



Disabled
Children's
Partnership

Support not Suspicion

Social Care, Ethnicity, Disabled Children and Their Families

Research by the Learning Hub at the Disabled Children's Partnership

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1. Executive Summary

1.1 Introduction

The system of support disabled children and their families rely on reaches across a range of health, social care and education services. The independent review of children's social care acknowledged that disabled children's needs differ from other children supported by social care and require specific consideration¹. The law on disabled children's social care in England is based on a number of separate pieces of legislation, some dating back to the 1970s, meaning that families with disabled children find themselves at the heart of a complicated system when accessing support from services.

The Law Commission's review of the legal framework for disabled children's social care aims to simplify and strengthen the law, ensuring the system is fairer and works better for disabled children and their families². All disabled children are classed as children in need as defined in the Children's Act 1989³, meaning they are entitled to an assessment of their needs by social care services. However, our previous research has found that parents are frequently told that their child does not meet the threshold for the assessment that they are entitled to.

Those that do receive assessments report a complex process, with workforce issues such as staff turnover and availability of care staff causing delays in getting provision in place, leaving families under unnecessary strain and pressure providing care for their disabled child. Providing disabled children and their families with appropriate support so that they can access the same life opportunities as their peers is overlooked by the current system. Spending on safeguarding children and young people and children in care has increased since 2009/10, whilst spending on other services has declined⁴, illustrating a system

dominated by a child protection and safeguarding lens. Lack of support leaves disabled children vulnerable and at risk of severe isolation with reduced life outcomes.

The Disabled Children's Partnership is a coalition of over 120 organisations that campaigns for improved support services for disabled children, young people and their families. During the pandemic our research revealed the impact that the lack of support had on disabled children and their families. In addition, disabled children from black and Asian ethnic minority groups experienced higher levels of isolation, anxiety and poor mental health than their white peer groups.

1.2 Overview

In this research, we looked at the experiences of families from black and Asian minority ethnic backgrounds with disabled children in accessing social care services. Our literature review showed that this was an under researched area. Through our research, we found that – in common with other families with disabled children – they face significant barriers accessing the support they need, due to high thresholds, a lack of services, poor understanding of their needs and a system focused on protection rather than support. However, families from black and Asian minority ethnic backgrounds faced significant additional barriers due to their ethnicity. This report covers our literature review and interviews with families; an analysis of social care data will be reported separately

1.3 Aims and Objectives

The aim of this project was to better understand the social care support needs of families with disabled children from black, Asian and minority ethnic backgrounds and, in particular, to examine

the social care support needs that may be unique to this group of families. Intersectionality refers to a range of connecting social categories that create a unique set of experiences for an individual. For example, in this project people from different ethnic backgrounds may have different experiences of social care based on their gender or social economic status.

This project is co-produced by parents of disabled children who also worked as parent-researchers, interviewing other parents or carers of disabled children. The ethnic backgrounds of parents or carers participating in the project were Asian British Pakistani, Asian British Bangladeshi, Asian British Chinese, Asian British Other, Black British African, Black British Caribbean, Mixed White /Asian and Mixed White/Black. Throughout the report we will refer to the group as black, Asian and mixed ethnic minority.

Co-production included the project concept & design, with parent carers of disabled children and young people from black, Asian and minority ethnic backgrounds in conjunction with staff from DCP organisations, either with lived experience or responsibility for working with diverse groups.

This project includes three phases drawing on mixed methodology.

- Phase One – Literature Review
- Phase Two – Primary Qualitative Research (Interviews)
- Phase Three – Review of social care data

This report provides the findings from phase one and two of the project.

1.4 Findings

1.4.1 Phase One

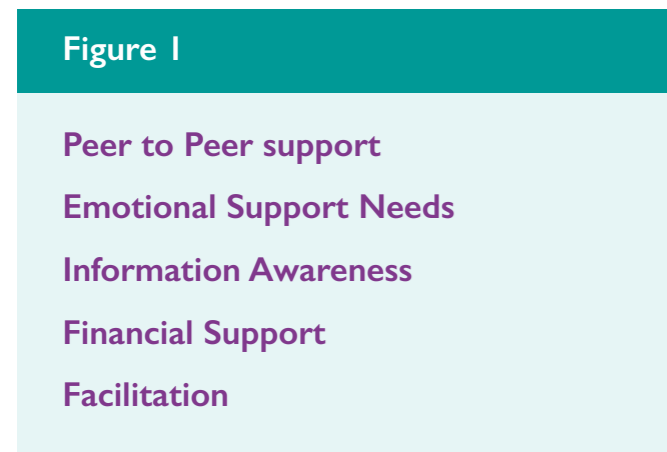
The literature was reviewed to understand what is already known about formal social care support needs and informal support needs of families with disabled children from black and Asian minority ethnic groups in the UK. Articles were included if they considered the whole family or individual family members: disabled children or young or young people aged 0-25 years, siblings or parent carers. The timeframe for articles included was 2007 to 2023, to account for 'Aiming High for Disabled Children' Government Policy⁵. Articles were excluded if they did not cover all three aspects of intersectionality: disability, ethnicity and children.

Search criteria was defined by parent-researchers with lived experience of social care. It included support within the home such as personal care or equipment needs and when out and about, such as transport or a personal assistant. A full list of search terms can be found in Appendix 2. 1026 articles titles and abstracts were screened, with fifteen articles meeting our search parameters. As expected, selected articles included a range of methodologies. Eight studies were qualitative, three used mixed methods, three were quantitative studies and one was a literature review. The majority of articles (nine) focused on parents or carers of disabled children. Disabled children or young people were the focus of four articles. Two articles included all family members and siblings were only covered as part of the whole family, rather than as a stand-alone focus.

The review confirmed the dominance of research studies conducted from a child protection, domestic violence or care system lens, as opposed to a position of supporting a disabled child and their

family to thrive and flourish. A high proportion of descriptive studies were retrieved that referred to disabled children within the children in need category. However, as there was no further exploration of disabled children needs as part of the children in need group, these studies were excluded. Greater emphasis appeared in the literature about children who may be in care, or families known to the criminal justice or asylum system. For example, support needs would be discussed in relation to mental health support due to trauma such as domestic violence or abuse as opposed to disability. It was also common to find studies that looked individually at either ethnicity, disability or children and young people rather than all three aspects of intersectionality or studies that reported these categories for descriptive purposes only, rather than exploring needs of this group of families.

Social care needs of families with disabled children from black, Asian and mixed ethnic minority groups are grouped into five key areas, illustrated in figure 1.



Families welcomed opportunities to meet other parents of disabled children from the same ethnicity, culture or religion to explore understanding of disabilities and conflicts between cultural and biomedical beliefs.

Parents valued support with understanding disability and around the impact on interpersonal relationships. Mental health support that was

empowering, such as providing coping resources rather than just symptom management of poor mental health was highlighted as a need for all family members.

Parents benefit from awareness raising sessions about disability and support available. A collaborative approach with community religious, cultural groups and charities for parents, wider family and community members may facilitate improved informal support.

Families need state support even when wider support may be available from family. Information and awareness sessions above should promote knowledge of grants and benefits, to ensure families know what benefits and financial support may be available.

Facilitation for tasks that depend on administration or communication, will provide support to families to identify and secure support and provision. There was also evidence of provision being used long term by families who were supported to identify and locate short break services in this way.

1.4.2 Phase Two

Twenty-three interviews were conducted by parent-researchers online with parents or carers of disabled children and young people (0 to 25 years) from black, Asian and mixed ethnicity, living in England. All families taking part in the interviews had social care needs. However, the type of social care support varied significantly across the group, ranging from families who had been denied social care to those with social care support in place.

Findings have been summarised into three key areas relating to the types of needs: needs from the social care process; practical needs of the family and informal needs from the community (eg parent groups, religious or cultural organisations and school). In this report, findings for each key area are presented in relation to more general social care needs applicable to all families with disabled

children from any ethnic background, with needs unique to families from black, Asian or mixed ethnic minority highlighted were applicable, in line with the intersectional nature of this project.

1.4.3 Social Care Process

Parents reported an information vacuum regarding social care support for their disabled child and family, from identifying need to securing provision. The current process is a complex system, often fracturing into sub-processes with arbitrary criteria applied. Parents describe informal processes for assessment being used outside of the formal system, with parents' expertise and knowledge often sidelined for the views of professionals.

“Without even assessing anything, even seeing your children, you’ve done that 6-7 week course out of your time, and then I’ve got a letter to say ‘oh, thank you, you’ve completed the course’, ‘we’ve closed their case’, ‘you can always do another referral, and it will be fast tracked’. It doesn’t matter if it’s fast tracked, there’s still a processing time...”

Parents need a process that is transparent in terms of the means to apply for support and the means of securing support once approved. The process should have a comprehensive, holistic family focus rather than just addressing the needs of one family member from a particular individual service eg, home adaptation, overnight care or transport. Partnership between social care professionals and parents is key to ensuring needs are understood accurately and planned for:

“I’ve learned so much from her (social worker), because she kind of held me along, as she was doing her job... She helped; I feel like she helped me be a better parent for my son, especially as it comes to advocacy for him, and having a voice”.

Families who do receive approval for social care support describe the difficulties securing provision, with workforce issues such as staff turnover and

lack of specialist staff, location, time and accessibility of venues, and provision not meeting needs of their disabled children or other family needs within or beyond the home. This results in families not being able to take up provision offered.

“I ended up with a young man but he had no real training in communication from what I could see. Didn’t seem to know anything about Makaton, or signing, that kind of thing”.

It was common for parents to talk about the lack of awareness of disability amongst family members and the wider cultural community. Findings suggest a lack of a reference point for parents of a disabled child and therefore families may delay seeking support or find navigating the system more challenging, due to starting from a point of greater social isolation.

“I just think that there might be an assumption that because, she was British (social worker), and she has family and she has friends, I think it’s very difficult, it was very difficult for her to understand my needs, to really understand that I am completely alone. That I don’t have the roots that she has”.

Parents also describe experiences of microaggressions, interactions based on cultural stereotypes and instances of racism at various stages of the assessment, approval and provision of social care.

“What type of marriage did me and my husband have? And I was thinking, ‘that’s not a question you would ask a white couple’. That clearly was asked because I’m South Asian or because I’m Muslim, I’m not sure what the reason was. But clearly that’s not a question you would ask other couples”.

In addition, such experiences in wider society, has a layering effect on parents' confidence and ability to engage with services when needing support. It is vital the social care process accounts for this when



designing support for families with disabled children from black, Asian and mixed ethnic minority groups.

“When we’re out together just the two of us (parent and daughter), I have to think about how it affects my child. I have to think about her disability and how other people are thinking of her in terms of her race. There’s so many things that I have to think about and act on. I think it would have been helpful if, within social services, we could have gotten more diverse support”.

Families need a support system that is adaptable to the changing needs of the child and the family. Families deserve a specialist trained workforce that understands how disability translates into particular needs, in accessible environments and with approaches that are inclusive and are culturally sensitive. Families should be aware of how to report negative experiences from the process, either anonymously or identified, when they experience covert or overt racism during interactions with staff. Processes should be in place for redress by families, without the fear that raising concerns will negatively impact on future provision of social care support.

1.4.4 Practical Needs of the Family

Good social care provision has the potential to flow into all aspects of a disabled child and their family’s life. Support within the home, with adaptations such as hoists and carers with “new energy” to help, for example with personal care, means that parents’ physical health remains good. This can enable the whole family to enjoy more quality time together, as well as giving parents the option to work.

Whether it’s provision within the home or outside of the home, families need to have confidence that their disabled child and their siblings are safe and secure. A disabled young person’s, siblings’ or parents’ voices and expertise needs to be central when arranging how care needs are met.

“I remember one carer one morning he was leaving, and he goes ‘oh, I’m going to another

job now’ and I was horrified, because I thought, ‘you’ve just been here all night looking after my son, you’re going to look after somebody else’s loved one, what capacity have you got to do that safely’?”

Due to an increased risk of social isolation, parents from black, Asian and mixed ethnic minority groups may need to be supported in the early parts of engagement with services, in order for confidence and trust to grow. Choice is crucial when planning support that is offered for this group of families. A one size fits all generalised provision involving a group may not be in the best interests of the whole family. One to one interaction with other parents of disabled children may be more appropriate, offering time needed for family adjustment to disability.

“Once people sit down, and think about every person’s situation and use not a standardised blanket application, but just say, just look at this family as an entity by itself and what their challenges are, and genuinely think about helping them and providing the support that would be helpful”.

However, families choosing to take up group provision need to be confident that professional carers have a good understanding of disability and associated needs, such as medical, communication and sensory needs. Parents need connection and enjoy the opportunity to reciprocate advice and support to others. Understanding families’ needs on an individual basis ensures those that want to access support from others from the same cultural background, and those that prefer provision based around their disabled child’s care needs or diagnosis or other family factors have that choice.

It just didn’t feel like they got it, in terms of what she needed her activities for. My non-disabled daughter who is 16, doesn’t have to answer to anyone and she can go and do what she likes – so why should my daughter be forced to choose an activity simply because you know it is or isn’t on the plan.

Families need accessible information about disability, support services and financial support available, both in terms of benefits and charitable grants. As there may be the lack of cultural reference points about disability for some parents from black, Asian and mixed minority ethnic groups, some families may need administrative or communication support in order to access information, apply for benefits or grants and complete paperwork needed to advertise or secure support from carer providers.

Approaches aiming to meet disabled children and their families' needs should incorporate choice and individualised preferences, including time for confidence in services to be developed and adjustment to disability and its impact on interpersonal roles within and beyond the family. A support system that meets families' needs builds parent's confidence, giving them the chance to be advocates for others. Disabled children and young people gain confidence away from their family with a wider social network and siblings also gain time with their own peer groups. Time with family becomes about being with family rather than planning or navigating the world of support systems.

1.4.5 Community Needs

Parents report a lack of disability awareness in wider society, including from various social groups that results in a reduction in the availability of informal support. This increases their isolation from peers and the non-disabled community. Negative attitudes associated with a lack of understanding, stigma or prejudice were reported by parents in relation to their ethnicity, their child's disability and their parenting ability.

There were positive reports from parents when religious, cultural or community organisations established groups or sessions where they could either meet other parents with disabled children, other members of the non-disabled community or peers from the same ethnic, religious or cultural background. However, there was also evidence of such events being dependent on the knowledge,

education and training of community members.

I thought, I can't be the only Muslim Asian parent who's got a child with special needs, who's struggling, who'd like to meet other parents who understand our cultural and faith nuances that other people may not understand. The first time they did the coffee morning, 21 women came. So it just goes to show how much of a need there is for community centres, faith centres, to have that provision.

Parents would benefit from a collaborative approach between the disability community and religious and cultural organisations in three ways. Firstly, providing support to parents of disabled children who would like it, secondly providing awareness sessions and training to non-disabled members of the community and thirdly exploring adjustments so that families with disabled children can continue to engage in chosen spiritual or religious practices.

Although parents wanted connection with other families with disabled children, it didn't always have to be the common focus. Parents talked about the benefits of groups without a disability focus, such as groups based on gender, ethnicity, religion, social or political events or hobbies.

I was going through very low mood in the beginning of this year, and I had to actually up my antidepressants, I was really struggling, and the only thing we had in common (at a group) was that we were all black females. Attending that really, really did help because I hadn't spoken to so many black women.

Wider acceptance and attitudinal work across key communities would benefit families with disabled children to pursue connections with others around aspects of their identity, including and beyond

disability or ethnicity. This has the potential to reduce levels of isolation along with poor physical and mental health, currently common in this group of families.

1.5. What Is Required?

Disabled children and their families need a social care system designed around support needs rather than inspection. A support system that promotes parent and professional partnership at the heart of the process, will more appropriately meet the needs of disabled children and their families.

Parents need a transparent social care system, right through from information and awareness to the type of support provided, moving from a crisis led model towards early intervention. The system should be comprehensive in assessing the holistic needs of the family and adaptable to the changing needs in the long term rather than short term fixes. It is vital that assessments incorporate the intersectional needs of the individual, not just regarding disability and ethnicity but needs that arise due to gender, socio-economic status, education, language and residential status.

Investment is needed to ensure the social care workforce for disabled children have the knowledge, training and expertise so that families are confident their children will be safe and secure, supported by teams who understand the aspiration of their disabled children.

Local authority commissioning of social care provision needs to offer disabled children from black, Asian and mixed ethnic minority groups choice in the type of support available. Support that acknowledges needs from severe social isolation, varied cultural reference points of disability and provides safe spaces for parents to adjust to their child's diagnosis, develop confidence and advocacy skills and receive emotional support, if they so wish.

Collaboration between the disability charitable sector; non-disabled organisations and religious and spiritual associations, would offer greater understanding and inclusion of families with disabled children, encouraging belonging and reducing isolation.

Narratives of children's social care that reduce disabled children and their families to passive recipients, needing help with basic needs such as washing or dressing, must be replaced with an aspirational system of support. One in which disabled children and their families are viewed as valued members of society, with access to a support system that wants them to flourish, thrive and enjoy the same life opportunities as their peers.

1.6. Recommendations

Local authorities should

- Review their services and processes, and the information and guidance they provide about them, to ensure they meet the specific needs of families with disabled children from black and Asian minority ethnic backgrounds.

- Monitor the impact of their support on children and families, with a focus on intersectionality and the voice of children and families.

- Work with the voluntary sector and community groups to develop capacity, improve understanding of disability, and overcome isolation.

The Department for Education should

- Ensure a specific focus on support for families with disabled children from black and Asian minority ethnic backgrounds in its Families First For Children pathfinders.

- Monitor and evaluate the impact of its reform programme on families with disabled children from black and Asian minority ethnic backgrounds.

2. Background

The social care support disabled children and their families should receive from statutory services is underpinned by a mixture of legislation. Defined as a child in need by the Children's Act 1989³, the support they are entitled within and beyond the home is outlined in the Chronically Sick and Disabled Person's Act 1970⁶. Local authorities are obliged to assess the support needs of parent carers and disabled children's siblings (young carers) by duties within the Children and Families Act⁷, 2014 and Care Act 2014⁸ respectively.

Social care support that disabled children and their families could need may include support at home such as washing, dressing and eating; short breaks services such as sitting activities in the home or activities in the local community; assistance with travel and help with equipment and adaptations. Good social care support has the potential to yield benefits in all aspects of a disabled child and their families' life. For example, good overnight support in the home for children who need it, may ensure families are rested and children able to attend school. Support out and about in the community enables disabled children to develop life skills, have fun attending activities and provide them with opportunities to make friendships and take part in hobbies that their non-disabled peers may take for granted.

However, our previous research has revealed the impact that the lack of support has on disabled children and their families (DCP, 2021⁹). During the pandemic our research found families of disabled children experienced greater levels of poor mental health, stress, anxiety and social isolation than the general population. Despite being defined as a child in need and entitled to a social care assessment, our previous research (DCP, 2023¹⁰) found that one in four parents of a disabled child have been told that their child does not meet the threshold for a social care assessment. Those that have been fortunate

to have an assessment and approved for social care face delays and challenges getting and keeping that support in place.

For example:

- 7 in 10 parents of disabled children reported delays in getting a personal assistant for their child due to workforce issues.
- Half of families were facing delays in assessments for support for household tasks, equipment or adaptations.
- 2 in 5 faced delays accessing short breaks.
- Just 1 in 7 parents said that they had the right amount of support in place from social care.

This pattern was repeated during our research directly with disabled children and young people aged 11-25 years (DCP, 2024¹¹). Just one in five disabled young people reported that they had the right amount of support from social care staff at home and the same proportion felt listened to by social care staff. Starkly, just one in ten young people felt that their parents got the right level of support from social care.

Families of disabled children report that one size fits all assessments by social workers are overly intrusive and not tailored to the needs of families¹². Families find themselves scrutinised rather than supported, within the social care framework for children that is dominated by a safeguarding and child protection focus. Many families are only able to access support when they reach crisis point. Although the Government's social care implementation strategy¹² recommends early help for families, a distinct focus on disabled children and their families is needed as the plans move forward. However, the most recent data shows that one in five children's social work posts are vacant in England¹³.

In 2023, we undertook research with families



of disabled children from black and Asian ethnic minority groups¹⁴. During the pandemic our surveys with parents of disabled children found that parents from black and Asian ethnic minority groups experienced higher levels of isolation, anxiety and poor mental health than their white peer groups. During focus groups families told us about their experiences of social care provided through the lens of safeguarding, rather than support. Families also highlighted that it was common for services to assume that support would be available via their own families or ethnic, religious or cultural communities, due to racial stereotypes. Therefore, support needs were missed and unmet with the assumption that informal care would be in place.

The intersectionality of disability and ethnicity is not a new concept, with the experience of disablism and racism referred to as double exclusion or simultaneous oppression as early as the late 1990s¹⁵. However, the Covid-19 pandemic exposed systemic inequalities, shining a light on racial inequalities across all parts of society.

A study reviewing the characteristics of child deaths, 0-17 years, from Covid-19 in England, reported a higher rate of Covid-19 positive deaths for children from ethnic minority groups than those from white populations¹⁶. Wider studies investigating co-existing conditions within ethnic minorities and Covid-19 risk could not fully explain inequalities in infection and mortality. Social determinants of health such as socio-economic status, employment, housing and access to health services were important factors¹⁷ pointing to systemic racial inequalities.

Although more recent interest in health inequalities has focused on outcomes for ethnic minority groups, there is less information available specifically about young people from these groups¹⁸. The support disabled children in education should receive is outlined in a legal document called an Educational, Health and Care Plan (EHCP). However, ethnicity data collection is not consistent. As recently as 2023 data shows that 8.1% of children with EHCPs are Asian, 5.8% are Black and 5.9% are from mixed

ethnic groups. However, data shows that the ethnicity of children with EHCPs is not known for 1 in 10 children¹⁹. For families seeking redress via the tribunal, their ethnicity is not collated, making it difficult to review trends by ethnicity or gaps in support for disabled children²⁰.

It is known, however, that black children are more likely to be identified as having special needs, but they are less likely to get the support they need²¹, with behaviour rather than disability the focus when considering their needs in education. More children and young people from ethnic minority background experience suicidal thoughts, self-harm and anxiety than those from white backgrounds²². It is also known that families from ethnic minority groups face barriers to accessing services and financial support available to them²³.

Barriers for ethnic minority groups, who may need support, are attributed to a lack of trust of professional services, stigma around health or disability, language barriers, services not culturally appropriate, limited staff, education and training and previous experience of racist treatment²⁴. The obstacles families from ethnic minority groups may face when trying to access services across education, health and social care may be more commonly discussed, less is known about the social care needs of families with disabled children specifically accessing social care. This project focuses on the needs of this group, often overlooked when considering broader children's social care.

2.1 Objectives

The aim of this project was to better understand the social care support needs of families with disabled children from black, Asian and minority ethnic backgrounds. This includes examining the social care support needs that may be unique to this group of families and identifying gaps in support available that lead to increased risk of social isolation and marginalisation.

The project also explored the drivers of any gaps in support and how it may relate to intersectionality

with other demographic factors. Intersectionality refers to a range of connecting social categories that create a unique set of experiences for an individual. For example, in this project people from different ethnic backgrounds may have different experiences of social care based on their gender or social economic status.

2.2 Project Design

The project was developed using co-production with parent carers of disabled children and young people from black, Asian and minority ethnic backgrounds in conjunction with staff from DCP organisations, either with lived experience or responsibility for working with diverse groups. In addition, a group of parents from black, Asian and mixed ethnic backgrounds with lived experience of caring for a disabled child worked as parent-researchers on the project. This included the design of approaches and research materials, reviewing the literature, undertaking interviews with parents of disabled children and young people and discussing and agreeing key findings and recommendations.

The project used a mixed methodology design and was organised into three phases that are conducted consequentially (each phase undertaken following the other). The project is underpinned by an iterative process, whereby the findings from one phase feeds into the design of the following phase. The three phases are:

1) Literature Review

2) Primary Qualitative Research

3) Health and Social Care Datasets

This report outlines the findings from phases one and two. This project was co-produced by parents from black, Asian or mixed ethnic minority groups who have lived experience as parents of disabled children. Further information about the co-production design of the project is available in Appendix one. Parent-researchers from black, Asian and mixed ethnic minority groups were paid

members of the project team. In order to ensure input into the design of the project, materials and data collection, parent-researchers were provided with an overview of research methods and research training skills relevant to this project, prior to the project commencing.

Parent-researchers contributed to all three phases of the project. They provided input into the study design of each phase of the project. In addition they also designed materials and data collection tools for the project, undertook interviews directly with parents of disabled children and help decide key themes to investigate further and frame Freedom of Information questions for phase 3 of the project.

2.2.1 Literature Review

The literature was reviewed to understand what is already known about formal social care support needs and informal support needs of families with disabled children from black and Asian minority ethnic groups in the UK. Searches were undertaken between July and September 2023. The design of the literature review and search criteria parameters is outlined further in Appendix two. 1026 article titles and abstracts were screened in accordance with the search criteria parameters. Fifteen articles were selected as part of this review, with the findings outlined in section 3.1.

2.2.2 Interviews with Parent Carers

Parent-Researchers, who had lived experience as parents of disabled children from black or Asian ethnicity conducted 23 online semi-structured interviews with parents of disabled children living in England. Further information regarding the recruitment strategy is available in Appendix three, with an outline of interview questions in Appendix four.



3. Findings

3.1 Literature Review

3.1.1 Introduction

The literature was reviewed to understand the social care needs of disabled children, young people and their families in the UK from black and Asian ethnic minority groups. Scope of the service included formal and informal social care, with a view to supporting disabled children and their families within their own homes to have the same opportunities as families with non-disabled children.

The Children's Act 1989³ outlines the statutory framework that underpins local authority responsibility and involvement with all children and families. Disabled children are defined as "children in need", meaning the local authority has a duty to provide a range of, and level of support services for children in need in their area, where possible to support them in the context of their families.

The type of support this includes is defined by the Chronically Sick and Disabled Persons Act 1970⁶ and includes:

- Support at home (for example eating or personal care)
- Home based short breaks such as sitting services or activities
- Support to access the community, in the form of after school clubs or play schemes
- Assistance to travel to access community activities
- Help with adaptations at home and equipment to secure safety, comfort or convenience
- Help with costs or provision of holiday, meals and/or telephones.

In addition to the above legislation, the Children and Families Act 2014⁷, and the Care Act 2014⁸ place

a duty on the local authority to undertake parent carer needs assessments and to assess young carers' needs before they reach the age of 18, respectively. Therefore, disabled children, their parents and siblings have a right to have their needs assessed and social care provided to meet those needs.

Providers of social care for a family may include a mix of organisations that could include local government, private, independent, charities, voluntary organisations or schools. For the purpose of this project, we were interested in all types of providers of social care listed.

Families of disabled children may also draw on informal support from family and friends. This may include support from an extended family or religious or cultural organisations to help with childcare, transport, support within the home and respite for parents, siblings or disabled children.

Due to the wide range of activities that come under the banner of social care support, a scoping review of the literature was selected to map out the types of studies that included the social support needs of families with disabled children from black and Asian minority ethnic groups. We were interested in understanding the types of social care needs families have and what aspects families valued.

3.1.2 Search Criteria

Articles were included if they considered the social care needs of families from black or Asian ethnic minority groups, this may include the whole family or individual family members: disabled children and young people aged 0-25 years, siblings or parent carers. UK studies published in English, between 2007 and 2023 were included. This was due to the Government policy 'Aiming High for Disabled Children Policy'⁵ (2007) introduced at that time, with the expectation that this would capture social care activities aimed at the group of families we were interested in.

Articles were excluded if they did not cover all three aspects of intersectionality: disability, ethnicity and children and young people or they had a safeguarding or child protection focus, domestic violence focus or only looked at the care system.

3.1.3 Study Characteristics

The review confirmed the dominance of research studies conducted from a child protection, domestic violence or care system lens, as opposed to a lens of supporting a disabled child and their family to thrive and flourish. It was also common to find studies that looked at either ethnicity, disability or children and young people rather than all three aspects of intersectionality criteria within one study.

We found a high proportion of studies that reported children in need categories for descriptive purposes only, rather than exploring needs of this group. For example, the category of children in need included disabled children, young carers, children who have committed a crime, children who have parents in prison and asylum seeking children.

We identified 15 articles (See Table 1) between 2008 and 2023, articles were evenly spread over the time period. Eight studies were qualitative, three mixed methods, three quantitative and one literature review.

Four articles included families from all types of ethnicity. Three articles focused only on black and Asian ethnic groups, three on Asian groups only, two with Pakistani backgrounds and one on black families only. One article focused on Muslims only and another focused on Somali families.

The majority of articles (nine), focused on parents or carers of disabled children. Children and Young people were the focus of four articles and two articles included all family members. We did not find articles that only looked at siblings of disabled children from black and Asian minority groups and the type of social care support this project was interested in.

Seven articles included all types of disability, three included autism, two mental health, one developmental disability, one genetic conditions and one included children with complex needs only.

3.1.4 Literature Review Findings

Peer to Peer Support

The review of the literature revealed that parents from black or Asian ethnic minority groups with disabled children valued peer to peer support. Five articles included this type of support^{26,27,28,29,30}, this may be from other parents of disabled children from the same ethnic minority group or the opportunity to meet other parents who have a child with the same diagnosis.

Peer to peer support with parents from the same cultural background, offered parents the chance to explore cultural ideas about causality of disability with each other and with informed non-judgemental professionals. A safe space included sessions that allowed parents to share concerns or questions around cultural practices such as washing and prayer²⁷. Families were able to explore the connection between their lens of faith and disability, comparing biomedical versus religious explanations whilst giving support to each other²⁸. Safe spaces also provided emotional support for parents to adjust to changes experienced in their interpersonal relationships such as their marriage or connections to friends. It was also reported that safe spaces allowed time for siblings to explore possible expectations of their role in relation to their disabled brother or sister and receive emotional support to better understand their siblings' disability.

Safe spaces to discuss such issues allowed parents to deal with conflicting cultural beliefs and western medical understanding²⁹, and support to cope with experiences of unspoken attitudes around disability from family or community members³⁰. Parents valued practical support from community, cultural or religious organisations, reporting they were more likely to take up support delivered this way due to

suspicion of government or formal services²⁶.

Emotional and Mental Health Support

Emotional and mental health support needs and information needs were the most common type of social care need identified from the literature. A study reporting on diaries and interviews with parents of disabled children during the Covid-19 pandemic³¹, highlighted that people from black and Asian minority groups were more likely to be living in more deprived areas of the country, on a low income with a lack of social networks or wider family living in the same country. Therefore, they experienced higher levels of isolation and anxiety.

A study using semi-structured interviews with African immigrant mothers with an autistic child, identified support to deal with pain and rejection due to current racial discrimination and also previous trauma, such as war or violence that had led to them leaving their home country and wider family networks²⁹. A small study of parents with family in the UK and Pakistan, highlighted the level of isolation parents experience when their family network or partner is in another country, leading to high levels of isolation when caring for a disabled child³².

The approach taken when delivering mental health support to people from black and Asian ethnic minorities was highlighted by two studies^{33,34}. A quantitative study of over 14000 mental health records of young people, found that those with black, Asian or mixed ethnic minorities were more likely to be referred by social care or justice routes than by primary care practitioners³⁴. It was suggested that how mental health is perceived by people from ethnic minority groups, deterred young people or their families from seeking help. Good outcomes for this group required individual framed goals and coping resources. Empowerment within the approach of mental health support was key to successful outcomes rather than just symptom management of poor mental health such as anxiety or depression³³.

A study with seven parents of disabled children, emphasised the fluidity of culture³⁵. When assessing needs of families with disabled children, providing care based on stereotypes should be avoided. Cultural factors important to families may change over time and should be explored in conjunction with age, religious beliefs, home country and languages spoken.

A mixed methods study, that included a case study of an Asian family with five children, three who were disabled, described the reality of a family housebound, due to the lack of support from services³⁶. A multi-agency approach providing practical support in terms of equipment and activities directly to the disabled children and activities to siblings, then enabled the parents to gain emotional support from services. Mental health support in isolation for families severely isolated will not be practical unless systemic issues are also considered and support provided.

The review of the literature revealed that parents from black or Asian ethnic minority groups with disabled children valued peer to peer support.

Table 1: Articles included in scoping review.

Author	Date	Methods	Sample
Arif,Asif and Lunt	2022	Survey and Focus Groups	15 parents (11 mothers and 4 fathers) of disabled children from Black,Asian and Mixed ethnic minorities.
Chan,Vickers and Barnard	2020	In-depth Interviews	37 informal carers of young and adult children Ethnicity not included but the country of birth 11 born outside the UK, 2 from India, Caribbean, Jamaica, Ethiopia, Nigeria, China, Hong Kong, Pakistan & Mongolia
Cramer and Carlin	2007	Postal Survey to all UK short break providers for 4th survey	120 scheme coordinators responded responsible for following service users, all ethnicity 4544 children using overnight and day-care 1245 children using sitting services 492 children using befriending services 491 children using contract carer services
Edbrooke-Childs, Ruprect-Smith, Davies et al	2023	Mixed Methods study looking at differences in mental outcomes by ethnicity and a small qualitative study exploring reasons for difference	14534 data records young people age 6-25 years 15 CYP age 18-20 interviewed – 13 female & 2 male 8 Asian and 3 Indian
Edbrook-Childs and Patalay	2019	Quantitative Analysis of routine datasets Comparison by ethnicity	14588 young people, all ethnicity
Gilligan	2013	Literature review	Parents from muslim communities caring for children with autistic spectrum condition
Goodley	2013	In-depth Interviews	3 parents of disabled children
Keer	2015	In-depth Interviews	7 British South Asian parents of children with developmental disabilities, aged 7-14 years
Kramer-Roy	2009	Action Research	Fathers, Mothers and disabled young people and siblings from Pakistani families
Munroe, Hammond, Cole	2016	Semi-structured interviews	African immigrant mothers with a child diagnosed with an ASD
O'Shaughnessy, Collins and Fatimilehin	2010	Mixed Methods	1 case study of an Asian family with 5 children, 3 disabled
Raghavan, Pawson, Riasat et al	2014	Focus Groups with disabled young people and carers and a trial of 2 groups	34 disabled young people with moderate or complex support requirements from South Asian families
Selman, Fox,Aabe et al	2018	Participatory based approach with In-Depth interviews	15 Somali parents (12 mothers) of disabled children with autism
Twamley, Faircloth and Iqbal	2023	Longitudinal Interviews and diaries	38 families during COVID pandemic, 18/60 adults from ethnic minorities
Welch, Hatton, Emerson et al	2011	Questionnaire study	348 parents of disabled children from all ethnic backgrounds using short breaks

Information and Awareness

The role charities played in delivering peer to peer support between parents of disabled children and mental health support organised by charities was welcomed by parents of disabled children from black and Asian minority groups²⁶. Parent groups helping other parents of disabled children understand their diagnosis, care needs and support that may be available from both statutory and charitable organisations is welcomed by parents.

A study with in-depth interviews reported that confusion, anxiety and concern are common emotions for parents who have a disabled child when they first learn of a diagnosis, with emotions heightened for parents who do not have English as a first language³². Authors report that information provided in an empowering way can be beneficial for their skills and knowledge but often families find themselves drawn into disempowering systems of governance and surveillance.

Two studies, one with British South Asian parents and one with African immigrant mothers living in the UK, reported that parents value information about their disabled child's diagnosis, its cause and possible future implications of their children's lives at various milestones^{29,35}. Focus groups with South Asian disabled young people reported that young people valued information about leisure activities in an accessible format, with face to face access to staff for themselves and parents to seek clarifications³⁷.

The role of community organisations in providing information to black or Asian communities was highlighted by two studies^{26,37}. Disabled young people and parents of disabled children valued information provided at venues such as temples, mosques, guruwaras and churches³⁷. A participatory study, using in-depth interviews found that parents information to support wider understanding within the community²⁶. This was also echoed by three further studies^{25,28,29}.

In addition to information about diagnosis or care needs and activities, families with disabled children welcomed information about financial resources in terms of benefits or access to grants. Discussed further in the next section.

Financial Resources and Support

A stereotype applied to families who are from black and Asian ethnic minority groups is that they prefer not to access wider support and "look after their own". However, three studies found that a combination of financial support and improved social networks were needed^{28,30,31}. Financial support or material resources to support families was highlighted by a study looking at access to mental health support³³, with premature termination of support reported due to limited resources by young people accessing services. Some families did report wanting to undertake the full time care of their disabled child, however it was highlighted that this was not practical without state support to do this³⁸.

Information about financial support was valued by parents of disabled children and young people. A questionnaire study of parents of disabled children from all ethnic minority backgrounds using short breaks found that users of direct payments were more likely to be white³⁹. Therefore, information about benefits or financial support should be targeted more directly to families from minority ethnic groups to ensure they are promoted more effectively to all families.

Facilitation

There was evidence that families of disabled children from black or Asian minority ethnic groups welcomed support from key individuals, either at services, charities or from community or religious organisations²⁶. The role of key individuals was to facilitate support with other professionals, to engage with services, access support and financial resources^{28,36}. In addition, the study that included a case study of a family with multiple disabled children reported on the success of facilitated support to help the family access services, equipment and with administrative support to ensure provision was in place via direct payments and the employment of staff.

A survey of 120 short break scheme providers in England⁴⁰, reported that disabled children from ethnic minority groups were considered hard to place in previous surveys and were more likely to be without support unless placed with carers from white ethnic groups. The study emphasises lack of targeted services for families from ethnic minority groups. When considering the role that inequalities play in the creation of barriers for families of disabled children from black or Asian ethnic minority groups who would like support from services, facilitation from the start to the end of the process would be advantageous.

One study included a trial of two approaches to two groups of disabled children with moderate or complex needs³⁷. One group was given information about social activities with the other being supported by a facilitator from the same ethnic background as the family. Support included discussion about various types of activities available, with the facilitator clarifying key aspects of provision around the choice of the family. The facilitator supported the family in attending the sessions and stayed with them during the activities to help the young person or parent. It was found that the group who received support facilitated in this way were more likely to stay with the service in the long term.

3.1.5 Literature Review Summary

The scoping review of the literature confirmed that the social care needs of disabled children and young people from black and Asian ethnic minority groups are overlooked. There was a dominance of studies from the lens of child protection, safeguarding, domestic violence and the care system as opposed to support for families with disabled children.

A challenge for this project is the wide variety of support that constitutes social care for families of disabled children. Despite this, studies focusing on social care needs for this group of families was limited. It was difficult to identify studies that focused on disability, childhood, black and Asian ethnicity from the lens of social care support needs. Whilst improved reporting of ethnicity is evident in the literature as a characteristic of participants, further studies in this area that extrapolate findings or outcomes by ethnicity would be welcome. The review of the literature identified gaps in long-term planning for families, studies focusing on the experiences of siblings and single parent families.

To conclude, parents of disabled children from black and Asian ethnic minority groups welcome peer to peer support from other parents, either those with experience of looking after a disabled child with the same diagnosis or from the same ethnic, cultural or religious background. Safe spaces enable families to explore different or conflicting medical or cultural perspectives and offer opportunities for the whole family to connect with others in a non-judgemental environment, receiving support as they adjust to disability and its impact on their support network and relationships.

Families welcome emotional support that includes coping resources and mental health support that is empowering. They welcome information about their child's disability, care needs (short and long term) support available and information about benefits, grants and resources that may be available. Families from black and Asian ethnic minority groups benefit from facilitated support, from accessing information

about services to attending and receiving support whilst at activities.

The findings of the literature review were used by the project team to develop the interview questions for the online interviews with parents of disabled children from black and Asian ethnic minority groups (see Appendix 4).

3.2 Interviews with Parent Carers

3.2.1 Introduction

Online interviews took place with 23 parents of disabled children or young people, 0-25 years, from black, Asian or mixed ethnic minority groups, between November 2023 and January 2024. The methods used for this part of the project, including the recruitment strategy for participants taking part in phase two of the project is outlined in appendix three.

The demographic information of the group is listed in Table 2. The project approach aimed to gather a range of experiences in terms of type of families, disability, ethnicity, location and experience with social care services. Although a range of families took part in the project, there were no families from the North East or East of England in the research. All families taking part in the interviews, had social care needs however the type of social care support varied significantly across the group, ranging from families who had been denied social care to those with social care support in place.

Findings are presented in three parts by the type of needs identified.

1. **Social care process**
2. **Practical needs of the family**
3. **Needs from community**

For each key area findings are presented in relation to more general social care needs applicable to all families with disabled children from any ethnic background, with needs unique to families from black, Asian or mixed ethnic minority highlighted were applicable, in line with areas of intersectionality.

The scoping review of the literature confirmed that the social care needs of disabled children and young people from black and Asian ethnic minority groups are overlooked.

Table 2: Participant Demographics

Demographic	Number of participants
Parent Carer Type	
Mother	19
Father	2
Sibling	2
Number of children	
1	5
2	6
3	7
4 or more	5
Number of disabled children	
1	16
2	5
3 or more	2
Age of disabled children	
0-4 yrs	2
5-10 yrs	10
11-15 yrs	6
16-18 yrs	3
19-25 yrs	2
Ethnicity	
Asian	12
Asian British Bangladeshi	3
Asian British Chinese	1
Asian British Indian	3
Asian British Pakistani	3
Asian – Any other	2
Black	8
Black British African	7
Black British Caribbean	1
Mixed	2
White Asian	1
White Black	1
White (Parent White, Child Mixed White Asian)	1

Demographic	Number of participants
Education/ Training Setting	
Nursery	1
Mainstream	7
Home	2
Residential	2
Special School	9
Post-16	1
Employment	1
Single Parent	6
Region	
East Midlands	3
London	7
North West	2
South East	1
South West	5
West Midlands	2
Yorkshire and Humberside	3



3.3 Social Care Process

The process that families with disabled children should experience when engaging with social care or accessing support can be broken down into five phases (see figure 2). However, from a parent perspective the process deviates from these key areas into multiple sub-processes. Families are left following a complex series of disconnected interactions with services that often fail to capture the true extent of disabled children or their families' support needs. There are also bottle necks around the assessment and approval parts of the process that further complicate the process.

Two common narratives were interwoven throughout the process, firstly in relation to perceptions of social care and secondly regarding the impact of reduced budgets on the support that may be available. Parents frequently clarified the services that they felt constituted as social care for disabled children, emphasising differences in mainstream media that would refer to adult

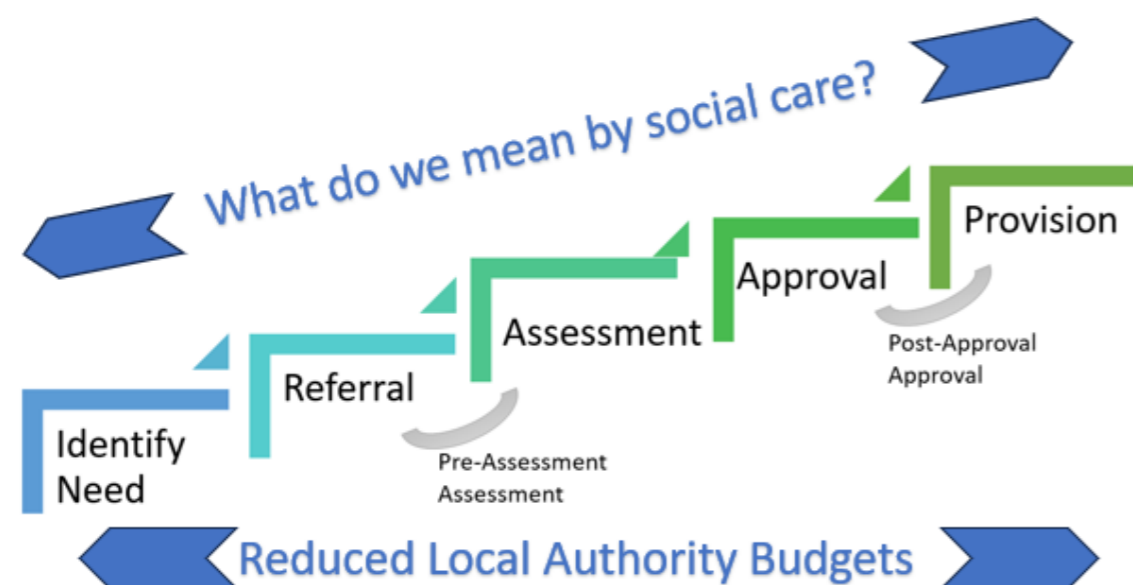
social care or child protection. There was also a consensus amongst parents that reduced local authority budgets over time had culminated in reduced services and a crisis-led model of support. This narrative was found in conversation about all aspects of the process.

Accessing social care is hard, but accessing social care in my borough is harder because they're bankrupt, so they have no money.

I do think that we are at the bottom of the list in terms of he's not an emergency case in the eyes of the council. So it's like we just have to bob along, and we have to figure out how we do, how we keep that even keel, because we're not an emergency case.

Unless it's an emergency you're just left to your own devices until something horrible happens.

Figure 2: Process to access social care support for families with disabled children



3.3.1 Identify Need

Wider understanding of social care for disabled children can be clouded by the role social care has in protecting children from abuse. Perceptions of social care revolve around child protection, safeguarding and the care system. Therefore, it may not be unusual for parents of disabled children to be unaware of their eligibility for support via social care.

3.3.2 Information Vacuum

Parents reported finding out about social care support available by chance from other parents of disabled children, rather than professionals. It was felt this information could have been provided in the early stage of their journey as a parent of a disabled child. This gap in information available meant that many parents missed out on support they were entitled to or only started the process when their needs were more complex or they were in crisis.

I don't get a lot of information, and I didn't know a lot of things, until some parents mentioned it to me.

We only started to get it when he was already 3 years old, so we lost 2 years on claiming because nobody told us.

Parents of older disabled children referred to a reduction in information events organised by local authorities for families with disabled children. Parents felt that this had been a positive way to ensure families were made aware of service available and their entitlements to support.

When they've had these events, they've had people from other organisations, like local charities attend. So they had stalls there, you know, so then you see a stall and you can find out more. They're not running anything like that now.

Information could be ambiguous for families who explored potential avenues of support independently.

I read the information and I was like, 'I do have this condition, I do fulfil this point, but I don't in some other points'. So that's what stops me a lot of time from going further.

3.3.3 Reversing stigma of social care narrative

It was common for parents to talk about their worries about engaging with social care, even when aware that they had social care needs and were entitled to support.

There's this inherent fear that social care will take your children away, so we're not going to contact social care even though we have a disabled child, we're on our knees, it's such a struggle.

Parents with and without social care support highlighted how the stigma and negative narrative about social care created a barrier for families with disabled children when they needed support. For example, one participant stated that their social care service that families had to contact to discuss accessing support included the word safeguarding.

They actually have a multi-agency safeguarding hub. Now when you look at that and you see safeguarding, I mean this is the doorway to get social care, you phone up the multi-agency safeguarding hub

Other parents were concerned at how their disabled child may be perceived by social care or how their parenting skills would be assessed as opposed to receiving the support they needed. As the second quote below illustrates poor experiences of families known to participants were quoted as reasons why they had not contacted social care for support.

So I think if they get involved, things might go the wrong way for us. Because he's got challenging behaviours, they'll always be in the house, they'll always start, you know interfering quite a lot. So I'm a bit scared with things like that. I don't know whether it's the best thing to do or not.

Because one family did get social care, and then they were in the house in the morning from half seven to see if the lady knew how to dress her kids, how to send her to school, so it was very interfering with everything else.

Although many parents credited other parents as an information source about social care support, the stigma of social care as a service diminished sharing information between some parents. This is an important aspect when planning information needs about social care compared with more generalised information about disability. The stigma of social care means that parents have less information readily available compared with other services they may come into contact with such as education or health.

I feel that, even though people (other parents) know, they won't tell you anything about what support they've got or if they've got any funds or grants and what can help, they keep it discreet. They won't share.

3.3.4 Considering ethnicity when identifying needs

Parents talked about a lack of disability awareness either in their wider family or community groups. This was sometimes attributed to religious or spiritual beliefs around disability or stigma associated with disability more generally. This resulted in an added complication for parents when needs were identified. Two examples below illustrate why additional support may be required for parents from black, Asian or mixed ethnicity when needs of their disabled child are being identified.

The first parent highlighted that disability and particularly autism was not discussed in her culture and therefore she found it difficult to understand the diagnosis and adjust to it, each time it was referred to. The lack of understanding of disability within her culture added an extra layer of need when adjusting to that news and therefore, what may be required in terms of support.

Because my child has needs, a lot of my friends didn't really understand, and also autistic is not something quite common, and you'll see that in my cultural background. So this is something quite difficult, I don't really know like what I'm entitled to. And every time you get a letter from somewhere, you always get diagnosis first, you go home with the, with whatever they said and then a few months later you got diagnosis letter, you get shocked, like, twice from the same thing.

I was just worried that I would come across as somebody who, who... My worry would be that because I am different, because I am from a different background, that I would look like the immigrant that's looking for free ride, and I was just, I was frightened of that image. I wanted them to understand that I would only ask for... (crying) I'm sorry, these are tears of rage...I would only ask for help if I really needed it. I wouldn't go round thinking that 'oh, I could get this free thing, oh yay, let's go round looking for free things. I would only ask for help if I absolutely needed it, and THIS was the time because I don't have a mum or dad, I don't have support.

The second parent describes how negative narratives around ethnicity and immigrants adds a layer of shame and trauma when seeking support. Negative narratives about benefit claimants and immigrants, delayed her making contact with services despite clear understanding that they have a need. Therefore, a family from a black or Asian minority group reaching out to engage with services may already have higher level of needs with greater complexity.

Parents from black, Asian and minority ethnic groups may have a reduced cultural reference point for disability and need extra support in order to adjust to a disability diagnosis and understand what this means in terms of support that may be required. Professionals need to consider this extra layer when identifying need.

3.3.5 Referral and Pre-Assessment Assessments

Parents who had first-hand experience of disability, for example other older disabled children or disability in the wider family, described difficulty in progressing referrals for support. The views of professional gatekeepers, from health or education, would override parents first hand knowledge. Parents describe a wait and see approach to their child's needs from professionals that delayed their applications for support.

Again, it was common for reduced budgets to be quoted along with the tendency to diminish the level of the disabled child's needs. Parents describe a referral process that included arbitrary pre-assessments before being accepted for a formal social care assessment. Referrals were also refused on the grounds of criteria such as the age of the child, diagnosis or severity of illness.

And at the end of it he said 'yes, you do meet the criteria'. And I was thinking 'we met the criteria 2 years ago, but a social worker refused in the sense of even looking into our case to support us. We could have had support two years ago. We've waited two years for you to say those words.

There was no point because, children with disabilities are only able to access disability clubs when they turn 8. So before the age of eight my son wasn't allowed or able to attend any clubs.

In view of funding restrictions of services, parents with higher income or socio-economic status reported that they were refused referrals on the grounds that they were reserved for lower income families rather than the statutory needs of the child. Parents also described how they felt their appearance played a part in interactions, including their religious clothing.

One thing I will say, I do feel, if they think that you're presenting yourself, like, in a way that, like, you've got you, you've combed your hair, you've got some make up on or whatever, you're not like

a complete mess, I feel like that counts against you that, you know, you don't look like you're in enough of a state, to need that kind of help.

Seeing my hijab and all of that stuff, you know, like, they don't feel like sharing information with you, I was thinking sometimes that other people, other ethnicity got more information, know more information because people just feel easy to share it with them and not with me.

Families report a lack of understanding of social care professionals about children's disability and how this may translate into need. They report misinformation around their rights in the form of advice, for example advising parents to use DLA rather than undertaking an assessment.

It was felt that Early Help services were an additional delay or hoop to jump through before undertaking an assessment, with such services having an inspection rather than a support focus.

Then there was a parenting course, because that's what they do now, you have to do the parenting course to be able to get an appointment. You can't just go through the process of, like, getting the referral, and getting an appointment.

So that was another thing you'd be asked, so it was just me and my husband here, he works full time, and I do the caring role, we do not have any family or friends in this country. Everything, our families are all based back home, elderly parents who themselves need care. But we had to wait while they checked before we could have an assessment, it added months.

Without even assessing anything, even seeing your children. So, you've done that 6-7 week course out of your time, and then I've got a letter to say 'oh, thank you, you've completed the course, but basically you don't need to go any further with him', you know what I mean, sort of thing. But then they was like 'ah, whoever has been told that we've closed their case, you can always do another referral, and it will be fast tracked'. It doesn't

matter if it's fast tracked, a fast track, there's still a processing time..."

But the only support they gave was Zoom meetings, you know, like once a week to have a Zoom meeting and talk about drugs and alcohol and you know, and all this. I didn't really, we didn't really benefit from it.

3.3.6 Assessment

It is imperative that time, space and focus is dedicated to assessing a disabled child's social care needs, with the disabled child and their family's voice at the heart of that assessment. An assessment that paints a clear picture of need ensures that appropriate support to meet those needs can be put in place. Therefore, positive communication with families is important to capture the needs fully, with staff who take time in undertaking a full assessment.

As already mentioned, when identifying need families with disabled children from black and Asian ethnic minority groups may have a reduced reference point about disability and need more time to adjust to a diagnosis. They may also present later to services when their needs are more complex. Parents emphasised that attempts to explain their level of isolation were not understood during the social care assessment.

It might not be the ethnicity so much, but first, first level immigrants, we've just moved, we don't have family support here, that never comes into the picture to be considered, when we say we do not have support here.

I just think that there might be an assumption that because, she was British (social worker), and she has family and she has friends, I think it's very difficult, it was very difficult for her to understand my needs, to really understand that I am completely alone. That I don't have the roots that she has. I don't have the social networks, the social stability that she has you know, and that other people like her share culturally. It will

be rare for you to find somebody from her cultural background experiencing the circumstances that I'm experiencing.

I don't have family, so it's, I think it was just very difficult for them to understand that. And I don't think it's because of a lack of understanding of humanity, I think it's a cultural thing.

As some families may have a different cultural reference point regarding disability and therefore social support systems, additional support would be welcome when navigating the requirements of social care assessment.

I mean I don't mind reading, but sometimes I myself find it difficult to start communicating with other people when asking something. But I mean how would you ask if you don't even know about that thing right?

(referring to husband reading reports) He read it and he had, he had tears in his eyes, and he's not a man who normally is that emotional, but he said, 'I read that and it felt like they've described the worst child ever'.

During assessment parents report feeling as though their parenting and family life is inspected and judged. Turnover in staff can result in information being incorrect or omitted, resulting in the level or type of support approved failing to meet their needs. Parents describe being given forms to complete themselves due to the pressures on staff due to high turnover and vacancy rates. Repeating their story over and over can be distressing for families.

She produced her first report and it was full of errors. Every name was spelled incorrectly, she had details that were wrong, this is really, it doesn't represent him: my family, or what we told her when she came, everything else about what I felt was important, which was my son's needs, was really, like I said, full of errors

This is my fourth social worker. There's been quite a few changes. So, the one with the oldest, I didn't like her, she was very disorganised, she wouldn't take notes. She was constantly calling me to get me to repeat myself, everything I told her, so I wasn't very happy with her, and she really took a long time to do the assessment, went way over and then he was awarded a lot less hours than his sister.

In that first year we had five social workers, and there's such a high turnover, they came and went.

There was no continuity. Every social worker that came hadn't read the previous report and was starting from scratch. So for me, as an exhausted parent, I'm already exhausted and you're asking me the same thing again and again, had you read the report, you would have been up to date and you could have asked me things that you were unclear on, things for clarification, rather than wasting our time.

Staff turnover and poor communication by social care create additional pressures on families during the assessment process. Parents describe the added administrative burden of chasing services and staff during the assessment process.

I can't, I can't get off this train, I've got to keep going. You know, maybe for you it feels like you can switch off whatever time - you get annual leave, you get weekends, but this is 24 hours for me, and I'm coordinating so many people, and a lot of my time is taken up chasing people who are in a role, and they're not doing what they're supposed to do.

As when identifying needs earlier, the parent or young person's voice is not included in a meaningful way in the process. Attempts to clarify information from parents is not done in an effective way.

They'd have parents at the panel and it was, the panel was led by service managers, so then you could come in as a parent and kind of present your case. And then a few years ago it changed to

where it was just commissioners only, no parents, only professionals. So these decisions are made about you without you there, and the person representing you would be grilled about your family and not be able to give... you know, they did their best, but have to come back and say 'the panel had these questions' and then they have to go back to the panel again to present.

Parents report fragmented assessments that looked at a particular issue or focus on just one member of the family.

I've always got the message, and fair enough, it's about the well-being of my son and putting his needs first, even if that means challenging me as a parent... And actually that's OK, that makes sense. They're not parent social workers, they're children's social workers.

I would have liked my eldest daughter to be included in this, but the new social worker, who only just started last week, so another one, she's the first one that said, 'look, I am going to consider her', but the others have not been interested. So, we'll see what happens, it's early days, but I would have liked the whole family to be considered in that, you know, my oldest child (young carer) is in the equation as well, and actually she's been hospitalised because it's got that bad, but they've not been really interested.

Parents suggest a comprehensive and holistic way of assessing needs should be introduced as they have to highlight needs as they arise.

So to give you an idea, support for me would have looked like a one-stop shop. OK when his diagnosis was identified what it should have been was 'right, OK, now that he's been identified that he needs help, this is what we need to do for you, we need to check ABCDEFG. Are you getting disability allowance? Are you getting carers allowance? Do you need an assessment? How about your mental health? How about the mental health of your children and your family?

Parents describe assessments being held at times or locations convenient to social workers, rather than organising assessments in order to observe and understand needs as occurring at appropriate time and place. For example, observing spending more time at school where there is more support, rather than at home where support is needed.

I said 'you need to come after school so you can see what it's like, you know, don't come at the weekend when we've already regulated and calmed him, come straight after school so you can see what he's like'. So he was in the throes of a mammoth meltdown, screaming, thrashing, because that's what he did every day after school, for about 5 hours before bedtime. This social worker came, he lasted 15 minutes in my house, couldn't take it and had to leave because it was too distressing even for him, he couldn't cope.

There is evidence that parents of disabled children from black, Asian and minority ethnic groups experience interactions with staff that include microaggressions and assessments that are based around stereotypical assumptions. Parents describe questions during the assessment process that are not relevant to the needs of a disabled child.

What type of marriage did me and my husband have? And I was thinking, 'that's not a question you would ask a white couple'. That clearly

was asked because I'm South Asian or because I'm Muslim, I'm not sure what the reason was. But clearly that's not a question you would ask other couples. And that made both my husband and I uncomfortable, because it was a highly unprofessional question to ask as a social worker.

People assume that, because you are from a certain ethnicity, there is quite a lot of, erm, patriarchal things, or the way of living is quite patriarchal, therefore when I would say you know, 'I need to think about it'. There's "is that because you need to consult your husband about it" thing.

I don't know the right word, but you know those indicators. If you have a certain accent, you know, your physical appearance, you know, technically your educational background a lot of the time... It's almost like they're surprised... I don't know if they're surprised just with any parent who's relatively capable, or they're surprised because of my ethnicity, and they have to have another reason for why I'm able to do what I do for my son and advocate for him... I've always found that question a bit strange.

There was evidence where the focus of the assessment was about inspection and not support. Combined with racial and cultural stereotypes families report feeling judged during appointments with social care staff. Parents also highlighted cultural norms misconstrued by professionals in a judgemental way.

So when it comes to my house, they see a clean, tidy house and they're like thinking, 'well, this woman can keep a clean, tidy house, she doesn't need any support ... You know, well, obviously, being clean is part of our faith [muslim] isn't it.

[when talking about eating with hands] So listen to the word, listen to the terminology,she goes to me, 'oh, I'm not quite sure how to say this, but she comes to school a bit mucky'.

3.3.7 Approval and Post-Approval Approval

Parents describe a lengthy process for assessments to be compiled and be presented to panel, with decisions not communicated to families. Parents are not informed of the standard process and this adds to the confusion around expectations of what should happen, following cases presented to panel.

I chased and they said "oh, yeah, social care package of 3 hours has been approved' and I'm like 'when?' 'Oh, it was a month ago', and I was like, 'Can you give me the details because we need those carers, and we should have had them a month ago'.

Again due to funding pressures, parents report delays refining assessments to ensure they will not be rejected by panel. Reduced funding has resulted in more stringent expectation of panels creating delays in approval for parents.

There's a lot of issues in the local authority with funding these packages, and they're being rejected by panel, and being told to come back and make changes because of the cost. Erm, and even on appeal some families are struggling, so what's happening is his social worker, she's saying, you know, we've kind of agreed a plan, but she's saying we have to make it robust enough that it won't be challenged at panel. So it's taking a long time to get it to panel, like there've been about three dates. She said 'I'm going to take it to panel' and then something has stopped it going."

Parents described interactions that felt combative, evolving from a lens of inspection, rather than facilitating a productive supportive approach between professional and parent. Parents report their fear of challenging social workers due to the perceived power professionals have to affect the approval of their assessments.

So, I've learned you've got to be firm, you've got to kind of stick up for yourself, because I have a social worker who offended me and, you know, was really ignorant, but I had to kind

of be firm with her, and correct what she was saying, because if I fall out with her, I end up with nothing, you know?

But the hardest thing from this journey is the intrusion. This is the bit that I find the most hardest. And this is the first time I put my foot down and I've said to them, 'no, I've already had somebody here 2 weeks before this phone call, I've had a family support worker tell me 'oh, well if you refuse the visit then we might take a package away'.

A post-approval process is described by parents. Despite the approval of social care support, families experience attempts to reduce the level of care provided before it is in place.

The new social worker visited and said "yeah, because if things are better, I'm wondering whether you still need the package.

She very much came with the agenda of pulling the process of their assessment. So rather than completing her predecessor' work, she was looking to end it and I was like, 'no, I'm not having that, this needs to go to the manager because the previous social worker said we're eligible, and I want a manager to look at it and tell me what's what'.

Post-Approval approval also includes care provision failing to materialise or be organised despite approval, with service managers prioritising other cases and leaving others without support. The example below is regarding a disabled child with a terminal illness.

It was awarded, erm, but the person in charge didn't think that we should have it - she made that very clear for 2 years. She told me 'he's not sick enough', 'there's other kids that are sicker', and she just didn't ever send anyone to the house. And I had a breakdown. And I cried, and I cried, and I cried, and that was the end of that. And she decided for some reason that we weren't deserving, and she just didn't send anybody.

Support approved tends to be short lived, short term and reactionary to current family circumstances. It fails to plan long term or consider how needs may change as disabled children grow and develop or family circumstances change. A cause of anxiety for parents of disabled children.

I'm 65 now, I will be next year, you know, And I thought, I don't want my child... I basically wanted him to have independent living as early as possible whilst I, so if he needs help, I'm still around and his dad's still around, you know.

3.3.8 Provision

Parents want to feel confident in the support approved and provided for their family. A comprehensive assessment at the start of the process, with a holistic focus on all members of the family is vital to ensure provision meets needs in a practical and meaningful way.

Once people sit down, and think about every person's situation and use not a standardised blanket application, but just say, just look at this family as an entity by itself and what their challenges are, and genuinely think about helping them and providing the support that would be helpful, but I don't think that... At least in our case, that's not happening.

It's hard to do things with all four children, that's where that's where I struggle. So if there is something for him and it's like, 'OK, that's great, there's something for him', but then what do I do with the rest of the children?

Families report that provision fails to understand the level of isolation some families have, with no social network local to them.

I said 'look I, I feel incredibly isolated, I'm in an area that, where I have no family, no friends, and I mean, just simple things like going to the doctor are impossible for me, because I don't have anybody that I could possibly leave my child with.

Central to all provision, whether within or beyond

the home, is the ability to meet the holistic needs of the family, ensuring that parents feel confident in the care received. Confidence in support comes from interactions in a well-trained specialised workforce, working with families in a consistent way. There were reports of social care involvement only for specific tasks, even in cases of disabled children with life limiting conditions.

If we want a specific thing, we can have a social worker for that specific request, and as soon as that's finished, bye, no more social worker.

Families receiving approval for social care support, describe difficulties securing provision due to staff turnover and lack of specialist staff familiar with disabled children's needs. Parents wanted a provision where they feel their disabled child will be supported well and be safe.

But because I didn't have a PA, they were like, 'you're going to have to use our agency, use the agency to get somebody'. So, erm, I ended up with, like, a young man, which I didn't want. I tried to show willing and go along with it, but he had no real training in kind of communications from what I could see. Didn't seem to know anything about Makaton, or signing, that kind of thing. So I was a little bit like 'I'm not sure', but I didn't want to lose the package

It'd be good... like during just holidays and stuff, to actually have more available for SEN kids, they can go and they'll do things like nappies and things like that, or they'll be confident to deal with children that, you know are non-verbal, or have like you know difficulties communicating.

Positive examples of effective parent professional partnerships were based on good communication and trust built up over time. Illustrating what can be achieved if workforce turnover is reduced. Parents valued having time dedicated to preparation before meetings or planning time with a key social worker and illustrates good practice in supporting parents who need more support with their confidence.

Sometimes, I'll just struggle to, to start - because when I talk about things like my child's needs, and then it's really, like, it stuck me, like I don't know what's the word now, I couldn't even say it. And she said 'we will have a little mini meeting before the official meeting saying this is what I wanted to say, this is what I want this meeting come out with.

Parents talked about social workers and professionals that they perceived as good advocates for their children and for their families.

She gives some advice, and that the school also respond very well, and they follow her advice.

She's just been a great advocate, but also I've learned so much from her, because she kind of held me along, as she was doing her job... She helped; I feel like she helped me be a better parent for my son, especially as it comes to advocacy for him, and having a voice and that those are the professionals that stand out for me.

I probably can't even remember her name, but, honestly, she was amazing, and she fought so hard for us.

For families from black and Asian ethnic minority groups experiencing severe isolation, the role of the social worker facilitating contacts with other families from the same cultural background is vital to parents.

And then one of the case workers said, 'look I have a mum, she lives very close to you, she's Chinese as well. Her son is a little bit older but would you like me to put you guys in touch?' I said 'of course!' So erm, so we start to contacting, we start to become really good friends, and we sometimes hang out together even. She understands my daughter's need, I understand her son's needs, we have same background and that was really important.

Good social care ensures parents feel confident to advocate for their disabled children and their family.

More detailed support needs identified by families will be discussed further in the following section.

3.4 Practical Needs of the Family

3.4.1 Introduction

Good social care support has the potential to flow into all aspects of a disabled child and their family's life. For example, short breaks provide opportunities to take part in activities away from family, developing confidence and forging friendships, that benefit all areas of their life moving forward to adulthood. If needs are not met either within the home or away from the home, needs escalate and a greater level of intervention is required to support families.

Challenges parents experience during the assessment and approval process often mean families experience social care support that does not meet their disabled child's needs. A one size fits all approach was often referred to by parents, with reports giving the impression they had support however it did not achieve the desired outcome or overlooked essential needs, for example medication needs, moving and handling needs, personal care or communication and sensory needs.

At the moment it comes with the condition that he has a carer or a parent, a one-to-one because of his level of needs, otherwise he can't attend.

3.4.2 Confidence

Parents want to be confident that the social care support their disabled children and their family access will keep their disabled child safe. Provision at special needs schools meets needs for families, not just in terms of education but also ensures the specialist workforce and understanding of disability parents want when accessing activities and short breaks. However, away from specialist provision, workforce or provision encountered by families were not always disability or child specific.



And I remember one carer, it was an agency carer who you know, I didn't have back again, but I remember one morning he was leaving, and he goes 'oh, I'm going to another job now' and I was horrified, because I thought, 'you've just been here all night looking after my son, you're going to look after somebody else's loved one, what capacity have you got to do that safely?'

So, actually, saying that, it would be good to get like, a proper kind of safety assessment, like he breaks stuff, so I've had to get plastic drawers and things like that. But coming in and telling me what we can pay for or get, there should be like a basic level of safety things that they're willing to do for autistic children that are non-verbal and quite physical.

It was common for parents to emphasise the discrepancy between the social care role for child protection and safeguarding children from abuse, however, parents felt their children were left vulnerable and at risk due to absent or partial support provided by social care.

When he's having a meltdown, from when he doesn't wanna come out the car, when he's running across the road, all those different reasons I can't really manage him safely, if he decides to, you know, run off or lay on the floor, I needed an extra pair of eyes that was older than my 11-year-old to keep up with him, that's what I needed.

Where I've struggled, is having proper overnight respite, because we have carers in the house at night and two nights a week there's two people to give me a total break, and the rest of the week I'm the second person, so I can be woken up by the care if they need help with him.

In order to keep their disabled children safe, parents gave examples of limiting what they did as a whole family as a lack of additional support in the community meant that they were unable to attend social events safely.

My child that was hearing impaired, he had no awareness of danger; didn't have a clue. Erm, he would dart across the road if I didn't grab onto his hand. So, it would be nice to get a bit more support to attend various events, or social events, where - not just him but him and his siblings could attend together. There were times where we couldn't go to places unless there was both my husband and myself, you know, because one person had to physically look after him, just in case, he decided to dart across the road or something, you know.

3.4.3 Financial Support

Parents of disabled children may be able to access direct payments, increasing choice for some in the types of activities that their children can attend. However, this also increases the administrative burden on families who report they have to manage discrepancies in funds received from local authorities.

Even though I hadn't used it all, the money just seemed to run out. Even though she's not been to the activities that she was funded for, I had to spend an entire weekend working out exactly what had happened. When I worked it out, they were actually putting in a lot less than she should have, and it took me the whole weekend and a bit to work it out, seeing that something's not right, and then obviously I had to go back and forth with the local authorities, not getting replies back from them, arranging a meeting when they went through everything... Eventually they finally agreed that I was right, but it took me probably close to a year or just under a year before I got it sorted; in the meantime, she couldn't then access those activities, because she didn't have any funding for it because it had run out, even though she should have had it..."

Parents also reported funds received from local authorities failing to match costs to employ staff. There were examples given of local authorities restricting the types of activities that could be accessed or clawing back funds given.

But I'm not able to employ them [after finding care staff], because you know what I was told was 'yeah you can employ them but we can only pay £14 odd an hour and if they're charging £20 you have to make up the difference', and I'm like 'hang on a minute, why?' you know..."

It just didn't feel like they got it, in terms of what she needed her activities for my non-disabled daughter who is 16, doesn't have to answer to anyone and she can go and do what she likes – so why should my daughter be forced to choose an activity simply because you know it is or isn't on the plan.

3.4.4 Choice

Support that enables disabled young people to have the same life opportunities as their non-disabled peers was cited as examples of good practice by parents during interviews.

There's a group that actually takes young people, they pick them up from their home, you know, do activities during the day, take them out, whether it's bowling, cinema, you know, boxing, even just for a meal out, things like that. And then they dropped them back home as well.

Again, as with families who received financial support, parents describe the lack of available sessions for their disabled children when compared with their non-disabled children.

I mean what we, you know, what we need quite clearly is, is clubs and supports that can be available and open, and not... so, you know, in terms of school holidays, half terms, in advance, you know, whenever, if its for my neurotypical daughter, I can book a club now, for her half term. For my son, nothing. We need children with

disabilities should be treated like children and given the same opportunities. And I just don't feel that we get those at the moment.

Narratives of social care that are dominated by older people needing care at home, meant that some families felt they were unable to secure a Personal Assistant to take their children out and about, as the workforce was prepared for more passive clients who needed care at home.

I explained I've got a direct payment, this is how much we're getting, this is how much I would be able to pay you, and this is what we would like to do. So every weekend on a Saturday we'd like to do this, and then on the holidays we would like to do that. And they would say actually they weren't interested in that sort of type of support. They were looking more to go into somebody's house, and they were more prepared to support somebody who was either elderly, or maybe in a disabled adult who they could support at home, not go out for activities.

Choice is key to meeting individualised needs so that families can utilise provision. This may be needs arising from their disability, personal preference, cultural needs or needs of the whole family. A one size fits all approach was evident in the majority of parent stories, meaning provision was not suitable when offered.

He would not go to any place like that, where all the children are together and they're playing. He wouldn't go. It's a new thing for him. So we had to decline that.

Families wanted provision where aspirations matched the ability of their young person to participate, aspirations were sometimes perceived too low.

There's no way my son is going to go gardening, he wouldn't be able to cope, I can only turn up to things that, you know, they're suitable and if you're happy doing that, fine I know that my son would not be.

However, parents report workforce issues resulting in inconsistent staffing levels, with sessions cancelled or parents working around availability of staff rather than what they need.

It's hard. It's very hard, because PAs they don't get paid a lot, they're on minimum wage, so if they've got their own families, I've got to kind of be... You know what it is, the parent has to be the more grateful one, and you have to kind of try and fit in more with them, rather than them fit in with you, because there's a shortage of PAs anyway and support staff.

Our PA has been off quite a lot, so it's not... it's not consistent, how I wanted it for her.

Within the home, housing adaptations provide space and right to privacy and family life, ensuring families with disabled children can remain together. Families describe challenges with adaptations combined with staff spending time within the family home.

I don't want him to live separately from me, but an ensuite bedroom would help, because I don't like having to use the toilet, erm the carers could come in, or knock on the door. When they're here, it's not my own home.

We have not had any adaptations done. We got to the point of contract, erm, which I took to get legal advice and they said 'don't sign it, it's illegal'. Basically they (Local Authority) wanted me to sign a blank cheque. And then on top of that they said, 'oh, and by the way, we put a £10,000 loan on your house'. At the time I'd been told my child wasn't gonna live past the end of that year maybe, and I said, 'so what happens if my son passes away while you're building?' 'We stop, we walk away that day, that's it - but you still have the £10,000 loan on your house.'

We've done work to make it so that I can get him in and out of the house, because they wouldn't even give us the ramp, we've done all that ourselves. But things like hoists, I can't - you know, where do I buy a hoist?

Carers within the home affect the nature of family life for the rest of the household.

But actually the thing is not that I wanted to go and do my things, but I just wanted to relax and sit down. I don't know but it wasn't such a relaxed experience to have her around (Personal Assistant) while she was around.

Families talked about a new energy that carers can bring to the household, benefitting the family and giving respite from the mental load to parents

And this is when a carer is useful because they don't have that life, so they can come in for those hours and give that energy and leave. Whereas for us, you don't even know if we're gonna sleep that night.

3.4.5 Holistic Needs of the Family

Families talk about losing time to the process to get social care in place, chase staff and secure provision that prevents time together as a family. Parents want support for their disabled children and their family, that is delivered in a way to benefit their whole family and enables them to spend time together.

I think we don't get to do much as a family. We tend to be split all the time, so it's me and the older two, or my husband and the older two, and the other one stays with him, just because he's been so poorly recently. I'd love us to be able to go out, all five of us together.

Siblings attending young carer activities get to meet young people with similar experiences, reducing the isolation they may feel when they are with peers who are not young carers. As with disabled children's support it can often be provided in a fragmented way. For example, the family below have access to a local provider for short breaks but as they do not have a car and it is over 40 minutes away their siblings cannot attend. However, the provision does provide activities within the home that they can access.

We don't have a car, from here its about 40 minutes so we cant access the facilities but for things like sibling support they will come out and see the kids and come see them in school and stuff so that's helpful.

As a family it would be nice to have some help. I think mental health help would be good, just checking in on the family, maybe support with the siblings as well, you know. Because we've had to, we've challenged everything ourselves as a family, and you worry, you know about the rest of your siblings that - obviously the focus has been on him for so long and trying to make sure he's OK you don't want to forget about the other ones as well. So, I don't know, it's, it's kind of hard, it's really hard.

Group sessions for parents facilitate individual friendships that continue outside of groups, a source of information, emotional and practical support.

3.4.6 Changing Needs

Provision needs to be responsive to changing needs, either as their children grow and develop or as their circumstances change as a family. However, parents gave examples where support was short term only.

When my child was younger, we had a personal worker, I don't know what her title was and she was like my little personal assistant. She was amazing. She helped me organise appointments, and she'd speak to doctors, and she'd chase things up, and she'd sign paperwork, and she'd help me apply for grants and things, all that and then once they turned 5, that was gone.

Parents describe changes to their health, but due to lack of support their health deteriorated further or they developed a long-term issue being long term.

Because they gave me no support, it meant that my back condition has now become permanent. Had I received support then I could have recovered, been back on my feet and all would have been well, because of those weeks of them

neglecting to give any support, my condition is now permanent, my back injury.

I myself, I have a benign brain tumour, and I am due to go for surgery anytime now - and I've also got aneurysms on the brain as well. Now, obviously, it's quite a serious condition, it's classed as a disability. Erm, I've been trying like hell to try and get some sort of respite care for the kids to go to... he's [husband] obviously going to book the week off when I'm in hospital, but after that, I'm on my own again, so I won't have any support, and obviously having major surgery, Her [staff] solution was to put my kids in temporary care, and I'm like, 'hell no, not happening'.

Support plans that included options for emergency provision, was provided in some areas and alleviated fears of parent carers about what may happen to their disabled children if they were unavailable to them if there was an emergency.

They've done like a emergency plan, where if I'm ever stuck somewhere or something, they can come and sit with the children or something like that.

3.4.7 Cultural or needs due to ethnicity

As already discussed, parents of disabled children from black and Asian ethnic minority groups may need support to develop their confidence when contacting social care. Services should also be prepared to offer support for families experiencing racial bias when trying to secure provision for their disabled children. Parents describe such instances within social care and in the wider community as affecting their confidence and reducing the energy needed to engage with service.

I don't know that people didn't want to automatically want to be around but I think it was more that some people just weren't confident enough to be around somebody of a different culture.

Parents describe the additional emotional pressure placed on them when dealing with a combination of ableist attitudes and negative attitudes regarding their race.

When we're out together just the two of us, I have to think about how it affects my child. I have to think about her disability and how other people are thinking of her in terms of her race. There's so many things that I have to think about and act on. I think it would have been helpful if, within social services, we could have gotten or support to find a more diverse, more diverse support.

Service provision also needs to include processes for families to report issues of discrimination they may experience. Parents report instances where they feel they do not get the same level of service as their peer group from a different ethnicity.

They will come and see him once a week for an hour, which is the same information that I got from other parents as well. But when they get to come back in touch with me again the next week, they were saying that they were only going to see him for every 2 weeks. And I was like, 'um, I told you, you told me it's supposed to be every week, right?' And I got from other parents as well and they were like, 'oh, no, no, no, you got it wrong, we only come to visit every 2 weeks'.

I would say with them, I've had a couple of, like, I felt were a bit negative experiences, because I felt the person I was speaking to wasn't really showing any empathy. And I did, I did feel in my gut it was to do with race, but obviously, you know, they're not saying it, but you know, you know, don't you? You can sense it, you can feel it.

There were instances when parents felt that they were unable to secure support due to their ethnicity or negative interactions with staff were racially motivated.

I found it very hard to find the carer. I think there may be some, erm, some... I find this really hard to say that there may be some racial bias because

I interviewed quite a few people and I live in a very homogenous area. I felt that was part of the issue.

A parent described an incident with a care provider that escalated due to the racism of staff involved.

I phoned the carer, saying he's running late, can you ask the carers to wait outside?', yeah. So anyway, I got him ready, we went outside and the carers were outside but they've gone off, they're driven off, Rather than waiting outside the house, they've driven off now. Then, oh, I've got a complaint from the carer, you need to have a meeting because, you know, you signed this document on working together, so on the basis of that, we need to, we need to talk about this complaint'. So if that's not racist, what is it? She didn't give me a courtesy call on Monday to say, 'look, I'm sorry, you know, the carer didn't turn up', but then she's wanting a letter, a meeting because the carer call... raised a complaint about me, saying that I've got problem, that I'm not working together with them properly.

The focus of this project was social care but parents highlighted microaggressions, racial bias and racism across all aspects of their lives. A cumulative impact on parents confidence and mental health was clearly evident. In addition to their ethnicity, parents also reported their needs being minimised in relation to other parts of their identity, for example gender or socio-economic status.

I think I've been dismissed a few times, but I also, you know, I don't know if that's ethnicity as well as being a woman. You know, it could be both things.

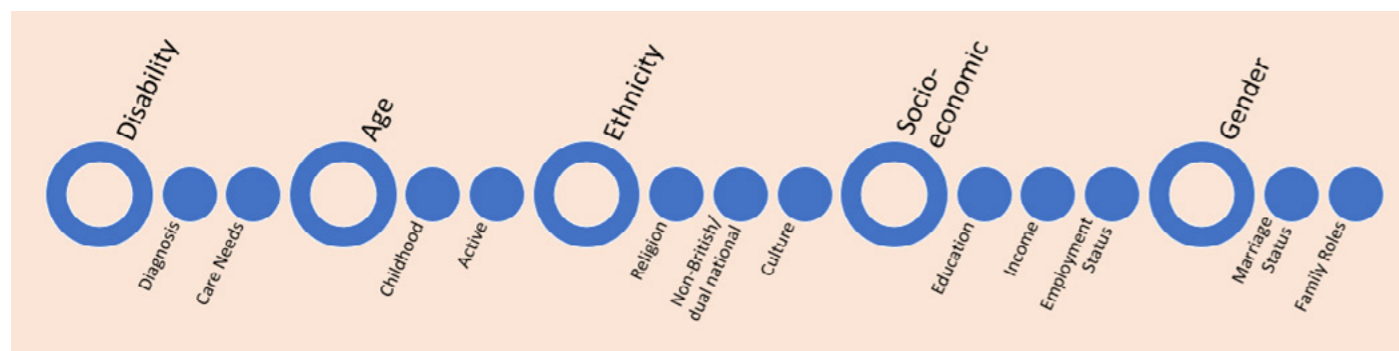
I think there's, definitely a monetary situation, where, basically, if you've got the money to pay for it, they hope that you will. Because, to the point where, it just feels like, if you can pay for it, they'll allow you to do so.

Parents report support from other people from the same ethnicity as being beneficial for their mental health. Groups and activities did not necessarily need to include a disability focus. Parents valued groups based on activism and hobbies and interests.

I was going through very low mood in the beginning of this year, and I had to actually up my anti-depressants, I was really struggling, and the only thing we had in common was that we were all black females,. Attending that really, really did help because I hadn't really, other than friends, I hadn't spoken to so many black women.

Disability and ethnicity and their child's age was the most common characteristic that parents referred to when talking about their needs, however parents would welcome more choice in support available. Figure three provides an overview of the intersectionality of parent's identities. Support that looks beyond their child's disability or ethnicity and moves away from a one size fits all approach and takes into account their individual needs associated with each part of their identity.

Fig 3: Intersectional characteristics highlighted by parents of disabled children from Black, Asian and Mixed ethnic minority groups.



The following section provides an overview of the various community groups that parents valued for support, outside of statutory services.

3.5 Community

3.5.1 Introduction

Parents of disabled children and young people taking part in the interviews for this project, talked about the benefits that being members of various communities and social groups brought to them and their families. They also welcomed more awareness raising and work to change the narrative and attitudes towards people with disabilities in wider society. Some described communities they were part of prior to their child's diagnosis and others described new groups. Parents also described

challenges in engaging with some community groups and this section discusses the needs of families from the wider community for example: other parent groups, groups run by charities, school communities and religious or faith-based organisations.

3.5.2 Parents of disabled children

Parents describe the support they get from other parents of disabled children, either online or in person. Groups may be based around diagnosis or more generalised disability, based around level of care need. Parents met other parents at courses run in person online by local or national charities or training providers.

I've been part of that group for about 6 years, and the most valuable information I've had is from them and not professionals, because they've lived through it, so they know what I'm going through.

Yeah, we used to have, erm, ASD. We used to have an autistic, like, support groups, but that was closed down due to funding.

Parental support in the form of online forums was a source of expertise, advice and moral support.

Because I've been speaking to other parent carers who had, you know, in the forum - so we all sort of knew what should be happening, so as soon as something didn't happen, we would go back to the local authority saying, you know, 'I haven't had this'.

So there's a parent WhatsApp, which I'm on for our local area and they have been a hive of knowledge, to be able to pass on information.

3.5.3 School Community

Additional benefits of a school community were highlighted by parents of disabled children that attended specialist provision. Parents valued spending time with other parents who were part of the school community, again a source of information and emotional support.

I do interact with other parents. It's nice, it's nicer to talk to somebody who's going through it. Because you know that with a person from school you're not feeling like it's a burden.

Parents emphasised a camaraderie culture with other members of the school community. They accepted support as they knew that parents and staff at the school understood their experiences and needs.

They're really supportive. So, for example, when my son was in hospital, we had visits from the head teacher, school teacher. We did FaceTime so that he could join in the classes when he was able to. Individual staff members have said, you

know, 'if you need me to do this, if you want me to pick up this' - because everybody's quite local, you know, for me to go and pick up a prescription for you, because there are times when I'm literally housebound with my son.

Opportunities for parents to meet other parents of disabled children need to be beyond the school. Many disabled children travel away from their local community to school due to the lack of specialist support available, with parents and disabled children losing out on opportunities to connect with other families. For some parents, the school community did not feel to be the most appropriate environment for them to receive emotional support. This may be connected to the stigma of using social care services that parents referred to when discussing their needs from the process.

The school said if I ever need a chat, I can go in and have a chat with them, but then who wants to go to the school? ...And it's, I don't know, I just don't feel comfortable going and chatting to teachers.

3.5.4 Parents with disabled children from same ethnic background

Online forums were beneficial for parents who lived in areas with lower numbers of families from black and Asian ethnic minority groups to reach out to families in other areas for advice and support. Online groups also give parents the chance to build up their confidence, before interacting in person, when the lack of support meant parents were unable to attend groups.

Because it's always been online, there was no way I could have gone out because my daughter wasn't at school. I wasn't able to go, I was unable. I just didn't, I didn't have the confidence to be in any setting with her so without it I'm not able to interact with anybody.

Sometimes I can't go and come to peoples' houses and like other people, they don't understand why I have to come back early,

or you know, they don't understand.

Parents valued spending time with parents of disabled children from the same ethnic group. Group activities enabled parents to form friendships, that were a source of advice and emotional support.

I did a course, and then at the end I met two other parents, who was African, and I spoke to them, we exchanged numbers. They're more understanding, they're more sympathetic, more than somebody who's not going through it.

It's been organised by the community. It started off with them doing something for the older generation who, you know, during COVID were all stuck at home and then its since then moved on to family. So the term they use is 'family nights'. So you bring your family there and, you know, it's actually been quite nice, because the other day, all of us, our whole family went together, my husband, my other daughter and all of us. And, you know, because there was other people there that we knew, we could all do our own thing and also get together as a family.

Community events described above provide all members of a disabled child's family the opportunity to connect with other families with or without a disability focus. The religious community here providing an example of support with a holistic family focus.

3.5.5 Religious Organisations

Parents gave examples of religious, cultural or faith organisations establishing groups for support for families with disabled children but participants acknowledge that this tended to depend on the experiences of community leaders regarding disability. Parents talked about large numbers attending newly created groups, emphasising needs within the community. The long-term impact sessions had on support outside of the group, continued long after initial connections were made.

I thought, I can't be the only Muslim Asian parent who's got a child with special needs, who's

struggling, who'd like to meet other parents who understand our cultural and faith nuances that other people may not understand. The group it's based in the local area, and it was amazing the first time they did the coffee morning, 21 women came. So it just goes to show how much of a need there is for community centres, faith centres, to have that provision.

Some parents described a lack of disability awareness within their community organisation that translated into a lack of practical support.

I think sometimes there can be a lot of stigma, in different cultures, some people kind of like 'oh yeah, they'll grow out of it, there's nothing wrong with them', you know what I mean? 'Let's pray for them'. They're not actually, they're not actually understanding of everything behind it.

Parents suggested places of faith and disability organisations working together to offer support to families with disabled children, and to provide disability awareness sessions to non-disabled members of the community.

[faith based organisations] I don't think they are trained up in this kind of thing, they should be because they should be able to help people in the community. I mean, the mosque is not just for praying, they should do outreach work as well.

Families also value religious or spiritual teaching to be organised in a more accessible way.

I don't know if you know much about Islam, but one of the things we do is we learn our religious book, and we haven't been able to source anyone that can support him to do that. So, we've just been supporting him at home ourselves.

3.5.6 Charity

As with the findings around process, it was common for parents to talk about the financial pressures on charities to provide support for families. Parents had experiences of finding that charities or voluntary groups on the list of services given by

local authority staff having reduced sessions or had closed completely. Families welcomed choice in activities and felt that over time this had reduced in line with reductions to local authority budgets.

It was a charity they offered a very good service. For whatever reason or other, that charity broke down, but the council did nothing to replace it.

However, the role of charities offering advice on their rights, their child's diagnosis and support available through grants or benefits were highly valued by parents. Parents gave examples of grant applications for equipment and technology for their disabled children, household items and accessing trips out or holidays funded through local or national charities. As with statutory services, parents highlighted the need for cultural awareness to be embedded in the support provided as well as increased representation of staff from black and Asian ethnic groups.

Charities gave parents opportunities to be with other parents of disabled children, facilitating peer to peer support and advocacy both in-person and online. In order for parents to receive more culturally embedded support, it was felt that collaboration between charities and cultural organisations would be appropriate in order to provide support to families where the needs from disability and ethnicity intersect

"I thought, I can't be the only Muslim Asian parent who's got a child with special needs, who's struggling."

4. Summary

Disabled children and their families from black, Asian and mixed ethnic minority groups need access to a social care system that places their voices at the heart of the process. Parent and Professional Partnerships need to be enhanced in order to navigate and advocate support that meets individual needs.

The process needs to be comprehensive in assessing the holistic needs of family members. It needs to be transparent, from the point of needing information right through to provision of care and support, with parents aware of their rights and the expected process, including avenues to address or report inappropriate interactions. Support needs

to address changing needs and plan for expected long term needs of the family, rather than the crisis model that parents currently experience.

A social care workforce supporting disabled children and their families must have the knowledge, training and expertise to ensure families are confident their children will be safe and secure, supported by teams who understand needs related to their disability (communication, medication, sensory, mobility, dietary and equipment or technological needs), incorporating cultural needs and other intersectional needs such as gender or language, examples shown in figure 4.

Figure 4: Components of a social care support system for disabled children and their families from black and Asian ethnic minority groups



Families with disabled children are at risk of social isolation, leaving them at risk of reduced life outcomes. Services for disabled children from black, Asian and mixed ethnic minority groups need to be designed to support families who may have different cultural reference points of disability, provide safe spaces for parents to meet others from the same ethnic group, supported to understand and adjust to their child's diagnosis, develop confidence and advocacy skills and receive emotional support and practical advice.

Parents taking part in this project described microaggressions, interactions based on cultural stereotypes and instances of racism at various

stages of the assessment, approval and provision of social care. It was also clear that racist experiences in wider society, has a layering effect on parents' emotional strength, confidence and ability to engage with services when needing support. A system that views families with disabled children through the lens of support as opposed to inspection and risk would be significant in supporting families better.

Parents would also welcome collaboration between the disability charitable sector, non-disabled organisations and religious and spiritual associations, to offer greater understanding and inclusion of families with disabled children, encouraging belonging and reducing isolation.

Projects that focus on the social support needs from an intersectional perspective are required. The strength of this project includes the role of parent-researchers in the co-production of the design and execution of the research. Their lived experience ensured prompts used during interviews generated rich and full qualitative data, providing insight into the needs of families with social care needs from this seldom heard group of parents. Although, it was more common for participant's social care needs to be unmet, conversations elicited thoughts about what good quality support would be in a system that viewed disabled children through the lens of support, with the aim of supporting families with access to life opportunities that enables them to thrive and flourish.

Local authorities should:

- Review their services and processes, and the information and guidance they provide about them, to ensure they meet the specific needs of families with disabled children from black and Asian minority ethnic backgrounds.
- Monitor the impact of their support on children and families, with a focus on intersectionality and the voice of children and families.
- Work with the voluntary sector and community groups to develop capacity, improve understanding of disability, and overcome isolation.

The Department for Education should:

- Ensure a specific focus on support for families with disabled children from black and Asian minority ethnic backgrounds in its Families First For Children pathfinders.
- Monitor and evaluate the impact of its reform programme on families with disabled children from black and Asian minority ethnic backgrounds.

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6. Appendices

Appendix I – Co-Production Project Design

This topic was highlighted as a research priority by parents of disabled children taking part in focus groups about their experiences during the Covid-19 pandemic. The proposal was developed with parents of disabled children from black and Asian backgrounds and staff from across the Disabled Children’s Partnership, with responsibility for working with families from ethnic minority groups.

Parents of disabled children worked as parent-researchers and parent-advisors on this project. All had previous experience working as parent-consultants on behalf of Contact, providing advice to other parents or had experience representing parents of disabled children as part of the Disabled Children’s Partnership campaign work. Eight parents were involved in the project. One worked as a parent-advisor, providing input into the overall strategy for the project and seven worked as parent-researchers.

The research experience of parent-researchers ranged from managing research projects either professionally or through graduate and postgraduate study, to no former research experience. Principles of co-production published by the Social Care Institute for Excellence (2022)³⁸ were reviewed and adapted for this project. In order for parents to input into the project effectively, training was provided at the start of the project covering research concepts, research paradigms and how they translate into research methodology. Training also covered research methods and covered tools, data collection and analysis techniques relevant to this project, so that discussions around options for design of each of the phases could be productive.

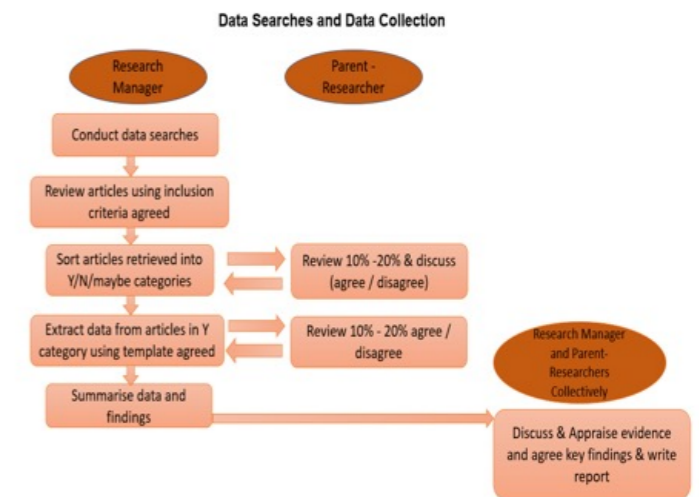
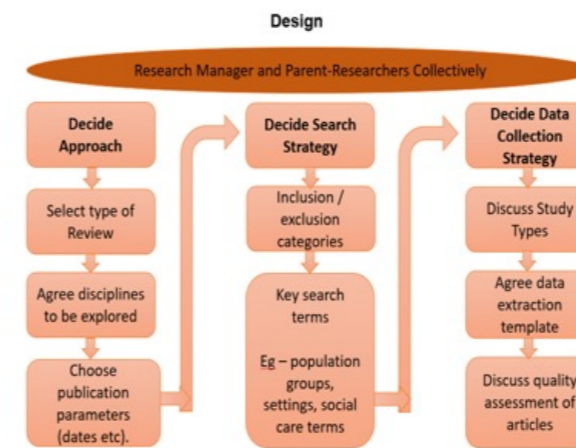
Parents of disabled children by nature of their lived experience have the skills required to undertake research projects. For example,

assessing information (often conflicting) given to them about their disabled child’s support needs from professionals and comparing it from other sources means that they already have critical skills needed for research, developed in a non-research environment. Their lived experience of caring for a disabled child meant they already had attributes needed to undertake interviews with other parents, such as emotional intelligence and empathy. Their knowledge of the social care support system also meant that during interviews, parent-researchers could draw on their experience to prompt participants, drawing out rich data.

In addition to caring for their disabled child, parent carers spend a large amount of time managing multiple care providers and liaising with multiple professionals across education, health and social care. It is common for parents to report fighting the system leaving little time for them to work and therefore giving up employment. The project was designed with adjustments to ensure parent-researchers could fully participate at the forefront of workplan, rather than as a contingency “in case” flexibility was needed. The project was designed on the basis that changes in needs and availability of parent-researchers was an “expected” element and approaches to co-production were developed with this in mind.

Parent-researchers were split into sub-groups to work on each phase. Workshops were arranged so that the whole group would meet to input into key concepts that should be included into the design at the start of the phase and review themes and findings at the end of the phase. Materials to aid discussion were sent in advance of each workshop and input was provided by parent-researchers during each session with the option to send additional feedback later.

Phase I Literature Review – Co-Production



Phase 2 Interviews – Co-Production



Appendix 2 - Literature Review Design and Search Parameters

A scoping review of the literature was chosen as the method to be used as it is beneficial for studies that are exploratory in nature. It is undertaken in a rigorous manner to identify themes in the literature⁴⁰. Scoping reviews provide a rapid way of mapping the literature in a systematic way, without then need to quality assess selected articles⁴¹.

The academic literature was searched using Sociology Source Ultimate and google scholar. The research team also reached out directly to academics within this field. A Spider search template (Sample, Phenomenon of Interest, Design, Evaluation, Research)⁴² was used to design the parameters of the scoping review.

Sample: Disabled Children and their families from black, Asian and Mixed ethnic minority groups.

Families – Parent, Parent Carer, Mother, Father, Guardian, Disabled Children Disabled Young People and Sibling(s).

Ethnicity – Asian/Asian British (Indian, Pakistani, Bangladeshi, Chinese, any other Asian background), Black / African / Caribbean / Black British (African, Caribbean, Any other Black/African Caribbean background), Mixed/Multiple ethnic groups (White and Black Caribbean, White and Black African, White and Asian, Any other mixed/multiple ethnic background). Other Ethnic group (Arab, Any other ethnic group).

Disability – Acquired Brain Injury, ADHD, Autism, Genetic Condition, Hearing impairment, learning disability (mild, moderate, profound), life limiting or life threatening, multi-sensory impairment, newly acquired impairment, newly acquired impairment, physical disability, rare condition, social emotional and mental health needs, speech and language and communication difficulties, visual impairment, undiagnosed.

Phenomenon: Social Care Needs

Formal support in the home – Personal care, personal assistant, domiciliary care, overnight respite in the home, equipment provision, equipment maintenance, home adaptations, activity worker within the home.

Formal Support Away from the home (community or other settings) – Transport, Short breaks/ respite, family link scheme, day care, club, activities, holiday club

Formal Provider – Charity, local government, voluntary, private, independent, school

Informal Support Family & Friends – childcare, transport, support within the home, respite.

Design: Published literature, grey literature, academic teams from 2007 to present day.

Evaluation (eg, characteristics): experiences, needs, opinion, stories, views.

Research Type: expected to find mostly qualitative studies but include all research type. UK studies.

Appendix 3 – Phase Two (Interview) Methods

Recruitment Strategy

A Participant Information Sheet was co-produced with parent-researchers. It was distributed via the charity Contact and Disabled Children's Partnership campaign list. Potential participants were encouraged to contact the lead for the research project to express their willingness to take part in the interviews or to ask any questions. 60 parents initially expressed their interest in taking part or finding out more about the project.

Parents were sent a link to complete further demographic information about themselves and their family. This was used to recruit a wide cohort of parents based on their ethnicity, geographical location and the needs of their disabled children. Parents completed a consent form based on Informed Consent Principles⁴⁰ prior to the interview being arranged. Parent-researchers arranged online interviews to take place at a time convenient to participants using Microsoft Teams.

Research Methods

All interviews were recorded and parent-researchers checked consent verbally before each interview and recording commenced. All participants were reminded that they did not need to answer any questions that they were uncomfortable with and they could postpone or withdraw from the interview at any point (prior to data synthesis) without giving a reason.

Qualitative interviews were the chosen method for phase 2 (see Appendix one for co-production methods) as they possess greater flexibility enabling the parent-researcher to respond dependent on the direction in which the interviewee takes the conversation⁴⁴. Semi-structured interviews were selected, as although unstructured interviews may give greater flexibility to participants to tell their

story, it can also add more pressure and burden. Therefore, semi-structured interviews were felt to be more appropriate.

At the end of the interview, for parents who had gaps in support, parent-researchers signposted them to appropriate organisations. All participants were given a voucher as a thank you for their participation. Interview recordings were transcribed in full. All parents taking part in the interview were offered a copy of their transcript.

Transcripts were coded using a deductive and inductive approach and analysed using thematic analysis⁴⁵.

Appendix 4 – Interview Questions

Interview Questions

1. Could you start by giving an overview of your child's needs / disability
2. Could you give a little bit of an overview of your disabled child's social care needs and what help they need in terms of social care support.
3. [if applicable] What support do you feel is needed for your other children? What is in place and what is not available or outstanding?
 - young carers support
 - opportunity to meet other young carers
 - support from professionals
4. What support do you feel you need for yourself? do they have a disability? What is in place and what is not available or is outstanding?
5. Thinking about the support you mentioned above – what has your interaction with professionals been like?
6. What role do you feel your ethnicity plays in the type of support you get and what you may need?
7. Can you talk a little about the role professionals (eg care worker, activity coordinator, PA, social worker) play in the support that you get, how do professionals meet your needs?
8. Can you talk a little about the support you get or may want from other parents?
9. How have you found out about the support that might be available to you?
10. If you had a blank canvas and could choose exactly the type of support you need, what would that look like?
11. Could you talk a little about how any provision of support you have received has met your needs as a parent carers/you own disability/health condition.

12. [if not already covered above] what has your experience been finding out about the type of financial support you might be eligible for such as:

- Direct payments
- Grants (charitable & local authority)
- Benefits

12b. If you have received financial support or access to grants, what has this enabled you to do?

Does it enable you to choose more of the things you need and enjoy or are you restricted

13. [if not already covered above] could you talk a little about any mental health support you or your children might have needed and if you have tried to access support

14. [if not already covered] what would help with your families mental health – what would good support look like

- Activities – sessions (home or community),
- Respite
- Childcare
- Resilience strategies
- Support from GP such as anti-depressants

15. Is there anything I haven't asked you that you think is important for us to know for this project – is there anything that you would like to tell us?



 disabledchildrens.partnership@mencap.org.uk

 [@DisabledChildrensPartnership](https://www.instagram.com/DisabledChildrensPartnership)

 [@DisabledChildrensPartnership](https://www.facebook.com/DisabledChildrensPartnership)

 [@DCPCampaign](https://twitter.com/DCPCampaign)

 disabledchildrenspartnership.org.uk

The Disabled Children's Partnership (DCP) is a growing coalition of more than 120 charities who have joined forces, working closely in partnership with parents, to campaign for improved health and social care for disabled children, young people and their families. We are administered by Royal Mencap Society (registered company in England and Wales no. 00550457; registered charity numbers are 222377 in England and Wales, and SC041079 in Scotland).

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