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University of Southampton

Faculty of Environmental and Life Sciences

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Towards Equitable SEND Systems: South-Asian and Indian-Panjabi Sikh Parents' experiences with SEND-Support in England

by

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Thesis for the degree of Doctorate in Educational Psychology

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University of Southampton

Abstract

Faculty of Environmental and Life Sciences

School of Psychology

Doctorate of Educational Psychology

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by

Sukhjagat Brar

The Special Educational Needs and Disability (SEND) code of practice mandates that education professionals ensure all children with SEND are treated fairly and have access to adequate services and education, irrespective of their ethnicity and culture. Despite this legislation, children from ethnic minority backgrounds receiving SEND-support continue to be disproportionately represented in England's education system. Understanding over- and under-representation is crucial to ensuring equitable SEND-support for all children in need. Culturally responsive practices can help ensure equitable access to support and are underpinned by guidance from governing bodies of the educational psychology profession in England. However, there is a dearth of literature exploring minority SEND experiences and the development of educational psychologists' culturally responsive practices.

A systematic literature review explored how South-Asian parents understand their children's SEND and how they describe their experiences with education professionals and SEND-systems in England. The findings from 11 studies were synthesised. Key findings suggest that South-Asian parents experience unmet language needs, cultural stigma and shame (sharam), and a lack of support, exacerbating power imbalances with education professionals, including educational psychologists. The empirical research used critical communicative methodology to explore Indian-Panjabi Sikh parents' experiences with SEND-systems. Parents face significant barriers in navigating SEND-systems and are vulnerable to isolation due to a lack of perceived professional, familial, and community support. They discussed issues related to unmet language needs, absence of interpreters, cultural considerations, informed consent, and clear information on EP involvement and parental rights during EHCP processes. These experiences contributed to disempowerment and vulnerability to SEND-stigma and sharam (shame). Moreover, parents described SEND-support for autistic children in mainstream schools as inadequate. These findings highlight the unique difficulties parents face in understanding SEND and accessing support. The findings suggest that children from minority ethnic and linguistic backgrounds are at risk of receiving inadequate support when EPs and teachers lack cultural responsiveness. Given the new UK government in power, research exploring accessibility to equitable SEND-support for families of children with SEND from minority backgrounds is timely. Culturally responsive practices are discussed and identified in response.

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Research Thesis: Declaration of Authorship

Print name: Sukhjagat Brar

Title of thesis: Towards Equitable SEND Systems: South-Asian and Indian-Panjabi Sikh Parents' experiences with SEND-Support in England

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission.

Signature: ....Date: 29.08.2024

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Definitions and Abbreviations

BEI	British Education Index
CASP	Critical Appraisal Skills Program
CRP(s)	Culturally Responsive Practice(s)
CYP	Children and Young People
EHCP(s)	Education Health Care Plan(s)
EMAS	Ethnic Minority Achievement Services
EPs	Educational Psychologist(s)
Gurudwara(s)	A Sikh place of worship
LA(s)	Local Authority/Local Authorities
ONS	Office for National Statistics: The UK's largest independent producer of official statistics.
ProQuest	Dissertations and Theses Global
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta Analyses
RED report	Race and Ethnic Disparities report
SENCo(s)	Special Education Co-Ordinator(s)
SEND	Special Educational Needs and/or Disability
SENDIASS	Special Educational Needs and Disabilities Information Advice and Support Service
Sharam	shame; a complex cultural construct interlinked with ‘family honour’, ‘self-respect’ and reputation
SNJ	Special Needs Jungle: a non-profitable parent-run organisation
Social GGRRAAACCEEESSS	A framework that outlines different elements of identities (i.e., gender, geography, race, religion, age, ability, appearance, culture, class, education, employment, ethnicity, spirituality, sexuality, sexual orientation), and how these can intersect and interact in affording people different levels of power and privilege
South-Asian	Individuals from Sri Lanka, Indian, Pakistan, Bangladesh, Nepal, Bhutan and or the Maldives

Stigma	A harmful societal perception experienced by those associated with the stigmatised individual, often leading to discrimination against family members, for example, due to the individual’s disability
WoS	Web of Science

Chapter 1 Thesis Introduction

1.1 Overview

The thesis is presented and structured in a three-paper format following the University of Southampton's code of practice for research degree candidature and supervision 2023-24 and the academic and research handbook for the doctorate in educational psychology programme. This research aims to

- explore 'South-Asian' parents' understanding of their children's special education needs and disability (SEND) and experiences with available SEND-support
- bridge the existing gap within the literature by exploring Indian-Panjabi Sikh parents' experiences with SEND-systems and support for their children
- identify collaboratively with interpreters, Educational Psychologists (EPs), and Indian-Panjabi Sikh parents, culturally responsive educational psychology practices for equitable and accessible SEND-support for all children and families.

Chapter 1 includes the rationale behind the language and terminologies used throughout the thesis, background literature building the rationale for the current research, researcher positionality (epistemology, ontology, and reflexivity), ethical considerations, and a dissemination plan.

1.2 Language and Terminology

As a researcher and aspiring EP who has English as an additional language, it was important to me that I was up to date with the appropriate language and terminologies, especially when describing minority experiences that have not been represented within the literature before. In support, I ensured to seek supervision and participants' views and attend an event on neurodiversity-affirming practices. Although this research did not specifically focus on autism but was inclusive of any parent whose child was receiving SEND-support in schools, I was mindful that my research included the experiences of parents who had autistic children. This prompted me to review prior research where Kenny et al. (2015) found that autistic adults and their families preferred identity-first language (autistic), whilst professionals preferred person-first language (person with autism). However, past research has not explored Indian-Panjabi Sikh parents' views. Therefore, I asked participants for their preferences on how to refer to their children in the empirical paper. Indian-Panjabi Sikh parents preferred to use identity-first language in English and person-first language in Panjabi. To respect parents' wishes, I have used identity-first language (e.g., Indian-Panjabi Sikh parent, autistic child) throughout the research when sharing parents' experiences. Additionally, 'children with SEND (support)' language will be used throughout the thesis, as advised by the parents in the empirical study. SEND-support refers to the current legislative support available for pupils in England (DfE, 2023; Children and Families Act, 2014).

'South-Asian' is a complex term that was coined by the British during 19th-century colonial rule (Singh, 2022). Currently, there is no consensus on which countries are classified as 'South-Asian'. For example, the term can be used to refer to people from India, Pakistan, Bangladesh, Nepal, Bhutan, Sri Lanka, the Maldives, and Afghanistan (Singh, 2022). The term has been criticised when it is used to refer to South-Asians as a homogenous group, overlooking the diversity of over two billion people with 30 different major languages written in over 16 different scripts. In recent years, attempts among the British South-Asian diaspora have been made to '*establish a sense of collective pride as well as learn from the past and the dangers of reductive conceptions of identity*' (Singh, 2022). This has been through initiatives such as an annual event called South Asian Heritage Month (SAHM). The event coincides with the weeks marking an end to British rule in South-Asia resulting in the birth of independent nations: India, Pakistan, Sri Lanka, Nepal, Bhutan, Bangladesh, and the Maldives. The current research will use the term 'South-Asian' to refer to individuals from these countries, aligned with the previous research (Bhatia et al., 2008). The term will be used with a recognition that the 'South-Asian' population is not homogenous. The rationale for focusing on 'South-Asian' parents' experiences in the systematic literature review is purely reflective of the limited research available to conduct a systemic review. This is because the past research has predominantly focused on 'South-Asian' parents' experiences, often without further specification of parents' ethnicity (Theara & Abbott, 2015).

Culturally Responsive Practices (CRPs) have been discussed under various terms, including cultural competence, cultural humility, and cultural awareness (Sakata, 2021). Cultural competence encompasses the importance of holding awareness, knowledge, and skills to work effectively with culturally diverse populations (Sue et al., 1992). However, the term has been critiqued for implying that one can achieve the expertise and competence of an entire culture, thereby overlooking diversity within cultural groups (Ellis et al., 2020). In contrast, cultural humility emphasises ongoing self-reflection and acknowledgment of power imbalances, aligning with the British Psychological Society's (BPS) call for professionals to be mindful of their ethnocentricity (BPS, 2017). While valuable, terms such as 'awareness' or 'humility' lack emphasis on active and reciprocal engagement required in professional practice (Barsky, 2018). Cultural responsiveness builds on these concepts emphasising both awareness of cultural differences and the active, dynamic process of tailoring professional interactions to respect and integrate cultural beliefs, values, and contexts (Sakata, 2021). I will be using the term CRPs for its fluid and ongoing process that integrates aspects of competence, such as knowledge and skills, with self-awareness and humility while also encompassing active, responsive engagement. This way the term enables me to not only address cultural diversity but also foster social justice through professional practices designed to reduce systemic inequities (Garcia-Vazquez et al., 2020).

1.3 Context and rationale for the research

Being brought up in two distinct cultures (born in Finland to first-generation immigrant parents of Indian-Panjabi heritage) has enriched my understanding and appreciation for diversity. It has also made me reflect on how identities can create and uphold privilege and discrimination within education systems. I witnessed this early on as a daughter of separated parents. My father, who is fluent in Finnish, always felt included by education professionals regarding my education. Consequently, my mother who was learning Finnish, faced linguistic barriers due to not being offered professional interpreters, and as a result, often felt excluded.

I became the first Asian to work as a classteacher in Finland. This made me aware of the impact limited cultural diversity within the education profession can have on children and young people and families. It also made me develop a deep sense of responsibility and desire to foster culturally responsive practices. This to me refers to an ongoing dynamic learning process to ensure that my practice best meets the needs of families and children I have the privilege to work with. Culturally responsive practice does not mean knowing all the cultures and their practices. Instead, it refers to the awareness that our understanding is shaped by our experiences and cultures which can differ from one another. Importantly, the difference does not mean to change the other person's beliefs. Instead, I hope the understanding will help professionals create a safe space for parents, children and young people to share their experiences and views that are meaningful to them. In return, this can help practitioners, such as EPs, adapt their practice in a way that is found helpful and empowering.

As a classteacher working in a joint primary and secondary school with a high number of pupils and families with refugee status, I noticed practices that made parents feel welcomed and understood, and conversely, excluded and misunderstood. Often professionals' assumed knowledge regarding parents' understanding of available SEND-support prevented parents from contributing to meetings. I noticed the difficulties teachers experienced in understanding why a non-Finnish speaking parent may decline intervention support for their child. I was able to support parents and colleagues through my awareness of cultural stigma around being 'different', and the importance of empathy, shared understanding and empowerment in response.

Upon coming to England, I was amazed by the way in which some schools were able to provide incredibly warm and welcoming ethos that helped all children and families to belong. I later found out that these schools were supported by the Local Authority's (LA's) Ethnic Minority Achievement Service

(EMAS) and employed bilingual learning support assistants. Equally I noticed schools that wished to do more for their non-English speaking culturally diverse families and children but expressed limitations with funding and thus, difficulties providing such services. The wider disparity in available support for families became clearer in my role as a trainee educational psychologist. I ended up translating an EP consultation between the EP, school and Urdu-speaking family because the school did not have funding for professional interpreters. The experience reminded me yet again about the assumed knowledge when concepts and acronyms are used without explanations. One memorable example of this was when the parent asked, 'will the EP help my (autistic) son recover?'. It was at this moment I realised the limited support the parent must have received prior to the EP involvement to understand her son's diagnosis and the important role EPs play to support parents in response.

The experience made me reflect on the responsibility EPs hold in ensuring informed consent for their involvement, as well as the importance of providing time and space to explore and reflect on what the diagnoses and EP involvement might mean to parents. Additionally, it made me reflect on the lack of racial and cultural diversity within the EP profession (similarly to Finland's teaching profession). I recognised my own assumptions where I presumed that greater cultural diversity in England would be reflected within the EP profession as well. As someone new to England, this prompted me to research further. I realised that lack of racial diversity among psychology profession was a wider issue in western countries. The American Psychological Association (APA) released an apology in '*promoting, perpetuating and failing to challenge racism, racial discrimination and human hierarchy*' (APA, 2021). The Association of Educational Psychologists (AEP; 2021) guiding EP professionals in England found that 86% of EP workforce identified as white female.

Currently, 33.9% of primary aged pupils and 32.3% of secondary aged pupils come from minority ethnic backgrounds (GOV.UK, 2021). As the population continues to diversify, EPs are more likely to work with families and children and young people who conceptualise SEND differently. However, without the EP services prioritising ongoing engagement with culturally responsive practices, families, children and young people from culturally diverse backgrounds are more likely to be at disadvantage in accessing SEND-support and be misunderstood by the professionals. Culturally responsive practices are underpinned by the practice guidance given by the governing bodies of EP profession in England (BPS, 2017; HCPC, 2023). Given that EPs are described to be well-positioned in promoting social justice through advocacy (Doll et al., 2020), identifying culturally responsive educational psychology practices can help EPs to be aware of discriminatory practices, their own culture, identities, and biases. In response, this can help EPs to adapt their practices accordingly to meet the needs of all children and young people and families.

This thesis aims to support EP practice through exploring South-Asian parents' (systematic literature review paper) and Indian-Panjabi Sikh parents' (empirical paper) experiences with SEND-support in

England. As such, the two papers are related but separate contributions to the research field. The systematic literature review aims to answer the question '*How do South-Asian parents come to understand their children's SEND, and how do they describe their experiences with education professionals and SEND-systems?'* The empirical paper aims to answer three questions:

- How do Indian-Panjabi Sikh parents describe their early support experiences before the Education and Health Care Plan (EHCP) process for their children?
- How do Indian-Panjabi Sikh parents describe their experiences with EHCP processes and available SEND-support?
- How do EPs and interpreters describe their experiences in supporting Indian-Panjabi Sikh parents, and what barriers do EPs face in promoting culturally responsive practices?

The critical communicative methodology is used in the empirical paper to co-identify culturally responsive educational psychology practices in collaboration with EPs, Indian-Panjabi Sikh parents, and interpreters. The methodology is an innovative research approach that aims to foster inclusive, participatory, and transformative social research through empowerment (Gómez et al., 2011). By focusing on reflective practice and critical analysis of power dynamics, the methodology not only seeks to understand social phenomena but also seeks to foster positive social change.

1.4 Ontology and Epistemology

In my systematic literature review, I was guided by a descriptive-interpretative epistemology within a relativist ontology. Descriptive-interpretative epistemology enables the construction of new knowledge based on both the participants' direct quotations and authors' interpretations (Timulak, 2009). The descriptive nature of epistemology aims to describe the lived experiences of participants, whereas the interpretative aspect aims to go beyond description and explore how these experiences are shaped by broader social and cultural factors. The emphasis on cultural context and the researcher's reflexivity, make it well-fitted for the review. While creating new meaning from existing research in my systematic literature review, I was mindful of the researchers' subjectivity shaping their meaning-making of participants' experiences.

My epistemology and ontology perspectives for the empirical paper were guided by an integrated adaptation of a social constructionist (Burr, 2015) position within a relativist perspective of ontology, and critical race theory (Crenshaw et al., 1995) within a critical realist ontology. The integrated approach provides a powerful framework to comprehensively understand the systemic inequalities faced by minorities (Crenshaw, 1991). Social constructionism suggests that reality and knowledge are constructed through personal experiences and social interactions that are influenced by historical, linguistic, and cultural contexts (Burr, 2015). This guided my epistemology and ontology by proposing that knowledge can be subjective and co-constructed. Within my empirical paper, EPs and an interpreter shared their experiences and understanding of working with Indian-Panjabi Sikh parents and vice versa.

While social constructionism and relativism enabled me to explore participants' understandings, critical race theory allowed me to address the systemic barriers participants might have experienced. One of the central tenets of critical race theory is the intersectional framework (Crenshaw et al., 1995). Per intersectionality, everyone holds multiple identities simultaneously, and these identities form people's experiences. The application of intersectionality within the critical race theory helps to understand how parents' varying elements of identity (e.g., religion and gender) interact with SEND-systems creating the potential for a compounding effect of privilege and discrimination (Oumar, 2022). This way, I was able to ensure a deeper understanding and exploration of potential systemic inequalities in accessing EP services and SEND-support.

The integration of both epistemologies and ontologies fits well within the Critical Communicative Methodology (CCM; Gómez et al., 2011). In CCM, researchers and participants have an active and equal role in co-creating new understanding through egalitarian dialogues. During the egalitarian dialogues, new knowledge is shaped by researchers' research-based knowledge and participants' expertise and lived experiences. The aim of CCM is to co-identify exclusionary (barriers) and transformative elements, which can only be achieved through a shared understanding of participants' experiences. This aligns with social constructionism where collective creation of meaning through social interactions and shared understandings is at the forefront. Similarly, critical race theory fosters the exploration of power relations in shaping participants' social realities and helps to both address systemic barriers and to co-identify with participants transformative practices.

The integrated approach not only enriched my understanding of Indian-Panjabi Sikh parents' experiences with SEND-support but also facilitated my advocacy for social justice and equity within educational psychology practice. The use of reflexive thematic analysis (Braun & Clarke, 2021) fostered ongoing reflections throughout the research.

1.5 Reflexivity

I highly value the collaborative and empowering nature within my practice as a trainee educational psychologist and I hoped to carry these values in my role as a researcher. I was aware that this was the first-time research sought to privilege Indian-Panjabi Sikh parents' SEND experiences in England. Therefore, I felt a deep sense of responsibility towards my participants as well as towards the research field and EP profession. I wanted to conduct research that would aim to benefit my participants, the research field and EP profession, in addition to fostering my personal growth and knowledge.

Building safe and trusting relationships with my participants was pertinent, especially after findings suggesting South-Asian parents experience power imbalances and language barriers with professionals (Akbar & Woods, 2019). In response, I had two events at the local Gurudwaras to advertise the research, with an opportunity to meet me and ask further questions to decrease researcher-participant power imbalances. I was aware that as a Panjabi Sikh, I have a gender-neutral name. By introducing myself at Gurudwaras, I sought to support Indian-Panjabi Sikh parents' informed decision on their involvement. Participants could also choose whether they wanted to take part online or in-person in the research. It was important that the research experience was as comfortable as possible given the sensitive nature of the topic and stigma. Moreover, to be mindful of professional-parent power imbalances, parents could decide whether they wished to join focus group discussions with other parents or with EPs and interpreters. All participants chose online participation and parents wished to discuss it with other parents. Online data-collection has been found to enable participants to be more expressive and open which helps to build rapport and reduce power imbalances between researchers and participants more easily (Deakin & Wakefield, 2013). Therefore, online data-collection was not seen as a limitation in this study.

I was aware that my positionality as an Indian-Panjabi Sikh trainee educational psychologist and researcher may have both been a barrier and facilitator to participants' ease when sharing their expertise and experiences with me. As an Indian-Panjabi Sikh who is fluent in Panjabi, I was able to build rapport with the parents quickly. Having the within-culture experience and knowledge placed me in an advantageous position as a researcher. For example, I called participants closer to my age as 'veerji' (brother) and 'bhenjhi' (sister) with respectful 'ji' at the end and avoided calling participants by their first names if they were closer to my parents' age following the cultural etiquette. On reflection, I felt that this sent parents a clear message early on that not only did I speak the language, but I was also aware of the social norms within the culture. This felt like a facilitating factor when parents shared their experiences with cultural stigma. Additionally, it was important that I shared in the beginning of the data-collection the visible shared identities (race) with the parents, as well as that I did not have an autistic child and thus, did not share parents' experiences. Therefore, the knowledge was co-constructed through my understanding of participants' lived experiences and expertise as well as through research-based systematic literature review knowledge; all this was aligned with CCM.

My positionality as an Indian-Panjabi Sikh trainee educational psychologist may have acted as a barrier with the EPs' ability to share their views and experiences with me with ease. An example of this is when a white-British EP shared that I must know more about the culturally responsive practices for Indian-Panjabi Sikh parents than the EP herself. I reflected in response that I did not have their years of experience working as an EP and serving the community the way they had, and therefore, it was an opportunity for me to learn from their expertise and experiences and co-create new understanding by combining my research-based knowledge. I felt relief when the EP felt comfortable in reflecting and disagreeing with my suggestion around translating EP reports. As a researcher I felt that I had created a safe space virtually for the EP to go against what I had presented.

Although the findings have been co-constructed with participants, I am aware that my own beliefs, values and experiences will inevitably influence how I view, interpret and draw conclusions from these findings. However, subjectivity is not seen as a limitation in this qualitative study. Braun and Clarke (2013) suggest that subjectivity can also be a source of analysis. Therefore, subjectivity is something to be recognised and kept ‘in-check’ through ongoing reflexivity. Throughout the research, I made sure to seek supervision and keep a reflective log of my influence on the research. I found this aiding my growth as a researcher, as I came from a quantitative research background. For example, the reflective journal helped me through the cycle of unlearning and learning which needed to take place to immerse myself fully into the world of qualitative research. Being supervised by two white men and having an Indian-Panjabi Sikh critical friend has further enriched my learning and reflections.

1.6 Ethical Considerations

Throughout the thesis project, I have encountered ethical decision points that have made me reflect on my values as a researcher and trainee educational psychologist further. These are reflected through the four ethics amendments that I made to the initial ethics application across the two years. For example, I wanted to ensure the validity and reliability of my transcript translations from Panjabi to English. The amendments were made to reflect this where I involved an external person to the research, who was proficient in both languages. This was done in a way that ensured participants’ anonymity. The person reviewed a brief excerpt from one of the translated transcripts and its corresponding audio interview recording shared via Teams. As a research team, we ensured that no identifiable information was disclosed in the shared data. The external person was advised about confidentiality. No concerns were found with the translations, and they were deemed accurate. Additionally, to meet the research timeframe, the communicative focus group discussion with an interpreter and educational psychologists was transcribed by a University of Southampton-approved transcription service following the data handling guidelines around confidentiality. The ethics amendment was made to reflect this.

In the empirical paper, I used a critical communicative methodology (CCM). As part of the methodology, new knowledge is co-created by participants and researchers using egalitarian dialogue. In egalitarian dialogue, researchers share their expertise and research-based insights alongside participants’ lived experiences and expertise, fostering a collaborative process. A core ethical consideration in using CCM is navigating the potential tension between sharing expertise and maintaining participants' autonomy. The egalitarian dialogue ensures that the research is not researcher-dominated, but instead collaborative and inclusive. This balance is critical to the methodology's commitment to social justice and transformative outcomes. To achieve this, it was important to share the methodology's core values with the participants and ensure to gather participants' views throughout the process. Building a trusting relationship with the participants was essential which was fostered by ensuring the full transparency about the research ethics, research process, and participants' rights to partake and withdraw from the study, as well as, sharing genuine reflections with participants on my positionality as a researcher.

The CCM approach required careful reflexivity to ensure that I did not inadvertently create dependency. Reflexivity involved frequent supervision that fostered ongoing reflections on the power dynamics at play, ensuring that my contributions supported participants' goals rather than imposing my own (Strogilos & Ward, 2023). To support this process, I shared a PowerPoint presentation with my supervisors for feedback before sharing it with my participants. The presentation (**Appendix K**) summarised the key findings from the participants alongside my research-based knowledge. Importantly, to ensure that my contributions were non-coercive, I only shared my expertise around topics identified as helpful by previous research and when explicitly expressed by my participants during the individual or communicative focus group discussions. For example, when participants expressed limited knowledge about specialist provisions, I shared that parents can request visits to specialist schools. I made sure that I expressed this as an option and a wonder rather than a directive, ensuring participants retained full agency in decision-making.

By fostering open, two-way dialogue, I positioned myself not as an authority but as an equal collaborator, helping to equalise power dynamics. As part of the communicative focus group discussions, I always ensured to gain participants' views on any suggestions that I brought. I was pleased to notice that the participants felt empowered to express their disagreements with the previous findings and suggestions. For example, parents disagreed with the previous findings suggesting that South-Asian parents have sufficient familial support (Gupta & Pillai, 2005).

It was important that the ethics application reflected an egalitarian relationship between participants and researchers where a consensus is not imposed but achieved interactively. The dialogic nature of CCM outlines the measures to protect participants' autonomy and ensure their empowerment. The emphasis on emancipation in CCM ensures that the methodology not only gathers data but also collaboratively produces knowledge that participants find empowering and addresses social inequalities.

After receiving the ethics approval (**Appendix A**) from Southampton University, one of the key priorities in recruitment was to ensure that participants could make an informed decision about partaking in the research. To support informed consent, I made sure to translate the participant information sheet, consent and debrief forms in Panjabi. Additionally, I created a video in Panjabi going through the participant information sheet and how to fill out the consent form. This was not only to foster informed consent but also to support participants with potential literacy difficulties. These videos were circulated with the help of Special Education Co-Ordinators (SENCOs) and local Gurudwaras.

Given the sensitive topic of the research and stigma, it was important to ensure that participants understood that their participation could not be fully anonymised due to the nature of focus group discussions as part of the critical communicative methodology. At the beginning of each individual reflective conversations and communicative focus group discussions, I shared in participants' preferred language (Panjabi or English) about the importance of confidentiality, not being able to ensure the full anonymity and their right to withdraw from the study up which was up to the point of data-analysis with a clear date indication. Participants were asked to give informed consent in two ways: by signing the consent form and sending it back to me, and by giving a verbal consent in the beginning of the individual reflective conversation. No participant requested to withdraw their data. An incentive to express gratitude for taking part in the study was given at the end of participation, however, I ensured that participants did not feel pressured by this. All participants wished to continue working with me and the other participants for future research purposes.

Although full anonymity was not guaranteed, I tried to protect participants' anonymity as much as possible during the focus group discussions. As part of the methodology, researchers share the individual reflective conversation findings in the communicative focus group discussions to aid further reflections. I shared these findings as generic views in the focus group discussions e.g., 'parents in this study shared that…' instead of revealing participants' identities by saying 'participant (name) shared that'. Additionally, due to the nature of sensitive topic being discussed, I was prepared to seek supervision to support with any difficult conversations. Further, the participant information sheet, consent form and the debrief forms were written to reflect the potential distress to participants for example, by signposting participants to helpful services available in Panjabi and English in debrief forms.

1.7 Dissemination Plan

I viewed research dissemination as a key element of this thesis, aligned with my values and the sense of responsibility towards my participants as well as towards the research field and EP profession. I planned the dissemination carefully with my supervisors' guidance as well as support from my Indian-Panjabi Sikh critical friend, participants, and the local Indian-Panjabi Sikh community. I intend to submit the systematic literature review to the *Journal of Research in Special Educational Needs* and the empirical paper to the *European Journal of Special Needs Education*, focusing on inclusive education. Both research papers are written following the chosen academic journals' author guidelines. In addition to this, I have presented the empirical research findings at Southampton University's Psychology Post-Graduate Research Conference and the Centre for Research in Inclusion (CRI) lab. I have also shared a poster presentation at the Educational Psychologist Autism Special Interest Group focusing on neurodiversity-affirming practices and inclusive education within the SEND-systems. The future dissemination plans include presenting the systematic literature review at the British Education Research Association Conference 2024, as well as sharing an overview of both papers with local Gurudwaras and the EP service where I will start working in the coming academic year.

Through this research, I have understood the limited representation of minority experiences within special education research. For example, this is the first study exploring Indian-Panjabi Sikh parents' experiences with EPs and SEND-support in England. This gave me a great sense of responsibility as a researcher and as an aspiring EP to share the research findings as widely as possible to help EP services to become more equitable and accessible for all children, young people and families. Moreover, participants' expressed gratitude for feeling heard within the research, and their wishes to collaborate with each other (EPs, other parents in the study and interpreter) and myself in the future, has inspired me to conduct follow-up research to develop an auditing toolkit. I am hoping to develop a toolkit in collaboration with my participants to support EP services' culturally responsive practices including collaborative work with interpreters during the EHCP meetings. My other future follow-up research plans include writing a methodological research paper on my experience of using the critical communicative methodology with Indian-Panjabi Sikh participants. I am hoping that this will support the future research with Indian-Panjabi Sikh participants, as well as foster the application of critical communicative methodology to privilege the unheard minority heritage experiences and expertise. The future research will hopefully be conducted with the current research team in collaboration with the CRI lab.

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Chapter 2 Systemic inequities within SEND-systems: A review of South-Asian families' experiences of having a child with SEND-support in England

Abstract

This systematic review explores the experiences of South-Asian parents of children with Special Educational Needs and/or Disabilities (SEND) in England. The review uses thematic analysis to synthesise findings from 11 studies. Despite mandates for equitable access to services, South-Asian families face unique challenges, such as cognitive dissonance in understanding and accepting SEND, and systemic disadvantages in accessing support. Key findings include unmet language needs, cultural stigma and shame (sharam), and a lack of support which exacerbates power imbalances with education professionals, including educational psychologists. Contrary to stereotypes of sufficient familial support, South-Asian parents reported isolation and stress. Their lived experiences suggest systemic disadvantages when professionals' support is perceived lacking in cultural responsiveness. Consequently, parents' cultural heritage and having a child with SEND forms a 'double disadvantage' in accessing SEND-support. The analysis employs cognitive dissonance and belongingness theories, as well as the intersectional framework, to support education professionals and policymakers to develop culturally responsive practices in response. This research is timely, given England's diversifying demographics and the long-standing policy rhetoric about equitable SEND-support for all children and families.

Key words: South-Asian, SEND, Double disadvantage, Sharam, Culturally Responsive Practice

2.1 Introduction

The United Nations (1992) highlights children's rights irrespective of culture, ethnicity, gender, religion, language, or abilities. Yet, pupils with Special Educational Needs and/or Disability (SEND) and their families from minority cultures are '*the least often heard and most often excluded*' (DfH, 2009, p.14). SEND in this review, refers to Children and Young People (CYP) between 0-25 who have a learning difficulty and/or disability and are receiving SEND-support within their educational environments (DfE, 2015). Culture has been identified as 'complex and multi-dimensional' (Krause & Miller, 1995) with varying definitions. This research aligns with Burnham's Social GRRAACEESS model (2012) where culture refers to a group or community with shared identity, values, behaviours, and beliefs. The model highlights that culture is both shaped by and shapes different elements of identity such as gender, race, religion, age, ability, class, and ethnicity. This research recognises that different elements of identity do not operate in isolation but intersect and interact in ways that influence power dynamics, privilege, and disadvantages (Crenshaw at el., 1995). The SEND code of practice (DfE, 2015) mandates education professionals, including educational psychologists (EPs), to ensure all CYP with SEND are treated fairly and can access adequate services and education, irrespective of their ethnicity and culture (DfE, 2015). EPs play a key role in identifying appropriate SEND-support; they contribute to Education Health Care Plans (EHCPs) which is a multi-disciplinary legal document identifying a learner's strengths, areas of support, and desired outcomes. The Children and Families Act (2014) emphasises parents to be equal partners with education professionals in decision-making for their children.

The UK Government commissioned an investigation on racial inequalities within education systems in their Race and Ethnic Disparities (RED) report (2021). The report concluded that institutional racism does not exist in the UK and instead, socioeconomic status played a more significant role in creating systemic disadvantages. The report has been criticised by Special Needs Jungle (SNJ, 2022), a non-profitable parent-run organisation, for overlooking the lived experiences of minority communities, downplaying the role of systemic racism, and hindering professionals' lack of Culturally Responsive Practices (CRPs). CRPs encompass an awareness of cultural differences and the active, dynamic process of tailoring professional interactions to respect and integrate cultural beliefs, values, and contexts (Sakata, 2021). CRP terminology will be used consistently for its reference to a fluid and ongoing process that integrates aspects of competence, such as knowledge and skills, with self-awareness and humility while also encompassing active, responsive engagement. Considering England's demographics diversifying over time where over 35% of pupils with SEND come from minority ethnic backgrounds (DfE, 2023a) and the education workforce consisting of predominantly white-British females (DfE, 2021), identifying education professionals' CRPs is pertinent to meeting the needs of culturally diverse populations effectively.

South-Asians are individuals from Sri Lanka, Indian, Pakistan, Bangladesh, Nepal, Bhutan and or the Maldives (Bhatia et al., 2008) and constitute the largest ethnic minority group in England (ONS, 2022). Emerson et al. (2004) found that South-Asian mothers of children with SEND reported poorer overall wellbeing compared to white and black mothers in the UK. To the author's knowledge, six systematic reviews (Akbar & Woods, 2019; Greenwood et al., 2015; Heer, 2012; Kaplan & Celik, 2023; Oumar, 2022; Shafiq, 2020) have included South-Asian parents when exploring parents' experiences from minority cultures. Heer (2012) explored UK-based South-Asian parents' experiences of caring for children with intellectual or developmental disability. They found that healthcare service uptake remained low among South-Asian parents, despite the prevalence of intellectual and developmental disabilities being three times higher than in other minority communities. Gupta and Pillai (2005) suggest that South-Asian parents may prefer to rely on familial than professional support. Shafiq's international review (2020) found Urdu vocabulary to describe inner psychological experiences to be limited based on the parent-researcher conversations. Shafiq (2020) concluded that these impacted

Pakistani adults' understanding of mental health by increasing their vulnerability to stigma. Oumar's review (2022) with culturally diverse parents, found stigma and sharam (shame) to increase the threshold for accessing mental health services among South-Asian parents. This highlights the need to explore how SEND-related terminologies are understood among minority languages and how it may influence parents' experiences. Aligned, Bickenbach and Bickenbach (2009) highlight that 'SEND' is socially constructed, encompassing what it means to be viewed as disabled by others, and this is influenced by one's language, culture, and society among other factors. Therefore, experiences with SEND should not be explored culture-free. Stigma is understood as a harmful societal perception experienced by those associated with the stigmatised individual, often leading to discrimination against family members, for example, due to the individual's disability (Ali et al., 2012; Oumar, 2022). Dorjee and Ting-Toomey (2015) describe stigma and fear of rejection among South-Asian communities through 'sharam', which is a complex cultural construct interlinked with 'family honour', 'self-respect' and reputation. The actions of an individual are reflected on the entire family; thus, one is expected to lead a life free of sharam (Sangar & Howe, 2021). Stigma and sharam can make parents vulnerable to isolation if the social environment lacks understanding and appropriate support (Oumar, 2022). To develop CRPs, understanding whether SEND stigma exists among South-Asian parents, is pivotal.

Out of the six reviews, only one has focused on minority ethnic parents' experiences of having a child with SEND (Akbar & Woods, 2019). However, the focus was not on SEND-systems. Akbar and Woods's (2019) international cross-cultural review with parents from 15 different minority groups found that South-Asian parents sought miracle cures for disability. Pakistani, Chinese, and Afro-Caribbean parents reported negative experiences with professionals due to perceived stereotyping and power imbalances. Akbar and Wood noted that parents can find it disempowering if professionals overlook parents' religious identities. Consistently, Greenwood et al.'s (2015) cross-cultural review on Indian and Pakistani parents' experiences with social care services found professionals' consideration for religion to be important. Kaplan and Celik's (2023) recent cross-cultural review on minority ethnic parents' experiences of having a child with a disability in England found that some parents viewed disability as a punishment from God and some, as a blessing. The researchers suggested that parents' understanding of disability can have implications on how they engage with education professionals. South-Asian parents' understanding of SEND and how it interacts with accessing SEND-support remains understudied. Out of the six reviews, Akbar and Woods (2019) explored parents' understanding of SEND; however, they did not focus on South-Asian parents' experiences with education professionals and systems in England as it was a cross-cultural international review. Heer's review (2012) was the only review focusing solely on South-Asian parents' experiences in the UK; however, they explored qualitative and quantitative studies on parents' experiences with healthcare support.

The current review aims to bridge the existing gap in the literature by asking: How do South-Asian parents come to understand their children's SEND, and how do they describe their experiences with education professionals and SEND-systems? The review also seeks to foster CRPs in policymaking and SEND-systems. Given the new UK Government in power, research exploring accessibility to equitable SEND-support for families of children with SEND from minority backgrounds is timely. The findings will be discussed in relation to the cognitive dissonance theory (Festinger, 1957) and belongingness theory (Baumeister & Leary, 1995) to gain a deeper understanding of parents' experiences and to identify CRPs in response. The cognitive theory suggests that people experience psychological discomfort (dissonance) when they hold contradicting beliefs, behaviours and attitudes, and the belongingness theory suggests that humans have a fundamental need to form and maintain strong and stable interpersonal relationships. The review will focus on England, instead of the UK, to ensure legislative consistency of SEND practices. Additionally, we acknowledge that there may be different preferences regarding the SEND terminology. 'SEND' terminology is used to stay consistent with the legislative language and past research (Akbar & Woods, 2020). We have decided to use identity-first language (e.g., South-Asian parents and autistic children), after a discussion with Indian advocacy group. However, we are aware that there may as well be readers who prefer person-first language. Additionally, while this research acknowledges other terms, such as cultural humility, awareness, and competence, CRPs will be used consistently to reflect an active, justice-oriented perspective.

2.2 Methodology

2.2.1 Search Strategy

For most up-to-date search, we conducted a systematic search at two points; May 2023 and April 2024. Five electronic databases were used: PsycINFO, ERIC, Web of Science (WOS), British Education Index (BEI) and Dissertations and Theses Global (ProQuest). The search terms in **Table 2.1** were applied to sources published between 1996 and 2024. The significant Education Act came into effect in 1996 entitling a right to a suitable education in England. The timeline was specified to focus on research papers which are relevant and rigorous to current EP practice. The Act (1996) is still in force and has been amended to reflect new legislations, such as the Children and Families Act (2004).

Table 2.1 *Search Terms*

1	''Education and health care plan'' **OR** EHCP **OR** SEN* **OR** ''special educational need*'' **OR** learning disabilit* **OR** ''learning disorder*'' **OR** ''learning difficult*'' **OR** ''intellectual disabilit*'' **OR** ''mental retard*'' **OR** autis* **OR** ASD **AND**

2	Parent* **OR** mother* **OR** father* **OR** maternal **OR** paternal **OR** guardian* **OR** carer* **OR** caregiver* **AND**
3	Experience* **OR** view* **OR** opinion* **OR** attitude* **OR** perception* **OR** perspective* **OR** reaction* **OR** response* **OR** belief* **AND**
4	''South Asian*'' **OR** Indian* **OR** Panjabi* **OR** Punjabi* **OR** Pakistani* **OR** Bangladeshi* **OR** Nepali* **OR** ''Sri Lankan*'' **OR** Bhutanes* **OR** Maldivian* **OR** BAME **OR** minorit* **OR** ''ethnic minority heritage'' **OR** ethnic communit* **OR** immigrant* **OR** migrant* **OR** refugee* **AND**
5	England **OR** UK **OR** ''United Kingdom'' **OR** Brit*

In line with other systematic reviews (Van Garderen et al., 2012), we hand-searched the references in the recent six review studies that have included South-Asian parents' experiences (e.g., Heer, 2012). Additionally, the references of authors whose studies surfaced three or more times in the eligible studies were examined to determine if they had additional eligible research. **Table 2.2** outlines the inclusion criteria for the eligible studies.

Table 2.2 *Inclusion Criteria*

Criteria	**Inclusion**	**Rationale**
Type of publication	1. Published studies and grey literature in or after 1996 till 2024	The Education Act 1996 introduced several key changes including redefining the role of Local Authorities (LAs). The LAs were required from here onwards to identify, assess, and suggest appropriate SEND provisions for pupils.
	2. Quantitative, qualitative or mixed-methods studies contain primary empirical data	To obtain an understanding that is relevant to parents' current experiences and relevant to current EP practice. Primary empirical data is required to conduct a systematic review.
	3. Studies that are produced in English, Panjabi, Hindi or in Urdu.	To benefit from the primary researcher's languages to find more studies
Participants	4. Studies include South-Asian parents who have a child with SEND and discuss their experiences in England	To understand the shared experiences of South-Asian parents. There is limited research on the lived experiences of South-Asian parents with children and young people (0 to 25 years old) receiving SEND-support in England (Slade, 2014).

Study Details	5. Studies focus on South-Asian parents' experiences of having children with SEND-support in England-based schools.	There is limited research focusing on South-Asian parents' experiences of having a child with SEND with regard to their education.

Overall, the search yielded 2819 studies, of which 1750 duplicates were removed. A further 887 studies were removed following title, keywords, and abstract screening using the inclusion criteria (**Table 2.2**). The remaining 184 articles were assessed for eligibility through full-text review. Further 173 articles were removed because they only focused on South-Asian parents' experiences of having a child with SEND but did not discuss the educational experiences of their child in England, leaving 11 qualitative studies for synthesis. The Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) approach (Moher et al., 2009) outlines the inclusion and exclusion process in **Figure 2.1**.

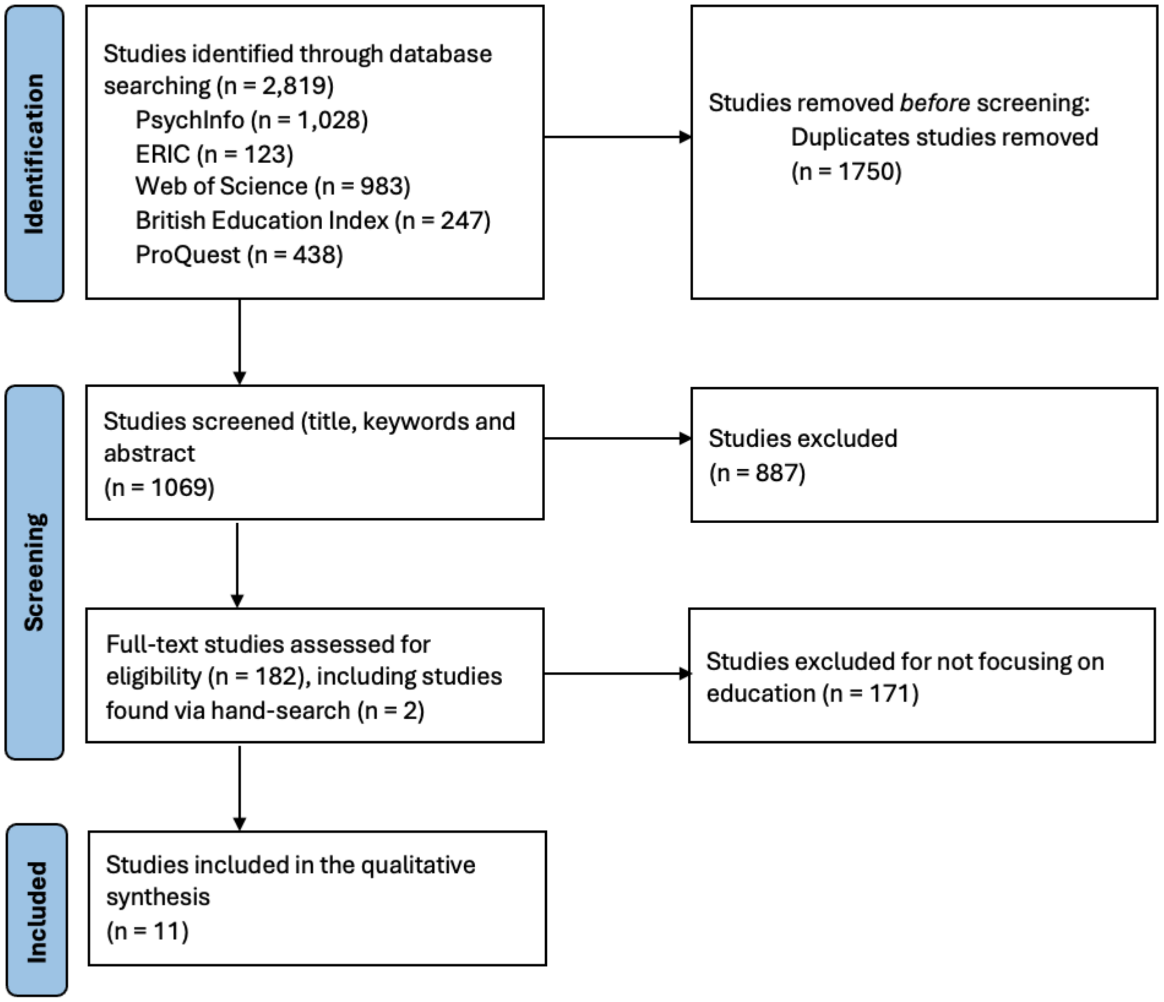

Figure 2.1 *PRISMA flow-chart (Moher et al., 2009) of search results*

The full texts were screened independently by the first author. The second and third researchers screened 30% each, out of 182 studies, by focusing on the titles, keywords, and abstracts. After the calculation of the number of agreements and disagreements of all examined studies, the interrater reliability for determining eligible studies was 99%. Following discussions among the three researchers, the first author scrutinised any further discrepancies to reach a 100% consensus.

2.2.2 Quality Assurance

The lead author quality-assessed all 11 articles using the Critical Appraisal Skills Program (CASP; Lachal et al., 2017; Appendix B), which consists of ten questions (

Table 2.3). The CASP tool is frequently used to evaluate qualitative research and is described as comprehensive in scope without being lengthy and complicated (Masood et al., 2011). To tackle potential biases, all authors independently reviewed the studies, scoring each CASP item from 1 to 3 (1: Little to no justification offered for the particular issue; 2: The issue was addressed but not fully elaborated; 3: Extensive justification and explanation of the issue was provided), following the approach suggested by previous research (Boshoff et al., 2017). Interrater reliability was 83%, with any discrepancies being no more than one point. Agreement was reached when the two raters provided the same score (e.g., 1, 2, or 3) in each item when rating the same study. Quality scores for the eligible studies ranged from 19 to 30 for raw scores, with an average number of 26.

Table 2.3 presents the percentage scores of 10 quality items met via CASP across 11 studies. This procedure aimed to gain insight into the relative methodological rigor of each study. If the quality assurance process had brought clear interpretative or methodological concerns to light in a study, consideration for exclusion would have been given, with reasons explicitly stated. We did not exclude any studies based on their scores.

Table 2.3 *Quality of Study Items Averaged for 11 Studies*

Quality Item	% Met Criteria
1. Was there a clear statement of the aims of the research?	97%
2. Is a qualitative methodology appropriate?	100%
3. Was the research design appropriate to address the aims of the research?	98%
4. Was the recruitment strategy appropriate to the aims of the research?	91%
5. Were the data collected in a way that addressed the research issue?	92%
6. Has the relationship between researcher and participants been adequately considered?	65%
7. Have ethical issues been taken into consideration?	65%
8. Was the data analysis sufficiently rigorous?	71%

9. Is there a clear statement of findings?	95%
10. How valuable is the research?	97%

The strength of the field lies within the clear identification of the research aim, choosing the appropriate research methodology and design to achieve these (as shown in **Table 2.3**), and describing the research findings and the contributions they make to the research field with great clarity. Studies received a lower score on Quality Item (QI) 4 if there was limited information provided on recruitment strategy. Additionally, studies scored lower on QI 5 if parents were not fluent in English and the study did not include an interpreter to support parents’ participation in the research. The weaknesses of the research field were identified to be around QI 6-8. The strengths and the limitations of the research field will be discussed further under the discussion. The characteristics of the included studies are detailed in **Table 2.4**.

Table 2.4 *Characteristics of included studies*

Author, year, research type	Aim	Participants	Research design, methods and data-analysis	Identified Themes
Akbar and Woods (2020) article	Exploring Pakistani parents' understanding of SEND and aiming to understand the facilitators and barriers to Pakistani parents' partnership with education professionals during the EHCP processes. Informing education professionals, including EPs on how to best support Pakistani parents through the SEND process.	Ten Pakistani participants: Seven mothers, two fathers, one sister who has a family member with an EHCP and moderate learning difficulty (MLD) or developmental delay (DD).	In-person semi-structured interviews in Urdu and Mirpuri Panjabi. Thematic analysis.	-Hidden disabilities more difficult to understand -Religious understanding of disability: protective factor -Experiences within educational setting: power imbalances with professionals -EHCP experience: language barriers, lack of understanding of the process, slow-paced and time-consuming, parental voice missing
Begum (2023) Doctoral dissertation	Understanding Bangladeshi parents' experiences of raising an autistic child within the cultural and educational context.	Five Bangladeshi mothers with an autistic child.	Narrative inquiry via Teams in English and Bengali. Clandinin and Connelly's (2000) Three-Dimensional Framework was applied.	-Parental meaning-making (of autism) -The emotional impact of parenting a child with ASC -Extended family relationships and support -Lack of understanding from the older generation -Connections that support cultural identity -Then, now and the future
Kramer-Roy (2012) Peer-reviewed journal article	Exploring ways to support Pakistani families with children who have SEND, including but not limited to educational provisions involving educational professionals.	Six Pakistani families, including both parents and sibling(s) of a child with SEND.	Participatory action research: individual in-person interviews with all family members and focus group discussions in English. *Analysis approach not specified.*	-Involving all family members -Continuity between and home school -Facilitating communication -Facilitating constructive peer-support -Belonging, being, becoming, doing -Occupational injustice -The need for occupation-centred practice
Kwan-Tat (2018)	Understanding Sri Lankan-Tamil parents' experiences who have a child with	Five first-generation Sri Lankan parents who	Episodic narrative semi-structured interviews in	Parents: -Responsibility, disempowerment & empowerment

Doctoral dissertation	SEND. Understanding the role of community and services such as educational services (working with educational psychologists during the EHCP process). Exploring EPs' and SENCos' experiences who have worked with the Sri Lankan Tamil community.	have a child with autism, speech and language difficulties, and/or global developmental delay. Two mothers two sets of parents. Five EPs (one male). Four female SENCos.	English only. Thematic analysis.	-Experiences of systems and structures -Representations of SEN SENCos: -duties, functions and representations of SENCos -experiences of supporting families within the school context -role of wider school community -building relationships EPs: -going on a journey with families -when representations of education and SEN meet
Nair (2015) Doctoral dissertation	Exploring Black and Minority Ethnic (BME) parents' perceptions and experiences of the support from the education system in response to having an autistic child. Exploring education professionals' perceptions of relevant support for BME parents who have an autistic child. Understanding in what way BME parents and education professionals identify improvements for the future.	Six Pakistani parents who have a child with autism. Eleven educational professionals: a deputy head, teacher, teaching assistant SENCo, LA officer, speech and language therapist, two specialist teachers two Ethnic Minority Achievement Service (EMAS) advisors. Additionally, three professionals from charity and parent support groups and two specialists from other charities.	A case study using semi-structured online interviews (except with key personnel interviews were in-person). All interviews were in English. Thematic analysis.	Parent: -pre-and early school experiences relate to parents understanding and concerns about autism through a cultural context -available services from staff in specialist and mainstream schools -support from health services and relevant support organisations outside of education -support from families and wider BME-community Practitioners: -support provided for BME pupils with autism in schools -support provided for BME parents of pupils with autism -specialist services provided by stakeholders -stakeholders' role in the provision of additional support for BME parents -recognising religious aspects of pupils' lives -support for BME pupils with autism during transition.

				Themes in response to the third research aim: -BME parents are being 'pushed off' by their own communities -BME communities are not homogenous -delivery of educational services is not culturally appropriate -BME parents have a choice of school that they want for their child -apportioning blame and shifting responsibility -parents have valuable insights when they close knowledge of autism -Continuous Professional Development (CPD) training for staff in mainstream and specialist schools
Oliver and Singal (2017) Peer-reviewed journal article	Generating understanding of new migrant families' experiences in a specialist school for young people with SEND via the intersectional framework.	Four Pakistani mothers whose children had cerebral palsy, Syndrome K, Down syndrome and/or other physical and learning difficulties. Six specialist school staff members: one male headteacher, female deputy headteacher, male teacher, and three female teaching assistants from Pakistan, Ukraine and Poland.	Exploratory case study design with semi-structured interviews. The interpreter was used for all interviews except one with Mirpuri Panjabi-speaking parent. Thematic analysis.	Parents: -responsibility -relying on religion, medical model of cure, change in new generation -gratitude towards the school -joint partnership with the school facilitated by having school staff members -tensions and challenges -parenting and social services. School staff: -migration -language -awareness of the past education experience -empathy towards immigrant parents
Raghavan et al. (2013)	Gaining an understanding of families' views on transitions from school to	24 Pakistani and two Bangladeshi parents	Two semi-structured interviews. The second	-Transition -Formal support

Peer-reviewed journal article	college or to adult life with special reference to ethnicity.	who have a young person with SEND.	interview was after a year to see if any changes had occurred. Interviews were translated from Urdu, Panjabi and Bengali via an interpreter. *The analysis approach was unspecified*.	-Family involvement, expectations and coping -Culture, language and acculturation -Religion -Ethnicity and socioeconomic status
Rizvi (2017) Peer-reviewed journal article	Exploring South-Asian mothers' understanding of their child's disability and parents' expectations and concerns regarding their child's schooling.	Five Pakistani mothers with a child who has SEND and is between the ages 13-15.	Case study. Semi-structured interviews were conducted in Urdu, the participants' preferred language. Pen-and-paper method to analyse the data.	-Understanding and perceptions of disability -School placement decisions and maternal experiences with professionals -Role of religion within parenting and supporting a disabled child
Rizvi (2018) Doctoral dissertation	Exploring how British-Pakistani mothers of children with SEND experience the school placement decision-making process, and the relationship between inclusion and different placement settings.	Eight British-Pakistani mothers who have children with SEND.	Feminist methodology (Weber, 2001). Intersection Framework: semi-structured interviews, unstructured interviews, and vignettes over 6 months. Interviews were conducted in mothers' preferred languages. Thematic analysis .	Based on the quotes, these can be identified: -Maternal views and experiences of inclusion within education -Factors that influence maternal placement preferences
Theara and Abbott (2015) Peer-reviewed journal article	Experiences of South Asian parents living in the UK who have a child with autism, with references to education and implications for educational professionals.	Nine Pakistani, Indian, and Sri Lankan parents (five mothers and two sets of mother and father) who have an autistic child. Two out of the nine parents were born in the UK.	Semi-structured interviews in English. Corbin and Strauss (2008) grounded theory model .	-Medical construction of autism -Cultural values and beliefs underpinning the construction of autism -Key elements of parents' experiences when their child received an autism diagnosis

Warner (1999) Peer-reviewed journal article	Exploring views of Bangladeshi parents who have a nursery-aged child with severe learning difficulties on their schools. Is there anything about the parents' views of the school and the communication between home and school, that is particularly related to the parents' Bangladeshi origin?	Seven sets of first-generation Bangladeshi immigrant parents who had children in nursery with SLD. Two with autism, one with Down syndrome, one with cerebral palsy and three with a global developmental delay	Semi-structured interviews, interpreter used 6/7. All interviews were held at the parents' home. *The analysis approach was unspecified.*	Parents: -views of their child's disability -general views of the school -views of the school: curriculum and issues relating to language and culture -views of the communication between them and the school -expectations for their child -feelings about whether their child would have been educated in Bangladesh

2.2.3 Data synthesis

Thomas and Harden’s (2008) three-stage thematic synthesis approach was followed. The approach enables to take a step further by developing descriptive and deeper analytical themes. I selected a descriptive-interpretative epistemology as the main framework for data synthesis to generate new concepts and questions and to identify gaps in the literature (Timulak, 2009). The epistemology enables the construction of new knowledge based on both the participants’ direct quotations and authors’ interpretations. Only the relevant findings and results to the review question, were coded creating a Microsoft Word table. For instance, Raghavan et al.’s (2013) findings with parents from other minority ethnicities were not included. The first thematic synthesis stage involved line-by-line coding of the data. Each sentence was given at least one code to capture its content and meaning. This yielded 29 initial codes that did not yet have a hierarchical structure. In the second stage, descriptive codes were formed following an iterative process of revisiting, re-naming, and grouping codes together by identifying similarities and differences between them. The process of moving between stages one and two of the thematic synthesis is detailed in **Appendix C**. Stage two resulted in seven descriptive themes illustrated in **Table 2.5** along with the occurrence of each descriptive theme in the reviewed studies. The illustrative quotes in each study can be found in **Appendix C**. Aligned with stage three, we took a step further and used the descriptive themes generated from the original content of the studies to develop two analytic themes; ‘Cognitive dissonance in understanding and accepting SEND’ and ‘Parents want equitable SEND-systems’ to answer the review question: How do South-Asian parents come to understand their children’s SEND, and how do they describe their experiences with education professionals and SEND-systems? To acknowledge the diversity among South-Asians, we adopt this definition primarily to address the limited research available in this area. As a result, an intersection lens (Crenshaw, 1989) will be applied when interpreting the findings to avoid over-generalisations. The framework helps to understand how parents’ varying elements of identity (e.g., religion and gender) interact with SEND-systems creating the potential for a compounding effect of privilege and discrimination (Oumar, 2022).

Table 2.5 *Prevalence table. The table shows the occurrence of the descriptive theme in each reviewed study.*

Descriptive Theme:	Akbar and Woods (2020)	Begum (2023)	Kramer-Roy (2023)	Kwan-Tat (2018)	Nair (2015)	Oliver and Singal (2017)	Raghavan et al. (2013)	Rizvi (2017)	Rizvi (2018)	Theara and Abbott (2015)	Warner (1999)
Unfamiliarity with SEND and language barriers	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓
Absence of physical signs in SEND	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓
Sharam and stigma	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓
Transformation to acceptance and advocacy through religion and belongingness	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✗
Limited perceived support in understanding specialist provisions	✗	✗	✗	✗	✓	✗	✓	✓	✓	✗	✓
‘*Omission of parental voice’* with education professionals	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✗
Professionals play a key role in building trusting relationships	✓	✓	✓	✓	✓	✓	✓	✗	✗	✓	✗

2.3 Findings

2.3.1 Synthesis overview

Ten studies conducted in England, and Nair's study in Wales including reflections on English education, contribute to a total of 11 studies reviewed. Ten studies were published between 2012-2023 and one in 1999. The participants (n = 91) identified as Pakistani (Mirpuri Panjabi and/or Urdu speaking n = 66), Bangladeshi (n = 12), Sri Lankan (Tamil speaking n = 10) and Indian (no specified language n = 3). The SEND, where specified, varied among the 89 children including moderate learning difficulties (n = 10), global developmental delays (GDD, n = 13), autism and/or speech and language difficulties (n = 22), cerebral palsy (n = 2), Syndrome K (n = 1) and Down syndrome (n = 2). **Figure 2** depicts the two analytical themes and seven descriptive themes.

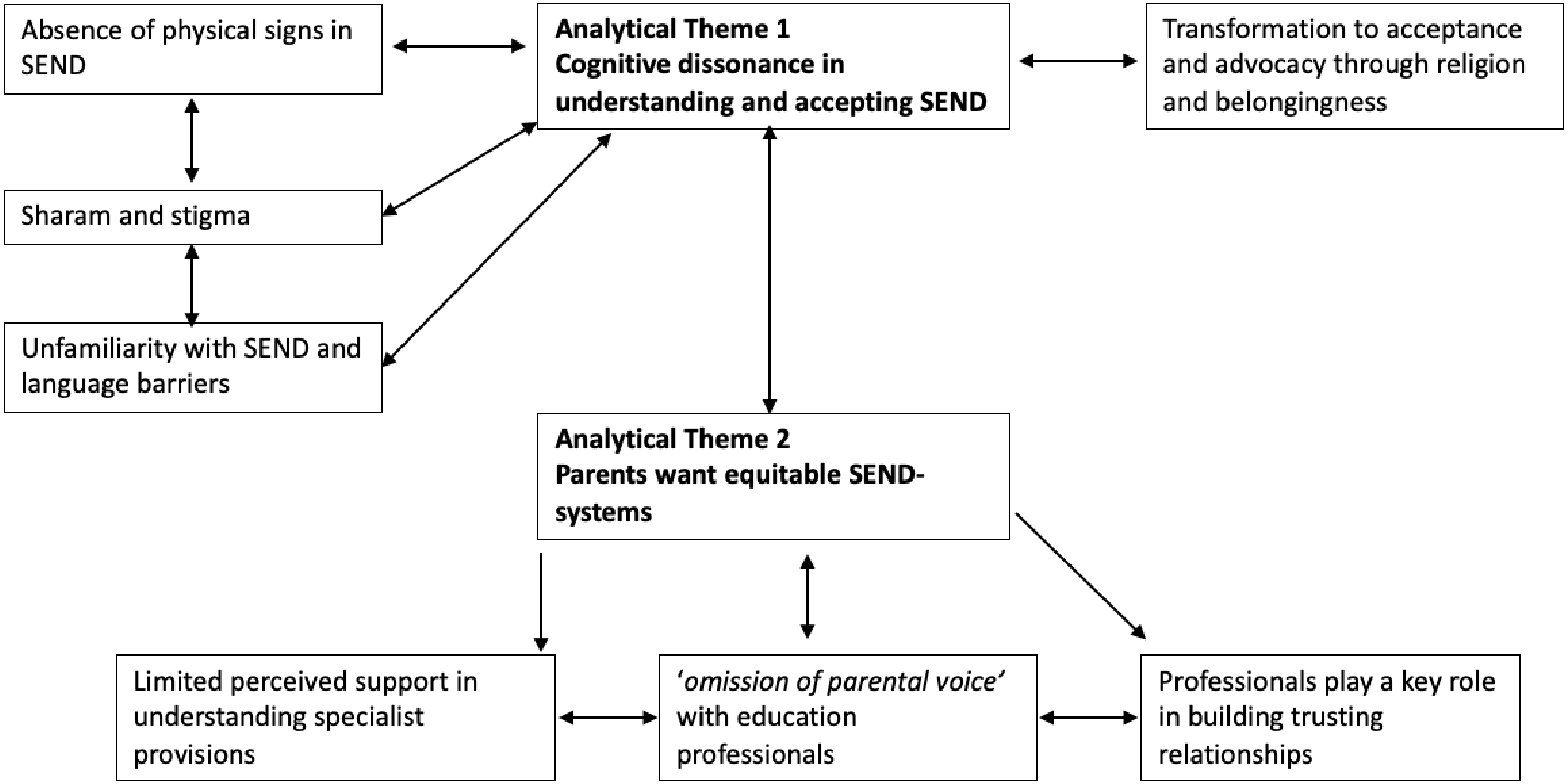

Figure 2.2 *Thematic Map*

2.3.2 Cognitive dissonance in understanding and accepting SEND

South-Asian parents shared a difficult journey of accepting their child's SEND which can be understood through cognitive dissonance (discomfort) caused by various key factors influencing their understanding and acceptance of SEND. These include unfamiliarity with SEND and language barriers hindering access to helpful information, absence of physical signs, the role of cultural factors such as sharam (shame) and stigma in accepting SEND, and the transformation to acceptance and advocacy through religion and belonging.

2.3.2.1 Unfamiliarity with SEND and language barriers

Many participants expressed a lack of knowledge about SEND, leading to shock upon receiving a diagnosis (e.g., Begum, 2023, Kwan-Tat, 2018). Parents explained that culturally, developmental delays are often perceived as part of typical child development and would not be identified as atypical (e.g., Akbar & Woods, 2020; Begum, 2023; Warner, 1999). This dissonance in familiarity of SEND influenced the extent to which parents and extended family understood and, consequently, believed the child's early diagnosis. In Akbar and Woods's study (2020), a Pakistani mother reported that her husband believes their son '*will be ok'* and that the child is '*a bit of a simpleton*' (p.668). Three other parents in the study shared that some extended family members still do not believe the child's SEND saying: '*You're making it up'* (Mohed); '*he's not very clever, that's not a condition*' (p. 668).

All parents expressed difficulties in understanding SEND due to the absence of equivalent words in Urdu, Tamil and Mirpuri Panjabi, making parents vulnerable to negative stereotypes (e.g., Kwan-Tat, 2018). This impacted their ability to understand and share their child's diagnosis in a meaningful manner as illustrated by a Bangladeshi mother in Begum's (2023) interview study:

> 'Mim's story shared some of the negative connotations that can come about in trying to explain using words that are found in the Bengali language. For example, phagol (mad, crazy): So, we know someone might say... he's delayed. Or...use Bangladeshi words like phagol...you know and I mean those are absolutely horrendous words...but again, it's just because people would not know any better... So, you can't, sort of bash them down for thinking like that' (p. 62).

Similarly, Raghavan et al. (2013) in their study with Pakistani and Bangladeshi mothers, noted that competency in English may vary, resulting in difficulties with understanding SEND when words are used that have no direct translation in their language, *'...or if the words used do not fit in their cultural context. These carers seldom used the term intellectual disability, describing their son or daughter as 'a little slow' or 'has a problem with the brain'* (p. 941).

2.3.2.2 Absence of physical signs in SEND

Parents expressed a particular difficulty in understanding SEND such as autism, due to the variability within the spectrum and an absence of ‘physical signs’ (e.g., Rizvi, 2017; Theara & Abbott, 2015; Warner, 1999). A Tamil-speaking Sri Lankan mother with an autistic child in Kwan-Tat’s study (2018) shared an internal conflict between understanding SEND as a physical disability with clear signs, such as children who are deaf, cannot speak, or have Down Syndrome, and knowing that her daughter has special needs despite the absence of physical signs*:*

> ‘…Anisha when you look at her she is normal and when you look at her she’s fine…But internally we understood there is a need for her…So we didn’t categorise it as a special requirement until we realised it is part of it. For me…a blind person, or a person who couldn’t speak (for them) we would use…special educational needs (term)’ (p. 120-121).

Similarly, in Nair’s case-study (2015), all Pakistani parents expressed initial difficulty in accepting their child’s autism diagnosis. The wider understanding of SEND among parents was reflected in comments such as *’but his face is normal’* indicating SEND to be understood as a physically visible disability (Begum, 2023, p. 44). Additionally, the notion of disability being curable was nearly universal among South-Asian parents and led to families trying to look for treatments and hope for a cure. In Theara and Abbott’s (2015) study with nine Pakistani, Indian and Sri Lankan families, autism was understood as a medical condition which is diagnosed by a medical practitioner, therefore parents ‘*focused on seeking treatment, medication and eventual cure. The diagnosis process itself was often described as a ‘medical examination’ which parents were not involved in’* (p.51). In Begum’s study (2023) parents shared how the wider family, the grandparents, started to immediately find ways to ‘fix’ autism to help their grandchildren. Some Pakistani parents in Akbar and Woods’ study (2020) returned to disbelieving the diagnosis when SEND did not fit within parents’ curable medical model (Akbar & Woods, 2020).

2.3.2.3 Sharam and stigma

The fear of being judged by society led many parents in this review to conceal their child’s SEND, often to avoid hurtful stereotypes (e.g Akbar & Woods, 2020). For example, one Pakistani mother in Akbar and Wood’s study (2020) expressed a fear of stigmatisation and had decided to conceal her son’s SEND to prevent him from being ‘labelled’ and having negative perceptions circulating about him within the community (p. 669). Pakistani parents in Nair’s study (2015) shared that the derogatory term ‘paagal’ (being mad) was the most common term being associated with SEND. This negative perception was considered extremely hurtful and believed to be held by the majority of the people in the community*: ‘…I’d say a good seventy percent of them still have the same attitude. You know, ‘to be looked down and frowned upon’* (Nair, 2015, p. 137). Moreover, parents in Begum’s study (2023), highlighted that the fear of stigma and sharam among South-Asian parents can continue existing despite them being born and educated in England. Some parents shared that they started to conceal their children's SEND after being continuously advised to do so by family and friends and advised not to bring their children to social gatherings such as weddings or at the mosque out of fear for stigma from the community (Akbar & Woods, 2020; Kramer-Roy, 2018).

Many parents decided to conceal their child's diagnosis after experiencing parental blame (e.g., Theara & Abbott, 2015). Sri Lankan (Kwan-Tat, 2018) and Pakistani (Akbar & Woods, 2020) parents shared that they were blamed for their child's SEND by their wider families, friends and/or community: *'Oh you've had so many kids close together, you obviously can't look after them'* (Akbar & Woods, 2020, p.668). In Raghavan et al.'s study (2013), Bangladeshi parents decided not to discuss their child's SEND because of how the wider family made them feel: *'they (wider family) think we brought shame on them, they don't say it to your face, but I know, when they come round here, you can tell you know'* (p. 941). Some parents and family members decided to conceal their child's SEND to avoid worrying other family members (Raghavan et al., 2013). One Pakistani parent in Rizvi's case-study (2017) who was not fluent in English shared that despite her being the mother of the child, she was deliberately excluded from finding out her child's diagnosis by her in-laws to shield her from potential distress: *'The doctors asked my family if I knew what my daughter had . . . as I had a happy expression on my face'* (p. 91). Contrastingly, desires to share the diagnosis with wider family members were also expressed to receive further support. In Kwan-Tat's study (2018), Sri Lankan parents expressed emotional distress due to living in different countries from your family and thus, lacking family support (p. 116). Parents continued to discuss the value of having support from family elders, which was not available: *'grandparents would have understood it…'* and *'with their experience they would have guided us to do the exercise when Anisha was six months'* (Kwan-Tat, 2018, p. 124). Interestingly while parents' motive to hide their child's SEND varied, all parents had concealed their child's SEND at some point. Concealing SEND led to parental isolation in Theara and Abbott (2015) and Nair's study (2015) where parents felt that they were '*the only parents of a child with autism'* (p. 114).

2.3.2.4 Transformation to acceptance and advocacy through religion and belongingness

Religion was seen as a transformative factor towards acceptance and advocacy of a child's SEND in nearly all the studies (e.g., Akbar & Woods, 2020; Oliver & Singal, 2017; Rizvi, 2017). Parents in Kramer-Roy's research (2012) shared how they:

> 'moved from the initial soul-destroying stage of people telling them that their child's disability was a punishment from God and that they must have sinned, through starting to pray more intensively and personally, to being convinced that this child was a blessing and a gift from God' (p. 446).

Nair's participants (2015) highlighted the difference between the culture and religion, where harmful attitudes towards SEND derive from cultural misconceptions rather than religious beliefs (p.134). Religion helped many parents to cope with their child's SEND: *'…the importance of being a Christian [was identified] as a means to cope, [with one parent] stating God gave us strength…'* in Kwan-Tat's (2018, p. 122) and in Akbar and Woods' study (2020): *'…despite daily challenges and struggles, Allah does keep you going'* (p. 670). Parents believed that it was God's will to become parents to children with SEND and 'children with special needs are God's angels…you are blessed with this child' (Raghavan et al., 2013, p. 941). Religion was also seen to foster a sense of belongingness which was integral to families in Akbar and Woods' study (2020): *'Both Qosar and Zubaida send their sons to the local mosque to build up a sense of belonging to the community'* (p. 670). The positive religious beliefs did not 'lessen the realities of life. But accepting God's will made mothers explore every opportunity to better their child's outcomes, to pass the parenting test' (Rizvi, 2017, p.94). For grandparents in the study, religion offered guidance through religious figures such as 'Fakirs' and 'Pirs' (Nair, 2015).

2.3.3 Parents want equitable SEND-systems

While some parents had positive experiences with education professionals (e.g., Oliver & Singal, 2017), most parents had almost entirely negative experiences navigating the SEND-systems (e.g., Akbar & Woods, 2020; Begum, 2023). Parents often described feeling '*stress, hurt and fear'* (Kwan-Tat, 2018, p. 112) when reflecting on their experiences with education professionals.

2.3.3.1 Limited perceived support in understanding specialist provisions

Advocating for children in schools posed significant challenges for South-Asian parents, particularly in decision-making for suitable educational provisions (e.g., Rizvi, 2017; Rizvi, 2018; Warner, 1999). Raghavan et al.'s study (2013) with 24 Pakistani and two Bangladeshi parents revealed that over half of non-English-speaking South-Asian parents were unaware of transition plans for their children. Similarly, Nair's study (2015) found that Pakistani parents lacked awareness of available school options for their children. Decision-making for suitable provisions varied; in Rizvi's study with Pakistani mothers (2018), decisions were based on where their child felt happy, while some deferred to teacher and SENCO opinions (Nair, 2015). In Akbar and Wood's research (2020), a Pakistani mother felt pressured to consider specialist provisions for her daughter, highlighting the necessity for better knowledge about SEND and children's rights. A SENCO in Kwan-Tat's study (2018) shared that she found it difficult to understand why after all the work, Sri Lankan parents would decline a specialist provision and instead want their children to go to a mainstream secondary school and say *'my child doesn't have a SEND, they just need to grow out of it'* (p.142).

Most parents initially preferred mainstream schools (e.g., Kwan-Tat, 2018), due to unfamiliarity with specialist schools, which worsened anxiety for many mothers in Rizvi's study (2017), who understood '*special*' to mean '*segregation*' (p. 93). Kwan-Tat's study (2018) echoed parents' desire for inclusion and preference for mainstream schools, viewing specialist schools as isolated and wanting their children to be socially included and supported by their typically developing peers. In Warner's study (1999) with Bangladeshi parents of children with severe learning difficulties (SLD), mainstream schools were preferred for opportunities to learn from typically developing peers. An EP in Kwan-Tat's study (2018) shared that some parents thought no learning occurred in specialist schools. In Rizvi's study (2018) parents preferred specialist schools after their negative experiences in mainstream schools. Similarly, parents in Rizvi's case study (2017) shifted their preference for specialist schools after visiting them and valuing the adequate one-to-one support available for children.

2.1.1.1 '*Omission of parental voice'* with education professionals

Pakistani parents in Akbar and Wood's study (2020) valued receiving an EHCP for their children. They expressed gratitude towards education professionals for being instrumental in ensuring EHCPs for their children before starting school, describing it as a '*golden key'* for their children's future (p. 672). However, when asked about the experiences of EHCP processes, these were described almost entirely negatively due to '*lack of knowledge of statutory processes…and omission of parental voice'* (Akbar & Woods, 2020, p. 672). The EHCP application was found confusing, slow, and difficult by parents (Kwan-Tat, 2018, p. 112), with one parent saying that they believed the process is deliberately difficult so that parents would '*give up'* (Akbar & Woods, 2020, p. 672). One common contributor to these negative experiences was a limited understanding of EPs' role and EHCP processes. Parents also expressed stress and regret for not being better informed before being asked to make important decisions about their children (Begum, 2023, p. 52). In Kwan-Tat's study (2018), SENCos shared that there were times when they needed parents to sign paperwork to move forward in the SEND process, and parents tended to sign whatever was given to them without understanding.

English proficiency played a crucial role in parents' ability to advocate for their children, where its absence led to the omission of parents' voices and power imbalances with professionals. Amirah believed that her mother's inability to speak English and lack of knowledge about SEND prevented effective advocacy for her sister (Akbar & Woods, 2020). Urdu and Mirpuri Panjabi-speaking parents found that their voices were not sought during EHCP processes, leaving some parents unaware that their child had an EHCP and that it was a legally binding document (Akbar & Woods, 2020). Similarly, one parent shared that they did not know what to do and who to ask for help because of the language barrier (Raghavan et al., 2013). The lack of inclusion was further expressed by fathers who reported feeling excluded by professionals despite accompanying the mother to their child's key meetings (Kramer-Roy, 2012). On power imbalances with professionals, two EPs in Kwan-Tat's study (2018) shared that families often viewed EPs as extensions of the school rather than independent advocates, due to having 'education' in the EP's role title, contributing to power imbalances between the parents and educational professionals. A parent in Begum's study (2023) highlighted the necessity of presenting oneself as highly knowledgeable to be taken seriously by the education professionals: '*I have to go into the room and know autism, know isms…to feel like I have to be taken seriously*' (p. 67-68). While reflecting on her own experience, Amirah shared that South-Asian parents find it more difficult to contribute in formal settings such as meetings '*due to lack of confidence unlike the host community who have more fight in them'* (Akbar & Woods, 2020, p. 672).

2.3.3.3 Professionals play a key role in building trusting relationships

Parents highlighted the need for CRPs to support parents from culturally diverse backgrounds (e.g., Begum, 2023). Kramer-Roy's study (2012) found mothers' relationship with professionals as '*superficial, rushed and too narrowly focused on the task in hand…due to poor cultural competence'* (p. 445). Parents expressed gratitude towards education professionals who took the cultural, linguistic, and religious context into consideration: '*they weren't Muslims, but they said things like this (SEND) is from Allah – they were right*' (Akbar & Woods, 2020, p. 670). In Akbar and Wood's study (2020), parents valued qualified interpreters in meetings over bilingual school staff, citing concerns about the quality of translation and potential bias toward schools. One parent hoped for resources in their language to learn about their child's SEND: *'I wish there was something in Bengali for grandparents, particularly that generation'* (Begum, 2023, p. 69). Parent network groups were highly valued when they were culturally and linguistically competent. In Begum's study (2023), parent groups helped to understand SEND and offered peer-support to navigate the uncertainties of raising children with SEND. However, barriers to accessing support groups were noted, such as organising meetings in pubs at late hours (Nair, 2015). Furthermore, the presence of school staff hindered parents from being open and honest about familial and cultural difficulties (Akbar & Woods, 2020). In Kramer-Roy's study (2012), mothers explicitly stated that parent groups became unhelpful when they '*were more superficial, perhaps aiming to distract members from their daily stress, and did not facilitate them to use practical or creative activities to explore and address issues*' (p. 445). In contrast, helpful parent groups allowed them to discuss specific concerns stemming from shared cultural and religious backgrounds (Kramer-Roy, 2012, p. 446).

Specialist school headteachers in Oliver and Singal's (2017) study emphasised the importance of employing *'linguistically and ethnically diverse migrant support staff'* to foster positive parent-school partnerships (p. 9). They organised a Panjabi cooking club with bilingual staff for parents to join to facilitate peer-support (p.9). Some SENCos found interpreters helpful after realising that parents would agree to everything without understanding (Kwan-Tat, 2018). Additionally, SENCOs stressed the importance of CRPs to dispel stereotypes among staff members: *'…our pastoral team said 'ah parents never come to meetings, they don't care, so they make judgments…so the knowledge is not there with our staff'* (Kwan-Tat, 2018, p. 147). EPs in Kwan-Tat's study (2018) acknowledged a shared responsibility with schools to use jargon-free language when explaining about SEND provisions and systems to enable informed decision making (p. 165).

2.4 Discussion

The present review makes a unique contribution to the research field by synthesising the experiences of 91 South-Asian parents to answer the question: How do South-Asian parents come to understand their children's SEND, and how do they describe their experiences with education professionals and SEND-systems? Two over-arching analytical themes were identified: '*cognitive dissonance in understanding and accepting SEND'* and '*parents* want equitable SEND-systems'. South-Asian parents' understanding of SEND was hindered by unmet language needs, cultural stigma (sharam), and a perceived lack of professional and familial support. This contributed to power imbalances with education professionals, including EPs. Parents felt excluded especially when language barriers were not removed effectively. Such experiences impacted parents' ability to form equal and trusting partnerships with education professionals to advocate for their children. As such, the findings do not support the stereotypes of South-Asian parents having sufficient familial support (Gupta & Pillai, 2005). Contrary to the Government's Race and Ethnic Disparities (RED, 2021) report which dismisses the existence of institutional racism and systemic disadvantages in the UK, South-Asian parents reported experiencing disadvantage within the SEND-systems compared to the host community. Parents' accounts suggest that the perceived disadvantage is exacerbated when education professionals do not seek to understand the difficulties parents continue to face within the SEND-systems and do take appropriate actions to eliminate the disadvantages. The interactions between the themes are explored through cognitive dissonance (Festinger, 1957) and belongingness theory (Baumeister & Leary, 1995), and an intersectionality framework (Crenshaw, 1989) seeking to help professionals and policymakers to prioritise the development of CRP for more equitable SEND-systems.

2.4.1 Cognitive dissonance in understanding and accepting SEND

Intersectional inequality can be understood through cognitive dissonance which provides an insight into how South-Asian parents' culture, interacted with their understanding of SEND (Crenshaw, 1989). The absence of equivalent SEND terms in parents' languages (Urdu, Tamil, Mirpuri Panjabi, Bengali), coupled with limited perceived professional support for understanding English 'SEND' terminologies, hindered parents' ability to share the diagnoses in a meaningful way. Consequently, parents faced stressful situations, having to understand their children's SEND, which aligns with British East-African parents' stressful experiences (Oumar, 2022). The findings suggest that the lack of support in understanding SEND and the existing cultural stigma and sharam around being 'different', created cognitive dissonance (discomfort). As a result, parents were often left alone to cope with cultural understanding of SEND. The cultural understanding of SEND across parents' respective countries (Bangladesh, Pakistan, Sri Lanka) was unifying; children are often labelled as 'phagol' (Bengali word for crazy) when their behaviour is not understood within the community. Parents strongly disagreed with this derogatory label which led to a dissonance between their personal and cultural belief regarding SEND. Consequently, parents sought alternative understandings, sometimes concealing or denying their children's SEND altogether. These findings are consistent with Tadesse (2013) who found Ethiopian, Somali, Liberia and Sudanese refugee parents to conceal their child's SEND out of fear of being stigmatised as disabled and stupid. Parents applied a medical view to understand SEND considering it as something treatable. This is aligned with Heer's (2012) study in which Pakistani parents looked for treatments and cures for SEND. Hearing about SEND the first time from doctors with lack of perceived culturally responsive support, might privilege the medical view, and contribute to dissonance in understanding SEND. It may be that when cures were not found, parents and grandparents were left again with the stigmatised view (phagol). This could explain why some parents and extended family declined SEND. For example, Pakistani mothers shared that their parents sought cures and, finding none, reverted to disbelief (Akbar & Woods, 2020). This suggests that disbelief may be a coping strategy to alleviate discomfort from conflicting views and beliefs. Religion helped to overcome SEND stigma and fostered acceptance and advocacy. It provided an alternative, meaningful perspective to understand and view SEND. Additionally, religion helped reconnect with culture and community and thus, fostered a sense of belongingness as described by both Muslim and Christian parents (Akbar & Woods, 2020; Kwan-Tat, 2018).

Interestingly, Pakistani mothers shared that their spouses took longer to accept SEND with fathers preferring to believe their children were not '*very clever'* rather than having a lifelong stigmatised condition (Akbar & Woods, 2020, p.668). The potential gender difference in accepting SEND raises questions about its causes. One explanation comes from Pakistani fathers sharing that they feel excluded by professionals despite joining school meetings (Kramer-Roy, 2012). This may further hinder parents' understanding of SEND, and even make parents feel distrustful towards schools. Additionally, Heer (2012) found that only Pakistani and Indian mothers and not fathers benefitted from religion, suggesting Pakistani and Indian fathers might have less available resources to build resilience against stigma. However, the current review is limited in exploring religious and gender differences, thus, generalisations should be avoided. Instead, education professionals should seek to build trusting relationships with parents and explore available resources with parents that could support their understanding of SEND and help overcome possible stigma. Following the SEND Code of Practice, professionals should also ensure where appropriate, that both parents are included in SEND processes (DfE, 2015). Gupta and Pillai, (2005) noted that South-Asian parents in the USA declined professional support due to sufficient extended family support when caring for children with SEND.

This was not the case in the current review. South-Asian parents in England felt isolated, lonely, and stressed due to limited perceived professional and familial support. To protect families from worry and stigma, SEND was often concealed from family and community. SEND may pose a threat to parents' being excluded from the community, impacting parents' sense of belongingness; parents reported being excluded from social gatherings if others knew that they had a child who was 'different' (Kramer-Roy, 2018). This exclusion could occur from friends and family wanting to shield parents from community's stigma. Alternatively, the exclusion may ensure that sharam is not passed on. According to my understanding as the primary author with Panjabi heritage, people engaging with those subjected to sharam, also face community's judgement. It may be that parents of children with SEND are socially excluded within the British South-Asian communities out of fear of sharam. Consequently, parents often felt like the only parents of children with SEND. Interestingly, parents shared that sharam and stigma persist despite being born and educated in England (Begum, 2023). This can be due to limited opportunities to learn about SEND within the English curriculum, highlighting teachers' important role in fostering inclusivity early on through education. In sum, the current findings suggest that parents concealing their children's SEND may perpetuate stigma in a bidirectional way. Concealment acts as a coping strategy against SEND and sharam, but also leads to isolation and limits community learning and advocacy. These interpretations exemplify how sharam and stigma can make parents vulnerable to isolation and hinder community's advocacy for SEND. These findings highlight the unique difficulties South-Asian families face in accessing community and family support and emphasise the importance of healthcare and education professionals not assuming that South Asian families have sufficient support.

2.4.2 Parents want equitable SEND-systems

The vulnerability to sharam and SEND stigma might be perpetuated by limited cultural responsiveness from education professionals. While parents appreciated EHCPs for their children, they often reported power imbalances with professionals. Power imbalances were perpetuated by a lack of support in understanding SEND processes and professionals' roles, and absence of interpreters (Akbar & Woods, 2020). Consequently, parents were unaware of EP role, often mistaking EPs for school staff (Kwan-Tat, 2018). In Theara and Abbott's study (2015), a parent shared that South-Asian parents tend to perceive social science professionals with fear and suspicion. The confusion between the titles 'Dr' and 'EP,' and EPs clarifying they are not part of the school, may add to parents' cognitive dissonance and distrust. This underscores the need for EPs to ensure their involvement and role is understood by parents through informed consents for SEND processes. Parents also shared limited support in understanding transition plans and specialist school provisions. They felt isolated, perceived support inaccessible and thus, dependent on professionals' views. As a result, parents often preferred mainstream provisions due to a lack of support in understanding specialist provisions. For example, a

Pakistani mother thought that ‘specialist’ meant segregation, and that no learning occurred in specialist provisions (Rizvi, 2017). Culturally, being ‘different’ is often frowned upon in many South-Asian cultures, and sending children to specialist provisions without understanding them may threaten parents’ sense of belonging within their communities further. In response, parents highlighted the need for collaborative and unbiased practices which would respond to parents’ cultural and linguistic needs.

Parents hoped for culturally responsive practices (CRPs) from all education professionals, highlighting the importance of trusting relationships to tackle power imbalances. Interestingly, they did not ask for service providers to match their ethnic background, as Asian, African Caribbean and white-British parents requested in Greenwood et al.’s (2015) review**.** Parents felt that they could not trust education professionals because they did not create space for their experiences and thus, felt at disadvantage in navigating SEND-systems (Akbar & Woods, 2020). The lack of trust may explain why some parents preferred professional interpreters over bilingual school staff in EP meetings (Akbar & Woods, 2020). SENCos’ reflections can help to understand why South-Asian parents expressed feeling misunderstood contributing to the distrust. In Kwan-Tat’s study (2018) a SENCo shared school staff to hold stereotypical views that South-Asian parents never attend meetings, suggesting them unworthy of education professionals’ time. Congruently, parents felt they were treated differently and had to be knowledgeable to be taken seriously (Begum, 2023). Parents felt that EHCP processes were deliberately made difficult, recognising their disadvantage compared to the host community, which had a better understanding of SEND-systems. Additionally, parents felt that professionals overlooked parents’ culture in discussions and failed to respond to parents’ unique difficulties (Kramer-Roy, 2012). A SENCo shared that they did not comprehend why parents would decline specialist provisions and deny SEND (Kwan-Tat, 2018). The perceived disadvantage highlights the need for culturally responsive practices for equitable SEND processes. SNJ report (2022), raises a valid question: ‘*Mental health counsellors have to go through the process of addressing their own trauma and bias as part of training, why not school staff who have such a massive impact on the lives of children?*‘ (para 15). Since the Government’s RED (2021) report, the SEND improvement plan (DfE, 2023b) has acknowledged the complexity of EHCP processes for all parents, however, it fails to address the experiences of parents from ethnic backgrounds. The following recommendations aim to contribute to this gap by fostering CRPs.

2.4.3 Recommendations for practice and policy

The implications for practice and policy are recommended in **Table 2.6** in response to the parents’ shared experiences with SEND-systems.

Table 2.6 *Implications for Practice*

Relevant people	**Implications**
School staff	-School leaders to prioritise ongoing training for all staff on CRPs to build trusting relationships with all parents to ensure equitable support. This includes meeting the language barriers effectively e.g., to ensure informed consent. Schools are advised to include parents in the decision-making in how they would like to be supported e.g., by asking parents' preference for professional interpreter or bilingual school staff in meetings. -Liaising with community centres to support parents' understanding for SEND-systems and to advertise job openings to support diversity within the workforce. -Signposting parents to resources and relevant services. Schools could help parents connect with other parents of children with SEND sharing the same language. -Training for school staff on how to support all pupils' understanding on SEND to foster inclusivity in classrooms.
Parents and families	Seek opportunities to take an active and valued role within the school community to support children with SEND from culturally diverse backgrounds.
EPs and EP services	-Delivering training to schools to aid whole-school level CRPs. This could include training on intersectionality and relational approaches. -Provide supervision opportunities to schools to allow safe space for ongoing development of CRPs and responding to the needs of the school staff when supporting families from culturally diverse backgrounds. This could include helping the school staff to manage their worries as well as, problem-solving barriers to CRPs. -Liaising with professional interpreters to ensure accessible EP involvement, starting from informed consents till the end. -Ongoing supervision and training opportunities for EPs to develop their CRPs. -Contributing to qualitative research with parents from ethnic minority backgrounds on SEND-systems and working with EPs. -Developing robust interpretation booking processes for EPs.

Local Authority (LA)	-Collecting relevant quantitative and qualitative data on parents' accessing SEND-support e.g., SEND Information Advice and Support Service (SENDIASS) to navigate EHCP processes. -Liaising with schools to understand the demographics they are serving and ensuring equitable access to interpretation services such as Ethnic Minority Achievement Services (EMAS). -Liaising with community centres to reach out to local communities to raise awareness on available SEND-support and services.
Wider UK policymakers	-Prioritising funding for education department and LA to support their communities more effectively. This could help for example, EP services to provide community -level support, as well as, providing training to professionals on CRPs. -All teacher trainings to include relevant SEND policies and strategies how to support children with SEND. Additionally, trainings should include parents' rights in SEND processes and provide opportunities to develop CRPs. -Supporting the diversification of education workforce for instance by liaising with the community and hosting events to learn about the profession and the application process for the doctorate degree. -Funding for qualitative and quantitative research to privilege the voices of unheard parents from minority backgrounds, to learn from parents' expertise and lived experiences. This could help to build equitable and just systems across the country.

2.4.4 Strengths, Limitations and Future Research

This review has noteworthy limitations and strengths. While I used a broad 'South-Asian' term to cope with the scarcity of research, it is essential to recognise the religious, linguistic, cultural and historic diversity within the umbrella term. Parents' gender, religion, country and language was not always clear in the eligible studies. Therefore, it would be oversimplistic to say that the derived themes are universal to all South-Asian parents' experiences. Future research should aim to include parents who share the same linguistic and religious identities to co-develop culturally responsive practices. Thematic synthesis was deemed appropriate to analyse qualitative studies in this review. However, a lack of transparency in understanding each study's contribution to theme formation is a common criticism within the synthesis (Smith & Firth, 2011). In response, **Table 2.5** was created to enhance rigor of the synthesis. Not consulting research area experts may have led to missing some relevant studies.

However, completing the systemic search at two separate times has ensured the validity and relevance of the search.

The review's strength lies in its pioneering contribution to an under-researched area, enhanced by the application of the CASP framework with independent quality assurance from the research team. This helped to identify strengths and weaknesses (**Appendix B**) for future research. Notably, eligible studies scored the lowest in acknowledging ethical issues and research-participant relationships. Given the power imbalances experienced by South-Asian parents, researchers should include reflections on research-participant dynamics and state explicitly how informed consents were obtained. As parents preferred professional interpreters, future studies should seek parents' views on the use of bilingual school staff in research (Oliver & Singal, 2017). Kramer-Roy (2012) found that focus group methodologies were valued by South-Asian parents, thus, future research is encouraged to consider incorporating focus groups in their methodologies. Further, participatory methodologies should be favoured to privilege parents' expertise and lived experiences.

2.5 Conclusion

This review highlights the significant barriers faced by South-Asian parents in navigating SEND-systems in England, stemming from unmet language needs, cultural stigma, and a lack of perceived professional support in response. These experiences contribute to power imbalances with education professionals, leading to feelings of exclusion and distrust. This review underscores the need for policymakers and education professionals to collaborate with parents of children with SEND from minority backgrounds to develop culturally responsive practices for more equitable SEND-systems. Future research should seek to co-identify culturally responsive practices with parents from culturally diverse backgrounds.

2.6 References

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Chapter 3 A call for culturally responsive educational psychology practices: Indian-Panjabi Sikh parents’ experiences with SEND-systems in England

Abstract

The study explores Indian-Panjabi Sikh parents’ experiences with SEND-systems and support in England. Four parents of children with SEND, four educational psychologists and one interpreter were recruited. Nine individual reflective conversations and two communicative focus group discussions were conducted following critical communicative methodology. Three themes were developed using reflective thematic analysis. Indian-Panjabi Sikh parents face significant barriers navigating SEND-systems and are vulnerable to isolation due to lack of perceived professional, familial, and community support. Parents discussed issues related to unmet language needs, absence of interpreters, cultural considerations, informed consent, and clear information on EP involvement and parental rights during EHCP processes. These experiences contributed to disempowerment and vulnerability to SEND-stigma and sharam (shame). Shame resilience theory emphasises the need for culturally responsive practices that foster parents’ sense of belongingness and accessible non-deficit-based understanding of SEND. Educational psychologists and the interpreter expressed systemic barriers to supporting parents and children from ethnic minorities. Moreover, parents described SEND-support for autistic children in mainstream schools as inadequate. The findings show persistent inequalities in SEND-systems that cannot be solely attributed to socioeconomic factors. These findings call for policy-level changes prioritising education professionals’ culturally responsive practices for equitable SEND-systems and support.

Keywords: Indian-Panjabi, SEND, Critical communicative methodology, culturally responsive practice, sharam

3.1 Introduction

Over 1.6 million children in England have Special Educational Needs and Disability (SEND), and over 0.4 million children have an Education Health Care Plan (EHCP; DfE, 2024). SEND refers to children and young people (CYP) aged 0-25 who have a learning difficulty and/or disability and are receiving SEND-support within their educational environments (DfE, 2015). SEND-support can include EHCPs, which are multi-disciplinary legal documents defining a learner’s strengths and needs, required support, and desired outcomes (DfE, 2023). Local Authorities (LAs) gather information from relevant professionals, such as Educational Psychologists (EPs), to decide whether an EHCP is needed to support SEND. EPs must follow the Children and Families Act (2014) which emphasises that parents should be equal partners with education professionals in decision-making for their children. The SEND code of practice (DfE, 2015) mandates that education professionals ensure that all children with SEND are treated fairly and can access adequate services and education, regardless of ethnicity and culture. Despite the legislation, children from ethnic minority backgrounds receiving SEND-support continue to be disproportionately represented in education in England (Kaplan & Celik, 2023). In this research, culture is defined by Burnham's Social GRRAACEESS model (2012) where culture refers to the shared group or community identity, values, behaviours, and beliefs. The model emphasises that different identities, such as gender, race, religion, age, ability, class, and ethnicity, do not operate in isolation but intersect and interact in ways that might compound the influence of power dynamics, privilege, and disadvantages (Crenshaw et al., 1995).

Indian children are half as likely to receive autism diagnoses or be recognised for social-emotional mental health needs compared to white-British children (Strand & Lindsay, 2009). Additionally, Indian autistic children are less likely to receive EHCPs compared to white-British autistic children (Stagg et al., 2023). The UK Government commissioned an investigation on racial inequalities within education systems in their Race and Ethnic Disparities (RED) report (2021). The report concluded that institutional racism does not exist in the UK and instead, socioeconomic status played more significant role in creating systemic disadvantages. The report has been criticised by a non-profit parent-run organisation, for overlooking the lived experiences of minority communities, downplaying the role of systemic racism and hindering professionals' efforts to support children and families from ethnic minorities (Special Needs Jungle; SNJ, 2022). Understanding over-and under-representations is pertinent to ensure equitable SEND-support for all children in need. Indians form the largest ethnic minority group in England, while Panjabi is the third most spoken minority language, where over 60% of Panjabi speakers identify as Sikhs (ONS, 2022). Yet, experiences of Indian-Panjabi Sikh parents of children with SEND, remain unstudied to date. Only Rehal's study (1989) has explored Panjabi parents' experiences of working with EPs for statutory processes.

Rehal found that parents were unaware of EPs' role, specialist provisions and their children having statements (now EHCPs). Moreover, parents thought that their children were temporarily placed in specialist schools. The limited but growing research has focused on Pakistani-Panjabi parents' experiences. Akbar and Woods (2020) explored British-Pakistani parents' experiences with SEND-systems. Parents reported negative experiences with EPs due to the omission of parental voice and feeling excluded in EHCP processes and decision-making for their children's future. Additionally, parents felt disempowered when professionals overlooked their religious and cultural heritage and experiences. Parents in Kwan-Tat's study (2018) found it difficult to understand SEND due to the absence of equivalent words in Mirpuri-Panjabi, Tamil, and Urdu which made all parents vulnerable to sharam (shame) and SEND-stigma. Sangar and Howe (2021) describe sharam a complex construct found in South-Asian cultures which is linked with self-respect, reputation, and family honour. When a person goes against cultural values, this results in community judgment, thus, one is expected to lead a life free of sharam. Consequently, Sangar and Howe (2021) found that the fear of sharam hindered British South-Asian girls from seeking professional mental health support. Exploring whether sharam manifests among other communities with a shared language, culture, and religion, is pertinent.

Older research tends to regard religion as a non-scientific way of addressing mental health and undermines its potential to support mental health (Ellison, 1994), whereas contemporary research is far more positive. Dolcos et al. (2021) highlight that religion can offer coping strategies, reducing stress and enhancing life satisfaction while fostering psychological resilience. Shame resilience theory (SRT; Brown, 2008) suggests that social roles and associated expectations significantly impact one's self-concept and wellbeing. To build resilience against shame, non-judgmental and empathetic environment is essential. Individuals who face unrealistic expectations within their social roles have limited empathetic social connections and feel trapped and powerless to overcome them. Decreased empathetic connections, push individuals to social isolation perpetuating shame, whereas freedom and empathetic social connections foster a sense of belongingness and understanding needed to overcome shame. Baumeister and Leary (1995) suggest that humans have a fundamental need to belong and form human connections. SRT can aid professionals' culturally responsive practice (CRP) and tackle harmful stereotypes, such as that South-Asian parents have sufficient familial support, and thus, do not need professional support (Gupta & Pillai, 2005).

The regulating authority of EP practice requires EPs to actively engage in anti-discriminatory practices and develop cultural competence (HCPC, 2023). While cultural competence focuses on knowledge, skills, and awareness, it has been critiqued for overlooking diversity within cultural groups (Ellis et al., 2020). Cultural humility, which emphasises self-reflection and acknowledgment of power imbalances, complements CRP but lacks emphasis on reciprocal engagement. Cultural responsiveness is the inaction of equalising power imbalances which integrates cultural humility and competence into a fluid, ongoing process that helps to identify practices among education professionals to meet the needs of culturally diverse populations effectively. This includes creating safe and empowering spaces for parents where their cultural expertise, experiences, and views, are valued are heard (Hopf et al., 2021). CRPs in education are often discussed through culturally responsive teaching (Gay, 2000) and culturally relevant pedagogy (Ladson-Billings, 2014), and highlight the importance of acknowledging students' culture for inclusive education. Similarly, EPS must consider children and parents' culture in their work with them. Identifying CRPs for EP practice is essential, considering the lack of cultural representation in the EP workforce (AEP, 2021) and England's demographics diversifying over time. For example, over 35% of children with SEND come from minority ethnic backgrounds (DfE, 2023a).

Consequently, exploring minority experiences and collaborating with interpreters, can help develop culturally responsive practices (CRPs) in educational psychology.

Edwards et al. (2005) highlight the nuanced role interpreters play; they do not merely convey linguistic meaning but also interpret cultural and contextual nuances. The British Psychological Society's guidance (BPS, 2017) notes the benefits and barriers to consider when working with interpreters in psychology practice. While working with interpreters helps to bridge the language barriers, the guideline cautions against power imbalances and potential misinterpretation, especially when professionals rely on terminology that is unfamiliar to interpreters and families. Nevertheless, there is a dearth of literature on collaborative practices between EPs and interpreters to develop CRPs. Therefore, this study aims to bridge the existing gap within the literature by exploring Indian-Panjabi Sikh parents' experiences with SEND-systems and support for their children and, identify CRPs collaboratively with interpreters, EPs and Indian-Panjabi Sikh parents for equitable SEND-systems. Interpreters are included after Akbar and Woods (2020) found professional interpreters to play one of the most significant roles to parents' inclusion in EHCP processes. The research questions are as follows:

- How do Indian-Panjabi Sikh parents of children with SEND describe their early support experiences before the EHCP process?
- How do Indian-Panjabi Sikh parents of children with SEND describe their experiences of EHCP processes and available SEND-support?
- How do EPs and interpreters describe their experiences in supporting Indian-Panjabi Sikh parents, and what barriers do EPs face in promoting culturally responsive practices?

The findings will be discussed using an intersectionality lens (Crenshaw, 1989), which fosters an awareness of how different elements of identity interact with larger systems of power, such as SEND-systems, creating privilege and discrimination. Brown's (2008) SRT framework (**Figure 3.1**) and belongingness theory (Baumeister & Leary, 1995) will be discussed to ensure sharam is not overlooked in discussions around CRPs.

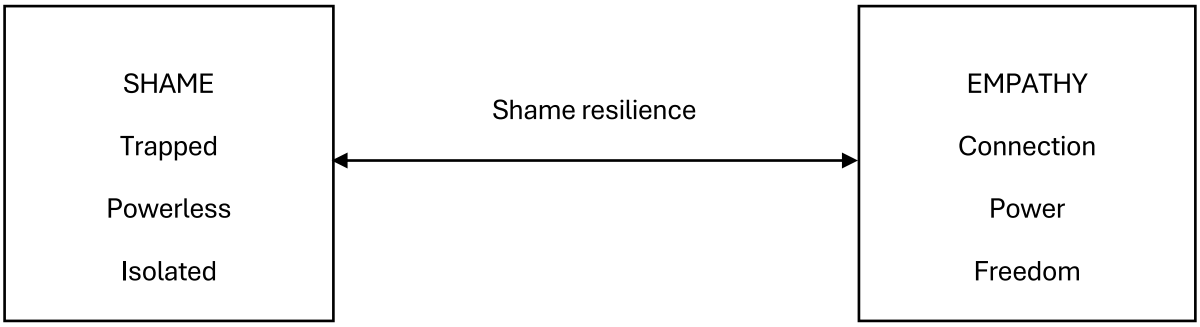

Figure 3.1 *SRT (Brown, 2008)*

We will use identity-first language (e.g., Indian-Panjabi Sikh parents and autistic children), following parents' wishes in the study. However, we are aware that some readers may prefer person-first language. This research acknowledges terms like cultural humility, awareness, and competence, but consistently uses the term CRPs to emphasise an active, justice-oriented approach.

3.2 Methodology

3.2.1 Researcher Perspective

We took social constructionist (Burr, 2015) and critical race theory (Crenshaw et al., 1995) positions. Social constructionism suggests that reality and knowledge is constructed through personal experiences and social interactions that are influenced by linguistic and cultural contexts. Critical race theory focuses on interactions between race, power and society and helps to identify factors creating systemic inequalities. The epistemologies were found well fitted with the adapted version of CCM (Puigvert et al., 2012; Strogilos, 2024). CCM aims to understand participants' realities, find ways to transform the exclusionary elements (barriers) and fosters a positive change. This is done in collaboration with participants based on egalitarian dialogues. In egalitarian dialogues, researchers and participants have an active and equal role in co-creating new understandings; researchers share their research-based knowledge and participants their expertise and lived experiences.

3.2.2 Ethical Considerations

The present study gained ethical approval from the University of Southampton's School of Psychology Ethics Committee (**Appendix A**). Culturally appropriate pseudonyms, chosen by participants, are used throughout the report. It was important to ensure that participants understood that their participation could not be fully anonymised due to the nature of CCM. I shared about the importance of confidentiality, not being able to ensure full anonymity and participants' right to withdraw from the study, prior each data collection point. Participants were asked to give informed consent in two ways: by signing the consent form and sending it back to me, and by giving a verbal consent in the beginning of the individual reflective conversation. No participant requested to withdraw their data. An incentive to express gratitude for taking part in the study was given at the end of participation, however, I ensured that participants did not feel pressured by this.

It is important to acknowledge that I hold biases and views in relation to working with Indian-Panjabi Sikh parents, as an Indian-Panjabi Sikh lead researcher, trainee EP and primary author. While the primary author's heritage allows an 'insider' lens into the cultural understanding of SEND, the research team does not have lived experience of having a child with SEND, giving an 'outsider' lens in relation to parents of children with SEND. Subjectivity is not seen as a limitation in this qualitative study. Braun and Clarke (2013) suggest that subjectivity can be a source of analysis and it should be recognised and kept 'in-check' through ongoing reflexivity. To become more aware of own biases and their influence on the research, the primary author sought regular supervision from her research team, including an associate professor and an educational psychologist to enhance reflections and foster alternative perspectives.

3.2.3 Participants

Purposive sampling was used to recruit nine participants across England: one interpreter, four parents and four EPs. Parents were recruited through advertising the research at Gurudwaras (Sikh place of worship), and contacts with schools and EP services. EPs were recruited through EP services and interpreters through a private interpretation service. The sample size was considered adequate for CCM (Gómez et al., 2011) and was based on the previous sample sizes within the research area (Akbar & Woods, 2019). The inclusion criteria for Indian-Panjabi Sikh parents living in England were that they have a child with SEND and have had EP involvement as part of the EHCP process within the last ten years. The inclusion criteria for EHCP involvement were increased from five to ten years to support recruitment while ensuring participants' ability to reflect on EHCP experiences. The inclusion criteria for EPs and Indian-Panjabi interpreters included supporting Indian-Panjabi Sikh parents during EHCP processes together with an interpreter/EP within the last year. This was deemed long enough to ensure reflections on recent CRPs. The additional inclusion criteria for EPs were that at least one EP would identify as Indian-Panjabi to aid EPs' within profession and culture reflections. Participant characteristics are outlined in **Table 3.1** and **Table 3.2** under pseudonyms**.**

Table 3.1 *Participant Characteristics (parents)*

Participant's pseudonym	Years living in England	EP involvement in	Interpreter in EP meeting	Fluent in English	Child's pseudonym/age/gender/ SEND	Does the child have an EHCP?	Does the child go to a specialist school provision
Amarjeet (father)	19	2022	No	Yes	Harman/6/male/autism	Yes	Yes
Simran (mother)	16	2015	No	Yes	Dimple/15/female/autism	Yes	No
Lilita (mother)	Second-generation immigrant	2015	No	Yes	Navdeep/15/male/autism	No	No
Preet (mother)	7	2022	Yes	No	Avu/6/male/autism	Yes	No: waiting for a specialist provision allocation

Table 3.2 *Participant Characteristics (EPs and interpreter)*

Participant's pseudonym/gender/ role	Work experience (years)	Does the professional support more than 10 parents annually who do not speak English?	Ethnicity
Eknoor/ Female/EP	5	Yes	Indian-Panjabi
Sargun/Female/EP	8	Yes	Indian-Panjabi
Chardi-Kala/Male/EP	36	Yes	Indian-Panjabi
Beth/Female/EP	5	Yes	White-British
Karan/Male/Interpreter	30	Yes	Indian-Panjabi

3.2.4 Research tools

CCM research tools emphasise active and equal collaboration between researchers and participants to co-create new understandings. These tools include reflective individual conversations and communicative focus groups, both of which are shaped by egalitarian dialogue. Reflective individual conversations, guided by topic guides (**Appendix I**), elicit reflective narrations of participants' lived experiences (Gómez et al., 2011). Communicative focus group discussions facilitate group discussions where participants and researchers interpret exclusionary elements (barriers) and identify transformative CRPs collaboratively. What distinguishes CCM's tools is the integration of researchers' expertise and research-based knowledge with participants' expertise during data-gathering. For example, in response to participants' expressed need for information on specialist provisions, I shared that parents can request visits to specialist schools. This ensures that participants not only contribute to the research but also derive direct benefits from the process. The reflective thematic analysis (RTA; Braun & Clarke, 2019) and adapted CCM steps are outlined in **Figure 3.2**, aligned with Strogilos' study (2024).

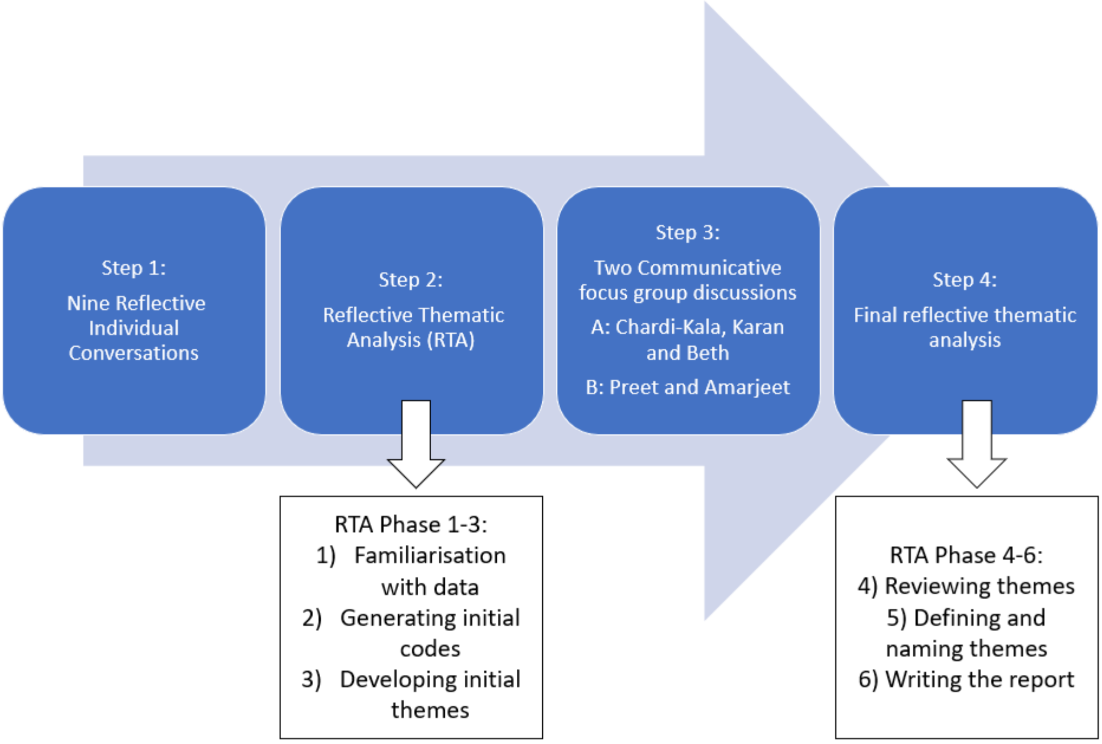

Figure 3.2 *CCM procedure step 1-4 and RTA procedure 1-6*

3.2.5 Research Procedure and Data Analysis

Data was gathered via Microsoft Teams or WhatsApp videocalls in English or Panjabi following participants' wishes to foster safety and participation. All video calls were audio-recorded using a university recorder. Step 1 involved nine semi-structured reflective individual conversations, each lasting approximately 70 minutes. These conversations aimed to understand participants' individual journeys using topic guides adapted from Oumar et al. (2022) as prompts (**Appendix I**). A pilot was completed with one parent to refine questions for clarity. No changes were suggested; therefore, this data was included in the analysis. In Step 2, the primary author translated, transcribed and anonymised the transcripts. To ensure translation reliability, an independent reviewer fluent in English and Panjabi verified and approved the quality of the translations. Data-analysis followed the phases of inductive reflective thematic analysis (RTA) (Braun & Clarke, 2019). First, the transcripts were carefully read. The meaning-making of the data was aided by the first author translating and re-reading the transcripts. The second phase of RTA involved creating initial codes using NVivo V.11 software (Bazeley & Jackson, 2013) and re-naming and merging codes. In RTA phase three, codes were grouped into initial themes and shared with participants aligned with Step 3 of the CCM procedure.

The primary author facilitated two one-hour-long communicative focus group discussions using Microsoft Teams. Based on the participants' availability, Amarjeet, Preet, Chardi-Kala, Beth and Karan partook in focus group discussions. Parents; Amarjeet and Preet, preferred to join a separate focus group with each other. The other focus group was joined by the EPs and an interpreter. The discussions aimed to identify transformative and exclusionary elements using prior research findings that I brought to the discussion along with the lived experiences of the participants as developed in the individual reflective discussions (i.e., feeling isolated in tackling SEND-stigma and sharam). PowerPoint slides (**Appendix K**), which included practice policies, prior research findings, and the initial themes from the reflective conversations, were used as a prompt with EPs and an interpreter to develop transformative CRPs in response. The aim was to discuss how our research addresses the issues that matter to participants such as the barriers to support. In focus group discussions with parents, similar prompts were shared (initial themes, policies, prior research), as well as CRPs shared by EPs and an interpreter in their focus group discussion. This enabled me to review and improve the CRPs with parents. For example, EPs and an interpreter shared that they would like to provide community-level support, by organising events on SEND at schools. Parents liked the idea and shared that organising events in Gurudwaras would be more impactful in reaching individuals from all age groups. Participants were emailed a summary of recommendations in English (**Table 3.3**) and Panjabi, for final feedback and reflections. To meet the research timeframe, the focus group with EPs and interpreter was transcribed by a University of Southampton-approved transcription service in Step 4. The initial themes were finalised into subthemes, and main themes were created to capture overarching themes, aligned with RTA phase four and five. Three main themes (**Figure 3.3**) were developed: parents perceive a lack of empathy and support, parents want culturally responsive practices against power imbalances, and EPs seek but feel restricted to support parents from diverse cultural backgrounds effectively. These will be discussed in **section 3.3** below, aligned with RTA's phase six of reporting findings.

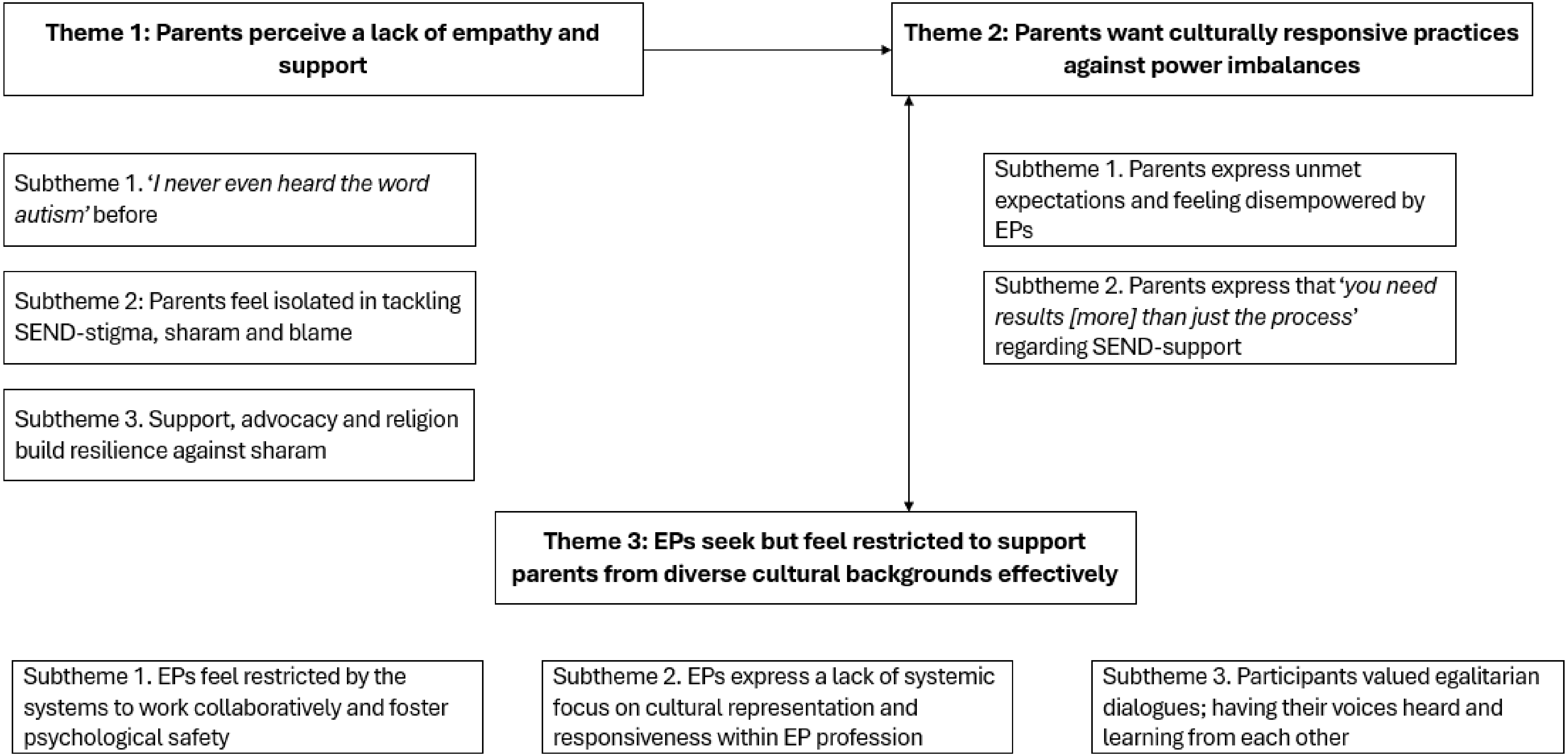

Figure 3.3 *Thematic Map*

3.3 Findings

The findings from the individual reflective conversations have been synthesised under themes 1 and 2, while communicative focus group discussions have been synthesised under theme 3.

Theme 1. Parents perceive a lack of empathy and support

Parents faced difficulties in understanding and accepting their child's diagnosis due to language barriers and limited perceived support. Sharam and stigma added additional pressures particularly on mothers. Advocacy, accessible resources, and religion played crucial roles in building family and parents' resilience against sharam and stigma.

Subtheme 1. 'I never even heard the word autism' before

Parents heard the term 'autism' for the first time from education and healthcare professionals regarding their children. Parents shared difficulties in understanding autism due to language barriers and lack of perceived support from professionals. It was particularly difficult for parents to understand SEND and autism due to their unfamiliarity with the words in English and unhelpful translations. Preet, who did not speak English, shared that language barriers were not met effectively when the autism diagnosis was shared with her. The interpretation was not in Preet's first language and autism was translated as a disability where children are picky and prefer to be by themselves. Preet felt that the description did not fit her son, who *'struggles to speak'*. Additionally, describing autism as a disability was found unhelpful and confusing: *'they [school] said that I can get disability allowance and I started to cry at home that he is walking perfectly well he is not disabled, and I said I am happy to work hard but don't want to receive money for disability…'*. She explained this dissonance by sharing that her son would not be categorised as disabled in India because *'disability is seen as not having an arm or leg. I am a nurse as well in India and that's how it would be and even in my qualifications, I never even heard the word 'autism'*. Lilita described her traumatic experience with healthcare professionals due to perceived absence of preparation and transparency:

> *…I've been coming to your appointments. I'm engaged…would it have harmed [to say that] …I'm really sorry, but today's appointment is…about the assessments we have done previously. There was no lead up. It was like we came in. We sat down…this is to tell you that your son has this…lifelong condition. He will be known as disabled for the rest of his life…I remember I started to cry and my son was wiping my tears…[the professionals] were basically like, OK, you can go now…* (Lilita)

Parents iterated the importance of empathy and transparency in diagnostic processes. One EP (Sargun) shared coming across similar experiences where some Panjabi parents weren't even aware their child had a diagnosis. All parents used the English term 'autistic' and opted for the phrase '*jadhe lod band bache' (Preet, Amarjeet, Lilita, and Simran)*, meaning children needing more support, to refer to their children. When asked about the support parents received right after the diagnosis, parents' accounts showed limited to no support received.

Subtheme 2: Parents feel isolated in tackling SEND-stigma and sharam and blame

Preet described that SEND-stigma existed within the Indian community where children with SEND are often referred to as '*kamla, pagal'* (crazy, mad) due to a lack of awareness and understanding. Parents shared how limited awareness of SEND subjected parents to sharam (shame) and judgment: people in the community assume that *'parents have not taught their child anything, they don't understand that the child might need extra help' (Amarjeet)*. Amarjeet shared that despite him advocating against sharam and stigma, his wife felt sharam and wanted to conceal Harman's diagnosis out of fear of *'what will other people say in our community, what will other people think'*. Simran and Lilita experienced additional pressures as mothers. Their spouses and in-laws blamed them for poor parenting, instead of believing in SEND: *'...I've got relatives over...I used to just give up and take him upstairs... [they] were like, look, she goes and takes him upstairs every time. She's...spoiling him'*. Lilita described the stigmatising language the relatives used, saying Lilita gave birth to a mute (gunga). Preet blamed herself for causing her son's autism: '*I used to cry so much...and I thought maybe [sadness] caused him to be like this'*. Consequently, all parents described their wider families concealing and/or denying SEND initially. Lilita's in-laws and husband living in England declined the concept of SEND saying, *'he doesn't look sick'* and suggested concealing autism from community and school. Simran described that even her mother-in-law, as an educated headteacher in India, declined autism. Such experiences made parents, particularly mothers, feel lonely and isolated in making sense of their children's diagnosis: *'...I was kind of left to figure it out'* (Lilita).

Subtheme 3. Support, advocacy and religion build resilience against sharam

Amarjeet described the nursery's support as invaluable in signposting helpful resources and explaining the diagnosis process prior: '*even today I appreciate (the nursery manager) ...she was an English lady, and she was so helpful'*. Conversely, Amarjeet shared that his wife took longer to accept autism due to the absence of accessible Panjabi resources. However, within-community advocacy for SEND and autism played a crucial role for Amarjeet's wife. A Panjabi mother with an autistic child encouraged Amarjeet and his wife to overcome sharam, advocate for their child and avoid repeating her regrets: *'...Our child got [SEND] support very late because I was stuck in the mentality 'lok ki kehn ghe' what will people say. Please do not repeat our mistakes'*. Amarjeet reflected that having an interpreter during doctors' appointments would have made his wife's journey much easier. Studying about autism helped Lilita to view autism as a superpower:

> *I told him [son] that he has a superpower and because he is autistic, he used to put the tea towel into the back of his top and run around thinking he was a superhero because…your brain and your hearing and your vision is so phenomenal…you can hear and see things that even Mommy can't…I sold it to him in that way because I never wanted him to think he was less special*

Lilita shared that it would have been helpful to have her husband and in-laws in doctors' appointments to support their understanding. Simran emphasised the importance of acceptance in the immediate environment: '*…there is support which just naturally comes and that's called acceptance*'. Advocacy and spending time with children helped wider families to gradually accept SEND (Lilita). Religion helped Amarjeet and his wife to cope with sharam by focusing on the Waheguru's (Eternal being's) blessings in the form of their child instead. Preet shared that life has become easier by '*finding sweetness in what the divine has given*'.

Theme 2. Parents want culturally responsive practices against power imbalances

Parents felt unheard and disempowered in EHCP processes due to the absence of professional interpreters, cultural considerations, and clarity on EP involvement and parental rights. Parents expressed concerns regarding SEND-support in mainstream schools and its impact on children's wellbeing.

Subtheme 1. Parents express unmet expectations and feeling disempowered by EPs

Parents appreciated EP involvement and viewed EPs as experts in supporting children with SEND. However, parents felt disempowered during EHCP meetings due to the absence of professional interpreters, cultural considerations, and support in understanding EP involvement and parental rights. For example, parents thought that only schools could apply for EHCPs and appeal EHCP decisions. Parents expected to have an opportunity to ask questions of EPs on *'…how best to support my son. Like what do I do when he has a meltdown? What do I do when he's feeling overwhelmed?'* (Lilita). Preet shared trying to understand EHCP processes and the EP role without informed consent:

> *A person who has no prior knowledge, it's very difficult (for parents) and that is why in schools…they just say sign here…without explaining…*a parent can start feeling like there is something wrong with them. I used to feel anxious about how to even ask questions when I haven't understood what has been sent to me

Preet felt powerless thinking that only professionals can support children with SEND: *'Don't feel like I would even be able to do anything differently. Relies so much on professionals'*. Amarjeet shared that his wife's participation was limited by the absence of professional interpreters. Lilita felt power imbalances during the EP meeting because the EP did not ask for parents' views nor create a safe space to explore cultural experiences and understandings:

> *she was a white lady so I don't know if she knew (sharam) because I don't think the culture was taken into account at all or the stereotypes (stigma)…or any kind of cultural difficulties…for her she came to do a job and she felt that she had fulfilled her job in her eyes, but obviously…we have to kind of piece everything together and I just think…there was no kind of support culturally for it and even a culture aside (no) compassion*

Amarjeet felt that he was not in equal partnership with EPs to plan SEND-support for his children because he did not feel informed about SEND provisions: '*…I was confused and sent my child to special(ist) school…the SENCo…explained…if he gets a place in a special(ist) school, he will get extra help, he can't have as much help in mainstream…'*. Amarjeet shared relying on school advice and wished to have known better about SEND provisions.

Subtheme 2. Parents express that '*you need results [more] than just the process*' regarding SEND-support

Amarjeet was the only parent of a child in a specialist school and was content with the SEND-support after the EHCP process. Other parents found SEND-support infrequent and inefficient in mainstream schools. Simran felt that: '*…(SEND) system is very slow…when you have kids (with SEND) …you need results [more] than just the process'*. Simran expressed infrequent specialist support in mainstream schools from speech and language therapists with *'eight weeks'* gap, adding: '*…kids who already struggle to understand if you have such a break in between, how you expect that kid will remember what you have told in the first intervention'*. Preet expressed concern about slow SEND-support. She was worried about her son missing out on learning while waiting for a specialist school allocation: *'…my worry is that while I am waiting, he is growing older'*.

Lilita shared Navdeep's traumatic experiences as an autistic child in a mainstream primary school without an EHCP. The council had decided he did not need an EHCP to do academically well in school. However, Lilita felt that the mainstream school did not consider Navdeep's needs and failed to tailor the learning content accordingly. For example, after learning about Egyptian mummies in class, Navdeep did not eat and sleep well for weeks, and he did not want to go back to school as he was scared that he was going to die. Navdeep was bullied after he had a cover teacher who was not informed about his needs and denied access to the toilet: '*…he ended up wetting himself because she didn't let him go in front of the whole class…she apologised but the damage was done'*. Per Lilita, the school did not intervene in bullying, and an *'older boy…threw punches at him (Navdeep)…and because my son is autistic, he didn't have the fight or flight instinct, so he stood there counting the* *punches…and that broke my heart'.* Lilita felt that teachers failed to ensure inclusive education for autistic children in mainstream schools, especially without an EHCP. She believed an EHCP would have helped the school to understand and prioritise Navdeep's needs, ensuring his psychological safety, and preventing traumatic experiences:

> *If he had an EHCP (and)…that person…he could go to for…support, instead the teachers passing on his needs and…that emotional social support…somebody…noticing that he's not happy…he wouldn't have had to go through all of this self-harm…He slashed the back of his hands…a 6-year-old autistic child shouldn't have to go through that just to get some attention and support*

Simran sought private SEND-support in England and India. She found the frequent support in India helpful but *'had to come back (to England) because while the therapy was working, the society was not'.* Amarjeet appreciated the support in England because there were no resources to learn about SEND in Indian villages.

Theme 3. EPs seek but feel restricted to support parents from diverse cultural backgrounds effectively.

EPs recognised the inequalities within the SEND processes and emphasised the need for collaboration with professional interpreters for culturally responsive practices (CRPs). However, EPs felt restricted, for example, by limited funding and increasing work demands. Participants called for systemic changes and discussed exclusionary and transformative practices in response, aligned with CCM.

Subtheme 1. EPs feel restricted by the systems to work collaboratively and foster psychological safety

Karan, a Panjabi interpreter, shared that parents '*are… stressed*' in EP meetings. Beth reflected on power imbalances and how her being a white-British native-English speaker with a doctor and psychologist title can contribute to parents feeling unsafe during EP meetings *'especially when cultural stigmas'* may prevent parents from sharing their experiences. Beth recognised that the understanding of SEND-systems was '*difficult enough for our English-speaking parents let alone our families that are non-English-speaking'*. In the absence of adequate support, Beth felt that parents experience a '*double disadvantage'* during EHCP processes due to language and socioeconomic barriers impacting their advocacy: while affluent English-speakers can advocate for their children's one-to-one support and funding for provisions, Indian-Panjabi Sikh parents may not even feel *'empowered to ask questions*'. Chardi-Kala reflected on disadvantages within SEND-systems: *'[parents] might be facing discrimination due to the colour of their skin, then language, and to overcome all that, a lot of work needs to be done with a very skilled approach'*.

Consequently, EPs wanted to work collaboratively with professional interpreters to foster psychological safety and to provide community-level support against sharam. For instance, Beth shared that she would like to be more *'available'* enabling families to get *'familiar with our faces maybe just having those meet and greet meetings and…running…workshops'*. Nevertheless, EPs felt restricted from supporting children and families from diverse cultural backgrounds effectively due to increasing job demands and limited resources allocated for CRPs. Chardi-Kala reflected on his 40 years of experience as an Indian-Panjabi EP; he used to support local communities more effectively unlike now with a constant '*pressure to reduce [EP] services'*. Eknoor referred to the lack of school funding and its impact on EP practice:

> [interpretation] company is mostly used for statutory [EHCP] work where it is [EP service] responsibility [to pay] …whereas for our [non-statutory] schoolwork…the responsibility is with schools and that's when you have unofficial interpreters…[schools] got no funding to pay for the interpreting company

Consequently, Eknoor, an Indian-Panjabi EP, reflected on feeling uncomfortable in having school staff or younger siblings interpreting for parents, and schools relying on acronyms without explaining them:

> you're trying to get school to explain and it's quite hard because you don't want to be…constantly saying OK explain that…but it's for the parent because you wanna do with them…and often with these parents it's done to them by schools and…EP service

Beth shared that ideally, EPs would work collaboratively with professional interpreters and have *'time to have multiple EP meetings…at various points throughout the year'* to build trusting relationships with parents.

Subtheme 2. EPs express a lack of systemic focus on cultural representation and responsiveness within the EP profession

EPs reflected on the varying levels of cultural responsiveness within the EP profession and felt that the EP services failed to prioritise CRPs. Chardi-Kala shared that he continues to find pupils from minority ethnic backgrounds misplaced in specialist provisions due to education professionals mistaking identifying SEND when instead pupils are simply learning English as an additional language. Eknoor shared that she did not receive training working with interpreters and instead relied on her childhood experiences translating for her parents. Eknoor reflected that while she was able to benefit from her personal experiences…

> there are some EPs who don't know the impact of sharam and stigma and how to work with interpreters as they never had any input on that…so I think if you were to interview a different EP, you'd get a different response

Consequently, EPs felt that CRPs including working with interpreters…

> should be an important part of the doctoral training but equally there should be a service responsibility because there is BPS guidance on working with interpreters, but you only know it if you look at it, and it should be services' priority to be aware of it and apply it (Eknoor)

Indian-Panjabi EPs felt that EP services overlooked the experiences of EPs from ethnic minority backgrounds. Chardi-Kala shared that as an older EP who is '*dark skinned, haven't cut my hair or beard, parents [from all ethnic backgrounds] often end up making judgements on my competence based on my appearance, can I speak English or not, what I am capable or not capable of doing*'. Eknoor expressed a lack of recognition and support for EPs who end up translating EP meetings due to limited funding for professional interpreters:

> …Your supervisors are in a position where they can understand or have no experience… it is important [to have] space after to reflect in terms of your position as the EP and…remove the two hats there as the EP supporting the child but also advocating for the parent and interpreting…

Consequently, EPs emphasised the importance of promoting CRPs across all levels of EP work and diversifying the education profession (Chardi-Kala).

Subtheme 3. Participants valued egalitarian dialogues; having their voices heard and learning from each other

All participants found egalitarian dialogues helpful and expressed gratitude for having their experiences heard. Karan shared that: '*it…is the first time someone has asked and listened to about my experiences*'. He continued to share that interpreters lack SEND-specific training, leading to difficulties in understanding EHCP processes and acronyms used in EP meetings. Karan emphasised the need to specify Panjabi dialects when requesting interpretation services. This enabled Beth as a non-Panjabi speaker to develop her practice as part of the transformative elements of egalitarian dialogues:

> Karan: the [dialects] must be specified right at the beginning, are the speakers [Indian] Panjabi…speakers [using Gurmukhi script]…or Mirpuri…
> Beth: it's just made me reflect…when I'm writing the language the family speaks in my reports…it's not enough to say just Panjabi and I need to be quite specific around a dialect that is spoken.

The egalitarian dialogues enabled parents to ask questions and learn from each other. The primary author shared academic knowledge to prompt reflections, and encouraged the parent to visit specialist schools to learn more about them:

> *Jagat (primary author): it has been found that parents from minority heritage can have hesitations towards specialist schools. Could you share your insights on this.*
> *Amarjeet: Yeah it can depend on parent to parent, some parents might not know what specialist schools are.*
> *Preet: yeah I want my son to go to a specialist school because the SENCo said it will help him, but I don't know more about it. I want to actually ask whether your child gets any work to do in specialist school?*
> [Amarjeet shared more about specialist schools]
> *Jagat:…I wonder if you could arrange a visit with a specialist school, maybe your son's current school could help with this?*
> *Preet: I do not know yet which school my son will get, I didn't know that I can go and see any. I will ask the school if they can help if they are not too busy.*
> *Jagat: You definitely can. Sometimes school staff can accompany you as well to see a setting which can be very helpful for parents.*
> *Preet: I will ask this next time*

3.4 Discussion

The present study makes a unique contribution to the research field by exploring Indian-Panjabi Sikh parents' experiences with SEND-support in England. Contrary to the stereotypes that South-Asian parents have sufficient familial support (Gupta & Pillai, 2005), the current study found that parents lack support from professionals, community, family, and spouses in navigating SEND-systems. The findings suggest that parents feel unheard and disempowered in EHCP processes due to the absence of professional interpreters, cultural considerations, informed consent, and clear information on EP involvement and parental rights. These findings replicated Rehal's (1989) over 30-year-old findings with Panjabi parents. In this study, SEND-support in mainstream schools was perceived as inefficient leading to concerns about children's wellbeing. Contrary to the Government's race and ethnic disparities (RED, 2021) report, findings suggest that inequalities within SEND-systems exist, and these cannot be reduced to socioeconomic differences. These are perpetuated when education professionals do not feel supported by the systems to meet the needs of parents from ethnic minorities. All findings will be discussed through belongingness (Baumeister & Leary, 1995) and shame resilience theory (SRT; Brown, 2008) to help education professionals, including EPs, develop CRPs. Policy-level changes will be discussed to improve SEND-systems for all children and families.

3.4.1 Parents perceive a lack of empathy and support

Parents described disheartening and traumatic experiences when healthcare professionals disclosed autism diagnoses. These experiences are not unique to parents from minority heritage. Crane et al. (2015) surveyed 1000 predominantly white-British parents and found over half were dissatisfied with diagnostic processes due to the healthcare professionals' manners and limited information and support provided throughout the process. However, these experiences manifest in culturally specific ways for specific communities. For Indian-Panjabi Sikh parents, healthcare professionals' support influenced their vulnerability to sharam and SEND-stigma. The impact of sharam in parents' lives was exacerbated by a lack of transparency in diagnostic processes, unmet language needs, and an absence of cultural responsiveness, empathy, and support from professionals. These findings suggest that Indian-Panjabi Sikh parents face additional barriers to accepting SEND and autism when early support is inaccessible, inadequate, or lacks empathy. Brown (2008) identified empathetic social connections as the most important factor in building resilience against shame. Empathy fosters a sense of belongingness and understanding needed to overcome shame (Baumeister & Leary, 1995). As a result, all parents were subjected to sharam; judgement for failing to uphold cultural expectations and values to excel as parents (Sangara & Howe, 2021). Simran and Lilita reported facing additional pressures from their in-laws and spouses, who blamed them for causing their children's delayed development. Blaming mothers may stem from traditional norms where mothers and daughters-in-law are expected to be primary caregivers for elders and children (Gupta & Pillai, 2005). Consequently, all parents or their spouses initially declined and/or concealed SEND. Concealing and declining SEND and isolating from the community may shield families from sharam and stigma. However, concealing SEND inevitably means the community's exposure to SEND is minimal, and, thus, knowledge and acceptance of people with SEND is less likely to be advocated. Limited opportunities to learn about SEND within the curriculum in England, may further limit SEND advocacy, decrease empathy, and perpetuate sharam among the British Indian-Panjabi community. Experiences of stigma and sharam linked with autism are not unique to Indian-Panjabi Sikh parents. British East-African parents also report shame and stigma around autism (Oumar, 2022). However, having specific vocabulary in Panjabi to address sharam may enable Indian-Panjabi parents to discuss it more easily compared to cultures where such terminologies are not as readily available.

Interestingly, parents' resilience against sharam varied. Per SRT, feeling trapped, powerless and isolated perpetuates shame, while empathy including freedom, power and social connection builds resilience. In the absence of empathy, access to information and alternative views on SEND helped parents feel empowered within their defined social role and fostered freedom from unrealistic expectations. Conversely, the absence of all protective factors against sharam increased vulnerability to internalising sharam as seen with Preet, who believed in causing her son's autism. Preet was the only parent who did not speak English and described unmet language needs when healthcare professionals did not provide interpreters in Panjabi. Moreover, professionals describing autism as a disability was unhelpful and stressful. This was because disability was understood as a physical limitation**.** These findings align with previous research indicating a shared cultural understanding of disability and stigma within South-Asian communities, where individuals with 'differing' behaviors often get labeled as "pagal" (crazy; Akbar & Woods, 2020). The conflict between Preet's understanding of her son's abilities and cultural understanding of disability and SEND can explain why Preet initially disbelieved and declined SEND. The findings suggest that disbelieving SEND may become a coping strategy to alleviate discomfort from conflicting views and beliefs. Preet's vulnerability to sharam was intensified by decreased empathetic social connections and support from professionals, family, and spouse while living in a new country. This meant that Preet's ability to share and learn about SEND in a meaningful way was limited which left Preet with stigmatised understanding of SEND. These findings show how unmet language needs create additional disadvantages for Indian-Panjabi Sikh parents of children with SEND.

Further, the findings suggest that mothers may experience additional pressures which may increase their vulnerability to sharam. The pressure to conform to traditional roles has been found to intensify feelings of stress and isolation among South-Asian mothers (Karasz et al., 2016). However, the current study is limited in exploring gender differences, thus, generalisations should be avoided. Instead, education professionals should seek to build trusting, non-judgmental, and empathetic relationships that foster safety for parents to share their experiences. Per SRT, Simran and Lilita were able to advocate against sharam, despite facing additional pressures from their in-laws and spouses because they were able to access resources on autism in English which enabled them to understand autism better and view it as a superpower. Preet's access to resources was hindered by language barriers, however, religion and connecting with other parents, helped her to accept SEND. All parents found religion and within-community advocacy helpful in building resilience against sharam. Religion may help parents reconnect with their community and culture, fostering a sense of belongingness (Baumeister & Leary, 1995) through empathetic and accepting social connections in their environments. Interestingly, the absence of direct translations for autism and perceiving the 'disability' term as a deficit-based term led parents to use the English word 'autistic' or describe their children in Panjabi as '*children needing more support*'. This is consistent with Oumar's (2022) findings, and highlights how language shapes understanding, and introducing direct translations of 'autism' or 'SEND' alone does not necessarily aid understanding. Instead, parents constructed culturally meaningful, non-deficit-based descriptions that align with their values and understanding. These findings reflect broader linguistic barriers, where professionals' language can become inaccessible or esoteric. Therefore, professionals should carefully consider using helpful and meaningful language that is culturally responsive to foster trust, understanding, and acceptance. To achieve this, labels should be explained and the emphasis should be on exploring with parents their understanding of their children's needs, and preferred language to be used in meetings.

3.4.2 Parents want culturally responsive practices against power imbalances

Contrary to Akbar and Wood's findings (2020), where South-Asian parents viewed EPs with hesitation, all parents in this study welcomed EP involvement. This may be because parents had already accepted their children's diagnosis and wanted to learn with EPs how to support their children. Limited perceived early support may further mean that parents wanted EP involvement to feel empowered. Per SRT, learning strategies to support autistic children at home can foster power and freedom over sharam (Brown, 2008). Congruently with Akbar and Woods (2020), parents wanted CRPs that include using professional interpreters and providing space for parents to share cultural experiences if they wished. Parents may perceive bilingual school staff as biased towards the school. Previous inadequate interpretation experiences might further explain their preference for professional interpreters.

The SEND Code of Practice (DfE, 2015) mandates that parents must be fully involved in decisions involving their children. However, this study replicated 35-year-old findings (Rehal, 1989), where Panjabi parents were unaware of their statutory rights and their children's statements. In the current study, parents felt powerless with EPs due to the omission of their voices, unmet language needs, lack of informed consent and perceived cultural consideration, and support in understanding EP role, EHCP processes, and parents' rights. For example, Preet was unaware of specialist schools' curricula despite her son awaiting allocation. These experiences contributed to Preet's loss of agency and lower self-efficacy in finding strategies to help her son at home. The findings align with Rehal (1989), where Panjabi parents thought that no learning takes place in specialist provisions. EPs must recognise that their involvement may be the first opportunity for parents to share their experiences and ask questions to enhance self-efficacy and build resilience against sharam. Misunderstandings about specialist provisions, such as equating 'special' with segregation, can increase stigma within the community as found among Pakistani parents (Rizvi, 2017). The current findings show Indian-Panjabi parents perceive a lack of support in understanding EHCP processes and their respective rights. This may contribute to Indian autistic pupils being less likely to receive EHCPs in England than their white-British counterparts (Stagg et al., 2023). The findings suggest a clear gap between SEND-legislations and professionals' practice.

Moreover, parents across the country found SEND-support in mainstream schools inadequate. Parents' accounts showed disadvantages linked to lower socioeconomic status, particularly for families from rural areas of India who are less likely to be aware of or have access to private SEND services. These findings are not unique to parents from minority heritages but reflect the national picture. 82% of mainstream schools have been found to lack sufficient funding and resources for adequate support for children with SEND and 89% of school leaders reported that a reduction in LA services including EP services, negatively impacted mainstream provisions (The Key 2016). Hasson et al. (2022) explored inclusivity in mainstream educational settings for autistic children. Parents and staff shared that schools struggled to meet the needs of autistic children due to funding and resource issues where teachers recognised their lack of expertise due to the absence of adequate training on SEND and autism. Additionally, parents who predominantly identified as white-British (Hasson et al., 2022) expressed the need to be in a constant fight to ensure SEND-support for their children. While these experiences are not unique to Indian-Panjabi parents, 'fighting for support' is inevitably harder for parents who do not speak English. Therefore, contrary to the RED report (2021), inequalities within SEND-systems cannot be reduced to socioeconomic differences alone. Instead, professionals and policymakers should consider the intersecting factors that create disadvantages for children and parents, perpetuating inequalities within SEND-systems.

3.4.3 EPs seek but feel restricted to support parents from diverse cultural backgrounds effectively

Inequalities within SEND-systems are perpetuated by the lack of legislation protecting and supporting education professionals' CRPs. For example, parents shared that EPs were unaware of SEND-stigma and sharam and lacked cultural responsiveness and empathy in response. This was reflected by EPs in the study who were employed by LAs, meaning their service priorities were influenced by the Government. EPs recognised the impact of unmet language needs and wanted to collaborate with professional interpreters to enhance psychological safety and build the community's resilience against sharam. However, EPs felt limited by increasing job demands and insufficient resources for CRPs. It is important to note that, unlike parents' experiences, EPs in the study were aware of SEND-stigma. EPs shared that this was because of their extensive experience of supporting Indian-Panjabi parents (Beth) and sharing the same culture (Chardi-Kala, Eknoor, Sargun). Consequently, EPs underlined that this cannot be generalised to all EPs meaning not everyone within their respective services would be aware of stigma, sharam, and the important dynamics to consider when working with interpreters. For example, Eknoor shared that she had to use her personal experiences to work with interpreters, as this was overlooked by her doctorate training and EP service. It may be that parents worked with EPs who did not feel supported by their EP services and doctorate training to advocate for parents from different cultural backgrounds and thus, failed to create a space for parents' unique experiences. The question arises: should all EPs feel supported and skilled to advocate for all children and families they encounter, including those who do not speak English? Per the registrating authority for EP practice, all EPs must adapt their practice to meet the needs of individuals across diverse backgrounds by developing their cultural competence (HCPC, 2023). Another critical question is: what is the impact of education professionals' cultural awareness, competence, humility, and CRPs to continue being overlooked?

EPs reflected on the consequences of education professionals lacking cultural responsiveness. Chardi-Kala shared that education professionals continue to misplace children in specialist provisions, particularly when those children do not speak English. The findings suggest that children from minority ethnic and linguistic backgrounds are at risk of receiving inadequate support when EPs and teachers lack cultural responsiveness. Similarly, teachers and SENCos have reported difficulties in understanding why South-Asian parents may decline specialist provisions (Kwan-Tat, 2018). Additionally, a SENCo shared that her school staff perceived South-Asian parents as unworthy of professionals' time because they never attended meetings (Kwan-Tat, 2018). The current findings show that parents want to attend meetings but face difficulties when efforts are not made to meet parents' language needs.

3.4.4 Implications for policy and practice

These findings highlight the need for ongoing training on CRPs for professionals to tackle discriminatory practices within SEND-systems and protect the rights of parents and children. It is crucial that all EPs feel competent and supported by their services to work with individuals from diverse backgrounds, particularly given the underrepresentation of Asian ethnicity within the EP workforce (AEP, 2021). EPs should engage in understanding and researching shame to develop CRPs in response. They can support parents build resilience against sharam and enhance their SEND understanding. The findings emphasise the importance of supporting a non-deficit-based understanding of SEND and adopting an empathetic and non-judgmental approach. To foster SEND-advocacy and tackle parents' isolation, EPs and schools can connect parents of children with SEND who share the same language and religion. EP services could also host events to raise SEND-awareness and introduce EP's role and involvement within wider communities. Wider literature underscores the importance of trust in positive experiences with interpreters **(**Edwards et al., 2005**).** According to the BPS guidelines (2017), professionals should not ask family members or other professionals to translate because interpreting is a highly skilled role and not something anyone can do. Instead, it is the service provider's responsibility to try to arrange a professional interpreter for the family. Interpreters should be fluent in two languages, understand cultural contexts, and ideally have relevant training and experience. The guideline (2017) specifies that if bilingual staff members are involved, their language competency should be assessed and verified prior, and they should have access to ongoing professional development.

The guideline also discusses the use of family members as interpreters. The choice ultimately lies with families, whether they prefer a professional interpreter or a family member. However, EPs should inform parents of their rights to accessible EP services and the option of having a professional interpreter, enabling them to make an informed decision. The use of family members as interpreters is justifiable when they are adults who understand the emotional and confidentiality demands of the role, and when EPs are aware of the associated advantages and limitations. For example, family members may be unclear about confidentiality and could unintentionally alter meanings during interpretation (Searight et al., 2013). On the other hand, they may also empower parents and foster a sense of safety during meetings. While the BPS (2017) has released these helpful guidelines, schools often lack resources and awareness of quality assurance procedures for interpreters. Similarly, EPs may lack the resources and awareness to implement the BPS guidelines (2017) within their practice. It is important to note that the BPS guideline (2017) is advisory, not mandatory. However, in line with the United Nations Convention on Children's Rights (1902), its implementation should be a service-level priority, not only dependent on individual EP's available resources. To achieve this, policy-level changes are needed to move from advisory to mandatory to ensure the needed resources for schools and EP services.

Since the previous Government's RED report claiming that systemic discrimination does not exist in England (2021), the SEND improvement plan (DfE, 2023b) has acknowledged the complexity of EHCP processes for all parents. However, it has been criticised for overlooking the disparities faced by minority ethnic families (SNJ, 2022). Current legislation is yet to ensure that the rights of parents from ethnic minorities do not get overlooked by education professionals and LAs in England. In the context of diversifying population and rising violence against refugees and immigrants in England (Human Rights Watch, 2024), it is pertinent that the new Government acknowledges systemic disadvantages and supports professionals' CRPs accordingly. Increasing funding to reform SEND-systems and improving legislation to bridge the gap between policy and EP practice should be at the forefront of discussions. Recommendations co-developed with participants following the CCM are outlined in **Table 3.3** and could be applied alongside guidance on working with interpreters (BPS, 2017) and Sakata's (2021) CRPs framework for EPs.

Table 3.3 *Implications for Policy and Practice*

Relevant people	Implications
School staff	• Training in culturally responsive practices that help understand the diverse needs of their pupils and families by creating welcoming and supportive environments e.g., by offering professional interpreters and encouraging parents to bring their spouses and families to meetings wherever found helpful • Training in understanding SEND and EAL, and how to consider this when supporting pupils • Liaising with community centres to support parents' understanding for SEND-systems and to advertise job openings to support diversity within the workforce • Signposting parents to relevant resources and services (e.g., SENDIASS) • Connecting parents of children with SEND sharing the same language and culture e.g., by hosting workshops and events
Healthcare professionals	• Transparent and empathetic approach throughout the work with parents while ensuring to meet the language needs effectively • Exploring and supporting parents' understanding of SEND • Pre-appointment preparation to ensure parents are fully informed about the nature of upcoming appointments, giving them time to prepare accordingly • Signposting parents to relevant and accessible post-diagnosis support and resources
EPs and EP services	• Providing training and supervision to schools to support their CRP • Liaising with professional interpreters to ensure accessible EP involvement • Ongoing supervision and training opportunities for EPs to develop their CRPs.

	• Receiving training and providing training on intersectionality; factors that create privilege and discrimination • Contributing to qualitative research with parents from ethnic minority backgrounds on SEND-systems and working with EPs • Developing robust interpretation booking processes for EPs. This could include defining the language and dialect used by the parents and a brief description of EP involvement. Sharing this prior would allow preparation time for interpreters. This should be followed by an appropriate pre-meeting and debrief with interpreters. • Holistic family support: EPs should involve the entire family in understanding and supporting the child's SEND wherever parents find this helpful • Incorporating trauma-informed practices wherever appropriate when working with parents. • Quality assuring the interpretation services
Local Authority	• Collecting relevant quantitative and qualitative data on parents' accessing SEND-support e.g., SENDIASS services when navigating EHCP processes • Liaising with schools to understand the demographics they are serving and ensuring equitable access to interpretation services such as Ethnic Minority Achievement Services (EMAS) • Liaising with community centres to reach out to local communities to raise awareness on available SEN- support, and services. For example, hosting SEND awareness events with local communities. • Establishing support networks for parents of SEND children, providing them with a platform to share experiences and access resources • Ensuring that all information about SEND-support and services is accessible in multiple languages and formats to cater to the diverse needs of the community. For this joint work between EP services across the country is recommended. • Engaging with local community leaders and religious figures to disseminate information about SEND and promote acceptance within the community

Universities	• Ensuring input on disproportionality within SEND-systems and training on collaboration with interpreters. • Ongoing training on culturally responsive practices. For example, inviting parents from different communities to share about their experiences within SEND-systems.
Wider UK policymakers	• Prioritising funding for the education department and LA to support their communities more effectively. This could help, for example, EP services to provide community-level support, as well as, providing training to professionals on CRPs. • All teacher training to include relevant SEND policies and strategies on how to support children with SEND. Additionally, training should include parents' rights in SEND processes and provide opportunities to develop CRPs. • Supporting the diversification of the education workforce through liaising with the community • Funding for qualitative and quantitative research to privilege the voices of unheard parents from minority backgrounds, to learn from parents' expertise and lived experiences. This could help to build equitable and just systems across the country • Improving the national SEND-policies to acknowledge, address, and protect from disadvantages faced by parents from minority backgrounds • Policies to foster interpreters' understanding of the SEND-system when they work within education systems.

3.4.5 Strengths, Limitations and Future Research

This study has notable strengths and limitations. As the first research to focus on Indian-Panjabi Sikh parents' experiences with SEND-systems in England, it makes a pioneering contribution to an under-researched area. The use of CCM privileged previously unheard voices by triangulating parents', interpreter's and EPs' experiences and expertise. The egalitarian dialogues of CCM allowed participants to be recognised as experts in their own experiences, which had transformative effects on their immediate understanding and enhanced the credibility and power of the recommendations. Additionally, online data-collection was not seen as a limitation, rather, a strength that enabled greater participation. Online data-collection enables participants to withdraw with greater ease (Janghorban et al., 2014), reducing power imbalances and fostering psychological safety with researchers. Unlike previous studies (Rehal, 1989) participants were recruited across the country which means the findings are not limited to one LA. The primary researcher's fluency in both English and Indian-Panjabi further aided in building rapport with participants. The study's limitations lie in short recruitment time which limited the study to include only one interpreter, father, and non-English speaking parent amongst the wider group. Future research should aim to include a broader range of interpreters to identify potential training needs and involve more parents who are not fluent in English, as they face additional barriers in navigating SEND-systems. The research was also limited in its ability to compare different SENDs, as all parents had autistic children. Future research could explore potential differences in understanding varying SENDs. Another limitation comes from the adaptation of CCM to fit within the research timeline. Future research could focus on developing an auditing tool in collaboration with participants to support education professionals' CRPs. Lastly, research should be conducted with Indian-Panjabi Sikh children with SEND to address the existing gap in the literature, and further improve SEND-support.

3.5 Conclusion

This study highlights that Indian-Panjabi Sikh parents face barriers in navigating SEND-systems in England, including a lack of professional, familial, and community support. The absence of interpreters, cultural considerations, informed consent, and clear information on EP involvement and parental rights contributes to disempowerment and vulnerability to SEND-stigma and sharam (shame). Educational psychologists feel restricted by services and lack Government funding to support ethnic minority parents and children effectively. The findings reveal persistent inequalities in SEND-systems beyond socioeconomic factors. These findings call for policy-level changes that prioritise education professionals' culturally responsive practices for equitable SEND-systems and support.

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Appendix A Ethics Application Form

Request for Amendment to Ethics Application

ERGO ID #: 80907 version 4

Title of study: The Experiences of South-Asian Parents with Children with SEND during the EHCP process

I would like to request the following amendment(s) to the above named study. I have amended the relevant documents and these changes are **highlighted in yellow on all of the amended documents, including a new version number and date.**

A summary of the changes I have made in each of the documents is detailed below.

I confirm that no other changes have been made.

Table of Changes

Document name and section	Change from	Changed to (Please include a reason and justification for the change. Please also highlight any ethical implications of the change).
80907_4. Ethics Application Form Section: 5.1	Only the research team (myself, my supervisors and the voluntary research assistant) will have full access to the collected data. To ensure the accuracy of Punjabi-English translations, we will involve an external person, Jyotsna Kaur (a friend of mine), who is proficient in both languages. Jyotsna Kaur will review a brief excerpt from one of the three translated transcripts and its corresponding audio interview recording shared via Teams. The research team will ensure that no identifiable information is disclosed in	Only the research team (myself, my supervisors and the voluntary research assistant) will have full access to the collected data. A reputable transcription service, approved and recommended by the University of Southampton, will be used to transcribe the focus group discussions. The focus group discussions do not contain identifiable data such as participants' names in the audio recording; instead, pseudonyms were used. A secure audio file transfer method will be used to send the audio recording to the transcription service. The service follows University guidelines of data protection where the audio file and the transcript will be deleted by the transcription service upon sending the transcript to me. To ensure the accuracy of Punjabi-English translations, we will involve an external person, Jyotsna Kaur (a friend of mine), who is proficient in both languages. Jyotsna Kaur will review a brief excerpt from one of the three translated transcripts and its corresponding audio interview recording shared via Teams. The research team will ensure that no identifiable information is disclosed in the shared data. Jyotsna Kaur will be advised about confidentiality. *The change has been made to take into account the remaining time available for the research, as having a University-approved transcription service can enhance efficiency.*

	the shared data. Jyotsna Kaur will be advised about confidentiality.	

ERGO II Ethics application form – Psychology Committee

1. Applicant Details

1.1 Applicant name	Sukhjagat Brar
1.2 Supervisor	Dr. Tim Cooke Dr. Vasilis Strogilos
1.3 Other researchers / collaborators (if applicable): *Name, address, email*	Volunteer Research Assistant Evie Parsons ep12g21@soton.ac.uk

2. Study Details

2.1 Title of study	The Experiences of South-Asian Parents with Children with SEND during the EHCP process
2.2 Type of project (e.g. undergraduate, Masters, Doctorate, staff)	Doctorate

2.3 Briefly describe the rationale for carrying out this project and its specific aims and objectives.

The United Nations Rights of the Child (UN, 1992) highlights the rights of all children regardless of ethnicity, gender, religion, language or abilities. However, people with special educational needs and disabilities (SEND) from culturally diverse communities are still the "least often heard and most often excluded" (Department for Health, 2009, p.14). Research suggests that children of minority heritage with SEND can experience social injustice created by the 'double disadvantage' in accessing support and opportunities due to their minority ethnic status and educational needs (Fazil et al. 2002; Singh & Orimalade 2009).

While the SEND Code of Practice encourages greater participation of parents from all backgrounds and emphasises that "local authorities must ensure that children, young people and parents are provided with the information, advice and support necessary to enable them to participate in discussions and decisions about their support" (DfE & DoH, 2015, p.21), there is lack of accessible support for parents from ethnic heritages (Mencap, 2009). The education and health care plan (EHCP) process in England to support children with SEND is found to be long and complex for all families, and especially confusing for parents from ethnically diverse cultures (Bentley, 2017).

Despite previous research finding language to be one of the biggest barriers in effective partnership with professionals among South-Asian parents in educational settings (Akbar & Woods, 2019), to the author's knowledge, no previous research has included the voice of professionals, such as interpreters or educational psychologists. Including interpreters and educational psychologists in research is crucial to enable professionals to reflect on their practice and how it can be tailored to support the needs of South-Asian parents and culturally and linguistically diverse communities in general. This can empower parents to become equal partners in promoting and protecting the rights of their children in accordance with the Article 5 of UNCRC (United Nations, 1992).

Therefore, the current study aims to seek, facilitate and help express the experiences of parents from a South-Asian heritage during the EHCP process. Further, educational psychologists and interpreters will be included in the study to reflect on their practice and consider along with parents, what a helpful practice for South-Asian parents would look like. The study findings will contribute to tackling a wider social injustice experienced by parents from minority heritages in England

2.4 Provide a brief outline of the basic study design. Outline what approach is being used and why.

This research is a qualitative study using Critical Communicative Methodology (CCM) design (Puigvert & Holford, 2012). The CCM uses an egalitarian dialogue between the researcher and participants to form an understanding of participants' social reality and collaboratively create ways to transform it. The CCM methodology holds the researchers accountable for sharing academic knowledge with participants so that the participants can integrate academic knowledge with their experiences and use it appropriately to create helpful solutions and a new understanding (Gómez et al., 2011).

Aligned with this, the researcher in the current study will use interviews and communicative focus groups with parents from ethnic minority heritages who have children with SEND and professionals; educational psychologists and interpreters, to share and reflect on the research evidence, (such as Akbar & Woods, 2019). These focus groups will consider in particular what has been shared by the participants and by the previous research to be helpful and unhelpful support to understand further how to ensure the parents of children with SEND from an ethnic minority, are better informed, heard, included and supported during the Education and Health Care Plan(EHCP) process .

The CCM is considered as an appropriate study design as it will help to explore the impact of the co-existing identifies during the EHCP process. The methodology will also aid collaborative solution-focused thinking during the focus-group stage between the researcher and participants. This methodology allows the participants to benefit from the research as much as the researcher benefits from gathering the research data. The CCM focus-groups will also contribute to educational psychologists' and interpreters' continuous professional development by creating an opportunity to reflect on the service delivery and how it could be improved further.

The strengths of the CCM approach come from its strong social justice and collaborative nature; it does not privilege the researchers' knowledge but interprets and applies this in the context of the participants' experience. In this way, it helps to identify alternatives that can improve the social situations and overcome the social problems studied for the participants (Puigvert, & Holford, 2012).

2.5 What are the key research question(s)? Specify hypotheses if applicable.

The study aims to address three research questions:
RQ1: How do parents of South-Asian heritage understand and experience the EHCP process and the strengths and needs of their child?

RQ2: What are the barriers and enablers to a collaborative EHCP process experienced by parents of South-Asian heritage?

RQ3: How can educational psychologists and interpreters work in a linguistically and culturally competent manner with parents of South-Asian community during the EHCP process?

3. Sample and setting

3.1 Who are the proposed participants and where are they from (e.g. fellow students, club members)? List inclusion / exclusion criteria if applicable.

The proposed participants are parents from South-Asian heritage who speak Hindi, Urdu or Punjabi and have children who are currently experiencing the EHCP assessment process. In order to achieve a broader understanding of the enablers and barriers during the EHCP process faced by the parents from South-Asian heritage, educational psychologists and interpreters will be recruited as well. All the participants: interpreters, educational psychologists and parents will be interviewed. The participants must have a recent experience of an EHCP (within the last two years) with interpreters and families of South-Asian heritage. The research will use a combination of online and in-person meetings. The in-person meetings will be held in participants' cities for instance, such as, but not limited to their children's schools or in the local authority's meeting rooms. Meeting places will be chosen and identified in advance as allowing ready access and as being neutral venues in which participants can contribute fully.

3.2. How will the participants be identified and approached? Provide an indication of your sample size. If participants are under the responsibility of others (e.g., parents/carers, teachers) state if you have permission or how you will obtain permission from the third party).

The parents will be contacted via the local SEN process and translation services using purposive sampling. Educational psychologists and interpreters will be invited to take part through a combination of invitations on EPNET (a message sharing platform based in the UK for information share and advice seeking for educational psychologists); Twitter (in particular using relevant hashtags such as #twittereps #special #educational #need); personal invitations through contacts known to the researcher.

Parents will also be contacted by sharing fliers in the community gathering spaces such as Gurudwaras. Snowballing sampling will be used to support the recruitment of parents further.
The study will aim to obtain a minimum sample size of 9: 3 groups of 3 people, reflecting on their experiences of the EHCP process (kindly see the specifications in section 4.1). This is aligned with

the sample size used in the previous studies within the similar research area aiming to understand the experiences of parents from ethnic minority cultures (Akbar & Woods, 2019; Heer et al., 2015; Oumar et al., 2022).

3.3 Describe the relationship between researcher and sample. Describe any relationship e.g., teacher, friend, boss, clinician, etc.

The participants won't be recruited using personal networks, thus, no relationship between the researcher and sample is expected. However, if the participants happen to be from the local authority the researcher works in, the researcher will disclose this to the participants with clarity and remind that the interviews will be confidential, and no specific actions will be taken as a result of interviews (safeguarding being an exception). Further, the researcher will remind that the participants can withdraw from the study if they wish so.

All the interviews will be recorded ensuring the same research procedure for everyone to minimise the researcher and participant bias in a situation where the researcher and participants are familiar with each other. Further the interviews will be transcribed and cross-checked with the volunteer research assistant. The data-analysis will be checked by the whole research team to minimise the bias further.

3.4 How will you obtain the consent of participants? (*please upload a copy of the consent form if obtaining written consent***) NB A separate consent form is not needed for online surveys where consent can be indicated by ticking/checking a consent box (normally at the end of the PIS). Other online study designs may still require a consent form or alternative procedure (for example, recorded verbal consent for online interviews).**

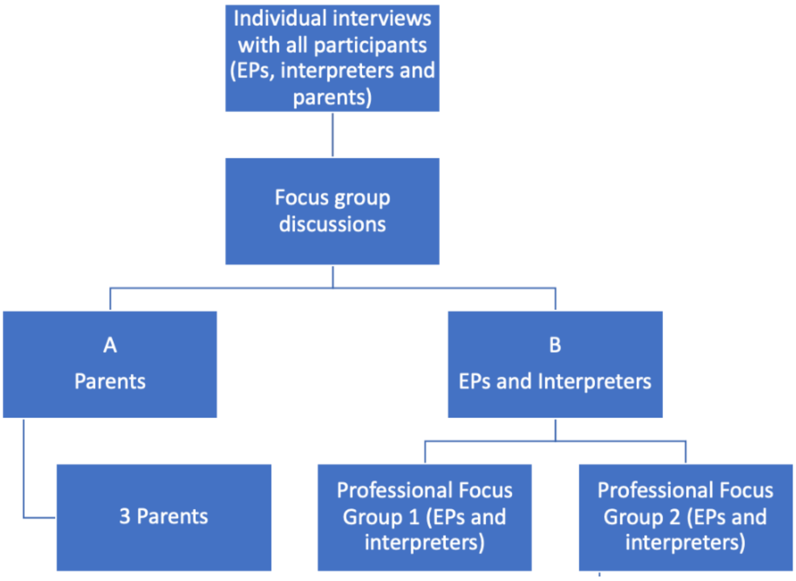
Informed consent will be directly gained from the participants prior to them taking part in the individual conversations or focus groups. Consent forms and participant information sheets will be provided in the participants' home language (Punjabi and Hindi). The consent form and information sheets are written using clear and unambiguous language. Participants will further have an opportunity to contact the researcher via phone or email to ask any questions that they have relating to the research aiming to provide clear and prompt responses. Moreover, at the start of the

interviews, time will be provided to go through the information sheet and consent form to answer any further questions. Consent and participant information sheets with translations are attached to the ethics application.

3.5 Is there any reason to believe participants may not be able to give full informed consent? If yes, what steps do you propose to take to safeguard their interests?
The participants in the study will be able to give full informed consent given there are no language barriers to consent. The researcher will ensure this by translating the consent, participant information sheet and debrief forms.

4. Research procedures, interventions and measurements

4.1 Give a brief account of the procedure as experienced by the participant. Make it clear who does what, how many times and in what order. Make clear the role of all assistants and collaborators. Make clear the total demands made on participants, including time and travel. *Upload copies of questionnaires and interview schedules to ERGO.*



<u>Individual interviews</u>

Aligned with the CCM, one individual reflective interview will be conducted with each of the nine participants either in person or online. Both parents of the child/young person will be invited. Each interview will be held over one session where in person interviews will be held in participants' cities in a familiar school to the participants for instance or in the local authority building. The individual interviews will last up to one hour.

The researcher will first remind the participants about the purpose of the research and the fact that they can withdraw from the research up until the point of synthesising the individual interviews into the shared understanding which will be brought to the focus groups. The researcher will make it clear that the participants can withdraw the use of their own data during the focus group stage, however, because some of their contributions will be shared within a group context, the completed research might still refer to the ways that other participants responses to and developed their ideas. This will be clearly mentioned in the information sheet and consent form as well as during the verbal communication with the participants. Participants will be informed again that they will remain anonymous in the reporting of results. Participants will be explained the CCM structure of the involvement consisting of an individual interview and a focus group in a months' time to engage in a solution focused thinking.

The researcher will ask the questions (indicated in the topic guide) and will encourage discussion surrounding each of the questions. The aim of the discussion will be to elicit a reflective narration of the participants' experiences, reflections and future expectations as part of the EHCP process.

Focus groups

Following the individual meetings, the participants will be invited to the focus groups to collaboratively think about the enablers and barriers for parents from ethnic minority heritage in supporting their children with SEND and feeling informed, included, heard and understood during the EHCP process.

To be mindful of the power imbalances between the professionals and parents (Woods-Jaeger et al., 2022), parents will be attending the focus group 'A'. EPs and interpreters will be invited to join a focus group 'B'. Two focus groups (1, 2) will be provided for professionals to pick from based on their availability to manage all six professionals' diaries. Participants will be given an opportunity to ask any further questions they may have prior starting the interview.

The researcher will actively engage in a dialogue with the participants and share previous research findings on what has been identified as enablers and barriers for parents from ethnic minority heritages (Akbar & Woods, 2019; Heer et al., 2015; Oumar et al., 2022) and discuss the initial findings gathered from the reflective individual stories (i.e., the individual participant conversations). The participants will be invited to co-evaluate, reflect and share their thinking to develop the ideas further. The aim of the communicative focus groups is to generate solutions in collaboration with participants on how best to generate collaborative practice in the EHCP process for South-Asian parents of children with SEND.

The volunteer research assistant will support for instance in transcribing the obtained data from the professionals and supporting with the systematic literature search for the systematic literature review.

4.2 Will the procedure involve deception of any sort? If yes, what is your justification?

N/A

4.3. Detail any possible (psychological or physical) discomfort, inconvenience, or distress that participants may experience, including after the study, and what precautions will be taken to minimise these risks.

Due to the participatory nature of this study, in which the participants contribute to its development, I do not consider any possible harm to them. However, I understand that some of them might feel discomfort or anxiety in case we discuss topics that they might feel ineffective. To avoid this, I will make clear from the beginning that the researchers are not the ‘experts’ in this project and that we want to consider the participants as the ‘practice experts’. I will make clear that there are no ‘wrong’ and ‘right’ views or practices. The CCM which is based on participants’ reflections on their practice and on egalitarian dialogue will help to avoid criticisms or feelings of discomfort.

In addition to this, I will be asking regularly the participants if they wish to continue a discussion or answer a specific question. I will end any discussion about a particular topic if it is causing distress, according to the participants’ wish. I will also monitor carefully the participants’ body language for signs of distress and respond to these signs accordingly. Finally, I will provide the participants with information about support services that they can access (Breathing Space 0800 83 85 87), in case the research has distressed them in any way.

I will ask the participants to commit time in the study, which could potentially disrupt their personal or professional life. I will manage the above risk by arranging any meetings with the participants at times convenient to them. The participants may worry about what they have shared. I will manage this through the focus groups where I will ensure that participants' views are represented, and the participants can rephrase or withdraw what they have said. I will also regularly reassure the participants that their identities will be kept confidential and anonymous in the research. The focus groups will also allow to share the research findings with the participants to further foster a safe research-participant relationship.

4.4 Detail any possible (psychological or physical) discomfort, inconvenience, or distress that YOU as a researcher may experience, including after the study, and what precautions will be taken to minimise these risks. If the study involves lone working please state the risks and the procedures put in place to minimise these risks (<u>please refer to the lone working policy</u>).

I do not consider any possible harm to me arising from this study. My main concern is to manage to collect the data using remote meeting platforms such as Teams or Zoom which is something I haven't done before, and I consider stressful. To minimise my stress, I am planning on attending training sessions on how to collect data using remote meeting platforms and seek advice from my supervisors which will be helpful.

4.5 Explain how you will care for any participants in 'special groups' e.g., those in a dependent relationship, are vulnerable or are lacking mental capacity), if applicable:

N/A

4.6 Please give details of any payments or incentives being used to recruit participants, if applicable:

The researcher is aware that the CCM studies are time consuming from a participant's point of view. To show gratitude for their valuable time, participants will be reimbursed with a thank you voucher worth £25 for instance to Amazon at the end of their participation.

5. Access and storage of data

5.1 How will participant confidentiality be maintained? Confidentiality is defined as non-disclosure of research information except to another authorised person. Confidential information can be shared with those already party to it and may also be disclosed where the person providing the information provides explicit consent. Consider whether it is truly possible to maintain a participant's involvement in the study confidential, e.g. can people observe the participant taking part in the study? How will data be anonymised to ensure participants' confidentiality?

Only the research team (myself, my supervisors and the voluntary research assistant) will have full access to the collected data. A reputable transcription service, approved and recommended by the University of Southampton, will be used to transcribe the focus group discussions. The focus group discussions do not contain identifiable data such as participants' names in the audio recording; instead, pseudonyms were used. A secure audio file transfer method will be used to send the audio recording to the transcription service. The service follows University guidelines of data protection where the audio file and the transcript will be deleted by the transcription service upon sending the transcript to me.

To ensure the accuracy of Punjabi-English translations, we will involve an external person, Jyotsna Kaur (a friend of mine), who is proficient in both languages. Jyotsna Kaur will review a brief excerpt from one of the three translated transcripts and its corresponding audio interview recording shared via Teams. The research team will ensure that no identifiable information is disclosed in the shared data. Jyotsna Kaur will be advised about confidentiality.

The data will be transferred to and stored on the University's secure server as soon as possible. Until data has been uploaded onto the secure server it will remain on university password protected laptops which will remain in possession of the researchers. Upon completion and reliability checks of the transcription, the audio data will be destroyed. The transcriptions will be stored on the University's secure server for 10 years after completion of the study.

All collected data (transcripts of individual interviews and focus groups), will be anonymised to protect individual participants' anonymity during the analysis and reporting stage. Each participant will be assigned a pseudonym which will be used when analysing and writing up the data. A list with the real names and their associated pseudonyms will be kept so that any data associated with an individual participant can be withdrawn up to the point at which final analysis starts. This list will be stored password protected separately from the data and it will be destroyed when the study has been completed. Nobody else apart from me and my research team will have access to this list. If participants choose to name specific people during the data collection process, these people will also be given pseudonyms.

I will encourage all participants in the focus groups to avoid repeating any opinions or experiences shared by others outside of the focus group to protect the anonymity of all the participants and to keep the data confidential.

5.2 How will personal data and study results be stored securely during and after the study. Who will have access to these data?

The researcher will record the audio data using the university's password protected laptop and university Dictaphones. Audio files from the Dictaphone will be immediately transferred to the university laptop and deleted from the Dictaphone.

Audio data will be transferred as soon as possible to the University's secure server and will then be deleted from the University's laptop. Audio recording data will be destroyed once transcription has been completed. The transcripts will also be stored on the University secure server.

Upon completion of the study, the interview transcripts will be stored securely on the University server for 10 years.

Only the research team will have access to the study data.

5.3 How will it be made clear to participants that they may withdraw consent to participate? Please note that anonymous data (e.g. anonymous questionnaires) cannot be withdrawn after they have been submitted. If there is a point up to which data can be withdrawn/destroyed e.g., up to interview data being transcribed please state this here.

Participants will be informed of participants' right to withdraw consent on the consent forms. They will also be reminded before and after the interview by a researcher. Participants will be provided with a unique pseudonym which they may quote up to the point of transcription in order to remove their data from the study.

Participants will be informed that it is possible to withdraw their individual data up to the point at which the final analysis of the data starts, after the focus groups, in order to identify themes across participants. Therefore, it will be impossible to remove all data belonging to one participant. This will be clearly mentioned in the information sheet and consent form as well as during the verbal communication with the participants.

6. Additional Ethical considerations

6.1 Are there any additional ethical considerations or other information you feel may be relevant to this study?

I cannot anticipate any additional risks as a result of the sensitivity of the research. Since I am planning to share all the findings anonymously with the participants in the focus groups, I believe that any risks will be discussed and resolved with the participants.

Appendix B CASP Quality Assessment Tool

Author	1. Clear statement of aims?	2.Is a qualitative methodology appropriate?	3.Was research design appropriate to address aims?	4.Was recruitment strategy appropriate to address aims?	5.Was data collected in a way that addressed the research issue?	6.Has relationship between researcher and participants been adequately considered?	7.Have ethical issues been taken into consideration?	8.Was data analysis sufficiently rigorous?	9.Clear statement of findings?	10.How valuable is the research?
Akbar and Woods (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Partially - Ethical approval stated. No further mentions on informed consent etc.	Partially - did not critically examine their role and potential bias influencing analysis and presentation of data.	Yes	Yes – gives a clear understanding on the unique contribution the research is making.
Begum (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes – gives a clear understanding on the unique contribution the research is making.
Kramer-Roy (2012)	Yes	Yes	Yes	Yes	Partially – no information on the data form (tape recordings, video	No	Partially - Ethical approval stated. No further mentions on	Partially - mind maps are mentioned but unclear how these were formed and developed into themes.	Yes	Yes – gives a clear understanding on the unique contribution the research is making.

					material, notes etc.)		informed consent etc.			
Kwan-Tat (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes – gives a clear understanding on the unique contribution the research is making.
Nair (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes – gives a clear understanding on the unique contribution the research is making.
Oliver and Singal (2017)	Partially – research questions are unclear.	Yes	Yes	Partially – unclear whether family could decide whether they wanted a professional interpreter or known person to the family to translate.	Partially	No	No mention of ethics	Partially	Yes	Yes – gives a clear understanding on the unique contribution the research is making.
Raghavan et al. (2013)	Yes	Yes	Yes	Yes	Partially – no information on the topic guide.	No	Partially – statement of ethical approval given. No further information on informed consent etc.	No - themes not clearly reported.	Partially	Yes – gives a clear understanding on the unique contribution the research is making.
Rizvi (2017)	Yes	Yes	Yes	Yes	Yes	Partially	Partially – statement of	Partially – the researcher did not	Yes	Yes – gives a clear understanding on the

							ethical approval given. No further information on informed consent etc.	critically examine their own role and potentially biases.		unique contribution the research is making.
Rizvi (2018)	Yes	Yes	Yes	Yes	Yes	Partially	Partially – statement of ethical approval given. No further information on informed consent etc.	Partially – the researcher did not critically examine their own role and potentially biases.	Yes	Yes – gives a clear understanding on the unique contribution the research is making.
Theara and Abbott (2015)	Yes	Yes	Yes	Yes	Yes	Partially – the primary researcher shares similar cultural background. Would have been helpful to include reflections on interviews being conducted in English.	Partially – statement of ethical approval given. No further information on informed consent etc.	Partially – the researcher did not critically examine their own role and potentially biases.	Yes	Yes – gives a clear understanding on the unique contribution the research is making.

Appendix C Thematic synthesis stage one to stage two: from initial codes to developing descriptive themes

Example of thematic synthesis stages one and two: developing themes from initial codes. Numbered items indicate initial codes developed during stage one of the thematic synthesis. Boxed items indicate descriptive themes developed from the initial codes as per stage two of the thematic synthesis.

Unfamiliarity with SEND and language barriers

3. No prior knowledge about SEND such as autism

6. SEND terminologies were found confusing

2. Extended family and older generations' understanding

27. Concerns regarding the child's future

Absence of physical signs in SEND

1. hidden disabilities more difficult to understand

4. Medical curable view of SEND

Sharam and stigma

8. Fear of stigma, what will others think (sharam, shame)

9. Feelings of isolation and disconnection

10. Parental blame

11. Strained marital relationship

12. Gendered experiences as a parent

13. Deciding not to share the diagnosis

Transformation to acceptance and advocacy through religion and belongingness

7. Parents actively searching about SEND to aid their understanding and to help their children

2. Religion helps/helped me to cope

29. Growth as a parent and love for the child

Limited perceived support in understanding specialist provisions

19. School provisions

‘Omission of parental voice’ with education professionals

14. Language acting as a barrier during the EHCP experience

15. Limited perceived support in understanding EHCP processes

16. Slow EHCP processes

17. Lack of time with EPs/educational professionals

18. Parental voice missing during the EHCP

21. Parents’ understanding of the EHCP strategies

22. Power imbalances with professionals

23. Working with interpreters/bilingual school staff members

Professionals play a key role in building trusting relationships

25. Culture as a protective factor, making parents feel heard and respected.

26. Language identity important to parents

27. Child-led approach used by parents

28. Culturally and linguistically competent support groups valued

5. Varying socioeconomic and educational levels and identified need for financial support.

Appendix D Descriptive themes identified in each reviewed study with illustrative quotes

Descriptive themes identified in the reviewed studies 1-6 with supporting quotations

Descriptive Theme	**Reviewed studies 1-6**					
	Akbar and Woods (2020)	**Begum (2023)**	**Kramer-Roy (2012)**	**Kwan-Tat (2018)**	**Nair (2015)**	**Oliver and Singal (2017)**
Unfamiliarity with SEND and language barriers	Nighat reported that her husband believes their son 'will be ok' and is just 'a bit of a simpleton'. …Mohed, Qosar and Nighat report that some family members do not believe the child has a disability: 'You're making it up' (Mohed); 'he's not very clever, that's not a condition' (668)	''To be told her son had autism was unexpected: "So, it was a shock. I was so shocked when he got diagnosed I just did not think at all it had anything to do that, and I didn't really know much about autism either (Tahira, line 527-529)''			''Tammy said, "most of the drivers have built good relationships with her (Tammy's daughter Nina) and she'd tell them where to go" (Tammy, 5/28). She said,… we had this group of, Muslim men who … had no experience and used to tell her to be quiet because she tend to talk too much. And they were always late and this really caused Nina a lot of problems. Urh … (pause) the lateness had become a real issue because the school had started before she got there (Tammy, 5/28). Tammy particularly felt that the	

					drivers, who were from an ethnic background similar to Nina, did not understand the special need of her child.'' (Page 124)	
Unfamiliarity with SEND and language barriers	''the term' global' was confusing and distressing as they thought their child would be delayed in every aspect of life such as eating, sleeping and toileting, whilst others thought it would eventually become a physical disability; others wondered whether 'delay' implied that their child would eventually 'catch up', or is it 'eternal?'' (Page 668)	So, we know someone might say… he's delayed. Or is you know at you use Bangladeshi words like phagol you know all of that stuff. Uhm, you know and, and, and I mean those are absolutely horrendous words…..but again, it's just because people would not know any better.. So, you can't, sort of bash them down for thinking like that" (Mim, line 797-804)'' (Page 62)		''Not knowing what autism means: ''Malini spoke of her first experience of being told her son had autism;"…find out that he has autism and special needs and first time I heard in my life. I didn't before heard about the autism. What does it mean? What is that? I don't know about anything. I think little bit (they) do everything quickly. They didn't give it time to discuss about this." (Page 120)	''A specific concern that emerged from the interviews with one parent was their search for information about autism in a language that they could understand.''(Page 132)	''In an interview for a TA position, the head teacher recognised Masha as related to one of their pupils, employed her initially for two months as a volunteer, and from there she was nurtured to take on more significant responsibilities. The situation was seen as 'win–win' because the school often provided a step- ping stone or first experience of the labour market for some mothers, while the appreciation by senior staff of migrants' work generated both positive

						esteem for migrants and a sense of shared goals (‘affective integration’).’’ (Page 1125)
Unfamiliarity with SEND and language barriers	‘You’re making it up’ (Mohed); ‘he’s not very clever, that’s not a condition’ (Nighat)’’(Page 668)	‘’Feeling supported in spaces outside the home was important and was experienced as encouraging, reassuring and sympathetic.’’ (Page 57)	‘’Another clear occupational injustice is that the disabled children who had learning and /or behavioural problems, and by extension their families, were often not welcome at community functions and /or at the mosque, limiting their participation in culturally highly valued occupations, such as attending weddings.’’ (Page 447)	‘’My parents were living in Sri Lanka, it is very emotional at that point… I’ll be feeling very emotional because we don’t have help here…then there’s nobody if there’s a problem….but if David had very serious needs, who’s there to help us?” (Page 116)	‘’One parent stated that her family “have started to understand and are coping” with her son’s difficulty (Mina, 3/6), although, this parent’s son was eighteen and attending a residential independent school at the time when she was interviewed.’’ (Page 140)	
Unfamiliarity with SEND and language barriers	’the term‘ global’ was confusing and distressing as they thought their child would be delayed in every aspect of life such as eating, sleeping and toileting, whilst others thought it would eventually become a physical disability; others wondered	‘’Raina has clear ideas about the need for information and support; for her, it is not simply about accessing additional money and resources: … support groups, one, we would learn how to deal with the condition better with our			‘’Ten parents in the study stated that they were worried about their child’s future: ‘’ what would happen to him when they were no longer there to care for them’’ (Page 115)	

	whether ‘delay’ implied that their child would eventually ‘catch up’, or is it ‘eternal?’’ (Akbar & Woods, 2020, p.668).	children. And two, we could support one another. And three, we would know what to expect because. Every day is like a new day for us every day. But it seems with an autistic child there's a lot of uncertainty of the future and what to expect” (Page 68)				
Absence of physical signs in disability	‘Noreen’s brothers believed that because their niece ‘looks completely fine, she is just simple and quiet’ (Page 668)	‘… Bengali people. The women in general. If I take him anywhere, they say, but his face is normal. I find that so offensive…’ (Page 44)		’…Special Educational Needs…Down Syndrome kids, or kids with physical disabled…not like Anisha…I was not expecting it to be for Anisha…Because Anisha when you look at her she is normal and when you look at her she’s fine…But internally we understood there is a need for her…So we didn’t categorise it as a special requirement until we realise it is part of it. For me, for example, a blind person, or a person who couldn’t speak or a deaf person. That is a term	‘You have your own intuitive understanding of what’s happened to him. … you go through phases of anger, pain, denial and then acceptance or whatever it is, we went through all that … and look for the miracle cures (Amin, 8/21).’ (Page 117)	

				we would use as special educational needs.’ (Page 120-121).		
Absence of physical signs in SEND	’’As there is no medication or cure for GDD some family members found it difficult to accept the diagnosis.’’ (Page 668)	"My mother-in-law is desperately looking for a cure. She's looking for CBD, oils, and so and so said this Indian spice. This Chinese thing and it's just. They, just think it's curable" (Nila, line 539-542) (Page 59)	’’frustrations of having a disabled child and in accepting their disabled child’’ (Page 446)	’’When I identified paediatrician, Tilan has autism and after that we looked so many people, read articles, I went Early Bird programme, I went here, I found out about that and basically before I never accept that and then finally I …(tried to do) everything best for him.” (Page 101-102	’’At the end of the first day at the nursery, the nursery teacher said to me if she could have a word with me. I knew … but I was hoping that they would say something like he’s got hearing difficulty. He wasn’t stringing sentences at 3. He had a lot of single words. It was a sort of a pattern you would see in deaf children … for me it was like something had died. That was badly wrong and it wasn’t going to be right (Jamilla, 11/1).’’ (Page 115)	
Sharam and stigma	’’Zalaikha hides the diagnosis out of fear for her son being stigmatised ‘I don’t want him to be labelled, you know like a story that’s going around’.’’(Page 669)	’’ Even people who, who sort of you know bought are raised and educated and born and bought up in this in this country in this day and age. Still, stigma is a big issue…. shaming is a big issue. You know, not wanting to			’’They just think that my child is “paagal” … that’s what they think. I’d say a good seventy per cent of them still have the same attitude. You know, ‘to be looked down and frowned	

		go out in the world" (Mim, line 364-365)'' (Page 68)			upon' (Jamilla, 11/37).'' (Page 137)	
Sharam and stigma	''Massarat was advised by friends and family against taking her daughter to social events such as weddings or parties.'' (Page 669)		''For all mothers, and some fathers, their children's intensive and constant care needs meant they had no time to do things unrelated to their child's disability. This limited their contact with the world outside the home and opportunities to work or study to develop themselves further.'' (Page 447)	EHCP: "so quantifying the difference – with the EHC plan and without the EHC plan is hard…I had to go by myself, take Anisha, change her and come –and I was stuck in the middle because I didn't know whom to speak to…" (Page 113)	" The denial and refusal to accept their child's condition initially led to ten parents feeling isolated since they believed that they were the only parents of a child with autism.'' (Page 114)	
Sharam and stigma	Some extended family members attribute the delay and/or behaviour to poor parenting: 'Oh you've had so many kids close together, you obviously can't look after them' (Zalaikha). (page 668)	''… felt under scrutiny and were somehow made to feel like they were responsible for their child's diagnosis: "And I feel like my parenting skills have always been questioned when it comes to him" (Nila, line 702)'' (page 60)		''Parents feeling guilty and thinking it is because of them: '' For example, Anura believed that his daughter's physical needs are the result of delayed identification: "I'm thinking, I give it to my child. This is my common idea." (Page 121-122)	''relates to her fears of being shamed and blamed for her child's disability. Further, another parent from the Pakistani community in speaking about his community's attitude towards a disability said that they "will blame it on you, they will blame it on anything but what that actually is (Amin, 8/35). (Page 136)	

Sharam and stigma	’’Strain on the marriage was also mentioned by one of the fathers in the study, indicating that the gender of the interviewee in this study did not impact themes. Mohed reported that ‘everything is put onto me, so I have to always take time off work, I have to contact people, so the workload isn’t shared, I had to work to support everyone ... there were things ... it would have been easier if both of us could have done . . . shared the load out’. (Page 667)		’’For all mothers, and some fathers, their children’s intensive and constant care needs meant they had no time to do things unrelated to their child’s disability.’’ (Page 447)			
Sharam and stigma	’’fathers find it more difficult to accept a son’s disability than a daughter’s because ‘their name’’ (Page 669)		’’fathers often felt left out despite accompanying mother and child to key appointments.’’ (Page 445)			
Sharam and stigma	’’When Saira’s daughter was first diagnosed, she wished to keep her at home close to her and had not shared the diagnosis; she did not wish to	“Even though I'm, you know, educated and you know born and brought up here. I think you can't help but you know, worry about the stigma, and you know				

	tell her family in Pakistan because she believed it would be an added source of stress for her because they would catastrophise.'' (Page 669)	the social aspect" (Mim, line 129-131) (Page 62)				
Transformation to acceptance and advocacy through religion	'Having faith was mentioned as a protective factor and it supported participants to 'count their blessings': 'My daughter could be worse, she can see, hear, understand and she can move her feet and hands' (Saira). Both Qosar and Zubaida send their sons to the local mosque to build up a sense of belonging to the community. Prayers were mentioned a number of times: 'There's a lot of strength in our faith, it is through prayers that she has come so far. The power of prayer is real.' (Saira). Zalaikha says despite daily challenges and struggles, 'Allah does keep you going'. '(Page 670)	'After her son Musa's initial diagnosis, both sides of the family employed religious coping strategies. "... they're still telling me... just pray, maybe go hajj. Maybe go umrah, he'll be fine. You know they're kind of seeing it as an illness" (Nila, line 233-235)'	'The concept of belonging was of utmost relevance to the Pakistani families, as their children were often not allowed to belong in their community and the families strived to offer them a strong sense of belonging at home.'(Page 446)	Role of religion, faith and god: 'she described the importance of being a Christian as a means to cope, stating "God gave us strength...' (Page 122)	'There was also help given by some of the grandparents who turned to other people in their communities for advice. Amin stated that those from the older generation still seek assistance from "Fakirs" or religious doctors and "Pirs" or living saints (Amin, 8/36).' (Page 140)	'Relying on religion, medical model of cure, change in new generation: ''Noor also described how some of the older families she worked with were more inclined to see a religious cause for their child's disability and hope for a potential 'solution', although she noted this was becoming much less common with younger families who were fluent in English and had access to the Internet and other sources of information.' (Page 8)

Transformation to acceptance and advocacy through religion	''When it was suggested that Amirah's sister move to a specialist placement, Amirah's mum searched online for religious remedies.'' (Page 670)	''...and I knew by the time I had done all my research I knew this is what he's got. Every single trait, he's got it" (Nila, line 217-231).'' (Page 46)	''The study gave the mothers particularly, and fathers to a lesser extent, the motivation to be more proactive in seeking contact with and supporting other Pakistani parents with disabled children and in challenging negative attitudes in the community, showing an increased motivation and ability to take action to improve their own situation.'' (Page 447)	''Malini communicated a tension between the school and home, whereby she felt the need to help her son reach his potential as a means to compensate for the perceived lack of support in school.'' (Page 104)	''It is noteworthy that all parents in this study, including those who had comparatively little English, began to search for information when they first became suspicious that something was not right with their child's development. Parents' search for information included scanning the internet for information, seeking those who provided respite care, as well as reading up information that was available through books'' (page 127)	
Transformation to acceptance and advocacy through religion		"I felt like the me that I was three years ago is completely different to me now. I, I put up with a lot of rubbish that was said to me, whereas now I'm just like no. You know, if my son doesn't talk, I don't care; that's how he is. He can communicate in other ways" (Nila, line 272- 279)'' (Page 66)	''It was the first time that the women shared their story of how they moved from the initial soul-destroying stage of people telling them that their child's disability was a punishment from God and that they must have sinned, through starting to pray more intensively and personally, to			

			being convinced that this child was a blessing and a gift from God.'' (Page 446)			
Need for equitable and accessible support				''The power imbalance between professionals and parents was further highlighted by reports of communication difficulties. With language being central to effective sharing of information and diffusion of information (Herzlich, 1973), it was critical to note that this was a major barrier between parents and professionals. Parents described difficulties in communication as a result of speaking EAL, as well as accessing the specialist language of professionals. Recognising gaps in his ability to speak scientific language, Anura spoke of receiving support from a friend (who was doctor) in order to know the right words to say when		

				approaching his GP; in doing so, Anura equipped himself with the resources to communicate effectively.'' (Page 193)		
Omission of parental voice with educational professionals	'' Two participants had positive experiences in which staff had been supportive and instrumental in ensuring EHCPs were in place before their child started school. Qosar felt the staff needed a 'push' but was pleased with their subsequent support in securing an EHCP for her son because it 'is the golden key, access to everything! To your child's future!'			'' On a practical level, Liz reflected on her use of interpreters as a way to facilitate communication with parents, "...get somebody in the school to interpret 'cause in the past we haven't always had that and the mums would agree to everything that they're being told. They go 'yes yes yes' and I realised they didn't understand..." (Page 140)		
Omission of parental voice with educational professionals	''did not know his son's EHCP was a legally binding document, and once the 'parent partnership' agency advised him of this, he realised that school staff were legally required to meet his son's			EHCP: ''Feelings of "stress", "hurt" and "fear" were reported by parents as they reflected on their experiences of engaging with the systems and structures		

	needs which currently he felt was not done.'' (Page 672)			of the SEN process.'' (Page 112)		
Omission of parental voice with educational professionals	''Participants considered the process to be slow, time-consuming and frus- trating particularly with regard to the conduct of school and LA staff: 'I just keep ringing them every day, they don't even get back to me and half of the staff are rude' (Zalaikha).'' (Page 672)					
Omission of parental voice with educational professionals			''The parents, particularly the mothers, described their relationships with professionals as superficial, rushed and too narrowly focused on the task in hand; they felt this was only partly due to poor cultural competence.'' (Page 445)	''Christopher identified barriers in carrying out statutory psychological advice: ''not having time to really explore the views and perspective of families…as part of a statutory assessment, it tends to be a bit of a snapshot…this journey the family goes on is a longer one sometimes and I think it would be helpful to be able to work with family's views and perspectives over		

				time" and added "I feel bad that I didn't spend longer with the family". (Page 161)		
Omission of parental voice with educational professionals	''Three Urdu and Punjabi-speaking parents' voices were not sought during the SEND process with some parents unaware that their children actually had an EHCP.''(Page 672)		''fathers often felt left out despite accompanying mother and child to key appointments.'' (Page 445)			
Limited perceived support in understanding special schools and transition plans					''seven parents stated that they did not have much choice and that they did not know what was available then for their child.'' (Page 121)	
Need for equitable and accessible support	''they weren't Muslims but they said things like this is from Allah – they were right'' (Page 670)				''here is a diverse range of backgrounds and various groups within the community. In highlighting this diversity, the role and involvement of BME parents in the education of their child should be taken into	

					account, particularly recognising that the community is not homogenous within and between themselves.’’ (p.174)	
Omission of parental voice with educational professionals			‘’One neglected area was that children with learning difficulties and /or autism were often very bored and their families strug- gled to know what toys or activities would be appropriate or how they might engage them in these.’’ (Page 446)			
Omission of parental voice with educational professionals	‘’Three participants felt ‘unwanted’ at the mainstream setting for various reasons. Amirah was told by the SENCo that her sister’s low academic attainment was negatively affecting the overall grades of the Year 3 class. Amirah feels that had their mum been able to speak English, and had knowledge of SEND as well as children’s rights, she would	‘’I found that I unless you present yourself as being like uber knowledgeable. It's really hard to assert yourself. So, I have to go into the room and know autism, know isms, Like, I need to talk the jargon to feel like I have to be taken seriously” (Aliya, line 1006-119)’’ (Page 67-68)	‘’fathers often felt left out despite accompanying mother and child to key appointments.’’ (Page 445)		‘’On the whole, parents were generally positive about the help that their children received in the school environment. One parent said that the support that she received for her son in the early stages of his education was, … quite fab, he has had support ever since play group (Bibi, 9/14, 15).’’ (Page 118)	

	have been able to advocate for her daughter, and not feel pressured to view specialist settings.’’ (Page 671)					
Omission of parental voice with educational professionals	’’two of the specialist settings’ parents reported qualified interpreters being used, which they found helpful.’’ (Page 671)					bilingual school staff: ’Gratitude towards the school. ’’Sahir’s mother also discussed in detail how her son participated well at school, reading books, watching television and going on visits. Her commendation of the school was in terms of ‘care’, explaining that ‘in this school they care for him like a mother would. They even change his nappy.’’ (Page 8).
Need for equitable and accessible support	’’they weren’t Muslims but they said things like this is from Allah – they were right’’ (Page 670)	“….we were at my parents' house, and he ate you know, ate fish with his hand, and my mom was so proud…you		SENCO on Culturally competent service: ’’It’s absolutely essential…it’s something that exercises everybody…” and colleagues		

		know...praising him" (Mim, line 553-556)'' (Page 64)		falling to stereotyping: ''experienced colleagues with "stereo typical ideas" about certain ethnic groups. "...our pastoral team said 'ah parents never come to meetings, they don't care'. So they make judgements and only because they didn't understand....So the knowledge is not there with our staff." (Page 147)		
Need for equitable and accessible support		''At the time, Riz displayed some language delay and professionals had become involved ...Mim was asked to make an important decision during a stressful time without having all the information... "I thought that I was like, oh no, you know he'll get confused ...I wish I had been, you know, been better informed...having that information would have been so much more helpful" (Page 52)				"clear that a large part of the success of the parent–school partnership was down to the employment of linguistically and ethnically diverse migrant support staff. Staff did not explicitly teach in home languages, but by recruiting female TAs, volunteer TAs and lunchtime supervisors

						from the same communities as the pupils (some of whom were able to speak up to six languages) there was always someone on site to facilitate individualised communication and smooth home–school relations.'' (Page 9)
Need for equitable and accessible support		"... You know we would work around him, and it's better we work around him rather than trying to make him fit in, because I think one of the things that you know we always try to do. We try to fit the child around us, with 'our' normal, you know, we need to work around the child. (Mim, line 539-543)'' (Page 54)	''There was also a sense of needing to let the child 'be' who he or she was by accepting the impairments; this did not lead to reluctance to help the child to make progress in his or her development.'' (page 446)			
Need for equitable and	''Zalaikha mentioned that the mainstream setting did arrange a coffee morning for parents	''And I think if more people had that or support groups, one, we would learn how to deal with	''Bringing the mothers, fathers and siblings together in their own groups was very	EHCP: "so quantifying the difference – with the EHC plan and without the EHC	''While three parents found support group meetings helpful there were eight parents who	

accessible support	but it was a ‘one-off’ and having school staff present stopped the parents from being open and honest about some of their familial and cultural issues.” (Page 671)	the condition better with our children. And two, we could support one another. And three, we would know what to expect because. Every day is like a new day for us every day. But it seems with an autistic child there's a lot of uncertainty of the future and what to expect” (Raina, line 291-299)” (Page 68)	effective. In all three groups, their shared religious and cultural background meant that the participants felt able to talk to each other about issues specific to their background.” (Page 446)	plan is hard…I had to go by myself, take Anisha, change her and come –and I was stuck in the middle because I didn’t know whom to speak to…” (Page 106)	did not. These parents were generally aware of meetings but they had their reservations about taking part in such gatherings. The concerns of these parents were with regard to venue and time. For example, one parent said, At XXX (a special school) they don’t have a parent group or a child group that I can access because it’s always in a pub, quite late on whereas in XXX (another special school), we did it on Tuesday mornings in school and I can’t do that for various reasons. Firstly, I don’t really want to be in a pub and secondly, the timing of it (Jamilla, 11/21).” (Page 131)	

Table 7 Descriptive themes identified in the reviewed studies 7-11 with supporting quotations

Descriptive Theme	**Reviewed studies 7-11**				
	Raghavan et al. (2013)	**Rizvi (2017)**	**Rizvi (2018)**	**Theara and Abbott (2015)**	**Warner (1999)**

Unfamiliarity with SEND and language barriers	‘’For South Asian carers whose first language was not English there was a greater sense of confusion and lack of awareness as to the availability of options: I haven’t looked into it (future options), I have not tried to look for any activities. I don’t know how to approach it because of my language problems. (CO40 Bangladeshi Mother)’’ (Page 939).				‘’The mothers of the two children with autism and the one with a child with Down’s syndrome did not understand the diagnosis. The former are still unclear about the meaning of autism and one stated, ‘They told me he’ll be a bit better… I’m hoping but I don’t know’. The parents of the remaining children appear to understand the nature of their children’s disability.’’ (Page 220)
Unfamiliarity with SEND and language barriers	’’ Family carers who did not speak English as a first language experienced a greater sense of confusion and unawareness of post transition options. South Asian families in general had low awareness of service providers and little understanding of their roles. Competency in English may vary and cultural misunderstandings may arise when words are used which have no direct translation in their language, or if the words used do not fit in their cultural context. These carers seldom used the term intellectual disability, describing their son or daughter as ‘a	‘’3/5 shared that doctors did not explain their child’s slow progress: ‘I don’t think he[doctor]explained properly…I did not understand why Alia was lagging behind.’’(p. 91).			‘’Six of the parents described feelings of great sadness on receiving the diagnosis. One mother stated, ‘I was crying… I felt very bad, like nothing was left in my body… I was heartbroken’. (Page 220)

	little slow' or 'has a problem with the brain'.'' (Page 941)				
Unfamiliarity with SEND and language barriers	''Family support (parents, siblings) was integral, however, support from extended families was not common. Why? ''Families did not live close by or because carers did not wish to burden them.'' : '' They have their own problem they have no time to look after her, we have a big family, they have no time, they have their own family. (CO2 Pakistani Father)'' (Page 940). ''The Pakistani and Bangladeshi carers reported greater concern about siblings taking on carer responsibility in the future, compared with the British White carers. They were also less likely to suggest that the young person should move to supported accommodation or residential homes when they got older…''(Page 940)			'' very few shared news of this diagnosis with members of their own family, including parents, as they did not want to unduly upset or concern them.'' (Page 53)	

Unfamiliarity with SEND and language barriers	’My Mum and Dad worry about him being on his own. So, that is what we worry. Hopefully when he is 30 he can get married and have a family because that is in our Asian culture anyway. (CO35 British Bangladeshi Sister)’’ (Page 941)	Concerns regarding future: employment, post-parental care, child protection and independence skills: ‘’After we are gone, how will Kiran be looked-after? There will be a time when I cannot do this anymore, so who will do it?’ (Page 94)		‘’Many parents under- stood autism as a potential barrier to their child’s success, which in turn drove their determination to help their child overcome it.’’ (Page 51.52)	’’ The parents of the two children with autism hoped their children would ‘be better’ by the age of ten. Others had more modest hopes, including their children being able to walk or talk, although some doubted whether such skills could be achieved.’’ (page 221)
Absence of physical signs in SEND	’’Family carers who did not speak English as a first language experienced a greater sense of confusion and unawareness of post transition options. South Asian families in general had low awareness of service providers and little understanding of their roles. Competency in English may vary and cultural misunderstandings may arise when words are used which have no direct translation in their language, or if the words used do not fit in their cultural context. These carers seldom used the term intellectual disability, describing their son or daughter as ‘a	2/5 mothers expressed distrust in doctors: ‘’ ‘The doctors don’t know what her sickness is, they have just given a name autism . . . they explain autism saying these children understand less, speak less.’ (Page 91)		‘’The huge variability within the autism spectrum led to many parents discrediting the term altogether, possibly because they felt that it was so unusual for a medical condition to be quite so variable in nature and inconsistent between individuals. Consequently there was often a strong tendency to focus on helping their child get over the condition and in the interim to ‘mask the problem’ to avoid long-term labelling.’’ (Page 51)	‘’The mothers of the two children with autism and the one with a child with Down’s syndrome did not understand the diagnosis. The former are still unclear about the meaning of autism and one stated, ‘They told me he’ll be a bit better… I’m hoping but I don’t know’. The parents of the remaining children appear to understand the nature of their children’s disability.’’ (Page 220)

	little slow' or 'has a problem with the brain'.'' (Page 941)				
Absence of physical signs in SEND		'' All mothers suggested the term sickness (bimari) best illustrated their understanding of their children's disability post-disclosure. Batool's daughter Alia has severe autism spectrum disorder (ASD): 'When she was one year old Alia wasn't talking... she was tested [but] they said she too has got this sickness.' (Page 91)		''mainly understood autism to be a label that had been diagnosed by a medical practitioner and therefore they generally focused on seeking treatment, medication and eventual cure. The diagnosis process itself was often described as a 'medical examination' which parents were not involved in.'' (Page 51)	
Transformation to acceptance and advocacy through religion	''For many families religious beliefs helped them to cope with their child's disability. They believed it was God's will and that they would cope with God's help. Some carers prayed and hoped the young person would get better: They are God's angels, they come into the world to get loved, they don't harm anybody, just to get loved. They are sin free. For everything there is	''As per Islam, children seen as a blessing: ''God is testing to see if we're good parents, how we look-after them.'' (Page 94)		''One parent suggested that religious leaders (such as 'Pathi's' or 'Granthi's') are well-respected influential figures within South Asian communities and could be key people to work with to help encourage a broader understanding of disability. It was suggested that this is a deeply embedded issue that will require consistent efforts in order to make meaningful changes and is something	

	a reason, I don’t worry now but sometimes human nature you wonder why this happens. Deep down you wonder why God, but if God’s happy, I’m happy. These children with special needs are God’s angels. . . . you are blessed with this child. (CO11 Pakistani Mother)’’ (Page 941)			that has been suggested in previous related research (Skinner & Weisner, 2007).’’ (Page 54)	
Transformation to acceptance and advocacy through religion					
Sharam and stigma	‘‘perceptions of shame and the stigma attached to disability were also present: ‘’ . Such feelings made some families feel more vulnerable, causing them to become more secretive and protective of the young person. They felt they had a duty to look after their children and did not wish members of the community to know about their support needs and the details of their child’s disability: ‘’Actually they think we brought shame on them, they don’t say it to your face but I know, when they come round here,			‘’‘fear’, ‘stigma’ and ‘prejudice’ that underpins attitudes towards disability in South Asian cultures and that this was the dominant view of disability and impairment. One parent went as far as to say disability ‘is the last form of prejudice’ that is ‘never talked about’ in most cultures, however this is especially evident in more traditional countries such as India.’’ (Page 52)	”I had also wondered whether mothers, when asked about their child’s disability, would reveal feelings of guilt as was suggested by Choudhury (1997) which I thought would influence their attitude to the SLD school. Only two mothers gave any indication of such feelings: one said that she had had ‘bad luck’ in her life; another arranged, after her daughter’s birth, to have an imman reading the Koran in Bangladesh to ask for forgiveness from God and to make her child ‘better’.’’

	you can tell you know. (CO31 Pakistani Father)'' (Page 941)				
Sharam and stigma	'' Older carers in this study were first generation Pakistani or Bangladeshi immigrants, many of whom did not speak English. Mothers often relied on their husbands or their adult son/daughter to attend meetings and interpret on their behalf. Mothers had the primary role of looking after the children and relied on their husbands to take care of other responsibilities, which allowed for less time to interact socially and created distance from mainstream society.'' (Page 941)			'' feeling of 'being isolated' as a result of their child's diagnosis of autism. Some parents discussed how they preferred to 'mask the problem' from others rather than openly discuss concerns about their child's label.'' (Page 53)	
Sharam and stigma		'The doctors asked my family if I knew what my daughter had . . . as I had a happy expression on my face.' – Rahat'' (Page 91)			
Sharam and stigma	''Older carers in this study were first generation Pakistani or Bangladeshi immigrants, many of whom did not speak English. Mothers often relied on	''reluctant to send their daughters on overnight trips despite school requests for parental support, fearing		''it was highly significant that mothers seemed to be more isolated than fathers as some discussed how their partners had 'distanced' themselves following	

	their husbands or their adult son/daughter to attend meetings and interpret on their behalf. Mothers had the primary role of looking after the children and relied on their husbands to take care of other responsibilities, which allowed for less time to interact socially and created distance from mainstream society.’’ (Page 941)	community criticism and gossip about their daughters’ reputations, indicating strong cultural influences affecting gendered perceptions.: ‘You know how it is to send your daughter alone . . . Pakistani people don’t like this, so I don’t do this.’ (Page 92)		news of their child’s diagnosis.’’ (Page 53)	
Limited perceived support in understanding special schools and transition plans	‘‘ I was looking after the children, my husband went to the school meetings. I didn’t know what to do, I was so busy. I couldn’t ask for help because of my language problem. (CO36 Pakistani Mother)’’ (Page 941)	’English proficiency regulated maternal experiences with professionals; four mothers were not English proficient so spouses managed professional interactions, despite mothers being the main decision-makers for their children.’’ (Page 92)	“The school was sold to me as a fantastic opportunity for Faraz where he’d progress. I didn’t know any different, I thought, I want the best for my child so I signed him up.” (Page 25)		‘‘Parents said that they valued the teachers at the school (including the headteacher), and approved the way in which the school cared for their children. The mother of Child F, for example, said, ‘They care for her… there’s someone to help her eat… someone looking after her. They change her nappy if she’s dirty; I like that’. (Page 220)
Omission of parental voice with educational professionals	‘‘ For many families there was also confusion about the identity of professionals, the agency they represented and the appropriate service	’Many of the parents had negative encounters with professionals: parents felt that professionals had been		’’One parent went as far as to say that South Asian parents will tend to treat social science professionals with ‘fear and suspicion’ and this might be because	

	to approach in order to address specific needs. I don’t know who, somebody did come, a lot of people visit and have been involved with my older son and all my children but I don’t know. (CO34 Pakistani Mother)’’ (Page 941)	dishonest with them about the child's diagnosis.’’ ⍰ ‘’ ‘The doctor said in 99% of cases children develop like this but become alright as they grow-up . . . But time went on and it [progress] didn’t happen . . .’ (Rizvi, 2017; p. 91).’’ From Oumar		of a lack of under- standing of what they actually do.’’ (Page 52)	
Omission of parental voice with educational professionals	’’South Asian carers who did not speak English as a first language expressed less awareness of the transition process: I don’t know but maybe the teacher will guide us as to what he would do. (CO23 Pakistani Father)’’ (Page 939)				
Need for equitable and accessible support	Socio-economic status and level of education also affected access to services regardless of ethnic background. Carers who were financially stable and in employment tended to access mainstream facilities and had the confidence to seek information about leisure pursuits and group activities, regardless of their			’Another value under- pinning this medical model construction of autism came from the implicit emphasis on perceived social hierarchy and status in South Asian countries. Parents discussed how they had come from a society where ‘social status’ is key and the measurement of effective parenting often comes from the successes of	

	ethnic background: ''I'm quite capable and I do find out my things, I sort of do explore channels. (CO6 British Pakistani Mother).'' (Page 942)			children. Some parents talked about how family success is more likely to be measured in economic terms or job status and that high earnings and wealth are deemed important markers of this.'' (Page 52)	
Need for equitable and accessible support / need for equitable and accessible support	''Further, it is also crucial for professionals to have knowledge of cultural systems in order to build links into community networks. Family support can both enable and restrict independence. It is important to acknowledge the collective nature of South Asian communities and to recognise that achieving independence for the young person may have a different meaning to these families. Achieving inter- dependence may be more appropriate (Atkin & Hussain 2003). The unwillingness by services to engage with South Asian families may result in the family's reluctance to engage in services.'' (Page 943)				

Appendix E Participant Information Sheet (English version)

Study Title: ''The Experiences of South-Asian Parents with Children with SEND during the EHCP process''

Researcher: Sukhjagat Brar, supervised by Dr. Tim Cooke & Dr. Vasilis Strogilos

Volunteer Research Assistant: Evie Parsons

ERGO number: 80907

Version and date: Version 1; 13.03.2023

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

I am a trainee Educational Psychologist at the University of Southampton, and I am conducting my Doctorate research. Previous studies show that the Education and Health Care Plan (EHCP) process to support children with special educational needs and disabilities (SEND) is found to be long and complex for all families, and especially confusing for parents from ethnically diverse cultures (Bentley, 2017). Studies have also found that parents of South-Asian heritage have almost entirely negative experiences of the EHCP process due to lack of knowledge of statutory processes, omission of parental voice and perceived power imbalances between the parents and professionals (Akbar and Woods, 2019). Based on these findings, I am conducting my doctorate research to gain South-Asian parents' views of the EHCP process and how the experience could be improved. I also want to gain views of educational psychologists and interpreters to think how the service delivery could be improved. The research is funded by the Educational Psychology Doctorate Programme at Southampton University.

Why have I been asked to participate?

South-Asian parents (who speak Hindi or Panjabi and have children with SEND and EHCP) and educational psychologists and interpreters who have worked with South-Asian parents as part of the EHCP process, are being asked to take part in the study. This will help me learn and share ideas on how to make the EHCP process more understandable. A sample of nine participants: three parents, three interpreters and three educational psychologists will be chosen to be part of the study.

What will happen to me if I take part?

The first stage of this study is an individual interview with the researcher lasting up to one hour. This can be done either in person or over a video call remotely using Teams or Zoom for example.

If you are taking part in this study as a South-Asian parent of a child with SEND, I will ask you about your understanding and experience of the EHCP process and the strengths and needs of your child.
I may give you some example pictures to show different stages of the EHCP process and ask you to organise them. I will also ask you about your experience of working with an educational psychologist and interpreter.

If you are taking part in the study as an educational psychologist or interpreter, I will ask you about your previous experiences of working with interpreters or educational psychologists during the EHCP process. (So, if you are an educational psychologist, I will ask you about your experience of working with an interpreter; if you are an interpreter, I will ask you about your experience of working with an educational psychologist.) I will also ask you what particular things you are aware of or thinking about when you are working with families from culturally and linguistically diverse communities.

I will then transcribe all the interviews and in three to four weeks' time, I will invite you to one of the two focus group discussions. Parents will be asked to join a focus group A together and educational psychologists and interpreters will be asked to join the focus group B together.

During the focus groups, I will be sharing the previous research findings on what has been identified as enablers and barriers for parents from ethnic minority heritages. This can be done by sharing a short document on the day translated and explained in your language. I will then discuss the initial findings gathered with you anonymously. You will be invited to co-evaluate, reflect and share your thinking to develop ideas together on how to improve the EHCP and SEND-support experiences for South-Asian parents.

All the interviews and focus group discussions will be audio recorded to help me transcribe the shared information later. The audio will be deleted after the transcription. All the transcripts will be anonymised in a way that the shared information cannot be traced back to you.

Are there any benefits in my taking part?

Taking part will allow you to have your say about the EHCP process and help the professionals to improve their service delivery. Every participant will also receive a thank you voucher worth £25 for instance to Amazon at the end of their participation.

Are there any risks involved?

Discussing about the EHCP process or your child's SEND might be upsetting. If this happens, we can take a break to make sure you're ok, get you a drink of water, and continue the interview only if you're happy for me to do so. It is your choice to take part and you are free to change your mind before, during the interview, or even after the interview if you felt unhappy with something you'd said. You will also be given a list of organisations that you can contact for further support or information after the interview and focus group.

What data will be collected?

The conversation with you will be voice recorded using a Dictaphone and moved to the university's password protected secure system where it will be stored securely and anonymously along with any notes taken during the session. The recordings from the Dictaphone will be immediately deleted after moving the data to the secure system. Once the data has been used for the research it will be deleted from the system as well. The only personal data I will collect will be your age, profession, ethnicity and gender.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

Your personal data will be kept confidential, and the research report will not allow any individual views to be traced back to an individual. It may, however, contain quotations from our conversations; these will not be able to be traced back to the individual who said them.

However, because of the nature of the study design, other people in your focus group will hear and will be able to respond to what you have said. We emphasise here and will emphasises in the meeting itself that all participants must respect the confidentiality of the other participants.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

What happens if I change my mind?

You have the right to change your mind and withdraw at any time before or during the individual interview stage with the researcher. You can withdraw from the study up to the point of the final analysis of the study. However, if this is done during or after the focus group stage, the final research paper might still refer to something you have shared if other participants' have responded to it. This is due to the nature of the focus group discussions. After the data-analysis, all the information shared will be confidential and not be able to be traced back to you. If you decide not to take part, you can email me Sukhjagat Brar (S.Brar@soton.ac.uk).

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

The data will be used to write the Doctorate thesis which will be read by the University staff. The research could be later published in a journal such as the Educational Psychology journal, but all the information about you will remain confidential.

Where can I get more information?

To get more information, kindly contact me (S.Brar@soton.ac.uk).

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Contact details of the research team:

Research supervisor: Dr. Tim Cooke (t.cooke@soton.ac.uk) and Dr. Vasilis Strogilos (v.strogilos@soton.ac.uk)

Researcher: Sukhjagat Brar (s.brar@soton.ac.uk)

Thank you for taking the time to read this information sheet. If you are happy to take part, please complete the attached consent form and email it to me to s.brar@soton.ac.uk.

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

Appendix F Consent Form (English and Panjabi examples)

CONSENT FORM English

Study title: ''The Experiences of South-Asian Parents with Children with SEND during the EHCP process''

Researcher name: Sukhjagat Brar, supervised by Dr. Tim Cooke and Dr. Vasilis Strogilos. Volunteer Research Assistant: Evie Parsons.

ERGO number: 80907

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (Version 1: 13.03.23) and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw my data from the study up to the point at which analysis starts in order to identify themes across participants.	
I understand that taking part in the study involves audio recording the interview. The recording will be transcribed and then deleted as set out in the participation information sheet.	

I understand that the anonymised transcript of the interview will be shared with other members of the University research group (listed at top of form)	
I understand that I may be quoted directly in reports of the research but that I will not be directly identified (i.e., my name will not be used).	
I am aware that because this research study involves a group focus group, my confidentiality cannot be guaranteed. However, I am aware that the researcher will emphasise the need to respect the privacy of all participants, so that I agree not to disclose what was said and by whom during the discussions.	

Name of participant (print name)……………………………………………………………………………

Signature of participant……………………………………………………………………………………

Date…………………………………………………………………………………… ……………………

Name of researcher (print name)……………………………………………………………………………

Signature of researcher ……………………………………………………………………………………

Date………

ਸਹਿਮਤੀ ਫਾਰਮ (ਪੰਜਾਬੀ- Panjabi)

ਖੋਜ ਦਾ ਨਾਮ: EHCP ਪ੍ਰਕਿਰਿਆ ਦੌਰਾਨ SEND ਵਾਲੇ ਬੱਚਿਆਂ ਨਾਲ ਦੱਖਣੀ-ਏਸ਼ੀਅਨ ਮਾਪਿਆਂ ਦੇ ਤਜਰਬਾ

ਖੋਜਕਾਰ: ਸੁਖਜਗਤ ਬਰਾੜ ਅਤੇ ਸੁਪਰਵਾਈਜ਼ਰ ਡਾ. ਟਿਮ ਕੁੱਕ ਅਤੇ ਡਾ. ਵੈਸਿਲਿਸ ਸਟ੍ਰੋਗਿਲੋਸ

ਖੋਜ ਸਹਾਇਕ: ਈਵੀ ਪਾਰਸਨਜ਼

ERGO ਨੰਬਰ: 80907

ਜੇਕਰ ਤੁਸੀਂ ਸਹਿਮਤੀ ਫਾਰਮ ਨਾਲ ਸਹਿਮਤ ਹੋ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਬਾਕਸ(ਆਂ) ਨੂੰ ਸ਼ੁਰੂ ਕਰੋ:

ਮੈਂ ਜਾਣਕਾਰੀ ਸ਼ੀਟ (ਵਰਜਨ 1: 13.03.23) ਨੂੰ ਪੜ੍ਹਿਆ ਅਤੇ ਸਮਝ ਲਿਆ ਹੈ ਅਤੇ ਅਧਿਐਨ ਬਾਰੇ ਸਵਾਲ ਪੁੱਛਣ ਦਾ ਮੌਕਾ ਮਿਲਿਆ ਹੈ।	
ਮੈਂ ਇਸ ਖੋਜ ਪ੍ਰੋਜੈਕਟ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸਹਿਮਤ ਹਾਂ ਅਤੇ ਇਸ ਅਧਿਐਨ ਦੇ ਉਦੇਸ਼ ਲਈ ਮੇਰੇ ਡੇਟਾ ਦੀ ਵਰਤੋਂ ਕਰਨ ਲਈ ਸਹਿਮਤ ਹਾਂ।	
ਮੈਂ ਸਮਝਦਾ/ਸਮਝਦੀ ਹਾਂ ਕਿ ਮੇਰੀ ਭਾਗੀਦਾਰੀ ਸਵੈ-ਇੱਛਤ ਹੈ ਅਤੇ ਮੈਂ ਅਧਿਐਨ ਤੋਂ ਉਸ ਬਿੰਦੂ ਤੱਕ ਆਪਣਾ ਡੈਟਾ ਵਾਪਸ ਲੈ ਸਕਦਾ/ਸਕਦੀ ਹਾਂ ਜਦੋਂ ਤੱਕ ਕਿ ਭਾਗੀਦਾਰਾਂ ਵਿੱਚ ਥੀਮਾਂ ਦੀ ਪਛਾਣ ਕਰਨ ਲਈ ਵਿਸ਼ਲੇਸ਼ਣ ਸ਼ੁਰੂ ਨਹੀਂ ਹੁੰਦਾ।	
ਮੈਂ ਸਮਝਦਾ ਹਾਂ ਕਿ ਅਧਿਐਨ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਵਿੱਚ ਇੰਟਰਵਿਊ ਦੀ ਆਡੀਓ ਰਿਕਾਰਡਿੰਗ ਸ਼ਾਮਲ ਹੁੰਦੀ ਹੈ। ਰਿਕਾਰਡਿੰਗ ਨੂੰ ਟ੍ਰਾਂਸਕ੍ਰਾਈਬ ਕੀਤਾ ਜਾਵੇਗਾ ਅਤੇ ਫਿਰ ਭਾਗੀਦਾਰੀ ਜਾਣਕਾਰੀ ਸ਼ੀਟ ਵਿੱਚ ਦੱਸੇ ਅਨੁਸਾਰ ਮਿਟਾ ਦਿੱਤਾ ਜਾਵੇਗਾ।	
ਮੈ ਸਮਝਦਾ/ਸਮਝਦੀ ਹਾਂ ਕਿ ਇੰਟਰਵਿਊ ਦੀ ਗੁਮਨਾਮ ਪ੍ਰਤੀਲਿਪੀ ਯੂਨੀਵਰਸਿਟੀ ਖੋਜ ਸਮੂਹ ਦੇ ਹੋਰ ਮੈਂਬਰਾਂ ਨਾਲ ਸਾਂਝੀ ਕੀਤੀ ਜਾਵੇਗੀ (ਫਾਰਮ ਦੇ ਸਿਖਰ 'ਤੇ ਸੂਚੀਬੱਧ)	
ਮੈਂ ਸਮਝਦਾ/ਸਮਝਦੀ ਹਾਂ ਕਿ ਖੋਜ ਦੀਆਂ ਰਿਪੋਰਟਾਂ ਵਿੱਚ ਮੇਰਾ ਸਿੱਧਾ ਹਵਾਲਾ ਦਿੱਤਾ ਜਾ ਸਕਦਾ ਹੈ ਪਰ ਇਹ ਕਿ ਮੇਰੀ ਸਿੱਧੇ ਤੌਰ 'ਤੇ ਪਛਾਣ ਨਹੀਂ ਕੀਤੀ ਜਾਵੇਗੀ (ਅਰਥਾਤ, ਮੇਰਾ ਨਾਮ ਨਹੀਂ ਵਰਤਿਆ ਜਾਵੇਗਾ)।	
ਮੈਂ ਜਾਣਦਾ ਹਾਂ ਕਿ ਕਿਉਂਕਿ ਇਸ ਖੋਜ ਅਧਿਐਨ ਵਿੱਚ ਇੱਕ ਸਮੂਹ ਫੋਕਸ ਸਮੂਹ ਸ਼ਾਮਲ ਹੁੰਦਾ ਹੈ, ਮੇਰੀ ਗੁਪਤਤਾ ਦੀ ਗਰੰਟੀ ਨਹੀਂ ਦਿੱਤੀ ਜਾ ਸਕਦੀ ਹੈ। ਹਾਲਾਂਕਿ, ਮੈਂ ਜਾਣਦਾ ਹਾਂ ਕਿ ਖੋਜਕਰਤਾ ਸਾਰੇ ਭਾਗੀਦਾਰਾਂ ਦੀ ਗੋਪਨੀਯਤਾ ਦਾ ਆਦਰ ਕਰਨ ਦੀ ਜ਼ਰੂਰਤ 'ਤੇ ਜ਼ੋਰ ਦੇਵੇਗਾ, ਤਾਂ ਜੋ ਮੈਂ ਇਹ ਖੁਲਾਸਾ ਨਾ ਕਰਨ ਲਈ ਸਹਿਮਤ ਹੋਵਾਂ ਕਿ ਚਰਚਾ ਦੌਰਾਨ ਕੀ ਕਿਹਾ ਗਿਆ ਸੀ ਅਤੇ ਕਿਸ ਦੁਆਰਾ।	

ਭਾਗੀਦਾਰ ਦਾ ਨਾਮ (ਪ੍ਰਿੰਟ ਨਾਮ) ....

ਭਾਗੀਦਾਰ ਦੇ ਹਸਤਾਖਰ..

ਤਾਰੀਖ਼..

ਖੋਜਕਰਤਾ ਦਾ ਨਾਮ (ਪ੍ਰਿੰਟ ਨਾਮ)..

ਖੋਜਕਰਤਾ ਦੇ ਦਸਤਖਤ ....

ਤਾਰੀਖ਼..

Appendix G Debrief (English)

Study Title: The Experiences of South-Asian Parents with Children with SEND during the EHCP process'

ERGO ID: 80907

Researcher(s) Sukhjagat Brar (lead researcher), Dr. Tim Cooke (supervisor), Dr. Vasilis Strogilos (supervisor), Evie Parsons (Volunteer Research Assistant)

University emails: s.brar@soton.ac.uk; t.cooke@soton.ac.uk; v.strogilos@soton.ac.uk; ep12g21@soton.ac.uk

Version and date: Version 1; 13.03.2023

Thank you for taking part in our research project. Your contribution is very valuable and greatly appreciated.

Purpose of the study

The aim of this research was to explore South-Asian parents' experiences of the Education and Health Care Plan (EHCP) process and working with educational psychologist and interpreters. Additionally, the aim was to think together collaboratively how to improve educational psychology and interpretation service delivery for South-Asian parents during the EHCP process. Your data will help build an understanding of how services can improve to provide culturally and linguistically competent service delivery.

Confidentiality and privacy

The results of this study will not include your name or any other identifying characteristics. Any information provided by you will be held anonymously so that it is impossible to trace the information back to you individually. As this study involved a focus group, your confidentiality cannot be guaranteed. We kindly ask you to respect the privacy of other participants and not to disclose what was said and by whom during the discussion.

Information will be held in secure cabinets in a locked room, or in a university protected online platform. In accordance with the Data Protection Act this information will be destroyed after 10 years. You have the right to withdraw any/all of your data without giving a reason, until the point of the final data-analysis (date will be confirmed and communicated after the focus groups.

Further support

If you have been affected by what we've spoken about today and would like to talk to about this with someone you can reach out to the following services:

Rethink Sahayak Asian Mental Health Helpline – a free helpline offering caring, non judgemental and empathetic support covering mental health and domestic abuse issues. It is free and confidential. You can speak to us in South Asian languages (Gujrati, Punjabi, Hindi and Urdu) or in English.

- 0808 800 2073
- sahayak@rethink.org
- https://www.rethink.org/help-in-your-area/services/advice-and-helplines/rethink-sahayak-asian-mental-health-helpline/

Sikhyourmind – free mental wellbeing support available in Punjabi and English.

- free helpline: 0333 210 1021 (open every day 7am to 9pm)
- live chat available at www.sikhyourmind.com (open 7am to 9pm)

Breathing Space – A free, confidential, phone and webchat service for anyone over the age of 16 experiencing low mood, depression or anxiety. Service available in different languages.

- 0800 83 85 87
- https://breathingspace.scot

Pause Psychology - A registered charity of educational psychologist to support mental health and build wellbeing and resilience for free:

- hello@pausepsychology.org.uk
- http://pausepsychology.org.uk/contact.html

You Trust – Registered mental health practitioners providing mental health support in different languages:

- 01329 825 930
- https://theyoutrust.org.uk/mental-health-services/

If you wish to get more support around your child's Special Education Needs and Disability, kindly contact your child's school. If you wish to get further support, you can contact your local SEND Information Advice and Support Service (SENDIASS), which you can find at https://councilfordisabledchildren.org.uk/about-us-0/networks/information-advice-and-support-services-network/find-your-local-ias-service

Study results

You can email the lead researcher Sukhagat Brar on s.brar@soton.ac.uk to request an anonymised summary of the findings; this will be made available to you once the research has been completed. If you have any further questions please contact me, Sukhjagat Brar on email via: s.brar@soton.ac.uk

Thank you for your participation in this research. If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the University of Southampton Head of Research Integrity and Governance (023 8059 5058, rgoinfo@soton.ac.uk).

Appendix H Recruitment flyer (English and Panjabi)

UNIVERSITY OF Southampton

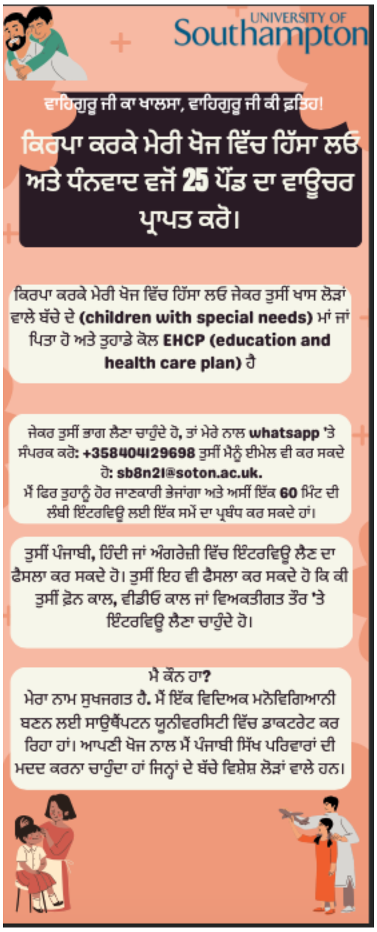
Are you a Panjabi identifying mother and/or father who has a child with special needs (Education and Health Care Plan)? We need to hear from you!

Taking part in the study will include
- A 60 minute individual interview
- 3-6 weeks later you will be invited to a group interview with other parents.

You can do the interview in Punjabi, Hindi, Urdu or English!

Your involvement will help professionals to know more how to best support Panjabi families. As a thank you, you will receive a £25 voucher.

To find out more, contact the researcher: a third year trainee educational psychologist Sukhjagat Brar at: sb8n21@soton.ac.uk
Or WhatsApp: +358404129698



UNIVERSITY OF Southampton

ਵਾਹਿਗੁਰੂ ਜੀ ਕਾ ਖਾਲਸਾ, ਵਾਹਿਗੁਰੂ ਜੀ ਕੀ ਫ਼ਤਿਹ!

ਕਿਰਪਾ ਕਰਕੇ ਮੇਰੀ ਖੋਜ ਵਿੱਚ ਹਿੱਸਾ ਲਓ ਅਤੇ ਧੰਨਵਾਦ ਵਜੋਂ 25 ਪੌਂਡ ਦਾ ਵਾਊਚਰ ਪ੍ਰਾਪਤ ਕਰੋ।

ਕਿਰਪਾ ਕਰਕੇ ਮੇਰੀ ਖੋਜ ਵਿੱਚ ਹਿੱਸਾ ਲਓ ਜੇਕਰ ਤੁਸੀਂ ਖਾਸ ਲੋੜਾਂ ਵਾਲੇ ਬੱਚੇ ਦੇ **(children with special needs)** ਮਾਂ ਜਾਂ ਪਿਤਾ ਹੋ ਅਤੇ ਤੁਹਾਡੇ ਕੋਲ **EHCP (education and health care plan)** ਹੈ

ਜੇਕਰ ਤੁਸੀਂ ਭਾਗ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਮੇਰੇ ਨਾਲ **whatsapp** 'ਤੇ ਸੰਪਰਕ ਕਰੋ: **+358404129698** ਤੁਸੀਂ ਮੈਨੂੰ ਈਮੇਲ ਵੀ ਕਰ ਸਕਦੇ ਹੋ: **sb8n21@soton.ac.uk.**
ਮੈਂ ਫਿਰ ਤੁਹਾਨੂੰ ਹੋਰ ਜਾਣਕਾਰੀ ਭੇਜਾਂਗਾ ਅਤੇ ਅਸੀਂ ਇੱਕ **60** ਮਿੰਟ ਦੀ ਲੰਬੀ ਇੰਟਰਵਿਊ ਲਈ ਇੱਕ ਸਮੇਂ ਦਾ ਪ੍ਰਬੰਧ ਕਰ ਸਕਦੇ ਹਾਂ।

ਤੁਸੀਂ ਪੰਜਾਬੀ, ਹਿੰਦੀ ਜਾਂ ਅੰਗਰੇਜ਼ੀ ਵਿੱਚ ਇੰਟਰਵਿਊ ਲੈਣ ਦਾ ਫੈਸਲਾ ਕਰ ਸਕਦੇ ਹੋ। ਤੁਸੀਂ ਇਹ ਵੀ ਫੈਸਲਾ ਕਰ ਸਕਦੇ ਹੋ ਕਿ ਕੀ ਤੁਸੀਂ ਫ਼ੋਨ ਕਾਲ, ਵੀਡੀਓ ਕਾਲ ਜਾਂ ਵਿਅਕਤੀਗਤ ਤੌਰ 'ਤੇ ਇੰਟਰਵਿਊ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ।

ਮੈ ਕੌਨ ਹਾ?
ਮੇਰਾ ਨਾਮ ਸੁਖਜਗਤ ਹੈ. ਮੈਂ ਇੱਕ ਵਿਦਿਅਕ ਮਨੋਵਿਗਿਆਨੀ ਬਣਨ ਲਈ ਸਾਊਥੈਂਪਟਨ ਯੂਨੀਵਰਸਿਟੀ ਵਿੱਚ ਡਾਕਟਰੇਟ ਕਰ ਰਿਹਾ ਹਾਂ। ਆਪਣੀ ਖੋਜ ਨਾਲ ਮੈਂ ਪੰਜਾਬੀ ਸਿੱਖ ਪਰਿਵਾਰਾਂ ਦੀ ਮਦਦ ਕਰਨਾ ਚਾਹੁੰਦਾ ਹਾਂ ਜਿਨ੍ਹਾਂ ਦੇ ਬੱਚੇ ਵਿਸ਼ੇਸ਼ ਲੋੜਾਂ ਵਾਲੇ ਹਨ।

Appendix I Topic Guide (used as a prompt for reflective individual conversations)

Parents

‘’Hello. Thank you for agreeing to meet me today… The purpose of today’s interview is to hear about your experiences as a parent of South-Asian ethnicity to a child with SEND. I would also like to know how you found the EHCP process, SEND-support, and working with educational psychologists and interpreters. Feel free to ask questions at any point of the interview. You can skip any questions should you wish to.’’

Reminders:

- There are no right or wrong answers
- You don’t have to answer anything that you don’t wish to share or talk about
- Go through the process, say that you are recording, ask if they are happy with this (verbal consent as well)
- Let them know this will take one hour.
- Ask in which language they prefer.

1. **Icebreaker questions:**

- Name and age of the child
- Child’s birthplace
- Special need
- how long parents have been in the UK
- How is your child, what do they like/enjoy doing?

2. **Before the EHCP** (experienecs with early support)
   - Who first noticed they had (difficulties/insert words they have used)?
   - What were your views/feelings at this time?
   - When you first had concerns who did you discuss it with?
   - What were the views/feeling of wider family/ friends/ the other parent?
   - When did they get an EHC NA

3. **Role of culture**
   - Tell me about your home country and culture. How are children with SEND supported?
   - How does this compare to the UK?
   - Are there any big differences or similarities across the two cultures?
   - What is the impact of this for your child?

4. **The understanding and experience of the EHCP process and EP involvement**
   - Could you organise the boxes according to how they happened first. I will then ask about individual stage

Can you tell me a little bit about how and when concern was first raised about your child’s progress.

- *Was a referral made and by whom?*

- *What was your understanding of the referral form? (did someone translate the referral form, how much of it did you understand)*

Can you tell me about the way that the EP was involved with your child?

- *Approximately when were you involved with an EP?*
- *Were there family concerns regarding the EP involvement?*
- *What did the EP talk to you about and what did the EP ask you?*
- *Did the EP explain why they were asking these questions. If yes/not, how did it make you feel?*
- *What have you found was helpful and unhelpful in your understanding of the EHCP?*
- *Did the EP ask, and did you get to express what you wanted out of the EP involvement?*

Can you tell me about the assessment process. What did the EP do with your child?

- *How did you and your child feel about that?*
- *What worked well and what could have been improved?*

Can you tell me how involved you were in planning the EHCP outcomes and provision for your child?

- *How involved were you in target setting discussions for your child?*
- *Did you receive a written EP report? Was this translated and how much of it were you able to understand?*
- *What worked well and what could have been improved to support your understanding of the report?*

Can you tell me about the review process: What went well and what could have been improved?

I would like to know how well you felt the EP considered your cultural and family context during the EHCP process. How well do you think the EP understood the culture and context of your family?

- *How heard, empowered and included you felt in the EHCP process to advocate for your children with SEND?*
- *What helped/could have improved this?*

Can you tell me what was found helpful and unhelpful working with and EP?

- *How well did the EP involvement match with what you were hoping to get from?*
- *How satisfied were you with the EP involvement (scale 1-5)?*
- *Do you think the EP involved has made a difference. If yes, how? If not, why? (e.g. did the EP involvement change how you view your child's strengths and needs?)*
- *How could have an EP supported you and your child better during the EHCP process?*

5. **Accessing services and support**
    - How did you find the SEND-support in school after the EP involvement?
    - ***Can you tell me what other services have been offered to support you and your child?***
    - *Do you access them?*
    - *Why/Why not?*
    - *Can you tell me more about that?*
    - *What have you found that was helpful?*
    - *What have you found unhelpful?*

Are you familiar with the SENDIASS resource?/ are there any helpful resources you would recommend?

- *Would it have been helpful to know about this resource, why/why not?*
- *Can you tell me more about that?*
- *What have you found that was helpful?*
- *What have you found that was unhelpful?*
- *How could have the professionals supported you in using the resource?*

6. **Final recommendations**

- *What would you like EPs to know when working with interpreters during an EHCP process?*
- *What would you like interpreters and EPs to know when working with South Asian parents? (apni community dhi matd karn lei, professionals nu ki pata hona chahidha?)*

Ask about pseudonyms
Share about the focus group discussion

EPs/interpreters:

1. Icebreaker Questions	• The purpose of today's interview is to hear from a(n) (Panjabi identifying) educational psychologist what have been their experiences of working with Panjabi families and interpreters during an EHCP with a hope to provide more culturally competent service delivery in the future. • Feel free to ask any questions • Everything you will share will be anonymised. I will ask you to come up with a pseudonym for me.
2. Professional Experience • *can you tell me how long you have been practising as an educational psychologist?* • *How many times/often have you worked with an interpreter?* • *How many times you have worked with Panjabi families?*	
3. Working with interpreters • *How much training and what type of training have you received to work with interpreters?* • *What was found helpful/unhelpful in the training?* • *How prepared you felt to work with interpreters?* • *What has your experience been working interpreters to support families from ethnic minority backgrounds?*	

- *How could EPs and interpreters support parents from Panjabi heritage better during the EHCP process?*	
- Collaborative work with parents Educational Psychologists and interpreters could reflect on how the experiences of culturally and linguistically diverse communities are being acknowledged and addressed within educational psychology practice and in the EHCP process - *What particular things are you aware of or thinking about when you are working with families from culturally and linguistically diverse communities such as Panjabi parents?* - *Tell me about your involvement specifically with a Panjabi family during the EHCP. What happened to make it successful/less successful?* - *What are the enablers and barriers of effective work with EPs when working with parents of linguistically and culturally diverse backgrounds during the EHCP process?* - ***what made it/could have made it collaborative?*** - ***What are some of the common questions, concerns parents often ask or express.*** - *how could EPs improve parents' role in the EHCP process?* - *What showed you that the parents (from South-Asian backgrounds) were/were not understanding the stages of the EHCP?* - *What other support services are there available in your local authority for working with this community, and what sort of working practices do you think would help them be most useful to families?*	
4. What does culturally competent and responsive practice mean to you and *what can it look like during an EHCP involvement?*	

5. What makes you feel supported/unsupported to promote culturally responsive practices within your service/company and role	
6. What should EPs know/be aware of when working with Panjabi families? - How is SEND perceived in Panjabi communities and how is this understood?	
7. Pseudonym	

Interpreters:

1. Icebreaker Questions	- The purpose of today's interview is to hear from a Panjabi identifying interpreter what have been their experiences of working with Panjabi families and educational psychologists during an EHCP with a hope to provide more culturally competent service delivery in the future. - Feel free to ask any questions - Everything you will share will be anonymised. I will ask you to come up with a pseudonym for me.
2. Professional Experience - *can you tell me how long you have been practicing as an interpreter?* - *How many times have you worked with an educational psychologist?* - *How do you see educational psychologists role?* - *What is your understanding of the education and health care plan?* - *How many times you have worked with Panjabi families during an EHCP meeting?*	
3. Working with educational psychologists - *How much training and what type of training have you received to work with educational psychologists during an EHCP* - *What was found helpful/unhelpful in the training?* - *How prepared you felt to work with educational psychologists during an EHCP?* - *What has your experience been working educational psychologists to support*	

families from ethnic minority backgrounds? • *How could EPs and interpreters support Panjabi parents better during the EHCP process?*	
4. Collaborative work with parents Educational Psychologists and interpreters could reflect on how the experiences of culturally and linguistically diverse communities are being acknowledged and addressed within educational psychology practice and in the EHCP process • *What particular things are you aware of or thinking about when you are working with families from culturally and linguistically diverse communities?* • *What are the enablers and barriers of effective work with EPs when working with parents of linguistically and culturally diverse backgrounds during the EHCP process?* • *When you think about your involvement with* Family X *, what happened that helped it be successful and what happened that made this more difficult?* • ***What are the difficulties when working as an interpreter during an EHCP meeting?*** • ***What helps?*** • ***what made it/could have made it collaborative?*** • *how could EPs improve parents' role in the EHCP process?* • *What showed you that the parents from South-Asian backgrounds were/were not understanding the stages of the EHCP?* • *What other support services are there available in your local authority for working with this community, and what sort of working practices do you think would help them be most useful to families?* • What would you like educational psychologists to know when they have EHCP meetings with Panjabi families and interpreters? (what could they be mindful of)	

5. What does culturally competent practice mean to you and *what can it look like during an EHCP involvement?*	
6. What makes you feel supported/unsupported to promote culturally responsive practices within your service/company and role	
7. What should EPs know/be aware of when working with Panjabi families? • How is SEN perceived in Panjabi communities and how is this understood?	
8. Pseudonym	

Appendix J Excerpt of Transcript

P1 = Parent 1

I yeah now I am almost at the end I have only few questions left
P1 no worries at all
I now if an educational psychologist is to work with a Panjabi family again what advice would you give to the professional if they are to work with someone from our community?
P1 if there is a professional interpreter, it would be good if someone does not speak English
I Yes absolutely, is there anything else professionals could know?
P1 I would say the same mostly parents struggle with the communication
I Yeah. There were few things you have mentioned which you have found helpful. One was that the SENCO explained everything to you prior about the EHCP and that this was a big help and the EP explained everything as well and gave you equal opportunity to contribute to.
P1 Yes absolutely, the EP asked me questions and explained everything very well.
I Now do you feel like the people around you from our community such as your family or friends are understanding better as well what is going on?
P1 One of my friend lives in a different city and his child has autism. He took his son to India and they got late with applying an EHCP and we used to talk to each other and I used to explain how the EHCP process went with us. His son is older than my son and the council's decision had gone for tribunal. The council agreed to assess him and he got an EHCP and will start from this September going to a special school. The son is one year older than mine.
I Oh poor soul he got late with the process, it's always helpful to have the plan earlier if possible.
P1 yeah they faced a lot of hardships on their way they weren't agreeing with me earlier either when I used to explain that the speech and language therapist has told me about autism. They would say that the doctors here are just saying that and that is not the case. It is normal for some children to start speaking later. No parent wants to believe that their child is like this (different).
I of course, of course it is very difficult and culturally, we often tend to think that many children just start to speak later
P1 Yeah my father started speaking later in India (when he was younger)
I yeah that happens as well, maybe this is something professionals could be advised to be aware of as well that in our community it is often considered typical for a child to start speaking a bit later.
P1 Yes the SENCo and speech and language therapist really explained to me what was autism. Here (in England) they don't say like in India that the child is stupid instead they say the child's brain just functions differently.
I yes having autism does not mean one is stupid although our people (in the community) often tend to think so.
P1 exactly.
I Thank you so much veerji, I am so grateful of your time. Is there anything you wish to ask or share more?
P1 I have already gone through my own pain but if someone benefits from my story, it will just make me feel happy to be able to help someone else. And if there is anything else in your research that I could contribute to, I am happy to do so. I am very grateful that you are doing such a good work for our community.
I I am very grateful to you as you may know it can sometimes be very difficult to get people from our community to participate as some feel ashamed as you described as well
P1 yes my Mrs feels as well but with time she has accepted this I felt it initially as well but it is what it is by Waheguru's grace. He is our child no matter how he is.
I Yes absolutely. I will next anonymise and transcribe the interview in a way that it cannot be traced back to you or anyone in your family what has been shared with me today.

P1 Yes there is another friend whose child is about 12 year-old now and he has autism as well and the mother of the child encouraged me and my wife a lot by saying the regret I am feeling today, I never wish you to feel that ever. Our child got the support very late because I was stuck in the mentality ‘lok ki kehn ghe’ what will people say. Please do not repeat our mistakes I wish that such thing would not happen with this. They supported me a lot in this journey and encouraged me a lot.

I Sometimes if we find even one person who gives us good advice, it can help us a lot.

P1 Yes for instance I did not know anything about financial support but it was the SENCo lady who shared this with me you know I did not know this. The lady printed the paper for me and invited me to the school and said to apply everything based on his needs because I did not know that he could get extra support. The teacher helped as well. I didn’t know about his extra needs I hadn’t heard about sensory needs, I need to stay with him at all times and cannot turn my face away.

I oh one thing I wanted to ask which I have not asked that clearly. Could you share with me the terminology you feel comfortable using to describe your child’s needs, e.g. would you describe their needs in this case based on the diagnosis they have, would you use more generic terms such as SEN, disability or something else.

P1 I would just say autism or SEND, some people find ‘disability’ word alone confusing.

I That is very helpful and good to know. Thank you so much for your time, it was very lovely to hear from you. I am aware that it is now 2pm and you must be getting late.

P1 Yeah and I am sorry if I was being a trouble during the Gurudwara visit.

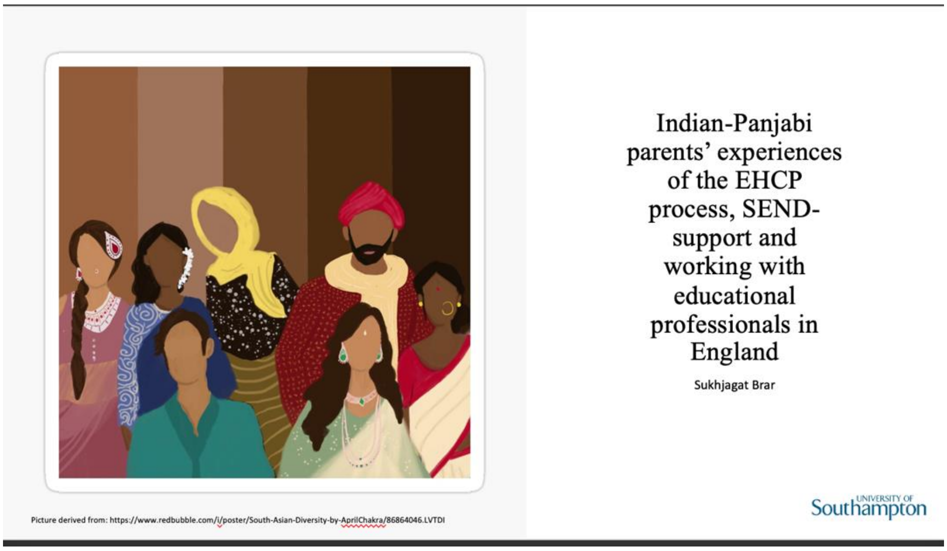
I Not at all, if I can say anything it is how grateful I am to you.

P1 We are grateful to you and if there is anything I can support further with your research, let me know. I want to be of help to our community and children. Life gets easier. I pray to Waheguru that my child will learn to speak more every day.

I Yeah, please do let me know if you have any questions at any point about the involvement. I will send an email regarding the focus group discussions.

P1 Yes

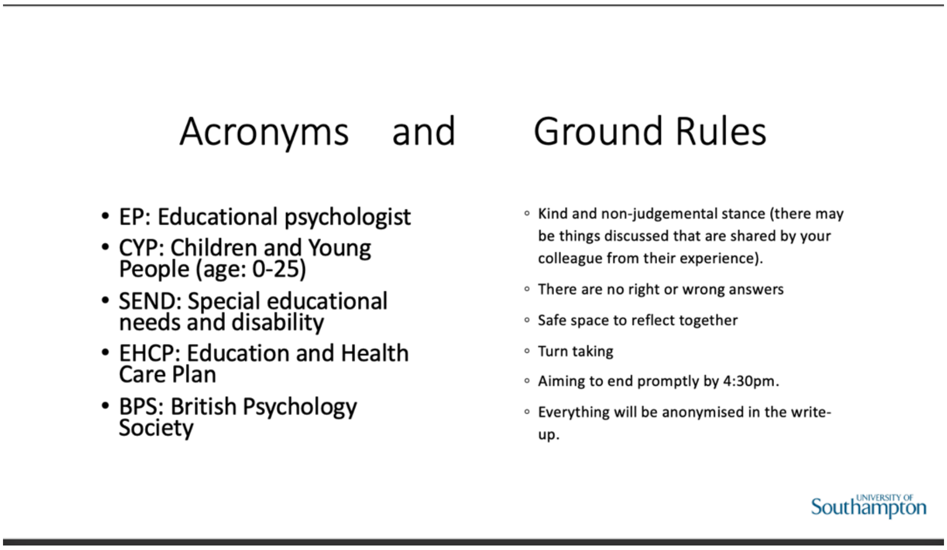
Appendix K EP and interpreter communicative focus group discussion prompt



Indian-Panjabi parents' experiences of the EHCP process, SEND-support and working with educational professionals in England

Sukhjagat Brar

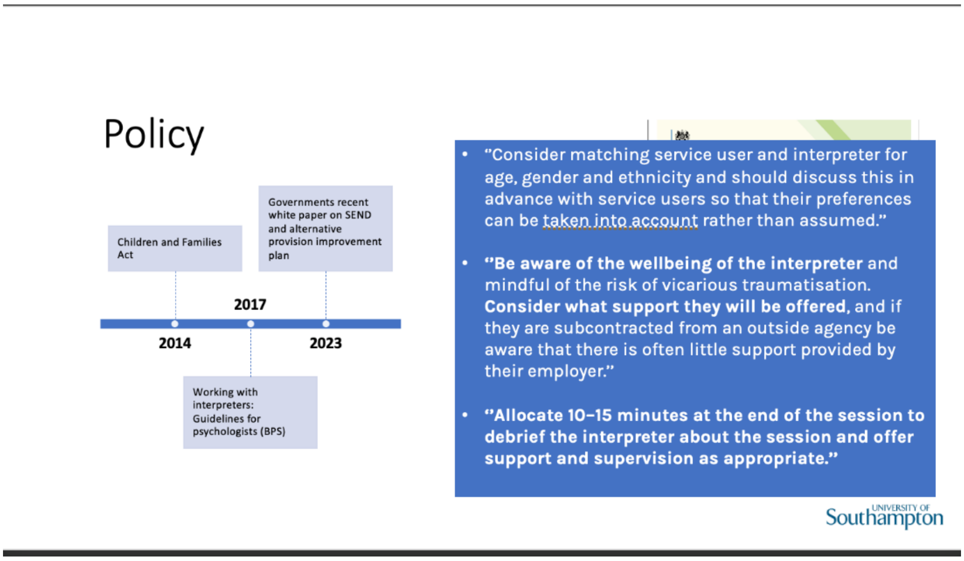
Picture derived from: https://www.redbubble.com/i/poster/South-Asian-Diversity-by-AprilChakra/86864046.LVTDI



Acronyms and Ground Rules

- EP: Educational psychologist
- CYP: Children and Young People (age: 0-25)
- SEND: Special educational needs and disability
- EHCP: Education and Health Care Plan
- BPS: British Psychology Society

- Kind and non-judgemental stance (there may be things discussed that are shared by your colleague from their experience).
- There are no right or wrong answers
- Safe space to reflect together
- Turn taking
- Aiming to end promptly by 4:30pm.
- Everything will be anonymised in the write-up.



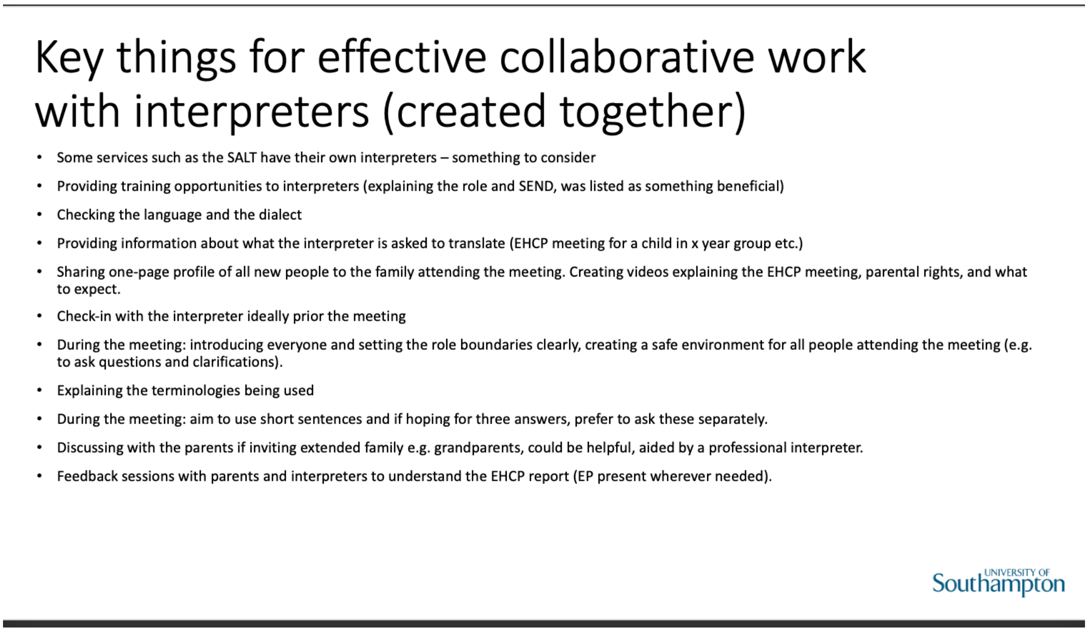
Policy

2014 – Children and Families Act

2017 – Working with interpreters: Guidelines for psychologists (BPS)

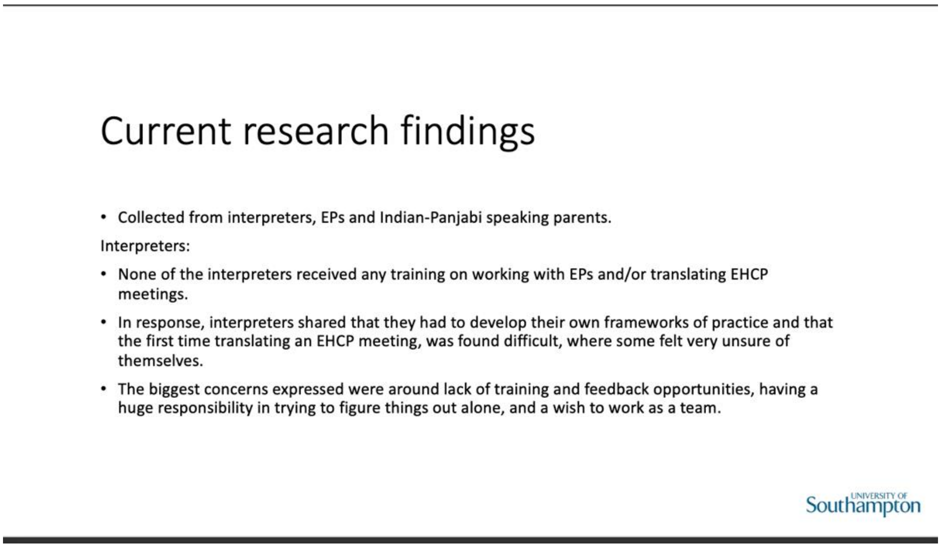
2023 – Governments recent white paper on SEND and alternative provision improvement plan

- "Consider matching service user and interpreter for age, gender and ethnicity and should discuss this in advance with service users so that their preferences can be taken into account rather than assumed."
- "**Be aware of the wellbeing of the interpreter** and mindful of the risk of vicarious traumatisation. **Consider what support they will be offered**, and if they are subcontracted from an outside agency be aware that there is often little support provided by their employer."
- **"Allocate 10–15 minutes at the end of the session to debrief the interpreter about the session and offer support and supervision as appropriate."**



Key things for effective collaborative work with interpreters (created together)

- Some services such as the SALT have their own interpreters – something to consider
- Providing training opportunities to interpreters (explaining the role and SEND, was listed as something beneficial)
- Checking the language and the dialect
- Providing information about what the interpreter is asked to translate (EHCP meeting for a child in x year group etc.)
- Sharing one-page profile of all new people to the family attending the meeting. Creating videos explaining the EHCP meeting, parental rights, and what to expect.
- Check-in with the interpreter ideally prior the meeting
- During the meeting: introducing everyone and setting the role boundaries clearly, creating a safe environment for all people attending the meeting (e.g. to ask questions and clarifications).
- Explaining the terminologies being used
- During the meeting: aim to use short sentences and if hoping for three answers, prefer to ask these separately.
- Discussing with the parents if inviting extended family e.g. grandparents, could be helpful, aided by a professional interpreter.
- Feedback sessions with parents and interpreters to understand the EHCP report (EP present wherever needed).

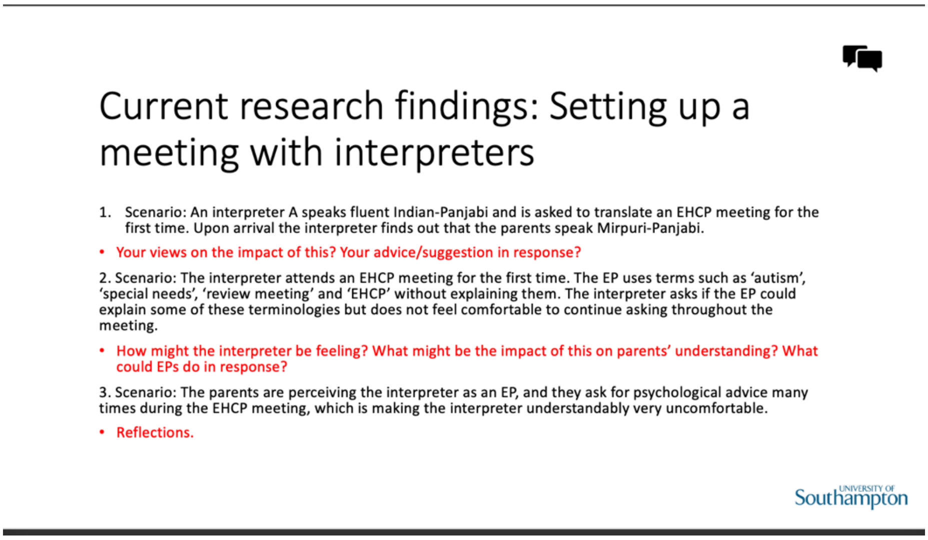


Current research findings

- Collected from interpreters, EPs and Indian-Panjabi speaking parents.

Interpreters:

- None of the interpreters received any training on working with EPs and/or translating EHCP meetings.
- In response, interpreters shared that they had to develop their own frameworks of practice and that the first time translating an EHCP meeting, was found difficult, where some felt very unsure of themselves.
- The biggest concerns expressed were around lack of training and feedback opportunities, having a huge responsibility in trying to figure things out alone, and a wish to work as a team.



Current research findings: Setting up a meeting with interpreters

1. Scenario: An interpreter A speaks fluent Indian-Panjabi and is asked to translate an EHCP meeting for the first time. Upon arrival the interpreter finds out that the parents speak Mirpuri-Panjabi.

- Your views on the impact of this? Your advice/suggestion in response?

2. Scenario: The interpreter attends an EHCP meeting for the first time. The EP uses terms such as 'autism', 'special needs', 'review meeting' and 'EHCP' without explaining them. The interpreter asks if the EP could explain some of these terminologies but does not feel comfortable to continue asking throughout the meeting.

- How might the interpreter be feeling? What might be the impact of this on parents' understanding? What could EPs do in response?

3. Scenario: The parents are perceiving the interpreter as an EP, and they ask for psychological advice many times during the EHCP meeting, which is making the interpreter understandably very uncomfortable.

- Reflections.