How can Educational Psychologists (EPs) support families of autistic children? An exploration of parents' experiences and perspectives.

Doctorate in Applied Educational Psychology
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May 2024

Declaration

This thesis is submitted to contribute to the award of Doctorate in Applied Educational Psychology. I declare that this work is my own and has not been assessed or submitted for any other qualification.

Dedication

This thesis is dedicated to my inspirational Mam -
You never got to see me complete this journey,
but you're the reason I did.

Acknowledgements

Special thanks to my supervisor, Dr Katie Gibson for your guidance during this research process. Thanks for calming me in moments of panic, offering critical guidance and support and believing in the importance of my research. Thanks also to my second supervisor, Dr Fiona Boyd for providing criticality, listening and encouraging me.

To my TEP Cohort – we have a shared empathy for one another having experienced this unique journey. Thank you for the ‘Thursday check-ins’, chats and fun times along the way, I have learnt so much from you all.

Thank you to all my family and friends who have supported me throughout my whole academic journey to this point and encouraging me to follow my dreams of becoming an Educational Psychologist. Especially thanks to my twin sister, Beth. You have been a constant source of support, laughter and offered a good dose of distraction and rationality when needed. I hope I have done the same for you as you do your important work in helping others.

Finally, thanks to Tom, for keeping me fed and watered. I couldn’t have done this without your unwavering love, care and support throughout my training. Thank you for being so patient and kind with me. Here’s to our future together - without weekends spent studying.

Overarching Abstract

This thesis aims to explore the experiences and perspectives of families of autistic children relating to support from professionals and services. Chapter 1 explores this more broadly, whilst the empirical research focuses on support from Educational Psychologists. It consists of four chapters: a systematic literature review, a bridging document to examine methodology and ethics, an empirical project, and a reflective synthesis.

Chapter 1: Research suggests families of children on the autism spectrum may experience increased levels of stress, impacting their wellbeing, thereby indicating the importance of these families receiving support. This systematic literature review aims to explore what is known about the experiences of support from professionals and services for families of children on the autism spectrum. Six papers were synthesised using meta-ethnography, resulting in a model which depicts varying experiences, relating to five overarching constructs: ‘provision of support’, ‘professional interactions’, ‘professional knowledge and skills’, ‘family-centred support’ and ‘facilitating community connections’. This contributes to an understanding of the varied experiences of support from professionals and services for families of children on the autism spectrum and offers a starting point for informing how formal support practices may be improved.

Chapter 2: This presents a bridging document between the findings of the systematic literature review to the empirical project. Within this, the methodological and ethical considerations are critically examined to provide a rationale for decision-making throughout the research process.

Chapter 3: Research suggests families of autistic children may experience elevated levels of stress, impacting their general wellbeing. Providing support for families, including formal support, such as from professionals and services may therefore be beneficial. Despite the role Educational Psychologists (EPs) have in working with families, there is a paucity of research that explores parents’ experiences and perceptions of formal support within the context of Educational Psychology. In relation to the literature gap, this qualitative research aims to explore how EPs can support families of autistic children, by exploring parents’ experiences and perspectives of support from EPs. Individual semi-structured interviews were conducted with seven mothers from five Local Authorities in Northeast England. Data was analysed using reflexive thematic analysis which generated four main themes: (1) equitable access to educational psychologist support; (2) adopt a family-centred approach; (3) assume a coordinator role; (4) empower others with knowledge and understanding.

Findings contribute to the literature exploring experiences of formal support for families of autistic children and are contextualised within a discussion of implications for individual EP practice, alongside broader service level considerations to support family systems.

Chapter 4: This chapter provides a reflective synthesis of the research journey, exploring the influence of the research process on me as a researcher and professional, alongside examining the potential broader implications of the research.

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Abstract

Research suggests families of children on the autism spectrum may experience increased levels of stress, impacting their wellbeing, indicating the importance of these families receiving support. This systematic literature review aims to explore what is known about families of children on the autism spectrum experiences of professional and service support. Six papers were synthesised using meta-ethnography, resulting in a model which depicts the varying experiences, relating to five overarching constructs involving: ‘provision of support’, ‘professional interactions’, ‘professional knowledge and skills’, ‘family-centred support’ and ‘facilitating community connections’. This contributes to an understanding of the varied experiences of professional and services support for families of children on the autism spectrum and offers a starting point for informing how formal support practices may be improved.

Keywords: autism; autistic; on the autism spectrum; families; parents; carers; support; professional; services.

This review will be submitted to Autism following examination and is therefore written in the style of review papers published in this journal.

1.1. Introduction

1.1.1 Autism

Autism is characterised by differences related to social interaction and communication and the presence of restricted, repetitive behaviours or areas of interests (International Classification of Diseases, Eleventh Revision (ICD-11), World Health Organization, 2022). An upward trend in the recognition and diagnosis of autism is noticeable worldwide (Chiarotti & Venerosi, 2020) and within the United Kingdom (UK) (Russell et al., 2022). Statistics vary globally (Salari et al., 2022) with estimations indicating a standardised prevalence of around 1.76% amongst children and young people aged 5-19 years old in England (Roman-Urrestarazy et al., 2021). Increased awareness, recognition and access to diagnosis (O'Nions et al., 2023) have led to lengthy diagnostic processes, often resulting in dissatisfaction amongst parents (Crane et al., 2018; Crane et al., 2016).

Considering the influential nature of linguistics, preferred terminology has been subject to ongoing debate (Vivanti, 2020), including the deliberation of language, such as ‘identity-first’ (autistic child) or ‘person-first’ (child with autism). Across autistic adults, families of autistic children and professionals in a UK study, the term ‘on the autism spectrum’ was liked across all groups (Kenny et al., 2016) and is considered to be a neutral term (Bottema-Beutel et al., 2021). A further study exploring language use amongst an international sample also found the term ‘autistic’ to be preferred amongst self-advocates, family, and friends (Lei et al., 2021). It is important to note possible understanding and experiences of autism may differ across cultures and societies (Begon & Billington, 2019) and individuals’ preferred language should be sought and respected in research (Bottema-Beutel et al., 2021; Lei et al., 2021). For this review, both terms will be used, reflecting available research, and respecting accepted terminology within the community.

1.1.2 Influence on families

Family systems support autistic children and young people (Tint & Weiss, 2016) and whilst this may be a rewarding, transformative and positive experience for families (Bayat, 2007; Myers et al., 2009), unique difficulties experienced by these families are also often associated with challenges to their wellbeing. Whilst it is important to note individual differences are likely to occur, parents and carers of autistic children often report increased levels of stress, depression, anxiety and feelings of stigma and isolation when compared to families without an autistic child (Broady et al., 2017; Cohrs & Leslie, 2017; Hayes & Watson, 2013; Ludlow et al., 2012; Valicenti-McDermott et al., 2015) or children with other needs, such as Down Syndrome and those with learning needs (Hayes & Watson, 2013; Hemati Alamdarloo & Majidi, 2022). The effects of which are suggested to potentially impact their quality of life (Vasilopoulou & Nisbet, 2016). Impacts can also be felt within family relationships, such as spousal relationships and those between parents and siblings (Mount & Dillon, 2014). It seems siblings of autistic children also report stress and restrictions on their social and educational engagement (Preece, 2014; Watson et al., 2021). Various contributing factors are thought to influence parental stress and wellbeing, with discussion of the impact of societal understanding of autism (Woodgate et al., 2008), the severity of the child's autism characteristics (Chan et al., 2018; Rivard et al., 2014) and presence of social communication difficulties (Al-Oran & Khuan, 2021). As well as parental based characteristics, such as experiences of hopefulness (Faso et al., 2013), the presence of their own autistic characteristics and the application of varying coping strategies (Bonis, 2016; Ingersoll & Hambrick, 2011). Furthermore, systemic issues such as parental dissatisfaction with the autism diagnostic process within the UK are thought to contribute to parental stress (Crane et al., 2016; Legg & Tickle, 2019), as well as parents advocating for and seeking support and navigating systems (Boshoff et al., 2018).

Considering the effects of increased diagnosis and potential influences on families highlights the necessity to support families (Crane et al., 2016), with calls to shift research focus to explore how families can be supported (Hayes & Watson, 2013; McCafferty & McCutcheon, 2021). English legislation recognises the importance of collaborating with parents and carers to inform provision, such as the Child and Families Act (Department for Education, DfE, 2014) and Special Educational Needs and Disabilities Code of Practice (SEND CoP) (DfE & Department of Health, DoH, 2015), which stipulate involvement in planning, commissioning, and reviewing support services. The importance of improving outcomes for children on the autism spectrum and their families was also reflected in the 'National Strategy for Autistic Children, Young People and Adults: 2021- 2026' (DoH & DfE, 2021) following findings of the "devastating impact" of the Covid-19 pandemic (Left Stranded report, National Autism Society, NAS, 2020, p.3). The report indicated the necessity for a focus and investment on specific autism policy and support, alongside highlighting the lack of research on what works best to support autistic children and their families.

1.1.3 Importance of supporting families

Support received from professionals and services is believed to be important for these families (Galpin et al., 2018; Hartley & Schultz, 2015; Milosevic et al., 2022). Access to support may ameliorate the impacts on families, with research indicating those who feel more supported feel more able to cope with stresses (Ludlow et al., 2012), experience increased parental wellbeing (Hodgetts et al., 2017; White & Hastings, 2004) and reduced parental stress (Goedeke et al., 2019). Whilst a lack of support seems to further exacerbate the effects of parental stress (Galpin et al., 2018). Despite this, reports of difficulties obtaining support are consistently referenced within the literature (Crane et al., 2016; Rivard et al., 2015). Indeed, there appears to be no clear, consistent pathway for accessing support for children and families following diagnosis within the UK (Crane et al., 2016; Milosevic et al., 2022).

Supporting families can be understood through an ecological systems lens, in which families operate within an individual's microsystem and are considered their primary developmental context (Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 2007). This assumes an interactionalist perspective, postulating individuals influence and are influenced by dynamic interactions occurring within their contextual systems, including with those within the family system (Bronfenbrenner & Ceci, 1994). Promoting family wellbeing, influenced by parental mental health, wellbeing, strong family relationships and resilience, has been recognised as a pertinent influence on children's wellbeing and resilience (Newland, 2014, 2015). Thus, by assuming a holistic approach, the importance of also supporting the family system is highlighted (Desmarais et al., 2018).

1.1.4 Defining support

In this review support is understood to encompass the provision of information, advice, guidance, and help, such as accessing support groups, signposting to further services and access to interventions (Avery et al., 2022; Milosevic et al., 2022), considering emotional, informational, financial, practical, and instrumental forms of support (Avery et al., 2022). Support can be received from formal or informal sources. Formal support is received from professionals and services, whilst informal pertains to support from family members, friends, and other families of autistic children (Fong et al., 2021; Galpin et al., 2018). Families are found to value informal support received, although formal support is also considered important and necessary, especially as families often deal with a plethora of professionals and services (Avery et al., 2022; Hartley & Schultz, 2015; Woodgate et al., 2008). Therefore, the review focuses on experiences of formal support from professionals and services, aiming to further inform practice and policy when considering how they may support families.

1.1.5 Rationale

Acknowledging the potential benefits of support on families, the review aims to consider their experiences relating to support from professionals and services. Research has examined parental experiences and perspectives related to the autism diagnostic process within the UK and internationally (Crane et al., 2016; Legg & Tickle, 2019; Makino et al., 2021). To my knowledge, there are no published reviews exploring families' experiences of formal support more broadly, thus the review aims to gain an understanding of these to explore this question: 'What is known about the experiences of support from professionals and services for families of children on the autism spectrum?'.

1.2 Method

Exploring experiences was central to the review's aim, thus studies examining qualitative data were sought to gain an understanding of experiences and perspectives (Atkins et al., 2008). Various approaches were considered, including thematic synthesis (Thomas & Harden, 2008), critical interpretive synthesis (Dixon-Woods et al., 2006) and meta-narrative (Greenhalgh et al., 2005). Meta-ethnography was deemed most appropriate, as a means of re-interpreting findings across studies to generate a greater conceptualisation and knowledge of the topic (Campbell et al., 2011; France et al., 2016; Malpass et al., 2009). Furthermore, it is regarded as the "most well-developed method for synthesising qualitative data" (Britten et al., 2002, p. 210) and provides rigour through a translation process (France et al., 2016). Noblit and Hare (1988) propose seven phases, which were followed accordingly (Table 1). Guidance from other authors outlining meta-ethnography was sought to provide clarity and operationalisation of the phases (Atkins et al., 2008; France et al., 2019; Sattar et al., 2021; Toye et al., 2014).

Table 1**:** Seven phases of meta-ethnography as proposed by Noblit and Hare (1988)

Phase	Process
1	Getting started
2	Deciding what is relevant to the research area
3	Reading the studies
4	Determining how the studies are related
5	Translating the studies into one another
6	Synthesising translations
7	Expressing the synthesis

1.2.1 Getting started and deciding what is relevant

This involved identifying a research focus through scoping searches (France et al., 2019; Noblit & Hare, 1988). As mentioned, it seems families of autistic children may experience challenges to their psychological wellbeing (Cassidy et al., 2008; Milosevic et al., 2022; Hayes & Watson, 2013) and may benefit from support. Therefore, the review aimed to explore their experiences of formal support, as a means of considering current practices and potentially informing future support.

A systematic review provided a comprehensive search of research to identify relevant studies (Boland et al., 2017) and scoping searches determined final search terms relevant to the research question (Table 2). To avoid excluding relevant information, an inclusive approach was adopted to include mixed methods, incorporating a qualitative component (Atkins et al., 2008). Four databases (Scopus, ERIC, Child Development and Adolescence Studies and British Education Index) were searched between August and October 2022 to cover a breadth of literature and searches were ceased when saturation was considered to be reached. Hand searches were also conducted. Restricting searches to the UK yielded few related results and therefore searches were broadened to include Ireland to allow applicability and comparability to the UK. This was chosen due to similarities in socio-cultural context and social, health and educational structures and legislation to the UK (e.g., Better Outcomes, Better Futures, Department of Children, Equality, Disability, Integration and Youth, 2014) and formation of the Child and Family Agency in 2014. This decision was made instead of including research from other western countries, given the variation in health, social and educational structures to the UK. The inclusion criteria was applied (Table 3), resulting in the inclusion of six studies (Figure 1 for PRISMA diagram).

Table 2: Final search terms

famil* parent* mother* father* carer* guardian* caregiver*	autis* "autism spectrum disorder*" "autism spectrum condition*' asc asd asperger* "autistic disorder"	child* adolesc* teen* youth "young people"	experience* perspective* perception* view* attitude*	professional* practitioner* service* "outreach support*" "outreach team*" organisation* agenc* network*	support* help* care advice involvement information practice* guidance

Note: Boolean OR was used between terms within each set, and these were merged with Boolean AND.

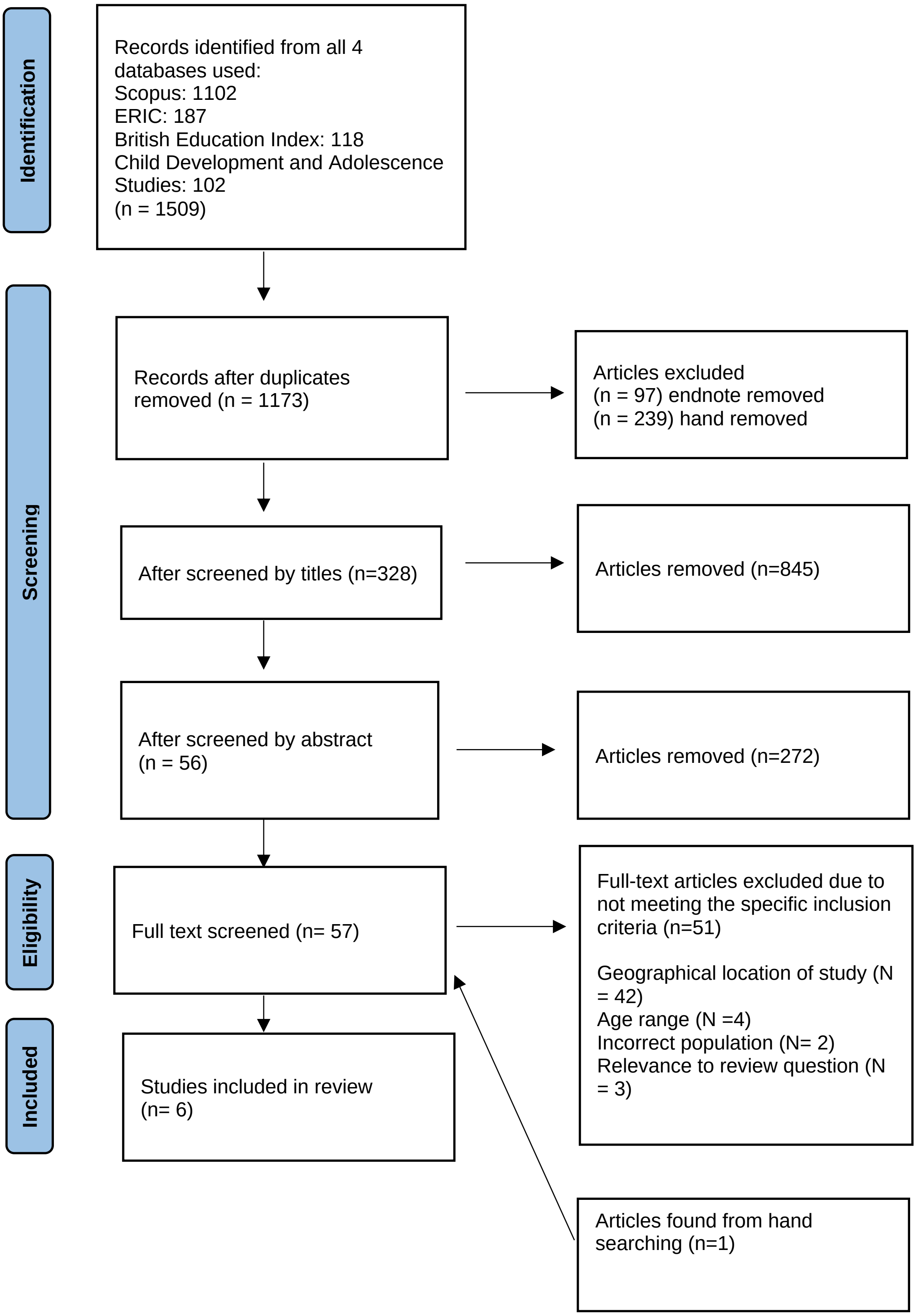

Figure 1: A PRISMA diagram of the SLR search process.

Table 3: Inclusion criteria table with rationale

Inclusion Criteria	**Rationale**
Journal articles from 2014 onwards	Recent research to ensure similarity to the current context. Relevant legislation at this time: Children and Family Act (DfE, 2014), followed by the SEND Code of Practice (DfE & DoH, 2015) which introduced families' involvement in planning, commissioning and reviewing local services related to special educational needs. Highlighted the importance of supporting families for positive outcomes for children. Introduction of 'Local Offer' for families to gain information on support within each Local Authority. In 2014, the sixty-seventh World Health Assembly adopted a resolution called 'Comprehensive and coordinated efforts for the management of autism spectrum disorders', which recognised the need to provide support for families and caregivers.
Peer reviewed	Quality assurance.
Written in English	Ensures accessibility of information.

Focus on families' experiences of professionals and/or services with a child diagnosed with autism or are on the autism diagnostic pathway. Families of children and young people (aged up to and including 18 years old). *Papers were excluded if: The research included children who were not diagnosed with autism/or on the autism diagnosis pathway or with other neurodevelopmental conditions, but not autism.	To examine a broad range of experiences of professional and/or services support i.e., pre, during and following diagnosis. Recognition of long waiting times for diagnosis. Include experiences of families of children and young people. To focus on families' experiences of children's services rather than adult services.
Included qualitative data.	Appropriate for meta-ethnography synthesis. Relevance to research question exploring experiences.
Conducted in the UK or Ireland	Direct applicability to professional and service practice in the UK. Ireland was included due to similarity in socio-cultural context to apply to the UK context. Ireland introduced similar legislation to the Children and Families Act (DfE, 2014) in regard to efforts to provide support for parents and families of children and young people as a transformational goal - Better Outcomes, Brighter Futures in 2014 (Department of Children, Equality, Disability, Integration and Youth, 2014). As well as the formation of the Child and Family Agency (2014) in Ireland which aimed to provide children and families services and view families as foundational for supporting children.

1.2.2 Reading studies and determining how they are related

Studies were repetitively read with close attention to details (Toye et al., 2014). An overview of information was obtained from the studies (Table 4) and key concepts and metaphors were noted from the results and discussion sections (Atkins et al., 2008; Cahill et al., 2018; Toye et al., 2014). Similar and contrasting key concepts and metaphors across the studies were identified and noted to determine the relationships between studies to be synthesised (France et al., 2019; Noblit & Hare, 1988). This process was complex, as studies had different focuses, agendas, and methods. Following Sattar et al. (2021), a list of key concepts emerging from each study was formulated and lines drawn to identify common concepts and examine how they were related (see Appendix A for an example). This process led to a judgement that there were both comparable concepts across studies, providing ‘reciprocal translations’ (comparable concepts) and contradictory concepts, which resulted in ‘refutational translations’ emerging (concepts in opposition) (France et al., 2019; Noblit & Hare, 1988). By noting similarities and differences across studies, both refutational and reciprocal elements were included, which France et al., (2019) argue may present a greater understanding of the phenomena, compared to exploration of commonalities alone.

Table 4: Overview of six papers selected for systematic literature review

Overview of six papers selected for systematic literature review						
Paper Title	**Researchers**	**Focus of study**	**Context**	**Participants**	**Data collection methods**	**Data analysis methods**
Irish parents' lived experience of learning about and adapting to their child's autistic spectrum disorder diagnosis and their process of telling their child about their diagnosis	Finnegan et al., (2014)	The study aimed to explore the experiences of parents of children with autism, exploring their experiences of the diagnosis process, adapting to the diagnosis, and disclosing this to their child, including professional and services support.	Ireland	Seven parents with a child with autism (Asperger's or high-functioning autism) (child aged 8-16 years old- all males). 6 mothers and 1 father. Applied snowball sampling to collect participants.	Semi-structured interviews.	Interpretive phenomenological analysis (IPA)
The dots just don't join up': Understanding the support needs of families of children on the autism spectrum	Galpin et al., (2018)	The study aimed to explore parents' experiences of support from professionals and services – what they have experienced and would benefit from in the future.	UK (England)	Families' experiences– 17 parents/carers (15 mothers – one foster mother and two fathers) Socioeconomically and culturally diverse parents. Parents/carers of children with autism (5-17 years old).	Mixed methods – survey and semi-structured interviews. Qualitative component involved a randomly selected subgroup of parents/carers (some who reported feeling supported and some who did not in questionnaires)	Thematic analysis

				Parents had 18 children (16 boys. 2 girls). All CYP attended a special school in inner-city London.	participating in individual semi-structured interviews to gain in-depth perspectives.	
Understanding the support experiences of families of children with autism and sensory processing difficulties: A qualitative study	Milosvek et al., (2022)	The study aimed to explore experiences of and access to support for families of children with autism and sensory processing difficulties. Perspectives of parents and carers. Study focused solely on the usual care families experienced outside the trial (SenITA programme).	UK (England and Wales)	Parents/carers of 30 children with autism or undergoing local pathway autism assessment (aged 5-11 years old – 23 boys, 7 girls). and associated sensory processing difficulties. Interviewees included 26 mothers, two mother-father pairs, one father and one grandparent.	Semi-structured interviews assisted with timelines. Questions were developed with SenITA management group and parent/carer advisory group. Asked to produce a chronological timeline to share their experiences with the researcher.	Framework analysis to identify themes.
A matter of perspective: the experience of daily life and support of mothers, fathers	Preece (2014)	The research aimed to explore families' experiences of having a child (aged 7-18 years old) with a diagnosis of autism.	UK (England)	14 families with a child with autism (Siblings and parents' experiences)	Individual or group interviews if participants preferred.	Data transcribed and imported to NVivo; a computer assisted data analysis software package.

and siblings living with children on the autism spectrum with high support needs		Asked about their experiences of formal/informal support.		In total thirty two interviews were undertaken with families (mothers, fathers, foster mothers, stepfathers, siblings). Families were interviewed individually or together (e.g., parents interview together, sister interviewed with mother present) as they preferred. Children with autism (aged 7-18 years old). 12 boys, 4 girls.	Looked at mothers, fathers, and siblings perspectives separately.	Thematic approach.
'Above and beyond': The perceptions of mothers of children with autism about 'good practice' by professionals and services	Stanford et al., (2020)	The study aimed to investigate positive experiences with professionals/support services from mothers with an autistic child. 'Good practice' – aspects of the support they value. Positive experiences has been less well researched.	UK (England)	17 mothers of children diagnosed with autism (aged 5-10 years old). 82% male.	Semi-structured interviews via telephone	Inductive thematic analysis

Parenting, autism spectrum disorders and inner journeys	Twomey and Shevlin (2017)	The paper aimed to acknowledge parents' voice by asking how parents experience their child's assessment, diagnosis, and educational experiences. Including experiences of professionals and services.	Ireland	5 longitudinal case studies - six parents interviewed (five mothers, one father) (individual interviews and focus groups) over a 15 month period. Children with autism aged 2.5 – 6 years old. 5 boys. Parental interviews, observations and focus group interventions with child participants, interviews with teachers and professionals, document analysis. Only parents' perspectives were included in the findings of the paper.	Phenomenological view to highlight lived experiences. Longitudinal case studies of 6 parents (5 families). Interviews/focus groups.	Thematic analysis

1.2.3 Quality appraisal of studies

There is a lack of agreement regarding the appropriateness of quality appraisal for qualitative research, with arguments that it contradicts the subjective nature of the approach (Carroll & Booth, 2015; Dixon-Woods et al., 2007; Sattar et al., 2021). However, in accordance with other qualitative reviews, quality assessment was not applied to exclude studies that met the inclusion criteria, but to determine their credibility, conceptual richness and relative contribution to the synthesis (Atkins et al., 2008; Toye et al., 2014). Quality assessment tools using a checklist were considered, for example the Critical Appraisal Skills Programme (CASP) tool (CASP, 2018). However, they do not allow for judgement of the study's relevance to the research question and therefore the Weight of Evidence (WoE) tool (Gough, 2007) was applied to consider the relevance of studies to the review, alongside considering their generic quality. WoE A judgement allowed consideration of quality assessment issues related to the specific study. WoE B, C and D judgements were review specific, allowing consideration of the relevance of the study design, focus and analysis to the review question. Although the subjective nature of quality judgements is acknowledged (Sattar et al., 2021), conducting quality assessment afforded further exploration of studies and determined their relevance to the review question. Quality assessment is documented in Table 5 and rationale for the judgements is provided in Appendix B. Studies considered high quality contributed more to the overall synthesis than those of low-medium quality, although, findings across all studies contributed to the development of the synthesis.

Table 5: Weight of Evidence Review of Studies (Gough, 2007)

	Study	**Milosvek et al., (2022)**	**Galpin et al., (2018)**	**Preece (2014)**	**Twomey and Shevlin (2017)**	**Stanford et al., (2020)**	**Finnegan et al., (2014)**
A	Weight of evidence - A: Taking account of all quality assessment issues, can the study findings be trusted in answering the study question(s)?	HIGH	HIGH	MED	HIGH	HIGH	MED
B	Weight of evidence - B How appropriate is the design and analysis in terms of answering the systematic review question?	HIGH	MED	MED	MED	HIGH	MED

C	Weight of evidence C How appropriate is the focus of the study in terms of answering the systematic review question?	HIGH	HIGH	MED	MED	HIGH	LOW-MED
D	Weight of evidence D Based on the answers to questions A – C, what is the overall weight of evidence this study provides to answer the systematic review question?	HIGH	MED-HIGH	MED	MED-HIGH	HIGH	LOW-MED

1.3 Findings

1.3.1 Translating the studies

A meta-ethnography grid compared studies and identified reciprocal and refutational concepts (Appendix C). First and second-order constructs (Schutz, 1962) were extracted to identify concepts that were pertinent to the review question (Atkins et al., 2008; Cahill et al., 2018) (Table 6 for definitions). Whilst challenges occurred in distinguishing first and second-order constructs, where possible, first-order constructs were used alongside second order constructs, to maintain the participants' unique experiences (Atkins et al., 2008; Cahill et al., 2018). These constructs were synthesised, leading to the development of third-order constructs, which involved collating reciprocal and refutational concepts to identify broader, overarching themes (Britten et al., 2002; Noblit & Hare, 1988) (Table 7). This process was iterative, as they were continually refined as an understanding of the data developed to reflect new interpretations and meanings. This was challenging due to the different focuses of the studies. For example, Stanford et al. (2020) focused on 'good practice; whilst other studies focused on general experiences of support.

Table 6: Descriptions of first, second and third-order constructs, as defined by Schutz, (1962).

Type of construct	**Description**
First-order interpretation	Constructs that reflect direct quotes from the participants, about their experiences.

Second-order interpretation	The researcher’s own interpretations of the participants experiences.
Third-order interpretation	Synthesis of first- and second-order constructs into a new interpretation about a phenomenon.

Table 7: List of themes (third-order constructs) which emerged.

Access and availability of support
Consistency of support
Engagement with professionals
Listened to and acknowledged
Demonstrating empathy and understanding
Knowledge of autism
Practical, hands on support
Lack of acknowledgement of family needs
Individualised support
Facilitating connections with other families

1.3.2 Synthesing the translation

A ‘line of argument synthesis’ was developed by broader third-order interpretations which emerged through consideration of reciprocal and refutational translations into the synthesis expressed in Table 8, to represent the interpretation of studies as a whole (Britten et al., 2002; France et al., 2019; Sattar et al., 2021).

Table 8: Outcome of themes, interpretation, and synthesis.

Themes	Interpretation	Synthesis
Access and availability of support **(refutational)**	Many parents and carers reported feeling left by professionals and services, particularly following diagnosis, leading parents, and carers to proactively seek their own support, conduct independent research and become advocates for their children. There was a clear narrative of having to fight and battle for support, leaving parents/carers feeling 'helpless, stressed and exhausted'. Accessibility is a major barrier, such as waiting lists and costs, meaning low income families, those living in rural areas or less able to 'fight for support' were not as able to access necessary support. Charities and local groups were often good support sources in the absence of formal statutory services. When families had good access to services, this was related to low cost and good availability. Parents also seemed to value 'proactive services', who contacted and consulted with them to ask what support was required, which eased the feeling of a battling for support.	**Provision of support**
Consistency of support **(refutational)**	Support services are often transient, resulting in a lack of consistency. Professionals changed regularly, meaning parents had to repeat their stories and impacted on rapport building. Parents reported experiencing changes in professionals as a 'loss' which 'left gaps'. Schools were seen by some as a constant source of support, perhaps because this is a more consistent involvement for children attending school. In contrast, when professionals had been constant, the support given was experienced as consistent and dependable.	
Engagement with professionals **(refutational)**	There was often restricted communication between professionals and parents, especially related to receiving a diagnosis and they were reported as 'too hard' to engage with. As such, parents commented on feeling a sense of powerless, with an uneven balance of power in favour of professionals, leaving them feeling 'disempowered'. Some mothers reported engagement with professionals who went 'above and beyond' their role to offer support. Collaboration with professionals and multi-agency working and those who engaged in open, honest, and clear communication were examples of good practice and made a positive difference.	**Professional interactions**
Listened to and acknowledged **(refutational)**	Parents felt they were not listened to by professionals (e.g., school staff, health visitors, clinicians), and often felt their concerns about their child were dismissed, meaning their child did not receive the diagnosis or support they desired. This was highlighted as a key barrier to receiving support, as professionals are often the 'gatekeepers'. Professionals were reported to be judgemental about parenting, resulting in them feeling blamed.	

	Feeling like they were listened to and heard by professionals was valued by parents, as they felt affirmed when professionals acknowledged their concerns regarding their child's needs and praised them for their parenting skills.	
Professionals demonstrating empathy and understanding **(refutational)**	Parents felt professionals lacked empathy, sensitivity and understanding of parent's needs, especially when discussing their child's diagnosis, which was poorly communicated and lacked sensitivity. Some parents felt bombarded with information from professionals following a diagnosis and felt they were not emotionally able to deal with 'too much' information that 'doesn't sink in'. Some mothers valued professionals who engaged with them in an empathetic and understanding manner. They also valued professionals who were personable, approachable, and friendly and who demonstrated an emotional understanding within their engagements with them.	
Knowledge of autism **(refutational)**	Some professionals have limited understanding and knowledge of autism, lacking in expertise, leaving parents feeling unsupported and feeling a sense of blame. Some parents valued specialist support from professionals who were 'highly skilled and knowledgeable' in autism. Parents appreciated professionals passing on knowledge and skills related to autism, for example through parenting skills programmes (i.e., Early Bird Programme). Professionals who had personal experiences of autism as supportive were valued, as they were able to relate to parents.	**Professional knowledge and skills**
Practical and hands on support **(refutational)**	Hands on, practical support and advice from professionals was reported as helpful. Parents also liked access to parenting training courses to gain practical skills and knowledge to support their child's needs. Parents reported professionals who went 'above and beyond' to offer support and advice for families. Charitable organisations who could offer support, advice and resources were also valued by parents. Some studies highlighted reports of families wanting professionals to be involved in hands on, practical support and experiencing professionals working with them, but wanting them to be directly involved with their child.	
Lack of acknowledgement of family needs **(reciprocal)**	Services and professionals failed to acknowledge the needs of the whole family, with some members e.g., fathers and siblings reporting less engagement and understanding of professional's roles. A lack of 'whole family support' resulted in other family members missing out and feeling unsupported, which impacted the relationships within families. Support did not fit their lives, as many parents were unable to access support due to work commitments and felt support needs to be more tailored to their family needs.	**Family-centred support**
Individualised support **(refutational)**	Services were reported to not meet the individual needs of autistic children, often failing to provide appropriate support and adopting a 'one size fits all' approach to meeting the needs of autistic children and families. On the other hand, some parents experienced support which was individually tailored and adapted to meet the unique needs of the child and families.	

Connections with other families **(reciprocal)**	Parents valued support gained from other parents who were also parenting an autistic child and were able to relate to and understand them, offering informal support. Services (e.g., children centres) and professionals were appreciated when they helped to bring parents together, forming a peer network and community or getting parents in touch with each other. This resulted in a sense of togetherness when such connections were formed.	**Facilitating community connections**

1.3.3 Expressing the synthesis

The synthesis is expressed textually, alongside visually to disseminate findings in an accessible manner (see Table 8 and Figure 2).

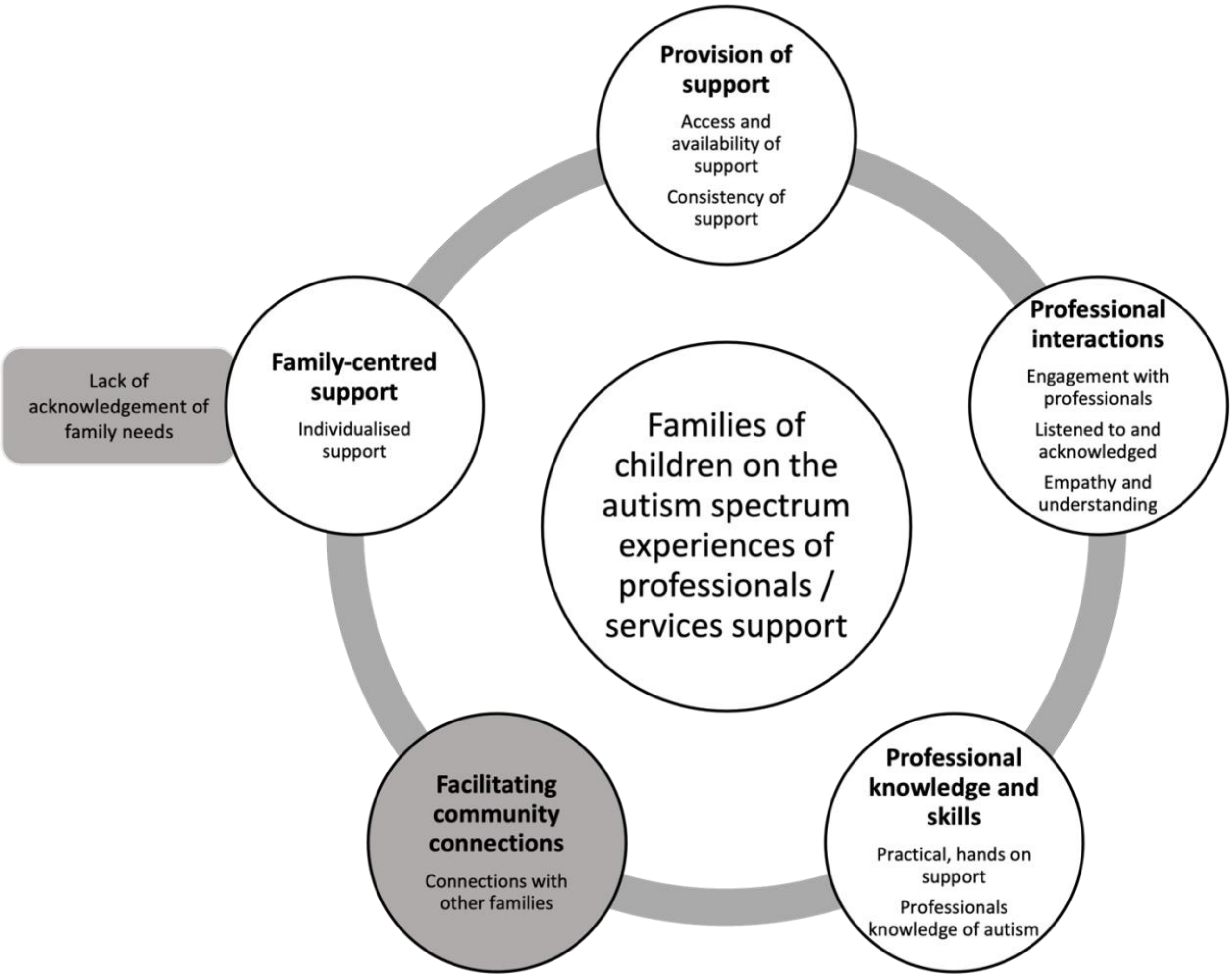

Figure 2: A visual representation of the experiences with professional and service support among families of children on the autism spectrum.

The model represents the synthesis, to understand families' experiences and examine ways in which practice may be improved. The structure represents related elements, which are equal, highlighting the equal value placed on all experiences of support expressed. Four elements included refutational translations, as represented by white circles and is illustrative of families' varied experiences of support from professionals and services. Facilitating community connections included reciprocal translations, as represented in the grey circle, which illustrates families' similar experiences. Within 'family-centred support', a reciprocal translation also emerged, in which comparable experiences were discussed and is therefore positioned outside of the main element, as highlighted in grey. This model highlights commonalities in what families' value relating to formal support, yet suggests varied experiences of these.

1.4 Discussion

1.4.1 Provision of support

The synthesis highlighted the importance families placed on the provision of support, in terms of its accessibility, availability and consistency. Experiences of difficulties obtaining access to and a lack of available support emerged as a key theme, evident across all studies and reflect a significant challenge experienced by families of autistic children (Avery et al., 2022). Parents discussed a sense of having to *"fight"* and *"battle for everything"* (Galpin et al., 2018, p. 577), resulting in the abandonment of their own needs, requirement to adopt various roles and taking charge of the situation for themselves, such as conducting self-research about autism. This reflects parental advocacy literature relating to autism, inferring the role of seeking support often falls to parents, with research suggesting some parents may be disadvantaged in their ability to do so, such as those from lower socio-economic and differing cultural backgrounds (Boshoff et al., 2016, 2018).

A high variation in post-diagnostic support was also indicated, with some families perceiving they receive little to no support, in contrast to others receiving support from several services and professionals. Easy to access and affordable support for families was reported as valued by mothers in Stanford et al. (2020). However, studies generally commented on families' experiences of limited access to support, even if it was available, such as long waiting lists for services and high costs of support for both themselves and their children, resulting in low income families and those living in rural geographical areas unable to access necessary support (Milosevic et al., 2022; Preece, 2014). This accords with research conducted by Preece and Lištiaková (2021) which found accessing support to be more challenging for families living in rural coastal areas due to several factors, including limited specialist services and the impact of austerity. Parents reported limited availability and access to support resulted in feelings of helplessness, stress, exhaustion and isolation, reflecting similar findings indicating the impact of negative experiences on parental stress and wellbeing (Desmarais et al., 2018; Ludlow et al., 2012). This is concerning given the high levels of parental stress experienced by those parenting a child on the autism spectrum and suggests the situation regarding accessibility and availability of support is exacerbating rather than improving parental wellbeing. Considering limited access and availability of support, parents sought proactive services that actively gained their perspective of what was wanted, which eased sense of fighting for support (Galpin et al., 2018).

Consistency of support also emerged as important for families. This related to the transient nature of support, resulting in a lack of consistent support, which was often time-limited or withdrawn following diagnosis (Milosevic et al., 2022). Professionals working with children and their families were changed regularly, seen sporadically with large gaps between contacts or were failed to be replaced when they left resulting in families feeling a sense of loss of support from valuable professionals and services (Galpin et al., 2018; Preece, 2014; Twomey & Shevlin, 2017). This "*necessitated telling the same story again and again*." (Preece, 2014, p. 9) and impacted families' ability to form ongoing relationships with professionals. Family-professional relationships are considered good practice in supporting families of children with special educational needs, whereby professionals and families work in partnership to engage in joint decision-making (Blue-Banning et al., 2004; Keen & Rodger, 2012). However, inconsistencies in professionals and services may impede the likelihood of supportive family and professional relationships developing. Stanford et al., (2022) found access to consistent involvement was valued, resulting in support received being viewed as dependable. Thus, having a key, ongoing contact as a consistent source of support and able to coordinate different professionals working within the family system is highlighted as beneficial (Avery et al., 2022; Desmarais et al., 2018; Milosevic et al., 2022).

1.4.2. Professional interactions

Interactions with professionals emerged as an important element within the synthesis, encompassing varied experiences of engagement with professionals, feeling listened to and acknowledged and experiencing empathy and understanding. Regarding professional engagement, mixed experiences emerged, with some parents feeling professionals are "*too hard*" to engage with and desired more contact and opportunities to work with them to develop their skills in supporting their child (Galpin et al., 2018, p. 557), whilst others felt professionals and services moved things forward and valued positive relationships between families, schools and other professionals (Stanford et al., 2020; Twomey & Shevlin, 2017). Some parents were dissatisfied with professionals throughout the diagnostic process, such as suggesting a 'wait and see' approach, resulting in parents feeling a sense of disempowerment when dealing with professionals (Twomey & Shevlin, 2017), which Boshoff et al., (2018) suggests calls for parents and professionals to develop a better understanding of one another's perspective in relation to diagnosis. Communication with and between professionals was valued. For some parents, this was restricted, whilst others experienced 'open, honest and clear communication' with professionals (Stanford et al., 2020, p. 5). Findings suggest some families experienced a misbalanced distribution of power favouring professionals and positioning them within an expert position. Such imbalance may impact positive parent-professional relationships, which are formed through mutual trust, respect and joint decision-making (Cohen & Mosek, 2019; Keen & Rodger, 2012), with such challenging interactions with professionals potentially detrimentally affecting parental wellbeing and stress (Ryan & Quinlan, 2018).

Parents valued being listened to and acknowledged by professionals, however, experiences of this varied. Repeated accounts of professionals (including school staff, health visitors, clinicians) dismissing parents' initial concerns for their child were discussed, highlighting a barrier to receiving appropriate support and delays gaining formal diagnosis (Milosevic et al., 2022). Some parents experienced professionals who were perceived to be judgemental and blaming, whilst others recounted experiences of being authentically listened to and heard, feeling affirmed when their concerns were acknowledged and empowered when professionals praised their parenting skills. Despite the 'Autism in Children and National Institute for Health and Care Excellence' (NICE, 2011) guidelines stipulating the necessity of acknowledging parental concerns, experiences of parents being dismissed by professionals is not surprising, substantiated with research exploring parents' experiences of the diagnostic process within the UK, Ireland (Connolly & Gersch, 2013; Legg & Tickle, 2019) and globally (Makino et al., 2021). Moreover, it is likely, by dismissing parental concerns, professionals are missing initial opportunities to develop positive relationships with parents (Legg & Tickle, 2019; Marvin et al., 2020).

Parents felt interactions with professionals who were empathetic and understanding influenced the emotional support received. Some felt professionals lacked empathy, sensitivity and understanding of their needs, particularly regarding information about their child's diagnosis, which was often communicated insensitively (Finnegan et al., 2014; Twomey & Shevlin, 2017). Galpin et al. (2018, p. 577) discussed parents feeling '*bombarded*' with information shared by professionals at diagnosis, demonstrating a lack of professional understanding of parents' emotional needs at this time. Others shared experiences of professionals being empathetic, understanding of their situation, approachable, friendly, and considerate (Stanford et al., 2020). The importance of professionals acknowledging and being sensitive to emotional needs has been acknowledged (Crane et al., 2018). Therefore, parents varied experiences of professional interactions are important to note, considering the influence of these positive attributes and interactions with professionals on the development of collaborative, parent-professional relationships (Carlson et al., 2010; Marvin et al., 2020).

1.4.3. Professional knowledge and skills

Parents discussed varied experiences of professionals' knowledge of autism. Experiences with professionals varied, as some parents felt professionals had limited understanding, knowledge, and expertise of autism (Galpin et al., 2018; Milosevic et al., 2022) leading to feeling concerns were dismissed and experiencing blame from professionals, whilst others commented on support from highly knowledgeable and skilled professionals (Stanford et al., 2020). These varying experiences highlight the need for the development of knowledge and understanding of autism, to be able to effectively support the children in their care alongside their families (Milosevic et al., 2022). This has recently been recognised in England, with the autism strategy (DoH &DfE, 2021-26) introducing training on autism for professionals across health, social and educational services. Findings suggested support was valued from specialist professionals and services who were knowledgeable and provided autism specific information and advice, such as signposting and parenting courses (Milosevic et al., 2022; Stanford et al., 2020). Professionals' personal experiences of autism were also valued, allowing them to relate to parents and demonstrate emotional understanding (Stanford et al., 2020). Overall, parents seemed to value professional expertise in offering specialist support for their child's and family's needs. However, I argue it is also crucial for professionals to also acknowledge and consider families' expertise (Crane et al., 2018; Gillespie-Lynch et al., 2017) to foster effective and positive parent-professional relationships, in which each other's expertise is valued and contributes to shared decision-making (Hodge & Runswick-Cole, 2008).

Furthermore, receiving hands-on, practical support, advice and knowledge promoted development of parents' knowledge and skills to be able to support their children. Greater knowledge and skills gained could potentially increase parents' feelings of self-efficacy regarding meeting their children's needs (Legg & Tickle, 2019), which is pertinent given parental self-efficacy is thought to be associated with a sense of competency and wellbeing (Galpin et al., 2018; Jones & Prinz, 2005; Kuhn & Carter, 2006). Professionals were reported to go “above and beyond their role” (Stanford et al., 2020, p. 5), offering personable, practical support to families, conducting home visits, and sharing practical knowledge, for example, information about short breaks and sharing practical resources (Stanford et al., 2020). However, these experiences were not shared by some parents, who felt there is a gap in direct involvement and support for their child specifically, for example, therapeutic support, feeling a focus can be on parents (Milosevic et al., 2022), suggesting families may value practical, hands-on formal support for both themselves and their children.

1.4.4 Family-centred support

The lack of acknowledgement of the specific needs of the family and child emerged as a common experience. Some family members (i.e., fathers and siblings) experienced less engagement with professionals and lacked an understanding of their roles (Preece, 2014). It seems support focuses on mothers, perhaps related to assumptions of traditional caregiving roles, reduced availability of fathers and lack of consideration of father-child relationships (Braunstein et al., 2013). However, given differing parental experiences and support needs of mothers and fathers of autistic children (Hartley et al., 2011; Legg & Tickle, 2019), consideration is required for how fathers may also be supported. Support often fails to fit with families' everyday life, considering factors including work commitments on access to support, for example, parenting groups and courses. A lack of *'whole family support'* (Galpin et al., 2018, p. 577) was noted, whereby support received focused on the child, failing to consider the needs of other family members, such as siblings. Such approaches left families feeling fragmented rather than supported to be a unit and negatively impacted their relationships and connections as a family unit (Galpin et al., 2018).

In considering family support, parents also framed experiences of support in terms of how well supported their child was, reflective of ecological systems by highlighting the bidirectional nature of interrelated child and family systems (Bronfenbrenner & Ceci, 1994). A varied appreciation for children and families specific needs was noted, with some adopting a *'one size fits all approach*' (Galpin et al., 2018, p. 567) and parents reflected on their experiences with a range of professionals and services, such as speech and language therapy and mental health services as being inappropriate and not tailored to their child's needs (Milosevic et al., 2022). Contrastingly, support which was adaptable and tailored to meet the specific needs of their children and families was valued (Stanford et al., 2020). Considering the impact of autism on the individual child and their wider family unit, support was perceived to be required which addresses the needs of the whole family, alongside the child (Desmarais et al., 2018; Galpin et al., 2018; Hodgetts et al., 2013). This reflects key elements of what is considered to be family-centred practice, including viewing the family as the unit of attention, family choice, family strengths, family-professional relationships and individualised services (Epley et al., 2010). However, whilst adopting a family-centred approach to support is considered best-practice for childhood professionals and services (Epley et al., 2010), this is not fully reflected in the experiences of parents of children on the autism spectrum within the reviewed studies. Therefore, the necessity for family-centred practice to be adopted to support the family is highlighted, whereby professionals and services work in collaboration with families, tailoring support to their changing needs to promote their general wellbeing (Blue-Banning et al., 2004; Galpin et al., 2018; Hartley & Schultz, 2015).

1.4.5 Facilitating community connections

Valued support from other parents of children on the autism spectrum was commonly discussed, specifically experiences of professionals and services facilitating community connections with other families of autistic children (Galpin et al., 2018; Stanford et al., 2020). Findings accord with research ascertaining families value access to informal support from other parents, as a means of reducing isolation through forming connections, fostering a sense of belonging and community, as relatable experiences can be shared (Avery et al., 2022; Ludlow et al., 2012; Mount & Dillon, 2014). Developing a sense of belonging is considered a fundamental human need (Baumeister & Leary, 1995; Maslow, 1943), reflecting the experience of relatedness, considered necessary in self-determination theory, through forming connections with other parents (Ryan & Deci, 2000), which may promote family wellbeing and resilience (Fong et al., 2021; Milosevic et al., 2022; Trew, 2024). Services such as children's centres professionals were appreciated for connecting parents, such as forming peer networks and encouraging families' connections with other parents. It seems professionals and services are valued in their roles as facilitators, bridging a gap between formal and informal support systems by helping families form community-based support networks. Support from professionals and services is often transient and unsustainable in the long term (Crane et al., 2018), highlighting the importance of helping families form community connections and networks as a means of accessing longer-term social support. However, Avery et al. (2022) note the importance of families receiving formal support alongside these informal mechanisms of support from family, friends and other parents. Literature advocates for the benefits of professionals co-facilitating parenting programmes; with value placed on collaborative working with professionals, alongside developing connections with parents who can relate to them (Banach et al., 2010; Connolly & Gersch, 2013).

1.5 Summary

The review offers an understanding of families' experiences of formal support from professionals and services, emerging as five constructs as reflected in the synthesis. Whilst the importance of support in promoting wellbeing of the family unit is highlighted (Desmarais et al., 2018; Ludlow et al., 2012), the review indicates support is not equitable for all families. Whilst families appeared to value each element of support, their experiences varied in terms of the provision of support, including accessibility, availability, and consistency. Whilst positive, collaborative interactions with professionals were experienced, other families felt unheard, isolated, judged, and blamed. Some families experienced professionals who were skilled and knowledgeable about autism and therefore able to offer practical support and advice, whilst others highlighted their experiences of the opposite. Family-centred support, which considered the needs of the whole family was generally not considered and met, as was provision of individualised support to meet the individual needs of families and children, with families valuing specifically tailored support. Furthermore, formal support which facilitated connections with parents with whom they could relate and gain informal means of support was valued. Exploring these families' experiences highlights the need for formal support services to improve in order to meet the needs of families and therefore aims to provide points for consideration in improving formal means of support for families of autistic children, with opportunities to consider how families of children with a range of needs may be supported.

1.6 Limitations

The subjective nature of meta-ethnography means assumptions, values and experiences influence interpretations formed (Atkins et al., 2008; France et al., 2016), hence it is pertinent to acknowledge the synthesis provides a single interpretation and others are entirely possible (Lee et al., 2015; Sattar et al., 2021). Meta-ethnographies are typically conducted by multi-disciplinary teams, thus, since the review was conducted by a sole reviewer, the potential for reduced rigour and scope due to resources and time constraints requires acknowledgment (Atkins et al., 2008). Furthermore, as commonly experienced in autism research, participants in included studies were predominately mothers (Braunstein et al., 2013). The impact of parenting a child on the autism spectrum may differ between mothers and fathers, with research indicating fathers report lower levels of stress (Ludlow et al., 2012), have fewer support needs and have differing experiences of support to mothers (Avery et al., 2022; Hartley & Schultz, 2015), highlighting the importance of continuing to consider fathers perspectives and experiences. It is also important to note the model was synthesised from a small number of studies, and therefore may require further development to inform practice, by considering the experiences of families of autistic children from diverse communities, such as those families who are more marginalised.

1.7 Implications for practice and research

Findings may contribute a starting point to tailor and improve support offered by those working with families of autistic children, helping adapt and improve support practice to promote and support the wellbeing of the family as a whole (Desmarais et al., 2018). For instance, focus on promoting equitable, consistent support and fostering positive, empathetic and sensitive interactions with families which may balance power, and promote parent-professional relationships. Consideration of professional training to increase knowledge and skills in supporting autistic children, to provide families with practical support, tailored to meet the unique needs of the family unit (Galpin et al., 2018), and continue to promote informal support through facilitating parental connections. Stanford et al., (2020) suggested aspects of good practice may be considered when supporting families of children with a range of needs, which is further illustrated by similar parental experiences of accessing formal support for those with children with other needs (Ryan & Quinlan, 2018). Whilst synthesised experiences presented a model as a starting point to consider support practices, adaptations to specific professions and contexts are likely necessary. Experiences mainly related to health and social care professionals and services, including some references to school-based professionals. Further exploration of professionals from educational services, for example, Educational Psychologists, may be beneficial to examine support received from families' perspectives. Additionally, whilst it is beneficial to explore families' experiences of formal support, it may be beneficial to contribute to existing research by further considering formal support families hope to receive.

Chapter 2: Consideration of research methodology and ethics

2.1 Introduction

This chapter contextualises the research by outlining the rationale and motivation to pursue exploration within the area of families of autistic children and consider how the meta-ethnography informed the empirical project. Philosophical positioning will be outlined, alongside the importance of reflexivity in acknowledging the influence of my values, experiences, and assumptions in shaping the research and negotiating ethical issues.

2.2 Rationale for thesis

Motivation for examining this research originates from my experience as an Assistant Psychologist, working with a social communication and interaction team. I worked extensively with children and young people on the autism spectrum, their parents or carers, and school staff. The team was commissioned to provide post-diagnostic support for children and young people. However, this was often limited to working with school-based staff. I noted a requirement for professionals and services to provide support for families, many of whom were struggling, such as to collaborate and develop a shared understanding of their child's needs and appreciate the impact on the family unit. The predominant focus on school support resulted in personal frustrations of feeling unable to support families more specifically. Since becoming a Trainee Educational Psychologist (TEP), I have noted coherence with the value I place on working collaboratively with families to support the family unit as a whole (BPS, 2023, Children and Families Act (DfE, 2014) Special Educational Needs and Disabilities Code of Practice (SEND CoP) (DfE & DoH, 2015). For me, the value and impact of this were further exemplified by working with Educational Psychologists (EPs) who support families of autistic children, such as through engagement in multi-disciplinary assessment teams, and practicing in ways which support the family systems of autistic children.

Wider contextual and legislative influences also informed the topic. Working with families is enshrined within legislation, including the Children and Families Act (DfE, 2014) which emphasises collaboration within the planning and commissioning of support from services (Galpin et al., 2018). The SEND Code of Practice (DfE & DoH, 2015) also endorses collaboration with families in decision-making to inform support, which has been further endorsed in the SEND and Alternative Provision (AP) Improvement Plan (DfE, 2023a). This follows a review of SEND systems, noting challenges families' experience accessing appropriate support and proposed changes aiming to improve families' confidence and trust.

Promoting outcomes for autistic children and their families was also highlighted within the first autism strategy relating to children and young people (National Strategy for Autistic Children, Young People and Adults: 2021 to 2026, DoH & DfE, 2021). This highlights the necessity for a focus and investment in policy and support specific to autism, requiring local authorities to implement an autism strategy to consider how it can improve services. Moreover, it emphasises the requirement for research on what support works best to support autistic individuals and their families.

2.3 Formulating the research question: From meta-ethnography to empirical research

The meta-ethnography highlighted families' varied experiences of formal support from professionals and services in terms of the provision of support, professional interactions, professionals' skills and knowledge, and family-centred practice. It also identified that families value professionals and services helping to foster community connections with other parents. A model was developed based on families' varied experiences, which may provide a starting point to inform how professionals and services may support families. This is primarily based on an exploration of their experiences and there remains limited research exploring what formal support families desire to inform future practice (Galpin et al., 2018).

Furthermore, the meta-ethnography discusses families' experiences with a broad range of professionals and services, including health and social care and some school-based staff. Whilst scoping and conducting the systematic literature review (SLR), there was a notable absence of experiences specifically of Educational Psychologists (EPs) within the existent literature. Whilst parents in Milosevic et al. (2022) study referenced EPs involvement within their visual timelines, there was a lack of explicit mention of EPs within interviews. The absence of such research is noteworthy given EPs operate at a holistic level, in which their involvement is often situated with those who directly support CYP, through applying psychological skills and knowledge to practice with their families (Farrell et al., 2006; Toland & Carrigan, 2011). Furthermore, working with families is considered elemental to good EP practice (Dunsmuir et al., 2014), alongside the necessity for EPs to demonstrate knowledge of parenting and family functioning as stipulated by the British Psychological Society and Health and Care Professions Council (BPS, 2023, HCPC, 2015). Working with parents is a common feature of EP practice, for example, through consultations and assessment processes, and research posits EPs are professionals who can offer support to families, such as through support groups (Connolly & Gersch, 2013). Despite this, recent literature examining EPs work with families is limited (Atfield et al., 2023; Lawrence et al., 2014;

Squires et al., 2007) and research indicates varying views amongst the profession regarding the extent to which such work is considered to be within their remit (McGuiggan, 2021).

Considering this, whilst findings from the meta-ethnography offer a starting point, further exploration is necessary to explore families' experiences and hopes of involvement and support from EPs, to inform their practice and policy. Thus, the research aims to explore what parents' experiences and perspectives tell us about what EPs can do to support families. The project aims to build upon the existing literature review to address this gap by listening to families' experiences of support from EPs specifically. Furthermore, it aims to contribute to the literature by exploring perceptions of what they think EPs could do regarding supporting families. In doing so, the research explores parents' experiences and perspectives, which I deem is crucial in placing them central within the research (Pellicano et al., 2014), as well as corroborating with the autistic community research priorities, by aiming to influence the support children and families receive in practice (Pellicano et al., 2013).

2.4 Methodology

2.4.1 Philosophical positioning

The philosophical positioning of the research was integral to decisions made throughout the process (Willig, 2013). Ontology relates to the assumptions about the nature of social reality (Grix, 2002). This research aligns with an ontological realism perspective, asserting an independent, real-world exists irrespective of our knowledge of it, whereby constructed processes and structures can be captured and explored (Maxwell, 2012; Willig, 2013). Epistemology refers to what we know about social reality and the manner in which knowledge can be elicited (Willig, 2013). A constructivist epistemological position is assumed, recognising absolute knowledge of reality is not possible, as individuals' concepts, beliefs and intentions are not directly observable (Maxwell, 2012; Scott, 2005). Thus, the SLR and empirical research adopt a critical realist positioning, which posits the presence of an external world, whilst acknowledging attempts to gain absolute knowledge of our stratified reality are fallible and relative, as influenced by subjective experiences of it (Scott, 2005; Taylor, 2018). This position assumes support can exist within the social world to be explored and researched but acknowledges differing experiences of this reality are likely to be present. Whilst subjective experiences are highlighted, it acknowledges the presence of reality irrespective of our direct awareness of it, thus knowledge created by this research intends to contribute to practice and policy regarding how professionals and services can support families.

Whilst the research does not aim to explore conceptualisations of autism, instead exploring families' experiences and perspectives of support, I deem it necessary to consider the philosophical lens through which the research considers autism. A critical approach to autism, which adopts a social constructionist stance has been discussed, aligning with a social model of disability and consistent with the neurodiversity paradigm, which conceptualises autism as constructed by society, culture, and history in rejection of a positivist, medicalised lens (Begon & Billington, 2019). However, recently autism researchers have reconciled shortcomings of positivist and social constructionist approaches, postulating a critical realism positioning can support an understanding of autism, whilst providing emancipatory research seeking social action and change (Botha, 2021a; Kourti, 2021). This acknowledges society, place, culture, and history shape the subjective construction, meaning and understanding of autism, yet does not reject the existence of autism as real (Botha, 2021a, 2021b; Kourti, 2021). In doing so, autism is not reduced to a biological or social level, instead acknowledging "the interplay between biology, environment, social and cultural values, and discourses, and further, how the autistic person interacts with each other those structures" (Botha, 2021a, p. 12). This aligns with the aims of the research, which acknowledges this and hopes to offer knowledge to impact future practice for families.

2.4.2 Semi-structured interviews

In accordance with the aim of exploring experiences and perspectives, a qualitative methodology was employed (Howitt, 2019; Willig, 2013). Individual semi-structured interviews were utilised in an attempt to provide rich accounts of individuals' experiences (Adams, 2010). Focus groups were initially considered, however, considering the respect ethical principle (BPS, 2021a), semi-structured interviews were considered more appropriately suited to the nature of discussions in recounting personal experiences, as individual opportunities to share these could be afforded rather than within a group (Rothwell, 2010). Unfamiliarity with one another was also considered a possible influence on the nature of discussions, as individuals may have felt uncomfortable sharing experiences in a group setting (Parker & Tritter, 2006; Rabiee, 2004). This was a particular consideration given the SLR indicated a potential for varying experiences.

During interviews, open-ended questions guided discussion, whilst also allowing flexibility to explore topics that emerged (Galletta, 2013; Terry & Hayfield, 2021). General exploratory questions were followed by specific questioning, aiming to establish rapport (Larkin et al., 2021; Willig, 2013). Prompts and follow up questions were asked where appropriate and relevant, whilst remaining cautious to not lead individuals, but to generate deeper exploration based on the direction and nature of their discussions (Terry & Hayfield, 2021).

2.5 Data analysis

Several data analysis methods were considered for their suitability to the research question, aims and philosophical positioning, including Grounded Theory, Narrative Analysis, Template Analysis, Interpretive Phenomenological Analysis (IPA) and Reflexive Thematic Analysis (RTA) (see appendix D for a discussion of each). In accordance with these considerations, decisions were made between IPA and RTA owing to their coherence with critical realism and commonalities related to their interpretative, inductive nature, exploration of experiences and use of qualitative methods (Alase, 2017; Braun & Clarke, 2022; Larkin et al., 2021; Willig, 2013). Ultimately, RTA, as defined by Braun and Clarke (2022) was judged most suitable. In contrast to the structured methodology of IPA, RTA offers an accessible, flexible approach to data analysis, affording a detailed overview across the data set, to examine a collective sense of experiences and perspectives to be interpreted and inform practice regarding support (Braun & Clarke, 2006; Byrne, 2022). Furthermore, consistent with the research aims, the approach’s flexibility afforded exploration of individuals’ perspectives of support they think families would benefit from, alongside their own lived experiences of EP involvement.

2.5.1 Reflexive Thematic Analysis

RTA was adopted, utilising a flexible, hybrid approach to analysis, following the six-step process outlined by Braun and Clarke (2022). In accordance with the research’s experiential orientation and aims, analysis was predominately inductive, whereby data generated themes in attempts to prioritise individuals' experiences and meanings through openness and curiosity (Braun & Clarke, 2022). However, separating one’s own ideas, experiences, assumptions, and knowledge of the literature is considered impossible to achieve (Braun & Clarke, 2006, Braun & Clarke, 2022). Accordingly, a hybrid inductive-deductive approach was adopted, which was primarily inductive, whilst incorporating features of deductive analysis, whereby these influences were acknowledged to have shaped the analysis. According to Braun and Clarke, (2022) coding occurs on a continuum from semantic, relating to explicit meaning to latent, reflecting implicit meaning within the data. Given the predominately inductive nature of analysis and my positioning as a novice researcher, codes of a semantic nature were more prevalent than latent (Braun & Clarke, 2022).

Reflexivity is deemed integral to engagement in RTA, whereby researcher subjectivity should be acknowledged and embraced (Braun & Clarke, 2022; Byrne, 2022). Reflexivity is also necessitated by the adoption of critical realism, which requires transparency of the values held (Botha, 2021a). Considered an ongoing process of personal discovery, reflexivity involves acknowledging the influence of my values, assumptions and experiences upon decisions made and meanings constructed, as an active participant in knowledge production (Guillemin & Gillam, 2004; Savin-Baden & Major, 2023). In recognising these influences as inevitable, neutrality was not aspired, although a stance of open curiosity was adopted throughout the research process (Willig, 2013).

2.5.2 Reflexivity and positionality

Practicing reflexivity required a critical examination of my positionality, to consider others' perceptions of my role and potential influences on the nature of interactions and power dynamics (Breen, 2007). Researcher positionality is commonly viewed as a dichotomy between either an ‘outsider’ or ‘insider’, dependent on shared identities with participants (Thomson & Gunter, 2011). In this regard, I may be considered more of an ‘outsider’, as I do not share an identity with participants as parents of autistic children. Whilst acknowledging this potential positioning is important, I do not consider this to be a disadvantage. Rather, I align with the assumption that through remaining openly curious and interested, a shared membership is not essential to appreciating and representing their experiences (Dwyer & Buckle, 2009). Some have contested this dichotomy, considering positionality to be fluid, in which researchers can occupy the ‘space between’ on an insider-outsider continuum dependent, upon contextual influences (Dwyer & Buckle, 2009; Milligan, 2016; Thomson & Gunter, 2011). I consider my position as occupying this space, as many positions were likely to be adopted depending on individuals' perceptions of my positioning. For instance, concerning my shared membership with the profession being explored, my experience and enthusiasm for supporting families of autistic children (Clarke & Braun, 2013). Furthermore, by acknowledging knowledge was gained from parents’ experiences, I recognise I am unable to remain a full ‘outsider’ within the research process (Willig, 2013, Dwyer & Buckle, 2009).

It was imperative to acknowledge the potential influences of positionality and shared identity with the profession on power relations. For instance, influence on the extent to which parents felt able to honestly share their experiences or may have perceived me in an expert position to advise them (Mercieca, 2009). Balancing power relations was required so individuals could be considered co-constructors of knowledge within the research process (Karnieli-

Miller et al., 2009). To address this, I was transparent in communicating my membership to the profession and explicit about my role as a researcher rather than a professional within the process from the outset. This influenced recruitment decisions, which involved contacting local parent-carer forums and charities to provide a more neutral means of recruitment compared to relying on EPs as ‘gatekeepers’, who may have contributed bias in who was recruited or influenced those willing to be involved (Miller & Bell, 2012). During data collection, reflexivity afforded me an awareness of my own experiences on interview discussion and subsequent interpretation. Thus, attempts to build rapport and trust were made through active listening to prompt open and curious dialogue in exploring individual experiences and following their agenda where possible (Clarke & Braun, 2013). Indeed, I noted individuals appeared comfortable, openly and honestly sharing their experiences, despite not sharing elements of their identity and belonging to the profession discussed (Breen, 2007).

2.6 Quality in qualitative research

Generation of good qualitative research is valuable and provides useful knowledge, which some argue requires assessment of quality (Meyrick, 2006; Yardley, 2017). Whilst there is disagreement on the necessity for assessment, it may support researchers to reflect on what needs to be considered when conducting qualitative research (Hammersley, 2007). Qualitative quality assessment rejects scientific assumptions relating to objectivity, instead noting knowledge obtained is influenced by the “people, activities and understandings that make up their ever-changing context” (Yardley, 2017, p. 295). Therefore, also reflecting the assumptions of critical realism this research adopted. Relating to RTA, Braun and Clarke (2021) also argue positivist indicators of reliability and removing bias are incongruent with its subjective and reflexive nature and posit researchers should produce good quality qualitative research, evaluated in its own right. As such, their guidance on good quality RTA was carefully considered during the analysis process (Braun & Clarke, 2021). To evaluate the research overall, dimensions developed by Yardley (2000) were applied, which can be used flexibility to reflect on research (Yardley, 2017). This presents four dimensions of qualitative research quality: sensitivity to context, commitment and rigour, transparency and coherence and impact and importance. Each have been considered throughout the process, to promote the production of good quality, useful research which can hopefully be impactful in informing practice and policy (Appendix E).

2.7 Ethical considerations

2.7.1 Procedural ethics

Ethical considerations were managed according to the British Psychological Society's (BPS) 'Code of Human Research Ethics' (BPS, 2021b) and ethical approval was obtained from the Newcastle University Ethics Committee. Such ethical considerations relate to 'procedural ethics', which are examined at the outset (Guillemin & Gillam, 2004), such as using semi-structured interviews in favour of focus groups, to help individuals feel comfortable and protect their wellbeing.

Informed written consent was gained prior to involvement, through provision of information and consent forms (Appendix F). Whilst written consent was necessary, ensuring ongoing consent was also essential (Miller & Bell, 2012). Thus, consent was revisited at the outset to reiterate their involvement was voluntary and they were able to request the interview be stopped at any point. Throughout interviews, I continually ensured individuals wished to continue and upon conclusion, verbal and written debrief were shared (Appendix F). Interviews required reflections on experiences regarding potentially sensitive topics of involvement and support from EPs, which may have provoked negative feelings not otherwise elicited (Willig, 2013). Whilst this was not the intention of the research, I aimed to reduce this by ensuring individuals were aware they did not have to answer any questions they did not wish to. A copy of the questions was offered prior to interviews if individuals wished, and continued opportunities were offered to ask questions. Participants were reminded of their right to withdraw in the prior information and at the start of interviews. Similarly, they were reminded of their right to request the removal of data until the finalisation of the analysis.

2.7.2 Ethics in Practice

The dynamic, relational nature of qualitative inquiry requires consideration of ethical issues beyond procedure to acknowledge potential issues arising during personal interactions. These involve 'ethically important moments' which cannot be pre-empted (Guillemin & Gillam, 2004, p. 262), but warrant sensitive responses to maintain research integrity (Baker et al., 2016; Taquette & Borges da Matta Souza, 2022). Adopting reflexivity is considered to facilitate the management of ethical issues, which was relied upon during interviews. For instance, some parents shared challenging experiences related to their children's needs and involvement with EPs. Thus, to ensure my researcher positioning was maintained, I ensured I was aware of the emotions this provoked for me and resisted unethical practices, such as offering advice and temptations to input my professional thoughts to allow them to share their experiences. Communicating my role as a TEP researcher from the outset enabled me to do so and afforded space for individuals to hopefully feel listened to and heard without the expectation involvement would result in direct change for them personally. Throughout the process, reflection space was sought using supervision and a research diary to promote reflexivity and maintain my wellbeing.

2.8 Summary

This chapter considered the empirical project relating to the meta-ethnography. Within this, the philosophical positioning adopted within the research has been examined to warrant the approach used and acknowledge its influence on the research. Alongside this, the importance of reflexivity has been acknowledged in recognising the influences on aspects of the research process and managing ethical considerations.

Chapter 3: How can Educational Psychologists (EPs) support families of autistic children?: An exploration of parents' experiences and perspectives.

Abstract

Research suggests families of autistic children may experience elevated levels of stress, impacting their general wellbeing. Providing support for families, including formal support, such as from professionals and services may therefore be beneficial. Despite the role Educational Psychologists (EPs) have in working with families, there is a paucity of research that explores parents' experiences and perceptions of formal support within the context of Educational Psychology. In relation to the literature gap, this qualitative research aims to explore how EPs can support families of autistic children, by exploring parents' experiences and perspectives of support from EPs. Individual semi-structured interviews were conducted with seven mothers from five Local Authorities in Northeast England. Data was analysed using reflexive thematic analysis which generated four main themes: (1) equitable access to educational psychologist support; (2) adopt a family-centred approach; (3) assume a coordinator role; (4) empower others with knowledge and understanding. Findings contribute to the literature exploring experiences of formal support for families of autistic children and are contextualised within a discussion of implications for individual EP practice, alongside broader service level considerations to support family systems.

This study will be submitted to Educational Psychology in Practice following examination and is therefore written in the style of papers published in this journal.

Keywords: autism, parents, families, support, Educational Psychologists

3.1 Introduction

3.1.1 Context

Statistics indicate an increase in diagnoses of autism within the United Kingdom (UK), thought to be related to increased awareness and recognition of autism, alongside increased access to diagnosis (Russell et al., 2022), with rates of diagnosis higher amongst children and young people (O'Nions et al., 2023). Within England, the number of children and young people with special educational needs and disabilities (SEND) has continued to rise in recent years; autism is currently the most prevalent special educational need amongst those with Education Health and Care Plans (EHCP) (HM Government, 2023).

Research suggests families of autistic[1] children may be more likely to experience challenges in managing their children's needs, advocating for them, and navigating support systems and services which may then impact their wellbeing (Boshoff et al., 2018; Hartley et al., 2012; Hayes & Watson, 2013; Keville et al., 2024). Research has been encouraged to explore how this can be mitigated through support from professionals and services, corroborating with the autism community research priorities (Pellicano et al., 2014; Pellicano et al., 2013). However, there is a paucity of research exploring this within the UK context, with the limited literature demonstrating families' varied experiences of formal support provision from professionals and services (Galpin et al., 2018; Milosevic et al., 2022; Preece, 2014).

In England, the importance of working with and supporting families is enshrined in legislation, exemplified in the Children and Families Act (Department for Education, DfE, 2014) and subsequent SEND Code of Practice (SEND CoP) (DfE & Department of Health, DoH, 2015), which endorse collaboration with families and promote their greater control of support provision. The recent SEND and Alternative Provision Improvement Plan (DfE, 2023a) has also advocated for collaboration with families, aiming to improve access to the right support at the right time and the experiences of families navigating the SEND system. Specific to autism, commitment to improve support access was proposed in the introduction of the National Strategy for Autistic Children, Young People and Adults: 2021 to 2026 (DoH & DfE 2021) setting out aims to improve support for children and young people, and families.

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[1] This chapter uses identity-first language (autistic children) in accordance with terminology used by participants and reflective of liked terminology within the autism community in favour of person-first language (i.e., child with autism) (Bottema-Beutel et al., 2021; Kenny et al., 2016).

Such commitment to working with and improving support for families seems underpinned by a holistic perspective, acknowledging the influence of complex interactions occurring within the family systems influence on children, echoing an ecosystemic perspective (Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 2007). This posits promoting family-wellbeing (encompassing parental wellbeing), is likely to influence the wellbeing of the child through interactions across the system (Newland, 2014, 2015). In highlighting the influential nature of the family system, the importance of working with and supporting families is emphasised (Desmarais et al., 2018).

3.1.2 Educational Psychologists working with families

Research examining families' experiences of formal support has typically focused on the autism diagnostic process or support primarily pertaining to social and health care professionals and services and school-based professionals (Galpin et al., 2018; Hasson et al., 2024; Milosevic et al., 2022, Preece, 2014). Whilst working with families is considered central to good Educational Psychology practice (Dunsmuir et al., 2014; McGuiggan, 2021), there is a dearth of research exploring families of autistic children's experiences with Educational Psychologists (EPs). This is noteworthy given EPs often work directly with adults supporting children and young people, including parents and carers (Farrell et al., 2006; Toland & Carrigan, 2011). Moreover, due to EPs' statutory role in providing psychological advice for Education, Health, and Care Needs Assessments (DfE & DoH, 2015), they are likely to engage with a high number of autistic children and their families. Indeed, Sadreddini et al. (2019) found in a study of assessment practices, around 25% of the EPs' workload related to autism.

It is suggested that to meet the needs of families, EPs must establish a rationale for developing systems to engage in family work (Dunsmuir et al., 2014). McGuiggan (2021) postulates espousing a holistic, ecosystemic perspective on child wellbeing affords such rationale. Therefore, EPs should seek to operate within the influential systems in a child's life, including their families. However, whilst small scale, exploration of EPs' experiences and perspectives on family work portrays a cautiously critical perspective of current engagement (McGuiggan, 2021), inferring the profession may be continuing to serve bureaucratic educational functions rather than delivering family-focused support to meet the needs of children and their families (MacKay, 2006; McGuiggan, 2021).

Recent research exploring EP support from families' perspectives is limited. Previously, Squires et al. (2007) found parents valued EP involvement, reporting support offered was helpful. However, some parents have discussed a lack of EP role clarity, documented in Black African parents' experiences of an Educational Psychology Service (EPS) (Lawrence, 2014). Recently, Department for Education research examining the EP profession suggested families can experience positive outcomes, improving understanding of children's needs, feeling listened to and empowered and enhancing parenting skills (Atfield et al., 2023), whilst noting current systemic issues, such as EP retention, capacity and resources impacting EP practice. Relating to autism, parents have discussed benefitting from support from workshops and groups to develop their understanding, which has involved EPs as part of multi-disciplinary teams, although more recent research is necessary (Connolly & Gersch, 2013; Flynn et al., 2010). This research hopes to contribute to our understanding of EP family work and autism specific support by exploring how families' experiences and perspectives on support from EPs can inform both EP practice, alongside service level development relating to family work.

3.2 Methodology

3.2.1 Research context

The research adopted a qualitative approach using semi-structured interviews conducted with seven mothers from five Local Authorities (LAs) in Northeast England. Families typically access support through LA support services. Educational Psychology Services (EPSs) operated a partially or fully traded model with schools, alongside statutory functions. Some EPSs were under increasing statutory pressures, restricting their capacity to engage in traded work.

3.2.2 Ethics

The research obtained ethical approval from Newcastle University Ethics Committee and was conducted according to the British Psychological Society (BPS) 'Code of Human Research Ethics' (BPS, 2021b). Issues of informed consent, right to withdraw, and appropriate use of data were discussed with participants from the outset and they were reminded following interviews of their right to request the removal of data until completion of analysis. To ensure confidentiality, identifying information has been removed and pseudonyms used.

3.2.3 Participants

Participants were recruited through parent/carer forums and charities across Northeast England. Inclusion criteria were parents or carers of a child or young person with a diagnosis of autism or on the diagnostic pathway and who have experienced involvement with EPs. The decision to recruit families of children and young people who were on the autism diagnostic pathway was taken to reflect the waiting times to receive a diagnosis (Crane, 2018; Crane et al., 2016) and suggestion of the need to support families whilst awaiting formal diagnosis (Sapiets et al., 2023). Recruitment involved emailing parent/carer forums and charities to request information be shared, as well as attendance at a local parent/carer forum meeting. This approach aimed to recruit a diversity of parents, for example fathers, however, only mothers volunteered to participate in the research. Participants contacted the researcher via email and were sent information and consent forms to ensure an understanding of the research purpose and gain informed consent (Appendix F). Seven mothers from five LAs were interviewed. Based on parental reports, children were diagnosed with autism. Four children had additional needs and diagnoses (Table 9).

Table 9: Participant Information, Child's Details and Relevant Contextual Information

Participant Pseudonyms	Child's gender	Child's age	Educational context and co-occurring needs	Relevant contextual information in relation to involvement with Educational Psychologists	Local Authority
Mother 1 (Angela)	Male	13 years old	Attends mainstream provision Attention Deficit Hyperactivity Disorder (ADHD) and Tourette's syndrome	Had previous EP involvement when child was in Year 4, prior to EHCP process. Then again during the EHCP process, contributing to the assessment Referred for Educational Psychology involvement in Year 7 and is awaiting involvement	A
Mother 2 (Maria)	Female	10 years old	Attended specialist provision but currently not attending an educational provision. ADHD and anxiety	Had involvement from Educational Psychologist as part of EHC assessment	B
Mother 3 (Hannah)	Male	16 years old	Attends mainstream provision	Had Educational Psychologist involvement when child was on the diagnostic pathway	B
Mother 4 (Olivia)	Female	8 years old	Attends mainstream provision	Had involvement from Educational Psychologist as part of EHCP assessment process	C
Mother 5 (Susan)	Male	7 years old	Attends specialist provision	Had involvement from an Educational Psychologist as part of EHCP assessment process	D

Mother 6 (Sally)	Female	12 years old	Attends mainstream provision Moderate learning disability	Educational Psychology involvement to conduct assessment following transition to secondary school. Child recently received EHCP	C
Mother 7 (Lynne)	Female	11 years old	Attended mainstream, but currently not attending educational provision Anxiety	Educational psychologist involvement at points from around 5 ½ years old. Educational Psychologist involvement during autism diagnosis, following diagnosis and for an EHCP assessment involving a private EP.	E

3.2.4 Semi-structured interviews

Semi-structured interviews were conducted using a schedule to structure discussion, informed by the research question and aims (Willig, 2013). Contextual questions were followed by open-ended questions to explore individuals' experiences of support from EPs and their perspectives on how EPs can support families of autistic children. Follow up and prompt questions were used to support the flow of interviews. To ensure the questions asked were appropriate and accessible, they were shared with a local parent/carer forum lead and the language was modified based on feedback (see Appendix G for interview schedule).

Interviews were conducted in person or virtually using Zoom based on individual preference. One participant elected to meet in person, which occurred in a quiet room in a university building. Interviews were audio recorded, transcribed verbatim, and deleted following transcription. Whilst it is important to acknowledge videoconferencing has limitations, such as potential technological difficulties, this approach was adopted as a practical data collection method to increase accessibility and convenience and allow for geographically dispersed participants across Northeast England to participate from home (Archibald et al., 2019; Thunberg & Arnell, 2022).

A timeline of participants' involvement with EPs was developed with the researcher at the outset of interviews. This chronological tool aimed to provide contextual information, aid discussion and elicit exploration of experiences which may not have been provoked by interview questions alone (Milosevic et al., 2022). As interviews were predominately virtual, the researcher created timelines that were discussed with participants.

3.3 Data Analysis

Following transcription, data was analysed using reflexive thematic analysis (RTA) following the six-steps outlined by Braun and Clarke (2022) (Table 10). This was adopted as a flexible approach to qualitative analysis, allowing patterns of meaning to be explored within the data and allowing novel interpretations to be generated through active researcher involvement (Braun & Clarke, 2022; Byrne, 2022). Furthermore, the flexibility afforded exploration of experiences of support from EPs, alongside gaining their perspectives on how EPs could support families.

NVivo assisted with coding and data management of transcripts (QSR International, 2023). Whilst primarily inductive coding occurred which approached data with open curiosity, RTA acknowledges the subjective nature of the analysis, whereby the researcher plays an active role (Braun & Clarke, 2022). Therefore, elements of a deductive orientation were also present, as influenced by the researcher's professional experience as a Trainee EP and topic knowledge. Coding reflected semantic and latent levels, offering descriptive and interpretative meaning (Byrne, 2022) and analysis was recursive, as data and codes were continually revisited to generate themes.

Table 10: Six steps involved in reflexive thematic analysis, as documented in Braun and Clarke (2022, p.35-36).

Phases	**Description of stage in practice**
Familiarisation with the data	Process of repeated listening to audio recordings of interviews, transcribing verbatim and repeated reading and re-reading of transcripts to become familiar with the data.
Generating initial codes	Systematically reading through the full data and coding any aspects of the data that are relevant to the research question. Coding was conducted several times, going through the dataset in a different order.
Generating initial themes	Process of exploring patterned meaning across the dataset by compiling codes which are similar to generate initial themes that capture a shared concept.
Reviewing themes	Review the fit of themes with the data set by revisiting the coded data and the full dataset. Begin to consider the relationship between themes and relevant existing knowledge.
Defining and naming themes	Refining themes to ensure they capture the data and are clearly demarked. Involves generating relevant definitions and names for each theme.
Producing the report	Identifying data extracts to provide a coherent explanation of the data set that answers the research question and aims to produce a report of the analysis process.

3.4 Results and Discussion

Findings explore how EPs can support families of autistic children, based on the experiences and perspectives of parents. Analysis generated four overarching themes: *(1) equitable access to educational psychologist support; (2) adopt a family-centred approach; (3) assume a coordinator role; (4) empower others with knowledge and understanding* (see Appendix H for thematic map). Themes are visually represented (see Figure 3), with equitable access to EP support around the periphery, reflective of the broader, systemic influences impacting access to appropriate EP support for families of autistic children. Elements of individual EP practice discussed by parents are centrally situated, illustrative of noted systemic influences, such as capacity and resources on individual EP practices.

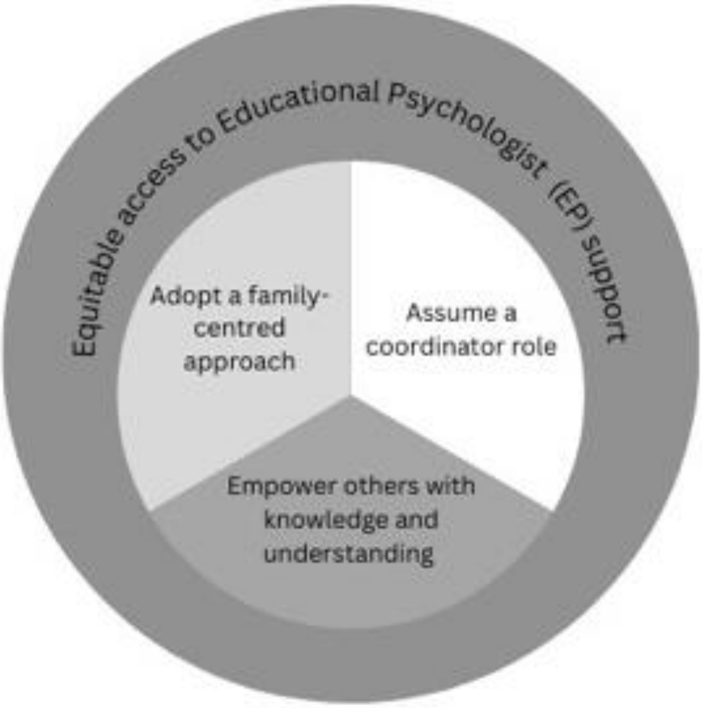

Figure 3: Visual representation of how EPs can support families of autistic children based on parents' experiences and perspectives.

3.4.1 Theme one: Equitable access to Educational Psychologist support

The socio-political context influences the EP role and Educational Psychology Services (EPSs) (Farrell, 2010; Lee & Woods, 2017). This theme pertains to systemic factors contributing to inequitable access to support, relating to school factors, resources, and capacity constraints.

Parents perceived schools as gatekeepers of Educational Psychologist support. Referrals were requested, but they inferred schools were not forthcoming or willing to fund. Differing behavioural presentations at home compared to school were related to accessing EP support. Parents inferred their children masked difficulties and appeared to be coping in school, meaning needs were less likely to be recognised unless they reached "*crisis point*" (Sally). This is reflective of recent research inferring schools may lack an appreciation of children's differing presentations, impacting referrals for support (Keville et al., 2024). This may also be understood within the context of school budgeting pressures, reducing resources for special educational needs (Hasson et al., 2024) and restricting capacity to refer those without the highest level of need (Atfield et al., 2023). Such funding constraints have been recognised in the recent SEND improvement plan (DfE, 2023a), which promises funding increases within education.

> *"If the child masks and obviously this is specific, because children who are acting out in school. They are more likely to get support easier. Get a referral and everything, but that should change". (Hannah)*

This may relate to the traded nature of service delivery, positioning schools as main stakeholders, with ownership to commission EP support (Lee & Woods, 2017). Findings therefore reflect McGuiggan's (2021) assertion that EPSs seem to be serving bureaucratic educational purposes and becoming increasingly inaccessible to families who would value support. Further, school staff's perceptions of the EP role may constrain support, associating EPs with statutory work and individual assessment rather than systemic family work (Ashton & Roberts, 2006; Atfield et al., 2023). Working with schools, EPs may be positioned to explore when referrals may be appropriate, highlight differing presentations of autism and encourage systemic work to provide proactive, early intervention for children and families who may benefit from support (Mount & Dillon, 2014).

Parents referred to a lack of resources limiting access to EPSs, further indicating the demand for EP support seemingly exceeds capacity (Atfield et al., 2023). Long waiting times influenced access to timely support, assessment of need and early intervention, as noted by Angela, who had waited over two years for further involvement for her son. Regarding this, parents noted systems as being "*overstretched*", resulting in them having to fight for "*finite*" services:

> *"they are swamped with applications, and I know they are short staffed, so you know it has got to give somewhere in the system, I do understand that, but I don't know what the solution is, other than loads more money". (Angela)*

> *“but I just know as a parent of a SEND kiddy…services are so, so finite and everything's a struggle and you've really gotta have sharp elbows to get things done”. (Maria)*

This reflects an examination of EPSs, which highlights the impact of service cuts, recruitment and retention difficulties on capacity and extended waiting times (Atfield et al., 2023). EPs share frustrations, reporting insufficient time and resources to engage in preventative work and meet the needs of children and their families (Atfield et al., 2023). Issues accessing timely EP support has been recognised, with the government further increasing EPs numbers, with hopes of addressing this (DfE, 2023a). Such constraints led Lynne to seek a private EP, but she reflected this as a privilege other families may be unable to access. Parents reflected on skills required to advocate through self-education to gain information, advice and navigate the educational system and requested equitable EP support for all families. This corroborates literature indicating families require financial and social resources to navigate the education system (Boshoff, 2018, Sales & Vincent, 2018, DfE, 2022, Crane et al., 2023), inferring changes within the wider SEND system are also necessary so all families can access support.

> *“Well I think it is about that equity, so it shouldn’t be about those that are more articulate get more and I think ermm every child and every family should get what they need”. (Angela)*

3.4.2 Theme two: Adopt a family-centred approach

The central concept of this theme relates to the value of practice reminiscent of a family-centred approach. Such approach is founded upon family systems theory and more broadly ecological systems theories (Dempsey & Keen, 2008; Keen & Rodger, 2012; McGuiggan, 2021) acknowledging the interrelatedness of the family system in which a child is situated. Effective parent-professional partnerships are considered foundational to a family-centred approach, underpinned by collaboration, mutual respect, trust and joint decision-making (Keen, 2007; Keen & Rodger, 2012).

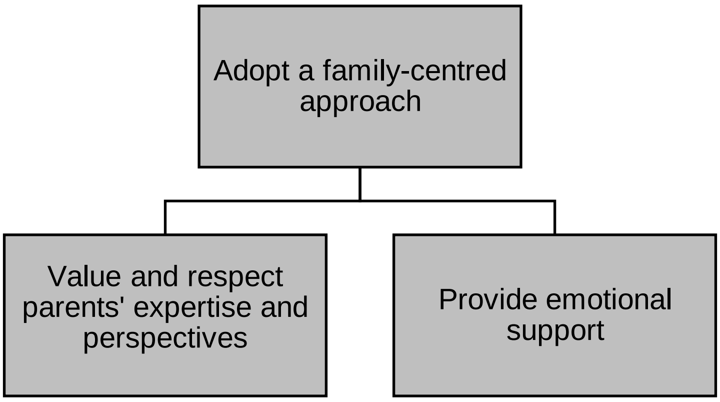

Figure 4: Thematic map for 'Adopt a family-centred approach'

3.4.2.1 Subtheme: Value and respect parents' expertise and perspectives

This pertains to a family-centred approach, based on the importance of EPs valuing and respecting parents' perspectives and expertise of their child. Seeking parental views is a statutory requirement, as discussed in legislation (DfE, 2014, DfE & DoH, 2015), which is significant given parents are considered to have "detailed knowledge and understanding of their own child" (Keen & Rodger, 2012, p. 26). Parents spoke of valuing EPs who sought their experiences and views and communicated these within written reports.

> *"I do think that report had a lot in like about experiences as a family in terms of like what I have to support [child] with daily and stuff...so, like my experience as like a parent/carer". (Sally)*

Conversely, some parents felt EPs were more likely to value the perspectives of professionals, such as school staff. Parents recounted feeling discredited and dismissed when "*professionals listen to professionals*" (Susan) and privilege professionals' views over parents. Hannah reflected she felt the EP had shared the school staff's perspective regarding her child's difficulties without considering her views. This is pertinent, as research highlights the importance of acknowledging these perspectives may differ in relation to autism. School staff's views may be influenced by children's behavioural presentation in school, as some children may mask differences compared to home (Keville et al., 2024; Tomlinson et al., 2020), as well as school staff's understanding of autism (Galpin et al., 2018; Milosevic et al., 2022). Parents are significant in their children's life, bringing unique insight professionals do not possess. Thus, valuing them as experts of their child was emphasised across interviews. In doing so, parents felt validated, represented, and involved in decision-making influencing their child.

> *"it's that somebody [EP] who's actively involved in the process, respect my opinion and therefore, I feel like I'm going to be represented…as a parent, he valued more than anything else what our opinion was...[he said] you know him better than anybody". (Susan).*

Research infers feelings of blame and judgement is common in interactions with professionals (Galpin et al., 2018; Milosevic et al., 2022). Parents in this research commented on the need for EPs to "*hear people, respect them*" (Lynne) and be "a*s non-judgemental as possible*" to reduce feelings of "*shame and blame*" (Hannah). In doing so, parent-professional relationships are likely to be more effective, founded on mutual trust and respect for one another (Keen, 2007; Keen & Rodger, 2012). This is pertinent given statutory requirements to promote parental voice and involvement in decision-making (DfE, 2014, 2015). Parents commented on pursuing partnerships with EPs, seeking balanced power in which EPs "*work with the family to identify how to support the child*" (Angela) and the importance of "*stand[ing] with parents*" (Hannah). This echoes a family-centred approach, which endorses professionals working as a team alongside families (Keen & Rodger, 2012). Illustrative of this, Susan shared how working as a collective in the best interests of her family and child felt supportive:

> *"I felt like they [EP] were kind, they were on, they were on our team, and they were on his [child's] team".*

A family-centred approach requires parents to feel respected and valued, as well as listened to, heard and validated (Dempsey & Keen, 2008; Epley et al., 2010). Parents' experiences of this within interactions with EPs were disparate. Some felt EPs displayed genuine interest, afforded time and space to share experiences, elaborate on responses and discuss what was important to them. Contrastingly Maria felt interactions were inauthentic during a statutory assessment, and a "*data collection exercise*". EPs typically engage in brief interactions with parents during statutory assessments. However, these contrasting experiences emphasise seeking opportunities for open dialogue to actively listen should be an important consideration for EPs, irrespective of the nature of involvement.

> *"there was a discussion around, so what does sleeping well look like for him and you know, really took the time to understand more than just a tick box exercise". (Susan)*

> *"particularly the private provisions [EPs], I felt supported, I felt heard…It was really nice to be able to have that conversation". (Lynne)*

3.4.2.2 Subtheme: Provide emotional support

Recognising the emotional impact on families of managing their children's needs and navigating the education system was highlighted. This reflects recent research whereby mothers commented on stress caused by navigating the EHCP process (Keville et al., 2024), alongside general research indicating increased stress related to challenges parenting autistic children (Hayes & Watson, 2013; Vasilopoulou & Nisbet, 2016). Parents generally commented on limited recognition and acknowledgement of this from professionals and services:

> *"It's kind of your whole life gets turned upside down. I mean, my whole life has been completely turned upside down…But there's no appreciation of that sometimes, services of that you know". (Olivia)*

> *"And just the basic struggle of, you know 30 different triggers…they just don't know that because they're not living it and why should they?" (Hannah)*

Olivia expressed, "*there is an element of looking after the parent too*", although she felt this was not experienced within her interactions with the EP, leaving her feeling "*forgotten*". Openly sharing challenges with professionals is likely to be difficult for parents (Gibbs et al., 2022), and thus, it is important they demonstrate empathy, warmth and understanding toward parents. A lack of emotional support received from EPs and professionals generally was discussed, echoing findings from Crane et al., (2018), whereby parents endorsed a professional role in promoting parental wellbeing, allowing them to feel more able to support their children. This view was shared within this research, as exemplified by Lynne:

> *"and the better off I feel and the more supported I feel, the more effectively I care for her. And therefore the less I will need those services in the first place and that is missing". (Lynne)*

This endorses the adoption of a family-centred approach, recognising the child as situated within the family unit (Keen, 2007; Keen & Rodger, 2012) and the association between parental wellbeing and child wellbeing, highlights the potential benefits of supporting parents in promoting positive child outcomes (Newland, 2014, 2015). In espousing to an ecological systems approach which recognise the influential interactions within the family systems (Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 2007), EPs should appreciate parental challenges and seek to offer emotional support to promote parents' ability to support their child. Regarding this, parents discussed how showing a genuine interest in how the parents are, beyond a sole focus on the child may be experienced as supportive:

> *"I think most professionals don't ask you, how are you as a parent, so that is not unique to Ed Psychs, it is really rare for somebody to say, 'how are you?' and actually mean it". (Angela)*

EPs are considered skilled professionals, who can adopt interpersonal skills to demonstrate warmth and empathy when engaging with parents (Nolan & Moreland, 2014). Family-centred literature posits being sensitive to parents' feelings may foster positive relationships between parents and EPs and potentially reduce parental stress (Keen & Rodger, 2012). However, whilst offering such emotional support for families is endorsed, EPs should also attend to the potential impacts of doing so on their own emotional wellbeing (Cohen & Mosek, 2019).

3.4.3 Theme three: Assume a coordinator role

This theme pertains to EPs assuming a broader coordinator role to support families, relating to coordinating support with other professionals, providing follow up and ongoing support, and signposting families to support.

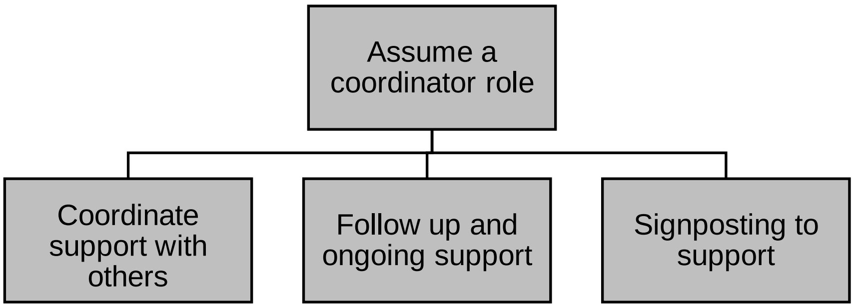

Figure 5: Thematic map for 'Assume a coordinator role'

3.4.3.1 Subtheme: Coordinate support with others

Families may experience a high level of engagement with health, social, and educational professionals and services and are often solely responsible for coordinating this (Desmarais et al., 2018), for instance, Angela recalled 52 appointments in the year her son received an EHCP. Such level of engagement has practical and emotional implications for families, often at the expense of their needs (Avery et al., 2022). EPs assuming some responsibility for coordinating support and promoting joined-up working were suggested as potentially supportive:

> *"I don't know if this is part of the role, but it would have been nice for somebody to take charge, because you have you know, loads of organisations involved… and for somebody to just coordinate that would have been nice". (Angela)*

This is further inferred through Lynne's experience of a private EP assuming a coordinator role and reducing the responsibility on her to do so. Parental autism advocacy literature indicates parents are often required to fight for support (Boshoff et al., 2018), and thus value having a consistent point of contact to improve provision of and coordinate services (Milosevic et al., 2022). Lynne reflected the EP assumed a "*care coordinator role*", taking a greater responsibility and she felt they were "*carrying the torch*" during that period. A focus on multi-agency working in education has long been reflected in legislation, particularly the SEND CoP (DfE & DoH, 2015) which endorses greater communication and collaboration between professionals and services, in attempts to reduce pressures on families (Ahad et al., 2022; Cochrane & Soni, 2020). EPs are skilled in fostering collaborative relationships so involvement in promoting joint working is suggested to be experienced positively by parents, although sufficient time is required to dedicate to this role, which is likely impacted by current constraints on the profession (Atfield et al., 2023).

EPs were typically associated with education, reflected in suggestions of coordinating support with schools. Maria commented parents are "*always like looking for support. Who's gonna, you know, hold your hand through this process or whatever*" and inferred they would have benefited from the EP working with the school to explore how support could be implemented following statutory assessment. This was echoed in discussions of facilitating and opening of communication between parents and school. EPs were noted to work as a team alongside families and schools to structure discussions and coordinate support in the interests of the child. EPs also coordinated support without direct engagement, as through offering insight into the child's needs and offering recommendations, parents noted communication with schools was facilitated to inform support for their child.

> *"we've got recommendations that we can start talking about and that helps us to communicate with school effectively". (Lynne)*

> *"It opened that conversation between me and school sort of thing, so now it's easier". (Olivia)*

EPs may be involved in situations where home-school relationships have deteriorated. These are often acknowledged as time consuming and difficult to manage (Atfield et al., 2023) and therefore may be less able to support during brief involvement. This was reflected in Olivia's account of sharing with the EP that she would like communication to be opened with school, yet recalled no attempts to share this with school or document it within the report:

> *"I really wanted the lines to be opened and I've kind of asked her, could she put that in the report, like mam would want some like more fluid conversation, communication, but that didn't get documented". (Olivia)*

Whilst time consuming, mediating these relationships is further valued by schools (Atfield et al., 2023). EPs are skilled in bringing parties together, for instance, joint home-school consultations to facilitate a shared understanding and promote collaborative working (McGuiggan, 2017). Consultation research further illustrates this, inferring this promotes positive communication and home-school relationships, which may persist beyond EP involvement (Nolan & Moreland, 2014).

3.4.3.2 Subtheme: Follow up and ongoing support

Parents considered follow up and ongoing support to be lacking within their experiences. Involvement was typically brief, reflective of the general episodic, transient nature of formal support for families (Galpin et al., 2018; Milosevic et al., 2022). EPs contribution of recommendations within reports, particularly in statutory work was highly valued. However, this was considered to be reduced by lacking follow up. Support was considered to fall short when recommendations were not always implemented within school. For Lynne, attempting to uphold and reinforce these without EP support was effortful:

> *"And the only, the only person left to fight that corner is me. Now that takes quite a lot of understanding to pick apart why that wasn't quite right what they did…read that Ed psych report and then stand up for what it represents". (Lynne)*

This is echoed in existing research inferring schools lack adherence to professional recommendations (Squires et al., 2007) and is potentially reflective of a broader issue concerning competence, knowledge and resources. Indeed, Hasson et al. (2024) asserted school staff felt ill-equip to support autistic students, related to lack of funding and resources. Whilst it was acknowledged EPs "*don't have much control*" (Hannah) to enforce recommendations, parents consistently expressed follow up would be beneficial to explore how they may be implemented within the school's context.

> *"I'm guessing the Ed Psych gave the report, I don't know. They assume other people do stuff with it, and that's not necessarily the case". (Maria)*

Parents had hoped for follow up with EPs to check in, review needs, progress and modify support. They noted their child's presentation changed over time and a lack of follow up and ongoing involvement limited opportunities to do so. Requests for follow up support were extended to parents. Olivia described feeling overwhelmed by information provided during her brief interaction with the EP and suggested follow up would have allowed her to "*come back and ask questions*" following a reflection period, alongside formation of a consistent relationship to seek support until no longer needed.

> *"You know that kind of continuous sort of process until actually parent goes, you know what, we're alright now, we're tootling along nicely". (Olivia)*

The benefits of this were exemplified by Lynne, who suggested she may feel "*less alone*" if ongoing support was provided. Banach et al. (2010) assert the necessity to provide follow up and consistent support for families to adapt to their own and children's needs and a focus on review is coherent with the graduated response to support endorsed in the SEND CoP (DfE & DoH, 2015). Moreover, brief involvement may jeopardise the formation of positive parent-professional relationships, limiting opportunities to develop rapport over time (Ahad et al., 2022; Keen & Rodger, 2012). Nevertheless, as reflected in theme one, constraints on time, capacity and resources were acknowledged by parents as limiting opportunities to do so. This is further echoed by EPs, who expressed workload pressures were currently limiting the formation of ongoing relationships to monitor impact (Atfield et al., 2023). Moreover, findings infer parents require greater clarity on the nature of EP involvement at the outset, as a means of managing expectations (Squires et al., 2007).

3.4.3.3 Subtheme: Signposting to support

Signposting was discussed across interviews, pertaining to signposting to informal supports, such as from other families and to services to meet the family's needs. As discussed, EP engagement can be short-term, thus, signposting to more consistent support was noted as beneficial. However, provision of information about local forums, organisations and charities offering informal supports varied. Sally regarded the EP as supportive, as they "*help[ed] in* *terms of…she signposted to a lot of organisations as well, which I hadn't actually heard of"*, whereas this was not experienced by all parents, as some commented on not being signposted to other support means.

Support from other parents is perceived as supportive within the literature, particularly in the absence of formal support (Avery et al., 2022; Galpin et al., 2018; Ludlow et al., 2012). Such support may offer a safe space to share and learn from other parents who demonstrate an understanding of their situation, which may foster a sense of belonging and promote family resilience and wellbeing (Fong et al., 2021; Milosevic et al., 2022; Trew, 2024). Such benefits were illustrated by Angela, as having benefited from parent coffee mornings coordinated by her son's school to form supportive peer relationships; she suggested a role for EPs in facilitating or promoting the utility of such groups. The majority of parents were involved in parent-carer groups, although typically through self-research. Literature infers families from lower social economic status and ethnic minorities may be less equipped with information to access local support (Boshoff et al., 2018). Informing parents of local support services is discussed in the SEND CoP (DfE & DoH, 2015) (Adams et al., 2017) and may be beneficial for EPs to be aware of local support or signposting to the Local Offer websites to gain information (DfE, 2014).

> *"the [LA] parent carer forum, nobody signposted me there. I had to do it myself…but I think at the time I would have really have benefited from something". (Olivia)*

Comments also concerned signposting to other professionals and services. Sally discussed how EP support led to involvement from autism outreach support for her daughter, whilst Hannah was disappointed when the EP did not refer her son for speech and language assessment. In some instances, parents appreciated EPs may be unable to support with specific concerns, but inferred support to access those who can, would be beneficial, therefore, potentially reducing the burden on parents to research and seek support (Boshoff et al., 2018).

> *"somebody would go ohh, you made a valid point or well, it's not, it's not technically something we get involved with, but I know from experience this, or you might be worth speaking to so and so…" (Susan)*

3.4.4 Theme four: Empower others with knowledge and understanding

The value of EPs empowering others with knowledge and understanding was conceptualised as two-fold. Sharing psychological knowledge to develop an understanding of the child, alongside informing parents of their role, involvement and processes.

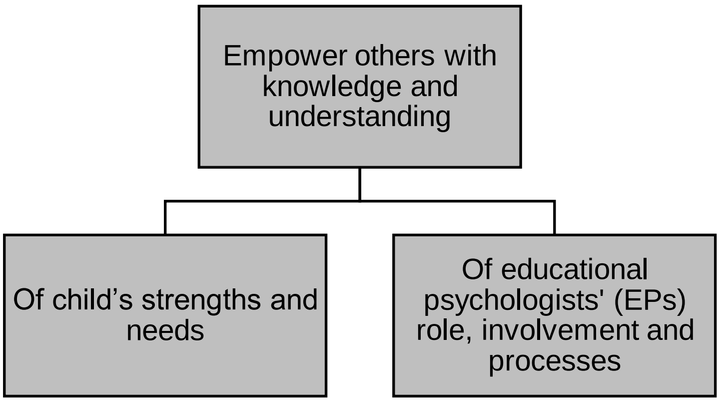

Figure 6: Thematic map for 'Empower others with knowledge and understanding'

3.4.4.1 Of child’s strengths and needs

Support related to forming a greater understanding of their child, to help inform support within the school and family contexts. EPs were inferred to have psychological expertise, which could offer insight and understanding, reflective of a conceptualisation of EPs as contributing psychological skills and knowledge (Birch et al., 2015; Farrell et al., 2006). Furthermore, it aligns with the profession’s acknowledgement of their skills in empowering and upskilling those supporting the child through sharing psychological knowledge (Atfield et al., 2023). Parents viewed support relating to developing new understandings of their child, inferring the provision of additional information would inform their conceptualisation of the child’s presentation.

> *“I think it's again, it's just knowledge, isn't it. Your knowledge is power, if you know your child behaves in that way, then you're gonna adjust how you think or how you, your expectation”. (Maria)*

> *“There have been times when we have been really on our knees and we have really, really needed help and you know help to understand him better, so that we can meet his needs better”. (Angela)*

Parents commented on either gaining or hoping to develop a better understanding of their child through EP involvement, particularly within the context of assessment. Research posits EPs are more likely to engage in assessment related to social skills and communication than non-EP professionals (Atkinson et al., 2022). However, interestingly, parents also associated expertise with assessment in the context of learning, although parents differed in regard to whether understanding of this was achieved within EP involvement.

> *"I kind of wanted more of a greater understanding of where she was at. I knew she had a learning difficulty, but I wasn't quite sure when, why and how…And that give me that understanding of actually this is the gap that we're trying to bridge". (Olivia)*

> *"I am waiting for a report on or an assessment on, this is how he learns well, this is how, this is what he struggles with… that is where their expertise lies, as an Ed Psych team". (Angela)*

Linking to wider constraints, some parents felt insufficient time was spent on assessment to fully understand their child's situation. Parents discussed assessment as a 'snapshot', for instance, Angela cautioned EPs to "*not read too much into a 30 minute classroom observation*", inferring the importance of a holistic assessment of the child, a skill EPs are considered to have regarding assessment (Atkinson et al., 2022), alongside an appreciation of parental expertise.

Parents inferred a greater understanding of their child helps tailor support and considered the influence on support offered for their child in school. This was discussed regarding schools' positioning of EPs as experts and thus parents felt they were more likely to respond to their advice.

> *"…and things that we talked about toilet training. And nobody had ever put it across to me in the way and I've explained this to so many people since and they've gone, oh I totally get it now." (Susan)*

Empowering others with knowledge and understanding reflects the notion of 'giving psychology away', by providing those who consistently support children with psychological knowledge (Miller, 1969). This was recently reiterated by EPs, who considered sharing expertise with those around the child effective in improving outcomes (Atfield et al., 2023) and reflects an appreciation of the influencing family system on the child (Bronfenbrenner & Morris, 2007). However, imparting knowledge may be considered to undermine collaborative working with parents, positioning the EP as the expert (Todd, 2007). A distinction between sharing expertise and adopting an expert position is therefore necessary. Whilst parents acknowledge psychological expertise EPs may offer, invariably parents consider themselves to be the experts on their child. Expert positioning is considered problematic to collaborative practice (Mahdi, 2020) and thus, EPs should seek to balance power relations by acknowledging parents' expertise (BPS, 2023). Such practice may facilitate equitable parent-professional relationships, with EPs offering psychological expertise parents may not possess to co-construct knowledge (Keen & Rodger, 2012), through which others can learn, be empowered and feel efficacious in applying their skills to support the child (Wicks, 2013).

3.4.4.2 Of EP role, involvement, and processes

A lack of clarity on the EP role and support offered was demonstrated across interviews. This resulted in differing assumptions of EPs' role and limited knowledge of their support remit, echoing reports of misunderstandings and uncertainty of the role amongst parents (Atfield et al., 2023). This reflected parents' experiences with services generally not being forthcoming with this information. For some, experiences were restricted to statutory involvement, meaning parents were unaware of the broader role, which limited the extent parents could comment on support they felt families would benefit from:

> *"I do think that a lot of the time it's not very clear what you can get from a service…that everybody likes to keep it to themselves what they can offer and they want to be in control, instead of letting you know". (Hannah)*

Greater information and communication of the role and what can be offered were suggested as beneficial to promote transparency. Findings of a lack of understanding and knowledge of the EP role may be related to the lack of consensus amongst the EP profession on what their role can and should entail. This reflects the assertion of EPs as "a puzzle to ourselves as well as others" (Parker, 2013, p. 87), leading to difficulties articulating the role. Nevertheless, parents have a right to be informed when involved with EPs and parents suggested EPs attend local groups to communicate their role and facilitate transparency and accessibility to parents.

The significance of being informed extended to knowledge of EPs' involvement, reflecting findings that suggest professionals who inform parents of involvement are valued (Stanford et al., 2020). Frequent, open communication with professionals is emphasised as helpful in working together with parents (Boshoff et al., 2018). Sally felt being informed of EP involvement through open, regular communication, meant she felt more involved.

> *"Just about the process and stuff. Like about what would happen, when she was going into school, she would ring me after and tell us exactly what happened and how [child] had been and stuff…because sometimes, even now I think with the other services, if there's like you're left in the dark, even though it is your child". (Sally)*

When such communication failed to occur, parents did not feel informed about EP involvement, including knowledge of EP visits and gaining feedback.

> *"I don't recall being told officially when they were gonna go in. There was no kind of like [child] was gonna get her assessment today". (Olivia)*

> *"I think there had been an observation, class observation, but there was no written report from that, that I got, so, ermm and it wasn't really fed back to me". (Angela)*

Gaining feedback from EPs was inferred to be helpful, with parents suggesting EPs may engage in face-to-face meetings or provide short letters summarising involvement, so parents feel informed and involved.

EPs are involved in their practice processes, alongside broader SEND processes, as part of the EHCP assessment process. The need for clarity of how processes occur to navigate them is highlighted within research (Ahad et al., 2022) and, in this study an EP explaining the statutory process was highly valued and supportive. Such processes are potentially unfamiliar, confusing and overwhelming for parents (Keville et al., 2024; Skipp & Hopwood, 2016). Moreover, it has been suggested such processes exclude parents who lack understanding or the resources to seek it (Ahad et al., 2022; Sales & Vincent, 2018), highlighting the importance of EPs ensuring parents are informed of processes involving them. Although, research infers EPs may require additional information about processes in their authorities, as they may also lack this understanding (Atfield et al., 2023). For Susan, explanation of the process increased her confidence and knowledge of what happened next and steps to take.

> *"It wasn't just, 'I'm here to assess him within this framework, it was about 'and this is what this means moving forward', and 'this is how it fits into the process' and 'these are the things that you probably need to be aware of". (Susan)*

Knowledge and understanding of processes were discussed as helpful for families, with Angela suggesting *“a nice little leaflet which could come from the Ed Psych service”* explaining the EP role in the EHCP process to parents, which may be extended to communicating broader EP involvement.

3.5 Implications

Findings extend literature pertaining to the experiences of formal support for families of autistic children by specifically exploring EP support. Findings may inform both individual EP practices and broader service level developments, reflecting the systemic influences related to equitable access to EP support, alongside their influences on individual EP practices (see Figure 3).

Working with families is considered an important aspect of EP practice (Dunsmuir et al., 2014) and findings reflect an ecological systems perspective, offering suggestions of how EPs may engage in a holistic approach to practice by supporting families of autistic children (Bronfenbrenner & Ceci, 1994; McGuiggan, 2021). Parents acknowledged difficulties accessing EP support, related to constraints on EPSs and wider SEND systems (Atfield, 2023, DfE, 2023b). Constraints were also considered as influencing aspects of individual EP practice, for instance preventing early intervention, limiting coordination of support and opportunities for prolonged involvement. Whilst SEND improvements are hoped to alleviate constraints, including increasing EP numbers and improving accessibility of SEND systems (DfE, 2023a), further consideration is likely necessary to inform commissioning of community-oriented EPSs, which promote families access to EP support and enables individual EP practice in accordance with parents’ perspectives of valued support (Dunsmuir et al., 2014; McGuiggan, 2021). Furthermore, EPs may utilise their positions engaging with schools to highlight the benefits of a holistic approach to facilitate opportunities to engage with family systems, for instance promoting joint school-home consultations and parental support groups (Connolly & Gersch, 2013; Nolan & Moreland, 2014).

Whilst addressing resource and capacity issues will likely facilitate individual EP practices engaging families, it was promising that relational practices were valued as supportive, which were discussed within brief involvement with EPs. For instance, adoption of a family-centred approach to practice, by acknowledging, listening to and valuing parental perspectives and expertise and acknowledging emotional needs (Keen & Rodger, 2012), alongside utilising psychological knowledge to empower the family system to tailor support for their children (Birch et al., 2015; Farrell et al., 2006). Additionally, findings suggest EPs should ensure transparency to manage parental expectations and ensure they are informed of their role and involvement (Squires et al., 2007), alongside sharing information about EPs with local parent groups. Seeking knowledge of community support networks and familiarity with the Local Offer to signpost are also likely to be beneficial in promoting families engagement in longer-term, informal supports (DfE, 2014).

Similarly to Stanford et al., (2020), which explored perspectives of mothers of autistic children on good professional practice, some aspects of support discussed by parents were not autism-specific. Indeed, similar challenges accessing family-centred support are noted by parents of children with other special educational needs (McCarthy et al., 2022; Ryan & Quinlan, 2018), hence findings may extend beyond families of those with autistic children. This is pertinent considering limited research has explored families experiences with EPs (Squires et al., 2007; Lawrence, 2014) and adds weight to the commissioning of community-oriented EPSs to facilitate practices which do not solely serve the needs of bureaucratic educational functions but extend to family systems, operating holistically to promote positive outcomes for children and their families (MacKay, 2006; McGuiggan, 2021).

3.6 Limitations

Reflective of a wider trend in autism research, the study explored mothers' experiences and perspectives, despite being open to all parents and carers (Braunstein et al., 2013). Reasons in this research were unclear but may reflect a broader issue of unequal involvement of fathers in EP practice, as noted within statutory assessment processes (Hart, 2011) and may reflective the demographics of parents attending services approached in recruitment. Whilst questions related to perspectives on support for the family system, the perspectives of fathers may have added insight, which is pertinent given suggestions that fathers of autistic children may have differing parenting experiences to mothers (Mount & Dillon, 2014) and therefore future research would benefit from engaging fathers in providing a diversity of parental views.

Although varying perspectives were explored, self-selecting sampling may have meant parents who are more isolated and not accessing groups used for recruitment may lack representation. Furthermore, suggestions of how EPs could support families were likely based on their own experiences and understanding of the EP role and engagement with other professionals. Involvement was often brief and restricted, and parents were often not reliably informed of EPs remit, which may have impacted their suggestions for further support. Furthermore, research exploring EPs experiences and perspectives on supporting families of autistic children may be beneficial, exploring how EPs consider how their practice may be informed reflective of these findings.

3.7 Conclusion

This research aimed to explore parents' experiences and perspectives on how EPs may support families of autistic children to inform EP practices and offer implications for broader service level development pertaining to family work. Findings corroborate with wider literature reflecting families' of autistic children varied experiences of formal support and hope to contribute to EP practice. This highlights how families may be supported through equable access to EPs by addressing systemic level issues, whilst considering how individual EP practices may support families by adopting a family-centred approach, a coordinator role, and empowering others with knowledge and understanding. The research calls for consideration of the provision of holistic, ecosystemic EP practice, which not only serve the needs of schools, but families too.

Chapter 4: Reflective Synthesis

4.1 Introduction

This chapter presents a reflective synthesis, in which I consider the influence of the research process on a personal and professional level. This will involve an exploration of how the process has enhanced my skills, knowledge, and thinking whilst considering the influences on my practice as a Trainee Educational Psychologist (TEP) and the potential implications on my career as an Educational Psychologist (EP). Furthermore, the wider implications relating to practice and research will be considered.

4.2 Embracing reflexivity

Being a reflexive researcher requires acknowledgment of "the impossibility of remaining 'outside of' one's subject matter while conducting research" (Willig, 2013, p. 10) and being aware of the relationship between the researcher and the research. I discussed reflexivity in Chapter 2, in which I explored my positioning in the space between an insider-outsider (Dwyer & Buckle, 2009). I have contended with my positioning throughout the research journey, but think being open and honest about my professional identity may have resulted in participants openly sharing their experiences. I have considered whether my position may be akin to allyship, committing to social justice and attempting to address power imbalances between myself and participants (Scholz et al., 2021). Allyship in research considers how privileged groups can operate as advocates for those who are considered less privileged (Scholz et al., 2021). As a researcher and member of the profession being explored, I acknowledged the privilege this afforded and aimed for participants' voices to be heard, listened to and ultimately influence implications for practice and policy.

True allyship is associated with co-produced, participatory research (Dierckx et al., 2021). I acknowledge that co-production, whereby parents were co-researchers did not occur, which was related to a desire to avoid tokenism and inauthentic practices within the practical constraints of the project. However, whilst acknowledging the limitations of this, I hoped to reflect calls from the autism community to conduct research, that "more research was needed to identify effective services and supports for autistic people and their families" (Pellicano et al., 2014, p. 761). I hope by listening to and sharing these parents' experiences and perspectives, I have acted as an ally with those involved, aiming to inform practice to improve the lives of families of autistic children and beyond. Whilst co-production within the autism community is acknowledged as challenging, it is heavily endorsed to enable more equitable research, and therefore I agree that future research should continue exploring opportunities to engage these families in participatory action research (Bottema-Beutel et al., 2021; Keating, 2021; Pellicano et al., 2013).

Engaging in reflexivity also afforded consideration of the influences of the research on a personal level (Willig, 2013). Listening to the stories and experiences of parents was often emotive. Parents reflected on the difficulties experienced as parents managing the needs of their children and the challenges they faced navigating children's services and the education system. At times, these were emotional to listen to and whilst the literature discusses these, through active engagement in discussions I developed a more profound empathy and compassion for the pressures and challenges families I work with may be experiencing. An awareness of the emotional impact of listening to their experiences on myself as a researcher was pertinent, alongside recognition of when support should be sought to protect my wellbeing (BPS, 2021a,b). Engaging in reflexive journaling and regular supervision were important to maintain this throughout the research process. As an active influence on the research, this also provided an opportunity to consider the influence of the emotional impact of listening to families experiences on myself and the research process.

4.3 Journey as a researcher: managing uncertainty

"Being tolerant of uncertainty is an important skill to practice for good reflexive thematic analysis" (Braun and Clarke, 2022, p.11).

Reflecting on the above quote, I have considered my research journey to have been embroiled with uncertainty, often provoking feelings of anxiety. On entering doctoral training, my prior research was largely approached from a positivist, quantitative and empirical positioning, and thus I resonate with experiencing engagement in qualitative research as a "culture shock" (Howitt, 2010, p. 1). This research hoped to gain an understanding of experiences and perspectives, in which individuals' experiences were viewed as unique and thus reflected a qualitative methodology. Braun and Clarke (2022) propose becoming a qualitative researcher requires thinking differently about research to engaging in quantitative inquiry. I have noted a significant shift in my philosophical positioning relating to research throughout doctorate training, from one which initially privileged objectivity and certainty, towards valuing and embracing subjective judgement and becoming increasingly comfortable with the uncertainty and anxiety such an approach may bring (Braun and Clarke 2022, Willig, 2013).

Furthermore, accepting research as an ‘adventure’ and ‘journey’ (Braun and Clarke 2022, Willig, 2013) with a greater focus on process than outcomes, has resonated with me. I have noted an increasing acceptance and comfort in embracing the messiness of real-world research, particularly through the iterative process of reflexive thematic analysis. I have become more comfortable with plans changing and resilient to the research adapting accordingly. Managing uncertainty in research parallels my experience of educational psychology practice, dealing with the ‘messiness’ of real-life situations (Sedgwick, 2019). Reflecting the espoused role of EPs as scientific-practitioners (Cameron, 2006; Fallon et al., 2010), research skills and knowledge have been beneficial throughout training and are likely to continue to be influential as a qualified EP. Parker (2013) postulates real-world practice is a form of research, in which various information is integrated and synthesised to inform understanding and actions. This is further contemplated by Willig (2013), who considers an integration of research and practice, as new knowledge and understandings develop through practice-based applications of research principles and reflection. Indeed, I regularly apply systematic frameworks to inform problem solving within complex casework that parallel aspects of research (Fallon et al., 2010; Sedgwick, 2019). Furthermore, acknowledgement and reflection on philosophical positioning are necessary to inform how we practice (Kelly, 2017; Parker, 2013). Whilst educational psychology as a profession contends to establish a coherent philosophical positioning (Briggs, 2019; Kelly et al., 2008), engagement in research from a critical realism positioning has further refined and solidified my world view and assumptions made about the nature of reality and truth, which are reflected in my approach to professional decision-making and practice.

4.4 Journey as a professional: dealing with critique

Despite practising humility and openness to critique as a means of promoting positive change, I acknowledged an internal struggle to resist the desire to defend the practice of EP colleagues. As a TEP practicing in the current complex socio-political context (Atfield et al., 2023), I was empathetic to the experiences with EPs described and reflected on commonalities with my practice. At times this was challenging, as I began to question the extent to which my practice may be considered supportive by parents and reflective of an ecosystems approach to working with families (McGuiggan, 2021). However, as an espoused ally within this research process, I valued the importance of providing a space in which parents could openly and honestly share their experiences without judgement. Indeed, I contend that the site of change is often enabled through the acknowledgement of and response to critique and scrutiny. A process arguably familiar to the EP profession through periods of reconceptualisation and reconstruction (Farrell, 2010).

Through exploring, interpreting, and reflecting upon experiences and perspectives shared, the research has been truly transformative and profoundly influences my professional practice. Findings are reflective of values inherent in my practice, of good, open communication, collaboration, and respect, which I have attempted to further promote. I have noted practical changes to my practice, such as organising feedback meetings with parents, engaging in joint home-school consultations, explicitly communicating my role, signposting to further support, and promoting the value of reviews. Furthermore, this has involved greater consideration of interpersonal skills, such as active listening and empathy, to facilitate positive, collaborative parent-professional relationships (Keen & Rodger, 2012). Additionally, by considering the potential transferability of the research findings, I have broadened the applicability of many of the findings beyond working with families of autistic children to engagement with all families.

Whilst I have valued the research process to explore the type of EP I hope to be (Mahdi, 2020), I have noted an influence on my self-concept as a TEP. At times, I have been unable to practice in accordance with the suggestions discussed by parents. Reminiscent of findings, socio-political factors influence the extent to which EPs can practice in preferred ways. Thus, I am required to acknowledge that I am endeavouring to practice in accordance with my values and findings, whilst appreciating current constraints within the EP profession which are often beyond my immediate control (Atfield et al., 2023). Nevertheless, findings have provided hope and a renewed sense of purpose, irrespective of these constraints, by reiterating the importance of relational aspects of practice, attending to the space to listen and hear experiences, which I argue can occur even within brief involvement.

4.5 Implications for practice

The research intends to inform Educational Psychologists practice. In alignment with an ecological systems approach, the research highlights the importance of supporting families to promote their wellbeing and foster positive outcomes for children, young people, and their families (Bronfenbrenner & Morris, 2007; McGuiggan, 2021). Through the transferability of findings and the synthesised model (Figure 3), it is hoped to offer some guidance for psychologists to consider in their practice to do so. The research acknowledges the current situation families are experiencing, both within the broader children's services and specifically within educational psychology. Through highlighting these, the hope is to learn from good practice and acknowledge what is valued by families to work towards improving their experiences of formal support. The research will hopefully emphasise the importance of this practice and invite opportunities to engage in a diversity of work with families, informed by what they value regarding support from EPs. To summarise the research findings, Table 11 highlights potential implications for EPs to consider in their practice when working with families of autistic children and wider practice with families, as well as recommended next steps for Educational Psychology Services to consider when supporting families.

Table 11: Implications of research findings on practice for Educational Psychologists and Educational Psychology Services.

Specific implications for Educational Psychologists working with families of autistic children	**Wider implications for Educational Psychologists practice working with families**	**Recommended next steps for Educational Psychology Services (EPSs) to consider**
• Develop knowledge of autism to be able to share knowledge with families of autistic children. Share knowledge of their child's strengths and needs to help inform support they offer. • Understand the different presentations of autism and how a child may present at home may differ from school. • Communicate with schools how families of autistic children may benefit from support at a family level. • Provide emotional support for parents, for example, ask how they are. Acknowledge the	• Adopt a family-centred approach to practice i.e., listen to and validate parental perspectives and expertise. Acknowledge the perspectives of families. • Importance of interpersonal skills. Listening to parents, showing empathy and understanding. • Share psychological knowledge and expertise with families to help their understanding of their child's strengths and needs. • Coordinate support with other professionals and services for families, for example multi-agency working. • Encourage engagement in joint home-school consultations.	• Consider the commissioning of Educational Psychology Services to be community focused, ensuring they meet the needs of the family system as well as schools. • Consider how Educational Psychologists can be more involved with families, for example running support groups, training etc. • Provide families with information about Educational Psychologists and their role. • Provide families with information about processes Educational Psychologists may be involved in, for example

difficulties they may be experiencing. • Acknowledge, listen to and respect the perspective of the parents and their expertise of their child.	• Clearly communicate role, involvement and processes to families. • Feedback about involvement with families to ensure they are informed. • Signpost families to support, for example to community groups, parent/carer forums, local offer. • Provide follow up support and ongoing involvement where able, for example highlight benefits of review meetings.	Education Health and Care Needs Assessments. • Provide opportunities for Educational Psychologists to develop positive partnerships with families through opportunities for follow up and ongoing support when needed. • Consider opportunities for parents to gain informal support through facilitating support groups for example.

4.6 Implications for further research

As mentioned above, there are opportunities for further research relating to family support. Considering the SEND review in 2022 (DfE, 2022), the UK government has initiated investment and changes to the SEND system, outlined in the 'Special Educational Needs and Disabilities (SEND) and Alternative Provision Improvement Plan' (DfE, 2023a) focusing on bettering support for children with SEND and families. This also sets out plans for increasing the number of EPs qualified in 2024 and 2025, which may alleviate pressures. The recent Ofsted SEND Area Inspection Framework (Ofsted & Care Quality Commission, 2024) and Delivering Better Value in SEND (DfE, 2023- 2024) also aim to improve access to services and outcomes for children, young people with SEND and their families. Amidst these continued changes, I remain hopeful that families' experiences may improve and future research exploring the impact on families' experiences of EP support will be beneficial to further inform practice and policy. Furthermore, exploring EPs perspectives on the research findings may be beneficial, to examine ways in which they feel able to apply findings to practical changes in practice within their contexts.

To contribute to the hoped outcomes of informing practice, I intend to disseminate findings from the systematic literature review and empirical project within my placement EPS and encourage dialogue with EPs regarding their perspectives on how findings may inform practice with families within their context. I am currently exploring opportunities to share findings during a service development day and inclusion meeting within my placement Local Authority. I also hope to explore means of disseminating findings in an accessible manner, for example, an academic poster or presentation to Northeast LA's, through local conferences, forums, and networks. A write up of the empirical project will also be shared with research participants.

4.6 Summary

Through the lens of reflexivity, this chapter has considered the impact of the research on me both personally and professionally, alongside consideration of the wider influences. Undoubtedly, the research will continue to shape the nature of my practice and hopefully open dialogue to consider the practice of EP colleagues and services when working to promote positive outcomes for children and young people. Inspired by the participants' experiences and perspectives, I have a renewed desire to ensure I practice in a manner reflective of the predecessor, Cyril Burt's assertion that appreciates the importance of also providing support "outside of the school gates" (Parker, 2013, p. 86), working with both school staff and families. Reflecting upon a simple, yet powerful comment made by Angela, I have come to consider it a necessity to appreciate the influential nature of family systems on children and young people and thus, the necessity of supporting their families.

> *"if the one member of the family is feeling stronger, then you are all feeling stronger as a family group."* (Angela)

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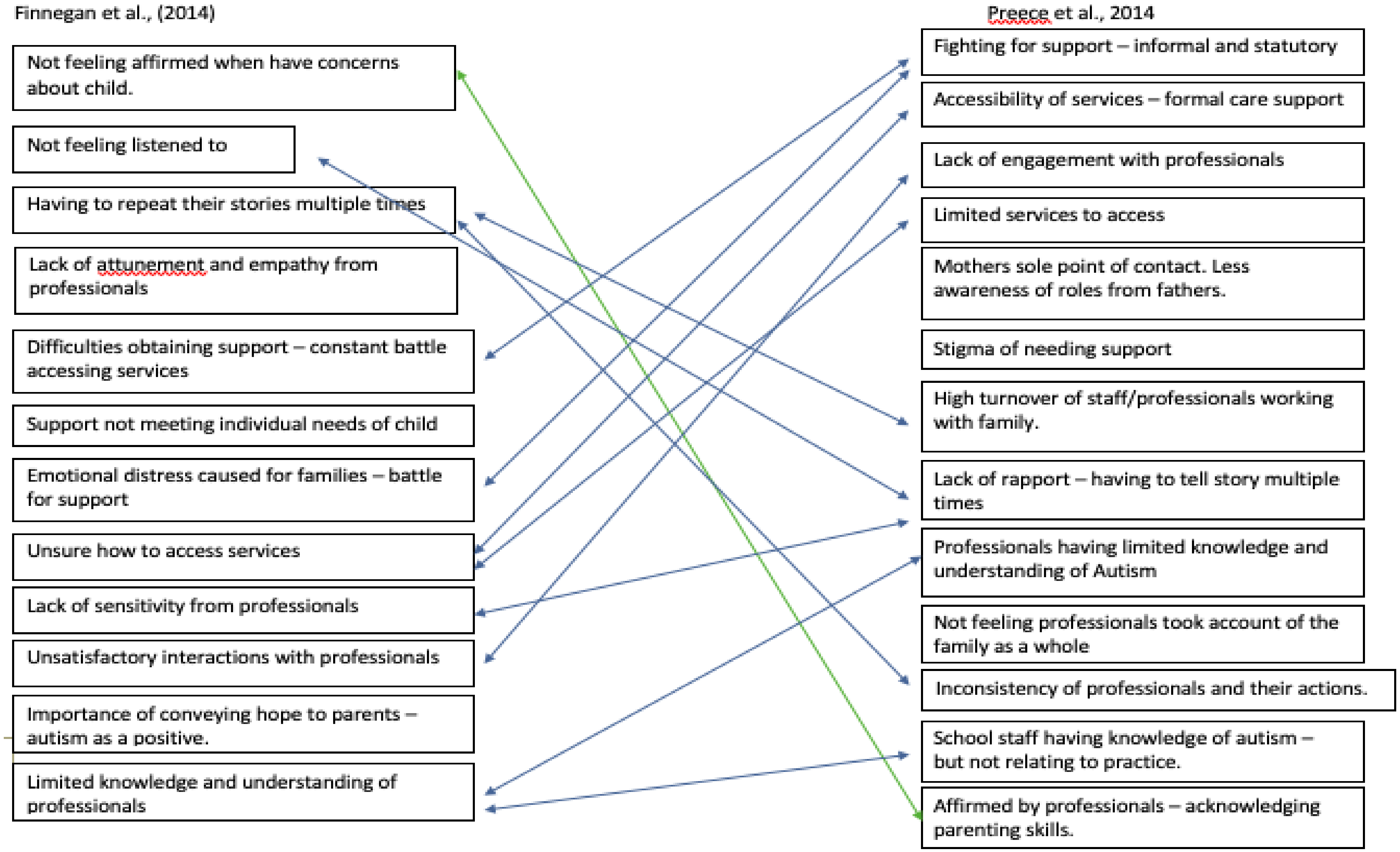
Appendices

Appendix A: Example of establishing how studies are related. Blue arrows represent reciprocal translations. Green arrows represent refutational translations.



Appendix B: Weight of Evidence (Gough, 2007)

	Study	**Milosevik et al., (2022)**	**Galpin et al., (2018)**	**Preece (2014)**	**Twomey and Shevlin (2017)**	**Stanford et al., (2020)**	**Finnegan et al., (2014)**
A	Weight of evidence - A: Taking account of all quality assessment issues, can the study findings be trusted in answering the study question(s)?	HIGH The research aims to explore the experiences of and access to support for families of children with autism and sensory processing difficulties. Considers the perspectives of parents/carers. Research questions were developed with researchers and the SenITA (intervention children were accessing) management group and parent/carer	HIGH The study was co-produced with researchers and school-based professionals. Conducted with parents of children attending an educational setting. Survey's and then semi-structured interviews were conducted with a random selection of participants to gain in-depth perspectives. Mix of mother and fathers perspectives. The study explored families' experiences of support received and what they wished support to be like. Problems with recording – all but two interviews	MED Explored experiences families (including mothers, fathers and siblings) Families were selected from a previous study (Preece & Jordan, 2007). All families has children with high support needs (rated 7/10 on an adapted scale). Data collection in two step process. First visit to discuss research and gain consent. Then second visit to conduct interview. Data obtained through interviews conducted individually or in groups if participants preferred.	HIGH The study aimed to describe how parents experience assessment, diagnosis and education, exploring the potential of utilising a parental lens. Explored parents need to negotiate services. Longitudinal case studies. Interviews and focus groups. Sample of 6 parents from Irish context.	HIGH The study aimed to explore mothers positive experiences of professionals and services. Sample of mothers from England. Looked at 'best practice'. Used Inductive Thematic Analysis.	MED The study aimed to explore parents experiences of diagnosis, living with a child with autism and how they experienced communicating with their children in relation to autism. Used Interpretive phenomenological analysis (IPA). Used snowballing for recruitment.

		advisory group. Framework analysis is used to examine themes, with two researchers to ensure agreement. Acknowledged the limited demographics (geographical location, ethnic backgrounds) of participants.	were transcribed verbatim, as two participants did not wish to be recorded. Participants were from diverse ethnic backgrounds.	Sample of transcripts and completed matrices were analysed independently to increase reliability.			
B	Weight of evidence - B How **appropriate** is the **design** and **analysis** in terms of **answering the systematic review question**?	HIGH Appropriate design – semi-structured interviews assisted by timelines with parents/carers of children and young people with autism and associated sensory processing difficulties.	MED The study was mixed-design. Qualitative aspect of study is relevant, using semi-structured interviews with parents of children with autism. Included parental experiences and perspectives of support (formal and informal) Researchers asked questions about:	MED Appropriate design – interviews on individual or together if wished (e.g., parents interviewed together, or sibling interviewed with mother present). Participant quotes were then interpreted by the researchers to inform broad themes.	MED Qualitative longitudinal in-depth case studies (six parents). Phenomenological view. Parents interviewed over 15 month period. Research was dedicated to eliciting parent voice to know what is needed by them. Included (1) parent interviews (2) observations (3)	HIGH Appropriate design – bespoke interviews designed to explore parents experiences of professionals and services. Interviews were designed to develop rapport with participants before asking direct questions about their experiences.	MED Appropriate design – qualitative design with semi-structured interviews with parents of CYP with Asperger’s or high-functioning autism to gain in-depth understanding of their experiences. Parents from an Irish context

		Eight focused questions and follow up questions appropriate for systematic review question.	(1) Parents' perceptions of the specific abilities and needs of their child, their child's wellbeing and their own wellbeing (physical and emotional), (2) Their experiences of support received both at school and at home, (3) Types of support they have benefited from and/or feel that they would benefit from in the future.	Individual questions asked are not provided, but quotes and themes are relevant to the systematic review question. Data was transcribed and coded using NVivo.	interviews with school based professionals (4) document analysis. Findings were presented through the lens of parents. In Irish context – limited sample. Small sample of parents. Analysed for themes from parental perspectives – using transcripts transcribed verbatim. Phenomenological view to highlight everyday lived experiences of parents.	Used inductive thematic analysis. An independent reviewer was used to look at themes and increase credibility. Discussion of themes amongst three researchers was used to reduce bias. Only focused on mothers experiences – not as diverse.	(mothers and one father) Small sample size Used Interpretive phenomenological analysis (IPA) – external auditor checked data collection and analysis coherence.

C	Weight of evidence C How **appropriate** is the **focus of the study** in terms of **answering** the **systematic review question**?	HIGH The research aims to explore the experiences of and access to support for families of children with autism and sensory processing difficulties (aged 5-11 years old). Considered the perspectives of parents/carers. Framework analysis identified relevant themes to systematic review question.	HIGH Parents experiences of support from professionals and services – what they have experienced and would benefit from in the future.	MED The research aimed to explore families' experiences of having a child (aged 7-18 years old) with autism. Asked about their experiences of formal/informal support.	MED Key focus on parents perceptions of early intervention services for children– focusing on parents experiences and perceptions of professional and services support. Also asked about negotiating children's education. Several relevant themes for parental experiences of professionals and services.	HIGH Key focus of research was exploring mothers of CYP with autism positive experiences with professionals and services. Experiences of access to support from professionals and services.	LOW-MED Focus on parents experiences of receiving information regarding the diagnosis, living with a child with autism and how they experienced communicating with their children in relation to autism. Including comments in relation to experiences with professionals and services.
D	Weight of evidence D Based on the answers to questions A – C, what	HIGH	MED-HIGH	MED	MED-HIGH	HIGH	LOW-MED

	is the overall weight of evidence this study provides to answer the systematic review question?						

Appendix C: Meta-ethnography grids (separated into refutational and reciprocal)

Refutational is highlighted in grey

Refutational	Theme (third order constructs)	Milosvek et al., 2022	Stanford et al., (2020)	Galpin et al., (2018)	Twomey and Shevlin (2017)	Preece (2014)	Finnegan et al., (2014)
	Access and availability of support	**First order construct** I went off and did ASD parenting courses, as you do. And probably went into doing quite a lot of self-led learning and finding support groups for me and for the children... Everything we've done, we've done ourselves. **Second order construct** While one parent reported that services seemed to be provided automatically following their child's diagnosis, others found	**First and second order construct** One factor encompassed in this is speech: "but as soon as we had concerns [...] they [heath visitors] jumped (Bethany). Affordability was also commented on: "the prices are affordable to go on these [training courses] (Diane). The universality of provision was also noted in relation to ease of access: "so even if you didn't qualify for any service, you could still go along every day to the children's centre". **Second order construct** Ease of access was also	**First order constructs** "as a parent you have to battle for everything" and that you have to "keep pressing, keep pressuring them and keep pushing them and ringing them". **Second order construct** Finally, parents repeatedly lamented the *adversarial nature of the system*. **First order construct** "The constant fighting, knocking away on the doors for support, support that is supposed to be there but you are not getting it and then you have to keep knocking and knocking."	**Second order constructs** Their responses varied between challenging the system or withdrawal. Fighting the system was frequently accompanied by abandonment of their own needs. **First order construct** Kate described this change: It was like waking up one day and everything had changed. It was as if you turned the pages of a book in the wrong order... it was like the end of the world. (P2, phase 1) **Second order construct**	**First order construct** *"We're sort of left out, aren't we? Which is probably what's made our relationship so strong, and ...you know, we love each other to bits, and we love each other's company all the time...and it's probably 'cos there's nobody else, is there* (Father, family G*)?"* **Second order construct** Given this lack of both informal and statutory support and understanding – and taking account of other factors such as the impact of autism, the child's dependence and	**First order constructs** P3: I rang every single day, every single day looking for someone to work with (child) or do something with him, but there was just nothing, nothing. It was only that I broke down one day. I just couldn't take it anymore. P5: You're just constantly battling. I mean the teachers don't have a clue. The secondary teachers just don't have the time, the interest, or the training. If the children need it in primary, then they're going to need teachers like that in secondary level as well. It's

		they had to be proactive in seeking support. **First order construct** They just give you a book... there's nothing, there's no therapy available or anything... I thought they'd be like, he's diagnosed, here are some therapies you can access... The only thing the assessment changed is my peace of mind that it's not me, it's not my parenting... but that was the only [benefit] because we haven't got access to anything extra really... it's pointless, well it's hard. **Second order construct**	identified by mothers as a dimension of good practice.	**Second order constructs** Parents felt that accessing support often ‘comes down to who is more able’ or those who ‘shouts loudest gets heard’. Those parents who ‘don’t really deal well with paper and things that come through the post’ felt the most alienated from support, with some stating they ‘don’t even know who to turn to’. **Second order construct** Many parents noted the stress that this caused. **First order construct** ‘can do nothing really’ as ‘the process is too long, too hard’ and they ‘don’t really know what happens’. **Second order construct**	After diagnosis, parents restructured their lives, prioritising their children’s needs. Common considerations emphasised the need for an appropriate educational placement and support from multidisciplinary professionals. **Second order construct** parents became therapy procurers and interventionists; grappling without adequate training with the need to be both.	the routines and ways of adapting that had become norms – it is unsurprising that many families spoke of having a ‘siege mentality’, presenting and perceiving themselves as united against the outside world. **First order construct** *“I’ve only seen her once, and she just sat there at the school review. What she actually does I don’t really know* (father, family D)*.”* **Second order construct** Families had varying experience of formal social care support, which was limited and difficult to access. Some accessed services such as short breaks	just ridiculous what’s going on. **Second order construct** The struggle to attain appropriate services on this journey was a quest that appeared to reach both exasperation and an exhaustion point. **First order construct** P2: We’re in the difficult position that (service) won’t provide us with services and no one else will provide us services. You know (service) say (child) has an intellectual disability so they won’t go near him, the other services say (child) has autism, so they won’t go near him. **Second order construct**

		However, the effect of diagnosis varied, with some families continuing to receive the same level of support as they had before diagnosis and others accessing no support. **First order construct** When we started to go down the ASD route, I threw myself at every available bit of training... and that really helped... The biggest thing it gave me was just to drop all the 'shoulds'. You know, I thought as a ten, eleven-year-old boy you should be able to wash your hands. You should be able		the feelings of helplessness, particularly from parents who felt unsupported. They also reported feeling guilty for not having the time or resources to keep 'fighting' or 'asking for enough help', not doing everything they could to ensure their child received support. **First order construct** One parent said, "the best kind of support you can get, something that gives you a tool to actually navigate the system that you are about to engage with". **Second order construct** Many also wanted support to help them navigate support services because, at the moment, they felt		(respite care) or young carers groups for siblings; others did not, either through choice or due to service shortfall.	The first years following diagnosis were the most challenging for the parents. Obtaining support was difficult and when they received it, it was often inappropriate to their needs.

		to brush your teeth... It completely allowed all those ‘shoulds’ to dissolve, and what was left was just enquiry really. Okay, why is this hard, what can we do to support you?... It revolutionised our family life to be honest. From nagging and moaning and just frustration, to oh okay, you know, your brain works a bit differently, so we need to do different stuff. **Second order construct** Although diagnosis did not always result in increased support provision, parents reported that it enabled them to seek		‘the dots just don’t join up’. **First order constructs** “they asked me what I wanted” “they called me” “they consulted a lot” “an easy process” “(eased) a bit of a battle” **Second order constructs** Parents sought proactive services Being consulted contributed to a sense of togetherness and eased accessing support, and the constant fighting parents felt they had to engage in to access support. **First order construct** Parents highlighted the need for *respite*, to be able to “recharge your batteries” or take care of everyday “things what I need,			

		resources for themselves. **First order construct** I've looked into private SI [sensory integration therapy], but... it's stupidly expensive... it's like £50 odd a session. I mean, I can't afford that. There's an EarlyBird programme for parents of children with autism, but it's like a year's waiting list. And then I was offered one and I was either away or I couldn't get out of work, and I said is there another date at all, I really can't go to this. They went no, go away, another		like dentists and appointments". **First order constructs** "that's where we get stuck, that's where we need a little bit of support". "have time to myself' and 'the time to do all the things, the cooking and cleaning". 'a larger variety of play schemes' in the holidays as this time, especially if they were also working, was 'just too hard, sometimes we need a break'. **Second order constructs** This was particularly pronounced during school holiday time, with parents noting They felt that support during the school terms, like after-school clubs, was beneficial. But			

		year or something. **Second order construct** Resource limitations (such as helpful sources of support being under- funded or over-subscribed) meant some families faced long waiting lists for services or could not afford the support their child needed. **First order construct** We haven't had a huge amount of involvement because there isn't a huge amount of resources in... Cornwall. It's very hard in Cornwall to get onto any parenting course that's in the evening, and		parents wished there was more support available. ‘They also wanted respite that was flexible including, for example, support available during the evenings so that parents ‘could go out’ every once in a while. **Second order construct** Interviewed parents also reported that their encounters with formal support services were overly bureaucratic, that they needed constantly to ‘fight’ to obtain the services to which they were entitled, and ultimately felt isolated from, and misunderstood by, services they perceived should be supporting them. **First order construct** ‘like there’s a sort of investment in			

		[the courses are far away, so] I have to either catch the ferry... or drive the hour round trip, all around the coast... It's not practical and it, it puts you off, you think... what's the point, and... try and battle on. **Second order constructs** There was wide variation in the support received by families, with some accessing between one and three sources of support, while others were supported by 10 or more organizations or professionals. **First and second order construct** So the health visitors suggested		separating people' with no 'interactive quality' to the way support is provided. **Second order construct** Some went so far as to say that the nature of the bureaucracy felt			

		Camau Bach [an early intervention disability support service] and then SNAP Cymru was [suggested by] Camau Bach and then the National Autistic Society was one that I found myself on Facebook. Often there was a domino effect, whereby families were referred into one service, which referred them to another, and so on. **First order construct** She had an official diagnosis of being autistic, and she was referred to the Autism Outreach Service... we attended the EarlyBird course... she received her					

		statement of special educational needs and went full time to... a specialist school. **Second order construct** Receiving an autism diagnosis enabled some children to access additional support, most notably in school; for example, by receiving a statement of special educational needs (a legal document detailing the educational needs of an individual child and how these will be met) or gaining a place at a specialist school.					

		First order construct A local] charity helping disabled children [learn] through play... has been a lifeline... [The psychologist] is able to talk to him with the action figures, or with the Lego... they can talk about feelings through that, which is a great asset because... empathy was really hard for him. He really struggled. **Second order construct** Unlike statutory services (such as health visiting and SALT), charities and local disability groups were seen by parents as being the most helpful forms of support, even					

		where these were not specific to autism or sensory processing difficulties. They appeared to fill some of the gaps in statutory provision and provided much-needed help and advice to families. **Second order construct** We found that in some cases, autism support was accessed by families as a result of parents' professional or social networks. Some had the ability to proactively seek out sources of support or information, or to pay to access services privately, while this was not an option for others.					

	Consistency of professional/ services	**First order construct** What I find now... if there's an issue that crops up, because [three sources of support] have all finished, [I've] only really got the school to deal with now, so if I have an issue, I have got I suppose the Autistic Society... but I find I haven't got anyone... like a professional I can actually ask... you know, what could I do to help this sort of situation? **Second order construct** Parents highlighted a need for a key ongoing point of contact, who could signpost to services or help them deal with new issues arising. For	**First order construct** “I’ve seen the same paediatrician since [child] was diagnosed at four [...] and I believe that has helped immensely” (Chloe). Similarly, services were valued for being dependable when accessed: “they just were. They were always available to talk” (Leah). **Second order construct** Mothers reported good practice to reflect services that were consistent and dependable. Mothers, for example, being able to see the same professionals and access the same services was a constant source of support.	**First and second order construct** They (parents) also reported being let down by the system. For example, one family who had received a visit from a social worker a year before pointed out that they ‘haven’t heard anything from [them] again’. Another parent reported being told that they ‘could get one hour [of home support] a day, that would help, but I am still waiting’.	**First order construct** Parents’ levels of loss of service when a professional went on maternity leave, where there was frequently no professional replacement for lengthy periods. Amy succinctly described the effects of the lack of support during an earlier phase: There’s no ‘someone’ to turn to and say. . . can you explain to me please - what is this? (P1, Phase 1) **Second order construct** Notwithstanding the excellence of professional support when available, problems rose from its lack of frequency and significant gaps between visits.	**Second order construct** families spoke of high turnover, which made building relationships difficult, and necessitated telling the same story again and again. **First and second order construct** Numerous examples were recounted where families felt poor service exacerbated their difficulties. One family’s short breaks stopped when the respite foster carer became pregnant. The mother (a single parent with four children, and no relatives in the country) requested that the service continue provided by another family; however almost a year later she	

		many families, school was their main or continuing source of support. **First order construct** I find the support have stopped... [the] Occupational Therapist has gone, it's like everyone's gone now. So we've got no support... [and] he's still struggling every day. He's had so many like different departments involved in his care... Now... it's like right... we've helped you... we can't do no more... so basically everybody's signed him off. He's confused because he now thinks that	**First order construct** Phoebe, for example, discussed a learning mentor having "worked with [her child] using interactions with play dough to start using other cutlery" but also remarked, "she has been that constant for him no matter what grade or part of school he is in". **Second order construct** Hands-on working and skill development was also mentioned alongside comments that services were consistent and dependable.		Helen (Chairperson of the local parents Autism Support Group) referred to services in terms of 'loss'	found the social worker had not actioned this request and they were not even on a waiting list.	

		everyone's just dropped him and doesn't care. **Second order construct** In addition to gaps in support provision, the support families did receive seemed to be time-limited or ended following diagnosis. Where support had been helpful, this was confusing for children and frustrating for parents. **Second order construct** Parents identified unmet support needs, including the need for an ongoing point of contact for information and advice.					

	Engagement with professionals		**First order construct** “I even ended up phoning her [child development coordinator] a few times because [...] I didn’t know who the point of contact was and I phoned her and she actually said he’s gone past that age [...] but she spent hours on the phone with me anyway, just out of kindness” (Megan). **Second order construct** Good practice was also reported by mothers to be seen in professionals who go above and beyond in their role requirements to support families. **First order construct** “they [university] took photos of the room so [child]	**First and second order construct** Others felt that ‘there should be more contact with parents’ from the school and more ‘opportunities for families to work with professionals’. **First order construct** it’s not just your child being educated [there], it’s you as well’. **Second order construct** Sometimes, engaging with professionals was perceived to just be ‘too hard’, which meant that they were missing out on learning key skills for supporting their child **First order construct** “I don’t really feel connected to [the school], I don’t really understand how things work there”	**First order construct** Having voiced all my concerns, I was more or less told that I needed the psychologist, not my child. I gave him (medical professional) the word Autism and he said that he wouldn’t be worried about it. . . so I waited eight months. (FG P3, phase 1) **Second order construct** There was a consensus of evidence supporting constricted forms of communication between diagnostic professionals and parents. Restricted communication between		**Second order construct** Unsatisfactory interactions with health care professionals were reported by most parents at some stage in their journey. At diagnosis, parents expressed dissatisfaction with a professional’s manner and the information they were given about ASD.

			could see the room before he got there, they explained what was going to happen [...] instead of saying twenty minutes because at that stage [child] wouldn't understand so instead of saying twenty minutes they'd say three episodes of 'Thomas the Tank Engine" (Chloe). **Second order construct** Mothers commented that they appreciated professionals' informing them of what to expect when engaging with a service or process, as well as professionals taking measures to ensure mothers' and children felt comfortable. **First order construct** "and	**Second order construct** The lack of this support led to a sense of alienation. **Second order construct** professional support for their child (better understanding of those working with their child). **Second order construct** They highlighted the importance of *close home–school partnerships*, having clear and open lines of two-way communication, including via home–school diaries, face-to-face meetings and phone calls. **First order construct** They felt this was critical given that	diagnostic professionals and parents. **First order construct** Kate described diagnosis as somewhat emancipatory: I'm tired of people sparing my feelings. What is wrong with my child? And he [the GP] finally said...I think your child has autism. (P2, phase 1) **Second order construct** Parents felt a sense of powerlessness and imbalance in their dealings with professionals. When asked if they had access to support from specialist resources, five parents, Amy, Kate, Sue,		

			then of course doing the [Autism Diagnostic Observation Schedule; ADOS) with [university] as well that helped myself with the diagnosis and that helped them with actually going through the process [with a paediatrician]" (Bethany). **Second order construct** Mothers felt that good practice was reflected by professionals or services moving things forward. Some comments related to diagnosis. **First order construct** "if it wasn't for the SENCO and his keyworker at the pre-school we wouldn't have got where we are now" (Leah).	school staff were often the first 'people that I turn to because [my child] spends a lot of time there' and that 'if they need something they contact me, if I need something I can call them'. ('when you work together, it can help') ('they tell us what they are doing there, so here we do the same thing'). **Second order construct** Such communication enabled them to collaborate more effectively to support their child and ensured consistency of support across home and school settings.	Carrie and David reported dissatisfaction with professional procrastination or 'wait and see' approaches. **Second order construct** When services were perceived by parents to be indifferent or unresponsive, this added considerably to a sense of parental disempowerment. Having attained diagnoses, phase 2 illustrated more pronounced parental needs of a personal nature. Parents perceived that they had to give in to the professional expert's judgement as a		

			Second order construct Other comments, however, focused more generally on professionals or services moving things forward. **First and second order constructs** Rapport with children highlights that mothers valued professionals who were able to build up a relationship with their child. This includes examples during a singular experience with a professional: “and she [neurological development professional] spoke to [child], she acknowledged [child] and sat him down and gave him an activity to do” (Phoebe). This sub-theme also includes comments		result of diagnosis. **Second order construct** Positive relationships with the child and between parents, school personnel and professionals, made a significant difference.		

			concerning long-term rapport and relationship building: “I think they [Child and Adolescent Mental Health Services, CAMHS] took the time to build up a relationship with [child’s name]” (Olivia). **First order construct** It’s quite unsettling when you don’t know anybody and you’re kind of there to get support and she’s [centre staff member] just been there from the start, super friendly and really nice and welcoming” (Stephanie). **Second order construct** Mothers also commented on open, honest,				

			clear communication as being related to good practice. This is when professionals communicated with mothers in a clear and transparent manner.				
	Listened to and acknowledged	**First order construct** Throughout [her] schooling they’ve never had any concerns… [never] any suspicions of ASD, but she’s an incredibly able masker. **Second order construct** A key barrier to accessing support was the dismissal of children's difficulties by professionals, resulting in delays in diagnosis, rejection of referrals for additional	**First and second order constructs** “she [learning mentor] has been amazing, a lot of the stuff she has listened to us, and taken on board some of the things we would recommend for child” (Phoebe). Mothers also, felt listened to by professionals in turn. **First order construct** “empowering, you know she was the one who told me we were doing a really good job and you know [...] sort of	**Second order construct** The reliance on standardised assessment measures for support, the constant form-filling to which parents in this study referred, also tacitly implies that greater value is given to the expertise of the professionals who create and interpret the assessment measures than parents’ own understanding of their support needs.	**First order construct** We just didn’t have a clue, I felt there was something wrong but I felt that no one was going to believe me, and you know. . . we were literally, as a family we were at breaking point. (P1, Phase 1) **Second order construct** Assessment perceived as quest and diagnosis as holy grail	**Second order construct** One mother spoke of how professionals had praised her for her parenting skills and positivity.	**First order construct** P2: we were told by the time they were two years and three months old, they were probably autistic. In fact the first diagnosis we got on (child) was that there was absolutely nothing wrong with him, that he was a very bright child, but the second diagnosis said that he had severe autism. P7: Sheer relief knowing that there was a name to it, that we weren’t imagining it, because we

		support, and needs not being provided for in school. For example, several parents described noticing signs of autism when their child was a toddler, but waiting years to receive a diagnosis. This was sometimes due to children masking outside the home, meaning behaviours indicative of autism were missed. From timelines - At that stage, the families' key contact was the health visitor, with whom parents raised initial concerns (which were often dismissed). **First order construct**	acknowledgement that we were doing the right thing” (Megan). **Second order construct** Mothers also reported good practice to be professionals providing affirmation for their concerns about their child, confirming that mothers were engaging in helpful strategies or practices to support their children.				had been brushed off by so many professionals and that now we knew this is what it is let’s do something about it. **Second order construct** Parents reported that their concerns were brushed-off by professionals and that despite repeated sharing of these concerns, they felt their comments fell on deaf-ears.

		I raised issues about speech quite early on. And [the health visitor] said oh he'll get it, he'll get it. They just constantly kind of brushed it aside. He passed these very basic tests and [the health visitor] was like there's nothing to worry about, there's nothing to worry about, he's a bright boy... [It] just seemed like no-one was listening. **Second order construct** Health visitors tended to be parents' first source of help and advice (and were gatekeepers to specialist services) but were mostly described as					

		being dismissive of the early signs of autism. **First order construct** She was very negative... towards [our] parenting... And I actually spoke to CAMHS after all this and said, ‘I don't want her coming back’, because... she made me, well she made us both feel like [we] haven't done enough really. **Second order construct** They (professionals) were described in some cases as being dismissive or judgemental. **Second order construct** The dismissal of children's needs by professionals was a key					

		barrier to families accessing support.					
	Empathy, understanding		**First order construct** "it was really good to have somebody [speech and language therapist] tell you in advance that they want to see you at the school [...] she could have turned up and then said can I have a minute to speak to you and it wouldn't have been productive" (Phoebe). **Second order construct** Considerate practice by professionals was also highly valued by mothers. **First order construct** you feel like you are talking to someone [paediatrician] who is under-	**First order construct** ('I was exhausted') as the experience 'was so full on' **Second order construct** The experience of receiving a diagnosis was highly emotional for parents and many reported feeling unable to cope. **Second order construct** As a result, many parents indicated that the initial support they received was not entirely beneficial, either because it was simply not enough, or that they were not in a position to process any support they were offered. **First order construct**	**First order construct** And this sort of carried on, it was all very informal with the creche, no formal meeting. . .you know, he'll catch up. . . and the same thing with the GP, and I wasn't happy with that… (P3, Phase 1) **Second order construct** Sue was frustrated with the amount of time she spent waiting for an assessment and the detachment and paternalism of professional discourse associated with diagnostic encounters. **First order construct**	**First order construct** *"...they don't see how it is. They don't see me when I'm p***ed off and sitting on the floor crying* (Mother, family A)".	**First order construct** P6: That psychologist in particular was a very stern person, and maybe that was the best way to be, but I just felt there was no emotion with her. So it was very matter of fact and I went home and I bawled. I have to say I cried my eyes out. **Second order construct** The manner in which people were told did not necessarily contain the emotional reality for some parents. Evidence of professionals being attuned in an empathic manner was reported to be lacking in some of the interactions

			standing, the manner that they interact with you. You can be talking about something upsetting, and just helpful when they say don’t worry” **Second order construct** Good practice was also reported by mothers as professionals’ emotional understanding and experiences, where professionals engage with mothers showing understanding and empathy. **First order construct** It’s quite unsettling when you don’t know anybody and you’re kind of there to get support and she’s [centre staff member] just been there from the start, super	‘emotionally, you are a bit incapable of dealing with anything other than trying to get through your trauma’. **First and second order construct** Some parents felt that professionals simply bombarded them with ‘too much information’ that ‘doesn’t sink in’. Instead, they suggested ‘counselling to come to terms with a diagnosis’ should be the primary focus for initial support, with ‘follow-up maybe a couple of weeks later’ to provide further information, or to go over the earlier information given, as the initial period around the diagnosis ‘was actually quite an awful time’.	Finally she had to pull me… you know, together… and said look you know, your child has autism. He’s not dying of cancer. You’re lucky really. You’ve a lot to be thankful for. **Second order construct** Following diagnosis, Sue described a discomfiting analogy with terminal illness used during a professional encounter to abate her reaction to her son’s diagnosis.		regarding their child’s diagnosis. **Second order construct** A number of parents perceived that the way in which they were informed of the diagnosis was on occasion lacking in sensitivity or poorly communicated. **Second order construct** Furthermore, hope was highlighted as a vital message to be communicated by professionals during the diagnostic process (i.e. that having a diagnosis is a positive thing around which a child’s needs can be structured) though unfortunately in the current study many parents reported the contrary.

			friendly and really nice and welcoming” (Stephanie). **Second order construct** Mothers reported professionals’ personable manner to be related to good practice. This sub-theme primarily described professionals who were friendly, relatable and approachable. **First order construct** Wendy, for example, indicated that her child’s play group was valuable because “they really were a wealth of information” but also identified “**I** think you just get emotional support, you get the information”.				

			Second order construct Both knowledge and emotional understanding and experience were commented on by mothers in relation to individual professionals.				
	Professional knowledge of autism	**First order construct** You see it time and time again, it's schools being unsupportive. Professionals saying, ‘There's absolutely nothing wrong’, even though it's staring them in the face. It's the parent, you know, the parental blame... your parenting skills. **Second order construct** As previously stated, parents reported that professionals often lacked expertize in	**First order construct** “I think what was nice about her [speech and language therapist] as well she had been through similar things like I sometimes find if you’re talking to somebody that has got experiences that you can relate to as well it just opens it up a little bit, that helps as well sometimes” (Diane). **Second order construct** Mothers also noted that professionals with	**First and second order constructs** Those in positions of authority were also perceived to have limited knowledge of autism. Some felt that there could have been better support for their child in mainstream education settings but, instead, they ‘felt lonely and pushed aside, [the school] did not do anything or know anything’. **second order construct** While some families were enthusiastic about the support they received, many felt			**Second order construct** The value of the support parents received at this time, both from professionals and family and friends, was determined by the perceived level of knowledge and understanding of the child’s difficulties and needs

		autism, and were unable to provide support tailored to the child's needs. **First order construct** I've been on loads and loads of [parenting] training... the only course I can honestly say that I did enjoy was the EarlyBird course. Now... that was a great help... more realistic... I really got on with the parents there, they were in the same situation as me and that's what I wanted... it opened my eyes, I understand, understood a lot more. **Second order construct** In contrast, specialist support was	personal experiences of autism or disabilities had heighted emotional understanding (experience with Autism). **First order construct** “yeah she was an excellent, experienced [Special Educational Needs Coordinator; SENCO]. She knew exactly what she was talking about” (Rebecca). **Second order construct** Knowledge, at both the service and professional staff level, was commented on by mothers. Mothers commented that good practice was related to professionals’ who were highly skilled and knowledgeable.	social workers had little understanding of autism.			

		viewed as very helpful, particularly autism-focused parenting courses and advice from specialist occupational therapists, for example, in relation to sensory processing difficulties that affected children's daily routine.	**First order construct** “[Special Educational Needs and Disabilities Information Advice and Support Service; SENDIAS] and [Independent Provider of Special Education Advice; IPSEA] are brilliant for information” (Wendy) **Second order construct** Mothers also identified good practice as related to the knowledge of services that provided information.				
	Practical support (professionals working directly with children and families)	**First order construct** The integrated autism service... have an OT [Occupational Therapist] and all sorts but they don't actually	**First order construct** the [charity] kept telling me “you’ve got to apply for [Disability Living Allowance; DLA] for him [...] I didn’t understand why	**First order construct** “that was his first introduction to [Picture Exchange Communication System; PECS]”, but also how Portage was “very	**First order construct** The psychologist was in my house and the intervention specialist was in my house – it		

		see the child, they just speak to the parents... People give me advice but it's easy for them to say do x, y and z... we need like hands on [support]. **Second order construct** An important gap in provision related to direct therapeutic support for children, particularly occupational therapy for sensory issues. Some parents identified that most services their family had accessed were focused on the parents rather than the child, or on diagnosis rather than support.	you needed DLA, because without DLA you couldn’t access some of the other short break and other provisions” (Phoebe). **Second order construct** Practical knowledge was also mentioned by mothers as relating to good practice. **First order construct** “because they’re [charitable services] helpful as well, the service that they provide ensure that family life is a bit easier and more... makes family life easier and more manageable” (Alice). **Second order construct** Meaningful outcomes were also related to	personal […] very personalised to him and interactive, working with him and showing me what to do with him”. **Second order construct** Many mothers commented on professionals or services that demonstrated hands-on working and skill development and personalised and adaptable service delivery. Emily, for example, discussed concrete examples of Portage working with her child. **First order construct** “so the Portage [home visit education service] […] it was very good because it was trying to teach her like social skills like in an easy fun way” (Alice).	was all kind of linked in with the Early Bird course. (P3, Phase 2). **Second order construct** She later captured the benefits of receiving a diagnosis and parent training.		

			impacts on the mother themselves. **First order construct** “well just because of how they [Portage] helped both the children and me. It was about us” (Stephanie). **Second order construct** Mothers also identified personalised and adaptable service delivery to be related to good practice. Personalisation may take place through home visits, and the working practice of professionals. **First order construct** “whereas with me I was able to catch it early so all these courses and things I went on helped	**Second order construct** Mothers also reported good practice as involving hands-on working and skill development. This includes skills children were taught via practical work. **First order construct** “the best strategy that I have always found is to move their attention onto something else […] that was learnt from Portage” (Stephanie). **Second order construct** Hands-on working and skill development was also related to skills mothers learned directly. **Second order construct** Home visits from professionals were felt to strengthen the perceptions of support with one parent noting it			

			[Communication and Interaction Support Service; CIASS]” (Erica). **Second order construct** mothers regarding how they felt they and their child had benefitted from early intervention. **First order construct** Stephanie, for example, notes that a professional “seemed to have all the answers” but also went above and beyond their role saying “if you want me to come out and help you go through it [EHCP information] I will. She was willing to come out and fill out forms with me and read through it all”.	allowed them ‘to people about what we can do’. They also felt that it was extremely beneficial when the school was able to provide support with difficulties in areas other than education and learning such as housing and help with Disability Living Allowance (a social security benefit in the United Kingdom) and ‘do some courses’. **First order construct** ‘thank God I did that. I knew nothing about [autism] and that was really helpful’. **Second order constructs** Others noted the need to actively ‘do some research’ into autism, which helped them to cope. Specific courses aimed at			

			Second order construct Mothers also linked both knowledge and acting above and beyond in relation to individual professionals or services. **First order construct** “[Charity] they have given us a grant to get all new bedding and also for an iPad” (Alice). **Second order construct** Mothers also valued when services provided resources.	developing parents’ understanding, such as the UK’s National Autistic Society’s Early Bird course (Shields, 2001), were also seen to be highly beneficial. Being more informed had the biggest impact on their day-to-day lives, leading them to ‘understand [my child], how to communicate [with him]’. Nevertheless, they noted that the vast amount of information on autism was also overwhelming, with ‘a lot of information that is probably best avoided’.			
	Individualised support	**First order construct** We've seen Speech and Language, because he stammers, and he seems to have selective	**First order construct** “and then things went horribly wrong at school [...] and she was unsure of even going to CAMHS, and CAMHS were	**First order construct** Similarly, when parents spoke to the local educational authority about their ‘child with special needs, autism, they			**First order construct** P2: We’re in the difficult position that (service) won’t provide us with services and no one else will provide us

		mutism... but they just let us go because he wouldn't speak in... the appointment and his understanding was fine. [CAMHS are] just... not equipped to deal with autism... she's got severe, severe anxiety... but she's not being treated for it because they don't know how... We did a bit of work with one lady, after four weeks, she said ‘Oh I'm unable to help her... she just doesn't understand it’... Meanwhile... it's getting a whole lot worse and having a massive impact on her life.	“that’s ok mum can come in too [...] so they have been very adaptable to [child’s] needs and how she is feeling” (Olivia). **Second order construct** Adaptable provision was mentioned in relation to tailoring services to suit each child.	don’t seem to understand’, **Second order construct** They were seen as adopting a one-size-fits-all approach. **Second order construct** When we probed issues surrounding support during interviews, parents highlighted the distinct lack of services and supports available to address them and their child’s specific needs, which ultimately made them feel isolated and alienated. **Second order construct** Many of the parents interviewed herein supported this view, reporting that they felt disconnected from formal services, which they perceived to have little			services. You know (service) say (child) has an intellectual disability so they won’t go near him, the other services say (child) has autism, so they won’t go near him. **Second order construct** The first years following diagnosis were the most challenging for the parents. Obtaining support was difficult and when they received it, it was often inappropriate to their needs.

		Second order constructs Similarly, parents reported that Speech and Language Therapy (SALT) and Child and Adolescent Mental Health Services (CAMHS) did not appear able to provide appropriate support to their child. **Second order construct** Parents in the present study explained that services such as SALT and CAMHS did not seem equipped to support children with autism, discharging them due to assessment difficulties or an inability to address their specific needs.		understanding of their child and family and their specific needs.			

		Second order construct Specialist rather than generic support was described as most helpful to families in this study.					

Reciprocal	Theme	Milosvek et al., 2022	Stanford et al., (2020)	Galpin et al., (2018)	Twomey and Shevlin (2017)	Preece (2014)	Finnegan et al., (2014)
	Lack of understanding of family needs			**First order construct** They were 'very busy working', 'so busy [they] don't really have the time', which meant that they were unable to access parents groups or courses: 'because I work I don't really get to go there very often'. **Second order construct** Parents felt that *existing support does not fit with their lives.* Many parents spoke of work commitments impacting on their ability to access		**Second order construct** Though all families in this study had some experience of social work involvement, the mothers were the primary and often sole point of contact with professionals. Husbands and siblings were unclear about social workers' roles and functions, and many had never	

				weekday, day- time support. **First order construct** Parents noted that more could be done ‘in the evenings every now and then’ and to provide ‘help during the weekends’. **Second order construct** Parents, particularly those who had reported feeling unsupported in the survey, felt that ‘we need someone who will help us [on] our time’. Many of the parents interviewed herein supported this view, reporting that they felt disconnected from formal services, which they perceived to have little understanding of their child and family and their specific needs. **Second order construct** Parents frequently drew attention to the fact that, while there may		met their family’s social worker. **Second order construct** Researchers must seek to understand and acknowledge the differing perspectives that can be held by family members; and, crucially, so must practitioners. **Second order construct** Assessment of all family members’ perceptions of daily life and support needs is essential if services are to be effective. **Second order construct** This study identifies that a range of perspectives exist within families and between family members. A family-centred	

				be some support available for their autistic son or daughter, there was a serious *lack of whole-family support*. **First order construct** Indeed, one parent said, ‘you manage your life as a family, you don’t manage it in these isolated pockets’. **Second order construct** They mentioned that ‘there are very few opportunities for siblings to attend places with their disabled siblings’, which resulted in them missing out on opportunities to ‘help them be closer together, to understand their brother or sister better’, which ‘can be quite upsetting for them’. Parents noted that this lack of focus on the whole family ‘seems to isolate people’ and did not promote ‘developing		focus, taking account of all family members’ perspectives, will help researchers and professionals alike to understand better the impact of living with autism on all concerned.	

				relationships and connections’ as a family. **Second order construct** And that they (social workers) made little effort either to get to know the child or to take account of family members’ wider caring or work responsibilities. **Second order construct** When support was available, it was often perceived to be extremely difficult or even impossible to access and failed to fit with the realities of their everyday lives. Instead, they called for services that are proactive and family-centred in their approach, ultimately making them feel more connected and cared for. **Second order construct** Consequently, formal support services need to take a more holistic			

				approach to support provision that looks beyond the categorisation of need and subsequent allocation of resources based solely on clinically defined difficulties experienced by the child him/herself to the perceived stress experiences of families more broadly. **Second order construct** They noted both how difficult it can be to navigate the support system (‘the dots just don’t join up’) and how they wished professionals would be more proactive and understanding of their needs as a family.			
	Facilitating connections with other families	**First order construct** I am with a lot of forums... I can ask them anything... Talking to other parents is brilliant... they're probably the	**First order construct** “they’ve always been [children’s centres] really good for meeting other parents and getting out when you’ve got a new-born” (Diane). This might also be	**First and second order construct** For some, having contact with other parents in the period immediately following diagnosis was particularly important: ‘the only useful thing they done, professionals at the	**Second order construct** Parents sought support from parent support groups to validate and		

		best [source of] advice. You know that somewhere [on the Facebook group] there'll be... someone saying, yeah I hear what you're saying, I've been there, I get it, you're not the only one. And that can be a massive thing, because obviously being a parent of a child who's got extra needs, it can feel quite lonely... and it's nice to know that someone actually understands. **Second order construct** In contrast, online and face-to-face contact with other parents of children with autism was valuable in	because of a secondary outcome: “so it was really helpful to be there [community autism talks] with other parents, grandparents, or carers who have children on the spectrum can be really helpful” (Emily). **Second order construct** Provision leading to community building was also mentioned by mothers in relation to good practice. This refers to services that provide families with a peer network. One way a service may do this is through its primary provision purpose.	time, was getting other parents to contact me. **First and second order construct** parents of autistic children were universally identified as being an additional source of support and helped to create a sense of community and togetherness. Being able to connect with other parents meant ‘not feeling like you are isolated’ because there are times when ‘you feel so alone’	share these experiences. In response to parental isolation, an urgency for acceptance prompted the need for membership in a community where their voices were recognised and heard.		

		enabling the sharing of strategies and ideas and providing non-judgemental support and understanding. **Second order construct** For parents themselves, being able to socialize face-to-face or online with others in a similar situation was an important source of support and advice.					

Appendix D: Data analysis methods and rationale

Analysis method	**Key information**	**Rationale for suitability for empirical research project**
Grounded Theory (Glaser & Strauss, 2017)	• Aims to generate a theory based on the data and phenomena studied. • Analysis occurs at a group level rather than individual first. • Explores experiences of a phenomena and develops a theory of social processes. • It is compatible with a range of qualitative methods. • Full implementation of the method involves moving between data collection and analysis to refine the theory. • A literature review should be avoided prior to conducting data collection and analysis to ensure theory is based on the data.	• The current research does not aim to generate a theory from data as an end product. • Research is not aiming to develop a theory of social processes. • The nature of the research project (i.e., resources and time constraints) means I will be unable to move between data collection and analysis to fully implement. • I have conducted a Systematic Literature Review (SLR) prior to the data collection. **Deemed unsuitable for empirical project**
Template analysis (King & Brooks, 2017)	• A *priori* coding template is used to analyse the data. • A technique which can be used across different philosophical stances. • Used to analyse qualitative data (including from semi-structured interviews, focus groups).	• A *priori* coding template is not being used, as it may be argued this may impact on the predominately inductive nature of analysis. • Previous literature (highlighted through SLR) is related to general experiences with a broad range of professionals and services, so using *priori* codes may not be appropriate to transfer.

		Deemed unsuitable for empirical project
Narrative analysis (Chase, 2003)	• Examines individuals narratives of their experiences. Believes that the context has a great influence on experiences – aligns with social constructionism positioning. • Focuses on examining individual narratives of experiences rather than looking for themes across these individuals experiences.	• Philosophical assumptions are incompatible with positioning of research, which is critical realism. • Research hopes to look for themes across accounts of support from EPs to inform practice and policy. • Exploring experiences and perspectives on how EPs can support other families of autistic children. **Deemed unsuitable for empirical project**
Discourse analysis (Willig, 2013)	• Focuses on the importance of context and language. Language is considered the construction of reality and influences our experiences. • Exploring how individuals "use language to create and enact identities and activities" (Starks & Brown Trinidad, 2007, p. 1373) • Usually conduced on naturally occurring conversations, dialogue which are unconstraint and use probes.	• Inconsistent with research question and aims (i.e., focusing on experiences). • I am not considering how individuals "use language to create and enact identities and activities" (Starks & Brown Trinidad, 2007, p. 1373) • Inconsistent with use of semi-structured interviews which provide constraint. • Novice researcher. **Deemed unsuitable for empirical project**
Interpretative Phenomenological Analysis (IPA)	• Critical realism philosophical stance and phenomenological theory.	• Appropriate for philosophical

(Larkin et al., 2021; Smith, 2017)	- IPA is a prescriptive methodology. - Explores phenomenon of interest from the experiences of individuals. - Analysis interprets individuals experiences. - Questions need to be open ended and non-directive. - Requires a homogeneous group and a small sample size (<10) - Develops an understanding of individual participants (ideographic focus) prior to exploring patterns across participants.	positioning of research. - Research will use open-ended, non-directive questions. - Aiming to explore experiences of parents/carers who have all had involvement from EPs, however, they may have different experiences of the phenomenon of interest (i.e., support from EPs) and therefore homogeneity may not be satisfied. - Gaining families perspectives of how EPs can support families – which is not related to directly asking questions about their own lived experiences. **Deemed somewhat suitable for empirical project**
Reflexive Thematic Analysis (Braun & Clarke, 2022).	- Offers flexibility – is not affiliated with a particular philosophical or theoretical positioning but is a qualitative approach. - Provides a process for data analysis rather than a methodology. - Can address a variety of research questions, including experiences views and perspectives. - Provides rich, detailed accounts of individuals experiences. - Can be used to analyse qualitative data. - Accessible for novice qualitative researchers.	- Allows flexibility in questions which can be asked about their experiences and perceptions. Open-ended. - Aligns with aim of research to gain rich, detailed accounts. - Consistent with critical realism stance of research. - Aligns with aim to explore individuals experiences and perspectives within the research. - Aligns with aim to explore patterns

		and themes across the data set. - Able to use TA to analyse qualitative data gathered from semi-structured interviews. - I am a novice qualitative researcher. - Offers flexibility to explore experiences and ask about perspectives of future support. - Likely to be a hybrid of reflexive inductive (data-driven) and deductive analysis (theory driven). **Deemed most suitable analysis method for empirical project**

Appendix E: Questions in relation to (Yardley, 2000) quality assessment of qualitative research.

Sensitivity to context

Theoretical, relevant literature, empirical data, sociocultural setting, participants perspectives, ethical issues.

This has been exemplified in this research by:

- Awareness of the relevant literature and related work by completing a systematic literature review on the topic.
- Examination of relevant theory related to research topic.
- Discussions with individuals to understand their context such as family set up, local area context, historical information and individual experiences with Educational Psychologists.
- Analysis is sensitive to the data (using a predominately inductive orientation to data analysis).
- Awareness of the socio-cultural setting of the study. Reflexivity was maintained throughout the process.
- Careful consideration of positionality within the research and possible influences. Attempts made to reduce power dynamics between researcher and participant.
- Careful consideration of ethical considerations e.g., power dynamics, reflexivity, consent, minimising harm, maintaining own wellbeing.

Commitment and rigour,

In-depth engagement with topic, methodological competence, skills through data collection, depth/breath of analysis.

This has been exemplified in this research by:

- Engagement with topic area as a researcher and professional (e.g., working with families of autistic children).
- In-depth exploration of literature and research around topic.
- Careful consideration of philosophical positioning and influence on methodological approaches and data analysis method adopted to ensure appropriateness.
- Use of supervision to reflect on decisions made during data collection e.g., reviewing interview questions.
- Careful engagement and extensive reading on reflective thematic analysis. Consideration of ensuring good analysis by following guidance from authors on this approach (Braun & Clarke, 2021, Braun & Clarke, 2022).

Transparency and coherence

Clarity and power of description/argument, transparent methods and data presentation: fit between theory and method, reflexivity.

- Careful consideration of philosophical positioning and influence on methodological approaches and data analysis method adopted to ensure appropriateness.
- Transparency of identity as member of profession being researched from the outset with participants to address issues of power.
- Transparency of data analysis method shown by steps followed. Including experts of the data to demonstrate interpretation.
- Transparency in regard to decision making for methodology, data analysis method and process taken during data collection and analysis.
- Engagement in personal reflexivity to consider personal motivations, experiences, values and influence on research process.
- Use of a reflexive diary throughout research process.

Impact and importance

Theoretical (enriching understanding); socio-cultural; practical contribution.

This has been exemplified in this research by:

- Contribute to reflections on own practice working with families.
- Consideration of the wider socio-cultural influences on practice e.g., issues of capacity, resources and pressures.
- Research to contribute to Educational Psychologist practice to support families of autistic children.
- Research may contribute to practice of other professionals who work with families of autistic children.
- Potential for findings to contribute to ways in which Educational Psychologists and services work with families.

Appendix F: Forms used for participants (information, consent form, debrief)

Participant Information Sheet

School of Education, Communication and Language Sciences

My name is Alex Otty and I am a Trainee Educational Psychologist at Newcastle University, currently on placement at (Local Authority) Educational Psychology Service. As part of my doctorate programme in Applied Educational Psychology, I am carrying out research to explore how Educational Psychologists can support families of children and young people on the autism spectrum.

To do so, the research aims to explore the experiences of parent and carers of children and young people on the autism spectrum of support and involvement from Educational Psychologists (EPs).

What is the research about?

As part of this research, I hope to recruit parents and carers of children and young people on the autism spectrum or currently undergoing assessment on the autism diagnosis pathway, who have been involved with Educational Psychologists (EPs). The research aims to find out about parent and carers experiences of support and involvement from EPs. It will include questions about these experiences. It will also include questions about how EPs can further support families of children and young people on the Autism Spectrum.

The possible benefits of this research will be to help inform practice and policy within Educational Psychology when offering support to families of children and young people on the autism spectrum.

What will I be asked to do?

The research will include a one – to -one interview with me and will provide an opportunity for you to share your experiences of support and involvement from EPs.

The individual interviews will last between 30 to 60 minutes and will be carried out by me. These will be audio-recorded so that I will be able to listen back to them following the interviews.

What happens next?

The interviews will be transcribed word for word and then analysed. The transcribed data will then be included within a written report and may also be included in a published report in a research journal. However, your information will remain confidential and be anonymised, so that it cannot be identified. Upon completion of the research (approximately September 2024) all information will be destroyed.

Do I have to take part?

Your involvement in this research is voluntary and there is no obligation to take part. You are able to withdraw at any time, without needing to give a reason. You also do not need to answer any questions you do not feel comfortable answering.
If you would like to withdraw at any point, you can let me know via email or on the day we meet. If you choose to withdraw, your time and participation in the research is much appreciated.

What happens next?
Please carefully read all of the information in this document and feel free to ask any questions at this point. If you would like to be involved in this research, please carefully read the consent form and sign.
If you do not wish to be involved, thank you very much for your time reading this document.

If you would like to contact me or my research supervisor about the research and to find out more information, please do not hesitate to get in touch. Contact details for myself and my research supervisor, Katie Gibson, are included below.

Alex Otty (Researcher. Trainee Educational Psychologist): a.otty2@newcastle.ac.uk
Katie Gibson (Research Supervisor): Katie.Gibson2@newcastle.ac.uk

School of Education, Communication & Language Sciences,
Newcastle University,
King George VI Building,
Queen Victoria Road,
Newcastle,
NE1 7RU

Thank you for taking the time to read this information.

Kind Regards,

Alex Otty

Participant Consent Form

What do the experiences and perspectives of parents and carers tell us about what EPs can do to support families of children on the autism spectrum?

Dear Sir/Madam,

Please read the statements below and place a tick in the box if you agree.

I confirm that I understand the nature and purpose of the research project. ☐

I have read the participant information sheet and understand the information provided. ☐

I agree for the conversation within the interview to be audio-recorded and only the researcher and research supervisor will have access to the recordings, which will be transcribed for the purpose of the research project ☐

I understand that all information collected will remain confidential and anonymous and no information will be identifiable. ☐

I understand that my information will remain anonymous in any report or other publication resulting from this research. ☐

I understand that my participation in this research is voluntary. ☐

I understand that I am free to withdraw: ☐

- at any time
- without having to give reason

I have been provided with contact details of the researcher and research supervisor and I understand that I can request further information if required. ☐

I consent to taking part in this research ☐

Print Name: ____

Your Signature: ____

Date: ____

I am available via email at: a.otty2@newcastle.ac.uk

My supervisor is available via email at: katie.gibson2@newcastle.ac.uk

Kind Regards,

Alex Otty

Debrief Form

School of Education, Communication and Language Sciences

Thank you for being involved in this research project. I appreciate you giving up your time to share your experiences and views with me.

What was the research aim?
The research aimed to explore how Educational Psychologists (EPs) can support families of children and young people on the autism spectrum.

To do so, it hopes to explore the experiences of parent and carers of children and young people on the autism spectrum of support and involvement from Educational Psychologists.

What happens next?
The data collected from the interview will be anonymised using codes or pseudonyms (fake names) so that your responses are not identifiable. All data will be stored in a safe and secure place, on a password protected hard drive, which only myself and my research supervisor will have access to.

Your responses to the questions will be transcribed word for word. Once your responses have been transcribed, the data will be destroyed from the hard drive. The transcribed data will then be analysed and written up into a report using codes or pseudonyms.

What happens next?
The interviews will be anonymised, transcribed word for word and then analysed. All transcribed data will be stored on in a safe and secure place on a password protected hard drive, which only myself and my supervisor have access to.

The transcribed data will then be included within a written report and may also be included in a published report in a research journal. However, your information will remain confidential and be anonymised using codes or pseudonyms (fake names) so that it cannot be identified. Once your responses have been transcribed the data will be deleted from the hard drive. Upon completion of the research (approximately September 2024) all other information will be destroyed.

What if I would like to withdraw?
You are able to ask for your data to be withdrawn from the research, up until the point of data analysis. At this point it will not be possible to remove individual data.
If you wish to withdraw your data from the research, please feel free to contact me via my email address as shown below.

Contact details:
Please do not hesitate to contact me if you have any further questions. You can contact me (Alex Otty) or my research supervisor (Dr Katie Gibson) via our email addresses:

Alex Otty (Researcher/Trainee Educational Psychologist) a.otty2@newcastle.ac.uk
Dr Katie Gibson (Research Supervisor): katie.gibson2@newcastle.ac.uk

Further support and advice:

If you feel you would like further support and advice, please refer to the websites and contact details of organisations below:

National Autistic Society (NAS): https://www.autism.org.uk
Ambitious about Autism: https://www.ambitiousaboutautism.org.uk
North East Autism Society (NEAS): https://www.ne-as.org.uk/?gclid=Cj0KCQjw1rqkBhCTARIsAAHz7K3bP6kViaCIgMSvI_35-qDvmU_wp0lkkmxaUTAMcGOJ8eq4dh7CM18aAqklEALw_wcB

Thank you for taking the time to be involved in this study, your participation is much appreciated.

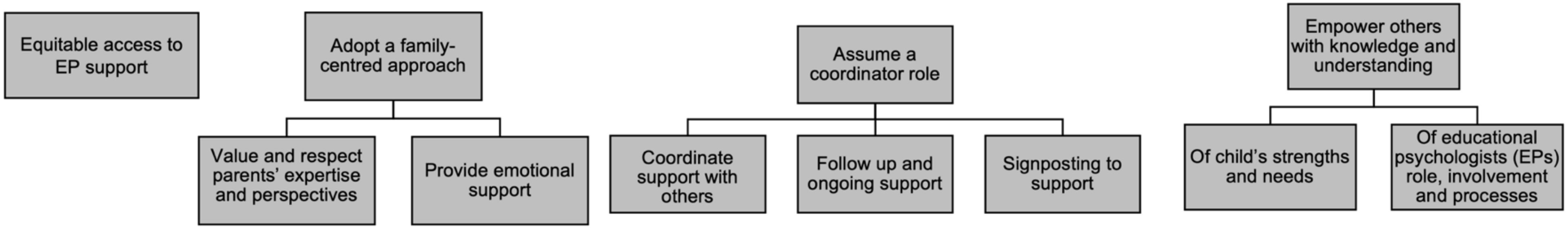
Kind Regards,
Alex Otty

Appendix G: Interview questions and schedule

Area	Questions
Background/Contextual information	*Question* - How old is your child? *Question* – What type of school does your child attend e.g., mainstream or specialist? *Question* – How old was your child when they received a diagnosis of autism? Or When did your child begin their journey on the diagnostic pathway? *Question* - Have your family had any involvement from any other professionals or services?
Experiences with Educational Psychologists	*Question 1* – Can you tell me about your family's experiences of involvement from Educational Psychologist(s)? *(family's to discuss their timeline if completed in the interview).* *Follow up – W*hat were you hoping for from their involvement? In what ways did these experiences meet your hopes for their involvement? Prompts – What did this involve? Can you tell me more about that? *Question* 2 - Can you tell me about your family's experiences of support from the Educational Psychologist(s)? Follow up – In what way did your experiences meet your hopes for support from Educational Psychologists? Prompts – What did this involve? Can you tell me more about that? *Question 3* – Can you tell me whether there were any ways the Educational Psychologist(s) helped you as a family during their involvement? Prompts- Can you tell me more about this? if so, can you tell me about if there was any advice/help/information offered by EP(s)? *Question* 4 – Can you tell me about whether any of the support from Educational Psychologist(s) has been particularly useful? *Prompt* - Can you think of any specific examples of experiences of useful support you have received? *Follow up* – Why do you think this was useful?

	Question 5 – Can you tell me about any ways the involvement and support from the Educational Psychologist(s) made a difference to your family? *Question 6*–Can you tell me what could have been better about the involvement and support from the Educational Psychologist(s)? Follow up –what would have liked to change? Prompts – what support you would have liked to have received from Educational Psychologists?
Future support	*As you have shared your experiences with EPs, I would like to ask about your views on how EPs could support in the future.* *Question 7* – Can you tell me about what you think Educational Psychologist(s) could do to support families like yourselves in the future? *Follow up* –How do you think this could make a difference to families? *Question 8* – Based on your experiences, what advice would you give to Educational Psychologists who are working with families like yourselves?
Additional questions	Is there anything else you would like to tell me or talk to me about?

Appendix H: Full thematic map of themes and subthemes



Appendix I: Themes, subthemes and examples of participant extracts

Theme	Subtheme	Characteristics	Example participant extracts
Adopt a family-centred approach Central organising concept is the role of the EP in adopting a family-centred approach to practice, providing families with emotional support, listening to and validating parents and valuing their experiences and perspectives.	**Emotional support**	This subtheme relates to the importance of EPs recognising the emotional impact on families of the needs of the child and the difficulties in navigating the nature of the education system. Parents highlighted the importance of EPs offering emotional support by acknowledging these difficulties, showing an interest in the wellbeing of parents, so that they feel more supported and able to support their child.	P4 It's kind of your whole life gets turned upside down. I mean, my whole life has been completely turned upside down. I had a full time job, the career of 20 year. I work one day a week now. I've had to leave my job all through this and I wouldn't change that, that's happened. But there's no appreciation of that sometimes, services of that you know. P7 It's about the fact that this is an incredibly difficult thing, and the better off I feel and the more supported I feel, the more effectively I care for her. And therefore the less I will need those services in the first place and that is missing. That is sorely missing and I think it's quite cruel. P4 Uhm, I think it. I think if I remember rightly, every phone call that I had, I'd hoped that somebody would pick up, you know, not I'm not coping and help me. I don't know how well that could have screamed help me, kind of thing. P1 And we have also needed emotional support, I'm not sure if Ed Psych's would provide that but ermm, you go through like probably a grieving process in terms of coming to terms with your new life and you know my children are brilliant, but it is not what I thought it would be and I am not the sort of parent I thought I would be because of the situations we find ourselves in. P1 That would definitely be helpful if that was part of the remit. I think most professionals don't ask you, how are you as a parent, so that is not unique to Ed Psych's, it is really rare for somebody to say, 'how are you?' and actually mean it.
	Value and respect parents perspective and expertise	This subtheme relates to the importance parents placed on of EPs valuing their	P2 Obviously, he was asking us about, you know, like lived experiences, which I suppose, you know, fed into fed into what his plan. So, I mean just for that process and because, you know, for the diagnosis process, you kind

		perspectives and expertise of their child and to work ‘with’ them to support their child. This relates to parents valuing feeling listened to and their perspectives heard, which provided parents with a sense of validation e.g., confidence in what they were doing, that they knew their child well. This was important for some parents as they felt the ‘system’ value EPs expertise and so they mentioned a sense of needing to be validated by EPs. Aspect of advocacy for their children.	of get used to collecting examples of evidence that you might, can use. So we had all this information to hand. P5 I find sometimes people ask you a question and what they want is a couple of words answer and that doesn't cover what you're trying to explain, for example, how is he with routine? You know, children with autism sometimes really struggle. Well, the answer actually to that. If you want a quick answer is yes and no. Because if you take him completely out of the routine and he's got no idea where he's going he doesn't really bother, it's fine. If you do something that you tend to do the same way every day, and you make a small change, that he would have a problem with. So, does he struggle with changes in routines, yes and no. So it’s, but some people don’t want that level of explanation, they just want ‘oh no, he’s fine’. Ermm and I just thought that it would just be a bit of, you know you see these questionnaires and you get so many in this column and so many in this column, then you’re diagnosed with this, or you know. P5 But there was nothing really, because basically from his observation, he kind of put in his report, just said I concur with what parents and the staff have said, observed XYZ, which was what they highlighted blah blah blah so. P5 I felt like what we discussed was reflected in them and I honestly couldn't have asked, so I think we've been really fortunate and had a really positive experience. P7 Hear people, respect them. Because I think sometimes that's missing. P3 Oh the biggest word is not judgmental. So be as non-judgmental as possible because that's what I'm big on, so that's luckily I got into that. P7 I need people who are going to hear me and respect me. I don't want them to roll over and do whatever I say. I want them to have a conversation with me, a debate about why they might have a different point of view, but

			one that's based in accurate information and remains respectful. And that's what I need. P5 I think, just the being willing to sort of engage and listen to us, give those like contextual examples and you know, anecdotes of things that have happened. And because sometimes, I mean, I clearly don't have a problem talking. I think we're all very.
Assume a coordinating role Central organising concept is the role of the EP in assuming a coordinating role, coordinating support with other professionals, Providing follow up and ongoing support and signposting parents to further support.	**Coordinate support with others**	This subtheme relates to parents valuing EPs who took a coordinating role for families with other professionals, such as opening up communication with school staff.	P1 Ermm. I mean I don't know if this is part of the role, but it would have been nice for somebody to take charge, because you have you know, loads of organisations involved, so paediatrician, psychiatrists, nurses, occupational therapy, speech and language, Ed Psych, school, SENDIASS and for somebody to just coordinate that would have been nice. I don't know if that is part of the role, but it would have been nice to pass some of that on. P1 I guess the other thing to add is, because I am working, so you know my husband works full time so it is a lot of work. It is like another job. Not the child, but paperwork and the meetings. P7 but also for somebody to say I've got this, I'm going to take this forward for you and have a look…and suddenly I had a period of time where I didn't feel like I was carrying the torch…And that was really important. And it felt like, whilst other people had an opinion, it felt like the ed psych, like was almost like the care coordinator of that. P4 Yeah, it, it just felt very disjointed and I think what you have to appreciate as well sometimes is that when you're newly diagnosed or recently diagnosed and you're going through an EHCP, you've got about 50 million people ringing you every single day. I mean, I have spoke to possibly every SALT in the whole of [LA]…And you've got paediatrician, you've got autism outreach team, you've got Ed Psych, your head's battered and you're trying to get through the day as well, you know, so. They all, none of them seem to join up either.

			P2 As parents, yes, you're always and you're always like looking for support. Who's gonna, you know, hold your hand through this process or whatever. And I think, as I say, I suppose factually he did what he what he had to do, he did provide the report, but I think it would have just have helped us and probably possibly the school in actually been quantifiable in what the school had to deliver.
	Provide follow up and ongoing support	Most parents experienced short-term involvement with EPs e.g., EHCP and wished for longer, more continuous support from EPs and EP services. Parents mentioned EP support typically falling short when recommendations which were made were not always occurring and followed up by EPs and they wished for support to help reinforce recommendations made and review their child's progress. This promotes ongoing relationship with EPs and involvement to see progress of the child and adapt support.	P4 There's nothing. There's nothing else. I think there's a lot of kind of once you've got your EHCP. That's it, you know, everything's plain sailing and it's absolutely fine, but it's not. P4 I think that follow up piece needs to happen as well. It can't just be about writing a report and that's it. It's about, you know, saying actually we want to go back and and see [child], we want to you know. Them [EPs] writing a report and making recommendations is that actually happening, is that, you know being done in school. If it's not what more can we do, or if it is being done in school what more can be done to help and support her. P7 What we haven't got is because we've never had follow up from that. I think what happened, where it, where I guess it, I feel like it's failed for us and that's not to do with anything of the people involved, it's to do with the fact that if this doesn't fit directly in a school setting, whether that be for COVID or whether it be for the fact that the school refused it. Then there's no alternative. P7 We know there's a visual, what's the easiest we have providing visual, but we've completely forgotten the fact that she can't do it, decode individual words, that you've used generic terms, not specifics, of what she has to expect from her day. And then there is no follow up from anybody. P7 And that. And I don't think in all of my interactions with Ed Psychs, anyone has ever been there to effectively do the follow up with school. P7 So the implementation of the recommendations have been the weakest point, so personally I've been able to put some of those things in, but that's

			kind of a drop in the ocean of a day of a child who spends 6 hours at school every day. P2 but it's kind of like it's alright identifying this stuff, but who actually helps with it afterwards? P2 And I think. I kind of hoped that, not necessarily him but the service per se would have maybe just checked in on us, you know like a month, three months down the line, you know how you getting on? Has it had an impact? Is there anything that you need a bit more help with? Is anything not being delivered? Or, you know, could the school be doing something different or better? P7 I'd feel less alone and that that's the issue with lots of services being episodic. In fact, I don't know one that isn't now that actually you are left alone.
	Signposting to support	This subtheme relates to the importance highlighted of EPs role in signposting parents and the child to further support e.g., parent carer forums, other professionals, services and suggesting referrals.	P1 I will tell you the best input we had and I don’t know if Ed Psych’s could facilitate this, but the most helpful thing I ever had was the middle school, so the SENCO from the middle school when my son was still at the first school, used to put on a coffee and cake morning once a term for parents of children from the feeder schools, who had mainly autism, but you could broaden it out to any children with additional needs and the first time I went into that meeting with the other mums, it felt like coming home. And I felt really emotional, in fact I feel emotional now just thinking about it and some of those mums are now my best friends. And so, there probably could be a really nice role for Ed Psych’s in facilitating that peer support, because I felt completely on my own. P2 I think because we weren't actually like signposted elsewhere or anything like that. I can only think about the actual report writing and how we how we fed into that. P6 Yeah, I think it definitely accesses support from other services and stuff like that.

			P6 she would like help in terms of that and she signposted to a lot of organisations as well… so she referred you to the through charities and that sort of thing. P6 Because she was quite good at when I didn't understand something, she would like help in terms of that and she signposted to a lot of organisations as well…Which I hadn't actually heard of, despite having like five years of being, you know, like in between all of these services. So that was helpful as well.
Empower others with knowledge and understanding Relates to subthemes emphasising the importance of EPs using the expertise to provide knowledge and understanding for families of a child's strengths and needs, so others feel equipped to understand and support them, as well	**Knowledge and understanding of child's strengths and needs.**	This subtheme demonstrates that parents felt EPs could offer support around providing knowledge and understanding of their children's strengths and needs, however, some felt this has been constraint by factors such as time, capacity. Some parents felt EP involvement provided them with new understandings of their children (strengths and needs) and provided ways in which they could support them, whereas others would have valued this from EPs.	P2 I think so yes, because I think again, had he had had eyes on, I think that would have helped us understand as well. Because as I say how my daughter behaves at home is different to how she behaves in a school environment. P2 But yeah, so I think I think it would have been nice to have had that observation, from a professional. P7 I think it gave us things that we could talk about as a family and quantify that and and look at the positives as well, so look at strengths and talk about strengths and kind of lead with strengths, which was really important and so day-to-day we often kind of spend our time converting what can feel like a fail into a strength and the ability to do that comes from having that level of understanding all of those cognitive tests. P5 Ermm and I just thought that it would just be a bit of, you know you see these questionnaires and you get so many in this column and so many in this column, then you're diagnosed with this, or you know. Ermm That kind of thing, and I think I expected it to be more like that and less about him as an individual child, more about where does he sit on the spectrum. P3 so that's a very good word, curiosity. So that that you want to find out why and you don't have the dogmas that it's this and that and that, but look at the child individually. Look at them, you know, try and collect information and all

as informing them of the EP role, involvement and processes involved in their work.			the factors and see what is actually, might be going on with that child and what are other reasons? P6 Completely two different, two different like worlds in comparison. Like, I've said with the educational psychologist, it was like I would say, I can't really fault her. She did everything like to benefit [child], to make sure that she was, like you know every area was covered. P4 I think what was helpful was the fact that the scoring put her below where she needed to be. So and then obviously she wrote kind of the characteristics of [child] and she included again around. Yeah, so she included kind of a strengths and then she had, like a lot of, like, special education needs as well. P4 And she documented that really quite well, and she gave quite good examples of the different things as well, like that she struggled with. P3 And that in autism is obviously very, very relevant because there can be lots of frustration, lots of, you know, not being able to express, well my child is on the high spectrum or how do you say that that's not used anymore I know, but he can communicate. He can do these things, he can be selectively, you know, selective mutism is a feature with him, but he's overcoming now and trying. But again lots of masking and lots of trying to fit in and all that. But I know obviously there are more severe cases of autism. P7 And and for my husband as well, where it was then, like it might not be what we'd anticipated. But it started to help us to kind of give a background to what was happening so that. We could start almost to create another paradigm of how we were seeing. P7 And that became more comfortable that also became for some of those more tense situations, where we were seeing differences. Before we would have or particularly for my husband, where there's always that difference between mam and Dad and I and I know that professionally and certainly it's what we experience personally.

			P2 Yeah, that would have been amazing had he have done that. And again, I think it's again, it's just knowledge, isn't it. Your knowledge is power, if you know your child behaves in that way, then you're gonna adjust how you think or how you, your expectation. P5 It's achieved a lot, I think and as you said, there are things that even now are still kind of keep in the back of my mind and think about it or have been able to pass on to other people because it is hard, like it is hard. It's hard for all parents, but especially because things change all the time, so yeah.
	Informed of EP role, involvement and processes	This subtheme relates to the need to inform parents of the EP and services role and remit, EP involvement and processes they are involved in e.g., EHCP process. Parents expressed that they were generally uncertain about the EP role and what support could be offered. This was linked to parents often being involved in a narrow aspect of the role and so were unfamiliar with what their role could involve.	P3 I'm probably not even sure what other things they can do…I do think that a lot of the time it's not very clear what you can get from a service. So it's like a minefield when you're in the thick of it, when things already going badly and you would need the support and you're hearing from here and there from other parents and other groups and things. P3 But then you are not told, so when you get involved with the service, and that's actually a very big experience of mine with all sorts of service, that everybody likes to keep it to themselves what they can offer and they want to be in control, instead of letting you know that we have all these things that we could put in place, we could support you with. We could offer you or advise you, and that's not happening. So much clearer, much clearer information and communication would be very important, because when you're in the thick of it, it's just impossible to remember everything. You're under a lot of stress. P1 So in terms of support, I don’t know what is on offer or Ed Psych’s offer elsewhere or what they should offer, but there hasn’t been any support. P2 I think in a way, I think I had in my head. And again, I don't know if that's because I wasn't sure as to what the actual service did. P2 Yeah, I think being clear about what their remit is, I think that would be good.

			P2 I think I mean personally I think, I had no clue what Ed Psychs and I still probably don't know what, what do Ed Psychs do with the greatest respect. So I don't think you like sell yourselves enough out there. There's not enough information out there about what Ed Psychs do and how they can help. P2 Because you know, I'm just talking about that very. I'm sure it's a very narrow stream of EHCP. I'm sure you do much more than that, but because that's the only bit I've been involved in…I don't know what else you know Ed Psych's do, so that I think that would be interesting. It's communication. P6 I don't really know what that service offers in terms of like support. All I thought was, that they, do the assessment of school, but as a family, I don't know of any other support or stuff like that, I'm not really. P6 Maybe knowing what the actual support that you can get from them is, because I'm not 100% sure because, but that's very similar CYPS, because when I when we were referred to them, they said what support do you want? I said well, this is what's happening. I don't know what support you offer. We've been referred, like we are like you know when you don't have any experiences of these organisations. P6 I just think you know if you know what support is there or what a service like offers, then you can access it if needed. You know like if it's there, if you know it's there. However, I think if it's, you might know something's there and you don't have a clue what they offer as an organisation. Yeah, I think that might be helpful to actually know what these services offer. P3 So it does feel that the services don't tell you and don't share with you what they could actually do for you. But they decide without you having a say in it, so more communication and yeah, more empowering the parents with information. P2 Yes, absolutely. Getting into like you know parent carer groups into the local charities, etcetera, maybe some drop in sessions, you know, local. Just getting out there becoming, you know, if it more known a bit more. Ah, so

			yeah, I've seen you before the at a group kind of thing, just so you're not so removed. P2 I think not to assume that everyone knows everything and that it's good to actually set out what the service does. What support can be given. Yeah, I think really to just put themselves out there and to see to see what the family want or what their aspiration is. P6 I felt like I could contact her, like she said along the process of when [child] was assessed, that I could contact her at any time. I think that her communication was fine, like I didn't feel like I needed to, but I never felt like I was in the dark about anything. P6 I would just say that like it would be good to be like approachable and. Yeah. Approachable, open, like with the process and stuff like that, keeping the parents involved with what's happening in the timeline and stuff and what to expect. I think all that helps. P4 I think being able to sit down in a room and kind of speak about it properly, you know, go through it, go through her assessments in a bit more detail, get a greater understanding, think about long term support for her. Like what would she benefit from. P4 There were we didn't have a great deal of involvement. If I'm honest with you. I don’t recall being told officially when they were gonna go in.There was no kind of like [child] was gonna get her assessment today. P4 I remember they rang me, the lady rang me afterwards and kind of went through the assessment with me. Yeah, and her recommendations. R: Did the Ed Psych explain those systems to you, do you feel? P1 No. I suppose a really practical recommendation would be a nice little leaflet which would come from the Ed Psych service saying this is how a

			child with an EHCP gets. This is what we can offer and if it is in the EHCP it would need to go back to panel or not. P1 good communication. I like letters, pop it in a letter. Because what I have discovered since having children with additional needs is that you need evidence, you need evidence for this meeting, for you know DVLA, EHCP and this that and the other, so you know actually let's just summarise the meeting. I don't need long letters, just give me four bullet points on what we have agreed and what next and then I don't have to remember it and then we don't get into a situation where perhaps we have remembered differently what we agreed. P6 I would just say that like it would be good to be like approachable and. Yeah. Approachable, open, like with the process and stuff like that, keeping the parents involved with what's happening in the timeline and stuff and what to expect. I think all that helps. P5 I think the bit that was a massive support, which we hadn't expected to get was all around. This is how the process works for school. And even down, you know, ohh well, you will still have to apply for a mainstream place, even though it seems like he's not going to go there. That you still have to do that, and that gets him in the system and then this is what happens. P5 And explained the process from beginning to end and I think I kind of assumed that he wouldn't give that support that would have to come from the SEND officer or somewhere else, they have a specialist health visitor for children with additional needs. P5 I think that it wasn't just, 'I'm here to assess him within this framework, it was about 'and this is what this means moving forward', and 'this is how it fits into the process' and 'these are the things that you probably need to be aware of'. And just it wasn't as clinical, I think as I thought it would be, does that make sense.

Equitable access to EP support		This theme relates to the systemic level factors which impact on equitable access to EP support. This outlines constraints of the system from a school and wider system level related to lack of resources impacting on access to EPs such as long waiting times and lack of EPs.	P2 That was the only time. I've since, I've asked for EP involvement in the past six months and it's just not forthcoming. P6 As she was up, the paediatricians asked for her to be assessed when she was 7, but the letter went directly to the school, but the primary said because she was coping in the school, although she was having these behaviours at home, that they wouldn't invite the educational psychologist in. P6 Ermm but that's when the paediatrician was saying that she needed that assessment at that time and I just felt like I was being ignored basically because she was so quiet in in school. She wasn't making any noise, she wasn't kicking off, she was kicking off when she got home, but they weren’t really bothered about that. P7 Because they were providing for those very subtle needs that then meant that she wasn't screaming. She wasn't throwing tables; she wasn't causing a problem. So really nobody really wanted to know too much about it. P3 So from then on, a lot of it depends on if the child doesn't, if the child masks and obviously this is specific, because children who are acting out in school. They are more likely to get support easier. Get a referral and everything, but that should change. P6 I think sometimes it's a case of when they get diagnosed, you're basically just left to get on with it, even though it can feel like you're drowning the majority of the time, and then it will reach crisis point and then people get involved, like when [child] it took for to basically be at crisis point before she got assessed, before the secondary school, like initiated the assessment. And I just think that maybe when there is the first, like before the diagnosis. It shouldn't take for a child to reach crisis point or the family to reach crisis point before, like educational psychologists are called in, and I understand that there's the shortages and stuff. P4 And so she did them and obviously she gave [child] the score if you like. But obviously they're now out of date. So I have requested since, just a few

			months ago actually, that they get repeated because obviously we're going to be transitioning to high school soon, and I need obviously that updated to change her EHCP. P1 We’ve also seen, we’ve been involved with Ed psych twice. Well, one, he has been referred twice but we are still waiting for the second input. P1 And then, more recently, so he is in year 8 so beginning of year, so two years ago, the beginning of year 7, he was referred back to Ed Psych for help with understanding his learning strengths and difficulties and his learning style, ermm and that was done to prepare him for the high school, so we had a two year window to get that sorted. And he is still waiting to be seen. P1 it might just be what our local authority. Because I know they are swamped with applications and I know they are short staffed, so you know it has got to give somewhere in the system, I do understand that, but I don’t know what the solution is, other than loads more money. P2 Because it is a. It's just that, you know, just life, life's hard for everyone. Don't get us wrong, but I just know as a parent of a SEND kiddy that it is especially hard and services are so, so finite and everything's a struggle and you've really gotta have sharp elbows to get things done. P5 I think it's. That that seems to be, and I think it's probably a symptom of the system being overstretched, haven't. P6 I think all if all the services were saying that. The waiting time now for the education psychology as well as it might be different now would have been two years later but. At the time it was fast, like everything was done. But then now it has taken her two years to be granted that educational healthcare plan off the back of that. P4 I don't foresee anything coming, but you never know, you never know. [LA] really lacking of anything.

			P1 And you know, I am an articulate and I can. But some family just can't fight because they are tired or they don't know how to, so I always think about other families and it's not fair. You know, the fairness. And I, I think that families who are more articulate. You know if I hadn't have pushed for the EHCP, he wouldn't have one, he probably would by now I think but you know, some families would have given up because they are too tired and too worn out with it all. P1 Yeah, Ermm. Well I think it is about that equity, so it shouldn't be about those that are more articulate get more and I think ermm every child and every family should get what they need. So I think it is about standing together with the child and thinking I suppose in a person centred way, thinking what does this child need instead of what can the Local Authority afford and who am I going to say no to this week.