



## **Brighton & Hove Special Educational Needs & Disability (SEND) Strategy 2020-2025 PaCC and Amaze consultation with BAME<sup>1</sup> SEND families, September 2020**

### **Introduction**

Findings and recommendations from this consultation with BAME SEND families will feed into the current Brighton & Hove Local Authority consultation on SEND Strategy 2020-2025.

Brighton and Hove City Council (BHCC), together with Brighton and Hove Clinical Commissioning Group (BHCCG), with help from other organisations including Amaze and the Parent Carers Forum (PaCC), have put together a five years plan on how services and support will be organised and provided for families with children and young people (CYP) who have additional needs and/or disabilities. The main aspiration of this plan/strategy is that children and young people with Special Educational Needs and Disability (SEND) will achieve the very best they can so they can lead happy, healthy, independent and good lives.

### **Methodology**

This consultation consisted of:

- An online survey which was sent to 500+ BAME families on Amaze Compass Register and to families involved in mASCot Kids at Home, mASCot Cultureinc, plus it was disseminated across various community groups. 60 BAME families replied to the online survey
- A series of one to one semi-structured phone interviews carried out by:
  - o Liz Soper, a dual heritage parent carer, from the new group A Seat at the Table. 15 BAME families were interviewed from various communities and ethnic backgrounds. For 40% interviewees English was not their first language. All CYP of parent carers interviewed were on roll and attending school
  - o The Hangleton and Knoll Project (HKP). 10 BAME families were interviewed whose backgrounds included Bangladeshi, Indian, Pakistani, Iranian French and Eritrean.

PaCC partner group Fresh Youth Perspective are undertaking a complimentary piece of work drawing out their learning from recent evidence of solution-based practice with BAME young people (YP).

### **Scope**

BAME – Black, Asian and Minority Ethnic, is the terminology normally used in the UK to describe people of non-white descent. It is important to note our understanding that many discreet cultural groups sit within this broad umbrella term. In neither the online survey nor interviews were participants asked in detail about their ethnicity, which means it is not possible to disaggregate findings or analyse how different BAME communities' experiences may differ. Similarly, we didn't collate information on CYP ages/conditions/diagnosis/need. In reaching 85 families, we are not reporting these findings to be comprehensive of the whole and diverse BAME SEND community in Brighton and Hove. The report draws out some clear themes from a sample group while

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recognising different parent carers will have wide and varied experiences, potentially of different barriers and discrimination, and of more or less positive interactions with services.

It should also be noted that some BAME parent carers said they did not want to participate in this consultation. This is because in some communities SEND is not something that is talked about and there is a stigma attached to a CYP being labelled or judged, when the CYP is seen as being 'mental', 'naughty' or having 'something wrong' with them. Parents may not wish others in the community to know about their child's needs, so stay distant to avoid being ashamed or embarrassed.

We know that some of the wider experiences recorded in this report are not unique to BAME families. It was necessary to do this piece of targeted work to ensure parent carers' views of BAME CYP are heard, but many of the issues identified are experienced by SEND families across the city and have been the subject of PaCC and others' representation for many years in working to strengthen services for the whole SEND community. We hope that in highlighting some of the BAME community's experiences that the recommendations for change can have wider benefit in shaping the SEND strategy to meet the needs of the whole SEND population.

While families raised with us the issues they have been experiencing during the Covid-19 pandemic, and how this has heightened the challenges they face, these haven't been analysed separately in the report, given the focus is on the long-term SEND strategy.

### **Presentation of findings and recommendations**

The structure of the report follows the SEND strategy survey questions which align with the SEND strategy priority themes. Recommendations are located under the survey/SEND strategy most relevant theme, though some cut across different the themes.

Some parent carers' contributions to the consultation are reported in verbatim and some summarised through translation, to ensure the detail of their experiences is captured and considered and to provide depth to the report. However, it is recognised the consultation didn't provide an opportunity for exploring or co-producing solutions in response to the issues parents raised. It is therefore recommended that there is a deep dive review of BAME families' concerns as part of the SEND Sufficiency planning process and that more cases of good practice are identified locally, and from other parts of the country where BAME families and services have co-produced successful support strategies.

Finally, many generic and familiar themes / issues were identified in this engagement process, such as the need to minimise waiting times for services, which identify, assess and provide support, and the need for greater collaboration across agencies/services/schools etc to develop more joined up services. We haven't on this occasion included recommendations on such broad themes but instead focused on specific actions which can be taken forward in the SEND strategy.

## Findings and recommendations framed around the SEND Strategy

	Findings	Recommendations
	<b>Inclusion</b>	
1	Greater race/cultural awareness is required across the city's SEND services. Having a greater level of understanding is essential to engaging more effectively with BAME CYP and helping them to achieve their goals.	All staff across all settings should participate in mandatory training and be supported to improve their understanding of different cultures, backgrounds and identity and how this impacts upon SEND needs (ASC, anxiety and others).
2	Schools in particular need to get on board with cultural diversity and awareness, to recognise the importance of their actions and to model compassion, kindness and true inclusivity, from the outset when supporting BAME (and all) families.	<p>Head teachers need to implement whole school strategies to ensure all staff have awareness of SEND BAME needs and pathways. Children need to be exposed to different cultures at early age 'to plant the seed'.</p> <p>Schools need to accept racism as trauma and develop trauma informed practice that reaches all staff. All children should be able to cultivate a sense of belonging.</p>
3	<p>SEND BAME CYP and their families can feel isolated and excluded, from each other, from school, the wider community and from services more broadly.</p> <p>For example:</p> <ul style="list-style-type: none"> <li>• Help, advice and leaflets may be given but they are not always read and understood. As a consequence, families do not understand the full extent of what is happening with their CYP</li> <li>• When not participating within their local community, due to language barriers / lack of culturally appropriate activities etc, BAME SEND families rely on school for help. Where relationships aren't strong, a family can end up falling between the gaps.</li> </ul>	<p>More specific support, activities, events and opportunities are required in the city for BAME CYP and their parent carers to come together, and for service providers to hear from and build relationships with these communities.</p> <ol style="list-style-type: none"> <li>a. A safe space (for YP and for parent carers) to talk: about conditions, concerns, responding to individual needs</li> <li>b. Pastoral support which nurtures parental engagement, provides parents with a contact they can speak to directly with any concerns and helps them link with service providers</li> <li>c. EAL support for families to access information</li> <li>d. Building trust and relationships with the BAME SEND community</li> <li>e. Listening to and believing in the family, being supportive to prevent issues spiraling</li> <li>f. Funding for community groups to provide activities for BAME families to facilitate community participation and social engagement, including in specialist groups where parents share common experiences/CYP conditions etc</li> <li>g. Service providers reaching out, holding focus groups/workshops, to gain perspectives from diverse BAME communities and building trust to make the step change required.</li> </ol>
4	Stigma and taboos within BAME communities create barriers to families engaging with services. Plus parents may be neurodiverse themselves, disabled and/or have health conditions which impact upon their caring abilities.	The advocacy and support needs of parents of BAME CYP needs to be better recognised and addressed within parent carer support services.

	<b>Findings</b>	<b>Recommendations</b>
5	Increasing the diversity of trainers with lived experience and BAME backgrounds will strengthen cultural voice and representation.	Co-design and co-deliver SEND training with BAME parent carers so that training content is more relatable and impactful.
6	Parent carers of BAME CYP need to see system-wide change to believe it!	<ul style="list-style-type: none"> <li>a. The quality standard for inclusion must drive change and be more than a tick-box exercise.</li> <li>b. Greater BAME representation is needed on all levels in a number of key institutions and organisations in the city. Key SEN teams should review their staff diversity profile and set targets to increase BAME % representation. Similarly, membership of the Children's Committee and other key boards should be reviewed and BAME and disability represented.</li> <li>c. If they experience racism in receiving SEND services, BAME families need to (know how to) access support which will help them take action to address this.</li> </ul>
<b>Early identification and intervention</b>		
7	Parent carers of BAME CYP can feel they aren't listened to in relation to the identification of their CYP's needs. Because of cultural/communication barriers, they face challenges contributing to plans / approaches for their child and accessing information on services, which reduces their awareness of options available to address their CYP's needs and restricts actions they might take. Quality of relationships with 'professionals' affects CYP outcomes.	Provide more targeted SEND support for parent carers of BAME CYP, including pastoral care or mentoring provided within the community. This additional relational support is needed to help CYPs, families and professionals to develop constructive relationships.
8	BAME families report they are being diagnosed later than their white counterparts, struggling to access assessments, with late identification or no identification/intervention, which is impacting negatively on CYP and resulting in poor outcomes. Failed school experiences are driving many families into home education.	Monitor and publish the ethnicity breakdown of key services to increase transparency and assess whether BAME families' early help experiences are disproportionate to the wider SEND community eg CYP who are home educated, SEN Support vs EHC assessment request, vs EHCPs, families awaiting CAMHS/NDP assessments and resulting diagnoses.
9	There needs to be an increased focus on mental health and wellbeing, to try to break down the barriers around 'accepting' the condition within the BAME community and support families in engaging in and discussing a sensitive matter.	Primary school age BAME children having priority access to the schools wellbeing service would help create positive change early.
<b>SEND service pathways</b>		
10	BAME CYP can drop out of the system very easily when parent carers do not have the school or GP on board, and lack the relationships/ knowledge/ confidence/ language skills to secure this.	In these situations, additional further effort/information/ support/service to ensure parent carers are aware of pathways/options for support and their CYPs' rights.

	<b>Findings</b>	<b>Recommendations</b>
11	Due to cultural assumptions BAME CYP with ADHD, SEMH and PDA can be inappropriately labelled as 'naughty'.	Cultural assumptions need to be challenged to ensure parent carers of BAME CYP with these conditions are supported, especially where the level of service and referrals on from CAMHS is inadequate.
12	The service pathway needs to look at BAME CYP needs through the lens of the whole child's development, including anxiety and behaviours that BAME CYP find challenging.	Increase support for parents who have had to home school their children due to anxiety issues and those waiting for diagnosis. Expand which parents can access BHISS support/courses to include those who are awaiting a diagnosis.
13	BAME CYP can experience high levels of exclusions.	School leaders and SENCOs to work with BAME parent carers to develop and put in place alternative strategies to exclusions, eg consequence behaviour activities.
14	Siblings of BAME CYP lack support	SEND pathways need to address the support needs of siblings to BAME SEND CYP.
<b>Achievement and outcomes</b>		
15	Some BAME SEND CYPs do not have (adequate) individual plans in place to support their progress. Agencies need to recognise this and collaborate around BAME CYP attainment as a shared goal	Schools should develop a mentor system to support BAME CYP in developing effective individual plans.
16	Parents of BAME CYP need to have a greater awareness of education/ support interventions their CYP is entitled to and / or understand why they are not receiving them.	Raise the profile of the Ethnic Minority Achievement Service and the support it can provide to SEND EAL families. A varied number of therapeutic interventions / subjects should be offered to BAME CYP including art, drama, talking, group work, and sport.
<b>Transitions and preparing for the future</b>		
17	Some BAME SEND CYPs and their parents lack awareness of transition options available and guidance/ support on how to access them. This affects preparations for their journey to adulthood. Accessing appropriate pathways is even harder where supportive relationships aren't in place with services, with stark consequences eg a CYP risks becoming NEET (Not in Education, Employment or Training)	<ul style="list-style-type: none"> <li>a. Ensure YP has a transition plan which is agreed by YP and their families, and they have clear information and guidance (in other languages) on where to get advice on their future options, eg training, education, volunteering, traineeships, work experience, apprenticeships, employment etc</li> <li>b. Increase services which provide mentoring and peer support to SEND YP around preparation for adulthood and development of life skills.</li> <li>c. Provide more information on financial support options for YP and their families (eg DLA/PIP)</li> </ul>
18	Transition needs are particularly great amongst BAME SEND YP in the youth offending service	Increase the educational hours for BAME YP in the Youth Offending Service.
19	Transition support needs are continuous within and not just between schools	Individual CYP plans need to take account within the school year of what transition support is needed when there is a classroom change, new teacher and children are re-mixed etc
<b>Sufficiency of SEND services and provision</b>		
20	Recognising current gaps, and monitoring and gathering feedback from parent carers on an ongoing basis is vital in supporting families' ever-changing needs	Carry out a deep dive of the BAME SEND community to properly understand needs and co-produce services in response

	<b>Findings</b>	<b>Recommendations</b>
21	Address current gaps in services	a. Improve the SEMH offer to all CYP with SEND in schools and monitor access by BAME CYPs. b. Increase support for BAME CYP with an ADHD diagnosis and recognition of PDA
	<b>Governance of the SEND Strategy</b>	
22	Relevant laws must be followed and schools held to account by the BHCC	When a BAME CYP's needs can't be met, eg eating issues, gender identity, education, mental health, there needs to be a framework in place for alternative provision.
23	Governance oversight needs to be specialist and expert.	SEND governors should have experience of SEND, either gained through lived experience or by developing skills/knowledge through engaging/working with parent carers to properly hear and understand their views. There should also be more BAME/culturally appropriate governors to ensure schools are able to handle issues around race/racism.



## Detailed findings from online survey and one to one interviews

1. **Inclusion:** the strategy wants services and support to be inclusive to children, young people and adults with Special Educational Needs and or Learning Disabilities, from early years to adulthood. Do you feel your children and/or young people and the whole family are included a) at school b) in their community?

- Online consultation: 42% of respondents felt that their family is included at school; 28% felt only sometimes; 21% don't feel included and 9% don't know. 31% reported that they feel included in their community; 31% only sometime, 26% don't feel included, 12% didn't know
- 66% of all interviewees don't feel included by school
- 90% HKP interviews said they didn't feel included in the community

*'The school aren't actually trying and would rather he wasn't there. They need to be **less prejudice, more flexible** and actually take action. I cannot keep leaving work 10 minutes into him being in school, he has an EHCP'*

*'We don't have a **school coffee morning** or get to meet other parents with children with SEND'*

*'For the school to **stop punishing my child for his behaviour** and see it as communication'*

*'**Lack of SEN safe spaces & groups.** We have experienced humiliation by individual staff due to our child's behaviour at a soft play'*

*'I wish for my school to be kinder, more understanding and not so dismissive'*

*'My child is often **excluded from special trips and activities** and it's really unfair and unhelpful'*

*'For **incidents around race and or friendships** to be taken more seriously and be addressed'*

*'They did **not take our worries seriously**. He was suicidal by year 1 and had two attempts to take his life. We offered to help support but they declined us coming in, eventually we got a one-hour slot at the end of a Friday! They were hiding things from us'*

*'She told him (teacher) "You must be a disappointment to your parents" he was so young and his self-esteem is low'*

*'The staff deliberately broke down familial relationships'*

*'Complete **disregard of racially charged bullying** and failure to offer an investigation'*

*'Unneeded restraint as he was safe within the locked school building'*

*"There is fast becoming a racial and class divide often initiated by schools as to who receives the right support and at the right time. The middle class white are getting support, with some paying for this, and some not. And if you're a single parent it can be so much harder'*

*'In our experience, **lack of inclusion is a major, serious impactful issue.** We have been pushed to take our primary aged child off roll many times. It has taken 6 years to get in place the support, which has denied him (and us parents, his sibling) of the childhood he had the right to have'*

*'Sadly some schools despite making some improvements over the years are far from inclusive, **lack understanding and are not interested in the outcomes for the SEND children but are focused on the achievers.** Learners and often girls or introverted children with high anxiety or emotional and mental health needs (or undiagnosed ASC) are often overlooked as they not seen to be causing an issue in the classroom to the teacher although the child is actually falling apart'*

***'Neglected or misunderstood children are often - Black or mixed race, children with ASC/ADHD, those struggling with anxiety, adopted or from single parent backgrounds'***

*'Not having mode of **transport** eg: spouse only driver but at work. Do not know how to use local transport to get to venue – need leaflets for events/services with detail on how to travel.'*

*'Having other siblings cannot take them to coffee mornings or with SEN child. Family and religious commitments such as Friday 'pray day', weekends the only family time so avoiding groups.'*

***'English being second language, feel do not fit in'***

*'Physical and emotions are up and down not necessarily feel like going out if having a bad day or feeling poorly so things can change very quickly and unlikely to attend groups.'*

**1.1 More inclusion:** what would help to make you feel more included?

**Targeted BAME mentoring and support – good practice eggs shared:**

- Mentivity with Fresh Youth Perspectives provide targeted mentoring is a good example of collaboration with a positive impact for BAME YP. This has been particular responsive to BAME YP's emotional and mental wellbeing needs during Covid when they have been experiencing high levels of bereavement and anxiety around infection
- University:School mentoring and role model programme where students of colour at the University of Brighton connect with pupils of colour in schools. University students are matched carefully with school pupils, they meet for 1 hour a week for 5 weeks in a mentoring relationship and in the 6<sup>th</sup> week pupils visit students at their campus to get a taste of university life and celebrate the programme. Parent carers from Patcham High and Varndean talked about the positive impact on their YP. Mentees then often become mentors
- John Lynch training and consultancy provides peer to Peer BAME mentoring programme training for members of staff in schools
- BMEYPP also run mentoring projects, and their latest project (supported by ASATT) is providing tutoring to young people of colour (Black, Asian, Arab and Dual heritage) who may have struggled during lockdown or fallen behind. BMEYPP need a building/space to run activities like this.

***'For schools to acknowledge problems children face in school and trust parents who tell them their child is struggling in school, instead of threatening or blaming parents. We were told by the deputy head not to pursue a diagnosis, as labelling is bad. They bullied my son out of school. The HE community is supportive and he has found his place there but it shouldn't be the only viable option for the child'***

***'More family BAME events'; 'To have more events that culturally match us and other people'***

***'A holistic wrap around support package providing one to one carer (PA) for all necessary and required circumstances. My partner works. My Neuro-typical daughter needs my attention and my autistic son who has extremely challenging behaviour needs constant support. He has been 'excluded' from his junior school and has no secondary school lined up because there is no school suitable in Brighton. There is no inclusion for children who have his level of complex need.'***

***'It is hard to do inclusion from our side. The majority in my kids' schools are white British and hardly do any eye contact. How can I impose myself? I tried couple of years to do play-dates and running after parents. The majority in the school are those who hates nonwhite British, I guess.'***

***'Most of SEN activities run by and include non BAME persons/children'***

***'Set up of **advocacy or rep** which they can speak to directly with any concerns and link with service providers.'***



## Inclusion conclusions

The following key messages summarise the views of the BAME parent carer community engaged in this consultation. These need to be heard and better understood as the foundations on which the SEND strategy must build:

- BAME CYPs feature disproportionately in statistics around off-rolling, exclusions, alternative provision, isolations, restraint of CYPs, NEET, youth offending service etc
- BAME parent carers feel therefore that the rhetoric and the reality of inclusion in B&H are very different.
- SEND BAME CYP need to be given the opportunities and support which enables them to succeed. Like all children, they should be able to be happy and be given the chance to thrive. Their needs and emotional wellbeing must come first, before resources, and the SEND code of practice needs to be enforced.
- BAME parent carers that raise concerns should be listened to, instead some feel they are labelled as being part of the problem. Racial and cultural prejudices, unconscious bias, judgement and assumptions need to be recognised and addressed. The SEND system needs to facilitate BAME families' participation, instead of acting as a challenger.
- Where BAME communities intersect eg with LGBT/single parents, SEND CYP and their families experience even more significant barriers to inclusion.

## Recommendations to strengthen inclusion in the SEND strategy:

	Findings	Recommendations
1	Greater race/cultural awareness is required within services. Having a greater level of understanding is essential to engaging more effectively with BAME CYP and helping them to achieve their goals.	All staff across all settings should participate in mandatory training and be supported to improve their understanding of different cultures, backgrounds and identity and how this impacts upon SEND needs (ASC, anxiety and others).
2	Schools in particular need to get on board with cultural diversity and awareness, to recognise the importance of their actions and to model compassion, kindness and true inclusivity, from the outset when supporting BAME (and all) families.	Headteachers need to implement whole school strategies to ensure all staff have awareness of SEND BAME needs and pathways. Children need to be exposed to different cultures at early age 'to plant the seed'.  Schools need to accept racism as trauma and develop trauma informed practice that reaches all staff. All children should be able to cultivate a sense of belonging.
3	SEND BAME CYP and their families can feel isolated and excluded, from each other, from school, the wider community and from services more broadly.  For example: <ul style="list-style-type: none"><li>• Help, advice and leaflets may be given but they are not always read and understood. As a consequence, families do not understand the full extent of what is happening with their CYP</li><li>• When not participating within their local community, due to language barriers / lack of culturally</li></ul>	More specific support, activities, events and opportunities are required in the city for BAME CYP and their parent carers to come together, and for service providers to hear from and build relationships with these communities. <ul style="list-style-type: none"><li>a. A safe space (for YP and for parent carers) to talk: about conditions, concerns, responding to individual needs</li><li>b. Pastoral support which nurtures parental engagement, provides parents with a contact they can speak to directly with any concerns and helps them link with service providers</li><li>c. EAL support for families to access information</li><li>d. Building trust and relationships with the BAME SEND community</li></ul>

	appropriate activities etc, BAME SEND families rely on school for help. Where relationships aren't strong, the family can end up falling between the gaps.	<p>e. Listening to and believing in the family, as being supportive and inclusive can prevent issues spiraling</p> <p>f. Funding for community groups to provide activities for BAME families to facilitate community participation and social engagement, including in specialist groups where parents share common experiences/CYP conditions etc</p> <p>g. Service providers reaching out, holding focus groups/workshops, to gain perspectives from diverse BAME communities and building trust to make the step change required.</p>
4	Stigma and taboos within BAME communities create barriers to families engaging with services. Plus parents may be neurodiverse themselves, disabled and/or have health conditions which impact upon their caring abilities.	The advocacy and support needs of parents of BAME CYP needs to be better recognised and addressed within parent carer support services.
5	Increasing the diversity of trainers with lived experience and BAME backgrounds will strengthen cultural voice and representation.	Co-design and co-deliver SEND training with BAME parents so that training content is more relatable and impactful.
6	Parent carers of BAME CYP need to see change to believe it!	<p>a. The quality standard for inclusion must drive change and be more than a tick-box exercise.</p> <p>b. Greater BAME representation is needed on all levels in a number of key institutions and organisations in the city. Key SEN teams should review their staff diversity profile and set targets to increase BAME % representation. Similarly, membership of the Children's Committee and other key boards should be reviewed and BAME and disability represented.</p> <p>c. If they experience racism in receiving SEND services, BAME families need to (know how to) access support which will help them take action to address this.</p>

**2. Early identification and intervention:** the strategy underlines the importance that children's needs are identified, assessed and supported both early in life and when issues arise, that will be achieved through more Early Help support and consistent offer of mental health and wellbeing services. Do you feel your child's additional needs were identified and assessed early enough?

- Online consultation: 41% of respondents felt that their child's additional needs were identified and assessed early enough; 5% felt only sometimes; 21% stated 'No' and 3% don't know
- 76% of all interviewees said needs were not identified or helped early enough

Families overall described a worrying pattern of poor access to help early on in the parent carer journey:

- BAME families say they identified their CYPs' needs early but didn't feel listened to in getting them understood or acted upon
- BAME families report they are being diagnosed later than their white counterparts, with late identification or no identification/intervention, impacting negatively on CYP and resulting in poor outcomes. Failed school experiences are driving many families into home education.

- Over 25% of parent carers interviewed said that their CYP had not been able to access assessments at Seaside View and/or are awaiting support from CAMHS. These parents are unaware of services they could/should be accessing for their BAME CYP, sometimes because English may not be their first language, because they turned away for support and gave up trying, and/or they fell through a gap in the system. These CYP maybe in school now, but they are in danger of dropping out because adequate support isn't in place
- Many parent carers have explored identifying their CYPs' needs/conditions on YouTube
- Earlier support and recognition of needs such as ASC should be considered, not dismissed, due to BAME children being adopted or premature birth.

*'Refusal to actually diagnose Dyslexia despite all the evidence and I am worried for my daughters mental health as we experienced issues with our son due to his masking and it feels like we are going down that path again'*

## 2.1 Who helped you understand your child's additional needs?

- Online consultation: 65% of respondents said a professional helped them; 16% said a particular community, support group or service; 35% said someone else

Professions mentioned included: *Health Visitor, SENCO, GP, School nurse, Nursery, Paediatrician, Support Groups, CAMHS, Amaze, EMAS, Barnados, Seaside View, Presens, Portage, Specialist Community Disability Service, specialist support on Facebook on condition, Children Centre group, interpreters, keyworker.*

*'Most of what we have learned has been from friends in the adoption community with similar issues. Also we have done all the training available over the years'*

*'My own daughter and my own son, as their anxiety and depression persisted and we finally started recognising the reality of their experience. Also, my dear friend who had struggled for years to get CAMHS involved in supporting her daughter, the same age as mine. And two other friends who I met through the Women of Colour Brighton FB group who validates the experiences and helped and are helping us now'*

*'I took advice from an advocate, thankfully or I don't believe he would have diagnosis today'*

*'My own research. I flagged up concerns first to nursery then to primary school because I was aware of developmental delays and problems with writing and dysregulation. Unfortunately, the teachers all dismissed my concerns thereby delaying my child getting a proper assessment and needs met. My child could not cope in mainstream secondary but we received threats of penalties and prosecution instead of help. Finally, my child was assessed and got an EHCP but has missed almost 3 years of school. Had teachers and SENCOs responded appropriately and sooner there'd be less chance of yet another person in disability benefits for the rest of their life'*

## 2.2 Help on identifying and assess: What would have helped to make you feel your child's needs were identified /assessed supported earlier?

*'I feel the professionals have a collection of strategies that they pull out of a bag and hope will work, without looking at the child's individual needs. Listening to me and spending focus time with my son would have benefited them to develop the correct strategies'*

*'An annual review at least.'*

*'Anyone listening to our concerns; support from the school. The school seemed to sit on our child's referral for years / Staff at school having a better understanding of ASC/ADHD / He was August born and they would not allow us to defer a year, and with unidentified but obvious SEN'*

**‘Teachers listening to me** when I told them at age 5 my child was autistic. A diagnosis before the LAST YEAR of secondary school.’

‘With the dire situation going on I took my son off roll before they excluded him (Year 2), I home educated my son for two years during which time he was Diagnosed with ADHD, Sensory Processing Disorder, and Generalised Anxiety Disorder, his doctor said his symptoms were so clearly present, that she was sad he was not referred earlier. He is now in a new school and thriving with an education and learning plan. His new **SENCO and teachers are supportive and understanding** as they guide him through school in a way that is suitable for his needs.’

‘SENCO at my daughter’s primary school decided that she doesn’t have enough symptoms to be diagnosed! That delayed her diagnosis by at least one year and we are still struggling with receiving help at her school. It might be a good idea **to have more SEN support at school to speed up the assessment and diagnoses**’

‘**Condition was identified early enough, but the professionals just wanted to put a label on it, then they all disappeared.** Seriously, they all disappeared. We had no support, we didn’t know who to ask or where to go. We had a speech therapist who eventually stepped in and helped organise some general things for us, and the mainstream nursery which my child attended really did their best. But we muddled around in the dark for years’

‘I only know about BHISS now, I will talk to SENCO about it / **I wasn’t aware of Seaside view for longtime, I wish I knew earlier.**’

‘Not discriminating him. **Promote the positive behaviour not just always giving negative comments**’

‘Behaviour needs to be seen as a **communication of need not as "bad" or a poor choice.**’

‘**GP’s need to have better knowledge of some of the conditions**’ ‘Spending time out of the city for specialist care’

‘**The support of an independent, Black & Brown-led Community group that isn’t connected to the school and college.** A trusted organisation of folks whose own experiences help them recognise and support the needs of young people.

‘What is the point in talking about it to your school, if this was approached by school [in the first place], we would get better outcome.’ [Parents can believe school is the main source of help and support and are the only profession who should know about their families’ needs, along with GP. They do not understand the community plays a vital part in providing support.]

‘**No support whilst waiting** – should be able to see paediatrician as soon as you suspect a problem. Support group for mental health and wellbeing whilst waiting for diagnosis as can be ‘lonely road’. **Once the child is identified help should be automatic**’.

## Recommendations to strengthen early identification and intervention in the SEND strategy:

	Findings	Recommendations
7	Parent carers of BAME CYP can feel they aren’t listened to in relation to the identification of their CYP’s needs. Because of cultural/communication barriers, they face challenges contributing to plans / approaches for their child and accessing information on services, which reduces their	Provide more targeted SEND support for parent carers of BAME CYP, including pastoral care or mentoring provided within the community. This additional relational support is needed to help CYPs, families and professionals to develop constructive relationships.

	awareness of options available to address their CYPs' needs and restricts actions they might take. Quality of relationships with 'professionals' affects CYPs' outcomes.	
8	BAME families report they are being diagnosed later than their white counterparts, struggling to access assessments, with late identification or no identification/intervention, which is impacting negatively on CYP and resulting in poor outcomes. Failed school experiences are driving many families into home education.	Monitor and publish the ethnicity breakdown of key services to increase transparency and assess whether BAME families' early help experiences are disproportionate to the wider SEND community eg CYP who are home educated, SEN Support vs EHC assessment request, vs EHCPs, families awaiting CAMHS/NDP assessments and resulting diagnoses
9	There needs to be an increased focus on mental health and wellbeing, to try to break down the barriers around 'accepting' the condition within the BAME community and support families in engaging in and discussing a sensitive matter.	Primary school age BAME children having priority access to the schools wellbeing service would help create positive change early.

**3. SEND Pathways:** the strategy will ensure that children, young people and adults with SEND and their families can access the right support from services easily and quickly, including reduction in the duplication of meetings you have to attend and short-breaks/respite services that meets the needs of your family. Do you feel your child's additional needs were supported in the right way?

- Online consultation: 25% of respondents felt that their child's additional needs were supported in the right way; 36% felt only sometimes; 39% stated 'No'
- 52% of interviewees said their CYP's additional needs weren't supported in the right way

*'Need support in **ongoing changes to needs from childhood to adulthood**. Household support required to support other **siblings** and family members due the **insecurities in the home** and changing need of additional need child.'*

*'I get the support I need from **charities and support groups**. I use the support to help me work with the school who are a bit slow to respond but do work with me. I don't have much to do with services from the council. We don't rely on them and we don't expect much from them'*

*'He's not really getting an education; **they are just keeping him contained**'*

*'**She's not getting the support** but we give it to her after school as she isn't processing or retaining the information/learning'*

*'No he is a masker. **We had to battle to be believed**. This led to complete shutdown'*

*'I would like to attend **more courses for parents and see different cultural representation**'*

*'They need to take **action when you mention the issues**, not put all the attention on the bullies and ignore the victim'*

*'Professional bodies, head teachers and SENCO, and services **working together**.'*

### 3.1 Support: Who did you get your support from?

Both online consultation and interviews highlighted a variety of professionals, organisations and individuals who provided support. Among these were schools, ITF (family coach), CAMHS ADHD support group, CAMHS Assertive Outreach team (no longer running) and key worker preschool, Early Help from school years, speech and language therapy, BHISS, Amaze, Council SEND team, NHS health visitors and specialists, School Health Visitors, nursery play workers, Children's Centres, Extratime, Presens, Portage, Seaside View, signposting to Family Funds, Blue Badge, Community Disability Service, Talking Therapies, EMAS, Barnardos.

*'Once our child was finally referred and assessed the experience was good. In 2017/18 the **waiting time was long** and a combined assessment was not at that time possible'*

*'**No one. I was repeatedly told I was "projecting my own mental health problems" and that my child was coping at school.** My poor child tried to end her own life. Social services dismissed this as "attention seeking" she was NEVER given counselling despite me begging and white children were always prioritised 100 %'*

*'The **nursery were fab**. The specialist support that came to the nursery were a waste of time'*

*'Swan Centre at BACA was a life saver. Team Domenica also a God send after very poor education/support at City College / the MET in special needs section'*

*'**Had to get private diagnosis** then was easier to get a diagnosis from Scott Unit and Dr. Liebenberg. Amaze and mASCot charity gave me some help'*

### 3.2 More Support: What more support do you think you need?

*'**Pre-school access to respite'***

*'**Respite.** CAMHS feel that my child and our family would benefit from it, but SS disability team say my child does not meet the criteria. We have had early help, SS involvement and numerous referrals to FDFP'*

*'For the next child; **supportive relationship with school, believe parents, more one on one support in classroom, proper supervision at break time** (multiple injuries and unnoticed bullying). Mainly for teachers to approach parents with curiosity not blame, we are on same side!'*

*'Access to **more weekend/ holiday activities'***

*'**More communications from the school to me** rather than me bringing things forward. **A quieter environment to talk to school staff at parents evening** and more regular contact with their teachers instigated by them'*

*'**A complete re-training of schools** and an **urgent review of why girls are waiting 15 years in Brighton for an ASC diagnosis.** And the **racism and ableism in our schools.** **Education about hidden disabilities'***

*'**EHCP without a fight.** Son under-performed at school. School just wanted him out as he was difficult to teach. Schools need to be rewarded for supporting SEND rather than penalised due to poor exam performance & financial penalties'*

*'The Child Development Centre should be able to refer SEND children to an appropriate approved service. In our case it was left to us to **try repair the damage done to our son** through mis-management and source and pay for help at the same time as trying to get what he needed educationally through a second tribunal for EHCP and provision.'*

*'**Pastoral support, emotional, mental health and wellbeing.** Help in transitioning easing in new setting. Such as building up days of return to school setting and shorter class time.'*



***‘Support in staying fit and healthy – sports engagement.** Extra support and tuition in school specialised sports for SEN and in community. Holiday clubs to keep them stimulated, affordable and easy to access suitable activity. **Health and confidence building nurtured at early age,** encouraging to take exercise for good physical and mental health and building self-esteem.’*

***‘Respite care** needed as and when required and should be easily arranged, having to take up to 2 years in some cases. **Parent/carer unable to work due to child having frequent episodes** and needed to be collected from school.’*

#### **Recommendations to strengthen SEND pathways in the SEND strategy:**

	<b>Findings</b>	<b>Recommendations</b>
10	BAME CYP can drop out of the system very easily when parent carers do not have the school or GP on board, and lack the relationships/ knowledge/ confidence/ language skills to secure this	In these situations, additional further effort/information/ support/service to ensure parent carers are aware of pathways/options for support and their CYPs’ rights.
11	Due to cultural assumptions BAME CYP with ADHD, SEMH and PDA can be inappropriately labelled as ‘naughty’	Cultural assumptions need to be challenged to ensure parent carers of BAME CYP with these conditions are supported, especially where the level of service and referrals on from CAMHS is inadequate.
12	The service pathway needs to look at BAME CYP needs through the lens of the whole child’s development, including anxiety and behaviours that BAME CYP find challenging.	Increase support for parents who have had to home school their children due to anxiety issues and those waiting for diagnosis. Expand which parents can access BHISS support/courses to include those who are awaiting a diagnosis.
13	BAME CYP can experience high levels of exclusions.	School leaders and SENCOs to work with BAME parent carers to develop and put in place alternative strategies to exclusions, eg consequence behaviour activities.
14	The siblings of BAME CYP need support.	SEND pathways need to address the support needs of siblings to BAME SEND CYP.

**4. Achievement and outcomes:** the strategy will ensure that all children, young people and adults with learning disabilities are able to achieve their full potential across Health, Education and Social Care. That will mean a more flexible curriculum and ‘lifelong learning’ pathways for adults with learning disabilities. Do you feel your children and/or young people is able to achieve their full potential across health, education and social care?

- Online consultation: 26% of respondents felt that their child’s and/or young person was able to achieve their full potential across health, education and social care; 34% felt only sometimes; 29% stated ‘No’ and 11% don’t know
- 40% of interviewees reported they were not confident their CYP would achieve their full potential in terms of outcomes, because of their negative experiences, EHCPs not being fulfilled or because their CYP slipped through the net

***‘With the right support, we haven’t experienced that yet! We have written off this next year as **the school want us to take him off roll but we won’t do it*****

***‘Achievement and outcomes are an issue for our children in our city.** Sadly, some schools, individuals or experiences add to the harm’*

***‘Some may write our children off or not care about their outcomes.** Some schools behavioural approach/ ethos or pressures from government do not give our children a chance.*

*The attainment gap between them and their peers can become hugely different especially if they are just contained, left to wander corridors or excluded from various activities or the classes'*

*'Off-rolling needs to stop'*

**4.1 More support:** What more support do you think children need to achieve their full potential?

*'Independent living skills. OT support. A mentor to help my teen access the community with support and it increase his independence'*

*'Because he is now home educated, he gets proper support. Free swimming for children plus carers during school hours would be great too'*

*'Quieter learning spaces, smaller classrooms, more contact with teaching staff on their progress, more funding going into schools for additional creative writing, social narratives and forest schools'*

*'All the professionals involved in my child's care should be talking to each other and sharing information with each other, not citing "data protection" as a reason to not share, as this is the OPPOSITE of what those laws are meant to protect'*

*'Specialist support after school, activities in the weekend'*

*'There was no joined up strategy, despite my son needing meds & CAHMS. His main diffs was in learning & this was often punished. Few teachers and certainly not the education authorities tried to get had best out of him'*

*'We try to access what we think will help but sometimes hard to identify! However, we have been fortunate with our last daughter to be able to opt for a small private school, since appalling school experiences was the last straw for our older daughter, who eventually left home, partly as a result of dreadful school experiences, and went back into care. At 21 she now has no GCSEs. The private School has been very good at listening to our needs and taking appropriate action.'*

*'I need the right support for my child and our family's wellbeing. I do not demand for 'more ' help. Just addressing my son's basic needs. For example, he needs enough language and speech therapy to gain understanding of communication, while at the moment the amount is set for the rest of population at school. Children have different needs so their amount of support should be addressed based on the needs of the child not on how much the authorities want to give away.'*

*'Trauma informed education staff -teachers, guidance counsellors and administrators - who are focused on supporting the individual student rather than protecting institutions'*

*'Being challenged in school, flexible learning, one to one in core subjects. Flexible Individual learning plan, contingency plan, behaviour support plan'*

*'Encouraging participating in sports and activities and music in school and in community. Affordable and accessible'*

*'More community engagement - social engagement outside of homes – making friends social interactions'*

*'Challenging the child further academically, adapting curriculum to their needs and abilities. Having individual needs assistance in school, one to one.'*

*'Reassess regularly as needs are changing so need to amend and adapt to change. Making sure a plan is in place which is regularly assessed, amended and updated'*

## Recommendations to strengthen CYPs' achievements and outcomes in the SEND Strategy:

	Findings	Recommendations
15	Some BAME SEND CYPs do not have (adequate) individual plans in place to support their progress. Agencies need to recognise this and collaborate around BAME CYP attainment as a shared goal	Schools should develop a mentor system to support BAME CYP in developing effective individual plans.
16	Parents of BAME CYP need to have a greater awareness of education/ support interventions their CYP is entitled to and / or understand why they are not receiving them.	Raise the profile of the Ethnic Minority Achievement Service and the support it can provide to SEND EAL families. A varied number of therapeutic interventions / subjects should be offered to BAME CYP including art, drama, talking, group work, and sport.

**5. Transitions and preparing for the future:** the strategy will ensure that moves between services, including transition for children going into reception and secondary schools, or changes in provision and support across all ages are smooth, well planned and supportive, including will be well planned and supported. For example, there will be increased employment and training opportunities for young people and adults with SEND. Do you think your children and/or young people have been adequately supported at key transition points?

- Online consultation: 23% of respondents felt that their child's and/or young person have been adequately supported at key transition points; 26% felt only sometimes; 43% stated 'No' and 9% don't know
- Around 25% of interviewees felt their child was supported in transition.

*'BACA Swan Centre was excellent and to an extent Downs Junior'*

*'So much has been attempted but is has no benefit, I think we will be forced to homeschool'*

*'No photo of teacher, no video call, don't have a name for teacher - to know this would have been helpful'*

*'Why focus on particular points, children's classes are mixed up, they change classroom and get a new teacher - support for transition should be there not us parents trying get into place because or child wasn't considered'*

**5.1 More support:** What more support is needed at transition points or to plan for their future?

*CAMHS appointment we've been waiting 18 months'*

*'Targeted Salt & OT support to aid transition into new environments, how to communicate with new people in new settings, life skills etc. Psychologist's input to assess what kind of support and strategies would be appropriate'*

*'A keyworker to ensure continuity and prevent having to reiterate at each contact'*

*'Information on how to apply for universal credit when you are the parent of a young adult who cannot work- information to assessors, job centre staff and government officials'*

*'Help to keep track of child belongings (secondary); it's so expensive & his mental age is about 6'*

*'My child's transition to Secondary was awful. **The secondary school did not provide additional support because my child didn't have an EHCP at that point.** Things went horribly wrong. He had an EHCP by the end of year 7, but the trauma was too much and my child could not attend school. He is now in specialist. Things might have been different if the EHCP was in place before going to Secondary. He had high levels of support in primary'*

*'My son has not been in school since Dec 2019. He was in year six. He has not made the transition to secondary school because he was not integrating for the required 80 % of mainstream classes. **There should be a school, or unit for secondary age autistic children who are unable to integrate into mainstream**'*

*'**Children to be supported and helped to start making friendships.**'*

*'**Work placement** and giving her the right course that she wants or needs'*

*'**A written down plan** with possibilities and options on how to transition and what supports will be available in the next stage'*

*'For example there is **no specialist careers help at the moment.** I am left to struggle with my son trying to find a foundation course & degree that might be course work based as he does not fit the usual pattern'*

*'**Emotional and wellbeing support in transitioning at key stages eg keystage2 to keystage3** it can be lost easily. It is anxious times seen 'as the big school' 'to fit in' tour of schools, at least two weeks of transitioning support'*

*'**Clear guidance and support in GCSE** planning, higher education, training and employment. Lifelong progression and pathways. Career advice and right support which requiring to be followed through'*

*'**Information being passed on at key transition points** and discussed with family. Should be the school responsibility and not the parent/carers. Information can get lost. Once the receiver receives the info and acknowledgment call would be useful to re assure families. Parental engagement on how 'settled in' identifying problem factors and working on them.'*

*'Should be a **pastoral transition phase** where the support is gradual and continuous. Building up hours/days and easing them in the learning setting with the One to one support and emotional support – nurturing groups. Individual time and space to meet and greet teacher. Supervisions and Keyworker to follow through once settled.'*

*'**Mentoring SEN children using 'older buddies'** to help promote building confidence. How to go about everyday essentials such as travel: how to get on bus, travel on train. Going shopping, buying things independently. Money managing. Peer mentor support. As parents can be seen as 'embarrassing'.'*

*'**Transition to adulthood – body changing PSHE/RSE** support at school and in the community. Seeing doctor/nurse.'*

## Recommendations to strengthen transitions in the SEND strategy:

	Findings	Recommendations
17	Some BAME SEND CYPs and their parents lack awareness of transition options available and guidance/ support on how to access them. This affects preparations for their journey	a. Ensure YP has a transition plan which is agreed by YP and their families, and they have clear information and guidance (in other languages) on where to get advice on their future options, eg

	to adulthood. Accessing appropriate pathways is even harder where supportive relationships aren't in place with services, with the consequences stark eg a CYP risks becoming NEET (Not in Education, Employment or Training)	training, education, volunteering, traineeships, work experience, apprenticeships, employment etc b. Increase services which provide mentoring and peer support to SEND YP around preparation for adulthood and development of life skills. c. Provide more information on financial support options for young people and their families (eg DLA/PIP), recognising
18	Transition needs are particularly great amongst BAME SEND YP in the youth offending service	Increase the educational hours for BAME YP in the Youth Offending Service.
19	Transition support needs are continuous within and not just between schools	Individual CYP plans need to take account within the school year of what transition support is needed when there is a classroom change, new teacher and children are re-mixed etc

**6. Sufficiency of SEND services and provision:** the strategy will ensure that the right provision of services is available at the right time for all children and young people with SEND. Do you feel there are enough services and activities in B&H available for your children and/or young people?

- Online consultation: 26% of respondents felt that there are enough services and activities in B&H available for your children and/or young people; 63% stated 'No' and 11% don't know
- 52% of interviewees reported that there are enough services and activities in B&H available for their CYP; the others said don't know

*'Albion in community was a massive help. SEND kids just want to do what all kids do but often can't compete, therefore parallel arms of organisations need to be set up so there is less stigma'*

*'Whoopsadaisy stopped when our kid learned to walk but he needs long term support with motor skills. Whoopsadaisy were fantastic but we know they are a charity and have to limit what they do'*

**6.1 More services:** What services would you like to see offered?

*'Allow us to take children out of school for the interventions they need and aren't getting'*

*'Schools to be accountable for their treatment of our children'*

*'Access to **activities that neuro-typical children enjoy**, but with one to one wrap around support would be a good start. Scouts, Art clubs, sports etc. with one to one support'*

*'**Properly funded youth services.** Properly funded, accessible youth centres. More outreach work from youth services'*

*'**There is very little for PMLD children.** I regularly scour the Amaze newsletters, Scope info, Pebbles info. There is little I can involve her in. When there is, I jump at it. INCLUDING where on earth I can take her to get changed (a changing places toilet for example) if I do take her anywhere ... I feel we are ghettoised'*

*'Despite support from Social worker, medication turned down by CAMHS **we have been in crisis for the whole year-** We need more support to get this sorted' An alternative to CAMHS because the wait is too long and they may not help anyway*

*'**More easily available emotional help** (but not through CAMHS!) and a **1/1 peer support system to help with the relational issues.** More **incentive for schools to take up free attachment training etc.'***



**'CAMHS is really underfunded.** School budgets are cut so badly that they made bad decisions and its children with special needs that suffer'

**'Better service for girls** (with ADHD or ASC)'

**'ASC Training for teachers, not just for the TAs or INAs'**

**Accredited courses for parents** – 'The only thing I can say is support for myself. As I find that helps me to cope, which I believe must help my son'

Something for us continuing to **homeschool- online tutor/tutorials**

**'Mental health and disability can be seen in negative way in BAME communities** and culture: being stigmatised, labelled, and looked down upon. Hence people are not approaching services and help that they need and not talking about it so feeling alone.'

**'More regular groups to meet other families with similar conditions** - more than just coffee mornings for SEN need to be more specific to condition. BAME groups. Parent/carer group, family groups. One to one groups as can be tricky when having other siblings. Grouping children at their levels and ability. So they have a feeling of 'sense of belonging'

**'Day trips out as family with other families,** with supervision in place.'

**'Being involved more:** Physical activities. Taking part in activities, competitions. Establishing teams and tournaments etc, youth camps, access and affordable holiday clubs. Giving the children the chance to show their talents and being recognised. Physical, social interaction and engagement is needed in the community.'

**Online, virtual platforms** to meet others especially during this pandemic which is required more: Zoom exercise, physio, therapies on line classes/workshops around positive behaviour, managing behaviour

Having an **experienced rep, advocate, peer support** – First point of contact as some are simply not getting the right support at the right time and not aware of services.

**Assistance in filling in forms** can be lengthy process – things should be done automatically such as DLA, Disability badge, bus/rail ID.

**Specialised groups, sessions, activities for SEN children in school and community.** Listening to 'pupil voice' what they want and need

**Counselling support, mentoring support. Transition from childhood to adulthood.** Building independence. Career support to higher education, training and employment

## Recommendations:

	Findings	Recommendations
20	Recognising current gaps, and monitoring and gathering feedback from parent carers on an ongoing basis is vital in supporting families' ever-changing needs	Carry out a deep dive of the BAME SEND community to properly understand needs and co-produce services in response
21	Address current gaps in services	a. Improve the SEMH offer to all CYP with SEND in schools and monitor access by BAME CYPs. b. Increase support for BAME CYP with an ADHD diagnosis and recognition of PDA



## 7. Governance

Parent carers made the following observations on ensuring accountability around delivery of the SEND strategy:

22	Relevant laws must be followed and schools held to account by the BHCC	When a BAME CYP's needs can't be met, e.g. eating issues, gender identity, education, mental health, there needs to be a framework in place for alternative provision.
23	Governance oversight needs to be specialist and expert.	SEND governors should have experience of SEND, either gained through lived experience or by developing skills/knowledge through engaging/working with parent carers to properly hear and understand their views. There should also be more BAME/culturally appropriate governors to ensure schools are able to handle issues around race/racism.

## Appendix 1 Example of a simple infographic that demonstrates how expectations could be made clearer for BAME families

### WHAT CAN I EXPECT AT MY LOCAL SCHOOL IF MY CHILD HAS SPECIAL EDUCATIONAL NEEDS?

A set of expectations for schools have been co-produced with Birmingham Stakeholders (including parents and schools) as part of the Local Offer. As part of the implementation of the strategy, we will work in partnership to co-produce what parents can expect from health and social care sectors.

