University of Southampton

Faculty of Environmental and Life Sciences

Health Sciences

Access to Speech and Language Therapy for preschool children suspected or diagnosed autistic

by

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Abstract

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Speech and Language Therapy (SLT) is a service commonly accessed by young autistic children. Despite the importance of early communication support, access to SLT is challenging for autistic children and their families. Long waiting times and unmet needs are reported. Access to healthcare is a complex process influenced by individual, service and contextual factors. However, few studies have explored access to SLT in depth, and from different stakeholder perspectives. This study aimed to explore and identify factors relating to children, families and SLT services that influence access to SLT for preschool autistic children.

A qualitative instrumental case-study methodology was used to facilitate a holistic, in-depth understanding of access to SLT. Semi-structured interviews were conducted with 23 individuals including parents/carers, Speech and Language Therapists, early years health, education, and social care staff, and leads, managers and commissioners of SLT services. Data were analysed using reflexive thematic analysis.

The study identifies several barriers to accessing SLT services. Despite SLT services being highly regarded and focused on supporting children's communication in everyday contexts, demand outstripped capacity and resulted in prolonged waits for families. Service changes aimed at increasing productivity had unintended impacts on quality of care and on service accessibility. Additionally, SLTs' uncertainty about their role in supporting autistic children influenced clinical decisions and service delivery models, further impacting access to SLT. Some families received no or insufficient service due to high demand and many faced practical and emotional challenges in trying to gain access to SLT.

To ensure early access to communication support for autistic children and their families, several barriers need to be addressed. The study highlights the importance of recognising that access is influenced by a parent's ability to advocate for their child and suggests further exploration of how SLTs perceive their roles and make decisions when working with autistic children in real-world situations. Improving service access is a complex process, but doing so has the potential to lead to positive change for autistic children and their families in areas that are important and meaningful in their everyday lives.

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Research Thesis: Declaration of Authorship

Print name: Iona Wood

Title of thesis: Access to Speech and Language Therapy for preschool children suspected or diagnosed autistic

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

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
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7. None of this work has been published before submission.

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Definitions and Abbreviations

Definitions

Care Quality Commission: Independent regulator of UK health and social care.

Developmental disorder: A group of conditions present at birth that impact on children's intellectual, physical and language skills, and behaviours.

Early intervention: Provision of early support to children and young people who are at risk of poor outcomes (usually initiated <6 years).

Gatekeeper: An initial point of contact for an individual seeking a healthcare service. They may assess, diagnose, provide support and facilitate onward referrals to other healthcare professionals.

Health and Care Professions Council: Regulator of UK health and care professions.

NHS Trust: An organisation in the UK National Health Service (NHS) providing health service to a geographically defined population or providing a specialist service. NHS foundation Trusts are Trusts with a greater degree of autonomy.

NICE: The National Institute for Care Excellence provide evidence-based summaries and guidance to health and care staff to improve outcomes for all.

Royal College of Speech and Language Therapists: The UK professional body for Speech and Language Therapists that aims to maintain and improve standards within the profession.

Speech and Language Therapy/Therapists: SLTs work with parents, carers, and other professionals to provide treatment, support and care for children and adults with communication difficulties or difficulties with eating, drinking and swallowing. In the UK, SLT is an Allied Health Profession (AHP). All practicing SLTs must be registered with the Health Care Professions Council (HCPC) and adhere to the code of practice set out by the HCPC.

Abbreviations

AAC: Alternative and Augmentative Communication

ASD: Autism Spectrum Disorder

CQC: Care Quality Commission

DLD: Developmental Language Disorder

DSM-5: Diagnostic and Statistical Manual of Mental Disorders, 5th edition

HCP: Healthcare Professional

ICB: Integrated Care Board

ICD 11: International Classification of Diseases, 11th Revision

NICE: National Institute for Heath and Care Excellence

RCSLT: Royal College of Speech and Language Therapists

SLT: Speech and Language Therapy/Speech and Language Therapist

SLTA: Speech and Language therapy Assistant

WHO: World Health Organisation

Chapter 1 Introduction

1.1 Autism

The focus of this thesis is access to Speech and Language Therapy (SLT) for preschool autistic children. Autism describes common and lifelong, neurodevelopmental differences, also known as autism spectrum disorder (ASD). It is estimated that between 1% and 2% of the population are autistic (Baio *et al.*, 2018; Centers for Disease Control and Prevention, 2024; Elsabbagh *et al.*, 2012). Since it was first recognised in the 1940s (Asperger, 1944; Kanner, 1943), autism has been predominantly viewed through a medical lens that focuses on deficits and the dichotomy of normal and abnormal behaviour (Bottema-Beutel, 2020). For instance, within the Diagnostic Statistical Manual (DSM-V) (American Psychiatric Association, 2013) and International Classification of Diseases 11 (ICD 11) (World Health Organization, 2020), ASD is described in relation to significant "deficits" in social communication and interaction, along with patterns of restricted and repetitive behaviours.

Although autism has long been understood as a medical condition that needs to be treated or cured (Kenny *et al.*, 2015; Meyerding, 2014; Singer, 1999; Taboas, Doepke and Zimmerman, 2022), autism is increasingly recognised as existing on a broad continuum of neurodiversity. This has led to a more positive and inclusive perception of autism and this shift is reflected in changes to the ways autism is described. Autism and autism spectrum are now more widely accepted terms than ASD, and identify-first language, such as 'autistic person' is the preferred terminology of many autistic people (Bottema-Beutel *et al.*, 2020; Kenny *et al.*, 2015).

Medical views of autism tend to focus on supporting and improving areas of difficulty, whereas the neurodiversity view considers autism as existing on the continuum of normal variation, and promotes a social model of disability that looks beyond a person's differences, and prioritises the removal of societal barriers to inclusion and participation (Hughes, 2010; Oliver, 2013). Lai *et al.* (2020) argues that these differing views of autism are not mutually exclusive, and autistic people can benefit from both social and medical models of support. Regardless of the specific focus of support, all decisions about a person's support should be collaborative, with joint decision-making at all stages between autistic people, their families and support services (Elwyn *et al.*, 2012; Lai *et al.*, 2020).

1.2 Identification of autism

Early identification of autism is important for increasing the likelihood the child and their family receive the support they need and the understanding of others around them (Barbaro and Dissanayake, 2009; Webb *et al.*, 2014; Zwaigenbaum *et al.*, 2015; Fuller and Kaiser, 2019). Parents are often first to recognise signs of possible autism (Ozonoff *et al.*, 2018; Smith *et al.*, 2023) and concerns commonly relate to their child's language development and socio-emotional responsivity (Ozonoff *et al.*, 2018). Concerns such as these are often identified by parents before their child is two years of age (De Giacomo and Fombonne, 1998). This can then lead to parents seeking support from health and care professionals (Howlin and Moore, 1997; Webb *et al.*, 2014). There can be delays as parents may wait for these concerns to be shared by others such as health professionals before seeking further support or diagnostic assessment (Smith *et al.*, 2023). Delays to diagnostic assessment can be experienced at this stage due to health professionals dismissing parents' concerns (Oswald *et al.*, 2017). This, along with some professionals' lack of empathy can lead to frustration for parents (Oswald *et al.*, 2017).

Autism is currently diagnosed through developmental history and clinical observation of the child (NICE, 2017), and can be reliably diagnosed from two years of age (Webb and Jones, 2009; Constantino and Charman, 2016). However, in the UK, the average age for diagnosis is 4.5 years (Brett *et al.*, 2016). The National Institute for Health and Care Excellence (NICE) recommend that children should wait no longer than 13 weeks between referral and diagnostic assessment (NICE, 2017). Following referral for diagnostic assessment, parents frequently report long waiting times (Howlin and Moore, 1997; Wiggins, Baio and Rice, 2006; Crane *et al.*, 2016) and the average wait time for autism assessment in UK children's community health services is 2 years and 2 months (Children's Commissioner for England, 2024). Although support for children should be based on their individual needs rather than on a specific diagnosis (HM government, 1989;2010; Department for Education and Department of Health, 2015) some parents report that a formal diagnosis of their child was needed to gain a shared understanding of their needs (Children's Commissioner for England, 2024).

Waiting times for assessment are impacted by several factors such as increasing demands for assessment due to greater awareness of autism, insufficient workforce to meet the demand and the ongoing impact of the COVID 19 pandemic disruption to services (Department of Health and Social Care & Department of Education, 2021). Parents describe access to diagnosis and the assessment processes as confusing (Smith-Young, Chafe and Audas, 2020; Children's Commissioner for England, 2024) and find the waiting time stressful (Crane *et al.*, 2016).

Parents also report dissatisfaction with the diagnostic assessment itself and report that assessments do not adequately take into account their child's strengths, and do not recognise their expertise as parents (Crane *et al.*, 2018).

Although parents consider early diagnosis as important for supporting access to early interventions (Smith-Young, Chafe and Audas, 2020), even after diagnosis families can experience insufficient support and further long waiting times (Children's Commissioner for England, 2024). Both delayed diagnosis and insufficient support following diagnosis impacts negatively on children and their families. Improving access to diagnostic assessment and early support is recognised as a priority in several national policies, reviews, guidance documents and strategies including the NHS Long Term Plan (NHS England, 2019) and The National Strategy for autistic children, young people and adults: 2021-2026 (HM Government, 2021). Along with recommendations for expanding and streamlining diagnostic services and availability of assessments, improved coordination between services facilitated by Integrated Care Systems, and further training for healthcare professionals, improving reporting and review of assessment waiting times for autism diagnostic assessment is also a priority to ensure visibility of services that require greater support and improvement (NHS Digital, n.d.).

1.3 Challenges

While autistic people share core features of autism, there is considerable diversity within the autism spectrum, and the impact of autism can vary widely from one individual to another (Wozniak *et al.*, 2016). Some people face few challenges and can live independently, whereas others face significant challenges throughout their lifetime. Autistic people may experience challenges related to core aspects of autism, or the way these are understood and supported by others. Autistic people experience higher rates of several neurodevelopmental, physical and mental health conditions compared with non-autistic individuals (Brugha *et al.*, 2016). As a result, many autistic people have health and support needs related to co-occurring difficulties as well as autism-related needs (Rydzewska *et al.*, 2019; Simonoff *et al.*, 2008).

Social communication differences are a defining feature of autism (American Psychiatric Association, 2013; World Health Organization, 2020). Social communication is the use of verbal and non-verbal communication to interact with different people across different contexts (Bottema-Beutel, 2020). Delayed language development is commonly seen alongside social communication difficulties in children who go on to be diagnosed as autistic (Herlihy *et al.*, 2015; Hudry *et al.*, 2014; Talbott, Nelson and Tager-Flusberg, 2015). Studies of verbal ability in

autistic children and adults have found that approximately 25-30% of autistic children remain minimally verbal or non-verbal (Anderson *et al.*, 2007; Tager-Flusberg, 2016; Tager-Flusberg and Kasari, 2013). Additionally, approximately 50% of autistic individuals experience difficulties with aspects of structural language such as phonology (how sounds are organised and used in language), grammar (the rules that guide how words are combined in sentences) and semantics (meaning of words) (Baird *et al.*, 2006).

The importance of early language and communication ability for future life outcomes is well recognised for all children (Tager-Flusberg and Kasari, 2013). Concern about language development is the most common reason for the first clinical consultation for children who are later diagnosed as autistic (Bolton *et al.*, 2012; Richards, Mossey and Robins, 2016). Communication difficulties can impact on autistic people's social interaction and emotional wellbeing (Müller, Schuler and Yates, 2008), act as a barrier to healthcare due to challenges communicating with healthcare professionals (Raymaker *et al.*, 2017) and impede future employment (Hurlbutt and Chalmers, 2004).

1.4 Early support

There is a strong emphasis on the importance of early intervention to improve outcomes for autistic people (Edwards *et al.*, 2017; Zwaigenbaum *et al.*, 2015). Early intervention is the provision of health, education and social support in early childhood (typically when the child is 0-6 years old) with the aim of optimising a child's future outcomes (Dunst, 2000). In addition to optimising future outcomes related to core areas of difficulty or difference, early intervention often aims to reduce the likelihood of co-occurring difficulties that may be prevented or minimised with adequate early support (Reichow *et al.*, 2016). Early intervention has shifted from a focus on the child's impairments and a view of professionals as expert, to one which focuses on the child's strengths and takes a family-centred approach to empower carers (Dunst, 2000).

Specialist autism support can encompass a broad range of areas relating to a child's development, but early social communication support is a key recommendation for young autistic children (Green, 2019; NICE, 2013) . Understanding and supporting early communication skills has been the focus of considerable study over several decades (Bottema-Beutel, 2020). Research particularly highlights the importance of joint engagement for social communication and language development (Adamson and Bakeman, 1991; Adamson *et al.*, 2009; Bottema-Beutel *et al.*, 2014). Joint engagement occurs when a child and an adult are

interacting and are aware of each other while focused on the same object or event (Adamson and Bakeman, 1991). Coaching parents/carers to utilise strategies to promote joint engagement routines has been found to be an effective way to improve autistic children's social communication skills (Green *et al.*, 2010; Kasari *et al.*, 2014; Pickles *et al.*, 2016; Rogers *et al.*, 2014). Social communication interventions that are child-centred and family-led are recognised to have strong evidence for their effectiveness, and are recommended as specialist interventions in several professional and clinical guidelines related to autism (Autistica, 2021; NICE, 2013; Royal College of Speech and Language Therapists, 2023a; UK Parliament POST, 2020). As specialists in language and communication, SLTs play an important role in the speech, language and communication assessment and support for the autistic children who require this (NICE, 2013; 2016; 2017; Royal College of Speech and Language Therapists, 2023a).

1.5 Speech and Language Therapy

SLTs are trained to work with people with a wide range of language and communication difficulties. SLTs should work sensitively and reflectively with others (Royal College of Speech and Language Therapists, 2023) and assessments of the language and communication needs of a child should be holistic and consider their individual skills and abilities, the communication environment and the context (Royal College of Speech and Language Therapists, n.d.). Although autistic children commonly experience difficulties in the areas of speech, language and communication (Baird *et al.*, 2006), not all children and their families will require SLT support. The SLT support will vary in response to the child's specific speech, language and communication needs and may target more than one area of development. SLTs may work directly with the autistic child in 1:1 or groups, and/or support family members and others around the child so that they can effectively communicate their feelings, needs and wishes using verbal and/or non-verbal means (Royal College of Speech and Language Therapists, 2023a).

The main approaches to SLT with autistic children may be categorised as child-centred, clinician-centred or hybrid approaches which utilise a mixture of both approaches (Binns *et al.*, 2021). Child-centred, family-led social communication interventions for young autistic children take a developmental-naturalistic approach (NICE, 2013; Green, 2019). The SLT aims to empower parents and other carers to enhance language and communication skill in everyday interactions (Sussman, 2012). SLTs may also consider clinician-directed approaches based on behavioural theories (Binns *et al.*, 2021). Clinician-directed approaches tend to focus on

Augmentative and Alternative Communication (AAC) which may use high or low-tech approaches to support communication. Picture Exchange Communication System (PECS) (Bondy and Frost, 1998) is a low-tech system where a child is supported to use pictures to communicate their needs. High-tech approaches use computers or mobile devices to support a child to communicate. AAC approaches with autistic children have been found to most effectively support their ability to make requests rather than to communicate for social reasons (Ganz *et al.*, 2012).

SLT services vary in the type and amount of support offered to children and their families due to variation in service funding, clinical pathways and SLT workforce between different areas (I CAN and RCSLT, 2018). SLTs may take an eclectic approach and draw on several different approaches and/or deliver specific packaged interventions such as PACT (Aldred, Green and Adams, 2004; Green *et al.*, 2010; Pickles *et al.*, 2016) or Hanen: More Than Words (Sussman, 2012). In the UK, SLTs also often contribute to a young autistic children's Education, Health and Care Plan (EHCP). An EHCP is a legal document for children and young people up to the age of 25. It states their education, health and care needs and the support required to meet those needs. For children with communication difficulties, the SLT plays a key role in assessing needs, identifying goals for therapy and determining the support required to achieve these goals.

SLT is an important aspect of care for many families of autistic children (Pituch *et al.*, 2011; Sapiets *et al.*, 2022) and SLTs have a varied and complex role in assessing and supporting the language and communication needs of autistic children. All SLTs should engage in evidence-based practice (Health Care Professions Council, 2016), and provide intervention influenced by the needs of the child and their family, the SLT's clinical knowledge, skills and experience as well as research. Research and systematic reviews have predominantly focused on the efficacy of specific interventions, with interventions grouped according to the area of development being targeted, rather than considering interventions according to the professional groups that most commonly provide these interventions (Binns *et al.*, 2021). This has contributed to challenges in understanding the evidence base for SLT services for autistic children, particularly given the wide range of interventions an SLT may draw upon in their work with autistic children and their families.

A scoping review by Binns *et al.* (2021) aimed to address this challenge through conducting a scoping review of research on preschool autism interventions in the field of SLT. The review identified an increase in research on interventions commonly delivered by SLTs, and highlighted the diverse role and potential positive impact of SLT across a wide range of child and family

outcomes, however, it concluded that overall the quality of studies is mixed (Binns *et al.*, 2021). The review identified 114 papers and the authors note how this is a very limited number of studies in comparison with research on other interventions such as behavioural interventions (Binns *et al.*, 2021). Most studies included in the review by Binns *et al.* (2021) utilised a single subject design (n=58, 51%), followed by single pre-post design groups (n=21, 18%) and randomised controlled trials (RCT) (n=21, 18%), and finally, quasi-experimental group design (n=14, 12%). Single subject designs, although widely used and useful for understanding individual experiences, do not facilitate the generalizability of findings to a wider population and are often excluded from systematic reviews of autism interventions (Binns *et al.*, 2021). Whilst the recent increase in RCT is viewed positively within the field of SLT and autism interventions, there is a call for further pragmatic RCT studies that consider real-world delivery of interventions (Binns *et al.*, 2021). Considering real-world delivery is particularly important given the mulitprofessional delivery of autism interventions and the differing role of SLTs such as in providing direct SLT or supervising colleagues such as SLT assistants (Binns *et al.*, 2021)

Most studies identified in the scoping review by Binns *et al.* (2021) targeted social communication development. There is a strong evidence base developing for the effectiveness of early social communication and interaction interventions (French and Kennedy, 2018; Sandbank *et al.*, 2020). Child-centred, family-led social communication interventions for young autistic children take a developmental-naturalistic approach (Green, 2019; NICE, 2013). Manualised interventions that take a developmental-naturalistic approach to supporting social communication development have been developed, such as Hanen (Sussman, 2012) and the Paediatric Autism Communication Therapy (PACT) (Aldred, Green and Adams, 2004; Green *et al.*, 2010; Pickles *et al.*, 2016). These interventions aim to work directly with parents and other carers and include therapists' modelling strategies and video-interaction feedback for parents/carers, incorporating the essential features of social communication interventions for autistic children recommended by NICE (2013). Parent-mediated interventions have been found effective for supporting a child to generalise the skills they develop to different contexts (Aldred, Green and Adams, 2004; Pickles *et al.*, 2016). These interventions should be delivered by a trained professional (NICE, 2013) and as SLTs are trained to work with both children and adults with a range of speech, language, and communication needs (Royal College of Speech and Language Therapists, 2024) they are commonly the professional group that offer these types of interventions.

Several areas for further research and for improving research quality have been identified in relation to early intervention for autistic children. A review of non-pharmacological interventions for autistic children by Trembath *et al.* (2022) concluded that it remains unclear how the mode of intervention delivery and different child characteristics impact the child's outcomes following several different interventions (Trembath *et al.*, 2022). What works, for whom and why is frequently cited as an important area for future research (Vivanti *et al.*, 2018; Trembath *et al.*, 2022). Another important research gap to address is in the long-term follow up of children following intervention in outcome measures that are meaningful and valuable to children and their families (Trembath *et al.*, 2022). Limited or no information on the professional background of those delivering interventions leads to challenges both in understanding the SLT role in interventions, and in understanding the training and background of those delivering interventions and how this may impact on outcomes and experience of care (Binns *et al.*, 2021). Insufficient detail on the dosage of interventions and the mode of delivery are also noted as limitations in the existing literature on SLT for preschool autistic children (Binns *et al.*, 2021).

Social communication interventions for autistic children should be delivered by a trained professional (NICE, 2013) and SLTs are trained to work with both children and adults with a range of speech, language, and communication needs (Royal College of Speech and Language Therapists, 2024). SLTs are expected to engage in evidence-based practice (Health Care Professions Council, 2016), and to provide intervention influenced by the needs of the child and their family, the SLT's clinical knowledge, skills and experience as well as research. SLTs are therefore able to select from a wide range of interventions to support the individual needs of autistic children (Gillon *et al.*, 2017). SLTs may work directly with the autistic child and/or support family members so that they can effectively communicate their feelings, needs and wishes (Royal College of Speech and Language Therapists, 2023a). The main approaches to SLT with autistic children may be categorised as child-centred, clinician-centred or hybrid approaches which utilise a mixture of both approaches (Binns *et al.*, 2021).

Child-centred, family-led social communication interventions for young autistic children take a developmental-naturalistic approach (Green, 2019; NICE, 2013). The SLT aims to empower parents and other carers to enhance language and communication skill in everyday interactions (Sussman, 2012). Manualised interventions that take a developmental-naturalistic approach to supporting social communication development, such as Hanen (Sussman, 2012) and the Paediatric Autism Communication Therapy (PACT) (Aldred, Green and Adams, 2004; Green *et al.*, 2010; Pickles *et al.*, 2016), may also be followed. These programmes aim to work directly

with parents and other carers and include therapists' modelling strategies and video-interaction feedback for parents/carers, incorporating the essential features of social communication interventions for autistic children recommended by NICE (2013).

SLTs may also consider clinician-directed approaches based on behavioural theories (Binns *et al.*, 2021). Clinician-directed approaches tend to focus on Augmentative and Alternative Communication (AAC) which may use high or low-tech approaches to support communication. Picture Exchange Communication System (PECS) (Bondy and Frost, 1998) is a low-tech system where a child is supported to use pictures to communicate their needs. High-tech approaches use computers or mobile devices to support a child to communicate. AAC has been found to support the development of spoken language alongside supporting children to communicate their needs (Kasari *et al.*, 2014). AAC approaches with autistic children have been found to most effectively support their ability to make requests rather than to communicate for social reasons (Ganz *et al.*, 2012). However, a hybrid approach as described by Binns *et al.* (2021) presents opportunities to combine child-centred and clinician-focused approaches to support communication (Kasari *et al.*, 2014).

1.6 Access to Speech and Language Therapy

Despite the need for further high-quality research in the field of SLT for autistic children (Binns *et al.*, 2021; Trembath *et al.*, 2022) there is growing evidence for the effectiveness of some social communication interventions commonly delivered by SLTs (Aldred, Green and Adams, 2004; Green *et al.*, 2010; Pickles *et al.*, 2016). Ensuring every autistic person is offered proven supports, tailored to their needs is one of three main goals of the Autistica Support Plan (Autistica, 2021), which aims to build a support system for autistic people by 2030 (Autistica, 2021). Additionally, ensuring health and care services are accessible and equitable is one of six main priority areas of the national strategy for autistic children, young people and adults (Department of Health and Social Care & Department of Education, 2021). SLTs have a key role to play in supporting young autistic children, and access to SLT is a high priority for parents of children with developmental disabilities including autism (Pituch *et al.*, 2011; Sapiets *et al.*, 2022). Despite this, delays and difficulties in accessing early support tailored to autistic people's needs is recognised as a significant challenge (Department of Health and Social Care & Department of Education, 2021; National Autistic Society, 2020), one compounded by the impact of the COVID-19 pandemic (National Autistic Society, 2020).

1.6.1 Understanding access to healthcare services

The NHS Constitution expresses a commitment to providing a comprehensive service to improve the health and wellbeing of all (Department of Health, 2012), and access to timely support and prevention of difficulties is a key policy priority reflected in the 'NHS Long Term Plan' (NHS England, 2023) and the 'NHS 2024/2025 priorities and operational planning guidance' (NHS England, 2024a). Understanding barriers to access, and the experience of care for people with speech, language and communication needs is also specifically recognised as a high priority for research (National Institute for Health and Care Research, 2022).

Recognising influences on access to healthcare is important for reducing health inequalities, and for ensuring access to timely, high-quality care for all. Access to a healthcare service can be understood as access to the right support, at the right time, and in the right place (Gulliford *et al.*, 2002). However, despite this broad and straightforward definition of access to healthcare, access is a complex and multifaceted concept and process (Cu *et al.*, 2021; Derose, Gresenz and Ringel, 2011). Frameworks have been developed to understand and identify key areas impacting on access to services (Aday and Andersen, 1981; Andersen, Davidson and Baumeister, 2014; Freeborn and Greenlick, 1973; Levesque, Harris and Russell, 2013; Penchansky and Thomas, 1981; Shengelia *et al.*, 2005). One the most commonly known is Andersens' Behavioural Model of Health Services Use (Aday and Andersen, 1981) which consists of three main elements: predisposing factors, which relate to characteristics of the person seeking healthcare; enabling factors which relate to the person's resources and availability of healthcare services, and need factors, which relate to the way the person's need for healthcare is understood.

Numerous other frameworks have been developed, and vary in relation to the elements included and the detail and emphasis placed on different patient, service and contextual factors (Levesque, Harris and Russell, 2013). Frameworks increasingly recognise the influence of the context, such as the economic, geographical and cultural context on access to services (Dixon-Woods *et al.*, 2006; Meade, Mahmoudi and Lee, 2015; Sapiets, Totsika and Hastings, 2021). The Levesque Framework for Healthcare Access (Levesque, Harris and Russell, 2013) is one of the most recently developed frameworks and is widely used (Cu *et al.*, 2021). It refers to five dimensions of accessibility and considers an individual's ability to identify health needs, seek services, reach resources, use services, and be offered services appropriate to their needs (Levesque, Harris and Russell, 2013).

Studies have defined, conceptualised and measured access in several different ways (Chapman *et al.*, 2004; Levesque, Harris and Russell, 2013). Patient health outcomes, service availability, and utilisation have all been used in work to understand access to healthcare (Chapman *et al.*, 2004) and each have strengths and limitations in understanding access. Availability focuses on the extent to which the healthcare service has the necessary resources, including settings, equipment and trained staff, to meet the needs of those who require it (Levesque, Harris and Russell, 2013). Service availability, however, does not automatically lead to equal access or to service utilisation by those in need (Chapman *et al.*, 2004). It does not consider the perceptions of the person seeking care, the costs of access such as travel time and expense or the timeliness and quality of care (Chapman *et al.*, 2004). It should also be remembered that availability does not indicate patient uptake or engagement.

Utilisation is a commonly used measure of access that does capture service use or realised access (Chapman *et al.*, 2004). Utilisation is a particularly valuable measure for identifying patterns of usage, indicating where further work may be required to explore barriers to access. Effective service utilisation requires a good degree of fit between the person requiring healthcare and the service. Utilisation as a measure of access, however, is limited as it is impacted by several factors such as patient expectations, knowledge and awareness, and features of the service, such as its acceptability and appropriateness for patients, and the local context and culture (Chapman *et al.*, 2004). Utilisation does not consider unmet needs or the reasons for this. Like availability, utilisation fails to consider service quality or waiting times.

Frameworks for understanding access to healthcare, such as Levesque's Conceptual Framework (Levesque, Harris and Russell, 2013) have informed some empirical research and literature reviews on access to healthcare for autistic children and adults such as Babalola *et al.* (2024) in providing a comprehensive definition of access to inform the review and Chinn and Abraham (2016) in supporting and structuring discussion of their findings through application of the Candidacy Framework (Dixon-Woods *et al.*, 2006). Application of a framework can broaden a study perspective on the different dimensions and abilities required for effective healthcare access. However, although these frameworks exist and can deepen our understanding of access to services (Koehn *et al.*, 2024), the application of frameworks deductively within studies may also lead to important issues not captured within existing frameworks to be overlooked (Braun and Clarke, 2021; Byrne, 2022). The role of frameworks for understanding access to healthcare within the study presented in this thesis is explored further in Chapter 3.

1.6.2 Barriers to healthcare services

Autistic people experience several healthcare service-related barriers (Babalola *et al.*, 2024; Doherty *et al.*, 2020), including those that impact on the general population. Factors such as ethnicity, socioeconomic status, and geographical location, have all been found to impact on autistic people's access to healthcare (Mello *et al.*, 2016; Monz *et al.*, 2019; Payakachat, Tilford and Kuhlthau, 2018). As well as barriers to healthcare that impact on the general population, autistic people experience challenges that are unique to them. These include barriers related to healthcare professionals' understanding of autistic people's communication needs and perspectives, autistic people's sensory sensitivities in healthcare settings, and autistic people's difficulties recognising healthcare needs and communicating with healthcare providers (Doherty *et al.*, 2020). Due to recognition of the significant challenges autistic and learning-disabled people face in accessing services, Oliver McGowan training on learning disability and autism is mandatory for UK health and social care staff. A recent systematic review of UK healthcare access for autistic children identified similar areas of challenge for children seeking access to General Practitioners, hospital, mental health and dental services (Babalola *et al.*, 2024). Barriers included professional and parental knowledge of autism, the child's sensory issues and presence of challenging behaviour. In addition to this, system-level barriers were identified similar to those experienced by autistic adults, including communication issues between the child, their parent and the healthcare provider, and a lack of person-centred care (Babalola *et al.*, 2024). Research on access to services for autistic children has primarily focused on access to primary healthcare and mental health services (Babalola *et al.*, 2024; Doherty *et al.*, 2020).

As a result, access to SLT services has been largely sidelined. Access to SLT is challenging for children with a range of communication needs. UK children's SLT services have been under increasing pressure over the last decade, with significant challenges in meeting demands for the service (Bercow, 2008; I CAN and RCSLT, 2018; Royal College of Speech and Language Therapists, 2023b). Workforce pressures and high vacancy rates have, alongside the impact of COVID-19, contributed to long waiting times for SLT for children and their families (NHS Confederation and NHS Providers, 2022; Royal College of Speech and Language Therapists, 2021a; 2023b), contributing to high levels of dissatisfaction for families.

In response to widespread dissatisfaction with SLT services, a comprehensive review of speech, language and communication needs and support for children in the UK was commissioned by the Government in 2008 (Bercow, 2008), with a follow-up ten years later (Bercow: Ten Years On)

(I CAN and RCSLT, 2018). Five themes, all related to access to services, were identified through analysis of surveys, oral evidence sessions and focus groups (I CAN and RCSLT, 2018): children's needs should be identified early and support offered; support should be evidence-based and effective; services should be equitable; systemic changes should be made to ensure communication is a core part of national and local plans; and there should be greater awareness of communication needs (I CAN and RCSLT, 2018).

SLT workforce pressures pose a significant challenge to service delivery and improvement in areas linked to access, with an average vacancy rate of 25% in children's SLT services across England (Royal College of Speech and Language Therapists, 2023b). Several changes in funding and staffing structures over recent years have also impacted on the SLT services offered to children. 'Bercow: Ten Years On' reported several examples of restructuring of services and the downgrading and removal of specialist posts (I CAN and RCSLT, 2018). A reduction in spending on children's SLT has also been identified, with considerable variation between different commissioning groups (Longfield, 2019). Royal College of Speech and Language Therapists (2023b) highlight concerns that reduction in funding and restructuring often leaves services without senior leads and specialists to support children and their families where there are more complex needs. An overall decline in specialist SLT posts impacts both the delivery of evidence-based practice (Pring *et al.*, 2012) and the service's ability to influence strategic-level decisions (I CAN and RCSLT, 2018).

The COVID-19 pandemic has exacerbated existing challenges in areas previously identified as impacting access and requiring improvement (Bercow, 2008; I CAN and RCSLT, 2018). Waiting times for SLT have become a significant issue and NHS Confederation and NHS Providers (2022) reported in January 2022 that 65,500 children were waiting for SLT with an estimated 4,000 waiting more than a year to be seen. A survey by the Royal College of Speech and Language Therapists (2021a) of children and young people, and their carers from across England, Wales, Scotland and Northern Ireland, found that 81% of the 425 respondents received less SLT than they did prior to the pandemic. As well as receiving less or no SLT during the pandemic, many of those surveyed who received SLT before the pandemic had it delivered differently, in ways that were more challenging to access, with fewer face to face SLT appointments and phone and video calls replacing these (Royal College of Speech and Language Therapists, 2021a). Changes and disruption due to the pandemic have widened areas of existing inequality. For example, those who can afford to pay for treatment privately are able to access support sooner than those who cannot (NHS Confederation and NHS Providers, 2022).

Despite the importance of early language and communication support, there is little research that has examined autistic children and their families' experiences of real-world access to SLT. This is despite language and communication being the 2nd highest research priority area for autism from the autism community after mental health (Autistica, 2017) and the recognised challenges in access to UK SLT services for autistic children (Sapiets *et al.*, 2022). The impact of unmet SLT needs are not as immediate and visible as the impact of delays in access to other services (NHS Confederation and NHS Providers, 2022) and the nature of the challenges in access to SLT and unmet SLT needs for autistic children are not currently well understood.

1.7 Introduction to the research

The thesis attempts to explore and answer the following question:

What factors and processes impact on access to SLT for preschool autistic children from the perspective of key stakeholders?

The following objectives were set:

- To map the existing pathway for access to SLT intervention for preschool autistic children within the research setting and to consider this in relation to existing local and national guidelines.
- To understand factors and processes impacting on access to SLT for preschool autistic children from the perspectives of key stakeholders such as parents, carers, early years health and care professionals and SLTs.
- To identify opportunities to improve access to SLT for preschool autistic children.

A qualitative case-study methodology is applied within this study to facilitate a holistic, in-depth understanding of access to SLT for preschool autistic children, studied in its natural context and constructed from the perspectives of a range of stakeholders.

1.8 Researcher interest and rationale for the study

My interest in this research area has developed over 20 years of clinical practice as an SLT working with autistic people and their families in the UK. Supporting access to high quality, effective communication interventions has been important to me throughout my clinical career working with young autistic children and their families, and now through my research. My decision to focus on children of preschool age comes from an appreciation of the way in which

effective early intervention has the potential to impact on a child's long-term outcomes (Hampton and Kaiser, 2016), the importance placed on access to SLT by parents and carers (Pituch *et al.*, 2011) and my experience of working closely with young children and their families. I have observed some of the difficulties that families experience when attempting to access support and also the benefits of SLT for those who have successfully accessed a service to meet their needs. This is what has motivated me to explore the research topic presented in this thesis.

1.9 Introduction to the Thesis

Chapter Two: Scoping review of access to SLT for preschool autistic children

Following this introductory chapter, Chapter Two examines the current research on access to SLT for preschool autistic children through a scoping review of the literature. This provides the research context for this topic area and a justification for this study.

Chapter Three: Methodology and methods

The theoretical perspective of this study is outlined together with an overview of the methodologies and methods considered and a justification for decisions made. This is followed by a description of the research design including the ethical considerations throughout the conduct of the study, recruitment, data collection and data management. The process of data analysis is described along with steps taken to increase the trustworthiness of the study.

Chapter Four: Findings

A rich and in-depth description of the research setting and participants is presented along with the process of access to SLT in the service context. The findings of the study are then presented in a reflexive thematic analysis report. The relevance of each theme and sub-theme to the research aim, objectives and question is described and presented with relevant quotes from participants.

Chapter Five: Discussion

The findings of this study are discussed in the context of existing literature on access to SLT for preschool autistic children. The chapter describes the contribution of this study to knowledge in this area and the ways in which the study has answered the research question and addressed the research objectives.

Chapter Six: Conclusion

A summary of the main strengths and limitations of this study are presented with a reflection upon the learning and challenges gained throughout the conduct of the research. The final recommendations for clinical practice and further research are provided.

1.10 Chapter summary

Early interventions have the potential to improve the lives of autistic people, and are considered cost-effective for society and health and care systems, through a reduction in the long-term support needs of autistic people (Buescher *et al.*, 2014). Effective early language and social support for autistic children and their families is particularly important, improving outcomes for the child (Green *et al.*, 2010; Kasari *et al.*, 2014; Pickles *et al.*, 2016; Rogers *et al.*, 2014), reducing stress for families (Lord and Bishop, 2010) and minimising the financial burden for families who may otherwise be paying for private SLT in addition to, or in place of, NHS SLT (Sapiets *et al.*, 2022). Several challenges have been identified in access to UK SLT services (Bercow, 2008; I CAN and RCSLT, 2018; NHS Confederation and NHS Providers, 2022; Royal College of Speech and Language Therapists, 2021a; 2023b).

Exploring real-world access to SLT services is an important topic for research. It aligns with autism community priorities for research (Autistica, 2017), is relevant to the everyday lives of autistic people (Pellicano, Dinsmore and Charman, 2014) and crucially has the potential to help ensure autistic children and their families receive the support they need to reach their potential (Lai *et al.*, 2020).

Chapter 2 Scoping review of access to SLT for preschool autistic children

2.1 Introduction to the chapter

A thorough understanding of the nature of what is known, and the strengths and limitations of research completed in a field, can illuminate gaps and opportunities for research (Boland, Cherry and Dickson, 2017). A detailed description of the scoping review conducted is presented, followed by a summary of what is currently known and a rationale for the research question and objectives.

2.2 Rationale for selecting a scoping review of the literature

Firstly, the purpose of the review should be established to determine the most appropriate type of literature review to complete (Peters *et al.*, 2020a). A brief, unstructured exploration of research on the topic identified no systematic reviews, and few highly relevant articles. This could be partly explained by the complex nature of access, which, as discussed in the previous chapter is multi-faceted. This, along with the complexity of access, suggested a broad approach to reviewing the literature was required.

Literature reviews can take various forms, differing in purpose, scope, degree of structure and flexibility. Various types of review were considered for this research, including systematic, rapid, narrative, integrative and scoping reviews (Boland, Cherry and Dickson, 2017). A systematic review takes an explanatory or analytical approach to answer a precise, narrowly focused question (Peters *et al.*, 2021) and is well-suited to questions to inform clinical decisions rather than exploring a topic (Munn *et al.*, 2018; Peters *et al.*, 2020b; Tricco *et al.*, 2018), hence why it was not selected. A rapid review aims to understand what is known about a clearly defined and focused issue as efficiently as possible (Boland, Cherry and Dickson, 2017) and, thus, would not capture the necessary breadth and depth of knowledge in this topic area. At the other end of the spectrum, although a narrative review is well suited to understanding what is known on a broad topic area, it is typically completed by experts to provide a historical overview of a topic or to identify areas where further research is needed (Boland, Cherry and Dickson, 2017). A narrative review would not meet the needs of this study. An integrative review was considered as it is appropriate for developing a holistic understanding of a topic by integrating information from

diverse data sources (da Silva, Brandão and Ferreira, 2020). However, its purpose is to provide a comprehensive understanding of a phenomenon and contribute to theory development which was not the purpose of this review.

Having assessed various options, a scoping review was selected. It enables available evidence on a topic to be identified, clarifies key topics and definitions, examines how research has been completed in a field and identifies knowledge gaps (Munn *et al.*, 2018). It does not aim to contribute to theory development or identify best research available to answer a specific question, but aims to map literature on a topic (Peters *et al.*, 2020a). A scoping review is well suited to exploring complex, heterogenous literature using an exploratory and descriptive approach (Peters *et al.*, 2021). It enables a systematic, transparent, and reproducible approach to review, with data extracted and presented in a structured way (Peters *et al.*, 2015), and it requires the same rigorous and systematic methods as a systematic review to ensure the results are relevant, credible, and reliable (Munn *et al.*, 2018; Sucharew and Macaluso, 2019).

2.3 Scoping review methodology

Although scoping reviews are relatively new, they have become increasingly popular due to their use in mapping relevant literature on emerging topics and identifying gaps in knowledge (Pham *et al.*, 2014). Arksey and O'Malley first published a scoping review guide in 2005 (Arksey and O'Malley, 2005) due to lack of uniformity in the conduct of such reviews (Pham *et al.*, 2014). Since 2005, further development and refinement has occurred in relation to terminology, enhancing rigor, and reporting guidelines to support the conduct and appraisal of scoping reviews (Colquhoun *et al.*, 2014; Levac, Colquhoun and O'Brien, 2010).

The Joanna Briggs Scientific Committee convened a Scoping Review Methodology group in 2014, which led to the publication of the first Joanna Briggs Institute (JBI) chapter describing guidance for scoping reviews (Peters *et al.*, 2015). It set the expectation for a rigorous, transparent and trustworthy approach to conducting a scoping review (Peters *et al.*, 2015). Minor updates were made to JBI scoping review methodology in 2017 (Peters *et al.*, 2017), and a more significant update as a result of the development of Preferred Reporting Items for Systematic Reviews extension for Scoping Reviews (PRISMA-ScR) (Tricco *et al.*, 2018).

PRISMA-ScR consists of a checklist of 20 essential reporting items and two optional items for a scoping review (Tricco *et al.*, 2018). This is consistent with JBI guidance for the conduct of

scoping reviews, developed following the guidance of the Enhancing the Quality and Transparency of Health Research Network (EQUATOR) (Tricco *et al.*, 2018).

2.4 Review question and objectives

The scoping review was guided by a broad question:

What is currently known about factors impacting on access to SLT for preschool autistic children?

Specific objectives were also set:

Objective 1: To understand the context of current research on access to SLT for preschool autistic children.

Rationale: Healthcare services and their funding differ worldwide. An understanding of the context of research, such as the social, cultural, political, and geographical context enables their impact on access to SLT for preschool autistic children to be considered.

Objective 2: To identify which perspectives are captured on the topic of access to SLT for preschool autistic children.

Rationale: Access to SLT is impacted by factors and processes related to children and their families, SLT services and wider health, education and support services. Understanding what is currently known on this topic, and from which perspectives, will help identify gaps in knowledge.

Objective 3: To identify the barriers and facilitators to access to SLT for preschool autistic children.

Rationale: Mapping the barriers and facilitators to access in existing literature may identify areas for further investigation.

2.5 Methods

To ensure a high-quality review, up to date guidance on the conduct of scoping reviews was followed (Peters *et al.*, 2020a).

2.5.1 Protocol and registration

The review was conducted following a pre-specified protocol. This was not published or registered (Appendix A.1). The protocol specified the methodology followed (including search strategy and inclusion/exclusion criteria) (Peters *et al.*, 2020a). Scoping reviews are often used to explore new or emerging topics of interest, and consequently, it is recognised that an exploratory, flexible and iterative approach may be needed (Peters *et al.*, 2020a). To ensure a flexible, but structured and systematic approach, deviations from the pre-specified protocol were tracked and a rationale for changes are given within the relevant sections of the scoping review report (Peters *et al.*, 2020a).

2.5.2 Eligibility criteria

The review focus was structured according to population, concept and context (PCC) (Peters *et al.*, 2020a). **Error! Reference source not found.** presents information on the literature being s ought and search limits applied. The eligibility criteria were established prior to conducting the review and discussed with the supervision team, with minor adaptations to expand the child's age range and to include literature that did not explicitly state or recognise a link to access.

A scoping review can include all relevant literature (Peters *et al.*, 2020a) and information was considered for inclusion from several sources.

Table 1 Inclusion criteria

Review element	**Application/decision within this review**
Population	Preschool autistic children. Studies either focus exclusively on preschool autistic children or include preschool aged children along with older autistic children. Where there is wide age range, demographic data on child age is provided.
Concept	Articles that mainly focus on factors that impact on access to services for autistic children (including child, carers, and service factors). Relevant papers were included even if they did not explicitly state or recognise a potential link to access.

Review element	Application/decision within this review
Context	SLT intervention services provided in any setting and in any geographical location, worldwide.
Sources of information	Any type of literature, including research utilising any methodology, published, peer-reviewed journal articles, books, discussion papers, campaign reports, theses, webpages, clinical and professional guidance, and books.
Date range	1994- 2023 This date range would capture the recent diagnostic criteria for autism (World Health Organization, 1993; 2020). Date limits were also set to understand contemporary SLT practice and experiences of access rather than to provide a historical overview of access to SLT.
Language	English only. Translation services were not available to support this study.

2.5.3 Information sources

Information sources were identified under the guidance of University of Southampton Engagement librarians; V. Fenerty and N. Beckett-Jones, University of Southampton and are summarised in Appendix A.2. Cumulative Index of Nursing and Allied Health (CINAHL), PsychINFO and MEDLINE databases were searched due to their broad coverage of literature related to psychology and allied health professions. These were systematically searched using a free text and subject heading approach. Although the original review protocol did not include grey literature searches, the information sources were expanded in updates to the scoping review to identify as much relevant literature as possible on this topic. The final scoping review considered all types of literature and research methodologies. Several searches of grey literature were conducted. These searches were informed by guidance on sources (UK Health Security Agency, 2023) and followed good practice guidance to ensure a systematic approach (Godin *et al.*, 2015).

Four authors (A.V. Binns, S.Y. Chu, V. Sandham and D. Trembath) of highly relevant articles were contacted to identify any other relevant literature. A response was received from D. Trembath, who suggested no further inclusions in the review, however, information relevant to the introduction and discussion of the thesis were suggested.

2.5.4 The search and selection of sources of evidence

Subject heading and free text searches followed a three-step approach as recommended by JBI for all review types (Peters *et al.*, 2020a).

Step 1: initial search. An Engagement Librarian from the University of Southampton Hartley Library (V. Fenerty) supported with planning the initial search strategy in 2018 (**Error! Reference s ource not found.**) which yielded 57 results (with duplicates removed), five of which met the eligibility criteria at screening within CINAHL, and 41 results (with duplicates removed) with one meeting the eligibility criteria within Medline.

Table 2 Search terms (v1 August 2018)

Population	**Concept**	**Context**
autis* **AND** child* **OR** preschool* **OR** young* **OR** toddler* **OR** parent* **OR** carer*	access* **OR** barrier* **OR** factor* **OR** perception* **OR** experience*	“speech and language therap* ”**OR** “speech and language patholog*” **OR** “speech-language patholog**” **OR** “SLP” **OR** “speech patholog*” **OR** “speech therap*” **AND** Intervention* **OR** therap* **OR** treat* OR service* **OR** provision

Step two: database searches. Following the initial search, changes were made, including the addition of search terms and use of subject heading searches. The search was then updated in 2020. In September 2023 a full literature review was completed rather than an update. This was due to the time that had passed since earlier searches and aimed to ensure a robust and consistent approach to the review. This final review was completed under the guidance of an Engagement Librarian at the University of Southampton. The search was updated in 2020 and a comprehensive and final full search completed in September 2023 under the guidance of N. Beckett-Jones, Engagement Librarian, University of Southampton. One full search of the Medline database search is provided in Appendix A.3.

All search results were saved in folders labelled with the name of the database searched within EndNote (The Endnote Team, 2013). Results of all three database searches were then grouped into one EndNote folder, where duplicates were removed using the EndNote 'Find duplicates' tool and manual review and removal of remaining duplicates. The title and abstract of all de-duplicated results were screened independently by Dr Richard Wagland (RW) working in a Microsoft Excel spreadsheet, and Iona Wood (IW) in EndNote. IW screening outcomes were then added to the spreadsheet so they could be compared and differences in opinion discussed. Inter-rater reliability was assessed using Cohen's kappa, resulting in a kappa value of 0.86 indicating substantial agreement between IW and RW. IW and RW met to discuss differences and then agreed the final outcome of screening.

Literature that met eligibility criteria at screening was saved in a separate EndNote folder labelled 'for full text review' and full text articles were retrieved and saved as Portable Document Format (PDF) attachments to EndNote records. Eligibility criteria were applied following full text review by IW and Dr Ellen Kitson-Reynolds (EKR). Inter-rater reliability was assessed using Cohen's kappa, resulting in a kappa value of 0.94 indicating very high agreement between IW and EKR. IW and EKR discussed and resolved differences in opinion via email.

Step three: Identification of literature from other sources. The reference lists of all included literature were examined to find further relevant literature, and included articles were searched within Web of Science to identify items citing this literature. Multiple grey literature searches were completed (Appendix A.2). The literature identified as potentially relevant was screened at title and abstract level (or contents pages, executive summaries etc. for other types of literature) by IW and RW, and the above process of full text review (completed by IW and EKR), hand searching of reference lists and Web of Science searching was again followed for all further included literature.

2.5.5 Data extraction process

Data extraction aimed to map relevant information from the literature to meet the purpose and objectives of the review (Peters *et al.*, 2020a). A data extraction form was created specifically for the review within Microsoft Excel by IW and discussed with the supervision team. It initially included the headings author, country, sample, data collection method, selected themes/findings, limitations and relevance, and articles were grouped according to their methodological approach. During an update to the scoping review (January 2021), minor changes were made to the structure and an additional category to capture the link to

access/aspect of access was included. This ensured greater alignment with the scoping review title, question, objectives, and search strategy. The column 'findings' was also amended to 'Findings relevant to access to SLT' as several studies did not specifically focus on access to SLT and so not all study findings were relevant to this review.

The following information was extracted:

- Title, date, author, and country of origin
- Aim
- Design, methods
- Participant characteristics and characteristics of the child considered the focus of the literature
- Aspect of access explored
- Findings relevant to access to SLT
- Critical appraisal findings

An abbreviated data extraction table is presented in the body of the thesis in **Error! Reference s ource not found.** (section 2.6). Studies are listed alphabetically according in the first author's surname. Additional information on study quality is presented in Appendix A.5.

2.5.6 Data items

Data extraction was completed by two reviewers (IW and Dr Sarah Worsfold (SW)) to ensure a consistent and rigorous approach. This was completed independently, with differences discussed and consensus achieved.

2.5.7 Critical appraisal of individual sources of evidence

In their seminal work on the scoping review framework, Arksey and O'Malley (2005) state that a quality assessment is outside the scope of a scoping review. However, this has been considered a limitation (Pham *et al.*, 2014). Further development and refinement of the scoping review methodology (Colquhoun *et al.*, 2014; Levac, Colquhoun and O'Brien, 2010) concluded that quality appraisal may be appropriate if it is a specific aim of the review (Peters *et al.*, 2020a).

A quality appraisal of the literature was completed using the Mixed Methods Appraisal Tool (MMAT) (Hong *et al.*, 2018) to understand the quality of included research and to identify gaps and weaknesses requiring further research. MMAT was selected as it enables high-quality

review of studies with different methodologies, ensuring a consistent approach with the use of a single tool.

Studies were scored using MMAT guidance (Hong *et al.*, 2018). Although Hong *et al.* (2018) originally discouraged reviewers from generating a quality score, it was subsequently acknowledged that this may sometimes be required (Hong, 2020). Hong (2020) recommended that scores are presented alongside a written description of the quality issues. MMAT was used if the screening questions (S1: 'Are there clear research questions?' And S2: 'Do the collected data allow to') were answered 'Yes'. Five further MMAT questions were asked using the category of questions appropriate to the study design. All 'Yes' responses scored one, and zero points for 'No' or 'Can't tell'. All appraised articles were scored out of five, with a score of four or five indicating a higher quality study. MMAT scores are reported, alongside a summary of any quality issues in Appendix A.5.

2.5.8 Synthesis of results

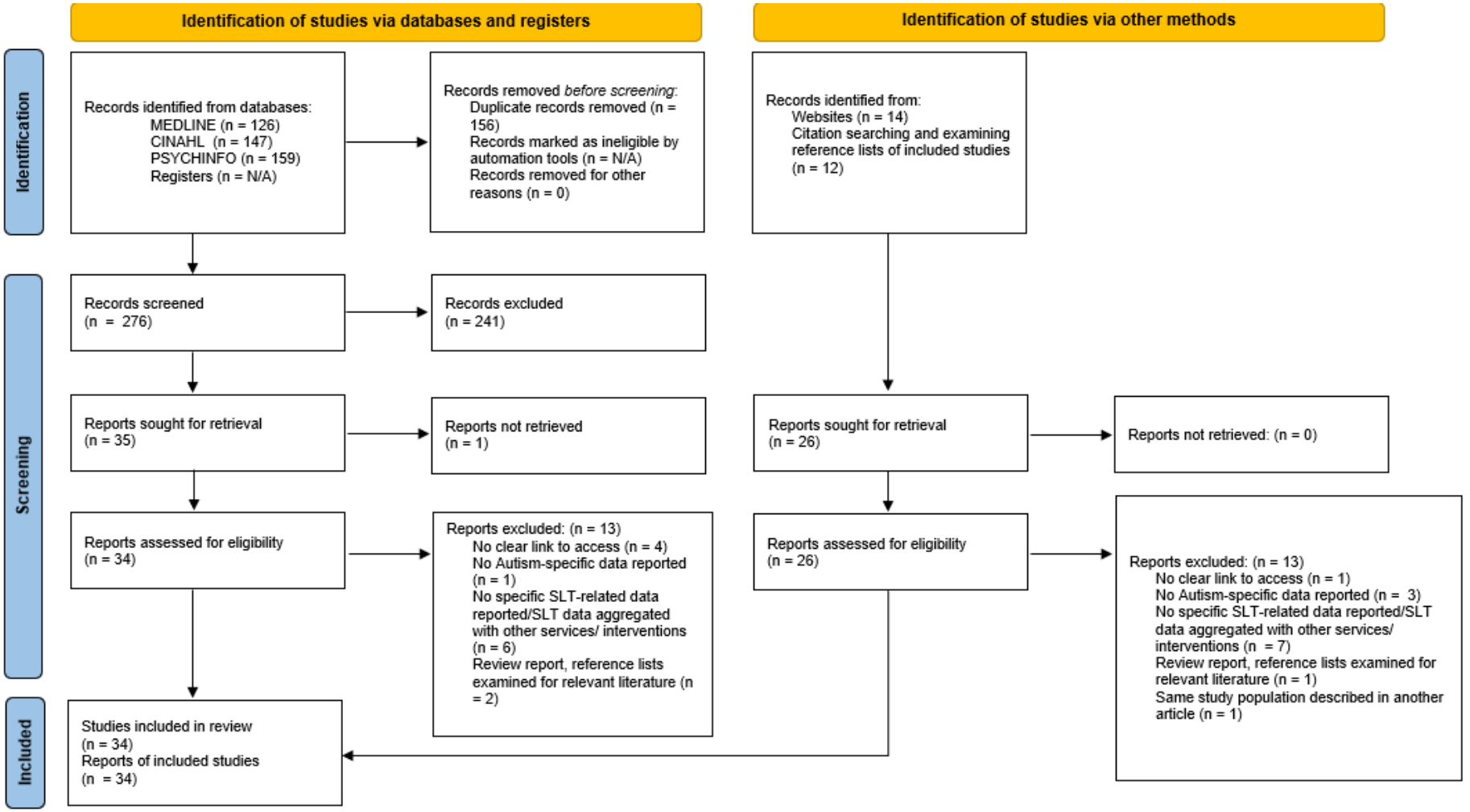
Within a scoping review, results may be presented in the most appropriate way for the topic and evidence identified, such as through a visual mapping or narrative of results (Peters *et al.*, 2020). Synthesis of both quantitative and qualitative data together is considered to be controversial due to the challenges around summarising findings generated using different study methodologies (Dixon-Woods *et al.*, 2005). However, descriptive qualitative techniques are recommended for synthesising scoping review findings from a wide range of literature (Peters *et al.*, 2020), rather than an integrative approach where quantitative or qualitative study findings are combined to develop synthesised results (Peters *et al.*, 2020). Although the majority of included studies utilised quantitative methodologies, a thematic analysis was selected as it enables evidence from separate qualitative and quantitative studies to be grouped, connections identified, and information synthesised and presented (Dixon-Woods *et al.*, 2005). This was achieved using qualitative coding techniques, following a structured, transparent approach (Peters *et al.*, 2021). NVivo (Version 13, 2020, R1) (Lumivero, 2020), a Computer Assisted Qualitative Data Analysis Software (CAQDAS) package, supported the analysis. PDFs of included articles were imported into NVivo. Both qualitative and quantitative study findings and information relevant to the review were coded with a short descriptive label, following an inductive and iterative approach. Annotations captured thoughts and reflections and additional information of interest. Coding enabled key information from across all included literature to be easily retrieved and patterns identified across all included literature.

2.5.9 Selection of sources of evidence

Review outcomes are presented in a PRISMA flow chart (Page *et al.*, 2021) (**Error! Reference s ource not found.**), followed by a report using the most up to date guidance for reporting scoping reviews (Peters *et al.*, 2020b).

Database searches identified 432 articles. After duplicates were removed, 276 titles and abstracts were screened by two reviewers (IW and RW). 34 full-text articles were subsequently read and assessed for eligibility, having eliminated one article that was not accessible. Along with a further 26 articles identified through other means such as citation searching, hand searching reference lists and grey literature searches, a total of 60 articles were assessed for eligibility by two reviewers (IW and EKR). 26 articles were excluded for a number of reasons: no clear link to access to SLT (n = 5); no autism-specific data reported (n = 4), no specific SLT-related data reported/SLT data aggregated with other services/ interventions (n = 13), review report not directly relevant (although reference lists were examined) (n = 3) and same study population described in another article (n = 1). This resulted in 34 articles that were included in the review. The papers excluded at full text and the reason for exclusion are presented in Appendix A.4.

Figure1 PRISMA Diagram (Page et al., 2021)



2.6 Findings

The abbreviated data extraction table is presented in Table 3.

Table 3 Data extraction table

Author, year, country	Study aim	Study design	Participants and child characteristics	Aspect of access explored	Findings relevant to access to SLT
Araripe *et al*. (2022), Brazil	To describe the profile of service use, barriers to access and factors related to those barriers.	Quantitative, online survey.	927 families with children: - Diagnosed ASD - Aged 3;0 – 18;0 years	Patterns of SLT utilisation and parent perspectives on barriers to access.	Barriers: Waiting lists. Costs of services. Scarcity of specialist resources. Regional variation in service availability and accessibility. Private vs public health insurance.
Auert *et al*. (2012), Australia	To explore the expectations, awareness, and experiences of parents of accessing evidence based SLT services for their child with autism.	Qualitative, focus group and thematic analysis.	20 parents of children: - Diagnosed ASD - Aged 3;0 – 6;0 years - Receiving SLT	Parent perspective of access, from first concerns about their child to initial experiences of SLT, including involvement in decisions.	Barriers: Challenges finding appropriate and effective SLT services. Limited information on the SLT intervention and the rationale of it, impacting on parents' degree of involvement. Facilitators: SLTs with relevant clinical skills and experiences. Effective communication between the SLT and parent to support empowerment. Provision of information on the SLT intervention to parents.
Becerra *et al*. (2017), USA	To describe services and treatments used by children with ASD and their families and to present methods to create a research resource.	Quantitative, descriptive. Online and telephone and postal survey.	1155 parents of children and adolescents - Diagnosed ASD - Aged 17 years and younger	Utilisation of SLT and perceived effectiveness.	Facilitator: SLT perceived positively (88.6% of those who had accessed SLT perceived it as helpful). Other: SLT amongst most accessed interventions. 60% of parents reporting that they had used SLT.
Binns *et al*. (2022), Canada	To explore practices of SLTs and communicative disorders assistants for preschool children with suspected/diagnosed autism. To identify barriers and facilitators to providing services.	Cross-sectional online survey with mixed methods of analysis.	258 clinicians (SLTs and communicative disorders assistants) providing SLT to preschool children with suspected or diagnosed autism.	SLT service delivery, experiences of SLTs, and barriers and facilitators to service delivery.	Barriers: Insufficient professional opportunities for collaboration. Long waiting lists. Insufficient time and funding. Large caseloads. Clinician knowledge and access to professional development opportunities. Family readiness for SLT. Facilitators: SLT knowledge and access to autism -focused professional development. Intra- and inter-professional collaboration opportunities.

Author, year, country	Study aim	Study design	Participants and child characteristics	Aspect of access explored	Findings relevant to access to SLT
Bromley *et al*. (2004), UK	To examine the impact of different factors on psychological wellbeing of mothers of children with ASDs to explore social support, mental health status and satisfaction with services.	Quantitative descriptive, structured interviews.	68 mothers of children: - diagnosed ASD	Family factors and utilisation of support services. Accessibility, appropriateness and sufficiency of services also examined.	Barriers: The SLT service was considered sufficient by only 61% of participants who had accessed SLT in the preceding 6 months. Facilitators: Mothers' awareness of the SLT service. The SLT service is considered accessible and appropriate.
Carson *et al*. (2021), USA	To conduct a needs assessment of paediatric therapy services and to explore the perceptions of parents with ASD regarding therapy services and access to care.	Phenomenological approach utilising face to face, semi-structured group interview in the form of a focus group.	11 caregivers aged at least 18 years and older who have children: - aged 0–21 years - diagnosed ASD	Parent perception of therapy services and access to care.	Barriers: Limited-service availability, long distances to travel, high staff turnover rates due to cost of living in the specific location. Staff with limited specialist experiences and autism knowledge, insufficient communication between professionals (across all services (Occupational Therapy, Applied Behavioural Analysis and SLT). Insufficient SLT capacity to meet the predicted SLT needs of autistic children.
Cassidy, McConkey and Slevin (2008), UK	To discover parental perceptions of the child's difficulties and their impact on family life. To identify child and family characteristics and to identify the support available, and those required.	Quantitative, descriptive. Structured questionnaires. Thematic analysis.	104 parents of preschool aged (<5 years) children: - diagnosed ASD - recently diagnosed within one of two community-based specialist clinics.	Patterns of service utilisation, parental perceptions of child's communication needs and helpfulness of the SLT service.	Barriers: Variation in access to SLT unrelated to child and family characteristics (child's severity of needs, parental perception of child improvements and parental stress). Other: Parents reported speech and communication difficulties to be the problems they had greatest challenge dealing with. SLT service reported to be most accessed service. Improved access to services was the most common answer to questions about service improvement. Access to SLT was the most frequently mentioned service to improve access.
Cheung *et al*. (2013), Australia	To explore views of SLTs working with autistic children on Evidence Based Practice (EBP); to identify workplace factors impacting on EBP; to determine whether SLTs' responses differ based on type of workplace or years of experience.	Quantitative survey, with qualitative, analysis for responses to open-ended questions.	105 SLTs who identified themselves as currently working with autistic children.	SLT service delivery, focused on provision of evidence-based practice.	Barriers: Limited provision of EBP for autistic children. Unsupportive department culture. Service decisions and interventions not informed by EBP. Limited time for SLTs to engage in EBP activities. Facilitators: Strong, positive attitudes of SLTs towards EBP.

Author, year, country	Study aim	Study design	Participants and child characteristics	Aspect of access explored	Findings relevant to access to SLT
Chu *et al*. (2018), Malaysia	To explore parents' perspectives of their knowledge of ASD, the impact of ASD on life, and barriers when seeking SLT services.	Qualitative, explorative study, series of three semi-structured interviews conducted.	Eight parents of children: - Diagnosed ASD. - Aged 3-6 years.	Parent perspective of access, from first concerns to initial experiences of SLT.	Barriers: Lack of knowledge about ASD. Lack of information about services and resources available. Difficulties obtaining professional advice. Long waiting times and high costs. Facilitators: Positive outcomes associated with SLT.
Cohen, Miguel and Trejos (2023) USA	To understand ASD diagnosis and treatment pathways for Mexican heritage families.	Case study methodology; multiple case studies.	4 representative case studies drawn from a sample of 38 Mexican heritage families (parent-child dyads) Children aged 3-15 years All diagnosed ASD	Experience of access to SLT from first concern to SLT input.	Barriers: Abrupt cancellation of services without explanation Undocumented immigrant status impacted on access to healthcare insurance to enable access to SLT. Facilitators: Access to SLT before autism diagnosis. Positive experience of therapy support. Positive child outcomes following SLT input. Other: Complex diagnostic processes and delays impact on continuity of support.
Dababnah and Bulson (2015), Palestinian West Bank	To understand the services available to children with ASD and their families in the West Bank, to explore barriers to access and to identify additional services parents feel are needed.	Qualitative, grounded theory. Group and individual semi-structured interviews.	24 parents of children: - diagnosed ASD - aged 4-17 years	Experience of access to SLT from first concern to SLT input.	Barriers: Cost of SLT. SLT unavailable in local centres. SLT service withdrawn without explanation. Health professionals downplaying/dismissing parents' concerns. Lack of autism-specific interventions (for all services, not specific to SLT). Facilitators: SLT perceived as effective by parents. Others: Parents stated they wanted more specialised centres to provide several services including SLT.
Denne, Hastings and Hughes (2017), UK	To understand the interventions currently and historically used by parents of children with ASD in the UK.	Quantitative, online survey.	176 parents of children: - Diagnosed ASD - Aged 2-19 years	Patterns of utilisation.	No association between reported household income and the use of any intervention. Use of interventions associated with child's language use. Younger child more likely to be using at least 1 intervention.
Dymond, Gilson and Myran (2007), USA	To obtain recommendations of parents of children with ASD for improving school and community services.	Quantitative, paper-based survey.	783 parents of children - with a medical diagnosis of ASD - aged birth to 22 years	Parent perspectives on areas of services in need of improvement.	Barriers: Insufficient SLT/communication training Need to fight for services. Other: Need for improved education/training for all around the child (parents, and all professionals) and quality and dissemination of information on interventions and services to families. Increase funding for staff training, service delivery, staff pay and research. Need to improve the quality, quantity, accessibility and availability of services. Greater levels of accountability and research-based approaches needed.

Author, year, country	Study aim	Study design	Participants and child characteristics	Aspect of access explored	Findings relevant to access to SLT
Fernandes *et al*. (2014), Brazil	To present an overview of the Brazilian health system and to discuss the delivery of SLT services to children with ASD, including the challenges, and actions taken to address them.	Discussion paper.	N/A	SLT service delivery challenges.	Barriers: SLT professional training in autism. Access to appropriate assessment and intervention tools.
Gevarter, Siciliano and Stone (2022), USA	To examine early intervention providers' knowledge and training needs surrounding evidence-based practices for autism spectrum disorder.	Quantitative, descriptive. Online survey (with quantitative and qualitative components).	87 early intervention providers (speech-language pathologists and developmental specialist) in a rural Southwestern US state.	SLT service delivery. SLT knowledge of evidence-based practices/self-reported training needs and barriers to working with children with ASD.	Barriers: Perceived low levels of SLTs, university training in autism following SLT professional qualification. Parental acceptance and understanding of ASD. Child behaviour and limited foundation skills for communication. Facilitators: High proportion of SLTs reported completing professional development hours related to ASD. SLTs assessed as having higher levels of knowledge compared with other developmental specialists. SLTs years of experience impacted on knowledge, with significant differences identified between those with 16+ years of experience and those with 1-5 years' experience.
Irvin *et al*. (2012), USA	To examine child and family characteristics thought to affect the dosage and type of common in-school and private services received by children with autism.	Quantitative descriptive.	137 caregivers of children: - Diagnosed ASD - Aged 3-5 years	Patterns of utilisation.	Barriers: Ethnicity. Hispanic caregivers received significantly less SLT for their child ($p < 0.0001$) compared with students with White caregivers. Other: Socioeconomic status was not associated with the use of private SLT or dosage of in-school or out-of-school SLT services.
Kasilingam, Waddington and Van Der Meer (2021), New Zealand	To evaluate parent reported use of, and demand for, early intervention services for young children with ASD in New Zealand.	Quantitative, online questionnaire.	64 parents/ caregivers of children: - Diagnosed ASD - Aged <6;0 - Not yet attending primary school	Patterns of utilisation and parent perspective on services.	SLT most accessed, but also most commonly the intervention parents wanted to access for their child.
Khanlou *et al*. (2017), Canada	To present the challenges that immigrant mothers of children with ASD encounter in accessing the needed social support and services.	Qualitative, descriptive study. Semi-structured telephone interview.	21 immigrant mothers of one or more children: - diagnosed ASD	Access to SLT from parent perspective from first concerns to initial service access.	Barriers: Waiting times lead to missed opportunities for early intervention and to uncertainty for families. Lack of awareness of services available (for all services, not SLT specific). Missed offers of services due to missing calls when away from home, financial difficulties and paperwork challenges (for all services, not SLT specific).

Author, year, country	Study aim	Study design	Participants and child characteristics	Aspect of access explored	Findings relevant to access to SLT
Magaña *et al.* (2013), USA	To understand disparities and factors that contribute to these in relation to age at diagnosis and utilisation of services between Latino and non-Latino white children.	Quantitative descriptive, cross-sectional analytic study. Postal survey.	48 Latina and 56 non-Latina white mothers of a child/young person: - diagnosed ASD - between the ages of 2 and 22 years old	Patterns of utilisation of services.	Barriers: Latino children were less likely to ever receive Birth to Three services and the Medicaid Waiver– funded intensive autism therapy, which may include SLT. Other: No significant differences between Latino and non-Latino children in relation to whether SLT was ever accessed or whether it was perceived as an unmet need.
Mansell and Morris (2004), UK	To assess changes in the quality of services over time and to identify patterns of service use and information available to parents. To capture the impact of diagnosis and the parent perception of their child over time.	Mixed methods service evaluation. Postal questionnaire.	55 parents of children: - diagnosed ASD	Access to services and sources of information following autism diagnosis.	Barriers: Although most accessed, SLT availability is stated to be an issue for parents. Other: SLT not rated as highly as other services as a useful source of information for families.
Mello *et al.* (2016), USA	To compare the service use of families of children with autism who live in rural vs. non-rural areas.	Quantitative descriptive, online survey.	415 caregivers of children: - Diagnosed ASD	Patterns of utilisation.	SLT in the top 3 most recommended interventions for children. Rural and non-rural families similarly satisfied with the services accessed. SLT more commonly available than ABA, with SLT available in almost all rural and non-rural counties. No difference was found in the average number of services accessed in rural and non-rural areas; however there were differences in the most used services between rural and non-rural areas. Rural and non-rural respondents stated SLT as least needed (as already available).
Millau, Rivard and Mello (2018), Canada	To describe immigrant families' perceptions of their child's diagnosis to inform how information, support, and coaching programs are adapted for this population to support access and use of interventions.	Qualitative, semi-structured interview.	45 parents of children: - Diagnosed ASD - Aged 2;0 6;08 years	Parent perspective of access, from first concerns about their child to initial experiences of SLT.	Facilitators: Verbal and non-verbal communication difficulties were the most commonly observed first signs of autism. SLT strongly valued and a priority for access. Information on available services. Information on the importance of early intervention. SLT most often mentioned as a priority for treatment (35%) followed by behaviour interventions (24%), natural treatments (11%), and Occupational Therapy (8%). For mothers, speech and language therapy was the most frequently mentioned treatment priority (46.4%) but it came second for fathers (17.6%). Barriers: cultural, linguistic and service awareness.

Author, year, country	Study aim	Study design	Participants and child characteristics	Aspect of access explored	Findings relevant to access to SLT
Monz *et al.* (2019), USA	To describe caregiver-reported patterns of non-drug autism treatment and its variation by geography and healthcare coverage across the USA.	Quantitative descriptive, cross-sectional study, online survey.	5, 122 caregivers - Diagnosed ASD - Aged 3–17 years	Patterns of utilisation.	Barriers: Children in non-metropolitan areas more likely to receive individual SLT sessions than those in metropolitan areas. Metropolitan areas reported higher frequency of waiting list but lower frequency of 'not available in area'. Costs associated with access to SLT. Metropolitan areas reported higher intensity of any therapy. Other: Therapy use decreased from the lowest age group to the highest age group.
Murphy and Ruble (2012), USA	To examine parent report of access to and satisfaction with services for children with ASD in rural areas and compare results to parents from urban areas.	Quantitative, survey.	112 parents and caregivers of children: - Diagnosed ASD	Patterns of utilisation. Distance of child from professionals and professional availability.	Barriers: Limited availability of SLT services for rural vs. urban parents. For rural and urban areas, SLT was reported as a relatively high need service (ranked third for rural parents and second for urban parents). Metropolitan parents rated speech and language therapy as a significantly higher need than nonmetropolitan parents. Approximately 29% of metropolitan parents rated speech and language therapy services as their highest priority need compared to 13% of non-metropolitan parents.
Pemble (2014), Australia	To present an overview of a report on access to early intervention funding for disabilities and autism.	Discussion paper.	Young children with autism and disabilities and their families up to the age of 7.	Funding for SLT and variation in relation to geographical location.	Barriers: Rural children less likely to be registered for early intervention programs. Children who are not registered are not able to access funding for key early intervention services such as SLT, Occupational Therapy and Psychology.
Ruble *et al.* (2005), USA	To report the frequency and type of behavioural health services utilised by children with ASD in the TennCare managed care programme and to compare rates of service utilization to rates of children expected to have an ASD in the TennCare population.	TennCare data collected previously for another project, titled the IMPACT Study, were analysed.	1, 474 children: - diagnosed autism-related disorders - aged 0-17 years	Utilisation of SLT.	Barriers: Only approximately 5% of children received SLT input, but those who did received input on more days. Responsibility for provision of SLT and other therapies is unclear in relation to "medically necessary" or "educationally related" which may impact on services received by children. Other: The proportion of children receiving SLT remained at a similar % over time.
Salomone *et al.* (2015), 18 European countries	To describe the current use of behavioural, developmental and psychosocial intervention for children with ASD aged 7 or younger in 20 European countries.	Quantitative descriptive, online survey.	1680 parents of children: - diagnosed ASD - aged 7 years or younger	Patterns of service utilisation.	Barriers: Parent with a lower educational level. Autism diagnosis less than a year before survey completion. Variation in access between different European regions. Other: Speech and language therapy was the most widely used intervention (64% of total sample) with a uniform pattern of use by European regions, except for Northern Europe (46%) where reported use was significantly lower than in Western (68%), Eastern (68%) and Southern Europe (70%).

Author, year, country	Study aim	Study design	Participants and child characteristics	Aspect of access explored	Findings relevant to access to SLT
Sandham, Hill and Hinchliffe (2021), Australia	To identify current practices in communication service delivery, to explore the use of outcome measures and intervention; and to report on barriers to EBP and strategies to facilitate EBP.	Quantitative, cross-sectional online survey.	109 SLTs providing communication intervention to children diagnosed ASD.	SLT service delivery, focused on provision of evidence-based practice.	Barriers: Most participants reported use of eclectic approaches and did not adhere to specific intervention protocols including frequency of input. Participants reported inadequate resources to engage in EBP processes, including time and skill. The most common barrier to implementing research evidence was inadequate resources.
Sapiets *et al.* (2022), UK	To describe access to various early interventions for families of young children with suspected or diagnosed developmental disability. To investigate ease of access, unmet need, and barriers and facilitators of access to support.	Quantitative, survey.	673 parental caregivers of children: - Suspected or diagnosed Developmental Disability (e.g., developmental delay, intellectual disability, autism. - Aged 0 to 6 years	Patterns of utilisation and parents' perspectives on ease of access and unmet needs.	Barriers: Parental caregiver barriers (limited knowledge, other responsibilities, time pressure). Despite high access, SLT rated as difficult to access. Insufficient SLT resources and capacity, inflexible services and lack of continuity. Unhelpful professionals, e.g., limited knowledge and unhelpful communication style. Complex service system (lack of coordination and collaboration). Having to fight for services and/or pay for private SLT due to limited capacity/complete absence of SLT services. Facilitators: Supportive and competent professionals. Empowered parental caregivers. Peer and family support.
Srinivasan *et al.* (2021), USA	To assess the current impact of ASD diagnosis on families of children/youth with ASD to understand experiences of accessing healthcare and family support services.	Quantitative, survey (online and paper versions).	263 caregivers of children and youth: - Diagnosed ASD - Aged 3 to 24 years	Patterns of utilisation and parent perspectives on unmet needs.	Barriers: Although services were available to families, the levels of services received were inadequate to meet the families' needs. Overall, unmet needs were uniformly expressed by families across all age groups for social skills training and SLT. Other: SLT identified as the 2nd most accessed service.
Thomas *et al.* (2007), USA	To identify the family characteristics of families and their child with ASD that are associated with use of autism related services.	Quantitative, telephone or in-person survey.	383 families of children: - Diagnosed ASD - Aged 11 years old or younger	Patterns of utilisation.	Barrier: Medicaid or other publicly insured families more commonly accessed PECS and SLT compared to families whose children were covered by private insurance. Families with an annual income above $50,000 had a higher odds of using a developmental paediatrician and SLT. Other: Families of children 4 years old or less more likely to access SLT. When parents had higher levels of stress, families had slightly higher odds (OR = 1.1) of using several services: summer camp or respite care, a case manager, medication and supplements, or PECS.

Author, year, country	Study aim	Study design	Participants and child characteristics	Aspect of access explored	Findings relevant to access to SLT
Trembath *et al*. (2016), Australia	To explore what SLTs think parents of children with ASD expect of them when it comes to the delivery of evidence-based interventions.	Qualitative, semi-structured telephone interview.	22 SLTs self-identifying as specialising in ASD working with children and young people aged 2.5–21 years.	SLT service delivery.	Barriers: Factors affecting collaborative decision-making included parents' mental health difficulties, disability, difficulties with speaking the dominant language (English) and recency of their child's autism diagnosis. Understanding parents' knowledge, expectations and motivation in relation to SLT can be challenging for SLTs. Facilitators: Strong support for EBP amongst SLTs and willingness to share information with families. SLTs understanding parents' knowledge and motivation. SLTs desire to get the timing right for provision of information. Provision of general and tailored information to enable parents to make informed decisions. Parents' previous experiences with services.
Yingling and Bell (2020), USA	To examine the relationships between predisposing, enabling and need characteristics and utilisation of speech-language, occupational and physical therapy by diagnosis of ASD.	Quantitative, descriptive, prevalence study.	1,968 children enrolled in early intensive behavioural intervention in a south-eastern state of the USA.	Service utilisation and disparities in access.	Barriers: Children in urban areas were more likely to utilise speech-language, occupational and physical therapy by the time they are diagnosed with autism spectrum disorder. Children who enrolled in a U.S. early intervention programme for children younger than three are more likely to receive therapies including SLT. Children with intellectual disability received services earlier than children without intellectual disability. Other: 65.8% children received SLT within a month of diagnosis.
Young, Ruble and McGrew (2009), USA	To understand the relationships between insurance funding and access to a variety of ASD services including SLT.	Quantitative, survey.	113 parents/ caregivers of children: - Diagnosed ASD - Aged 2.5 to 21 years	Patterns of utilisation and accessibility of services.	Barriers: Significantly higher percentage of total out-of-pocket expenditures were allocated to SLT among publicly insured children than among privately insured children. Other: No difference in outcome variables (satisfaction with payer, variety of services used, parents stress and access to care, family and child outcomes) between publicly and privately insured individuals. Private and public insurance were similar in terms of out-of-pocket expense, individual service use, overall variety of services used, and accessibility of services.

2.6.1 Study design

Most studies took a quantitative approach (n=24) and predominantly utilised survey methods (n=18). Two studies conducted structured interviews to gather data for quantitative analysis, and the remaining two accessed and analysed health information records within large observational studies. Most quantitative studies analysed and presented numerical data, including in the analysis and presentation of participant responses to open survey questions. A small number (n=6) used an embedded mixed methods design with some limited qualitative analysis, primarily taking deductive, codebook and coding reliability approaches.

Seven studies took a qualitative approach. Most did not state the use of a specific methodology (n=4), one utilised a case study methodology, one took a grounded theory approach, and one used a phenomenological approach. Six of the seven qualitative studies gathered data using semi-structured interviews. One of these also utilised focus groups methods and the final qualitative study used only focus group methods. Three of the seven qualitative studies followed Braun and Clarke's (2006) approach to analysis, and the remaining studies used content analysis (n=1) a structured codebook and coding reliability approach (n=2), a constant comparative method (n=1) and one stated use of inductive coding methods.

Further details on study design are presented in **Error! Reference source not found.**.

2.6.2 Quality of included studies

Quality appraisal was approached systematically and supported by the use of MMAT (Hong *et al.*, 2018). Three papers were not assessed for quality, as two were discussion papers and one was a service evaluation. No studies were excluded based on quality. Most studies (n=20) were assessed to be of high quality (scoring 4-5/5). A variety of quality issues were identified related to studies scoring under four. Frequently, quality issues arose due to differences between participant groups and the target population within quantitative descriptive studies. For example, some reports stated that participants were representative of the target population but did not present evidence for this. Other issues included recruitment from a single source and no reporting of response rates. A main issue within qualitative studies also related to recruitment of participants from intervention services or their waiting lists. Experiences of those who successfully accessed a service are therefore captured, but not experiences of those who chose not to, or were unable to access the service. Other quality issues included insufficient information on the research perspective of the study or on the approach to analysis.

2.6.3 Country of origin

Most (n=15) studies took place in the USA, which has no universal health insurance coverage. Healthcare funding in the USA consists of a mix of public and private (for profit and non-profit) insurers and providers, with private health insurance accounting for approximately 1/3 of health expenditure (The Commonwealth Fund, 2020). While some studies took place in the UK, characterised by free healthcare coverage and relatively low levels of private spending, most of the studies included countries with high levels of private healthcare (The Commonwealth Fund, 2020). This includes Australia (n=5) where approximately half of Australians pay for private insurance, aided by government penalties and benefits, despite Australians being enrolled in a universal healthcare insurance programme (The Commonwealth Fund, 2020). Across several countries, SLT may form part of healthcare or educational provision depending on the child's needs and the context. Countries are categorised in four income groups: low; upper-middle; lower-middle; and high (Hamadeh, Van Rompaeyeric and Metreau, 2023). Most included literature originates from high income countries.

Understanding patterns of access related to funding and insurance arrangements was a specific objective of some included studies (Monz *et al.*, 2019; Ruble *et al.*, 2005; Young, Ruble and McGrew, 2009) and an important variable/topic within others (Fernandes *et al.*, 2014; Irvin *et al.*, 2012; Pemble, 2014). The country of origin and country income classification is presented in **Error! Reference source not found.**.

Table 4 Country of origin of included literature

Country	**World Bank Group classification by income level**	**Number of papers included**
USA	High	15
Australia	High	5
UK	High	5
Canada	High	3
Brazil	Upper-middle	2
New Zealand	High	1

Country	World Bank Group classification by income level	Number of papers included
Malaysia	Upper-Middle	1
Palestinian West Bank	Upper-middle	1
18 European countries (Western Europe (Belgium, France, Germany, The Netherlands), Northern Europe (Denmark, Finland, Iceland, Ireland, Norway, United Kingdom), Eastern Europe (Czech Republic, Hungary, Poland, Romania) and Southern Europe (Italy, the former Yugoslav Republic of Macedonia, Portugal, Spain)).	High (n = 17) Upper-middle (n = 1, the former Yugoslav Republic of Macedonia)	1

2.6.4 Perspectives captured

To achieve the first objective of this review, information on the perspectives captured within studies was recorded. Most studies (n=25) captured parental caregiver reported information on utilisation/perspectives on access. Only a small number (n=5) captured the perspectives of SLTs, one of which also captured perspectives of Communicative Disorder Assistants who work alongside SLTs (Binns *et al.*, 2022). Finally, two papers were discussion papers: one providing an overview of historical, political and social factors impacting on access to SLT for autistic children in Brazil (Fernandes *et al.*, 2014), and another providing a brief overview of a recent report on access to early intervention programmes (Pemble, 2014). No studies captured both parent and professional perspectives on access. Two studies examined data from health records (Ruble *et al.*, 2005; Yingling and Bell, 2020) and did not include parental/professional perspectives/responses.

2.6.5 Participant characteristics

Across the 34 included studies, data were collected/analysed from a total of 16, 474 people. This included data collected from 12, 451 parents/carers of autistic children and from 581 SLTs/SLTA, and data captured directly from health records for 3, 442 children. The demographic data collected within studies varied considerably with differences in type and amount of

demographic data collected. The participant demographic data was reviewed and is summarised in the following section.

Studies capturing data from SLTs/SLTAs gathered demographic data such as number of years since qualification as an SLT, specialist/non-specialist SLT role, highest education level, gender, private/non-private service delivery and employment setting. Some studies referred to a high proportion of SLTs being experienced/specialist SLTs (Cheung *et al.*, 2013; Trembath *et al.*, 2016; Sandham, Hill and Hinchliffe, 2021) and it was also observed that a high proportion of SLT respondents worked in privately funded services (Cheung *et al.*, 2013; Sandham, Hill and Hinchliffe, 2021). Cheung *et al.* (2013) note that within their study of Australian SLTs the high proportion of SLTs working in private practice is similar to the proportion of SLTs working in private practice across Australia. Similar to other studies, Gevarter, Siciliano and Stone (2022) collected data on SLT training and also captured information on ongoing professional development in relation to autism. All 22 SLTs interviewed by Trembath *et al.* (2016) were female, however participant gender was not shared in other studies with SLT/SLTA participants.

Studies capturing data from parents and carers gathered considerably more demographic data than those with SLT participants and gathered data such as parent age, gender, household income, ethnicity, employment status and health insurance status and type. Most study participants were female mothers (Cassidy, McConkey and Slevin, 2008; Auert *et al.*, 2012; Mello *et al.*, 2016; Denne, Hastings and Hughes, 2018; Monz *et al.*, 2019; Kasilingam, Waddington and Van Der Meer, 2021; Araripe *et al.*, 2022; Sapiets *et al.*, 2022; Cohen, Miguel and Trejos, 2023).

Several studies recognised that due to the nature of voluntary participation, they were able to gain perspectives and engagement of those with the resources, experiences and education levels including literacy and digital literacy to engage in research studies. Participants were recognised to have a higher level of education than the general population in some studies (Denne, Hastings and Hughes, 2018; Araripe *et al.*, 2022). The requirement to have a degree of digital literacy to participate in several studies was recognised as a barrier within studies such as Araripe *et al.* (2022). Similarly, the ability to participate in English was also recognised as a barrier for some who did not have English as their first language (Auert *et al.*, 2012). Additional languages other than English were offered to support some families to participate in studies such as Becerra *et al.* (2017) and Cohen, Miguel and Trejos (2023). Although parent ethnicity or cultural background of families was collected within several studies, this was not consistent, with some studies not capturing this at all, such as Auert *et al.* (2012) and Cassidy, McConkey and Slevin (2008). Some studies capturing family ethnicity noted a high proportion of

participants were white (Mello *et al.*, 2016) (Sapiets *et al.*, 2022) compared with local population data.

Families were recruited from specific intervention providers within several studies (Cassidy, McConkey and Slevin, 2008; Auert *et al.*, 2012; Chu *et al.*, 2018) and a high proportion of families had accessed private SLT services suggesting that they had the resources to be able to pay for and engage with these services (Auert *et al.*, 2012). Some studies reported participants were in middle to high income groups predominantly, such as Chu *et al.* (2018), whilst other studies reported household income but did not compare this with local population data.

2.6.6 Child characteristics

Although the review focused on preschool autistic children, some of the studies also included participants that exceeded the preschool age. Although several studies (n=9) focused exclusively on younger children <8 years, most studies focused on children across a wider age range (0-18 years) (n=18). Some studies included children and young adults up to their early 20s (n=6).

Almost all included studies focused exclusively on children diagnosed ASD. A small number also included children with suspected ASD (n=2) and children with diagnosed or suspected developmental disabilities (including ASD) (n=2). Within these studies, child demographic details, including their diagnosis, were provided which allowed for each study's relevance to be assessed against the aim of this review.

2.6.7 Aspects of access explored

Most studies (n=15) contributed to understanding access to SLT through exploring patterns of utilisation (Araripe *et al.*, 2022; Bromley *et al.*, 2004; Cassidy, McConkey and Slevin, 2008; Denne, Hastings and Hughes, 2017; Irvin *et al.*, 2012; Kasilingam, Waddington and Van Der Meer, 2021; Magaña *et al.*, 2013; Mansell and Morris, 2004; Mello *et al.*, 2016; Monz *et al.*, 2019; Murphy and Ruble, 2012; Salomone *et al.*, 2015; Sapiets *et al.*, 2022; Srinivasan *et al.*, 2021; Yingling and Bell, 2020). Studies used quantitative descriptive methodology and cross-sectional research designs, enabling researchers to examine several child and family variables at once. Although some studies exploring utilisation also captured participant perspectives (Araripe *et al.*, 2022; Cassidy, McConkey and Slevin, 2008; Sapiets *et al.*, 2022), SLT was only one of several support services/interventions, and so was not explored in depth. Some of these studies (n=3) also considered service accessibility (Bromley *et al.*, 2004; Murphy and Ruble, 2012; Sapiets *et*

al., 2022). However, only one presented SLT-specific information (Bromley *et al.*, 2004). This provides some insight into parents' general experiences and challenges but makes it difficult to judge the relevance of findings to specific services and to consider implications for practice.

Three studies considered parents'/carers' perceived unmet needs (Magaña *et al.*, 2013; Sapiets *et al.*, 2022; Srinivasan *et al.*, 2021). One captured unmet needs related to any early intervention service (Sapiets *et al.*, 2022) and two specifically considered unmet needs for SLT (Magaña *et al.*, 2013; Srinivasan *et al.*, 2021). Measures of unmet need, even when specific to SLT, require further exploration to understand the way in which needs are perceived to be unmet.

A small number of studies (n=6) focused specifically on SLT (Auert *et al.*, 2012; Binns *et al.*, 2022; Cheung *et al.*, 2013; Chu *et al.*, 2018; Sandham, Hill and Hinchliffe, 2021; Trembath *et al.*, 2016) and these explored aspects of service delivery or experiences linked to access from a single perspective of parents (Auert *et al.*, 2012; Chu *et al.*, 2018) or healthcare professionals (Binns *et al.*, 2022; Cheung *et al.*, 2013; Sandham, Hill and Hinchliffe, 2021; Trembath *et al.*, 2016). Two studies captured parent perspectives on access to SLT and provided valuable insights into some of the challenges experienced (Auert *et al.*, 2012; Chu *et al.*, 2018). These were not conducted in the UK, and it is, therefore, difficult to determine the relevance of findings to the UK context, particularly given the differences in funding and delivery of healthcare services.

Although the selected studies identified some barriers to service delivery for preschool autistic children, understanding access to SLT was not the primary aim of the studies. The studies did not, therefore, examine access specifically or holistically from SLT perspectives (Binns *et al.*, 2022; Cheung *et al.*, 2013; Chu *et al.*, 2018; Sandham, Hill and Hinchliffe, 2021; Trembath *et al.*, 2016).

2.6.8 Themes in the literature

An objective of the review was to identify barriers and facilitators to access in existing literature. Although studies consistently found SLT to be one of the most commonly accessed interventions for autistic children (Araripe *et al.*, 2022; Becerra *et al.*, 2017; Bromley *et al.*, 2004; Denne, Hastings and Hughes, 2017; Irvin *et al.*, 2012; Kasilingam, Waddington and Van Der Meer, 2021; Mansell and Morris, 2004; Mello *et al.*, 2016; Monz *et al.*, 2019; Salomone *et al.*, 2015; Sapiets *et al.*, 2022; Srinivasan *et al.*, 2021), several barriers to access were identified.

These are presented along with facilitators and other influences on access in Table 3 and discussed within five main themes in the following synthesis:

- Child characteristics
- Resource issues
    - Geographical location
    - Funding
- Parent/carer factors
    - Knowledge and awareness of communication difficulties
    - Awareness of the service and ability to gain access
    - Ability to prioritise SLT and to advocate for their child
- SLT service issues
    - Meeting the needs of the child and their family
    - Waiting times
    - SLT service delivery
- SLTs and parents working in partnership

2.6.8.1 Child characteristics

The ways in which a child's age, communication and intellectual ability influence utilisation of SLT was a focus of several studies (Cassidy, McConkey and Slevin, 2008; Denne, Hastings and Hughes, 2017; Irvin *et al.*, 2012; Salomone *et al.*, 2015; Thomas *et al.*, 2007; Yingling and Bell, 2020). Within some studies, children with a cognitive impairment were more likely to have accessed SLT services (Irvin *et al.*, 2012; Yingling and Bell, 2020), along with children with more significant communication difficulties (Denne, Hastings and Hughes, 2017) and those of a younger age (Denne, Hastings and Hughes, 2017; Thomas *et al.*, 2007). Additionally, children who were enrolled in broader early intervention programmes (Yingling and Bell, 2020) were more likely to be in receipt of SLT. Given the emphasis on early intervention and the prevalence of communication difficulties amongst the autistic population, the ways the child's age and communication ability impact on access to SLT are unsurprising. This pattern was not consistent across studies, however, suggesting other factors beyond the child's degree of communication difficulty impacts access to SLT.

Studies that focused exclusively on younger children (Cassidy, McConkey and Slevin, 2008; Salomone *et al.*, 2015) found access to services, including SLT, did not appear to vary according to communication ability. A study of preschool autistic children who had all accessed one diagnosis and intervention service in Northern Ireland found that children with more

communication difficulties and higher levels of parental concern, were no more likely to access support than other children. Access to services was unrelated to the severity of the child's communication needs, parental perception of the child's improvement and parental stress levels (Cassidy, McConkey and Slevin, 2008). Although this was a relatively small study of 104 families, a similar pattern was identified in a large survey of 1,680 families across 18 European countries that identified children who did not receive any type of intervention did not differ by age, gender or verbal ability from those accessing interventions (Salomone *et al.*, 2015). These studies suggest that access to, and utilisation of, interventions including SLT, is not only related to the child's clinical need but influenced by other factors. Understanding underlying reasons for differences is challenging due to the wide age range of children included in some of the studies and due to limited/no information on the SLT service available or service delivery models.

Access to SLT has been found to vary according to parent ethnicity (Irvin *et al.*, 2012). Although no significant difference was found in severity of autism symptoms or cognitive ability of 137 children aged 3-5 years in the USA, children with Hispanic caregivers received significantly less SLT ($p < 0.0001$) within school SLT services compared with children with White caregivers (Irvin *et al.*, 2012). While the study provides valuable information on broad patterns of access to SLT, this quantitative survey does not facilitate further exploration of the patterns identified, capture stakeholder perspectives on challenges, or provide contextual service information to understand the differences in access. Magaña *et al.* (2013) examined patterns of service use in the USA between Latino and non-Latino white children. Latino children were less likely to be enrolled in the early intervention programme, Birth to Three, which includes SLT, therefore, reducing access to early funded autism therapy (Magaña *et al.*, 2013). Although, differences in service use and perceived unmet needs were observed across the whole age group (parents of children between 2 and 22 years old participated) and across a wide range of services, no significant differences were found in rates of use of SLT or in perception of unmet need for SLT between the Latino and the non-Latino white groups at the time interviewed. The authors suggest this may be due to the effectiveness of early childhood services for children aged between 4 and 6 years in providing SLT (Magaña *et al.*, 2013).

2.6.8.2 Resource issues

2.6.8.2.1 Geographical location

Several studies explored differences in access to services according to geographical location (Carson *et al.*, 2021; Dababnah and Bulson, 2015; Fernandes *et al.*, 2014; Monz *et al.*, 2019;

Murphy and Ruble, 2012; Pemble, 2014; Salomone *et al.*, 2015; Yingling and Bell, 2020). Studies explored the ways that location impacts on access to SLT at a national level to identify differences in utilisation (Salomone *et al.*, 2015) and to explore how national policy, healthcare funding and service delivery models impact access (Dababnah and Bulson, 2015; Fernandes *et al.*, 2014). Studies also explored differences in access between rural and metropolitan areas (Carson *et al.*, 2021; Monz *et al.*, 2019; Murphy and Ruble, 2012; Pemble, 2014; Yingling and Bell, 2020).

A study of 1,680 parents of children diagnosed with ASD, aged under 7 across 18 European countries, identified differences in use of SLT across different areas of Europe (Salomone *et al.*, 2015). Although overall 64% families reported current use of SLT, there was significantly lower use of SLT reported in Northern Europe (46%) compared with Western (68%), Eastern (68%) and Southern Europe (70%). Variation in the mean number of hours was also identified, with significantly lower mean hours of SLT for children living in Western Europe (M = 0.93, SD = 1.60) and Northern Europe (M = 0.54, SD = 1.12) compared with Eastern Europe (M = 1.74, SD = 3.50) and in Southern Europe (M = 1.53, SD = 1.86) (Salomone *et al.*, 2015). This suggests that although there is no evidence that autism, communication difficulties or a child's need for support varies between areas, there is evidence that utilisation of SLT varies. Due to the nature and purpose of the Salomone *et al.* (2015) study, the reasons for differences are not explored and may be due to several factors such as service funding and availability, the nature of service delivery, SLT workforce issues, referral patterns and parent-related factors.

SLT service availability, frequency and intensity have all been found to vary according to the urban/rural classification of areas in the USA (Carson *et al.*, 2021; Monz *et al.*, 2019; Yingling and Bell, 2020). Likelihood of receiving SLT was found to be significantly greater in metropolitan areas than in non-metropolitan areas (Monz *et al.*, 2019) and at an earlier stage following diagnosis (Yingling and Bell, 2020). Murphy and Ruble (2012), however, identified that metropolitan parents rated SLT as their highest priority need (a service they would like to get or increase) (29%), compared with non-metropolitan areas (13%) which may be due to long waiting lists in some metropolitan areas. The most commonly experienced barrier in non-metropolitan areas was lack of SLT in the area (Monz *et al.*, 2019). Registration for early intervention has also been found to differ between rural and metropolitan families in Australia (Pemble, 2014) which subsequently impacts on funding for SLT. Families in rural Australia were 23% less likely to register for early intervention programs than those in metropolitan areas (Pemble, 2014).

The ways in which the geographical location impacts on access to services including SLT were explored within a qualitative, grounded theory study of parents of autistic children aged 3-5

years in the Palestinian West Bank (Dababnah and Bulson, 2015). The study identified that basic services such as SLT were not available in local centres, leading to a lack of service for some and higher costs for those able to privately fund SLT and travel costs (Dababnah and Bulson, 2015). Limited workforce availability was also an important factor within a qualitative study of the therapy needs of children in a rural island community in the USA (Carson *et al.*, 2021), with high costs of living cited as a possible reason for a high number of SLT vacancies.

Several barriers to SLT for autistic children were identified at a national level in an exploration of protocols for health and education services and their influences on SLT for autistic children in Brazil. Similar to other studies, geographical barriers related to limited availability of specialists (as well as related to financial barriers) for those in rural areas were discussed (Fernandes *et al.*, 2014). Additionally, other important national level barriers were explored including political barriers to developing SLT services and limited availability of assessment tools in Portuguese (Fernandes *et al.*, 2014).

2.6.8.2.2 Funding

Considerable variation in access to SLT has been identified based on insurance status of families in the USA (Ruble *et al.*, 2005; Thomas *et al.*, 2007). A study of 383 families of autistic children found that families covered by Medicaid, a public health insurance program for people on low income, had significantly more chance of accessing services including SLT and PECS than privately insured families (Thomas *et al.*, 2007). A study of TennCare, a Medicaid Managed Care programme which aims to ensure access to support for those with complex health needs who frequently require several services, found that only approximately 5% of autistic children received SLT input (Ruble *et al.*, 2005). This is considerably lower than the percentage reported in other studies such as Thomas *et al.* (2007) who reported 91%, 79% and 65% of children aged ≤4, 5-8 years and 9-11 years respectively were accessing SLT, and Monz *et al.* (2019) who reported 71.4% of 5,122 children in their USA survey accessed SLT in the preceding 12 months. A lack of clarity in relation to responsibility for provision of SLT and other therapies and whether they are "medically necessary" or "educationally related" was also considered a funding-related factor impacting access to SLT (Ruble *et al.*, 2005).

Families experience additional expenses, financial strain and hardship in pursuit of SLT for their child (Chu *et al.*, 2018; Dababnah and Bulson, 2015; Monz *et al.*, 2019; Sapiets *et al.*, 2022). This includes the UK, where although SLT is free at the point of care delivery, parents report paying for private SLT due to no/limited service availability (Sapiets *et al.*, 2022). In the USA, publicly-insured families experience greater out-of-pocket expenses related to accessing 1:1 SLT (Monz

et al., 2019). Parents have cited costs of services as one of the most significant barriers related to their health insurance (Monz *et al.*, 2019) and costs associated with access to SLT have been found to influence whether a child receives 1:1 SLT or group input (Monz *et al.*, 2019).

Greater odds of using an SLT service is associated with higher household income in the USA (Thomas *et al.*, 2007) but not within a study in the UK (Denne, Hastings and Hughes, 2017). This may be related to the differences in healthcare funding between countries, although it is noted that costs associated with access to private SLT were commonly cited in another, more recent UK study (Sapiets *et al.*, 2022). Families with lower income are less able to meet the additional costs of SLT for their child and more likely to experience inequity due to lack of/limited SLT service (Sapiets *et al.*, 2022). Costs associated with access to SLT are important to consider in the context of financial strain already associated with raising an autistic child such as parental loss of earnings (Chu *et al.*, 2018).

2.6.8.3 Parent/carer factors

2.6.8.3.1 Knowledge and awareness of communication difficulties

Parents play a crucial role in identifying their child's communication needs and gaining access to SLT (Auert *et al.*, 2012; Chu *et al.*, 2018; Millau, Rivard and Mello, 2018). Communication difficulties are cited as the first concerns of parents of children who go on to receive a diagnosis of autism in a study of first generation immigrant families in Canada (Millau, Rivard and Mello, 2018). Parents' knowledge and awareness of their child's needs is an important factor in access within this study (Millau, Rivard and Mello, 2018). Similarly, insufficient parental knowledge of autism and communication was presented as a barrier to SLT by Chu *et al.* (2018). The study participants were recruited from a university-based intervention clinic who had successfully been able to access SLT for their child . The findings of the study by Chu *et al.* (2018) therefore, reflect the challenges of those who had been able to access support and may not reflect the challenges of families who had been unable to do so. Parents' beliefs that children may grow out of their communication challenges was considered to lead to delays seeking access to SLT and this view was reinforced by family members (Chu *et al.*, 2018). Knowledge of typical communication development and the ability to engage with services is an important aspect of health literacy. Health literacy was proposed as a concept in the 1970s to capture some of the complexity of demands related to promoting and maintaining health in society (Simonds, 1974). The findings of the study suggest that parents' knowledge of communication is important, however, this is not explored explicitly in relation to health literacy. Therefore, the different

factors that may influence parents' health literacy and in turn their child's access to support are not explored in depth.

2.6.8.3.2 Awareness of the service and ability to gain access

Once the decision has been made to seek SLT support, access to SLT is not easy (Auert *et al.*, 2012; Chu *et al.*, 2018; Dababnah and Bulson, 2015). Parents have reported several challenges in their search for effective and appropriate SLT services (Auert *et al.*, 2012), including not knowing where to seek help (Chu *et al.*, 2018; Millau, Rivard and Mello, 2018) and challenges meeting referral requirements such as completing forms (Khanlou *et al.*, 2017). Health professionals downplaying/dismissing parental concerns has also been cited as a barrier (Dababnah and Bulson, 2015). These barriers lead to parents spending time searching for information on services and delaying their children's access to support (Chu *et al.*, 2018).

2.6.8.3.3 Ability to prioritise SLT and to advocate for their child

Parents' motivation, previous experiences with services and ability to advocate for their child impact on access to services (Sapiets *et al.*, 2022; Trembath *et al.*, 2016). Parents' commitment to supporting their child's SLT interventions through reducing working hours and leaving employment was identified as an enabler to access in a small qualitative study in Malaysia that specifically focused on parents' experiences of access to SLT (Chu *et al.*, 2018). This may also be viewed as a barrier for those unable to make these commitments. Gaining access to services has been described as a fight by parents (Dymond, Gilson and Myran, 2007; Sapiets *et al.*, 2022). Although the study by Sapiets *et al.* (2022) was not specific to SLT or to autistic children, the majority of the 673 parents with a child aged 0 to 6 years responding to the survey had an autistic child (77.9%), and SLT was one of the most commonly accessed interventions (84.2%). The possible need to fight for SLT raises concerns about the equity of access to services, which may depend on a parents' ability to advocate for their child (Sapiets *et al.*, 2022). A study of 1,680 families across Europe found that children who were not receiving any type of intervention (including SLT) were significantly more likely to have a parent with a lower educational level than children receiving some intervention (Salomone *et al.*, 2015), suggesting that educated parents may be better equipped to advocate and successfully access services.

The impact of parents' experience, confidence and knowledge in working with professionals was also raised as a possible issue in relation to access to evidence-based practice (Trembath *et al.*, 2016). Although this study did not focus specifically on access to SLT, it suggested that from the perspective of SLTs, parents of younger children with less experience of working with

healthcare professionals may be at a disadvantage when engaging with services for their child (Trembath *et al.*, 2016).

2.6.8.4 SLT service issues

2.6.8.4.1 Meeting the needs of the child and their family

SLTs play an important role in providing intervention support to some young autistic children who require this (Binns *et al.*, 2022), and children with diagnosed or suspected autism form a significant proportion of a general SLT paediatric caseload (Binns *et al.*, 2022). Access to SLT has been described as a complex process for some families, where the presence of a specific diagnosis/change in diagnosis required a change to the SLT service received in some contexts, as evidenced in the Palestinian West Bank (Dababnah and Bulson, 2015) and for Mexican-heritage families in the USA (Cohen, Miguel and Trejos, 2023). Some parents also experienced SLT services being withdrawn with no explanation (Dababnah and Bulson, 2015).

The studies included in the review found that SLT was commonly perceived positively by parents, and that parents felt positive about their child's outcomes following SLT (Bromley *et al.*, 2004; Cohen, Miguel and Trejos, 2023; Dababnah and Bulson, 2015). Study findings are, however, inconsistent, indicating variation in practice. Although SLT is a high priority for families and commonly accessed, it is still often considered a high-priority, unmet need within studies (Cassidy, McConkey and Slevin, 2008; Dymond, Gilson and Myran, 2007; Murphy and Ruble, 2012; Sapiets *et al.*, 2022; Srinivasan *et al.*, 2021). A perceived unmet need may be influenced by a parent's understanding of the SLT role and potential impact the service may have on their child's development and the effectiveness of any current input. Although unmet needs are reported, the reasons for these are not explored within included studies.

A survey of 263 parents of autistic children aged 3- 24 years identified SLT as an unmet need across the whole age range, but it was a particular issue for families of younger children aged 3-7 years (Srinivasan *et al.*, 2021). This may be due to insufficient levels of support to meet families' needs. This is supported by an online survey of Canadian SLTs' who found insufficient resources as a barrier to service delivery (Binns *et al.*, 2022). Insufficient SLT service availability was also identified by Sapiets *et al.* (2022) who highlighted the importance of SLT for parents of children with diagnosed or suspected developmental disorders of whom most respondents had an autistic child (77.9%). When asked to identify barriers and facilitators to access to early intervention, several respondents raised SLT accessibility issues. This led to parents paying for private SLT or accessing SLT through a setting such as a nursery due to a lack of service or

limited capacity of publicly funded SLT. Similarly, two further UK studies found that SLT was considered insufficient to meet the child's needs (Bromley *et al.*, 2004), and improving access to SLT was shared by parents as the main priority for improvement (Cassidy, McConkey and Slevin, 2008). Although the nature of the barriers to access were not explored in depth within these studies, and these studies did not focus specifically on SLT, they provide valuable information on the areas of potential need in relation to SLT service delivery in the UK.

2.6.8.4.2 Waiting times

Waiting times are a consistent barrier across several studies, regardless of country, healthcare funding model and geographical location (Binns *et al.*, 2022; Chu *et al.*, 2018; Khanlou *et al.*, 2017; Monz *et al.*, 2019), although waiting times do vary slightly according to funding arrangement and geographical location (Monz *et al.*, 2019). Time passed after receiving the diagnosis was the only significant independent factor for use of SLT in the total sample of children in a survey of children across Europe, with children diagnosed more than one year before the survey more likely to use SLT ($p < 0.001$). This pattern was observed in all parts of Europe other than Northern Europe (Salomone *et al.*, 2015) where the timing of access to SLT may be related to SLT service waiting times.

Long waiting times for SLT can impact on families emotionally and financially as well as delay access to support for children. Waiting and not knowing when an SLT appointment may be offered was identified as particularly difficult for immigrant families in a qualitative study of 21 families in Canada (Khanlou *et al.*, 2017). Khanlou *et al.* (2017) conclude waiting times disadvantage immigrant families who may miss calls when away from home, leading to feelings of uncertainty, missed appointments and longer waits (Khanlou *et al.*, 2017). Long waiting times for government-funded SLT were particularly difficult for families who were unable to afford access to private SLT services in Malaysia (Chu *et al.*, 2018). This led to financial hardship for some families in their pursuit of earlier access (Chu *et al.*, 2018).

2.6.8.4.3 SLT service delivery

Initial access to a service is one issue, but it is also imperative that families access adequate support and that this is delivered with the appropriate knowledge, skills and experience. Training and skills in autism-specific SLT interventions is a high priority and considered crucial for effective service delivery (Binns *et al.*, 2022). Despite this, there are specific gaps in SLT knowledge and skills, such as in how best to support children who present with behaviour that

challenges and with fewer foundational skills for communication (Gevarter, Siciliano and Stone, 2022).

SLT knowledge and skills of autism has been considered through the lens of Evidence Based Practice (EBP) (Gevarter, Siciliano and Stone, 2022). Despite a high proportion (94%) of SLTs reporting autism-related professional development hours (Gevarter, Siciliano and Stone, 2022), delivery of EBP is not straightforward, with gaps reported between research and practice (Cheung *et al.*, 2013; Sandham, Hill and Hinchliffe, 2021). A study exploring views of SLTs working with autistic children found that although EBP was important to SLTs, only 34% felt service delivery was based on research evidence, and only 23% of participants agreed most SLTs work according to the principles of EBP when providing services to autistic children (Cheung *et al.*, 2013). The studies do not explore whether this is due to an absence of evidence to inform practice, or whether this is due to services not implementing existing research evidence in service delivery for another reason. Inadequate investment of time, financial resources and training to support EBP impacts on service delivery (Cheung *et al.*, 2013; Sandham, Hill and Hinchliffe, 2021) and can lead to service decisions based on administration-related issues rather than clinical issues (Cheung *et al.*, 2013).

Autistic children and their families' access to EBP may also be impacted by wider SLT service resource issues. Insufficient resources for service delivery, not only resources for EBP activities, can lead to changes to the SLT support offered to children and their families. Binns *et al.* (2022) found that Canadian SLTs identified difficulties meeting caseload and documentation expectations due to insufficient funding and time to deliver the required service. Sandham, Hill and Hinchliffe (2021) identified almost all (99%) SLTs surveyed reported adapted therapies or use of eclectic approaches. Whilst adapting therapy to meet a child and their family's needs is a key aspect of EBP and person-centred care, this should be done carefully and systematically to maximise outcomes for children and their families (Sandham, Hill and Hinchliffe, 2021). However, Sandham, Hill and Hinchliffe (2021) suggest SLT input is commonly amended due to staff shortages, rather than for clinical reasons as 97% of SLTs surveyed identified lack of skills and resources as barriers to implementing manualised programs as designed. These workload demands ultimately impair the quality of delivery as SLTs are forced to prioritise patient flow due to high demand (Binns *et al.*, 2022).

2.6.8.5 SLTs and parents working in partnership

Parents play a crucial role in supporting their child's communication development. Effective communication between SLTs and parents helps establish an equal partnership and parental

empowerment in therapy (Auert *et al.*, 2012). The SLTs' passion for their work, their ability to relate to the child and their family, and their empathy and understanding of individual needs were the most important personal qualities from the perspectives of parents (Auert *et al.*, 2012; Chu *et al.*, 2018).

Parents' knowledge of the SLT goals and the rationale for strategies enables parents to have a sense of control and to feel informed as partners (Auert *et al.*, 2012; Chu *et al.*, 2018; Fernandes *et al.*, 2014; Trembath *et al.*, 2016). Early interactions between the child, their family, and SLT are, therefore, a key part of enabling access to appropriate SLT support. The personal qualities of SLTs may influence access to SLT/service delivery as the SLT will most often be working with and through parents to support the child's communication skills (Chu *et al.*, 2018). Additionally, the ways in which parents view the role of the SLT influences their expectations and engagement with SLTs (Auert *et al.*, 2012; Chu *et al.*, 2018). Taking the time to understand and acknowledge parents' unique expectations, experiences and need for information is important to SLTs and helps them to determine the parents' need for information and discussion around EBP (Trembath *et al.*, 2016) and the SLT service offered.

Whilst effective partnership between SLTs and parents is essential, there are several barriers and challenges to establishing this partnership. SLTs identify parents' language ability, challenges around use of interpreters, and parents' additional learning/education needs or mental health difficulties as barriers to discussing SLT interventions and EBP with parents (Trembath *et al.*, 2016). Effective partnership and communication may also be impacted by the recency of the child's autism diagnosis, with a more recent diagnosis perceived to impact on families' readiness to discuss and engage in SLT interventions for their child (Binns *et al.*, 2022; Trembath *et al.*, 2016). Ensuring parents are not overwhelmed and are able to process relevant information supports effective partnership working, and was identified by SLTs as a high priority (Trembath *et al.*, 2016).

Although parent empowerment through information is important for both SLTs (Trembath *et al.*, 2016) and parents (Auert *et al.*, 2012; Chu *et al.*, 2018; Dymond, Gilson and Myran, 2007), the degree of parental involvement in therapy and decisions has been found to be variable (Auert *et al.*, 2012). Some parents have reported little understanding of their own role and the role of the SLT in the therapy process, with little information or feedback given to parents (Auert *et al.*, 2012). To further examine communication and parental empowerment in therapy, Auert *et al.* (2012) explored parents' confidence asking SLTs questions about their child's therapy. Despite being a self-selecting group of 20 parents, not all felt confident asking about their child's SLT.

The scarcity of SLT resources impacted on some parents' willingness to challenge services (Auert *et al.*, 2012).

2.7 Overall summary

The scoping review has met the literature review objectives through presenting a comprehensive description of what is currently known in the literature on access to SLT for preschool autistic children. The review has described the perspectives that have contributed to what is known on this topic and the contexts within which this issue has been examined. Finally, the barriers, facilitators and influences on access have been presented across five main themes.

Accessible, family-centred, and high-quality evidence-based SLT is important for families and SLTs. The scoping review has identified that access to SLT not only varies in relation to child characteristics, but in relation to several other factors unrelated to the child's clinical need for SLT. These factors include child and family characteristics, factors related to the SLT service and factors related to the broader context, including the geographical location and healthcare funding models. The challenges associated with access not only impact on the communication support for children; they also affect families who can suffer financially and are forced to expend time and energy in pursuit of support for their child.

2.8 Gaps in the literature

The scoping review has presented a comprehensive description of access to SLT for preschool autistic children. However, there remain several gaps and limitations to knowledge on the topic:

- Although different geographical, socio-political and cultural contexts have been considered, the current literature on the topic is primarily from high-income countries. This limits the transferability of findings to lower income countries due to potential differences in areas such as health priorities and infrastructure (Yegros-Yegros *et al.*, 2020).
- No study considered access holistically and studies didn't consider the various stages of access and perspectives of those involved in access to SLT.
- Healthcare is recognised as a complex, adaptive and multi-faceted system consisting of several interacting elements and stakeholders (Braithwaite, 2018; Levesque, Harris and Russell, 2013). Despite this, studies have explored topics linked to access from single stakeholder perspectives. Capturing the perspectives of a wider range of stakeholders

has been identified in two studies (Carson *et al.*, 2021; Dymond, Gilson and Myran, 2007) as a specific recommendation for future research.

- Professional perspectives feature in the literature on access to SLT, however these studies do not predominantly focus on access and so the perspectives are limited to specific issues linked to access (such as EBP) rather than on access specifically.
- Studies have primarily contributed to understanding access through focusing on utilisation and unmet needs using quantitative designs. This has provided useful information on broad patterns of service availability, use, and the extent to which needs are met. However, these measures do not capture the complexity of access and the broad range of cultural, ethnicity, personal, financial and social factors that may impact on access. Additionally, studies that have reported 'accessibility' have presented this as a single measure (Bromley *et al.*, 2004) or only a narrow range of measures, such as distance to travel to SLT and professional availability (Murphy and Ruble, 2012).
- Few studies have taken place in the UK and none of these has focused on access to SLT for preschool autistic children. UK healthcare funding differs from funding models of other countries included in the review. This leads to challenges in determining the relevance of study findings to the UK context, particularly due to insufficient contextual information provided in some study reports.
- Several studies have a broad focus and examined children's access to many health and educational interventions, not only SLT. Those studies did not, therefore, present in-depth information in relation to access to SLT, limiting the extent to which findings can inform SLT clinical practice and policy.
- The review has identified some challenges that appear to be unique to parents of preschool-aged children. These include challenges recognising their child's needs, seeking and processing a diagnosis of autism for their child and navigating and accessing support for multiple child and family needs. However, relatively few studies focused exclusively on this age group, with most studies adopting a wide age range. We, therefore, lack the depth of understanding around the preschool population.
- Several studies acknowledge the higher education and income of participating parents compared with the general population. Studies may, therefore, not fully capture the range of challenges families with lower income and education levels may experience in gaining access to SLT for their children.

2.9 Strengths and limitations of the review

The scoping review has comprehensively mapped and synthesised information related to access to SLT for preschool children. The review has not been restricted to a specific geographical location and has drawn on a diverse body of literature to identify five themes.

The scoping review has followed up to date guidance on the conduct of scoping reviews. The double review at all stages (screening, selection, data extraction and appraisal) has strengthened the quality of the review, along with the expert guidance of V. Fenerty and N. Beckett-Jones, Engagement Librarians, University of Southampton, in designing the search methods and reporting of the review. A transparent process has been followed and reported within this chapter.

The eligibility criteria for inclusion in this review was broad to identify relevant studies that are not explicitly or solely focused on access to SLT. There are strengths and limitations associated with this. The wide inclusion of studies provides a more holistic and comprehensive overview of access, although it is recognised that some studies may have been missed. Determining whether there was a sufficient link to access for inclusion in the study relied on the interpretation and judgment of the reviewers. The use of double review at all stages, personal reflection, detailed records of decisions, and engagement with the supervision team facilitated a consistent and transparent approach.

The review excluded studies that only presented SLT service data aggregated with other service data and studies that did not focus predominantly on autistic children. Although exclusion of these studies has enabled a more focused approach to understanding access to SLT for autistic children, some relevant barriers and facilitators relevant to this group of children may have been missed from this review. For example, relatively few studies focused on the relationship between access to service and family ethnicity. This may have been due to studies related to ethnicity and access to general services for autistic children being excluded as they did not meet the review inclusion criteria due to not reporting SLT service specific findings. The findings of the review should, therefore, be considered alongside the information on issues impacting access to SLT generally and impacting on autistic children's access to a wide range of services. The context of SLT service delivery in the UK and service access barriers and facilitators for autistic children are summarised in Chapter One.

Although the search strategy may have led to the omission of relevant literature (for example, non-English articles were omitted along with publications prior to 1994), all included studies

were published between 2004 and 2023, well within the date limits set, and no non-English study reports (unavailable in English) were identified in searches or excluded. Search terms for this scoping review focused on SLT as a service and did not include terms related to specific interventions commonly delivered by SLTs. This may, therefore have led to some other relevant studies being missed.

The scoping review focused on preschool aged children. However, the eligibility criteria allowed for studies related to older children to be included where considered sufficient or relevant to the preschool age group. This flexibility was important to gain a comprehensive understanding of access to SLT for preschool aged children, especially as few studies have focused exclusively on this age group. However, there are also limitations associated with this as although study participant demographic data was reviewed when considering the relevance of findings to this study, it is not always clear to what extent the findings reported in this review are relevant to preschool aged children and their families.

2.10 Research questions and objectives

The gaps in knowledge identified through the scoping review have guided the development of the specific aims and objectives of the research presented in this thesis. In response, this thesis examines access to SLT for preschool-aged autistic children:

- In the UK
- From the perspectives of a range of key stakeholders.

The following research question has guided this study:

What factors and processes impact on access to SLT for preschool autistic children from the perspective of key stakeholders?

The following objectives were set:

- To map the existing pathway for access to SLT intervention for preschool autistic children within the research setting and to consider this in relation to existing local and national guidelines.
- To understand factors and processes impacting on access to SLT for preschool autistic children from the perspectives of key stakeholders.
- To identify opportunities to improve access to SLT for preschool autistic children and their families.

Chapter 3 Methodology and methods

3.1 Introduction to the chapter

This chapter provides an overview of the theoretical perspective that guided this study. Methodologies and methods of data collection and analysis are discussed, and the justification for decisions made is presented. Ethical considerations and steps taken to improve study trustworthiness are then shared. Recruitment methods and outcomes are presented, followed by the process of analysis.

3.2 Research perspective

The study design was influenced by the researcher worldview and the nature of existing knowledge on access to SLT for preschool autistic children. A research paradigm consists of four elements: ontology, epistemology, axiology and methodology. These elements capture the overall beliefs and worldview of a study (Lincoln and Guba, 1985). The position of this research, and the assumptions that have guided its design, will now be described to support the integrity of the research (Guba and Lincoln, 1994).

3.2.1 Ontology and epistemology

Ontology relates to the nature of reality (Crotty, 1998). The author's view is that reality cannot be understood outside our perceptions of the world. This perspective has been shaped by clinical practice as an SLT, working with stakeholders with different perspectives on access to SLT. This position aligns the relativist perspective of the study which is well suited to exploring complex processes such as access to healthcare.

Epistemology is the way in which our perception of reality may be understood (Denzin and Lincoln, 2018). An interpretive epistemological perspective facilitates understanding of access to SLT from the perspectives and observations of different stakeholders aligning with a relativist ontology (Guba and Lincoln, 1994). Interactionism also influences the study research perspective through a focus on participants' values and beliefs in the context of their past and current experiences in complex healthcare organisations (Haralambos and Holborn, 2013).

3.2.2 Axiology and origins of the research study

Axiology refers to the values that guide and influence all aspects of the study. The researcher's values and beliefs, and the influence these may have on decisions, were considered at every stage of planning and throughout the conduct of the study. These reflections have been captured in a research diary and discussed during academic supervision.

3.2.3 Qualitative methodology

Methodology is the overall design and process of the research (Denzin and Lincoln, 2011). The worldview, epistemology and aims of this research naturally lead to a qualitative methodology. Qualitative research supports an in-depth and holistic examination of a phenomenon from the perspective of participants within their natural settings and makes sense of situations through people's interpretations of them (Denzin and Lincoln, 2011). Creswell (2013) describes five main qualitative methodologies: narrative, phenomenology, grounded theory, ethnography and case study. All were considered for this study.

Narrative and phenomenological approaches, which focus on the unique experiences of participants and the specific meaning of these for individuals (Riessman, 2008) were not selected as they are incompatible with the research question of the study. Grounded theory builds theory that is rooted in the data (Glaser and Strauss, 1967) and enables the views of several participants to be gathered. It is suitable for studying a process where little is already known, such as access to SLT. However, as this study did not aim to develop theory, grounded theory was not selected.

Ethnography and an ethnographic case study were not selected as they focus on understanding the culture of a specific group (Harris, 1968) and would not meet the aim of understanding access to SLT. While ethnography seeks to understand a group who share the same culture, a case study focuses on a group that shares a particular problem or issue which is then explored within a bounded system, or specified context (Merriam, 1988; Stake, 1995; Yin, 2018). A qualitative case study methodology was selected as it supports a holistic, in-depth understanding of the phenomenon of access to SLT to be studied in its natural context and from the perspectives of different stakeholders (Harrison *et al.*, 2017).

3.3 Case study methodology

3.3.1 Qualitative case study

Qualitative case studies have been used to address research questions in many disciplines, including health, social sciences and education (Crowe *et al.*, 2011; George and Bennett, 2005; Harrison *et al.*, 2017; Merriam, 1988; Phoenix *et al.*, 2021; Stake, 1995; Voss and Lin, 2024). The main approaches to case study described by Yin (2018), Stake (1995) and Merriam (1988) share a common purpose of understanding a complex phenomenon holistically and in-depth within its natural context, where the boundaries are unclear and there are several variables (Creswell, 2013; Flyvbjerg, 2006; Merriam, 1988; Simons, 2009; Stake, 1995; Yin, 2018). Differences between case study approaches reflect the worldview of methodologists and the specific purpose of case study in their field of research (Harrison *et al.*, 2017). Yin's realist and post-positivist perspective emphasises testing of theories and seeking the truth, with a focus on objectivity (Harrison et al., 2017). Stake's relativist and interpretivist perspective takes a qualitative case study approach to understanding experience in context (Harrison *et al.*, 2017), recognising the researcher's central role. Merriam emphasises the researcher's' own interpretation of participants' experiences (Merriam, 1988). A qualitative case study using a Stakian approach aligns with the ontology and epistemology of this study and has the potential to address gaps identified in the scoping review presented in Chapter 2.

3.3.2 Instrumental qualitative case study design

Case study design involves several decisions relating to the type of case study to conduct, the boundaries of the case, sources of data, and methods of data collection. Stake describes three main approaches to case study: intrinsic, instrumental and collective (more than one intrinsic case study). Within an intrinsic case study, the case itself is the primary interest. Within an instrumental case study, the case is secondary to the issue of interest and is used to facilitate our understanding a phenomenon. A single instrumental case study was selected to gain a holistic view of access to SLT within the bounded system of the case study.

One issue was selected as the focus and is captured in the research question:

> *What factors and processes impact on access to SLT for preschool autistic children from the perspective of key stakeholders?*

As the study focused on access to SLT, several frameworks for understanding access to healthcare were reviewed (Freeborn and Greenlick, 1973; Penchansky and Thomas, 1981; Shengelia *et al.*, 2005; Dixon-Woods *et al.*, 2006; Levesque, Harris and Russell, 2013) to consider how they may help inform and guide the design and conduct of the study. Theoretical and conceptual frameworks provide a visual representation of important concepts, processes and relationships (Sale and Carlin, 2025) that have been identified regarding a phenomenon of interest. Whilst conceptual framework, theory and theoretical framework are terms that are often used interchangeably, each has a specific meaning (Kivunja, 2018). A theory summarises concepts, relationships and interactions that have been identified in previous research and tested to help explain and predict what will happen in a particular situation (Kivunja, 2018). A theoretical framework within a study is the way in which theory may structure the research. A conceptual framework is the logical presentation of ideas and relationships, however these have not been tested through research and developed into theory (Kivunja, 2018).

There are several advantages and disadvantages associated with the use of theoretical and conceptual frameworks within qualitative studies. Within some studies, existing frameworks may support researchers to organise, observe and interpret information through considering the elements and relationships that have already been identified as important in previous studies (Hudon, Gervais and Hunt, 2015). This deductive approach is considered helpful for novice researchers and for situations where research time is limited as it can simplify the process of analysis and the time required for this (Miles, Huberman and Saldana, 2014). However, where the focus of research is on highly complex social phenomena, an inductive approach may be more appropriate (Miles, Huberman and Saldana, 2014) as the use of existing frameworks can limit deep engagement with data. Sale and Carlin (2025, p.2) state that the use of existing frameworks can lead to a "prescription for data collection and analysis". Therefore, while existing frameworks can provide an efficient way to compare study findings with other studies and against existing theory, it may be at the expense of depth of analysis (Sale and Carlin, 2025).

Frameworks for understanding access to healthcare informed the definition of access and boundaries of the case within this study. The Candidacy Framework (Dixon-Woods *et al.*, 2006) and the Levesque Framework for Healthcare Access (Levesque, Harris and Russell, 2013) were both reviewed in detail to ensure a broad view of access to services. The Candidacy Framework (Dixon-Woods *et al.*, 2006) helped ensure the interactions and negotiations that take place between healthcare providers and those who are seeking a service were considered, and the Levesque framework Access (Levesque, Harris and Russell, 2013) helped ensured a focus on both service and individual factors. The use of existing frameworks in this way aimed to ensure

the study considered key elements found to be important in previous studies on access to healthcare. A specific framework was not selected as a deductive lens for this study. This aimed to minimise the potential for missing or ignoring data that does not fit within a specific pre-existing framework. A more open and inductive approach aimed to support creativity and novel interpretation of data (Sale and Carlin, 2025). This was considered particularly important as access to SLT for autistic children had not previously been researched in detail.

3.3.2.1 Bounding the case

Bounding the case involves defining the context within which the issue of interest will be explored. The case was bound by time, geographical location and the process of access to SLT. A broad view of access was taken and the case bound from when a parent/carer became aware of their child's communication difficulty through to their initial experience of SLT. Table 5 presents the rationale for decisions on bounding the case.

Table 5 Bounding the case

Bounded by	Description	Rationale for decision
Experience or influence on the issue of interest	Individuals who influence/experience access to SLT for preschool autistic children.	To understand factors and processes impacting on access to SLT from the perspective of stakeholders.
Geographical location	This is the research setting. A clearly defined geographical area within which access to SLT will be explored.	A defined location enables information on the SLT service setting and processes to be captured and to provide a context for participant views.
Time	Parents/carers accessed preschool SLT for their child in the last two years. Healthcare professionals influenced/worked with preschool autistic children with the last year.	To enable as many participants as possible to participate, whilst balancing recall bias and difficulties recalling details of experiences that are important to the study.

3.3.2.2 Sampling of the case and activity sites

A purposeful approach was taken to select a bounded system to meet the study aims. A typical bounded system, likely to be representative of others, was selected as access to SLT has not yet been explored in detail, and this can work well in an instrumental case study (Stake, 1995).

The case was bound by the geographical location of two community and mental health NHS foundation Trusts in the South of England (site A and site B). These locations were considered due to the researcher's proximity to the sites. Information available from Care Quality Commission (CQC), the NHS staff survey and the NHS friends and family tests for both NHS Trusts were reviewed prior to data collection and did not suggest that the settings were particularly atypical compared to other Trusts nationally or to each other. However, the researcher remained aware of potential differences between sites throughout data collection and analysis. An anonymised summary of information on both NHS Trusts is provided in Table 6 and further detail provided in Appendix B.

Table 6 Information on the health Trusts in the research setting

Context	**Site A**	**Site B**
Geographical location	South of England	South of England
Employees (headcount)	4,559 total staff 2,444 professionally qualified staff (1,186 nurses and health visitors, 1,029 scientific, therapeutic and technical staff)	5,695 total staff 2,859 professionally qualified staff (1,506 nurses and health visitors, 1,071 scientific, therapeutic and technical staff)
Trust status	Established as a health trust in 2001. Foundation trust status gained in 2007.	Established as a health trust in 1994. Foundation trust status gained in 2011.
Commissioning	Two Clinical Commissioning Groups	One Clinical Commissioning Group
Partnerships	Six local unitary authorities	Five local unitary authorities
Care Quality Commission rating	Outstanding	Good

3.3.2.3 Information domains and units of analysis

Information domain relates to the scope within which information is collected and interpreted. The use of multiple sources of data to gather rich information is a key characteristic of a Stake case study (Stake, 1995). All participants had experience of NHS SLT services within site A or B areas. The following individuals were identified as key stakeholders through engagement with local SLT and autism services:

- Parents/carers of preschool autistic children
- SLTs
- Leads/managers/commissioners of SLT services
- Early Years health, education or social care staff**Error! Bookmark not defined.**

Units of analysis relate to the specific elements of interest in the case study. The study aimed to capture the knowledge, beliefs, and experiences of individuals.

3.3.3 Summary of the case

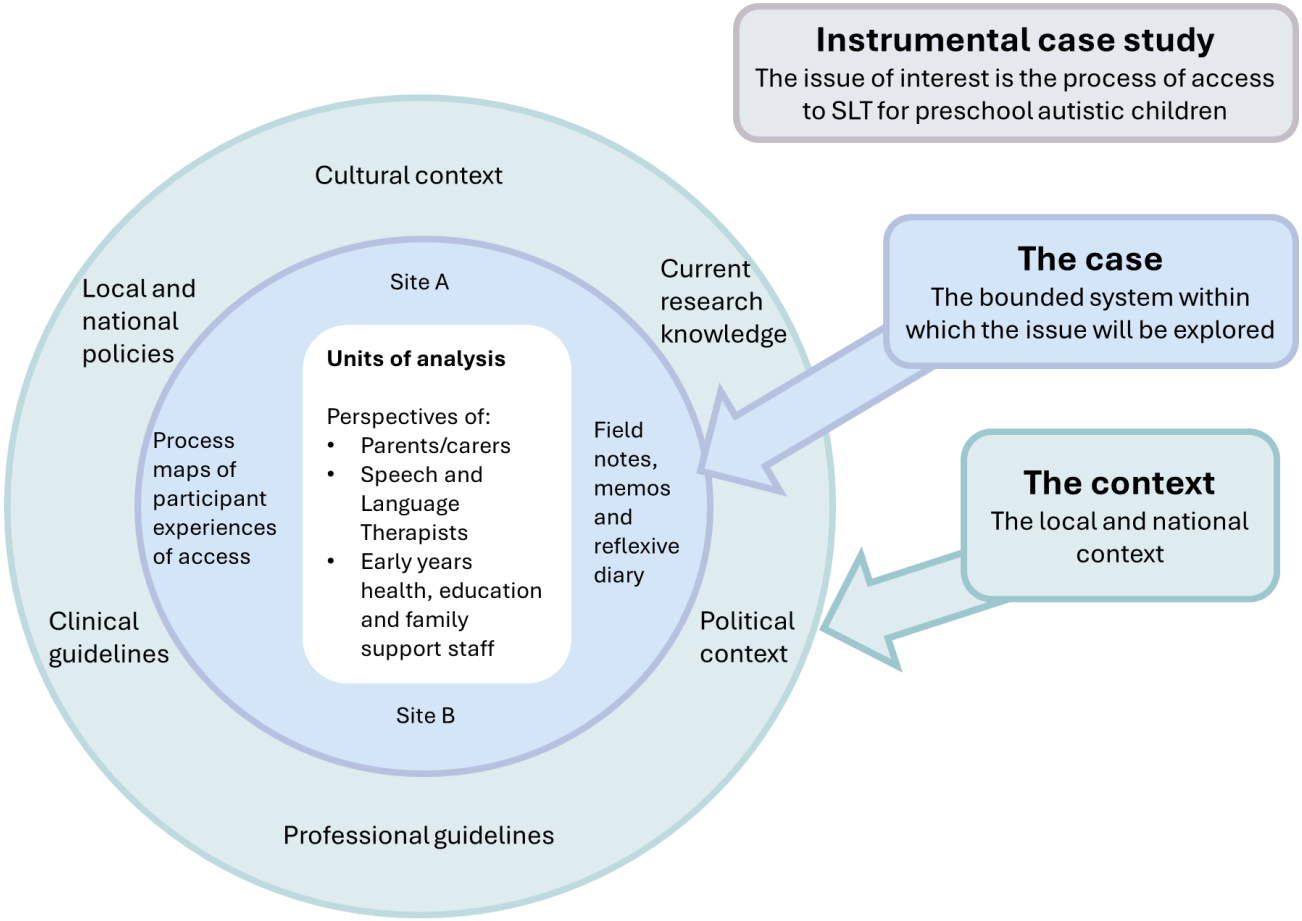
Selecting and bounding the case involved several key decisions, as summarised in Table 7and presented visually in **Error! Reference source not found.**.

Table 7 Summary of key definitions and decisions for this single instrumental case study

Key elements of the case study	**Definition**	**Application within this study**
The issue	The focus/ phenomenon of interest.	Access to SLT for preschool autistic children is the issue of interest.
The case	The bounded system within which the issue will be studied.	The case study is bound by geographical location, time, and experience/influence of individuals on access to SLT for preschool autistic children.
Research setting	Two healthcare Trust sites in the South of England.	This enables access to be explored from a range of perspectives within this large geographical area.

Key elements of the case study	**Definition**	**Application within this study**
Information domains	The broad context of information to answer the issue question(s).	The knowledge, experiences and perspectives of stakeholders on access to SLT so that access may be examined in relation to: • Processes and actions • Interactions within the processes and actions (perceptions, reactions and consequences) Together, enabling a thorough interpretation of the meaning of these by the researcher (Njie and Asimiran, 2014)
Units of analysis	Specific elements of the phenomenon of interest that will be examined.	Experiences and views of individuals on access from the following perspectives: • Parents/carers • SLTs • Early Years health, education or social care staff • Leads/managers/ commissioners of SLT services. Process of access influenced/experienced by the above stakeholders.

Figure 2 The case study



3.4 Quality of qualitative research

Several frameworks have been developed to assess the trustworthiness and rigour of qualitative research (Guba, 1981; Lincoln and Guba, 1985). Due to the central role of the researcher in a case study, researchers should continuously question their interpretations to minimise the risk of misunderstanding or misrepresenting participants' views (Stake, 1995). A framework initially developed by Guba (1981) proposed that trustworthiness of qualitative studies is determined across four concepts: credibility, dependability, conformability and transferability. A fifth concept – authenticity was added following further development (Lincoln and Guba, 1985) and these five will now be considered for this study.

3.4.1 Credibility

Credibility is the extent to which findings make sense to others (Lincoln and Guba, 1985) and present the truth of a phenomenon (Guba, 1981). Credibility is enhanced through prolonged

engagement, triangulation, member checking, peer debriefing and thick description (Lincoln and Guba, 1985).

Prolonged engagement relates to understanding the culture, social setting and context of a phenomenon (Lincoln and Guba, 1985). Close stakeholder engagement with researchers, autism support organisations, health service managers and clinicians influenced the design and conduct of the study and helped ensure relevant and credible sources of data. Attendance at team meetings in the research setting to share study information enabled the researcher to learn about the context, supported credibility with key individuals, and helped establish trust and rapport.

Triangulation involves the use of varied methods and sources of data to increase credibility (Lincoln and Guba, 1985). Triangulation of sources enabled access to be explored with individuals in different roles, and space triangulation was achieved through seeking the views of individuals across different sites. Method triangulation involves the use of multiple methods or data sources. Method triangulation was achieved through capturing information on processes, perspectives, and on the context of access to SLT in the research setting.

Member checking relates to formal and informal ways in which data, analysis, interpretations and conclusions are checked with those from whom data was collected (Lincoln and Guba, 1985). Research findings were shared with participants at the end of the study and their reflections sought and incorporated into the conclusion.

Peer debriefing enables the researcher's assumptions, decisions and interpretations to be explored (Spall, 1998) collaboratively through sharing and discussing the study with others (Guba and Lincoln, 1994). Regular meetings with the supervision team supported reflection and the study was presented to autism research and academic groups to gain other perspectives during the design and conduct of the study (presentation dates:19/02/2021, 20/05/2021, 16/02/2023, 14/02/2024).

Finally, an in-depth description of the immediate and broader context of the case is provided as well as multiple perspectives on the issue of interest, ensuring a thick description of the case.

3.4.2 Dependability

Dependability relates to the stability of data over time and conditions, and the extent to which the study may be repeated by others (Lincoln and Guba, 1985). Dependability has been supported using a research diary and attention to detail in recording decisions and

amendments. This, along with a structured and clearly documented approach to analysis, provides an audit trail for the conduct of the study and supports transparency (Guba, 1981). An excerpt of a diary entry related to participant criteria is provided in Appendix F. A detailed description of analysis is provided in section **Error! Reference source not found.**.

3.4.3 Transferability

Transferability is supported by a rich description of the context and participants of this case study, which allows readers to determine the relevance of findings to other groups or situations (Lincoln and Guba, 1985)

3.4.4 Authenticity

Authenticity is present when researchers accurately and sensitively convey the realities of participants as they are experienced and shared (Lincoln and Guba, 1985). Data collection aimed to provide a flexible approach for participants to share their views and experiences in a comfortable and logical way for them. Data analysis and reporting of findings aimed to convey the story of a wide range of participants through a rigorous and transparent approach to analysis, which is presented in section 3.12.

3.4.5 Confirmability

Confirmability relates to the accuracy, relevance and meaning of findings (Lincoln and Guba, 1985) and the extent to which these are shaped by participants rather than by researcher motivation and interests. Confirmability was supported through detailed record keeping, demonstrating the ways in which the findings were reached from the data collected.

Reflexivity was an important aspect to support confirmability. Within reflexive thematic analysis and a Stake approach to case study, the researcher's role is central. Personal reflexivity relates to the beliefs, interests and motivations of the researcher and functional reflexivity considers the role of the researcher during data collection (Wilkinson, 1988). This following section aims to introduce the thoughts, experiences and relationships of the author to position the author in relation to the study and how they may have influenced the study.

3.4.6 Reflexivity

3.4.6.1 Personal reflexivity

I am a married, working mother to two boys. I graduated as an SLT in 2002 and specialised in autism and worked in clinical leadership roles in diagnostic assessment and intervention services. I am passionate about providing the best possible services to children and their families and have worked hard to understand the unique needs of those I am working with.

My experiences, interests, character, personality and values have together influenced all aspects of the study. The focus of the study, methodology and methods selected have been shaped by my decisions (Davis, 2020). The process of writing in a research diary supported me to reflect on my thoughts, background and beliefs and the ways in which these influenced the study. Olmos-Vega et al. (2023) emphasise the importance of planning and concrete actions in reflexivity. Reflexive writing was the main way in which I was able to develop my self-awareness and explore some of my biases around this research topic. This was a regular activity throughout the study and included writing in a research diary, completing field notes and through adding memos and notes to published literature and to research data.

It was crucial that the approach to the study aligned with my world view (Davis, 2020). The study topic and the approach taken both connect deeply with my values and this has played an important part in sustaining my interest in the study over time. To gain deeper insights into my personal values I completed a Values in Action Classification of Strengths questionnaire (Institute on Character, n.d). I was struck by how closely my identified values aligned with different aspects of the research topic and process. My most dominant value was love of learning. This was unsurprising to me as since my BSc in Speech and Language Therapy I have engaged in several academic and professional development activities. For example, whilst working towards the doctorate in clinical practice, I completed a 3-year consultant practitioner secondment with Health Education England (HEE) and worked with children and adults in different mental health, learning disability and autism services. This broadened my experiences and understanding of autism, communication needs and service delivery.

My love of learning and my inquisitive and questioning approach have led to me questioning and challenging what is done in SLT services and why things are done as they are. This has occasionally led to me feeling frustrated with service processes in particular in situations where standardised packages of care have been offered but have not appeared to meet the needs of families. As I had a previous role as an SLT in diagnostic assessment clinics as well as a role in

providing interventions, I encountered children and their families at different points in their journey through SLT services. I heard their views on different aspects of SLT services and processes. Also, as my role spanned different health, care and education contexts I often heard the perspectives of a wide range of health, care and educational professionals working with children and their families.

This interest in different views on topics connects with another value identified as important to me on the Values in Action Character Strengths questionnaire (Institute on Character, n.d) - perspective. Perspective refers to the importance of appreciating different viewpoints on situations and issues. I feel that this has had a considerable influence on the design of the study and the importance of making sure that a range of perspectives on the complex issue of access to a service are heard.

The other values I identified as important for me were honesty, kindness and fairness. These have all contributed to my interest in this topic. I strongly believe that children and their families should receive the services and supports they need and that access to this support should be based on the needs of children and their families rather than on parents' ability to negotiate for services. I also believe in being honest with people and sharing information so they can make informed decisions about their care and next steps (e.g., to challenge a gap in service provision or to make their own private arrangements for support).

I was aware my role as a qualified, experienced and specialist SLT gave me a privileged position in relation to the study. I also had good knowledge of SLT service processes and service cultures and needed to recognise this and how this might both influence my conduct of the study and how I may be perceived by others. Due to my background as an SLT and the ways in which I view my profession I also appreciate that I have a bias towards focusing on the value and impact of SLT for children and their families. Although my experiences and perspectives cannot be separated from me, my move to a corporate, non-clinical role in an NHS Trust prior to engaging in this research was helpful in gaining some distance from SLT issues.

Reflecting on the different aspects of my personality, experiences and roles has been an important aspect of supporting transparency within this study. Overall, I have found the insights I gained through my professional roles and experiences, and my personal role as a busy mum, working part-time and studying towards a doctorate, helpful in engaging with participants and stakeholders during this study. However my areas of bias and privilege and the ways in which these have shaped the study must also be acknowledged.

3.4.6.2 Functional reflexivity

I was employed by one of the NHS Trusts in this study for 12 years, the first five as an SLT. The following three years were outside of the Trust on secondment with Health Education England and the remaining years on maternity leave and in a corporate role in the Trust. My familiarity with autism and SLT services presented both challenges and opportunities. Familiarity with the context of SLT and autism services can support greater levels of trust with stakeholders (Price and Hawkins, 2002) and support recruitment (Coyne, Grafton and Reid, 2016). I quickly achieved a comfortable rapport with stakeholders and participants and felt able to communicate confidently and with credibility.

The possibility of conceptual blindness (Hockey, 1993), and for assuming knowledge (by the participant and me) needed to be considered (McDermid et al., 2014). This was managed through discussion with the supervision team, the use of a research diary and through being open and transparent with all stakeholders and participants. It was important to consider possible power imbalances in the conduct of the study. Participants were aware of my previous practice as an SLT and particular care was given to avoid communicating in ways that would lead to me being viewed as an 'expert' or 'judge' (McDermid et al., 2014). To work towards achieving this I ensured that I followed the semi-structured interview guide and engaged in active listening. I worked hard on paying attention to what participants were sharing with me to try to understand their perspectives, feelings and the different meaning of things to them. I often reflected back what I had heard from them. This meant that I listened without taking a position on issues or making judgements and this supported me to build trust and empathy with them. This was particularly important given the importance of the topic for those taking part in the study.

3.5 Participants

3.5.1 Sampling approach

Purposive, criterion-based sampling was selected to meet the aims of data collection. This aligned with both the interpretivist research perspective (Patton, 2014) and the aim to gain multiple perspectives on access to SLT. Close engagement with stakeholders and an iterative, flexible approach to sampling ensured relevant data was gathered (Negrin *et al.*, 2022). Eligibility criteria aimed to maximise opportunity for participation whilst maintaining a clear focus on the

study topic (Kristensen and Ravn, 2015). The eligibility criteria are presented in Table 8**Error! Reference source not found.**.

Target recruitment numbers for participant groups aimed to achieve a balance in roles/experience of access, and guided recruitment priorities. The study required participants who would be able and willing to share their thoughts and experiences with the researcher and a convenience sampling approach was used.

Table 8 Final participant eligibility criteria

Stakeholder/ participant group	**Target number of participants**	**Final eligibility criteria**
Parents/ carers of preschool autistic children	8-10	Main carer, living with the child who may have parental responsibility or have assumed a parenting role of a child: • aged <8 years at the time of data collection. • with a confirmed diagnosis of autism or waiting for autism assessment. • attempted to/accessed NHS SLT in the research setting during their child's preschool years. Adequate English language skills, with no requirement for an interpreter.
Leads/ managers/commissioners	3-5	Has commissioned, led, or managed SLT service for preschool autistic children in the past year.
Speech and Language Therapists	6-10	SLT who has worked with at least two preschool autistic children in any role (e.g., assessment or intervention) in the past year.
Early Years health, education or social care staff	6-10	Has worked with a minimum of two families of a preschool autistic child in the past year.

3.5.2 Number of participants

In accordance with qualitative research, the priority of this study was to gain an in-depth understanding of the topic from those with the relevant thoughts and experiences to share (Patton, 2014) rather than seeking a large sample size (Staller, 2021). Nevertheless, lack of researcher justification of small sample size in qualitative studies is a common criticism (Boddy, 2016). Saturation is commonly referred to within qualitative studies, however this does not support researchers in planning studies as it is not possible to definitively know when saturation will be reached within a study. Marshall *et al.* (2013) suggests a theoretical approach to sampling that considers the precedent set in similar studies. Studies utilising semi-structured interviews identified in the scoping review (Chapter 2) included between 8 and 45 participants (Chu *et al.*, 2018; Cohen, Miguel and Trejos, 2023; Dababnah and Bulson, 2015; Khanlou *et al.*, 2017; Millau, Rivard and Mello, 2018; Trembath *et al.*, 2016) and a systematic review of sample sizes of qualitative studies on varied topics, utilising different methodologies typically included between 9 and 17 participants to achieve saturation (Hennink and Kaiser, 2022). Hennink and Kaiser (2022) note this was achieved with a homogenous group of participants and a narrowly defined focus.

Information power has been introduced as an alternative concept to saturation to support researchers to determine sample size in qualitative research (Malterud, Siersma and Guassora, 2016). This is recommended by Braun and Clarke (2021) over the concept of saturation. This concept therefore aligns with the approach to analysis within the study which is presented in section 3.8. Information power emphasizes the importance of the relevance and richness of data in relation to the study aims. A framework has been developed for researchers to consider different criteria when determining sample size (Malterud, Siersma and Guassora, 2016). Malterud, Siersma and Guassora (2016) provide a description of how each element of their framework influences sample size, for example, a narrow aim suggests a smaller sample size may be appropriate, whilst a broad aim suggests a larger sample size is needed to achieve information power. The ways in which each of these elements has been considered within the study is presented in Table 9.

Table 9 Framework for sample size evaluation (Malterud, Siersma and Guassora, 2016)

Element and description	How the element relates to the study presented in this thesis
1. Aim: narrow or broad?	There is a clear and focused research question, however it is recognised that despite this, access is a broad concept and so

A clear and focused research question requires fewer participants	may require more participants to fully understand the different steps of access, from different perspectives and across different contexts. The study, therefore, has moderate information power in relation to this element.
2. Sample specificity: dense or sparse? A highly specific and relevant sample can lead to more powerful insights	The purposive, criterion-based sampling approach utilised within this study is recognised to improve the depth and relevance of data to the topic of interest (Kristensen and Ravn, 2015). The study is therefore considered to have high information power in relation to this element.
3. Use of theory: applied or none? The use of existing theory can reduce the number of participants required to gain valuable data on a topic.	The study has moderate information power in relation to this element. Although theory is not used as a deductive lens within the study, the definition of access and the elements of interest have all been influenced by existing frameworks for understanding access to healthcare.
4. Quality of dialogue: strong or weak? Strong and clear communication between the researcher and the participant requires fewer participants.	The researcher is experienced in interviewing families as part of diagnostic assessments for autism and of communicating with a wide range of professionals. The researcher is confident across a range of situations and has skills in quickly building rapport with people and putting them at ease. This element supports high information power within this study.
5. Analysis: case or cross-case? A more complex, cross-case analysis can increase the required sample size.	A detailed, thorough approach to analysis utilising recognised methods supports information power within this study. Additionally, all data is analysed together to form a holistic view of access rather than through separately analysing data from the different participant groups for comparison.

Information power (Malterud, Siersma and Guassora, 2016), the precedent set in previous studies and guidance of methodologists have all influenced the study sample size. As a result of this, a sample size at the higher end of the range shared by Hennink and Kaiser (2022) was considered appropriate and the study aimed to recruit between 23 and 35 participants. Several study stakeholders such as service managers and leads were consulted on target recruitment

numbers, and these were deemed realistic based on the number of people who may be eligible to participate in the research setting.

3.6 Ethical considerations

Ethical considerations were informed by interpretivist research principles and various ethical frameworks.

3.6.1 Participant recruitment and informed consent

Informed consent is central to ethical research (Health Research Authority, 2018). It supports individuals to participate voluntarily, having had sufficient time and information to consider whether to participate. Informed consent consists of two distinct stages: giving information and obtaining consent. Both were iterative, on-going processes in this study. Sharing study information in different ways at different times gave potential participants several opportunities to reflect before deciding to participate (Health Research Authority, 2020).

3.6.1.1 Giving information

Clear and understandable study information was crucial, and plain-English participant information sheets formed the basis for discussion with participants (Appendix D.3 and D.4). Participants were given at least 48 hours to consider whether to take part which was considered appropriate for the nature, sensitivity, and context of this study.

3.6.1.2 Obtaining consent

Consent information was shared with participants before the interview so that they may familiarise themselves with this before meeting with the researcher (Appendix D.5 and D.6). Recorded verbal consent was gained before data collection took place.

3.6.2 Participant wellbeing and safety

The main ethical issues and risks related to the study are explored in the following section, and the specific plans in place to reduce and respond to risks can be found in a risk assessment (Appendix C.4). The health and wellbeing of everyone involved in the study was a priority. Data collection took place at a time when many COVID-19 restrictions were still in place. Although interviews were conducted remotely, the potential for the study to place stress and burden on participants at an already difficult time was monitored through discussion with key

stakeholders. Engagement with potential participants was sensitive to the personal and professional demands on them.

3.6.2.1 Safeguarding and professional practice

Safeguarding of those involved in the study was paramount, and it was important to remain vigilant for information that may indicate a safeguarding or professional practice concern. The researcher completed NHS safeguarding children and adults training to ensure up-to-date knowledge of safeguarding and familiarity with local processes so that any concerns could be addressed.

The researcher is registered with the Health and Care Professions Council (HCPC) and bound by the HCPC Standards of Performance, Conduct and Ethics (Health Care Professions Council, 2016). Participants were informed that malpractice or safeguarding concerns would be shared with managers and the HCPC in conjunction with the employer if serious concerns were identified.

3.6.3 Data handling and data protection

Establishing a clear legal basis was necessary to hold personal information (European Union General Data Protection Regulation, 2016). General Data Protection Regulation (GDPR) requires researchers to be fair and transparent regarding the personal data held. As a result, information was provided in a section of the Participant Information Sheets (Appendix D.3 and D.4). Data were collected, managed, stored, and destroyed in line with GDPR and the University of Southampton policies. The data management plan can be found in Appendix C.5 and steps to reduce breaches in confidentiality and the action to be taken should a breach occur were documented in a risk assessment (Appendix C.4).

3.6.4 Ethical approval

The study gained ethical approval from the University of Southampton via the Ethics and Research Governance Online (ERGO II) system (Appendix C.1) and HRA via the Integrated Research Application System (IRAS) (Appendix C.3). Minor amendments to documentation were requested via ERGO II before approval. Following ERGO approval, the HRA Research Ethics Committee (REC) requested changes to wording of participant information sheets and requested justification for the initial eligibility criteria for parents/carers to have accessed a minimum of two NHS SLT appointments for their child. It was initially felt to be important to capture those with some experience of NHS services and this was justified and subsequently

approved by the committee. However, following further reflection and engagement with stakeholders this was changed so individuals who had, as a minimum, only attempted to access SLT were eligible to participate. This was due to stakeholders sharing the considerable challenges many families of young children in the research setting were experiencing in accessing any SLT appointment. Minor, non-substantial amendments were requested following full approval and accepted via ERGO II and the HRA via the REC.

3.7 Methods of data collection

The interpretivist perspective of this study considers reality to be socially constructed from the views of several individuals (Guba and Lincoln, 1994). Data collection needed to allow individuals to share their thoughts and experiences in their own words. It also required a flexible approach so that areas of interest, such as influences of the healthcare context and interactions with others, could be explored. Focus groups and interviews were considered for data collection. Focus groups were not selected as the purpose of data collection was not to understand the collective experiences of participants (Gill and Baillie, 2018). Interview methods were selected as they enable the unique perspective of participants to be explored (Clarke and Braun, 2013).

Interviews are commonly used in case studies (Yazan, 2015) and vary in purpose, length, degree of predetermined structure and flexibility (Robson, 2002). Standardised interviews have a formal structure with no flexibility to adjust or ask additional questions (Green and Thorogood, 2011). At the other end of the spectrum, unstructured interviews tend to follow the interviewees narrative and the interviewer may ask questions spontaneously (Berg, 2009). Structured and unstructured interviews were not selected as they would not have met the aim of collecting in-depth data on a defined issue. Semi-structured interviews were selected to gather data on a specific topic, whilst being sensitive to participants' personal accounts and preferences (Kvale, 1996; May, 2001).

3.8 Case study analysis

Analysis aimed to reflect the views of participants as accurately as possible whilst acknowledging the researcher's role in interpretating the information shared. The aim was not to tell the story of a specific participant or group of participants, but to unearth and synthesise important patterns of meaning on access to SLT into one holistic report.

Stake (1995) emphasises researcher intuition and creativity in selecting methods of analysis, and provides advice and issues for researchers to consider rather than a detailed guide (Fearon, Hughes and Brearley, 2021; Stake, 1995). Within this study, an overall Stakian approach to analysis was complemented by more structured guidance (Fearon, Hughes and Brearley, 2021; Yazan, 2015) and analytical methods that align with the study research perspective. The main stages of analysis described by Stake (1995; 2005) will now be described in relation to this study:

- Description
- Categorical aggregation
- Establishing patterns
- Naturalistic generalisations

3.8.1 Description

A description of the context is crucial within a case study (Stake, 1995). Within an instrumental case study, contextual information is typically closely linked to the phenomenon of interest (Stake, 1995). A detailed description of the context and process of access to SLT is provided in Chapter 4, section 4.3.

3.8.2 Categorical aggregation

Stake (1995) describes two main approaches to analysis: direct interpretation and categorical aggregation. Direct interpretation takes a specific incident as indication of an important issue and is mostly used within intrinsic case studies (Stake, 1995). Categorical aggregation is more frequently used within instrumental case studies and was selected for this case study as it enables important recurring issues for a wide range of stakeholders to be captured. Stake (1995; 2005) does not specify a specific approach for identifying recurring patterns, so methods of analysis that may meet the study needs were explored.

Thematic analysis (TA) is an umbrella term that incorporates several approaches that seek to identify patterns in data (Braun and Clarke, 2019a). It is a foundational approach to analysis within qualitative studies (Braun and Clarke, 2006). TA varies according to the philosophical perspectives of studies and their researchers (Boyatzis, 1998; Braun and Clarke, 2019a). Braun and Clarke (2019a) identify three main approaches to TA: coding reliability, codebook, and reflexive TA. Table 10 provides a summary of TA approaches and the rationale for decisions made in this study and for selecting reflexive TA.

Table 10 Approaches to thematic analysis

Approach to TA	Summary	Decision and rationale
Coding reliability	Coding reliability (Boyatzis, 1998; Joffe, 2011) is highly structured and focuses on accuracy and reliability. It values consistency and coding consensus (Byrne, 2022) and aligns with a positivist perspective.	Not selected as it does not align with the interpretivist perspective of this study.
Codebook thematic analysis	Codebook TA typically uses as a deductive approach where codes are determined in advance or identified from an initial review of the data.	Not selected as it does not align closely with the research perspective of the study and risks trying to fit data into a pre-defined structure.
Reflexive TA	Reflexive TA recognises the central role of the researcher in interpreting data (Braun and Clarke, 2019a). It is an inductive, flexible approach that encourages researchers to view subjectivity and creativity as an asset (Braun and Clarke, 2019a).	Reflexive TA was selected as it aligns well with the research perspective of this study and with a Stake case study.

3.8.2.1 Reflexive thematic analysis

Reflexive TA is an inductive approach that enables codes and themes to be generated from data, ensuring that patterns and meaning are constructed from the views of multiple participants (Braun and Clarke, 2021). Reflexive TA was selected as it facilitates the generation of important patterns of meaning across the entire dataset, supporting the aim to gain a holistic view of access to SLT. A detailed description of the process of analysis is provided in section 3.12.

3.8.3 Establishing Patterns

Patterns are identified through considering the consistency of themes across the entire data set. The purpose of this stage of analysis is to consider issues that are important across the whole data. Patterns are explored within the reflexive TA report (section 4.4). Themes and sub-themes are presented with contextualising information and participant quotes.

3.8.4 Naturalistic generalisations and lessons learned

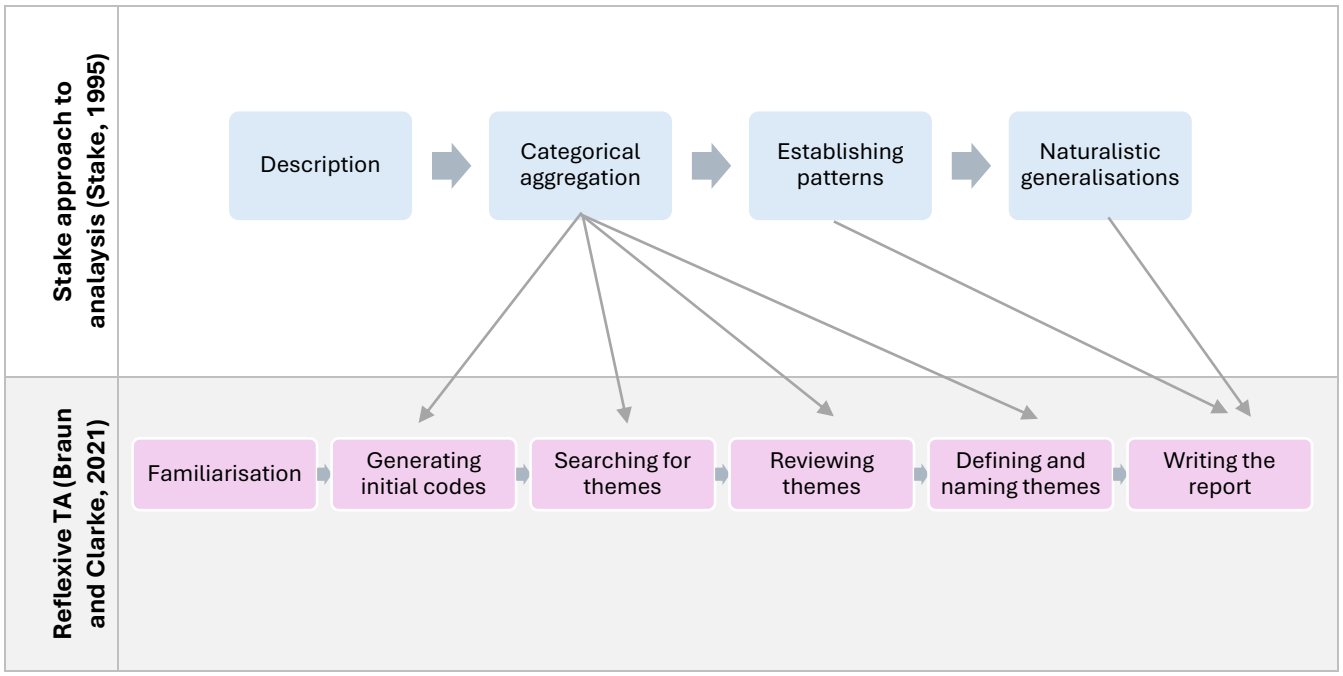
Stake (1995) defines naturalistic generalisations as conclusions reached through a person's personal engagement with the case study. Readers are supported to make their own naturalistic generalisations through provision of relevant contextual information on the process of access to SLT in the research setting, and through providing a detailed description of themes and those who contributed to them (Stake, 1995). Naturalistic generalisation is also supported through a transparent report of the role and perspective of the researcher (section 673.4.63.4.5) and the analytical methods used (section 3.12).

3.8.5 Summary

Summary

In summary, Reflexive TA is used within an overall Stakian approach to analysis. The methods applied align with each other and with the research perspective of the study. Figure 3 shows how these approaches to analysis interface within this study.

Figure 3 Approach to analysis



3.9 Approach to recruitment

Participant recruitment is a core element of study methodology (Negrin *et al.*, 2022) and influences the ethical conduct of a study and its findings (Newington and Metcalfe, 2014). Participation was voluntary and no financial incentive offered. Recruitment was tailored to each participant group and direct and indirect recruitment approaches were used (Negrin *et al.*, 2022). Participants are drawn to studies they feel are important (Keightley *et al.*, 2014) and this was considered in written and verbal communication. Potential participants were offered the opportunity to discuss the study and a participant information sheet outlining the study purpose and background, the benefits and risks associated with participating, details of what would be involved in participating and information on confidentiality, data handling and storage (Appendix D.3 and D.4),

The researcher's professional experience and understanding of the target population supported recruitment through enhancing credibility and rapport with potential participants and stakeholders (Kristensen and Ravn, 2015; Negrin *et al.*, 2022). Recruitment was phased to prevent over-recruitment, which also allowed the researcher to be responsive to participant availability. Recruitment was tracked to gain a balance in perspectives and to ensure the sample size did not become too large and lead to difficulty completing timely, in-depth analysis (Ritchie *et al.*, 2013; Sandelowski, 2001).

3.9.1 Recruitment of parents/carers

Parents/carers were not recruited directly by the researcher or SLT services to avoid them feeling under pressure to participate. Nine early years, education, voluntary groups and organisations working with autistic children and families were invited to act as an intermediary and to share study information with parents/carers. Seven of the nine organisations agreed to share information with families. Organisations shared study information (Appendix D.2 D.3 and D.4) directly (e.g., in person) and indirectly via social media such as Facebook and X. Parents/carers then contacted the researcher directly via email about participating. Parents/carers could also ask the intermediary to share their contact details with the researcher if they preferred.

3.9.1.1 Recruitment of SLTs and early years health staff

Within NHS Trusts, the study was supported by a local collaborator and research engagement manager, who along with the Research and Development (R & D) Teams provided invaluable support for recruitment. Study information was shared in clinical team meetings, where the research was discussed and those present had the opportunity to ask questions. Local family and autism support organisations were contacted to invite non-NHS early years staff to participate. Communicating with potential participants formally and via official channels sought to avoid staff potentially feeling pressurized to participate. Individuals were asked to contact the researcher directly via email if they were interested in participating.

3.9.1.2 Recruitment of service leads, managers, and commissioners

The researcher invited service leads, managers, and commissioners to participate directly via email (Appendix D.1). An intermediary was not used to recruit these participants due to the small number or potential participants in eligible roles and due to the benefits of direct discussion of the research and its aims between the researcher and the potential participant.

3.9.2 Engagement with potential participants

Emails from potential participants received a prompt, personalised response to maintain their interest in the study (Boxall, Hemsley and White, 2016). A participant information sheet (Appendix D.3 and D.4) and consent information (Appendix D.6) were shared via email, along with a short plain-English summary of the study. Participants were asked about their availability for interview and whether they preferred a phone or video call. The expected duration of the

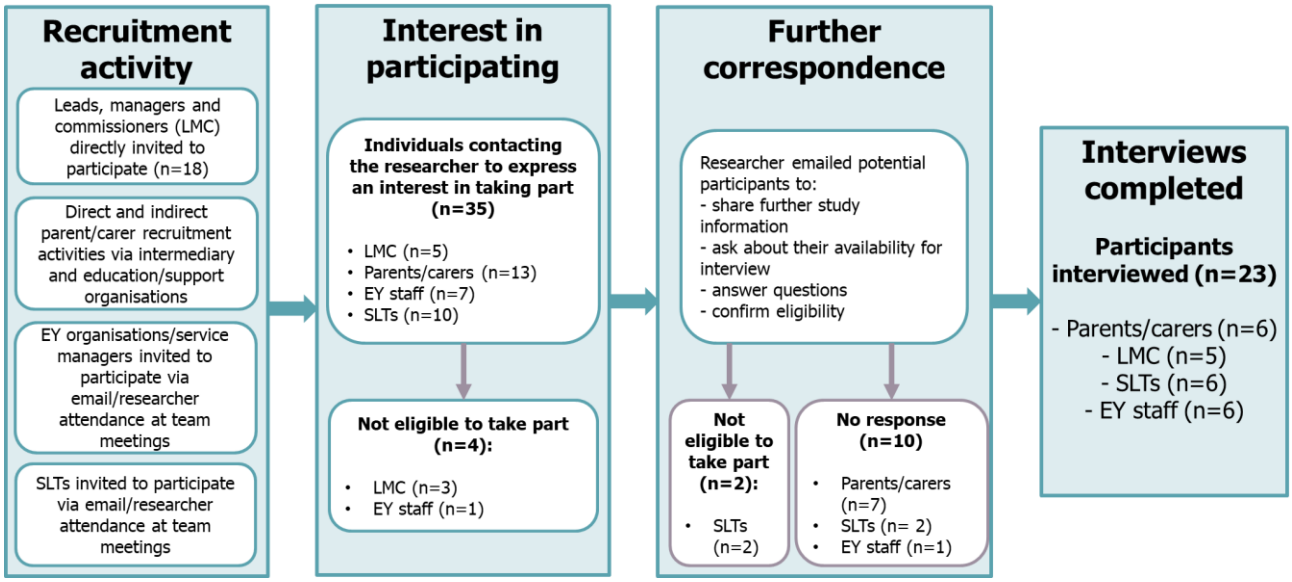
interview was highlighted to support preparation for interview (Thompkins, Sheard and Neale, 2008).

There were no more than three attempts to contact potential participants following their message to the researcher for ethical reasons to avoid perceived coercion. Recruitment activities and communications were captured in a password-protected Excel spreadsheet to track engagement with potential participants and to guide recruitment priorities.

3.10 Recruitment outcomes

Interest in the study suggested this was an important and relevant topic for local stakeholders and 23 individuals were recruited (Figure 4). Interviews took place between March 2021 and August 2022. This length of time was due to other time demands on the researcher, not due to recruitment challenges. Most interviews were completed between January and August 2022. Planned recruitment numbers were achieved in all groups other than parents/carers. As a large amount of rich data had been collected, the supervision team agreed to close the recruitment window before reaching the planned minimum of parent/carer participants. This decision was also influenced by the limited time available to continue with data collection. The possibility of over-recruitment associated with reinvigorating recruitment activity through approaching further groups and organisations to support recruitment of parents and carers was also considered. Over-recruitment could have led to turning people away. Although two fewer parents had participated than hoped (six parents instead of eight) the final number of parents (n=6) was the same number of participants in the SLT and EY staff group and one more than in the LMC group (n=5). There was, therefore a balance across the different perspectives. Closing recruitment at this time ensured that sufficient time was given to data analysis. Recruitment outcomes are summarised in Figure 4.

Figure 4 Outcome of recruitment



3.11 Gathering data

3.11.1 Preparation

Preparation for interviews involved reading about interviews, discussion with supervisors and participation in a university interview methods workshop. Participating as an interviewee in another study also gave useful insight into the experience of being a participant in a research interview. Two practice interviews were completed with a Health Visitor and a Speech and Language Therapist which improved practical interview processes and supported familiarity with the questions and flow of the interview. These were not included in analysis and the people interviewed did not work in the research setting.

3.11.2 Semi-structured Interview topic guide

The topic guide was influenced by existing literature on access to SLT and frameworks for access to healthcare (Dixon-Woods *et al.*, 2006; Levesque, Harris and Russell, 2013). Four topic areas were established: context, process of access, influence on access, evaluation and strengths, and opportunities. Questions tailored to participant groups were developed within these areas (Berg, 2009). This supported a transparent alignment between the research question and the interview guide. A description and rationale for the topic areas is presented in Table 11**Error! Reference source not found.** and the interview guides are in Appendix D.7.

Table 11 Interview topics

Focus	Purpose and rationale
Context	To capture information on the participant role and context of the SLT service. This provides context for participants' thoughts and experiences.
Process of access	To understand: - steps involved with access to SLT and decision-making processes. - experience of access and perceived ease of access to services. Access is a multi-step process with various decision-points. Some steps to access SLT may be easier/more challenging than others.
Influences on access	To identify the factors and processes that impact access to SLT. Questions aim to probe for possible influences on access to SLT. These include the participant's role, knowledge, expectations, perceptions and influence of others.
Evaluation	To give participants the opportunity to reflect on current services, including possible areas of tension or challenge. To probe for deeper reflections and insights to understand influences on access.
Strengths and opportunities	To identify what is currently working well and is valued in relation to access to SLT as well as ideas and areas for improvement. This provides opportunities to share positive aspects of access to SLT and service delivery so these may be recognised and ideas for further improvement identified.

3.11.3 Conduct of the interviews

With COVID-19 restrictions in place for most of the data collection period (Institute for Government Analysis, 2022), interviews were conducted remotely. 19 interviews were conducted via Microsoft (MS) Teams video call and the remaining four via a phone call recorded on MS Teams. Despite its increasingly common use (Ofcom, 2020) and preference for some (Weller, 2017), there were additional issues to consider for remote interviews, including ease of use of technology and the ability to establish rapport (Weller, 2017).

Interviews were carefully planned to minimise risk of distractions and interruptions, or of being overheard. The interviewer's camera was on for all video calls, and a neutral background was set for the call. Care was taken to ensure the researcher presented as calm, friendly and

professional to put participants at ease. All participants engaging in a videoed interview put their cameras on for the duration of the call, however this was not requested or expected of participants. Each interview started with a welcome, a recap of the purpose of the study and an overview of interview topics. The interviewer's role as a doctoral student and qualified SLT was explained along with their previous work as an SLT in one of the participating health Trusts.

Recorded verbal consent was gained for all interviews and securely stored electronically, separately from the interview recording (see Data Management Plan Appendix C.5). Demographic data was captured before starting a separate recording for the interview.

Participants were asked open questions about themselves and their role/child. This allowed them to start to share their stories (Rubin and Rubin, 1995) and supported a natural, conversational flow to the interview (Mathers, Fox and Hunn, 2000). The interview guide was used flexibly and participants often pre-empted questions, vindicating the relevance of the questions. Carefully observing and listening to participants throughout the interview supported an interview approach that met their needs. For example, some participants were keen to chat and would ask questions in conversation and appeared to value the time to connect and to share their stories. Some professionals appeared to value the time out to reflect on their practice, with one joining the meeting with tea and toast and looking ready to settle in to the interview. Another professional appeared under time pressure and so a slightly more direct and faster pace was used to match their communication style and needs.

Questions were asked in open, neutral and non-judgmental ways and wording tailored to the language needs and language used by participants. This included simplifying language, integrating brief examples and explanations, and inviting participants to let me know if they wanted me to repeat anything or explain what was meant. Participants were asked if they had further thoughts to share at the end of the interview so that issues important to them were not overlooked. Care was taken to transition gradually out of the interview through moving to general conversation. The purpose of this was to end the conversation on a positive note and demonstrate respect for participants and to recognise their unique contributions to the study. This part of the interview often included referring back to information the participant had shared earlier in the interview, e.g., one participant shared at the start of the interview that she would soon be retiring and so we returned to this topic in closing the interview.

A process map of access to SLT was constructed within the natural flow of the interview as participants described their service/experience. These were saved within interview field notes.

All interviews were completed as planned and no practice or safeguarding concerns identified. Field notes were completed immediately after each interview and reflections on the initial relevance of the interview as well as reflections on conduct of the interview to capture learning and minor adjustments for future interviews.

3.11.4 Support for participants

Immediately after the interview, participants were given information on support services tailored to their role (Appendix D.8). This was accompanied by a short message thanking them again for their time and contribution to the study.

3.12 Data analysis

The 23 interviews took between 23:56 and 59:18 minutes (mean interview time: 37 minutes), comprising a total of 14 hours, 7 minutes and 36 seconds of audio data. Up to date guidance for reflexive thematic analysis was followed (Braun and Clarke, 2021), supporting study credibility (Finlay, 2021; Yardley, 2000).

3.12.1 Preparing for analysis

Interviews were transcribed using an intelligent verbatim approach (McMullin, 2023), capturing spoken words and non-verbal aspects, such as laughing, to support authenticity (Lincoln and Guba, 1985), but removing some repetitions and fillers to support readability. Written English grammatical conventions were followed to present the interview in a way that was easy to process during analysis.

The researcher transcribed four interviews, and the remaining 19 were transcribed by a professional, University-approved transcription service to ensure a high-quality transcript. Although researcher transcription is an important aspect of familiarisation (Braun and Clarke, 2006), transcribing all interviews was not possible and would have delayed analysis. Once completed, audio recordings were revisited to ensure accuracy and support familiarisation Personal information that could directly or indirectly identify any individuals was removed.

NVivo (Lumivero, 2020) was used throughout analysis. This supported transparency and provided an audit trail during analysis. A two-day NVivo course was completed by the researcher followed by 1:1 coaching with Dr Christina Silver, Associate Professor, Director of Computer Assisted Qualitative Data Analysis Networking Project. This helped ensure the full

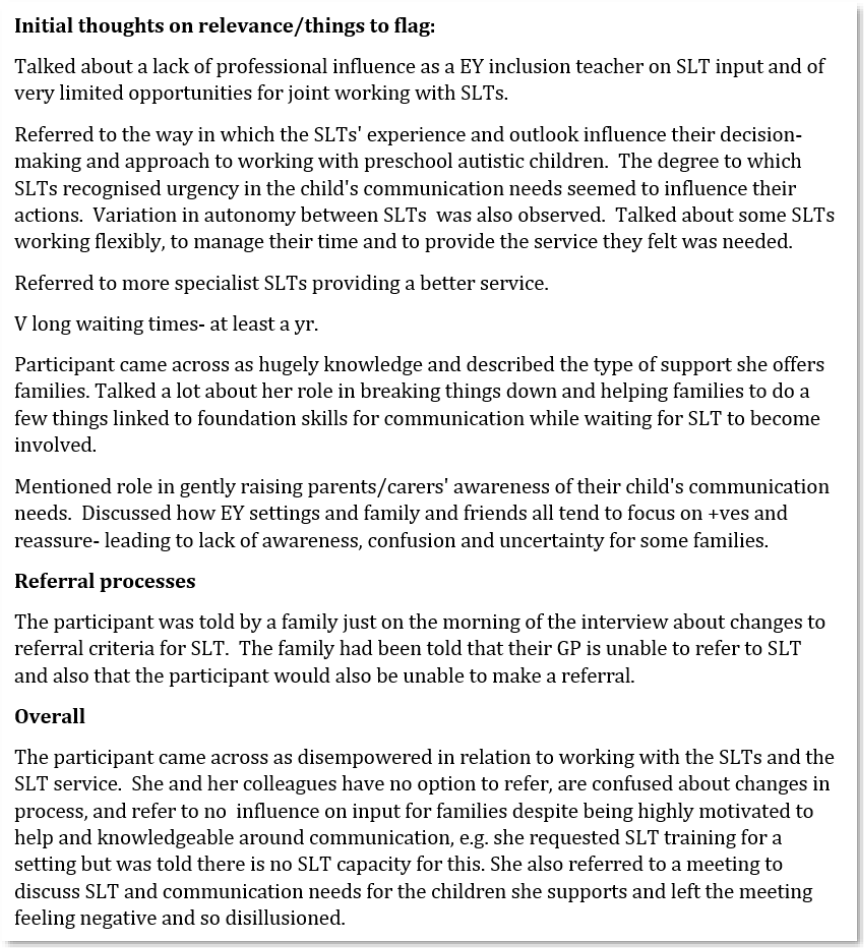
benefit of software to efficiently code, organise data and to perform queries and also supported flexible use of NVivo tools to inform analysis (Creswell and Poth, 2018). Reflexive TA followed six main phases. However, these were not all linear and took an iterative approach (Braun and Clarke, 2021).

3.12.2 Phase 1: Familiarisation with the data set.

This is a process of becoming familiar through immersion and critical engagement with the data (Braun and Clarke, 2021). Audio recordings and the interview transcripts were re-visited several times, along with field notes taken immediately after interviews. Field notes for each participant were saved within NVivo (Lumivero, 2020) memo files. Further reflections on what was interesting in the data were captured in the memo while re-reading transcripts. Storing transcripts and memos in NVivo facilitated smooth switching between transcripts and memos to capture ideas as they occurred, a recognised strength of CAQDAS (Saldana, 2016). Other ideas and reflections that were not specific to a single participant were captured in the research diary (in a Microsoft Word document).

The process of access, barriers, and facilitators to access, the ways in which decisions were made and the influences on these were considered during familiarisation. This supported familiarity with the interview as a whole before detailed analysis (Stake, 2005). Familiarisation was deepened throughout all phases of analysis (see Figure 5 for example of a memo).

Figure 5 Extract of memo for participant EY4



Initial thoughts on relevance/things to flag:

Talked about a lack of professional influence as a EY inclusion teacher on SLT input and of very limited opportunities for joint working with SLTs.

Referred to the way in which the SLTs' experience and outlook influence their decision-making and approach to working with preschool autistic children. The degree to which SLTs recognised urgency in the child's communication needs seemed to influence their actions. Variation in autonomy between SLTs was also observed. Talked about some SLTs working flexibly, to manage their time and to provide the service they felt was needed.

Referred to more specialist SLTs providing a better service.

V long waiting times- at least a yr.

Participant came across as hugely knowledge and described the type of support she offers families. Talked a lot about her role in breaking things down and helping families to do a few things linked to foundation skills for communication while waiting for SLT to become involved.

Mentioned role in gently raising parents/carers' awareness of their child's communication needs. Discussed how EY settings and family and friends all tend to focus on +ves and reassure- leading to lack of awareness, confusion and uncertainty for some families.

Referral processes

The participant was told by a family just on the morning of the interview about changes to referral criteria for SLT. The family had been told that their GP is unable to refer to SLT and also that the participant would also be unable to make a referral.

Overall

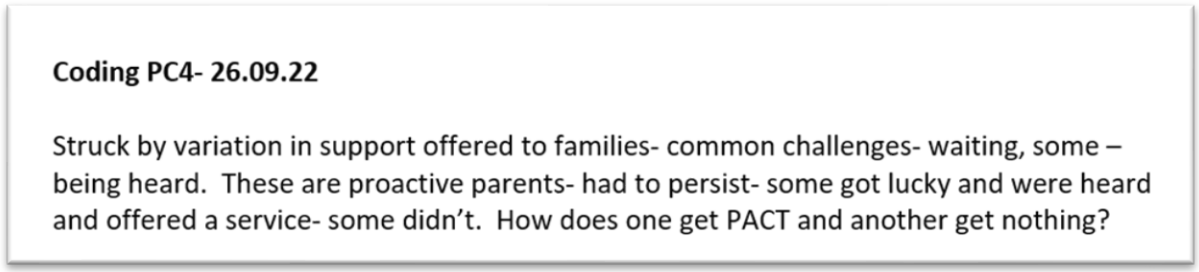
The participant came across as disempowered in relation to working with the SLTs and the SLT service. She and her colleagues have no option to refer, are confused about changes in process, and refer to no influence on input for families despite being highly motivated to help and knowledgeable around communication, e.g. she requested SLT training for a setting but was told there is no SLT capacity for this. She also referred to a meeting to discuss SLT and communication needs for the children she supports and left the meeting feeling negative and so disillusioned.

3.12.3 Phase 2: Coding

As recommended by Stake, coding commenced while data collection was ongoing (Stake, 1995). Coding involves assigning a short descriptive label to capture the meaning of an item. Transcripts were reviewed, line by line, and coded using an inductive, open coding approach. This aimed to ensure coding was not influenced by pre-existing frameworks or ideas and aimed to reduce the risk of overlooking important issues. (Saldana, 2016). Codes referred to behaviours, incidents, reactions, and emotions and were continuously refined during coding.

Reflections were captured in the research diary/participant's memo throughout coding (see example in Figure 6). A 'memorable quotes' code was also created to easily retrieve interesting quotes when writing up.

Figure 6 Reflection captured in a memo during coding of PC4 interview transcript.



The first coding cycle took an inclusive approach and generated 240 codes, due to "coding for as many potential themes/patterns as possible" (Braun and Clarke 2006, p18). Codes were captured in an NVivo hierarchy chart. This showed the codes applied and the number of coded references was reflected in the varying size of boxes (Appendix E.1). The codebook (codes and definitions) was shared with the supervision team for feedback and reflections.

The aim of the next phase of coding was to review and consolidate codes, carefully considering each code in relation to the research question. A new copy of the NVivo project file was saved so that the previous version could be revisited. Several NVivo tools were utilised to consolidate codes. Each code's link to the research question was carefully considered. The colour coding of codes showed the code's link to the research question:

- Green: a strong link
- Yellow: possible/less clear link
- Red: not linked (see redundant codes folder in Appendix E.2)
- Blue: relevant information on the research context

All red codes were moved to a 'redundant codes' folder in NVivo and blue codes were moved to a folder labelled 'research context'. The codes and all information assigned to them could be retrieved if needed.

The definition and contents of remaining codes were reviewed and considered in relation to the research question. Codes were merged, separated, and amended. NVivo static sets enabled similar codes to be grouped without changing the main coding structure. This supported detailed review without prematurely sorting codes into categories (see example of a static set in Appendix E.3). Codes grouped into static sets were exported as PDF files for review by the supervision team; for example, SW reviewed the static set of 'waiting for SLT' codes and contents and made suggestions relating to the precision of code definitions. Additionally, the supervision team reviewed three coded transcripts in full (SLT4, LMC1 and EY1). This gave a

different view on the data and increased awareness of alternative interpretations and perspectives on the data. Discussions ranged from when to develop a new code/apply existing code to discussions on definitions of access and how this influences coding.

This phase of refining codes aimed to ensure each code contained a single concept. More than one code could be applied to the interview text. Applying more than one code to a segment is common with CAQDAS coding, as one of its key strengths is the ability to flexibly explore multiple coding patterns. Cross-cutting perspective codes captured the emotion/perception of the participant; for example, 'satisfied', 'ineffective' were applied consistently. These perspective codes were then aggregated according to their influence on access (barrier or enabler) so that both higher-level and more detailed patterns could be observed in the data.

Coding followed a thorough and systematic approach. This supported deep immersion in the data and involved continuously moving between code contents (capturing all data assigned to the code) and interview transcripts to view data in the context of the full interview. Codes were reduced and refined from 240 to 73 codes, and 15 cross-cutting codes by the end of this phase. Code definitions became increasingly detailed and supported a consistent, transparent, and trustworthy approach to coding (Appendix E.6).

3.12.4 Phase 3: Generating initial themes.

Phase 3 aimed to generate initial themes through exploring patterns across the data (Braun and Clarke, 2021). A theme captures data that share a core organising concept or idea (Braun and Clarke, 2023). Confusion between codes, categories and themes is a common issue within weaker thematic analysis and can lead to underdeveloped analysis or too many themes or levels of themes (Finlay, 2021). Where categories are typically used earlier in analysis to group codes that share a particular feature, themes capture deeper patterns of meaning (Byrne, 2022).

Generating themes involved actively identifying relationships between codes to consider how they may contribute to a theme related to the research question. Codes were first grouped into two broad categories: parent/carer factors, and SLT service factors (Appendix E.4). The intersection between cross-cutting codes (Appendix E.5) and the main codes (Appendix E.4) was viewed. The ability to easily view and explore the intersection between two lists of codes is an advantage of CAQDAS (Saldana, 2016). Additionally, as each transcript was linked to a case (participant), with attributes (such as role) uploaded into an attribute table within NVivo it was possible to view the prominence of codes across the whole data set and for each participant group (who shared an attribute such as professional role). However, frequency did not

necessarily capture the most important patterns of meaning (Braun and Clarke, 2006). Frequency of codes was reviewed primarily during early stages of analysis to identify high-level patterns in the data (Sandelowski, 2001). Queries then led to areas for further exploration and were considered with reflections captured in the research diary and memo files (see Appendix E.7 for a sample of query results).

Generating themes was an active process that involved grouping codes that seemed to represent an important idea linked to the research question (Braun and Clarke, 2021). This facilitated a shift from more general and concrete ideas to abstract ones (Morse, 2015). At this stage, codes that appeared to share a core organising concept were clustered into static sets so that they may be easily viewed together. Five candidate themes were identified through an active process of exploration (Braun and Clarke, 2021) (Table 12). Codes that contributed to development of the candidate themes are presented in Appendix E.8.

Table 12 Candidate themes

Candidate themes and sub-themes	**Description**
Theme: "The *vision* I can buy into" Sub-themes: - A shared vision for support - Service delivery under pressure	Participants made several references to the vision and purpose of the service and queries identified this as both a facilitator and barrier for service delivery. The candidate theme was created with two linked sub-themes, the first related to the vision and the second related to the barriers to realising this vision.
Theme: Overwhelming effort to gain access.	This captured the work parents/carers needed to put in to gain access to SLT for their child.
Theme: A dire need, but not for us Sub-themes: - Balancing act - Nothing to offer	This captured the ways in which service pressures and SLTs' understanding of their role with autistic children impacts on SLT service decisions and the service received by children and their families.

Candidate themes and sub-themes	Description
	The first sub-theme related to the challenges in balancing the needs of all children (with different communication needs) and the second sub-theme captured the perceived absence of a service or unmet SLT needs.
Theme: Worth the effort	This theme captured views that SLT is worth the effort it takes to access the service. SLT is highly valued once access has been successfully achieved.

3.12.5 Phase 4: Developing and reviewing themes.

This phase started with a review of all study data. Interview transcripts, memos, research diary entries, and contents of the 'memorable quotes' code were read to determine the extent to which candidate themes captured important patterns of meaning in the data. At this stage, themes could be removed, combined or changed from a theme to a sub-theme (Braun and Clarke, 2012). As candidate themes and sub-themes were reviewed, attributes of good themes, and the following questions recommended by Braun and Clarke (2012) were considered:

- Is this a theme or a code?
- What does it tell me about the data and my research question?
- Is there enough data to support this theme?
- Is the data too diverse?

A description of changes made following this review is provided in the next section.

3.12.5.1 Candidate themes

Candidate theme 1: "The *vision* I can buy into".

This theme consisted of two sub-themes: 'a shared vision for support' and 'service delivery under pressure'. Following a draft write up of the candidate theme, feedback and discussion with the supervision team, and detailed review of data within each sub-theme, it was decided this theme would be split (Figure 7). Although for many participants, particularly SLTs, 'The *vision* I can buy into' captured their commitment to delivering the service, and frustration and challenges in realising the shared vision for support, both sub-themes also contained data that

did not reflect the overall theme. Splitting the theme would enable a greater depth of meaning and would more accurately capture the views of more participants. For the theme relating to the vision for SLT support, two competing views were identified, and the following theme was generated:

Theme 1: Competing visions for communication support

Themes should not contain any contradictory ideas, unless the theme itself is about contradiction (Braun and Clarke, 2021). A thorough review of codes and their contents relating to the vision for communication support identified competing visions. These were reflected in various ways in interviews and suggested tension between a social vs. medical model view of SLT support. Several participants reflected on how these different visions for communication support was a source of confusion, frustration and disappointment.

Theme 2: Barriers to service delivery was generated as a main theme to capture all challenges impacting on service delivery.

Candidate theme 2: Overwhelming effort to gain access.

A considerable amount of data had been coded within this theme. This theme was selected as the first theme to write up with the aim of gaining greater analytical insights through the writing process (Bazeley, 2013; Braun and Clarke, 2020). Writing up the theme supported analysis and in-depth discussion with the supervision team. As a result of this, a revised theme was generated from the same codes as the candidate theme, but split into two sub-themes:

Theme 3: Gaining access: “a bit of a hurdle at every stage”

3a) Parents and carers’ practical and emotional readiness for the work

3b) “So, who’s helping me?” Inaction and unresponsiveness of professionals on the journey to SLT.

‘Readiness for the work’ was felt to more accurately capture the meaning and emotion reflected in interviews rather than effort to gain access. The second sub-theme was developed to work alongside ‘readiness for the work’. This sub-theme consisted of codes related to the inaction and unresponsiveness of professionals on the journey to SLT. The addition of this sub-theme enabled the different roles that the parent and the professional play in facilitating or hindering access to SLT to emerge.

Candidate theme 3: A dire need, but not for us

This candidate theme captured the ways in which service pressures and the ways in which SLT support for autistic children is viewed and impacts on service delivery. It consisted of two sub-themes:

- Nothing to offer
- A balancing act

The first sub-theme captured gaps in service and unmet SLT needs from different stakeholder perspectives. The second sub-theme captured challenges balancing the support needs of all children seeking SLT.

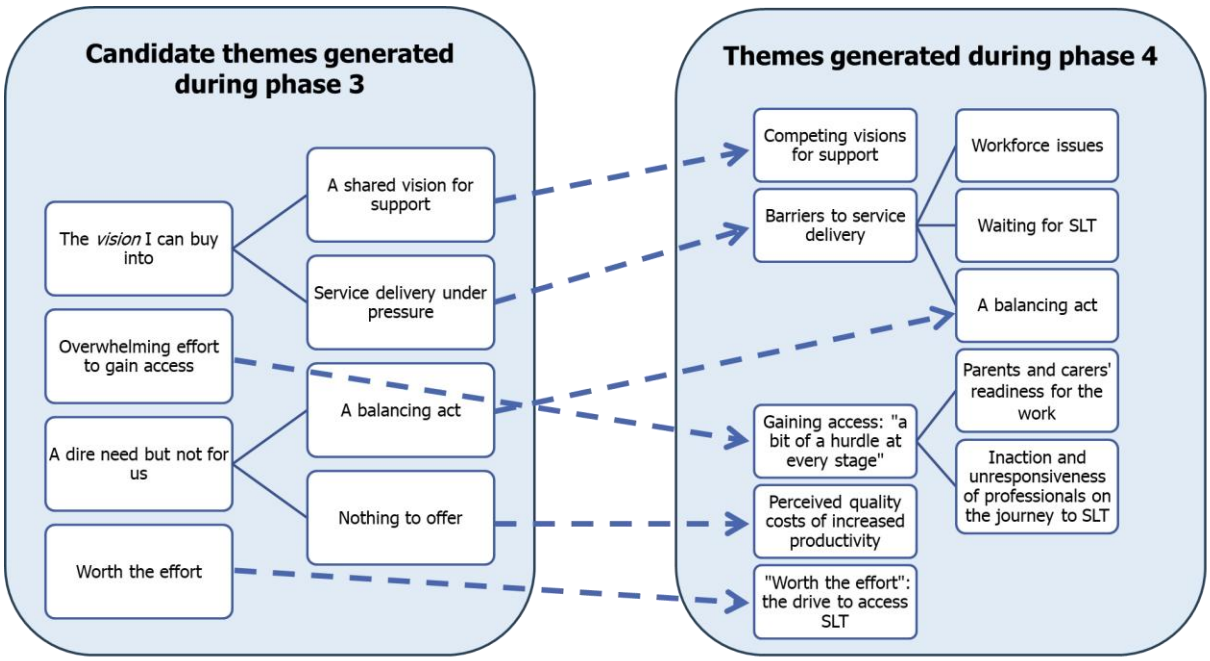
A detailed review of this theme, the sub-themes, codes and coded references concluded that the theme was too broad and complex. 'A balancing act' was renamed as sub-theme 2c: "Not our main priority": clinical decision-making and prioritisation and moved to the newly formed theme 2: Barriers to service delivery. The sub-theme 'nothing to offer' was changed to a main theme and renamed, theme 4: The quality costs of productivity.

Candidate theme 4: Worth the effort.

This candidate theme captured views that SLT is worth the effort it takes to access the service. The theme reflected the numerous positive perceptions and experiences of SLT that appeared to drive parents to seek and persist in seeking access to SLT for their child. There was a good degree of internal consistency in this theme and a close link to the research question, with a clear recurring pattern in the data.

Figure 7 summarises theme development during Phase 4.

Figure 7 Theme development



A new NVivo project file was saved, so that the process followed in theme development could be captured, preserving an audit trail. Within the new file, codes were moved into the final coding structure for the themes and sub-themes. Code names and definitions were refined and some data re-coded to ensure codes meaningfully reflected the data. Some codes had contributed to more than one theme, for example with a barrier code applied within one theme, and with an enabling code within another. These codes were split and renamed to capture the meaning of both the main code and the cross-cutting code in the code name.

3.12.6 Phase 5: Refining, defining and naming themes.

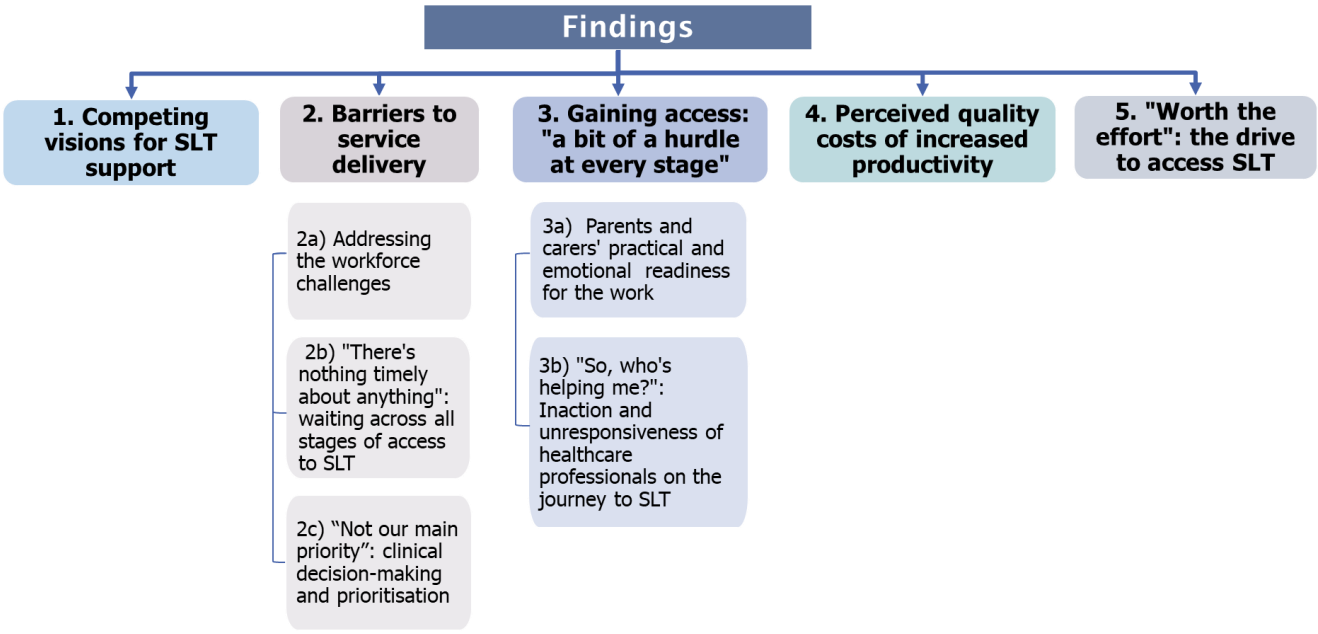
Naming a theme is an important part of reflexive thematic analysis (Braun and Clarke, 2021). Names need to be concise, informative and memorable (Braun and Clarke, 2021). Braun and Clarke (2021) encourage creativity and the use of participants' words in theme names. Two of the final five themes included participants' original words and two out of five sub-themes (Table 13). Final themes and sub-themes and the codes contributing to these may be found in Appendix E.9. Table 13 presents the definitions of the final themes and themes are presented visually in Figure 8.

Table 13 Final theme definitions

Theme/sub-theme	Definition
Theme 1: Competing visions for SLT support	This theme captures the conflicting visions for communication support for autistic children communication development. This is a contradictory theme (Braun and Clarke, 2020) that captures differing expectations for the SLT service: medical model vs social model of support and the tension and frustrations generated through these differing views.
Theme 2: Barriers to service delivery Sub- themes: • 2a Addressing the workforce challenges • 2b "There's nothing timely about anything": waiting across all stages of access to SLT • 2c "Not our main priority": clinical decision-making and prioritisation	This theme captures the service challenges impacting access to SLT service for children and their families when the service is under significant pressure, under-resourced and when demand outstrips capacity.
Theme 3: Gaining access: "a bit of a hurdle at every stage" Sub-themes: • 3a Parents and carers' identification of concerns and practical and emotional readiness for the work • 3b "So, who's helping me?" Inaction and unresponsiveness of professionals on the journey to SLT	This theme captures the knowledge, skills, emotional and practical resources and effort parents/carers need to use to gain access to SLT, often to overcome the unresponsiveness/inaction of professional gatekeepers to SLT services.

Theme 4: Perceived quality costs of increased productivity	This theme captures the inconsistent quality of care and accessibility issues within SLT because of efforts to increase service productivity.
Theme 5: “Worth the effort” The drive to access SLT	This theme captures participants’ views that SLT is worth the effort it takes to access the service. Once successfully accessed, person-centred, tailored care is provided to meet the child and their family's needs.

Figure 8 Final themes



3.12.7 Phase 6: Writing up.

The reflexive TA report is presented in section 4.4. Each theme reflects core patterns of meaning from the contributions of several participants. Descriptive language such as ‘few’, ‘many’ ‘most’ or ‘all’ was used rather than numbers to provide information on the strength and consistency of a theme (Braun and Clarke, 2022). Contextualising information was provided alongside participant quotes. Features of spoken language such as repetitions, hesitations and digressions were removed for quotes presented in the report to support readability (Davidson, 2009).

3.12.8 Summary of reflexivity on the process of analysis

Data collection and analysis was a long and challenging but rewarding process.

Data collection: I thoroughly enjoyed meeting people with different experiences. I was struck by the huge commitment made by participants to be part of the study. They often sacrificed their time, called on friends and family members to support with their children, used their child's nap time to meet with me and often worked late or in their work administration time to talk to me. I was able to collect high quality, in-depth data as planned and was pleased with the conversational style established in the interviews whilst still following the semi-structured interview guide. The interviews were often long and intense. I was fascinated by the stories shared and gathered rich data, but found the intense focus required for interviews tiring. I decided early on in the study that I would interview no more than two people in one day and this was usually no more than one. This, along with careful reflection on each interview enabled me to learn from each experience and give my full attention to each participant.

Data analysis: The main challenge was capturing patterns of meaning across the whole data set without reducing this to topic summaries with limited analytical depth. The transition from codes to broader patterns of meaning was supported by the multiple and flexible ways the data could be explored within NVivo and the detailed memos, research diary entries, and notes tables created during theme development. Writing up draft theme descriptions supported further insights. Analysis required considerable detailed work and a high-level of organisation. A structured, well-documented approach to reflexive TA along with QADAS and expert coaching on the use of NVivo was helpful as a novice researcher alongside academic supervision. A twenty-item tool developed by Braun and Clarke (2020) to support assessment of quality of reflexive thematic analysis was completed as a self-assessment to support reflection (Appendix E.10).

Chapter 4 Findings

4.1 Introduction to the chapter

This chapter presents the findings of the study. The first section presents information on the study participants. The second describes the healthcare context of SLT services within the bounded system of the case study and a description of the process of access to SLT within the bounded system. Finally, the reflexive thematic analysis report of the themes and sub-themes generated through reflexive thematic analysis is presented. Together, these sections provide a rich description of the context and study findings and aim to enable readers to determine the relevance of findings to their own settings.

4.2 Participants

4.2.1 Participant identifier and demographic information

Participants' demographic information was collected during the interview. The amount and type of demographic information collected from participants was considered carefully, with the aim of capturing sufficient data on participants to set the research findings in context, whilst ensuring only information directly relevant to the study was collected. The demographic data reported in studies included in the scoping review (Chapter Two) influenced the data gathered. The information gathered was tailored to each participant group, and GDPR principles (GDPR, 2018) relating to collecting only information that is relevant and necessary for the purpose of the study were followed. All participants were assigned a unique participant identifier related to their role and then a number indicating the sequence they were interviewed:

- Parents/carers: PC[1-6]
- Speech and Language Therapists: SLT[1-6]
- Leads, managers or commissioners: LMC[1-5]
- Early years staff: EY[1-6]

Demographic data for all participants are shared in tables Table 14 and Table 15 along with the participant identifier.

4.2.2 Parents and carers

All participants in the parents/carer's group were female mothers to children with either a confirmed or suspected diagnosis of autism. Four participants were married and two were in non-registered partnerships. Four mothers were White British, two had a Pakistani background and one had a South Korean background. Three mothers were employed as Early Years (EY) practitioners (one was on maternity leave at the time of the interview) one was self-employed, and the remaining two were not in employment. Parents who were also EY professionals had training in child development and experiences of working with health professionals in their professional roles which may have impacted on their experiences of access to SLT. This may have impacted on the study in several ways, including how these parents' experiences of access to SLT may have differed from the experiences of others' parents not in EY roles, the parents' ability to engage in discussion on the topic, and the parents' depth of insight as a result of their dual perspective as both parents and EY professionals.

The mothers talked about their experiences of access to SLT for their children. One parent had two preschool autistic sons, but primarily talked about her experiences with her eldest son. Information on a total of seven children was therefore captured. Five children had received a confirmed diagnosis of autism, one was waiting for diagnostic assessment, and one was under review with suspected autism. At the time of interview, three of the children were aged four years, three were aged three years and one was aged seven years. Three were female and four were male. All mothers were asked to share information about their child at the beginning of the interview and they talked about their child's likes, dislikes, strengths and challenges. This helped to set the scene for the discussion and helped keep the child as an individual in mind during interview.

All parents reported challenges accessing SLT, particularly around waiting times for the service. Four mothers shared predominantly positive experiences of SLT once accessed (PC2, PC3, PC5, PC6). One parent reported not being offered support for her child (PC4) and one reported dissatisfaction with the service received (PC1). The demographic information for parents is presented in Table 14.

Table 14 Parent/carer participants' demographic information

Participant ID	Site	Gender	Relationship to the child	Age-group	Employment status	Marital status	Ethnicity	Religion	Languages spoken at home	Child's gender, age, and diagnosis at the time of interview
PC1	A	Female	Mother	45-49	Self-employed	Married	South Korean	No religion	English	Female, 7 years, autism.
PC2	A	Female	Mother	30-34	Not in employment	Married	Pakistani	Islam	English and Urdu	Female, 4 years, autism.
PC3	A	Female	Mother	35-39	Not in employment	Non-registered partnership	White British	No religion	English	Siblings: 3 and 4 years, both male, both diagnosed: autism, non-verbal, complex sensory processing disorder.
PC4	A	Female	Mother	25-29	On maternity leave (EY practitioner)	Non-registered partnership	White English	Christian	English	Male, 4 years, diagnosed with autism and global developmental delay.
PC5	A	Female	Mother	35-39	Employed (EY practitioner 4 days a week)	Married	Pakistani	Islam	English and Punjabi	Female, 3 years, waiting for autism assessment.
PC6	B	Female	Mother	25-29	Employed (EY practitioner)	Married	White British	No religion	English	Male, 3 years, suspected autism.

4.2.3 Speech and Language Therapists

Six SLTs were interviewed. All SLTs were asked whether they identified as a specialist SLT in autism. Only one SLT (SLT4) self-identified as a specialist in autism. She worked in a specialist role with children with complex needs. The remaining five SLTs worked with preschool aged children with a wide range of speech, language, and communication needs, including children with confirmed and suspected autism. All SLTs were female, and none voluntarily shared a personal connection to autism. The SLTs had different clinical experiences and had been qualified for between 6 months and 23 years (mean = 17 years, median = 14 years).

4.2.4 Early Years staff

Individuals from a diverse range of roles who offer support to preschool children and their families were recruited, including a specialist public health nurse, family worker, early years inclusion teacher, and hearing and balance specialist. Participants reported being involved with supporting children and their families across all stages of access to SLT, including before referral/request for SLT input. Two participants shared a personal connection to autism, and both had autistic children. They participated in the study to share their experiences in their professional roles rather than as parents. They both described how their experiences with their own children provided greater insight into their work with autistic children and their families.

4.2.5 Leads, managers and commissioners of SLT services

Two participants were in commissioning roles, one was a manager for a children's complex care service and two were operational leads for SLT and worked clinically as SLTs.

The demographic information for participants from all professional groups is presented in Table 15. Job titles were captured; however, these are not shared in the table to reduce the possibility of participants being identified.

Table 15 Professional participants' demographic information

Participant ID	Site	Gender	Role	SLT years qualified
SLT 1	B	Female	Speech and Language Therapist	10 years
SLT 2	A	Female	Speech and Language Therapist	18 years
SLT 3	B	Female	Speech and Language Therapist	6 months
SLT 4	A	Female	Speech and Language Therapist	20 years
SLT 5	A	Female	Speech and Language Therapist	2 years
SLT 6	A	Female	Speech and Language Therapist	23 years
EY 1	A	Female	EY professional	N/A
EY 2	A	Female	EY professional	N/A
EY 3	A	Female	EY professional	N/A
EY 4	A	Female	EY professional	N/A

Participant ID	Site	Gender	Role	SLT years qualified
EY 5	A	Female	EY professional	N/A
EY 6	A	Female	EY professional	N/A
LMC 1	B	Female	Lead, manager or commissioner	N/A
LMC 2	B	Male	Lead, manager or commissioner	N/A
LMC 3	A	Female	Lead, manager or commissioner	N/A
LMC 4	A	Female	Lead, manager or commissioner	N/A
LMC 5	A	Female	Lead, manager or commissioner	N/A

4.3 The pathway for access to SLT in the research setting

4.3.1 Understanding local processes for access to SLT

A process is defined as a series of connected steps or actions to achieve an outcome (Institute for Innovation and Improvement, 2005). Participants were asked to describe the process of access to SLT from their knowledge and perspective. Participants' knowledge, roles, and experiences in relation to access to SLT influenced the depth, detail and stages of access shared in their description.

Participant descriptions of access to SLT enabled a high-level process map to be constructed for access to SLT within both health Trusts (Figure 9 and Figure 10). These provide an overview of service processes, decision points and intervention options in the research setting from the perspectives of several participants. Although some participants expressed confusion and referenced gaps in knowledge, there were no areas of contradiction identified between participants. Almost all participants referred to long waiting times for SLT. Where waiting times were shared, these were captured on the process maps for access to SLT (Figure 9 and Figure 10) and provide a snapshot of delays to first appointments as well as information on bottlenecks and further delays.

4.3.2 Local and national guidelines relevant to access to SLT

Policies, position statements and guidelines relevant to access to SLT for preschool autistic children were identified through searching the RCSLT webpages for members and NICE guidance webpages. RCSLT autism clinical guidelines (Royal College of Speech and Language Therapists, 2023a), RCSLT assessment guidance (Royal College of Speech and Language Therapists, n.d.) and a position statement on caseload management (Royal College of Speech and Language Therapists, 2022) were identified as relevant. These were considered alongside 'NICE guidance: autism: the management and support of children and young people on the autism spectrum' (NICE, 2013) and an RCLST position statement on supporting children's access to, and engagement with SLT (Royal College of Speech and Language Therapists, 2021b).

The main stages of access to SLT in the research setting will now be described and discussed alongside professional and clinical guidelines relevant to each step in the process.

Figure 9 Typical process of access to SLT: site A

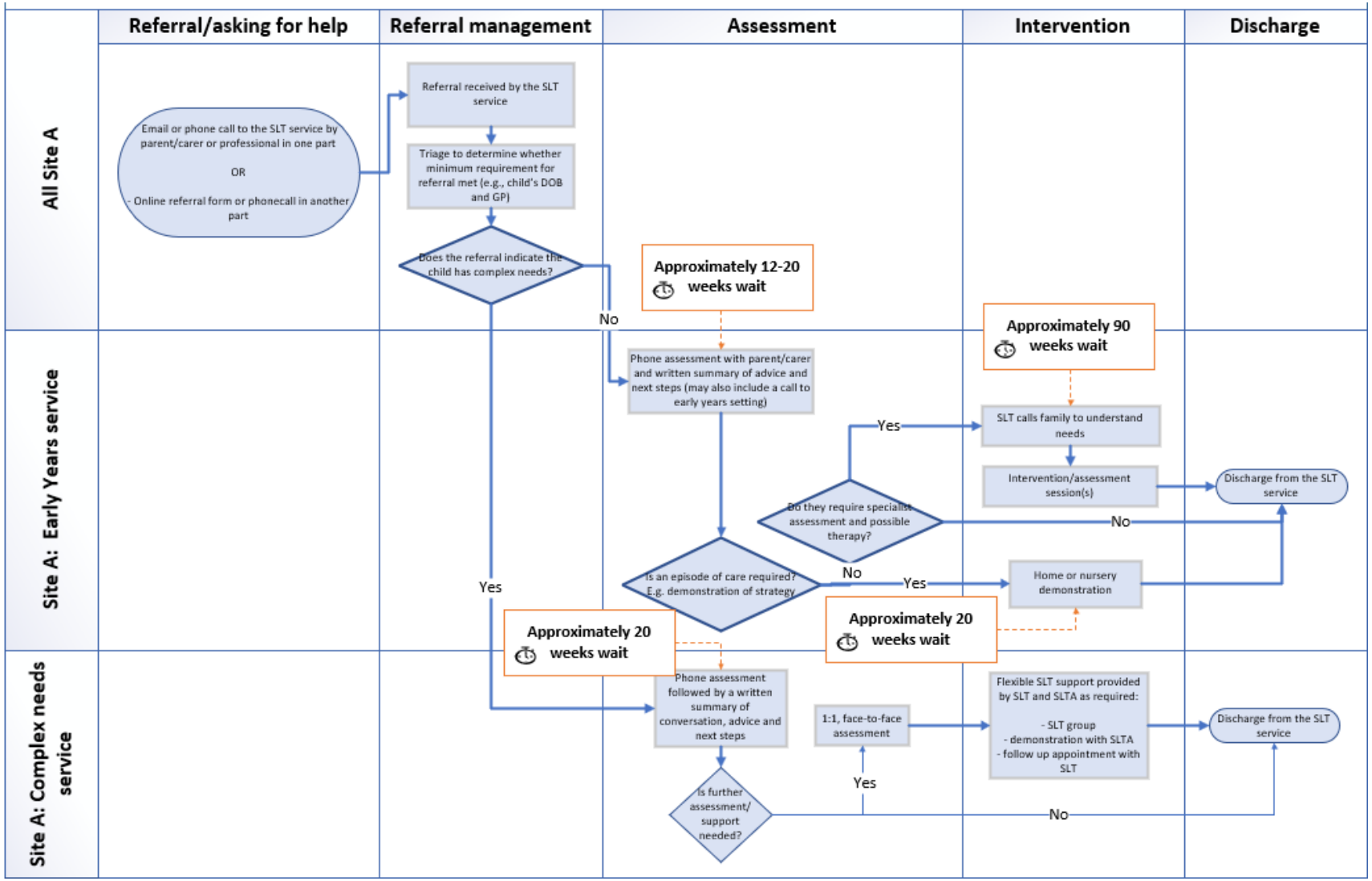
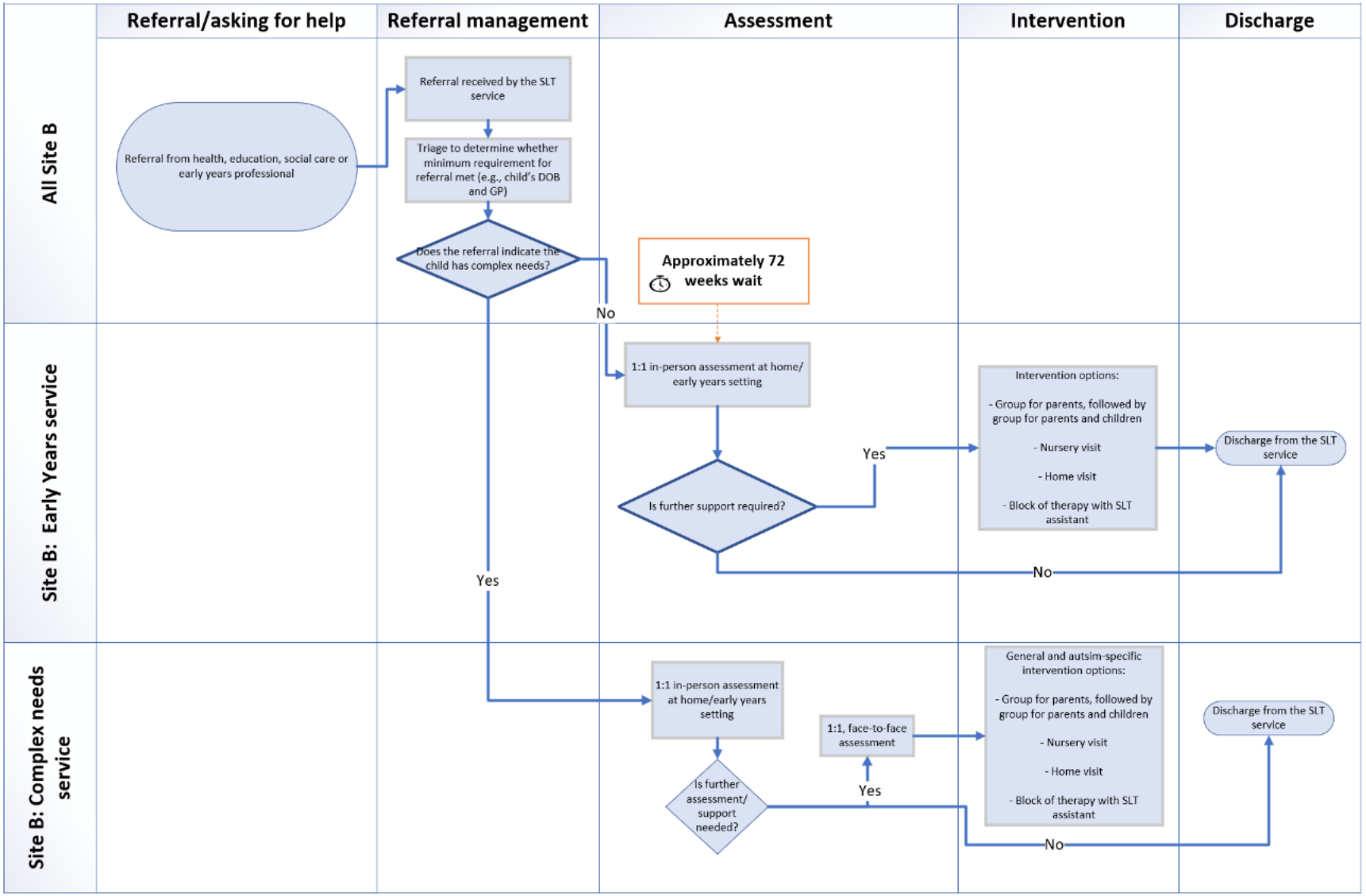


Figure 10 Typical process of access to SLT: site B



4.3.3 Referral

Both site A and site B SLT services operated an open referral process until shortly before data collection commenced, meaning that any person could make a referral on behalf of a child and their family, or the parent/carer could request help directly. At the time of data collection, site B (Figure 10) had recently changed their criteria for referral and required a professional to complete a referral form to gain access to the service and parents were no longer able to request support directly.

A professional referral was not required in site A (Figure 9). In one part of the site, SLT could be requested via a phone call or email to the SLT service, and in another part of the site, a referral form needed to be completed (by any person). Although these were the primary routes to SLT, there was also the option across the whole of site A to request SLT help directly by calling the service.

Some participants expressed confusion about the process of access to SLT, with some EY professionals perceiving that they and others, such as General Practitioners (GPs), were unable to refer a child to SLT. They believed the referral needed to be completed through another route, such as asking parents to make contact with the SLT service directly. SLTs in the service, however, stated that although a referral from a parent or carer was *preferred*, any person could refer a child. Both services operated a single point of referral in line with good practice for SLT referral practice (Royal College of Speech and Language Therapists, 2019). Where a referral form was required, this was a multi-agency referral form and another area of recognised good practice (Royal College of Speech and Language Therapists, 2019).

4.3.4 Referral management

Both sites described an initial triage of referrals to determine the appropriateness of the referral and to identify the specific SLT service that may best meet the child's needs. Referrals for both sites were triaged by an experienced SLT, employed at Agenda for Change pay Band 6 as a minimum (NHS Employers, 2022).

Accepted referrals were reviewed and then directed to either the Early Years SLT service for speech, language, and communication support or to the service for children with more complex needs if there was evidence of significant developmental delays or disorders typically impacting on the child's development in at least two areas of development. Across the whole research setting, autistic children could access both types of services, depending on the extent of their support needs and presence of any co-occurring difficulties. No service required a diagnosis of

autism to access an assessment, and all children were offered a service based on their clinical need rather than on a specific diagnosis, in line with good practice guidelines (Royal College of Speech and Language Therapists, 2019).

Services in both sites described a person-centred process for understanding the specific needs of the child and their family. This is a key part of determining the SLT needs and the ways in which these needs may best be met; one of the key considerations for promoting access to SLT (Royal College of Speech and Language Therapists, 2021b).

4.3.5 Assessment

The purpose of an SLT assessment is to understand the child's needs, skills and goals (Royal College of Speech and Language Therapists, n.d.). Assessment should involve those who know the child well and may include formal standardised assessment tools as well as informal means to gather information (Royal College of Speech and Language Therapists, n.d.). An assessment helps determine the appropriateness of the referral and considers whether referrals to other professionals are needed (Royal College of Speech and Language Therapists, n.d.).

Following triage, the service in site A completed an assessment over the phone with the child's parent/carer. If the SLT felt they had sufficient information from the phone call to understand the child's needs and determine the most appropriate next steps, they would provide verbal advice (also sent via email/post) and discharge the child from the SLT service. Alternatively, they may offer a face-to-face appointment with the child for direct assessment or offer a face-to-face demonstration session to provide further information on strategies to use with the child. Following these appointments, the child may be discharged from the SLT service or added to a waiting list for intervention. Within site B, following triage, the child was assessed face to face with their parent or carer before deciding on next steps, which may include ongoing assessment in another setting such as the child's nursery, discharge or intervention, usually with the same SLT.

The degree of flexibility for assessment of children's needs seemed to differ between the services in site A and site B. Less flexibility was described within site A and phone assessments were described as the first step of access and main approach to assessment. The Royal College of Speech and Language Therapists (2021b) emphasizes the importance of avoiding a 'one size fits all' approach to access and guidance for assessment of the communication needs for autistic children (Royal College of Speech and Language Therapists, 2023a) and emphasizes the need for a holistic assessment of the child's needs and consideration of information from a variety of sources such as observation, informal and standardised assessment, and information from key individuals on the impact of difficulties, the nature of the communication environment

and their support network. Further face-to-face assessment was reported to be an option; however, the ways in which autistic children's needs were perceived suggested this may be less likely to be offered to autistic children (see theme two, sub-theme 2c, section 4.4.2.3) and, therefore, that they may be less likely to receive a holistic assessment of needs as described in the RCSLT guideline for Autism (Royal College of Speech and Language Therapists, 2023a). Prioritising one group over another based on features such as age or diagnosis is not supported due to the wide continuum of need and different timings of intervention required (Royal College of Speech and Language Therapists, 2019).

4.3.6 Intervention

SLT-led groups for parents and carers (which may or may not include the child directly) were offered to families where referral suggested this may meet their needs in both site A and site B. This could be offered in addition to, or in place of, 1:1 assessment or therapy input. The groups available varied and some groups aiming to meet the needs of children with language and social communication difficulties associated with autism were described as not consistently available due to insufficient resources.

RCSLT guidelines state that following assessment, decisions on intervention should be informed by the needs of the child and their carers (Royal College of Speech and Language Therapists, 2023a) and by the best available evidence and the clinical judgement of the SLT (Royal College of Speech and Language Therapists, 2018; 2023a), with the RCSLT guidance on caseload management specifying that decisions should be based on the assessed needs of the child and not on the availability of resources (Royal College of Speech and Language Therapists, 2018). The study focused on access to SLT rather than in detail on the intervention provided. However, participant descriptions suggested variation in the type and amount of intervention input provided for autistic children. This variation appeared to be related to SLT service configuration, decision-making and prioritisation, as well as the available resources.

NICE (2013) recommends developmental, play-based, and naturalistic social-communication interventions. These should be delivered by trained professionals who then train families to support the child's attention, engagement and reciprocal communication. Therapist modelling of strategies and video-interaction feedback for parents/carers are specified as key features of the intervention.

Several participants described service decisions and offers of support based on available resources rather than their perception of the child's clinical need (see theme four, section 4.4.4). Where decisions on SLT interventions are influenced by resources, services should be honest with children's families (Royal College of Speech and Language Therapists, 2022).

Services should also consider the impact of providing services that are not supported by the evidence on service resources. Limited progress related to lack of individualisation could lead to disengagement of families and other key stakeholders related to children's communication development (Royal College of Speech and Language Therapists, 2022). Whilst SLTs, leads and managers participating in the study described the impact of demand outstripping capacity and the resulting impact on the effectiveness of the SLT service they were able to offer, the degree to which this was discussed with families was less clear.

4.4 Reflexive thematic analysis report

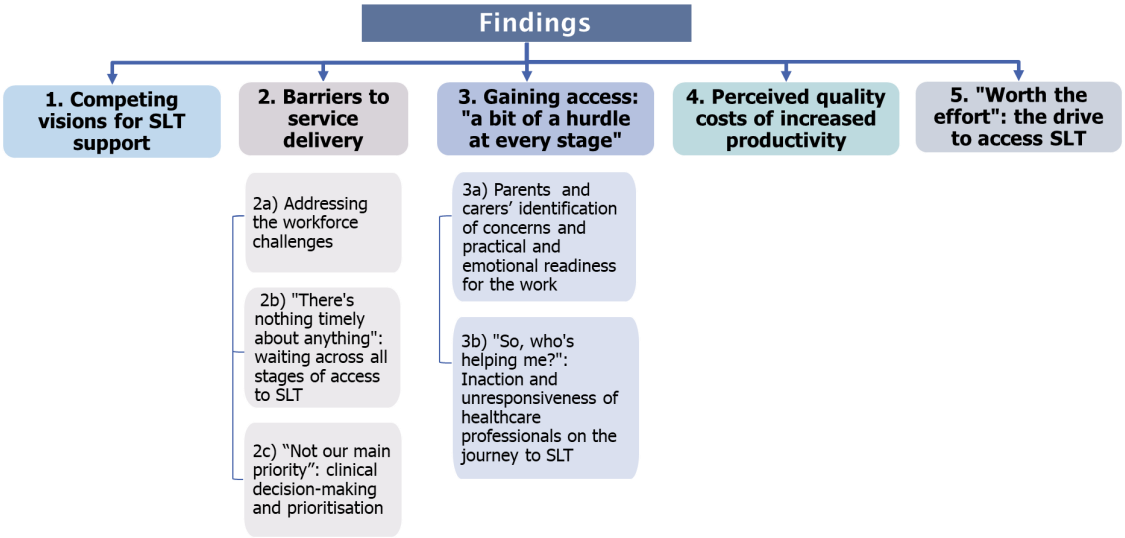
The themes and sub-themes generated through reflexive thematic analysis are described in this section, along with participant quotes to illustrate the patterns of meaning identified across the data set. The meaning and implications of these themes and sub-themes will be explored in relation to existing research findings, theory and clinical practice in Chapter 5.

Analysis has sought to identify important patterns of meaning across the entire dataset to answer the following research question:

What factors and processes impact on access to SLT for preschool autistic children from the perspective of key stakeholders?

Five main themes were generated through inductive, reflexive thematic analysis of the entire dataset, with two of these themes consisting of sub-themes (Figure 11).

Figure 11 Themes and sub-themes



The themes are presented in the following sequence:

1) Competing visions for SLT support
2) Barriers to service delivery
    a) Addressing the workforce challenges
    b) "There's nothing timely about anything": waiting across all stages of access to SLT
    c) “Not our main priority” clinical decision-making and prioritisation
3) Gaining access: "a bit of a hurdle at every stage"
    a) Parents and carers’ identification of concerns and practical and emotional readiness for the work
    b) "So, who's helping me?": Inaction and unresponsiveness of healthcare professionals on the journey to SLT
4) Perceived quality costs of increased productivity
5) Worth the effort: the drive to access SLT

4.4.1 Theme 1: Competing visions for SLT support

There were competing visions for the SLT service. One vision of SLT highlighted the significance of parent/carer-mediated approaches and the other emphasised the importance on direct interaction between the SLT and the child. These differences led to differing/unmet expectations and frustrations. Almost all participants contributed to this theme across all participant groups.

The vision shared by several SLT service participants was for an SLT service that would empower those closest to autistic children with the knowledge, skills, and confidence to support children’s communication development. This developmental, naturalistic approach to communication support takes an indirect, parent-mediated approach. As an operational lead for a complex care SLT service LMC4 states, this vision is underpinned by both the perceived benefits to the child and the perceived limitations of direct input for the child:

> “[I] view my role as trying to support parents and carers to understand the things that they can do to give their child the best chance of developing their communication [...]. Me and a child, that dyad- I don't think that's the best way of supporting a child. You need the strategies to go in all the time and effectively delivered all the time.” LMC4

This view was echoed by a commissioning lead, LMC1 who emphasised the role of early years settings to work alongside parents to support communication:

> “Early Years settings are really key because they're the ones who are spending time with children observing their development, and they usually would be the ones who can identify difficulties early on.” LMC1

Although efficient use of SLT resources was acknowledged as a benefit of enabling others to support communication, it was presented as the right thing to do regardless of whether there were pressures on SLT services. Belief in this way of working appeared to be shared within SLT teams:

> "I think everybody in the service understands the concept that, unless people are doing stuff around communication consistently across the week, it's not going to make a difference [..] that core belief is a strength." LMC4

This contrasts with the expectations of others, such as paediatricians, who were reported to make recommendations for high-intensity SLT that should take place directly between the child and the SLT. These differing perspectives created challenges:

> "We're increasingly finding that somebody like a paediatrician might write, "Child needs intensive speech and language therapy," and that's really difficult. [...]. We're saying [to parents], "We don't have that magic wand. You know your child the best. I'm going to try and help you." They're sometimes suspicious, "Is this due to service cuts? Is this COVID?" "Actually, no, it's thinking about what is best for your child."" SLT2

The view of the professional as the expert appeared to influence some parents' expectations of SLT, and undermined their confidence to engage in parent-mediated interventions:

> "It's an expectation of themselves really that they won't be good enough to do it, and I guess that then feeds into the professional being the expert". SLT5

Several SLTs talked of the importance of trying to manage expectations and support families during early interactions with the SLT service. SLT6 talked of struggles to come to a shared understanding on the way forward due to differing perspectives on the parent role and benefits of parent-mediated communication support:

> "Sometimes they feel, "No, I don't have the answers, you have the answers," so the conversation does go around, "I know I'm the parent but you're the therapist," therefore they feel, "Why aren't you doing it? Why are you expecting me to do it?" So, you know, there is an element where they feel that their role isn't as important as I feel it is. I think they're the most important." SLT6

The challenge of achieving a shared understanding of the way forward for SLT support was echoed by other SLTs:

> "I had a family saying to me, "We are high-rate taxpayers, you are going to see my child every week, and you're going to do this.." [...] managing the expectations - that's what takes the most energy and time, but there is a real benefit to doing it." SLT2

A mismatch in expectations and visions for the SLT service appeared to impact on access to communication support while waiting as well as during interactions with the SLT service once seen. SLTs expressed concerns that expectations of a medical model approach to support and the view of SLT as 'expert' delayed access to communication support:

> "No-one was doing anything because they're thinking, we're waiting for speech and language therapy as if we have some magic wand - which of course we don't." SLT4

It was suggested that long waiting times may also contribute to parental expectations and build frustrations with the SLT service while waiting:

> "We're giving them a session and demonstration and then leaving them to it and letting them implement it in the child's everyday life [...] but parents' expectation is, "Oh, we've waited, and I want to see a therapist now."" SLT5

Although SLT service participants felt that empowering those close to a child was the best approach to communication support, some expressed concerns around the effectiveness of the SLT support they were able to provide. Resource constraints meant they were not able to provide parents with the frequency and intensity of support needed:

> "I think we're having difficulty getting that done effectively. [...] I am not sure that, however much you explain it to people and show them [...] it translates into people effectively delivering those strategies always." LMC4

The doubts and reservations expressed by some EY and SLT staff echo and support the view that the strong practical foundations as well as the mindset and shared principles that need to be present to support the vision for this way of working are not yet consistently in place:

> "You have to rely on the pre-school staff to put that intervention in place and to sustain it. They're not trained for it. They're trained for their role, but they're not trained for all the additional needs as well as running a pre-school." EY2

The experience of working to deliver the service vision was presented as challenging by some participants. The importance of effective, long-term investment to support this model of service delivery was raised by LMC2, a manager of children's services, when discussing gaining approval for a business case from the Integrated Care Board (ICB):

> "This is a process that's been going on for a long time. A year ago, we presented a model. We were told to go away and do some further work. A year later we presented a similar model but with different finance implications and it seemed like we weren't making progress. There's difficulty finding the level of investment that's needed, because it's significant. If we don't get the investment that we need [...] that will have serious consequences on the number of children we can support and will only worsen the access issues that families have." LMC2

This theme has captured the conflicting vision and expectations of the SLT service for preschool autistic children and their families. Although SLT service participants agreed on the value of developmental, naturalistic parent-mediated approaches, this was not shared by all parents and stakeholders. This led to different expectations and frustration with the SLT service. Expectations of a medical model service and view of professional as expert also impacted on parental confidence in therapy. A complicating factor appeared to be the inadequate resources participants reported to effectively support and empower families to support children's communication development. This appeared to reduce confidence in parent-mediated, developmental naturalistic, communication support as the frequency and intensity of support did not meet their needs.

4.4.2 Theme 2: Barriers to service delivery

This theme captures the service challenges impacting on access to SLT for children and their families.

4.4.2.1 Sub-theme 2a: Addressing the workforce challenges

An important issue for most participant groups was how the recruitment and retention challenges impacted the development of an SLT workforce to meet the needs of the service. This was particularly important for SLTs who expressed frustration and a sense of being stuck with a continuous, uncapped demand for their service that they are unable to meet:

> "The waiting list for the caseload [SLT intervention] is 18 months and because we're so focused on enquiries [initial call to access the SLT service] and firefighting there's not much throughput on the caseload either. And we're 50% short staffed. Yeah, it's all awful." SLT4

Across all SLTs, SLT managers and SLT leads there was a strong desire to improve access to SLT. However, this was presented as very challenging without sufficient staff to support with planning and implementing service changes and to work in ways which may ultimately reduce waiting times, as SLT2 states:

> "The difficulty at the moment in our team is we've got massive vacancies. We want to change, but we haven't got the staff. We can't recruit to the vacant positions." SLT2

The workforce challenges primarily related to difficulties recruiting staff, resulting in high vacancy rates. LMC2, an operational service manager, highlighted the particular challenge of recruiting experienced staff:

> "We've advertised three or four times and have not been able to recruit, and that really impacts then on us being able to deliver therapy to those that need it. So, there is an access problem, absolutely." LMC2

There was a clear acceptance that the services would need to work differently to respond to the workforce challenge. As a commissioner, LMC1 provided a valuable insight into the extent of the challenge, the national context and the need to think differently:

> "We can't just increase the service by double the number of therapists because they are not out there to recruit to. We know there's a national shortage of therapists, and we also don't have the money just to double the funds for the service either." LMC1

Leads and managers recognised a need to work differently to improve recruitment and retention and shared several ideas and recent initiatives. LMC5 shared an example focused on developing the expertise of existing staff:

> "We've worked with HR [Human Resources] to create development posts that have just gone out to advert that are Band 5, with a view to becoming Band 6 posts, to try and support people who perhaps aren't quite ready, and don't have quite enough confidence to just jump straight into a Band 6 post." LMC5

The leads and managers all talked about efforts to recruit staff, and LMC2 also emphasized the importance of investing in staff from the outset to both recruit and retain staff:

> "Our [...] policy is about growing our own [...] and giving people the experience to then move through and hopefully stay here rather than trying to recruit people at more experienced roles because we just can't get them." LMC2

LMC2, an operational service manager, described working creatively to address workforce challenges. They described utilising the skills of locums working remotely from a wide geographical area to deliver virtual parent groups and described students working under the guidance of qualified SLTs to increase capacity.

Addressing the considerable workforce challenge facing the SLT service is a shared high priority across all roles linked to the SLT services and one that is driving services to think differently about recruitment, retention and the development of staff in post.

SLT vacancy rates and recruitment challenges were raised by several participants as having a direct impact on the delivery of the SLT service and contributed to waiting times for children and their families:

> "There is a huge recruitment issue and staffing issue on the early years side. So, they've got an enormous amount of vacancy. So, the impact of that is that waiting times are just going up." LMC4

The impact of long waiting times on access to SLT is explored in the next theme.

4.4.2.2 Sub-theme 2b: "There's nothing timely about anything": waiting across all stages of access to SLT

Waiting played a significant part in delaying access to SLT and impacted negatively on those waiting across both sites. Almost all participants, across all participant groups talked about the significant challenges associated with long waiting times for SLT.

Site A (Figure 9):

> "We have been waiting 20 months for his speech and language therapy." PC2

> "We have almost 600 families waiting for a call back. The family I last called had been waiting about 180 days." SLT2

Site B (Figure 10):

> "There's about 1500 children on the waiting list, and 1300 of them are for speech language therapy." LMC1

> " There are some referrals that are still from 2020 that we haven't yet seen." LMC2 (interviewed January 2022)

LMC3, a children's commissioner shared the challenge of a continuous uncapped demand for the service:

> "So, we are seeing this tsunami of demand [...] increasingly for speech and language as well. And in the NHS, we can't switch demand off. So, if you're a restaurant and you've got 20 seats, when your 20 seats are full, you say to the people queuing outside, "we're full, go away". You can't do that in the NHS." LMC3

For many parents, SLT was accessed around the time concern about possible autism was discussed with a professional. For PC3, her child's referrals to CAMHS and for SLT were both made following an SLT drop-in session (drop-in sessions were a pre- COVID-19 route into services on site A). Learning of the significant wait for further SLT input was particularly challenging due to the emotional significance of sharing her first concerns with a professional:

> "I felt emotional, because I knew deep down that she [drop-in SLT] was going to agree with me, but I was grateful that she did because I finally felt someone was listening. I thought, now I need to get him every service he can get. I was so upset … when I heard it is a year [wait for SLT], I thought are you joking? It was really hard. I think that was probably one of the hardest knocks that I had the whole journey that I wasn't expecting." PC3

For many parents, this early stage of recognising their child's needs involved referrals to, and waiting for, many services at the same time. An early years professional highlighted the feelings of frustration associated with multiple waits:

> "Generally, they've had to wait a long time for an autism diagnosis, a long time. 21 months is the average at the minute. So then to go on another waiting list can make people roll their eyes." EY5

A sense of urgency around access to SLT was expressed by most parents when seeking early SLT intervention for their child. PC2 described observing her child missing key developmental milestones:

> "You know, waiting is always frustrating and when I see that he is growing up, day by day, and he's missing milestones. It's always worrying me." PC2

A lack of communication with families while they were waiting led to additional uncertainty and stress for families. Most of the mothers interviewed reported taking an active role in communicating with the SLT service while waiting, to seek reassurance, to ensure the referral was in place, to receive updates on waiting times and to access interim support. For PC2, this meant making frequent contact with the service. Although this resulted in some information on strategies while waiting, there was also continued frustration and uncertainty about the future following these interactions:

> "Yeah, I just keep ringing them and they say that he is on number 45. The last time when I asked them, they said he is on number 45 […] I don't know when it [the help] is going to come." PC2

Having been told that the waiting time for NHS SLT was a year, PC3 accessed private SLT for her child. This came at a cost they would not have been able to afford without the support of their wider family:

> "I was quite fortunate that in the year that I was waiting, [partner's] grandparents paid for private speech and language therapy sessions [..] If I didn't have the private speech and language sessions initially in that year of waiting, I think I would have struggled! We were just very lucky that [partner's] grandparents offered it – I think they could tell how upset I was. That [..] saved my mental health." PC3

Access to private SLT due to waiting times was also observed by other professionals who expressed concerns about additional costs for families:

> "There seems to be a real barrier to children accessing National Health speech and language therapy, and many of them are seeking private therapists at a cost that they can't actually afford." EY4

Parents who had managed to access SLT generally expressed satisfaction with the quality of care provided. Waiting times were, however, an ongoing issue within services, with several additional waits following initial access, for assessment, advice, face to face appointments and reports. As LMC2, an operational manager of several children's services described, the multiple bottlenecks within the service were a source of frustration for families:

> "The parent group isn't timely enough at the moment. Because we can run [the groups] virtually, they're running far ahead, [but] then sometimes you can wait eight, nine months to have a follow-up to get more intervention if you need it. They're getting something early on, which is good, but it can be then frustrating for families to have to then [...] wait when they know there's more of a need." LMC2

Long waiting times for reports and therapy plans can lead to missed opportunities for families and early years settings to effectively implement SLT strategies. It can also create additional work for families, who are already under significant pressure, such as PC3:

> "It has been about two months to get the report [...]. It has got slower [...] because they are so over-stretched. That report is helpful for two reasons – one because I have been mega-stressed, and, I have had to chase a lot. And then two because I struggle to retain that information; time is going on and I have probably forgotten a lot of what has been said! [..]. Also I then can't give that information to the nursery, so that they could invest in working on the strategies." PC3

Waiting times were a significant issue as effective throughput was described as an essential part of the SLT service model. Discharging children from the service following support for the immediate presenting issue aimed to reduce waiting times for all children and to provide a responsive service:

> "We're saying to families, [...], "We want you to go and try this with your child. [...] If you've got any new concerns, come back to us." But then that's the difficulty. When they do come back and send that email, which is the easy point [...], it's then the wait time it's taking for us to then get back to the families." SLT2

As SLT4 describes, successfully transitioning to a new way of working that aims to be responsive when there are long waiting times and a reduced workforce is challenging.

> "It's become a wait in itself so it's not responsive enough at the moment. The theory is that we'll get more responsive, and we'll get this revolving door in a good way so that advice is timely, but of course it's all clogged at the moment so there's nothing timely about anything." SLT4

4.4.2.3 Sub-theme 2c): "Not our main priority": clinical decision-making and prioritisation

This sub-theme captures the tensions and challenges faced by SLT services in balancing the various needs of children with speech, language, and communication difficulties. SLTs and leads, managers or commissioners of services contributed to this theme, and no EY professionals or parents. Delivering high-quality care and ensuring the best use of resources was a priority for all those in SLT and SLT lead/manager positions. However, services faced several challenging clinical decisions in trying to meet the needs of all children and families. A manager of children's services talked of the importance of clinical expertise and the evidence base of interventions in guiding decisions:

> "Making the best use of the resource that we have doesn't mean children should suffer…so I [..] need the clinicians to tell me what the [...] evidence base is and what their professional opinion is and then I have to try and balance that with, okay, what does that mean for us in terms of meeting need and meeting our other obligations? [...] In an ideal world, everybody would get what they need." LMC2

More experienced SLTs observed a considerable increase in autistic children on the SLT waiting list and caseload over recent years and many, including LMC4, talked about the way in which they saw this impacting on access to SLT for children with other conditions:

> "I'm not quite sure to phrase it appropriately, but the sheer volume of children on the early years' caseload with quite significant autistic traits is swamping the caseload and [...] it's impacting on everybody's ability to get to the children with more specific speech and language difficulties, so [...] verbal dyspraxia, especially the developmental language disorders. And because there's so many children, it means that they're often waiting a very long time to be spotted, as that's a real specific problem." LMC4

The high demand for the SLT service and the growing proportion of autistic children whose parents are requesting SLT led several SLTs and their leads and managers to reflect on their role with children with different needs. Some appeared to suggest that autistic children require less SLT, and were less deserving or less in need of SLT input than other children:

> "Because people [families of autistic children] are waiting for this therapy that they think they should have, it's all taking up lots of time and it's impacting on the services' ability to be able to see the [other] children who require that increased level [...]. I think it's very difficult for them to be able to get to those children and certainly get to those children early [...]. There's the tension there of lots of children with autism, a lot of whom are quite pre-verbal or early communication that don't need weekly speech therapy." LMC4

LMC4 refers to a high volume of referrals for autistic children due to a parental expectation of what they should be receiving, suggesting this differs from the view that SLTs hold with regards what is needed. SLTs contributing to this theme suggested parents' expectations of SLT input were higher than they should be. This expectation generated a high demand for the service from autistic children and their families and led to difficulties meeting the needs of children with other conditions who were perceived by SLTs to have a greater need for direct and/or frequent SLT. It was not clear from the data whether parents wanted an SLT service that their child did not need or whether differences between SLT and parents' views related only to the nature and the frequency of SLT input. Participants contributing to this theme described the importance of focusing on children with specific needs such as Developmental Language Disorder (DLD). In the context of considerable pressure on SLT service resources and high demand from autistic children and their families, this was expressed on a couple of occasions as autistic children impacting on timely support for children with DLD and of autistic children "swamping" the service. LMC5, an SLT in a leadership role, also presented a view of autistic children as not needing SLT time, echoing the view expressed by others that the needs of autistic children impacts upon access to SLT for other children:

> "A significant volume of our caseload is children who are either diagnosed with [autism] or are waiting for a diagnosis. That can mean that they don't *not* need our time, but the more children you have the slower the whole process becomes. It can be difficult to find the other children with those other needs as well. We know that these [autistic] children need help, and we know that we can sometimes have a role and are best placed to support them, but also that their progress will be slow, or certainly could be slow." LMC5

SLT5, a Speech and Language therapist working in an early year's community SLT team, described the purpose of SLT support with autistic children and the typical amount of support provided within their service:

> "It's only really one or two sessions normally and then the child is discharged because we feel that the parents or nursery are equipped and that we've given them what they need for that child to communicate at the time, then using that waiting list as a list for only children that need a speech and language therapist." SLT5

This quote suggests a limited offer to autistic children based which appears to be determined by their diagnosis. The data suggests multiple factors influence SLTs decisions on interventions, such as the SLTs' perception of their own level of expertise and the value of their input, their view of other groups of children as being in greater need of their SLT input than autistic children , and also the belief that autistic children will make slower progress than some other children. Whilst autistic children's need for communication support was recognised by most SLTs participating in the study, SLTs did not necessarily view their own role as key in providing this support.

> "It was always felt that they [autistic children] weren't our main priority, but they can't not be - no-one else takes them on if you see what I mean. It's not very clear actually where these children should sit naturally." SLT4

This sub-theme captures the tensions arising in SLT support for autistic children and support for children with other speech, language and communication difficulties.

4.4.3 Theme 3: Gaining access: "a bit of a hurdle at every stage"

This theme captures the knowledge, skills, emotional and practical resources, and the effort parents/carers need to use to gain access to SLT, often to overcome the unresponsiveness/inaction of professional gatekeepers to SLT services. Parents described having to fight and develop strategies and skills to work with professionals, including gatekeeping services.

4.4.3.1 Sub-theme 3 a): Parents and carers' identification of concerns and practical and emotional readiness for the work

This sub-theme captures the crucial role that parents and carers of preschool autistic children play in gaining access to SLT for their child. Knowledge of typical communication development, an awareness of their child's communication needs, and the practical and emotional resources required of parents/carers were all important factors in seeking access to SLT. Parents and EY professionals mostly contributed to this subtheme.

For most parents, concerns about their child's communication skills were part of wider concerns regarding their child's pattern of development. All parents interviewed had clear concerns about their child's development, and these were a driver for seeking professional support for their child and a facilitator for access to SLT. Parents were both consciously and sub-consciously observing patterns of communication development they were not expecting, which concerned them.

Early concerns about their child's communication development were influenced by parents' instincts, their previous experiences with their other children and their knowledge of child development. Many parents expressed their first concerns as a feeling that things were not right, including PC1 who referred to 'mother's instinct' as an important driver for seeking help:

> "So, I think it's something not right for her. Of course, my family thinks about the same. So, my husband didn't agree for the first time, but it's mother's instinct I should go to [the] GP and find out." PC1

Three mothers were trained early years professionals (PC4, PC5 and PC6). They reflected on the knowledge and insight they gained through their professional backgrounds, and the ways this supported early identification of their child's communication difficulties.

> "I was used to working with children with additional needs and things like that. So, I noticed the signs from around, I'd say 13/14 months old." PC4

> "Yes, I have looked after a lot of kids over the years and one of the children I looked after was exactly like [my child]. [...] I spotted it straightway and my husband became aware – I was just quietly watching him and then my husband became aware at 12 months that there was an issue as well." PC6

Two out of the six mothers also had an older child diagnosed with autism. PC3 shared how this strengthened her confidence in her knowledge and instincts related to her second child's development:

> "As first-time mums you don't have that confidence, whereas the second time around – with regards to anything, not just special needs, but just being a mum – you go oh yes, I trust my instinct. I don't need to listen to anyone else – that confidence builds. The first time around it is scary, and you do seek people's reassurance more whereas the second time around you are like I have done this before, I have listened to my gut, I am their mum and I know them the best." PC3

> "I was keeping an eye on her anyway, because I have sons who are autistic. [...] I know there's something going on, because it doesn't feel quite right." PC5

Having an awareness of their child's communication needs, either through their own instinct as a parent or knowledge of child development, facilitated greater access to SLT. Once communication difficulties had been recognised as requiring SLT support, most of the mothers proactively sought to develop their knowledge of services that may be able to help them and their child. Most were able to find information about SLT services, for example, through searching the internet:

> "I referred myself because I googled it. I found out all the therapy she might get from the NHS. [...] I start[ed] with speech and language [...]. Yeah, I filled the form, and they rang me later." PC1

However, not all parents were aware of the services available and how to access them. PC2 described a high level of concern about her child's communication, but as she had only been in the UK for two years at that time, she did not know about support services:

> "I didn't know anything. I came here just a few years before and, at that time, he was my only child and I didn't know anything about the help. [...] I'm new here, I don't know anything, what help I can get." PC2

PC2 was unaware of services which she may have been able to access directly (without a referral) and had to rely on perceived gatekeepers of services, which in her case was the GP, to act. PC2 experienced greater challenges in access to SLT compared with some of the other parents interviewed. However, her own instinct and concerns about her child led to her persistence in seeking support, despite reassurance from professionals:

> "But you know, I was still not confident because I knew there is something they can't figure out." PC2

The crucial role of parents' knowledge, confidence, and motivation to access SLT services was not only reflected in the comments of parents and carers, who self-selected to participate in the

study and may not represent other parents and carers, but also in the comments of professionals. EY2 talked about the lack of information about SLT referral processes:

> "It's knowing how to access that support, which needs to be made much clearer. I think that would empower [parents]. If us as professionals aren't quite sure, it's a minefield for parents, and we want to empower parents so that they are doing these phone calls and attending the appointments and that they feel that they have everything under control." EY2

PC6 was well equipped with the knowledge of services and the support she may be able to access for her child, resulting in some interim support while waiting for SLT, which had positive outcomes for her child:

> "I just did a lot of research online and I am not afraid to ask for help, so I did ask the professionals and we were given interim help. That has boosted his language – he can do Makaton; he can use visual aids and he can speak." PC6

The parent's ability to prioritise SLT was also an important influence on access to SLT:

> "The biggest barrier is having the parent that will bring the child to the appointments and to the groups and drop ins because we can regularly tell parents about what support is here, the access to that clinician is here, but sometimes the parent for whatever reason was busy or didn't put it to the top of their list" EY1

All mothers interviewed presented as highly motivated, organised, and persistent in pursuit of SLT for their child. Despite this, most still experienced challenges in access to SLT. PC5, a parent of an autistic child and also an early years professional, expressed concerns about barriers to access to SLT for some parents. She highlighted that some families do not have adequate communication skills and knowledge to successfully advocate for services for their child.

> "I would say, take time to understand your child, write down what your concerns are. If they are able to explain properly, then they will get the support they need. I know some families, they still refer to the speech therapist, but they're not getting the support, they're unable to explain what their concerns are. So, I think it's more about parents[...] to understand what they are asking for, what sort of support [they need]." PC5

Parents and carers' practical and emotional readiness for the work captures the need for parents/carers to use their existing knowledge and to proactively seek out information on support services. It also captures the importance of their motivation, confidence and their ability to prioritise seeking access to SLT. This was considered important by several

participants. The additional effort of parents/carers did not necessarily translate into easy access to SLT for all parents, however, with some expressing frustration and dissatisfaction, despite their efforts.

4.4.3.2 Sub-theme 3 b): "So who's helping me?": Inaction and unresponsiveness of professionals on the journey to SLT

This sub-theme captures the ways in which the inaction and unresponsiveness of professionals impacts the child's journey to SLT. Parents mostly contributed to this theme, with EY professionals also sharing similar views from their experiences of working with other families. The challenges often related to professionals not taking parents' concerns seriously and not recognising their expertise as parents. Challenges arose for parents when their concerns, instincts and feelings about their child's communication development were not shared by others. Rather than feeling reassured by family members, friends and professionals, some parents found a gulf between their concern as a parent and the extent to which others perceived there to be a problem. The lack of shared concern led to feelings of doubt and isolation for some parents as well as frustration as they remained concerned and feeling unsupported. For PC4, this gap between her instincts and beliefs as a mother and the perceptions of others was further magnified through the impact of professional reassurance on the views of family members and friends:

> ""Oh, he's little. It's fine, don't worry." They thought I was just getting a bit worked up about it, and I probably was, because I knew there was something there, that the professionals weren't supporting me and backing me with. So, it made me look like I was going insane. Family and friends never dismissed my concerns, but they just thought, "Oh well, if a professional can't see it, then maybe you are just being a bit dramatic, so just don't worry yourself about it, and just keep going."" PC4

PC2 described having to present repeatedly for support due to professionals not taking her concerns seriously. The doctors didn't recognise her expertise as a parent and, therefore, they did not act on the information shared with them. The unresponsiveness of professionals was frustrating and worrying for parents and, like PC4, PC2 was not reassured by the professional:

> "So, I took him to the doctors two or three times to just check..... and he said, "No, he's a healthy baby, and you're just worrying for nothing." PC2

The analogy of a fight was used by most parents, including PC6 who also talked about additional actions she took to make her child's needs more visible to service gatekeepers:

> "I had to be quite proactive which means badgering people! I had to email a lot of different professionals, I had to keep going backwards and forwards to the GP and it sounds odd, but the more exposure to the professionals he had, the more they became aware that this child has some problems, we need to help." PC6

The lack of shared concern and responsiveness of professionals and services led to feelings of worry, frustration, isolation and anger for parents. PC4 also expressed regret and guilt at not having done more to challenge what professionals had told her:

> "The way they're doing it at the moment is making you feel more alone than ever [...]. I would just say if you've got a concern, please, please do not do what I did and just take it. If you feel like there is something not right with your child and they need intervention, do not just sit back and just take what they say, you have to push and you have to fight for everything. It shouldn't be that way, and you shouldn't have to fight that way. Just don't take a back seat, take the driver's position and push for what you want, because if you don't push, you're not going to get it." PC4

PC4 was not offered a service for her child despite her attempts to access the SLT service and her child's significant communication difficulties. However, even when parents had been able to access a service, such as PC6 (albeit after a considerable wait time and paying for private SLT while waiting for NHS SLT), the frustration and need to fight on the journey to SLT was still expressed:

> "Unfortunately, the system is a long road, and you are going to have to fight for your child. And that means chasing, contacting, not resting on your laurels, being really proactive and basically, if you don't hear something for months, badger them a little bit and say "this is what is going on with my child, my child is getting worse", or "we are struggling as a family". It is a battle, but once you find the good speech therapists and other professionals, the help will be there – it is just getting your foot in the door for your child." PC6

4.4.4 Theme 4: Perceived quality costs of increased productivity

This theme relates to variation in quality of care as a result of service efforts to improve flow through the service and to increase productivity. Most dissatisfaction with the SLT service was related to service practices aimed at increasing efficiency and making the most of available SLT resource. Despite the clear commitment to high quality care for children expressed within all interviews with SLTs, service leads, and managers, there was variation reported in both ease of

access to services and in the SLT service offered to children and their families as a result of some of these practices. All participant groups contributed to this theme.

Participants across all groups shared concerns about the conduct of initial SLT assessments over the phone. During COVID-19, one service established phone appointments as the main means of SLT assessment and route into the service. Phone assessments were then adopted as an ongoing process after COVID-19 restrictions had been lifted to increase efficiency and to try to meet the high demand for the service:

> "Our way in at the moment [...] started during COVID [...] but actually we've made the decision [...] [to] run what we call an enquiries line telephone service." LMC5

Although telephone assessments are seen as an efficient way of managing demand, many participants, including SLTs, perceived phone assessments as a barrier to SLT. This was despite the option for SLTs to offer an in-person assessment where necessary. SLT4 expressed dissatisfaction related to the requirement to assess the communication skills of a child through a phone conversation with their parent/carer:

> "Yeah, so the vision I can buy into but, no, awful. I mean as you can see, I'm not clapping my eyes on children, I don't see them, I'm on the phone.... Awful. I didn't sign up to this to be on the phone, did I? I mean it's crazy." SLT4

As well as SLT dissatisfaction, several barriers were raised related to phone assessments, such as difficulties contacting parents. There were concerns that phone assessment did not provide an accurate representation of the child's communication ability and that assessments relied heavily on the degree of concern of the child's parent/carer and their ability to communicate their concerns and their child's ability and support needs to others:

> "When we see patients for [early years education] reviews, a lot of them have had [SLT] assessments done over the phone, and they found that quite frustrating because they feel that that's not an accurate representation of how the child's ability or lack of ability is being assessed. So, that is an issue." EY6

Concerns were also raised from parent perspectives. Although PC5, a parent and early years practitioner, was generally satisfied with the effectiveness of phone appointments while she waited for in person appointments (during COVID-19 restrictions), she expressed concerns about how parents who did not have the same knowledge may be able to engage with the calls.

> "I had to do phone calls until last year.... She [SLT] used to give me advice before I got actual appointments with the speech therapist. I work with the children as well, so I

> know [...]. But if there is another parent, another parent who has no clue, how are the telephone appointments going to help them?" PC5

In addition to challenges and concerns around phone assessments, SLTs expressed frustration related to the gap between what they were able to offer and what they would like to provide. SLT1 shared her desire to work more closely with the more complex children than she felt able to because of pressure on the service.

> "With more complex children, I think it would be much better if we were able to do it ourselves [rather than utilise SLT technical instructors who work alongside SLTs as assistants]. It's something I wish we could do.... It often that feels like there's not enough time to do a full demonstration and really get the adult there, having a go themselves [...] making sure they feel confident in knowing exactly how to do it." SLT1

This was echoed by others who described how time pressure impacted on quality of care. SLT5 described the challenge in achieving the throughput required to reduce the waiting time for the service:

> "I feel like I want to give them their time. I want to give them [...] what they deserve but because we want to have a really quick throughput [...], it's quite hard to get that throughput and build the trust for parents." SLT5

The ways in which the service was delivered also appeared to impact on the learning and development opportunities of some SLTs. SLT4 expressed frustration about wanting to do more for children and their families, and shared the limited degree of flexibility and expertise she had to offer this within her role:

> "I haven't got many levers to pull as you can hear.... for starters I'd like to feel confident myself that I can do what I'm telling them to do (laughing) I don't have a great deal of confidence that I can actually do what I want them to do. [...] I did try an intensive interaction to show mum what I was wanting and I've watched it on a YouTube video, I've never been taught it and there I am, the blind leading the blind trying to teach a mum tell her what I'm doing." SLT4

When asked a follow up question about opportunities for developing knowledge and skills within the current service delivery model, SLT4 raised further concerns:

> "Oh yeah, no, nil, absolutely very little, very little. I mean one is being deskilled. One isn't really a therapist, the SLTAs [Speech and Language Therapy Assistants] and the Band 5s are getting more experience, aren't they?" SLT4

Some children and their families were also reported to have been offered no service at all due to SLT waiting times:

> "Not meaning to sound negative, but when I've tried to put referrals through, I'm told there's such a long waiting list that actually referrals aren't being taken at the moment." EY5

PC4 described her experiences of trying to access SLT for her four-year old son. At the time of interview, he communicated using occasional single words. He had first been seen by SLT at the age of 2.5 years, following a 6-8 month wait for an appointment and offered no further input.

> "That was literally it. So, we had, like, an hour visit and then I heard nothing from them since then." PC4

Her son was then seen by an SLT to complete an Education, Health and Care Plan (EHCP) assessment over a year later. Following this, the SLT decided to discharge him due to the long waiting time for further SLT input:

> "When I spoke to them on the phone …towards the end she was, like, "Oh, we're not going to put him on the speech and language waiting list because it's so long that he won't get it by the time he goes to school, and I'm sure the school have a speech and language intervention for him, so we're just going to leave it." And I was, like, "Well, you've left him for two years anyway, like, you've done nothing for him." So, it's been a bit of a nightmare. They just didn't seem like they could be bothered to help him […] That's how that made me feel, very pushed back, disregarded, "He'll be fine." And they just did nothing. He wasn't even waving or pointing at anyone, and they just did nothing." PC4

PC4 experienced strong feelings of distress, and felt ignored and dismissed by the SLT service. This quote suggests that PC4's concerns may have been minimised and not taken seriously by the SLTs who saw her child. It raises the question of what this experience may be like for others with less agency.

Some SLTs raised concerns that those around the child may not take action to support the child's communication skills themselves, such as through implementing general strategies to support communication if they were on a long waiting list for SLT. Although a few SLTs referred to this, and felt strongly this was the case, the evidence to support this belief was not explored specifically during interviews. Additionally, the views shared by others such as parents and EY professionals did not support these statements that parents and others around the child did not act to support the child while waiting for the SLT service.

SLTs also referred to unrealistic expectations of the SLT service:

> "These children were just sitting on that list [waiting for intervention following assessment] for 18 months doing nothing; no-one was doing anything because they're thinking, we're waiting for speech and language therapy as if we have some magic wand, which of course we don't. So, we felt it was a risky service that we were offering. Basically, they're sitting on a list and nothing's happening now because everyone's just waiting for that amazing day when I will see them for an assessment." SLT4

Despite inaction of parents while waiting for SLT being a clear concern for some SLTs, the data from participating parents and carers do not provide support for this assertion. There did not appear to be evidence of unrealistic parent expectations and there was no reference to this by EY professionals. Nevertheless, the reference here to risk associated with seeking access is interesting and suggests possible harm to children and/or their families in their pursuit of SLT. This is supported by data from parents who refer to the considerable stress associated with seeking access to SLT and suggests there may be iatrogenic harm associated with seeking to gain access to the SLT service.

4.4.5 Theme 5: "Worth the effort": the drive to access SLT

Several barriers to SLT have been heard in relation to service delivery and access to SLT support. Whilst these voices have described access to SLT in mostly negative terms, participants have also claimed that, despite these challenges, SLT is worth the effort it takes to access the service and worth the wait. This is a contradictory theme (Braun and Clarke, 2021) to sub-theme 3 b): "So who's helping me ?": Inaction and unresponsiveness of professionals on the journey to SLT, which captures the inaction and unresponsiveness of a range of professionals, including SLTs on the journey to SLT services. As there was considerable data supporting a view that SLT was worth the effort and worth the wait, this theme was generated. SLT was regarded as a highly valued service by several participants including parents, EY professionals and LMCs. SLTs also shared positive feedback they'd received from others. This positive view of the service and its impact was expressed in numerous ways. As the operational lead for an early years SLT service described people to tend to be pleased with the service once accessed:

> "I've never had to deal with a complaint about a member of staff. The service that [families] receive, they always seem to be relatively happy with. It is just accessing it in the first place." LMC5

This view of the service was reinforced by most of the parents interviewed, including PC3:

> "Being completely honest, I have got nothing bad to say about the actual therapy itself. The speech and language therapists that we have had have been absolutely lovely, they have been very knowledgeable, they have been very helpful and the reports that we are given are very, very good. And the strategies that they write in the reports and are discussed with me, very good." PC3

The reputation of the service established through both professional relationships and family interactions with SLT appeared to be a facilitator to access. Most participants, spanning all participant groups, referred to the high-quality care provided by SLTs, and it was presented as a precious and valued service, with several references to the personal qualities of SLTs and their passion for their work. This is illustrated by EY1, a very experienced Health Visitor working in an area with high levels of deprivation:

> "I've never once come across a Speech and Language Therapist where [...] I've thought, why are you doing this job? They're all very passionate and their assessment skills and skills are just fabulous. They do great reports on children, and I think the ones I have met they do feel frustrated that they wish that they could do more." EY1

This is echoed by another early years professional working as a preschool support teacher who stated that families rarely refuse the offer of SLT, though she recognised that not all families were necessarily able to implement the advice provided by the SLT. The perception of SLT amongst early years professionals, who are often the first professionals to discuss a child's communication with parents, appeared to be an important influence on access to SLT.

> "They are like gold dust, and I think the majority of families really do appreciate that and appreciate the support that the therapist is able to give them." EY4

Most parents shared very positive experiences of SLT, once accessed, and referred to the personal attributes of SLTs and the relationships established with SLTs over time. Being listened to and believed were two clear aspects of the interaction with SLTs that were important for the mothers, and this supported a family-centred approach. PC5 compared her more recent experiences of accessing SLT for her daughter with her experiences with her older son who is also autistic:

> "I was really surprised [the SLT] listened to me, because I felt that with my son, nobody helped me [...]. I think [the SLT] are really good, I think they are really listening. They already believed me, and that's the most important thing, because at the end of the day, parents do know their children. She would ask me for my concerns and help me, and then ask me [...] if there is anything I feel is not working or could still be added [...]. She used to ask me every time." PC5

The value of more experienced SLTs and those with autism expertise was expressed by some participants, not only in their specialist knowledge, skills and experience, but in the confidence and freedom to work more autonomously:

> "I think it's the more specialist speech and language therapists that probably offer a better service, if I can dare say that, as opposed to our more generic speech and language therapists that are picking up our kids, but they're picking up loads of other children as well. So, they haven't maybe got quite that specialist viewpoint. Whereas we've got certain therapists that are very focused, very specialist, and they kind of, dare I say, do their own thing, which does benefit our children." EY4

The value of specialist intervention that specialist SLTs are able to provide was highlighted by PC6 who described her positive experience of accessing an evidence-based, autism-specific SLT intervention for her child:

> "PACT [Paediatric Autism Communication Therapy] was the technique. She taught me how to do it, how to speak to him, and she got me to video my interactions with him.... Yes, she is amazing, she is really brilliant [...]. I feel he has definitely got a good support network from his professionals and that she is in for the long run to help him speak." PC6

The references to specialist SLTs and specialist autism-specific interventions are important as access to general strategies and advice by non-specialist SLTs will differ significantly from specialist interventions delivered by an SLT specialising in autism. As the focus of the study was on access to SLT services, the issue of specialist and non-specialist SLT and specific interventions were not explored specifically or in-depth. Comments on specialist input arose when discussing the service offered generally. The data gathered on this topic suggests that specialist input is important, however.

4.5 Summary of the chapter

The findings of reflexive thematic analysis have been presented along with contextual information on the process of access to SLT in the research setting in relation to current policy and practice guidelines and information on the study participants.

The themes and sub-themes reflect important, recurring patterns of meaning across the data set. They also highlight areas of tension and challenge where differences in perspectives between participant groups on shared issues have been identified. Whilst the SLT service once accessed is often valued and highly regarded, several challenges have been identified that

contribute to difficulties achieving initial entry to the service ‘access-entry’ (Rosen, Florin and Dixon, 2001) as well in access to a meaningful intervention once initial entry has been achieved ‘within-service access’ (Rosen, Florin and Dixon, 2001).

The ways in which the themes relating to access to SLT link to the existing literature will be discussed in Chapter Five, followed by recommendations for practice, policy and further research in the final chapter.

Chapter 5 Discussion

Chapter Five critically discusses the research findings presented in this thesis. The study aimed to contribute to the existing evidence base and to address gaps in knowledge through answering the research question: What factors and process impact on access to SLT for preschool autistic children from the perspective of key stakeholders?

The following objectives were set:

> Objective one: To map the existing pathway for access to SLT intervention for preschool autistic children within the research setting and to consider this in relation to existing local and national guidelines.
>
> Objective two: To understand factors and processes impacting on access to SLT for preschool autistic children from the perspectives of key stakeholders.
>
> Objective three: To identify opportunities to improve access to SLT for preschool autistic children.

Objective one was met in chapter four with a full description of the service pathways to SLT in the research setting which comprised two sites. This aimed to provide a rich description of the research setting to support readers to consider the relevance of the study findings to their own setting.

This chapter discusses the findings presented in the reflexive thematic analysis report (Chapter Four), interprets their significance, and presents the ways these connect with existing literature. This aims to meet the second objective of the study. Opportunities to improve access to SLT are described in the final chapter to achieve the third objective.

The ways in which each objective has been addressed within this thesis will be described in the following sections.

5.1 Objective one: To map the existing pathway for access to SLT intervention for preschool autistic children within the research setting and to consider this in relation to existing local and national guidelines

Objective one was met in chapter four with a full description of the service pathways to SLT in the research setting which comprised two sites. This aimed to provide a rich description of the research setting to support readers to consider the relevance of the study findings to their own setting.

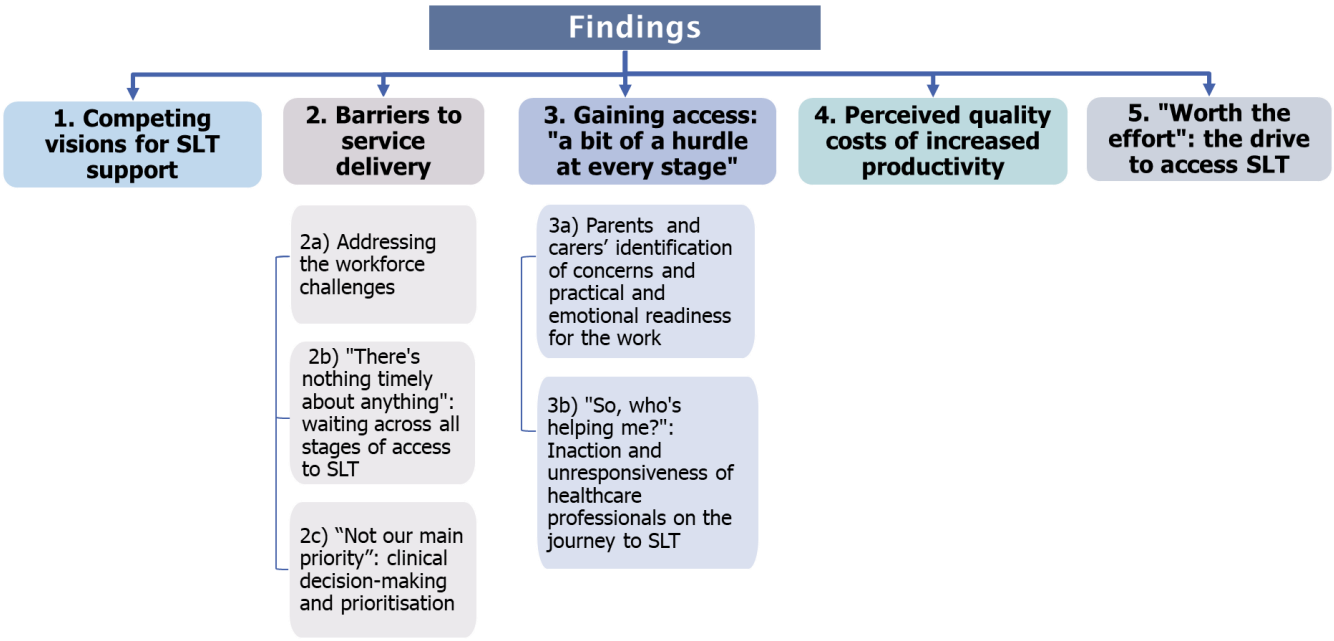
Comparing the processes for access to SLT within the research setting with national guidelines identified that services mostly followed the available national guidance. Access processes within the research setting did not differ significantly from recognised good practice. However, some potential issues impacting on accessibility were identified. These included parents at one site being unable to directly request SLT input for their child, and the use of telephone assessments within another site rather than direct assessment of the child by the SLT through observation and interaction.

5.2 Objective two: To understand factors and processes impacting on access to SLT for preschool autistic children from the perspectives of key stakeholders.

This section discusses the findings presented in the reflexive thematic analysis report (Chapter Four), interprets their significance, and presents the ways these connect with existing literature. This aims to meet the second objective of the study.

The study has identified several factors and processes impacting on access to SLT from multiple perspectives, expanding on, and contributing to, existing research on barriers, facilitators, and influences on access. The themes and sub-themes generated through reflexive thematic analysis are presented in Figure 12.

Figure 12 Themes and sub-themes



To demonstrate how factors and processes impacting on access to SLT are interrelated, a conceptual model was created based on study findings. Issues that explain children's access to SLT were combined into four categories:

- The parent
- The social context
- The SLT context
- The individual SLT

The link between these four categories and the themes and sub-themes from which they were generated is presented in Table 16. Each theme and sub-theme was also considered in relation to whether it acted as a barrier or facilitator to access to SLT. Some themes and sub-themes were related to more than one category of the conceptual model, and some acted as both facilitators and barriers to access to SLT.

Table 16 Links between elements of the conceptual model for understanding access to SLT and the study findings

Element of conceptual model	Barrier to access	Facilitator of access
The parent	Theme 1: Competing visions for SLT support. Sub-theme 3a): Parents and carers' practical and emotional readiness for the work.	Sub-theme 3a): Parents and carers' practical and emotional readiness for the work.
The social context	Theme 1: Competing visions for SLT support. Sub-theme 3b): "So, who's helping me?": Inaction and unresponsiveness of healthcare professionals on the journey to SLT.	Theme 5: "Worth the effort": the drive to access SLT
The SLT context	Theme 1: Competing visions for SLT support. Sub-theme 2a: Addressing the workforce challenges Sub-theme 2b: "There's nothing timely about anything": waiting across all stages of access to SLT Theme 4: Perceived quality costs of increased productivity	Theme 1: Competing visions for SLT support.
The individual SLT	Sub-theme 2c: “Not our main priority”: clinical decision-making and prioritisation	Theme 5: "Worth the effort": the drive to access SLT

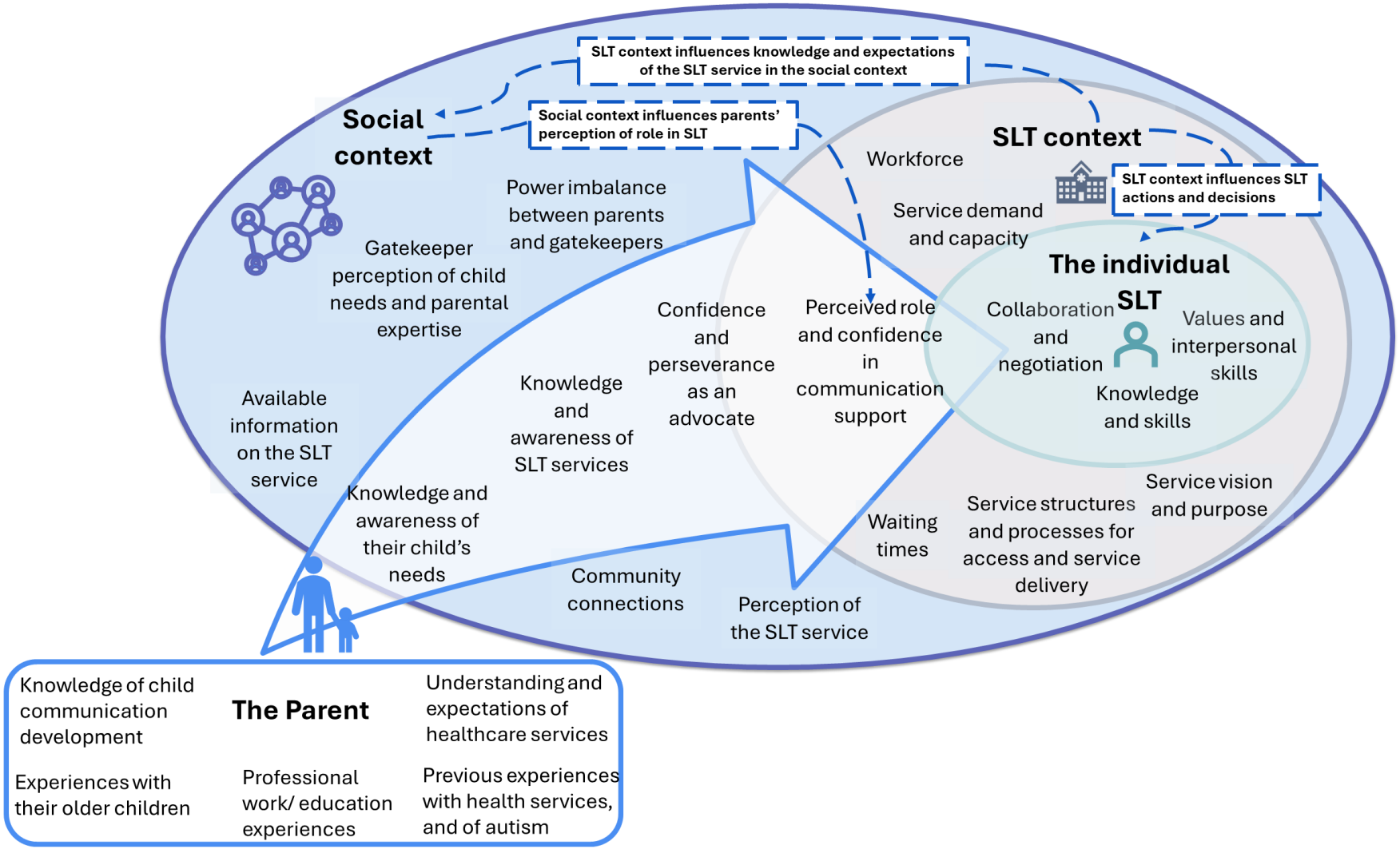
The graphical representation of the conceptual model (Figure 13) aims to demonstrate the main processes, relationships and interactions between the different categories that influence access to SLT. It is centred around the parent and child’s linear journey to SLT. The start of the journey captures the predisposing knowledge, skills and experiences of parents impacting on

access to SLT. As the parent starts to recognise their child's need for SLT support, the way in which their knowledge, skills and behaviours are influenced by the social context are captured. As the parent and child continue their journey, the SLT service context influences access. The service structures and processes for both access and service delivery influence the experience and ease of access for the parent and child. The parent's ability to advocate for their child and to be persistent in their pursuit of SLT was important at this stage.

Parent expectations of SLT were shaped throughout their journey into the service, by their own beliefs around the roles of healthcare professionals and through their interactions with others, such as service gatekeepers. These expectations influenced how they perceived their role in supporting their child's communication development. The individual SLT decisions, priorities and actions are influenced by the SLT service context around them as well by the SLT's own knowledge, skills, values and beliefs. The negotiations and interactions between the SLT and parent were, therefore, shaped by several individual and contextual factors for both the SLT and parent, and the degree of alignment between them varied and influenced experience of the SLT service.

The conceptual model generated inductively to explain access to SLT for this study shares features with several published conceptual frameworks for access to healthcare services. Access is presented as a multi-step, linear process, similar to the Levesque Conceptual Framework for Access to Healthcare (Levesque, Harris and Russell, 2013) and the Candidacy Framework (Dixon-Woods *et al.*, 2006) (see Appendix G.1 and G.2). Patient and service-related influences are captured (similar to Levesque, Harris and Russell (2013) framework) and the ways in which the individual and health service issues influence each other are captured similar to the Penchansky and Thomas (1981) model for access to healthcare. Both the Levesque (Levesque, Harris and Russell, 2013) and the Candidacy Framework (Dixon-Woods *et al.*, 2006) represent contextual influences as occurring as a discrete step/stage in access. Within this study, the SLT service context heavily influenced several aspects of access. The SLT context directly impacted the available service capacity and waiting times, and indirectly impacted SLT decisions (for example, on whether to add a child to a waiting list) and priorities. The SLT context also influenced the social context and what was known and believed about SLT in the research setting. The service context, therefore, is a prominent part of the model and the direct and indirect influences on access to SLT are visualised. Generating a conceptual model to explain study findings inductively has enabled the main influences to be presented and important interactions between the different influences on access to be captured, which may have been missed if a deductive approach was taken within the study.

Figure 13 Conceptualisation of access to SLT based on study findings



This next section discusses the study findings in the context of current literature on access to SLT for preschool autistic children. Although several elements influencing access to SLT are interrelated, this section is structured according to the four main elements of the conceptual model (Figure 13), and both barriers and facilitators to access are discussed together.

5.2.1 The parent

This section discusses the study findings in the context of current literature on access to SLT for preschool autistic children. Although several elements influencing access to SLT are interrelated, this section is structured according to the four main elements of the conceptual model (Figure 13), and both barriers and facilitators to access are discussed together.

The study findings highlight the crucial role that parents play in supporting access to SLT for their child. Identifying the child's need for SLT support was the first step in access. The study has identified that parents draw on several skills and experiences, such as their knowledge of child development and autism, to identify their child's needs and facilitate access to SLT. Some participants gained knowledge through their professional roles and personal experiences with their child's older siblings (two of the six participants also had an older child diagnosed with autism and three were also early years professionals). Previous studies have identified parents' lack of knowledge about autism and child communication development as important influences on access to SLT (Chu *et al.*, 2018; Millau, Rivard and Mello, 2018), alongside awareness of available services (Auert *et al.*, 2012; Bromley *et al.*, 2004; Chu *et al.*, 2018; Khanlou *et al.*, 2017; Millau, Rivard and Mello, 2018) and ability to complete referral paperwork (Khanlou *et al.*, 2017). The findings of the study presented in this thesis align with what is already known, and have identified the positive attributes, skills, strengths and previous experiences of parents that facilitate access to SLT.

Parents' confidence, motivation and previous encounters with healthcare professionals were identified as important for facilitating access to SLT in this study. This is similar to the findings of an Australian study by Auert *et al.* (2012) on parents' expectations, awareness and experiences of evidence based SLT for their autistic child. The study found that parents' confidence, motivation and previous experiences influenced their engagement with SLTs in therapy once access had been gained. Due to the characteristics of participants, the study presented in this thesis has also identified the parent strengths, abilities and qualities that support access. These include parent motivation and persistence, knowledge of child development and ability to engage and communicate with professionals. Several participants considered what this may mean for access to SLT for families who are less well equipped or have less capacity to advocate for their child. Concerns were raised about inequity within services for children whose

parents were not able to advocate as effectively for their child. Thie highlights the ways in which existing healthcare systems, including the beliefs and behaviours of staff as well as service processes and structures disadvantage many of those they are there to support.

The study findings suggest parents' knowledge and expectations of SLT impacts on their engagement with services, service design and improvement, as well as access to SLT for the child. The findings of this study suggest the way in which the role of the SLT is viewed by parents prior to access is linked to how parents then view their own role in therapy. Parents and SLT perceptions and expectations of each other did not always align. A parent perception of SLT as expert and an expectation of 1:1, regular, direct SLT support with their child influenced some parents' confidence in their ability to support their child and led to feelings of frustration when expectations were not met. This is similar to Auert *et al.*'s (2012) study that found that parents with less experience of SLT services expected the SLT to provide direct support to the child, rather than relying on the family to support their child. The study presented in this thesis identified that parents' expectations of the SLT were influenced by the views of other healthcare professionals and gatekeepers to services in the social context, such as paediatricians, and this is explored in the next section (section 5.2.2). Given how crucial parents are in providing communication support for their child (Aldred, Green and Adams, 2004; Green *et al.*, 2010; Pickles *et al.*, 2016), it is important for SLTs to understand parents' unique perspectives and expectations when working with autistic children and their families.

The crucial role of parents in facilitating access to SLT was also highlighted through participant references to some families being unable to prioritise the time and work needed to gain access to the SLT service and to apply intervention strategies. The factors that may contribute to difficulties prioritising SLT for the child were not explored in further depth within this study. However, the findings do raise the important question of how factors associated with disadvantage such as poverty, education level, health literacy may also impact access to SLT as well as parents knowledge, motivation and previous healthcare experiences.

Capturing parent and other healthcare professionals' perspectives together in this qualitative case study has facilitated a greater insight into some of the parental factors that impact on the child's access to SLT and parent engagement with SLT services. Some views were shared directly by participating parents and others were captured as observations of other participants such as health, education and care professionals working with families. Several influences on access to SLT were identified which not only impact the child's access to SLT support, but also impact on parents' ability, readiness and confidence in sharing views with SLTs to inform service design and improvement. This ultimately impacts on the service received by all children and their families.

5.2.2 The social context influence on access to SLT

As discussed in the previous section, parents' knowledge and expectations of the SLT services were influenced by various interactions with those in their social context, and the available information on the SLT service. A positive view of SLT was identified as a strong driver for access to SLT in this study, and this positive perception along with positive child outcomes is also recognised in other studies (Bromley *et al.*, 2004; Cohen, Miguel and Trejos, 2023; Dababnah and Bulson, 2015).

Access to the SLT service was influenced by service gatekeepers. Gatekeeping is a means by which access to care is controlled through a decision-making process within a system (Greenfield, Foley and Majeed, 2016). SLTs and other health and care professionals can act as gatekeepers to services. The ways in which the inaction and unresponsiveness of professionals such as GPs impacted on access to SLT was captured as a barrier in sub-theme 3b 'Who's helping me? Inaction and unresponsiveness of professionals on the journey to SLT.' The study highlighted that some families received reassurance or felt their concerns were not taken seriously, which impacted on parents emotionally and delayed or blocked access to support for the child. These findings are consistent with those of other studies which describe the ways health and educational professionals' views can act as a barrier to access through downplaying and dismissing concerns of families (Dababnah and Bulson, 2015). The findings of this study highlight the important part relational factors such as communication and interaction between professionals and parents play in gatekeeping of services.

Parents' knowledge of child development, and their confidence and previous experiences in working with health professionals have been identified as important for access to services. Parental knowledge and experience may be described as their cultural health capital (Shim, 2010). Cultural health capital describes how the cultural, verbal and nonverbal communication skills and attitudes, behaviours, and interactional styles of the person seeking healthcare influences their relationship with the healthcare professional. The ways in which parents' expertise is then perceived impacts professionals' decisions around access to services (Hunt and May, 2025). Cognitive Authority Theory has been developed to describe how relational factors such as the healthcare professional's judgement of a family's expertise and competence impacts several aspects of a person's care including their access to services (Hunt and May, 2025). The study presented in this thesis has found that parents with a good understanding of their child's communication needs and of the available support services did not rely on the knowledge, degree of concern and actions of gatekeepers (such as GPs) to facilitate access to SLT. Parents with less knowledge, experience and confidence may, therefore, be at an increased disadvantage due to their reduced health capital and subsequent

reliance on services gatekeepers who may not act to support access to SLT. Gatekeeping decisions impact on several aspects of care including utilisation of services, health outcomes and patient satisfaction (Greenfield, Foley and Majeed, 2016).

The study identifies this as an important issue specifically in the context of UK NHS SLT, where access to support was delayed, even though overall SLT rates of access are high (Sapiets *et al.*, 2022). Autistic children and adults frequently experience additional health and support needs that co-occur with autism, and so negative healthcare seeking experiences in relation to SLT may also have implications for health-seeking behaviour for other services at other points in their lives (Dixon-Woods *et al.*, 2006).

5.2.3 The SLT service context influence on access to SLT

Service-related factors influence access to SLT in several ways. The study revealed that long waiting times are an important issue from participant perspectives, and this was captured as a sub-theme within 'Threats/barriers to service delivery'. This finding echo that of other studies that have cited waiting times as a significant barrier to SLT (Binns *et al.*, 2022; Chu *et al.*, 2018; Khanlou *et al.*, 2017; Monz *et al.*, 2019). This study identifies this as an important issue in the UK, specifically for preschool autistic children seeking to access SLT and has additionally identified that families often experience multiple waits within the SLT service after initial SLT access, leading to further delays. The impacts of long waiting times are consistent with those identified in other studies, such as the financial impact of seeking SLT privately in response to waiting times (Chu *et al.*, 2018), stress and uncertainty for families (Khanlou *et al.*, 2017), as well as delays in access to initial intervention. By viewing access through a holistic lens and adopting a qualitative methodology, this study has enabled the views of SLTs and other professionals to be captured on waiting times and identified the nature of the waits and multiple challenges as well as the impact of these.

The study found that high rates of vacancies were a considerable challenge for services in the research setting. Services need to think differently about SLT posts advertised, such as considering development posts and other ways to attract applicants and embracing different ways of working. Recruitment or availability of SLTs is a particular challenge in some contexts, with differences observed linked to geographical location and other barriers such as high costs of living for SLTs in some areas (Carson *et al.*, 2021). Challenges in SLT training and recruitment were recognised as difficult at a national level within some of the included literature in the scoping review in the context of autism support (Dababnah and Bulson, 2015; Fernandes *et al.*, 2014) and also in relation to general SLT services for children in the UK (Royal College of Speech and Language Therapists, 2023b).

This study identified that high vacancy rates impacted on waiting times for children and the service offered. Some efforts to reduce waiting times and increase access to SLT impacted negatively on other aspects of access, for example, many participants expressed dissatisfaction with the telephone appointments offered (to increase efficiency and reduce waiting times) instead of face-to-face appointments. The negative, unintended consequences of efforts to increase accessibility of SLT services was not explored within any of the studies included in the scoping review (Chapter 2).

Previous studies have captured challenges in providing evidence-based practice for autistic children due to insufficient resources (Cheung *et al.*, 2013; Sandham, Hill and Hinchliffe, 2021) and identified challenges in SLT service delivery due to reduced capacity (Binns *et al.*, 2022). Studies have also identified unmet SLT needs and insufficiency of available SLT services from the perspectives of parents as important issues impacting on access to SLT (Bromley *et al.*, 2004; Cassidy, McConkey and Slevin, 2008; Dymond, Gilson and Myran, 2007; Murphy and Ruble, 2012; Sapiets *et al.*, 2022; Srinivasan *et al.*, 2021).However, few of these studies explored the nature of these challenges, specifically in relation to access to SLT for autistic children. This study has addressed a gap in existing literature through capturing SLTs' and other stakeholders' perspectives on unmet needs and insufficiency of SLT, expanding on what is currently known about service-delivery barriers impacting on access to SLT.

At a time when SLT services are under considerable pressure to improve access to services and to reduce waiting times (NHS Confederation and NHS Providers, 2022; Royal College of Speech and Language Therapists, 2021a; 2023b), ensuring that increased productivity is not at the expense of quality of care is important. This qualitative case study has deepened knowledge of the ways in which waiting times and workforce issues not only directly impact on service delivery in relation to waiting times and amount of SLT input for children but can also impact on quality of care and on other aspects of access. The ways that the SLT context also influences SLT decisions and shapes models of service delivery is explored in the next section.

5.2.4 Individual SLT influences on access to SLT

The study highlighted the multiple ways individual SLTs' knowledge, skills, and perspectives impact on clinical decisions and service delivery for autistic children. Service pressures, such as high vacancy rates and long waiting times, had a considerable influence on the clinical decisions of SLTs. These included decisions on whether to offer a service and, if offered, the type and amount of input. Almost all participating SLTs felt they offered less support, in ways they considered to be less effective than they would like due to capacity constraints.

Waiting times appeared to be the main influence on clinical decisions from the perspectives of participating SLTs, leads managers, parents and other stakeholders. Some children were discharged from SLT due to long waiting times for the service, despite experiencing communication difficulties that would otherwise have led to SLT support. Participating SLTs, managers and leads shared their rationale for these decisions. Although SLTs reported parents and EY settings were signposted to general information on how to support communication development while waiting for SLTs, concerns were expressed by SLTs that families and other carers around the child may not be proactive in implementing this advice when waiting for SLT. This was due to the view of SLTs as experts who should provide direct SLT input. Several SLTs' believed that placing a child on a waiting list for SLT would reduce the communication support by those closest to them in every day settings. This concern, along with the SLT's awareness of the limited service available to families after waiting influenced SLTs' decisions on whether to add a child to a waiting list for further SLT or to discharge the child.

Whilst participating parents described a proactive approach to seeking support and implementing strategies while waiting, they may not be representative of other parents waiting for SLT who may behave differently. SLTs were concerned that parents and EY professionals not taking action to support children's communication while waiting for SLT may delay the child's access to communication support in their natural settings. Few studies have considered barriers to SLT for autistic children from SLT perspectives. However, a study of Canadian SLTs service provision for autistic children identified lack of time and funding to meet children's needs as a barrier to service delivery which impacted on the amount of SLT input offered to families (Binns *et al.*, 2022). The impact of waiting lists or service pressures on SLT clinical decisions relating to access to a service was, however, not identified in the scoping review (Chapter 2).

The ways in which participating SLTs perceive their role in supporting autistic children also influenced access to SLT. Although participating SLTs recognised the considerable communication support needs of autistic children, autistic children were at times perceived as a lower priority group compared with children with specific speech, language, and communication difficulties. The ways in which autistic children's needs have been perceived and prioritised by SLTs, and the impact of these perceptions and decisions on both access to and service delivery of SLT for children and their families, were not identified within the literature presented in the scoping review (Chapter 2). This is a novel finding within this study and has, therefore, drawn attention to another important issue which may impact access to SLT for preschool autistic children in other contexts.

These issues relating to clinical decisions of SLTs in pressured service contexts may have come to light in this study for several reasons. Firstly, this study deliberately sought the views of SLTs, leads and managers in both specialist and generalist roles, and so their views may differ from those of participants in some other studies on SLT service delivery who recognised themselves as autism specialists (Binns *et al.*, 2022; Trembath *et al.*, 2016). Secondly, in-depth, semi-structured interviews facilitated exploration of several barriers to service delivery and specifically asked for any areas of tension and challenge in service delivery and meeting the needs of children. Thirdly, the findings of this study may reflect the views of SLTs in the research setting of this bounded system and may not be a view shared by other SLTs beyond the research setting.

For autistic children who were offered SLT support, the study found SLT knowledge and skills was an important influence on the nature and quality of support offered. The study findings suggest that SLT knowledge and skills were influenced by the SLT context and changes aimed to increase efficiency of the service. For example, some SLTs talked about more experienced therapists completing phone assessments but not having broader opportunities to further develop their knowledge, skills and experiences due to more junior SLTs and SLT assistants providing direct input. Gaps in clinical knowledge and experience of SLTs has been identified as a barrier to service delivery within this study and others (Binns *et al.*, 2022; Gevarter, Siciliano and Stone, 2022). This study has additionally identified the ways in which efforts to increase efficiency may impact on how SLTs may build and maintain their clinical knowledge and skills in working with autistic children. There appeared to be a trade-off between different elements of access, where actions to improve one element of access inadvertently impacted on other aspects of access and quality of care (Chapman *et al.*, 2004).

5.2.5 Overall summary

Overall, the findings suggest there is little evidence-based SLT intervention available to children and their families, and families face considerable challenges in their pursuit of SLT. This raises the question of whether the work required to access SLT and stress this can cause families is ultimately worth the effort taken to try to gain access. Although the SLT service was highly valued by several participants and captured in theme five: “worth the effort”: the drive to access SLT, a worsening picture of SLT service delivery was also presented. SLT support described by participants often involved generic strategies with limited support for families to then effectively embed strategies in everyday routine and play activities with their children. The considerable stress and emotional impact of the challenges gaining access could be viewed as iatrogenic or systems-related harm for parents. Iatrogenic harm is a concept that has been considered in the

field of medicine and physical harm for several decades, however the psychological impact of systems related harm is also increasingly recognised (Rees, 2012) .

This concept of psychological harm and access to services has been explored in the context of autistic children and access to mental health services (Ashworth *et al.*, 2025). Iatrogenic harm associated with access to SLT was acknowledged by some SLTs in relation to how it may impact on children's outcomes through those around the child not implementing strategies due to the perception that SLT should happen directly between the SLT and the child. When the wellbeing of parents is also considered, this risk of systems-related harm also extends to parents due to the ways in which existing systems and processes impact on their experience of seeking access to SLT for their child. Given the considerable challenges relating to access SLT services, psychological harm from the process of access as well as potential harm related to not receiving an evidence based SLT services needs to be considered in decisions on services offered to autistic children and their families.

5.3 Objective three: To identify opportunities to improve access to SLT for preschool autistic children.

Opportunities to improve access to SLT were identified through thoughtful engagement of stakeholders and recruitment of participants who shared important perspectives on different aspects of access to SLT. This generated rich data on the topic that was then analysed inductively using reflexive thematic analysis. Prominent themes impacting on access to SLT were generated and enabled identification of the importance elements influencing access to SLT. Opportunities to impact on these areas were then identified through consideration of the potential root causes of issues identified. The importance of engaging stakeholders in generating solutions is recognised across all possible opportunities for improvement identified during the course of this study. The opportunities to improve access to SLT for preschool autistic children developed from the study findings are described in the final chapter.

5.4 Summary of the key findings

The key findings and the novel contribution of the study are summarised in Table 17.

Table 17 Key findings and novel contribution of the study

Element impacting access to SLT	**Key findings**	**Novel contribution**
Parents' role	Parents play a crucial role in gaining access to SLT for their child. Access is influenced by parents' motivation, confidence and previous encounters with healthcare professionals. Parents also draw on personal and relevant professional experiences to support access to services.	They study has captured the strengths, abilities and qualities of parents that act as facilitators to access. This adds to what is already known on this topic as, to date, existing literature has primarily focused on parent-related barriers to access. The study also presents a holistic view of parents' influence on access to SLT through directly capturing the views of parents and also though gaining the insights of health, education and EY professionals who work closely with parents.
Perceptions and expectations of SLT	There is a mismatch in expectation of SLT intervention between SLTs and parents which impacts access to SLT. Differences in opinion relating to the roles of parents and SLTs in therapy and the mode of delivery, frequency and intensity of SLT contributes to confusion and frustration for all involved. This then ultimately influences the SLT support received by the child.	This study finding has deepened understanding of the issue of differing expectations of SLT through exploring this topic in the UK context. It also extends what is known on this topic through identifying the ways in which different expectations and views of the SLT service impact how SLTs make decisions and how parents view their role in therapy.
Social context	Professionals' unresponsiveness, inaction,	This study finding deepens understanding of difficulties accessing support services for

	and lack of recognition of both parental expertise and children's needs contributes to delays in access to SLT support.	autistic children and their families specifically in the UK SLT context. The study captures the financial and emotional impacts on families and the additional work needed to advocate for their child.
SLT service issues impacting access	Long waiting times for SLT services due to the high demand for the service and the SLT workforce gaps impacts on several aspects of access including timeliness of input and the quality and experience of care.	This finding extends what is currently known about waiting times and SLT through focusing specifically on SLT intervention and autism in the UK context. The study captures multiple perspectives on how waiting times influence both entry to the service and access to meaningful intervention within the SLT service. This includes the ways in which long waiting times influence the decisions for SLT. Through exploring this topic from the perspective of SLTs, parents and other health, education and EY professionals, additional impacts on access have been identified in addition to the delays in support identified in other studies.
SLT knowledge, skills and perspectives	SLT service pressures and SLT views of autistic children's need for support influenced SLT decisions on whether or not to offer an SLT service to children and influenced the type and amount of support offered. Input was also influenced by the knowledge and experience of the SLT.	The finding that some SLTs perceive autistic children as being lower priority for support is novel to this study. This is an important finding that influences not only the clinical decisions of SLT relating to individual children but also influences models of service delivery.

5.5 Summary of the chapter

This chapter has discussed the findings presented in Chapter Four and positioned them within the existing literature on access to SLT. The ways in which the study has answered the research question have been presented. Access to SLT is impacted by several factors related to parents and SLTs and further influenced by gatekeepers to services and the context of service delivery. Recommendations for improving access to SLT are made in the following final chapter which will then conclude with a consideration of the study's strengths and limitations, and a reflection on the research process.

Chapter 6 Conclusion

6.1 Summary of the study

The importance of early communication intervention and access to SLT for autistic children is well-recognised. However, despite this, very few studies have focused specifically on access to SLT for autistic children. This dearth of research is particularly surprising given the healthcare barriers and inequalities faced by autistic people and the wider awareness of the challenges that all people in the UK with communication needs encounter in accessing SLT. The scoping review presented in Chapter 2 identified several barriers and facilitators to access. However, these were primarily identified through examining patterns of utilisation, with few studies exploring stakeholder perspectives and no studies exploring the views of different stakeholder groups together. This limits the strength of these studies given how access is a complex, multi-dimensional process that involves several individuals and is influenced by many factors. Additionally, previous studies have primarily sought to understand autistic children's access to a wide range of services, including SLT, or focused on broader SLT service-delivery issues. Although these studies make references to the theme of access, it is not the primary focus and, therefore, the studies provide limited insight into the specific challenges related to access to SLT services and fail to facilitate a holistic understanding of access to SLT in the UK.

Access to SLT for preschool autistic children has, therefore, been an area where there has been little specific research focus to date, leading to limited recognition of the specific challenges associated with autistic children's access to SLT. The study presented in this thesis was designed to address gaps in the existing literature and to provide a holistic view of access to SLT for preschool children in the UK in its real-world context. A qualitative case study methodology was selected to facilitate this study. In-depth, semi-structured interviews were completed with 23 participants from different roles related to access to SLT, and five main themes identified through reflexive thematic analysis of the whole data set. This enabled patterns of meaning to be generated, revealing the important barriers, facilitators and influences on access from a range of people involved with access to SLT. The findings have addressed the research question and, along with a rich description of the context of service delivery, have presented information for readers to determine the relevance of the findings to their own settings. The findings and their links to existing evidence have been discussed in Chapter Five, and recommendations for policy, practice and research linked to these will now be presented.

6.2 Recommendations for policy and practice

The following policy and practice recommendations have been developed based on the study findings and their relationship with the existing evidence base and the practice context of SLT for preschool autistic children in the UK.

6.2.1 Recommendation 1: Professional awareness of parent influences on access to SLT

Parents influence access to SLT for their child in several ways. Parents can facilitate access to SLT through their knowledge of autism and child development, their motivation and confidence, and their previous healthcare and parenting experiences. Greater professional recognition of these influences on access and of the challenges and inequity parents can face when these are not present is important. This is a key area for policy and practice that could be achieved through integrating information on parent-related barriers and facilitators to access into core professional training as well as within continuous professional development training and existing clinical and professional guidelines for primary care staff, such as GPs, health visitors and SLTs. Including information on healthcare barriers experienced by autistic adults may also be important given that autism is highly heritable (Sandin *et al.*, 2014) and the barriers that autistic adults face in accessing healthcare services may also impact on parents of autistic children in their efforts to access SLT for their child.

As autism is a common, lifelong condition, often associated with additional health and support needs, autistic people may require access to several forms of support across all stages of their lives (Green, 2019). Healthcare professionals' understanding, support and actions to facilitate access to services will, therefore, not only support access to autism diagnosis and support services, such as SLT, but also a range of other healthcare services that provide support for the co-occurring difficulties associated with autism throughout a person's lifetime (Shaw *et al.*, 2024). The *Health and Care Act 2022* explicitly states that from 1 July 2022, all CQC registered providers should ensure all health and social care staff receive training on autism and learning disability appropriate to their role. The Oliver McGowan training (NHS England, 2024b) is the training recommended by the government and has been co-produced and will be co-delivered by people with lived experience of autism and learning disability. This training provides an opportunity for organisations to explore barriers to healthcare that are relevant to the people they are working with and reflect on the accessibility of their own services (NHS England, 2024b).

6.2.2 Recommendation 2: Proactive referral of the child to SLT

The study findings suggests proactive referral to SLT for autistic children should be considered. Referral to SLT at the point of referral for autism assessment or at autism diagnosis would reduce the need for parents to fight for services. It would also start to address inequity in service access through reducing reliance on the knowledge, experience and skills of parents to self-refer to SLT, or to request a professional referral to SLT services. Not all children and their families need or would like SLT input and therefore a proactive *offer* of referral rather than referral of all children would support access to early intervention for those requiring this, whilst making best use of resources and respecting individuals' choices (Royal College of Speech and Language Therapists, 2023). Proactive offer of referral would support access-entry part of access to a service, however, it would not address the within-service access challenges also identified during the course of this study that relate to decisions on the type and amount of SLT once initial access to a service has been gained (Gulliford *et al.*, 2002).

6.2.3 Recommendation 3: Co-production of SLT services with parents and continuous quality improvement

Access to SLT for autistic children could be supported through a stronger focus on the needs, preferences and experiences of parents in service design. This could be achieved through co-production of services with parents and routine patient feedback to inform continuous improvement of services. This is a key area for policy and practice development to improve access to SLT.

Although co-production is increasingly recognised as a crucial part of service development and quality improvement (Realpe and Wallace, 2010), it remains challenging in pressured contexts where productivity is often prioritised (Mukoro, 2023). However, organisations that have focused on quality of care for patients, rather than on externally set performance targets, have achieved additional improvements in productivity as a result of their patient-focused efforts (Care Quality Commission, 2018). Co-production facilitates a greater degree of empathy and understanding, and may be enhanced through principles of experience-based design (NHS Institute for Innovation and Improvement, 2009) to support a move from good processes from a service delivery perspective to processes that provide a good experience for those seeking to access a service (Pickles, Hide and Maher, 2008). Focusing on the family's journey from recognition of the child's possible need for SLT through to access to an SLT service enables a holistic, person-centred view of access rather than a focus on discrete service steps and

processes. Local co-production of SLT services with families with different experiences, knowledge, and skills and engagement of wider stakeholders would support development of a shared understanding of the challenges. Inclusion of wider stakeholders who work with families enables them to bring their own insights gained through working with families and provides an opportunity for them to advocate for, and bring in, the perspectives of families who are unable to/choose not to participate in service co-production. Newcastle Autism Team share an example of adapting SLT service delivery to meet the needs of the local population through online delivery of an autism-specific intervention (Povey, 2024). However, although the project was considered to be successful, parents who wish to access this support face longer waits unless additional funding can be secured (Povey, 2024). This highlights the challenge to embedding good practice that meets the needs of children and their families into everyday practice and the importance of adequate resource to support with embedding improvements into everyday practice.

To ensure continuous quality improvement informed by the needs and preferences of families, there should be a focus on creating conditions where families feel comfortable and psychologically safe to provide regular feedback to services. Effective processes for gathering, analysing and responding to feedback are crucial for improving services and ensuring high-quality services that make best use of available resources. This is particularly important for families of young autistic children who, due to various factors associated with having a young autistic child, may not feel comfortable or able to share concerns and feedback with services (Auert *et al.*, 2012; Trembath *et al.*, 2016). Processes for gathering feedback should be integrated into routine care and co-created with families to ensure that this is effective and does not create unnecessary burden on families or unrealistic workload for SLTs. This could be supported by the knowledge and insights of Special Educational Needs and Disabilities (SEND) Parent Carer Forums. Most areas of the UK have a forum where parents and carers work with local authorities and health and education services to inform commissioning and service delivery to meet the needs of children and their families (Contact, n.d.).

NHS IMPACT (NHS England, n.d.-a) is a single, NHS-wide improvement approach that aims to build the conditions for continuous quality improvement and high performance. Engaging people with lived experiences of services is a key aspect of NHS IMPACT and one that is supported by other elements of NHS IMPACT, including development of leadership for improvement, improvement capability and developing an integrated improvement management system. A holistic approach to embedding all elements of NHS IMPACT within NHS Trusts,

therefore, has the potential to build a supportive foundation for both patient co-production of services and continuous improvement in the everyday work of organisations. This aligns with key themes of Lord Darzi's report on the state of the NHS in England, 'Independent investigation of the NHS in England' (Department of Health and Social Care, 2024) which highlights the importance of working to re-engage staff and re-empower patients to improve care.

6.2.4 Recommendation 3: Understanding and managing service capacity and demand

The study has identified workforce issues and waiting times as two important and interlinked barriers to service delivery. SLT participants also raised the challenges of working to address issues to improve service delivery and access when demand outstrips capacity, with limited time and resource available to make changes aiming to improve the service. The significant capacity and demand issues and multiple waits within the SLT service emphasises the importance of in-depth work to accurately map capacity and demand, considering the whole patient journey and all the steps involved with access (NHS England and NHS Improvement, 2022).

Addressing capacity and demand challenges involves a focus on the whole patient journey, understanding how the system currently works, and identifying what aspects of SLT service delivery really matter to children and their families. Once the current system has been understood and activities that are considered valuable from the perspective of children and their families identified, an in depth understanding of demand is required (NHS Improving Quality, 2014). Understanding demand means identifying the characteristics and needs of those who are seeking the service and considering the type of support that is most appropriate and effective for meeting these needs. This can be explored locally through patient co-production approaches to service improvement and also in further research on which autistic children and their families are most likely to benefit from SLT support. Identifying those who will most benefit from SLT support may then lead to a reduction in demand for SLT service and release time for SLTs to focus on providing higher quality SLT care for those who are accessing the service.

In addition to managing demand for the service, techniques to maximise existing capacity can be applied such as considering team roles and training needs, and avoiding batching of tasks such as report writing (NHS Improving Quality, 2014). A process of continuous quality improvement is required within all healthcare services to ensure services are safe, timely,

effective, efficient, equitable and patient-centred (NHS England, n.d.). Improving service processes through removing duplication, time spent completing unnecessary work and time spent making and fixing errors can release time to spend on autistic children and their families.

Changes that aim to reduce waste and streamline process can then be tested using small tests of change (plan, do, study, act cycles) to facilitate rapid cycles of learning and improvement (The Health Foundation, 2021) may be useful alongside work to understand service capacity and demand. This enables services to test changes aimed to maximise capacity and provide high quality care whilst minimising disruption and the resources required to test changes (Reed and Card, 2016). Robust measurement of tests of change would help identify the benefits and unintended negative consequences of changes (Institute for Healthcare Improvement, n.d.).

Policy and practice that promote opportunities for services to connect to share ideas, good practice, and other relevant learning in relation to addressing workforce issues both locally and nationally would also be helpful. This may be supported by clinical improvement networks (NHS Elect, n.d.) and approaches such as improvement collaboratives where several groups from separate organisations come together and apply a structured improvement methodology to support with understanding and addressing common issues in ways that are efficient and maximise learning and connection (Zamboni *et al.*, 2020). It may also be possible to prioritise and influence improvement in the area of access to SLT through Joint Forward plans (NHS England, 2022); these are mandatory five-year plans developed by Integrated Care Boards that can facilitate collaborative learning and improvement across several Trusts in the local health and care system.

6.2.5 Recommendation 4: Transparent SLT decision-making and provision of evidence-based information on SLT support

The study findings identified that SLT input was often deemed insufficient to meet the needs of children and their families from parent, SLT and other stakeholder perspectives. This was captured in theme four: the perceived quality costs of increased productivity. The RCSLT states the importance of being open and honest with families in relation to clinical decision-making and about modifications to support due to resource constraints (Royal College of Speech and Language Therapists, 2022). Families, therefore, need information available on evidence-base for support as well as information on modifications or unavailability of support. Whilst this information needs to be available for families, SLTs also need to be sensitive to parents'

information needs and timing of information (Trembath *et al.*, 2016). Information needs to be communicated sensitively so that information does not increase expectations or lead to additional burden and worry for families. The provision of high-quality written information alongside open discussions between families and SLTs has the potential to support parents' ability to engage in meaningful discussion about SLT interventions. It may also highlight unmet needs and gaps in service provision that could inform service delivery and the commissioning of services. Families could also be empowered through information to make their own informed decisions on whether to access private SLT services, if able to.

In addition to this, the study findings identified that parents and SLTs differed in how they viewed the most effective SLT support for children. The provision of evidence based information on the importance of parent-mediated therapy would help manage parents' expectations and may increase their confidence in parent-mediated approaches. Creating and updating evidence-based summaries on SLT support for autistic children and their families is challenging as there is no one best specific intervention for autistic children and their families. However, clinical decisions should be made based on the best available evidence (Royal College of Speech and Language Therapists, 2018; 2023a) and SLTs have a responsibility to be open with families (Royal College of Speech and Language Therapists, 2022). Clear, evidence-based summaries may help support parents and other stakeholders to understand the overall approach to SLT support (social vs medical model) and rationale for decisions. High-quality, written information may also address another study finding related to limited knowledge and skills of SLTs. Up-to-date evidence-based summaries may support SLTs' knowledge and confidence in summarising and discussing the evidence base with families. The RCSLT clinical guidelines and information for the public on autism (Royal College of Speech and Language Therapists, 2023a) could form a basis for the development of concise, accessible information tailored to families' needs.

6.3 Recommendations for further research

There have been few studies exploring access to SLT for preschool autistic children. This study has identified several factors impacting on access to SLT, including service pressures and processes, healthcare professionals' understanding of autism and communication difficulties, and SLTs' knowledge, skills and perceptions of autism and autism-specific communication supports. As well as generating new findings about access to SLT, the study has identified several potential areas for further research.

The study has identified that the way in which autistic children's needs are perceived by SLTs, relative to children with other speech, language and communication needs impacts on service delivery for autistic children. An examination of SLT clinical decision-making processes and the roles of SLTs as gatekeepers to their services, as well as the roles other professionals with a gatekeeping role in relation to referrals, is important. Even within structured care pathways, several individual decisions may still be made based on gatekeepers' values, beliefs and judgments (Greenfield, Foley and Majeed, 2016). This may result in variation in the care provided to families. Considering gatekeeper perspectives and gaining insight into the ways in which gatekeeping decisions impact on access to SLT is particularly important as resources become more constrained and more challenging decisions emerge in relation to SLT service delivery and allocation of the finite resources available.

The study presented in this thesis has identified important issues related to SLT and service gatekeeper beliefs about autistic children and how these influence access. Further research that focuses specifically and in further depth on the communication and interactions between parents, SLTs and gatekeepers to SLT services would be valuable. This aspect is particularly relevant as service resources are increasingly constrained. Theories that support examination of health care interactions and unequal treatment, such as cultural health capital (Shim, 2010), may be useful to consider in the context of specific service changes, such as changes from face to face to telephone appointments. Cultural health capital considers the ways in which the verbal and non-verbal communication, interactions, attitudes and behaviours of both patients or their carers and healthcare professional interactions influence access to treatments (Shim, 2010).

6.4 Dissemination of findings

Sharing the study findings with the people who gave their time and information to the study was essential. During the study, information has been shared with several groups and communities in various ways (see section **Error! Reference source not found.**). The National Institute of H ealth and Care Research (NIHR) summary for this study was also published online.

People engaging in research have a right to know what was achieved with their information. This is an important part of building trust, engagement and participation with people and engagement with future studies (National Institute for Health and Care Research, 2024). All participants were asked at interview whether they would like a copy of the findings to be shared with them; all participants stated that they would. Their response was clearly recorded in a

password protected spreadsheet with their contact details. The research summary was written following guidance from NIHR (National Institute for Health and Care Research, 2024) and is found in Appendix G. Several participants acknowledged receipt of the summary and expressed thanks and interest in the findings, but no other comments were received.

The following manuscript titles are currently being prepared:

- Barriers and facilitators to access to Speech and Language Therapy: a scoping review, for submission to Review Journal for Autism and Developmental Disorders
- Access to Speech and Language Therapy for Preschool Autistic Children: a qualitative case study, for submission to International Journal of Speech-Language Pathology

The findings will also be shared with autism and communication charities and organisations such as the National Autistic Society, Autistica, I CAN and the Royal College of Speech and Language Therapists. Findings will be disseminated via publications and presentations so that organisations may utilise the findings in their work to influence policy.

6.5 Study strengths and limitations

The study has the following strengths and limitations:

6.5.1 Strengths

- This is the first study to specifically look at access to SLT for preschool autistic children in the UK. The specific focus on this age group, along with the specific focus on SLT, has supported recognition of the unique challenges and opportunities in relation to access to SLT.

- Collaboration with several stakeholders in the design and conduct of the study ensured valuable perspectives on access could be captured through enabling some barriers to participation in the study to be identified and addressed. Stakeholder engagement also guided the approach to recruitment and aimed to provide a wide range of stakeholders an opportunity to participate, crucially including those who had been unable to/chosen not to access SLT.

- Despite the considerable pressures on healthcare and SLT services, the study successfully recruited a range of participants. The researcher's knowledge and insight

into service values, ways of working and professional credibility may have supported this level of engagement. Positive engagement with the study also indicated that this was an important topic for stakeholders in the research setting.

- Although the study does not seek to generalise from the findings, but to understand access to SLT, there was some diversity in the sample in some areas including the mix of specialist and generalist SLTs, the diversity of roles of all professional participants and diversity in relation to parent ethnicity. This helped capture different perspectives on access to SLT.

- The transparent approach to this study has enhanced the trustworthiness of the research. A clear account of the research process, the rationale for decisions made, the nature of the data collected, the process of analysis and researcher interpretations have been provided. This supports the trustworthiness of findings and provides information for readers to consider the ways in which the findings apply to their own contexts.

- Reflexive thematic analysis enabled a rigorous, inductive approach to analysis aligned with the research perspective and study methodology. This has aimed to ensure that all issues that were important from the perspectives of participants were considered, which may have been missed through a deductive approach to analysis. The application of the most recent guidance on reflexive thematic analysis (Braun and Clarke, 2021) as well as use of NVivo (Lumivero, 2020) has supported a methodical and transparent approach to analysis. Training and coaching on use of NVivo has reduced the impact of common barriers to effective use of computer assisted qualitative data analysis, such as the time needed to learn to use the software (Creswell and Poth, 2018), and maximised the benefits associated with quick and easy access to data and the ability to view data in different ways.

- This instrumental qualitative case study has supported the design and structure of the study and supported key decisions around defining the context or bounded system for the study. It has ensured that access to SLT as a phenomenon has been at the centre of the study, enabling a rich and deep exploration of access. It has also supported clear alignment and coherence between the study research perspective, methodology and

approach to data collection and analysis and has recognised the value and centrality of the role of the researcher within the study. Together, this enables readers to make sense of the findings, and the strengths and limitations of the study.

- Understanding the complexity of access to SLT in the UK has been facilitated through the constructivist research perspective. The constructivist perspective has ensured that multiple perspectives on access have been captured and considered in the context of the SLT service and wider healthcare context. The study has enabled the experiences of parents and other stakeholders to be captured directly. The study aimed to take an inclusive approach and gained some insight into the experiences of parents *not* participating in the study through hearing the perspectives and observations of professionals working with a wide range of families.

6.5.2 Limitations

- Although a range of perspectives were captured in the study, there were notable gaps in relation to the views of children themselves and in relation to the views of fathers and other key caregivers. It is also recognised that stakeholders may not have chosen to/been able to participate for several reasons such as time, not being interested in the topic or not feeling they had a valuable perspective to share. This may, therefore, impact on the relevance of the findings to others involved with access to SLT. Although stakeholders such as GPs and SLT assistants were eligible to participate, none participated. Given their key roles in supporting autistic children and their families, gaining insight into their perspectives and experiences, both of access to services and of the available SLT support, would be a valuable area for future research.

- Study materials were distributed in hard copy and electronic format in several ways. However, the primary route to participation was via an email to the researcher to express interest in the study. This may have presented a barrier to some potential participants due to the impact of literacy, digital access, language and confidence issues. Positively, some parents asked an intermediary to share their contact details with the researcher which supported their participation. Additionally, information from study stakeholders did not suggest that this was an area of particular concern or barrier to participation from their perspectives.

- Child details such as diagnosis were not verified in any way. Additionally, detailed information on the child's speech, language and communication abilities and the specific SLT and other interventions offered and received were not captured formally. This is like many other studies on this topic, and although there was no cause to doubt the diagnosis or clinical need for SLT of any child, more in-depth information may be important within future studies if there is a greater focus on how child and family factors influence SLT decisions relating to the service offered. This would be particularly important in studies focusing on how SLT services prioritise support for children and make decisions on which interventions to offer.

- All study materials were in English and there was no interpreter to enable those whose first language was not English and did not have sufficient language skills to participate. It is not known to what extent the findings are relevant to those who were unable to participate for this reason. As participants self-selected to participate, the extent to which the findings are relevant to others not participating in the study is not known.

- The study took place in a single setting in the south of England. Although information on the two health Trusts within this setting suggests the Trusts did not differ significantly from others on high-level performance measures and staff/patient feedback, it is not known to what extent service cultures and practices in the research setting differ from others. The presentation of SLT service processes and waiting times in the research setting aimed to provide some contextual information on the services to be considered alongside reflexive thematic analysis of interview data.

- The aim of analysis for this study was to gain a holistic view of access. The entire data set was, therefore, analysed using reflective thematic analysis. This captured important patterns of meaning across the entire data set. Differences in perspective between participant groups may have become apparent if data had been analysed separately.

- Information power (Malterud, Siersma and Guassora, 2016) was an important concept that guided sample size in this study and this was considered along with more traditional approaches to determining sample size such as through considering the precedent set on sample size in similar studies, and the guidance of methodologists. The data gathered in this study was rich and focused on the issue of interest and from

individuals with highly relevant knowledge and experiences of this topic. It is recognised, however, that some participating parents had additional experience and knowledge (e.g., roles as EY professionals and experiences with older siblings and other autistic children), which may have influenced the topics discussed and data gathered. Gathering information from a wide range of stakeholder perspectives enabled the experiences of more parents to be captured, albeit through the lens of health, education and care professionals. However, directly capturing the views of parents with a wider range of experiences would have been useful and could have been achieved through recruitment via the participating NHS Trusts.

- The limitations and challenges associated with remote interviews were recognised from the outset and attempts to minimise these were carefully considered. High-quality, in-depth data was gathered despite being unable to engage in face-to-face interviews. However, remote interviews may have dissuaded some participants from engaging in the study. Furthermore, the use of a video conferencing tool may have inhibited participants from speaking openly and honestly, as well as possibly influencing the rapport between the participants and the researcher.

6.6 Reflections

6.6.1 Reflections on the study

The use of a qualitative case study methodology has enabled in-depth focus on an important aspect of intervention for autistic children that has been largely unexplored. Access to early and effective intervention is not only crucial to addressing the immediate needs of the child, but it also has the potential to impact on several future lifetime outcomes for a child and their family. An inductive approach within this study has illuminated some of the challenges and opportunities around access to SLT and these findings have then been explored in the context of existing literature on access to SLT. A conceptual model to explain access to SLT has been developed from the study findings and opportunities to improve access have been identified.

Recruitment and data collection for the study took place during a very challenging time due to COVID-19. This impacted on all aspects of the study, across stakeholder engagement, participant recruitment and data collection. The personal, emotional, professional and health impact of COVID-19 impacted on all individuals including the researcher and all participants in

one way or another during this time. The study design was amended in response to the national COVID-19 restrictions. Although there were challenges associated with a reduction in face-to-face interaction with participants and stakeholders, there also appeared to be some benefits. The use of virtual meetings enabled the researcher, stakeholders and participants to engage flexibly in ways that may not have been possible face-to-face due to practical issues such as time constraints and travel time and costs.

6.6.2 Reflections as a researcher

My clinical experiences as an SLT led to my focus on this research topic, and my aim has been to contribute to knowledge on the important topic of access to SLT to improve outcomes and experiences for children and their families. Although I am not currently practising as an SLT, I view my insider knowledge and experience of this research topic as a strength of this study that supported study design and engagement with stakeholders and participants. I was aware of the possibility that my clinical background may have led me to make assumptions about SLT practice and decisions and worked to maintain a high level of awareness and reflexivity throughout the conduct of the study.

The personal challenges associated with balancing my work in the NHS, and various research activities with having a young family, were very demanding at times. There were many points I doubted my ability academically, and my ability to balance all the things that I wanted to dedicate my time and attention to both personally and professionally. I felt a strong moral obligation to persevere, however, as this is a topic that has interested me, and I have felt passionate about for many years. I also felt a responsibility to complete the study for all those who had given their time, their information, and their support to the study and to my development.

Although experiencing doubts, stress, and low confidence was, at times, challenging, it also drove me to seek out support and feedback from others. This contributed significantly to my learning and development, and the ways in which I face challenges. I felt it also brought a greater degree of empathy for the pressures experienced by study participants, with whom I often had much in common. I have remained interested in this topic and committed to contributing to improving the lives of children and their families through effective communication support throughout the study.

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Appendix A Scoping review

A.1 Scoping review protocol (2018)

Review question	What is currently known about factors impacting on access to SLT for preschool Autistic children?
Eligibility criteria	Population: Autistic children Concept: Access to services (including child, carer and service factors). Context: Speech and Language Therapy services in any country. The search will be limited to English language literature due to no funding for translation of articles. The search will also be limited by date (from 1993) to reflect the most recent diagnostic criteria for Autism.
Types of sources	Peer-reviewed journal articles. PhD and Doctoral theses.
Search strategy	The search strategy will aim to identify relevant literature through searching MEDLINE, PsychINFO and Cumulative Index of Nursing and Allied Health (CINAHL). The reference lists for all included articles will be examined to identify further potentially relevant literature. Articles citing the included literature will also be searched using Web of Science citation searching.
Evidence selection	Following the search, all identified citations will be imported into EndNote and combined in one folder and duplicates removed. Potentially relevant articles will be reviewed by two reviewers and the eligibility criteria applied. The full text of selected citations will then be retrieved and assessed for eligibility. This will be completed by two reviewers and differences discussed. The results of the search and included literature will be presented in a Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) flow diagram (Moher *et al.*, 2009).

Review question	What is currently known about factors impacting on access to SLT for preschool Autistic children?
Data extraction	Data will be extracted by two reviewers using a tool developed by IW and reviewed and agreed with the 2nd reviewer. The data extracted will be relevant to the review question. The draft extraction form includes the following headings: • Author • Country • Sample • Data collection method • Selected themes/findings • Limitations • Relevance Although critical appraisal for included sources of evidence is not generally required for a scoping review (Peters *et al.*, 2017), this will be completed and provided in the data extraction table as the purpose of this review is to identify opportunities for further research.
Data analysis and presentation	A thematic analysis of issues impacting on access to SLT in the included literature will be presented.

A.2 Literature sources searched and rationale

Source	Rationale
Google Scholar	Google scholar is a web-based academic search engine that provides access to a substantial amount of academic and grey literature such as articles not published by commercial academic publishers. This was selected to help identify any literature that may be relevant to access to SLT for preschool autistic children.
NICE	Independent organisation providing national guidance on promoting good health / preventing ill health. NICE produce clinical guidance on Public Health, Health Technologies and Clinical Practice. This was selected to identify evidence-based information relevant to the study.
Google	Google is a web-based search engine that provides access to a wide range of literature. Advanced searches of specific sites including Autistica, National Autistic Society, UK government website, UK Parliament, House of Commons Library and The Royal College of Speech and Language Therapists were completed in addition to general searches within Google.
Trip database	Medical search engine with emphasis on evidence-based medicine and clinical guidelines and queries, including content from Cochrane and Bandolier.
The British Library	This was selected to identify any literature relevant to the study. Reports, conferences and theses can be searched through the British Library Integrated Catalogue.
Cochrane Library	Collection of six databases that contain different types of high-quality, independent summaries on the effectiveness of various health treatments and interventions.
EThOS (e-theses online service)	This is a free research tool that provides access to over 600,000 UK University awarded doctoral theses.

Source	**Rationale**
ProQuest Dissertations & Theses	The most comprehensive available record of doctoral theses from the United Kingdom and Ireland.
Cumulative Index of Nursing and Allied Health (CINAHL)	CINAHL is a comprehensive database of full text literature related to midwifery, nursing, occupational therapy, physiotherapy, podiatry, health education and other related subject areas. As Speech and Language Therapy is an Allied Health Profession, this database was selected.
PsychINFO	This is a database for psychology related subjects. It was included as literature relevant to experiences of access to Speech and Language Therapy may be contained in the journal articles, books and dissertations.
MEDLINE (EBSCO)	MEDLINE is a comprehensive medicine and clinical science database, covering literature across all areas of healthcare including allied health services. It was included as this work focuses on access to a healthcare service.
Web of Science	Includes access to a wide range of databases that provide reference and citation data from academic journals, conference proceedings and other relevant academic literature. It was selected as it enables citation connections across a wide range of literature to be explored and enables access to a wide range of literature.

A.3 Full strategy in MEDLINE (EBSCO)

MEDLINE Search Strategy (EBSCO) (Literature search performed: 29 September 2023)

Search #	Search terms
S1	TI autis* OR AB autis*
S2	(MH "Autistic Disorder")
S3	(MH "Autism Spectrum Disorder")
S4	(MH "Neurodevelopmental Disorders")
S5	(MH "Child Development Disorders, Pervasive")
S6	OR/S1-S5
S7	AB (child* OR preschool* OR young* OR toddler*) OR TI (child* OR preschool* OR young* OR toddler*)
S8	(MH "Child, Preschool")
S9	S7 OR S8
S10	S6 AND S9
S11	AB (access* OR barrier* OR factor* OR experience* OR provision) OR TI (access* OR barrier* OR factor* OR experience* OR provision)
S12	(MH "Health Services Accessibility")
S13	S11 OR S12
S14	AB (“speech and language therap*” OR “speech language therapy” OR “speech and language patholog*” OR “speech-language patholog*” OR “SLP” OR “SLT” OR “speech patholog*” OR “speech therap*”) OR TI (“speech and language therap*” OR “speech language therapy” OR “speech and language patholog*” OR “speech-language patholog*” OR “SLP” OR “SLT” OR “speech patholog*” OR “speech therap*”)
S15	(MH "Speech-Language Pathology") OR (MH "Speech Therapy")
S16	S14 OR S15
S17	S10 AND S13 AND S16
S18	S10 AND S13 AND S16 [Limit to 1994 - current]
S19	S10 AND S13 AND S16 [Limit to English]

MeSH terms [MH]

A.4 Literature excluded after full text review

Author and Year	Title	Reason excluded at full text review
Bejarano-Martín *et al*. (2020)	Early Detection, Diagnosis and Intervention Services for Young Children with Autism Spectrum Disorder in the European Union (ASDEU): Family and Professional Perspectives	No SLT specific data reported in relation to access, other than SLT is commonly accessed. All other data on accessibility, and challenges for all interventions.
Benevides, Carretta and Lane (2016)	Unmet Need for Therapy Among Children with Autism Spectrum Disorder: Results from the 2005-2006 and 2009-2010 National Survey of Children with Special Health Care Needs	No SLT-specific information reported.
Benevides (2014)	Access to therapy for children with autism: A population-based analysis	No SLT-specific information reported.
Benevides *et al*. (2017)	Therapy access among children with autism spectrum disorder, cerebral palsy, and attention-deficit-hyperactivity disorder: a population-based study	No SLT-specific information reported.
Bhat (2021)	Analysis of the SPARK study COVID-19 parent survey: Early impact of the pandemic on access to services, child/parent mental health, and benefits of online services	No SLT specific information other than SLT was the most disrupted service during COVID-19.
Binns *et al*. (2021)	Looking back and moving forward: A scoping review of research on preschool autism interventions in the field of speech-language pathology	No clear link to access to SLT. Focus is on evidence base for SLT, not factors impacting on SLT service delivery or access by families.
Bitterman *et al*. (2008)	A National Sample of Preschoolers with Autism Spectrum Disorders: Special Education Services and Parent Satisfaction	No SLT-specific data reported, other than SLT commonly accessed. All other data on accessibility, and challenges for all interventions grouped.
Dallman *et al*. (2021)	Systematic review of disparities and differences in the access and use of allied health services amongst children with autism spectrum disorders	The systematic review focuses on use of allied health services and is not focused on SLT (reference list reviewed to identify studies of specific relevance to this scoping review).
Daniels *et al*. (2017)	Autism in Southeast Europe: A Survey of Caregivers of Children with Autism Spectrum Disorders	No SLT-specific issues in relation to access reported.

Author and Year	Title	Reason excluded at full text review
Drummer Taylor (2007)	The perceptions and experiences of mothers of autistic children regarding support services received (California)	Unable to retrieve.
Gillon *et al*. (2017)	International survey of speech-language pathologists' practices in working with children with autism spectrum disorder	Focus is on the nature of the available Interventions, not on issues related to access to SLT.
Hussain and Tait (2015)	Parental perceptions of information needs and service provision for children with developmental disabilities in rural Australia	Relevant issues and themes to access to SLT, however children with developmental disabilities are the focus, with no % diagnosed as autistic provided in the results. Several services considered alongside SLT.
I CAN and RCSLT (2018)	Bercow: Ten Years On	No Autism-specific data reported.
Khetani, Richardson and McManus (2017)	Social Disparities in Early Intervention Service Use and Provider-Reported Outcomes	No information provided on the child's diagnosis.
Lim *et al*. (2021)	A Review of Barriers Experienced by Immigrant Parents of Children with Autism when Accessing Services	No reference to SLT. Reference list reviewed for other potentially relevant articles to include.
Liptak *et al*. (2008)	Disparities in Diagnosis and Access to Health Services for Children with Autism: Data from the National Survey of Children's Health	No SLT specific data reported.
Longfield (2019)	We Need To Talk: Access to Speech and Language Therapy	No autism specific findings reported.
Malik-Soni *et al*. (2022)	Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood	No SLT specific data reported. Relevant background information for introduction and discussion.
Mandak and Light (2018)	Family-centered services for children with ASD and limited speech: The experiences of parents and speech-language pathologists	Focus on ongoing service-delivery and family-centred care, not access to SLT services.
McBain *et al*. (2020)	Systematic review: United States workforce for autism-related child healthcare services	The systematic review focuses on a range autism-related health care services (reference list reviewed to identify studies of specific relevance to this scoping review).
NICE (2013)	The NICE guideline on the management and support of children and young people on the Autism Spectrum	Reference list reviewed, and relevant articles identified.

Author and Year	**Title**	**Reason excluded at full text review**
Paul (2018)	Rural-urban disparities in the diagnosis and treatment of children with autism spectrum disorders (ASD)	No SLT-specific information relevant to access to SLT reported.
Sapiets (n.d.)	Does where families live influence access to early years support? Embracing Complexity Webinar	This is a presentation of a study that is already included in the review (Sapiets 2022).
Sandham, Hill and Hinchliffe (2022)	The perspectives of Australian speech pathologists in providing evidence-based practices to children with autism	Focus is on EBP rather than access to the SLT service.
Smith-Young, Chafe and Audas (2020)	"Managing the Wait": Parents' Experiences in Accessing Diagnostic and Treatment Services for Children and Adolescents Diagnosed with Autism Spectrum Disorder	No SLT-specific data reported on access to interventions.
Warren *et al.* (2013)	Brief report: Service implementation and maternal distress surrounding evaluation and recommendations for young children diagnosed with autism	No clear link to factors impacting on access specifically related to SLT.
Volden *et al.* (2015)	Service utilization in a sample of preschool children with autism spectrum disorder: A Canadian snapshot	No SLT-specific data reported.

A.5 Quality appraisal of included literature

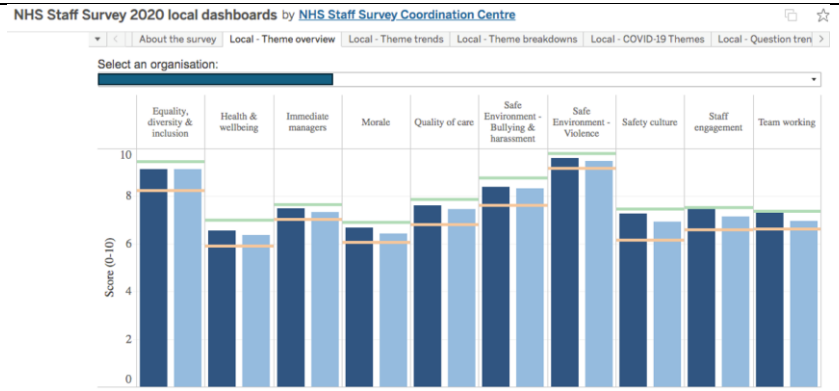
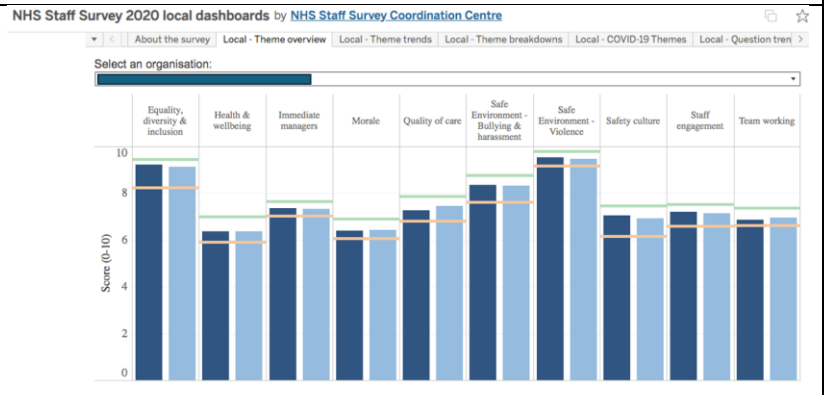
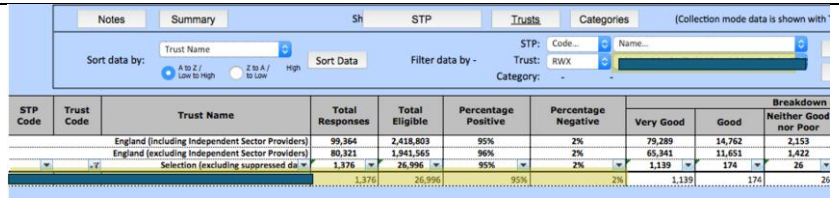
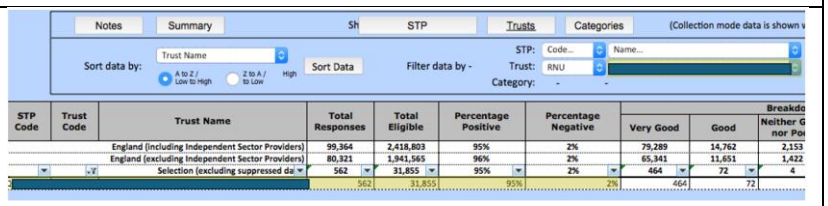
Author(s), year	Study design	MMAT quality score	Reviewer comments
Araripe et al. (2022)	Quantitative, online survey.	3	Sample recognised as not representative of the population (higher than average education level of mothers, children attending private schools). Non-response bias associated with digital access and literacy issues discussed.
Auert et al. (2012)	Qualitative, focus group and thematic analysis.	4	Participants all recruited from one early intervention parent support program. Limited demographic data reported. 85% of participants accessed private SLT in addition to the early intervention program. Unclear to what extent participants differ from the target population, e.g., in relation to their ability to pay for additional SLT.
Becerra et al. (2017a)	Quantitative, descriptive. Online and telephone and postal survey.	5	Fewer non-white respondents. Sample otherwise mostly representative of the target population. Health and digital literacy required to complete the online questionnaire; however, a phone option was also available. Follow up recruitment activities varied across the four participating sites due to study budget differences.
Binns et al. (2022)	Cross-sectional online survey with mixed methods of analysis.	5	Detailed account of methods used and rationale for decisions provided throughout. Practice-based research methods utilised to design a study relevant to the topic of SLT service delivery and to SLTs. Response bias acknowledged towards those with an interest in Autism.
Bromley *et al*. (2004)	Quantitative descriptive, structured interviews.	4	Wide range of recruitment approaches. Detailed participant and child demographic information reported. Unclear whether participants were representative of the target population, however authors suggest it was likely fewer mothers from ethnic minority communities participated given the demographic profile of the local area.
Carson et al. (2021)	Phenomenological approach utilising face to face, semi-structured group interview	5	All participants recruited through social media and via one established group. The impact of recruiting from one group on the diversity of perspectives within the study is not discussed.
Cassidy, McConkey and Slevin (2008)	Quantitative, descriptive. Structured questionnaires. Thematic analysis.	2	All participants were recruited via two specialist clinics and had a child diagnosed as autistic and their views may differ from those who were unable to or had chosen not to access the specialist clinics. The sample was stated to be representative of families who had accessed these clinics, but no evidence of this presented. There is reference to thematic analysis, but no information provided on the type of thematic analysis utilised, or how this was completed.
Cheung et al. (2013)	Quantitative survey, with qualitative, analysis for responses to open-ended questions.	2	Authors recognised SLTs with fewer workplace pressures and time may be more able to participate (and may provide a different perspective to other SLTs). Participants may also have a greater interest in EBP and autism. Response rate not possible to report due to the recruitment methods used. Survey developed based on one previously used in research on this topic and found to be effective. The survey utilised in this study was not piloted, however, and no information on reliability and validity of survey provided.

Author(s), year	Study design	MMAT quality score	Reviewer comments
Chu et al. (2018)	Qualitative, explorative study, series of three semi-structured interviews conducted.	4	Participants were recruited through a university-based speech clinic. No opportunity to capture the views of those who had not been able to/chose not to access SLT. In-depth interviews completed with participants. Limited information provided on approach to qualitative analysis within the report.
Cohen, Miguel and Trejos (2023)	Case study methodology; multiple case studies.	5	Participants were all recruited from two centres providing assessment and intervention services for autistic children and their families. Views of families who chose not to or were unable to access services are not captured. All participants were mother-son dyads.
Dababnah and Bulson (2015)	Qualitative, grounded theory. Group and individual semi-structured interviews.	5	Detailed description of research methods. Participants could choose to participate in group or individual interviews. Participants were offered transportation and childcare to support participation. Most participants were mothers and so the view of fathers may not be reflected in the findings.
Denne, Hastings and Hughes (2017)	Quantitative, online survey.	3	Authors recognised the sample are not representative of the target population. Higher levels of education and income of participants acknowledged. Challenges associated with digital literacy requirements for participation and access for non-English speakers discussed. Time since diagnosis and time utilising the intervention not gathered and there were no questions on the frequency, intensity or quality of input.
Dymond, Gilson and Myran (2007)	Quantitative, paper-based survey.	4	Demographic data provided, but no discussion of how representative this group is of the target population. Wide age range of children (0-22 years), and both school and community services considered in the study. Analysis completed by a small multi-disciplinary group with different perspectives.
Fernandes et al. (2014b)	Discussion paper.	n/a	Discussion paper.
Gevarter, Siciliano and Stone (2022)	Quantitative, descriptive. Online survey (with quantitative and qualitative components).	3	Unclear whether participants are representative of the target population. High attrition rate particularly amongst developmental specialists.
Irvin et al. (2012)	Quantitative descriptive.	2	Sampling strategy not described; response rate not provided. Although participants are described, there is no information on inclusion and exclusion criteria for this or the wider study from which participants were drawn. No description of the other/alternative therapies accessed, and group and individual therapy combined.
Kasilingam, Waddington and Van Der Meer (2021a)	Quantitative, online questionnaire.	3	Very small sample size in this national survey. Detailed demographic data on participants presented, but not explored in relation to representativeness of the target population. Digital and literacy access to the survey assumed.

Author(s), year	Study design	MMAT quality score	Reviewer comments
Khanlou et al. (2017)	Qualitative, descriptive study. Semi-structured telephone interview.	4	Participants from one area of Canada self-selected to participate. All participants needed to be able to communicate in English and their experiences may differ from immigrant mothers with more significant language barriers. Limited detail on how themes and sub-themes were generated.
Magaña et al. (2013)	Quantitative descriptive, cross-sectional analytic study. Postal survey.	4	Demographic data on Latino participants were reported to be consistent with other studies, however white families participating had considerably higher level of education compared with white families in the local area. Differences in data collection approach may impact findings (Latina mothers were interviewed and white mothers completed a survey).
Mansell and Morris (2004)	Mixed methods service evaluation. Postal questionnaire.	n/a	Service evaluation.
Mello et al. (2016)	Quantitative descriptive, online survey.	4	Online survey. Promoted online and recruitment was mostly via email (reducing opportunities to access for those without internet/email access). Ethnicity, sex, income and education levels not representative of the target population.
Millau, Rivard and Mello (2018)	Qualitative, semi-structured interview.	4	Families were waiting for/accessing services at rehabilitation centre and may differ from families who choose to access other or no intervention for their children. Clear description of research process. Research perspective of the study not described. Deductive and reliability coding approach to analysis. Differences between parents originating from different parts of the world are discussed, but groups are not represented equally, and similarities are assumed based on country of origin, despite the potential for families from the same area to hold different religious beliefs to have cultural differences and to speak different languages.
Monz *et al.* (2019)	Quantitative descriptive, cross-sectional study, online survey.	2	Children were deemed to be largely representative of Autistic children in the USA in terms of gender, severity of autism and age of diagnosis, however white/non-Hispanic participants were over-represented. Higher income levels and parent education levels of participants compared with the state information on the target population.1:1 and group interventions were grouped, making it difficult to capture different models of intervention.
Murphy and Ruble (2012)	Quantitative, survey.	5	Participants reported to have higher education and income levels compared with state demographic data. Measures for access calculated in relation to professional availability in the local area and their distance from families.
Pemble (2014)	Discussion paper.	n/a	Discussion of report on early intervention access.
Ruble *et al.* (2005)	TennCare data collected previously for another project, titled the IMPACT Study, were analysed.	5	Service access patterns examined. Differences in the duration of appointments was not considered (counted as one service contact on one day). The type of input (direct, group, parent training etc.) was not captured. The application of ASD codes to patients may differ between providers and impact findings. Patterns of access do not consider quality or impact of services.

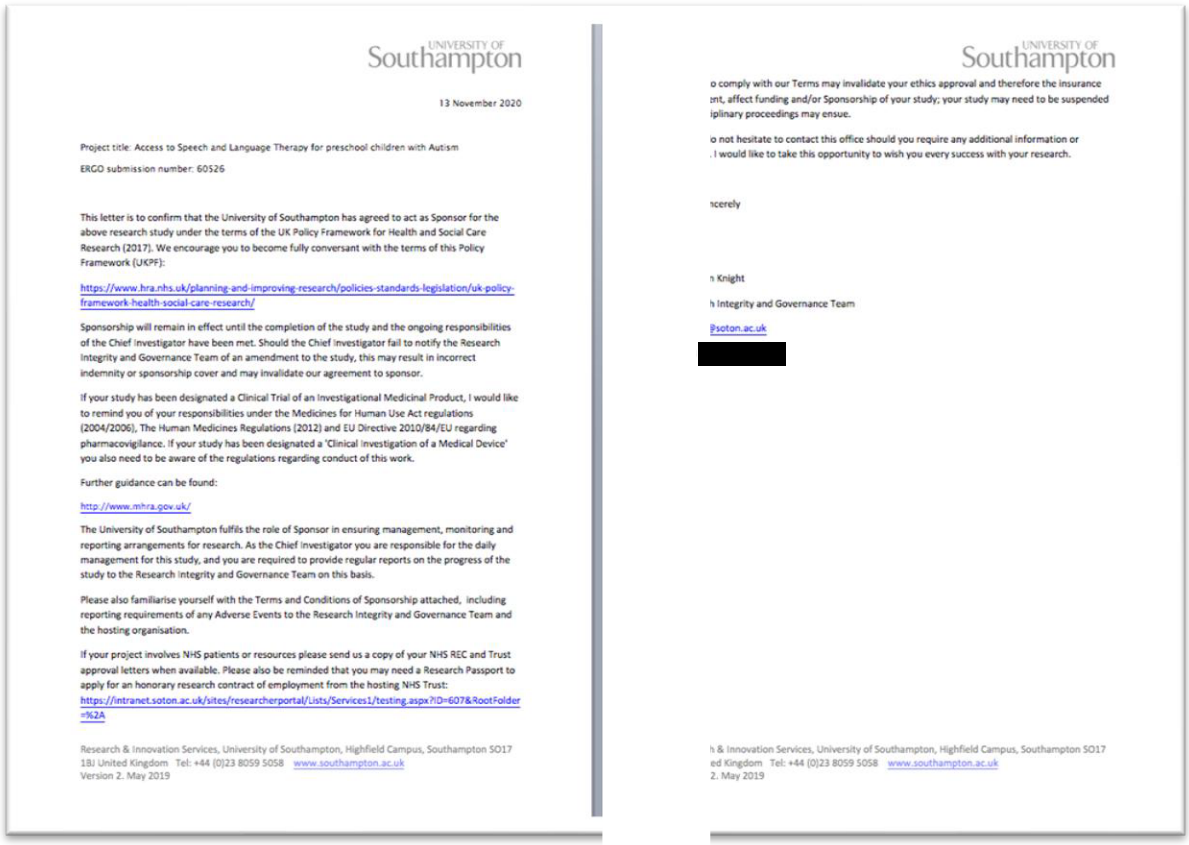
Author(s), year	Study design	MMAT quality score	Reviewer comments
Salomone *et al.* (2015)	Quantitative descriptive, online survey.	3	Participants had a higher than expected education level. Digital access issues acknowledged. Recruitment approaches varied between countries and regions and may have led to differences between participants from different regions.
Sandham, Hill and Hinchliffe (2021)	Quantitative, cross-sectional online survey.	5	Participants were grouped based on their self-report of their degree of expertise. Authors suggest the survey may not differentiate effectively between attitude, knowledge and use of EBP. Closed questions may have led to over-simplification of views on EBP and the extent to which factors impact on EBP was not captured.
Sapiets *et al.* (2022)	Quantitative, survey.	4	Stakeholder involvement in developing the survey. Survey only available in English. Wide range of recruitment activities, however, sample recognised not to be representative of the target population. Framework analysis for qualitative data captured in the survey.
Srinivasan *et al.* (2021)	Quantitative, survey (online and paper versions).	4	Limited discussion of non-response bias, but clear attempts to distribute information on the study via different means to relevant groups.
Thomas *et al.* (2007)	Quantitative, telephone or in-person survey.	3	Large proportion of participants (60%) recruited via a registry for a specific intervention. Participants recognised to be of a higher income and education level than the target population, with less ethnic diversity.
Trembath *et al.* (2016)	Qualitative, semi-structured telephone interview.	5	Self-selected, convenience sample. Views may, therefore, differ from those who did not participate.
Yingling and Bell (2020)	Quantitative, descriptive, prevalence study.	5	Non-Hispanic black and non-Hispanic white children underrepresented in the sample. Unclear whether children not accessing SLT through Medicaid were accessing SLT privately or through private medical insurance.
Young, Ruble and McGrew (2009)	Quantitative, survey.	3	Individuals with lower income and education levels less well represented small sample size. Access measures restricted to distance to professionals and availability of service professionals.

Appendix B Research setting

Data source and key	Site A	Site B
NHS staff survey results (2020 NHS staff survey, 2021) Organisation score Benchmark group - Average Benchmark group - Best Benchmark group - Worst		
NHS friends and family test (NHS England, 2021)		

Appendix C Study approval, risk and data management plans

C.1 University of Southampton ethical approval



University of Southampton

13 November 2020

Project title: Access to Speech and Language Therapy for preschool children with Autism

ERGO submission number: 60526

This letter is to confirm that the University of Southampton has agreed to act as Sponsor for the above research study under the terms of the UK Policy Framework for Health and Social Care Research (2017). We encourage you to become fully conversant with the terms of this Policy Framework (UKPF):

https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/

Sponsorship will remain in effect until the completion of the study and the ongoing responsibilities of the Chief Investigator have been met. Should the Chief Investigator fail to notify the Research Integrity and Governance Team of an amendment to the study, this may result in incorrect indemnity or sponsorship cover and may invalidate our agreement to sponsor.

If your study has been designated a Clinical Trial of an Investigational Medicinal Product, I would like to remind you of your responsibilities under the Medicines for Human Use Act regulations (2004/2006), The Human Medicines Regulations (2012) and EU Directive 2010/84/EU regarding pharmacovigilance. If your study has been designated a 'Clinical Investigation of a Medical Device' you also need to be aware of the regulations regarding conduct of this work.

Further guidance can be found:

http://www.mhra.gov.uk/

The University of Southampton fulfils the role of Sponsor in ensuring management, monitoring and reporting arrangements for research. As the Chief Investigator you are responsible for the daily management for this study, and you are required to provide regular reports on the progress of the study to the Research Integrity and Governance Team on this basis.

Please also familiarise yourself with the Terms and Conditions of Sponsorship attached, including reporting requirements of any Adverse Events to the Research Integrity and Governance Team and the hosting organisation.

If your project involves NHS patients or resources please send us a copy of your NHS REC and Trust approval letters when available. Please also be reminded that you may need a Research Passport to apply for an honorary research contract of employment from the hosting NHS Trust:
https://intranet.soton.ac.uk/sites/researcherportal/Lists/Services1/testing.aspx?ID=607&RootFolder=%2A

Research & Innovation Services, University of Southampton, Highfield Campus, Southampton SO17 1BJ United Kingdom Tel: +44 (0)23 8059 5058 www.southampton.ac.uk
Version 2. May 2019

University of Southampton

o comply with our Terms may invalidate your ethics approval and therefore the insurance
nt, affect funding and/or Sponsorship of your study; your study may need to be suspended
iplinary proceedings may ensue.

o not hesitate to contact this office should you require any additional information or
. I would like to take this opportunity to wish you every success with your research.

ncerely

h Knight

h Integrity and Governance Team

@soton.ac.uk

[redacted]

h & Innovation Services, University of Southampton, Highfield Campus, Southampton SO17
ed Kingdom Tel: +44 (0)23 8059 5058 www.southampton.ac.uk
2. May 2019

C.2 University of Southampton insurance letter

UNIVERSITY OF Southampton

Iona Wood
Faculty of Environmental and Life Sciences
University Of Southampton

Date: 13 November 2020

Dear Iona Wood

Professional Indemnity and Clinical Trials Insurance

Project Title: Access to Speech and Language Therapy for preschool children with Autism

ERGO Ref: 60526

Participant Type	Number of participants	Participant age group
Patients	0	ADULT
Patients	0	MINOR
Healthy	35	ADULT
Healthy	0	MINOR

Thank you for submitting the completed questionnaire and attached papers.

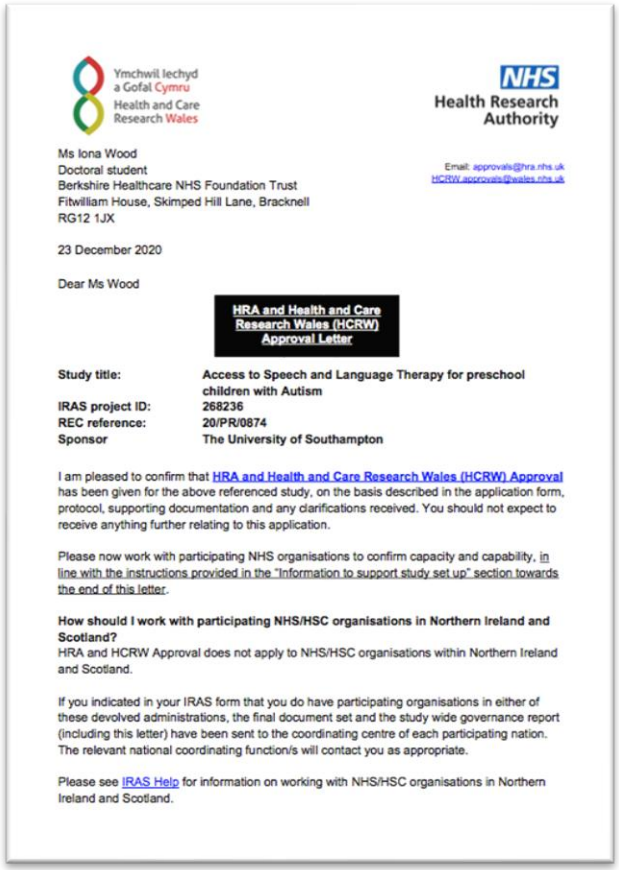
Having taken note of the information provided, I can confirm that this project will be covered under the terms and conditions of the above policy, subject to informed consent being obtained from the participating volunteers or their parent, guardian, next of kin as appropriate.

If there are any changes to the above details, please advise us, as failure to do so may invalidate the insurance.

Insurance Office

Tel: 023 8059 2417
email: [redacted]
Finance Department, University of Southampton, Highfield Campus, Southampton SO17 1BJ U.K.
Tel: [redacted] Fax: [redacted] www.southampton.ac.uk

C.3 Health Research Authority ethical approval



Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

Ms Iona Wood
Doctoral student
Berkshire Healthcare NHS Foundation Trust
Fitwilliam House, Skimped Hill Lane, Bracknell
RG12 1JX

23 December 2020

Dear Ms Wood

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Access to Speech and Language Therapy for preschool children with Autism**
IRAS project ID:	**268236**
REC reference:	**20/PR/0874**
Sponsor	**The University of Southampton**

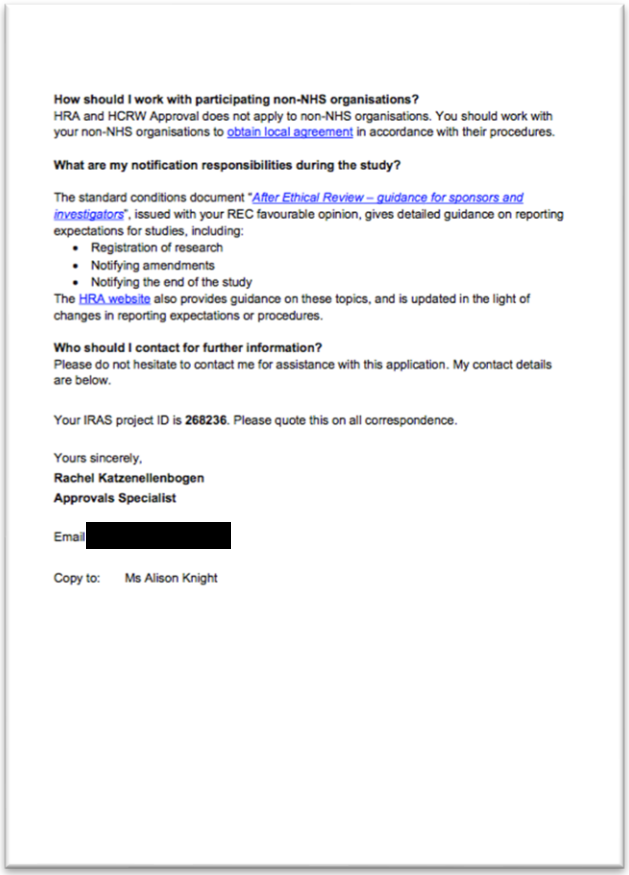
I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.



How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

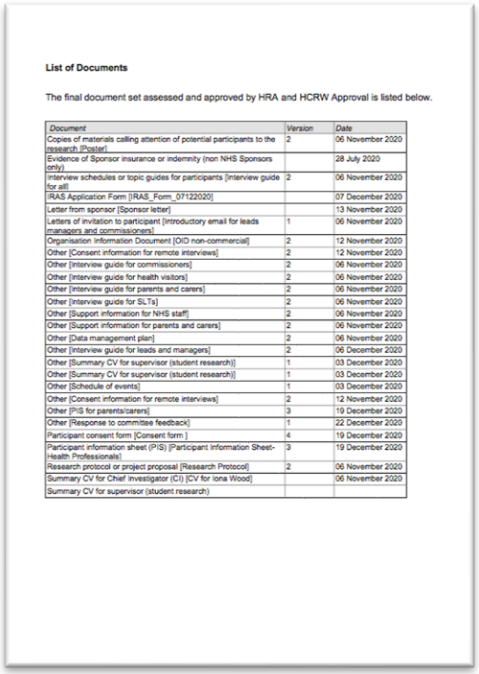
Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **268236**. Please quote this on all correspondence.

Yours sincerely,
Rachel Katzenellenbogen
Approvals Specialist

Email [redacted]

Copy to: Ms Alison Knight



List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Poster]	2	06 November 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		28 July 2020
Interview schedules or topic guides for participants [Interview guide for all]	2	06 November 2020
IRAS Application Form [IRAS_Form_07122020]		07 December 2020
Letter from sponsor [Sponsor letter]		13 November 2020
Letters of invitation to participant [Introductory email for leads managers and commissioners]	1	06 November 2020
Organisation Information Document [OID non-commercial]	2	12 November 2020
Other [Consent information for remote interviews]	2	12 November 2020
Other [Interview guide for commissioners]	2	06 November 2020
Other [Interview guide for health visitors]	2	06 November 2020
Other [Interview guide for parents and carers]	2	06 November 2020
Other [Interview guide for SLTs]	2	06 November 2020
Other [Support information for NHS staff]	2	06 November 2020
Other [Support information for parents and carers]	2	06 November 2020
Other [Data management plan]	2	06 November 2020
Other [Interview guide for leads and managers]	2	06 December 2020
Other [Summary CV for supervisor (student research)]	1	03 December 2020
Other [Summary CV for supervisor (student research)]	1	03 December 2020
Other [Schedule of events]	1	03 December 2020
Other [Consent information for remote interviews]	2	12 November 2020
Other [PIS for parents/carers]	3	19 December 2020
Other [Response to committee feedback]	1	22 December 2020
Participant consent form [Consent form]	4	19 December 2020
Participant information sheet (PIS) [Participant Information Sheet-Health Professionals]	3	19 December 2020
Research protocol or project proposal [Research Protocol]	2	06 November 2020
Summary CV for Chief Investigator (CI) [CV for Iona Wood]		06 November 2020
Summary CV for supervisor (student research)		

C.4 Research risk assessment

Risk Assessment for the activity of	Doctoral research	Date	23.07.20

Unit/Faculty/Directorate	Faculty of Environmental and Life Sciences	Assessor	Iona Wood
Line Manager/Supervisor	*Dr R Wagland*	Signed off	[redacted]

Hazard	Potential Consequences	Who might be harmed (user; those nearby; those in the vicinity; members of the public	Inherent risk likelihood	Inherent risk impact	Inherent risk score	Control measures (use the risk hierarchy)	Residual likelihood	Residual impact	Residual score	Further controls (use the risk hierarchy)
Lone working: potential for physical violence and verbal abuse.	Injury and emotional harm.	Researcher and others in the vicinity.	2	4	8	If the visit is deemed to be high risk, then the researcher will not work alone/conduct the interview in the participant's home. If the researcher feels uncomfortable at any time during a visit an excuse will be made and the researcher will leave. The researcher will ensure she is familiar with exits and avoid being cornered. Effective means of communication between researcher and participant re: voluntary participation and consent. Researcher is trained in managing conflict. Emergency plan in place in line with University of Southampton lone working policy including process for informing supervisor or whereabouts and contact at the end of visits. Mobile phone will be kept on and charged.	1	4	4	If subjected to violence/verbal abuse, complete an incident report form, report it to the University and relevant NHS Trust. Post-incident support from Occupational Health.

Hazard	Potential Consequences	Who might be harmed (user; those nearby; those in the vicinity; members of the public	Inherent risk likelihood	Inherent risk impact	Inherent risk score	Control measures (use the risk hierarchy)	Residual likelihood	Residual impact	Residual score	Further controls (use the risk hierarchy)
Discussion of a sensitive topic in an interview.	Distress to participant.	Participant	**2**	**3**	**6**	The researcher will be sensitive to any verbal/non-verbal signs of distress/agitation. The researcher will ask the participant if they would like a break/to end the interview if there are any signs of verbal/non-verbal distress. Participant will be informed of the topic of the interview so that they can make an informed decision on whether or not they would like to participate. The participant will be reminded that: • participation is voluntary • a break can be taken at any time • the interview can end at any time. The participant will be provided with a list of support services at the end of the interview and the researcher will discuss support with any participant in distress.	**2**	**2**	**4**	
Research participant in danger of harm to self or others.	Harm to participant/other.	Participant and others.	**1**	**5**	**5**	Researcher will be aware of and follow relevant health and safety, safeguarding and risk protocols for the location, including NHS training in safeguarding children and adults.	**1**	**4**	**4**	
Risk of accusation from others.	Harm to reputation of researcher and the university and emotional distress.	Researcher and the University.	**1**	**3**	3	The researcher will not be alone with any child or vulnerable adult. The researcher has an up to date Disclosure and Barring Service check.	**1**	**4**	**4**	

Hazard	Potential Consequences	Who might be harmed (user; those nearby; those in the vicinity; members of the public	Inherent risk likelihood	Inherent risk impact	Inherent risk score	Control measures (use the risk hierarchy)	Residual likelihood	Residual impact	Residual score	Further controls (use the risk hierarchy)
Risk of COVID-19	Ill health and disruption if self-isolation is required.	Participant and their friends/family and the researcher and their friends/family.	**2**	**4**	**8**	All up to date government COVID-19 guidance will be followed. Alternatives to face to face assessment will be used wherever possible (phone and video interviews)	**1**	**4**	**4**	
Data breach, including personal lost, stolen, corrupted, disclosed or released to unauthorised persons.	**1**	**3**	**3**	**4**	**4**	The researcher will adhere to the research data management plan (attached). Measures to protect data include the following: • Minimal personal details are collected. • Data is coded as soon as possible. • All documents containing personal information is password protected. • Documents will be saved on the university network, not on personal computer/removal storage devices. • Personal information, e.g., name of participant, contact details etc will only be kept for as long as required. • Laptop/notebooks with field notes will have the researcher's contact details on them to support swift return to the researcher. • The researcher will only use her University of Southampton email address. • The researcher will not use CC or Bcc when communicating with participants. • The researcher will use SafeSend to ensure in-transit and at rest encryption. Notice will be given to the Data Protection Officer, the Chief Information Officer and the Head of Information Security immediately a data breach occurs, is threatened or is suspected.				

Hazard	Potential Consequences	Who might be harmed (user; those nearby; those in the vicinity; members of the public	Inherent risk likelihood	Inherent risk impact	Inherent risk score	Control measures (use the risk hierarchy)	Residual likelihood	Residual impact	Residual score	Further controls (use the risk hierarchy)
						This will be done by e- mailing [redacted]. Data breaches will be contained and responded to immediately on discovering the breach. A Data Protection Impact Assessment will be undertaken immediately to identify the measures required to contain or limit potential damage and recovery from the incident.				

#	Impact	Health & Safety
1	Trivial - insignificant	Very minor injuries e.g. slight bruising
2	Minor	Injuries or illness e.g. small cut or abrasion which require basic first aid treatment even in self-administered.
3	Moderate	Injuries or illness e.g. strain or sprain requiring first aid or medical support.
4	Major	Injuries or illness e.g. broken bone requiring medical support >24 hours and time off work >4 weeks.
5	Severe – extremely significant	Fatality or multiple serious injuries or illness requiring hospital admission or significant time off work.

#	**Likelihood**
1	Rare e.g. 1 in 100,000 chance or higher
2	Unlikely e.g. 1 in 10,000 chance or higher
3	Possible e.g. 1 in 1,000 chance or higher
4	Likely e.g. 1 in 100 chance or higher
5	Very Likely e.g. 1 in 10 chance or higher

C.5 Data Management Plan

About your Research

PhD title:	Access to Speech and Language Therapy for preschool autistic children
Student name:	Iona Wood
Supervisor(s):	Dr Richard Wagland, Dr Sarah Worsfold, Dr Sarah Parsons
Ethics No. (if appropriate)	

About this plan

Date of plan:	24.07.20	Frequency of reviews	12m / **6m** / 3m
Date of next review:	24.01.21		
Agreed actions to help you implement the plan	*Training on NVIVO* Training on anonymising data		
Agreed equipment and/or resources required:	Digital Audio device		
Further information (as appropriate):			

Version Table

Version	Changes made	Date

Appendix C

1. Project Description:

A qualitative study to understand access to Speech and language therapy for preschool autistic children from the perspectives of key stakeholders. NHS staff and parents/carers of autistic children will be interviewed in person, over the phone or via video call.

2. What policies will apply to your research?

- Research Data Management Policy

https://www.southampton.ac.uk/~assets/doc/calendar/Research%20Data%20Management%20Policy.pdf

- Data Protection Policy

http://www.calendar.soton.ac.uk/sectionIV/dppolicy.pdf

3. What data/research material will you collect or create?

Type of data	**File format (software):**	**Approximate file size:**	**No. of files:**	**Total size:**
Digital audio files of interviews.	WAV	400MB	23-35	140GB
Participant contact details and consent forms.	docx	2KB	23-35	70KB
Interview transcripts.	docx	60KB	23-35	2MB
Background data list	docx	6KB	1	6KB
NVivo	NVPX	400 MB	23-35	140GB

4. How will your data/research material be documented and described?

Research data files will be stored using a systematic and consistent approach to the naming of data files. Each participant group will have a separate folder. Each of these folders will contain a folder with audio files, a folder for transcripts and a folder for analysis.

The following file naming convention will be used:

<date><type><ID1><datatype><fileformat>

20200122_interview1_audio.wav

20200122_interview1_trans.docx

The following metadata will be collected for each interview:

- Interview date
- Interviewer
- Context of data collection
- Participant ID
- Occupation of interviewee

The above data will be systematically entered at the beginning of each interview transcript in a standardised manner and added to a background data list document. This will contain a table with the following columns:

Interview date:	**Interviewer:**	**Context of data collection:**	**Participant ID**	**Occupation of interviewee**	**File format:**	**Duration of the interview:**

5. How will you deal with any ethical and copyright issues?

I will share my data with my supervisors using a shared folder due to the sensitive nature of my data.

No intellectual property rights exist in the Research Data. The University is the owner (as between the University and the Researcher) of all legal rights in relation to the Research Data which is collected, created or generated by Researcher.

Paper based notes from interviews will be shredded using confidential waste. Electronic files containing participant contact details will be overwritten multiple times using specialist software once interviews have been transcribed.

Raw data and all files containing personal or contact details for individuals will only be stored on University servers, within the University network.

Data will be held locally on a University build laptop during collection. The data will be encrypted.

No direct or indirect identifiers will be stored with research data. Each participant will be given a pseudonym and file labels will include the participant group and an ID number, e.g., Speech and Language Therapist 01. The research will take place at two sites. To avoid the possibility of indirect identification of individuals in roles where there are few/no others in similar posts, the locality of the participant will not be given. Each interview transcript will be carefully reviewed and information that would identify the participant/any other person will be removed.

6. How will your data/research materials be stored, and backed up?

AES-128 or AES-256 encryption methods will be used. A strong password will be used as the encryption key.

During analysis, research data will be stored on the university Network Home Directory (\\filestore.soton.ac.uk\Users\<username>\.

This is backed up in the following ways:

- Snapshot on primary every 2 hours, retained for 30 days
- Sync to replica every 6 hours (at 04:00, 10:00, 16:00, 22:00), retained for 3 months

Research data will be saved on the university Filestore

- Snapshot on primary every 30 minutes, retained for 30 days
- Sync to replica once a day (at 20:00hrs), retained for 3 months

Research data will be backed up weekly on a password protected external hard drive.

7. What are your plans for the long-term preservation of data/research materials supporting your research?

Transcripts of all interviews, but not recordings will be retained. Personal data and the anonymization key will be destroyed securely at the end of the project. In accordance with The University of Southampton 2019-2020 Research Data Management Policy, all Research Data will be held for a minimum period of 10 years from collection, creation or generation of the Research Data or publication of the research results (whichever is later). The research data will be held in the University of Southampton Repository.

All research data files will be saved in XML file format. A README file will accompany the dataset in TXT format and will include the following information:

- Name/institution/address/email information for the researcher
- Date of data collection
- Information about geographic location of data collection
- Links to publications that cite or use the data
- Method description, links and references to publications
- Description of relationships between the data files
- For each filename, a short description of what data it contains
- Abbreviations used

8. What are your plans for sharing the data/research materials after the submission of your thesis?

All research data will be made available on the University of Southampton repository, accompanied by a readme file describing the data and the data linked back to the relevant part of my thesis. The data will only be made available after a three-year embargo period as I plan to publish articles from my thesis. During the embargo, only the README file (described above) will be available.

A dataset record will also be added to the University of Southampton data catalogue (via Pure).

The research data will be referenced in associated research papers and will include a statement describing how the supporting Research Data may be accessed, including a DOI for datasets held in the Repository.

Appendix D Study documents

D.1 Email invitation for leads, managers and commissioners

Dear

Re: research into access to speech and language therapy for preschool autistic children

I am a fully qualified and experienced Speech and Language Therapist specialising in autism and I am currently working towards a Doctorate in Clinical Practice at the University of Southampton. I am conducting a qualitative research study focusing on increasing our understanding of the process of accessing Speech and Language Therapy for young autistic children. I am keen to understand the process of access from a range of perspectives including:

- Parents/carers
- Speech and Language Therapists
- Health Visiting team members
- Managers, commissioners and leads of services.

The study has secured the ethical approval of The University of Southampton (date) and Health Research approval (date).

As a [commissioner/lead/manager] of a Speech and Language Therapy service for preschool autistic children, I am interested in understanding your perspective on the needs, challenges and strengths of current services.

I have attached a participant information sheet and information on consent with further information on what is involved with taking part in this research.

Please contact me if you are interested in participating in this research or if you would like to discuss this study with me.

The aim of the study is to help improve access to Speech and Language Therapy for young autistic children and to help improve the future outcomes for children and their families.

I look forward to hearing from you,

Many thanks

Iona Wood

Doctoral Student

The University of Southampton

D.2 Recruitment poster

UNIVERSITY OF Southampton

Speech and Language Therapy services for Autistic Children

RESEARCH PARTICIPANTS NEEDED

Are you the parent or carer of an Autistic child under 8 years old?

Are you a Speech and Language Therapist or Health Visitor?

If yes, you could help us understand and improve access to Speech and Language Therapy for preschool Autistic children by taking part in this important research.

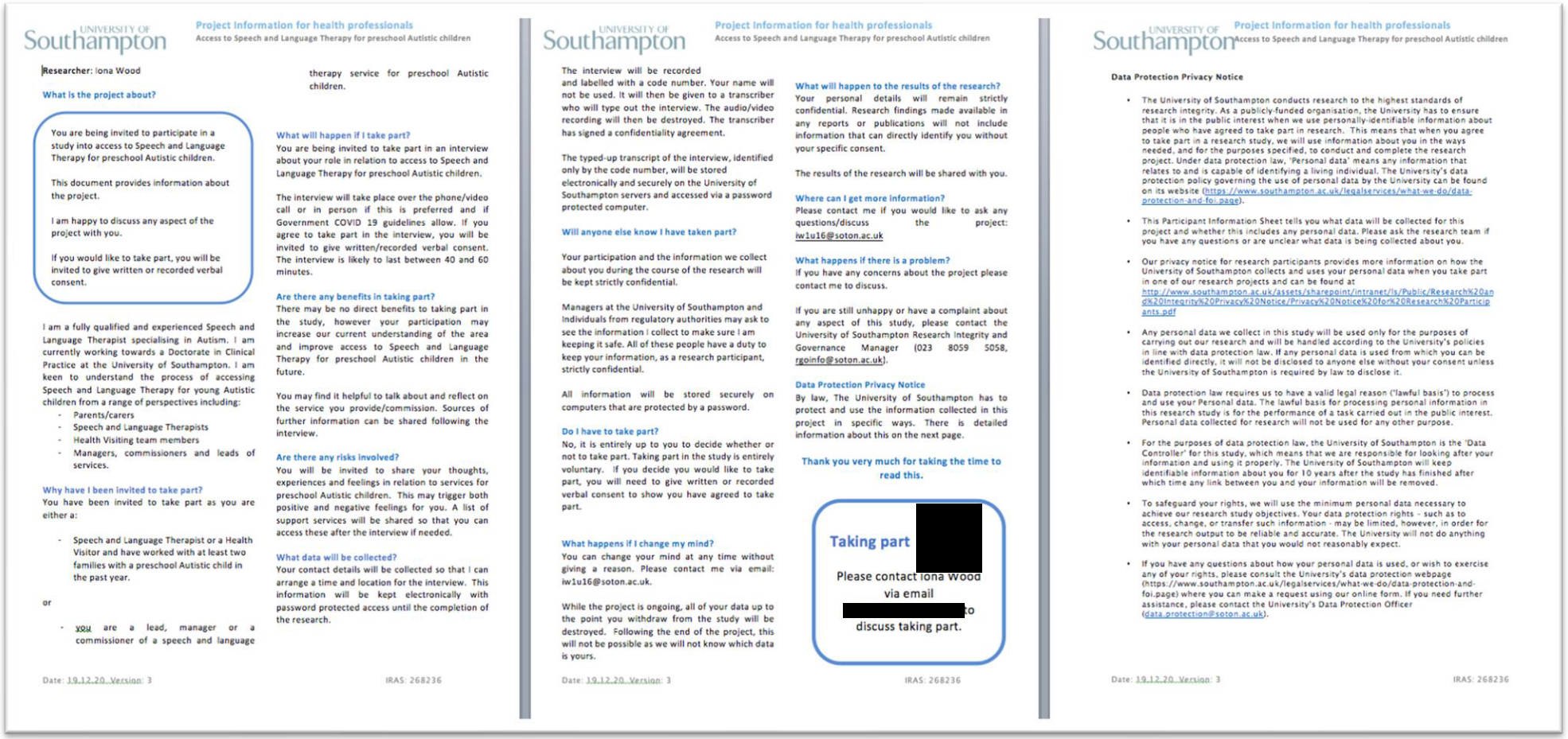
You will be asked to share your thoughts and experiences in an informal interview with the researcher.

Interviews will take place at a time convenient to you.

EMAIL IONA WOOD AT [redacted]

Interviews can take place via phone/video call.

D.3 Participant Information Sheet: Health Professionals



University of Southampton

Project Information for health professionals

Access to Speech and Language Therapy for preschool Autistic children

Researcher: Iona Wood

What is the project about?

You are being invited to participate in a study into access to Speech and Language Therapy for preschool Autistic children.

This document provides information about the project.

I am happy to discuss any aspect of the project with you.

If you would like to take part, you will be invited to give written or recorded verbal consent.

I am a fully qualified and experienced Speech and Language Therapist specialising in Autism. I am currently working towards a Doctorate in Clinical Practice at the University of Southampton. I am keen to understand the process of accessing Speech and Language Therapy for young Autistic children from a range of perspectives including:

- Parents/carers
- Speech and Language Therapists
- Health Visiting team members
- Managers, commissioners and leads of services.

Why have I been invited to take part?

You have been invited to take part as you are either a:

- Speech and Language Therapist or a Health Visitor and have worked with at least two families with a preschool Autistic child in the past year.

or

- you are a lead, manager or a commissioner of a speech and language therapy service for preschool Autistic children.

What will happen if I take part?

You are being invited to take part in an interview about your role in relation to access to Speech and Language Therapy for preschool Autistic children.

The interview will take place over the phone/video call or in person if this is preferred and if Government COVID 19 guidelines allow. If you agree to take part in the interview, you will be invited to give written/recorded verbal consent. The interview is likely to last between 40 and 60 minutes.

Are there any benefits in taking part?

There may be no direct benefits to taking part in the study, however your participation may increase our current understanding of the area and improve access to Speech and Language Therapy for preschool Autistic children in the future.

You may find it helpful to talk about and reflect on the service you provide/commission. Sources of further information can be shared following the interview.

Are there any risks involved?

You will be invited to share your thoughts, experiences and feelings in relation to services for preschool Autistic children. This may trigger both positive and negative feelings for you. A list of support services will be shared so that you can access these after the interview if needed.

What data will be collected?

Your contact details will be collected so that I can arrange a time and location for the interview. This information will be kept electronically with password protected access until the completion of the research.

Date: 19.12.20 Version: 3 IRAS: 268236

University of Southampton

Project Information for health professionals

Access to Speech and Language Therapy for preschool Autistic children

The interview will be recorded and labelled with a code number. Your name will not be used. It will then be given to a transcriber who will type out the interview. The audio/video recording will then be destroyed. The transcriber has signed a confidentiality agreement.

The typed-up transcript of the interview, identified only by the code number, will be stored electronically and securely on the University of Southampton servers and accessed via a password protected computer.

Will anyone else know I have taken part?

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

Managers at the University of Southampton and individuals from regulatory authorities may ask to see the information I collect to make sure I am keeping it safe. All of these people have a duty to keep your information, as a research participant, strictly confidential.

All information will be stored securely on computers that are protected by a password.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. Taking part in the study is entirely voluntary. If you decide you would like to take part, you will need to give written or recorded verbal consent to show you have agreed to take part.

What happens if I change my mind?

You can change your mind at any time without giving a reason. Please contact me via email: iw1u16@soton.ac.uk.

While the project is ongoing, all of your data up to the point you withdraw from the study will be destroyed. Following the end of the project, this will not be possible as we will not know which data is yours.

What will happen to the results of the research?

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

The results of the research will be shared with you.

Where can I get more information?

Please contact me if you would like to ask any questions/discuss the project: iw1u16@soton.ac.uk

What happens if there is a problem?

If you have any concerns about the project please contact me to discuss.

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

Data Protection Privacy Notice

By law, The University of Southampton has to protect and use the information collected in this project in specific ways. There is detailed information about this on the next page.

Thank you very much for taking the time to read this.

Taking part

Please contact Iona Wood via email [redacted] to discuss taking part.

Date: 19.12.20 Version: 3 IRAS: 268236

University of Southampton

Project Information for health professionals

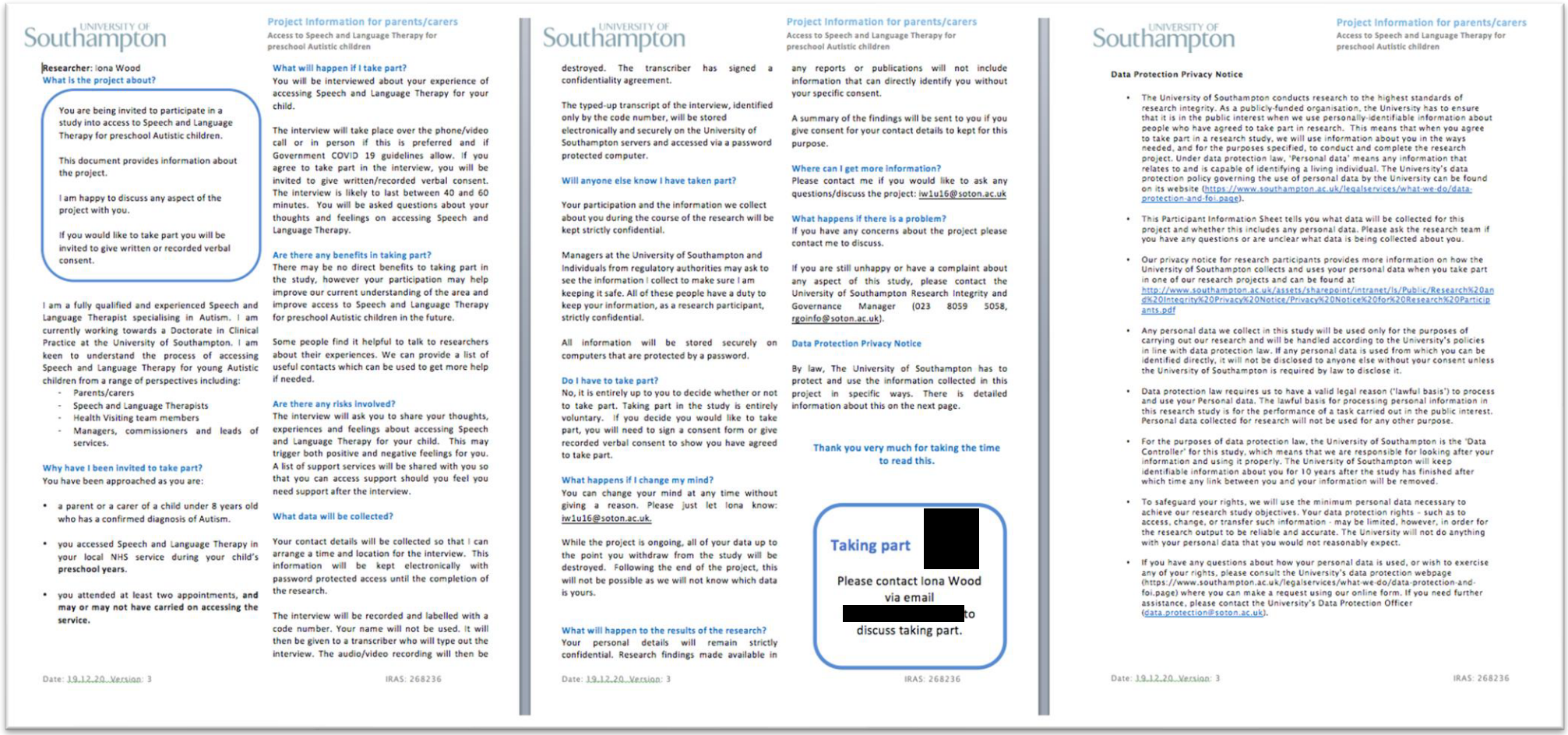
Access to Speech and Language Therapy for preschool Autistic children

Data Protection Privacy Notice

- The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).
- This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.
- Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/is/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf
- Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.
- Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.
- For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.
- To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights - such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.
- If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Date: 19.12.20 Version: 3 IRAS: 268236

D.4 Participant Information Sheet: Parents/carers



University of Southampton

Researcher: Iona Wood

What is the project about?

You are being invited to participate in a study into access to Speech and Language Therapy for preschool Autistic children.

This document provides information about the project.

I am happy to discuss any aspect of the project with you.

If you would like to take part you will be invited to give written or recorded verbal consent.

I am a fully qualified and experienced Speech and Language Therapist specialising in Autism. I am currently working towards a Doctorate in Clinical Practice at the University of Southampton. I am keen to understand the process of accessing Speech and Language Therapy for young Autistic children from a range of perspectives including:

- Parents/carers
- Speech and Language Therapists
- Health Visiting team members
- Managers, commissioners and leads of services.

Why have I been invited to take part?

You have been approached as you are:

- a parent or a carer of a child under 8 years old who has a confirmed diagnosis of Autism.
- you accessed Speech and Language Therapy in your local NHS service during your child's **preschool years.**
- you attended at least two appointments, **and may or may not have carried on accessing the service.**

What will happen if I take part?

You will be interviewed about your experience of accessing Speech and Language Therapy for your child.

The interview will take place over the phone/video call or in person if this is preferred and if Government COVID 19 guidelines allow. If you agree to take part in the interview, you will be invited to give written/recorded verbal consent. The interview is likely to last between 40 and 60 minutes. You will be asked questions about your thoughts and feelings on accessing Speech and Language Therapy.

Are there any benefits in taking part?

There may be no direct benefits to taking part in the study, however your participation may help improve our current understanding of the area and improve access to Speech and Language Therapy for preschool Autistic children in the future.

Some people find it helpful to talk to researchers about their experiences. We can provide a list of useful contacts which can be used to get more help if needed.

Are there any risks involved?

The interview will ask you to share your thoughts, experiences and feelings about accessing Speech and Language Therapy for your child. This may trigger both positive and negative feelings for you. A list of support services will be shared with you so that you can access support should you feel you need support after the interview.

What data will be collected?

Your contact details will be collected so that I can arrange a time and location for the interview. This information will be kept electronically with password protected access until the completion of the research.

The interview will be recorded and labelled with a code number. Your name will not be used. It will then be given to a transcriber who will type out the interview. The audio/video recording will then be destroyed. The transcriber has signed a confidentiality agreement.

The typed-up transcript of the interview, identified only by the code number, will be stored electronically and securely on the University of Southampton servers and accessed via a password protected computer.

Will anyone else know I have taken part?

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

Managers at the University of Southampton and individuals from regulatory authorities may ask to see the information I collect to make sure I am keeping it safe. All of these people have a duty to keep your information, as a research participant, strictly confidential.

All information will be stored securely on computers that are protected by a password.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. Taking part in the study is entirely voluntary. If you decide you would like to take part, you will need to sign a consent form or give recorded verbal consent to show you have agreed to take part.

What happens if I change my mind?

You can change your mind at any time without giving a reason. Please just let Iona know: iw1u16@soton.ac.uk.

While the project is ongoing, all of your data up to the point you withdraw from the study will be destroyed. Following the end of the project, this will not be possible as we will not know which data is yours.

What will happen to the results of the research?

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

A summary of the findings will be sent to you if you give consent for your contact details to kept for this purpose.

Where can I get more information?

Please contact me if you would like to ask any questions/discuss the project: iw1u16@soton.ac.uk

What happens if there is a problem?

If you have any concerns about the project please contact me to discuss.

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

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By law, The University of Southampton has to protect and use the information collected in this project in specific ways. There is detailed information about this on the next page.

Thank you very much for taking the time to read this.

Taking part

Please contact Iona Wood via email [redacted] to discuss taking part.

Data Protection Privacy Notice

- The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).
- This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.
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- Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.
- Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.
- For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.
- To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights - such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.
- If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

D.5 Consent form (in-person interviews)

University of Southampton

CONSENT FORM- for interviews taking place in person

Study title: Access to Speech and Language Therapy for preschool Autistic children

Researcher name: Iona Wood

Consent form: Do you agree to take part in the project?

If you do not agree leave this form blank.

If you agree please put your initials in the boxes highlighted below to show this and then give this form back to Iona Wood:

	Your initials go here
I have read and understood the information sheet (06.11.20/v2)	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I have had the chance to ask Iona questions about the project and my questions have been answered to my satisfaction.	
I agree to take part in the interview for the purposes set out in the participation information sheet and understand that this will be audio/video recorded.	
I understand that I may be quoted directly in reports of the research but that I will not be directly identified (e.g. that my name will not be used).	
I know that I do not have to take part if I do not want to.	
I understand that the audio/video recording will be transcribed and then destroyed for the purposes set out in the participation information sheet.	
I understand that personal information collected about me such as my name or where I live will not be shared beyond the study team.	
I would like my contact details to be retained in order for me to receive the findings of the study.	

Your name (print): Researcher's name:

Your signature Researcher's signature:
Date: Date:

Date: 19.12.20 Version: 4 IRAS number: 268236

D.6 Consent information (remote interviews)

UNIVERSITY OF Southampton

CONSENT INFORMATION - for phone/video call interviews

Study title: Access to Speech and Language Therapy for preschool Autistic children

Researcher name: Iona Wood

Do you agree to take part in the project?

If you do not agree, please inform Iona Wood (email: iw1u16@soton.ac.uk) that you wish to withdraw and you will not be contacted again about the study.

If you agree you will be asked to give recorded verbal consent via phone/video call before you are interviewed.

The researcher will ask you the following questions:

- Have you read and understood the information sheet (06.11.20/v2)?
- Do you agree to take part in this research project and agree for your data to be used for the purpose of this study?
- Do you give your permission for me to interview you?
- Do you give your permission for this interview to be audio/video recorded?
- Do you give me permission to quote you directly without using your name?
- Have you had the opportunity to ask questions about the research?
- Are you aware that you don't have to take part and can stop at any time?
- Are you aware that the audio/video recording will be written up and then destroyed?
- Are you aware that your personal information will not be shared beyond the study team?
- Would you like me to keep your contact details in order for me to send you summaries of the research findings?
- Are you happy to be interviewed?

Date: 12.11.20 Version: 2 IRAS number: 268236

D.7 Interview guides

D.7.1 For all interview participants

Field notes will be taken during the interview and after the interview to include an evaluation of the researcher's own experiences, thoughts, and feelings and to add context to the interview transcript.

Length of interview: 40-60 minutes.

Welcome and introductions.

"I will start recording now."

Goal of the interview: "The interview will be a conversation between us. I'm interested in your thoughts, feelings and opinions on the things we will talk about. There are no right or wrong answers. Your experiences are important and will help to inform research on service provision for autistic children."

Consent- if the interview is taking in place in person:

"Thank you for signing the consent form. Have you read the information sheet? Do you have any questions for me?"

Or

"Have you read the information sheet? Do you have any questions for me? Please sign the consent form if you are happy to be interviewed by me today."

"Taking part in the interview is entirely voluntary and you have the right to stop at any point."

Consent for video/audio calls:

The researcher will read through the participant information sheet/check the participant has read the sheet.

The researcher will then ask the following questions:

- Do you give your permission for me to interview you?
- Do you give your permission for this interview to be audio/video recorded?

- Do you give me permission to quote you directly without using your name?
- Have you had the opportunity to ask questions about the research?
- Are you aware that you don't have to take part and can stop at any time?
- Are you aware that the audio/video recording will be written up and then destroyed?
- Are you aware that your personal information will not be shared beyond the study team?
- Would you like me to keep your contact details for me to send you summaries of the research findings?
- Are you happy to be interviewed?

Once consent is gained, the researcher will stop recording so that consent is saved separately from the interview recording.

The researcher will then start recording again to complete the interview.

"Please let me know if you would like us to stop or take a break at any point."

The relevant semi-structured interview schedule for the participant will then be followed.

Interview questions tailored to participant roles

Participant role in the study	Context	Process of access	Influences	Evaluation	Strengths and opportunities
SLTs	Can you tell me about what is available for preschool autistic children in your service? What do you feel is the role of the SLT in supporting preschool autistic children? How confident do you feel in your ability to support autistic children and their families?	Can you please describe a typical journey for a child into your service? How easy or difficult do you think it is for autistic children to get a referral/request your service? Are there situations where you may not accept a referral for a preschool autistic child?	What do parents and carers tend to expect of you when they first come to your service? What do you see as the family's role in making decisions about therapy for their child?	What do you see as the biggest challenge for families in attending appointments? How might you support them to make the most out of their appointments? What is your greatest challenge in supporting preschool autistic children? How do you feel about balancing supporting preschool autistic children with children with other conditions on your caseload?	If you were setting up a brand new SLT service for young autistic children, what would you like to see? Is there anything you would like to change about how you offer your service?

Participant role in the study	**Context**	**Process of access**	**Influences**	**Evaluation**	**Strengths and opportunities**
SLT leads/ managers	Can you please tell me about your role? Can you please describe the services available to preschool autistic children? To what extent do you feel specialist autism interventions are available in the service? What do you feel is currently the main role of your service for preschool autistic children?	Can you describe how child may access/be referred to the service? Are there situations you may not accept a referral for a preschool autistic child? Are you aware of any difficulties families may encounter in accessing services?	What degree of flexibility do therapists have to determine the type, amount and frequency of support offered to families? What do you perceive as the barriers families may encounter in accepting the service available?	What do you feel are the pros and cons of the current service? How are the needs of autistic children balanced with the needs of other children with communication difficulties? Are there any clinical dilemmas/areas of challenge? What do see at the greatest challenge for this service?	What do you think are the greatest strengths of this service?
Commissioners	Tell me about your role and how services are commissioned for preschool autistic children in your area? What is the strategy for this over the short and medium term?		Which groups/individuals influence commissioning?	What are services telling you about their ability to meet the needs of children? Are there any areas of challenge in relation to commissioning for these services?	What do you see as the main opportunities? Are you able to signpost me to any other relevant information?

Participant role in the study	**Context**	**Process of access**	**Influences**	**Evaluation**	**Strengths and opportunities**
Early years professionals	Please tell me about your role and background. How might you respond to a child with communication needs? What do you know about the SLT service offered locally? How equipped do you feel in your role to support children and their families with communication needs?	In your experience, once a referral's been made, what typically happens next for families? How easy or difficult do you feel it is for autistic children to get support for their communication? What might you do if the child and their family are struggling while waiting?	Have there been any times where you and the family or others have had a difference in opinion about the child's needs? Do you feel you have any influence on the communication support received by children and their families?	Are you aware of any challenges for families in engaging with SLT? Any examples of children not being offered a service or not taking up the service offered?	What do you see as pros and cons of how things are working now?

Participant role in the study	**Context**	**Process of access**	**Influences**	**Evaluation**	**Strengths and opportunities**
Parents/carers	Can you please tell me about your child? Can you tell me about when you first realised your child needed support with their communication?	Can you tell me about your experiences of asking for help/referrals? What happened once you'd asked for help/the referral was made? Can you please describe the 1st appointment with SLT? What was the plan after this first appointment? How was the decision made about what would happen next? What happened next?	What did you know then about services that could help your child with his/her communication? How did you decide what to do next? How did other people react to your first concerns about your child's communication? Did you talk to anyone else before trying to get help?	How easy was it for you to share your concerns and say what you wanted to say? What do you think the appointment was like for your child? What advice would you give SLT services about how to support families of autistic children? What advice would you give to other families who were about to access SLT for their child?	What do you see as the pros and cons of the therapy offered to you? What did you appreciate/value most about the service you received?

D.8 Support information for participants

D.8.1 Information and support for NHS staff

Network Autism

An online network for people working in autism around the world. The website contains articles, case studies and research from others working in autism. There are opportunities to share, learn and collaborate with specialist interest groups and discussions.

https://network.autism.org.uk

The National Autistic Society

A national charity providing help and advice for autistic people, their families and professionals involved with them. It can provide a comprehensive set of publications relevant to autism and also has an informative website.

www.autism.org.uk

NHS Staff support line

A confidential staff support line, operated by the Samaritans and free to access **from 7:00am – 11:00pm, seven days a week.**

This support line is here for when you've had a tough day, are feeling worried or overwhelmed, or maybe you have a lot on your mind and need to talk it through. Trained advisers can help with signposting and confidential listening.

Tel: 0300 131 7000

D.8.2 Information and support for parents/carers

The National Autistic Society

A national charity providing help and advice for autistic people, their families and professionals involved with them. It has an informative website as well as a helpline and parent-to-parent support lines.

www.autism.org.uk

Helpline: 0808 800 4104

Contact a family

UK-wide charity providing advice, information and support to the parents of all disabled children.

www.cafamily.org.uk

Tel: 0808 808 3555

Family Lives

Family Lives offer advice and support on any aspect of parenting with a free confidential helpline open 7 days a week 7am to midnight (diverted to Samaritans out of hours). Support also available via free text messaging, live chat online and email.

www.familylives.org.uk

Tel: 0808 800 2222

Cerebra

Cerebra offer a wide range of support services for children with neurological conditions and their families.

Cerebra Stress Helpline: 0800 043 9385.

Autism Berkshire

Autism Berkshire co-ordinates a range of local events and can offer support and sign-posting services, including a post-diagnosis service.

http://www.autismberkshire.org.uk/

Tel: 0118 9594594

Oxfordshire Autistic Society Information and Support (OASIS)

OASIS is a charity run by parents for parents/carers who are bringing up children/young adults with Autistic Spectrum Disorder or related conditions such as Global Developmental Delay or Sensory Processing Disorder in Oxfordshire.

Email: chair@oasisonline.org.uk

Autism Family Support Oxfordshire (AFSO)

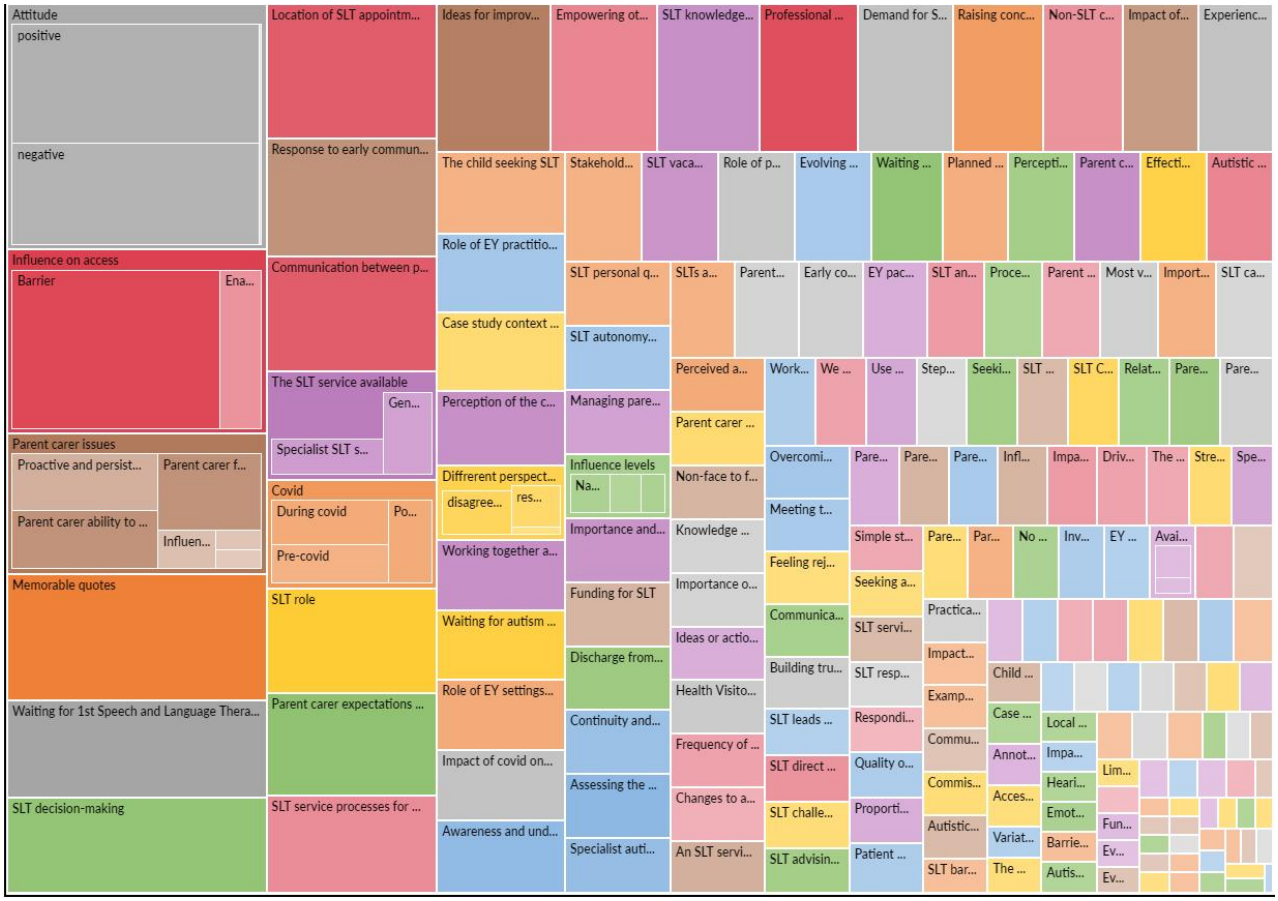
AFSO is a charity that provides support to children and young people aged 0-25 years old, with a diagnosis of an Autism Spectrum Condition (ASC), and their families; who live within Oxfordshire or access services in Oxfordshire.

Tel: 01235 754700

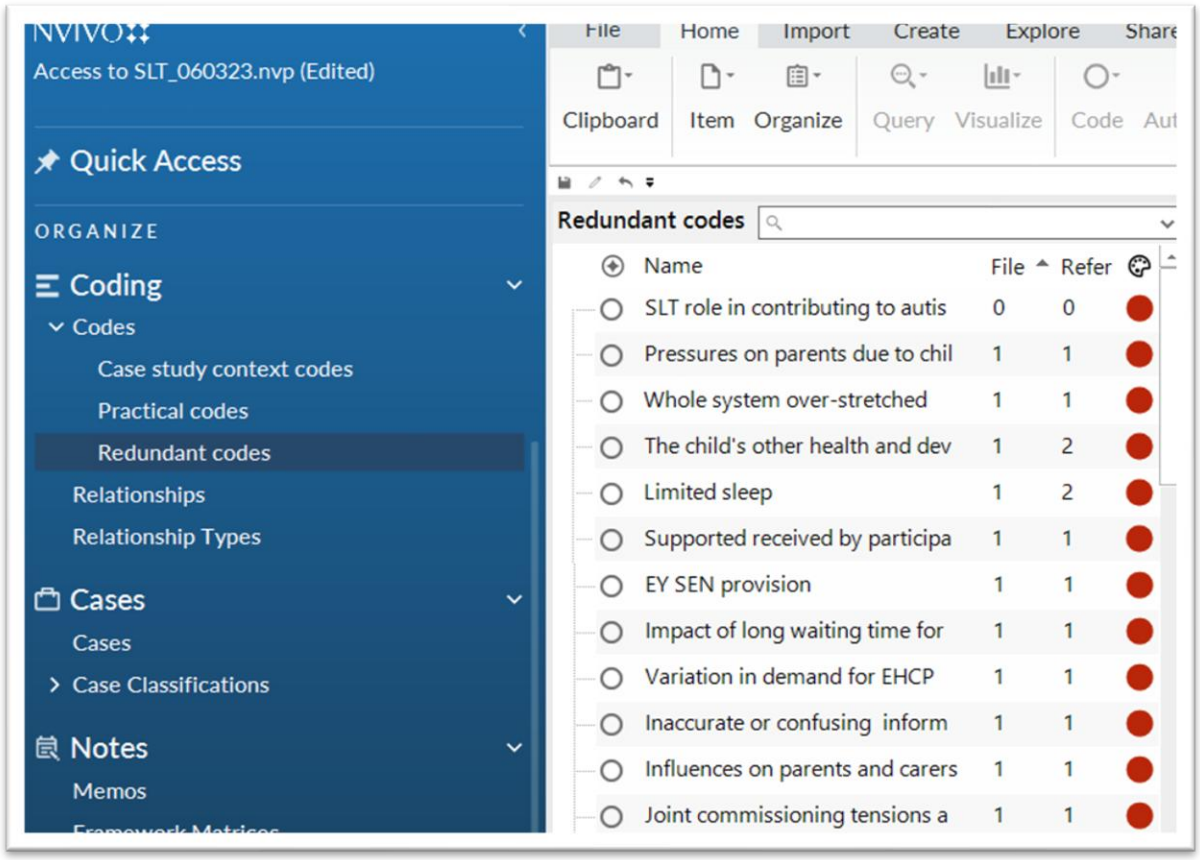
Email: judith@afso.org.uk

Appendix E Data analysis

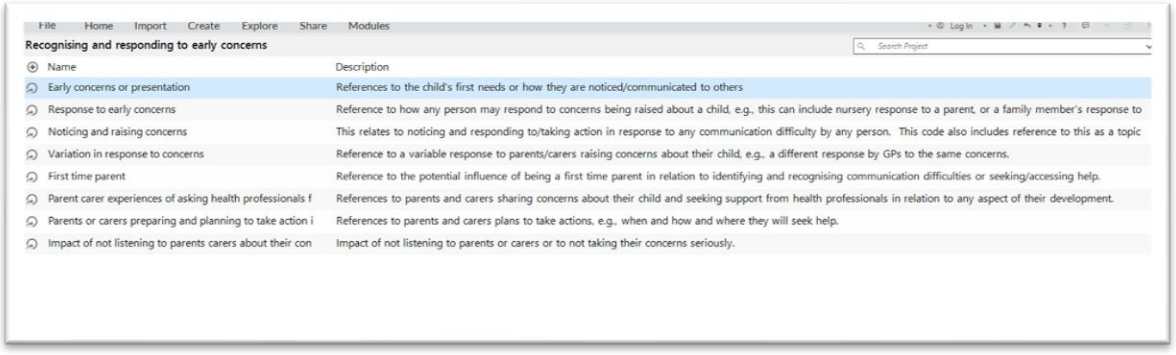
E.1 Hierarchy chart of codes



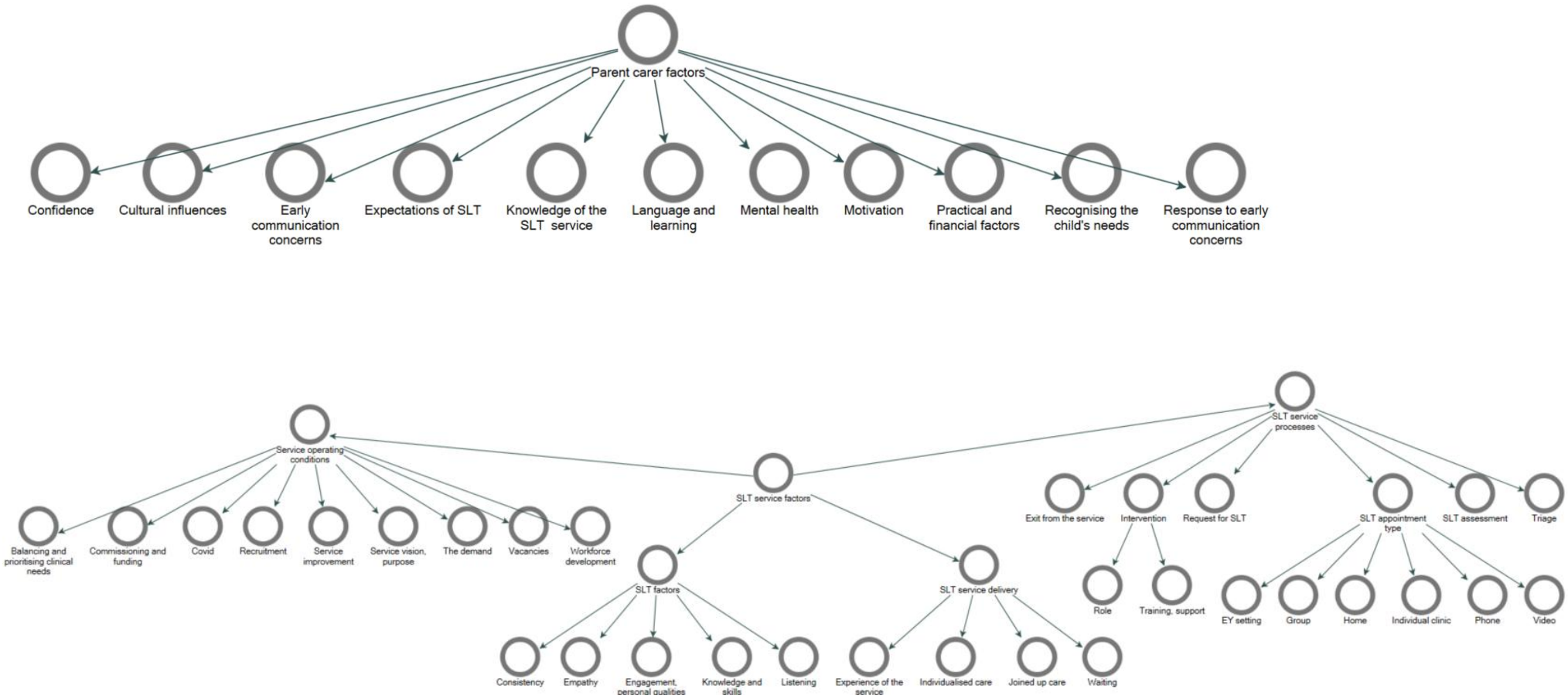
E.2 Redundant codes



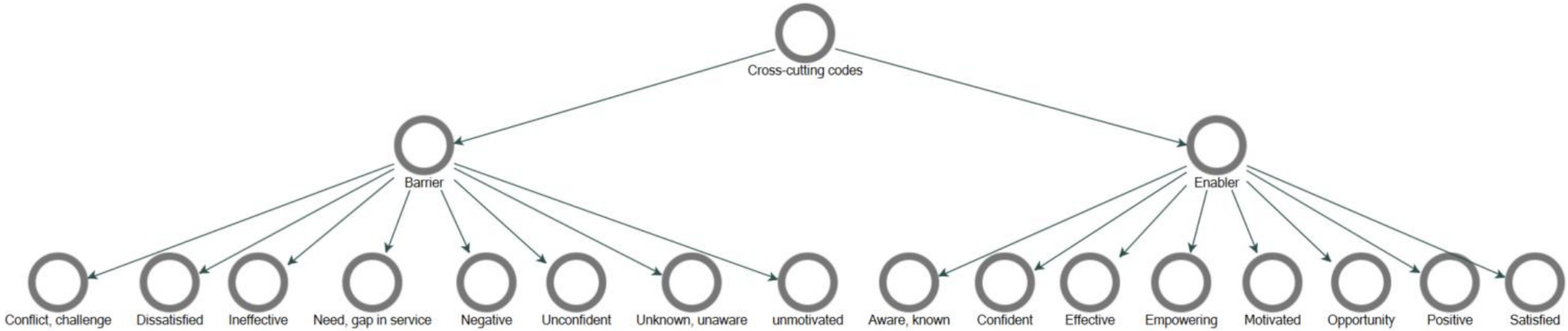
E.3 Static set used to review codes on a similar topic: 'Recognising and responding to early concerns'

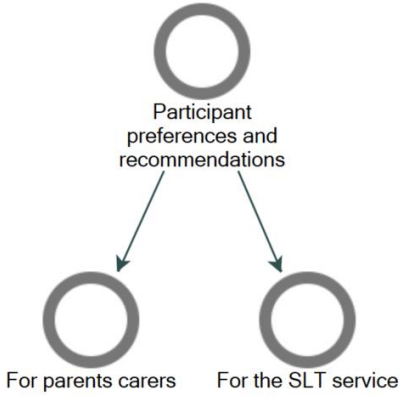


E.4 Code categories generated during phase 3 (Braun and Clarke, 2021)



E.5 Cross-cutting codes





E.6 Codebook exported at the end of phase 3 of analysis

Name	Description	Files	References
Cross-cutting codes		0	0
Barrier		23	288
Conflict, challenge		17	89
Dissatisfied		14	60
Ineffective		13	27
Need, gap in service		16	43
Negative		5	13
Unconfident		10	23
Unknown, unaware		12	30
unmotivated		2	3
Enabler		23	235
Aware, known		8	16
Confident		10	22
Effective		18	63
Empowering		14	34
Motivated		11	30
Opportunity		7	20
Positive		9	15

Name	Description	Files	References
Satisfied		13	35
Memorable quotes		20	65
Parent carer factors		21	189
Confidence	Any reference to the way in which a parent or carer confidence level impacts on access to SLT for their child.	5	7
Cultural influences	Any reference related to how the cultural background of a family may impact on access to SLT.	3	4
Early communication concerns	References to the nature of the communication difficulties observed.	10	26
Expectations of SLT	References to the parent/carer expectations of SLT. This may be from any perspective, such as the parent/carer themselves, or from the perspective of another participant interviewed.	9	26
Knowledge of the SLT service	Reference to knowledge of the SLT service, including what they do, who they are for, and when and how to access the service.	7	12
Language and learning	References to parents' or carers' language or learning abilities impacting on access to SLT.	3	8
Mental health	Any reference to the parent/carer's mental health impacting on the child's access to SLT.	2	2
Motivation	Any reference to the parent or carer's degree of motivation influencing access to SLT.	12	33
Practical and financial factors	Reference to practical issues such as travel, time, money, or childcare impacting on access to SLT.	11	14
Recognising the child's needs	References to the ways in which the child's communication needs are recognised (or not).	11	18
Response to early communication concerns	Reference to how any person may respond to communication concerns being raised about a child, e.g., this can include a nursery's response to a parent, or a family member's response to a parent, or a parent's response to nursery's concerns.	13	39
Participant preferences and recommendations		17	34

Name	Description	Files	References
For parents carers	Participant recommendations for other parents considering/seeking access to the SLT service.	6	6
For the SLT service	Participant recommendations for SLT services.	14	28
SLT service factors		23	718
Service operating conditions		19	211
Balancing and prioritising clinical needs	References to the ways in which clinical needs are determined and children prioritised accordingly. Includes references to challenges and how these are managed/considered within the service as well as how they are viewed by others.	10	26
Commissioning and funding	Any reference to commissioning or funding of preschool autism SLT service, or the SLT services that provide this care.	5	28
COVID	Any reference to COVID-19 and its impact on access to SLT.	16	30
Recruitment	Any reference to SLT recruitment.	5	8
Service improvement	Reference to actions, ideas, and thoughts around SLT service improvement relevant to preschool autistic children.	11	34
Service vision, purpose	References to the vision or purpose of the service.	8	28
The demand	Reference to the demand for SLT services for children.	9	26
Vacancies	Any reference to unfilled SLT posts.	8	19
Workforce development	References to activities, plans or the need to support and develop the existing workforce.	5	12
SLT factors		18	92
Consistency	References to continuity and consistency in relation to any aspect of SLT.	6	11
Empathy	Any reference to the empathy of the SLT and/or the impact of this.	9	17

Name	Description	Files	References
Engagement, personal qualities	Reference to the personal qualities of SLTs as individuals and how they engage with others.	8	10
Knowledge and skills	References to the SLT's knowledge, skills and confidence related to Autism communication assessment and intervention.	13	39
Listening	References to the SLT listening to parents/carers.	9	15
SLT service delivery		21	142
Experience of the service	Any reference to the experience of accessing SLT. This may include a participant describing their own experience or describing the experience of another.	13	35
Individualised care	Any references to ideas and actions related to patient centred, tailored SLT support for a child and their family.	13	41
Joined up care	Reference to the way in which services do/don't work together to provide a joined-up service to children and their families.	5	12
Waiting	Any reference to the child and their family having to wait for SLT. This may be waiting for a phone call, a report, an assessment, or intervention etc.	21	54
SLT service processes		23	273
Exit from the service	Reference to exit from the SLT service, e.g., not being added to a waiting list/offered any input, or to being discharged from SLT after assessment or intervention.	9	22
Intervention		18	86
Role	Reference to an individual's role in providing intervention for a preschool autistic child, e.g., SLT, parent or nursery staff.	10	36
Training, support	Reference to training and/or support for parents/carers provided by SLTs.	17	50
Request for SLT	References to actions taken to request SLT or to make a referral/self-referral for the service.	17	46

Name	Description	Files	References
SLT appointment type		20	75
EY setting	Individual assessment/intervention/review appointment in the child's early years setting, e.g., private day nursery.	6	16
Group	Reference to group SLT intervention/education session for children and/or their carers.	7	15
Home	Individual SLT appointment in the child's home for assessment/intervention/review.	5	10
Individual clinic	Individual SLT assessment or intervention appointments in a clinic environment.	4	8
Phone	Reference to any SLT appointment taking place over the phone.	10	20
Video	Any SLT appointment via video consultation.	3	6
SLT assessment	Any references to the SLT assessing the communication needs of the child, from any perspective and in any way, e.g., phone, video call or in person.	14	32
Triage	A review of the SLT referral/request for help by SLT to determine the urgency and nature of support requested/potentially required.	5	12

E.7 Sample of matrix coding query results

E.7.1 Matrix query of main codes and barrier/enabler codes (grouped)

	A : Enabler	B : Barrier
1 : Waiting	9	50
2 : Workforce	5	26
3 : Service improvement	8	16
4 : Covid	5	16
5 : Commissioning and f...	2	7
6 : The demand	2	11
7 : Balancing needs	2	17
8 : Training, support	25	22
9 : Role	8	15
10 : Phone	7	13
11 : EY setting	9	6
12 : Group	4	6
13 : Home	7	5
14 : Individual clinic	1	5
15 : Video	3	2
16 : Request for SLT	26	22
17 : Individualised care	36	13
18 : Experience of the s...	10	33
19 : SLT assessment	8	17
20 : Service vision, purp...	14	14
21 : Exit from the service	0	11
22 : Joined up care	8	4
23 : Triage	1	2
24 : Practical and financi...	4	12
25 : Recognising the chil...	6	13
26 : Knowledge and skills	20	21
27 : Empathy	8	8
28 : Listening	9	3
29 : Consistency	7	4
30 : Engagement, perso...	8	4
31 : Response to early c...	17	22
32 : Early communicatio...	14	14
33 : Expectations of SLT	4	9
34 : Knowledge of the S...	3	10
35 : Confidence	2	6
36 : Language and learn...	2	7

E.7.2 Service factors codes and barrier/enabler codes (grouped)

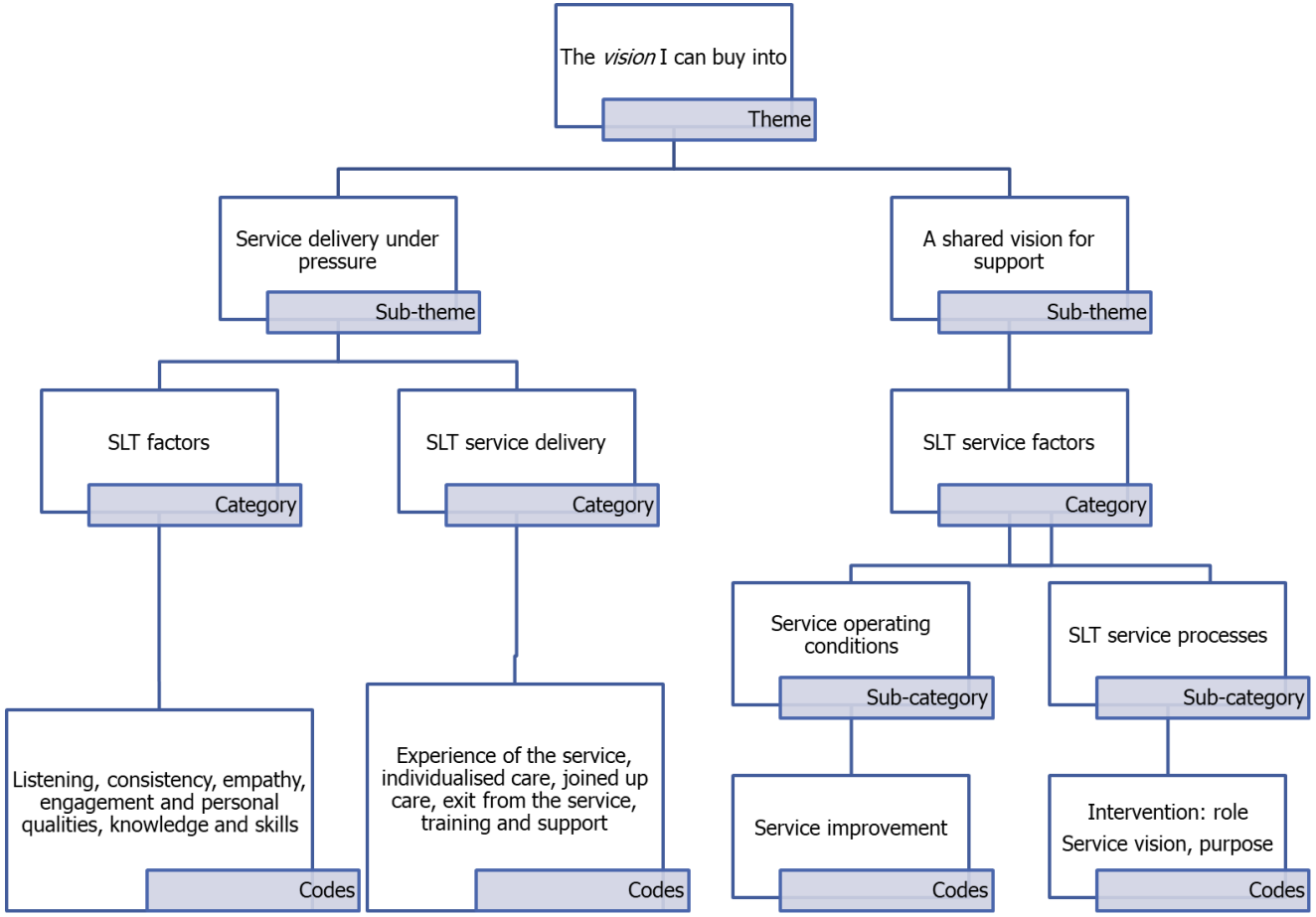
	A : Balancing needs	B : Service improvement	C : Service vision, purpo...
1 : Enabler	2	8	13
2 : Barrier	14	13	12
3 : Positive	0	3	0
4 : Aware, known	0	2	0
5 : Confident	0	0	0
6 : Motivated	0	0	0
7 : Empowering	2	1	12
8 : Satisfed	0	2	1
9 : Effective	0	0	0
10 : unmotivated	0	0	0
11 : Negative	0	0	0
12 : Unconfident	0	0	1
13 : Ineffective	1	0	0
14 : Unknown, unaware	1	0	1
15 : Need, gap in service	1	6	0
16 : Dissatisfied	0	3	2
17 : Conflict, challenge	12	4	8

E.7.3 Parent/carer factors by barrier/enabler codes (ungrouped)

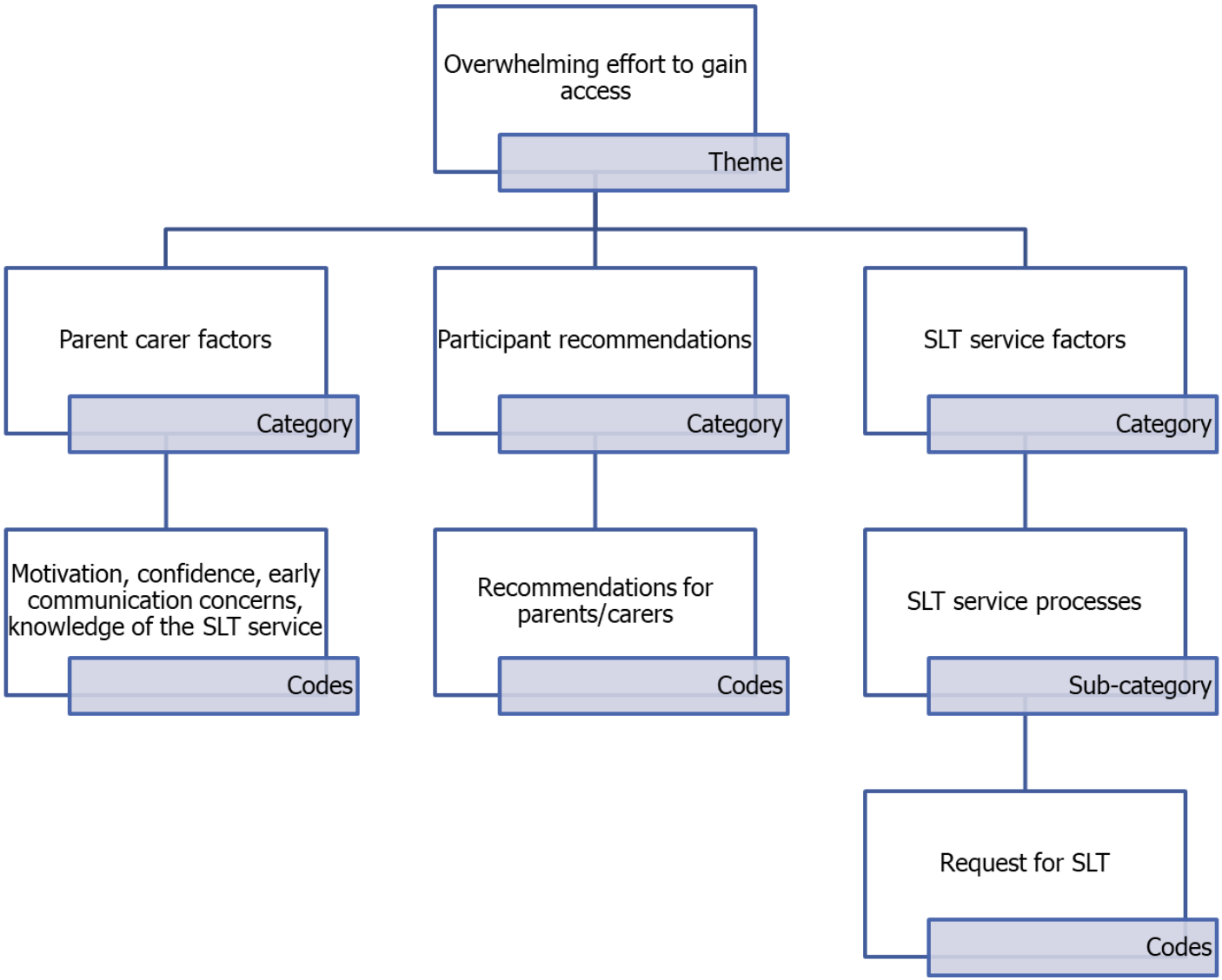
	A : Motivation	B : Practical and financi...	C : Language and learning	D : Confidence
1 : Conflict, challenge	0	11	3	2
2 : Dissatisfied	3	0	0	0
3 : Need, gap in service	0	0	1	0
4 : Unknown, unaware	1	1	1	0
5 : Ineffective	3	0	2	1
6 : Unconfident	1	1	1	5
7 : Negative	0	0	0	0
8 : unmotivated	3	0	1	1
9 : Barrier	8	12	6	6
10 : Enabler	30	4	2	2
11 : Effective	1	3	2	1
12 : Satisfed	2	0	0	0
13 : Empowering	1	0	0	0
14 : Motivated	30	1	1	1
15 : Confident	3	0	0	1
16 : Aware, known	1	0	0	1
17 : Positive	1	0	0	0

E.8 Candidate themes, sub-themes, categories and codes

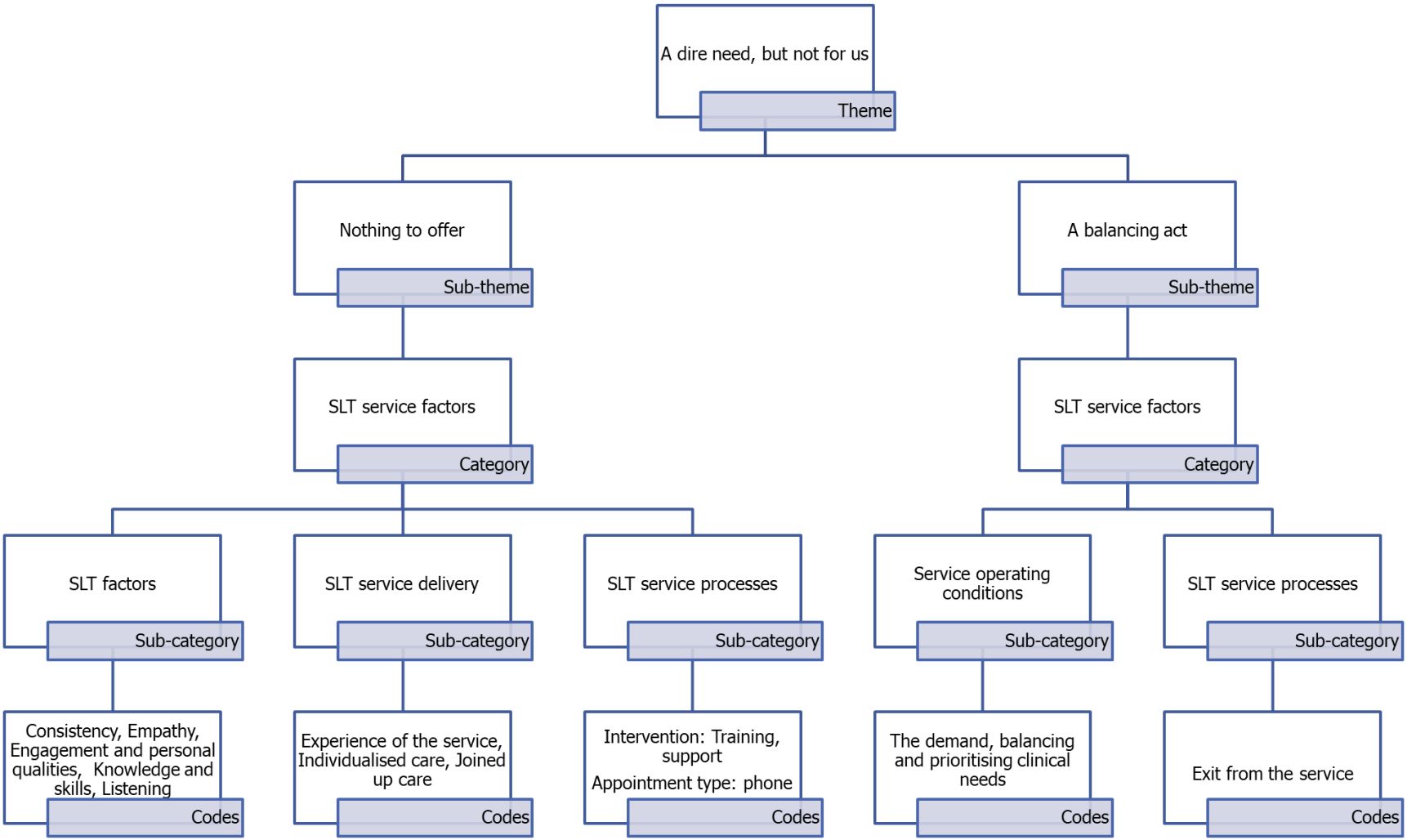
E.8.1 The *vision* I can buy into



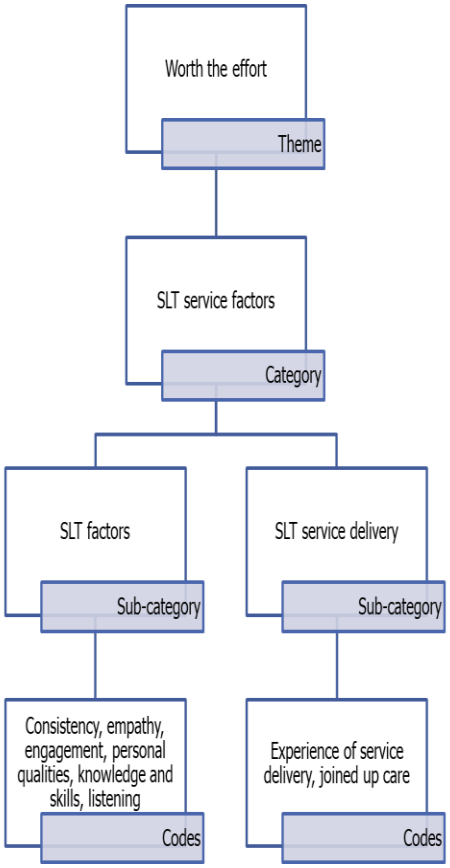
E.8.2 Overwhelming effort to gain access.



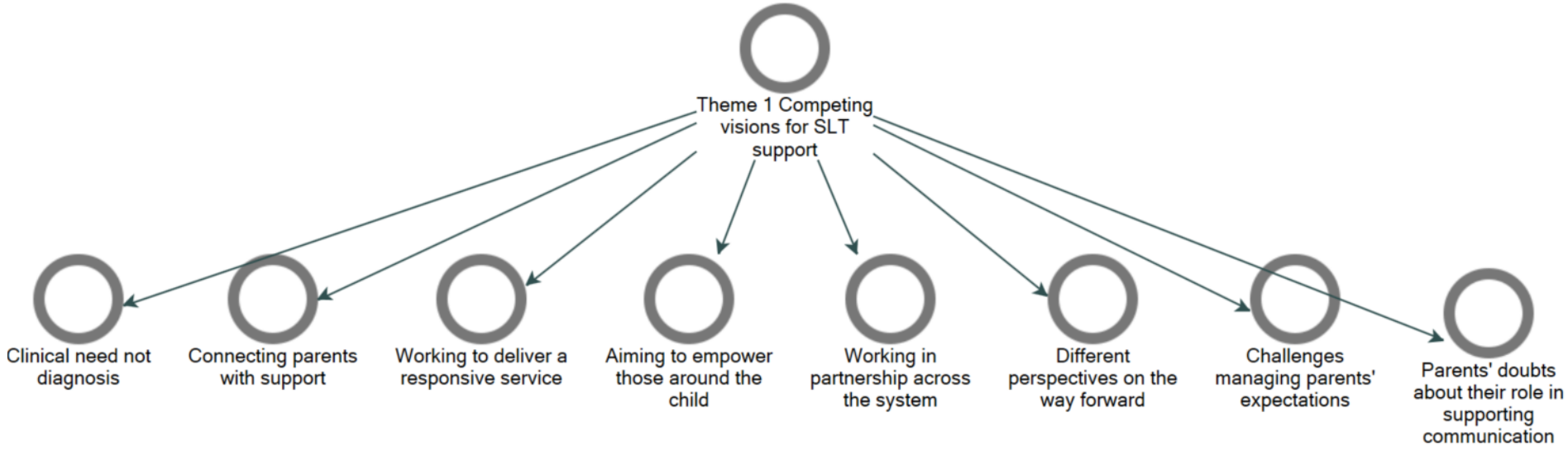
E.8.3 A dire need but not for us

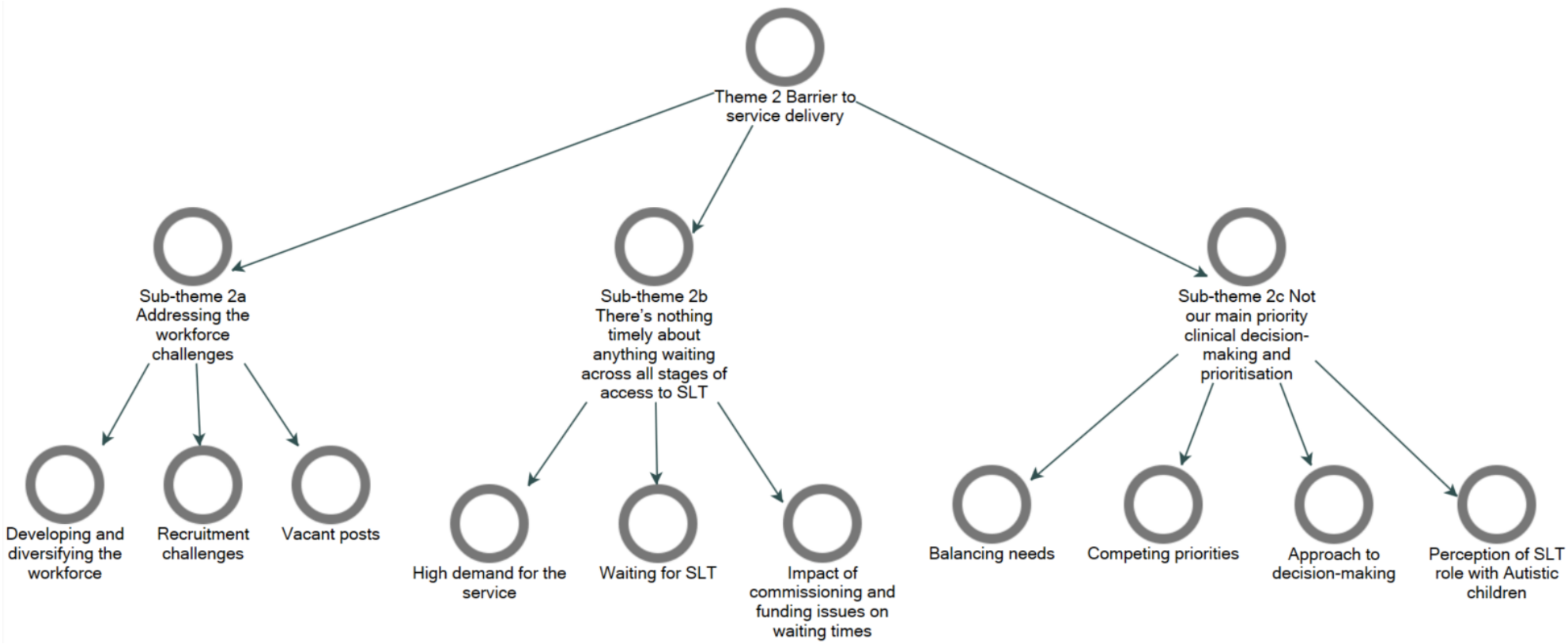


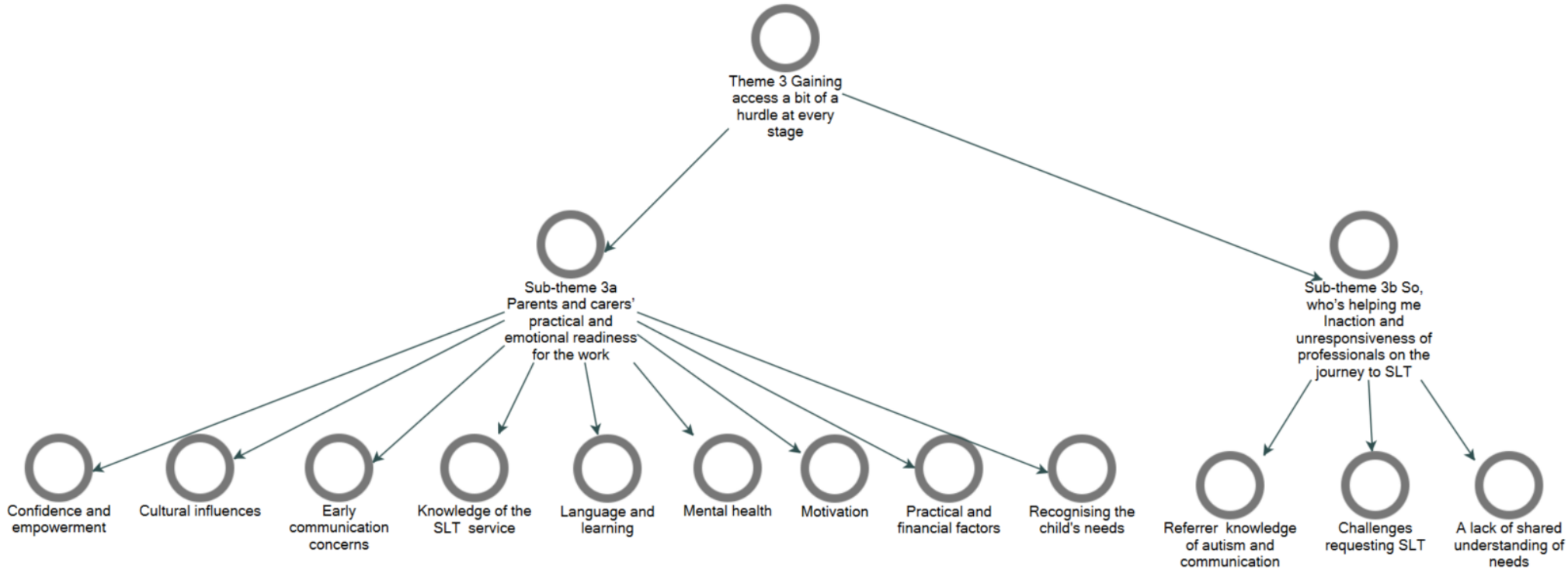
E.8.4 Candidate theme 4: Worth the effort

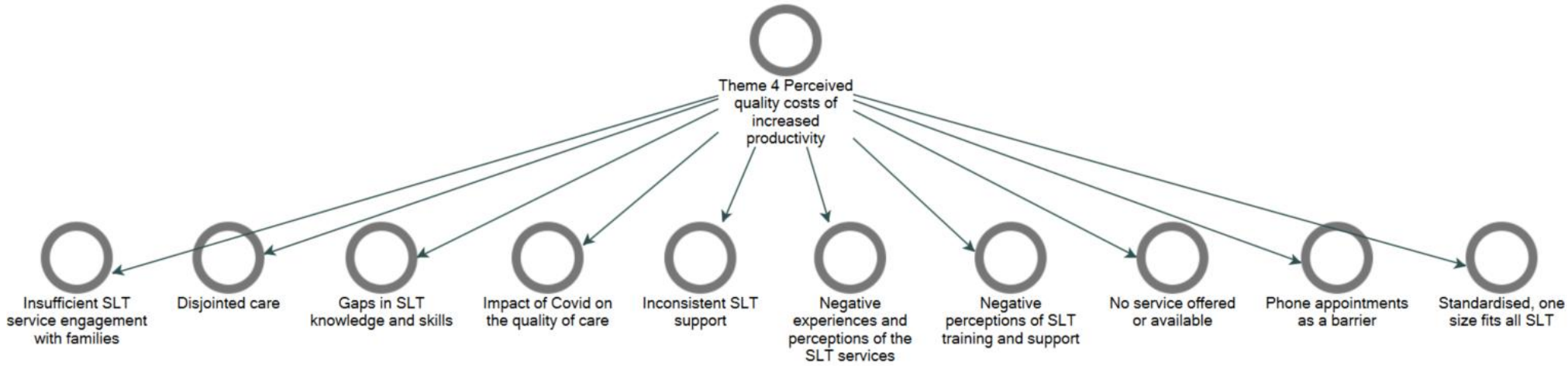


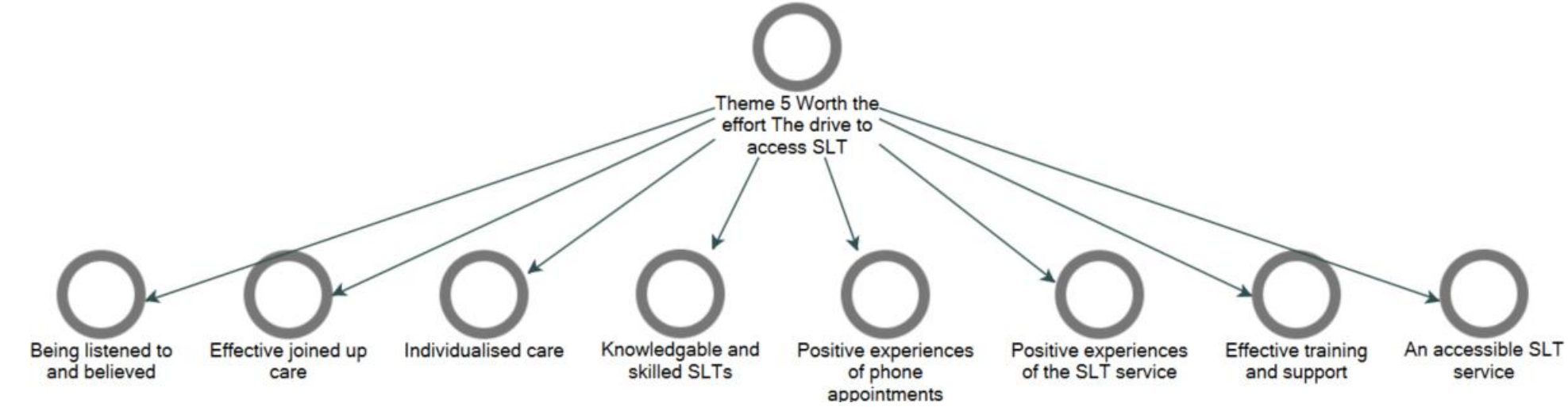
E.9 Codes contributing to the final themes and sub-themes




Theme 2 Barrier to service delivery
Sub-theme 2a Addressing the workforce challenges
Sub-theme 2b There's nothing timely about anything waiting across all stages of access to SLT
Sub-theme 2c Not our main priority clinical decision-making and prioritisation
Developing and diversifying the workforce
Recruitment challenges
Vacant posts
High demand for the service
Waiting for SLT
Impact of commissioning and funding issues on waiting times
Balancing needs
Competing priorities
Approach to decision-making
Perception of SLT role with Autistic children


Theme 3 Gaining access a bit of a hurdle at every stage
Sub-theme 3a Parents and carers' practical and emotional readiness for the work
Sub-theme 3b So, who's helping me Inaction and unresponsiveness of professionals on the journey to SLT
Confidence and empowerment
Cultural influences
Early communication concerns
Knowledge of the SLT service
Language and learning
Mental health
Motivation
Practical and financial factors
Recognising the child's needs
Referrer knowledge of autism and communication
Challenges requesting SLT
A lack of shared understanding of needs


Theme 4 Perceived quality costs of increased productivity
Insufficient SLT service engagement with families
Disjointed care
Gaps in SLT knowledge and skills
Impact of Covid on the quality of care
Inconsistent SLT support
Negative experiences and perceptions of the SLT services
Negative perceptions of SLT training and support
No service offered or available
Phone appointments as a barrier
Standardised, one size fits all SLT


Theme 5 Worth the effort The drive to access SLT
Being listened to and believed
Effective joined up care
Individualised care
Knowledgable and skilled SLTs
Positive experiences of phone appointments
Positive experiences of the SLT service
Effective training and support
An accessible SLT service

E.10 Self-assessment using Braun and Clarke (2020) quality checklist for Reflexive Thematic Analysis (RTA)

Adequate choice and explanation of methods and methodology	Self-assessment
1. Do the authors explain why they are using thematic analysis (TA), even if only briefly?	✓
2. Do the authors clearly specify and justify which type of TA they are using?	✓
3. Is the use and justification of the specific type of TA consistent with the research questions or aims?	✓
4. Is there a good 'fit' between the theoretical and conceptual underpinnings of the research and the specific type of TA (i.e. is there conceptual coherence)?	✓
4. Is there a good 'fit' between the methods of data collection and the specific type of TA?	✓
5. Is the specified type of TA consistently enacted throughout the paper?	✓
7. Is there evidence of problematic assumptions about, and practices around, TA? These commonly include: • Treating TA as one, homogenous, entity, with one set of – widely agreed on – procedures. • Combining philosophically and procedurally incompatible approaches to TA without any acknowledgement or explanation. • Confusing summaries of data topics with thematic patterns of shared meaning, underpinned by a core concept. • Assuming grounded theory concepts and procedures (e.g. saturation, constant comparative analysis, line-by-line coding) apply to TA without any explanation or justification. • Assuming TA is essentialist or realist, or atheoretical. • Assuming TA is only a data reduction or descriptive approach and therefore must be supplemented with other methods and procedures to achieve other ends.	Reflexive TA clearly differentiated from other TA approaches and aligns well with research perspective.
8. Are any supplementary procedures or methods justified, and necessary, or could the same results have been achieved simply by using TA more effectively?	N/A
9. Are the theoretical underpinnings of the use of TA clearly specified (e.g. ontological, epistemological assumptions, guiding theoretical framework(s)), even when using TA inductively (inductive TA does not equate to analysis in a theoretical vacuum)?	✓
10. Do the researchers strive to 'own their perspectives' (even if only very briefly), their personal and social standpoint and positioning? (This is especially important when the researchers are engaged in social justice-oriented research and when representing the 'voices' of marginal and vulnerable groups, and groups to which the researcher does not belong.)	✓

11. Are the analytic procedures used clearly outlined, and described in terms of what the authors actually did, rather than generic procedures?	✓ Detailed description of all stages.
12. Is there evidence of conceptual and procedural confusion? For example, reflexive TA (Braun & Clarke, 2006) is the claimed approach but different procedures are outlined such as the use of a codebook or coding frame, multiple independent coders and consensus coding, inter-rater reliability measures, and/or themes are conceptualised as analytic inputs rather than outputs and therefore the analysis progresses from theme identification to coding (rather than coding to theme development).	✓ Up to date guidance followed.
13. Do the authors demonstrate full and coherent understanding of their claimed approach to TA?	Overview of approach, and its development over time provided. Compared with other approaches considered.

A well-developed and justified analysis	**Self-assessment**
14. Is it clear what and where the themes are in the report? Would the manuscript benefit from some kind of overview of the analysis: listing of themes, narrative overview, table of themes, thematic map?	✓ Presented in a table and figure.
15. Are reported themes topic summaries, rather than 'fully realised themes' – patterns of shared meaning underpinned by a central organising concept? • If so, are topic summaries appropriate to the purpose of the research? • If the authors are using reflexive TA, is this modification in the conceptualisation of themes explained and justified? • Have the data collection questions been used as themes? • Would the manuscript benefit from further analysis being undertaken, with the reporting of fully realised themes? • • Or, if the authors are claiming to use reflexive TA, would the manuscript benefit from claiming to use a different type of TA (e.g. coding reliability or codebook)?	No modification to RTA approach. Analysis aimed to develop themes rather than topic summaries and this was carefully considered throughout analysis.
16. Is a non-thematic contextualising information presented as a theme? (e.g. the first theme is a topic summary providing contextualising information, but the rest of the themes reported are fully realised themes). If so, would the manuscript benefit from this being presented as non-thematic contextualising information?	No, contextual information on processes and research setting are separate from the RTA report.
17. In applied research, do the reported themes have the potential to give rise to actionable outcomes?	✓ Clear link between findings and recommendations

18. Are there conceptual clashes and confusion in the paper? (e.g. claiming a social constructionist approach while also expressing concern for positivist notions of coding reliability, or claiming a constructionist approach while treating participants' language as a transparent reflection of their experiences and behaviours)	Alignment of methodology, methods, analysis and reporting carefully considered throughout the study.
19. Is there evidence of weak or unconvincing analysis such as: • Too many or two few themes? • Too many theme levels? • Confusion between codes and themes? • Mismatch between data extracts and analytic claims? • Too few or too many data extracts? • Overlap between themes?	Guidance on minimising theme levels followed (2 levels of themes generated in analysis), no. of themes generated consistent with guidance (2-6 themes in a single analytic chapter in a doctoral thesis) (Braun and Clarke, 2019b).
20. Do authors make problematic statements about the lack of generalisability of their results, and or implicitly conceptualise generalisability as statistical probabilistic generalisability.	No

Appendix F Excerpts from reflexive diary

January 2022

Recruitment of professionals- feels slow. Pandemic impacting on staffing, response to emails etc.

Participant eligibility - decided to broaden from Health Visiting team members to wide range of early years staff due to commissioner, service manager and charity manager engagement conversations all stating that a wider perspective would be valuable for understanding this topic. Need to go through ethics to do this.

April 2022

Recruiting parents/carers:

Many children are believed to have autism- but are waiting for assessment.
Many of these children are accessing Autism-specific services.

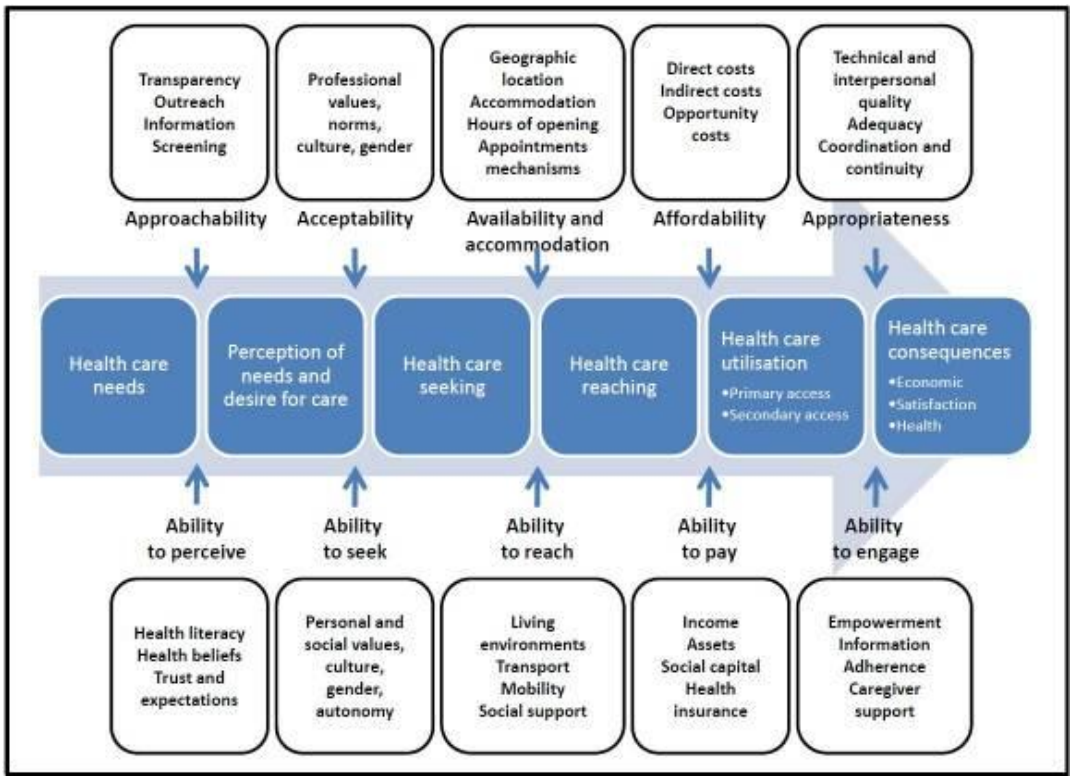
Stakeholder conversation with a local Autism charity manager. She stated the SLT service is under pressure and they now may not offer any SLT input before school. This was also highlighted by two intermediaries supporting parent/carer recruitment:

May 22

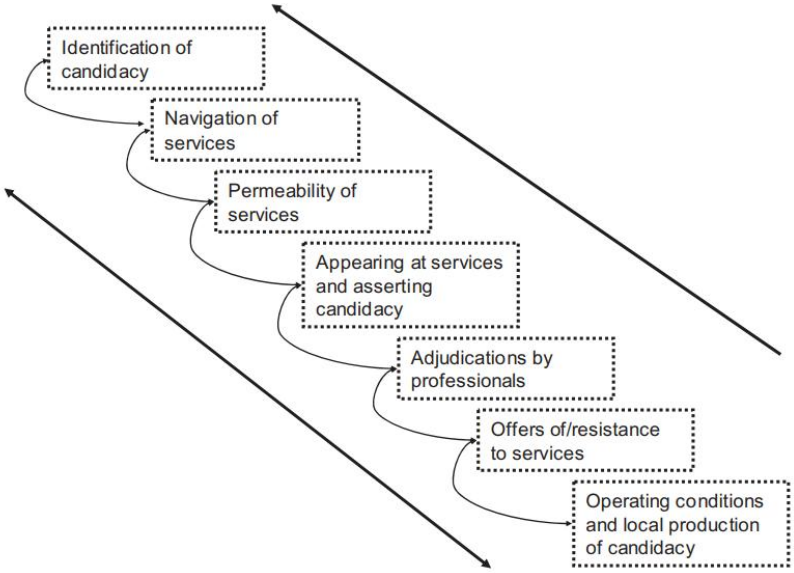
Amendment to ethics submitted to request parents/carers waiting for a diagnosis now included and also children referred only to SLT included in the study (not having to access 2 appt) this seemed really important for a study on access to SLT. I'm asking all stakeholders- how can I best engage with parents/carers. Not getting any new suggestions- a bit of signposting.

Appendix G Frameworks for understanding access to healthcare

G.1 Levesque conceptual framework of access to healthcare (Levesque, Harris and Russell, 2013)



G.2 Candidacy Framework (Dixon-Woods *et al.*, 2006) as depicted by (Mackenzie *et al.*, 2013)



Appendix H Summary of findings for participants and stakeholders

UNIVERSITY OF Southampton

Research summary

Sent via email June 2024

Email subject: Research Feedback for Participants

Body of email:

Dear [Insert name]

I hope you're well. It is a long time since we met and you were interviewed for my study on access to Speech and Language Therapy for preschool autistic children. Thank you very much for taking the time to share your thoughts and experiences with me. I really appreciated the time and effort involved with being part of the study.

I'm now in the final stage of the study and would like to share the findings with you. I hope you feel our discussion and your experience is represented, and would really appreciate hearing your views before I submit my final thesis.

I welcome any thoughts at all on the attached research summary.

Best wishes

Iona

IRAS ID: 268236 REC Reference: 20/PR/0874

UNIVERSITY OF Southampton

Research summary

Access to Speech and Language Therapy for preschool Autistic children – what did we learn?

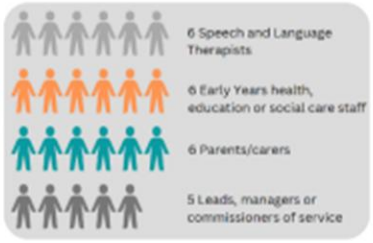
Thank you very much for taking part in the study and for sharing your thoughts and experiences on access to Speech and Language Therapy (SLT) for preschool autistic children. It is now some time since you were interviewed by Iona Wood, doctoral student, and we would like to share what we found out with you.

Purpose of the study

Around the world, access to SLT is challenging. Understanding the range of service, family and child factors affecting SLT access is important to support and improve access for children and their families. This study aimed to find out about people's thoughts, feelings and experiences of access in everyday, real-world, situations.

Who did we speak to?

We spoke to 23 people who have experiences of access to SLT. Interviews took between 20 and 60 minutes.



The study took place in the South of England

How did we analyse the data?

Each interview was typed up and studied carefully and systematically. The meaning of what was said in interviews were labelled and grouped together into themes. These themes aimed to find important patterns of meaning linked to the research topic across all interviews.

What did we learn?

Access to SLT was an important topic for people who need or provide SLT. We gathered lots of information.

Some people talked very positively about access to SLT, and the SLT support provided. This was not always true however, and people talked about several barriers to access to SLT.

The five main themes below were important to the people interviewed.

IRAS ID: 268236 **REC Reference: 20/PR/0874**

UNIVERSITY OF Southampton

Research summary

Theme 1: Barriers to service delivery

Addressing the workforce challenge	• SLT teams worked hard to find and keep staff. • High job vacancies made it difficult to meet children's needs, and to make improvements that would lead to help for more families.
"There's nothing timely about anything": waiting across all stages of access	• Waiting times were long. • Waiting was reported at several stages in access, even after the child had had their first appointment. • Waiting delayed children's access to support, and was a source of stress for all involved. • Waiting times affected clinical decisions on the type and amount of service offered, or whether to offer any service at all.
"Not our main priority": clinical decision-making and prioritisation	• Some SLTs, leads and managers talked about it being difficult to balance needs of different groups of children. • Many autistic children need SLT support, and the long waiting times for all children meant some SLTs reflected carefully on their role in supporting autistic children. • Some felt they could not give autistic children the support they need and that trying to do this without enough resources affected access to SLT for other children.

Theme 2: Competing visions for SLT support

- There were different expectations and visions for how SLT support would be provided.
- SLT services aimed to support those around the child (parents and early years staff) to support communication through the day.
- Some parents and other professionals viewed the SLT as the expert and expected SLT to happen directly between the SLT and child.
- Different views led to confusion and frustration and coming to a shared understanding on the way forward could be challenging.

Theme 3: Perceived quality costs of increased productivity

- Efforts to increase the number of families being helped had unintended effects on service quality.
- SLTs reported they provided less support overall, and worked indirectly through others (such as SLT assistants) when they felt more direct support from an SLT was needed.
- Some SLTs felt working indirectly reduced their skills in working 'hands-on' with children.
- Many SLTs were unhappy about the effectiveness of the level of support they were able to provide.

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Research summary

Theme 4: Gaining access: "a bit of a hurdle at every stage"

Parents and carers' practical and emotional readiness for the work	• Parents and others interviewed described the knowledge, motivation, commitment and confidence parents needed to access SLT. • Despite parents' efforts, this did not always lead to easy access to SLT for families.
"So who's helping me?" Inaction and unresponsiveness of professionals on the journey to SLT	• Many parents experienced problems on their journey to SLT. • This was often described as a fight to be believed, and many experienced self-doubt, worry and stress. • Those working with children observed that parents with less knowledge, confidence and experience working with professionals were affected more by unresponsive or unsupportive professionals.

Theme 5 "Worth the effort" the drive to access SLT

★★★

- Despite the effort and problems in accessing SLT, it was often described as a highly-valued service.
- Most parents and other professionals interviewed appreciated the high-quality SLT assessments and reports completed once the service had been accessed.
- Parents who had good experiences particularly valued the person-centred approach of SLTs.
- Being listened to, believed and being part of decisions about their child was important for all parents.

What next?

We will write up the results in an article for a scientific journal so that others may also learn from what we found out.

This will include recommendations for therapists, SLT services and other professionals working with young autistic children and their families.

We will share the results with Speech and Language Therapists and the autism community to help find ways to improve access to Speech and Language Therapy for children and their families.

We hope you have found this summary interesting. Thank you very much, again for giving your time to share your thoughts with us. Any more thoughts and reflections on the findings are welcome. Please email Iona.

Iona and the research team

[redacted]

IRAS ID: 268236

REC Reference: 20/PR/0874