Portfolio Volume 1: Major Research Project

The Experiences of Professionals Supporting Children with Autism and their Families in Britain's Orthodox Jewish Communities

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Glossary of selected Jewish terms

G-d (God) – The Torah forbids using G-d's name in its complete form, as it prohibits erasing, destroying or desecrating the name of G-d (Deuteronomy, 12:4).

Halakhah (also spelt *Halachah*) is the ''way'' a Jew is directed to behave in every aspect of life, encompassing civil, criminal and religious law.

Hebrew – a Semitic language used in biblical and modern texts, and the main language of prayer and other religious texts. According to Jewish scriptures, Hebrew played a crucial role in the creation of the world, and G-d created the world by speaking Hebrew in Genesis 1.

Pesach/Passover - a major Jewish spring festival that commemorates the Israelites' departure from enslavement in Egypt to freedom. Celebrated annually from the 15th to the 22nd of Nissan, the first month of the Jewish calendar, it commemorates the birth of the Jewish nation.

Rabbi – a religious and spiritual leader and teacher in Judaism, qualified through academic study of the Hebrew Bible and the Talmud.

Rebbe – a teacher, guide, and spiritual leader of the Hasidic community, serving as a personal mentor, mystic, and intermediary between their followers and G-d.

Shabbat - (also known as *Shabbos* or *Sabbath*) is the Jewish day of rest and celebration, observed from Friday evening to Saturday night. It is the cornerstone of Jewish life.

Talmud – a collection of writings covering a full gamut of Jewish law and tradition.

Torah – literally 'instruction', a compilation of the first books of the Hebrew Bible and the foundation of all Jewish traditions and guidance.

Abstract

Introduction: Research has identified racial and cultural disparities in autism diagnosis and access to interventions. At the same time, the prevalence of autism has been rising in England, and the UK is home to an estimated 76,000 Charedi Jews. The Charedi (Orthodox Jewish) community is among the fastest-growing populations globally. Evidence suggests that Charedi children may be at risk of delayed autism diagnoses and inconsistent access to support. In light of the paucity of research on the subject, the current study sought to explore barriers and facilitators to obtaining an autism diagnosis and accessing support services among Orthodox Jewish families, through the lens of professionals who work with them.

Method: A critical realist lens was adopted to explore the experiences of professionals working with children with autism and their parents from the Orthodox Jewish communities in Britain, based on nine semi-structured interviews. The data was analysed using Reflexive Thematic Analysis.

Results: Six themes were identified, three of which had subthemes. Theme 1: Autism awareness, knowledge, and negotiation of labels, Sub-theme: Variability in parental access to knowledge Sub-theme: The impact of language in shaping the acceptability of autism. Theme 2: The meaning of diagnosis, Sub-theme: Meaning within the family: emotional and practical dimensions of diagnosis Sub-theme: Meaning within the community: stigma and social dimensions of diagnosis. Theme 3: Varied layers of knowing, Sub-theme: Experts by knowledge: learning from cultural differences Sub-theme: Experts by experience: diversity within Orthodox Jewish communities. Theme 4: Embedding cultural and religious awareness into practice. Theme 5: Negotiating support through religious authority, trust and safety, Theme 6: Autism as a whole-family challenge.

Discussion: The study's findings are discussed in relation to the existing literature and the research questions. Strengths, limitations and clinical implications of the study are outlined. Recommendations for future research and dissemination plans are discussed.

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CHAPTER 1: INTRODUCTION

Chapter Overview

This project explores the experiences of professionals working with Orthodox Jewish parents and carers of children with autism in the UK. This chapter begins by outlining my positionality in relation to the research subject and my adopted epistemological stance. It then introduces the key concepts relevant to this research. This chapter also aims to situate the project within a broader context and highlight the relevance of the topic.

Positionality and Epistemology

Epistemology

Ontology concerns the nature of reality and whether it exists independently of human perception or is shaped by human experience and social constructs (Braun & Clarke, 2022; Ylönen & Aven, 2023). This study adopted a critical realist (CR) ontological stance, which holds that reality comprises both observable and unobservable features (Stutchbury, 2022). According to critical realists, phenomena exist independently of human awareness, and their understanding is shaped by social, cultural and historical contexts (Pretorius, 2024). Epistemology refers to the study of the nature of knowledge and the process through which we come to understand it (Nairn, 2012). It asks questions about how knowledge is acquired and what counts as valid knowledge (Braun & Clarke, 2022). Adopting a critical realist epistemological stance in this project enabled exploration of how professionals construct knowledge about working with Orthodox Jewish families, while recognising that knowledge is influenced by context and interpretation (Bhaskar, 2011). From this perspective, individuals may experience the same event, but their interpretations may differ according to their background, cultural, religious and historical contexts (Pretorius, 2024). In this project, critical realism provides a framework for examining the underpinnings of the phenomenon related to professionals' work with families from Orthodox Jewish communities who raise children with autism. Understanding professionals' experiences is only possible when broader historical, social, and cultural factors are considered, as these shape the interpretations and experiences that influence their interactions with Orthodox Jewish communities (Pilgrim, 2019). The data collected from participants reflect my interpretation, influenced by the lenses I bring, rather than an absolute truth or direct reality.

Considering alternative epistemologies, such as a positivist approach, would not be suitable for this study, as positivists argue that a tangible reality exists and can be understood, identified and measured, and that knowledge can be developed objectively (Park et al., 2020). The dilemmas in this study are contextual and cannot be reduced to measurable variables, and a positivist's positionality

might have led to participants being viewed as objects of measurement rather than as interpreters of experience.

Another epistemology, social constructionism, although it postulates that realities and knowledge can be socially constructed through language, stories, histories, and narratives (Galbin, 2014) and could offer insights into professionals' perceptions of autism and families' experiences as socially constructed, would not account for participants' subjective accounts, which are influenced by broader personal, cultural and institutional factors.

''*In-betweener'' positionality*

Positionality refers to the researcher's worldview and relational stance towards participants, shaped by broader social and political contexts. It influences the research focus, methodology, and interpretation of findings (Rowe, 2014; Savin-Baden & Major, 2013).

Before discussing my positionality, I will briefly introduce my background and explain how I became interested in this topic.

I was born in a small town in Poland, a country among the most ethnically and religiously homogeneous in Europe. Surrounded by sameness, I became interested in difference. Narratives about being different, whether based on ethnicity, appearance or ability, were often shaped by negativity, discomfort and fear. These experiences made me reflect on how perceptions of difference can be unjust and narrowly constructed. Fortunately, I grew up in an open-minded household that embraced diversity. Visiting places different from my homeland throughout my childhood and adolescence has further fuelled my curiosity about how cultures shape lived experiences. I became fascinated by how people live and think, and how they understand and solve problems differently. All of these experiences have given me permission to question dominant views. The not knowing, yet wanting to understand, has guided me throughout my personal and professional life.

Having lived in London for the past two decades and worked with autistic children and young people from diverse religious and ethnic backgrounds has exposed me to multiple layers of difference. These experiences contributed to a greater appreciation of the unique autism-related realities and the importance of viewing them within a person's cultural and ethnic context.

Reflecting on the diversity of the communities I worked with, I realised I had never encountered Orthodox Jewish families. This was particularly thought-provoking, as I lived close to the Orthodox Jewish community in London and often visited places where I met the community members. On the one hand, I was close enough to observe their ordinary life, while on the other, I was distant enough to understand their realities.

When a topic concerning the Orthodox Jewish community was presented at a research fair, I immediately became interested and shaped the project to combine my interest in autism with my curiosity about a distinct religious and cultural group.

A researcher is considered an 'insider' when they share similar characteristics or experiences with participants, whereas an 'outsider' is outside the group being researched (Braun & Clarke, 2013). Outsiders' lack of familiarity with the group under study is claimed to confer objectivity, whereas the insider position can be seen as a privileged one that enables researchers to gain critical awareness of and nuanced insight into a research phenomenon through identification with the lived experiences of research participants (Gair, 2012)

However, researchers recognise that viewing insider and outsider positionality as a binary is oversimplified (Eppley, 2006; Katyal & King, 2014). Milligan (2016) suggests that a researcher does not occupy a fixed position as either an insider or an outsider but rather shifts between roles depending on the context. As I neither identify entirely as an insider nor as an outsider, and shifting between these positions is not straightforward, I adopted an 'in-betweener' positionality (Chhabra, 2020)

Due to my professional background, I can, to some extent, be regarded as an insider among participants who worked in statutory mental health services and did not identify as Jewish. I have worked across multiple Children and Adolescent Mental Health Services (CAMHS). I am trained to conduct autism assessments, developmental interviews, and to deliver interventions to children and their carers. I have sat with families to share their child's diagnosis and to support them in navigating its meaning, expectations and support needs. I am aware of the structural and systemic barriers that families from ethnic minority backgrounds face in accessing diagnostic and support services. These experiences give me access to some of the knowledge of participants with whom I share similar experiences and backgrounds. However, while I have worked with many distinct religious and cultural groups, I have no direct experience of working with Orthodox Jewish communities.

Given my personal background, I am a religious and cultural outsider in relation to Jewish participants and I am positioned as external to their communities. Although I was brought up in the Catholic faith, I am not religious, and religion has never played a significant role in my life. However, I bring my own cultural history, values and experience of migration. While I live in an individualistic society, I was raised in a collectivist, community-oriented culture, which gives me insight into life in a society structured around shared norms and traditions. I also belong to an ethnic minority group in the UK, which means I have experienced my cultural identity being misunderstood and stereotyped. These aspects of myself mean that I may not be completely neutral towards insider participants.

Furthermore, I worked in educational settings and third-sector organisations as a professional supporting families in accessing diagnostic and intervention services. I experienced families'

frustration, sadness and confusion when things did not work out and they were left without support, or when their children's needs were not understood and consequently unmet. Conversely, I also witnessed success stories in which difficulties were supported and managed, and strengths were celebrated. These experiences mean that I have existing views on how supporting children with autism and their families from diverse backgrounds may look.

This highlights that my positionality is fluid and complex, depending on whose story I am engaging with. The dynamic nature of insider-outsider positionalities, which vary by context, determines participants' responses, depending on the positionality embodied by the researcher (Mason-Bish, 2019).
For the purpose of this thesis, the terms 'insider' and 'outsider' will be used throughout to refer to participants who are either strictly Orthodox Jewish or not members of Orthodox Jewish communities. This terminology was chosen over 'in-group' and 'out-group', which are well established in Social Identity Theory (SIT) (Tajfel & Turner, 1979) and relate to the psychological processes of social categorisation, whether individuals identify as part of a group or view another group as distinct. In this project, the terms 'insider' and 'outsider' more broadly describe a person's position in relation to the community and are used here as descriptive labels rather than as theoretical constructs derived from SIT. Previous research explicitly used the terms 'insider' and 'outsider' to distinguish participants by community membership or social position (Irby et al., 2012). The terminology adopted in this study was used by the individuals who informed this research, including both members and non-members of the OJ community. Furthermore, participants themselves used these terms, and adopting their language was perceived as a meaningful way to reflect how they experienced reality.

Research Decision-Making and Project's Significance

The original idea for this project, developed in the summer of 2023, concerned parents from Orthodox Jewish communities raising children with autism. The current project is the outcome of considerable time and effort spent reshaping and developing a new inquiry.

The 7th of October 2023 marked the start of the conflict between Israel and Hamas, which led to a humanitarian crisis. Jewish communities worldwide were overwhelmed by grief, fear and sorrow (Bar-Halpern & Wolfman, 2025) and were reminded of the traumatic experiences endured by previous generations (Abrams & Armeni, 2023). Following the Hamas attacks and the subsequent war in Gaza, Jewish communities have experienced substantial social and political changes that have influenced everyday life, trust in institutions, and societal engagement. In 2023, the UK recorded its highest number of antisemitic incidents ever, which remained high throughout the year 2024, suggesting that antisemitism has persisted. Many of these incidents have occurred in public spaces, schools, workplaces, healthcare settings and online, with visibly Orthodox Jewish individuals particularly vulnerable due to distinctive religious dress (Community Security Trust, 2024). Such experiences may

have reinforced concerns about discrimination and reduced trust in statutory services among Jewish communities.

Taking that into account, I wondered whether it was the right time to ask questions about such a sensitive topic, and I considered changing the project to something less emotionally charged. However, upon reflection, I recognised that my profession is largely about asking difficult questions in complex circumstances. I acknowledged that this thesis could present challenges, and it did. I also understood that attempting to start a respectful conversation about autism in strictly Orthodox Jewish communities was simply part of my role as a trainee clinical psychologist and a curious individual. Moreover, current socio-political developments do not diminish the importance of understanding the experiences of Jewish families raising children with autism; they should reinforce the need to gain insight into carers' needs. Nevertheless, recruiting parents from the community to discuss potentially sensitive issues related to autism, including help-seeking and family life, was considered likely to pose practical and ethical challenges (see Chapter 3 for more details). To minimise potential distress, the research team decided to change the study population to professionals working with Orthodox Jewish families. This change meant that participants did not need to identify as Orthodox Jews to take part, provided they had relevant experience working with families from strictly Orthodox communities. The importance of including professionals' perspectives will be discussed in this chapter. To ensure the study was conducted with sensitivity and respect and captured nuance, guidance from an expert by experience (EbE) was sought, and the representation and involvement of community members were essential (see Chapter 3 for more details).

Key Terms and Language

The terms below pertain to this project and highlight its main concepts, though the list is not exhaustive. I found it challenging to navigate decisions about terminology throughout the writing of this thesis. I experienced uncertainty about the 'right' way to define Judaism, and its subgroups and the varying spellings and definitions across the literature. While selecting the most appropriate terminology, I aimed to use language consistently and respectfully, drawing on feedback from members of Jewish communities, an insider secondary supervisor, a research consultant, and community-informed sources, where possible. Nonetheless, I recognise that the terms and language adopted in this project are shaped by my lens, and I acknowledge that other researchers may use different terminology to discuss the same concepts.

Culture

Culture can be understood as a dynamic system shaped by people, places, and practices. It encompasses the shared values, beliefs, social norms, and behaviours of a group of people living in the same environment within a specific region of the world. Culture is passed down from one generation to the next through socialisation, the process by which people learn the norms, values,

and behaviours of the society they belong to. Culture shapes how people understand the world and gives them a sense of belonging (Naik et al., 2023). Language, a component of culture, transmits ideas, beliefs, and knowledge, strengthening social support, interpersonal relationships, and shared identity (Chandler & Lalonde, 1998).

Religion

Religion is a multidimensional construct that incorporates beliefs, practices, and rituals related to the transcendent. In Western traditions, this may refer to God, Allah, HaShem, or a Higher Power, while in Eastern traditions, it includes Brahman, its manifestations, Buddha, Dao, or the ultimate truth or reality. Religions usually have specific rules governing conduct and beliefs about life after death. Practices and symbols are designed to facilitate closeness to the transcendent and to foster an understanding of one's relationship and responsibility to others in community life (Koenig et al., 2012).

Judaism

Judaism is multidimensional and complex, and it can be defined in various ways, including as a religion, an ethnicity, or even a civilisation (Hoffman, 2021). For this thesis, Judaism will be regarded as a religion, as well as a cultural and ethnic identity, in line with DellaPergola and Staetsky's (2022) findings and my discussions with members of Jewish communities. Distinct ethnic divisions among Jews, resulting from migration and dispersal, have led to the formation of separate ethnic groups in several geographical regions (Manitoba Education, 2019). Judaism is a monotheistic faith centred on belief in one transcendent God, and the laws that guide Jewish life are grounded in the Torah (Encyclopaedia Britannica, n.d.). The main denominations of Judaism include Reform, Liberal, Masorti, and strictly Orthodox (Taylor-Guthartz, 2019). These denominations vary in their teachings, interpretations of the Torah and Talmud, and adherence to Jewish law (NHS Race and Health Observatory, 2024).

Cultural Competence and Cultural Humility

Cultural competence is the ability to work effectively with individuals from diverse backgrounds, including but not limited to race, ethnicity, culture, religion, and physical or mental abilities (Appleby et al., 2011) and to distinguish problems from cultural norms while offering culturally appropriate responses (Kirmayer, 2012). The core components of cultural competence essential to competent practice are self-awareness and cultural awareness, together with practical knowledge and skills appropriate to clients' cultural backgrounds (Nguyen et al., 2021). Some argue that cultural competence is insufficient when working with diverse populations, and that the "core critique of cultural competency frameworks involves the explicit goal of competence itself" (Fisher-Borne et al.,

2015, p.170). The risk is that professionals may generalise broad knowledge of different groups to knowledge about individual clients (Fisher-Borne et al., 2015), which can lead to a perceived mastery of skills for working with a specific population without considering their own biases (Hook, 2014). Cultural humility, on the other hand, emphasises ongoing self-reflection and learning, recognising that knowledge alone is not enough, and must be accompanied by changes in attitudes and behaviours. Combining both concepts into practice leads to more effective care and greater responsiveness to clients' unique needs (Nguyen et al., 2021).

Autism

Autism spectrum disorder (ASD; hereafter autism) is a lifelong neurodevelopmental condition and a disability (National Autistic Society, n.d.) characterised by varying degrees of difficulty with social interactions, communication, as well as atypical behaviours and patterns of activity (World Health Organisation, 2025). Individuals with autism are more likely to experience co-occurring mental health difficulties, including but not limited to anxiety and mood disorders (Kirsch et al., 2020) as well as attention deficit hyperactivity disorder (ADHD) eating disorders and obsessive-compulsive disorder (OCD) (Lai et al., 2019). Additionally, 1 in 3 people with autism has a learning disability (Autistica, n.d.).

Language of Autism

Language use impacts how people are viewed, and historically, autism was discussed within the medical model, which focuses on symptoms and deficits (Bottini et al., 2024). Two widely used diagnostic schedules, namely the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) and the International Classification of Diseases (ICD-10) (World Health Organisation, 2016) define autism as a series of deficits and abnormalities. According to the medical model, divergence or difference from what is seen as a typical brain is perceived as a ‘disorder’ that should be ‘cured’, and autistic characteristics, which cause impairments, should be ‘fixed’ (National Autistic Society, n.d.). In contrast, the neurodiversity paradigm offers a powerful challenge to the medical model of autism and positions autism as a ‘’combination of disability, difference and identity’’ (Botha & Cage, 2022, p.2). From a neurodiversity perspective, autism is viewed as a natural variation among people, and the difference is seen as neutral, neither good nor bad (National Autistic Society, n.d.).

The language used in relation to autism has been a topic of debate, and preferred terminology is, to some extent, culturally determined (Botha et al., 2021). The term disorder reflects an outdated medical model of disability, and many people with autism, their families and researchers reject it

(Cook et al., 2022). Similarly, terms such as ASD/ASC frame autism through a medicalised lens (Neurodiverse Connection, 2026). Functioning labels (high/low functioning) can often dismiss support needs, and adopting support-based language (high/low support needs) honours capacity and lived realities (Alvares et al., 2020). Additionally, severity labels (e.g., mild, moderate, or severe) and Asperger's are outdated (Antalek et al., 2025).

Although the majority of 'autistic people' favour identity-first language (Kenny et al., 2016) because being autistic is seen as part of their identity (Sinclair, 2013), others prefer person-first language (Buijsman et al., 2023) reflecting mixed preferences even within autistic communities. Throughout this thesis, the person-first language 'child with autism' will be used. I recognise that some readers may find this language jarring or uncomfortable, however, it seemed to reflect the language choices of community members involved in this study, which I chose to center and respect.

Background and Context

Orthodox Jewish communities in the UK

The UK's Jewish population is estimated at approximately 300,000 (Graham & Boyd, 2024) and the 2021 census revealed that London is home to over half of the Jewish population. Greater Manchester, Leeds, and Gateshead are other places with significant Jewish communities (Office for National Statistics, 2023). Orthodox Jewish communities are diverse, comprising subgroups and sects, each with its own theological beliefs and varying degrees of engagement with the outside world (Popovsky, 2010). While a full examination of all Jewish movements would exceed the scope of this thesis, a brief overview of Orthodox communities will be provided. Modern Orthodoxy, Charedi Judaism, and Hasidic Judaism are among the movements within Orthodox Judaism.

Modern Orthodox Jews have a broad range of beliefs and, while following Jewish law and values, they also interact with the modern, secular world (Liebman, 1998). Charedi (also spelt Hareidi or Chareidi; plural Charedim) *"those trembling before the words of God"* (Isaiah 66:5), is a subgroup within Judaism that comprises different sects (Dödtmann, 2022). Guided by strong faith in God and strict adherence to religious laws called Halacha (Staetsky & Boyd, 2015) Charedim remain insular, live within close-knit social structures (Malach & Cahaner, 2022) and seek to have their needs met within their community (Sublette & Trappler, 2000). Interactions with members of the modern secular world are avoided (Batnitzky, 2011) due to antisemitism and to safeguard the purity of culture and values (Holliman & Wagner, 2015). There is a strong emphasis on strict adherence to dietary restrictions, Shabbat observances, learning Torah, and maintaining physical and behavioural modesty (Tkatch et al., 2014). Marriage is regarded as a religious duty and a communal obligation that helps ensure the continuity of community life (Zalcberg, 2022). Charedi culture is family-oriented

(Greenberg et al., 2004), and children are viewed as a blessing (Loewenthal et al., 1995). Households are large, with high fertility rates, and women typically have six to seven children (Hleihel, 2017) resulting in a predominantly young population (58% aged 0–19) (Malach et al., 2021). As strict gender separation is enforced, boys and girls have no contact outside the immediate family (Lev-On & Shahar, 2011).

The Hasidim, or the *pious* ones in Hebrew, are part of the broader Charedi category and follow the rulings of a religious and political authority known as a Rebbe (Manitoba Education, 2019). Hasidic communities are unlikely to make major decisions without consulting the Rabbi (Margolese, 1998), who provides guidance to community members in all aspects of their lives (Slanger, 1996).

In 2020, the number of Charedi Jews in the UK was estimated at 76,000 (Staetsky, 2022). The London Borough of Hackney is home to the largest Charedi community in Europe and accounts for almost 7.4% of the borough's population (Mayhew et al., 2011). It is predicted that Charedi communities will rise from 14% today to an estimated 23% globally by 2040 (Staetsky, 2022), making them one of the fastest-growing communities in the world. It is important to note that, due to the isolated nature of these communities, the estimated increase could be larger (Sapiro, 2023).

The Charedi community is the focus of this research. Within literature, Charedim are also referred to as strictly Orthodox or Ultra-Orthodox/Ultraorthodox; however, the latter term is considered pejorative due to negative associations with community practices (Shafran, 2014). The terms 'Ultra-Orthodox' or 'Ultraorthodox' will not be used in this thesis unless directly quoting authors, and will be placed in brackets. The terms Orthodox Jews (OJ) and strictly Orthodox will be used interchangeably throughout this thesis to refer to Charedi Jews, as will the term 'community'.

Autism Assessment, Support and Role of Professionals

It is estimated that 1 in 100 children has autism, rising to 1 in 34 among 10 to 14-year-olds (O'Nions et al., 2023). The prevalence of autism in England has been rising. The Department for Education reported that 9.7% of children receiving SEN (Special Educational Needs) support in the 2024/25 school year had autism as a main need, rising from 4.7% in 2015/16 (Antalek et al., 2025). Autism varies widely among individuals and is often referred to as a spectrum condition because it can affect individuals at different levels of support (National Autistic Society n.d.).

National plans and guidelines, such as the UK's National Autism Plan for Children (NIASA) 2003 (Molteni et al., 2013) and the National Institute for Health and Care Excellence [NICE] (2014), emphasise the importance of multidisciplinary team working with individuals with autism and their families. The autism pathway comprises five stages, including i) identification and referral, ii) screening and triage, iii) pre-assessment support, iv) assessment, and v) post-assessment support (Robinson et al., 2024). To develop a comprehensive understanding of a child across settings, the

diagnostic process involves taking a developmental history, administering questionnaires on current behaviours, and conducting an observational assessment, typically using the ‘gold standard’ Autism Diagnostic Observation Schedule (ADOS-2) (Lord et al., 2012). The ADOS-2 is a standardised, semi-structured, interaction-based tool designed to evaluate social interaction, communication skills, play, and creativity (Lord et al., 1989).

Early diagnosis plays a crucial role in enhancing outcomes for children with autism, enabling early interventions that can boost cognitive, language, and social communication skills. It can also help families access appropriate services and reduce stress. Early diagnosis can also lead to more targeted interventions, better social outcomes, and increased independence in adulthood (Okoye et al., 2023). Parents can benefit from support programmes targeting different age groups that aim to empower them to develop their understanding of autism and explore supportive approaches for a variety of situations and experiences (National Autistic Society, n.d.).

Different professionals are involved with children and their families as they navigate the autism pathway. In an educational setting, parents are likely to encounter a Special Educational Needs Coordinator (SENCo). SENCOs are qualified or due-to-be-qualified teachers who support pupils with SEN in identification and in meeting their needs (National Autistic Society, n.d.). They work with parents and alongside colleagues across education, health, and social services, including the Children and Adolescent Mental Health Service (CAMHS) and family social workers (Department for Education & Department of Health, 2015). Clinical, counselling, and assistant psychologists are likely to be among the psychological professions formally involved in the assessment process (Robinson et al., 2024) as well as in intervention (Gillis & Beights, 2012). The complexity of comorbidity in autism, as well as intervention needs, requires interdisciplinary collaboration (e.g., Kelly & Tincani, 2013). Hence, partnership across professionals is central (LaFrance et al., 2019), as a child’s development is influenced not only by the individual setting but also by how these work together.

The Microsystem and Mesosystem

Several theoretical perspectives could have informed this research. Adopting an intersectionality perspective (Crenshaw, 1989) could have provided valuable insights into how participants’ multiple social identities, including culture, ethnicity, religion, gender, and professional identity, combine to influence families’ experiences from professionals' perspectives, as well as professionals’ experiences of delivering support. This approach would have been particularly valuable for exploring how structural inequalities and systems of power contribute to disparities in access to services. Adopting the interactionist approach (Blumer, 1986) would have provided insight into how professionals construct the reality of working with Jewish families through shared meanings, interpretations and interactions. However, neither of these approaches was chosen, as the aim of this project extended beyond how intersecting identities shaped experiences and how participants constructed meaning, and concerned identifying the relational and contextual aspects of working with Orthodox Jewish families.

Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1977, 1979) was considered the most appropriate framework because it conceptualises human development as an ongoing, reciprocal influence between an individual and interconnected environmental systems. Although Ecological Systems Theory concerns five systems through which children develop (Bronfenbrenner, 1979, 1986), only the microsystem and mesosystem were considered in this project, as these levels aligned most closely with the research aims. While the wider ecological levels, including the exosystem, macrosystem and chronosystem, were acknowledged, they were not explored within this study. This approach was adopted because it reflects the importance of working relationships and can enable professionals' experiences to be understood within the interconnected system in which they work.

The microsystem is the immediate environment surrounding the child and has the most direct impact on them (Bronfenbrenner, 1977; Ravindran & Mayers, 2012). Family, friends and neighbours form relationships within this system, and their interactions are bidirectional (Guy-Evans, 2024). Although the original model situated culture outside the microsystem, this has been found problematic given its crucial role in daily routines and practices within families and communities. Consequently, researchers have argued that culture should be positioned as a critical component of the microsystem (Vélez-Agosto et al., 2017). Cultural norms and expectations may influence how autism is perceived by family and community members. Similarly, religious involvement and spirituality may form a key part of the microsystem for members of faith communities (Crawford, 2020). Given the central role of religion and culture in Jewish families' lives, both will be regarded as elements of the microsystem.

The mesosystem refers to the interactions and relationships between different contexts within a child's life, including those between parents and professionals, for example, in education or healthcare. Children's outcomes depend on the quality and effectiveness of these relationships (Ravindran & Mayers, 2012). These interactions are based on effective communication and understanding of others, including sensitivity to religious and cultural aspects. Where barriers to communication between families from ethnic minority groups and professionals exist, or where professionals lack understanding, trust may be limited and relationships poorer, leading to culturally inappropriate care (Sterman et al., 2025). As parents, teachers and clinicians hold different and valuable perspectives on a child's difficulties and strengths, these views must be shared and integrated collaboratively. This is particularly crucial, as timely identification of autism can reduce parental stress, help parents understand a child's needs and strengths, and facilitate access to appropriate support (Brett et al., 2016). Conversely, late diagnosis tends to lead to worse mental health outcomes (Mandy et al., 2022). Positive interactions within the mesosystem can therefore enhance outcomes for the child (Kaushik et al., 2023). For example, consistent collaboration between a school and a statutory service can support behavioural outcomes. In contrast, if education provides inconsistent support and statutory services do not fully address the extent of the difficulties owing to cultural factors or limited engagement, this can pose challenges to outcomes. Understanding the root causes of misunderstandings or conflicts is crucial for identifying areas for support and intervention (Kaushik et al., 2023).

Autism and Jewish Communities

Cultural factors can be critical in determining how families from ethnic minority backgrounds seek, access, or accept an autism diagnosis (Slade, 2014). Cultural perspectives can shape interpretations of the challenges associated with autism, contributing to differences in identification (de Leeuw et al., 2020). Research has identified racial and cultural disparities in the diagnosis and interventions for autism (Maenner et al., 2020; Zablotsky et al., 2019) as well as in outcomes following support (Broder-Fingert et al., 2020; Sterman et al., 2025).

Research on Jewish communities and autism is sparse both globally and in the UK. Worldwide, studies have examined experiences of motherhood (Shaked, 2005) understanding and coping with autism (Shaked & Bilu, 2006) and the role of religious beliefs in motherhood (Alon & Achituv, 2024). There appears to be a focus on motherhood and coping, which is important given the gender roles in Jewish culture and the role of religion, making these findings vital contributions to the topic of autism. In the UK, autism-related literature addresses Hebrew-English bilingualism among children with autism (Sher et al., 2022; Sher et al., 2025) and stigma towards autism in Orthodox Jewish communities (Sher et al., 2022). Most of the research cited above will contribute to the systematic literature review (SLR) in Chapter 2; therefore, it will not be discussed here.

Research on diagnosis found that children in the Charedi communities in Israel are less likely to be diagnosed with autism, and those who are identified receive recognition years after the critical early intervention period, when treatment is most effective (Silverman et al., 2026). More locally, a health needs assessment of Orthodox Jewish communities in Stamford Hill found that professionals at a local service for children and young people with disabilities or special educational needs encountered patients who had received a very late diagnosis of autism, which had not been identified earlier (City and Hackney Health and Wellbeing Board, 2018).

Moreover, the UK's oldest Jewish charity supporting families of children with neurodevelopmental disabilities drew attention to the inconsistent implementation of the government's 2021-26 strategy, which aims to improve the lives of people with autism, across councils. It was highlighted that health, education and social care services seem to operate in silos. This creates barriers for families navigating complex needs, particularly as they experience disparities in accessing diagnostic and post-diagnostic services (Norwood, 2025).

These findings suggest that Orthodox Jewish children may be at risk of late autism diagnosis and inconsistent support. Given rising prevalence rates, the benefits of early diagnosis, and opportunities for early intervention, there remains a gap in understanding how Jewish families can be supported, particularly given the underrepresentation of ethnic minorities in autism research (West et al., 2016).

Help-seeking behaviour in Jewish Communities

Religion can profoundly influence people's beliefs, behaviour and values, as well as cultural, social and contextual factors (Jonte-Pace & Parsons, 2002). A common belief in Judaism is that the challenges Jews face are divine tests that faithful individuals are expected to overcome without external assistance (Rabinowitz, 2014). Anxiety and sadness can be seen as signs of weak faith (Greenberg & Witztum, 2013). Furthermore, help-seeking may be perceived as a personal weakness, particularly considering the image of Jewish women striving to be regarded as perfect housewives, managing domestic, spiritual, and family duties (Goshen-Gottstein, 1994; Loewenthal, 1998). Research on mental health difficulties amongst Orthodox Jews has revealed concerns about confidentiality and stigma (Loewenthal & Rogers, 2004). The stigma is intensified by the emphasis placed on the health of the prospective groom or bride in strictly Orthodox communities, where marriage is arranged (Rockman, 1994) a concern heightened by the close-knit nature of the Orthodox community (Schnall, 2006). Individuals with physical or mental health challenges may be considered less desirable (Lehmann & Siebzehner, 2009). Additionally, the likelihood of finding a match for siblings or other family members may be compromised if Orthodox Jews receive professional support for their difficulties (Margolese, 1998; Sublette & Trappler, 2000). Research by Feinberg and Feinberg (1985) found that Orthodox Jews hold more negative attitudes towards those seeking psychological support than other sects of Judaism.

Whilst a higher level of stigma towards mental health difficulties may be linked to limited knowledge and exposure to information about it in the ‘Ultraorthodox’ community (Struch et al., 2007), stigma in relation to mental health services within Orthodox Jewish communities may be decreasing owing to increased knowledge, disseminated through community media and word of mouth (Galloway & Byrne, 2016).

Orthodox Jews tend to seek guidance from their Rabbi before they approach services (Schnall, 2011), and the Charedi community would typically require a blessing and permission from their Rabbi before they engage with mental health services (Schnitzer et al., 2011). Charedi Rabbis may hesitate to refer to a non-Jewish mental health professional, and the preference would be an Orthodox practitioner of the same gender (McEvoy et al., 2017). Schnall (2006) noted that a Rabbi’s referral to psychotherapy might be important in persuading Orthodox Jews to attend therapy.

Mental health practitioners are often viewed by many Orthodox Jews as immodest representatives of a decadent secular world to be avoided and kept at a distance (Bilu & Witztum, 1993), and Jewish clients may worry about being placed in a position where they must choose between faith and their mental health (Heilman & Witztum, 1997). An additional concern is that therapists may lack competence in Jewish culture or religion (Loewenthal & Rogers, 2004) and may not respect values

that are crucial to their community (Sublette & Trappler, 2000). By contrast, secular professionals are perceived as having extensive knowledge and training, and confidentiality is assumed. Additionally, engaging with professionals from outside the community is perceived as safer and offers an alternative perspective on difficulties (Rowland, 2016).

Working with Jewish Communities

Cultural adaptations involve tailoring an intervention to account for language, culture, and context, aligning it with an individual's cultural patterns, meanings, and values (Bernal et al., 2009).
Due to Judaism's multidimensional nature, professionals who work with Orthodox communities would benefit from understanding it as a culture, ethnicity, and religion, as Torah principles are applied by community members across all aspects of life (Holliman & Wagner, 2015). The importance of cultural adaptations and culturally sensitive treatment in strictly Orthodox Jewish communities has been recognised among others, in social work (Band-Winterstein & Freund, 2015), in a prevention programme for eating disorders (Casasnovas et al., 2021), in OCD (Huppert et al., 2007), in cognitive behavioural therapy (CBT) (Kada, 2019), in the delivery of mental health services (Greenberg & Witztum, 2013; McEvoy et al., 2017), in counselling, psychotherapy and support groups (Loewenthal & Rogers, 2004; Holliman & Wagner, 2015), and in interventions for ADHD (Golos et al., 2021).

Professionals' perspectives on working with Orthodox Jewish parents

While the perspectives of professionals supporting children with autism and their families within Orthodox Jewish communities remain unexplored in existing research, Golos and colleagues (2021) have examined how clinicians view the cultural adaptation of ADHD interventions for children from 'Ultraorthodox' backgrounds. Occupational therapists perceived that, whilst parents had a basic understanding of ADHD, they had limited knowledge of its biological basis and functional impact, particularly when the child was relatively successful academically but struggled with executive functioning. According to clinicians, parental awareness of ADHD varied widely, and personal and professional experience, as well as access to information sources, influenced their knowledge of ADHD. In families where more than one child was diagnosed with ADHD, parents working in education and those with internet access seemed to be better informed. According to professionals, families often kept the diagnosis secret from others, including the school and even the child. Awareness of cultural differences between professionals and families was emphasised to ensure the therapeutic relationship was based on trust. An important sensitivity regarding modesty was raised in the context of dress code interventions, interactions between men and women, and liaising with schools as a female practitioner speaking to a teacher (Rebbe). Participants discussed the importance of understanding families' daily routines and broader family structures when considering interventions. Adaptations included accounting for routines, a hectic environment, siblings, and being realistic about what is possible and helpful, to ensure the intervention is helpful rather than a burden.

Clinicians who were not from the community noted the importance of adaptations for varied subgroups within the 'Ultraorthodox' communities. The religious habits and values of families significantly influenced the intervention, and adaptations to graphic contexts were made in accordance with community norms.

These findings provide a useful point of reference for the current study, as they highlight the importance of cultural adaptation and awareness of the religious and cultural values and realities of Orthodox Jewish families. Whilst ADHD and autism are distinct conditions, both require collaboration and communication between carers and professionals, making these insights relevant.

The rationale for the present study

Although the importance of early autism diagnosis and intervention is recognised, there is limited awareness of how social, cultural, and economic factors shape this process (Yaylacı & Güller, 2023). As the UK has become increasingly ethnically diverse, health and social services are engaging with families for whom religious beliefs are central to their understanding of and response to their child's needs. Understanding these beliefs is therefore key to providing ethical and effective support (Hasnain et al., 2008; Bywaters et al., 2003). Professionals play a crucial role in identifying and supporting individuals with autism, and the absence of providers attuned to the cultural contexts and unique needs of families often leads to delayed diagnoses and inadequate treatment (Turner et al., 2016).
As noted, it is crucial to explore the experiences and needs of Orthodox Jewish families, particularly in light of the current political climate, in which heightened concerns about antisemitism and cultural misunderstanding may limit trust in mainstream service providers. Importantly, findings from a rapid evidence review on health inequalities and barriers facing Jewish communities in England highlighted the need to focus on the strictly Orthodox/Charedi community and to consider the influence of family and religion on healthcare (NHS Race and Health Observatory, 2024).

To the best of my knowledge, no research has specifically examined barriers and facilitators to diagnosis and access to services for children in these communities in Britain. Parents are considered gatekeepers of their children's care (Stiffman et al., 2004), and insights into their children's behaviour outside clinical settings help inform diagnosis and intervention strategies. However, there appears to be a lack of research on how Jewish parents experience parenting a child with autism. Therefore, exploring their experiences before considering professionals' perspectives is warranted. Due to the paucity of literature on strictly Orthodox parents raising children with autism, the inclusion of parents who identify as Jewish is necessary and will be examined in the systematic literature review (SLR) in Chapter 2.

Conclusion

The aim of this chapter was to provide background for the current inquiry, including my epistemological positioning and positionality. An overview of Jewish communities in the UK, with a focus on the Charedi community, was provided. Additionally, it offered an overview of help-seeking behaviour among Jewish communities, highlighting the influence of religious and cultural values. The rationale for the current research was also stated. The following chapter will review the existing literature on Jewish parents raising a child with autism to understand their experiences.

CHAPTER 2: SYSTEMATIC LITERATURE REVIEW

Chapter Overview

This chapter presents the completed Systematic Literature Review (SLR), including the aims, search strategy, synthesis of findings, and quality appraisal. The themes identified through synthesis will be discussed in relation to the literature, and future recommendations will be proposed. Finally, the rationale and objectives of the current study will be outlined.

Scope and aims of the SLR

A Systematic Literature Review (SLR) is a comprehensive methodological approach to identifying, evaluating and synthesising relevant literature to answer a particular question (Muka et al., 2020). SLRs should be transparent and follow a rigorous, high-quality process to enable replication (Siddaway et al., 2019). The aim of SLRs is to broaden understanding of the phenomenon, rather than to aggregate primary texts as in a meta-analysis (Grant & Booth, 2009). A preliminary scoping review of Jewish parents' experiences of raising a child with autism was carried out. A search using Google Scholar, PROSPERO and the Cochrane Library was conducted to ensure whether any existing reviews were registered. Following the scoping search, it was determined that no existing reviews exploring the experiences of Jewish parents raising a child with autism existed.
The SLR aim to integrate and synthesise current literature to explore the following question:

What are the experiences of Jewish parents and carers of children with autism?

This SLR was registered on 8 April 2025 with the international systematic review registry (PROSPERO; CRD420251021529). Minor amendments to the inclusion and exclusion criteria were submitted on 29 May 2025 and are briefly outlined below. This review is reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines (Page et al., 2021). A copy of the PRISMA checklist is provided in Appendix A.

Methods

Using a framework when setting up a SLR is fundamental, as it aids in formulating a specific, well-defined research question (Martinez et al., 2023). Designed for qualitative and mixed-methods studies, the SPIDER tool (Cooke et al., 2012) was used to identify the key components of the research question as detailed in Table 1.

Table 1

SPIDER Tool

Sample	Jewish parents/carers
Phenomenon of **I**nterest	Experiences of raising a child with autism
Design	Interviews, Case Studies, Focus Groups
Evaluation	Experiences, Stories, Views, Feelings
Research Types	Qualitative, mixed method

Search strategy

A systematic search was completed to identify studies relevant to the research question, using the search terms listed in Table 2. The search terms were discussed with a university librarian, who provided expert advice on the most effective search strategies. Search terms were trialled to ensure sensitivity and precision. Search terms were adapted with quotation marks and truncation where appropriate to capture all relevant literature. Boolean operators 'AND'/'OR' were used with the search terms to locate relevant papers. All terms listed in Table 2 were searched for in the titles and abstracts across all databases.

Table 2

Search Terms Used in Systematic Literature Review

Key Term	Search Terms
Jewish parents	Jewish OR Jew OR Judaism OR "Jewish parent*" OR "Jewish carer*" OR "Jewish communit*" OR "Jewish mother*" OR "Jewish father*''
	AND
Autism	autism OR ASD OR "Autism Spectrum Disorder*" OR autistic OR "autistic child*" OR Asperger* OR neurodiver*

The following five databases, CINAHL, MEDLINE, PsycINFO, PubMed, and Scopus, were searched between March and April 2025. These databases were selected to gather evidence across multiple disciplines, including allied health, clinical psychology, social psychology, and social care. Alerts were set up where possible to monitor relevant studies until analysis. A snowballing approach (Sayers, 2007) was used to enhance the search by reviewing reference lists. For articles not available via open access, requests were made through the UH library. The final search was conducted on 31st May 2025.

Grey Literature

Relying solely on peer-reviewed literature may exclude relevant knowledge, particularly from marginalised backgrounds offering diverse insights (Mahood et al., 2014). In line with the critical realist stance, which acknowledges multiple realities and given that the topic of this SLR concerned an underrepresented community, including grey literature, was essential. Grey literature, including, theses, dissertations, and government documents, can considerably enhance systematic reviews by providing unique data, thereby reducing publication bias and providing a more balanced evidence base (Paez, 2017). However, because grey literature is not always formally published or peer-reviewed, its reliability can vary. Despite this, it supports decolonial principles by including diverse perspectives, in contrast to traditional peer-reviewed journals that often favour Western authors (Henrich et al., 2010). Grey literature was identified through online searches using Google Scholar, Worldcat, and ProQuest. As Google Scholar yielded a large number of results, only the first 13 pages were reviewed, as the relevance of papers decreased thereafter. The final search of grey literature was completed on 30th June 2025.

Inclusion and Exclusion Criteria

This SLR aimed to explore lived experiences, therefore it relied on qualitative data, which offers rich insights that quantitative research might not capture (Willig, 2008). Consequently, only studies using qualitative or mixed-methods approaches with a qualitative focus on experiences were included. The review aimed to include studies which spoke to experiences of raising a child with autism up to the age of 25 to reflect a broader understanding of caregiving during this extended support period. This age was selected based on the Education, Health and Care Plan (EHCP), which supports young adults up to 25 (Department for Education, 2017), and the NICE guidelines, which emphasise support for disabled children and young people beyond childhood (NICE, 2023). Non-English papers were excluded due to resource limitations, namely translation costs, time constraints, and greater difficulty in obtaining them (Morrison et al., 2012). The rationale for including only studies with all Jewish participants was that it would have been challenging to identify papers containing accounts from Jewish parents if they included other mixed-religion participants. Moreover, including multi-faith samples risked indirectly inferring Jewish experiences and potentially shifting the review towards comparisons with other religions.
The inclusion and exclusion criteria are listed in Table 3.

Table 3

SLR Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
• Studies using qualitative design or mixed-method design gaining qualitative information	• Studies using solely quantitative design
• Studies where participants are parents/carers/primary caregivers	• Studies where participants are not parents/carers/primary caregivers
• Studies where all participants are Jewish	• Studies where not all participants are Jewish
• Studies where primary focus is on autism (either diagnoses or suspected)	• Studies where primary focus is on co-occurring conditions, not on autism
• Studies where 'children' and young people are up to 25 years old	• Studes where 'children' are older than 25 years old
• Studies written or translated into English	• Studies not available in English
• Primary/empirically based	• Not empirically based, secondary sources
• Published in any time period	• Reflective pieces
• Grey literature (thesis, dissertations)	

Selection process

The search results were exported into Covidence (2024), an online software platform, to organise and screen papers. Two reviewers, including a qualified Clinical Psychologist and myself, independently screened titles and abstracts of all identified studies to determine inclusion. Papers deemed ineligible based on their titles and abstracts were excluded at this stage. Where there was a disagreement between reviewers, or the eligibility of papers was unclear, a discussion took place between reviewers. Where two reviewers were unable to reach a decision on inclusion through discussion, the views of a third reviewer were sought to make the final decision.

Data extraction

The primary reviewer alone extracted data from each paper and created an extraction table in a Word document. The process was performed manually. Decisions about what counts as data in qualitative reviews have been identified as a challenge (Thomas et al., 2017). Following a discussion with the research supervisor, I decided to extract direct quotations from participants found in themes or key

findings, and from the discussion section relevant to the review question, to ensure that no rich data were excluded (Thomas & Harden, 2008). Additionally, the critical realist position aligns with thematic synthesis, as the findings are based on the experiences of participants, researchers, and authors. Due to limited resources, there was no second extractor. All extracted information is detailed in Table 4:

Table 4

Data collected from extracted studies

Title, author(s), year & location, study format (e.g. peer-reviewed article, unpublished Phd thesis)
Study aims
Sample characteristics: • Sample size • Religious affiliation
Method: • Study design • Sample strategy • Data collection • Data analysis
Findings: Broad and varied experiences reported in relation to being a parent/carer to a child with autism
Strengths
Limitations

Methodology for synthesis

There are several forms of data synthesis, including meta-ethnography, narrative synthesis, and thematic synthesis (Pope et al., 2007). Thematic synthesis integrates findings from multiple qualitative studies, including mixed-methods studies, with a focus on qualitative data (Thomas & Harden, 2008). The results of thematic synthesis can assist policymakers and practitioners by connecting research findings to people's experiences and beliefs about their health and social matters (Booth, 2016). Thomas and Harden's (2008) thematic synthesis was considered a suitable method for data synthesis, as it offers flexibility in integrating results from diverse methods, a clear, step-by-step process, and transparent auditability, making it a robust and assessable approach (Noyes et al., 2018).

Thematic synthesis was used to synthesise the relevant content in the results and findings sections of each paper (Thomas & Harden, 2008) with the data focusing on parental experiences. Direct quotes from parents featured in themes were synthesised alongside key findings and discussion sections. This approach allowed exploration of recurring patterns and themes across the included papers, providing an understanding of the experiences of Jewish parents raising a child with autism. All papers were read twice to aid familiarisation. Thematic synthesis involved three stages: i) open, line-

by-line coding of data, using quotations from parents and the study's findings, ii) developing descriptive themes, and iii) generating analytical themes. These stages were conducted in NVivo (NVivo, 2024) to analyse qualitative data. Coding was conducted in NVivo (NVivo, 2024) and the completed codes were exported to Excel and cut into stripes for theme development (Appendix B). To enhance credibility, codes and themes were discussed with the supervisor.

Quality Assessment

Assessing the quality of papers included in a SLR is a vital part of the process (Shaw, 2011) involving a critical evaluation of the strengths, limitations, and validity of the research (Linares-Espinós et al., 2018). Although several appraisal tools are available for qualitative studies (Hannes et al., 2010), the Critical Appraisal Skills Programme (CASP) (Critical Appraisal Skills Programme, 2018) is the most commonly used tool for the critical appraisal of qualitative papers and is endorsed by the Cochrane Qualitative and Implementation Methods Group (Noyes et al., 2018). Furthermore, because this review was informed by Thomas and Harden's (2008) thematic synthesis, CASP was deemed the most appropriate given its interpretative nature, compared with appraisal tools such as JBI (Lockwood et al., 2024). CASP is the most widely used quality appraisal instrument in health and social research (Dalton et al., 2017) and is recommended for novice researchers (Hannes & Bennett, 2017). Due to project's scale and time constraints all five peer-reviewed papers were appraised by the main researcher alone using the CASP for qualitative studies. Each paper was evaluated against 10 questions, which can be answered with 'Yes', 'No' or 'Can't tell'.

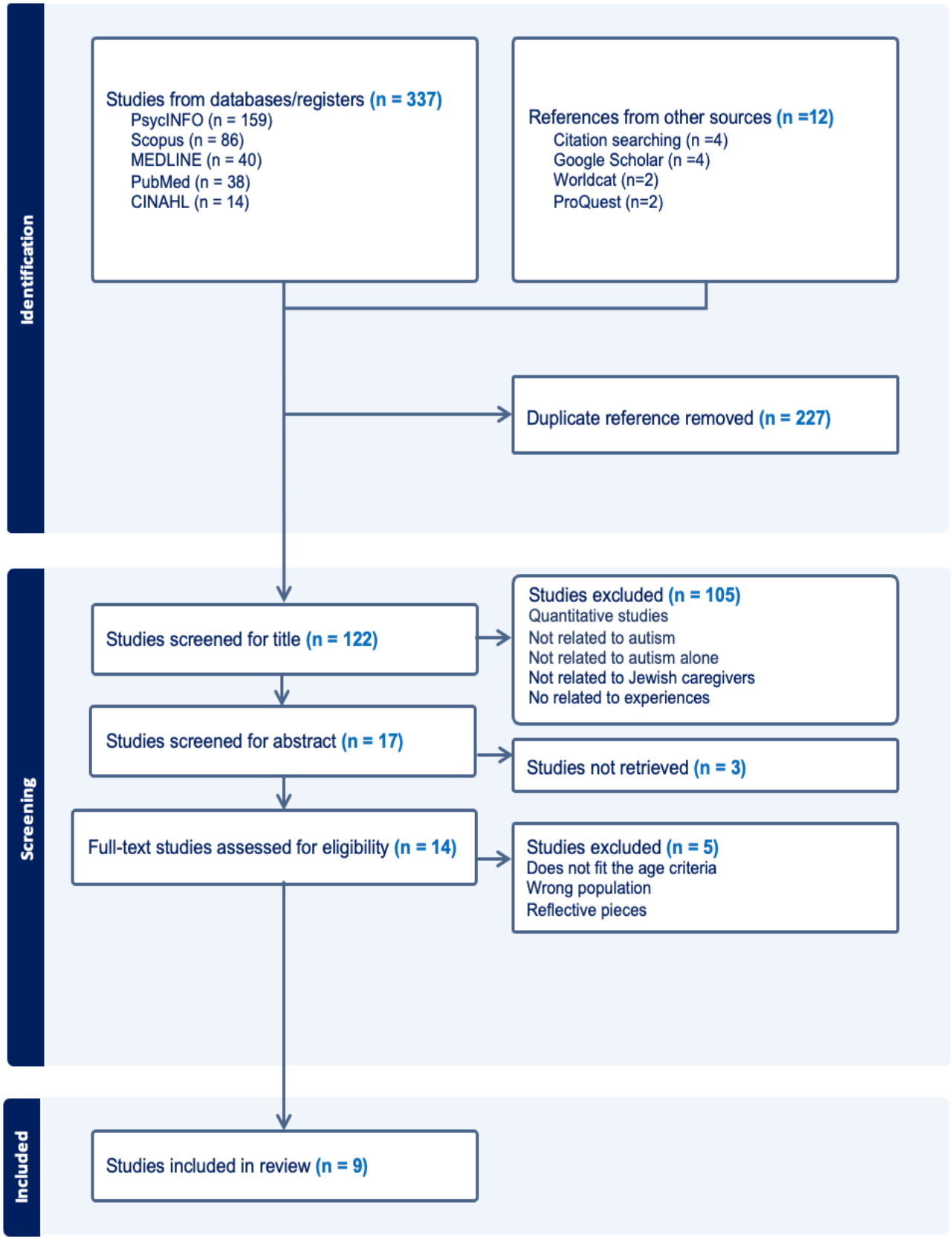
The grey literature was evaluated and critically appraised using the Authority, Accuracy, Coverage, Objectivity, Date, Significance (AACODS) checklist (Tyndall, 2010; Appendix C), which focuses on information relevant to grey literature formats. This tool was developed as an evaluation and appraisal tool for grey literature, and there is evidence supporting the utility of AACODS and the use of grey literature to support the commissioning of health services in England (Sabey, 2020). Each paper was evaluated against six domains, each of which can be answered with ''Yes'', '' No'' or '' Unsure''.

Results

Following screening of the title, abstract and full text, nine studies were included in the review. The PRISMA screening process is outlined in Figure 1.

Figure 1

PRISMA Flow Chart for SLR



Whilst no conflicts between reviewers were noted, a discussion was initiated regarding the clarity of the inclusion and exclusion criteria. A conversation with the supervisor followed, and a decision was made to review and update the wording of the inclusion and exclusion criteria, then to update the PROSPERO protocol. Some of these changes included defining a specific age for children, focusing on autism alone rather than co-occurring difficulties, where autism-related experiences could be extracted, and including studies with both a formal diagnosis ([1]including PDD and Asperger's) or suspected autism. Details of the amendments are in Appendix D. Following the changes, both screeners independently read the full texts of the remaining studies to determine eligibility. No disagreements were noted at this stage.

In total, 349 papers were retrieved, of which 227 duplicates were removed. A further 105 articles were excluded as they were either found to be quantitative studies; not related to autism alone; not autism related; not related to Jewish caregivers and not related to experiences. Additionally, three articles could not be retrieved, leaving 14 papers for full-text screening. An additional 5 studies were excluded due to incorrect age or population, or being reflective pieces. There were three potentially relevant grey literature papers, however, two could not be retrieved, and one was a poor-quality scanned copy. Despite contacting the authors, copies could not be obtained.

A total of nine papers that focused on the broad experiences of Jewish parents raising a child with autism met the inclusion criteria and were included in the review.

Study characteristics

Five were peer-reviewed, and four were grey literature texts, including two PhDs, one EdD in leadership, and one master's dissertation in Occupational Therapy. Of the nine studies, the largest number (N = 4) was conducted in the United States, followed by Israel (N = 3) and the United Kingdom (N = 2). Whilst not all authors reported parental role, overall, experiences were gathered from at least 86 mothers and 21 fathers. Only three studies reported participants' ages, which ranged from 20 to 60 years. Recruitment sources varied across studies. Participants were recruited via online platforms, including Facebook groups for parents of children with autism, in two studies (N = 2). Community-based recruitment, including synagogues and community centres, was reported in two studies (N = 2). Other recruitment sources included educational settings combined with online recruitment (N = 1), therapeutic and educational settings (N = 2), educational and community settings (N = 1), and local newspaper advertisements (N = 1).

Regarding study methodology, three studies used phenomenological approaches/Interpretative Phenomenological Analysis (IPA) (N = 3), while three used thematic approaches/Thematic Analysis (N = 3). One of the latter also incorporated a qualitative component within a mixed-methods design. Two studies used narrative analysis (N = 2), and one used content analysis (N = 1). The quantitative component of the mixed-methods study included measures of parental stress (Parental Stress Scale)

[1] Pervasive Developmental Disorder (PDD) and Asperger's studies using DSM-IV terminology were included as some were published before DSM-5 was published in 2013.

coping (COPE and Jewish Religious Coping Scale [JCOPE]), religious beliefs, practices and community context (Q-sort ratings), and adaptive functioning (Vineland Adaptive Behaviour Scales).

Participants were affiliated with various denominations of Judaism, including Centrist Orthodox, Conservative Orthodox, Traditional, Modern Orthodox, Strictly Orthodox, Reform, and national-religious. Religious affiliation details were not reported in every study. However, based on the denominations reported, the majority of parents identified as Strictly Orthodox (minimum N=59), followed by Centrist Orthodox (minimum N=5), national-religious (minimum N=5), and Traditional (minimum N=4). The studies were published between 2005 and 2025, with most conducted in the last seven years (n = 5). Eight studies used a qualitative methodology, and one utilised a mixed-methods approach. Topics examined included parents' religiosity and its relation to raising a child with autism, coping strategies and understanding of autism, perceptions of support, stigma, bilingualism versus monolingualism among Jewish children with autism, and experiences of mothering a neurodiverse child. Six studies employed purposive sampling, which is well-suited to the intentional selection of individuals who can offer insight into complex phenomena (Tajik et al., 2025). A snowball sampling technique was used in three studies, a common approach for underserved communities facing systemic barriers to participation (Törnävä et al., 2025), with one combining snowball with convenience sampling. A summary of the study characteristics is presented in Table 5.

Table 5

Summary of Studies Included in SLR

Title, author(s), year & country	Aim(s) of study	Participants	Method	Findings	Strengths (+) and limitations (-)
Perceptions of motherhood amongst Israeli religious and Haredi mothers of children on the Autism spectrum: From *"I feel like with him I'm lost" to "It's a gift in my life".* Alon, & Achituv (2024) Israel Peer-reviewed article	Explore how religious beliefs shape motherhood perceptions among Israeli national-religious and Haredi mothers who raise children with autism	N= 12 (mothers) Religious affiliation: national- religious, and ''ultra-Orthodox''	Study design: Qualitative Sample strategy: Snowball sampling Data collection: Semi-structured interviews Data analysis: Content Analysis	Motherhood is an ongoing journey involving continuous self-awareness and adaptation to challenges Mothers evolved from helplessness and guilt to growth and empowerment, reflecting a shift from crisis to strength Solidarity with other mothers of autistic children offers validation and support, while a divide is felt from mothers of typically developing children	+Implications for healthcare providers to consider religious beliefs as coping mechanism when providing support +Recommendations and suggestions for further research + Offers limitations - No mention of reflexivity regarding the analysis
Coping strategies of orthodox Jewish mothers of children with Autism spectrum disorders. Kopolovich (2007) USA	Explore the coping strategies of Orthodox Jewish mothers of children with autism	N=3 (mothers) Religious affiliation: Orthodox Jewish	Study design: Qualitative Sample strategy: Convenience and snowball sampling Data collection: Unstructured interviews	Religious faith offered meaning and resilience, aiding mothers in raising a child with autism, however some practices were difficult to maintain Mothers faced significant emotional and practical stress, including managing	+ Researcher identified as Orthodox Jew with a lived experience of raising a child with autism +Reflexivity and researcher bias acknowledged and managed (reflexivity, peer debriefing)

Unpublished MSc dissertation			Data analysis: Phenomenological approach	therapies, feelings of guilt, and community stigma Support from family and peers was crucial, with husbands, siblings, and other parents playing a key role in emotional and practical support	+Implications of findings discussed considering occupational therapy +Utilised field jottings/notes and member checking +Interviews were conducted at location/time chosen by participants -Unclear analysis -Small sample size - No rational for exclusion of unmarried, single, widowed, foster and adoptive mothers
Jewish American Parents' Perceptions of Culturally Responsive Autism Supports: A Qualitative Case Study. Raiola (2025) USA Unpublished PhD	Explore Jewish American parents' perceptions of therapeutic, educational, and social support for their child with autism	N=13 parents (gender not specified) Religious affiliation: not specified	Study design: Qualitative Sample strategy: Snowball sampling Data collection: Semi-structured and unstructured interviews and focus groups Data analysis: Thematic approach	The cultural and ethnic needs of American Jewish parents are not integrated into public education and treatment programs Parents were satisfied with the quality of education and autism supports, however some lacked cultural connections	+ Member checking to validate the congruence between participants' experiences and the data analysis +Validation of instruments used in the study through field testing with three Subject Matter Experts +More than one data collection method +Offers recommendations for future research and implication for leadership -No information about the background of the researchers

					-No information about participants' characteristics
The social trajectory of illness: Autism in the ultraorthodox Community in Israel. Shaked (2005) Israel Peer-reviewed article	Explore autism in 'ultraorthodox' Jewish community through the lens of mothers raising children with autism	N= (unclear, but the 27 mothers were interview alone, one father was interviewed alone, and two interviews with both parents) Religious affiliation: ''ultraorthodox''	Study design: Qualitative Sample strategy: Purposive sampling Data collection: Open-ended Interviews Data analysis: Narrative analysis	-Mothers' roles as mediators between children and the community, promoting inclusion through religious education Mothers actively seek to change their children's social status by including them in religious practices and educating others The ''ultraorthodox'' community often challenges the status of children with autism, requiring mothers' advocacy	+ Research identified as secular Israeli +Interviews conducted at participants houses +Exploration of intersection of disability, religion and culture -Partial data collection issues- eight interviews were not audio-recorded which could have affected data reliability and richness -Focus only on mothers' perspective potentially overlooking fathers' perspective -No mention of ethical procedures -Limited details on recruitment strategy
Grappling with affliction: autism in the Jewish Ultraorthodox community in Israel. Shaked & Bilu, (2006) Isreal	Explore how the Jewish ''ultraorthodox'' community in Israel culturally understands and copes with autism.	N= (27 mothers, one father and two couples) Religious affiliation: ''Ultraorthodox''	Study design: Qualitative Sample strategy: Purposive sampling Data collection: Open-ended interviews Data analysis:	Understanding of autism can be achieved through both biomedical and religious-spiritual frames Families use mainstream medicine, alternative therapies, and religious interventions simultaneously	+Interviews were structured to cover comprehensive set of topics including child's functioning, family life and interventions +Insight into how medical and religious models coexist in a conservative religious community

Peer-reviewed article			Narrative methodology	Autism was reframed as a divine mission, a test of faith, helping mothers cope with stigma and suffering Mothers often followed the advice of rabbis when there was a conflict between medical and religious views.	+Acknowledgement that interviews were conducted years before this paper was published as a part of another study -Partial data collection issues- eight interviews were not audio-recorded which could have affected data reliability and richness -Unclear analysis -No mention of ethical procedures
"It's Like Stealing What Should be Theirs." An Exploration of the Experiences and Perspectives of Parents and Educational Practitioners on Hebrew–English Bilingualism for Jewish Autistic Children. Sher, Gibson, & Browne (2022) UK Peer-reviewed article	Explore the experiences and perspectives of educational practitioners and parents on bilingualism and monolingualism among children with autism	N= 22 (4 fathers and 18 mothers) Religious affiliation: Strictly Orthodox Centrist Orthodox, Traditional,	Study design: Qualitative Sample strategy: Purposive sampling Data collection: Semi-structures interview and written responses Data analysis: Interpretative Phenomenological Analysis	Monolingualism is seen as unfair and limiting for children with autism. Hebrew is vital for religious and cultural inclusion. Community connection and identity supported by identity, which parents prefer despite professional discouragement.	+Multiple modes of participation to encourage an inclusive research approach +First author identified as a Rabbi +Rich, multi-perspective data from parents and educators +Fills a gap in autism and bilingualism research +Paternal experiences included -Relatively large sample for IPA which could have compromised in-depth analysis -No mention of reflexivity regarding the analysis

'We've come a very, very, long way' Overcoming stigma of autism: An interpretative phenomenological analysis within the UK Jewish community. Sher, Gibson, & Sher, (2022) UK Peer-reviewed article	Explore experiences of parents, educators and rabbis from the Jewish community towards sigma associated with autism	N= 5 (2 mothers, 3 fathers) Religious affiliation: Centrist and Strictly Orthodox	Study design: Qualitative Sample strategy: Purposive sampling Data collection: Semi-structured interviews Data analysis: Interpretative Phenomenological Analysis	There has been significant progress in reducing the stigma associated with autism; however, a level of stigma persists. Lack of knowledge about autism is a more urgent issue than stigma. Fear of stigma in certain sectors of strictly Orthodox communities due to concerns about matchmaking.	+ First study on stigma of autism within the UK Jewish community + Community-based participatory research + Participants were from several UK regions and several stakeholder groups +Two authors were members of the Jewish community - No mention of reflexivity regarding the analysis
Exploring the role of perceived religiosity on daily life, coping, and Exploring the role of perceived religiosity on daily life, coping, and parenting for Jewish parents of children with autism parenting for Jewish parents of children with autism. Victory (2014)	Explore how Jewish parents, with and without a child with autism, perceive the role of religiosity on daily life, parenting and coping	N= 20 (12 mothers 8 fathers) Religious affiliation: Reform, Conservative, Modern Orthodox Jewish	Study design: Mixed methods Sample strategy: Purposive sampling Data collection: Online *Q*-sort survey and phone open-ended interviews Data analysis: Thematic Analysis (qualitative component)	An autism diagnosis can impact parental stress levels. Religious practices connected parents to their cultural and family history. Parents of children with autism faced challenges incorporating Judaism into family life. The research highlights the need for clinicians to understand the role of religion in parenting	+Multi-method design +Parents received compensation for taking part +*Q*-sort accuracy consulted with rabbis and community members + Mothers and fathers interviewed separately, and paternal perspective included -No mention of author's background/demographics -No mention of reflexivity

USA Unpublished PhD				children with additional needs.	-Interview questions developed by principal researcher alone
A case study of ultra-orthodox mothers' experiences raising a Child with autism. Yaroslawitz (2018) USA Unpublished PhD	Explore the experiences of 'ultra-Orthodox'' mothers raising a child with autism.	N= 10 (mothers) Religious affiliation: ''ultra-Orthodox''	Study design: Qualitative Sample strategy: Purposive sampling Data collection: Semi structured interviews Data analysis: Thematic Analysis	Floortime therapy and ABA therapy are identified as supportive resources. Stigma related to autism in the ''ultra-Orthodox'' community. Impact on family members-siblings affected, some marital relationships strained, while others strengthened	+Identified as ''ultra-Orthodox'' researcher +Phone call to participants who did not meet criteria/to inform them when recruitment was complete +Use of triangulation and member-checking - Reflexivity is mentioned but a deeper exploration of potential bias and its impact on data would have been helpful

As described in the methods section, the CASP and AACODS quality assessment tools were used to appraise all nine papers included in the review by one reviewer. The details of the appraisal are presented in Tables 6 and 7

Table 6

Quality Appraisal for Included Studies using the CASP tool

Author(s)	Clear Aims	Method	Design	Recruitment	Data collection	Relationship	Ethics	Data Analysis	Findings	Value
Alon, & Achituv (2024)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Highlights the roles of faith, identity transformation, and cultural context, and focuses on motherhood within the religious community.
Shaked (2005)	Yes	Yes	Yes	Can't tell	Yes	Can't tell	No	Yes	Yes	Highlights the intersection of religion, disability, and culture and offers insights into how cultural frameworks can promote inclusion.
Shaked & Bilu, (2006)	Yes	Yes	Yes	Can't tell	Yes	Can't tell	No	Can't tell	Yes	Offers insight into how a traditional community copes with a dual system of illness perception that blends biomedical and spiritual frameworks.
Sher, Gibson & Browne	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Explores how forced monolingualism

(2022)										can harm the inclusion of children with autism, identity, and access to religious life.
Sher, Gibson, & Sher, (2022)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Explores stigma related to autism within the UK Jewish community.

Table 7

Critical Appraisal using the AACODS tools

Author	Authority	Accuracy	Coverage	Objectivity	Date	Significance
Kopolovich 2007	Yes	Unsure	Yes	Yes	Yes	Addresses a very under-researched population in autism studies. Provides culturally specific insight into coping strategies for practitioners and researchers.
Raiola 2025	Yes	Yes	Yes	Yes	Yes	Addresses the cultural needs of Jewish carers in autism support services for their children. Fills a gap in the literature on culturally responsive autism support and offers insights that could inform service provision, culturally competent practice and future research.
Victory 2014	Yes	Yes	Yes	No	Yes	Offers insight into parents' (including fathers) experiences and a multi-dimensional influence of religiosity on coping and parenting.
Yaroslawitz 2018	Yes	Yes	Yes	Yes	Yes	Offers practical insights for clinicians, educators and policymakers regarding culturally sensitive interventions Strong relevance for practitioners, policy makers, and academics focusing on cultural dimensions in autism care.

Quality Evaluation of the Literature

Thomas and Harden (2008) postulate that the validity of excluding relevant qualitative studies solely on quality grounds is limited. All five studies appraised by CASP stated clear aims, used an appropriate design, and provided clear findings. However, none of the five papers adequately addressed the relationship between the researcher and the participants, making it difficult to assess how the researcher's perspective may have shaped data collection and interpretation. In Alon and Achituv's (2024, p.7) study the first author, described as ''an expert in autism and counselling'' mentioned maintaining '' an awareness throughout the data collection and analysis processes of her own potential biases relating to autism''. Similarly, in Sher et al. (2021, p.4443), one of the authors briefly referenced using reflexive journals to ''consider choice of data collection methods, possible limitations and researcher positionality''. Shaked's (2005, p.2192) paper noted that the researcher is a secular Israeli and she may have missed ''some of the details, contexts, and meanings of the narrative''. However, she also acknowledged that her secular status gave her '' the possibility to probe and search into those areas that for those born into ultraorthodox society may seem completely self-evident''. Consequently, researcher bias was assumed in all studies. Two studies, Shaked (2005) and Shaked & Bilu (2006) did not report whether ethical approval for the research was obtained. Although this is concerning, both papers were published in peer-reviewed journals and were part of one of the author's PhD. While the ethics details were not included in the written format, they are likely to have received the necessary approval. The same studies, Shaked (2005) and Shaked and Bilu (2006) which used the same sample of participants but emphasised different aspects of the same data collection, did not detail their recruitment strategy, raising concerns about the transferability of the findings. Moreover, Shaked and Bilu's (2006) paper did not present their analysis in detail, making it challenging to evaluate how transparently the interpretations were developed.

Of the four grey literature papers appraised by the AACODS, one paper (Victory, 2014) was found to have low objectivity, which is concerning given that it was a doctoral thesis and therefore permitted a greater word limit than journal articles. As the researcher's background and reflexivity were not discussed, it remains unclear how their positioning and assumptions may have influenced the research. The accuracy of Kopolovich's (2007) paper was considered moderate due to unclear analysis. Nonetheless, given the dearth of research in this area, these authors have used their doctoral and master's studies to uncover often-overlooked experiences, thereby providing a valuable foundation for future research and contributing to the profession.

Thematic Synthesis

From the data synthesis, five main themes were identified: i) Meaning-making and coping through religion, ii) The struggles of parenting and family life, iii) Efforts to embrace Jewish identity, iv) Conflicting views on stigma, and v) Help-seeking and support in the face of challenges. Additionally,

two subthemes were identified: i) Parenting, identity and transformation, and ii) Challenges and changes in the family ecosystem. Themes and subthemes are presented in Table 8 below.

Table 8

SLR Themes and Subthemes

Theme	Subthemes
Meaning-making and coping through religion	
The struggles of parenting and family life	*Parenting, identity and transformation* *Challenges and changes in family ecosystem*
Efforts to embrace Jewish identity	
Conflicting views on stigma	
Help-seeking and support in the face of challenges	

Theme 1. Meaning-making and coping through religion: This theme explores how parents interpret their child's autism diagnosis through their religious beliefs, with religion providing both a framework for understanding and support for coping. Across several studies, a spiritual meaning was assigned to the diagnosis, which was described as coming *''…from above"* (Shaked & Bilu, 2006) or a test from God (Alon & Achituv, 2024). Raising a child with autism carried greater significance and was experienced as a mission:

''Everything is for a reason, and I believe that this is who I am supposed to be. I am supposed to be a mother of a kid with autism" (Victory, 2014)

For others, their role was divinely assigned and viewed as a sacred duty:

"What is so special about us that God has chosen us to take care of him and love him"? (Shaked, 2005)

A child's diagnosis was imbued with mystical significance, linking their behaviours and qualities to the soul and emphasising their spiritual uniqueness:

***''**These children have a special soul, and we do not know what their understanding is, so give them whatever you can"* (Yaroslawitz, 2018)

Similarly, another parent was able to capture when their child's spirituality became more visible:

‘’ … on the Sabbath there is something special in him, on a different level. I cannot explain it, except on some spiritual level” (Shaked, 2005).

In contrast, findings from other studies highlighted that raising a child with autism was seen as a punishment and parents felt they could not turn to God (Victory, 2014), whereas others expressed anger:

‘’[God]…doesn’t love us, ‘’He’s trying to mess up our lives,” (Alon & Achituv, 2024)

Whilst a reference to God was made in relation to parenting a child with autism across most studies, the differences concerned the significance of parental roles and God’s plan, and the questioning of God’s intentions.

Nonetheless, faith and praying were regarded as key coping strategies across most studies (Alon & Achituv, 2024; Kopolovich, 2007;Shaked & Bilu, 2006; Shaked, 2005; Victory, 2014; Yaroslawitz, 2018), highlighting their significance and their role as a source of strength when faced with adversity.

Overall, these accounts unveil how parents use religion and spiritual frameworks to construct meaning and support their coping. Carers balance gratitude with abandonment and anger. They position autism as both a sacred purpose to be received with appreciation and a spiritual challenge that may test their faith.

Theme 2. The struggles of parenting and family life: This theme speaks to a complex yet transformative, identity-shaping journey that can alter a parent’s sense of self following a diagnosis. It also emphasises that the entire family system undergoes change and that challenges can promote growth.

Subtheme: Parental identity and transformation: Parents across several studies described experiencing a range of emotional responses to their child’s diagnosis. Denial was reported as an initial reaction by some (Victory, 2014), followed by overpowering feelings of inadequacy (Alon & Achituv, 2024; Kopolovich, 2007; Victory, 2014) and guilt (Yaroslawitz, 2018). Over time, some carers moved towards acceptance (Yaroslawitz, 2018; Shaked & Bilu, 2006):

“Today, I learned to accept, and I can be happy with what he is, because I completely changed my expectations from him, I can accept him more now.” (Alon & Achituv, 2024)

Whilst this quote illustrates an attempt to redefine the future and a process of coming to terms with a child’s disability, there seems to be an unnamed loss and grief associated with the potential future

that parents had envisioned for their children. However, hope was also expressed (Yaroslawitz, 2018), as in the following example:

''I believe there is more out there for him and we will figure it out" (Victory, 2014)

Across studies, parents described caring for their children as exhausting and overwhelming (Alon & Achituv, 2024; Kopolovich, 2007; Yaroslawitz, 2018). Due to relentless routines and the multiple roles they occupy, their personal needs, social activities and friendships suffered (Alon & Achituv, 2024; Victory, 2014). Some carers spoke about the loss of self:

''In the first years... it was like I erased myself" (Alon & Achituv, 2024)

A demanding caregiver role can alter parents' self-perception, particularly at the outset. With time, a shift from self-erasure towards reclaiming their identity was reported:

"Slowly, slowly, I learned that this is really not right. A person first has to be with himself or herself." (Alon & Achituv, 2024)

This account illustrates that prioritising parents' own needs is a gradual process which involves negotiation.

Taken together, these accounts illustrate that caring for a child with autism can be a significant and transformative journey for parents, one that involves profound emotional struggles, sacrifices in personal self-care, and negotiations in the process of regaining their identity.

Subtheme: Challenges and changes in family ecosystem : Families experienced shifts in structure and rhythm due to the demands of caring for a child with autism. Across studies, carers named ongoing stress (Victory, 2014; Yaroslawitz, 2018), financial struggles (Victory, 2014; Yaroslawitz, 2018), and difficulty allocating attention fairly among siblings.

''…as a family trying to balance a child that needs such unique attention with everything else that's going on with other children, work and balancing that attention, you can't just create an environment that's a one-on-one therapy centre in your home. So that's very challenging" (Yaroslawitz, 2018)

This quote illustrates the almost impossible task of managing and accommodating the home environment to meet the needs of a child with difficulties while attending to the other children, each with their own unique requests.

Conversely, several studies noted unexpected growth within families when they adapted by changing their attitudes and parenting approaches. Greater maturity and sensitivity among the other children,

as well as increased compassion within the family unit and teamwork, were observed (Alon & Achituv, 2024; Kopolovich, 2007; Yaroslawitz, 2018).

Taken together, these accounts illustrate that a family unit can experience autism as a strain which can impact on different aspects of family life. As families adapt to new routines and realities, they can experience transformation and growth.

Theme 3: Efforts to embrace Jewish identity: This theme highlights the central role of Jewish identity reported in most studies. It drew attention to the need to prioritise traditions and religious belonging alongside caregiving. Judaism was described as "*the most important thing"* (Kopolovich, 2007; Sher et al., 2021), stressing its significance in Jewish life. Involving children in religious rites was vital for parents (Shaked, 2005), alongside Jewish education (Raiola, 2025). Learning Hebrew was perceived as *''heritage"* that was *"…central to their daily lives,"* (Sher et al., 2021). Children's preference for order and routine (Victory, 2018) made weekly Jewish rituals accessible and meaningful, as one example explains:

''…he fits into that because he likes routine. It comes naturally to him when Shabbos comes every week. It is nice we have the same dynamic because it's the structure, and he likes structure"
(Yaroslawitz, 2018)

Given the stressed importance of religious rituals and customs, parents whose children struggled to meet cultural expectations expressed disappointment and grief. Challenges included difficulties with synagogue participation, wearing ritual garments (Kopolovich, 2007), or adhering to behavioural codes regarding modesty and scholarship (Shaked, 2005). Carers feared their child would face exclusion and alienation from family and community if unable to fulfil the Torah or master Hebrew, both central to Jewish identity and belonging:

'If she [the child with autism] cannot fulfill our commandments, then why was she born Jewish at all? What for?'' (Shaked, 2005)

Here, the child's worth may be diminished or questioned if they cannot meet religious expectations, particularly when those spiritual goals are unreachable.

From looking across studies, these accounts demonstrate that children's participation in Jewish life is considered crucial. Equally, autism-related difficulties can be perceived as a threat to religious identity and belonging, not only for the child but also for the family and the wider community.

Theme 4: Conflicting views on stigma: This theme highlights parents' contrasting experiences of stigma and their communities' awareness of autism (Sher et al., 2022; Yaroslawitz, 2018; Kopolovich, 2007; Victory, 2018). Several parents reported stigma in their communities:

“There is still much stigma around the area of autism” and ‘’…there is not enough awareness with developmental challenges” (Yaroslawitz, 2018)

Other carers who expressed similar views on stigma said that *‘’people don’t want to know’’* and linked this to ignorance (Sher et al., 2022). An attempt to organise an awareness event in the Orthodox community failed because ‘’*…no one signed up. Not one person’’* (Sher et al., 2022), suggesting ongoing discomfort.

Parents across several studies found public outings emotionally burdensome (Kopolovich, 2007; Yaroslawitz, 2018; Victory, 2018) due to perceived judgment and limited understanding:

‘’If I take him to the grocery, sometimes he can act up, whatever, he doesn't act like a six-year-old. They're all staring and staring” ……’’… I hate people talking. I see that they talk” (Kopolovich, 2007)

Interestingly, it was found that views on stigma within the same studies varied, with parents sharing that:

“Thankfully, there is so much awareness on autism and children with special needs…” (Yaroslawitz, 2018)

And that attitudes were improving and that stigma towards autism in the Orthodox Jewish community *‘’had appreciably decreased” (* Sher et al., 2022).

These conflicting accounts suggest that parental experiences are not universal and vary considerably across communities. Exposure to stigma and community scrutiny can heighten the daily difficulties of parenting, leaving caregivers exposed and vulnerable.

Theme 5: Help-seeking and support in the face of challenges: This theme demonstrates how parents navigate seeking help and build support systems. Carers described their efforts to obtain guidance and support as a ‘*’constant battle”,* and a *‘’ fight”* (Kopolovich, 2007). In their search for answers, they consulted a range of resources, including *‘’doctors”, ‘’famous professors”,* and rabbis, reflecting both religious and secular strategies for seeking help (Shaked & Bilu, 2006).

One mother received reassurance from a religious figure who said that her child *‘’is normal’’* but after a year, the same figure suggested that the parents consult a doctor when the child’s difficulties had not improved. This caused anger, and the parents felt that the person they sought support from was *‘’playing games’’* with them, and they refused to see him again (Shaked, 2005).

Some carers placed hope in spiritual remedies as they navigated their child's challenges. One described an amulet given to their child who:

''Started to talk... but after two weeks the amulet disappeared... and she went back to the same level where she had been before." (Shaked & Bilu, 2006)

Spousal support varied widely across studies. In some families, fathers were involved (Kopolovitch, 2007; Yaroslawitz, 2018), whereas in other studies mothers reported parenting alone (Yaroslawitz, 2018).

Peer support from other carers who had a child with disability was received as deeply meaningful, as they were:

''(…) in the same boat" (Kopolovich, 2007)

and felt: *''(…) lucky to have each other to have those relationships because it makes it easier"* *(*Raiola, 2025).

Additionally, parent-led initiatives and online spaces created much-needed opportunities for openness and mutual aid (Sher et al., 2022). Parents took on a role of advocates and initiated support groups for other caregivers (Raiola, 2025), to learn from shared experiences (Victory, 2018) and offer practical advice (Kopolovich, 2007).

Culturally aware non-Jewish professionals who *''recognise that this is a thing that is significant in his life and experience"* (Raiola, 2025) were valued by parents, while frustration was experienced with interventions lacking cultural competence (Yaroslawitz, 2018), highlighting how culturally sensitive care is central to their experience.

Taken together, these accounts demonstrate that seeking support and respite is another challenging aspect of life for parents. Caregivers seek guidance both in religious and secular contexts, sometimes with disappointing results. Self-initiated spaces where they share experiences and learn from other parents with similar challenges are highly valued, as is the cultural competence of non-Jewish professionals they encounter

Discussion

This SLR aimed to explore the experiences of Jewish parents and carers raising children with autism. Nine studies were identified that met the inclusion criteria. From these studies, five main themes and two subthemes were identified to answer the review question. Below, all themes and subthemes will be discussed in terms of findings and links to existing literature.

Theme 1: Meaning-making and coping through religion

This review illustrated the central role of religion in the lives of Jewish parents as caregiving was intertwined with faith, aiding parents' sense-making about their child's challenges and their ways of coping. This aligns with Pargament's theory of religious coping (1997), which suggests that individuals turn to religion to find meaning during difficult times. Religious coping involves a variety of feelings, behaviours, and thoughts, and the theory distinguishes between positive forms, such as seeking comfort, and negative ones, such as feeling punished by God. Both were used by Jewish carers. The findings from this SLR align with existing research, demonstrating that parents' perceptions of their child's disability may be connected to their spiritual beliefs (Salkas et al., 2016; Pandya, 2018). For example, research on Muslim parents found that their children's autism was considered a blessing from Allah (Jegatheesan et al., 2010) and the caregiving role was understood as a gift from God (Nahal et al., 2017). Research concerning Orthodox Jewish mothers who cared for children with disabilities perceived their role as reserved for those with the greatest faith (Teman et al., 2011). This may be explained by the fact that caring for another is viewed as a fundamental religious value for 'Ultra-Orthodox' caregivers, and despite challenges, caregiving is seen as a divine test (Edelstein et al., 2017). Some parents in the review questioned God's intentions in having a child with challenges. This finding aligns with Vaz Mouyal's (2021) research on infertility among Orthodox Jewish women, as some viewed the inability to conceive as God's punishment. Lastly, with reference to parenting, experiences of anger and disconnection from God expressed by carers during their child's suffering were also reported in the literature (Azbell, 2023).

Theme 2: The struggles of parenting and family life

Subtheme: Parenting, identity and transformation

This review found that parenting a child with autism is a complex journey, and initial responses often include feelings of inadequacy, guilt, and denial. These findings align with the literature on parenting a child with autism across different cultures (Tümlü & Akdoğan, 2022) and on parenting a child with disabilities (Ziapour & Khosravi, 2020). However, the psychological impact on parents of children with difficulties, as well as the increased burden related to caring responsibilities (Gogoi & Jha, 2025) is not limited to Jewish parents but can affect all carers. The review revealed that parents' needs were compromised by care demands, consistent with previous research identifying a loss of self and neglect of one's own needs (Rodriques et al., 2019). Interestingly, research concerning 'Ultra-

orthodox' mothers parenting children with ADHD found that whilst some prioritised their children's needs over their own, others perceived looking after themselves as important to being a better caregiver, and some spent time focusing on their career goals (Budman & Maeir, 2022).

Subtheme: Challenges and changes in family ecosystem

Caregivers in the review reported that raising a child on the autism spectrum can have a profound impact on the entire family. Previous research found that caring for a child with a disability affects the structure and functioning of the family system (Aydogan & Kizildag, 2017; Miller et al., 2012). Similar to the findings from this review, these effects can include family stress (Staunton et al., 2023), economic burden (Cidav et al., 2012; Emerson et al., 2010) and difficulties in meeting the needs of other children (Łada-Maśko et al., 2025). Notably, despite these challenges, family members can experience transformation, with parents reporting growth, compassion, and maturity among family members as supported by existing literature (Roper et al., 2014). Importantly, the literature indicates that siblings of a child with autism have to grow up faster and take on more responsibilities (Petalas et al., 2012), which may contribute to their maturing, even if not chosen.

Theme 3: Efforts to embrace Jewish identity

This review found that it was fundamental for parents to include their children in religious practices and education, emphasising the importance of a strong Jewish identity. Research has demonstrated that religious carers seek to pass on spiritual and religious values to their children with autism by engaging them in conversations about faith and teaching them about prayer (Crawford et al., 2019; Edgell, 2006). A Jewish charity working with families of children with autism highlighted that faith-based practices can help create a safe, predictable environment that supports self-regulation (Norwood, 2025). In line with this review's findings, religious parents of children with disabilities in Speraw's (2006) study believed in their children's spirituality and connection to God. They felt it was their responsibility to nurture their children's faith and encourage participation in rituals, rites of passage, and the life of the faith community. On occasions when children were excluded, parents were driven to act and subsequently experienced anger, sadness and despair as the stability of faith was lost to them and their children.

Theme 4: Conflicting views on stigma

The review found that experiences of stigma varied considerably among parents. This may reflect diversity within Jewish communities and differing levels of exposure to the secular world, as reported in the literature. Research has demonstrated that cultural stigma and negative attitudes towards children with developmental difficulties (Khalil et al., 2025) can further exacerbate isolation, as families may avoid disclosing their child's diagnosis for fear of social judgement (Faraji-Khiavi et al., 2021; Heydari et al., 2015). The contrasting findings may be attributed to differences between

Orthodox Jewish subgroups in their attitudes towards people with disabilities, as well as to spirituality. The protective role of spiritual-religious beliefs in relation to perceived stigma associated with autism has been reported in the literature (Shokouhi et al., 2025). Interestingly, the Norwood charity noted ongoing discomfort around autism in Jewish communities, meaning that people with autism and their families may feel unwelcome in spaces common to community members, leading to isolation from community life. At the same time, an increased number of diagnoses was observed, potentially suggesting a shift in how autism is perceived in Jewish communities (Norwood, 2025).

Theme 5: Help-seeking and support in the face of challenges

This review found that caregivers experienced help-seeking as a long, effortful process that drew on both religious and secular sources of support. Family support varied, with some reporting shared caregiving and others experiencing isolation. As discussed in Chapter 1, a Rabbi may be the first point of contact for Jewish families regarding health matters. However, research on help-seeking behaviour among 'Ultra-orthodox' Jewish parents found that they sought help through a variety of options, including statutory and private services, rabbis, famous mehanhim (Rebbes with educational insights) or Jewish psychologists abroad (Schnitzer et al., 2011). As some of these sources were consulted simultaneously, this may suggest that parents try different solutions until they find one that works, and also indicates a level of openness. Consistent with existing literature, parents appreciated support from other carers of children with disabilities, which provided an opportunity to learn from one another and to share feelings and practices related to children's difficulties (Nematollahi et al., 2025). Parents emphasised the importance of culturally sensitive care, and previous research suggests that carers report that healthcare providers lack the cultural sensitivity required to accurately diagnose their children with autism and address specific concerns, fostering mistrust and dissatisfaction with the services received (Burkett et al., 2015; Dababnah et al., 2018). Additionally, research found that carers may respond to professionals' lack of awareness and interest in spiritual wellbeing and religious observance with sadness and anger (Speraw, 2006).

Microsystem and Parental Experiences

Although it is acknowledged that some findings of the review relate to broader ecological systems, viewing the experiences of Jewish families through the lens of the microsystem closest to the child emphasises the complexity of their realities. Children's outcomes are shaped by interactions among interconnected personal, social, religious and cultural practices embedded in the everyday lives of Jewish families. Findings indicate that diagnosis may be viewed as a test from God, a divine mission, or God's punishment. These findings demonstrate how religious and spiritual meanings within the family microsystem help parents make sense of a child's diagnosis and cope with challenges. As a result, interactions between carers and children may be shaped by their beliefs and attitudes. An autism diagnosis may influence parental roles, as self-perception, expectations, and emotional well-

being within the system can affect everyday responsibilities. Carers' identity and social interactions can be compromised by the intense demands of caregiving, potentially affecting the quality of interactions within the family microsystem. The review found that autism can affect the entire family, creating both strain and opportunities for growth. In line with the bidirectional nature of systems theory, parents who accept their child's difficulties and cope with daily challenges may, in turn, positively affect siblings and other family members. Jewish theology, religious norms, and cultural expectations embedded in this system shape parental decisions regarding the inclusion of children in religious practices and education.

Strengths, limitations and future research

Strengths

This SLR is believed to be the first to examine how Jewish parents experience caring for children on the autism spectrum. A key strength is that it addresses a gap by offering insights from the religious and cultural perspectives of under-researched communities. The transparency and robustness of the review were enhanced by registering the protocol on PROSPERO (Stewart et al., 2012). Additionally, studies were double-screened, which can help identify a greater number of eligible studies than a single screener (Stoll et al., 2019). The inclusion of multiple databases, grey literature, snowballing from reference lists, and input from two reviewers strengthened the SLR's search strategy. Given the dearth of peer-reviewed literature on the topic, including grey literature strengthened this review by providing contextual understanding and broader perspectives. No time frame was applied to ensure that all literature published on the topic was captured.

Limitations

Nonetheless, the findings should be considered in light of their limitations. I recognise that my interest in experiences that highlight the depth of the topic, which could only be captured in qualitative papers, has strongly shaped this review and may have led to the overlooking of important quantitative studies. To ensure that the voice was given to participants, reflexive journaling (Braun & Clarke, 2022) and supervision to explore reflections on my positionality were used. However, it cannot be determined that the impact of this interest was fully managed. Minor amendments to the PROSPERO protocol were necessary to improve the consistency and clarity of the inclusion and exclusion criteria. Although these changes were carefully considered and implemented before the full-text screening and data extraction, a potential bias must be acknowledged. While the Cochrane handbook recommends at least two data extractors (Li et al., 2024), capacity and time constraints, made this impossible for this project, and this should be noted as a limitation.

Due to small sample sizes in individual studies, findings must be interpreted with caution, which affects their representativeness and rigour. The review overrepresented Orthodox Jewish perspectives and underrepresented other Jewish denominations. Studies were primarily centred on mothers' voices, excluding the experiences of fathers, foster and adoptive parents. The selected papers were dominated by two researchers, with four of the nine papers authored or co-authored by them, potentially leading to overrepresentation bias and skewed perceptions of the literature. Given the nature of exploratory research projects, the dominance of the same qualitative methodology may overemphasise how people experience a phenomenon rather than how common or widespread it is. Furthermore, limited information on reflexivity, particularly when the research is done with the same collaborators, may lead to performative rather than critical reflexivity. Moreover, two papers were published using the same data set (Shaked, 2005; Shaked & Bilu, 2006). Although the aims differed and there was no double-counting of results, both studies relied on the same sample. Given the scarcity of studies, it was felt important to include both papers in the review, as they reported unique data and met the inclusion criteria. As non-English papers were excluded, some important studies conducted in researchers' native languages may have been omitted. While some researchers argued that the exclusion of non-English language papers has a limited impact on the findings and conclusions of reviews (Hartling et al., 2017), others noted that experiences of culturally specific matters may be missed and limit the transferability of the results (Butler et al., 2016). Lastly, as studies were conducted in Israel, the United Kingdom and the United States, the systemic and policy differences need to be acknowledged. Parental experiences of access to or availability of services would have been shaped by differences in private American health care versus the publicly funded British National Health Service.

Overall, the evidence base remains limited, as the field is characterised by a small number of studies, several of which are grey literature or reuse the same participants' sample. Whilst the synthesis identifies important patterns, it cannot be considered representative of all Jewish parents who raise children with autism. The methodological limitations, combined with the context-specific evidence base, may suggest that findings are likely to be transferable to similar Orthodox Jewish contexts, but they should not be assumed to represent the experiences of all Jewish parents or other religious or cultural communities.

Future research

Future research could broaden the focus to include fathers' voices, which remain considerably underrepresented in autism research on caregiving (Shorey & Pereira, 2023). Research concerning siblings who grow up alongside other children with disabilities could shed light on their needs, long-term consequences and well-being. Additionally, in many Orthodox Jewish families, older siblings, particularly girls, assume responsibility for their younger siblings and are perceived as parental figures (Bachner-Melman & Zohar, 2019; Gemara & Nadan, 2022). Researching their experiences could contribute to the literature on parentification. Furthermore, future inquiry could consider secular Jews, whose perspectives were not captured in this review. Lastly, as mothers from Orthodox Jewish

communities are often the primary breadwinners in their families (Kalagy & Braun-Lewensohn, 2019) and their role is seen as central (Budman & Maeir, 2022), gaining insight into their needs seems pivotal.

Clinical Implications

The findings indicated that Jewish parents' experiences of caring for a child with autism are ecologically distributed and shaped by complex systems where faith and culture intersect. Services working with Jewish parents may benefit from recognising that making sense of autism through a religious perspective (Alon & Achituv, 2024; Victory, 2014; Shaked & Bilu, 2006) can be central to parents' understanding of their child's presentation and their role as caregivers. Furthermore, sensitive exploration of religious beliefs may be important in supporting parents, as these beliefs can offer comfort but also cause emotional suffering. Families experiencing grief linked to exclusion and unmet expectations for children unable to participate in Jewish life (Shaked, 2005; Kopolovich, 2007; Sher et al., 2021; Raiola, 2025) might benefit from spaces where concerns about religious belonging can be raised sensitively. Integrating self-compassion into parental interventions may be vital, as raising a child with autism can impact caregivers' identity (Victory, 2014; Kopolovich, 2007; Yaroslawitz, 2018; Alon & Achituv, 2024), leading to sacrifice and loss of self due to the demands of their role. As autism can strain the entire family system (Yaroslawitz, 2018; Victory, 2014), services may benefit from adopting a systemic, family-centred approach when considering interventions, including support for siblings. Furthermore, creating safe spaces that allow parents to explore experiences of community exclusion due to autism-related stigma (Kopolovich, 2007, Yaroslawitz, 2018) and the process of increasing inclusion as awareness grows (Sher et al., 2022) are important indicators of worry and support needs. Services may benefit from adopting a non-judgemental approach while recognising that support-seeking can be a complex journey, navigating both religious and secular contexts (Shaked & Bilu, 2006). This can heighten parental mistrust and vulnerability and, as a result, delay seeking help (Shaked, 2005). Parents may benefit from peer-led support networks that foster advocacy, learning, and mutual aid (Sher et al., 2022; Victory, 2014). Lastly, support is more effective and valued by parents if it is culturally sensitive and relevant (Raiola, 2025).

Conclusion

This SLR aimed to explore how Jewish parents experience caring for a child with autism. The review highlighted that raising a child with autism is a multilayered experience for Jewish parents, shaped by religious, cultural and social norms, and emphasised the importance of considering autism and the complexities of caregiving within a religious and cultural framework.

Rationale for the present study

The evidence emphasises the benefits of collaboration among multidisciplinary teams and carers to meet the needs of children with autism (NICE, 2025). For this collaboration to succeed, it is vital to examine how ecological factors interact to shape relationships among professionals and parents, who play key roles within the mesosystem, where family-service interactions and relationships occur. While the SLR provided insight into how Jewish parents experience parenting a child with autism, understanding professionals' experiences can shed light on barriers and facilitators to obtaining an autism diagnosis and accessing support services. These perspectives can reveal how religious and cultural values are recognised, respected, or overlooked, and what relevant care may look like and what adaptations are required.

Aims and Research Questions

The present study aims to capture the experiences of professionals who work with children with autism and their carers from Orthodox Jewish communities in the UK.

Research Q 1: What are the experiences of professionals working with Orthodox Jewish families who have autistic children?
Research Q 2: Perspectives of professionals on the barriers and facilitators to obtaining a diagnosis of autism and accessing support services for Orthodox Jewish parents who raise autistic children.

CHAPTER 3: METHODOLOGY

Chapter overview

This chapter presents the methodological approach used to explore ‘The Experiences of Professionals Supporting Children with Autism and their Families in Britain's Orthodox Jewish Communities’. It provides a rationale for adopting a qualitative design and for choosing reflexive thematic analysis (RTA). The chapter also details the study design, recruitment strategy, participant information, and ethical considerations.

Rationale for qualitative methodology

Qualitative methodologies focus on experience, perspective, meaning, and subjectivity, offering a distinctive approach to understanding the complexities of social phenomena (Lim, 2025). Given the study's novel topic, an exploratory qualitative design (Busetto et al., 2020) was well suited, enabling a more in-depth and nuanced understanding of Orthodox Jewish families raising a child with autism, as viewed through professionals’ lenses. In line with the critical realist stance, the focus was on individuals' subjective perspectives, which quantitative methods may have limited.

Rationale for Focus on Professionals

The decision to shift this study's focus to professionals' perspectives on parents was driven by ethical and practical concerns. As ethical issues may arise at any point in the research, it was important to consider their implications before ethical approval was obtained (Guillemin & Gillam, 2004). Given the socio-political climate and the rise in antisemitism, approaching families could have seemed invasive and heightened their sense of threat. Some community members involved in this project who had direct access to relevant families were uncomfortable sharing details about the study. In conversation, one professional expressed a willingness to discuss their experiences professionally, which led to the idea of speaking to professionals. Further conversation with the research consultant highlighted the practical relevance of exploring barriers and facilitators to diagnosis and support services.

In practice, recruitment became more feasible because I was already in contact with professionals in relevant settings who could signpost me to others. The shift within the participant group required a methodological change from IPA to RTA, as the two approaches made different assumptions about the purpose of the research and the type of knowledge it generates.

Professional perspectives have been widely used in health and social care research to understand the experiences and needs of service users and families. For example, studies have examined healthcare professionals’ perspectives on the challenges faced by parents of children with autism (Ma et al., 2026) on parental experiences of the diagnostic process for autism spectrum disorder, with a

focus on the perceived impact of assessment on families (Daniels et al., 2021) or on autism services (Gholipour et al., 2023).

Although parents are the primary source of their experiences, professionals' accounts offer a broader perspective on barriers and facilitators, informed by their experience with multiple families across services. The present study does not claim to represent the authentic experiences of Orthodox Jewish parents of autistic children. Instead, the shift from lived experiences to situated perspectives seeks to understand how professionals make sense of parents' experiences and how these understandings influence clinical practice, service provision, and family support.

Rationale for Reflexive Thematic Analysis

Reflexive thematic analysis (RTA) recognises the contexts in which participants' experiences occur and utilises the researcher's subjectivity when interpreting these experiences (Braun & Clarke, 2019). As discussed in Chapter 1, my identity does not neatly fit into the 'insider' or 'outsider' box, as I navigate multiple identities. Reflexive thematic analysis (RTA) was chosen as the analysis method for its suitability in helping me navigate 'the space between' (Dwyer & Buckle, 2009). RTA is a qualitative approach for analysing and reporting patterns and themes within a dataset, particularly useful for exploring participants' experiences within broader contexts (Braun & Clarke, 2006). RTA allows both semantic and latent interpretations, supporting exploration of participants' explicit statements and the deeper meanings embedded in their accounts. A critical realist stance informed this study, and RTA is seen as epistemologically flexible (Braun & Clarke, 2006) aligning with my perspective. A central element of RTA is its focus on the researcher's perspective as an essential part of knowledge creation. It discourages the pursuit of accuracy or reliability in coding, consensus between coders, or the use of inter-rater reliability (Braun & Clarke, 2019). Reflexivity is a core feature of RTA, positioning the researcher as a co-creator of meaning through ongoing engagement with the data and continuous reflection on how their positionality influences interpretation (Braun & Clarke, 2019).

Rationale for RTA over IPA

Initially, Interpretative Phenomenological Analysis (IPA) was considered for this study's research design. IPA seeks to offer a detailed understanding of individual experiences, capturing participants' unique meanings (Eatough & Smith, 2017). However, this could be a limitation here, as the aim is to identify broader patterns across participants rather than focusing on individual accounts of shared experiences. These patterns relate to barriers and facilitators to obtaining a diagnosis or support among Orthodox Jewish families. RTA was more appropriate for revealing collective insights rather than individual stories (Braun & Clarke, 2022). While IPA involves selecting a homogeneous, purposively recruited sample (Larking et al., 2019) this study's sample is expected to be diverse in

terms of occupations, religious beliefs, and locations. Additionally, IPA requires bracketing the researcher's experiences to focus on participants' meanings and reduce subjectivity (Neubauer et al., 2019) a requirement that has been criticised as unrealistic and potentially reinforcing power imbalances (Holmes, 2020). Since I share some relevant experiences with the participants, using IPA would not fully acknowledge my active role in the analysis; hence, it did not fit the aim of this project.

Reflexivity in RTA

Reflexivity is a form of critical thinking that involves researchers being conscious of their role and positioning during fieldwork, as well as the dynamics of their interactions with participants. It includes awareness of how their voice influences the research while aiming to authentically represent the voices of those they study (Hertz, 1996). Since a researcher's perspective will affect all aspects of the inquiry, transparency about their viewpoint and position is essential (Emerson & Frosh, 2004). Reflexivity involves the researcher critically examining the nature of the knowledge produced and how it is generated (Guillemin & Gillam, 2004). It also entails acknowledging how personal and contextual factors influence the research process and its outcomes (Bradbury-Jones, 2007). According to Braun and Clarke (2022), reflexivity is key to producing high-quality analysis. Subjectivity in RTA is treated as an asset to be engaged with intentionally, rather than as something to be minimised or eliminated (Braun & Clarke, 2019). RTA recognises that researchers will interpret data differently, so identical coding or theme development across individuals is not expected. Reflexivity is an ongoing, multi-dimensional process, and several practices were employed throughout (Finlay & Gough, 2008). I used a reflexive journal during data collection and analysis to reflect on my reactions and decision-making. Collaborative reflexivity in supervision helped reveal aspects of my identity I was less aware of, through discussions about assumptions and decisions related to the project (Bieler et al., 2021). Olmos-Vega et al.'s (2022) framework on types of reflexivity was applied to ensure thorough consideration of my positionality and reflection on my privileges and marginality (Braun & Clarke, 2022). Table 9 details how different types of reflexivity were utilised.

Table 9

Types of reflexivity taken from Olmos-Vega et al., (2022).

Personal reflexivity ***Question: How are our unique perspectives influencing the research?***
As I am not religious this may have influenced how I interpret parents' decisions about faith and spirituality when caring for a child with challenges. Being exposed to Jewish neighbours in my

childhood and adulthood, may have shaped my understanding on how working with Jewish communities 'may' or 'may not' look like. I am aware that my clinical training predisposes me to interpret autism through developmental and diagnostic frameworks. Throughout my career, I have observed systemic barriers faced by religious and cultural minorities that restrict access to essential services. With all of the above, it is crucial that I remain mindful of how my personal perspectives influence this project and be transparent about my approach to the data.

Interpersonal reflexivity

Question: What relationships exist, and how are they influencing the research and the people involved? What power dynamics are at play?

I hold multiple relational positions that may influence how data is generated. As an NHS Trainee Clinical Psychologist and former CAMHS clinician trained in ADOS, I recognise that I may hold inherent power relative to participants outside the NHS. This could affect how rapport is built, how trust is developed during interviews, and how experiences are shared. Similarly, dynamics with NHS clinicians need to be considered, as shared institutional knowledge may create a sense of common ground. My ideas for this project stem directly from my clinical practice, including successes, mistakes, and failures. Therefore, it is important to remain aware of this dynamic throughout.

Contextual reflexivity

Question: How are aspects of context influencing the research and the people involved?

Broader socio-political tensions, such as rising antisemitism, misunderstandings of religious and cultural identities, societal views on autism, assessment waiting times in the UK, and various organisational factors, may influence participants' experiences. Considering these contextual factors, I must be attentive to how they shape participants' experiences and my understanding of them.

Methodological reflexivity

Question: How are we making methodological decisions and what are their implication?

The decision to use RTA recognises my subjectivity in the research process. It is crucial to reflect on how my decisions regarding coding, theme generation, and analysis may influence the final interpretations of data and findings.

Expert by Experience Consultations

To enhance the study's credibility and rigour, consultations were utilised (Forero et al., 2018). Given the thesis's nature as an educational project with tight deadlines, including an expert by experience (EbE) early on was essential to ensure their perspective was incorporated from the outset, and to guide the project's direction (Stanley et al., 2013; Thompson et al., 2009). Furthermore, establishing relationships and demonstrating a commitment to ethical and culturally appropriate practices should be addressed early in the research planning phase, well before data collection (Herring et al., 2013). The study's consultant was a respected member of the Orthodox Jewish community with direct insight into the lives of children with autism and their families. The consultant was known to the research supervisor, who personally approached him to confirm his interest in participating. Although the research supervisor had experience working with the Orthodox Jewish community, my limited familiarity with it made it crucial for the consultant to be a community member, as this facilitated understanding of the ‘insider’ perspective at various research stages (McDavitt et al., 2016). The role of the EbE was crucial in shaping this inquiry, particularly after the decision to change the topic. He brought practical knowledge of working with families and highlighted the need to understand the barriers and facilitators parents face when accessing services. As it was important for this research to be driven by a clinical need, I appreciate that the project had a strong practical focus. Additionally, the consultant served as a community representative, which was particularly helpful given my lack of experience in direct work with strictly Orthodox families. Whilst the value of this professional relationship was recognised, I needed to remain mindful of the scope of this project and ensure the research remained manageable and focused. Details of the consultant’s contributions are outlined in Figure 2. It was essential to manage the consultant's involvement ethically, with clear expectations and a defined engagement duration. The consultant was offered £20 per hour. Efforts were also made to include another relevant perspective by seeking a consultant with an educational or therapeutic background. Although an individual was identified and initially agreed to support this project, the offer was subsequently withdrawn.

Critical Realism Lens

Critical realism shaped this research by supporting a focus on identifying practical changes that could improve families’ access to services, while recognising that barriers may reflect real underlying social, cultural and structural processes that could be accessed through professionals’ accounts. Working alongside community EbE and reflecting on my own ‘in-betweener’ positionality enabled me to view barriers not as individual or culture-related, but as arising from interactions between services, Orthodox Jewish families and the wider social context. A practical focus in this study allowed me to consider how understanding contextual and relational processes can inform more culturally relevant

practice by adopting services' communication and approaches to better accommodate families' needs.

Peer Consultations

I connected with four other researchers who had prior or ongoing experience in conducting research with Orthodox Jewish communities in the UK. Their input, from researchers with diverse backgrounds and interests, was crucial in informing my thinking about the cultural appropriateness of my research idea and served as 'reality checks' on potential challenges. They stressed the importance of doing the groundwork, including speaking with stakeholders, identifying barriers to recruitment, and contacting people in the field. Speaking with non-Jewish researchers helped me consider my 'outsider' status as both a barrier and a strength for engagement with Orthodox Jewish communities. A Jewish researcher prompted me to consider further potential challenges related to willingness to participate, which was described as 'hard but not impossible', and reiterated the importance of trust before the data collection can take place. Taking their advice, a significant amount of time was spent building relationships, trust and transparency with various members and organisations within Orthodox Jewish communities.

Time, Trust and Transparency

Engaging communities in research requires meaningfully involving those affected by research findings (Brett et al., 2014) increasing research relevance and participation among diverse, often underrepresented groups. This engagement can take many forms, including raising awareness of research projects, seeking input on specific aspects, and involving representatives (Foregonese, 2018). To foster community engagement in community-focused research, trust is essential (Willkins, 2018). As Orthodox Jewish communities tend to live insular lives, establishing trust can be difficult (Coleman, 2007) especially for outsiders.

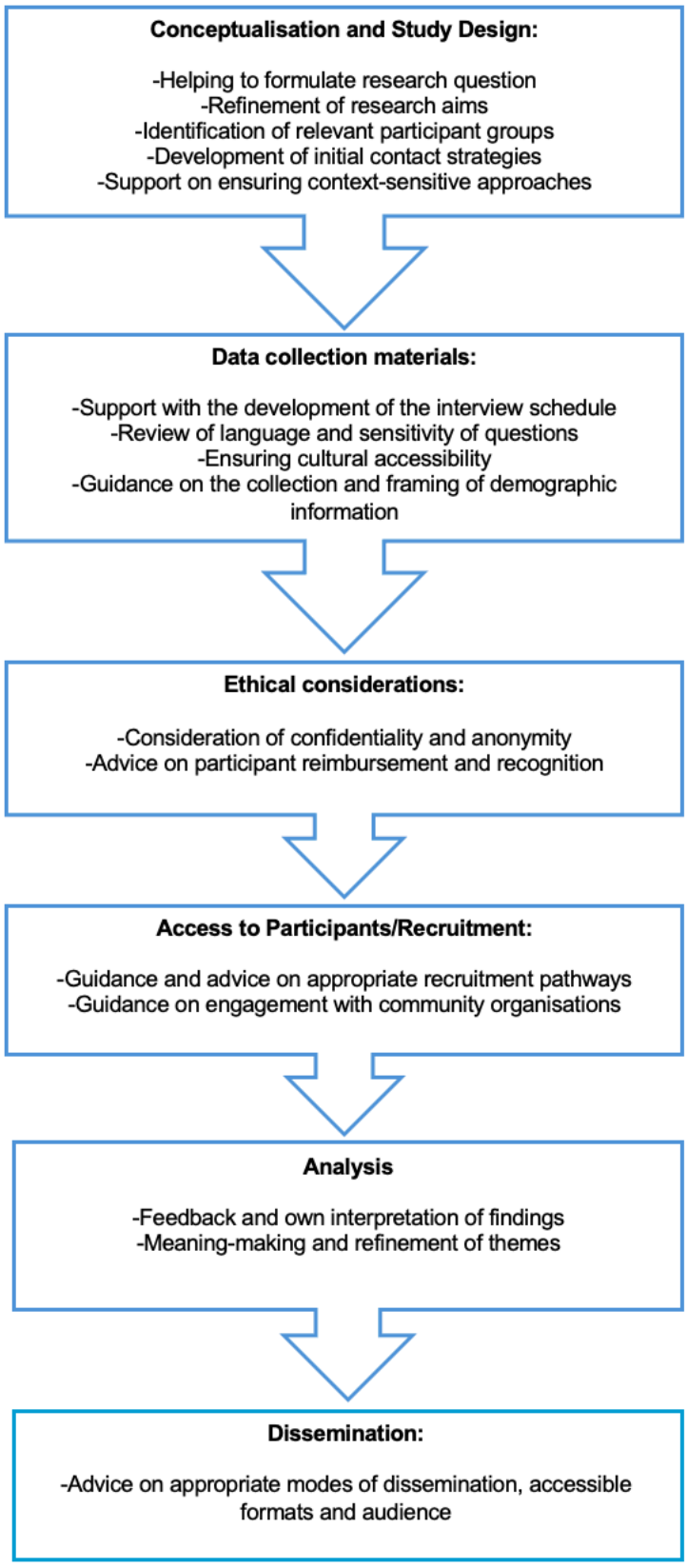
I initially approached this project with a naive understanding of what trust looks like within Orthodox Jewish communities. I contacted organisations identified by the research consultant and shared the project idea with as many people as I could to initiate conversations. Some individuals responded positively and offered encouragement, which I took as signs of interest. However, no one expressed interest in participating. A few organisations declined to be involved, and others did not respond to my emails. Although I initially felt quite hopeless about my ability to promote my research, receiving one email from a key member of the community changed my approach. Building relationships with respected community members can increase the community's willingness to participate in research,

especially in under-researched communities (Khodyakov et al., 2017) including faith communities (Shaghaghi et al., 2011).

Drawing on the consultant's guidance and my peers' practical insights, I began making telephone contacts, which proved to be a more meaningful way to engage. I realised that sending an email and expecting a response was a shortcut. Taking time to have conversations to introduce my project required me to answer questions about my background and interest in the topic, none of which could have been meaningfully addressed via email. Given that the aim of this project was practical, as identified with the consultant, it was important to collaborate with someone with expertise in the community and in the needs of children with autism and their families. A Rabbi who also worked in education was a valuable person to have conversations with, as were local charities. Some of these interactions were different from what I imagined. They did not start by asking about my project, but by sharing their stories, pride in their achievements, and hope for the future. Honesty about the project's benefits, as well as my limitations, namely time and limited resources, was crucial. With that in mind, I wanted to think of this research as just the start of the conversation regarding autism rather than a final product. The openness about families' needs reported by those who engaged in conversations about this project was striking. However, I was cautious not to assume that directness was welcomed by everyone, so it was paramount to approach each conversation with curiosity and to be led by individuals.

Figure 2

Consultant's involvement at different stages of the study



Data Collection

Semi-Structured interviews

After considering various qualitative data collection methods, including structured interviews and focus groups, semi-structured interviews were chosen as the most suitable for this study to explore professionals' experiences. A close comparison using the same script in each interview was not the objective of this study (Punch, 2005) hence, structured interviews were deemed inappropriate. Due to potential familiarity among participants, focus groups were deemed unsuitable for ethical reasons, including concerns about anonymity and confidentiality (Sim & Waterfield, 2019) and stigma. Semi-structured interviews provide a balance of structure and flexibility, allowing follow-up on participants' responses (Thomas, 2017) and changes in topic as the interview progresses (Magaldi & Berler, 2020).

Interview Schedule

As an 'in-betweener' researcher, it was important to acknowledge my influence on the nature of questioning in the interviews (Braun & Clarke, 2022a). The semi-structured interview schedule was partly developed from existing literature, in consultation with my supervisory team and research consultant, and refined through pilot testing. The topics in the interview guide were drawn from de Leeuw and colleagues' (2020) research, which aimed to identify cultural and contextual factors that may influence identification, help-seeking, and the diagnosis of autism worldwide, from the perspectives of individuals and their families. Although the current study explored professionals' perspectives, the framework proposed by de Leeuw et al. (2020) was deemed relevant, given professionals' roles in families' lives and their contributions to developing culturally relevant and sensitive services. Given the expected diversity among professionals, two interview schedules were created to accommodate participants from educational and non-diagnostic settings (Appendix E) and from healthcare and diagnostic services (Appendix F). Both interview schedules were structured to address four themes (identification, help-seeking, diagnosis, and post-diagnostic support) while reflecting different roles and areas of expertise. The process of finalising the schedule was iterative (Braun & Clarke, 2013). Two online pilot interviews were conducted using the same procedures as the actual interviews to practise skills, identify areas for improvement, and simulate the interview setting (Huss et al., 2017). The first interview was with a fellow trainee clinical psychologist with experience working with autistic children, young people, and their families in CAMHS and inpatient settings. Following the interview, it was decided to reorder some questions and reduce the number of questions concerning the diagnostic process. I recognised that my CAMHS background influenced the queries I hoped participants would answer about diagnostics, and while this felt important, it was important not to assume participants' experiences prior to the interview.

The second pilot interview with a CAMHS practitioner with extensive experience of working with neurodivergent children and their families from ethnic minority backgrounds highlighted the need to rephrase questions to improve clarity and elicit more specific responses. It also identified areas where adding prompts would be helpful. Further discussions with the research consultant centred on question phrasing, leading to the rewording of some questions to account for diverse cultural, educational, or linguistic backgrounds. For example, overcomplicated questions such as *What factors influence whether families see sharing concerns and seeking support as more approachable, or easier to do?* were simplified to *What makes sharing concerns and seeking support easier?* After the first two interviews, I realised it would be beneficial to have access to both interview schedules in future interviews, especially if some participants have experience working with the community across multiple settings in roles relevant to this research.

Participants

Inclusion and Exclusion Criteria

The study aimed to explore the experiences of professionals who work with children and their families in Orthodox Jewish communities, delivering services across healthcare and educational settings. As discussed in Chapter 1, community-based multidisciplinary care is recommended to support children with autism and their families (NICE, 2021). Accordingly, participants were invited to take part in the study if they a) were over the age of 18, b) identified as professionals in the healthcare, education or third sectors[2] who work or have worked with children with autism and their parents from Orthodox Jewish communities in the UK, and c) were sufficiently fluent in English. The exclusion criteria included professionals who a) were under the age of 18, or b) had no prior experience of working with Orthodox Jewish families. If participants identified as healthcare professionals, e.g. clinical psychologists or social workers, but worked in charities or other third-sector organisations, they were eligible to take part as long as they met the other criteria.

Sampling Strategies and Sample

A purposive sampling strategy was used to select participants with shared experiences or characteristics relevant to the study (Creswell & Poth, 2016). As purposive sampling aligns with the qualitative research paradigm, it was the most suitable approach, given the aim of exploring professionals' experiences rather than generalising the findings or controlling for potential selection bias (Palinkas et al., 2015). Additionally, snowball sampling was employed, an effective method for research involving personal or sensitive topics, as individuals are more likely to participate when signposted by a trusted source (Boehnke et al., 2011; Noy, 2008).

[2] Given the exploratory nature of this research, insights from various professionals were welcomed and inclusion criteria was broad

However, while the generalisability of qualitative findings is typically not expected, as studies aim to examine a specific phenomenon or issue within a particular population and defined context (Leung, 2015) some argue that shared features identified across a diverse group of cases are more likely to be generalisable than those found in a homogeneous group (Mason, 2002).
Given the project's refined topic, broad inclusion criteria were applied, and heterogeneity among participants was expected. The sampling strategy ensured that all participants had direct experience of working with Orthodox Jewish families, without requiring them to identify as Orthodox Jewish. Variables such as profession, religious affiliation, or geographical location contributed to heterogeneity in their experiences.

The concept of saturation in qualitative research is debated and may not always apply to qualitative samples (Levitt et al., 2018). In reflexive TA, data saturation is not a supported concept (Braun & Clarke, 2019). Human experiences are nuanced and multifaceted, making complete saturation within any given sample unrealistic (Nelson, 2017). However, having a target sample in mind was helpful, and a range of 6-15 participants has been recommended for UK professional doctorates using thematic analysis (Terry et al., 2017). Given that recruitment was approaching the time of the Passover and there was uncertainty about recruiting additional participants, a flexible approach that tailored the sample size to the study's needs was adopted (Ahmed, 2025). The decision was made to conclude with a final sample of nine participants. It was also felt that sufficiently rich data had already been collected, that the participant pool demonstrated demographic diversity (Vasileiou et al., 2018) and that this was sufficient to address the research questions.

Recruitment

The recruitment process took place between December 2024 and April 2025. A recruitment poster (Appendix G) was initially shared with schools and organisations identified by the consultant. Gatekeepers disseminated the study information to their staff and asked prospective participants to contact the researcher directly if they wished to participate. The study was advertised on social media, including Instagram, the ‘’UK Clinical Psychology Doctorate applicants’’ Facebook group, and LinkedIn. Posters seeking participants were shared with members of the ‘’Psychologists for Social Change’’’ WhatsApp group, with Clinical Psychology Doctoral courses in the UK and via ‘word of mouth’. I actively sought participants from the healthcare and educational sectors, including, but not limited to, special educational needs co-ordinators (SENCos), educational psychologists (EPs), and clinical psychologists (CPs). While it felt important to interview NHS professionals, it was not feasible to obtain NHS ethics approval from the NHS Research Ethics Committee (REC) within the timeframe of this project. Eligible NHS staff could take part in this study if they learned about the project through the above methods. No recruitment via any NHS trust took place.

After recruiting several participants, snowball sampling was used to enhance recruitment, and participants were asked to refer eligible colleagues interested in taking part in the study. After

establishing relationships with a number of organisations and professionals, I was careful not to rely too heavily on snowball sampling from a single network, as that might lead to a biased sample (Solberg, 2025). Twenty-two people expressed an interest in the study, and nine met the inclusion criteria. Among those who did not take part in the study:

- Two individuals worked in the US and had no UK experience.
- One individual worked in Israel and had no UK experience.
- Three individuals had experience working with Jewish families rather than Orthodox Jewish families.
- Three individuals worked with adults rather than children.
- Four did not respond to follow-up emails.

All individuals who were unable to participate were thanked for their interest in the study and for taking the time to reach out.

Participant Characteristics

The sample consisted of nine participants. All participants were based in either the South East or the North West of England. The participants' characteristics are detailed in Table 10.

Table 10

Participants' characteristics

Pseudonym	Gender	Age	Religion	Ethnicity	Profession
MM	Female	55-64	Jewish Charedi	White other	Social worker
Evie	Female	35-44	Jewish Other	White other	Counsellor
Meir	Male	35-44	Jewish Charedi	White British	SENCO
Michael	Male	35-44	No religion	Mixed Asian and British	CAMHS Clinician/Assistant Psychologist
Adina	Female	45-55	Jewish Charedi	White British	Therapist
Pearl	Female	55-64	Jewish Other	White British	Family Support Worker
Elza	Female	25-34	Jewish Charedi	White British	SENCO/Designated Safeguarding Lead
Bella	Female	18-24	Atheist	White British	CAMHS Assistant Psychologist
Maya	Female	25-34	No religion	White other	Clinical Psychologist

Whilst no specific details will be provided to ensure anonymity, it is important to note that some participants held multiple identities, including being a Charedi professional, working with families from Orthodox Jewish communities, and being a parent or family member of a child with autism.

Ethical Considerations

Ethical Approval

The initial ethical approval was not granted, and further clarification was required on several points. A detailed letter addressing the research committee's questions can be found in Appendix H. A revised ethics application was resubmitted, and subsequently, ethical approval was obtained from the University of Hertfordshire Health and Human Sciences Ethics Committee in December 2024 (protocol number: 0278 2024 Dec HSET; Appendix I). The project adhered to the British Psychological Society's Code of Human Research Ethics (Oates et al., 2021) to ensure ethical compliance. Careful consideration was given to the ethical dilemmas and potential risks associated with the research topic and participant group.

Informed Consent

All participants who expressed interest in the project were emailed a participant information sheet detailing the study's aims, procedures, and what to expect from the interview (Appendix J). They were invited to discuss the study without obligation to take part. Two participants accepted this invitation and either asked questions about eligibility (e.g., the length of time required to work with families) or inquired about my interest in the topic. Participants who expressed interest were offered a brief screening phone call (to ask about their roles and experiences), which also provided an opportunity to build trust and rapport (Pietkiewicz & Smith, 2014). Participants who met the criteria and agreed to take part were emailed a consent form (Appendix K). They were offered the opportunity to see the interview questions in advance to support more informed and transparent consent (Haukås & Tishakov, 2024), fairer involvement (Day & Carroll, 2003), and reduce stress (Szulc, 2022). Five participants opted to receive the interview questions beforehand. Prospective participants were given time to consider whether to participate. Those who decided to proceed after making an informed decision were asked to electronically sign a consent form agreeing to participate in the research and to have their interviews audio-recorded.

Confidentiality/Anonymity and Data Management

The study adhered to the confidentiality and anonymity principles outlined in the participant information sheet and consent form. Each interview involved only the researcher and the participant, and confidentiality and privacy arrangements were discussed before scheduling. Participants were informed that any identifying information would be anonymised. They were invited to choose their

pseudonym to protect their anonymity, as research suggests that assigning a pseudonym reduces participants' ability to influence how they are portrayed in research (Itzik & Walsh, 2023) and perpetuates colonialism within research (Pretorius & Patel, 2024). They were also informed that their data would be kept confidential unless there were safeguarding concerns. No concerns were raised. Eight interviews were conducted online, and one in person. All participants confirmed that their spaces ensured confidentiality. Data was securely stored in line with the university's data management guidelines. All interviews were recorded via Microsoft Teams and stored on the lead researcher's university OneDrive, which I had exclusive access to. The automatic transcript function in Microsoft Teams was used for all interviews. Identifiable information about participants was removed or altered from each original transcript to safeguard anonymity. All data containing non-anonymised information (e.g., participants' demographics) was also stored securely on the university's OneDrive. Any paper documents (e.g. a receipt confirming payment received) signed after the in-person interview were digitised and paper copies were destroyed.

Right to withdraw

Participants were informed of their right to withdraw and reassured that doing so would not affect their involvement in future projects. They could withdraw at any time within seven days of the interview, without providing a reason. No participants chose to withdraw from the study.

Potential risk of distress and minimising harm

Given the sensitivity of the research topic and the current socio-political context, it was anticipated that interviews could cause psychological distress for participants. My priority was to minimise harm, and I used my therapeutic skills to monitor participants' emotions throughout the interview. Participants were reminded of their right to decline to answer any questions, to share only what they felt comfortable with, to request a pause in the recording, or to end the interview at any time, without giving a reason. No participant requested a break. In remote interviews, it was agreed with all participants that, if a connection was lost or the participant could no longer be heard or seen, a phone call would be made to ensure the disconnection was not due to distress. At the end of the interview, participants had the option to engage in a debrief to discuss their reflections. Participants were provided with a debrief sheet containing information on local support they could access (Appendix L). Various safety measures for my psychological and physical well-being were considered, with potential risks and mitigating strategies outlined in the risk assessment (Appendix M). No harm occurred and no apparent distress was observed.

Renumeration

The decision on reasonable compensation was informed by a discussion with the research consultant. An equivalent of £20 was offered as a one-off payment for participation. To reflect the community's collective nature and its highly valued practice of charity (Holman & Holman, 2002) participants could choose between a monetary payment, a shopping voucher, or a donation to a chosen charity or organisation, rather than individual payments. Five participants received £20, with five via bank transfer and one in cash; one participant opted to donate to a local charity; and three declined any form of payment. I am not aware of any out-of-pocket expenses related to participating in this research, and no participants received reimbursement.

Procedure

Participants who met the inclusion criteria and agreed to take part in the study were emailed the participant information sheet and a consent and agreement form for volunteers and lay members' involvement in research (Appendix N). Once the signed consent was received, interview dates and times were arranged by asking participants to provide their availability. Due to the researcher's limited availability, in-person interviews could be conducted only if the travel distance was no more than 15 miles. The demographic questionnaire was completed verbally with all participants before the interview began, and their responses were recorded directly in a OneDrive document. At the start of the interview, participants were asked for verbal consent to record. To protect participants' well-being, they were reassured with a confidentiality statement and informed that they did not have to answer any questions they found uncomfortable. Additional information about the study's aim was provided to participants before the interview began. Eight interviews were conducted remotely via Microsoft Teams with cameras on, and one in person. Online interviews were recorded as video and audio using Microsoft Teams, and the in-person interview was recorded only as audio using the same platform. One online interview ended earlier than anticipated due to an internet connection problem, and the participant requested that the remaining questions be emailed.
All interviews lasted between 45 and 60 minutes. At the end of each interview, participants received a debrief sheet and £20 in compensation of their choice. All nine transcriptions generated via MS Teams were verified against the recorded interviews for accuracy.

Data Analysis

Braun and Clarke's (2022) RTA was used to analyse the data using the six phases of RTA serving as a flexible guide. The process is recursive and iterative rather than linear, allowing the research to move back and forth between phases (Braun & Clarke, 2022). Hence, I endeavoured to fully engage with each phase while remaining flexible throughout the process.

Table 11

Six phases of Reflexive Thematic Analysis

Phase 1: Familiarisation with the data
This first phase focused on intimate familiarisation with the data, and I intentionally spent more time to facilitate immersion (Braun & Clarke, 2006). The familiarisation process began when I recorded my initial thoughts and responses straight after each interview. I then read each transcript while listening to the recording without taking any notes. On the second occasion, I listened to each interview while reading alongside the audio to check and correct the transcriptions. I found transcribing interviews a useful way to engage with the data, as it slowed the process. By taking every word in, I noticed things that had not been apparent during the interviews. Listening to each interview a second time was accompanied by writing reflections in a reflexive diary (Appendix O) about what each interview evoked in me. I then read each transcript once more in an 'active way' (Braun & Clark, 2006) and began writing down thoughts on patterns, ideas, and concepts that might be worth exploring in relation to my research question.
Phase 2: Generating initial codes
All transcripts were imported into NVivo for coding. Only data relevant to the research questions were coded line-by-line (Braun & Clarke, 2022). The majority of coding was semantic (explicit), interpreting what was directly stated and staying close to participants' understanding of their experiences. However, when each transcript was re-visited, some latent (implicit) coding was applied to delve deeper into the underlying meaning of what participants had said (Braun & Clarke, 2006). The codes were then extracted into an Excel spreadsheet. As I became more familiar with the data, I found myself redefining codes during this phase (Byrne, 2022). I check all codes and the data linked to each code for consistency when renaming or changing codes. Considering the limited research in this area, an inductive, data-driven approach was applied across the entire data set, capturing meaning directly from participants' accounts as opposed to analysing the data with a pre-conceived theory (Byrne, 2022). However, I wondered if truly inductive coding can take place, given that I already had knowledge of the literature. An excerpt of a coded transcript is provided in Appendix P.
Phase 3: Generating initial themes
Once the initial coding was complete, I examined broader patterns across the dataset and searched for shared meaning (Braun & Clarke, 2006). The codes were printed from Excel and cut into strips to begin the process of clustering them based on relationships between codes. Codes that did not fit wider themes were placed in a miscellaneous theme. These clusters then elicited initial themes and subthemes. In some cases, I moved codes to different clusters where they appeared to fit more naturally. During this phase, codes that did not fit the overall analysis or convey meaningful information were discarded. I was able to work more fluidly with the data,

drawing on my in-depth knowledge of it (Braun & Clarke, 2021a). It was difficult to let go of codes and themes that did not fit the overall analysis, and supervision supported this process. At the end of this phase, mind maps of the initial clusters aided visualisation of the data (Appendix S).

Phase 4: Developing and reviewing themes

At this stage, I explored the viability of the themes and subthemes by revisiting the data to assess whether they aligned with the original codes and whether they told a meaningful story in response to the research questions (Braun & Clarke, 2021a). I checked whether there was a clear distinction between themes and whether there was sufficient data to support each theme (Braun & Clarke, 2021a). Ensuring clear boundaries and coherence for each theme was challenging, given the variety of experiences, and some themes and subthemes needed to be reconstructed by adding or removing codes. Sharing themes with the supervisor and reviewing them against the original data helped remove those that did not address the research question, despite being interesting and intriguing. Keeping in mind Braun and Clarke's (2006) suggestion that themes do not 'emerge' but are constructed by the researcher, and what they bring to the process, was helpful and kept the focus on the research questions despite seeing some themes that naturally 'emerged'. Further discussions with the supervisor allowed me to refine themes and clarify which subthemes linked to which themes.

Phase 5: Defining, refining and naming themes

Member checking with participants on initial themes was not undertaken, as it was considered important not to treat it as a verification of a fixed objective truth, which is consistent with principles of critical realism (Braun & Clarke, 2022). Considerable time was spent to ensure that theme names were not topic summaries (Braun & Clarke, 2022). Writing abstracts for each theme to present the central organising principle led to revisions to the themes. The process supported coming up with names for each theme and amending names that did not capture the richness and full meaning of the theme.

Phase 6: Writing the report:

The final phase involved writing up the analysis, which I found difficult as it was challenging to capture the richness of the data in a coherent and, meaningful way. Nonetheless, Braun and Clarke's (2021a) remark that "there is always more to be said about the data than a single analysis can capture" was reassuring. Therefore, I relied on my reflexivity to continue to analyse, interpret, and refine themes during the writing process and aimed to reflect the nuance within data (Braun & Clarke, 2022). Some aspects of the theme were refined and reconceptualised to ensure they tell an engaging story. The write-up of the data analysis is presented in the next chapter, as each theme will be discussed using data extracts to illustrate the narrative.

CHAPTER 4. RESULTS

Chapter Overview

This chapter presents the themes and subthemes constructed through RTA. They illustrate how participants in the study experienced working with children with autism from Orthodox Jewish communities and their perspectives on barriers and facilitators to obtaining a diagnosis and accessing support. As RTA is a subjective and reflexive process, the codes and themes generated from the data are actively shaped by the researcher's subjective position (Braun & Clarke, 2022). Reflexive writing will be woven throughout the results section, written in the first person, *italicised,* and placed in a footnote*,* to guide the reader in understanding how the study's findings are influenced by my interpretations and assumptions (Braun & Clarke, 2023).

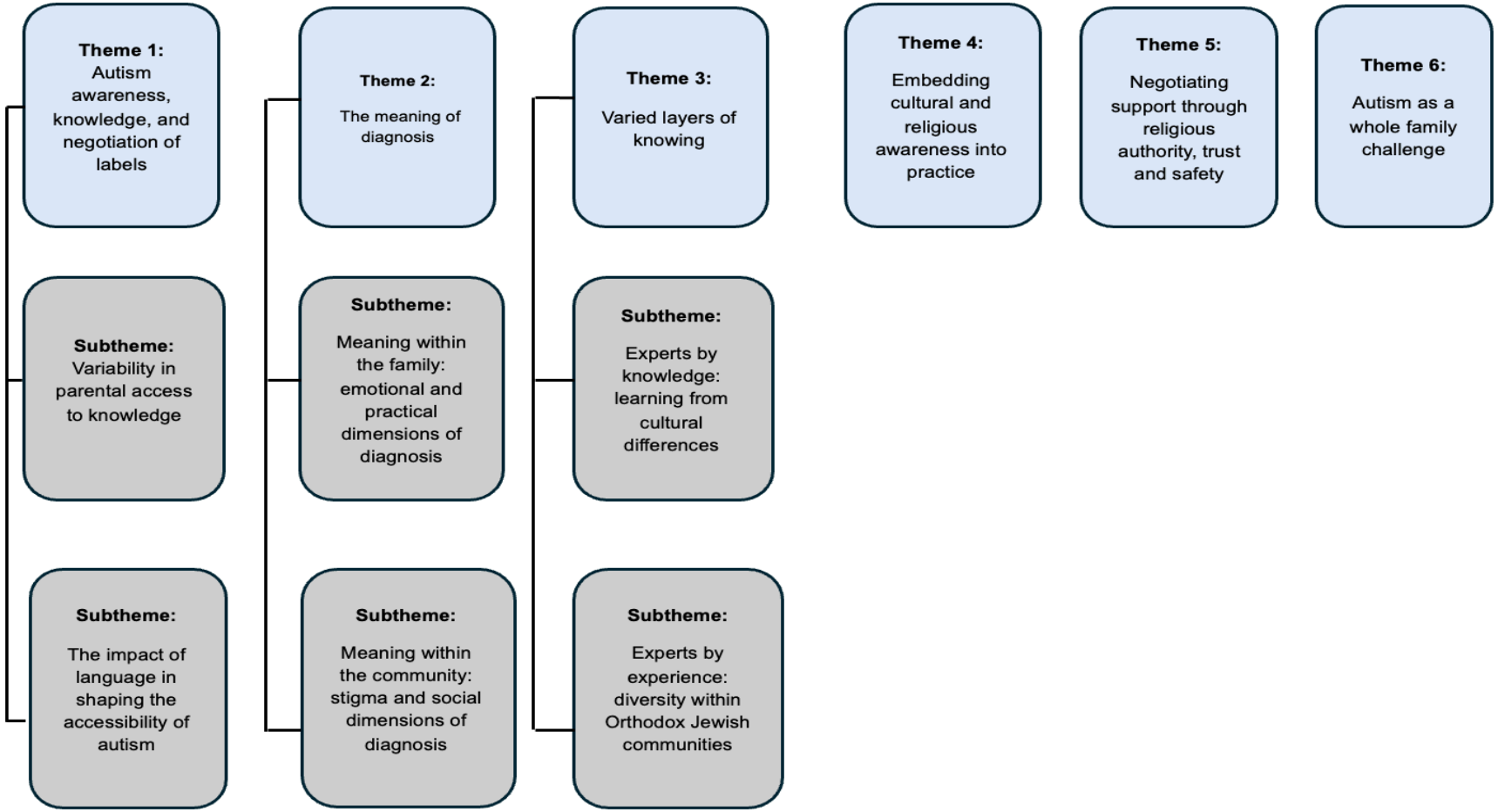
To understand the experiences of Jewish parents and carers who raise children with autism, two questions were asked:

What are the experiences of professionals working with Orthodox Jewish families who have autistic children?
Perspectives of professionals on the barriers and facilitators to obtaining a diagnosis of autism and accessing support services for Orthodox Jewish parents who raise autistic children.

Six main themes were constructed with six subthemes, which are presented in the thematic map below (Figure 3)

Figure 3

Thematic Map



[3]**Theme 1: Autism awareness, knowledge, and negotiation of labels:** This theme explores participants' polarised views on unequal access to knowledge about autism within Orthodox Jewish communities. It also speaks to their experiences of how the language used to describe autism shapes how the condition is received. Participants' reflections highlighted that variability in understanding is shaped by cultural, linguistic, and social factors, affecting whether autism is recognised and named.

Subtheme: Variability in parental access to knowledge: Participants perceived considerable variability in parental understanding of autism, which they attributed to prior parenting experience, education, or degree of integration. These differences were understood to reflect unequal access to autism-related knowledge. Several insider participants who also had lived experience of caring for a child with autism shared that families are mostly unaware of the condition. /…/'s quote is one example that shows that for some families, autism was an unfamiliar concept:

'' Generally, parents are in the dark, which is why I started these conference groups (…) to actually educate them and help them understand". /…/

Here, a professional is taking on an educational role to increase parental understanding, and their role extends beyond delivering interventions and responding to difficulties and involves creating a learning environment that facilitates access to information. She further described her experience of autism as not being grounded in parental understanding. This was particularly evident among first-time parents who naturally lack comparative developmental experience, making it harder to recognise or interpret concerns:

''Well, that sometimes comes [lack of awareness] because it's their first child, never heard of it before, heard the words floating around, but didn't realise that actually this is what it means". /…/

/…/ account demonstrates that early signs of difference can remain unclear or be mistaken for typical behaviour, which may delay carers' concern and search for support.
In contrast, parents who already had children with autism and experiences of accessing CAMHS services, seemed to be well informed, as Bella summarised:

'' And actually, the parents I met a lot of the time we were meeting some of their younger children, and they had really solid understandings of autism, and we're really aware of it, and I imagine because they've kind of gone through these processes with their other children, and they had, yeah, really clear understandings of the needs and differences". (Bella)

[3] Note on language:
[…] indicates words that have been omitted
(…) indicates words that have been added to improve clarity
/…/ indicates names/words that have been omitted to protect anonymity

Other outsider participants observed *''pockets of knowledge",* further suggesting that awareness is unevenly distributed:

''So you would meet parents who are incredibly well informed, and then you would meet parents who have very little understanding". (Michael)

In the process of understanding the community's awareness of autism, some insider participants noted that carers' misconceptions about autism can stem from visible stereotypes of disability. As Evie explained, sharing a direct quote from a parent:

''Well, my child has a normal face. So how can he have autism?". (Evie)

This suggests that if parents rely on explicit or physical signs of difference to define it, neurodevelopmental conditions that do not align with these signs are harder to conceptualise, potentially leading to concerns being ignored or overlooked.
Similarly, another insider participant shared a quote from a parent that reflects a narrow understanding of the spectrum:

''…But she talks and she, you know, I know she started late, but she's still OK". (Elza)

Here, autism may not be considered a concern if a child is verbal, as the ability to speak may be interpreted as a sign of typical development, leading to delayed referral for assessment, even when difficulties are present.
In Meir's experience, these disparities are attributed to structural and cultural factors that shape access to information:

''So, and there's many, many families which don't have Internet access at home (…). So, with that kind of isolation…. You just don't have access to the knowledge about it". (Meir)

Here, isolation described by the insider refers to a communal practice that can have epistemic implications, as limited awareness may be embedded within a wider cultural framework that restricts access to specific kinds of knowledge. Meir further spoke about the relationship between education, openness, and engagement with the scientific models of autism within his own community:

"(…) the people who are more educated may tend to be more open to engaging with the current kind of scientific way of looking at it, for the people who are more isolated will tend, you know, not to….". (Meir)

Overall, these accounts suggest that, according to participants, disparities in knowledge about autism vary greatly among families and depend on their previous parenting experiences and access to

information. These factors shape understanding of presentation, symptoms, and concerns. This means that professionals must be flexible in how they communicate and support families, adapting their approach to parents' level of understanding.

Subtheme: The impact of language in shaping the acceptability of autism: Professionals' interpretations of language describing autism were that it played a significant role in how difficulties were perceived and emotionally received. They noted that some terms were considered more acceptable and less alarming, whereas others were avoided.
Several insider participants reported that, in their view the term 'autism' was avoided by parents. Elza stated:

'' Autism is really, really not acceptable". (Elza)

Adina provided further context on that point, linking the rejection of the term to the potential images it can evoke:

''Autism (…) comes across as harsh, and people don't want to associate their child as autistic because (…) it's somebody who's very, very low functioning…". (Adina)

Meir echoed this:

''When you say someone's autistic, (…) the connotation is someone who you know is nonverbal". (Meir)[4]

These accounts suggest that the term 'autism' may be perceived as shorthand for severe impairment and dependence, rather than a diverse spectrum of challenges and needs, which could explain why families are reluctant to adopt it.

Drawing on her outsider experience of working in Orthodox Jewish schools, Maya's account illustrates that other professionals seem wary of the term 'autism' and recognise a potential impact of diagnostic language:

''(…), I got told don't say the word autism in consultations [with] families. If they say it...We can use that, but we don't want to go in and say that [difficulties] might be part of autism". (Maya)

[4] *I felt that including insights into language was crucial, as only insider participants were able to comment on it in detail. I wondered whether this might suggest that these conversations occur only within the community, or that outsider professionals are not asking questions.*

As an outsider working in Jewish schools, her experience of the language aligns with that of insider participants, further underscoring the importance of the language used within strictly Jewish environments. Furthermore, participants noted that some alternative terms were more acceptable. 'ASC' was described as *''more manageable than saying autistic,* and 'ASD' was a term that *''parents are more willing to hear".* The term 'Asperger's' in particular was understood to mean that children ''*were like normal".* This can be seen as a parental attempt to position their child closer to typical development and to distance them from images of life-long impairment.
Interestingly, insider participants also highlighted their experience of discourses surrounding functioning labels, and how these can create confusion and complicate communication:

''High functioning means he's got a high level of autism. People confuse the terms. I see that often, so it doesn't help to say high functioning". (Evie)

Evie's reflection suggests that some labels can hinder rather than clarify carers' understanding and inadvertently mislead them about the nature or significance of difficulties.
Conversely, Meir offered a different perspective:

''(…) if you say they have high functioning autism [it] doesn't sound that bad". (Meir)[5]

These accounts illustrate that the same term can be a source of misunderstanding for some and a source of reassurance for others, depending on how it is construed.

Finally, all participants described the use of need- and behaviour-focused language, such as *'communication difficulties'* or *'sensory challenges'*, rather than a label that could be too threatening to be clinically useful. Pearl shared an example of a parent-led approach, highlighting ways to engage parents in autism related conversations:

'' We talk about behaviours rather than the label, because I will always deal with what the parents are bringing to us''. (Pearl)

[5] *I noticed discomfort when participants spoke about the term 'high-functioning' autism. I tend to avoid functioning labels because I believe they are invalidating and create a false, linear spectrum that overlooks the complexities and multifaceted nature of autism. Although I no longer encounter these labels, I think it's important to include these accounts, as they may reflect experiences of families that are not always voiced. The fact that participants have experienced different discourses about these labels may indicate confusion and suggest that their use is more common than I expected. I also believe that these accounts highlight how the autism spectrum can be an intimidating concept, so perspectives on how families may experience it are valuable.*

Overall, this sub-theme highlights that, according to participants, the language used to talk about autism is significant, as professionals navigate the use of terminology carefully while allowing space to discuss difficulties and encourage families to share.

Theme 2: The meaning of diagnosis: This theme reflects participants' understanding of what a diagnosis means for parents and their children, and its effects within the broader Orthodox Jewish community.

Subtheme: Meaning within the family: emotional and practical dimensions of diagnosis:
Professionals shared their perspectives on how they experienced parents' emotionally complex responses to a diagnosis. Their accounts also captured the opportunities the diagnosis may present, and its role within the rigid constraints of structural requirements.
All participants perceived that receiving an autism diagnosis was an ongoing process for carers, involving multiple emotional responses over time. Some of the observed responses included *''grief"* yet later feeling *''relieved"* and *''less isolated and ashamed".* At the same time, insiders perceived forms of parental denial or resistance, with some carers stating that children *''were fine"* and that the diagnosis *''was a mistake*''. These accounts highlight that diagnosis is something that parents gradually come to terms with, interpret, or sometimes dispute.
Michael recalled meeting a mother who showed almost no reaction after receiving a diagnosis for her child:

''(…) We had one mum… she didn't have that many questions, she was remarkably kind of… I didn't know if she was just processing it later or if it was too much, but she stayed for maybe 20-30 minutes and then asked to leave". (Michael)

The absence of engagement could be interpreted as a sign of shock or emotional overload, and processing may occur outside the clinical setting.

Participants who had a personal experience of autism described the diagnosis as a means of understanding a child. /…/'s account is one example of this:

'' (…) when they know what a child has, they can then go and get help... They can learn to understand their strengths and their limitations (…) and to regulate themselves and to put measures in place, what they can do and can't do instead of trying the whole time to fit into the neurotypical friends or circles…and then they can actually achieve their best". /…/

/…/'s account highlights that a diagnosis can serve as an explanatory and organising framework. It can help reframe the child's behaviour and identify strengths and needs. Additionally, families can be supported in stepping away from the pressure to conform to neurotypical expectations for their child and instead focus on achievable goals and support.

Finally, the diagnosis was also positioned as a gatekeeping tool in the healthcare setting, essential for accessing services:

'' I think if a child that's going to need access to services or additional funding or additional sort of support and adaptations, they will need to have a diagnosis because we know that, that is a red tape in NHS provision or social care provision for a lot of things". (Maya)[6]

In this context, families may have limited choice about whether to diagnose their child, as a diagnostic label can serve as a practical and somewhat necessary tool.

Overall, these accounts suggest that participants' understanding of a diagnosis is that, within the family, it functions both as an explanatory and a practical tool, while parents experience emotional ruptures and repairs.

Subtheme: Meaning within the community: stigma and social dimensions of diagnosis: The perception of all participants was that an autism diagnosis carries significant social meaning within the Orthodox Jewish community. In a tight-knit, marriage-oriented community, the label was described as extending beyond the child and having social consequences.
Participants spoke about their impressions of how an autism diagnosis can affect the prospects of marriage and how it may become a factor in parental decision-making. Maya shared her observation:

"'So once you have a label like that, I guess in a way, your value gets decided based on that, like in the marriage market. (…) That's why people were a bit more hesitant about getting labels because of how it might impact their child". (Maya) [7]

Her account suggests that perceptions from those outside the community are that a diagnosis can function as a social indicator, shaping how an individual is evaluated against communal expectations.

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[6] *Maya's account captured my interest, and I wondered whether she might have assumed our shared professional identity, which could have encouraged openness. I received her comment as something shared among those who 'know', and wondered whether this knowledge is shared with families and, if so, what sense they make of a situation in which getting a diagnosis is the only option.*

[7] *The language of 'value' and 'market' was difficult to hear and resonated personally, as such labels still carry negative connotations where I come from. Was this language used with Maya during interactions with families, or did she hear it from other professionals? I wondered whether the explicit and harsh language was used intentionally to avoid being overlooked, or whether it was meant to depict the complex realities of Orthodox Jewish families. While this is her personal perception, I felt her quote needed to be included, as it may reflect the decisions parents in the community face when prioritising difficult-to-rank matters, both of which directly affect their children's futures.*

In this context, parental hesitation about seeking a diagnosis can be understood as a response to anticipated social consequences.
Several participants understood that the perceived consequences of diagnosis are far-reaching and can affect the entire family. Pearl's account illustrates this intergenerational impact:

''(…) if you had children to marry and have more children, and if they had a disability of any kind, it was a shadow over your family, and it was always a worry that other families wouldn't marry [your children]". (Pearl) [8]

In this context, disability can influence a family's future opportunities as the diagnosis extends beyond clinical or parental matters and can affect the entire family, including their reputation and future opportunities.

Overall, participants' perceptions of the meaning of an autism diagnosis suggest that parents may need to deal with their own responses while making sense of new realities. They also navigate very complex decisions, considering the needs and consequences for their child, other siblings, and the entire family.

Theme 3: Varied layers of knowing: This theme captures participants' perceptions on what it means to 'know' Orthodox Jewish communities and how that knowledge is shaped by background, experience, and relationships. Across accounts from those outside the community`, an emphasis on the importance of curiosity, reflexivity and learning was stressed. Insider participants highlighted the significance of diversity within strictly Orthodox communities.

Subtheme: Experts by knowledge: learning from cultural differences: Participants who were not members of Jewish communities reflected on how encountering lived realities different from their own fostered learning, self-awareness, shifts in understanding and facilitated engagement.
Bella described how her identity and upbringing initially acted as barriers to understanding and engagement:

''Our own identity can have strengths and barriers, and how that can kind of interact with the patients we're seeing. And I do think in this setting, it does create a barrier because there's a lack of understanding, and I think when I first went into the role, yeah, as being British and kind of raised in a

[8] *Similarly, the use of the word 'shadow' was met with discomfort, as it signifies something enduring and difficult to escape. I have not encountered that language in clinical settings, which makes me think that maybe not enough exploration has taken place. It felt important to include her account as a community-based narrative. I wondered whether concerns related to marriage are shared across services and, if so, what creates a safe space to discuss these matters.*

fairly kind of like white setting and not knowing much about Judaism. And yeah, not even really knowing much about religion, being an atheist." (Bella) [9]

Her further reflection illustrates how becoming more familiar with the community's practices helped her challenge her assumptions:

'' The more learning I did about the Orthodox Jewish community and understanding things like why people in the community might choose to have more children and things. Then yeah, breaks down those stereotypes, breaks down those stigmas, breaks down the lack of understanding". (Bella)

Here, learning is a transformational process that makes choices and behaviours easier to interpret. She recognises that practices that may initially be misconstrued become more intelligible when situated within cultural and religious contexts.

Other participants spoke about their outsider status and how it enabled them to adopt a curious stance while working with the community:

''I guess [not being from the community] allowed me to take the position of not knowing and curiosity quite easily, and often I think people were…..people value, when you show interest in their culture." (Michael)

Here, curiosity serves as a relational resource, enabling him to attend more carefully to parents' accounts and to situate their concerns within meaningful cultural contexts.
The value of showing interest in another culture that Michael spoke about translates to engagement, as participants observed that culturally responsive and respectful support for families was appreciated. As *''the word spreads very quickly in the Orthodox Jewish community''* Maya recalled being approached by more families:

'' …after the six consultations I made, people talked to each other. They found it helpful, so they told each other about this. And now a lot more people were keen to sort of come to the consultations and they knew me by name somehow." (Maya)

[9] *I found myself particularly drawn to Bella's account, which discuss recognising issues related to one's own background within the context of barriers to ethically responsible practice. She acknowledges that her worldview is shaped by a specific cultural framework that may not align with families' lived experiences viewed through a different lens. I appreciate her recognising that her positioning influences what is regarded as 'normal' or 'problematic' rather than claiming she is 'biased'. While her reflection reveals a slight shift in the boundaries of authority, the power imbalance between a clinician and a family remains, as individual reflexivity cannot counterbalance structural inequalities.*

Taken together, these accounts illustrate that insight into one's own positionalities can facilitate a shift in practice, particularly when accompanied by openness to learning. Curiosity, paired with self-awareness, increased knowledge, and respect, facilitated successful interactions and engagement with families.

Subtheme: Experts by experience: diversity within Orthodox Jewish communities: Drawing on insider perspectives, strictly Orthodox participants emphasised that their communities are internally diverse and *''not so simple".* Participants challenged the assumption of uniformity and stressed that superficial markers of similarity can obscure less visible differences within communities, with implications for professional practice.

Elza explicitly challenged the notion that Orthodoxy should be regarded as a monolithic culture:

''I know that you might see us as Orthodox Jewish (…)(…). But actually we're very much divided in different …I don't know how to explain different sects…(…) our traditions are really different…I don't know how to explain.. It's hard to explain so.. the sects but then there's also the people that come from Hungary and the people who used to come from, let's say, Poland. I'm talking about where our ancestors came from". (Elza)[10]

She suggested that, to those with limited understanding, the community might seem homogeneous. This simplification could lead professionals to respond in ways that are culturally insensitive or poorly suited to the community's needs.
Adina further emphasised that diversity is also organised across different institutional structures:

''Within the Orthodox community, there'll be different schools and different synagogues and different styles". (Adina)

Her account highlights how key institutional affiliations structure everyday life and where beliefs, norms and practices are reinforced and differentiated. These institutions influence children's education, family social networks and norms around behaviour. The range of practices and values, such as attitudes towards disability or engagement with services, shapes what support feels accessible and how they relate to services for their children.

[10] *This is where I felt like a religious and cultural outsider. I was careful not to assume that knowledge of Orthodox professionals is more 'authentic', but she made me consider her intentions in sharing her account. It seemed important to her to share this message, and I wondered whether this was her experience with other non-Jewish professionals she worked with, or whether she was speaking on behalf of her community. It felt significant to include this, as it could have been one of the few platforms where she could begin the conversation about diversity within Orthodox Jewish communities.*

Overall, these insider perspectives shed light on diversity within Orthodox Jewish communities, a recognition of which is paramount to culturally sensitive practice and crucial for engagement.

Theme 4: Embedding cultural and religious awareness into practice: This theme highlights practical, relational, and ethical adjustments that outsider participants perceived as crucial to aligning professional practice with Orthodox Jewish cultural and religious norms. Participants' accounts emphasise the importance of attentiveness and adaptation essential for building trust, preventing harm, and making services more culturally relevant and accessible.
Across accounts, cultural awareness was presented as an aspect that participants paid attention to and demonstrated through their appearance, practices and interventions.
Participants from outside the community spoke about the importance of adapting their appearance:

''I would make sure I'm wearing skirts that cover my knees. I'd make sure my elbows are covered". (Maya)

Her account shows that professionals can demonstrate respect through the visible aspects of their presentation to align with community expectations. This indicates that engagement with families from the community can begin before any clinical work.
Further, mindfulness of religious and gender norms was emphasised:

''…We need to be aware not to offer appointments on Friday afternoons or Fridays in general or [to know] about how young boys might not make eye contact with female clinicians". (Maya)

Here, awareness is framed as a preventive measure that helps avoid placing children or families in uncomfortable or culturally inappropriate situations, thereby reducing exclusion from services.
Further, the adaptations to suit the family structures and working patterns, when accessing CAMHS, were discussed:

'' [the mothers' groups] (…) would be offered during the working hours, but if they were the father's groups, they would be offered at, like, the earliest 7:00 PM, probably 8:00 PM for a two-hour group (…) That was just a preferable time for the fathers to be able to engage". (Michael)

Here, his account demonstrates an approach in which services adapt to families' life rhythms, thereby facilitating access.
Participants also emphasised the importance of culturally adapting assessment materials to avoid causing distress and to ensure their appropriateness within the Orthodox context:

''ADOS book that had the, I don't know if you've seen the Tuesday book, but it has pigs flying at the end. So we tended to have, we had a special book that had those pages stuck together". (Bella)

In this context, exercising judgement prevents unnecessary rupture of rapport, ensuring that the assessment context does not pose a barrier to engagement.
Bella provided a further example in which she adapted a standardised protocol to avoid misrepresenting a child's social understanding:

''So when I would see little girls in the Orthodox Jewish community, we tended not to ask the ADOS questions about do you think you'd like to get married one day? Because there was a bit of an understanding that this would be a different cultural expectation and might not really elicit the kinds of answers that we're looking for in terms of (…) do you understand social relationships and things like that?". (Bella) [11]

Here, cultural attentiveness is used to preserve the validity of the assessment by considering how and whether to ask certain questions, thereby preventing distorted and invalid clinical conclusions.
Maya also described an example of how interventions could be co-constructed to incorporate religious values that support ownership and engagement:

'I gave them the tools to create their own social stories, and they created it in a Torah [informed way]". (Maya)[12]

This illustrates a step towards genuine collaboration by supporting families in authoring materials within their own religious framework, ensuring relevance and engagement.
Finally, she described a culturally cautious practice and an anticipatory approach to sharing resources:

''And with regards to resource sharing, I would always look at the websites beforehand to make sure that there wasn't anything in there that would be offensive for them". (Maya)

Taken together, these accounts demonstrate professionals' willingness and commitment to adapt to meet families' needs while ensuring services operate ethically.

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[11] *I was drawn to these accounts about ADOS adaptations because she provided very concrete examples of a service that is culturally aware and mindful of valid adaptations. I wondered whether CAMHS professionals saw me as an 'institutional insider' and whether there was anything about my profession that made them perceive me as culturally sensitive.*

[12] *Whilst I am not surprised that cultural adaptation and awareness of sensitive practice were discussed only by outsider participants working in statutory services, I wondered whether this was a common practice across services serving Orthodox Jewish communities.*

Theme 5: Negotiating support through religious authority, trust and safety: This theme captures how participants perceived parental decisions to seek support as rooted in religious, cultural, and moral frameworks. They experienced help-seeking as a socially and religiously influenced process, driven by religious authority, trust, and the protection of values.
Several insider participants framed autism as *''G-d-given''* and described that decisions involving a child with disabilities often require rabbinic approval, underscoring the central role of religious authority in decision-making. MM explained:

''I need my rabbi to approve anything I do or whoever I go to speak to. I can't do anything unless my rabbi says yeah, that's a good course of action". (MM)

Here, seeking support is framed as a religious rather than a practical decision, with authority resting with religious leaders rather than with professional expertise.
According to insider participants, working with outsider professionals can raise concerns among parents due to cultural and religious differences. Evie shared a direct quote from a parent:

''They're less religious than I am [non-Jewish professionals], and they won't understand our way of life, and they'll contaminate my son somehow. Or they won't accept him, or they'll have a mix of boys and girls". (Evie)

Evie's account indicates that help-seeking behaviour is driven by an active effort to protect religious identity and boundaries. This implies that services might be assessed not only by what they can provide but also by the potential risks they pose.
Meir's insider perspective was that Jewish professionals may be perceived as more credible because they are assumed to be guided by shared religious values:

''The perception is that OJ professionals, being that their main goal is to serve G-d, will be more likely to have a fresh perspective on things, rather than simply parroting what the NHS policy happens to be at the time". (Meir)

Values and principles of secular services may be viewed as not aligning with community values and principles, thereby, professional authority is less credible for families from the community.
At the same time, insider participants also spoke about a powerful cultural pressure to appear 'perfect' which can make seeking support within the community emotionally risky. Elza explained:

''Talking to someone, not from the community, is safer in that way, because no one's gonna know that you're not perfect"… the culture is very much that we want to show that we are perfect and we are OK". (Elza)

While external services may be received as morally risky, they also offer anonymity and protection from community scrutiny. In this context, seeking support from an insider professional may expose imperfections and vulnerabilities, making help-seeking a careful negotiation between the risk of moral misalignment and social exposure.
Pearl similarly suggested that working with an outsider may facilitate disclosure:

''I'm not within their community, so sometimes it's easier for them to talk to me because I'm someone new". (Pearl)

Here, the distance from the community is understood as safety, grounded in confidentiality and unfamiliarity, and it protects community members from long-standing social consequences.
Taken together, these accounts illustrate the various aspects that participants understood parents need to consider when seeking support for their children. According to professionals, engaging with support requires families to carefully weigh religious, cultural and community factors, highlighting the dilemmas Orthodox Jewish parents face.

Theme 6: Autism as a whole-family challenge: The final theme captures participants' perceptions of caring for a child with autism as a relational and emotional challenge that can affect the entire family system. The challenge of caregiving with limited resources, particularly in the context of large families, was emphasised by all participants. Across accounts, autism was perceived as a struggle that can reorganise the functioning of a family unit and test the limits of coping over time.
Adina's insider perspective demonstrates how the ongoing needs of one child can contribute to chronic strain and exhaustion among other family members:

''When there's a child and a family that has ASD, that's having regular meltdowns, has been very difficult and really, really been challenging, then the other members of the family are very, very tested, so the household becomes weakened with literally weeks of havoc, and they're not coping". (Adina)

Her account suggests that the chaos is ongoing and uncontained rather than short-term. It can destabilise routines and coping capacities, and the usual strategies may not control the level of demand.
MM similarly highlighted the ''*impact on the other children at home''* and the uneven distribution of parental attention as direct consequences of care demands and limited time:

''A lot of times, and also the majority of the parents time is spent dealing with the children with autism, so those children who don't have additional needs often get overlooked. And they feel invisible, sometimes in their own homes and their own families. And, you know, and it builds resentment" (MM)

Her insider experience highlights a vital aspect of how siblings may feel unseen and unsupported. Moreover, services that focus solely on a child with challenges may inadvertently reinforce these

imbalances, as standard interventions may not provide relief if they are not designed to support large families.
Michael recalled a conversation with a father in a CAMHS setting responding to suggested behavioural strategies:

”I have 10 kids at home I don't have enough time in order to put in place these strategies for things [behaviours] to change… and you know I truthfully, was a bit stumped at that point. I thought yeah, that's a big point. How do we manage that?”. (Michael)

His reaction reveals a gap, particularly for someone outside the community, between intervention models and families’ lived realities, suggesting that approaches designed for smaller or differently structured families may not be realistic or accessible for strictly Orthodox families. In this context, families are unable to access services because the interventions offered do not align with family ecology.

Overall, these accounts illustrate the challenges large Jewish families may face in balancing the needs of a child on the spectrum with those of other children in the family home. Particular attention was given to siblings who might be overlooked, while the focus remains on the child with challenges due to parental constraints.

Perspectives of ‘Insiders’ and ‘Outsiders’

Across the themes, there was considerable convergence between insider and outsider participants. Both groups highlighted uneven knowledge of autism, the key role of language in shaping perceptions and acceptance, and the positive and negative consequences of diagnosis. Similarly, both groups emphasised the importance of trust, culturally responsive practice, flexible services, and recognition of autism’s impact on the entire family.

However, there were differences in how these issues were interpreted among participants. Insiders located limited access to knowledge within community-specific structural contexts, for example, restricted internet access. This positioned knowledge gaps as structurally determined rather than as reflecting families’ lack of awareness. Insider participants emphasised the diversity within the community, while outsider professionals tended to position themselves as learners, and their accounts emphasised adapting to the community, reflecting on how their own identities shaped their assumptions, and the importance of adapting clinical practice. Insiders provided context for the role of religious authorities and values as an important part of the parental decision-making process. Insider participants shared perspectives on how autism affects the wider family, and their accounts were closely connected to lived experiences, while outsiders drew on learning about family strain from their clinical practice.

Importantly, these positions were not fixed, and insiders interpreted the same issues differently, highlighting multiple perspectives. For example, one insider participant found the term ‘high functioning’ autism confusing, while another regarded it as reassuring. Positionality shaped what participants noticed and how they interpreted it.

CHAPTER 5. DISCUSSION

Chapter overview

This chapter summarises the main findings I have generated through RTA. Six themes and six subthemes were constructed to summarise participants' perspectives. The findings should be viewed as my construction, shaped by my experience and positionality. The findings are discussed in relation to the research questions and the existing literature, followed by an appraisal of the research, including its strengths and limitations. I will also offer clinical implications and dissemination plans.

Revisiting the research questions

To examine the experiences of professionals working with Orthodox Jewish parents and carers of children with autism, two questions were explored:

1. *What are the experiences of professionals working with Orthodox Jewish families who have children with autism?*

2. *Perspectives of professionals on the barriers and facilitators to obtaining a diagnosis of autism and accessing support services for Orthodox Jewish parents who raise autistic children.*

Summary of findings

The analysis presented six themes capturing participants' perspectives, linked by their perceptions of how families understand and accept autism, which are shaped by what autism means, what feels safe and acceptable, and the type of support that aligns with their cultural, religious and social contexts.

The first theme, ***''Autism awareness, knowledge, and negotiation of labels''***, highlighted participants' perceptions of disparities in access to information about autism in Orthodox Jewish communities. Unequal access to knowledge was attributed to a combination of cultural, individual, and structural determinants. Participants' understanding was that some families viewed autism through a deficit lens, suggesting severe impairment, due to limited familiarity with the condition and limited exposure to developmental frameworks. Language was crucial in shaping understanding of the spectrum. Diagnostic labels frequently carried social and emotional meaning, whilst terminology related to the individual's functioning created confusion. Theme two, ***''The meaning of diagnosis''***, captured participants' perceptions of carers' emotional reactions to diagnosis, including grief, relief, and denial. They also interpreted the diagnosis as a way to understand a child and as a practical tool for accessing support. Professionals perceived stigma associated with diagnosis in the community and its social implications, particularly its impact on marriage prospects and the family's reputation. Theme three, ***''Varied layers of knowing''***, highlighted the importance of reflexivity, self-awareness, curiosity, and recognition of diversity in understanding and supporting Orthodox Jewish communities.

Participants' perceptions of their knowledge of these communities were shaped by their insider or outsider status. Theme four, ***''Embedding cultural and religious awareness into practice''***, captured professionals' adaptations to appearance, communication, and assessment tools to align with cultural and religious norms. These adaptations were viewed as crucial for avoiding harm, building trust, ensuring the validity of assessments, and improving service accessibility.
Theme five, ***''Negotiating support through religious authority and trust''***, highlighted that help-seeking behaviour was understood as morally and socially guided, often requiring rabbinic approval. Services were assessed on the emotional and moral safety they could offer families, as well as on their expertise. Trust could be fostered by shared religious and cultural identity, or, conversely, by professional distance, which offered anonymity and protection from the community.
The last theme, ***''Autism as a whole family challenge''***, highlighted the impact of autism on the entire family system, understood as a relational challenge, particularly within large households. Professionals perceived chronic stress and uneven distribution of parental attention.

Link with existing literature

Autism awareness, knowledge, and acceptance of labels

Professionals' perceived variation in awareness of autism required flexibility in supporting parents, tailoring approaches to their existing knowledge and responsiveness to create a learning environment for those "*in the dark*", thereby facilitating access to diagnostic and support services within the mesosystem. These findings align with existing literature indicating that limited knowledge about autism can be a significant barrier to early diagnosis and accessing services. The literature on barriers to help-seeking among carers from ethnic minority groups accessing autism diagnostic and intervention services found that low autism literacy, defined as knowledge about autism and how to access relevant services (Khalil et al., 2025; Zuckerman et al., 2014) as well as claims that autism does not exist in some communities (Zuckerman et al., 2014) can impede early identification of difficulties. Professionals' awareness of misconceptions about visible indicators of disability could support parental understanding and improve access to services. This theme corroborates findings from the literature, which indicate that early developmental differences among minoritised communities are often misunderstood when parents' knowledge of typical development is low (Khalil et al., 2025) and when children are verbal or do not fit the stereotypical image of disability (Hussein et al., 2019). Additionally, individuals with no knowledge or experience of autism rely on visible or stereotyped cues of disability and often draw on normative assumptions about disability to make sense of it (Huws & Jones, 2010) a pattern the participants in this study perceived when autism was excluded based on the child's *''normal face''*. Notably, findings from this theme highlight the perceived use and meaning of language to describe autism, with some participants interpreting it as implying severe impairment. This may suggest that, before autism is mentioned to families, meaning is made based on a limited understanding, leaving little opportunity for further exploration. According to professionals, a sound understanding of autism among parents was attributed to lived experience of

autism, education and having access to the secular world, reflecting the microsystem. Working with Orthodox Jewish families required tailoring terminology and using it carefully, given the perceived harshness of the terms. Functioning labels were perceived as confusing, and if understood as implying that high functioning autism *''doesn't sound that bad''*, could further create a barrier to help-seeking. While the use of functioning labels has been reported in the literature to be misleading and clinically unhelpful (Kenny et al., 2016) participants' experience was that these were used by Orthodox Jewish parents. Participants in the study used needs- and behaviour-based language to facilitate engagement, which is important because people with autism can have a range of challenges, and their needs can change over time and present differently across situations and environments (Monk et al., 2022). Prioritisation of needs-led interventions, regardless of diagnosis, to allow families to get timely help and access services, as noted by a Jewish organisation supporting families of children with autism (Norwood, 2025).

The meaning of diagnosis

Participants perceived that receiving a diagnosis elicited a range of emotional reactions in parents, which required respectful responses. This is consistent with what is known about the complexity of the parental journey, including grief, denial and acceptance, following their child's autism diagnosis, which is well documented in the literature (e.g. Barak-Levy & Paryente, 2023; Phetoe et al., 2023) and universal for parents regardless of their religion or ethnicity. These findings align with those of the SLR outlined under Theme 2: The struggles of parenting and family life, *Subtheme: Parenting, identity and transformation.* In this research, diagnosis was perceived as a tool that supports carers' understanding of their child and as a facilitator of the diagnostic process. This aligns with findings from a similar study, in which professionals working with children with ADHD from the 'Ultraorthodox' community viewed diagnosis as a helpful way for parents to explain a child's behaviour as attributable to their specific challenges (Budman & Maeir, 2022). The study found that professionals perceived an autism diagnosis as a gateway to accessing post-diagnosis support; however, this finding should be interpreted with caution. Depending on the type of support, a diagnosis of autism is not always required to access services and educational, health, and social care needs can be accessed based on an individual's needs assessment, though this may vary across the UK (National Autistic Society, n.d.). Research, however, suggests that a lack of diagnosis can pose an immediate barrier to accessing support, even though the legislation ensures that support is not diagnosis-dependent (Crane et al., 2021) highlighting the role of the mesosystem. With that in mind, it has been documented that Jewish children without a diagnosis often face significant barriers to accessing support (Norwood, 2025). Moreover, the literature indicates that support provision can depend on carers' own learning and research and may be time-limited or end following a diagnosis (Milosevic et al., 2022) which, given the varied awareness of autism highlighted in theme 1, may be an additional challenge for parents to navigate.

Findings highlighted that diagnosis could have far-reaching systemic consequences for the child and the entire family, posing a dilemma for parents about whether to pursue it and potentially acting as a

barrier to accessing diagnostic services within the family and community microsystem. Participants perceived stigma associated with diagnosis as a direct threat to the child's marriage prospects, as well as to other children in the family.

This may be explained through Social Identity Theory (Tajfel & Turner, 1979) which suggests that individuals derive part of their identity and self-worth from their social group membership. When group identity and social reputation are particularly salient, a diagnosis perceived as stigmatising might extend beyond the individual child and be viewed as a potential threat to family's social reputation and future.

Cultural stigma towards developmental difficulties such as autism has been reported in the literature, referring to experiences of parents from ethnic minority backgrounds (Khalil et al., 2025). Research on mental health difficulties in Orthodox Jewish communities found that a label was experienced as having potentially lifelong repercussions (Rowland, 2016) and as affecting marriageability (Bayes & Loewenthal, 2013). However, Rowland (2016) found that although Orthodox Jewish parents acknowledged stigma, they prioritised the mental health needs of their children, and Orthodox Jews experiencing depression and anxiety utilised mental health services just as much as non-Jewish patients (Pirutinsky & Rosmarin, 2022). While autism related stigma has been documented in Orthodox Jewish communities (Budman & Maeir, 2022; Rowland, 2016; Shaked & Bilu, 2006) a gradual shift in attitudes has been found (Sher et al., 2022) alongside a significant increase in autism diagnoses (Norwood, 2025). The contrasting findings suggesting variability in autism-related stigma were also found in the SLR outlined in theme 4: *Conflicting views on stigma*.

Varied layers of knowing

Findings highlighted that participants who identified as outsiders navigated their work with families through self-reflection to challenge their assumptions. Whilst these accounts concern professionals who did not share a cultural background with families, it is important to consider the dynamics and potential clashes for professionals who identify as Orthodox Jewish. As found by Franklin and colleagues (2024), Orthodox Jewish therapists can experience difficulties accepting ideas that clash with their values while supporting Charedi clients. The current study found that non-Jewish participants adopted a curious stance and sought to increase their knowledge of Jewish culture to deliver culturally sensitive and relevant care, thereby facilitating access to services. Interpreting practices or behaviours within a cultural framework was crucial for overcoming barriers to understanding and facilitating engagement, drawing attention to the microsystem. These findings are important and add to the literature on professionals' awareness of their own ethnic background, values, and perceptions that may affect their relationships with clients, and on the importance of knowledge of clients' culture (Chau, 1990), especially in the context of the health care system, where the dominant culture may regulate which problems are recognised (Kirmayer, 2012). Additionally, cultural differences between professionals and clients can contribute to personal growth, humility and patience (Keidar et al., 2021).

Findings from insider participants underscored the importance of recognising heterogeneity within Orthodox Jewish communities, aligning with previous research emphasising variation within these communities (e.g. Rowland, 2016; Wikler, 2001). Additionally, an NHS project focused on improving access to healthcare for Jewish communities in England warned that recognising and understanding Jewish identity is crucial and that assumptions about homogeneity create barriers to identifying appropriate services (NHS Race and Health Observatory, 2024). Consistent with insider professionals' accounts, the diversity among subgroups of Orthodox Judaism may be difficult for outsiders to notice, yet it is taken very seriously among members of these subgroups (Wikler, 2001). A barrier to engagement can be a limited understanding of what it means to be Charedi, as captured in the literature, *''Being Haredi is beyond culture. It is something much deeper, much more complicated…''* (Band-Winterstein & Freund, 2015, p.980). If distinctions are not made and diversity is not fully understood within services, the risk is that the care provided may be irrelevant.
Positively, evidence suggests that therapists unaffiliated with 'Ultraorthodox' Jewish families can identify differences among subgroups by speaking with families and, as a result, adapt the intervention, for example by changing the language for Hassidic families (Golos et al., 2021). Cultural humility positions professionals as lifelong learners, open to families' cultural and religious contexts. It involves self-reflection, recognition of power imbalances, and partnering with communities, and it challenges the idea that professionals can acquire fixed cultural knowledge (Tervalon & Murray-Garcia, 1998) pointing to the importance of the mesosystem.

Embedding cultural and religious awareness into practice

Participants navigated support provisions by carefully and intentionally considering cultural, religious, and moral factors. Previous research has identified understanding family culture as crucial for service provision and as a facilitator of autism diagnosis and service access for underserved families (Stahmer et al., 2019). The SLR also found that Jewish parents valued culturally sensitive care, which is outlined in Theme 5: *Help-seeking and support in the face of challenges*. Outsider professionals reported being mindful of their appearance, for example, making sure elbows were not exposed and shirt covered knees, when working with strictly Orthodox families. These findings align with research highlighting the importance of secular professionals recognising the cultural needs of Charedi clients (Band-Winterstein & Freund, 2015) and of being aware of cultural differences to deliver successful and ethical interventions for Orthodox Jewish families and their children (Golos et al., 2021).
CAMHS professionals engaged with Orthodox Jewish families by consciously adapting interventions for example by giving parents tools to *"create own social stories"* and assessment tools to ensure their appropriateness for the community, thereby facilitating access to services within the mesosystem. This aligns with the approach of CBT therapists from Golker and Cioffi (2021), research who refrained from using resources or ideas that conflict with the religious beliefs of the Orthodox Jewish community.
Although research on the use of diagnostic instruments with minority ethnic, cultural, or religious groups is limited (Mandell et al., 2009) previous literature indicates that culturally inappropriate tools

can lead to mistrust of the diagnosis among parents from ethnic minority backgrounds (Weitlauf et al., 2024; Thang et al., 2025).

Negotiating support through religious authority and trust

Professionals perceived families' help-seeking behaviour as a process negotiated through religious authority, trust and moral indicators. Orthodox Jewish professionals in the study believed families would consult their Rabbi about their child's difficulties. The literature on Jewish parents seeking support from a Rabbi is inconsistent. While some 'Ultra-orthodox' carers in Belgium sought a blessing and advice from their Rabbi before deciding to access mental health services for their children (Schnitzer et al., 2011) others did not feel the Rabbi could help with their children's mental health difficulties and instead shared their concerns with family or friends (Rowland, 2016). Although the Rabbi was found to be someone families turned to, the SLR findings also identified other religious and secular sources of help-seeking in Theme 5: *Help-seeking and support in the face of challenges*, reflecting the influence of the microsystem.

According to participants in this study, the dilemmas parents may face when seeking help include the worry that a secular professional would not understand their way of life, as also reported by 'Ultra-orthodox' carers (Schnitzer et al., 2011). Similarly, Orthodox Jewish therapists working with Charedi adolescents perceived that their clients sought support from them because they could offer culturally and religiously relevant care grounded in shared values (Franklin et al., 2024). Participants also perceived that working with someone not from the community may be safer and less likely to expose their imperfections.

These findings can be understood through a relational conceptualisation of trust within the mesosystem, which develops through family-professional interactions and is shaped by expectations of the relationship, mutuality, and the professional's perceived intention (Lynn-McHale & Deatrick, 2000). From this perspective, families might be willing to discuss concerns if they perceive the professional as trustworthy, culturally understanding, and respectful of their values and confidentiality. Conversely, perceived differences or concerns about being misunderstood may hinder engagement. Additionally, the literature reports the importance of preserving confidentiality within the community and the consequences of being seen as a failure or inadequate when seeking support from services (Loewenthal & Rogers, 2004). Orthodox Jewish individuals, particularly women, may be concerned about not being seen as perfect and capable of managing the household, children, and daily life (Loewenthal & Rogers, 2004). However, working with an 'outsider' may also affect how willing children and their families are to disclose (Keidar et al., 2021). Working with outsider professionals can both facilitate and be a barrier to engagement in diagnostic and intervention services.

Autism as a whole family challenge

Professionals navigated work with strictly Orthodox Jewish families amid perceived complexities in care demands, limited time, and difficulties affecting household functioning. Research found that challenges associated with raising a child with autism may strain family functioning and engagement in social rituals and traditions, which are crucial for maintaining cohesion and stability (Ağırkan et al., 2023). Challenges in family functioning were also identified in the SLR under Theme 2: Subtheme: *Challenges and changes in family life*. Professionals highlighted families' struggle to cope and observed unrealistic, hence unhelpful, strategies that may not work for large families, which can act as a barrier to accessing support. These findings echo the importance of whole-family support, including siblings, as highlighted by the Norwood charity (Norwood, 2025). The importance of considering family routines, when planning interventions was highlighted by Golos et al. (2021). Gaining a good understanding of families' habits and routines seemed pivotal, and considerations were given to gender norms, such as boys having a long day at school and a hectic home environment which may mean that implementation of strategies creates a further burden rather than help (Golos et al., 2021) highlighting the influence of the microsystem.
Participants perceived that due to care demands, siblings may be overlooked and *''feel invisible''* which in turn can create resentment. Research indicates that siblings of a child with autism have to grow up faster, take on more responsibilities, and receive less attention from their parents (Petalas et al., 2012; Fletcher et al, 2012; Molinaro et al., 2020). Whilst this was not observed by professionals in the study, research also found that children without additional needs may be exposed to violence and aggression, which may lead them to feel anxious or unsafe (Benderix & Sivberg, 2007).

Quality appraisal

A CASP (2018) was utilised to appraise the current study, in line with the appraisals of the studies reviewed in the SLR and can be found in Table 12

Table 12

A critical appraisal of the current study

Questions	Yes, No, Can't tell	Evidence for meeting CASP criteria
Was there a clear statement of the aims of the research?	Yes	The study aimed to explore the experiences of professionals working with children with autism and their families from Orthodox Jewish communities in Britain. The aims and research questions are stated in Chapter 2.
Is a qualitative methodology appropriate?	Yes	Since this is a novel and exploratory study, the qualitative method was suitable as it allowed for gathering detailed data on professionals' experiences working with Orthodox Jewish communities.
Was the research design appropriate to address the aims of the research?	Yes	The use of semi-structured interviews enabled an in-depth exploration of professionals' experiences. Choosing the Reflexive Thematic Analysis provided flexibility and a transparent stance, which aligns with critical realist epistemology.
Was the recruitment strategy appropriate to the aims of the research?	Yes	A combination of purposive and snowball sampling was used to enhance participant recruitment. Snowball sampling was particularly effective, given the study's aim to reach underserved groups facing systemic barriers to participation (Törnävä et al., 2025).
Was the data collected in a way that addressed the research issue?	Yes	Data was collected through semi-structured interviews, which were piloted before being used in interviews. Full details can be found in Chapter 3
Has the relationship between the researchers and participants been adequately considered?	Yes	A detailed ''in-betweener'' positionality (Chhabra, 2020) is provided, detailing bias, assumptions, and how they may influence analysis, allowing the reader to consider findings within context. This was documented through reflexivity (discussed in Chapter 3), reflexive comments are included throughout Chapter 4 and additional excerpts are provided in Appendix L.
Have ethical issues been taken into consideration?	Yes	Ethical considerations have been central to this inquiry. The study received ethical approval from the University of Hertfordshire (Appendix X). A decision to change the project's topic was made collaboratively with the research team in response to a rise in antisemitism following the war that began in 2023. Given the sensitive nature of the topic, efforts were made to minimise potential harm to parents, and the focus shifted to professionals, as detailed in Chapter 1. The ethical considerations are outlined in Chapter 3. Attention was paid to how quotes were presented and how demographic information was reported to protect anonymity

Was the data analysis sufficiently rigorous?	Yes	Supervisors were involved in reviewing the development of the themes. Themes were discussed with the supervisors allowing for reflexions to be considered in analysis
Is there a clear statement of findings?	Yes	A summary of the research findings can be found in Chapter 4. 6 themes and 6 subtheme were generated and answer research questions
How valuable is the research?	Yes	The current study is believed to be the first to explore the experiences of professionals who work with children with autism and their families from Orthodox Jewish communities in the UK. Chapter 5 discusses professionals' perspectives on barriers and facilitators to obtaining an autism diagnosis and accessing support services, together with clinical implications

Strengths and limitations

Strengths

To my knowledge, this project is the first to examine, from professionals' perspectives, the barriers and facilitators to accessing diagnostic and support services for Orthodox Jewish families raising children with autism in the UK. This is important research, given the prevalence of autism, the rising number of strictly Orthodox children whose needs may not be timely recognised and the underrepresentation of Jewish communities in research. This research also has clinical implications for services and professionals working with Jewish families and, if implemented, can help provide more relevant and culturally sensitive support.
The study collected rich data from a heterogeneous sample that varied by professional role, religion, and region across the country. Exploring professionals' perspectives offers a broader, system-level view of recurring barriers and facilitators and provides insight into the organisational and systemic contexts. Professionals' accounts may therefore illuminate how those experiences are understood within the professional and service contexts in which families navigate support.

Overall, perspectives were provided by professionals with backgrounds in education and health and social care. This is a definite strength, as they represented diverse settings and worked with children and families at different stages of their journey in two regions of the country with the highest number of Orthodox Jewish communities.

Moreover, four of the nine participants identified as Charedi, and two others as Jewish. Some Charedi participants held multiple roles and, in addition to their professional positions, were parents or family members of children with autism, offering a wealth of insight from an insider perspective grounded in lived experience. Professionals who identified as outsiders and worked in statutory services offered their perspectives on diagnostic and support needs. Importantly, some findings from the empirical study aligned with those identified in the systematic literature review, strengthening the reliability and validity of the generated themes.

The research team, comprising the EbE consultant and an insider secondary supervisor, was a strength of this project. The study was informed by collaboration with members of the strictly Orthodox community, including a Rabbi and charitable organisations. The research was guided by real clinical dilemmas shared by the consultant, which shaped its focus on barriers and facilitators to diagnostic and support services. Initially, recruitment was supported by respected members of the community, which may have instilled trust.

Lastly, RTA was a well-suited method for exploring an under-researched topic (Braun & Clarke, 2006). Transparency about my ‘’in-betweener’’ positionality and reflexivity were strengths, and I

considered and reflected on them. My perceived insider perspective among participants who worked in CAMHS settings may have provided a shared language and a more nuanced understanding of their experiences. Among insider participants, my ethnic background may have positioned me as an ally or as someone trustworthy, given that some participants had relatives in Eastern Europe.

Limitations

This study must be viewed in light of its limitations. Firstly, the small sample (N=9) limits the generalisability of the findings. A limited demographic and professional background information was collected, raising concerns about the transferability of the findings. In particular, no information was collected on participants' breadth and depth of professional experience, knowledge of autism, or extent of experience within Orthodox Jewish communities, all of which would have influenced their experiences and perspectives and should be considered when interpreting the findings. Given the interconnected and potentially identifiable nature of Orthodox Jewish communities, where some individuals may have occupied distinctive roles or worked within their small community networks, collecting extensive participant demographic information may have increased the risk of deductive disclosure (Kaiser, 2009; Tolich, 2004). In consultation with the research consultant, demographic data were limited to information considered necessary for describing the sample and its relevance to the findings, to balance the methodological value of participants' characteristics with the ethical obligation to protect confidentiality.

Another important limitation is that the study relied on professionals' perspectives on parental experiences. Participants' accounts may be shaped by their professional training, organisational context, and assumptions about autism or parental support-seeking, thereby privileging a service-based understanding of parental experiences. Participants may have had particularly positive or negative experiences of working with OJ communities; hence, their accounts may not reflect the full range of professional perspectives. Consequently, professionals' experiences should be understood as interpretations of carers' experiences rather than as representations of parents' voices.

As most participants were mental health professionals, their perspectives may not represent the experiences of other professionals working with Orthodox Jewish individuals, such as GPs, paediatricians, or nurses, who may be in a position to notice early concerns related to autism and may also have more involvement with younger children.

Furthermore, participants with experience of working in CAMHS services were from the psychological professions (clinical and assistant psychologists). As their profession requires engagement in reflexivity and awareness of bias and assumptions (British Psychological Society, 2024) their responses may have been influenced by their professional training and expectations. Moreover, since

they were all non-religious, they may have been more consciously aware of differences, which might have led to more thoughtful perspectives.

Whilst the contributions from the EbE consultant and members of the Orthodox Jewish community were invaluable and implemented wherever possible, there was a wish for this research to be more meaningful to the community. Specifically, they hoped to see tangible changes for families and their children. The fact that I was completing a doctoral-level qualification and was bound by deadlines, limited funding, and time meant that I was unable to meet their expectations in full. Whilst the limitations of this research were made clear from the beginning and throughout the project, I acknowledge that some conversations may have felt tokenistic at times.

A further limitation to note is that, because it was advertised online, it may have captured the perspectives of strictly Orthodox Jewish professionals who used the internet, thereby excluding those without access to these platforms and potentially missing valuable insights.

Given my background and professional roles, I approached this research with preconceptions about participants' experiences. To address this, a reflexive diary was kept throughout the research, but this may not have fully mitigated the risk.

Although the interview schedule was pilot-tested prior to conducting interviews, on completing the analysis it became apparent that some questions asked did not add value, for example, questions about private autism assessment, as only a small number of participants were able to provide detailed perspectives, and their answers on the topic were not used in the analysis.

Clinical implications

The clinical implications of this research's findings can be considered within Bronfenbrenner’s Ecological Systems, recognising that responsibility for improving access and engagement is distributed across multiple levels, including families, professional networks and wider organisations.

While it is common for parents to first notice developmental variations in their child (Crane et al., 2018) caution should be applied in the case of Orthodox Jewish families, and baseline knowledge of autism should not be assumed. At the microsystem level, professionals working with Orthodox Jewish families are responsible for building trusting relationships and adapting communication to families’ needs and understanding. They would benefit from using concrete, needs-based, focused language, as diagnostic language that does not align with community meanings can lead to misunderstandings and disengagement rather than facilitating understanding. To strengthen relationships with carers, professionals may benefit from asking about their observations of their child’s behaviour or

communication and by showing curiosity about how such differences are understood within their community context. This approach may help create a collaborative space for exploring families' perspectives.

Within the mesosystem, consistent communication across the professional network is key, with responsibility shared among professionals from statutory and voluntary services, schools, and community organisations. Careful consideration of terminology can help ensure that language serves as a bridge rather than a barrier to engagement. Professionals would benefit from exploring the language families feel most comfortable with, which can support relationship-building and may offer a gentle, respectful introduction to the term 'autism'. This is particularly important, as increasing autism literacy among caregivers from ethnic minority backgrounds is essential given the importance of early identification and intervention (Khalil et al., 2025). Drawing on recommendations from Khalil and colleagues (2025) autism-related information could be disseminated through psychoeducation in Jewish communities, in collaboration with parents, community professionals, and religious leaders, ensuring a whole-system approach (Perry et al., 2018). At the macrosystem level, this requires recognition of the wider cultural and religious values that may influence how professional support is understood. To ensure that materials distributed to families do not cause worry about heresy, these could be approved by a Rabbi beforehand (Kada, 2019). Strengthening the relationship between the community and stakeholders could help increase trust in statutory services within the Charedi community and reduce the underutilisation of NHS services (McEvoy et al., 2017). As Conde et al. (2005) suggest, stakeholders could gather information from families about interventions and the relevance of the cultural context, together with professionals experienced in specific interventions, given that culturally adapted interventions are associated with greater effectiveness than non-culturally adapted ones (Griner & Smith, 2006). Given the substantial variations within the strictly Orthodox community (Milevsky et al., 2011), curiosity, respect, and tools such as the Cultural Formulation Interview (American Psychiatric Association, 2013) could be used by professionals across diagnostic and support services. Embedding cultural factors and interpretations into assessment and formulation could be crucial to ensuring that Jewish communities are not viewed as homogeneous. Treating religious or cultural groups as homogeneous risks misaligned interventions and reduced effectiveness (Hackett et al., 2020). Following diagnosis, professionals may consider offering a follow-up session to allow parents to revisit information once initial emotions have settled, thereby supporting ongoing engagement between families and services. Professionals working with Orthodox Jewish families should be mindful that concerns about stigma, including potential marriage-related implications, may influence how some families engage with services. While experiences of stigma may vary across communities, it is crucial to create opportunities for discussion about stigma, which may help strengthen trust and support carers in making decisions about their child's needs and in balancing community expectations.

Parents may benefit from clear guidance on available support pathways, both with and without a formal diagnosis. Professionals could offer a collaborative exploration of direct referral options with parents, rather than expecting families to self-refer, while remaining sensitive to differing preferences

regarding involvement and autonomy. At the exosystem level, services also have a responsibility to consider how service structures, processes and referral pathways may create or reduce barriers to engagement. This may include taking into account individual circumstances, such as the availability of professional support. This may be particularly important, as some Jewish families described the process of securing an EHCP without professional help as lengthy and challenging, particularly where SENCO support is limited (Norwood, 2025). To promote a systemic approach, family-based interventions could be considered where possible. One example is the manualised Systemic Autism-related Family Enabling (SAFE) intervention for families of children with autism. SAFE aims to help families build on their strengths and enhance their problem-solving and coping strategies to manage everyday challenges (McKenzie et al., 2019). Although it may not be feasible to implement such interventions across services, the principles underpinning a whole-family approach should remain central at organisation level and be recognised by all stakeholders when working with families from Orthodox Jewish communities, as the ecological perspective recognises that supporting the child requires consideration of the wider family system in which the child is embedded.

The chronosystem highlights the importance of considering how the needs of Orthodox Jewish families may change over time, including their family circumstances and socio-political contexts. Consequently, it would be the responsibility of professionals working with families to revisit support needs rather than viewing them as a single intervention following diagnosis.

Future research

The current study focused on professionals' perspectives, which echoed several findings from the systematic literature review of parental experiences. Future inquiry could examine parents' accounts of raising a child with autism, as originally envisioned for this project. However, it is recognised that such a project requires careful planning and time to ensure trustful and respectful engagement with families.

Several participants held multiple roles, including being members of the Orthodox Jewish community, parents of children with autism, and professionals supporting families within the community. Further exploration of how these intersecting identities are experienced and managed would be valuable, as they may present both unique opportunities and challenges. This is particularly important, as majority of OJ participants in the current study with lived experience of autism also worked in professional roles supporting families of children with autism. The boundaries between the professional and personal lives of Orthodox Jewish professionals working with Charedi families may require careful navigation.

Given that educational settings are often the first point of identification of neurodevelopmental differences, future research could examine how SENCOs communicate their observations to Orthodox Jewish families. This is particularly significant in light of findings that language and awareness of autism can both hinder and facilitate support-seeking and engagement. SENCOs

occupy a critical role between schools, families and outside professionals hence, gaining their insights could shed light on how these concerns are identified and communicated.

Dissemination

Dissemination involves distributing research outputs to relevant audiences, including communities, academics, or policymakers, through traditional methods such as peer-reviewed articles, seminars and conferences. Dissemination and communication of research should be considered a fundamental component of any research project (Marín-González et al., 2017). The thesis will be publicly accessible online via the University of Hertfordshire Research Repository.
In recognition of the contributions of professionals who participated in this study and of members of Orthodox Jewish communities who supported this project, I intend to publish both the thesis and the SLR in a peer-reviewed journal relevant to the topic. The identification of appropriate dissemination channels was informed by input from EbE, ensuring the findings would be shared in ways that are meaningful and accessible to the communities concerned. A Jewish newspaper, *'Hamodia'*, which is specifically designed for the Charedi community, will be approached regarding publication of an article summarising the findings. Summaries will be shared with relevant CAMHS teams that support Orthodox Jewish communities in the UK, for example, in Hackney and Gateshead. Additionally, findings will be disseminated to organisations that provide support to Jewish families, such as the Jewish Community Council of Gateshead (JCCG), Gateshead Jewish Family Service and Norwood in London. An effort will be made to submit a report to the Board of Deputies of British Jews. This is particularly relevant, as deputies represent synagogues and communal organisations, including social welfare charities, regional councils, and youth movements. Finally, an invitation from BPS West Midlands to write an article has been received, and the article will be completed in due course.

Conclusions

The findings of this study, from the perspective of professionals, highlight barriers and facilitators to obtaining a diagnosis of autism and accessing support among Orthodox Jewish parents of children with autism. The results indicate various religious and cultural factors that should be considered when working with Orthodox Jewish families. Although distinct, barriers and facilitators often overlap and do not fit neatly into categories, reflecting the complexity of Orthodox families' lives. While it is important for those who support these families to be aware of the nuanced, multidimensional aspects of their religion and culture, it is unrealistic to expect every professional to have a comprehensive understanding of these complexities. A recommended approach for professionals is *''to take the position of not knowing and curiosity''* to foster a culture of collaboration, compassion, and openness to learning from Orthodox communities, enabling them to deliver culturally relevant and sensitive care.

Final thoughts

Throughout the study, I experienced a range of emotions, from hopelessness to gratitude. Initially, I felt discouraged by the lack of responses and unanswered phone calls. However, these feelings gradually shifted to encouragement and optimism as my inbox filled with questions and offers of support for this project. I continue to hope that Orthodox Jewish families have access to support systems that are both culturally sensitive and relevant. The complexities highlighted by this research require significant attention and ongoing collaboration between Orthodox Jewish communities and service providers. While hope is important, meaningful change requires systemic and institutional commitment. This project sets a direction for further exploration. I trust that it also serves as a reminder that although something may appear difficult, it does not mean it is impossible. To conclude with words of one Charedi teacher *"This will not be easy, but once you see how many people are prepared to share, you will know it was worth it".*

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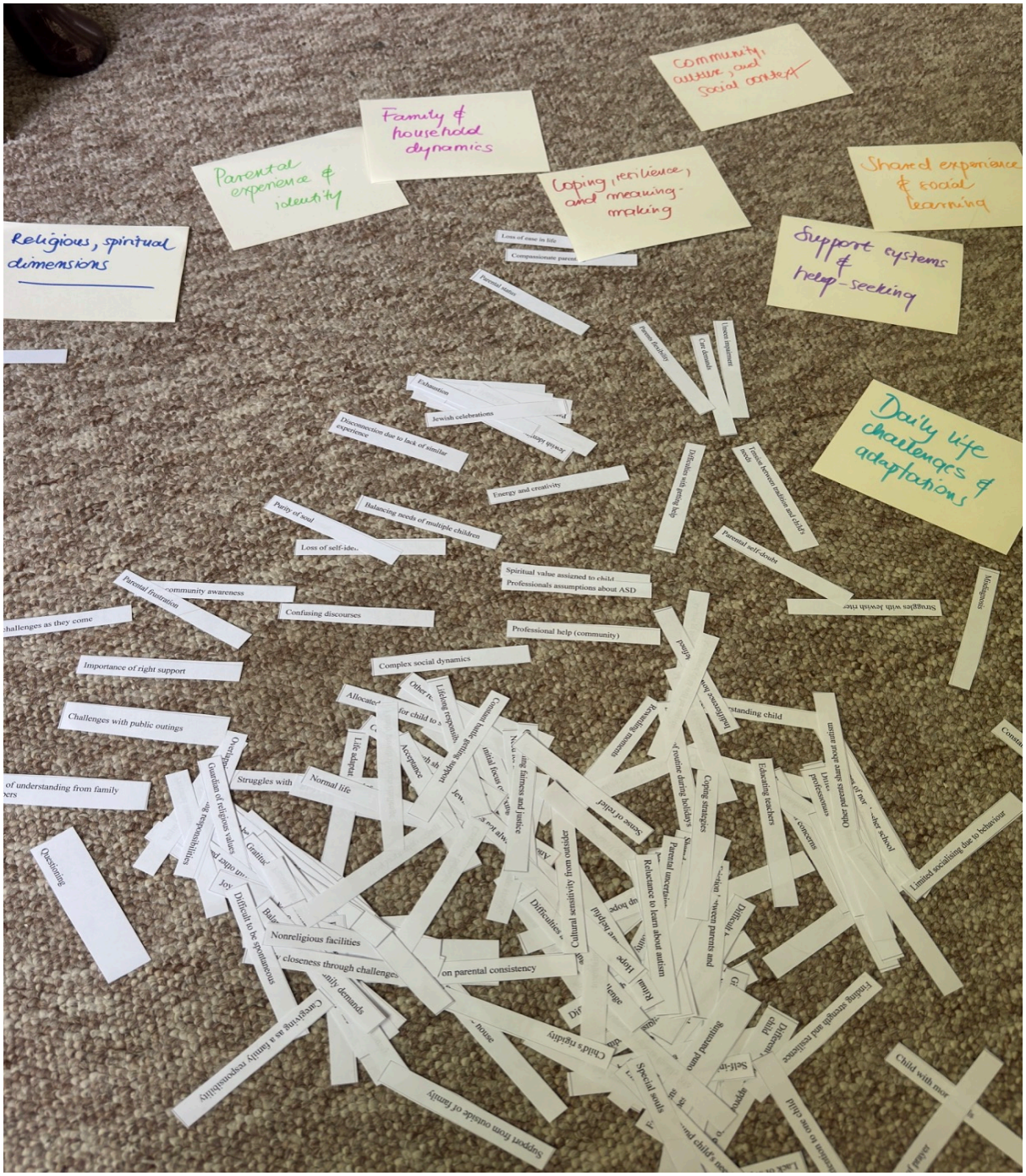
APPENDIX A PRISMA checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	N/A
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	N/A
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	P25
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	P25
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	P29
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	P28
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	P28
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	P30
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	P30
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	P30
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	N/A
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	P32
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	N/A

Section and Topic	Item #	Checklist item	Location where item is reported
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	P30
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	P46
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	P44
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	P32
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	P33
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	N/A
Study characteristics	17	Cite each included study and present its characteristics.	P35
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	P42
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N/A
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	P42
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A

Section and Topic	Item #	Checklist item	Location where item is reported
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	P53
	23b	Discuss any limitations of the evidence included in the review.	P56
	23c	Discuss any limitations of the review processes used.	P56
	23d	Discuss implications of the results for practice, policy, and future research.	P57/58
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	P27
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	N/A
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	N/A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

APPENDIX B SLR themes development



APPENDIX C AACODS tool

AACODS		YES	NO	?
Authority	Identifying who is responsible for the intellectual content. **Individual author:** • Associated with a reputable organisation? • Professional qualifications or considerable experience? • Produced/published other work (grey/black) in the field? • Recognised expert, identified in other sources? • Cited by others? (use Google Scholar as a quick check) • Higher degree student under “expert” supervision? **Organisation or group**: • Is the organisation reputable? (e.g. W.H.O) • Is the organisation an authority in the field? **In all cases:** • Does the item have a detailed reference list or bibliography?			
Accuracy	• Does the item have a clearly stated aim or brief? • Is so, is this met? • Does it have a stated methodology? • If so, is it adhered to? • Has it been peer-reviewed? • Has it been edited by a reputable authority? • Supported by authoritative, documented references or credible sources? • Is it representative of work in the field? • If No, is it a valid counterbalance? • Is any data collection explicit and appropriate for the research? • If item is secondary material (e.g. a policy brief of a technical report) refer to • the original. Is it an accurate, unbiased interpretation or analysis?			

Coverage	All items have parameters which define their content coverage. These limits might mean that a work refers to a particular population group, or that it excluded certain types of publication. A report could be designed to answer a particular question, or be based on statistics from a particular survey. • Are any limits clearly stated?			
Objectivity	It is important to identify bias, particularly if it is unstated or unacknowledged. • Opinion, expert or otherwise, is still opinion: is the author's standpoint clear? • Does the work seem to be balanced in presentation?			
Date	For the item to inform your research, it needs to have a date that confirms relevance • Does the item have a clearly stated date related to content? No easily discernible date is a strong concern. • If no date is given, but can be closely ascertained, is there a valid reason for its absence? • Check the bibliography: have key contemporary material been included?			

Significance	This is a value judgment of the item, in the context of the relevant research area • Is the item meaningful? (this incorporates feasibility, utility and relevance) • Does it add context? • Does it enrich or add something unique to the research? • Does it strengthen or refute a current position? • Would the research area be lesser without it? • Is it integral, representative, typical? • Does it have impact? (in the sense of influencing the work or behaviour of others)			

APPENDIX D PROSPERO amendments

Updated version	**Original version**
Inclusion: - Parents or primary caregivers of autistic children who identify religiously or culturally as Jewish, including diverse Jewish communities (e.g. Orthodox, Reform, Secular) - Studies where all participants identify as Jewish - Papers which include experiences of other populations (e.g. teachers/professionals) together with parental experiences where direct quotes from parents can be extracted - Research exploring the lived experiences of Jewish parents/caregivers raising a child with autism (formal diagnosis (including PDD, Asperger's etc.) or suspected ASD) - Papers where the primary focus is on autism, not on co-occurring difficulties - Papers where children are up to 25 years old **Exclusion** - Papers where Jewish identity is not explicitly specified - Studies where not all parents are Jewish - Studies where the primary focus is on co-occurring difficulties, not autism - Papers where children are older than 25 years old - Papers where full texts are not available - Non-English papers - Systematic, meta-analyses, and literature reviews	Inclusion: -Parents or primary caregivers of autistic children who identify religiously or culturally as Jewish (biological, adoptive/foster) -Studies including diverse Jewish communities (e.g. Orthodox, Reform, Liberal) -Studies with direct quotes from parents/carers related to autism, themes/focus related to autism -Studies where all participants are Jewish -Research exploring lived experiences of Jewish parents/caregivers raising a child with autism -Research with a focus on the experience of what parents said about raising their children, first-person accounts, stories **Exclusion:** - Papers where religion of parents is not explicitly specified and where it is not clearly stated that children are autistic (e.g. described as neurodivergent) -Papers where children experience other co-occurring conditions e.g. ADHD, dyslexia, OCD alongside autism and it is not possible to be certain which experiences are related to autism alone -Research focusing on educators, therapists or healthcare providers -Papers where full texts are not available -Non-English papers -Systematic, meta-analyses, and literature reviews. -Studies where not all participants are Jewish

APPENDIX E Interview schedule 1

Identification and help-seeking

What is the OJ community approach to autism?

What is the (parental) awareness of autism within the OJ community?

Is there a stigma in the community related to autism?

-Follow-up question: If so, what role might stigma play in how ASD is discussed/thought of?

How do parents react when/if you suggest that their child exhibits autistic traits/might be on the spectrum?

Do parents talk about developmental concerns related to autism?

Prompt (e.g. social interactions, speech and language delays, repetitive behaviours)

If yes, what do they hope to achieve by sharing these concerns?

Prompt (e.g. support, referrals)

If not, why may they not talk about their concerns?

What makes sharing concerns and seeking support easier? What helps?

What makes sharing concerns and seeking support harder? What is a barrier?

Diagnosis and post-diagnostic support

Do you think it is helpful for parents to find out their child is on the spectrum?

Why may it be unhelpful for parents to find out their child is on the spectrum?

Do parents choose to diagnose their child privately or via NHS?

Why might they get a diagnosis privately?

What support (if any) do you provide to children on the spectrum?

What support is available to parents?

What support do parents ask for? Do they engage with support?

What are the challenges with delivering support to parents?

What makes supporting parents from the community successful?

What makes it unsuccessful?

What would you need to provide effective support to parents from the community?

APPENDIX F Interview schedule 2

Identification and help-seeking

Do/did you see many parents/carers from the orthodox Jewish (OJ) community in your service?

If, not, why do you think that may be?

How aware is the OJ community of autism?

How are difficulties associated with ASD talked about in the community? (e.g. social interactions, speech and language delay, behaviour)

How might stigma play a role in how ASD is discussed/thought of?

Do/did parents initiate referrals to your service?

If yes, what are their expectations from the referral?

If not, how do they feel about the referral?

What makes seeking support easier? *facilitator*

What makes seeking support harder? *barrier*

Diagnosis and post-diagnostic support

Are/were you involved in the assessment/diagnostic process?

If, yes, what is/was your role in the process?

How is/was the diagnosis communicated to parents?

What might the diagnosis mean for the family?

Do parents choose to diagnose their child privately or via NHS?

Why might they want to do it privately?

How does your service reach out to families?(for example, to invite to groups or other forms of support)

Are these attempts successful?

If yes, what support does it provide, and what are their hopes/expectations?

If not, why might these attempts be unsuccessful?

How do you/your service adapt support for the OJ community?(give examples)

What would staff need to provide effective support to parents from the OJ community?

APPENDIX G Research poster

University of Hertfordshire UH

Call for participants

Do you support children with autism and their families from the Orthodox Jewish community?

What is the study about?

We are conducting research to understand professionals' perspectives on the needs of Orthodox Jewish families raising children with autism. We hope this research will contribute to a better understanding of support needs and will inform services in the community.

Are you?

- 18+ ?
- An educational or healthcare professional who works/has worked with children with autism and/or their parents/carers from the Orthodox Jewish community?
- Fluent in English?

What will you need to do?

You will be invited to participate in a 1:1 interview online (via Microsoft Teams) or in person at a location of your choice. The interview will last up to 70 minutes, and participants will be reimbursed for their expenses.



Who am I?

My name is Paula Nyklewicz, and I am a 3rd year Trainee Clinical Psychologist at the University of Hertfordshire. For more information or to join, please contact me at pn22aau@herts.ac.uk

This study has been approved by The University of Hertfordshire Health,Science, Engineering and Technology ethics committee with delegated authority. The UH protocol number is :**02782024 Dec HSET**

APPENDIX H ETHICS AMENDMENTS

Dear UH Ethics Committee,

Subject: Response to concerns and questions regarding the study 0278: *Experiences of Professionals Supporting Autistic Children and Their Families in Britain's Orthodox Jewish Community*

Thank you for taking the time to review our application for ethical approval. The feedback on the application is greatly appreciated and based on this, I have updated the online form accordingly. I am writing to clarify the matters you raised and provide more context to ensure our study aligns with the highest ethical standards.

The experiences for the OJ community and rise in anti-semitism will need consideration with regards the ethics of the design. How will risks in further marginalising OJ communities be considered?

Having a research team including members of the Orthodox Jewish (OJ) community has always been a priority to ensure stakeholders from within the community have a voice in directing and co-producing the research. Involvement from the community has also ensured consideration of cultural sensitivity and ethical principles in how we conduct this study while being aware of the broader political climate. The extensive discussions about his project, including the design and recruitment, have been taking place since 2023 with stakeholders, including [redacted] from the OJ community and the project's consultant, [redacted] the OJ community [redacted] members of the community. Additionally, we have spoken with clinicians from the NHS who work in the area. The project design was adapted based on their feedback. In the beginning, this project was intended to focus directly on the experiences of parents from the Orthodox Jewish (OJ) community who raise autistic children, as it was felt these were the most important voices to capture. However, we re-evaluated this idea considering the world events and political climate and concluded that this would have been too challenging at the present time and changed our focus to professionals working with the OJ community. This was in line with guidance from our wider research team.
While professionals recruited for the study may or may not be from the OJ community, we hope that our findings will benefit the OJ community and inform services in the area. We are very aware of heightened concerns about anti-semitism and carefully considered how to approach organisations and services which work with the community. We considered safety in terms of potential places for interviews and will be guided by participants' own preferences on where to conduct the interview in order to ensure feelings of safety around taking part. We are respectful of religious practices and will not schedule interviews around participants' religious observances (if they happen to be Jewish).

The last research question should be more clearly phrased: e.g., From the perspective of professionals, what are the barriers and facilitators to obtaining a diagnosis of autism and accessing support services for Orthodox Jewish parents who raise autistic children?

This has now been changed to : *" Perspectives of professionals on the barriers and facilitators to obtaining a diagnosis of autism and accessing support services for Orthodox Jewish parents who raise autistic children?"* the online ethical application form has been updated.

Ethics of approaching OJ schools at a time of increased anti-semitism and violence to the community. How will this be managed and supported?

The researcher will not approach schools without seeking advice and support from trusted members of the community/staff/professionals who work with schools/other organisations in the community. Once permission is gained, the study poster will be shared. The debrief sheet was updated and now includes contact details of an organisation which helps those who are victims of antisemitic hatred, harassment or bias (CST Protecting our Jewish Community).

Purposive sampling will be used to recruit professionals who have experience working with autistic children and/or their parents from Britain's Orthodox Jewish community.
Inclusion criteria:
Adults over 18, mixed gender. Healthcare and education professionals who work/have worked with autistic children and/or their parents from the Orthodox Jewish community in Britain. Participants will be required to be sufficiently fluent in English, however English does not need to be their first language. Participants can identify with any religion and ethnicity (they are not required to be from the OJ community). Participants will not be required to currently work with autistic children and/or their families from the OJ Community as long as they have past experience.
Exclusion criteria:
Professionals who have never worked with autistic children and/or parents from the OJ community in Britain.
The online ethical application has been updated with these criteria.

The researcher should not approach any potential participants before they have given consent for any information about them to be shared. Someone can identify and give information to potential participants, but this cannot be the researcher. The interested potential participants will have to approach/contact the researcher themselves.

The recruitment strategy will be based on contacting organisations and managers/professionals working in healthcare/education in [redacted] and our recruitment approach is based on targeting services/professionals based on their occupation and geographical location. This means that we are interested in interviewing professionals who work with the Orthodox Jewish community and are not necessarily members of the community. However, given the nature of the geographical areas, it is expected that some of those professionals who work with the community will happen to be members of the community. If participants are members of the community, [redacted]
With the help of the research consultant, [redacted] we have already made links with schools, community organisations and professionals in the community, with some of these agreeing to be contacted about potentially being involved in the study once it receives ethical approval. We understand that any organisation or professional may change their minds about taking part, and participation will be entirely voluntary.
From stakeholders' feedback, we understand that trust and familiarity within the community and between professionals who work with the community are essential, and we endeavour to respect and maintain this in how we go about conducting this research. We hope to employ snowball sampling with participants who are comfortable with connecting the researchers with potential recruits. Professionals will also be identified and recruited via social media by sharing the poster and giving information about the study (platforms such as X, Linkedin or Instagram), academic institutions- other Clinical Psychology courses in the country, networks of professionals (e.g. ''Psychologists for Social Change'') and personal contacts.

The HRS/REC approval for this study will not be required as it will not be taking place in the NHS and we will not be identifying or recruiting NHS staff from NHS staff records or by contacting NHS staff via an NHS organisation. NHS staff can participate in this research if they are not identified or recruited via the methods specified above. This research does not require NHS confidential or otherwise privileged information. This is taken directly from the NHS Health Research Authority Student research toolkit. The online ethical application has been updated with this information.

The risk assessment should include consideration of travel and lone working for any interviews that will conducted face-to face with participants in various locations.

The risk assessment has been updated, and the lead researcher will follow policies for lone working (NHS,UH) and will be in telephone contact with the supervisor. For more details, please see an updated version uploaded to the online ethical application.

The advert has the £20 incentive on it. Please remove. Also, please follow the advisory on this system about including space for information about the ethics approval of this project (name of the approving ECDA and space for the UH protocol number).

We have now removed a reference to £20 payment for participation in the advert. The name of the approving ECDA and the space for the UH protocol number are on the poster. An updated version has been uploaded to the online ethical application.

The HRA approval button is ticked yes and should be no.

This has now been changed to no.

Please check [redacted] as to whether a DPIA is required for this study.

[redacted] has confirmed that there is no requirement for a full DPIA to be carried out. She advised going through the Data Protection requirements checklist to make sure we have considered all of the data processing requirements, and we did.

In the information sheet, please include that this study is being carried out for an academic qualification.

This has been amended, and the new PIS form has been uploaded to the online ethical application.

I would have some concerns about the advertisement of reimbursement for participant's time. Research with the OJ community at this time will likely be met with some trepidation, given the global context and experiences of anti-semitism.

The decision about providing reimbursement was based on conversations with the project's secondary supervisor, [redacted] from the Orthodox Jewish community, and the project's consultant, [redacted] from the Orthodox Jewish community. They both suggested that reimbursement will be important as an indicator of valuing the time and contribution of busy professionals. The proposed compensation reflects the amount of time, expenses, effort and expertise involved, is not excessively attractive and hopefully does not cloud participants' ability to consent to the research freely.
It is important to ensure that participants feel valued and respected and that we are sensitive to diverse needs and circumstances hence we adopted an inclusive reimbursement approach:

- monetary compensation: £20 cash OR
- shopping voucher for £20 OR
- the option of donating £20 to community projects/organisations rather than individual payments/vouchers to align with the collective nature of the community (PIS updated).

''The main cost to you will be the time needed to take part in the individual interview, and you will be compensated £20 for your time and expenses. This can be paid to you by cash or Bankers' Automated Clearing System (BACS) payment, and you will be asked to sign a receipt confirming that you have been compensated for your time. If you prefer you can receive a shopping voucher for £20. Alternatively, you can also choose to donate £20 to a project or organisation of your choice if you do not wish to receive an individual reimbursement, and the researcher can make a payment on your behalf."

How will the community at the centre of the research be safeguarded here? How might members of the OJ community be invited into the research team to support this? I hold some concerns about whether the strategy to obtain a sample viable within the timeframe.

As mentioned above, members of the OJ have been involved in the study design, and their feedback has shaped this research to ensure it aligns with their values and needs. Potential participants will be given PIS and informed consent; their participation will be voluntary, and they will have the right to withdraw without giving a reason. Participants' data will be anonymised and safely stored with controlled access. Obtaining the required sample has been a topic of conversation with the research team. Hence, this conversation started early on, and some professionals gave consent to be contacted about participation when this study received ethical approval.

- I would like clarification about the requirement to have worked with parents from the Orthodox Jewish community for at least six months; what is the rationale for this time frame? I think it is important that the researcher is circumspect regarding remuneration and potentially this should not be specified on the add. Consideration needs to be given to the current world climate and impact this has had on the Jewish community and any potential implications.

The six-month time frame has been reviewed with the supervisor and removed.

Thank you for your time and thoughtful review of additional details about the study. I am confident that additional information and adjustments will ensure the ethical integrity of our study while allowing us to pursue meaningful and crucial research.

Sincerely,

Paulina Nyklewicz



APPENDIX I Ethical approval

To: Paulina Nyklewicz

Your application for ethics approval for the study listed below has been approved by the Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. **Please read this letter carefully.**

Study Title: Experiences of Professionals Supporting Autistic Children and Their Families in Britain's Orthodox Jewish Community.

Your UH protocol number is: **0278 2024 Dec HSET**
This reference must be quoted on all paperwork, including advertisements for participants.

If you wish to use the UH Ethics Committee logo disclaimer in your communications with participants, please find it in our UH Ethics Canvas site under 'Units - Application Forms': UH Ethics Approval (instructure.com.

This ethics approval expires on 30/09/2025

Amending your protocol

Individual protocols will normally be approved for the limited period of time noted above. Application for minor amendments (including time extensions) of a protocol, may be made for a maximum of 4 working weeks after the end date of that protocol.

It is expected that any amendments proposed via the online system will be minor. Should substantial modification be required, it would be necessary to make a fresh application for ethical approval.

Note that you must obtain approval from the relevant UH Ethics Committee with Delegated Authority **prior to implementing any changes**. Failure to do so constitutes a breach of ethics regulations (UPR RE01).

Adverse circumstances
Any adverse circumstances that may arise because of your study/activity must be reported to ethicsadmin@herts.ac.uk as soon as possible.

Permissions
Any necessary permissions for the use of premises/location and accessing participants for your study/activity must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

Ethics Administration Team

ethicsadmin@herts.ac.uk

APPENDIX J Participant information sheet

University of Hertfordshire UH Ethics Committee

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ('ETHICS COMMITTEE')

FORM EC6: PARTICIPANT INFORMATION SHEET

1 **Title of study**
Experiences of Professionals Supporting Autistic Children and Their Families in Britain's Orthodox Jewish Community

2 **Introduction**
You are being invited to take part in a doctoral study carried out for an academic qualification. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, can be accessed via this link:
https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

3. **What is the purpose of this study?**
This research aims to explore the experiences of healthcare and education professionals who have worked or are currently working with autistic children and their families from the Orthodox Jewish community in Britain.

4 **Do I have to take part?**
It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.
Agreeing to join the study does not mean that you must complete it. You are free to withdraw without giving a reason, and your data will not be used for the project. Once the interview is completed, you can withdraw from the study at any time within 7 days of the interview and can do so by emailing the primary researcher, Paulina (Paula) Nyklewicz. You will not need to give a reason for this, and a decision to withdraw any information or interview responses you have provided will not affect you in any way. You will not be asked to return the compensation provided for taking part in the research.

5 **Are there any age or other restrictions that may prevent me from participating?**
You must be 18 or over to participate in this study. You will not be able to take part in this study if you have never worked with autistic children and/or their parents/carers from Britain's Orthodox Jewish community. You would need to be fluent in English; however, English does not need to be your first language. You can identify with any religion or ethnicity.

6. **How long will my part in the study take?**
You will be asked to participate in a 1:1 semi-structured interview. Interviews will last up to 70 minutes and will take place at a mutually agreed meeting space that provides privacy and confidentiality to the conversation or via remote conferencing (Microsoft Teams).

7. **What will happen to me if I take part?**
Depending on whether you choose to meet with me online or in person, you will be given/emailed this information sheet to keep, and you will be asked to sign a consent form. You will then be invited to take part in an interview, which will be voice recorded. You will be asked to provide your contact details (email and telephone/mobile number). During the interview, you will also be asked to provide some information about yourself, including some basic demographic information. We will never ask you for personal details of the families or children you work with.

APPENDIX K Consent form

University of Hertfordshire UH Ethics Committee

UNIVERSITY OF HERTFORDSHIREFORM EC3
CONSENT FORM

I, the undersigned [*please give your name here, in BLOCK CAPITALS*]

……

hereby freely agreed to take part in the study entitled:

Experiences of Professionals Supporting Autistic Children and Their Families in Britain's Orthodox Jewish Community.

UH Protocol number: 0278 2024 Dec HSET

1 I confirm that I have been given a Participant Information Sheet giving specific information about the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study.

2 I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason.

3 In giving my consent to participate in this study, I understand that voice , video or photo-recording will take place, and I have been informed of how/whether this recording will be transmitted/displayed.

4 I have been given information about the risks of my suffering harm or adverse effects .

5 I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

6 I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.

Signature of participant	**Chosen pseudonym**	**Date**



Signature of {principal} investigator	____13.02.25_____ **Date**

Name of the principal investigator *PAULA NYKLEWICZ*

APPENDIX L Debrief sheet

DEBRIEF SHEET

Dear Participant,

I would like to take this opportunity to thank you for participating in my study and sharing your experiences of working with the Orthodox Jewish community.

If you feel that participating has brought up difficult feelings or things you maybe just want a space to be able to process, please find a list of services below.

Samaritans	Telephone: 116 123 (24 hours, any day of the year) Email: jo@samaritans.org Website: https://www.samaritans.org/
Jami	Telephone: 0208 458223 Website: https://www.jamiuk.org/
The Helpline (24/7 mental helpline for the Jewish Community)	Telephone: 0330 127 3333 Email:info@thehelpline.org.uk Website: https://thehelpline.org.uk/
Relief (mental health referral service for the Jewish community)	Telephone: 0333 344 5595
Jewish Listening Line Monday-Thursday 12pm to 12am Friday 12pm to 3om Closed on Saturdays, Sundays, Shabbat and Jewish festivals	Telephone: 0800 652 9249 (freephone) 0203 096 2975
Shout	Text SHOUT to 85258 (24/7)
CST Protecting our Jewish Community. Help those who are victims of antisemitic hatred, harassment or bias.	**To report a non-urgent incident:** incidents@cst.org.uk Psychological Support Helpline: 0800 032 8477

APPENDIX M Risk assessment

UNIVERSITY OF HERTFORDSHIRE
ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ('ETHICS COMMITTEE')

FORM EC5 – HARMS, HAZARDS AND RISKS:
ASSESSMENT AND MITIGATION

Name of applicant: Paula (Paulina) Nyklewicz Date of assessment: 20.10.2024

Title of Study/Activity: Experiences of Professionals Supporting Parents and Carers of Autistic Children in London's Orthodox Jewish Community.

Activity Description					
1. IDENTIFY RISKS/HAZARDS	2. WHO COULD BE HARMED & HOW?		3. EVALUATE THE RISKS		4. ACTION NEEDED
Activities/tasks and associated hazards Describe the activities involved in the study and any associated risks/ hazards, both physical and emotional, resulting from the study. Consider the risks to participants/the research team/members of the public. In respect of any equipment to be used read manufacturer's instructions and note any hazards that arise, particularly from incorrect use.)	Who is at risk? e.g. participants, investigators, other people at the location, the owner / manager / workers at the location etc.	How could they be harmed? What sort of accident could occur, eg trips, slips, falls, lifting equipment etc, handling chemical substances, use of invasive procedures and correct disposal of equipment etc. What type of injury is likely? Could the study cause discomfort or distress of a mental or emotional character to participants and/or investigators? What is the nature of any discomfort or distress of a mental or emotional character that you might anticipate?	Are there any precautions currently in place to prevent the hazard or minimise adverse effects? Are there standard operating procedures or rules for the premises? Have there been agreed levels of supervision of the study? Will trained medical staff be present? Etc/	Are there any risks that are not controlled or not adequately controlled?	List the action that needs to be taken to reduce/manage the risks arising from your study for example, provision of medical support/aftercare, precautions to be put in place to avoid or minimise risk or adverse effects NOTE: medical or other aftercare and/or support **must** be made available for participants and/or investigator(s) who require it.

Psychological/emotional distress	Participants	The study may cause some emotional distress and difficult feelings.	Risk to participants: Every effort will be made to ensure the participants feel safe and comfortable in the interview process. Participants will be made aware of the topic through the research advert and information sheet, and explicit consent will be obtained before starting the interviews. Participants will be sent the interview questions before the interview and will be able to withdraw at any time. They will be made aware that they should only answer questions they feel comfortable with. The investigator will be attending regular supervision to discuss potential issues related to risk. Participants will receive contact information of places they can seek support following the interview if required. The investigator will be checking with participants for any potential distress and the support will be offered when needed.	No.	Risk to participants: All participants will be provided with a list of organisations they can contact. Interviews will be conducted on weekdays only (Monday-Friday) and during standard office hours (9 am- 5 pm); this will ensure that support will be available should it be needed. If only in the interview it is noticed that the participant is emotionally distressed, the researcher will allow them to share their experience if this is what they wish, however, a protocol will be followed regarding managing heightened distress, but participants will be invited to have regular breaks and remind that they can withdraw. If the researcher is concerned about their wellbeing, relevant information will be shared with a third party as per the confidentiality agreement. The lead researcher is a trainee clinical psychologist who has experience and training in working with people who experience distress and difficult emotions.

Risk of infection/COVID-19	Lead researcher(interviewer) Participants	Risk of infection	Any face to face contact will be in line with guidance by the government, UH, visited school/locations in the community.	No.	To mitigate potential risk of infection the following will be implemented: -frequent hand washing, and if soap and water isn't available use a hand sanitizer (the lead researcher will have a bottle with her) -wear a mask in crowded areas -keep the distance with participants- there will be no reason for less than one meter contact with participants -signing forms e.g. consent form- participants will be asked to bring their own pen, if they forget then they will be provided with one so that separate pens will be used -use disinfectants on common surfaces -ensuring good ventilation (e.g open windows where possible) -lead researcher will stay at home if feeling unwell to reduce the risk of spreading infections to others -follow public health guidance and alerts
Personal/physical/psychological safety risk	Lead researcher	Risk of accidents	Any location of the in-person interview will be discussed with the supervisor to identify any risk. We are following policies for lone working (NHS, UH).	No	To mitigate potential risks the following will be implements: -pre-trip planning- researching the destination, identify any potential risk -having a list of contacts in the destination area (e.g. nearest hospital or local authority) -communication protocol-there will be a reliable communication system in please with the supervisor (time and location of the interview will be shared ahead of the meeting, the supervisor will be messaged when the interview starts and when it's expected to be completed/when I come out, if I cannot be reached on my phone, then the Police will be called). -regular supervision to discuss challenges -emergency contacts will be in place -charged power bank always with the researcher -stay updated on travel conditions The lead researcher is a culturally sensitive trainee clinical psychologist with

					years of lone working experience including home visits.
Signed by applicant: 					Dated: 20.10.2024

APPENDIX N Agreement for volunteers & lay members involvement in research



AGREEMENT FOR VOLUNTEERS & LAY MEMBERS INVOLVEMENT IN RESEARCH

Doctorate in Clinical Psychology research study:

Title: *Experiences of Professionals Supporting Autistic Children and Their Families in Britain's Orthodox Jewish Community*

This research project is a study based at the University of Hertfordshire [or for NHS studies: XXXX Trust and the University of Hertfordshire]. The researcher is [Paulina (Paula) Nyklewicz]. The purpose of the study is to explore the experiences of healthcare and education professionals who have worked or are currently working with autistic children and their families from the Orthodox Jewish community in Britain.

Payment will be made to volunteers and lay members of the public for their participation in meetings and other research involvement activities. The project will finish in the summer/autumn of 2025.

This form must be completed by the participating volunteer before payment can be made. Any queries concerning this Agreement should be referred to the relevant Head of Research Centre at the University of Hertfordshire

Between:

The University of Hertfordshire

And

Name :

(The "Participating Volunteer")

Address:

Tel No.

Email Address:

ACTIVITY

Volunteer for Doctorate in Clinical Psychology research study

The **Participating Volunteer** has agreed to assist the University by voluntarily taking part in the research **Activity**.

1. The Activity to be undertaken is described below and it is the Activity for which you have given your consent/agreement.

Complete e.g., Attend meetings to discuss recruitment, study progress, findings and how to share our results. Review participant information and materials as a Participating Volunteer Give his/her views to inform the research process and direction. There will be no requirement for the participating volunteer to attend all meetings or take part in all activities.

CONFIRMATION OF ATTENDANCE

2. The Researcher will confirm the Participating Volunteer has attended the Activity outlined above.

PAYMENT

3. The Participating Volunteer will receive a participation payment of £20 in the form of vouchers / one-off payments for completion of the activities described above. Payment will not be made for any activities in which the Participant did not participate at all.

RELATIONSHIP BETWEEN THE UNIVERSITY AND THE PARTICIPATING VOLUNTEER

4. **The University does not regard the Participating Volunteer as an employee of the University nor as a worker, and the payment made to the Participating Volunteer for the participation is not made with respect to any employment relationship with the University.**
5. **The Participating Volunteer is advised that it is their personal responsibility to declare any payment for participation to HM Revenue & Customs under Self-Assessment, if that is appropriate to their personal circumstances. The University will not deduct income taxes from the payment.**

SIGNED FOR AND ON BEHALF OF THE UNIVERSITY

The signatory for the University confirms they have authority to enter into this agreement on behalf of the University e.g., Principal Investigator

SIGNED 

PRINT NAME Paula Nyklewicz

Position at UH Trainee Clinical Psychologist

DATE

SIGNED BY THE PARTICIPATING VOLUNTEER

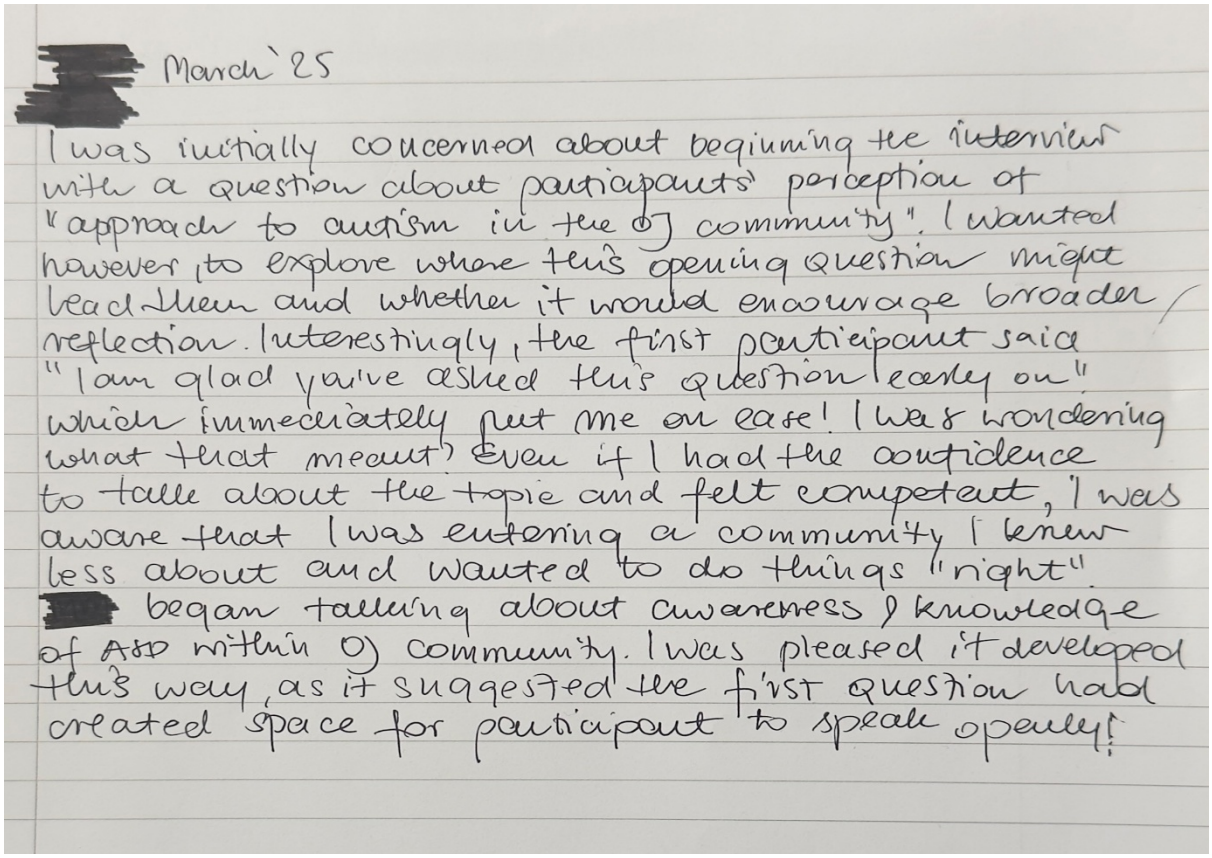
I acknowledge receipt of a copy of this agreement and accept its terms.

SIGNED

PRINT NAME

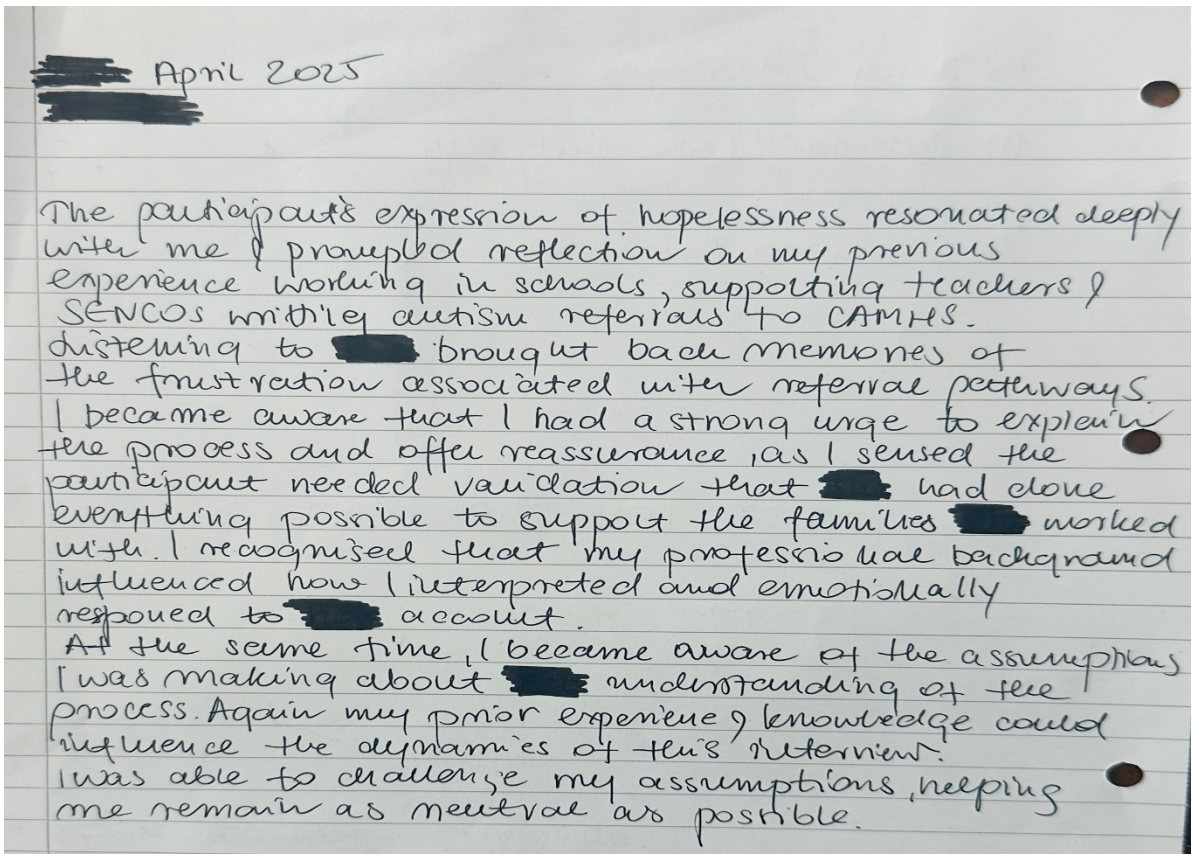
DATE

APPENDIX O Reflexive diary excerpts



[redacted] March '25

I was initially concerned about beginning the interview with a question about participants' perception of "approach to autism in the OJ community". I wanted however, to explore where this opening question might lead them and whether it would encourage broader reflection. Interestingly, the first participant said "I am glad you've asked this question early on" which immediately put me on ease! I was wondering what that meant? Even if I had the confidence to talk about the topic and felt competent, I was aware that I was entering a community I knew less about and wanted to do things "right". [redacted] began talking about awareness & knowledge of ASD within OJ community. I was pleased it developed this way, as it suggested the first question had created space for participant to speak openly!

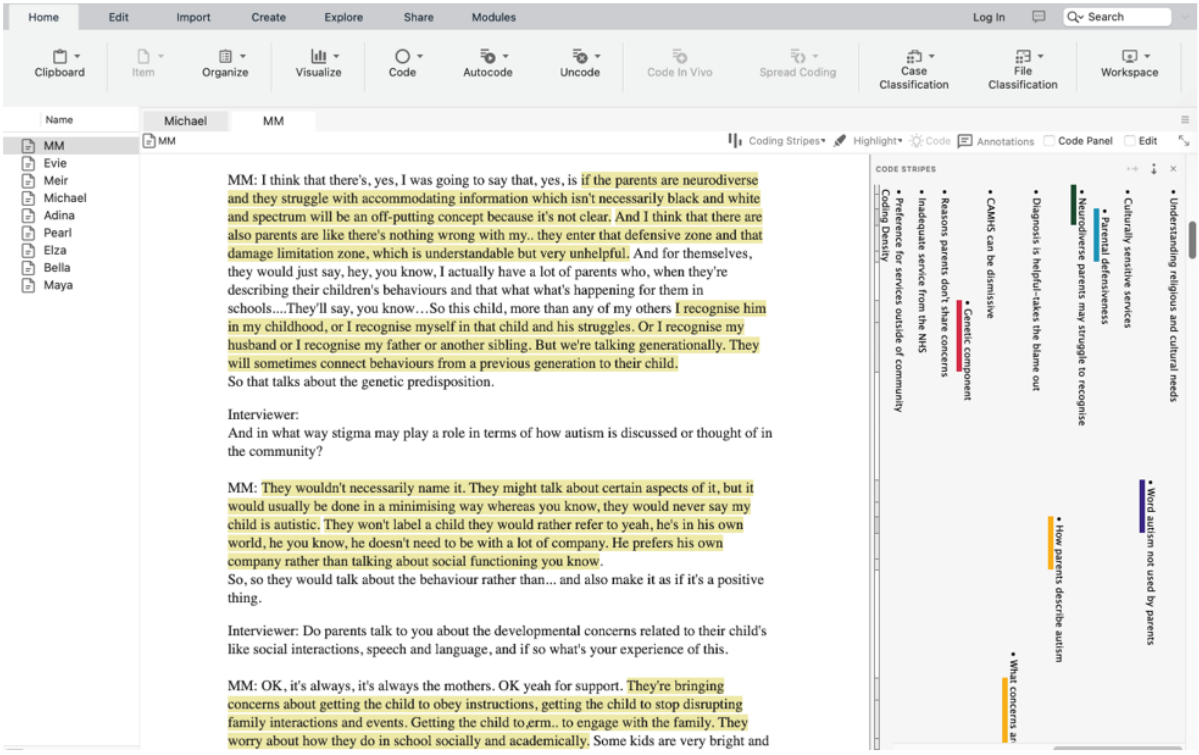


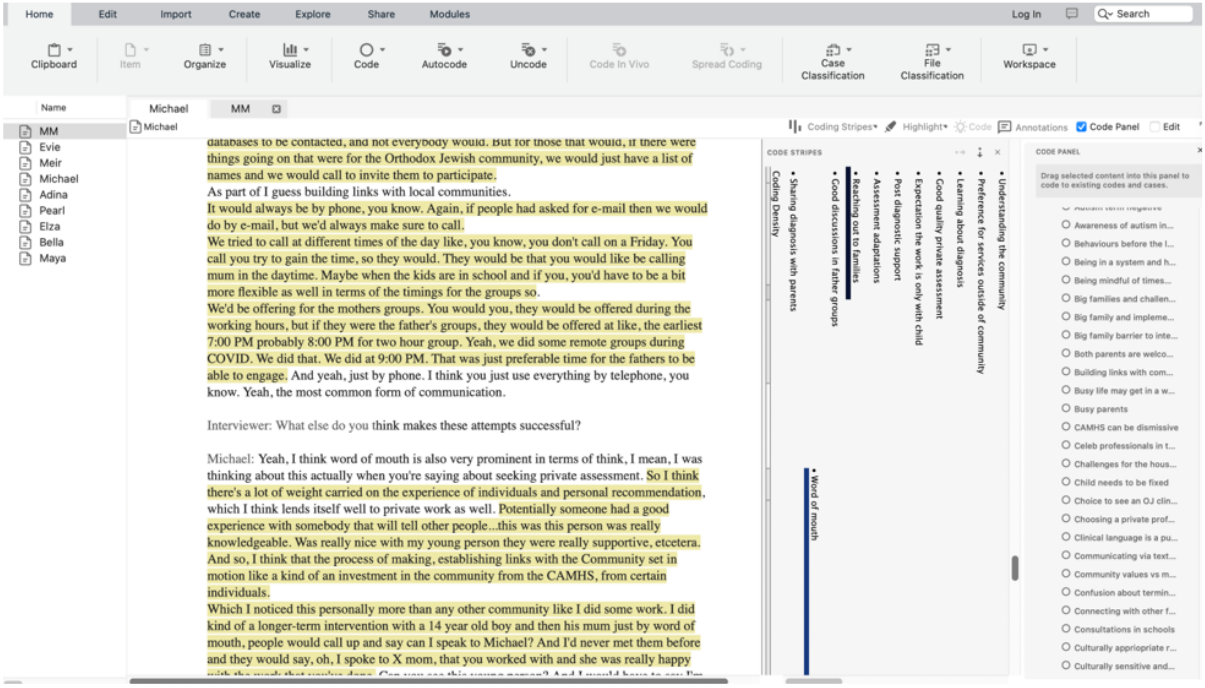
[redacted] April 2025

The participant's expression of hopelessness resonated deeply with me & prompted reflection on my previous experience working in schools, supporting teachers & SENCOs with/eg autism referrals to CAMHS. Listening to [redacted] brought back memories of the frustration associated with referral pathways. I became aware that I had a strong urge to explain the process and offer reassurance, as I sensed the participant needed validation that [redacted] had done everything possible to support the families [redacted] worked with. I recognised that my professional background influenced how I interpreted and emotionally responded to [redacted] account.

At the same time, I became aware of the assumptions I was making about [redacted] understanding of the process. Again my prior experience & knowledge could influence the dynamics of this interview. I was able to challenge my assumptions, helping me remain as neutral as possible.

APPENDIX P Excerpts of coded transcripts





APPENDIX R Mind mapping of clusters to theme development

