

Bedford Borough Parent Carer Forum Outcomes Report: One Year On

December 2019



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 represents the refresh one year on from our initial survey.

Our methodology

Between October and November 2019, we asked parent carers of CYP with SEND to complete a survey to capture their lived experiences in Bedford Borough. The survey could be completed online or in person at the many events we hosted and attended during this period such as our coffee mornings and the virtual SEND team meetings. Parents were able to add comments to each answer.

The 2019 survey was based on the survey we conducted in 2018 to ensure comparability. However, we 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 107 parent-carers in 2019 (151 in 2018).

Summary Results

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

The average score across all questions in our survey was 3.35.

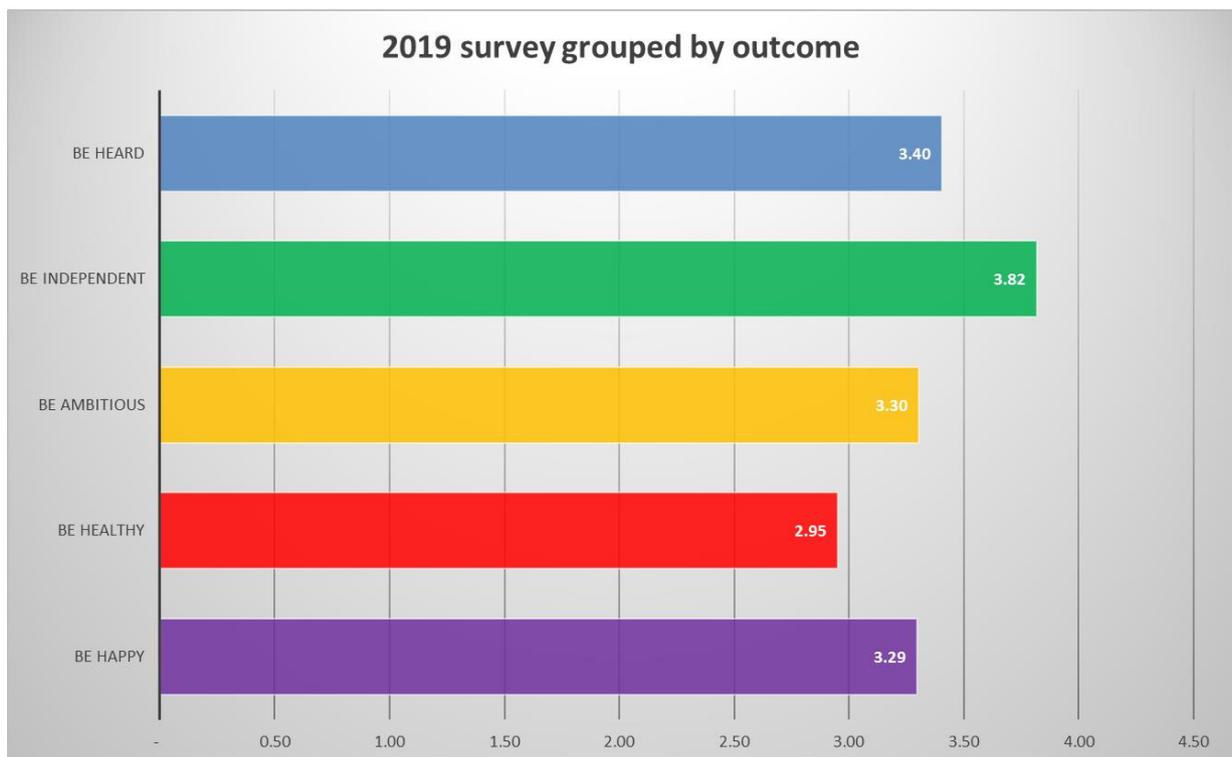
This means that the needs of children and young people with SEND are only being adequately met at best. This falls short of our stated ambition that needs should be being well met (a target score of 4 or more). Given that the questions were based on the United Nations Convention on the Right of the Child,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

Average score

3.35

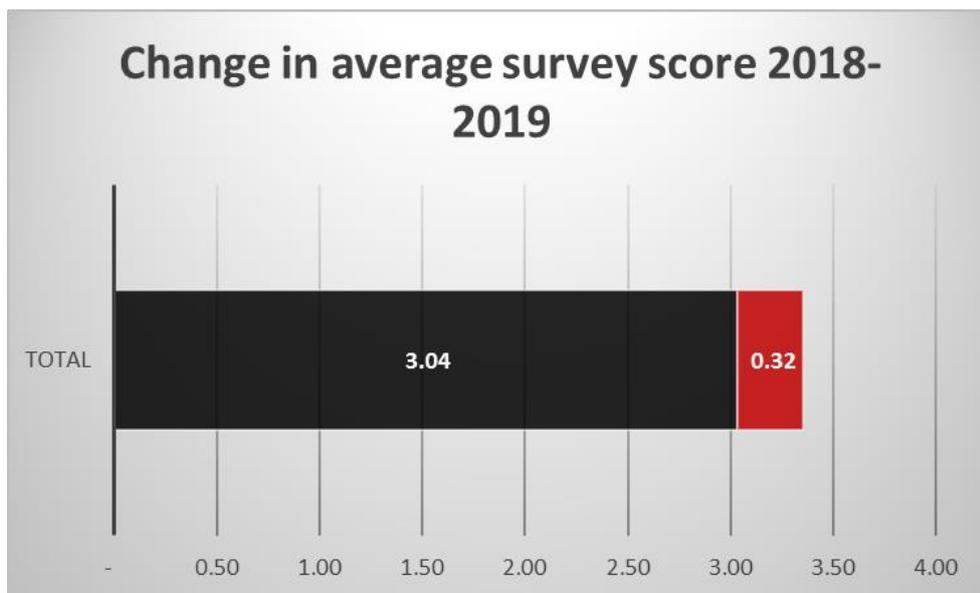
(out of 5)

The average scores for each outcome were as follows:



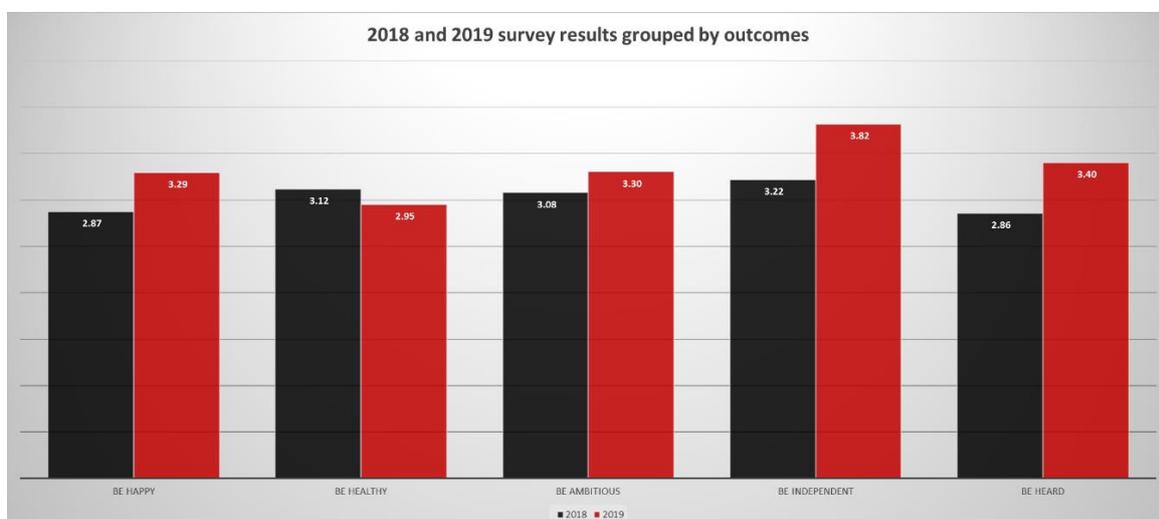
There has, however, been an improvement in scores in comparison to 2018, which evidences that some of the changes that have been made are starting to have an impact.

There was a modest improvement in scores in comparison to the results in 2018 when the average score was 3.04. This represents an improvement of 0.32 year on year. This suggests that the changes that have been made in the local area over the last year are beginning to have some impact.



Excluding the new questions that were added (which attracted the lowest scores), the overall improvement is an average 0.4 to 3.48.

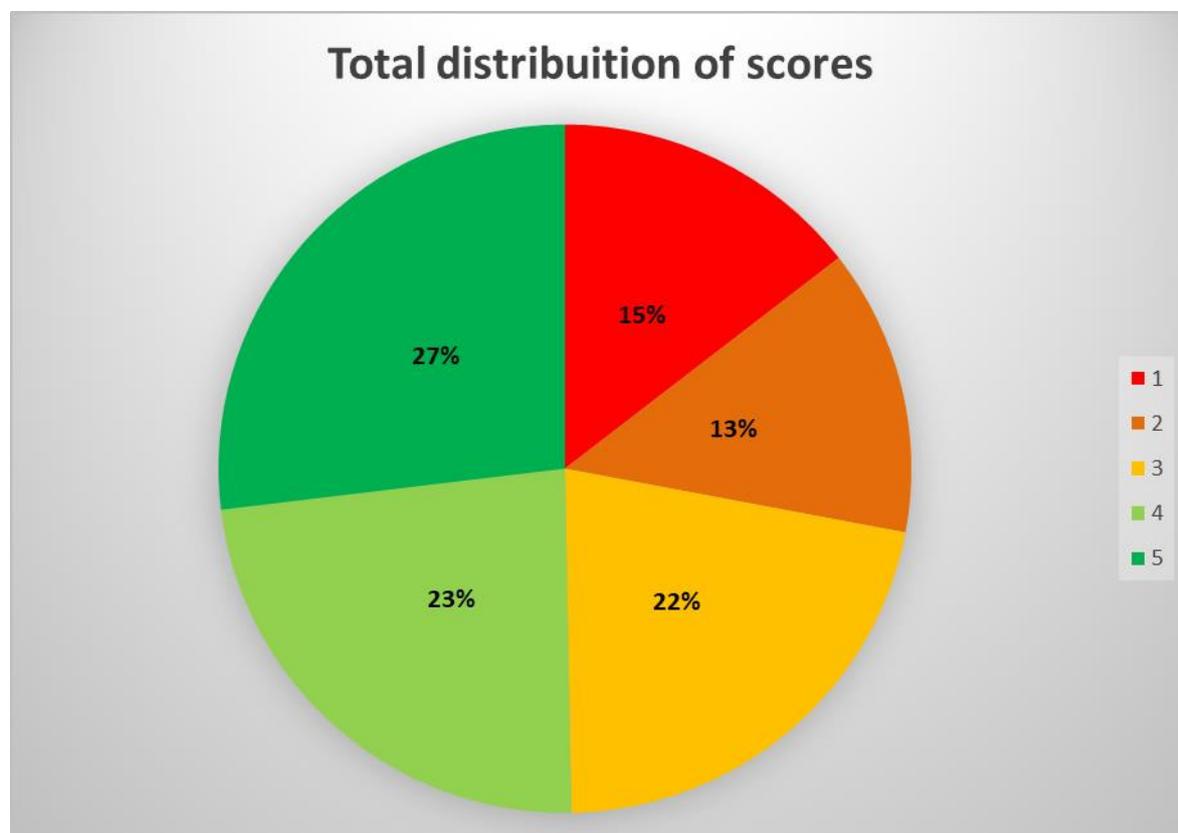
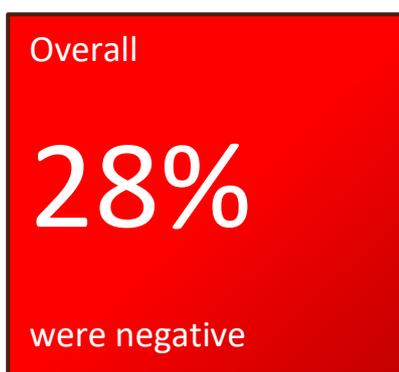
Generally, there was a reasonable improvement across all of the outcome areas with the exception of the "Be Healthy" category where the two new questions introduced for 2019 attracted the lowest scores of the survey.



Scores for only one question failed to improve year on year (“Does your child have access to education”) and the fall here was an average 0.02 marks which is not statistically significant.

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, 50% of all responses were positive (scores of 4 or 5) whilst 28% were negative (scores of 1 or 2).



This marks a notable improvement from our survey in 2018 when 38% of scores were positive and 38% were negative.

More respondents reported having a positive experience than last year (up by 12%) and fewer respondents reported having a negative experience (down by 10%).

Key Findings

There are positive messages from our survey that show progress is being made in key areas

1. Parents are feeling more positive that their voices are being heard and that they and their children are trusted to participate in key decision making

- Over 50% of respondents gave positive ratings (scores of 4 or 5) when asked about whether they and their child were supported and trusted to participate in decision making about them. The average scores for these two questions improved by 0.58 and 0.42 marks respectively.
- Over half of respondents (53%) gave a positive response when asked if they felt that decisions were being made in the best interests of their child – a dramatic increase from just 27% a year ago.
- Parents made positive comments about the availability and transparency of information. The local offer was mentioned a number of times in this regard.

2. Parents were very positive about the special schools in Bedford Borough.

Parents described settings that provided joined up personalised education that supported the child and the family in a holistic way.

3. The overall trajectory for all but one question year on year is positive. The majority of the improvements are modest and we have not seen dramatic increases across the board but parents are measurably more satisfied with the outcomes for their children and young people than they were one year ago.

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

4. The experience of children with SEND in mainstream schools is too varied and often poor.

- Families described concerns about the inclusivity of mainstream schools with approximately 20% having experienced some sort of unofficial exclusion in the last 12 months.
- Parents commented that the unique talents of their children were not being recognised with too much focus on academic success.
- Too often we heard about either a failure to agree reasonable adjustments or to apply them consistently when they had been agreed.

5. Parents continue to express real frustration with access to key medical services, most notably community paediatricians, Child and Adolescent Mental Health Services, Speech and Language Therapy and Occupational Therapy.

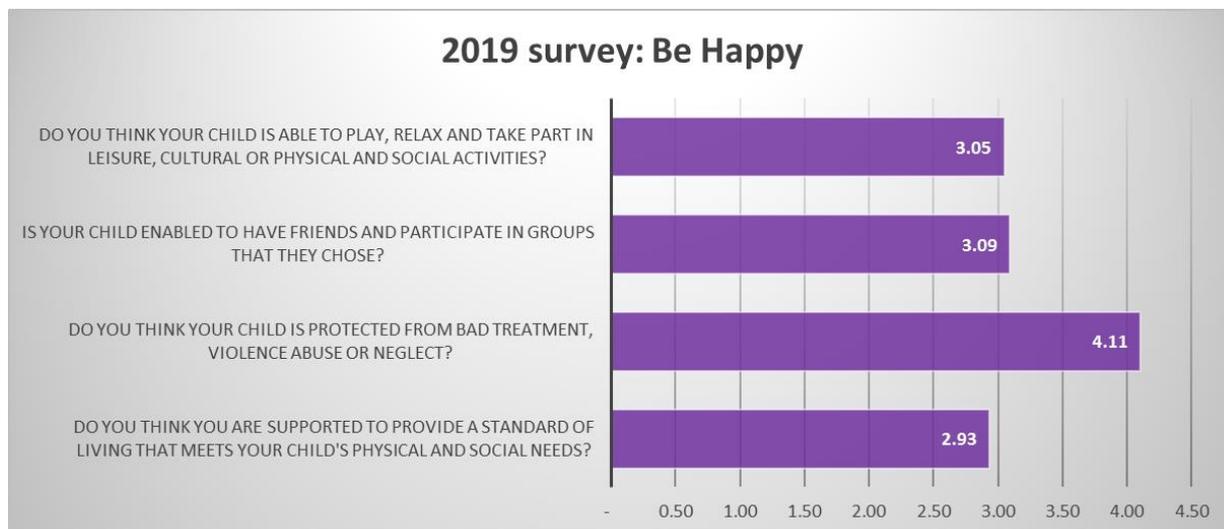
- Families told us that they did not understand how to get access to medical services – some pathways are not well understood and too often they described difficulties in who could refer them and how
- There was a sense that there is too much gatekeeping of key services with too much emphasis on thresholds and not the needs of the child
- They also told us that they had to wait too long to be seen once access was granted and that the waits between appointments was too long. The question on how quickly they could access medical services received the highest negative scores across our whole survey with 54% of respondents scoring a 1 or 2.

The local area has made recent efforts to address both of these areas. Additional resources have been identified to support SEN provision in mainstream schools, KPIs from the new CAMHS contract are favourable and additional resources have been put into SALT services after failings were highlighted.

However, it is clear from our survey that many families are not yet feeling the benefit of these changes.

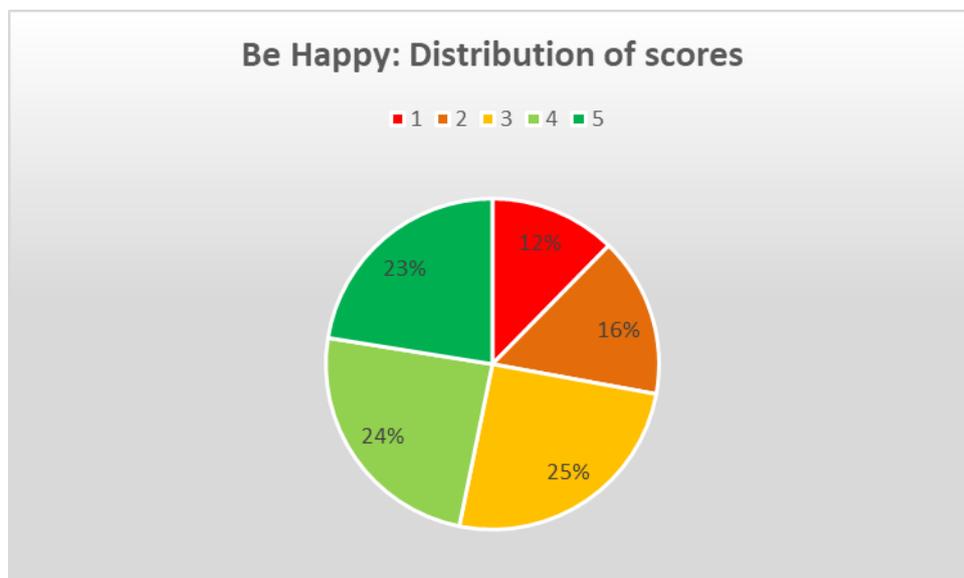
Be Happy

The average score for parent-carers in this category was 3.29. This represents an improvement year on year of 0.42.



This was one of the lowest scoring areas in our 2018 survey with an average score of just 2.87.

There has been a consistent improvement across all questions with the biggest increase (0.7) in the question about children being protected from bad treatment, abuse or neglect. The only question with an average score of less than 3 is the one about families being supported to provide a standard of living that meets their child's needs.



In this year's survey 47% of responses were positive and 28% were negative

This is an improvement from the 2018 results in which 33% of responses were positive and 42% were negative.

Many families feel there should be more social activities for their children or do not know about the social activities that are available

Most of the comments in our survey about access to social activities mentioned that parents felt that there were not appropriate activities for their children. For example

"We are lucky that finances are not an issue, however, our 18 year old does not have a social life outside of her apprenticeship. Lack of facilities for young people with MLD that she can access."

"There is little to no support for children suffering with ADHD."

"Hard to find appropriate social, sporting, fun activities. Especially in school hols."

"SSG are making a real effort with their FUN 4 ALL programme and SEN proposed football but we still have a long way to go"

"Have struggled to find appropriate groups. Only attend frame football, which is great, but only happens once a month."

"Big improvement in accessing 'social' activities across Bedford Borough - local offer has been key in this"

However, the overall score for this question improved by 0.27. We believe this may be because of an improved local offer and families being more aware of what is available, most notably through the well-established local disability charities.

Some parents raised concerns about the well-being of their children outside of the family home

Generally, families felt their children were safe but some parents reported concerns about their well being at schools. Some of these comments were historic and many parents reported recent improvements.

"I do feel secure that any person involved with my child would not harm her/him."

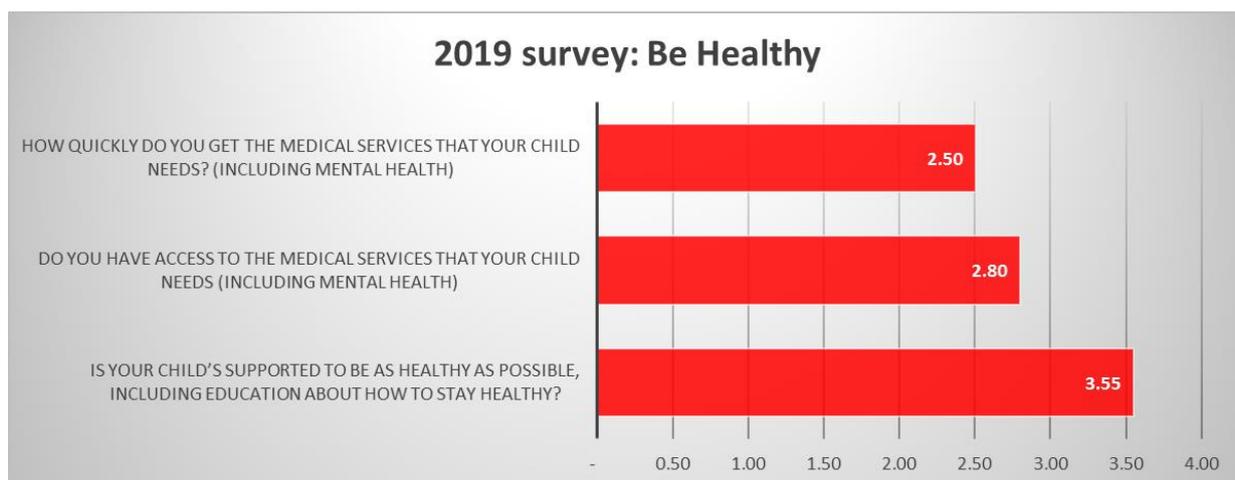
"Ongoing bullying not dealt with adequately"

"Safe now but in the past no, he was regularly shut in a cupboard during autistic meltdowns at his autism provision. We have now moved him"

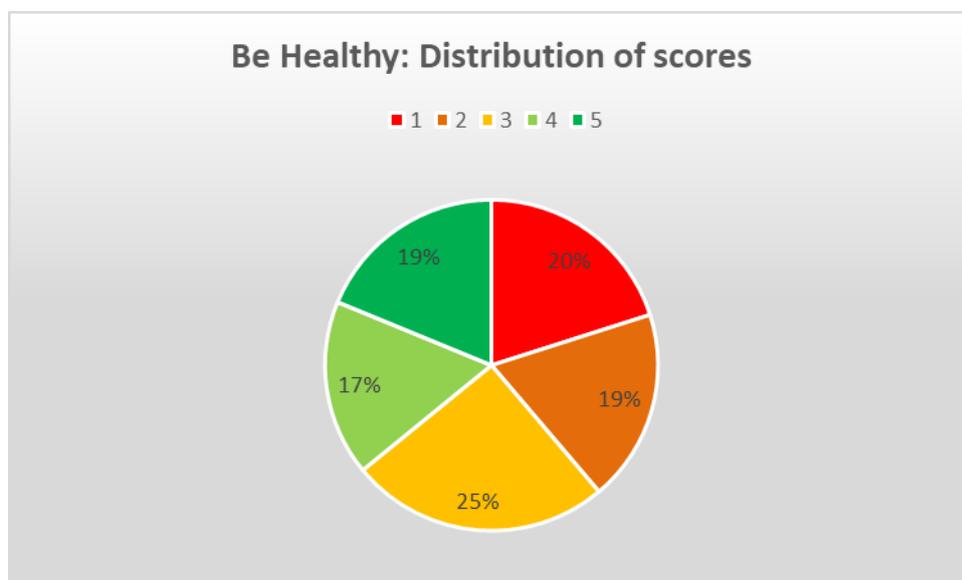
Be Healthy

The average score for parent-carers in this category was 2.95. This was skewed by the two new questions that were added for 2019 which asked about access to medical services and waiting times.

A like for like comparison of the question that was asked in 2018, shows an improvement of 0.43 from 3.12 in 2018 to 3.55 in 2019.



The two new questions resulted in the lowest scores in our survey. This clearly suggests that whilst some priority has been given to these areas by the local authority and the CCG, families are not yet feeling the benefit and more work needs to be done with regards to access to medical services and waiting times. These two questions attracted the greatest proportion of negative responses (1 or 2) with 44% dissatisfied with the amount of access they had to medical services and 54% dissatisfied with how quickly they got access to medical services.



In this year's survey 36% of responses were positive and 39% were negative

Families do not know how to access to key services – pathways are unclear and entry thresholds are considered too high.

Four services were mentioned as being difficult to access time and time again in the comments from parents. These were Child and Adolescent Mental Health Services (CAMHS), Speech and Language Therapy (SALT), community paediatricians and Occupational Therapy (OT).

Parents also commented on difficult transitions between children's and adult services.

"Unable to access chums / CAMHS as too many criteria to go through."

"No access to CAMHS (told ASD kids don't meet criteria)"

"Sometimes difficult to know who to contact, the transition from child (where everything is basically done automatically) to adult (where parent/carer needs to make the arrangements) is abrupt."

"Getting an appointment with the paediatrician is virtually impossible. My child started on strong medication in March this year and wasn't seen or checked by a doctor until the end of August and the only reason he was seen then was because I went on a cancellation list."

Some families have experienced long waits in accessing services

Families reported long waits to be seen once referred to services and long intervals between services. There were some comments recognising the recent changes that have been made to improve access to SALT and CAMHS services.

"Have to wait for EVERYTHING."

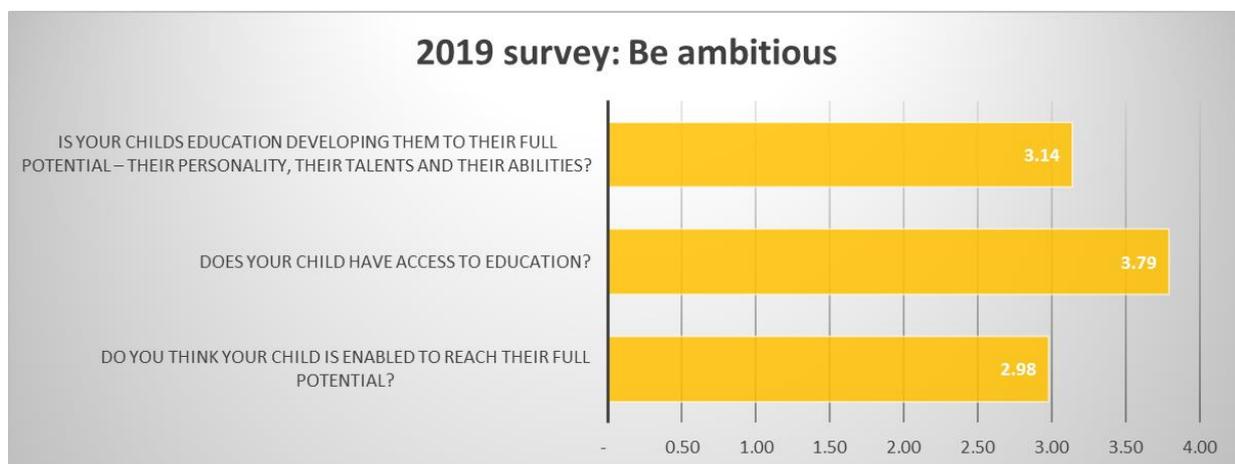
"Atrocious. We were told we would be seen again in 4 months, it's now 10 months later"

"SALT taken years but is now in place but needs to be consistent"

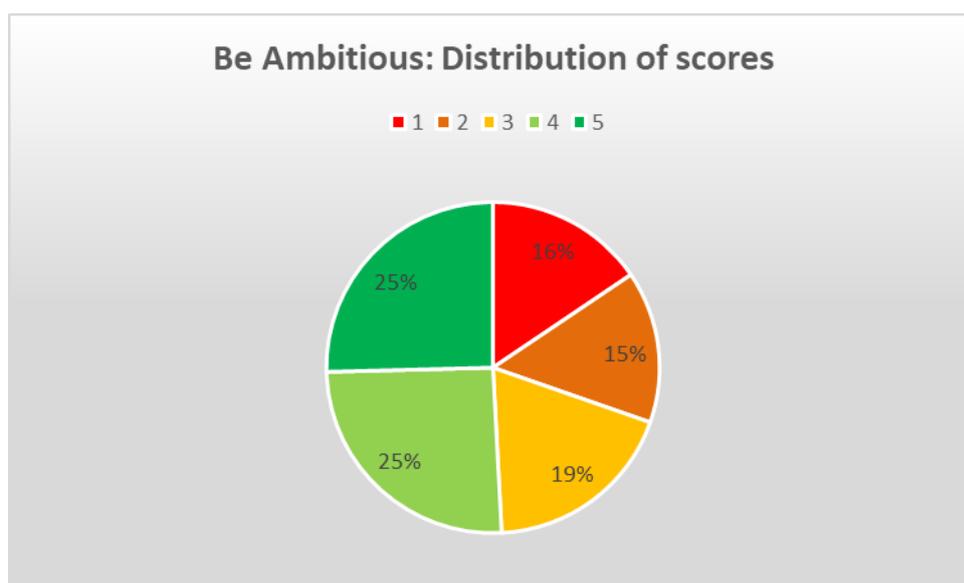
"We access single point of entry for CAMHS and CHUMS"

Be Ambitious

The average score for parent-carers in this category was 3.30. This represents a 0.22 increase from the previous year.



The overall distribution of scores was:



In this year's survey 50% of responses were positive and 31% were negative

This is an improvement from the 2018 results in which 40% of responses were positive and 37% were negative.

The survey offered very different results depending on whether children attended mainstream or special schools

Mainstream schools

Many respondents expressed concerns about their experiences in mainstream schools. Many described situations where:

- Schools were not working in a joined-up way with the other agencies to provide the support that their child needed
- There was a focus on the challenges faced by children with SEND rather than on their talents and abilities
- Reasonable adjustments were not being made and applied. Parents sometimes described situations when adjustments and provision were agreed but not put in place.

“He can achieve so much more with the right support but instead we see him falling further behind every day and this in turn affects his mental health self-esteem.”

“They don't see him the way we do, if only they knew how amazing he can be but nobody takes the time.”

“School concentrates more on things he is unable to do rather than what he is able to do.”

“He is extremely academically able, however is hugely anxious and does not receive adequate support to achieve his potential.”

In addition, we asked families whether they had experienced any of the following forms of unofficial exclusions in the last year. Our parents continue to express real concerns that mainstream schools in Bedford Borough are not inclusive. Of the parent carers that completed our survey, approximately one in five had experienced some sort of unlawful exclusion practices in the last 12 months:

Part-time school timetable	20%
Missing school trips or only allowed on a school trip if accompanied by a carer	21%
Asked to stay at home for a period of time without a formal exclusion	19%
Discouraged to attend or apply to a certain school	21%
Off-rolled	7%
Encouraged to be home educated	8%

Special schools

The experiences of children in special schools was dramatically different. Parents described a setting that provided joined up personalised education that supported the child and the family in a holistic way.

"All areas are covered within the setting and working with outside agencies this has been achieved."

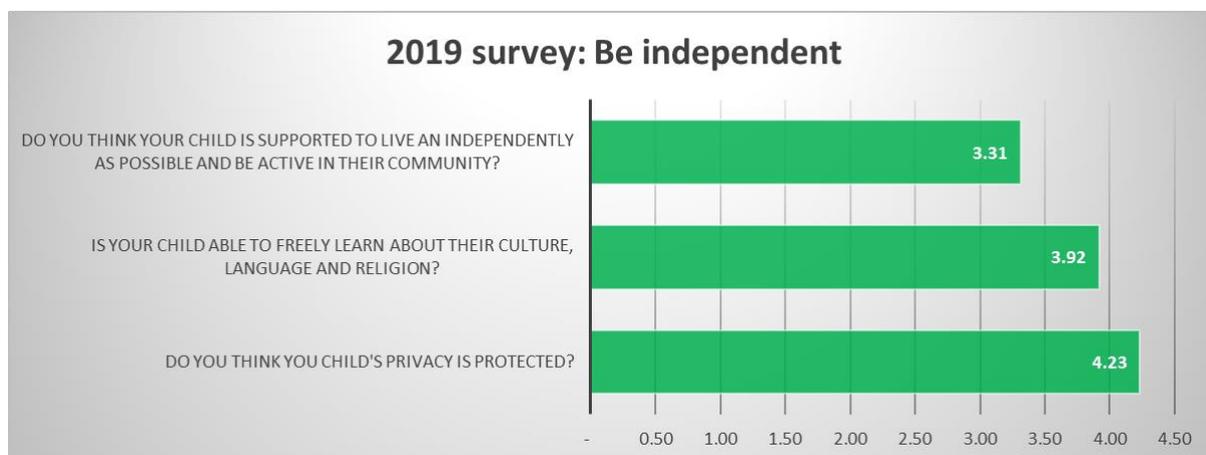
"They are very well supported and school and advice has been given to me to help at home"

"Special needs school... thank goodness"

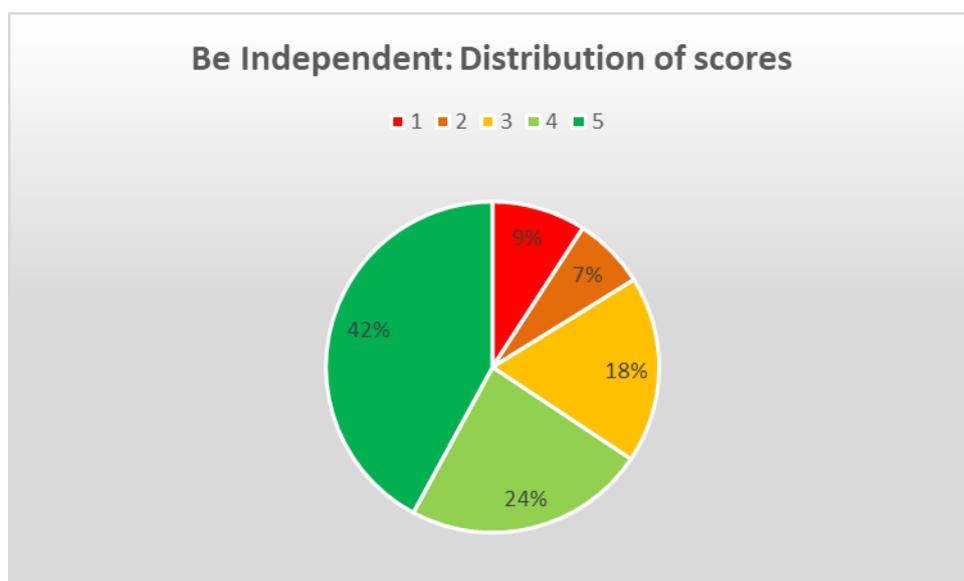
"At the beginning we had loads of trouble but when he entered special school things changed massively."

Be independent

The average score for parent-carers in this category was 3.82. This is an increase of 0.6 from 2018 when the average mark was 3.22



The standard deviation of scores in this category was relatively low with a majority of respondents giving a positive answer (either a 4 or a 5) to all questions.



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

This compares favourably to the 2018 survey results in which 59% of responses were positive and 24% were negative.

Parents feel that their children’s privacy is protected and that they are able to learn about their culture, language and religion.

These two areas attracted some of the highest marks across our survey. The multi-cultural nature of Bedford as a town is clearly reflected here and services in Bedford were noted to reflect this.

Parents did express concerns about the support that they were getting in preparing their children for independence and independent living in particular

This was an area that was highlighted in the local area inspection and it attracted a score of 3.31 with those parents that were thinking about their child’s future independence clearly expressing concerns. The local authority has made concerted steps to make Bedford a more inclusive town but this is clearly not being felt yet by the families who responded to our survey.

“We are developing independence skills....I don't feel supported in this and I feel uncertain what her longer term options will be”

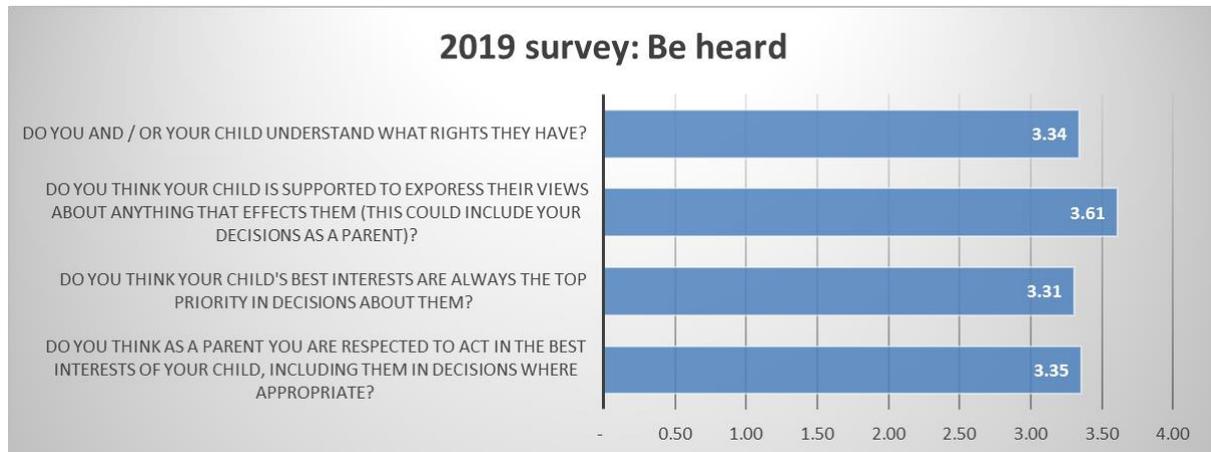
“No support in this respect at the moment. I am awaiting a revised EHCP but I don't think the appropriate provision will be included”

“Really well in specialist provision, virtually non existent in mainstream services”

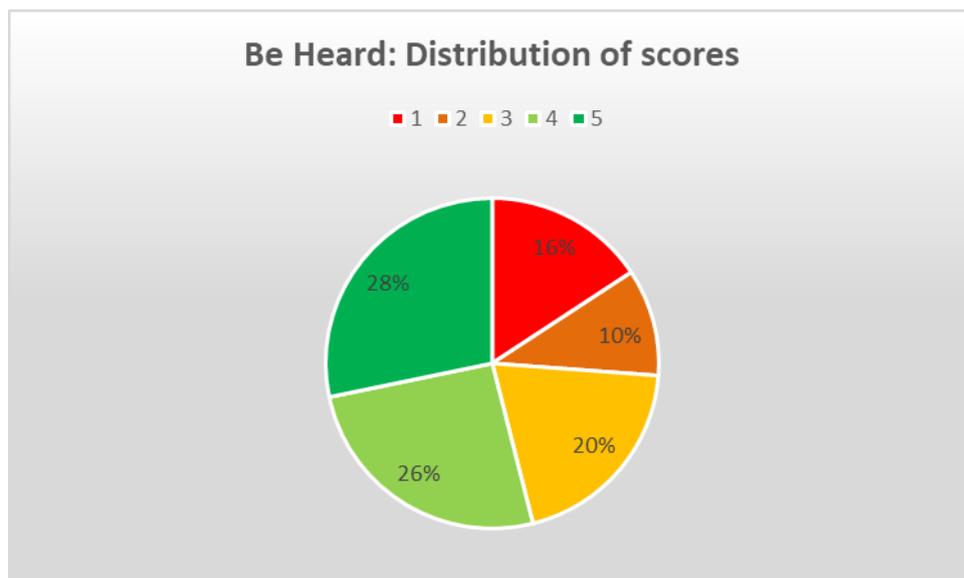
“No support from the outside but in the home we present an environment where he is given as much independent learning opportunities as possible.”

Be Heard

The average score for parent-carers in this category was 3.40. This increased by 0.54 from 2018 when the average score was 2.86.



This represents a significant and important increase. In the 2018 survey, being heard received the lowest average score across all of the outcomes. The voice of the child, young person and their parents is the heart of the principles of the Children and Families Act and previously, families clearly did not feel that they were listened to. These scores have seen notable improvements over the last year with over 50% of respondents giving a positive answer (a 4 or a 5). However, the average scores remain short of our targets but clearly progress is being made. Nevertheless, amongst those that gave low scores, there were some consistent themes that provide areas of focus.



In this year's survey 54% of responses were positive and 26% were negative

This is an improvement from the 2018 results in which 34% of responses were positive and 44% were negative.

Many parents who gave low scores expressed cynicism about the motivation of services – they believe financial considerations are put before the needs of their child.

This question attracted the greatest variation in responses (a standard deviation of 1.5 – the highest across all questions) – over half of respondents gave a score of 4 or 5 believing that their child’s best interests were the top priority whilst almost one fifth gave a score of 1. The local area clearly has some work to do convincing some parents that financial considerations are not paramount.

“Money and targets are the priority”

“Always cost and who is going to pay for it is a bigger priority”

“All conversations are resource led discussions = not needs led discussions. Almost as if because the funding is not there, his needs don't exist”

Many parents also expressed concerns that they were not listened to as much as they should be

In particular there was a theme that parental views are not listened to early and that the system responds only when things get to a crisis point.

“Only very occasionally are my views listened to. But mostly, the LA do whatever they like, regardless of the effect on my children.”

“No one listens to me until it's too late.”

The changes made to the local offer and increased transparency about what is available received positive comments

The parents who gave higher scores in this category, cited improved information availability as a key factor. They were pleased that they knew what services were available and that they knew where to look to find more information.

“The updated graduated response will be so helpful and useful”

“Will need to access Local Offer to check now I know where to look”

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”

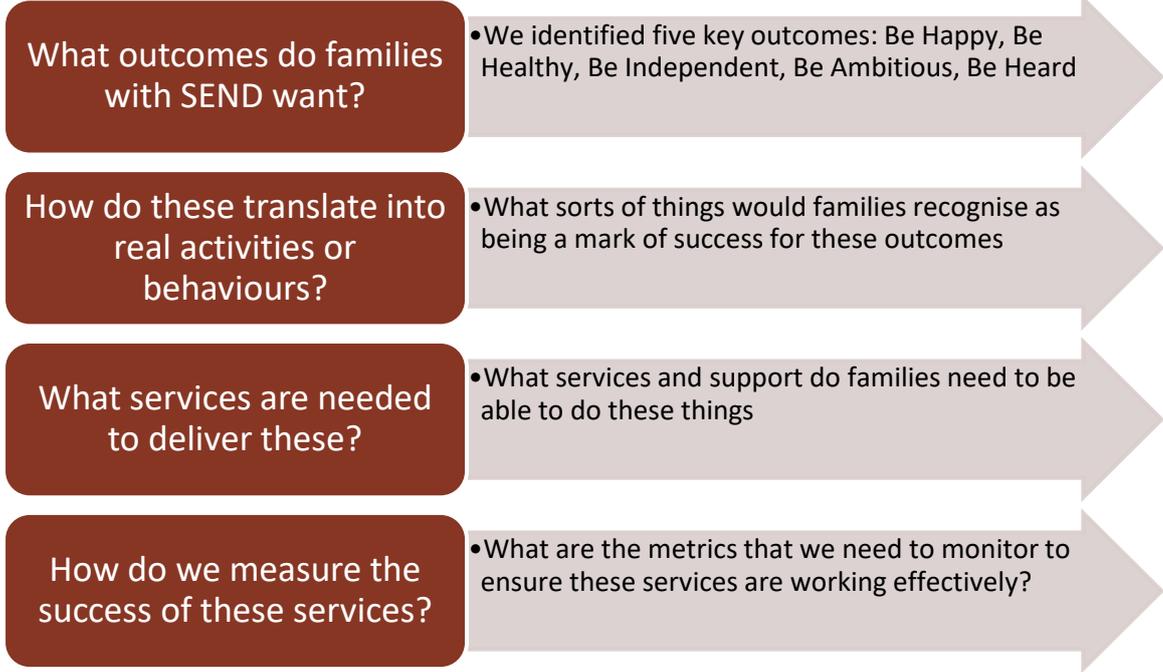
Outcomes framework

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.

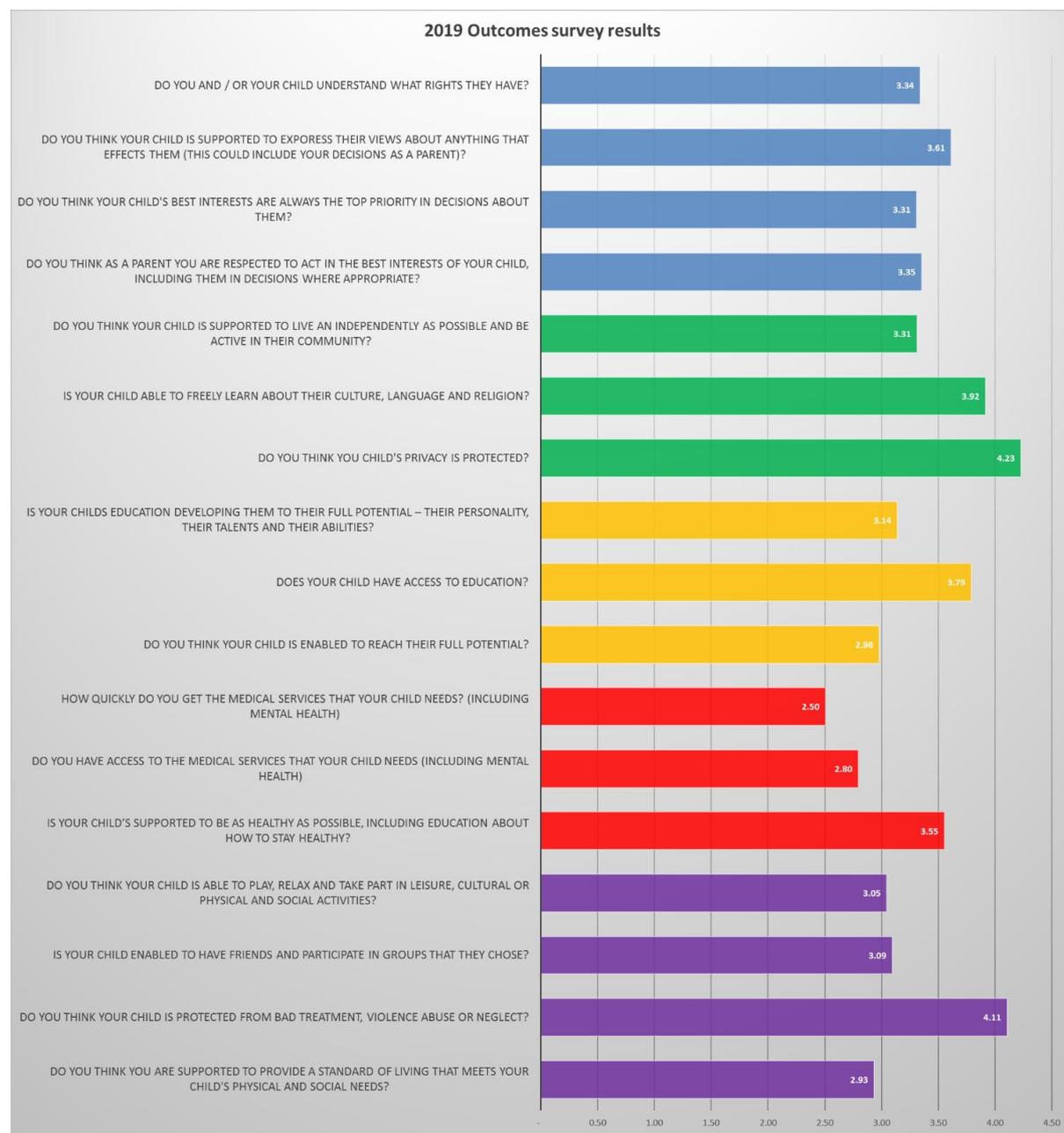


Appendix 2: Survey questions

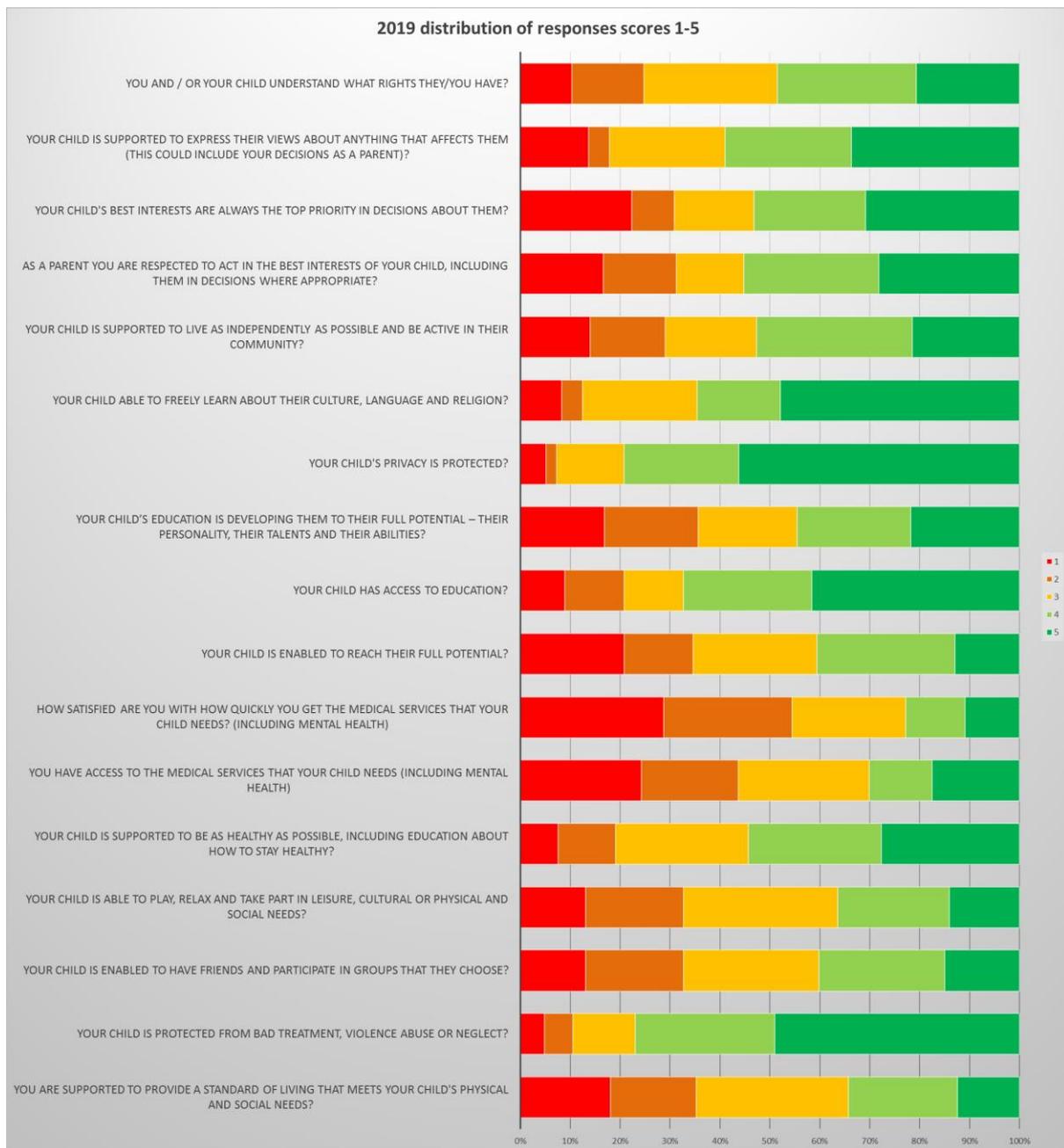
Outcomes	Questions	
1 Be Happy	Do you think you are supported to provide a standard of living that meets your child's physical and social needs?	
1 Be Happy	Do you think your child is protected from bad treatment, violence abuse or neglect?	
1 Be Happy	Is your child enabled to have friends and participate in groups that they chose?	
1 Be Happy	Do you think your child is able to play, relax and take part in leisure, cultural or physical and social activities?	
2 Be Healthy	Is your child's supported to be as healthy as possible, including education about how to stay healthy?	
	Do you have access to the medical services that your child needs (including mental health)	NEW
	How quickly do you get the medical services that your child needs? (including mental health)	NEW
3 Be Ambitious	Do you think your child is enabled to reach their full potential?	
3 Be Ambitious	Does your child have access to education?	
3 Be Ambitious	Is your child's education developing them to their full potential – their personality, their talents and their abilities?	
3 Be Ambitious	Has your child experienced any of the following (tick each one that applies) in the last 12 months: <ul style="list-style-type: none"> - a part-time school timetable - missing school trips or only allowed on a school trip if accompanied by a carer - being asked to stay at home for a period of time without a formal exclusion - being discouraged to attend or apply to a certain school - off-rolled - encouraged to be home educated 	NEW
4 Be Independent	Do you think your child's privacy is protected?	
4 Be Independent	Is your child able to freely learn about their culture, language and religion?	
4 Be Independent	Do you think your child is supported to live as independently as possible and be active in their community?	
5 Be Heard	Do you think as a parent you are respected to act in the best interests of your child, including them in decisions where appropriate?	
5 Be Heard	Do you think your child's best interests are always the top priority in decisions about them?	
5 Be Heard	Do you think your child is supported to express their views about anything that affects them (this could include your decisions as a parent)?	
5 Be Heard	Do you and / or your child understand what rights they have?	

Appendix 3: Detailed Survey Results

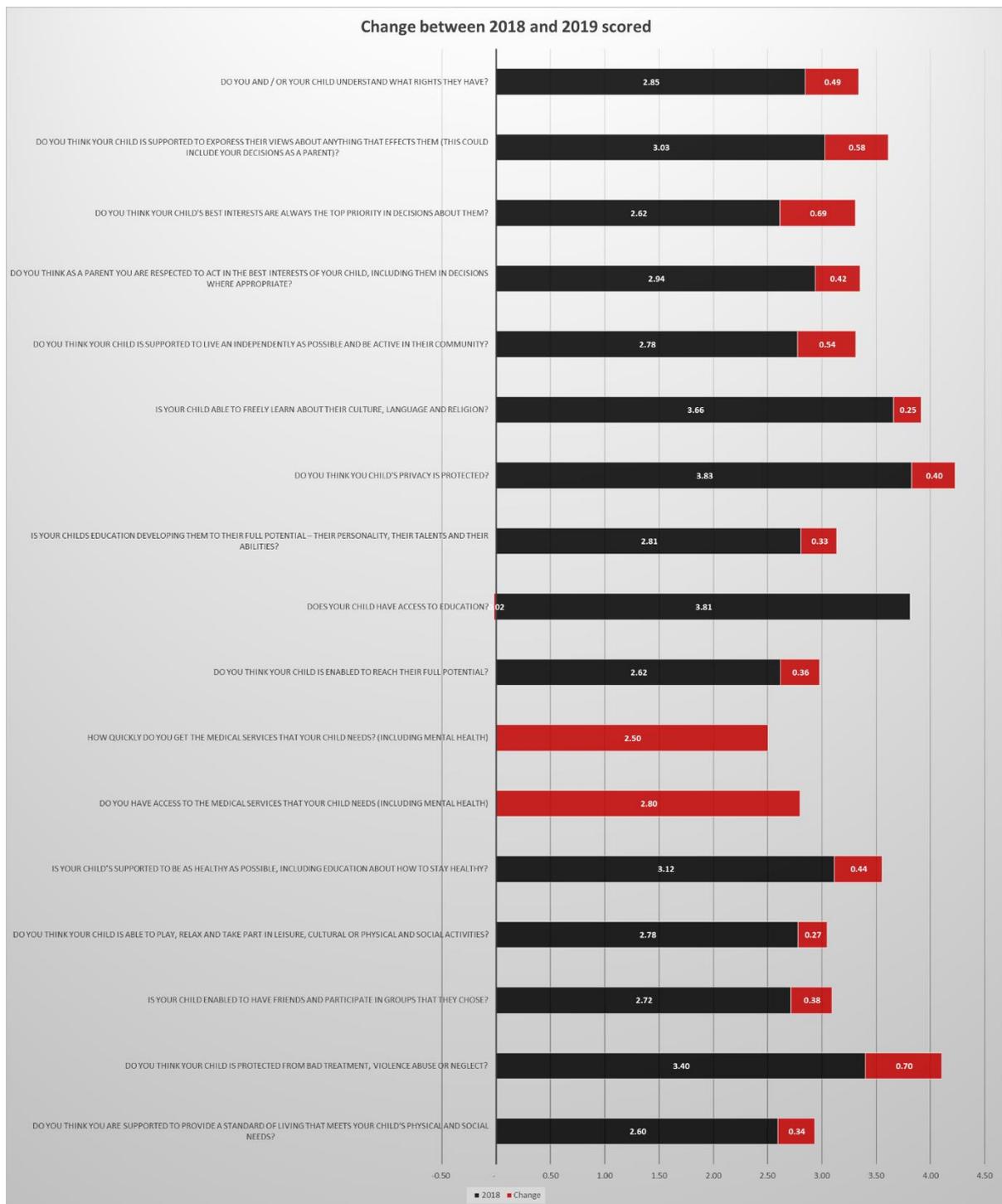
The average scores for each question were:



The distribution of scores for each question was as follows:



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



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.