

# Bedford Borough Parent Carer Forum Outcomes Report

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February 2022



# Introduction

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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. This survey has been repeated annually since.

## **Our methodology**

Between October and December 2021, 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 2021 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.

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

The survey was completed by 543 respondents in 2020 (556 in 2020). In addition, there were 1084 comments. Note many 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

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**In absolute terms we are still not meeting the needs of children and young people with SEND well enough. The average score remained stable year on year but the overall experience of families has improved over the last 4 years.**

Average score

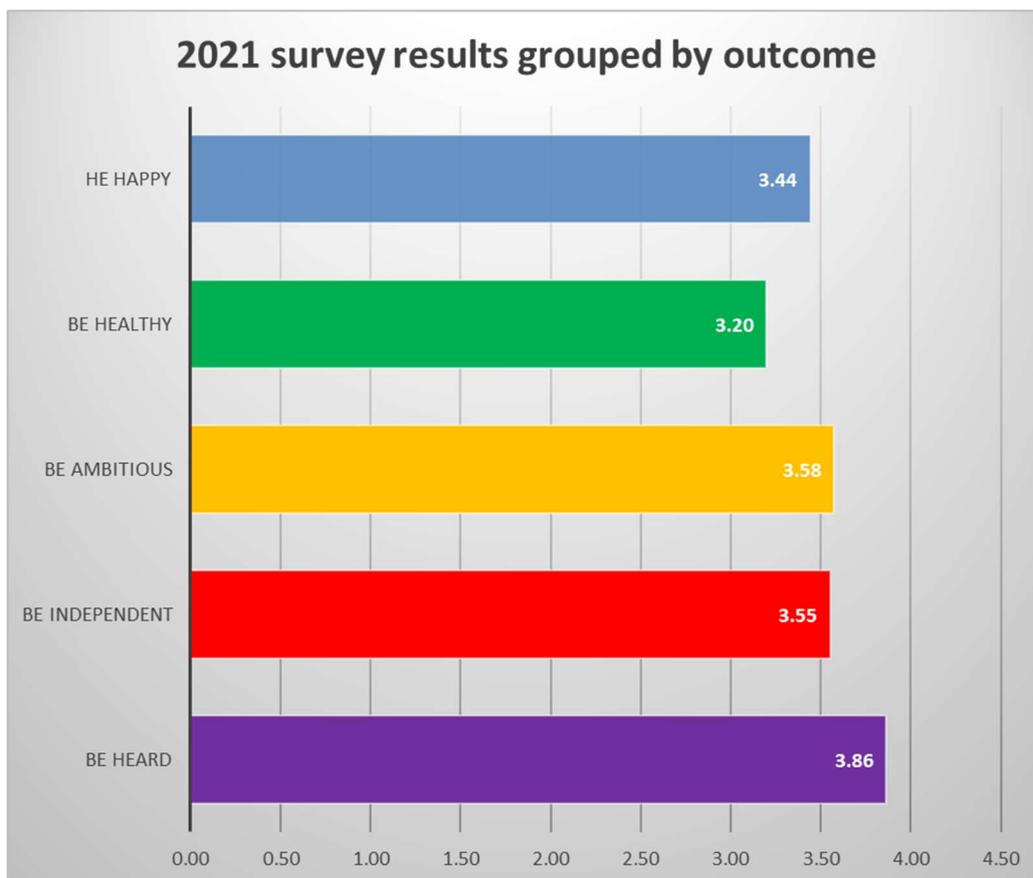
**3.53**

(out of 5)

The average score across all questions in our survey was 3.53 (2020:3.52)

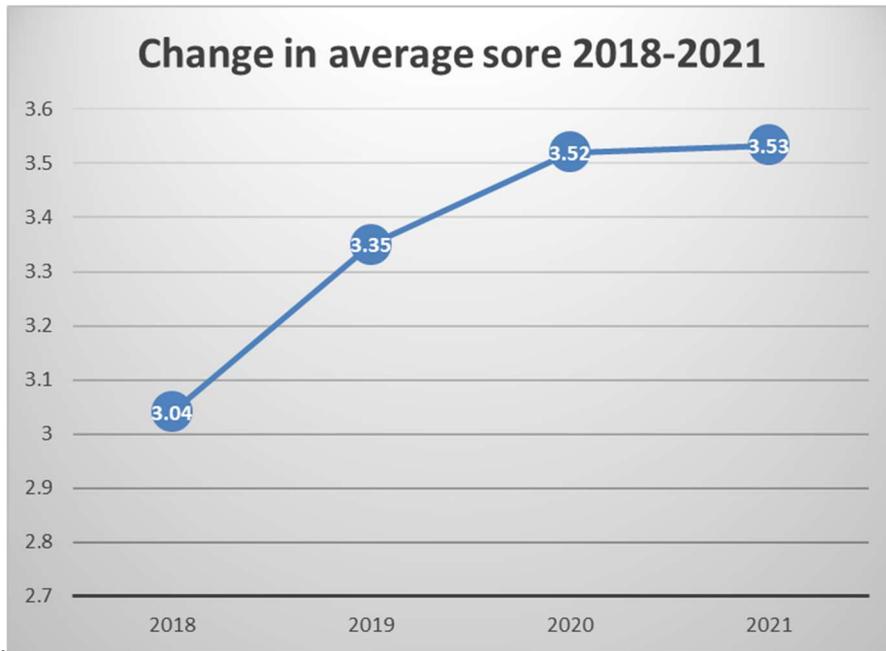
This means that the needs of children and young people with SEND are only being adequately met at best. This falls short of our stated ambition that needs should be being well met (a target score of 4 or more). Given that the questions were based on the United Nations Convention on the Right of the Child,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

The average scores for each outcome were as follows:



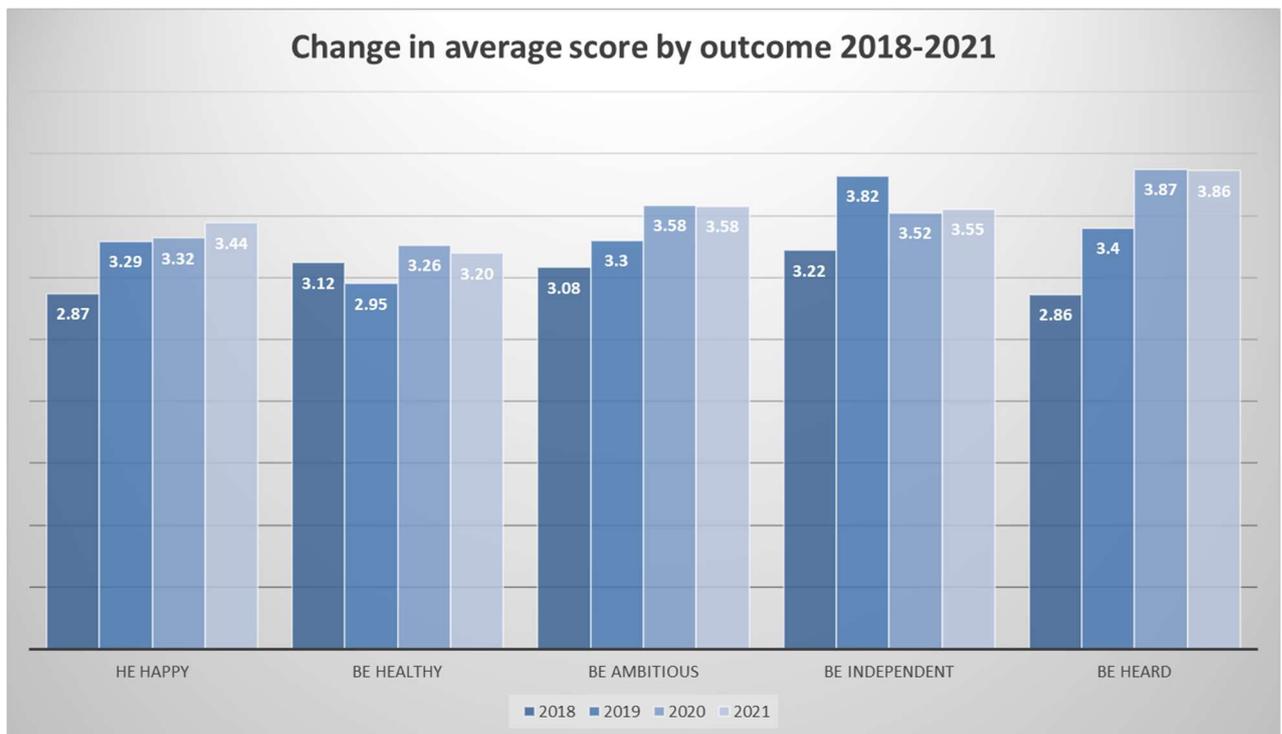
**There has, however, been an improvement in scores in comparison to previous years, which evidences that some of the changes that have been made are having an impact.**

The average score in 2021 was 3.53. This was very stable in comparison to last year when the average score was 3.52. Prior to this results improved from an average of 3.04 in 2018.



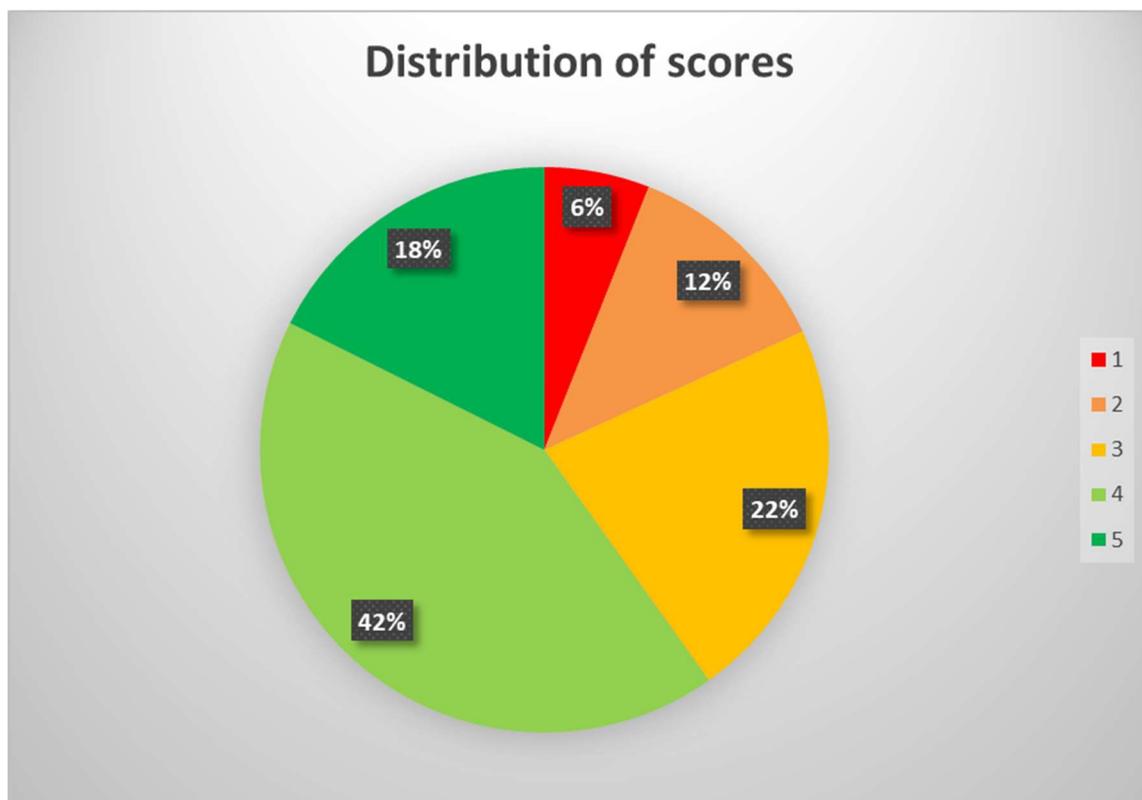
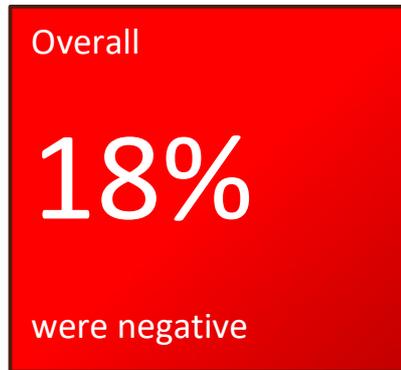
3.

Generally, there was an improvement across all the outcome areas since 2018.



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, 60% of all responses were positive (scores of 4 or 5) whilst 18% were negative (scores of 1 or 2).**



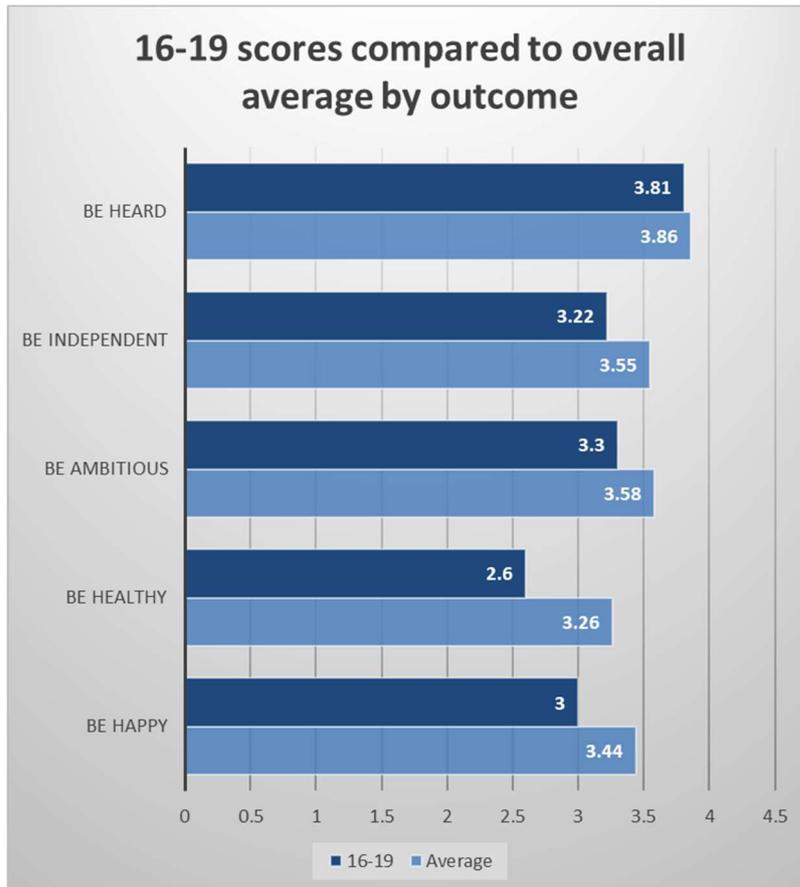
**This is broadly in line with 2020 when 61% were positive and 17% were negative but marks a significant improvement from earlier years.**

# Commentary

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## 1. The 16-19 age group reported the worst experiences – we are not getting transition to adulthood right

In four of the five outcomes categories, the scores for the 16 to 19 age group were the lowest by age categorisation. Often the 16-19 age group scores significantly lower than the average for the outcome. The exception being “Be Heard” where the 20-25 age group scored marginally lower.



We had a good sample size in this age group (48 responses or 9% of the total) and so these results cannot be discounted.

## **2. Families tell us they cannot access the health services they need quickly – this was the lowest single average score across the whole survey**

At an average of 2.98, this was the only average score below 3 in the entire survey, this reflects the anecdotal evidence that the parent carer forum is hearing. Families are telling us of extremely long waits, high access thresholds and gatekeeping to access health services ranging from GPs, paediatricians, therapy services and mental health services. The feedback to the parent carer forum is that this is a growing problem that is causing increasing frustration and impacting outcomes.

## **3. Families described real barriers to accessing services that their children want to use.**

Despite the success of the summer of SEND, comments revealed that many families still could not access day to day activities for their children. They described a number of barriers to this, most notably:

- Many universal clubs and services are not inclusive and do not welcome children with SEND
- Targeted and specialist clubs and services are over-subscribed and there are long waiting lists to access them
- Many families told us that they could not afford to access targeted and specialist clubs and activities

## **4. There are very mixed experiences and opinions about mental health services**

Consistent with last year, 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.

## **5. 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

## **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.

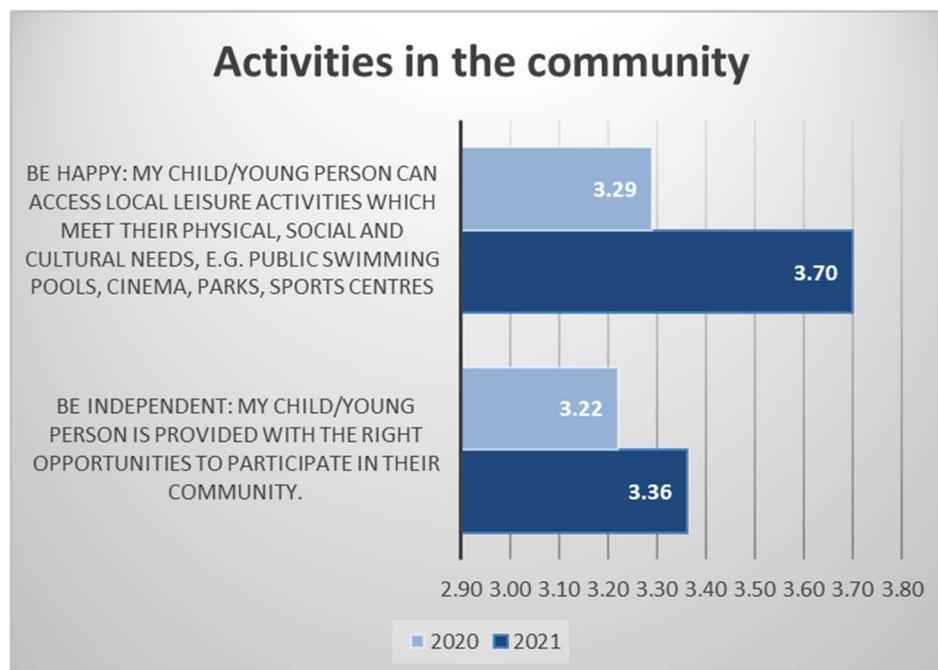
**7. Parents want more support to understand their rights and be heard. Many talked about an emerging culture of “parent blaming”.**

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.

There was also an emerging theme of parents saying that they did not feel listened to and that they were being “blamed” for asking for services and being held responsible for some of the issues that their child was facing.

**8. The Summer of SEND seems to have made a difference**

The local area put a lot of effort into putting on a wide range of activities for families over the summer. The “Summer of SEND” appears to have been well received by families. Two of the questions that relate to activities in the community saw the greatest increase year on year.



**9. Finally, the overall scores are remarkably similar to 2020. This is despite a tough year for children and young people with SEND and their families because of Covid 19.**

Despite very difficult circumstances for children and young people with SEND because of the ongoing pandemic, the average overall score increased slightly from 3.52 to 3.53. During a period of school closures and health and social care services being under significantly increased pressures, the efforts of the local area to protect services for CYP with SEND and their families clearly had some impact.

Given the pressures the system was under, leaders and practitioners deserve credit for being able to maintain overall scores.

There is, however, no room for complacency, anecdotal feedback to the parent carer forum indicates that many of the pressures are starting to take their toll and the experiences of families are deteriorating and frustration is now growing. Also, a score of 3.53 remains a long way from our stated ambition of an average score of 4 or more.

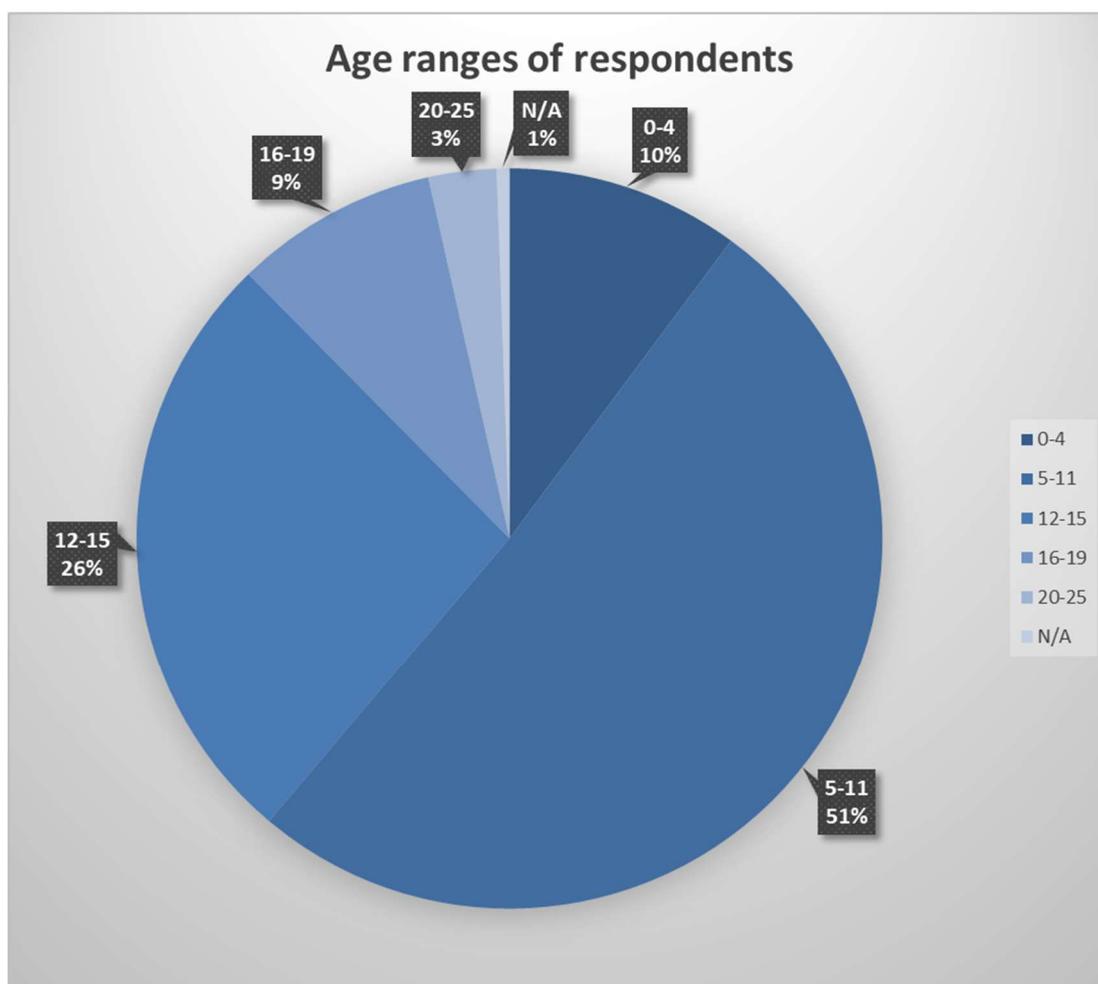
# Analysis by age, setting and EHCP / no EHCP

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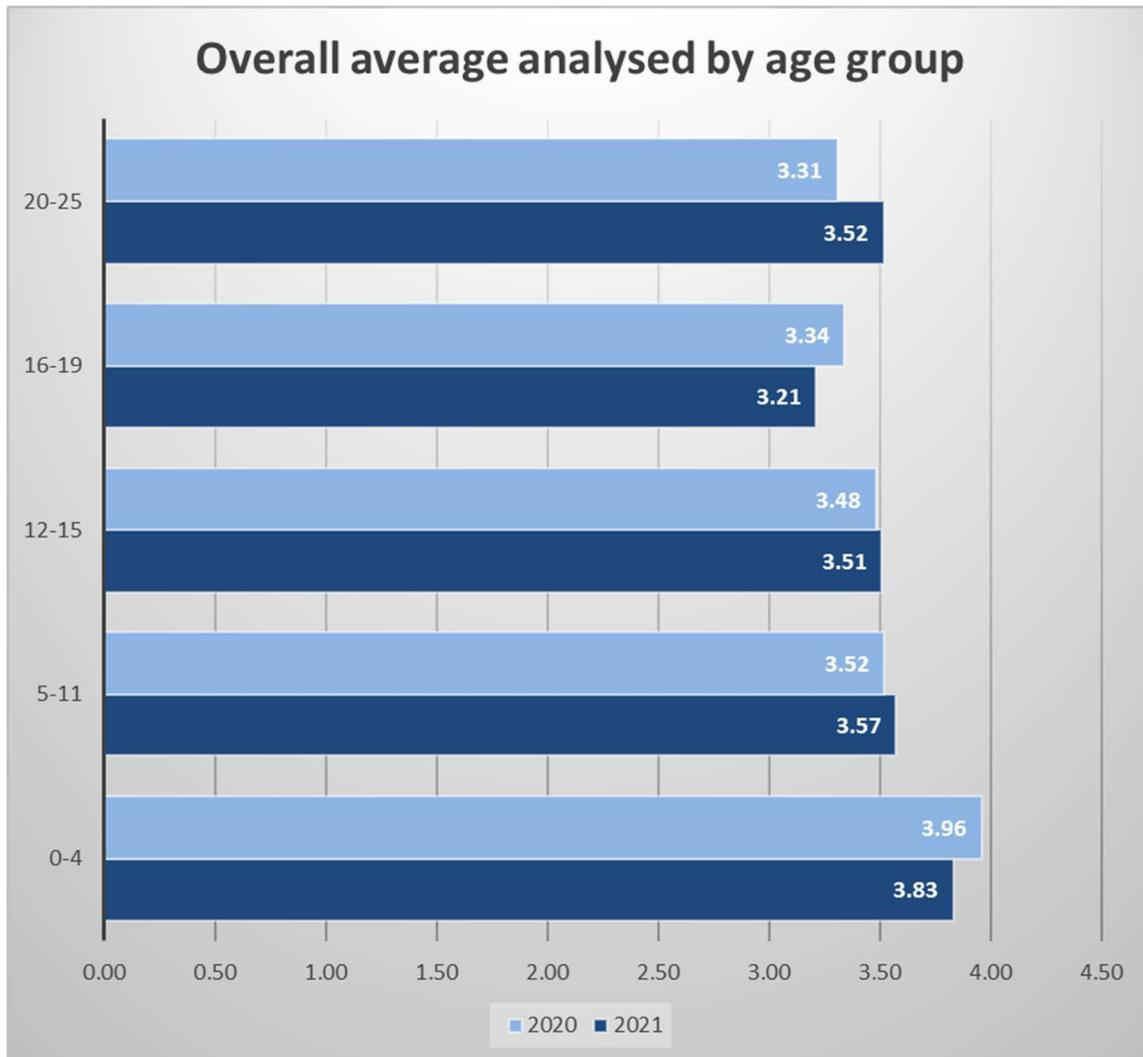
## By Age

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	Percentage
0-4	55	10%
5-11	277	51%
12-15	144	27%
16-19	48	9%
20-25	16	3%
N/A	3	1%



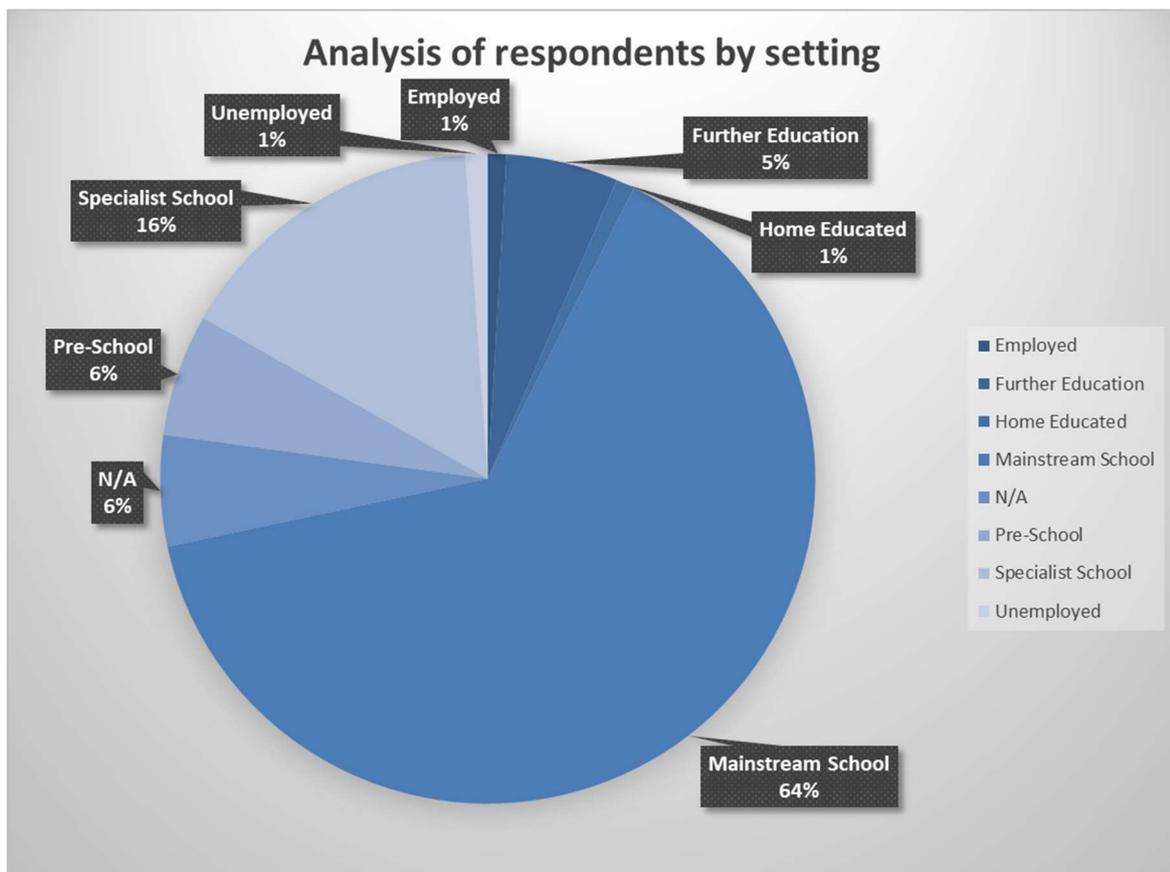
Analysis of the overall average mark by age shows that the 0-5 age group have the highest average score (3.83) with the 16-19 age group with the lowest scores (3.21) a marked decline, the older our children and young people with SEND get. Unlike previous years, there was no clear pattern of decreasing scores as age increases.



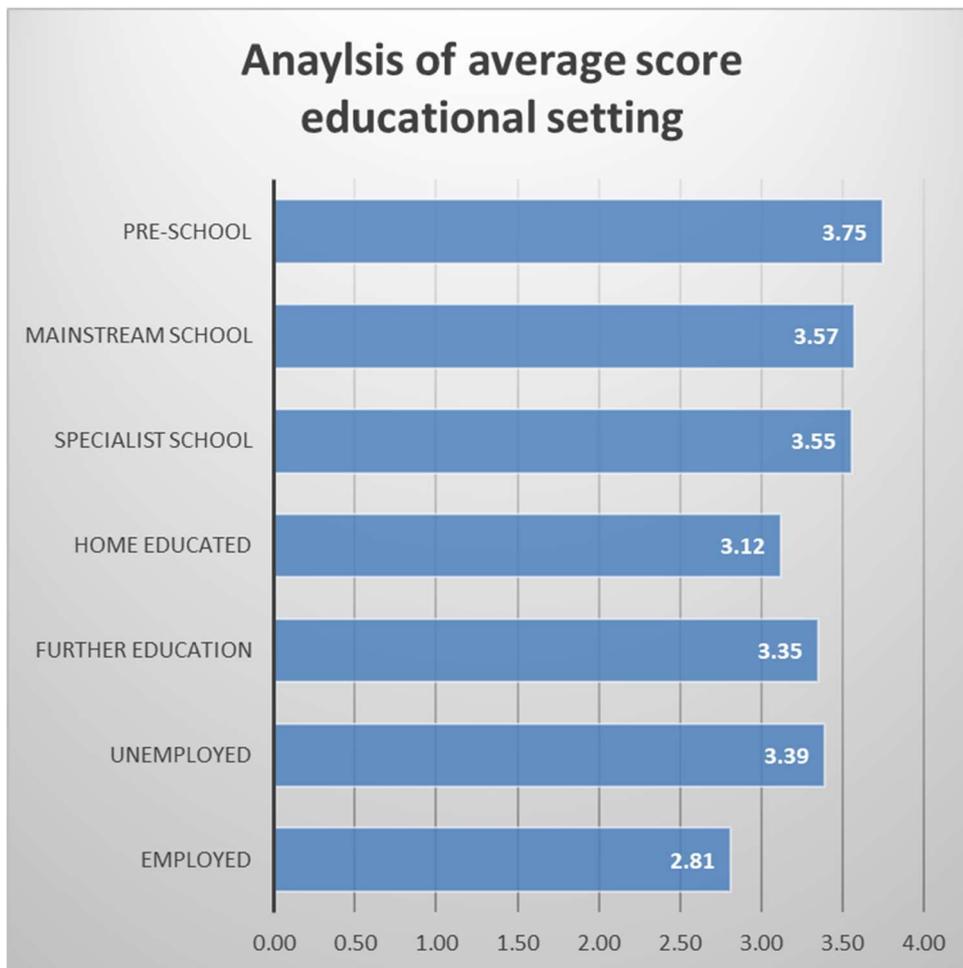
## By setting

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 (80%)

Setting	Number	Percentage
Employed	5	1%
Further Education	30	6%
Home Educated	5	1%
Mainstream School	349	64%
N/A	30	6%
Pre-School	33	6%
Specialist School	85	16%
Unemployed	6	1%

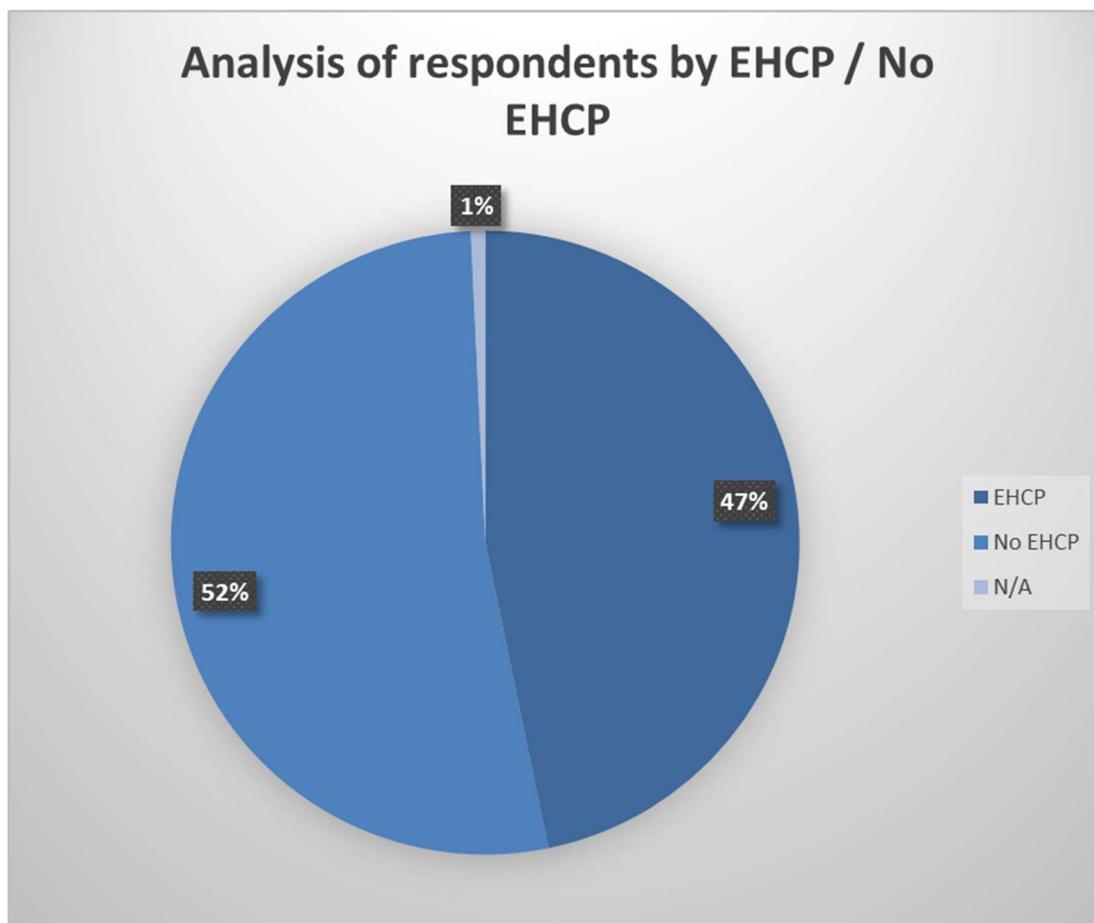


As in previous years, the survey shows no significant difference in overall average scores between children and young people in mainstream settings (3.57) and those in special schools (3.55). Those in pre-school settings had the highest average scores (3.75).



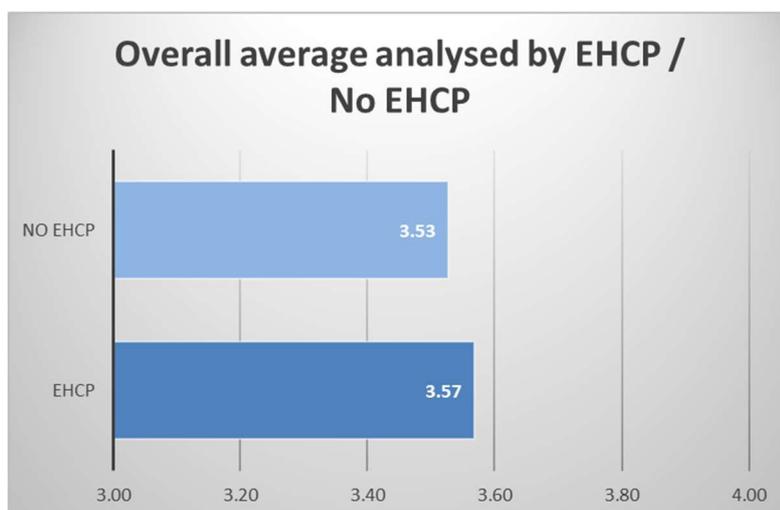
### By EHCP / no EHCP

There is a good split of responses between those who have EHCPs and those who do not. With 47% having an EHCP and 52% not (1% responded N/A).

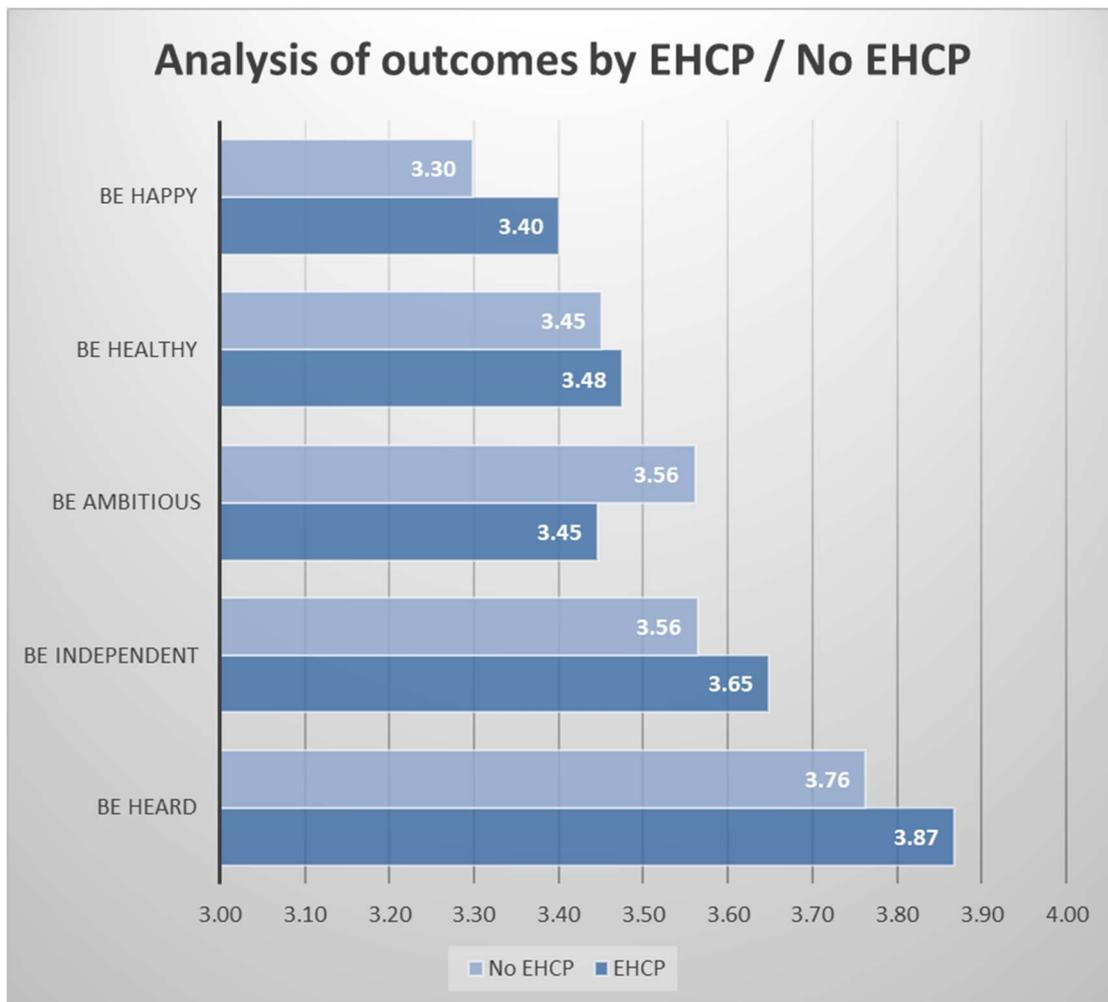


Again, there was no significant variation in scores between those children and young people who have an EHCP and those who do not.

There was a small difference in average scores for children who had an EHCP and those that didn't. Those that had an EHCP scored slightly higher (3.57) than those that did not (3.53)



Analysis by outcomes shows that there were some variations in average scores by outcomes between those with and without an EHCP. Significantly, those without an EHCP scored higher in all categories with the exception of be ambitious.

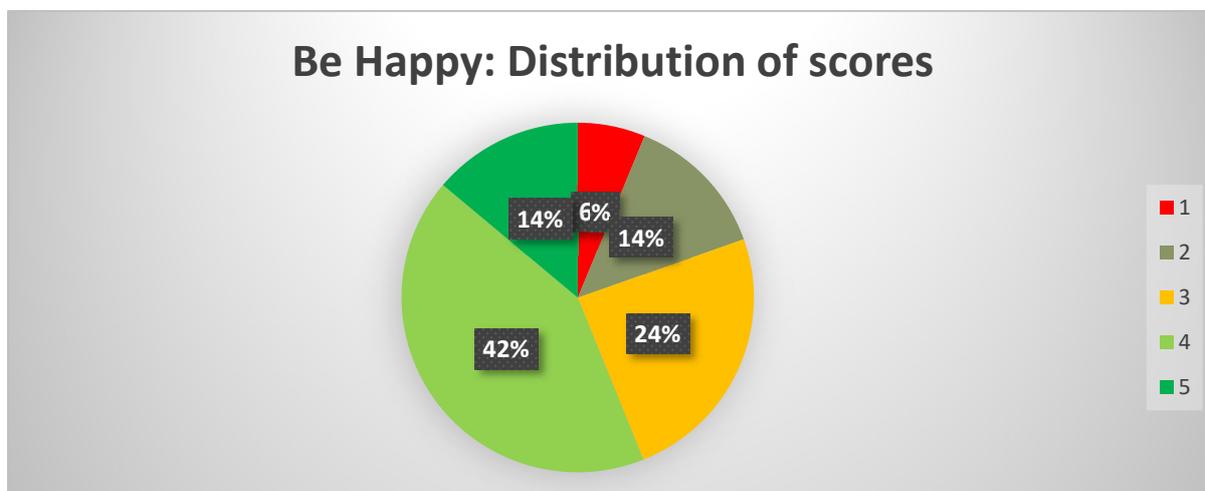


# Be Happy

The average score for parent-carers in this category was 3.44. This represents a small increase year on year from the score of 3.32 last year and a steady improvement over the last 4 years from 2.87 in 2018.

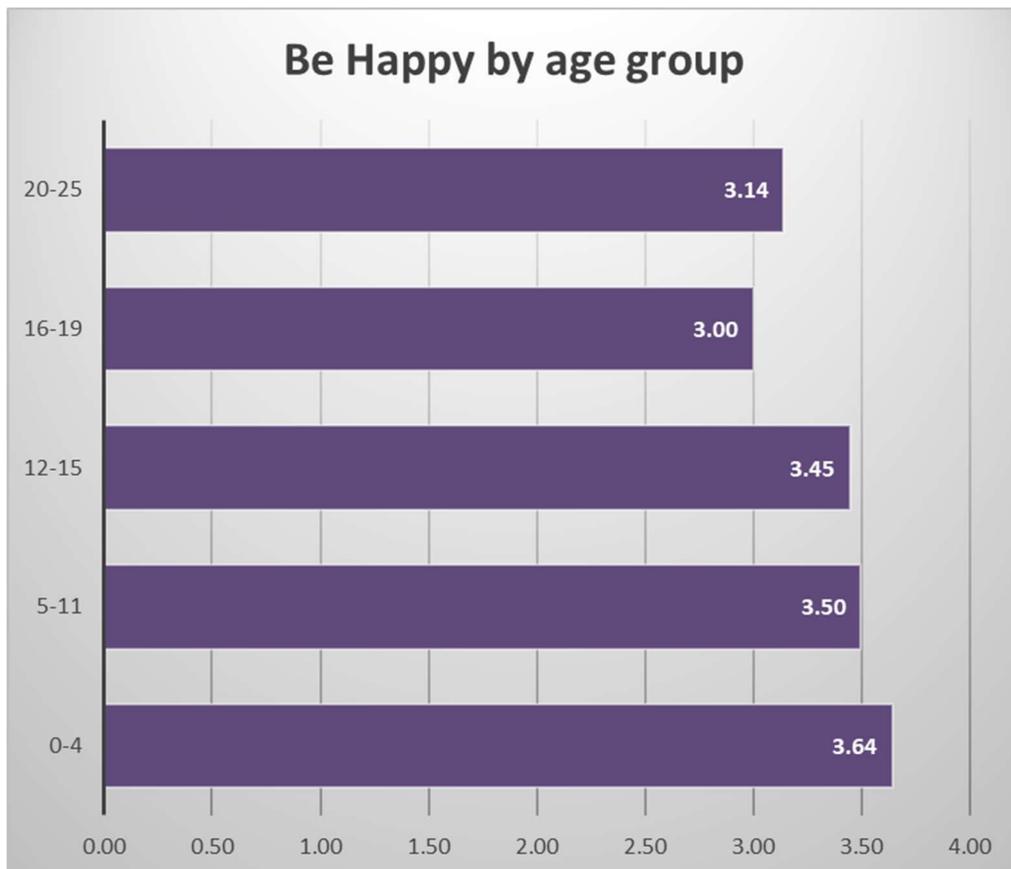


The majority of the scores for individual questions have remained steady, showing small improvements across the board. However, the question about access to leisure activities has improved significantly rising by 0.41 from 3.29 to 3.70 year on year. There was no single driver for this identified in the comments but families mentioned a variety of support offers that enabled their children to feel involved in leisure activities.



In this year's survey 56% of responses were positive and 20% were negative. This is an improvement on last year (49% and 23% respectively).

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 0.64 fall in average marks between preschool children and the 16-19 age group (although there is a small recovery for the 20-25 age group but given the smaller number of respondents in this age category, this cannot be regarded as definitive). The broad theme of happier younger CYP is consistent with results from previous years.



**There were many comments about a shortage of appropriate activities for CYP with SEND and many complained of .oversubscribed clubs with long waiting lists.**

Parents spoke about a lack of the right activities for their CYP and many said that where the right services did exist they could not use them because of long waiting lists and clubs being full.

*There aren't regular sport/activity groups for Children with special needs.. yes you can access some things but they don't compare to activities mainstream children can access*

*No access to normal recreation and childcare.*

*There was the summer of SEND, but the "good" activities were over subscribed and this was during a limited time period. There were some sporadic SSG events throughout the pandemic. I'm unaware of any other appropriate activities for my CYP*

*nothing meet (sic) for deaf child*

*Access is good if you are prepared to go on waiting lists.*

*Long waiting lists, not always signposted to free support.*

## **Many comments described universal services that were not accessible or welcoming for CYP with SEND.**

Many mainstream clubs and activities were described as unwelcoming for CYP SEND. Families described a lack of understanding of SEND issues, an unwillingness to make reasonable adjustments and children being excluded or removed from activities when things became challenging.

Families also described a lack of accessibility for many CYP for core universal services – most notably parks and cinemas.

*Group don't want a child that is seen as naughty,*

*No, my daughter cannot attend any of these clubs because none of these clubs can provide or accommodate for a child with a disability. My daughter has tried ballet, dance, swimming lessons, and the worst group Brownies*

*The majority of these groups and activities are not accessible to neurodivergent people, and as often run by low-or-no-pay staff, there is no expertise in supporting disability and difference.*

*He went to one but they didn't really understand him*

*I have tried to get my son into beavers for over a year now as I feel he would really benefit from this. I still have not heard back from them. There is nothing else out there for him*

*Impossible to get her into brownies*

*not enough afterschool clubs and clubs that are provided during the school holidays are too expensive.*

*She has left or been asked to leave.*

*We have yet to find one who are truly welcoming and understanding of my child and his needs. Beavers and Cubs in Brickhill were awful and did not understand my child. Football and rugby were not inclusive either*

*Parks are awful, no accessible play equipment, no accessible tracks. Cinemas are good but it's more screen time. Would be better to have more outdoor activities available.*

*Parks aren't particularly inclusive.. especially if children aren't able to climb independently.. I don't feel there's good access to quiet / warm swimming pools and haven't found sports centres with accessible activities either*

*Play parks are difficult to access. There are few parks with equipment accessible to those with physical disabilities*

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

Time and time again, parents mentioned bullying.. Families were particularly critical of the response from schools – they did not feel that schools took their concerns seriously or addressed them proactively. They described a lack of support, understanding and action from school teachers and leaders.

*My child is bullied daily and she has not been supported by the local services*

*My son was bullied on several occasions while in secondary school*

*When out in public my son is mimicked and no-where to go.*

*my son had 18 months of violence, bullying in school provision and no support*

*Previous school: My son had awful experiences of bullying which have had lasting mental health consequences.*

*There are concerns in school, repeat targeting by the same few individuals can ruin a week.*

*Police and social services were brilliant. The school not so much.*

### **The comments outlined many real barriers to accessing services that would support CYP with SEND. These included costs, carers to provide help to access services**

When services are available, families described very real challenges in accessing them. It is encouraging that so many families would like to access services available in Bedford Borough, but many felt that obstacles such as cost and the need for parents to accompany children were preventing their CYP using potentially very valuable services.

*True, but he will almost certainly need to be accompanied by a carer.*

*Nothing around for SEN children where parents can leave them to partake in a club ie football as those are things that he can access with his parents to navigate. He cannot access them alone.*

*Again only if I'm to attend with him. It's hard to find places he can go to and I can leave him.*

*Only places where parents can stay*

*These are all unaffordable for a single parent*

*Hardly any clubs near me and if there is they too expensive for single mum that don't (sic) drive*

### **There were many positive comments about the holiday activities on offer.**

*The council has stepped up in terms of short breaks and some activities offered to SEND children*

*Holiday activities have been great - need more of these please. Can't access Autism Beds groups and would want more after school type activities for my older children with SEND*

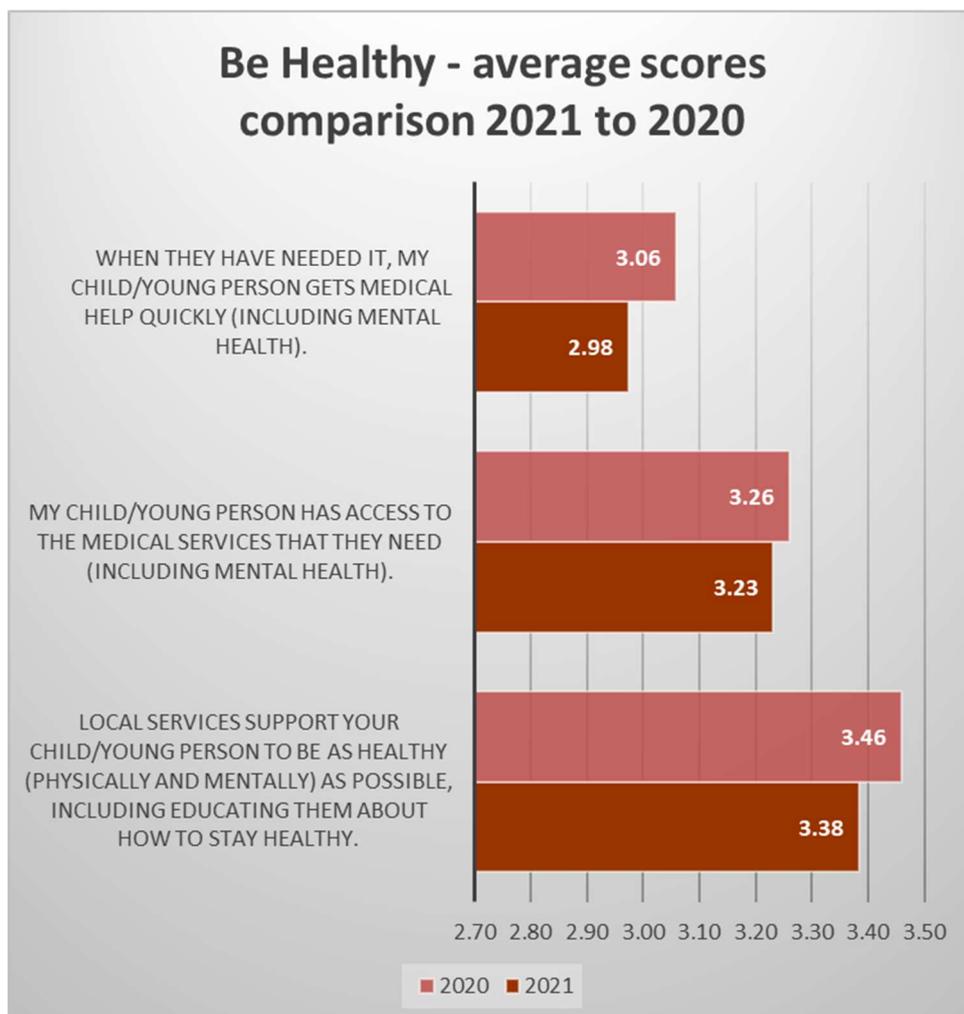
*Summer activities were really good as a family*

# Be Healthy

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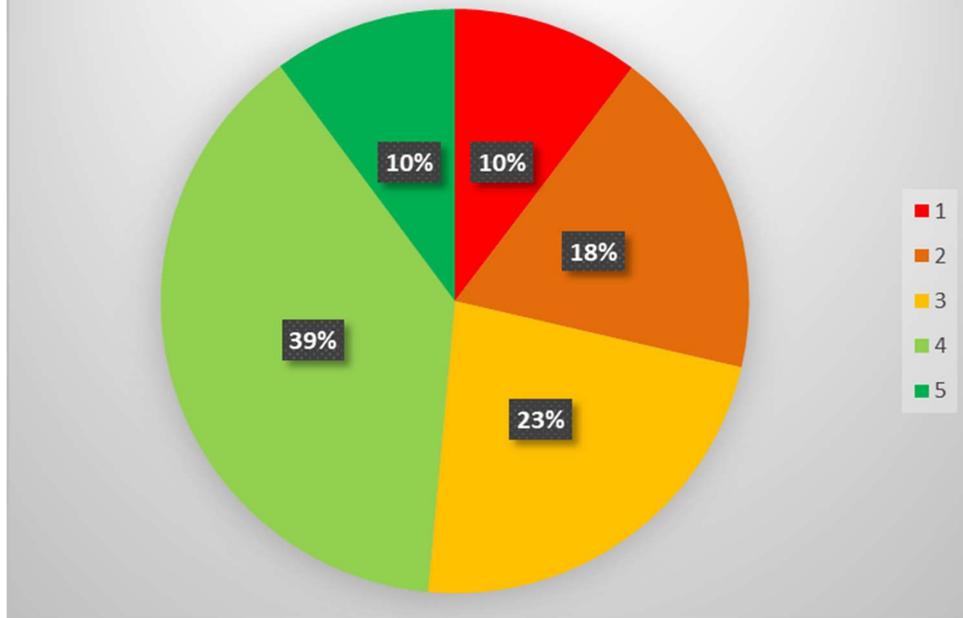
There was a slight decrease in the average Be Healthy score year on year. In 2021 the average score was 3.26 whereas it was 3.20 the previous year. This was the lowest scoring section by some margin.

This decrease was spread across all three Be Healthy questions.



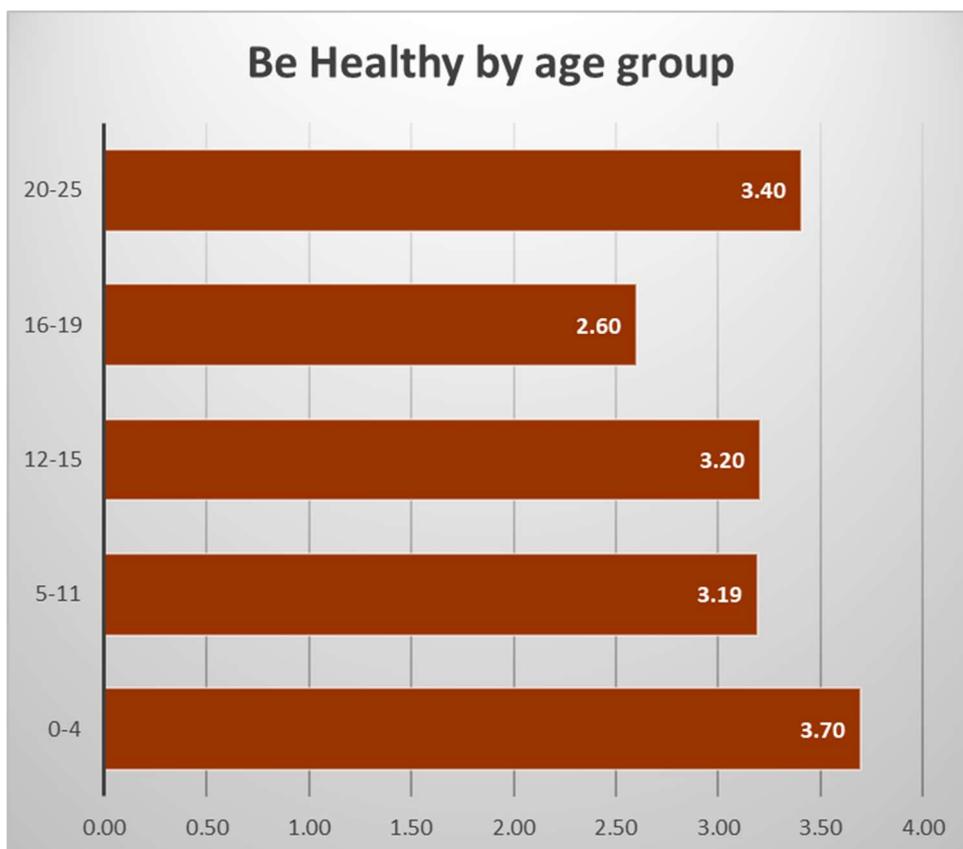
In this year's survey 49% of responses were positive (marked 4 or 5) and 28% of responses were negative. This is broadly in line with last year's results when 50% were positive and 26% were negative.

## Be Healthy: Distribution of scores



There was no clear pattern in the scores broken down by age group. The best scores came in the 0-4 and the 20-25 age ranges suggested that school aged children and young people were least satisfied with their health provision. The 16-19 age group showed the lowest scores – this was the single lowest score by age category across the whole survey..

## Be Healthy by age group



**Families of 16-19 year olds reported real concerns with mental health services. They also mentioned access to GPs and paediatricians.**

The survey shows a particular concern with medical services for 16-19 year olds. This suggests some issues with transitional arrangements. A deep dive into the comments for this cohort reveals a focus around mental health services in particular. In addition, many parents also reported concerns with access and support from GPs and paediatricians.

*Mental health transition is a joke, no one listens.*

*We've repeatedly tried to get help with my sons (sic) mental health and were passed from one department to another until we gave up after about two and a half years*

*Access to mental health support is very difficult and limited to so few sessions. They also don't understand continuity once they have established a rapport*

*The barriers to accessing help, support and specialist therapy for neurodiverse individuals with mental health needs are far too high. We have experience of being bounced by CAMHS even when my son was actively suicidal. The neurodevelopment team CAMHS, whilst staffed with well meaning individuals is vastly under-staffed and this means the team cannot function in the best interest of children.*

*We have been on the waiting list for CAMHS since before the summer. We are currently under paediatrics but as she is 16 expect to be moved to adult services soon. She is also currently under the physiotherapy team at the CDC but again expect this will change soon and she is now under the adult podiatry team.*

*She was discharged from community paediatrician and needs to be seen again but can't get an appointment. She is being looked after by CAMHS, but the wait time was very long.*

*CAMHS closed my child due to care co-ordinator being on long term sick. This was not communicated to us. Social worker found out when she chased for different worker to cover in the interim*

*The paediatrician states that my son should have a review every 6 months but this doesn't happen. He had previously had treatment from CAMHS and although he expresses passive suicidal thoughts he does not meet the criteria for treatment from CAMHS and therefore private therapy is the only option as voluntary agencies do not provide the long term support he needs*

*Requested referral to CAMHS over a year ago - no contact at all.*

**Parents reported that they had limited choices when it came to supporting their children stay physically healthy.**

There were many comments that expressed concerns about the support offered the CYP with SEND maintain and healthy diet and weight. Families also spoke of a lack of physical activities for CYP with SEND.

*I applied to more life to assist with excess weight. Since COVID - there has been no support*

*My daughter is extremely obese and struggles with losing weight to have a more healthy weight*

*I've not seen anything to help apart from the odd leaflet throughout the year to do with healthy eating*

*They don't get enough activities to exercise. Parents have to often stay to help which is no break.*

*Without extra support my children cannot access a number of activities to keep them active. We find it difficult to find information on support for dentistry and diet*

*My son does not seem to be engaged with anything healthy.*

### **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 and physical education. Many respondents contrasted this with the support they get from the local authority.

*Not sure I'm aware of anything outside of education that promotes healthy living to this group*

*The school is great. The local authority is another matter*

*Support and education have come via school.*

*We've not had much outside of school setting, but they themselves are good.*

### **CAMHS services split opinion – it is often mentioned as a reason for both high and low scores in comments. CHUMS services are generally well thought of.**

There were many comments that were very positive about CAMHS but there were just as many that were very critical. The key critical themes broke into broad categories – that services were difficult to access, CYP needed to be at breaking point before help was available and the waiting times were too long.

A selection of the positive comments

*Recent investments in counselling for young people with autism has been an improvement in services in Bedford Borough.*

*when we needed support it took less than 2 weeks to see chums*

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 closed my child due to care co-ordinator being on long term sick. This was not communicated to us. Social worker found out when she chased for different worker to cover in the interim*

*Getting access to CAMHS is ridiculous*

*I have been trying to get help from both chums and cahms (sic) as an urgency for my son but as of yet have received no help 1 year on.*

*My son desperately needs help with his mental well being, but not getting anywhere. Again we've had chums & Camhs but Chums you only get about 3 sessions that doesn't do anything it needs to be longer term. Camhs have just said it's really a school Issue and close it down, no help to help in school though???*

*3 months without mental health services and due to camhs closing no ability to link with specialist crisis teams*

*Camhs refuse to see autistic children*

*Mental health CAMHS nightmare to get referral (Doesn't meet criteria)!!!!*

**There were a lot of comments about long waits for many community based services – this included paediatricians, autism diagnoses, speech and language therapies and General Practitioners.**

*The paediatrician states that my son should have a review every 6 months but this doesn't happen.*

*Unable to get referrals as not enough consultants.*

*Paediatrician but not seen for 3 years*

*Very limited access to SALT, currently trying to raise the funds to go private.*

*Over a year for speech and language*

*We have been waiting for an OT appointment for over 6 months, this was a re-referral as he is struggling after being discharged from the service. We were told it is easy to refer back in when they discharged him.*

*Waiting list for Speech and Language assessment, for over 8 months*

*We filled our first autism questionnaire (along with school in November 2018, and never had an appointment to discuss results) after multiple chasers and a complaint, we've just had another form sent out.*

*we've been waiting three full years for an appointment at the CDC to discuss the autism questionnaire*

*GP not seen anyone in last 2 yrs*

*Huge problem getting Dr's appointments. I keep getting reminders about weight and BP on my child's prescription but can't get routine appointments to do this. I've sent readings done at home by email, but they ignored them. Been told by a nurse at gp to take him to hospital to get it done as they don't do this at gp.*

*Impossible to get a doctors appointment*

*My daughter has not been able to see a medical practitioner since 2019 (D Pary's Group). Until we recently changed GP Practice we were reliant on the walk in centre and out of hours doctors.*

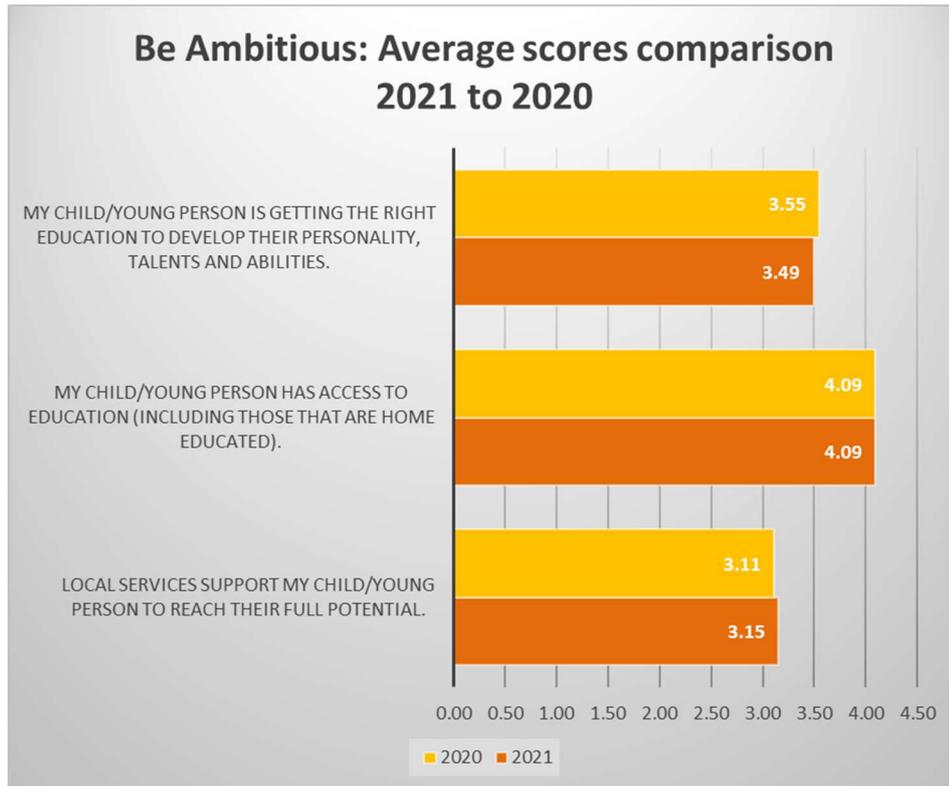
*Our local GP is shocking. When we first went to her to seek support for any learning differences and what we were sure about that was effecting (sic) our daughter she turned us away, telling me I had to write a referral requesting support and I had to seek support from school.*

### **There was praise for special school nursing teams**

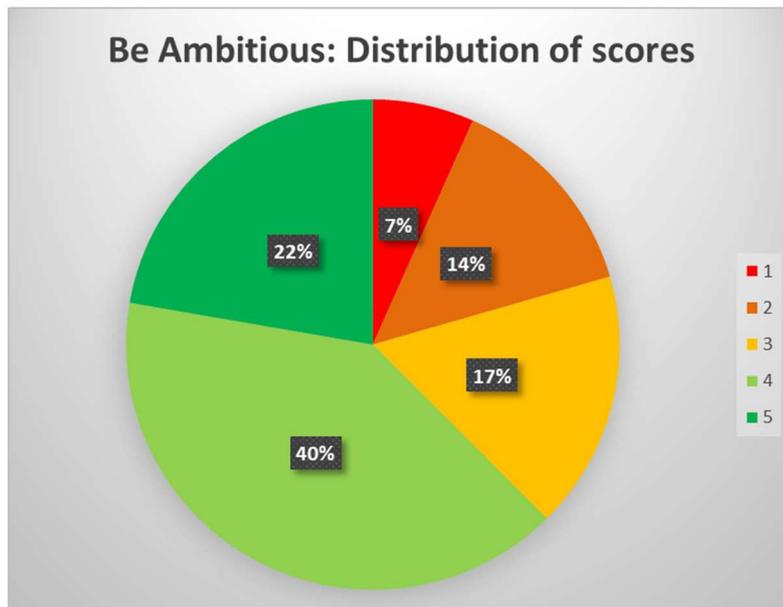
No specific comments but nursing teams were mentioned next to many 4 and 5 scores.

# Be Ambitious

The average score for this category was 3.58 which was the same as last year. There was little significant movement in scores for individual questions year on year.

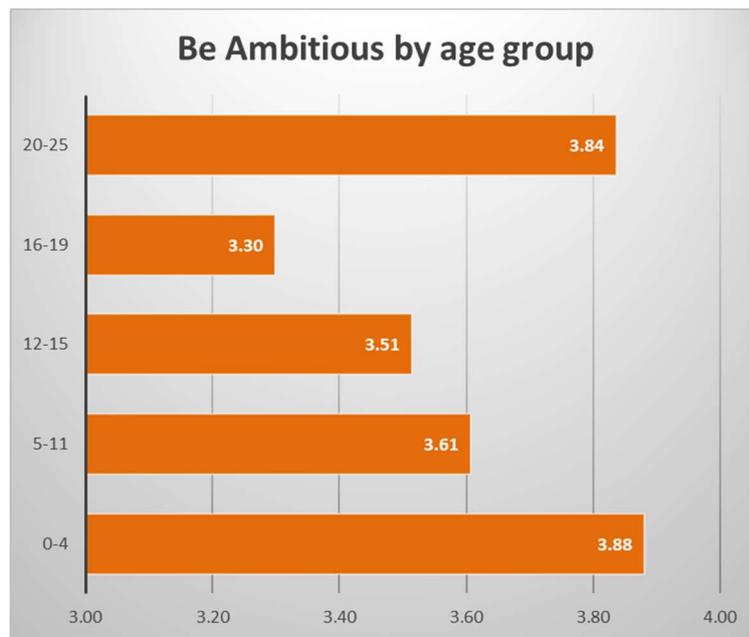


The overall distribution of scores was:



In this year's survey 66% of all responses were positive (grades 4 or 5) and 21% were negative (grades 1 or 2) . This represents an improvement of last year's scores when 64% of responses were positive and 23% 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

We continue to get many comments describing 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.

*All I want is my potentially dyspraxic child with ligament laxity to have a shot at achieving her GCSEs but without a proper assessment and diagnosis the school can't offer extra exam time etc so she will probably fail*

*Schools need the support to be able to support our children properly. They need proper training, they need have support there when they need it straight away. There is not enough flexibility in the system to support children even with an Ehcp*

*Been told my child wouldn't get an EHCP, due to them not being 3 years behind, but it's their social and emotional needs that need to be met*

*Refusal to assess for EHCNA has led to months of delay in accessing support and assessment which will enable my child's needs to be identified. In that time the whole family has suffered and been unable to thrive*

## Supporting children to attend school

There were many comments about the barriers to children with SEND attending school. These ranged from anxiety, transport, the lack of appropriate school places and services not working together to enable continued attendance. Parents clearly want their children to attend school. Some reported turning to home education as a last resort.

*Still waiting for appropriate adjustments to be made to allow my daughter to fully participate in school again*

*My son was attending a setting but they are unable to meet his needs and therefore we have been forced to find an alternative. He is receiving no education currently*

*LA refuse to accept she needs medical tuition, despite not being able to attend school. All local policies of course.*

*My son is on a part time timetable due to his struggles to cope all day but there has not been much in the way of structured work to help what he is missing*

*New school, transition has been hard and anxiety has built and needs are not being met. Now out of school for 6 weeks, not much support from school*

*Not at all. My son has Ehcp, just done a 6 week placement at a PRU? No issue their (sic), goes back to his Mainstream school and excluded on first day? It's destroying his mental health. School just don't seem to understand his struggles and communication for him to understand isn't good either:*

*He goes to school this year but needs not met is very unhappy and not coping. Mental health declining. Autism provision is not allowed to support autism as it was previously and students pushed to attend mainstream beyond what they can reasonably manage. When behaviour deteriorates as a result they get sent home. My Child can't access taxi due to anxiety so I have to transport him.*

*My son isn't an academic, but loves sport and potentially music/theatre. I don't think there is enough focus on the other talents/skills children have that could boost their confidence in other ways, rather than feeling that school is all about the classroom.*

*No available suitable nursery*

## Many families feel that the education system does not recognise their children's diverse strengths or celebrate their different successes.

Families reported that the focus on academic results, attendance and behaviour did not recognise their children's strengths. Many felt that they were not given the opportunities to flourish in more holistic or diverse ways and when they did they were not praised or celebrated enough.

*I feel that there is a distinct lack of ambition for children with special needs in education!! Where's the baseline, where's the distance travelled.. how are we supporting wider skill development for our young people*

*Again there doesn't feel to be a lot of ambition for children with SEND more could be done to routinely measure their progress and set stretching targets for children*

*My child's self-esteem is very low - caused by his teachers not encouraging him.*

*No he's pushed to attain academically but socially and emotionally no progress is made to prepare him to function beyond school at all or even accept his disabilities. It's all negative*

*I don't think primary school nurtures creativity they seem to be more concerned about children reaching their targets at such a young age.*

*I think the pressure of GCSE for those who are borderline in need of a special school is a travesty. There needs to be a broader curriculum choice for those who are not going to get 4+ on their GCSEs so they don't feel they have failed.*

*My child is not academically enclined (sic) and at her current age education is all about academics, there should be a balance so that children like mine can also strive in school*

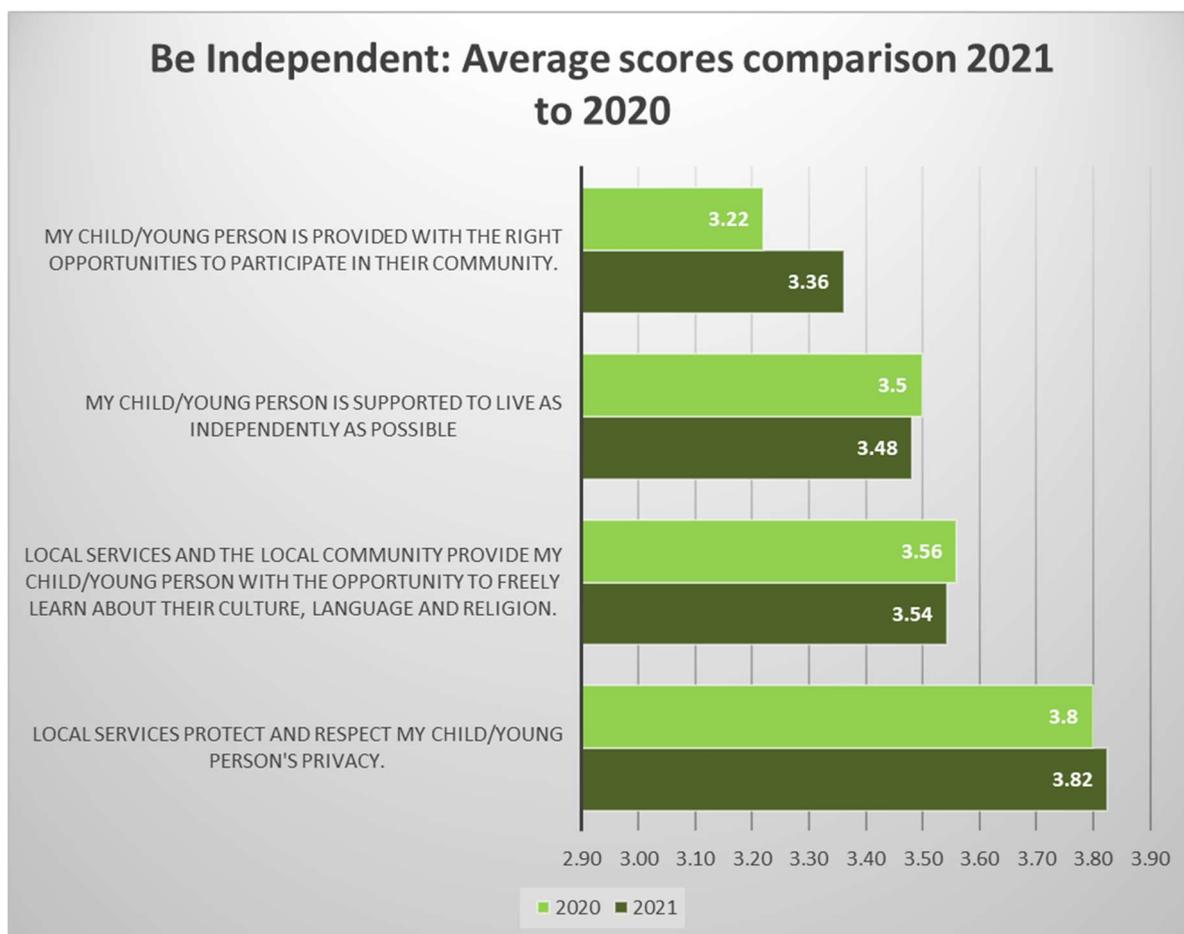
*He needs a curriculum that meets his strengths. Making him do dance when it triggers the worst behaviours is pointless for everyone involved.*

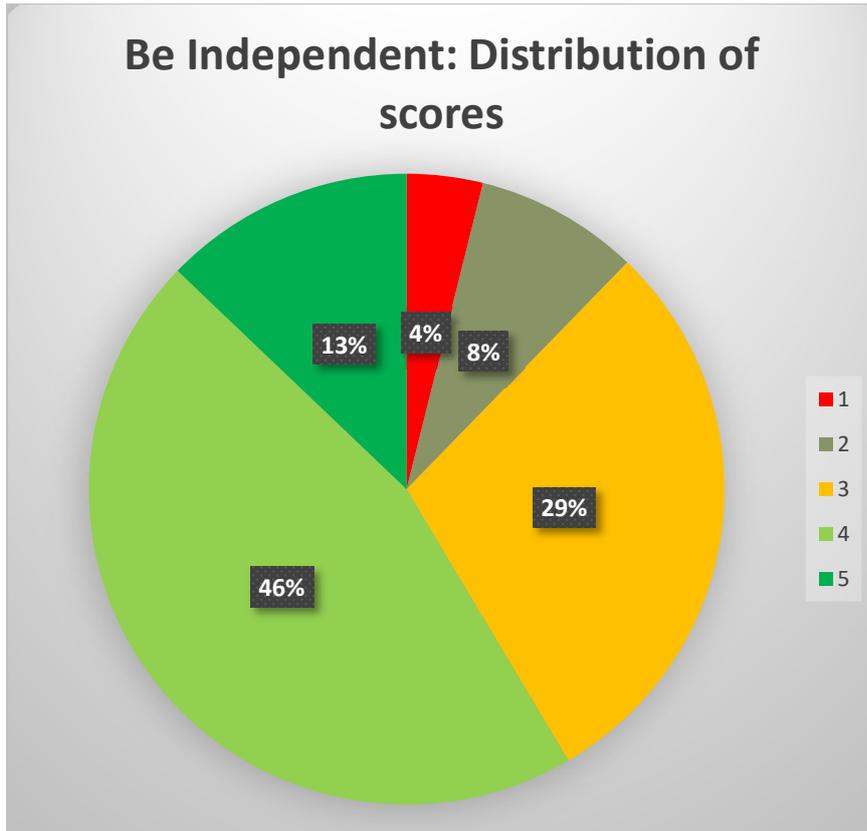
# Be independent

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The average score for this outcome was 3.55. This is very similar to the score last year which was 3.52.

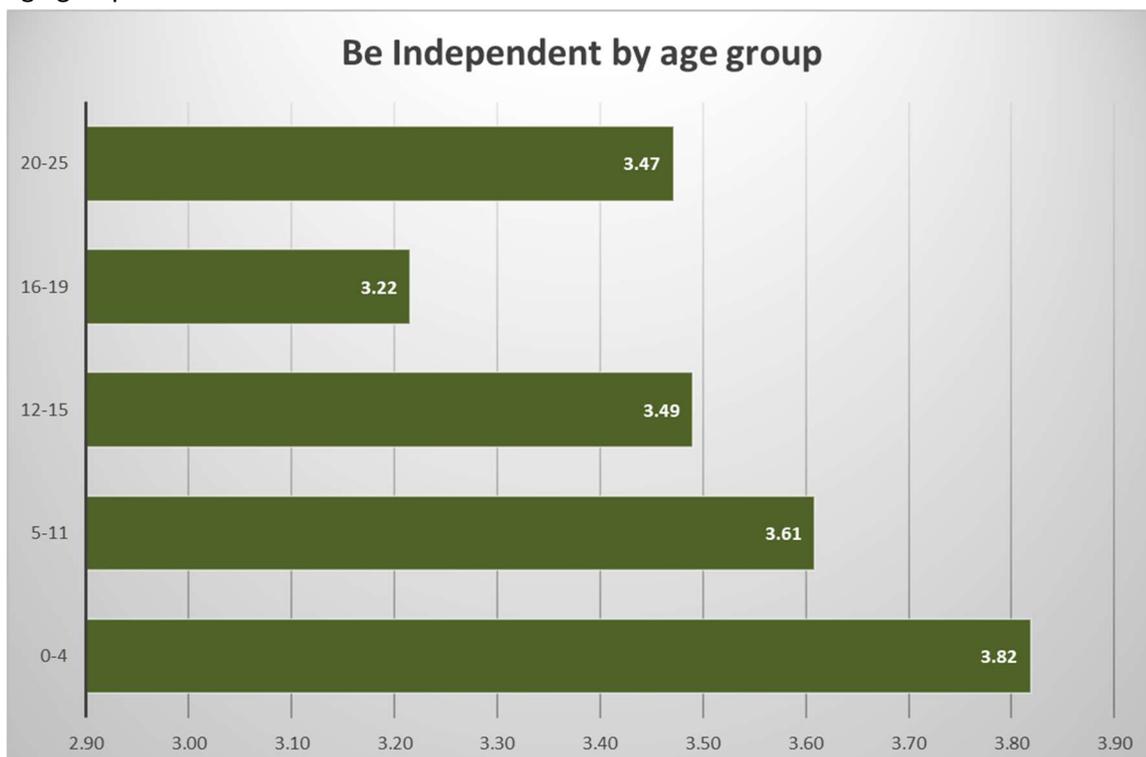
The individual question scores were also very similar year on year. The only notable move was an increase in the score for the question about “my child is provided with the right opportunities to participate in their community” which increase by 0.14.





In this year's survey 59% of responses were positive and 12% negative. Last year 55% of responses were positive and 12% were negative.

In line with other outcomes, we see a deterioration in scores, the older that children and young people get until the 16-19 age group which records the lowest score. This picks up again in the 20-25 age group.



## **Families wanted more support, options and planning to help their children and young people achieve a degree of independence**

There is a sense that services do not support the need for independence until it is too late. There is not enough of the right interventions at the right time which means that opportunities are missed and long term independence is compromised.

*I've tried and failed to find support for my son to access independent living support*

*Independence requires that basic skills are taught NOW, before the CYP becomes old enough to be considered for independence. It's too late then. These basic skills, are acquired through speech/language and occupational therapy services. Unfortunately in my case, these therapy sessions aren't meeting the needs of my CYP. And there is a real unwillingness to want to consider more therapy. It's a false economy, by starving my CYP of the 5-6 years of therapy needed now, they are just passing the buck to social services 10 years from now, and they will need to be involved for the next 40+ years ensuring my CYP has the support needed.*

*Not at all. All the provisions needed to help my child become independent are meagre. I have no faith that my child will be able to develop much level of independence in the future. All that the LA are doing is kicking my child's needs into the long grass, and at some point in the future social services will have to look after her. It's a false economy. They could save so much money later by investing in my child now. But LAs are only worried about current budgets. #myopic*

*Still waiting for OT to help with life skills dressing eating toileting etc.*

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

*Don't hear much about what's on offer*

*My child is not able to access the same services as other young children*

*Needs improvement in local community for adults to access to reach full potential*

*Never had any access to peer group supported activities. Worse now he is an adult*

*Struggles to fit in and be understood by the community*

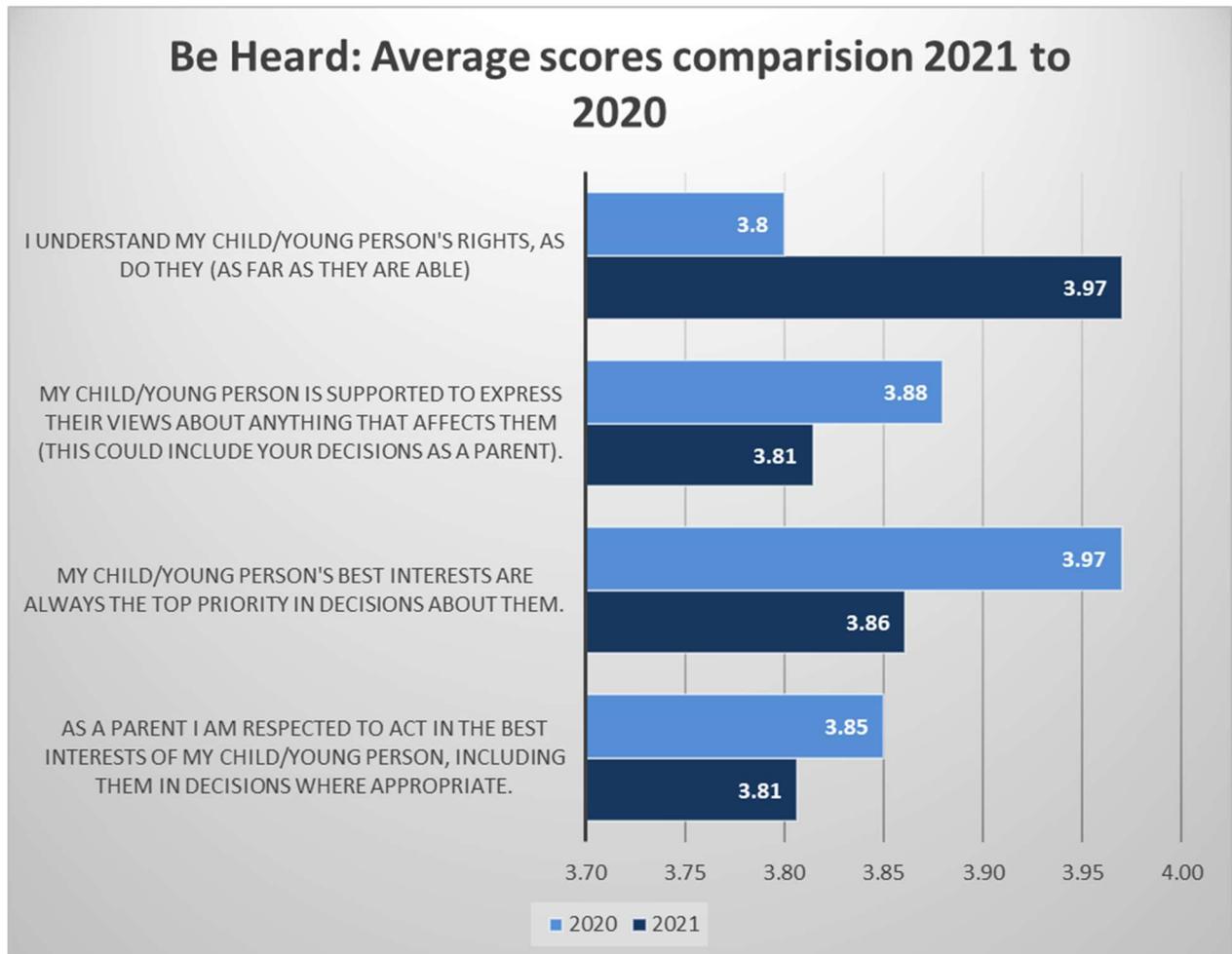
*They're only able to access specialist services.. there isn't a lot of community participation*

# Be Heard

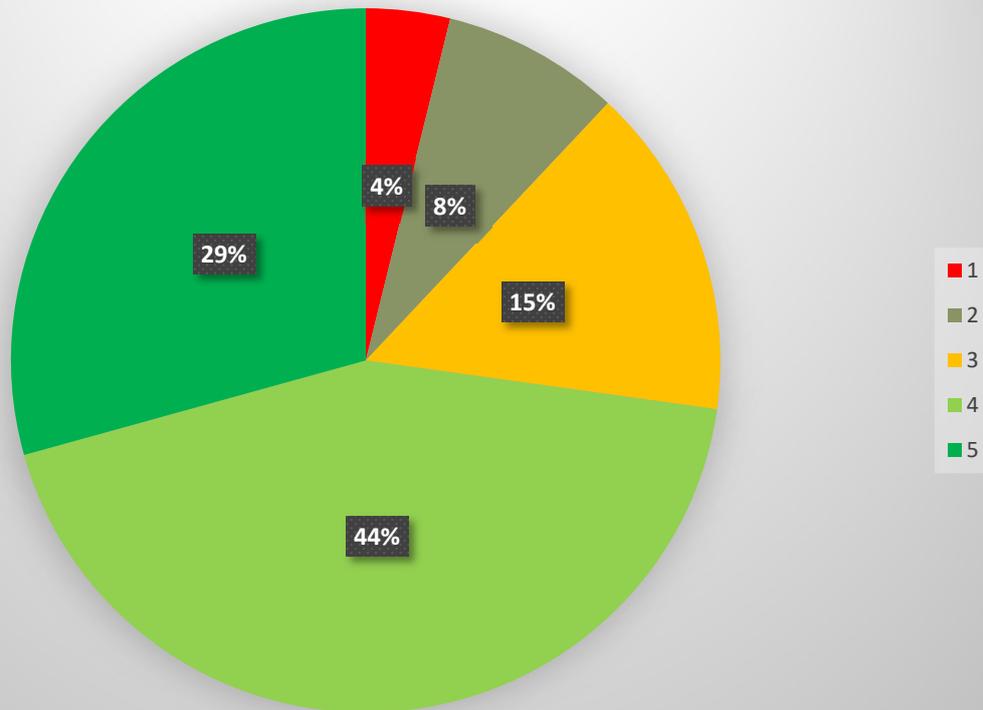
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The average score for this category was 3.86 which is materially similar to last year when the score was 3.85.

The biggest changes in individual question scores came in the understanding of rights which increased by 0.17 and the belief that best interests were always the top priority in decisions about them which decreased by 0.11 points.



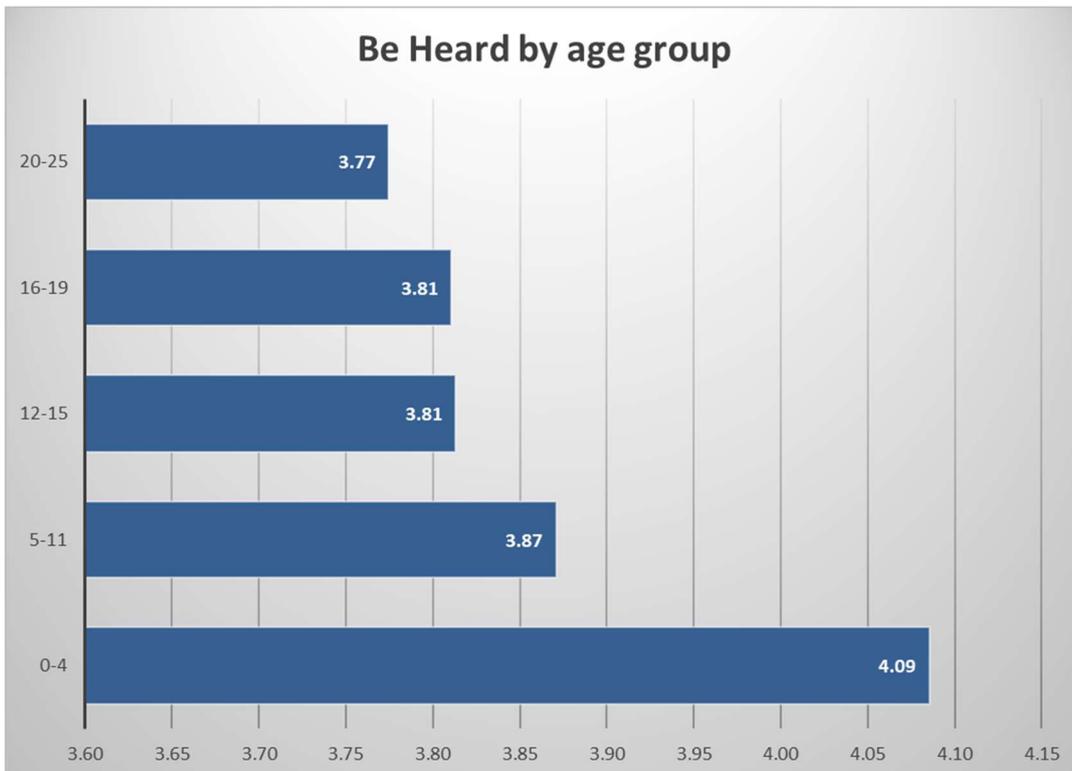
## Be Heard: Distribution of scores



In this year's survey 73% (2019: 73%) of responses were positive and 12% (12%) were negative..

The age profile of the scores is significant. The older they get, parents think that they and their children are listened to less and less.

## Be Heard by age group



**There was a strong theme of “parent blaming” in many of the comments. This has not been a strong message in previous years**

The comments here related predominantly to schools and council officers.

*A lot of parent blame exists still. Especially from school if they don't like what I say it's ignored or ridiculed behind my back SAR this*

*Blamed and shamed by most professionals in most meetings. Schools are the worst. Primary especially but they then send that info to secondary school..*

*Parent blame culture within the LA*

*Respect would be wonderful but currently is none (sic) existent. Council officers appear to prefer to question and criticise my mannerisms, body language and facial expressions rather than concentrating on my son's needs.*

**Despite improving scores there are still many parents who do not believe that they are heard and that the quality of coproduction with them and their child is poor.**

*Absolutely no co production takes place within BBC*

*I said mainstream wasn't suitable for my daughter - but apparently people with a notepad know my daughter better. Now she is struggling tremendously.*

*If people respected me and my knowledge on the situation, my child wouldn't have been out of education 2 years with severe MH issues!*

*I feel like I am not always listened to and heard but also my boy is so different in school*

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

*Appears money is more important than the child*

*It appears that budget concerns are top priority*

*This is in relation to the Education side of the EHCP. Cheapest option is always the only one that is available. Borough puts money before needs.*

*Budget is a greater factor than the needs of the individual - this isn't necessary (sic) the LAs fault, more the years of austerity and funding cuts at a higher level*

*It always comes down to availability of resources*

**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't .....I 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

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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”*

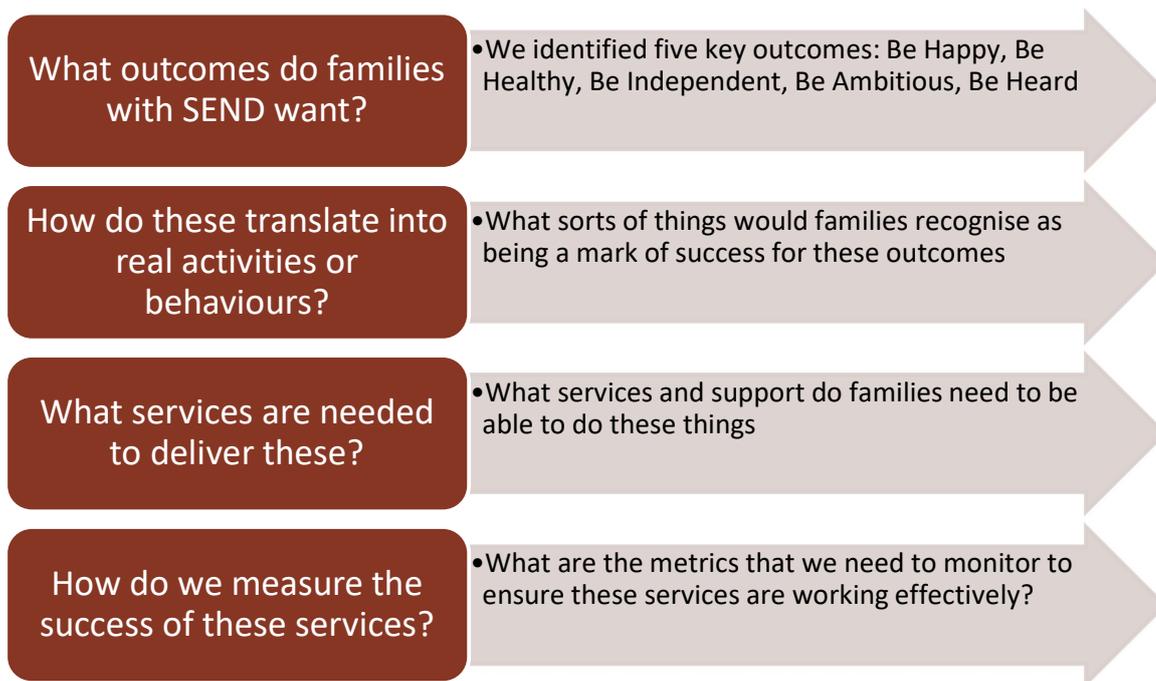
## **Outcomes framework**

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

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: Bedford Borough Parent Carer Forum

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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.