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Research & Evaluation



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Unheard voices: Education experiences of London Black and minority ethnic families caring for children with SEND

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Executive Summary

This summary presents findings from Year 2 of a three-year research project funded by the City Bridge Foundation and commissioned by Contact in December 2023. It provides a detailed insight into the lived experiences of London families regarding the education of their children with special educational needs (SEND). It highlights the current educational challenges faced by children with SEND and their families, with particular focus on the experiences of families from minority ethnic backgrounds.

Methodology

This mixed-methods research project is being conducted by an independent researcher in partnership with a Project Group established to co-produce and guide the research. Year 2 of the research involved three strands of qualitative and quantitative research:

- Online interviews with three professionals from Contact
- An online survey of parents/carers in London
- In-depth interviews with 15 parents from minority ethnic backgrounds.

Key findings

- The majority of parents face ongoing challenges in accessing education support for their child.
- Children are not receiving the education support they need and are entitled to, and many parents are unhappy with the support that their child is currently receiving.
- Some schools are not making reasonable adjustments for inclusion, and children and young people with SEND are missing out on school activities such as after-school clubs, school trips and school performances.
- Getting an EHCP was a challenging process for many parents, and children are not always receiving the support they are entitled to.
- Despite the level of dissatisfaction that many parents have with their child's education provision, most parents lacked confidence in raising concerns with their child's school or Local Authority (LA).
- The barriers faced by parents in accessing education support for their child included:
 - Insufficient funding for SEND
 - Accessing support is complex and time-consuming
 - Parents' concerns are not listened to
 - Lack of information and guidance for parents
 - LAs are not fulfilling their statutory duties
 - Lack of support, understanding and accountability in schools.
- Families from minority ethnic backgrounds often experience additional barriers. These include language barriers, stigma associated with disabilities, racial discrimination and mistrust of services or professionals.
- Navigating the complex SEND system and struggling to access education support for their child has a detrimental impact on parents and their children, including mental health problems, self-harm, relationship problems and financial difficulties.

- A minority of parents had more positive experiences of accessing support and emphasised the significant role of their child's educational setting, and specific individuals, in supporting the early identification and diagnosis of children and providing advice and guidance to parents.
- Parents of children with additional needs require support to help them navigate the complex SEND system. However, not all parents are getting the information and support they need, which is putting further pressure on families.
- The challenges and pressures faced by parents demonstrate a clear need for families to be adequately supported while navigating the SEND system – from assessment and diagnosis to the provision of support for children and young people. Parents would particularly welcome clear and consistent information on SEND, an advocacy service to support parents and a holistic package of support for families.
- While most parents felt that support for SEND families should be universal, they acknowledged that some parents from minority ethnic backgrounds would require additional support. This included translation services, cultural competency training, and parent support groups specifically for families from minority ethnic backgrounds.

Next steps for the research

Year 3 of this research project will further explore how families from racially marginalised and minoritised communities can be better supported. It will also identify the actions that policymakers and practitioners should take to enhance their support and help families overcome barriers to accessing SEND support.

1. Background

This summary presents findings from Year 2 of a three-year research project funded by the City Bridge Foundation and commissioned by Contact in December 2023.

The overall aim of this research is to examine the experiences of education for London families with children with special educational needs (SEND) (in particular, Contact service users), with a specific focus on black and minority ethnic groups¹. Importantly, it will also explore how policymakers, statutory services and community organisations and charities such as Contact can improve their support and help families to overcome barriers.

Rationale for the research

The challenges and tensions in the SEND system nationally have been well-documented (e.g. Starkie, 2024²). However, the increasing number of children and young people in England being identified with SEND, particularly those with high-level needs, is placing unprecedented pressure on the current system. This growth is reflected in London, as the cohort of school pupils with SEND increased by 21% between 2019 and 2024, to more than 250,000 pupils (17% of the pupil population in London). Seven London boroughs now have more than a fifth of school pupils identified with SEND (Miller et al., 2024)³, and financial and capacity challenges in London's school system are adding further pressure to the SEND system.

Our Year 1 literature review (O'Donnell, 2024)⁴ summarised the existing research evidence regarding parents' experiences of the education system. It highlighted the challenges for parents in navigating the complex and increasingly adversarial SEND system. The review also revealed that such challenges are compounded by the intersectionality of SEND with other factors such as ethnicity and socio-economic background. Given the increasing ethnic diversity in the UK, and specifically London, it is crucial to understand the diverse experiences of different communities to ensure that SEND provision is equitable. However, there is currently limited research which hears directly from the families of children and young people with SEND (particularly those from minority ethnic groups), about their educational experiences, and which explores the factors contributing to variation in families' experiences. Given that parents should be at the heart of the SEND Code of Practice⁵, it is essential that their voices are heard and listened to. This research project aims to fill the evidence gap and gathers feedback directly from parents from a range of different communities across London about their child's education.

This interim report provides a detailed insight into London families' lived experiences regarding the education of children with SEND. It highlights the current educational challenges faced by children with SEND and their families, with particular focus on the experiences of families from minority ethnic backgrounds. Although the research focuses on London and the issues faced by families in London, the findings are likely to be relevant

¹ The research questions for this project are summarised in Appendix 1.

² Starkie, Z. (2024). Parental experiences of accessing assessments for special educational needs. *Journal of Research in Special Educational Needs*, 24(1), 25–38. <https://doi.org/10.1111/1471-3802.12609>

³ Miller, J., Nethercott, R., Mehew, W., Preston, S., Rossiter, P., Jones, L. & Choulerton, D. (2024). Inclusion in London's schools: a review of inclusion of young people with SEND in London. Available at: <https://www.mimeconsulting.co.uk/wp-content/uploads/2024/11/Inclusion-in-Londons-Schools-Report-Mime-London-Councils-20241104.pdf>

⁴ O'Donnell, L. (2024). Research on the experiences of education of London families with disabled children from black and minority ethnic groups – Year 1. Available at: <https://contact.org.uk/wp-content/uploads/2024/06/Contact-City-Bridge-ODonnell-Interim-report-1-13-May-2024-with-logos-1.pdf>

⁵ <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

to families across England. We hope that these research findings will give policymakers and practitioners an insight into the experiences of parents and how families from different ethnic backgrounds can be better supported within the education system.

2. Methodology

This mixed-methods research project is being conducted by an independent researcher in partnership with a Project Group established to co-produce and guide the research. This Project Group involves key frontline staff from Contact and parents with lived experience of SEND from a range of ethnic backgrounds.

Year 2 of this research project involved three strands of qualitative and quantitative research:

- Online interviews with three professionals from Contact
- An online survey of parents/carers in London
- In-depth interviews with 15 parents from minority ethnic backgrounds.

Further details about each strand are provided below.

Strand 1: Interviews with professionals from Contact

In order to gain an overview of the issues faced by families with children with SEND and the support provided by Contact, online interviews were conducted in Spring 2024 with three members of Contact staff responsible for supporting parents or campaigning on behalf of families.

Strand 2: An online survey of parents/carers in London

Between June and September 2024, parents/carers in London were invited to take part in an online survey about their child's educational experiences. Whilst the research is primarily focused on the experiences of parents from minority ethnic backgrounds, this survey sought the views of any parent in London with a child with SEND, regardless of their ethnicity. The survey aimed to provide a broad overview of the experiences of all families and to explore any differences in experiences by ethnic background. The survey included a mix of closed questions and open-ended questions that allowed parents/carers to write a response in their own words.

The survey was distributed through Contact's national and London office email newsletters, as well as via social media and other organisations and networks that support parents (e.g., parent carer forums). It was offered in three languages – English, Somali and Punjabi – to reach community groups that Contact has specifically worked with in London. However, all the responding parents completed the English language version of the survey.

A total of **412 parents/carers** responded to the survey and met the screening criteria - parents/carers living in London with a child aged 5-19 with special educational needs⁶. An additional five parent/carers completed the survey; however, their data were excluded from the complete survey analysis as they indicated that their child was outside of the 5-19 years age range.

Families from across the whole of London are represented in the survey responses, with at least one parent/carer response from each of the London boroughs. Responses were most common in the boroughs where Contact has offices - 19% of parents were from Ealing, 10% from Lewisham and 6% from Lambeth.

⁶ This also includes five parents of children aged 4 years old, who were included in the survey sample because their children attended Reception in primary school and were deemed to meet the screening criteria for the research.

Half (50%) of responding parents/carers described themselves as White, with White British the most common ethnicity (36%). A total of 43% of parents were from a non-White background⁷:

- 24% described themselves as Black or from a Mixed White and Black background
- 15% described themselves as Asian or from a Mixed White and Asian background.
- 4% were from an 'other' ethnic group.

Further details of the characteristics of the responding parents and their children are presented in Appendix 2, while the survey responses are summarised in Appendix 3.

Strand 3: In-depth interviews with 15 parents from minority ethnic backgrounds

At the end of the parent survey, respondents were asked if they would be willing to take part in a telephone or online interview with a researcher. The parent interviews aimed to explore families' experience of education in more depth, with a specific focus on parents from minority ethnic backgrounds.

A total of 95 parents from minority ethnic backgrounds provided their contact details in the survey, and a sample of 35 parents/carers were invited to participate. A total of 15 in-depth interviews were completed in November and December 2024. The characteristics of these parents and their children are summarised in Appendix 4.

Parents were asked about any access needs or support requirements they may have for the discussion (e.g., sign language, interpreter, or chaperone during the interview). However, none of the parents who participated in an interview requested access arrangements.

Analysis

Data from all three strands of the research were summarised, and themes were coded as they arose using a thematic analytic approach aligned with the project's key research questions. The report primarily focuses on the perspectives of parents and carers, supplemented by insights from Contact professionals. Numerous quotes from parents are included throughout the report, from both the open-ended survey questions and the in-depth interviews, so that the views and experiences of families are told in their own words.

2.1 Potential limitations of the findings

While this research aimed to include parents and families from a range of backgrounds, it is important to note that the survey and interview samples represent only a small proportion of the families in London with a child with SEND, therefore, the findings summarised in this report may not be generalisable to all relevant parents in London.

From a methodological perspective, the use of an online survey may have been a barrier to some parents due to a lack of digital access or skills. Given the survey distribution approach (via Contact's mailing list and social media), it is likely that many of the parents who responded to the survey were those who are already engaged with support services in some way or were able to access online information about support services. The

⁷ The remaining 7% of survey respondents did not provide details of their ethnicity.

findings may not, therefore, be representative of parents who do not currently access such support services. Furthermore, all the parents who responded to the survey completed the English language version of the survey, and 85% reported that English was their primary language. Consequently, the findings may not fully reflect the views and experiences of parents for whom English is an additional language.

Where possible, statistical analysis was conducted to explore any differences in the views and experiences of parents from different ethnic backgrounds, to examine if different communities of parents face specific issues or barriers. Due to the small numbers of survey respondents in some of the ethnicity categories, parents were grouped into 'White background' or 'minority ethnic background' for this analysis. However, it is important to note that there may be significant variation in the views and experiences of parents from different ethnic backgrounds within these broad categories.

Although parents with access needs were offered appropriate support to participate in the video/telephone interviews, participation may have been challenging for some parents due to language or literacy barriers or digital exclusion. Consequently, we may not have reached parents who are not currently accessing any support services or who are marginalised. Many of the parents who participated in the telephone interviews were professionals, and some worked in areas related to SEND, including education, nursing, and social work. It may be that their experiences do not reflect those of parents without a professional background. However, as discussed throughout this report, despite the relevant knowledge and expertise that some of these parents had, they still found navigating the SEND system extremely challenging.

3. Findings from the research

Overall, the personal stories recounted by parents regarding their child's experience of education present a stark picture of a SEND system that is failing children and young people and putting huge pressures on families. Parents were frustrated with the complexities of the SEND system, the lack of information and support available for parents, and the lack of high-quality specialist provision for children and young people with SEND. Many of the parents involved in this research were in a desperate state – struggling with their child's needs, financially stretched, exhausted from the fight of advocating for their child, & feeling very alone. Indeed, one parent described the current SEND system as *'a truly appalling system - inhumane'*, while another stated that it was *'failing children'* and *'destroying lives'*.

This research included parents from diverse ethnic backgrounds and with children with a variety of needs. Common themes emerged in their experience of their child's education; however, some also described the discrimination that they and their children had faced, and the additional barriers for parents from minority ethnic backgrounds. Overall, no large differences in the findings were observed between ethnic groups. However, where differences were observed, these are highlighted throughout the report in a pink box. The specific experiences of families from minority ethnic backgrounds are also discussed in Sections 3.4 and 3.9.

3.1 What are parents' experiences of accessing education support for their child?

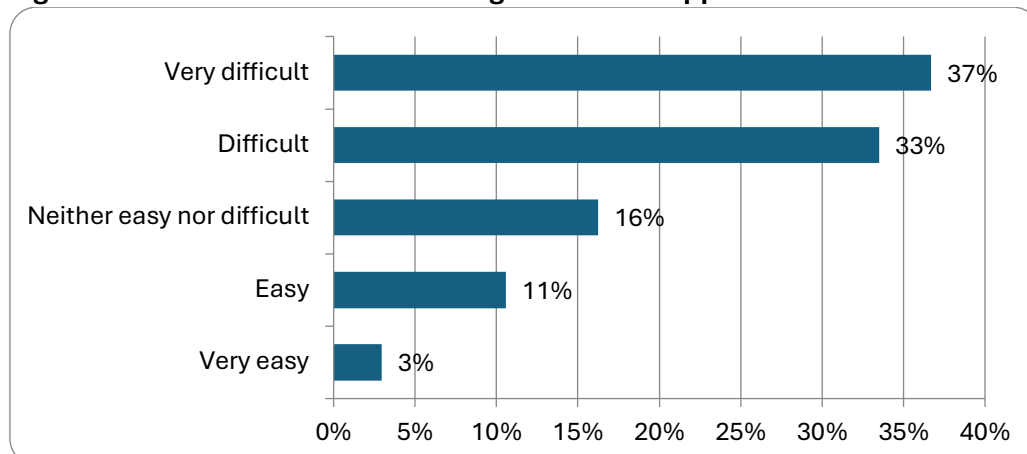
The majority of parents face ongoing challenges in accessing education support for their child.

In order to access education support for a child or young person with SEND, there are a number of broad steps that parents generally have to go through. Firstly, a child's needs have to be recognised and identified; they then need to be assessed; and tailored support needs to be put in place for them – either SEN support or an Education, Health and Care Plan (EHCP). This often requires the cooperation and collaboration of schools/educational settings, health and education professionals, as well as Local Authorities.

Both the survey and in-depth interviews with parents/carers highlighted the challenges that parents from a range of ethnic backgrounds have faced in accessing education support for their child and navigating these key steps in the process. Overall, 70% of parents who responded to the survey reported that they had found it 'very difficult' or 'difficult' to access education support for their child (see Figure 1).

Getting their child referred for assessment by professionals seemed to be the most challenging aspect of accessing support, with 41% of parents describing this as 'very difficult' and a further 20% as 'difficult'. In addition, more than one-third of parents (36%) said that their child's school had refused to refer them to external professionals for assessment.

Figure 1. Parents' views on accessing education support for their child



Source: Contact Survey 2024 - Parent Experiences of SEND Education

A minority of parents reported that their child had received an early diagnosis and appropriate provision in place (often through their child's early years setting). However, many parents were facing ongoing battles to get the support that their child needs and described the process of navigating the SEND system as an '*absolute nightmare*' and '*roller coaster*'. The key challenges and barriers to accessing education support are discussed in detail in Section 3.3.

Analysis by parental ethnicity revealed that the White parents who responded to our survey were slightly more likely than those from minority ethnic backgrounds to report that they had found it difficult/very difficult to access education support for their child (75% of White parents, compared with 64% of parents from minority ethnic background).

White parents were also more likely to report difficulties in various aspects of accessing education support for their child (e.g., 66% of White parents found it difficult to agree on what support their child needs, compared with 42% of parents from a minority ethnic background). The reasons for these differences are unclear from the current survey and require further exploration, particularly given the relatively small numbers of parents in these ethnicity categories.

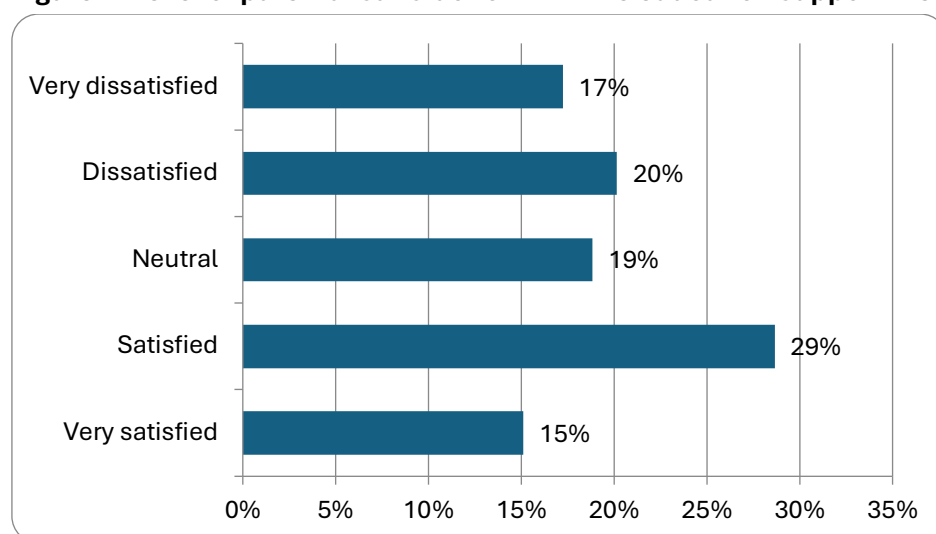
Some parents reported going to great lengths to get a diagnosis for their child and access to the education support they were entitled to. As well as educating themselves about the SEND system and their rights, this included:

- paying for private assessments
- making subject access requests
- making formal complaints to their child's school
- making complaints to the Department for Education
- accessing legal aid
- making an appeal to the SEND Tribunal
- contacting their local MP.

Children are not receiving the education support they need and are entitled to, and many parents are unhappy with the support that their child is currently receiving.

As well as difficulties in trying to access education support for their child, a notable proportion of parents were unhappy with their child's current provision. As shown in Figure 2, 37% of parents stated that they were dissatisfied or very dissatisfied with the education support their child was currently receiving. Only 44% reported being satisfied or very satisfied.

Figure 2. Level of parental satisfaction with the education support their child is currently receiving



Source: Contact Survey 2024 - Parent Experiences of SEND Education

Even where children had received a SEND diagnosis, appropriate provision was often still not in place for them. For example, more than half (51%) of the parents reported that their child's school/setting had not put in place the support their child was entitled to. Furthermore, 44% of parents disagreed or strongly disagreed that their child had been able to get the help and support they needed, with more than half of these parents *strongly disagreeing* with this statement.

Parents highlighted the *'many barriers and poor practice when trying to navigate the system and advocate for SEND children effectively'*. They reported *'constant battling'* with their child's school or LA to have their child's needs recognised and assessed, and for appropriate provision to be put in place and argued that *'it should not be this hard to get your children the support and education they are entitled to.'* The following comments are illustrative of many parents' experiences:

'The staff at the school were reluctant to refer him for a diagnosis. I struggled for him to get SEND support in school. I struggled for the school to agree to do the referral for EHCP....He gets no support in the class. The headteacher says there is no money to support him in the classroom. He now struggles to attend school.' (Parent, 'other' ethnic background)

'We have to fight for everything, every little thing, when it comes to our child's support - it's emotionally draining, extremely time-consuming and simply not sustainable. It's a full-time job if your child has complex needs.' (Parent, 'other' White background)

In some cases, parents were so dissatisfied with the provision in their child's school that they changed settings, or took the decision to home educate their child, as they felt that this was the only option available to them. The issues in school settings highlighted by parents included schools not providing the support that their child needs, a lack of flexibility for children and young people with SEND, rigid attendance and behaviour management policies, and non-inclusive environments.

Some schools are not making reasonable adjustments for inclusion.

One of the major concerns expressed by some parents about their child's provision was that schools were not inclusive for children and young people with SEND. Despite schools/educational settings having a legal obligation under the Equality Act 2010⁸ to make reasonable adjustments for disabled children and young people to ensure they are not at a substantial disadvantage compared with their peers, it is concerning that many parents felt that their children were not treated equally or fairly by schools:

'You see the difference in how kids with needs are treated and their parents are, you know, compared to kids who don't have needs, there's a massive gap... primary schools, at least this primary school, saw disabled kids as a problem.' (Parent, Black Caribbean)

'Families of SEND children should get to experience everything that other families experience who have mainstream children. That includes before-school and after-school enrichment and extra-curricular activities.' (Parent, White British)

Through the survey and in-depth interviews, parents recounted distressing stories of schools failing to make reasonable adjustments to include their children in normal school activities. This included children with additional needs being removed from the classroom due to their behaviour (or unmet need, as stressed by parents), as well as not being allowed to join in with school activities such as after-school clubs, school trips and school performances. This is reportedly due to schools not recognising or fully understanding children's additional needs and not having sufficient staff to cope with the number of children with SEND and make reasonable adjustments. Such practices were reported by parents even when their children had an EHCP.

3.1.1 Views on Education Health and Care Plans

Three-quarters (75%) of the parents who responded to our survey reported that their child either had an EHCP (70%) or was currently being assessed for an EHCP (5%). These parents were asked their views on their experience of getting an EHCP for their child and their satisfaction with their current provision.

Nationally, there has been an increase in the number of children and young people with high-level SEND needs and EHCPs. However, there are concerns that the level of central government funding for high-needs children is insufficient for the number of children with an EHCP. This was summed up by one Contact professional who explained the impact of reduced funding on the SEND system and the experience of families going through the EHCP process:

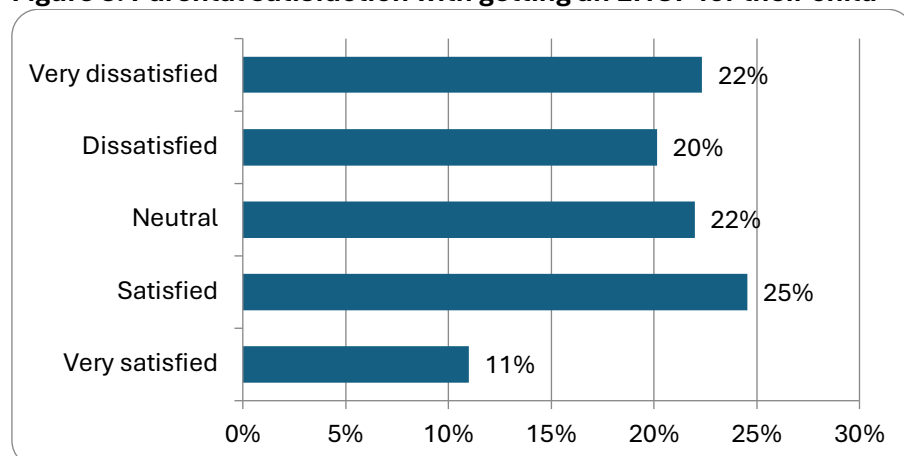
⁸ <https://www.gov.uk/guidance/equality-act-2010-guidance>

'Schools' funding has been reduced so much through years of austerity that they don't really have the funds to provide the special education provision that they used to in school. So, more schools are applying for EHCPs for children because that's the only way they can get the funding. So, everyone's kind of being funnelled down the EHCP road. But you know an EHCP is not the golden ticket at all, because no one really wants an EHCP. It's such an awful process to go through. It's really hard to get. It's a really hard process to go through.' (Contact professional)

Where parents had been well-supported by schools and other professionals, the EHCP process was easier for parents.

As Figure 3 illustrates, 36% of surveyed parents with a child with an EHCP were 'very satisfied' or 'satisfied' with their experience of getting this plan in place.

Figure 3. Parental satisfaction with getting an EHCP for their child



Source: Contact Survey 2024 - Parent Experiences of SEND Education

These parents praised the communication and support they had received from professionals and the provision put in place for their child, and it was clear that where schools, and particularly early years settings, had supported parents in early diagnosis and EHCP application, the process was much smoother for parents:

'We have been fortunate enough to have an amazing SENCO at my child's nursery who helped us to navigate resources and support. She guided us through the process and helped us come to the conclusion of which setting would be best suited for all my children.' (Parent, Black African)

'The only reason I found getting an EHCP so easy was because of the incredible support and knowledge of his specialist nursery. The SENCO there was amazing, well-trained and experienced. She has enabled my child to be in the right education setting for his school years and I will be eternally grateful to her and the rest of the staff at the Children's Centre specialist autism unit.' (Parent, White British)

Getting an EHCP was a challenging process for many parents and children are not always receiving the support they are entitled to.

Despite some positive experiences, more than a fifth (42%) of the parents surveyed stated that they were 'very dissatisfied' or 'dissatisfied' with their experience of the EHCP process. Indeed, one parent described it as *'the worst and most stressful experience of my whole life'*, and another describing the process as *'truly shocking – a system intended to wear the parent down'*.

Analysis by parental ethnicity revealed that White parents were more likely than those from minority ethnic backgrounds to report dissatisfaction with their experience of getting an EHCP for their child – 47% of White parents said they were dissatisfied/very dissatisfied, compared with 36% of parents from minority ethnic backgrounds.

Many parents felt alone and unsupported in the challenging process of applying for an EHCP for their child and were frustrated by the lack of information and guidance for parents: *'No one really explains the EHC. You have to take the time to read it and make sure you understand. I feel like you have to jump through so many hoops and then you are kind of left in the wilderness.'* (Parent, Black Caribbean). One parent also highlighted the additional challenges that parents with language or literacy barriers would face in the EHCP process due to the complexity of the system: *'I had to do my own research. Fortunately, I am able to navigate the system, but I dread how much more difficult it is for those whose English is a second language, cannot read or write or have access to IT.'* (Parent, Indian)

Parents often reported that EHCPs were only put in place after months or years of trying to apply, and in some cases, only after making a formal complaint, employing a solicitor or taking their LA to Tribunal. Some parents indicated that they had had to pay for private assessments and reports, at significant personal financial cost, due to refusal from their child's school or LA to undertake the necessary assessments for their child.

'The whole EHCP process was incredibly stressful and we had little help or guidance...We had a terrible case worker who was unhelpful, at times rude and unprofessional...The process ran well over time, we constantly had to chase our case worker.' (Parent, White British)

'Long delays, poor communication and constant advocating to ensure provision is being implemented. It has been relentless.' (Parent, Mixed ethnicity, 'other' origin)

The main issues with the EHCP process reported by parents were:

- **It took a long time to get their child's EHCP agreed** – 57% of responding parents reported that it took longer than 20 weeks (the legal limit for LAs) to get their child's EHCP in place, and 46% disagreed/strongly disagreed that the final plan was issued at the right time for their child. Parents reported that deadlines were not met by their LA, and they had to constantly chase their EHCP caseworker and other professionals. Consequently, due to delays in the EHCP process, many children

had been without the support they needed for significant periods of time: *'Took me 2 years to get one. They kept refusing to assess my child. She missed out on so much education due to that....They only decided to do an assessment once I took it to Tribunal.'*

- Children's needs were not always fully understood in the EHCP process** – Less than half (44%) of parents agreed or strongly agreed that their child's needs were fully understood in the EHCP process, while 40% disagreed/strongly disagreed: *'The whole experience was incredibly stressful as we felt those working on our EHCP had no interest in what was best for our child...People were making decisions about our child when they had never met her.'*
- EHC plans are not always easy to understand** – While 46% of responding parents agreed/strongly agreed that their child's EHCP is easy to understand, nearly a third (31%) of parents disagreed/strongly disagreed that it is easy to understand. One parent, for example, commented: *'The EHCP paperwork is very confusing. I am very curious to know who actually reads this and ensures everything is being followed through. I think it's a very disappointing document.'* Another parent said: *'It was very poorly written with professional reports left out. In the end I virtually ended up writing it myself.'*
- Some parents did not feel listened to by professionals** – While 56% of parents felt that they had been listened to, 28% of parents disagreed or strongly disagreed that they had been listened to by professionals and that their views had been included in their child's EHCP. Parents were also frustrated by multiple changes in LA personnel and poor communication from professionals, especially their EHCP coordinator/case-worker, who one parent described as *'virtually uncontactable...multiple phone calls and emails with no response.'*
- Parents were unsure what the EHCP should include** – Parents commented on the lack of guidance they had about what information and evidence an EHCP should include, and some reported having to pay for external experts to support them in making the application: *'When it was first written, it wasn't worth the paper it was printed on. The first school [child's name] attended didn't know how to write one, and neither did we. It wasn't until we got an outside opinion that it was made fit for purpose.'* (Parent, White British)
- Not all children are receiving the support outlined in their EHCP** – Even when the EHCP was in place, it is concerning that less than half (42%) of parents indicated that their child was now receiving appropriate support. Indeed, 35% of parents disagreed/strongly disagreed that their child is receiving the support outlined in their plan, and 27% disagreed that the support set out in the EHCP had improved their child's education. The following quotes are typical of parents' comments: *'The plan is never followed. Constantly fighting to get a fraction of what is in it'; 'Despite a high-level EHC plan, this was often not read or implemented.'*
- Annual EHCP reviews are not carried out** – Regardless of their experience of getting an EHCP in place, parents consistently complained that annual reviews and updates to the plan were not made: *'With regards to yearly reviews, amendments and making changes to the plan, the borough have been extremely slack/very slow. Constant chasing by parents and school SENCO. Often EHCPs are left not updated.'* (Parent, Black Caribbean)

These findings highlight the need for greater support for parents in applying for an EHCP, and more effective communication and partnership working between professionals and parents. Furthermore, greater transparency and increased accountability are required within the system to ensure that LAs and schools are fulfilling their statutory duties regarding children and young people with SEND.

3.2. How do parents feel about raising concerns about their child's education?

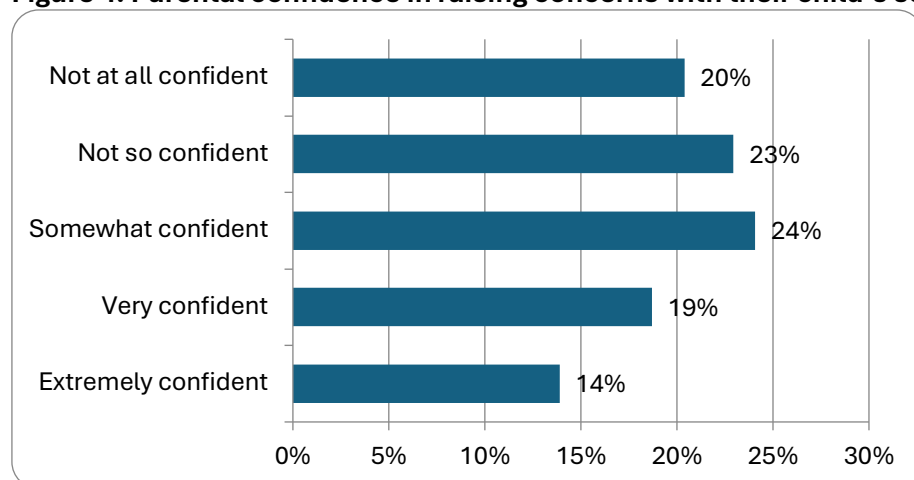
Despite the level of dissatisfaction that many parents have with their child's education provision, most parents lacked confidence in raising concerns with their child's school or LA.

One of the parents interviewed explained that *'to really support your child, you really need to know about law conduct and whether something's lawful or not and what to do next. And as well as that, you have to know how to complain because the complaints procedure both at the Council and the schools are literally not fit for purpose.'* However, as shown in Figure 4, most of the parents who responded to our survey lacked confidence in raising concerns with their child's school or LA about the education support their child is receiving:

- 20% of parents said that they did not feel at all confident about raising concerns, while a further 23% indicated that they were 'not so confident' and 24% were 'somewhat confident'.
- Only one third (33%) of parents felt 'very confident' or 'extremely confident' about raising concerns with their child's school or LA.

Given the dissatisfaction that many parents expressed about accessing support and the quality of provision for their child (as described in Section 3.1), it is concerning that such a large proportion do not feel confident in raising this with education professionals.

Figure 4. Parental confidence in raising concerns with their child's school or LA



Source: Contact Survey 2024 - Parent Experiences of SEND Education

Where parents were confident about raising concerns, they explained that this was because it was necessary to drive change and get the support their child was entitled to: *'It is the only way to get anywhere - I have tried being patient and it doesn't help me or my children'*, and *'To begin with, I suffered in silence. But then had to find my voice and advocate for my child.'*

Where parents were less confident about raising concerns with their child's school or LA, this was commonly because they were *'not convinced anyone would be interested'* and *'nothing happens when you complain. They just ignore you.'*

Analysis of parental confidence in raising concerns by parental demographics revealed some small variation between parents from different ethnic backgrounds. White parents were slightly more likely to report that they were not confident about raising concerns, compared with parents from minority ethnic backgrounds (46% of White parents, compared with 37% of minority ethnic parents).

Further breakdown of minority ethnic parents revealed that Black parents were more likely than Asian parents and White parents to express confidence in raising concerns about their child's educational setting (45% of Black parents felt 'extremely confident' or 'very confident' in raising concerns, compared with 30% of Asian parents and 31% of White parents). However, it is important to note that due to the small numbers of respondents in the different ethnicity categories, it may not be possible to generalise these findings to all parents from a particular ethnic background.

SEND Tribunal

Some parents felt they had no choice but to appeal to the SEND Tribunal regarding their child's education provision. Just under a quarter (24%) of the parents who responded to our survey reported that they had submitted an appeal to the SEND Tribunal concerning their child's education support. More than half (59%) of parents did not know how to submit an appeal to the SEND Tribunal. There were no observable differences in knowledge of how to submit an appeal between parents from different ethnic backgrounds.

The SEND Tribunal was a last resort for accessing education support for many families, as one parent explained: *'It feels as if the only way you get anything is to make formal complaints and go to Tribunal (which most parents win), but this wastes money and more importantly, time. This is her education we are talking about, yet no one seems to care.'*

The Contact professionals who were interviewed as part of this research argued that *'in many LAs, there has been an active reduction in EHCPs, and EHCP needs assessments are becoming increasingly automatically refused first of all.'* Consequently, they confirmed that many parents are having to appeal this decision through the SEND Tribunal:

'It's really sad, but that is the only way that a lot of children are getting the support that they are legally entitled to....The only accountability is when parents assert their right to appeal. Which they shouldn't have to do. The law should be complied with in the first instance.... It's expensive for the local authority to go to Tribunal... that's money that they could be using to support children in schools without EHCPs.' (Contact professional)

This view is consistent with recent research by the Disabled Children's Partnership (DCP)⁹, which found a marked increase in the number of EHCP cases nationally being taken to the SEND tribunal. In 2021-22, 11,052 SEND tribunals were registered in England – an increase of 29% from the previous year. The DCP research also revealed that 96% of SEND tribunal hearings were won by parents and young people, highlighting the huge waste of public funding (£59.8 million was spent on lost SEND tribunals in 2021-22) and the futility of the process for families.

Both parents and Contact professionals expressed their frustration that parents with SEND children had to make such appeals to get their child the support they are entitled to. This was summed up by one parent who stated:

'There needs to be a different way to gain education support that does not involve litigation. Mediation should be looked at as a way of accessing support, and the mediators should be better trained. Therapists and legal professionals should not be allowed to exploit concerned parents: this side of SEN "support" needs to be better regulated so that parents are not re-mortgaging their houses just to access an education which is freely available to the majority of the population.'
(Parent, ethnicity unknown)

This was reinforced by one Contact professional who explained that appealing to the SEND Tribunal is *'a very stressful thing. It's not an easy thing to do at all...It can be very daunting, very intimidating....You need to supply lots of evidence and get evidence from professionals which quite often is hard to get. And if you can't get that, then some parents feel like they have to pay for private assessments and then that's not always possible.'*

⁹ Jemal, J. & Kenley, A. (2023). Wasting money, wasting potential. The cost of SEND tribunals. Available at: <https://www.probonoeconomics.com/Handlers/Download.ashx?IDMF=93a69e8a-fe29-4567-b594-9ad874f1a348>

3.3. What challenges do families face in accessing education support for their child?

Both the parents and Contact professionals involved in this research reflected on the barriers and challenges to accessing education support for children and the reasons why this proves to be so difficult for many families. The challenges reported by parents can be grouped into six key areas, and these are discussed in further detail below:

1. Insufficient funding for SEND
2. Accessing support is complex and time-consuming
3. Parents' concerns are not listened to
4. Lack of information and guidance for parents
5. LAs are not fulfilling their statutory duties
6. Lack of support, understanding and accountability in schools

These barriers were reported by parents across all ethnic backgrounds. Section 3.4 discusses the *additional* challenges faced by parents from minority ethnic backgrounds.

1. There is insufficient funding within the school system to support children and young people with SEND, and a shortage of special schools in London.

Parents and professionals commented on the lack of funding and resources for SEND provision and felt that this was having a detrimental impact on the support available for children and young people. One Contact professional, for example, emphasised *'the sad reality is years of austerity and a reduction in the specialist workforce'*, which has resulted in a lack of adequate provision for children with SEND. This includes a lack of educational psychologists, occupational therapists and other professionals, and long waiting lists for support. Similarly, parents commonly described repeated failures and delays to their children getting the education support they needed, often over several years, due to the lack of specialist staff and resources being available.

Many parents also highlighted the difficulties they had faced in finding a local school to meet their child's needs and the lack of specialist settings in London. Most of the parents interviewed were unhappy with the provision offered by the mainstream schools that their children had attended, as they felt it did not meet their needs. One parent, for example, stated that: *'Mainstream schools are extremely fast-paced and are simply there to teach and not support.'* However, even when specialist settings were available in their area, schools were often oversubscribed, with long waiting lists. Parents were frustrated by the lack of school choice for children and young people with additional needs and were uncertain about the next stage of their child's education due to the limited number of school places available. One parent, for example, explained: *'It's not like we're even having a chance to see what is the setup? Who are the teachers? Would this work for him or not? We're just hoping for a place in this unknown.'*

This parental experience clearly reflects the funding challenges faced by schools and LAs, both nationally and within London. A recent survey by the School Leaders Union NAHT (2024)¹⁰, for example, found that only 1% of senior leaders believed they have enough funding to meet the needs of their pupils with SEND, and 99%

¹⁰ Summary available at: <https://www.naht.org.uk/News/Latest-comments/Press-room/ArtMID/558/ArticleID/2411/Pupils-with-special-educational-needs-suffering-amid-funding-crisis-say-school-leaders>

disagreed that funding was sufficient. Many local authorities, including London boroughs, also have significant deficits in their SEND budget and these are projected to rise.¹¹

2. The SEND system is complex, and accessing education support is a lengthy, complicated process.

As the following parent comments illustrate, the length of time taken to access education support for their child, the complexities of the process and the resulting missed education for their child, have caused frustration and stress for many parents and families. In many cases, parents had to 'fight' for years to get the education support that their child needed, and this had caused delays to their child receiving the support they needed. This was particularly the case among parents with a child with an EHCP (as discussed in Section 3.1.1).

'It was really hard to get all paperwork done it took us almost 3 years and if it wasn't for me we would possibly still be waiting for any changes.' (Parent, Mixed White and Asian heritage)

'Took us 6 years to get reasonable adjustments in mainstream school. However, the school does not have the capacities to check and review the adjustments they put in are working for the individual. Very frustrating! This process is hindering my son to thrive in school.' (Parent, Chinese)

'Very complicated process, and way too lengthy!!! The time matters so much for children with learning disabilities.' (Parent, 'other' White background)

3. Many parents face difficulties and delays in getting a diagnosis for their child and feel that their concerns and views are not listened to by professionals.

As outlined in the SEND Code of Practice (2014), identifying SEND needs early is crucial for providing timely support and preventing challenges from becoming significant barriers to learning. However, our Year 1 literature review highlighted inconsistencies in approaches to identifying children and young people. Hutchison (2021)¹², for example, concluded that the variation in SEND identification in England is largely determined by which school a child attends. There is also some evidence of ethnic disproportionality in SEND identification, with children from Asian backgrounds consistently less likely to be identified with SEND than White British children. However, the reasons for this disparity are currently unclear.

Our Year 2 primary research with parents also revealed inconsistencies in how children and young people with SEND were identified, and some parents reported struggling, often for months and years, to get a diagnosis for their child: *'Years of fighting and missing out on education because they didn't listen.'* A common complaint

¹¹ Isos Partnership (2024). Towards an effective and financially sustainable approach to SEND in England. Available at: <https://static1.squarespace.com/static/5ce55a5ad4c5c500016855ee/t/669fcedacd1a1f608546f52b/1721749338168/SEND+report.pdf>

¹² Hutchison, J. (2021) Identifying pupils with special educational needs and disabilities. Education Policy Institute.

among parents was that their concerns about their child's needs and their repeated requests for support were ignored by the school and LA staff.

This seemed to be partly due to the lack of educational psychologists and other professionals to carry out assessments of children and young people. However, parents also voiced complaints about not being listened to by professionals and reported that they are *'brushed away repeatedly'* and *'often gaslit, ignored or blamed for my son's behaviour'*. These views were consistent with comments from the Contact professionals, one of whom explained that *'professionals are dismissive with parents, or don't take them seriously. Or they phrase things in a way that is difficult for parents to understand.'*

Parents expressed their distress and frustration that their children's symptoms were overlooked or ignored by professionals, and children and young people were often labelled as 'naughty' or difficult, instead of their additional needs being recognised:

'They told me that he was just naughty. I was seen as an over-protective mum, that I was worrying about nothing.' (Parent, Black African).

'The level of understanding of both culture and environmental influences have made communication difficult. The school doesn't accept aspects of my child's disability. He has had punishment instead of understanding and his feelings undermined. So much so that he has learnt how to expertly mask his struggles.' (Parent, Black Caribbean)

Both the parents and professionals interviewed attributed this to a lack of specialist knowledge and understanding of children's needs among school staff, with children labelled as having behavioural issues, rather than exploring whether a child has additional needs. This led to delays in accessing education support and, in many cases, a deterioration in children and young people's health and well-being:

'Teachers did not believe me when I tried to ask them to help... If school had listened initially my daughter wouldn't have lost trust in the teachers ... the situation has become far more difficult to manage than if effective support had been provided from the start.' (Parent, White British)

4. Many parents lack access to timely and appropriate information and guidance on support provision and their rights.

Given the complexities and barriers in the SEND system, both parents and Contact professionals emphasised the importance of parents having timely information about the support their child is entitled to so that they can advocate for their child. However, many parents lack access to appropriate and timely information and guidance about their rights, or do not possess the knowledge, skills, or confidence to fully advocate for their child. This was even more of a barrier for parents with limited language or literacy skills.

Parents were frustrated that they had been given very little information by schools and other professionals about the support that their child was entitled to, and many were reluctant to challenge the guidance given to

them. Parents felt that they needed to know *'how to play the game'* and that *'knowledge is power'*, and while some families do seem to have the necessary knowledge and resources required, those that do not were thought to be at a disadvantage within the system:

'I've always joked with people that when you become a SEND parent, you become by default a lawyer, an advocate, everything all in one... You need to keep fighting. But not everyone will challenge. I just kept fighting back, I just kept writing the letters. I find that it's always 'no' first, and then it's what you do with that 'no'.' (Parent, Black African)

'Families aren't told what the processes are from the start. So you're trying to navigate system you know nothing about. What you tend to see is the families that have the knowledge and the resources can fight and go to tribunal and appeals and get their child into a school place, versus those that don't. They don't even know the law - information just doesn't reach parents at the right point and at an early point. They're just not being given the advice.' (Contact professional)

5. Parents feel that there is a lack of accountability in Local Authorities fulfilling their statutory duties.

The SEND Code of Practice (2014) outlines the duties of local authorities, health bodies, schools and colleges to provide for those with special educational needs under the Children and Families Act 2014¹³. For LAs, this includes a legal duty to identify and assess the special educational needs of children and young people for whom they are responsible and to ensure that they receive support to help them in 'achieving the best possible educational and other outcomes'.

Despite this legal framework, parents commonly complained that LAs were not fulfilling their statutory duties to provide the education and support that their child was entitled to. Furthermore, parents were angry and frustrated that LAs were generally not held to account for such failures. As well as long delays in accessing support, parents' comments about LAs referred to a high turnover of EHCP caseworkers, poor communication from staff and disjointed working, and perceptions of deliberate attempts by LAs to obstruct or delay the EHCP process:

'The LA I feel deliberately stalled at every opportunity, tried to waste time at tribunal hearings, which meant unbelievably more expense for me. The LA paid for a top barrister to fight their corner. The whole process cost me over £48k!... The LA will lead a family round and round the garden for as long as they can because the more time they can do this, the more money they can save! Meanwhile, the child continues to suffer in a school which cannot meet their needs, or at home, unable to receive the education they are legally entitled to. This can have a devastating impact on the whole family.' (Parent, White British)

¹³ <https://www.legislation.gov.uk/ukpga/2014/6/contents>

'It was a wake-up call that SEND laws, regulations, policies are in place but that doesn't mean institutions follow and implement them. In mainstream...parents are left defeated, left to think that we have no choice or recourse, and tend to accept that what is happening is their fault'. (Parent, Asian)

6. There is a shortage of school staff trained in SEND, a lack of accountability in schools, and often poor communication between schools and parents.

Although some parents expressed gratitude for the support and guidance of school and early years staff, others were concerned that *'some schools are failing children miserably.'* Parents expressed concerns about insufficient SEND knowledge among school staff and the subsequent lack of understanding of children's needs, often resulting in punitive approaches to behaviour management and unmet needs:

'Gaslighting of parents, professionals not listening, assumptions made. Teachers not clinically trained but making decisions as if they had clinical knowledge (for example, not following the exercises given by OT [Occupational Therapy] or putting EHCP in place as they think child is 'fine'. (Parent, Mixed White and Black heritage)

'It feels like I am having to tell the school how to do their job and educate them on autism in girls...they seem to have a very old-fashioned idea of what autism looks like and how to support.' (Parent, White British)

It is clear from other recent research that workforce challenges are contributing significantly to the SEND crisis. High-level SEND needs are continuing to increase; however, schools are struggling to recruit and retain staff, particularly teaching assistants and support staff, who play a crucial role in supporting SEND pupils. Whilst there has been a 21% increase in the number of pupils with SEND in state-funded schools in London since 2016, the size of the teaching assistant workforce has fallen by 7% across the same period (Miller et al., 2024), resulting in fewer staff to provide the support that pupils with SEND need.

Parents were frustrated with schools' refusal to assess their child's needs or follow recommendations from other professionals, and with poor communication between school staff and parents. Parents also commented on the lack of joined-up working between education and healthcare professionals, which meant that children and young people were *'falling between the gaps with regards who is responsible'* for provision. Among the parents who responded to our survey, almost one-third (31%) disagreed or strongly disagreed that they felt well-supported by their child's educational setting, and 38% disagreed/strongly disagreed that they felt listened to by professionals and part of decisions about their child's education.

Some parents also expressed their concern that schools were not providing the support that their child was entitled to, even when they had an EHCP, and called for greater transparency and accountability in how schools use EHCP funding. One parent, for example, explained: *'The head teacher has the attitude that she*

can use the EHCP funding however she chooses, so the school do not provide the allocated support, and we have been told as parents that if we don't like it, we can take our children to another school.' (Parent, White British)

As well as specific complaints about their child's school, some parents argued that the education system as a whole, particularly mainstream education, is failing children with SEND due to its inflexibility to accommodate children with additional needs, particularly regarding expectations for attendance and attainment:

'The system is simply not catering to the vast majority of children who are divergent. This can be the fault of the teachers, senior leadership, or the overall philosophy of the school, but is far more about the utter archaic nature of the national curriculum and ludicrous expectations regarding academic attainment and attendance.' (Parent, White British)

'My son felt very claustrophobic in the school...and they were trying to force him to wear a hot woollen school jumper under his blazer in the hot school. They put him into detention day after day after day because of the jumper and he was even made to do his GCSE mock exams outside of exam conditions in the detention room.' (Parent, Mixed White and Asian heritage)

3.4. What additional barriers to accessing education support do minority ethnic families face?

While many of the barriers to accessing education support appear to be shared by families from all ethnic backgrounds, it was clear that families from minority ethnic backgrounds often experience additional barriers. This may ultimately result in delays to support and unequal outcomes for children and young people from different ethnic groups.

The parents involved in this research reported mixed experiences regarding additional barriers to accessing education support for their child because of their ethnic background. Whilst the intersectionality of barriers and ethnicity was not explicitly explored through the parent survey, the in-depth interviews with minority ethnic parents asked parents to reflect on whether their experiences were influenced at all by their ethnicity, and whether they had faced any additional challenges.

Some minority ethnic parents felt that the challenges in the SEND system were universal and were not influenced by ethnicity: *'The SEND system is just not great regardless of what background you're from...so that's reassuring because then you do think, OK, well, at least I'm not alone, it's just a mess everywhere.'* (Parent, Black African).

Other parents and the Contact professionals highlighted the potential additional barriers that minority ethnic families could face, and indeed, some parents reported direct experience of such additional barriers themselves. These included:

- **Language barriers** – Both parents and Contact professionals agreed that navigating the SEND system (including understanding a diagnosis, completing forms and speaking with professionals) is more challenging for parents for whom English is an additional language. One parent, from an Indian background, explained: *'When my son was diagnosed. I couldn't speak a single sentence in English.'* Another said that *'if English is not [your] first language, completing paperwork and being able to advocate for your child is very challenging.'*
- **Stigma/ lack of understanding of SEND in different communities** – As other research (e.g. Akbar & Woods, 2020)¹⁴ has found, there are some cultural differences in acceptance and understanding of SEND, and there is some stigma associated with disabilities and additional needs in some cultures. One parent, from a Black African background, explained, for example: *'In African backgrounds, a lot of people don't really want to accept that this is what's going on. They don't want to accept that label.'* This is particularly the case with 'invisible' disabilities (such as autism or dyslexia). Consequently, parents from minority ethnic backgrounds sometimes find it difficult to accept a diagnosis or seek support, or they do not tell their family or friends, which means that they have less of a support network:

¹⁴ Akbar, S. and Woods, K. (2020). Understanding Pakistani parents' experience of having a child with special educational needs and disability (SEND) in England. *European Journal of Special Needs Education*, 35(5), pp.1–16. doi: <https://doi.org/10.1080/08856257.2020.1748428>

'We haven't told our family about his autism. We won't tell anybody because they don't understand. For them, he's walking, talking, going to school...and everything is fine. The community's not open to these things...if it's a physical disability, which they can actually see, everybody will help....But this they can't see.' (Parent, Indian)

- **Racial discrimination or bias** – 6 of the 15 parents who participated in the in-depth interviews reported that they had experienced racial discrimination or prejudice from professionals and/or felt that their child had been unfairly treated due to their ethnicity: *'The challenge of raising children with special education needs is obviously difficult anyway. Adding to that, when you have institutional racism and powers which are working against you'* (Parent, Black Caribbean).

These parents reported being dismissed by professionals or unfairly labelled as being difficult. One parent from a Black Caribbean background, for example, explained that school staff would only meet with her in pairs because they perceived her to be aggressive:

'I am still up against the stereotypes and the tropes of the angry black woman...I am very, very cautious to make sure that my tone is never really raised or annoyed, even when they are doing things which I think are really outrageous. So it's really upsetting to then still have to come up against this treatment – institutional racism.' (Parent, Black Caribbean)

A few parents also felt that Black children with SEND are more likely than White children to be seen as defiant or badly behaved rather than recognising their underlying needs, and they are more likely to be unfairly labelled as naughty, aggressive or unmotivated. These views are consistent with findings from other research (e.g., Timpson, 2019)¹⁵ which has found that SEND children from Black backgrounds are more likely to be suspended or excluded from school. The following comments are illustrative of parents' responses to the survey and in-depth interviews:

'In terms of my daughter's needs being picked up early enough, I do think there's been racial bias. She's always been seen as an aggressive child. Now my daughter is mixed race. She's half black, half Asian. She looks black... She would be perceived to be aggressive, defiant, not motivated... but it's her being dysregulated.' (Parent, Mixed ethnic background)

'It's quite common for Black children in particular to be parentified, so they're treated as if they're older than they actually are. They're expected to be emotionally older, more mature, because they might look it.... there needs to be a lot more done about that, particularly when the staff don't reflect the community.' (Parent, Mixed ethnic background)

¹⁵ Timpson, E. (2019). Timpson Review of School Exclusion. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/807862/Timpson_review.pdf

- **Mistrust of services/professionals** – parents from minority ethnic backgrounds may be less likely to accept a diagnosis or seek support for their child due to a lack of trust in formal services or professionals. These can lead to delays in their child receiving the necessary support.
- **Lack of knowledge of the education system** – Parents can benefit from knowing the SEND system and their child's rights. However, many acknowledged that families who are new to the country and unfamiliar with the English education system are at a disadvantage in being able to advocate for their child:

'If you haven't gone to school in the British education system, this is totally new to you....so that's a big gap.' (Contact professional)

'I can imagine parents who just moved into the country who don't know the system, or don't speak the language very well, wouldn't have access to anything. It's like a maze. How would they navigate all of that? That's a big hindrance.' (Parent, Arab)

- **Cultural differences in parents' views of education** – Based on their experience of supporting families from a range of ethnic backgrounds, the Contact professionals indicated that they have observed cultural differences in parents' views of the importance of education: *'I think Black and Asian parents...I guess they really think the child needs to be in school. They don't see an alternative to that.'* This can sometimes be combined with a reluctance to accept that their child might have additional needs, and ultimately result in a delay in parents seeking support for their child:

'You do get parents who are like, I'm going to put my child in tutoring lessons. They're ignoring that there's a disability there, but it's more focused on getting the child to the level of what their peers are, what they should be...rather than supporting the child with their additional need.' (Contact professional)

- **Cultural differences in challenging systems or professionals** – The Contact professionals observed that parents from minority ethnic backgrounds are often more reluctant than white parents to challenge professionals, as the following comments illustrate:

'They sort of take what the professionals say and don't know they can say something back and can disagree. It's almost like they just don't have the confidence or feel empowered and know what they can actually disagree with and ask for.' (Contact professional)

'Non-White parents are more likely to feel they can't really challenge it or that they almost feel shy – that they are not entitled to support, or challenge decisions. Whereas I guess White parents come with a bit more confidence that they are entitled to this.' (Contact professional)

3.5. What is the impact of challenges in the SEND system on children and families?

Navigating the complex SEND system and struggling to access education support for their child has a detrimental impact on parents and their children.

Through both the survey and in-depth interviews, parents conveyed the detrimental impact that struggling to access educational support for their child has had on their families. Parents recounted distressing stories of personal and financial problems, describing their experiences *as 'a nightmare that left me totally drained'* and *'a long and arduous journey that often tears families apart.'* As well as the challenges of navigating the SEND system, many of the families involved in this research were facing multiple additional issues and potential disadvantages that placed further pressure on them, including being single parents, having more than one child with SEND, having their own health issues or disabilities and experiencing housing or financial challenges.

3.5.1 Impact on children and young people

A common view among parents was that their child had experienced trauma in school due to not being given appropriate support for their needs. As previously discussed, long delays in support or being given low-quality support meant that their underlying needs were not being addressed. Not only did this mean that children and young people struggled to fully access the curriculum and achieve their potential, but it also often led to a worsening of their symptoms and knock-on effects on children's health, well-being and behaviour, including anxiety, low self-esteem, self-harm and school avoidance:

'This whole term, she's gone without any counselling, and actually her mental health has declined really badly to the point where she was having suicidal thoughts.' (Parent, Mixed ethnicity)

'He has suffered from severe PTSD due to trauma from his previous school, and he hasn't left the house in over three years.' (Parent, Chinese)

'There's been a massive increase...we get families and children that are saying they want to die. They are self-harming. They're not leaving their rooms. It's all because of unmet need.' (Contact professional)

Parents also criticised schools for often compounding the problem by taking a punitive approach to children and young people's behaviour that takes little account of unmet needs. One Contact professional, for example, reported that young people who had developed emotionally based school avoidance because of unmet needs were facing sanctions for low attendance, and parents were receiving fines. This is consistent with other research (e.g. Epstein, Brown and O'Flynn, 2019¹⁶) that has highlighted the negative effects of punitive approaches to attendance on children with SEND and their families.

¹⁶ Epstein, R., Brown, G. & O'Flynn, S. (2019). Prosecuting parents for truancy: who pays the price? Available at: <https://covrj.uk/wp-content/uploads/2019/01/PROSECUTINGParents.pdf>

A total of 21% of parents who responded to our survey stated that their child had been suspended or excluded from school, and parents attributed this to *'unmet need'* due to their child's school not providing the appropriate support for their child.

As has been found in other research (e.g., Timpson, 2019), SEND children from Black backgrounds were more likely to have been suspended or excluded from school - 25% of Black parents reported a suspension or exclusion, compared with 20% of White parents and 14% of Asian parents.

3.5.2 Impact on parents and the wider family

As well as detailing the detrimental impact on their child, parents emphasised the *'ripple effect'* on their whole family and described themselves as *'exhausted, burnt out and mentally drained'* from the *'emotional toll'* of navigating the SEND system. The following comments from parents clearly expressed the extent of these impacts:

'It was an absolute nightmare. I felt that I was in a dark tunnel with no way out...We spent every waking moment working on court cases and fighting the next issue...We got no more than 4 hours sleep a night for years because all this had to be done in the middle of the night once our daughter was in bed...It has left me a shell of the person I was before all this blew up....I suffer from extreme depression to this day and have attempted suicide twice in the past....I feel utterly betrayed by governments and councils alike.' (Parent, White British)

'I am alone. I persevere as much as I can. I do fear that there will be a breakdown within myself...But I haven't got time to think and put a plan in place. So, I've got a lot of weight on my shoulders. I've got no outlet.' (Parent, Asian)

'Trauma is an accurate description and no exaggeration whatsoever. It took me a couple of years to adjust to her having her condition...but our treatment at the hands of state agencies (health, schools, and government departments) has been the worst element.' (Parent, 'other' Asian background)

The impacts on parents included:

- **Physical and mental health problems** – parents commonly spoke of ill-health, anxiety, sleeping problems and a general feeling of exhaustion as a direct result of navigating the SEND system and coping with the challenges described in Sections 3.3. and 3.4:

'I've cried, felt frustrated and depressed and everyone has told me that it's normal. That getting support is a fight. I don't believe that it should be this way. Our experience has been harrowing at best, and I know I speak for the majority of the parents at our school. My mental health has suffered. Frankly, it's a national scandal.' (Parent, White British)

'We have both suffered with our mental health due to stress. Mother is now on long-term antidepressants due to stress of dealing with the LA.' (Parent, White Irish)

- **Financial difficulties** – Due to spending significant amounts of time communicating with professionals, attending meetings, dealing with paperwork and in some cases, educating their child at home, some parents had had to reduce their working hours or leave their jobs to be able to support their child, especially if they were not in full-time education. Parents also reported self-funding aspects of their child's education, including private assessments, therapies and specialist solicitors. One parent, for example, reported spending more than £45,000 to take their LA to Tribunal, while another set up a Crowdfund to pay for independent assessments of their child's needs. As a result, many families now find themselves in significant financial difficulty:

'I find it exhausting as I have no immediate family in the country and my son requires all my time when not in school...Out of school activity camps during holidays are not available to me due to his need for support, so I am unable to work. And despite having my husband's salary I have used all my life savings just to live.' (Parent, White British)

'The financial cost has been huge: normally I would have liked to be able to keep working, but not possible; had to pay out so far for assessments and tuition...but now looking at having to pay for neuropsychological testing.' (Parent, 'other' Asian background)

'Some of our parents are still feeling the impacts of the pandemic. A lot of families come to us and emotionally...they're on the floor. They've had to give up work. A lot of our families, you know, are being pushed into poverty because their child's not in full-time education - they can't keep a job.' (Contact professional)

- **Relationship problems** – the stress of fighting to access support for their child has reportedly caused tensions and relationship breakdown within families, and parents spoke of arguments over their child's diagnosis and the best way to seek support. Parents also talked about the wider effects on other siblings, as parents had less time to devote to their other children because of the challenges they were facing.

3.6 What does high-quality SEND provision look like?

Despite the considerable challenges in accessing education support reported by most parents, a minority (14%) of the parents surveyed said that it had been 'very easy' or 'easy' to access educational support for their child. These parents viewed themselves as the '*lucky*' parents and felt that it was '*a lottery of which staff you work with and the borough you live in.*' However, they also emphasised the significant role of their child's educational setting, and specific individuals, in supporting the early identification and diagnosis of children and providing advice and guidance to parents, highlighting the importance of specialist SEND training for education professionals and early intervention:

'We have been fortunate enough to have an amazing SENCO at my child's nursery who helped us to navigate resources and support. She guided us through the process and helped us come to the conclusion of which setting would be best suited for all my children.' (Parent, Black African)

'The staff at my child's nursery were the ones who first identified that he was not meeting social communication milestones and referred us into the NHS services. My child's current school were extremely receptive to the information we provided before he started, despite lacking a formal diagnosis. We have had excellent support from the staff and SENCOs in the three years he has been there.' (Parent, White British)

Parents with a child attending a special school were over-represented among parents who easily accessed education support – 60% of parents who indicated that it had been 'easy' or 'very easy' to access educational support had a child at a special school, compared with 25% who had a child at a mainstream school. It is perhaps unsurprising that special schools, with specialist staff knowledge and resources, can make the process of accessing specialised support an easier journey for children and their parents. However, this was not the case across the board.

Some parents stated that, although it had taken them a considerable amount of time to access education support for their child, they were now satisfied with the quality of the provision their child was receiving. Indeed, 44% of the parents surveyed said that they were satisfied or very satisfied with the support their child was currently receiving.

Some parents were also able to reflect on the contrast between provision that had *not* met their child's needs and provision that had met their needs, and they spoke of the relief and reassurance they felt knowing that their child was now receiving appropriate support. Parents described the positive impact that high-quality provision had on their child's happiness, well-being and progress – a stark contrast to the detrimental effects that poor-quality provision reportedly had:

'Once he got into the specialist provision, he pivots... he's like talking, he started doing so much. So it makes me wonder, if this was done sooner, where would he be in his development now?' (Parent, Black Caribbean)

'These children have so much potential...and if you give them just a chance to push them forward, they will do so much and they will do well. And I've seen it with my own eyes. My child came out as a completely different child...he became completely stable. Now he loves school so much.' (Parent, Black 'other' background)

Provision that was regarded as high-quality by parents seemed to include the following features:

- **Care, kindness and respect for the child** – This was particularly important for parents, and they praised the caring, empathetic and compassionate approach of some of the staff supporting their child: *'His one-to-one is really caring and loves him and tries to understand what he likes.... you do feel he goes somewhere where he is loved and cared...And that's such a big relief.'* (Parent, Arab). Feedback from the Contact professionals supported this view and they emphasised the importance of kindness towards children with SEND and staff building a positive rapport with them: *'I just think that so many problems would be almost solved if the adults were a little bit kinder to these children.'* (Contact professional)
- **Inclusive environment** – One parent, for example, talked about her son's experience of a mainstream primary school, which she felt was very inclusive: *'It felt like you were part of the school. You were accepted, your child was accepted, and you became a family of that school ... it's amazing how if you meet a good school, you see it'* (Parent, Black 'other' background). One of the Contact professionals also highlighted the importance of schools taking a flexible approach and *'adapting the approach to the child's needs.'*
- **Good communication and partnership working with parents** – Parents appreciated the regular communication and updates that their child's school provided and valued the collaborative relationship they had with staff, where they felt listened to: *'All staff at my son's school are approachable, kind, supportive and knowledgeable. They are eager to assist me in any way possible, and I am eternally grateful for all of them.'* (Parent, Black Caribbean)

'They communicate with me daily, and we regularly have meetings about my child's progress. I feel like I am in partnership with my son's school, and they truly have his best interests at heart.' (Parent, White British)

- **High-quality interventions that meet the needs of children.** Parents commented on the range of interventions that have supported their child: *'As a school, I cannot fault them. They are absolutely amazing, and I am very thankful...great teachers, great support, everything is under one roof, and I cannot fault their curriculum at all, I can't fault the interventions that they've got in place for her.'* (Parent, Black Caribbean)
- **Experienced staff, trained in SEND** – Parents noted the positive impact that specialist staff had on them and their child, including knowing how best to support children's needs, to providing information and advice to parents: *'My school has always been supportive throughout their schooling in relation to SEND. Our SENCO is supportive, knowledgeable and listens to the needs of each parent/carer in order to help the needs of our children.'* (Parent, Black African)

3.7. What information and support have families received?

Parents of children with additional needs often require support to help them navigate the complex SEND system. However, not all parents are getting the information and support they need, which is putting further pressure on families.

Parents were asked for their feedback on the information they had received about their child's additional needs and the support they required. Their mixed responses to the survey clearly show that there is scope for improvement in the information and advice available for parents with children with SEND:

- While 44% of parents agreed/strongly agreed that they had been given enough information about their child's special educational need or disability, 35% of parents disagreed/strongly disagreed.
- 50% of parents disagreed/strongly disagreed that they had been given enough information about the education support their child is entitled to, and 51% disagreed/strongly disagreed that they had been given enough information about *how to access* education support.

Analysis of these survey responses by ethnicity revealed that there was very little difference between parents from different ethnic backgrounds in their views of the information they had received.

The in-depth interviews with 15 minority ethnic parents also revealed a mixed picture – a few parents felt that there was lots of information and support available for families with a child with SEND:

'Lots of people complain and moan about it. Trust me, there's so much help available. You just have to ask for it; look for it; find it rather than just sitting and complaining about it.' (Parent, Indian)

In contrast, others struggled to find suitable information and support or were unsure of how to access it. Through the survey and in-depth interviews, parents reported not knowing how to find out relevant information, with no central place or consistent approach to provide information to parents about their child's diagnosis or the support available. Even where parents had some experience of the health or education systems (e.g. as a teacher, SENDCo or nurse), they still found it very challenging:

'No information has been given to me at any point....It would have been helpful to have access to information from the start with regards to what is available and how to get it. But no one is prepared to give that information.' (Parent, White British)

Parents reported feeling that they had been *'left to fend for themselves'*, and even where advice or information had been given, *'you are left to navigate the whole process yourself, which is very daunting.'* A few parents explained, for example, that they had just been given a list of websites: *'This is where you can access support and then sort of like get on with it - that's it'*. Another parent stated that *'when my child was diagnosed, the clinician handed us a bunch of leaflets and basically waved goodbye.'*

This view was reinforced by one of the Contact professionals, who indicated that the lack of coherent and consistent information for families was often due to fragmented partnership working between schools and LAs:

'There's always this conversation between school and local authorities – 'Whose duty is it? Is it the local authorities' responsibility to tell parents about what support is available, or is it schools?... There's not one sort of resource pack that's been given to schools, and what we always tend to find is this is the reason why parents fall through the gap.' (Contact professional)

The Contact professionals also noted the additional difficulties for parents from minority ethnic backgrounds, or who are new to the country, due to differences in the terminology associated with SEND:

'They're not being told what having a special education need is. No one breaks it down for you. What does it actually mean to be told your child's got a special educational need? Because in other places it's not even called special educational needs? Some people call it special needs, in some places they call it having an additional need.... What disability means is a different thing as well.... so there's that's a lot to understand for these families.' (Contact professional)

There was consensus that parents had to be proactive and work hard to educate themselves. Parents who said that they were not very proactive were the ones who seemed to have struggled more with accessing information and support. Parents particularly sought information on how to get their child assessed, what education support their child was entitled to and how they could access that support (particularly specialist education). One parent commented, for example, that *'It's like having a new job. But not having anyone to train you'*, while another said that it had taken *'extensive research and sheer determination'* to find the information and support they needed: *'I don't sleep at night because I'm forever looking up things, writing down things, screenshotting things, and then the next day I'm ringing up places and trying to find, you know, things to do with these with the kids.'* The following comments are illustrative of parents' views and experiences:

'It has felt with NHS/educational professionals that they don't seem to explain anything in layman's terms. Nobody wants to tell you what you could get help with. There's little communication; a distinct lack of info sharing - you feel very alone.' (Parent, Pakistani)

Everything I've learned about his needs and how to support him I have learned by researching, reading, accessing private training courses, attending the Parent Forum, etc...I don't know what I don't know and keep finding stuff out and thinking I can't believe no one ever told me that....I feel like I'm just fumbling my way through and there's probably huge amounts of stuff I'm still missing.' (Parent, White British)

Both parents and professionals acknowledged, however, that not all parents have the knowledge, skills, confidence, or resources to be able to spend considerable time and effort proactively seeking out such information, resulting in inequity among parents.

Parents/carers also emphasised the vital information and advice provided by other parents with children with SEND (e.g. through local parent carer groups) and voluntary groups and organisations:

'It is because of other mums and through word of mouth, that I can get the support my children need. The professionals do not seem to want to help!' (Parent, ethnicity unknown)

'You have to do your own research. And I found that the best source of information is actually the families and their own experiences.' (Parent, Arab)

'I found most of the invaluable and full information through inclusive SEND parent groups. Having a SEND support network has been more informative than any agency or professionals I have engaged with.' (Parent, 'other' Black background)

Parents appreciated both in-person opportunities to meet other parents with children with SEND, as well as online opportunities, and social media channels and groups were a valuable source of information and guidance for many parents: *'I've had to do a lot of research. And I'm on a lot of Facebook groups, which, without them, I think I'd be lost. Because I knew nothing. Social media is a great place for information.'*

The challenges and pressures faced by parents demonstrate a clear need for families to be adequately supported while navigating the SEND system – from assessment and diagnosis to the provision of support for children and young people.

In addition to information and advice, parents discussed the support they and their children had received. Parents again had mixed experiences of accessing such support. Some parents felt that they had a good support network and that a wealth of support was available for families. One parent, for example, stated: *'There is so much help available. You just have to reach out and find the right one for you,'* while another agreed: *'Trust me, there's so much help available. You just have to ask for it. Look for it. Find it rather than just sitting and complaining.'*

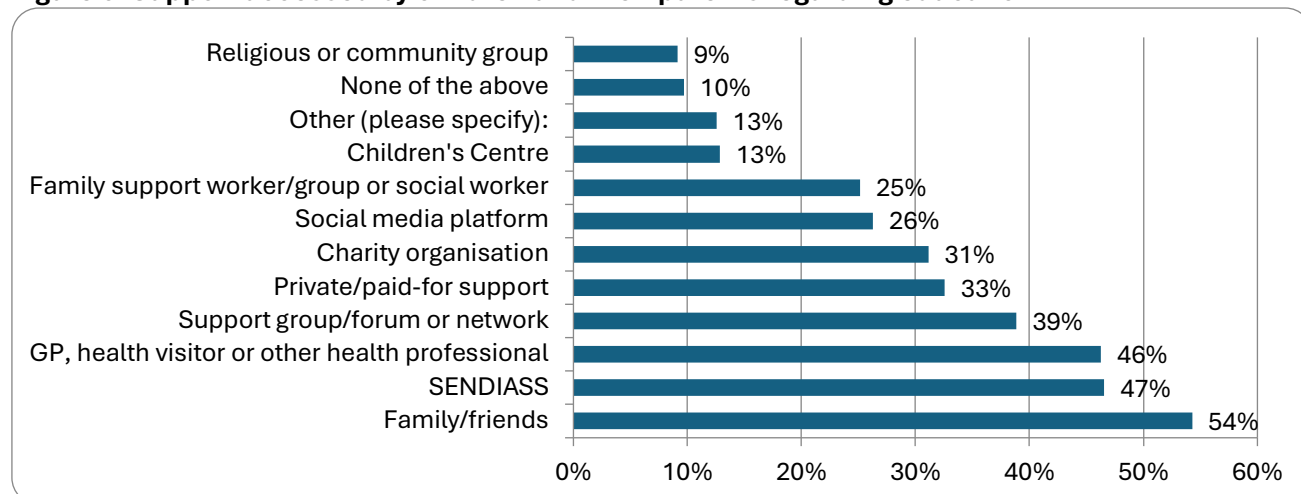
In contrast, other parents felt that little support was available and that they had to *'struggle alone'*, either because they did not know how to access support or because they did not live near family or felt unable to ask family or friends for support. One Contact professional interviewed also highlighted that digital exclusion was also a significant barrier to support for both children with SEND and their parents:

'A lot of our families, I know it might be so simple, but just joining a Teams meeting or a Zoom meeting...that is sometimes such a barrier...So there's all these digital things that have been put in place, but for a lot of families, it is actually a barrier. Not every family has a laptop. Not every family has an iPad or a tablet or device that can access things.' (Contact professional)

The extent of support that parents require differs across families – while some are simply looking for some guidance and reassurance, others need more intensive support and 'hand-holding'.

As Figure 6 shows, the parents surveyed reported that they had accessed support regarding their child's education from a range of people and organisations, most commonly family or friends (54% of parents). Generally, this involved practical support (such as childcare), emotional support, and in a few cases, financial support.

Figure 6. Support accessed by children and their parents regarding education



Source: Contact Survey 2024 - Parent Experiences of SEND Education

Throughout the survey, parents praised the key role that some individuals and organisations had played in supporting them and/or their child, most notably:

- SENDIASS (47% of parents said they had accessed support)
- GP or other health professional (46%)
- SEND support group or forum (39%).

Charity organisations (e.g., Mencap, Action for Children, Contact) were also viewed as a lifeline to valuable advice and support by nearly a third (31%) of parents.

A total of 10% of parents said that they had not accessed support from any of the people or organisations listed regarding their child's education, highlighting the need for a more consistent approach to providing information and support to parents with children with SEND. One parent, who had not accessed any support, stated, for example: *'I wasn't aware of what support I could get and where to get it'* (Parent, Black African). Another parent said that they had given up trying to access support: *'I have always been ignored or palmed off when I have asked for support, so I now don't rely on anyone for support. I have given up asking anyone for anything and get on with things myself'* (Parent, White Irish).

There were some indications from the survey of differences in the support accessed by parents from different ethnic backgrounds, although it is important to note the small numbers of respondents in some ethnicity categories:

- White parents were more likely than parents from minority ethnic backgrounds (particularly Asian) to have accessed support from family and friends and from support groups or networks.
- Black parents were more likely than White and Asian parents to have accessed support from a religious group.
- Asian parents were less likely than White and Black parents to have accessed support from a GP or health professional, but they were more likely to have accessed private or paid-for support.

Parents commented on the people and organisations that had supported them, and the reasons they had found their support so valuable. These included adopting an empathetic approach with parents and young people and ensuring that parents felt they were not alone in navigating the SEND system. This contrasts with many of the parents' critical comments about how schools and LAs had treated them:

'[Autism charity] has always supported. One of their workers...he is excellent, always guided in the right direction, I still read through his emails before I write an email to school. It feels as if he understands exactly what's happening. I wish SEN teachers were on his level.' (Parent, Indian)

'I really appreciate the support from all the charitable organisations that support SEND parents. I have four children in total and have had to rely on these organisations for my first child who was born with multicomplex medical needs. They make you welcome, that you are not alone and do all they can to help.' (Parent, 'other' ethnic origin)

Parent-carer groups and forums, where parents can share experiences and learn from other parents with children who have SEND, as well as parent groups on social media, were praised as invaluable sources of support and guidance. As a result, a small number of parents reported that they now volunteer with other parents, sharing the knowledge and experience they have gained with parents who are new to the SEND system:

'As SEND parents we really are the experts and have a lot of knowledge without even realising it. To go through this experience with friendship and support of other parents who really do get it made a huge positive difference for me in my times of greatest need. With a little financial investment around setting up a SEND friendship support group, a huge amount of positive change can come about for all.' (Parent, White British)

Counselling was also seen as helpful for parents struggling with the emotional and practical challenges of having a child with SEND.

3.7.1 Support from Contact

Parents were explicitly asked about their experience of accessing support relating to their child's education from the charity Contact. Although the survey was primarily distributed through Contact's communication channels (e.g., newsletters, social media), only 29% of responding parents said that they had received any support relating to their child's education from Contact. In comparison, 67% had not accessed support on education from Contact (although it is worth noting that parents may have received support in other areas such as benefits).

Where parents had received support on education from Contact, nearly all (85%) of the parents rated the support as 'excellent' or 'good'. They praised both the information and resources they had accessed, as well as the direct support they had received from the London offices (through for example, workshops and groups with other parents). Parents expressed their gratitude at the invaluable support they had received from Contact, describing it as *'an anchor in a storm'*, and stating that *'Contact gave me hope, understanding and reassurance across a range of topics around my child's education.'*

The comments from parents provide an insight into the aspects of Contact's support that they found most useful, and it seems that they particularly appreciated:

- the knowledgeable, friendly and compassionate staff
- easy access to resources
- useful and relevant information and guidance
- the opportunity to meet other parents with children who have SEND.

3.8. What additional information and support do families need?

Both parents and Contact professionals were asked for their views on what information and support would be most helpful for families with a child with SEND. Some common themes emerged in how information and support services could be improved:

- **Clear and consistent information should be available to all families** – parents highlighted the need for information to be accessible in a consistent way for parents, either through an information booklet or guide, or a central website. This could include, for instance, information on their child's condition, the support available to them, and the process for accessing such support. This information should be available to all families, for example, through their child's school or GP surgery.

One parent called for '*an easy read document for what a SEN child is entitled to and how to ask for them as a parent*', while another recommended '*A booklet provided to all parents going through the EHCP process [which] clearly outlines the process, stages, timelines, contact info, etc. Not just a list of numerous websites where parents have to sift through endless amounts of information when they are already tired and overwhelmed. Parents need all the information in one place, where it's easy to access and refer back to.*'

There are a number of potential barriers to parents being able to access such information, including literacy and language skills and digital access. It is, therefore, crucial that such information is accessible to parents from different ethnic and demographic backgrounds and with differing levels of literacy and knowledge of the education and SEND systems. The language used should be simple, avoiding complex terminology or acronyms, and should be in a manageable, user-friendly format for parents to prevent confusion or overwhelm.

- **An advocacy service to support parents is needed.** Parents would welcome an advocacy service that supports them through the complex SEND process, ensuring they and their child access available support services. This could be in the form of a family support worker who supports the family on their journey, providing reassurance and dealing with the complex process of accessing support. While advocates are currently available, generally as a paid service, many parents are unable to afford this, and they feel strongly that this should be free to parents. The following comment is illustrative of the views of many parents:

'For a parent or carer with a SEND young person or child, you almost need someone to coordinate things for you. Because it's a full-time job trying to keep on top of everything. So having one key person to kind of signpost you and guide you through the process is going to be very reassuring.' (Parent, Mixed ethnicity)

- **Families need a holistic package of support** – Parents and professionals emphasised the importance of families receiving support across a range of areas. This includes information and advice on SEND processes and provision, support for parents' own mental health, support for siblings and respite for

parents, especially those from single-parent families. A few parents recommended Family Support Hubs as a valuable resource for accessing a package of support, as they allow parents to access information and guidance from a range of professionals and get signposted to other organisations:

'Having a support hub specifically for these families with these needs, for example, representatives from school once a month; open session for questions, queries etc; help with form completing...Advice hubs provide support for the local community in areas such as housing, Welfare, Immigration, benefits, and debt. Why not one for SEND support? (Parent, 'other' Asian background)

- **A range of support services need to be available** – It is essential that a variety of support services are offered to parents, allowing them to access support according to their individual preferences. Such services could include a telephone or email helpline, in-person or online workshops, and one-to-one or group support, such as coffee mornings or walk and talk sessions. Offering support services at different times of day also makes it accessible to as many parents as possible, including working parents.

The Contact professionals also highlighted the importance of support services for families being non-judgmental, sympathetic and understanding, and ensuring that organisations draw on the lived experience of parents when designing services so that they are accessible, relevant and useful for families.

3.9. What additional support do families from minority ethnic backgrounds need?

While most parents felt that support for SEND families should be universal, they acknowledged that some parents from minority ethnic backgrounds would require additional support.

Given the additional challenges and barriers faced by some parents from minority ethnic backgrounds (as discussed in Section 3.4), it is reasonable to expect that they might require extra support to access the SEND system and get education support for their child. This was explored with the 15 parents from minority ethnic backgrounds who took part in the in-depth interviews, as well as with the three Contact professionals interviewed. Recommendations for how parents from minority ethnic backgrounds could be better supported included the following:

- **Translation services** – Information and guidance materials should be translated, and translation services or interpreters should be available to help parents who have English as an additional language to fully access information and support services and communicate with professionals about their child's needs. One Contact professional also emphasised the importance of professionals communicating with parents with limited English proficiency in simple, plain language, without the use of acronyms or complex terminology.
- **Professionals should receive cultural competency training** – Due to cultural differences in attitudes towards SEND, some parents may require additional support to accept their child's diagnosis and access appropriate support. Professionals need to be aware, therefore, of how parents from different ethnic and religious backgrounds might perceive SEND. Learning about the various cultural norms, values, communication styles, and beliefs between community groups will also enable professionals to better understand the communities they are supporting and ensure that families have an equitable chance of accessing the support they need.
- **Support services should ideally have a diverse workforce that reflects the communities they aim to reach** – Not only can this help address any language barriers, but it can also foster a better rapport between parents and professionals, making parents feel that they have a *'safe space to talk.'*
- **Support services need to find creative ways of engaging with parents from different communities** – Given that families from some minority ethnic backgrounds are more reluctant to seek help and support, the Contact professionals noted the importance of trying a range of ways to engage them in support services. This can include partnering with local organisations and individuals *'that have the ear of the community you want to reach'* and attending community and religious events or places that families from minority ethnic groups frequent.
- **Parent support groups specifically for families from minority ethnic families** – these were viewed as safe spaces for parents to talk about the issues they were facing.

4. Conclusion

Year 2 of this research project aimed to explore the experiences of education for London families with children with SEND, and to examine the extent of any differences between ethnic groups.

The findings from both the survey of parents across London and the in-depth interviews with parents reveal that navigating the SEND system and trying to access education support for children with SEND is a complex, stressful and challenging journey for many parents. Most parents, irrespective of their ethnicity, have faced considerable challenges, including long delays, poor communication from professionals and a lack of information and support. This experience has had a detrimental impact on not only the children and young people who are missing out on crucial education support, but also their parents and families, as they have faced lengthy and exhausting battles to get the support their child is entitled to.

Although many of the barriers associated with the SEND system seem to be universal across families, there is evidence that racial and cultural factors can compound these challenges. Parents from minority ethnic backgrounds have faced additional challenges, primarily due to language barriers and cultural differences in attitudes towards SEND and challenging systems and professionals. It is clear that these parents require extra support to help them navigate the SEND system. Most worryingly, some parents reported experiencing racial discrimination or bias, targeted at either them or their children. There is urgent work to be done by schools, LAs and other professionals to ensure that their services and provision are culturally appropriate and provide a more equal playing field for children and families from different ethnic backgrounds.

Despite the considerable challenges in accessing education support reported by most parents, a minority of families reported more positive experiences and spoke highly of the education support that their child was receiving. They emphasised the significant role of their child's educational setting and specific individuals in supporting the early diagnosis of children and praised the good communication provided by caring and knowledgeable staff. This highlights the importance of early intervention, as well as specialist SEND training for education professionals to ensure high-quality, inclusive provision is available for all children and young people. Further research is needed which provides evidence of good inclusive practice, particularly in mainstream schools.

It is clear that reform of the SEND system is required to ensure that children and young people with additional needs can access the education support they are entitled to. The current government is undertaking efforts to address the SEND crisis, including a curriculum review and increased funding for SEND provision. Policymakers, LAs, schools, and other professionals have a shared responsibility to review their current practices and contribute to driving improvements in inclusivity and outcomes for all children with SEND.

This research also demonstrates a clear need for improved advice, guidance and support for the parents of children and young people with SEND. Parents report being emotionally and physically drained, feeling alone, and having limited support available to them. This highlights the importance of parents not only having support to navigate the complex education system (such as advocacy or clear guidance documents) but also support around the issues that arise *as a result* of the problems with the system (such as counselling or family support groups). It is essential that policymakers and support services carefully consider the most effective ways to provide clear and consistent information and guidance to parents and to empower them to access the support they need. This is particularly important for parents from marginalised minority ethnic backgrounds, who may

experience additional barriers to accessing the support that they and their child need. Workforce development related to SEND is a critical element of the necessary SEND reforms to improve practitioners' knowledge of SEND. Cultural competency training should be a key feature of this development. This will help ensure that access to education support and information and guidance is as equitable as possible for all families, ultimately leading to improved outcomes for all children and young people with SEND.

4.1 Next steps for Contact research

Year 3 of this research project will further explore how families can be better supported and identify the actions that policymakers and practitioners should take to enhance their support and help families overcome barriers to accessing SEND support. While the Project Group has not yet agreed upon the methodology for Year 3, we intend to focus more on racially minoritised and marginalised families to explore what specific support they need. This is likely to include face-to-face interviews or small focus groups with parents from different ethnic communities that Contact works with, and interviews with professionals supporting these families. We would also like to focus Year 3 of the research on mainstream school provision and seek further examples of good practice in provision for children and young people with SEND in order to develop recommendations for policymakers and practitioners.

Appendix 1: Research Questions

Over-arching research questions:

- What are the experiences of education for London families with children with special educational needs and disabilities (SEND) (aged 5-18 years) from black and ethnic minority groups?
- Specifically, what are parents' experiences of identification/diagnosis of SEND, participation in decision making, the EHCP process, SEND appeal/Tribunal process, their children receiving the support they need/are entitled to, and support for transition between different phases of education?
- To what extent are there differences in the experiences of education for London families from different ethnic groups? What are the factors affecting this?

Specific research questions:

- To what extent are children with SEND from black and ethnic minority groups receiving the support they need/are entitled to? What are the factors facilitating/hindering this?
- To what extent are families with children with SEND from black and minority ethnic groups facing barriers in accessing appropriate support? What are these barriers, and how can they be overcome?
- To what extent are barriers impacting some ethnic groups more than others? What are the factors affecting this?
- What does high-quality SEND provision/support look like for families? What factors do parents feel should be in place?
- What support around education and learning have London parents found helpful for their children (e.g., from local authorities, schools, community organisations and charities)? What further support would families find helpful?
- What are London families' experiences of the support provided by Contact and what areas for improvement would they recommend?
- How can statutory services/policy makers and community organisations/charities improve their support and help families to overcome barriers to accessing SEND support?

Appendix 2: Parent and Child Characteristics – Survey

A total of 412 parents/carers took part in the survey. The key characteristics of the responding parents and their children are outlined below:

Location of respondents

- Families from across the whole of London are represented in this survey, with at least one parent response from each of the London boroughs.
- Responses were most common in the boroughs where Contact have offices - 19% of parents were from Ealing, 10% from Lewisham and 6% from Lambeth.

Ethnicity

- 50% of parents/carers described themselves as White, with White British the most common ethnicity (36%).
- 43% of parents were from a non-White background:
 - 24% described themselves as Black or from a Mixed White and Black background
 - 15% described themselves as Asian or from a Mixed White and Asian background.
 - A further 4% were from an 'other' ethnic group.
- 85% of parents/carers indicated that their primary language is English.

Children's characteristics

- 70% of responding parents had only one child with SEND, however, 22% had 2 children, and 8% of parents had 3 or more children with an additional need. Where parents had more than one child with a special educational need or disability, they were asked to answer the survey questions in relation to their eldest child (aged 5-19).
- The age of the children reported about in this survey ranged from 4-19 years, with a mean age of 11 years. There was a roughly even split of parents with children of primary school age (48%) and secondary school age (45%).
- 42% of parents reported that their child attends a mainstream school, while 33% had a child at a special school. Fifteen parents (4%) reported that their child was not currently in any form of education, or they were waiting for a school space.

Children's primary area of need

- 61% of parents indicated that their child's primary area of need was Autism/Autistic Spectrum Disorder, while 10% reported social, emotional and mental health difficulties as their child's main need.
- Three-quarters of parents/carers indicated that their child either has an EHC plan (70%) or is currently being assessed for an EHC plan (5%). A further 10% were receiving SEN support. Five per cent of parents reported that their child was not receiving any support, most commonly because they were waiting for an assessment, or their child's needs were not recognised by their school. There was little difference by ethnicity in the support the children were reportedly receiving, parents from Asian backgrounds were slightly less likely than White or Black parents to report that their child has an EHCP or is being assessed for one (70% of Asian parents, compared with 77% of White and Black parents).

Appendix 3: Survey Findings

Table 1. Which London borough do you and your family currently live in?

	Response %	Response N
Ealing	19%	78
Lewisham	10%	39
Wandsworth	7%	29
Hillingdon	6%	25
Lambeth	6%	23
Greenwich	5%	19
Brent	4%	15
Croydon	3%	14
Islington	4%	15
Barnet	3%	12
Bexley	3%	12
Bromley	3%	11
Hackney	2%	10
Haringey	2%	10
Harrow	2%	10
Hounslow	2%	9
Redbridge	2%	7
Enfield	2%	7
Havering	2%	7
Merton	2%	7
Southwark	2%	7
Sutton	2%	7
Barking and Dagenham	1%	5
Waltham Forest	1%	5
Hammersmith & Fulham	1%	4
Kingston-upon-Thames	1%	4
Richmond-upon-Thames	1%	4
Camden	1%	3
City of London	1%	3
Westminster	1%	3
Newham	<1%	2
Tower Hamlets	<1%	2
Royal Borough of Kensington and Chelsea	<1%	1
Other	<1%	1
Prefer not to say	0%	0
Total=		410
No response		2

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 2. How would you describe your ethnicity?

	Response %	Response N
White		
White: English/Scottish/Welsh/Northern Irish/British	36%	148
White: Irish	3%	10
White: Gypsy or Irish Traveller	<1%	1
White: Roma	0%	0
White: Any other White background	11%	46
Black/Mixed White & Black		
Black / African / Caribbean / Black UK: African	11%	44
Black / African / Caribbean / Black UK: Caribbean	7%	28
Black/African/Caribbean/Black UK: Any other background	2%	9
Mixed/multiple ethnicity: White & Black African	2%	7
Mixed/multiple ethnicity: White & Black Caribbean	3%	10
Asian/Mixed White & Asian		
Asian / Asian UK: Bangladeshi	<1%	1
Asian / Asian UK: Chinese	2%	6
Asian / Asian UK: Indian	7%	27
Asian / Asian UK: Pakistani	2%	6
Asian / Asian UK: Any other Asian background	4%	15
Mixed/multiple ethnicity: White & Asian	1%	5
Other Ethnic Origin		
Mixed/multiple ethnicity: Any other origin	1%	6
Other ethnic group: Arab	2%	7
Any other ethnic origin	1%	4
Prefer not to answer	7%	28
Total=		408
No response		4

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 3. What year group is your child in?

	Response %	Response N
Reception	6%	25
Year 1	6%	23
Year 2	6%	26
Year 3	5%	20
Year 4	7%	28
Year 5	9%	38
Year 6	9%	36
Year 7	10%	42
Year 8	6%	25
Year 9	4%	18
Year 10	8%	34
Year 11	9%	37
Year 12	4%	15
Year 13	3%	11
Other	6%	23
I don't know	2%	7
Total=		408
No response		4

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 4. How many children do you have with a special educational need or disability?

	Response %	Response N
1	70%	289
2	22%	89
3	5%	22
More than 3	3%	11
Total=		411
No response		1

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 5. What type of educational setting does your child attend?

	Response %	Response N
Mainstream primary or secondary school	42%	171
Special primary or secondary school	33%	135
Further education or sixth-form college	6%	24
Alternative provision or pupil referral unit	2%	10
Education otherwise than at school (EOTAS)	2%	8
Elective home education	1%	5
I don't know	1%	5
Other*	12%	51
Total=		409
No response		3

Source: Contact Survey 2024 - Parent Experiences of SEND Education

*Where respondents indicated that their child was in an 'other' educational setting, the most common responses were an Additional Resource Unit and an independent school.

Table 6. What is your child's primary area of need?

	Response %	Response N
Autism/Autistic Spectrum Disorder	61%	247
Social, Emotional and Mental Health	10%	41
Severe Learning Difficulty	7%	27
Speech, Language and Communications needs	5%	20
Other	4%	17
Specific Learning Difficulty	3%	13
Moderate Learning Difficulty	3%	14
Profound & Multiple Learning Difficulty	3%	11
Physical Disability	2%	8
I don't know	1%	4
Visual Impairment	1%	3
Hearing Impairment	<1%	2
Multi-Sensory Impairment	0%	0
Total=		407
No response		5

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 7. What level of support is your child currently receiving in education?

	Response %	Response N
SEN support	10%	42
My child has an EHC plan	70%	287
My child is currently being assessed for an EHC plan	5%	19
My child is not receiving any support	5%	21
I don't know	1%	3
Other	9%	38
Total=		410
No response		2

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 8. How easy or difficult have you found it to access education support for your child?

	Response %	Response N
Very easy	3%	12
Easy	11%	43
Neither easy nor difficult	16%	66
Difficult	33%	136
Very difficult	37%	149
Total=		412
No response		6

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 9. How satisfied are you with the education support your child is currently receiving?

	Response %	Response N
Very satisfied	15%	57
Satisfied	29%	108
Neutral	19%	71
Dissatisfied	20%	76
Very dissatisfied	17%	65
Total=		377
No response		35

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 10. How easy have you found the following:

	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Not applicable	Response Total
Getting your child referred to be assessed by a professional such as Educational Psychologist or Speech and Language Therapist?	5%	14%	18%	20%	41%	3%	377
Starting the process of getting support for your child (SEN support or EHC plan)?	6%	13%	20%	25%	35%	2%	376
Agreeing on what support your child needs?	3%	16%	23%	26%	32%	1%	373

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 11. How satisfied have you been with your experience of getting an EHC plan for your child?

	Response %	Response N
Very satisfied	11%	30
Satisfied	25%	67
Neutral	22%	60
Dissatisfied	20%	55
Very dissatisfied	22%	61
Total=		273

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 12. What are your views on the information you have received about your child's education?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Response Total
I have been given enough information about my child's special educational needs or disability	10%	34%	22%	22%	13%	377
I have been given enough information about the education support my child is entitled to	6%	24%	20%	27%	23%	377
I have been given enough information about how to access education support for my child	5%	20%	24%	28%	23%	377

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 13. What are your views on the education support your child is receiving?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable	Response Total
I feel I am listened to, and I can take part in decisions made about my child's education	8%	33%	20%	17%	21%	1%	377
My child has been able to get the help and support they need	8%	25%	23%	21%	23%	1%	376
I know who to ask if I need help and support with my child's education	10%	41%	17%	15%	16%	1%	375
I feel well supported by my child's school/educational setting	17%	31%	19%	13%	18%	2%	378

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 14. Have you experienced any of the following:

	Yes	No	Don't know	Response Total
School/educational setting refusing to refer your child to external professionals to be assessed for a specific diagnosis?	36%	55%	9%	359
School/educational setting not agreeing with a diagnosis given to your child by a professional?	18%	70%	12%	357
School/educational setting not putting in place the support your child is entitled to?	51%	38%	11%	357
Difficulty getting a place at your school of choice?	44%	45%	10%	357
Your child being suspended or excluded from school?	21%	76%	3%	356

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 15. How confident do you feel about raising concerns with your child's school or Local Authority about the education support your child is receiving?

	Response %	Response N
Extremely confident	14%	49
Very confident	19%	66
Somewhat confident	24%	85
Not so confident	23%	81
Not at all confident	20%	72
Total=		353
No response		59

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 16. Have you submitted an appeal to the SEND Tribunal regarding your child's education support?

	Response %	Response N
Yes	24%	85
No	74%	261
I don't know	2%	7
Total=		353
No response		59

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 17. Do you know how to submit an appeal to the SEND Tribunal?

	Response %	Response N
Yes	41%	145
No	59%	208
Total=		353
No response		59

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 18. Have you or your child accessed support from any of the following people or organisations regarding your child's education?

	Response %	Response N
Family/friends	54%	190
SENDIASS	47%	163
GP, health visitor or other health professional	46%	162
Support group/forum or network	39%	136
Private/paid-for support	33%	114
Charity organisation	31%	109
Social media platform	26%	92
Family support worker/group or social worker	25%	88
Children's Centre	13%	45
Religious or community group	9%	32
Other	13%	44
None of the above	10%	34
Total=		350
No response		62

More than one answer could be given, so percentages do not total 100%

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 19. Have you received any support relating to your child's education from Contact?

	Response %	Response N
Yes	29%	102
No	67%	236
I don't know	3%	12
Total=		350
No response		62

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Table 20. How would you rate the quality of education support provided by Contact?

	Response %	Response N
Excellent	25%	70
Good	10%	29
Fair	4%	11
Poor	1%	2
Very poor	2%	5
Not applicable/I have not received support from Contact	59%	165
Total=		282

Source: Contact Survey 2024 - Parent Experiences of SEND Education

Appendix 4: Parent and Child Characteristics – In-depth Interviews

	N
Relationship to child	
Mother	14
Father	1
N=	15
Ethnicity	
Asian/mixed Asian	5
Black	8
Arab	1
Mixed	1
N=	15
London Borough	
Barnet	1
Bexley	1
Bromley	1
Ealing	1
Greenwich	2
Hammersmith	1
Hillingdon	1
Islington	1
Merton	2
Redbridge	1
Southwark	1
Wandsworth	2
N=	15
Child's stage of education	
Primary	7
Secondary	6
Further education	2
N=	15
Child's primary area of need	
Autism/Autistic Spectrum Disorder	7
Moderate Learning Difficulty	3
Speech, Language and Communications needs	2
Specific Learning Difficulty	1
Social, Emotional and Mental Health	1
Profound & Multiple Learning Difficulty	1
N=	15
Educational setting attended by child	
Mainstream primary or secondary school	7
Special primary or secondary school	5
Further education/sixth form college	3
N=	15

Level of support received by child	
SEN support	2
EHCP	12
Being assessed for EHCP	1
N=	15

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For more information about the support available to families of children with SEND, please visit Contact's website: www.contact.org.uk