Parental experiences of professional involvement for children and young people with selective mutism and their preferred support.

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A thesis submitted in partial fulfilment of the requirements of the University of East London for the Professional Doctorate in Child & Educational Psychology

Date of submission: April 2022

Abstract

Selective Mutism (SM) is a rare childhood disorder that affects the ability to speak in certain social environments, despite having the physical ability to speak. Without appropriate support and intervention, it can persist into adulthood. Despite its potential long-lasting effects, knowledge of the disorder and how to support those with it is limited. Research into SM is mostly quantitative, or case studies focused on the effectiveness of interventions.

This research aimed to explore parental perspectives of professional support for their child with SM, how this support has influenced their experience of SM, and ideal support for the children and families of those with SM. Despite the key role that parents have in their child's life and recovery from SM, they are currently almost voiceless within the literature. Likewise, the support that professionals provide that is beneficial is unclear.

Eight parents with a child in key stage 3 or 4 with traits of SM took part in semi-structured interviews. Thematic analysis was used to qualitatively analyse the data. A first master theme of 'the parent and SM' was identified, followed by a superordinate theme of 'experiences of professional input', which contains two further master themes of 'input of professionals' and 'the system'. A master theme of 'impact of professional's input' was identified, followed by the final master theme of 'looking forwards'. Parents reported both supportive and unhelpful input from professionals affected by factors such as the professional's personality, communication, and knowledge of SM. Parents also identified barriers in the systems around professionals which affected the support they received. They noted the high impact a professional could have on the life of the parent and their child, and expressed hope for more awareness of SM, and an SM pathway. Further research could explore the viability of such a pathway.

Key words: Selective Mutism, parent experiences, professionals

Acknowledgements

First and foremost, I would like to thank my fiancée, James, who has supported me every step of the way through this research and the entire professional doctorate journey. James, you have been my rock during one of the biggest and most enduring challenges I have ever faced. I could not have done this without you telling me to take breaks, making me smile every day, and keeping me confident. Of course, our two cats, Tux and Loki also deserve a special thank you, for keeping me company curled up next to me as I spent hours in the study and bringing me joy through their sweetness.

I would like to thank my parents, Jocelyn and Peter, who instilled in me a belief that I can do anything I put my mind to. The reason I have been able to choose and succeed in this career is because of the support you have always given me. Thank you to my best friends, Becky and Naomi, for listening to my complaints, and not complaining about the lack of gals holidays we've been able to take while I'm on the student bursary! You two have been the best chief bridesmaids I could ask for; you've helped me stay excited about my wedding when it felt so far away and unimportant compared to the many other things that needed my time and attention.

A huge thank you to my Director of Studies, Helena Bunn. Helena, thank you for containing my worries, guiding me with your own knowledge and wisdom, and sharing with me your infectious joy! Thank you to all of the tutor team at UEL for your support over the last three years. And thank you to Cohort 14; we made it! You've been an amazing support network, and I could not have shared this journey with better people.

Thank you to SMIRA, for letting me reach so many parents of SM children. Thank you to those in Portsmouth EPS; Liz Robinson, Victoria Parker and Andrea Findlay, for your support of my development, and your kindness. Thank you to Bedford EPS; Tim Long and Aneta Wawrentowicz for your help with recruitment. Tim, without you I'd never be in the EP world! Thank you for taking a chance when you hired me as AEP.

And finally, a huge thank you to the parents who took part in this research. Thank you for giving up your time to speak to me, and for sharing your experiences with me. I am honoured to have been given such insight into your world, and the challenges you have faced. I am so grateful to you all for reaching out; I could not have done this without you.

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List of Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
AEP	Assistant Educational Psychologist
APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
BPS	British Psychological Society
CAMHS	Child and Adolescent Mental Health Service
CBT	Cognitive Behavioural Therapy
COVID-19	Coronavirus Disease
CPD	Continuing Professional Development
CYP	Children and Young People
DSM	Diagnostic and Statistical Manual of Mental Disorders
EAL	English as an Additional Language
EHCP	Education Health and Care Plan
EP	Educational Psychologist
GP	General Practitioner
HCPC	Health and Care Professions Council
ICD	International Classification of Diseases
IPA	Interpretative Phenomenological Analysis
KS	Key Stage

LA	Local Authority
NAPEP	National Association of Principal Educational Psychologists
NHS	National Health Service
OT	Occupational Therapist
PEP	Principal Educational Psychologist
RCPC	Raven’s Controlled Projection for Children
SALT	Speech and Language Therapist
SENCo	Special Educational Needs Coordinator
SEND CoP	Special Educational Needs and Disabilities Code of Practice
SEND	Special Educational Needs and Disabilities
SLP	Speech-Language Pathologist
SM	Selective Mutism
SMIRA	Selective Mutism Information and Research Association
SP	School Psychologist
SSRIs	Selective Serotonin Reuptake Inhibitors
TA	Teaching Assistant
TEP	Trainee Educational Psychologist
UEL	University of East London
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

1. Introduction

1.1 Chapter Overview

This research explored the experiences of professional support by the parents of children and young people (CYP) with Selective Mutism (SM). The researcher became interested in parental experiences of SM whilst working as an Assistant Educational Psychologist (AEP) within a Local Authority (LA) Educational Psychology Service. A common theme that arose during discussion with parents was the lack of awareness of SM, and the subsequent difficulty parents could face in understanding SM, and securing support for their child with SM.

The introduction explores a variety of relevant areas around SM, including terminology, onset and prevalence, proposed underlying causes, interventions, the impact of SM on CYP and their parents, the role of professionals in cases of SM, and the current national context. The introduction predominantly uses medical based language when discussing SM. This reflects that it is a medical diagnosis, and the discourse around SM in the current literature. In the chapter's final parts, the rationale and aims of this study are outlined, as well as the structure of this thesis.

1.2 Terminology

SM was first identified in 1877 by Kussmaul as 'aphasia voluntaria' and renamed 'elective mutism' by Tramer in 1934 (cited in Viana et al., 2009, p. 59). Possibly these historical labels suggest the view that individuals were 'electing' not to speak. Over time, there has been a shift away from this thinking with the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association [APA], 1994) introducing the term 'selective mutism'. More recently, SM has been classified as an anxiety disorder in the DSM-V (APA, 2013) and the 11th edition of the International Classification of Diseases (ICD-11) (World Health Organization [WHO], 2019) (diagnostic criteria outlined in table 1 and 2), reinforcing the view that it is not a voluntary behaviour.

Table 1

DSM 5 Diagnostic Criteria for SM

	Selective Mutism
Diagnostic Criteria	312.23 (F94.0)
A. Consistent failure to speak in specific social situations in which there is an expectation for speaking (e.g., at school) despite speaking in other situations. B. The disturbance interferes with educational or occupational achievement or with social communication. C. The duration of the disturbance is at least 1 month (not limited to the first month of school). D. The failure to speak is not attributable to a lack of knowledge of, or comfort with, the spoken language required in the social situation. E. The disturbance is not better explained by a communication disorder (e.g., childhood-onset fluency disorder) and does not occur exclusively during the course of autism spectrum disorder, schizophrenia, or another psychotic disorder.	

Note. From American Psychiatric Association. (2013) *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Association.

Table 2

ICD 11 Diagnostic Criteria for SM

6B06 Selective Mutism
Description
Selective mutism is characterised by consistent selectivity in speaking, such that a child demonstrates adequate language competence in specific social situations, typically at home, but consistently fails to speak in others, typically at school. The disturbance lasts for at least one month, is not limited to the first month of school, and is of sufficient severity to interfere with educational achievement or with social communication. Failure to speak is not due to a lack of knowledge of, or comfort with, the spoken

language required in the social situation (e.g., a different language spoken at school than at home).

Exclusions

- Schizophrenia (6A20)
- Transient mutism as part of separation anxiety in young children (6B05)
- Autism spectrum disorder (6A02)

Note. From World Health Organization. (2019). *International statistical classification of diseases and related health problems* (11th ed.).

Though the SM diagnostic criteria differ between DSM and ICD (table 1 and table 2), they both consider the primary presentation of the condition to be a persistent difficulty speaking within specific situations.

1.3 Onset and Prevalence

The typical age of onset for SM is recognised to be before five years old (Black & Uhde, 1995; Cunningham et al., 2004). Sharp et al. (2007) note nonetheless a delay between the onset of SM symptoms, and CYP being referred for diagnosis, with age at diagnostic assessment ranging from 6.5 to 11 years old (Ford et al., 1998; Kumpulainen et al., 1998). Imich (1998) suggests that this may be as a result of CYP with SM speaking at home, and so symptoms only being noticed once CYP begin to attend school.

The prevalence rates of SM are low, with an estimated one in 140 children in the UK currently affected (National Health Service [NHS], 2016). Additionally, some believe that the setting in which SM is sampled may affect the reported rates (Viana et al., 2009), for example, school and community-based studies report higher prevalence rates than clinical samples (Standart & Couteur, 2003). Standart and Couteur (2003) also report higher levels of SM in females, which is in keeping with gendered anxiety records (Slee et al., 2021). Cunningham et al.

(2004) and Kristensen (2000) support this with reportedly higher rates in girls in clinically referred samples.

Cultural factors in SM should also be considered. The criteria for SM in the DSM IV and DSM V stipulate that the presenting SM must not be due to lack of knowledge or comfort with the spoken language required within that situation. This includes children who may have English as an Additional Language (EAL). However, Elizur and Perednik (2003) indicate that if this criterion is removed, prevalence rates amongst immigrant CYP in Israel are significantly higher than native speaking children.

1.4 Theories Proposing Understanding of the Cause of SM

Differing psychological theories have been used to explain the aetiology of SM and explore prospective treatment. This uncertainty regarding the cause of SM may in part be linked to the low prevalence rates and lack of gold standard empirical studies. There is a view that existing data is still developing and often open to bias due to being based on case studies and reports or observations by others, e.g., parent or teacher reports and clinician observations (Scott & Beidel, 2011). The differing theories explaining the possible causes of SM will briefly be explored, as well as whether they are supported by research.

1.4.1 Familial Factors

Several theories have considered the possibility that environmental factors within the family may contribute to SM behaviour. Psychodynamic theory (Elson et al., 1965; Dow et al., 1995; Leonard & Topol, 1993) viewed SM as a way for CYP to punish their parents, and to cope with feelings of anger and anxiety as a result of unresolved conflict. Family systems theory proposed that SM is an anxious behaviour caused by an unhealthy relationship between parent and child. This is characterised by interdependency, and fear and distrust of the outside world (Meyers, 1984; Wong, 2010). Both theories lack empirical validation (Wong 2010; Cunningham et al., 2004).

Research has further explored the link between child and parental temperament, with higher levels of parental social anxiety and phobia (Chavira et al., 2007; Kristensen & Torgersen, 2001). Black and Uhde (1995) note that 37% of participating first degree relatives reported a history of SM, whilst 70% reported historical or current social phobia or avoidant disorder. Despite this, the link between parental pathology and SM lacks empirical validation. Whilst the link between child and parental temperament has face validity, it remains unclear in the literature if familial factors play an environmental or genetic role in SM either separately or together (Kristensen & Torgersen, 2001).

1.4.2 Neurobiological Factors

Biological causes have also been proposed, with a particular focus on neurodevelopmental delay or impairment. Kristensen (2000) reported that 68% of their SM sample in Norway met the criteria for developmental delay or disorder, compared to 13% of the control group. Additionally, Manassis et al. (2007) reported their SM participants as scoring significantly lower than control groups for language, phonics, and grammar skills. This is a relatively new proposed aetiology and requires further support (Wong, 2010), with careful consideration to avoid causation, which in fact may be correlation of symptoms. Additionally, only the study by Kristensen (2000) ensured participants met a recognised diagnostic criterion for SM, whilst Manassis et al. (2007) used a questionnaire to ascertain SM behaviours.

1.4.3 Psychological Factors

Trauma was an early suggestion of the cause of SM (Andersson & Thomsen, 1998), as was oppositional behaviours (Browne et al., 1963, cited in Standart & Couteur, 2003). Neither is supported by literature (Black & Uhde, 1995; Dummit et al., 1997; Cunningham et al., 2006). The oppositional behaviours theory appears to have emerged from descriptive case studies, and it is instead suggested by Dummit et al. (1997) that oppositional behaviours may be a means of the child avoiding anxiety-provoking situations.

SM has also been proposed as being a symptom of social phobia or social anxiety rather than a distinct disorder by itself (Black & Uhde, 1995; Golwyn &

Wenstock, 1990). Literature has identified high levels of SM participants also meeting the diagnostic criteria for anxiety disorders (Kristensen, 2000; Dummit et al., 1997) compared to control groups. Anxiety levels have also been reported as higher for SM children than control children by parents and teachers (Cunningham et al., 2004), and Yeganeh et al. (2003) note comparable self-reported levels of anxiety in SM participants and social phobia participants. Studies in this area are critiqued for recruiting participants through anxiety centres, therefore potentially biasing the samples towards anxiety. Despite methodological concerns, the link between anxiety and SM is generally supported in the literature, though Cleave (2009) notes that further consideration of aetiological factors must be given for CYP with SM who display other social behaviours competently, e.g., using gestures.

Behavioural theory suggests that SM is an adaptive response; a learned strategy for changing and manipulating the environment (Cohan et al., 2006; Dow et al., 1995). Behavioural inhibition contributes to this theory; initial withdrawal and seeking of a parent after encountering a new situation or person becomes a continued avoidance of such experiences (Manassis et al., 2003).

1.4.4 Multidimensional Framework

The differing theoretical views have been integrated from a developmental psychopathology perspective, considering the ‘dynamic process resulting from multilevel, complex transactions between the individual and the environment over time’ (Viana et al. 2009, p. 58). This accounts for the differing aetiological factors within one framework and proposes that the cause of SM is multidimensional (Wong, 2010). For example, Elizur and Perednik (2003) report that immigrant CYP with SM in their study had extremely high social anxiety, whilst CYP with SM native to the country had higher levels of neurodevelopmental delay such as motor, language, and cognitive skills. This theory is supported by the differing levels of communication shown by CYP with SM. For example, some may communicate through gesture and facial expressions, whilst others may be unable to interact nonverbally as well as verbally (Yeganeh et al., 2003).

1.5 Interventions

There is limited literature regarding the interventions for SM, likely impacted by the low prevalence rate. Several interventions have attempted to treat SM, often linked to a proposed theory of aetiology. Empirical data is however scarce, with the bulk of studies consisting of case studies (Østergaard, 2018). Few randomized control trials have been completed, and those that have often have small sample sizes, resulting in limited power and generalisability of findings.

1.5.1 Familial Interventions

Psychodynamic therapy aims to identify underlying unconscious conflict through art or play (Leonard & Topol, 1993). The efficacy of this intervention is uncertain as literature demonstrates only case study examples (Wong, 2010). Family systems therapy considers how the CYP's functioning is being impacted upon by the larger social system. It targets the whole family unit, rather than the individual CYP, and attempts to alter the patterns of interaction within the family (Stone et al., 2002). There is currently a lack of empirical support for the impact of family therapy on SM. However, incorporating the systems around a CYP, such as family and school staff, is speculated to be likely to aid recovery (Wong, 2010).

1.5.2 Neurobiological Interventions

Medication for SM primarily targets social anxiety. Antidepressants such as selective serotonin reuptake inhibitors (SSRIs) have been identified as the most common pharmacological intervention for SM, followed by anti-anxiety medications (Carlson et al., 1999). Though studies have reported some positive effects of various types of medication, e.g., fluoxetine (Dummit et al., 1996; Black & Uhde, 1994), this is not consistently reported by those around the CYP on medication. For example, Black & Uhde (1994) report a significant difference in parent rated measures following intervention, but no difference rated by teachers and clinicians. In comparison, Dummit et al. (1996) report significant differences across all three participants groups. Sample sizes for such studies are small, and few have unmedicated comparison groups or use double blind methodology (Manassis et al., 2016; Bergman et al., 2013). Carlson et al. (2008) conducted a meta-analysis and reported that 81% of studies were case studies, frequently without standardised measures of behaviour change used to assess change.

These methodological issues make it difficult to draw conclusions on the efficacy of medication intervention. In addition, there is limited evidence of treating young children with such medication, and psychosocial intervention should therefore be considered first (Manassis et al., 2016).

1.5.3 Behavioural Interventions

Behavioural therapy is one of the most common and evidence-based interventions for SM (Dow et al., 1995). The emphasis is on targeting overt behaviour and modifying the environment to create desirable change (Stone et al., 2002), for example, changing the reinforcers of SM behaviour through techniques such as stimulus fading and systematic desensitisation (Wong, 2010).

Cognitive behavioural therapy (CBT) for SM includes anxiety management approaches (such as relaxation training), parent psychoeducation, cognitive techniques (such as identifying and challenging maladaptive beliefs), and behavioural exercises (Cohan et al. 2006). Modified CBT which focuses on changing the behavioural components has been recommended as an effective intervention for SM (Cohan et al., 2006; Østergaard, 2018; Schwartz et al., 2006), with the majority of CYP showing improvement. In randomized control trials, Bergman et al. (2013) reported that CBT resulted in significantly more speaking behaviour and number of words spoken, and Oerbeck et al. (2014) reported a significant improvement compared to the waitlist.

1.5.4 Multidimensional Interventions

Literature suggests emerging support for multidimensional interventions. Lang et al. (2016) used modular CBT, behavioural interventions, and psychoeducation of parents and school staff. 84% of children had recovered from SM three years after intervention. Additionally, Klein et al. (2017) included elements of CBT and psychoeducation, as well as incorporating the support of parents into the therapy. After nine weeks of intervention all participants were rated by their parents as showing significantly increased frequency of speaking, and reduced level of anxiety and withdrawal. Whilst these results indicate emerging support for multidimensional interventions neither study used a control group, reducing validity of the findings.

1.5.5 Summary

Overall, there is great difficulty considering the efficacy of SM interventions due to the lack of quantifiable data for many interventions. As a result, comparison amongst interventions is difficult. Behaviour therapy, including CBT, has been found to be more effective than no intervention (Stone et al., 2002), and is the current intervention of choice.

There is limited data on the long-term outcomes of SM interventions. A study by Remschmidt et al. (2001) found that of the 45 CYP, 39% were considered to have completely recovered an average of 12 years after treatment. Unhelpfully, the types of intervention used are described vaguely as inpatient therapy or family counselling. In addition, the recovery rates were not differentiated by type of intervention received. For those who had not recovered, a family history of SM was found to strongly correlate. Lang et al. (2016) followed up 24 children two years after CBT intervention. 84% of children no longer met the diagnostic criteria for SM, and parents and clinicians reported significant improvements. Oerbeck et al. (2018) found that five years after a six-month CBT intervention, 21 of the 30 children were in remission, five were in partial remission, and four continued to meet the diagnostic criteria for SM. However, studies focusing on medication such as Black and Uhde (1994) and Manassis and Tannock (2008) found that those treated with selective serotonin reuptake inhibitors (SSRIs) improved, but continued to display symptoms and met the diagnostic criteria for SM.

1.6 The Impact of SM

1.6.1 On Individuals with SM

Literature indicates that CYP with SM are disadvantaged socially, emotionally, and academically in both the short and long-term. Whilst recovery is possible, there is some suggestion that individuals can continue to struggle with social anxiety and shyness throughout their life (Omdal, 2007).

SM is considered a major barrier to learning due to the emphasis on verbalisation within the United Kingdom (UK) curriculum (Cleave, 2009). Research has linked

SM to lower academic performance (Bergman et al., 2002), lower scores for receptive language, grammar, and phonemic awareness (Manassis et al., 2007) and narrative skills (McInnes et al., 2004).

Wong (2010) suggests that SM can affect social functioning and is associated with social isolation. Whilst this certainly presents as having face validity, it is not supported by any research. Additionally, little research has explored the long-term implications for SM. Lower educational attainment and difficulties with social and intimate relationships have been noted (Cunningham et al., 2004, 2006), and a higher risk of developing other mental health problems such as further anxiety disorders, depression, stress and eating disorders (Steinhausen et al., 2006). There is some suggestion that those with SM may be more vulnerable than others (Hayden, 1980).

1.6.2 On Families

Some literature demonstrates a delay between when SM behaviour is first noticed in school, and when parents are informed of their child's difficulties. School staff in Sweden reported a difficulty in raising the concern with parents, perhaps due to lack of knowledge and understanding of SM, or parental belief that the problem lies at school due to the child speaking at home (Kopp & Gillberg, 1997).

The input and involvement of parents in cases of SM is deemed essential, as they may be some of the only people with whom the CYP speaks, and empowering parents may increase the likelihood of recommended intervention being implemented at home (Schill et al., 1996). However, much more research is needed to explore the role of parents in supporting CYP with SM.

1.7 The Role of Professionals in Cases of SM

Support for SM from professionals has been highlighted as key, with Omdal (2008) finding that a lack of professional support and guidance can contribute to the maintenance of SM.

A paper by Roe and Phil (2011) identified a number of professionals who SM CYP and their parents identified as having worked with in the past. However, no research exists on the role or input of many of these professionals. Ponzurick (2012) approaches SM from a health perspective as a school nurse and suggests that professionals from a variety of backgrounds are needed when supporting SM.

1.8 National Context

As previously stated, there is a great emphasis on spoken language as part of the National Curriculum (Cleave, 2009; Department for Education, 2014). Additionally, a review into the provision for and the experiences of CYP with speech, language and communication needs identified amongst its key themes that ‘communication is crucial’ (Department for Children, School and Families, 2008, p. 6). SM therefore presents as a barrier to learning with possible negative consequences for CYP.

The Special Educational Needs and Disabilities Code of Practice (SEND CoP) (Department for Education and Department of Health, 2015) places CYP and their families at the heart of and involved in discussions and decision making about their individual support and provision. Given the difficulty CYP with SM have in speaking in some contexts, it is even more important that professionals work cooperatively with their families in order to hear the voice of the child. Research indicates that CYP with SM report that they are most comfortable speaking at home (Roe & Phil, 2011). Their families may therefore be best placed as their advocate and may often be interacting with professionals on their behalf. Consequently, it is imperative to begin to understand the experiences of how professional input and support is experienced by the parents of children with SM.

A cursory internet search of guidance for SM brings up numerous results from charities and NHS departments in various local authorities. There are currently no national guidelines regarding the identification or treatment of SM, only the recognition, assessment, and treatment of social anxiety disorder (National Institute for Health and Care Excellence, 2013). This may be a reflection of its low prevalence rate, or of the debate regarding it being a disorder of its own or a symptom of social anxiety or phobia. Much of the guidance regarding SM comes from a resource manual by Johnson and Wintgens (2016), both of whom are qualified Speech and Language Therapists (SALTs). Additionally, the Selective Mutism Information and Research Association (SMIRA) is a UK Registered Charity which offers support and information to families with SM CYP, as well as health and education professionals. Their website provides information regarding what SM is, who can give a diagnosis, and treatment, and is a key resource for those wanting to learn more about SM.

NHS (2016) suggests that a formal diagnosis of SM can come from a SALT, who can be contacted through the child's GP. It further notes that 'older children may also need to see a mental health professional or school educational psychologist'. Whilst the NHS webpage briefly describes common treatments for SM, it does not detail who will be involved in delivering them.

1.9 Present Study Rationale and Aims

This research is filling a gap within the current literature exploring SM. The aim of the research is to explore parental perspectives of professional support. This is due to the key role that parents have in their child's life, in the management of the behaviours associated with SM, and in recovery from it (Johnson & Wintgens, 2016). Despite this important role, the parents of CYP with SM are currently almost voiceless within the literature. In addition, professional input has been highlighted as key in overcoming SM, however, what exactly it is that professionals contribute that is so key remains unclear.

This research is informed by Bronfenbrenner's (1979) eco-systemic theory of development, which supports the exploration of different systems within a CYP's life, and how these systems interact and contribute to the context which the CYP is in. The theory will be applied as an executive framework. This will allow for the consideration of the interplay between professionals, parents, and the individual CYP, whilst still enabling the data analysis to be inductive, with no prior analytic preconceptions.

1.9.1 Research Questions

The research questions were generated based on the gaps in the literature and will touch on exploring the impact and interaction between the different systems (Bronfenbrenner, 1979).

The following questions will be answered in this research:

1. What are the experiences parents have had of professional involvement for their child with selective mutism, and how do they feel that this has influenced theirs and their child's experience of selective mutism?
2. What support from professionals would the parents of children with selective mutism like to have?

1.10 Outline of the Thesis

This introductory chapter has outlined the background and aims of this research. The following Literature Review chapter will explore and critique the existing literature about the experiences and perspectives of stakeholders within SM. The subsequent Methodology chapter will outline epistemology and ontology, how the research data has been collected, and ethical considerations. This will be followed by Findings, and Discussion of these findings and how they fit within the existing literature.

2. Literature Review

2.1 Chapter Overview

This chapter explores the literature available on SM related to parental perspectives. Due to the paucity of literature exploring parental perspectives, literature related to perspectives of other stakeholders were also considered. This includes those who have or have had SM, their families, and relevant professionals working with SM individuals and their families. Eleven papers were critically reviewed using Yardley's (2000) framework of good qualitative research, with additional quantitative analysis for four of the papers.

This chapter will outline the systematic review conducted and the methodology used for identifying and analysing the papers. The papers have been grouped by participant; individuals with SM, families, and professionals. The papers are briefly outlined, critiqued, and key themes identified.

2.2 Systematic Review and Methodology used for Identifying and Analysing Studies

2.2.1 Search Terms and Search Engines

On 25.02.2021 a scoping search was conducted (Grant & Booth, 2009) to answer the question of 'what are the perspectives and experiences of parents of CYP with SM?' The databases EBSCO, Google Scholar, and Proquest were all explored using the terms 'parent', "selective mutism" and (perspectives OR experiences). This generated a result of two papers to critique. As a result of the paucity of the results, the literature review was widened to include stakeholders in SM, such as parents, individuals with SM, and relevant professionals. This terminology 'stakeholders' builds on that used in a study by Hoyne (2014), one of the papers identified in the literature review.

On 26.02.2021 a systematic review (Grant & Booth, 2009) was conducted to answer the question of 'what are the perspectives and experiences of stakeholders in SM?' The databases EBSCO, Google Scholar, and Proquest were all explored using the terms "selective mutism" and (perspectives OR experiences). Please refer to appendix 1 for further details regarding the systematic review, informed by Moher et al.'s 2009 PRISMA model.

2.2.2 Inclusion and Exclusion Criteria

Table 3

Literature Search Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
Research must be a primary source.	Research is not a primary source.
Research must have been published within the last 20 years.	Research was published over 20 years ago.
Research must gather views of stakeholders using qualitative or quantitative methods.	Research does not explore the experiences and perspectives of key stake holders.
'Selective Mutism' must be in the research title or research subjects.	'Selective Mutism' not included in the research title or subjects.
Research must be conducted on SM specifically, or findings with SM participants are clearly outlined.	Research is conducted on a similar subgroup, with some SM participants included, e.g., social anxiety.
Research must be at or above doctoral level.	Research that is below doctoral level (i.e., masters or undergraduate).

Table 3 details the inclusion and exclusion criteria for the systematic literature review. This literature review considers only primary sources in order to consider only original, first-hand information. Literature must have been published no more than 20 years ago in order to ensure its relevance to current discussions. As this research is at doctoral level, only research at a similar or higher level was considered. This also ensured a degree of competence in the methods used by researchers, and a level of criticality in the paper. SM must appear in the research title or research subjects in order to facilitate the literature searching.

This aided with ensuring that the research applies to SM specifically, or that SM participants are central to the research. This criterion was included due to the argument present in the literature that SM may be a symptom of social phobia or social anxiety (Black & Uhde, 1995; Golwyn & Wenstock, 1990). As SM is currently regarded as a separate disorder in DSM V and ICD 11, it was regarded as being so for this research. The inclusion criteria were expanded from parents to include stakeholders due to paucity of research. Stakeholders include those with SM, their families, and other professionals involved. As this research focused on people's experiences and perspectives, this was also the area of interest for the literature review.

2.2.3 Total Papers Included

Moher et al.'s 2009 PRISMA model was utilised to systematically identify and screen the research papers (see appendix 1). A total of 11 papers were identified, including five peer reviewed journal articles, one published but not peer reviewed journal article, and five doctorate dissertations. Included in the search results for stakeholders were the two papers identified in the search for parents' views.

2.2.4 Appraising the Quality of the Literature

The qualitative studies identified were critically evaluated using Yardley's characteristics of good qualitative research (2000), which focused on sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. Please refer to appendix 2 for more detailed identification of Yardley's characteristics of good qualitative research across the papers.

The quality of the studies identified varied, resulting in a mixed picture with areas of strengths and weakness. Most studies were appraised as demonstrating good sensitivity to context, with review and synthesis of current literature and theory notably strong. Given the paucity of literature in this area many of the studies also demonstrated a degree of impact and importance, often broadening knowledge in relation to the research objectives, and offering socio-cultural impact. The primary areas of identified weakness in the literature are commitment and rigour and transparency and coherence. Several studies do not clearly outline aspects of their data collection and analysis, which results in a lack of thoroughness and transparency. Further details regarding the strengths and weaknesses of individual studies will be explored in the coming sections of this chapter.

In addition to qualitative data, four of the identified 11 studies reported quantitative data, primarily in the form of descriptive statistics. These four papers reporting quantitative data collection and analysis were also analysed for validity and reliability. Please refer to appendix 3 for more detailed quantitative analysis.

2.3 Analysis and Critique of the Literature Identified

For this analysis the literature has been separated into three sub-groups based on research participants. This includes individuals with SM, their families, and relevant professionals. The purpose of this is to enable the identification of similar themes within the literature identified by type of participants.

The studies have been labelled according to level of quality. For example, the paper by Hoyne (2014) was assessed as being of high quality due to meeting all of Yardley's characteristics of good qualitative research. In contrast, the research by Omdal and Galloway (2007) met very few of Yardley's characteristics, and so was assessed as being of low quality. This paper particularly lacked commitment and rigour, transparency and coherence, and impact and importance. Papers which met a few of Yardley's characteristics were assessed as being of medium quality. For example, Omdal's (2007) paper inconsistently demonstrated some sensitivity to context, commitment and rigour, and transparency and coherence. It was subjectively judged to be of medium quality due to consistently demonstrating impact and importance. Whilst the studies have been labelled according to level of quality, it must be noted that this is a subjective analysis reflecting the researcher's own interpretative biases. Although the review has increased transparency through the use of a research diary and explicit use of the critical evaluation framework, it is possible that another researcher may appraise the studies differently (Grant & Booth, 2012).

2.3.1 Literature Exploring Perspectives of Individuals with SM

Six of the papers reviewed focused on the voices of those with SM. Four papers explored the views of CYP with SM (Omdal & Galloway, 2007; Roe & Phil, 2011; Patterson, 2011; Albrigsten et al., 2016) and two focused on adult voices (Walker & Tobell, 2015; Omdal, 2007).

2.3.1.1 Adults

Both studies exploring adult views used semi-structured questionnaires to gather responses, though had slightly different purposes. Walker and Tobell (2015) aimed to present ‘the subjective experiences of adult sufferers and to enable these excluded voices to broaden our understandings of this difficulty’ (p. 453), whilst Omdal’s (2007) focus was to consider if adults who have recovered from SM could shed light on their childhood experiences of SM and the recovery process.

Walker and Tobell’s (2015) four participants had SM at the time of research. This influenced the data collection method, with semi-structured interviews being conducted via online instant messaging. In contrast, as Omdal’s six participants had recovered from SM, semi-structured interviews were able to take place face to face. Both gathered qualitative data focusing on emerging themes, with Walker and Tobell (2015) analysing using interpretative phenomenological analysis (IPA), and Omdal (2007) analysing using N-Vivo software.

The paper by Walker and Tobell (2015) was of high quality, with sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance all considered and addressed. Of particular note is the transparency demonstrated through the use of autoethnographic methods, as a result of one of the researchers having SM. This study uniquely demonstrates that it is possible to gather insight into the experiences of those with SM using instant messaging as a method of communication.

In comparison, the paper by Omdal (2007) was of medium quality. It offers high impact and importance into the retrospective insight of experiences of SM, and demonstrates the ongoing difficulties for those who have ‘recovered’ from SM. It does however particularly lack transparency and coherence due to unclear coding and analysis of the data, and no clear research question guiding the narrative.

2.3.1.2 Children and Young People

Four studies explored the views of CYP with SM. Participants for three of the studies (Omdal & Galloway, 2007; Patterson, 2011; Roe & Phil, 2011) presented with selective mutism at the time of participation. Twin boys who had recovered from SM took part in a case study in Norway by Albrigsten et al. (2016).

Albrigsten et al. (2016) explored the whole family experience of SM, including the twin boys who had recovered from SM. The family had previously been hospitalised for inpatient treatment, but at the time of the case study, two years on from treatment, the twins were reported to speak spontaneously. Two members of the original treatment team visited the family and conducted a semi-structured interview at their home. This study was judged to be of low quality, primarily due to a lack of transparency. There is a marked lack of reflexivity considering the impact on the findings of the researchers being part of the original treatment team, and of having just eaten a meal with the family prior to the interview.

Roe and Phil (2011) devised a questionnaire to explore the opinions and experiences of CYP with SM. Thirty participants aged 10 - 18 years old took part, drawn from the SMIRA membership database, along with their parents. The questionnaire used likert scales and open and closed questions to generate both qualitative and quantitative data, though the researchers state that the overall aim was qualitative. This paper was assessed to be of medium quality. It demonstrated good sensitivity to context, however, has limited coherence. The authors state that the research aimed to ‘provide a means by which the opinions and experiences of children with SM could be expressed’ (p. 8), and that parental views were also sought to give ‘validation by triangulation for certain aspects of the young person’s responses’ (p. 9). Arguably, gathering parental views to triangulate those of the CYP suggests some doubts on the validity of the CYP’s voices. With regards to the quantitative methods used, the questionnaire lacks reliability as it was generated for the research. An attempt to address validity has been made, with the ‘advice of others knowledgeable in the field’ (p. 9) being sought, and the questionnaires being piloted. There are however no further details outlining this piloting, lowering the study’s transparency.

Patterson (2011) conducted a high quality doctoral thesis exploring the personal constructs of six adolescents with SM. Anxiety and depression symptoms were measured, and tools from Personal Construct Theory (Kelly, 1955) were utilised to explore the participants constructs, with the hope that obstacles to change might be identified, and appropriate interventions informed. The study is the only identified literature to explore the use of personal construct tools with CYP with SM. It does however lack some coherence; as the aim was to explore the personal constructs of the participants, it is unclear why mental health assessments were used to measure anxiety and depression symptoms.

Omdal and Galloway (2007) used Raven’s Controlled Projection for Children (RCPC) with three participants ‘to record…the meaning and significance a child attaches to situations of everyday life’ (p. 207). This method includes a CYP drawing, whilst imagining and describing through written communication a series of events. The aim of the study was to illustrate ‘a medium in which communication with the selectively mute child is possible, and in which clinically useful data may be obtained’ (p. 206). This study was deemed to be of low quality. Of particular note is the lack of sensitivity to context, with minimal relevant literature identified. As a result, is it unclear what methods of interaction had previously been used in research with CYP with SM, and why the RCPC would be appropriate.

2.3.1.3 Common Themes Identified

The six papers outlined above all explore the voices and experiences of individuals with SM using different methodology and focusing on different age groups. Despite these obvious differences there are some similarities between the research findings.

A common theme in the findings is the negative emotions linked to being selectively mute. Walker and Tobell (2015) report a major theme of ‘isolation’, which is again echoed in Omdal’s (2007) findings. Omdal’s (2007) participants further expand on the loneliness they felt and discuss the ‘suicidal gestures’ they made. Feelings of loneliness and isolation are present not just in the literature with adults, but also with CYP, with Roe and Phil (2011) reporting that ‘left out’ and ‘lonely’ are key descriptive words used by CYP with regards to how they feel in social situations, and the twins in the study by Albrigsten et al. (2016) feeling they were ‘being ignored’. Other negative adjectives linked to being selectively mute include ‘distressing’, ‘uncomfortable’, ‘frustrating’, ‘inferior’, and ‘abnormal’ (Walker & Tobell, 2015). Patterson (2011) speculates from their findings that the adolescents in their study have low self-esteem, however, Roe and Phil (2011) report that feelings of low self-esteem were not commonly reported by their CYP participants. This is perhaps influenced by the researchers' methodologies, with Roe and Phil (2011) reporting explicit wording used by their participants in a questionnaire, and Patterson (2011) interpreting their participants’ constructs of themselves.

Several papers have common themes in the factors identified as causing, maintaining, and supporting recovery from SM. Omdal (2007) and Albrigsten et al. (2016) report commonalities in SM onset coinciding with trauma or bullying, and that having a new environment was important and beneficial in order for those with SM to recover. Omdal (2007), Albrigsten et al. (2016) and Walker and Tobell (2014) all report that those with SM felt that the behaviour was being reinforced by others around them, e.g., others expecting them not to speak, or the negative reactions of others if they did speak. Omdal (2007) and Patterson (2011) both report an element of choice for those with SM. For Omdal’s (2007) recovered participants, they retrospectively report that they began to recover from SM after making a conscious choice to do so. Patterson (2011) uses Personal Construct Theory (Kelly, 1955) tools to hypothesise that SM is a choice for CYP and is preferred to other options as it enables the most predictable environment and is a way of managing anxiety. This finding is directly in contrast with the finding by Roe and Phil (2011) whereby CYP with SM report by questionnaire that ‘I want to talk but can’t and don’t know why. It’s not a conscious choice’ (p.

26). Walker and Tobell's (2015) findings also dispute this, and report that participants display a desire and determination to speak and are frustrated that they are not able to. Notably, the finding that SM is not a choice is supported by the papers that have actively and directly sought the views of those who currently have SM. Of the papers that argue that SM recovery is a choice, the participants are considering this retrospectively (Omdal, 2007) or it is the researcher's interpretation of a projective measure (Patterson, 2011).

2.3.1.4 Summary of Literature Exploring Perspectives of Individuals with SM

Six of the papers identified in the systematic review explored the perspectives of individuals who currently or previously had SM. Two papers explored the perspectives of adults, and four explored the experiences of CYP. A variety of topics were explored in these papers, including the individual's perspectives and experiences of the causes, maintenance, and recovery from SM. The studies identify similar results with regards to the importance of the environment around a person with SM, with environmental factors felt to have the power to influence the cause, maintenance, and recovery from SM. A resounding similarity in the literature findings is the negative feelings associated with SM, with Omdal's (2007) adult participants describing the very real consequence on their mental health, and their resulting 'suicidal gestures'.

The literature as a whole is of mixed quality, with two papers judged to be high (Walker & Tobbel, 2015; Patterson, 2011), two papers medium (Omdal, 2007; Roe & Phil, 2011) and two papers of low quality (Albrigsten et al., 2016; Omdal & Galloway, 2008). Regularly lacking is commitment and rigour, and transparency and coherence of research, with unclear coding and analysis of qualitative data, as well as a lack of reflexivity (Omdal, 2007; Albrigsten et al., 2016; Omdal & Galloway, 2007; Roe & Phil, 2011).

There is notably a negative focus within the current literature exploring the perspectives of individuals with SM, with much emphasis put on the problems associated with SM. Whilst this is understandable, less attention has been paid to what is considered helpful for those with SM. Roe and Phil (2011) pay some attention to this, finding that CYP find family, friends, and school staff the most helpful in managing their SM. Omdal (2007) also considers what has helped their participants to recover from SM, however, their suggestion that SM is a conscious choice is directly at odds with findings by Walker and Tobell (2015) and Roe and Phil (2011) resulting in an unclear picture which needs to be further explored.

2.3.2 Literature Exploring Perspectives of Families

Three of the papers identified in the systematic search explored the experiences and perceptions of parents of CYP with SM. Roe and Phil (2011) and Albrigsten et al. (2016) have already been explored in the subsection above, as they also studied the voices of those with SM. In addition, a doctoral dissertation by Hoyne (2014) explored the perspectives and experiences of two parents in understanding, identifying, and supporting their child with SM.

In addition to exploring the views of twins who had recovered from SM, Albrigsten et al. (2016) included their parents in the interview. Whilst quotes from the parents are given throughout the paper, the questions originally asked by the researchers are not detailed, contributing to the lack of transparency of the study.

The research by Roe and Phil (2011) has already been noted as lacking coherence with regards to the study aims, and the purpose of gathering both CYP and parental views. The thoroughness of data collection, analysis and reporting is also affected by including both types of participants, due to inconsistent reporting of results for each participant group. For example, the researchers report that 53% of CYP felt that SM had affected their family. This topic was also explored with parents, however, no quantitative data is given for a parental view on this, as it has been for the CYP. Instead, some quotes are given which indicate that parents perceive that the CYP’s SM had a negative effect on their family. For example, ‘a lot of stress on us as parents’, ‘very worrying for us as a family’, and ‘tends to isolate the family’ (p. 23).

Finally, a doctoral dissertation by Hoyne (2014) aimed to 'inform the work of EPs and other professionals and individuals involved in cases of selective mutism by expanding the knowledge base and promoting awareness of the role key stakeholders can play in identifying, assessing and supporting children and young people' (p. 8). Semi-structured interviews with two parents were conducted, and the data analysed using thematic analysis. The questionnaire was piloted with a parent of a child with SM, and minor changes were made with the aim of putting parents at ease during the initial stages of the interview. This study was of high quality with excellent sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. It has particular impact and importance for being the only paper identified in the review which gains an in-depth qualitative understanding of the perspective of parents. It particularly highlights that having a child with SM can be felt by parents to have a negative impact on their skills and role as a parent.

2.3.2.1 Common Themes Identified

The research with parental participants is limited, and Hoyne (2014) notes that recruiting parental participants was difficult. Perhaps this is influenced by some of the common narrative emerging around how parents are impacted by their child having SM. Hoyne (2014) reports parents having negative feelings such as anger towards their child as a result of the SM, with Albrigsten et al. (2016) noting that the parents seemed helpless, exhausted, and desperate. This is further echoed in the quotes given by Roe and Phil (2011). This clearly links with the literature exploring the experiences of individuals with SM, which also identifies the negative feelings associated with the disorder. Additionally, the research by Hoyne (2014) and Albrigsten et al. (2016) both note that participants' children having SM impacted negatively on their skills and role as a parent. Participants described not understanding what was wrong, and not knowing how to help or 'what to do to make them talk' (Albrigsten et al., 2016, p. 8).

All three papers explore parental perceptions of professional input to a degree. Both Albrigsten et al. (2016) and Hoyne (2014) note positive experiences of professional input. Albrigsten et al. (2016) report that the parents feeling understood and their experiences validated made a difference to them. Hoyne

(2014) reports that professional input made parents feel empowered and informed. The paper by Roe and Phil (2011) asked CYP and their parents about their experiences of professionals. Those in the psychology world such as Clinical, Child and Educational Psychologists (EPs), Psychiatrists and Psychotherapists had mostly positive experiences reported, with 22 positive and 10 negative comments. The Child and Adolescent Mental Health Service (CAMHS), however, received less positive feedback, with 4 positive and 7 negative comments. Medical professionals such as SALTs, General Practitioners (GP's), Health Visitors, and Paediatricians received 26 positive and 7 negative comments, with SALT noted as receiving the most positive remarks. Educational professionals had 33 positive and 8 negative comments. Unfortunately, the parental and CYP data was not separated for this question, nor were further details given regarding what the professionals had done that had been positive or negative.

2.3.2.2 Summary of Literature Exploring Perspectives of Families

Parental views are notably absent in the SM literature, and as demonstrated in this literature review always appear in conjunction with others, e.g., individuals with SM and professionals. The negative impact of SM on parents and family life is a similar theme found across the research, and comparable negative wording is also found in the research focusing on individuals who have or have had SM.

There is no literature purely exploring the experiences of professional input, though all three papers identified in the review exploring parental perceptions did touch on this topic. In the two papers where semi-structured interviews were held (Hoyne, 2014; Albrigsten et al., 2016) positive effects of professional input were reported. However, as already noted, of particular concern here is the lack of reflexivity in Albrigsten et al.'s (2016) study. There is a high possibility of demand characteristics, with the participants possibly wanting to please the researchers with positive feedback, given that the researchers had been part of the family's treatment team. Roe and Phil (2011) report much more mixed experiences of professional input, however, sadly the results are not differentiated between the experiences of parents and CYP, and no further details are given as to what constitutes a negative or positive experience with a professional.

The literature as a whole is of mixed quality, with the paper by Albrigsten et al. (2016) deemed to be of low quality, Roe and Phil (2011) of medium quality, and Hoyne (2014) of high quality. As both Albrigsten et al. (2016) and Roe and Phil (2011) were previously mentioned in section 2.3.1, common areas of concern with regards to quality are the commitment and rigour, and transparency and coherence of research.

2.3.3 Literature Exploring Perspectives of Professionals

Five papers were identified as exploring the perspectives of professionals who work with CYP with SM; four of these are doctoral theses, and one is a published and peer reviewed journal article. Two of these focus solely on teachers (Ramos, 2018; Davidson, 2012), with Hoyne (2014) further including teacher participants. Three explore the experiences of psychologists; Ellis (2015) focuses on school psychologists (SPs) in the United States of America (USA), Frazier and Howard (2020) include school counsellors, and Hoyne (2014) additionally includes EPs as participants. Finally, two papers include SALT; Frazier and Howard (2020) also explore the perceptions of Speech-Language Pathologists (SLP) in the USA, with Hoyne (2014) also including SALT in the UK.

Ramos' (2018) doctoral thesis explores the experiences, thoughts, feelings and perspectives of five Early Years teachers working with SM children. Semi-structured interviews were conducted and analysed using IPA. This study is of high quality and demonstrated excellent sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. From it we learn of the frustrations of teaching a child with SM, and the importance of a support system for the teacher both from adults and other children in their classroom.

Davidson's (2012) doctoral thesis explores the knowledge and experiences of teachers working with CYP with SM in New Jersey, USA. A semi-structured interview was conducted by telephone with six teachers, and both qualitative and quantitative data created. This study is of medium quality, with good sensitivity to context evidenced with a clear literature review and awareness of the sociocultural setting of the study. However, the analysis used for the qualitative data is unclear, impacting on its commitment and rigour and transparency and coherence. Further impacting transparency and coherence is the scarcity of interview quotes given to support the analysis, as well as no discussion of reflexivity and the researchers own impact. There is low reliability; the questionnaire was devised for the study, with no detail regarding if other similar tools were drawn from in its creation.

A doctoral thesis by Ellis (2015) surveyed SPs experiences, knowledge, and perceptions of SM. A 35 item survey was filled out online by 165 participants, who were school psychologists practising in California, USA. The study is key for highlighting the lack of confidence and training that school psychologists felt they had for SM casework. Care must be taken when generalising this to a UK population however, due to the different training experiences and requirements needed to qualify. This study is of medium quality, with good sensitivity to context. The data collection methods are clear, resulting in a degree of transparency, though no reflexivity. Considerations have been given to validity, with the questionnaire presented originally to an SM expert and a focus group. The qualitative analysis and generation of themes is however unclear, affecting both commitment and rigour to the methods used, and transparency and coherence of data analysis and the narrative generated.

Frazier and Howard (2020) conducted a survey with School Counsellors and SLPs as participants. A 10 item online survey was created for the study, with a mix of qualitative and quantitative data gathered. The researchers note that qualitative responses were analysed using grounded theory. The research showed a high level of agreement among professionals as to anxiety being the common characteristic of SM, and as to treatment and intervention methods. This study was deemed to be of low quality, with commitment and rigour, transparency and coherence, and impact and importance particularly lacking. The use of grounded theory is unclear, and therefore lacking commitment and rigour, and transparency. Furthermore, as the researchers aim was to ‘obtain an understanding of the lived experiences and perception of public school SLPs and counsellors when treating students with SM’ (p. 1049) it is unclear why a quantitative analysis appeared to be the focus of the research, with little opportunity for qualitative responses across the questionnaire. As a result, there is a lack of coherence in the study.

In addition to exploring parental experiences, Hoyne (2014) explored the perspectives and experiences of three teachers, nine EPs, and five SALTs in understanding, identifying, and supporting CYP with SM. As already outlined, this study is of high quality with excellent sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. Of particular note in the findings are the expressed negative feelings and low confidence in relation to SM casework, and the systemic barriers felt to be influencing the work of professionals. For example, teachers felt unsupported by their school, EPs perceived time barriers to working with SM CYP, and SALTs felt frustrated with schools and parents.

2.3.3.1 Common Themes Identified

A number of the identified studies in this literature review incorporated numerous professionals as participants. We can see clear themes emerging from the literature with regards to professionals' experiences and perspectives of working with SM casework.

A commonly occurring theme is the negative emotions professionals feel because of SM casework. All three studies of teachers (Ramos, 2018; Davidson, 2012; Hoyne, 2014) report 'frustrated' as a common word used by participants, as does Hoyne (2014) for EPs and for SALTs. A few of the additional negative feelings described by participants include 'isolation' (Ramos, 2018), 'stressed', 'anxious', and 'guilty' (Hoyne, 2014). This theme has further been found in the literature exploring the perspectives and experiences of both individuals with SM, and their families. In contrast to this, Ramos (2018) also notes that teachers reported teaching a child with SM could be a rewarding experience and resulted at times in a sense of achievement for the participant. It is however noted that this was directly linked to the child beginning to start talking through what was felt to be the teacher's support and assistance.

Linking with the identified theme of negative emotions, there is a recurring theme in the literature of professionals feeling that they lack competence in supporting SM cases. Davidson (2012) and Ramos (2018) report that teachers feared they may worsen the SM child's difficulties. The teachers participating in Hoyne's (2014) study similarly report that they felt less confident and deskilled in their teaching skills for SM CYP. EPs and SALT's in Hoyne's (2018) study noted that SM cases were challenging and had a negative impact on their professional confidence. This is supported by Ellis' (2018) survey of SPs in the USA, 51% of whom lacked confidence in assessing a CYP with SM, and 90% of whom felt they had not been adequately prepared by their training programme. As a result of this perceived lack of competence, a need for professional development is highlighted. Teachers report a need for input and training from external professionals, such as psychologists (Ramos, 2018; Davidson, 2012). 98% of SPs felt they would benefit from further training (Ellis, 2015). This is supported by Hoyne's (2014) finding that EPs want SM to be included on the initial professional training course. Hoyne reports that awareness of SM needs to be increased in schools, as well as an awareness of which professionals can offer support. Joint working is advocated for to ensure best practise, as well as more resources, and more time for SM casework.

There is a difference among professionals as to what causes and maintains SM. Some professionals such as EPs and SPs (Ellis, 2015; Hoyne, 2014) and SALTs and SLPs (Hoyne, 2014; Frazier & Howard, 2020) believe that SM is rooted in anxiety, with several also linking it to trauma. The view across professionals is not however consistent, with a fraction of teachers, EPs, and SALT's identifying SM as being a choice (Ramos, 2018; Davidson, 2012; Hoyne, 2014) for reasons such as power and control or seeking attention. This may be linked to the changing diagnosis of SM, with it first being explicitly linked to anxiety in the DSM V in 2013 (APA, 2013).

2.3.3.2 Summary of Literature Exploring Perspectives of Professionals

Five of the papers identified in the systematic review explore the experiences and perspectives of a range of professionals who work with those with SM. The research occurs in the UK and USA, and the professionals participating include speech and language professionals, educational and school psychologists and counsellors, and schoolteachers. The literature demonstrates inconsistencies both across and within groups of professionals with regards to the factors that are believed to cause and maintain SM. Whilst the vast majority of professionals linked the cause to anxiety, a number of professionals believed it to be a choice or caused by trauma. There is much similarity in professionals feeling negatively as a result of SM casework and feeling deskilled and lacking competence. There is consensus among the research regarding professionals believing that they need further input and training in order to support SM casework.

The literature as a whole is of mixed quality, with the doctoral dissertations by Hoyne (2014) and Ramos (2018) deemed to be of high quality, Davidson (2012) and Ellis (2015) of medium quality, and Frazier and Howard (2020) of low quality. Across the literature a common point lowering quality of research is the coherence between the research questions, researcher's philosophy, and method of data collection and analysis used.

2.4 Summary

The literature exploring the perspectives and experiences of stakeholders in SM is emerging, with those with SM, their families, and various professionals currently evident in the research. Literature in this area currently varies in focus of perspective, with some research emphasising knowledge and understanding of SM and its treatments, and others on experiences and feelings.

A common finding across the literature is the apparent debate regarding whether SM is or is not a choice. Patterson (2011) interprets their adolescent participants' data to indicate that SM may be a choice. Omdal's (2007) adult participants retrospectively indicate that they chose to start speaking, whereas Roe and Phil's

(2011) and Walker and Tobell's (2015) participants currently living with SM indicate that it is not a choice. This is further reflected in studies with professionals, whereby teachers, EPs, and SALTs all identified that SM is routed in anxiety or other needs, but several in each professional group also identified that SM is a choice (Ramos, 2018; Davidson, 2012; Hoyne, 2014). This perhaps reflects the changing discourse around SM, also mentioned in Chapter 1, with it only being recognised as an anxiety disorder in the DSM V in 2013 (APA, 2013).

The literature also exposes a range of negative feelings invoked by SM across stakeholders. For those who have SM themselves, feelings of loneliness and isolation were particularly common. Parents reported feelings of anger (Hoyne, 2014), exhaustion, desperation and helplessness (Albrigsten et al., 2016) and stress, isolation and worry (Roe & Phil, 2011). Professionals too note negative feelings both towards SM case work, and to how it affects their confidence as a professional. Feelings of frustration were reported by teachers (Ramos, 2018; Davidson, 2012; Hoyne, 2014), EPs and SALT's (Hoyne, 2014). A negative impact on professional confidence was apparent in studies with teachers (Hoyne, 2014; Davidson, 2012), SPs and EPs (Hoyne, 2014; Ellis, 2018) and SALTs (Hoyne, 2014). Again, this may be a reflection of the changing discourse around SM, as well its relative rarity, with a prevalence rate of 1 in 140 children in the UK (NHS, 2016).

Research in this area faces challenges, including the difficulty of gaining the views of those with SM, given the nature of the disorder. As a result of this some researchers have understandably opted for closed and multiple-choice questions (Roe & Phil, 2011), and some for projective testing methods (Patterson, 2011; Omdal & Galloway, 2007). However, the validity of these measures in gathering the experiences, voices, and perspectives of those being studied must be questioned.

In addition, nearly all papers included in the review analyse data qualitatively as a result of data gathered from open questions, semi-structured interviews, and projective testing. However, the quality of this analysis is questionable as the data analysis process is not clearly stated for some papers (Roe & Phil, 2011;

Ellis, 2015; Davidson, 2012; Frazier & Howard, 2020; Ellis, 2015; Albrigsten et al., 2016; Omdal, 2007; Omdal & Galloway, 2007). Furthermore, there is a lack of reflexivity in the literature, leaving the qualitative data open to researcher bias and influence in the collection and analysis.

2.5 Next Steps

Six of the 11 papers reviewed in this chapter have been completed internationally in countries such as Norway and the USA. Whilst including international research has further enriched this literature review, there may be differences in the context in which SM is understood, supported, and talked about in different countries. As a result, further research exploring the experiences and perspectives of SM stakeholders is greatly needed, both in the UK, as well as across the world.

Additionally, further research is needed to explore the experiences of CYP with SM who are currently in a school setting. Such research could explore their experiences of the setting and what support they find beneficial. Exploring the voices of those who have recovered from SM would also be valuable, as they may be able to provide useful insights into what enabled this recovery. As Walker and Tobell (2015) state there is a ‘need to progress toward a co-constructed awareness of SM by incorporating the voices of sufferers’ (p. 457).

Research has begun to explore the perspectives and experiences of professionals involved in SM. However, the range of professionals has so far been limited to teachers, psychologists and counsellors who work in schools, and speech and language professionals. The research by Roe and Phil (2011) noted a wide range of professionals who had supported CYP with SM, including –

- Psychological professionals – Clinical Psychologists, Child and Educational Psychologists, Psychiatrists and Psychotherapists.
- Medical professionals - SALTs, GPs, Health Visitors, Paediatricians, Occupational Therapists (OTs), School Doctors and Nurses.
- Educational professionals - Teachers, Special Educational Needs Coordinators (SENCos), and Teaching Assistants (TAs).

There is clearly a wide range of professionals who support those with SM and who have not yet been included in research exploring their experiences and perspectives.

Parental perspectives were evident in three studies found in this systematic literature review. Interestingly, parents were always included in conjunction with an additional participant group, such as with CYP with SM (Roe & Phil, 2011; Albrigsten et al., 2016) or professionals (Hoyne, 2014). The current study is unique in being the first to focus solely on the perceptions and experiences of parents.

The case study by Albrigsten et al. (2016) identified the importance of the parents being 'understood and validated in their experiences' by the professionals supporting them. The study by Hoyne (2014) reported that parents felt empowered and supported by professionals, though did not elaborate on what professional input resulted in this. Similarly, Roe and Phil (2011) reported descriptive statistics of how CYP and parents felt about professionals they had received support from, however, did not go into further detail about what input had been perceived positively or negatively. This research aimed to build on the current literature exploring parental perceptions of professional input. It provides new information as to what it is that parents find helpful and unhelpful from professionals, what they envisage ideal support as being, and how they feel that the input and support they have received has influenced theirs and their child's experiences of SM.

As a result of the researcher's belief in the importance of collaboration between different systems, this research used Bronfenbrenner's (1979) eco-systemic theory of development as an executive framework. This is in keeping with Hoyne's (2014) study and enabled the consideration of the interplay between professionals in the exosystem, parents in the microsystem, and the individual CYP at the centre of these layers, from the perspective of parents. The eco-systemic model acknowledges the role of different people in shaping the CYP's experiences. The purpose of this exploratory research is to consider the interaction between parents and relevant professionals from a parental perspective, in particular the support that parents perceive as being unhelpful, being beneficial, what additional support they would have liked to have had, and how this professional input and support has influenced theirs and their child's experience of SM.

3. Methodology and Data Collection

3.1 Chapter Overview

The previous chapter reviewed the literature on the perspectives and experiences of key stakeholders in SM. This included individuals who had or currently have SM, their families, and professionals such as SALTs, EPs, and teachers. The chapter identified gaps in the research, and how this study aims to address some of those identified gaps.

This chapter will detail the research methodology and data collection for this study. This includes the researcher's philosophical position, and research questions and design. This is followed by the specific methods used to conduct this study, including details of participant recruitment and participant inclusion and exclusion criteria. The procedure for the pilot and main study are described, and the interview schedule used is given. The data analysis is defined and outlined, with ethical considerations and research quality discussed.

3.2 Philosophical Position

This section is written in the first person. A paradigm has historically been defined in a variety of ways, and Guba (1990, p.17) defines it as "a basic set of beliefs that guides action". Within the context of research, the researcher's paradigm guides disciplined inquiry. As the aim of this research is to seek to understand a phenomenon through the point of view of the participants, my research paradigm is constructivist. This means that I am not focusing on finding a universal truth, but on identifying patterns in the experiences and perceptions of the participants with regards to professional involvement for their child with selective mutism, and their preferred support.

Within a paradigm there are three considerations (Guba, 1990, p.18):

1) 'Ontology: What is the nature of the "knowable"? Or, what is the nature of "reality"?
2) Epistemological: What is the nature of the relationship between the knower (the inquirer) and the known (or knowable)?

3) Methodological: How should the inquirer go about finding out knowledge?’

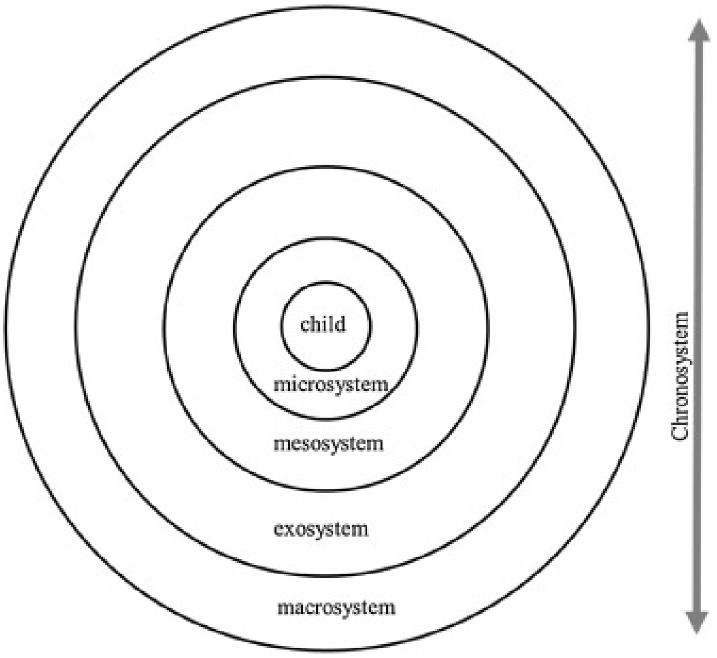
In keeping with my constructivist paradigm, my ontology is relativist, as I believe that reality is constructed in the mind of the individual, and that there are multiple psychological realities which vary between individuals and are based on experience and social construction (Guba, 1990). I therefore accept that the reality of each participant and their experiences with regards to SM will differ. My epistemology is subjectivist, as I believe that meaning is the product of interaction between the inquirer and the inquired into (Guba, 1990). The findings later discussed in Chapter 4 are therefore the individual constructions of each participant, influenced by factors such as their culture, and previous experiences of SM and with professionals. Finally, my methodology is hermeneutic, which focuses on understanding and interpreting data within its socio-cultural context. This approach views meaning as being hidden and needing to made clear. This was achieved through reflection and interaction between the researcher and participant (Sciarra, 1999).

3.3 Theoretical Stance

This research used Bronfenbrenner’s eco-systemic model (1979) as an overarching executive theoretical framework. The use of this theoretical model is not embedded in the current SM literature, with research by Hoyne (2014) being the only identified paper in the literature review to have utilised it. Within this model the child is regarded as being nested at the centre of layers of different environments, likened by Bronfenbrenner to a set of Russian dolls (see figure 1). These environments interact together to create the context from which the child develops.

Figure 1

Diagrammatic illustration of Bronfenbrenner's eco-systemic model (1979). Taken from Bailey & Im-Bolter (2018)



Bronfenbrenner (1979) also describes within his theory the notion of a dyad; a two-person system which forms when 'two persons pay attention to or participate in one another's activities' (p. 56). He describes the dyad as a developmental system, and that 'the capacity of a dyad to function effectively as a context of development depends on the existence and nature of other dyadic relationships with third parties' (p. 77). This research explores the interaction between professionals and parents of CYP with SM, and how parents perceive that this interaction has impacted upon them and their child. In doing so it draws from Bronfenbrenner's belief of the influence of interacting environments on the development of the child. Furthermore, this research contemplates how the third party professionals influence the dyad of parent and child. This directly draws from Bronfenbrenner's reflection of considering 'the particular ways in which a third party can enhance or impair the capacity of a dyad to perform its developmental functions' (p. 80).

3.4 Research Questions

The following questions were answered in this research:

1. What are the experiences parents have had of professional involvement for their child with selective mutism, and how do they feel that this has influenced theirs and their child's experience of selective mutism?
2. What support from professionals would the parents of children with selective mutism like to have?

These questions explored the impact and interaction between the different systems and were generated based on the gaps within the literature, as explored during the previous Literature Review chapter.

3.5 Design

This research is exploratory and seeks to enhance understanding about something that little is known about. This is due to the current paucity of research into parental experiences, as highlighted in the literature review. As such it follows a qualitative design using semi-structured interviews to gain insight into parental experiences and perceptions of professional support in SM, what support would be considered ideal, and how experiences with professionals have influenced theirs and their child's experience of SM. Data was analysed using thematic analysis, in order to identify patterns in the experiences and perceptions of the participants.

3.6 Method

This section details participant recruitment and participant inclusion and exclusion criteria. The procedures for the pilot and main study are described, and the interview schedule used is given.

3.6.1 Participants

3.6.1.1 Recruitment

Eight parents were recruited nationally. Participants were recruited by placing a recruitment poster on the SMIRA Facebook page (appendix 4) following approval from SMIRA to do so (appendix 5). In addition, two LA Principal Educational Psychologists (PEPs) were contacted directly by the researcher and asked to circulate the poster; this included the PEP in the LA where the researcher was a Trainee Educational Psychologist (TEP) on placement, and the LA where they had previously worked as an AEP. The poster was then made available to all LA PEPs by being placed on the National Association of Principal Educational Psychologists (NAPEP) forum. Finally, the recruitment poster was shared with other University of East London (UEL) TEPs for circulation in their placement LAs. Please see appendix 6 for a recruitment timeline.

It was originally planned that 16 parents would be recruited. This number of participants was chosen in accordance with Braun and Clarke's (2013) recommended number of 10-20 participants for a 'medium project' such as a Professional Doctorate thesis. However, this was not possible due to the time limited nature of the project, and amount of participants who volunteered and met the inclusion criteria for the study.

For the pilot study, one parent was recruited through the LA the researcher was placed in as a TEP. The purpose of the pilot study was to consider if the planned interview schedule was appropriate, from the perspective of a parent with a CYP with SM.

This study was conducted at a time when the international Coronavirus Disease (COVID-19) pandemic had significantly altered the lifestyle and freedoms of residents of the UK. As a result of this the study was planned and run online on Microsoft Teams. This was due to the possibility of social distancing restrictions resulting in face-to-face interviews not being possible. Positively, it also opened up the research to be UK-wide. A national, rather than a local, sample was felt to be appropriate due to the low incidence rate of SM, and therefore the anticipated difficulty of participant recruitment at a local level.

3.6.1.2 Inclusion and Exclusion Criteria

Inclusion and exclusion criteria, outlined in table 4, were utilised for participant recruitment.

Table 4

Participant Inclusion and Exclusion Criteria for the Study

Inclusion Criteria	Exclusion Criteria
Parent of a child in key stage (KS) 3 or 4.	The individual is not a parent of a CYP with SM who is in KS 3 or 4.
The parent must have spoken with a professional about the SM difficulties.	There has been no professional involvement to date.
The parent and child must be residents of the UK.	The child and parent are not residents of the UK.
Child must present with SM symptoms, as outlined in the DSM V (APA, 2013). The child may not necessarily present with SM currently but will be in KS 3 or 4 and have presented with SM whilst in these key stages. The child must meet the following DSM V diagnostic criteria - A. Consistent failure to speak in specific social situations (in which there is an expectation for speaking, e.g. at school) despite speaking in other situations. B. The disturbance interferes with educational or occupational achievement or with social communication. C. The duration of the disturbance is at least one month and is not limited to the first month of school. D. The failure to speak is not due to a lack of knowledge of, or comfort with,	Child does not currently present with SM symptoms or has not presented with SM symptoms during KS 3 or 4. SM symptoms include the following DSM V diagnostic criteria - A. Consistent failure to speak in specific social situations (in which there is an expectation for speaking, e.g. at school) despite speaking in other situations. B. The disturbance interferes with educational or occupational achievement or with social communication. C. The duration of the disturbance is at least one month and is not limited to the first month of school. D. The failure to speak is not due to a lack of knowledge of, or comfort with, the spoken language required in the social situation. E. The disturbance cannot be better

the spoken language required in the social situation. E. The disturbance cannot be better accounted for by a Communication Disorder (e.g. stuttering) and does not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder.	accounted for by a Communication Disorder (e.g. stuttering) and does not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder.

The purpose of limiting the research participants to currently having a child in KS 3 or 4 was to ensure a level of consistency in life experiences. For example, the parents were likely to all have experienced their child transitioning between primary and secondary school. Similarity in such life experiences was deemed to be important to the research in terms of increasing the possibility that parents would have encountered similar professionals to other participating parents. For example, each child would likely have changed from one class teacher in primary school, to being taught by a larger number of different teachers in secondary school. The parents of CYP who were currently in KS 3 and 4 and had recovered from SM could also participate. This was in order to not rule out CYP with SM who may have recovered following appropriate support and intervention, which may provide particular insight into positive experiences of professional input and support. A diagnosis was not essential due to potential difficulty with diagnosing. Instead, the researcher verbally discussed the DSM V diagnostic criteria (outlined in table 4 above) with parents to check their child presented with traits of SM. This did not give a diagnosis of SM. There was no available information as to whether DSM V or ICD-11 were most frequently used in the UK for diagnosis of SM. The DSM V criteria was selected due to its similarity to the ‘diagnosis guidelines’ section of the NHS webpage regarding SM (https://www.nhs.uk/mental-health/conditions/selective-mutism/).

As this study explores parents’ perceptions of professional input, it was part of the inclusion criteria that the participant has spoken to at least one professional about their child’s SM. For this study, ‘professional’ was defined as ‘relating to work that needs special training or education’ (Cambridge University Press, n.d).

Finally, the criteria of the parent and their child being residents of the UK was included due to the perceived potential of variability internationally. This could include for example cultural differences regarding the beliefs surrounding SM, and differences with professionals available to give input and support for SM.

The inclusion and exclusion criteria for the pilot study was almost identical to the main study. The only change was that the participant be a parent of a child in KS 2, as opposed to KS 3 or 4. This was in order to still gain the views of a parent of a CYP with SM, but not to lose a potential main study participant. This was driven by concerns with recruiting the number of participants desired for the main study, as Hoyne (2014) noted that recruiting parents was particularly difficult.

3.6.2 Pilot Study Procedure

The researcher initially contacted EPs in two LAs they had worked in (as an AEP and TEP). The EPs were invited to identify any primary schools that may currently have SM CYP in them. Two EPs each suggested a school and placed the researcher in contact with the SENCo of the school. The researcher shared the pilot study invitation letter (appendix 7) with the SENCos, who then shared this with parents of SM CYP in their school. Following a parent giving verbal consent to participate, the SENCo copied the researcher and the parent into an email to begin communication. The researcher then emailed the participating parent the pilot study consent form (appendix 8) and the pilot study invitation letter again.

Following completion and return of the completed consent form, a Microsoft Teams meeting was arranged, and the planned interview schedule for discussion emailed to the participant.

The purpose of the pilot study was to consider if the planned interview schedule was appropriate, from the perspective of a parent of a CYP with SM. Prior to the commencement of the interview the researcher emailed the following proposed interview schedule to the pilot study participant (original interview schedule also provided in appendix 9):

1. How did you first become aware that your child was presenting with selective mutism?
   (Prompts – can you tell me more about…? Did anyone else mention SM to you? What did you notice in your child? How did you feel about that? What impact did that have on you/your child/his/her schooling/your family?)

2. What input and support have you received from professionals with regards to your child’s SM?
   (Prompts – did you have any input from your GP/Paediatrician/SALT/EP/school staff? Anyone else, e.g. voluntary organisations? What was involved in that input? What was said in that conversation? What support was offered? How did you feel about that? What impact did that have on you/your child/your family?)

3. Thinking back over the support you have/your child has received, what would you pick out as being particularly helpful and supportive, and why?
   (Prompts – you mentioned that X was helpful before….can you tell me more about that? How did you feel about that? What was it about that support that made it helpful? What impact did it have on you/your child/your family?)

4. Thinking back over the support you have/your child has received, what would you pick out as being particularly unhelpful and unsupportive, and why?
   (Prompts - you mentioned that X was unhelpful before….can you tell me more about that? How did you feel about that? What was it about that support that made it unhelpful? What impact did it have on you/your child/your family?)

5. What would support ideally look like for you/your child, and why?

(Prompts – is there support from a particular professional that you would like more of? What do you hope that further support from that professional could give you and your child? Why would support like X be helpful to you/your child/your family?)

The interview lasted 40 minutes, during which time the researcher wrote key notes of the interview (appendix 10). Following the interview, the researcher emailed the pilot participant a debrief letter (appendix 11), the key notes made during the interview, and the following revised interview schedule (also provided in appendix 12):

1. When and how did you first become aware that your child has traits of selective mutism?
   (Prompts – can you tell me more about…? Did anyone else mention SM to you? How did you feel about that? What impact did that have on you/your child/your family?)

2. At what point did you seek professional support about the SM traits?
   (Prompts – did you seek it out yourself or were you asked to by someone else, e.g. your child's education setting? Did someone else suggest you seek out support, e.g. paediatrician recommending you speak to your child's school?

3. Which professionals have you received input from for your child's SM? What support have you received?
   (Prompts – did you have any input from your GP/Paediatrician/SALT/EP/school staff? What was involved in that input? What was said in that conversation/correspondence? What support was offered? How did you feel about that? What impact did that have on you/your child/your family?)

4. Thinking back over the support you have received, what would you pick out as being particularly helpful and supportive, and why?

(Prompts – you mentioned that X was helpful before….can you tell me more about that? How did you feel about that? What was it about that support that made it helpful? What impact did it have on you/your child/your family?)

5. Thinking back over the support you have received, what would you pick out as being particularly unhelpful and unsupportive, and why?
   (Prompts - you mentioned that X was unhelpful before….can you tell me more about that? How did you feel about that? What was it about that support that made it unhelpful? What impact did it have on you/your child/your family?)

6. What would support ideally look like for you, and why?
   (Prompts – is there support from a particular professional that you would like more of? What do you hope that further support from that professional could give you and your child? Why would support like X be helpful to you/your child/your family? Could you name 2 key things about how you would like the support from professionals to look in the future? Could you name 2 key things about how you would like support for SM to look in the future?

The purpose of sending on the revised interview schedule and key notes was to ensure that the researcher had accurately understood the pilot participant and the changes they had suggested.

Changes made to the interview schedule included –

1) Changing question 1 from ‘How did you first become aware that your child was struggling with selective mutism?’ to ‘When and how did you first become aware that your child has traits of selective mutism?’ This was in order to remove the negative phrasing of ‘struggling’, and including ‘how’ was to promote and encourage an element of participants telling the story of their child’s SM.
2) Adding an additional question of ‘At which point did you seek professional support about the SM traits?’ This was to promote

storytelling and encourage participants to consider when the SM began to hold their child back.

3) Inclusion of ‘correspondence’ within the prompts of question 3. This was due to the pilot study participant reporting that input and support from professionals can occur through written communication, rather than during a conversation.
4) Changes to the prompts of question 6 due to the pilot study participant suggesting that it may be too large an open question. Therefore, the question began open, with the possibility of narrowing it if participants struggle to answer the open question.

Whilst the pilot study participant could not foresee any distress being caused by the questions, they did suggest that consideration should be given to the terminology ‘professionals’ and to ensuring that all participants have a similar understanding of this term. The example given was that some participants may think that this applies only to mental health professionals. Similarly, ‘traits’ was suggested to be a word which may need further description. Following on from this, the participant suggested creating a pre-interview checklist of what SM traits the parent’s child has, and of which professionals they have had input from. This was ultimately decided against as the SM traits shown by a child or young person was not relevant information for the research questions, and therefore, gathering data on this was not felt to be justified. The creation of a list of professionals was also not felt to be appropriate as this could limit the scope of professionals discussed to only those deemed appropriate by the researcher. Finally, it was felt that the completion of pre-checklists would be an additional layer of pressure and requirement on participants, which may result in a lower participant recruitment rate.

3.6.3 Main Study Procedure

The researcher initially approached SMIRA in March 2021, enquiring if it would be possible to recruit participants through the charity. Following confirmation of this from the SMIRA chair, the researcher placed a recruitment poster on the SMIRA Facebook page (appendix 4). Parents interested in participating then emailed the researcher at the given university email address, whereupon they received a reply including the participant invitation letter (appendix 13) and consent form (appendix 14). A number of parents contacted the researcher through Facebook messenger and were directed to email the researcher at their university address, or alternatively provide their email via messenger for the researcher to send them the relevant documents from their university email account. A copy of the semi-structured interview schedule was also attached in this initial email for full transparency (appendix 12).

An initial meet and greet was organised on Microsoft Teams between the participant and researcher. The purpose of the meet and greet was to ensure all aspects of the consent form were understood by participants, and to ensure participants met the inclusion criteria. It also served as an opportunity for participants to become more familiar with Microsoft Teams. During this meeting participants chose their pseudonym, and the terminology of 'professional' was clarified as 'a person who has a type of job that needs a high level of education and training' (Cambridge University Press, n.d.). 'Traits' was clarified as relating to the DSM 5 diagnostic criteria. Following the receipt of a signed consent form, an interview was scheduled on Microsoft Teams.

Semi-structured interviews took place virtually with the participant and researcher present. This included set questions, as well as additional prompts that could be used, with qualitative data being generated. The interviews lasted between 50 and 150 minutes, and at the start of the interview, participants were invited to choose how they would like the interview to be recorded (audio or video). The researcher transcribed the recordings within three weeks of the interviews. At the point of transcription, all identifying data was removed and participants were referred to by a pseudonym of their choosing. Other identifying details for individuals discussed during the interview were anonymised according to their role, e.g., names were changed to be 'child', 'paediatrician' etc. The recordings and their transcriptions were stored securely on the UEL One Drive and backed up to UEL Home Drive.

Following interviews participants were emailed a debrief letter (appendix 15).

3.6.4 Interview Schedule

Prior to the commencement of interviews, an interview schedule was created. Following the pilot study, the schedule was edited for reasons stated previously in section 3.6.2. Please refer to appendix 12 for the final revised interview schedule.

The purpose of the interview schedule was to support the exploration of parental perceptions of professionals, what support has been unhelpful, what has been beneficial, what support parents would ideally like, and how experiences with professionals have influenced theirs and their child's experience of SM. The schedule provided a structure for asking open ended questions in relation to these aims, whilst allowing flexibility to adapt questions and probe areas of further interest as they emerged during the interview (Robson, 2002).

3.7 Data Analysis

Following transcription, the data was analysed using thematic analysis. Thematic analysis aims to identify, analyse, and report rich and detailed patterns within data (Braun & Clarke, 2006). The analysis followed Braun and Clarke's (2006) six phases of analysis, presented in section 3.7.2. The use of this framework supported rigour, as did consideration of Braun and Clarke's (2006) questions to inform thematic analysis, presented in section 3.7.3.

Following transcription of interviews, the data was coded. The trustworthiness of the data analysis was enhanced by the researcher's University Director of Studies checking the initial coding for an interview.

An inductive approach was followed with the data being coded without trying to fit it into the researcher's theoretical interest or analytic preconceptions (Braun & Clarke, 2006). Therefore, the data was not coded into Bronfenbrenner's (1979) layers of systems. It is however noted that the analysis occurred within the framework of the researcher's constructivist paradigm.

3.7.1 Rationale for Selecting Thematic Analysis

A variety of other methods were considered but ultimately deemed less appropriate for this research. For example, quantitative methods were rejected as they are not in line with the researcher's constructivist paradigm, and include testing hypotheses, rather than exploring participants experiences. IPA was not deemed appropriate due to its focus on the particular and unique details of each interview, as well as across interviews (Braun & Clarke, 2020). Additionally, IPA typically uses small sample sizes, and this study strove for a larger sample size, in order to build on the small sample sizes in previous literature.

Thematic analysis was ultimately chosen as it is able to support a relativist ontological view. It does not impose or presuppose an objective reality but allows the researcher to explore the subjective realities of individuals (Gilham, 2000). It is also not linked to one specific theory, and therefore is a flexible tool which gives a rich account of the data (Braun & Clarke, 2006). It allows for the identification of themes across data and can locate personal experiences within the wider socio-cultural contexts (Braun & Clarke, 2020).

3.7.2 Braun and Clarke's Six Phases of Analysis

Braun and Clarke (2006) note that thematic analysis is widely used but poorly defined. As a result of this they have created a clear six phase guide to analysis (table 5), which has been used for this research in order to enhance the trustworthiness of the analysis. It is acknowledged that this is a guide rather than strict rules, and that these six stages are recursive rather than linear (Braun & Clarke, 2006). The following exploration of the six phases of analysis is reported in first-person.

Table 5

Braun and Clarke's Six Phases of Thematic Analysis (2006)

Phase	Description of the process
1. Familiarising yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systemic 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.

3.7.2.1 Stage 1: Familiarising Yourself with the Data

I transcribed my own data and therefore following transcription I arrived at the analysis already familiar with the data to an extent. As Braun and Clarke (2006) propose, when the researcher transcribes their own data (rather than commissioning transcription externally) they become immersed and have a more thorough understanding of the data. I further immersed myself in the data through repeated listening to the interviews and reading of the transcripts in order to become familiar with the depth and breadth of the content (Braun & Clarke, 2006).

As recommended by Braun and Clarke (2006), I read the transcripts of all interviews before I began coding to avoid the identification of patterns with an incomplete data set. This lessened the possibility that the analysis of later transcripts would be viewed through the lense of codes and themes already identified earlier.

3.7.2.2 Stage 2: Generating Initial Codes

Following stage 1 I began to produce initial codes. A code is described by Braun and Clarke (2006) as identifying ‘a feature of the data…that appears interesting to the analyst’ (p. 12). They are ‘the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon’ (Boyatzis, 1998, p. 63). As my analysis was inductive, it was led by the data. The entire data set was worked through, and emerging bases for repeated patterns (themes) were identified (Braun & Clarke, 2006). The initial codes generated for a single interview were checked by my University Director of Studies. Please see appendix 16 for an example page of coding and initial identification of themes.

3.7.2.3 Stage 3: Searching for Themes

Following this initial coding of data, I began to sort the codes into possible themes. I created an initial thematic map in order to consider the ‘relationship between codes, between themes, and between different levels of themes’ (Braun & Clarke, 2006; p. 89). By the end of this phase I had a collection of candidate themes and sub themes, linked to coded data extracts. I understood a theme to capture ‘something important about the data in relation to the research questions’ and to represent ‘some level of patterned response of meaning within the data set’ (Braun & Clarke, 2006; p. 90).

3.7.2.4 Stage 4: Reviewing Themes

I reviewed the themes I had collected so far as candidate themes, considering if any did not have the data to support them, the data was too diverse, or if themes needed to be merged or divided into other separate themes. Reviewing the themes included reviewing the coded data extracts to ensure they formed a pattern. From this a new, adjusted, thematic map was formed. The themes were then reviewed in relation to the entire data set and I considered if the thematic map created reflected the meanings within the data set as a whole. As Braun and Clarke (2006) note, coding data and generating themes could go on endlessly. I stopped reviewing codes and themes when the 'refinements were not adding anything substantial' (p. 92). In addition, the final thematic map was discussed with my University Director of Studies. By the end of this phase I understood my themes, how they fitted together, and how they told the story of the data (Braun & Clarke, 2006).

3.7.2.5 Stage 5: Defining and Naming Themes

I defined and refined the themes identified by 'identifying the essence of what each theme is about (as well as the themes overall) and determining what aspect of the data each theme captures' (Braun & Clarke, 2006, p. 92). The collated data extracts for each theme were organised with an accompanying narrative, in order to ensure that each theme was not too complex or diverse. The accompanying narrative for each theme detailed the story of the theme, as well as how the theme fitted within the broader story of the whole data in relation to my research questions.

I ended this phase following Braun and Clarke's (2006) recommendation of being able to 'describe the scope and content of each theme in a couple of sentences' (p. 92). These descriptions were sent to participants as a summary of the research findings on 20.02.2022.

3.7.2.6 Stage 6: Producing the Report

Finally, in the next chapter I have attempted to report my analysis in a 'concise, coherent, logical, non-repetitive and interesting account of the story the data tell' (Braun & Clarke, 2006, p. 93). This analysis includes a wealth of extracts within a narrative in relation to my research questions. Included below (table 6) are a selection of complete coding maps showing the process from transcript, to code, to theme. Please refer to appendix 17 for a complete coding map example for the theme 'system barriers'.

Table 6

Example Coding Map

#	Transcript	Code	Initial theme
1.33	referral to speech therapy…which was ridiculously long waiting lists.	Long wait list for SALT.	Hard to access professionals
1.253	it's difficult when you've got 30 - 30+ kids in a class, it is difficult. A lot of the TA's have gone now so staff are often on their own with a group of kids.	Difficult with large class sizes in schools.	Limits on public services
1.281	I think there's no honesty with the systems	No honesty in systems.	Lack of honesty in the system
1.282	if somebody would've said to me this is what we're allowed to do. We're only commissioned to do X Y and Z.	Professionals should say what limited to do.	Lack of honesty in the system
1.284	it just took me so long to realise that we needed more than what they were ever going to offer	Took parent a long time to realise needed more than professionals could offer.	Lack of honesty in the system
1.285	you feel that well he obviously doesn't need direct therapy. He doesn't need therapy because if he did surely they'd say that	Parent felt child didn't need therapy because someone would say if he did.	Lack of honesty in the system
1.300	what's really interesting is if he – when we have tribunals…kids are all on waiting lists for all these professionals for so long…oh well yes it's a long waiting list we'll see…but it went as soon as there's a tribunal and especially if you've already got a private report of some sort – that disagrees with their stance…their professionals can get in there and do their assessment within hours even, certainly within days.	Professionals can do assessments very quickly for tribunal.	Lack of honesty in the system
1.301	kids are all on waiting lists for all these professionals for so long…	Kids on long wait lists for professionals	Lack of honesty in the system

3.7.3 Braun and Clarke's (2006) Questions to Inform Thematic Analysis

As outlined by Braun and Clarke (2006) thematic analysis does not only summarise what a participant has told the researcher but attempts to understand what they have said and why they have said it. As a result of this, they suggest that during the analysis interpretation, the researcher draws from six questions to aid interpretation. I have used these six questions to guide my analysis interpretation.

1) 'What does this theme mean?
2) What are the assumptions underpinning it?
3) What are the implications of this theme?
4) What conditions are likely to have given rise to it?
5) Why do people talk about this thing in this particular way (as opposed to other ways)?
6) What is the overall story the different themes reveal about the topic?' (Braun & Clarke, 2006, p. 94).

3.8 Ethical Considerations

This research was granted ethical approval by UEL School of Psychology Research Ethics Committee (appendix 18). In applying for ethical approval and throughout my research, the British Psychological Society (BPS) Code of Ethics and Conduct (2018) were also abided by. The ethical principles of respect, competence, responsibility and integrity were upheld throughout the research process.

As the research was carried out online, the BPS Ethics Guidelines for Internet-Mediated Research (2017) were adhered to during the research. Furthermore, in keeping with UEL guidance on online working, Microsoft Teams was chosen as a secure method of data collection. Given the possibility that participants may not be familiar with Microsoft Teams, the initial meet and greet aided with participant familiarity and comfort using this tool.

3.8.1 Informed Consent

Prior to taking part in this research participants were emailed a participant invitation letter. This outlined the purpose of the research, what participating would involve, advantages and risks of participating, confidentiality and how their data would be used, and right to withdraw. Participants consented to all aspects mentioned.

Additionally, an initial meet and greet was organised for participants to ask questions, and for key ethical messages to be reiterated to ensure informed consent.

3.8.2 Confidentiality and Data Protection

Participants were informed of how their data would be confidential and protected in the participant invitation letter, consent form, and debrief letter. These details were further reiterated during the meet and greet, and at the end of the interview.

Only the researcher and their University Director of Studies had access to participants identifying data. Identifying data was stored securely on UEL databases, and separately from anonymised data. At the point of transcription, all identifying data was removed and replaced by pseudonyms, the generation of which was participant-led during the interview in order to ensure cultural sensitivity.

3.8.3 Potential Distress

Generally, it was not anticipated that participants would be distressed or adversely affected by taking part in the research. Considerations of possible causes of distress influenced the design of the study. For example, the initial meet and greet was included in order to familiarise participants with Microsoft Teams, with the researcher, and to ensure any additional questions from participants could be answered prior to participants taking part.

Participant distress was considered and discussed during the pilot study. As a result of the pilot study changes were made to the language used in the interview schedule. With these changes made, the pilot study participant and researcher did not foresee participant distress as likely.

During the interviews, participants chose whether to have their interview audio or video recorded in accordance with what would make them feel more at ease. Participants were able to choose pseudonyms, in order to ensure cultural sensitivity. During the interview the researcher was mindful about the possibility of their own or participants distress, and ready to halt interviews if necessary. Finally, participants were emailed the semi-structured interview schedule in advance in order to have time to consider and prepare their responses and be sure that they wanted to take part in research asking such questions.

In addition, immediately after completion of the interview, participants were emailed a debrief letter. This debrief letter included signposting to SMIRA for further SM support.

3.8.4 Right to Withdraw

Participants were informed of their right to withdraw from the study in the initial participant invitation letter, consent form, and debrief letter. Additionally, right to withdraw was further iterated during the meet and greet, and at the end of interviews. It was made clear that participants could withdraw from the study at any time, and that they could withdraw their data for up to two weeks following data collection. Data could no longer be withdrawn after two weeks as data transcription and analysis would have begun.

3.9 Validity and Quality

There are a number of issues regarding trustworthiness and validity in qualitative research, as outlined by Yardley’s (2000) characteristics of good qualitative research. As a result of this a number of measures were undertaken, which will now be outlined in the following sub-sections, in order to promote the reliability of the research. Yardley’s characteristics were chosen for this research in order to be consistent with the analysis used for the literature review.

3.9.1 Sensitivity to Context

A thorough literature review was conducted, outlined in Chapter 2, in order to place the research within the context of the current literature, and to build on the understandings already created through prior research (Yardley, 2000). Within some of the literature reviewed there was a lack of theory clearly identified for the research, though the history of the theoretical underpinnings of SM was often clearly and coherently outlined. This research therefore builds on the context of theory used in prior research by using Bronfenbrenner's eco-systemic model (1979) as an overarching executive framework. This was previously utilised by Hoyne (2014) to explore the perceptions of parents, teachers, EPs, and SALTs.

Awareness of the socio-cultural setting of this research is also important. Included in the introductory chapter is a description of the national context of this research. This includes the current lack of legislation for SM and the current position that it is an anxiety-based disorder. A further aspect of social context to consider is the relationship between the researcher and the participants. This study therefore includes a section on reflexivity where the researcher considered their own beliefs and actions, and how these may influence power dynamics and the outcomes of the research (please see section 3.9.3 transparency and coherence).

Sensitivity to the SM community, for whom this research is relevant, has been considered through the inclusion of a pilot study. This allowed for a focus on language and resulted in a change in the interview schedule questions. Being open to the perspectives of a participant in this manner has resulted in further considerations of the socio-cultural setting of this study, through the consideration of language.

3.9.2 Commitment and Rigour

Yardley (2000, p. 221) defines commitment as 'prolonged engagement with the topic…the development of competence and skill in the methods used, and immersion in the relevant data'. The researcher has engaged with SM as an area of interest for close to six years, and during the course of the professional doctorate sought to expand their knowledge and skill with qualitative research methods. This has included private study, as well as drawing from the knowledge of those more informed and experienced.

Yardley (2000, p. 221) defines rigour as ‘the resulting completeness of the data collection and analysis’. The data collection has been partly informed by the researcher’s paradigm and ontological and epistemological beliefs, as well as by the methods of data collection previously used in studies in this area. The sample was deemed adequate for the research questions due to the inclusion criteria for participants. In order to be thorough with the data analysis and interpretation, Braun and Clarke’s (2006) 15 point checklist of criteria for good thematic analysis was used (see table 7). Additionally, using Braun and Clarke’s (2006) six phases of thematic analysis and questions to inform thematic analysis enabled the data analysis and reporting to be thorough and rigorous.

Table 7

Braun and Clarke’s 15 Point Checklist of Criteria for Good Thematic Analysis (2006)

Process	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate level of details, and the transcripts have been checked against the tapes for ‘accuracy’.
Coding	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent, and distinctive.
Analysis	7	Data have been analysed – interpreted, made sense of – rather than just paraphrased or described.
	8	

	9	Analysis and data match each other – the extracts illustrate the analytic claims.
	10	Analysis tells a convincing and well-organised story about the data and topic.
Overall	11	A good balance between analytic narrative and illustrative extracts is provided.
Written report	12	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over lightly.
	13	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
	14	There is a good fit between what you claim you do, and what you show you have done – i.e., described method and reported analysis are consistent.
	15	The language and concepts used in the report are consistent with the epistemological position of the analysis.
		The researcher is positioned as *active* in the research process; themes do not just ‘emerge’.

3.9.3 Transparency and Coherence

Yardley (2000) proposes that transparency and coherence relates to the quality of the narrative and the persuasiveness of the research, with many qualitative researchers aiming ‘not to describe but to *construct* a version of reality’ (p. 222).

There is coherence between the ‘research questions and the philosophical perspective adopted, and the method of investigation and analysis undertaken’ (Yardley, p. 222). As the researcher has a constructivist research paradigm the aim is not to identify a universal truth, but to identify patterns and understand a phenomenon through the point of view of the participants. This is reflected in the research questions, and appropriately investigated through qualitative interviews and thematic analysis, and method of analysis which can be applied flexibly to any philosophical perspective and method of qualitative investigation.

Transparency has been sought wherever possible by using transcript quotes to support the interpretation of the data, and by detailing all aspects of the research process. In addition, the researcher will now reflect on how their own experiences, beliefs and actions may have affected the outcomes of this research. This section will be written in first-person.

I am approaching this research as someone who perceives SM as being rooted in anxiety, with a possible predisposition to anxiety due to genetic or environmental factors. This may influence my interpretation of the data, and transparency has been supported through the keeping of a research diary (Fox et al., 2007) in order to be more conscious of these factors and how they may be influencing the research. Additionally, I attempted to mitigate against it through the use of a second researcher (University Director of Studies) to check coding and initial identification of themes. A key benefit of thematic analysis is that it can be used flexibly, however, this can also result in difficulty conducting a rigorous thematic analysis. Keeping a research diary as an audit trail supported this research to be as rigorous and transparent as possible.

I am aware that I conducted the research as a TEP, and that the term ‘psychologist’ places me in the role of ‘professional’ which I am exploring with participants. This may have influenced what some parents felt able to discuss and disclose. Additionally, the term ‘psychologist’ may carry a level of ‘expert’ expectation from parents. My own constructivist perspective means that I am not entering this research with pre-conceived expectations but looking to hear and explore the perspectives of parents. This was stressed to participants, and during the interviews I remained mindful of my interpersonal skills to ensure any perceived power differential was guarded against as much as possible.

I am further aware that the questionnaire has been generated by me, and that a semi-structured interview enabled me to develop the interview discussion as I saw appropriate. This meant that I influenced the discussion and the direction of the discussion. I ensured that I did not demonstrate bias in my thoughts or actions by having consideration of the social GGRRAAACCEEESSS framework (Burnham, 2012) in my reflections on analysis and discussions, explored in my reflective diary and via tutorials with my University Director of Studies.

3.9.4 Impact and Importance

Yardley (2000) proposes that impact and importance is the most important criterion for any piece of qualitative research to be judged. Ideally, the researcher's data interpretation influences the beliefs and actions of others. This may have a practical impact, or the research may have theoretical worth by bringing a new perspective to a topic. 'The ultimate value of a piece of research can only be assessed in relation to the objectives of the analysis, the applications it was intended for, and the community for whom the findings were deemed relevant' (Yardley, 2000, p. 223).

One of the objectives of this research was to explore what is helpful, unhelpful, and ideal support for the parents of CYP with SM. This research therefore aims to have impact for parents of CYP with SM, and through them to also positively impact CYP with SM. Additionally, the findings of this research may be beneficial for professionals supporting SM families, in clarifying what is helpful and unhelpful for them from professionals. Whilst this has been achieved and will be further discussed in the following Findings and Discussion chapters, the impact and importance of this research is likely to be determined by others, not the researcher.

3.10 Chapter Summary

This chapter has detailed the research methodology and data collection, including the researcher's philosophical position, and research questions and design. The study's methodology has been clearly outlined, including participants, procedure of both the pilot and main study, and the interview schedule used. The data analysis has been described, and finally, issues of ethics and research quality have been noted.

The following chapter will present the findings of this research.

4. Findings

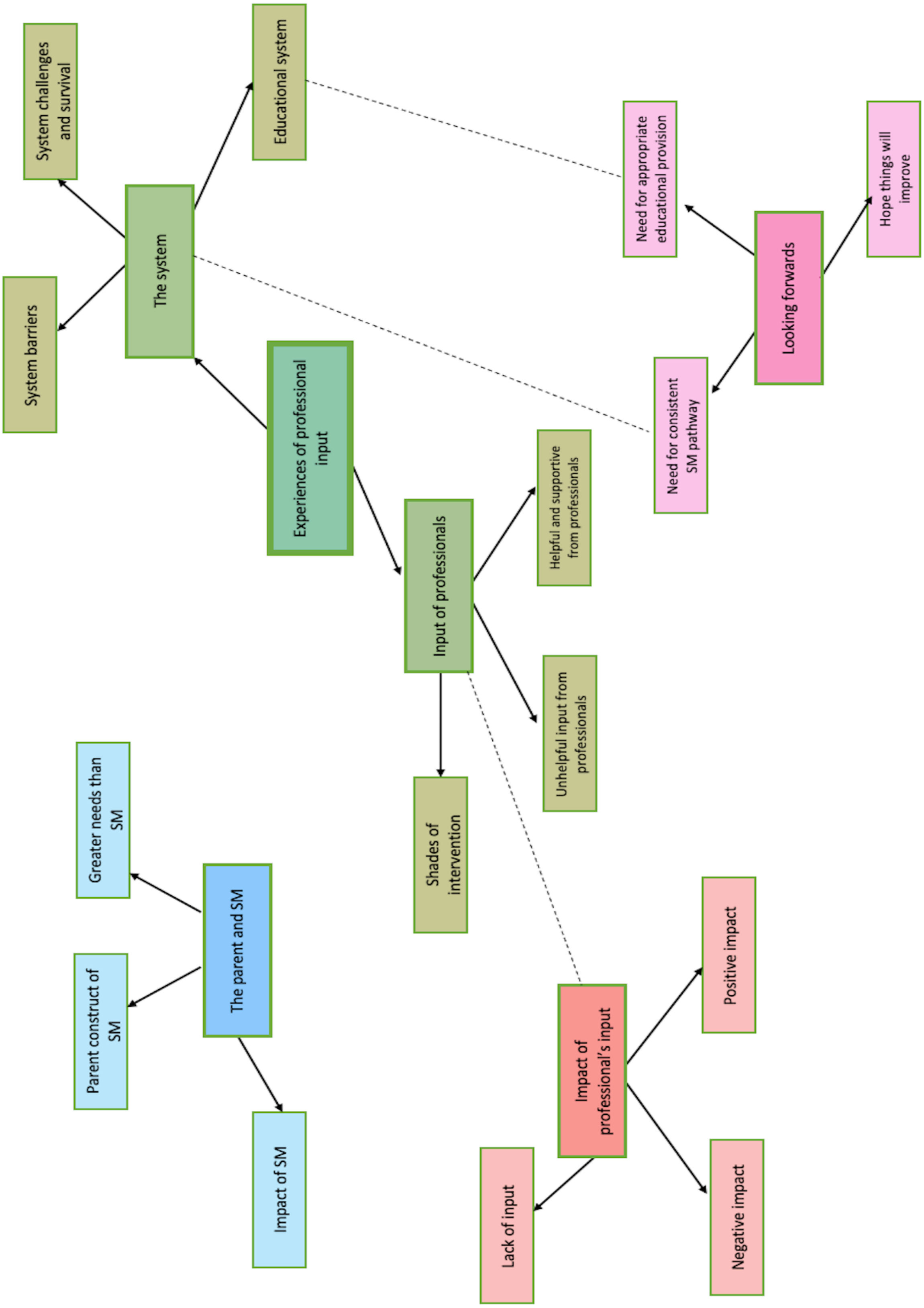
4.1 Chapter Overview

This chapter will summarise the key findings in relation to the identified superordinate theme, master themes, and themes that emerged from the parental interviews (see figure 3 for a graphic depiction of the whole thematic map). The chapter will first introduce the thematic maps graphically, with narrative summaries and excerpts from the interviews following the maps to illustrate the themes generated.

The first master theme identified is ‘the parent and SM’. This master theme provides background and foundation knowledge which allows for the important consideration of context for other findings. Following this, a superordinate theme of ‘experiences of professional input’ is considered, which then contains two further master themes of ‘input of professionals’ and ‘the system’. The next master theme identified and discussed is ‘impact of professional’s input’, followed by the final master theme of ‘looking forwards’. After the detailed exploration of the findings, the chapter will end with a brief summary of them.

Figure 3

Whole Thematic Map



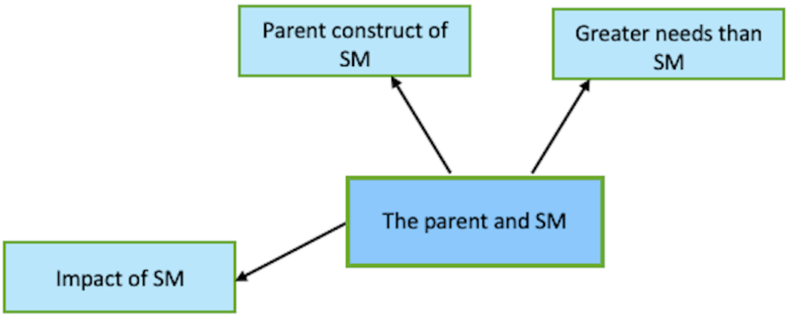
4.2 Master Theme: The Parent and SM

The first master theme identified in this study is ‘the parent and SM’. This was an unexpected but powerful finding, which provides context as to how parents construct SM and the knowledge they have of it. The master theme also incorporates the background information about the young people with SM, such as their family context, that SM is not their only difficulty, and their needs have been present for a long time. Additionally, parents outlined the impact that SM has had on them, their child, and their family.

The master theme and themes are depicted graphically below (figure 4).

Figure 4

Master Theme of ‘the Parent and SM’



4.2.1 Parent Construct of SM

For many parents their journey with SM began with no knowledge of it, with several highlighting that they had never heard of SM and were not aware that their child was presenting with traits of it, as Sarah explains: ‘*I had absolutely no idea she had selective mutism. She also has erm…ASD so I just thought everything was because she struggled erm socially and struggled to communicate’.* Sarah attributed the SM behaviours instead to her child’s other identified need of Autism Spectrum Disorder (ASD). This was echoed by other parents, who linked the traits to other factors such as shyness, ‘*I just thought (child) was shy’* (Charlie), speech and language needs, *‘I thought it was delay on speech’* (Tula) or having English as an Additional Language, ‘*we had thought it* *was because we speak at home Farsi language and at school is English’* (Parvaneh).

Parents provided detail about how they gained knowledge about SM through their own research, *‘I researched into it’* (Sarah), attending training, *‘I've done the Maggie Johnson training’* (Penelope), and through their experiences with other children with SM, ‘*we had had a child in the setting with possible selective mutism’* (Charlie). Tula spoke of the particular importance of connecting with other parents with a child with SM, and of how this developed her own knowledge, ‘*I’ve learnt more through SMIRA than I have through any book I’ve ever read. Er, which is you know parents telling you what you should and shouldn't do and how to get help and how to get your way round the system’.*

Finally, parents spoke of the strength of their knowledge of their child and their needs, and of how they know their child best, ‘*I’m not allowing anybody to tell me about my son when I know him better’* and *‘I’ve always been right about my child’* (Penelope). Tula goes on to explain more about this knowledge specifically in relation to SM, ‘*there’s a thing with an SM parent where it's less than a beat where you can figure out if they will answer or they won't. Or it's a look or a…and then you quickly get in. And it's that – it’s the parent knowledge that you can't teach to somebody else. That erm is the thing that I wish professionals understood’.*

4.2.2 Greater Needs than SM

Parents gave contextual details about factors which may have contributed to their child’s SM. Croft-Callou spoke of a family history of SM, ‘*her brother was the same, he took till year – year 2 till he started to talk to people’.* Maria spoke of a family history of SM traits spanning several generations, ‘*what (child) has is erm I think is my husband he had the same problem when he was young’* and *‘my husband father he had - he’s exactly the same. He had the same problem, so maybe that is some family problem’.* Tula gave details about her child’s experience of trauma, and the positive reinforcement of silent behaviour he had received during his early years, ‘*his dad he erm was very…he was an angry man.*

Constantly angry. Wanted total silence…so even as a young child (child) learned that being silent was a good thing'.

Some parents explicitly spoke of how their child's additional needs had been present from a young age, with Sarah aware of serious concerns from three years old, '*at 3 referred into CAMHS and speech and language'.* Similarly, concerns regarding Tula's child were noted upon immediate start at pre-school, '*he started pre-school a little bit early...and within two weeks they said…something not right Tula'.*

Many parents identified that SM is not their child's only additional need, with a range of other developmental and mental health disorders present, '*autism, the erm…anxiety disorder diagnosis, sensory sensitivity, he's dyspraxic…disturbance of affect recognition'* (Penelope), '*been diagnosed with autism, ADHD, anxiety, and sensory processing disorder'* (Charlie), '*she's also got an eating disorder as well'* (Croft-Callou), *'she's borderline eating disorder. She's very very underweight and she is extremely restrictive with food'* (Sarah).

4.2.3 Impact of SM

Parents talked of the impact SM has had on their child. A number of areas were spoken of across the participants, including impact on the child socially, '*he didn't speak with children in the playground. And then er then he wouldn't speak in after school club'* (Parvaneh), and impact on the child in the classroom, *'if she doesn't understand something, she won't tell them, she will just sit there and do nothing'* (Croft-Callou). A particularly severe impact that parents spoke of was how the child's school attendance was affected, *'she didn't go, her attendance was always like in the 40s'* (Sarah). Penelope spoke of how this pattern of school avoidance and refusal continued over time, *'he's not done a full year in school since year 5', 'year 7 was basically spent with me trying to get him out of the car while he was clinging on and shaking with fear and saying I'm scared I'm scared'*, and of the impact this had on her child's academic success, *'his academic work was going'*.

Parents also spoke about the pervasive impact SM has had on their child outside of education settings. Parvaneh spoke of how her child could not communicate with his friends at home but could in the classroom *'he would speak to his friends in the classroom but he wouldn't speak to them at our house or if they want to play at you know in other places'* and of how he was unable to speak to anyone at a club he attended every week, *'(child) used to go to erm ice skating. Erm, I think for 6 years or something. He didn't speak to any single person there'.* Maria detailed the stigma her child receives from peers as a result of her SM, '*the kids ask her…she's crazy why she not speak?...she not feel good at school because you know the - the – the boys or girls they – they use not good word for her'.*

Parvaneh also noted that her child was unable to speak to extended family, '*my parents at the time, er they lived er in Dubai. We went to visit. He wouldn't speak. To anyone'.* Two parents noted even more significant impact in that their child was not always able to communicate with them, '*we talk mainly by text…But we - we very rarely talk'* (Sarah) and '*she won't speak to me sometimes, she won't speak - very rarely speaks to her dad, who she doesn't live with'* (Croft-Callou).

Penelope and Charlie spoke of times their child's health had in the past been affected by their inability to verbalise their needs. For Charlie, this took the form of the child not being able to stop adults around her from giving her a second dose of medication, '*they gave her piriton, she'd already had piriton at home – they double dosed her because nobody gave them a call to ask. Erm she wouldn't tell them no'.* Penelope detailed how her child had been unable to tell adults about being accidentally severely injured, '*broke his wrist badly in school...he didn't tell anyone, despite having a teaching assistant sat next to him in the full lesson'.* Similarly, Sarah spoke of current concerns regarding her child's health, and of how SM is impacting on meeting her child's health needs, *'she's now got a perineal hernia…because she can't and won't let anybody near her or speak to anybody and tell them stuff it's now impacting on her physical health'.* Sarah is acutely aware of the impact of SM not only on her child's health, but also on the safety of her child and others, '*if something happened she couldn't phone an ambulance, she couldn't phone the police. She couldn't go outside and knock on erm a neighbours and say my mum's fell down the stairs or…we really are kind of out on our own… it's really really unsafe'*.

In addition to the impact SM has had on their child, parents also noted the impact it has had on them and the family dynamics. Sarah spoke of the impact on the nuclear family, ‘*the impact is massive. It's erm completely taken over our lives. I don't really get much chance to leave the house because she won't go out so I'm – we’re both pretty trapped to be honest. It gets quite suffocating and overwhelming. Even taking the dog out for a walk can be a massive trauma’.* Croft-Callou reported the difficulty of her child’s father not understanding SM, ‘*her dad gets really frustrated with her, really really frustrated with her, because he thinks she's being rude’.* In addition, Croft-Callou spoke of the upset for herself in seeing her child unable to communicate with her grandparents, ‘*it gets upsetting when my parents come to - to visit and she doesn't communicate, and she loves them, she absolutely loves them to bits, but she won't communicate with them’.* Tula also described the devastating impact SM has had on her wider family, ‘*family just thought that I was an overbearing parent…we were close as close could be, er me and me sister…there's always this kind of slight awkwardness’* and *‘family has been completely separated really for four years’.* Participants accounts were saturated in high, complex and consuming emotions and experiences.

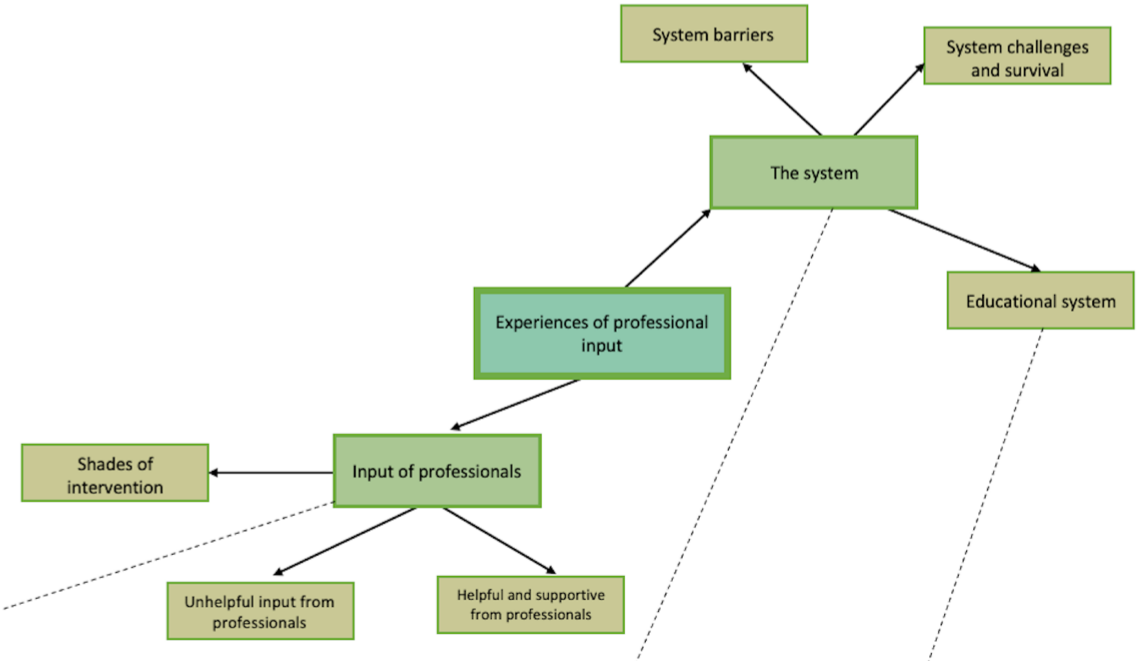
4.3 Superordinate Theme: Experiences of Professional Input

One superordinate theme was identified in the data analysis, which overarches the large area of ‘experiences of professional input’. This superordinate theme features two master themes, the first of which is ‘input of professionals’. This explores the more direct contact and input parents have from professionals for their child with SM. The second master theme of ‘the system’ focuses on the experiences parents have of being inside the SEN system.

The superordinate theme, master themes and themes are depicted graphically below (figure 5).

Figure 5

Superordinate Theme of 'Experiences of Professional Input'



4.3.1 Input of Professionals

The first master theme explored within the superordinate theme of 'experiences of professional input' is 'input of professionals'. This master theme contains the themes of 'helpful and supportive from professionals', 'unhelpful input from professionals' and 'shades of intervention'. This master theme also links with the master theme of 'impact of professional's input', which will be explored later in the chapter.

4.3.1.1 Helpful and Supportive from Professionals

Parents detailed the support they have received in the past that has been beneficial and helpful to them and their child. This included professionals noticing traits of SM in the child and actively naming the SM, '*straight away she said he's got selective mutism'* (Tula). Parents spoke positively of their child receiving a diagnosis, and of how this gave them a reason for the behaviour and hope for overcoming it, as exemplified by Charlie and Tula, *'I was dead chuffed because er, I had a diagnosis…I just thought right we'll fix this now, you know. I've got something to hold on to and at the time I thought I'll read everything I can about it* *and I'll fix it'* (Tula), *'I felt relieved because there was a reason why she wouldn't talk'* and *'I thought great we've got a diagnosis, we know what we're looking at'* (Charlie). As well as the positivity of labelling and diagnosis, a couple of parents did also note that the wording of 'selective' is misleading and indicates that it is a choice, as detailed by Louise, *'I think the name is very misleading cause it's as though they choose not to speak'.*

The personal characteristics of individual professionals contributed to parents experiencing that professional's input as supportive and helpful. This included characteristics such as going beyond what is expected to meet the child's needs, '*she spotted him in the playground…she went straight to the head, and she said that child…there's something going on there. She was amazing. She went above and beyond'* (Penelope). Croft-Callou spoke of how her child benefitted from the effort her teacher put into understanding and connecting with them, '*she looked into like why (child) was shy and she spent a lot of time with (child) and she erm, she actually watched My Little Pony movies so that she could talk to (child) about My Little Pony movies'* and *'she spent that time with (child) getting to know (child)'.* Sarah spoke of the importance of professionals listening and having compassion, *'knowing that they were - they were there and they were listening because they wanted to and they want to change things…some compassion it - it makes such a difference'*. Charlie spoke of the importance of warm personal characteristics, '*she was just honest and friendly and helpful'.*

Penelope was positive about professionals who are open to learning, '*he was always willing to learn'*. Croft-Callou built on this by speaking positively of professionals who proactively sought further knowledge to support her child through whatever means they had available, '*her sister is speech therapist or an occupational therapist, something, so she asked her sister, so she got lots of information'.*

Communication between parent and professional was felt by participants to be key in the parent's experience of that professional input. Parents felt supported by proactive and regular communication between the parent and the professional, particularly with education staff, '*they ring like every other day to* *see if we're OK, do we need anything'* (Sarah), and '*we used to have this chat at the door every morning at the end of the day we'd have a chat, they'd have the diary. The communication was brilliant'* (Tula). In addition, parents felt more supported by external professionals who they were able to have ongoing communication with, as exemplified by Sarah talking about the EP, *'we still speak by email. She's – she's always around and says that she will always answer any questions or help in any way that she can'* and Louise speaking about the OT, '*that communication's been ongoing with her. She does ring me every couple of weeks'.*

Parents also discussed the benefits of professionals who would share information and build up the parent's knowledge of SM, as indicated by Sarah, '*she would send me home with lots of information to read'.* In addition to this, parents noted that communication between professionals was more supportive for their child, '*the paediatrician has worked really well with school and they've come up with strategies'* (Sarah) and *'she's worked in every department over the last 30 years, knows everyone. Erm and has opened doors to all kinds of things'* (Tula).

As well as communication between professional and parent or professional and professional, parents also spoke favourably of professionals who build a relationship with their child through appropriate communication and interaction, as illustrated by Penelope, *'he just trusted her because she didn't let him down. We had a few incidences where stuff happened but she would be honest with him and she'd say I wasn't here yesterday I'm really sorry that such such a thing happened. She would just be really straight with him and it worked'.*

Some of the parents detailed their perceived need to seek support from privately funded professionals. Penelope did so in order to ensure the advice given was specific to her child, *'because she doesn't work for the local authority she hasn't got a clue what provision is, what he may be allowed so she puts what in her professional opinion is allowed'.* Tula felt that a privately funded professional was able to work more creatively, '*she's done full assessments on him without him ever knowing',* and Charlie sought a privately funded EP assessment as reassurance for herself, *'I paid for one at mainstream, basically so I knew I wasn't* *completely losing my marbles and there were things going on'.* Privately funded professionals were therefore felt to have served as a source of support for both parent and child.

4.3.1.2 Unhelpful Input from Professionals

Parents detailed the unhelpful input they have received from a variety of professionals across health, social care, education, and LA settings. As with the helpful input previously discussed, the personal characteristics of professionals were reported by parents as contributing to the parent's experience of that professional as unsupportive. For example, Penelope spoke of a secondary school SALT, '*I would describe as lazy...he got nothing'*, and Tula of a secondary school pastoral manager who would not listen to her, '*no matter what I said he just would do the opposite'.*

The personal beliefs and attitudes of a professional could impact negatively on the input and support they gave. Croft-Callou noted that the attitude of a secondary school's SENCo to SEN resulted in them being unsupportive, '*SENCo is absolutely appalling...If it's got initials she doesn't believe in it',* whilst Sarah raised concerns regarding sexism, '*the next person that came along was horrendous...He was erm…misogynist…he was old school and he was very much women don't speak until you've been spoken to. Women are not - oh he was horrendous'.*

Parents found professionals unhelpful and unsupportive due to limited or a lack of knowledge of SM. Croft-Callou, who works as a teacher, noted '*as a school ourselves, we'd had no training on selective mutism, we'd never had a kid with selective mutism…so I think as a school we didn't have that knowledge'.* As a result of this professionals could be dismissive of parent's concerns, '*when I went to see the GP erm she said er – she hadn't heard of it she said maybe something that goes, erm, goes away. Erm, and then you know her sister had been like that when she was very young and they grow out of it'* (Parvaneh) and *'it's like because they couldn't see it it wasn't happening'* (Sarah). Croft-Callou felt that the SENCo actively disbelieved her child had additional needs, '*SENCo of the high school said erm that she had no special needs and that erm she wouldn't be on* *their special needs register even though she's got three diagnoses…they didn't believe in it'.*

However, for some parent's professionals were not only dismissive, but shifted blame to the child '*they just thought that she was a defiant girl who didn't want to speak because she didn't want to be at school. They thought that she was just awkward'* (Sarah), or to the parent, *'I've been called neurotic, erm it's me - someone at one point said they thought that I was making it up, that I – it was because I was a single parent at the time, because I went back to work too soon, because I went back to work too late. I've had every single reason you can think of'* (Sarah) and '*they thought that I was paranoid and being over the top'.* (Charlie).

As well as a lack of knowledge, Sarah noted a perceived reluctance by some professionals to further their knowledge and learn about SM, '*people don't really know about it and they don't really want to know about it either'* and *'nobody went out of their way to do a bit of research'.*

Parents placed high value on communication with professionals and spoke negatively of professionals who are difficult to contact, for example, not answering phone calls and emails from the parent, as exemplified by Charlie, *'my SEND officer she didn't reply to emails, she didn't reply to phone calls…if you get an email you reply to it, especially if you're doing a job like that'.* Parents also spoke poorly of professionals who do not communicate and liaise with other professionals, for example Sarah noted that CAMHS staff did not respond to the school SENCO's attempts to contact them, '*CAMHS haven't been great with her…as in getting back to her…erm, but they're not really great with anybody'.* Finally, parents discussed professionals who communicate and interact poorly with their child. For Croft-Callou, this appeared to come from a position of not understanding the child's needs, '*year six she actually had two teachers. Erm, the one on Thursday she absolutely hated, she hated her with a passion and would actually not go to school on a Thursday. Erm, and when she was in school on a Thursday she'd be asked questions and she'd just sit there with the rabbits in headlights and she'd just go Mummy I can't say anything'.* For Penelope, her child questioned the purpose of SALT and their yearly interactions, '*he said what's the point of them? They come in once a year, make me do things, and then go away again'.*

Parents spoke of professionals attempting to put support in place but doing so ineffectively. Penelope noted the difficulty of implementing a structured intervention such as the Sliding-in Technique (Johnson & Wintgens, 2016) consistently in a school environment, '*they did start doing the – carrying on with the programme, and - but because when you get nearer to the Christmas and they started practising the play and things it just drops away'.* On similar lines, Louise discussed school staff not supporting her child to implement strategies, '*they might try it once and it works and – and that's it and it needs to be regular, ongoing, and (child) needs to be encouraged…they implement things and they don't follow them up'.* Sarah identified that external services do not offer support for long enough to make a difference for her family, *'every service that we - we become involved with, they're only ever temporary. There's never anything long term'.* As a result of this she is now unwilling to bring in additional support due to the sheer volume of professionals who have input for short intervention only, *'I don't really want to introduce anyone else in, even if it is long term because it's another person, and do you know at the minute, the running count is 44 professionals. And she's 13'.*

Parents also spoke negatively of professionals who contribute minimally, as illustrated by Louise, *'it's just well this is my advice, off you go. I wouldn't say any of them have been particularly helpful or supportive to be honest'* and Sarah*, 'went back to speech and language…she agreed that she was selective mute and offered no, erm, no insight into it, no try this try this'.* Penelope also notes the minimal contribution of services who continually try to stop supporting her child, '*we ended up discharged from speech therapy, something like 3 times by the end of reception'.* Finally, Sarah noted concerns regarding professionals who give no support, despite being recognised by others as the best placed to provide certain input. For example, she spoke of her child's primary school not implementing strategies other professionals had identified her child as needing, '*advice that was given to them by other professionals wasn't adhered to',* and of her general experiences of professionals not acting to meet her child's needs, '*we have a lot of issues with professionals not following through on things'.*

Six of the eight parents involved in this study had sought support from privately funded professionals. For some this had been a negative experience with minimal beneficial impact for them or their child, *'we also saw a private psychologist…she said after 18 months she's not interacting with us we're going to sign you off. And when she signed me off and said we can't do anything else for you, then I - I know – there were a lot of tears then, because I thought a private one we're paying £150 an hour for can't interact with her what we going to do?'* (Charlie). In addition, parents noted the steep financial implications of seeking this support, '*we've had to slap all sorts of assessments on the mortgage'* (Penelope), which at times made this support unattainable, '*we try looking some Polish psy - psychologist who can work with her but erm we need to pay for that so we can't use…no every week because it was too expensive for us'* (Maria).

4.3.1.3 Shades of Intervention

Parents identified and reflected on the pros and cons of the range of interventions their child had received from professionals. Parents discussed their own role in intervention and the impact the COVID-19 pandemic has had on intervention for their child.

Three of the parents discussed medication as a form of intervention. Tula identified her child's need for medication due to their presenting anxiety, and of the difficulty in obtaining this medication, '*no one would prescribe meds other than a CAMHS consultant but I can't get to a CAMHS consultant'.* Once her child was receiving medication, Tula spoke of the beneficial impact it had, *'the meds have made a huge difference',* as did Penelope, '*a small dose of Prozac. Which was wonderful. It took away a lot of the physical shakes and that – and the heart rate and that sort of thing'.* Conversely, Sarah expressed frustration that medication is the only intervention being offered because her child presents as demand avoidant and refuses to take medication, *'medication keeps being offered at every 3 months when we see the psychiatrist. That's kind of it. There's* *no input. There’s no extra support. There’s no deal with it this way or deal with it that way. It's just…you won't take medication so deal with it’.*

The Sliding-in Technique was reported to have been recommended as an intervention by many parents. They spoke positively of how their child’s communication progressed with this intervention, *‘it worked really well. By the end of him finishing nursery about 2 weeks before the end of term he had started to speak’* (Penelope), and ‘*started in August or something or September and just before the Christmas he started to speak to her. That was breakthrough’* (Parvaneh). However, parents also spoke of the difficulty of implementing the intervention consistently, and the subsequent repeating effect this had on their child and their SM, as exemplified by Penelope, *‘when you get nearer to the Christmas and they started practising the play and things it just drops away. So then we wasted quite a lot of time. Then, again, they did start it again. And, started speaking a tiny tiny bit, literally, again, in the last week of term. We had a bit of a pattern for a while, and then in the end I just thought this is just the same thing each year’.*

In addition to medication and the Sliding-in Technique, parents discussed the benefits of changes being made in their child’s environment to accommodate their needs. The majority of these centred around adaptations to the school or education environment, with a focus on trying to reduce the child’s anxiety. This was done through changing school rules and routines for the child, as described by Penelope, ‘*he was not wearing a tie. He was allowed to go in in his trainers because he couldn’t cope with his shoes. He was allowed to go in early and miss the early morning rush’*. Tula’s child was supported to try and communicate nonverbally in school, *‘let us know how you’re feeling by turning a pencil case over from green to red or, you know, or by here's a card if you want to get out of the room’.* Penelope also detailed the changes put in place during a hospital trip with her child, ‘*we didn’t have to wait. They didn’t even put us in the waiting room’* and the benefit of medical staff recognising that the parent is a valuable source of communication with the child, *‘they got me there and she had me doing, you know, checking his circulation and asking him things, which was – that was brilliant’.*

As previously explored for medication and the Sliding-in Technique, the difficulty of putting environmental changes in place was discussed, as noted by Louise: *'I don't think they use it – they try it often enough, you know, they might try it once and it works and – and that's it and it needs to be regular, ongoing, and (child) needs to be encouraged'.*

The final intervention parents discussed was therapeutic support for their child's mental health. Unanimously, parents spoke of the difficulty of receiving this support due to the reliance mental health services have on speech for therapeutic input, '*he would go into this dark place and he'd end up suicidal and er you know CAMHS wouldn't deal with him erm because they could only do talking therapy. Erm, they would assess him and say well yeah he's suicidal but he looks fine to me'* (Tula), '*this is a recurring thing with CAMHS and selective mutism. That they can't help because the child won't speak and everything they offer is reliant on the child talking'* (Croft-Callou). Penelope detailed that adapted CBT was recommended for her child by a professor at a multi-agency clinic, but not provided by local mental health services, '*he said in his reports CBT, so when we went for the follow up I said but how can they do CBT or anything like that with a child that's selectively mute. He said they can it needs to be adapted. And I said well are (the borough) capable of doing that. He said they should be. Nothing. It didn't happen'.*

The parents felt that they had a key role to play in supporting the implementation of interventions with their child. Penelope described how she would try and support her child to attend school, '*me and him go in on our own just in the library for half an hour just to look at a book'.* Parvaneh and her husband completed a CBT workbook with their child, '*with the direction of (2nd CAMHS psychologist) we continued to see her to do CBT er at home. So I would - there was a book called…the worry book…er bag of worries…And we do CBT with something something gremlin…and then there were chapters and then we did we print out the chapter, we did all the work every single night'.* Whilst Penelope and Parvaneh both seemed to feel that this was reasonable, Sarah spoke of the school's unreasonable expectations on her to support her child and of the potential impact this could have had, *'it was very much…you just come in and deal with her, so I'd be sat in the classroom for hours every day. I don't know I didn't lose me job'.*

Finally, parents raised how the COVID-19 pandemic had interrupted interventions in place, '*everything was absolutely fine then erm, then we had meeting with Mrs - because then start lockdown. So er, we still continue meeting with (teacher) online'* (Maria) or had stopped a possible intervention beginning, *'if it hadn't have been for COVID they might have possibly done like art therapy with her'* (Croft-Callou).

4.3.2 The System

The second master theme explored within the superordinate theme of 'experiences of professional input' is 'the system'. This master theme features three themes, 'educational system', 'surviving the system', and 'system barriers'. It also links with the later explored theme of 'need for consistent pathway' within the master theme of 'looking forwards'.

4.3.2.1 Educational System

Parents specifically discussed the educational system. In particular they spoke of the challenges they faced through the Education Health and Care Plan (EHCP) process, the lack of specialist provision available for children with SM, and of how their child is treated differently from other children with special educational needs and disabilities (SEND) within the educational system. This theme links with the later theme of 'need for appropriate educational provision' under the master theme of 'looking forwards'.

Parents spoke of the journey they had undertaken in seeking an EHCP for their child. Though education forms only part of the EHCP assessment, parents seemed to have particularly encountered barriers with education and LA professionals. This included parents having to apply themselves due to a lack of support from education professionals, *'I asked and asked and asked for them to apply for an EHCP and every time they refused….so I applied meself and it got rejected because they wouldn't submit anything'* (Sarah), and *'I asked the school* *in about year three year four to put an EHCP in place for her. They said don't be so silly, you don't need one, there's nothing wrong with her…that's fine I'll do it, not a problem. I have nothing better to do than working full time and having two children and running a house...initially we were refused which was expected and which is the general answer*' (Charlie). As already described by Sarah and Charlie, having overcome the initial barrier of applying for an EHCP assessment, the parents then met further barriers when the application was declined. Penelope reported further barriers during the EHCP journey, '*they did an assessment which was deliberately terrible. Then it was refusal to issue'.* Penelope and Charlie noted that they sought legal advice in order to secure the support their child needed, *'nothing else was still been done, so I got a solicitor'* (Charlie), *'I've used a solicitor once when I were just so fed up with them…that was for one of - one of the tribunals'* (Penelope). Penelope repeatedly faced the tribunal process in order to ensure support for her child, *'I think I've had about 5 tribunals over the space of 6 years'.*

Croft-Callou differed from the other parents as her experience of the EHCP process had been extremely positive, *'my experience has been that they have been very contactable, and when I will have contacted them they've contacted me back, erm and you know they've been very positive, and they've put forward good ideas, and written very thorough and concise reports, so, I've had a really good experience with the EHCP. I might be the anomaly'.* Croft-Callou partly attributed this to the personal support she had received from friends and colleagues with the application, *'my SENCo in the primary helped me fill it all out…the girl who was one – 1:1 in my class at the time, her little boy's got one, so she helped me fill in all the application form and everything…I found it quite easy to apply but then I did have that support, and it was more friends' support than school support'.*

Parents identified their child's need for specialist provision, with Penelope speaking positively about how her child will attend specialist provision in the future, *'he is going into a specialist college…we found somewhere for him that's small. They understand him and I think it will hopefully be fine'.* For Tula and Charlie, their child was already attending specialist provision and having their needs met, '*we got him into a hospital school', 'they all know how to deal with him and he's you know, much calmer there'* (Tula). Charlie spoke positively of the staff in the specialist provision, *'they talk to you. They communicate. They email. They understand selective mutism. They're very caring, very nurturing, very hands on and take all the children as individuals and at their own time'* and of their proactive approach to identifying and meeting need, *'I mean we have a speech therapist weekly at new school. I didn't even need to ask for it…her new school have just done it'.* Finally, parents spoke about the lack of appropriate provision currently available, as exemplified by Penelope, *'there aren't a lot of options out there'* and '*there aren't schools for his profile'.*

Some parents detailed how their child is treated differently from other children with SEND. Croft-Callou felt strongly that her child was invisible due to their quietness, *'she's obviously going completely under the radar, no-ones noticing her. No-one - possibly they don't even know who she is and what her name is because she's so…just sits there quietly…she's just going to be left to sit there and is probably going to be known as one of the lit - the quiet children'.* Penelope expressed similar concerns about the visibility of her child and noted a specific incident where she had noticed the differences between her child and another with ASD, *'there was another child in the class that was just autism. Came new to the school and within weeks he was out of the school and in an independent out of borough provision with no diagnosis and no EHCP. Because he had behavioural issues...(child) had a birthday party…and I looked and the other child was there doing things and everybody was piling – you know sorting him out. My child I looked I thought where is he? He was sat in the corner with his hood up, and I thought…that's not right. It's not right. It's not right. But that's been the issue all along. Quiet children always go under the radar'.*

Concerningly, Sarah and Tula reported incidents where they felt that their child was being unfairly discriminated against as a result of their needs. For Sarah, this centred around accessing a clinic which could provide support for her child, *'I told him that I thought he was discriminating against her, because he was setting her tasks that were completely unobtainable. She would never ever meet the threshold for this clinic. And I thought it was really unfair'.* Tula described the daily discrimination her child faced in school as a result of staff not understanding SM, *'you are scaring the life out of my son, that's why you've not seen him all year and you're the head of SENCo, you know, for everybody in this school. Why? Why, you know, if he didn't have any legs, if he was deaf, if he was blind, you would make adjustments. Why won't you make adjustments for him? And he just went…well everyone can talk, you said he can talk'.*

4.3.2.2 Surviving the System

The second theme within the master theme of 'the system' is 'surviving the system'. Parents spoke of how the system needs to be navigated, the power of making a complaint, and of the need to fight for their child.

Parents noted needing to navigate the system, *'I can navigate the systems. It's not easy, and it's a lot of hard work'* (Penelope). Tula referenced drawing on the knowledge and experiences of other parents in order to achieve this, '*I've learnt more through SMIRA than I have through any book I've ever read. Er, which is you know parents telling you what you should and shouldn't do and how to get help and how to get your way round the system'.* Both Tula and Penelope noted their frustration with the system and feeling that it dehumanises their child and reduces them to paperwork or a tick box, *'I feel like he was just a tick'* (Penelope), '*it's this constant fight that you have and people not either not understanding or not seeing actually at - at the other end of that is somebody, just a kid who is frightened…they forget that, you know, they just go you haven't ticked a box, therefore here's another years wait'* (Tula). Tula noted that even with her skills and knowledge she still encountered every barrier in accessing support, *'it's knowing where to go and who to ask and asking the right questions and erm and even when I got really good at it…I still came up against every barrier'.*

Half of the parents spoke of making complaints as being a way to access or secure support for their child. Penelope had to make a complaint in order to have part of the provision in her child's EHCP delivered, '*it took 18 months and a judicial review threat to get the selective mutism training at secondary school. Even – it was in the EHCP. 18 months it took. And I had to go to the leader of the council'.* Sarah had to complain in order to access a multi-agency clinic, *'I had to* *threaten him with legal action for him to refer her in. I went to see a solicitor and sent CAMHS a letter saying that I was going to take legal action and that I thought that they were neglectful. Magically decided he was going to refer her'.* Louise highlighted how it felt as though placing a formal complaint was the only way to be heard and noticed, *'just feels like you're banging your head against a brick wall, because I mean you put in a complaint and it takes weeks and weeks for them to respond…(child) leaves school next year. It just takes too long, but I think if you just email and don't put it as a formal complaint they just ignore you. They just don't respond at all'.*

Parents repeatedly used the language of fighting and battles to describe their journey through the system, '*I have got it in the EHCP now because I fought for it', 'battle after battle because he doesn't throw things and cause trouble'* (Penelope), '*I've had to fight for everything'* and *'everyone says the same it's this - it's this constant fight that you have'* (Tula). Penelope expressed feeling wearied by the system, *'the whole system is just – it's almost like it's there to wear you down'* and *'the whole system as an endurance test'.* Finally, Sarah reported feeling that she and her child were given tokenistic support in an effort to keep her quiet, '*it was just a shutting up exercise it was just – let's shut that parent up and get rid of her'.*

4.3.2.3 System Barriers

Parents spoke of their experiences of encountering barriers in the system which stop or slow their ability to access support for their child. This includes long wait times to be seen, *'it's just this constant referrals and waiting and then when you get there, it's literally 10 minutes in the room and someone says no'* (Tula), and limitations being put in place as to how frequently a child can be referred, *'community paediatrics especially erm would say oh you've had a referral within the last 12 months. It was like yeah but it's taking you a year to reply to me, so now it's two years'* (Tula). Charlie noted the high threshold to access a specialist SM SALT, *'we had a selective mutism specialist SALT come in…but not until I started the EHCP process, because she wasn't allowed to until we did that'.* As explored previously, Charlie was not supported by school staff and had to apply for an EHCP herself.

Parents discussed other limits on public services, such as long-term support not being offered, *'sometimes services mean well and they come in and they say yeah we're going to do this and we're going to do that. And then they realise the extent that, you know, this can go on for a good 18 months before you even get a nod…and then they withdraw then because their times run out'* (Sarah). Parents also spoke of the lack of multi-agency working, as reported by Sarah, '*(child's) like package has always been really disjointed'* and of public services professionals being limited in what they could say, *'she would never like officially put it on a piece of paper what she thought'* (Sarah). This was particularly picked up by Penelope, who viewed it as a lack of honesty that had directly impacted on her child's needs being met, *'I think there's no honesty with the systems either because if somebody would've said to me this is what we're allowed to do. We're only commissioned to do X Y and Z…it just took me so long to realise that we needed more than what they were ever going to offer'.* This was also noted by Louise, who felt that support was not offered, and instead had to be specifically requested by her, *'that's for them to tell me what support they can offer and they - they just don't do that. It's only if you find out about things, you say well why are you not doing this or can you do that…that they actually seem to…'well yeah we can do'. They never offer it you'.*

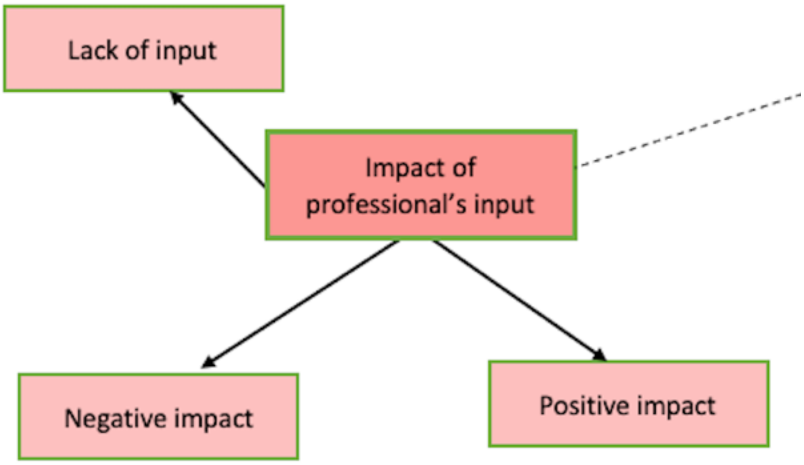
4.4 Master Theme: Impact of Professional's Input

Another master theme identified in this study is 'impact of professional's input'. This master theme contains three themes which consider both the positive and negative impact professionals have had on the child, their parent, and their family, and which also considers the lack of input parents feel they and their child have received.

The master theme and themes are depicted graphically below (figure 6).

Figure 6

Master Theme of 'Impact of Professional's Input'



4.4.1 Positive Impact

Parents discussed the beneficial impact professionals had had on their child, them, and on their family as a result of helpful intervention and the personal characteristics of professionals. Parents described the positive emotions they felt and experienced as a result of professional input, with powerful descriptions used to highlight impact.

Parvaneh spoke of the impact of the progress made by the CAMHS paediatric psychiatrist with the Sliding-in Technique, '*just before the Christmas he started to speak to her. That was breakthrough. It was very emotional for all of us even for – for the – for (CAMHS paediatric psychiatrist)…and then he was so happy. Er, that's - that was him - for him with a breakthrough as well, er he felt it in that way. And erm they er then wanted to speak to my cousin over the phone and my cousin was emotional – oh he spoke to me after 2 years! And then we call my sister, er call my - my parents'*. Parvaneh's description highlights the positive effect of this professional's input on the child, nuclear, and extended family, with Parvenah reporting *'(CAMHS paediatric psychiatrists) effect was kind of liberating'.*

Tula also reported the positive impact a privately funded SALT has had on her child, '*before he was house bound he just literally couldn't go out the door…we're starting to see progress', 'it's a cliche thing saying the weight's come off your shoulders, but he just physically looked lighter, you know kind of…finally we've got someone who understands me. I think that was the first person who he genuinely thought got him…she'll never ever know what she's done for my lad. Never…it's you know life changing isn't, you know, it's complete flip. It's phenomenal'.*

Little progress has been made with Sarah's daughter, however she noted the life changing impact for herself that the compassion and care the EP had shown her had had, *'the ed psych….she made me realise that I wasn't cracking up. That somebody else could actually see exactly what was happening…once she got involved the pressure kind of came off me…she was pretty much life changing to be honest. She helped me get past it's my fault. It's my parenting and all that beating myself up'.* Likewise, Charlie reported the benefits for her of professionals being supportive, *'it's nice without all the additional thinking I've got to email them I've got to speak to them, where are we with this. That's nice now, we don't need to worry about that and it took me a while to stop waiting for a phone call from the school…I'd get constant phone calls throughout - whilst working so it took a while for her having started at her new primary school without those phone calls thinking - to actually think I can relax a bit, she's being looked after, she's being understood'.*

4.4.2 Negative Impact

Alongside positive experiences, parents also gave accounts of the detrimental impact of professionals' input on their child, and of their subsequent negative feelings towards these professionals. This was due to factors such as professionals not understanding their child's SM, *'it's made him more anxious going into school feeling like he might be forced to talk'* (Louise). Penelope explained that her child had realised that support was not consistent, *'he probably quickly realised…the programme he was doing – oh, we won't keep doing – it won't be every single week because it isn't – because if something happens or if* *a child's behaving badly – it's not going to happen'* and noted the subsequent impact on his trust in those around him, *'he's got no trust in the system'.*

Parents also spoke of the detrimental impact of professionals' input on themselves, with Louise noting, *'I'm up till silly times in the morning sending emails and chasing people up and trying to fit it all in with work and supporting (child) anyway, you know that's a struggle in itself, so you know yeah it has been really stressful'*. Parvaneh was left upset by how a privately funded child psychologist spoke about her child and their SM, *'she write a report and so that is a lengthy thing er it – it takes – will take a lot of time, he is quite anxious, er er and then it would be very expensive if you want to you know er continue private sessions and it has kind of you know it was like oh gosh, what we're going to do, you know. And then we wrote back to her and said well that is not very helpful because we are parents we are – we are scared'.*

4.4.3 Lack of Input

Lastly, the participants spoke negatively of how their child has not received the input from professionals necessary to support them. This includes input being put in place too late, *'it was too little too late to be honest'* (Charlie), '*I think the school er working…they start work er too late. If they start on year 2 – 3 what I said probably (child) will be you know start speaking'* (Maria). It also includes support not being given, as exemplified by Penelope, *'everything has just been lazy. It's been shoddy…it's almost like people are just doing the bare minimum that they can get away with. And at the end of the day it's the kid that suffers', 'the selective mutism's really entrenched now because nobody did anything when they should've been doing it', 'I feel like we're in a worse place than when he was 3, because then there was – you know – whereas now it's going to be a lot of hard work to fix it'.*

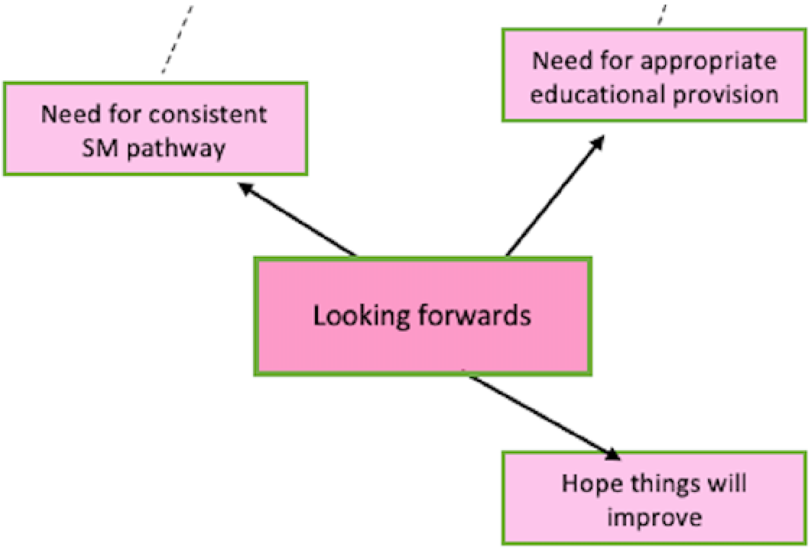
4.5 Master Theme: Looking Forwards

The final master theme identified in this study is 'looking forwards'. This master theme considers the parents' beliefs as to what support they would have liked their child to have, and what they would like going forwards. The master theme encapsulates three themes which explore the need for a consistent SM pathway, the need for appropriate educational provision, and parent's hopes that things will improve for the future for children with SM.

The master theme and themes are depicted graphically below (figure 7).

Figure 7

Master Theme of 'Looking Forwards'



4.5.1 Need for Consistent SM Pathway

Parents believe there is a need to have a formalised SM pathway, with Charlie drawing comparison with ASD pathways, *I know there's like big autism diagnosis pathways so you can go somewhere else…there isn't anything for selective mutism, you can't just make a phone call'.* Additional support identified which could be placed within a pathway included a case worker who would act as a single point of contact for a family, *'there should be a single point of contact. There should be a person that has that child on the case that liaises with people…I think that would be useful because then you've got a person to go to and then they could chase things up for you'* (Penelope). Parvaneh highlighted access to the same individual professionals as key, *'continuation with the same* *healthcare professional would help',* as well as more frequent access, '*to have access to the healthcare professionals, erm yes. I think access and their time erm…access means erm as frequently as needed'.* More access was further identified by Sarah, who felt longer term intervention was key, '*if it could be something that could go on for…12 months. 12 months could make a real difference'.* Mental health intervention was reported as being crucial going forwards, '*serious input with her mental health'* (Sarah). Finally, Penelope noted that ongoing support for CYP with SM and their families must be consistent, '*whatever you do has just got to be consistent'* and honest in terms of what is needed, and what is available, *'you've got to be honest not just with me. You've got to be honest even with the child, even a 3 year old'.*

4.5.2 Need for Appropriate Educational Provision

Parents identified the need for appropriate educational provision for children with SM. This included schools making the changes needed to support CYP with SM, such as finding methods of nonverbal communication for the child, '*working to find a way that he can communicate, that he is comfortable with'* (Louise), and ensuring CYP and their families are kept informed, *'they need just consistency and if rooms are going to change or teachers are going to change…how hard is it to just tell a child? Make sure a child knows, send the mum an email, send the child an email'* (Penelope).

Other parents felt that specialist provision is needed for some children and young people. Charlie's concern going forwards is that her child is able to build functional and independence skills, which she can be supported with more freely in specialist placement, '*from September they'll start taking her into shops and trying to get her to order things in shops, erm so she starts talking to the outside community as well… to be able to talk and go out on her own…to be able to go out and me not worry where she is because I know that she can talk and ask somebody a question or if she falls off and hurts – off her bike and hurts herself she can ask for help…and then obviously down the line can get a job'* (Charlie). Penelope spoke of the need for post 16 provision for young people with the SM profile, and of the risk of them not becoming a functioning member of society without such provision, *'there just is nothing they're just left and they're just on a* *cliff edge because once whatever it is they can cope with has finished, once that course has finished, well, what will you do next? Stay at home in your room potentially for a lot of them'.*

4.5.3 Hope Things will Improve

Parents spoke of how important it is to build awareness of SM. Penelope felt this was particularly important for schools, *'all staff need to know about selective mutism. You don't need massive hours and hours of courses. But the basics – what it is, how it affects that child, more than anything good things to do which is not asking questions that they're not going to be able to answer, and what not – you know – just simple stuff about being kind, don't shout'.* Parvaneh spread the net wider, identifying a number of professionals who need more awareness of SM, '*I think the awareness about it is very important. Erm, no-one knows about it. Perhaps it needs to go into the training of the doctors, therapists, nurses, schools. Er, think more awareness about it, um if people know about it it's much easier to deal with'.* A couple of parents detailed that they had continually pushed for staff training, in the hope that things would improve for the next child, as exemplified by Penelope, *'for me the other side of it is what if another child comes along after him? I want that to be recognised for if - just if another one comes along with the same sort of profile. Somebody might just pick up on it when it's needed rather than when it's a bit too late'.*

4.6 Summary of Findings

This chapter has presented the superordinate and master themes that emerged from this study's participant interviews. Overall, findings indicate that SM has had a wide impact on parents, families and the children with SM. Parents report that their child's needs are often greater than SM, with other health, neurodiversity, and mental health needs also identified. Parents describe how they gained knowledge about SM within this process, and also how they feel they lack knowledge.

Parents have had a variety of both positive and negative experiences of working with professionals. Whilst some of these experiences are attributed as being due to personal factors linked to the professionals, others are seen as being linked to features of the system within which professionals work. Similarly, when exploring the impact of input from professionals, parents reported both positives and negatives. The cumulation of these factors resulted in parents' identification of what is needed for their child and SM children in the future, including an SM pathway, appropriate educational provision, and more awareness of SM.

5. Discussion

5.1 Summary of Main Findings

The previous chapter explored the superordinate, master themes and themes that emerged in this study. This includes both positive and negative experiences of working with professionals, as well as the positive and negative impact of professionals on the lives of the parents and their child. SM clearly has a wide impact on the families of those with SM, and parents identified how their child's needs were often broader than SM. Parents explored their own process of gaining knowledge of SM, and how the cumulation of their experiences had led to their ideas of what is needed for their child and SM children moving forwards. Parents defined their ideal support as including an SM pathway with consistent access to support, increased knowledge of SM, and appropriate educational provision.

This chapter will consider the findings in relation to the study's research questions and chosen theoretical framework. The findings will also be linked to existing research, and this study will be critiqued with strengths and limitations identified. Implications for the practice of all professionals will be considered, as well as further exploration of EP practice specifically. Avenues for future research and dissemination of findings will be discussed, as well as final reflections on this research.

5.2 Summary of Findings in Relation to Research Questions

Research question 1: What are the experiences parents have had of professional involvement for their child with selective mutism, and how do they feel that this has influenced theirs and their child's experience of selective mutism?

As explored in the previous chapter, the participating parents have had mixed experiences of professional involvement. Positively, they appreciated professionals noticing traits of SM in their child and actively naming SM. Personal characteristics of individual professionals influenced their experience, as well as their knowledge of SM and openness to learning and communication with others.

As a result of this, the participants believed that the interventions put in place were appropriate, the impact of SM was lessened, and progress was seen. This resulted in strong positive emotions for the parent and child in relation to SM and the professionals.

Parents found professionals unsupportive when they demonstrated negative personal characteristics to parents, such as being *'lazy'* (Penelope). In addition, a lack of knowledge of SM, and at times a perceived unwillingness to learn about SM were other features that negatively coloured the parents' perception of professionals. This lack of knowledge is particularly pertinent for parents as it resulted in professionals seeming to disbelieve the child's needs, place blame with the parent or child, and subsequently not put any support in place, or put it in place inconsistently. Parents felt that their child was treated differently to others with SEND, in a manner which some described as discriminatory. As a result of this, some felt they were fighting for their child alone, battling against both professionals and the wider systems that professionals work within. Unhelpful and unsupportive input from a professional resulted in subsequent negative and generalised feelings towards the professional, the system, and towards the SM.

Research question 2: What support from professionals would the parents of children with selective mutism like to have?

The 'looking forwards' theme explores what parents believe their child needs and would like them to have in the future. Main findings in this area relate to parental belief that an SM pathway is necessary, with access to a case worker, resources, interventions, and more time with professionals. Parents felt strongly that there is a need for consistency in support, with interventions needing to go on for longer, and access to the same professionals who know the family. Finally, parents expressed a desire for honesty, with professionals being clear about what the child needs, and what is available and not available for the child. In addition to a specific SM pathway, parents spoke of the need for appropriate educational provision for children with SM, including post-16 provision. This included mainstream education settings putting in place the support needed, and appropriate specialist provision for some CYP. The futures of the CYP were considered, with it recognised that support is needed from an educational setting to promote independence and readiness for adulthood. Finally, parents spoke of the importance of building awareness of SM among professionals.

5.3 Summary of Findings in Relation to Theory

Bronfenbrenner's eco-systemic model (1979) was used as an overarching executive theoretical framework for this study. Hoyne (2014) has previously used the model in relation to SM research. This research draws from Bronfenbrenner's belief of the influence of interacting environments on the development of the child by considering the interaction between professionals and parents of children with SM, and how parents perceive that this interaction has impacted upon them and their child. In addition, this research explores how the dyad of the parent-professional influences the dyad of parent-child.

A number of professionals in this study were placed by the participants within the exosystem and contributed to the child's development either negatively or positively, through interacting with other adults placed in the child's microsystem (such as their parent and school staff). For example, an EP may meet the child once or not at all, with the majority of their input being through communication with the parent and other professionals. For professionals in the exosystem, parents linked their contribution as affecting the child's development through the professional's ability to successfully or unsuccessfully contribute strategies and recommendations to meet the child's needs. For example, Maria spoke of a helpful EP who did not directly work with her child, but informed Maria and the school how best to support the child and monitored progress with them. Similar stories arose throughout the interviews in this study.

Some professionals were placed in the child's microsystem, for example, school staff and others who had regular input such as a privately funded SALT. Parents descriptions of these professionals indicate that they had a profound impact on their child's development and level of need. For example, Penelope noted the positive impact of a secondary school SENCo on her child's ability to attend school, whilst Tula noted the negative impact of a pastoral manager’s lack of understanding on her child’s mental health and school attendance.

In relation to dyads, parents indicated that their interactions with a professional could influence how they regarded their child’s SM and possible outcomes. For example, Parvaneh described the fear she and her husband felt about their child’s needs as a result of a privately funded psychologist indicating that things were ‘*hopeless*’. The relationship between professional and parent could have a positive or negative impact on the parent’s relationship with their child and experience of SM. For example, Sarah described the incredible benefits to her emotionally and practically of her child being enrolled with a supportive secondary school. In addition, the relationship between professional and child could positively impact the parent-child dyad. Charlie spoke of how she could relax, knowing that her child is being supported by specialist provision staff. Tula spoke of how the whole family are in a more positive place as a result of the support her child receives both directly and indirectly from a privately funded SALT.

5.4 Findings Linked with Existing Research

This section will explore the current study’s findings in relation to previous research in this area, including areas of similar findings, as well as the new contributions of this research. The findings will be explored by research question.

CYP view SM as impacting on their own and their families lives (Roe & Phil, 2011). All of the parents and professionals in Hoyne’s (2014) study considered SM to have had a major impact on the child in terms of their learning progress. The parents in this study and Douglas’ (2021) highlight the impact SM has on their child emotionally, socially, academically, and on their child’s safety and ability to have their basic needs met. As well as impact on the child, both studies note the impact it has had on parents’ emotional well-being and the functioning of the family. In addition, the parents in this study expressed concern about their child’s future as a result of SM. Professionals have a part to play in the journey families undertake with SM.

This is the first study to focus on parental experiences of professional input. A variety of professionals were spoken about during interviews, including professionals from a health background (Paediatricians, GPs, health visitors, mental health staff such as psychiatrists, and SALT), education professionals (teachers, SENCos, TAs, pastoral staff, and specialist provision staff), and LA professionals (SEND officers, EPs, and social workers).

5.4.1 Experiences and Impact of Professional Input

Research question 1: What are the experiences parents have had of professional involvement for their child with selective mutism, and how do they feel that this has influenced theirs and their child's experience of selective mutism?

The parents in this study reported a combination of positive and negative experiences with professionals, and how this has impacted on theirs and their child's experience of SM. From the researcher's knowledge, this study is the first to explore the experience and impact of these professionals in depth. It is important to note that very few single groups of professionals were described as solely helpful or unhelpful. For example, Penelope described one NHS SALT as '*lazy*' and another as '*amazing'* and *'went above and beyond'*. The findings by Roe and Phil (2011) indicate something similar, with a number of positive, negative, and mixed comments made by CYP and their parents regarding professionals. This cited paper does not however go into detail regarding what these positive, negative, and mixed comments may contain. How professionals were experienced by parents in this study seemed to depend on a number of factors such as the professionals' personal characteristics, experience and knowledge of SM, and the system in place around that professional.

The participants in this study spoke positively of professionals who named their child's SM, and when a diagnosis was given. Tula described a diagnosis as something '*to hold on to'*, and Charlie described her hopes that the diagnosis would be a '*magic wand'* that would lead to answers and support for her child. The pros and cons of diagnosis is a relevant debate, with parents having to consider their child being at risk of stigma due to a diagnosis, or of losing access to resources that diagnosis can release (Russell & Norwich, 2012). How the CYP felt about diagnosis was not explored in this study, though Roe and Phil (2011) report that both the CYP and their parents were positive about receiving a diagnosis of SM, and of professionals who identified the child's SM. Findings therefore indicate that labelling SM is beneficial for parents and CYP. Parents perhaps felt positively about diagnosis and professionals who named their child's SM because it reduced uncertainty, a feeling which is typically aversive (Carleton, 2016). Appraisal theories of emotion propose that we appraise factors in our environment which affect our well-being. Uncertainty versus certainty about outcomes is a proposed appraisal dimension (Moors et al., 2013) which considers how parents may have different responses to the same diagnosis. For example, some of the parents in this study reported feeling more certain of their child's needs and how to meet those needs as a result of diagnosis. In comparison, other parents might feel uncertain about the future as a result of diagnosis, and so perceive it more negatively. This finding indicates that parents may feel more positively about professionals who reduce uncertainty in regard to their child.

Despite this positive experience of diagnosis, some of the parents in this study reported difficulty understanding the diagnosis, and not always finding professionals helpful in expanding their knowledge. For example, Sarah reported her child was diagnosed by an NHS SALT, but the professional offered '*no insight into it'*. Instead, parents learnt through their own reading and research, and by linking up with the parents of other CYP with SM. Ellis (2015) reports that 90% of participating USA SPs did not feel they had been adequately prepared for work with SM CYP by their training, with 66% actively seeking to further their knowledge of SM themselves. Naturally, a professional who does not feel knowledgeable about SM is unlikely to be able to further the knowledge of others. Louise described that through her own research she became more aware and noticed that some of her actions were unhelpful for her child and forced them to talk. She expressed concern for CYP whose parents may be unable to do their own research and further their own knowledge, e.g., parents who have limited free time, or literacy needs. This highlights the need to raise awareness of SM, which will be explored later on in more detail.

One of the new findings in this study is that certain factors contributed to parents having a positive experience of a professional. This includes personal characteristics that the professional displays, having knowledge of and understanding SM, and furthering the knowledge of others such as other professionals and the parents. A study by Topor et al. (2018) reported the benefit that 'micro-affirmations' had on the relationship between individuals with mental health needs and mental health staff. Micro-affirmations include small displays such as the gestures professionals use, eye contact, facial expressions such as smiles, use of words, and making contact with the individual outside of their usual scheduled contact. Similarly, parents in this study reported positive experiences with professionals who '*listened*' (Charlie), '*cared*' (Sarah), and exchanged further communication by email, which resulted in the parent feeling that they were supported in this journey with SM.

Another important positive feature identified in professionals was ability to communicate well with parents, but also with their child. For example, Penelope spoke of a secondary school SENCo who she was able to email whenever necessary, who coordinated support for the child around the school, and who built a trusting relationship with her child by accepting their nonverbal communication. This combination of factors appeared to be particularly important in education settings, with parents reporting that their child who had previously been refusing to attend school began to be able to attend either mainstream or a specialist provision. No research has directly linked SM with school refusal, however there is much history detailing the link between anxiety and school refusal (Finning et al., 2019; Archer et al., 2003), and stressing the importance of effective long-term pastoral support (Archer et al., 2003), and close links between school and family (Elliot & Place, 2019). Using Bronfenbrenner's eco-systemic model (1979), this directly highlights the importance of the mesosystem as the supportive interactions between the microsystems of the child's home and school can lead to positive outcomes for the child. In addition, the mesosystem between home and school functioning well had a beneficial impact on the parent; Charlie described how she was able to relax, knowing that her child was in a place where they were understood and looked after.

Parents spoke of how their experience could be negative due to the reverse of these factors being displayed by professionals. Participants spoke of professionals with personality characteristics such as being '*unapproachable*' (Croft-Callou). Alongside this, parents reported a lack of understanding of or knowledge of SM, which was also reported by the CYP in Roe and Phil (2011) and the parents in Douglas' (2021) study. This resulted in some professionals perceiving the child's behaviour as being oppositional, such as '*rude*' (Parvaneh), '*defiant'* or *'awkward'* (Sarah). Previous research from the perspective of professionals supports parents' opinions in this study. Ramos (2018) reports a teacher participant describing their SM pupil as 'challenging and oppositional'. In Hoyne's (2014) study, all three participating teachers and a number of EPs and SALTs attribute SM to being a choice, and as being linked to power, control, and attention. The attitudes to SM in previous literature may be linked to SM only recently being classified as an anxiety disorder in the DSM-V (APA, 2013). Within this study, parents were speaking retrospectively of professionals they may have interacted with at any point in their child's life, so it is difficult to conclude if there is a shift in knowledge of the underlying cause of SM. The impact of understanding the underlying cause was highlighted by Albrigtsen et al. (2016). The mother in the case study reported a positive shift in how school staff treated the children when there was a change in their mindset from seeing SM as oppositional to anxiety based. Cognitive dissonance theory (Festinger, 1957; Aronson, 1968, 1992) suggests that we all have an inner drive for our behaviour to reflect our inner attitudes and beliefs. This indicates the importance of changing underlying knowledge and attitudes of professionals to consider it as an anxiety disorder, in order for professionals to demonstrate behaviour that is congruent with this belief.

A new finding in this study is that in some cases, parents felt that their child's needs were disbelieved due to poor understanding and knowledge of SM. Whilst this study is the first to have parents explicitly label the feeling of being disbelieved, Douglas (2021) notes a parent indicating that professionals did not take their concerns seriously. As a result of this disbelief parents felt that their child was not appropriately supported in school as blame would instead be placed with the child or parent. This feeling is echoed in prior research into the underlying causes of SM, with psychodynamic approaches and family systems therapy focusing on identifying and changing unhealthy family dynamics (Leonard & Topol, 1993; Stone et al., 2002). This perception that professionals are placing blame with the parent is particularly concerning given Hoyne's (2014) previous finding that parents felt their confidence in their skills was negatively impacted by SM. This might indicate a knock-on effect of a parent losing confidence in their skills as a result of the SM, as well as feeling blamed for it by professionals.

The lack of knowledge and awareness of SM is well documented in previous literature (Hoyne, 2014; Davidson, 2012; Ramos, 2018; Douglas, 2021). This study developed this further, with parents also reporting they perceived a reluctance from some professionals to learn about SM from more knowledgeable others or through their own Continuing Professional Development (CPD). The cause for this may be linked to another finding of this study, which is that parents believe that professionals in public services often have a high caseload, and so have more limited time for case work. In addition, a contributing factor may be the emotions that SM casework can create in professionals. Ramos (2018), Davidson (2012) and Hoyne (2014) all reported that their teacher participants felt deskilled and frustrated by the SM child in their class. Likewise, EPs and SALTs had feelings of frustration towards the child (Hoyne, 2014). From a psychoanalytic perspective, the feelings of frustration felt by professionals as a result of their lack of knowledge may be projected onto the SM child or parent, labelling them as a frustrating individual (Klein, 1946). As a result of this professionals may not feel the need to expand their knowledge as the blame is placed with the individual child or parent.

Due to the combination of negative personality characteristics of professionals and lack of knowledge and understanding of SM, four parents in this study described a gradual process of their child becoming unhappy at school with no support or accommodations made, until they reached a position of total school refusal. Three of the four children then became more withdrawn, being unable to leave their room or house. Similarly, Omdal's (2007) participants reported that a combination of stressful experiences and adults who did not recognise their needs gradually resulted in withdrawal from the social environment. This highlights the importance particularly of the education environment and the role education staff have, as withdrawal from school may signify the beginning of wider social withdrawal. The impact of this total withdrawal could be devastating, with the parent and family also becoming near house bound. This finding may support the suggestion that SM is a symptom of social phobia or social anxiety rather than a distinct disorder (Black & Uhde, 1995; Golwyn & Wenstock, 1990).

Parents discussed the positive impact some interventions can have for their child. This included medication to help manage the child's anxiety, and a range of interventions that were particularly prominent in the school environment, such as environmental changes and use of the Sliding-in Technique. As a result of these interventions parents believed that their child was able to attend school, to take part in more things outside of school, and in some cases showed increased communication. However, a parent in Douglas' (2021) study notes a lack of commitment by school staff to delivering the Sliding-in Technique for their child. This study builds on this with parents sharing the detrimental impact inconsistent support had on the child and the parent and family, for example, variable administration of the Sliding-in Technique, or not all teachers in a secondary school putting a strategy in place. One of the consequences of support being inconsistent was that SM became a recurring issue or a '*pattern*' (Penelope), with progress made before things would slide back to where they had been previously. This highlights the possible perception that once the child starts to speak, the support is no longer necessary. Parents expressed negative feelings as a result of inconsistent support, such as it being '*infuriating'* (Penelope) and '*difficult*' (Maria). Sarah described how she is now '*at the point where I don't really want to introduce anyone else in'* due to the sheer volume of professionals input over the years which has failed for her child. She described how a total of 44 professionals had inputted for her 13 year old child. Penelope reported that her child began to distrust the systems around them as a result of this inconsistency, and her concerns that as a result of years of inconsistent interventions her child's SM is now '*entrenched*'. Parents expressed feelings of time having been wasted, and Maria and Penelope both wondered about where their child could be now if intervention had been successful. Drawing from Bronfenbrenner's eco-systemic model (1979), the perception held by parents is that the continual withdrawal of support in the systems around the child not only meant that the child did not make progress but was actively detrimental to the child. Current literature does not explore how long intervention is needed for, but it is beginning to support multidimensional treatment for SM, including modular CBT, behavioural interventions, and psychoeducation for parents and school staff (Lang et al., 2016).

In addition to inconsistent support, parents spoke of the total lack of input and support from some professionals, also reported by parents in Douglas' (2021) study. This was accompanied by feelings of frustration due to referrals often taking a long time, only to then be turned down. Input from mental health professionals was felt to be lacking by parents and seen as key due to each parent's belief that SM is routed in anxiety. A few of the parents in this study discussed their child's suicidal thoughts and incidents of self-harm, which links with the 'suicidal gestures' made by three of Omdal's (2007) adult SM participants. Parents in this study described their experience of mental health services being reluctant to offer any therapeutic support or being unable to, due to relying on the child to speak. Penelope expressed her extreme frustration that her 16-year-old child had received no input from children's mental health services and was unlikely to meet the criteria for adult services. This lack of mental health input is directly in contrast with the case study by Albrigtsen et al. (2016), where the family benefitted from a multidimensional treatment of intensive intervention in a residential clinical setting for five weeks, followed by psychoeducation with school staff. In the UK however such intensive therapeutic input may be difficult to access, with mental health services for CYP struggling to meet levels of need (Whitehead, 2021; Trade Union Congress, 2018). In addition, some parents may struggle to take part in family-based therapy given their past perception of being blamed for their child's SM. Concerningly, the professional participants in Hoyne's (2014) study did not perceive that SM had an impact on the child's emotional well-being. This is despite previous research demonstrating higher likelihood of having psychiatric diagnoses in early adulthood such as phobias or eating disorders (Steinhausen, Wachter, Laimbock & Metzke, 2006). This indicates an increased need for understanding of the long-term impact on mental health of SM amongst professionals.

Parents identified the systems around individual professionals and felt that these systems had barriers within them which influenced their experience of professional input. For example, parents were aware of the difficulty accessing professionals, and of this being linked to the limitations on public services and high caseloads. Ellis' (2015) SPs felt that it was challenging for them to be the lead professional in SM casework due to their high workload. In addition, Davidson (2012) notes that 50% of participating teachers reported being unable to implement interventions due to time constraints. Hoyne's (2014) teachers, SALTs and EPs felt that SM casework was challenging due to it being time consuming, complex in nature, and interventions taking a long time to produce progress. Parents spoke of elements within the systems not being joined up, and of professionals in public services being limited in what they are allowed to do and say. Parents were particularly concerned at what they perceived to be a lack of honesty from professionals as to what support the child needed, and what they were able to offer. They felt that this had directly negatively influenced them and their child as it had taken the parent longer to discern what their child needed, e.g., intensive therapeutic input. This is a new finding within the SM literature, and of particular concern to professionals given the ethical codes many professions have to abide by, e.g., EPs must abide by the BPS Code of Ethics and Conduct (2018) and the Health and Care Professions Council (HCPC) Standards of Proficiency (2015). Although this study is focusing on the impact of professionals on the child and parent, we can apply Bronfenbrenner's eco-systemic model (1979) to consider and acknowledge that professionals are equally part of a system which influences their behaviour.

The barriers within the systems resulted in parents feeling that they needed to fight for their child and viewing the SM experience as a battle to overcome. Louise described the detrimental impact on her life of this fight; '*I'm up till silly times in the morning sending emails and chasing people up and trying to fit it all in with work…it has been really stressful'*. Douglas (2021) echoes this finding, reporting that parents had to be proactive in seeking support for their child. A particular system which six parents spoke of is that of the EHCP process. The parents mostly had negative experiences of this, with poor communication with the SEND team, parents having to apply themselves with no support, the assessment being done poorly, and needing to resolve concerns through legal disputes. A survey of parents and CYP in relation to EHCP's reported significantly more positive experiences than the parents in this study (Adams et al., 2017). For example, 25% of parents and CYP found starting the EHCP process to be difficult, compared to five of the six parents in this study. This links with a new finding in this study, whereby several parents reported that they felt their child was discriminated against and treated differently from other children with SEND. This likely is founded in the lack of knowledge and awareness of SM. Charlie detailed that her SEND officer and the head of the SEND team admitted they did not have any knowledge of SM, and so she felt that they could not make a decision about her child's support. Despite the range of barriers that parents encountered within the EHCP system, they all hoped that having an EHCP meant their child would be appropriately supported. As a result of this belief parents continued to push for an EHCP, seeking legal advice and getting involved in several tribunals. For some, an EHCP meant being able to attend a specialist provision, which was a setting and group of professionals that parents consistently spoke positively about. This identification of systemic barriers is a new emergence in this area of research.

This is the only SM study in which parents have spoken of their need to seek support from privately funded professionals and how this was often needed due to barriers within the public services. Parents used privately funded professionals to work directly with their child, e.g., addressing their anxiety, and to produce reports which would come from what they felt was a more honest position than reports by professionals in public services. In addition, Charlie noted that she privately funded an EP '*so I knew I wasn't completely losing my marbles*'. In looking for this reassurance, Charlie sought certainty in understanding her child's needs. Previous research based in appraisal theories has noted that people are willing to pay financially in order to reduce feelings of uncertainty (Lovallo & Kahneman, 2000). Parents did speak negatively of the financial burden of funding private professionals; Penelope detailed assessments needing to be made against their mortgage, whilst Tula was only able to afford private SALT due to Disability Living Allowance. Despite this, parents were mostly positive about privately funded professionals, and spoke of how they had improved the situation for the parent and the child. For example, a private SALT had increased Tula's child's attendance at a specialist provision and participation in activities outside of school with their friends and other supporting services.

5.4.2 Support Parents Would Like

Research question 2: What support from professionals would the parents of children with selective mutism like to have?

The parents in this study outlined the support they would like to have going forwards, or in hindsight feel would have been beneficial. A new contribution in this area is that parents identified a need for an SM pathway, with Charlie noting that there are clear pathways for other disorders such as ASD. There do appear to be some pathways for SM in local authorities; Essex Partnership University NHS Foundation Trust have one available through a cursory internet search (https://eput.nhs.uk/wp-content/uploads/2017/01/Selective-mutism-care-pathway.pdf). In addition, during this study the researcher was made aware of a further three LAs creating SM pathways, however as these are in the formative stage permission to share current plans was not given. However, a pathway in three out of 333 LAs is clearly not the norm, with this indicating geographical differences as to how coordinated support for SM may be.

Within the SM pathway parents wanted the initial assessment for SM to be better. This links with professional views, with key areas of the in-process Wandsworth Care Pathway identified as prompt identification of SM, and prompt and appropriate assessment and intervention (Keen et al., 2008). Parents in this study wanted a caseworker and honest communication about what support was available. They wanted consistent access to resources, professionals, and interventions over time. This builds upon a parent in Douglas' (2021) dissertation study noting the benefits for their child of one consistent staff member ensuring consistent delivery of interventions. Whilst parents wanted more consistent access to some services they may already have, e.g., for a primary school EP to be able to follow the child to their secondary school, parents also wanted access to new resources such as mental health input. Parents in this study identified they would like more time with professionals, whilst the professionals in Hoyne's (2014) study identified that they too would like more time for SM casework. The range of support in the SM pathway identified as desirable by parents supports research findings of the benefits of multidimensional treatment for SM (Lang et al., 2016).

Several of the parents in this study advocated for their child to access appropriate support and adaptations in a mainstream school, such as teachers not asking them to speak, and the use of recommended interventions. Many parents felt that this was more likely to be achieved with an EHCP, with a specific adult watching out for their child. Douglas (2021) reports that three parents felt that it had been helpful to have a dedicated member of staff for their child in school, and that the child had been able to build a trusting relationship with this adult. Alternatively, other parents felt passionately that their child needed specialist provision, partly due to the mainstream class sizes being unmanageable for their child, but also because of the better understanding of staff in specialist provision. This focus on what educational provision is needed for a child with SM is a new contribution in the SM literature. Penelope expressed concern at the lack of appropriate post-16 provision, and how her child would not be able to cope in a large college. Charlie's child is now in a specialist provision, and she expressed a desire for them to develop independence skills, such as being able to ask for help when out in the community and to one day be employed. This need to improve the situation before the child leaves education is relevant, with Walker and Tobell (2015) reporting that a participant had found their SM recognised and accommodated at school but had no such adaptations in higher education or a workplace. Subsequently, they were in neither and were dependent on their parents as a young adult.

Literature continually identifies the need to raise awareness about SM. A number of different services have produced materials to improve awareness and knowledge of SM. However, the findings from previous research indicate that a deeper level of knowledge is felt to be needed for those supporting a child with

SM. Davidson (2012) reports that five out of six of the participating teachers wanted CPD about SM for all adults around the child, and Ellis' (2015) participating SPs felt that educating and raising awareness about SM being an anxiety disorder in school staff was a primary area to address. Hoyne's (2014) participants identified the need to raise awareness and knowledge about SM itself, but also about the different roles and contributions different people can have to this casework. It was felt that this was needed during professional training courses and through CPD. This need for more awareness of SM was also evidenced in the parent interviews in this study. However, as stated by Dean (2012), current training courses may not include SM due to its relative rarity. However, teachers who had access to SM training reported feeling supported, less anxious, and more confident in supporting pupils with SM. Therefore, its inclusion in CPD may be critical, with Roe (2002) highlighting that CPD is important for the competence of psychologists when working with CYP. Alternatively, Hoyne's (2014) participants suggested that it may be helpful for courses to include more training on children's emotional needs and anxiety generally, in order to combat this.

5.5 Strengths and Limitations of Study

A strength of this study is that a pilot study was conducted, with the purpose of considering from the perspective of a parent of a CYP with SM whether the planned interview schedule was appropriate. Pilot studies are beneficial for considering feasibility and success of the intended methods before undertaking the whole research effort on a larger scale (Thabane et al., 2010). The pilot study participant reported that the planned interview schedule would garner the information being sought. Whilst the pilot study participant did not believe the original schedule would cause participants distress, they did recommend some changes of wording to further minimise the possibility of this, for example, removing the negative phrasing of 'struggling' from a question.

A limitation of this study is the possibility of sampling bias caused by participants needing to volunteer to share their experiences. As a result of this they may have been especially motivated to speak about their experiences with professionals, perhaps due to particularly positive or negative experiences. This may have reduced the validity of the study as the themes identified in the findings are not representative of the entire population. Further, in relation to sample, all participants were mothers, which raises questions as to paternal experiences of SM and professionals. Additionally, the need to take part in a spoken online interview may have further restricted the sample, as those with social anxiety may have felt unable to take part in this way. This is particularly pertinent given previous research findings of higher rates of social anxiety and phobia in the parents of CYP with SM (Chavira et al., 2007; Kristensen & Torgersen, 2001). A traditional written questionnaire was not conducted as it was felt that it would not garner the depth of information being sought. However, interview through online instant messaging could have been considered, as evidenced in Walker and Tobbell's (2015) study. A strength of the study was that the interview questions were sent to participants in advance of them giving signed consent to take part. This increased transparency and possibly contributed to the research retention rate, with no participant who gave signed consent later withdrawing from the research. It was also beneficial that participants were sent the interview schedule in advance as parents spoke of professionals they had interacted with many years ago. Recall bias of retrospective experiences is known to have a negative impact on the accuracy of recall (Hassan, 2006). However, the pre-awareness of interview questions will have prevented answers from having to be 'on the spot' with little thinking time.

Finally, a key benefit of thematic analysis is that it can be used flexibly. This can however also result in difficulty with conducting a rigorous analysis. In order to combat this, frameworks that already exist within the thematic analysis literature were followed, for example, Braun and Clarke's six phases of analysis, and questions to inform thematic analysis. In addition, the trustworthiness of the data analysis was enhanced by the researcher's University Director of Studies checking the initial coding for an interview and thematic map.

5.6 Implications for Professional Practice

This study suggests that professionals can have a life changing impact on parents and their child with SM both for the positive and the negative. The findings highlight some considerations for professionals across settings, which can ensure that CYP with SM and their parents are adequately supported.

A primary area to consider is the personal characteristics parents reported in professionals. Professional training programmes may benefit from including communication skills in their curriculum, for example attuned interactions (Kennedy & Landor, 2015). This includes, but is not limited to, behaviours that demonstrate the professional is being attentive, encouraging the parent to speak, and guiding them and supporting them. In addition, whilst the professional may have some relevant knowledge, there is a desire for them to not take the position of ‘expert’ and to also look to the parent to understand the child and their needs. This supports emerging research indicating that parents are experts in regard to their child’s care (De Geeter et al., 2002; Kirk & Glendinning, 2002). The parents’ indication that they appreciated more communication from professionals links with ideas of work with CYP and families not being done to them, but in collaboration with them (Bruner, 1991).

There is a clear need for increased awareness of SM across many groups of professionals, with the staff in specialist provisions being the only group of professionals to be consistently spoken about as understanding the CYP with SM. Public services often have limited resources and may find it difficult to enable all staff to access external CPD on a topic. However, this barrier can be overcome by one professional in a team or setting attending CPD and cascading their learning to other members. Additionally, professionals can educate themselves in the same way as the parents in this study through further reading and SMIRA, which has a range of information available for anyone seeking to improve their knowledge of SM.

Parents spoke of the need for honesty in the systems, and of needing to know what support is available. This could be approached by professionals making their role and scope of input clear. There is indication of a lack of clarity between the roles of EPs, schools, LA advisory services, and other support services (Kelly & Gray, 2000). Kelly and Gray (2000) promote the use of a 'clear statement of the service they can expect' (p. 4) to counter this. The parents in this study felt that honesty and clarity from public service professionals would have enabled them to make a timely decision about the appropriateness of needing to seek input from privately funded professionals.

Finally, a range of system barriers were raised within this study which it is likely will be challenging to address, e.g., professionals in public services having a high caseload, and so not having much time for SM casework. However, other barriers within the systems were raised which could be addressed. For example, the EHCP system was heavily critiqued by parents. There is currently a major review into the SEND system, which may address some of the gaps and barriers identified by parents. Amongst other things, the review will put forward new actions for 'better helping parents to make decisions about what kind of support will be best for their child' and 'making sure support in different local areas is consistent, joined up across health, care and education services' (Department for Education, 2019). Parents in this study spoke of the need for joint working between professionals, which contributes to positive outcomes for service users (Atkinson et al., 2002; Atkinson et al., 2007).

5.6.1 Implications for EP Practice

As with all other professionals, a key implication for EP practice in the findings is the need for EPs to develop their awareness of SM. As previously mentioned, this could be through one team member attending CPD training and cascading learning to other EPs in the team, perhaps during a team meeting, a sentiment also echoed by Hoyne's (2014) EP participants. It may be beneficial within a team to have an EP who specialises in SM. Whilst it would not be necessary for this individual EP to take on every piece of casework, they would be able to provide peer support and professional insight to other EPs. In addition to educating EP colleagues about SM, EPs are ideally placed to educate others about SM (Carlson et al., 2008). They particularly develop close links with education settings, and would be able to provide whole setting training, as well as small group supervision for adults around a pupil with SM (Farrell et al., 2006).

One of the key factors to consider is how EPs interact with the parents of CYP with SM. The parents in this study had encountered a number of barriers and negativity which impacted on them and on the support their child received. EPs should consider the journey a parent may have been on prior to accessing their support, and how attuned their interactions with parents are. Helpfully, some of the current EP training courses include Video Enhanced Reflective Practice (VERP) (Kennedy & Landor, 2015) as part of the initial training, which supports reflections on attuned interactions with service users. The use of VERP could be incorporated through CPD for EPs to revisit attuned interaction skills.

Furthermore, when considering interactions with parents, EPs should make the boundaries of their role clear, as has been mentioned as being appropriate for all professionals. For example, within the context of traded services, an EP may only be able to provide a single assessment in one school for an SM CYP but provide ongoing support in a nearby school for another child due to the amount of EP time that the school has purchased. EPs should be clear with parents about what they can expect, and also work with schools to identify and prioritise SM CYP. Educating others to recognise the severity of SM and how to support it may be one of the primary contributing factors an EP can make. Many parents in this study described their child not being supported by school staff and how this resulted in school refusal and their child withdrawing from society in other ways. If EPs can promote awareness of SM in schools and how to meet the needs of CYP with SM, school refusal and social withdrawal could be reduced, with clear benefits for both child and parent. Finally, EPs need to be promoting communication and joint working for CYP with SM. The need for this is already stipulated in the SEND CoP (2015) and the Children and Families Act (2014).

5.7 Implications for Future Research

This study explored the experiences parents have of helpful and unhelpful input from professionals for their child with SM. It also explored what support they would ideally like to have. This research has impact and importance as the voices of parents of CYP with SM are currently underrepresented within the literature.

However, in focusing on the voices of parents, the voices of the professionals being spoken about and the CYP themselves have been excluded. The voices of professionals and those with SM have been explored in prior literature, however, future research could look at triaging the experiences of professionals, parents and CYP. For example, it would be beneficial to understand all three perspectives regarding implementing a strategy. Additionally, a limitation of this study was that only mothers took part. It would be beneficial to gain other family voices in SM research, such as fathers and siblings.

This research is the first to focus on parents speaking about the strengths and barriers in the systems for CYP with SM. It would be useful to gain further insight from parents and professionals about occasions when they have successfully increased other's knowledge and awareness of SM, or when such attempts have failed. This would allow for more in-depth learning of the factors which would promote or prevent the implementation of learning.

Finally, parents in this study identified an SM pathway as one of their key areas to develop in order to improve support for CYP with SM. At the time of writing, the researcher identified that only one of the 333 LAs in the country had such a pathway, with a small handful of others being created. Future research should explore outcomes and experiences for families and CYP with SM on these pathways, in comparison to those who are in a LA without such a pathway. In addition, it would be beneficial to not only compare a pathway LA with a non-pathway LA, but to explore how to continually develop and improve a pathway for SM CYP.

5.8 Dissemination of Findings

At the end of the interviews participants were asked if they would like to receive information about the findings in the form of a summary of the themes. All parents expressed interest in this and a summary of findings was emailed to the participants on 20.02.2022.

At a local level, the researcher will share the findings with other TEPs and academic staff on the UEL training programme via the yearly Research Conference. In addition, the researcher will share the study findings with the LA EP service within which they are on their final placement year and are due to join once qualified.

At a national level, the researcher will share their findings with SMIRA. If this research is deemed of a high enough quality for publication, attempts to reach a wider audience will be sought through links with SMIRA and LA's.

5.9 Reflections and Reflexivity

This section is written in first-person and will consider my personal reflections on the research process, including positioning as a professional, possible sources of bias, and key learning.

I created the interview schedule and its semi-structured nature enabled me to develop the discussion as I saw appropriate. In keeping with my social constructionist perspective, I aimed to hear and explore the perspectives of the participants, rather than entering the interviews with pre-conceived expectations. However, it must be accepted that I will have influenced the direction and content of the discussion. In order to guard against this insofar as is possible, I tried to be aware of my beliefs, feelings and interpretations throughout the research process (Creswell, 2014). I kept a research diary (Fox et al., 2007) with the aim of being more conscious of these feelings and how they may be impacting upon my research. Please refer to appendix 19 for a brief extract of this diary. I therefore acknowledge this research may incorporate some subjectivity.

I am aware that there was very little active participation from participants in this study; this research was led by the researcher and participant participation falls at only rung four on Hart's (1992) ladder of participation. I therefore positioned myself in a place of power as an 'expert researcher'. Simultaneously, I conducted the research as a TEP, and the term 'psychologist' may likely carry a level of 'expert' expectation from parents. I am completing a professional doctorate working towards becoming an EP, which is a professional many of the parents in this study had interacted with in relation to their child's needs. As a result of this parents may have felt the need to temper their opinion when reporting their experiences with EPs. In order to guard against this, I stressed to participants that I wanted to understand their experiences and was mindful of my interpersonal skills to guard against a perceived power differential as much as possible.

I have enjoyed the qualitative research process and also found it a steep learning curve. It has been an incredibly humbling experience, and I am honoured that parents have spoken to me so openly about the incredible challenges they have faced, as well as the joys. Whilst I have always been aware of the importance of putting in place evidence based and robust support plans for CYP, my experience conducting research, and the findings of this research have emphasised the importance of core 'soft skills' such as ensuring interactions are attuned. In the busy daily demand of EP work and a need to evidence impact, the importance of these basic skills can at times feel lost.

5.10 Conclusion

The aim of this research was to explore parental experiences of professional involvement for their child with SM. This included exploring how professional input had affected the parent and child's experience of SM, and what support would be ideal for the child. This area was chosen due to a lack of parents' voices being present in the SM literature.

Eight parents participated in semi-structured interviews via videoconferencing. The interview schedule was created by the researcher and edited following feedback during a pilot study. The parents reported a mixture of positive and negative experiences with professionals across public services, and also privately funded professionals. Factors such as the personal characteristics of the professional, their communication with others, and knowledge of SM were all identified as contributors to the parent's experience with that professional. Professional knowledge of SM and how to support it played a huge role in the parent and child’s experience of SM. Professionals who knew how to support SM and displayed positive personal characteristics were highly thought of by parents and described at times as life-changing for both parent and their child. Conversely, those who did not know how to support SM and had negative personal characteristics had a negative impact that affected the child and parent’s life, e.g., school refusal and withdrawal from other social situations. Parents identified barriers within the public service systems, and how these had a detrimental impact on professionals and the parents’ and child’s access to them. For example, parents named the high caseload and lack of time public service professionals have, additional to a lack of joint working, as barriers, and spoke of the systems as being something they need to fight against in order for their child to be supported.

Ideal support for the parents in this study would include a pathway for SM, as indeed there is for other disorders such as ASD. Within this pathway parents felt it critical that there is an assigned caseworker, access to the same professionals to promote consistency, that professionals have more time for them, more resources, mental health support for their child, and honesty as to what support is available. In addition, parents identified the need for appropriate provision and accommodations to be made for their child in mainstream school, or for there to be specialist provision available for children with SM who are unable to manage in a mainstream setting. Finally, parents identified a need for there to be more awareness of SM.

Using Bronfenbrenner’s eco-systemic theory (1979) as an overarching executive theory, there are clear lines between the influence professionals have, and the child’s development. This can be through direct contact with the child, through their parent, or through other professionals. Additionally, the relationship between parent and professional can also influence the relationship between parent and child.

These findings have various implications for professionals. A primary area is the need to build awareness and knowledge of SM, a role for which EPs may be among the best placed professionals. However, there are barriers regarding EP knowledge of SM, as well as limitations within which EPs work, e.g., traded services. In conjunction with this is the need for joint working on SM cases; this is beneficial for the child and family, and would also be a good space for professionals to share and develop their knowledge of SM.

A second key implication of the findings is the importance of soft skills such as active listening and the demonstration of empathy and compassion. Parents reported that this made a huge difference, particularly when discussing a disorder in which poor understanding had often resulted in them being blamed for their child’s needs.

Through dissemination, the findings of this study could increase understanding of parental experiences for professionals. It is a chance for a professional to view it from the side of the parent and could provide a source of reassurance to other parents who have had similar experiences to those who have participated in this research. The experiences shared in this research are truly humbling, and the voices of the parents are well worth listening to.

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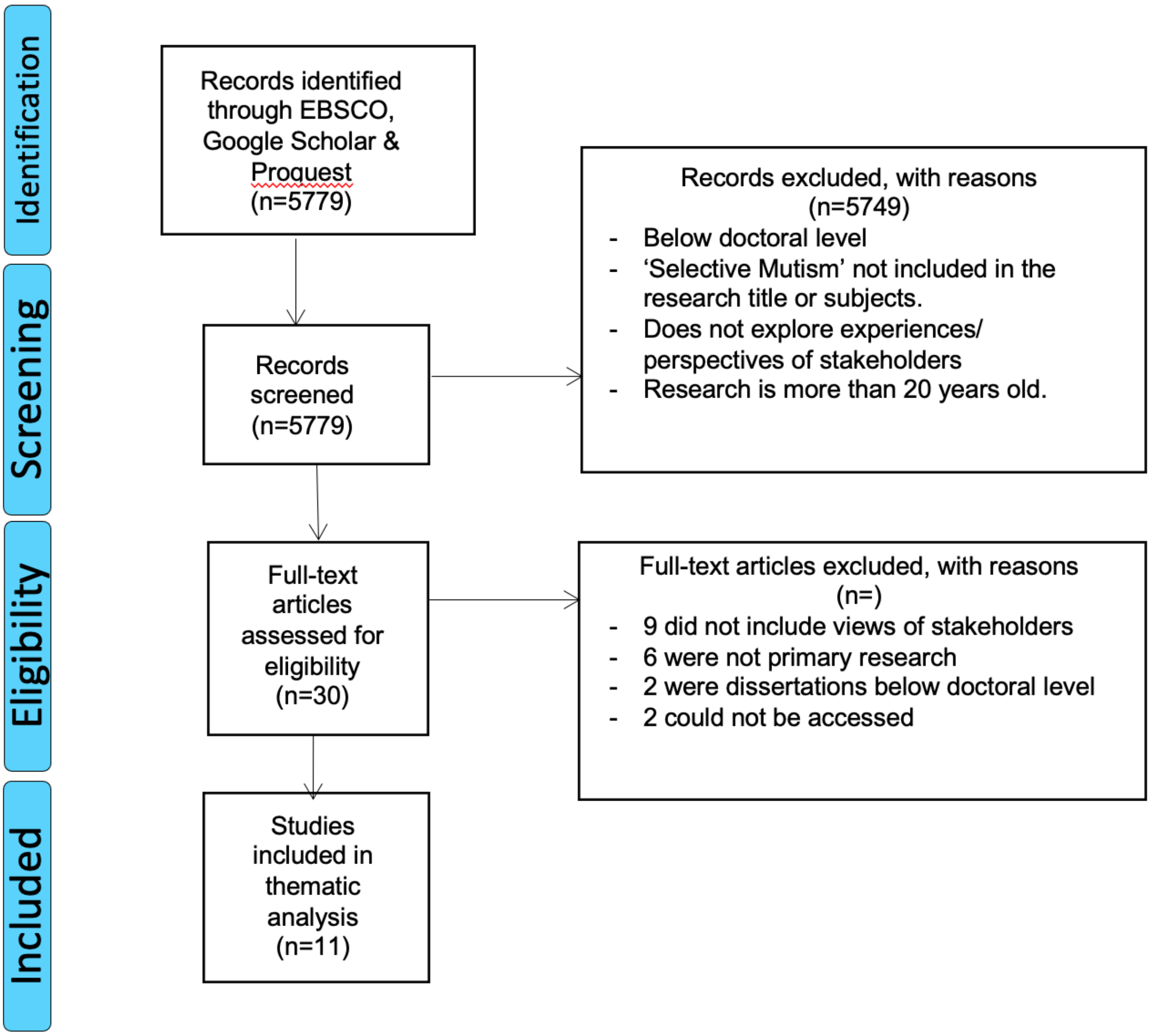
Appendices

Appendix 1 - PRISMA Model (Moher et al. 2009) of Systematic Literature Review Conducted on 26.02.2021



Appendix 2 - Analysis of Quality of Literature Reviewed Using Yardley's Characteristics of Good Qualitative Research (2000)

Sensitivity to context

- Context of theory and understandings created by previous investigators when have used similar methods/analysed similar topics.
- Good literature review and synthesis.
- Awareness of socio-cultural setting of study. Influences on beliefs and expectations. Sensitivity to each utterance and the context of it.
- Participant involvement. Openness to perspectives of all participants.

Commitment and rigour

- Thoroughness in data collection, analysis, and reporting.
- Prolonged engagement with the topic, the development of competence in the methods used, immersion in the data.
- Completeness of data collection and analysis. Depends on adequacy of sample – its ability to supply all the information needed for a comprehensive analysis. Analysis should address all of the variation and complexity observed.

Transparency and coherence

- Quality of the narrative.
- Coherence – the fit between the research question, the philosophical perspective adopted, and the method of investigation and analysis.
- Transparency – detailing every aspect of the data collection process and the rules used to code the data. Presentation of excerpts of data.
- Disclosure of all relevant aspects of the research process, including reflexivity.

Impact and importance

- The value of the piece can only be assessed in relation to the objectives of the analysis, the applications it was intended for, and the community for whom the findings were deemed relevant.
- Socio-cultural impact – belief that all our speech and actions arise from a particular social context and have social effects. Research can contribute to a change in the way we think/talk.

	Sensitivity to context	Commitment and rigour	Transparency and coherence	Impact and importance
Walker & Tobell (2015) Lost voices and unlived lives: exploring adults’ experiences of Selective Mutism using IPA. HIGH	Context of theory – ✓ Review and synthesis - ✓ Context of social – ✓ Openness to participants - ✓	Thorough data collection and analysis – ✓ Competence in methods used – ✓ Immersion in data – ✓	Quality of narrative – ✓ Coherence between RQ, philosophy, and method – ✓ Transparency of data collection and analysis – ✗ Use of quotes – ✓ Reflexivity - ✓	Met objectives of analysis - ✓ Socio-cultural impact - ✓
Patterson (2011) Personal constructs of adolescents with Selective Mutism. HIGH	Context of theory - ✓ Review and synthesis - ✓ Context of social – ✓ Openness to participants - ✓	Thorough data collection and analysis – ✓ Competence in methods used – ✓ Immersion in data – ✓	Quality of narrative – ✗ Coherence between RQ, philosophy, and method – ✗ Transparency of data collection and analysis – ✓ Use of quotes – ✓ Reflexivity - ✗	Met objectives of analysis - ✓ Socio-cultural impact - ✗
Roe & Phil (2011) Silent voices: listening to young people with Selective Mutism. MEDIUM	Context of theory - ✓ Review and synthesis - ✓ Context of social – ✓ Openness to participants - ✓	Thorough data collection and analysis – ✗ Competence in methods used – ✗ Immersion in data – ✗	Quality of narrative – ✗ Coherence between RQ, philosophy, and method – ✗ Transparency of data collection and analysis – ✗ Use of quotes – ✓ Reflexivity - ✗	Met objectives of analysis - ✗ Socio-cultural impact - ✗

Albrigsten et al (2015) Tiers of silence – family lived experiences of Selective Mutism in identical twins. LOW	Context of theory - ✓ Review and synthesis - ✓ Context of social – ✗ Openness to participants - ✓	Thorough data collection and analysis – ✗ Competence in methods used – ✗ Immersion in data – ✗	Quality of narrative – ✗ Coherence between RQ, philosophy, and method – ✗ Transparency of data collection and analysis – ✗ Use of quotes – ✓ Reflexivity - ✗	Met objectives of analysis - ✓ Socio-cultural impact - ✗
Hoyne (2014) Understanding, identifying and supporting CYP with Selective Mutism : perspectives and experiences of key stakeholders. HIGH	Context of theory - ✓ Review and synthesis - ✓ Context of social – ✓ Openness to participants - ✓	Thorough data collection and analysis – ✓ Competence in methods used – ✓ Immersion in data – ✓	Quality of narrative – ✓ Coherence between RQ, philosophy, and method – ✓ Transparency of data collection and analysis – ✓ Use of quotes – ✓ Reflexivity - ✓	Met objectives of analysis - ✓ Socio-cultural impact - ✓
Davidson (2012) Selective Mutism: exploring the knowledge and needs of teachers MEDIUM	Context of theory - ✓ Review and synthesis - ✓ Context of social – ✓ Openness to participants - ✓	Thorough data collection and analysis – ✗ Competence in methods used – ✗ Immersion in data – ✗	Quality of narrative – ✗ Coherence between RQ, philosophy, and method – ✗ Transparency of data collection and analysis – ✗ Use of quotes – ✓ Reflexivity - ✗	Met objectives of analysis - ✓ Socio-cultural impact - ✗
Ramos (2018)	Context of theory - ✓ Review and synthesis - ✓	Thorough data collection and analysis – ✓	Quality of narrative – ✓	Met objectives of analysis - ✓

Breaking the Silence: An IPA study exploring the experiences, thoughts, feelings and perspectives of teachers working with Selectively Mute children. HIGH	Context of social – ✓ Openness to participants - ✓	Competence in methods used – ✓ Immersion in data – ✓	Coherence between RQ, philosophy, and method – ✓ Transparency of data collection and analysis – ✓ Use of quotes – ✓ Reflexivity - ✓	Socio-cultural impact - ✓
Ellis (2015) Selective Mutism: a survey of school psychologists experience, knowledge and perceptions. MEDIUM	Context of theory - ✓ Review and synthesis - ✓ Context of social – ✓ Openness to participants - ✓	Thorough data collection and analysis – ✗ Competence in methods used – ✗ Immersion in data – ✗	Quality of narrative – ✗ Coherence between RQ, philosophy, and method – ✗ Transparency of data collection and analysis – ✓ Use of quotes – ✓ Reflexivity - ✗	Met objectives of analysis - ✓ Socio-cultural impact - ✗
Omdal & Galloway (2007) Interviews with selectively mute children LOW	Context of theory - ✓ Review and synthesis - ✗ Context of social – ✗ Openness to participants - ✗	Thorough data collection and analysis – ✗ Competence in methods used – ✗ Immersion in data – ✗	Quality of narrative – ✗ Coherence between RQ, philosophy, and method – ✗ Transparency of data collection and analysis – ✗ Use of quotes – ✗ Reflexivity - ✗	Met objectives of analysis - ✗ Socio-cultural impact - ✗
Omdal (2007)	Context of theory - ✗ Review and synthesis - ✓	Thorough data collection and analysis – ✗	Quality of narrative – ✓	Met objectives of analysis - ✓

Can adults who have recovered from selective mutism in childhood and adolescence tell us anything about the nature of the condition and/or recovery from it? MEDIUM	Context of social – ✗ Openness to participants - ✓	Competence in methods used – ✗ Immersion in data – ✓	Coherence between RQ, philosophy, and method – ✗ Transparency of data collection and analysis – ✗ Use of quotes – ✓ Reflexivity - ✗	Socio-cultural impact - ✓
Frazier & Howard (2020) Perspectives of Speech-Language Pathologists and School Counselors on the Nature and Treatment of Selective Mutism. LOW	Context of theory - ✓ Review and synthesis - ✓ Context of social – ✓ Openness to participants - ✗	Thorough data collection and analysis – ✗ Competence in methods used – ✗ Immersion in data – ✗	Quality of narrative – ✗ Coherence between RQ, philosophy, and method – ✗ Transparency of data collection and analysis – ✗ Use of quotes – ✗ Reflexivity - ✗	Met objectives of analysis - ✓ Socio-cultural impact - ✗

Appendix 3 – Quantitative Data Analysis

	Validity	Reliability
Roe & Phil (2011) Silent voices: listening to young people with Selective Mutism.	✗ Questionnaire not provided so unclear. Some attempts to ensure valid – sought advice of knowledgeable other to ensure clear meaning of terms.	✗ Questionnaire used once – created and used for this.
Davidson (2012) Selective Mutism: exploring the knowledge and needs of teachers	✓ Questionnaire provided and measures what claims to.	✗ Questionnaire used once – created and used for this.
Ellis (2015) Selective Mutism: a survey of school psychologists experience, knowledge and perceptions.	✓ Questionnaire provided, checked with focus group and individual knowledgeable about SM.	✗ Questionnaire used once – created and used for this.
Frazier & Howard (2020) Perspectives of Speech-Language Pathologists and School Counselors on the Nature and Treatment of Selective Mutism.	✗ Questionnaire not provided so unclear. No clear attempts to promote validity.	✗ Questionnaire used once – created and used for this.

Appendix 4 - Participant Recruitment Poster

Parents wanted!

Would you like to share your experiences of working with professionals? If so I'd love to hear from you!

What is it?

I am currently a Trainee Educational Psychologist in my 2nd year of study at the University of East London. For my thesis I am conducting research titled '*Parental experiences of professional involvement for children and young people with selective mutism and their preferred support*'. The research will explore your experiences of input and support previously offered by professionals with regards to your child's selective mutism, and what support you would like to have.

Who can take part?

- Parent of a child in key stage 3 or 4 (school years 7 – 11) with selective mutism, or who has had selective mutism up until very recently (still experienced during key stage 3 or 4).
- You must have spoken with at least one professional about your child's selective mutism at any point in their lifetime. Professionals spoken to may include (but are not limited to) members of school staff, Speech and Language Therapist, Paediatrician, Education Psychology, Clinical Psychologist etc.
- You must be a resident of the UK.

What will participants have to do?

- If you are interested contact me at u19443258@uel.ac.uk.
- Following this you will receive an email including an information sheet with further details about the research, and a consent form. You will also be invited to an initial meet and greet online on Microsoft Teams to ensure you are eligible to take part, and to enable the researcher to answer any additional questions you may have.
- If you are eligible you will then take part in an online video/audio interview (according to your preference) on Microsoft Teams. This will be semi-structured with some interview questions prepared. This interview will be recorded for transcription purposes. It is estimated that the interview will last between 30 minutes – 1 hour.
- The purpose of the study is to identify similar themes in parental experiences of working with professionals.

Confidentiality?

- Your participation in this will remain completely confidential and anonymous throughout the process. At the point of transcription any identifying data will be

removed and replaced. For example, you will choose a pseudonym for yourself to be referred to as, and any additional people who you mention in the interview will be referred to by their role within your or your child’s life, e.g. ‘my child’s class teacher’ ‘the Paediatrician’ etc.
- You have the right to withdraw your data from the study at any point up until 2 weeks following the interview. At this point the interview is likely to have been transcribed.

If you are interested in taking part, please contact Felicity Ang at u1944328@uel.ac.uk

Appendix 5 - Approval to Recruit from SMIRA

[redacted]com>

Fri 09/04/2021 17:08

To: Felicity Alexandra ANG

Dear Felicity,

SMIRA's Chair
have given their agreement for you to place a post in the group requesting participants for your research, but ask you to include the phrase 'Approved by Admin' at the beginning of your message. Good luck and please let us know your findings when your research is completed.

Regards,

[redacted]
SMIRA Hon. Sec.

Appendix 6 - Recruitment Timeline

Pilot Study Timeline
22.03.2021 – researcher contacted SENCo in placement LA
17.05.2021 – pilot study invitation letter sent to 2 potential pilot participants and SENCo
18.05.2021 – researcher contacted AEP LA EP
19.05.2021 – pilot study invitation letter shared with SENCo
20.05.2021 – initial contact with pilot study participant
08.06.2021 – return of pilot study consent form
18.06.2021 – researcher emailed pilot participant planned interview schedule
22.06.2021 – pilot study interview
24.06.2021 – researcher sent revised interview schedule and meeting notes to pilot participant
29.06.2021 – confirmation from pilot participant of interview schedule and notes
03.07.2021 – FA sent debrief to pilot participant

Timeline of contact with study participants

	P1	P2	P3	P4	P5	P6	P7	P8
Initial contact from participant (via facebook messenger or email)	03.07.21	02.07.21	09.08.21	09.08.21	23.08.21	15.09.21	01.10.21	19.10.21
Researcher reply with invitation letter, consent form, interview schedule	03.07.21	03.07.21	09.08.21	09.08.21	23.08.21	15.09.21	01.10.21	19.10.21
Participant consent form returned	05.07.21	03.07.21	20.08.21	22.08.21	24.08.21	24.09.21	07.10.21	21.10.21
Initial meet and greet	08.07.21	05.07.21	20.08.21	23.08.21	26.09.21	17.09.21	04.10.21	19.10.21
Interview	16.07.21	23.07.21	22.08.21	23.08.21	31.08.21	24.09.21	08.10.21	21.10.21
Debrief letter sent	16.07.21	23.07.21	23.08.21	23.08.21	03.09.21	24.09.21	08.10.21	21.10.21

Timeline of contact with potential participants

	PA	PB	PC	PD	PE	PF
Initial contact from participants (Via facebook messenger or email	03.07.21	07.07.21	28.07.21 – did not meet criteria	07.09.21	19.09.21	20.09.21 – did not meet criteria
Researcher reply with invitation letter, consent form, interview schedule	03.07.21	08.07.21 – did not meet criteria		07.09.21	19.09.21 – did not meet criteria	
Participant consent form returned	03.07.21			13.09.21		
Initial meet and greet	07.07.21 – did not meet criteria			15.09.21 – did not meet criteria		

Advertising of study timeline

02.07.21 – recruitment poster placed on SMIRA facebook page
11.07.21 – recruitment poster sent to 5 UEL TEPs
23.07.21 – recruitment poster placed on SMIRA facebook page
04.08.21 – recruitment poster placed on SMIRA facebook page
03.09.21 – recruitment poster placed on SMIRA facebook page
08.09.21 – recruitment poster shared with 2 PEPs and placed on NAPEP forum
01.10.21 – recruitment poster placed on SMIRA facebook page
18.10.21 – recruitment posted placed on SMIRA facebook page
01.11.21 – recruiting closed

Appendix 7 - Pilot Study Invitation Letter

PILOT STUDY PARTICIPANT INVITATION LETTER

You are being invited to participate in the pilot study for a research study. Before you agree it is important that you understand what your participation would involve. Please read the following information carefully.

Who am I?

I am a postgraduate student in the School of Psychology at the University of East London and am studying for a Doctorate in Educational and Child Psychology. As part of my studies I am conducting the research you are being invited to participate in.

What is the research?

I am conducting research into 'parental experiences of professional involvement for children and young people with selective mutism and their preferred support.' My research questions are:

1. What are the experiences parents have had of professional involvement for their child with selective mutism, and how do they feel that this has influenced theirs and their child's experience of selective mutism?
2. What support from professionals would the parents of children with selective mutism like to have?

This research is exploratory and aims to bring insight into parental experiences of their child's selective mutism, of how professional input can influence this, and of preferred support from professionals. It is hoped that themes will be identified in parental experiences, which may guide professionals to consider how they interact with and support the parents of children with selective mutism

My research has been approved by the School of Psychology Research Ethics Committee. This means that my research follows the standard of research ethics set by the British Psychological Society.

Why have you been asked to participate?

You have been invited to participate in my pilot study in order to consider if my interview schedule is appropriate from the perspective of a parent. I am looking to involve parents who have a child with selective mutism. You have identified yourself as someone who fits this description.

You are quite free to decide whether or not to participate and should not feel coerced.

What will your participation involve?

If you agree to participate you will need to sign and return the participant consent form to me via email. We will then arrange a time to meet on Microsoft Teams at a time that is convenient for you. You have the option to have your camera on and to therefore be physically visible during the interview, or to turn it off and to have only your audio on. We will look at the interview schedule together and consider if the questions are appropriate, and if you think they could be posed using different language. During the meeting I will take notes of key feedback that you give, and share this with you both during the meeting, and via email afterwards. The meeting is expected to last 20 – 40 minutes and should feel like an informal chat.

I will not be able to pay you for participating in my research, but your participation would be very valuable in helping to develop knowledge and understanding of your experiences of professional involvement, and the support that you would prefer.

Potential advantages and risks to participation

By participating in this research, you will have the opportunity to give voice to the experiences of parents with a child with SM when interacting with professionals. There is currently a lack of research in this area, and it is hoped that this research will enhance understanding about something which little is known.

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways you may find the following service and their resources helpful in relation to obtaining information and support: Selective Mutism Information & Research Association (SMIRA) (http://www.selectivemutism.org.uk/) is a free UK charity who can support the families with SM children.

Your taking part will be safe and confidential

Your privacy and safety will be respected at all times:

- You will not be identified by the data collected, on any written material resulting from the data collected, or in any write-up of the research. You will only be identified by a pseudonym which you will chose during the interview.
- You do not have to answer all questions in the interview and can stop your participation at any time.

What will happen to the information that you provide?
What I will do with the material you provide will involve:

- Your personal contact details and signed consent forms will be stored in a secure password protected file on UEL One Drive. This will be accessible only to the researcher and their Director of Studies.
- The final version of this work may include extracts or references to your feedback. This will be done anonymously.
- Once the researcher has graduated from their university course (estimated end of year 22/beginning of year 2023) the data will be destroyed.

What if you want to withdraw?
You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Separately, you may also request to withdraw your data even after you have participated, provided that this request is made within 2 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).

Contact Details
If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Felicity Ang – u1944328@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dr. Helena Bunn. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: Helena.bunn@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Professor Ian Tucker, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: i.tucker@uel.ac.uk)

Appendix 8 - Pilot Study Consent Form

UNIVERSITY OF EAST LONDON

Consent to participate in a pilot study

‘Parental experiences of professional involvement for children and young people with selective mutism and their preferred support.’

☐ I have the read the participant invitation letter relating to the above pilot study and have been given a copy to keep. The nature and purposes of the study have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

☐ I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher involved in the study and their Director of Studies will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

☐ I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun (2 weeks after interview).

☐ I consent to all of my data being destroyed upon the researcher’s graduation (estimated end of year 2022/beginning of year 2023).

Participant’s Name (BLOCK CAPITALS)

……………………………………………………………………………………….

Participant’s Signature

………………………………………………………………………………………..

Researcher’s Name (BLOCK CAPITALS)

………………………………………………………………………………………..

Researcher’s Signature

…………………………………………………………………………………………

Date: …………………….……..

Appendix 9 - Original Interview Schedule

Interview Schedule

6. How did you first become aware that your child was presenting with selective mutism?
   (Prompts – can you tell me more about…? Did anyone else mention SM to you? What did you notice in your child? How did you feel about that? What impact did that have on you/your child/his/her schooling/your family?)

7. What input and support have you received from professionals with regards to your child's SM?
   (Prompts – did you have any input from your GP/Paediatrician/SALT/EP/school staff? Anyone else, e.g. voluntary organisations? What was involved in that input? What was said in that conversation? What support was offered? How did you feel about that? What impact did that have on you/your child/your family?)

8. Thinking back over the support you have/your child has received, what would you pick out as being particularly helpful and supportive, and why?
   (Prompts – you mentioned that X was helpful before….can you tell me more about that? How did you feel about that? What was it about that support that made it helpful? What impact did it have on you/your child/your family?)

9. Thinking back over the support you have/your child has received, what would you pick out as being particularly unhelpful and unsupportive, and why?
   (Prompts - you mentioned that X was unhelpful before….can you tell me more about that? How did you feel about that? What was it about that support that made it unhelpful? What impact did it have on you/your child/your family?)

10. What would support ideally look like for you/your child, and why?
    (Prompts – is there support from a particular professional that you would like more of? What do you hope that further support from that professional could give you and your child? Why would support like X be helpful to you/your child/your family?)

Appendix 10 - Key Notes of Pilot Study Interview (Approved by Pilot Study Participant)

Pilot Study Interview 22.06.2021 10:00 – 10:40

Purpose – to consider the appropriateness of the language used in the questions, e.g. is it likely to result in distress? Will it garner the information this research hopes to gain?

5 How did you first become aware that your child was struggling with selective mutism?
(Prompts – can you tell me more about…? Did anyone else mention SM to you? How did you feel about that? What impact did that have on you/your child/your family?)

- ‘Struggling’ is negative as it is not always a struggle, especially once you start to get help you do not feel like you are struggling so much.
- ‘How’ – try and follow the story of what’s happened with ‘when’ instead of just how.
- ‘Selective mutism’ – be aware that not all will have the diagnosis. Might have used phrase in a report, rather than anything in person.
- Better question choice - ‘When and how did you first become aware that your child has traits of selective mutism?’

6 ‘At which point did you seek professional support/do something about it?’
- Add in this. Asking the parent when did it become a problem/hold their child back? Did it affect you as a family first and you had to be proactive, or did someone from education raise it first?

7 What input and support have you received from professionals with regards to your child’s SM?
(Prompts – did you have any input from your GP/Paediatrician/SALT/EP/school staff? What was involved in that input? What was said in that conversation/<u>correspondence</u>? What support was offered? How did you feel about that? What impact did that have on you/your child/your family?)

- Seems fine. Add in correspondence as not always in person.
- Better question choice - ‘Which professionals have you received input from? What support have you received?’

8 Thinking back over the support you have received, what would you pick out as being particularly helpful and supportive, and why?
(Prompts – you mentioned that X was helpful before….can you tell me more about that? How did you feel about that? What was it about that support that made it helpful? What impact did it have on you/your child/your family?)

- Seems fine.

9 Thinking back over the support you have received, what would you pick out as being particularly unhelpful and unsupportive, and why?

(Prompts - you mentioned that X was unhelpful before….can you tell me more about that? How did you feel about that? What was it about that support that made it unhelpful? What impact did it have on you/your child/your family?)

- Seems fine.

10 What would support ideally look like for you, and why?

(Prompts – is there support from a particular professional that you would like more of? What do you hope that further support from that professional could give you and your child? Why would support like X be helpful to you/your child/your family?)

- A very open question. Might want to narrow it, or begin with an open question and then narrow it with prompts if they find it difficult to answer.
- Is it about support for them based on their own experience, or about support that they feel the SM community needs?
- Alternative prompts to help narrow it – ‘could you name 2 key things about how you would like the support from professionals to look in the future?’ ‘Could you name 2 key things about how you would like support for SM to look in the future?

Additional comments –

- Think about explaining the terminology of ‘professionals’. Some may think it’s only psychologists and MH.
- Can’t foresee distress. Make sure explain terminology like ‘traits’ and ‘professionals’. Think about doing a questionnaire of what traits their child has and the professionals who’ve been involved.

Appendix 11 - Pilot Study Debrief Letter

PARTICIPANT PILOT STUDY DEBRIEF LETTER

Thank you for participating in my research study on: Parental experiences of professional involvement for children and young people with selective mutism and their preferred support.

This letter offers information that may be relevant in light of you having now taken part.

What will happen to the information that you have provided?

The following steps will be taken to ensure the confidentiality and integrity of the data you have provided:

- Your contact information will be saved in a password protected online storage cloud, accessible only to me and my Director of Studies. You will have up to 2 weeks to notify me should you wish to withdraw.
- The anonymised key feedback notes will be accessible to me and my Director of Studies only.
- The anonymised key feedback notes may be referenced in the final analysis and write up on this research.
- All data will be destroyed upon the researcher's graduation from their university course (estimated end of year 2022/beginning of year 2023).

What if you have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways you may find the following service and their resources helpful in relation to obtaining information and support:

Selective Mutism Information & Research Association (SMIRA) (http://www.selectivemutism.org.uk/) is a free UK charity who can support the families with SM children.

You are also very welcome to contact me or my supervisor if you have specific questions or concerns.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Felicity Ang – u1944328@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dr. Helena Bunn. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: H.bunn@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Professor Ian Tucker, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: i.tucker@uel.ac.uk)

Appendix 12 - Revised Interview Schedule

Revised Interview Schedule

1. When and how did you first become aware that your child has traits of selective mutism?
   (Prompts – can you tell me more about…? Did anyone else mention SM to you? How did you feel about that? What impact did that have on you/your child/your family?)

2. At what point did you seek professional support about the SM traits?
   (Prompts – did you seek it out yourself or were you asked to by someone else, e.g. your child's education setting? Did someone else suggest you seek out support, e.g. paediatrician recommending you speak to your child's school?

3. Which professionals have you received input from for your child's SM? What support have you received?
   (Prompts – did you have any input from your GP/Paediatrician/SALT/EP/school staff? What was involved in that input? What was said in that conversation/correspondence? What support was offered? How did you feel about that? What impact did that have on you/your child/your family?)

4. Thinking back over the support you have received, what would you pick out as being particularly helpful and supportive, and why?
   (Prompts – you mentioned that X was helpful before….can you tell me more about that? How did you feel about that? What was it about that support that made it helpful? What impact did it have on you/your child/your family?

5. Thinking back over the support you have received, what would you pick out as being particularly unhelpful and unsupportive, and why?
   (Prompts - you mentioned that X was unhelpful before….can you tell me more about that? How did you feel about that? What was it about that support that made it unhelpful? What impact did it have on you/your child/your family?)

6. What would support ideally look like for you, and why?
   (Prompts – is there support from a particular professional that you would like more of? What do you hope that further support from that professional could give you and your child? Why would support like X be helpful to you/your child/your family? Could you name 2 key things about how you would like the support from professionals to look in the future? Could you name 2 key things about how you would like support for SM to look in the future?

Appendix 13 - Participant Invitation Letter

PARTICIPANT INVITATION LETTER

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please read the following information carefully.

Who am I?

I am a postgraduate student in the School of Psychology at the University of East London and am studying for a Doctorate in Educational and Child Psychology. As part of my studies I am conducting the research you are being invited to participate in.

What is the research?

I am conducting research into 'parental experiences of professional involvement for children and young people with selective mutism and their preferred support.' My research questions are:

11 What are the experiences parents have had of professional involvement for their child with selective mutism, and how do they feel that this has influenced theirs and their child's experience of selective mutism?

12 What support from professionals would the parents of children with selective mutism like to have?

This research is exploratory and aims to bring insight into parental experiences of their child's selective mutism, of how professional input can influence this, and of preferred support from professionals. It is hoped that themes will be identified in parental experiences, which may guide professionals to consider how they interact with and support the parents of children with selective mutism

My research has been approved by the School of Psychology Research Ethics Committee. This means that my research follows the standard of research ethics set by the British Psychological Society.

Why have you been asked to participate?

You have been invited to participate in my research to help me explore my research topic. I am looking to involve parents who have a child with selective mutism. You have identified yourself as someone who fits this description.

I emphasise that I am not looking for ‘experts’ on the topic I am studying. You will not be judged or personally analysed in any way and you will be treated with respect.

You are quite free to decide whether or not to participate and should not feel coerced.

What will your participation involve?

If you agree to participate you will be asked to initially meet with me on Microsoft Teams. This will be in order to answer any questions you may have, check you meet the criteria for participating in the research, and to begin to familiarise yourself with Microsoft Teams.

Once you have consented to take part and returned the consent form to me, I will arrange an hour slot to meet with you online via Microsoft Teams at a time that is convenient for you. Interviews will be conducted online via video or audio call. You have the option to have your camera on and to therefore be physically visible during the interview, or to turn it off and to have only your audio on. The interview will be recorded via Microsoft Teams recording, and will be transcribed by me. During this interview you will be asked some questions about your experiences of support offered by professionals for you and your child. Interviews are expected to last 30-45 minutes and should feel like an informal chat. They will consist of some open-ended questions, giving you the opportunity to tell me about your experiences, as well as some prompting questions.

I will not be able to pay you for participating in my research, but your participation would be very valuable in helping to develop knowledge and understanding of your experiences of professional involvement, and the support that you would prefer.

Potential advantages and risks to participation

By participating in this research, you will have the opportunity to give voice to the experiences of parents with a child with SM when interacting with professionals. There is currently a lack of research in this area, and it is hoped that this research will enhance understanding about something which little is known.

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways you may find the following service and their resources helpful in relation to obtaining information and support: Selective Mutism Information

& Research Association (SMIRA) (http://www.selectivemutism.org.uk/) is a free UK charity who can support the families with SM children.

Your taking part will be safe and confidential

Your privacy and safety will be respected at all times:

- You will not be identified by the data collected, on any written material resulting from the data collected, or in any write-up of the research. You will only be identified by a pseudonym which you will chose during the interview.
- You do not have to answer all questions in the interview and can stop your participation at any time.

What will happen to the information that you provide?

What I will do with the material you provide will involve:

- Your personal contact details and signed consent forms will be stored in a secure password protected file on UEL One Drive. This will be accessible only to the researcher and their Director of Studies.
- The transcripts of the recordings will be anonymised, the only identifying feature will be the pseudonym you have chosen. Full anonymised transcripts will only be accessible to the researcher, their Director of Studies, and UEL Trainee Educational Psychologists for data analysis.
- The final piece of analysed work with the findings will be seen by supervisors, examiners, and UEL Trainee Educational Psychologists. The final version of this work will include short extracts from the interviews. This will not include any identifying information. Should the research be deemed good enough for publication, the findings will be shared with a wider audience, which will probably include professional and voluntary services and research journals.
- All data collected, including contact details and interview recordings will be kept on UEL One Drive, which is password protected. Data will be backed up to UEL Home Drive, which is also password protected.
- With your consent, anonymised transcripts will be placed in the UEL Research Repository, where they will be available for research purposes for 5 years from the completion of the research (estimated to be April 2022). After 5 years they will be reviewed and retained, transferred, or destroyed. If you do not consent to this your data will be kept until the researchers graduation from their university course (estimated end of year 2022/beginning of year 2023).

What if you want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Separately, you may also request to withdraw your data even after you have participated, provided that this request is made within 2 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).

Contact Details
If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Felicity Ang – u1944328@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dr. Helena Bunn. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: Helena.bunn@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Professor Ian Tucker, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: i.tucker@uel.ac.uk)

Appendix 14 - Participant Consent Form

UNIVERSITY OF EAST LONDON

Consent to participate in a research study: Parental experiences of professional involvement for children and young people with selective mutism and their preferred support.

☐ I have the read the participant invitation letter relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

☐ I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher involved in the study and their Director of Studies will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

☐ I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun (2 weeks after interview).

☐ I consent to the anonymised transcript of my interview being placed in the UEL Research Repository. I understand that this means that the interview will be available for research purposes for 5 years from the completion of the research (estimated to be April 2022). After 5 years they will be reviewed and retained, transferred, or destroyed. I understand that all other data will be destroyed upon the researcher's graduation (estimated end of year 2022/beginning of year 2023).

OR

☐ I consent to all of my data being destroyed upon the researcher's graduation (estimated end of year 2022/beginning of year 2023).

Participant's Name (BLOCK CAPITALS)

……………………………………………………………………………………….

Participant's Signature

………………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

………………………………………………………………………………………..

Researcher's Signature

…………………………………………………………………………………………

Date: ……………………..…….

Appendix 15 - Debrief Letter

University of
East London

PARTICIPANT DEBRIEF LETTER

Thank you for participating in my research study on: Parental experiences of professional involvement for children and young people with selective mutism and their preferred support.

This letter offers information that may be relevant in light of you having now taken part.

What will happen to the information that you have provided?

The following steps will be taken to ensure the confidentiality and integrity of the data you have provided:

- Audio/video recordings will be stored securely in a password protected online storage cloud. I will use the audio/video interview to create anonymous transcripts. Any identifying features, such as names or schools will be redacted, and transcripts will be labelled with a number.
- Your contact information will be saved in a password protected online storage cloud, accessible only to me and my Director of Studies. You will have up to 2 weeks to notify me should you wish to withdraw, after this point data analysis will have begun.
- The anonymised transcripts will be accessible to me, the Director of Studies, and UEL Trainee Educational Psychologists. Findings, including anonymised excerpts from the interviews, will be shared with UEL Trainee Educational Psychologists, UEL supervisors, and examiners. Should the research be deemed good enough for publication it will be shared with a wider audience. To reiterate, your responses will be anonymised, so there will be no identifying features in the analysed data that is shared.
- If you have given permission, the anonymised transcript of your interview will be placed in the UEL Research Repository, where it will be available for research purposes for 5 years from the completion of the research (estimated to be April 2022). After 5 years they will be reviewed and retained, transferred, or destroyed. If you have not given this consent, your interview transcript will be destroyed upon the researcher graduating from their university course

(estimated end of year 2022/beginning of year 2023). All other data will be destroyed at this point.

What if you have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways you may find the following service and their resources helpful in relation to obtaining information and support:

Selective Mutism Information & Research Association (SMIRA) (http://www.selectivemutism.org.uk/) is a free UK charity who can support the families with SM children.
You are also very welcome to contact me or my supervisor if you have specific questions or concerns.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Felicity Ang – u1944328@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dr. Helena Bunn. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: H.bunn@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Professor Ian Tucker, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: i.tucker@uel.ac.uk)

Appendix 16 - Coding and Initial Theming Example

Transcript	Codes	Themes
I think that compared with other children that I hear about I think we've been unbelievably lucky because all of the staff it was in a small primary school and both my other children had been there so a lot of the staff were the same. We were lucky enough to have a male teacher that was newly qualified that he had twice who just got him. He got him. Didn't always get things right he called me once and he said to me…well he said, this morning, he said, I said to (child) can you take those chairs off the tables? And (child) just looked at him, gave him a look, and walked off. I said ok, I said because you said can you, so in his mind, yes I can, off I go. I said what you should've said was (child) take those chairs off the table. And he was like oh! He was always willing to learn. He was an amazing teacher. All of the others were kind. There were 2 teachers in primary that I just thought oh please no. One of them was not a good teacher – my other son had had her and we ended up getting a tutor, so teaching wise she wasn't – and she ended up leaving teaching. But, to give her her dues, she was kind. She was a little bit inappropriate once or twice with wanting eye contact from him. And I just thought ok. Because…knowing he was autistic, he had the diagnosis then. But she was kind, and then year 6, the year 6 teacher was the one that I really did not want and I just thought…he was not going to – it started off really well – listening, and then I think he – the first week he did put things in place, tried really hard, and then it just went to pot. He lost (child's) iPad that he'd been supplied with for communication. It just…I that obviously had a lot to do with (child) not going in. I don't think he felt safe, as in, the teacher wasn't particularly aware of him. But, but I think we've been lucky.	1.216 Parent feels has been lucky compared to others. 1.217 Staff in primary were the same as when older siblings were there. 1.218 Had teacher for 2 years who got child. 1.219 Teacher didn't always get things right. 1.220 Teacher called parent with specific question and parent advised teacher on how to speak to child. 1.222 Teacher was amazing and always willing to learn. 1.224 Primary teachers all kind. 1.225 One teacher was kind but not a good teacher. 1.226 Teacher occasionally inappropriate wanting eye contact. 1.227 Year 6 teacher tried hard for first week only. 1.232 Year 6 teacher lost child's communication iPad. 1.233 Child had been given an iPad for communication. 1.234 Child did not feel safe in year 6.	Prof valuing parents advice. Prof willing to learn. Prof kind – personality Support not consistent Strategy for alternative communication

Appendix 17 – Coding Map Example for Theme 'System Barriers'

#	Transcript	Code	Initial theme
1.33	referral to speech therapy…which was ridiculously long waiting lists.	Long wait list for SALT.	Hard to access professionals
1.253	it's difficult when you've got 30 - 30+ kids in a class, it is difficult. A lot of the TA's have gone now so staff are often on their own with a group of kids.	Difficult with large class sizes in schools.	Limits on public services
1.281	I think there's no honesty with the systems	No honesty in systems.	Lack of honesty in the system
1.282	if somebody would've said to me this is what we're allowed to do. We're only commissioned to do X Y and Z.	Professionals should say what limited to do.	Lack of honesty in the system
1.284	it just took me so long to realise that we needed more than what they were ever going to offer	Took parent a long time to realise needed more than professionals could offer.	Lack of honesty in the system
1.285	you feel that well he obviously doesn't need direct therapy. He doesn't need therapy because if he did surely they'd say that	Parent felt child didn't need therapy because someone would say if he did.	Lack of honesty in the system
1.300	what's really interesting is if he – when we have tribunals…kids are all on waiting lists for all these professionals for so long…oh well yes it's a long waiting list we'll see…but it went as soon as there's a tribunal and especially if you've already got a private report of some sort – that disagrees with their stance…their professionals can get in there and do their assessment within hours even, certainly within days.	Professionals can do assessments very quickly for tribunal.	Lack of honesty in the system
1.301	kids are all on waiting lists for all these professionals for so long…	Kids on long wait lists for professionals	Lack of honesty in the system
1.302	as soon as there's a tribunal and especially if you've already got a private report of some sort – that disagrees with their stance…their professionals can get in there and do their assessment within hours even, certainly within days.	Professionals can do assessments very quickly if parent has a private professional report that disagrees with the LA one.	Lack of honesty in the system
1.324	a lot of teachers won't admit to not knowing things I think in my experience	In parents experience teachers often won't admit not knowing.	Lack of honesty in the system

1.360	Where the other lady was going to come to tribunal and be truthful, regardless of what her bosses said, the other one wouldn't really – you know – she was kind of a bit oohh. You know?	Next SALT would not speak mind at tribunal.	Lack of honesty in the system
1.365	I know why they don't in a lot of instances it's because they know that you're potentially – somebody like me would know…I know the systems, so I would then get an independent report, like I have done recently, and then make sure it goes in the EHCP.	Professionals aren't honest because of parents who know the system and will use independent professionals.	Lack of honesty in the system
1.379	if I'd have known all this – if I'd have known you don't get the full package, you don't – I would've definitely got an independent speech therapist in when he was 3.	Parent would have got independent SALT at 3 years old if known don't get the full package.	Lack of honesty in the system
1.438	it took over 3 months to get a tutor which after 15 days out of school they're entitled to home tutoring.	Took 3 months to get tutoring was entitled to receive after 15 days out of school.	Hard to access professionals
1.442	There's been no joined up system in anything whatsoever.	No joined up system.	System is not joined up
1.443	It's almost like people are just doing the bare minimum that they can get away with.	Seems like people are doing the bare minimum they can.	Limits on public services
1.462	the criteria was that the child had to be…have a letter from CAMHS to access the medical education service. So, and I was just like, this is insane, is it – he's under CAMHS. How - why do we need a letter?	Parent unsure why child needed letter from CAMHS to access medical education service when child is already under CAMHS.	System is not joined up Hard to access professionals
1.468	He said I am not writing a letter. He said if they want to speak to me they can pick up a phone or come and see me. He said they know this child is under CAMHS they're being utterly ridiculous.	CAMHS psychiatrist refused to write letter as SEND were being ridiculous as child is known to be under CAMHS.	System is not joined up
1.471	I felt like it was a way of delaying things	Parent felt it was to delay things.	Lack of honesty in the system
1.483	(the borough) are all just little bitty things and then it takes ages and ages to get a diagnosis.	Takes ages to get a diagnosis through borough.	Limits on public services
1.571	it would just all be quite disjointed.	Borough way was disjointed.	System is not joined up

1.575	The local authority ones no. And after the first one that we saw when he was what…six or seven, I haven't let them near my son. Because they are in house and they basically write their recommendations depending on what is available	LA EPs not helpful because they are in house and recommend what is available.	Limits on public services
1.577	I don't want them near my son because I just don't think there is any point	No point in letting LA EPs near child.	Limits on public services
1.578	I think they've got a clouded view of anxiety.	Parent feels LA EPs don't understand anxiety.	Limits on public services
1.650	I know that the local authority ones are not. They've got bigger caseloads	LA EPs have bigger caseloads.	Limits on public services
1.651	they're restricted in what they're allowed to offer and say	LA EPs are restricted in what they can offer and say.	Limits on public services
1.656	I've seen a lot of EHCPs, I've seen a lot of EP reports from (borough) children because I'm a counsellor and the parent - I'm in the parent forum and I know a lot of parents of kids and I'm appalled - I'm appalled. They're all very generic…would benefit from, you know, that kind of thing.	Generic EP and LA reports.	Limits on public services
1.766	they are meant to work together. And they do speak to each other but nothing - it just…your end product doesn't end up as – as kind of a team effort. It just doesn't.	End product is not multi-professionals.	System is not joined up
1.768	they are meant to do that but it doesn't happen in practise. It doesn't happen. It just doesn't happen.	Liaising with everybody doesn't happen in practice.	System is not joined up
2.127	she was only an interim person. She wasn't - her job description didn't allow her to stay any period of time with people	Support worker's job description meant she was only interim.	Limits on public services
2.140	she would never like officially put it on a piece of paper what she thought.	2nd SALT never put opinion on paper.	Limits on public services
2.142	it's frustrating because we have that quite - not just me, other parents I've spoken to have had similar erm experiences.	Frustrating when professional won't put opinion on paper.	Limits on public services

2.238	Every service that we - we become involved with, they’re only ever temporary.	Every service is temporary.	Limits on public services
2.239	There's never anything long term	Never any long term support.	Limits on public services
2.245	sometimes services mean well and they come in and they say yeah we’re going to do this and we’re going to do that. And then they realise the extent that, you know, this can go on for a good 18 months before you even get a nod…and then they draw then because their times run out.	Services mean well but withdraw because their time runs out.	Limits on public services
2.248	it didn't work because she had to stop	Family support charity unsuccessful because worker had to stop.	Limits on public services
2.251	Three months is – is nothing	3 months of support is nothing.	Limits on public services
2.253	now I'm at the point where I don't really want to introduce anyone else in, even if it is long term because it's another person	Parent now doesn’t want to introduce anyone else in.	Limits on public services
2.254	at the minute, the running count is 44 professionals	Child has had 44 professionals involved so far.	Limits on public services
2.255	That’s an awful lot of people	44 professionals is a lot of people.	Limits on public services
2.278	no professional has ever taken erm the lead for - for organising meetings and for keeping everyone in check to make sure that what should be done has been done if it's not when is it going be done.	No-one has ever taken on role of lead professional for child.	System is not joined up
2.279	No one's ever done that so (child’s) like package has always been really disjointed.	Child’s package has been disjointed because of no lead professional.	System is not joined up
2.287	CAMHS haven't been great with her…as in getting back to her	CAMHS not great at getting back to SENCo.	System is not joined up
2.288	but they’re not really great with anybody.	CAMHS not great at getting back to anybody.	System is not joined up
2.523	it's like they know - they understand that it's - it's an issue and what the issue is, but there's no…there’s no speed	Issues are recognised but no speed in tackling them.	Hard to access professionals
2.526	It’s just everything – there’s always an excuse for everything	There is an excuse for everything.	Lack of honesty in the system

3.33	we waited maybe few months or something…or six months to...I don't know, four to six months, can't remember exactly erm and then to get the first appointment.	Wait of 4-6 months for first CAMHS appointment.	Hard to access professionals
3.34	during that time we saw the decline.	Child declined whilst waiting for CAMHS input.	Hard to access professionals
3.165	if you think seeing his condition you can't help – yeah that's another issues, you tell us you can't help and that's it. That's that, you know. Sometimes it doesn't mean that you are not good if you cannot do something	Parent wanted 1st private child psychologist to say if they couldn't help.	Lack of honesty in the system
3.174	I think erm maybe she was not totally honest what she can do what she cannot do.	1st private child psychologist not honest about what she can do.	Lack of honesty in the system
3.175	I think she could be - perhaps she could do very well with the general anxiety because we know that - now I know that selective mutism is a form of in a way anxiety you know, er related to anxiety, maybe she was good at anxiety and knowing this she thought that she could deal with it but she couldn't deal with it	1st private child psychologist maybe better with general anxiety and thought could deal with SM.	Lack of honesty in the system
3.203	For example, when (CAMHS paediatric psychiatrist) no longer needed, she - (CAMHS paediatric psychiatrist) which was the – the resident doctor – psychiatrist – er when she needed to move because you know her - her training finished so that was again you know if that hadn't happened I think it'd be quicker, have managed to do things better but that was stopped	Feel things would have been quicker if CAMHS paediatric psychiatrist hadn't moved and stopped support.	Limits on public services
4.151	not until I started the EHCP process, because she wasn't allowed to until we did that.	NHS SM SALT specialist only allowed to become involved after EHCP process started.	Limits on public services Hard to access professionals
4.152	it was either – either because of (child's) age and – or we had to wait for her to come in to the school and be referred to deal with - look after (child) or see (child). Or maybe because the school said I'm now	Parent unsure why NHS SM SALT specialist only allowed to come on board once applied for EHCP.	Limits on public services Hard to access professionals

	applying for an EHCP. We need somebody specialist on board, maybe, I don't know.		
4.153	I found her myself – I had to Google and find selective mutism NHS specialists in (county)	Parent had to find NHS SM SALT specialist themselves.	Hard to access professionals
4.200	well why are you saying that she can go to mainstream secondary then with no support. She said well that’s what everybody else has decided.	SEND officer places blame of decisions with others.	Lack of honesty in the system
4.213	not only are you generally on hold for half an hour to 45 minutes to even get through to anybody	Long time waiting to speak to SEND team on phone.	Limits on public services Hard to access professionals
4.214	they’re not very helpful. Erm, there were a couple of more helpful guys when you could get through to, but there's no guarantee you’d get through to them	Unsure if will get someone helpful or unhelpful in SEND team when call.	Limits on public services Hard to access professionals
5.9	the ed psych, erm as we all know - I know it's your field – erm, generally have a much longer waiting list, and it took about another 18 months – 2 years to see a psych.	18m-2y wait to see an EP.	Hard to access professionals
5.37	we do have one specialist in SM in our area but she retires in August.	SM SALT specialist in area due to retire.	Hard to access professionals
5.38	that specialist erm, we should have been referred to somebody else but they were on maternity leave and that's who we've ended up with now she's back from maternity leave, erm, but obviously he’s in year 11 now, not year 7, so about to go in year 11.	Referred to SALT SM specialist 3 years later than should have been.	Hard to access professionals
5.80	Nothing. They just said I'm sorry there's nothing else we can do.	SALT unable to support beyond 6 week intervention.	Limits on public services
5.233	she said how long you been waiting? And I went 12 years. Well, it's probably about 10	Parent has waited 10 years to see EP	Hard to access professionals
5.234	we've had a referral in for an ed psych erm…well I put one in after he saw the previous one so that we could get a better report. Then we put one in at his new - at (second primary school) when he - when we moved over here. We put one in year seven, one in year eight, and one in year nine, so when he went - eventually saw the ed psych	Have been 5 failed referrals to EP over the years.	Hard to access professionals

5.235	I mean there is a super long waiting – they reckon at the moment at least 2 1/2 years wait.	Currently 2 ½ year waiting list for EP.	Hard to access professionals
5.236	but on the other side with CAMHS, I put an appeal in erm and then I appealed the appeal	Parent has had to appeal several times with CAMHS.	Hard to access professionals
5.239	But no one would prescribe meds other than a CAMHS consultant but I can't get to a CAMHS consultant. So it – this kind of chicken egg thing.	Parent unable to access CAMHS consultant needed for medication.	Hard to access professionals
5.280	it's just this constant referrals and waiting and then when you get there, it's literally 10 minutes in the room and someone says no. And you think, or you might get too - you might get a referral in…I waited a year for a response from a referral for them to say no	Constant referrals, waiting, then 10 minutes with a professional who says no.	Hard to access professionals Limits on public services
6.46	after that erm we back to the (tier 1 & 2 MH organisation) and erm they sent erm they can't anymore working with - with her	MH organisation couldn't do anymore work with child.	Limits on public services Hard to access professionals
7.41	she said I can't diagnose it in this role I'm in now	SALT unable to diagnose SM in ASD pathway role.	Limits on public services
7.124	the appointment was on Monday, so that's what a year and a…a year and two months - three months since the initial request, for the appointment.	Over a year's wait for SALT SM appointment.	Hard to access professionals
7.125	it was a long wait.	Long wait for SALT SM appointment.	Hard to access professionals
7.215	she said I'm concerned that the high school will turn round and tell you that they can't put these things in place. Erm, so she was like I'm pre warning you.	Primary SENCo concerned secondary may say they cannot meet need.	Limits on public services
7.291	the length of time it took to get the speech and language appointment was extreme	Extreme length of time to get SALT appointment unhelpful.	Limits on public services Hard to access professionals
8.97	we are still awaiting an assessment for that.	Waiting on MH assessment.	Hard to access professionals
8.90	we're just on a waiting list, we don't know how long it will be	Don't know how long waiting list will be.	Hard to access professionals

8.91	We were told the end of October beginning of November, but we've got no appointment or anything	No appointment despite being told would be October/November.	Hard to access professionals
8.132	(child) leaves school next year. It just takes too long	Takes too long when child leaves school next year.	Hard to access professionals
8.145	the SENCo’s I think cover things up.	Parent feels SENCo’s cover things up.	Lack of honesty in the system
8.146	they don't answer you directly. If you ask them a question they can’t - they can't give you an answer dir – a truthful honest answer	SENCo’s don’t answer directly or honestly.	Lack of honesty in the system
8.270	that's for them to tell me what support they can offer…they just don't do that	Professionals don’t say what they can offer.	Lack of honesty in the system
8.271	It's only if you find out about things, you say well why are you not doing this or can you do that…that they actually seem to…’well yeah we can do’.	Parent needs to find out about things and ask for professionals to agree to do.	Lack of honesty in the system
8.272	They never offer it you.	Professionals don’t offer.	Lack of honesty in the system

Appendix 18 - UEL Ethical Approval

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER:	**Matthew Jones Chesters**
SUPERVISOR:	Helena Bunn
STUDENT:	**Felicity Ang**

Course: Prof Doc Child Edu Psych

Title of proposed study: Parental experiences of professional involvement for children and young people with selective mutism and their preferred support

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

APPROVED

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES / NO

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐ MEDIUM (Please approve but with appropriate recommendations)

☒ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: Matthew H Jones Chesters

Date: 5th March 2021

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

Appendix 19 - Research Diary Excerpts

Excerpt 1
31.08.2021
Interview with participant 5 held

Key reflections

- I felt very acutely aware of my own positioning during this interview. The parent made repeated references to 'EP' being 'your domain' etc. I very much felt positioned as an expert professional by the parent. And I was very conscious that she herself has experienced what she perceives as a fall from a professional job that carries a lot of social capital to being on benefits as a result of health needs. I found being positioned in this way very uncomfortable, and I would say this is the first interview where I have perceived this power differential quite so strongly. In hindsight I wonder if I could have done more to minimise that power difference from the beginning. I think that with each interview I am keen to get going quickly as I recognise that parents are taking time out of their day to speak to me, but perhaps I should have a longer period of time checking in with them and establishing a little more rapport first.

Excerpt 2
10.10.2021
Finished transcribing participant 7 interview

Key reflections

- As with other participants, parent raised key feelings of not being believed. I feel that I am already identifying this as a theme purely from interviews and transcribing; I will need to be mindful when coding and theming that there is the data to support this, and it is not being led by own initial biased reflections after interviews and transcribing.
- The positioning of this parent was interesting as she works in the primary school her child attended, and so knew all of the staff much more intimately than a typical parent might. I did notice that when speaking about what was unhelpful from professional's she spoke more about the personality of teachers in the primary school she works at and the child attended, whilst for the secondary school she was quite damning of the SENCo not believing in SM. Whereas for the primary she attributed it much more to a lack of knowledge, and linked this with herself and how the school had had no training for SM and no prior experience with SM children. Her own positioning as a member of the primary school staff has impacted on how she reflects on her child's time there.
- I was very personally emotionally affected by what she said about her own parents 'my dad's a big kid, he's like a big 5 year old, erm and he messes around and gets her to giggle and laugh, and you can see when – when she does that my mum and dad you know they're just like oh we've - we've had communication with her, we feel that love'. I was so touched by this both during the interview and each time I re-listen and re-read it, checking for errors. It really just conveys the plight of the extended family in trying to

connect with the child, and to find alternative ways of communication. I have been quite focused in my work on how hard it must be for a child with SM to connect with others, but this has made me reflect much more on how difficult it must be for others to connect with a child with SM. The grandparents are clearly understanding and putting in effort, but I accept it must be harder for others, such as secondary school teachers, to find connection with a child they only see a few times a week. I think the shift in mindset needed to see any form of communication as connection must be challenging to achieve.