“Our Lives are Completely Different to Anyone Else”: An Exploration into the Experiences of Pakistani Parents’ Accessing and Engaging with Services and Professionals Who Work Together to Support Children with Special Educational Needs and Disabilities and Their Families

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Abstract

School census data from 2005 to 2011 showed that students from minoritised ethnic groups such as Indian, Pakistani and Bangladeshi backgrounds were half as likely to be identified with autism as their white British peers (Strand & Lindorff, 2018). This may be the consequence of parents not engaging with services and professionals who work to support children and their families with SEND due to their limited understanding or awareness of SEND. Research highlights that minoritised ethnic communities experience significant difficulties in accessing and engaging with services due to factors such as power imbalances, communication difficulties and lack of knowledge of the roles of professionals and services (Akbar & Woods, 2020; Lawrence et al., 2014; Nnalue & Mahmud, 2024). To date, there is limited research on minoritised ethnic communities accessing and engaging with services conducted in their own language.

This research aimed to explore the experiences of five Pakistani parents accessing and engaging with services and professionals working together to support children and their families with SEND. Participants were parents who identified as belonging to the Pakistani community, with a child with SEND and they had been through the EHCP process. Semi-structured interviews in Urdu were used to gain the views of the parents. Inductive analysis was applied to develop key themes from the parents' views of their experiences. Reflexive thematic analysis was used as a method to analyse data and the theoretical assumptions and researcher's prior knowledge, and experience were used to guide this.

The results indicated facilitators and barriers for parents accessing and engaging with services and professionals who work together to support children and their families with SEND. Barriers for parents included access to services including awareness and understanding of services. They also included parents not feeling valued during decision making processes and delays in accessing support. Other barriers included relationships between professionals and parents including communication difficulties and their perceptions of services and professionals. Facilitating factors included parental motivation and advocacy, open and honest communication between parents and professionals and flexibility of professionals. A key implication of this research was that that parents would prefer the negotiation model, where parents and professionals are able to negotiate and work together collaboratively. However, this may not be the case, dependent on their confidence levels, and their personal journey and attitudes towards disability.

Dedication

"Verily with hardship comes ease"

[Quran: 94:5]

For my 'Nana-Abu', your legacy and values remain with me today and always ….

For my Nanny, your duas and love always make the world a better place …

For my Mum, for your unfaltering belief in me, you are my inspiration ….

For my Baby Yusuf, your smile brightened the difficult days, you are the source of my motivation …

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To my sister, Kiran, thank you for babysitting and allowing me to have the head space to finish my thesis. Thank you for your words of wisdom when I started to lose hope. Here's hoping my schedule is 'less busy' now and we are able to spend more time together.

To my Mum and Dad, you both are my inspiration and strength. Whatever I am, is because of you. 'Thank you' will never be enough.

Finally, thank you to my Yusuf. Your smile brightens my world, and your cuddles were much appreciated on long writing days! All my time is now yours …. We made it!

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Abbreviations

AP – Alternative Provision

BERA – British Educational Research Association

BPS – British Psychological Society

DCSF – Department for Children, Schools and Families

DfE – Department for Education

DfES – Department for Education and Skills

DoH – Department of Health

EHCP – Education, Health and Care Plan

EP – Educational Psychologist

EPS – Educational Psychology Service

IPA – Interpretative Phenomenological Analysis

LA – Local Authority

RTA – Reflexive Thematic Analysis

SEND – Special Educational Needs and Disabilities

TA – Thematic Analysis

UK – United Kingdom

Chapter 1: Introduction

This chapter outlines the process of identifying the research topic, followed by the rationale for the research. An overview of the chapters is also included.

1.1. Personal and Professional Journey

This research explores the experiences of Pakistani parents' accessing and engaging with services and professionals who work to support children with special educational needs and disabilities (SEND) and their families. I was motivated by my personal and professional experiences to research this topic area.

I am from a Pakistani background, my Mum and I were born in Birmingham, whereas my Dad was born in a small town in Pakistan called Dina. Growing up, I regularly visited my extended family in Pakistan, and I remained connected with my ethnicity through traditions, and interactions within the community. I have first-hand witnessed how difficult it can be for members of my community to access and engage with services, particularly with services and professionals who work to support children with SEND and their families, as the procedures and processes can be very complicated. My cousin is from Pakistan and her son was diagnosed with autism at the age of 3 years old and I saw how difficult it was for her to navigate the SEND system to get help for her son. She found it very overwhelming when trying to engage with professionals and she was very unsure about their roles. I also witnessed how often, when individuals from my community finally managed to access services and professionals who work to support children with SEND and their families, they did not engage, and I wanted to explore the reasons for this.

On placement I continued to reflect on the role of the Educational Psychologist (EP) in promoting anti-oppressive practice and how they engaged with communities who experience difficulties in accessing services. Working with parents and families and working consciously to promote anti-oppressive practice and social justice are at the core of the values of my practice.

1.2. Rationale for research undertaken

1.2.1. National Context

Nationally in the 2021 Census within England and Wales, 81.7% (48.7 million) of usual residents in England and Wales identified their ethnic group within the “White” category, a decrease from 86.0% (48.2 million) in the 2011 Census (Office for National Statistics [ONS], 2021) (see Figure 1). The next most common ethnic group was “Asian, Asian British or Asian Welsh” accounting for 9.3% (5.5 million) of the overall population and this ethnic group also saw the largest percentage point increase from 2011, up from 7.5% (4.2 million people) (ONS, 2021). Within the 2021 Census, the category “Asian, Asian British or Asian Welsh” referred to individuals who identified as belonging to the following ethnicities, “Bangladeshi, Chinese, Indian, Pakistani and Other Asian” (ONS, 2021).

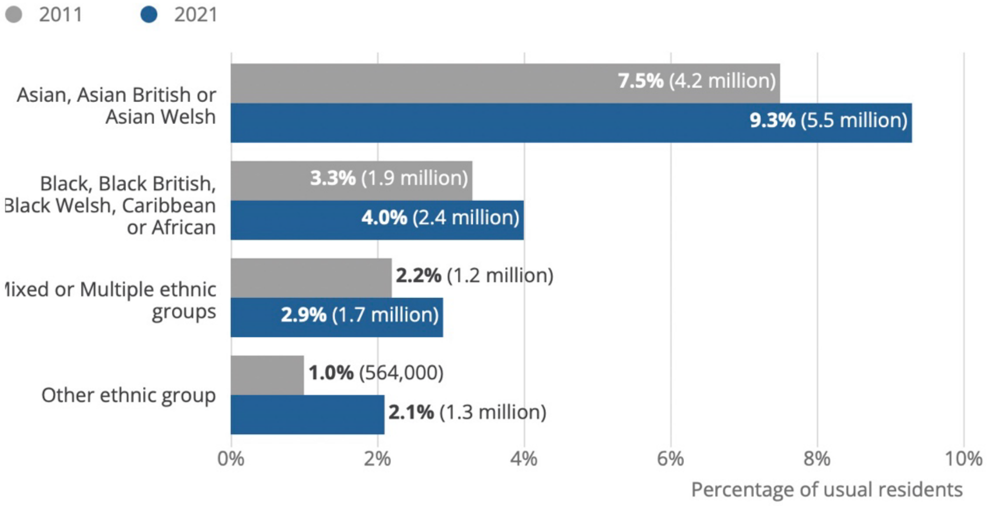

Figure 1: Differences in the ethnic group distribution in England and Wales between 2011 and 2021 as reported by the Census 2021, (ONS, 2021)

1.2.2. Local Context

Locally within Birmingham, according to the Office for National Statistics, after the group “White: English, Welsh, Scottish, Northern Irish or British who account for 491,211 people in the city, the next largest group are the individuals who identify themselves as “Asian, Asian British or Asian Welsh: Pakistani” who account for 195,102 people in the city (ONS, 2021).

According to a publication released by the Special Educational Needs Statistics Team on the Special Educational Needs in England (DfE, 2023) (see Table 1 below), within Birmingham, the percentage of the population classed as having SEND and being Pakistani has increased from 22.3% in 2015/2016 to 24% in 2022/2023.

Percentage of the population classed as having SEND in Birmingham between 2015/16 and 2022/23			
	Asian – Pakistani (%)	White – White Background (%)	White – any other white background (%)
2015/2016	22.3	28.6	3
2016/2017	24.5	30.7	3.8
2017/2018	24.6	29.7	3.9
2018/2019	24.4	29	4.1
2019/2020	24.4	28.3	4.1
2020/2021	24.3	27.8	4
2021/2022	24.2	26.9	4
2022/2023	24	25.8	4.1

Table 1: Percentage of the population classed as having SEND in Birmingham between 2015/16 and 2022/23 (DfE, 2023).

Despite these figures being published, it is important to note that children and young people from minoritised ethnic groups have been found to be under-represented for SEND (Strand & Lindorff, 2018) and the actual figures may be a lot higher. School census data from 2005 to 2011 showed that students from minoritised ethnic groups such as Indian, Pakistani and Bangladeshi backgrounds were half as likely to be identified with autism as their white British peers (Strand & Lindorff, 2018). This may be the consequence of parents not engaging with services and professionals who work to support children with SEND and their families due to their limited understanding or awareness of SEND.

1.2.3. Intended Research

There is substantial research to show that parents from minoritised ethnic groups struggle to engage with services which can often lead to a delay in accessing support for their child, particularly for families who come from a South Asian background (Azmi et al., 1996; Hatton et al., 1998; Mir et al., 2001). Furthermore, due to language barriers, it can be difficult to gain an understanding of the difficulties that families experience, and this can leave parents experiencing high levels of anxiety and depression (Hatton et al., 2011). Whilst there is research on Pakistani parents' experiences of SEND (Akbar & Woods, 2020; Habib et al., 2017; Heer et al., 2015), there have not been any recent studies that have conducted interviews fully in home language to gain the views of Pakistani parents and therefore this research fills a gap within the literature. Heer at al. (2015) conducted interviews with parents and some parents used phrases in Urdu which the researcher was able to understand and translate but the majority of the interview was in English. I was interested in gaining the views of Pakistani parents' and I wanted to capture their voice by interviewing them in Urdu to fully describe their experiences which has previously not been represented in the qualitative literature on the experiences of parents accessing services. I decided to interview the parents in Urdu as it is considered to be the national language spoken within Pakistan (Coleman, 2010; Zaidi & Zaki, 2017).

I aimed to add to the literature on the experience of minoritised ethnic parents', specifically Pakistani parents' experiences of engaging and accessing services and professionals who work to support children with SEND and their families. I aimed to include implications of my research and provide recommendations for EP practice and service delivery for those who work with children with SEND and their families.

My personal and professional journey led me to the following research questions:

1. What are the experiences of Pakistani parents' accessing and engaging with services and professionals who work to support children with SEND and their families?
2. What barriers do Pakistani parents' experience when accessing and engaging with services and professionals who work to support children with SEND and their families?
3. What facilitators do Pakistani parents' experience when accessing and engaging with services and professionals who work to support children with SEND and their families?

1.3. My positionality

My position before beginning this research, was that I assumed that all parents would want to work using a negotiation model (Dale, 1996) where parents and professionals would negotiate, share perspectives on issues of mutual concern and thereby make joint decisions. I therefore thought that parents would want to be actively involved with all decisions relating to their child and they would have the confidence to do so. I believed that few parents would want to work with professionals using an 'expert' model where professionals adopt the role of the 'expert' and assess and suggest strategies for a problem without considering the parents' own wishes, views and feelings (Appleton & Minchom, 1990). This is because I thought parents would feel a loss of control and further minoritised by not being involved with decisions relating to their child.

professionals assessing and suggesting strategies for a problem without referring to the parental wishes, views and feelings (Appleton & Minchom, 1990).

1.4. Overview of the Research

Chapter two of this research reviews the relevant literature in the area including the current legislation relating to SEND, statutory processes and exploring the experiences of minoritised ethnic parents accessing and engaging with services and professionals who work to support children with SEND and their families. Next, chapter three details the methodology and research design used in this research. Chapter four summarises the findings for this research and discusses them in relation to the wider literature reviewed in Chapter two. Chapter five explores the implications of this research for professional practice and service delivery. This is followed by a discussion on the strengths and limitations of the current research, suggestions for future possible research and a concluding paragraph on the current research.

1.5. Key Terms

Thompson (1998, p. 34) defines oppression as “inhuman or degrading treatment of individuals or groups; hardship and injustice brought about by the dominance of one group over another; the negative and demeaning exercise of power”. This suggests that oppression and power are linked. Anti-oppressive practice refers to an approach where practitioners are reflective, reflexive and committed to promoting change. They also engage in social work facilitating those who are oppressed in regaining control of their life and re-establish their right to be full and active members of society (Dalrymple & Burke, 2000).

Definitions for the term “minority ethnic groups” are largely debated in research. However, United Kingdom’s (UK) government’s preferred definition of ethnic minorities refers to all ethnic groups except the white British group (UK Government, 2021). There is a suggestion from the government that the term “black Asian and minority ethnic” should not be used because they emphasise certain ethnic minority groups, namely Asian and black, and excludes other groups such as mixed, other and white ethnic minority groups (UK Government, 2021).

Moreover, there is a suggestion that ethnic groups exist as a global majority in the wider world rather than existing as a statistical minority within the UK and so these groups should not be referred to as minority ethnic groups (Sangar & Sewell 2022, p.110). Milner and Jumbe (2020) looked at racial disparities in Covid-19 and found that after using a social constructionist approach to ethnicity, people are actively minoritised rather than existing as a minority. They suggested that social processes are shaped by power and domination and so for this reason, groups should be referred to as minoritised ethnic groups. For the purpose of this research, I will be using this definition and will be referring to the groups as minoritised ethnic groups, as although the groups exist as the global majority in the wider world, they are minoritised by power and domination within certain parts of the world.

Chapter 2: Literature Review

2.1. Introduction

In this chapter, I review key literature, first I review the key legislation relating to SEND, focusing particularly on the role of parents. After this I explore the different models of parent partnerships and I move onto explaining the SEND system and levels of support in the local authority in which I conducted the research. I consider parents' experience of services before discussing specifically minoritised ethnic parents' experiences of services. Finally, I specifically consider parents' experiences of working with EPs and minoritised ethnic parents' experiences of working with EPs, and this is used to provide the rationale for the present study based on gaps in the literature, ending with the research questions.

2.2. Literature Search Strategy

In order to search the literature relating to my research, I used a snowball search strategy. I used the following phrases as search terms: "minority ethnic parents", "ethnic parents", "experiences", "perceptions" and "views". I also used terms such as "special needs", "disability", "special educational needs" and "special educational needs services". I used these phrases in different combinations using "and/or". After completing the search using different databases such as Web of Science, and APA PsychInfo,I looked at the abstracts and drew on the main articles that seemed relevant to my research. I initially focused on minoritised ethnic parents and then further focused on South Asian parents or Pakistani parents. I read these articles and looked at the reference lists for further articles that may be relevant to my research. I only included papers from 2000 onwards within United Kingdom and excluded papers from other countries.

2.3. Legislation

In this section, the key legislation relating to SEND have been identified, from 2001 to present. I began looking at legislation from 2001, as The Special Educational Needs and Disability Act (Her Majesty's Stationery Office [HMSO], 2001) was introduced to extend the Disability Discrimination Act (HMSO, 1995). Under the Act discrimination against pupils with SEN as well as disabilities, was seen as unlawful, and it emphasised meeting the needs of pupils in mainstream education by making 'reasonable adjustments' (HMSO, 2001, p.189). As a result, the legislation after 2001 is more relevant to the present legislation relating to SEND. I will also explain the statutory processes including formal processes such as applying for an Education, Health and Care Plan (EHCP) within the local authority in which my research was undertaken.

2.3.1. The SEN Code of Practice (Department for Education and Skills [DfES], (2001)

The SEN Code of Practice (DfES, 2001) acknowledges the integral role and contribution that a parent has in their child's education. It recognises that parents have knowledge and experience that they can contribute to a shared understanding of their child's needs. The document highlights that professionals should actively work with parents, and they should be treated as partners and should feel empowered to share their opinion in decisions relating to their child's SEN. Parents also should have knowledge about their child's SEN and have access to information and support whilst being informed of any decision-making processes about provision.

2.3.2. The Lamb Inquiry (Department for Children, Schools and Families [DCSF], 2010)

The Lamb Inquiry (DCSF, 2010) was commissioned as parental confidence was found to be a key issue for children with SEN (DCSF, 2008). As a result of this, the Government set up a group of advisers to report on the most effective ways of increasing parental confidence through the SEN assessment process. During the inquiry, it was considered whether parental confidence could be achieved by sharing best practice in developing relationships between local authorities and parents; by developing the 'team around the child' approach in the school stages and by drawing on other evidence from other work commissioned by the Government.

The Lamb Inquiry (2010) found the following:

> In the most successful schools, the effective engagement of parents has had a profound impact on children's progress and the confidence between the school and parent. Parents need to be listened to more and brought into a partnership with statutory bodies in a more meaningful way. (p. 3).

As a result, it was considered that best practice was for professionals to work in an anti-oppressive way to ensure that they were empowering parents to work in an equal partnership to avoid the 'power' remaining with the professionals.

2.3.3. SEND Code of Practice (Department for Education/Department of Health [DfE/DoH], 2015)

The SEND Code of Practice (DfE/DoH, 2015) is statutory guidance which sets out the duties, policies and procedures following on from the legislation set out in the Children and Families Act 2014 (HMSO, 2014). As a result of this legislation being introduced, the shift was made from SEN to SEND as it covered special educational needs and/or disabilities from birth to age 25 (DfE/DoH, 2015). Within the SEND Code of Practice (DfE/DoH, 2015), it outlined the organisations that must follow the guidance: Local Authorities, headteachers, early years providers, Special Educational Need Co-ordinators, NHS Trusts and First Tier Tribunal (Special Educational Needs and Disability).

The SEND Code of Practice (DfE/DoH, 2015) introduced Educational, Health and Care Plans (EHCPs) as a replacement to Special Education Needs Statements and Learning Difficulty Assessments. The document also provided statutory guidance on identifying needs, the special educational provision in schools, EHCPs, reviews and tribunal appeals. The code also emphasised the children's and parent's right to participate in decisions relating to their life and specified that local authorities in England must have regard to "…the importance of the child or young person, and the child's parents, participating as fully as possible in decisions, and being provided with the information and support necessary to enable participation in those decisions" (DfE/DoH), 2015, p. 19).

The SEND Code of Practice (DfE/DoH, 2015) also brought significant changes to SEND processes, promoting greater participation of families and children in decision-making (Holland & Pell, 2017). The concept of parents as partners was firmly embedded as the guidance states that partnerships with parents should be established, involving them “in planning support and, where appropriate, in reinforcing the provision or contributing to progress at home” (DfE/DoH, 2015, p. 81). Therefore, it became a statutory requirement to engage parents in decision making and there was an emphasis on their participation.

2.3.4. Special Educational Needs in Mainstream Schools (Education Endowment Foundation, 2021)

The Education Endowment Foundation (2021) released a report to support the implementation of the SEND Code of Practice (DfE/DoH, 2015) by focusing on the evidence available on improving outcomes for pupils with SEND in mainstream schools. The review consisted of recommendations and suggested that for parental engagement to be effective, strategies need to show understanding of families’ lives and barriers that may cause them to disengage with schools. Goodall and Vorhaus (2011) also acknowledge that for parental engagement to be effective, strategies must be tailored to the families’ needs, taking into account their experiences and barriers to engagement so that the recommendations are effective and practical for them to follow.

2.3.5. Special Educational Needs and Disabilities and Alternative Provision Improvement Plan (DfE, 2023)

The Government published the SEND and Alternative Provision (AP) Plan (DfE, 2023) in response to the SEND Green Paper that was published in consultation for improvements within the SEND and AP system in England. There were several reforms that were proposed within the improvement plan, particularly focusing on three areas: fulfilling children’s potential; building parents’ trust and providing financial sustainability. Building the parents’ trust refers to improving the parents and carers experience to be fairer, and an easily navigable system across education, health and care that restores their confidence that their children will get the right support in the right place, at the right time.

2.3.6. Summary

In summary, as legislation has changed over the years, the role of parents in decisions relating to their child’s SEND needs and their SEND provision has been recognised as being ‘statutory’ meaning that all organisations working with children, must by law, involve parents rather than it being ‘best practice’. Increasing parental engagement over the years has also been identified as a significant factor in the successful outcomes for children with SEND (Holland & Pell, 2017).

2.4. Statutory Processes and Local Offer

2.4.1. Introduction

Within this section, I will outline the statutory processes within my local authority such as applying for Educational, Health and Care Plans (EHCP) and the SEND local offer.

2.4.2 Educational, Health and Care Plans

In response to the SEND Code of Practice (DfE/DoH, 2015) being introduced, one of the most significant changes was introduction of EHCPs. They were introduced as replacement of the ‘Statements of SEN’ and it aimed to outline the education, health and social care needs and required provision of children with difficulties. Within the EHCP, the four categories of SEND are identified:

- Communication and interaction;
- Cognition and learning;
- Social, emotional and mental health needs and
- Sensory and/or physical needs

After which, provision is identified to meet the needs and outcomes for each child. There is an emphasis on multiagency support and involvement as part of this process and a promotion of the views and aspirations of the child and family which are considered when planning outcomes for the child. Figure 2 below outlines the process of the EHCP.

An EHCP can provide support from birth to the age of 25 years old to support with school, further education and eventually in the workplace. Requests for the assessment for an EHCP can be sought by the parent or young person if they are aged between 16-25 years old, or by the school. The local authority makes the decision whether to go ahead with the assessment. In the local authority in which this research took place, the criteria for the EHCP particularly focused on evidence of the young person not making progress despite the educational setting taking steps to meet their needs.

2.4.3 Local Offer

The SEND Code of Practice (DfE/DoH, 2015) indicates that where specialist support is required, it should be provided as soon as possible, and the Local Offer should outline what support is available from different services and how it can be accessed.

The SEND Code of Practice (DfE/DoH, 2015) outlines some of the specialist services that schools work with the local authority to commission support and this may include:

- EPs;
- Child and Adolescent Mental Health Services;
- Specialist teachers or support services, including specialist teachers of visual, hearing or physical impairment; therapists including speech and language, occupational therapy and physiotherapists

Within the local authority in which the research was undertaken, the local offer named the following SEND specialist services:

- Communication Autism Team;
- Early Years Inclusion Service;
- Educational Psychology Service;
- Physical Support Service;
- Hearing Support;
- Vision Support and
- Pupil Support Service.

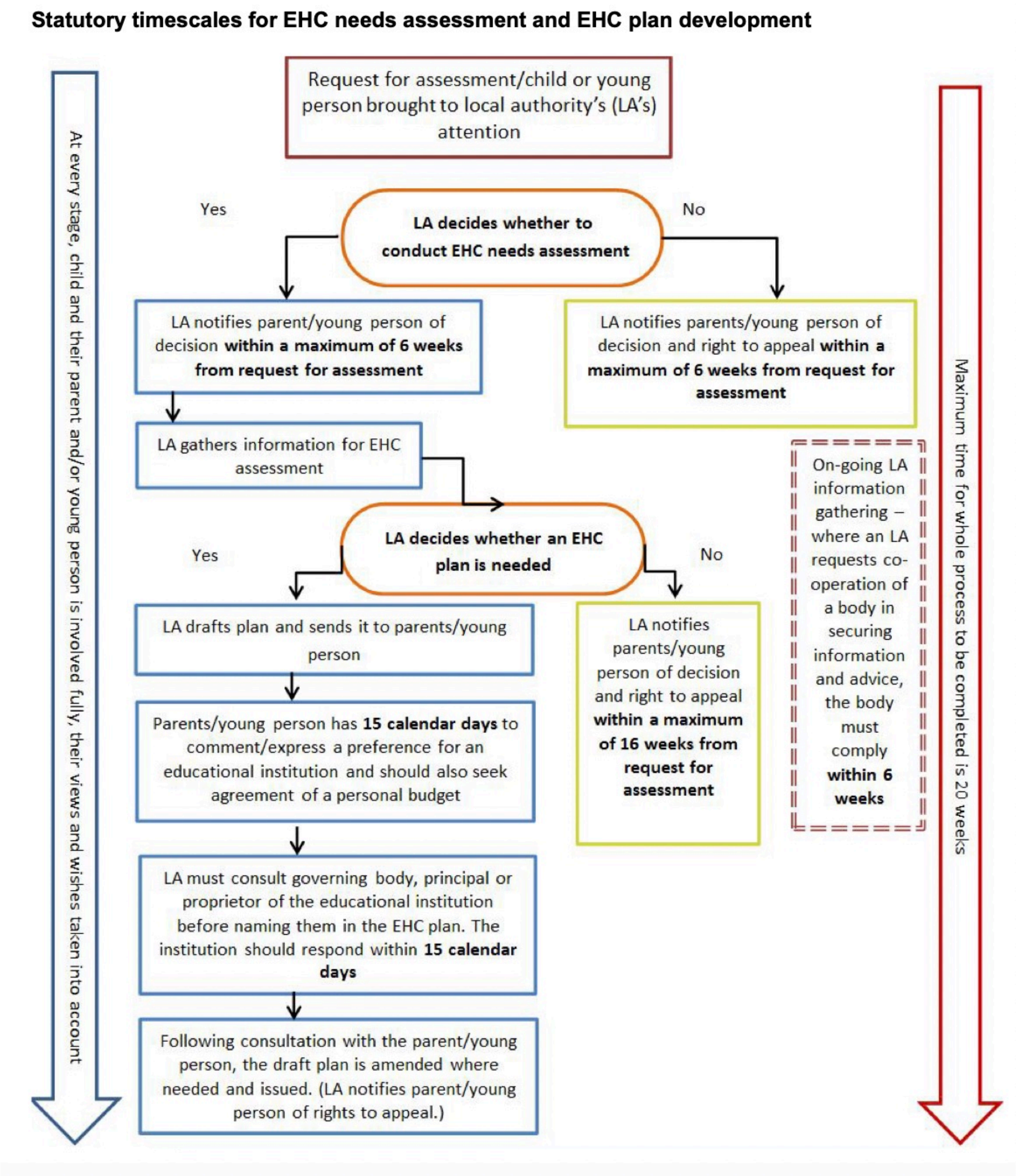

Figure 2: Statutory timescales for EHC needs assessment and EHC plan development, taken from the SEND Code of Practice (DfE/DoH, 2015)

2.4.4. Summary

This section outlines the context for the research undertaken, including the statutory processes within the local authority as well as the local offer, particularly highlighting the need for parents to be involved during decision making processes as highlighted in the SEND Code of Practice (DfE/DoH, 2015). As a result, parents should be involved in statutory processes such as EHCPs. The Local Offer also should be accessible and transparent on the services that are available for them to access to support their needs and should include how to access them (DfE/DoH, 2015). This would promote a collaborative partnership between parents and professionals and ensure that they feel empowered to be involved in decisions relating to their child's SEND.

2.5. Models of Parent Partnerships

In this section, different models of parent partnership for children with disabilities have been discussed, Cunningham and Davis (1985) refer to three types: the expert model, the transplant model and the consumer model. Subsequently, Dale (1996) introduced the idea of the empowerment model and negotiation model.

2.5.1. The Expert Model

The 'expert model' refers to professionals assessing and suggesting strategies for a problem without referring to the parental wishes, views and feelings (Appleton & Minchom, 1990). Using this model, parents are less likely to question the professionals as negotiation between parents and professionals is given low priority. It also means that there are limited chances for collaboration between parents and professionals, resulting there being the possibility of a disconnect between parental goals and professional goals (Cunningham & Davis, 1985; Marteau et al., 1987). Furthermore, within this model, although professionals may ask parents to share information with them, the decisions that they make, would not prioritise taking parental views into consideration.

2.5.2. The Transplant Model

The 'transplant model' refers to the parents engaging in an assessment or with strategies after being directed by a professional (Appleton & Minchom, 1990). Cunningham and Davis (1985) described the following as features of the model:

- Parents know their own children better than any professional;
- Parents are motivated to help their own children;
- Parents are with their child 24 hours and so are in a better position to follow through assessments or treatments;
- Professionals will direct the objectives and method of intervention and the professional will be skilled in communication and teaching methods.

This model allows parents to become involved and develop their knowledge on supporting their child's needs using professional directed interventions, but it does not acknowledge the skills that parents have (Beveridge, 2005). This model does not account for differing parental styles and family relationships as well as authority and power are still viewed as remaining with the professional, resulting in increased dependency and therefore this does not lead to equitable relationships. Parents' skills are not recognised, and they are not encouraged to contribute with their knowledge, rather they are viewed as lacking in skills (Hatcher & Leblond, 2001).

2.5.3. The Consumer Model

The ‘consumer model’ refers to parents being ‘consumers’ and in the control of services (Cunningham & Davis, 1985). Within this model, the in-depth knowledge and experience of parents is recognised, and they are encouraged to use it to decide on the services and interventions that they think are most appropriate for their child (Beveridge, 2005). There would also be the assumption that parents not only know their child best, but also their current life situation best and have the expertise to make judgements about their involvement with services; the services would need to be highly flexible, providing individually tailored help according to parental wishes (Appleton & Minchom, 1990). Using this model empowers parents to have differing views from professionals and implies that they would comply with parents’ wishes for specific interventions for a child or if they wanted to opt their child out of a service. This model would also encourage parents and professionals to collaborate on planning assessments and interventions based on the parents’ views and wishes. This model also relates to the SEND Code of Practice (DfE/DoH, 2015) where guidance stated that parents should be involved in “in planning support and, where appropriate, in reinforcing the provision or contributing to progress at home” (DfE/DoH, 2015, p.81). However, this model is reliant on parents being familiar with the services and interventions that are available for their child, and it assumes that parents will have the confidence to exercise their rights to advocate for their child. It does not consider parents who lack in understanding of services and interventions or do not feel confident to make decisions relating to their child’s needs.

2.5.4. The Empowerment Model

The ‘empowerment model’ (Appleton & Minchom, 1990) refers to the parents having power and being in control, however, highlights the need for professionals to be considerate to the needs of the parents. This model encourages the professionals to consider how they could help the parents and meet their needs for them to feel empowered and to feel like equal partners. This model solely focuses on one type of empowerment, but it does not consider other forms that may be needed to address power balances as professionals may have different understanding of what it means to be a partner, consequently resulting in inequitable partnerships (Dale, 1996). This model also does not consider parents who may not have the same view of disability, thus impacting on their engagement with services and professionals.

2.5.5. The Negotiating Model

The ‘negotiation model’ (Dale, 1996) defines partnership as “a working relationship where the partners use negotiation and joint decision-making, and resolve differences of opinion and disagreement, in order to reach some kind of shared perspective of a jointly agreed decision on issues of mutual concern” (Dale 1996, p. 14). This model recognises that parents and professionals both have differing perspectives, but the aim of this model is to bridge the gap between them. This model assumes that parents are confident and articulate in order to use negotiation to make decisions jointly, however, does not consider those parents who may not be as confident at articulating themselves. This model also does not consider parents who have differing views of disability or community attitudes to SEND, for example, if they adopt a view that disability is from God, accessing support would be seen as ‘sinful’ (Akbar and Woods, 2020; Lawrence et al., 2014). This results in limited opportunities to negotiate and engage with this model.

2.5.6 Summary

In summary, over the years, the models and ideas of parent partnership have developed from parents’ opinions and views considered as a low priority to the relationship between professionals and parents seen as “a working relationship”. This working relationship accepts that parents and professionals will have differing perspectives, but they work together and jointly decision make. However, all the models described in the above section, all assume that parents are articulate and confident enough to conversate with professionals. They do not take into consideration parents from minoritised ethnic communities who may experience barriers such as communication skills and confidence in being able to advocate for their child. The models also do not account for differing views of SEND and the implications of this working with professionals to support with SEND. This creates a power imbalance between parents and professionals as the parents may not be able to express their views or contribute to decision making processes, resulting in them having to trust professional judgement.

2.6. Parents’ Experiences of Services of Professionals Working in Education and Schools

2.6.1 Introduction

This section covers the wider literature on parents’ experiences of professionals working in education and schools, including working with educational psychologists (EPs). There are themes of communication between parents and professionals; the working relationship between parents and professionals and lack of knowledge and understanding of role of professionals including support and resources available that are discussed.

2.6.2. Communication between Parents and Professionals

Parents stressed the need for frequent, honest and open communication between home and school. This became especially significant for children who had difficulties with communication (Stoner et al., 2005). Parents indicated that they highly valued certain professional qualities and behaviour such as being open and honest with others; taking their suggestions into account regarding their child’s plan and professionals who were able to be present to assist; respond quickly when needed; help to access resources; communicate well and open to parents’ input (Tucker & Schwartz, 2013). This suggests that there are situations where parents value professionals using the ‘consumer’ model of partnership (Cunningham & Davis, 1985) where they respond to the needs of the parents such as responding quickly and support with resources. Furthermore, parents found that repeated interactions with positive teachers had the potential to enhance trust between parents and educational professionals (Stoner et al., 2005).

However, some parents reported that their ideas and suggestions were not included and there was no regular communication (Tucker & Schwartz, 2013), similar to the ‘expert’ model where parents’ wishes are not considered (Cunningham & Davis, 1985). Parents also found that they were having to repeat information concerning their children’s needs to different professionals, leading to the needs of children and young people being misunderstood and therefore not met (Holland & Pell, 2017).

2.6.3. Working Relationship between Parents and Professionals

Parents felt that their involvement and engagement with professionals was reliant upon the qualities of the professional they worked with, such as how motivated they were to include parents (Bentley, 2017; Sales & Vincent 2018). Some parents believe that the commitment to listen and take their child’s view seriously resulted in appropriate adjustments being made after experiencing challenges with their child’s struggles not being recognised (Sales & Vincent, 2018). Furthermore, parents perceive amicable and kind attitudes of school professionals as a sign of personal interest or an authentic relationship which led to positive working partnerships between parents and professionals (Woo Jung, 2011).

Positive working relationships between professionals resulted in appropriate referrals, however parents experienced difficulties in attempting to access assessments and a reluctance from schools to involve external agencies (Starkie, 2024). Parents report that they believe that it is their responsibility to force the experts to focus on their child and they must be persistent in accessing support for them (Stoner et al., 2005). In some cases, parents found that their persistence alienated professionals and their concerns surrounding their child’s needs were dismissed, this left them feeling ridiculed (Starkie, 2024), suggesting that using the ‘consumer’ model of partnership (Cunningham & Davis, 1985) may have implications. As a result, parents felt that school professionals were viewing the child as the problem and that the focus was on changing the child, not changing the system (Starkie, 2024).

2.7. Parents’ Experiences of Working with EPs

2.7.1. Parents’ Perception of Working with Professionals

Generally, parents report that their experience of working with EPs was positive and satisfactory (Cuckle & Bamford, 2000; Dowling, 1994; McKeever, 1996). Parents were left wanting more time with EPs as they valued their contribution and thought that they were very helpful and some parents mentioned improvements in working with the school since EP involvement (Cuckle & Bamford, 2000; Dowling, 1994; Squires at al., 2007). Analysis of specific services parents reported receiving indicated that information and advice about educational provision and an assessment of their child’s special educational needs was the most reported type of help from the psychologist (Cross et al., 1991). Similarly, when the role of an EP was reviewed in light of Every Child Matters (DfES, 2004), parents rated most highly that EPs were helpful to achievement and enjoyment. This included access to resources, providing advice to teachers and parents and carrying out assessments (Squires et al., 2007). This suggests that more generally when working with EPs parents prefer an expert model where professionals are able to assess and suggest strategies for the child (Appleton & Minchom, 1990).

Parents expressed less satisfaction with their experience of working with an EP relating to service delivery such as referral response times, lack of funding and resources within the local authority (McKeever, 1996; Squires et al., 2007) as they viewed themselves as ‘consumers’. A few parents also reported that the EPs involvement had not been helpful for their child, however it has been helpful to them as parents (Squires at al., 2007). Parents found that the involvement of the EP was most helpful when the assessment matched the underlying questions that they had about their child, however it was less helpful when they felt that the EPs assessment did not explore their questions about their child resulting in a poorer understanding of their child’s needs (Squires et al., 2007). This suggests that in some situations, parents prefer EPs to take the ‘expert’ role in being able to answer questions that they may have about their child. Some parents also expressed dissatisfaction with the EP service concerning lack of information about procedures and length of time taken, the need for clearer explanations and repetition of questions by the different professionals involved (Cuckle & Bamford, 2000).

2.7.2. Communication between Parents and Professionals

Parents reported that good verbal and written feedback that was detailed and named their child’s condition with advice on strategies that parents and teachers could implement facilitated their further engagement with EPs (Squires et al., 2007). They also reported that the feedback should provide information about alternative sources of help, and it should be given in a way that is emotionally supportive of parents whilst being clear, simple and comprehensive (Squires et al., 2007). Some families felt that psychologists had explained their role to the parents and indicated the kinds of services that might be offered to them (Cross et al., 1991). Likewise, parents also commented on pamphlets and information brochures that they had received from the Educational Psychology Service as helpful in understanding the service but also helped to make schools accountable for providing support for children (Squires et al., 2007). This has implications for future work between EPs and parents want clear, accessible information through feedback. Research has found that parents were satisfied with EPs if they received clear information on the EP role, and worked in partnership with the EP (Sendrove, 2001).

2.7.3. Building Positive Relationships between Parents and Professionals

The way in which EPs developed positive interpersonal relationships with parents was seen as important in facilitating interactions with the profession (Squires et al., 2007). This included acknowledging parents' concerns by taking them seriously as well as advocating for parents and making them feel that they are understood (Dowling, 1994). Parents also reported that EPs were polite and courteous when working with them (Burnham, 2003; Cross et al., 1991). Furthermore, parents also appreciated when EPs made themselves accessible and available and valued their 'expertise' about their child (Dowling, 1994; Hart, 2011). This suggests that at times parents prefer the 'consumer' model of parental partnership where their expertise is taken into account, and they are able to collaborate with professionals on individually tailoring support for their child (Appleton & Minchom, 1990).

2.7.4. Lack of Knowledge and Understanding of the Role of the Professional

Parents report that a major barrier to their engagement with EPs is due to a lack of knowledge of how EPs support others in supporting their child (Squires et al., 2007). They also felt that a booklet or information describing the work of an EP would be helpful as had they known about the service, they may have approached an EP earlier (Dowling, 1994). Parents also wanted more involvement and information from EPs, particularly more follow up and explanations of processes and what the help offered was likely to achieve (Dowling, 1994). Some parents were also less willing to be involved with EPs, as at times, the purposes of meetings or assessment is not clear for them and they are unsure of what their contribution would be to the meeting (Hart, 2011).

2.7.5. Lack of Support and Resources

Another barrier that families felt they experienced when working with EPs was the inability to access support early enough and lack of resources (Squires et al., 2007). Families felt that they were rushed for time and that they could benefit from more time with EPs to support them and their families (Burnham, 2003; Dowling, 1994). Parents also commented on the need for more EPS or more consistent staffing and better access to services (Squires et al., 2007). Parents argued that inconsistent staffing and difficulties in accessing more time with EPs meant that EP suggestions were not followed by school and their recommendations were not seen through (Squires et al., 2007). Parents found it unhelpful when EPs did not explain terms or help parents understand tables and numerical information (Squires et al., 2007). Parents also felt that a lack of resources meant that excessive time was taken for assessments to be made and for statutory processes to be completed once they had started (Dowling, 1994).

2.7.6. Summary

In summary, communication between parents and professionals have been found to be significant in increasing the trust of parents in professionals. They valued professionals who were open and honest in their communication and who valued their opinions and contributions. This facilitated positive working relationships between parents and professionals so that they were able to use the negotiating model of partnership to jointly make decisions (Dale, 1996). Furthermore, parents felt their engagement with professionals was dependent on the professional being motivated to include and support parents and this impacted on their working relationship. A lack of motivation from professionals to include parents, particularly if there are communication difficulties, results in disparities in families being able to access support from professionals and services resulting in an 'expert' model (Cunningham & Davis, 1985). This may suggest that families who are able to articulate and engage with professionals without any difficulties are more likely to access support, leaving families who experience difficulties in doing so with little to no support. Barriers also included there being a lack of understanding and knowledge on the roles of professionals and there being a lack of support and resources which meant that parents had less time with professionals. These are valuable findings; however, these studies have not considered the experiences of minoritised ethnic families working with services and professionals who work to support children with SEND and their families.

2.8. Minoritised Ethnic Parents’ Experiences of Services that Support Children and their Families with Disabilities

2.8.1. Introduction

This section covers the experiences of minoritised ethnic parents’ in accessing and engaging with services. It summarises their experiences with the following themes: lack of knowledge and understanding; the perceptions of services by minoritised ethnic families; power imbalances and parental experience of cultural sensitivity and cultural humility.

2.8.2 Lack of Knowledge and Understanding

The majority of parents reported that they did not understand services which effected their choice in engaging with them (Fazil et al., 2002; Raghavan et al., 2013). Parents explained that they had very little information on the role of service providers, identifying who they were and where they came from and in some cases, they knew nothing more than the first name of the worker who came to their house (Fazil et al., 2002). For many families there was confusion about the identity of professionals, the agency represented and the appropriate service to approach to address specific needs (Raghavan et al., 2013).

Parents also reported that a lack of understanding and awareness of the services available to them, which resulted in their opinion of the value of the service (Fazil et al., 2002). Parents also perceived a lack of trust in some services such as respite care which effected their uptake as it was not seen as appropriate for their needs (Fazil et al., 2002). Similarly, Hatton et al. (1998) and Mir and Britain (2001) found that parents from minoritised ethnic families did not engage with family support services such as respite care and short breaks, due to limited knowledge and understanding of services. This resulted them in experiencing high levels of psychological distress (Hatton et al., 2011). However, from these studies it is unclear whether where there were any other factors contributing to a causal relationship between parental uptake of services and psychological distress they experience.

2.8.3. Service Perceptions of Minoritised Ethnic Families

For many families, the community attitudes to disability and the desire to maintain their privacy and hide their child's disability, resulted in the families being unwilling to engage in or access services for their child (Munroe et al., 2016; Raghavan et al., 2013). The perception of disability and community attitudes results in limited opportunities to be able to work in equitable partnerships with professionals where the negotiation model can be adopted (Dale, 1996). The families felt they had a duty to look after their children and they did not want members of the community to know about their support needs and the details of their child's disability (Raghavan et al., 2013). Similar findings have been found by Nair (2015) and Tarian (2014) where stigma attached to disabilities led to families feeling isolated within their community and this prevented them accessing appropriate support and services for their child.

Two studies (Fazil et al., 2002; Raghavan et al., 2013) also found that socio-economic status and the level of education affected access to services. Raghavan et al. (2013) found that the carers who were financially stable and in employment tended to access services and they had the confidence to seek information. This suggests that carers may use the consumer model (Cunningham & Davis, 1985) to be in control of the services that are involved with their family. However, Fazil et al. (2002) found those from low socio-economic status were reported as less likely to become involved with support groups and services.

2.8.4 Power Imbalance

For most of the families, they experienced power differentials when they accessed and engaged with services (Croot, 2012, Raghavan et al., 2013). Parents had a sense of feeling inferior to professionals, they felt that their concerns were not taken seriously and so they felt that professionals were not in a position to advise them, influencing their future choices about the use of services (Croot, 2012). As a result, their confidence in professionals and services significantly depleted, resulting in them disengaging with professionals and services. This also resulted in the 'power' remaining with the professional who is considered to be an 'expert' to make decisions without including the views or wishes of parents (Cunningham & Davis, 1985).

2.8.5. Parental Experience of Cultural Humility and Cultural Sensitivity

Cultural humility assumes that all individuals are diverse from each other in some way, yet part of a global community; humans are altruistic and have equal value; cultural conflict is a normal and expected part of life and all humans are lifelong learners (Foronda, 2020). Cultural humility also recognises and minimises power differences by promoting respect and supportive interactions by being self-aware and open to understand other people's cultures (Yeager & Bauer-Wu, 2013). Engaging in cultural humility resulted in interactions where individuals felt mutually empowered, respected and equal partnership (Foronda et al., 2016). This promotes partnerships where parents and professionals are able to share their perspectives during decision making processes (Dale, 1996).

Some parents found that there was a lack of cultural humility and sensitivity, and professionals were stereotyping members of the culture, this led to parents feeling very frustrated (Raghavan et al., 2013). Other parents felt that professionals were not sensitive to their culture when giving advice on accessing services or training and they were suggesting things that would not be culturally appropriate or meet their needs (Hussein et al., 2019). For example, parents were advised to ask their 18-year-old daughter to move out of the family home as it was too crowded (Fazil et al., 2002), however within the Pakistani culture, it is deemed inappropriate for a daughter to move out of the family home until they are married. Consequently, parents felt that the advice given to them by professionals and services did not consider their ethnicity or cultural practices which impacted on their confidence in the professionals (Fazil et al., 2002). Parents also felt that professionals who gave them advice and training should be culturally sensitive to ensure that it is appropriate for them and meets their needs

Parents of autistic children, in particular, called for professionals who understood their culture to deliver training: ‘Any training offered to families would have to be culturally sensitive to ensure that it’s appropriate for them and meets their needs

2.8.6. Lack of Diversity and Representation

Parents believe that there is a lack of diversity and representation in the educational workforce, and this left them feeling that staff did not understand their experiences, needs or their values (Fazil et al., 2002; Perepa et al., 2023). Jegatheesan et al. (2010) also found that parents preferred working with professionals who were of similar cultural and linguistic background because they spent more time informally speaking to them and were interested in their background. This resulted in parents feeling that they were able to trust the professionals and were able to freely discuss the barriers that they were facing when trying to engage with services, as the professional's familiarity with their language and culture provided a comfort zone for the parents (Jegatheesan et al., 2010). Parents also commented on there being a lack of representation in material provided by services and lack of cultural awareness present in parent training sessions which resulted them in being reluctant in engaging with professionals and services (Perepa et al., 2023).

2.8.7. Summary

In summary, exploring minoritised ethnic parents' experiences of services to support children with disabilities and their families highlighted that there was a lack of knowledge and understanding of services and therefore resulting in parents not engaging with services. Service perceptions by families also acted as a barrier for parents engaging with services as within minoritised families, there is a desire to hide disability and as a result, the services are perceived as having stigma attached to them. Minoritised ethnic parents also felt a sense of inferiority when working with professionals when they were enacting an 'expert model' (Cunningham & Davis, 1985). Subsequently, parents they felt that their opinions were not considered which prevented them in wanting to engage with services. In addition, minoritised ethnic parents also experienced a lack of cultural sensitivity in their interactions with services.

The studies in this section, highlight that parents from minoritised ethnic communities aspire to work in partnership with professionals where they feel empowered to share their views and their culture, whilst understanding differing perspectives from professionals to negotiate positive outcomes for their child with SEND (Dale, 1996). Although these studies highlighted the experiences of the minoritised ethnic group, they did not focus on the experiences of accessing and engaging with the services and professionals who work to support children with SEND and their families.

2.9. Minoritised Ethnic Parents' Experiences of Working with Services and Professionals Who Work to Support Children with SEND and their Families

2.9.1. Introduction

Within the literature there are very few studies that have explored minoritised ethnic parents' experiences of working with services and professionals who work to support children with SEND and their families. This section summarises the current literature available and begins to form a rationale for the current research.

2.9.2. Community Influences

For some families a major barrier to working with EPs was the community attitude to SEND. This may be a result of the thought processes and responses of families which are influenced by intercultural and intracultural differences, family past experiences and their knowledge of SEND (Lawrence, 2014). For many families, the community attitudes to SEND and the desire to hide their child’s disability, resulted in the families being unwilling to engage or access services for their child (Fox et al., 2017; Lawrence, 2014). When parents did share their child’s diagnosis, they were discouraged by the community and told to disregard the diagnosis as their child would be fine (Fox et al., 2017). The stigma and shame that is associated with disability and SEND meant that although some families may have wanted to access services, however they did not want to feel shame from the community for accessing services as this was not seen ‘normal’ in their culture (Lawrence, 2014). A significant number of parents believed that their child’s needs were from God or “Allah” and having help or assistance from professionals or services would be “sinful” as only God or “Allah” can help (Akbar & Woods, 2020, p. 673; Lawrence, 2014). Some parents also reported that professionals made insensitive comments and using diagnostic language which included being rigid in their thoughts over their child’s future which they did not consider to be culturally sensitive (Lawrence 2014). Parents also felt that professionals did not understand their journey as immigrants and the impact of this, on their experience of their child with SEND (Nnalue & Mahmud, 2024). These parents described how they had limited support and as a result limited understanding of SEND which also meant that they were in denial of their child’s needs at first (Nnalue & Mahmud, 2024).

2.9.3. Power Imbalance

For most of the families, they experienced power differentials when they accessed and engaged with services (Akbar & Woods 2020). Some parents also felt disempowered by the perceived higher status of professionals, and their knowledge of the SEND processes as well as the ability to be able to communicate in English effectively which resulted in parents being forced into decisions even if they have been advised against it by friends (Akbar &

Woods 2020). Some parents also believed that regardless of the family's wishes, professionals would eventually make decisions about their child, and they were forced to accept it due to language barriers (Akbar & Woods 2020). This suggests that parents view professionals as 'experts' and in turn, overlook their own rights within minoritised ethnic communities. Lawrence (2014) also found that whilst the parents appreciated the expertise from professionals, they did not feel that their relationship with the professional facilitated them in being able to be actively involved in decision-making for their child. This resulted in limited opportunities for the 'negotiating' model (Dale, 1996) which caused them to reject service input (Lawrence, 2014). Some parents also found that the relationship that they shared with professionals was negatively influenced through professional mistrust after power struggles for their child's support (Nnalue & Mahmud, 2024). They felt that they were spoken down to and not treated as the expert in their child's needs, this resulted them in feeling that they did not achieve true partnership in working with professionals (Nnalue & Mahmud, 2024). It was found that a large part of the success of parent and professional relationship was down to the employment of linguistically and ethnically diverse staff which would minimise power imbalances experienced (Oliver & Singal, 2017). Holland & Pell (2017) found that there needed to be considerable effort in directing parents to information and to share some of the power that had historically remained with professionals, however there is limited research into this process, particularly with parents from minoritised ethnic backgrounds.

2.9.4. Lack of Knowledge of Roles of Professionals and Statutory Processes

Parents from minoritised ethnic communities have reported that even though they believe it is their duty as a parent to be proactive and seek knowledge, they experience a lack of knowledge of statutory processes and lack of understanding when it came to statutory processes such as applying for EHCPs (Akbar & Woods, 2020; Perepa et al., 2023). One parent described it as a “maze” and wished that she was guided by school staff during the process (Akbar & Woods, 2020, p. 672). There was also confusion around the role of the EP. Some parents thought that they were “gatekeepers” to other services as parents perceived other professionals as being more effective in supporting their child’s needs due to their more direct involvement compared to EP involvement (Lawrence, 2014, p. 248).

2.9.5. Communication Difficulties

When working with minoritised ethnic families, language barriers have been found to be significant barriers in effective partnerships between families and professionals (Akbar & Woods, 2020; Fox et al, 2017; Lawrence, 2014; Nnalue & Mahmud, 2024). Where interpreters were provided by schools, this was not considered as good practice, due to the staff availability changing quickly as a result of schools demands and the bias towards school being present resulting in the quality of service being influenced (Akbar & Woods, 2020). The use of technical and diagnostic vocabulary was also considered to be a barrier to parental involvement and therefore, resulting in a delay in parents accessing support for their child (Akbar & Woods, 2020; Lawrence, 2014). Barriers in the articulation of processes was also present from professionals when discussing next steps for the processes, and the one-directional nature of communication left the parent feeling rushed and talked down to, rather than professionals being mindful of the language they are using (Nnalue & Mahmud, 2024).

2.10. Pakistani Parents' Experiences of Working with Services and Professionals Who Work to Support Children with SEND and their Families

2.10.1. Introduction

Within the literature there are very few studies that have explored first-generation Pakistani parents' experiences of working with services and professionals who work to support children with SEND and their families. This section summarises the current literature available and begins to form a rationale for the current research.

2.10.2. Communication Difficulties

Communication was considered to be an important factor in facilitating parental engagement with professionals, a lack of fluency in English results in parents experiencing difficulties in sharing their concerns about their child (Habib et al., 2017). Parents were also left confused and suspicious of professionals when communication was unclear, preventing them being willing to engage with services and professionals (Kaur-Bola & Randhawa, 2012).

2.10.3. Access to Services

Parents expressed their concerns about the difficulties in accessing services which included long waiting times which caused them increased stress as well as inaccessibility of the services due to lack of education or awareness of special educational needs for parents from a Pakistani background (Habib et al., 2017).

2.10.4. Feelings of Isolation

Some parents mentioned feelings of isolation following the stress of the diagnosis of their child with SEND as well as being far from their extended family and friends (Habib et al., 2017). Parents also felt excluded and isolated in mainstream classrooms due to lack of resources and support and felt forced to consider alternative educational placements in an attempt to access inclusive spaces for their children (Rizvi, 2018).

2.10.5. Perception of SEND within the Community

Community perceptions of SEND resulted in parents being advised against obtaining a diagnosis for their child as they were told by family members that their child would grow out of the symptoms, therefore they were less likely to access services (Habib et al., 2017). Parents also felt shame from the community and stigma attached to their child with SEND which increased parental anxiety and prevented them in asking for help or support from support services (Kaur-Bola & Randhawa, 2012; Rizvi, 2017).

2.10.6. Disability is from God

Some parents believed that disability was from God (‘Allah’) and therefore they turned to religious places for a cure rather than placing their trust in a service which may be a reflection of their understanding of disability or negative experiences of relevant services (Croot et al., 2012). This belief also meant that parents believed it was their responsibility to look after their child without external help and as a result, they did not engage with services (Croot et al., 2008; 2012).

2.10.7 Summary

In summary, Pakistani parents' experiences when working with services and professionals who work to support children with SEND and their families is similar to previously discussed themes. There are themes of community perceptions of SEND, beliefs about disability, feelings of isolation and communication difficulties. However, there is little research on the experiences of first-generation Pakistani parents' experiences who are not able to communicate in English. Most of the studies assume that parents are able to articulate and explain themselves. They do not consider those parents who are not able to speak in English and therefore they have not able to share their views or experiences of working with services and professionals who work to support children with SEND and their families. Therefore, this creates a gap within the literature and the rationale for my research.

2.11. Research Aims and Questions

I aimed to add to the literature on the experience of minoritised ethnic parents', specifically Pakistani parents' experiences of engaging and accessing services and professionals who work to support children with SEND and their families. I aimed to include implications of my research and provide recommendations for EP practice and service delivery for those who work with children with SEND and their families. The following are my research questions:

1. What are the experiences of Pakistani parents' accessing and engaging with services and professionals who work to support children with SEND and their families?

2. What barriers do Pakistani parents’ experience when engaging and accessing services and professionals who work to support children with SEND and their families?
3. What facilitators do Pakistani parents’ experience when engaging and accessing services and professionals who work to support children with SEND and their families?

Chapter 3: Methodology

3.1. Introduction

This chapter covers the methodology used in the research. This includes my philosophical perspectives that guided the research methods and the method of data collection to answer the research questions. Furthermore, information about the participants is provided as well as ethical considerations and research procedures that were followed. Data analysis methods and considerations relating to the quality of qualitative research are explored.

3.2. Research Questions

This research aimed to explore the views of Pakistani parents' accessing and engaging with services and professionals who work together to support children with SEND and their families. This led to the following research questions:

1. What are the experiences of Pakistani parents' accessing and engaging with services and professionals who work to support children with SEND and their families?
2. What barriers do Pakistani parents' experiences when accessing and engaging with services and professionals who work to support children with SEND and their families?
3. What facilitators do Pakistani parents' experiences when accessing and engaging with services and professionals who work to support children with SEND and their families?

3.3. Philosophical Assumptions

This section outlines the philosophical assumptions that guided and underpinned this research.

3.3.1. Ontology and Epistemology

In educational research, the researcher's paradigm is used to describe a researcher's 'worldview' (Mackenzie & Knipe, 2006). This refers to the researcher's beliefs and principles that shape how a researcher sees the world and how they interpret and act within that world (Kivunja & Kuyini, 2017). The researcher's paradigm has significant implications for the decisions made for the ontology, epistemology, methodology and analysis of data within the research (Kivunja & Kuyini, 2017). In this research, I adopted an interpretative paradigm to gain a deep and rich understanding of the subjective experiences of the participants within my research (Hussain et al., 2013).

Ontology refers to the meaning of concepts and the nature of social reality that exists (Goertz & Mahoney, 2012). The ontology underpinning this research is relativism. The assumption of relativist ontology is that a situation may have multiple realities and those realities can be explored and meaning can be made of them or reconstructed through human interactions between the researcher and research participants (Chalmers et al., 2009). Interpretative researchers hold the assumption that reality is complex and multi-layered, and they include themselves as part of the process depicting the phenomenon under study (Cohen et al., 2017).

Epistemology refers to the theory of knowledge (Ernest, 1994) and how knowledge can be acquired and communicated (Cohen et al., 2017). An interpretative paradigm and relativist ontology perspective lends itself to subjectivist epistemology. This is the belief knowledge is value laden and even though that external reality exists, universal and unaffected knowledge of external reality is not possible without individual reflections and interpretations (Levers, 2013).

By adopting a relativist ontology, subjectivist epistemology and interpretivist paradigm, I accepted that reality is individually constructed, meaning that there were multiple realities and in turn parental experiences of engaging with services and professionals who work to support children with SEND and their families. Therefore, I believed the experiences of Pakistani parents accessing and engaging with services and professionals who work to support children with SEND and their families could be understood by talking with and listening to the individuals from that community living that reality. Furthermore, I recognised that each participant's experience is their reality and, as a researcher, I aimed to interpret their experiences through my own reality and value-laden lens. I also used a relativist approach as I explored shared experiences across participants as well as looking at individual experiences. My goal was to understand the participants' experiences by using Reflexive Thematic Analysis (RTA) as the primary data analysis method which lent itself to the interpretivist research paradigm (Braun & Clarke, 2021).

3.4. Methodology

Methodology refers to how we discover knowledge in a systematic way. Methodology is guided by a researcher's ontological and epistemological belief and the best way of studying the reality (Hussain et al., 2013).

Within this research, the design used was a multiple case study. Thomas (2011) suggests that using a case study design goes beyond description or observations and helps in understanding theoretical issues. It also helps to understand a phenomenon in depth whilst understanding the contextual conditions which may have impacted on experiences (Yin & Davis, 2007). Using a multiple case design allows multiple cases to understand the similarities and differences between the cases (Baxter & Jack, 2008; Stake, 1995), therefore the suggestion is that the evidence generated from it is strong and reliable (Baxter & Jack, 2008). Using a multiple case study design also allows a more convincing theory developed as a consequence of the different empirical evidence generated (Eisenhardt & Graebner, 2007).

3.5. Positionality

Within this research, I was able to reflect on my own assumptions and experiences as being part of the Pakistani community and therefore I was able to engage more closely with the data. Furthermore, being an ‘insider’ and explicitly communicating to participants that I was of Pakistani ethnicity, communicated a non-threatening researcher disposition which allowed them to feel safe and engage in prolong discussions without feeling judgement (Mayorga-Gallo & Hordge-Freeman, 2017). Moreover, being an ‘insider’ also meant that I was able to show understanding of the culture and could understand some of the cultural traditional views on SEND that some of the participants referred to (Adu-Ampong & Adams, 2020). There is also a suggestion that being an insider can lead to more thorough findings, however being an insider can also have limitations such as reduced explanations from the participants (Bukamal, 2022).

3.6. Participants

The table below describes the inclusion and exclusion criteria that I used to recruit participants to take part in the research.

Inclusion Criteria	Exclusion Criteria
Participants who are of Pakistani ethnicity, based on place of birth	Participants who have not been through EHCP process
Participants who are originally from Pakistan	Participants who are originally from England
Participants who speak Urdu	Participants who are not from a Pakistani ethnicity
Participants for whom English is not their first language	
Participants who have a child with SEND	
Participants who have a child that has been through the EHCP process within the last 10 years	

Table 2: Inclusion and Exclusion Criteria for Participants

3.7. Recruitment

Participants were recruited using purposive sampling. This method of recruitment meant that participants could be identified due to the qualities that they possessed, which in this research was their knowledge and experience (Bernard, 2002). Purposive sampling also allows for information-rich participants to be selected to take part in the study (Patton, 2002). Firstly, the Special Educational Needs Coordinator (SENCo) of schools within the placement region were asked to identify potential participants that fit the inclusion criteria. The SENCos were given the information sheet (see Appendix 1 for the information sheet) and consent form (see Appendix 2 for the consent form) to share with the potential participants and they were asked for their permission for their details to be shared with the researcher.

If they gave permission, I contacted by phone call to discuss the research in more detail and to answer any initial questions. I explained to the participant in Urdu what the research would involve and what would be expected of them. If they were happy to take part, I invited them to meet them in the school to go through the form verbally, explaining what the project is about, the ethical risks of taking part and confidentiality. For participants who were not literate or experience difficulties in reading, I read the participant information sheet and consent form in their preferred language, i.e. English or Urdu. If the participant was unable to provide written consent but could provide verbal consent, I noted this down on the consent form. I gave the participant the information sheet (Appendix 3) and consent form (Appendix 4) that had been translated into Urdu and asked them to take them away if the participant wanted time to think about it or to sign it if they are happy to take part.

3.8. Data Collection

Langridge (2007) stated that when investigating a particular issue qualitative methods should be used to gain naturalistic first-person accounts of the experiences of individuals. Therefore, I used semi-structured interviews with each participant separately as it allows me to use questions whilst trying to understand the social and psychological world of the respondent (Smith, 2007). It also gave me the flexibility to ask further questions or seek clarity on particularly interesting responses from participants. Using semi structured interviews also gives the respondent the maximum opportunity to be the expert and to share their stories and experiences (Smith & Osborn, 2007). The questions that were included in the interview were a mixture of descriptive questions as well as more analytical or evaluative questions that had been generated from literature.

Magnusson (2015) suggests that pilot interviews should be completed to assess the suitability of questions and to gain experience in interviewing. After the interview schedule was designed, I used a pilot interview to check the length of the interview and to refine and develop any questions to minimise confusion in understanding of the questions. I conducted the interview with a participant who partially met the inclusion criteria as they were not originally from Pakistan and English was their first language. As a result, the data gathered could not be included in the research findings. This pilot interview however affirmed that my interview schedule as appropriate and no further adjustments were needed (See Appendix 5 for interview schedule).

3.9. Conducting and Analysing Interviews in Another Language

I used the pilot interview to check the questions that I asked made sense in Urdu and they were a direct translation of my interview schedule. I also checked with family members who were native speakers of Urdu that the interview questions made sense before interviewing my participants. After collecting and transcribing the data in English, I contacted an EP in another local authority who was able to speak in Urdu. I asked her to listen to a clip from a recording of an interview and to check my choice of words in translation. This can be seen in Appendix 6.

I decided to use this method as there is a suggestion that translation becomes increasingly challenging when languages have dissimilar linguistic roots and as a result, word-for-word translation becomes difficult. Consequently, a committee approach to translation has to be adopted instead (Furukawa et al., 2014). The committee approach to translation aims to decrease the cultural bias in the native language by encouraging collaborative and consensus translation where one individual translates initially and presents this to an expert panel (Martinez et al., 2006; Douglas & Craig, 2007). In my research, I initially translated the data after transcription, then presented to my family and EP colleague to adopt the committee approach to translation.

3.10. Procedure

Before the recorded interview, I built rapport informally with all participants for them to feel comfortable. This involved asking the participants questions relating to Pakistan, a commonality that we both shared as the researcher and participant. This allowed the participant to understand my background and my motivation for conducting this research.

The interviews were recorded using a Dictaphone and they lasted between 45 minutes to an hour. The interviews were held in a venue of the participant’s choice, and for all the participants this was in their child’s school.

3.11. Ethical Considerations

Ethical approval was granted by the University of Birmingham's Ethical Review committee (Appendix 7). Ethical considerations in this research were guided by the British Psychological Society (BPS, 2021) and British Educational Research Association (BERA, 2024).

I followed guidelines for freely given, fully informed consent from the British Psychological Society (BPS, 2021), the British Educational Research Association (BERA, 2024) and the University of Birmingham Code for Practice Research. After participants who met the inclusion criteria were identified by the school's Special Educational Needs Co-ordinator (SENCo), I contacted them via phone call to explain the project. Following contact, prospective participants were given an information sheet that had been translated into Urdu (Appendix 3), consent form translated into Urdu (Appendix 4).

At the beginning of the interview, I checked consent had been freely given by talking through the information sheet which included information about the study, the study's aims and what the participants would be asked to do. Participants were given the opportunity to ask questions, and if they still were interested in participating, they were asked to confirm oral and written consent using the consent form (Appendix 4). Circle boxes were provided and if participants agreed to all statements, participants were asked to sign and date the document.

Participants have a right for their information to remain confidential (BERA, 2024; BPS, 2021), this is particularly pertinent as parents were discussing very sensitive information within their interviews. As a result, all the information about the participants and information that they provided were not identifiable as belonging to them. All data was kept securely.

The participants' data was pseudo-anonymised. To ensure confidentiality, participants were informed that names of participants, the local authority, names of professionals and any other identifying information would be redacted from all interview transcripts. Some information about the participants (e.g. gender, age) and the nature of their children's SEND was gathered and is included to provide contextual and background information. Excerpts from interview transcripts have been included in this thesis and participants were made aware of this.

Complete anonymity was not possible due to conducting face-to-face interviews. However, all information about and from participants was kept confidential. All data including transcripts, recordings and consent forms were securely stored on encrypted devices using pseudonyms.

Participants had the right to withdraw from the research for any or no reason (BERA, 2024; BPS, 2021). Information regarding participants' right to withdraw was detailed on their information documents and at the beginning and end of the interview participants were reminded of their right to withdraw within a given timeframe.

Researchers have an obligation to disclose harmful behaviours to the participant or to others, to the appropriate authorities (BERA, 2024; BPS, 2021). Safeguarding procedures were checked with school staff, such as identifying the safeguarding lead within the school, prior to the interviews being conducted. It was also recognised that if there were any disclosures that this would override confidentiality and anonymity considerations.

As a researcher, I needed to consider the potential physical and/or psychological harm, discomfort or stress to the participants throughout the research process (BERA, 2024; BPS, 2021). I checked the safeguarding procedures with school staff, such as identifying the safeguarding lead within the school, prior to the interviews being conducted. I also considered and kept in mind that if any disclosures were made by participants during the interviews, this would override confidentiality and anonymity considerations. I also carefully considered the power dynamics and the potential impact in terms of the discomfort of participants. I was aware that if participants viewed me as a ‘professional’ and as a representative of the local authority that I was on placement with, they may not feel comfortable in having an honest conversation with me about their experiences. Consequently, the rapport building activity alongside participants choosing the venue was an attempt to address the power relations and make participants feel more comfortable.

Furthermore, it was anticipated that the participants may find reflections in the interview stressful or upsetting, particularly when narrating their experience of their child’s difficulties, engaging with services or professionals. To minimise this, I suggested participants could bring along a friend or family for emotional support as included in the participant information sheet. However, none of the participants brought anyone with them during the interviews.

Participants were also debriefed following their interview, giving them the opportunity to ask questions or to share any concerns that they had. If required, participants were signposted to relevant external services and agencies.

I intend to share my research with participants who were involved once I have completed the course and also intend to disseminate my research by sharing findings with the local authority and beyond.

3.12. Data Analysis

Reflexive Thematic Analysis (RTA) was used to analyse the data in this research. The process of RTA is described, as well as the rationale and process of data analysis is described in the next section.

This research used Reflexive Thematic Analysis (RTA) as the primary method to explore the experiences of Pakistani parents accessing and engaging with services and professionals who work to support children with SEND and their families.

Thematic analysis (TA) is a useful method when studying under-researched areas (Braun & Clarke, 2006) and is used to “identify patterns within and across data in relation to participants’ lived experiences, views and perspectives, and behaviour and practices” (Clarke & Braun, 2016, p. 297). As a result, this method was particularly useful for interviewing Pakistani parents about their lived experiences. It was appropriate for analysis as the interviews were conducted in one language and the analysis was undertaken in another language. Using TA accounts for this as the analysis focuses on patterns and themes within data and across the participants. However, using a method such as interpretative phenomenological analysis (IPA), means that during analysis, the researcher is required to comment on specific language use, including repetition and tone during the initial coding phase (Smith et al., 2009).

Reflexivity encourages researchers to continually reflect on assumptions and expectations, through the research process which may impact on the choices that they make and actions they take (Finlay & Gough, 2008). It allows the researcher to develop their positionality and assumptions about the world which shapes and informs the research intended to carry out (Braun & Clarke, 2019). RTA is an accessible and robust method for developing, analysing and interpreting patterns across a qualitative dataset whilst valuing the researcher's reflexivity and the impact and influence of this on research (Braun & Clarke, 2021). Within this method, the researcher's role in knowledge production is key, and philosophical and theoretical assumptions are clear through the analysis process (Braun & Clarke, 2019). RTA allows the researcher to reflect and engage with their data whilst considering their theoretical assumptions through the analytical process to construct themes that provide creative, interpretive stories about the data (Braun & Clarke, 2019). I drew on my knowledge as a researcher through the analysis, acknowledging my assumptions and drawing on my own experiences whilst thinking reflexively.

Temple (2006) suggests that being an insider to the research and sharing the same ethnicity and language does not mean that meaning can be shared, as each individual has a particular language history within a socio-cultural context and therefore cannot share a single uniform cultural perspective. Consequently, translating the data into English and engaging in discussions with my peers and research supervisor encouraged me to reflect on the data, notice patterns across datasets and analyse the data avoiding any potential bias.

3.12.1 Data Analysis Procedure

Phases as outlined by Braun and Clarke (2021)	**Actions and Reflections**
Phase 1: Familiarisation In this stage, the researcher becomes immersed in the dataset which involves reading and re-reading data. It also includes recording any initial analytical insights that may arise when becoming familiar with the dataset.	I read each transcript at least twice to ensure my familiarity with the data. During this process, I did not make any notes, however after I read the transcripts, I made some notes that captured my ideas and thoughts on each transcript.
Phase 2: Coding In this stage, the researcher works systematically through the dataset and identify segments that are relevant to the research questions. Coding is aimed at capturing single meanings or concepts and code labels are assigned to these segments. Coding occurs at two levels: semantic coding which refers to surface or explicit meaning or latent coding which refers to conceptual or implicit meaning	The following steps below describe how I coded the data set: 1. I began by highlighting each transcript with the research questions in mind. I found this useful as I could visually see the most useful parts of the transcripts that related to my research questions. 2. I coded each script with one research question in mind and completed this at least twice to ensure that I did not miss coding any important bits of the transcript. This also helped me to revise my initial codes to ensure that the highlighted extracts related to the codes that I had suggested. (Appendix 8) 3. Step 2 was repeated with the other research question in mind. (Appendix 9) 4. I spent time reading and refining codes to ensure that they were not too precise or narrow. I also tried to ensure that the codes were not too broad or general and that they 'identified a range of meanings related to the same general concept' (Braun & Clarke, 2022, p.69). Appendix 10 shows the codes developed for research question two and Appendix 11 shows the codes developed for research question three.

	After I had been through the data set a few times, refined and finalised my codes and checked coding for consistency and thoroughness, I was able to move onto the next phase.
Phase 3: Generating initial themes In this stage, researchers identify shared patterned meanings across the dataset. Clusters of codes are compiled that relate to research questions. Themes are then constructed by the researcher based around the data, the researcher's questions, knowledge and insights. Themes describe broader, shared meanings and once identified, all coded data relevant to each theme are collated.	I generated and developed initial themes by 'engaging with the data codes to explore areas where there is some sort of similarity meaning' (Braun & Clarke, 2022, p. 79). I clustered the similar data codes together to develop the themes. I produced thematic maps to explore how themes may relate to each other
Phase 4: Developing and reviewing themes In this stage, the researcher assesses the provisional themes and the viability of the overall analysis by going back to the dataset. This stage also includes checking that the themes make sense in relation to the coded extracts and the full dataset. In this stage, the central organising concept needs to be considered as well as the relationship between the themes, and existing knowledge and practice in the research field as well as the wider context of the research.	During this phase, I discussed my initial themes with my research supervisor and peers to ensure that they related to the research questions that I intended to answer. It was useful to talk through my initial themes and to gain feedback from my peers and research supervisor.
Phase 5: Refining, defining and naming themes In this stage, the researcher fine-tunes the analysis ensuring that each theme is demarcated and built around a strong core concept. In this phase, a brief synopsis of each theme is written, and themes are further refined and developed if necessary.	Final themes were refined, and Appendix 12 and 13 shows the codes and final developed themes for each research question.
Phase 6: Writing up In this stage, the researcher weaves the analytic narrative and data extracts to provide a coherent account about the dataset that addresses the research questions.	The results from the data analysis in relation to the previous literature are discussed in Chapter 4: Findings and Discussion.

Table 3: Outline of the Process of RTA (Braun & Clarke, 2021)

3.13 Quality Assurance

Within qualitative research, one of the most used tools is Yardley's criteria of quality, which includes sensitivity to context, commitment and rigour, transparency and coherence and impact and importance (Yardley, 2000; 2008).

3.13.1 Sensitivity to Context

Sensitivity to context includes considering my awareness of previous literature whilst considering the socio-cultural context of the studies and how these are interpreted (Yardley, 2000; 2008). In addition, it was important for me to consider power dynamics and the influence of this on participants in qualitative studies (Yardley 2000; 2008).

Within this thesis, the literature review outlines previous literature, whilst highlighting the gaps within the evidence base which provided the rationale for the current research aims and questions. I also reflected on the influence of power imbalance and dynamics by ensuring that I built rapport with the participants prior to beginning their interviews.

3.13.2 Commitment and Rigour

Commitment and rigour refers to my in-depth engagement with the topic, including data collection and showing understanding of the methods used, including undertaking a detailed, in-depth analysis (Yardley 2000; 2008).

Within this thesis, the methodology chapter outlines the methodology used including the rationale and data analysis steps undertaken. I collected the data using semi-structured interviews and used reflexive thematic analysis to analyse the data collected.

3.13.3 Transparency and Coherence

Transparency includes communicating how I obtained the data, including practicalities such as recruiting participants, equipment used as well as reflecting on how they influence the research (Yardley, 2000). Coherence refers to the process of ensuring that the philosophical assumptions align with the methodology used and analysis undertaken (Yardley 2000; 2008).

Within my thesis, my philosophical assumptions are discussed within the methodology chapter, and they guide the decisions taken during the research process. This includes thinking about the research questions and adopting the appropriate methodology and methods of data analysis whilst taking into considering my assumptions.

Braun & Clarke (2019; 2021) describe the importance of reflexivity within the method of RTA and this included keeping a reflexive journal throughout the research process which detailed my thoughts, feelings and reflection as I moved between the research process (extracts in Appendix 14). I also had numerous discussions about my research with my peers and research supervisor which encouraged me to broaden and deepen my reflections.

3.13.4 Impact and Importance

Impact and importance of the research includes reflecting on the impact of the results obtained, implications of the research and applications of the research undertaken (Yardley, 2000; 2008).

Within this thesis, the conclusion chapter discusses the strengths and limitations of the research including the implications for educational psychology services.

3.14. Summary

This chapter outlines the philosophical position of the researcher to rationalise the methodology adopted in this study, reflexive thematic analysis. I included an outline of the method, using semi-structured interviews, that was used to investigate my research questions, as well considering the ethical issues that may arise before, during and after data collection. Finally, I used Yardley's (2000) principles to reflect on how I have developed quality research.

Chapter 4: Findings and Discussion

4.1. Introduction

This chapter describes the findings from the participant interviews and provides data analysis. Each research question is presented with themes and subthemes supported by quotes from participants. Each theme is explored, and similarities and differences are highlighted in relation to previous literature. The following table shows the research questions, the themes and sub-themes generated from the analysis.

Research Question	Theme	Sub-Theme
What are the experiences of Pakistani parents’ accessing and engaging with services and professionals who work to support children with SEND and their families?	Parents’ Awareness of Services	
	Parents’ Understanding of Services	
	Support in Understanding Child’s Needs	
What barriers do Pakistani parents' experience when accessing and engaging with services and professionals who work to support children with SEND and their families?	Access	• Parents’ Understanding of Processes • Parents’ Understanding of Services and Professionals • Services are Oversubscribed • SENCo as a Gatekeeper
	Time	• Processes are Time Consuming
	Participation	• Parents Are Not Involved in the Process • Communication Difficulties between Parents and Services • No Follow Up • Language Barriers
	Relationships	• Parental expectations of help from services/professionals

		• Parents not feeling heard, concerns not taken seriously • Cultural Awareness
	Understanding of SEND	• Parent acceptance of SEND • Perception of SEND within community
What facilitators do Pakistani parents' experience when accessing and engaging with services and professionals who work to support children with SEND and their families?	Within Parent Domain	• Parental Perseverance and Motivation • Parental Advocacy
	Within Professional Domain	• Communication between Professionals and Parents • Professionals Being Culturally Competent • Professionals Directing Processes • Flexibility from Professionals

Table 4: Research Questions with Themes and Sub-Themes Generated from Analysis

Five participants were interviewed in this study and their demographic details are listed in the following table.

Participant	Gender	Age	Immigration History	Job	Ages of Children	Experience
Ahmed	Male	38	Born in Pakistan Arrived in the UK 10 years go	College Teacher	2 boys aged 13 and 9	• 2 boys with social, communication difficulties • 1 son was in a special school and had an EHCP • Other son was in a mainstream primary school with an EHCP
Sehrish	Female	35	Born in Pakistan Arrived in the UK 4 years ago	Housewife	2 daughters aged 12 and 7	• 2 daughters with communication and language difficulties • 1 daughter had an EHCP and was in a special school • Other daughter was mainstream primary school and she did not have an EHCP
Amina	Female	34	Born in Pakistan Arrived in the UK 1 year ago	Financial Accountant	1 son aged 9 and 1 daughter aged 6	• 1 son with social, communication difficulties • Family recently moved to the UK from Dubai • Son currently was not in education but had an EHCP
Neelam	Female	36	Born in Pakistan Arrived in the UK 18 years ago	Housewife	3 boys aged 16, 12 and 6	• 1 son with social, communication difficulties and a visual impairment • He was in a mainstream primary school and had an EHCP
Zainab	Female	35	Born in Pakistan Arrived in the UK 15 years ago	Housewife	3 boys aged 15, 12 and 5 years old	• 1 son with social, communication difficulties • He was in a mainstream primary school and had an EHCP

Table 5: Demographic Information for Each Participant

4.2. Research Question 1

What are the experiences of Pakistani parents' accessing and engaging with services and professionals who work to support children with SEND and their families?

From the analysis, there were three themes generated to answer research question one:

- Parents’ awareness of services;
- Parent’s understanding of involvement of services and
- Support in understanding child’s needs.

4.2.1. Parents’ Awareness of Services

Amina, Zainab, Neelam and Ahmed expressed concerns around not knowing what services were available for their child and how to access them. They felt like they did not know who to ask or where to find this information and this resulted them in feeling deflated and discouraged in engaging with services and professionals.

“… this is one of my main concerns that I don’t know which services are available and which services we are entitled to … we have absolutely no idea … when I first moved here to the country someone said to me that you should have a social worker, something like that, I don’t know, I don’t think anybody from social services have helped us or given us any information” (Amina)

"I was worried, didn't know who to speak to, or who could help, that I have this problem so how can I come out of it. I didn't have anybody that I could turn to" (Zainab)

Amina had heard of services that they may be able to access such as social services, but she was still unsure of how to access them. This also left her feeling helpless as she was not able to receive support that she felt she needed to manage with the difficulties that she was facing. Similarly, within literature, it was found that the majority of parents reported that they did not understand the services available which effected their choice in engaging with them (Fazil et al., 2002; Lawrence, 2014). Leiter and Krauss (2004) also found that parents may be unaware of the services that they may be able to access for their child, which results in parents' expectations of special education services being compromised by what they do and do not know. This consequently may affect their engagement with services in the future and may also contribute to less children from minoritised ethnic communities being identified with special educational needs compared to their white British peers (Strand & Lindorff, 2018).

4.2.2. Parents' Understanding of Involvement of Services

Sehrish, Ahmed and Neelam were unsure of which services were involved with their child. Sehrish and Ahmed were unaware of any services that were involved with their child whereas Neelam knew there were some services involved but she was not sure which. This also meant that their understanding of each of the services and their role is also limited. Although parental understanding of the services involved with their child was limited, services and professionals were still seen as helpful and regarded positively in supporting their child's difficulties.

"No, no idea" (when asked if she knew which professionals had been involved with her daughter) (Sehrish)

"My son attends special school; I'm not sure which services are involved" (Ahmed)

"I don't know much about it (services that are involved). But you know, they give him help in school for his education" (Neelam)

Communication difficulties between school and parents appeared to lead to a lack of understanding and knowledge of the services that were involved with their child as they reported that schools did not share this with them. Similarly, Raghavan et al. (2013) found that for many families there was a confusion on the identity of the professionals, the agency they represented and what support each service offered.

4.2.3. Support in Understanding Child's Needs

Sehrish, Neelam and Amina wanted support in understanding their child's needs. They stated there was an absence of support for parents within the community and would like more information on their child's diagnosis, such as autism, as well as strategies to cope with some of the associated difficulties.

"Yes, our community should get information … there should be some activity in which parents are given information" (Sehrish)

"I want to learn about it (autism) because you know, sometimes he becomes very aggressive and angry, and I want to learn something, because I want to learn something, because he's gonna soon become 18. And if he's having this problem, and then his teenager years start, it's going to be hard …. Yeah, like I said. I want to learn something. Yeah, more about this autism thing … Like, somebody that show you something? You know when he's having his moment? You can control him?" (Neelam)

The parents demonstrated a willingness in wanting to learn, alongside frustration that they feel they receive inadequate information about both their child's diagnosis and strategies that could support them at home. This suggests that parents would like to engage with the 'transplant model' where parents can be directed by professionals on strategies to use at home (Appleton & Minchom, 1990).

4.3. Research Question 2

What barriers do Pakistani parents' experience when accessing and engaging with services and professionals who work to support children with SEND and their families?

From the analysis, there were five themes generated to answer research question two:

- Access;
- Time;

- Participation;
- Relationships and
- Understanding SEND

Each theme was further analysed to generate sub-themes. The relationship between the themes and sub-themes can be seen in Table 5.

4.3.1. Access

Parents' Understanding of Processes

All the parents who were interviewed mentioned the difficulties in understanding the processes within the SEND system that was a barrier to them engaging with services and professionals. This included the vocabulary and terminology used within meetings with professionals, the different stages of support within school and applying for formal support such as EHCPs (Nnalue & Mahmud, 2024). They explained that being from a different country meant it was harder for them to understand and they spent a lot of time trying to finding out how things work as there is not much clarity within the system.

"… I mean you're in a different country, you're from Pakistan, you have difficulties in understanding (needs) … It gets very difficult, you don't know, you don't know, you haven't been educated here, we don't even know what help my child can get, we don't know, we don't know what to do, we don't know how to get help for our child so that he doesn't experience any difficulties, nor do we." (Zainab)

"… being in a new country, and everything is new, you spend a lot of time trying to figure out how things work here, and there is not much clarity either … I think things need to have more clarity and processes should be expedited especially in the case of special needs" (Amina)

"I didn't even know about EHCP, but my family friend asked me that does he get help from EHCP, I said no what's that, I don't know about it…." (Neelam)

Furthermore, Zainab explained that she did not know what documents such as EHCPs were and what support they could provide her son. Parents also reported a lack of knowledge and understanding of statutory processes and were in the process without any clarity of procedures which led to parents being confused and frustrated (Eccleston, 2016; Skipp & Hopwood, 2019).

Parents' Understanding of Services and Professionals

Sehrish, Neelam, Ahmed and Amina expressed frustration in not understanding what services were available to them and the role of the services in supporting their child. Consequently, parents shared that they felt worried as they did not know who they could rely on for support and guidance in supporting their child.

"I'm not sure about the roles and services and I don't understand the processes" (Ahmed)

"That hasn't been given to us (information on different services), but she (SENCo) gives us support" (Sehrish)

Zainab explained that she had heard from other people that there were certain services available that could support their child however she had not received any information or support from services or professionals, and she was unsure of how to access it.

"….Yeah who knows where they are (services) because I haven't found any ….. Yeah I haven't received any support. I hear from external people, that this is available, that is available, but I haven't received any support, I don't know … I was so worried, didn't know who to speak to, or who could help. I have this problem, how can I come out of it. I didn't have anybody that I could turn to" (Zainab)

Parents explained that when they did eventually manage to access services or professionals, in most cases the professionals or services did not explain what their role was and how they could support them. This led to parents being confused about their role and them perceiving the services or professionals as less helpful than intended, resulting in an expert model (Cunningham & Davis, 1985). Skipp and Hopwood (2019) also found that parents found roles of different services unclear which led them feeling confused about who was responsible for acting when needed. Perepa (2019) also found that families from minoritised ethnic communities were unaware of services because the nature of support that is available to them in this country, may be very different to their native country, impacting on their access to support.

"I think it has been 4, no, 3 years since we came here, and we have no idea on who has what profession and what they can do. It's easier if you are born here or here for a long time so you understand the system. We don't know. Even when I got some help from some services, I didn't know who they were or what they did" (Sehrish)

Services are Oversubscribed

Amina and Neelam reported that when they were made aware of certain services that were available, a barrier in them accessing or engaging with them was the fact that services were heavily oversubscribed. Amina mentioned that she felt that there was no hope in being able to access services such as respite care and she wanted her son to be able to access it as she felt like she needed a break away from caring for him as she was struggling mentally. This shows how limited services can potentially impact parents' mental health.

"… I didn't know respite was a thing, I don't know if I am entitled or not entitled. What if I can take it or not take it. For example, there are resources for XXXX so I have called resources for XXXX, and I wanted my son to go they are so oversubscribed that you have no hope that your child will ever get there" (Amina)

Neelam also mentioned that services were so oversubscribed that it was very difficult to get an appointment for her son which resulted in delays for receiving support.

"…it started from there, but it was very difficult to, you know, to get an appointment for him" (Neelam)

Bywaters et al (2003) found that services such as respite care were not available at the time when Pakistani and Bangladeshi families needed a break the most and the type of respite care that they wanted was not made available or was not found**.**

4.3.2. Time

Processes are Time Consuming

Ahmed, Amina, Zainab and Neelam mentioned that time was a barrier to them accessing services. They found that procedures were so time consuming, and this made them feel disappointed and made them feel pessimistic in having help or support from services. Two out of five parents particularly referred to the EHCP process and the length of time that it took for the process to be completed. They suggest that procedures should be expedited especially in the case of special needs. Keville et al. (2024) explored the experience of parents accessing an EHCP and found that it was a time-consuming and intimidating process which led to feelings of isolation, anxiety and helplessness.

"I would say it's a time-consuming process. The process (EHCP) took us 6 months, if it was reduced to a month or 2 months … Ok, I know there are lots of professionals involved, it might not be possible in 1 month but if it could happen in 2 months, because according to me if you are a parent of a special needs child, and you need to do your work and that child is home…. I wouldn't even be able to talk to you … The amount of time things take actually sometimes disappoints toy … you know, things aren't happening, when will we get what we need?" (Amina)

"In 2018 when we tried to get help for our son, it was covid times and very busy. There was a long waiting list, and this made us very frustrated and at the end of the day impacted on my son" (Ahmed)

Parents also were frustrated with the time it took to get an appointment after being referred to services as the waiting lists were long. They felt frustrated as they believed that the long waiting lists eventually impacted their child. Within the literature, parents also expressed dissatisfaction in the referral response times and time taken to see professionals (Coates et al., 2023). Habib et al. (2017) also found that parents experienced stress due to lengthy timelines for diagnostic and intervention services.

"… even the GP would just refer me so I think the referral process and the time that is taken there it is so time consuming and I think if this was minimised then it would be helpful for parents" (Amina)

"…it was really hard to get an appointment. I used to phone them every month and every week. Just to get an appointment I had to wait I think 18 months and then after 18 months I started calling them and said now is the time you need to see him because you know he was in the school in reception at that time…." (Neelam)

4.3.3. Participation

Parents Are Not Involved in the Process

Ahmed, Amina, Neelam and Zainab reported that they felt at times that they were not involved in decisions or in processes. They felt like they were outsiders and not aware of what was happening in school in terms of services or professionals that are involved with their child. Parents said that they could not physically see what support their child was getting but they had to believe schools when they said that they were helping their child. They also felt like decisions were being made without their consultation at times and this led to them feeling that they are not being heard and their opinion is not valid, similar to the 'expert' model (Cunningham & Davis, 1985).

"… this is the problem, my son should be in mainstream secondary school, he shouldn't be in special school forever, but they (service) aren't listening to us … parents could have been involved in the decision making but we are not part of the decisions" (Ahmed)

"… you know, there should be a person that should be able to give you a solution … I mean we are outsiders, so we don't know who is going to make the decision" (Amina)

When asked, Sehrish said that the school did not ask for her views or hopes for her child, as a result, her opinion was not taken into consideration when services or professionals were making decisions for her child.

Researcher "But did the school ask you for your views or your hopes for your child?" "I don't think they did" (Sehrish)

Similarly, parents experienced strong feelings of isolation and powerlessness during decision-making processes, and they felt that professionals' suggestions were final and inevitable (Woo Jung, 2011). Akbar and Woods (2020) found that Pakistani parents felt disempowered as professionals were perceived to have a higher perceived status, more knowledge of the processes and a superior command of the English language. This resulted in parents feeling that regardless of the family's wishes, professionals would make decisions as they had the 'upper hand', and Pakistani families were 'gullible' with professionals (Akbar & Woods, 2020). This suggests that families experience professionals using the 'expert model' (Cunningham & Davis, 1985) where there were limited chances for collaboration between parents and professionals, resulting in a disconnect between parental goals and professional goals, leaving parents feeling disempowered. This finding also suggests that statutory guidance such as the SEND Code of Practice (DfE/DoH, 2015) which emphasises the inclusion of parental voice and wishes is considered, in some cases, to be a low priority for professionals working with minoritised ethnic families.

4.3.4. Communication

Communication Difficulties between Parents and Services

Amina, Zainab and Neelam felt that there were communication difficulties between them and services. They particularly felt that there was no communication from services on procedures or clarity on steps to follow, particularly for formal processes such as EHCP. They felt confused and unsure of who they should contact to follow up to ascertain where their child was in the system or procedure. Adams et al. (2018) found that there was a lack of clarity and communication around EHCP processes, and many parents were unclear about the progress of their child's EHCP even though it had exceeded the 20-week process. This led to feelings of heightened anxiety and distress (Adams et al., 2018; Cullen & Lindsay, 2019).

"…there should be clarity that if your child has special needs this is the next step for you, and then this step is next and then this step is next. What currently happens is that you contact XXXX Council, and they then refer you to this services, that service. We don't know what procedures to follow, who to contact, who to follow up, who is in charge. We have no idea. There is such a confusion in the system." (Amina)

No Follow Up

Neelam and Zainab mentioned in their interview that services did not follow up communication with them. They were told by the schools or by the services that they would be back in touch with them or will provide them with support, however this was not followed up, resulting in parents losing trust with the professionals and services. Angell et al., (2009) found that parents lose trust in services or professionals when they do not follow through with recommendations, thus effecting their willingness to engage with them as they develop negative feelings. This causes poor collaborative partnerships between parents and professionals which impacts their engagement with services and professionals leaving them to make decisions as 'experts' (Cunningham & Davis, 1985) rather than involving parents to make decisions (Blue-Banning et al., 2004) as in the 'negotiation' model (Dale, 1996).

"Mrs X …. She told me that she will tell somebody to get in touch with me … but I never heard anything" (Neelam)

"..they say that they will help, they say we will do this, and we will do that, but it's not happening" (Zainab)

Language Barriers

All five parents mentioned that a significant barrier to parents accessing services was language barriers. Amina mentioned that although she was an educated professional and had passed an English proficiency test before moving to this country, she still found it difficult to understand English at times. She suggested that parents who maybe did not have the same education level as her would struggle even more to understand professionals speaking English.

"Wherever you go it's difficult. For example, if an English person had to speak Urdu, then they would also find it difficult. The same for Pakistani parents who are coming here. The professionals who are coming here have to do a test so they have a basic level of English but there is a difference between native speakers and people who have learnt the language. With time things get easier but even me being a professional environment for many years I am not able to understand a lot of times. If they speak fast or if I am in a rush I think, oh, what did that person just say, never mind the parents who haven't been educated or who aren't in professional jobs." (Amina)

Other parents mentioned how not being able to speak the language meant that they experienced more difficulties and having a translator meant that they could speak their own language otherwise it was very difficult to explain anything or to understand.

“There were language barriers, there should be some translators for parents like us” (Ahmed)

“The health visitor was ok, she used to bring someone with her that could speak my language otherwise it was very difficult to explain anything or to understand… because my husband works, so I struggle by myself and when you can’t speak the language you experience more difficulties” (Zainab)

There are language barriers are present and difficulties have arisen from poor communication between families and services, providers’ lack of knowledge of the different social norms, cultural beliefs and practices of people who come from a wide range of minoritised ethnic backgrounds (Azmi et al., 1996; Hatton et al., 1998; Nnalue & Mahmud, 2024). Lim et al., (2021) also found in a review that families who were not English-speaking, received fewer hours of contact with service to support their children with Autism compared to families who were English speaking, resulting in their access to services being reduced. Furthermore, parents also reported that the presence of a language barrier prevents them in being able to fully engage with service providers and as a result, the service providers spend less time communicating with them and taking their opinions into consideration (Miller-Gairy & Mofya, 2015).

4.3.5. Relationships

Parental expectations of help from services/professionals

Zainab, Neelam and Amina expressed that they had expectations of help from services and professional, however the help or support that they received did not meet their expectations. Zainab mentioned that services were suggesting things that she already knew, and this left her feeling unsatisfied as she felt that if she had received support from them as she had expected, this would have led her to feeling more confident in supporting her child's needs at home.

"I'm not able to give my other son time as this son needs 1:1 time otherwise he will do something dangerous like breaking something, because he is hyper. This is why I needed help, but I didn't get it …. Some services are just calling me and suggesting things to me on the phone like take him to the park, but we know these things. We know simple things like this, that if a child is being difficult for their mother, to take him outside. So, I don't feel I got the help as I should have done because even if trained professionals spend a small amount of time (with parents) they have more of an impact. Here in school when he does things with his teacher, has more of an impact on him than if I do things with him because I don't understand how to deal with these things. When I don't have knowledge about things, and I do things differently to the professionals, the child becomes confused and children like this need to be handled in a specific way, that's the issue …. Yes, they give advice but nothing like what we are expecting" (Zainab)

Amina also mentioned that if services were able to spend more time in special schools, she thought that there would have been more progress within children.

"… I just think that the more time that they (professionals/services) allocate their time in these schools (special schools), you will see more improvement" (Amina)

Neelam said that her intentions were questioned by the SENCo of the school and she was questioned as to whether she wanted an EHCP for her child for financial reasons. This interaction did not meet the expectations of the parents as her expectations of help from services and professionals were entirely supportive rather than questioning intentions. Phoenix et al. (2019) suggested that parents had specific expectations relating to the service providers' knowledge and skills and their relationship and communication with children and parents and when these expectations were not fulfilled, this led to parents feeling dissatisfied. The knowledge and skills that they expected service providers related to their specific role which included recommendations for strategies at home, whilst they expected service providers to communicate in a warm and enthusiastic way, encouraging their participation and ideas (Phoenix et al., 2019). This results in a 'negotiation' model of parent partnership being adopted where parents feel empowered to contribute and share their ideas (Dale, 1996).

"Even you know the teacher that I'm talking about, the SENCo, she even asked me once, why you need the EHCP, you after money or what? I was so upset. I said no, I'm not after money. I want the best for my child" (Neelam)

Parents not feeling heard, concerns not taken seriously

Zainab, Amina and Neelam felt that their concerns were not taken seriously, and they were not heard. They felt that when they were requesting involvement from services, as they had concerns about things, their concerns were not taken seriously, and they were told that their child did not need involvement.

"The speech language therapists said that he doesn't need speech and language therapy, but I think he does because I think he needs someone who tells him this is how you speak in a sentence and don't say it like that, say it like this …" (Zainab)

Similarly, when requesting schools to apply for documents such as the EHCP, Ahmed and Neelam felt that schools were not listening to their request, and they refused to support parents in applying for it. They also felt that their opinion was not considered or that they were heard by professionals when decisions were being made about their child.

"I feel I am not being listened to or my opinion is not taken seriously. They (professionals/services) just feel that once a child goes to special school they should stay there, they don't listen to what the parent is saying" (Ahmed)

"It was too hard. I used to tell the school that you know, my son is having a problem. The school said to me, you know, the SENCo before she wasn't good. I'm not saying that she wasn't good, but she had too much on her plate I think, yeah …. She used to tell me that, you know, we do give him help in school…. I used to tell the SENCo every time to apply for him (EHCP), she said no, we're gonna wait…. She wasn't listening basically" (Neelam)

Another barrier to parents accessing services is professionals being dismissive of their concerns, leading to them feeling that they are not being heard (Cohen et al., 2014; Gerdes et al., 2014). Croot (2012) also found that the confidence of parents in professionals and services significantly depleted as a result of their concerns not being taken seriously by professionals, resulting in parents disengaging with professionals and services.

Cultural Awareness

Zainab and Ahmed believed that services were not culturally aware, or they did not take their culture into consideration when talking to them or giving them advice. Ahmed also mentioned that the professionals were not understanding or sensitive to their home life, and this may have resulted them in not wanting to engage with professionals or services.

Researcher "..do you think that they (professionals/services) understand your culture when they are talking to you or giving you advice?" Z – "No they don't understand" R – "Can you give me an example of this, or do you just feel they don't understand" Z – "They just don't understand" (Zainab)

"..culture was not taken into consideration, they (professionals/services) don't have understanding and they are not sensitive to our home life" (Ahmed)

Families also report that they experienced a lack of cultural competency and culturally sensitive experiences when accessing and engaging with professionals which leads to negative feelings towards professionals and services, preventing them in engaging with them in the future (Akbar & Woods 2020; Fazil et al., 2002; and Raghavan et al., 2013). Similar findings were found by Perepa et al. (2023) who found that there was a lack of diversity and representation within services which prevented parents in engaging with services.

4.3.6. Understanding of SEND

Parent acceptance of SEND

Zainab, Amina, Neelam and Ahmed referred to their understanding of their child's needs and accepted that they had limited knowledge about their child's needs, which has been a barrier for them accessing services. Zainab and Amina explained that they had limited understanding of child development, and they did not recognise any differences in their child's development meaning that they did not engage in services or with professionals as they had not accepted that their child had needs.

"… I had 3 older children, they were absolutely fine, this child of mine I had after 10 years … so because of this I didn't understand any different. I thought this was normal, I didn't know, because of the gap. Like when you have children you know, the first child could do xyz, and this child can't. You think why he can't do the same. So, I didn't understand and when they told me that he has some problem, I was shocked. I was thinking what is the problem? He's ok because he used to walk around fine, he just had problems with understanding …. Because I had never seen anything like this before, I found it hard to accept it and I didn't know what to do, I didn't know who could help me" (Zainab)

"So, we were really happy, and we used to monitor him a lot but because he was our first child and we had him after 5 years, we didn't know much about children or child development and that it was possible to have problems" (Amina)

When Amina had accepted that her child had needs, her next challenge was to articulate her child's needs which she found difficult to do. This also meant that she could not engage with services or professionals as she did not know what support she needed to help with her child's needs.

"Honestly speaking, even after me being a very educated person, when someone asks me what your child's needs are, I used to find it very difficult to articulate this" (Amina)

Similar findings have been found where parents received limited support as a result of their denial of their child's needs and their limited understanding of SEND. Likewise, within the literature, parents had limited understanding of their child's needs and thought that they were from God and therefore accessing services for their child's needs would be "sinful", preventing them from engaging with professionals and services (Akbar & Woods, 2020; Lawrence, 2014).

Perception of SEND within community

Zainab and Amina referred to the perception of SEND within the community as a barrier to access services. Zainab mentioned that the older generation in particular viewed children with SEND as not being able to do anything in the future and as a result, they believe that engaging with services or professionals is not of any benefit.

“In our community, we think that children like this won’t be able to do anything … people were like this in the older generation when they found out that their child has problems, they think that their child is not able to do anything in the future. This is the issue, the older generation mothers came from Pakistan but now the times are a bit different, we learn a bit from external people or from our friends. The older generation of mothers just stayed in their house and went from home to drop their child to school and back home again. So, they just used to accept that their child was not well, and they did not try to get help for their child and so their children today are not able to do much” (Zainab)

Amina reported that when she was attempting to engage with services and professionals, she was discouraged by her family and questioned as to why she was taking her son to the doctor.

“… but you know for the family to accept … because to them my son seemed normal and they kept saying why are you taking him to the doctor you know … they said you have some problem with you … he seemed normal to them and they said there's no problem with him the problem is with you but you know instinctively that there is something wrong that you haven't been able to understand … but I think awareness is something that would really help” (Amina)

Pearson and Meadan (2018) interviewed minoritised ethnic parents and found that extended family member’s perceptions of their child delayed them accessing services as they did not share the same concerns although they may have noticed characteristics and behaviours, they were passive and may have viewed them as typical behaviours. Similar findings have also been found in the literature where for many families, the community attitudes to SEND and the desire to hide their child’s disability results in them not engaging or accessing services for their child even though they may have wanted to (Lawrence, 2014). Moreover, similarly Perepa (2019) found that where families and communities did not acknowledge the concept of SEND such as autism, they would not seek services which causes a barrier to service and professional engagement. This has implications for the models of partnership that can be drawn on and, in most situations, results in the ‘expert’ model (Cunningham & Davis, 1985) being used.

4.4. Research Question 3

What facilitators do Pakistani parents' experience when accessing and engaging with services and professionals who work to support children with SEND and their families?

From the analysis, there were two themes generated to answer research question three:

- Within parent domain and
- Within professional domain

Each theme was further analysed to generate sub-themes. The relationship between the themes and sub-themes can be seen in Table 5.

4.4.1. Within Parent Domain

Parental Perseverance, Motivation and Advocacy

Amina, Zainab, Ahmed and Neelam explained that their perseverance, motivation as well as advocacy facilitated them in accessing and engaging with services and professionals. They believe that if they need to remain positive and motivated to persevere in getting support for their child. Parents recognise that if they stay motivated, they will be able to support their child and engage with services by accepting their help. They also needed to be aware of their rights and being able to communicate these with service providers. Cunningham and Davis (1985) also found that when the 'transplant' model of parent participation was used, parents were motivated to support their own children and became more involved whilst persevering.

"My advice would be to give your child all your time, give them all your support, try all the support that you are given in this country and accept the help that you can get. Don't think that your child has Autism and that they are a lost cause, and they have no future, don't leave them. If your child need exercise, help them do this, do whatever you can to help their needs. Don't think that you have done something one day and it has not had an impact so you will stop it, please persevere, give your child a lot of time so that your child is able to become independent in the future and can look after themselves. Please don't think that your child is ill and so he is a lost cause. Don't think like this, don't let these thoughts come into your head. Don't become weak when thinking about your child's problems and don't go into depression, keep yourself strong, because your child needs you. If the Mum is strong, she can support her child, if Mum is not strong, she will not be able to cope herself so then how can she support her child? So, give your maximum time to your child, speak to other people as well, wherever you can get information from, wherever you can help from, take it, don't leave it" (Zainab)

"I would say to them to exercise their rights as soon as possible because it is very difficult you can never compare a normal parent to a special needs parents journey have probably nearly 1000 more challenges than a normal parent would have. I would say to them to exercise their rights as soon as possible and I would say to accept as many services that you are able to" (Amina)

Pearson and Meaden (2018) also found that parental advocacy was a facilitator to parents accessing and engaging with services. Parents also show motivation and perseverance to seek information through various mediums such as online and from other parents of autistic children in order to advocate for their child (Lee & Meadan 2021; Stahmer et al., 2019). Parents found that culturally specific support groups would be beneficial to them as they would be able to understand the culture and traditional family norms which informs their outlook and parenting styles (Gemegah & Perepa, 2023).

4.4.2. Within Professional Domain

Communication between Professionals and Parents

Ahmed and Sehrish spoke positively when they had received good communication from professionals and services. This included professionals taking the time to listen to their concerns seriously and showing them empathy. This made them feel heard and valued, particularly when services or professionals had arranged for interpreters for example to avoid parents experiencing any communication difficulties. This also meant that parents were able to express their opinions, concerns and views freely. Dowling (1994) also found that acknowledging parental concerns by taking them seriously as well as advocating for them makes them feel they are understood, resulting in parents being more likely to engage with services.

"Regular communication and advice from professionals helped us a lot" (Ahmed)

"We can speak a little English, but until now our experience has been good because when we have appointments or meetings we are asked in advance if we need an interpreter, and they arrange it … they listened to us, and we asked some questions. We spoke at good length, and they answered any concerns that we had" (Sehrish)

Families from minoritised ethnic communities have been found to value service providers in providing them with clear information, support and the time to answer any concerns that they may have or follow up with any further questions that they may have which facilitates the families in engaging with the service providers (Luelmo et al., 2022; Nilses et al., 2019).

Professionals Demonstrating Cultural Humility and Sensitivity

Sehrish mentioned during the interview that her daughter's school had taken their culture into account when making decisions. For example, she mentioned that the school had arranged for her daughter to have a female chaperone whilst swimming as they were aware that being a Muslim female, within the Pakistani culture, it would not be permissible for her to be with a male chaperone.

"…since we have had this meeting few days ago, they have satisfied us that they will send a female with her not a male. They said, now we know you are Muslim so we will put a Muslim lady with her. She will guide her and be with her in the swimming pool, she will do everything, and they said boys go with boys. Then we were satisfied and said ok she can go …. Yes, understood that we are Muslim, so we have a level of modesty. This is what the interpreter explained to the school, and they understood so we were satisfied, and we agreed to send our daughter for swimming" (Sehrish)

During the interviews, Sehrish was the only parent who mentioned that professionals had demonstrated cultural humility and sensitivity during her discussions with them about her daughter going swimming. This was mentioned several times during her interview as it left her feeling that her culture was respected and valued. Professionals and services that were culturally sensitive facilitated parental engagement as parents felt that their views and opinions on certain topics particularly sensitive topics was understood. Sensitivity, respect and empathy were found to be highly appreciated by minoritised ethnic parents, particularly when discussing their cultural and traditional beliefs (Birkin et al., 2008; Guler et al., 2018). It was also found that parents felt most comfortable with professionals from their own culture or background as they understood their experiences and family norms which allowed them to share their views openly (Jegatheesan et al., 2010).

Flexibility from Professionals

Zainab and Amina mentioned in the interviews that they appreciated when professionals were flexible and came to their house for example, which allowed the parents to engage with them, particularly if travelling to see professionals was difficult for them. They also mentioned that they would like more services and professionals to be flexible enough to accommodate them which would allow them to engage with services.

"And when the people came (home) and you know, saw my child … so that was also that was also very helpful and even for like say for example his transportation (to school) or …. everything is very very positive uh I I would say that here really what my expectations for the standards, you know, of UK with special education … I actually … I'm very happy with that. I think what may have been helpful … is that to see the doctor we have to leave the house but if there was access to a doctor that could come to the house. It would have been easier for me rather than me having to take my son out each time because sometimes he sits OK in the car sometimes, he doesn't and initially when I moved to the country to take him out alone anywhere, I was really worried. I was not comfortable I could only take him if someone was with me and sitting in the back of the car with him whilst I drove otherwise it was very difficult for me, I think this is something that would have helped me" (Amina)

"Yeah, it's hard to know, the people who speak English are able to come into school and they understand more but we don't understand so that's why I think if someone was able to come to my house or if I can take him somewhere to see a trained professional who has knowledge my son may be able to understand better" (Zainab)

Flexibility from service providers in terms of offering appointments or support outside of normal working hours or considering individual family needs such as providing support in the home setting has been found to facilitate parents in being able to access and engage with services (Guler et al., 2018).

4.5. Summary

In this chapter the findings from the analysis of the data from the interviews have been presented. General experiences of parents accessing and engaging with services and professionals who work together to support SEND found that there were difficulties around awareness and understanding of services as well as support in understanding their child's needs. The analysis highlighted barriers to engagement such as access; time; participation; relationships between professionals and parents and parental understanding of SEND. Facilitators were identified as parental motivation and advocacy and communication between professionals and parents and flexibility from professionals. Many themes were similar to previous findings in previous literature in Chapter Two. However, this research particularly highlights that in working relationships between minoritised ethnic parents and professionals, most of the times, the 'expert model' (Cunningham & Davis, 1985) is adopted, either by the parents themselves due to reasons such as perceptions or attitudes to SEND or by professionals. This leaves parents feeling further minoritised and disempowered in decisions relating to their child. The next chapter discusses the implications of these findings, relating to services and professionals and EP practice.

Chapter 5: Conclusion

5.1. Introduction

This chapter includes a recap of the findings and then discusses the implications of this for services and professionals who work together to support children and their families with SEND as well as implications for EP practice. This is followed by strengths and limitations of the research and future research directions as a result of this research.

5.2. Recap of Findings

The findings from this research highlights parents of children with SEND experience difficulties in awareness and understanding of services including their involvement with supporting their child's needs. They also experienced difficulties in understanding their child's needs. Several barriers that parents experience were identified in accessing and engaging with services:

- Being able to access services;
- The time it took to access services;
- The perception of their participation with services;
- The relationships between them and service providers and
- Parental understanding of SEND.

Facilitators were also identified in parents accessing and engaging with services:

- Within parent domain which included parental perseverance and advocacy and
- Within professional domain which included communication between parents and services; flexibility from services and services demonstrating cultural humility and sensitivity.

5.3. Implications of the Research

Firstly, the key implications for services and professionals who work together to support children with SEND and their families, after which implications for EP practice are discussed.

5.3.1. Implications for Services and Professionals who Work Together to Support Children and their Families with SEND

One of the implications of my research is the need for supportive parent groups for children with SEND and their families. Previous literature also suggests that parents would like to take ownership for the groups and engage with it so they can gain maximum benefit from attending them (Gemegah & Perepa, 2023). However, when professionals are present, this prevents parents from feeling that they can be open and honest about the issues they were facing (Akbar & Woods, 2020), consequently suggesting that there should be limited professional presence. Nonetheless, Heer et al. (2015) found such groups can segregate minoritised communities from mainstream services as they may focus on addressing societal barriers relating to disability. As a result, professionals could facilitate groups between parents of similar backgrounds to provide peer support and connections based on shared experiences.

Another implication of my research is the need for roles of professionals and services to be clearer for parents to have awareness and understanding of how they can support them and their child with SEND. Currently, parents report that they have a lack of awareness of services and professionals that can support them with the difficulties that they are experiencing, meaning that they do not know how to access support. They also lack in understanding which also prevents them in engaging with services and professionals. Professionals could make their role more explicit to parents on how they can support their family and their child with SEND. Parents also were unsure of processes such as applying for EHCPs. Professionals could try and make these processes clearer by providing parents with guidance in various community languages using materials such as videos to make information accessible, as a number of families who speak in their community language are not able to read in it due to their immigration history (Perepa, 2019).

Within my research, families also reported that they experienced a lack of cultural sensitivity and humility when engaging with services and professionals. Therefore, professionals and services could ensure that they become more culturally aware. This may include increasing diversity and representation within services as parents are less likely to engage with services when they experience a lack of representation (Perepa et al., 2023). Services that are able to increase the diversity and representation or that are able to become more culturally sensitive will result in parents being able to feel that they are able to trust professionals and engage with them, discussing freely their concerns and barriers (Jegatheesan et al., 2010).

5.3.2. Implications for EP practice

From my research, there are also implications for EP practice. For example, the first implication is communication between parents and EP. Parents from my research valued open and honest communication between themselves and the EP. This facilitated them in trusting professionals and subsequently engaging with them. This communication may include EPs explaining their role and their involvement with the child and family to develop a shared understanding of how they will support the child's needs.

Another implication is ensuring that parents have a way to communicate their views and wishes through decision making processes by adopting the negotiation model of parent partnership (Dale, 1996). Parents feel most valued when they are able to express themselves without any barriers and they are able to contribute to discussion about their child's needs as well as asking professionals questions. In order to do this, best practice would be for a professional interpreter to be commissioned for the work rather than depending on school staff to interpret as there may be various bias involved. However when using interpreters, Perepa (2019) suggests taking time to clarify various terminology such as 'autism' to avoid any misconceptions and to ensure that the interpreter has an understanding of the information prior to the meeting. Guidance has also been issued for psychologists using interpreters which should also be considered when working with families where English is not the first language (BPS, 2017).

Moreover, implications of my research also included EPs ensuring that they work in a culturally sensitive way. This includes valuing family norms and traditions and finding out what is important to the family. Working in this way ensures that parents feel comfortable and feel empowered to share what is important to them which facilitates their engagement with professionals and services. This relates to the negotiation model (Dale, 1996) where parents feel that they are equitable in the partnership working with professionals.

Another important implication for my research relates back to the models of parent partnership models. Prior to my research, I assumed that all parents would want to work using a negotiation model (Dale, 1996) where they could work collaboratively with professionals around decision making relating to their child. However, during the interviews I realised that this was not the desired parent partnership model for all parents. Theara & Abbott (2015) found that South Asian parents' construction of disability related to a medical model which was underpinned by cultural values and beliefs. This impacted in how they responded to their child's diagnosis and the way in which they worked with professionals. For example, Sehrish spoke about how she was satisfied with her experience with services that support her child, however when I asked whether she had been involved in decision making, this was very minimal. This suggests that professionals may have used the 'expert' model (Apple & Minchom, 1990). Sehrish shared that she was happy for professionals to take the role of the expert as she had confidence in the decisions that they made related to her child. Other parents such as Amina and Zainab spoke at length during their interviews, their need and want to be involved with decisions relating to their child, suggesting that they preferred a 'negotiation' model of parent partnership where they could work collaboratively with the professionals. I reflected on the reasons for the difference between the parents and thought that this may due to parental acceptance and attitudes to disability. Where parents may be struggling to accept disability and may feel more comfortable with the medical model of disability, this may impact on their expectations of working with professionals. They may prefer the ‘expert’ model (Apple & Minchom, 1990) and the professionals taking the lead in problem solving relating to their child. However, where parents have accepted their child’s disability and feel more comfortable with the social model of disability, they may feel more confident in advocating for their child. This would allow them to work with a ‘negotiation’ model (Dale, 1996) where they are able to collaborate with professionals on decisions relating to their child. This finding may suggest that professionals should not assume that all parents would want to work with a ‘negotiation’ model (Dale, 1996), rather they should ask the parent which partnership model they would prefer working with which may relate to their journey of acceptance of their child’s disability.

The main finding was that parents’ construction of autism privileged ‘medical model perspectives’ and this was largely underpinned by cultural values and beliefs. This is turn had a significant impact on how they responded to their child’s autism label and how they worked with professionals.

5.4. Strengths and Limitations of the Research

One of the main strengths of this research is this is a unique contribution as there is very limited research on exploring experiences of the minoritised ethnic communities of accessing services in their own language. This research has allowed parents to express and explain their experiences without any language barriers and has given an insight into the understanding and awareness of services within the community. This population is considered to be under-represented, and this research has allowed them to voice their views and experiences.

Another strength is that I identify as belonging from the same culture and ethnicity and so I was an ‘insider’ to this research. This diminished any power differentials as I took time to explain that my purpose of conducting the research, and my motivation for exploring the experiences of parents from my culture. As a result of this, I was able to understand some of the traditions and cultural expectations and issues that arise when talking about disabilities. I was able to communicate sensitively with them around these topics and ensured that they felt comfortable to do so. I was also able to make quick connections with the participants in my research and build rapports quickly, which subsequently meant that my participants were able to share their views and opinions confidently and honestly (Adu-Ampong & Adams, 2020; Bukamal, 2022).

In addition, this research used semi-structured interviews, which allowed for flexibility within the interview as I was able to build on questions and explore topics which were of particular interest. Using semi-structured interviews allowed the participants to be the expert in the conversation and to share their stories and experiences in detail (Smith & Osborn, 2007). I was not bound to a script and so the conversations with the parents in the research were fluid and similar to a conversation rather than being like an interview.

Moreover, a strength of this study is the use of reflexivity. Using this process of acknowledging my position and assumptions before analysing the data, allowed for greater awareness during the analysis, which resulted in deeper understanding of the experiences of parents. This is because I was able to apply meaning to the data through actively being involved with data collection as well as through my engagement with the literature and my theoretical assumptions (Braun & Clarke, 2021). However, using reflexivity may also be a limitation of this research, as this method depends on the analysis of the researcher and can be subjective based upon their theoretical assumptions, prior knowledge and experiences. Therefore, the analysis is subjective to the researcher, and different results may be obtained if the data was analysed by another researcher. Nevertheless, when exploring the experiences of under-represented populations or communities, reflexivity allows a deeper understanding of their experiences.

There are some other limitations for this research. In this research, the sample size was limited to five participants, therefore the results and themes from this study may not be generalisable to the wider Pakistani community. As a result, the study lacks in external reliability as there may be different results obtained if another sample of participants were interviewed from the Pakistani community. This means that conclusions and implications should be drawn tentatively from this research as it may not reflect the experiences of all parents from the Pakistani community. Furthermore, in this study, most of the participants were female and there was only one male participant. This may impact on the internal reliability as the results and themes that were discussed in the interviews may only be relevant to female Pakistani parents. It would be beneficial next time to interview a larger sample, with an equal number of male and female participants, to determine whether there is consistency between the experiences of Pakistani Mothers and Pakistani Fathers.

In addition, another limitation was the participant who took part in the pilot interview only partially met the inclusion criteria as she was not originally from Pakistan and her first language was English. She chose to speak in Urdu in order for me to check the interview schedule and to determine whether any changes had to be made to make the questions clearer. As a result, this may have impacted on the participants' understanding of the questions during the interview and particularly if they perceived me as an ‘outsider’ they may not have felt comfortable enough to ask for clarification.

Another limitation is that during the research, although I considered myself to be an ‘insider’ and therefore I believed that I was able to relate to some of the experiences and traditions that participants were discussing, participants may have viewed me as being an ‘outsider’. This is because, although I explained my positionality and motivation to do the research before beginning the interview, there may still have been power differentials perceived by the participants. This may be due to the interviews being taken place in a school setting where generally power differentials exist between members of staff and parents. As the interviews were conducted in a school building, I always had my local authority identification badge on, and although I stressed that I was conducting my research independently from the local authority, participants may have still perceived me as being an ‘outsider’. This may have impacted on their openness and honesty during the interviews as my position may have moved between an insider and outsider throughout the interview process. Bukamal (2022) found that positionalities can differ professionally and culturally. For example, within my research, I was an ‘insider’ culturally, however I believe that parents would have perceived me as an ‘outsider’ professionally. In order to compensate this, it may be advantageous to conduct the interviews in a neutral setting where there are no underlying assumptions of power difference to see if the results differ.

There are also limitations of me being an ‘insider’ to the community. Bukamal (2022) suggests that being an insider may result in reduced explanations from participants. This may result in inferences being made and these may be influenced by my own biases or assumptions which would have affected the results and data analysis (Greene, 2014).

However, I did try and ensure that when there were reduced explanations, I followed up with further questions, but this did not always result in clarification.

Moreover, another limitation is that although I attempted to use the committee approach to translation as described by Furukawa et al. (2014), I did not have an 'expert panel' to collaborate with when it came to translating the data. Although my EP colleague verified that my translation was correct, there was not an opportunity for another Urdu speaking researcher to collaborate with me to decrease the cultural bias in the native language (Martinez et al., 2006; Douglas & Craig, 2007). In future, I would collaborate with an Urdu speaking researcher to allow for the committee approach to translation to take place.

5.5. Directions for Future Research

There are several directions for future research, as a result of this current study. Currently, the parent-partnership models are dependent on parents being able to communicate and express themselves easily. They do not account for parents from minoritised ethnic communities who may have difficulties doing so, and therefore there is a need for parent-partnership models to be developed in a culturally sensitive way allowing for the needs for minoritised ethnic communities. The model would also need to accommodate for differing views and limited understanding of concepts such as SEND. This would allow services and professionals to use the model as a framework when working with children and families from minoritised ethnic communities and will result in families feeling empowered and willing to engage with them.

There is also a need for further research into the experiences of other minoritised ethnic communities working with services and professionals who work together to support children with SEND and their families. It would be important to conclude whether similar patterns emerge exploring other communities which has implications for EP practice and wider services and professionals.

5.6. Concluding Remarks

To conclude, the present study has added to the knowledge and understanding of professionals and services who work to support children with SEND and their families. The current study explored the experiences of parents accessing and engaging with services and professionals and provided them with an opportunity to be able to share their views in their own community language. Using reflexive thematic analysis, I was able to gain rich and detailed data on the lived experiences of Pakistani parents and I was able to analyse the data using my theoretical assumptions as well as my prior knowledge and experiences as an 'insider' of the community. This study is novel as till date there is limited research into the experiences of an under-represented community such as the Pakistani community, and interviewing them in Urdu, ensured that they were able to voice their experiences and views openly and honestly.

This study has demonstrated barriers to parents engaging and accessing services and professionals who work together to support children with SEND and families. These include accessing services; the value of their participation; delays in accessing support and the relationships between parents and professionals. It also highlighted facilitators to their engagement such as parental motivation and advocacy for their child with needs, flexibility from professionals and communication between professionals and parents. These findings have important implications for services and professionals who work together to support children with SEND and their families as well as EP practice.

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Appendices

Appendix 1

Appendix 1: Information sheet (Page 1 of 3)

An exploration of Pakistani parents' experiences of accessing and engaging with Special Educational Needs and Disabilities services

UNIVERSITY OF
BIRMINGHAM

Background Information

My name is Miriam Chaudhry, I am a trainee educational psychologist, and I am undertaking the three-year, full-time professional training in educational psychology at University of Birmingham. As part of my training, I am undertaking a two-year supervised practice placement within XXXXXX and I am undertaking this substantive research study for my thesis.

This information leaflet has been given to you because I am seeking your agreement to take part in this research project. Before you decide whether you would like to take part, please read this leaflet so that you understand why the research is being conducted and what being part of the project will entail. If you would like further information or would like to ask any questions about the information below, please do not hesitate to ask (contact details are provided at the end of this leaflet).

My Research Aims

I would like to explore Pakistani parents' experiences of accessing and engaging with services for children with Special Educational Needs and Disabilities (SEND). Although Urdu is not the mother tongue for all Pakistanis, I would like to capture the voice of the Pakistani community in Urdu as I would like to include participants who may not have had a chance to share or offer their view or opinion due to barriers such as language barriers. I am interested in investigating the barriers and facilitators faced by the community when engaging and accessing the services. I would like to use my findings to suggest how practice, policy and delivery could be changed to possibly account for some minority ethnic communities.

Justification

There is substantial research to show that minority ethnic parents struggle to engage with accessing services which can often lead to a delay in accessing support for their child, particularly for families who come from a South Asian background.

Furthermore, it can be extremely difficult to gain an understanding of the difficulties and barriers that they experience due to language barriers, and this can leave parents experiencing high levels of anxiety and depression. Therefore, this research will aim to capture the voice of these parents in their own language in order to describe their experiences.

It is expected that the findings will influence and drive policy changes, SEND service delivery and it will highlight the need for sources of professional support in community languages through literature and resource availability for minority ethnic communities.

Your involvement

If you are willing to take part in the study, I will arrange an initial meeting or call which will last approximately ten minutes where I can introduce myself, answer any questions you have and explain what your participation will include.

We will arrange the research interview (of approximately one-hour's duration) at a time and location convenient to you. The process will involve an in-depth discussion about your experiences of accessing and engaging with SEND services and professionals. There will be a mixture of descriptive questions where you will be invited to share your experiences and there will also be reflective questions for you to reflect on your experiences.

You are welcome to bring along a family member or friend for emotional support if you prefer.

The interview will be audio-recorded to enable me to capture the detail of your account and ensure accuracy: I would not be able to maintain a full or accurate written record if not recorded

What will the findings be used for?

The research findings will also be written in my doctoral thesis for the University of Birmingham, which will be published, in full, online in the University e-theses database. Shorter papers summarising the research may be written for submission to a peer-reviewed journal for publication, and findings from the study may also be disseminated at professional conferences.

Please note, your name, school and any other identifying information will not be included in any of the reports.

What will happen to the data that is collected?

Immediately after your interview, the electronically audio-recorded data will be transferred from the devices to a password-protected folder on the University of Birmingham's secure electronic data storage system, BEAR DataShare. The files will then be erased from the recording devices. Electronic transcripts and notes will also be held in a password-protected folder on BEAR DataShare. Any written notes and forms will be scanned in and also stored on BEAR DataShare in a password protected folder. Original paper notes and forms will be shredded. In accordance with university research policy, data will be stored on BEAR DataShare for 10 years after completion of the project. A 10-year expiry date will be set for the electronic data stored on BEAR DataShare.

If I change my mind, can I withdraw from the study?

- You have a right to stop the interview (and the recording) any time, without having to give a reason.

- You also have the right to ask me to redact any part of your interview transcription. You can choose to exclude specific comments from the interview transcript, which will not be analysed. However, it will not be possible to erase excerpts from the audio recording.
- If you choose to withdraw completely from the study during or immediately after the interview, the recording will be deleted from the recording devices immediately.
- Following the interview, you can withdraw your data from the research, for a period of up to fourteen days, by contacting the researcher (see contact details below).

Will my information be kept confidential in the study?

- Yes! Anything that you say will be treated as confidential, which means that it cannot be identified as yours.
- Pseudonyms will be used throughout the transcript and research report. Family relationships or professional roles may be referred to (e.g. brother, teacher or doctor).
- Every care will be taken to minimise the reporting of specific or unique case details that may reveal your identity. Please contact me if there is anything that you would like to be left out.
- If, for any reason, I become seriously concerned about your own or others' safety and/or well-being, I have a responsibility to pass on this information to the university tutor or placement supervisor, in order to decide how to offer support. This would be fully discussed with you first.

Where can I seek further information?

- Please feel free to ask me any questions you may have now.
- There will also be opportunity for questions and discussion after the interview.
- If you have any remaining questions or concerns after the interview, please use the following contacts:

Researcher: Miriam Chaudhry

Research supervisor: Dr Anita Soni

[redacted]

Thank you very much for taking the time to read this information leaflet and for considering your participation in the study.

Appendix 2

Consent Form

I ______________________________ would like to take part in the study looking at Pakistani parents' experiences of accessing and engaging with Special Educational Needs services. This study is being carried out by Miriam Chaudhry, Trainee Educational Psychologist, as part of a Professional Doctorate in Educational Psychology at the University of Birmingham.

Please read and complete the participant consent form.

I have read and understood the project information sheet.	Y	N
I have had an opportunity to ask questions about the project.	Y	N
I confirm that I have had experience with SEND services through EHCP processes	Y	N
I understand that the interview will last approximately one hour.	Y	N
Right to withdraw: I understand my participation in the study is voluntary. I understand I can withdraw from the at any point without explanation. I can also ask for my interview information not to be used in the study up until two weeks after the interview date. If I decide to withdraw from the study during or after the interview, all interview data will also be destroyed.	Y	N
Confidentiality: My views and identity will be kept confidential unless I say anything that suggests I or another are at risk from harm, in which case Miriam would seek guidance from her research supervisor and follow the necessary safeguarding procedures.	Y	N
Privacy: I understand that my voice will be recorded during the interview and Miriam may also take some hand-written notes. I understand that the voice recordings will be transcribed. I know that neither my name, nor the name of the school, will be included in these reports. I understand that basic details about me (i.e. gender, length of experience with SEND services and type of experience with SEND services) will be summarised in the methodology section. I give permission for my interview recording to be typed up with a different name and for this to be used in her research. I agree to anonymised quotes being used as part of the study.	Y	N
Data storage: All hand-written notes and audio recordings will be typed-up using pseudo-names, the original recordings and notes will be deleted or destroyed. The notes and recorder will be kept locked in a filing cabinet that only Miriam Chaudhry has access to. The anonymised transcripts will only be available to Miriam, her University Supervisor and University assessors. In adherence to the Data Protection Act (2018), All electronic versions of anonymous documents will be stored on the University of Birmingham secure network for a period of 10 years, after which point, they will be destroyed.	Y	N
Data usage: I understand that the results of this study: • Will be used for Miriam's Doctoral Thesis • Will be shared with professionals from the Educational Psychology Service • Will be made available to other professionals working in children's services in XXXXX • May be written up for professional journals or shared at conferences for people working in education (XXXX will not be named when reporting outside of the area).	Y	N

Participant Name: ______________________

Signature: ______________________

Date: ______________________

Researcher: Miriam Chaudhry ______________________

Signature: ______________________

Date: ______________________

Appendix 3

Information Sheet (Translated in Urdu)

معلوماتی پرچہ

خصوصی تعلیمی ضروریات کی خدمات تک رسائی اور ان سے منسلک ہونے کے پاکستانی والدین کے تجربات کی کھوج

پس منظر کی معلومات

میرا نام مریم چوہدری ہے، میں ایک ٹرینی تعلیمی ماہر نفسیات ہوں اور میں برمنگھم یونیورسٹی میں تعلیمی نفسیات میں تین سالہ کل وقتی پیشہ ورانہ تربیت لے رہی ہوں۔ اپنی تربیت کے حصے کے طور پر، میں XXXXX کے اندر دو سالہ زیر نگرانی پریکٹس پلیسمنٹ شروع کر رہی ہوں اور اپنے مقالے کے لیے اس اہم تحقیقی مطالعہ کا آغاز کر رہی ہوں۔

یہ معلوماتی کتابچہ آپ کو اس لیے دیا گیا ہے کیونکہ میں اس تحقیقی منصوبے میں حصہ لینے کے لیے آپ کا معاہدہ چاہتی ہوں۔ اس سے پہلے کہ آپ یہ فیصلہ کریں کہ آیا آپ حصہ لینا چاہتے ہیں، براہ کرم اس کتابچے کو پڑھیں تاکہ آپ سمجھ سکیں کہ تحقیق کیوں کی جا رہی ہے اور اس منصوبے کا حصہ بننے سے کیا فائدہ ہوگا۔ اگر آپ مزید معلومات چاہتے ہیں یا نیچے دی گئی معلومات کے بارے میں کوئی سوال پوچھنا چاہتے ہیں، تو براہ کرم پوچھنے میں ہچکچاہٹ محسوس نہ کریں (رابطے کی تفصیلات اس کتابچے کے آخر میں فراہم کی گئی ہیں)۔

میری تحقیق کے مقاصد

میں اسپیشل ایجوکیشنل نیڈس سروسز تک رسائی اور ان سے منسلک ہونے کے پاکستانی والدین کے تجربات کو دریافت کرنا چاہوں گی۔ میں پاکستانی کمیونٹی کی آواز کو ان کی مادری زبان میں حاصل کرنا چاہوں گی کیونکہ میں ان شرکاء کو شامل کرنا چاہوں گی جنہیں زبان کی رکاوٹوں جیسی رکاوٹوں کی وجہ سے اپنا نقطہ نظر پیش کرنے یا پیش کرنے کا موقع نہیں ملا۔ میں اس بات کی چھان بین کرنے میں دلچسپی رکھتی ہوں کہ خدمات کو شامل کرنے اور ان تک رسائی کے معاملے میں کمیونٹی کے لیے کیا رکاوٹیں اور سہولت کار ہیں۔ میں اپنے نتائج کو یہ تجویز کرنے کے لیے استعمال کرنا چاہوں گی کہ کس طرح عمل، پالیسی اور ترسیل کو اقلیتی نسلی خاندانوں کے اکاؤنٹ میں تبدیل کیا جا سکتا ہے۔

جواز

یہ ظاہر کرنے کے لیے کافی تحقیق موجود ہے کہ اقلیتی نسلی والدین خدمات تک رسائی حاصل کرنے کے لیے جدوجہد کرتے ہیں جس کی وجہ سے اکثر ان کے بچے کے لیے امداد تک رسائی میں تاخیر ہو سکتی ہے، خاص طور پر ان خاندانوں کے لیے جو جنوبی ایشیائی پس منظر سے آتے ہیں۔

مزید برآں، زبان کی رکاوٹوں کی وجہ سے ان کو درپیش مشکلات اور رکاوٹوں کا ادراک حاصل کرنا انتہائی مشکل ہو سکتا ہے، اور یہ والدین کو بے چینی اور ڈپریشن کی اعلی سطح کا سامنا چھوڑ سکتا ہے۔ لہذا، اس تحقیق کا مقصد ان والدین کی آواز کو ان کی زبان میں حاصل کرنا ہے تاکہ ان کے تجربات کو بیان کیا جا سکے۔

یہ توقع کی جاتی ہے کہ نتائج پالیسی میں تبدیلیوں کو متاثر کریں گے اور آگے بڑھیں گے، سروس ڈیلیوری بھیجیں گے اور یہ اقلیتی نسلی برادریوں کے لیے ادب اور وسائل کی دستیابی کے ذریعے کمیونٹی کی زبانوں میں پیشہ ورانہ مدد کے ذرائع کی ضرورت کو اجاگر کریں گے۔

آپ کی شمولیت

اگر آپ مطالعہ میں حصہ لینے کے لیے تیار ہیں تو میں ابتدائی میٹنگ یا کال کے لیے انتظامات کروں گا جو تقریباً دس منٹ تک جاری رہے گا جہاں میں اپنا تعارف کروا سکتی ہوں، آپ کے کسی بھی سوال کا جواب دے سکتی ہوں اور وضاحت کروں گا کہ آپ کی شرکت میں کیا شامل ہوگا۔

ہم تحقیقی انٹرویو (تقریباً ایک گھنٹے کے دورانیے کا) آپ کے لیے مناسب وقت اور مقام پر ترتیب دیں گے۔ اس عمل میں SEND کی خدمات اور پیشہ ور افراد تک رسائی اور ان سے منسلک ہونے کے آپ کے تجربات کے بارے میں گہرائی سے گفتگو شامل ہوگی۔ وضاحتی سوالات کا ایک مرکب ہوگا جہاں آپ کو اپنے تجربات بتانے کے لیے مدعو کیا جائے گا اور آپ کے تجربات پر غور کرنے کے لیے عکاس سوالات بھی ہوں گے۔

انٹرویو کو آڈیو ریکارڈ کیا جائے گا* تاکہ میں آپ کے اکاؤنٹ کی تفصیل حاصل کر سکوں اور درستگی کو یقینی بنا سکوں: میں مکمل یا درست تحریری ریکارڈ برقرار نہیں رکھ سکوں گی!

نتائج کو کس کے لیے استعمال کیا جائے گا؟

تحقیقی نتائج برمنگھم یونیورسٹی کے لیے میرے ڈاکٹریٹ کے مقالے میں بھی لکھے جائیں گے، جو یونیورسٹی کے ای تھیسس ڈیٹا بیس میں مکمل طور پر آن لائن شائع کیے جائیں گے۔ تحقیق کا خلاصہ کرنے والے چھوٹے مقالے اشاعت کے لیے ہم مرتبہ نظرثانی شدہ جریدے میں جمع کرانے کے لیے لکھے جا سکتے ہیں، اور مطالعہ سے حاصل ہونے والے نتائج کو پیشہ ورانہ کانفرنسوں میں بھی پھیلایا جا سکتا ہے۔

براہ کرم نوٹ کریں، آپ کا نام، اسکول اور کوئی دوسری شناختی معلومات کسی بھی رپورٹ میں شامل نہیں کی جائیں گی۔

جو ڈیٹا اکٹھا کیا جائے گا اس کا کیا ہوگا؟

آپ کے انٹرویو کے فوراً بعد، الیکٹرانک طور پر آڈیو ریکارڈ شدہ اور ویڈیو ریکارڈ شدہ ڈیٹا کو آلات سے برمنگھم یونیورسٹی کے محفوظ الیکٹرانک ڈیٹا اسٹوریج سسٹم، BEAR DataShare کے پاس ورڈ سے محفوظ فولڈر میں منتقل کر دیا جائے گا۔ فائلوں کو پھر ریکارڈنگ آلات سے مٹا دیا جائے گا۔ الیکٹرانک ٹرانسکرپٹس اور نوٹ بھی BEAR DataShare پر پاس ورڈ سے محفوظ فولڈر میں رکھے جائیں گے۔

کسی بھی تحریری نوٹ اور فارم کو اسکین کیا جائے گا اور پاس ورڈ سے محفوظ فولڈر میں BEAR DataShare پر بھی محفوظ کیا جائے گا۔ اصل کاغذی نوٹ اور فارم کاٹ دیے جائیں گے۔ یونیورسٹی کی تحقیقی پالیسی کے مطابق، پراجیکٹ کی تکمیل کے بعد ڈیٹا کو BEAR DataShare پر 10 سال تک محفوظ کیا جائے گا۔ BEAR DataShare پر محفوظ الیکٹرانک ڈیٹا کے لیے 10 سال کی میعاد ختم ہونے کی تاریخ مقرر کی جائے گی۔

اگر میں اپنا ارادہ بدلتا ہوں تو کیا میں مطالعہ سے دستبردار ہو سکتا ہوں؟

- آپ کو بغیر وجہ بتائے کسی بھی وقت انٹرویو (اور ریکارڈنگ) کو روکنے کا حق ہے۔
- آپ کو یہ حق بھی حاصل ہے کہ آپ مجھ سے اپنے انٹرویو ٹرانسکرپشن کے کسی بھی حصے کو دوبارہ ترتیب دینے کو کہیں۔ آپ انٹرویو ٹرانسکرپٹ سے مخصوص تبصروں کو خارج کرنے کا انتخاب کر سکتے ہیں، جن کا تجزیہ نہیں کیا جائے گا۔ تاہم، آڈیو ریکارڈنگ سے اقتباسات کو مٹانا ممکن نہیں ہوگا۔
- اگر آپ انٹرویو کے دوران یا اس کے فوراً بعد مطالعہ سے مکمل طور پر دستبردار ہونے کا انتخاب کرتے ہیں، تو ریکارڈنگ کو فوری طور پر ریکارڈنگ آلات سے حذف کر دیا جائے گا۔.
- انٹرویو کے بعد، آپ محقق سے رابطہ کرکے، چودہ دنوں تک تحقیق سے اپنا ڈیٹا واپس لے سکتے ہیں (نیچے رابطے کی تفصیلات دیکھیں)۔

کیا میری معلومات کو مطالعہ میں خفیہ رکھا جائے گا؟

- جی ہاں! کوئی بھی چیز جو آپ کہیں گے اسے رازدارانہ سمجھا جائے گا، جس کا مطلب ہے کہ اس کی شناخت آپ کی نہیں ہو سکتی۔

- نقل اور تحقیقی رپورٹ میں تخلص استعمال کیا جائے گا۔ خاندانی تعلقات یا پیشہ ورانہ کرداروں کا حوالہ دیا جا سکتا ہے (جیسے بھائی، استاد یا ڈاکٹر) .
- مخصوص یا منفرد کیس کی تفصیلات کی رپورٹنگ کو کم سے کم کرنے کے لیے ہر طرح کا خیال رکھا جائے گا جس سے آپ کی شناخت ظاہر ہو سکتی ہے۔ براہ کرم مجھ سے رابطہ کریں اگر کوئی ایسی چیز ہے جسے آپ چھوڑنا چاہتے ہیں۔
- اگر، کسی بھی وجہ سے، میں آپ کی اپنی یا دوسروں کی حفاظت اور/یا بہبود کے بارے میں سنجیدگی سے فکر مند ہو جاتا ہوں، تو میری ذمہ داری ہے کہ میں یہ معلومات یونیورسٹی کے ٹیوٹر یا پلیسمنٹ سپروائزر کو پہنچاؤں، تاکہ یہ فیصلہ کر سکوں کہ مدد کی پیشکش کیسے کی جائے۔ اس پر پہلے آپ سے مکمل بات کی جائے گی۔

میں مزید معلومات کہاں سے حاصل کر سکتا ہوں؟

براہ کرم بلا جھجھک مجھ سے کوئی سوال پوچھیں جو آپ کے پاس ہو سکتا ہے۔

اگر انٹرویو کے بعد آپ کے کوئی باقی سوالات یا خدشات ہیں، تو براہ کرم درج ذیل رابطوں کا استعمال کریں:

محقق: مریم چوہدری
ریسرچ سپروائزرز : ڈاکٹر انیتا سونی۔

[redacted]

اس معلوماتی کتابچے کو پڑھنے کے لیے وقت نکالنے اور مطالعہ میں اپنی شرکت پر غور کرنے کے لیے آپ کا بہت بہت شکریہ۔

Appendix 4

Consent Form (Translated in Urdu)

میں ____________________ خصوصی تعلیمی ضروریات کی خدمات تک رسائی اور ان میں مشغول ہونے کے پاکستانی والدین کے تجربات کو دیکھتے ہوئے مطالعہ میں حصہ لینا چاہوں گا۔ یہ مطالعہ مریم چوہدری، ٹرینی ایجوکیشنل سائیکالوجسٹ، یونیورسٹی آف برمنگھم میں ایجوکیشنل سائیکالوجی میں پروفیشنل ڈاکٹریٹ کے حصے کے طور پر کر رہی ہے۔

براہ کرم شرکت کنندہ کی رضامندی کا فارم پڑھیں اور مکمل کریں۔

N	Y	میں نے پروجیکٹ کی معلوماتی شیٹ کو پڑھ اور سمجھ لیا ہے۔
N	Y	مجھے اس منصوبے کے بارے میں سوالات پوچھنے کا موقع ملا ہے
N	Y	میں تصدیق کرتا ہوں کہ مجھے EHCP کے عمل کے ذریعے SEND سروسز کا تجربہ ہے۔
N	Y	میں سمجھتا ہوں کہ انٹرویو تقریباً ایک گھنٹہ جاری رہے گا۔
N	Y	دستبرداری کا حق: میں سمجھتا ہوں کہ مطالعہ میں میری شرکت رضاکارانہ ہے۔ میں سمجھتا ہوں کہ میں کسی بھی وقت وضاحت کے بغیر دستبردار ہو سکتا ہوں۔ میں انٹرویو کی تاریخ کے دو ہفتے بعد تک اپنی انٹرویو کی معلومات کو مطالعہ میں استعمال نہ کرنے کے لیے بھی کہہ سکتا ہوں۔ اگر میں انٹرویو کے دوران یا اس کے بعد مطالعہ سے دستبردار ہونے کا فیصلہ کرتا ہوں، تو انٹرویو کا تمام ڈیٹا بھی تباہ کر دیا جائے گا۔
N	Y	رازداری: میرے خیالات اور شناخت کو صیغہ راز میں رکھا جائے گا جب تک کہ میں کوئی ایسی بات نہ کہوں جس سے پتہ چلتا ہو کہ مجھے یا کسی دوسرے کو نقصان سے خطرہ ہے، ایسی صورت میں مریم اپنے تحقیقی نگران سے رہنمائی حاصل کرے گی اور حفاظتی طریقہ کار پر عمل کرے گی۔
N	Y	رازداری: میں سمجھتا ہوں کہ انٹرویو کے دوران میری آواز ریکارڈ کی جائے گی اور مریم ہاتھ سے لکھے ہوئے کچھ نوٹ بھی لے سکتی ہیں۔ میں سمجھتا ہوں کہ آواز کی ریکارڈنگ کو نقل کیا جائے گا۔ میں جانتا ہوں کہ ان رپورٹس میں نہ تو میرا نام، نہ ہی اسکول کا نام شامل کیا جائے گا۔ میں سمجھتا ہوں کہ میرے بارے میں بنیادی تفصیلات (یعنی جنس، SEND سروسز کے ساتھ تجربے کی لمبائی اور SEND سروسز کے تجربے کی قسم) کو طریقہ کار کے سیکشن میں خلاصہ کیا جائے گا۔ میں اپنے انٹرویو کی ریکارڈنگ کو مختلف نام کے ساتھ ٹائپ کرنے اور اسے اس کی تحقیق میں استعمال کرنے کی اجازت دیتا ہوں۔ میں مطالعہ کے حصے کے طور پر استعمال کیے جانے والے گمنام حوالوں سے اتفاق کرتا ہوں۔
N	Y	ڈیٹا سٹوریج: تمام ہاتھ سے لکھے گئے نوٹ اور آڈیو ریکارڈنگ کو سیوڈو ناموں کا استعمال کرتے ہوئے ٹائپ کیا جائے گا، اصل ریکارڈنگز اور نوٹس کو حذف یا تباہ کر دیا جائے گا۔ نوٹوں اور ریکارڈر کو فائلنگ کیبنٹ میں بند رکھا جائے گا جس تک صرف مریم چوہدری کی رسائی ہے۔ گمنام ٹرانسکرپٹس صرف مریم، اس کے یونیورسٹی سپروائزر اور یونیورسٹی کے جائزہ لینے والوں کے لیے دستیاب ہوں گی۔ ڈیٹا پروٹیکشن ایکٹ (2018) کی تعمیل میں، گمنام دستاویزات کے تمام الیکٹرانک ورژن 10 سال کی مدت کے لیے یونیورسٹی آف برمنگھم کے محفوظ نیٹ ورک پر محفوظ کیے جائیں گے، جس کے بعد، انہیں تباہ کر دیا جائے گا۔
N		ڈیٹا کا استعمال: میں سمجھتا ہوں کہ اس مطالعہ کے نتائج: • مریم کے ڈاکٹریٹ تھیسس کے لیے استعمال کیا جائے گا۔ • ایجوکیشنل سائیکالوجی سروس کے پیشہ ور افراد کے ساتھ شیئر کیا جائے گا۔ • XXXXX لوکل اتھارٹی میں بچوں کی خدمات میں کام کرنے والے دیگر پیشہ ور افراد کو دستیاب کرایا جائے گا۔

🟧	🟩	- پیشہ ورانہ جرائد کے لیے لکھا جا سکتا ہے یا تعلیم میں کام کرنے والے لوگوں کے لیے کانفرنسوں میں شیئر کیا جا سکتا ہے (علاقے سے باہر رپورٹنگ کرتے وقت XXXXX کا نام نہیں لیا جائے گا)۔

محقق: مریم چوہدری

شریک کا نام:

دستخط:

دستخط:

تاریخ:

تاریخ:

Appendix 5

Interview Schedule

Rapport Building

How are you?

Where are you from in Pakistan?

My response: My Mum was born in this country and my Dad was born in Pakistan, he moved here 30 years ago. He is from Dina near Jhelum in Pakistan. My husband is originally from Pakistan and he is from Jhelum

When did you last go to Pakistan?

My response: I last went to Pakistan in February 2022. I took my son to Pakistan for the first time to meet my Dad's family and to meet my in-laws. I thoroughly enjoyed my experience and so did my son. The weather was perfect and we were able to spend a lot of quality time with family.

How often do you go back?

My response: Growing up I used to go back to Pakistan every 2 years to see my Dad's family and his Mum. However, this decreased as I became older as I started college and university and it was more challenging to make the time to go. Nevertheless, I still maintained contact with my family in Pakistan and my parents, in particular my Mum, always made sure I was deep rooted within my culture and that I could speak Urdu fluently.

I have decided to study this area as I am from this community and I see first hand how difficult some of the families find accessing and engaging with services. I decided to research this area to give families a voice and to empower them to share their views in their own community language. I hope that by taking part in my research you can help me make a difference to our community. A reminder that you may withdraw at any time before, during and 2 weeks after the interview has taken place. 2 weeks after the interview takes place it will not be possible to withdraw the data as analysis of the data would have commenced.

Discussion Topic	Question	Probes
Understanding of child's needs	Tell me about your child (age, gender, background info, diagnosis, needs etc) What do you understand by your child's needs?	Ask parent what difficulties their child experiences
Understanding of SEND	What do you understand by Special Educational Needs and Disabilities?	Share the definition of SEND according to SEND Code of Practice (DfE/DoH, 2015)

Parents' understanding of services and general experiences of accessing and engaging with services and professionals	What services have been involved with your child? What services are you currently involved with? What information have you been given about services? Do you understand the role of the professionals/services? Tell me about your experience of services and did this change as you went through the Education Health and Care Plan process?	Provide parent with local offer, name the different services Ask parent if they remember being informed of any services that were coming to observe or work with their child Ask parent if they remember attending any meetings or meeting any professionals Outline what EHCP is and ask if parent remembers going through the process
Experiences of cultural sensitivity and humility	Do you feel your culture was taken into consideration when professionals/services were engaging with you?	Ask parent if they think professionals working with them considered that they were Pakistani
Barriers to accessing and engaging with services	What was unhelpful when engaging with services and professionals? Is there anything that may have made you less likely to engage with services?	Ask parent why
Facilitators to accessing and engaging with services	What did you find most helpful/useful when engaging with services and professionals? Is there anything that may have made you more likely to engage with services?	Ask parent why
Areas for development	In your opinion what are the most important things professionals/services need to consider when engaging	Ask parent how and why

	with parents from minority ethnic backgrounds? What advice would you give to someone who is yet to engage with services? How have you found today being interviewed in home language? Is there anything else you would like to share with me?	

Appendix 6

Translation Moderation

Researcher: So your son comes here?

Sehrish (Pseudonym): Yes, my son

Researcher: From Reception or …?

Sehrish: Yes, from nursery

Researcher: Oh ok from nursery?

Sehrish: At that time he was not diagnosed, so …

Researcher: Ok so that came through later?

Sehrish: Yes, later, so they said they were watching him, the teachers and they said you have to tell the doctor so they can see what problem he has, and I told them he has these problems so that the teacher can understand

Researcher: Yes

Sehrish: So then I told staff here

Researcher: Yes

Sehrish: So then these guys …

Researcher: They took further action?

Sehrish: Yes

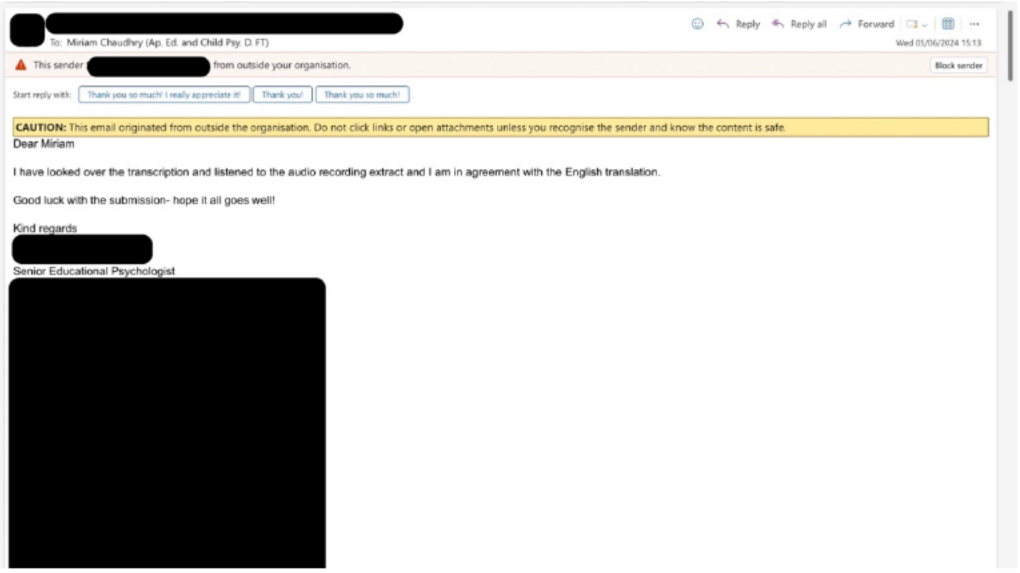
Researcher: So did you tell the health visitor first about your son?

Sehrish: He didn't pass the check, they do it I think ….

Researcher: Yeah they do it at 2 years old

Sehrish: Yes he didn't pass that

Researcher: Oh right ok



[redacted] [redacted]

To: Miriam Chaudhry (Ap. Ed. and Child Psy. D. FT)

Wed 05/06/2024 15:13

This sender [redacted] from outside your organisation.

CAUTION: This email originated from outside the organisation. Do not click links or open attachments unless you recognise the sender and know the content is safe.

Dear Miriam

I have looked over the transcription and listened to the audio recording extract and I am in agreement with the English translation.

Good luck with the submission- hope it all goes well!

Kind regards

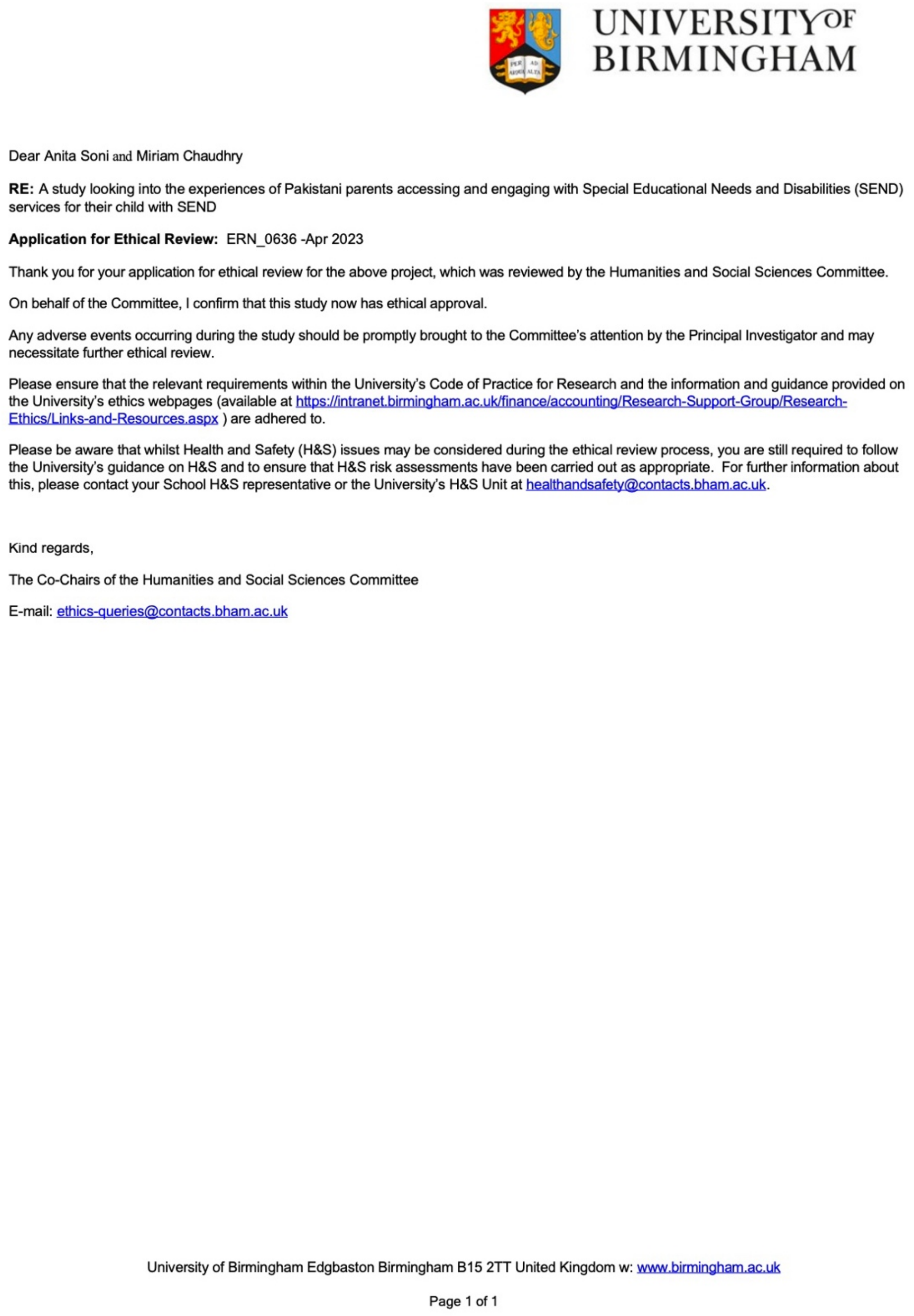
[redacted]

Senior Educational Psychologist

[redacted]

Appendix 7

Ethical Approval



UNIVERSITY OF BIRMINGHAM

Dear Anita Soni and Miriam Chaudhry

RE: A study looking into the experiences of Pakistani parents accessing and engaging with Special Educational Needs and Disabilities (SEND) services for their child with SEND

Application for Ethical Review: ERN_0636 -Apr 2023

Thank you for your application for ethical review for the above project, which was reviewed by the Humanities and Social Sciences Committee.

On behalf of the Committee, I confirm that this study now has ethical approval.

Any adverse events occurring during the study should be promptly brought to the Committee's attention by the Principal Investigator and may necessitate further ethical review.

Please ensure that the relevant requirements within the University's Code of Practice for Research and the information and guidance provided on the University's ethics webpages (available at https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Links-and-Resources.aspx) are adhered to.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's H&S Unit at healthandsafety@contacts.bham.ac.uk.

Kind regards,

The Co-Chairs of the Humanities and Social Sciences Committee

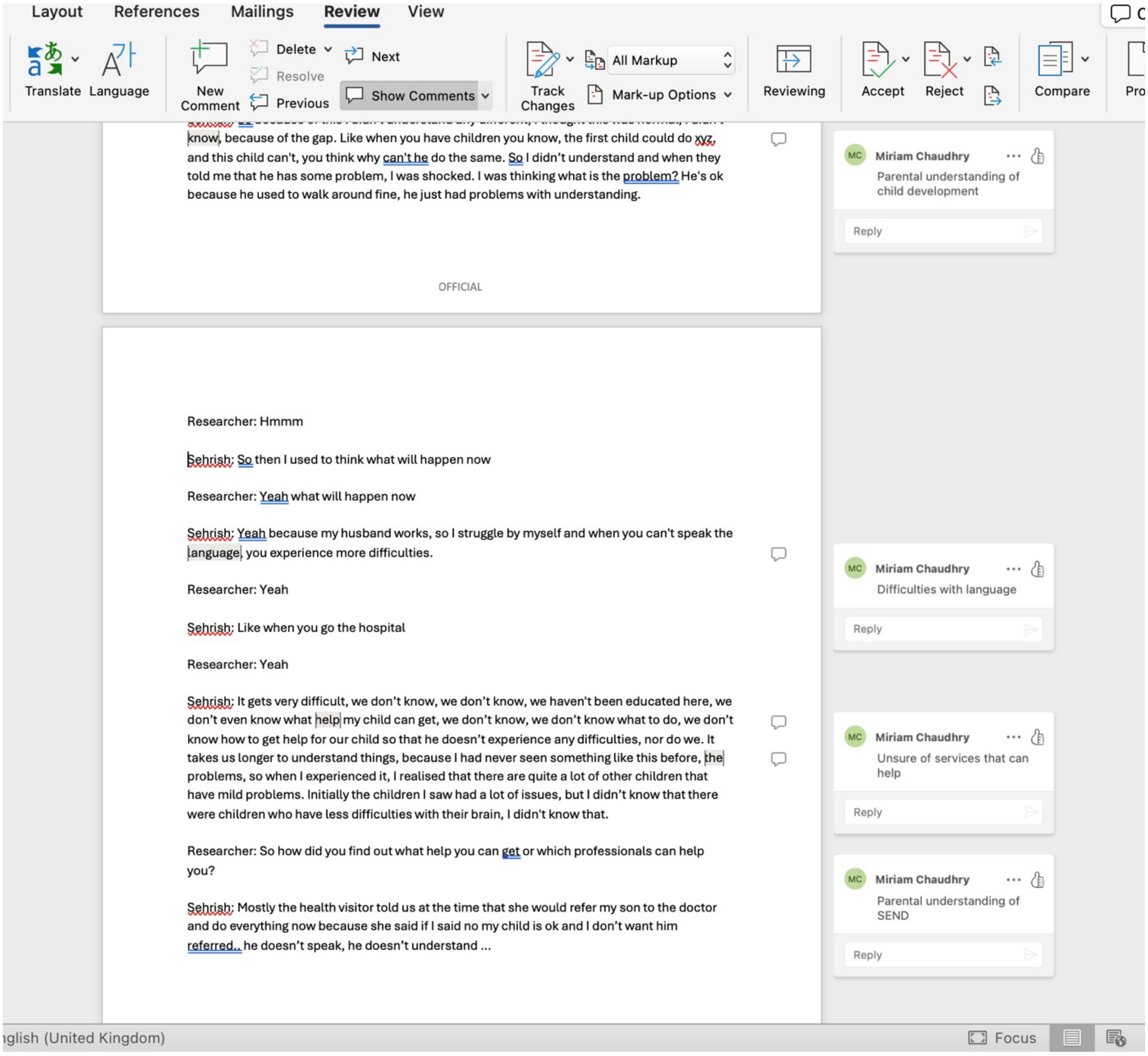
E-mail: ethics-queries@contacts.bham.ac.uk

University of Birmingham Edgbaston Birmingham B15 2TT United Kingdom w: www.birmingham.ac.uk

Page 1 of 1

Appendix 8

Extract from Sehrish's Interview, example of analysis with Research Question 2



know, because of the gap. Like when you have children you know, the first child could do xyz, and this child can't, you think why can't he do the same. So I didn't understand and when they told me that he has some problem, I was shocked. I was thinking what is the problem? He's ok because he used to walk around fine, he just had problems with understanding.

Miriam Chaudhry: Parental understanding of child development

Researcher: Hmmm

Sehrish: So then I used to think what will happen now

Researcher: Yeah what will happen now

Sehrish: Yeah because my husband works, so I struggle by myself and when you can't speak the language, you experience more difficulties.

Miriam Chaudhry: Difficulties with language

Researcher: Yeah

Sehrish: Like when you go the hospital

Researcher: Yeah

Sehrish: It gets very difficult, we don't know, we don't know, we haven't been educated here, we don't even know what help my child can get, we don't know, we don't know what to do, we don't know how to get help for our child so that he doesn't experience any difficulties, nor do we. It takes us longer to understand things, because I had never seen something like this before, the problems, so when I experienced it, I realised that there are quite a lot of other children that have mild problems. Initially the children I saw had a lot of issues, but I didn't know that there were children who have less difficulties with their brain, I didn't know that.

Miriam Chaudhry: Unsure of services that can help

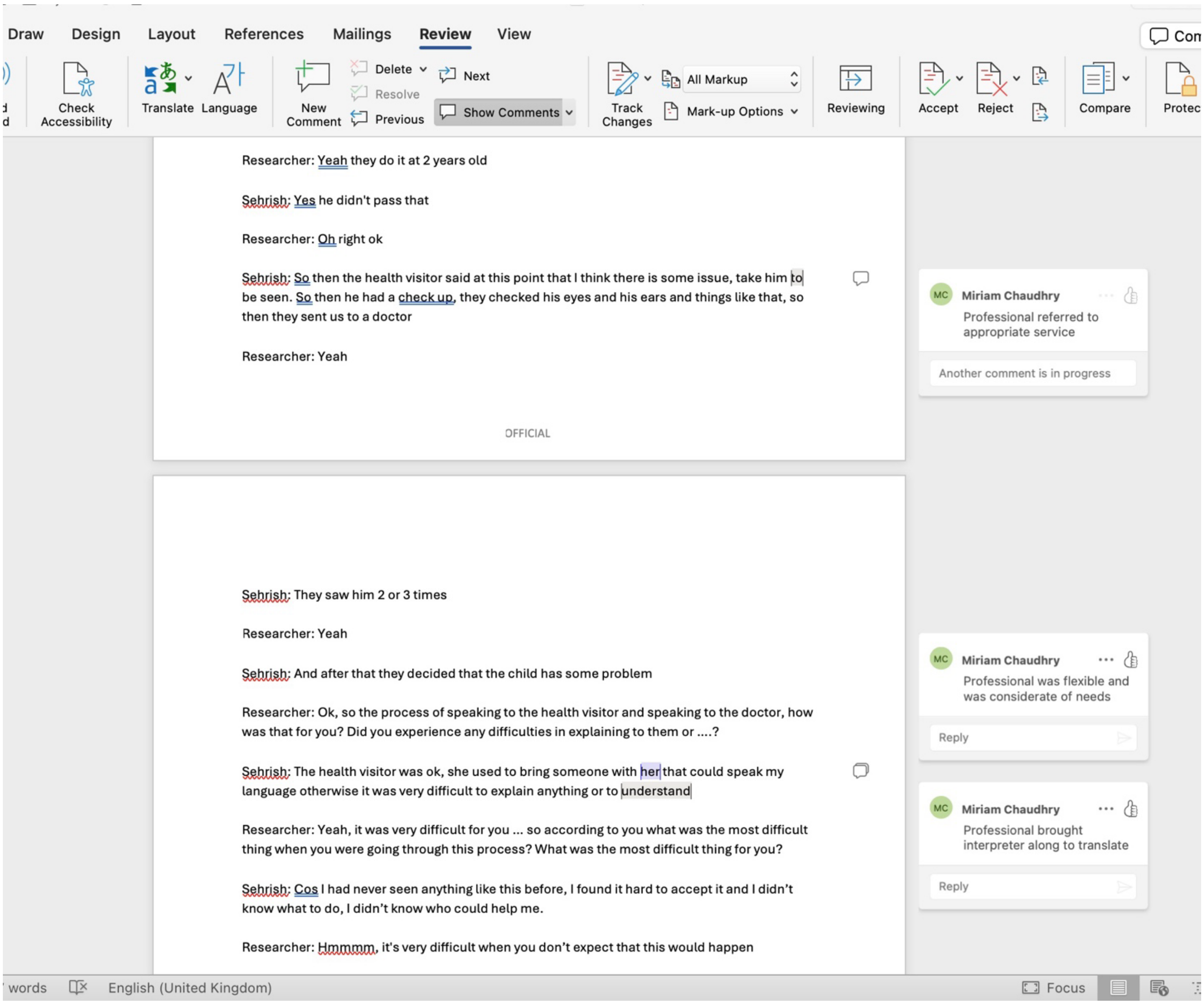
Miriam Chaudhry: Parental understanding of SEND

Researcher: So how did you find out what help you can get or which professionals can help you?

Sehrish: Mostly the health visitor told us at the time that she would refer my son to the doctor and do everything now because she said if I said no my child is ok and I don't want him referred., he doesn't speak, he doesn't understand ...

Appendix 9

Extract from Sehrish’s interview, example of analysis with Research Question 3



Researcher: Yeah they do it at 2 years old

Sehrish: Yes he didn't pass that

Researcher: Oh right ok

Sehrish: So then the health visitor said at this point that I think there is some issue, take him to be seen. So then he had a check up, they checked his eyes and his ears and things like that, so then they sent us to a doctor

Researcher: Yeah

OFFICIAL

Sehrish: They saw him 2 or 3 times

Researcher: Yeah

Sehrish: And after that they decided that the child has some problem

Researcher: Ok, so the process of speaking to the health visitor and speaking to the doctor, how was that for you? Did you experience any difficulties in explaining to them or ….?

Sehrish: The health visitor was ok, she used to bring someone with her that could speak my language otherwise it was very difficult to explain anything or to understand

Researcher: Yeah, it was very difficult for you … so according to you what was the most difficult thing when you were going through this process? What was the most difficult thing for you?

Sehrish: Cos I had never seen anything like this before, I found it hard to accept it and I didn’t know what to do, I didn’t know who could help me.

Researcher: Hmmmm, it's very difficult when you don’t expect that this would happen

MC Miriam Chaudhry
Professional referred to appropriate service

MC Miriam Chaudhry
Professional was flexible and was considerate of needs

MC Miriam Chaudhry
Professional brought interpreter along to translate

Appendix 10

Codes for Research Question 2

- Professionals referring to services – time
- Waiting lists – time
- Difficulty in access e.g. appointments
- Communication between parents and services
- Parents feeling like things are done to them rather than with – participation
- Parents not feeling heard, concerns not taken seriously
- Parents unaware of processes/documents
- Parent's understanding of processes
- SENCo being gatekeeper
- SENCo referring to services
- SENCo “allowing” to apply for EHCP
- Relationship between parent and professional/service
- Professional/Service assumptions of parent's intentions
- Unsure of professional's involvement with their child, their role and what they can offer
- No follow-up
- Parent's perception of service/professional's understanding of their child's needs
- Parental acceptance of SEND
- Parent finding it difficult to understand child's needs
- Lack of understanding of SEND
- Services not following up with promises
- Unable to speak English
- Parental understanding of child development
- Language difficulties
- Unsure of how to access help
- Parental expectations of help from services/professionals
- Parents are not involved in processes
- Professionals/services lack of cultural understanding
- Perception of SEND within community
- Some services oversubscribed
- Professionals not understanding home life
- Processes take too long
- Some services don’t have enough resources
- Some services don’t have enough space

Appendix 11

Codes for Research Question 3

- Parental perseverance and motivation
- Parents driving processes
- Professionals agreeing with parent
- Parent's resilience
- School driving processes for some parents
- Being listened to and concerns taken seriously
- Handover between professionals
- Professionals taking culture into consideration
- Parental wishes/aspirations taken into consideration
- Interpreter arranged and involved
- Parental acceptance of SEND
- Flexibility from services
- Regular communication from professionals
- Creating awareness and acceptance of SEND

Appendix 12

Final Codes for Research Question 2

Theme	Sub-Theme	Codes
Access	• Parents' Understanding of Processes • Parents' Understanding of Services and Professionals • Services are Oversubscribed • SENCo as a Gatekeeper	• Difficulty in getting appointments • Parents unaware of processes/documents • Parent's understanding of processes • SENCo referring to services • SENCo "allowing" EHCP • Unsure of professional's involvement with their child, their role and what they can offer • Unsure of how to access help • Some services don't have enough resources • Some services don't have enough space
Time	• Processes are Time Consuming	• Professionals referring to services • Waiting lists • Processes take too long
Participation	• Parents Are Not Involved in the Process • Communication Difficulties between Parents and Services • No Follow Up • Language Barriers	• Communication between parents and services • Parents feeling like things are done to them rather than with them • Services not following up with promises • Unable to speak English • Language difficulties • Parents are not involved in processes •

Relationships	• Parental expectations of help from services/professionals • Parents not feeling heard, concerns not taken seriously • Cultural Awareness	• Parents not feeling heard, concerns not taken seriously • Relationship between parent and professional/service • Professional/Service assumptions of parent's intentions • Parent's perception of service/professional's understanding of their child's needs • Parental expectations of help from services/professionals • Professionals/services lack of cultural understanding • Professionals not understanding home life
Understanding of SEND	• Parent acceptance of SEND • Perception of SEND within community	• Parental acceptance of SEND • Parent finding it difficult to understand child's needs • Lack of understanding of SEND • Parental understanding of child development • Perception of SEND within community

Appendix 13

Final Themes for Research Question 3

Theme	**Sub-Theme**	**Codes**
Within Parental Domain	• Parental Perseverance and Motivation • Parental Advocacy	• Parental perseverance and motivation • Parents driving processes • Parent's resilience • Parental acceptance of SEND • Creating awareness and acceptance of SEND
Within Professional Domain	• Communication between Professionals and Parents • Professionals Being Culturally Competent • Professionals Directing Processes • Flexibility from Professionals	• Professionals agreeing with parent • School driving processes for some parents • Being listened to and concerns taken seriously • Handover between professionals • Professionals taking culture into consideration • Parental wishes/aspirations taken into consideration • Interpreter arranged and involved • Flexibility from services • Regular communication from professionals

Appendix 14

Extracts from Reflexive Diary

Before data collection:

I am thinking of the method to use to explore experiences of Pakistani parents. I enjoyed the lecture at university on IPA and it seems that this method is generally used when exploring experiences on a certain topic. I have started researching this method and considering whether it would work for my thesis. I am also considering thematic analysis, in particular reflexive thematic analysis as using this method means that I can look for patterns within the data. IPA seems like it is very detailed analysis of words, pauses and any utterances in the language used within the data. However, RTA is just looking for themes and patterns within the data, and it allows me to use my reflexivity as a researcher to guide the analysis. I need to consider which method would be best to use as I have the added complication of translating from Urdu to English for transcription. I need to raise this during supervision with my tutor and need to delve deeper into the literature.

During data collection:

I am experiencing a lot of issues with recruitment. I have approached SENCos and when I approach the parents, they don't seem to engage. I also had some comments from some parents saying that they didn't believe that I would keep the information confidential as they didn't trust professionals. This made me think of the experiences that they were basing this assumption on. Although I tried to reassure them they still did not want to engage. This made feel quite sad about what they must have been through and validates why I am trying to do this research.

After data collection:

I have managed to collect data from 5 parents. I tried to ensure that this was a mix of males and females, however it was really difficult to recruit participants. Reflecting on the data that I have collected, there were some surprises. I was surprised that some parents were happy to be 'consumers' when working with parents and services, as I had assumed that they would want to work in equitable partnerships. Some parents also happy for the professionals to be the 'expert'. I wondered whether this was the result of their previous experiences and assumptions of parent-professional partnerships. Furthermore, I wonder whether this is also the result of them not feeling confident enough to engage in equitable partnerships. Moreover, I also wonder whether this is related to their understanding of SEND and their concept of disability.