

**Social Representations and Special Educational Needs: The
representations of SEN among Sri Lankan, Tamil families and
educational professionals**

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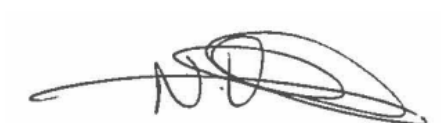
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Declaration

I, Natasha Kwan-Tat confirm that the work presented in this thesis is my own.
Where information has been derived from other sources, I confirm that this
has been indicated in the thesis.

Signed:

A handwritten signature in black ink, appearing to be 'N. Kwan-Tat', with a large, sweeping loop at the end.

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Abstract

In the United Kingdom, the Sri Lankan, Tamil population has grown as a result of asylum movements. Previous discussions about Special Educational Needs or Learning Disabilities within 'South Asian' communities have tended to overlook this community. Previous literature has highlighted that families with children and young people with learning disabilities and mental health problems from minority ethnic communities face challenges when accessing services (Raghavan, 2007). Given the differing cultural backgrounds of Sri Lankan, Tamil parents and educational professionals trained and practicing in London, this research aimed to develop an understanding of how Special Educational Needs (SEN) is understood and experienced by Sri Lankan, Tamil parents, Educational Psychologists (EP) and Special Educational Need Co-Ordinators (SENCOs). Social representations theory (Moscovici, 2004) provided the theoretical mechanism to explore the shared and unshared meanings and experiences of parents and professionals connected with children who have SEN, whilst taking into account cultural relevances.

A qualitative methodology was employed underpinned by a social constructionist paradigm. Data was collected in a London based local authority, which has experienced increases in numbers of the Tamil population over the past few decades. Episodic narrative interviews (Flick, 2009) were used to gather data. In total four parents, four SENCOs and five EPs were interviewed using a semi-structured format. Thematic analysis was used to analyse the narratives of parents and professionals.

Findings were presented in three sections. Overall the findings from the three participant groups signified the role of socio-cultural contexts in building representations and shaping practices. The dominance of the biomedical model in the discourse of professional's non-normative representations of SEN was highlighted in the SENCo's and EP's data. SENcos and EPs spoke of SEN in categorical terms and made direct references to legislation. Parents did not have pre-prescribed representations of SEN and made sense of their child's needs through various sources of information.

All three participant groups drew upon experiences of tension and conflict resulting from differences in how SEN was understood. Parents took an active role in supporting their child in the home and were pro-active in engaging with services.

Whilst specialised provisions in the form of a special schools were important amongst the SENCos and EPs, findings from parent's data highlighted tensions regarding ideas of inclusion and labelling of SEN. Power inequalities amongst Sri Lankan, Tamil parents and professionals are addressed, and the role of the EP as intermediaries between scientific and lay knowledge is discussed as a way forward in developing partnership with parents.

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List of Abbreviations

| | |
|-------|--|
| ASD | Autistic Spectrum Disorder |
| CYP | Child or Young Person |
| EHC | Education Health and Care |
| EP | Educational Psychologist |
| EPS | Educational Psychology Service |
| LA | Local Authority |
| LTTE | Liberation Tigers of Tamil Eelam |
| ONS | Office for National Statistics |
| SEN | Special Educational Needs |
| SENCo | Special Educational Needs Co-ordinator |
| SEND | Special Educational Needs and Disability |
| TA | Thematic Analysis |
| UK | United Kingdom |

Chapter 1 INTRODUCTION

1.1 Overview of the research

With National Statistics showing a progressive rise in net migration (White, 2017), the cultural landscape of London, the geographic centre point of this study and the context within which educational and health professionals are practicing, finds itself changing alongside the developments and increases of migration

In 2015 the non-UK born population was 8.6 million, a statistically significant increase when compared to previous years. Statistically London has the highest proportion of non-UK born residents (White, 2015). It is also the most ethnically diverse area in the UK and has the highest proportion of minority ethnic groups with the most common countries of birth being Poland, India and Pakistan.

Some have argued that certain wards in London can now be defined as 'super-diverse', a notion that looks beyond classifications such as ethnicity, social class, age, to address aspects of migration journeys, language, lifestyle and access to employment (Vertovec, 2007).

A local authority is an organisation that is responsible for all public services and facilities in a particular area. The Local Authority (LA) in London that is the focus of this study is home to the highest percentage of Indian born residents in London¹. The Office for National Statistics (ONS) states that in 2011, 40,824 South Asians lived in this LA, making them the largest

¹ Made anonymous for ethical purposes

community to be born outside of Europe in this area. The census category of South Asian is a heterogeneous group and refers to people from the Asian sub-continent - namely, India, Pakistan, Bangladesh, Sri Lanka, Nepal, Bhutan and Maldives. Amongst these subgroups, the Sri Lankan, Tamil community have a unique political history and diaspora in comparison to other named groups of South Asia (Siddhisena & White, 1999). It is a group that has grown steadily since the 1960s and as a result of asylum movements, has grown further in recent years (David, 2012).

Sri Lanka is the eighteenth most common country of birth for first generation migrants to the UK and the LA within which this research took place is home to 10,392 people born in Sri Lanka (White, 2017). ONS statistics further show that of all South Asian languages spoken, Tamil is the third most popular language spoken in this LA.

Discussions about learning disabilities within 'South Asian' communities tend to have overlooked the Sri Lankan, Tamil community. However, contact and interaction between education professionals and the Sri Lankan Tamil community have been notably increasing in the LA in which this thesis takes place. Anecdotal evidence from professionals within the LA have recounted differences and resistance in the decision-making process, especially regarding the labelling of SEN. For this reason, it was deemed important to develop an understanding of the Sri Lankan, Tamil population and raise their profile within research. The Sri Lankan Tamils are considered a settled community within Britain (Jones, 2016) and engaging them in research offers a distinctive opportunity to explore a group who have experienced a history which has included discrimination, war and the movement of refugees.

Between the ages of 5 and 34 years of age, the prevalence of severe learning disabilities among the South Asian communities is broadly three times higher when compared with the non-Asian community in the UK (Emerson et al., 1997; Emerson & Hatton, 2007). It is recognised that despite the higher prevalence of learning disabilities amongst this community, black, minority and ethnic (BME) groups tend to be under represented in accessing health and social care services and experience disadvantage and discrimination (DoH, 2012).

The drive to develop culturally sensitive services has become increasingly pertinent as migration continues to rise (ONS, 2017) and the needs of the population become apparent. The term “cultural competence” has been defined as a system which “acknowledges and incorporates-at all levels-the importance of culture, assessment of cross-cultural relations, vigilance toward the dynamics that result from cultural differences, expansion of cultural knowledge, and adaptation of services to meet culturally unique needs” (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003), p. 294). Discussion in this area has raised questions around the implications of complex migration on public services and have recognised that there is a need for services to adapt to diverse migrant communities, (Ahmad & Atkin, 1996; Phillimore et al., 2015; Shah, 1997; Vertovec, 2007).

In response to the changing profile of pupil populations, the DfE (2017) has recognised the increasing need for the education system to be culturally sensitive. Latest population statistics record that minority ethnic pupils made up 66.3% of the increase in pupil numbers in primary schools

between 2016 and 2017. Recent statistics show that the largest population of minority ethnic pupils in primary and secondary schools is among the Asian affiliated communities (DfE, 2017). Difficulties and barriers have been documented by previous studies which have provided fruitful insight into the experiences of South Asian families who have children with a learning disability. Barriers in language, having limited information and parents feeling that their culture was not understood are some of the challenges as reported by families, (Hatton et al., 2010; Hatton, Akram, Robertson, Shah, & Emerson, 2003; McGrother, Bhaumik, Thorp, Watson, & Taub, 2002). Disparities in the quality of health services for ethnic minority groups have included, preventative, diagnostic and therapeutic behaviours and the individual's interactions with health care providers, (Anderson, Scrimshaw, Fullilove, Fielding, & Normand, 2003; Beach et al., 2005; Betancourt et al., 2003).

It is worth considering however, that the process of delivering culturally sensitive services is more than just 'being mindful', (Campinha-Bacote, 2002). It is a matter which affects policy and takes time. Professional services that interact with parents whose children have SEN are aware that they need to be culturally sensitive, however, it is unclear how parents, and professionals who work with them, understand SEN in relation to the particular community needs of Sri Lankan Tamil parents. It is therefore important to take into consideration how differing knowledge systems may account for barriers in dialogue between services and hard to reach communities. Social representations theory (Moscovici, 2008) as a framework from which to explore this, provides a foundation from which to understand an individual's values, ideas and practices within a social context. Understanding how the Sri

Lankan, Tamil group, and the professionals who work closely with them (Educational Psychologists and Special Educational Need Co-Ordinators), represent Special Educational Needs, may facilitate collaborative communication and in turn positive partnership.

1.2 Aims

The study looks to draw upon social representations theory (Moscovici, 2004) in order to develop an understanding of how Special Educational Needs is understood and experienced in the context of England's education system. At the same time, it looks to develop an understanding of the experiences of Educational Psychologists and Special Educational Need Co-ordinators who have supported Sri Lankan, Tamil families within the context of pre-existing legislative practice.

The Sri Lankan, Tamil community will be brought to the forefront of this research, with the recognition that ethnic groups are influenced by their culture, religion, migration history, and pre- and post- migration geographical and social location. It is hoped that by hearing the parent's perspectives, LA professionals may begin to respond to the diverse and complex social setting in which they practice, (Nazroo, 2006).

Drawing upon the theory of social representations, it has been recognised that little research has focussed on the representations of professionals such as psychologists. EPs play an important role in bridging the gap between the lay person and science and for this reason play an influential role in the construction of social knowledge within the education sector. Engaging professionals and the organisational context of education

within this research may provide a critical perspective upon the practices taking place amongst the community it is working for. The research questions are as follows:

Research question 1. How do parents from the Sri Lankan, Tamil community, EPs and SENCos in a North-West London local authority represent Special Educational Needs?

Research question 2. What role does pre and post migration views of parents from the Sri Lankan, Tamil community play in their experiences of accessing services in a North-West London local authority?

Research question 3. What role does the community and services play in parents from the Sri Lankan, Tamil community experiences of supporting their child?

Research question 4. What has been the experiences of SENCos and EPs in supporting Sri Lankan, Tamil families in a North-West London local authority?

1.3 Organisation of thesis

The following chapter will address the context of SEN in England, the Sri Lankan, Tamil community and previous literature which has explored the experiences of South Asian families who have children with learning disabilities. In Chapter 3, a discussion of Social Representations Theory will take place in relation to the topic of SEN. Here, the interplay of scientific lay knowledge and the implications of different paradigms in conceptualising SEN will be discussed. Chapter 4 outlines the methodology, including research design, data analysis and ethical considerations. The results of the data

analysis from the three participant groups will be presented in Chapters 5, 6 and 7. Each chapter focuses on the perspectives of the key stakeholders: parents, SENCos and EPs. A discussion of the findings will take place in Chapter 8 in which implications for educational professionals will be discussed.

CHAPTER 2

EXPLORING SEN, MIGRATION AND THE SRI LANKAN, TAMIL COMMUNITY

2.1. Chapter Overview

The chapter will discuss the legislative context for SEN in the UK. An overview of the British Sri Lankan, Tamil community will be provided, including their migration history and settlement in the UK. Literature highlighting the experiences of South Asian families with children with disabilities will be discussed.

2.2. Definitions, SEN legislation and prevalence

A number of terms are used to refer to learning disability internationally; 'Intellectual Disability' is used by the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-V), and refers to disorders with onset during the developmental stages. It refers to both intellectual and adaptive functioning deficits in three areas; conceptual, social and practical. Another term used by the World Health Organisation's International Classification of Diseases (World Health Organisation, 2013) includes 'Intellectual Developmental Disorders'.

In this research however, "Special Educational Needs" (SEN) will be the language used to form the line of reasoning. In part, this is because the interviews were designed using the term "Special Educational Needs" (SEN) to communicate with participants and it is a legal term adhered to in the education system and legislation in the UK (DfE/DoH, 2015). It is the vocabulary educational professionals, including Educational Psychologists,

Special Educational Needs Co-Ordinators and parents are likely to use in their discourse about learning disability. When referring to “Special Educational Needs”, the abbreviation SEN will be used. However, a significant body of literature used in this thesis uses the term ‘learning disability’, therefore, discussion surrounding previous research will use this term.

Educational Psychologists (EP) in this research are employed and commissioned by the LA. As outlined in SEND legislation (DfE/DoH, 2015), EPs are one of many specialist services commissioned to provide their services to support schools, families, children and young people. EPs work alongside Special Educational Need co-ordinators and teachers in the school setting as well as with parents in their home or school.

Special Educational Need co-ordinators (SENCOs) are designated teachers who are responsible for co-ordinating SEN provision within the educational setting. SENCOs work within the school setting and liaise with families and specialist agencies (such as EPs, speech and language therapists or occupational therapists) in the process of supporting children with SEN.

From a legislative perspective, The Special Educational Needs and Disability Code of Practice (DfE/DoH, 2015) provides statutory guidance on duties, policies and procedures relating to Part 3 of The Children and Families Act 2014 (the Act). It focusses on providing for children/young people with SEN and disabilities by guiding schools/colleges to carry out their functions under the Act. The SEND Code of Practice (2015), puts forward key principles which local authorities must have regard to, including the involvement and

participation of children and their parents, opportunities for greater choice and control over the support they receive. The principles are designed to support collaboration between education, health and social care, the early identification of children and young people's needs and early intervention to support them. High quality provision to meet needs and a focus on inclusive practice is also supported by the principles. Various organisations are expected to draw upon the Code of Practice including; Local Authorities; governing bodies of schools; early years providers; alternative provisions; and NHS trusts. Educational professionals are also guided to refer to; The Special Educational Needs and Disability Regulations (2014), The Mental Capacity Act (2005) and Equality Act 2010.

As defined in the SEND Code of Practice (2015):

A child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for him or her. A child of compulsory school age or a young person has a learning difficulty or disability if he or she:

- has a significantly greater difficulty in learning than the majority of others of the same age, or
- has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions (pp.15-16).

The legislation, which saw changes from the SEN Code of Practice (2001), now covers children and young people from birth to 25 years old and places greater emphasis in supporting those with SEN to make successful transitions to adulthood.

A fundamental principle of the SEND code of practice (DfE/DoH, 2015), is the close involvement of children, young people and parents in the planning, commissioning and reviewing of services (DfE/DoH, 2015). Local authorities have a duty to consult with children as well as parents in reviewing service provisions, making decisions and ensuring effective participation in decisions about the support available to them in their local area. For example, parents may express a preference for provision or contribute to the educational intervention to support their child. There is emphasis on young people and parents having greater choice and control over the support they receive.

Within this remit, the notion of the authority imposing power for the passive participant has been reframed, therefore allowing for greater control and choice in the decision-making process and provision of support. What impact such collaborative working may have for minority ethnic communities is worth considering, as it is generally acknowledged that they are more likely to have difficulties in accessing services, (Dura-Vila & Hodes, 2012; McGrother et al., 2002). It is therefore more pertinent than ever to consider cultural expectations and norms during 'person-centred planning' approaches within education, taking into consideration the dynamics of extended communities as well as the individual (Heer, Rose, & Larkin, 2012).

EPs and SENCos are positioned at the interface of the families, children and young people, and their statutory roles. As professional practitioners they have opportunities to share and implement expert theoretical knowledge, whilst at the same time sharing a platform for social communication with parents and other professionals. Joint planning and

commissioning of services between education, health and social care services are central to the graduated approach to identifying and supporting children and young people with SEN. Local authorities have a duty to ensure integration between educational provision, health and social care in order to improve the quality of provision for those with SEND, (Section 25, Children and Families Act 2014,) and EPs and SENCos have a duty of being part of this joint working agenda.

The LA has a responsibility in assessing the needs of children and young people with SEND and ensuring effective provision for those with high needs, (Children and Families Act, 2014). Children and young people with more complex needs and who are in need of support beyond the early years, school or college setting are regarded as having high needs and may apply for an Education, Health and Care (EHC) Plan. An EHC plan is a statutory document which outlines the child's needs and the provision they should receive in order to secure the best possible outcomes for them. Collaborative input from parents, CYP, EPs and SENCos contribute to the assessment and review process of EHC plans in line with the SEN Code of Practice (DfE/DoH, 2015).

Taking into consideration the prevalence of SEN, national statistics from the Department for Education's 2016 school census reported 236,805 individuals identified as SEN with an EHC plan (2.8% of the total pupil population and an increase of 640 since 2015). Of these, 25.9% of pupils have Autistic Spectrum Disorder as a primary need. Additionally, 991,980 children were reportedly on SEN support (11.6% of the total pupil population). Of these, 26.8% have Moderate Learning Difficulty as a primary need,

(Department of Education, Special educational needs in England, 2016.) The LA in which this research was conducted has 2.6 percent of the pupil population identified as SEN and with an EHC plan, (Department of Education, Special educational needs in England, 2016).

2.3 The Sri Lanka Tamil community

Sri Lankan, Tamils are the largest group amongst the British Tamil population which comprises of migrants from south India, Mauritius, Malaysia and Singapore, (David, 2012). Tamil is the main language of this community. The Tamil language belongs to the Dravidian family of languages spoken by those who live primarily in South India (Tamil Nadu) and Sri Lanka. The majority of Sri Lankan, Tamils are of Hindu faith whilst the minority follow the Muslim or Roman Catholic faith.

2.3.1 The Sri Lankan Education System

The United Nations Development Programme (2000) classifies Sri Lanka as a developing country. The country's social indicators, as measured by life expectancy, education and standard of living, are relatively high for the region (UNICEF, 2009). Gender parity has been evidenced regarding access to education and literacy rates are shown at 90.7% (UNICEF, 2009).

With the growing literate population, education is valued in Sri Lanka. 95% of children between 5-14 years old and 65% between 15-19 years participate in school (Muttiah, Drager, & O'Connor, 2016). Despite these statistics, analysis have highlighted discrepancies between provinces as a result of unequal economic development, a history of civil conflict and regional imbalances, (UNICEF, 2009b).

As reported by Muttiah, Drager, & O'Connor (2016), statistics indicate that 10.6% of school age children present with a disability. Challenges in facilities, resources and teacher training have led to difficulties in attendance in education and the application of inclusive practice (UNICEF ROSA, 2007).

Whilst legislation and policy have passed to encourage inclusive practice for those with disabilities, there is currently no education law that mandates children with disabilities to receive education (Muttiah et al., 2016). Additionally, stigma and negative attitudes attached to disability often make communities unwilling to admit they have a family member with a disability, consequently preventing children from accessing specialist resources (Kalyanpur, 2008).

There are four educational settings for those with disabilities in Sri Lanka: specialised schools, special education units within regular education schools, inclusive regular education schools, and special resource centres attached to regular education schools (Hettiarachchi & Das, 2014).

Despite the free opportunities for school, Furuta, (2006) discusses the continuing challenges faced by children with disabilities in Sri Lanka in accessing education. Barriers include, a limited number of rural schools having special education units, administrators denying children with disabilities admission to schools, an insufficient number of qualified teachers, and parents lacking awareness regarding educational facilities (Furuta, 2006).

Recognising a dearth in disability studies in Sri Lanka, Muttiah et al., (2016) set out to explore three key questions; Who are the children receiving special education services? (Sampled across three provinces in Sri Lanka);

What are the current special educational practices in these provinces?; What are parents' views on communication supports, inclusion and literacy? Muttiah et al., (2016) acknowledged it necessary to explore these questions in order to shape appropriate government policies and special education in Sri Lanka.

Parents shared their concerns over the gap in services for children in government schools older than 14 years of age and young adults. Reports from parents highlighted that an age limit of 14 years was imposed on special education units. Additionally, adult services for those with disabilities as well as transition to adulthood were limited.

Muttiah et al., (2016) argued for the need to make school settings accessible for all needs. Their findings highlighted that children with the most 'visible' needs such as Down Syndrome or cerebral palsy had access to services and were mobile and physically independent. Approximately 10% of the total sample had a diagnosis of autism spectrum disorder suggesting an awareness of this need. Results highlighted services did not reach out to those with severe mobility and communication difficulties.

Children with severe needs were most often refused entry into schools due to barriers in teacher training and resources. As Muttiah et al., (2016) identified, there is a need to develop staff confidence and expertise in supporting those with disabilities. This has been further reported by UNICEF ROSA (2007).

The need for professional support from Speech and Language Therapists to work in government schools were also highlighted, as well as the need to train teachers on communication support and strategies. At the

time of research, speech and language therapists were not employed by government schools in Sri Lanka (Muttiah et al., 2016).

Overall, research has indicated the need to improve and pay further attention to inclusive education for special needs in Sri Lanka. This includes, increasing teacher capacity and skills; integrating more services such as speech and language therapy; allowing more specialised in class adult support; and investing in resources to accommodate those with more severe disabilities.

2.3.2 Migration and mobility. Movement of the Sri Lankan, Tamil community to the UK can be traced back to the early 1960s when many of the country's well-educated population migrated for work or higher education (Siddhisena & White, 1999). Many who arrived were high-caste professionals with proficient linguistic skills who engaged in professional work. A younger population also migrated during this time to study at universities. As a result of the enactment of the 1956 Sinhala Only Act, Sinhalese was made the official language of Sri Lanka in opposition to Tamil, therefore causing tensions and placing the Tamil speaking population at a disadvantage, (Deegalle, 2006). Migration from Sri Lanka at this point was the result of discriminatory employment policies in the government sector and riots in 1958, which found Tamils attacked, (Velamati, 2009). Migration to Britain increased during the 1960s and 1970s as discrimination against Tamils continued.

Strained relationships between the majority Sinhalese and the minority Tamil communities resulted in three decades of conflict between the Government of Sri Lanka and the Liberation Tigers of Tamil Eelam (LTTE).

The civil war which lasted from 1983 to 2009 led to a large exodus of Tamils from Sri Lanka. Many Tamils left as refugees and sought asylum in Britain as well as Western Europe, North America, India, Singapore, Malaysia and Australia (Daniel & Knudsen, 1995; David, 2012).

In recent years, the Sri Lankan population has continued to grow through onward migration to the UK from initial asylum destinations across Europe (David, 2012) and an increase in regrouping and relocating of family groups from Europe to the UK. Marriage migration, whereby Tamil women from Sri Lanka engage in transnational marriages with Tamil men who arrived in the UK as refugees, has been a factor in recent waves of migration. Sri Lankan, Tamils are now considered a settled community within England (Jones, 2014).

2.3.3 Community, culture and identity. David (2012) emphasises how issues of resettlement, relocation and dislocation are significant factors in the lives of those who arrived as refugees. Under the backdrop of such political conditions, culture and religion have been observed to play significant roles in the settlement and diasporic place-making of the population (David, 2012). For example, previously settled communities invested in helping new arrivals through means of organising accommodation, providing support in accessing services, and providing and facilitating employment (Velamati, 2009). Participation in religious practice, having access to places of worship and having kinship ties have been reported as reasons for moving to certain areas of London (Bloch, 2002).

Employment was facilitated in the UK as a result of the high education and skill levels of the population (Velamati, 2009). Those who migrated in the UK after 1983 settled into divergent fields, with Sri Lankan groups being strongly represented in health and education, business services and clerical occupations (Velamati, 2009).

It is recognised that those who have migrated as refugees have experienced the dis-locatory elements of forced migration and consequently face redefining their identity. The distinctive make-up of the Tamil community has attracted research which has explored how the experiences of migration have affected cultural and ethnic identities (David, 2012; Jones, 2014, 2016). In a study which adopted an ethnographic approach in British temples and in the Tamil community, David (2012) aimed to explore how cultural expressions have shaped the migratory experiences of the Sri Lankan, Tamil community in London. In shaping the context of this research, the researcher considered the impact in which forced migration and powerful dislocatory elements in the Sri Lankan, Tamil's lives may have had upon their identities. Taking an anthropological approach, David (2012) observed that dance, religious customs and ritual practices were essential in maintaining the Hindu identity and a distinctive part of the Sri Lankan, Tamil's migratory experience. Tamil cultural expressions were observed as vital in creating a discourse of solidarity, kinship, tradition and survival across local and global trajectories of the Tamil communities.

Little is written regarding the methodology; details regarding the duration of data collection, nature of immersion in the community, specific locality and methods of data collection are not outlined. Critical reflection of

this research raises questions regarding David's (2012) depth and duration of data collection and whether they meet the traditional criteria of ethnographic methods. As described by Hammersley, (2006), 'part-time', geographically and socially segmented data collection will have implications upon conclusions drawn from specific observations from one particular locality. Data from ethnographic research is also at risk of disregarding the social context and temporal cycles affecting the situation being studied. For example, the importance of dance and ritualistic traditions in David's (2012) study may have been accentuated as data were collected in religious temples – naturally a place for customs and religious practices to take place. In line with this, Brewer (1994) emphasises the need for ethnographic research to take on a reflexive and critical approach and a strength within David's (2012) research was the exploration of social processes and context surrounding the Sri Lankan, Tamil communities.

Language has a significant role in the socialisation of individuals and their affiliation with the Tamil culture (Canagarajah, 2008). The Tamil language has been deemed crucial in sustaining ethnic identity amongst Sri Lankan, Tamils who have migrated to the west (Amarasingam, 2010) and has been found to provide diaspora groups with opportunities to communicate between different communities, resolve tensions in diverse identities and negotiate relationships.

In a study which explored the interaction between religion, the Tamil language and ethnic identity in the lives of immigrant youths in Canada, Amarasingam (2010) highlighted the significance of symbolic transnationalism in the construction of their identity. Individuals within this study expressed the

importance of attending a place of worship as a means for passing on their cultural heritage. The use of the Tamil language, as well as simple acts such as wearing saris and eating with their hands were seen as essential in maintaining ethnic identity. In London, efforts have been made to engage younger generations in cultural affairs through establishing Tamil schools in which the Tamil language, arts, music, dance and sports are taught (David, 2012).

It is important to think about cultural practices of this group in exploring the wider research question. Various theorists, notably Greenfield, Keller, Fuligni, & Maynard, (2003) have argued that human development is conceptualised as a cultural process whereby children develop as active participants in their cultural communities so that individuals engage in shared endeavours and build on cultural practices of past generations. It is recognised that each culture develops its own system of beliefs which dictates what socialisation practices are needed in child development, (Greenfield & Cocking, 2014). Two distinct sociocultural pathways have been theorised; 'individualism' whereby independence of the self in relation to others is reinforced and 'collectivism' whereby interdependence and relatedness with others is prioritised (Triandis, 1989).

Western ideals reinforce individuality of the self and independence of others, encouraging behaviours such as being unique, expressing self and promoting own goals. Contrastingly, other cultures such as South Asian ones, stress the fundamental relatedness of individuals to each other. Within an interdependent culture, belonging, promoting others' goals and occupying one's proper place are encouraged (Markus & Kitayama, 1991).

It has been proposed that these differences in socio-cultural pathways lead to different self construals; an independent self or interdependent self, which, in turn affect cognition, emotion and motivation. Differences also arise in the development of socialisation values such as child-rearing practices (Triandis, 1989). Child rearing patterns in individualistic cultures promote self-reliance, independence and self-actualisation. Contrastingly, in collectivist cultures, child-rearing emphasises the collective self and relationships with other.

Conceptualisations of constructs such as intelligence, are also influenced by the different values held by different groups. For example, Rogoff, (2003) has highlighted research which found that whilst Western society value literacy intelligence as a way to promote success, West African mothers place higher value on the social functions of learning in order to enhance social relationships and to support children participating with their local communities.

How professionals in England and migrants engage with certain phenomenon such as SEN because of differences in cultural processes are worthy of note. Additionally, the different trajectories of migration and settlement of the Sri Lankan, Tamil community contribute to the development of a multi-layered and multi-valent diasporic space (David, 2012) offering an opportunity for this research to explore a unique group within the South Asian community.

2.4 South Asian families and learning disabilities

Research evidence around ethnic minority families who have a child with a disability have predominantly regarded larger South Asian populations and their findings have been generalised to account for South Asians as one group (Bhaumik, Tyrer, McGrother, & Ganghadaran, 2008; Dura-Vila & Hodes, 2009; E. Emerson, Robertson, & Wood, 2004).

Whilst a critique of this gap is an evident rationale for undertaking this study, an evaluation of the literature from this wider group will provide a summary of the overall experiences and issues which have been raised by research.

2.4.1 Resources and accessing services. Studies have found that children and young people with learning disabilities and mental health problems from minority ethnic communities face barriers when accessing services (Raghavan, 2007). A systematic review of literature reinforced that South Asian children, adolescents and adults with learning disabilities in the UK had lower use of mental health services than White British comparison groups, (Dura-Vila & Hodes, 2012b).

Service need and use amongst South Asians was assessed in a cross-sectional comparison between South Asian (N = 206) and White British (N = 2334) individuals registered on the Leicestershire Learning Disabilities Register in 1991 by McGrother, Bhaumik, Thorp, Watson, & Taub, (2002). Interview data was also collected using semi-structured interviews over the period of 1987 to 1998. Analyses found that South Asians made significantly lower use of psychiatric services, residential care and respite care than the

White group. When community services were accessed, South Asians reported substantially greater unmet needs (McGrother et al., 2002).

The implications of carrying out this study over an 11-year period was not acknowledged by the authors, therefore it is worth noting that changes in demographics, migration patterns or system structures were not recorded in this research. Although South Asian and white populations are both heterogeneous groups, analysis approached each as a homogeneous group, thereby neglecting to differentiate between the prevalence, differences in socio-economic positions or housing between each subgroup. As recognised by McGrother et al., (2002) differences in cultural compositions may have informed analysis for ethnic group differences.

In relation to limitations within services, Hatton et al., (2010) interviewed 14 family carers of adults with learning disabilities in a city in Northern England. Seven families were from minority ethnic groups, (five families reported themselves as Muslim, one as Hindu, and one as Christian) and seven families were from the majority ethnic group of the local area. Limitations within services were reported in terms of timing, duration, flexibility and relevance. A constant change in service staff and service delivery contributed to ethnic minority family's negative experiences of services. Negative experiences of service support were compounded by reports that services did not communicate with families in their preferred language. Language and ethnicity was also found to be an important barrier to accessing services in a study by Fazil, Bywaters, Ali, Wallace, & Singh's, (2002).

The small sample in Hatton et al.'s, (2010) study meant that there were limitations in understanding nuances and variabilities amongst the different Asian communities. As with McGrother et al's.,(2002) study, Asian subgroups were not differentiated or identified, therefore not allowing for subcultural differences to be identified. Having collected data in one city in the UK also has implications for the generalisability of the data. Perceptions of services as lacking cultural understanding has reportedly led to feelings of isolation, forced dependency on family members and anxiety and distress. Collectively, negative experiences appear to result in a lack of trust in service provision, (Hatton et al., 2010; Vernon, 2002). Greater formal service support and a great ability to meet practical challenges has been related to good practice in the disclosure process. Good practice in disclosure includes sharing information in the parent's preferred language, providing clear information about the child's disability and responding to parental concerns. This also has an impact on the meaning and understanding parents place on their child's learning disability, (Hatton et al., 2003).

This is worthy of note as we consider how SEN diagnoses are disclosed to parents within education. Although multidisciplinary work is encouraged (DfE/DoH, 2015), more often than not, medical professionals have the privilege of disclosing diagnoses such as autistic spectrum disorder (ASD). Discussions with medical professionals are pertinent for parents, however the impact of isolated and disjointed conversations with medical, school, and LA professionals (i.e. EPs) should be considered in the context of working with Sri Lankan, Tamil parents.

As well as difficulties in accessing services, material deprivation has also been explored as a discriminating factor for South Asian families with disabled children, (Fazil et al., 2002). The role of material circumstances, the use of formal services and social and psychological well-being of 15 Pakistani and 5 Bangladeshi parents living in Birmingham, England were explored using interview and questionnaire formats. Parents reported unsuitable housing for their child's disability and difficulties in moving to more suitable accommodation. Limited contact with professional service providers appeared to be the result of difficulties in understanding the role of service providers and obstacles in accessing information.

2.4.2 The role of the community. As discussed earlier, the wider Sri Lankan, Tamil community, including religious, cultural and language-based establishments have contributed to the settlement of new arrivals into Britain. As the Sri Lankan, Tamil population increases, the role of the community amongst families with children with a learning disability is worthy to consider, especially as caring for a child with disabilities has been linked to elevated levels of stress, poor mental health and depression (Fazil et al., 2002; Hatton et al., 2010; Singer, 2006). With parents reporting feelings of isolation, the wider community play a part in the multi-faceted factors which contribute to the poor wellbeing of families. Evidence of the perceived social exclusion and limited social support by parents has been widely reported (Croot, Grant, Cooper, & Mathers, 2008; Fazil et al., 2002; Hatton et al., 2010; Vernon, 2002).

In a northern city in the UK, Pakistani parents with a child with LD, reported exclusion from religious and social activities because of the

community's lack of acknowledgement of the family's needs (Croot et al., 2008). Negative ideas and stigma amongst the local community were also discussed with parents highlighting feelings of being judged, scrutinised and discriminated against. Parents reported that the responses they faced from their own Pakistani community, were different to those from wider society and this impacted on their willingness to attend Pakistani community events.

South Asian family carers interviewed in Hatton et al's (2010) study reported similar feelings of unacceptance of disability by the local community. Differences in attitude between the English community and their own Asian community were commented on, with one participant perceiving that the English community as more accepting, commenting that they 'do not mind at all' when speaking about learning disabilities. This compared to feelings of being unable to talk to their own Gujarati community. Another participant reported her desire to protect her son from 'nasty tongued' comments and therefore chose not to share information about his learning disability. In line with Croot et al.,'s (2008) study, feelings of isolation and difficulties of being part of their Asian community was reported. Such findings of being marginalised within the community, highlight the role sociocultural contexts have on stress and wellbeing of families. Feelings of discrimination on the grounds of disability and race by service providers as well as within communities have also been reported (Hatton et al., 2010; Vernon, 2002).

2.4.3 The role of beliefs and attitudes of disabilities Researchers have asked whether the attitudes and beliefs of South Asian families caring for children with a disability have contributed to the low uptake of health and social services. The important role of culture in shaping the beliefs and

perceptions of disability are apparent in South Asian parents with disabled children (Yousafzai, Pagedar, Wirz, & Filteau, 2003) and it has been suggested that theological beliefs and the associated stigma of having a disabled child have played a role in this.

A qualitative study carried out by Bywaters, Ali, Fazil, Wallace, & Singh, (2003) with 19 Pakistani and Bangladeshi families found that theological explanations of disabilities were only used by a minority of the participants, particularly when parents were poorly informed about the medical understanding of their children's impairment and about the management of their child. Theological ideas included disability being 'God's will' or a test or punishment from God. Parents expressed theological or biomedical factors in isolation of each other which led to the researchers to conclude that poor uptake of services were likely to be associated with practical and material barriers, rather than religious beliefs.

In-depth interviews focussing on Pakistani parents and a grandparent of children with a disability living in a northern city in the UK found that all parents offered theological explanations of some sort for their children's disability and were offered alongside biomedical explanations (Croot et al., 2008). Unlike Bywaters et al's., (2003) study, theology and biomedical were not treated as exclusive from each other and referred to beliefs they had heard of from others in the community. Croot et al., (2008) discussed the sophisticated way in which parents incorporated theological and biomedical constructs, for example, choosing to turn to a biomedical discourse when needing to dispel perceived unhelpful or negative ideas from others. This difference in findings suggests that migratory patterns between families may

have had an impact on perceptions and beliefs. As noted by Croot et al. (2008) families who had come from large cities in Pakistan or Bangladesh, or where both parents were brought up in the UK, may have developed different ideas about disability and made more references to biomedical explanations compared to those who came from a smaller region of Pakistan, therefore implicating the importance of social context in developing knowledge.

The perspectives and attitudes of British South Asian (N = 355) and White British (382) adolescents towards the inclusion of those with learning disability were explored by Sheridan & Scior, (2013). Results from a questionnaire procedure indicated that British South Asians were less in favour of the social inclusion of people in the community with a learning disability than White British young people. Fatalistic beliefs that learning disabilities could be cured was reported in this study. An earlier study, which found similar attitudes discussed the possibility that attitudinal differences may not simply be the result of cultural differences but linked to the fact that Asian families were less informed about the cause of learning difficulties compared to White British families (Fatimilehin & Nadirshaw, 1994).

The role of how religion and culture can impact on how parents collaborate with professionals has been highlighted by Jegatheesan, Fowler, & Miller, (2010) who found that South Asian Muslim parents who have children with autism strongly contested expert's understandings of autism which they perceived as undermining of their child's development. Instead, parents drew upon their religious principles of Islam and aimed to raise their children as normally as possible, ensuring that they are included in ordinary social, linguistic, and religious practices at home and within the community.

These findings have implications for how professionals collaborate with parents and the recognition that families are more likely to adapt and engage in practices that are consistent with their goals and beliefs.

2.4.4 Limitations of studies. The studies presented here have been useful in providing an overview of some of the issues relevant to the South Asian families taking care of disabled children, however no studies were inclusive of Sri Lankan communities. Differentiation by migration status (i.e. first or second-generation migrants), socio economic status or religion were not accounted for in the above studies therefore variations in sub groups cannot be discussed or associations between culture and religion made.

The generalisability of results to the wider South Asian community are limited due to research being carried out in one locality and the small sample sizes of the qualitative studies. The prime focus of many of the studies were the Pakistani and Bangladeshi communities (Bywaters et al., 2003; Croot et al., 2008; Fazil et al., 2002; Hatton et al., 2003) who are of Muslim faith. Although religion and culture are deeply intertwined, they are not comparable to the Sri Lankan community who are of Hindu, Muslim or Christian faith, therefore assumptions based on prior research evidence cannot be made for the Sri Lankan, Tamil families.

2.5 Chapter Summary

In this chapter the legislative context for SEN in the UK was discussed. A description of the British Sri Lankan, Tamil community was provided, including their migration history and settlement in the UK. Key literature highlighted the experiences of South Asian families with children

with disabilities which could potentially be significant to the Sri Lankan, Tamil community. Barriers in accessing formal systems and structures were noted as well as experiences of social exclusion. The meaning and explanations parents gave for their child's learning disability appear to be related to how well they had been informed about their child's disability and the nature of the disclosure process. The next chapter will present Social Representations Theory as a framework to understanding how parents and educational professionals understand SEN.

Chapter 3 Theory of Social Representations

3.1 Introduction

This research draws upon the theory of Social Representations to explore how SEN is understood and experienced by Sri Lankan, Tamil parents, EPs and SENCos in the context of England's education system. Social representations form the backdrop from which ideas, attitudes and behaviours are evaluated and justified (Joffe, 1996) and provides us with a way of exploring social knowledge and how meaning evolves through culture, social environment and social interaction, (Moscovici, 1988). As such, social representations theory provides the theoretical mechanism to explore the shared and unshared meanings and experiences of parents and professionals connected with children who have SEN, whilst taking into account cultural relevances.

A social representation has been described as a 'preparation for action'; behaviour and the network of relations that surround it are made meaningful through the constellations of beliefs and social practices embedded in the action (Moscovici, 2004). The actions taken are the result of reconstructing and reconstituting the elements in the environment so that views and opinions of individuals are adapted and adjusted to the particular occasion and interaction taking place. In such social contexts, language is given a central role to the communication and sharing of knowledge (Herzlich, 1973).

The significance given to socio-cultural influence on forming Social Representations raises questions around how parents from Sri Lanka and UK

educational professionals conceptualise SEN given their differing backgrounds. The interplay between different knowledge bases and worldviews when these groups come together will be explored using the theory of social representations.

This chapter will now provide an overview of social representations theory and explore its application to this research. The following areas will be explored; the relationship between scientific and lay knowledge; how new knowledge becomes embedded in pre-existing knowledge bases; and the implications of power relations upon communication.

3.2 An overview of Social Representations

Social Representations theory was developed by Serge Moscovici (1961) in La "Psychanalyse, son image et son public" and soon after became incorporated into Herzlich's, (1973) research of representations of health and illness.

As a social psychological theory, research employing social representations has been applied broadly across different countries and has also featured quite prominently in the area of health, mental health and community (Gervais & Jovchelovitch, 1998; Howarth, 2001; Joffe & Bettega, 2003; Morant, 2006) Moscovici defines social representations as:

a system of values, ideas and practices with a twofold function; first, to establish an order which will enable individuals to orientate themselves in their material and social world and to master it; and secondly to enable communication to take place among the members of a community by providing them with a code for social exchange and a code for naming and classifying unambiguously the various aspects of their world and their individual and group history.

(Moscovici, 1973 pp.ix- xiv)

Establishing a shared reality enables the possibility of understanding, communication and collaborative engagement. In being intertwined with wider society, social representations essentially structures one's understanding of reality in the context of collective thought, (Moscovici, 1988). Within collective society and culture lies the essential symbolic functions, ideas and content which provide the foundations from which social representations are built. Through culture and education, social constructs become projected or transcribed into symbolic forms and reified in artefacts, i.e. tools, monuments, documents and institutions.

As well as provide meaning, collective representations in the form of myth, beliefs or political ideologies allow communities to solidify and shape actions and thoughts around established identities (Van Niekerk & Boonzaier, 2015 ; Renedo & Jovchelovitch, 2007).

As a result, collective representations have implications for identity formation, community integration and social cohesiveness (Jovchelovitch, 2007). In order to understand the true construct of a social representation, it is important to observe the social context from which it has come from.

Emphasising the notion that an individual's reality does not originate in isolation, Joffe, (1996) draws parallels with a new born baby's acquisition of knowledge within a world of existing representations and adults who develop knowledge of new phenomenon such as a disease (i.e. AIDS).

Researchers working within social representations theory have largely drawn on qualitative approaches for exploring the relationship between the social sphere and the individual. For example, Niekerk & Boonzaier utilised

individual episodic interviews and drawing methods to explore the complexities of intimate partner violence within two marginalised communities in Cape Town, South Africa. The researchers were in pursuit of exploring violence against women in contexts which differed from existing North American 'individualised' and western viewpoints. Niekerk and Boonzaier (2015) recognised that in contexts such as South Africa, the individual and the social are closely linked together. It is this interrelationship between culture and individual behaviour which led to their questioning of how the southern African cultural context can broaden understanding of how and why gender-based violence occurs. The socio-cultural context and the social groups within which partner violence had occurred were found to be deeply interwoven and intimate partner violence was closely linked to the social arena in which it took place.

Howarth (2002) also undertook focus groups with young people in Brixton to gain an in-depth understanding of how the struggle for recognition and esteem permeates everyday experiences in the context of young people living in Brixton, South London, UK.

As a social constructionist perspective, the in-depth information that can be provided by such methods lends themselves to exploring the interwoven wider sociocultural contextual with the individual (Niekerk and Boonzaier, 2015). Unlike quantitative approaches which capture a moment in time, qualitative methods allow the researchers to document the transitory nature of the social world. The episodic interview format (Flick, 2009) for example seeks both experiential and semantic knowledge that incorporate past, present and future.

Research into social representations recognises that the social milieu and the individual cannot be separated. Culture and the social interactions which take place support the maintenance, generation and construction of reality as was observed by Jodelet's, (1991) research into the social representations of madness.

With this to consider, knowledge being held by Sri Lankan, Tamil families and educational professionals will be shaped fundamentally by the social frameworks each group adhere to, making it essential to recognise the variability of enculturation between each group. In the context of this research, individuals who train as EPs or work as SENCOs within schools would have engaged in dialogue, theory and policy embedded within western culture. Migrants who have recently arrived from Sri Lanka are likely to have variable avenues of learning about SEN and an understanding embedded in their Sri Lankan, Tamil origin. It is for this reason that the varying worldviews between Sri Lankan, Tamil parents, SENCOs and EPs will be explored and consideration taken of how the reified knowledge of SEN is translated into consensual knowledge.

3.3 The interplay between scientific and lay knowledge in exploring SEN

Moscovici was deeply concerned with the interactions between scientific knowledge and common knowledge in the process by which phenomena become embedded as social representations. In the context of this research, this is particularly relevant to the ways in which professional services and parents interact or provide support for children with SEN. Moscovici, (2000) makes a distinction between consensual and reified universes in discussing the process by which social representations takes

their place in a “thinking society”. By this definition, Moscovici viewed thoughts as being constructed through social interaction - talk and actions therefore making the essence of a social representation inextricably linked with collective belief systems and society.

The consensual universe takes the form of common sense whereby all individuals are of equal status and use conversation as a means to share and gain knowledge; it is here that social representations are positioned. The reified universe is one of science. Here, objects lack identity and individuality is irrelevant. Reified knowledge is devoid of emotion and is given status to impose its authority over individual thought and experience (Moscovici, 2000). Professional practice, including those of EPs, are subject to reified knowledge; through their training, the literature they read as well as in the conversational discourse shared between colleagues. In the context in which this research takes place, reified knowledge about SEN places professionals at an automatic advantage. However, in this thesis, attention is drawn to the interplay between the reified knowledge of professionals and reified cultural forms of knowledge presented by parents.

The popularisation of scientific knowledge takes place through mass media and school education. In this way ‘expert’ knowledge becomes simplified and transformed amongst lay discourse (Wagner, Elejabarrieta, & Lahnsteiner, 1995). For example, biomedically based AIDS information was spread to a wider audience through mass communication in the 1980s so that people were able to crystallise their ideas about a phenomenon which little was known about at the time (Joffe, 1996).

Of particular interest to Moscovici was the diffusion of scientific knowledge into common knowledge and the complex process by which social representations are formed and transformed (Joffe, 1996). Fundamentally, social representations are not static, meaning that ideas, concepts and insights are susceptible to continued developments. Its dialectical nature allows for scientific insight to permeate societies and contribute to social evolution.

Moscovici endeavoured to instil appreciation for ‘common knowledge’ that is grounded in language and everyday life. Moscovici set out to ‘rehabilitate’ common sense and understand its relationship to science and ideology. He took a stance against Marxist views that scientific knowledge was superior to common knowledge and the need for scientific knowledge to strip away “ideological, religious and folk irrationalities” (Moscovici & Marková, 1998, p. 375). With this approach, Moscovici, (2004) noted how it would be possible for scientific investigation to instil a reliable way of controlling societies which are becoming increasingly diversified from greater mobility and heterogeneous cultural practices.

Related to the area of health research, discussions surrounding HIV prevention in Uganda has recognised the importance in exploring how scientific models are translated into ordinary thinking (Ngobi, 2015). In Uganda, a model for behavioural change to prevent HIV is known as ABC; Abstinence, Be faithful and Condom use. Ngobi (2015) highlighted that in spite of accurate knowledge of ABC, high levels of HIV persist amongst high risk groups such as sex workers. This research considered that in order for effective behavioural change to occur, social representations theory could

contribute to a better understanding of how scientific ideas such as ABC are translated into ordinary thinking. As argued by Ngobi (2015), analysis of the dissemination of ABC may improve understandings of behavioural change processes and support the efficacy of HIV prevention interventions.

In relation to this research, this has implications for parents from Sri Lanka who find themselves embedded in a world where medical discourses and approaches take precedence over cultural resources like religion or traditional models of parenting style.

Moscovici argued for the power mass communication can have in diffusing scientific images, ideas and vocabulary which then become integral to the layperson's intellectual baggage (Moscovici and Hewstone, 1983). Individuals use this information to converse with others, interpret and combine their new knowledge. As a result, people come to agree about a view of reality and hence maintain an identity with group members (Moscovici and Hewstone, 1983). Herzlich, (1973) discusses how representations and practices in any community are linked with the global value system of that society. Differences in representations will have an impact on the practice taken to attend to it, for example, conceptualising illness as having origins in magic, medicine or religion will lead to varying approaches and any change that goes against the established values will be difficult to adopt. Similarly, how one conceptualises SEN will in effect direct their response to it.

The influences of social, economic and political factors in shaping social representations is also an aspect to consider (Howarth, Foster, & Dorrer, 2004). Through migration, the parents in this research have had to navigate new social and political structures, and are expected to engage with

England's pre-established structures of SEN. Scientific insights which have become widely accepted by educational professionals in the UK are adhered to and used as platforms from which to communicate. This raises questions of how post-migratory experiences of the education system may have affected how SEN is conceptualised by parents.

Professionals who have contact with lay persons are deemed important characters in shaping and influencing information parents receive; Morant (2006) highlights the important role 'intermediate' communities play. EPs in particular can be classed as an 'intermediary' social group – a professional group who applies 'expert' scientific knowledge in their interaction with lay people. These groups play a key 'intermediary' role in converting knowledge which has previously been produced by 'experts' such as academics and policy makers into common sense (Morant, 2006). For this reason, the interactions EPs and SENCos have with parents are of interest in the discourse of SEN.

3.3.1 Exploring the conceptualisation of SEN through anchoring and objectification. In the process of receiving new knowledge, an individual's identity and cultural norms come under threat and may be challenged. This may be especially true for individuals who have migrated and traversed cultures but also for professionals who perceive their knowledge to be of 'expert' status. In order to explain how unfamiliar phenomena become accommodated as less threatening, Moscovici referred to the processes of 'anchoring' and 'objectification'.

Anchoring is the process whereby science is transformed into a "hierarchy of values and into its operations" (Moscovici, 2004). Anchoring

takes what is unfamiliar, compares, and inserts it into pre-existing social frameworks. Moscovici, (2004) describes anchoring as a personal investment in deciding whether to accept or reject a new object based on what is already known and accepted. When learning of new external information, individuals ascribe the meaning of similar phenomenon, as already embedded in the culture, to the new unknown phenomena. Culturally accepted ideas and understandings are used as the foundations from which new knowledge is built, allowing the new knowledge to assimilate in a way that is less threatening to one's identity. It is a process which allows for the restoration of traditional views and challenges the potential for new social representations which may threaten identities and communities (Jovchelovitch, 2007). For example, when studying the social representations of 'madness' in a rural French community, Jodelet, (1991) explored how the mentally ill were received and viewed upon by the community they stayed with. Jodelet, (1991) found that the community attributed familiar ideas to the new concept of mental illness. In this way, existing prejudices, opinions and judgements are given platforms to remain. Such a process serves to safeguard an individual's ideas and ideologies during times of movement, such as migration. Anchoring may be a way to explain how families settling into the UK maintain their cultural identities in the context of the unfamiliar social environment, but also supports an understanding of how the practice of SENCoS and EPs are anchored in pre-established social structures.

Take for instance the role of using standardised measures to sort and group children into special education or the system of selective elite education. These systems, as with the role of educational psychology, have

been strongly influenced by diverse social, political, ideological and philosophical milieu. As pointed out by Hill (2013) the discord between psychological and political/legislative influences have led to polarised opinions and practices within the profession. Psychology emerged as an independent discipline and as a profession in the early twentieth century. This was in part due to the challenging context of compulsory education as introduced by the 1870 Education Act.

The evolution of psychology together with psychometric methods of assessment were the result of pressures of the early twentieth century to screen and classify individuals as a means to rationalise resources (Hill, 2013). In 1904, a French Psychologist Alfred Binet was asked to help the French education system to devise a method that would differentiate which students required special education programmes beyond the standard classroom. The Binet test was successful in predicting scholastic outcomes however was mistakenly accepted as a measure of intelligence and cognitive ability. As discussed by Hill (2013) this began the discord about intelligence tests and paved the way to notions of intelligence as innate, hereditary and predetermined.

Cyril Burt, a passionate believer of innate intelligence, was appointed as the first Educational Psychologist to the London County Council (LCC). With the prominence of standardised testing, Burt engaged in work to review the British education system and provided a rationale for selective education at the age 11 years old. This notion was based on the idea that a child's 'general intelligence' could be determined by the age of 11. With this, the implementation of 11-Plus – a test of abilities based on elements of the IQ test

was established and entry to different school types was determined by their outcome. From here on, this system of educational meritocracy is anchored within today's educational system.

The process of objectification also takes place in the formation of social representations. On a socio-cognitive level, abstract links which anchoring has categorised are turned into concrete form. Through the use of everyday discourse, naïve recipients turn concepts which are difficult to grasp into a 'figurative nucleus' (Wagner, Elejabarrieta, & Lahnsteiner, 1995). The 'image structure' that is held by the 'figurative nucleus' forms complex ideas into images, symbols and metaphors. Wagner et al., (1995) discuss how objectification has ontological implications as novices are likely to view their assimilated ideas as real therefore leading them to behave in a way that suggests their ideas are something outside of their mind. For example, the media objectifies scientific concepts, usually through concrete images. Climate change, an abstract and long-term phenomenon has been objectified through pictures of specific storms, heat waves or floods, making it an easier concept to grasp (Höijer, 2017).

Anchoring and objectification assimilate content in ways which preserve existing frameworks and culture. This happens over time and allows for communities and groups to transform scientific knowledge in ways which remain applicable and relevant to different fields of expertise amongst the lay population (Wagner et al., 1995). As a means to understand the frameworks in which SEN is embedded, the next section of this chapter will look at two models of disability.

3.4 Models of disability and mental health in British Society

In order to understand the context in which SEN sits in British society, this discussion will now turn to the paradigms of learning disability and mental health within the structures of disability, psychology and education. Paradigms are systems of thoughts, concepts and values held by an intellectual community. Paradigms are influential in what is considered adaptive or maladaptive and influences what actions are to be taken.

3.4.1 The biomedical model. The biomedical model looks to disability or illness as constitutional in origin and views the onset of disease in terms of causal relationships (Wade & Halligan, 2004). It focusses on the impairment and how the individual deviates from the norm. The biomedical model looks to cure or manage the disability through the power of professional intervention or medicalisation so that the individual may function in more 'normalised' ways. Psychiatrists and mental health professionals, including EPs may refer to classification and diagnostic tools such as the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (American Psychiatric Association, 2013) or the World Health Organisation's International Classification of Diseases (World Health Organisation, 2013) to outline mental health conditions. Although there have been growing professional concerns regarding the proliferation of mental health classifications in the DSM and their evidence base (Pickersgill, 2013), mental health professionals continue to rely on diagnostic measures to guide their decision making and work.

With regards to learning disability, the SEN Code of Practice (DfE/DoH, 2015) represents SEN under four broad areas of need and support; (1) communication and interaction, (2) cognition and learning, (3) social,

emotional and mental health, and (4) sensory and/or physical needs. Specific labels can be found under each area of need. For example, ASD, dyspraxia, depression, anxiety or attention deficit hyperactive disorder (ADHD) are all labels a child or young person may be given.

In line with a biomedical model, EPs are guided to make reference to the SEN Code of Practice (DfE/DoH, 2015) and use assessment tools to measure and quantify behaviours in line with symptoms listed in the DSM, for example. The Beck Depression Inventory Second Edition (BDI-II) and Spence Children's Anxiety Scale (Spence, 1998) are examples of such assessments.

By maintaining this understanding of disability, the medical model maintains a social representation that generates an imbalance in power relations between the 'professional' and lay community (Jovchelovitch, 2007). This passive representation of disability has been noted to impact upon the identity formation of disabled people and encourage feelings of being a burden; in need of special care and helpless. Viewing disability as, 'something to fear', 'makes you helpless' and 'special or exceptional' can lead to social categorisation (Devenney, 2004). Devenney (2004) argues that such representations result in disabled people being unable to develop an identity beyond that social representation. Labelling of this kind often leads to institutionalisation, being segregated within education and exclusion from employment.

How passive representations impact on the experiences parents have in the process of supporting their growing child and how this model influences attitudes toward children with a SEN is worthy of attention as it is likely to impact upon how SEN is responded to. The implications of differential power

relations upon communication and interaction will be discussed in more detail later in this chapter.

3.4.2 Social Constructivist Model. Beyond the biomedical model, psychological and sociological factors are also accepted as playing a role in understanding health and illness. This is the crux of the Constructivist Biopsychosocial model. From a social constructivist perspective ‘illness’ is a social matter and is a concept which is dependent on the norms and values of specific cultures. For example, in discussing the concept of health and illness, Burr (2003) raises questions which address the notion of illness in society; for example she asks, is someone who needs regular dental treatment, ill? Or is someone who is born with malformed limbs determined as ill?

Burr (2003) discusses the notion of being disabled and noted that the cause of ‘disability’ is at least in part environmental. By which she means, one could view disability as the result of constraints in the environment, such as inaccessible entrances or inappropriate facilities for wheelchairs users. Making accommodations for the wheelchair user would therefore reduce his or her disability. This view has been coined the ‘social model of disability’ and opposes the medical model’s view of disability as an innate function. In this respect, the assumption that people have determined personalities, identities or should be labelled with a mental illness is also critically questioned and the oppressive nature of ‘pathologising psychology’ is rejected (Burr, 2003).

The Amhara people in Ethiopia, for instance, have a different conceptualisation of medical beliefs and place emphasis on external events as causes of disease. For example, eating poisonous foods, having intense negative emotions or being attacked by evil spirits can lead to physiological as

well as mental health problems (Young, 1976). For the Amhara people, cures chosen in response to disease accommodate their beliefs, for example, herbal remedies are given in order to restore balance to the individual within the moral order of society whilst others join cults to treat illnesses caused by spirits (Young, 1976).

The Western society have also shown increasing use of 'alternative medicines' which are often based upon belief systems quite different to biomedicine, for example, homeopathy and acupuncture. Such developments challenge the notion of predominant biomedical views of disease as correct. Effectiveness of alternative treatments are often treated as placebos as a means to protect preconceived dominant ideas. How illness and disease is defined is not simply a matter of identifying pathology but as argued by Burr, (2003) is embedded in social and cultural contexts and involves the interpretation of experiences within the norms, values and economic structure of society.

Power relations also exist to reinforce norms and cultural practices which set the criteria for what is locally classed as illness. For instance, the biomedical approach of ordering and classifying the anatomy into related illnesses can be connected to broader social developments. Foucault, (2012) argued that biology and political discourses as closely related. Through classifying and ordering illness, for example, what is normal or abnormal, populations can be governed through a set of power techniques that discipline, regulate and integrate the body into economic and social life (Gastaldo & Holmes, 2002). Governing and controlling the individual and social body takes place at many levels in society. The discipline of health

holds a privileged place for the management of illness as it can differentiate between health and unhealthy, sane or mad and in doing so regulate work, domestic and political behaviours of the people (Burr, 2003).

The education system has also over time been shaped by regimes of power (Thomas & Loxley, 2007). As discussed by Foucault, this is the result of continuous and long-term exposure, coupled with a reflective engagement with a certain types of practices, rules and discourses that are encountered in daily lives across institutions. Just as the health discipline governs illness, so too can the education system regulate what it means to be 'educated'.

Individuals submerged within institutions become accustomed to rules over 'styles of dress', 'time keeping', or 'curriculum planning for example. In this way, social norms are constructed within society as individuals apply the rules governed by institutions.

Epistemologically, social representations theory adopts a social constructionist perspective which centres on interactional processes for meaning making. When representations between groups or individuals align with each other, effective communication is facilitated. Shared representations between groups or individuals facilitate communication and guide social action (Moscovici and Hewstone, 1983). The paradigms held by parents, EPs and SENCos influence understandings, language and actions taken; differences or similarities in paradigms will consequently affect communication between professionals and parents.

3.4.3 SEN and tensions between the medical and social model of disability.

The distinction between medical and social models of disability should not, however, be regarded uncritically and as oppositions to each other (Norwich, 2013). Through an interactionist perspective, tensions between the medical and social model of disability may be understood in the context of how environmental and societal attitudes have influenced conceptions of disability.

The concept of SEN was introduced by the Warnock Committee as a means to encourage an interactional perspective between the child, their environment and contextual factors (DES, 1978). Although this was the intention, the medical model has remained a dominant influence in special education. The deficit/medical model has influenced labels and categories within education such as 'SEN', 'learning difficulty' or medical labels such as 'dyslexia'. Opponents of the medical model argue that it invites the idea that children diagnosed with learning disabilities are abnormal and inferior to children not diagnosed as such. The assumption is that the failure lies in the child with the diagnosis rather than caused by the poorly developed regular classroom programmes that fail to meet the needs of a diverse student population (Ho, 2004). Critically addressing 'learning difficulties', Goodley, (2001) argues that regardless how much attention is paid to socio-cultural factors, 'learning difficulties' continue to be conceived of as a biological deficit.

Labels of SEN however, are not value free and objective observations (Ho, 2004). As Hacking (1999) points out, classifying children into types

learning or behavioural deficit, is a social construction reflective of the medical and social attitudes of a particular society in a specific era. When embedded in institutional practices, it allows judgement to be made on what behaviours are or are not acceptable. With this comes justification to segregate or control difficult children. Disciplinary powers within society reproduce pathological understandings of different bodies and minds and in doing so, individuals with 'learning difficulties' or SEN have been considered isolated or perceived as personal tragedies of their unchangeable 'organic impairments', with their difficulties viewed at the individual level as opposed to social levels (Goodley, 2001b; Norwich, 2013a). Goodley, (2001) commented on the concerns this raises considering the developments within social theories which aims to dispel de-humanising attitudes of disability and proposes a need to reconsider the epistemological orientation of the social model of disability to be inclusive of those with learning difficulties.

Much of inclusive and special education thinking centres around the idea that barrier to participation and learning are external and alterable, for example, steps which are external that impede wheelchair access can be changed into ramps or lifts which are alterable. Associated with this is also the notion that internal factors (e.g. impairments) are a given and not alterable, leading to the fact that within the social model, impairments are not seen as barriers. With that said, Norwich (2013) points out that some internal factors (barriers) can be altered, for example, a visual impairment can be ameliorated by wearing glasses.

Whilst the notion of 'making reasonable adjustments' and 'removing barriers' within special education falls in line with the social model, the

interrelation between both paradigms and the medical model's influence upon the social construction of special education is worthy of note. Teaching strategies, interventions and professional practice which have become the norm in today's social context have historically been established by the medical model (Thomas & Loxley, 2007). Ideas around the eugenics movement, the 'intelligent quotient' or IQ and psychometric tests all result from a medical paradigm.

In today's practice, questions such 'What's wrong with this child?' means the focus is directed to within-child or deficit models of learning. The medical approach to judging learning difficulties overlooks that people with impairments can have varying experiences depending on culture and social structure. As Thomas and Loxley point out, medical models of disorder are applicable when thinking about measles or chicken pox but are less helpful when considering people and the social arena in which they live. It is as a result of the interplay between the individual and organisation that a distinct concept of the medical model breaks down.

Language plays a role in building and bridging ideas and in special education, for example 'the language of buckets and other instruments of capacity measurement' (Thomas and Loxley, 2007 p. 39) are normalised ways of describing children with learning difficulties, for example, children are described as showing poor phonological awareness or weak perceptual reasoning. The successful establishment of such metaphorical language in educational discourse establishes itself with the backing of experimental, measurement and statistical language – the language of psychometrics. Decisions are made based on observations of academic work and

performance on standardised tests – both are social constructions which infer a deficit exists due to biological bases. Such language is often given the appearance of being rational and accepted as they are ‘discovered’ and interpreted by respected professionals such as medicine and psychology (Ho, 2004) however, this type of language is considered a ‘myth’ by Thomas & Loxley (2007) and leads practitioners and researchers down a dead end.

Being able to unpick the metaphors which underlie the work of learners, teachers, and researchers has been thought to enable the crossing of borders between the spontaneous everyday conceptions and scientific theorizing (Sfard, 1998). Shifts from individualised models of learning to social theories of learning draws parallel to what Sfard, (1998) calls the ‘acquisition metaphor’ and ‘participation metaphor’. The acquisition metaphor conceives that the learner is responsible for constructing meaning and knowledge. This metaphor is reflected in psychological theories about learning and ability, such as Piagetian or Vygotsky’s theories of internalisation. Common language of learning has been noted to reflect the idea of acquisition of learning, for example ‘Children’s Construction of Number’ or ‘Concept-Mapping of Science’ (Sfard, 1998 p.5).

While the acquisition metaphor emphasises the individual mind and what goes into it, the ‘participation metaphor’ draws attention to the evolving bonds between the individual and others. The participation metaphor (Sfard, 1998) attributes learning to social processes and participation in the community. It is assumed that knowledge is gained through interaction with others, belonging to a community, participating and communicating.

Both metaphors may influence how learning difficulties or disabilities are perceived. The acquisitional approach may attribute learning difficulties as a deficit – the individual is seen to lack and have gaps in knowledge. Whereas the participation approach views learning difficulties as a process and activity embedded in environmental contexts (Norwich, 2013a). Recent thinking about inclusive pedagogy and socio-cultural theories of learning and teaching can be seen to reject traditional medical models in favour of more social-participatory models (Florian, 2008; Norwich, 2013a).

The medical and social model have been explored as has metaphors for learning which differentiate between individualised and social approaches. As argued by Sfard, (1998) neither metaphor or approach to learning can be regarded as exclusive of the other or regard learning as purely “acquisitional” or purely “participational”. A plurality of metaphors is argued whereby both approaches should be accepted as different ontological ideas about learning and utilised in localised ways to fit the purpose. Tensions between the medical and social model of disability have highlighted the importance in acknowledging family, social and educational context before pathologising difficulties.

3.5 Context, discourse and identity

Context and social discourse are important to observe when looking at the creation of social representations. This is illustrated by a study carried out in Patna, a city in India, by Wagner, Duveen, Themel, & Verma (1999) who looked to explore change in contemporary urban Indian social representations of madness. Taking into consideration India’s rich traditional belief system about the causes and treatment of ‘madness’, the researchers were

particularly interested in asking to what extent 'modern' or 'western' ideas had influenced Indian lay representations. In particular, the researchers questioned whether 'modern' ideas displaced traditional beliefs or were lay representations reconstructed to allow for both traditional and modern ideas to co-exist. Wagner et al., (1999) interviewed 19 men and 20 women from the emerging urban middle class in Patna. Interviews found respondents uncritically embraced psychiatric models of medical science and rejected notions of ghost possession and healing procedures, even if their wisdom about mental illness exceeded their knowledge of psychiatry. At the same time, other respondents remained faithful to traditional healing procedures which contradicted their expressed belief in science. Responses highlighted the significance of social context in establishing or communicating representational systems. In public life, the discourse of modern ideas dominated whilst traditional ideas were more appropriate amongst family life. Wagner et al., (1999) highlighted the dynamic and flexible nature of representations in the context of social relations. As highlighted by the researchers, innovative changes in representations begin in public discourse before they extend to areas of family life, where traditional models are most entrenched. The findings of this research reinforces the flexibility and negotiable nature of collective and cultural representations.

Different identities, social roles and group memberships impact on the meaning making which takes place. For example, within the context of HIV prevention programmes in South Africa, Campbell, (1997) has shown the association between culture and social identity as markers in understanding risky sexual behaviour amongst migrant miners.

By expressing or rejecting different representations, an individual aims to position and identify themselves with the social context they perceive themselves to be in (Arthi, 2011). The role of positioning is highlighted in a study exploring the representations of mental illness among Tamil Singaporeans (Arthi, 2011). Upon reflecting on traditional models of mental health, participants situated themselves in opposition to those who believed in traditional models and framed those who did, as less educated and backward. By rejecting traditional models of thinking, participants identified themselves as belonging to Singapore – an advanced community where traditional beliefs would not survive.

Maintaining traditional beliefs may however serve a purpose in maintaining cultural identity for ethnic groups. In the context of health research, Jovchelovitch & Gervais, (1999) found that social representations of health and illness were greatly related to the cultural identities of Chinese individuals living in the UK. Representations of health and illness were found to be more about cultural identity as opposed to health itself. Responses from lay and expert members of the Chinese community demonstrated a hybrid representation of Chinese traditions and western biomedical knowledge. The authors discussed the role contradictory representations played in maintaining cultural identities and supporting individuals to navigate through the challenges of being in a new environment. The co-existence of different forms of knowledge within individuals and communities has been where ‘traditional’ and ‘modernity’ meet (Jovchelovitch & Gervais, 1999; Renedo & Jovchelovitch, 2007; Wagner, Duveen, Themel, & Verma, 1999).

One way in which the meeting and grappling of the modern and the traditional has been theorised is through the concept of Cognitive Polyphasia. Cognitive Polyphasia is a concept to understanding how people make sense of their reality once new information is received. It is the notion that different modalities or conflicting forms of knowledge can co-exist within the same group or individual (Moscovici, 2004). Originally, this was explored in the context of how psychoanalysis, a new science, was accepted in France. Today, not only does science, medical and technological advances continue to infiltrate modern society, but developments in migration and the transcendence of western scientific knowledge across cultural borders means that individuals exposed to these contexts are having to negotiate and compromise traditional knowledge-bases in order to accommodate new forms of thinking. In relation to this study, it is therefore important to consider the position Sri Lankan, Tamil parents take when engaging with UK systems and structures such as schools and the health system. Presuming there are differences in representations between the knowledge of parents and that of educational professionals, it raises the question of how parents relate to or identify with representations foreign to their common understandings and vice versa, how do professionals respond to representations which differ to their own?

In view of Jovchelovitch & Gervais', (1999) findings, are parents able to hold 'hybrid' representations when making sense of SEN and how much fluidity in their representations is apparent in their day to day experiences of SEN? Do the systems and structures of the UK education system allow parents the scope to identify with their personal representations or do parents

have to re-identify themselves with new ideas as a result of authoritarian expectations?

3.5.1 Communication and positional identity. The implications of representations as underlying foundations for self-other relations is important when taking into consideration forms of communication. When observing interactions, Jovchelovitch, (2007) notes the importance in noticing the ‘how’ in conversations, particularly how dialogues are influenced by powers in place and the influences such powers have in allowing turn taking or the sharing of knowledge. The constraints of asymmetrical dialogues between authoritative figures and the other has further been discussed, with a recognition that collective representations can lead to uni-directional communication and submission to authority. In this instance, the professional-parent relationship observed in the education setting automatically places both in an asymmetrical relationship as the professionals represent the authorities whilst the parents are the ‘clients’ who hold the subjugated knowledge (Howarth et al., 2004).

In health research, inequalities in power structures across lay and professional groups have resulted in conflicting definitions and understandings of mental health and eating behaviour. Expert knowledge regarding mental health and women’s representations of healthy eating has been favoured, leaving the layperson’s representation rejected or dismissed (Howarth, Foster, & Dorrer, 2004). As discussed by Howarth et al., (2004), such positioning between professionals and clients can have detrimental consequences in relation to effective communication, trust, disclosure and treatment. Furthermore, Jovchelovitch, (2007) highlights, it is the nature of

collective representations to induce oppression and domination if one group is recognised as more vulnerable. At the same time, it can be the role of research to address the connection between power, language and representations as a means to instigate social change (Van Niekerk & Boonzaier, 2015).

This research recognises that discourses regarding SEN could be differentiated based on the context within which the communication about SEN takes place; usually parents and professionals engage in dialogue and the concept of SEN within official and institutionalised settings, i.e. schools. Such a setting automatically creates a context in which professionals are empowered and in effect influence the exchanges which take place.

Inequalities in intergroup relations are guided by social representations which support the practices of communities, therefore, they have the power to legitimise social exclusion by supporting the status quo or be used as tools of empowerment to further social inclusion and challenge injustices (Howarth, 2001).

3.6 A critique of Social Representations Theory

Given the developing attraction of social representations theory amongst social researchers, a critique of its application will be explored. The socially orientated elements of social representations theory, have been noted as a necessary challenge to dominant notions of US social psychology which are often led by individualistic, behaviourist and experimental ideas, (Jahoda, 1988). The social position within social psychology has also led Howarth,

(2006) to argue its responsibility as a theory which can address contemporary social problems and confront social inequalities, (Moscovici & Marková, 1998).

A common criticism of social representations theory is its ambiguity and lack in conceptual precision. Certain terminology within the theory has been labelled as 'fragmented' and 'unclear' (Jahoda, 1988) whilst others have highlighted it as too elaborate (Markova, 2000).

For this reason, critics warn of difficulties between the theory and empirical research as ambiguous concepts are not easily tested through empirical methods, (Raty & Snellmam, 2017; Voelklein & Howarth, 2005). However, in the context of social thinking and communication – that which is the crux of social representations theory, Moscovici points out that the value of the theory is its intent to reach and connect with complex social phenomena, (Moscovici & Marková 2000). According to Moscovici, the dynamic and transformative nature between the triadic asymmetry of self, other and object, lends itself to more inductive and descriptive approaches in studying social representations. As a result, emphasis is taken away from the more individualist empirical research and instead allows for the transitory nature of the social world. As advocated by Moscovici, the importance of conversational exchanges and observational studies have been encouraged instead as methodologies to explore the social world of representations.

Much of the debates around social representation theory centre on the complex and dynamic relationship between social structure and social cognition. The notion of social representations are simultaneous between individuals and their society has led critiques to highlight issues around social

determinism and cognitive reductionism. This is in contrast to other social psychological theories which outline the separation between individual cognition and socio cultural contexts. Social representations theory therefore becomes difficult to integrate into US and British social psychology, (Voelklein & Howarth, 2005).

Emphasis on the social has led to social representations theory being accused of social determinism. As Jahoda, (1988) points out, the capacity for reflexivity is not accounted for if an individual is 'shackled by representations'. Jahoda challenged the notion of collective thinking or 'group mind,' as by this account people are perceived as passive recipients and unable to break free from existing elite dominant representations. The notion that representations and group identity are inextricably linked are also criticised for encouraging deterministic ideas (Potter & Litton, 1985) along with the notion that individuals develop a consensual view of reality based on the same images, explanations and group experiences. Moscovici however, aimed to present thought, language and socio-cultural practices interdependently and argued for a dynamic understanding of consensus, not a deterministic one (Voelklein & Howarth, 2005).

Concepts such as anchoring and objectification within the theory have led to criticisms of cognitive reductionism. Both process have been noted for being overly cognitive and relatable to other cognitive psychologist's descriptions of categorisation and schemata (Billig, 1988). For this reason, the notion of cognitive processes within a theory of social knowledge raises tensions in Moscovici's claim that representations are developed in the 'unceasing babble' of ordinary talk and collective thought. Potter and Billig

(1992) describe the cognitive ideas as ‘decontextualized, desocialized and uncultured universe of laboratory experiments’ (p. 16). They argue that problems will arise by trying to connect cognition with the processes of talk - instead, it is suggested that social psychology should engage in the pragmatics of conversational discourse not cognitive processes.

A critical question of *‘what do social representations actually do?’* has been asked (Howarth, 2006). Questions include does observing and applying social representations theory to the social world merely supports and consolidates the process which maintain uneven social patterns and inequalities? Or can research using social representations be catalysts for transformative developments? By exploring different research utilising social representations Howarth, (2006) reinforces the value in using the theory to understand psychological processes and social practices and in turn challenge social inequalities.

As suggested by Voelklein & Howarth, (2005) empirical work in this field should build up a critical agenda that promotes a social psychology which understands the ‘interconnections between social structures and subjectivities, culture and cognition, the social and the psychological’ (p. 449) in order to encourage societal change.

3.7 Chapter Summary

This chapter has provided an overview of the theory of social representations. It is a theory embedded in social psychology and one which takes into consideration socio-cultural influences in the formation of knowledge. The principles of this theory provides scope for this research to

explore the representations of SEN amongst Sri Lankan, Tamil parents, EPs and SENCo's. The dialogical nature of social representations is taken into account together with the implications this has when different social groups meet and communicate; in particular the impact of power relations between parents and professionals. The bio-medical model and social constructivist paradigms of SEN were explored as models from which disability are embedded, whilst the processes of anchoring and objectification help to explain the development of new knowledge.

Chapter 4 METHODOLOGY

4.1 Introduction and research questions

This thesis brings to the foreground, the representations and experiences of Sri Lankan, Tamil parents who have a child identified with SEN. It also aims to explore the experiences of EPs and SENCos who have worked with the Sri Lankan, Tamil community. A number of elements have come together to create the methodological conceptions and procedures used within this study. This chapter gives an account of the role of Social Representations Theory and its implications for the research design. Following a discussion about the theoretical positioning, ontological and epistemological positioning of this work, the chapter will discuss, I.) The research design, II.) The characteristics of the sample, III.) Method of data collection and IV.) The data analysis. Ethical considerations within the research will also be outlined. This chapter begins by presenting the research questions.

Research question 1. How do parents from the Sri Lankan, Tamil community, EPs and SENCos in a North-West London local authority represent Special Educational Needs?

Research question 2. What role does pre and post migration views of parents from the Sri Lankan, Tamil community play in their experiences of accessing services in a North-West London local authority?

Research question 3. What role does the community and services play in parents from the Sri Lankan, Tamil community experiences of supporting their child?

Research question 4. What has been the experiences of SENCos and EPs in supporting Sri Lankan, Tamil families in a North-West London local authority?

4.2 Ontological and Epistemological Position

This research employed an ontological perspective of constructionism and interpretive paradigm. Social constructionism proposes that knowledge is constructed between people. It is those interactions between groups and the use of language which builds and forms knowledge (Burr, 2003). When looking to form an understanding of a person or group, social constructionism proposes that there can be no such thing as objective fact or direct perception of reality. According to this theory, the world is perceived and observed by each one of us in unique ways, with no two ways being identical to another's and what essentially links our perceived understandings of the 'world' with each other is the use of language (Burr, 2003). Social constructionism is well-suited as an interpretive framework from which to establish this research. Engaging with participants through this lens supports an understanding that the research is an interactive process which is shaped by one's personal history, biography, ethnicity, social class, gender and race (Denzin & Lincoln, 2011).

By subscribing to an interpretive framework, this research aimed to acquire multiple perspectives through the qualitative method of interviewing. Acknowledged here is the importance of subjectivity and that the position and values of the researcher are integral in constructing 'reality' (Robson, 2011).

4.3 Research Design and Social Representations Theory

Meaning and interpretation are fundamental to both qualitative research (Bauer, Gaskell & Allum, 1999) and social representations theory. This research used an episodic narrative interview technique which falls in line with the need for researchers to employ inductive and qualitative strategies as a means to be sensitive to the empirical study of social issues (Flick, 2009). Adopting an episodic interview design also had particular relevance to studying the meaning and everyday life from a social constructionist perspective.

As argued by Flick, (2009) the 'pluralisation of life worlds' in today's modern society has resulted in increased relevance of such research. This research was interested in the narratives and viewpoints of parents who had experienced migration to a new country and subsequently experienced having a child with SEN in a very different temporal and local context to their place of upbringing. Therefore the aims of this research supported Flick's, (2009) argument, that there is a need for 'locally, temporally, and situationally limited narratives' (p.12) which reflects the rapid social change and diversification of societies we are experiencing. Adding to this, the views of educational psychologists (EP) and special educational need co-coordinators (SENCo) were also sought to provide the perspectives of educational professionals within the social context in which parents were narrating their experiences. Triangulation in the study of social representations is valuable in that it allows the researcher to explore the social distribution of representations (Bauer & Gaskell, 1999). Gathering views of parents, EPs and SENCos allowed for the exploration of differences in knowledge and viewpoints when thinking about

the subject of SEN. Of particular interest in gathering the data were how representations played out in the day-to-day lives of the three groups.

Gathering perspectives from three different groups also took into account the importance of studying the everyday lives and common-sense knowledge as deemed essential from a social representations perspective.

The study of 'common knowledge' alongside 'expert knowledge' was well suited using qualitative approaches as it allowed for an in depth exploration of the development, interaction and influence between different knowledge bases (Foster, 2003; Moscovici & Marková, 1998) and allowed the researcher to place common sense knowledge in the foreground as a means to understand the constructs of SEN from the parent's perspective. Placing emphasis on common knowledge took into account the notion within social representations theory that common knowledge is ordinarily denigrated and organised in a hierarchy inferior to other forms of knowledge.

Interview schedules were designed and organised for each participant group. Table 1 outlines the research organisation and questions addressed for each group.

Table 1.

Organisation of interviews and research questions

| Participant group | Research question addressed |
|-------------------|--|
| 4 Parents | <p>RQ1. How do parents from the Sri Lankan, Tamil community, EPs and SENCos in a North-West London local authority represent Special Educational Needs?</p> <p>RQ2. What role does pre and post migration views of parents from the Sri Lankan, Tamil community play in their experiences of accessing services in a North-West London local authority?</p> <p>RQ3. What role does community play in parent's experiences of supporting their child?</p> |
| 5 EPs | <p>RQ1. How do (parents and) professionals in a North-West London local authority represent Special Educational Needs?</p> <p>RQ4. What has been the experiences of EPs in supporting Sri Lankan, Tamil families in a North-West London local authority?</p> |
| 4 SENCos | <p>RQ1. How do (parents and) professionals in a North-West London local authority represent Special Educational Needs?</p> <p>RQ4. What has been the experiences of SENCos in supporting Sri Lankan, Tamil families in a North-West London local authority?</p> |

4.3.1 The Episodic Interview: a narrative approach. This study used the episodic interview approach as a means to better understand the concept of SEN in the participant's everyday life. The methodology was informed by Flick, (2009) who developed the episodic interview format in the context of a social representation study looking at people's relationship with situational change (Flick, 1996). The episodic interview distinguishes between narrative-episodic and semantic knowledge (Flick, 2009). Semantic knowledge relies on concepts and assumptions which are generalised and decontextualized from specific situations whilst episodic knowledge is attached to concrete situations and experiences. The interview method used in this research, allowed for links between both semantic and narrative-episodic knowledge. This was done through reference of concrete focussed questions and the use of narrative interview (Flick, 2009).

Interviewing, specifically a form of narrative approach was chosen as the method of data collection because the aim of this research was to engage in the everyday experiences and understandings of SEN by parents, EPs and SENCos. Studying the everyday lives of individuals, as promoted by social representations theory, is well suited using qualitative approaches as it allows the researcher to explore meanings in depth using a narrative discourse (Flick, 2009; Willig & Stainton-Rogers, 2008).

The narrative model was employed as it is an approach which facilitates the characterisation of the culture from which it is constructed (Bruner, 1987) and provides space for generating context in the telling of stories. During data collection, situational differences between the personal

stories of parents and those of the educational professionals were taken into consideration as playing a part in their acquisition of knowledge.

Considering the cultural backdrop in which narratives are told, Bruner (1987) describes the importance of carrying out research which addresses the “development of autobiography” and how the stories one tells about themselves changes and shape the story teller’s way of life. In this research, participants had the opportunity to interweave stories about their personal life histories. In doing so, parents were able to “traverse temporal and geographical space” – a function made possible by narrative interviews. Through telling narratives, participants were able to make references to their past experiences, reflect on the present moment as well as speak of the future. As a result, pre and post migration references could be heard from the stories parents told.

The changes parents had experienced in discovering their child’s SEN as well as the changes which had taken place through migration were paramount in the stories they told. Flick (2014) highlighted the difference in how change can occur – through concrete situational contexts or little changes which occur over time which lead to general change in some parts of everyday life. Fittingly, the episodic interview model was designed to understand the impact of changes on the social representations of everyday life therefore enabling the exploration of the changes parents had experienced.

The subject of SEN and the systems and structures surrounding SEN was the ‘topical domain’ addressed in unifying the participant’s narratives and shaping the interview schedule. The parents, SENCos and EPs interviewed

for this study had experience and knowledge of SEN within their own social contexts. All interviews followed the same structure, however two separate interview schedules were designed; one for parents and one for professionals. Interviews were semi-structured so further exploration of key issues took place when appropriate. Appendix D and E provide examples of interview schedules for parents and professionals.

In order to tap into the participant's narrative-episodic and semantic knowledge, interviewees were first asked to describe a significant experience regarding a topic, i.e. *'What has been your most significant experience of (name's) SEN?'* This was then followed by asking interviewees to provide concrete responses based on significant experiences, i.e. *'Could you please tell me about that situation?'*²

4.4 Data Collection

Data was collected from a borough of Greater London where I had been working during practice placement. All parents interviewed were residents of this local authority where their children also attended school. All EPs and SENCos worked within this local authority.

4.4.1 Parent Participants. In all, 4 parent interviews were carried out.

Parents had to meet the following inclusion criteria;

- All parents were first generation immigrants from Sri Lanka.
- All parents had a child with special educational needs as identified by the school or health professionals and had received involvement from the EP service.

² Please see Appendix D and E for full interview schedules.

- All parents had a competent level of English in order to access the interview without a translator.

Table 2 provides a summary of the parent participants³. Two of the four parents chose to be interviewed as a couple whilst just the mother came forward for the other two interviews. There were no single parents.

Table 2.

Summary of parent participant details

| Pseudonym | Relationship to child | Year of Migration from Sri Lanka | Age of child at interview (years) | Child's identified SEN |
|-------------------|------------------------------|---|--|---|
| Anura and Fathima | Mother & Father | 2010 (mother) 2001 (father) | 5 | Global Developmental Delay |
| Malini And Dinesh | Mother & Father | 2002 (mother) 1999 (father) | 7 | Autism Spectrum Disorder |
| Patricia | Mother | 1997 | 15 | Autism Spectrum Disorder |
| Mona | Mother | 1984 (migrated as a young child) | 3 | Speech and Language Difficulties/ Autism Spectrum Disorder |

4.4.2 Access and recruitment of parents. A purposive sampling technique was used to recruit all participants (Silverman, 2016). Difficulties in recruiting parents were anticipated, therefore I had decided that their length of stay in the UK and their reason for migration would not inform the recruitment

³ Please refer to Appendix J for an overview of parent's biography.

process. The nature of their child's need was not specified during the recruitment stage and given the heterogeneous nature of SEN, the definition of SEN as outlined in the introduction was used.

As supported by Ellard-Gray et al., (2015) there was a need to take a pre-emptive recruitment strategy and recognise that the parents may be a 'hard to reach' and vulnerable group. Difficulties relating to barriers in language, being a migrant group and the sensitivity of the research topic were taken into consideration. Strategies for effective sampling included recognising the context surrounding the parents and developing tailored means for recruitment (Faugier & Sargeant, 1997; Hoppitt et al., 2012).

One interview was facilitated through my previous casework experience (i.e. Anura and Fathima). Both parents had previously met with me through my work as a Trainee Educational Psychologist whilst completing my doctorate, therefore relationships and rapport were established. My previous involvement with these families had put me in good stead to access and engage with them. Both parents recruited via this avenue were willing and enthusiastic to support this research.

I initially identified parents through EPs, the portage⁴ team, and specialist autism teachers within the Local Authority. Involvement with these professionals would indicate that the child had an identified SEN and parents would have had experience of engaging with services within the local authority. EPs, the portage team and specialist autism teachers were provided with the inclusion criteria for recruiting parents and asked to identify Sri

⁴ Portage is a home-visiting educational service for pre-school children with SEND and their families.
<https://www.portage.org.uk/about/what-portage>

Lankan, Tamil families whom they had previously supported. 20 parents were identified via these means. Of those contacted, one mother and father agreed to speak with me (i.e. Malini and Dinesh).

It became evident that my attempts to recruit parents over the telephone were unsuccessful and it was necessary to reflect upon the difficulties I was experiencing.

In an endeavour to better understand the community and make adaptations to my recruitment process, Anura (father from pilot interview) and I had a conversation to address the matter. He outlined that parents may be feeling fearful of the situation they are in and not have the 'courage' to come forward. He drew upon his own experiences and explained that had he been approached before things had settled down for the family, he would have hesitated to come forward. Anura highlighted a lack of trust and that parents would not be speaking of SEN in Sri Lanka, therefore would question why they should speak of it now.

My reflections and this conversation highlighted that, the absent relationship between myself and the parents, mistrust of the system and 'fear' were potentially a pivotal reason for the lack of engagement. I therefore chose to use a snowball sampling approach to facilitate further contact with parents. Snowball sampling involved using my acquired sample of parents to recruit others from their social network to participate in the research (Ellard-Gray et al., 2015; Shaghghi, Bhopal, & Sheikh, 2011). Although these parents identified and began a dialogue with potential participants, our efforts never came to fruition.

Considering the importance of building relationships and trust (Ellard-Gray et al., 2015) I decided to use EPs as gatekeepers to potential participants. Two parents were recruited via this method (i.e. Patricia and Mona).

4.4.3 The parent interview.

Of the four interviews, two took place in the family home (Anura and Fathima & Malini and Dinesh). The LA home visiting protocol was followed accordingly. During our arrangement, consideration was taken regarding the family's routine, privacy and who would be speaking to me (mother or father). Interviews lasted between 56 minutes and 103 minutes. Interview questions were devised with keeping in mind social representations theory. The interview schedules were developed in line with the phases outlined by Flick (2014)⁵. All interviews covered six phases; phase 1 acted as the pre-amble and phase 6 the evaluation and debrief.

In phase 2, the parent's concept of SEN and education were explored through questions such as '*How do you describe (child's name) SEN?*' and '*what does education mean to you?*' In order to explore their pre and post migration views, parents were asked to reflect on whether their definition of SEN had changed since moving to the UK. The parents were also asked to explore their most significant experience of their child's SEN.

Phase 3 explored the meaning of SEN for the parent's everyday life. Parents were asked to recount their daily routine and the role SEN played in it.

⁵ Please see Appendix D and E for examples of the interview schedules

Phase 4 focussed on exploring the role services played in the parent's experiences of supporting their child. The questions in this phase centred on the parent's experiences of engaging with professionals and their views on what facilitated as well as what acted as a barrier to their experiences.

Phase 5 covered the topic of migration and the parent's biography of their pre-migration life. Space was provided for parents to speak about the concept of SEN in Sri Lanka and how their systems and structures compared to that of the UK.

4.5 Data Collection: SENCOs and EPs

4.5.1 SENCo participants. Four SENCOs were interviewed. SENCOs had to meet the following inclusion criteria; All SENCOs had to have experience of supporting Sri Lankan, Tamil parents of children with SEN. Table 3 provides a summary of the SENCo participants.

Table 3.

Summary of SENCo participant details

| SENCo Participant | School | Years working as a SENCo |
|--------------------------|--|---------------------------------|
| Kate | State primary School | 7 |
| Liz | State secondary School | 27 |
| Gloria | State secondary School | 3 |
| Trystan | State Special Educational Needs School - Primary | 7 |

4.5.2 Access and recruitment of SENCOs. Initial identification of SENCOs occurred through discussion with EPs who were able to recommend

schools with a Sri Lankan, Tamil population. SENCoS were contacted via email. Arrangements regarding the location and time of meeting were made prior to my arrival and each interview took place in the SENCo's office. Two SENCoS highlighted time constraints and prescribed maximum time limits on our meetings. Consideration of this and the busy nature of the school setting meant that it was necessary to refine the interview schedule in preparation. Phase 2 (the interviewee's concept of the issue and his/her biography in relation to the issue) and phase 4 (focusing the central parts of the issue under study) were given priority under time constraints. Interviews lasted between 38 minutes and 62 minutes.

4.5.3 EP Participants. Five EPs were interviewed. EPs had to meet the following inclusion criteria;

- All EPs had to have previous involvement or were currently involved with supporting Sri Lankan, Tamil parents of children with SEN. Table 4 presents an summary of the EP participants.

Table 4.
Summary of EP participant details

| EP Participant | Years practicing as an EP | Years working in designated LA |
|----------------|------------------------------|-----------------------------------|
| Zahra | 7 | 2 |
| Gaby | 26 | 17 |
| David | 7 | 7 |
| Christopher | 10 | 7 |
| Irene | 13 | 13 |

4.5.4 Access and recruitment of EPs. EPs were recruited from within the local authority in which the research took place. I contacted EPs using face to face conversations and email. Interviews took place in a meeting room at the EP service's office. Interviews were arranged on an individual basis depending on each EP's availability and they lasted between 59 minutes and 91 minutes. There were no time constraints placed on the interviews. This location allowed for uninterrupted meetings and privacy, therefore allowing for each element of the episodic interview to be explored.

4.5.5 The SENCo and EP interview. The same interview schedule was used to guide interviews for both groups. For ease of reading, SENCos and EPs will be referred to as 'professionals' in this section. As with the parent interview, phase 1 acted as the pre-amble to the interview. Phase 2 started the interview by asking about the professional's concept of SEN. This exploration was extended by also asking the professionals to explain how their conceptualisations compared to the Sri Lankan, Tamil families they have supported. In phase 3, the meaning of SEN in the professional's everyday life was explored.

Questions in phase 4 centred on exploring the professionals experience of supporting Sri Lankan, Tamil families. Professionals were asked to recount what their most significant experience has been and what part had supporting Sri Lankan, Tamil families played in their everyday work.

Ending the interview, professionals were asked to reflect on their own cultural background and whether this had played a part in their work. They

were also asked to reflect on the notion of 'cultural sensitive' services in light of their professional roles.

4.6 Pilot Study

Taking the time to build trust and make links with the research community is crucial for understanding the potential issues of data collection and the social context within which the research was taking place, (Ellard-Gray et al., 2015; Shedlin, Decena, Mangadu, & Martinez, 2011). Prior to collecting data, I met with a Tamil community member (who works closely with families, schools and leads a community centre). Conversation took place which supported a better understanding of the local Sri Lankan community.

Pilot interviews were carried out with parents Anura (father) and Fathima (mother) and Zahra. Both interviews have been included in the analyses as they elicited rich data and a positive response to the interview format. In carrying out the pilot study, I aimed to observe;

- i. How accessible the language of the interview questions were.
- ii. Whether the questions elicited information relevant to the research questions.
- iii. Whether any questions needed excluding or adding and how participants responded to the episodic interview format.

Considering the differences in participant groups, the pilot study also provided the opportunity to observe my relationship and position as a researcher alongside the participants. No structural changes were made to either interview formats, however, it was recognised that there was a need to address the concept of education alongside the exploration of SEN. Allowing

participants to think about their representations of education was deemed useful as 'SEN' cannot be conceptualised without education. This was done by adding the question, '*what does education mean to you?*'

4.7 Data Analysis

All data was analysed using thematic analysis (TA). TA was chosen as a suitable method for analysis due to its flexibility and compatibility with the theoretical underpinnings of this research, (Braun and Clarke, 2006). Using TA allowed for the analysis to take place across an entire data set and enabled the opportunity to draw out interesting and relevant themes to arise from all participants. This method differs from other forms of analysis which focus on single cases, for example, narrative analysis. For this reason, it was not possible to maintain a consistent account of individual narratives as other biographical approaches to research would have enabled (Braun and Clarke, 2006).

Following interviews, the data was transcribed and grouped into three separate data sets; parent data, SENCo data and EP data. Within each data corpus for each participant group, analysis was carried out on data sets relevant to addressing the research question. Of particular pertinence were questions relating to the participant's representations of SEN as well as their experiences of engaging with services, professionals or in the case of SENCos and EPs, the parent. As guided by Braun and Clarke (2006) it was important to draw upon the theoretical framework underpinning the research in which analysis was taking place as a way to inform the themes being

generated. In relation to this research, a theoretical thematic analysis took place through the lens of the theory of social representations.

This research employed a social constructionist perspective making TA an appropriate method to employ, given its flexibility. In order to examine the conceptualisations and underlying meanings of what was being said, data coding was carried out at a latent level (Braun and Clarke, 2006). Analysis at the latent level enabled a more interpretive approach linked to the sociocultural contexts within which the speaker told their story. The researcher took an 'active' role in the analysis by selecting, demarcating notable information and formulating the themes.

In coding the data, the content was read with the intent to capture important and relevant information related to the research question. The frequency of codes were not quantified. Themes which arose from the data reflected its importance in addressing the research question. When only one participant contributed to the content of the theme, this was made clear in the analysis chapter. The process taken to carry out TA was guided by Braun and Clarke's (2006) six steps framework⁶. Appendix G, H and I provide examples of coded transcripts from each participant group.

4.8 Ethical Considerations

Procedures for protecting and maintaining ethical guidelines was informed by the British Psychological Society, Code of Ethics and Conduct (2009). Importantly, I was conscious of the cultural sensitivities and personal

⁶ Please refer to Appendix F for an outline of the six steps of TA taken as guided by Braun and Clarke (2006).

nature of the topic. All participants were fully informed about the nature of the study, gave consent and were made aware of their right to withdraw. All the participants were able to understand English and did not require any translated materials.

Information gathered was kept confidential and used in accordance with the Data Protection Act (1998). Participants were made aware that breach of confidentiality would only take place under exceptional circumstances under which there appears a need to safeguard the participants or related others, (standard of privacy and confidentiality; BPS Code of Ethics and Conduct, 2009). Following the participation of parents, it came to light that there was a need to pass on certain information to the child's allocated Educational Psychologist from the Local Authority Educational Psychology service. The parents were fully informed about this situation and their consent was obtained. When parents required further support regarding the support of their child, I followed the interview with consulting and supporting the parents using my knowledge and skills of a Trainee Educational Psychologist.

4.8.1 Establishing Rigour. The importance of establishing rigour, validity and transparency in qualitative research is deemed vital in qualitative research (Mertens, 2014; Riessman, 2007; Yardley, 2000). In relation to narrative research, Riessman, (2007) states that two levels of validity are important; the story told by the participant and the validity of the analysis. This research drew on Yardley, (2000) to ensure rigour and transparency by focusing on the following characteristics of good qualitative research: i)

Sensitivity to context, ii) Commitment and rigour, iii) Transparency and coherence and iv) Impact and importance.

As suggested by Yardley (2008) the following strategies were applied as a means to enrich the validity of this research. In order to enrich understanding of representations of SEN, triangulation of data took place in gathering the perspectives of three participant groups. In choosing the episodic interview, socio-cultural perspectives of the parents and professionals were considered.

The questions asked during interviews as well as the research setting were adapted to suit the relative participant group. During analysis, all data were given equal consideration; commitment to the participant's perspectives were taken into account and reported even if disconfirming evidence arose. In order to ensure views were not misrepresented, member checking took place during analysis of EP data, (Yardley, 2008).

4.9 Researcher in context and Reflexivity

As argued by Howarth, Foster, & Dorrer, (2004), social representations theory provides a tool from which to reflect on the role of the researcher as a 'learner'. During the course of data collection, I was conscious of the co-constructing nature of narrative research and interviewing (Silverman, 2016; Willig, 2008). As Silverman, (2016) argues, interviews are interactive processes; the stories participants share and how they are told are shaped by the rapport established as well as the social similarities or distances between the researcher and participant. In conducting social representation research, Howarth, (2002) highlights the need to be self-conscious of our own knowledge systems and representations, and how these compare to those of

the participants. The importance of reflecting on our differences in race, culture and social-context as researchers is also stressed.

I engaged in reflexive practice throughout the research in order to enhance the transparency of the process and my position within it. The dual role of my professional and personal identity is notable. I acknowledged that my background of having been a primary school teacher and my current position as a TEP positioned me within a professional context of the education system hence enabling me to draw upon symbolic resources, i.e. language, when interviewing EPs and SENCOs.

Additionally, I am second generation British, born to first generation migrant parents. Although, I am an outsider in terms of ethnicity, culture and language in relation to the Sri Lankan, Tamil community, I approached this with an awareness of my personal cross-cultural experiences. My professional identity alongside my personal identity enabled some mutual understandings between myself and each participant group, (Howarth, 2002).

At the time of the research, I was a Trainee Educational Psychologist (TEP). I remained conscious of my position during data collection and considered the implications and effects that this may have had upon the participant's engagement and conclusions drawn. I was conscious of my prior involvement with one family and the implications this may have had on my interpretations and understanding of their stories. I attempted to detach any prior knowledge or judgements that I had as an employee of the local authority. Instead, I positioned myself as a 'learner' in approaching each participant group and remained focussed on the research's aims.

5.0 Chapter Summary

This chapter outlined the methods taken in carrying out this research. A description of the ethical considerations and analysis was also presented.

Chapter 5. Analysis of parent interviews

5.1 Chapter Overview

This chapter presents the results of the thematic analysis, which aims to explore parent's understanding of SEN and their experiences of accessing the systems and structures in the process of supporting their child. Data sets from the three participant groups were analysed separately. In order to preserve the authenticity of each participant group, the results will be presented in separate thematic maps together with demonstrative verbatim responses.

The analysis is split across three chapters: Chapter 5 – the parent data; Chapter 6 – the SENCos data and Chapter 7 – the Educational Psychologists data. The analysis of parent data covers three research questions:

RQ 1. How do parents from the Sri Lankan, Tamil community, EPs and SENCos in a North-West London local authority represent Special Educational Needs?

RQ2. What role does pre and post migration views of parents from the Sri Lankan, Tamil community play in their experiences of accessing services in a North-West London local authority?

RQ3. What role does the community and services play in parents from the Sri Lankan, Tamil community experiences of supporting their child?

This chapter is divided into three thematic sections which were generated through the thematic analysis of 4 semi-structured interviews with parents. Theme 1 looks at '*Responsibility, disempowerment & empowerment*'

which refers to the parent's role and position in supporting their child. Theme 2 titled, '*Experiences of systems and structures*' speaks of the experiences parents have had as they accessed services in the context of being migrants. Theme 3 explores '*Representations of SEN*' and addresses how parents conceptualise SEN for their child. Figure 1 presents themes and subthemes generated from the parent's data.

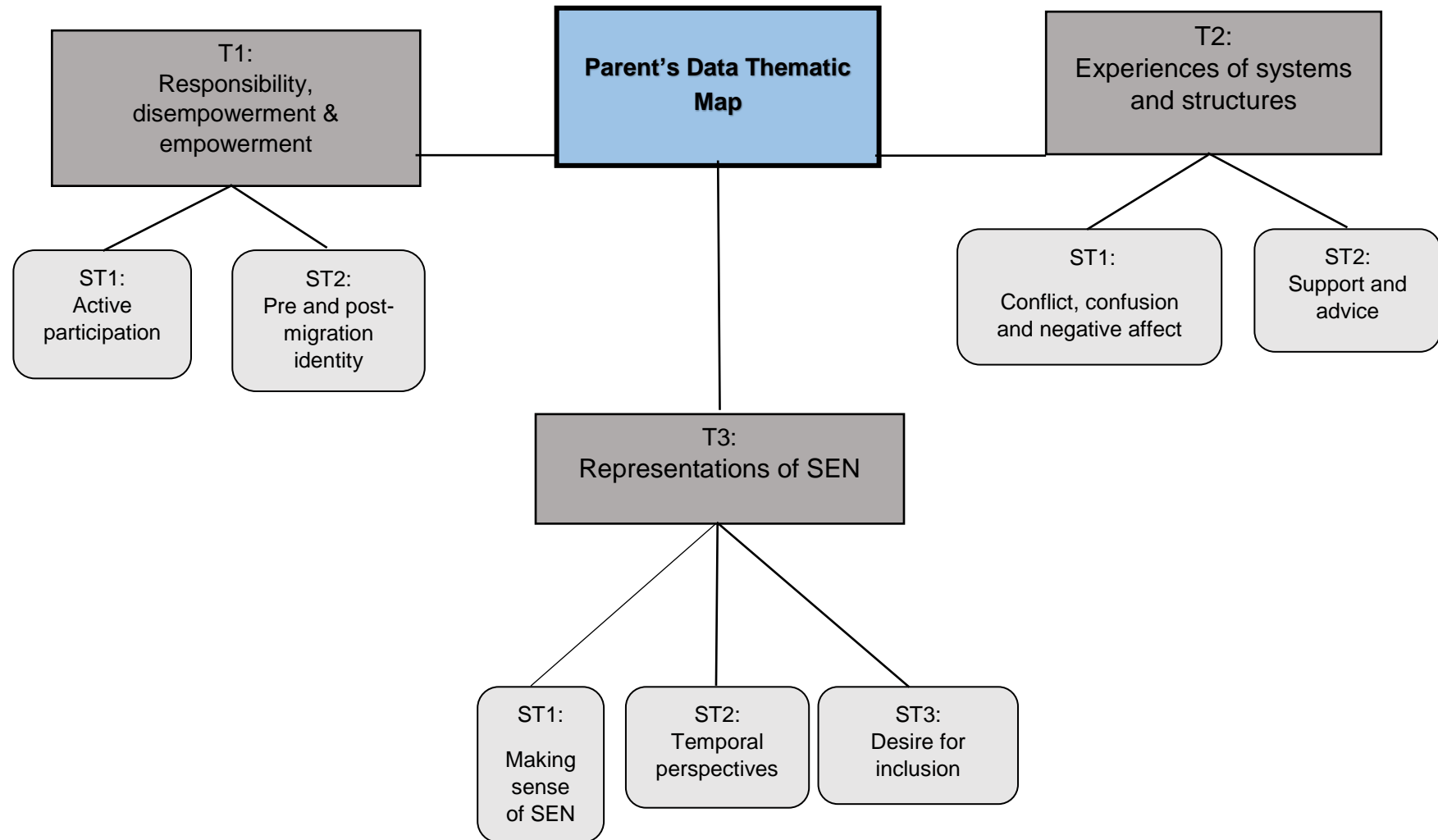


Figure 1: Thematic Map presenting themes from Parent's data.

5.2 Theme 1: Responsibility, disempowerment & empowerment

Theme 1 outlines the role parents take as the caregiver of a child with SEN, including the responsibility in providing support and navigating through the systems and structures of the UK's education and health system. The subthemes under this theme relate to the impact that being a migrant has had on the parent's experiences; including the role of language in facilitating communication, the notion of being under surveillance and how parents compare their pre-migration identity to their perceived post-migration identity.

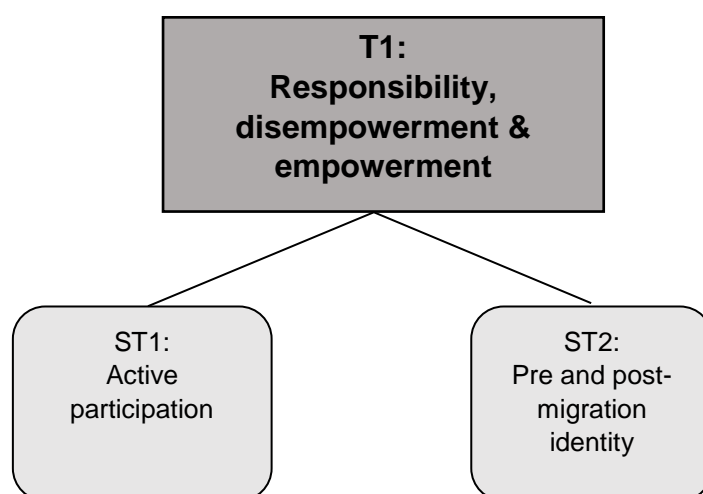


Figure 2: Theme 1 and subthemes from analysis of parent Data

5.2.1 Subtheme 1: Active Participation. '*Active participation*' speaks to representations of parents as an active force in the course of supporting their children. Far from being passive recipients of the demands of formal structures and systems, parents illustrated the actions, roles and responsibilities they took on as a means to support their children.

When talking about roles and responsibilities, parents spoke about what makes the parental relationship unique in comparison with other influences and forces outside of the family. For example, one parent described the importance and “*permanence*” of their relationship with their children, highlighting their responsibilities as ongoing and having longevity. This compared to the “*temporary*” relationship between children and the school. The notion of parents wanting and giving what is best for their child was highlighted with parents describing their role of agency in seeking information and navigating through the educational, medical and SEN system. Parents actively sought information, in order to understand SEN, the organisation of services and how to best support their child. Feelings of being alone were also communicated.

Parents gave examples of their “*active participation*” through describing pro-active behaviours, such as encouraging learning behaviours, setting up social situations and as active seekers of resources following the diagnosis of their child.

Malini, the mother of a 7-year-old son with ASD, spoke of her search for clarity after his diagnosis. Malini’s narrative of her son’s diagnosis followed her retelling of the hardships she experienced during the war in Sri Lanka. Malini’s emotive telling of her “*suffering*” ended in her relief and feelings of liberation and “*luck*” when she moved to the UK. Contrasting this, Malini told of her son’s diagnosis in her narrative of life events which she framed as ending her “*luck*” of having escaped the war.

“When I identified paediatrician, Tilan has autism and after that we looked so many people, read articles, I went Early Bird programme, I went

there, I found out about that and basically before I never accept that and then finally I ...(tried to do) everything best for him."

Malini discusses her initial reluctance to accept her son's diagnosis, however once she did, she sought different avenues of information. In her experiences, Malini spoke of her self-perceived struggles to speak and understand English which she attempted to overcome in her discourse of independence and autonomy.

Similarly, Mona, the mother of a 3-year-old girl with social and communication delay, drew upon her position as an academic and lecturer at a university to support her information-seeking. Mona's academic status facilitated her access to resources and provided the skills to search for information. She drew upon this as a means to make sense of a potential autism diagnosis and alleviate her anxiety following concerns of her daughter's development;

"So I started to do my own research and one of the things that really helped calm my anxiety was, I found literature which suggested that actually the speech delay and autism are not the same thing."

Being proactive and taking ownership in information-seeking appeared to empower parents as they tried to make sense of their child's diagnosis. Mona refers to herself as "*the expert*" of the situation and draws upon advice to "*just forget about what everybody says and try and think through your own judgement*". Mona spoke of rejecting a diagnosis of autism for her daughter until she had further information and concluded that "*speech delay and autism are not the same thing*" which reinforced her rejection of an ASD diagnosis.

Mona does not show deference to the scientific and expert knowledge presented by the doctors. Instead of observing her lay knowledge as inferior to medical information (Moscovici & Marková, 1998), Mona elevates her own judgement and allows it to take precedence in her decision making.

Similarly, Anura, the father of a 5-year-old daughter with global developmental delay spoke of the benefits of having the internet as a resource which enabled him to independently learn about his daughter's global developmental delay. Anura showed his lack of confidence in professionals being able to provide all the information he needed by expressing his concern that GPs may not be highly informed of his daughter's unique case. Instead, Anura chose to lean on his own research;

“...I wonder in (LA) how many similar kids will be there, so I'm not sure if I go to GP I'll be able to find information for this. The best place would be online...”

In a way, Anura is rejecting the 'expert knowledge' base – not necessarily because he does not trust it, but because he is not convinced that they have the depth of knowledge to help. For Anura, the internet is a more accessible source of information, although potentially less reliable. In carrying out their own research, parents appear to diffuse expert knowledge (Renedo & Jovchelovitch, 2007) and use different sources to anchor representations unique to their pre-existing notions of disability (Moscovici, 2008). How this information is received is also dependent on the parent's prior socio-cultural backgrounds.

“Active participation” was also explored when parents discussed the support they provided their children within the home. Such support included academic and therapeutic activities with parents incorporating this in their daily routines. For example, Malini expressed the importance of the parent’s role in teaching and supporting their autistic son. She talked about understanding her son’s capabilities and having to demonstrate his skills to the school. 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.

“Everything we did at home, he can read, he can write, he do maths...Whatever we’re doing, I show it to them. He can do. They said no he can’t do. ‘He can’t do the phonics,’ then we try, he can do! ... ‘He can’t cut it’. He can cut it! Then everything we video, take the video from here and show it to them... Everything we do it here! We show it to them.”

Malini’s frustration is evident in this excerpt as it highlights her desire for the school to view her son’s academic ‘competence’ in the same way she does. Her proactive participation in her son’s life (*“everything”* is done at home) provides opportunities and evidence for her to share with others. For Malini, what she has observed contradicts what officials have said about her son’s capabilities. When Malini said *“he can’t do, he can do!”* she highlighted her frustration in the differences in expectations or observations of her son and again highlighted a clash between expert knowledge (teachers) and the knowledge of the ‘lay’ parent.

Malini used a range of other 'active participation' strategies to ensure her involvement in her child's healthcare and school services. For example, Malini talked about her frustration and worry of health services and the school setting not doing enough which led her to wanting to engage with the strategies herself. To address this, Malini talked about her desire to observe a speech and language therapist session in the school setting so that she could follow the same activities at home, however liaising with school staff and the speech and language therapist proved to be difficult. In this instance, Malini's 'active participation' in her son's progress was precluded by organisational factors.

Speaking of the family's daily routine at home, Fathima, the mother of a 5-year-old daughter with global developmental delay explained how she and her young children engage in homework and therapy;

"...We have a small table and chair so they both sit and do homework and things...And then we do some therapy after the homework...Once in a while we'll do a few exercises"

This excerpt highlights how Fathima draws on a social representation of the traditional academic model as a way to work with her children, which is likely to be at odds with recommendations from professionals who advocate play for early years education. This is evident in the physical set up of the room ("*a small table and chair*") as well as the academic activities taking place. The influence of cultural models upon parental understanding of education has been discussed by Crafter, (2012). Parents were found to make sense of their child's mathematical achievement by using and

incorporating resources within the boundaries of their cultural models. The parents in Crafter's (2012) study drew upon cultural models to reinterpret double meanings from teachers talk about their child's mathematics achievement. Constructs of child development in Crafter's (2012) study were also embedded in values, expectations, practices and past experiences. This resonates with Fathima and Malini's representations of what good learning should look like.

Participating actively was not only confined to the home setting, as two parents found themselves needing to give care and support to their child who have EHC plans whilst they were at school. For example, Fathima spoke about her experiences of having to support her daughter with toileting during the school day in the midst of confusion regarding what support should be provided and by who;

"...the SENCo, called me...she said, 'are you not coming to change her?' So we were a bit confused...and then I went and I take her to the toilet ...I went to school...then she asked me "are you taking her home?" And I said "no, I'm not taking her home, I came to change her'."

This incident was a source of confusion for Fathima, as it contradicted legislation guidelines (Equality Act, 2010 and Children and Families Act, 2010⁴) which hold the school accountable to support pupil's toileting needs when they have medical conditions. The lack of clarity for who was responsible for her daughter had impacted on Fathima's day – the boundaries between home and school responsibility as laid out by legislation were not evident here. The lack of structure and support for her daughter left

Fathima feeling unsupported and *“upset”*. This was further accentuated by not knowing who to speak to *“because no one was around”* and *“there to guide”* her.

Subtheme 1 has demonstrated the parent's willingness to take an active role in supporting their child. This includes seeking information in order to better understand their child's needs as well as actively engaging their child in therapeutic and academic tasks. The parent's role as information seekers and as parents who work hard as active participants to support their child were also highlighted.

5.2.2 Subtheme 2: Pre and post-migration identity. Subtheme 2 describes how parents related to their pre-migration identities and how this compares to their perceived post-migration identity. This subtheme provided information regarding the parent's representations of disability and takes into consideration factors of the parent's migration, (Vertovec, 2007) which have helped to shape their experiences.

Three parents spoke about the war as a catalyst for moving to the UK and spoke fondly of their pre-migration lifestyle. Patricia explained that life in Sri Lanka was positive before the war;

“I wouldn't have come to London if there was no war because there, there wouldn't have been any purpose because we were very comfortable family in Sri Lanka.”

In response to questions regarding pre-migration life in Sri Lanka, parents referred to social status labels, describing their families as *“middle class”*, *“upper middle class”* and one parent described herself as *“upper caste English-educated, English-speaking elite”*. Patricia highlighted the significance

of the class system and education in Sri Lanka as an indicator of wealth. Being recognised for your level of education and employment status was communicated as important;

“... here we are just like anyone, whereas there we were somebody.... Somebody important... like a family is known and then we had good jobs, like if you work in a bank you’re considered quite well-off...you’re somebody important.”

Patricia describes her new identity as *“just like anyone”*. Prior to migration, Patricia and her husband occupied positions of privilege and status but that was not carried with them to the UK. Instead, their migrant and minority status becomes the foreground aspect of their identity. Patricia emphasised, that there is *“no point telling an English person, “Oh, I was that in Sri Lanka...nobody cares who you are...”* In Sri Lanka, status and social class would have contributed to how an individual accessed and engaged with resources, therefore the impact this may have on their SEN experiences in the UK is worthy of note.

The significance of speaking English was highlighted by Patricia who explained that *“speaking English is a symbol of affluence”* in Sri Lanka and represents education under the British regime. Malini makes reference to the importance of English in order for her to feel accepted by the professionals she engages with in the UK. She justifies that using her mother language Tamil takes precedence in Sri Lanka therefore she has not had opportunities to practice English beyond schooling. In the following quote *“they”* refers to the education professionals she has engaged with;

“They think we’re uneducated, because our language level...they believe, ‘these people are foreigners’....they are hiding behind their job and doing very bad thing so if speak very well English and I know very well, then I can meet them but I couldn’t do anything because my language level... that’s why I want to teach my (children) education and everything very carefully.”

Malini signifies her position as a “foreigner” as a result of language differences and hopes that her children may override this identification by being educated. Malini expresses a disempowerment in her ability to confront challenges with professionals who she perceives as hiding behind their jobs. She envisions that good English competency would enable her to engage with others in more productive ways. How Malini believes she is perceived as a migrant is notable here.

Three parents drew upon the notion of accessing private services. In speaking of their pre-migration life in Sri Lanka, husband and wife, Anura and Fathima, drew upon the culture of accessing services privately. They were accustomed to accessing private drivers, a chef and cleaner;

“Normally if it’s in Sri Lanka, or our area. We would be privately having a carer and they’d be looking after her. So we haven’t had an idea of having the council supporting us – because in Sri Lanka you don’t have this system. Everything is private. If you want, there are many people. We pay them. They come.”

Anura and Fathima considered accessing resources in the UK in this way until they understood the UK system better;

“...we were initially thinking of having a private treater or teacher or exercise, all these things. Physio...And ((incomp)) we realised there is educational system...Only now we know a bit more about it.”

Similarly, Mona talked of buying in speech and language therapy privately for her daughter. The parent's willingness to access services and having the autonomy to do this is highlighted through these excerpts.

The challenges that have arisen when different cultural expectations meet were also addressed by Malini who contributed a generous amount of time on talking about her experiences of having social services involvement. Their involvement was in the context of misunderstanding of her son's communication. Feelings of being accused, the need to be obedient and her feelings of vulnerability were communicated. Talking about the details of social service involvement, Malini resolved that there is a need to “*co-operate*” and “*follow rules*”, suggesting that she sees herself as a passive agent of authority. Feelings of being “*hurt*” and being “*scared*” were communicated.

Malini described how her children are growing up in the UK and feared that her Sri Lankan parenting style may be misunderstood by them. The potential for inter-generational shifts in attitude in what is acceptable within her own family was reflected upon;

“Our children, they are growing up... in front of them we have to be very careful, we have very honestly, show our behaviour, – because they are learning from us... Even my husband and me, our behaviour in front of my children, very very careful and honestly...”

Malini reflected on the representations and practices of childhood and parenting style she and her husband hold from Sri Lanka and understood that

this may conflict with her children's representations as they grow up in the UK. Malini anticipated the differences in representations within her own home as well as with professionals. From Malini's description of contact with professionals, she recognised that their gaze goes beyond her son's SEN and every aspect of her parenting was scrutinised. Malini highlights her awareness of different cultural ways of parenting and makes an effort to adapt to suit expectations.

Subtheme 2 highlights parent's willingness to draw upon resources and access services, but in doing so, they became more aware of their own social and migration status. This was partly to do with speaking English and the status this brought them. The spotlight of the institutional gaze also foreground cultural differences in parenting and care.

5.2.3 Summary of Theme 1.

This theme has presented the parent's role in taking responsibility in supporting their children. Parents report drawing upon their own resources and taking an active role in supporting their children. Parent's pre-migration identity highlighted pride and positive recollections of their lifestyle and education level in Sri Lanka. Themes of disempowerment were demonstrated from difficulties in language, feelings of not belonging, and feelings of being perceived as uneducated amongst the wider professional networks they engaged with.

5.3 Theme 2: Experiences of systems and structures.

Theme 2 describes parent's experiences as they accessed formal services. Themes of conflict and confusion were communicated as well as experiences of distress and negative affect. Parents talked about their reliance on their spouse as main sources of support and an openness to access medical and educational services.

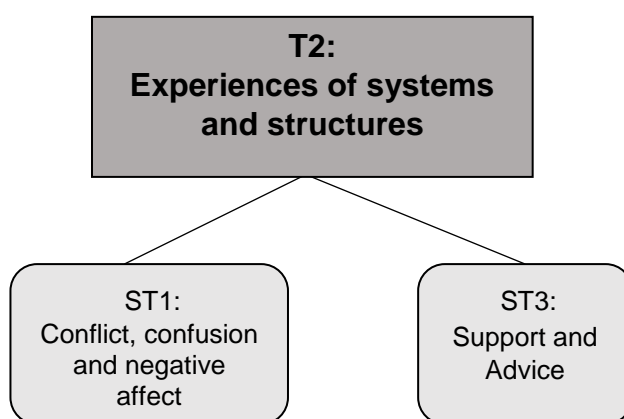


Figure 3: Theme 2 and subthemes from analysis of Parent Data

5.3.1 Subtheme 1: Conflict, confusion and negative affect.

Feelings of “*stress*”, “*hurt*” and “*fear*” were reported by parents as they reflected on their experiences of engaging with the systems and structures of the SEN process. Anura and Fathima reported confusion over the EHCP application (Educational Health Care Plan) and spoke of not having “*a clue about it*” (the process). The parents described themselves as being “*on the other side*” of knowing. Anura and Fathima were striving to make sense of what their daughter’s support should look like with regards to the EHC plan

and spoke of being *“in confusion of what the need is and what the support should be”*.

Part of the confusion that Anura and Fathima expressed was with their daily routine over who should provide the support for their daughter's toileting needs in school. The following quote narrates Fathima's recent experience of going into school to support her daughter;

“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...”

This excerpt highlights Fathima's feelings of feeling alone and being *“stuck”*. Although her daughter was provided with an EHC plan, Fathima and Anura found an added stress in trying to understand what this meant for their daughter. Fathima's narrative highlights her feelings dis-empowerment against the school systems and structures.

Malini spoke of a difficult relationship with her son's school. Conflict involved disagreement about the support her son was receiving, her son's progress and how the EHC plan described her son;

“You know when we received the report, 50% I agree with that, 50% I never agree with that, he doesn't have that habit. He never do that, but they make him trouble. But this is the not good for him, so many trouble so many problems.”

“Problems” formed much of Malini and Dinesh's narratives. From her perspective, some of her son's *“troubles”* can be attributed to the school environment as *“half he has some need, half this school give it to him”*.

The impact of this conflict was emphasised by Dinesh who spoke of *“fighting”* and the effect it has had on their wellbeing;

“They broke our strength, our energy, everything. We are losing. Then how can we give it our best to our children? You know. We are fighting, all the time fighting, every day you can’t fight.”

The notion of *“losing”* against the school has resulted in Dinesh feeling *“broken”* and has illustrated the strain they have experienced. The affective nature of this subject was evident during the interview as the strain upon Dinesh and Malini could be observed in their voices and demeanour. Daily activities such as picking up his children from school appeared to be a source of stress for Dinesh who described himself as feeling *“mad, (and) scared”*. Dinesh explained that he fears the moments when teachers *“come straight away in front of other parents”* to speak about his son. Dinesh describes himself as being *“ill”* as a result of their difficult relationship with the school. He explained *“I’m not concentrating on my work”* and according to his colleagues looks *“very sad”*.

How migration status, language barriers and ethnicity compounded upon Malini and Dinesh’s experiences of *“losing”* their *“fight”* is worth considering. Disempowerment of marginalised or minority parents has been found to result from their difficulties in drawing upon resources to challenge schools and professionals. The ability to challenge cultural models of the system, i.e. the school, has been linked to social class status and the cultural logic that this entails, with middle class parents being most empowered and

having the most resources to fight for themselves (Crafter, 2012; Lareau, 2002; Vincent & Ball, 2007).

For Mona, a deference to professional input generated anxiety. She believed that being assured in her own judgement may have lessened her confusion;

“My anxiety was in part fuelled by this, “Oh my god, the experts are saying this.” Then my mother-in-law and my mother becoming, you know, almost hysterical, about why we were not doing more to make sure she was speaking, you know.”

Conflict amongst the medical knowledge of professionals and her family’s knowledge which focussed on environmental factors appeared to be a source of confusion for Mona. The concept of cognitive polyphasia (Moscovici, 2008) is relevant here as Mona tried to accommodate information of her daughter’s needs. Mona had subsequently decided not to take on board her family’s advice or agree with the professional’s diagnosis of ASD and instead stood firm in her own decision making.

This subtheme has shown that confusion arises for parents regarding the EHC process and how this translates to the practice the parents are seeing. Experiences of negative emotions have also been reported as a result of conflict and disagreements with professionals.

5.3.2 Subtheme 2: Support and Advice. The parent’s distal relationships with their family members in Sri Lanka, as a result of migration led to narratives of separation and aloneness. Parents relied primarily on their spouses as sources of support. When Patricia spoke about her son’s

diagnosis she communicated her concerns about the support she would receive;

“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?”

Later in the interview, Patricia reinforced; *“...but husband and myself, we have been each other's comfort...as support, we don't have anybody”*.

The essence of this quote was repeated by Anura who spoke about being alone with his wife and the role extended family could have had in identifying his daughter's needs. He believed that family elders could have changed the course of his daughter's developmental difficulties by helping him and his wife to foresee her needs earlier. Anura appears to have represented his daughter's SEN as something that could have been avoided had he been around his parents in Sri Lanka.

These narratives highlight lack of social support, however, as described in Theme 1, parents acknowledged their need for help and were willing to access this independently. Support from formal services such as paediatricians, physio therapists, occupational therapists and speech language therapists were willingly accessed by all parents.

When positive experiences were reported it appeared that parents valued support which engaged with the family at home, for example the Portage service. This appeared to be the case for Anura and Fathima who actively sought support from a charity to support them through the statutory process. Here, Fathima spoke of her opinion of this charity;

“...they do everything you know, they have a nice way of doing it...They come home and they tell us, “ok what’s the problem?” They give their full support. I was talking to the Banardos, she said shall I come and talk to the SENco?...they’re ready to help us at any time.”

A neutral intermediary to negotiate on the family’s behalf was needed in the form of a charity in this case, and the connections made with the home environment appeared to be successful in providing accessible and approachable support for Fathima. Having someone to represent the family at meetings, provide advice for next steps and provide explanations over the phone meant that Fathima felt she received their *“full support”*

Whilst parents lamented the distal nature of relationships with family, the SEN diagnosis posed as a challenge for developing proximal relationships in England. Parents accepted and would seek support from trusted relatives and friends but spoke of their reluctance to discuss their child’s SEN amongst the wider Sri Lanka, Tamil community. Mona explained that a big support for her was her child-minder whilst Anura and Fathima recalled the advice they received from a trusted friend who was a qualified doctor.

Recalling his experiences of identifying his daughter’s needs, Anura talked about the impact of a language barrier and feelings of disempowerment in explaining himself to medical professionals. Being a new parent, Anura and his wife depended on a friend’s advice for recognising what would constitute normal developmental progress. Their friend, who was a qualified doctor himself, highlighted concerns regarding their daughter’s development and advised Anura to raise this with his GP. Anura explained their initial

uncertainty, *“we didn’t know what to search and how to search for it, we didn’t know what Special Educational Needs – the words...”* In this instance, the confusion encompassed the practical aspects of communicating clearly and effectively as Anura explained that *“we didn’t know how to explain to the doctor.”* To overcome this, the fine details of which words to use when meeting their doctor was revised with their friend; *“...so my friend had to tell me, this is the word you have to mention so that the doctor would understand.”* Here, Anura’s friend played an important role in mediating between scientific and lay language.

The role of the school in supporting parents was emphasised. Patricia spoke positively of the role school had played in supporting her and facilitating her friendships. Malini spoke of relying on the school to help her read and understand documents;

“... we don’t want to show it to other people, we can go to friends or we can ask them but we don’t want to ask them. This is confidential you know...so if you very well Tamil speaker, you are involved with my child, so you should explain about that...”

By providing support, Malini hoped that the school would help to keep information about her circumstances private and reduce the need to ask friends.

This subtheme outlined the sources of support parents have drawn upon. Three parents have reported being alone as family units without extended family support. Parents spoke of their willingness to access support from formal and informal services.

5.3.3 Summary of theme 2 .Theme 2 highlighted parent’s experiences of accessing health and education systems and structures. Confusion and conflict were reported as well as negative affectivity. Parents accessed and sought formal as well as informal services as a means to receive support. Family relationships with close relatives were desired but also challenging for parents due to the “confidential” nature of their child’s SEN. Parents felt a distance between themselves and the community which led to a sense of isolation.

5.4 Theme 3: Representations of SEN

Theme 3 discusses parents’ representations of SEN. The four interviews showed how these parents had to make sense of the representations of SEN presented by the UK system. Parents looked upon the labelling of SEN through a temporal perspective and viewed labelling as deterministic of the child’s future. The importance of the socio-cultural context and the inclusion of children within mainstream education were highlighted.

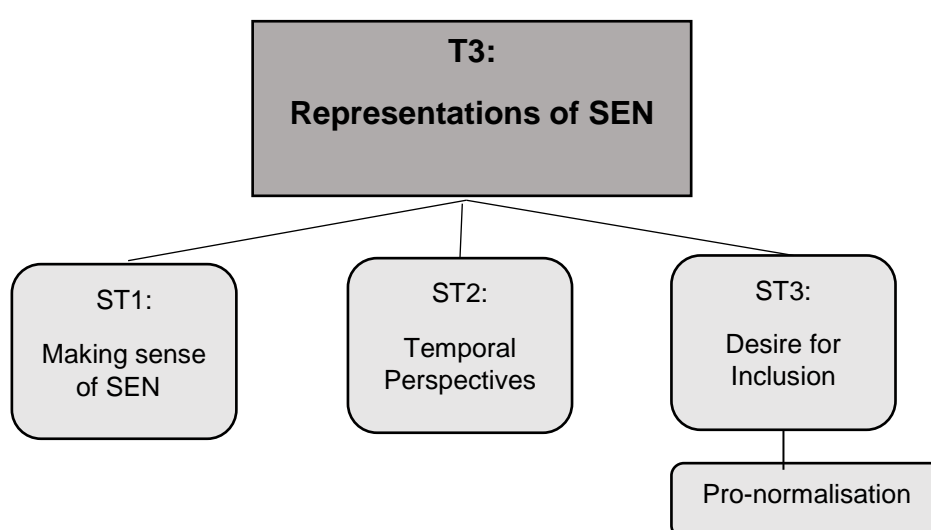


Figure 4: Theme 3 and Subthemes from Analysis of Parent’s Data

5.4.1 Subtheme 1: Making sense of SEN. Each parent identified their child's SEN through dialogue with a health professional and shared their experience of learning about SEN for the first time. Accessing the specialist language of professionals and speaking English as an additional language posed difficulties in communication and understanding for parents.

Difficulties in language and communication between South Asian families and professionals have previously been addressed (Fazil, Wallace, Singh, Ali, & Bywaters, 2004; Hatton et al., 2010) and resonates with the findings of this research. Of particular relevance was Hatton et al's., (2003) discussions regarding the importance of the disclosure process in supporting parents understand their child's disabilities. In relation to this research, 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."

Similarly, Anura recalled his initial reaction to learning about his daughter's needs in the context of it being his first and only experience of SEN. Anura highlighted their difficulties in making sense of the diagnosis and described his conceptualisation of SEN prior to his experiences of the UK system;

"...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 we would use as special educational needs."

For Anura special needs was seen as something explicit, tangible and physically obvious. He makes reference to his daughter's appearance and describes her as looking "*normal*" and therefore "*fine*". When referring to physical disability, Anura disqualified his daughter as belonging to this label saying, "*not like Anisha*". For Anura, his daughter's walking development was key to recognising her needs. Anura explained "*we were worried about her walking and our initial worry only was would she walk?*" He now understands that there is an "*internal*" need and recognises that this had not formed part of his prior categorisation of disability. Anura explicitly explains and recognises that it has been a "*big change in looking into things like this*". In line with this notion, all the parents appeared to view speech and language development as an indicator for concern or progress. Mona explained her rationale for rejecting an autism diagnosis as she bases her decision on her daughter's speaking ability;

"I'm not going to go ahead with the assessment...Because I just think you can't tell. Until she's speaking...I also think that she will speak because she's not so severely autistic."

Efforts to make sense of their child's SEN and varying responses highlighted that parents had developed unique scripts for themselves and drew upon various reasoning and explanations. For example, Anura believed that his daughter's physical needs are the result of delayed identification

whilst Malini resolved that *“I’m thinking, I give it to my child. This is my common idea.”*

Patricia took me on a journey of how she tried to make sense of her son’s autism. She was initially open to a bio-medical perspective and reflected on her pregnancy and her son’s birth. Patricia noted that her son was *“born small for some reason”* and the autism could potentially be attributed to this. Having explored the reasons for her son’s low weight, Patricia considered her and her husband’s health, their age and finally concluded ... *“so there was no reason but then anyway, God’s given the child to us and we took him forward.”*

In this instance, inconclusive answers in the area of biomedicine had resulted in Patricia accepting a theological reason. The role of religion, faith and God was further extended upon by Patricia as she described the importance of being a Christian as a means to cope, stating *“God gave us strength...”* Similar to Croot et al's., (2008) findings, Patricia held hybrid representations of theology and biomedicine to make sense of autism.

Mona made reference to her research of cognitive development to understand her daughters’ speech delay. Here, she concludes that speech development takes a separate pathway to developing autism.

“...the fact that she’s not speaking...I have my sense of it – from the reading that I’ve done – is that the language is generative; it’s not cognitive, you know? It’s just a part of the brain that has to switch on and for some people that happens later than others, right?”

Mona had formulated her own understanding from what she had researched. She admitted that taking the approach to independently develop her understanding has alleviated her anxiety.

Malini talked about blaming herself for “*giving*” her son autism, however she also provided a rationale that some of her son’s behaviours could be attributed to the school environment. In the following quote Malini concludes that neither God nor parents have contributed to some of the difficulties her son had experienced, suggesting that for Malini there is scope for multiple representations in how her son has experienced autism;

“some of the behaviour, they give it for him. We are not. Or God not give it. That’s school give it. That is the little bit struggle with him...that is they did it...”

This subtheme has illustrated that SEN is a new concept for the parents, especially when it concerned their first-born child as parents talked about being unfamiliar with the progression of child development. Language barriers posed a challenge between communication and shared understanding between parents and professionals. Parents reported a variety of representations towards what they attributed their child’s SEN to, with biomedical, environmental and theological reasons given. This subtheme highlights the need for a disclosure process which supports parent’s understanding of their child’s diagnosis.

5.4.2 Subtheme 2: Temporal Perspectives. This subtheme illustrates the links parents made with the past, present and future. All parents spoke of how they perceived their past decisions to have had consequences for their

child. Looking back, Malini communicated a sense of blame for choosing the school her son attends;

“I feel fool. Because I take to my child, I broke his life. You know, I go there, because I just went there to give him early support to improve him but that’s everything wrong. I spoilt him life. That’s why I’m so worried about that you know. I spoilt my son’s life. I feel that.”

Malini describes feeling a “fool” as she reflects on the school she chose for her son. In saying “*I broke his life*”, Malini communicates quite powerfully the magnitude of how a decision like this is generalised to “*life*” in general and how as a result, “*everything is wrong*”. Given that schooling can have such an effect for Malini, the significance of school in her child’s life, is also highlighted here.

Similarly, Mona reflected on sending her daughter to nursery and communicated a sense of regret when considering her daughter’s language delay. Mona believed that she sent her daughter to nursery “*too early*” and that listening to the advice of her relatives was not useful. Upon reflection, Mona had decided that her daughter needed longer at home as a means to support her language development.

In discussing his daughter’s diagnosis, Anura made reference to his experience of identifying her needs. Anura talked about the possibility of a different outcome if they had the support of family elders. Anura explained that had the family been in Sri Lanka, “*grandparents would have understood it...*” and “*with their experience they would have guided us to do the exercise when Anisha was six months*”. Anura spoke of the importance in identifying

his daughter's needs early and promptly; he resolved that relying on the system had delayed this for them *"which resulted in Anisha's delay"*. The importance of family support is highlighted here and, for Anura, may have changed the outcome for his daughter.

All parents talked about their child's future prospects with the general essence being positive. Speaking about his daughter's school placement, Anura hoped for his daughter to make progress;

"I hope, give her two or few years – she will definitely come other age (catch up). And then – our hope is for her to stay in a mainstream school."

Malini expressed the same sentiments regarding her son's development in anticipation of choosing his school placement;

"But I believe still, my son is seven years old. He's got time to improve...Good progress, we believe that. But I tell you I never fall him down, he always going up...If after one year or after six months, it's really no good for him, this mainstream, then definitely we take him to whatever he needs...Now we believe strongly he will improve."

This quote expresses Mailni's desire to wait and observe progress before she makes decisions for her son. A deterministic view of the child's future was expressed as it appeared that decisions now may affect their child for the rest of their life. This is reinforced by parent's representation of the 'permanent' relationship of parents. Malini justifies her reasons for not sending her son to a special school. To Malini, a decision made now to *"separate"* him will result in separation for his *"whole life"*;

The notion of waiting to observe progress was also communicated by Mona who is choosing to wait before she agrees to a diagnosis;

“...It’s still a big if for me – even if she is on the spectrum, we’ll have a much clearer idea of where specifically on the spectrum she is...there’s no need to diagnose her now. There may be later.”

This subtheme highlighted how parents relate to the past, present and future. Parents look towards their child’s future as being impacted by decisions made today. The idea of waiting in hope was common across all parents.

5.4.3 Subtheme 3: Desire for Inclusion. Parents conveyed the importance of the environment and relationships in supporting their child’s development. All parents valued the socio-cultural context in helping their child develop friendships and progress in their learning. Below shows a quote whereby Malini discusses the importance of the educational environment for her son’s future;

“...they want communication with other children, talking, the environment. He has to move like a normal person - that definitely need education, for he has to find a good job and this is not good enough for him. His need friends. He needs relations, he needs the environment.”

Malini expressed that education alone is “*not good enough for him*” and there is a need for relationships and social interaction. In line with this, Fathima’s discussion about her preference for mainstream education emphasised the importance of social learning for her daughter; “*...the mainstream school is important for us – she learns from other children. That’s the first thing she does...they are good for a child like Anisha.*” Fathima

recalled her daughter's progress in walking and explained that this was largely due to the practical and physical support she received from her peers in a mainstream class. For Fathima, going to a mainstream school provided opportunities which a special school could not.

Parents spoke of their desire for their children to be socially included. The SEN label was perceived to be the catalyst for perceived exclusion in relation to school placement and wider society. Malini explained her rejection of sending her son to a special school. She understood her son's need for extra support, however disagreed with the notion of separation. Inclusion was an important construct in thinking about her son's future and contradicted her idea of what a SEN label and a special school means; speaking of special schools, Malini said *"I feel this is completely separate from the world..."* Malini stressed that living in *"a common world with other same as a human..."* was important for her as this would facilitate others being able to *"encourage him and teach him"*.

To Malini, a label of SEN signified the objectification and dehumanisation of her son. Malini perceives that her son was being viewed as an *"animal"*. This is in line with Devenney (2004) who discussed the role which labels play in shaping disability as 'something to fear' or 'special'. The emotive nature of this subject was apparent as Malini highlighted the anger she felt as a mother;

"...I don't want a label. This child – no. Because these people, they never look 'this is a human'. They look like animal. 'They will behave like that'. I can't accept that as a mum. I never accept that. Sometimes I get very angry you know."

In light of this, parents illustrated their concern for how their child was perceived by others and having inclusive attitudes towards those with SEN were deemed important. As illustrated by Malini, she did not want others to “*look a different way*” when they see her son. Anura described his daughter as looking “*normal*” therefore her SEN is not visible for others to see or judge; “*...Anisha when you look at her she is normal ...when you look at her she’s fine.*”

Subtheme 4 demonstrated the importance parents placed on their child’s inclusion in mainstream education and wider society. Special educational settings represented separation from others during schooling years as well as in the child’s future. Being perceived as “*normal*” and “*human*” were also deemed important.

5.4.5 Summary of theme 3. This theme has explored parent’s representation of SEN. It has highlighted that the concept of SEN as it is understood in the UK is new to parents. Parents made their own attempts to make sense of SEN whilst labelling a child with SEN and choosing a special school setting was perceived as deterministic for their child’s future and a barrier to inclusion within society. Parents longed for inclusion within school placement and social experiences.

5.5. Chapter Summary

This chapter highlighted how SEN was a new concept for parents. Emerging from the data were the parent’s feelings of disempowerment and negative affect experienced in the process of engaging with professionals. Conflict arose between parents and professionals when addressing special

school provisions. From this, the parent's desire for their children's social inclusion highlighted the importance of integration within the community.

Resourcefulness in supporting their children highlighted the influences of the parent's pre-migration identities.

Chapter 6. Analysis of SENCo interviews

6.1 Chapter Overview

EPs and SENCos, whilst both educational professionals, have distinct roles within the education system, therefore data from their interviews will be presented independently from each other. This chapter presents the findings of the thematic analysis of 4 semi-structured interviews which aimed to explore the SENCo's understanding of SEN and their experiences in supporting Sri Lankan, Tamil families. SENCos occupy a significant role within the school's SEN system and structure. They play a part in co-ordinating provision for children with SEN as well as liaising with parents and outside agencies, including EPs.

The data was analysed with the following research questions in mind:

RQ 1. How do parents from the Sri Lankan, Tamil community, EPs and SENCos in a North-West London local authority represent Special Educational Needs?

RQ 4. What has been the experiences of SENCos and EPs in supporting Sri Lankan, Tamil families in a North-West London local authority?

Two overarching themes are presented. Theme 1, titled '*Duties, functions and representations of SENCos*', addresses research question 1 by exploring the role of the SENCo and their representations of SEN within this context.

Theme 2 examines the '*Experiences of supporting Sri Lankan, Tamil families*'.

This theme looks to answer research question 4 and addresses how the

SENCoS described their collaboration with parents during SEN procedures and decision-making stages. The role of the wider school community and the importance of positive relationships with parents are outlined. SENCoS talked about barriers in communication and collaboration with parents which were associated with the parent's migratory status, including contrasting representations of SEN. Figure 5 presents themes and subthemes generated from the SENCo's data.

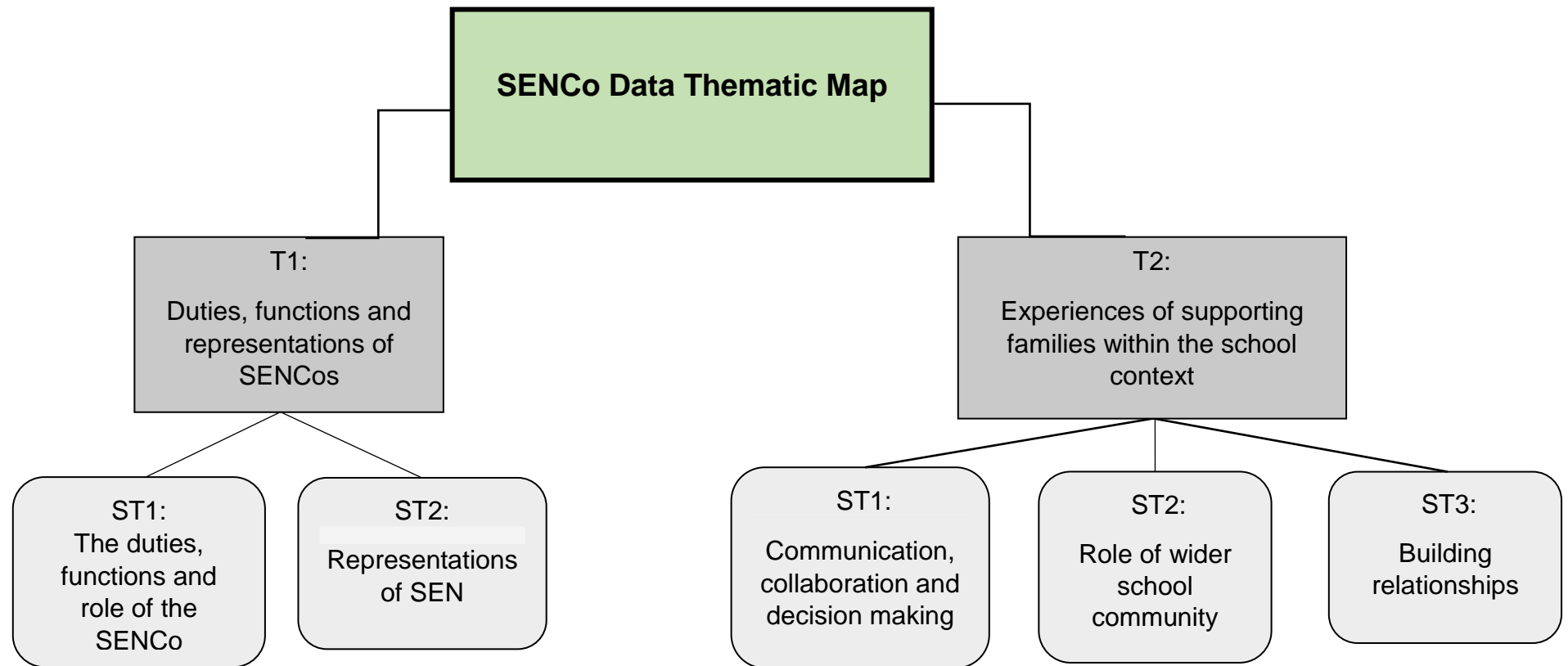


Figure 5: Thematic Map presenting themes from SENCo data

6.2 Theme 1: Duties, functions and representations of SENCo's

The analysis begins with Theme 1, which explores how the SENCo's describe their role within the school and community setting. This theme begins with looking at how SENCo's position themselves within the school contexts and how they describe their duties in light of legislative changes. It provides an opportunity to understand the SENCo and their diverse role in relation to others. Theme 1 also explores the SENCo's representations of SEN and how this is predominantly shaped by definitions laid out by the SEN Code of Practice (DfE/DoH, 2015).

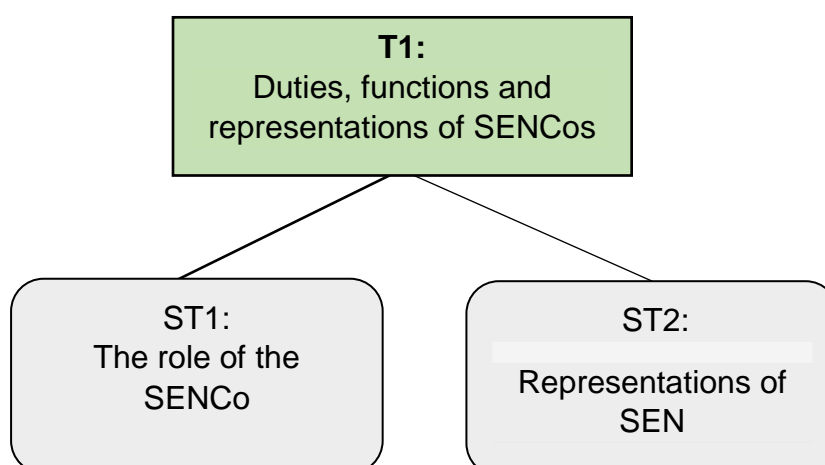


Figure 6: Theme 1 and subthemes from analysis of SENCo data

6.2.1 Subtheme 1: The Role of the SENCo. *'The role of the SENCo'*

captures how SENCo's describe their role within the context of education, including their relations to others, their daily roles and their compliance to legislation. SENCo's described themselves as being in a position to 'co-ordinate', 'to oversee', 'mediate' and 'provide resources'. When SENCo's discussed their role of supporting children and young people, they spoke

about this in process-driven ways; their narratives centred on following statute, processes and procedures. For example, Gloria spoke of the statutory process, making references to “*funding*” and the “*Educational Health Care Plan*” in ensuring vulnerable young people with high levels of need are appropriately supported.

Evident from the four interviews were the SENCO’s duty to observe and be guided by the SEN Code of Practice (DfE/DoH, 2015). All SENCOs made reference to this legislation highlighting its important role in steering their work and guiding the decisions they make. Of particular pertinence for SENCOs was the “*statute*” status of legislation as a facilitator for change and hearing the parent and child voice. Gloria spoke of the Code of Practice (DfE/DoH, 2015) as “*instrumental*” and giving “*leverage*” in encouraging a culture whereby SEN is engaged with by teachers in the classroom. Speaking of the SEN Code of Practice, Gloria explained,

“The latest Code of Practice is a work of art. It’s beautiful, it really is...I love it. I love it for lots of reasons, the definitions in there are clear, and straight forward and also what it’s done is sort of put the class room teacher right at the centre of catering for any child who considered to have whatever special need...”

SENCO’s paid regard to the SEN Code of Practice (DfE/DoH, 2015) when defining and understanding ‘SEN’ as a concept; subtheme 2; ‘*Representations of SEN*’ extends upon this.

6.2.2 Subtheme 2: Representations of SEN. When thinking and defining ‘SEN’, SENCOs described it as a “*cover all phrase*” and a “*broad*”

concept (as described by Gloria). Their descriptions encompassed a range of needs including; those *“impacting on the ability to learn”*, specific learning difficulties such as dyslexia, biomedical labels, including cystic fibrosis and cerebral palsy, social and communication difficulties, and emotional and behavioural difficulties. The process of objectification in social representations theory is pertinent here as it appears educational professionals have accepted anchoring broad labels and concepts as a means to turn what is abstract (SEN and the complexities of child development) into something almost concrete. The use of diagnostic labels facilitates individuals in the same educational club to communicate in such a way so that describing needs and problems, making decisions and understanding outcomes are simplified. As a result of this, SENCos are likely to relate diagnostic labels with interventions, classroom strategies and services which parents can access. In meetings involving parents or other lay individuals, such concrete language place professionals at an advantage for efficient dialogue but disadvantages others who are new to the context in which it is taking place – essentially this is where barriers in communication may take place with some parents who have different worldviews.

Liz reinforced the notion of categorical representations by making reference to the categories outlined in the SEN Code of Practice (DfE/DoH, 2015),

“...anything on the new code of practice really... obviously there are four categories... initially it would be for those that the mainstream class room can meet.”

Liz noted that SEN should be met within the mainstream classroom initially and could encompass “...*a specific learning difficulty, a language difficulty, vision impairment...*”

The regard for school placement as forming part of how SEN is defined was discussed by Trystan who differentiated between the “*mainstream*” and “*special*” setting. Trystan, who works in a special school for children who have been labelled as having “*Moderate Learning Difficulty*” described SEN in terms of categories on a “*sliding scale*” of “*mild, moderate, severe, profound and multiple*”. His description of what SEN meant referred to the application of resources in meeting the needs of children. To Trystan, SEN was described as,

“...an additional need that can’t be met within the normal remit of a mainstream classroom...when mainstream classes have exhausted their resources and exhausted their skills...”

As well as viewing SEN as being on a ‘*sliding scale*’ and varying in severity, it was also represented with regard to placement and environment. “*Mainstream*” was viewed as a place which may have limited resources and skills, at which point a “*Special School*” would be best suited to meet the child’s needs. There is also the representation that it is possible to ‘exhaust’ skills and resources in a mainstream setting and that only a specialist group of staff and setting can provide for those children. In effect, SENCos have drawn upon bracketing placement in mainstream and special, ordered severity and categorised SEN concepts as a way to organise their practice.

This categorical way of representing SEN contrasts with the parent's desire to maintain their children in mainstream education. Additionally, parents did not share the same representation of the label that is held by professionals, who were more likely to draw on policy guidelines and legislation. Evidently, narratives from SENCos as well as parents have highlighted the conflict that has occurred when these two worldviews meet in the decision-making process. For example, Kate spoke of an experience in which she felt it necessary for a child to attend a special school and access medical services, however this conflicted with the parent's view of the child's need. Speaking of this, Kate said;

"...couldn't persuade them to go CAMHS⁷ or paediatric or somewhere to get any other kind of diagnosis, and as I say, couldn't persuade them mainstream high school was not appropriate..."

In this instance, Kate felt the need to 'persuade' parents to move in a certain direction.

6.2.3 Summary of Theme 1. Theme 1 presented how the four SENCos interviewed viewed their role and how they defined SEN. SENCos appeared to be largely led by the SEN Code of Practice (DfE/DoH, 2015) and process driven ways of working. SENCos defined SEN broadly and spoke of it as a concept which encompasses a range of needs. SEN was represented in categorical terms with reference being made to the four categories as laid out in the SEN Code of Practice (DfE/DoH, 2015). The designation of SEN into "mainstream" or "special" school placement was also highlighted.

⁷ Child and Adolescent Mental Health Services (CAMHS)

6.3 Theme 2: Experiences of supporting families within the school context

Theme 2 was derived from the SENCo's narratives of their experiences in supporting Sri Lankan, Tamil families. The subtheme "*Communication, collaboration and decision making*" captures how SENCos described their experience of collaborating with parents during decision making processes. The role of the wider school community was deemed important in developing an ethos which fosters cultural awareness and "*building relationships*" with parents was described as important in collaborative decision making. Figure 7 presents theme 2.

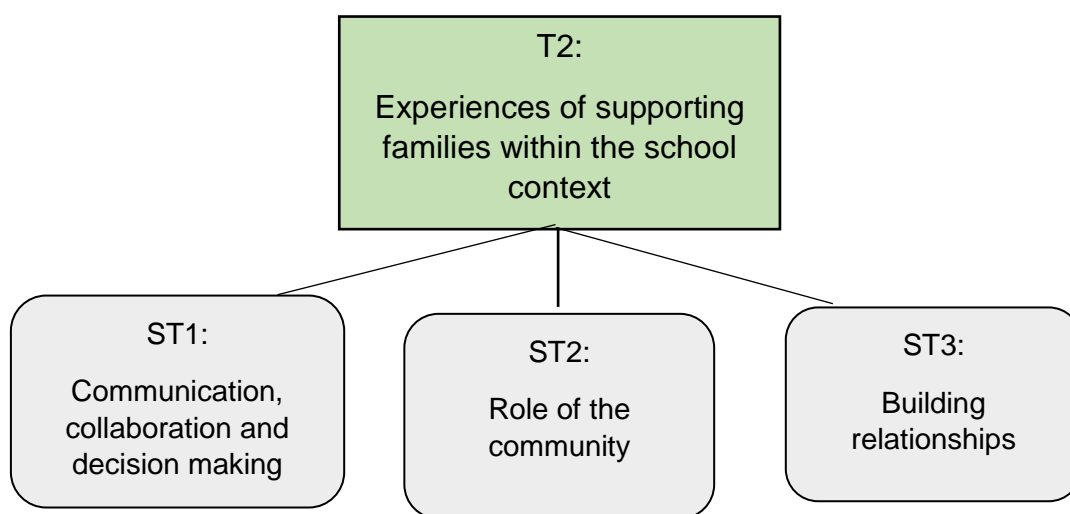


Figure 7: Theme 2 and subthemes from analysis of SENCo data

6.3.1 Subtheme 1: Communication, collaboration and decision making. Subtheme 1 illustrates how SENCos described their experiences of supporting and collaborating with families, however when SENCos discussed collaboration, they usually focused on the barriers to communication, which they said were compounded by the differences associated with the parent's

ethnic minority status. They included contrasting conceptualisations of SEN, differences in education systems in Sri Lanka and the UK as well as differences in language.

Speaking of their definitions of SEN and how this compared to those of the Sri Lankan, Tamil parents, Kate emphasised differences in what was *“seen as a need”*. In Kate’s narrative, parents are *“focussed on academics”* and parents believe that *“the ability to rote learn is more important... a need that’s not an academic... is not seen as a need”*. Kate drew upon the story of a family who found it difficult to accept a diagnosis of autism and the conflict which arose from this;

“...there was no acceptance throughout his school life no matter what we said... that (the autism) was a significant difficulty for the child. It was just that ‘he’s learning, he’s getting better’. End of....”

To Kate, the family’s focus on academia conflicted with her own view of SEN which *“encompasses a huge range”* and includes the label of autism. For Kate ‘a need’ may represent any area of a child’s development, including social, emotional or communication development, which requires additional intervention or support. Kate concluded that for parents *“...there wasn’t understanding to do with the impact of these social and communication needs would have on his life....”*

The differing perspectives created an obstacle to Kate’s plea for the young boy to leave the mainstream setting. Eventually, the family accepted *“a bit of difficulty with speech but otherwise he’s fine.”* Whilst accepting their son’s speech and language difficulties was a step closer to the representation

held by Kate, being *“fine”* contradicted what a diagnosis of autism meant to her. It appears that to Kate, autism cannot be anchored to ‘being fine’ – in Kate’s worldview being fine and accepting a label are essentially different.

Kate believed that unless parents understand what a need is, in accordance with formal school systems, *“they’re not going to put the effort into the things we think are important”*. She stressed the difference between *“parents who don’t have a clear understanding of what a need is to us”* and what is *“important for education”*. In these statements Kate differentiates between *“us”* (the school) and *“parents”* (them) and emphasises the need to do what school *“think are important”*. Essentially, Kate illustrates the power differentials between the school and parents; in doing so, she places the school as leading and having the overarching knowledge and view which must be followed. According to Kate, the school is viewed as holding the correct way of doing things and it is parents who have to change their viewpoint in order to know *“what good learning is all about.”* Inequalities in power structures across lay and professional groups as addressed within social representations theory (Howarth et al., 2004; Jovchelovitch, 2007) is evident here as expert knowledge are represented as dominant whilst parents are viewed as lacking and failing in their understanding.

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...”

Liz conveyed the importance of using interpreters as communicators of social norms as a means to ensure understanding by parents. Here, she highlights parents as passive participants by saying they would “*agree to everything*” without fully understanding what it is they were agreeing to. Gloria spoke of her worry and the difficulties “*to get them (parents) to engage or really understand what we’re doing with their children*”. From Gloria’s experiences, parents were “*totally on board but in a sort of passive way...*” She described that parents “*would be extremely supportive and make all the right noises but...they don’t really know what’s going on*”. This statement again highlights the SENCos model of Sri Lankan, Tamil parents as having a deficit in their understanding and incapable of having the knowledge necessary to be in agreement with the education system. Important for Gloria was her desire for parents to be more “*vocal*” and recognise that “*they’re the expert in the kid*”. With this stance, Gloria made reference to the SEN Code of Practice (DfE/DoH, 2015) as a facilitator to empower parents.

The consequences of communication barriers became most apparent during decision making processes, particularly when schools identified a need for parents to concur with professional decisions. This was demonstrated explicitly by Trystan who spoke of the transition process for children moving on from their primary to secondary placement. Trystan’s position as a special school SENCo placed him in a unique position to experience dialogue with parents who were part of the special school community for children with moderate learning difficulties. Trystan’s narrative, in the context of working in a special school, conveyed the conflict and “*wrangling*” that takes place when deciding upon the most appropriate placement for the children at the end of

Year 6 and how differences in opinion become apparent during this time. The following quote illustrates misunderstandings between parents and the school;

“we have thought that we are on the same page as our Tamil families. Which is, your child has a special educational need, is making good progress... that SEN need won’t go away...it’s often at year 6 at transition and the conversation turns to which high school are we going to go to, “oh we’re going to go to mainstream high school...it’s “well my child doesn’t have a special educational need”, they just need to grow out of it. They’re fixed now, they’re mended...”

Trystan reflected that circumstances involving major transition points, such as pupils transitioning to secondary school, show that the parents understanding of SEN differed with that of the school’s and was something that was never jointly established. Use of language became evidently pivotal in developing a shared understanding, for example, Trystan spoke of using the word *“improvement”* in the context of progress. From Trystan’s perspective, parents may have constructed this to mean the *“child becoming non-SEN”*. Trystan resolved that *“expectations on the outset were fundamentally different to those we had understood them to be”* and therefore created barriers to collaborative working.

This statement was part of Trystan’s expression of his confusion that parents had agreed to send their child to a special school (in which he was the SENCO), however as is highlighted, this outward behaviour did not relate with how parents were implicitly constructing SEN.

In relation to social representations theory, the relationship between language, representations and culture is notable here. Representations are interwoven with the culture in which it resides (Joffe, 1996) and are dependent on patterns of communication which conjoin the shared realities within the culture. As Triandis, (2001) discusses, time, language and space are important in determining and transmitting culture. The same historical period and geography are deemed desirable in transmitting cultural ideas efficiently and language within this is particularly pivotal. For example, SENCos and EPs are able to engage in dialogue which finds them sharing a joint understanding of SEN and the practices that are embedded within it.

From the data presented, SENCos have an expectation that parents will join them in shared language (Marková, 2003) and also engage in practices that comes with this shared reality, for example, agreeing to diagnoses or agreeing to an established process (e.g. attending a special school). As Trystan recognised, sending their child to a special school did not change the core constructs of the parent's representations. This highlights the complexity in how representations are anchored. For parents learning about SEN for the first time, the time and space which Triandis, (2001) mentions is important in developing an understanding of SEN which also translates to practices and cultures.

Essentially, conflict appeared to arise for SENCos when they deemed it important to take a dominant position in the decision-making process. Gloria and Trystan spoke of action being taken by engaging Social Services, especially when concerns in child rearing styles arose as well as when parents were in disagreement with how to proceed in supporting the children.

In these circumstances, schools are in a more powerful position because they have recourse to draw on state institutional powers, leaving the parents at a disadvantage.

The need for influencing decisions and imposing procedures upon parents was discussed by Kate who raised her concerns around practice which takes place when there are communication difficulties with parents. At times when there was a need to sign paperwork to move processes forward, Kate explained that;

“...they signed whatever we gave them...And we knew that’s what he needed. I’m not sure that they knew what they were signing. But it was like we know he needs it so it’s good that they signed it. I don’t think they did really understand...”

Kate admitted that it was not always clear whether parents understood the paperwork they were filling in however moving forward regardless was important as long as the school believed it would lead to a positive outcome for the child. Ensuring that children received a certain type of support was of prime importance and according to Kate there was a worry that if parents *“understood the full implications it might have been a no and then he wouldn’t have got what he needed”*. With this view, Kate believed that better understanding of the systems and processes may hinder and be an obstacle for the school’s plan in supporting children. Kate, with the best intentions, was implicit in ensuring that parents were left in unequal power situations in terms of knowledge.

Subtheme 1 has highlighted the importance of how language can facilitate power or mutual collaboration during decision making. When SENCos spoke of barriers in communication it was at times the result of differences in conceptualising SEN, differences in systems and structures between Sri Lanka and the UK and when parents spoke EAL.

6.3.2 Subtheme 2: Role of the Community. In subtheme 2, the role of eco-systemic factors are explored in the family's experiences and interaction with the school. Significant to the SENCo's experiences of supporting families from minority ethnic backgrounds was the role others within the school and wider community played. SENCos communicated the need to develop an ethos throughout the whole school system in which all school staff could engage in professional practice which promotes an understanding of different cultures. The SENCo's readiness for accessing community organisations was apparent through their use of interpreters.

In describing 'SEN', SENCos described their need to consider aspects of a child and family's life beyond the classroom setting. SENCos spoke of "*complex needs*" which may at times be the result of socio-cultural influences such as poverty and housing issues. Talk regarding this subject was not exclusive about families from Sri Lankan, Tamil backgrounds (or this research's parent participant sample who came from well-educated backgrounds), however, Liz made reference to being "*holistic*" and "*establish the history*" in her approach to supporting Sri Lankan, Tamil families as she reflected on the school's pupil intake which results from families migrating.

Liz drew upon the importance of understanding the migration history of a particular family who had originally migrated from Sri Lanka to France and eventually England. In this respect she talked about a need to consider how migration had affected the pupil's educational history, their use of language and what their housing circumstances were. Both Liz and Trystan spoke of the impact of housing and how being "*house movers*" may be affecting families. In line with this, Trystan describes the subject of housing as "*a huge issue*" and "*having a massive impact on our families...*" Trystan expressed concern and interest in understanding how poverty, including living in temporary accommodation "*sits underneath an awful lot of other things*". In addition, Trystan expressed the challenge that schools have in providing appropriate support to address such issues;

"...the challenge is to work with those other services...the mental health services for our children is massively important, housing is having a massive impact on our families at the moment..."

This quote illustrates Trystan's desire for families to access services beyond that of the school setting. It appears that concern for migrant families stretches to socio-economic areas and beyond the school setting. SENCOs appear to have drawn upon stereotypical ideas of migrant families as deficient as a result of their minority status, (Crozier, 1996)

In addition to this, the importance of accessing and building relationships with community group leaders was also deemed important in working with families from ethnic minority backgrounds. Kate and Trystan, spoke of "*the responsibility of the school to engage with the wider community*"

and building relationships with group leaders in order to overcome the communication barriers discussed earlier. Liz drew upon her experience of successful liaising with community leaders from other ethnic groups and explained that *“once you’ve broken the barriers down...then you’ve won them around and you work with them.”*

To ‘win around’ a family was demonstrated in a narrative about persuading a parent to send her son to a special school, as Liz explained, *“the mum and boy could not have done it without this organisation”* (a Sri Lankan community organisation) because *“you do need somebody from the community to communicate with the family.”* In this circumstance, it was more than speaking the language; working with a community leader allowed the school to learn about the complexities regarding citizenship for this family who had migrated to the UK and acknowledge that there was a stigma attached to going to a special school. For Liz, *“a relationship between the school, the family and somebody between the community”* was *“the only way”* to do it.

As a means to develop culturally sensitive services, SENCos drew attention to the wider school community as barriers or facilitators. Gloria responded to the notion of cultural competence by saying *“it’s absolutely essential...it’s something that exercises everybody...”*

Interestingly SENCos positioned themselves as different to other teacher professionals – as having greater understanding of inclusion and what it means to have cultural knowledge. The importance of engaging school staff in recognising cultural differences in communities was highlighted by Liz who

had 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.”

Liz highlighted that school staff may misjudge the actions of parents because they “*didn’t understand*” and advocated the need to explore the subject of being culturally competent further in order to address the “*lack of knowledge*” amongst school staff. Liz recognised differences in knowledge between herself and other school professionals and viewed herself as an advocate for greater cultural understanding. Of particular pertinence for Trystan was the significance of parents building relationships with each other as a way to develop a supportive community. This is further explored in Subtheme 3.

6.3.3 Subtheme 3: Building Relationships. SENCOs talked about the value of building relationships with parents as a means to facilitate smooth decision making and understand the needs of families more. Three SENCOs described the positive outcomes which were the result in developing relationships with parents. Gloria spoke of a family who were initially resistant and in disagreement with the school’s involvement. From doing “*a lot of work with mum and dad to get them to open up...*” the school were able to “*establish(ed) a really good relationship with dad...*” For Gloria, the good relationship was pivotal in supporting the young person to progress and become “*successful*” - by settling into secondary school and transitioning to

college. Liz promoted the need to recognise differences between cultures and explained *“you have to really take the time to get to know them...”* and develop suitable ways of working for that particular group.

The implications of the special school context on building relationships with parents was recognised by Trystan. Trystan explained attempts to set up family learning groups whereby parents were provided opportunities to meet and engage in group discussion. From his experience, it was difficult to engage parents from the Sri Lankan, Tamil group;

“...we work quite hard to build relationships with our families...the children come on the bus and there’s an in-built remoteness there for a lot of our families there’s a language barrier there as well....we invite families to come in and spend time but nevertheless relationships with families are often built to a superficial level...”

Arriving to school by the school bus, is a unique element of attending a special placement and in this excerpt, Trystan highlighted the *“in-built remoteness”* which results from this set up. When children arrive by bus, parents and school do not meet on a regular basis or engage in regular dialogue. Therefore, the school have had to *“invite families to come in and spend time”*, however Trystan explained that this has not been enough as relationships have remained *“superficial”*. At a *“superficial”* level difficulties in understanding parent’s true opinions regarding SEN do not surface until *“there’s a significant life event”*, and conflicts arise, for example, at transition to secondary school. Regular and early dialogue with parents was deemed important in developing a better understanding of parent’s views.

The disconnection between school and parent within the special school setting was further elaborated upon to describe a disconnection within the parent community. According to Trystan, there is value in developing a social network amongst other parents who have children with SEN. Trystan described the parents within the special school setting as *“isolated”* and spoke of the struggle to *“get hold of them”*. From his perspective, parents *“...live as islands from the rest of their community”* and from his observations, not engaging with each other means that parents are not forming their own supportive parent community. The combination of parents not meeting at the school gate (because children are dropped off by the school bus) as well as the parent’s apprehension regarding SEN are likely to be contributing factors to the disjointed relationships between them.

This subtheme has explored the SENCo’s desire to build relationships with the families they support. Positive relationships enable collaborative discussions whilst poor relationships have hindered dialogue and mutual decision making.

6.3.4 Summary of theme 2 Theme 2 presented the SENCo’s experiences of supporting Sri Lankan, Tamil families within the school context. Highlighted within this subject were the SENCo’s desire to build relationships with the parents and to promote a school ethos which encompasses cultural awareness. SENCos spoke of their desire to overcome barriers in communication.

6.4 Chapter Summary

This chapter described the two themes developed from the SENCo's interviews. The SENCo's role in following processes and statute was key in supporting children with SEN. However, the SENCos often focused on issues of how conflict, barriers and communication hindered collaborative dialogue with parents. Dissonant social representations of SEN were talked about by SENCos which further contributed to difficulties in decision making. The need for parents to follow processes as laid out by statute was important to SENCos and building relationships with community leaders and parents was seen as key to moving forward.

Chapter 7. Analysis of EP interviews

7.1 Chapter Overview

EPs are professionals within the education sector who play a pivotal role in supporting families, schools, children and young people with regards to SEN. The EPs interviewed for this research were employed by the local authority within which the research took place, therefore their role also encompassed supporting local authority processes and procedures. This chapter presents the results of the thematic analysis of 5 semi-structured interviews which aimed to explore the EP's conceptualisation of SEN and their experiences in supporting Sri Lankan, Tamil families in the context of SEN.

The data was analysed with the following research questions in mind:

RQ1. How do parents from the Sri Lankan, Tamil community, EPs and SENCos in a North-West London local authority represent Special Educational Needs?

RQ4. What has been the experiences of SENCos and EPs in supporting Sri Lankan, Tamil families in a North-West London local authority?

Two overarching themes developed from 5 EP interviews. Theme 1, labelled '*The EP, the families and the school*', engages with the EP's experiences of working alongside schools and supporting families. It illustrates how EPs regard the work they do with families as '*a journey*' and highlights their approach to having families at the centre of their work. In

theme 2, titled '*When representations of education and SEN meet*', the EPs representations of SEN and education are examined in the context of their work with families. Here, the EP's perceptions of how SEN is understood by parents are also explored.

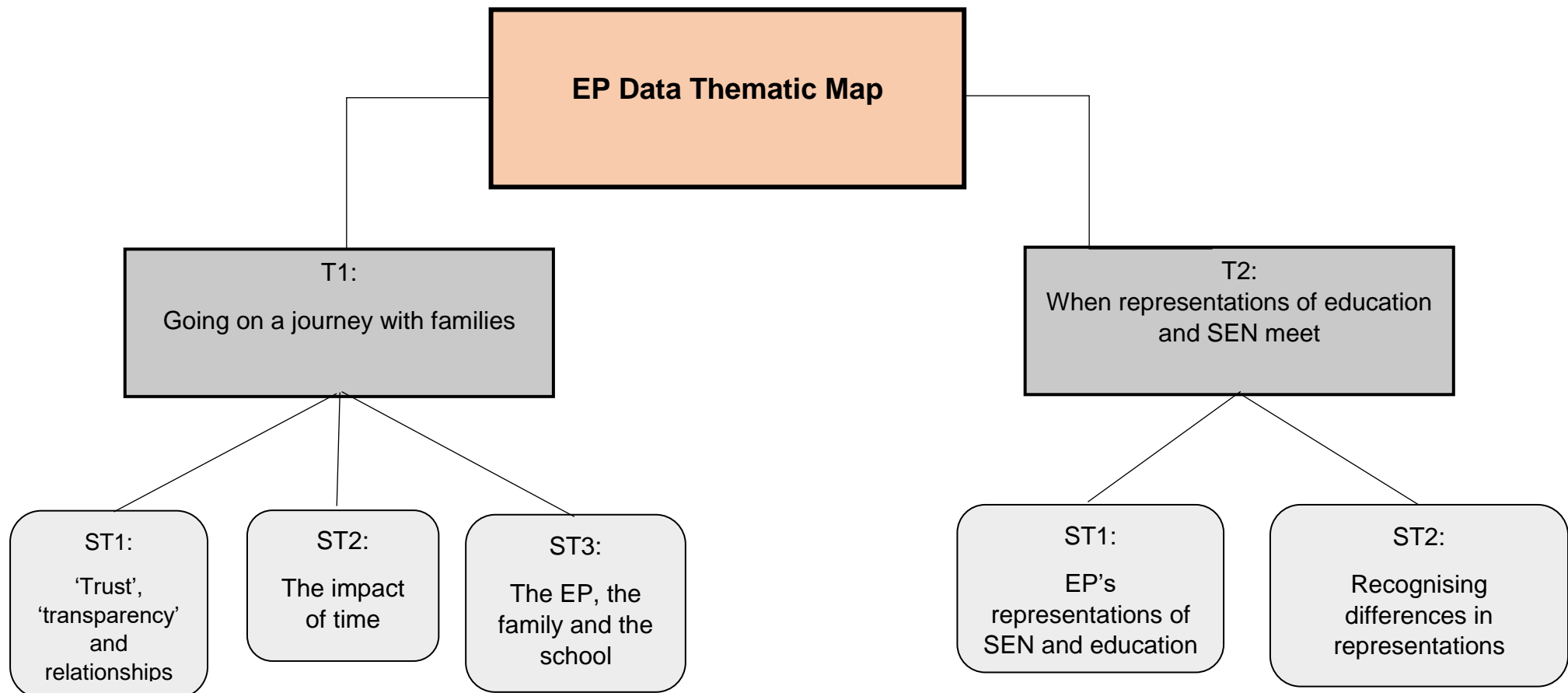


Figure 8: Thematic Map presenting themes from EP data

7.2 Theme 1: Going on a journey with families

‘Going on a journey with families’ explores how EPs reflected on their time spent with Sri Lankan, Tamil families and the progression of the work they carried out. For ease of reading, Sri Lankan, Tamil parents will be referred to as *‘families’* or *‘parents’*. Questions asked in the interview made specific reference to Sri Lanka, Tamil communities therefore EPs generally responded with using the term *‘families’* when talking about Tamil parents.

Theme 1 focusses on the EP’s broad representations of their role in relation to working with Sri Lankan, Tamil families. Commonly shared between the EPs was how they represented movement and change through the systems of the SEN process as *“a journey”*. The essence of travelling through the disclosure process, making decisions for their child and coming to understand their child’s SEN was considered to be a process which took place over a period of time with the EP as the observer as well as the mediator within this. Evident in the narratives were the EP’s commitment to positioning families at the centre of their work and their advocacy for developing trust, relationships and a good understanding of families. The impact of time in the ‘journeys’ parents went on appeared to be a prominent theme in shaping the EP’s narratives. Theme 1 also explores the EP’s role in working alongside families and the school and how challenges are mediated along the way.

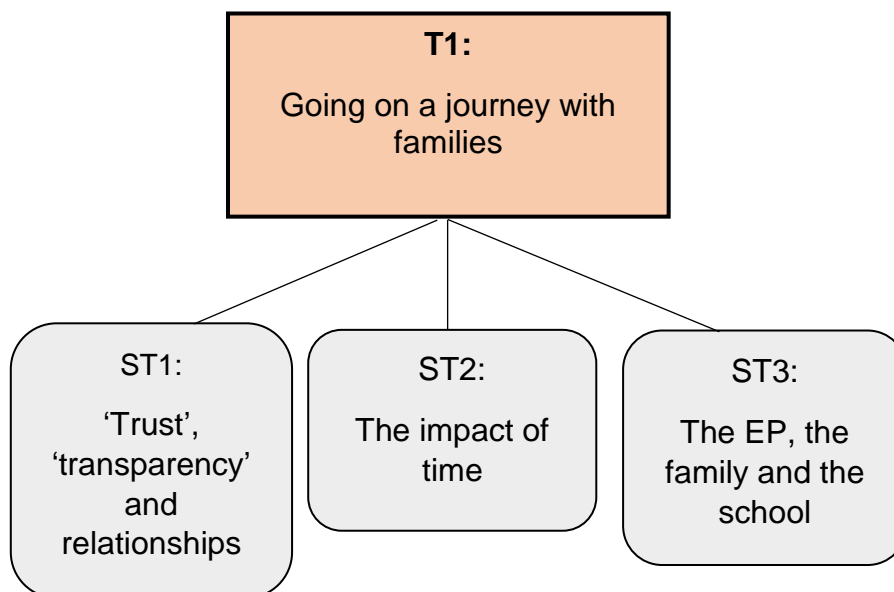


Figure 9: Theme 1 and subthemes from analysis of EP data

7.2.1 Subtheme 1: ‘Trust’, ‘transparency’ and relationships. The importance of developing rapport, trust and positive relationships were significant themes amongst the EP’s recollections of working alongside families and schools. In describing recent activity at the beginning of the academic year, Zahra (who has been practicing as an EP for seven years) explained “...for me obviously at the moment it’s about developing rapport with my schools, building that trusting symbiotic relationship”. Here, the intent to foster positive working relationships with the school was of priority for Zahra from the outset. A positive relationship with the school appeared to facilitate Zahra’s idea of herself as a mediator between the school and families.

Most explicitly however, were the EP’s reflections of building positive relationships with parents; Irene reflected on the impact being an “*expert*” and “*professional*” may have on the interactions she has with migrant parents;

“...when we meet with a parent...you’re having to form a relationship – you’re having to ask them really in-depth questions, personal questions...sometimes parents do find it difficult to speak... you’re a doctor – and there’s almost that deference, that power imbalance.”

In order to lessen the ‘power imbalance’, Irene noted her way of making parents feel comfortable by *“listening to that person’s story and having time”*. By doing so, Irene hoped to better understand the personal and social contexts of families and provide opportunities for families to regain ‘power’ in meetings. Interestingly, however, Irene did not refer to Sri Lankan, Tamil parents here – her generalisation that all parents may feel a ‘power imbalance’ ignores the fact that not all parents have equal power status. Parents, migrant or not, will have access to varying degrees of resources. In this instance, Irene spoke of rapport building in relation to meetings and the question- answer format of dialogue. Looking into the narratives of other EPs, relationship building with parents appeared to serve as a way to guide parents towards making decisions and to share mutual understanding of SEN with educational professionals.

Gaby made reference to a *“success story”* and a *“positive situation”* in which the parents of a young boy with SEN *“were in dispute”* and were *“beginning to fall out with the school”* as differences in perceiving the child’s needs became apparent. In Gaby’s narrative, her role as an EP was deemed as a catalyst in supporting parents choose a special placement for their son. Following previous involvement with the family, Gaby explained that,

“...the father said that he trusted me and would listen to me if I was advising that a change in school placement was required...he ceased to be

quite so angry with the school and the change of placement occurred in a more positive note..."

Gaby's established relationship with the family was considered a foundation from which dialogue could be had, about the 'move' the educational professionals wanted the child to make. The EP's involvement and approach was noted as a facilitator to the parent's positive responses instead of *"if the school had said 'hang on we can't meet needs."* The direction in which the school and the EP had wanted the parents to take appeared to have been mutual between the two professional groups and pre-decided; that is, a change in school placement was necessary. In essence, the relationship dynamic between professional and parent is suggestive of disciplinary power at play. Building a relationship and engaging in the *"trust"* the parents had in the EP allowed for this change to happen and diffuse the difficult relationship parents had with the school. Essentially, Gaby highlighted her role as a mediator in reframing the school's stance of *"can't meet needs"* to *"trusted advice"*.

According to David, *"developing that good rapport, the therapeutic relationship, is essential for instigating change. Positive change."* Additionally for David, a *"secure base"* and *"solid relationship"* were important qualities within the dialogical relationship between EP, parents and school staff and was something to be conscious of *"beyond assessing, psychological frameworks and interventions"*. David reflected on the nature and sensitive content which may be endured during meetings; challenges include *"having to give bad news sensitively, that relies on having developed a really good rapport and relationship"*. Showing that *"you understand and care"* and that

“they know it’s coming from a place of what’s in the very best for the child” was highlighted by David as being of prime importance. David spoke of the impact which *“trust, relationship and transparency”* can have on *“moving forwards”* for parents when ‘moving forward’ was challenged by differences in opinions. By perceiving the professional as committed and being *“invested”*, parents were described as more likely to engage with and listen to an EP’s opinion;

“...very much a sense of trust. If David is saying this. He’s been to our house on several occasions...he’s been contactable. He’s given us advice, he appears to be invested in our son, care about our son and want the best. If this what he says. If this is his professional opinion, we have to at least go and see the school...”

Here, he distinguishes ‘professional opinion’ as separate to that of the parent’s and notes that trust can develop through showing commitment and investment in the family. By noting *“if this is his professional opinion”*, David highlights the overriding status he believes parents may have of the EP’s point of view, however, having a professional opinion alone is not enough. From David’s perspective, it is necessary to take time to develop a relationship which parents can trust and be led by.

Subtheme 1 demonstrated that relationship building, whilst positive, appears to be established as a facilitator for professional knowledge sharing, consequently leading to mutual understanding in dialogue. Through developing trust with Sri Lankan, Tamil parents, EPs engaged parents in making decisions which professionals deemed to be necessary and

appropriate, thus maintaining a sense of authority over what is considered the right direction to move forward. Notably, EPs did not raise the ethnic status of parents as the reason for their need to build relationships and rapport. EPs spoke in general terms which upon reflection could be applied in practice with all parents.

7.2.2 Subtheme 2: The impact of time. Taking a temporal perspective, ‘time’, was noted as an element within the narratives of all five EPs as they narrated the importance of *“moving forward”* and making progress whilst *“going on a journey”* with parents. Time was observed as a pertinent point of analysis as EPs discussed how obstacles (as perceived by professionals) which resulted from differences in opinions and ideas between parents and professionals, could be overcome. EPs made reference to selective cases which they felt were significant within their role of working with Sri Lankan, Tamil families and in doing so, their narratives occupied a length of time and events.

Gaby drew upon the importance in *“working with the family and going through their journey... over the years”* when reflecting on her time as an EP in the local authority. To Gaby, who had worked in the local authority for over 18 years, being in a service for a longer length of time can be a *“valuable”* thing as *“parents get to know you”*. *“Length of time”* was valuable to Gaby as it allowed EPs to be present at the beginning of a family’s journey *“when they first had concerns raised”* and provides opportunities for monitoring progress. Over time, Gaby reflected that *“...they may not like what you’re saying but they like the fact it’s a familiar face.”*

When exploring her representation of what ‘support’ means, Irene explained that *“it’s like you’re working alongside the family over time. You might see them regularly and you have that input with them.”* Christopher described *“that lack of continuity between EPs particularly at an early stage... is probably not very helpful.”* Christopher spoke of barriers that arise as a result of *“tight time frames”* when carrying out statutory psychological advice or when he *“recognised that there was a journey to be gone on but it then (the case) transferred to someone else”*. Christopher reflected upon the barriers of such work;

“...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.”

This quote was spoken of in the context of Christopher recognising that views between parents and EPs can be different. Gaining a *“snapshot”* of a particular time is not sufficient in fully understanding the ‘longer’ journeys some families go on – only time can facilitate this. Concluding his narrative about the work he carried out with a family, Christopher stated, *“I feel bad that I didn’t spend longer with the family”*, highlighting the significance of time in building relationships and nurturing the family’s needs.

Whilst lack of ‘time’ was described as a barrier to engaging with families by Christopher, David spoke of how *“investing”* in a family over a length of time was significant in facilitating movement and change in the

parent's perspective. David described the *"very slow, long journey"* a family went on in the process of accepting their son's SEN which eventually led to a change in school placement (as advised by educational professionals). David described that *"understanding was reached after involvement"* as a result of the relationship he built over *"a long period of time and spending time with them (the family)"*. David reflected that through this, a sense of *"validity"* in his advice was established and parents were more willing to make changes according to the professional's point of view. Longevity in the contact David had with the family was deemed central in the validity of his advice.

This subtheme has signified how contact between EPs and parents overtime may facilitate positive relationships, trust and foster a sense of validity in the EP's role. Over a period of time, EPs reported experiences whereby parents displayed a shift in their perspective of SEN when they were initially met with differences. Time allowed EPs to influence the decisions they wanted to observe. With time, EPs felt they could resolve the disconnections they believed sat between the relations they had with the families.

7.2.3 Subtheme 3: The EP, the family and the school. Subtheme 3 looks at the experiences of EPs when they come together with families and school. This subtheme brings to the surface how EPs position themselves in relation to parents and the schools and outlines the EP's position and role in *"mediating"*. EP's spoke of holding a distinctive professional position and role from that of the school's. So when challenges arose between families and professionals, EPs spoke of the importance of focussing on strengths and 'building a bridge' in order to move forward and instigate progress.

Zahra drew upon a particular experience of working alongside a school and supporting a family who were in dispute with each other. Zahra's narrative in telling of her experiences highlighted the significance of her role amongst the discord as events unfolded. Tensions observed by Zahra included a broken relationship between school and parents and her own difficulties in establishing a collaborative relationship with the school. In the process of working alongside the school, Zahra spoke of difficulties in applying her role in accordance with her own philosophy and principles. Meeting with parents and sharing a dialogue was essential to Zahra's practice, however, this was not mutually valued by the school;

"...for me it's about making sure we adhered to the code of practice...that we are working with parents so they feel that this is something we do with them not to them. And that we stick to our own principles."

Zahra spoke the above quote in the context of defending her desire of having joint meetings with parents. Having emphasised *"with"* parents recognises the potential power imbalance between parents and professional, however Zahra attempts to defuse this on the onset of involvement. *"Checking the parent is with you"* is something Irene also spoke of when reflecting on meetings with parents as a means to ensure that her descriptions of their child is balanced with *"drawing out the positive"* as well as *"recognising they have needs"*. Continuing, Zahra stated that *"...my problem formulation always comes with parents, my hypothesis building always comes with parents as an essential part of that puzzle, not just from school."* Evidently, Zahra viewed parents as *"essential"* individuals in her understanding of the child.

As well as developing a personal understanding of families, Christopher noted the need to support school staff to recognise cultural differences. Christopher reflected on a particular case whereby differences in conceptualisations of SEN were made apparent during a meeting between parents and professionals, (this will be further explored in Theme 2). Upon reflection, Christopher spoke of this as an opportunity to develop empathy and understanding of the parent's perspective. Christopher negated the notion of viewing these parents as "*lacking*" but as individuals who were trying their best;

"...these weren't wacky parents who were sort of completely misguided or sort of lacking in understanding about their child... actually they want the best for their child and it's potentially a tough journey to go through... we need to support them in that."

Here, Christopher appears to defend families who may be viewed negatively and advocates the need for others to also take this view. In support of this, Christopher later in the interview described staff "*who have had experience of working with a range of families of differing needs and perspectives... (and have) more empathy and understanding*" as facilitators of his work.

The notion of being a "*critical friend for the school*" whilst operating as "*an independent person*" was explored by Zahra. Zahra explained the pressure of having 'education' in the EP's role title as "*people automatically think you are an off-shoot of the school*". Importantly for Zahra, she explained that she "*would never collude with the school*" but works under her "*own*

ethical guidelines". For Zahra, being "boundaried" and "*not taking sides*" were important in her dialogue with the school and family. Zahra explained that she felt it was important to "*reflect back that we are all here to support this little boy*" whilst Christopher spoke of "*bringing some of our psychology in being able to explore the views of others*" as a means to mediate misunderstandings between home and school.

Additionally, Irene spoke of her will to ensure clarity and transparency in her dialogue with parents. Irene reflected on communication with parents saying;

"...you see a parent nodding and you're thinking, 'Right, are you nodding because you agree with me? Or are you nodding because you feel that's what you need to do.' ...so it's checking in with the parent..."

In order to facilitate effective and 'comfortable' communication with parents and school, Irene spoke of accessing translators and "*thinking about the language*" that she uses. Irene spoke of taking the parent's perspective into consideration by recognising that meetings with professionals and parents might leave parents feeling "*shell-shocked*" whilst she may have thought it "*a brilliant meeting*". The need to take on the parent's perspective was further explored by Christopher who spoke of the need to consider that families "*may not understand the systems around mainstream and special schools*" therefore Christopher supported that "*there's a responsibility for us (EPs) and for school staff to help them (the parents) understand that*". For Christopher, this allows parents to "*make an informed decision*". Evident in the

EP's dialogue was their will to *“build that bridge to between home and school”* and it appeared that taking on the perspective of parents was pivotal in this.

Subtheme 3 highlighted how EPs positioned themselves in relation to parents and the school. EPs appeared to view themselves as individuals who could mediate in times of dispute or conflict between families and schools. When differing perspectives arose, EPs viewed themselves as in a position to bring to light better understanding of the parent's perspective.

7.2.4 Summary of theme 1. Theme 1 has presented how EPs represented the 'journey' they go on with families. On this 'journey', EPs spoke of the importance of developing trusting relationships with parents and the notion of 'having time' was seen as pivotal in engaging the trust between EPs and the family. The final subtheme described how EPs positioned themselves as professionals who could mediate and explore differing perspectives so that a mutual understanding could be reached between home and school.

7.3 Theme 2: When representations of education and SEN meet

Theme 2 describes how EPs spoke of their representations of SEN and education. Referring to the process of anchoring, it appeared EPs anchored their concept of SEN firmly in the guidance laid out in the SEN Code of Practice (DfE/DoH, 2015 and the medical model. It is in speaking of their representations that the EPs talk moved from the general to the specific differences between cultural representations of the Sri Lankan, Tamil families.

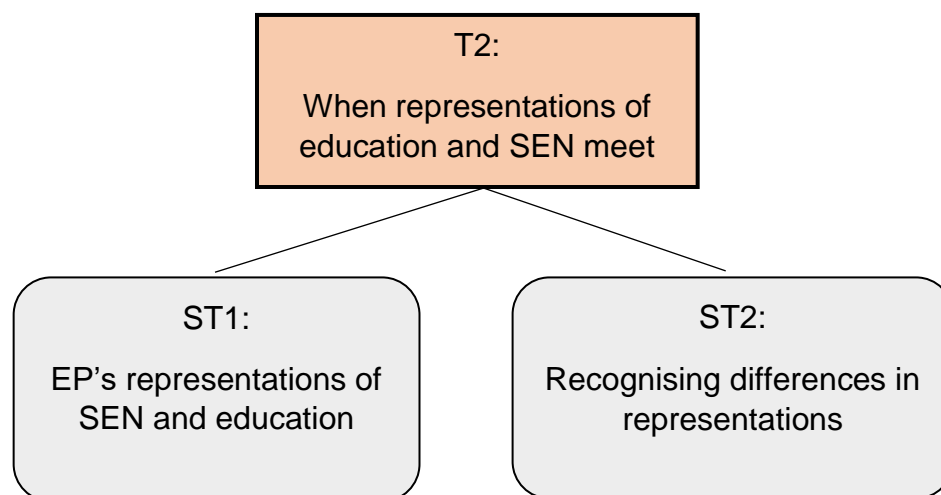


Figure 10: Theme 2 and subthemes from analysis of EP data

7.3.1 Subtheme 1: EP's representations of SEN and education.

Common across all EPs was 'SEN' as a barrier to *"progress"* and *"learning"*. The notion of 'progress' appeared to be set against the expectation that children and young people are expected to *"access the curriculum"* in normative ways - in line with their peers. Zahra explained she *"would be looking at whether they (the children) are making value added progress"* suggesting the importance of measurement when observing SEN. When defining progress, David described SEN as *"a child who is finding it difficult to progress at the expected developmental rate"* whilst Christopher made reference to *"a greater difficulty in learning or in accessing the curriculum, more so than other children of their age and stage, because of either a learning difficulty or a disability..."* Evident from the above quotes, is a sense of SEN as being outside of a stage usual of other children; both EPs appeared to represent SEN as linked to childhood *'development'* and *'age'* related stages as laid out by curriculum criteria.

SEN as a “*barrier to learning*” was viewed as a “*wide umbrella term*” by Irene and it appears other EPs addressed the “*broad*” concept of SEN by identifying different areas of development in which SEN may be observed. Speaking of barriers to learning, David explained that they;

“...might be around language, cognition and learning, around communication and interaction, around social and emotional, mental health and of course it might be around sensory needs...so they are apparent when a child is facing some kind of barrier to progressing at typical developmental rate...”

Representing SEN in these compartmentalised and segmented areas of development were also explicitly mirrored by Zahra, Gaby and Christopher who mirrored the same language in their descriptions – for example, Gaby labelled “*cognition, learning, emotional development or physical needs*” just as David did in the above quote. As prescribed in the SEN Code of Practice (DfE/DoH, 2015), SEN areas are labelled as such under “four broad areas of need and support” indicating the EPs representations of SEN as anchored within this legislation. Giving unknown ideas a name facilitates its anchoring into collective frames of references. The naming of SEN labels and categories provides an illusion that SEN as ‘real’ and comprehensible, (Höijer, 2017; Wagner et al., 1995).

At the core of the EPs representations of SEN was their reference to academic progress. As explained by Christopher, it’s a special need if “*extra support is needed to help that child participate in learning and to participate in doing what all children do in school so that they can progress...*” Similarly,

Zahra referred to needs which are *“are impacting on their learning and education, and their progress and attainment”*. For EPs, SEN is socially constructed within the context specific field of education. In turn, constructs within education are applied to measure whether something is SEN or not; SEN is a deficit in academic attainment and progress - it is non-normative against the backdrop of the widely accepted notion of ‘mainstream’ and ‘typical’ development.

Irene’s talk was reflective of an ecological perspective as she reflected on the importance of the environmental context in identifying SEN. Irene spoke of taking into consideration the school setting and the other children within it; *“...if a child has got special education needs in a mainstream school, their educational needs will be different...”* At the same time, Irene challenged the notion of using the term special needs’ when considering the varied nature of needs in a special school setting. So for Irene, it was important to consider the social context in using terminology such as SEN, concluding *“...is there really a need?”...or is it the social climate or environment that’s creating a need?”*

‘SEN’ appeared to be a concept which EPs felt required a response. When defining SEN, Gaby said *“...it’s something that needs to be addressed...from just a consultation method where you talk to the school and they make adaptations within the school or something more complex...”* From this, Gaby highlights that SEN needs to be responded to so that changes can occur in the environment.

David placed the responsibility on EPs by saying, “...it’s for us to assess, to consult, to draw upon information from a broad range of sources to the nature of special educational needs...” Likewise Zahra explained that she would be “supporting schools with putting in place a graduated cycle of support of ‘assess, plan, do, review to monitor those needs...” These quotes suggest that EPs represent SEN as adaptable to change and adjustments, and that through ‘assessing’, they consider themselves equipped to formulate the SEN they are observing.

The notion of education and SEN support as a joint endeavour beyond the individual child was highlighted by David who spoke of “*working collaboratively*” with the adults around the child to “*co-construct a narrative and a shared understanding*”. In doing so, the goal of generating “*a plan for intervention to help the child overcome barriers*” was seen as possible. Likewise, Christopher emphasised the importance of “*relationships with key people*” as key to good education and the idea that “*children need to learn within their local community and with peers so that they can develop their understanding through active learning experiences....*” Both Irene and Christopher appeared to represent ‘good’ learning from a Piagetian ‘mini-scientist’ lens, where the “*the right type of support and environment*” would allow children to progress “*holistically*”. The teacher “imparting knowledge” was rejected by both EPs.

Addressing and highlighting the EP’s discourse around how they address and respond to SEN demonstrates the importance placed on the social environment in shaping progress. For EPs, SEN can be identified and measured against developmental factors such as chronological age,

developmental milestones or academic progress. SEN therefore cannot be identified without a socially constructed measurement tool from which to compare or quantify against. Even in “*addressing*” SEN, EPs spoke of their responsibility to respond to the deficit in progress by assessing and gathering contextual information. Once this has been achieved, the SEN may be supported by engaging the environment and those actors within it so that progress can be made. EPs appeared to view SEN as something set into categories but also fluid within a “*whole person*” principle.

7.3.2 Subtheme 2: Recognising differences in representations.

Speaking of their experiences when supporting families, EPs outlined interactions which illustrated differences between themselves and parents in understanding SEN. In this subtheme, differences in representations of SEN are explored alongside the EP’s interpretations and reflections of these - it is recognised that the EPs interpretation of the parent’s view is only that, and cannot be construed as representing the parent’s voice in this research. Amongst the differences spoken of, EPs recognised that child rearing practices and expectations for the child’s future, have played a part in tensions when making decisions and moving forward. Differences in understanding the UK systems and structures also posed as challenges in the EP’s dialogue with parents.

Speaking of Sri Lankan, Tamil parents, David explained that, “*the main challenges were their (the parents) views about what SEN is*” whilst Christopher noted that the “*fixed views*” professionals have “*may not be the same as those of different families.*” Differences appeared to transpire in dialogue with regards to; developing ways forward, including interventions and

strategies; choosing school placement; and in describing progress for the child.

Christopher narrated a specific interaction with the parents of Sam, a four year old boy who had a diagnosis of ASD. Sam was described by Christopher as “*non-verbal*” and at the “*very early stages of interacting with others*”. Sam required a high level of supervision from nursery staff and had received input from other health services. Christopher recounted his initial encounter of meeting parents which was to explore the views of parents and what concerns they had. As told by Christopher;

“...they brought out these text books... three or four quite thick text books, and bearing in mind this is a child with no language. I think he was repeating some things so he was repeating numbers but echolalic, I don’t think he had any awareness of one to one correspondence....he was really in the very early stage of development in a number of areas...within these books there were pages and pages of calculations that they said Sam had done...these weren’t 1 plus 1 is 2, with pictures. This was three digit addition and subtraction so it was kind of $354 - 123 = \text{whatever}$. Pages and pages, I just remember being really shocked...”

Christopher described this encounter as “*shocking*” as well as “*powerful*” – the evidence of work being presented to Christopher appeared to go against his expectations and representations of what Sam should be capable of – a disconnection between the UK educational system and criterion for success set against the parent’s views of traditional academia can be seen here. In this recount, Christopher’s conceptualisation of SEN as ‘non-

normative' is challenged through the parent's view of 'official' or 'concrete' evidence to prove their son's academic capabilities. Christopher's non-normative representation of SEN is emphasised when he later notes *"this is what you would expect from a year five or six child at age appropriate levels"*. From Christopher's perspective, Sam had not reached age-related expectations of communication or academic ability therefore could not have achieved this work. Christopher's representations of Sam's 'dis'-ability is evident in his description of Sam as *"echolalic"* and that Sam *"wasn't at a stage where he could independently copy.... I think he was really at a scribble stage..."*

In trying to make sense of this encounter, Christopher reflected on what the parents were trying to *"convey"* and felt that regardless of *"...whether I felt that was appropriate or not, the underlying message was that they were doing everything they could to support him."* Through this, Christopher looked to understand the parent's underlying intentions of having 'evidence' for professionals to see their son's academic work. Christopher reflected upon his own ideas of seeing learning as play based during early years education and compared this to parents believing;

"being able to do sums, being able to write and read were paramount and they were doing all they could to support him with that...working with him tirelessly at home to prepare him to learn as they saw it."

Christopher appears to recognise that above all the parents were *"investing"* a lot into Sam's progress - a notion recurrent within the narratives of other EPs.

Highlighting further examples of cultural representations different from the medical model perspective, Gaby spoke of parents who *“invested quite a lot”* to find a cure for their child’s SEN *“...and tried what I can only describe as slightly wacky type treatments because they’ve read somewhere that they’re going to be cured.”* Gaby drew upon information in which parents of a young boy with ASD was taken to Sri Lanka to be on a *“treatment...a special diet”* which upon his return to the UK *“didn’t have a significant impact”*. Gaby highlighted the mother’s lack of acceptance and anger that the school *“hadn’t made him better because (there was) that feeling that there was an illness there that could be treated.”* What Gaby brought to the forefront of her narrative was the difference in how SEN was responded to by parents. For Gaby, the differences in understanding SEN was a *“negative”* as it led to behaviours such as the above which ultimately challenged Gaby’s idea of how to address SEN. To view SEN as ‘treatable’ or as something that could be ‘cured’ suggests that parents hold onto the prospect of normalising their child – a representation that goes against Gaby’s non-normalisation view of SEN.

Both, Christopher’s and Gaby’s narratives as described above made reference to children with ASD. Gaby reinforced that developing an understanding of ASD can be more challenging as *“you look like any other child.”* According to Irene, *“the concept of autism”* is a difficult one for parents to accept and understand and from her experiences, parents appeared to look towards tangible or physical indications of development as a way to measure their child’s progress. Making reference to a parent who had a child with ASD, Irene spoke of the mother’s emphasis on speaking and communication. From the mother’s point of view, *“things will get better... (the child) will understand”*

and *“things will be ok”* once the talking starts. Interpreting ASD in this way was evidence for Irene that the mother had not fully conceptualised autism in the manner she does. For Irene, there is a need to look beyond the narrow focus of talking when measuring progress. Additionally, Gaby observed that parents *“set their own criteria of success”*, for example, she had experienced parents who measured progress through their child’s ability to walk whilst failing to consider other areas of development.

The notion of ‘being fine’ was also highlighted by David who drew upon an experience with parents who were *“not seeing the significance and the severity”* of their son Ben’s needs as they too were communicating that their son who also had a diagnosis of ASD would *“be fine”*. David reflected that the parents had concerns regarding labelling, the stigma of having SEN and accessing professional services.

Differences of understanding their son’s SEN meant that David experienced further differences when addressing future school placements for Ben. David spoke of the need to *“drip feed”* the idea of sending their son to a special school. As described by David, the parent’s rejection of a special school *“came through with the idea that Ben can learn...because in special schools, children don’t learn. They’re in special schools because they can’t learn....”*

Again, David believed that the *“more traditional focus on those academic skills”* brought *“tension”*, particularly if other professionals viewed other areas of development as important. In such cases, David deemed it important to ensure that parents view EPs as someone who *“see the whole of their son, the little human being and caring for and wanting the best for him...”*

Subtheme 2 has demonstrated how differences in perspectives come to arise during work with families. Above all, it was evident that EPs felt it important to query the meanings behind the parent's perspectives and actions. EPs spoke of the importance to *"build a bridge"* and when differences in opinion or views created tensions between parents and professionals, EP's highlighted the importance in trying to understand the parent's perspective and to take into consideration what underlying differences meant. With this in mind, Zahra clarified her role in *"meeting parents to hear their views, to clarify what they think of the child's strengths and areas of difficulty, to clarify what they think works for that young person"*.

As reported in Chapter 5, parents placed little emphasis on academic achievement for their children with SEN, instead they reinforced the prospect of social inclusion. In light of this research, the professional's short moments of interaction with parents do not fully reflect the parent's perspectives.

7.3.3 Summary of Theme 2. Theme 2 explored the EPs representations of SEN and highlighted their views in viewing SEN as areas of non-normative development. SEN was deemed as an area of deficit set against a success criteria from which to measure progress in children. Areas included those categorised in the SEN Code of Practice (DfE/DoH, 2015). Subtheme 2 brought to the forefront incidences which have highlighted differences in the parent's representations of SEN when compared to those of the EPs.

7.4 Chapter Summary.

Chapter 7 has described two main themes as developed from the EP's interviews. EPs spoke of the importance of having time in order to develop

trusting and transparent relationships with parents. From the EP's perspective, building relationships lent to greater opportunities for parents to trust their opinions and judgements. EPs spoke of their role in mediating between parents and school staff. Theme 2 explored the EP's representations of SEN and described their reflections on their interactions with parents who appeared to have differing representations when compared to EPs.

Chapter 8 Discussion

8.1 Chapter Overview

There has been no known research which has explored Sri Lankan, Tamil parents and their representations of SEN, or has attempted to triangulate the perspectives of key professionals and parents. This research aimed to explore the representations of SEN of three groups; first generation Sri Lankan, Tamil parents, EPs and SENCOs. Specifically, it looked to draw upon the theory of Social Representations in order to develop an understanding of how special educational needs is understood and experienced in the context of UK's education system.

In this chapter, a discussion of the main findings in relation to the theory of social representations and the wider literature on SEN will take place. Findings from the three participant groups will be amalgamated and the research questions will be addressed through a discussion of key issues relating to i) representations of SEN and its implications, ii) the role of power and inequality between professionals and the Sri Lankan, Tamil parents of this study, and iii) how parents empower themselves in their pursuit to support their child. Reference to literature and theoretical frameworks will be made. Implications for school professionals and future research will be addressed and the limitations of this research will be discussed.

8.2 Representations of SEN and its implications

8.2.1 Non-normative versus normative representations. In this research, categorical representations of SEN, largely stemming from a biopsychosocial paradigm were communicated by professionals. Terminology

ranged from '*mild, moderate, severe*' and revolved around segmented areas of development, such as '*cognition*' or '*social communication*' were confidently spoken about by SENCos and EPs. The findings showed that the professional's concepts were predominantly anchored within legislation (DfE/DoH, 2015) and highlight how an abstract concept such as SEN goes through the process of objectification and becomes a 'figurative nucleus' in the form of symbols and images (Wagner et al., 1995). In this particular case, professionals objectified SEN in terms of the four areas of need outlined in the SEN Code of Practice (DfE/DoH, 2015). The certainty in which both professional groups described their representations of SEN highlights the weight in which legislation and policy has had in shaping the discourse of SEN for the professionals. These findings go against previous research which explored the representations of mental health professionals in France and Britain during times of policy change (Morant, 2006). Abstract knowledge in reified forms was found to be limited amongst professionals with a defining feature of their representations being 'uncertainty'. Morant, (2006) discussed that the mental health professional's heterogeneous representations were characterised by ambiguity and debate, with few fixed anchors from which to make sense of mental ill health. For the practitioners in Morant's (2006) research, theories and reified forms of knowledge played a limited role and was used only to aid communication and enhance professional legitimacy. Morant, (2006) concluded that for this reason, the conceptualisation of distinct reified and consensual universes is questionable as more space was given to consensual and practical knowledge bases in the mental health professional's practice.

Unlike Morant's (2006) findings, it appears that in this study, the assured and distinct representations of SEN as reported by EPs and SENCos posed as a catalyst for tensions between parents and professional. As Christopher (EP) clearly recognised, the *"fixed views"* professionals have *"may not be the same as those of different families"* and other EPs spoke of differences as causing *"tensions"* and being *"negative"*. For example, Gaby made reference to parents who *"set their own criteria of success"* and turned to *"wacky treatments because they've read somewhere that they're going to be cured"*. Ideas that were not legitimised by evidence were deemed inappropriate and the manner in which this was addressed by SENCos and EPs consequently led to narratives of dissonance between professionals and parents.

It appears that the resistance to accept new external information from consensual sources (such as the parents) reflects the SENCo's and EP's determination to protect their identities and their professional community (Jovchelovitch, 2007). Anchoring is a personal investment in deciding whether to accept or reject a new object (Moscovici, 2008), and through successful anchoring, new knowledge can build on pre-existing cultural ideals. Here, it appears that professionals find it difficult to deviate away from their scientific models of understanding and shy away from accepting non-evidence based ideas put forward by the parents. Malini (mother) highlighted her feelings of inferiority in pleading for professionals to *"listen"* to her. After receiving visits from social services, Malini believed that parents are perceived as *"lying"* by professionals and think *"bad"* of them. Evidently, this exemplifies the notion that scientific knowledge is deemed superior to lay knowledge and is at work

to strip away “ideological, religious and folk irrationalities” (Moscovici & Marková, 1998, p. 375).

Whilst professionals made sense of SEN through labels, parents communicated how they had to make sense of SEN independently as they had no prescribed framework from which to be guided by. For example, upon hearing that her daughter may have autism, Mona explained, *“I looked at the good journals, I started to do my own research and one of the things that really helped calm my anxiety was literature which suggested that speech delay and autism are not the same thing.”*

As a result of drawing upon their own resources, parents developed multiple scripts and representations to understand their child’s needs. Sources of information included support from charities, online resources, medical professionals and advice of immediate family members. Comparable to previous research (Bywaters, Ali, Fazil, Wallace, & Singh, 2003; Croot et al., 2008; Sheridan & Scior, 2013) the fluidity in which parents represented SEN is apparent in their talk of biomedical, environmental and theological ideas.

How scientific knowledge around SEN was diffused and anchored within pre-existing cultural norms (Joffe, 1996) are likely to have been influenced by the variations in which parents sought information which in turn allowed for cognitive polyphasia to take place.

Notably, the parent’s migration to the UK had led them to draw less on familial resources, for example, Patricia (mother) questioned *“who’s there to help us?”* when highlighting the distance between herself and her parents in

Sri Lanka. Mona (mother) made reference to increased anxiety from the experts giving her information and her mother and mother-in-law becoming *“hysterical about why we were not doing more”* to make sure her daughter was speaking. Mona’s dissonance was partly due to her reluctance in accepting an ASD diagnosis. Here, Mona shows that she was in the middle, between pressures from her own family and from the professionals. This quote signified that her mother and mother-in-law lay responsibility of their granddaughter’s progress at Mona’s door. Progress in speaking development appeared to be anchored in their ideas of parental actions, a notion which has been demonstrated in previous research exploring ethnic minority communities (Khanlou, Mustafa, Vazquez, Davidson, & Yoshida, 2017; Riany, Cuskelly, & Meredith, 2016).

Parents engaged openly with formal services such as paediatricians, EPs and speech and language services. Parents spoke of their reluctance to engage with the wider community for support however turned to trusted members of their inner circle. For Anura and Fathima, a source of *“full support”* was their use of a charity representative who acted as an intermediary between the family and school professionals. Drawing upon their pre-migration lives, parents talked about practical resources that their affluence in Sri Lanka would have provided them, but which were no longer available. For example, Anura spoke of *“having a private treater or teacher”* before learning of different systemic practices in accessing support from the council.

In the sub-themes ‘Conflict and confusion’ (from the parent’s data) and ‘Communication, collaboration and decision making’ (from the SENCo’s data),

interactions between professionals and parents highlighted contention within the areas of decision making and dialogue. Built upon biomedical representations and use of criterion in judging SEN, the professional's talk highlighted the rehearsed manner in which children with SEN are categorised into areas of need, and subsequently classified into which school type they should belong to, i.e. '*mainstream*' or '*special school*'. Parents resisted the idea of labelling or sending their child to a special school whilst professionals spoke of efforts to win the parent's understanding. For EPs, labels and accessing specialist resources acted as a means to support children progress and become "*productive members of society*" and "*included in life*" (Christopher, EP). For Daniel (EP), the notion of special schooling was an idea that required "*drip feeding*" to parents. SENCos appeared to take a more hard lined approach in moving through processes and placed emphasis on procedural tasks such as filling in documents and facilitating decision making.

As expressed by Malini, the mother of 7 year old Tilan who was given a diagnosis of ASD, the special school setting felt "*separate from the world*" and she desired for Tilan to live in "*a common world...same as a human*". Referring to the responses the ASD label had generated for her son, Malini highlighted feelings of objectification and dehumanisation which she believed encouraged professionals to view her son as an "*animal*". A similar type of representational dehumanisation was discussed by Renedo & Jovchelovitch, (2007) in their study of the homeless. They critique the labels attached to 'homeless' cut past personal histories and subject the individual to feelings of loss of self and feelings of exclusion. This has resonances with the form of language used by Malini.

Relating to literature, the ‘dishuman’ child is a concept explored by Goodley, Runswick-Cole, & Liddiard, (2016) who have highlighted the extent to which categorisations and labels of non-normative conditions are embedded in disability discourse through labels and diagnoses. Goodley et al., (2016) highlight how re-descriptions of labels, diagnoses and conditions in the DSM-V contribute to making disability a signifier of human diversity in today’s society. Emphasis to such concrete references to disability encourages professionals, including those within education, to maintain an ideation of children with SEN as the ‘other’. Representations of being ‘dis’-(abled) are further reinforced by the language used to describe SEN in today’s discourse, for example, ‘*social communication disorder*’, ‘*developmental delay*’ or ‘*speech and language disorder*’. Here, all terms suggest a dysfunction from the ‘order’ at which “*progress*” should be made – a concept important in the measurement and objectification of SEN for EPs and SENCOs.

For professionals, admitting children with SEN into specials schools reinforced meeting their ‘need’ and was deemed a suitable resource to facilitate the child’s development and progress. For parents, however, it foreground their child’s ‘otherness’. Yet, against this discourse, parents maintained strong hopes for their child to follow the normative course of everyday human life; ideas of engaging in the normative activities of daily life included socialising with ‘normal’ developing children, having a ‘normal’ appearance and attending university in the future. Fathima spoke the reasons why she wanted her daughter integrated in mainstream school, “*they (daughter’s friends) used to bring the walker, hold her hand and walk. So she liked them...they used to crack jokes... she learns from other children*”. When

projecting to the future, Malini spoke of the importance for her son *“to study and find a good job...live happily, he needs money...he needs friends...”* For parents, these markers support the idea of what it means to be human, (Goodley et al., 2016) yet were considered *“blinkered”* or *“wacky”* ideas by one SENCo and EP.

8.2.2 Paradigms, representations and practice. The bearing of paradigms upon how professionals spoke about SEN was apparent in their discourse of educational setting. For parents, social constructs took precedence in how they viewed their child’s development, with ideas around social participation dominating. Parents perceived that inclusion in mainstream society begins with inclusion in mainstream education. Whilst a dominant theme amongst both groups of professionals was their reliance on biomedical categorisation, they also drew upon the impact which the environment can have in assisting the daily lives of children. EPs especially took a *“holistic understanding of the child’s needs”* (Zahara, EP) and spoke of *“social barriers”* as an aspect of SEN. The SEN Code of Practice (DfE/DoH, 2015) is in itself a document which guides schools to make adequate adaptations in the environment to support those with SEN. It appears that for this reason, the SENCos and EP’s advocacy for special educational provision is based upon the social model of disability (Shakespeare & Watson, 1997) yet measured against biomedical criterion. Inclusion for children with SEN by making accommodations within a mainstream classroom setting is promoted as good practice in the legislation, however, as Trystan (SEnCo) explained, the need to access special schools is preferred when *“mainstream classes have exhausted their resources and exhausted their skills”*. Coupled with the

notion that children with SEN are on a “*sliding scale*” of severity, professionals reinforced the idea of placing some children with SEN on the periphery of mainstream education by encouraging access to special schools. Kate justified her reasons for encouraging a young boy with ASD to join a special school, she explained that “*he will not cope in a mainstream high school... he will not be able to do the work*” whilst Gaby spoke of a “*success story*” which saw a “*young person move on to a more appropriate setting*”.

Opting between mainstream or special school settings is a routine practiced by the standards of the local authority’s educational provision structure, however, was perceived by the parents in this sample as another de-humanising practice. Under the sub-theme ‘temporal perspectives’ parents emphasised the importance of inclusion. Malini advocated for her son by saying “*...they want communication with other children, he need friends. He needs relations...he has to move like a normal person...*” Likewise, Fathima expressed, “*...the mainstream school is important for us – she learns from other children*”. Constructs such as these highlight how representations of SEN have been anchored in collectivist cultural values, i.e. the importance of relationships and the social environment in development. The school setting in this instance served as a symbol of exclusion for parents but a symbol of belonging for professionals.

The separation of children with SEN into special schools is an example of the marginalisation and exclusion from the expectations, opportunities and aspirations given to ‘typically developing children’, (Goodley & Runswick-Cole, 2010; Goodley et al., 2016). The assurance of this practice was reinforced by the SENCo and EP’s decisive manner in which they presented their narratives

when identifying the dichotomy of mainstream and special schools. For professionals, the benefits of accessing specialist provision outweighed reasons to stay in mainstream. Specialist provision facilitated children to accomplish skills beyond academic progress such as *“their language skills, their social and interaction skills... they’re physical skills”* (David, EP).

The professional’s conviction in their practice can be critically considered by taking a look through history and the social environment that have helped to shape their ontological reality and in turn maintain representations (Marková, 1996). Marková, (1996) cautions how ontological status, in the form of languages, institutions and traditions can become unnoticed or taken for granted as individuals often recycle and reproduce representations through unconscious and habitual activities and practices. It is worth considering how representations through time have remained embedded and continue to influence modern day thinking, (Farr & Moscovici, 1984; Howarth et al., 2004). Howarth et al., (2004) draw upon how representations and the social exclusion of the mentally ill have been sustained overtime, for example, in the form of mental asylums and the ‘otherisation’ of the mentally ill. This too can be applied to the establishment of schools for children with disabilities.

The practice of separating children with SEN into special schools has its origins in legislative history. Special education provision was made the statutory responsibility of the local authority (LA) in the 1914 Education Act; at this time, LAs had the responsibility to ascertain ‘children between seven and sixteen who were incapable of education in the ordinary school’ (Hill, 2013). With regards to practice, the notion of segregation was encouraged as the

medical profession, psychologists and teachers joined forces to identify SEN. By 1929, educational psychology saw the establishment of psychometric testing together with the conceptualisation of 'IQ'. The use of psychometric testing became a key tool for placement decision making and the segregation of children. For example, with the use of psychometric tests, it was deemed that children with IQs between 50 and 80 could be classed as '*retarded*' and be considered for special educational provision (Hill, 2013). Segregated education thrived because the transaction of power between doctors, psychologists and teachers made it possible and provided a tool for the exclusion of any children who deviated from 'normal' classrooms. For parents, feelings of exclusion may have additionally been compounded by being a migrant. Inequalities as a result of asymmetrical dialogues and decision making between professionals and parents are likely to reinforce Malini's feelings of being perceived as a "*foreigner*".

It is well recognised that the medical mode has historically held power in shaping the representations of society and encouraged deference to experts, (Zola, 1972) - this is particularly true in the West. The evolution of categorical and biomedical terminology can also be traced back to legislation. The 1944 Education Act classified SEN under 11 categories, including 'educationally subnormal', 'maladjusted', 'blind' and 'deaf'. In line with new terminology, legislation increased the range of specialist school provision.

The legacy of this practice can be heard in Trystan's (SENCo) description of the special school he works in. The "*sliding scale*" of SEN including "*mild, moderate, severe, profound and multiple*" was spoken of and Trystan described his school as for those who have "*Moderate Learning*

Difficulty". Even, in today's practice a child would have been assessed within the medical and psychological arena before being deemed as having 'moderate learning difficulty'. This was reinforced in the EP's data in talk of SEN as something that needs responding to through assessing and monitoring. Such descriptions are evident of the 'taken for granted' ontology which Marková, (1996) discussed and examples of how practices can be reproduced and perpetuate representations unconsciously.

Although specific terminology has changed over time, today, multidisciplinary work with medical professionals such as paediatricians and clinical psychologists are encouraged as good practice. Consequently, discourse through biomedical terms (for example, 'developmental delay' or 'ADHD') and the use of assessments to identify need, continue to prevail as symbolic representations of SEN for SENcos and EPs.

8.3 Accessing and providing support: Parents, EPs and SENCos

8.3.1 Power relations. Findings from SENCos highlighted the misconception of parents as passive participants in the role they play as supporters of their children, whilst both professionals identified parents as individuals who lack appropriate understanding of SEN. Conflict and disagreements in decision making were recognised amongst all three groups of participants and in this regard, EPs spoke of themselves as "*mediators*" between schools and parents. They highlighted the importance of building relationships as a means to instigate change. "*Positive change*" and "*trusted advice*" were terms used by EPs as means to lead parents to "*shift*" their ideas and conform to the decisions prescribed by the official systems and

structures, for example, accepting a diagnostic label or enrolling their child at a special school.

The perception of parents as deficient in their understanding of SEN positioned EPs as the facilitators who could build the trust and shape the parent's views. Working closely with parents is deemed a positive move by the standards of current legislation; close parent partnership and 'participating in decision making' are ideals of the SEN Code of Practice (DfE/DoH, 2015) and Children and Families Act 2014. Seemingly the notion of parent participation encourages a positive dialogical relationship between educational officials and parents, and ideally empowers parents to have their voices heard. As argued by Campbell, (2001) however, close partnership of service users and their (expected) compliance over how they engage with services may be incompatible. Campbell (2001) suggests that the voices of mentally ill clients have continued to be perceived as less than that of the authorities. A similar expectation was evident in the discussions of SENCoS and EPs who described differences in understanding SEN as a shortfall of parents. Reflecting on the Sri Lankan, Tamil parents who refused special schools for their child, Trysten (SENCo) explained, *"in some cases we have seen before the children have left (the special school)...and there's been safeguarding issues around that"*. In this instance, the authorities view themselves as qualified in judging decisions made by parents and in need of safeguarding attention if choices do not reflect the professional's view.

In this research, professionals highlighted their conscious endeavours to participate and collaborate with parents, however the notion of partnership as a device for 'surveillance' is worth noting here. Crozier, (1998) discusses

the use of parent partnership in schools as a method of surveillance whereby teachers are empowered to persuade parents to adopt their value system of what it means to be a 'good' parent and pupil. Crozier, (1998) notes that partnership can serve as a way to maintain balance of power between middle-class parents and teachers but is a means of social control for working-class parents. How this relates to migrant parents with little or no English is worthy of note as with minimal English, parents are unable to equalise their power status as well as White middle-class parents may be able to.

Through close partnership and relationship building, parents lean toward self-regulating their behaviour in order to meet the agenda of those dominating – a process described by Foucault as disciplinary power (Foucault, 1991). In this instance, the perception of parents as deficit in their knowledge whilst EPs and SENCos are the holders of 'superior' scientific knowledge, enables them to engage in 'surveillance' through the relationships they build.

The power imbalance here can be further understood by addressing the theory of cultural capital (Bourdieu, 1973). Cultural capital encompasses the social attributes of a person, these include education, skills, dress, language and the understandings of cultural codes and practices in the dominant culture. Having more cultural capital facilitates a more powerful social position and sharing forms of capital creates group cohesion. In this instance, EPs and SENCos represent the same educational agendas as well as symbolic resources therefore endowing them with power in relation to migrant parents. Emphasis on the parent's cultural capital, educational status, immigrant status and material resources have been deemed important in

establishing positive relationships between schools and parents, (Becker, 2014; Lareau, 1987, 2002). Inequalities in the amount of cultural capital an individual can have is dependent on the fit between an individual's culture and the culture of the larger society or institutions. '*Habitus*' is used to describe this concept (Jung-Sook & Bowen, 2006) and is acquired from social training and past experiences. Social advantage is facilitated when an individual's habitus is aligned with the society he is operating, that is, he is disposed to act, grasp experience and to think a certain way. With this in mind, being a migrant can greatly compromise an individual's cultural capital within the dominant culture and create opportunities for power imbalances, (Jung-Sook & Bowen, 2006).

The concept of 'educational knowledge and awareness' as a form of cultural capital is addressed by Crozier, (1996). Educational knowledge is the understanding of the educational processes and systems, and having such knowledge has been deemed as a requisite for effective parent-school relationships. With regards to teacher's perceptions of ethnic groups, Tomlinson, (1981) pointed to stereotypes of West Indian and Asian parentage as 'disadvantaged' groups and schools felt that their goal was to support the families in overcoming disadvantage. Material disadvantage such as poor housing and perceptions of parents as unskilled or unemployed also contributed to ideas related to race and immigration within multiracial schools, (Tomlinson, 1981). Liz (SENco) noted the importance of establishing a "*holistic*" view on family circumstances whilst Trystan (SENCo) talked about migrant families in his school, saying, "*housing is having a massive impact... we need to think about the impact of poverty on our families and how that*

intersects with safeguarding". The concern for migrant family's socio-economic status and employment status were echoed in other EP and SENCo interviews. Notably, there was a disjuncture between how professionals talked about migrant parents and how the small sample talked about themselves. Professional's drew upon stereotypical views of immigrant stereotypes however, the parents interviewed were a heterogeneous group who spoke highly of their pre-migration identities; being of middle or upper class, being educated, and having good English speaking skills were attributes they proudly recalled.

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.

The same theme arose from the professionals' data too. Barriers in language is a theme which resonates with previous literature exploring the experiences of South Asian families as they access services, (Hatton et al., 2010, 2003; McGrother et al., 2002). Barriers in language coupled with the professional's view of parents as lacking knowledge meant that SENCos acted in ways to "*break barriers*", for example by making links to the

community and building relationships. Again, these methods were ways in which SENCos tried to undo their perceived “*remote*” nature of families.

Positive outcomes were reported by SENCos when these actions succeeded and SENCos reported positive relations which facilitated easier decision making.

The significance of power inequality between the professional and parent however, was highlighted by Kate (SENCo) who spoke of difficulties in knowing whether parents understood procedures and the paperwork that it entailed. Kate concluded that it was easier to let parents sign paperwork regardless of whether they understood what they were signing or not. Kate also proposed that if parents acquired knowledge, they would more than likely protest against the process she was working for – essentially empowering parents would be detrimental to the school’s agenda and pose a threat to the authority’s ideals. As highlighted by Morant, (2006) the interface between politics, academic and research expertise and the lay public, constructs unequal power relations. As a result, decisions of policy makers carry unbalanced weight in influencing the working practices of professionals which in turn affect the lives of laypeople.

8.3.2 Empowerment through active participation. Evident in the current findings were the parent’s feelings of disempowerment. Discussions about their child’s SEN also led them to reflect on own pre and post migration identities. A particular instance was Malini’s (mother) reflections upon her parenting style. Malini resolved that it was necessary to distance herself from traditional models of disciplining her children in fear of social care involvement and being misunderstood. Parents were aware of being perceived as

“uneducated”, “foreigner” or lacking knowledge because of their language ability. As Patricia, noted “no point telling an English person, “Oh, I was that in Sri Lanka...nobody cares who you are...”

As discussed previously, conflict and tension arose between parents and professionals. From the professional’s perspective, issues arose from underlying differences in conceptualising SEN and during critical decision-making moments. Trystan (SENCo) defended his ideas of SEN with *“...fundamentally there is an SEN need there and that SEN need won’t go away...”* Differences in representations have influenced the expectations of children’s progress. This can be seen in Trystan’s outline of confusion in dialogue, and how the word ‘progress’ was interpreted by parents, *“we were talking about genuine pupil progress, we were not talking about pupil mending”*.

From the parent’s perspectives, frustrations and confusion acted as catalysts for them to confront difficult conversations with professionals. As well as actively seeking information to increase their understanding of SEN, parents engaged in therapeutic and academic activities at home and provided practical support to schools. For example, Fathima helped the school with her daughter’s toileting needs.

Parents spoke of using traditional models of learning and teaching in the home. For example, sitting the child at a table and completing sums. Such practices reflect traditional systems of their motherland but creates a disconnection with systems in England which tends to promote play instead of academics in the early years of education (Goodley & Runswick-Cole, 2010).

Reflecting on the parent's representations of SEN, the abstract nature of a learning difficulty is a new concept for parents; it challenged their pre-existing ideas and encroached on their need to learn the language that accompanies SEN. In making sense of SEN, parents described their ideas as something explicit, tangible and physically evident. Anura (father of Anisha) makes an explicit distinction between "*physical*" appearance and something "*internal*" whilst other parents placed attention on speech and language development as a determiner of their child's progress. Intangible needs such as a cognitive difficulty or autism did not fall under the parent's umbrella of disability. Understanding this may allow us to understand why parents turn to traditional models of teaching as a way to progress their child's learning. Could it be that parents aim to overcome the 'internal' and intangible difficulty they believe professionals are seeing by presenting concrete and tangible evidence in the form of academic work? By providing reason to minimise the professional's concern and by establishing academic achievement, parents also equip their child with reason to remain in mainstream education.

It is worth noting the influences of the parent's pre-migration identities as educated, middle class and resourceful individuals upon how they responded to supporting their children. The impact of social-class upon child rearing practices has relevance here (Lareau, 2002) as parents appear to have translated their class status, life experiences and resources from Sri Lanka to influence their actions in England. Certain patterns of child-rearing practices have been linked with being middle-class, such as being assertive when interacting with and challenging professionals and engaging children in structured and organised activities (Lareau, 2002). Observing the parents

from this perspective, dispels the notion of them as passive and quiet recipients of the system as was commonly perceived by professionals.

Referring to the notion of ‘educational knowledge’ research which explored the relationship of black parents and schools, found that although the parents had educational knowledge, partnerships with schools was difficult and tensions arose when issues underpinning ‘race’ brought to light differences in expectations and perceptions, (Crozier, 1996).

Crozier, (1996) also found that parents were not passive in facing their concerns and were at times outspoken and insistent. Distrust of teacher’s judgements and the education system were expressed together with frustration. With parents drawing from their views of the Caribbean education system, frustration appeared to be built on opposing views between parent and teacher of how the children should be taught. This is relatable to this research which found the Sri Lankan, Tamil parents proactive in their approach to advocating for their child. For example, Mona (mother) spoke of *“trusting”* and not *“second guessing her own judgement”* in refusing a diagnosis of ASD for her daughter. Malini (mother) spoke of *“fighting”* for the appropriate support for her son. She spoke of making phone calls and trying to communicate with the school – *“everything I made myself ...we are always asking, keep ask ask ask.... finally, we went to parent partnership, we took them to talk to the school”*. Similar to Anura and Fathima’s narrative, Malini accessed further support through parent partnership as a way to make her voice heard. The parents of this research, showed strength in challenging or questioning school staff and engaged in resisting ideas they did not agree with.

Previous literature has highlighted lower uses of services by ethnic minority families. Regarding learning disabilities, BME groups are reportedly underrepresented in accessing health and social care services and experience disadvantage and discrimination (DoH, 2012). Barriers to accessing services have included material deprivation and language, (Fazil et al., 2002; Hatton, 2002; McGrother et al., 2002). As discussed earlier in the thesis, these findings represent the larger groups of the South Asian population and cannot be generalised to the Sri Lankan, Tamil demographic. Contradictory to this, the parents of this research showed willingness in accessing services and resources in order to support their child and appeared to be a chosen route for parents facing challenges in being heard. Activities parents drew upon included; attending courses to learn about autism; accessing readings via the internet or in the case of Mona, academic journals; actively seeking advice from speech and language therapists and actively engaging in therapy activities at home. Parents also monitored their child's support in school and when necessary they questioned and challenged school professionals. It appears that parents drew upon their pre-migration, resourceful and resilient identities as a means to support themselves and their child.

Three out of the four parents spoke of their isolation from close family members. This was mainly due to their migration from Sri Lanka. Parents accepted and would seek support from trusted relatives and formal services but spoke of their reluctance to discuss their child's SEN amongst the wider Sri Lanka, Tamil community. These findings resonate with previous research which has widely reported feelings of social exclusion and isolation by

parents, (Croot et al., 2008; Qulsom Fazil et al., 2002; Hatton et al., 2010; Vernon, 2002).

8.4 Tensions amongst labelling and inclusive education

The emotive responses from parents in this research have highlighted tensions regarding the labelling of SEN and how educational settings can meet their child's needs. Such tensions have suggested a false dichotomy between special schools as being automatically exclusive and mainstream education as being inclusive. However, the nature of inclusion is a multi-layered and complex subject. Dilemmas around inclusion involve discussions around the wider political and social context of the purpose and function of schools within society and the economy (Norwich, 2013a). By trying to fulfil both humanitarian and controlling aims of society, special education has been historically judged as paradoxical in nature which in turn led to the development of inclusion (Florian, 2008).

Inclusive education is the notion that local schools should provide for all children, regardless of any perceived difference, disability or other social, emotional, cultural or linguistic difference. Inclusion has been widely accepted globally as part of a human rights agenda that demands access to, and equity in, education (UNESCO, 1994). In Western societies, legislations have promoted inclusion of children with learning difficulties or disabilities in educational settings. In the UK the Special Educational Needs and disability Act 2001 provides a legal framework for meeting the educational needs of all disabled children.

School specialisation can be modelled on different dimensions and go beyond disability specialisation, for example age, gender, religion, disability, attainment-abilities. Certain dimensions of specialisation have historical or social significance, for instance specialisation by funding is embedded in the socio-economic structure of the country (Norwich, 2013a). As discussed earlier, school systems as utilitarian structures and the widely held ideas that intelligences is fixed and normally distributed has sustained a continuation of 'special' or 'additional' support (Florian, 2008). As a result, it is proving particularly difficult to articulate a process of inclusion as practice. Instead, as Norwich (2007) has recently explained, teachers and other school staff face dilemmas about how to respond when learners experience difficulty.

The results of this research have found parents assert their views of SEN schools as socially exclusive. As Florian, (2008) points out, the reliance of different forms of provision for different types of learners poses both a problem and solution to injustice in education. Special needs education is one specialism by which students with learning difficulties are both included in an excluded from the forms of schooling that are otherwise available to children of similar ages.

A central argument regarding disabilities and inclusion, involves the 'dilemma of difference' (Minow, 1991). The dilemma brings to the foreground that recognising difference runs the 'risk of non-neutrality' and the 'risk of discrimination' – to both ignore and to recognise difference in equal treatment and special treatment risks associated stigma, devaluation, rejection or denial of relevant opportunities. Minow, (1991) asks 'Why does difference seem to pose choices each of which undesirably revives difference or the stigma or

disadvantage associated with it?' and highlights that difference is perceptibly linked to stigma or deviance whilst sameness is a prerequisite for equality. Relating to practice, Florian, (2008) questions how can all learners be provided for without perpetuating stigmatising effects and which differences matter.

Dilemmas and differences are relevant to legislation in different areas of social policy including education and special education. Dilemma of difference relates to dilemmas about identification of SEN and has been recognised by educational practitioners internationally (England, USA and the Netherlands) as causing tensions and difficulties related to 'stigma', 'over-identification' and 'SEN labels as negative' (Norwich, 2013b).

Such dilemmas prompt questions around the organisation of special/inclusive schools in providing for everyone and around the role of specialist teachers in the context (Florian, 2008).

In favour of special education, it is preferable for children to have access to different forms of provision where individual needs might be met as opposed to education in a mainstream environment whereby children are judge to fail. Benefits of labelling 'learning disability' also establishes eligibility for people who require and request accommodations as laid out by disability and civil rights legislation (Florian, 2008; Ho, 2004).

Identifying and categorising SEN using labels (e.g. moderate learning difficulties, autism spectrum disorder or specific learning difficulties) can have various functions and be useful in their application within teaching and learning. Function of labels include;

- 1.) Whether there are distinctive characteristics associated with the category.
- 2.) Whether the category provides a basis for communication and understanding of particular difficulties
- 3.) Whether the category has significance and is useful for teaching.
- 4.) Providing the grounds for allocating additional resources.
- 5.) Providing a basis for a positive social identity and solidarity for those who have the difficulty. (Norwich, 2013a p.46).

On the other hand, critics of 'special education' have challenged the idea of labelling individuals as having 'special needs' and its associated problems of marginalisation and exclusion. In studying inclusion and exclusion, Booth, (1996) opposes that 'inclusive education' should only be concerned with students who are disabled or are categorised as having 'special needs'. Instead, advises for the discourse of 'special needs' to change in order to accommodate diversity and reduce exclusionary processes in education. Ho (2004) describes categorisation of learning disabilities as an excuse for school officials and legislators to adopt a medical model and ignore other educational and social systems that contribute to pupil's learning difficulties.

Ho's (2004) analysis of US and UK policies and practices regarding SEN identification showed that resolving dilemmas of difference can involve a range of options. It is possible to emphasise differences between pupils whilst at the same time look for what is similar. As a resolution to the dilemma of difference, Ho (2004) proposed that educational systems should first and foremost be designed and managed with the assumption that all children learn in unique ways. Neurological differences are acknowledged, however,

the idea of pathologising differences is argued against and deemed counterproductive. Instead, Ho (2004) advocates designing a flexible curricula that can accommodate learning diversity. Plural values to address the dilemma of difference supports a creative practice which can promote inclusive education. It is the idea that by identifying children who experience difficulties in learning under a particular title (e.g. a disability, SEN or additional needs), leads to identifying needs that are specific to a subgroup of learners (Norwich, 2013b). However, it is argued that whilst a child identified as belonging in a subgroup has unique needs distinct from others, they also share some needs or requirements with all other children. The resolution to dilemmas of difference is therefore finding a balance between needs/requirements that are common/different to specific subgroups, unique individuals or common to all (Norwich, 2013b).

In line with this, Florian, (2008) asserts the importance of drawing attention to how educational practice at the classroom level can promote inclusion. Beyond the tensions that arise on a political and structural level, it is the classroom teachers who are given the onus to think about the nature of 'learning difficulties' and how they can respond to barriers to learning. Focus should turn to practice and how to support teachers to make sense of exclusionary structures that differentiate learners on the basis of 'ability'. It is at this level that inclusionary practices can begin despite the often restrictive structures of schooling and the constraining nature of educational outcomes (Florian, 2008).

As previously discussed the social and educational system of the UK are influenced by paradigms which create various educational and learning norms

that are used as inclusionary and/or exclusionary criteria. Tensions between the medical and social model as well as tensions between special or mainstream school have highlighted how a social constructionist perspective can help us to recognise how environmental and social contexts contribute to the learning barriers children experience. Instead of viewing learning difficulties in objective and clinical terms ideas around inclusion should consider the complex combination of social structure, history, and power relations (Ho,2004).

8.5 Limitations within the research

The data gathered can only partially represent the Sri Lankan, Tamil parent population as only those who were able to speak English at length were selected. Considering the association between language and socio-economic status in Sri Lanka, the parents who opted to participate were likely representative of the middle class demographic of Sri Lanka. Excluding parents with little English therefore excluded opportunities to hear narratives which may have enriched our understanding of the experience of these parents. In addition, it must be recognised that the parents who agreed to participate were likely to have reached a stage of their 'journey' in which they felt confident to speak.

Using a narrative approach facilitated an understanding of the political and cultural backdrop of the parents; the parent's personal histories were explored within the interview and informed our understanding of their lives in Sri Lanka, including educational background and social status. However due

to the nature of the research questions and analytic approach, it was not possible to extend or hold onto the 'whole' narratives presented by parents.

Caution should be taken with regards to the generalisability of the professional's data as they spoke from their experiences of working in a particular local authority in which the shared language and discourse of SEN (and the systems and structures surrounding it) would have influenced their representations and how they place meaning on events, (Burr, 2003). For this reason, the SENCo and EP's reflections are embedded and cannot be separated from the position of the local authority in which this research took place. Similar research carried out elsewhere may elicit different representations.

Howarth, Foster, & Dorrer, (2004) discuss the need for social representations studies to take into account the position and representations of the researcher as a means to identify biases. The researcher was a trainee EP; this would have had implications on how each group related to and spoke in the interviews. It may have influenced the language used by SENCos and EPs if it was assumed that certain concepts were already established by the researcher. Effort was made to ensure that the researcher's role was made clear to parents, however, it is possible that power relations between parents and the researcher remained.

8.6 Future research.

As reinforced by other previous studies, social representations theory is a valuable tool for community based research (Campbell & Jovchelovitch, 2000; Howarth et al., 2004; Renedo & Jovchelovitch, 2007). As increases in

migration continue to change the demographic profile of communities within the UK, the notion of super-diversity (Vertovec, 2007) may become further important in the discourse for culturally sensitive services. As (Vertovec, 2007) argues, addressing super-diversity includes looking beyond fixed ethnic identity and instead take into account 'plurality of affiliations' of immigrants. This includes, country of origin, migration channel, legal status, migrants' human capital, access to employment and transnationalism. Research engaging with the context of migration, policy and service delivery will benefit from further research which informs the debate concerning the diverse social groups being served. Taking this stance suggests that engaging South Asians as a homogeneous group is no longer enough in research. Instead research should address the complex interplays as highlighted by (Vertovec, 2007). Further research with the Sri Lankan community may want to explore representations of the Sinhalese group in order to explore the impact of socio-political histories on migrant experiences and perceptions.

Power inequalities in representations, as a result of differences in status, language and identities have been highlighted in this research and will require further exploration. (Howarth et al., 2004) question the imperialist nature of researchers who act as 'parachutes' overlooking a group from a distance, and for this reason encourages a more participatory methodology for carrying out community based research using social representations theory. Taking this on board, extension of this research should encompass a more inclusive approach of the wider Sri Lankan community and adopt more participatory methodology. For example, in order to observe social representations in everyday practices, ethnographic methods may facilitate

the way representations are actioned in everyday life through the environment and social routines. On a larger scale, there is scope for cross-country comparison of practices between England and in Sri Lanka.

8.7 Implications for EP practice

The findings in this research have highlighted how differences in representations of SEN can impact on parent and professional partnership in the process of supporting children with SEN. Current methods of disclosing a child's need appear to leave parents confused and distressed. Being left to make sense of their child's SEN 'diagnoses' alone, parents in this research actively sought and accessed different avenues of resources. In their self-identified mediating role, EPs are well placed to bridge the consensual universe of families and the reified universe of medical professionals. The unique positioning and social role of EPs have been recognised by Morant, (2006) who describes the 'intermediary' approach of professionals, such as mental health workers, as integral in the interplay between scientific and lay spheres. EPs also have scope to mediate between parents and SENCOs and hence triangulate relationships and discussions.

EPs working within the LA are representative of the policies and procedures built within this formal community. The dissonance felt by EPs when their representations were met with resistance was evident in their interview. Although the rules of legislation and medical criterion dominate, EPs may need to deconstruct their own conceptions of child development and disability in order to fully represent parents and promote inclusion (Goodley & Runswick-Cole, 2010). EPs are heavily guided by ecological frameworks

(Bronfenbrenner, 1977) in their practice, yet, there may be scope for social representations theory to serve as a framework around which to understand representations which are unfamiliar or run counter to their own understandings. Social representations theory can potentially contribute to the EP's own perspectives and approach on other cultures when aiming to practice with cultural sensitivity.

Reported difficulties of how parents make sense of SEN, as well as tensions in parental partnership in education (Norwich 2014) raises questions around how EPs may moderate their practice and expectations in ways which satisfy the hopes of parents as much as the expectations of formal structures. There is a fundamental important opportunity for EPs to create a 'space of potential' and advocate for a child or family, is during consultation. Through the consultation model, communication and collaboration with others becomes integral in facilitating change and meeting the needs of children and young people. As discussed by Wagner (2008), consultation provides a platform from which EPs can facilitate solution focussed discussions. Consultations can be managed in ways which explore and apply varying psychological frameworks for the best potential of the child or family. By marrying psychological frameworks with an awareness of a theory such as social representations theory, EPs may unpick and satisfy the hopes of parents as much as the expectations of formal structures. Being guided by constructivist principles, EPs are continually reminded of the interactive nature of how human beings form meanings and understanding of the world they live in.

Consultations are opportunities for dialogue to explore new or difficult to understand concepts that arise within SEN. Medical terminology and language used within the SEN communities may be explored, not as a means for EPs to superimpose formal representations of SEN, but as an opportunity to reflect on what is ambiguous within discussions. It is vital that EPs are reminded of the impact of power relations within dialogue and use consultation as a space for which to actively listen to and respond to cultural sensitivities. The interplay of knowledge systems between parent and EP is therefore crucial during such settings. Consultation can be an opportunity for EPs to understand aspects of the parent's pre-migration lives and how this informs their practices in their post-migration lives. By allowing more space for learning about family and cultural practices (as deemed appropriate within the parent's consensual universe) and being reflective in their practice, EPs can aim to alleviate the power disparity by giving equal status to the parent's ideas and actions.

EPs are reminded that although representations can change, they do so within the constraints of past and present and under the influences of individual agency, society and history, (Moscovici, 1984). Adopting a self-reflexive approach within their practice may support EPs in understanding the make-up of their own representations and how they impact on their use of language, identity and relationship with others. Respect of the constraints of socio-cultural influences for both parents and the professional self should therefore mediate expectations of the interplay between scientific and lay knowledge.

EPs may consider going beyond statutory processes and their use of standard resources in adapting their practice. This may include recording information to meet the needs of families (as opposed to meeting the needs of the EP service), providing useful information related to the family's questions or extending support to the family home.

In order for collective change to take place within an organisation such as an EP service. An evident barrier for EPs is the pressure to meet statutory deadlines and complete work within the remit of local authority processes. Considering the weight in which the SEN Code of Practice (DfE/DoH, 2015) plays in the working practice of professionals it is worth noting its neglect in addressing the notion of cultural diversity and cultural sensitivity in the delivery of SEN services. It brings to our attention the need for local policies to engage with discussions regarding cultural sensitive service delivery as well as attend to the changing socio-cultural profiles of local communities.

8.8 Conclusions

Recognising that the Sri Lankan, Tamil community have previously been neglected amongst other research, this study provided an opportunity to extend our understanding of the growing Sri Lankan population in England by bringing the families to the foreground. An episodic interview approach was used as a means to capture representations within the everyday practices of the parents and professionals.

The findings highlight that the concept of SEN as it is understood in England is new for first generation Sri Lankan, Tamil parents. Whilst this could be said for any parent with a child with SEN, the parents of this study have

highlighted how social and cultural contexts can impact on how an individual responds to new information.

Parents recognised that their pre-migration understandings of disability required developing in order to encompass England's conceptualisation of SEN. Their narratives drew upon their pre-migration identities as well-educated individuals; although having left this identity behind, parents spoke of their resourcefulness in taking action to advocate and support their child. Parents emphasised the importance of social inclusion for their child and saw the education setting as central to this, however, aspirations for normalising practices to support their child were conflicted by the professional's agenda for segregated schooling and labelling.

The findings highlight that EPs and SENCos anchored much of their representations of SEN on the biomedical model of development. Categories and labels based on the medical model were applied in approach to SEN and formal processes and procedures were dominant in their discourse of supporting children. In line with the ideas of social representations theory, the dominance of scientific knowledge over lay knowledge was evident in this research and a source of conflict.

Moving forward, it is considered that EPs are well placed as mediators between the scientific and lay world in the move to encourage the integration between the two.

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APPENDIX A

Literature Search Strategy

A review of literature focussing on the experiences of South Asian and ethnic minority parents of children with learning disabilities was carried out. I carried out an electronic search of educational and psychological databases including ERIC, Google Scholar, PsychINFO, PsychARTICLES, PsycEXTRA, Web of Science and Medline. Papers on Social Representations (PSR) was used to access research on social representations theory.

Search terms included, 'learning disability; intellectual disabilities; South Asian; Sri Lanka; Tamil; culture; education and services; social representations. Peer reviewed articles were shortlisted and suitable studies selected had to:

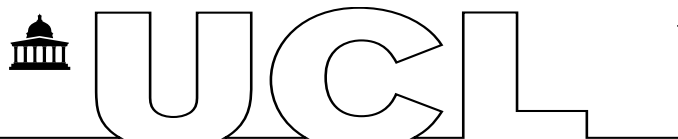
- focus on the experiences of South Asian or ethnic minority families who have children with learning disabilities in the context of education, accessing services and community.
- be peer reviewed,
- include a qualitative methodology
- address social representations

Other sources of documents were also read, namely, books, government legislation, policy documents and critical commentaries in order to understand the political and social context of special educational needs within the UK.

A snowballing technique was also adopted during my reading in order to identify relevant literature.

APPENDIX B

Research Information Sheet and Consent Form – Parents



What this research is about:

I am Natasha and I am studying for a doctorate at UCL Institute of Education.

I would like to find out more about your experiences of being a parent of a child with SEN. In particular, I would like to understand how you understand SEN and what it has been like for you accessing services that are there to help your child.

As someone interested in culture, I am approaching people from the Sri Lankan, Tamil community as there has been very little work done with Tamil people on this topic.

If you are happy to take part, I would come and talk to you for about 1 to 1 and a half hours. We could split that into two visits if that would be better for you.

A few important things to note:

- The interview will be recorded. Only I will listen to the recording and your information will be held digitally in password protected files. The information you share will only be used for this study.
- It is up to you whether you take part in this study. Even if you agree to take part, you are free to end involvement at any time during the research project.
- When the results are written up I will not use real names of the school or children. Information which might make you identifiable will not be reported.

The project has been reviewed by the Ethics Committee of UCL, Institute of Education and has received ethical approval.

I will provide you with details of findings at the end of the project.

Please show whether you agree to participate in the interview by filling in the form below. Please show your decision and return the form to myself.

If you would like to know more, you can get in touch by email or by phone; XXXXX or XXXXX Thank you for your time and attention,

Natasha Kwan-Tat

Trainee Educational Psychologist
UCL, Institute of Education.

.....

Please circle

1. Have you read the information sheet? **YES / NO**

2. Do you understand you are free to withdraw from this study?

- at any time

- without giving a reason for withdrawing **YES / NO**

3. Do you agree to take part in this study? **YES/ NO**

4. Do you agree to allow the interview to be tape recorded? **YES / NO**

Signature of Parent/Guardian

Printed Parent/Guardian Name

Date: _____

APPENDIX C

Research Information Sheet and Consent Form – Professionals



Why is this research being done?

I am Natasha and I am currently completing a doctorate at the UCL, Institute of Education.

This research aims to explore Sri Lankan, Tamil parents experiences of having a child with SEN and their experiences of accessing services. I would also like to understand the perspectives of the Educational Psychologists when working with families from Sri Lankan, Tamil backgrounds.

This research recognises that different cultures may have differing understandings of Special Educational Needs and aims to understand the conceptual lens Sri Lankan, Tamil parents and professionals have about disabilities. This is important in order to develop culturally inclusive services.

Whilst previous research has explored the South Asian population, there is little research regarding Sri Lankan, Tamils within the education sector. Considering their growing population within the XXXXX Local Authority, the need to pay particular attention to this population is evident.

If you are happy to take part, I would like to interview you. The interview will take about an hour and a half.

A few important things to note:

- The interview will be recorded. Only I will listen to the recording and your information will be held digitally in password protected files. The information you share will only be used for this study.
- It is up to you whether you take part in this study. Even if you agree to take part, you are free to end involvement at any time during the research project.
- When the results are written up I will not use real names of the school or children. Information which might make you identifiable will not be reported.

The project has been reviewed by the Ethics Committee of UCL, Institute of Education and has received ethical approval. I will provide you with details of findings at the end of the project.

Please show whether you agree to participate in the interview by filling in the form below and return the form to myself. If you would like to know more, you can get in touch by email or by phone; XXXXXXXXXX or XXXXXXXXXX

Thank you for your time and attention,

Natasha

Consent Form

Please indicate whether or not you wish to participate in this research by ticking the appropriate statement below, signing your name and returning the form to Natasha.

☐

I have experience in supporting Sri Lankan, Tamil families/ **I am currently** supporting a Sri Lankan, Tamil family. *(Please tick if this applies to you)*

☐

I agree to participate in a one to one interview which will explore my experiences when supporting Sri Lankan, Tamil families.

☐

I am an EP

☐

I am a SENCo

Signature

Printed Name

Date: _____

APPENDIX D

Episodic Interview schedule for parents

Phase 1 Interview Preamble

My name is Natasha and I am carrying out this research to find out about your experiences of being a parent of a child with SEN. I would like to understand how you understand SEN and what it has been like for you accessing services that are there to help your child.

You have been asked to take part in this research because your child has been identified as having Special Educational Needs and you have had experience of being supported by the school and other professionals.

In this interview, I will ask you to recount situations in which you have had certain experiences regarding your child's special educational needs.

Only I will listen to the conversation after this interview and I may include parts of what we have spoken about in my research. I will change your name on any written documents so no one will be able to identify you or your family.

Please feel comfortable to speak about your experiences because it will not be shared with anyone else but if something that you have said means you or someone else is unsafe, I will discuss this with my supervisor. I will tell you if I need to do this.

Do you have any questions about what I've said?

If at any stage you would like a break or you would like to stop the interview completely just say so. It is ok if you ask me to stop.

You do not have to answer any question you do not want to.

Is there anything you would like me to explain?

Phase 2: The interviewee's concept of the issue and his/her biography in relation to the issue.

- 1.) Tell me about yourself and your family.
- 2.) Tell me about (name). What is going well for him/her at the moment?
- 3.) When you look back when did you first begin to notice/identify your child's SEN? Tell me about that situation. (*Prompt: How was it identified? / Who was involved in the identification?*)
- 4.) What has been your most significant experience of (name's) SEN? Could you please tell me about that situation?
- 5.) How do you describe _____ SEN?
- 6.) Has your definition of Special Educational Needs changed since moving to the UK? What did SEN mean to you before you moved to the UK?

7.) What does education mean to you?

Phase 3: *The meaning of the issue for the interviewee's everyday life*

8.) Could you please recount how your day yesterday went off and when (name's) SEN played a role in it?

9.) Who in your household or family takes care of (name)? Can you tell me about their routine or what they do during the day?

Phase 4: *Focusing the central parts of the issue under study*

10.) When you look back, who was the first professional you met who was there to help with (name's) SEN? Can you tell me what happened?

11.) What professional services do you access now? Can you tell me about that?

12.) What have you found helpful when accessing services with regard to (name's) needs? What have you found difficult? Can you tell me about that?

Phase 5: *More general topics referring to the issue under study.*

10) What is the system for working with children with special educational needs in Sri Lanka? (*How different/similar is it to your experiences in the UK?*)

11) Tell me about your life in Sri Lanka before you came to the UK.

12) What role do you think being from a Sri Lankan, Tamil background has played in your experiences of accessing services? Tell me about a situation which shows this.

13) Tell me about the role of the wider community and family in your experiences since identifying (name) with SEN. Please tell me about a situation which shows this.

14) What are your main hopes for the future of (name)? Please imagine and tell me a situation, which would make this clear for me.

Phase 6: Evaluation and small talk

15) Is there anything else you would like to say?

For researcher's reference only:

Participant Code: Interview Date:.....

Who was present at the interview:

Place of the interview:

Year of migration to UK:

Focus Child's identified SEN:

Peculiarities of the interview:

APPENDIX E

Episodic Interview Schedules for EPs and SENCoS

Phase 1 Interview Preamble

My name is Natasha and I am carrying out this research to explore Sri Lankan, Tamil parent's experiences of having a child with SEN. This research also aims to explore the Educational Psychologist's/SENCo's conceptualisation of Special Educational Needs and their experiences of working with Sri Lankan, Tamil families.

In this interview I will ask you questions about what Special Educational Needs means to you and I will ask you to draw upon times you have supported Sri Lankan, Tamil parents. I want you to reflect on your understanding of SEN in relation to the families you have supported and draw upon how your views compare.

Only I will listen to the conversation after this interview and I may include parts of what we have spoken about in my research. Anything that I use from what you have said will remain anonymous.

Please feel comfortable to speak about your experiences because it will not be shared with anyone else but if something that you have said means you or someone else is unsafe, I will discuss this with my supervisor. I will tell you if I need to do this.

Do you have any questions about what I have said?

If at any stage you would like a break or you would like to stop the interview completely just say so. It is ok if you ask me to stop. You do not have to answer any question you do not want to.

Is there anything you would like me to explain?

Phase 2: The interviewee's concept of the issue and his/her biography in relation to the issue.

- 1.) Tell me a bit about yourself and your professional background.
- 2.) How do you describe _____ SEN? Can you tell me how this compares to the Sri Lankan, Tamil families you have supported?
- 3.) What has been the most significant or meaningful experience of your role in supporting SEN? Could you please tell me about that situation?
- 4.) What does education mean to you?

Phase 3: The meaning of the issue for the interviewee's everyday life

- 5.) Could you please recount how your day yesterday went off and when SEN played a role in it?
- 6.) What role does the concept of SEN play in your everyday life? Please tell me about a situation typical of that.

Phase 4: *Focusing the central parts of the issue under study*

- 7.) If you look back, what was your first encounter of supporting a Sri Lankan, Tamil family? Can you tell me what happened?
 - 8.) What part does supporting Sri Lankan, Tamil families play in your work today? Could you please recount a situation which makes this clear?
 - 9.) What has been your most significant experience in supporting Sri Lankan, Tamil families? Could you please recount this situation?
- Prompt: *What has been challenging or facilitating during such work.*

Phase 5: *More general topics referring to the issue under study.*

- 10.) In considering your cultural background, what role do you think this has played in your professional work as an EP/SENCo? Tell me about a situation which shows this.
- 11.) The literature has highlighted the need for culturally sensitive services. How do you feel this relates to your work as an EP/SENCo in London's cultural climate today?
- 12.) What are your main hopes for the children you support?

Phase 6: *Evaluation and small talk*

- 13.) Is there anything else you would like to say?

For researcher's reference only:

Participant Code:

Interview Date:

Professional Role:

Number of years practicing:

Peculiarities of the interview:

APPENDIX F

Table 5.

Six step process of thematic analysis based on Braun and Clarke (2006)

| Phase | Description of the process |
|--|--|
| Familiarising yourself with your data | Transcribing data, reading and re-reading the data, noting down initial ideas. |
| 2. Generating initial codes: | Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code. |
| 3. Searching for themes: | Collating codes into potential themes, gathering all data relevant to each potential theme. |
| 4. Reviewing themes: | Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis. |
| 5. Defining and naming themes: | Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme. |
| 6. Producing the report: | The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis. |

APPENDIX G

Coded extract of Parent Interview Transcript

| Transcript | Initial Codes |
|--|---|
| <p>The problem with us was, was me and my wife, are alone, there are no grandparents here. So we didn't have a way of weighing what a baby's ability should be for a given age. So we were thinking this is normal, until two of my friends. They were GPs. They are GPs. They visited us for the, for a family (incomp) for the Eid.</p> <p>I: In England?</p> <p>A: Yea in the UK. And then, when they visited us, and then said "Anura, have you had a chance talking with your midwife? Or have you had a chance to talk to your GP?" And then we went and talked to them and then –</p> <p>F: The health visitor.</p> <p>A: Health visitor. And then the only answer we got was yea eventually she will walk. This was when she was at nine. You don't need to worry.</p> <p>I: Nine months?</p> <p>A: Nine months, yes. And then we don't need to worry about it, (clears throat) some kids get delayed in all and then my second friend who is also a GP, he ((incomp)) for the next Eid when she was around twelve months, almost a year and he said "Oh Anura, I have a little concern she might have delayed gross motor skills and better consult your GP, and put it forward."</p> <p>A: And then, I said "ok" I've been there because the other friend told me and this is what we been told. And he guided me a little bit on picking up the correct words, and explaining to them so the doctors would understand what we meant.</p> <p>A: And then, we put forward in that manner and then, they said go to hospital and do the assessments.</p> <p>A: And when they did the assessments, um, they said "oh Anisha is so floppy". She should be stable but she's so floppy. These things. And then they</p> | <p>Alone as parents Separation from close relatives</p> <p>Close friend (with professional background) share knowledge/provides advice.</p> <p>Draw upon friend's advice</p> <p>Support in using appropriate language for professional understanding</p> <p>Doctor identified consanguineous Relationship</p> <p>Joint identification with friend (friend provide contact with scientific knowledge).</p> |

| | |
|--|--|
| <p>asking questions about us. And then we said we are relatives, and we are first cousins</p> <p>A: And then that's how we identified it. Rather, we identified it, our friends identified it.</p> <p>I: It sounds that having those friends around you, were really helpful.</p> <p>A: It is, it is. Yea we took her to hospital. And we searched online and we took her to Portage.</p> <p>I: Portage, yea.</p> <p>A: And even though then. All the other parents were looking at Anisha and saying "what's the problem? Why is she coming here for?"</p> <p>I: Because it wasn't obvious?</p> <p>F: Yea, and then everyone, you know, like, she had these green eyes.</p> <p>A: She had a good look ((incomp)) So, that's the starting point and so initially with both of my friends. And then we went to GP and I explained to them. It was hard for them to understand what the problem is. Fortunately, one of the doctors he has been on one of these courses</p> <p>And then he said this will be the (thing).</p> <p>I: What has been your most significant experience of Anisha's SEN? Could you please tell me about that situation?</p> <p>A: When we went initially – Portage it was fine. Because I expected to have – not fully able kids. But when we had to make an application for *** preschool, we went there and we explained to them we want to make an application for Anisha. And then Anisha was on the push chair they didn't realise it and then I explained to her, look she won't be able to walk. And then they was, "oh really" and then they start to ask, what is this thing. What's the issues and needs (are).</p> <p>A: And by looking at Anisha and I took her and put her on the table. She was holding and she was</p> | <p>Engage in independent information gathering</p> <p>Delay not physically visible to others</p> <p>Physical appearance did not show delay</p> <p>Process of applying to nursery involved questions</p> <p>The need to explain child's SEN</p> <p>Physical delay becoming apparent</p> |
|--|--|

| | |
|--|--|
| <p>((incomp)). And once she was on the floor she can't get up.</p> <p>I: How old was she at this time?</p> <p>A: Um, thirteen, sixteen months.</p> <p>F: nearly two</p> <p>I: Nearly two. You were looking to start nursery?</p> <p>A: Nursery. That's correct. And then, er, -</p> <p>F: She was walking. She could hold a ((incomp)) and walk. And she (close to walk) but she couldn't walk –</p> <p>A: Independently.</p> <p>F: Independently.</p> <p>A: So the experience over there was – we didn't know how to express ourselves. There is a need for her but didn't know how to define to them.</p> <p>A: And we initially – one of the other problems was this is our first kid and first time we are experiencing it. And when we mention it they made us check Anisha's application.</p> <p>That's the other problem. We had to put them in a manner so they would understand it. And they would get it. So slowly, we said we want to make an application and then slowly gradually we explained to them what is this problem. But for the information we can contact Portage.</p> | <p>Difficulty in communicating her needs</p> <p>Lack of experience as a first time parent</p> <p>Ensure our way of communication was understood by nursery</p> <p>Access Portage for extra support</p> |
|--|--|

APPENDIX H

Coded extract of SENCo Interview Transcript

| Transcript | Initial Codes |
|--|---|
| <p>T: So we work quite hard to build relationships with our families, 1/2 of the children come on the bus and there's an in-built remoteness there for a lot of our families there's a language barrier there as well. My Tamil is lousy and their English is better than my Tamil but nevertheless they are anxious about sharing and spending time so we invite families to come in and spend time but nevertheless relationships with families are often built to superficial level, so there is often not a realisation there.</p> <p>The realisation doesn't surface until there's a significant life event and your child moving on to high school is often that trigger.</p> <p>I: And it's at that point you have the context for which to have a conversation?</p> <p>T: That's right, that's right. When that happens, families respond in a variety of ways, typically our Tamil families will politely decline and disengage conversation or nod and smile but will go ahead and investigate mainstream anyway.</p> <p>I: What type of conversation?</p> <p>T: So, we would have a meeting together at the start of year 6, there would be lots of little conversations that class teachers would have, but we would have a big group conversation together at the start of year 6 where we would talk about transition to high school and the nuts and bolts, what are the processes you have to go through. Who would you have to tell, SENARs would have to know, what's the timeline, all those kind of things that any family would have to go through.</p> <p>It's at that moment when you first ask so which high school would you like your child to go to.</p> <p>You begin to realise, and some families I think have realised that and attend and are up for the conversation, and some of them don't, and they're never up for that.</p> | <p>Difficult to build relationships with our families</p> <p>Remoteness of families Language barrier</p> <p>Relationships are built to superficial level</p> <p>Significant life event trigger difficult conversations</p> <p>Disengagement of families</p> <p>Process and procedure of moving to high school</p> <p>Realisation that some families are not willing to engage with conversation</p> |

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| <p>So in those moments, some will nod and smile politely and politely decline, some will listen and you can see will engage with the conversation, we need to be very careful, we cannot tell a family where to go, if asked we can provide a view, um, and in some cases we have seen before the children have left...and there's been safeguarding issues around that.</p> <p>I: Can you tell me more about that?</p> <p>T: Yea I can. So. In the last two years there have been, with Sri Lankan families, there have been two notable examples that stand out for me, and I link that, and I think it's linkable directly to an expectation with the family expectation which comes from being part of a Tamil culture and ultimately clashed in a way which was inappropriate.</p> <p>So the first was a child who came to us to say that they had been hit at home and we are advised to pass that information on social care. We are permitted to show no judgement in that so we pass that on, we provided that view as to why that had happened. And gave family history but there was a response, there was a section 47 response and that effectively ended any meaningful relationship with that family at that.</p> <p>I: The school's relationship?</p> <p>T: Yea that's right. So social care went to visit the home, they found that the child was being well cared for, which was exactly what we would have said and – but the social care made it very clear, you mustn't hit etc, that clashed with the family's values, um they were very afraid in that moment as you would expect them to be.</p> <p>Um they were also then very distrustful of school. "You took some information private to us and passed that on".</p> <p>I: Yes, yes.</p> <p>T : The hitting came from the hand analogy. There's an expectation that you will be clever now, you will work hard now, you will do your</p> | <p>Some families are passive in approach</p> <p>Authority cannot command but safeguarding issues are a threat to non-compliance</p> <p>Clashes in Tamil culture with school expectations</p> <p>Discipline at home led to social care involvement</p> <p>Meaningful relationship with school ended as a result of social care involvement</p> <p>Social care did not raise concerns after visit</p> <p>Parents given warning on appropriate ways to discipline</p> <p>Parents lose trust in school</p> <p>Parent's expectation of child highlighted child's needs were not understood.</p> |
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| <p>homework now, and the child wasn't able to do that. And that's where that led to.</p> <p>Second example was similar, so this was a child with more severe learning difficulties, significantly more severe learning difficulties and very very limited speech, echolalic only in their speech. But we were concerned around the kind of behaviours the child would show. They would cow away from adults who came, um, on one occasion the school saw the child being physically hit by their family, um, there were a set of circumstances which meant we referred on. There was some social care involvement again, an attempt at a section 47 which felt wholly inappropriate giving the broader context, there was some physical chastisement there but there was physical chastisement, there wasn't – ok there wasn't physical abuse.</p> <p>Discuss. Is there a difference between physical chastisement and physical abuse, in terms of outcome ,no there's no difference, the experience of the child is still wrong however, you've got to understand some of the finer social issues and expectations around why a family might behave that way.</p> <p>It's one thing to hit a child because culturally you believe that acceptable, it's another thing to hit a child because you mean them harm. I think there was very poor interpretation really in working with the family at that time.</p> <p>That put pressure on the family but equally, that family could not come to terms with that child's level of need. It was very clear to us that that child had very severe learning difficulties and should go to an appropriate school, the family were dead against that and as a result of all of that they elected not to put the child into school. There was some wrangling –</p> <p>I: Into (special school name)?</p> | <p>Another case of social care involvement because of chastisement</p> <p>Acknowledge that it is not physical abuse</p> <p>Difference between abuse and cultural expectations which influence child rearing</p> <p>Acknowledge that school did not interpret family's cultural context appropriately.</p> <p>Pressure put on family to make decisions</p> <p>Differences in school and parent's opinion re. school placement</p> <p>Wrangling</p> <p>Consider parent's legal rights to home school child</p> |
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| <p>T: They decided not to put the child in any high school. There was some wrangling and eventually the child was put place at the end of September, early October, but the child was out of school for a little while. And legally the family would have had every right to say we are going to home school this pupil.</p> <p>Yes they were going to explain how they were going to do that, defend their position. So when you have that as a backdrop and issues around physical chastisement of a child, who isn't growing up, who isn't behaving in a way that they were wanting that child to do, who wasn't being normal, that's an issue.</p> | <p>Issues are complex for families</p> |
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Appendix I

Coded extract of EP Interview Transcript

| Transcript | Initial Codes |
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| <p>D: I think, really, I think it kind of goes back to what I said about the relationship to an extent. Which I think being involved just a little bit for over such a long period of time and spending time with them kind of, I think they, they could see that there's some validity here.</p> <p>This person is invested and um, you know, yea, this person is invested, we understand now, we can see there is a marked difference between her and his peers and nieces and nephews who (inaudible) we can see that difference. I think really on that occasion there was – as I say it was quite a difficult one. And time passing.</p> <p>I: Time passing?</p> <p>So there were those concerns, parents were feeling like, going back to what we were saying before, parents were feeling like he knows some of his letters sounds and he can recognise some numbers and some colours so what's the concern?</p> <p>Um, ok he hasn't got any words yet, but he'll pick up some words, he'll be ok. So it was that kind of idea.</p> <p>Um, so as I say, I saw him and a few months later he was to transfer to (school name) um, and we went through the statementing process which in itself that took quite a lot of encouragement and support for the parents to see that was actually necessary and again, that was really about time spent, examples given of children at this age usually do, such and such.</p> <p>It's good that SS is doing <u>this</u>, um and that's great to see him progressing in this area and it was apparent that the mother was doing loads and loads and loads with SS at home, um so there is a lot of that discussion about what she's doing and how she's doing it to help him to progress but coming back to, it's great to see him progressing in this area, it look's like he still needs some extra support here and here and that will help him to progress even faster.</p> | <p>Relationship facilitated by time spent with family</p> <p>Validity in professional opinion</p> <p>Professional knowledge accepted over time</p> <p>Parents showed concerns over child's academic understanding</p> <p>Hope that he will start speaking later</p> <p>Going through process of EHC plan took encouragement and support</p> <p>Acknowledge parent's efforts and child's progress but highlight needs.</p> <p>Need to be sensitive</p> |

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| <p>So all advice and conclusions of how he was doing with his development needed to be put in a very sensitive way.</p> <p>But also I did several home visit throughout that year just giving some more intensive support, I think I might have seen them about 4-5 times that year which is not really typical at all but it was apparent that a.) he needed that extra support b.) we as in the EPS, the school, SENARs and parents all agreed he's not ready for school yet. So let's do some intensive support, let's see if by January, by that point statement will be in place and we can if he's at that point where he can join reception in January.</p> <p>I: Was it intensive support within the setting or intensive support with mum and dad?</p> <p>D: Both. But more so with mum and dad. That's where there was more need.</p> <p>I: Can you tell me more about this?</p> <p>D: Yes. Definitely. And that was about, um, activities to put in place to help him progress in various areas, it was also about just literally being available to hear their thoughts about how he was doing.</p> <p>Their concerns with how he was progressing. Um, unpicking their thoughts on how he's – where he's at developmentally, so um, giving a bench mark. Giving a bench mark.</p> <p>So that they can see, he is doing this now but actually we like him to be here and in fact he needs to be here (making hand gestures) to join the school – this is where he is at the moment.</p> <p>Um and going an modelling different activities to do with SS, um and sort of discussion about what difference settings are like because it was clear if after this year he's not made the progress that we would hope for then main stream school would be too stressful for him and are we going to think about a specialist.</p> <p>So throughout the year we were sort of drip feeding in, thinking about what is specialist support here in</p> | <p>Make links with home/family</p> <p>Joint work between authorities</p> <p>Future plans for child</p> <p>Viewing parents as having a 'need'</p> <p>Supporting child's progress with activities</p> <p>Giving a benchmark to progress</p> <p>Making plans for future progress – measuring progress</p> <p>Share expertise with parents – model activities with parents</p> <p>Drip feed information to parents</p> <p>Inform parents of different school placements</p> |
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| <p>this country. What it does look like; What it doesn't look like. Um, what the physical environment will be like. What the expectations of that setting will be like. Kind of routines there will be. How they might enrich learning. How it will be different to main stream. All of those discussions were sort of drip fit in. As I say, on each visit that I went round and made, um –</p> <p>I: Throughout the whole process. Very transparent.</p> <p>D: Very very explicit. Very transparent. And it was very useful for me to see how they were working with SS as well. So just to put that reality, if you will, to marry, how they would talk about how SS was doing, with what that actually looks like.</p> <p>And in so doing, I could see that when they say that he knows his letter sounds, that's actually them standing up. Mum's standing up, let's say SS standing here let's say, (gesture position of parent and child) moving around and literally barking and sort of saying, oh ok, "SS, a ,a , press b,b,a,a,a,!" and him sort of pointing at a few and then maybe and also pointing at a let's say. So that's - again seeing that it's good he's done that but what we want to him to be able to do is that, we need to be secure know about knowing what he can and can't do. But always all the way through coming back to this is not about proving what he can do, or proving that he can learn, because that can is the impression I got throughout. They wanted to prove that SS can learn, if he can learn then he should be in a mainstream school. Sort of feeling that I got from my discussions from them.</p> <p>So I said listen, the main thing that we – fundamentally we need to have actions, best his needs at the centre in everything that we do. Simple as that. We just want the very best for SS. And if that means SS can be best supported in a specialist setting then let us consider it.</p> <p>And as the year continued we moved from wanting, they moved from wanting him in a mainstream school, you know discussion in a mainstream with an ASD unit to then what about (school name), what (inaudible) that was very hard, they came to (special school name), they came to that point, but that final step, that was very very hard for them. Very very hard for them.</p> | <p>EP observed 'reality' of how child was performing</p> <p>Use as evidence to compare with what parents said</p> <p>Parents trying to prove to professionals that child is learning</p> <p>Child centred approach</p> <p>Parents able to change opinion of school setting over time</p> <p>Parent's accepted specialist setting</p> <p>Final leap in journey, difficult for parents</p> |
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| <p>I: Final step?</p> <p>D: Moving from understanding and accepting that yes actually, a specialist setting would be best for Shaun. But to slide, if you will, because they perceived it as a slide from him being in a mainstream school, sliding to that expectation of him, and being in a (school name) specialist setting for SLD. That was such a big leap from where they had started that that final part of the journey that they needed to go on was very difficult. Very very difficult but again, you know, lots of discussions were had, advice about going to schools, what questions to ask, what documentation to take with them. So that SENCos and heads could have a proper full understanding of SS and understand how they could meet his needs.</p> | <p>Engage parents with discussions and advice</p> |
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Appendix J

Descriptions of Parent Participants

Anura (father) and Fathima (mother)

Anura and Fathima are parents of two children. Their 5 year old daughter has global developmental delay. Both are Muslim and come from a village called Beruwala in Sri Lanka. When living in Sri Lanka, they were educated in and accessed most services in the city of Colombo. Anura migrated to the UK in 2001 and Fathima in 2010, soon after marrying.

I had previous involvement with the family through my work as a trainee educational psychologist, this included statutory work which facilitated their daughter receiving an Educational Health Care plan (EHC). I had developed a good rapport with both parents therefore facilitating an interview was easy. My previous work also meant that I had understanding of the context – including the school context, their daughter's needs and the family's history with accessing services. My position as an 'outsider' versus being an 'insider' was blurred during our interview as my responses may have been influenced by my own understandings of the family's history.

The interview took place in their home and Anura stated that this research would be a good chance to tell their story. At the time of the interview, the local authority had agreed to provide an Educational Health Care plan to support their daughter. Their story spoke of the struggles in making sense of their daughter's SEN.

Anura and Fathima spoke frankly about their journey as new parents of a child with SEN. They spoke of their difficulties in understanding the processes and procedures entailed with applying for an Educational Health Care plan. Anura and Fathima sought the support a charity.

Anura and Fathima spoke fondly of their lives in Sri Lanka. The differences in how parents access services in Sri Lanka when compared to the UK was also discussed.

This interview highlighted Anura and Fathima's perseverance and determination in moving forward during difficult times and how amongst all the confusion, they embraced an independent position in seeking out their own support separate from the local authority. They now hope to support a friend who is going through similar experiences.

Malini (mother) and Dinesh (father)

Malini and Dinesh were from Jaffna in Sri Lanka and described themselves as middle class citizens in Sri Lanka. Dinesh arrived in the UK as a refugee in 1999 and Malini joined him in 2002 after marrying. I was told that Malini studied at university level and her husband studied up to A level. Malini and Dinesh have three children. Their second son who is 7 years old has been diagnosed with Autism Spectrum Disorder.

I met Malini and Dinesh for the first time at the interview. I contacted them having received their contact details from an EP who had previously supported the family. Malini spoke of the struggles she and her family faced during the civil war. Speaking with me about the trials she had experienced became too difficult for Malini and it was necessary to stop to the interview. Consent was obtained again to continue with the interview.

Much of the interview explored experiences of suffering and struggles. Malini spoke about the journey the family went on in accepting their son's diagnosis, the drive to provide their children with the best that they can and how their difficulties in speaking English posed a barrier in engaging with the system. Reference was made to being perceived as a "foreigner" in the UK.

Malini and Dinesh spoke extensively of the difficult relationships they have had with services and their feelings of exclusion within their school community. Stories were told about the involvement of social services and how these experiences inflicted on their life as a family. Stories of dissonance between the school and family were highlighted and Malini and Dinesh spoke of their current struggles in applying and appealing for a new school for their son. The interview ended with a sense of hope for the future; hope that their son will improve and hope that their appeal to change school will succeed. Their final message for me was to ensure that I hear the parent's voice in my role as an EP.

Patricia (mother)

Patricia's interview took place in a school setting as this was her place of work. Prior to meeting, the head teacher of the school had authorised for Patricia to meet with me and arrangements were made to meet in the school SENCo's office. Patricia was recruited through an EP who had previously supported the family. I met Patricia for the first time at the interview. She works as a learning support assistant at a primary school and the interview took place in the school setting. Patricia's son is fifteen years old and has a diagnosis of Autism Spectrum Disorder.

Patricia came from Colombo, Sri Lanka and her husband from Batticaloa, Sri Lanka. Patricia migrated to the UK in 1997 after marrying her husband. She told me her husband came to the UK as a student in the early 1980s. Patricia described herself as Roman Catholic and her husband as Methodist. Both were privately educated in religious based schools in Sri Lanka. Patricia described their life in Sri Lanka as well-off and comfortable and explained that the war was the catalyst for moving to the UK.

Patricia's story was positive, hopeful and forward thinking. Patricia highlighted that her and her husband's level of education may have contributed to the positive experiences they had when collaborating with professionals.

Patricia spoke of having an attitude and approach which did not resist support and made references to how being "broadminded" and fluency in English may

have supported this. Patricia spoke of her role as a learning support assistant and the confidence this has given her. At the time of the interview, Patricia was thinking about her son's future and how they hope to move forward as a family.

Mona (mother)

Mona was recruited through an EP who had previously supported the family. Mona chose to meet at the EP service's office and the interview took place in a meeting room. Mona has a daughter who is three years old. There are concerns regarding her daughter's speech and language development and possible autism spectrum disorder. At the time of the interview no diagnosis had been made but Mona had accessed various health and education services. Mona and her husband are both academics. Mona and her family come from Jaffna, Sri Lanka. Mona migrated to the UK in 1984 when she was a young child following some time in Nigeria. She describes her family as upper-middle class and part of the 'English speaking elite'.

I met Mona for the first time at the interview. Mona was eager to engage in the interview and began to tell her story without an opening question. Mona spoke of the initial shock and confusion when her daughter's nursery first raised concerns about her daughter's speech delay. She spoke of months of anxiety and exhaustion as a result of trying to understand and make sense of it all.

Mona spoke of her reluctance to accept a diagnosis of autism spectrum disorder and would like more time to observe her daughter's progress before such a conclusion is made. Mona emphasised how she used her position in academia to engage in further reading about language development and autism. She believes that this has informed her and supported her decision in holding back on a diagnosis of autism.

Mona draws upon her upbringing in the UK as making a difference between her and her mother's deference to institutions. Mona spoke of how she has drawn strength from her daughter's childminder.

After what has been an exhaustive and stressful period, Mona spoke of feeling in control and in trusting her own judgement as a mother. She spoke of feeling hopeful that her daughter's needs will change in the future.