



**Bristol Parent
Carer Forum**

Shaping the Future *Together*

Written
Statement
of Action
Parent Carer
Experience





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INTRODUCTION

Bristol Parent Carer Forum (BPCF) was established in 2009 as an independent, parent-led organisation. Its aim is to shape the future of Special Educational Needs and Disability (SEND) services in Bristol.

In order to achieve this we work together with parents and carers, capturing their views and experiences and we share this feedback with colleagues from Bristol City Council, the Clinical Commissioning Group and Social Care.

We hope that this feedback helps local SEND services to make changes to ensure the support required by families is the right support, at the right time.

A significant opportunity to showcase local services came by way of the Ofsted and Care Quality Commission inspection, which took place between September and October in 2019. The inspection looked at SEND provision across Education, Health and Social Care.

During the inspection process, 5 significant areas of weakness were identified and the inspectors concluded that a Written Statement of Action was needed to help the services think about how they were actively going to solve the problems that families were facing.

The WSoA was published in April 2020. Key milestones on the WSoA were due in July 2020, November 2020, March 2021 and July 2021. Bristol City Council published updates on the WSoA on their local offer in September 2020, January 2021 and November 2021.

In March 2020 the Coronavirus pandemic began in England, just as the WSoA was published and as the Forum Chair resigned from their post. An interim chair was appointed for 1 day a week between April 2020 and June 2021 but like many organisations, the pandemic affected us greatly. We are a volunteer-led organisation and many of our own children, some of them with significant Special Educational Needs and Disabilities, were at home during this time.

New officers were voted into post at the Forum in January 2022 and the forum is currently in a period of strengthening; both our internal capabilities as well as our relationships with strategic partners.

Unfortunately, as a Forum we were not in a position to capture the views of parents and carers effectively during the WSoA update periods. We decided to run 5 surveys between January and February 2022 to help us understand how families feel about the progress that has been made and what other work needs to happen to ensure families get the right support at the right time.

905 responses were received but this is not the total individual response number as some families may have completed more than one survey; there is a breakdown per survey provided below.

EXECUTIVE SUMMARY: OVERVIEW

KEY SUCCESSSES

Bristol City Council, the Clinical Commissioning Group and Social Care have made some inroads on the aims of the WSoA.

Most of the progress made has been around creating various frameworks and putting processes in place that will hopefully lead to better outcomes for families in Bristol.

For example, the Ordinarily Available Provision document will help schools understand what support they should implement as part of the graduated support for SEND.

The outcomes framework will help families identify aspirational outcomes for the children they care for. Both of these documents need time to embed and families need to understand how they can utilise both when advocating for the children they care for.

The clinical commissioning group has taken steps toward a 'needs-led pathway' which includes support for families whilst they are on the Autistic diagnosis pathway.

KEY CHALLENGES

The progress made so far has been primarily strategic, families are unlikely to have directly felt the impacts of the changes to processes yet.

The EHCP systems remain dysfunctional and a source of stress and anxiety in Bristol. Families report that some schools do not have an understanding of how to support SEND students, especially where the child may not have problematic behaviours. Families worry their children are not in the right settings and too many children with SEND do not attend school full time.

Social care provision is very community-based and in high demand meaning that some children and young people do not have access to social care support. Families report a lack of clarity around how to access social care advice and support, particularly for respite and wrap-around services.

Health services can be difficult to access and reports do not always help inform others around the family how best to implement the support needed. Contributions to EHCP are not always helpful.



SURVEY ANALYSIS: ACCOUNTABILITY

What the original Ofsted inspection determined: Parents and carers want services to have a much better understanding of the SEND population and how well they are meeting their needs. They want visible leaders and a mechanism for letting them know when they are not happy.

Our Data: 243 parents and carers responded to this survey which was advertised on social media and directly to schools and other community groups.

1 Of the reasonable requests you have made since March 2020, how well did the school the child / young person attends implement them?

■ They do them right away 22.7% ■ They refuse them 4.5%
■ Only if I complained 58.9% ■ They were not effective - 13.9%



2 Do you think or know that the child you care for has been discriminated against by an education setting, since March 2020?

■ No - 31.8% ■ Maybe - 27.3% ■ Yes - 40.9%



Since March 2020 have you experienced improvements in the following services?

3 Bristol's SEND team processes and provisions:

■ Yes - 13.8% ■ No - 72.6% ■ Not sure - 4.5% ■ N/A - 9.1%



4 Bristol's social care provisions:

■ Yes - 4.6% ■ No - 40.9% ■ Not sure - 4.5% ■ Not Eligible - 50%

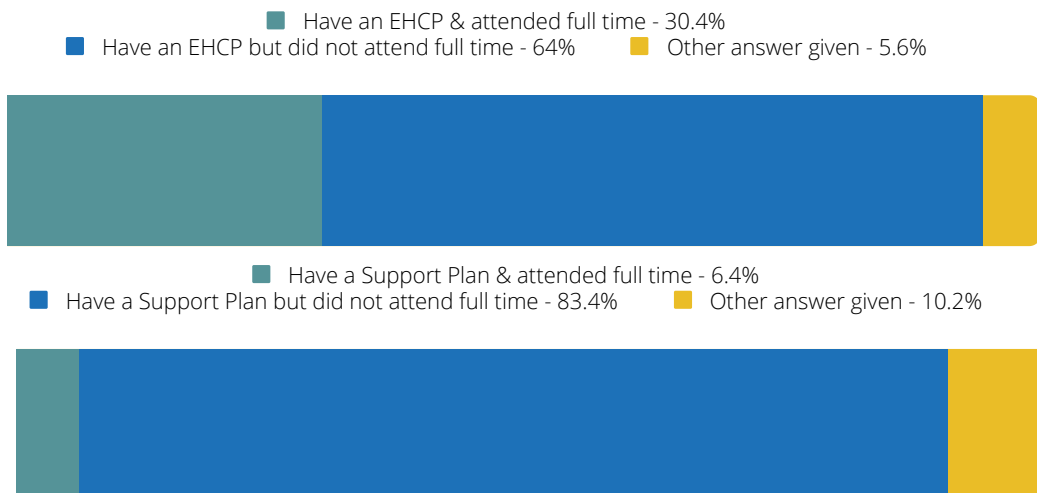


5 Bristol's health care provisions:

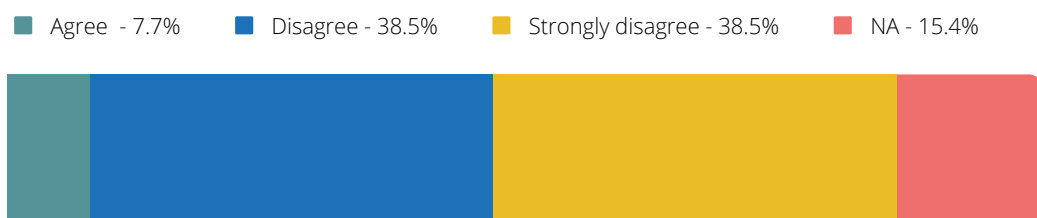
■ Yes - 12% ■ No - 54.5% ■ Not sure - 13.7% ■ NA - 19.8%



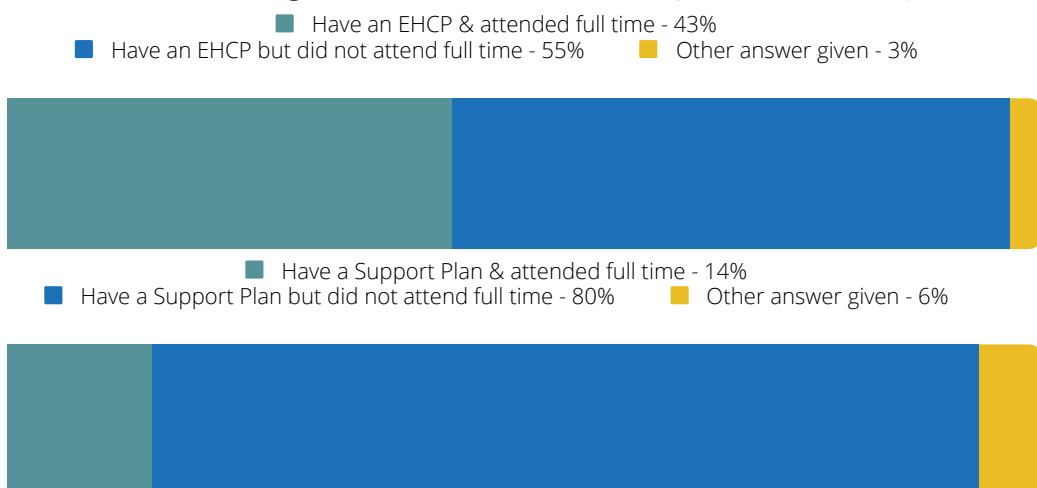
6 If the child you care for has an EHCP / Bristol Support Plan, did they receive full-time education during the first lockdown period March-May 2020?



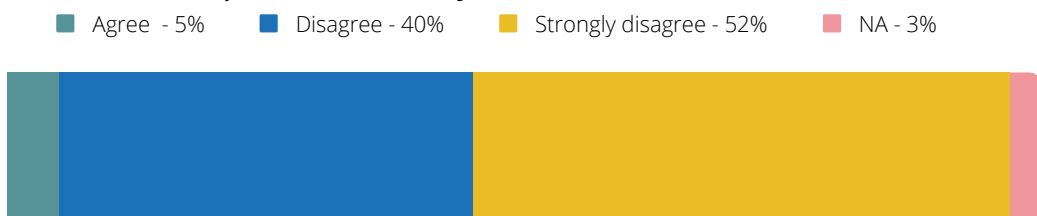
7 During the first lockdown period of March-May 2020, did the child you care for receive all the provisions they needed at home?



8 If the child you care for has an EHCP / Bristol Support Plan, did they receive full-time education during the second lockdown period January-March 2021?



9 During the second lockdown period of January-March 2021, did the child you care for receive all the provisions they needed at home?



ACCOUNTABILITY: PARENT CARER VOICE

“it was not provided until after we had twice instructed solicitors in connection with a Judicial Review pre-action protocol letter”

“Unable to access education due to reasonable adjustments not been made”

“My case officer is lovely and very helpful”

“I just backed off because I'm too tired to argue anymore”

“He has been at home and not attending school now for over 3 yrs”

“They do try, but the support is so inconsistent”

“I had to fight really hard to get my child into school during the first lockdown, even though he has an EHCP”

“My son's school are amazing and quick to pick up any needs/areas of support”

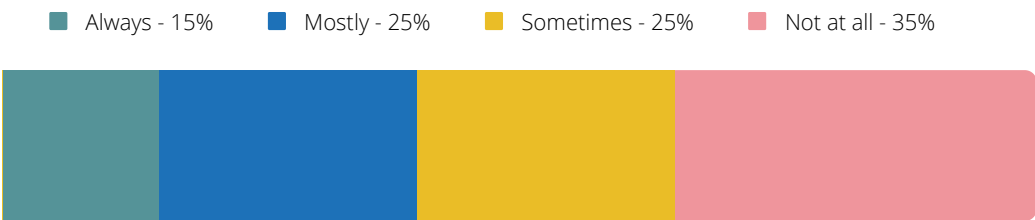


SURVEY ANALYSIS: IDENTIFICATION OF SEND

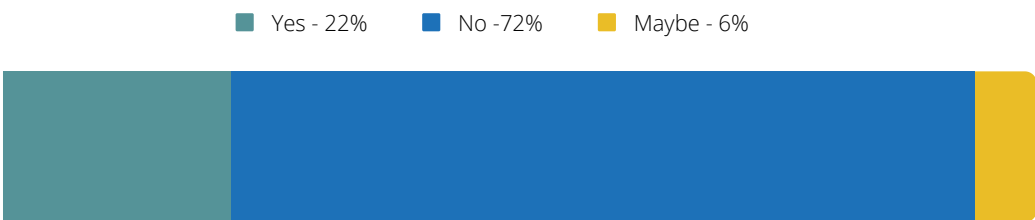
What the original Ofsted inspection determined: Families want professionals to listen to parents and respond quickly when they tell agencies that they think their child has a special educational need. They would like professionals to work better together and share information so that they don't have to repeat themselves and that all assessments provided need to be of high quality so that they lead to a good quality plan, this includes those families who are 'not known to service'.

Our data: 180 parents and carers responded to this survey which was advertised on social media and directly to schools and other community groups. 27% of our support group enquiries between September 2021 and March 2022 were around the identification of SEND.

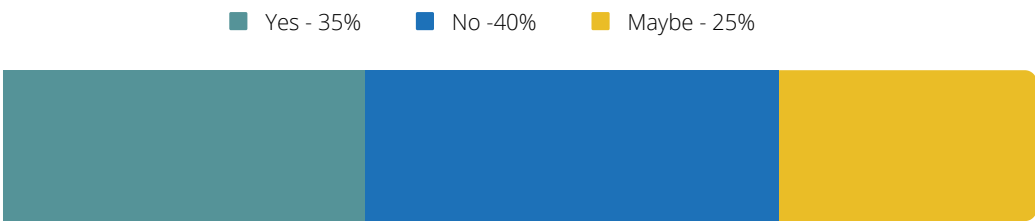
1 Do you think the place where the child you care for gets their education, meets their needs?



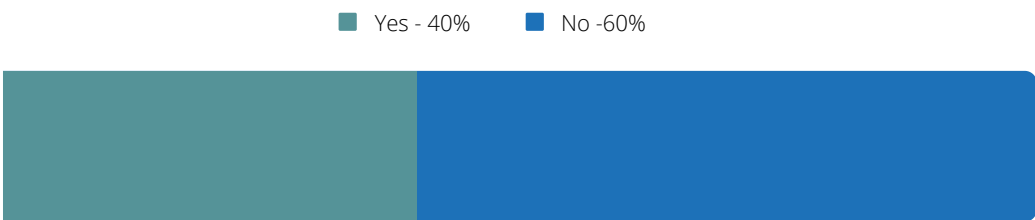
2 Since March 2020, do you believe initial or additional support has been implemented at the right time?



3 Do you believe the child you care for is in the right educational setting?



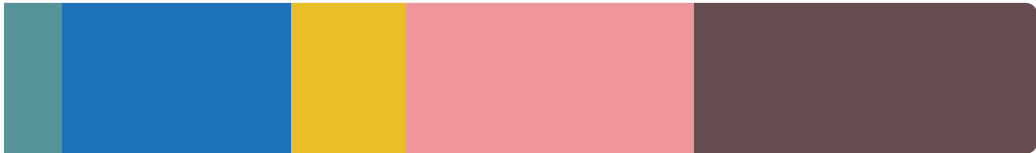
4 If your child has an EHCP, did you receive advice from professionals that you specifically asked for to help with understanding your child's SEND needs?



SURVEY ANALYSIS: IDENTIFICATION OF SEND

5 80% of parents and carers told us that the child they care for has SEMH needs. We then asked; have you received advice to support social, emotional and mental health? Do you think this advice was given in a timely manner?

■ Yes - 5.6% ■ Had advice - it was not timely - 22.1%
■ Yes - but it was not helpful - 11.2% ■ Still waiting - 27.8%
■ Did not meet service criteria - 33.3%



6 Bristol City Council say that parents and carers are aware of the multiple routes to early intervention and happy to use them. Is this reflective of your experience?

■ Somewhat true - 10% ■ Not true at all - 80% ■ I am not sure - 10%



7 Has there ever been a time (since March 2020) that you have tried to get early support/intervention for the child you care for, but were unable to?

■ No - 30% ■ I am not sure - 15% ■ Yes - 55%



IDENTIFICATION OF SEND: PARENT CARER VOICE

“It took quite a long time (3 years) for my son to be diagnosed but while we waited we felt very supported and had a course to go on, My child is moving to Specialist provision when he starts year 7 in September”

“It didn't take very long at all for the school to notice my child has ADHD and they gave us great tips”

“She hit a crisis point before support was implemented”

“We had to self fund her initial dyslexia assessment”

“It took over a year to get an EHCP I started in November 2020”

“Our son has had 1:1 care since he was 2”

“I've been liaising with school since Dec 2020 - even paid for assessments but school totally ignore all of the advice and say it's my parenting”

“By the time people were trying to put support in place he was so anxious he had a mental breakdown”



SURVEY ANALYSIS: DYSFUNCTIONAL EHCP PROCESS

What the original Ofsted inspection determined: Parents and carers want to receive an EHC Plan on time and be kept informed of progress, they like queries to be answered within 2-3 days if they email or for someone to answer the phone if they call. They would like answers to be clear and compliant with the SEND Code of Practice and for EHC plans to be issued within the statutory timeframes with specified and quantified advice and meaningful outcomes. They also want annual reviews of EHC Plans to be on time and for them to be better quality.

Our data: this survey received the lowest number of responses with 72 parents and carers responding. At last check (31st August 2021) Bristol City Council had 320 EHC plans or assessments that had exceeded the 20-week statutory deadline. 39% of our support group enquiries focus on EHCP support and signposting.

For families that had made an EHCP request since March 2020 we asked:

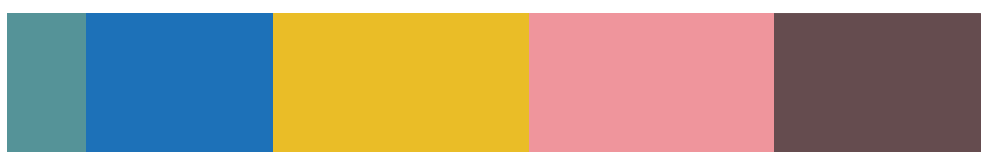
1 How was the service provided by Bristol City Council during week 1-6 when you asked for the EHC needs assessment?

■ Excellent - 8% ■ Good - 36% ■ Fair - 33% ■ Poor - 16%
■ Very poor - 7%



2 How was the service provided by Bristol City Council during weeks 6-14 when you were having the assessment done & waiting for the reports?

■ Excellent - 8% ■ Good - 19% ■ Fair - 26% ■ Poor - 25%
■ Very poor - 22%



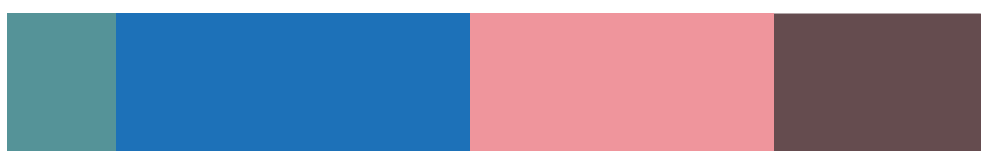
3 How was the service provided by Bristol City Council during weeks 14-20 when you were waiting for a decision or draft / final EHC plan?

■ Excellent - 5% ■ Good - 22% ■ Fair - 14% ■ Poor - 30%
■ Very poor - 29%



4 Did the EHC process make you or anyone in your family feel worried, anxious or stressed?

■ No, never - 11% ■ Yes, a small amount - 36% ■ Yes, Sometimes - 31%
■ Yes, a lot - 22%



SURVEY ANALYSIS: DYSFUNCTIONAL EHCP PROCESS

5

If you need to contact the SEND team for reasons related to an EHCP how long do they take to reply?

■ Within 3 days - 16.7% ■ More than 3 days - 5.6% ■ More than 7 days - 55.6%
■ NA - 22.1



6

Was your EHCP issued in 20 weeks?

■ yes- 26% ■ No - 66% ■ Not sure - 8%



For families that had completed an annual review since March 2020, we asked:

7

Did you find the EHC plan review process easy to understand?

■ Yes - 28% ■ Maybe - 15 ■ No - 57%



8

How involved did you feel in the annual review process?

■ Very Involved - 14% ■ Involved - 41% ■ Neutral - 22%
■ Not at all involved - 16% ■ Actively excluded - 7%



9

Did your annual review take place on time or was it late?

■ On time - 39% ■ Unsure - 30% ■ Late - 31%



10

Did you feel like the provision in the EHC plan helped the child you care for to reach the stated goals and outcomes?

■ Yes- 56% ■ No - 31% ■ Not sure - 13%



DYSFUNCTIONAL EHCP PROCESS: PARENT CARER VOICE

“We had to fight tooth and nail for any advice from speech despite my son being on a waiting list. OT refused to see him at all even through single entry and we had to be seen privately where they confirmed DCD and DLD”

“Current EHCP issued 1.5 years late. Now going to Tribunal after 10 months of EHCP being issued”

“We saw a lovely Educational psychologist and she really 'got' us”

“provide the resources to deliver the required support”

“We were really worried about it but school were great, we are waiting for a specialist space now”

“The whole process was done in 19 weeks for us”

“I think the whole EHCP/support process relies far too much on parents "knowing" what provision is right for their child”

“My son had to wait 4 months for EHCP provision because his school had to get the money”



SURVEY ANALYSIS: UNDERACHIEVEMENT AND LACK OF INCLUSION

What the original Ofsted inspection determined: Parents and carers have a mixed experience of support at school and in the community with varying quality advice & support. Some children have experienced poor support in education settings, particularly post Early Years. They tell us their children are often sent home during parts of the day or they are formally excluded, sometimes permanently. There is a wait for funding to support needs and lengthy waits for placements in specialist settings that parents have been told their children need.

Our Data: 221 parents and carers responded to this survey which was advertised on social media and directly to schools and other community groups. 36% of our support group enquiries between September 2021 and March 2022 were around the underachievement of children and young people and inclusion in schools and by service providers.

1 Do you feel that the child you care for is always included automatically in school/education/their community, without you having to ask?

■ Yes - 6% ■ Mostly - 19% ■ Sometimes - 20%
■ Only now they are in specialist - 18% ■ No - 37%



2 Has your experience of inclusion changed at all since March 2020?

■ Yes it has got better - 20% ■ It has stayed the same - 39%
■ Yes it has got worse - 17% ■ I am not sure - 24%



3 Do you feel like the child you care for attends an Educational setting that allows them to fulfil their educational potential?

■ Yes - 22% ■ No - 46% ■ Child is not receiving an education - 9%
■ Other - 23%



4 It is important that children and young people with SEND attend the right provision to meet their needs. Do you feel the child you care for is in the right setting?

■ Yes - 45% ■ No, we are waiting for specialist - 34% ■ Unsure - 21%



SURVEY ANALYSIS: UNDERACHIEVEMENT AND LACK OF INCLUSION

5 Is the child you care for receiving a full-time education?

■ Yes - 65% ■ No - 35%



6 Is the child you care for attending the education setting named in their EHC plan full time?

■ Yes - 53% ■ No - 37%



7 Since March 2020 have you experienced any type of exclusion?

■ No - 44% ■ Yes - 39% ■ Maybe - 17%



8 In your opinion could the education setting have done something or put support in place for the child you care for, which may have meant they would not have been excluded?

■ Yes - 100%



9 If the child you care for has an EHCP did the school put support in place immediately or did they say they had to wait for funding?

■ immediately - 26% ■ We had to wait - 61% ■ Unsure - 14%



Bristol City Council fund EHCPs via Top Up Panels which run 3 times a year and receive around 700 applications each time. SENDCos can request funding via an EHCP consult but of the 30 SENDCos we asked, none had secured funding in this way as they were not aware that they could.

UNDERACHIEVEMENT & INCLUSION: PARENT CARER VOICE

“Please stop fighting parents with unlawful and/or cost-saving policies, designed to limit support and not designed to help children fulfil their academic potential”

“My son's school has bent over backwards for us, the support has been fantastic”

“My son has had access to so many inclusive sports clubs”

“I don't even know if my child is on a school roll any more”

“We need more advice about what school should be doing to support children”

“We just want him to attend a school where he will be taught things”

“Our outcome is very happy but the fight to get here nearly broke us. Our EHCP took 18 months from request to assess to issue and then a further 6 months to appeal”

“My child will never get that time back and will probably never catch up”



SURVEY ANALYSIS: THE FRACTURED RELATIONSHIPS WITH PARENTS AND CARERS, LACK OF CO-PRODUCTION AND VARIABLE ENGAGEMENT AND COLLABORATION.

What the original Ofsted inspection determined: Parents and carers don't trust the council to do what it says because they haven't always followed through on promises made in the past. They feel frustrated by the years of issues with the EHC Plan process and feel the SEND system processes are not clear and have led to their families being let down. Families want to share their views but don't have time to get involved in co-production and feel when they do get involved they are often not listened to.

Our data: 189 parents and carers responded to this survey which was advertised on social media and directly to schools and other community groups. 41% of our support group enquiries reference parents not feeling listened to or not being able to contact anyone to help them solve their problems.

1 Since March 2020 have you been involved, in any capacity in shaping any services in Bristol, it could be health, social care or education?

■ Yes - 30% ■ No - 60% ■ Other - 10%



2 Since March 2020 have you felt that Bristol City Council, health and social care agencies are taking your concerns, over any issue, more seriously?

■ Yes - 22% ■ No - 78%



3 Since March 2020 have you had to make a complaint about education, health or social care? Either directly to Bristol City Council or one of their partners ?

■ Yes - 70% ■ No - 24% ■ I'm considering it - 4%



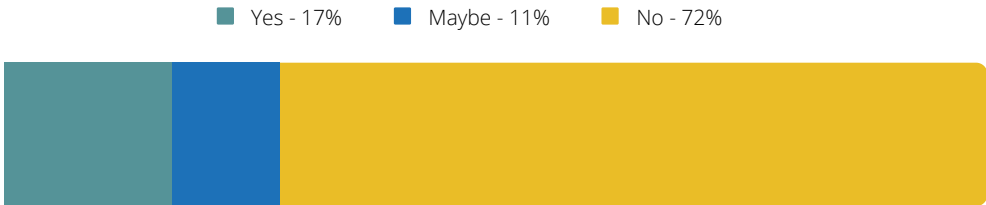
4 Were you happy with the way your complaint was handled? For example, were you kept up to date, was the complaint answered on time, did you feel heard?

■ Yes - 33% ■ No - 67%

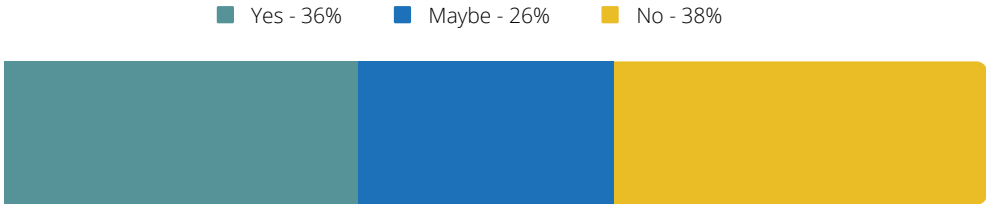


SURVEY ANALYSIS: THE FRACTURED RELATIONSHIPS WITH PARENTS AND CARERS, LACK OF CO-PRODUCTION AND VARIABLE ENGAGEMENT AND COLLABORATION.

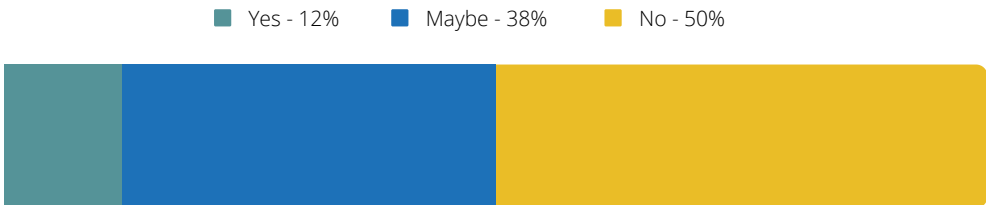
5 Do you believe that Bristol City Council has the best interests of the child you care for at heart?



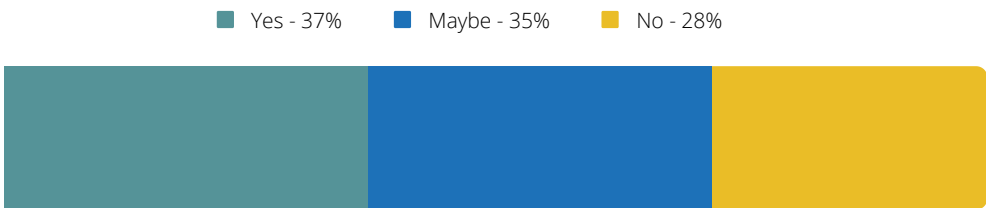
6 Do you believe that health services delivered by the clinical commissioning group have the best interests of the child you care for at heart?



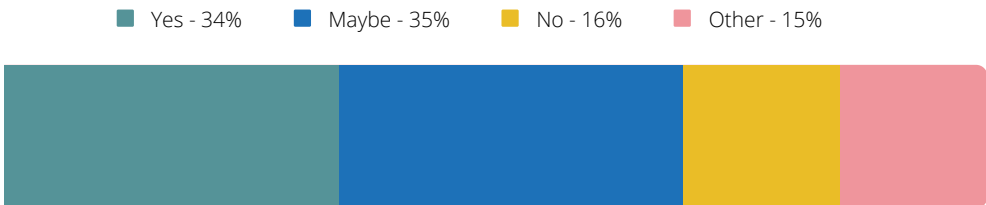
7 Do you believe that social care services have the best interests of the child you care for at heart?



8 Do you believe that education settings have the best interests of the child you care for at heart?



9 Do you believe and trust the advice that you get from organisations within Bristol? Such as SEND and You/Supportive Parents, Bristol Parent Carers, etc?



FRACTURED RELATIONSHIP: PARENT CARER VOICE

“ Stop the requests for more evidence and prepare EBSA guidelines and support so the focus is on helping children struggling with school-based anxiety ”

“ the complaints need to be reviewed independently and not by the manager of the team the complaint relates to ”

“ I've found services very willing to listen and engage ”

“ I found the process very simple info was easy to find ”

“ The process is so adversarial, it's a real 'us v them' culture, I felt lied to ”

“ Taken meaningful corrective action, rather than just restating the problem ”

“ Actually listened and tried to find answers, rather than pass the buck so we just chased round various organisations and departments ”

“ Apologise sincerely. Show you are actually invested in resolving the issue ”



SUMMARY: IN DEPTH

ACCOUNTABILITY

Accountability is a key issue for parents and carers. When things go wrong families want honest answers about why decisions have been made. They want leaders to make sure that the people running the services take the right action to make things better.

BCC (Education & Social Care) and the CCG (Health) have taken some steps to increase accountability. For example, there is now a governance structure with reliable data.

The impact this had had on families directly is marginal and we are looking forward to working with our partners to ensure this and other areas are carried through to the new SEND Partnership Plan.



IDENTIFICATION OF SEND

Families often feel that they need to 'shout' to be heard, especially when it comes to supporting the needs of their children in school.

Health services can take a long time to become actively involved and reports do not always effectively identify needs, this, in turn, affects the quality and impact of the provision.

The CCG has worked closely with Parent Carer Forums in the area (Bristol, North Somerset and South Glos) to offer support for those waiting to be diagnosed as autistic. Education services have developed SENDCo clusters and there is currently a review of SENDCo training regarding the role schools play in SEND identification.

The Families, Local Offer, Resources and Advice (FLORA) team offer help to navigate the Local Offer but their services are not well known in the community (61% of parents and carers indicated they had not heard of or used this service).

DYSFUNCTIONAL EHCP PROCESS

Bristol City Council (BCC) reported a 13% increase in the number of Education, Health and Care Plans (EHCP) that were completed within 20 weeks during 2021 compared to the previous year. But 189 fewer EHCPs were issued in 2021 compared to 2020 and at least 320 families waited more than 20 weeks for a plan, with at least 100 families waiting 40 weeks or longer.

DYSFUNCTIONAL EHCP PROCESS CONTINUED...

At the end of December 2021, there were 461 families that had been through a needs assessment and were waiting for a decision on whether an EHCP would be issued. The same figure for our statistical neighbours at the end of 2020 was an average* of 96 EHCPs.

All relevant departments have jointly reviewed the EHCP templates with the expectation that this will lead to more effective joint contributions and increased timeliness but families may find it difficult to match needs and provisions since the new EHCP templates do not place them close together on the plan.

The new addition of Specialist Health Advisors for SEND provides advice for some families who previously were told they were 'not known to service', but they do not always identify the child or young person's need and so provision is not always effective.

When making EHC needs assessment requests there are references to many various panels but there is a lack of parent-friendly information which means the process is not explained transparently and this can be stressful for families. *<https://explore-education-statistics.service.gov.uk/data-tables/permalink/23713f32-f867-4951-825d-0325b859f0ff>

UNDERACHIEVEMENT AND LACK OF INCLUSION

BCC published an Ordinarily Available Provision (OAP) document and SENDCo clusters have been established to help schools know what support they ought to implement and when. This, in turn, will support inclusion. However, some families and some schools do not understand the OAP or how to utilise it and there is little awareness of The Equality Act.

Families are also concerned that the children they care for are not in the right types of settings; they are often told their children need to be in specialist settings to have their needs met whilst also being told there are no available spaces. This inevitably leads to mainstream settings carrying out 'caretaker' roles and families feeling frustrated as their child's needs, particularly around social, emotional and mental health, escalate.

FRACTURED RELATIONSHIP AND LACK OF CO-PRODUCTION

Agencies are developing their understanding of Bristol's diverse population and have recently begun to think about how to support all parent carers to 'have their say' about SEND provision in Bristol. This was delayed, in part due to the pandemic. A parent carer survey has been developed by BCC and the Local Offer is being redesigned to support transparent information around services and how to access them.

Bristol Parent Carer Forum is keen to develop a co-production charter and recognises that accountability and the fractured relationship go hand in hand. We are looking forward to working with agencies to develop these further.



Bristol Parent Carer Forum

Shaping the Future *Together*

Bristol Parent Carer Forum is a group of parents and carers of children with Special Educational Needs and Disabilities, living in Bristol. Our aim is to work with the Bristol City Council, Social Care and Health services in order to make sure they meet the needs of disabled children and their families.

To contact us or to get involved, please get in touch:



Email: info@bristolparentcarers.org.uk

Tel: 07306 650 222

Web: www.bristolparentcarers.org.uk

