GLOBAL BLACK
MATERNAL HEALTH

BLACK CHILD
SEND
supporting access to special educational needs
& disabilities provision

BLACK CHILD SEND

Accessing special educational needs and disabilities (SEND) provision for Black and mixed Black heritage children: Lived experiences from parents and professionals living in South London.

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A MESSAGE FROM GLOBAL BLACK MATERNAL HEALTH'S CEO

Agnes Agyepong
CEO and Founder of Global Black Maternal Health

As I reflect on the creation of this report, it's more than just a professional piece of work for me – it's deeply personal.

Over the past 18 months, I've journeyed back through my own experiences in primary and secondary school in South London where I was born, educated, and still live.

I loved learning and had a natural curiosity, but at school this was misunderstood. Marked as having SEND (Special Educational Needs Disabilities) – a label that often saw me being given educational activities that were neither helpful nor stimulating, the support I actually needed was never offered. I felt under constant scrutiny by teachers, and this led to a cycle of defensiveness and adultification bias, an experience routinely felt by Black girls. It left me feeling resentful and my experiences with SEND support felt more like punishment than help.

This is a pattern that many Black children face.

SEND in children of Black heritage is frequently misinterpreted as purely behavioural rather than an opportunity to develop their innate abilities. This flawed perspective contributes to misunderstandings about neurodiversity in these communities, resulting in incorrect assessments, delayed recognition, and lack of early, appropriate support.

As a Black British African female, this resonates deeply with me.

It wasn't until later in life that I came to understand that I fit the profile of someone with high-functioning ADHD. This revelation, in hindsight, explains so much and has since emerged as my superpower.

Unfortunately, it remained unnoticed through my childhood and educational journey, affecting my mental health and well-being well into adulthood.

The UK's SEND system is in crisis, with long delays in diagnosis and a lack of a cohesive approach. Race and poverty only exacerbate these issues.

That's why I'm thrilled to present our ground-breaking report: Black Child SEND.

Without understanding the diverse experiences of different communities, reforming SEND equitably and justly for all children in the UK is impossible.

Black Child SEND is a step towards ensuring that no child is left behind.

FOREWORD

Stephanie Woodrow
Portfolio Manager at Impact on Urban Health

When a child starts to communicate distress that affects their learning at school, they are entitled to support from the special educational needs and disabilities (SEND) system. However, parents are often left to navigate what can feel like an overly complex, judgemental system before they get any of the support they are entitled to.

We know that the intersection of race, gender and ethnicity hugely impacts children's access to support. Funding what we believe to be first-time research on Black families' experiences of the SEND system has enabled us to pull together the data and insights that so many of our partners already had but that were not compiled in one place. This project has helped us to identify what's needed in order to improve children's mental health and development.

The voices and expertise of Black families and professionals are centred in this research, opening up a community-wide conversation about the issues faced by Black families with children with SEND.

As a result, the complexity and nuances around these issues have been brought to the fore. This research provides clear recommendations for policy makers to improve families' experiences of navigating the support system for children with SEND and highlights the strength and leadership of Black parents who have spent years advocating for their children.

Our children's mental health programme has heard repeatedly from families, community organisations and healthcare professionals about the ways racism impacts both the mental health of children and the likelihood of them getting safe, compassionate support. We are working

with local experience-led partners, like Global Black Maternal Health, to test changes that will tangibly improve young peoples' ability to access timely, culturally intelligent support. The recommendations in this report are some of the ways we can put our words into actions to improve the lives of, and outcomes for, young people in Lambeth and Southwark.

ACKNOWLEDGEMENTS

This project would not have been possible without the insight and support of our strategic partner, Dr Catherine Benhura (Mum's Pride) and our advisory team Atinuke Awe (Learning with Ez) and Marsha Martin (BlackSENMamas).

Thanks must also be given to our funders, Impact on Urban Health.

Our biggest thanks go to the parents and professionals who gave up their time to take part in the survey and share their experiences in an interview. Your contribution will be instrumental in instigating the change that is needed to ensure that Black voices feed into decision-making around SEND policy.

INTRODUCTION

All children deserve the opportunity to realise their potential. The chance to harness their greatness. The right to learn in an environment that recognises their strengths, that nurtures their talents and that champions their achievements.

We know, however, that not all children are afforded these rights.

Children with special educational needs and/or disabilities (SEND) (that is, children whose needs call for educational provision beyond that available to their peers) are disproportionately and negatively impacted by education practices in the UK. Not only are school exclusion rates higher for children with SEND[1], but the process of obtaining SEND provision is complex for parents[2] and the often-extensive waiting times for referrals, assessments and approvals result in support not being put in place within legally mandated deadlines[3]. This means that the children with some of the greatest needs are being denied the opportunity to capitalise on their capabilities at school.

The picture is further complicated by the intersectionality of SEND with other factors, namely poverty, race and ethnicity. These overlap, bringing about a pattern of disadvantage for Black children such that they are more frequently identified as having SEND without provision of adequate SEND support. Research from as long ago as the 1980s indicated that Black Caribbean students in the UK, particularly boys, were over-represented for SEND[4]. Today the pattern remains unchanged: data shows that Black Caribbean and mixed white and Black Caribbean school children in the UK are over-represented for any SEND relative to white British schoolchildren[5]. This is, in part, related to greater social disadvantage experienced by this group. In spite of this over-representation, Black children are less likely to receive adequate support for their additional needs. For instance, Black children are more likely than white children to have a diagnosis of autism spectrum disorder (ASD) but are less likely to receive support for their condition[6]. With this disadvantage in mind, it is important to consider that the rate of permanent school exclusions is higher for children with SEND who do not have adequate support[7], and that even without an identified SEND, Black children are nearly twice as likely to be permanently excluded than their white British counterparts[8]. The trajectory for

Black children's education is, therefore, quite clearly one where the odds are stacked against them.

Although reassuring that the UK Government has recognised that the formal process of accessing SEND support requires improvement[9,10], the problem is clearly deeper than simply the process itself. Regardless of their educational needs, Black and mixed Black heritage children face additional challenges within the UK schooling system because of social and racial inequalities in treatment that continue to operate at multiple levels. Bringing to light the experiences of those directly involved in accessing SEND support for these children is a necessary step towards developing meaningful ways to overcome these difficulties.

The aim of this study, therefore, was to gain insight into the process of obtaining SEND support for Black and mixed Black heritage children living in South London from the perspective of both parents and professionals. By focusing on South London, we aimed to provide insight into local systems with the view to developing recommendations that would have relevance locally with national scalability. Our hope is that this research will positively impact those working within the SEND system and those who will need to access it, because improving the system for Black communities will improve the system for all.

Before reporting on our work, we briefly provide the context for England's SEND framework and the evidence highlighting the socioeconomic, cultural and institutional factors associated with the identification and rates of children with SEND in the UK.

PARENTS AS THE LINCHPIN IN THE SEND PROCESS

The SEND code of practice describes that "a pupil has SEN (special educational needs) where their difficulty or disability calls for special educational provision, namely provision different from or additional to that normally available to pupils of the same age"[11]. Over 1.5 million school children in England have an identified SEND, with autism spectrum disorder (ASD) being the most common SEND requiring an Education, Health and Care (EHC) plan[A], and speech, language and communication needs most often requiring SEND support[B]. Because Local Authorities (who provide the majority of SEND provision within a borough to state-funded schools) have a legal duty placed upon them to educate children in accordance with their parents' wishes[12], the process of accessing this support in England is one that offers families the opportunity to input into their children's SEND support and educational experience. Whilst this approach puts families at the heart of the process, it means that support

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[A] An EHC plan is a legal document that identifies: 1) a child or young person's special educational needs; 2) the specialist provision required to meet these needs; 3) the outcomes the provision should help them to achieve; and 4) the school or college they should attend.

[B] SEND support is the system by which schools and colleges identify and meet the needs of children and young people with SEND in mainstream education. This support outlines the additional provision needed to remove barriers to learning. However, the provision detailed in a support plan does not have the same legal authority as an EHC plan.

can be impacted by a number of parent-centred factors including their knowledge, understanding and views on SEND, their advocacy skills, the relationships they have with the educational professionals supporting their children, and the time they have available to input into this process. The framework also places responsibility upon parents to secure their child with an 'efficient full-time education' suitable to 'age, ability and aptitude, and to any special educational needs'[13]. In this way, parents in England are viewed as central to the process of accessing SEND support for their children.

The significant role that parents play in SEND provision has prompted research exploring parental perspectives of navigating the SEND process, with findings revealing that they find it to be: 'complex'[14], 'slow' and 'not parent friendly'[15]; that they have to navigate 'long difficult processes to access information and support;'[16] and that the system was 'simply not

helping their children well enough to achieve their goals'[17] . Given the wealth of evidence highlighting racial disparities in the identification of SEND and access to requisite provision, it remains unknown whether these experiences are more prevalent amongst parents of Black and mixed Black heritage children who may face additional challenges related to wider societal factors.

SOCIOECONOMIC, CULTURAL, AND SYSTEMIC FACTORS THAT IMPACT ACCESS TO SEND SUPPORT

Socioeconomic factors: Deprivation, educational attainment and ethnicity

Links between low-income indicators, race, ethnicity, and SEND have been noted. Pupils with SEND are more than twice as likely to be eligible for free school meals (FSM) than pupils without SEND[18], and Black Caribbean and Black African pupils are more than twice as likely to be in receipt of FSM than White British pupils[19]. Moreover, pupils in receipt of FSM are less likely to have attained GCSEs or a university education and are less likely to experience financial stability or obtain full time work at the living wage by the age of 30[20]. Thus, there is a concerning relationship between the impact of families' low-incomes and the educational outcomes of Black children with SEND.

CULTURAL FACTORS

Misunderstandings and racial biases impact treatment of Black schoolchildren

Supported by findings from research observing teacher-child interactions, the over-representation of SEND for Black Caribbean children – particularly needs associated with behavioural, emotional, and social difficulties, could be attributed to an incongruence between teachers' views on acceptable school behaviour versus culturally sanctioned behaviour[21]. For example, early education staff in the US have been found to observe Black boys more closely when challenging behaviours are expected, suggesting that preschool teachers hold differential expectations of behaviours that are based on race. Even more concerning, is that these biases are not implicit: when staff were asked to state the children that they felt required most of their attention, 42% (68% more than expected by chance alone) explicitly reported this to be Black boys[22]. Similarly, interactions between African-Caribbean children and teachers have been shown to be more often for disciplinary and administrative purposes than for teaching purposes[23]. Black Caribbean and Black African students have also reported feeling that teachers have lower expectations of their abilities[24] which can have detrimental effects over time.

SYSTEMIC FACTORS

The judicial system, Black children, and SEND

To add to this, a wealth of evidence has indicated that young offenders are likely to have undiagnosed language problems for which they have received no professional support[25]: at least 60% of young people accessing youth justice services in the UK have a speech and language need[26,27,28] compared to rates in the general population which range from 5%[29] to 14%[30]. Boys from Black and mixed Black heritage backgrounds are particularly impacted, with a significant number experiencing racial discrimination and as having SEND and emotional and mental health difficulties that had not been addressed prior to entering the Youth Offending Service (YOS)[31].

THE CURRENT PROBLEM

The pattern of racial disparities is clear: compared to their white British counterparts, Black children in the UK are found to perform worse in school, are more likely to be excluded, and are at greater risk of being identified as having an additional need. These issues may be due to social deprivation but may also be related to implicit biases held by teachers and care providers who misinterpret culturally appropriate behaviour as pathological, and who have lower expectations for these children compared to their peers. Furthermore, Black children who come into contact with the YOS are more likely than Black children in the wider population to have an unidentified or unsupported additional learning need or difficulty with speech, language, and communication. In other words, Black children are over-represented for SEND, but also have needs that are unrecognised by the educational system and children's services. Together, these issues highlight the importance of the accurate and early identification of those children whose learning, behavioural, social, and emotional difficulties inhibit them from making use of educational facilities in a mainstream school. Given that learning difficulties, particularly with language, are a risk factor for the development of behaviour problems[32], it is clear that no identification or even late identification of SEND provision could lead to long-term negative outcomes for these children. Early identification is, therefore, important for ensuring that appropriate support is put in place so that, not only will children be equipped with the skills to achieve their best from the UK educational system, but engagement in education will act as a protective factor against involvement in criminal activities[33].

This project will be the first (of which we are aware) to focus exclusively on access to SEND provision from the perspective of parents of Black and mixed Black heritage children and professionals involved in supporting the process. Gaining insight into their lived experiences will shed light onto those areas of the process that are working well to support Black children and those where improvement is needed. We are hopeful that our findings will be useful for contributing to SEND policy to ensure that it is both equitable and adaptable to the varying needs of different communities.

METHODOLOGY

STUDY DESIGN

This study used a mixed methods design. An online survey and semi-structured interviews were used to assess the experiences of parents of Black and mixed Black heritage children living in South London who have engaged with statutory services to access SEND support for their Key Stage 1 or 2 child. Semi-structured interviews were also used to understand the experiences of professionals involved in supporting parents to obtain SEND provision for their Black or mixed Black heritage child.

PARTICIPANTS AND RECRUITMENT

Survey

The survey was hosted on the online platform SurveyMonkey. Survey participants were those who identified as being a parent of a Black or mixed Black heritage child, living in South London, and with experience of accessing SEND support for their Key Stage 1 or 2 child (age 4-11yrs). Consent to take part in the study was sought at the start of the survey, and respondents were given the option at the end of the survey to provide their email address for the purpose of receiving a copy of the final report, to remain updated about Global Black Maternal Health's activities, and to indicate whether they were willing to be contacted about taking part in an interview. All respondents answered screening questions and provided demographic information before being routed to a specific pathway based on the information they had given. Recruitment was via a combination of purposive, snowball, and e-snowball sampling which involved recruitment via social networks and group leaders known to the research team for distribution amongst their networks. To this end, the survey was disseminated across social media platforms to a number of relevant networks.

Semi-structured interviews

Semi-structured interviews were conducted with 1) parents of a Black or mixed Black heritage Key Stage 1 or 2 child living in South London who have experience of engaging with statutory services to access SEND support and, 2) professionals who have been involved in accessing SEND support for Black or mixed Black heritage Key Stage 1 or 2 children living in South London. Professionals worked across healthcare, education, and mental health services. All participants provided written consent before taking part in an interview. Information on how the survey and topic guides for interviews were developed can be found in the appendix.

DATA ANALYSIS

Survey

Demographic data and closed-text responses from the survey were analysed quantitatively. Descriptive statistics have been used to present these findings. Open-text box responses were analysed qualitatively to provide context to the closed text answers. The survey was open from March 2023 until November 2023.

Interviews

The interviews were conducted by MP and RW via Microsoft Teams and took place between March 2023 and October 2023. All interviews were audio-recorded and transcribed using the automatic transcription function in Microsoft Teams. Transcripts were immediately edited to correct any errors or nuances not picked up by the automatic transcription. They were then read and re-read (by MP and RW) to gain an overall sense of parental and professional experiences. Codes were assigned to the responses and themes were coded as they arose using a thematic analytic approach. Throughout coding, additional codes were added when appropriate, according to an inductive approach. The parent data was analysed separately from the professionals' data.

FINDINGS

PARENT SURVEY FINDINGS

A total of 153 respondents began the survey. Ninety-three respondents were screened out because they did not meet the following inclusion criteria, 1) being a parent or carer based in South London; 2) having a child aged between 4 and 11 years old/ currently in Key Stage 1 or 2 with additional needs that required SEND support; 3) the child being of Black or mixed Black heritage; 4) currently being in receipt of SEND support provided by a public service. A further 12 respondents were excluded for providing demographic information only. The final dataset includes responses from 46 respondents. Data tables A1 through to A11 are included in the appendix of this paper.

Parents completed survey questions asking about their child's demographic characteristics; their child's special educational needs or disability; their experiences of working with services and professionals to support their child's SEND; the type of support their child accesses; and their opinion of the quality and impact of the support provided. A summary of demographic information relating to parents and parents' children can be found in Tables 1 and 2, respectively.

Table 1. Parent demographic information - surveys

SEX	N	(%)
Female	45	98%
Male	1	2%

ETHNICITY		
Black British/Caribbean	23	50%
Black British/African	15	33%
Other Black/African/Caribbean	3	7%
White British	3	7%
Black British/ Caribbean and white	2	4%

AGE (YEARS)		
21-34	15	33%
35-50	28	61%
51-60	2	4%
61 and over	1	2%

PARENTS WITH A LEARNING DISABILITY		
No	30	65%
Yes	9	20%
Don't know	7	15%

RELIGION		
Christian	30	65%
Muslim	3	7%
None	10	22%
Prefer not to say	3	7%

RELIGIOSITY		
Not at all	1	3%
Somewhat	19	58%
Very	13	39%

AREA		
Lambeth	10	22%
Southwark	10	22%
Lewisham	8	17%
Greenwich	5	11%
Bexley	4	9%
Croydon	4	9%
Bromley	2	4%
Sutton	2	4%
Merton	1	2%

HOUSEHOLD INCOME		
Under 10,000	4	9%
10,001 - 30,000	13	28%
30,001 - 50,000	19	41%
50,001 - 70,000	3	6%
70,001 - 80,000	1	2%
Over 80,001	5	11%
Prefer not to say	1	2%

FINANCIALLY ACTIVE ADULTS		
Only 1	24	52%
2	20	43%
3	2	4%

EDUCATION		
Undergraduate degree	26	57%
Postgraduate degree	9	20%
Vocational	8	17%
A-level or similar	2	4%
GCSE or O level	1	2%

Note: Some categories do not reflect the total number of respondents (n = 46), since provision of this information was optional; percentages are calculated over known information.

Table 2. Child demographic information - surveys

SEX	N	(%)
Male	35	76%
Female	11	24%

AGE (YEARS)	N	(%)
5	8	17%
6	7	15%
7	7	15%
8	6	13%
9	5	11%
10	9	20%
11	4	9%

ETHNICITY	N	(%)
Black British/African	17	37%
Black British/Caribbean	17	37%
Other Black/African/Caribbean heritage	4	9%
Black British/African and white	4	9%
Black British/Caribbean and white	3	7%
Black British/Caribbean and Asian	1	2%

AREA	N	(%)
ASD[a]	33	72%
ADHD[b]	17	37%
GDD[c]	10	22%
Dyslexia	5	11%
Anxiety	2	4%
Asperger's Syndrome	2	4%
Hearing Impairment	2	4%
Visual Impairment	2	4%
Dysgraphia	1	2%
Down Syndrome	1	2%
Dyspraxia	1	2%
PTSD[d]	1	2%
Pica	1	2%
SEC[e]	1	2%

AGE WHEN SEND IDENTIFIED* (YEARS)	N	(%)
Under 1	6	13%
1	7	15%
2	12	26%
3	6	13%
4	6	13%
5	4	9%
6	1	2%
7+	4	8%

AGE WHEN SEND SUPPORT RECEIVED (YEARS)	N	(%)
Under 1	4	9%
1	2	4%
2	6	13%
3	7	15%
4	7	15%
5	6	13%
6	6	13%
7+	8	17%

EXCLUSION FROM SCHOOL	N	(%)
No exclusion	37	80%
Temporary exclusion	9	20%
Permanent exclusion	0	0%

MOVED SCHOOL TO SUPPORT SEND	N	(%)
No school move	40	89%
Moved school	5	11%

Note: Some categories do not reflect the total number of respondents (n = 46), since provision of this information was optional; percentages are calculated over known information.

Key: * = SEND identified by parents, family or professionals; [a] = Autism Spectrum Disorder; [b] = Attention Deficit Hyperactivity Disorder; [c] = Global Developmental Delay; d = Post Traumatic Stress Disorder; [e]= Social, Emotional and Communication difficulties;

Background information

Parents indicated that health services were most frequently the first provider of SEND support, with 37% (n = 17) of children initially accessing support via their GP, Child and Adolescent Mental Health Services (CAMHS) worker or Health Visitor. This was closely followed by education services (n = 16; 35%) (see A1). Fifty-nine percent (n =27) of children were supported by an EHC plan, whilst 22% (n = 10) did not have an EHC plan but had received an official diagnosis and were accessing SEND support in school. Just under 20% (n = 9) did not have an EHC plan or official diagnosis but were in receipt of SEND support (see A2). Three quarters (n = 35) of children were in a mainstream school whilst 15% were in a specialist school (n =7) (see A3).

Parents' experiences of working with services

Parents were asked to rate their experience of working with education, health and other professionals to support their child's special educational needs (see A2). The experience of working with current class teachers and paediatricians was rated most favourably.

> *"My GP and the school have played a big role in the ease in which we have obtained SEN support"*

For experiences with educational services and professionals, 43% (n = 17) of parents said that their experience of working with their child's school was good or excellent, whilst 48% (n = 19) said their experience was average or below. A further 23% said their experience of working with the SENCo was below average or poor (n = 9), but more than half (53%, n=21) rated working with their child's current class teacher as good or excellent.

> *"I have had very terrible experience with the SENCo, I haven't gotten any help, or explanation of how things works. I would email and they would literally not reply to me, I will send follow up and follow up email and same thing, just last week my SENCo came back to me saying my son has no school placement"*

When asked about their experiences of working with health professionals, 43% (n = 17) reported working with GPs as good, and half of parents said their experience with the paediatrician was good or excellent (n= 20; 50%,) (see A4).

> *"When no one would believe me, it was a very attentive Health Visitor at a children's play centre who actually listened to and believed me, and she helped get the ball rolling with the referral to the community paediatrician and later to the ASD diagnosis clinic".*

Seventeen parents had worked with child mental health services, and over half of those reported the experience to be below average or poor (n = 9).

Parents' views on the SEND support received

Parents were asked the extent to which they agreed or disagreed with statements about a) the usefulness of the SEND plan; b) the changes the plan has brought about; c) the future impact of the plan to their child and d) how professionals worked together to deliver the SEND plan (see A5). Fifty-four percent (n = 23) of parents agreed or

strongly agreed that the SEND plan was easy to understand, and 49% (n = 19) felt that their wishes were included in their child's SEND support plan. Further, most parents (n = 17; 45%) agreed or strongly agreed that the SEND support plan had led to their child getting the educational support they need and improved their child's experience of education (n = 18; 47%) and health and wellbeing (n = 18; 47%).

When asked to consider the future impact of the SEND support on their child, 37% (n = 14) reported that they felt the plan would improve their child's chance of living independently in adult life, whilst 49% (n = 18) thought the plan would contribute to the chance of their child fully participating in the wider community. Over one third agreed or strongly agreed that the support plan would help their child to identify their hopes for the future (n = 13; 34%). Despite this, 29% (n = 11) of parents felt that the SEND support plan did not contribute to their family living the life they want to lead. Almost one third (n = 15) of parents reported that their child's SEND plan did not include preparation for their child's next transition. Although half of parents felt that professionals worked well together to support their child's needs, 29% (n = 11) disagreed or strongly disagreed with this statement.

"Unfortunately, the process has not been as joined up as we would have liked. Our SENCo has done her best to coordinate, but constant follow up is required to move things along, which is draining."

Regarding the process of obtaining SEND support for their child, 59% (n = 22) reported that they had found it difficult or very difficult to start to process (see A6).

"Professionals were dismissive and generally inattentive which was very off putting"

When asked to consider the quality of support they had received from education, health, social care and other public services, 53% (n = 20) reported being dissatisfied or very dissatisfied with the overall process of accessing SEND support (see A8). Fifty-four percent (n = 15) stated that they had informally raised their concerns or made a complaint during the process of obtaining support (see A9). However, there was a significant gap in parents' knowledge of how to formally escalate issues (see A10).

Support networks
Parents were asked about the networks they accessed to support them and their child (see A11).

The most frequently used support network was family and friends (n = 32; 82%), followed by social media platforms (n= 28; 72%) and then community groups (n = 16; 41%). Despite respondents indicating high levels of religiosity, 56% (n = 22) said they never used religious groups for support, and 56% (n = 22) said they never or rarely accessed charitable organisations.

"Family plays a big part. I work full time so if my son is not at school my mum is doing the pick ups and drop offs. Sometimes it makes me feel bad because I don't feel I do enough but family is a great help…"

PARENT INTERVIEW FINDINGS

Ten parents and 19 professionals took part in an interview. Participant characteristics for both parents and professionals are presented in Table 5.

Table 5. Parent and professional demographic information - interviews

Parents	N	(%)
SEX		
Female	10	100%
Male	0	0%
ETHNICITY		
Black British/Black Caribbean	8	80%
Mixed ethnicity	1	10%
White	1	10%
LOCAL AUTHORITY		
Greenwich	1	10%
Lambeth	3	30%
Lewisham	3	30%
Southwark	2	20%
Croydon	1	10%
WORKING STATUS		
Full-time carer	5	50%
Employed	3	30%
Self-employed	1	10%
Student	1	10%
AGE (YEARS)		
18 - 24	1	10%
25 - 34	4	40%
35 - 44	4	40%
55 - 64	1	10%

Professionals	N	(%)
GENDER		
Female	18	95%
Male	1	5%
ETHNICITY		
Black African/Black Caribbean	17	89%
Mixed ethnicity	2	11%
EDUCATION		
CAMHS professional	1	5%
Education professional	6	32%
Legal professional	2	11%
Medical professional	5	26%
SEND professional	3	16%
Social worker	1	5%
Therapy professional	1	5%
RELIGION		
Christian	14	88%
Muslim	1	6%
Spiritual	1	6%
AGE (YEARS)		
25 - 34	4	31%
35 - 44	8	62%
55 - 64	1	8%
WORKING STATUS		
Full-time	7	50%
Part-time	7	50%

Note: Some categories do not reflect the total number of interviews with professionals (n = 19), since provision of this information was optional; percentages are calculated over known information

Parents' views and experiences of accessing SEND provision are described within six overarching themes: 1. The fight for SEND support; 2. Professional perceptions vs parent experiences; 3. Professionals working in silos; 4. Parental time and priorities; 5. Access to support networks; and 6. Feelings of grief and hope.

1   THE FIGHT FOR SEND SUPPORT

Parents often used language depicting combat when asked about the process of accessing SEND support for their child. Commonly describing it as a 'fight' for their child to obtain the right support, many parents felt that the process was one in which they were regularly reminding those tasked with decision-making to 'do the job they're supposed to be doing'.

> *"It's just the first step in, then 20-30 more steps of fighting. You know, I'm still fighting for my 16-year-old now…"*

Parents expressed frustration at 'constantly having to exert this energy', and explained that the 'battle' required their continuous involvement to ensure their child had the right support throughout their educational journey.

> *"I've had a rough time trying to access the right support for my daughter… My child hasn't had many speech and language sessions and hasn't received much support from the local authority. I had to take my child out of mainstream school as the staff seemed as though my child was a burden to them… They couldn't wait to take her off the register…It's now been over a year and I'm still fighting to find my child a school place. She finally has an EHCP but is yet to receive any support."*

Some Black mothers also felt that the battle for support contributed to them being perceived as 'aggressive', 'difficult' and 'hard to work with'. For them, these perceptions added to the difficulty they faced in advocating and obtaining the right support for their children.

> *"It's a Black woman's experience, it's a Black woman's pain. We can't all be depressed, crying, hysterical. We shouldn't have to play up to that role to be heard or seen. They want me to express myself in one way. When I express that something isn't working, I appear to be problematic or difficult to deal with, and they use that against me and my son."*

Additionally, mothers expressed that the perceptions professionals held about them, contributed to a cycle of silencing them which, in turn, erased the validity of their views and wishes, undermining them and their advocacy.

> *"It's tiring to fight what they think of me all the time, because all I wanna do is raise decent humans, decent Black human beings into the society, but everything I'm doing is being pushed back on. As a Black neurodiverse woman, I've joined a lot of organisations to support and help SEN families. Most recently I've been shunned out of it because me and another Black female colleague were accused of bullying the white senior leadership"*

2 PROFESSIONAL PERCEPTIONS VS PARENT EXPERIENCES

Parents indicated a disconnect between professionals' perceptions of their child's additional needs and their own lived experiences, with the sense that those with decision-making power 'have their tick boxes up in their offices' but that they are not 'asking the real people on the ground'. Some parents had attributed these experiences to their hyper-involvement in ensuring the delivery of SEND support to their child. Lack of understanding about the challenges that parents face was evident for one parent who was invited to a local authority meeting with senior members of children's services:

> *"The head of my local authority said they hadn't received any complaints about SEND support. I don't think these professionals realised there were parents in the group".*

This parent went on to share that only through publicly highlighting the issues she was facing in obtaining early support for her daughter with suspected autism spectrum disorder, was she given a much-needed appointment to start the assessment process:

"…she asked 'what are your opinions'? And it was painful, but I was telling my truth and I told my truth. And even in the meeting…the head of service was privately messaging me saying 'Can I contact you separately? Could you stop talking?' And then she contacted me a week and a half later, and then that's how I managed to magically get my daughter's appointment"

Another parent of a pre-school child with additional needs who was awaiting a diagnosis explained the importance of the funded nursery care her daughter received. Reflecting on a call she had received informing her that her daughter would not be able to attend nursery that day, she described feeling that the staff did not appreciate her daughter's needs:

"They basically said they don't have enough staff, so she can't come in today and I asked why, and they said something about they only have space for the parents that work and pay them."

There were, however, instances where parents shared the impact of positive relationships with professionals and organisations. Parents described these relationships and practices as 'just making life easier'. One parent spoke about the difference in the level of support received when she moved from one borough to another to be closer to her son's specialist school:

"We've been lucky enough to have… the kind of other professionals that get it and they support us or do a bit more than they're supposed to…they do it because they understand and see what's happening…other things like giving me 600 syringes instead of only 20 a week, and the extra support being increased from 22 to 55 hours a week, it makes a difference."

Another parent's concerns had been alleviated by building a relationship with the SEND team at her son's future secondary school. Familiarity with the team had helped this parent to feel reassured that, despite not yet having a diagnosis, her son's needs were 'still something that they will adhere to'. This type of early positive and collaborative communication was experienced by others, with one parent who described herself as 'proactive', explaining how she had already met with the team at her son's future school to initiate a line of communication about his support needs:

> *"I've already met with the SENCo to make sure that the school do play their part…They suggested all sorts of stuff like letting him have time out, making sure that I get a regular report…they've been quite understanding so far and I feel like this will prevent my son from being labelled as aggressive or the relationship with the school breaking down."*

3   PROFESSIONALS WORKING IN SILOS

Despite positive relationships with individual professionals, most parents shared that services in general (for example, health, education, social care and local authority SEND teams) worked in isolation of one another. Concerns were raised that professionals do not communicate outside of their departments, ultimately leading to poor multi-agency working practice. This led often to increased administrative work for parents, such as having to chase up referrals or agreed actions, or communicating outcomes from one department to another:

> *"There wasn't much joint working until the EHCP was done. There wasn't much coordination…For instance, if speech and language therapy sent out [a report] with any views, tasks or targets, I would be the one to forward that to the nursery rather than them."*

Despite professionals working within the same building, the administrative burden of coordinating their child's care was felt

by a number of parents who reported communication between professionals as 'really bad':

> *"The funny thing is, they're all in the same building. You would have thought it would have been easier…It's like I have to let the appointments team know what the paediatrician said and so on and so forth…but there's five steps between the departments."*

Crucially, parents were concerned about the impact of this poor communication on their child's SEND support and the likely delays incurred as a consequence of information not being passed on without their intervention:

> *"Communication between people involved in his care has been lacking at times, when he first started school, the teachers were not made aware he has ASD, even though the SENCo was made aware"*

4   PARENTAL TIME AND PRIORITIES

For various reasons, including issues with multi-agency communication and the needs of the child, parents reported being heavily involved in the process of obtaining SEND support. Not only did this take up a significant amount of their time but, for many parents, this required the learning of new skills, systems, and processes to ensure that their child's needs were understood by others.

> *"I've had to dedicate my life to my son's care. So, I haven't worked since having him. I've had to try and learn a lot and advocate on his behalf from the beginning."*

For others, restrictions on working outside of their home because of their child's needs had had consequences for their mental health, perception of self, the adult interactions they could have and the financial position of the family. For instance, a mother of three explained how her inability to return to work due to her child's mental health needs had meant that her husband had had to take on an extra job to keep the family afloat financially, whilst another parent shared that, although she had hoped to return to work, she felt that it was a decision between her happiness and her son's welfare:

> *"I've had to sacrifice a lot: My life, my personality, everything, my friendships, family. There's been so many different sacrifices along this journey in order to advocate for my son and try and keep him alive."*

Feelings of shame and stigma around returning to work were also expressed. One parent reflected on being encouraged by a well-meaning professional to go back to work to provide 'a positive example' for her son. Describing her reaction to this comment, she explained how the situation had left her feeling judged:

> *"I felt really defensive, do you know what I mean? I'm in a situation where it's positive that my child is alive and that I'm focussing on his needs. I've worked from when I was 16 years old. I'm not a mother that has never worked. So, you'll get these individuals that judge people."*

5 | SUPPORT NETWORKS

Family and friends

Parents commonly reported that support from family and friends was influenced by their awareness and understanding of SEND. Some parents felt that their children were misunderstood with needs often viewed as 'bad behaviour'. This could sometimes result in parenting and behavioural management strategies being critiqued and an unhelpful disciplinarian culture being encouraged:

> "I suppose there's a thing of people thinking that he's odd or weird, or that he's naughty because of the way that he reacts and the way that he has meltdowns without actually understanding autism and I've had many comments from family and stuff like 'you need to be strict with him. You shouldn't let him get away with stuff'."

For some, this contributed to negative feelings about their parenting and led to isolation from others. One mother talked about the difficulty in maintaining family relationships and explained how attending events was challenging because of how others responded to her son's disability. Questioning whether it could be 'because they're uncomfortable' or because 'people don't know how to deal with it', she described the hurt when people do not acknowledge her son or invite him to parties. Explaining how 'it's just like he doesn't exist', this parent felt strongly that raising awareness about SEND is key to helping others understand people's different needs. Similar sentiments were echoed by others who felt that there is not enough education within their cultural or social networks about SEND. In particular, being blamed for their child's additional needs was described as 'a very cultural thing of people of colour' with the view from family members that 'it must have come from her side of the family'. Being discouraged from talking about their child's additional needs was also reported:

> "I will sing and dance about autism all day long, but my mother-in-law would kind of try and hush me up…It's quite a big stigma."

There was evidence, however, that family and friends had become more supportive over time – especially after being present during a meltdown or developing a better understanding of the condition. One parent explained how her brother's well-meaning intentions to pacify her dysregulated child had required an explanation on how to manage the situation more effectively in the future:

> "He just took my daughter off of me when she was screaming and kicking. He was really struggling. But he was determined…everyone could see that it wasn't working, they said 'just go and take her and when he comes back down we can talk to him about how that approach won't help. I'm glad he understood and listened. It was a beautiful moment."

Professional support and care

Several parents found it a challenge to obtain adequate professional support and care for their child. This was particularly difficult for parents of children with physical disabilities who struggled to obtain the support they needed inside of local authority or NHS funded care packages. One parent described a long-standing difficulty in hiring carers to support her child in the community. A lack of qualified carers who could meet her son's needs had resulted in an incident that had impacted him significantly, with one situation in particular resulting in him being severely burned. Feeling that she should be able to 'switch off' when leaving her child with qualified carers, she explained that instead, she always has to remain 'alert' to prevent potential adverse events:

> *"Unfortunately, earlier this year one of the carers didn't seal the lid to the hot water bottle properly and the boiling water seeped out…the main carer identified the issue…he removed the bottle and he put another one in its place and covered him up. But he didn't change his clothes or check him…I had to take my son to A&E, he had suffered third degree burns."*

Another mother shared how, after receiving a rare genetic diagnosis for her daughter, professionals who had limited understanding of her daughter's condition, had been overly negative about her prognosis and potential development. Describing how the professionals she encountered would comment that 'you know more than we do', she decided to seek advice from doctors in Europe who undertook assessments and put in a place a plan to improve her daughter's quality of life:

> *"We had decided the NHS wasn't for us originally and we went abroad to get medical advice from there…They wouldn't start physiotherapy, they said they were waiting to see how she got on and they wanted to put a peg in and although I understood why, it reduced her chances of being able to learn to use her mouth muscles, they were forcing this on me and I didn't feel it was fixing the overall problem, it was just a band aid."*

Dismissive attitudes and a lack of consideration for the difficulties of navigating daily tasks, such as using public transport were also reported. One parent whose child requires oxygen explained how 'there's so much stuff to carry' when travelling to nursery in the morning, and how unhelpful comments from professionals could add to her stress:

> *"I remember one of the social workers saying 'Ohh, you mothers like to walk around with these chariots…we used to carry our children" Like, are you OK? Where's your head at? You just have professionals that are so detached from the work…They don't understand us culturally, and they make judgments."*

6 | GRIEF AND HOPE

It was clear that the process of identifying their child's need and receiving a diagnosis was difficult for many parents to manage. Coming to terms with what a diagnosis would mean for their child's progress, their attainment, and their quality of life now and in the future was experienced by many as grief. Evident throughout their child's SEND journey, grief was experienced in a number of ways, including sorrow that their child might not reach expected milestones, frustration at being unable to access age related activities because of a physical disability, sensory or behavioural need, and sadness at the dramatic shift in the life they had imagined:

> *"It's been difficult…like a grieving process and all of that for the child that I planned for, what I planned and wanted to do with him…it's been really, really tough…We're constantly faced with it through social media, peers that were pregnant around the same time and you see their children's milestones in terms of birthdays and things like the activities that the children have."*

Parents also grieved for their own hopes and dreams. Many had had ambitions for their career and plans for their future which they had been forced to rapidly change in order to meet their child's care and support needs:

> *"Before my son was born, I had planned to buy the property that I was living in. I had loads of savings…but I've had to sacrifice that…I have to focus on properties my son can live in and areas that are good for him…He's always going to be at my centre."*

Lack of support after receiving a diagnosis could also exacerbate the grief experienced. One parent described how the explanation from a non-specialist doctor who stated that 'your child is going to depend on you forever' had left her with what she felt was no choice other than to do her own research:

> *"I started Googling things and found whole lists of things she might have. I got so into my head and I was constantly on the lookout for symptoms she might have, thinking 'does she have this or that?', rather than just enjoying my baby. It made me very paranoid."*

Other parents reported similar issues, explaining that they had not being told what to expect in the future or what practical or emotional support they could access for their child or themselves. Lack of signposting to relevant support groups meant that parents often had no one to turn to for emotional and psychological support.

Despite these experiences, parents remained hopeful for the future. Keen for their children to understand that 'difference is not a bad thing', they spoke of their wishes for their children to embrace their uniqueness. Being an example of 'an amazing neurodiverse family' was shared by one parent who went on to explain their dreams of raising awareness about SEND more widely to 'help people understand and accept and grow.' Overwhelmingly, however, parents were emphatic that their children know that they are loved:

> *"I've had people ask me, you know, would I give them up and I think they are a blessing, they are the reason why I wake up in the morning…And they will see that every single one of them was made with love."*

PROFESSIONAL INTERVIEW FINDINGS

Professionals' views and experiences of supporting parents to access SEND provision for their child are described within six overarching themes: 1. Parental factors influencing SEND access; 2. Attitudes towards SEND; 3. Challenges of the SEND system; 4. Ways to support parental engagement; 5. Consequences of inadequate SEND support; and 6. Ambitions for a future SEND system.

1	PARENTAL FACTORS INFLUENCING SEND ACCESS

Understanding about SEND

Nearly all professionals described how parental factors influence the process of accessing SEND support, with a consistent view that parents' understanding of SEND plays a key role. Whilst it was felt that there was a lack of understanding about SEND in the general population, many of the professionals described this as being particularly evident within Black communities. In some cases, professionals talked about how parents are better able to understand needs that can be seen.

> "…a lot of times you will tend to find that within the Black community, there is a lot of lack of education around SEND needs. Only when it's visible then they'll be like 'ohh OK'. You might have cerebral palsy, but anything that's not visible. They dismiss it."

Needs that present with a behavioural dimension, were felt to be more challenging for parents' understanding, with behaviour sometimes being attributed to teachers having lenient disciplinary practices.

> "Behaviour problems like ADHD, you know for some it's like 'No, there's nothing wrong, he's naughty…he needs discipline'. So, do you know what? They will send them to the Caribbean or to Africa for the summer…Because there they say 'it's more strict, the teachers here are not doing what they need to do'."

Others described how, in cases where parents have no awareness of the signs that their child has an additional need, the responsibility of accessing SEND support is sometimes placed entirely upon education providers:

> "Some parents don't even know what autism is. You know, they just think this is how their child is. Their child can't sit still. Their child don't like change. Their child don't like certain things. And they just kind of leave it to the school to manage with."

Limited understanding of how various systems operate and deference to authority (due to cultural differences) was also highlighted. One professional recounted an incident in which a family's lack of understanding around their child's needs and lack of confidence to challenge education providers had resulted in his needs being managed by the school through isolation during lunch:

> *"They managed to talk the parents into agreeing that at a lunchtime this little boy will sit by himself and face the wall with his lunch while other children sit around their peer groups… I found out there was a major culture difference where they did not quite understand what the child was actually going through in school…when there is a cultural difference…they're almost scared of the school. And so, I brought it up to the head teacher…I was just like surely this is not right".*

Religion, faith and culture

Parents' religion, faith, and cultural views around SEND were also described as factors that moderate the process of accessing support. Professionals reported how some parents call upon their religion and faith, relying on prayer as a way to 'correct' their child's need:

> *"What we've found is a lot of our Caribbean and West African community…we find that sometimes the acceptance of the diagnosis is a real issue. So, religion is very heavily tied to the diagnosis and sort of praying things away and believing that, you know, that they can be fixed."*

The process of accessing SEND support could sometimes be affected by parents whose faith takes precedence over standard therapeutic interventions. One professional explained that some families will get 'offended' if support groups are offered, believing instead that 'prayer is gonna do the magic'. When asked how to support parents who rely on their religious views during these times, one professional stated that the key to reaching common ground is to explain that their own beliefs and professionals' views on their child's needs can co-exist:

> *"…you've got religious backgrounds who believe that, no, we're just gonna go pray. I use my own personal experience to say I'm a Christian too and I got family that are Muslims…It's not about religion, it's about the child."*

Lack of trust in services

Negative experiences with services and 'a massive mistrust' was felt to influence how likely parents would be to engage in the SEND provision process, with one professional explaining that many parents from marginalised communities are 'very anti-establishment unless they see someone they can relate to.' Some parents' past experiences had led them to be particularly fearful of external agencies being alerted in relation to their child's potential need, choosing to distance themselves from education providers to avoid further contact from other agencies:

> *"So that family in particular, they've had past involvement from social care. So, there was a lot of fear, I think, that her children were gonna be taken away, even though that wasn't the case."*

Another professional recounted struggling to engage with parents from a school with

a large Somali population, describing it as 'the hardest thing I think I've done work wise'. Explaining how she would stand at the school gate every morning to welcome parents and share information about her therapy sessions to support children's learning, she reflected on how she was met with overwhelming refusal from parents to allow their child to attend the sessions:

> *"So, I'd call the parents up and say, '[child's name] wants to come to this. Is that possible?' And they'll just say 'No. No, I don't want to do that'… One parent who's quite popular, she said that some of them are scared that my organisation is associated with social services. And that's what they see me as."*

Professionals also reported that sometimes parents from Black communities felt that the professionals involved in their child's care did not relate to them and made little effort to engage with them in a way that they could understand, further promoting a lack of trust:

> *"It's really hard because…within the community that we're talking about, I think there's a lack of trust with external agencies, often professionals not coming from backgrounds similar to them or being quite you know, technical in the language they use."*

Awareness of support and rights

Professionals highlighted how parents' awareness of the support available to them played an important role in their involvement. Some professionals had worked with parents who had gone to great lengths to research their rights and were well read on their entitlements, in these cases asking for supporting letters for disability allowance and for help with the application for disability badges. More often, however, professionals had had experiences with parents who 'don't realise how much there is out there' and 'don't know how to ask questions'. Many described how parents had struggled to understand the potential entitlements afforded to them with one professional explaining that 'parents don't actually know what they can and can't do with a EHC plan'. Reporting that lack of understanding about the SEND system is 'really common', one professional described how some parents see professionals 'as a demi God', willing to accept 'whatever's dished out'. Awareness of available support and the ability to navigate the SEND support process was also felt to be moderated by a parent's level of education with it being explained that involvement in the process is down to 'who is well educated around the topic':

> *"Honestly speaking, I find the less literate the parent is, the less involved they are. And I think that is because they don't understand more than anything else."*

Energy, time, and the ability to self-advocate

In line with the experiences described in the parent interviews, having the confidence to raise concerns and to challenge education providers and other external agencies was highlighted. A number of professionals explained how some parents will be heavily involved in the process of obtaining an assessment or accessing support for the child, making sure to 'question everything'. One professional joked that the process of accessing support is so lengthy that parents deserve a qualification for their efforts:

> *"It's a full-time job, and I meet parents with folders that are this big as if they're barristers, and at the end of it I say, 'well, you should have just done a law degree because in essence you've had to become a lawyer to navigate SEND'."*

Other parents were described as taking a hands-off approach. In some instances, this could be because they view the process as the responsibility of the professionals. In other cases, disengagement could be attributed to previous negative experiences with service providers:

> *"…if a parent doesn't believe that they can advocate strongly enough for their children, and they've had an experience where maybe they've gone into panels… and they're faced with all these professionals and they don't know how to deal with that situation, they kind of shut off because they don't wanna go through those experiences anymore."*

Remarkably, a number of those interviewed described how they had gone beyond their role to advocate for parents such as providing support with letter writing, attending appeal meetings, and explaining documentation associated with the SEND application:

> *"He's refusing to go to school…he says he doesn't have one to one support, even though he's meant to have one to one support…I've been trying to help her read through his EHC plan to help her because she's literally said, 'I am clueless'."*

Whilst for many this advocacy was often provided in an unofficial capacity, some had recognised the need as great enough that they had incorporated this support into their professional practice.

2 | ATTITUDES TOWARDS SEND

The attitudes towards SEND of both parents and professionals working for external agencies (predominantly education providers) were frequently described. Denial, self-blame, shame, stigma and labelling were common sentiments attributed to parents, whilst interviewees recognised discriminatory attitudes and behaviour towards families from professionals. Crucially, misconstruing a child with SEND as having bad or challenging behaviour was observed in both parents and education providers.

Denial

Parents' denial of their child's needs was commonly described, with many professionals explaining how, for some parents within Black communities this was 'almost like their first time hearing these things'. Often denial was felt to be related to parents' lack of understanding about SEND or typical development:

> *"This child went to a nursery. They identified speech and language needs and I think what they were trying to identify is likelihood of autism. Mum shut it down, she said, 'He's young, he'll start speaking soon'. And then the child came to our school and I had a good relationship with her and I spoke to her about it and she said 'no, no, no, let's just wait. Let's just wait'."*

In some instances, it was the fear of judgement from others that led to denial:

"I love my people, but some Black people they're embarrassed to feel that their child's got something. Yeah, so they start to play things down."

Self-blame, stigma, and labelling

Professionals described how parents often felt that they had in some way been the cause of their child's need. Feeling that they had 'done something wrong' during pregnancy or that their parenting was being scrutinised, a number of professionals talked about the guilt expressed by parents living with a child with SEND and how they can 'feel like they're judged':

"I think it all comes down to... having a SEND child and through cultural learnings as in, 'is there something wrong with my child now? Who is to blame for this? Is there a cure?'"

Parents being reticent towards obtaining a diagnosis because of the shame and stigma around their child being 'labelled' was raised by a number of professionals. Concerns about how their child would be viewed by others was a common worry and professionals talked about how parents' fear of labelling could negatively impact children's access to SEND support. One professional described finding it 'really hard to engage' with a parent who viewed SEND in this way, describing a situation where 'even getting their child to come to therapy was a push', whilst another explained that they try to convey to parents struggling to accept their child's need that they are just 'wired differently'. Another reported how some Black communities continue to perpetuate historic views of SEND, fearing the impact of a diagnosis on their place in the community.

> *"…there are the parents that just don't want their children to be labelled because they have this idea of what it means for a child to be labelled from maybe back in the 80s or the 70s…Having that label would get the additional support it would give them access to resources and professionals. They don't see that. Instead, they see that their child is gonna be labelled, their child is gonna be treated differently."*

Similar views were shared by another professional who had observed some parents' reluctance to acknowledge their child's need, attributing this perspective to 'a cultural thing':

> *"I mean, I'm half Ghanian and I do see that a lot more with African parents that it's an issue. I guess it's that stigma thinking 'Oh, your child's special needs'.*

Others reported that sharing personal information outside of the community is frowned upon, with one professional explaining that 'within the family, if we deal with stuff, we don't seek help'. Speaking forthrightly, however, another professional was emphatic in his argument that Black communities need to be willing to understand SEND and overcome their fear of what it means to have a child with an additional need:

> *"I think culturally as a people, we have to educate ourselves to SEND. It exists and it's in our community. It's not something to be ashamed of…if we do need our children to be assessed, we need to be open to having those assessments. But sometimes we don't, and I get that resistance…I understand the inequalities that are there, but I also think, and I say this respectfully, we shouldn't allow our level of ignorance to stop our children accessing services."*

Discriminatory behaviour towards families

Many professionals shared their experiences of witnessing discriminatory attitudes and behaviour towards families, attributing this behaviour to professionals who had failed to take the time to understand a family's personal circumstances or consider their cultural values:

> *"Sometimes professionals who don't share the same kind of cultural identity, they don't get it. I've got into many kind of confrontations with colleagues because of how judgmental they are about parents and their approaches to things, the way they parent, and you know it really gets my back up because instead of being supportive and focusing on the positive, it's like just wanting to shame the parent…you don't know what trauma they've experienced, their past relationships with education. You know, there's a lot more. There's a wider context than people think."*

For many professionals who reported these types of experiences, families from Black and ethnic minority backgrounds were felt to more often be on the receiving end, with the situation being described as 'horrendous' by one professional:

> *"You know, when you're in meetings and people are like 'I don't want to take on a child because their parent is difficult' and it's not a difficult parent, it's just an ethnic parent being as expressive as a white parent".*

It was also felt by some that, some schools will focus their energy only on those parents they think will bother to challenge them:

> *"Something really important to know, and this really, really infuriates me, is that dependent on who the parent is and the level of understanding and their confidence and ability to hold the school accountable, they do things they can get away with…nothing that they can get in trouble for, but you know, efforts won't be made…the support is for which parents they think are gonna bother."*

SEND misconstrued as bad behaviour

Worthy of note, is that professionals described how both parents and education professionals frequently displayed attitudes towards SEND that highlight a lack of understanding. Just as the parents in our interviews described family and friends misinterpreting their child's needs as bad behaviour, the professionals also explained that some parents mistakenly view their child with SEND as 'naughty'.

> *"With the Black parents who have not been so willing to accept that their child has ADHD, it has been that, 'No, it's just a behavioural issue'. But again, that's been reinforced to them by schools. And now they're excluded, and I'm saying 'your child has been excluded because their needs are not being met because they have a special educational need'. And it's like, 'no, we don't have those things'".*

It was also felt that education professionals often misconstrued children's additional needs, and that 'for Black children, people are happy to rather deem it as behaviour than a need'. Thus, many of the professionals interviewed attributed these attitudes to differential expectations of behaviour based on race and ethnicity:

> *"…especially for young Black boys, you know, they could be vilified. Their behaviour could be misunderstood and actually they have a special need and they need, you know, specific provision."*

Misinterpreting SEND as challenging behaviour was also argued to stem from limited knowledge about how needs might present differently in children from different backgrounds – particularly for Black boys:

> *"…autism does not look the same for a white child as it does for a Black child. I've had Black boys being excluded for being disruptive because they were stimming by beatboxing to regulate themselves, and it's been noted by teachers that they have been spitting at other people and aggressively banging."*

Some professionals reported that they had openly challenged colleagues who displayed these attitudes, describing these conversations as 'necessary':

> *"I do have it with teachers and a lot of the times it can be quite uncomfortable for them because automatically it's about, 'oh, I'm not a racist teacher' and we have to be open to talk about the inequalities, particularly within SEND… because I've been in those rooms where I've spoken to many of those teachers and I've actually gone and said, 'look, I'm a Black professional here and this is a Black child' and the language you're using for this child where there's an undiagnosed need is not conducive to them - it's not, when you're using terminology like aggressive."*

Keen to address gaps in knowledge and misconceptions about behaviours that reflect a need, one professional spoke about her mission to educate the professionals around her about SEND:

> *"So, I've worked a lot around SEND with my teachers, giving them training, how to identify if you think there's a need because sometimes it's not being able to regulate your emotions. They just need help to know appropriate strategies to use if they get angry… And it could be something as simple as learn to walk away. But you've got teachers that walk into the classroom, a student is not happy and you're forcing them to do what you're going to do or you're going to get a detention…And it escalates when, if you just gave the student 5 minutes, they will just calm down and they will cooperate."*

All professionals were forthright about the challenges of accessing SEND support, feeling strongly that economic, systemic, and organisational issues were key drivers behind the difficulties experienced by both professionals and parents. The majority of professionals expressed frustration at the bureaucracy of the SEND system and at how unnecessarily complex and obstructive the process could be. As experienced by the parents who were interviewed, there was also exasperation from professionals at the lack of joined up working between agencies both at a department and individual level; poor communication often led to the compartmentalisation of responsibility which, in turn, resulted in support not being accessed in a timely manner. Constraints on resources were felt to be the main contributor to the extensive wait times which could be over a year long, and a number of professionals reported feeling unsupported by the teams in which they worked, describing how they had individually shouldered the responsibility of supporting parents and acted as champions in their respective organisations. More details about professionals' views on the challenges of the SEND system can be seen in Table 6.

Despite the numerous challenges reported by professionals, they also talked about some of the ways that parents can be supported through the process of accessing SEND support for their child.

Building relationships and trustworthiness

As reported in our parent interviews, building a trusting relationship with parents – especially those who had had negative experiences with services and who had limited understanding of the benefits of a diagnosis or support for their child, was viewed as crucial for initiating and maintaining parental engagement. Professionals noted that some parents will even ask for 'specific members of staff that they trust'. Understanding that establishing trustworthiness is a process that takes time, some professionals had gone beyond their remit to support parents with issues not directly related to their child's suspected need:

"I had to build a relationship with the parent, and in order for her to gain my trust, I supported her with other things, so applications for her younger son to nursery, support during COVID…it took a long time and mum finally agreed to a CAMHS assessment."

Table 6. Challenges of the SEND system

CHALLENGES	SUB-THEME	DESCRIPTION
Economic	Lack of funding and staffing	Financial constraints limit what services can offer.
	Inequity in financial distribution	Postcode lottery of support due to uneven distribution of local funding.
Systemic and bureaucratic	Complicated administrative processes	A difficult system to navigate for both parents and professionals.
	Extensive wait times	Long waiting lists for referrals, assessments, and responses from other agencies protract the SEND support process.

ILLUSTRATIVE QUOTE

"They definitely don't have the resources. I feel like a lot of schools there isn't the support that's needed. So, a lot of children with SEND do get left behind and they just focus on the school, on those that can do it because it's those children that will bring up their Ofsted rating."

"There is not enough money. Unfortunately, SEND is not a need that the Government seems to think is important enough to spend enough money on, cause it doesn't."

"So, some parents would go through the GP route because I was working in a state school at the time and you know, budgets, there's not enough money. If we wanted any assessments, that would have to go through the EP [educational psychologist] and we only had her like twice a month and the waiting list was endless."

"Like I say, it's budgets. Some schools might not have that in their borough to access [support]…So there are differences across like in terms of equity, like it's where it is you live that will determine what the budgets are."

"As I said, geographics. Because from borough to borough it's different. So, we might be charged from a different borough and they might have money."

"Are you familiar with the local offer? The website and for most parents that come back, the information is such a jungle it's a minefield. It's not very straight forward".

"It's such a long process filling out the forms and, you know, getting social care to help with the respite or whatever, it's a long process."

"They say, 'well, this is what the SEND policy online said from the Government. But this is what the school's policy said' and you try to get them to understand that, you know, they're different things. There's a little different box everywhere."

"To get to get an EHCP? Like a year. It can take quite long. And the children aren't always successful. They don't always get one."

"Some children don't get seen at all. One and half years to get an actual diagnosis. It takes a long time."

CHALLENGES	SUB-THEME	DESCRIPTION
Organisational	Poor communication	Lack of joined up care between services.
	Lack of support	Rapid staff turnover and lack of continuity.
	Lack of SEND-trained professionals	Lack of mandatory training on SEND leads to inequitable services.
	Reactive not proactive practices	Late recognition of needs.
	Lack of diversity at senior leadership level	Poor cultural awareness affects who policies and guidelines benefit.

"...the stance that social care have on what schools can provide is ridiculous. You know, we are educators, we're not psychiatrists...I think the expectation from external services sometimes can be quite high. I'm quite lucky because I've worked in a number of professions...But I think the expectations of services on schools is unrealistic."

"A lot of agencies don't communicate well with each other, and information takes so long to be passed from one place to the other. That kind of slows the process down as well. For example, we had one case where the process was literally brought to a halt simply because the parent hadn't provided a full NHS number, and because the full NHS number hadn't been provided, CAMHS couldn't move forward with doing their assessment and it just seemed like the silliest thing to slow down a process for a child."

"I worked in one local authority where there was one decision maker and if that decision maker was not in, everything halted."

"And at one school in particular, their turnover is not helping the kids because they're getting different people. They're getting agency people come in, they're getting dysregulated cause it's another stranger."

"I find it hard to get social workers to talk, and I know they have like a huge caseload, but also they change so I can have a family that's like, 'I do have a social worker. It was this person. But that person left. And now I'm waiting for another one to be allocated'."

"Another issue is the change, the rapid change of EHCP coordinators. I can be emailing and then it might take a month to realise that actually, no, this person is no longer there. Yeah, it's ridiculous. And just them not communicating with the parent or not communicating with me because I don't know and I've wasted a month trying to get hold of somebody that is no longer the child's coordinator and then I have to pick that up, go back to the parent, re arrange a meeting so that we can all introduce ourselves."

"It's not working because the teachers are largely not trained to identify what, you know, they don't know what's indicative of that. They don't know what to look for."

"I think they have the training for the permanent staff which is fine, but then every school that you tend to find that you go into, it's full of agency workers...I don't know what goes on with agency staff. I don't think they get training."

"A lot of times with children that don't have plans, a lot of these meetings are kind of put in place out of something that has occurred when a child has done something, so the child is on the verge of getting excluded, and it's almost like the parents are forced to take on these additional support groups which can be a lot for the parents".

"It's really hard working in that job and being a Black woman, they found me quite combative because...I would challenge their processes...And when you looked at their panel decision makers, they were all white women, blonde hair and it's, you know, you ask yourself, are these decisions being made from an intersectional perspective?"

Professionals with a shared cultural identity or cultural awareness

The process of building a relationship was seen as more straightforward when the professional and family had a common cultural identity, enabling the parent to better relate to and more freely open up to the professional:

> "In the school I was in it was predominantly white. There was three Black members of staff and the families of the Black and ethnic children would go specifically to the Black staff because they trusted them, I guess. So, one of them…she was pastoral support and honestly, I think that school would fall apart if she wasn't there because the families loved and trusted her so yeah, I do think if you can relate to someone, you're probably more likely to listen to what they have to say about your kid."

Similarly, having a workforce that reflects the diversity of local communities was felt to be fundamental for putting families at ease and instilling trust:

> "I think representation is very, very important. And that is the reason why, when I work with a lot of these Black boys, I want them to see that you've got a man from the ends. That actually you can be something, that you don't have to be pigeonholed."

Advocacy and support

Parents having an advocate to support them through their journey was also felt to be a positive and necessary solution to those with a lack of understanding and confidence around navigating the SEND process. Some professionals were able to signpost parents to additional support or organisations that could help, whilst others had been involved more practically. One professional explained how, when she attends parents' meetings she does so in a purely supportive capacity, being clear that she is not there to speak on their behalf but that instead, her role is 'making sure that they understand and that all the right questions are being asked'. Another professional described how she felt that making the school aware that she was supporting a particular parent had encouraged them to be less combative in their interactions with the parent:

> "Mum's been visited and being threatened with going to court, etcetera, etcetera. And then I stepped in and sort of said legally this is what the law says and this is what you need to follow through first and then at this point in time, the school's realised that she's got somebody who understands what should be done and they kind of backed off a little bit."

5 CONSEQUENCES OF INADEQUATE SEND SUPPORT

Professional views on the consequences of late or no SEND support for children who need it were unanimous in that either option would lead to negative outcomes both immediately and in the long term. Late or no SEND support was seen to be 'catastrophic', leading to negative attitudes towards school and behaviour in the classroom because of problems learning how to communicate ideas, thoughts and feelings:

> *"…it can impact those children and their mental health as they go through into adulthood. They're frustrated because they can't talk or they can't socialise… And actually some of those children, they become school refusers…they are not ready to sit down in a classroom because they are actually, they've been failed."*

Others described the importance of SEND support for obtaining the academic and social skills children need to become 'well-rounded members of society':

> *"Having that support earlier on helps those children be able to manage and regulate their behaviour. It also addresses the needs that helps them to be able to access education and curriculum in a way that's more positive, so it keeps them in school. It keeps them engaged; it allows them to get the qualifications to be able to move on successfully."*

Looking to the future, lack of adequate support was viewed as a direct route into the criminal justice system. One professional reflected on how the pathway for the young boys he works with can often be traced back to lack of SEND identification and appropriate implementation of support early on:

> *"Both of our Black boys who are in pupil referral units, you go through their case file and there's a level of SEND that started when they were young… I always go and say, why were they not assessed when they were young? What stopped them from being assessed? Sometimes it's parents' resistance but other times the parents were asking and asking."*

Similar sentiments were expressed by another professional who explained that, in many cases, if the support had been put in place early, 'the behaviour patterns that are being exhibited would not be there'.

Although despairing at the red tape of the SEND system and the social injustices faced by families from certain backgrounds, professionals were clear on ways that the process of accessing SEND support can be improved to allow for a better, fairer service for all. Their suggestions can be found in Table 7.

Table 7. Ambitions for a future SEND system

AMBITIONS	SUB-THEME
Economic	Upfront investment
Systemic	Improvements to pathways and access to assessments
Organisational	Improved communication and joined up holistic services

"There needs to be more funding and you know, having to wait a year for your child to be seen by CAMHS is ridiculous. You know there needs to be more access to external support and assessment."

"There needs to be some recognition of the additional support that community organisations add to this. I think a lot of community organisations are picking up the slack and not being recognised for how much intervention these organisations put in place."

"Schools should be realistic in terms of the capacity that they have to provide the support for those that have EHCPs and I think they should have a system in the schools where the SEND team have all these EHCPs and have a plan or intervention plan in place before the student starts the school."

"My daughter's school, they've recently done a face to face meet the year nine team. Why can't you do that with SEND? Just do these little clusters of sessions online at the beginning and meet with the SEND team. This is what we can do, this is our contact, if you need help with this, this is what we have the capacity to do. If you need any information outside of this, we can sign post you here."

"I think there has to be a universal approach, so the moment that a child, her family accesses that service, everything within the service is working together, so school are working with CAMHS, CAMHS are working with the local authority. If there's social services, involvement, if there's GP involvement, everybody's working together."

AMBITIONS	SUB-THEME
	Training for professionals about SEND and how to provide culturally appropriate support
	Diversification of the workforce at senior level
Parental	**Raised awareness about SEND to empower parents**

"Actually, I think that teachers, whether they're SEND specialists or not, they should all be trained to be able to identify when a child has special needs."

"So, I think part of what we need to be doing is that we need to be educating kind of like our white teachers surrounding, you know, SEND within the Black community so they can be equipped but also getting an understanding from them in terms of how the families from our community are saying we need support."

"It's the reason why being a Black male social worker and progressing high up the chain is quite important for me…I think representation is very, very important…when I go out and see these young Black boys and they're like 'that's the manager there?' 'Yeah, I'm the manager. Let's come, bro. Let's talk'. They're like, OK, so the approach is different because they don't see this often…they know that I'm from the ends and I think they know that I can relate to them."

"I think also when we speak about special needs, it's actually really reframing in the kind of way in which you're approaching it and also honing in on the positives, I think people think that if you've got a special need that you can't succeed in life and that's absolutely not true."

"You gotta have advice. I'd like advice for parents who with children who have SEND needs. We need more SEND hubs…to raise awareness amongst families early on. Yeah, we need more adverts. We need like a whole publicity kind of thing, I hope. A publicity drive."

"It's about ensuring that we dispel all the ignorance as far as new neurodivergence and mental health within our community, and that takes a lot of educating."

DISCUSSION

In this project, we explored the experiences of parents and professionals who have accessed special educational needs and disability (SEND) support for children of Black and mixed Black heritage. Here, we discuss our findings and what they mean for the future of SEND.

Provision of culturally appropriate support through education and training

In keeping with other research, our survey findings indicated autistic spectrum disorder (ASD) as the most common SEND[34]. Professionals who were interviewed also referred to ASD as the condition they encounter most often when supporting parents to access SEND provision. This could reflect the increased attention that ASD has received over the last three decades[35, 36] - both parents and professionals may have better awareness about the signs of ASD over other needs because more information is available. However, early identification of any need, not just those in public consciousness, is essential for ensuring that appropriate and timely support is put in place so that better outcomes for children can be achieved[37]. Notably, the parents who completed our survey rarely described their child as having one SEND: 79 conditions were reported across 46 children, highlighting the level of complexity of the SEND identification process. Raising awareness to parents and professionals about the possibility of dual diagnosis is crucial for accurate SEND identification and subsequent support.

Our findings also highlighted a disproportionate number of boys identified with SEND compared to girls, as has been established elsewhere[38]. This pattern could be attributed to the ability and propensity of females with additional needs to suppress their symptoms[39]. For instance, female adolescents with ASD have been found to use compensatory techniques such as imitating the behaviours of others to camouflage their social struggles[40,41]. Highlighting this behaviour to both parents and professionals is essential to increase awareness that some girls may require support for their additional needs but may mimic neurotypical behaviour in order to socially connect with others and be viewed more favourably amongst their peers. The over-representation of boys for SEND could also be explained by cultural and societal expectations of behaviour

from girls and boys. Findings from our interviews with professionals suggest that the physical type of play associated with boys (e.g., playing with swords, climbing, enjoying rough and tumble play) can be misinterpreted as pathological and that this is particularly marked for boys from Black and mixed Black heritage backgrounds who may face further discriminatory attitudes because of their race and ethnicity. In line with other work[43], the professionals that we interviewed observed that responses to the behaviour of Black children (boys especially) by education professionals could be reactive and overly punitive. These attitudes are fairly unsurprising given the negative perceptions of Black men and boys as engaging in criminality and the depictions of Black men as animalistic[45] (i.e., lacking in self-control and rationality) - factors that contribute to the justification of and actual disproportionate use of

excessive force against them by police[46]. Black boys are also more likely to be subject to adultification[47, 48] (the perception of being older than they are), an effect by which there is assumed deviance and culpability[49], and a disregard of rights typically afforded to children. It is imperative, therefore, that those working in education, health and social care recognise how the intersection of race, ethnicity, and gender shapes the way in which Black children experience services. Mandatory cultural competency training that takes an intersectional approach is necessary for ensuring that expectations around behaviour and the care that is offered are not informed by negative assumptions and biases.

Raising awareness and supporting families

The overwhelming view amongst both parents and professionals was a lack of

understanding about SEND in the general public and, in particular, amongst Black communities. Parents described the stigma of having a Black child with SEND and how this had led to social isolation from their community. Professionals also explained how cultural views around disability could often lead to denial of needs, and reticence towards obtaining a formal diagnosis and acceptance of support. We found that parents were relying on family and friends as their support networks, but our interview findings also suggest that family and friends are not necessarily well-informed about SEND. Our work, therefore, demonstrates the need for dedicated spaces where parents can interact, share, and normalise experiences with other like-minded families. Professionals working in these spaces could also signpost parents to relevant charities or organisations and provide them with information about their entitlements; over half of the parents who completed our survey had only one financially active adult in the household. Additional financial support (e.g., Disability Living Allowance) could be of value to parents with limited resources.

We also noted that, for over two thirds of parents, their child's SEND was identified under the age of three years old. Thus, wider education about SEND within local communities is needed to explain the value of early and appropriate support for activating their child's unique abilities. The consequences of late or no support were made clear by the professionals we interviewed who worried about the vulnerability of Black children with SEND - specifically since, without early intervention, Black children with SEND face greater risk of exploitation[50] setting them on a pathway

to the well-documented school-to-prison pipeline. Thus, we reiterate the importance of early support and intervention to optimise children's learning and mitigate negative encounters with the education and criminal justice system.

Remarkably, the professionals we spoke to reported that often the education professionals that they had worked with had had little training in SEND. Thus, lack of understanding about SEND was apparent even amongst those who should be knowledgeable about it. Even amongst those who had received training, it was felt that little consideration was given to how needs might present in children from different racial and ethnic backgrounds. As it stands, access to SEND support relies in part on the interests and enthusiasm of individuals who have taken it upon themselves to specialise in this area of learning. This type of inequity of access to support is sure to exacerbate inequalities in outcomes for children and their families. Our study calls for a bigger focus on SEND in undergraduate degrees with Qualified Teacher Status (QTS) and the Postgraduate Certificate of Education (PGCE) as well as further training post-qualification so that all education providers are able to recognise and support children with additional needs.

Improvements to capacity and resources

Across both the surveys and interviews, parents reported difficulties navigating the process of accessing SEND support. These difficulties were also observed by professionals who described the process

as obstructive and especially challenging for parents with poorer communication skills such as those with lower educational levels and those with English as a second language. Our study highlights, however, that being well educated is not necessarily a protective factor; over three quarters of the parents who completed our survey reported having been awarded at least an undergraduate degree. Despite this, struggles with the process of accessing SEND support were still evident amongst this group. This highlights the need to simplify the process so that all parents regardless of educational background are able to access support for their child. We noted also that a fifth of respondents reported that they themselves had a learning disability. This is unsurprising given that a number of conditions have a genetic component[51,52.] The challenges in accessing SEND support are likely to be exacerbated for those with a learning disability, and so improving accessibility through the use of dedicated SEND support workers would be of value to all parents but particularly those with additional needs themselves.

The reported lack of co-ordination between different services was felt to be a major contributor to the administrative and cognitive responsibility taken on by parents. As has been described elsewhere[53], both parents and professionals felt that agencies do not share information with one another, and that a lack of joined up communication negatively impacted their access to timely support. Excessive paperwork was felt to protract referral processes and extensive waiting times were attributed to demand

that outstrips capacity and resources. It is easy to see why parents who require SEND support for their child would strive for an EHC plan: the legal obligation of a school to provide the support outlined in the plan ensures accountability and penalisation of schools and authorities that fail to fulfil legal duties. However, the struggle to obtain an EHC plan only serves to reinforce the idea that it is the only type of support worth having. Without an EHC plan, parents must rely on school resources and often the good-will of individuals to put support in place that meets their child's needs. As demonstrated in this study, there is clear variation in funding and professional knowledge about SEND across services. It was evident from our interviews that professionals and parents had felt the consequence of services being under resourced and over-stretched. These issues will only worsen if the demand for EHC plans increases which is a distinct possibility if plans to make 20% cuts to EHC plans via the Delivering Better Value in SEND scheme[54] go ahead. Rather than cutting costs in key areas of need, we call for an injection of funding to support the recruitment and training of SEND-qualified professionals who can work closely with families to obtain the support they need throughout the course of their education.

The SEND journey as a Black parent

Finally, the experience of navigating the SEND journey as a Black parent, especially a Black woman, was significant. Women made up all parent interviewees and almost all survey respondents, reflecting what has been shown elsewhere: that women take on the major caring role and consequently,

experience higher levels of stress[55]. The challenge of navigating a complicated and under resourced system creates a scenario in which parents feel that their only option is to fight, and yet in doing so, they risk being viewed as combative. Black women are, in effect, forced to live up to racial stereotypical tropes of the 'angry Black woman'. Indeed, reports of being labelled as 'aggressive' or 'difficult to work with' were common in this study, and treatment towards Black families was felt to lack consideration of personal circumstances and cultural values. Thus, navigating the SEND process as a Black parent whilst also managing the psychological burden of caring for a child with additional needs (which has already been linked to increased psychological distress, anxiety and changes to family life[56]) could have long-term consequences for parents' mental health. This is concerning given the inequalities that see Black people accessing mental health services less often than other groups[57].

Acknowledging the mental health of parents of children with SEND from Black and mixed Black heritage backgrounds is, therefore, essential: these parents must be given the opportunity to focus on their wellbeing in order to equip them with the psychological resources to manage their caring duties. Signposting parents to relevant support organisations that offer culturally appropriate mental health support or that can provide a period of respite should be formally integrated into the pathway of accessing SEND support, ensuring a holistic model of care that puts both parents and children at the heart of the process.

STRENGTHS AND LIMITATIONS

The voices of Black communities are often not included in research studies. A strength of this work is that it provided an opportunity for parents of Black and mixed Black heritage children to discuss their experiences and be included in an area of SEND work that is under-researched. Furthermore, triangulation of the data was made possible through the collection of both quantitative and qualitative information - an approach which guided our understanding of access to SEND support from different perspectives. The study is limited by the small number of parent interviews, and the inclusion of only parents living in South London. A final limitation refers to recall bias and self-selection: parents may selectively remember aspects of their experiences and parents with an overly negative experience may have been more motivated to take part in the study.

OUR FINAL MESSAGE

When viewed together, the findings from this study raise a number of points for consideration.

First, we acknowledge the wellbeing of parents and children with SEND: Parents are required to play a central role in their child's SEND support journey, but careful consideration must be given to the consequences of this responsibility on parents' physical and mental health, as well as the wellbeing of their child. Given that little support and information is easily available to ease the burden felt by parents, we need to identify how the efforts and energy of parents can be used more effectively as part of the SEND process.

Second, we reflect on developing avenues of support: Parents reported that their experiences of accessing SEND support were rarely straightforward. There is a need, therefore, to improve this process. Provision of advocacy as a statutory service for parents of children with SEND could be an option, as is the case for Looked After Children.

Third, we consider the sustainability of an under resourced system: Legislative changes, such as our proposal of the mandating of SEND advocacy, could improve the experiences and outcomes for parent and children. However, as historic issues regarding funding within education and multi-agency working continue, we must consider the feasibility of such changes when capacity and resources are being cut.
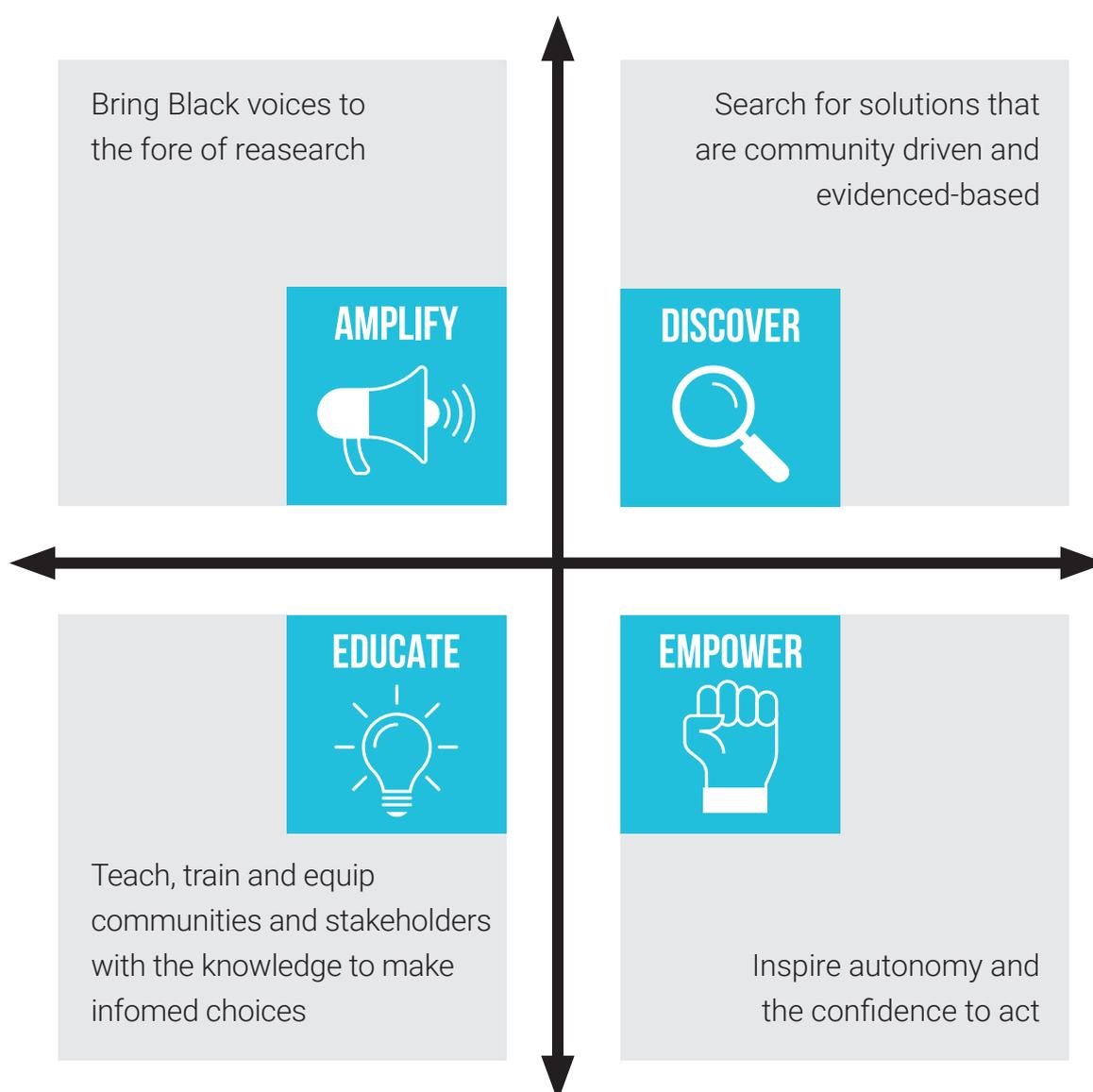
Lastly, we note the system vs the individual: There are issues with the administration of SEND support that go against the power of individual professionals to make an impact. We need to discover what is needed to support both parties to achieve the shared goal of accessing SEND support.
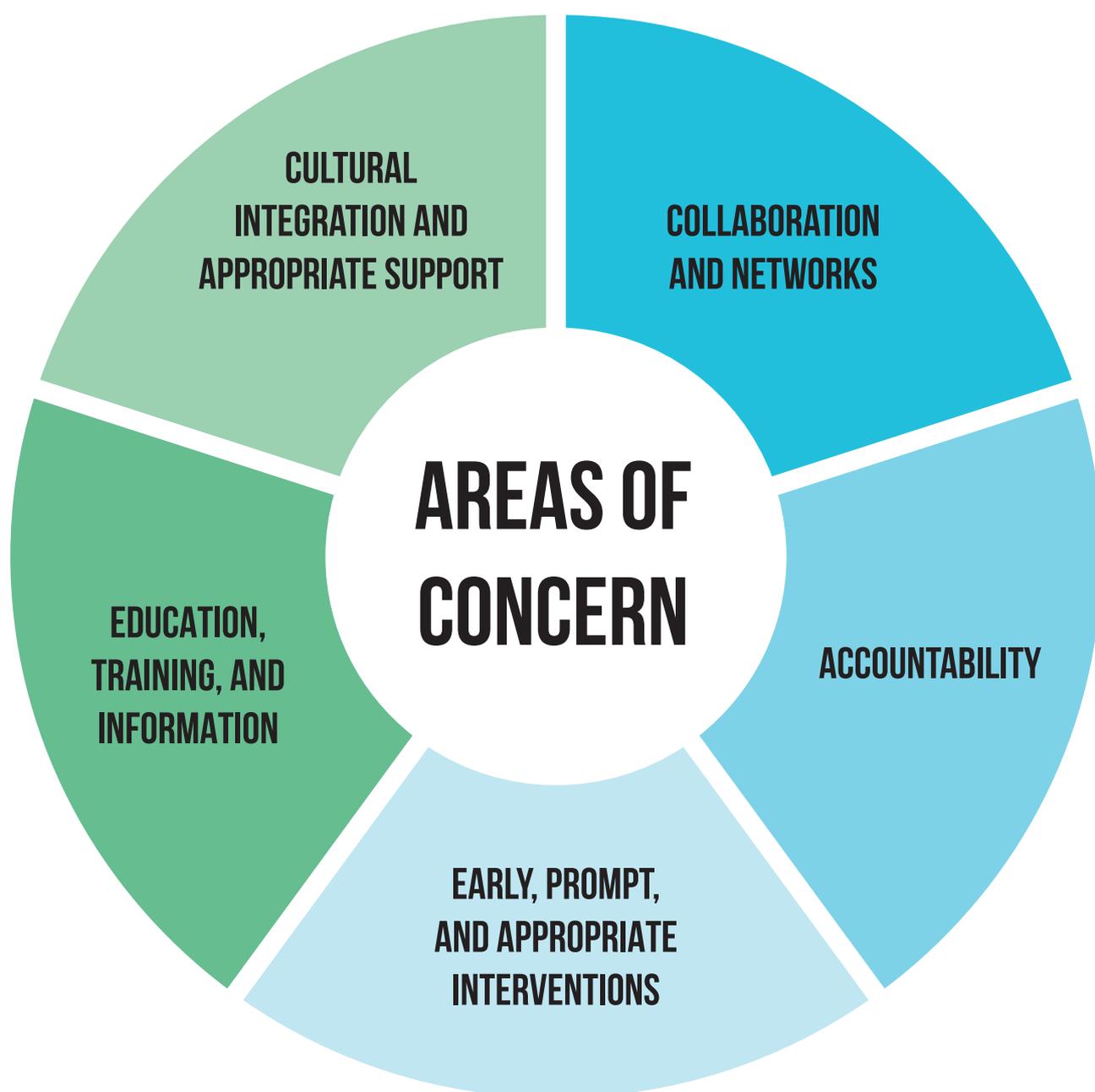
RECOMMENDATIONS

Through collaboration with parents of Black and mixed Black heritage children with SEND, we have developed a set of recommendations to improve the process of accessing SEND support for parents and professionals. Though our findings reflect the experiences of parents and professionals residing and working in South London, our hope is that our recommendation will be implemented more widely.

All recommendations are centred around the virtues that are fundamental to the ethos of Global Black Maternal Health (see below).

Bring Black voices to the fore of reasearch

AMPLIFY

Search for solutions that are community driven and evidenced-based

DISCOVER

EDUCATE

Teach, train and equip communities and stakeholders with the knowledge to make infomed choices

EMPOWER

Inspire autonomy and the confidence to act

Our recommendations below fall under five key areas of concern and focus on the issues that parents of Black and mixed Black heritage children with SEND have told us would most effectively improve their families' experience.

AREAS OF CONCERN

CULTURAL INTEGRATION AND APPROPRIATE SUPPORT

COLLABORATION AND NETWORKS

ACCOUNTABILITY

EARLY, PROMPT, AND APPROPRIATE INTERVENTIONS

EDUCATION, TRAINING, AND INFORMATION

AREA OF CONCERN	RECOMMENDATION	RESPONSIBLE PARTIES
1 **COLLABORATION AND NETWORKS**	1. Outline and imbed the cross-agency working practices and expectations for all professionals and services working with children with SEND.	
	2. Adopt and integrate transparent and communicative cross-agency working methods in the EHC assessment, planning and review process (such as the 'team around the child/ family' approach) to foster and improve collaborative working and network solutions.	Education settings Local Authorities
	3. All children receiving SEND support whether coordinated and delivered by their educational setting or formalised in an EHC plan should have a named lead/ responsible professional for the coordination of their support (such as a SENCo or EHC Coordinator)	Policy Makers
	4. Develop London-wide practices and procedural expectations of cross-agency and network working that consider the impact of poor or low-level cross-agency working, taking key learnings from the London Safeguarding Children Procedures and the statutory Working Together to Safeguard Children guidance.	Local Authorities Greater London Authority Policy Makers
	5. Establish and embed a caring, child-focussed and family-centred culture across services working with children with SEND and their families.	Education settings Local Authorities Individual Professionals

AREA OF CONCERN	RECOMMENDATION	RESPONSIBLE PARTIES
	6. Take active steps to improve the experience of parents accessing SEND support and the EHC process by: a. Developing relationships between individual professionals or services and families. b. Centring the practice of collaborative and rapport focussed working styles. c. Ensuring that work with parents considers their financial and emotional resources and personal commitment.	Local Authorities Individual Professionals Education settings
2 **ACCOUNTABILITY**	7. Provide all parents engaging with or seeking SEND support with clear information on the formal appeals and complaints processes at the start of working together. This should include: a. How to prepare for tribunals. b. How to complain to independent bodies, such as OFSTED and the Local Government Ombudsman. c. Explanation of the right to make formal representations.	All SEND services, including Education settings, Health and social care services, Local Authorities Charities, and non-statutory community support services.
	8. Clearly outline the opportunities parents have to engage in regular feedback loops. This should be done for all local authority funded professionals and services providing statutory and non-statutory SEND support to children at the start of working together.	Local Authorities

AREA OF CONCERN	RECOMMENDATION	RESPONSIBLE PARTIES
3 **EARLY, PROMPT AND APPROPRIATE INTERVENTIONS**	9. Improve accurate early identification and appropriate interventions for Black children with SEND by increasing the awareness and training about SEND amongst professionals in the early years, primary school, healthcare and community services.	Education settings Health and social care services Local Authorities Charities and non-statutory community support services
	10. Ongoing review of how financial resources for SEND can be best used to meet the varying needs of families and children with SEND from different ethnic backgrounds.	Local Authorities
4 **EDUCATION, TRAINING AND INFORMATION**	11. Increase awareness of and access to Independent Supporters for families undergoing the EHC needs assessment and plan development process.	Local Authorities
	12. Expand access to independent support, advice and guidance by offering independent advocates to all families of children identified with SEND.	Local Authorities

AREA OF CONCERN	RECOMMENDATION	RESPONSIBLE PARTIES
	13. Improve the knowledge of SEND, interventions and the appropriate processes by: a. Updating the Initial Teacher Training Core Content Framework to address gaps in SEND knowledge and teaching practice. b. Mandating high level teaching on SEND for qualifying teachers. c. Requiring all current teaching staff to undertake SEND awareness training.	Education settings Department for Education
	14. Improve the dissemination of information to families of children with SEND children on SEND processes, rights, and entitlements, made available in a variety of mediums, including collaborating with cultural and grassroots organisations and digital groups.	Local Authorities
	15. Improve the awareness and understanding of socio-cultural difference in SEND for Black communities and other groups experiencing poorer educational outcomes among teaching, health and social care professionals.	Department for Education Local Authorities Charities and non-statutory organisations Global Black Maternal Health

AREA OF CONCERN	RECOMMENDATION	RESPONSIBLE PARTIES
5 **CULTURAL INTEGRATION AND APPROPRIATE SUPPORT**	16. Design and develop a SEND Advice Bureau serving families who are impacted by the injustice of racial and socio-economic predictors of poorer outcomes.	Global Black Maternal Health Local Authorities Charity and non-statutory organisations
	17. Raise awareness among communities impacted by insufficient knowledge and awareness of SEND by developing local SEND advocates. This should be done through collaboration with parents and families of SEND children from the relevant racial and ethnic groups and knowledgeable professionals and practitioners.	Local Authorities Education settings
	18. Include routes to SEND-specific and culturally appropriate mental health support for SEND parents and children requiring additional support – which may be delivered local, voluntary and charity sector organisations.	Local Authorities Health and social care services Policy makers
	19. Demonstrate a commitment to cultural competency for SEND children from non-white British backgrounds through ongoing training and development of professionals working with children with SEND.	Local Authorities

1   Office for National Statistics, 2019/2020.

2   Department for Children, Schools, and Families. (2009). Lamb Inquiry: Special Educational Needs and Parental Confidence. Nottingham. Department for Children Schools and Families.

3   Education, health and care plans: England 2023. Data on the number of children and young people with a statement of special educational needs (SEN) or education, health and care (EHC) plan in England. Department for Education. June 2023. Available at: https://www.gov.uk/government/statistics/education-health-and-care-plans-england-2023.

4   Cooper, P., Upton, G., & Smith, C. (1991). Ethnic minority and gender distribution among staff and pupils in facilities for pupils with emotional and behavioural difficulties in England and Wales. British Journal of Sociology of Education, 12(1), 77-94.

5   Strand, S., & Lindorff, A. (2021). Ethnic Disproportionality in the Identification of High-Incidence Special Educational Needs: A National Longitudinal Study Ages 5 to 11. Exceptional Children.

6   Roman-Urrestarazu, A., van Kessel, R., Allison, C., Matthews, F. E., Brayne, C., & Baron-Cohen, S. (2021). Association of Race/Ethnicity and Social Disadvantage With Autism Prevalence in 7 Million School Children in England. JAMA pediatrics, 175(6), e210054.

7   Office for National Statistics, 2019/2020.

8   Strand, S., & Fletcher, J. (2014). A Quantitative Longitudinal Analysis of Exclusions from English Secondary Schools. In UO Department of Education Report. University of Oxford.

9   Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan. Right Support, Right Place, Right Time. March 2023 . Available at: https://www.gov.uk/government/publications/send-and-alternative-provision-improvement-plan.

10 Supporting SEND: How children and young people's special educational needs (SEN) are met in mainstream schools. Ofsted. May 2021. Available at: https://www.gov.uk/government/publications/supporting-send.

11 SEND Code of Practice, DfE, 2015.

12 Children Act 1989, c. 41. https://www.legislation.gov.uk/ukpga/1989/41

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A1	SERVICE OR BODY THAT PROVIDED INITIAL SEND SUPPORT	N	(%)
	Health e.g., support provided by, or referral made by GP, consultant, health visitor, CAMHS etc.	17	37%
	Education e.g., support provided by, or referral made by a school, teacher, teaching assistant, SENCo or any other in-school intervention	16	35%
	Community Support e.g., children's centre, drop-in sessions in community spaces	8	17%
	Social Care e.g., support provided by, or referral made by a social worker, early help, family support worker etc.	2	4%
	Private support e.g., paid for support/ accessed via health insurance	2	4%
	Charity or community organisation e.g., non-statutory organisation for example IPSEA, SOS!SEN, Scope, Action for Children etc.	1	2%

A2	EDUCATION, HEALTH AND CARE PLAN (EHCP) STATUS	N	(%)
	Child has an EHCP	27	59%
	Child does not have an EHCP but has a <u>confirmed</u> learning disability/difficulty or behavioural need and receives SEN support	10	22%
	Child does not have an EHCP but may have an additional learning disability/difficulty or behavioural need and currently receives SEN support	9	20%

A3	TYPE OF SCHOOL CHILD ATTENDS	N	(%)
	A mainstream primary school	76%	35
	A specialist primary school/ a special school	15%	7
	Not currently enrolled at a school	4%	2
	A pupil referral unit	2%	1
	Home-schooled	2%	1
	Grand Total	**100%**	**46**

RATING	Parents' rating of experience of working with child's School to support their special education needs (%)	(N)	Parents' rating of experience of working with child's current class teacher to support their special education needs (%)	(N)	Parents' rating of experience of working with the Education Psychologist to support their child's special education needs (%)	(N)	Parents' rating of experience of working with the school SENDCO to support their child's special education needs (%)	(N)	Parents' experience of working their child's GP to supp their special education needs (%)
Average	25%	10	23%	9	20%	8	33%	13	23%
Below average	23%	9	10%	4	13%	5	18%	7	13%
Excellent	5%	2	25%	10	2%	1	18%	7	0%
Good	38%	15	28%	11	15%	6	15%	6	43%
N/A	0%	0	5%	2	38%	15	13%	5	8%
Poor	10%	4	10%	4	13%	5	5%	2	15%
Grand Total	**100.00%**	**40**	**100.00%**	**40**	**100.00%**	**40**	**100.00%**	**40**	**100.00%**

Parents' experience of working with child's ...support special...	Parents' experience of working with their child's paediatrician to support their special education needs		Parents' experience of working with their Child Mental Health Services to support their child's special education needs		Parents' rating of experience of working with the child's Social Worker to support their child's special education needs		Parents' rating of experience of working with Speech and Language Therapists to support their child's special education needs		Parents' rating of experience of working with Occupational Therapists to support their child's special education needs	
(N)	(%)	(N)	(%)	(N)	(%)	(N)	(%)	(N)	(%)	(N)
9	23%	9	5%	2	18%	7	32%	13	35%	14
5	10%	4	13%	5	0%	0	28%	11	20%	8
0	20%	8	0%	0	3%	1	18%	7	18%	7
17	30%	12	13%	5	8%	3	13%	5	18%	7
3	15%	6	58%	23	65%	26	5%	2	8%	3
6	3%	1	13%	5	8%	3	5%	2	3%	1
40	100.00%	40	100.00%	40	100.00%	40	100.00%	40	100.00%	40

The extent to which parents agree or disagree that:	USEFULNESS OF THE PLAN				CHANGES THE PLAN HAS BROUGH ABOUT						
	their SEND support plan is easy to understand		their wishes and opinions were included in their child's SEND support plan		the SEND support plan has led to their child getting the support they need		the SEND support provided has improved their child's experience of education		the SEND support has improved their child's health or wellbeing		t s h a f t v
RATING	**(%)**	**(N)**	**(%)**	**(N)**	**(%)**	**(N)**	**(%)**	**(N)**	**(%)**	**(N)**	
Agree	51%	20	41%	16	34%	13	37%	14	39%	15	
Disagree	15%	6	8%	3	16%	6	13%	5	8%	3	
N/A	8%	3	10%	4	5%	2	5%	2	5%	2	
Neither agree nor disagree	15%	6	31%	12	26%	10	26%	10	29%	11	
Strongly agree	3%	1	8%	3	11%	4	11%	4	8%	3	
Strongly disagree	8%	3	3%	1	8%	3	8%	3	11%	4	
Grand Total	**100%**	**39**	**100%**	**39**	**100%**	**38**	**100%**	**38**	**100%**	**38**	

the SEND support has helped them and their family to live the life they want to lead		the SEND support plan includes preparations for their child's next move in life (e.g., secondary school)		the SEND support plan will help to improve their child's chances of living independently in adult life		the SEND support plan will help to improve their child's chances of fully participating in the wider community		the SEND support plan will help their child to identify their hopes for the future		professionals have worked well together to support their child's special educational needs	
(%)	(N)	(%)	(N)	(%)	(N)	(%)	(N)	(%)	(N)	(%)	(N)
16%	6	28%	11	26%	10	41%	15	26%	10	35%	14
21%	8	31%	12	11%	4	11%	4	13%	5	25%	10
5%	2	13%	5	13%	5	14%	5	16%	6	0%	0
45%	17	21%	8	34%	13	22%	8	34%	13	23%	9
5%	2	0%	0	11%	4	8%	3	8%	3	15%	6
8%	3	8%	3	5%	2	5%	2	3%	1	3%	1
100%	38	100%	39	100%	38	100%	37	100%	38	100%	40

A6 **Parent's rating of how easy or difficult it was to:**

RATING	start the process of getting SEND support		be involved in the process of getting SEND support		agree on the needs and support described in the SEND plan	
	(%)	(N)	(%)	(N)	(%)	(N)
Difficult	39%	15	39%	15	26%	10
Easy	21%	8	21%	8	32%	12
Neither easy nor difficult	21%	8	32%	12	37%	14
Very difficult	18%	7	8%	3	5%	2
Very easy	0%	0	0%	0	0%	0
Grand Total	**100%**	**38**	**100%**	**38**	**100%**	**38**

A7 **Parents' rating of the quality of support the received as a family from education, health, social care or other public services to address their child's special educational needs.**

RATING	(%)	(N)
Average	39%	15
Good	24%	9
Below average	18%	7
Poor	18%	7
Grand Total	**100%**	**38**

A8 **Parent's overall satisfaction with the experience of accessing SEND support for their child**

RATING	(%)	(N)
Dissatisfied	39%	15
Neither satisfied nor dissatisfied	32%	12
Satisfied	16%	6
Very dissatisfied	13%	5
Grand Total	**100%**	**38**

A9 **Parents who raised their concerns or made an informal complaint about their experience of accessing SEND support for their child**

RATING	(%)	(N)
No	46%	13
Yes	54%	15
Grand Total	**100%**	**28**

A10 Parents who were aware of how to raise their concerns or make an official complaint

RATING	(%)	(N)
Unaware of how to raise concerns or make a complaint	52%	15
Aware of how to raise concerns or make a complaint	48%	14
Grand Total	**100%**	**29**

A11 How often parents used external networks to support them and their child:

RATING	Family		Community groups		Religious groups		Social media platforms		Charitable organisations	
	(%)	(N)	(%)	(N)	(%)	(N)	(%)	(N)	(%)	(N)
N/A	0	0	10%	4	21%	8	3%	1	36%	14
Never	3%	1	28%	11	56%	22	13%	5	21%	8
Often	38%	15	21%	8	3%	1	28%	11	18%	7
Rarely	15%	6	21%	8	5%	2	13%	5	18%	7
Sometimes	44%	17	21%	8	15%	6	44%	17	8%	3
Grand Total	**100%**	**39**	**100%**	**39**	**100%**	**39**	**100%**	**39**	**100%**	**39**

SURVEY DEVELOPMENT AND CONTENT

The survey was developed by the researchers with input from the wider Global Black Maternal Health Team. Comprising questions that captured both quantitative and qualitative data (open-text comments), the survey initially assessed: a) Whether the parent had a child of Black or mixed Black heritage, b) Whether the parent was concerned that their child had a SEND, and c) Whether the child in question was at Key Stage 1 or 2. Those stated that they were concerned <u>and</u> whose child was at Key Stage 1 or 2, were asked whether they had acted upon their concern by engaging with agency services. Those who disclosed that they had <u>not</u> acted upon that concern and/or whose child was not in Key Stage 1 or 2 were screened out of the survey. Those who disclosed that they had <u>not</u> acted upon that concern but who <u>did</u> have a child in Key Stage 1 or 2 were given the opportunity to provide further details about why they had not yet engaged with agency services via an open-text comment box.

Those who disclosed that they had acted upon their concern <u>and</u> who had engaged with agency services, were directed to complete the remainder of the survey.

TOPIC GUIDE DEVELOPMENT AND CONTENT FOR INTERVIEWS

Two interview topic guides were developed: one each for parents and professionals. Topic guides were first drafted by MP and revised following feedback from RW, AA, and CB.

COMMITMENT TO CHANGE

Thank you for reading the Black Child SEND report. We at Global Black Maternal Health welcome you into our community of changemakers. We invite you to participate in the cycle of change for Black and mixed Black heritage children with SEND by sharing a commitment you will act upon.
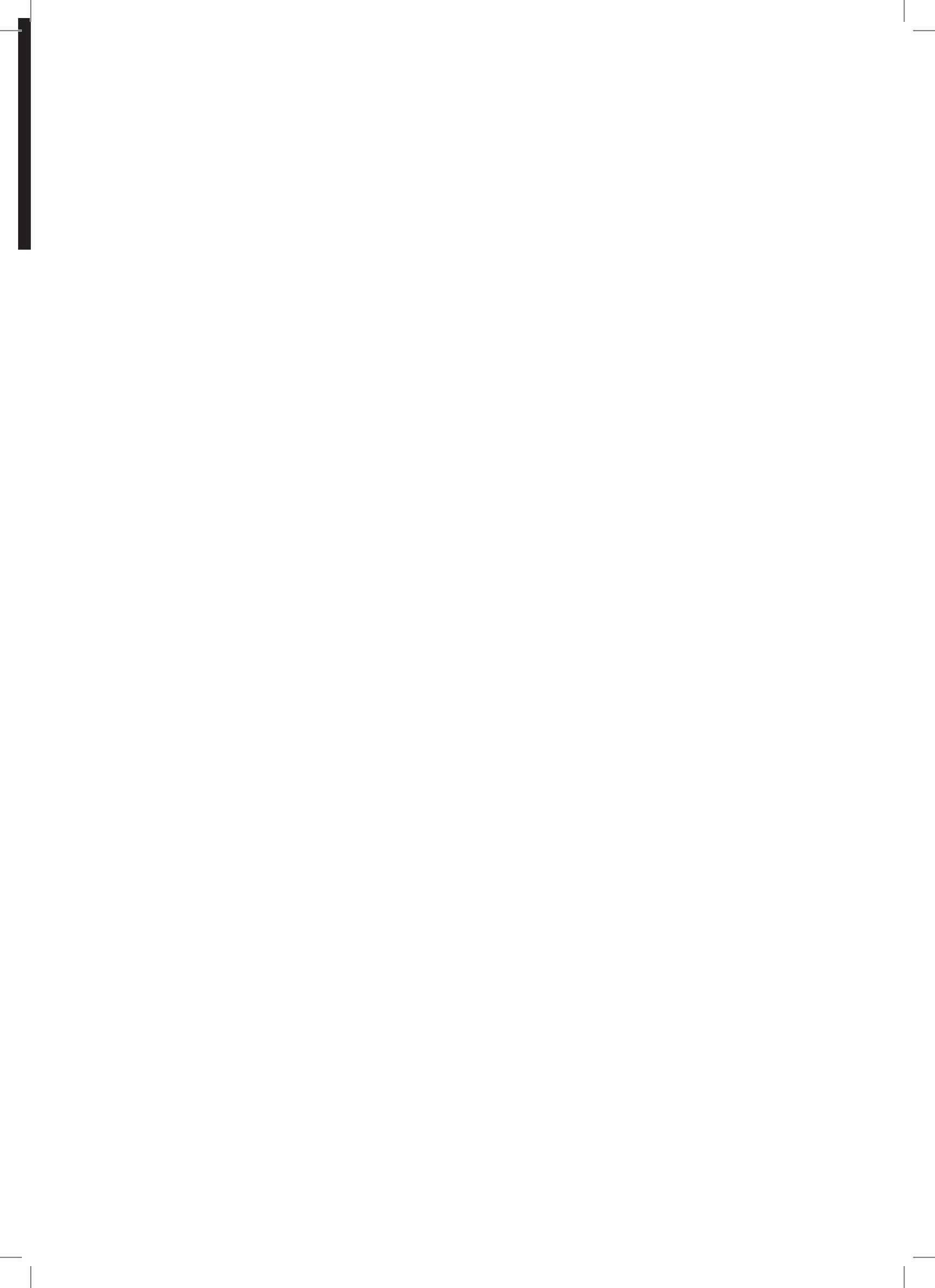
No matter how big or small, together we will improve the support and experience for Black SEND families.

NAME:

DATE

TIME:

I commit to supporting Black and mixed Black heritage children with special educational needs and disabilities to have the education they deserve through the following action:

GLOBAL BLACK
MATERNAL HEALTH