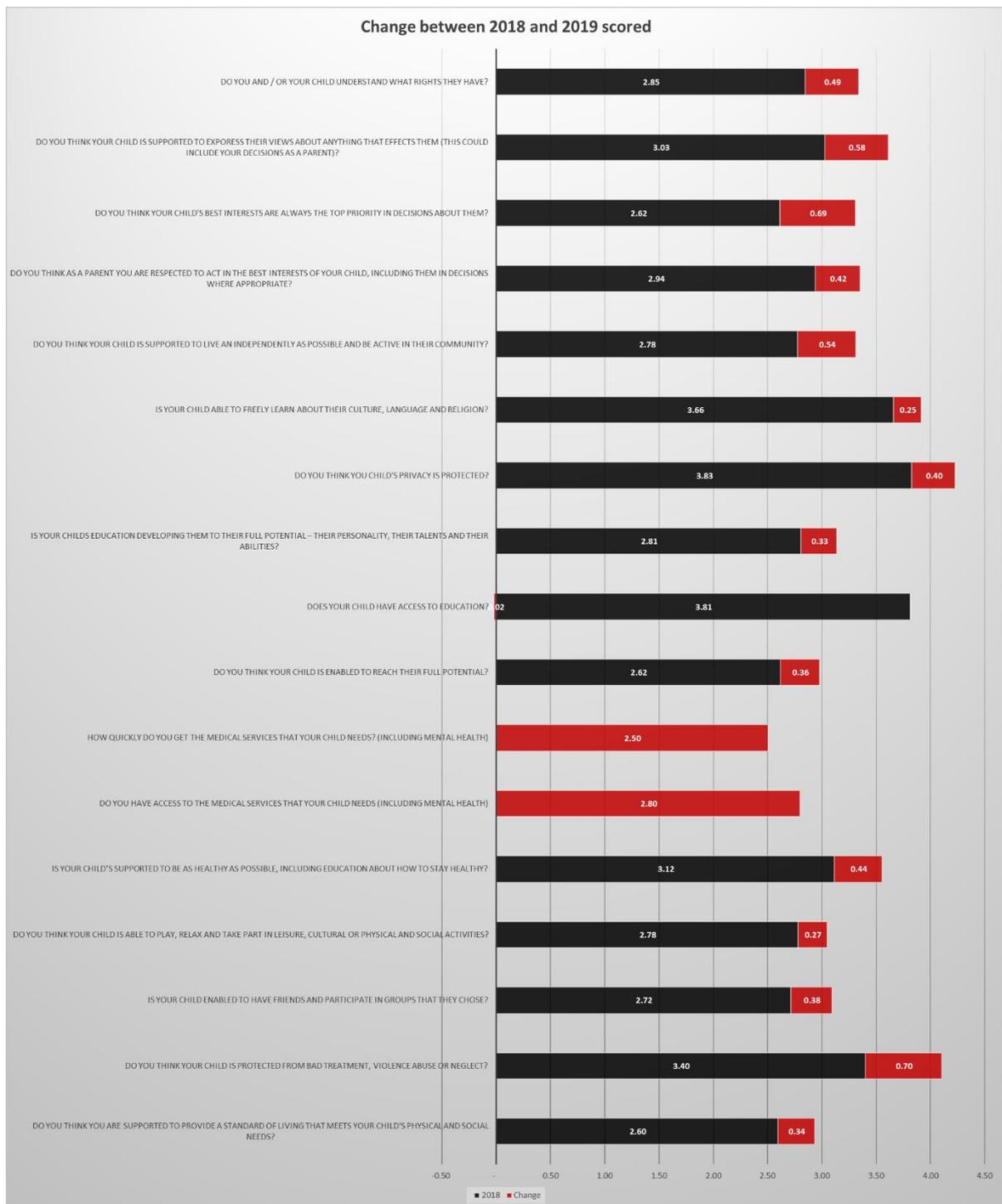
The average scores for each question were:



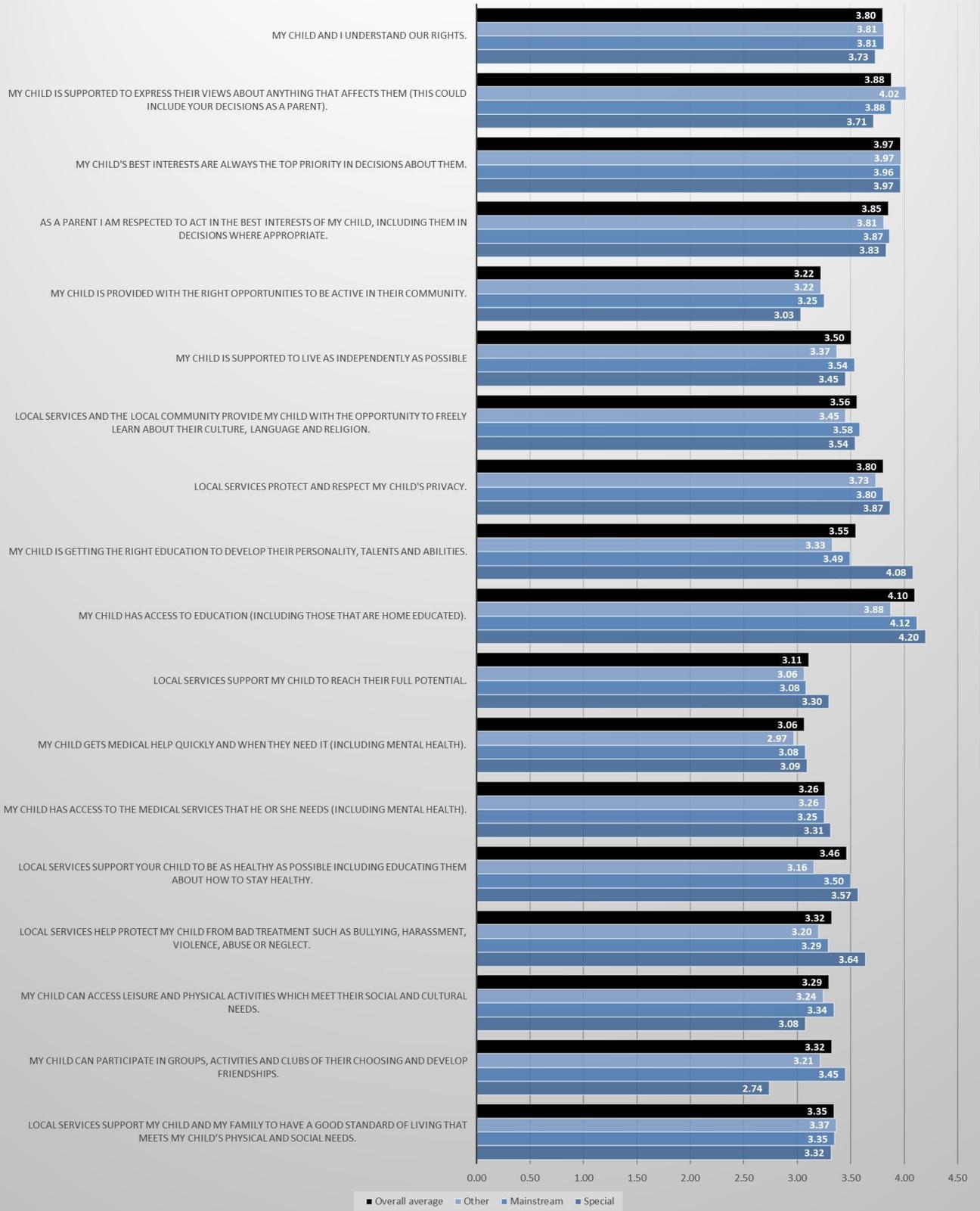
The distribution of scores for each question was as follows:



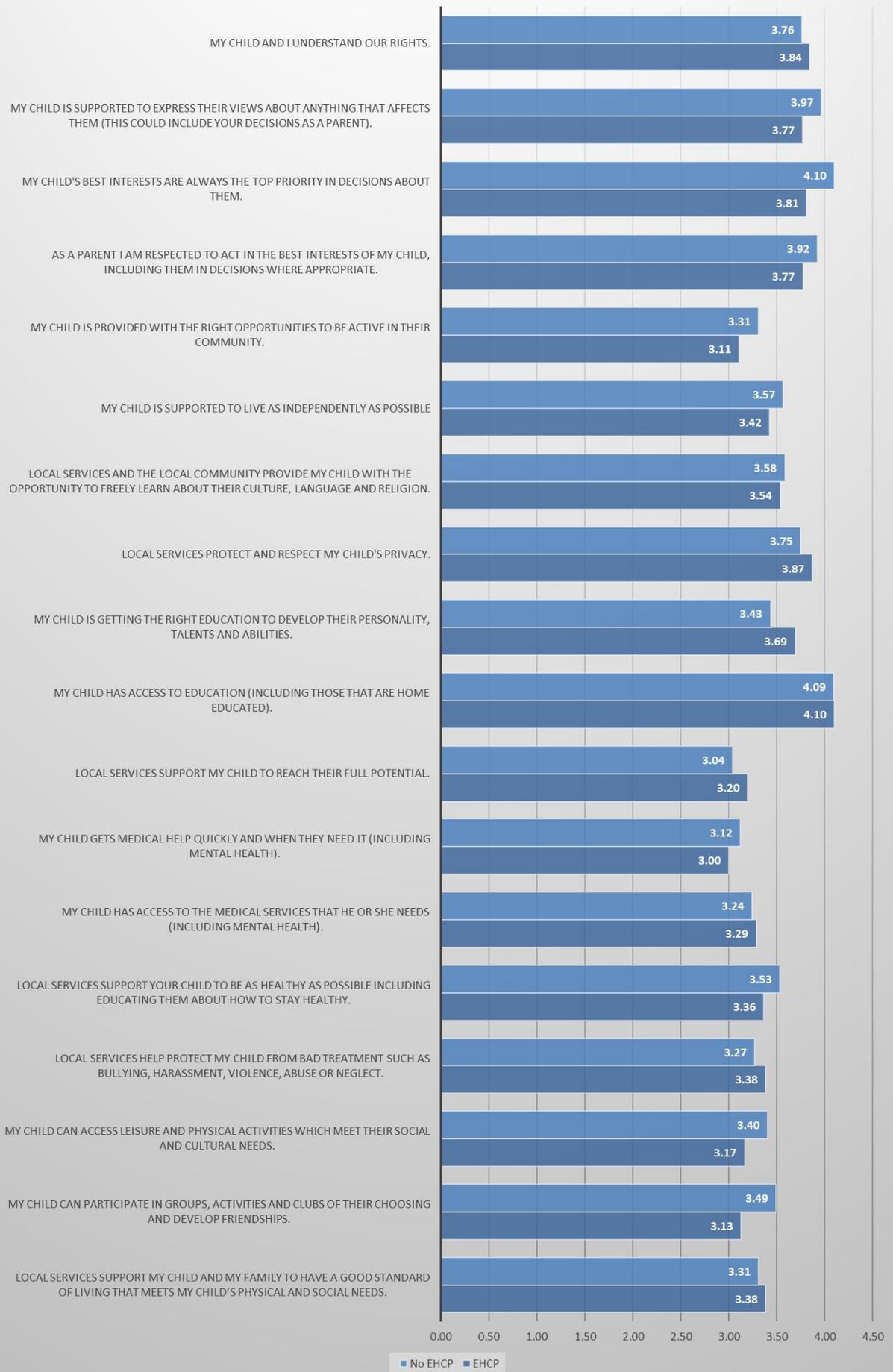
The change in survey results between 2018 and 2019 were as follows:



Analysis of answers by educational setting



EHCP vs No EHCP Analysis



Appendix 4: 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 400 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.