# Bedford Borough Parent Carer Forum Outcomes Report 2022

February 2023



### 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. This survey has been repeated annually since.

#### Our methodology

Between October and December 2022, 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 2022 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 522 respondents in 2022 (543 in 2021 and 556 in 2020). In addition, there were 1,190 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**

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

Average score

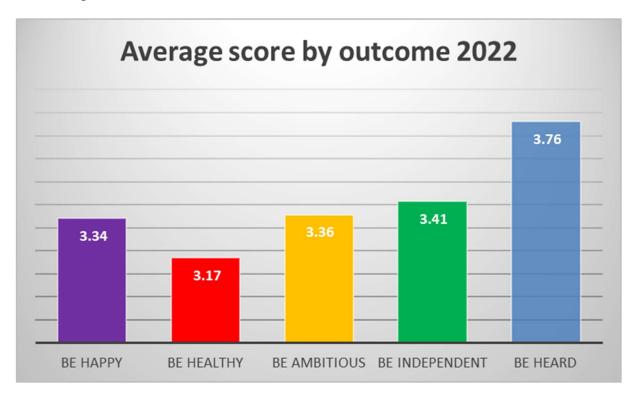
3.41

(out of 5)

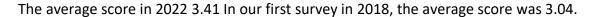
The average score across all questions in our survey was 3.41 (2021:3.53)

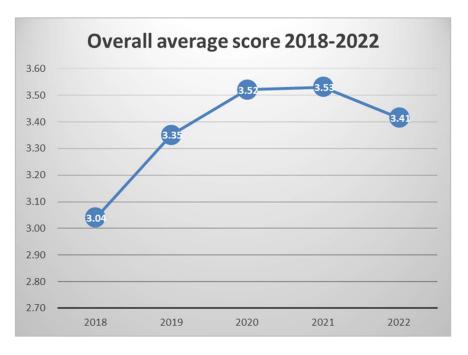
This means that the needs of children and young people with SEND are only being adequately met at best. This falls short of our stated ambition that needs should be being well met (a target score of 4 or more). Given that the questions were based on the United Nations Convention on the Right of the Child,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

The average scores for each outcome were as follows:



There has been a small fall in the overall average score year on year but the five year trend still shows an increase..





Generally, the average of individual outcome scores has improved since 2018 although all scores show a deterioration between 2021 and 2022

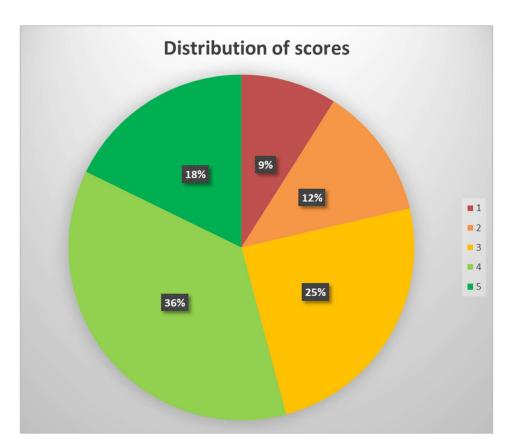


Despite the overall improvements in scores, the majority of the comments collected were negative but give a good indication of what needs to be done to continue to improve scores year on year.

Overall, 54% (2021:60%) of all responses were positive (scores of 4 or 5) whilst 21% (2021: 18%) were negative (scores of 1 or 2). This is a ratio of approximately 2.57:1 positive to negative.



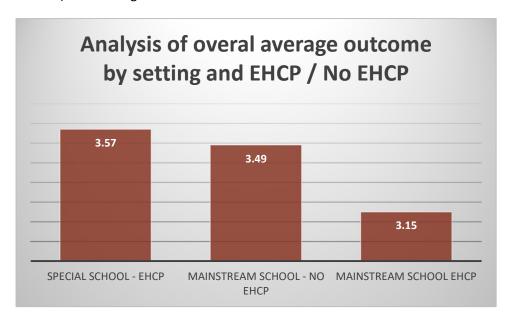




### Commentary

# 1. Children with EHCPs in mainstream schools show significantly worse scores that those in special schools.

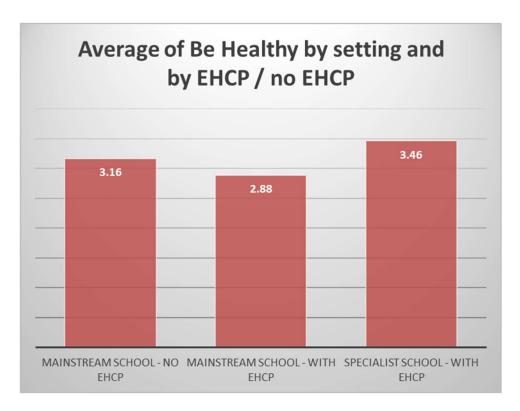
The average score for children with an EHCP in mainstream schools is 3.15 compared to those in special schools which is 3.57 (or 3.59 for those in special schools outside of Bedford Borough – for the purposes of further comparison, we will reference those in Bedford Borough special schools). The average score for those in mainstream schools with no EHCP is 3.49.



More detailed analysis of these scores shows a very clear reason for this difference:

### i) Children in with an EHCP in mainstream schools report significantly lower average Be Healthy scores.

The average be heathy score for CYP in mainstream schools with an EHCP is 2.88 compared to 3.46 for those in specialist settings Comments further support these scores with it being very clear that parent carers of CYP with an EHCP in mainstream schools report many frustrations accessing health services.

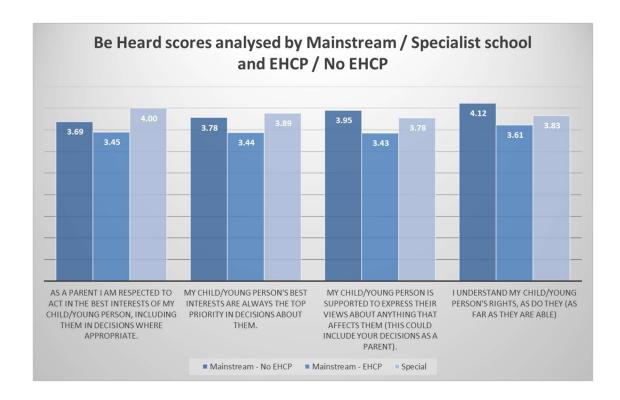


Interestingly, the special school nurses are singled out by many respondents for praise – it is possible that the co-ordination role of special school nurses plays a significant part in higher scores for those with EHCPs in mainstream schools when they are accessing health services.

ii) Families of children in mainstream schools do not feel as if they are listened to as well as those of families in special schools.

The scores for as a parent "I am respected to act in the best interests of my CYP" and My young persons best interests are always the top priority in decisions" are 0.55 and 0.45 lower for CYP in mainstream school with and EHCP compared to those in special schools.

Be Heard scores have always been a leading indicator for other scores – i.e. the direction of travel for Be Heard scores will be followed by other scores in subsequent surveys. Therefore, we should regard this movement in scores as significant.



Recommendation 1: BLMK Integrated Care System should consider commissioning school nurses to specifically support children and young people in mainstream schools who have special needs, notably those with EHCPs

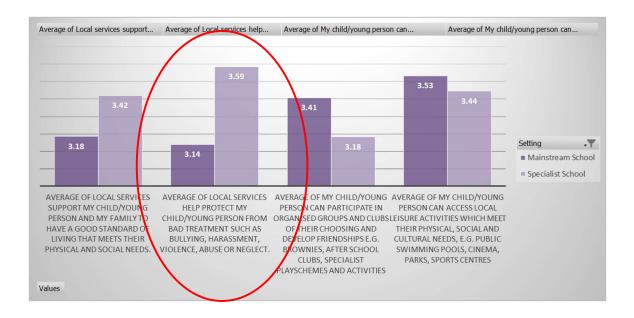
Recommendation 2: Bedford Borough should develop a programme of work to promote better coproduction in mainstream schools – this will include further investigation with families and schools to understand the reasons for differences, endorse best practice and coproduce different approaches.

2. More generally, children and young people in mainstream schools with SEND have lower scores than those in special schools.

The table above, illustrates this.

There are three main reasons where the difference in scores between special schools and mainstream schools is significant for this:

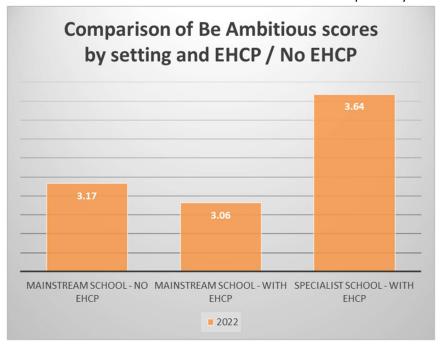
i) Children with SEND in mainstream schools feel significantly more vulnerable to bullying.



There is a 0.45 difference in whether CYP SEND feel protected between mainstream schools and special schools. The comments section in the Be Happy section make difficult reading with many families describing harrowing and damaging instances of bullying, many of which they feel were not taken seriously or dealt with appropriately by schools.

ii) The average Be Ambitious scores for CYP with SEND in mainstream schools were significantly lower than those for children in special schools.

The average be ambitious scores for special schools were 0.47 and 0.58 higher than for CYP in mainstream schools without and with and EHCP respectively.



Recommendation 3: Bedford Borough should promote a culture of zero tolerance of bullying of children with SEND. They should consider:

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

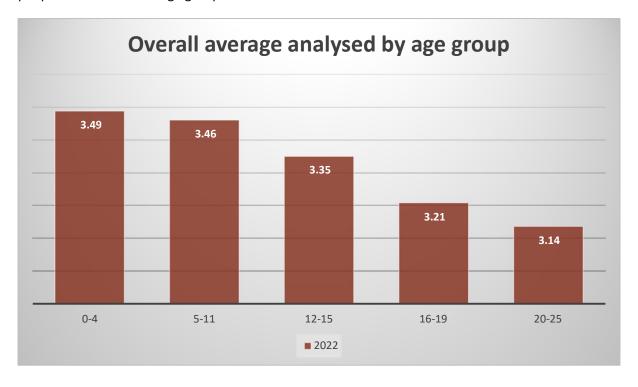
Recommendation 4: Focus and emphasise the support offered for children and young people with SEND in mainstream schools. Currently 1.5 Teaching and Learning advisors for schools are funded by the Education Improvement Strategic Grant to support best practice and policy and Bedford Borough funds approximately 10 posts specialist services in HI/ VI, autism, early years and other specialist outreach to provide specialist support for schools with individual children and young people. Two more speech and communication needs outreach specialists are planned.

The Borough should review the work of this team using the intelligence gathered in this survey to further target and improve their work.

See also recommendation 5 below

#### 3. The older children and young people get, the lower their average scores

The 0-4 age group recorded an average score of 3.49 which declines to 3.14 by the time young people are in the 20-25 age group.



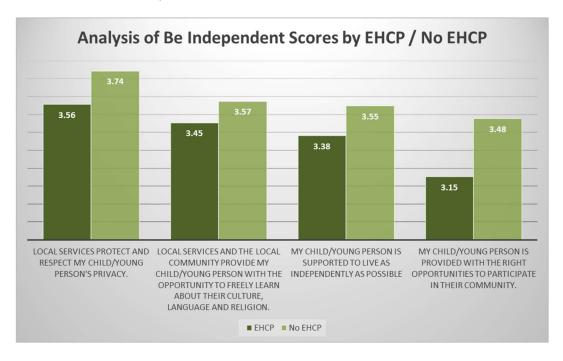
This is a theme consistent with previous years with comments indicating families worried about the quality of life across the four preparing for adulthood categories of independent living, health, employment and community.

Recommendation 5: Bedford Borough has compiled a preparing for adulthood guide. This should be reviewed to ensure that every preparing for adulthood plan will highlight the potential of each young person. This should be supplemented by case studies of recent successful preparing for adulthood journeys. In addition, Bedford Borough should consider using the 2023 Summer of SEND to highlight positive long term outcomes and destinations for local young people with SEND.

# 4. Parents of CYP with EHCPs were significantly more worried about their ability to be independent

The families of children and young people with EHCPs were significantly more worried about their ability to be independent than those of families without EHCPs. All four of the questions showed a negative difference for those CYP with EHCPs. The largest single difference was in opportunities for community inclusion where those with EHCPs felt significantly more challenged to be included in their local community (a score of 0.33 lower than those without EHCPs).

The comments indicated families felt that they were not given the support (e.g. support workers) to enable access to the community whilst many others felt that there were not enough activities children with more complex needs.



Recommendation 6: Bedford Borough should continue to promote community access for children and young people with SEND. This will include:

An additional spend of £250,000 to boost community inclusion (confirm details)

- Continue with annual summer of SEND activities to provide access for CYP with SEND and their families to community activities
- The re-tendering of the short breaks contract in 2023 will focus on ensuring widening access to a broader group of families

#### 5. Many families mentioned access to leisure facilities as an issue

Some of the bounce in the two key community access scores from last year from the first Summer of SEND appears to have worn off with scores for Be Happy: My CYP can access local leisure facilities and Be Independent: MY CYP is provided with the right opportunities to participate in their community falling by 0.18 and 0.11 respectively. Although interestingly, both scores remain higher than the year before Summer of SEND was launched.

In particular, local leisure facilities were singled out by many comments as a cause for concern. There were many comments that mentioned poor access to swimming facilities – either settings did not understand the needs of children with autism or sensory needs and do not make reasonable adjustments.

The inclusive play area in Russell Park did, however, receive a lot of favourable comments.

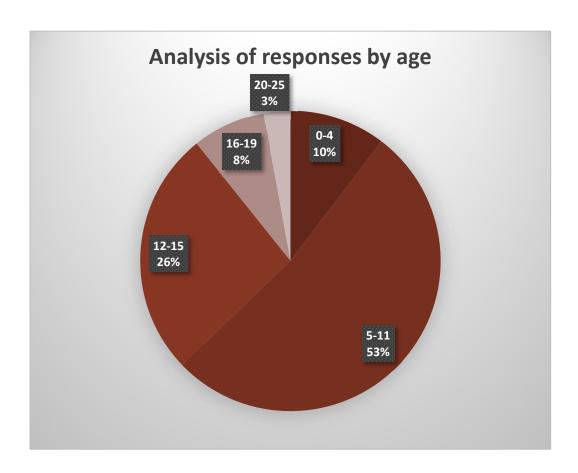
Recommendation 7: Bedford Borough Council is currently in discussions with the leisure facility providers to increase access to swimming facilities. This includes a grant of £50,000 to improve facilities for disabled children (e.g. pool hoists) in up to five local pools. In return, providers will need to ensure that they increase access for CYP with SEND including more dedicated accessible swimming offers.

# Analysis by age, setting and EHCP / no EHCP

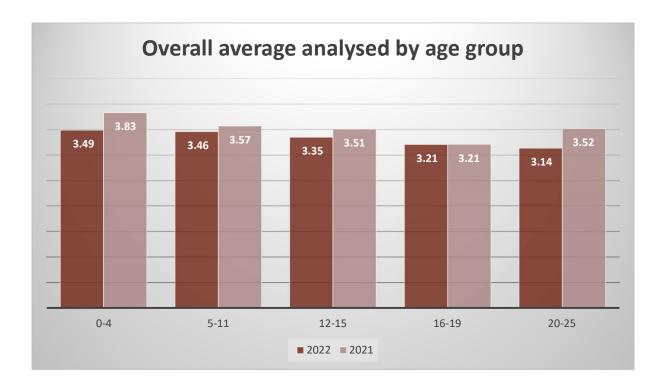
#### By Age

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

Age range	Number	Percentage
0-4	54	10%
5-11	274	52%
12-15	138	26%
16-19	41	8%
20-25	156	3%
N/A	0	



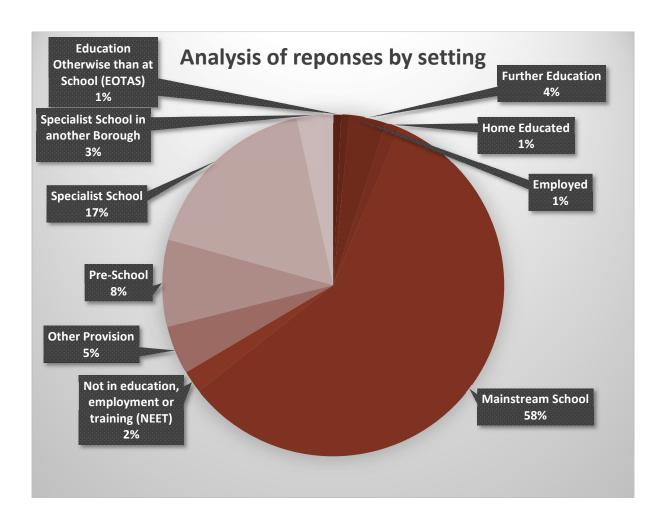
Analysis of the overall average mark by age shows that the 0-5 age group have the highest average score (3.49) which gradually declines as children and young people age with the 20-25 age group having the lowest average score of 3.14. This is consistent with the trends from previous years (2021 being an exception which showed the 16-19 age group with the lowest scores).



#### By setting

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

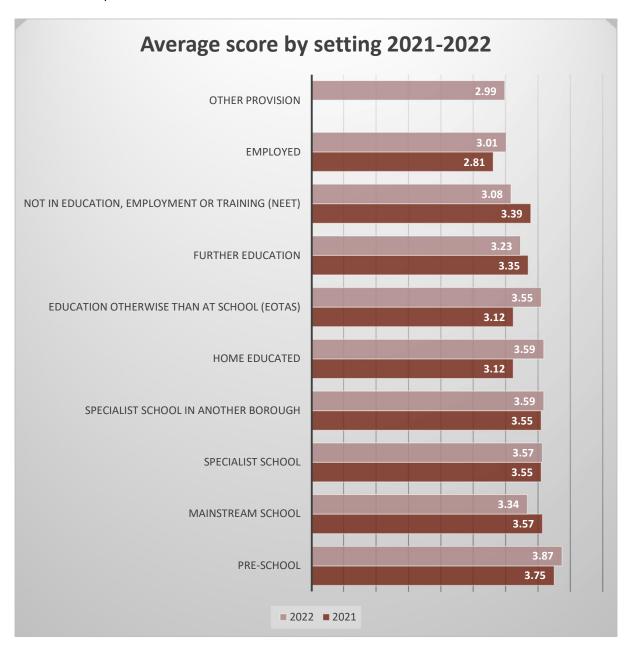
Setting	Number	Percentage
Education Otherwise than at School (EOTAS)	4	1%
Employed	4	1%
Further Education	18	3%
Home Educated	7	1%
Mainstream School	303	58%
Not in education, employment or training (NEET)	11	2%
Other Provision	24	5%
Pre-School	43	8%
Specialist School	90	17%
Specialist School in another Borough	18	3%
Grand Total	522	



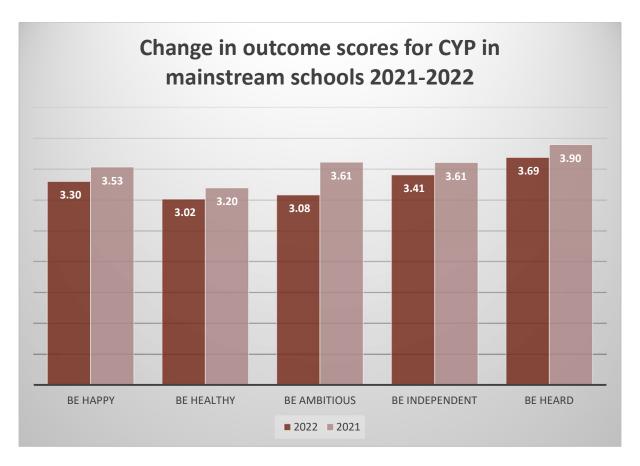
In a significant change from previous years, there is a clear difference between the average scores of children and young people in mainstream schools (3.34) and specialist schools inside and outside the

borough (3.57 and 3.59). In all previous surveys there has been no significant difference between specialist and mainstream settings.

Consistent with the findings of the age analysis, those in pre-school have the highest scores (3.87) and those who have left school have the lowest scores (Employed 3.01, NEET 3.08 and Further Education 3.23).



Further analysis of the drop in scores for mainstream schools shows that scores have fallen across all outcomes. The biggest fall is in the "Be ambitious" outcome (0.53) which directly relates to education provision.



Further analysis shows that the experiences for be ambitions have fallen for both those with and without an EHCP in mainstream schools (0.62 and 0.41 respectively).

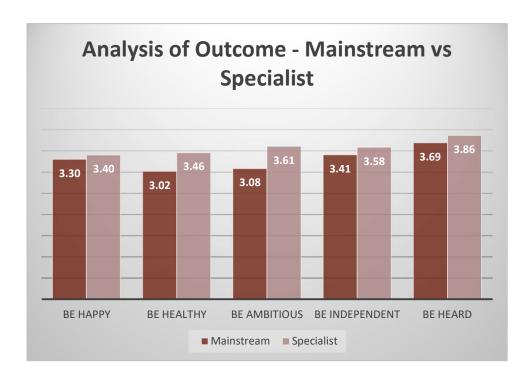
For further analysis of this, see the be ambitious section.

An analysis of mainstream scores versus scores of children in specialist settings gives a clear picture of where the significant differences lie.

There are large variations across the whole be Healthy and Be Ambitious sections – children in mainstream settings scores significantly lower across all the individual scores in these outcomes.

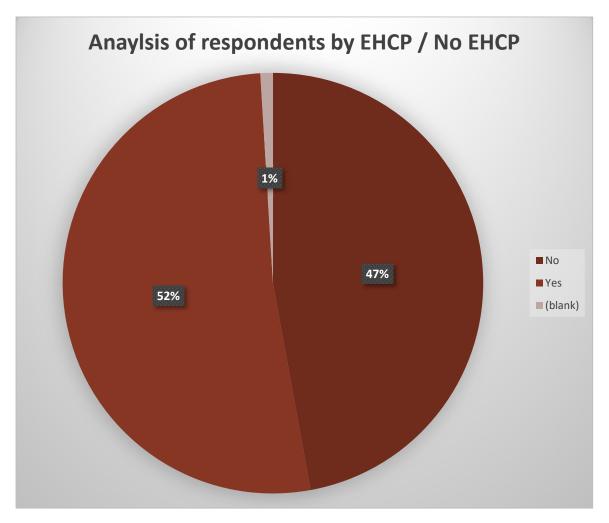
In addition, there are two other scores where children in mainstream setting score lower than those in specialist settings:

- Local services help protect my child/young person from bad treatment such as bullying, harassment, violence, abuse or neglect 0.47 difference
- As a parent I am respected to act in the best interests of my child/young person, including them in decisions where appropriate.0.43 difference

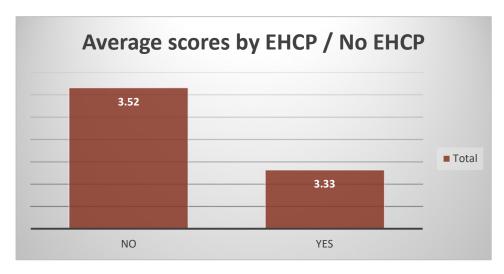


#### By EHCP / no EHCP

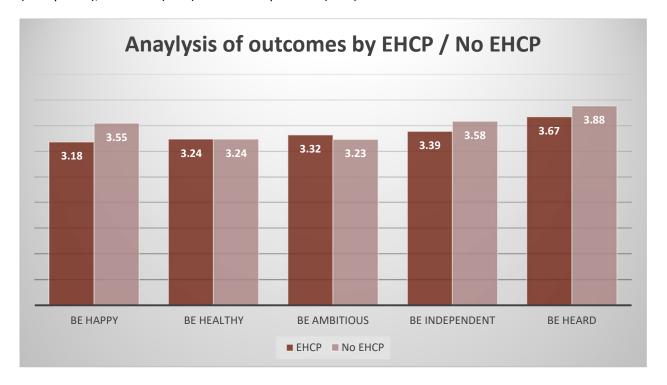
There is a good split of responses between those who have EHCPs and those who do not. With 47% having an EHCP and 52% not (1% responded N/A).



In a change from previous years, there was a notable difference between the scores for those with an EHCP and those without an EHCP. Those without an EHCP scored higher 0.19 points on average.



Upon further analysis it is clear that the main drivers for this difference are scores in the Be Happy (0.27 points), Be Heard (0.21) and Be Independent (0.19) outcomes



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.

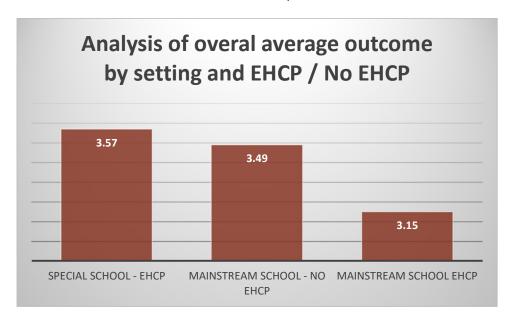
The individual scores that differed the most are consistently those which relate to community inclusion. The three items that showed a difference of greater that 0.3 points were:

- My child/young person can participate in organised groups and clubs of their choosing and develop friendships e.g. Brownies, After School Clubs, Specialist Playschemes and Activities -0.7 points difference
- My child/young person can access local leisure activities which meet their physical, social and cultural needs, e.g. Public Swimming Pools, Cinema, Parks, Sports Centres – 0.4 points difference
- My child/young person is provided with the right opportunities to participate fully in their community – 0.32 difference.

#### Analysis by Setting and EHCP / NO EHCP

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

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

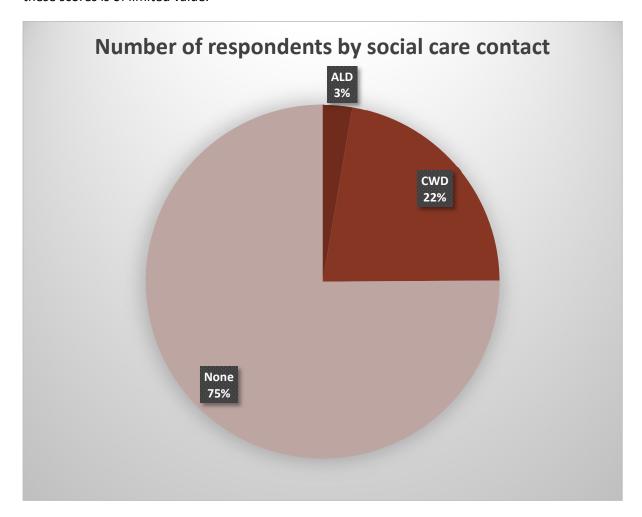


#### By social work status

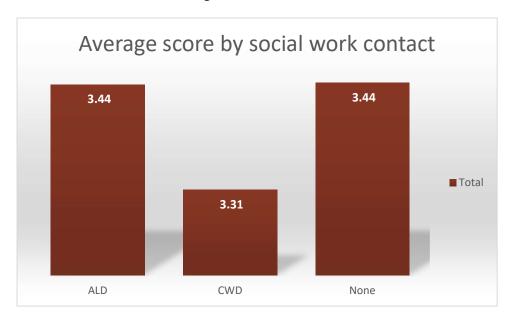
For the first time we asked respondents to share whether they had a social worker and identify which team the social worker came from.

Team	Number	Percentage
Adult Learning Disability (ALD)	14	3%
Children with Disability (CWD)	116	22%
None	392	75%
Total	522	

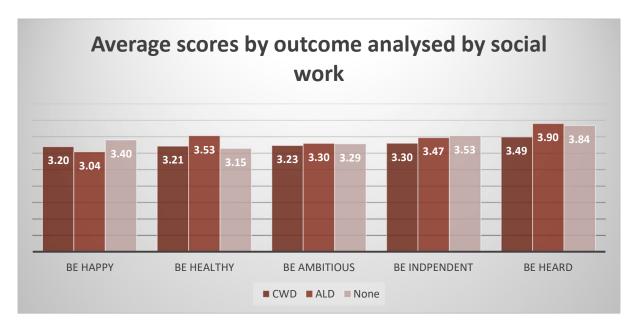
The number of respondents with contact with the ALD was relatively small which means analysis of these scores is of limited value.



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



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



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

 My child/young person can participate in organised groups and clubs of their choosing and develop friendships e.g. Brownies, After School Clubs, Specialist Playschemes and Activities -0.44 points difference

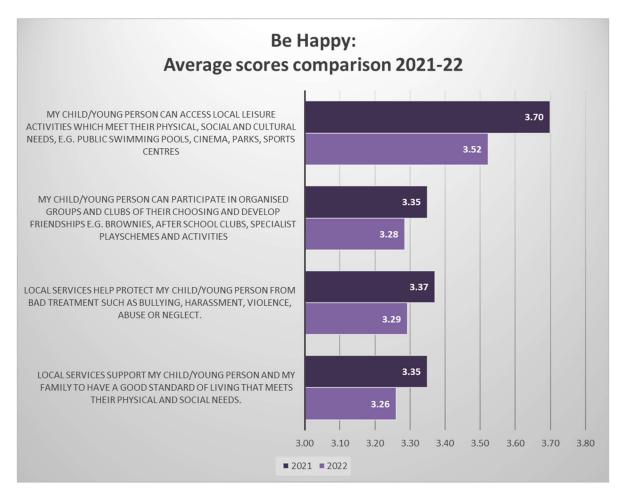
- My child/young person can access local leisure activities which meet their physical, social and cultural needs, e.g. Public Swimming Pools, Cinema, Parks, Sports Centres – 0.36 points difference
- My child/young person is provided with the right opportunities to participate fully in their community 0.33 difference.

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

- As a parent I am respected to act in the best interests of my child/young person, including them in decisions where appropriate 0.3 difference
- My child/young person's best interests are always the top priority in decisions about them –
   0.43 difference
- My child/young person is supported to express their views about anything that affects them (this could include your decisions as a parent) 0.41 difference

### Be Happy

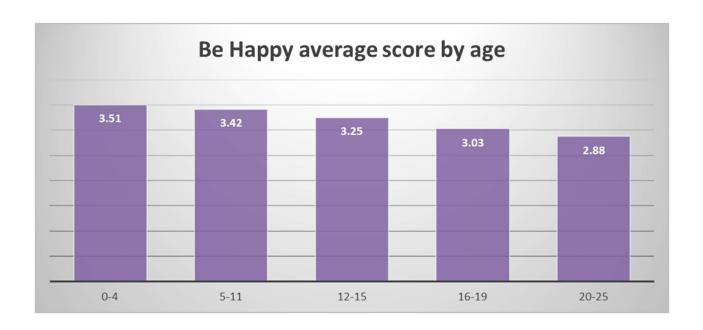
The average score for parent-carers in this category was 3.34. This represents a small drop from 3.44 last year. It is more in line with previous surveys which recorded scores in a similar region. Our first survey in 2018 recorded an average score of 2.87 for Be Happy.



All average scores for Be Happy questions showed a drop year on year. The largest and most significant drop came in the question about access to local leisure facilities which fell by 0.18. All other scores fell less significantly with year on year differences ranging between 0.7 and 0.9.

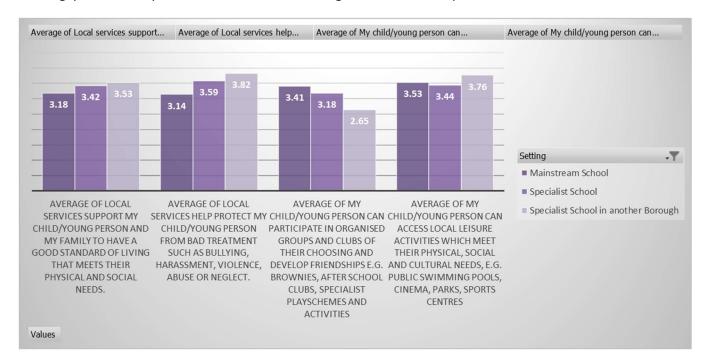
#### Children and young people with SEND feel less happy the older they get

As a theme, analysis by age groups shows that families of younger children tend to feel happier than families with older children and young people with a 0.63 fall in average marks between preschool children and the 20-25 age group. This is broadly consistent with previous years.



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

There is a worrying increase in the number of comments that speak about bullying. Detailed analysis of the data shows that there is a significant gap between the scores for local services help protect my child / young person from bad treatment for those attending mainstream and special schools with a gap of over 0.5 points between those attending mainstream and special schools.



This is supported by a large number of comments drawing attention to bullying, largely in mainstream settings. One concerning feature of this is that many comments refer to the fact that schools have not taken bullying concerns seriously or have not taken enough or the right action. IN addition, there are some comments that indicate that school staff themselves have bullied children and young people with SEND.

After many years written complaintes in regards to bullying at XXXXX, Head Teacher denied the facts, didn't manage records as required and defended her inability to act behind the policy telling us "Your kids need to toughen up!" This has caused our child to have permanent nervous ticks since year 2.

My child she 12 took a overdose due to bullying which my local Cmht refused to help her

My son is constantly bullied at school for being small and teachers do nothing.

sending my child to a school that doesnt support him to access his lessons meaning he is lost & loosing years of his education. to also be bullied by teachers who when asked for help make statements like "youre a retard" or "why do you think i sit you next to her? because she is smart sso ask her how to do it" whilst recieving threats from attendance & my child being told by the school that i will be fined or sent to prison (which just adds to his stress)

Bully on a child with learning difficulties is openly allowed in school in bedford by staff and other students

Bullying in school is down played for a child with needs, mocking needs is allowed

My son is bullied all the time by other students

Our child was bullied, physically, mentally and emotionally.

School are no tackling bullying of children with SEND ourchildren are misunderstanding or to sensitive. We need awareness.

Teachers have bullying behaviour that needs to be addressed

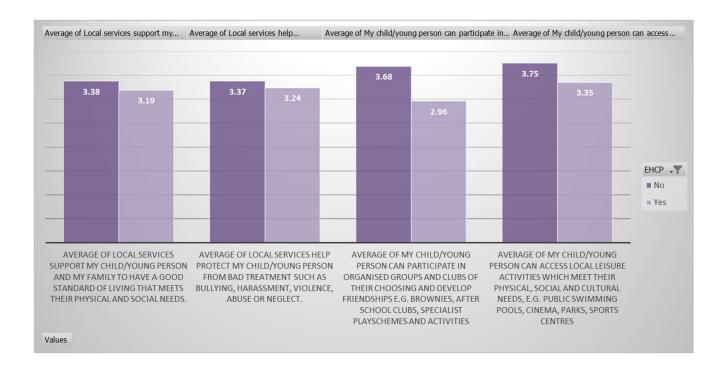
My son is being bullied at school and although they are trying to tackle it my son is struggling badly emotionally due to this.

Our son and some of his friends from the unit were being bullied when in mainstream but it has now been dealt with.

Bullying of children is allowed in our mainsteam school. No thought for the impact it has on our children.

There were many comments about a shortage of appropriate activities for CYP with SEND and many complained of oversubscribed clubs with long waiting lists. This is particularly notable for children and young people with EHCPs.

Detailed analysis of the Be Happy questions broken down by EHCP vs No EHCP shows that the problem is more pronounced for those with an EHCP.



There is a significant gap in the ability of CYP with an EHCP to participate in organised activities (0.72 points)

The comments also bear this out:

Again, unless an individual has Autism with an Intellectual Disability, I have not seen evidence of appropriate groups, clubs or activities in Bedford Borough.

Most clubs are not accessible to him- he would love to do football clubs for example (as his friends do) but they don't accommodate his needs (taking the time to give clear instruction for what he needs to do, nor give him extra time to change etc)

My child was kicked out of beavers as they could not accommodate his needs.

My sons after school club will not accept him due to his needs

No clubs available for more challenging

None for children who 'dont fit in'

There's nothing for disabled to access

I am not aware of any specialist clubs

I am unaware of real out of school clubs for children with learning disabilities.

The only group that my son has ever attended is the Mencap playscheme - I'm unaware of any other SEN groups suitable for him.

There's only a provision for the summer holidays and then it's only partial cover.

# Families also reported difficulties in accessing local leisure facilities, particularly swimming

Analysis of the data (see previous graph), again shows a significant difference between those with an EHCP and those without – the gap being 0.4 points.

Comments support these scores:

We are asked to leave when my child meltdowns

Hard to find services that can accommodate child with special needs, behaviour issues in the local area

I try from 3 years to find swimming pool and no one help me

No place in swimming pool No sport center No music center

Swimming is a big issue for us. Locally, the Kempston pool is freezing and Robinson pool is usually quite busy. We pay a lot for private lessons to help my son as water is a big sensory comfort for him, but there is nothing really accessible and affordable in Bedford for small children with SEND who are not confident swimmers.

It has got better with the inclusive park but swimming pools are not inclusive enough

Swimming has become increasingly difficult following covid and although there are a few special sessions eg Marlins, finding family friendly sessions is very difficult. Also the 'autism' friendly sessions at play centres and cinemas etc are very difficult to find for older children.

Swimming has been difficult. We currently travel to a specialist SEND swim school on Milton Keynes

The new play park in Russell Park attracted many positive comments. The summer of SEND also got some positive comments although fewer than last year.

Some comments include:

Love the new play park at Russell Park!

Really appreciate the new accessible play park in particular!

Summer of SEND and holiday activities have been great. The new play park is also brilliant. So nice to have dedicated sessions for my kids that their siblings can also engage with

The new Russell Park play equipment has been amazing. We would like to see more like that.

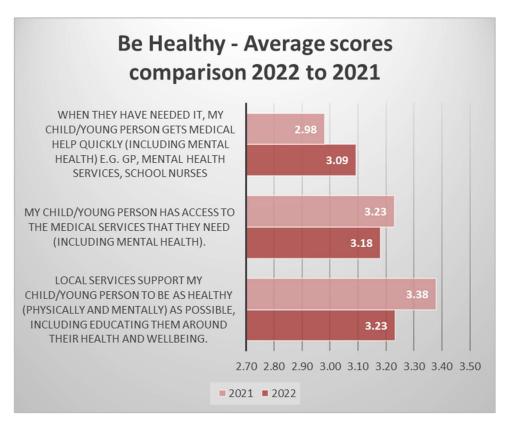
Summer of SEND and play park are great

Love being able to go to the new play parks with my whole family. SEND activities have been great. SSG Brilliant

### Be Healthy

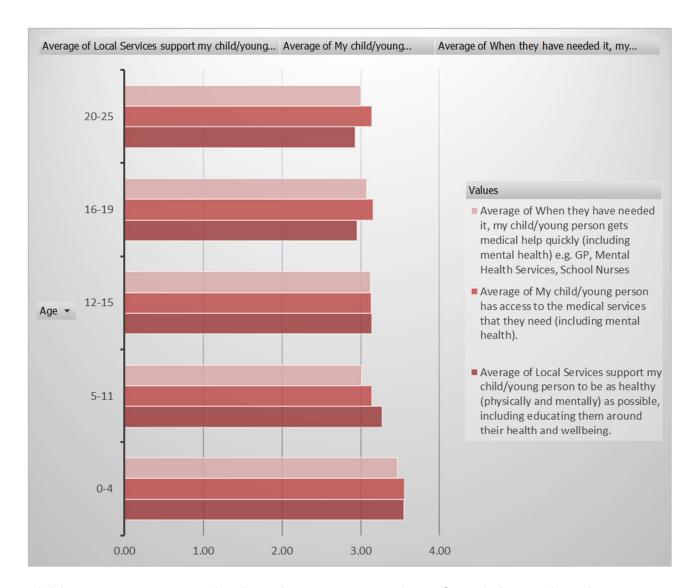
There was a slight decrease in the average Be Healthy score year on year. In 2022 the average score was 3.17 whereas it was 3.20 the previous year. Consistent with previous years, this was the lowest scoring outcome.

However, not all of the three Be Healthy outcomes saw a decrease.



Respondents scored a small increase in the outcome related to how quickly they gor health services from 2.98 to 3.09. However, the other two outcomes measuring how easy health services were to access and whether health services supported children and young people to be as healthy as possible saw decreases of 0.05 and 0.15 respectively.

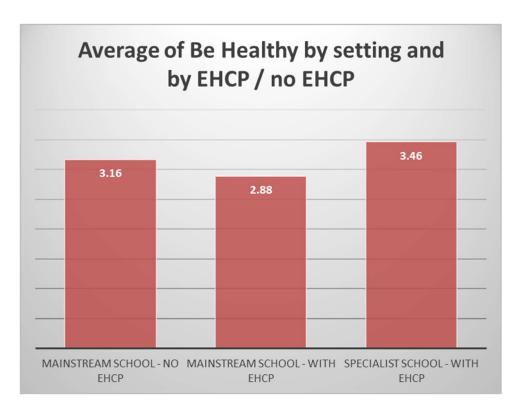
There was no clear pattern in the scores broken down by age group. The best scores came in the 0-4 age range with all other age ranges recording similar scores.



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

The average score across all health outcomes for children with an EHCP in mainstream schools was 2.88. This compares to 3.26 for children in mainstream schools with no EHCP and 3.46 for children in special schools

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



An analysis of the comments offers some insight into what the key difference may be.

#### Special school nursing service is singled out for praise by many respondents

There are many comments that praise the service that is provided by the special school nurses. Whilst there are few comments (see those listed below), special school nurses are frequently mentioned by respondents who scored health provision as a 4 or a 5 indicating that this is the service that has most influenced their score.

His school nurses are great. Others not so much

School nurse is amazing!

Hats off to the special school nursing team.. they are a fantastic source of support and do a brilliant iob.

specialist nursing team are amazing

Special school nurses and the hub are very responsive

There is clear learning for the local area here – see recommendations.

# CAMHS came in for a lot of criticism. There were some positive comments but they were outweighed by negative by some margin.

The key critical themes broke into broad categories – that services were difficult to access and had very high thresholds before children were accepted by them (CYP needed to be at breaking point before help was available) and the waiting times were too long.

A selection of the negative comments

Refusal by CAMHS to support child despite multiple professionals, Bedford Hospital and Addenbrookes requesting it.

CAMHS have refused my son 5 times

mental health support available & camhs took ages to get an appointment & then they couldnt help as most anxiety is based on unreal events. After speaking to my son they said he was already using tools they would advise & that the anxiety training would not help as his fears are based on very real every day events.

I've seen no evidence or input from anyone regarding his mental health and well being,

Camhs discharge when no progress made

CAMHS triage comepleted months ago and no support offered to date

Rejected 3 times by CAMHS despite escalating self harm

Camhs were shocking! I've had a fight for support every step of the way

Impossible to access mental health support, so difficult I gave up trying

## There are many comments highlighting the long wait times to see a paediatrician, particularly for autism assessments

These included long waits for an initial assessment and for regular consultations including medication reviews being months overdue.

A selection of comments

Average waiting time for asd assessment is 71 weeks. We've been waiting 43 weeks so far with no individual support.

access to community paediatrics is very difficult, see a different doctor each time so no continuity of care

No local services involved due to lack of diagnosis while on waiting list for peads

Awaiting paediatrician appointment. First referral completed jan 2022, 3rd referral only just accepted Oct 2022!

Been on a waiting list for over a year withe local CDC for an assessment with paediatrician for autism/ social anxiety

Delay, delay, delay.

Waited too long for paediatrician appointment as was referred at 3 years old and by starting school at 5 we had no contact. Realised the health visitor forgot to refer. Then had just phone calls with paediatricians and speech and language only. Son is 6 years old and non verbal. No help at all, no

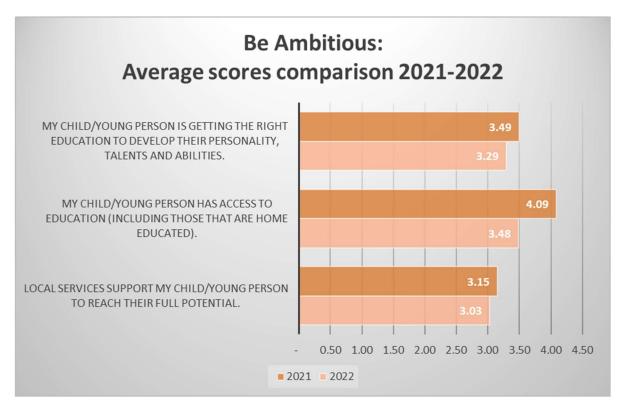
therapy in place. EHCP doesn't have the funding to offer him a fair place in mainstream school forcing us to look into special school which we don't think he needs

Waiting list times are beyond awful- ASD assessment currently has a 64 week wait and there appear to be no attempts from the authority to out source or use private help so our children wait and suffer Constantly passed from one person to another New joint phone line means you can't get hold of anyone

Waiting times are huge, we haven't spoken yo our paediatrician on over 7 months despite a meds review being due 5 months ago. Everything is a battle to speak to anyone

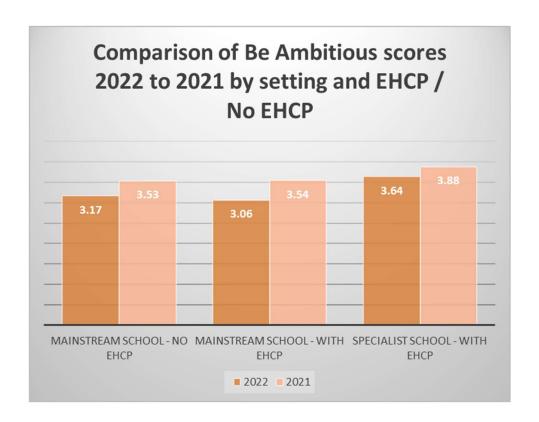
### Be Ambitious

The average score for this category was 3.36 which is a fall of 0.22 on the previous year (3.58). All of the three questions in this category saw falls in their average score. However, the most significant and marked fall came in the access to education score which fell by 0.6 marks on average.



Further analysis of these numbers shows that the biggest fall comes for children in mainstream schools.

Whilst the average score for those in special schools fell by 0.22, the average scores for those in mainstream schools fell by 0.36 and 0.48 for those with and EHCP and No EHCP respectively. In addition, the gap in average scores for those in special schools and in mainstream schools is now significant with a 0.47 point difference between those in mainstream schools with an EHCP and 0.58 for those without an EHCP.



### The quality of support offered by mainstream schools was the biggest area of concern in the comments

Respondents described concerns with the quality of education being offered for their children with additional needs in mainstream schools – they commented on the lack of differentiation for their children, concerns about the skills and capability of schools to support their children and also about the capacity of mainstream schools.

Dyslexia appears to be completely ignored by the system despite it being a significant issue.

School are unable to meet need so out of education

School give some support but not enough

Failed by the school system due to unmet needs, ended up in mental health crisis and now home educated. Have sought private therapy and now looking for specialist provision for next steps.

Practice suport and training in school is needed

His going backwards in school as the work they do is not age and ability appropriate for him.

My child is educated in mainstream. They say that you will have access to suitable teaching tools, but it's bargain basement over and over again.

Sen support isn't monitored or supported

The discriminatory practice towards SEN support children is awful. School are not getting not all children learn the way they impose. All we need is a big of time and less pressure

Mainstream school not set up to meet needs and unaware of basic reasonable adjustments that could have been made.

No training in a mainstream setting and no moderate learning school available

Still a way to go with reasonable adjustments, limited at school and a struggle to get help from LA so children either have to make do or do without if parents can't fund themselves.

Teachers are overworked and are largely left to their own devices. They do their best, but it's so frustrating that us parents are having to educate the teachers, the SENCOs, the LA authority about the needs of our children

School seem to be struggling to educate their children with no additional needs. SEND provision is still poor

## Community based health services were criticised for not supporting children adequately in mainstream schools

There were many comments about the support that was available to children from other services, most notably SALT, to enable successful schooling

The LA commission the NHS SALT Service. Currently the LA only commission the NHS SALT Service to provide direct therapy to children that cannot be understood by their parents and others or if the child only has speech and language difficulty. This means that children with speech and language difficulties with other difficulties, e.g. ADHD, ASD, etc., have no access to direct therapy based on the LA's criteria

Could be better access to therapies, school seems to be really struggling with staff, EHCplan was reviewed in June - no sign of updated version, struggling to find social opportunities.

I feel speech and language therapy is reserved for those non verbal. My sons speech and language is delayed but doesn't get hands on support because others are more delayed

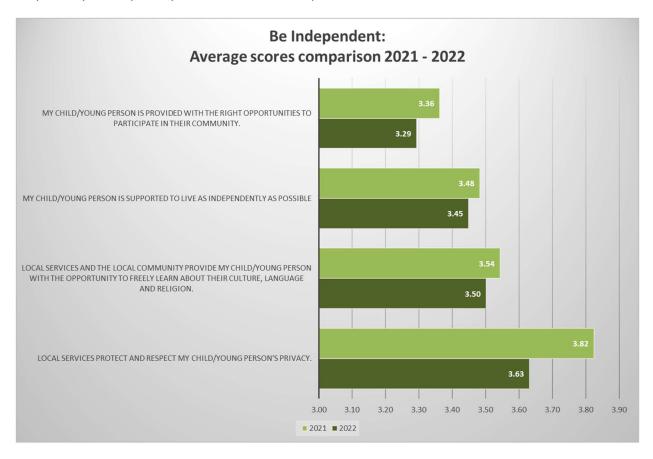
I would like to see more SALT involvement for my son. We have no support from services other than school. His Direct Payments are not being used because we have no PA.

School tends to be primary support and struggle to get outside help

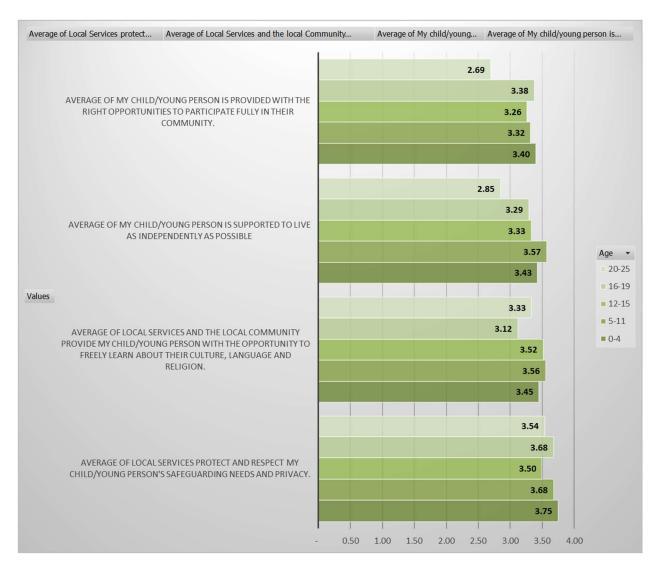
### Be independent

The average score for this outcome was 3.47. This is very similar to the score last year which was 3.55 but shows a small (0.08) point fall.

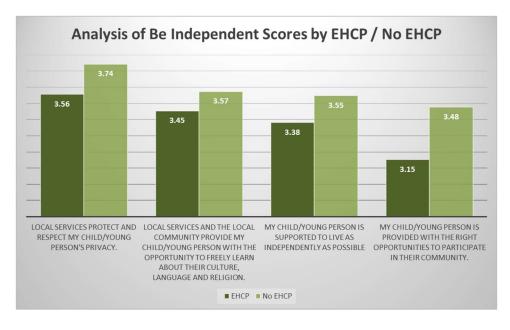
The individual question scores were also very similar year on year with all scores showing a small fall. The only significant movement was in the score for local services protect and respect my CYP's privacy which showed a drop of 0.19.



There is no clear pattern of scores based on age. In previous years we have seen a notable deterioration in scores, the older a CYP gets. This year, whilst there is some fall of in scores, there is not as strong a relationship between age and Be Independent scores.



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



## Families are very concerned about the difficulties in preparing for adulthood. Many do not think there is enough support or planning at an early stage

There were many comments from worried parents about the lack of clarity in preparing for adulthood pathways. They were not aware of support that was on offer and many felt that there was not enough support for their young people to make a successful transition to meaningful independence.

Not at all. Token effort is made to produce outcomes that will lead to independence. If it happens, it will be by luck.

PfA is non existent

extreme difficulty in accessing support services

Poor EHCP no preparation for adulthood

Need a clearer pathway towards independence

Many families described problems in accessing activities that would support greater independence for their children and young people. There were lots of comments that the only way that CYP could access independence was through the involvement of parents, family and friends

There were many comments that described barriers to accessing services that would support independence for children and young people. In particular, the lack of support workers or carers that could help CYP engage in activities without their parents were mentioned. In some of these comments, parent carers commented that there were plenty of activities but they could not use them because there was no one who could take their CYP to the activities.

Again he's not getting the support to do this

requests for personal budget and mentor for activities away from family home refused despite it aligning with ehcp

That's down his parents.

There's very little she can join in with without us as parents both being there to support.

With support from strong family members and friends.

There was a real mixture of comments about the availability of community based services that would support independence. Many parents-carers responded that there was very little available for their CYP whilst others reported that there were lots of activities. This suggests that more communication and publicity is needed about the clubs and activities available

Some of the comments describing the lack of services

How? Where? When? Local offer does not cater for children with complex needs.

No BSL/Ddeaf activities or events for children within the local area

No support for people with ASD to participate

There are not enough send suitable activities

Some of the comments describing the availability and range of services

If their community is the send community.. there are now lots of activities that children can do.. there just doesn't seem to be high numbers taking it up

Lots of activities run by local community

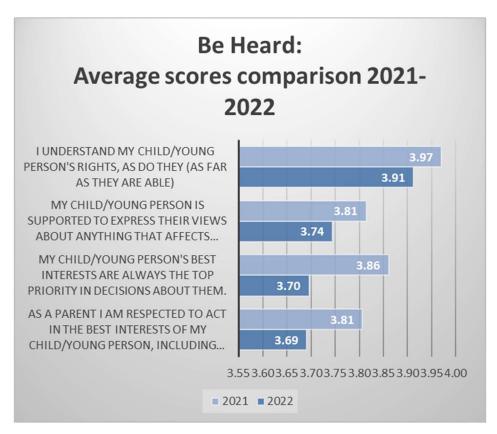
Very much funded by parents and rural communities could do with more youth groups not church or scout/guides based.

Could have more community activities but cannot find a person to help take them out to clubs erc

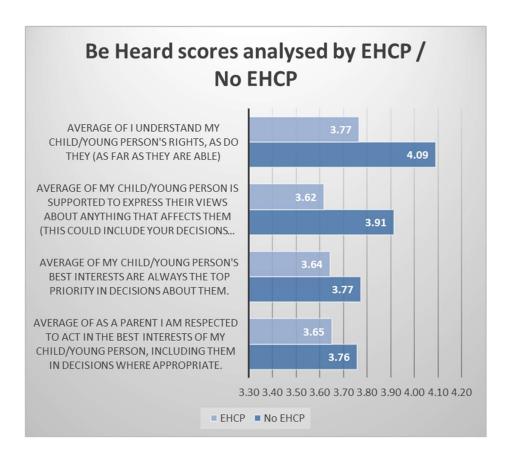
#### Be Heard

The average score for this category was 3.76 which is a fall on last year's score of 3.86.

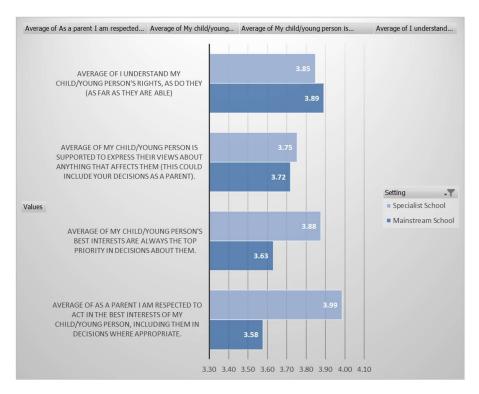
All of the individual questions saw a fall in scores, the largest fall being in the belief that the CYP's best interests were always the top priority in decisions about them which fell by 0.16. Next to this, the score for parents being respected to act in the best interests of their CYP fell by 0.12.



The Be Heard scores analysed by EHCP / No EHCP, show that respondents whose CYP had an EHCP feel they are heard less well than those that did not have an EHCP. Here there were some significant differences, most notably in the score for understanding of rights which showed a 0.32 difference between those with an EHCP and no EHCP. The next largest difference was in the score for the support that young people get to express their views which was 0.29.



The analysis of those in mainstream schools compared to those in specialist settings shows a marked difference in the other two questions. Parent carers of children in mainstream schools believe they are significantly less respected to act in the best interests of their CYP where the gap is 0.41 points.. Similarly, they do not believe as strongly that decisions are always in the best interests of their CYP- here the gap is 0.25.



# There are many parents who do not believe that they are heard and that the quality of coproduction with them and their child is poor. Many parents do not feel listened to

This was particularly prevalent with mainstream school, although other teams and services were mentioned.

Constantly made to feel like I am exaggerating or not accurate, passed from person to person, written feedback doesn't reflect what I am told in conversation

I feel ignored. I'm sure I'm catalogued as a problem parent. I'm just trying to do the best for my son, I'm fairly certain nobody else will.

No Co production taking place at all

No one listens

Parents views are dismissed.

School sees a parent fighting for their child's best interests as a problem.

Teachers are condescending and patronising. Telling me I am imagining the challenges my son faces with his genetic condition despite me providing evidence.

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

In our experience, the LA are only interested in saving money and often disregard independent experts' advice

It about the adults not the children. Money, pressure of school staffing ect ect

It's all about money and resources.

Money is the top priority in decisions made by services

Nope. The answer here is money money money. My son's best interests are only top priority in decisions about them when it's cheap.

money and resources factor in quite often above child's best interests.

I think that a lot of decisions have been made about my son based on cost, how easy it is to do, staffing, equipment etc. I don't htink his best interests are at the centre of every decision.

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.

I don't think we do this very well.. it's not easy and we're relied on as parents to interpret the child's voice..

I have to act on behalf of child for everything and thus is when i feel my voice isn't always heard, even tho my child is unable to express himself

My child openly say "no one listens, my needs are not bad enough yet" She slso say "no one listens because I am well behaved" My child has dyslexia and looking at ADD

Not really asked sometimes what my child wants

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.

Do not know my child's rights, don't know where to look to find them.

It's taken me literally years just to get a simple grasp of the system.

No formal explanation of these rights has ever been forthcoming. It is one of the first and most pressing things I would implore the Local Authority to get a grip on. It's not news when our children reach 18 years of age. There should be reading matter and advice instantly available.

Some education on this would be very helpful

Confusing information about what is available and from whom.

You have to dig to find out ... and thats never easy

### 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.

What outcomes do families with SEND want?

•We identified five key outcomes: Be Happy, Be Healthy, Be Independent, Be Ambitious, Be Heard

How do these translate into real activities or behaviours?

 What sorts of things would families recognise as being a mark of success for these outcomes

What services are needed to deliver these?

 What services and support do families need to be able to do these things

How do we measure the success of these services?

• What are the metrics that we need to monitor to ensure these services are working effectively?

#### Local area inspection revisit 2020

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

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

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

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

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

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

## Appendix 2: Survey questions

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

If your child/young person has had a significant change to their education setting/placement within the last year has there been adequate planning, preparation and support from local services.

If your child transitioned from the Children with Disabilities Team to Adult Services within the last year did you find the process worked well? (was it started in a timely manner? were you kept informed?)

If your child transitioned from Children's to Adult's Health Services within the last year did you feel that you had appropriate support?

My child/young person is supported to express their views about anything that affects them (this could include your decisions as a parent).

I understand my child/young person's rights, as do they (as far as they are able)

# Appendix 3: Bedford Borough Parent Carer Forum

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

The Bedford Borough Parent Carer Forum was formally launched in February 2014 but has functioned with a steering committee since May 2013. We have approximately 1400 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.